What do you need?

2007-2008

Findings from a national survey of people with diagnosed HIV

Peter Weatherburn
Peter Keogh
David Reid
Catherine Dodds
Adam Bourne
John Owuor
Gary Hammond
Kathie Jessup

Original Research Report

Acknowledgments

Survey design and recruitment collaborators: Our thanks to the 110 agencies who collaborated on *What do you need?* in 2007-08. They include agencies who suggested content for the survey or commented on drafts of the questionnaire, requested survey booklets directly from Sigma, or got their booklets from a third party and those that promoted the survey via their websites. Web addresses are given for agencies who promoted the survey online (some of which also distributed booklets).

- ABplus (Birmingham)
- Adur, Arun & Worthing PCT
- Africa Advocacy Foundation
- African Caribbean Resource Centre
- The African Child
- African Institute for Social Development
- African Refugee Community Health and Research Organisation (ARCHRO)
- Africans Getting Involved
- Alcohol & Drug Services in Staffordshire (ADSIS)
- Armistead Project
- Ayrshire & Arran Sexual Health and BBV Team
- Barnardo's Street Level Family Services (South Shields, Tyne & Wear)
- Barnet African Health Organisation
- Black Health Agency
- Body Positive Cheshire & North Wales
- Body Positive Dorset
- Body Positive Grimsby
- Body Positive Tayside
- The Brigstowe Project (www.brigstowe.org)
- Brunswick Centre
- Catholic HIV/AIDS Ministry – Westminster Archdiocese (CATHAM)
- The Cara Trust (www.caralife.com)
- Chelsea and Westminster Hospital, Kobler Clinic, St Stephen's Centre (Chelsea and Westminster NHS Foundation Trust)
- Children in Scotland
- The Core Trust
- The Crescent Support Group
- Croydon Citizens Advice Bureau, HIV Project
- DHIVERSE
- Ethiopian Community Centre in the UK (ECCUK)
- www.GaySwansea.com
- George House Trust (www.ght.org.uk)
- GMFA (www.gmfa.org.uk)
- Greenway Centre at Newham Hospital (Newham University Hospital NHS Trust)
- The Harbour
- HART (Hillingdon AIDS Response Trust)
- Healthy Gay Life (Heart of Birmingham PCT)
- Herts Aid
- The HIV Support Centre (Belfast)
- HIV/AIDS Carers & Family Services Provider
- Homerton Hospital Department of Sexual Health (Homerton University Hospital NHS Foundation Trust)
- Hope Gate (formerly HIV/AIDS Association of Zambia or HAAZ)
- Huddersfield Royal Infirmary (Calderdale & Huddersfield NHS Foundation Trust)
- www.i-base.info
- Islington Zairian Refugee Group
- Kenya Women's Association
- Leeds Skyline (Black Health Agency)
- Leicestershire AIDS Support Services (LASS)
- Leicester Royal Infirmary, GUM Department (University Hospitals of Leicester NHS Trust)
- Luton and Dunstable Hospital GUM Department

- Mildmay Hospital
- NAM (www.aidsmap.org.uk)
- www.nat.org.uk
- Naz Project, London
- Newham Hospital (Newham University Hospital NHS Trust)
- New Prospectives
- Open Door
- Open Road Visions
- Palmers Green Citizens Advice Bureau
- Pan Afrique Centre
- PHACE Scotland (Promoting Health & Challenging Exclusion)
- Pomadozi
- Positive Action Aldershot
- Positive East
- Positive Health (Lincolnshire)
- Positive Parenting & Children
- The Positive Place (www.thepositiveplace.org.uk)
- Positive Voice
- Positively Women
- Project 6 (Airedale Voluntary Drug & Alcohol Agency)
- The Rainbow Project
- River House Trust
- SACOMA
- SCOT-PEP (Scottish Prostitutes Education Project)
- Sheffield Centre For HIV & Sexual Health
- Shropshire Buddies and Body Positive
- South West Essex PCT
- St. Mary's Hospital, Jefferiss Wing, Centre for Sexual Health (Imperial College Healthcare NHS Trust)
- St. Peter House (Redhill)
- Staffordshire Buddies (www.staffordshirebuddies.co.uk)
- Summit House Support Ltd.
- Terrence Higgins Trust Cymru (Cardiff)
- Terrence Higgins Trust Cymru (Swansea)
- Terrence Higgins Trust East (Southend on Sea)
- Terrence Higgins Trust East (Colchester)
- Terrence Higgins Trust LADS (London)
- Terrence Higgins Trust Lighthouse East
- Terrence Higgins Trust Lighthouse Kings
- Terrence Higgins Trust Lighthouse South
- Terrence Higgins Trust Lighthouse West
- Terrence Higgins Trust London (www.tht.org.uk)
- Terrence Higgins Trust Midlands (Birmingham)
- Terrence Higgins Trust Midlands (Coventry)
- Terrence Higgins Trust Midlands (Telford)
- Terrence Higgins Trust Midlands (Wolverhampton)
- Terrence Higgins Trust Scotland
- Terrence Higgins Trust South (Brighton)
- Terrence Higgins Trust SW5 (London)
- Terrence Higgins Trust Thames (Oxford)
- Terrence Higgins Trust Thames (Woking)
- Terrence Higgins Trust West (Bristol)
- Terrence Higgins Trust West (Swindon)
- Terrence Higgins Trust Wirral (formerly Jigsaw Centre)
- Terrence Higgins Trust Yorkshire (Leeds)
- Thames Valley Positive Support (TVPS)
- Tyddyn Bach Trust
- Uganda Community Relief Association
- UK Coalition of people living with HIV and AIDS (UKC, now closed)
- Wandsworth Oasis Trading Company Ltd.
- Waverley Care SOLAS
- West African Networking Initatives
- Yorkshire Mesmac

Questionnaire development: For comments and constructive feedback on the draft questionnaire thanks to: Alison Begley on behalf of the Crescent Support Group; Casper Thomson on behalf of NAM; Chris Woolls on behalf of The Cara Trust; Darryl Clarke; Jack Summerside on behalf of the UK Coalition; John Masterson; Mark Ballentine; Rob Dawson and Carl Burnell on behalf of GMFA; Steve Moralee on behalf of DHIVERSE; Tina McMichael on behalf of Ayrshire & Arran's Sexual Health and BBV Team; and Will Nutland on behalf of Terrence Higgins Trust.

Questionnaire pre-testing: Piloting of the questionnaire occurred with 25 people with diagnosed HIV in London and Luton. Martha Chinouya conducted five interviews with Africans resident in Luton and Peter Keogh conducted twenty interviews with men and women of various ethnicities recruited via Positively Women and Terrence Higgins Trust Lighthouse West.

Survey co-ordination: Peter Keogh.

Booklet design: Clifford Singer at Edition. Printing by White Horse Press.

Booklet distribution: Co-ordination by Peter Keogh, Kathie Jessup and Gary Hammond. Thanks to the agencies (listed above) that distributed the booklet version of the questionnaire.

Online survey design by David Reid at Sigma Research using www.demographix.com.
Thanks to Derek Cohen and Bobby Pickering of Demographix for all their help.

Translation of the questionnaire into French was undertaken by Sylvie Beaumont.

Online survey promotion: Co-ordination by Peter Keogh and David Reid. Thanks to the agencies (listed above) that promoted the survey free of charge and to the various web-masters for making it happen. Banner ads and buttons designed by Clifford Singer at Edition.

Data suppliers: Many thanks to the 1929 people who participated in this survey.

Booklet database design: Nick Christou at QualIT.

Booklet data input: Gary Hammond and Kathie Jessup.

Quantitative data management and analysis: David Reid and Peter Weatherburn.

Qualitative data management and analysis: Peter Weatherburn, Adam Bourne, Catherine Dodds, John Owuor.

Draft readers: For comments on earlier drafts of this report thanks to Will Nutland of Terrence Higgins Trust.

Funding: The survey was funded by Terrence Higgins Trust and the Department of Health.

www.sigmaresearch.org.uk

www.tht.org.uk

March 2009

ISBN: 1 872956 95 5

Contents

Summary

Over the past twenty-five years, both the needs of people with diagnosed HIV and our understanding of them have changed dramatically. During this time there have been many assessments of need, usually within specific geographic boundaries (such as Primary Care Trusts) but no consistent approach to describing needs has been adopted. Most needs assessments have been shaped by a variety of local factors, including the profile of existing services.

This study provides an insight into the needs of people with diagnosed HIV living in the UK, based on a final sample of 1777 people. The approach taken to measuring and describing need is the same as our previous national survey (Weatherburn *et al.* 2002). This approach was shaped by our earlier qualitative studies exploring the experience of people with diagnosed HIV in the early days of anti-HIV treatments (Anderson *et al.* 2000, Anderson & Weatherburn 1999, Anderson & Weatherburn 1998).

While this study uses the same methods as our 2001-2002 survey we do not draw direct comparisons with our previous data or discuss change over time. The limitations of self-completion surveys using convenience samples make change comparisons hazardous. However, it is worth noting that in any comparison with our prior data (Weatherburn *et al.* 2002) current levels of need very rarely seem lower than we have previously reported.

The range and extent of medical and social care, support and information needs we present here reveal significant challenges for service commissioners and providers. The first challenge is to avoid drawing quick conclusions about what the patterns of need mean for service commissioning and delivery. Needs have deliberately been separated from service use because the question of what services are 'needed' cannot be answered simply by identifying the extent of personal needs. The overall pattern of need is a useful starting point, but this pattern is complex.

KEY FEATURES OF THE PATTERN OF NEED

The overall pattern of unmet need is summarised in chapter 3, including the analysis of needs for ten key demographic groups (see section 3.5). The following are some very broad observations:

- A small proportion of people with diagnosed HIV have very few needs or have found satisfactory ways of meeting the needs they have. HIV can be a chronic manageable condition (see section 3.1).
- The most common needs concern quality of daily life rather than the practical problems which help to secure this. They relate to the intimate details of personal experience: how people cope with the pressures of life (see chapter 12); how people feel about themselves (chapter 13); the value of sexual pleasure (chapter 18); the importance of sleep, rest and recovery (chapter 7).
- The practical and physical needs of daily life continue to be a burden to many people with HIV. Basic problems with housing (chapter 5), mobility (chapter 6), household chores and self-care (chapter 8), eating well (chapter 9) and child care (chapter 17) remain the experience of a large minority, but their impact on all aspects of life and personal opportunities is considerable.
- Dissatisfaction with current jobs and job opportunities (see chapter 22) is now more common than dissatisfaction with personal income (chapter 10), though the relationship between these is not straightforward.
- Information services about living with HIV appear to be effective – relatively little unmet need is reported in this area at least among this sample of service using people with HIV (see chapter 19).

- The widespread experience of discrimination and social isolation point to the particular harshness of living with diagnosed HIV, compared to most other chronic conditions (see chapter 23). That families, communities and health and social care staff are common perpetrators of such discrimination must contribute to the difficulties people with HIV have managing their lives and meeting their needs.

These observations may help service providers to think about where their priorities lie, but the questions of how and where to act remain open. There is considerable 'capacity to benefit' among people with diagnosed HIV, but decisions about how to deliver these benefits have to take account of the complexity of the experience and causes of need.

THE COMPLEXITY OF NEED

In chapters 4-23 respondents' own accounts of their problems are described. These accounts expose the complexity and inter-relatedness of needs, with each need closely linked to a variety of similar or dependent needs. Each need has many different possible causes ranging from things over which individuals have great control to others over which they have no control. Each individual perceives the need and its impact in a different way. Each individual has different ideas about how best to tackle the need. Some needs may be resolved by a single intervention; others may require ongoing support; others will persist despite everything.

It is precisely because of this complexity that quantitative measures of need are useful in identifying broad trends. However, service providers must address this complexity directly. Three key issues are the individuality of need; the many possible causes of need; and the vast array of potential interventions to address them.

The complexity of need may make it difficult for service providers to decide exactly how and where they should focus their efforts, but every service provider should take seriously the individuality of need, which lies at the heart of the problem. This means doing some fairly basic things consistently: listening to what people say; respecting individual values and how people prioritise their own needs; taking seriously the secondary or unexpected impacts of interventions (especially medical ones); and ensuring that decisions are shared, not imposed. According to respondents, needs that affected quality of life, rather than simply health and illness, were often disregarded, especially in medical environments.

The causes of need range from physical health problems to the quality of housing conditions to the pervasive impact of social stigma and discrimination. Perceptions of where the causes of problems lay varied considerably, as did suggestions for interventions to address these problems. Consequently, the options for intervention are usually considerable, and can be directed at individuals, communities, existing services and society as a whole. Every service provider is likely to have commitments or strengths that will partly determine where among these choices its energies should be directed. However providers should recognise, at least collectively, the importance of addressing every level of potential influence over need.

In the era of combination therapy, the challenge for service providers is to respond sensitively, flexibly and creatively to the variety of needs of people with HIV. Medicine may have shifted the pattern of need, but it has not transformed it. Interest in gaining skills and retraining is now more common than problems with money, mobility, housing or coping with self-care and household chores. However, HIV still takes it toll on mental health, personal relationships and quality of life. Lots of people remain constrained by their immediate circumstances – by poor housing, illness and disability, immigration problems, discrimination and poverty.

Shifting the pattern of need will require greater attentiveness to the particularity of individual need as well as action at all levels to remove the obstacles to the full participation of people with diagnosed HIV in communities and society as a whole.

1 Introduction and survey methods

Anti-HIV treatments have had a huge impact on people with diagnosed HIV but this impact has been diverse, individual and unpredictable. The increased possibilities which treatments now offer have come with new risks: the risks of side-effects and treatment failure and the risks of giving up security and investing in hope when the future remains uncertain. For many people, the problems associated with having HIV – disability, discrimination, poverty, anxiety, isolation and loss – remained. Expanding treatment options have not always translated into reductions in need.

Changes in service provision (Weatherburn *et al*. 2007) and use have also been idiosyncratic. The complexity of changes in need has been compounded by the unpredictable relationship between needs and service use. People meet their needs in many ways, drawing on their internal resources and on the support of partners, family and friends. When they do turn to services, they do not always have a clear idea of the 'need' that they are trying to meet. Service use is often a process of trial and error in which individuals find their own ways of understanding and meeting needs. This study aimed to describe the needs in such a way that they were disentangled from any description of service use. The model of need adopted also reflected a commitment to letting people describe their needs on their own terms.

Changes in service provision over the last five years have been driven by funding pressures rather than an understanding of the changing needs of people with HIV (Weatherburn *et al*. 2007). Such pressures remain, but a clearer assessment of needs will hopefully improve our capacity to plan and fund appropriate services. This study offers such an assessment. We hope that it captures something of the reality of life with HIV in the UK and gives this reality a higher profile in the decision-making of HIV service providers and commissioners.

1.1 A MODEL OF NEED

Needs are difficult to pin down. A consistent approach to describing them requires a clear concept – disentangled from the various daily uses of the word. There are two ways of talking about need that are similar enough to cause confusion. 'Need' can express both a lack of something and the means of overcoming this lack. For example, compare "I need to worry less" with "I need counselling". The former describes a personal lack, the latter a way of addressing this lack. This dual use of language creates confusion between needs and services. It is possible to talk about needs entirely in terms of the services that might address personal lacks. But most services have the potential to address more than one lack. Counselling might help to overcome a lack of peace of mind or self-esteem, or it might help with managing stress and anxiety *etc*. Describing needs solely in terms of services can therefore be misleading as the underlying problem may remain unexplored.

For the purposes of our model need always refers to a lack, an unwanted deficit, and not to the interventions which might help to overcome these lacks or deficits. If needs are deficits, how are these deficits to be defined and identified? What counts as a needs-defining deficit? There are a number of different ways of answering these questions, all of which have relevance to the model we use:

- Complete accounts of need
- Subjective accounts of need
- Economic accounts of need

1.1.1 Complete accounts of need

In common language, 'needs' are often distinguished from 'wants'. This suggests that needs are somehow more fundamental and so should only relate to the things which people cannot do without. This in turn leads to attempts to describe complete accounts of human need, such as Maslow's (1954) hierarchy of needs, with basic physiological needs at the bottom and the need for 'self-actualisation' at the top with safety, belongingness and love in between.

Although such models strive to be descriptive, they always involve judgements about what should (and should not) be a need. Hence, there is no complete account of need that everyone will agree with. Needs are determined by individual circumstances, aspirations and priorities. One person's needs may seem irrelevant to another person.

It is impossible to conduct a needs assessment without some imposition of a framework to understand needs. The framework used in this study is based on the findings of our earlier in-depth qualitative research with people with diagnosed HIV. It was also informed by discussions with service providers but was constrained by the limitations of a self-completed questionnaire. It is not a complete account of need, merely an attempt to capture some of the most common needs among people with HIV.

The question of what 'counts' as a need was left to the survey respondents: they were asked if they had experienced any problems in each need area, over the previous year. If, for example, someone reported that they had a problem sleeping, this was taken as one indication of a need for sleep. Experience of problems is a key indicator of need in this study. However, this indicator does not capture how someone feels about their experience – the subjectivity of their need.

1.1.2 Subjective accounts of need

To address the subjectivity of the experience of need, our model draws on the theory of need proposed by Per-Erik Liss (1993). Liss defines need as the difference between someone's current actual state and their desired goal. This seems very simple. Need is wholly defined by the individual, on their own terms – not by researchers, service-providers or any other 'authority'.

This theory helps to clarify the ways in which needs can change:

- Needs reduce if the actual state improves and moves closer to the desired state;
- Needs increase if the actual state worsens and moves further away from the desired state.

However:

- Needs also reduce if the desired state is lowered and brought nearer to the actual state;
- Needs also increase if the desired state is heightened and taken further away from the actual state.

For example, an improvement in health may reduce need by improving someone's 'actual state' (daily life gets easier to manage) but also increase need by heightening the 'desired state' (a larger social circle becomes possible but obstacles that were irrelevant before now become important). Similarly, illness can increase needs by worsening the 'actual state' but decrease needs by lowering the 'desired state'.

The difference between actual and desired states was captured in the model by asking respondents to describe, for most need areas, their satisfaction with their current state. Hence, as well as asking respondents whether they had experienced any problems with sleep (for example), the survey also asked them how they felt about their ability to sleep as and when they wanted to.

Crucially, respondents who reported having particular problems were not always dissatisfied with their current state. This reflected either an acceptance of the problem and its impact on life (a lowering of desired state) and / or ongoing strategies to cope with the problem (improving the actual state through services or other interventions). In some circumstances respondents who did not report problems were nonetheless unhappy with their current state. This was common for needs with a strong aspirational quality, such as housing and money.

1.1.3 Economic accounts of need

Economists like precise, measurable concepts to work with. Consequently they have been among the fiercest critics of the concept of need and have sought an unambiguous definition (Culyer 1995). They argue that, from the perspective of those charged with spending NHS money, need is only interesting in as much as it relates to the use of services.

In order that a service cost can be identified need is defined as an individual's 'capacity to benefit' from health care. Whatever it costs to exhaust this capacity to benefit is the cost of meeting the need. This definition can create the absurd situation where a need is only a need if there is a service available to meet it – if there is nothing to benefit from, there can be no capacity to benefit. In reality, though, the 'commonsense' use of need does not extend to things that are completely unattainable.

Our model includes the idea of 'capacity to benefit', but respondents decided for themselves whether they had such a capacity. Furthermore, potential help or support to address any need were not assumed to derive solely from services. For most need areas, respondents were asked to indicate where they had got help from in addressing their problems in the previous 12 months. They were then asked *With more help or support, do you think you could reduce, or overcome, these problems?* Those who answered *yes* or *don't know* were assumed to have a capacity to benefit from further help or support.

Clearly, some respondents who answered *no* to this question might not have been aware of the range of interventions that could address their problems, so it would be wrong to assume that they had no capacity to benefit. Nonetheless, this question provides a useful indicator of need for service providers: the extent to which there is a willingness to accept help or support to meet needs.

1.1.4 Summary of understandings of need

This report focuses on twenty needs areas. These need areas are not comprehensive but provide insight across the range of physical, psychological, social and medical needs.

For each need area described here there are three key indicators of need:

- Dissatisfaction with current state.
- Experience of problems in the last year.
- Personal perception of capacity to benefit from further help or support.

Each of these indicators has its strengths. In particular:

- Dissatisfaction with current state is true to the subjectivity of people's lives, taking account of their priorities, aspirations and coping skills, as well as their problems.
- Experience of problems in the last year is a more objective indicator of need – a retrospective description of the actual problems experienced by respondents. However, respondents still made their own judgements about which experiences counted as a problem.
- Personal perception of capacity to benefit from further help or support provides a measure of the scope for action to address their needs, through services or informal support.

1.2 METHODS

Priority was given to obtaining a large and geographically diverse sample. This required a questionnaire that was relatively easy to complete and a wide-ranging recruitment strategy.

In order to maximise the speed with which the questionnaire could be completed, most of the questions only required a tick, unless the range of answers could not be prejudged from our comparable survey (Weatherburn *et al.* 2002). Respondents were asked to describe in their own words the problems they had experienced in need areas where the same question had not been asked in our previous version of the survey (Weatherburn *et al.* 2002).

The questionnaire was designed as a 24-page A5 booklet, which stated that all responses would be anonymous. It included 20 questions about the demographic characteristics of respondents and another 9 on their personal HIV history. It then asked nine very similar questions about each of the 20 need areas. We estimate that, on average, the questionnaire took twenty minutes to complete.

Piloting of the questionnaire occurred with 25 people with diagnosed HIV in London and Luton. All pilot respondents were asked to complete the draft questionnaire and then feedback individually or in a group discussion. The discussion focused on their feelings about the questionnaire including ease of completion and their understanding of questions. Pilot participants were paid for their time and effort.

As there was no national sampling frame available, recruitment was opportunistic but purposive: *ie.* using as many different avenues as possible to reach as many different people as possible. Distribution lasted seven months, from 5th June 2007 until 5th January 2008. By using multiple recruitment methods, we sought to reduce the biases of opportunistic recruitment. However, the sample will not include people who do not have any contact with services, unless given a questionnaire by friends. It will also be skewed away from people who are not literate in English, worried about confidentiality or wary of social research. The sample description in chapter 2 demonstrates that the survey was successful in recruiting a diverse national sample but the comparison with national prevalence data (on page 16) reveals biases towards people who were male, gay or bisexual, White and older.

The study received approval from Oxford A Multi-centre Research Ethics Committee with confirmation that the research fell within the Department of Health's (November 2000) Supplementary Operational Guidelines for NHS Research Ethics Committees on Multi-Centre Research in the NHS – the process of ethical review when there is no local researcher.

The majority of questionnaires were distributed via charitable AIDS service organisations and HIV out-patient clinics. Using NAMbase we wrote to 382 charitable agencies who were listed as providing service to people with HIV. We also approached the ten HIV-outpatients clinics with the highest caseload of Africans with diagnosed HIV in the UK (with data provided by the Health Protection Agency). A wider range of clinics could not be approached, because of the inordinate amount of administration needed to establish specific permission to undertake research with the R&D units of each and every local NHS trust where we wanted to collaborate with a clinic.

In total, 107 organisations distributed the self-completion written questionnaire directly to their patients, clients and service users (see *Acknowledgements*). 17,815 booklets were requested by and sent out to 95 agencies. We assume the twelve remaining agencies received blank booklets from agencies they collaborated with. The average (median) number of booklets requested per participating agency was 50 (range 5 to 800 excluding NAM, see below). All agencies were invited to mark booklets they distributed with their stamp to indicate its source. All these agencies that recruited more than 20 people to the final sample have received a targeted data report on the people they recruited.

NAM also sent the booklet questionnaire by post to 4,950 subscribers to their HIV treatments newsletter (called HTU). While not everyone subscribing to HTU has diagnosed HIV infection, NAM estimates 70-75% of their mailing list has diagnosed HIV. At least two other collaborators mailed the questionnaire directly to service users who had consented to receive such mailings – The Cara Trust and Positively Women. Other agencies may have done the same without informing us. We also agreed to send the questionnaire directly to 1000 subscribers to Positive Nation magazine but the host organisation, the UK Coalition of People with HIV and AIDS, closed prior to doing so.

Our previous version of this study (Weatherburn *et al.* 2002) suggests that of the 17,815 booklets distributed from Sigma Research to agencies, 30% will not have been distributed by the agencies receiving them. Hence, approximately 12,500 copies of the questionnaires were distributed including the mass mailings above. Of course some of these would not have gone to people with diagnosed HIV and some people with HIV probably received multiple copies.

The questionnaire was also available to complete and submit online in both English and French. The online version of the survey was hosted by www.demographix.com with identical questions to the booklet. Its availability was promoted via the websites of eleven collaborators (see *Acknowledgments*). Ultimately 815 people completed the survey online in English, and 1 did so in French.

Overall, we received 1929 questionnaires, including 1113 booklets and 816 online responses. Of these, 152 (8.6%) were excluded from further analysis because they gave no evidence of living within the UK (n=33) and / or having diagnosed HIV infection (n=103) and / or they had previously taken part in the study (n=36). This left a final sample of 1,777 people with diagnosed HIV that were resident in the UK.

2 Sample description

After exclusions there were 1777 respondents in the sample. Of all respondents 60% (n=1074) were recruited via the booklet and 40% (n=703) were recruited online. This chapter provides a description of the characteristics of the entire sample. It closes (section 2.12) with a comparison of the demographic profile of our sample and the National Survey of Prevalent HIV Infections Diagnosed (SOPHID) undertaken by the Health Protection Agency.

2.1 GENDER

More than three quarters (79%) of the entire sample was male, and just over a fifth (21%) were female (see section 3.5.1 for a full description of all female respondents). Among the booklet sample, a quarter (27%) were female compared to one-in-nine (11%) of the online sample.

2.2 SEXUALITY

The sample included 1154 gay and 60 bisexual men (71% of the entire sample); and 7 lesbians, 3 women who identified as gay and 6 bisexual women (1% of the entire sample). It also included 137 heterosexual men (8%) and 327 heterosexual women (19%).

Sexuality (n=1710, missing 67)	**% (n) overall**	**% by gender**	
		Female (n=351)	**Male** (n=1359)
Heterosexual (straight)	27 (464)	93	10
Gay	68 (1157)	1	85
Lesbian	<1 (7)	2	0
Bisexual	4 (66)	2	4
Other	1 (16)	3	1

A minority of female respondents (5%) had a gay, lesbian or bisexual sexual identity compared to the majority of males (90%) – see section 3.5.2 for a full description of gay and bisexual male respondents. White respondents were significantly more likely to have a gay, lesbian, bisexual or other queer identity (85%) compared to Asian (69%), or Black African (4%) respondents.

2.3 COUNTRY AND REGION OF RESIDENCE

All respondents were asked what country and which local authority/ city or town they currently lived in. Respondents were excluded if there was no evidence they lived in the UK.

Country and Strategic Health Authority of residence for England residents (n=1777, missing 0)	**% (n) overall**	**% by gender**	
		Females (n=366)	**Males** (n=1372)
UK-resident but area unknown	**2 (37)**	**5**	**1**
All England	**91 (1608)**	**89**	**91**
East of England	5 (80)	7	4
East Midlands	3 (57)	4	3
London	43 (760)	40	44
North East	2 (33)	1	2
North West	10 (174)	5	11
South Central	4 (79)	6	4
South East Coast	7 (117)	3	8
South West	4 (78)	4	4
West Midlands	8 (133)	8	8
Yorkshire & Humber	5 (96)	10	4
All Wales	**4 (67)**	**3**	**4**
All Scotland	**3 (49)**	**3**	**3**
All Northern Ireland	**1 (17)**	**1**	**1**

2.4 AGE

The age of respondents ranged from 17 to 78 with an average (median) of 42 (mean 42, standard deviation (sd) = 10). The majority were in their 30s (31%) or 40s (39%). The online sample was significantly younger (mean 40 years, sd = 9, median 39, range 17-68) than the booklet sample (mean 44 years, sd = 10, median 43, range 18-78).

Women were significantly younger (mean 40 years, sd = 10, median 40, range 19-73) than men (mean 43 years, sd = 10, median 42, range 17-78).

Age groups (n=1765, missing 12)	**% (n) overall**	**% by gender**	
		Females (n=358)	**Males** (n=1369)
under 25 years old	3 (50)	5	2
25 – 29 years old	6 (106)	6	6
30 – 34 years old	11 (195)	16	10
35 – 39 years old	20 (345)	23	19
40 – 44 years old	22 (394)	20	23
45 – 49 years old	17 (294)	16	17
50 – 54 years old	9 (165)	6	10
55 – 59 years old	7 (116)	5	7
60 years old or over	6 (100)	3	6

2.5 ETHNICITY AND MIGRATION HISTORY

Four fifths (79%) of the sample was White, including 67% who were White British. Of the remainder the majority (15%) defined themselves as Black African, with 6% specifying other ethnicities which were not White.

Ethnic groups (n=1765, missing 12)		**% (n) overall**	**% by gender**	
			Female (n=364)	**Male** (n=1364)
White	*British*	67 (1180)	32	76
	Irish	4 (62)	2	4
	Other White	9 (160)	6	10
Black / Black British	*Caribbean*	1 (18)	2	1
	African	15 (258)	51	5
	Other Black	<1 (5)	1	1
Asian / Asian British	*Indian*	1 (10)	1	<1
	Pakistani	<1 (3)	0	<1
	Bangladeshi	<1 (4)	1	<1
	Other Asian	<1 (6)	1	<1
Dual Ethnicity	*White & Black Caribbean*	1 (10)	1	1
	White & Black African	1 (13)	2	<1
	White & Asian	<1 (3)	1	<1
	Other mixed	1 (15)	1	1
Chinese		<1 (4)	0	<1
All other ethnicities		1 (14)	1	1

While White respondents were significantly more likely to be male (90%) than female (11%), Black Africans were significantly more likely to be female (73%) than male (27%) – see section 3.5.5 for a full description of Black African respondents.

Asian respondents were significantly younger (mean 38 years, sd = 12, median 38, range 20-66) than either Black Africans (mean 41, sd = 9, median 40, range 19-74) or all White respondents (mean 43 years, sd = 10, median 42, range 18-78).

2.5.1 Country of birth

Respondents were asked the open ended question: *What country were you born in?* In total, 75 countries were represented. The table below shows the 14 countries in which at least ten respondents were born, the proportion of the total sample that group represents, what proportion of females and males were born there, and the average (median) age of people from that country.

Country of birth (n=1771, missing 6)	**% (n) overall**	**% female** (n=363)	**% male** (n=1371)	**average age** (n=1761)
United Kingdom	69 (1226)	35	78	42
Zimbabwe	5 (94)	19	2	41
Uganda	3 (51)	11	1	43
Republic of Ireland	2 (43)	1	3	40
France	2 (26)	3	1	41
Germany	1 (24)	1	2	44
Zambia	1 (24)	5	<1	43
Republic of South Africa	1 (23)	3	1	37
Italy	1 (19)	1	1	39
United States of America	1 (19)	0	1	46
Nigeria	1 (18)	3	<1	44
Kenya	1 (16)	3	<1	40
Spain	1 (13)	<1	1	43
Australia	1 (11)	0	1	41

People born in the United Kingdom accounted for 69% of all responses, including three quarters (78%) of males and a third (35%) of females. African-born respondents accounted for 16%, including 6% of males and more than half (55%) of females. Other respondents were born in the rest of Europe (9%), North America (2%), Asia (2%), Oceania (1%) and South America (1%).

2.5.2 Length of time living in the UK

Among migrants to the UK (31% n=551) the average (median) length of time resident in the UK was 9 years and 4 months (mean 155 months, sd = 132, range 1-756).

On average, African migrants (16% n=284) had lived in the UK for a significantly shorter time (mean 107 months, sd = 90 months, median 79 months, range 1-756) than migrants from other areas of the world (mean 207 months, sd = 150, median 168 months, range 1-672).

2.5.3 *First Language*

Unsurprisingly the vast majority of respondents had English as a first language. Shona, French, Spanish, Italian and Luganda were the only other first languages of more than 1% of respondents.

First language (n=1763, missing 14)	**% (n) overall**	**% by gender**	
		Female (n=357)	**Male** (n=1369)
English	82 (1438)	56	88
Shona	3 (56)	12	1
French	2 (39)	3	2
Spanish	1 (23)	1	1
Italian	1 (19)	1	1
Luganda	1 (17)	3	<1
other languages	10 (171)	24	6

Other first languages mentioned by more than 3 respondents included: German (15 people); Kisawhil / Swahili (13); Ndebele / Sindebele (13); Portugese (11); Welsh (7); Zulu / Fanagalo (7); Bemba (6); Greek (6); Kinyarwanda (5); Thai (5); Dutch (4); and Luo (4).

Booklet respondents (77%) were significantly less likely to be native English speakers compared to internet recruits (90%), as were females (56%) compared to males (88%).

2.6 EDUCATIONAL LEVEL

Very small proportions of all respondents had no education (1%), or left school after primary or elementary school (1%). Over a quarter (28%) had secondary or high school education and more than two thirds (69%) had been educated to university or college level.

Highest educational level (n=1758, missing 26)	**% (n) overall**	**% by gender**	
		Females (n=357)	**Males** (n=1359)
None	1 (22)	2	1
primary / elementary school	1 (22)	4	1
secondary / high school	28 (493)	29	28
university / college	69 (1214)	65	70

Internet recruits were significantly more likely to have a university or college education than booklet recruits (75% compared to 65%) and less likely to have a secondary or high school education (24% compared to 31%). University education did not significantly vary by gender or ethnicity. However, respondents with a gay, lesbian or bisexual identity were significantly more likely to have a university or college education (72% compared to 64%).

2.7 HAEMOPHILIA

Seventeen men and four women reported having haemophilia or similar bleeding disorder (1% of all respondents, see section 3.5.7 for a full description of these respondents).

2.8 INJECTING DRUG USE

Previous experience of injecting drug use was reported by 8% of all respondents (n=143), of which 45 reported injecting drug use in the previous six months (3% of all respondents, see section 3.5.8 for a full description of these respondents).

2.9 PARTNERS AND CHILDREN

Just under half (49%, n=875) of all respondents had a partner, husband, wife or civil partner at the time of completing the survey. Three quarters (70%) of these respondents lived with their partner (35% of all respondents).

One-in-eight (12%, n=202) respondents had day-to-day responsibility for the care of a child (see section 3.5.10 for a full description of these respondents) but only 9% (n=151) were living with children. For some, children had grown up; others were separated from their children.

2.10 EMPLOYMENT, EDUCATION AND INCOME

Half (52%) of all respondents were in some form of paid employment (n=930), most of whom (42%, n=740) were working full-time. Others were working part-time (9%, n=166) or casually / cash-in-hand (1%, n=22). Of respondents who were not in paid employment (47%, n=838), the largest proportion (42%, n=349) were unable to work because of a long-term illness, disability or medical retirement but another 13% (n=110) described themselves as retired. Of those that were not in paid employment 9% were not allowed to work for immigration reasons. Of those that described other activities the majority were doing voluntary work.

Compared to respondents completing the booklet, respondents recruited online were more likely to be in full-time employment, and less likely to not be employment, or to be unable to work, not allowed to work or retired.

Women were less likely to be in any paid employment compared to males (40% compared to 56%) and were more likely to be currently in education (20% compared to 9%).

Current activity: employment and education (n=1768, missing 9)	**% (n) overall**	**% by gender**	
		Females (n=364)	**Males** (n=1365)
Full-time employment	42 (740)	24	46
Part-time employment	9 (166)	15	8
Casual / cash-in-hand	1 (22)	1	1
On a training scheme / Back-to-work activity	1 (15)	1	1
Full-time education	4 (66)	8	3
Part-time education	7 (122)	12	6
Carer / homemaker	2 (40)	7	1
Not in employment & registered for benefits	19 (341)	23	19
Not in employment & not registered for benefits	4 (61)	5	3
Unable to work (long-term illness /disability / medically retired)	20 (352)	14	22
Not allowed to work	4 (75)	16	1
Retired	7 (117)	4	7
Other	3 (57)	5	3

Black African respondents were less likely to be in paid employment (35%) compared to Asian (50%) and White respondents (57%). However, Black Africans were more likely to be engaged in any education (28%) compared to Asian (13%) or White respondents (8%).

Those with a gay, lesbian or bisexual identity were more likely to be in paid employment (57% compared to 43%) and less likely to be in education (8% compared to 19%).

Of all respondents, a third (32%) lived on a personal income of less than £10,000 per year, and almost half (48%) survived on less than £15,000 per year.

2.11 LIVING WITH HIV

The length of time since respondents had first been diagnosed with HIV ranged from a week to over 25 years, with an average of 8 years 4 months (median 6½ years). Nine percent of all respondents had been diagnosed in the year prior to completing the survey (see section 3.5.9 for a full description of these respondents). Compared to males, females had been diagnosed for a shorter period of time. This was also the case for Black Africans compared to Asians, all White respondents and all 'other' ethnic groups. Heterosexuals had been diagnosed more recently than those with a gay, bisexual or other queer identity.

Chapter 20 provides a description of the proportion of respondents taking anti-HIV treatments and the problems they experienced.

2.11.1 Place of initial HIV diagnosis

Two thirds of all respondents (66%) were first diagnosed with HIV in a GUM or STD or HIV clinic.

Place of initial HIV diagnosis (n=1759, missing 18)	**% (n) overall**	**% by gender**	
		Females (n=361)	**Males** (n=1359)
in a GUM or STD or HIV clinic	66 (1154)	48	70
in hospital (on a ward)	15 (259)	21	13
at your GP (family doctor)	7 (130)	10	7
at a private clinic	4 (65)	4	4
at an ante-natal clinic (during pregnancy)	2 (32)	8	<1
at a community testing service (eg. fasTest)	1 (24)	2	1
other places	5 (95)	8	5

Other places where first HIV diagnosis had occurred included: other hospital out-patients clinics (23 respondents); via the blood donation service (16); for insurance or mortgage purposes (5); when participating in research (4); in a tropical diseases unit (4); haemophilia centre (4); haematology department (4); in prison (4); in a drug dependency unit (3); via a private doctor (3); during an employment medical (3); after a miscarriage (1); during a visa application (1).

Females were significantly more likely to have received their first HIV diagnosis while in hospital as an in-patient, from a GP and from an ante-natal clinic. Males were more likely to have been diagnosed via GUM out-patient services.

Black respondents were less likely to have been first diagnosed in GUM services (47%) compared to White (69%) and Asian (81%) respondents, and more likely to have been diagnosed as an in-patient (28%), compared to White (12%) and Asian (6%) respondents.

Those with a gay or bisexual identity were more likely to have been first diagnosed in GUM services (73%) compared to heterosexuals (48%), and less likely to have been diagnosed in hospital (11% compared to 23%).

2.11.2 HIV disclosure or knowledge

All respondents were asked whether they had disclosed – or otherwise made known – their HIV diagnosis to a range of family members and other likely people in their lives. The table below excludes those that answered not applicable or failed to answer a specific question within this set. They were assumed not to have a relationship of that type (for example an employer or siblings).

HIV disclosure	% Yes	% No	
Partner (n=974)	93	7	
Mother (n=1257)	56	44	
Father (n=1015)	48	52	
GP (family doctor) (n=1658)	85	15	
Employer (n=889)	48	52	
	% All	**% Some**	**% None**
Children (n=380)	35	14	52
Brothers / sisters (n=1423)	53	15	33
Friends (n=1583)	29	62	9
Work colleagues (n=946)	14	34	52
Other people you live with (n=483)	46	15	40

While the majority (93%) of those with a partner had disclosed their HIV infection to them, and most (85%) had disclosed to their GP, the proportion who had disclosed in other relationships was much lower. About half had disclosed to parents, all siblings, any of their children or an employer.

While there were no differences in disclosure to partners, GPs, work colleagues or employers, compared to males, females were more likely to have disclosed to their mothers, fathers, children, brothers and sisters and were less likely to have disclosed to friends or the people they lived with. Black African respondents were more likely to have disclosed to their children and at least some of their siblings compared to other ethnic groups and they were more likely to have disclosed to any friends but less likely to have told all of them. Those with a gay, lesbian or bisexual identity were less likely to have disclosed to their mother, father, GP, children or siblings but were more likely to have disclosed to employers, friends, work colleagues and people they lived with.

2.11.3 Other long-term illnesses

Over a quarter (28%) of respondents considered themselves to have a long-term illness in addition to HIV. There were a huge range of other illnesses and conditions reported. By far the most common problem mentioned was poor mental health – with 5% of all respondents reporting mental health problems. Respondents usually described the illness as depression, or clinical or chronic depression. While other mental health diagnoses were mentioned, these were relatively uncommon.

The only other health problem described by more than 3% of all respondents was hepatitis – with a hepatitis C diagnosis more than twice as common as hepatitis B. While hepatitis was most common among people with haemophilia it was common across the whole sample. The health problems mentioned by 1-2% of the entire sample were arthritis; diabetes; high blood pressure / hypertension; asthma; haemophilia; and heart disease / problems. Health problems mentioned by 0.5% to 1% of the sample included neuropathy; back pain / injury / problems; mobility impairment; ulcerative colitis; epilepsy; cancer; alcoholism and tuberculosis.

2.12 COMPARISON WITH NATIONAL DATA

The difference between our sample and the UK population of people with diagnosed HIV was estimated by comparing sample demographics with the National Survey of Prevalent HIV Infections Diagnosed (SOPHID), conducted annually by the Health Protection Agency's Centre for Infections and Health Protection Scotland. SOPHID 2007 data is used.

This comparison reveals that our sample was geographically distributed in roughly the same proportions as SOPHID. However, our sample over-represents people with diagnosed HIV in Wales and Northern Ireland and under-represents people in Scotland. Across England, our sample over-represents people in the North West and West Midlands and under-represents people in East of England and East Midlands. However the main problems with our sample are that it is disproportionately male and gay or bisexual, White and older. The biggest divergence from SOPHID was the relatively low proportion of respondents who were Black African, especially among women. Because of these differences, service providers should consider the pattern of needs within the target populations relevant to them (see section 3.5) and the broad patterns across the sample.

Comparison of WDYN sample and SOPHID		WDYN %	SOPHID %
Gender	**Female**	**21**	**34**
	Male	**79**	**66**
Area of residence	**All England**	**90**	**93**
	East of England	5	7
	East Midlands	3	4
	London	44	45
	North East	2	2
	North West	10	9
	South Central	5	5
	South East Coast	7	7
	South West	5	4
	West Midlands	8	6
	Yorkshire & Humber	6	5
	All Wales	**4**	**2**
	All Scotland	**3**	**5**
	All Northern Ireland	**1**	**1**
Age group	**15 – 24**	**3**	**4**
	25 – 29	**6**	**9**
	30 – 34	**11**	**15**
	35 – 39	**20**	**21**
	40 – 44	**22**	**21**
	45 – 49	**17**	**14**
	50 – 54	**9**	**7**
	55 +	**12**	**9**
Ethnicity	**White**	**79**	**53**
	Black African	**15**	**37**
	Black Caribbean	**1**	**3**
	Black other	**<1**	**2**
	Indian / Pakistani / Bangladeshi	**1**	**1**
	Other Asian / Oriental	**1**	**2**
	Other / Mixed	**3**	**4**
Sexual identity (sexual exposure categories in SOPHID)	**Men that have sex with men**	**72**	**46**
	Heterosexual men	**20**	**20**
	Heterosexual women	**8**	**34**

3 Twenty needs: an overview

The need areas explored in this study include a range of personal, social and medical issues. They are not a comprehensive list of all the needs of all people with diagnosed HIV but they provide an insight into some of the key concerns of people living with HIV. This chapter summarises the results across all need areas prior to an in-depth examination of each need area in chapters 4 – 23 .

By quantifying and comparing levels of need, a pattern across the whole sample can be described. However, such comparisons should be made with care, as each need area encompasses a range of specific needs that was sometimes quite broad. The incidence of need is therefore partly a reflection of the range of meanings that any need could have for respondents. Each of the following need chapters explores these variations in detail.

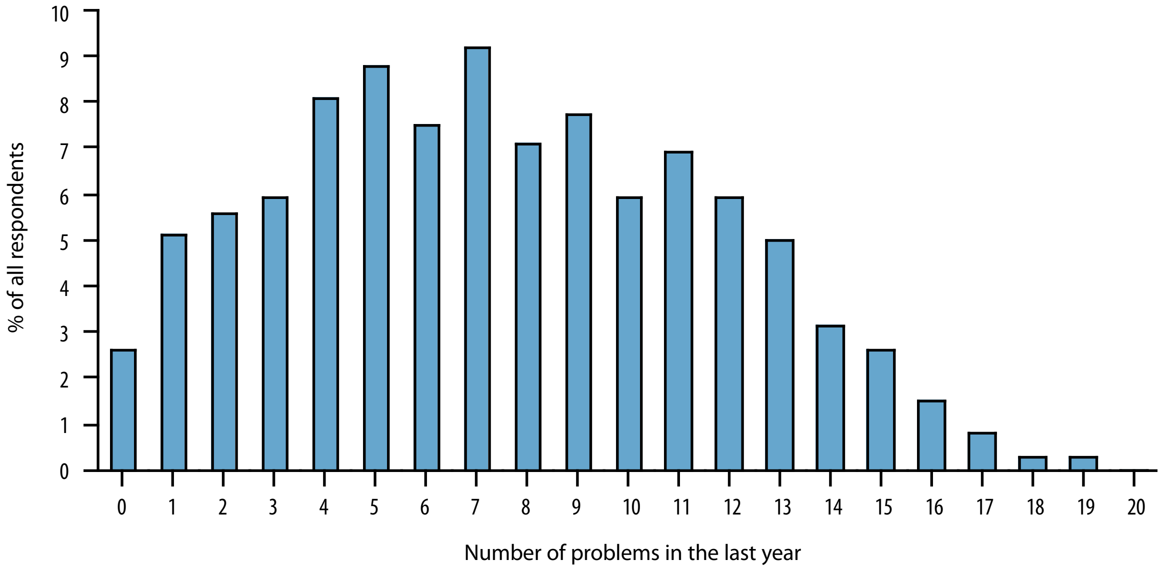
While the findings below are effectively a picture of 'unmet need' across all people with diagnosed HIV, they tell us nothing about the needs of any specific individual. Patterns of need can be very different for every individual, and the significance of any single problem will vary for the individuals that have them. Many respondents expressed the importance to them of being treated as an individual with personal needs and priorities.

Despite these qualifications, the findings challenge anyone with an interest in the lives of people with diagnosed HIV to examine their own assumptions about the reality of living with HIV in the UK today.

3.1 MULTIPLE NEEDS

Chart 3.1 illustrates the incidence of multiple problems in the whole sample. Less than 3% of all respondents did not report any problems in the last year and a sixth (16%) identified between one and three needs (experiences of problems). In the last year, another third (34%) of all respondents identified between four and seven needs, and a similar proportion (34%) identified between eight and twelve needs. One-in-eight (14%) of all respondents reported between thirteen and nineteen of the twenty needs areas asked about. No respondent reported having had all 20 problems in the last year.

Chart 3.1: Multiple incidence of problems



3.2 INCIDENCE OF NEEDS

The three key indicators of need used in the survey are summarised in Charts 3.2 to 3.4. Chart 3.2 describes how respondents felt about their current situation with regard to each of the need areas. These feelings may reflect many different aspects of life including the experience of specific problems, personal acceptance of problems, the extent of available support and individual aspirations to improve personal circumstances and exploit the possibilities of life. Chart 3.2 provides the best indication of respondents' personal perceptions of need. This chart does not include feelings about four of the needs areas: taking treatments, immigration, discrimination and alcohol and drugs as questions about feelings on these topics were not asked in the same way.

Chart 3.2: Feeling unhappy about current state (% of all)

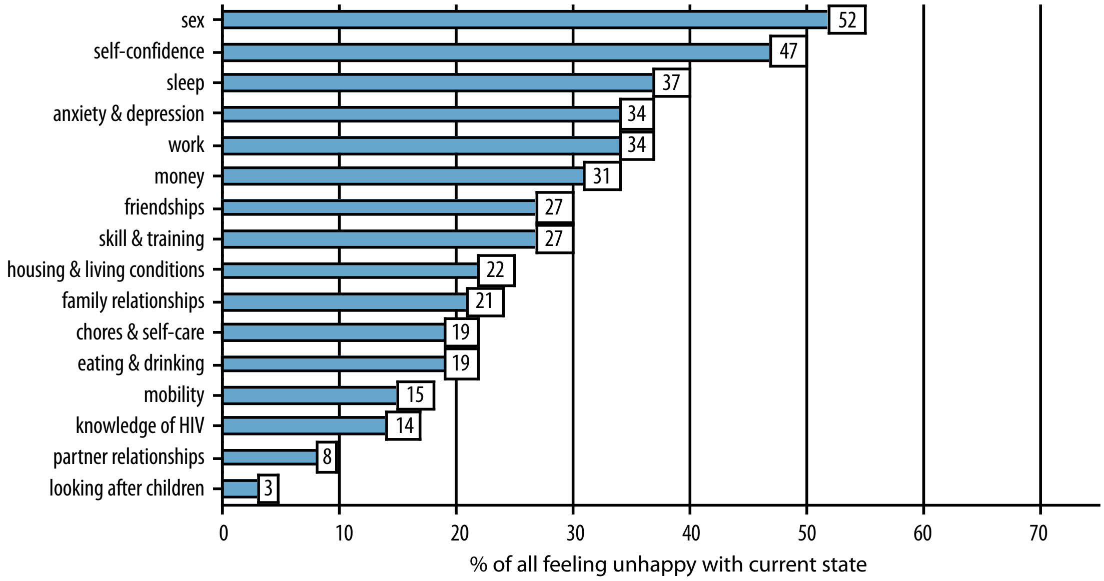


Chart 3.3 describes respondents' experience of problems in each of the need areas over the previous year. This chart omits training, skills and job opportunities because these questions were based on interests, not problems (see chapter 21). Whereas Chart 3.2 is informed by many different aspects of respondents' attitudes and experience, Chart 3.3 has a single focus: the experience of problems. This focus is the strength of this indicator and makes comparison between the need areas easier.

Chart 3.3: Problems in the last year (% of all)

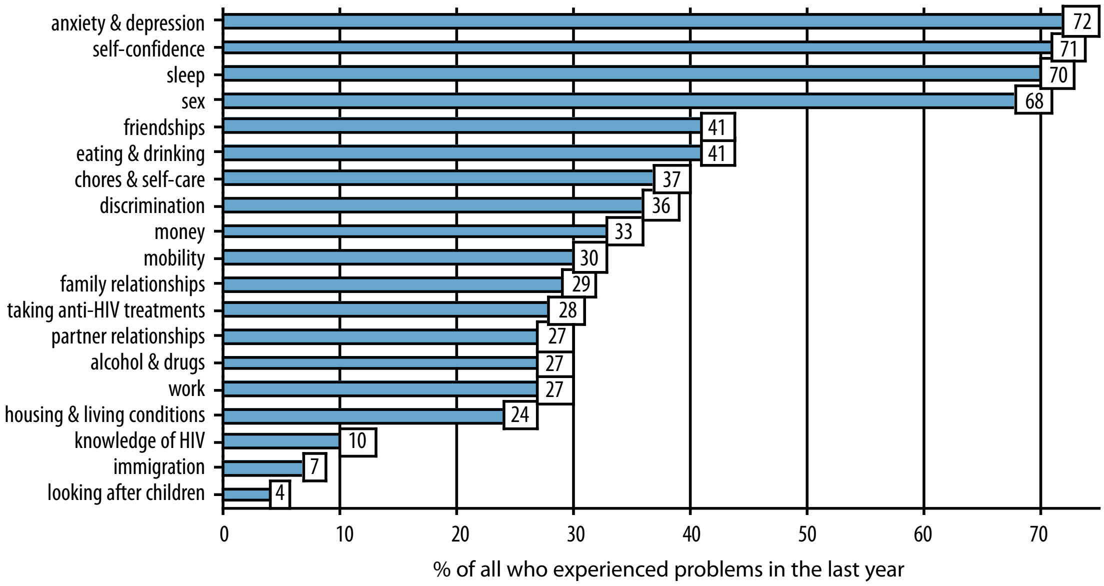
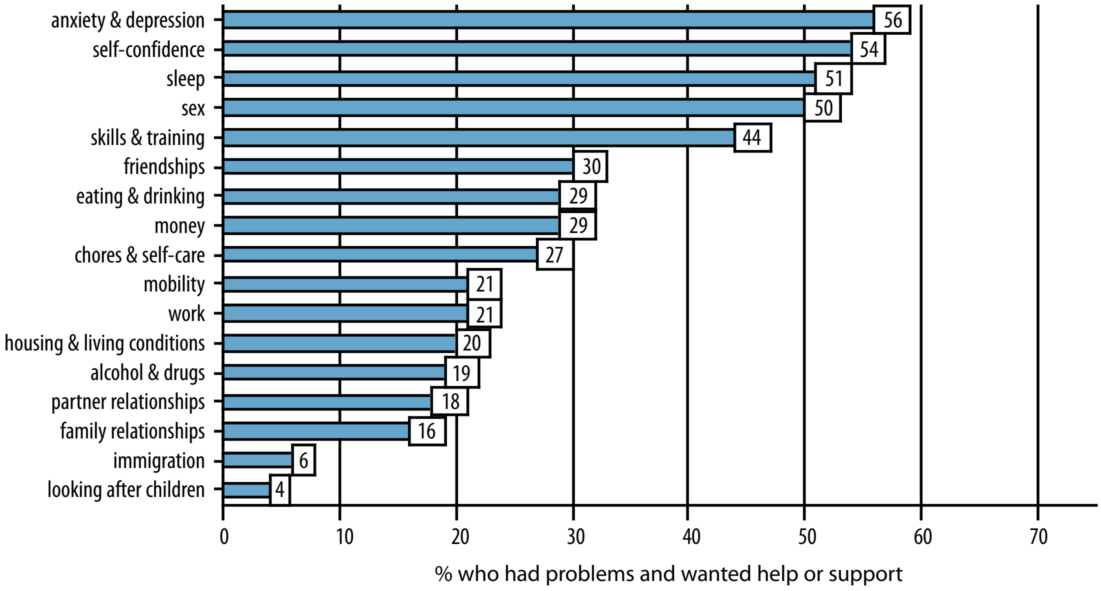


Chart 3.4 describes respondents' personal perceptions of their 'capacity to benefit' from further help or support, whether or not any had been received any help or support with that problem. This is the most important chart for service providers, informal carers and others with an interest in addressing unmet needs. This chart does not include three needs areas: taking anti-HIV treatments, getting information about HIV and experience of discrimination as questions were asked differently for these three areas.

These charts reveal that although the choice of indicator makes some difference to the absolute level of reported need, the pattern of needs is broadly the same for each. In particular, the top four needs – related to anxiety and depression, self-confidence, sleep and sex – remain most common whichever needs indicator is used. Moreover, if we compare problems in the last year (Chart 3.3) and capacity to benefit (Chart 3.4) these four needs, all related to mental health, occur in the same rank order.

Chart 3.4: Capacity to benefit (% of all)



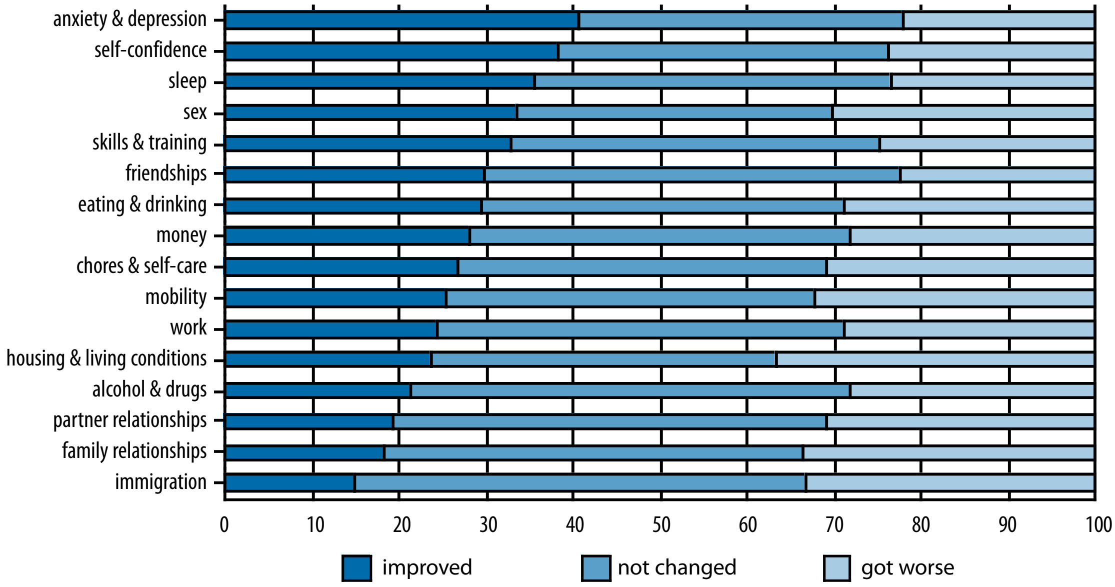
Charts 3.2 to 3.4 illustrate the frequency with which each of the twenty needs was reported among all respondents. However, some of the needs listed are irrelevant to a significant proportion of the sample, and the experience of those respondents for whom these needs are relevant is under-represented. In particular:

- Among the respondents with day-to-day responsibility for the care of a child, 27% were unhappy about their ability to look after children, 37% had experienced problems looking after them in the last year, and 33% had ongoing problems and felt that further help or support would be useful, or did not rule this out.
- Among those respondents who had a current regular partner, 38% were unhappy about their relationship, 40% had experienced problems in their relationship in the last year, and 27% had ongoing problems and felt that further help or support would be useful, or did not rule this out.

3.3 CHANGES IN NEED

Respondents' retrospective assessments of changes in their needs are summarised in Chart 3.5. The need indicator used is experience of problems. For each need area, people with that problem were asked whether in the last year the problem had got better, got worse or not changed. This question was not asked for four of the need areas – taking treatments, experience of discrimination, getting information about HIV, and interests in getting further training and skills. From the top downwards, the order of needs in the chart is based on the proportion of people who said the problem had improved in the last year.

Chart 3.5: % changes in problems over the last year



For the first seven of the sixteen need areas from the top of the chart, the news was optimistic – more people saw the problem improve or resolved in the last year than saw it get worse. However, for the bottom nine needs areas in the chart the opposite was true – more people saw the problem get worse than saw it improved or resolved. In an identical analysis from our previous version of this survey (Weatherburn *et al.* 2002) the overall picture was considerably more optimistic. In that survey, for thirteen need areas, problems had got better more often than they had got worse and for only four needs, problems had got worse more often than better.

3.4 CURRENT PROVISION OF HELP AND SUPPORT

In each need area, respondents turned to a different combination of people and places for help and support. On the following chart all the service and support categories which were predefined in the survey are included, as long as they appeared as a source of help or support in more than one needs area. The sources of help and support are listed in descending order of their overall use. The need areas are listed in the order of the chapter structure of this report.

If you read down the columns it is feasible to establish which sources of support were most common for specific need areas. For example, reading down the friendship column it is feasible to see that the most common sources of help and support were (other) friends, followed by HIV organisations and counselling or psychology services, followed by GUM (HIV) out-patients clinics, partners and spouses and other family members. Alternately, we can look across rows to examine what needs or problems specific kinds of help and support are most useful for. For example, HIV organisations make their greatest contribution to needs concerning immigration, housing, money and friendships.

	immigration	housing	eating & drinking	sleep	household chores	mobility	money	alcohol & drugs	anxiety & depression	self-confidence	friendship	family relationships	partner relationships	children	sex	training and skills	work
my friends	2	5	4	3	5	5	4	5	5	5	6	6	6	5	4	3	4
HIV organisation	5	5	3	2	3	3	5	3	4	4	5	4	4	3	3	3	4
partner / spouse	2	3	4	3	5	4	3	4	4	4	3	4	4	4	3	3	3
HIV (GUM) clinic	3	3	6	4	3	3	1	4	5	5	3	3	5	3	6	1	3
counselling / psychology								6	6	6	5	5	6		5		
GP practice	3	2	4	5	3	3	1	4	5	4	2	2	3	2	3	1	3
other family	1	3	2	1	3	3	3	3	3	3	3	3	3	3	1	1	2
council / social services	4	5	2	1	3	3	4	1	2	1	2	2	2	3	1	2	2
parents	2	3	2	1	3	3	4	3	2	3	2	2	3	4	1	1	2
prescribed medications				6					4								
general charity		1	1	1	1	2	2	1	1	1	1	1	1	1	1	2	2
children	1	1	1	1	2	1	1	1	1	1	1	1	1	3	1	1	1
a back to work service																2	3

1	**2**	**3**	**4**	**5**	**6**
0 – 5%	**6 – 10%**	**11 – 20%**	**21 – 30%**	**31 – 40%**	**41 – 50%**

The chart demonstrates the essential role of informal sources of help and support – especially friends and partners but also other family and parents. Support from these sources is utilised to deal with most needs. This is one reason that rejection from partners, friends, families and communities was so profoundly felt. It is also important to recall that many respondents said they wanted more opportunities to meet and talk to other people with diagnosed HIV. For some this was seen as a means of overcoming isolation and loneliness, and an opportunity to deal with treatment issues, sexual problems and the many needs of everyday life.

The chart also demonstrates that HIV organisations continue to play an important role in many need areas, though there is clearly scope for them to do more. HIV organisations have freedom to choose where to act – they can deliver at all the levels described above except possibly the medical. Their role is probably slightly under-represented here, given the focus of the question on personal help and support. National anti-discrimination campaigns or lobbying to improve clinical services would not show up here, for example.

The importance of HIV (GUM) out-patients clinics and GP surgeries in meeting the needs of people with HIV is also demonstrated, as is the impact of counselling and psychology services. It is striking that these clinical services, which can include a whole range of professions, are the most common source of help in addressing the four most common needs – related to sex, anxiety and depression, sleep and self-confidence – as well as the needs related to appetite and eating problems. To some extent, clinical services have a captive client group as almost everyone uses them for HIV treatment or monitoring. However, some service providers need to consider how they can address this broad range of needs in a clinical setting. In addition, a common complaint among respondents in full-time employment was the difficulty of accessing clinics (or any other HIV services) outside standard working hours.

3.5 DEMOGRAPHIC VARIATION IN NEEDS

There were considerable differences in the patterns of need between different socio-demographic groups in the sample. In the following section we examine patterns of need across ten key demographic groups: all women; gay and bisexual men; heterosexual men; people age 25 or less; people with haemophilia; people who have injected drugs in the last year; Black African people; people with immigration problems; people who have been diagnosed with HIV in the last year; and people with day-to-day responsibility for the care of children.

This data is not intended to encourage competition among groups or the organisations that serve them, but to provide a clear indication of the level of specific needs among those groups which specific organisations or specific interventions, seek to serve.

3.5.1 *Women and need*

While the vast majority of women were heterosexual, the sample included seven lesbians, three women who identified as gay and six bisexuals. The average age of all women was 40 (range 19-73). Almost half (48%) of women had a current regular partner at the time of the survey, and a similar proportion (46%) had day-to-day responsibility for the care of a child. Two thirds (65%) were migrants to the UK, and more than half (55%) had migrated from Africa. While half (51%) of females were of Black African ethnicity, 39 countries of birth were represented among the 366 women in the sample. The majority (65%) had a university education and a fifth (20%) were studying at the time that they participated in the survey. Less than half were in any paid employment (40%) with less than a quarter in full-time employment (24%).

All women (n=366)	**% of all with problems in the last year**	**% of all unhappy with their current state**	**% of all with capacity to benefit**
self-confidence	74	51	61
anxiety and depression	74	40	62
skills and training opportunities	72	40	64
sleep	70	42	56
sex	62	52	48
money	51	46	48
household chores & self-care	46	24	37
eating & drinking	46	23	37
mobility	41	22	31
discrimination	39	not asked	not asked
family relationships	38	23	26
friendships	38	24	29
housing and living conditions	37	32	33
work	35	40	29
partner relationships	28	not asked	20
taking anti-HIV treatments	26	not asked	not asked
immigration	24	not asked	20
looking after children	20	not asked	17
alcohol and drugs	18	not asked	10
knowledge of HIV	16	18	not asked

On average (median), women had 9 of the 20 problems listed above (mean = 8.6, standard deviation (sd) 4.3). Less than 2% of all women did not report any problems in the last year but a seventh (13%) identified between one and three problems. Another quarter (27%) of women reported between four and seven problems, and a larger proportion (32%) identified between eight and eleven problems in the last year. A quarter (26%) of all women reported problems in between thirteen and nineteen of the twenty needs areas asked about. No woman reported problems in between all twenty of the needs areas in the last year.

3.5.2 Gay and bisexual men and need

Gay and bisexual men were similar to heterosexual men in terms of age (median 42, range 17-76). Although the majority were UK born (82%), almost a fifth (18%) were migrants to the UK, including a small proportion (2%) that had migrated from Africa. While the majority (95%) were White, 48 countries of birth were represented. The majority of gay and bisexual men had a university or college education (70%) and a small proportion (8%) were currently studying. Almost half (48%) of gay and bisexual men had a regular partner at the time of the survey but only 1% reported having day-to-day responsibility for the care of children. More than half (57%) of all gay and bisexual men were in paid employment at the time of the survey, most of whom (48%) worked full-time.

All gay or bisexual men (n=1217)	**% of all with problems in the last year**	**% of all unhappy with their current state**	**% of all with capacity to benefit**
anxiety and depression	73	33	56
self-confidence	72	47	55
sleep	71	36	50
sex	71	52	52
skills and training opportunities	48	22	38
friendships	44	29	32
eating & drinking	40	17	27
discrimination	36	not asked	not asked
household chores & self-care	35	18	25
alcohol and drugs	30	not asked	22
taking anti-HIV treatments	29	not asked	not asked
family relationships	27	19	14
partner relationships	27	not asked	17
money	27	26	23
mobility	26	12	19
work	23	31	17
housing and living conditions	18	18	15
knowledge of HIV	9	12	not asked
immigration	<1	not asked	<1
looking after children	<1	not asked	<1

On average (median), gay and bisexual men had 7 of the 20 problems listed (mean = 7.5, sd 3.9). Less than 3% of all gay and bisexual men did not report any problems in the last year and a sixth (17%) identified between one and three problems. More than a third (36%) identified between four and seven problems, and a similar proportion (32%) identified between eight and twelve problems. One-in-eight (12%) of all gay and bisexual men reported thirteen or more problems in the last year. No gay or bisexual man reported problems in all twenty of the needs areas.

3.5.3 Heterosexual men and need

Heterosexual men had a similar age range to gay and bisexual men (median 43, range 21-74). Around half (48%) of all heterosexual men were UK-born and a slightly smaller proportion (41%) had migrated from Africa. Overall, 28 countries of birth were represented. Similar proportions identified their ethnic group as White (53%) and Black African (40%). The majority of heterosexual men had a university or college education (63%), and a sixth (16%) were currently studying. More than half (60%) currently had a regular female partner, and a quarter (26%) reported having responsibility for day-to-day care of children. Less than half (44%) were in paid employment including a third (32%) who worked full-time.

All heterosexual men (n=142)	**% of all with problems in the last year**	**% of all unhappy with their current state**	**% of all with capacity to benefit**
sex	62	53	38
sleep	59	33	44
skills and training opportunities	58	39	48
self-confidence	55	36	36
anxiety and depression	55	32	41
eating & drinking	46	18	34
money	41	40	37
work	40	48	30
household chores & self-care	36	19	24
housing and living conditions	34	26	29
friendships	32	23	19
mobility	32	17	21
family relationships	29	23	16
discrimination	27	not asked	not asked
immigration	21	not asked	18
partner relationships	21	not asked	14
taking anti-HIV treatments	21	not asked	not asked
alcohol and drugs	19	not asked	12
knowledge of HIV	11	13	not asked
looking after children	10	not asked	8

On average (median), heterosexual men had 7 of the 20 problems listed (mean = 7.3, sd 4.0). Less than 6% of all heterosexual men did not report any problems in the last year and a fifth (20%) identified between one and three problems. Another third (31%) identified between four and seven problems, and a similar proportion (32%) identified between eight and twelve problems in the last year. One-in-nine (11%) of all heterosexual men reported problems in between thirteen and sixteen of the twenty needs areas asked about. No heterosexual man reported having problems in more than 16 of the 20 different needs areas in the last year.

3.5.4 People under the age of 25 and need

Only 50 people with diagnosed HIV who were under the age of 25 (range 17-24) were recruited to the survey (3% of the whole sample). Among these 50 young people, 19 (38%) were female. The majority of males (26/30, 87%) identified as gay or bisexual, but the majority of females (17/19, 90%) identified as heterosexual. Similarly among the young males the majority were White (86%) and UK-born (83%). Among the young females a much smaller proportion were White (53%) and UK-born (58%), and a higher proportion were Black African (26%) or a migrant from Africa (32%). Less than half (43%) of all the young people currently had a regular partner at the time of the survey, and one-in-eight (12%) reported having responsibility for day-to-day care of children. The majority had been to university (63%), and a quarter (28%) were currently studying. More than half (54%) were in paid employment, most of whom (40%) worked full-time.

Under 25 years old (n=50)	**% of all with problems in the last year**	**% of all unhappy with their current state**	**% of all with capacity to benefit**
self-confidence	80	43	60
sleep	68	37	43
anxiety and depression	67	41	54
skills and training opportunities	63	27	49
sex	60	55	37
eating & drinking	42	21	31
alcohol and drugs	42	not asked	24
partner relationships	42	not asked	26
family relationships	40	23	14
money	38	47	36
taking anti-HIV treatments	36	not asked	not asked
friendships	33	17	16
work	27	28	16
housing and living conditions	24	22	24
discrimination	22	not asked	not asked
mobility	16	6	10
knowledge of HIV	15	19	not asked
immigration	10	not asked	10
household chores & self-care	8	8	6
looking after children	8	not asked	2

Respondents under the age of 25 had problems, on average, in 8 of the 20 problem areas in the last year (mean = 7.1, sd 3.4). None of the respondents under 25 reported no problems in the last year but a fifth (20%) identified between one and three problems. Another third (30%) identified between four and seven problems, and a similar proportion (34%) identified between eight and ten problems in the last year. Of the remainder 14% reported eleven or twelve problems and 2% (one person) reported 16 problems. No young person reported having problems in more than 16 of the 20 different needs areas in the last year.

3.5.5 Black African people and need

Of the 256 respondents that identified their ethnicity as Black African or Black British African, eight were born in the UK and one was born in another European country. The remainder cited 24 African countries of birth, most commonly Zimbabwe (85 people) and Uganda (50). This section excludes 35 respondents that were born in Africa but did not identify their ethnicity as Black African – they were White (17 people), of dual or mixed ethnicities (13) or Asian (4). Almost all respondents that identified as Black African were migrants to the UK (97%). Most were female (73%) rather than male (27%). The majority (96%) identified as heterosexual rather than gay or bisexual (4%). The median age was 40 (range 19-74). Almost two thirds (61%) were in a current relationship and half (50%) had day-to-day responsibility for the care of children. Two thirds (63%) had a college or university education and a further quarter (28%) were currently in education. Just over a third (35%) were currently in paid employment, including a fifth (21%) who worked full-time.

All Black Africans (irrespective of immigration status) (n=258)	**% of all with problems in the last year**	**% of all unhappy with their current state**	**% of all with capacity to benefit**
skills and training opportunities	82	47	74
anxiety and depression	65	43	60
money	65	57	60
self-confidence	64	48	53
sleep	60	38	55
sex	57	49	45
housing and living conditions	54	43	48
work	50	51	42
eating & drinking	48	21	39
immigration	42	not asked	36
mobility	40	24	34
household chores & self-care	40	21	35
discrimination	40	not asked	not asked
family relationships	39	30	28
friendships	38	26	31
taking anti-HIV treatments	25	not asked	not asked
looking after children	24	not asked	20
partner relationships	23	not asked	18
knowledge of HIV	16	19	not asked
alcohol and drugs	12	not asked	8

Black African respondents had problems, on average, in 9 of the 20 problem areas in the last year (mean = 8.7, sd 4.6). Less than 2% of all Black Africans did not report any problems in the last year and a sixth (16%) identified between one and three problems. A quarter (27%) identified between four and seven problems, and a third (33%) identified between eight and twelve problems. More than a fifth (22%) of all Black African respondents reported between thirteen and nineteen of the problems, though none reported all twenty.

3.5.6 People with immigration problems and need

Our data did not show that those migrants that had been in the UK a shorter time period had more needs. This was probably the result of large-scale changes in migration to the UK in the last few years, such that African migrants were less common among those that had been in the UK less than a year, than among groups that had been in the UK 3 or 5 years. However, examining the range of needs experienced by the 124 people who reported problems with immigration in the last year (see chapter 4) reveals both the extent and range of their needs. Among respondents with immigration problems most were heterosexual women (66%) or heterosexual men (27%) rather than gay or bisexual men (7%). The majority were Black African (86%) and 26 countries of birth were represented. The average age was 39 (median, range 19-74). Half (50%) were in a current relationship and 42% had day-to-day responsibility for the care of children. Sixty percent had a university education and a further quarter (23%) were currently in education. Less than a fifth (19%) were currently in paid employment and only 10% were in full-time employment.

Respondents that had immigration problems in the last year (n=124)	**% of all with problems in the last year**	**% of all unhappy with their current state**	**% of all with capacity to benefit**
immigration	100	83	89
skills and training opportunities	88	60	80
money	82	73	78
anxiety and depression	79	56	71
housing and living conditions	73	54	66
sleep	72	50	67
self-confidence	69	51	59
work	67	70	59
eating & drinking	63	33	52
sex	63	52	50
family relationships	55	47	41
mobility	51	37	44
friendships	50	36	38
discrimination	49	not asked	not asked
household chores & self-care	48	30	42
looking after children	31	not asked	27
taking anti-HIV treatments	25	not asked	not asked
alcohol and drugs	23	not asked	14
partner relationships	22	not asked	19
knowledge of HIV	14	28	not asked

People with immigration problems in the last year had, on average, 10 of the other 19 problems (mean = 9.7, sd 4.1). None reported no other problems in the last year, and only a quarter (24%) reported six other problems or less. Another third (32%) identified between seven and ten other problems, and a similar proportion (36%) identified between eleven and fifteen. The remainder (7%) reported between sixteen and eighteen of the other nineteen problem areas.

3.5.7 People with haemophilia and need

Seventeen men and four women reported having haemophilia or a similar bleeding disorder. Their average age was 39 (median, range 20-66). The average length of time since HIV diagnosis was considerably longer than respondents without haemophilia (median 22 years compared to 6½ years among the rest of the sample). The majority of people with a bleeding disorder were heterosexual (80%) rather than lesbian, gay or bisexual (20%). While most were White (72%), a fifth (19%) were Black and 10% were Asian. Just a fifth (19%) were migrants, the majority (14%) being African. Two thirds (67%) were in a current relationship at the time of the survey, and 22% had day-to-day responsibility for the care of children. Sixty percent had a university education but none were currently studying. A third (33%) were currently in paid employment, including 14% in full-time employment.

All people with haemophilia (n=21)	**% of all with problems in the last year**	**% of all unhappy with their current state**	**% of all with capacity to benefit**
sleep	81	52	62
sex	76	68	53
anxiety and depression	71	40	65
self-confidence	71	45	53
eating & drinking	67	38	57
household chores & self-care	67	24	52
skills and training opportunities	62	43	52
mobility	62	32	50
discrimination	52	not asked	not asked
money	50	35	50
work	48	50	29
taking anti-HIV treatments	45	not asked	not asked
friendships	38	21	24
family relationships	38	25	29
partner relationships	38	47	10
alcohol and drugs	35	not asked	21
housing and living conditions	35	16	25
knowledge of HIV	20	16	not asked
looking after children	19	not asked	14
immigration	10	not asked	10

People with haemophilia or similar bleeding disorders had, on average, 10 of the 20 problems listed in the last year (mean = 10.2, sd 5.2). None of the people with haemophilia reported no problems in the last year and only 10% identified between one and three problems. A third (33%) identified between four and seven problems, and a similar proportion (33%) identified between eight and fourteen problems in the last year. A quarter (24%) of all people with haemophilia reported between fifteen and nineteen problems, though none reported all twenty.

3.5.8 People who had injected drugs in the last year and need

Forty-five respondents had injected drugs in the last year, of which the majority were men (91%) rather than women (9%). Among the men the vast majority (97%) were gay or bisexual rather than heterosexual (3%). Of the four women who had injected in the last year, three were heterosexual. The average age of those that had injected was 40 (median, range 20-66). The majority were White (89%) and UK-born (82%). Just a fifth (18%) were migrants, the majority (14%) of which were from European countries. Two thirds (60%) were in a current relationship at the time of the survey, and 9% had day-to-day responsibility for the care of children. More than two thirds (71%) had received a university education but only 2% were currently studying. Just over half (53%) were currently in paid employment, including 44% in full-time employment.

People who had been involved in injecting drug use in the last year (n=45)	**% of all with problems in the last year**	**% of all unhappy with their current state**	**% of all with capacity to benefit**
anxiety and depression	89	34	64
sleep	84	59	60
self-confidence	80	57	61
sex	77	57	57
alcohol and drugs	65	not asked	50
eating & drinking	64	35	39
discrimination	62	not asked	not asked
household chores & self-care	58	31	42
friendships	52	41	39
skills and training opportunities	46	23	35
partner relationships	44	not asked	18
money	42	45	37
mobility	40	11	23
family relationships	36	27	24
housing and living conditions	33	31	29
taking anti-HIV treatments	33	not asked	not asked
work	33	37	24
knowledge of HIV	7	17	not asked
looking after children	7	not asked	4
immigration	2	not asked	2

People who had injected drugs in the last year had, on average, 9 of the 20 problems in the same time period (mean = 9.6, sd 3.9). None of the respondents that injected in the last year reported no problems in the same time period, and less than a quarter (22%) identified between one and seven problems. More than a third (38%) identified between eight and ten problems, and a similar proportion (40%) identified between eleven and nineteen problems in the last year, though none reported all twenty.

3.5.9 People recently diagnosed with HIV and need

One hundred and fifty-two respondents had been first diagnosed with HIV in the year prior to the survey. Three quarters (74%) of these respondents were gay or bisexual men, a fifth (21%) were women and 8% were heterosexual men. They were considerably younger on average (median 35) than those who had been diagnosed with HIV longer (median 42, range 18-73). Most (80%) were White, and two thirds (68%) were UK-born. A third (32%) of newly diagnosed respondents were migrants, with 28 countries of birth represented. One-in-seven (14%) identified as Black African and a similar proportion (16%) were born in Africa. Less than half (42%) were in a current regular relationship, and 10% were responsible for the day-to-day care of a child. More than two thirds (67%) had received a university education and 14% were currently studying. Two thirds (64%) were currently in paid employment, including half (55%) who were in full-time employment

All respondents first diagnosed with HIV in the last year (n=152)	**% of all with problems in the last year**	**% of all unhappy with their current state**	**% of all with capacity to benefit**
self-confidence	72	51	57
sleep	69	31	46
anxiety and depression	68	33	53
sex	67	62	51
skills and training opportunities	54	28	40
eating & drinking	45	18	29
money	34	38	31
household chores & self-care	34	14	22
partner relationships	33	not asked	21
friendships	30	20	21
alcohol and drugs	30	not asked	19
discrimination	25	not asked	not asked
mobility	24	14	16
housing and living conditions	22	22	20
family relationships	22	19	12
work	21	33	15
knowledge of HIV	15	18	not asked
taking anti-HIV treatments	9	not asked	not asked
immigration	6	not asked	6
looking after children	5	not asked	4

People who had been first diagnosed with HIV in the last year had, on average, 7 of the 20 problems in the same time period (mean = 7.0, sd 3.7). Two percent of people who were first diagnosed with HIV in the last year, reported no problems in the same time period and 18% identified between one and three problems. More than a third (41%) identified between four and seven problems, and a third (32%) identified between eight and twelve problems. Eight percent reported between thirteen and seventeen of the twenty problems asked about, and none reported eighteen or more.

3.5.10 People with day-to-day responsibility for the care of children and need

There were 202 respondents with day-to-day responsibility for the care of a child or children: 12% of the whole sample. Three quarters (75%) of those lived with a child. Two thirds (64%) also had a regular partner, though less than half lived with one (43%). Three quarters (77%) were women and a quarter (23%) were men. The majority were heterosexual: ten men and two women identified as gay, lesbian or bisexual. Those with responsibility for the care of children were younger on average (median 40) than other respondents (median 42, range 19-73). More than half (56%) were Black African, and a third (34%) were White. More than two thirds (68%) were migrants, including half (50%) who were migrants from Africa. Thirty countries of birth were represented. More than two thirds (71%) had a university education, and a fifth (20%) were currently studying. Less than half (43%) were currently in paid employment, including 28% who were in full-time employment

All adults with day-to-day responsibility for the care of a child (n=202)	**% of all with problems in the last year**	**% of all unhappy with their current state**	**% of all with capacity to benefit**
skills and training opportunities	73	42	66
anxiety and depression	69	39	57
self-confidence	67	45	53
sleep	64	42	53
sex	59	47	45
money	56	54	53
eating & drinking	43	22	34
household chores & self-care	40	21	32
housing and living conditions	39	32	34
looking after children	37	27	33
work	37	44	30
discrimination	36	not asked	not asked
family relationships	36	20	22
mobility	36	16	26
friendships	35	21	26
partner relationships	31	not asked	25
taking anti-HIV treatments	23	not asked	not asked
immigration	22	not asked	18
alcohol and drugs	17	not asked	11
knowledge of HIV	13	18	not asked

People who had day-to-day responsibility for the care of children had, on average, 8 of the 20 problems in the last year (mean = 8.3, sd 4.6). Only 1% had none of the above problems in the last year and 18% identified between one and three problems. More than a quarter (27%) identified between four and seven problems, and more than a third (37%) identified between eight and twelve problems. One-in-six (17%) of people who had day-to-day responsibility for the care of children reported problems in between thirteen and nineteen of the twenty needs areas asked about.

4 Immigration

People from Black and minority ethnic backgrounds make up 49% of people with diagnosed HIV in the UK and among this group, 89% are Black African (Health Protection Agency 2007). Hence, although people with HIV come to the UK from many countries, African people make up the vast majority of UK-residents with HIV infection which was "acquired abroad".

Migrants often have complex pre-existing social care, support and health-related needs. This is especially the case for refugees, forced migrants or those seeking asylum. Health can be compromised by pre-existing poverty, trauma, the presence of communicable diseases in the country of origin, and can be exacerbated by poverty and inadequate housing on arrival in the UK (Hobson *et al.* 2008, Lewis 2008). In addition, the conditions of departure and the conditions that people are forced to live in when they arrive in the UK lead to greater mental health morbidity.

4.1 PROBLEMS WITH IMMIGRATION STATUS

7% of all respondents had experienced immigration or asylum problems in the last year (n=124).

Predictably immigration problems were not evenly distributed across our sample – they were far more common among African migrants than other migrants, let alone White British respondents. Four White British (0.3% or 4/1187) respondents reported problems with immigration services in the last year. All were either referring to the uncertainty that arose because their spouses were awaiting decisions on their right to reside in the UK or were having difficulty getting or retaining working visas for other countries, which they required for their jobs.

Nine (4% or 9/258) of the migrants to the UK who were not born in Africa reported problems with immigration services in the last year. They were nationals of Jamaica (3), Brazil (2) and one each from Afghanistan, Argentina, Germany and Thailand.

Four-in-ten (39%, or 110/279) of all African migrants had experienced immigration or asylum problems in the previous year (see section 3.5.6 for a description of people with immigration problems). Most African migrants who reported immigration problems described their own unsettled immigration or asylum status. Although some had already had their applications rejected, others were facing long delays in the processing of their applications. Those currently awaiting a decision complained of restrictions on their movement and of having to regularly report to immigration centers or police stations. Those whose applications had already been rejected commonly felt that their HIV status and associated healthcare needs had not been taken into account by immigration service staff when making their decision. A small number of people described what they perceived as harassment by immigration service staff, such as repeated detainment or threats of deportation, seemingly without reason. One individual reported that they had been denied appropriate HIV medication while being detained at an immigration center.

Financial insecurity was also highlighted as a problem by many people with immigration problems. Difficulties navigating the benefit system or, indeed, the termination of benefits, had a huge impact on day-to-day living. This problem was compounded when the respondent had been refused the right to work while their applications were being processed. A few described difficulties paying for legal representation or being able to afford visa renewals.

4.1.1 Changes over 12 months

Almost a third (30%) of respondents that had experienced immigration problems in the previous year said the problem had improved (24%) or been resolved (6%). For a similar proportion (29%) things had become worse. The largest proportion (42%) of respondents reporting a problem with immigration or asylum in the last year, said they had seen no change in their situation.

4.2 GETTING HELP WITH IMMIGRATION PROBLEMS

Among the respondents who reported immigration or asylum problems in the previous year three quarters (76%) had received some form of help to deal with these (see table below). This leaves a quarter (24%) who had not received any help, or:

2% of all respondents had experienced immigration or asylum problems in the last year, and had not received any help to address these problems (n=29).

Sources of help with immigration or asylum problems, among those that received any help (n=89, missing 5)	**Number**	**%**
an HIV organisation (charity)	33	37
an immigration advisory service	28	32
a private immigration lawyer	28	32
the council / social services	20	23
my HIV (GUM) clinic	17	19
my GP practice (family doctor)	11	12
my friends	9	10
my parents	8	9
my partner / spouse	7	8
other family	5	6
my children	4	5
other sources of help with immigration or asylum problems	2	2

The *other* two sources of help cited were the Home Office and a local MP.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome them. One-in-twenty (5%) did not think that any further help would make any difference. The remainder either felt that more help would make a difference (70%) or did not know what might be gained (25%). Combining these last two groups, we can say that overall:

6% of all respondents had ongoing problems with their immigration or asylum status and felt that further help or support would be useful, or did not rule this out (n=98).

Respondents whose problems with immigration had not been solved in the last year, and who felt that more help or support might help, were asked *Realistically, what help do you think would make a difference to your problems with immigration?* Among a wealth of suggestions a large number felt that being granted asylum or settled status would end the uncertainty they were currently facing. This would allow them to find legitimate employment and enable them to lead more independent and self-sufficient lives. A decision on their right to stay in the UK would also end uncertainty about continued access to HIV medication which, for most, was a serious concern.

A significant proportion felt that improvements to the immigration or asylum application process would make the biggest difference to the problems they were currently facing. Respondents felt they would benefit from more information about the workings of the immigration service and greater assistance dealing with what many felt were confusing procedures. Some felt that immigration service staff should try to treat applicants on an individual basis, rather than applying blanket policies based on their country of origin. More effective representation and someone to help them 'fight their corner' were frequently cited as a way of improving the situation.

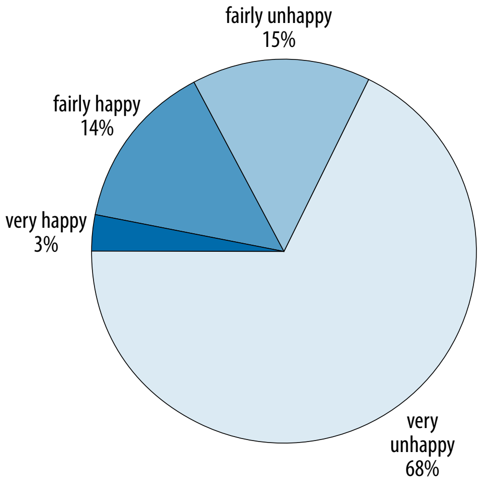
4.3 FEELINGS ABOUT IMMIGRATION PROBLEMS

Respondents who reported a problem with their immigration or asylum status in the last year were asked how they currently felt about their immigration status. Overall, only one-in-six felt very or fairly happy (Chart 4.3).

83% of respondents with immigration or asylum problems in the last year, currently felt unhappy about their immigration or asylum status (n=98).

Among respondents who reported immigration problems that had not improved in the last year most (92%) felt unhappy about their current situation (89% of those whose problems had not been resolved).

Chart 4.3: Feelings about immigration or asylum status (among those that had the problem in the last year)



4.4 SUMMARY

Of all the respondents to the survey:

- 7% had experienced immigration or asylum problems in the last year.
- 6% had ongoing problems with their immigration or asylum status and felt that further help or support would be useful, or did not rule this out.

5 Housing and living conditions

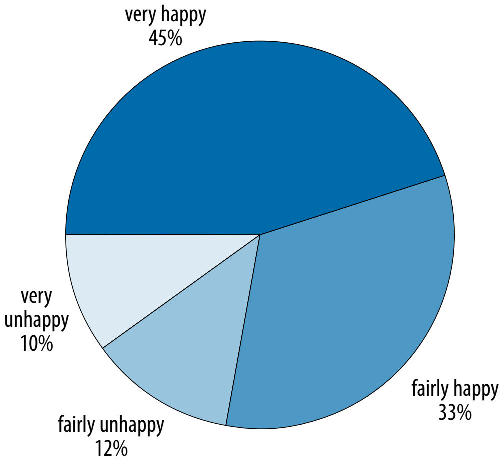
Housing is a basic need. Without shelter, both quality of life and life itself can be hard to sustain. Poor housing and living conditions increase many of the other needs of daily life. Housing need is also aspirational. Current living conditions may be adequate but limit future possibilities, perhaps for greater independence, well-being, prosperity, social contact or family life. A need for better housing and living conditions may reflect a desire to achieve such possibilities.

5.1 FEELINGS ABOUT HOUSING AND LIVING CONDITIONS

All respondents were asked how they felt about their current housing and living conditions. Overall, three quarters (78%) felt very or fairly happy (Chart 5.1).

22% of all respondents felt unhappy about their current housing or living conditions (n=376).

Chart 5.1: Feelings about housing and living conditions



5.2 PROBLEMS WITH HOUSING AND LIVING CONDITIONS

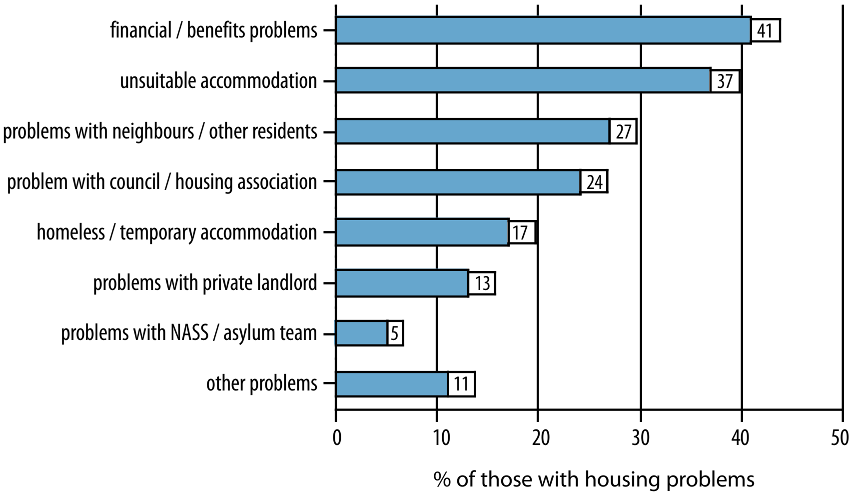
24% of all respondents had experienced housing problems in the last year (n=414).

Chart 5.2 illustrates the problems (and causes of problems) that respondents described in relation to housing or living conditions. Financial and benefits problems were most common, and were cited by 41% of all those with housing problems. Previous data (Weatherburn *et al.* 2002) suggests these would have included difficulties paying rent and mortgages or finding appropriate and affordable accommodation. These problems were probably compounded by failures of the welfare benefits system, ranging from long delays to mistakes leading to threats of eviction and the withdrawal of benefits at times of acute need.

A further third (37%) of people with housing problems described having unsuitable accommodation probably because of damp, disrepair, inadequate heating, lack of equipment and problems with access to bath and toilet facilities. Others described problems with their immediate environment because of harassment and violence from neighbours and / or noise and vandalism.

Others reported problems with social and private landlords. Of those with housing problems one-in-twenty (5%) cited NASS or asylum services as the cause, and among Black Africans this rose to 15% of those with a housing problem. Sixty-eight respondents (4% of all) had experienced homelessness in the last year, which could have a profound effect on all their other needs.

Chart 5.2: Housing problems (causes) among those that had them



Other causes of problems with housing and living conditions included difficulties with moving home, even where it was absolutely necessary. Many respondents reported that the break-up of a relationship necessitated them moving, sometimes at short notice, when they had neither the financial resources or energy to do so. Others remained in the same accommodation as ex-partners with all the problems that could bring. In addition, some reported dissatisfaction with living conditions because of a lack of privacy in shared accommodation or because of difficulties with noise or other people smoking.

5.2.1 Changes over 12 months

A third (33%) of those who had experienced housing problems in the last year reported that the problem had improved (27%) or been resolved (7%). Previous data (Weatherburn *et al.* 2002) suggests this may have been because of a move to new accommodation; changes in their financial circumstances; improvements in the condition of their housing; better relationships with landlords; changes in personal relationships and constraints put on troublesome neighbours.

For almost another third (30%) of those who had experienced housing problems, things had got worse, probably because the people with a responsibility to deal with the problem – the council or landlord – had ignored or exacerbated it. However some respondents may have suffered worsening health, physical or psychological, which increased their need for more suitable accommodation.

At the time of the survey, 62% of those who had experienced housing problems felt unhappy with their housing or living conditions (79% of those whose problems had not improved). Among those who did not report any housing problems, 10% were unhappy about their housing and living conditions, suggesting a strong aspirational quality to housing need.

5.3 GETTING HELP WITH HOUSING PROBLEMS

Among the respondents who had experienced housing problems in the last year, more than half (57%) had received some form of help to deal with them. This leaves 43% who had not received any help, or:

10% of all respondents had experienced housing problems in the last year and had not received any help to address these problems (n=169).

Sources of help with housing problems, among those that received any help (n=214, missing 13)	**Number**	**%**
an HIV organisation (charity)	87	41
the council / social services	78	36
my friends	69	32
my partner / spouse	34	16
other family	30	14
my HIV (GUM) clinic	29	14
my parents	25	12
a housing association	22	10
my GP practice (family doctor)	22	10
a general charity	12	6
my children	5	2
other sources of help with housing problems	41	20

A wide range of *other* sources of help and support were cited. Most common were solicitors or lawyers, closely followed by the Police. Also mentioned were debt advisors and advocates, hostel workers, mental health workers and advocates, social workers, HIV nurses and housing officers. Others mentioned receiving help from other people with HIV, ex-partners, church workers, therapists, local councillors and work colleagues.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would help reduce or overcome them. A small proportion (5%) did not think that any further help would make a difference. The remainder either felt that more help would make a difference (80%) or did not know what might be gained (15%). Combining these two groups, we can say that overall:

20% of all respondents had ongoing housing problems and felt that further help or support would be useful, or did not rule this out (n=345).

Most respondents with ongoing housing problems felt they needed better access to adequate, affordable housing stock including private, council-owned, or housing association tenancies. Many also felt that a permanent and immediate solution to their situation was required, such as a move into accommodation with adequate space and security, or finding employment. They also wanted dedicated local authority housing staff who could address the problems arising from long-term chronic health conditions like HIV. Complaints about inaccessible and incomprehensible housing services were accompanied by requests for improved housing advocacy and support.

Other people in financial difficulty felt that increasing disability benefits, provision of funding for necessary housing modifications, and mechanisms to provide temporary financial relief for disabled people struggling to meet mortgage payments could minimise their housing problems. Finally, African people with unresolved immigration status felt there were no means of accessing adequate and secure housing until they had leave to remain in the UK.

5.4 SUMMARY

Of all the respondents to the survey:

- 22% felt unhappy about their housing and living conditions.
- 24% had experienced housing problems in the last year.
- 20% had ongoing housing problems and felt that further help or support would be useful, or did not rule this out.

6 Eating and drinking

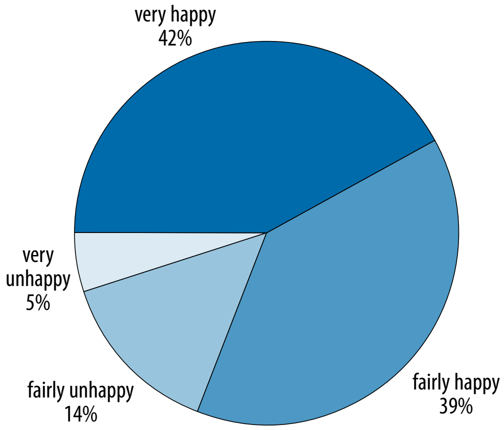
Everyone has a daily need for sustenance, fulfilled by eating and drinking. But if eating or drinking become difficult, because of loss of appetite or physical problems, the need remains. The need may also remain if food is unattainable, though this is a less common problem in the UK. Problems with appetite and ability to eat and drink affect all other needs in daily life including health, mobility and well-being.

6.1 FEELINGS ABOUT EATING AND DRINKING

Respondents were asked how they felt about their appetite and ability to eat and drink. Overall, 81% felt very or fairly happy (Chart 6.1).

19% of all respondents felt unhappy about their appetite and ability to eat and drink (n=319).

Chart 6.1: Feelings about ability to eat or drink



6.2 PROBLEMS WITH EATING AND DRINKING

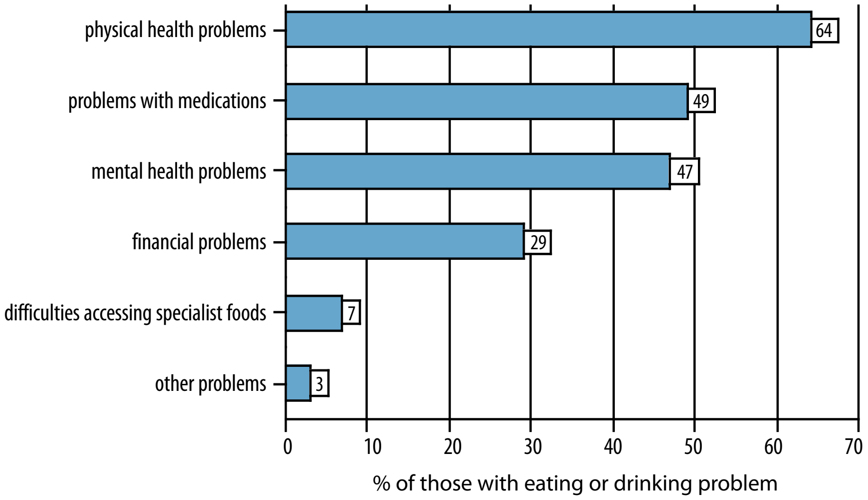
41% of all respondents had experienced problems with their appetite or ability to eat and drink in the last year (n=730).

Among those respondents that reported a problem with their appetite or ability to eat or drink, 83% reported appetite problems only, 13% reported a physical problem with their ability to eat or drink only, and 4% had both appetite and physical problems with eating and drinking.

Chart 6.2 illustrates the causes of the problems described. Physical health problems with eating or drinking were reported by two thirds (64%) of all those with eating problems. Previous data (Weatherburn *et al.* 2002) suggests that these will have included problems with the mouth, throat or digestion, lack of energy to cook or eat, and loss of appetite or taste.

Problems associated with taking HIV treatments and problems created by illness or specific conditions were listed by almost half (49%) of those with eating problems. These will have included nausea, vomiting, diarrhoea, weight loss or weight gain. A similar proportion (47%) of respondents mentioned the impact of mental health problems on eating and drinking including depression, anorexia and bulimia. Fewer respondents mentioned a lack of money as the main reason for their difficulty eating properly but not having enough money to eat well was a reality for more than a quarter (29%) of those with eating or drinking problems. Some respondents reported difficulties accessing (or affording) specialist foods.

Chart 6.2: Specific problems with eating and drinking among those that had any



Other causes of problems with eating and drinking included drug or alcohol dependence and lactose or other food intolerances. Finally, some respondents reported difficulties with eating and drinking because of the limited choices available to them in hospital or prison.

6.2.1 Changes over 12 months

Two fifths (41%) of those who had experienced problems in the previous year said the problem had improved (33%) or been resolved (8%). Previous data (Weatherburn *et al.* 2002) suggests that for some, changes in lifestyle would have helped, alongside better stress management, giving up smoking, taking more exercise or a change in living conditions. However, for most, improvements were probably down to medical treatment. Whereas some will have seen their health and appetite improve through starting anti-HIV treatments or dealing with specific illnesses, others had gained from changing anti-HIV treatments. Medications that addressed the immediate problem, such as anti-nausea pills and thrush treatments will also have helped.

For a fifth (22%) of those who had experienced problems, things had got worse. Starting or changing medications and coping with side-effects was probably a common reason. However many would also experienced increased unhappiness or depression as the source of the problem, created by a deterioration in health or by the loss of important people or sources of support.

At the time of the survey, 40% of those who had experienced problems in the last year were unhappy about their current appetite and ability to eat and drink (58% of those whose problems had not improved). Among those who did not report any problems, only 3% were unhappy about their appetite or ability to eat or drink.

6.3 GETTING HELP WITH EATING AND DRINKING

Among the respondents who had experienced problems with their appetite or ability to eat and drink in the previous year, less than half (47%) had received help to deal with these problems. This leaves more than half (53%) of those with problems who had not received any help, or:

21% of all respondents had experienced problems with their appetite and ability to eat and drink in the last year, and had not received any help to address these problems (n=366).

Sources of help with appetite, eating and drinking problems, among those that received any help (n=325, missing 4)	**Number**	**%**
my HIV (GUM) clinic	142	44
a nutritionist or dietician	95	29
my friends	81	25
my partner / spouse	80	25
my GP practice (family doctor)	73	23
an HIV organisation (charity)	60	19
my parents	35	11
other family	29	9
the council / social services	21	7
my children	11	3
a general charity	9	3
other sources of help with appetite, eating and drinking problems	34	11

The *other* sources of help were mainly other NHS staff, especially doctors and counsellors and psychologists. However, other respondents mentioned NASS workers and the vouchers they provide, church workers, dentists, house-mates, complementary therapists and cannabis.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would help reduce or overcome their problems. A fifth (21%) did not think that any further help would make any difference. The remainder either felt that more help would make a difference (48%), or did not know what might be gained (31%). Combining these last two groups, we can say that overall:

29% of all respondents had ongoing problems with their appetite or ability to eat and drink and felt that further help or support would be useful, or did not rule this out (n=510).

Suggestions for what might help were very diverse. Financial support was a major need to enable respondents to afford healthy food, a healthy living environment and reduce psychological problems. All those on welfare benefits wanted increased allowances. However while many White British respondents wanted better paid employment, many African respondents wanted the right to seek employment. Respondents also wanted help with cooking, shopping, better housing, someone to eat with or talk to. Others stressed the importance of peer support, family and friends and stable relationships, and less stigma and discrimination.

Respondents also wanted nutritional support from dieticians or other health professionals. Many also wanted dietary supplements and appetite improving drugs. Many felt eating problems were a side-effect of anti-HIV drugs and wanted more tolerable regimes. They expressed the need for health professionals to increase their awareness of how medications affected appetite and eating habits since some were not responsive to problems and complaints.

There was also a desire for counselling to help deal with stress, anxiety, depression and trauma, all of which affected appetite and ability to eat and drink. Respondents suggested psychotherapy, anti-depressants, health advisors at the clinics and addressing triggers for mental health problems such as financial instability and immigration issues, a concern for many African respondents. Lastly some felt that healthy food was either not available in their area or not affordable. Though both White British and Black African respondents singled out affordability as a barrier to healthy eating, Africans also wanted access to more culturally appropriate foods.

6.4 SUMMARY

Of all the respondents to the survey:

- 19% felt unhappy about their appetite and ability to eat and drink.
- 41% had experienced problems with their appetite or ability to eat and drink in the last year.
- 29% had ongoing problems with their appetite or ability to eat and drink and felt that further help or support would be useful, or did not rule this out.

7 Sleep

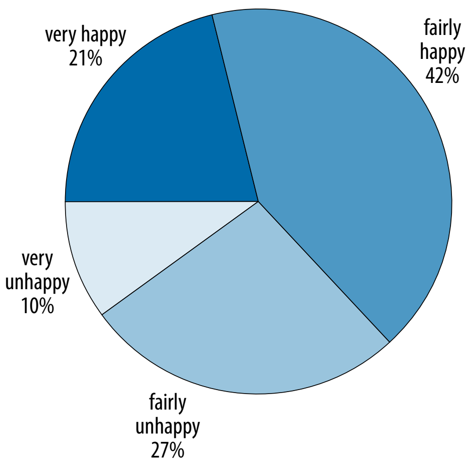
Sleep is a fundamental human need. Different people may require very different amounts, but everyone needs regular sleep to thrive. Lots of people who sleep well have aspirations about getting more sleep or wishing they could live with less. However, the need for sleep is most acutely felt by people who do not sleep well, for whom sleep disturbances can seriously undermine quality of life.

7.1 FEELINGS ABOUT ABILITY TO SLEEP

Respondents were asked how they felt about their ability to sleep as and when they wanted to. Overall, almost two thirds (63%) of respondents were very or fairly happy (see Chart 7.1).

37% of all respondents were unhappy about their ability to sleep as and when they wanted to (n=645).

Chart 7.1: Feelings about ability to sleep



7.2 PROBLEMS WITH ABILITY TO SLEEP

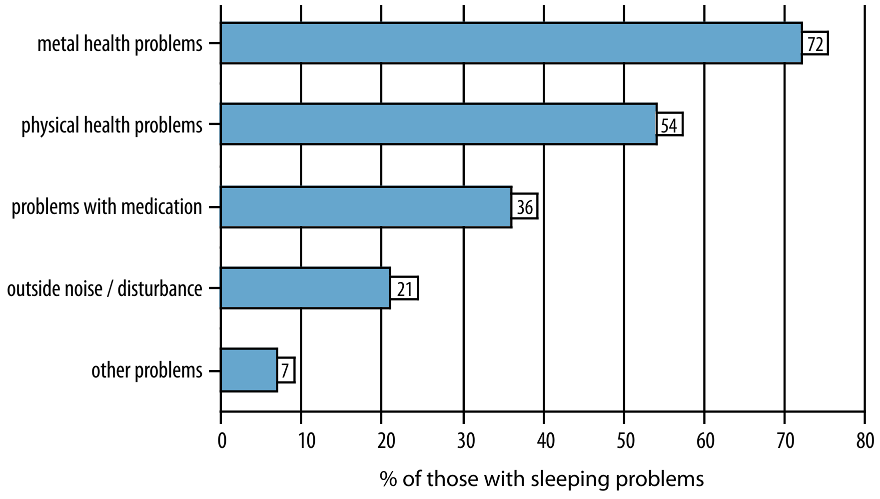
70% of all respondents had experienced sleep problems in the previous year (n=1238).

Data from our previous study (Weatherburn *et al.* 2002) suggests that most sleeping problems concerned insomnia of some type or other: restlessness and lack of sleep; intermittent and disturbed sleep; problems going to sleep or waking early; and irregular sleeping patterns. For some, fatigue and exhaustion probably led to long periods spent asleep and difficulties staying awake or getting up.

In this survey we asked respondents with a sleep problem to describe the reasons for the problems (see Chart 7.2). Mental health problems were cited as the most common source of sleep problems (72%) and our prior work suggests this will have included stress, anxiety, inability to relax, panic attacks and depression and nightmares and vivid dreams. Worry generates insomnia but insomnia also creates more opportunities to worry.

More than half (54%) of people with sleep problems described physical health problems as a cause. These will have included various forms of pain and soreness, fevers and night sweats, nausea and vomiting, skin irritations and regular trips to the toilet. Another third (36%) felt the medications they took were, at least part of, the cause. Outside noise or disturbance were mentioned by a fifth (21%) of people with sleep problems.

Chart 7.2: Causes of sleep problems among those that had them



Other causes of sleep problems were dominated by accounts of insomnia, which was a constant problem for some and occasional for others. Many stressed they had no idea what the causes were and instead described the symptoms – from frequent waking through the night to others who could not get to sleep or always woke early, tired and groggy. Some slept for 7-8 hours but still remained exhausted, although many did not feel this was an HIV-related problem, that they had always suffered from sleep disorders or that it was caused by children who slept badly. Others were struggling with night-shift work disrupting their sleep patterns, or were worried about money, immigration problems or family separation. Others put it down to the stress of falling ill, or being harassed by partners, ex-partners or family. Others put the problem down to sleep apnoea, menopause, hot flushes, tinnitus, having stopped smoking, alcoholism, drug dependence including addiction to sleeping tablets and side-effects from anti-depressants. Finally, some reported beds that were broken or so old they provided little support or comfort.

7.2.1 Changes over 12 months

More than a quarter (30%) of those who had experienced sleep problems in the last year said that the problem had improved (26%) or been resolved (4%). Our previous work (Weatherburn *et al.* 2002) suggests that improvements were probably due to changes in respondents' lives and outlook, including changes in anti-HIV treatments or adapting to treatment regimens; better health and self-confidence; and changes in personal circumstances such as starting work, taking time off work, moving house or separating from a partner. More direct strategies for dealing with sleeping problems will have included taking sleeping pills or anti-depressants; getting counselling or more social support; and the use of complementary therapies and cannabis.

For more than a fifth (22%) of those who had experienced sleep problems, things had got worse. The reasons for deterioration probably included recent HIV diagnosis, starting or changing treatments and their side-effects, pain, depression and the many worries of life such as poverty, housing problems, work pressures and the demands of living with others.

At the time of the survey, half (52%) of those who had sleep problems in the last year were unhappy about their ability to sleep (63% of those whose problems had not improved). Among those who did not report any problems, less than 2% were unhappy about their ability to sleep.

7.3 GETTING HELP WITH ABILITY TO SLEEP

Among the respondents who had experienced sleep problems in the last year, just less than half (46%) had received some form of help to address these problems (see table below). This leaves just over half (54%) who had not received any help, or:

37% of all respondents had experienced sleep problems in the last year and had not received any help to address these problems (n=638).

Sources of help with sleep problems, among those that received any help (n=540, missing 11)	**Number**	**%**
prescribed medication	278	52
my GP practice (family doctor)	191	35
my HIV (GUM) clinic	160	30
complementary therapies	141	26
Alcohol or other (non-prescribed) drug	107	20
my partner / spouse	97	18
my friends	63	12
an HIV organisation (charity)	55	10
the council / social services	21	4
other family	19	4
my parents	18	3
sleep clinic	15	3
a general charity	8	2
my children	6	1
other sources of help with sleep problems	49	9

The *other* sources of help included psychologists, counsellors and psychiatrists, HIV doctors, nurses and other HIV specialist NHS staff. Other people who had helped included church staff and parishioners and carers. Some respondents had stopped anti-HIV therapies or had simply got used to regimes. Others relied on meditation and exercise, yoga, hypnotherapy, osteopathy, herbal remedies and ear plugs. Finally some mentioned cannabis and the occasional bottle of wine, and others had bought sleeping medications online (without prescription).

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. A quarter (24%) did not think that any further help would reduce or overcome their problems. The other three quarters either felt that more help would reduce their problems (39%) or did not know what might be gained (37%). Combining these last two groups, we can say that overall:

51% of all respondents had ongoing sleep problems and felt that further help or support would be useful, or did not rule this out (n=870).

Suggestions of what might help were similar to the reasons for actual improvements described above. A reduction in stress and anxiety was perceived to be the change needed by many. Generalised anxieties about life with HIV impeded sleep as did worries about work, housing, immigration, partners and family, money and health. Many felt that sleep problems would only really be solved when their underlying needs were met – for re-housing away from noisy neighbours, for better accommodation or more privacy. Many (African) migrants sought the end to uncertainty about their immigration status, and the right to work or to re-unify their family.

Other respondents focused more on interventions that might reduce the immediate problem with sleeping. Here medical interventions were paramount – many had sought and failed to get sleeping pills, finding GPs and HIV clinics largely unsympathetic and unwilling to prescribe. Others, had considered a change of anti-HIV medication as a solution, but been discouraged from doing so by medical staff. Some felt a medical solution might work but were unwilling to take any more medicines. Many respondents wanted access to counselling and other talking interventions, or to sleep clinics and the teaching of relaxation techniques. Others sought complementary therapies including homeopathy, aromatherapy and massage.

7.4 SUMMARY

Of all the respondents to the survey:

- 37% were unhappy about their ability to sleep as and when they wanted to.
- 70% had experienced problems with sleep in the last year.
- 51% had ongoing sleep problems and felt that further help or support would be useful, or did not rule this out.

8 Household chores and self-care

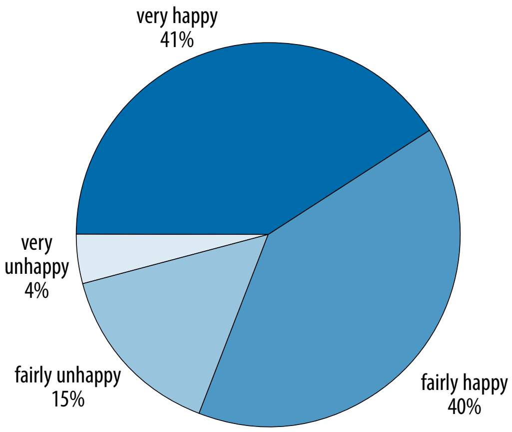
To get through the day, we all have to manage a steady succession of tasks from washing and dressing to shopping, cooking and cleaning. Some of the tasks can be put off, at least until tomorrow, but others, particularly those relating to self-care, are more critical to maintaining independence and quality of life.

8.1 FEELINGS ABOUT HOUSEHOLD CHORES AND SELF-CARE

All respondents were asked how they felt about their ability to do household chores and look after themselves, with any help they were getting. Overall, four fifths (81%) felt very or fairly happy (see Chart 8.1).

19% of all respondents felt unhappy about their ability to do household chores or look after themselves (n=336).

Chart 8.1: Feelings about ability to do household chores



8.2 PROBLEMS WITH HOUSEHOLD CHORES AND SELF-CARE

37% of all respondents had experienced problems doing household chores or looking after themselves in the last year (n=657).

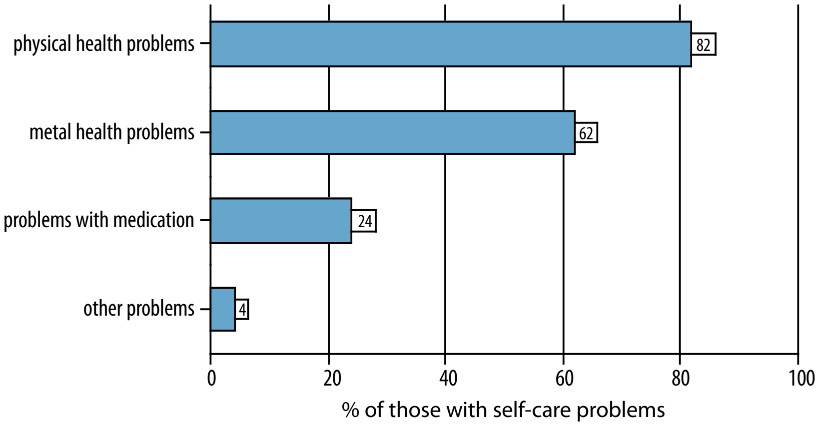
Data from our previous work (Weatherburn *et al.* 2002) suggest problems with household cleaning and cooking would have been most common, followed by problems related to self-care including difficulties dressing, bathing and washing.

In this survey respondents were asked to identify the reasons for these problems (see Chart 8.2). The main causes of problems with household chores and self-care were physical health difficulties (mentioned by 82% of those with the problem). Previous data suggest these health problems will have included fatigue and lack of energy, often linked to loss of mobility and physical strength. Debilitating illnesses will have included opportunistic infections of HIV disease and the demands of other chronic illnesses such as haemophilia, hepatitis and arthritis.

Mental health problems, including lack of motivation, and side-effects of medications were also cited as sources of problems with household chores and self-care.

Other reasons for problems with household chores and self-care included lack of time (because of work), lack of co-operation from house-mates, agoraphobia and lack of money for cleaning materials.

Chart 8.2: Causes of problems with household chores among those that had them



8.2.1 Changes over 12 months

Over a quarter (28%) of those who had experienced problems in the previous year said that they had improved (25%) or been resolved (3%). Previous data (Weatherburn *et al.* 2002) suggests this would have been because of better health and mobility. Improvements had probably also been achieved through getting help from the council, voluntary services or friends and family. Stress reduction, greater personal motivation and better housing were also likely to have been important.

For another quarter (28%) of those who had experienced problems, things had got worse. This was probably because of deteriorating health, mobility and energy, loss of domestic support services, increasing mental health problems, and degenerating living conditions.

At the time of the survey, half (49%) of those who had experienced problems felt unhappy about their ability to do household chores and look after themselves (59% of those whose problems had not improved). Among those who did not report any problems, only 2% were unhappy.

8.3 GETTING HELP WITH HOUSEHOLD CHORES AND SELF-CARE

Among the respondents who had experienced problems with household chores and self-care in the previous year, half (50%) had received some form of help to deal with them (see table below). This leaves another half (50%) who had not received any help, or:

19% of all respondents had experienced problems doing household chores or looking after themselves in the last year and had not received any help to deal with them (n=322).

Sources of help with household chores and self-care, among those that received any help (n=322, missing 0)	**Number**	**%**
my partner / spouse	109	34
my friends	105	33
my HIV (GUM) clinic	55	17
the council / social services	52	16
my GP practice (family doctor)	51	16
other family	49	15
an HIV organisation (charity)	48	15
my parents	43	13
a private home-help / cleaner	32	10
my children	24	8
a general charity	6	2
other sources of help with household chores and self-care	21	7

The *other* sources of help with household chores included counsellors, therapists and neighbours.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would enable them to reduce or overcome their problems. More than a fifth (22%) did not think that any further help would make a difference. The remainder either felt that more help would make a difference (48%) or did not know what might be gained (30%). Combining these last two groups, we can say that overall:

27% of all respondents had ongoing problems with household chores or looking after themselves and felt that further help or support would be useful, or did not rule this out (n=472).

Among respondents who thought additional support might help, most suggested general domestic help would improve their difficulties with household chores and self-care. Specific suggestions included receiving greater support to navigate the complex social care system, including help with selecting domestic workers. Others felt that improved communication between clinicians and social care providers would make it more feasible to obtain home-help. Not all respondents wanted access to home-help, with some mentioning that if they had more money, or were able to afford reduced hours at work, they could either hire help themselves, or have increased time and energy to do it themselves. Some felt that routine responsibilities were manageable, but that unusual circumstances or tasks required support either from friends and family, or from outside agencies.

Many others felt that interventions were required to help clinicians and care assessors better understand the extent to which having HIV could be accompanied by persistently low energy levels, which in turn hampered capacity for self-care. A few felt that it may be possible to tackle the issue directly by implementing changes in medication, exercise, relaxation and diet. However, a significant proportion felt that the largest barrier to household management was their psychological state and motivation, and felt that counselling or buddying could help.

At its most basic, a settled, orderly home requires decent, stable accommodation, and those without control over their own housing (including those with uncertain immigration status) felt that change was not possible without this basic necessity. Further suggestions to improve living conditions included re-housing, amendments to showering arrangements, and having a washing machine in the home.

8.4 SUMMARY

Of all the respondents to the survey:

- 19% felt unhappy about their ability to do household chores or look after themselves.
- 37% had experienced problems doing household chores or looking after themselves in the last year.
- 27% had ongoing problems doing household chores or looking after themselves and felt that further help or support would be useful, or did not rule this out.

9 Mobility

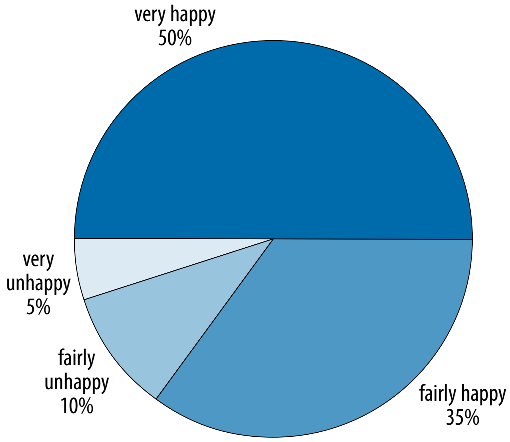
Mobility is integral to a variety of needs: sustaining an active life, obtaining the everyday necessities of life, accessing services and maintaining friendships and relationships. The extent to which these various needs can be met following loss of mobility, and the importance that different people attach to these needs, will reflect the overall need for mobility. Although loss of mobility can be a serious problem for someone within their own home, the survey took a broader perspective, asking respondents about their ability to get around locally – to hospital, the shops, services and to see friends *etc.*

9.1 FEELINGS ABOUT MOBILITY AND ABILITY TO GET ABOUT

Respondents were asked how they felt about their ability to get around locally. Overall, 85% felt either very or fairly happy (Chart 9.1).

15% of all respondents felt unhappy about their ability to get around locally (n=254).

Chart 9.1: Feelings about ability to get about



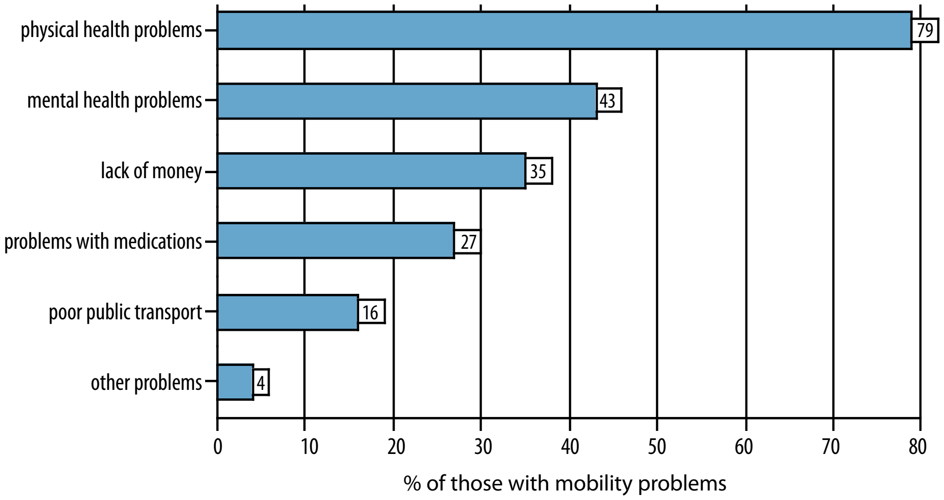
9.2 PROBLEMS WITH MOBILITY AND GETTING ABOUT

30% of all respondents had experienced mobility problems in the last year (n=522).

Almost a third (30%) of all respondents reported some problems with their ability to get about in the last year. Our previous research (Weatherburn *et al.* 2002) suggests these problems would have been with walking, getting to shops and services, visiting friends and family, driving, carrying shopping and using public services.

Chart 9.2 illustrates the diversity of reasons for these mobility problems. Physical health problems were reported as the most common cause (79%) and our previous data suggests this would have included lack of strength and energy, chronic pain and peripheral neuropathy. In many cases health problems will have been compounded by lack of money and / or poor access to public transport. While physical health problems can increase the need for public transport, they also make public transport harder to use, especially if services are unreliable or insensitive to less able users.

Chart 9.2: Causes of mobility problems among those that had them



Mental health problems also contributed to mobility problems among almost half (43%) of those that reported difficulties getting around. Anxiety and depression can be debilitating and isolating and are exacerbated by the prospect of having to cope with the world. Our previous data (Weatherburn *et al*. 2002) suggests respondents will have had problems because of agoraphobia, panic attacks, lack of confidence and paranoia in crowds or social contexts. The results of this survey show that over a third (35%) of respondents reported lack of money as a contributing factor in their mobility problems, many of which also bemoaned poor (or expensive) public transport. Finally, a quarter (27%) of respondents with mobility problems reported problems with medications and their side-effects as a contributing factor. The *other* causes of mobility problems included lack of choice of accessible (nearby) shops; difficulties accessing mobility aids from walking sticks to wheelchairs; and difficulties caused during their recovery from surgical procedures, mainly caesarean section.

9.2.1 Changes over 12 months

A quarter (24%) of respondents who had experienced mobility problems in the last year, said they had improved (20%) or been resolved (4%). Previous data suggests the majority of those will have seen improvements in their health, often linked to starting or changing treatments. Better diets, physiotherapy, exercise and gym sessions had probably also helped. Other respondents will have managed to get better access to transport or received more support from partners, friends or carers.

For 29% of those who had experienced problems, things had got worse. Previous data suggests this will have almost always because of a deterioration in health, although some respondents may have experienced increased financial problems, greater isolation and loss of local services, transport or shops.

At the time of this survey, half (47%) of those who had experienced problems were unhappy about their ability to get around locally (58% of those whose problems had not improved). Among those who did not report any mobility problems, less than 1% were unhappy about their ability to get around.

9.3 GETTING HELP WITH MOBILITY PROBLEMS

Among the respondents who had experienced problems getting around in the previous year, more than half (57%) had received some form of help to deal with these problems (see table below). This leaves 43% of those with problems who had not received any help, or:

13% of all respondents had experienced problems getting around locally in the previous year and had not received any help to address these problems (n=218).

Sources of help with problems getting about, among those that received any help (n=275, missing 11)	**Number**	**%**
my friends	106	38
my partner / spouse	76	28
the council / social services	54	20
an HIV organisation (charity)	49	18
my GP practice (family doctor)	45	16
other family	43	16
my mobility transport service	39	14
my parents	36	13
my HIV (GUM) clinic	34	12
a general charity	17	6
my children	9	3
other sources of help with mobility problems	38	14

The *other* sources of help included improvements in access to transport (freedom passes, taxi cards, Motability cars and disabled badges); therapeutic interventions such as physiotherapy, osteopathy, podiatry and hydrotherapy; and talking interventions from psychiatrists, psychologists and other therapists. Relatively few mentioned either complementary therapies or use of surgical appliances.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome them. A fifth (22%) did not think that any further help would make any difference. The remainder either felt that more help would make a difference (48%) or did not know what might be gained (31%). Combining these last two groups, we can say that overall:

21% of all respondents had ongoing mobility problems and felt that further help or support would be useful, or did not rule this out (n=366).

There were many suggestions for improving access to transport. The majority felt that the solution to their problems required more accessible and more affordable transport options. Most wanted transport schemes that were subsidised, such as discounted taxi services or Motability cars. Alternatively they required increased income through better access to disability benefits and employment.

Some also commented that the organisation of mobility support mechanisms needed to be streamlined and made more responsive, so that transport and in-home mobility solutions could be quickly provided for those in need. A smaller proportion suggested that improved frequency, reliability and physical accessibility of mainstream public transport would greatly increase their ability to use it.

Others considered the ways that changes to their own circumstances would improve their ability to get around. Exercise programmes, complementary therapies, and medical solutions were suggested as means of tackling fatigue or painful treatment side-effects. Others felt that addressing their anxiety and feelings of isolation through medical and / or talking therapies, or the provision of befriending and informal support initiatives would provide the motivation they required to get out and about.

9.4 SUMMARY

Of all the respondents to the survey:

- 15% felt unhappy about their ability to get around locally.
- 30% had experienced mobility problems in the previous year.
- 21% had ongoing mobility problems and felt that further help or support would be useful, or did not rule this out.

10 Money and income

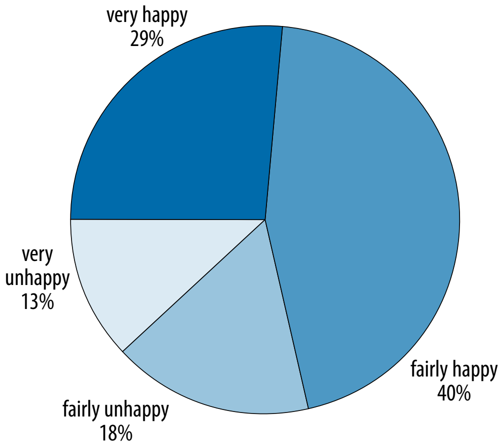
Strictly, no-one needs money, but the things that money can buy. Nonetheless, when access to money is problematic, this is often perceived as a need, especially when income drops below the threshold required to maintain the basics of daily life. The emphasis in this survey was on getting 'enough money to live on'. However, individual interpretations of this will have varied, depending both on personal circumstances and personal aspirations. How much money you feel you need 'to live on' reflects the costs of your current life and your sense of the greater possibilities of life, especially if you are currently coping with very little income.

10.1 FEELINGS ABOUT MONEY

Respondents were asked how they felt about the money they got to live on. Overall, more than two thirds (69%) felt very or fairly happy (Chart 10.1).

31% of all respondents felt unhappy about the money they were getting to live on (n=518).

Chart 10.1: Feelings about money and income



10.2 PROBLEMS WITH MONEY

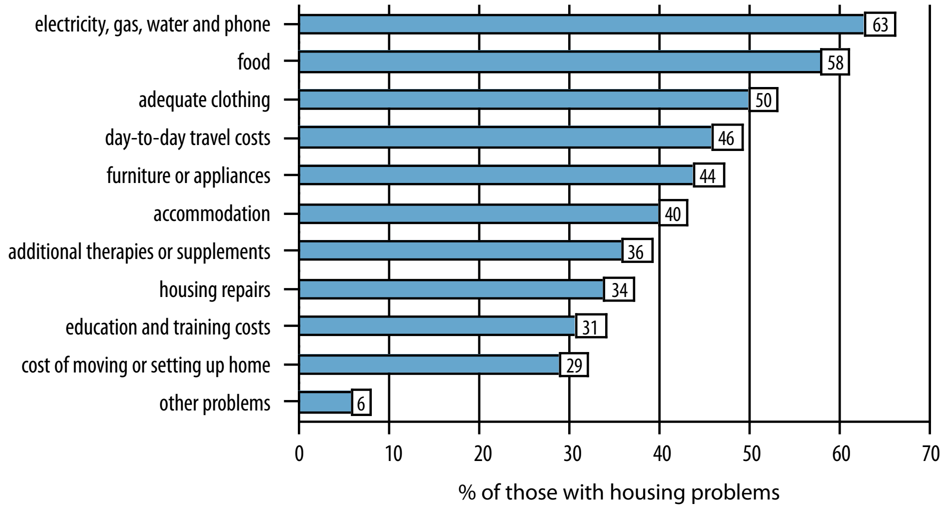
33% of all respondents had experienced problems getting enough money to live on in the last year (n=565).

In our previous work (Weatherburn *et al.* 2002) most problems with money were described in terms of the inadequacy of personal income and the difficulty of meeting the costs of daily life. The respondents with the lowest incomes were migrants seeking leave to remain in the UK, who were denied the opportunity to work and had to survive on vouchers and whatever other support they could find (see also, Ibrahim *et al.* 2008). However, the tension between income and costs was felt by respondents in many other circumstances, including some who were in paid employment. Welfare benefits, pensions, vouchers, sick pay, savings, student loans and salaries were all singled out as insufficient to meet personal needs. The majority of complaints about income were, however, focused on the value of welfare benefits.

In this survey we concentrated on establishing which expenses were most often identified as being difficult to meet, among the third (33%) of respondents with money problems (see Chart 10.2).

Household bills (63%), food (58%) and adequate clothing (50%) were the costs that were most commonly cited as difficult to meet. Others reported difficulty affording day-to-day travel costs, furniture and household appliances, accommodation, additional therapies and supplements, housing repairs, education and training costs and the costs of moving or setting up home.

Chart 10.2: Specific expenses that were difficult for those with money problems



Other specific costs that many struggled to meet included debts, prescription and dental costs and travel costs to seek HIV care and treatment. Others struggled to afford respite care, general social outings and activities, costs associated with having children, visiting other family and having a holiday. Finally, some struggled to meet the cost of most things that were not basic necessities, especially those who were dependant on vouchers.

As we have previously demonstrated (Weatherburn *et al.* 2002) the struggle to meet daily costs of living can be compounded by debt and exclusion from financial services including mortgages, loans, (life) insurance, pensions and even bank accounts. We have also shown there is widespread dissatisfaction with welfare benefits administration. Failings included lengthy delays and administrative mistakes; the insensitivity and bureaucracy of the system; and refusal, withdrawal or depletion of specific benefits, particularly Disability Living Allowance.

10.2.1 Changes over 12 months

Almost a quarter (24%) of the respondents who had experienced problems getting enough money to live on said that their problems had improved (21%) or been resolved (3%) in the last year. Our previous survey (Weatherburn *et al.* 2002) suggests the most common reason for improvement was probably the award of a new welfare benefit, restoration of old benefits or the resolution of problems obtaining benefits. Other respondents had probably (re)entered paid employment or found new sources of financial support, or received pay rises or cleared prior debt.

For over a third (37%) of those who had experienced money problems, things had got worse in the last year. The dominant problems were probably the increased costs of living and burgeoning personal debt, both of which can put pressure on static or declining incomes. Many respondents had probably lost crucial income through job losses, benefit reductions and the depletion of savings. Confidence in managing financial problems could also be undermined by illness, fatigue and depression.

At the time of the survey, three quarters (77%) of those who had experienced problems felt unhappy about the money they were getting to live on (87% of those whose problems had not improved). Among those who did not report any problems, 9% were unhappy about the money they were getting to live on, reflecting the aspirational nature of the need for money.

10.3 GETTING HELP WITH MONEY PROBLEMS

Among the respondents who had experienced problems in the previous year, half (50%) had received some form of help to deal with these problems (see table below). This leaves half (50%) of those with problems who had not received any help, or:

16% of all respondents had experienced problems getting enough money to live on in the last year and had not received any help to address these problems (n=274).

Sources of help with money problems, for those who received any help (n=547, missing 17)	**Number**	**%**
an HIV organisation (charity)	91	34
my parents	67	25
the council / social services	67	25
my friends	65	25
my partner / spouse	55	21
other family	37	14
a general charity	21	8
specialist debt or financial service	15	6
my HIV (GUM) clinic	11	4
my GP practice (family doctor)	6	2
my children	5	2
other sources of help with money problems	30	11

Other sources of help with financial problems included banks, credit card companies and a range of sources of income, such as community care grants and allowances, social loans, benevolent and hardship funds, welfare benefits or vouchers. Others, reported receiving advice from a Citizens Advice Bureau, church members and employers.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome them. A small proportion (6%) did not think that any further help would make any difference. The remainder either felt that more help would make a difference (73%) or did not know what might be gained (21%). Combining these last two groups, we can say that overall:

29% of all respondents had ongoing problems getting enough money to live on and felt that further help or support would be useful, or did not rule this out (n=489).

The obvious answer to the question *what would help with money problems?* was simply more money. However, many respondents identified ways in which this could be achieved, which ranged from increased benefits through to better paying jobs. Most respondents wanted increases in the amount of benefits available, which they felt did not reflect the current cost of living. They also wanted a simplified benefits system and increased efficiency among those handling claims. Many respondents said they wanted the benefits system to be more flexible and sensitive to the reality of living with HIV, especially for those who wanted to start working but were concerned about the impact of this on their health – ie. those facing the 'benefits trap'.

Other suggestions included tax breaks on mortgages; increased wages for those in employment; more flexible working conditions to cope with sudden illnesses; help with transport costs; removal of prescription charges; access to further training to get better jobs; support to get back to employment; financial advice to manage debts; help with utility bills or any other form of support that would help with daily living costs. Some people wanted to be re-housed in social housing to reduce their costs.

A significant number of African migrants needed a resolution to their immigration applications to enable them to seek employment. Also important was the support from family and friends during financial difficulties.

10.4 SUMMARY

Of all the respondents to the survey:

- 31% felt unhappy about the money they were getting to live on.
- 33% had experienced problems getting enough money to live on in the last year.
- 29% had ongoing problems getting enough money to live on and felt that further help or support would be useful, or did not rule this out.

11 Alcohol and other drugs

For many people, alcohol and other drugs are experienced as a regular need which is closely linked to needs for relaxation, stress-management, social contact *etc*. As such, alcohol and drugs can be seen as offering solutions to other problems and support for other needs. However, they also create needs. Dependence on, or excessive use can affect many other daily needs including health, well-being and self-confidence. Serious problems with alcohol and drugs can impact on all aspects of daily life.

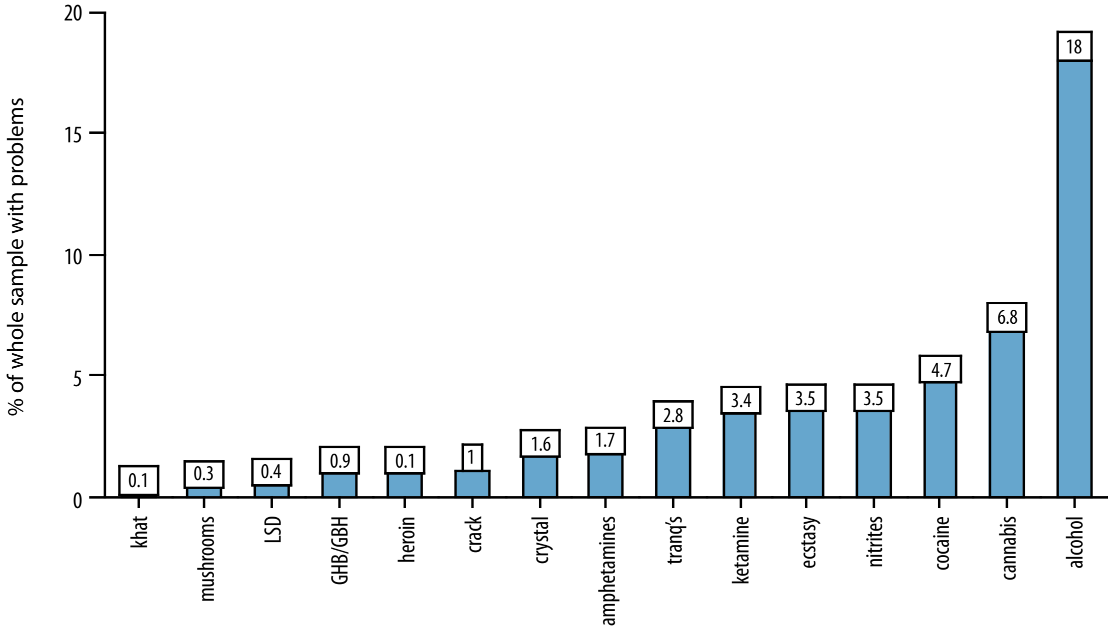
This chapter examines respondents' problems with alcohol and drugs and the support they received to address these problems. This focus on problems excludes any consideration of the positive impact of alcohol and drugs on personal needs.

11.1 PROBLEMS WITH ALCOHOL AND DRUGS

27% of all respondents had experienced problems related to alcohol and / or other drugs in the last year (n=447).

Among those that reported any problems with drugs and alcohol, alcohol accounted for more problems than all the other drugs put together (see Chart 11.1). Of those reporting any problems, more than a third (38%) reported problems with alcohol only, a further third (29%) reported problems with alcohol and other drugs, and a third (33%) described a problem with drugs but not with alcohol.

Chart 11.1: Problems with specific drugs and alcohol among the whole sample



The only data from the survey on actual drug use was the incidence of injecting drug use: among the 45 respondents who said they had injected drugs in the last year, two thirds (65%) described a problem with drugs or alcohol. However, although incidence of non-injecting drug use is much higher, problems with cocaine, ecstasy, amphetamines, and prescription drugs were relatively rare.

Among respondents reporting problems with alcohol or drugs the most common concern was a feeling that they were drinking too much, or taking too many drugs, or that they were doing so in inappropriate circumstances. Alcohol or drug use was also considered the cause of undesirable behaviour, such as being aggressive or argumentative, and had a negative impact on work, social relationships and financial stability. A number of physical and psychological harms were also identified, ranging from sickness and fatigue to paranoia, depression and memory loss. A large proportion of people felt that they were becoming reliant on alcohol or drugs to help them deal with, or distance themselves from, personal or relationship difficulties.

11.1.1 Changes over 12 months

A third (36%) of those who had experienced problems with alcohol or drugs in the last year said they had got better (31%) or been resolved (5%). Our previous research (Weatherburn *et al.* 2002) suggests some respondents will have stopped drinking or taking drugs altogether, and others will have reduced their intake. Some will have gained greater awareness of their problems and greater control over their lives – tackling both their alcohol or drug use and the aspects of their lives that created or sustained these problems. The support of partners, friends and counselling services will also have been important in achieving this new sense of control.

For a quarter (24%) of those who had experienced problems, things had got worse. Our previous research suggests, for many, this would have been because of increased consumption or a greater sense of dependence. However, some respondents will also have suffered worsening stress and depression; increased isolation; the demands both of living with illness and coping with treatments, and loss of support.

At the time of the survey, half (46%) of those who had experienced problems with alcohol or drugs in the last year, felt unhappy about their ability to cope with these problems with any help they were getting (60% of those whose problems had not improved). Among those who did not report any problems, only 2% were unhappy about their alcohol or drug use.

11.2 GETTING HELP WITH ALCOHOL AND DRUG PROBLEMS

Among respondents who had experienced problems with alcohol or drugs in the last year, a quarter (28%) had received some form of help to deal with these problems (see table below). This leaves three quarters (72%) of those with problems who had not received any help, or:

19% of all respondents had experienced problems related to alcohol and / or other drugs in the last year and had not received any help to address these problems (n=306).

Sources of help with alcohol or drug problems, among those that received any help (n=116, missing 1)	**Number**	**%**
counselling or psychology service	53	46
my friends	39	34
my GP practice (family doctor)	34	30
my partner / spouse	30	26
alcohol or drugs organisation	26	23
my HIV (GUM) clinic	25	23
an HIV organisation (charity)	21	18
other family	20	17
my parents	15	13
the council / social services	6	5
a general charity	5	4
my children	2	2
other sources of help with drugs and alcohol	9	8

The *other* sources of help included Alcoholics Anonymous meetings and sponsors, rehabilitation services, ex-partners and an employer.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. Almost a quarter (23%) did not think that any further help would make any difference. The remainder either felt that more help would make a difference (41%) or did not know what might be gained (36%). Combining these last two groups, we can say that overall:

19% of all respondents had ongoing problems related to alcohol and / or other drugs and felt that further help or support would be useful, or did not rule this out (n=298).

Many respondents expressed a desire for ongoing counselling or personal support that was sensitive to their cultural circumstances and familiar with the particular problems facing people with HIV. The opportunity to meet other individuals facing similar problems was suggested as being potentially beneficial.

Problematic alcohol and/ or drug use was often seen as the result of psychological distress or a general sense of feeling ill at ease with one's life situation. Overcoming these problems was often considered an essential first step in re-establishing control over alcohol or drug use. Achieving change was perceived to require not only clarity of mind, but also ongoing support from friends and services and, for some, improvements in living conditions and personal relationships.

11.3 SUMMARY

Of all the respondents to the survey:

- 27% had experienced problems related to alcohol and / or drugs in the last year.
- 19% had experienced problems related to alcohol and / or drugs in the last year, and had not received any help to address these problems.
- 19% had ongoing problems related to alcohol and / or drugs and felt that further help or support would be useful, or did not rule this out.

12 Anxiety and depression

Anxiety and depression are problems, not needs, and do not relate to a single, clear need. Although 'mental health' is commonly used to describe this need, it is a technical term that is ambiguous. No-one ever says that they 'need mental health', though they may say that they need peace of mind, strength to cope with daily life, or happiness and contentment.

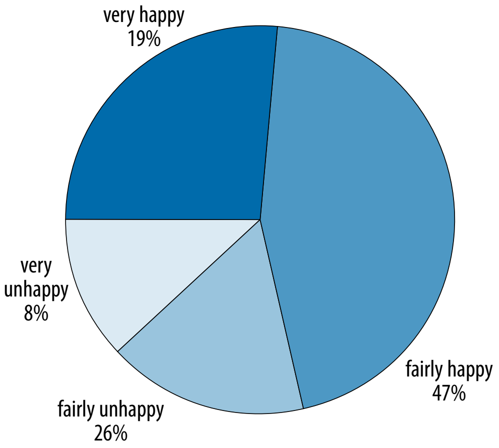
The emphasis of this chapter is on the experience of anxiety and depression, so it does not capture the aspirational elements of mental health, which is clearly more than the absence of depression and anxiety. Respondents who did not experience anxiety or depression may nonetheless have felt the need for greater purpose, security or happiness in their lives.

12.1 FEELINGS ABOUT ANXIETY AND DEPRESSION

Respondents were asked how they felt about their ability to cope with anxiety or depression. Overall, two thirds (66%) felt either very or fairly happy (see Chart 12.1).

34% of all respondents felt unhappy about their ability to cope with anxiety or depression (n=583).

Chart 12.1: Feelings about anxiety and depression



12.2 PROBLEMS WITH ANXIETY AND DEPRESSION

72% of all respondents had experienced problems managing anxiety or depression in the previous year (n=1255).

Problems with depression and anxiety ranged from mild anxiety (worry) created by specific events to chronic and severe depression and other psychiatric disorders. Given that these are self-reports, no attempt is made to quantify the severity of problems. However, the scale of problems is inescapable: most respondents had experienced some mental health problems that, for some, were overwhelming.

Many respondents described the causes of their anxiety or depression. These were very diverse. Indeed every other need explored in this report was cited as cause of anxiety and depression. Unsurprisingly, the most common cause was living with an HIV diagnosis and the many uncertainties this created, particularly for prospects of health and well-being. Respondents were worried about their life expectancy and the long-term impact of having HIV and taking medication. Other health problems such as hepatitis B and C, lipodystrophy, and sexual dysfunction were mentioned also.

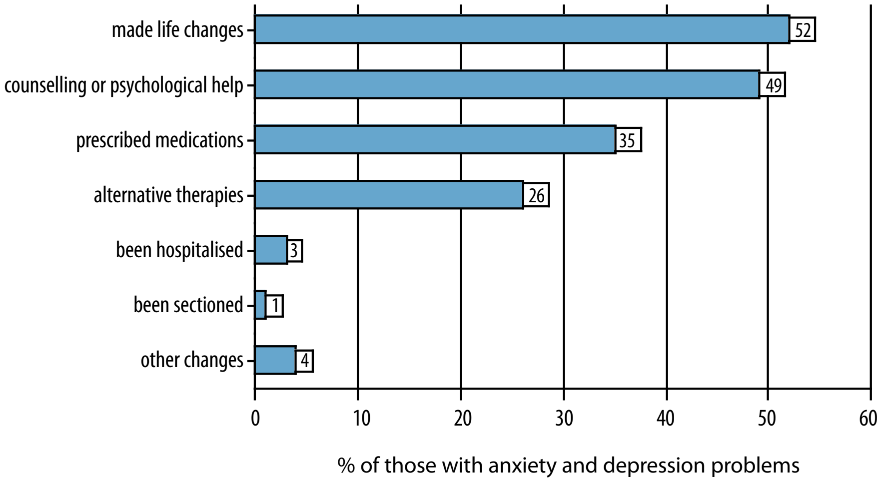
Beyond the shared reality of HIV infection, the identified causes of anxiety and depression ranged from difficulties with disclosure, financial insecurity, social exclusion, stigma, treatment side-effects, problems with alcohol and recreational drugs, relationships and immigration. Especially common was financial insecurity due to loss of jobs, unemployment, insufficient benefits, and debts. Also rejection by family and friends was a common cause of problems, as were traumatic childhood or relationship events, such as physical and sexual assault. Other causes of anxiety and depression included alcohol and drug use, homelessness and poor housing, ill-health or bereavement, and the burden of caring for other family members. Some respondents worried about the potential of infecting partners and being prosecuted for transmitting HIV to others. Others were angry about the circumstances in which they got HIV, or guilty about having potentially passed on the infection.

Experiences of HIV stigma and discrimination were also common causes of problems, as were difficulties with status disclosure, which led to isolation, loneliness and fear of never finding someone to love. In addition, some respondents were depressed about their childrens' uncertain futures. Also, for many African respondents the fear of deportation and living away from family and friends were cited as causes of anxiety and depression.

Those who experienced problems with anxiety and depression were asked how they had tried to address them. Categories were based on the reasons respondents to our previous survey (Weatherburn *et al.* 2002*)* had given for improvement in their anxiety and depression problems. Most commonly life changes were made (52%) or professional counselling or psychological help (49%) had been sought. A third had taken prescribed medication (35%) and a quarter (26%) had used alternative therapies. A small minority had required hospitalisation, voluntarily or forced, under the mental health act.

Other attempts to affect anxiety and depression included, time off work; respite or rehabilitation; seeking support from partners, friends, family, pets, community, church members or HIV professionals; reading self-help books or participating in self-help groups; prayer; engaging in activities such as reading or gardening, the use of non-prescription drugs such as cannabis or non-prescribed diazapam.

Chart 12.2: Changes made by people managing anxiety and depression



12.2.1 Changes over 12 months

Over a third (38%) of those who had problems with anxiety and depression in the last year said the problem had improved (35%) or been resolved (3%). Our previous research (Weatherburn *et al.* 2002) suggests there would have been four main reasons for improvements: treatment interventions, psychological interventions and support, changes in personal outlook and changes in personal circumstances. Anti-depressants will have worked for some respondents. Others will have found that starting or changing (and in a few cases stopping) anti-HIV treatments will have helped. Various approaches to talking it through will also have helped: counselling, clinical psychology, psychiatry, self-help groups or discussions with doctors, partners and friends. Gaining the support of others was often linked to personal success in adjusting to HIV, accepting personal problems and finding inner strength and personal confidence. Other changes in circumstances will have helped respondents to overcome anxiety and depression such as finding a new partner, moving house, starting employment, returning to education and socialising more. Some respondents will have seen the value of leading less stressful lives, others were enjoying more activity and excitement in their lives.

For almost a quarter (24%) of those who had experienced problems with anxiety or depression, things had got worse in the last year. The reasons for deterioration will follow the pattern of problems described above, including HIV diagnosis, poorer health, starting treatment, loneliness, relationship and family breakdown, lack of support, bereavement, employment difficulties, debts, housing problems and harassment.

At the time of the survey, almost half (47%) of those who had experienced problems were unhappy about their ability to cope with anxiety or depression (58% of those whose problems had not improved). Among those who did not report any problems, less than 2% were unhappy about their ability to cope with anxiety and depression.

12.3 GETTING HELP WITH ANXIETY AND DEPRESSION

Among the respondents who had experienced problems in the previous year, two thirds (67%) had received some form of help to deal with them. This leaves a third (33%) of those with problems who had not received any help, or:

23% all respondents had experienced problems with anxiety or depression in the last year and had not received any help to address them (n=398).

Sources of help in dealing with anxiety and depression, for those that had received any help (n=813, missing 5)	**Number**	**%**
counselling or psychology service	357	44
my friends	325	40
my GP practice (family doctor)	289	36
my HIV (GUM) clinic	277	34
an HIV organisation (charity)	237	29
my partner / spouse	234	29
prescribed medications	218	27
other family	123	15
my parents	75	9
community mental health service	66	8
the council / social services	55	7
my children	32	4
a general charity	27	3
other sources of help or support	44	5

The *other* sources of help included a variety of alternative and complementary therapies: from yoga and hypnotism to acupuncture, homeopathy and massage. Others mentioned exercise, work, study, religion, pets and themselves.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome them. One-in-six (18%) did not think that any further help would make any difference. The remainder either felt that more help would make a difference (51%) or did not know what might be gained (31%). Combining these last two groups, we can say that overall:

56% of all respondents had ongoing problems with anxiety or depression and felt that further help or support would be useful, or did not rule this out (n=949).

There were many ideas for help to reduce anxiety and depression. Most respondents wanted appropriate counselling and support or some broader change in their life circumstances. Respondents wanted easy access to free counselling with specific interventions such as psychotherapy, Cognitive Behavioural Therapy, life coaching, couples counselling, debt management counselling and Community Psychiatric Nurses. In addition, many wanted access to local support groups to meet and talk to other people with HIV who were facing similar problems.

Advice, support and counselling were described as opportunities to come to terms with having HIV, gain confidence and self-esteem and achieve greater self-understanding and control. Related to this was the need to love and feel loved and a call for support from family and friends. Others wanted support in dealing with bereavement and grief. Some also wanted increased public awareness and education to reduce HIV stigma and discrimination.

Respondents' suggestions for changes in life circumstances reflected the diversity of causes of anxiety and depression. Respondents wanted to find employment or greater income to afford daily expenses such as utility bills, transport, healthy food and access to recreational activities to reduce stress. They wanted help to access training or education, employment, better paying jobs and flexible working conditions to reduce job-related stress. Others wanted help with debt repayment, tax relief and housing, to find a (new) partner, to exercise and get out more. Many African respondents wanted their immigration status resolved so that they could seek employment, become independent and plan their lives better.

There were also calls for greater support around physical symptoms and side-effects of anti-HIV treatments. Many respondents wanted health professionals to be more sensitive to complaints about the tolerability of certain drugs, with sustiva given as an example. Easier access to anti-depressants and complementary therapies, such as hypnotherapy and meditation, was also requested.

12.4 SUMMARY

Of all the respondents to the survey:

- 34% felt unhappy about their ability to manage anxiety or depression.
- 72% had experienced problems managing anxiety or depression in last year.
- 56% had an ongoing problem managing anxiety or depression and felt that further help or support would be useful, or did not rule this out.

13 Self-confidence and self-esteem

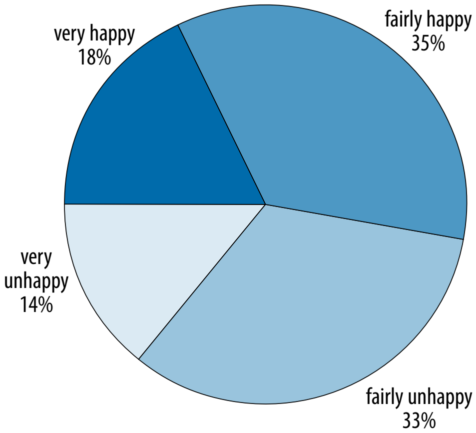
There are many ways of characterising the internal resources people need to get through their lives: courage, determination, inner strength, sense of purpose, integrity, *etc*. 'Self-confidence' or 'self-esteem' are two of the least ambiguous. They were used in the survey to capture something of the complexity of these personal internal needs. Self-confidence is not usually thought of as a 'basic need' but, without it, life can become a struggle to sustain. It is crucial to negotiating daily life and meeting many of life's needs, including needs for happiness and fulfilment.

13.1 FEELINGS ABOUT SELF-CONFIDENCE

Respondents were asked how they felt about their self-esteem or self-confidence. Overall, half (53%) felt either very or fairly happy (Chart 13.1).

47% of all respondents felt unhappy about their self-confidence or self-esteem (n=797).

Chart 13.1: Feelings about self-confidence



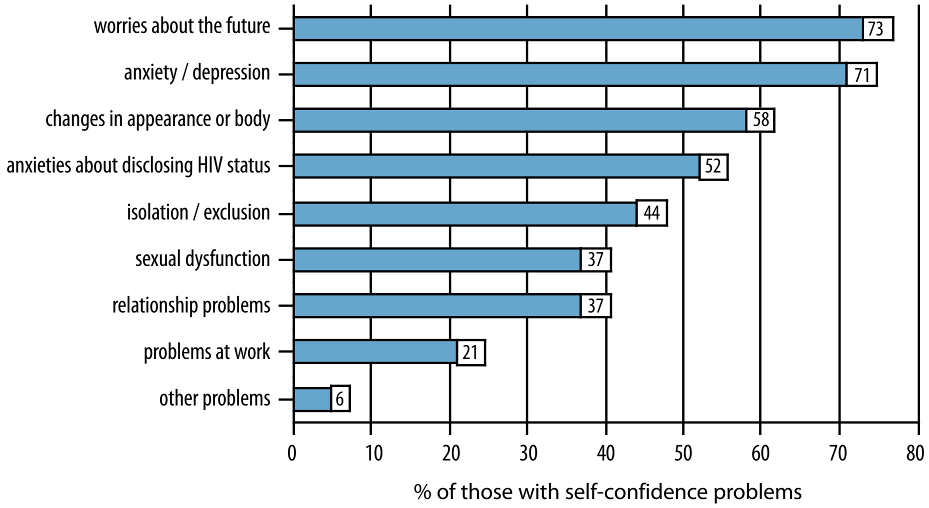
13.2 PROBLEMS WITH SELF-CONFIDENCE

71% of all respondents had experienced problems with self-confidence or self-esteem in the last year (n=1234).

The reasons given for lack of self-confidence are illustrated in Chart 13.2. In this survey worries about the future (73%) and anxiety and depression (71%) were cited as the most common causes of problems with self-confidence. Our previous work (Weatherburn *et al*. 2002) suggests that self-confidence is strongly linked to self-perception: with problems arising from changes in physical appearance due to HIV, illness or treatments.

Anxiety about disclosing status, isolation and exclusion, sexual dysfunction and relationship problems all contributed to problems with self-confidence. Our previous survey (Weatherburn *et al*. 2002) showed that within relationships problems included bereavement, breakdown, rejection, loss of trust or loss of support and serial rejection encountered when seeking new relationships. Common problems with work included the loss of jobs, struggles to maintain existing employment or to find new employment.

Chart 13.2: Causes of self-confidence problems among those with them



Other causes of problems with self-confidence and self-esteem included dealing with having HIV and feeling bad about it and the need for constant medical treatment. Having limited economic capital also led to low self-confidence, including being poor, requiring benefits, not having a job or having limited education or work skills. Also important was a lack of social capital and the associated stigma and discrimination that come from being part of a minority ethnic group, an immigrant, transgender, gay, obese, unattractive or a drug user. Historical incidents such as rape or a history of childhood problems continued to have an impact on self-esteem for some, as did shyness or mental health problems. For some a lack of independence also contributed.

13.2.1 Changes over 12 months

For a quarter (27%) of those who had experienced self-confidence problems in the previous year, the problem had improved (25%) or been resolved (2%). Our previous research (Weatherburn *et al.* 2002) suggests some will have turned to counsellors or other sources of support, including partners, to recover a sense of self-esteem. However, many will have either come to a greater acceptance of their circumstances or have made an active effort to change them by socialising more, looking for work, studying or finding a new partner. For others increasing self-confidence will have come from health improvements achieved through starting HIV treatment, changing treatment or more exercise.

For another third (31%) of those who had experienced problems, things had got worse. Our previous research suggest this might have often been due to a deterioration in health or physical appearance, though for some it may have been the impact of another year living with chronic problems – including the attitudes and insensitivity of others. Some respondents would also have simply felt older, poorer, more isolated and more depressed. Separation from partners or loss of other sources of support will also have contributed to the sense of isolation.

At the time of the survey, two thirds (65%) of those who had experienced problems felt unhappy about their self-confidence (78% of those whose problems had not improved). Among those who did not report any problems less than 2% were unhappy about their self-confidence.

13.3 GETTING HELP WITH SELF-CONFIDENCE PROBLEMS

Among respondents who had experienced problems with self-confidence in the previous year less than half (44%) had received any help to deal with these problems (see table below). This leaves more than half (56%) of those with problems who had not received any help, or:

40% of all respondents had experienced problems with self-confidence or self-esteem in the last year and had not received any help to address them (n=678).

Sources of help in dealing with self-confidence problems among those that received any help (n=521, missing 10)	**Number**	**%**
counselling or psychology service	248	48
my friends	191	37
my HIV (GUM) clinic	191	37
an HIV organisation (charity)	145	28
my partner / spouse	131	25
my GP practice (family doctor)	121	23
other family	73	14
my parents	60	12
the council / social services	26	5
surgery (eg. New fill)	23	4
a general charity	16	3
my children	13	3
other sources of help dealing with self-confidence problems	41	8

Other sources of help included complementary therapies. Help had also come from religion and those sharing the same faith, liaison workers, work colleagues, union representatives, occupational health workers, support groups, exercise, diet and drugs such as Viagra and sleeping pills.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would help reduce or overcome their problems. A fifth (21%) did not think that any further help would make any difference. The remainder either felt that more help would make a difference (41%) or did not know what might be gained (38%). Combining these last two groups, we can say that overall:

54% of all respondents had ongoing problems with self-confidence or self-esteem and felt that further help or support would be useful, or did not rule this out (n=899).

Respondents expressed diverse views on what kind of help would boost their self-confidence, including more psycho-social support via counselling, training and employment. Though general counselling was a preference among the majority, specific interventions such as Cognitive Behavioural Therapy, psychotherapy, peer support and life coaching were mentioned. People felt these interventions would help them understand themselves and deal with their situation better. Others suggested alternative therapies; a change of jobs or career; more social support; access to training to enhance assertiveness; flexible working conditions to reduce stress; help with immigration / legal issues and more information about HIV to widen their understanding.

Some wanted help with body image and physiological functioning. Dealing with lipodystrophy was a priority for many respondents. They suggested measures such as facial filling to deal with fat losses and improve physical appearance. However, there was a concern about lack of free access to such procedures via the NHS. Other respondents had issues with weight gain and needed support to access weight loss programmes, a gym or other sporting activities. A significant number expressed need for treatment and support to overcome sexual dysfunction. This combined with past trauma such as HIV diagnosis or bereavement undermined self-esteem and their ability to engage in long-term relationships

Financial support was also cited as a key to regaining self-confidence. Respondents' suggestions included subsidised gym access, funds for studying, free fertility treatment and money to retrain without losing welfare benefits. Many respondents indicated that if they could afford to, they would eat better, engage in more physical activity, and do other things that gave life some meaning.

There were also a variety of suggestions for improving the attitudes of wider society. Most suggestions involved widespread public education addressing the attitudes of society as whole, which were perceived to perpetuate stigma, secrecy and fear. Some respondents said criminal prosecutions for sexual HIV transmission and the threat of deportation hindered disclosure and instilled fear.

13.4 SUMMARY

Of all the respondents to the survey:

- 47% felt unhappy about their self-confidence or self-esteem.
- 71% had experienced problems with self-confidence or self-esteem in the last year.
- 54% had ongoing problems with self-confidence or self-esteem and felt that further help or support would be useful, or did not rule this out.

14 Friendship

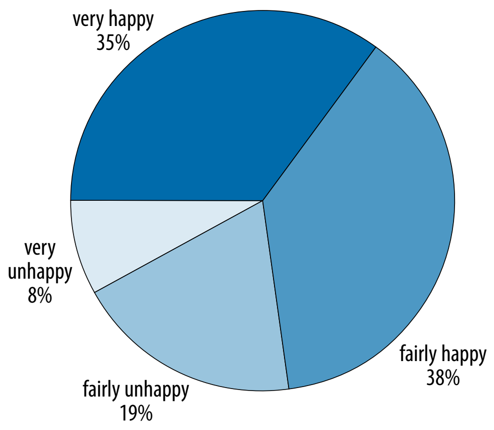
Like partners, friends can both meet needs and create them. If there is a distinct 'need for friendship', this is always closely related to other needs: for support, intimacy, self-expression and quality of life. This section treats friendship as a meaningful need in itself. However, this need is very dependent on personal priorities and aspirations: some people are happy to live with few or no friends; others lead lives in which friends are centrally important. Feelings about friendships will therefore reflect these attitudes as much as they reflect the state of current friendships.

14.1 FEELINGS ABOUT FRIENDSHIPS

Respondents were asked how they felt about their friendships. Overall, almost three quarters (73%) felt either very or fairly happy (Chart 14.1).

27% of all respondents felt unhappy about their friendships (n=462).

Chart 14.1: Feelings about friendships



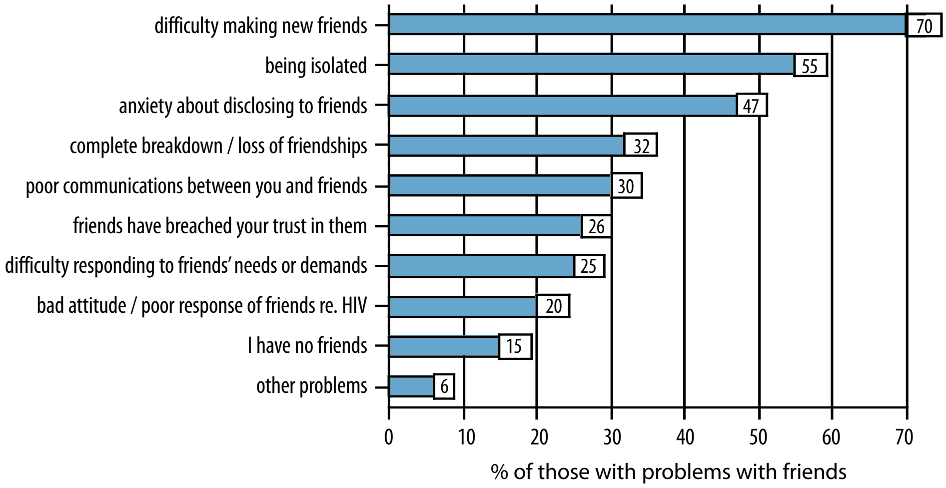
14.2 PROBLEMS WITH FRIENDSHIPS

41% of all respondents had experienced problems with their friendships in the last year (n=723).

The most common reported problems with friendships was difficulty making new friends (70% of those with problems with friends), feelings of isolation (55%) and anxiety about disclosing HIV infection to friends (47%, see Chart 14.2).

Almost a third (32%) of respondents with problems with friends reported a complete breakdown or loss of friendships and poor communication between them and their friends. Friends had disappeared, distanced themselves or reacted so badly that respondents had turned away themselves.

Chart 14.2: Problems with friends



A quarter of respondents with problems with friends, reported breaches of trust with existing friends (26%) and difficulty responding to friends' needs or demands (25%). A fifth (20%) reported poor responses from friends regarding HIV. Friends who stuck around after HIV diagnosis could still be unsympathetic to illness, fatigue, depression and the demands of living with HIV. Finally, one-in-seven (15%) of those with a problems with friends said they had no friends – this represents 6% of the entire sample.

Other problems arose from health problems making friendship difficult or adding to difficulties in finding time to spend together; a fear of friendships becoming relationships with potential for sex and onward HIV transmission; and lack of confidence making and keeping friends.

14.2.1 Changes over 12 months

A fifth (19%) of those who had experienced problems with their friendships in the previous year said that their problems had improved (17%) or been resolved (2%). Previous data (Weatherburn *et al*. 2002) suggests this may have been achieved by separating from the friends causing problems or actively seeking new friends. Other problems would have been resolved because of changes in the respondents' themselves: acceptance of personal circumstances, adjustment to living with HIV and increased confidence, self-awareness and control over life.

For almost a third (31%) of those who had experienced problems with friendships, things had got worse in the last year. For many this meant the loss of friends (for all the reasons described above) and increased isolation. This could become a vicious circle: loss of confidence or strength leading to greater isolation, which in turn undermined any sense of control over life.

At the time of the survey, two thirds (64%) of those who had experienced problems were unhappy about their friendships (71% of those whose problems had not improved). Among those who did not report any problems, less than 2% were unhappy about their friendships.

14.3 GETTING HELP WITH FRIENDSHIPS

Among the respondents who had experienced problems with their friendships in the last year, a quarter (25%) had received some form of help to deal with these problems (see table below). This leaves three quarters (75%) of those with problems who had not received any help, or:

30% of all respondents had experienced problems with their friendships in the last year and had not received any help to address these problems (n=524).

Sources of help with friendship problems among those that received any help (n=173, missing 3)	**Number**	**%**
my friends	78	45
counselling or psychology service	68	39
an HIV organisation (charity)	60	35
other family	28	16
my partner / spouse	23	13
my HIV (GUM) clinic	19	11
my parents	16	9
my GP practice (family doctor)	13	8
the council / social services	12	7
my children	6	4
a general charity	5	3
other sources of help with problems with friends	12	7

The *other* sources of support included church members and pastors, LGBT youth groups, 12-step programmes and the internet.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. A quarter (25%) did not think that any further help would make any difference. The remainder either felt that more help would make a difference (34%) or did not know what might be gained (41%). Combining these last two groups, we can say that overall:

30% of all respondents had ongoing problems with their friendships and felt that further help or support would be useful, or did not rule this out (n=508).

To solve friendship problems, respondents wanted help to deal with personal issues and interventions to enable wider society to deal with HIV more sympathetically. Some saw public education campaigns as an important means to reduce the stigma of HIV and help people to understand what it is like to live with the virus.

For themselves, respondents wanted help to rebuild self-confidence and self-esteem to enable them to socialise more. They suggested counselling to deal with psychological stressors, local peer support groups to share experiences, more information and education on living with HIV, financial support to meet daily costs, flexible working conditions to create more social time and improved physical health to keep self-esteem high. They also wanted help with HIV disclosure because secrecy strained their friendships while disclosure brought the risk of stigma and discrimination. Others wanted housing support to enable them to relocate, reduced dependence on social services and help finding local support groups.

14.4 SUMMARY

Of all the respondents to the survey:

- 27% felt unhappy about their current friendships.
- 41% had experienced problems with their friendships in the last year.
- 30% had ongoing problems with their friendships and felt that further help or support would be useful, or did not rule this out.

15 Relationships with family

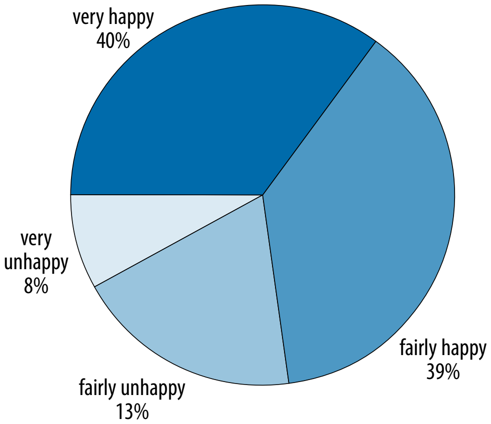
Relationships with family are an important means of meeting needs, such as care, support and continuity. However, relationships do not always fulfil these needs adequately and they can also create needs, especially when things go wrong. This section focuses on the needs generated within families rather than the needs fulfilled by them.

15.1 FEELINGS ABOUT FAMILY RELATIONSHIPS

Respondents were asked how they felt about their current relationship with their family. Overall, 79% felt very or fairly happy (Chart 15.1).

21% of all respondents were unhappy about their current relationship with their family (n=343).

Chart 15.1: Feelings about relationships with family



15.2 PROBLEMS WITH FAMILY RELATIONSHIPS

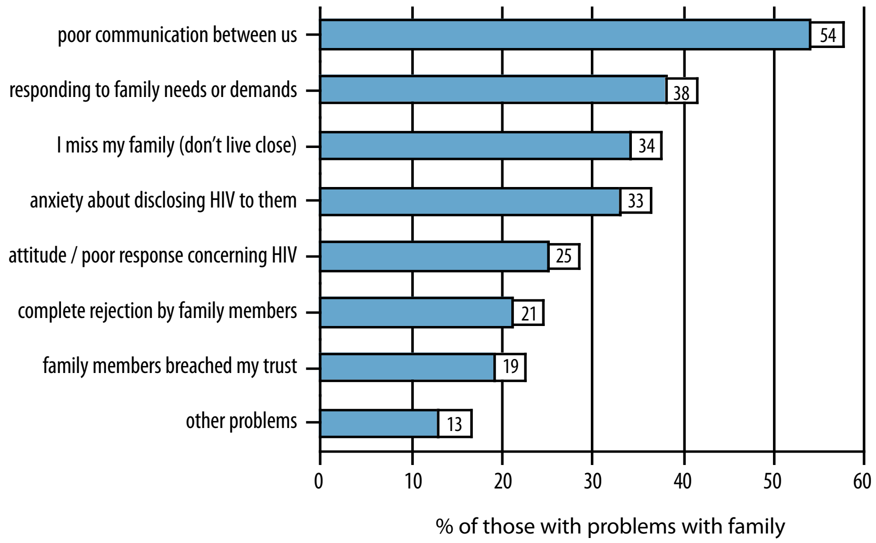
29% of all respondents had experienced problems with family relationships in the last year (n=512).

The three most common problems within families were poor communication between the respondent and their immediate family, which was reported by more than half (54%) of those with family problems; difficulties for the person with HIV responding to the needs or demands of the family (38%) and sadness that the family did not play a significant role in their lives (34%). In many respects these problems probably were not closely associated with the diagnosed HIV infection of the respondent, and may even be relatively "normal".

However, respondents with problems with their families did mention HIV in their descriptions of relationship problems. Problems arose because the respondent was anxious about disclosing their HIV infection to family members (33%), and because they suffered a poor response when they did (25%), including complete rejection by family members (21%) and breaches of trust (19%) when disclosure occurred.

Other problems with family included feuds and arguments over money and caring for elderly relatives, previous rejection when homosexuality was disclosed and resentment that they were not cared for by family members, or were still expected to care for others.

Chart 15.2: Problems with family among those that had any



15.2.1 Changes over 12 months

Among those who had experienced problems with their families in the last year, a fifth (21%) said the problems had got better (20%) or been resolved (1%). Previous data (Weatherburn *et al.* 2002) suggests that, for most, improvements would have been achieved through working at family relationships. This would have included improvements in communication, attitudes and willingness to compromise and the achievement of greater honesty and understanding. Some will have addressed root problems such as drinking and money disputes; others had experienced changes in circumstances – such as starting or stopping treatment – that had a positive impact on their relationships with family.

For more than a quarter (28%) of those who had experienced problems with family relationships things had become worse in the last year. Previous data (Weatherburn *et al.* 2002) suggests that stress, the demands of HIV treatment taking and communication breakdowns would have been prominent reasons for deterioration in relationships with family.

At the time of the survey more than half (59%) of those who had experienced family problems were unhappy about their family relationships (69% of those whose problems had not improved). Among those who had not experienced any problems, 4% were unhappy with their family relationships.

15.3 GETTING HELP WITH FAMILY RELATIONSHIPS

Among those who had experienced problems with family relationships in the last year, a third (32%) had received some help to deal with these problems (see table overleaf). This leaves two thirds (68%) of those with problems who had not received any help, or:

20% of all respondents had experienced problems with family relationships in the last year and had not received any help to address these problems (n=336).

Sources of help in dealing with problems with family relationships among those that received any help (n=157, missing 5)	**Number**	**%**
my friends	66	42
counselling or psychology service	57	36
an HIV organisation (charity)	44	28
my partner / spouse	42	27
other family	29	19
my HIV (GUM) clinic	21	13
the council / social services	14	9
my parents	13	8
my GP practice (family doctor)	11	7
my children	7	5
a general charity	5	3
other sources of help with family problems	10	6

The *other* sources of help included 12-step sponsors, solicitors, church officials and religion.

Respondents whose problems with family had not been resolved were asked whether they felt that further help or support would reduce or overcome them. Four-in-ten (41%) did not think that further help would improve matters. The remainder either felt that further help would make a difference (28%) or did not know what might be gained (31%). Combining these last two groups, overall:

16% of all respondents had ongoing problems with family relationships and felt that further help or support would be useful, or did not rule this out (n=278).

Respondents whose problems with family had not been solved in the last year, and who felt that more help or support might help, described two potential solutions to family problems: support interventions from outside the family and self-initiated change. Many mentioned a need for individual and group counselling or support, including accessible support groups comprised of other people with HIV. Along similar lines, many mentioned a desire to receive specific help with their ability to tell their family about their HIV status, accompanied by information and emotional support tailored to those receiving such news.

Although it was not always specified how this might be achieved, improved self-confidence was cited as a means to help people manage their family relationships. Many spoke of the need to change the frequency and intensity of contact they had with their family. For most this meant seeing more of them, or living closer to them, although for a few, there was a desire to gain some distance from problematic relationships. Having more money and having a greater capacity to care for relatives was also mentioned, as was a desire for respect and humane treatment.

A number of respondents felt that resolution of their immigration status (and the resulting freedom to travel) would enable them to see family whom they had not been able to see for some time.

15.4 SUMMARY

Of all the respondents to the survey:

- 21% were unhappy about their current relationship with their family.
- 29% had experienced problems within their family in the last year.
- 16% had ongoing problems with their family and felt that further help or support would be useful, or did not rule this out.

16 Relationships with partners

Relationships with primary partners are an important means of meeting needs, such as the need for intimacy, support, sex, family and continuity. However, relationships do not always fulfil these needs and they can also create needs, especially when things go wrong. This section focuses on the needs generated within relationships rather than the needs fulfilled by them, or the need for a relationship.

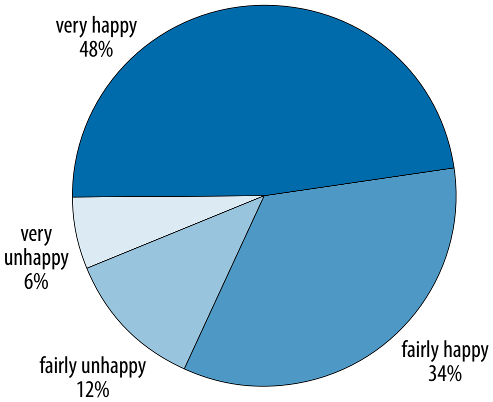
Half of all respondents (49%, n=861) had a husband, wife, civil partner or long-term partner, boyfriend / girlfriend at the time of completing the survey. Overall, almost two thirds (64%) of all respondents had been involved in a partner relationship in the previous year.

16.1 FEELINGS ABOUT CURRENT RELATIONSHIPS WITH PARTNERS

Respondents were asked how they felt about their current relationship, if they had one. Overall, 82% of those who had a partner felt fairly or very happy (38% of all respondents) (see Chart 16.1).

8% of all respondents were unhappy about a current relationship (n=142, 18% of those that had a current regular partner).

Chart 16.1: Feelings about partner / relationship (among those in a current relationship)



16.2 PROBLEMS WITH RELATIONSHIPS WITH PARTNERS

27% of all respondents had experienced problems with a relationship in the last year (n=469).

Over a third (39%) of respondents who described a problem in a relationship in the last year no longer had a partner at the time of the survey. Inevitably, the problems they described concerned break-up and loss. Some had been bereaved, others had been abandoned at HIV diagnosis or disclosure, but most simply described the 'normal' breakdown of trust and communication when relationships end. Relationships had broken down for many reasons: difficulties arising after HIV diagnosis or disclosure; dishonesty, mistrust and infidelity; problems with sex, money or alcohol and drugs; and general failures of communication, understanding and support.

The problems described by respondents who had a current partner were similarly diverse. Relationship problems necessarily affect at least two people, and in describing their problems, respondents focused on different aspects: the nature of the problem; who had the primary experience of it; the response of the other person; and the overall impact on the relationship.

Most respondents did not mention HIV in their descriptions of relationship problems and many clearly felt that their problems were just 'the usual': arguing, failing to communicate, loss of intimacy or trust, diverging priorities *etc*. Many also described problems with drink, money, depression and sex that may have been affected by HIV, though this was not always indicated. Sex was a very common source of problems, including loss of interest or potency and complete breakdowns of sexual relationships reported. Unsurprisingly sero-discordant relationships were especially fraught about sex, with a wide range of anxieties about HIV transmission reported.

Many respondents focused on their partner's poor response to their own experience. Partners had failed to understand or accept the impact of HIV diagnosis and illness and its effects on energy, confidence and productivity. Some partners had responded particularly badly: failing to offer support, becoming distant and demanding or verbally and physically abusive. However, some respondents were sympathetic to the demands they placed on partners, acknowledging how difficult it must be to deal with their mood swings, anxiety, fatigue, ill-health and side-effects.

Whether relationships were HIV sero-discordant or not, support had to be given and received. Several respondents described the challenges of supporting partners who were dealing with their own HIV diagnosis or ill-health, who had mental health problems, or who were habitually drunk or generally in need of their attention.

Changes in personal priorities and daily routines, such as going back to work or developing divergent interests also created problems and could lead to couples drifting apart or feeling trapped in relationships. Money problems were also a major cause of relationship difficulties, especially among African respondents.

16.2.1 Changes over 12 months

The respondents who had seen relationships end in the year prior to the survey had experienced the biggest changes. For them, problems in relationships were a thing of the past – they now had to deal with the loss and the difficulties of building a new relationship.

Among those who had a current partner and had experienced relationship problems in the previous year, a third (33%) said the problems had got better (28%) or been resolved (5%). Our previous research (Weatherburn *et al.* 2002) suggests that some will have split up and found new partners, but for most, improvements would have been achieved through working at their relationship. Some will have seen improvements in communication, attitudes and willingness to compromise and the achievement of greater honesty and understanding. Others will have addressed root problems such as alcohol and money disputes; or experienced changes in circumstances – such as starting or stopping treatment – that had a positive impact on their relationship.

For a quarter (25%) of those who had experienced problems in a relationship (but still had a partner), things had got worse. Our previous work suggests sexual problems, stress, the demands of treatment and communication breakdowns will all have been common reasons for deterioration.

At the time of the survey 41% of those who had experienced problems (but still had a partner) were unhappy about their relationship (80% of those whose problems had not improved). Among those who had not experienced any problems, 5% were unhappy about their relationships.

16.3 GETTING HELP WITH PROBLEMS WITH RELATIONSHIPS

Among those who had experienced problems in relationships in the last year (including those who no longer had a relationship), two thirds (64%) had got some form of help to deal with them. This leaves another third (36%) of those with problems who had not received any help, or:

10% of all respondents had experienced problems with a relationship in the last year and had not received any help to address these problems (n=171).

Sources of help in dealing with problems with partners among those that received any help (n=167, missing 4)	**Number**	**%**
my friends	72	44
counselling or psychology service	67	41
my HIV (GUM) clinic	54	33
my partner / spouse	39	24
an HIV organisation (charity)	35	22
my GP practice (family doctor)	23	14
other family	20	12
my parents	18	11
the council / social services	12	7
a general charity	4	3
my children	2	1
other sources of help with problems with partners	20	12

The *other* sources of help included the police, victim support and solicitors, medication for erectile dysfunction, Alcoholics Anonymous and religion.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. A quarter (25%) did not think so. The remainder either felt that further help would make a difference (39%) or did not know what might be gained (36%). Combining these last two groups, we can say that overall:

18% of all respondents had ongoing problems in a current relationship and felt that further help or support would be useful, or did not rule this out (n=292).

Some respondents felt that there was no realistic solution to their relationship problems, apart from breaking up. However, most felt that some form of counselling, advice or support might help. Some wanted couples counselling, others wanted counselling for themselves or their partner alone. Many felt that such professional support was hard to access with limited income, and that GUM or HIV clinics was their ideal place to access such support. Other suggestions included (family) support groups and opportunities to meet other couples facing similar problems.

Other respondents wanted help to resolve the basic problems that affected their relationships. These included problems with physical and mental health, with money, alcohol use, anxiety and depression and immigration law. Some wanted to spend more time within the relationship talking, listening and building mutual respect. Others wanted more education or information, for themselves or their partner, or for wider society. They assumed that they would receive more support if having diagnosed HIV was more widely understood and less stigmatised.

16.4 SUMMARY

Of all the respondents to the survey:

- 49% had a current relationship.
- 8% were unhappy about a current relationship.
- 27% had experienced problems with a relationship in the last year.
- 18% had ongoing problems with a current relationship and felt that further help or support would be useful, or did not rule this out.

17 Looking after children

Given the limitations of a self-complete questionnaire this study could not make any assessment of the needs of children and young people with diagnosed HIV. However, we did include an investigation into the needs of people caring for children and young people; ie. for the energy, time and resources to ensure that the needs of their children are adequately met.

This chapter only addresses the needs of respondents who had day-to-day responsibility for the care of children. There were 202 respondents with day-to-day responsibility for the care of a child or children: 12% of the sample. Three quarters (75%, n=151) of those with day-to-day responsibility for the care of a child, lived with that child. Two thirds (64%, n=128) also had a partner, though less than half lived with one (43%, n=86).

Among those with day-to-day responsibility for the care of a child, three quarters (77%) were women (n=153) and a quarter (23%) were men (n=45). Less than half (43%, n=86) were in any form of paid employment. Among those with day-to-day responsibility for the care of a child, there were 68 White respondents, including 58 White British. There were 112 Black African, 5 Black Carribean, and one other Black respondent and 6 Asian respondents and 8 of mixed or other ethnicities. The majority of respondents with responsibility for the care of a child were heterosexual: ten men and two women identified as gay, lesbian or bisexual.

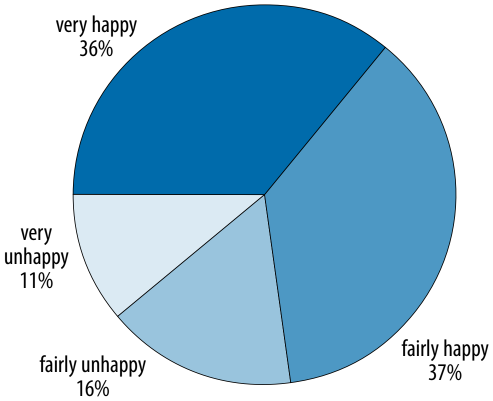
A fuller description of the demographic characteristics and needs of people with day-to-day responsibility for the care of children can be found in section 3.5.10.

17.1 FEELINGS ABOUT LOOKING AFTER CHILDREN

The respondents who had day-to-day responsibility for the care of children were asked how they felt about their ability to look after children. Overall, three quarters (73%) felt either very or fairly happy (Chart 17.1).

27% of respondents with day-to-day responsibility for the care of children felt unhappy about their ability to look after them (n=46, 3% of all respondents).

Chart 17.1: Feelings about looking after children



17.2 PROBLEMS LOOKING AFTER CHILDREN

37% of respondents with responsibility for the care of children had experienced problems looking after them in the last year (n=75, 4% of all respondents).

The problems respondents had looking after children were closely related. The most common complaint was of tiredness and exhaustion and the difficulties associated with caring for children when feeling unwell yourself. Many respondents stressed that fatigue, or a lack of energy, meant that they struggled to perform day-to-day parenting tasks. This was often the cause of great personal distress, with some respondents feeling that their children suffered as a result of the tiredness they experienced.

Also of concern was the absence of accessible childcare, which became a significant problem during periods of acute ill-health. Several respondents reported that the lack of any support in caring for children meant they found it difficult to work, study or socialise. Financial problems were most commonly reported as the reason for not utilising organised childcare facilities. A lack of money also meant that many felt unable to adequately provide for children in terms of clothes, food, transport or leisure activities.

17.2.1 Changes over 12 months

A quarter (25%) of the respondents who had experienced problems looking after children in the previous year said the problem had got better (21%) or been solved (4%). Previous data (Weatherburn *et al.* 2002) suggests these improvements would have been because children had aged or had started to communicate better. Other respondents will have seen improvements in their own health and mobility or had found support from local agencies or the church.

For a third (32%) of those who had problems, things had got worse. Previous data suggest most of these respondents will have experienced a deterioration in their health, energy or mobility.

At the time of the survey, more than half (57%) of those who had experienced problems looking after children in the last year were unhappy about their ability to look after their children (61% of those whose problems had not improved). A relatively small (5%) proportion of respondents who did not report any problems in the last year were unhappy about their ability to look after children.

17.3 GETTING HELP LOOKING AFTER CHILDREN

Over half (53%) of the respondents who had problems looking after children in the last year had received some form of help to deal with these problems (see table below). This leaves another half (47%) who had not received any help, or:

17% of respondents with day-to-day responsibility for the care of children, had experienced problems looking after children in the last year and had not received any help to address these problems (n=34, 2% of all respondents).

Sources of help in looking after children among those who received any help (n=36, missing 3)	**Number**	**%**
my friends	14	39
my partner / spouse	11	31
my parents	10	30
other family	7	19
my children	7	19
a children's charity	6	17
an HIV organisation (charity)	6	17
my HIV (GUM) clinic	4	11
the council / social services	4	11
my GP practice (family doctor)	3	8
a general charity	2	6
other sources of help looking after children	3	8

The *other* sources of help included a child-minder and Home-start.

Respondents were asked whether they felt that further help or support would reduce or overcome their problems. A small proportion (4%) did not think that any further help would make any difference. The remainder either felt that more help would make a difference (79%) or did not know (16%). Combining these last two groups, we can say that overall:

33% of respondents who had day-to-day responsibility for the care of children had ongoing problems looking after children, and felt that further help or support would be useful, or did not rule this out (n=64, 4% of all respondents).

Respondents whose problems with child-care had not been solved in the last year, and who felt that more help or support might help, were asked *Realistically, what help do you think would make a difference to your problems with looking after children*? Suggestions ranged from a need for more affordable childcare facilities, to someone being around to pick them up from school, or simply having someone to help with domestic chores. Others described a need for greater financial assistance which, they hoped, would enable them to provide their children with a better quality of life. A few respondents highlighted a desire to return to work should financially viable childcare become available.

17.4 SUMMARY

Of all respondents with responsibility for the day-to-day care of children:

- 27% felt unhappy about their ability to look after children (3% of all respondents).
- 37% had experienced problems looking after children in the last year (4% of all).
- 33% had ongoing problems looking after children and felt that further help or support would be useful, or did not rule this out (4% of all).

18 Sex

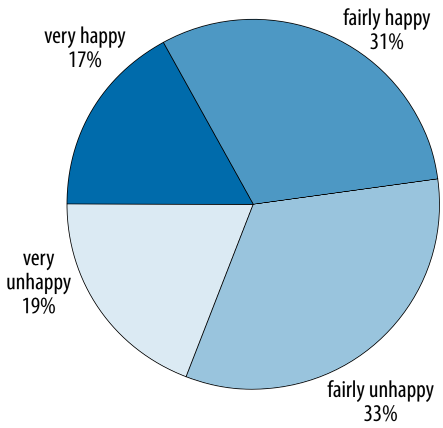
The need for sex is defined by both aspirations and problems. Some people have little or no interest in sex, whereas others feel that sexual pleasure is central to their life. Some people have no difficulty getting and having sex, but others face intractable problems. As aspirations for sex can be very strong, and problems rapidly undermining, the need for sex is especially sensitive to changes in personal circumstances.

18.1 FEELINGS ABOUT SEXUAL PROBLEMS

Respondents were asked how they currently felt about their sex lives. Less than half (48%) of all respondents felt either very or fairly happy (Chart 18.1).

52% of all respondents currently felt unhappy about their sex lives (n=878).

Chart 18.1: Feelings about sex



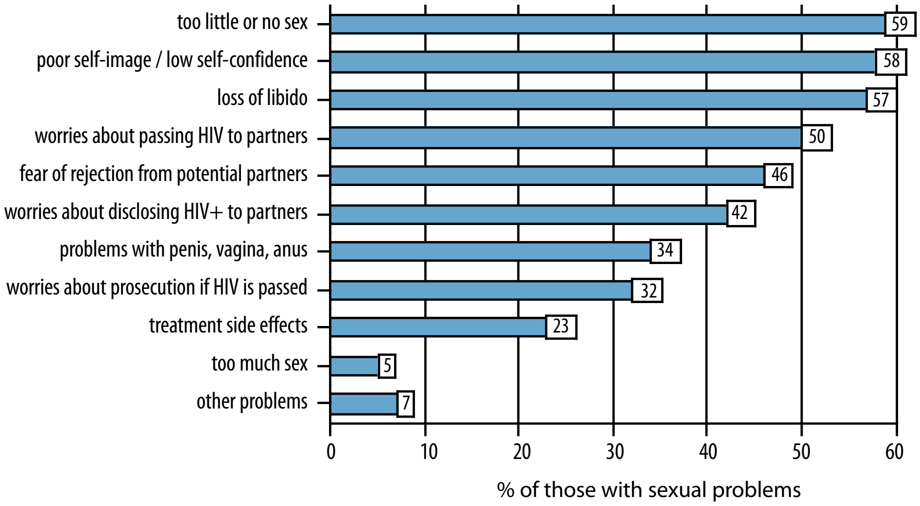
18.2 PROBLEMS WITH SEX

68% of all respondents had experienced problems with sex in the last year (n=1181).

The most frequent problem (59%) was simply not having any sex, or having very little (Chart 18.2). For many, this was linked to poor self-image or low self-confidence (58%) and a loss of libido or interest in sex (57%). Although we did not ask why their sex lives had diminished, the other problems indicated in the chart give some indication of the challenges that respondents may have faced. Anxieties about passing on HIV infection to partners (50%), rejection by potential sexual partners (46%) and disclosing to partners (42%) were all very common. In addition, a third (32%) described concerns about potential prosecution for onward transmission of HIV during sex.

Physical problems associated with sex were also reported by a third (34%) of respondents with sexual problems (and 23% of all respondents). Taking anti-HIV treatments and their side-effects were also cited as the cause of difficulties with sex by almost a quarter (23%) of those with problems.

Chart 18.2: Difficulties with sex among those with sexual problems



Among the *other* difficulties many respondents described sex being undermined by physical health problems including illness, pain and treatment side-effects. Fatigue figured prominently as did joint pain and problems with bowels, prostates and skin disorders. Most common though was erectile dysfunction and failure to reach orgasm. Respondents also revealed anxieties about HIV and the avoidance of other sexually transmitted infections. Some described being too worried about passing on HIV to have sex, even with regular partners. Problems also arose when partners were ill or suffering treatment side-effects, or when their sex drive was no longer compatible with their own. Some described a loss of desire for long-term partners and an ongoing fear of HIV transmission in sero-discordant relationships. Others were anxious about disclosing their HIV status to potential new partners and were fearful of rejection if they did. The actual experience of rejection by partners (new and old) was common. Anxiety was also expressed in a lack of self-confidence. This was sometimes the direct result of getting HIV infection through sex and sex now feeling 'dirty' – or alternatively arose through experience of illness and treatment side-effects. Some were afraid of meeting a new partner, or forming a new relationship. The fear of disclosure was paramount here. Some gay men found casual sex with strangers far easier, because of the lack of need for disclosure, and some felt they had become "addicted" to casual sex as a consequence. No respondents described specific problems with using condoms but the challenge of maintaining safer sex was implicit in the anxieties about HIV transmission described.

18.2.1 Changes over 12 months

A seventh (15%) of those who had experienced problems with sex in the last year said the problem had improved (14%) or been resolved (1%). Our previous research (Weatherburn *et al.* 2002) suggests reasons for improvement would have been diverse. A common source of help was probably Viagra and testosterone, reflecting the prominence of physical difficulties as a cause of problems. Others will have found that improvements in their general health (including changes in treatments) had led to a recovery in their sex lives. Changes in mental health and personal outlook will have also contributed to better sex lives: some respondents will have come to terms with having HIV; gaining greater self-confidence, in some cases through counselling; and developing new sexual interests. Within relationships, talking and reaching greater mutual understanding will have led to improvements in sex, and some will have found a new partner.

For a third (33%) of respondents who had experienced problems with sex, things had got worse. Some will have experienced a deterioration of potency, health and confidence. Others a sense of isolation, with the prospect of meeting a supportive partner ever more distant, not least because of the ongoing stigma of HIV. Relationships will have also deteriorated, with partners expressing increasingly divergent needs – some for less sex, others for more. Age, frustration with HIV and increased anxiety will all have contributed to worsening sex lives.

At the time of the survey, three quarters (72%) of those who had experienced problems were unhappy about their sex lives (74% of those whose problems had not improved). Among those who did not report any problems, a sizeable minority were unhappy about their sex lives (9%), reflecting the aspirational aspect of the need for sex.

18.3 GETTING HELP FOR SEXUAL PROBLEMS

Among the respondents who had experienced problems with sex in the last year, less than a third (28%) had received any help to deal with them (see table below). This leaves more than two thirds (72%) of people with problems with sex who had not received any help, or:

49% of all respondents had experienced problems with sex in the previous year and had not received any help to address them (n=832).

Sources of help in dealing with sexual problems among those that received any help (n=308, missing 14)	**Number**	**%**
my HIV (GUM) clinic	156	51
counselling or psychology service	97	32
my friends	72	23
an HIV organisation (charity)	64	21
my GP practice (family doctor)	62	20
my partner / spouse	58	19
other family	16	5
the council / social services	13	4
my parents	5	2
my children	2	<1
a general charity	1	<1
other sources of help in dealing with sexual problems	34	11

The *other* sources of help and support with sexual problems included a range of medical specialisms including dermatology, urology, psychiatry and specialist clinics dealing with erectile dysfunction and lack of libido. Some men also mentioned Viagra and other prescribed medication, with only one mention of complementary therapies: homeopathy. Finally, others mentioned support from ex-partners, life-coaches, 12-step sponsors and prayers.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. A quarter (24%) did not think that any further help would make a difference. The remainder either felt that more help would make a difference (35%) or did not know what might be gained (41%). Combining these last two groups, we can say that overall:

50% of all respondents had ongoing problems with their sex lives and felt that further help or support would be useful, or did not rule this out (n=829).

Asked what kinds of help or support might make a difference many expressed a need for help dealing with low self-esteem or self-confidence which they felt had a detrimental impact on their sex lives. Counselling was seen as a viable way of addressing these issues, though there were concerns that any counselling service should be culturally sympathetic and aware of the issues facing people with diagnosed HIV. The opportunity to explore self-esteem and self-confidence with others who had experienced similar difficulties was also suggested as a potential help.

Advice on when, where and how to disclose HIV infection to a sexual partner was also frequently requested. In addition, guidance on how to talk openly about sex and sexuality, both in relation to HIV and in order to achieve greater sexual satisfaction, was also seen as potentially beneficial.

Many respondents highlighted medical or physiological problems which were having an impact on their sex lives. Concerns about body image, particularly in relation to lipodystrophy and truncal adiposity were frequently cited. Greater awareness of, and improved access to, treatments to address these problems was suggested. Most important for others was the need for greater recognition by health professionals that sexual problems could have an impact on the psychological and emotional well-being of people with HIV. While prescription drugs for erectile dysfunction were welcomed by some, greater diversity in treatments, particularly for women experiencing low sex drive was encouraged.

Recent criminal prosecutions for 'reckless' transmission of HIV were of great concern to a large number of people. Many felt that the Crown Prosecution Service should stop pursuing such prosecutions and, at the same time, health promotion agencies should reiterate the importance of all individuals taking responsibility for their own sexual health. A need for greater awareness of HIV-related issues, particularly in relation to the likelihood of HIV transmission during sex, was highlighted. It was hoped this would help to reduce stigma, make sex more likely to occur, and make it more enjoyable when it did.

18.4 SUMMARY

Of all the respondents to the survey:

- 52% felt unhappy about their sex lives.
- 68% had experienced problems with their sex lives in the last year.
- 50% had ongoing problems with their sex lives and felt that further help or support would be useful, or did not rule this out.

19 Access to information about living well with HIV

The need for information about HIV is very dependent on individual attitudes – different people will be happy with very different levels of personal knowledge. It is possible to survive and live well with almost no knowledge of HIV at all. There are people with HIV who are well and choose to ignore medical and other specialist HIV services as long as they can; people who leave all treatment decisions to their doctors; and people who do not seek HIV-related information until it is absolutely necessary. However there are many people for whom knowledge of personal treatment and other choices is a very high priority.

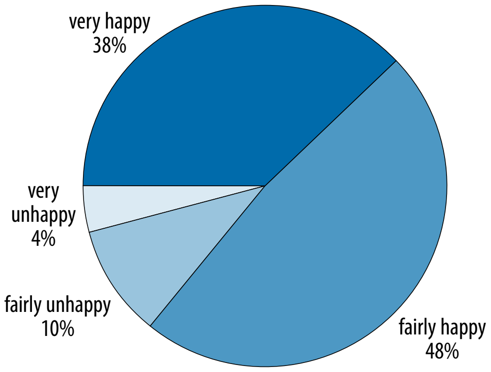
The emphasis in the survey was on problems gaining knowledge; or, more precisely, problems finding out about HIV. We did not directly address 'problems with knowledge', such as making sense of what you know, applying what you know to daily life and resolving the contradictions in what you know. By concentrating on the more fundamental need of gaining knowledge, this analysis excludes these subtle, but nonetheless important, problems.

19.1 FEELINGS ABOUT ABILITY TO ACCESS INFORMATION

Respondents were asked how they felt about their ability to access information about living well with HIV. Overall, 86% felt very or fairly happy (Chart 19.1).

14% of all respondents currently felt unhappy about their ability to access information about living well with HIV (n=230).

Chart 19.1: Feelings about ability to access information



19.2 PROBLEMS ACCESSING INFORMATION

11% of all respondents had experienced problems accessing information about living well with HIV in the last year (n=182).

Based on similar questions from previous research we asked all respondents that reported a problem accessing information what problems they had experienced (and offered the five answers in the table below). The most common problem was simply finding the relevant information to answer the questions raised by personal circumstances and interests. Somewhat fewer respondents did not know where to start looking for information or had concerns about the ability of professionals to communicate it to them. Others felt that the information available was of poor quality or too complex.

Specific problems accessing information about HIV in the last year (n=174, missing 9)	**Number**	**% of those with problem**	**% of ALL** (n=1719)
It's hard to find the information I need	91	53	5
I don't know where to start looking for information	64	37	4
the professionals I have contacted don't communicate properly with me	57	33	3
the information I have found is poor quality	43	25	3
the information I have found is too complex	42	24	2
other problems accessing HIV information	35	20	2

While the *other* problems accessing information about living with HIV were very variable, they fell into three broad categories – difficulties accessing "local" services; difficulties getting their specific needs met; and general dissatisfaction with the range and types of information available.

Many respondents reported problems based on where they lived – some felt there was little or no specialist support in their local area, including some that had seen organisations they valued close or severely curtail their services. Others only had easy access to organisations they felt did not respond well to their needs or did not offer the services they wanted. Finally some felt competition among service providers was problematic as they did not know who to trust. Others reported problems with access to the internet, or computers more generally. Some found that the HIV positive press were only available via their clinic and they often missed issues between visits.

Others had specific needs which they had found difficult to meet – some felt their capacity to benefit from information was curtailed because they were worried about disclosure of their HIV infection, because of mental health problems, because they had hearing difficulties or did not understand English or because they felt most services were tailored to a different ethnic group. Finally, some respondents reported that too little information was available, that is was often out of date or that it was too vague. Others complained there was too much information available.

19.3 LEARNING MORE ABOUT LIVING WELL WITH HIV

Whether or not they had experienced any problems getting information about HIV in the last year, all respondents were asked *Would you like to know more about living well with HIV*? More than a third (36%) said *No*.

64% of all respondents wanted to learn more about living well with HIV (n=1079).

All those that said they wanted to learn more about living well with HIV were asked *How would you like to learn more about these topics in the future?* and offered the responses outlined in the table below.

Reading interventions were the most commonly desired medium for learning more, especially via the HIV-positive press, online and via leaflets and pamphlets. However, talking interventions were also widely desired. Among the talking interventions most popular was the notion of talking informally with other people with HIV, followed by talking with workers from HIV organisations and attending courses and groups run by HIV organisations.

How would people like to learn more about living well with HIV (n=1051, missing 28)	**Number**	**% of those who would like to learn more**	**% of ALL** (n=1661)
by READING newsletters and HIV-positive press	678	65	41
by READING web pages / the internet	640	61	39
by READING leaflets and pamphlets	556	53	34
by READING medical journals	392	37	24
by READING mainstream newspapers and magazines	340	32	21
by TALKING informally with other people with HIV	595	57	36
by TALKING with workers from HIV organisations (charities)	570	54	34
by TALKING with medical staff like doctors or nurses *etc.*	534	51	32
by TALKING with other people with HIV at support groups	478	50	29
by TALKING with workers from gay organisations (charities)	369	35	22
by TALKING with my friends	313	30	19
by TALKING with workers from Black organisations (charities)	121	12	7
by TALKING with workers from drugs support organisations (charities)	76	7	5
by TALKING with workers from haemophilia organisations (charities)	47	5	3
by ATTENDING groups and courses run by HIV organisations (charities)	552	53	33
by ATTENDING presentations (seminars) from other positive people	443	42	27
by ATTENDING presentations (seminars) from medical staff	382	36	23

19.4 SUMMARY

Of all respondents to the survey:

- 14% currently felt unhappy about their ability to access information about HIV.
- 11% had experienced problems accessing information about HIV in the last year.
- 64% wanted to learn more about living well with HIV.

20 Taking anti-HIV treatments

Taking anti-HIV treatments, and taking them regularly, is not a personal need but a clinical requirement. People take treatments in order to meet needs for health and well-being, needs that would otherwise be undermined by illness. Nobody wants to take anti-HIV treatments but once someone has accepted the clinical requirement to take treatments, they have to cope with the consequences. This section explores some of these consequences, particularly the challenge of adherence, and the needs they generate.

20.1 USE OF ANTI-HIV TREATMENTS

More than three quarters (79%) of all respondents had ever taken anti-HIV treatments, and just over a fifth (21%) had not. Among those people that had ever taken anti-HIV treatments, the majority (95%) were doing so at the time of the survey, and another small proportion (2%) were thinking of re-starting.

75% of the sample were currently taking anti-HIV treatments when they completed the survey (n=1287).

As reported elsewhere (Elford *et al.* 2008a) there were no differences in current treatment taking by gender, ethnicity and sexuality. We also observed no differences by education or history of injecting drug use.

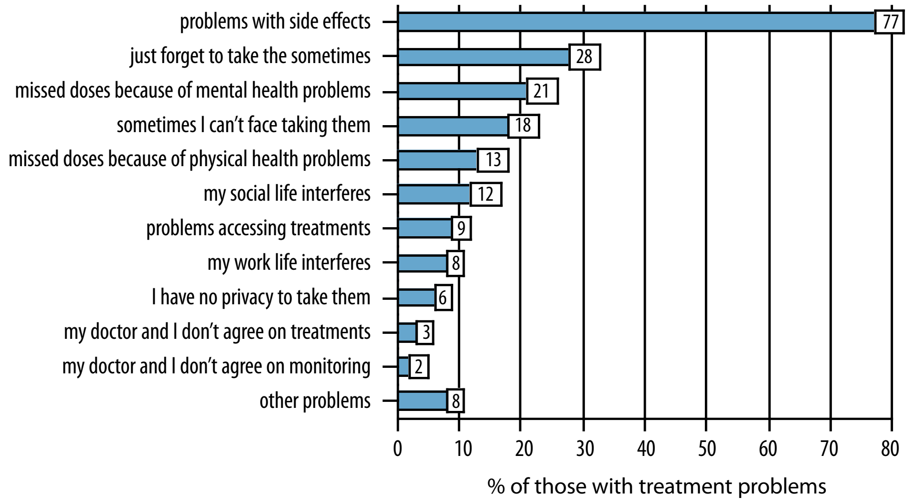
20.2 PROBLEMS WITH ANTI-HIV TREATMENTS

37% of respondents currently taking anti-HIV treatments had experienced problems with treatments in the last year (n=475, 28% of all respondents).

When we designed the survey we were especially concerned to capture the extent of problems accessing treatments, which we assumed would be most common among refused asylum seekers and undocumented migrants. Hence all respondents were asked to describe in words what problems they had accessing anti-HIV treatments in the last year, irrespective of whether they had ever taken treatments, or were currently doing so. Forty-seven respondents described any problems getting access to treatments in the last year, of which 43 had ever taken treatments and 38 were currently doing so. These problems mainly concerned getting appointments at busy HIV-clinics or seeing favored consultants that worked part-time. Some also reported difficulties with pharmacies and pharmacists and getting the wrong prescriptions or late delivery from home delivery services. Some mentioned losing treatments or running out while away from home. Only a few people had tried and failed to access anti-HIV treatments, and one of these was in prison and another had mental health problems which made attending appointments difficult.

Chart 20.2 illustrates the problems (and causes of problems) that respondents described in relation to taking anti-HIV treatments. Problems with treatment side-effects were most common, and were cited by three quarters (77%) of all those with problems with treatments. Previous data (Weatherburn *et al.* 2002) suggests these would have included nausea, vomiting, diarrhoea, lipodystrophy and neuropathy. These problems were identified elsewhere in this study as causes of need, sometimes with profoundly debilitating effects. Lipodystrophy, for example, could have a major impact on self-confidence and levels of anxiety and depression, leading to a loss of sexual confidence and experience of discrimination.

Chart 20.2: Anti-HIV treatment problems (causes) among those that had them

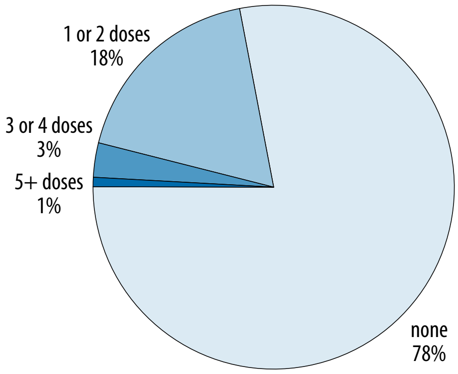


The only *other* problem described by more than a quarter of people with problems taking treatments was forgetfulness (reported by 28% of those with problems taking treatments). Other reasons for missing doses included mental and physical health problems and people's occasional inability to face taking the necessary pills. Other reported problems with taking treatments included failure of regimens and a lessening of their efficacy over time, and resistance.

20.3 ADHERENCE TO ANTI-HIV TREATMENTS

Chart 20.3 illustrates respondents' estimates of how often they missed a dose of anti-HIV medicine in the last fortnight. Eighteen percent of respondents currently taking anti-HIV treatments, estimated that they missed one to two doses in the last fortnight, and another 4% missed more than two doses.

Chart 20.3: Missed doses in the last two weeks



20.4 SUMMARY

Of all the respondents to the survey:

- 75% were taking anti-HIV treatments at the time they completed the survey.
- 28% had experienced problems with anti-HIV treatments in the last year (37% of those currently taking treatments).

21 Skills and training

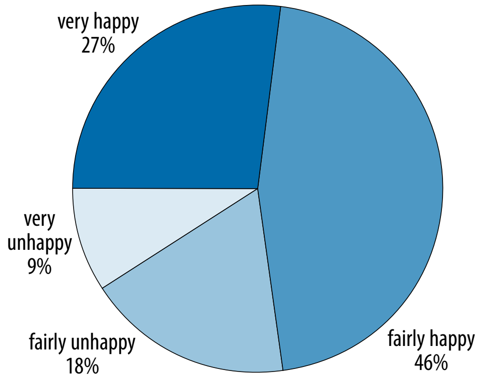
Learning new skills and (re)training is a means of meeting a wide range of needs. As well as improving job prospects, it can give structure and purpose to life, facilitate social contact and help increase self-esteem and self-confidence. This survey explored respondents' interest in learning new skills or retraining. Education and training are highly aspirational: they are pursued to increase the possibilities of life both within and beyond the job market. Although training needs are often linked to problems getting work, they need not be. The focus of this chapter was on respondents' interests, not their problems. Chapter 22 explores respondents' opportunities in their job or in the job market.

21.1 FEELINGS ABOUT ABILITY TO ACCESS TRAINING / SKILLS DEVELOPMENT

Respondents were asked how they currently felt about their ability to access training and skills development. Overall, 73% felt either very or fairly happy (Chart 21.1).

27% of all respondents felt unhappy about their ability to access training / skills development (n=451).

Chart 21.1: Feelings about ability to access training



21.2 INTERESTS IN LEARNING NEW SKILLS

54% of all respondents had considered learning new skills or retraining in the last year (n=934).

Respondents described a very wide range of training interests (see table overleaf). However, one need dominated: more than a third (40%) of those who identified a specific training interest mentioned computing and information technology (IT) skills. The next most common desires for training or learning were languages, counselling skills, management and business administration, art and design and complementary therapies. No other specific desire for learning was mentioned by more than 10% of those that wanted better access to training or learning opportunities.

Specific desires for training or learning new skills among the those that had any (n=918, missing 16)	**Number**	**%**
Computing & IT	371	40
Languages	253	28
Counselling	202	22
Management / business administration	187	20
Art & design	126	14
Complementary therapies	112	12
Teaching	90	10
Nursing	65	7
other desires for training or learning new skills	273	30

Most of the *other* responses revealed a generic desire to study or learn, or go to university or college. Most commonly, respondents wanted to study accountancy / finance, sign language, creative writing or journalism, complementary therapies, psychology and law. Other interests included HIV awareness and HIV treatments, DIY, self-confidence, office skills, photography, garden design and horticulture, customer care, driving, maths, fitness, dress-making, self-defence, cookery, film and television, proof reading, music, marketing, tourism and animal welfare.

21.2.1 Changes over 12 months

Over half (52%) of those who had an interest in learning new skills or training said their interest had increased in the last year. Previous data (Weatherburn *et al.* 2002) suggests this will have occurred because of improvements in health, energy and confidence and increasing expectations for the future. Such changes open up the possibilities of learning, but personal motivations will have been diverse. Some respondents will have wanted to get work or improve their opportunities in the job market. They will have wanted to improve their income, get off welfare benefits (or cope with the potential withdrawal of benefits), change their job or career, or realise personal ambitions. However, others would have been motivated to learn more generally, as a desire to make the most of life. Some will have wanted to overcome boredom and dissatisfaction, but others will have been more positive in their outlook, emphasising the many benefits of learning.

For 11% of those who had an interest in learning new skills or retraining, interest had decreased in the last year. Previous data suggests the most common reason would have been a deterioration of physical and / or mental health. Personal confidence may also have been undermined when training failed to bring about any change – in particular, if employment remained just as elusive.

At the time of the survey, a third (37%) of those who had an interest in learning new skills or training were unhappy about their ability to access training or learn new skills. Among the respondents who did not report any interest in learning new skills or retraining, 14% were unhappy about their ability to access training or learn new skills.

21.3 GETTING HELP ACCESSING TRAINING OR SKILLS DEVELOPMENT

Among the respondents who had an interest in learning new skills or training, half (50%) had received some form of training or other help in learning new skills (see table below). This leaves half (50%) of those with an interest in training who had not received any, or:

26% of all respondents had an interest in training or learning new skills but had not received any help to address this interest (n=453).

Sources of help for those seeking training or new skills, among those that received any help (n=429, missing 29)	**Number**	**%**
an HIV organisation (charity)	86	20
my friends	82	19
my partner / spouse	59	14
a 'back to work' service	38	9
a general charity	33	8
the council / social services	33	8
my parents	22	5
other family	18	4
my HIV (GUM) clinic	17	4
my children	10	2
my GP practice (family doctor)	7	2
other sources of help for those seeking training or new skills	200	47

The most common *other* answer was some form of education: university, adult or further education college or local authority college. Respondents were studying part-time and full-time, through evening classes and by distance learning, and at every level from GCSE, NVQ and 'A' levels through to postgraduate degrees. The other main source of support for learning and training were employers and work colleagues.

Respondents with an interest in training were asked whether they felt that they could further improve their skills with more help or support. One-in-seven (14%) did not think that any further help or support would make any difference. The remainder either felt that more support would make a difference (76%) or did not know what might be gained (10%). Combining these last two groups, we can say that overall:

44% of all respondents had an ongoing interest in training or learning new skills and felt that further help or support would be useful, or did not rule this out (n=741).

Among those respondents that wanted more help or support, most wanted to return to education or receive training, ranging from basic computing courses to postgraduate degrees. However, all sorts of obstacles had to be overcome. The main problems were the availability or accessibility of courses (especially outside major urban centres) and meeting the cost of joining them.

Many respondents were unclear about what opportunities were available to them or wanted advice about how they could find and access courses which would suit them. A few wanted to see more courses run specifically for people with HIV, but most just wanted something local, relevant and useful. In general, learning opportunities were perceived to be too hard to access, too demanding on time or health, or too insensitive to their personal and health needs.

However, the most common need was for funding. Many respondents wanted help with the funding of particular courses or the provision of free or cheap training. There was a sense of frustration that personal willingness to develop new skills and become more productive was not matched by a willingness to help them to do this. A more flexible benefits system that did not put you at risk of losing income because of enrolment in education was a common wish.

For some respondents, fairly basic personal obstacles had to be overcome. Some needed help with childcare or access to a computer or the internet at home. Others wanted to gain confidence and motivation, possibly through the encouragement of other people in similar circumstances or through good guidance and advice. Among African respondents many needed to resolve immigration issues before they could access the course they desired. Poor health and fatigue were also a problem, though the problem was usually perceived to lie with the inflexibility of education providers to allow for, or even try to understand, personal health needs.

21.4 SUMMARY

Of all the respondents to the survey:

- 27% felt unhappy about their ability to access training/ skills development.
- 54% had considered learning new skills or retraining in the last year.
- 44% had an ongoing interest in training or learning new skills and felt that further help or support would be useful, or did not rule this out.

22 Work

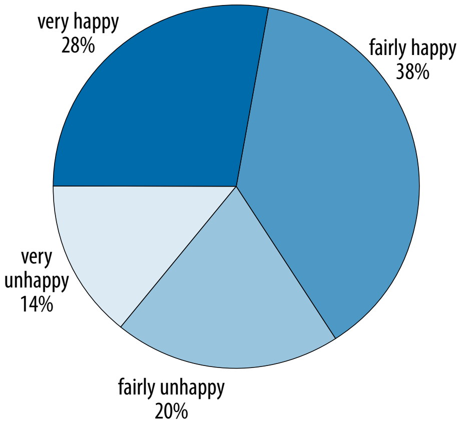
Paid employment is a means of meeting a wide range of needs. As well as providing an income, employment can give structure and purpose to life, enable social contact and build self-esteem and self-confidence. However, employment can also become a burden and a source of anxiety and poor health. This survey explored respondents' feelings about paid work including problems with getting a job or advancing in their current job. Chapter 21 explores respondents' interests in learning new skills and re-training.

22.1 FEELINGS ABOUT WORK AND JOB OPPORTUNITIES

Irrespective of their immigration status, or their current employment status, all respondents were asked how they currently felt about their opportunities in their job or in the job market. Overall, 66% felt either very or fairly happy (Chart 22.1).

34% of all respondents felt unhappy about their opportunities in their job or in the job market (n=536).

Chart 22.1: Feelings about their job or job opportunities



22.2 PROBLEMS WITH WORK AND JOB OPPORTUNITIES

27% of all respondents had experienced problems getting a job, or advancing in their current job in the last year (n=453).

Respondents described a very wide range of problems with jobs or job opportunities. For a large number, the problem was simply that due to unresolved asylum or immigration applications, they were not permitted to work. However, there were many with appropriate visa or citizenship status who still faced significant problems finding employment.

Respondents talked broadly of a lack of employment opportunities, particularly those suited to their skills and qualifications. Having large gaps in their CV's and extended periods of sick leave were common reasons why previous job applications had been unsuccessful. Many people had not been in paid employment for several years and, aside from not having any recent experience that would be relevant for the job itself, they had no recent experience of the job application and interview process.

A major concern for some respondents was if, how and when to disclose their HIV status to their (prospective) employer. Several people felt that they had not been seriously considered for a post after they had disclosed that they had HIV, but felt that such a disclosure was necessary to explain long periods out of employment. Many people had faced widespread ignorance about HIV and felt discriminated against as a result. HIV-related discrimination was also compounded by age, ethnicity or sexuality related discrimination, with older gay men facing particular challenges.

Those already in employment also reported being discriminated against because of their HIV status, such as being passed over for promotion or excluded from company activities. Where respondents had not disclosed their status they often felt isolated, anxious or misunderstood. Changing jobs was complicated by a perceived need to disclose their status to a new employer and set of work colleagues, risking further stigma and discrimination.

Working was described as a constant struggle by many respondents. Chronic tiredness or a lack of energy often meant people felt unable to reach their full potential, meaning that hopes for promotion or career progression were not realised. Managers were rarely sympathetic nor were they supportive during periods of absence due to ill-health. A lack of understanding of the need for flexible working or time off when starting or changing HIV medication was cited as a particular problem. Aside from the direct physical ill-health they often had to combat, a few people felt their employers took little account of the emotional and psychological problems they faced. Getting time off during periods of depression was very problematic. Finally, some respondents expressed concern that work-related pressure or stress might be having an adverse effect on their health, particularly their CD4 count.

22.2.1 Changes over 12 months

Almost a fifth (19%) of those who had problems with jobs said their problems had improved (16%) or been solved (3%) in the last year. For a third (34%) of those with a problem getting a job, or advancing in their current job, the problem had got worse in the last year.

At the time of the survey, 78% of those who had experienced problems with getting a job or advancing in their current job were unhappy about their opportunities in their job or in the job market. Among the respondents who did not report problems, 17% were unhappy.

22.3 GETTING HELP WITH WORK AND JOB OPPORTUNITIES

Among the respondents who had any problems getting a job, or advancing in their job, 38% had received some form of help with these problems in the last year (see table below), This leaves 62% of those with problems had not received any help, or:

16% of all respondents had experienced problems getting a job, or advancing in their job in the last year and had not received any help to address these problems (n=268).

Sources of help with problems with work and job opportunities, for those who had received any help (n=159, missing 4)	**Number**	**%**
an HIV organisation (charity)	45	28
my friends	37	23
my partner / spouse	33	21
a 'back to work' service	30	19
my GP practice (family doctor)	19	12
my HIV (GUM) clinic	18	11
my parents	16	10
A solicitor / lawyer	16	10
other family	13	8
the council / social services	12	8
a general charity	10	6
my children	3	2
other sources of help with problems with work	39	25

The *other* sources of help cited included Human Resources departments, line managers, trades unions, professional associations, occupational health departments, careers advisors / counsellors and employment agencies. Other sources of help included therapists and psychologists.

Respondents with problems with work were asked whether they thought they could reduce, or overcome these problems, with more help or support. One-in-five (18%) did not think that any further help or support would make any difference. The remainder either felt that more support would make a difference (54%) or did not know what might be gained (28%). Combining these last two groups, we can say that overall:

21% of all respondents had an ongoing problem with getting a job, or advancing in a current job and felt that further help or support would be useful, or did not rule this out (n=338).

Respondents whose problems with work had not been solved in the last year, and who felt that more help or support might help, were asked *Realistically, what help do you think would make a difference to your problems with work?* While a large number of African migrants needed to be granted working rights in the UK, a similarly large number highlighted a need for employers to gain a greater awareness of HIV, and how it might impact on staff in their organisation. Many felt a better understanding of the medical and psychological needs of people with diagnosed HIV might facilitate a more flexible working environment, and help reduce stigma and discrimination in the workplace. Some people expressed a need to better understand their own employment rights, and what to do if they felt these were breached.

Greater support and guidance was frequently suggested as a way of overcoming work-related problems. Many people felt that they would benefit from advice on filling out application forms, interview technique and career progression. Help with building confidence and self-esteem was also highlighted by some, as potentially beneficial. Several people were aware of 'back-to-work' schemes but felt these were too basic given their qualifications and experience. A definite need for job placements or work experience pitched at the right level for each individual was identified. While computer literacy and office administration training were appropriate for some, they were perceived to offer little to people who had previously been in highly skilled, well paid jobs.

Finally, the need for a more flexile and individually tailored approach by welfare benefits officers was widely stressed. Some people reported feeling pressured to find employment when they were not yet ready to do so. Others voiced concern that if they did find employment, and their benefits stopped, then they would not be able to access such financial support again, even if they found themselves unfit for work in the future.

22.4 SUMMARY

Of all the respondents to the survey:

- 34% felt unhappy about their opportunities in their job or in the job market.
- 27% had problems getting a job, or advancing in their current job in the last year.
- 21% had an ongoing problem with getting a job or advancing in a current job and felt that further help or support would be useful, or did not rule this out.

23 Discrimination

Discrimination is a problem, not a need but it can increase many different needs such as needs for health, security, self-confidence, social contact and quality of life (Dodds *et al.* 2004, Elford *et al.* 2008b). Nevertheless, discrimination was included in the survey because it remains a major problem for people with diagnosed HIV. The emphasis in this chapter is on experience of discrimination from three sources – family, wider community and doctors and other health or care professionals.

In our previous research (Weatherburn *et al.* 2002) discrimination on the basis of HIV status was widely identified, but respondents also described discrimination on grounds of sexuality, ethnicity, disability, physical appearance, age, drug use and gender. Social rejection and exclusion came from many sources: from friends, partners, families, neighbours, acquaintances and wider society. Although some discrimination was very explicit, such as family or friends who refused to have any contact, respondents also described more subtle but pervasive forms of exclusion, particularly the attitudes and ignorance that bred gossip, suspicion and rejection both in specific communities (including gay and African communities) and in society as a whole.

23.1 DISCRIMINATION FROM FAMILY MEMBERS

In this survey we asked all respondents if, *In the past 12 months, have you experienced discrimination from family members?* Those that answered *Yes* were asked to describe in words what discrimination they had experienced from family members. They were also asked on what basis family members had discriminated against them (and offered the responses below).

11% of all respondents had experienced discrimination in the last year, from other family members (n=192).

The basis of discrimination among people who had suffered any from family members (n=183, missing 9)	**Number**	**%**
HIV status	130	71
sexuality	97	53
disability	16	9
physical appearance	13	7
being a migrant / asylum seeker	11	6
gender	10	6
age	10	6
drug use	6	3
ethnicity	4	2
other basis for discrimination from family	18	10

The *other* basis for discrimination from family were most commonly described as ignorance and lack of understanding, though others mentioned unresolved childhood issues and family jealousies concerning caring for other family members or them having run-away. Other individuals mentioned religion, depression, alcoholism, lack of income and their choice not to work.

When asked to describe in words the discrimination faced from family, the most common problem was exclusion and rejection. Where respondents were gay or lesbian, the experience of being held at arms-length was just as likely to be an expression of homophobia, as it was about their HIV status, and one problem often compounded the other. Respondents also reported abuse (mainly verbal) from family members, ranging from homophobic comments, to being taunted about having HIV and having to manage negative attitudes about the lack of productivity that results from being ill (particularly among migrants). It was also common to have experienced excessive fear about HIV from family members, to the extent that kitchen utensils were not shared, and access to children was refused. Whereas breaches of confidentiality about HIV status by family members were only raised by a small number of respondents, a slightly more common experience was of total silence on the topic of sexuality and / or HIV within the family.

23.2 DISCRIMINATION FROM MEMBERS OF YOUR COMMUNITY

We also asked all respondents if, *In the past 12 months, have you experienced discrimination from members of your community?* Those that answered *Yes* were asked to describe in words what discrimination they had experienced from members of their community. They were also asked on what basis members of their community had discriminated against them (and offered the responses in the table below).

22% of all respondents had experienced discrimination in the last year, from members of their own community (n=360).

The basis of discrimination among people who suffered any from their own community (n=354, missing 6)	**Number**	**%**
HIV status	213	60
sexuality	166	47
physical appearance	76	22
age	57	16
ethnicity	36	10
disability	32	9
gender	25	7
being a migrant / asylum seeker	22	6
drug use	13	4
other basis for discrimination from their own community	21	6

The most common *other* basis for discrimination from members of their own communities were mental health problems, homelessness and poverty. Other individuals mentioned their Trans status, their hepatitis C co-infection, their sexual practices, their drinking, their job, that they were paid for sex and their dog.

When asked to describe in words, their problems with discrimination from members of their own communities most reported verbal abuse including "jokes", threats and gossip. The sources of such problems were often neighbours, work colleagues and those in wider social networks. Comments were variously rooted in homophobia, racism and HIV-related stigma. Others described being rejected and socially isolated once people found out that they had HIV. A smaller proportion (almost all gay men) reported pervasive sexual rejection by potential partners once their HIV status was disclosed, accompanied by some surprise that other gay men were not as supportive as they had hoped. Although not the experience of the majority, some people reported physical assaults and property damage against them because of their HIV status , their sexuality or their migrant status. In the main, those reporting violence were men, and they were also usually gay. Finally, there were a small number of respondents who felt that they had faced employment discrimination as a result of their HIV status, their immigration status and / or their ethnicity. Problems at work included overt prejudice, such as gossip and bullying, and more subtle forms of discrimination: marginalisation, obstacles to career development, pressure not to take time off and a lack of sensitivity to personal needs and circumstances.

23.3 DISCRIMINATION FROM DOCTORS OR OTHER HEALTH OR CARE PROFESSIONALS

In our previous research (Weatherburn *et al.* 2002) a quarter of all the discrimination described was experienced when using public services. The worst offenders were hospital staff, particularly those in departments or wards without HIV specialist experience. Respondents were most likely to encounter discrimination when they had to use health and social services for reasons other than HIV care. Discrimination was also encountered from other 'generic' service providers: housing department staff, GPs and dentists. The characteristic problem with dentists was almost always outright refusal of a service.

In this survey we asked all respondents, *In the past 12 months, have you experienced discrimination from doctors or other health or care professionals?* Those that answered *Yes* were asked to describe in words what discrimination they had experienced from doctors or other health or care professionals. They were also asked on what basis they thought health or care professionals had discriminated against them (and offered the responses in the table below).

19% of all respondents had experienced discrimination in the last year, from doctors or other health or care professionals (n=317).

The basis of discrimination among people who suffered any from doctors and other health or care professionals (n=305, missing 12)	**Number**	**%**
HIV status	252	83
sexuality	83	27
disability	21	7
ethnicity	21	7
physical appearance	20	7
being a migrant / asylum seeker	19	6
gender	18	6
age	18	6
drug use	9	3
other basis for discrimination from doctors and other health or care professionals	31	10

The *other* basis for discrimination from health and care professionals varied widely. A variety of respondents felt they were discriminated against by medical professionals because they knew their rights, were assertive or challenging – in short, because they expected to be involved in decisions about their care. Others mentioned their mental health problems as the basis for discrimination. Some gay men felt they were discriminated against because of their sexual practices, or numbers of partners. Others mentioned their Trans status, being a smoker and having heart disease or simply because they were on costly drugs. Finally, some felt they were discriminated against because they continued to refuse anti-HIV treatments. Others simply described their doctors' or health and care practitioners faults – usually ignorance or professional inadequacy.

When asked to describe in words, problems with doctors and other health or care professionals the two most common problems encountered involved a lack of respect, and significant (often unnecessary) restrictions in access to high quality health and care provision. Where individuals complained about lack of respect, this ranged from a feeling that generic health staff (particularly GPs, nurses and dentists) often lacked the HIV specialist knowledge or time to provide appropriate support, and were flustered by being in the presence of someone with HIV infection.

Others were subjected to hostile and judgmental assumptions, comments and inappropriate queries about how they had acquired HIV. Respondents also reported ways in which health and care providers inappropriately altered the ways in which they delivered care because they were aware of the presence of HIV. In the worst cases, this involved denial of services (particularly in relation to dentistry, surgery and the taking of blood). Others reported exclusion from timely access to health care, including being told by GPs that all health issues must be taken to the HIV specialist out-patients clinic. Finally, were those who reported undue / excess precautions, such as double gloves and only being able to take the last appointment of the day in order that dental instruments could be sterilised afterwards. Finally, a small number reported breaches of their confidentiality by medical and reception staff.

23.4 SUMMARY

Of all the respondents to the survey:

- 36% had experienced discrimination from other family members, and/or from members of their own community, and/or from doctors or other health or care professionals, in the last year.
- 11% had experienced discrimination from other family members in the last year.
- 22% had experienced discrimination from members of their own community in the last year.
- 19% had experienced discrimination from doctors or other health or care professionals in the last year.

References

Anderson W & Weatherburn P (1998) *The impact of combination therapy on the lives of people with HIV*. London, Sigma Research.

Anderson W & Weatherburn P (1999) *Taking heart? The impact of combination therapy on the lives of people with HIV*. London, Sigma Research.

Anderson W, Weatherburn P, Keogh PG, Henderson L (2000) *Proceeding with care. Phase 3 of an on-going study of the impact of combination therapies on the needs of people with HIV*. London, Sigma Research.
✎ www.sigmaresearch.org.uk/files/report2000a.pdf

Culyer AJ (1995) Need: the idea won't do – but we still need it. *Social Science & Medicine 40(6)*: 727-730.

Dodds C, Keogh P, Chime O, Haruperi T, Nabulya B, Ssanyu Sseruma W, Weatherburn P (2004) *Outsider status: stigma and discrimination experienced by gay men and African people with HIV*. London, Sigma Research.
✎ www.sigmaresearch.org.uk/files/report2004f.pdf

Elford J, Ibrahim F, Bukutu C, Anderson J (2008a) Uptake of antiretroviral treatment among people living with HIV in London: ethnicity, gender and sexual orientation. *Sexually Transmitted Infections, 84*: 176-178.

Elford J, Ibrahim F, Bukutu C, Anderson J (2008b) HIV-related discrimination reported by people living with HIV in London, UK. *AIDS and Behaviour, 12(2)*: 255-264.

Health Protection Agency (2007) *A complex picture: HIV & other sexually transmitted infections in the United Kingdom: 2006*. London, Health Protection Agency Centre for Infections.
✎ www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1194947365435

Hobson C, Cox J, Sagovsky N (2008) *Fit for purpose yet?* London, Independent Asylum Commission.
✎ www.independentasylumcommission.org.uk/files/Fit%20for%20Purpose%20Yet.pdf

Ibrahim F, Anderson J, Bukutu C, Elford J (2008) Social and economic hardship among people living with HIV in London. *HIV Medicine, 9(8)*: 616-24.

Lewis H (2008) *Leeds Destitution Inquiry: Experiences of people seeking asylum and supporting agencies*. Joseph Rowntree Charitable Trust inquiry into destitution among refused asylum seekers. London, Joseph Rowntree Charitable Trust.
✎ www.jrct.org.uk/text.asp?section=0001000200030006

Liss P-E (1993) *Health care need. Meaning & measurement*. Aldershot, Avebury.

Maslow A (1954) *Motivation and personality*. New York, Harper.

Health Protection Agency's Centre for Infections and Health Protection Scotland (2008) *Survey of prevalent HIV infections diagnosed (SOPHID) Data tables 2007*. London, Health Protection Agency.
✎ www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1203064766492

Weatherburn P, Anderson W, Reid DS, Henderson L (2002) *What do you need? Findings from a national survey of people living with HIV*. London, Sigma Research.
✎ www.sigmaresearch.org.uk/files/report2002c.pdf

Weatherburn P, Keogh P, Dodds C, Hickson F, Henderson L (2007) *The growing challenge: a strategic review of HIV social care, support and information services across the UK*. London, Sigma Research
✎ www.sigmaresearch.org.uk/files/report2007b.pdf