

A national study of ageing and HIV (50 Plus)

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This report describes the needs, concerns and characteristics of people aged 50 and over who are living with HIV in the UK.

With modern treatment advances, people are living with HIV into old age and will increasingly need social and clinical support. With complex health problems, fewer financial resources and greater isolation than many of their peers, they face major challenges. The report covers:

- work, money and housing;
- physical and mental health challenges and uncertainties;
- social care and the need to integrate people with HIV into services for older people;
- sexual health and lifestyle issues which impact on their wider health;
- disclosure and discrimination within a range of healthcare, work and social settings.

The report focuses on people with HIV's own views of the future and includes recommendations for action to policy-makers, NHS and local authority bodies, charitable funders and HIV and age-related organisations.

Contents

List of figures and tables	4
Executive summary	5
Introduction	8
1 Health and social care	17
2 Work, money and housing	28
3 Relationships, social well-being and seeking help	36
4 Disclosure, stigma and social support	41
5 Recommendations	51
Glossary	54
References and Further reading	55
Appendix I: Findings from the US research visit	58
Appendix II: About the respondents	62
Acknowledgements and About the authors	65

List of figures and tables

Figures

1	Year of diagnosis	17
2	Are you currently taking any medication for any non-HIV-related conditions?	18
3	Number of sexual partners in past twelve months	19
4	Satisfaction with sex life	20
5	Other major or long-term illnesses	21
6	Do you have any concerns with growing older with HIV and developing mental issues/depression?	23
7	How would you rate your emotional or psychological health?	24
8	Do you consider yourself as having a disability?	25
9	What support will you need in the future – counselling/emotional support?	26
10	Economically active	28
11	Gross income before deductions	29
12	Do you have enough money to cover your basic needs?	30
13	Largest source of income	31
14	Understanding of state benefits and entitlements	32
15	Process chart on HIV, age, money, health and work	34
16	Living arrangements	36
17	Do you currently do any voluntary work?	37
18	If you needed advice from an organisation, which would you prefer to get it from?	39
19	How has your relationship changed as a result of telling your husband/wife/partner your HIV status?	43
20	How has your relationship changed as a result of telling your GP your HIV status?	45
21	In the past twelve months have you been treated unfairly because of your age or HIV status?	46
22	Pension age	62

Tables

1	Qualitative samples	10
2	Do you have any concerns with growing older with HIV and ...?	10
3	Support and information needs in the future	11
4	Current housing status	35
5	Experiences of discrimination because of age or HIV status	47
6	Country of birth	63
7	Strategic Health Authority location	64

Executive summary

This report contains the views and concerns of people with HIV aged 50 and over, living into an old age that many of them never expected to see. The social care needs of this rapidly growing group have not previously been addressed in the UK. The 50 Plus research project asked 410 of them – 1 in 25 of all those currently being seen for care – for their views on their current and future lives.

The report also analysed the resulting data to compare three of the largest subgroups: gay/bisexual men, black African women and white heterosexuals. Gay/bisexual men were by far the largest community of need within this population; black African women had a series of complex challenges, which often differed from other populations; and white heterosexuals, while often neglected in HIV studies, were particularly well represented in this age group. While these groups had much in common, they also had significant differences. Caution should be used with some comparisons because of the relatively low numbers in some sample groups, but the data provides indicators for future direction of work.

Physical health

While the vast majority of people were receiving HIV treatment at the time of the study, over half of them reported side effects. Just under two thirds were on treatment for other long-term conditions and we found that the number of these conditions was almost double what we would expect within the general population at this age. Despite the fact that most people were registered with a GP, there were fears and experiences of poor treatment in primary and generalist healthcare settings. This indicates the need to improve the quality of primary care for people with HIV and for better interaction between HIV specialists and other clinicians. Personalised healthcare budgets could possibly work to improve the system if people begin to choose their care from HIV and LGBT (lesbian, gay, bisexual and transgender) friendly clinicians. Black African women and other migrants in particular reported difficulties in accessing healthcare and need to know their rights.

The single most common future need expressed was for good quality treatment and health information, indicating the high levels of clinical uncertainty and threats to health facing this group. Many of the co-morbidities reported were ones which could be mitigated by lifestyle interventions such as good nutrition, exercise and smoking cessation. Easy to understand and targeted information about treatment and health needs to be developed, along with interventions which maximise healthy choices.

Older people with HIV report varying levels of sexual activity, with gay/bisexual men most likely to have multiple partners. HIV testing and sexual health promotion services should take this into account when planning initiatives and should explicitly consider the needs of older adults who are sexually active.

Mental health

This group also reported substantial levels of depression and mental health concerns and a higher level of concern for future mental health. Counselling, emotional support and other strategies need to be developed to improve emotional well-being in older people with HIV, particularly black African women.

Social care

Three quarters of the respondents were concerned about future access to social care such as home help. Given that half of them already report mobility problems and almost half have difficulties with everyday activities, this is unsurprising. Again, many people expressed anxiety about needing to use home care or residential care because of perceived, and sometimes experienced, prejudice and ignorance about HIV within these services. Providers of social care services to older people need to train their staff and define good practice in management of clients with HIV, while funders should ensure this is included amongst quality measures. Personalised care budgets could, again, drive change if older people used their purchasing power to choose HIV and gay-friendly providers.

Money and work

People with HIV aged 50 and over were, in comparison with their peers, less likely to be economically active and far less likely to have a financial cushion for their old age. Almost half sometimes or never had enough money to manage on and they expressed serious fears about how they would manage financially in the future.

While around a third were working, almost as many were reliant on state benefits. Half of those surveyed were not confident that they understood their entitlement to benefits. Black African women were financially the worst off within this group. People with HIV aged 50 and over need support to stay in or re-enter the workplace where possible, including access to good, clear advice on benefit entitlements and to debt counselling and financial planning as part of long-term condition management.

Housing

Home ownership was lower in this group than among their peers, and they were more likely to be in council or housing association stock or in private rented accommodation. There was widespread concern about the possible future need to go into a care home or sheltered housing, as these settings were perceived to be unlikely to be supportive to people with HIV. Additionally, gay/bisexual men feared homophobia within these settings. HIV organisations need to work with providers of social housing and care homes for older people to help them audit and improve their policy and practice around HIV and LGBT issues.

Social well-being and seeking support

Many people reported social isolation and a need for greater social contact, including general social support. This is currently more likely to be met in services for older people than those for HIV. Again, however, the perception from many was that mainstream organisations for older people may not understand HIV. HIV services and those for older people need to work together to dispel this. Volunteering opportunities for older people with HIV should be maximised in order to increase social involvement and also contribute to making services more representative of, and appropriate to, older adults with HIV.

Disclosure and discrimination

The greatest surprise within the findings was the high levels of disclosure of HIV status within a wide range of settings and the overwhelmingly positive or neutral outcomes reported from this. This differs considerably from accepted narratives within the HIV sector, which often posit disclosure as a negative and dangerous action and this deserves greater scrutiny. This finding was not uniform within all groups and settings, however, and those outcomes which were negative could have important consequences. There is a need for services to constructively support older people with HIV in making informed decisions

about disclosure. Further research into the impact of disclosure should also be undertaken with a balanced sample of people with HIV across all age groups.

One in five people did report experiencing discrimination in a variety of ways in the past year, either because of age or HIV status. Overall, people were as likely to report age discrimination as HIV discrimination, but in two areas – healthcare and provision of goods and services – HIV discrimination was far more prevalent. Problematic relationships with primary and non-specialist healthcare are a common theme throughout HIV research. It is thus clear that governmental and NHS bodies need to show greater leadership in challenging HIV stigma. A good example of this is the recent Welsh Assembly inquiry into HIV discrimination by healthcare professionals.

Lessons learned

A number of other good practice examples were identified, including four projects from the US, which are outlined in Appendix I. There were clear lessons, including the importance of HIV and ageing experts, both clinical and policy, working together to improve services to older people with HIV and to challenge age and HIV discrimination in their respective areas. Although many individual respondents reported good service from particular agencies in both sectors, and in general respondents preferred to ask for support from HIV agencies, no service was widely identified as being suitable for older people with HIV.

Finally, in terms of the specific populations examined within the report, it is clear that, while much about HIV and ageing binds them together, each group showed strong and specific characteristics. Gay/bisexual men had immense fears for the future around how care services would cope with gay men, let alone gay men with HIV, and they also faced an ageist gay culture. Black African women had by far the hardest time overall, coping with poverty, poor housing, treatment access and migration issues as well as major HIV stigma within their cultures. White heterosexuals reported considerable isolation, financial concerns and a sense that existing services did not prioritise them.

The findings and recommendations contained in this report are far from the last word on HIV, ageing and social issues in the UK. Rather, they should be seen as the start of a dialogue between older people with HIV, the organisations and services that seek to support them and the policy-makers and funders who make that possible. Older people with HIV face an uncertain future in many ways; the knowledge generated by this report enables us to change for the better how our society supports them in that challenge.

Why this is important

HIV, first encountered in the early 1980s, has been an arena of constant change. Initially a terrifying mystery condition which rapidly killed, it has been transformed by scientific and community efforts into a chronic condition which continues to be debilitating and life threatening but which, if diagnosed and treated in a timely fashion, can be managed into old age.

As is often the case, science and medicine have outstripped public understanding and social care. Much public and media perception lags behind, continuing to characterise HIV as a 'killer disease' and to feed the widespread stigma associated with HIV. But in the UK, with good quality treatment, someone diagnosed now in their mid-30s (as is most common) can hope to live, on average, into their 70s; not a full lifespan, but equal to or better than that dictated by many other chronic, long-term, life-threatening conditions. We can now keep most people with HIV alive into old age – but what is the quality of life they will face?

The genesis of this project came in 2008 when the Department for Work and Pensions reviewed the Special Rules Benefits on which many people with HIV diagnosed before 2000 had historically depended. Initially assessed as likely to die soon, many people with HIV had been advised to leave work, cash in pensions, dump their mortgages and live as well as possible for the time they had left. Now, many were facing the reality of surviving to old age without hope of returning to employment, on reduced benefits and, eventually, a basic state pension.

Alongside this it became clear from Health Protection Agency (HPA) data (2008) that a 'greying of the epidemic' was taking place. By 2008 almost one person in six being seen for HIV care in the UK (10,286 out of 61,213, or 16.8%) was aged 50 or over. This figure is projected to double over the next five years as more people live longer and others continue to be diagnosed later in life. Evidence is also emerging that the ageing process is often hastened in people living long term with HIV, whether through complex side effects, through HIV interacting with the diseases of age, or through the ongoing impact of HIV disease on the body.

Terrence Higgins Trust (THT) and Age UK (formerly Age Concern and Help the Aged) identified that, while the clinical needs of older people with HIV in the UK were being researched, little was being done on the social impact of ageing with HIV comparable to that being undertaken in the US by ACRIA (the AIDS Community Research Initiative of America). THT and Age UK received support from the Joseph Rowntree Foundation (JRF) to survey the needs and concerns of people with HIV aged 50 and over, concentrating on social care needs within a wider context. The survey and qualitative interviews were undertaken with MBARC, who employed peer researchers. The project was called 50 Plus.

Since the start of the research, the UK's economic situation has deteriorated and in 2010–11 we face substantial reductions in levels of service in social care and possibly in healthcare too. In the light of this and numerous competing social priorities, it is more important than ever to have a good evidence base for any claims to service provision. Where possible, we have tried to make recommendations that are achievable and sustainable within this wider picture.

Outline methodology

We started the project with a review of the limited existing literature. A Community Advisory Committee was recruited, composed of older people with HIV, community leaders, researchers and clinicians, to advise on the questionnaire and the implications of the findings. In recognition of the fact that most of the existing work on this issue, including some service development, has been undertaken in the US, a brief research trip was included to two US locations, New York and Fort Lauderdale, where significant populations of older people with HIV were known to exist.

Building upon these, a survey was developed. The printed version was distributed via THT, Age UK, Advisory Committee members and a range of voluntary and community organisations. In addition, an online Survey Monkey version was made available through the THT website and in links within emails which 'went viral' within various HIV, gay and African community networks. The majority of respondents were recruited through THT, NAM's HIV Treatment Update and publicity in the gay and HIV media. Completion of the survey was incentivised with a prize draw. A small number of targeted 'survey completion parties' were held to encourage participation by African women.

With fieldwork undertaken by MBARC, in total, more than 500 surveys were started and this analysis is based upon 410 completed surveys (see below). The survey was analysed with SPSS (Statistical Package for the Social Sciences). Survey respondents were invited to participate in individual qualitative interviews. More than 40 interviews were completed, though for the purposes of analysis a balanced group of 40 was selected. A team of community researchers undertook all interviews, which were taped, transcribed verbatim and analysed with NVivo 8 software.

Further data, including all tables and the literature review, is available at www.tht.org.uk/50Plus

In line with the Greater Involvement of People with AIDS/HIV (GIPA) principle (UNAIDS, 2007), all community researchers were people living with HIV, as were over half the invitees to the Advisory Committee. THT staff living with HIV were also involved.

About the sample

More than 500 people participated in the survey. A total of 66 were excluded as they did not complete the questionnaire, as were 11 who did not give their ages. Those living outside the UK and/or those who were not HIV positive, as well as 6 duplicate responses, were also excluded. The statistical analysis is thus based on a final sample of 410 people aged 49+ (3 respondents were included who were due to turn 50 shortly), all with diagnosed HIV and living in the UK. The oldest respondent was 78.

The Survey of Prevalent HIV Infections Diagnosed (SOPHID) from the HPA (2008) indicates that there are 10,286 people over 50 living with diagnosed HIV in the UK. The response rate to this survey is therefore equivalent to 4% of the target population.

Survey responses are largely representative of this population in terms of gender, ethnicity and sexuality. For example, 19.3% of those over 50 with diagnosed HIV are women, compared to 19.8% of this sample. Similarly, according to SOPHID, 44% live in London and for respondents to this survey the figure was 46%. African men were, however, under-represented in the quantitative survey and we would urge further similar research into this group of older people with HIV.

Interviewees for the qualitative research were selected to provide a reasonable reflection of the range of experiences of different groups (see Table 1). A disproportionately large number of African men were included to compensate for the under-representation of this group within the quantitative analysis.

Following discussion within the Community Advisory Committee, the analysis in this report focuses upon the two groups most at risk of HIV in the UK: gay/bisexual men from all ethnic groups and black African women. In addition, we have disaggregated findings for white heterosexuals from the total, on the basis that this group was well represented in survey returns, well balanced between the sexes and often overlooked in the development of services for people with HIV.

Table 1: Qualitative sample (interviewees)

Population group	Total
Gay/Bisexual men	20
Black African women	11
White heterosexuals (male and female)	4
Black African men (heterosexual and gay/bisexual)	5
Total	40

Figures shown refer to numbers not percentages

It should be noted that the research uncovered a wealth of data that has not been included in this report and it is anticipated that this will be further explored by THT and Age UK in the future.

Key concerns and needs

Two key areas of enquiry lie at the heart of the 50 Plus research: what concerns people had about growing older with HIV, and what help they felt they wanted in addressing these concerns. The areas we asked people to rank were based on observation of the US experience, findings of the literature review and discussion within the Community Advisory Committee. The answers are examined in greater depth in the chapters which follow, but essentially they are contained in the two tables below.

Table 2 shows the ranking order of concerns, taken as the percentage of each key group who viewed an issue as very or somewhat important, followed by the rankings given by the overall sample.

Table 2: Do you have any concerns with growing older with HIV and ...?

Gay/Bisexual men	%		White heterosexuals	%
Difficulties with self-care	83.3		Financial difficulties	90.0
Mental health/depression	79.4		Inability to get healthcare	72.0
Financial difficulties	78.0		Mental health/depression	68.0
Inability to get healthcare	76.0		Loneliness	68.0
Social stigma/discrimination	67.9		Difficulties with self-care	66.0
Loneliness	61.7		Social stigma/discrimination	62.0
Employment	56.1		Employment	56.0
Finding a partner	44.9		Finding a partner	42.0
Black African women	%		Total (N=410)	%
Financial difficulties	72.2		Financial difficulties	79.0
Employment	72.2		Difficulties with self-care	76.3
Difficulties with self-care	58.3		Mental health/depression	72.9
Social stigma/discrimination	52.7		Inability to get healthcare	69.5
Inability to get healthcare	44.4		Social stigma/discrimination	66.3
Mental health/depression	44.4		Loneliness	61.0
Loneliness	47.2		Employment	57.6
Finding a partner	38.9		Finding a partner	43.2

Financial difficulties were the most prevalent concern, although gay/bisexual men ranked them lower than difficulties with self-care and mental health. From their comments, the self-care issue for gay/bisexual men appears to be particularly important due to the perceived homophobia in current care services. Interestingly, finding a partner was the lowest priority for all groups, though even that was still a priority for almost half the sample. Employment was a notably higher concern for black African women than the other subgroups and mental health a lower one.

We then asked respondents to tell us what support and information needs they expected to have in the future. While there were many correlations with the current concerns, there were also some variables (see Table 3).

In all groups, information about health and treatment issues for older people with HIV was the most commonly prioritised future need. Social care was in the top four in all three groups, as was social support. There was a striking anomaly between the high level of concern about financial issues and the relatively low ranking of it as a priority for future services. This was not clarified by the qualitative interviews, although a number of interviewees did discuss their worries. It may be that people feel this problem is intractable, though (as will be examined later) this is not necessarily the case. Black African women were notably more concerned about employment services and less concerned about counselling and physical therapy than other groups.

The key concerns contained here are examined further in the following chapters, along with illustrative quotes from the qualitative interviews.

Table 3: Support and information needs in the future

Gay/Bisexual men	%		White heterosexuals	%
Information about health and treatment issues	89.5		Information about health and treatment issues	86.0
Social care	81.2		Physical therapy	78.0
Physical therapy	77.7		Counselling/emotional support	74.0
Social support/networking opportunities	77.7		Social care	74.0
Counselling/emotional support	75.6		Social support/networking opportunities	72.0
Financial advice/debt management	61.7		Financial advice/debt management	66.0
Housing advice and support	53.7		Housing advice and support	62.0
Employment	42.9		Employment	42.0
Black African women	%		Total (N=410)	%
Information about health and treatment issues	75.0		Information about health and treatment issues	86.3
Social support/networking opportunities	69.4		Social support/networking opportunities	76.3
Employment	69.4		Social care	77.6
Social care	61.1		Physical therapy	75.4
Financial advice/debt management	61.1		Counselling/emotional support	73.4
Physical therapy	55.6		Financial advice/debt management	62.9
Housing advice and support	53.8		Housing advice and support	55.9
Counselling/emotional support	50.0		Employment	45.9

Recommendation 1: Governmental, NHS and other policy-makers, strategists and funders need to recognise the growing numbers of people aged 50 and over who are living with HIV in the UK; their health, social, financial and emotional needs; their diversity and complexity; and their dignity, rights and willingness to engage with change as they face an uncertain future and live with HIV into older age.

Recommendation 2: Future needs assessments for services for adults with HIV should specifically consider older adults. In particular, the complex and often acute needs of black African women with HIV must be addressed.

Case Studies

Mariah, James and Laura: voices and views on growing older with HIV

While of course there were respondents in our study who had fewer difficulties than the three people whose experiences are presented here, these particular stories were chosen because each provides a unique insight into the complexity of issues that are of particular concern to this diverse 'pioneer generation' of over 50s living with HIV. Pseudonyms were used in order to protect the identities of the individuals concerned.

Story 1: Mariah, 51, a black African woman from Cape Town, South Africa: "This is my chance of living"

Born in 1959 in Apartheid South Africa, Mariah grew up in a township on the outskirts of Cape Town. In her early 20s she was raped, fell pregnant and gave birth to a boy, only to be raped again just a few months afterwards. Unable to provide a home for her son as a single mother, she had to get married "to the first man that proposed", with whom she had three more children. When she finally got divorced after years of physical abuse by her husband, Mariah decided to leave her home and look for work abroad. When she arrived in the UK, she found work as a domestic worker and nanny. In September 2001, the mother of the children she was looking after asked her to take an HIV test. To Mariah's great shock, it came back positive:

I just remember when the twin towers in America – it was just few days before that, the morning it happened, that was the excuse for me I could use so I can scream and cry and get the pain out of my chest, because I was pretending that I was crying for [these people]. In a way I felt jealous that they were dying, that I am sitting here, I am living and those people are healthy they have got money to live on, what am I, what do I have to offer now there is HIV on top of my horrible life.

Knowing that, back in South Africa, there was little support or counselling available – let alone sufficient medical treatment – as well as tremendous stigma surrounding HIV, she did not want to return to her country:

I thought [that] hiding my rape from people, I thought that was harsh, but HIV is worse. HIV is like you are a slut, or you sleep with gays. People back home, they don't [know] because it will be a stigma, people won't come to your house, your children will be mocked and I was thinking I don't want to bring my children through this.

For her, living in London and being able to access HIV support groups here has given her a second, new life:

It's the only thing I'm hanging on because I've got my life back, at least I can walk tall, I don't have to be scared. I discovered that I am not going to die soon, I am going to live. There's places you could go to, where we get together once in a while and meet other people and talk and share and get information, you know there's a lot of support.

However, her life in the UK is characterised by a number of major uncertainties. Her insecure immigration status and the constant threat of deportation put Mariah under immense emotional stress. She is not allowed to legally work in the UK, which not only leaves her financially struggling but also makes her feel more isolated; sometimes, she says, she would like to work “just for the sake of talking to somebody or having a nice warm plate of food”.

Mariah is also supporting her daughter in South Africa – “every penny I get I have to share with her” – which she perceives as a tremendous burden. The financial responsibility for her daughter, combined with the worry that her child might also contract HIV, affected her mental health to the degree that she was admitted to a hospital. Suffering severe problems with her legs, high blood pressure and asthma, she now receives medical treatment, yet had a very upsetting experience with a xenophobic doctor at a London hospital: “My doctor was insulting me that I have to go to my own country, I am not this country's responsibility, I am abusing the country and he just refused to give me medication.” Nonetheless, despite all these uncertainties and difficulties, she is intent on not returning to South Africa:

I was just at peace and I can go to support and meeting other people and I thought to myself, you know this is a new life for me, I am living again. Why do I want to take this off? This is my chance of living. I don't think if I was at home I would get my 50th birthday – that's for sure. If I get deported, I am sorry to say that, I am going to kill myself because I am not going to face that.

Being in the UK has given her hope. She is writing poetry about her experiences with HIV and wants to enjoy her life as much as she can. Recalling a birthday party she was invited to, she explains:

... this Jamaican woman was going down [dancing], I said what's your secret, and she said when you are married, don't stay at home, go out, don't change because you are married. And I said to myself oh, now I am married now to HIV so I don't have to listen to it, I can still be me so that's my motto.

Mariah's most important concern, however, is her right to remain in the UK. Describing her wishes for the future, she says that the British government should reconsider their decisions when it comes to granting asylum, because people like herself “deserve to live a better life for themselves. They deserve to have a chance.”

Story 2: James, 61, a gay man: “My life now is so limited”

When James was diagnosed with HIV in 1986, he was told that he had only a few more months to live. He sums up his experience of life after the diagnosis: “My whole world came apart.” After more than 20 years of living with the illness, many of his friends who had HIV have died and he explains that he “never anticipated being here, because everyone else went”. He describes his life before the first symptoms of his infection became noticeable as active and fulfilling, with interests including politics, opera, travel and music. At present, however, he says: “My life now is so limited.” He has suffered from asthma, lipodystrophy and peripheral neuropathy since 1996 when he contracted tuberculosis: “It goes from not feeling my feet and legs, which is terrible because standing up I lose my balance, or, it is the opposite, because I get the sharp, short pains that immobilise me for a short while.” Because of the neuropathy, he has problems walking about, and also has trouble falling asleep: “I am usually exhausted all day. I am lucky to have one day a week when I have any energy at all.” After taking an experimental drug for treating CMV (*cytomegalovirus*), James became blind: “I had not signed for it ... panic stations when they discovered my eyesight was gone.”

Financially, James is struggling. Even though he receives the higher rate Disability Living Allowance, his budget is not enough to cover the additional costs he has because of his blindness: “All my access technology is vastly expensive. I am always shelling out money for a talking microwave or a talking watch.” He worries a lot about what the future will bring, in terms of both finances and social care:

I am dreading when I reach 65, because I have SERPS [State Earnings Related Pension Scheme] which will just take me out of the pension credit limit, which will mean I lose the Housing Benefit and Council Tax Benefit. I have no pension, because I cashed it in, in 1986, because I was told I had six months to live.

A much needed and appreciated course of psychotherapy had to be ended abruptly when funding was cut, and he can't afford the transport to get to a support group for gay men over 50 that he would love to join.

In terms of care, James is also concerned about having to enter sheltered housing later on: “I don't want to end up in sheltered housing with 90% women, who will want to know what my medication is for. I won't fit in.” He also feels that his current carers are not at all prepared for dealing with his needs as a blind, HIV-positive man: “All they are trained to do is fill out a time sheet, so the care agency can make a profit.” While he is very satisfied with his HIV consultant, James describes the GPs he has encountered as “an absolute waste of time”, frequently discriminating against him on the basis of both his sexual orientation and his HIV status, as well as lacking knowledge about HIV and related illnesses. Most of the discrimination he has encountered, however, went unchallenged by him; it is “often so subtle”, James says, “and it is difficult to do anything about ‘subtle’”.

Of all his worries, isolation is probably the most profound one in James's life. “I joined an elders group locally for the over 75s, even though I am nowhere near that ... just to have human contact.” There is nothing like that for people who are HIV. He also has a hard time convincing his few remaining friends to take him out for a walk, to the theatre or a weekend away: “I have not had a holiday since 1994. I can't get anyone to go. My friends say it is too much of a responsibility to go on holiday with me.” About once a week, he visits a local HIV charity for a free lunch. Yet, even there, he feels alone: “No one will sit on the same table as me, other than the staff. That is because of my blindness. The greatest fear people have, more than death, is fear of losing their sight. I have lost more friends through that, than HIV.” He struggles to cope with the sense of exclusion and isolation he experiences:

My life is empty. I tried so hard over the last ten years to fill the emptiness. Worked really hard at it. I am in a cul-de-sac. It would be nice just to have somebody to telephone. Like the Easter weekend, I am left alone in my flat, and I find it absolutely soul destroying. I am fed up with people at the top of HIV organisations saying because there is combination therapy everyone is fine. People with neuropathy, and in wheelchairs, we are the forgotten people.

Story 3: Laura, 51, a white heterosexual woman: “There are a lot of doors that are shut for people whose face doesn't fit”

Laura, a mother of two children in their early 20s, had just entered into a new relationship in 2009 after a “long and unhealthy marriage” when she became very ill. Feeling permanently exhausted and suffering from cystitis and thrush that would not clear up, she became alarmed when she spoke to a friend who had similar symptoms and had recently been diagnosed with HIV. Laura took the test, and both she and her new partner turned out to be positive. Her reaction, she says, was “numbness and shock”. She insisted that her partner came with her to receive the results:

I felt that if he wasn't there he wouldn't believe me and he might run off and turn his back on the whole thing and not get diagnosed himself. It was very dramatic; he sort of fell to the ground and became hysterical, then wondered who I'd got it from and thought I'd passed it onto him which was absolutely [ridiculous]. I stayed very calm but was feeling furious.

The doctor advised them that they could continue to have sex without protection as both of them were infected by the same virus: “He thought that we would have to stay together because of our diagnosis. There was a part of me that thought, yes, it would be very hard to find someone else and I continued in the relationship for another six months.”

While Laura says that she generally feels “optimistic”, she is very concerned about staying strong and keeping her life “in a better balance to stay healthy”. Working as a teacher, she earns a good salary at the moment, but worries about what will happen when her strength decreases more and more, as it has already begun to do:

I'm really feeling that it's wearing down now and it's very hard to maintain my professional life with so much turmoil going on in my personal life to do with my health. I get incredibly tired and I go to bed earlier than I used to and I would love to have a job where I started to work at midday and I'd be happy to work to mid evening but I don't, I work in education and I have to have an early start and I'm really, really struggling.

She also struggles emotionally:

[I feel] overwhelmed by my circumstances and the state of mind I was in that I made myself vulnerable to getting HIV, that I didn't take precautions, that I'm well educated and a well-informed person and I started the relationship and used condoms and then without getting tested we stopped using them and that was a big mistake. I've had to question why I allowed that to happen. It's to do with guilt and how one is seen.

Finding a support group that is tailored to her needs as a middle-aged, heterosexual woman is a major concern for Laura:

Given where I am demographically, that I'm in a minority and that the vast majority of people infected with HIV in the UK are black Africans and gay men so it feels as though services for heterosexual women, non-Africans are very difficult to access. I have been to events that the hospital has put on – of 20 people 1 or 2 are usually straight women in the group with mainly gay men. In an ideal world, I would like to go to a mixed group, culturally and [in terms of] sexuality.

Laura feels that support groups especially for older people would also be much better suited to discussing and sharing the concerns specific to this group of people. Family planning, for example, is not a concern any more, but social care, the long-term effects of early experimental treatments on this ‘pioneer generation’, and sheltered housing are. Also, she says, “there are so many issues to tackle particularly for people in their middle age because most people have quite ingrained habits, in terms of smoking or drinking or drugs or diet or exercise”.

It is not only peer support that she feels she is lacking, but also appropriate medical care and information on the interaction of HIV with other infections and conditions, such as the specifically female and middle-aged problem, the menopause:

I asked the consultant what could I do in terms of hot flushes and feeling exhausted and so on and could I continue with the herbal pills, and was quite shocked at his response which was ‘I don't really know much about middle-aged women with HIV; my area of expertise is black Africans and the gay community.’ I just found that so dismissive. Instead of saying ‘That's not something I know a lot about and I will find out for you from gynaecological specialists or I'll go and read up on it and get someone to find out something for you’ rather than just cut me off. There are a lot of doors that are shut for people whose face doesn't fit.

Yet she feels that it is especially people like her who need to be considered much more, in terms of both living with HIV and its prevention:

It's a rapidly increasing part of society, middle-aged men and women who come out of divorce or long-term relationships, haven't been dating since the 70s or 80s before HIV was on the map and have never thought of themselves as the kind of person who might get HIV and in that way are more vulnerable than ever.

1 Health and social care

Having not expected to live this long, it's quite a shock to have to deal with the onset of old age.

60-year-old gay man from Sussex

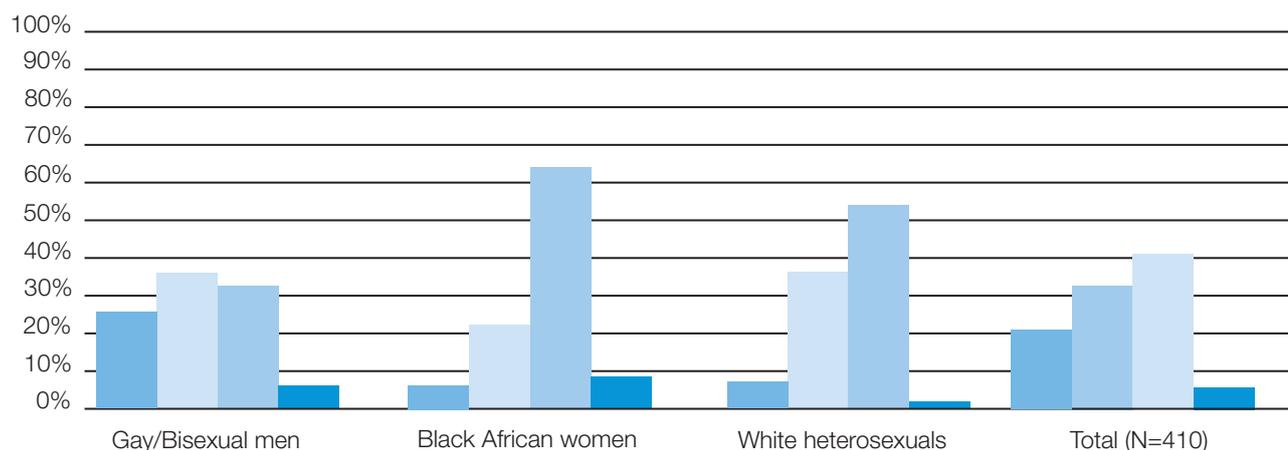
In common with most others, people with HIV may experience health problems as they grow older. However, recent clinical studies indicate that the impact of HIV may increase their risk of poor health, with HIV interacting adversely with other conditions. Similarly, the experience of stigma and discrimination may also impact negatively on people's mental health, along with the uncertainties of living with a fluctuating and potentially terminal condition.

Physical health

HIV

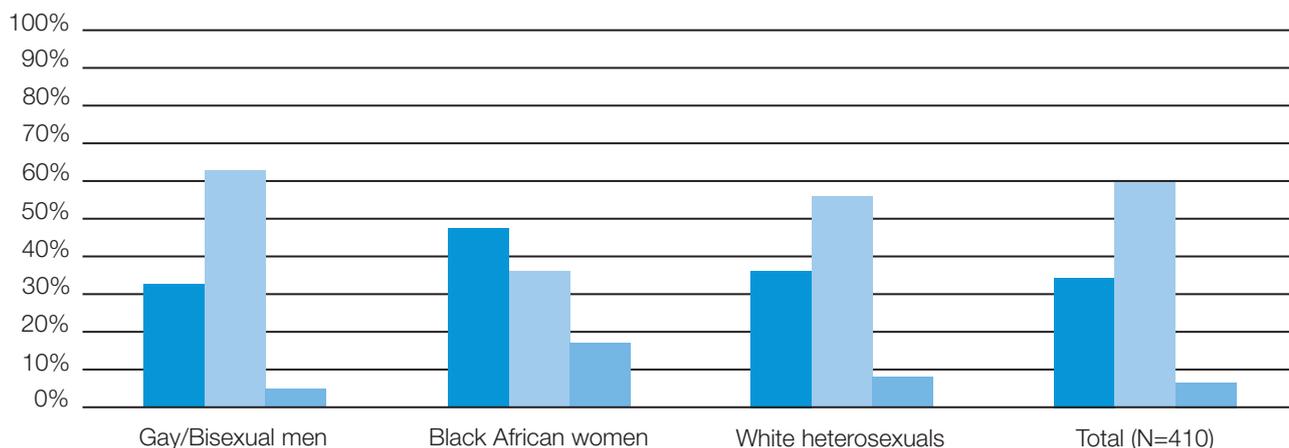
It is sometimes assumed that people over 50 with HIV are all long-term survivors with HIV, but this is far from accurate. One in five respondents (21%) were diagnosed in the 1980s, but the greatest number (41.2%) were diagnosed since 2000, one in five (21.1%) within the past five years (see Figure 1). This fits with HPA data (2008) which shows that almost 10% of all new diagnoses in 2008 were among the over 50s. Overall, black African women and white heterosexuals were likely to have been diagnosed more recently than gay/bisexual men, who represented the vast majority of the long-term survivors diagnosed in the 1980s and even the 1990s.

Figure 1: Year of diagnosis



Year of diagnosis	Gay/Bisexual men	Black African women	White heterosexuals	Total (N=410)
1980s	26.1%	5.6%	8.0%	21.0%
1990s	35.9%	22.2%	36.0%	32.4%
2000s	32.4%	63.9%	54.0%	41.2%
DNA	5.6%	8.3%	2.0%	5.4%

Figure 2: Are you currently taking any medication for any non-HIV-related conditions?



	Gay/Bisexual men	Black African women	White heterosexuals	Total (N=410)
No	32.4%	47.2%	36.0%	34.1%
Yes	62.7%	36.1%	56.0%	59.5%
DNA	4.9%	16.7%	8.0%	6.3%

The vast majority of respondents (94.1%) were currently attending an HIV treatment centre, and most of these (88%) were using treatments for HIV. Although early treatments were hard to manage and adherence to the treatment regime often difficult, only 4.8% said they found it quite or very hard to remember to take their treatments currently. However, side effects do still play a major part. Of those on treatment, over half (54.7%) reported side effects.

Just under two thirds of respondents (59.5%) were also taking treatments for conditions other than HIV (see Figure 2). Gay/bisexual men were most likely to be doing so (62.7%) and black African women least likely (36.1%). These are significant levels of treatments which may have interactions with the individual's HIV medication. As Pratt *et al.* (2010) point out, 'side effects and toxicities of ARVs [antiretroviral drugs] may be expected to occur more frequently in older patients who have more co-morbidities and a higher chance of pharmacological interactions with concurrent medications'. They also indicate high usage of GPs in addition to specialist HIV clinics – not surprising in a population over 50, but an important issue to consider, given the high level of complaints about treatment by GPs, discussed later.

In the light of such statistics, it is not surprising that information about health and treatment issues was the highest area of future need identified by respondents: 86.3% viewed it as very or quite important.

Basically we are just going into the dark and nobody is prepared, I am telling you, nobody knows what we are going to be doing in the next ten years ... these medications ... they haven't been tried on a long-term basis, we don't know exactly how we are going to react to the medication ... it's a very grey area.

55-year-old black African man from London

Recommendation 3: Easy-to-understand information on health and treatment issues pertinent to older people with HIV needs to be developed by HIV information providers. Such material needs to consider a range of common co-morbidities as well as common co-infections. Targeting of material to meet the needs of different social groups with high prevalence of HIV should also be considered.

Sexual relationships and health

We live in a society which often fails to acknowledge sexual activity in later life and thus any continuing need for sexual health support. As has already been shown by patterns of diagnosis, many older people with HIV are sexually active. Asked about sexual partners in the past twelve months, almost two thirds of respondents (63.8%) indicated that they had had one or more sexual partners (see Figure 3).

While just under a third (31.5%) had no sexual partners in the past year, one in four (26.8%) had 1 partner, 16.3% had 2–5 partners and smaller numbers had 6–10 partners (8.0%), 11–30 partners (7.6%) and more than 30 sexual partners (5.1%) in the past year. No black African woman reported more than one partner and two thirds (66.7%) stated they had no sexual partner. No white heterosexuals reported more than 2–5 partners.

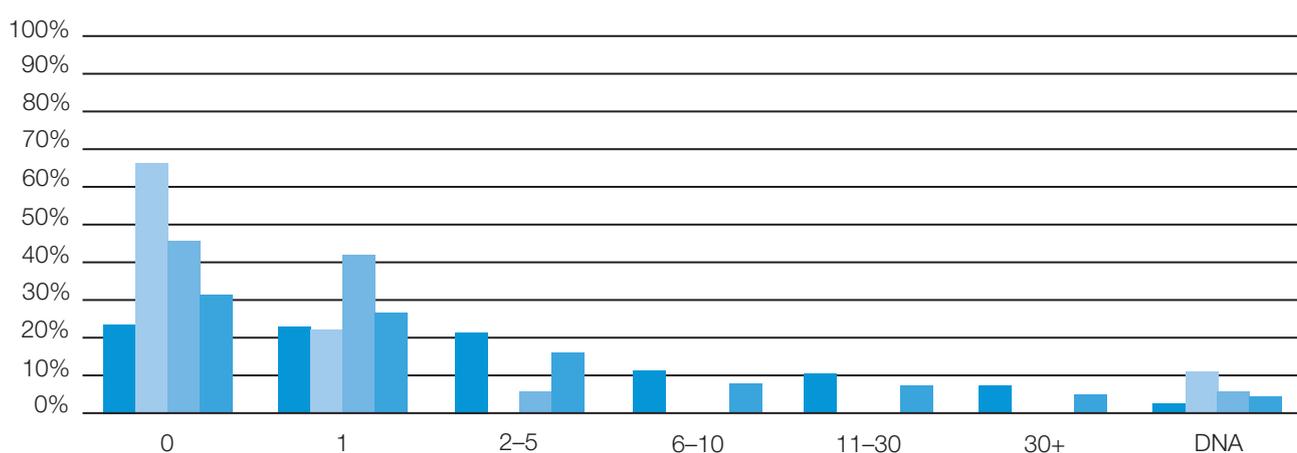
My lifestyle is affected by my condition because I was widowed in 1998 and I find it hard to find a partner ... because that means I would have to tell them about my HIV status ... It has affected my life because I am fearing to be with any partner.

56-year-old black African woman from Coventry

These figures indicate a substantial level of ongoing sexual activity for some older people living with HIV, including partner changes, particularly among some gay/bisexual men. Just over half of the group reported more than 1 sexual partner in the previous year, with just under one in five (17.8%) having more than 10 partners. Data from the Gay Men’s Sex Survey (Sigma Research, 2008) indicates that gay men who are sexually active over 50 (including those diagnosed with HIV and those not) are more likely to have five or more sexual partners each year than those in their 30s or younger. While this group is also more likely to have safer sex than other age groups, the number identifying that they had sex with a risk of HIV transmission was still over a quarter (25.4%).

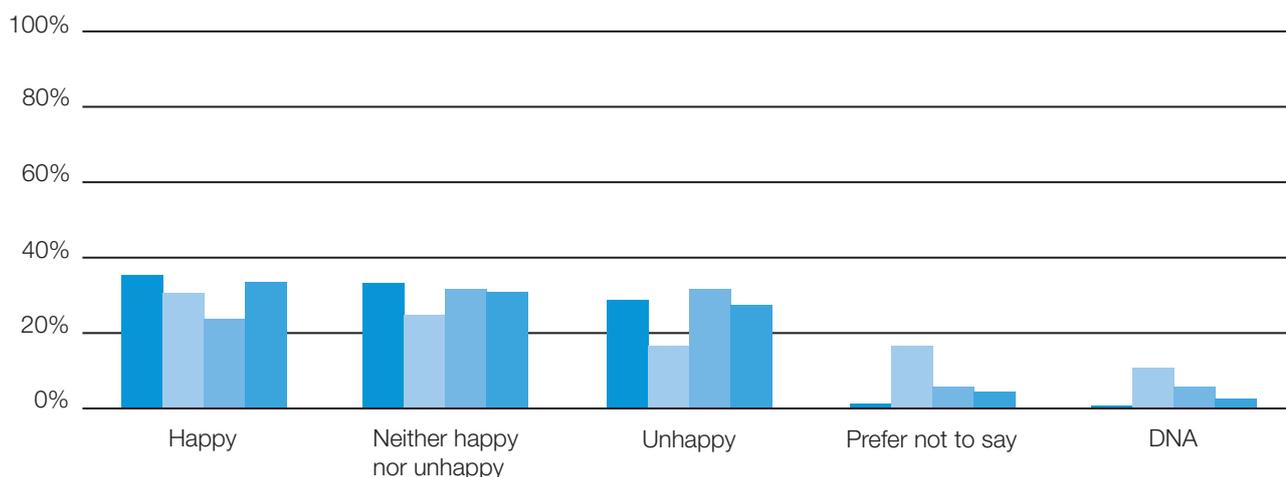
When respondents were asked about satisfaction with their sex life, “whatever it is”, there seemed to be little or no correlation with number of partners (see Figure 4 on page 20). Overall, around a third reported that they were happy (33.9%), another third (31.2%) neither happy nor unhappy and only just over a quarter (27.6%) unhappy.

Figure 3: Number of sexual partners in past twelve months



	0	1	2-5	6-10	11-30	30+	DNA
Gay/Bisexual men	23.7%	23.0%	21.3%	11.5%	10.5%	7.3%	2.8%
Black African women	66.7%	22.2%					11.1%
White heterosexuals	46.0%	42.0%	6.0%				6.0%
Total (N=410)	31.5%	26.8%	16.3%	8.0%	7.6%	5.1%	4.6%

Figure 4: Satisfaction with sex life



	Happy	Neither happy nor unhappy	Unhappy	Prefer not to say	DNA
Gay/Bisexual men	35.2%	33.4%	28.9%	1.7%	0.7%
Black African women	30.6%	25.0%	16.7%	16.7%	11.1%
White heterosexuals	24.0%	32.0%	32.0%	6.0%	6.0%
Total (N=410)	33.9%	31.2%	27.6%	4.6%	2.7%

I do think prevention work is focused on young people. They seem to forget you don't stop having sex after 40. I know I had unprotected sex and it's my fault. There's not a lot for older guys; you've managed to stay clear and you think you're invincible. You go to hospital each year, you get blasé ... it kept coming back negative and you think there must be something in me, that special. I don't think there's much campaigns at older guys; there's a lot of barebacking between older guys.

53-year-old gay man from London

Recommendation 4: HIV testing services and prevention initiatives, in particular those aimed at gay/bisexual men, need to consider people over 50 as a target group. Where such services are generic or aimed at the whole adult population, they need to explicitly consider and include the needs of older adults within this.

Other health issues

Compared with the general population at this age, older people with HIV appear, from this sample, to have almost double the number of other long-term health conditions. Asked what other major or long-term health conditions they had, between them respondents identified 574 instances (some people having multiple conditions). Only a third (32.4%) reported they had no other long-term conditions, which contrasts sharply with the 57% of adults aged 45–74 in Great Britain who had none (Office for National Statistics, 2010). This difference is even more striking when we consider that the 50 Plus group did not count their HIV within this, as the general statistics did.

The most common condition was high blood pressure (27.6% of respondents), followed by arthritis (19.2%) and neurological conditions (15%), of which a high proportion appears to be peripheral neuropathy, a common condition among people with HIV (see Figure 5 on page 21). Heart disease was reported by a further 8.7% and diabetes by 8.4%.

While many of the above could be long-term effects of HIV treatment, they are also classic conditions of ageing. Many respondents commented on the confusion and uncertainty which both they and their care providers felt about the causes of these conditions. There is increasing evidence to suggest

Figure 5: Other major or long-term illnesses

	Diabetes	High blood pressure	Arthritis	Heart disease	Hepatitis B	Hepatitis C	Neurological condition	Cancer	Other	None	Total
Gay/Bisexual men	19	64	43	26	14	12	47	12	72	94	266
Black African women	3	19	9	3	1	1	1	0	6	7	34
White heterosexuals	5	13	10	2	0	5	7	0	14	8	44
Total (N=410)	27	96	62	31	15	18	55	12	92	109	344

Figures shown refer to numbers not percentages. Multiple responses were possible

that the interaction between HIV and ageing presents highly complex clinical challenges and that the diseases and conditions of ageing present earlier or more severely in people who also have HIV. It is unclear as yet how much of this relates to HIV disease itself damaging the body and effectively ageing someone prematurely, and how much of it relates to the side effects of earlier, more toxic treatments. Both appear to be implicated in the premature ageing of people with HIV and these relationships are the subject of considerable current clinical research. This complexity was a lived reality for many people we spoke to.

I have suddenly been diagnosed with asthma, which I never had before. Also since 1996, when I had TB, I have peripheral neuropathy ... It goes from, not feeling my feet and legs, which is terrible because standing up I lose my balance or it is the opposite, because I get the sharp, short pains that immobilise me for a short while ... The only time I have a decent sleep is when I forget to take my tablets before going to bed ... I am usually exhausted all day ... I am going through new medication at the moment, and I am beginning to get worried it is affecting my kidneys.

61-year-old gay man from London

I am worried that too many clinics, hospitals and practitioners are treating me for separate illnesses. There is one hospital for my HIV, another for HPV and two GPs for cardiovascular problems.

60-year-old gay man from London

What this means for older people with HIV is that, despite treatment keeping them alive far longer than previously expected, their level of health and resulting quality of life are still highly uncertain. However, many of these other long-term conditions cited by multiple respondents are affected by lifestyle considerations – exercise, diet and smoking – and, whatever their origins, can be positively impacted by healthy choices and good self-management.

Recommendation 5: HIV clinicians should work together with specialist clinicians and with geriatricians for common co-morbidities to share and increase knowledge of diagnosis and treatment.

Recommendation 6: Long-term condition management courses and positive self-management courses for people with HIV should offer information and support to enable healthy choices and self-care to counteract or minimise the multiple co-morbidities which older people with HIV face.

Access to health services

Respondents were asked about their entitlement to free NHS services. A significant number of gay/bisexual men (8.3%) and black African women (8.3%) were unsure about their entitlement and a surprising number of gay/bisexual men (16.4%) and white heterosexuals (14%) stated they were not entitled to free NHS services. Most of these people were apparently nevertheless accessing such services without reported difficulties. By contrast, many of the smaller number of black African people who were not entitled reported many difficulties in negotiating the system in order to get the lifesaving treatment they needed.

Under current government guidelines on NHS entitlement, HIV treatment should be considered immediately necessary within the British HIV Association (BHIVA) treatment guidelines, and while it should be billed for, treatment should not be denied if the patient is unable to pay. Further investigation is needed, but it is of concern that black African women (and men in the qualitative responses) appeared to encounter more difficulties than their white counterparts or gay/bisexual men in accessing health services.

My doctor was insulting me that I have to go to my own country, I am not this country's responsibility, I am abusing the country and he just refused to give me medication.

51-year-old black African woman from London

Some black African women faced particular stresses around insecure immigration status and healthcare, which came through strongly in the qualitative interviews.

I spent ten years trying to build my future up in this country, and I have been very open and faithful about myself and saying my situation as it is. You feel a bit victimised for saying the truth about yourself. I'm actually talking for other people as well who are positive and in the country. If you are told to stop working and you have no money and no social network to support you what are you to do? You have to deal with food, the basics. You have to deal with the medication and everything and it actually makes you go down. Your health goes down.

51-year-old black African woman from London

Recommendation 7: Adults over 50 with HIV are most likely to need a range of other healthcare services alongside their HIV care. Greater efforts should be made by HIV information providers to inform them of their rights to healthcare and, where there are restrictions, provide support to negotiate the complex system of government caveats, enabling access to immediately necessary treatment. The impact of such restrictions should be further investigated in order to inform future policy development.

GP registration bore little relation to entitlement to secondary care. No white heterosexuals and less than 3% of black African women and gay/bisexual men reported that they were not registered with a GP. This was despite many people's profound dissatisfaction with their treatment by GPs and surgery staff. This dissatisfaction was to do with both levels of knowledge about HIV and disrespectful behaviour. However, a small number of respondents praised their GPs and a larger group spoke positively about their HIV specialist clinicians and staff. Given that older people in general make greater use of their GPs, this disconnection in care levels is unacceptable.

I have fungal problems in my ears, and lost my hearing for a year. I could not get treatment from my GP ... it was a nightmare. In the end I said, 'If you do not send me to ENT I am going to take you to the Family Practitioner Committee' ... I would like not to have to go to my GP.

58-year-old gay man from London

The local GP I don't think I've seen at all. I went to one at the very beginning and I thought I better check in with them and I found her so unhelpful and freaked out about the fact that I was HIV and I never went back there again ... If I do have something I go straight to the clinic and they're excellent. I mean I have no complaints at all ... the National Health Service in this country is amazing.

55-year-old white heterosexual woman from London

It is possible that, in future, a move towards personalised health budgets or sophisticated use of PBR (Payment by Results) could influence clinicians towards greater sensitivity regarding patients with HIV or those who are gay. However, these reforms are overdue and should not wait for structural change.

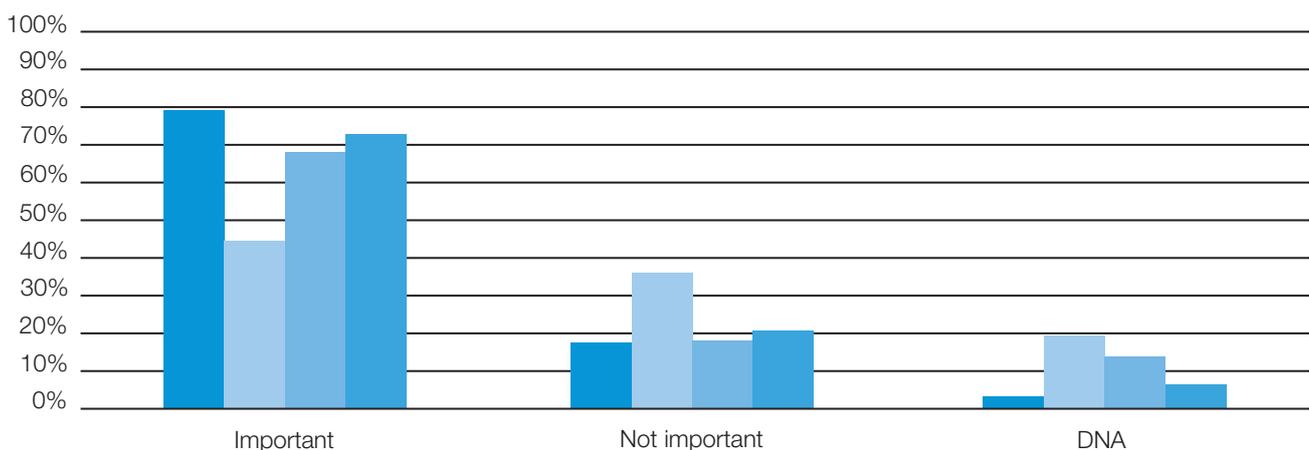
Recommendation 8: Further efforts should be made by the NHS, the Royal College of General Practitioners, specialist HIV clinicians and community groups to improve the quality of primary care for people with HIV.

Mental health

Given the uncertain long-term prognosis for HIV, the rapidly changing estimates of life expectancy and health levels and the amount of public prejudice and stigma surrounding the condition, it is unsurprising that mental health issues are of concern to people with HIV and those who care for them. People with HIV, particularly but not solely the long-term diagnosed, experience the combined stresses of a life-threatening condition with public stigma and frequent, complex information change. As demonstrated later, they often also face poor employment and healthcare experiences, social isolation and financial disadvantage, all of which can impact on mental health. Depression and poor mental health are also often present in old age, with depression affecting 22% of all men and 28% of all women over 65 (NHS Information Centre, 2007). In all, 72.9% of 50 Plus respondents said that mental health issues or depression were important concerns for them (see Figure 6).

Asked about the past year, one in five (18.8%) said they had been extremely anxious or depressed, while a further half (50%) said they had been moderately anxious or depressed. Gay/bisexual men were

Figure 6: Do you have any concerns with growing older with HIV and developing mental issues/depression?



	Important	Not important	DNA
Gay/Bisexual men	79.4%	17.4%	3.1%
Black African women	44.4%	36.1%	19.4%
White heterosexuals	68.0%	18.0%	14.0%
Total (N=410)	72.9%	20.7%	6.3%

Figure 7: How would you rate your emotional or psychological health?



	Excellent	Good	Fair	Poor	DNA
Gay/Bisexual men	12.5%	41.8%	31.4%	13.2%	1.0%
Black African women	5.6%	41.7%	44.4%	5.6%	2.8%
White heterosexuals	8.0%	32.0%	38.0%	22.0%	
Total (N=410)	11.5%	41.2%	33.2%	13.2%	1.0%

most likely to be moderately anxious or depressed, but black African women were significantly more likely to be extremely anxious or depressed (38.9%) than white heterosexuals (22%) or gay/bisexual men (16.4%). This is unsurprising given the range of other pressures on many of the black African women surveyed, but it suggests that special attention should be given to the mental health needs of this group. Despite this, when asked to rate their current emotional or psychological health, black African women were four times less likely to say it was poor (5.6%) than white heterosexuals (22%) and much more likely than other groups to describe it as ‘fair’ or even ‘good’ (see Figure 7). Gay/bisexual men reported the best emotional or psychological health overall.

Even with these variations taken into account, however, reported levels of depression and anxiety are significantly high in relation to the general population and suggest that action needs to be taken to identify and prioritise appropriate mental health support. During our US visit, ACRIA and others drew our attention to the high level of mental health needs in older people with HIV in the US and to the reported improved outcomes of ‘talking therapies’ rather than further medication. These outcomes were mirrored by some UK respondents.

The doctors and nurses at my clinic are actually fed up with hearing of our tales of woe, our continual difficulties. Almost every time I go they ask how I am of course and if I dare to tell them the truth ... they try to put me on anti-depressants. They just want to shut me up, stick a pill inside me and make me happy.

55-year-old gay man from London

Recommendation 9: Services which support the mental health and well-being of people with HIV over 50, including counselling, peer support and other emerging strategies within long-term condition management, should be prioritised for development, evaluation and funding.

Social care

Access to social care services

In the UK, social care for older people is largely provided through local authorities, either by direct service provision or by funding voluntary organisations such as Age UK, or through private care companies offering residential and home help. Social care services for other adults are often thin on the ground and thus specialist services for people with HIV have grown, particularly in England, through the use of a ring-fenced grant, the AIDS Support Grant (ASG), to local authorities. A wide range of social care provision – including specialist social workers, counselling, home helps and long-term condition management – was until 2010 funded through the ASG. However, with the ring fence now removed, it is likely that much existing English social care provision for people with HIV of any age will be reduced or defunded. The views of the 50 Plus respondents highlight concerns as to how social care needs will be met in the future.

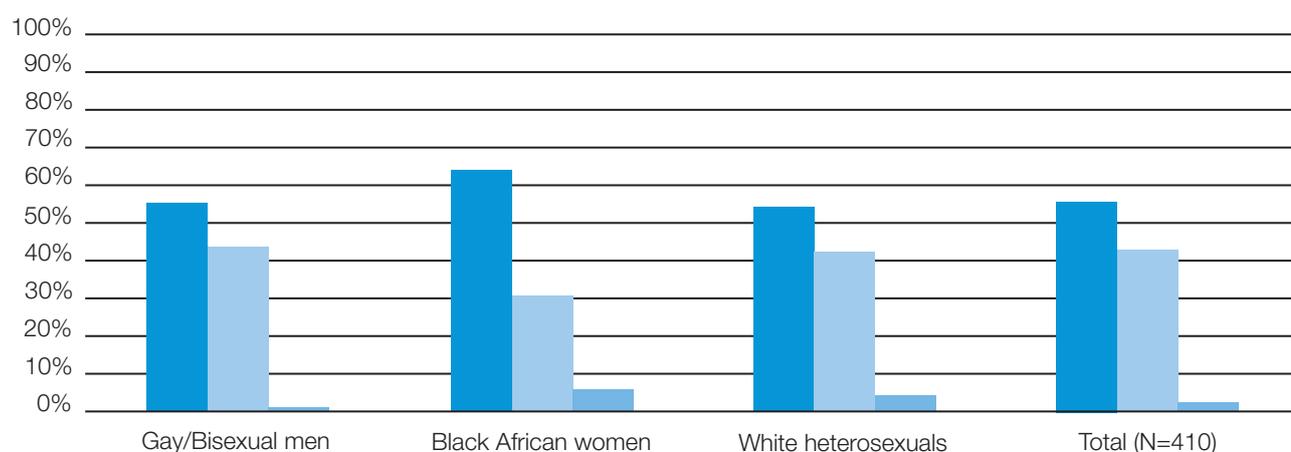
Over three quarters of respondents (76.3%) said that inability to care for themselves, or difficulty in managing everyday tasks, was an important concern for their future. A similar number (77.6%) said they expected to need social care services of some kind. In addition, 72.9% cited concerns about future mental health or depression, 50.5% already had problems with mobility in the past year, 23.9% had some problems washing and dressing themselves in the past year and 46.1% had problems with everyday activities in that timeframe.

Although the majority of respondents in every category did not consider themselves as disabled, 43.6% of gay/bisexual men, 42% of white heterosexuals and 30.6% of black African women did (see Figure 8).

These figures indicate potential high levels of social care need, particularly for home care. Yet between 2000 and 2008, the number of households in England receiving such care actually decreased by 18% (NHS Information Centre, 2008). The now defunct Commission for Social Care Inspection (Commission for Social Care Inspection, 2008) estimates that only just over 1 million of the 2.45 million older people with care needs in England actually receive social care, leaving just under 1.5 million without needed care.

If, as is indicated by many English local authorities, people with HIV are indeed on the verge of losing much of their specialised social care provision (and people in other areas of the UK have never had

Figure 8: Do you consider yourself as having a disability?



	Gay/Bisexual men	Black African women	White heterosexuals	Total (N=410)
No	55.4%	63.9%	54.0%	55.4%
Yes	43.6%	30.6%	42.0%	42.7%
DNA	1.0%	5.6%	4.0%	2.0%

the same levels), then most of this growing need among older people with HIV will have to be met through generic services for older people. If this is to be the case, it is important that such services are accessible and appropriate to older people living with HIV.

I also fear that in case I need to be cared for, the carer would be as ill-informed and prejudiced about HIV as the rest of the general public.

51-year-old bisexual man from London

Recommendation 10: Social care providers for older people and those for people with HIV should work together to address knowledge gaps and service gaps on each side, ensuring quality services for all.

Counselling and peer support

Counselling and peer support were singled out by many respondents as useful services, the latter being often mentioned in the qualitative data.

I would like to be a member of any support group just to know that I'm not alone and gain help and learn from others how I can manage myself better. If there's any support that we could be given just to keep moving, I would go for it.

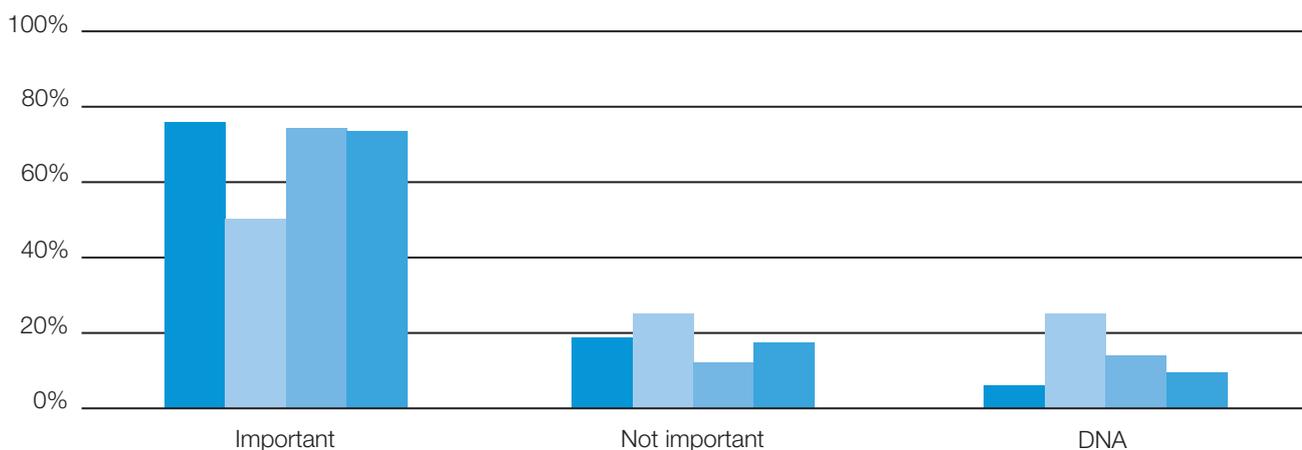
Black African woman from Oxford

I never felt suicidal because somebody was there to support me ... I attended a lot of support groups ... which were very useful because I met a lot of friends, everybody in there was HIV positive and we became one big family.

Black African heterosexual man from London

Counselling and emotional support were specifically asked about, with 73.4% of respondents identifying them as something they expected to need in the future (see Figure 9). Gay/bisexual men (75.6%) and white heterosexuals (74%) were more concerned to have these services than black African women, but even

Figure 9: What support will you need in the future – counselling/emotional support?



	Important	Not important	DNA
Gay/Bisexual men	75.6%	18.5%	5.9%
Black African women	50.0%	25.0%	25.0%
White heterosexuals	74.0%	12.0%	14.0%
Total (N=410)	73.4%	17.1%	9.5%

here 50% of women prioritised them as important. This contrasts with the higher numbers of black African women reporting anxiety and depression (mentioned above in 'Mental health'). There was a gap for black African women between reported concerns about mental health issues and a lack of expectation that these needs could be addressed by services. This needs further investigation.

Recommendation 11: Counselling and peer support mechanisms should be incorporated within long-term condition management strategies for older people with HIV by both funders and service providers.

Home care and care homes

Two areas of social care as yet accessed by few of the respondents, but commonly used by a substantial number of older people, were home care and residential care. Some of the concerns about residential care and whether it is ready for either LGBT people or people with HIV are considered in the section on housing. However, it is worth noting here that these are key areas of general social care for older people and they provoked repeated and unprompted comment.

Would residential homes or places for the long-term sick have the expertise to be able to look after an older person with HIV?

52-year-old gay man from Cardiff

I fear hugely going into a home, or getting so frail or ill and I have to be looked after by a paid care agency in my own home, i.e. I fear the attitudes towards HIV that I may find and ignorance from care staff. One of our HIV charity trustees died last year and a private care agency actually refused to provide him with care at home when he was dying of cancer ... they did not want to come into contact with his bodily fluids ... and if I get dementia ... I may not be able to fight this disrespect and stigma or educate them on my care.

57-year-old white heterosexual woman from Cornwall

Terrence Higgins Trust staff have previously advocated on behalf of older people with HIV who have been refused home care through fear or prejudice. In most cases this has been due to poorly informed managers and care staff and could be avoided by some basic training and best practice policies. Every care provider should have these in any case, given the prevalence of undiagnosed blood-borne conditions across the UK, of which HIV is only one.

It is possible that personalised care budgets could work through market forces to improve this situation, if people are able to stipulate that they need care from an organisation or individual who is sensitive to their HIV, ethnicity or sexuality. However, as with healthcare, we should not be forced to wait for uncertain structural policy change to find a remedy for such a major inequality.

Recommendation 12: Social care services for older people should have in place best practice policies for dealing with blood-borne conditions and should provide basic training in HIV awareness and sensitivity to all frontline and managerial staff likely to encounter service users with HIV. Those who commission and fund such services should require this as a basic quality measure.

2 Work, money and housing

Work and money

Employment and finance loomed large in the lives of the 50 Plus respondents. Many who had not expected to live were long-term unemployed with few savings, while others had lost employment due to ill health or discrimination. Apart from the financial issues, work can be important for mental health and a sense of purpose and can help to prevent social isolation.

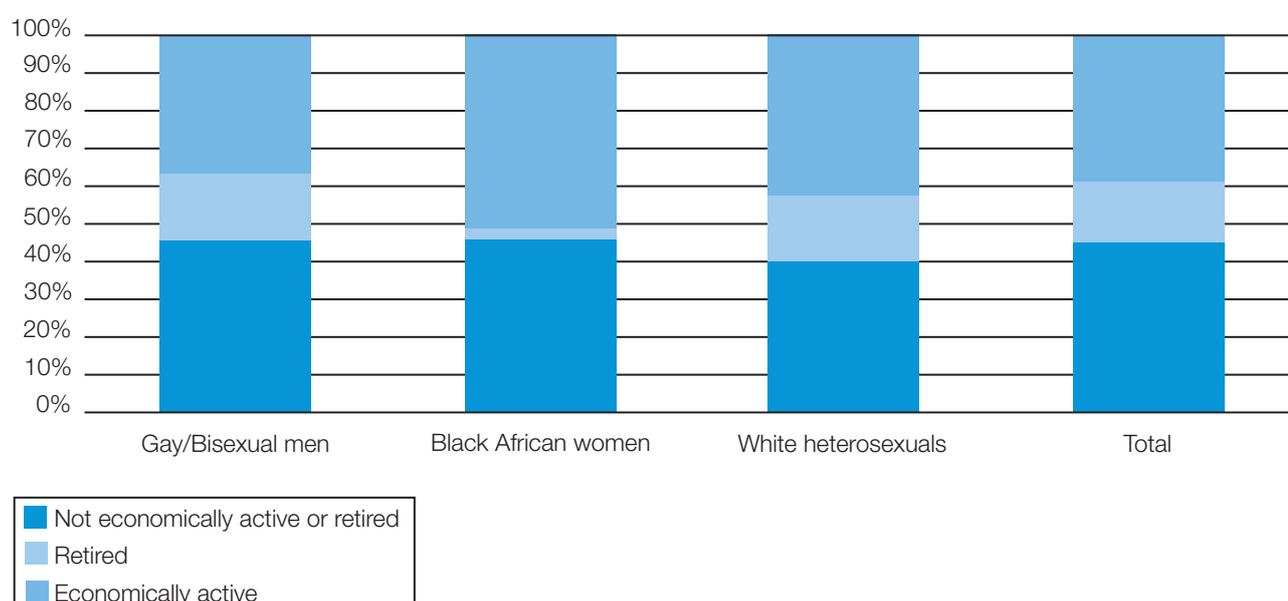
Employment status

The sample for this survey straddled those who might be expected to be economically active and those who had passed retirement age. It also included a greater proportion of migrants without a right to work than in the general population, factors which make comparisons problematic. However, it is clear that older people living with HIV are significantly less likely to be economically active than their peers.

The current unemployment rate for people between 50 and retirement age in the UK is 4.4%, whereas in this group it was 23% (see Figure 10). Within the general population, three quarters (74.9%) of older people below retirement age (men 50–64 years old and women 50–59 years old) are economically active (Office for National Statistics, 2010). Within the 50 Plus respondents, only half (50.3%) in this age bracket were economically active.

Predictably, given that many of them had immigration issues, black African women were least likely to be economically active but, in all groups of working age, economic activity was lower than would be expected within the general population. However, in the much smaller group of people over retirement age, there was an employment rate of 26% compared to 12% in the wider population.

Figure 10: Economically active



I had a fairly long period of not working in the '90s and not thinking about my future needs ... I feel I have to do my best now to build up a pension in my remaining years as an employable citizen. I also have a 4-year-old child now so I feel I need to keep working in order to provide us with financial security ... in this sense I am trying to cram quite a lot into my 50s and 60s.

54-year-old white heterosexual woman from Brighton

More than two thirds of black African women said that employment support was important to them, alongside two in five gay/bisexual men and white heterosexuals. There are few existing back-to-work projects within HIV services and little attention has been paid to the particular needs of people with HIV within projects to get disabled or disadvantaged groups into work.

Those who do seek employment within this group face the double jeopardy of age and HIV, either of which can deter a prospective employer, whatever the law may say.

I introduced computers and software to my previous company, but people think because I am 59, I don't know how to use them. Society thinks if you are over 50 and not physically fantastic, they don't really want to know.

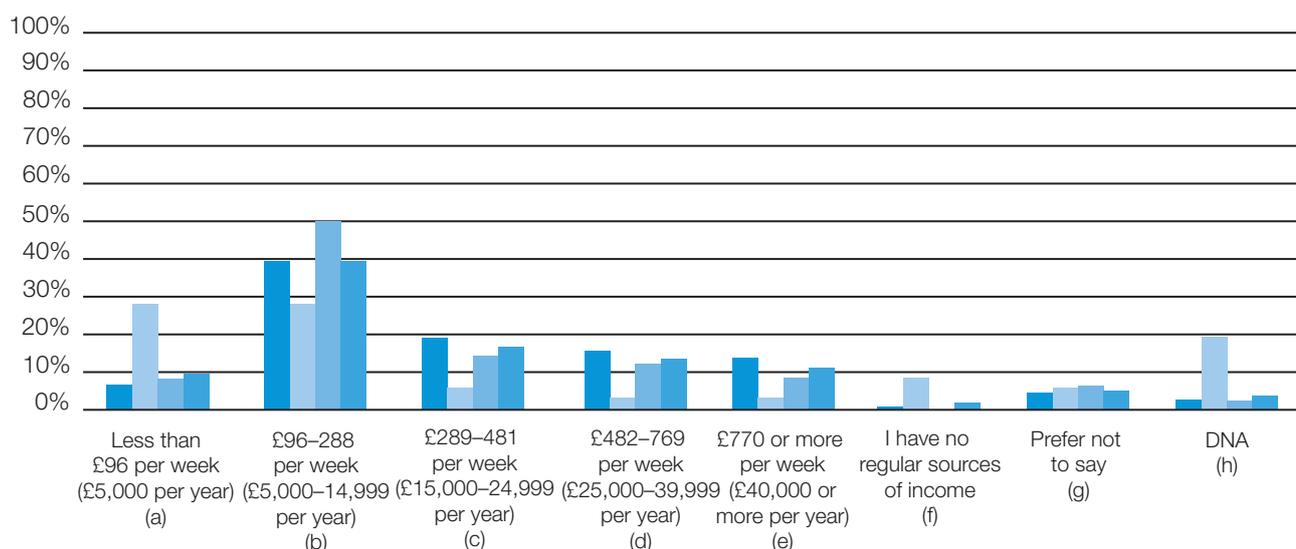
58-year-old gay man from London

Recommendation 13: Older people with HIV would benefit from greater support to re-enter or remain in the workplace. Voluntary and statutory services for people with HIV should consider how best to provide support, including joint working with generalist employment schemes.

Income

The relative lack of economic activity described above has a direct impact upon respondents' levels and sources of income. One in ten respondents had an income of less than £96 a week, or £5,000 a year (see Figure 11). Among the black African women, this ratio rose to more than one in four. These people

Figure 11: Gross income before deductions



	(a)	(b)	(c)	(d)	(e)	(f)	(g)	(h)
Gay/Bisexual men	6.3%	39.4%	18.5%	15.3%	13.2%	0.7%	4.5%	2.1%
Black African women	27.8%	27.8%	5.6%	2.8%	2.8%	8.3%	5.6%	19.4%
White heterosexuals	8.0%	50.0%	14.0%	12.0%	8.0%		6.0%	2.0%
Total (N=410)	9.8%	39.5%	16.3%	13.2%	10.7%	1.7%	5.1%	3.7%

were living significantly below the accepted UK poverty line for pensioners, which in 2010 was £115 for individuals and £199 for couples. A further 39.5% of those surveyed had an income between £5,000 and £15,000 a year, which means half those surveyed were living on under £15,000 a year.

In all, almost half (44.9%) said that they sometimes or never had enough money to cover basic needs, and one in ten of the whole sample never did (see Figure 12). This included half of all the black African women respondents.

Somehow the category 'financial difficulty' doesn't begin to address the unending stress of permanent financial anxiety.

60-year-old gay man from London

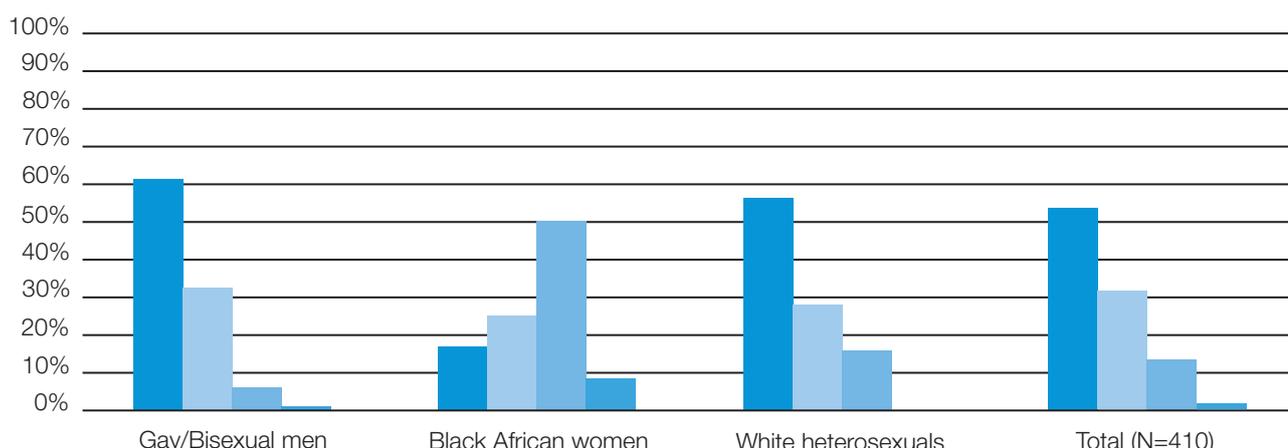
Even for those who are currently not in financial difficulty, fears about the future looms large. With the 2008–9 review of Special Rules Benefits and the constant political pressure to reduce the numbers of people claiming disability benefits, older people with HIV expressed considerable concern about managing in the future, particularly those who are facing life on a basic state pension. As of 2010 the state pension is £95.25 for single pensioners and £152.30 for couples per week, again below the poverty line.

Since I was diagnosed in 1985 I regarded this as a death warrant and ceased to make any pension provisions.

67-year-old gay man from London

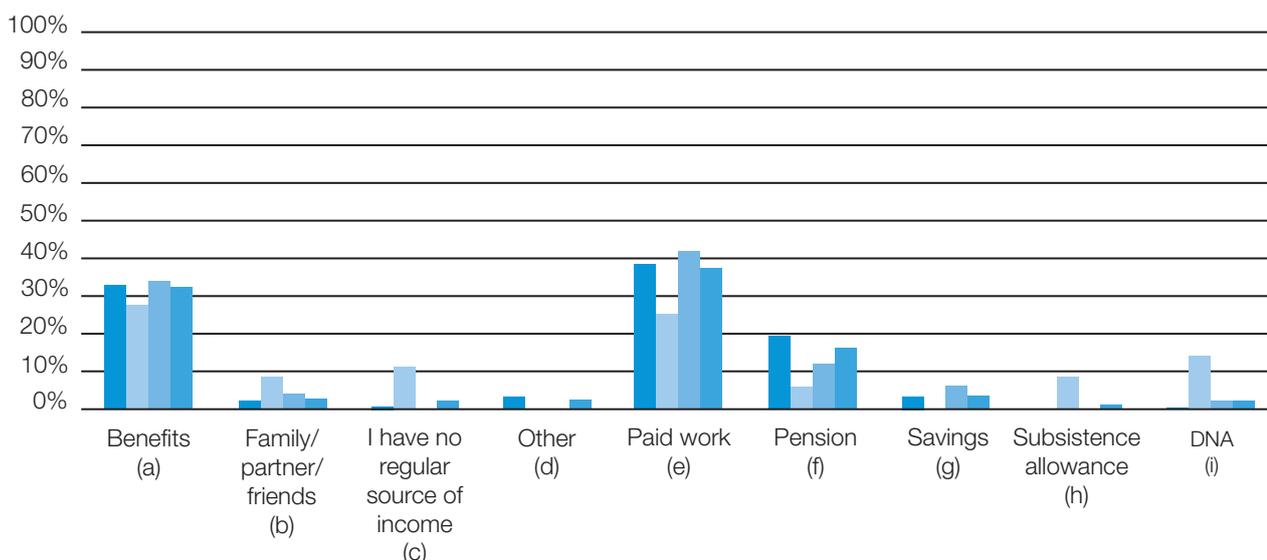
Although work was most frequently the largest source of income, it was so for only just over a third of people (37.3%). For all groups, benefits were the second most significant source of income, with around a third identifying this as their largest source of income (see Figure 13 on page 31). Disability Living Allowance and Incapacity Benefit in particular were key sources of income, although many black African women cited a complex web of low-level benefits, vouchers (see Glossary) and money from others. Again, this is likely to be linked to immigration difficulties.

Figure 12: Do you have enough money to cover your basic needs?



	Gay/Bisexual men	Black African women	White heterosexuals	Total (N=410)
Yes, all the time	61.0%	16.7%	56.0%	53.7%
Yes, some of the time	32.1%	25.0%	28.0%	31.7%
No	5.9%	50.0%	16.0%	13.2%
DNA	1.0%	8.3%		1.5%

Figure 13: Largest source of income



	(a)	(b)	(c)	(d)	(e)	(f)	(g)	(h)	(i)
Gay/Bisexual men	32.8%	2.1%	0.7%	3.1%	38.3%	19.2%	3.5%		0.3%
Black African women	27.8%	8.3%	11.1%		25.0%	5.6%		8.3%	13.9%
White heterosexuals	34.0%	4.0%			42.0%	12.0%	6.0%		2.0%
Total (N=410)	32.4%	2.9%	2.2%	2.4%	37.3%	16.1%	3.4%	1.2%	2.0%

At the moment I have no money because I am not working. I asked for asylum seeking and it's still with the Home Office and when I applied for benefits it was turned down. My daughter is looking after me. I live with her. When I was working ... before, the Home Office stopped me from working. I was contributing to a pension fund and my money is still waiting there.

56-year-old black African woman from Coventry

Accessing the benefits system, with its regular checks on disability status, was seen by some respondents as humiliating and therefore a possible deterrent.

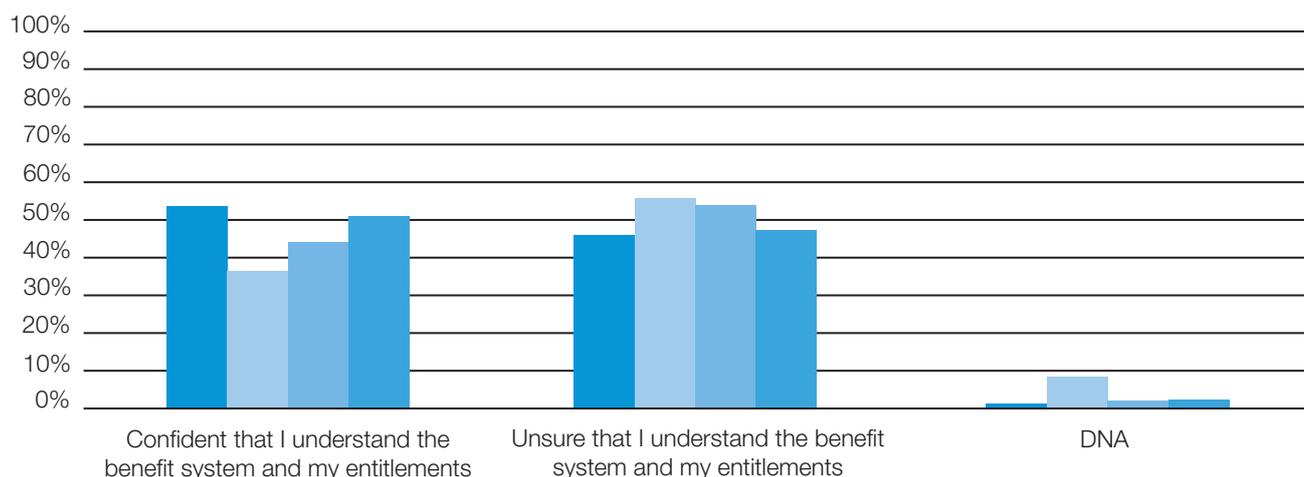
Having to go and sit in front of a different medical board each year to get assistance, it is so humiliating that I would rather go without than go through that over and over again. They have my hospital notes, why should I have to go and be humiliated and asked the same questions year after year?

51-year-old white heterosexual woman from Jersey

In spite of this level of reliance on state benefits, only half of the sample were confident they understood the system. Gay/bisexual men were the most likely to think they understood it and black African women the least, but in all groups there was a substantial level of insecurity about their understanding (see Figure 14 on page 32).

Two thirds (62.9%) of respondents felt that financial and debt advice were important kinds of support which would be needed in the future. Benefits and financial advice, including debt counselling and income maximisation, as well as improvements in access to employment, are all likely to be of enormous help to older people with HIV. However, even with advice, some people are resistant to the idea of going on benefits after a lifetime of work.

Figure 14: Understanding of state benefits and entitlements



	Confident that I understand the benefit system and my entitlements	Unsure that I understand the benefit system and my entitlements	DNA
Gay/Bisexual men	53.3%	45.6%	1.0%
Black African women	36.1%	55.6%	8.3%
White heterosexuals	44.0%	54.0%	2.0%
Total (N=410)	50.7%	47.1%	2.2%

Friends have told me that, you know, the recession is on. I am over 60, I should go on benefits and I have looked online and I find the whole area and system very difficult. Even a simple thing like do you consider yourself disabled, I find that very difficult to answer because I have always ticked no. But actually someone else who has [another long-term condition] might tick yes. So I have a problem here whereby if I am allowed support because of my HIV infection, how is it that I have spent all of my life doing what I need to do, going to work, earning, paying taxes, paying national insurance, all those things which I think are exciting and we need to do ... So I did look online and [a VCO worker] explained what I could apply for ... and I found her very helpful, she was very clear but I have a resistance to it, to applying for it.

60-year-old gay man from London

Currently, support for anyone in negotiating the benefits system varies hugely and depends on local funding priorities. Citizens Advice Bureaux and other benefits advice agencies are increasingly overloaded. This affects people with HIV, as one of the community researchers observed to us: “Navigating the benefits system seemed to be linked to where you live, social services support through the clinics or organisations like THT, respondent education and demographics.”

These difficulties are only likely to increase, given the May 2010 government announcement of a review of Incapacity Benefit and their stated intention of getting people off disability benefits and into work. In such reviews, it will be important for the HIV sector to ensure that the government understands the difficulties faced by this group of older people in managing work and the benefits system rules.

Recommendation 14: Older people with HIV need support on money and benefits entitlement issues, including the understanding that such help is available to them. VCOs and statutory agencies providing such advice should review their services to ensure they are accessible and appropriate to this group. Where such advice is not easily available, statutory and charitable funders should prioritise its availability.

Access to financial products and services

Restricted (and until recently non-existent) access to financial products such as life insurance has been a problem for people living with HIV since the start of the epidemic. Only 18.3% of respondents overall had any kind of life insurance, with very few black African women having any. Private savings and/or investments were more common, with around a third (35%) of respondents reporting that they had these. Again, the picture for black African women was much less positive.

Perhaps reflecting the fact that many respondents were relatively recently diagnosed, access to private and work-based pension schemes was higher than for other financial products. Of those already retired, 37.8% had a private pension and 56.1% had an employer-funded pension. Just one African woman had a private pension. Looking to the future, older people with HIV have considerably less pension provision than the general population. Nationally, 27% of men and 21% of women over 55 (Office for National Statistics, 2007) are paying into a private pension, compared to just 11.6% of 50 Plus pre-retirement respondents. 34.1% of pre-retirement people living with HIV have an occupational pension scheme, compared with 59% of men and 39% of women in general over 55. Black African women had the least financial security, with less than one in ten having any of these financial products. Many people in 50 Plus are facing a future with a basic state pension which will leave them below the national poverty line.

There was a disparity between the number of respondents who identified concerns about money and the significantly lower numbers who said they wanted more financial advice services. In the qualitative interviews, we were unable to clarify the reasons behind this, but it has been suggested that, while older people with HIV are worried about their financial future, some do not feel there is anything that can be done to change it. There may be a need to demonstrate to older people with HIV that financial planning, debt counselling, money management and other such tools are appropriate and beneficial for them.

Recommendation 15: HIV VCOs should consider developing financial advice services for people with HIV who need to plan for retirement and older age as part of standard long-term condition management of HIV.

HIV, illness, work and financial difficulties

Many respondents reported having to quit their jobs, or at least change their career, due to ill health. For many, reduced levels of energy marked a profound change, and, with few exceptions, respondents who were interviewed reported that their life had worsened since they had been diagnosed; for some only slightly, for some significantly.

I get incredibly tired and I go to bed earlier than I used to ... I work in education and I have to have an early start and I'm really, really struggling and I'm starting to think do I need to completely change direction because I just can't sustain this, it's just not tenable anymore.

51-year-old white heterosexual woman from London

I'm unable to work and because of that my total income has dropped by half but I'm unable to get any help because of my personal pension ... My outgoings are still exactly the same as when I worked but the money coming in now is halved ... Money wise it's always a struggle. It really is a struggle. I want to work ... At the end of the month I don't want to look in the cupboard and have to say, 'It's going to be baked beans on toast darling' because we've got nothing left.

54-year-old white heterosexual man from Birmingham

Figure 15: Process chart on HIV, age, money, health and work

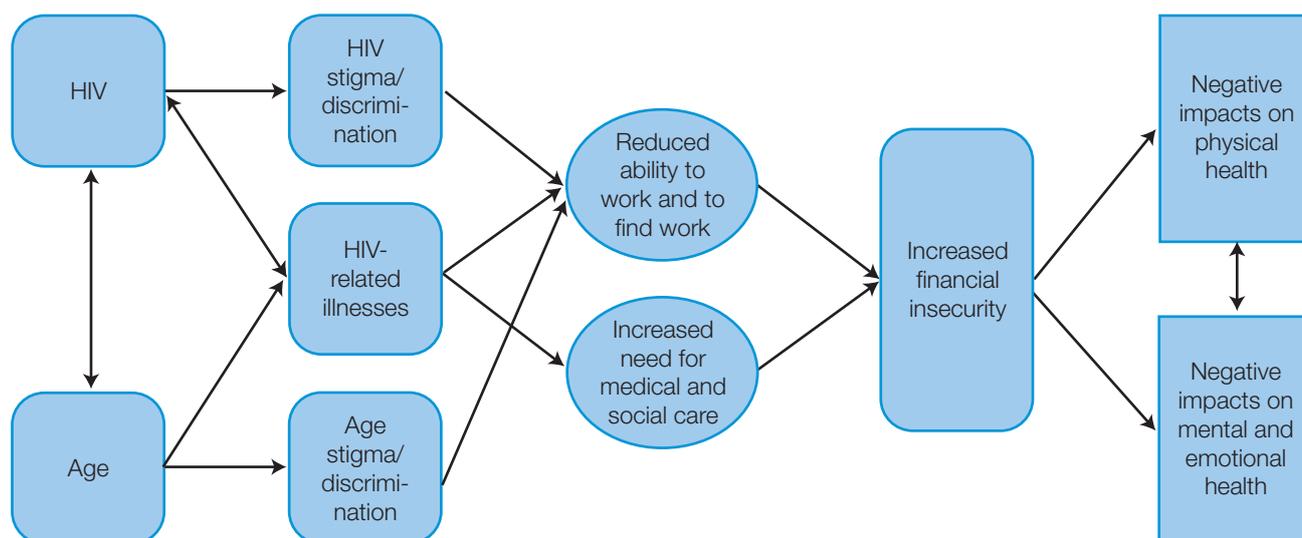


Figure 15 illustrates the complex relationships between HIV, age and stigma in impacting money, health and work.

Housing

Four out of five people in the UK (81.2%) who are 50 and over own or part-own their home (Department for Communities and Local Government, 2008), but only just over half (52.7%) of 50 Plus respondents were home-owners (see Table 4), with gay/bisexual men the most likely group to have this form of tenure (62.4%). The figures for black African women were substantially lower (16.7%). This may be a reflection on income levels and poverty overall, but it may also be linked to the difficulties faced in obtaining a mortgage. Although it has been possible for people with HIV to become home-owners, the substantial difficulties and financial penalties placed in their way have been a deterrent.

Just under a quarter of the respondents (22.5%) were living in council or housing association properties, which is a higher ratio than in the general population (14.7%). This may reflect the relatively easy access to social housing which people with HIV had in the 1980s and 1990s, when an HIV diagnosis gave priority in many local authorities and housing associations (which is no longer the case). For some, high rents in both private and social housing fed into a ‘benefits trap’; they could not afford to go back to work and keep their housing.

I would like to go back to work but I can't afford ... because of the rent and stuff like that. There's many out there like me – trust me. If we had the opportunity to get, like, cheaper housing ... there are many people out there that are willing to go back to work and do stuff and move on with their lives.

55-year-old black African man from London

A small number (3%) lived in supported housing, either sheltered accommodation or care homes. Given the problems with mobility and self-care reported by the respondents (see Chapter 3), this proportion is likely to increase over time. Some respondents, particularly gay/bisexual men, expressed worries about eventually needing to enter care homes because of the ignorance or prejudice they expected to encounter there. A substantial number of respondents, without prompting, communicated a desire for a ‘gay old people’s home’ or asked whether such a project might be underway. This concern was mirrored in some of the projects visited in the US, where older gay men had experienced considerable discrimination in care settings. ACRIA and others in the US are now

engaged in training care providers to reduce these problems and there are advocacy groups, most notably SAGE, who are lobbying for better provision for older LGBT people.

I have looked at sheltered housing, but have been put off as I would be the only gay in the building and certainly the only one with HIV.

61-year-old gay man from Brighton

I am somewhat fearful of a lonely old age. In practical terms, if I become mentally or physically frail, the prospect of being the only gay man in an old people's home is very frightening indeed. There must be a market for gay old people's homes, but I don't know whether any exist yet.

52-year-old gay man from London

Recommendation 16: Providers of social housing and care homes for older people should audit their policy and practice to ensure that they provide accessible and appropriate homes and supportive care for people with HIV, as well as for older LGBT people.

African women were the most likely group to be in insecure housing, including asylum support housing, private sector renting and renting a room in a house with other tenants. Two people were homeless. The majority of respondents (55.9%) identified housing advice and support as a key future need, with black African women most likely (62%) to identify this need and gay/bisexual men (53.7%) least likely.

Almost half of all respondents lived alone (46.8%), with black African women the least likely (38.9%) to do so (see Figure 16 in the next chapter). The figures for black African women were broadly similar to other groups in terms of those not living with partners or other family members (52.8%), but were skewed by the number living in shared accommodation with non-family members (13.9%). Just over a third of all respondents (35.9%) lived with partners, with black African women the least likely (11.1%) to be doing so.

Table 4: Current housing status

Type of housing	Gay/ Bisexual men	Black African women	White heterosexuals	Total
I am homeless or staying with friends but not paying rent	1	1	0	3
I live in a care home	2	0	0	2
I live in a housing association flat or house	31	6	8	47
I live in asylum support housing	0	5	0	8
I live in sheltered accommodation	4	2	2	11
I own my home	179	6	24	216
I rent a council flat or house	26	8	4	45
I rent a flat or house	29	3	11	53
I rent a room in a flat or house with other tenants	6	4	0	10
Other	7	0	1	12
DNA	2	1	0	3
Total	287	36	50	410

Figures shown refer to numbers not percentages. Where numbers do not add up this is due to the category of 'other groups' not being shown in this table

3 Relationships, social well-being and seeking help

Isolation and social contact

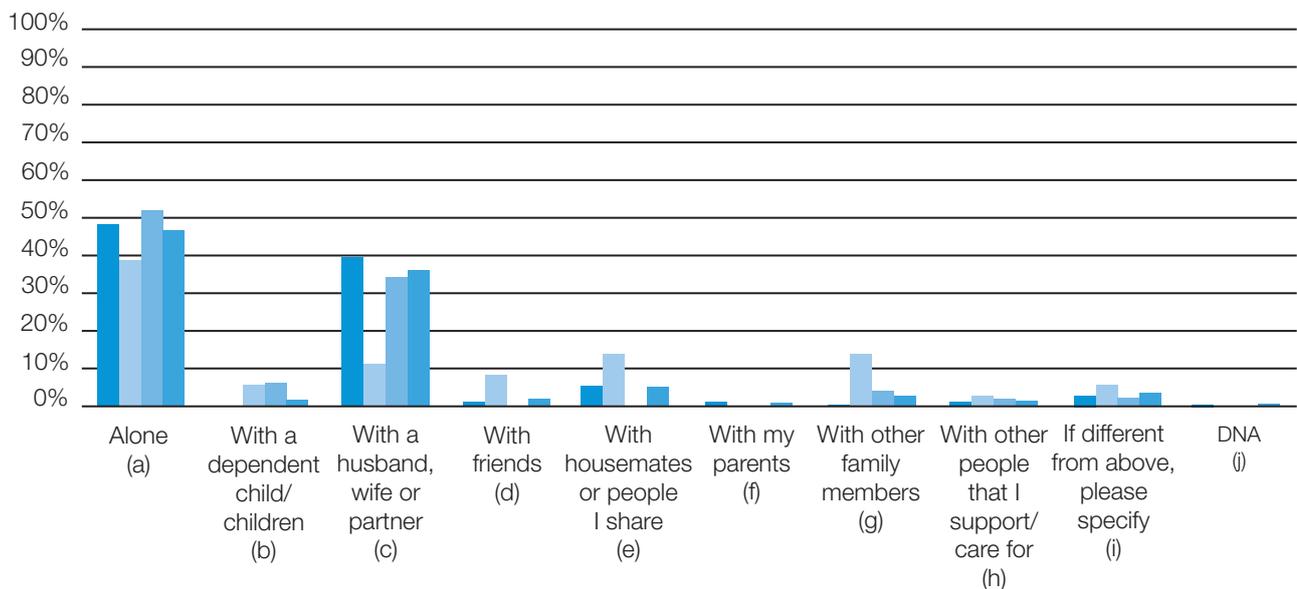
Isolation and difficulties in social interaction are frequently cited as a concern for older people. In our visits to US organisations this was also a common theme for older people with HIV, particularly older gay men who had outgrown a social culture which emphasises youth. Additionally, many of the migrant respondents, particularly the black Africans, were separated from some or all of their family geographically and those in this age group who were long-term survivors may have seen many of their friends, family and peers die with HIV.

I live in isolation. I do have a buddy who rings me once a week and visits me for two hours a week ... I can't afford to pay the carers because the council won't support them ... it would be nice just to have somebody to telephone.

61-year-old gay man from London

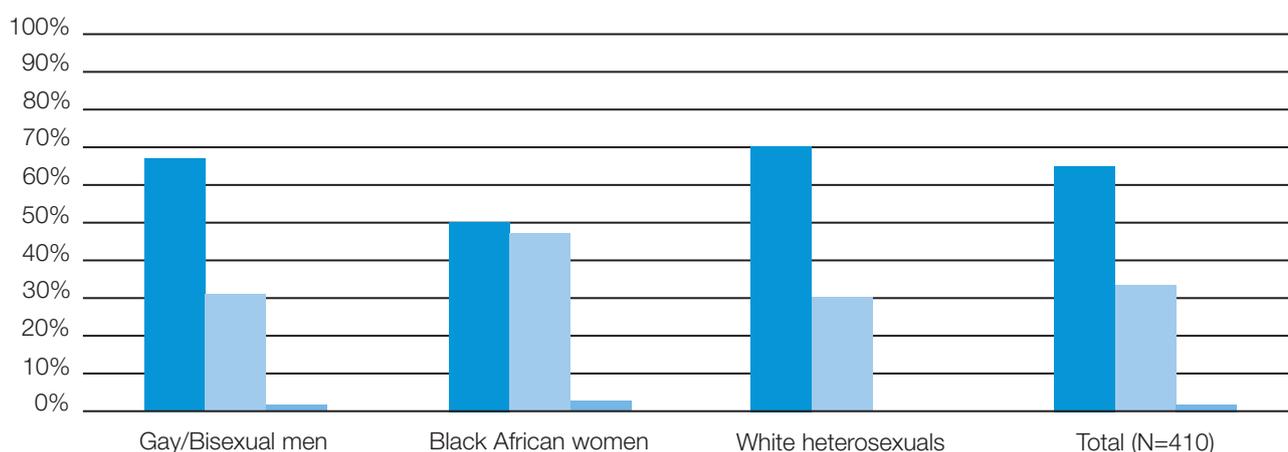
Although we did not ask directly about isolation, it is possible to see emergent patterns within the data. As discussed in Chapter 2, almost half the respondents lived alone (46.8%), with white heterosexuals the

Figure 16: Living arrangements



	(a)	(b)	(c)	(d)	(e)	(f)	(g)	(h)	(i)	(j)
Gay/Bisexual men	48.1%		39.7%	1.0%	5.6%	1.0%	0.3%	1.0%	2.8%	0.3%
Black African women	38.9%	5.6%	11.1%	8.3%	13.9%		13.9%	2.8%	5.6%	
White heterosexuals	52.0%	6.0%	34.0%				4.0%	2.0%	2.0%	
Total (N=410)	46.8%	1.7%	35.9%	2.0%	5.1%	0.7%	2.7%	1.5%	3.4%	0.2%

Figure 17: Do you currently do any voluntary work?



	Gay/Bisexual men	Black African women	White heterosexuals	Total (N=410)
No	67.2%	50.0%	70.0%	64.9%
Yes	31.0%	47.2%	30.0%	33.2%
DNA	1.7%	2.8%		2.0%

most likely to do so (52%) and black African women the least likely (38.9%). Over a third (35.9%) lived with a partner, however, which is more than the 27% shown in the Office for National Statistics data for the general population aged between 55 and 64 (ONS, 2007). Black African women were more likely than others to live with dependent children or other relatives.

Only a minority (43.7%) participated in organisations for people living with HIV, despite the likelihood of bias in the sample towards such participation because of distribution methods; 80.6% of black African women did participate, but only a third (33.1%) of gay men, many more of whom filled in this survey on the Internet through links in the gay or HIV press. Far smaller numbers (12.2% overall) took part in any kind of social group or organisation for older people.

Another way of reducing isolation is to get involved in voluntary work. One third (33.2%) of respondents, and 47.2% of black African women, currently did voluntary work (see Figure 17). This was higher than the English average of 26% for all adults (Department for Communities and Local Government, 2010). Volunteering by people with HIV within HIV VCOs is very common and people will often volunteer in the same centre where they receive services.

I come and volunteer at [the VCO] every Friday and do other activities and go to a support group. I feel more relaxed when I am with people who are already HIV and everyone is discussing issues on the same level. I get a lot of emotional support from it.

56-year-old black African woman from Coventry

Additionally, such volunteering provides a range of benefits to the services concerned and to the wider population of older adults living with HIV, through contribution to service provision, access to skills and work opportunities, role modelling and illustrating that older people are valued and welcome there.

Recommendation 17: HIV support organisations should seek to maximise volunteering opportunities for older people with HIV in order to decrease isolation and increase well-being and social attachment.

For some long-term diagnosed respondents, isolation increased as pressure on HIV services caused them to change from social day centre-type provision to short-term problem solving.

In the days of [long-standing VCO] there was always somewhere to come and sit in the garden, or have a coffee, and there would be other people there. I am sorry to say but now [it] is like a business service centre. I feel a stranger in my own environment. For someone who is going to get older, it is going to be a very lonely life.

61-year-old gay man from London

Older people with HIV can be caught between two stools: the HIV organisations which, in promoting self-reliance and self-management, have moved away from the day centre support model; and the organisations for older people where they may be able to access day centre facilities, but where they fear, as someone gay or with HIV, they will not find a welcome.

Recommendation 18: Where HIV organisations no longer offer ongoing social support groups, they should seek to identify other ways to support social networking for older people with HIV, including joint working to improve access to mainstream services aimed at decreasing isolation among older people.

Getting support

Where do older adults with HIV go, if they decide they want to either change their social habits or reduce their isolation?

Respondents were asked who they would go to for advice or support. The most popular source of support was friends, followed by a doctor or counsellor. The third most popular source of support was a partner; since not all the respondents had a partner, this ranking is unsurprising. Fourth was an HIV support group and, fifth, other people with HIV. Black African women were most likely to trust their HIV support group, while white heterosexuals were less likely than others to trust their doctor or counsellor.

Recommendation 19: Given the high levels of trust placed in clinicians and counsellors by many older people with HIV, provision should be made for other services promoting a healthy lifestyle and offering long-term condition management to work in collaboration with them, both directly and through improved referral networks.

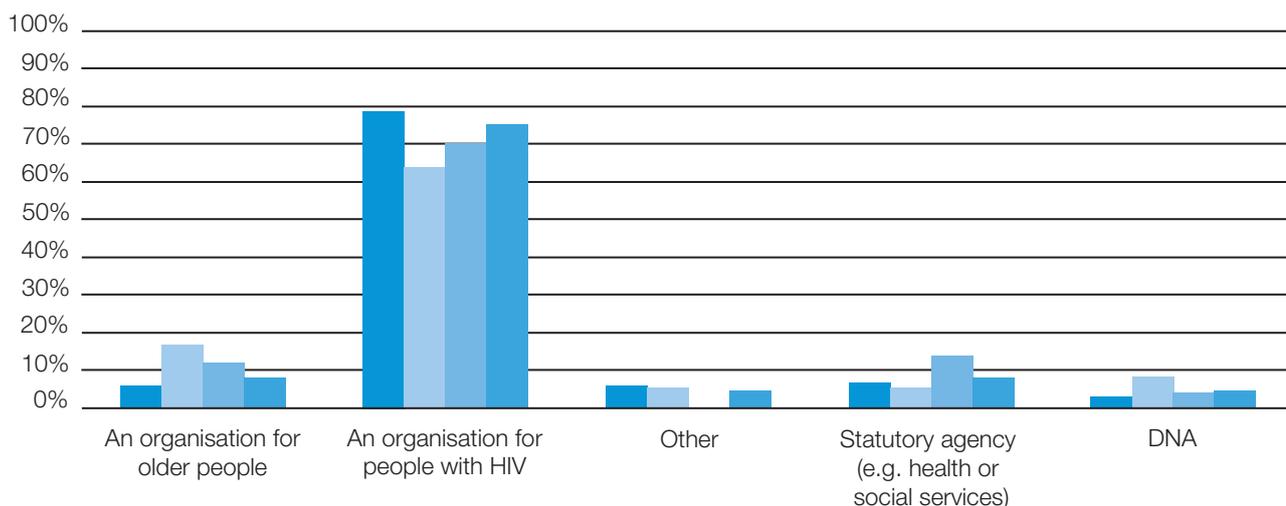
In terms of organisational advice, all groups much preferred to take advice from an HIV organisation rather than from either an organisation for older people or a statutory agency such as health or social services (see Figure 18 on page 39). Overall, 75.1% would pick an HIV organisation, 8% a statutory organisation and 7.8% an organisation for older people. It is important to remember that many respondents were below pension age and thus would not yet see themselves as 'older people'. However, the reluctance to consult an organisation geared towards older people also reflects a widespread concern about whether such mainstream organisations understand HIV. Given the lack of funding for HIV-specific work in many areas of the UK, this preference for HIV organisations may become increasingly difficult to meet. Work needs to be done to assure older people with HIV that they will be safe and supported in mainstream organisations for older people.

Some respondents, however, were already wanting to access services for older people, while others were doing so for lack of more targeted options.

[We want] programmes for the elderly where we can feel comfortable about our age. Because when we mix with young people, we don't talk about things that might affect us.

66-year-old black African woman from London

Figure 18: If you needed advice from an organisation, which would you prefer to get it from?



	An organisation for older people	An organisation for people with HIV	Other	Statutory agency (e.g. health or social services)	DNA
Gay/Bisexual men	5.6%	78.7%	5.9%	6.6%	3.1%
Black African women	16.7%	63.9%	5.6%	5.6%	8.3%
White heterosexuals	12.0%	70.0%		14.0%	4.0%
Total (N=410)	7.8%	75.1%	4.6%	8.0%	4.4%

I joined an elders group locally for the over 75s, even though I am nowhere near that. I can't believe I am going on day trips with women whose average age is 90, but I do it just to have human contact.

61-year-old gay man from London

How is support accessed?

Respondents were asked, in relation to their involvement with organisations for people with HIV and older people, how they interacted with people within those groups. As mentioned above (see pp. 36–8), they were currently considerably more likely to participate in groups for people with HIV (43.7%) than in groups for older people (12.2%). However, in both cases face-to-face interaction was considerably more popular than online interaction through chat rooms and online forums.

Many respondents stated that they felt existing support groups for people with HIV were predominantly geared towards a different age group.

[The support group was] full of young people but it is not convenient for elder people. I feel embarrassed.

66-year-old black African woman from London

There was also criticism of the images promoting services for people living with HIV.

I also feel that services are mainly geared to younger people with HIV. When I look at websites [for VCOs] it shows young somethings portraying the illness in a manner that is unrealistic and inappropriate.

52-year-old gay man from Hatfield

Because of funding constraints, a number of social care organisations are exploring greater use of the Internet to provide services to more people, often over a wide geographic spread. The vast majority of gay/bisexual men in this survey had regular access to the Internet, with just 4.2% saying they did not, but among the smaller group of older black African women respondents, 38.9% did not have regular access, and among white heterosexuals the proportion not regularly using the Internet was 22%.

If access to services is to be available to all who need it, online services will have to be developed with care and take into account groups with relatively poor access. Online contact is likely to be particularly important where people want to meet others specifically 'like me' who are living with HIV. Almost half of all people with HIV in the UK live in London and a substantial amount of the rest in a small number of other key cities. Thus, even in major towns, people with HIV who are not gay or African may be thin on the ground in peer support terms. In more rural areas, face-to-face contact with anyone else with HIV, outside of clinic visits, may be even rarer.

The biggest problem I have found in [major city] ... is that the majority of groups that are there to help people with HIV tend to be geared up to the gay, lesbian, bi community or the Afro-Caribbean community and there's nothing for me. The majority of people who go to [VCO] are gay, fine, I don't have a problem with that ... but I would like more of a straight, European mixed support group.

54-year-old white heterosexual man

In many of the qualitative interviews, peer support was mentioned as something that people had found helpful or that they wanted to access in the future. This links into the mental health needs of older people with HIV (discussed pp. 23–4) – the importance of knowing that you are not alone, that others have experienced (and managed their way through) what you are going through.

Sometimes, late at night if you're getting worked up, it would have been really nice if I could've sat down on the computer and gone to a chat room and talked to people ... I've had more help from other people with HIV and their experiences than I've had from the authorities.

54-year-old white heterosexual man from Birmingham

As many interviewees explained, older people with HIV have a distinctive set of worries, concerns and information needs, all quite different from those of younger people. While young people might be concerned about family planning and relationships, older people are more concerned, for example, with the approaching end of their working lives and the increasing financial difficulties, age-related co-morbidities and social care once they cannot look after themselves any more, or about dying in a dignified way.

Simple practical issues of particular importance to older people can also act as a barrier to access. Several respondents, particularly women, did not feel safe to go out to meetings and support groups held in the evening.

I tried to join programmes like [age and HIV VCOs] as a volunteer, but ... most of the services are provided in the evenings and I am not able to travel in the night because of security reasons.

66-year-old black African woman from London

Recommendation 20: HIV organisations and those for older people need to work together to ensure appropriate support and advice is available to all older people with HIV in the UK and to ensure both are welcoming to older people with HIV.

4 Disclosure, stigma and social support

HIV is highly stigmatised in our society. The Department of Health has recognised the need to challenge such stigma and it was a priority within the National Strategy for Sexual Health and HIV (Department of Health, 2002). The Independent Advisory Group's review of the strategy in 2008 (MedFASH, 2008) reiterated the need to continue to focus on challenging stigma and discrimination, stating that 'one third of HIV positive individuals report having experienced discrimination, half of which occurred in general practice ... [and] in the face of stigma and discrimination, people with HIV may experience difficulties finding jobs or secure housing'.

It was anticipated that older people might fear disclosing their status, as it may infer sexual activity or sexual orientation which are more likely to be taboo in older generations. We therefore asked not only about acts of disclosure but about their perceived impact on relationships. The research identified considerable fear of disclosure and the qualitative interviews showed incidents where disclosure led to adverse reactions. The quantitative data, however, clearly demonstrates that the vast majority of respondents' experiences of disclosure were generally positive. This is not a message commonly heard and it bears closer examination.

It may be that respondents were extremely successful in judging whom to safely disclose to. It is true that, in contexts where disclosure was not easily controllable (e.g. healthcare), the overall balance of experiences was less favourable. Nevertheless, in the light of the very high levels of disclosure reported by older people with HIV, and the overwhelming balance of favourable responses in most settings, it may be that current messages from HIV support organisations about the likely impact of disclosure, which are often highly negative, need to be revisited.

Respondents were asked about experiences of discrimination and whether they attributed these to HIV or to being older. In several contexts, it seems that age discrimination may be more frequently experienced, or possibly more identifiable, than HIV discrimination. This may also be because HIV status can be concealed rather more successfully than age. However, there are significant concerns about some experiences of HIV discrimination and in this study the most alarming are the reported experiences of HIV-positive older people in primary care settings.

Disclosure

In spite of many people feeling anxious about disclosing their status, within the context of most types of relationships there were very few people who reported negative consequences. For the majority of people, disclosure brought no change, and in all areas, though not always for all subgroups, it brought substantially more positive than negative reactions.

My Mum just carried on drinking her tea. I never had any fear of telling anyone I got it.

50-year-old gay man from London

I told all my family. From day one I wanted to be upfront because I am always upfront about everything. Being out about this was just another part of being out.

56-year-old gay man from Manchester

Disclosure to partners and family

The overwhelming majority of respondents with partners reported that they had disclosed their HIV status to them. All black African women and white heterosexuals stated that they had done so and less than 2% of gay/bisexual men indicated that they had not. In most cases, those who had disclosed to a partner reported a positive outcome (i.e. 'no change' or 'improved' in terms of relational quality), with only around 15% of respondents who had disclosed to a partner indicating that their relationship with their partner had worsened as a result (see Figure 19). Many of the gay/bisexual respondents in relationships at the time of diagnosis said that their partner of the time was HIV positive himself and could thus relate to their situation.

[My partner] was really supportive. He had not been diagnosed long himself ... he was fantastic, as was everyone I knew.

50-year-old gay man from London

Some respondents emphasised that, while they would always disclose their status to sexual or other partners, this was often accompanied by anxiety and a fear of rejection or getting emotionally hurt.

I am not embarrassed about being HIV positive. If somebody asks, I tell them. I do get worried about telling certain people and how they will react ... Past experience, my partner was HIV. He told all his friends he was HIV positive and they all went and dumped him, or left him. And that made me think about the ignorance.

53-year-old gay man from Cardiff

Some of the heterosexual respondents found disclosure to their partners very testing for their relationships.

I don't think my wife knew how to react. I can remember very early on we were sitting at home and we went to cuddle and she flinched. She didn't know whether we could even kiss and it hurt. I'm not saying she did it on purpose. I think we were both brought up in the very early stages of HIV when we had the 1980s scare tactics. All our knowledge tended to be from that. It hurt and I was embarrassed, I was ashamed and even now I just feel dirty.

54-year-old white heterosexual man from Birmingham

Due to the extreme stigma of HIV in some African societies, a number of the black African women reported difficulties after disclosure. While more than a quarter of gay/bisexual men and white heterosexuals reported that their relationship had improved, no black African women reported this outcome.

I told my husband but he refused to accept it. He actually blamed me for going for the test. He said, 'Look what you've done. You've gone and found out something that is going to affect the whole family now.' Because there is no medication in my country and there is the stigma, people would rather not know ... my husband was so bitter.

56-year-old black African woman from Coventry

Relationships with other family members followed similar patterns, although levels of disclosure were slightly lower. For example, just over half (56%) had disclosed their status to their mother, with white heterosexuals the most likely to disclose (70%) and black African women the least likely (50%).

My family, [they] don't know that I am HIV positive and there are a number of reasons for that. They know that I am gay although my dad is dead now, my mum is in a care home but my sister and my brother and their families know, but I didn't tell my mum and dad when I tested positive because

I thought there was nothing I could do about it. They had already been through a whole, you know, years of worrying about my health [an existing health condition] and I felt I didn't really see the point.

60-year-old white gay man from London

Where people did not disclose their status to family members, especially elderly parents, the decision was often motivated less by a fear of rejection or discrimination than by a desire to spare them the worry, and by the fact that parents would not be drawn on for support in the future very much.

Decisions not to disclose can also lead to considerable stress and enhance social isolation.

I went through a lot of stress. Did not know how my family would react. My doctor knew, my friends didn't. I kept myself secluded. Would not go out, would not mix.

53-year-old gay man from Cardiff

Of the respondents who did disclose to parents, around one in ten reported a negative outcome. While black African women were marginally more likely to state that the relationship with a parent deteriorated, they were also significantly more likely to report that disclosure improved their relationship (42% for black African women against 25% for all respondents).

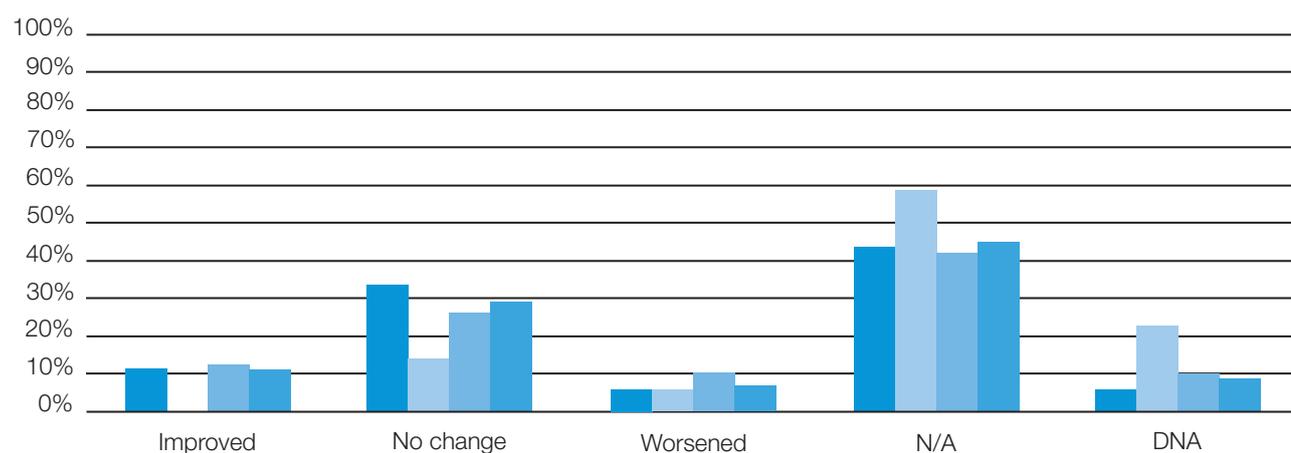
For those with children, more than two thirds had disclosed their status to all or some of their children. Around one in ten black African women and around one in five white heterosexuals had not disclosed to any of their children. Overwhelmingly, the response was positive.

Disclosing their status to children created particular problems for black African women, especially if their children were still living in the country of origin.

People back home, they don't [know I am HIV positive] because it will be a stigma, people won't come to your house, your children will be mocked and I was thinking I don't want to bring my children through this.

50-year-old black African woman from Glasgow

Figure 19: How has your relationship changed as a result of telling your husband/wife/partner your HIV status?



	Improved	No change	Worsened	N/A	DNA
Gay/Bisexual men	11.1%	33.4%	5.9%	43.6%	5.9%
Black African women	12.0%	26.0%	10.0%	42.0%	10.0%
White heterosexuals	11.1%	33.4%	5.9%	43.6%	5.9%
Total (N=410)	11.0%	29.0%	6.8%	44.9%	8.3%

Around 80% of respondents indicated that they currently had siblings. Again, the majority (69%) had disclosed their HIV status to some or all of them. Gay/bisexual men were least likely to disclose, with 35% telling none of their brothers and sisters. Black African women were the most likely to tell all or some of their siblings (87%). As with disclosure to their children, the vast majority reported a positive or unchanged outcome from this.

Disclosure to others

The patterns of disclosure in relationships with others show interesting variations within and across respondent groups. Nine out of ten respondents (88.8%) had disclosed their status to some or all of their friends, and a third of them to all of their friends. Black African women were the most likely to disclose to all of their friends (39.9%) and white heterosexuals the least likely (21%).

Of those who disclosed, less than one in ten (9.9%) reported that their relationships with friends had worsened, with no significant differences between groups. However, some respondents did report extremely negative experiences, sometimes from surprising sources, possibly prompted by personal fears.

[I] lost long-term friends when [I] told them, [they] made me feel like a low life. Even though my ex-best friend told me he hates condoms, he treated me like trash when I told him. And he told other people so now I don't trust anyone and don't go out.

50-year-old gay man from Brighton

Some respondents found that a decision to disclose to one person could have wider consequences. One man's friend passed on the diagnosis to others in the pub.

I don't know why he felt the need to divulge this, I don't know ... I don't think there was anything malicious, it might have been embarrassment, it might have been worry, whatever it was, but I was furious with him. When I met him the following week I said, 'You know that was totally out of order. It is my decision to tell people not yours.'

60-year-old gay man from London

Disclosure to work colleagues was less widespread. Just over half of respondents (53.4%) had told some or all of their colleagues. Black African women were least likely to disclose, with only one in five telling all or some of their colleagues. Gay/bisexual men were the most likely, with more than half (56.3%) telling all or some. Overall, disclosure at work was a positive or neutral experience for nine out of ten people (92.6%), with no significant variations between groups. This success rate may relate to the careful consideration of whom to disclose to, but the unexpected nature of these results merits further investigation in a wider group of people with HIV.

There were similar findings in relation to disclosure to employers. For those in work, 60.5% had disclosed their status. Black African women were the least likely to tell their employer (36.3%). Less than one in ten of all respondents (8.8%) reported that their relationship with their employer had changed for the worse as a result of disclosure.

While affecting only a minority of respondents, problems from disclosure in the workplace could have a major life impact. A number of respondents reported very negative experiences within their working environments. It remains the case that although there are now legal measures to support people with HIV who experience such discrimination, in practical terms these can be difficult to enforce, particularly for people without a permanent position.

At a school where I had been employed for a term in their inclusion unit I was asked to leave as a result of homophobic hatred stirred up by one colleague. The head was ok with me being gay and the fact I had HIV and I had not discussed my HIV with any other member of staff until one eventual après

conference drink – too late, by the morning the guy had whipped up so much hatred that I had to leave. Five teaching agencies have refused to put me on their books because of HIV status.

59-year-old gay man from Luton

Some respondents stated that they prefer not to tell colleagues or employers about their status in order to avoid discrimination in the workplace.

I've suffered no discrimination but I'm almost totally in the HIV closet, so no one has had a chance to discriminate. That, in a sense, is my only HIV problem ... I certainly would never tell anyone with whom I had professional contact.

54-year-old gay man from London

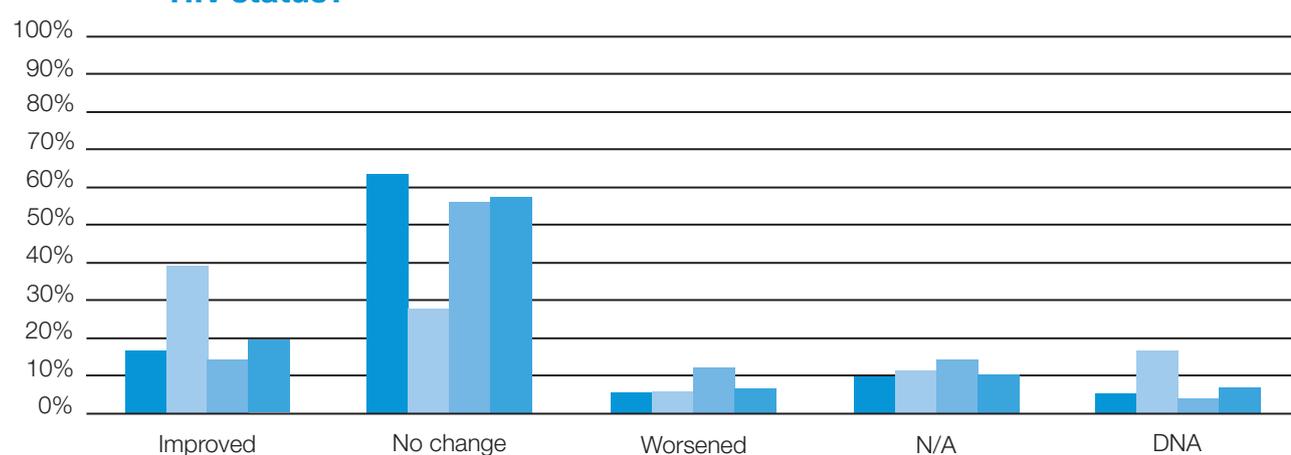
Despite the data showing high levels of disclosure to their GP (see below) and the vast majority of respondents stating that their relationship was either improved or unchanged as a result (see Figure 20), many of those we interviewed described discrimination at the hands of primary care staff and other medical professionals. Health workers with HIV were highly reluctant to discuss their status in their workplace.

Working as a healthcare worker ... I have seen and heard the nurses stigmatise patients. I've heard them say, 'Make sure you always wear gloves and use plastic spoons, plates ...' I think one day I am going to be ill and I am going to be treated the same way ... I will only talk about my HIV status to people who are also HIV positive, who I know will understand but not to anyone else ... I will always stick up for people on wards who are HIV positive.

56-year-old black African woman

More than nine out of ten respondents had disclosed their status to their GP. Of these, just 7.6% reported that their relationship had worsened as a result of disclosure, although twice as many white heterosexuals reported a negative outcome (14.6%). It is clear that many GPs have a positive working relationship with their patients with HIV. Nevertheless, many respondents still related negative experiences of primary care,

Figure 20: How has your relationship changed as a result of telling your GP your HIV status?



	Improved	No change	Worsened	N/A	DNA
Gay/Bisexual men	16.4%	63.1%	5.6%	9.8%	5.2%
Black African women	38.9%	27.8%	5.6%	11.1%	16.7%
White heterosexuals	14.0%	56.0%	12.0%	14.0%	4.0%
Total (N=410)	19.8%	57.1%	6.3%	10.2%	6.6%

and in our survey this was the area showing the highest levels of HIV discrimination in the past year. This finding is also supported by a number of other HIV studies on discrimination.

Recommendation 21: Further research should be undertaken into the experienced impact of status disclosure by people with HIV of all ages. Consideration should be given to re-evaluating the narratives current in many HIV services and information, which suggest that disclosure is always or most often a negative experience. Services should consider how they can constructively support people with HIV who wish to disclose, in order to achieve a positive outcome.

Stigma and discrimination

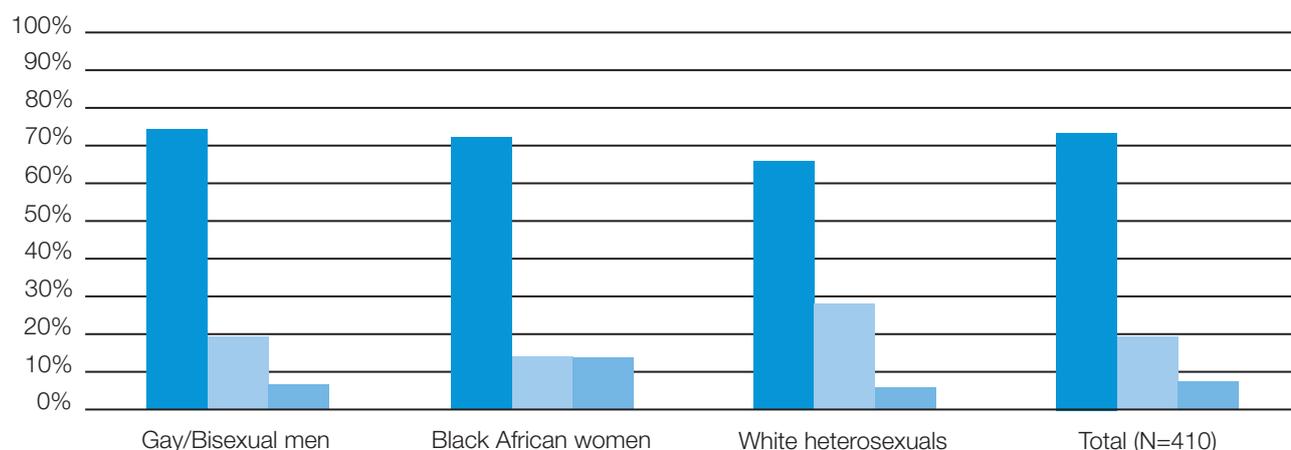
One in five respondents (19.8%) said that they felt they had been unfairly treated over the past twelve months due to either their age or their HIV status. Slightly less than three quarters (73.2%) stated that they had not experienced this. Figure 21 illustrates that white heterosexuals were the most likely, and black African women the least likely, to feel that they had been treated unfairly.

It should be noted that, in the qualitative interviews, while individuals did not necessarily experience discrimination in the past twelve months, many recounted instances prior to this.

Those who reported unfair treatment were asked to identify, from a menu of ten types of discrimination, whether they felt this had been because of their age or their HIV status (see Table 5). The three types of unfair treatment respondents were most likely to report were (in descending order):

1. Failed to treat you with respect (e.g. ignored you, left you out of something important or left you feeling 'invisible').
2. Ridiculed or insulted you or embarrassed you deliberately.
3. Refused or delayed your healthcare or treatment.

Figure 21: In the past twelve months have you been treated unfairly because of your age or HIV status?



	Gay/Bisexual men	Black African women	White heterosexuals	Total (N=410)
No	74.2%	72.2%	66.0%	73.2%
Yes	19.5%	13.9%	28.0%	19.8%
DNA	6.3%	13.9%	6.0%	7.1%

In most cases, the reason for such treatment was fairly evenly attributed between their HIV status and their age. Of those who felt they were not treated with respect, 53.8% ascribed this to their HIV status and 46.2% to their age. Black African women were significantly more likely than other groups to attribute to HIV rather than age.

Similarly, 53.6% of those who felt they had been ridiculed or embarrassed attributed this to their HIV status. However, gay/bisexual men were more likely to attribute this to their age (56%) than to their HIV status (44%). This may relate to the youth-oriented culture among gay men, which is even more pervasive than within general society.

With lipodystrophy you might as well have AIDS tattooed on your forehead. When it is bad people just stare and stare at me all the time, so much so that I become frightened to leave the house ... also, old and wrinkly is not a good look, so the chances of meeting anyone who fancies you decrease with time and combined with the death of most of my friends in the '80s and '90s, means that there is no one left alive to be friends with.

59-year-old gay man from London

In two areas, experiences of discrimination due to HIV far outstripped those due to age. Many more people were likely to attribute refusal or delays in healthcare to their HIV status. This mirrors other research into HIV discrimination (Weatherburn *et al.*, 2009), where non-specialist (and particularly primary) healthcare staff often feature prominently. This is similar to experiences related to us during the US research trip, where many HIV providers told us of serious stigma experienced by people with HIV as they aged and needed greater contact with primary care physicians and those managing co-morbidities. The other area of discrimination was in goods and services, where many people with HIV have been traditionally unable to access a range of financial products, as well as experiencing (now illegal) refusals of service, e.g. from dentists.

Experiences of discrimination due to HIV status cut across virtually all private and public realms. Respondents reported being excluded from a training course, being unable to get travel, medical or mortgage insurance, being denied visas for certain countries and being refused by a hairdresser.

Table 5: Experiences of discrimination because of age or HIV status

Type of discrimination	Because of age	Because of HIV status
Ridiculed or insulted you or embarrassed you deliberately	26	30
Denied you a job or interview	17	8
Denied you a promotion	8	7
Failed to treat you with respect	36	42
Denied you training or education	8	8
Treated you as if you were a child	11	17
Refused or delayed your healthcare or treatment	9	33
Treated you with hostility	12	21
Vandalised or damaged your property	5	4
Refused to provide goods or services such as insurance	2	17
Total	134	187

In all, 81 respondents reported discrimination. Respondents could identify more than one incident or type of discrimination

I was sitting in an HIV clinic reception and three women entered and sat down beside me. Sensing they were in the wrong place one of them asked me what clinic it was. I told her it was the HIV clinic. She pulled a face, jumped up and backed away from me as if I was a leper and told her friends to get out quick.

55-year-old gay man from London

However, the nature of stigma is that it can be, and often is, assimilated by those who are its object. Some respondents recounted situations where other people with HIV attempted to reinforce stigma because of their internalised fears of the possible consequences of exposure, despite others being apparently accepting.

The worst discrimination I have faced is from others with HIV. I have been ... shunned and denied their support many times over the last year by other people living with HIV in my very rural area ... because I am open about my HIV and refuse to live a secret or double life. I have a blog, I have been on the local radio, a newspaper, two magazines and done public speaking on HIV. Surprisingly my family, my friends, my neighbours and even most in my very small rural community have all been fine about this ... but others with HIV have actually been very angry about my being so public about my HIV and trying to educate and raise awareness. Many are scared of their own status being disclosed by association with me.

57-year-old white heterosexual woman from Cornwall

Discrimination in the workplace

As noted above, discrimination in the workplace can have life-altering consequences and cause serious economic harm to an individual. However, it can be very hard to challenge. Most people are unwilling to resort to legal action, preferring either to move on or to try and work through the situation. Challenging discriminatory behaviour by management or other staff while remaining in post is a stressful path at any time, which many people choose not to take. The prospect of legal action is expensive and intimidating and many people with HIV are unwilling to risk publicity at a tribunal.

Told my boss at work my HIV status ... was given a year off ... without pay, which I requested. On my return a year later I was made to feel unwelcome, unsupported, undervalued. I left after four days of returning.

50-year-old gay man from London

My former employers were unwilling to accommodate flexible working to enable me to rest more and take more exercise; I was spending 40 hours a week at a computer. They regarded me as 'obstructive', 'unhelpful' and 'difficult', although they could not produce any evidence to support this view, and gave me glowing reports in my annual performance appraisal. These confusing messages made me decide to leave, and I negotiated a settlement with them.

58-year-old gay man from London

Discrimination and medical professionals

Strikingly, medical professionals (such as GPs, dentists and nurses as well as other healthcare staff including pharmacists and receptionists at GP practices) were among the most commonly cited as perpetrators of (often outright) discrimination. Some respondents described being treated as "outcasts" or "lepers", with examples of exaggerated hygienic measures and always being treated last in order "to give them time to scrub the place down".

I went to my GP and saw a doctor I hadn't seen before. I wanted help with a fungus problem. I felt it was necessary to ensure he knew I was HIV because the fungus was probably HIV related. He then became fixated on making sure that my records on his computer had to indicate to all who saw them that I am HIV positive ... I told him I would prefer it if my HIV status was not stated in computer records. He snapped back that, 'They have to! For all our sakes!' I have avoided seeing that doctor ever since.

55-year-old gay man from London

GPs ... an absolute waste of time. I am not treated with any kind of respect.

61-year-old gay man from London

Many respondents described how difficult it was to find a dentist willing to treat HIV-positive patients, despite clear HIV guidelines from the British Dental Association.

Dental care was a nightmare to get. [I got] ridiculed and embarrassed due to my disclosure.

57-year-old gay man from London

I have ongoing problems with NHS dentistry; both in being able to find one prepared to take on a HIV patient, and then problems with the way they treat me, being over-zealous in taking normal precautions.

51-year-old gay man from Swansea

A lack of confidentiality was a major concern for many respondents in their experiences with GP receptionists and pharmacists. This is a particular issue for people as they grow older and generally need greater contact with such services.

My wife and I went for the flu jab together and the nurse said I would have to come back in three weeks' time and I asked why and she said, 'Because of what you are' and it was just thoughtless ... a receptionist was making an appointment for me ... and said in front of everyone, 'Make sure he gets his appointment with the doctor, he's HIV.' I hit the roof ... It wasn't done in a nasty way; it just wasn't done with any forethought ... it winds me up.

54-year-old white heterosexual man from Birmingham

Political leadership will be important in pushing through change in this area of long-standing problems, an area vital to the care of older people with HIV in the future. A recent example of such leadership is a Welsh Assembly's report (Welsh Assembly, 2010) which recognised these problems within general healthcare and recommended, among other things, improved training for health professionals about HIV. The report also encouraged HIV organisations to advocate for people with HIV who were reluctant to make formal complaints for fear of prejudging their future treatment.

Recommendation 22: Greater efforts should be made by HIV VCOs to support people with HIV who choose to challenge stigma and discrimination through disclosure. Support should be provided by a variety of means in information, groupwork, training and advocacy. Such efforts should particularly focus upon disclosure and discrimination in the workplace and in healthcare settings.

Recommendation 23: Primary Care Trusts and Health Boards must show greater leadership in challenging HIV stigma and discrimination within generalist healthcare settings and in making it clear that this is unprofessional and unacceptable behaviour towards a vulnerable group of patients.

Recommendation 24: Other governments of the UK should consider the findings of the Welsh Assembly report ‘Equality of Opportunity Committee: Inquiry into Discrimination against People Living with HIV by Healthcare Professionals and Providers’ and undertake a similar inquiry within their own countries and act on the findings.

5 Recommendations

Throughout this paper, we have placed recommendations in the context of the evidence on which they are based, in order to allow evaluation. Wherever possible, these recommendations are couched in flexible terminology so they can be tailored to specific countries, demographic groups and organisational structures. They also take the current economic situation for health and social care into account, as well as the uncertain policy landscape of the new coalition government of May 2010.

Older adults with HIV have a range of diverse characteristics. Their health and social care needs are substantial and they are currently facing considerable inequalities. Potential remedies for some of these are suggested in the recommendations below.

General

1. Governmental, NHS and other policy-makers, strategists and funders need to recognise the growing numbers of people aged 50 and over who are living with HIV in the UK; their health, social, financial and emotional needs; their diversity and complexity; and their dignity, rights and willingness to engage with change as they face an uncertain future and live with HIV into older age.
2. Future needs assessments for services for adults with HIV should specifically consider older adults. In particular, the complex and often acute needs of black African women with HIV must be addressed.

Health and social care

3. Easy-to-understand information on health and treatment issues pertinent to older people with HIV needs to be developed by HIV information providers. Such material needs to consider a range of common co-morbidities as well as common co-infections. Targeting of material to meet the needs of different social groups with high prevalence of HIV should also be considered.
4. HIV testing services and prevention initiatives, in particular those aimed at gay/bisexual men, need to consider people over 50 as a target group. Where such services are generic or aimed at the whole adult population, they need to explicitly consider and include the needs of older adults within this.
5. HIV clinicians should work together with specialist clinicians and with geriatricians for common co-morbidities to share and increase knowledge of diagnosis and treatment.
6. Long-term condition management courses and positive self-management courses for people with HIV should offer information and support to enable healthy choices and self-care to counteract or minimise the multiple co-morbidities which older people with HIV face.
7. Adults over 50 with HIV are most likely to need a range of other healthcare services alongside their HIV care. Greater efforts should be made by HIV information providers to inform them of their rights

to healthcare and, where there are restrictions, provide support to negotiate the complex system of government caveats, enabling access to immediately necessary treatment. The impact of such restrictions should be further investigated in order to inform future policy development.

8. Further efforts should be made by the NHS, the Royal College of General Practitioners, specialist HIV clinicians and community groups to improve the quality of primary care for people with HIV.
9. Services which support the mental health and well-being of people with HIV over 50, including counselling, peer support and other emerging strategies within long-term condition management, should be prioritised for development, evaluation and funding.
10. Social care providers for older people and those for people with HIV should work together to address knowledge gaps and service gaps on each side, ensuring quality services for all.
11. Counselling and peer support mechanisms should be incorporated within long-term condition management strategies for older people with HIV by both funders and service providers.
12. Social care services for older people should have in place best practice policies for dealing with blood-borne conditions and should provide basic training in HIV awareness and sensitivity to all frontline and managerial staff likely to encounter service users with HIV. Those who commission and fund such services should require this as a basic quality measure.

Work, money and housing

13. Older people with HIV would benefit from greater support to re-enter or remain in the workplace. Voluntary and statutory services for people with HIV should consider how they can best provide such support, including joint working with generalist employment schemes.
14. Older people with HIV need support on money and benefits entitlement issues, including the understanding that such help is available to them. VCOs and statutory agencies providing such advice should review their services to ensure they are accessible and appropriate to this group. Where such advice is not easily available, statutory and charitable funders should prioritise its availability.
15. HIV VCOs should consider developing financial advice services for people with HIV who need to plan for retirement and older age as part of standard long-term condition management of HIV.
16. Providers of social housing and care homes for older people should audit their policy and practice to ensure that they provide accessible and appropriate homes and supportive care for people with HIV, as well as for older LGBT people.

Relationships, social well-being and seeking help

17. HIV support organisations should seek to maximise volunteering opportunities for older people with HIV in order to decrease isolation and increase well-being and social attachment.
18. Where HIV organisations no longer offer ongoing social support groups, they should seek to identify other ways to support social networking for older people with HIV, including joint working to improve access to mainstream services aimed at decreasing isolation among older people.

19. Given the high levels of trust placed in clinicians and counsellors by many older people with HIV, provision should be made for other services promoting a healthy lifestyle and offering long-term condition management to work in collaboration with them, both directly and through improved referral networks.
20. HIV organisations and those for older people need to work together to ensure appropriate support and advice is available to all older people with HIV in the UK and to ensure both are welcoming to older people with HIV.

Disclosure, stigma and social support

21. Further research should be undertaken into the experienced impact of status disclosure by people with HIV of all ages. Consideration should be given to re-evaluating the narratives current in many HIV services and information, which suggest that disclosure is always or most often a negative experience. Services should consider how they can constructively support people with HIV who wish to disclose, in order to achieve a positive outcome.
22. Greater efforts should be made by HIV VCOs to support people with HIV who choose to challenge stigma and discrimination through disclosure. Support should be provided by a variety of means in information, groupwork, training and advocacy. Such efforts should particularly focus upon disclosure and discrimination in the workplace and in healthcare settings.
23. Primary Care Trusts and Health Boards must show greater leadership in challenging HIV stigma and discrimination within generalist healthcare settings and in making it clear that this is unprofessional and unacceptable behaviour towards a vulnerable group of patients.
24. Other governments of the UK should consider the findings of the Welsh Assembly report 'Equality of Opportunity Committee: Inquiry into Discrimination against People Living with HIV by Healthcare Professionals and Providers' and undertake a similar inquiry within their own countries and act on the findings.

Glossary

ACRIA – the AIDS Community Research Initiative of America

ASG – AIDS Support Grant, a ring-fenced social care grant to English local authorities

Asylum seeker – a person who has lodged an application for protection on the basis of the Refugee Convention or Article 3 of the European Convention on Human Rights

Disability Living Allowance (DLA) – a benefit for those who need someone to help look after them because they are physically or mentally disabled

DNA – Did not answer

ENT – Ear, nose and throat

GMSS – Gay Men’s Sex Survey, an annual survey of gay men’s sexual behaviour in the UK by Sigma Research

Housing Benefit – a means-tested benefit payable to low-income households to cover their housing costs

HPA – Health Protection Agency, collects epidemiological and statistical information on communicable diseases

Incapacity Benefit – paid to people of working age who cannot work because of illness or disability

Income Support – an income-related means-tested benefit for people who are on a low income

LGBT – lesbian, gay, bisexual and transgender

Refugee – a person who ‘owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion, is outside the country of his nationality, and is unable to or, owing to such fear, is unwilling to avail himself of the protection of that country’ (1951 Refugee Convention)

SOPHID – Survey of Prevalent HIV Infections Diagnosed (all persons currently seen for treatment)

Special Rules Benefits – non-means-tested benefits intended for persons with terminal conditions

VCOs – voluntary and community organisations

Vouchers – food and clothing vouchers issued to some people refused asylum but nonetheless allowed to stay in the UK, in lieu of cash, usable only at restricted major stores

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Appendix I

Findings from the US research visit

As part of the review of need and in order to stimulate thinking about appropriate service responses, two members of THT staff visited research and service projects in two key locations in the USA – New York and Fort Lauderdale – both of which have large populations of older people with HIV and older people at risk of HIV. A wide range of projects were visited and key comparative lessons drawn from observation and dialogue.

In New York, the population of older people with HIV differs significantly from that of the UK in that, due to US political opposition to harm-reduction measures, many more are people with histories of serious substance abuse. Additionally, heterosexual African Americans, although similarly disproportionately affected by HIV, are not analogous to heterosexual African people in the UK. They have (among other differences) more problems with drugs and fewer or no problems with immigration status. The large populations of gay men in both countries are, however, broadly similar and an analysis of 50 Plus quantitative data alongside ACRIA's Research on Older Adults with HIV data (Karpiak *et al.*, 2006) revealed striking similarities between the two samples of gay/bisexual men, despite differing health and social care systems. These similarities included needs, concerns and behaviours.

The key agencies visited in New York were ACRIA (a community-based research organisation), GMHC (a VCO providing multiple services for people with HIV and those at risk), Village Care New York (social care services), Services and Advocacy for GLBT Elders (SAGE) and the New York Association on HIV Over Fifty (NYAHOF, a support and advocacy group run by people with HIV). They presented a remarkably coherent picture of a population with high levels of social care need, high levels of isolation and mental health issues, chronic ill-health with complex co-morbidities and seriously underserved by mainstream health and social care services for older people.

Key learning points from New York were:

- Causes of mental health issues and depression in older people with HIV are highly complex, including multiple bereavement, uncertainty, debilitating chronic illness, stigma and isolation. Talking therapies were deemed to be of greater help than medication.
- HIV doctors do not understand ageing and geriatric clinicians do not understand HIV; nurse practitioners and other staff need training in HIV. In short, educating the primary care sector is the most vital and urgent action needed. Co-morbidities make managing one's own health increasingly difficult with ageing, and the support of informed medical staff is key.
- Partnership working between HIV organisations and those for seniors is essential, including cross-training, shared policy objectives and service development.
- Those people who choose to access generic services because they do not want to be defined by their HIV often find themselves 'bounced back' to HIV services by clinicians reluctant to engage with HIV.
- There is likely to be continued uncertainty about the interactive health impacts of ageing, HIV disease and HIV treatment for years to come and appropriate information will continue to evolve at a fast rate.

- There are high levels of undiagnosed and late diagnosed HIV among the over 50s, due both to clinicians' unwillingness to discuss sexual matters with older patients, and to the similarities in presentation of HIV disease and diseases of ageing.
- Social care providers for older people are often poorly informed about HIV and reluctant to engage with sexual health issues. Older people themselves can be reticent in talking about their sexual health issues and older LGBT people are relatively reluctant to disclose their sexuality.
- LGBT sensitivity is particularly poor in the care-home system.
- Isolation is as much a product of poverty as of HIV, if not more so.
- Older people with HIV often have good attachment to their clinical services but little connection with other social groups.
- Older gay men with HIV have particular difficulties arising from ageism within the gay culture.
- The economic situation is critical for many people who have unexpectedly outlived their savings and are unable to find or manage work.

Two New York projects – SAGE and the MATCH programme from GMHC – stood out as serving gaps which are known to also exist within the UK. They offer highly transferable lessons.

SAGE is a long-standing LGBT community organisation with no current equivalent in the UK. It offers a wide range of services and advocacy for older LGBT people, including HIV prevention, information and social care. Alongside this, it advocates strongly for the needs of older LGBT people with HIV to the wider clinical and social care sector, challenging homophobic and HIV stigma. Given the strong correlations between the gay/bisexual populations in the ACRIA and 50 Plus surveys, we believe the time is more than ripe for a similar LGBT community initiative in the UK that would work alongside HIV and other LGBT organisations in promoting sensitive and accessible elder care for this population, including gay/bisexual men with HIV.

GMHC's MATCH programme (Moving Ahead Toward Career Horizons) is a return-to-work scheme which has been running since 2003–4. It incorporates life coaching, counselling, skills enhancement/development and training. This combination of individual emotional support and skills building is vital in supporting people to get into work after many years and, in particular, in tackling their fears about both their own abilities and the wider world's attitudes to them. While they work on skills such as IT, they also address confidence and self-esteem, which are often as great a barrier to employment as lack of skills. The programme is not HIV-exclusive, so those within it are not forced to disclose by association. While some elements of this approach are currently being trialled within UK projects, there is an urgent need to upscale this kind of work in the UK and demonstrate to funders the positive impact of an integrated programme.

Alongside these two 'fill the gap' projects, we also recognised that ACRIA acts as a powerhouse of knowledge and skills in terms of serving older people with HIV and helping to bring people together to share knowledge and best practice. There is no similar co-ordinating organisation in the UK, and we believe there is much the UK HIV and social research sectors could learn from ACRIA.

Fort Lauderdale proved to be a very different situation. In contrast to New York, where we met with a wide range of social care providers funded either by the state or by charitable donations, in Florida there appeared to be very little state provision for social care for people with HIV beyond that provided by the Ryan White Care Act funds. Indeed, there was comparatively little organised social care outside clinical and prevention services. Nevertheless, a range of dedicated individuals and organisations were able to give us both information and inspiration, particularly in the areas of HIV prevention and sexual health work with older people.

Guided by the expert and dedicated hand of Broward County Health Department's Edid Gonzalez, we spoke with the county's Healthcare Elderly Division (HIV and substance abuse services for elders), Care Resource (a community health provider), the Gay and Lesbian Community Center of Fort Lauderdale (HIV testing and support groups), Memorial Regional Hospital (case management and medical care) and the unique Noble A. McArtor Senior Day Care Center, the first day centre designed to cater for LGBT elders including people with HIV.

Key learning points from Florida were:

- Many older people with HIV like to preserve their independence from the care management system, but often seek support with disclosure, especially to their families.
- Healthcare workers need to be proactive in talking about sexual health, as older people will seldom raise the issue independently.
- Older people need assurances of privacy for testing, and often prefer to do this at home.
- The best people to talk to seniors about sexual health and HIV are other seniors; they often do not listen to younger people.
- HIV education needs to be sited within wider health education and information, with the opportunity for private questioning later.
- Despite a large population of older gay men in Florida, they are not integrated with mainstream social care; there are hopes that the 'baby boomer' generation of socially confident and openly gay men will help to break this down.
- The over 50s take up a disproportionate amount of the available social care services, despite the absence of services targeted at them.
- No clear referral pathways exist and multiple referrals often have to be made.
- Older people are generally reluctant to access support and to disclose their status, which can contribute to isolation.
- There is much unacknowledged sexual behaviour and partner change among older people in retirement complexes.

In Florida as in New York, there were two projects where transferability to the UK was immediately imaginable. The first was an HIV-friendly day centre for older LGBT people (the UK is notable for a virtual absence of social care services aimed at older LGBT people). The second was a scheme run by the Health Department which recruits senior volunteers to speak about sexual health and HIV to their peers and advocate for the issue in public forums.

The Noble A. McArtor Senior Day Care Center is the first day-care centre to offer targeted support to older LGBT people and their families. It is aimed at people over 60 who need assistance with two or more daily activities, but whose functions are not severely impaired. Alongside LGBT elders, the centre also currently accepts the parents of LGBT people, because it has found that they experience stigma within mainstream elder day-care services if they speak with pride of their children. As far as we are aware, this is not a need currently recognised within the UK. Their programme is that of any elder day-care centre –

bingo, talks, fitness and a hot lunch – but with open acceptance and discussion of issues of interest to LGBT people. HIV is not singled out, but is accepted within the wider framework and they host a weekly shared event for their elders and local LGBT teenagers to come together and support each other.

In a less structured but equally important way, Broward County's Health Division also tackles the issues of stigma and ignorance – in their case, the reluctance of older people in mainstream elder care to access sexual healthcare, including HIV prevention, testing and support. By training older adult volunteers to offer talks and advice to people in retirement communities and care settings, they challenge the lie that older people do not have sex lives, and remind heterosexual older people that, while pregnancy is no longer a concern, sexual health may still be. Using peer speakers and siting their outreach within a wider health context, they are able to challenge stigma and encourage people to access services they may need but fear to access. The programme also acts as an empowerment tool for those delivering it, as they rediscover skills and enhanced social interaction. This kind of programme could be set up by almost any HIV or elder care service, statutory or voluntary, to work within their local community, and does not require much in the way of resources or special funding.

Further in-depth information on these projects, contact details and other aspects of the research trip can be found at www.tht.org.uk/50Plus

Appendix II

About the respondents

Of the 410 respondents included in the final sample 81 (19.8%) were female and 329 (80.2%) were male. 287 men identified as gay/bisexual, 36 were black African women and of the 50 white heterosexuals, 28 (56%) were female and 22 (44%) male.

Survey responses were largely representative of the population of over 50s living with HIV in terms of gender, ethnicity and sexuality, with a slight bias towards the white heterosexuals. For example, 19.3% of those over 50 with diagnosed HIV are women in the SOPHID (2008) data (ibid.), compared with 19.8% of this sample. Similarly, according to SOPHID (2008), 44% live in London; for this survey the figure was 46%.

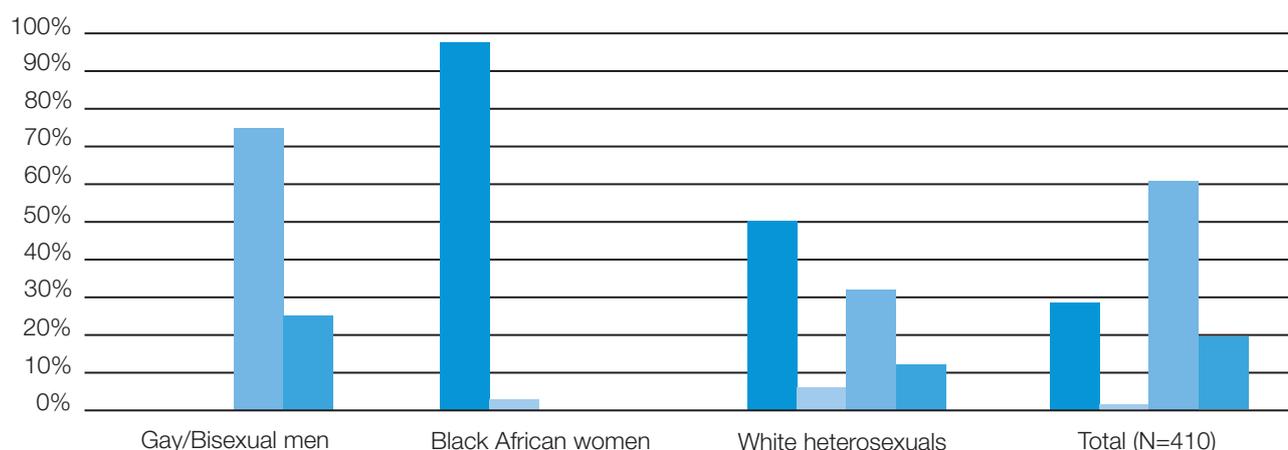
Age and pension age

In the whole group, three quarters of all respondents were in their 50s, with the remaining quarter being between 60 and 78. The black African women surveyed tended to be younger, with nearly 90% being in their 50s and only a very small group older. With regard to pension age, there were considerable differences across and within all three groups, as Figure 22 shows. For example, while only 32% of white heterosexual men were of pre-pension age, almost 75% – more than twice as many – of the gay/bisexual men were of pre-pension age.

Educational levels

Around two thirds of the group had a post-school education. Just under a third of gay/bisexual men and black African women had left school by the age of 18, with white heterosexuals slightly less likely to have done so (26%). Though the numbers were very small, black African women were most likely to have left school by the age of 12 or had no formal schooling at all.

Figure 22: Pension age



	Gay/Bisexual men	Black African women	White heterosexuals	Total (N=410)
Pre-pension-age women		97.2%	50.0%	18.3%
Pension-age women		2.8%	6.0%	1.5%
Pre-pension-age men	74.9%		32.0%	60.5%
Pension-age men	25.1%		12.0%	19.8%

Table 6: Country of birth

Country of Birth	Frequency	%
United Kingdom	280	68.3
Zimbabwe	18	4.4
Zambia	12	2.9
United States	11	2.7
Uganda	10	2.4
South Africa	8	2.0
Germany	7	1.7
Kenya	7	1.7
Other European countries	17	4.2
Other countries	14	3.4
Other African countries	12	2.9
DNA	14	3.4
Total	410	100.0

Figures shown refer to numbers not percentages

Country of birth and citizenship status

Of the 287 gay/bisexual men included in the sample, 246 were British citizens since birth, 17 were naturalised British citizens and 14 were citizens of a European country. A further 7 gay/bisexual respondents were migrants with varying immigration status, 2 described their status as 'other' and one respondent did not answer the question (see Table 6).

Of the 50 white heterosexual respondents included in the sample, 40 were British citizens since birth, 2 were naturalised British citizens and 5 were European citizens. A further 3 white heterosexual respondents were migrants with varying immigration status.

Of the 36 black African women included in the sample, 14 were asylum seekers, 13 were migrants with varying immigration status and 2 respondents had refugee status. No black African women had British citizenship by birth, but 6 were naturalised British citizens. One black African woman preferred not to answer the question.

Strategic Health Authority location

Combining all three groups, nearly half of all respondents resided within the Strategic Health Authority of London. However, as Table 7 shows, there were a number of significant differences between the three groups.

Disability

Less than a third of the black African women considered themselves as having a disability, compared with 43.6% of gay/bisexual men and 42% of white heterosexuals. Overall, at more than 55%, more people did not consider themselves to have a disability compared to those that did.

Table 7: Strategic Health Authority location

Health Authority	Gay/ Bisexual men	Black African women	White heterosexuals	Total
All Northern Ireland	2	0	1	3
All Scotland	6	6	8	21
All Wales	13	0	1	17
East Midlands	5	0	1	6
East of England	15	1	3	22
Isle of Man	0	0	0	1
Jersey	0	0	0	1
London	139	19	12	189
North East	9	0	1	10
North West	18	0	1	19
South Central	5	0	4	11
South East Coast	27	2	5	34
South West	14	0	5	20
West Midlands	9	1	2	14
Yorkshire & Humberside	7	0	6	14
UK-resident but area unknown	18	7	0	28
Total	287	36	50	410

Figures shown refer to numbers not percentages. Total figures include numbers of those categorised as 'other' which are not displayed here

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