

A national study of people over 50 living with HIV

Findings
Informing change

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With improved treatments, people with HIV in the UK can now hope to live longer into later life. But what *quality of life* can they look forward to, and how can it be improved? Terrence Higgins Trust and Age UK investigated the needs and concerns of older adults living with HIV.

Key points

- This group is highly diverse. Most are gay/bisexual men; other significant groups are African migrants and white heterosexuals. Some are long-term survivors; others are recently infected.
- Compared with their peers overall, this group:
 - report twice as many other long-term health conditions; many report mobility problems and difficulties with everyday tasks;
 - are less economically active, less likely to have a financial cushion for old age and more reliant on benefits. Many do not have enough money to manage on and have serious financial worries for their future;
 - are less likely to be homeowners and more likely to live in social or private rented housing
- Their highest future priority was for good quality health and treatment information.
- While they thought highly of their HIV clinicians, many reported poor experiences in primary care.
- Respondents feared that social care services, care homes and sheltered housing might be HIV prejudiced and/or homophobic.
- Many would like more social contact and support. Most prefer to find this through HIV organisations.
- Most were open about their HIV status in key relationships and had found reactions largely positive; however, disclosure is still seen as risky.
- One in five reported experiencing age- or HIV-related discrimination in the past year, with HIV discrimination worst in healthcare and goods and services.
- Black African women experienced substantially worse problems than others in a number of key areas.

The research

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Background

Until recently, older adults living with HIV have received little attention within social research and HIV services. It is clear though that, thanks to effective treatment, the over-50s are the fastest growing group of people with HIV in the UK. However, treatment is not a cure: people with HIV will have to cope with its effects for the rest of their life. Clinical understanding of HIV and its long-term management is still developing and those with the virus live with high levels of uncertainty about their future health.

This study (the 50 Plus project) surveyed a sample of adults aged 50 and over with HIV across the UK in 2009 to get a sense of their needs and concerns.

Experiences of health and social care

Older people living with HIV have exceptionally high levels of other long-term conditions which complicate and exacerbate their often poor health. Respondents had twice the expected level of these, including high blood pressure, kidney and liver problems and arthritis; almost two-thirds were taking treatments for such conditions. These are mostly conditions of ageing, but could also be linked to the long-term effects of HIV itself or to the side-effects of HIV treatments: half the respondents reported experiencing such side-effects. Many of these conditions could be improved if better management of lifestyles, including nutrition, smoking and exercise, were included within long-term condition management.

Older people in general make more use of their GP and general healthcare services. For older people who are also living with HIV relationships with GPs and other healthcare workers need to be as strong and as positive as those they report with their specialist HIV doctors. Yet respondents repeatedly told stories of discrimination, ignorance and poor clinical treatment in generalist healthcare, particularly in primary settings. This was despite high levels of disclosure to their GP – and generally positive outcomes from this. This finding mirrors the US experience: there they have begun to bring HIV clinicians, geriatricians and other physicians together to share expertise and improve practice.

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

Social care – both its current state and future provision – was of great concern to many. Half already experienced mobility problems and almost as many reported difficulty in managing everyday activities. Three-quarters identified social care as a future priority need. Given their financial situation (see below) much of this support is likely to be state provided. However, respondents (particularly gay/bisexual men) singled out care homes and home care as areas of major anxiety for their future: they perceived such places to be unused to both people with HIV and gay men.

“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.”

These fears are borne out by existing experiences, both within the survey group and within Terrence Higgins Trust (THT)’s advocacy work.

Financial circumstances

Older people living with HIV are overall more likely to be worse off in terms of money, work and housing than their peers. They are less likely to be economically active, more likely to be on a variety of state benefits and far less likely to have any kind of financial cushion for their old age. Many are likely to rely on a basic state pension. The situation is even worse for many of the black African women who responded.

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

Half of respondents were not confident that they understood the benefits system, even though many were reliant on it. Some were also reluctant to engage with it. Many wanted to work.

Respondents were also less likely than their peers to be homeowners and more likely to be in social housing or private rented accommodation. Again, they expressed fears about possible future moves into sheltered housing or care homes.

Social activities

Many respondents spoke (particularly in the in-depth interviews) of social isolation and their attempts to interact with others, be they people with HIV, people from their social group or other older people. These attempts were of varying success; some felt HIV services did not cater for their needs as older people and that services for older people (and their peer group) were not supportive about HIV. Three-quarters of the respondents identified counselling and emotional support as a future priority need.

The older adults had a wide range of levels of sexual, as well as social, activity. Almost two-thirds had been sexually active in the previous year. A quarter had one partner, but one in six (all gay/bisexual men) reported more than ten partners in the previous year. Just over a quarter said they were unhappy with their sex lives, but this appeared to have little correlation with number of partners. It is clear that sexual health and HIV prevention services need to ensure that they are appropriate to this group; there were a number of comments on being “invisible” in current promotional materials and campaigns.

Disclosure and discrimination

Levels of disclosure were high, covering a wide variety of settings and relationships. The greatest surprise within the findings (though not to some people with HIV with whom this was shared as it emerged) was that a great majority of these were reported as having positive or neutral outcomes. This differs considerably from the way in which disclosure is often seen within the HIV sector as a negative and risky action. It is undoubtedly true that disclosure can, and sometimes does, impact badly upon a person’s life: a number of respondents related such experiences in the qualitative interviews. But from this study, at least for older adults, it appears that most outcomes are neutral and far more are positive than negative.

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

In all, one in five in the study had experienced age-related or HIV-related discrimination in the past year; others related stories of HIV discrimination from further in the past. Overall people were as likely to report age discrimination as that related to HIV, but in two areas – healthcare settings and provision of goods and services – HIV discrimination was far more common. Respondents also recounted stories of both age and HIV discrimination in the workplace.

So, while many appear to be managing disclosure in a positive fashion, we need to know more about what influences outcomes so as to better support people with HIV in disclosing successfully and in challenging discrimination when it is encountered.

Implications for policy

The researchers conclude that much can be done to improve quality of life for the increasing numbers of those over 50 living with HIV. Government, the NHS and those organisations supporting older people and those with HIV will need to show leadership, particularly in light of funding constraints. But it should not be difficult, with goodwill, to share skills, to explore new ways of working and to increase understanding. There are clear gaps in provision of some services, but in others the problem is one of making people feel welcome and understood, of assuring them that they will not be stigmatised. This is important both for older people living with HIV as a group, and for the diverse communities represented within this population.

One way of driving change in social and clinical care may be the use of personalised budgets to choose HIV-friendly and gay-friendly services, but it is unclear as yet how these will evolve. There is also a need to reflect the concerns of this group in a renewed National Sexual Health & HIV Strategy for England (Department of Health, 2001) and within other country strategies as they are reviewed, particularly the priority on combating stigma. Government drivers to move people off benefits and into work will also need to include appropriate support for this group. Greater emphasis needs to be placed upon employers’ responsibilities in upholding age and disability related discrimination legislation.

Five specific areas for action include:

- *Improvements in healthcare to ensure access to good quality treatment in all settings and better information.* The finding that primary care is not serving people with HIV well is not a new one; but for older adults with HIV it is a more pressing problem than for others and one which will impact on their health and longevity if not tackled. There is a strong and urgent need for leaders in the medical profession and the NHS to challenge and change poor treatment.

- *Greater employment support, money management courses and benefits advice.* Given the existing gaps in benefits advice there is a real need for a range of services to address these issues and avert or minimise later poverty problems. These include support to stay in or re-enter the workplace, benefits advice and access to debt management and financial planning skills as part of long term condition management. Those with an overview of these problems need to advocate on behalf of older people with HIV to Government in any further revision of benefits rules.
- *Addressing homophobia, HIV discrimination and ageism in all services, but especially in social housing, sheltered housing, care homes and health services (particularly primary care).* Given the loss of the ringfenced grant for HIV social care from 2011 and the likely move into generic social care services, providers of social care need to ensure that these services are knowledgeable about HIV and gay issues. Advocates for these issues need to work with them to ensure that they are capable of supporting people with HIV as well as all LGBT people and funders should be requiring this as a quality measure.
- *Greater co-operation and information sharing between organisations and services for older people and those for people with HIV to improve policy and practice.* It will be important in the future for both HIV services and those for older people to work closely together on both policy and practice to ensure that older people living with can find appropriate ways of getting peer support and to ensure they know that services do welcome them and have considered their needs.
- *Improved emotional support and opportunities for social contact to prevent isolation.*

The findings and recommendations of 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 policymakers 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.

About the project

50 Plus was based on 410 responses to an online and paper questionnaire and 40 in depth interviews from a sample of adults aged 50 and over with HIV across the UK in 2009. The questionnaire was devised with the support of a Community Advisory Panel and interviews conducted by trained community researchers living with HIV. A literature review and visits to existing ageing and HIV work in the US were also undertaken.

For more information

Further data, including all statistical charts and the full literature review, is available from www.tht.org.uk/50Plus. All queries and requests for further information should be addressed to lisa.power@tht.org.uk or Lisa Power, Policy & Information Director, Terrence Higgins Trust, 314-320 Grays Inn Road, London WC1X 8DP.

A full report, exploring these issues further, will be published on www.jrf.org.uk in Summer 2010.

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