

**Supporting People with HIV:
Research into the housing and
related support needs of people
with HIV in Nottingham City**

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**Research by Sigma Research
on behalf of Supporting People
at Nottingham City Council**

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

What do you need? Findings from a national survey of people with HIV.
Weatherburn *et al.* (2002)



This report is available to download at:
www.sigmaresearch.org.uk/downloads/report06a.pdf

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1. Introduction

1.1 BACKGROUND TO SUPPORTING PEOPLE

Supporting People is a central Government initiative administered through the Office of the Deputy Prime Minister (ODPM). Supporting People grants are allocated to Administering Authorities (unitary authorities and counties in two tier areas) who then commission appropriate services within the context of a local Supporting People strategy that outlines how best to meet the needs of specified target groups (ODPM 2004).

Supporting People initiatives aim to provide housing-related support services to vulnerable people to enable them to live independently in accommodation that is decent, appropriate and affordable. The models of service provision developed and commissioned through Supporting People are intended to be flexible and client-centred and to address the needs of people living across a range of housing tenure - including owner-occupiers and private renters.

This approach targets resources at pre-emptive and ongoing support rather than just crisis intervention. In addition to the provision of housing for those in crisis, there are many aspects of 'housing-related support' that help individuals and families to maintain their accommodation and increase independent living skills. There seems to be no definitive list of what 'housing-related support' encompasses within the Supporting People policy framework. The text box below outlines the views of Leeds Supporting People which were generated from an ODPM designed list (in the Supply Mapping Supporting People SP3 form).

Potential areas included in the provision of 'housing support'

finding a home	copng with isolation	living with HIV / AIDS
claiming benefits	confidence building	treatment adherence
furnishing a home	alcohol use	dietary issues
settling into a new home	getting out of sex work	complementary therapy
independent living skills	relationship difficulties	health issues
returning to education	anger management	sexual health
staying in education	domestic violence	sexual abuse
accessing leisure activities	contacting family	accessing a GP
budgeting	making friends	pregnancy
finding a job	parenting	contraception / abortion
accessing other services	counselling	accessing a dentist
finding a school	drug use	mental health
	harassment	

One of the target populations for Supporting People initiatives is people living with HIV or AIDS. However, in the early stages of Supporting People's establishment, it was found that local authorities appeared to have little knowledge of housing-related support needs within this group (ODPM 2005). A broad range of needs assessment and evaluation has begun to emerge at local level in response to this knowledge gap - with some involving questionnaires, interviews and focus groups among service providers, people living with HIV or both (see local reports and strategies at: www.spkweb.org.uk including those for Oxfordshire, Brent, Leeds and North Yorkshire).

Housing-related support services funded through Supporting People are intended to operate around the individual needs of each particular service user, enabling them to access and sustain adequate independent tenancy. In order to achieve this, one of the unique models of

service provision developed through the introduction of Supporting People is 'floating support'. Floating support is usually made available to service users as visiting support in their own home, or in other suitable locations. Floating support services can assist individuals and families through particular periods of transition, as well as helping those in need to avoid housing crisis and gain access to the skills and support they require in order to achieve ongoing housing stability in a location that is affordable and suitable. Floating support services can cover the vast array of housing-related support issues identified above. They require skilled providers who can make clear assessments of need for particular client groups; develop and agree support plans with specific target outcomes; and implement referral protocols for expert advice and support relating to issues such as welfare rights, mental health and debt counselling.

Many of the specific details of targeted floating support service provision can be developed through a commissioning process that takes account of the identified needs of a particular group. Within the context of provision for people living with HIV, there are a wide array of support needs that a commissioned floating support service could address, including (but not necessarily limited to) provision of and access to:

- immediate crisis intervention where specific problems pose an immediate risk to sustaining tenancy, including responding to eviction notices, financial arrears, health, safety and security (including harassment from neighbours);
- finding appropriate housing where disclosure of HIV status can be managed successfully;
- support in taking up new tenancies including application processes, locating appropriate furniture and equipment, and establishing utilities, rental and tenancy arrangements;
- expert welfare rights advice;
- nutritional advice and support to eat well (particularly during times of crisis);
- primary and specialist HIV health and social care;
- information, community resources and social interaction;
- ethnic and cultural community involvement where appropriate;
- education, training and employment opportunities;
- mental health and addiction support services where required.

The extent to which a particular targeted floating support service is provided in a local setting is itself determined through local commissioning. Within standard parameters, it would be expected that floating support could be provided to a particular user for a maximum of 24 months (2 years). Commissioning targets will usually outline an average duration target for most of the support packages that are provided within a particular contract. For instance it may be specified that average duration of floating support service for a particular population will be 6 months per service user, however this also would take into account the broad spectrum of support need that can involve either much more or much less intervention depending on the needs of a particular individual. Service users who have already accessed floating support services will not be uniformly prevented from accessing them again in future. Another component of decision making in relation to service capacity is the amount of support time provided for each service user on a weekly basis. For example, service specifications could cover a range of provision for low (0-4 hours per week) to medium (5-10 hours per week) support time per service user. Support time includes contact hours, referrals and time to make other arrangements. Therefore if a floating support service for people living with HIV were to be commissioned, it could involve a specification of the average duration of individual support packages, the number of service users (or units) that such a service could accommodate, and an average number of support hours per week that would be dedicated to each individual - with recognition that in most cases time demands will fluctuate over the

course of support provision. We offer this detailed overview of floating support because of its significant potential to improve service provision for people with HIV in Nottingham, which is the main aim of this research project.

1.2 BACKGROUND TO RESEARCH PROJECT

The research findings reported here are based on work undertaken by Sigma Research. This research was commissioned by Supporting People at Nottingham City Council to “inform the Council and other strategic partners about the housing, support and related needs of people with HIV in the City”. The research was also intended to “identify appropriate models for future service provision and describe and prioritise options for services”.

With a limited budget and a time-frame of six months we have not attempted to conduct an exhaustive mapping of the housing needs of *all* people living with HIV in Nottingham City. Rather we have offered detailed insight into the lives, experiences and housing histories of a broadly representative sample of local people with HIV. This enables us to identify the major areas of housing-related need and to describe those situations and sub-groups where housing support need is most profound.

Three primary research methods were employed. A **review of HIV literature** on the housing-related needs of people with HIV was undertaken including the limited academic literature and other research outputs, and a review of strategies and policies from other Supporting People initiatives. We also examined national and local data from the Health Protection Agency to profile the population affected by HIV nationally and locally, identifying changes in this profile.

In the remainder of this chapter we use findings of this literature review to describe:

- The scope of social care needs of people with HIV in relation to housing and ways in which housing need can exacerbate other needs.
- The HIV and housing policy and service environment locally and nationally.
- The potential future changes in the environment which may impact on the needs of people with HIV and the services that are configured to meet them.

We also undertook 18 face-to-face, in-depth interviews with **key stakeholders** in the provision of HIV social care in Nottingham. These interviews allow us to describe the current context of service delivery to people with HIV in Nottingham City. In Chapter 2, we use the findings of these interviews to describe existing local services for people with HIV, including specific and generic services that can meet the needs of people with HIV. In Chapter 4 we describe the views of stakeholders on the need for re-configuration and innovation in local services.

Finally we undertook 20 in-depth, face-to-face **interviews with people with HIV** resident in Nottingham City and surrounds. Recruitment to these interviews was predominantly facilitated by staff of the Nottingham Positive Care Team, the GUM clinic, and the Refugee Forum. These interviews took 60 to 90 minutes each and all were audio-tape recorded (with consent) and fully transcribed. A reflexive thematic analysis was conducted on transcripts by two researchers working in collaboration. All respondents with HIV were offered £20 to cover their time and expenses.

We invested considerable time in recruitment to this sample to ensure that it contained a mixture of those who did not regularly access social care and support, as well as those who did. We also ensured diversity in the range of housing tenures of respondents and that the sample was gender and ethnically diverse, aiming to broadly reflect the numbers of African people and other migrants living with HIV in Nottingham.

As we outline in Chapter 3, these interviews enabled us to:

- Map service utilisation by people with HIV in Nottingham City.
- Describe the difficulties and obstacles encountered by people with HIV in managing their daily lives and realising the (new) possibilities of their lives.
- Describe the housing-related circumstances of people with HIV in Nottingham City, including: type of tenure, location, type and size of accommodation, housing history, condition and repair, adaptations, and access to related welfare benefits.
- Identify unmet housing-related needs of people with HIV in Nottingham City.
- Outline specific issues for people with HIV related to migrancy (including dispersal, refugee and asylum seeking), ethnicity, sexuality and gender.

This report concludes with a range of recommendations about increasing the capacity of all organisations to best meet the housing-related needs of people living with HIV in Nottingham City (Chapter 5). We include specific recommendations about how the Supporting People team might commission a floating support service that will best meet the needs of this population, and our view on the feasibility and desirability of a central access point for all services for people with HIV in Nottingham City (the one stop shop model).

1.3 EXISTING RESEARCH ON HOUSING NEEDS OF PEOPLE WITH HIV

People with HIV may have a range of inter-related needs which they meet, to varying degrees, through their own personal resources and pre-existing support networks (friends, family, services *etc*). For most people living with HIV, services only play a minor part in how their needs are met, while a smaller proportion may depend primarily on the provision of service and support during times of crisis (Weatherburn *et al.* 2002). Need is not, however, defined solely by the problems people encounter in their daily lives, but also by individual perceptions of the possibilities of life. Recent work among African men and women and Gay men with HIV demonstrates that these groups continue to face substantial HIV-related stigma that is directly linked to homophobia and racism, and this can have a pronounced impact on self-confidence and overall outlook (Dodds *et al.* 2004).

The only UK-wide needs assessment for people with HIV was undertaken by Sigma Research in 2001-2002 (Weatherburn *et al.* 2002; Anderson & Weatherburn 2004). It revealed substantial need associated with housing and shelter. Of the 1821 people with HIV taking part:

- 18% felt unhappy about their current housing or living conditions;
- 21% had experienced housing problems in the previous 12 months (including 4% who had experienced homelessness);
- 16% had ongoing housing problems and felt that further help or support would be useful.

In this national sample, among people with HIV who reported housing problems the majority described accommodation that was unsuitable because of damp, disrepair, inadequate heating, lack of equipment and problems with access or bath and toilet facilities. The immediate environment could also be debilitating, because of harassment and violence from neighbours and / or noise and vandalism. Difficulty meeting rent and mortgage payments, and problems finding appropriate and affordable accommodation emerged as a significant issue affecting housing stability.

Of those whose recent housing problems had been resolved, the most frequent resolution was a move to new accommodation. Other means of resolution included improved financial circumstances; housing improvements; better relationships with landlords; changes in personal relationships and constraints put on trouble-makers. Among those who described worsening problems, the council or landlord were frequently blamed for ignoring or exacerbating the situation. Deteriorating physical or psychological health also increased the

need for suitable accommodation when existing problems remained unresolved. Among those who did not report any housing problems, 8% were nonetheless unhappy about their housing and living conditions, suggesting a strong aspirational quality to housing need.

Among the respondents who had experienced housing problems in the previous 12 months, 63% had received some help, leaving 37% who had not received any help. Overall, 7% of people with HIV surveyed had experienced housing problems in the previous 12 months and had not received any help to address these problems.

Help with housing problems was primarily provided by HIV organisations and Councils/ Social Services, although friends, family and NHS services could also play a role. Most of those with ongoing difficulties in relation to housing felt that more help would lead to improvement. Overall, 16% of all people with HIV had ongoing housing problems and felt that further help or support would be useful, or did not rule this out. Those in need wanted a permanent solution without delay, including: re-housing somewhere safe, secure and, for some, with appropriate and non-discriminatory support to cope with illness and disability. Respondents wanted more information and advice, greater transparency and more specialist support. Among those where the fundamental problem was not having enough money, the typical suggestion for support related to receiving greater financial assistance while those with uncertain immigration status said their priority was for this to be resolved as soon as possible.

The research undertaken at national level demonstrates that housing and housing support need is related to, and has the potential to exacerbate many other social care needs - including eating and drinking, sleeping, self-care, mobility, financial security, anxiety and depression, self-confidence, job opportunities, caring for children and developing and maintaining relationships. For this reason we ensured that the information collected from the Nottingham residents in this study would enable us to situate housing need in the context of these wider social care needs.

Since the national needs assessment was undertaken the number of people living with HIV in Britain has increased year-on-year. In the intervening period, Sigma undertook *Project Nasah* to assess areas of need among 435 African people living with HIV in England (Weatherburn *et al.* 2003a). A comparison of those findings to data from the project outlined above, highlights the disparity of needs between White British and Black African people living with HIV. Black Africans were ten times more likely to report not having enough money to live on and seven times more likely to report problems with housing and living conditions than the White British respondents previously reported (Weatherburn *et al.* 2003b). African people living with HIV were also more likely than their White British counterparts to report difficulties with finding information on HIV treatments, relationships, access to jobs and training, mobility, discrimination and friendships. All of these needs were even more pronounced for those who had lived in England for less than two years.

More than half of the African people living with HIV who took part in *Project Nasah* reported experiencing problems with their immigration status in the previous 12 months. In many of these cases, individuals would have most likely been awaiting news on an application for asylum or leave to remain in the UK, and for some such requests would have already been denied, with the prospect of deportation looming. As a result of governmental policy on asylum, claimants are frequently dispersed away from expatriate communities and towards areas with a relatively low HIV prevalence (including Nottingham). This has dramatically altered the nature and burden of HIV treatment, care and support in settings where, until relatively recently, most of those diagnosed with HIV were homosexually active British men. The detrimental impact of policies such as dispersal, NHS charging, and withdrawal of state support among asylum seekers living with HIV - as well as the knock on effects within NHS

and voluntary support agencies - have been thoroughly documented (Creighton *et al.* 2004; Dodds *et al.* 2004; Fortier 2004; Pollard *et al.* 2004; Refugee Council 2004a / 2004b; Gazzard *et al.* 2005).

1.3.1 Leeds Supporting People study

A detailed research report on the housing and support needs of people living with HIV and / or Hepatitis C in Leeds (Griffiths *et al.* 2005) provides a snapshot of a very different environment of local service delivery and social care. Unlike the current situation in Nottingham (described in below), specific services designed for people living with HIV are predominantly delivered through a number of well-developed HIV voluntary organisations, leading to a range of recommendations relating to improving awareness of social care services.

The detail offered by the authors of the Leeds report was also of use during the design phase of this project, helping us to think critically about the questions for key stakeholders and people with HIV. However, the research team at Leeds has been open about the fact that their findings were likely to have been radically affected by a number of design and sampling decisions, including the decision not to interview any asylum seekers because of their lack of access to public funds (Griffiths *et al.* 2005: 27-29). Of the ten people living with HIV in their sample only one was female, none were heterosexual and all were White.

Key findings in the Leeds study related to problems in accessing adequate housing, in part because of bureaucratic confusion, and the detrimental impact of this on health and successful treatment options. For some respondents, access to medical treatment (particularly for those on interferon or methadone) was hampered by a lack of stable housing. It was also reported that individuals encountered difficulty finding suitable housing in a reasonable amount of time because of the complexity of social care bureaucracy - referral pathways tended to be unclear and inconsistent. Crisis points such as the time of diagnosis, release from prison or mental health breakdown were highlighted as times when more specialised support was required. Dealing with the anxiety caused by long housing waiting lists was also indicated as a particular problem. The authors concluded that the best way to provide adequately for the support needs of these client groups was to broaden out from the original ODPM definition, and develop a floating support service for 30 units of support (not accommodation) for clients with a life affecting illness - prioritising people living with HIV and / or Hepatitis C (Griffiths *et al.* 2005: 146). In this context, it is understood that one unit of support refers to provision of a set number of support hours per week for one service user. It was also recommended that joint working protocols and a clarification of roles and responsibilities within and between organisations offering support to this client group should be formalised, rather than relying on informal relationships (Griffiths *et al.* 2005:142).

1.4 HIV STRATEGIES OF OTHER SUPPORTING PEOPLE TEAMS

The Supporting People website www.spkweb.org.uk provides documentation from authorities where housing needs assessments of people with HIV have been conducted, as well as strategies that include priorities for this client group. This section reviews some of the information offered from other local authorities.

Apart from the detailed findings reported above from the study conducted by the Leeds Supporting People Research Team, some information was available on a consultation conducted with HIV diagnosed service users in York and North Yorkshire. The key finding highlighted in the North Yorkshire five year strategy was that referral and information pathways were inadequate. While specialised support for this client group was not advised in this locality due to low HIV prevalence, it was determined that signposting to housing and housing support services should be provided where people with HIV access their health care (North Yorkshire Supporting People 2005).

Other authorities' current five year plans also state that because of low HIV prevalence, provision of targeted Supporting People funding for this client group is not practicable, but further needs assessments are recommended to find the best ways to ensure that people living with HIV can easily access generic housing and support services (North Lanarkshire Supporting People 2003; Wigan Supporting People 2005). Wolverhampton's five year strategy document was based on a desktop review of services as well as interviews with providers (but not service users). People with HIV were assigned a low priority rating, although no reason was given (Wolverhampton Supporting People 2005).

In Edinburgh, consultation with 50 service users across a range of target client groups (including people with HIV) was reflected in strategic priorities in the five year plan (Edinburgh Supporting People 2003). These included:

- the need for people with HIV to be allocated individual rather than shared residences;
- more flexible and specialised services that adapt to needs of service users rather than providers;
- floating support provision including independent living skills training;
- more integration between support for people living with drug and alcohol problems and those living with HIV;
- post-diagnosis intensive support; and
- staff training to deal with minority ethnic and refugee populations, particularly where English is not the first language.

In Brent (North West London), an HIV specific needs assessment among service providers and one group of people with HIV accessing an African support agency resulted in various policy recommendations (Brent Supporting People 2005). Similar to Edinburgh, the need for private accommodation (including one's own toilet and kitchen facilities) for those living with HIV was highlighted, alongside provision of specialist HIV housing support where confidentiality and empathy were paramount. It was identified that those in the highest degree of need - particularly those whose first language was not English - were least likely to be receiving adequate support. The Brent strategy aims to develop a team of professionals and those providing voluntary services in order to meet needs relating to confidence building, problem solving, treatment adherence, dealing with stress and nutritional advice. Brent has decided to re-model its service for people with HIV, shifting from the provision of 13 supported accommodation units to a floating support service that will aim to meet the diverse support needs of more people.

Our review of the strategies of different administering authorities to meet the needs of people with HIV has uncovered a significant problem. There is no consensus on whether people with HIV who are currently seeking asylum are eligible to receive Supporting People services. Some administering authorities have made it absolutely clear that only people who have obtained leave to remain in this country - either by being legally accepted as a refugee, or having gained permanent leave to remain - are eligible, and that those with an asylum claim in process (asylum seekers) are not (Brent Supporting People 2005, Griffiths *et al.* 2005). Other authorities appear to be unaware of the distinction between refugees and asylum seekers (Oxfordshire County Council website, January 26th 2006). Interestingly, Oxfordshire's own Supporting People Team have raised this issue in their five year strategy, stating that very little dedicated housing support funding for people living with HIV exists, partly because the "Office of the Deputy Prime Minister has not clarified whether Supporting People grant can support people with no recourse to public funds" (Oxfordshire Supporting People 2003: 103). This demonstrates that even within one authority, there are those who recognise the distinction between asylum seekers and refugees, and those who believe that they are one and the same. The same confusion is also evident within other authorities (see North Lanarkshire Supporting People 2002: 32; North Lanarkshire Council 2006).

In a recent document from the Office of the Deputy Prime Minister (2005), at the bottom of a very long list of groups of people who might benefit from housing-related support it infers that unsuccessful asylum seekers and those in process cannot access support.

"Refugees, where support can assist in effective settlement and integration into a community, but where there will be a need to link with other arrangements in place following a successful application for asylum"
(ODPM 2005: 27)

1.5 HIV INFECTION IN NOTTINGHAM CITY AND SURROUNDS

This section presents an overview of local data on HIV prevalence from SOPHID - the *Survey of Prevalent HIV Infections Diagnosed*. Data on people with diagnosed HIV accessing medical HIV-related care in England, Wales and Northern Ireland is collected, collated and presented by the Health Protection Agency's Centre for Infections. The Primary Care Trust of residence of the patient is used as the indicator of location rather than where that patient accessed medical care.

The figures are cumulative, meaning that anyone with diagnosed HIV resident in Nottingham City and accessing medical care in 2003 and in 2004, will appear in both the year columns in the following tables. We cannot know from this data what proportion of the 179 people with diagnosed HIV resident in Nottingham City in 2003 were still resident in 2004. We know relatively few died and none were cured of their HIV infection. Some will have moved out of the city, the county or even the country while others moved in. Migration to, and within the UK is an important factor in all that follows.

PCT of residence in Nottinghamshire	Number of people with diagnosed HIV seen for care		% (number)
	2003 No. (% of county)	2004 No. (% of county)	INCREASE 2003 - 2004
Nottingham City	179 (63%)~	282 (68%)~	58% (103)
Broxtowe & Hucknall	17	25	40% (20)
Gedling	19	27	
Rushcliffe	14	18	
Ashfield	14	19	33% (19)
Bassetlaw	13	13	
Mansfield District	23	30	
Newark and Sherwood	7	14	
TOTALS (Nottinghamshire)	286	428	50% (142)

~ 179 total for Nottingham City residents in 2003 includes 5 children born to HIV infected women in 2003. 282 total for Nottingham City residents in 2004 includes 6 children born to HIV infected women in 2004. 95% of these children are likely to NOT be HIV infected.

Residents in Nottingham City account for two thirds of HIV infections in Nottinghamshire (63% in 2003 and 66% in 2004). Residents in Broxtowe & Hucknall, Gedling and Rushcliffe account for another sixth of HIV infections in the county (17% (n=50) in 2003 and 16% (n=70) in 2004). From 2003 to 2004, in Nottingham City (and across the County) there was a substantial rise in the number of people living with diagnosed HIV. In Nottingham City the rise was 58% (40% for Broxtowe & Hucknall, Gedling and Rushcliffe combined; 33% in the rest of

the county combined). This rise in the number of people with diagnosed HIV was due to a combination of factors: a movement of people with diagnosed HIV into Nottingham City (and the rest of the county); a diminishing death rate among people with diagnosed HIV; and new diagnosis of HIV among residents. The precise contribution of each of these factors to HIV prevalence is impossible to ascertain.

The overwhelming majority of those living with diagnosed HIV in Nottingham City (96%) attend Nottingham City Hospital for HIV-related treatment and care, while those living outside of the city also attend City Hospital for their care. Among residents of Nottingham City with diagnosed HIV, the majority are asymptomatic (56% in 2003 and 58% in 2004); and the next largest proportion are symptomatic/ pre-AIDS (26% in 2003 and 24% in 2004). In Nottingham City, women are more likely to be asymptomatic than men. For England as a whole in 2004, the proportions of all people with diagnosed HIV who were asymptomatic was 44%, and 31% were symptomatic/ pre-AIDS.

Among residents of Nottingham City with diagnosed HIV, 49% were Black African and 40% White in 2004, while the next largest ethnic group was Black Caribbean (7%). Across England the ethnic mix of the population of people with diagnosed HIV has changed substantially over the last 10 years and continues to do so. This is primarily a function of migration of people with HIV into the UK, rather than changing patterns of HIV incidence. For England as a whole in 2004, 39% of all people with diagnosed HIV were Black African; 3% were Black Caribbean and 52% were White. In these figures, the category White includes White British and White European, North American and Australasian (among others). It should not be assumed to include no migrants to the UK.

Number of people resident in Nottingham City with diagnosed HIV seen for care		2003				2004			
		Male		Female		Male		Female	
Ethnicity by gender	White	70	67%	16	21%	88	56%	25	20%
	Black African	25	24%	47	63%	49	31%	89	71%
	Black Caribbean	5	5%	7	9%	12	8%	8	6%
	Other ethnicities	4	4%	5	7%	7	5%	4	3%
	TOTALS ~	104	100%	75	100%	156	100%	126	100%

~ 179 total for Nottingham City residents in 2003 includes 5 children born to HIV infected women in 2003. 282 total for Nottingham City residents in 2004 includes 6 children born to HIV infected women in 2004. 95% of these children are likely to NOT be HIV infected.

There are increasing numbers of women living with HIV in the UK, and in Nottingham City 45% of all those living with a diagnosis in 2004 were female. Ethnicity varies considerably by gender, with 71% of women living with HIV being Black African compared to 31% of men.

The SOPHID data also indicates that among residents of Nottingham City, there appears to be trend towards a reduction in the average age of people with diagnosed HIV. From 2003 to 2004 the proportion of people with HIV in the 25-39 age group has risen from 53% to 58%, while the proportion in the 40-54 age group has fallen from 32% to 30%.

In 2004, sex between men and women accounted for 61% of all HIV infections among residents of Nottingham City and sex between men accounted for 28% of infections (50% among men and 0% among women). Injecting drug use was the route of transmission in 5% of all cases, and mother-to-child accounted for 4% of cases (though half of these were

unconfirmed HIV diagnoses). For England as a whole in 2004, 44% of all people with diagnosed HIV were infected as a consequence of *sex between men* and 49% were infected as a consequence of *sex between men and women*. The disproportionately high proportion of those living in Nottingham City whose infection is attributed to *sex between men and women* is a result of increased numbers of African migrants moving to Nottingham to study or to work or due to dispersal policy in the asylum system. Therefore these figures should not be interpreted as an indication of significantly high numbers of transmissions among heterosexual White British residents of Nottingham.

1.6 THE EXTENT OF HOUSING NEED

As we outlined in section 1.3, the best available population-level estimate on the proportion of people with HIV that have housing problems in any given 12 month period was 54% of Black-African UK-residents with HIV (Weatherburn *et al.* 2003b, data from 2002) and 18% of people with HIV of other ethnicities (Weatherburn *et al.* 2002; data from 2001). The estimates are based on direct answers to questions concerning housing and living conditions.

If we apply these proportions to what is known of the number of Nottingham City residents with HIV, we estimate 101 people with HIV had self-defined housing problems in 2004 - this is 75 Black-African people with HIV and 26 of other ethnicities (mainly White). Our estimate for 2003 is 58 people with HIV had housing problems - this is 39 Black-African people with HIV and 19 of other ethnicities (mainly White). While the numbers are not necessarily huge, the increase from 2003 to 2004 is substantial. It seems likely that this rising trend in the number of people living with HIV and in need of housing-related support will continue in Nottingham City. However, the exponential rate of increase that has been documented in the City in recent years is unlikely to continue given recent changes in immigration policy, such as the reduction in asylum applications at a national level.

2. Current service provision for people with HIV

The first phase of our research involved twenty interviews (of 60-90 minutes each) with key stakeholders related to HIV and / or housing services in Nottingham. Contacts were initially provided by the Nottingham Supporting People Team, and as interviews progressed, further contacts were recommended by interviewees. Those interviewed included staff from the Nottingham Positive Care Team, HIV health care providers, providers of statutory housing and social care services, and representatives from voluntary HIV and refugee support organisations in Nottingham.

The purpose of the consultation with key stakeholders was to establish the current range of clinical and social care services for people with HIV in Nottingham; to establish referral pathways; to assess gaps in service provision; and to assess support for the notion of a one stop shop model of service delivery. The following description of service delivery in Nottingham is based on the information offered by the key stakeholders.

It should also be noted that two other separate, but interlinked, reviews of service provision are currently underway. There is a generalised review of HIV service provision being undertaken which has prompted the formation of the *HIV/AIDS Service Development Group*, made up of many of the key stakeholders interviewed here. There is also a review of the roles and responsibilities of the Nottingham Positive Care Team that has been initiated and is being undertaken by the managers from different health and social services departments who each manage care team staff. It is expected that these two review processes will continue for some time, and that each of their outcomes are likely to influence the other.

We have attempted throughout this research to delineate the extent to which the findings from this project could directly contribute to the planning being informed by separate local review processes. This assessment of housing support need and existing service use among people with HIV enables us to make recommendations about gaps in service use and to propose various ways investment from Supporting People might address these. This report will probably have some bearing on the broader decisions that are currently being made about social care for people with HIV. However, as it is a needs assessment, this work remains focussed on the daily lives and concerns of people with HIV in Nottingham rather than a detailed investigation into the resourcing and structuring of all social care services for people with HIV.

2.1 HIV CLINICAL SERVICES

There are two clinics where people with HIV in Nottingham can access specialist HIV treatment and care. Both are located at Nottingham City Hospital, either at the Infectious Diseases Unit (IDU) or at the Genito-Urinary Medical Clinic (GU). Most individuals remain with the initial clinic where they were either assigned (after arrival in Nottingham), or where they were initially diagnosed. Most of those diagnosed through the IDU following an acute admission to hospital, or had been referred (either before or after testing) by a GP concerned about particular symptoms. Those diagnosed at the GU Clinic were mainly those who had referred themselves for a confidential HIV test, or following a positive test during ante-natal care. Of the population of people with HIV in Nottinghamshire, roughly one quarter access HIV services at the IDU clinic, while most of the rest attend GU for their ongoing care. SOPHID data suggests the number of people with HIV living in Nottingham who access clinical services elsewhere is small.

Most people with HIV in Nottingham attend their clinic every three months for a check up which includes blood testing, monitoring of treatment adherence and side effects, etc. Some who have more complicated health problems (such as cross-infection or severe treatment side effects) attend clinic more regularly.

Clinical staff in both locations mentioned addressing their patients' housing needs by writing letters of support upon application for a move, or to prevent their dispersal to another city by the National Asylum Support Service (NASS). Clinical staff also raised concern about the impact of inadequate housing provision for patients who were seeking asylum, as well as their concern about homelessness and access to treatment among those whose asylum applications have been refused.

2.2 THE HEALTH SHOP

Located in central Nottingham, The Health Shop is an initiative of Nottingham City Primary Care Trust. It offers accessible clinical and community services including: pregnancy, HIV, STI and Hepatitis testing, needle exchange, substance misuse and sexual health counselling, condom distribution, and HIV befriending project and psychology services. It coordinates harm minimisation and Gay men's sexual health outreach projects in the city. Various support groups also meet at the Health Shop premises, including: a coming out group for Lesbian, Gay and Bisexual young people, a married Gay men's group, and an older Gay men's group.

2.3 NOTTINGHAM POSITIVE CARE TEAM

The Nottingham Positive Care Team (NPCT) provides social support and care in the community to people with HIV in Nottingham, and is funded by the statutory sector (with funding for posts coming from either the Primary Care Trust or Social Services). The aim of the NPCT is to support clients to live safely and independently within their own community while ensuring that people with HIV do not experience discrimination when accessing health and social care. An important focus of the team's activity is to help clients avoid crisis by providing access to a flexible and accessible cross-disciplinary support network.

At present the team consists of:

- a social worker
- a community care officer
- a clinical nurse specialist
- a dietician
- a befriending service co-ordinator

While there was once a welfare rights officer post attached to the NPCT, this specialised post has recently been deleted, and NPCT staff have been advised to refer clients with HIV to the generic Welfare Rights Service when information and advice is required (for more information on the Welfare Rights Service see Section 2.9). When asked about the provision of housing support for people with HIV, most HIV specialists recommended that a specialist HIV floating support post for housing support should be attached to the Nottingham Positive Care Team. Those interviewed from generic agencies tended to feel that specialist support was not required for this population.

The Nottingham Positive Care Team is, in essence, virtual. Staff are situated across three settings (City Hospital, Queen's Hospital Social Services and the Health Shop), and have four separate managers. The intention is that newly diagnosed patients at either of the two clinical sites are made aware of the NPCT and direct referrals are made by health advisors or other clinical staff at the GU clinic. As the NPCT clinical nurse specialist is situated within IDU, this post provides a crucial access point to NPCT for some patients. In addition, the social worker has weekly personal contact with the clinical teams in both settings, during which social and

clinical care issues can be raised about particular individuals. The ideal is to provide a seamless service between the hospital and community for people with HIV, using an interdisciplinary case management approach.

People with HIV accessing non-HIV services in Nottingham - such as the Refugee Forum, addiction support or homelessness services - may also be referred to the team from these routes. However, the likelihood of such referrals is hampered by the fact that HIV disclosure tends to be infrequent in some of these settings, and those providing generic services are not universally aware of the existence of the NPCT. Where such referrals are made, continuity of care can be compromised when clients are readied to leave sheltered or supported housing and are effectively 'dumped' on the NPCT. It was recommended that the best way to overcome this problem is to involve the NPCT in case management early on so that the client experiences a better supported transition into independent living.

The current model of social care delivery for people with HIV is relatively unique to Nottingham, and is likely to have developed through a historical process of job appointments to best meet the needs of clients at a particular time. This explains the 'ad hoc' nature of where posts are housed, how they are managed, and how the team operates. While this offers a certain amount of flexibility where it is needed, it has also been recognised that a more formalised re-structuring of the team would benefit clients and stakeholders as well as team staff. As a consequence a "review" of the roles and responsibilities of the team has been underway for a considerable period of time.

In most other UK cities, the non-clinical needs of positive people tend to be addressed through a blend of voluntary and statutory services, and in many cases, Primary Care Trusts or Social Services Departments fund posts that are situated and managed in established (charitable) HIV support organisations.

Staff from the NPCT assist people with HIV across a broad spectrum of issues, almost all of which can be connected to housing support. These include: helping to assess and monitor community care packages and receipt of benefits, counselling, managing debt, mental health support and referral, managing a transition into independent living, applying for asylum, maintaining a balanced diet, managing treatments and combatting social isolation. Those who work in the NPCT are all highly mobile, and home visits are a frequent component of their work. At times this can make contacting them difficult.

A central element of the team's work is providing a listening ear and reliable information for individuals during times of crisis, or to those who require on-going low level support and life-skills development. The development of trust is fundamental to strong relationships between this client group and NPCT staff. Many people with HIV in regular contact with the NPCT commented on the importance of knowing that someone from the team was looking out for them when no one else was. The NPCT also provides HIV awareness training to health and housing providers and work to develop links between statutory and voluntary sector services. They encourage clients to take an active role in the planning and presentation of World AIDS Day events in Nottingham, working to increase HIV awareness in the community at large.

The social worker and the community care officer are probably the two staff members best placed to then make direct referrals to generic social and support services (voluntary, statutory and private) when clients' needs are best met elsewhere. In some instances such interventions will also mean assisting a client through a lengthy process, from first contact to the expected outcome. Some examples of this could be: arranging debt repayments; attending a homelessness interview; accessing benefits; enrolling in education and training; applying for accommodation; finding a solicitor or dealing with NASS or the Home Office on

immigration matters. The dietician and the clinical nurse specialist provide the clinical arm of the team, making formal and informal assessments, providing support and information where this is needed, and onward referral (either to HIV specialists or elsewhere) where appropriate.

A key aspect of the NPCT's activities is its management of the **weekly drop-in**. The drop-in is currently located in a church hall just outside the centre of the city, and is open from 10am to 4pm on a designated week day. It is intended to be a welcoming and accessible point for people with HIV to 'check in' with the NPCT, ask for advice on health or personal issues, eat a healthy and affordable hot meal and to socialise with other people with HIV in the city. About 15-20 people will attend the drop-in on a given session - with most arriving shortly before 12 noon, and leaving after lunch. It was frequently commented among service users that the same group of people tend to turn up on a weekly basis and some said that they found it an unwelcoming venue. Very few African people with HIV use the drop-in service.

2.4 TAGADERE

Having recently changed its name from 'Positive Attitude', Tagadere is a peer support group for people with HIV. The group is planning to apply for charitable status, and does not have a premises. The core group of people involved in Tagadere (5-6) meet weekly at a pub in central Nottingham, and increasingly the group has developed an advocacy dimension. Tagadere is usually represented at the weekly NPCT drop-in, and seeks to provide support to others with HIV - particularly those who have been recently diagnosed - on matters such as treatment adherence, dealing with stigma and the psychological impact of diagnosis.

Among those key stakeholders from Tagadere who were interviewed, there was a strong desire for growth into a significant and stable voluntary sector organisation providing services for people with HIV. This vision was also supported by the NPCT and staff of the Partnership Development Team at the Red Cross and the local CVS (two organisations that are helping Tagadere to become more viable in the long-term). A significant amount of work is being currently undertaken in order to develop a more formal existence, including writing a business plan and establishing a written mission for the group. The one stop shop model is an important component of this vision, in that Tagadere is being pitched as playing a key role in the coordination of a number of the services that would potentially be on offer at the one stop shop. However, there is a broad range of opinion about how soon Tagadere can realistically develop the capacity to be centrally involved in such an operation, as projections from key stakeholders ranged from less than two years to about ten years. It was also unclear from speaking to a range of stakeholders that there was consensus on the specific role to be played by Tagadere within this model.

2.5 THE NOTTS. HARDSHIP FUND

The Notts. Hardship Fund has been making grants to local people affected by HIV and AIDS since 1997. It has had charitable status in its own right since 2001, whereas before that it was administered by the Potter's House Trust. The majority of the Fund's income is generated via private donations, street collections and community fund-raising events in addition to bank interest.

In 2004 the Fund made 105 grants - most of which supported those who required food and baby milk and who were in need of meeting emergency costs. While the trustees generally do not administer grants valuing more than £250 to one applicant in a given year, there are exceptions to this general rule. The Fund's policy is to make grants through referrals from accredited professionals rather than in response to direct requests from applicants. Within Nottingham City such referrals have traditionally been made by the NPCT and it is unclear to what extent those providing generic support to people with HIV in the city are aware of the Fund.

In the past, most grants tended to be given for appliances, new carpeting or furnishing new accommodation. However, payments now tend to support migrants with HIV who are in acute housing and financial crisis. The trustees have recently decided to make grants entirely on the basis of need, regardless of an individual's immigration status. This follows the lead taken by a number of national charities who have implemented similar policies.

2.6 THE NOTTINGHAM AND NOTTINGHAMSHIRE REFUGEE FORUM

The Refugee Forum was known to most respondents in this study who had been a part of the asylum process. It has recently moved to a larger and more multi-use premises to the north of the city centre. It is a place where those claiming asylum can seek expert legal advice and social or emotional support. It is a welcoming haven for Nottingham's refugee and asylum community in general, while also being a place for those from specific ethnic and language groups to meet and socialise.

The Forum is open throughout the week, with advisors holding special advice surgeries, and various support groups meeting there on a regular basis. There is a specialised HIV counsellor who refers individuals to the NPCT where appropriate. Conversely, NPCT staff will sometimes refer their asylum and refugee clients for support at the Forum. HIV is described as a fairly taboo topic within the Forum itself, and public disclosure of HIV status is rare in that setting - however a significant amount of HIV awareness literature and information is made available to those who attend the Forum. The Refugee Forum distributes donated food to clients who are in need, and it also disperses monies from its Destitution and Emergency Grant Funds. Staff and service users of the Refugee Forum are uniquely situated to provide those providing HIV services with advice and support on working with specific migrant groups, particularly those from African regions with high HIV prevalence.

2.7 NOTTINGHAM REFUGEE ACTION

Refugee Action is a national voluntary organisation that supports refugees and asylum seekers. Refugee Action is contracted by the Home Office to provide emergency reception and one-stop services to dispersed asylum seekers in the East Midlands, and holds a weekly drop-in service for women at a central Nottingham church. Clients can access Nottingham Refugee Action at specified times through the week for support and advice, and the organisation also offers a second-tier service of advice and training to other organisations including: Citizens Advice Bureaux, Housing providers, health professionals *etc.* None of the respondents that we interviewed that had been part of the asylum process spoke of accessing Nottingham Refugee Action's services.

2.8 EAST MIDLANDS CONSORTIUM FOR ASYLUM AND REFUGEE SUPPORT

The East Midlands Consortium for Asylum and Refugee Support (EMCARS) office is based in Melton Mowbray and is hosted by Local Government East Midlands. It is EMCARS' responsibility to facilitate and co-ordinate housing and other support services for refugees and asylum seekers across the region, meaning it is central to the administration of National Asylum Seeker Support (NASS) housing and funds in the region. The Consortium's local partners are local authorities and other agencies especially Refugee Action, Refugee Housing Association and other housing providers, health and education providers, police and immigration services, voluntary organisations and emerging Refugee Community Organisations. The extent to which HIV among asylum seekers is a priority issue within EMCARS is unclear, however their newsletter has featured legal developments relating to the provision of housing for asylum seekers with HIV (EMCARS 2005a: 5).

EMCARS also provides estimates of those claiming asylum in the region who are not financially independent. In October 2005, the total number of asylum seekers estimated to be claiming support in Nottinghamshire was 1405, with 1007 of these in dispersal

accommodation and receiving a weekly subsistence payment, and 78 receiving subsistence payments only. Approximately 172 people were supported by Nottingham City Social Services (having received this support since a period that pre-dates the implementation of NASS) and a further 148 were estimated to be receiving Section 4 support. Section 4 support is intended for those whose application has failed, who are unable to return to their country of origin for a range of specified reasons (EMCARS 2005b: 2).

2.9 GENERIC SERVICES RELATED TO HOUSING

There are a number of services that provide housing, housing support and advice to those in need, and to professionals who are helping such clients. Although this is not intended to be an exhaustive list, each of the following organisations was identified during this research.

Council Housing (Nottingham City Homes) / Housing Associations

Many respondents with HIV either lived in council-owned housing or rented from housing associations. These public sector housing providers offer affordable housing, and are responsible for the ongoing maintenance and security of the properties. Most of the people with HIV taking part in the research who lived in such properties said that repairs tended to be conducted within a reasonable time-frame, and that ongoing improvements meant that most permanent placements were warm, dry and secure. However, temporary accommodation placements were described as unsafe, unclean and inappropriate.

Housing AID

Housing AID is the homelessness unit for the local authority. Individuals and families make a homelessness application through Housing AID and the agency helps to place them in appropriate accommodation. Housing AID has also implemented a proactive approach to the prevention of homelessness, with case management that includes links to floating support provision funded by Supporting People. It is unclear whether Housing AID frontline staff have received any recent HIV training, as very few were able to identify the NPCT as a referral point for clients with HIV. There is a key contact at Housing AID who provides specialist support for refugees.

Nottingham Hostels Liaison Group (HLG)

HLG is a registered charity which provides training, information and support services to organisations working with homeless people and others in need of supported housing throughout Nottinghamshire. The organisation also provides a range of direct services to homeless people through its Mental Health Support, Resettlement and Accommodation Access Teams. For the past two years HLC has had a specialist worker who supports refugees in Nottingham City who have not been accepted as being in priority need under the homelessness legislation. The worker helps refugees to find suitable accommodation and prevent homelessness, and agency or self-referrals are welcome.

National Association for the Care and Resettlement for Offenders (NACRO)

NACRO provides a range of practical support services for offenders, those at risk of offending and other people with special needs. The services offered by NACRO are wide-ranging, and they include the provision of housing, care and rehabilitation for ex-offenders, as well as help to find accommodation and complete applications.

Shelter - Nottinghamshire Housing Advice Service

For over 20 years Shelter has provided independent housing advice and advocacy on homelessness and housing issues in Nottingham. It is part of the National Shelter Housing Aid Network, and is a registered charity and a limited company. It receives funding from: Community Legal Services, Nottinghamshire County Council, National Shelter, Nottingham City Council, the Office of the Deputy Prime Minister and the Community Fund. The two

Shelter offices offer drop-in and appointment services and telephone advice as well as outreach services. Some of the issues on which Shelter staff can provide advice are: homelessness, seeking accommodation, housing benefit, rent and mortgage arrears, disrepair, landlord and tenant problems and domestic violence. None of the respondents with HIV described Shelter as a place that they had ever considered accessing for housing advice. However, key stakeholders who provide services to this client group have contacted Shelter for advice on specific cases.

Nottingham Social Services Department Welfare Rights Service

As a part of Nottingham City Council's Social Services Department, the Welfare Rights Service provides expert welfare benefits advice for Social Services clients (at Player's Court) and for the public (at its North & West Advice service). The Welfare Rights Service aims to improve the quality of life of members of the more disadvantaged sections of society by providing a service free at the point of delivery, which is confidential, impartial and professional. The ultimate aim is to maximise a service user's income, as well as their awareness of rights, independence and choice.

Following a service review, it has been decided that the specialist teams that were established to address the needs of specific groups of social services clients will now be merged into a generic, wide access team in order to provide best value and access across a larger proportion of the Social Services Department. There was a specialist HIV Welfare Rights Officer post attached to the NPCT that had been vacant for some time, and in light of this over-arching review that specialist post has not been retained. The focus of the new generic Welfare Rights Service (at Player's Court) will be to provide all social care staff (including those on the NPCT) access to information, advice, advocacy and representation regarding benefit entitlements of their service users, as well as working directly with service users where appropriate. Within the context of this reform of service provision, the Welfare Rights Service supports the provision of HIV awareness training and information to all its advice staff.

3. Housing-related support needs of people with HIV

3.1 DEMOGRAPHIC CHARACTERISTICS OF PEOPLE WITH HIV

Twenty in-depth, face-to-face interviews were conducted with people with HIV. As far as was possible in a sample of this size, the recruitment of respondents attempted to mirror local HIV epidemiology. Most importantly, extensive efforts were made to recruit migrants to the UK from countries of high HIV prevalence. As expected, ethnicity, migrancy and legal status in the UK were key characteristics in the housing support and social care needs described in interviews. In the following, data for the ten migrants and the ten UK-born respondents is presented separately, alongside overall figures for the whole sample.

Fourteen of the respondents were male and six were female. Nine of the male respondents identified as Gay or Bisexual, and five identified as heterosexual. All the females identified as heterosexual. Four of the heterosexuals had a history of injecting drug use. The average age of the sample was 42½ years old (median 44, range 25-57). Migrants were somewhat younger, on average.

Overall, respondents had been living with diagnosed HIV for 6½ years on average (median 3 years, range 6 months - 20 years). Migrants had been living with diagnosed HIV for a significantly shorter time (mean 3½ years, median 3, range 10 months - 10 years) compared to UK-born respondents (mean 10 years, median 11½, range 6 months - 20 years).

While formal registration as a disabled person has been phased out in most local authority settings, half the respondents (n=10) described themselves as 'registered disabled' and a total of twelve were in receipt of disability-related benefits. UK-born respondents were substantially more likely to say that they were registered as disabled and / or in receipt of benefits relating to disability. The majority were not in paid employment: only three were in formal paid employment and another three were students. The majority of respondents with a UK (or EU) citizenship received Disability Living Allowance and either Income Support or Incapacity Benefit. The financial situation of migrants from outside the EU was more problematic. Those that were not employed survived on money from their family or savings though two also received NASS payments. Some UK-born and migrant respondents also accessed emergency payments from the Hardship Fund or from a similar scheme of the Refugee Forum.

Demographic characteristics		Migrants (n=10)	UK-born (n=10)	All respondents (n=20)
Gender	Male	6	8	14
	Female	4	2	6
Sexuality	Gay / Bisexual	3	6	9
	Heterosexual	7	4	11
History of injecting drug use		2	2	4
Registered disabled		2	8	10
In receipt of welfare benefits		2	10	12
Employment status	Not Employed	5	9	14
	Student	2	1	3
	Working	3	0	1

Half the respondents were White British and all of these were UK citizens. Of those, the majority had been resident in the UK all their lives. While two had previously lived abroad, more than half had lived in Nottinghamshire all their lives. Among the migrant respondents, there were 5 Black Africans and 2 of Black Caribbean ethnicity. The others were of mixed or other ethnicities. The migrants had a range of legal status' in the UK: 4 were asylum seekers and 1 was a refugee. Of the remainder, 2 were EU citizens, 2 had been granted permanent leave to remain in the UK and 1 had a student visa. Of these respondents the majority had been resident in the UK for 3 - 5 years. Only two had been resident in the UK for a year or less.

Demographic characteristics		Migrants (n=10)	UK-born (n=10)	All respondents (n=20)
Ethnicity	White British	0	10	10
	Black African	5	0	5
	Black Caribbean	2	0	2
	Mixed or other ethnicities	3	0	3
Legal status	UK citizen	0	10	10
	EU citizen	2	0	2
	Leave to remain	2	0	2
	Student visa	1	0	1
	Refugee	1	0	1
	Asylum seeker	4	0	4

Most of the migrants had not moved to the UK with the intention of permanent settlement. Many had planned to gain qualifications or work temporarily in order to send money back to support family, ultimately aiming to return home. However, for almost all, HIV diagnosis ruled out the possibility of return. Not only was effective HIV treatment regarded as inaccessible in most countries of origin, but individuals strongly believed that living with an HIV diagnosis in their countries of origin would mean ostracism from family and friends. Of the small number of migrant Gay men in the sample, some had migrated to the UK to escape pervasive homophobia, and in these cases, a return home was not considered an option, even before an HIV diagnosis.

Among the respondents who were seeking or had obtained asylum or refugee status, a common chronology of life events emerged. Many had arrived in the UK either as students, visitors or on short working visas. After becoming unwell and receiving an HIV diagnosis, social workers (usually associated with an HIV clinic) had helped them to access anti-HIV treatment, and offered support to find a source of income and a place to live in the city where they were diagnosed. Most commonly individuals without residency rights reported that they had been encouraged to apply to remain in the UK. Most of these respondents described themselves as still awaiting news on asylum claims based on their HIV status, or on medical grounds - after making contact with specialist solicitors and refugee support agencies. The extent to which these respondents have separate asylum claims coupled with applications for discretionary leave to remain on medical grounds (under Article 3 of the European Convention on Human Rights) was unclear.

The House of Lords recently delivered a judgment on the matter of 'N' ([2005] UKHL31) where it was determined that deportation of a person living with HIV to a country where s/he was unlikely to receive adequate HIV treatment was not incompatible with their right to be free of inhuman treatment under Article 3 of the European Convention on Human Rights. In concluding their written judgment, the Lords made it clear that the Home Office can exercise discretion in deciding not to return such individuals to their home countries, but that if it decides on deportation, it will **not** be operating in breach of human rights legislation. Given this situation, and other changes being made to immigration and asylum policy by the Home Office, it is crucial that expert advisors are able to offer individuals making such applications a detailed and informed view on the likelihood of success of specific approaches. Despite the unpredictability of Home Office discretion, the respondents we interviewed reported that they lived in hope of achieving leave to remain in the UK, and few had any other desirable options.

Demographic characteristics		Migrants (n=10)	UK-born (n=10)	All respondents (n=20)
Housing tenure	Owner-occupier	0	2	2
	Council housed	2	5	7
	Housing Association	1	1	2
	Private rental	3	1	4
	With family, partner or friends	2	1	3
	NASS	2	0	2
Lives with	ALONE	2	5	7
	Partner only	0	2	2
	Child/ren only	0	1	1
	Partner + child/ren	3	1	4
	Children + other family	1	0	1
	Parent/s	1	1	2
	Shared (flatmates)	3	0	3

Housing tenure and living arrangements varied considerably across the sample and between migrants and UK-born respondents. Two of the UK-born respondents were owner-occupiers and the majority of the remainder were Council (or Housing Association) tenants. The majority of UK-born respondents had very stable housing histories. Six had been in their current residence 5 years or more (range 1½ to 16 years), and none had moved home in the preceding year. Of the four UK-born respondents that had moved residence in the last 5 years all had only moved once.

Migrants were more likely to be in private-rented or NASS accommodation or to rely on friends or family for accommodation. Regardless of their current legal status, housing tenure or country of origin, the majority of respondents who migrated to the UK described chaotic housing histories. Half had been in their current residence for six months or less, and most of the others had been in their current accommodation for about one year. The majority had changed accommodation frequently during their residence in the UK: half (n=5) had made 5-8 moves (including periods of homelessness) during their time in the UK and another three had moved 3-4 times.

Housing circumstances tended to fluctuate most at pivotal moments in respondents' lives, such as: immediately after arrival in the UK; immediately after making an asylum claim; following on from their HIV diagnosis; or once refugee status was granted or refused. During these periods of change, it was often necessary to rely on friends or family for food and shelter. Others had found themselves homeless or being moved through temporary accommodation by NASS or Nottingham City Council.

3.2 HOUSING NEEDS - MIGRANT RESPONDENTS

Of those people interviewed who had migrated to the UK, none owned the property in which they lived. Six lived in housing rented from a Housing Association, the Council or a private landlord, two were housed by NASS and two others relied on family to provide them with shelter.

All those renting property described current and/or previous housing conditions that were far from satisfactory. Key issues included drug dealing and prostitution among neighbours, ongoing problems with noise, lack of central heating or weatherproofing and cramped conditions. Many of those who had been resident in the UK for a number of years had been gradually working their way towards a reasonable standard of accommodation - either by making applications to the relevant authority or choosing better appointed private rentals.

Respondents living in public sector housing were sometimes supported by statutory sector staff - either key workers, health translators or Positive Care Team staff - particularly when an application to move was made on the grounds of physical or psychological well-being. Situations that led to such requests included:

- structural safety concerns;
- no longer being able to manage stairs;
- theft or violent attack;
- drug dealing by local residents;
- larger flat becoming available.

Those who were making their way through the private rental sector did not describe accessing any formal support or advice in relation to their housing options. In these cases, individuals felt forced to tolerate homes lacking central heating, that were overcrowded or in unsafe areas because they were not able to find affordable alternatives. Moving to a different rental property was usually prompted by a change in employment, or a change in household configuration (the arrival or departure of family or house-mates). One respondent who arrived in the UK to study moved from a clean and secure private rental flat into a shared rented flat in order to save on expenses. When those house-mates moved away, difficulty with finances meant that the only option was to move in (along with two children) with a family member. This individual described feeling like a burden in an overcrowded household.

Almost all of those who had been or continued to be a part of the asylum process described placements in accommodation that have damaged their health and well-being. As one respondent said:

NASS puts you into places where no one else wants to live.

Ultimately, the best that was expected from NASS accommodation was a safe temporary residence where individuals could subsist until their asylum claim was resolved. However, much of the NASS accommodation was described as being in neighbourhoods beset by violent crime, drug use and prostitution. In a number of cases, individuals' complaints to NASS about violent attacks by local residents or conflicts with their house-mates resulted in relocation of the person making the complaint. Almost all of the accommodation provided by NASS was

shared with other asylum applicants, and in most cases, respondents described themselves as being the only one in the household who took responsibility to clean the common areas. A number said that NASS had provided accommodation that was not centrally heated or adequately furnished, and as a result they felt that their health had suffered.

Those claiming asylum were unprepared for the poor conditions and unsafe neighbourhoods that typified NASS accommodation, as well as being unaware of the likelihood of dispersal. The prospect and lived experiences of being dispersed were deeply troubling to most of those claiming asylum. To this extent, one respondent had refused to take-up offers of accommodation in other cities, and had instead chosen to remain at a relative's house in Nottingham. Another asylum claimant who had been dispersed to Nottingham was lobbying to be returned to London at the time of interview, and was hoping to convince authorities of the health benefits of accessing family and social support (an approach that was ultimately successful for this individual).

Respondents with uncertain immigration status at the time of interview were completely constrained in their ability to freely attain suitable housing until they had been granted refugee status - a process unlikely to be resolved for months or years. Those in this situation felt that once they gained residency rights, they would be able to secure clean, warm, secure and independent housing. However, as descriptions given by other respondents made clear, a legal right to remain in the UK does not in itself eradicate housing need or housing support need - and none of these participants wanted to contemplate the outcome of a refused claim.

3.2.1 Current housing needs and aspirations

The most common need expressed in relation to current housing among this group of respondents was better heating and energy conservation. A number of people said that their current house or flat was too cold, exacerbating the problems faced by those with ongoing respiratory infections and tuberculosis. Some had to supply additional - and costly - electric heaters in homes that were without central heating. Other places were draughty because of a lack of weatherstripping on windows and doors, single glazed windows and poor insulation. There were some living in public sector housing who reported recent refurbishment that had made a significant impact on warmth, including: installation of double glazed windows, a new boiler and installation of loft insulation.

None of the respondents in this group reported problems with damp. Also, most were satisfied with the general cleanliness in communal areas (gardens / stairwells and hallways) and structural upkeep of the places where they lived. No one reported any problems with rodent or insect infestation.

Some respondents felt unsafe in the areas where they lived. Poor street lighting after dark made it difficult for one person to walk safely with secure footing at the front of the house. Another reported vandalism and theft as routine in the local area. While a proportion of those migrants who were interviewed had managed to make successive moves away from dangerous areas, some had not.

Four migrants living with HIV reported ongoing, unresolved issues with noisy neighbours, or having problems with nightly street noise (made by those leaving local pubs). One person's own house-mates played loud music during the night. Others described hearing neighbours' regular arguments through adjoining walls, dogs barking and loud music into the early hours. When asked how they thought that such anti-social behaviour might be resolved, none felt that change would be possible. There was one respondent who described a situation with an aggressive noisy neighbour in the past which he had sorted out on his own by approaching the individual and resolving the dispute through calm and friendly discussion. However, none

of the four with continuing noise disturbances felt that they could change the situation, and it was suggested that support from others would either have no effect, or would worsen relations.

Those in shared or family accommodation were usually likely to find that the space in which they lived was constrained. This was not an issue of particularly high priority for those in NASS accommodation, and was more likely to be raised by those living with friends and family, and those sharing private rental accommodation. Those who were renting were unable to afford a larger place that would accommodate themselves (and their families) more comfortably.

3.2.2 Shared accommodation

In many of the shared households described by migrant respondents, the other adults and children in the home were unaware that the respondent had diagnosed HIV. This finding emerged across different types of housing situation, including shared private rental, NASS accommodation and living with relatives. In such circumstances, the daily treatment regime, periods of ill-health, contact with the Positive Care Team and clinical appointments were described as routinely guarded secrets.

Concealing HIV medication (which in some instances requires refrigeration) was a particular problem. One person accomplished this by concealing medicine under other items in a plastic container in the shared refrigerator. Another felt that the risk of having others find the medicine in the fridge was too great, and chose to hide it in the bedroom instead, despite knowing that this could have a detrimental effect.

And I find it very difficult to keep my medicine. Because my medicines, they're supposed to be kept in a low place in a fridge. So it's a shared one. I cannot keep it there. Instead I keep it at a place where I'm not supposed to keep my medicine.

This is one example of the way that shared housing forced individuals to choose between behaviours that could harm their well-being, or risk disclosure of their HIV status. Given the extent to which these vulnerable individuals feared the repercussions of HIV stigma, they almost always chose to avoid disclosure within their own home.

In contrast, respondents living with others who were aware of their HIV status described a helpful and supportive atmosphere where partners and other family members filled required roles as necessary. One respondent was temporarily living with a relative during a health setback, working towards a return to full independence. Those living with partners who had also been diagnosed with HIV found that they were able to fill complimentary roles: taking over household tasks for one another during energy ebbs, and helping with reminders to take medication. In those situations where it is feasible and where the outcome is likely to be positive, supported disclosure of HIV status to other adults in the household has the potential to provide a significant benefit to people living with HIV.

3.2.3 Managing periods of crisis

Among this group of respondents, periods of poor physical and mental health and changes in legal status were common causes of personal crisis that precipitated housing and housing-related support need. Almost all of those who migrated were diagnosed in a UK hospital after a period of critical illness or collapse, indicating a pattern of late diagnoses occurring some years after transmission. National studies have demonstrated that African migrants are particularly likely to be diagnosed later than their UK born counterparts.

For a number of respondents, other peoples' response to their HIV diagnosis (or disclosure) resulted in housing crisis. In two instances, respondents returned from a hospital stay during which they had been diagnosed with HIV to find out that they had been turned out by the friend or relative with whom they had been living. Two other individuals described instances some time after they had been diagnosed when disclosure of HIV status to someone who had offered them shelter resulted in that offer being withdrawn.

Given the extent to which migrant respondents described their dependence on friends, family and acquaintances for interim housing or support in times of transition - this rejection and the HIV-related stigma it illuminates is significant. Given the substantial risks that such openness can carry, it was little surprise that guarding HIV status from other members of shared households was not uncommon. However, rejection was not a universal response. One respondent described a neighbour who knew of his HIV infection and kept a close eye on him while he was unwell had ultimately been responsible for getting him to hospital when he had collapsed alone. Others had stayed or were still staying with people who knew of their HIV status when they were not well enough to live on their own.

Migrant respondents who experienced significant bouts of ill health frequently described the Positive Care Team as an important source of emotional and practical support during times of acute need. The knowledge that someone was looking out for them was essential to individuals who were temporarily in hospital or house-bound. The drop-in was described by a few as a place where this 'checking-in' could continue once they were back on their feet. Two respondents also described the central role played by their health translator who operated as their advocate during times of crisis, and who provided ongoing social and emotional support.

Psychological crises were apparent among a high proportion of migrant respondents. Some were receiving specialist counselling from psychologists through the GUM clinic, or via GP referral. Others accessed counselling services provided by educational institutions where they studied. Most of those who suffered from pervasive depression and anxiety expressed the loss of control over the direction of their life (due to HIV) as the central cause of their distress.

As they saw it, HIV threatened to bring their life to a halt, and their choices - about health, income, country of residence, open communication with family and friends, finding a partner, and access to decent housing - were no longer their own. In a number of cases, respondents were prescribed anti-depressants and sleeping tablets, but most found that they did not want to remain on them in the long-term. Most described their counselling as having beneficial effects, but some also felt a need for emergency psychological support at times of crisis.

When individuals found themselves in these periods of emotional strain, they often found that their capacity to sustain independent living was compromised. Many talked of having had suicidal thoughts. One respondent had attempted to kill himself only days before our interview. Some found that they had lost the energy to shop or cook healthy meals. Others lost track of their financial situation, and soon found bills mounting up.

Because being in that... because it's situations like those you know, whenever I get in situations like that I tend to lead off track. Not taking... not focussed enough on my medication. And it just sends me back to zero.

Among those who have migrated to the UK, the material and psychological impact of an HIV diagnosis can be especially great because of the numerous other areas of life upon which such news will have an effect. All existing plans have to be realigned to the new reality of living with HIV - in particular ways that are not shared by those with existing citizenship and residency rights. This situation, combined with the high likelihood of later diagnosis amongst migrants, means that the likelihood of recurrent crises is high. Significant levels of expert

medical, immigration and housing advice, emotional support and expert psychological support are often required at these times of increased need.

3.2.4 Other current needs

One of the most pervasive issues that affected all migrant respondents was insufficient income. For those in the process of claiming asylum, the only legal means of income was a weekly NASS support cheque for £38. There were others whose application for asylum was not yet processed, or whose appeal had been rejected, meaning that they had no income whatsoever. Access to emergency monies from the Hardship Fund or from the Refugee Forum was sometimes sporadic. Others who remained here on short-term visas described their reliance upon funds being sent from home in order to manage. When such funds were not available, or delayed, respondents went without food, could not afford to use public transport and had difficulty keeping up with their bill payments, including rent.

Yeah I do worry about money. Sometimes I really need to have money but I don't have the money. So I wait until I get the money. But it's difficult sometimes.

One respondent described a recent downward economic spiral that was associated with spells of ill-health and difficulties with treatment adherence. With support from staff on the Positive Care Team, he went to court following a notice of eviction from the Council due to rental arrears.

And we went to Court and the judge made a ruling that, you know I should continue to stay there and as long as I pay something on the account. Like £5 plus my rent. So we've agreed to that. Because at the end of the day I don't want to be chucked out of my home because you know this condition that I'm there's no way I want to be out there on the streets on my own. And yeah. So the judge decided and he said well why... because being in my situation and I've been on and off work every so often, he said why the claims for housing benefits and things like that were denied. Why were they refused. And he said clearly you know I'm entitled to something.

OK.

And he wanted them to look in the matter and get back to him. So I don't know what's happening.

In this situation, the respondent described how important the ongoing support and financial advice he received from the Positive Care Team had been. However, a number of migrants living with HIV who did have access to public funds for financial support were not aware of the most reliable means of accessing help, and expressed some trepidation about where to begin. In one particular case, this may have been exacerbated by previous unhelpful experiences.

Then when they diagnosed me, the social worker asked me at the clinic about accommodation and I told them that I'm living in a rented house. But then he suggested about a Council house. But the problem... I did try to apply, actually I did fill in a form blah blah. But then they refused me they say because I didn't have the leave to remain there.

OK.

At the Council. But I didn't take it to the social worker for me to help me anyway. I just took it straight to the Council.

Do you think you would be interested in applying for a Council property now?

Oh yeah.

Because you do have leave to remain [now]?

If it's cheaper than the one that we're living in and if it's better and it's got all the facilities, yeah.

Is that something that you have looked into at all or again sort of like you were saying you're not sure where.. ?

We weren't sure... Oh we're not sure isn't it. We're discussing about it... Yeah we

weren't sure. And we didn't know the prices like a three bedroomed... this is a three bedroomed... So we're thinking how much is it?

Having been wrongly advised to make an application for Council housing before having leave to remain, this individual was later referred to a solicitor's office that mis-managed and delayed visa applications for other family members. Despite describing a household financial and health situation that was indicative of substantial housing need, this respondent was unaware of what benefits might be accessed, and unsure about asking for advice.

Of the three migrant respondents who were employed, two were experiencing significant ill-health that was interfering with their ability to work at the time of interview. One had been off work for a month due to HIV-related illness and depression, and it had been the fourth time in the year that sick leave had been taken. Another was trying to continue working at a physically demanding part-time job, despite suffering from peripheral neuropathy (a painful treatment side effect) that was exacerbated at work. This latter respondent felt compelled to persist with this low-paid job in order to help sustain the family in their privately rented home.

None of the migrant respondents felt that they required support from statutory or voluntary sector services to clean or maintain their homes. Some managed the onset of fatigue or periods of ill-health by sharing tasks with others in the home, or by prioritising tasks and aiming to achieve one a day in order to avoid becoming overtired.

Almost all migrant respondents indicated a strong understanding of the particular need for people with HIV to eat wholesome food in order to provide maximum benefit for their immune systems, as well as assisting with their treatments. However, achieving this aim was not always possible. One respondent who was suffering from depression was rarely motivated to seek out and prepare nutritious meals, and was instead consuming take-aways and processed ready-meals - which had started to take a physical toll. In this particular case, close monitoring by the GP had already been undertaken, however, further considerations such as enrollment in Nottingham City Council's *Meals at Home* appear not to have been raised. Others with family and friends in the home (or living nearby) sometimes relied on them to purchase and prepare healthy food during periods of ill health, or when they were excessively fatigued. However, provision of this type of support was usually only offered where HIV disclosure had occurred.

In a few cases, extreme poverty (and lack of access to welfare benefits) meant that regular access to good quality food was simply not possible. Two participants described going without in order to ensure that children's needs were met before their own. Those seeking asylum who were aware of the food bank provided by the Refugee Forum sometimes accessed additional stores there, but at least one participant described this food as less than adequate for a person with HIV. The affordable and nutritious hot meals available at the Wednesday drop-in were described as having some benefit for those migrants (n=4) who accessed them. However the remaining migrant respondents avoided the drop-in because of fears about loss of privacy (see Chapter 4). This concern was prevalent among those who had migrated from African countries, regardless of their immigration status.

There were other aspects of housing need articulated by this group of respondents that relate to disability and accessibility. Those who had experienced and continued to experience ill health required safe access to all areas of the home, including the bathroom. A small proportion described having been relocated (or having an application in process to relocate) to a single level premises on the ground floor or with lift access because their levels of fatigue and breathlessness made the use of stairs difficult. Two others (one who is currently in Council provided housing and another who is staying with family members) said that they

have difficulty managing the stairs in the place where they currently live. When asked if they required grab rails in the bath, two further respondents in this group said that these would be very beneficial. Neither seemed to be aware that applications could be made to have these installed through the Council. A further respondent had submitted an application for relocation and was aware that it would be possible to apply to have grab rails installed in the bathroom once the new place was allocated.

3.3 HOUSING NEEDS - UK-BORN RESPONDENTS

Among the total of ten UK-born respondents, five were in housing provided by Nottingham City Council, one rented from an Housing Association (NCHA) and one rented privately. Two were owner occupiers and one lived with immediate family.

The five who lived in housing rented from the Council were broadly satisfied with the standard of accommodation. All had lived in their current properties for at least 4 years.

I can see me being in the same place when my toes curl up love.

Two wanted larger properties but only one considered space problems sufficiently pressing to pursue the matter with the Council. As a single parent in a one-bedroom flat this person had recently been prioritised for re-housing but only after citing medical grounds. Two had previously been moved by the council - one because of domestic abuse and the other because of homophobic attacks from neighbours. One of these was considering applying for re-housing since the forced move had meant a loss of outdoor space which was regretted. However, all reported satisfaction with their current neighbours and neighbourhoods.

It's wonderful. It really is. It's quiet. We've got good neighbours. We've got good neighbours above us. Good neighbours below us. We don't get much noise. You know it's fine. It's warm as well.

One UK-born respondent reported difficulty with damp in a Council property, though this was eventually resolved. All reported relative satisfaction with the maintenance services offered by the Council and with the state of shared or communal areas in blocks (where applicable). All felt that properties were sufficiently warm and secure.

One of these respondents needed a shower because the bath with handles was not sufficient due to a decrease in mobility. While staff from the Positive Care Team had helped this individual pursue the matter with the Council, lack of any progress resulted in ongoing frustration. Otherwise none of the Council housed respondents had sought or received any adaptations to their property in light of HIV infection or disability.

The respondent who lived in a Housing Association property was similarly satisfied with the property's condition. Although finances dictated the need to move to a smaller property after bereavement it was not clear that the support mechanisms were in place to enable this transition. This individual had also had difficulties with infestations of ants and slugs in the kitchen, which made cooking and eating an unappetising prospect.

The one UK-born respondent that rented from a private landlord described the worst housing conditions including problems with damp, mould and rot, a lack of central heating and very little natural light. While the landlord had done some remedial work this had not solved the problems. It was also proving difficult to adequately heat the property because of financial problems. Positive Care Team staff had helped this person to apply to an Housing Association, though no offer of housing had yet been forthcoming.

The respondent in this group that lived with immediate family (including siblings) was seeking council accommodation, having identified increased independence as a personal priority. While being somewhat comfortable in the family home, this respondent had concerns about increased vulnerability if some other members of the household were to become aware of the HIV diagnosis.

And what do you think your life would be like when you're in your own place?

I'd be a lot happier. And I'd be more independent as well.

Do you think sometimes it would be hard to live by yourself in terms of being a bit lonely or are you actually wanting some peace and quiet?

Not really. Because I mean I've always thought about moving out. And I thought it would be a great opportunity for me to start thinking about moving.

What do you think has made that start happening now rather than some other time?

Well I'm on a lot of... I'm always falling out with my mum and she's always threatening to kick me out.

The two owner occupiers had both purchased property prior to their HIV diagnosis (including one on part-ownership with a Housing Association). Both were fiercely determined to maintain their status as property owners, in spite of financial uncertainties.

I didn't want to lose [my home] ... I didn't want to put my life into the hands of somebody else who would say well we can put you here or we can put you there or we can put you there. And you have to make a decision now. I see myself being in my home for a long time to come. I want to... I want to stay there. I don't want to sell it. Even if I was to sell it, where could I go. What can you buy? And I wouldn't want to go into a council or into a Housing Association or even at worse into a private rental. As long as I can pay my mortgage I shall be there.

One of the owner-occupiers had been offered some modifications (disabled shower) on the basis of their disability and had accepted a device to help with access to the bath.

None of the UK-born respondents reported the kind of fundamental difficulties with their housing conditions that were common among the migrant respondents. Several struggled with the day-to-day maintenance of the property (especially cleaning and shopping, and garden maintenance if they had one) but this was usually a function of being single, living alone and getting little or no help either from friends, family or social care professionals. Those that were in a position to share chores with a partner, or were financially stable enough to use Disability Living Allowance or Direct Payments to buy in help were usually relatively comfortable. Some respondents received assistance from friends or family and many were also supported by statutory sector staff - especially the Positive Care Team. The majority reported that this was of substantial benefit to their physical or psychological well-being.

3.3.1 Current housing needs and aspirations

Among some of the UK-born respondents, periods of poor physical health had previously precipitated housing and housing-related support need. Respondents who experienced significant bouts of ill-health frequently described the Positive Care Team as an important source of emotional and practical support during times of acute need. The knowledge that someone was looking out for them was essential to individuals who were temporarily house-bound, and the drop-in was described by some as a place where this 'checking-in' could continue once respondents were back on their feet.

Half (n=5) of the UK-born respondents were broadly content with their current home. While some of these lived fairly quiet lives, all were broadly satisfied with their current position. The

other half of the UK-born respondents wanted to move home. However, only one reported fundamental problems with the state of repair of their home. Unlike the migrant respondents, the majority were not dissatisfied with heating or energy conservation, damp or general disrepair. None were substantially dissatisfied with their neighbourhood or affected by (noisy) neighbours or street noise.

Among those wanting to move, just one (in private rented accommodation) felt his health was substantially and consistently undermined by cold and damp conditions. The others wanted to move to a larger property or to a property with some outdoor space (garden or even a balcony). One was seeking independence from their biological family.

3.3.2 Isolation and support

It was relatively unusual for UK-born people with HIV to live in the kind of shared households commonly described in the accounts of migrant respondents. Half (n=5) lived alone and three lived with long-term partners and no one else. One other lived with a child only and another lived with family.

The absence of larger mixed households had advantages and disadvantages - there was little need to conceal HIV status from others or manage non-disclosure to adults in close proximity. However, the result was that social isolation was common and several respondents described relatively solitary lives with very limited social or emotional support. Only one had disclosed their HIV status to any neighbours although two others had family who knew of their HIV status living in close proximity. Most described substantial fear of disclosure of their HIV status to friends and acquaintances, and even among the Gay men widespread disclosure was not the norm. Many people reported that Nottingham was a "small city" where HIV remained substantially stigmatised, including in the Gay social networks that exist. As a consequence privacy and confidentiality remained paramount concerns.

I'm not ready to face anybody's ignorance at the moment.. But then I'm not a victim of that ignorance you see. But it's such a vicious circle to be involved in. So I'd rather... I'd sooner not put myself amongst it. You know? I've isolated myself to this you know... one man band. And if it continues like that... I'm stronger on my own at the moment I feel.

Like the migrants with HIV, almost all of the ten UK-born respondents remained private about their HIV diagnosis - most were both very self-reliant and fiercely independent. Some relied on close friends and others received some emotional support from family, although most were too far from family for regular contact. Others actively resisted a return to the bosom of their biological family or had received a relatively unsupportive response on disclosure of their HIV infection. Loneliness and isolation were common, and those who did not use the drop-in centre run by the Positive Care Team were unlikely to know anyone else with HIV.

Are there situations where you feel that it would be really good to have somebody that you could call on to...

I wish I knew somebody else with HIV. I do yeah. But I can't go to drop-in centres and things like that where I think everybody's going to be.

Those with regular partners often relied on them substantially for everyday emotional support and to meet their everyday practical needs to buy and prepare food, pay bills etc. Those that did not use the Positive Care Team often felt particularly dependent on their partners.

3.3.3 Managing periods of crisis

More than half (n=6) of the UK-born respondents had been living with diagnosed HIV for a decade or more. The majority knew of the current (and former) staff on the Positive Care Team and their specific roles and responsibilities, and said they would feel confident contacting them if it was necessary. Users of the Positive Care Team were almost universally positive about the support offered.

The majority of UK-born respondents used the drop-in (n=8) with differing degrees of regularity. It was seen as a source of (peer) social support and a good way to “check-in” with Positive Care Team staff members to have informal discussions about their health and social care needs when these arose. Others used the drop-in as an opportunity to address concerns or seek advice, most commonly about money and welfare benefits or housing issues, and assistance with form filling.

I mean if it hadn't have been for the [Positive] Care Team I don't know where... who I would have turned to.

The drop-in was also cited as the easiest means to access the Hardship Fund, though few of the UK-born respondents accessed this service except on a very occasional basis, and usually in the case of emergency. Only one respondent used Direct Payments to fund help with shopping and a cleaner.

Three respondents reported substantial concern about entering services - including the drop-in - and hence being identifiable as a person with HIV. Concerns about the stigma associated with HIV, and the extent to which they might be discriminated against in their own communities made many substantially averse to seeking help, support and services beyond the NPCT.

Six of the UK-born respondents had experience of having a Buddy and all but one reported those relationships were useful. There was some variation in their relationships to Buddies - some saw it as a social opportunity, others received practical and emotional support. Not all of these respondents were entirely clear what they could rightfully expect from their Buddy, especially in terms of practical assistance.

One UK-born respondent accessed ongoing support from drugs support agencies. Only one reported any ongoing support from primary care, and this same individual's access to a District Nurse stemmed from difficulties maintaining independent living. All respondents used the local Genito-Urinary Medicine (GUM) or the Infectious Diseases Unit for HIV monitoring and associated health care and none reported a problematic relationship to the service they relied on. Most were very complimentary about the available out-patients services and some also received psycho-therapeutic support via this means.

3.3.4 Other current needs

Money and income was a substantial problem for many of the UK-born respondents. None were working with any regularity and most (n=9) survived exclusively on disability-related welfare benefits. Several had received financial advice and direct support with benefit applications from Positive Care Team staff. Others had relied on members of the Positive Care Team to help them through periods of financial crisis. Several wanted to return to employment, though only one felt sufficiently healthy at present to pursue full-time work. Most of the remainder with any aspiration to work had a perception that their benefits were insufficiently flexible to allow part-time working. Although recent rule changes should have improved the capacity of those on benefits to investigate flexible working arrangements, most respondents who expressed an interest in work were unaware of the options available to them.

Few of the UK-born respondents received support from statutory or voluntary sector services to clean or maintain their homes. Some (n=4) managed the onset of fatigue or periods of ill-health by sharing tasks with partners, or by prioritising tasks and aiming to achieve one a day in order to avoid becoming overtired.

The most common and the most immediate needs for many of the UK-born respondents with HIV were related to mental health. As we have already seen, most were socially isolated and few had an abundance of social or practical support. Some reported more profound difficulties, centred around anxiety and depression and their associated disorders (agoraphobia, obsessive compulsive disorders etc). Most of those who suffered from pervasive depression and anxiety felt a loss of control over the direction of their life due to HIV.

And the years kept ticking by and we're still alive and... ten years had gone by. Waste of ten years. Could have been doing something you know. Another ten years went by.

So have you had a sense that you're sort of waiting to see what's going to happen and not feeling like you're necessarily going to get better, but also not getting worse?

Uh. I'm sort of on a level... On an even thing with my health.

Yeah.

My CD4 and viral loads... viral load's quite low.

What I'm worrying about I'm very very anxious about... when I was diagnosed just before the summer I got into a little bit of debt with my rent through giving all my money to good food... I'm anxious. I've never been so anxious in my life. And I'm talking to myself and giving myself answers.

Not all of those respondents who felt they needed psychological support or counselling were getting it, and some bemoaned the lack of a HIV-specific counselling support service in the city. Some were receiving specialist counselling from psychologists through the GUM clinic. Others accessed counselling services through the educational institution where they studied.

For many respondents, concerns about their HIV infection and the stigma they might face if it were widely known, dominated everyday life.

I sometimes think people who say it's just a couple of tablets, it doesn't really bother me, are in partial denial. And that's just a sort of public display of bravado. That doesn't really reflect the way they really believe. I think it pretty much dominates me because everything I try to do seem... I seem I have to think about that before I engage in any sort of action.... It's always sort of looming, rearing it's ugly head [...] As something inescapable. So no I feel pretty much that it dominates me and that you know... yeah.

In a number of cases (n=6), respondents were prescribed or offered anti-depressants and / or sleeping tablets, but most found that they did not want to use these in the long-term. Most of those who had been involved in counselling described its beneficial therapeutic effects, but some also felt a need for emergency psychological support at times of crisis. When individuals found themselves in these periods of emotional strain, they often found that their capacity to sustain independent living was substantially compromised. Several had experienced suicidal thoughts.

4. Services and their improvement

One of the aims of this study was to assess the feasibility and desirability of a central access point for all services for people with HIV in Nottingham City (the one stop shop model). During our interviews with key stakeholders and people with HIV we asked people what they thought such a service might provide, as well as eliciting their overall views about the idea.

It is necessary to separate the rationales put forward for the one stop shop model from service enhancements and rationalisation exercises (particularly in relation to the NPCT) that could be undertaken quite separately from any consideration of a one stop shop. The difficulty in distinguishing between existing needs and proposed outcomes partly arises from the fact that so many processes of review and research that have been underway simultaneously. These include:

- this research project commissioned by Supporting People at Nottingham City Council.
- The review of the Social Services Welfare Advice Service conducted by Michael Bell Associates.
- The review of roles and responsibilities of the NPCT undertaken by Nottingham City PCT and Social Services
- Consultation and reviews undertaken by Tagadere / CVS and the Red Cross PDT as well as Social Services in relation to the development of a one stop shop model of service delivery

Within the past year Tagadere has surveyed 26 service users with HIV to ask what they thought a one stop shop should provide. Tagadere has also been working intensively with the Partnership Development Team at the Red Cross and the Change Team at CVS to elaborate a business plan and establish charitable status in order to develop capacity to eventually coordinate and manage a premises that would house the proposed one stop shop (Partnership Development Team 2005).

In November 2005, the Partnership Development Team at the Red Cross circulated a detailed review paper on the potential establishment of an HIV / AIDS one stop shop in Nottingham City. This paper outlines the ideological basis for the proposed model, and lists the potential services to be provided in such a setting (PDT 2005). It includes detail about what the premises should / could include, the service providers who would deliver services from this setting, and the resource and management implications of the plan. This model is based on significant voluntary sector involvement, and the Red Cross paper acknowledges the significant capacity building that will be required in order for Tagadere to take the lead on such a project.

In addition, discussions about the possibility of a one stop shop have been ongoing within the *HIV / AIDS Service Development Group*, which convenes providers of clinical, voluntary and statutory services to people with HIV in Nottingham City and surrounding boroughs.

First, we offer an overview of the responses among key stakeholders. Subsequent sections will provide a more detailed analysis of responses relating to the one stop shop from people with HIV.

4.1 KEY STAKEHOLDERS' VIEWS

Most of the functional services that key stakeholders envisaged being delivered through the one stop shop model are already provided by the Nottingham Positive Care Team (NPCT). The overall feeling was that a unified premises would help the team to cohere and work more collaboratively, and it would rationalise their management structure. Another central reason given was that this kind of centralised base for the team would increase service users' access to them. A number of individuals felt that the team might have offices located at the one stop shop as well as at City Hospital. One person did point out that rationalisation of the team's dispersed physical and management structure did not necessarily require a one stop shop, as the entire team could be permanently based at City Hospital instead.

Other key stakeholders discussed a range of new functions that could be incorporated into service delivery within this model. A number of individuals felt that the capacity for group-work (both educational and peer support) would be increased in such a premises. Some suggestions for this included: treatment adherence workshops, newly diagnosed groups, carers' groups, women's groups and nutritional workshops.

There were diverging opinions expressed among key stakeholders as to whether some or any HIV clinical services should be based at such a location. While some felt that blood samples taken for routine testing and basic prescribing could be conducted by clinical staff at the one stop shop (*ie.* one afternoon a week), others were concerned about the extent of 'medicalisation' that this could introduce. Some (n=3) were adamant that no clinical services of any kind should be delivered in this setting, either because of a lack of investigative equipment, gender sensitivity, or concerns regarding clinical / community possession of the space.

Most of the key stakeholders who considered the structural aspects of such a model advocated voluntary sector management of the scheme. A small number envisaged that within a year or two, the voluntary sector would commission statutory and other services to be provided at the location with at least one full-time paid voluntary sector employee. However, others raised significant concerns about the capacity of the existing voluntary sector in Nottingham to run such a project. Some approached this by regarding the one stop shop as a place that would help to foster Nottingham's voluntary sector, thereby recognising the existing capacity limitations. Those who took this view envisaged a premises that was initially managed and operated by statutory sector providers, with a view to eventual 'handover' to the voluntary sector. This was regarded as a means of developing a strong partnership model of working, while providing much needed support and assistance to Tagadere as it develops over time. It was also suggested that this model would redress the current imbalance of voluntary/statutory provision for people with HIV in Nottingham, and that ultimately an increasingly involved voluntary sector would help statutory staff to see more clients and carry out more of the professional tasks for which they are paid.

Some did query the financial viability of such a model, given their acute awareness of retreating Primary Care Trust and Social Services funding. Others who considered the financial implications of such a model felt that appropriate allocation of funds from the AIDS Support Grant would make significant contributions toward its economic viability.

About half of the key stakeholders expressed some concern about whether some client groups with HIV would be reluctant to access a one stop shop because of concerns about confidentiality and privacy. For instance, while the appointments system at the clinic allowed African people with HIV to avoid bumping into acquaintances, similar provisions could not be made in a one stop shop. Therefore many wondered if those with concerns about disclosure would ever consider going. Others mused about whether all people with HIV were keen to

have such a service, or if the idea was being advanced by a small but vocal minority. This calls the notion of 'accessibility' into question, as the availability of a centre which is open throughout the week, as well as weekends and evenings is not *actually* accessible if barriers to its use - such as stigma and loss of confidentiality - are unrecognised.

4.2 CURRENT SERVICE USE

Most of the respondents that depended on the Positive Care Team for social care and support found their approach and dedication impressive. A number said they did not know how they would have managed up until now if they did not have the care, advice and understanding that had been provided by those on the team. At least half of those interviewed reported that they tended to access the NPCT by attending the drop-in as a means of keeping in contact with relevant staff members. However, as outlined in section 4.3.1, significant concerns were raised among these service users about the context and content of drop-in service provision.

One third of all respondents with HIV (n=7) did not use the drop-in, yet most of these described having access to NPCT staff via other means such as the telephone, at the out-patients clinics or home visits. It was clear that those who did not access the drop-in were much less likely to have a broader understanding of the roles of the whole Positive Care Team and what help might be provided to them, particularly in terms of accessing benefits, or sorting out minor problems at home. In some cases, such respondents might have some contact with one staff member, but be unaware of how other team staff members might also be able to provide support. Migrant respondents were much less likely than UK-born respondents to access the drop-in regularly because they were not sure how it might benefit them, they had confidentiality concerns, or they were unsure that they would feel comfortable there.

Those who mentioned the **Hardship Fund** tended to talk about it solely within the context of the drop-in and the Positive Care Team. This makes a certain degree of sense, as the Fund's stated policy is to make grants 'through accredited professionals rather than in response to direct requests from applicants'. Those who accessed periodic or ongoing payments from the Hardship Fund spoke of the central role it played in their survival and comfort (from helping to provide one-off payments towards white goods or furniture to weekly subsistence payments of £20 for those who were destitute). A small number of respondents expressed concern about a lack of transparency relating to grant-making policy within the Fund. Some of the migrant respondents experiencing pervasive material and housing support need (including periods of homelessness, hunger and inability to pay for public transportation) did not express any awareness of the Hardship Fund, and in the main, did not access the drop-in or have strong relationships with the Positive Care Team as a whole.

All respondents used the City Hospital's out-patients Genito-Urinary Medicine (GUM) clinic or the Infectious Diseases Unit for HIV monitoring and associated health care. None reported a problematic relationship to their chosen out-patients service and many were very complimentary about the services received there.

Very few respondents accessed other HIV social care services at the time of interview, but where that did occur, it involved travelling to other cities and paying for travel and service fees. Some respondents mentioned being aware of the statutory and voluntary HIV services in other cities and towns, mainly because they used them before moving to Nottingham. In every case where such services were mentioned, they were regarded as highly superior (in terms of scope and facilities) to those available in Nottingham.

Because there's no set up in Nottingham. There's nobody there to... there's no... in London and other places they do like meals. They bring you a meal round.

Yeah.

I don't know what I'd do.

Yeah.

But it's non-existent. The services are non-existent. So I don't really know... I'd probably be sat in the house 24 hours a day by myself.

Yeah.

I don't know what... I really physically don't know what I'd do. I've said to [partner's name] many a time, I said if I hadn't got you and I was a bit further down the line, I don't know what I'd do. There's no phone numbers to call. They don't work at weekends. So if you go down ill at weekend I really don't know what you're supposed to do. It must be awful to be a single positive man.

4.3 SHORTCOMINGS OF CURRENT SERVICE PROVISION

4.3.1 Wednesday drop-in

The weekly HIV drop-in service is coordinated by the Positive Care Team. It is currently located in a church in a busy student area. This raised a number of concerns for respondents who were familiar with the service. The almost universal complaint was that the facilities were inadequate - mainly that there was a lack of comfortable, warm, multi-use and private spaces. Many also mentioned that the church location made them feel unwelcome, an issue that was particularly acute when they were aware that church staff were in the building at the same time. Some mentioned that because it was in a busy district near the university, that they could never evade being seen entering, and would prefer a quieter location.

And I thought well I don't want my business being bantered about. But eventually I came in [to the drop-in] and also walking through the doors here is an admittance to yourself.

Yeah.

And who the hell am I going to see walking through them doors.

Yeah.

I cringed. I still do when I see people I've known... [but] I've been thankful that this place... I've found this place. It's been the one day out of the week where I refuse to be a miserable old bugger.

A number of those who saw problems with the current Wednesday drop-in provision felt that far too much of the focus on went into the preparation and serving of the meal. Some felt that this detracted from their ability to talk privately to Positive Care Team staff. In addition, it was argued that this focus on the meal excluded consideration of other possible activities from which attendees could benefit, such as: games, presentations from clinical or holistic health experts, welfare rights and benefits surgeries, arts and crafts events *etc.* As such, there was considerable feeling that within the existing context of the weekly drop-in there should be more activities that helped attendees to socialise freely, gain useful information and learn new skills. Those who took this view (n=8 out of 13 who accessed the drop-in) felt that attendance at the drop-in was low and that there was little social mixing because in its current configuration it offered very little to 'do'. While therapeutic treatments such as massage and Reiki had been made available at a previous drop-in location, the rooms at the current facility were regarded as inappropriate and too cold to be used in this way.

Among the one third of respondents (n=7) that did not access the drop in, the most common reasons given related to concerns about privacy and stigma. It was not the case that these individuals were not in need, but that the risks associated with accessing the service outweighed the potential benefits.

4.3.2 Positive Care Team structure

Respondents who had regular contact with the NPCT felt that staff members on the team should be located in one accessible place. Some suggested that this should be City Hospital and others envisaged this reorganisation within the concept of the one stop shop (see below). The physical fragmentation of the Team, and the impression of impermanence (reflected by difficulty with telephone access at one point, and changes in telephone contact numbers) contributed to a sense that they were difficult to access. A number of respondents mentioned that they felt that the Positive Care Team were over-stretched, and that greater funding of the Team would help to alleviate the strain and allow the staff to get on with what they already do well.

A small number of respondents mentioned that there was no provision for respite care. Others also said that they would like HIV service provision in Nottingham to include skills development, training and career guidance.

4.3.3 Tagadere

In the main, those aware of this self-help group were White British people who accessed the Wednesday drop-in on a regular basis. None of the respondents described themselves as currently participating in Tagadere. Those who had taken part in the past, or who were aware of its existence did not currently participate because it was not regarded as personally beneficial. Some felt their meetings in a pub were too expensive and lacked privacy (and proved problematic for those with a history of addiction). Others felt the overall approach was too overtly politicised, which was seen as getting in the way of improving service delivery.

4.4 ONE STOP SHOP

4.3.1 What could it offer?

Most respondents considered that the major benefit of such a facility would be that it could provide reliable access to members of the Positive Care Team. Any one stop shop was regarded as mostly if not wholly populated by statutory sector workers. Quite distinct from the views expressed by the key stakeholders, none of the respondents automatically considered that such a service would be provided or managed by the voluntary sector. However, three respondents did mention that they could envisage themselves volunteering in such a setting, in order to 'give back'. Very few of the non-UK born respondents had considered this kind of HIV service provision prior to the research interview, and as a result, some found it difficult to configure detailed answers about such a new concept, particularly in relation to how it could benefit them personally.

The most common ideas about what such a place might provide were:

- A kitchen / canteen / food bank that would provide affordable and nutritious food to those who need it.
- Comfortable seating areas with access to tea and coffee-making facilities.
- Appropriate and private rooms to meet with Positive Care Team staff, and to receive counselling or complementary therapies.
- An accessible space to socialise with others with diagnosed HIV (that is, not just on Wednesdays and not in a church).
- Activities such as table tennis, sport, gym equipment and games to encourage interaction and stimulate attendees.

Other, less common ideas included:

- Employment training and skills development and advice (this issue arose frequently as an overarching need among respondents, but not always within the context of discussing the one stop shop model of service delivery).

- Access to computers and the internet.
- A garden or courtyard area.
- Arts, crafts and music workshops.
- Access to literature and information on HIV and other reading materials.
- Access to clinical services / blood testing / prescription collection point.
- A television.

4.3.2 Extent of support for the one stop shop proposal

A third (n=7) of respondents felt that going to a centralised premises dedicated to HIV service provision was not how they would choose to access social care and ongoing support, and in the main these were the same individuals who did not access the weekly drop-in service. Most of these felt that attendance would publicly identify them as having diagnosed HIV. They argued that Nottingham was too small a place to allow for any anonymity, and the possibility of being recognised was simply too great (either by other passers by, or by another service user). As such, their concerns about the drop-in were raised again within the context of questions about the proposed one stop shop.

[The drop-in] ... it's very exposed. There's a lot of people walking around there. And it's a small town and you can get noticed. And you know and as I say it's a small town.

There's quite a lot of concern about gossip and that being in a small town, if word gets out?

I mean it's all about discretion at the end of the day. And the place isn't discrete at all. There are a lot of people who just won't go there.

Yeah.

There are a hell of a lot of people who just won't go there.

And do you think that's mainly about their concerns about privacy? It's just too open or is it about they don't need or want what's on offer there?

They don't need or want enough what's on offer there.

Yeah.

They'd rather... there's no real need to go when they can get what they need when they visit the clinic or at the end of a phone call.

Four respondents discussed the problems that they saw with the one stop shop model from the perspective of other service users, although they would consider using such a facility themselves. Those who took this approach considered the potential stigma that such a place could draw, and also wondered how those with diverse cultural and sexual identities and experiences could all be served by placing all of the social care services in such a setting. So one of the rhetorical questions raised queried the assumption that people with HIV would want to spend so much time together given that they were likely to have divergent backgrounds and interests. Two people also wondered if the full time running of such a location was the best use of scarce resources, given that it would be unlikely to operate at full capacity at any given time.

This is why I have a problem with this drop-in new one. Is how are they going to attract all these disparate groups of people and get them to come back again and again. So the use is made up, the property, the building or whatever.

There were also those who expressed support for a one stop shop but made it very clear that it should not be publicly identified as an HIV service. Therefore it was suggested that location, branding and signage should be discreet and should aim to protect the privacy of service users.

Taken together, about two thirds of those participating in this research (n=13) expressed varying degrees of concern about the one stop shop model of HIV service delivery in Nottingham. There was no strong demographic pattern that emerged among those taking this

view; those raising concerns were just as likely to be heterosexual or Gay, UK-born or a migrant. However, four of the six women taking part did raise some concern about the idea. The acceptability of such a model was brought into serious question by these respondents who stated that the threat of public exposure as an HIV positive person would present a significant barrier to accessing such a setting. Many felt that its identification as a place for people living with HIV would be inevitable, regardless of its title.

But after so long there would be bricks going through windows... You know people being assaulted on the street when they find out what it is. And I think you do have to think about people's privacy and their own well-being. You know. I mean, Nottingham's not a clever place at the best of times.

Ten people expressed support for the idea of a one stop shop for people living with HIV, though some of these also raised some low-level concerns about signage and barriers to access for others. These respondents were much more likely to fully describe the functions that such a place could serve. Frequent mention was made of comparable facilities for people living with HIV in other towns and cities. From the perspective of these respondents the venue would be a means to resolve the shortcomings of the current drop-in setting. It could allow for increased and more private access to Positive Care Team staff, and could be regarded as a base for expanded social functions including activities, sports and making new friends. Some felt that such a venue may help to attract those from more diverse backgrounds than the majority of UK-born (and frequently Gay) men who populated the drop-in, because particular events or sessions could be arranged for cultural groups. Those with a high degree of social and material need felt that such a centre could be a place where they would spend much of their time, in the company of caring and understanding people. Several people argued that if such a centre provided increased social and health care for people living with HIV (including the provision of subsidised complimentary therapies) that it would be cost-effective because of the health benefits that it would deliver to this population.

5. Conclusion and recommendations

The people with HIV in Nottingham who took part in this study described a range of housing and housing support needs that they have had met in the past and that continue to be met by family members, friends, partners and statutory service providers especially the Nottingham Positive Care Team. However, there remains considerable unmet housing-related support need.

The provision of social care to people with HIV in Nottingham City and surrounds has been in a constant state of review for more than a year. Included have been reviews of the management and responsibilities of the Nottingham Positive Care Team and reviews of specialist Welfare Rights provision to people with HIV, AIDS Support Grant spending and investment from the local PCTs. The information provided here should strengthen the evidence base for decisions that can be made through each of these processes. In addition, this research demonstrates that the extent of housing-related need among people with HIV in Nottingham across different housing tenures is sufficient for Supporting People to consider commissioning a floating support service that is specific to this client group.

First we will review the most common unmet needs that this research highlights, and then we will move on to make specific recommendations in light of these findings.

5.1 UNMET HOUSING NEEDS

The most prevalent ongoing housing-related needs among this client group can be considered in three broad categories: *informational* need, *financial* need and *accommodation* need. Some of these needs are more acute among migrants with HIV in Nottingham (particularly those who are destitute). However, housing support need was apparent across all different tenure-types, ethnicities and migration status'.

Many respondents were clearly unaware of the different HIV specific and generic social services that were available to them. Those who were not regular attendees at the drop-in were unlikely to know the variety of support on offer within the Nottingham Positive Care Team. Some who were in need of emergency subsistence grants or access to food and clothing banks were similarly unaware of these resources. These types of information gaps were usually apparent when individuals had little substantive contact with the NPCT. Some were too embarrassed to ask for help, while others had concerns that their needs were not significant enough to bother busy professionals. Therefore, many respondents in **information need** were unaware of the extent to which their own situation might be improved with assistance.

Where **financial needs** were highlighted, their extent was usually significant. We found that most White British respondents had achieved a consistent degree of financial stability through good management of benefits, including Disability Living Allowance, Incapacity Benefit, Income Support and Housing and Council Tax benefit and in fewer cases, Direct Payments. However, a significant proportion of non-UK born respondents (including those with rights to access public funds) reported money problems. Some described their struggle to maintain demanding jobs in the face of their own deteriorating health. Advice about alternatives to physically demanding work, and supporting people to make HIV disclosures to employers and managers are important needs in this area. There is clearly a need to better inform a broader spectrum of people with HIV about accessing expert welfare advice, while also increasing support with form-filling, making telephone contact, organising letters of support and other documentation and following up on applications. For people with HIV facing acute poverty and destitution, there is a need to be better informed of potential charities that will help, including

the Hardship Fund, the Refugee Forum's Destitution and Emergency Grants Funds, and other voluntary sector support services at local and national level. Some described going hungry, failing health and homelessness as an outcome of their extreme circumstances. Unmet financial needs (ranging from the troublesome to the severe) tended to be most common among those who did not regularly access the drop-in service.

There were also a broad range of **housing-support needs** expressed by those taking part in this study, and once again, this was not confined to a specific type of housing tenure. Individuals in the asylum system had the least amount of housing security in the sample, feeling that they were at the whim of NASS for housing placement and possible dispersal. The problem of confidentiality was also compromised where people with HIV were placed in shared housing. There have been some developments in negotiation between NASS and national HIV organisations that should soon result in priorities for people with HIV such as: establishing whether or not a personal refrigerator is required and ensuring that dispersal does not interrupt continuity and quality of HIV care. These developments need to be monitored and implemented at local level.

Among those renting from public and private landlords, some continued to experience severe problems with cold and damp. Others wanted to move to safer and quieter areas. Some of these individuals were unaware that they may be able to get help finding a better place to live. In some instances, noise and disruption was keeping respondents awake at night and causing stress, but individuals saw no way of improving the situation. In other instances, minor improvements and modifications would make the home safer (with the installation of bathroom modifications and safety rails), and warmer (with weatherstripping, double glazing and loft insulation). Again, respondents were often unaware that assistance could be given to help them address some of these issues.

Independent living was another key area of accommodation need that was identified. Many respondents described chronic depression, for which some were receiving therapeutic support. However, a number were not accessing any help, and others said that they would benefit from access to emergency counselling in times of crisis. Social isolation was pervasive for respondents who lived on their own, and buying and preparing nutritious food, paying bills and maintaining the home became difficult during emotional and psychological low points.

5.2 UNMET PROVIDERS' NEEDS

Interviews with key informants and people living with HIV helped us to identify a number of unmet needs among those who provide housing-related services to people with HIV in Nottingham. Generic service providers demonstrate a lack of awareness about HIV and how it impacts on people's lives, or the available services for people with HIV in the city. Given the extent of unmet housing need outlined above, there appears to be a lack of resource capacity within the NPCT to routinely assess the housing situation of people with HIV, particularly those who do not access the drop-in regularly. NPCT staff and others who provide health and social services to people with HIV in Nottingham require training to better identify and signpost welfare advice and immigration needs affecting people with HIV in the city.

Referral pathways between the NPCT and other agencies would benefit from review and formalisation, and an obvious starting point for this process is to establish procedures for communications with, and referrals to, the generic wide-access team at the Welfare Rights Service. The recently re-structured non-specialist team providing Welfare Rights Advice for social services staff and service users would substantially benefit from HIV-related training.

5.3 RECOMMENDATIONS

1. People with HIV in Nottingham City would gain substantial benefit from the provision of a specialist floating support service funded by Supporting People. Many of the informational, financial and housing needs described here could be successfully addressed by an appropriate service utilising qualified and experienced staff with particular awareness of HIV infection (*ie.* HIV treatment issues, and concerns about confidentiality, HIV stigma and social marginalisation).

In order to be maximally useful a specialist floating support service would need:

- 1.1 A close working relationship with the NPCT and the Welfare Rights Service including protocols for referral and case-management.
- 1.2 Experience of working with migrants and Black and minority ethnic community members who find services less accessible.
- 1.3 Capacity for home-based service provision - for those most in need who do not attend the current NPCT drop-in.
- 1.4 Ongoing assessment and re-assessment of housing support needs for clients with HIV. Housing circumstances change rapidly, especially among migrants, and individuals' capacity to identify their own needs and access appropriate services relies upon them knowing all the services that are available and having the confidence to access them (especially in times of crisis).
- 1.5 Better cross-agency case management of housing transitions that aspires to provide more appropriate initial placements into public sector housing.
- 1.6 To help clients with access to Disability Living Allowance and Direct Payments to manage these funds to pay for cleaning, food shopping and meal preparation.

The following list (taken from Section 1.1) offers guidance to those commissioning a service that will best address housing-related support need among people with HIV in Nottingham. A targeted floating support service should include (but not be limited to):

- immediate crisis intervention where specific problems pose an immediate risk to sustaining tenancy, including responding to eviction notices, financial arrears, health, safety and security (including harassment from neighbours);
 - finding appropriate housing where disclosure of HIV status can be managed successfully;
 - support in taking up new tenancies including application processes, locating appropriate furniture and equipment and establishing utilities, rental and tenancy arrangements;
 - access to expert welfare rights advice;
 - access to nutritional advice and support to eat well (particularly during times of crisis);
 - access to primary care and specialist HIV health and social care;
 - access to information, community resources and social interaction;
 - access to ethnic and cultural community involvement;
 - access to education, training and employment opportunities;
 - access to mental health and addiction support services where required.
2. NPCT and any proposed HIV floating support service will require close liaison to monitor periods of crisis among clients, in order to develop a personalised package of support during periods of transition and during periods of physical and psychological ill health.
 3. NPCT and / or the proposed HIV floating support service should consider developing a shared housing 'match list' for individuals looking to share a private rental with another person with HIV. This idea could be raised within

the client group to see if it would be feasible, and then a pilot scheme could be launched. Proper consideration would need to be given to confidentiality concerns that may arise.

4. Housing support assessments of people with HIV in shared housing should closely examine how the individual manages HIV disclosure in the home setting, and the impact this has on treatment adherence and attendance at services. Plug-in cool bags or personal refrigerators should be routinely offered to those in shared accommodation whose medications require refrigeration. Changes to clinical treatment regimes will require routine re-assessment of such issues.
5. It seems people with HIV do not have access to a Home Improvement Agency (HIA) that can meet their needs in Nottingham City, unless they are 'older'. The Council should consider extending current HIA provision in Nottingham City to match the kinds of services provided to residents in other parts of the county by South Nottinghamshire Home Improvement Agency; Care and Repair CNHIA; and Newark and Sherwood Staying Put. If people with disabilities were to be included in Nottingham City's HIA provision then many people with diagnosed HIV would be eligible.
6. Many respondents and key stakeholders made it clear that the current drop-in service arrangements were inadequate. The location of the current church-based venue in a busy student area, with added concerns about the proximity of church staff made many people feel uncomfortable, unwelcome and personally exposed. In addition to a change of venue, respondents clearly vocalised their desire for increased value from this service. Recommendations included: less focus on the preparation of meals by NPCT staff, private consultations with staff during allotted 'surgery' hours, and education, activities and skills development components to encourage ongoing attendance. However, it is also important to point out that a third of respondents (2 UK-born, 4 African migrants and 1 migrant from elsewhere) did not access the drop-in service, and this was not because of lack of need. Barriers to access of services extend beyond limited opening hours and the immediate location of the current drop-in.
7. Due to the managerial and geographical fragmentation of the NPCT, a number of respondents commented that they found staff difficult to access. It is recommended that the current review of the NPCT advocates a unification of staff members at a single premises with accessible land-line phone numbers and identifiable contact hours. Innovative measures such as partnership with cultural and immigration support groups will also be required in order to clarify and promote the roles of the NPCT to those African migrants who are presently far less likely to benefit from their services.
8. Half of those participating in this research (n=10) did support the implementation of the one stop shop model. There is no evidence that the proposed one stop shop would substantially extend the range of people with HIV that routinely access the NPCT. Recommendations 6 and 7 include a number of innovations in existing service arrangements that do not necessitate the development of a one stop shop. As we have already highlighted, the considerable barriers to accessing services among different groups of people with HIV will not be overcome with the implementation of such a model. Centralising all services in such a setting would however, improve the efficiency of the NPCT and their accessibility to current service users. However, to provide any additional value, any future development will need to establish how the entire range of people with HIV would benefit from a one stop shop.

References

- Anderson WJ, Weatherburn P (2004) The needs of people with HIV in the UK: findings from a national survey. *International Journal of STDs & AIDS*, 15(12): 793-796.
www.sigmaresearch.org.uk/articles04a.html
- Brent Supporting People (2005) *Strategy for people with HIV and AIDS*. London, Brent Council. <http://tinyurl.com/82dbp>
- Creighton S, Sethi G, Edwards SG, Miller R (2004) Dispersal of HIV positive asylum seekers: national survey of UK healthcare providers. *British Medical Journal*, 329: 322-323.
- Dodds C, Keogh P, O Chime, 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/downloads/report04f.pdf
- Edinburgh Supporting People (2003) *Supporting People Strategic Plan (draft)*. Edinburgh, Edinburgh Council. <http://tinyurl.com/99l2z>
- EMCARS (2005a) *Emerging Communities Bulletin: June/July 05*. Melton Mowbray, EMCARS.
www.emrlga.gov.uk/services/EMCARSPublications.asp
- EMCARS (2005b) *Emerging Communities Bulletin: November 05*. Melton Mowbray, EMCARS.
www.emrlga.gov.uk/services/EMCARSPublications.asp
- Fortier E (2004) *Migration and HIV: improving lives*. London, All Party Parliamentary Group on AIDS. www.appg-aids.org.uk/publications.htm
- Gazzard B, Anderson J, Ainsworth J, Wood C (2005) *Treat with respect: HIV, public health and immigration*. London, Chelsea and Westminster Hospital, Homerton University Hospital NHS Foundation Trust, North Middlesex Hospital.
www.ukcoalition.org/migration/HIV-Treat_With_Respect1.pdf
- Griffiths S, James K, Curteis S, Best S (2005) *The housing and support needs of people living with HIV and/or Hepatitis C in Leeds*. Leeds, Leeds Supporting People.
<http://tinyurl.com/ch55k>
- N (FC) (Appellant) v. Secretary of State for the Home Department (Respondent) (2005) House of Lords, UKHL31. <http://tinyurl.com/breof>
- North Lanarkshire Council (2006) Web page on who is eligible to receive Supporting People services. <http://tinyurl.com/ar3c7>
- North Lanarkshire Supporting People (2003) *Supporting People in North Lanarkshire: North Lanarkshire Council Supporting People Plan 2003-2008*. Motherwell, North Lanarkshire Council. <http://tinyurl.com/credp>
- North Yorkshire Supporting People (2005) *North Yorkshire Supporting People five year strategy 2005-2010: individual client group strategy, people with HIV/AIDS*.
<http://tinyurl.com/cq2ef>

ODPM (2004) *What is Supporting People?* London, Office of the Deputy Prime Minister
www.spkweb.org.uk

ODPM (2005) *Creating sustainable communities: supporting independence, consultation on a strategy for the Supporting People programme.* London, Office of the Deputy Prime Minister
<http://www.spkweb.org.uk/Consultations/Supporting+People+Initial+Strategy.htm>

Oxfordshire County Council (2006) Web page on council services for asylum seekers.
<http://tinyurl.com/96n7e>

Oxfordshire Supporting People (2003) *Oxfordshire Supporting People Strategy 2004-2009.* Oxford, Oxfordshire County Council.
<http://tinyurl.com/7b54w>

Partnership Development Team (2005) *HIV/AIDS one stop shop.* Nottingham, British Red Cross.

Pollard, AJ, Savulescu J (2004) Eligibility of overseas visitors and people of uncertain residential status for NHS treatment. *British Medical Journal*, 329: 346-349.

Refugee Council (2004a) *Hungry and homeless: the impact of the withdrawal of state support on asylum seekers, refugee communities and the voluntary sector.* London, Refugee Council.
www.refugeecouncil.org.uk/downloads/rc_reports/hungry_homeless_apr04.pdf

Refugee Council (2004b) *Asylum seekers win back their rights to basic food and shelter.* Press Release. London, Refugee Council.
www.refugeecouncil.org.uk/news/2004/june04/relea171.htm

Weatherburn P, Anderson WJ, Reid D, Henderson L (2002) *What do you need? Findings from a national survey of people living with HIV.* London, Sigma Research.
www.sigmaresearch.org.uk/downloads/report02c.pdf

Weatherburn P, Ssanyu-Sseruma W, Hickson F, McLean S, Reid D (2003a) *Project Nasah: An investigation into the HIV treatment information and other needs of African people with HIV resident in England.* London, Sigma Research.
www.sigmaresearch.org.uk/downloads/report03a.pdf

Weatherburn P, Ssanyu-Sseruma W, Hickson F, McLean S, Reid D (2003b) *Project Nasah: briefing sheet 2.* London, Sigma Research.
www.sigmaresearch.org.uk/downloads/nasahbriefing.pdf

Wigan Supporting People (2005) *Wigan Supporting People strategy 2005-2010.* Wigan, Wigan Council. <http://tinyurl.com/hfp7k>

Wolverhampton Supporting People (2005) *Wolverhampton Supporting People strategy 2005-2010: Executive summary.* Wolverhampton, Wolverhampton Council.
<http://tinyurl.com/8xsi4>