



Terrence
HIGGINS
TRUST



Uncharted Territory

A report into the first generation
growing older with HIV

January 2017

**Health
& Wealth
Happiness**

Supporting over 50s
living with HIV



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Foreword

I write this foreword as the topic of social care is debated in the House of Commons. Vital discussions on how we ensure that the older generation is adequately supported and cared for have come to the fore. This report is therefore well timed.

We are entering uncharted territory. More people than ever before are living with HIV – living into older age with HIV. As Chair of the All Party Parliamentary Group (APPG) on HIV I meet regularly with individuals living with and affected by HIV from across the UK, and indeed the world. With the onset of effective HIV treatment, the clinical impact of HIV has changed. Absolutely. But as I am regularly told, and as this report sets out, what still remains is the social impact of an HIV diagnosis. Discrimination and prejudice remain.

As well as identifying the needs of people over 50 diagnosed recently, we must also remember the many individuals who were diagnosed before HIV antiretroviral therapy was available. The first generation of people with HIV are living into older age, learning as they go the effects of HIV on ageing and ageing on HIV.

I welcome the collaborative approach to this piece of research and thank the 12 peer researchers who worked with Terrence Higgins Trust to co-produce this report. To me this is key – we must be taking our cues from those directly affected by HIV.

The recommendations in this report make clear that we all have a role to play in ensuring that people living with HIV have the support they need as they grow older. I will use my role as MP and Chair of the APPG to raise awareness and push for change – based, as in this report, on the direct experiences and needs of older people living with HIV.

How will you play your part?

Mike Freer MP

Chair, All-Party Parliamentary Group on HIV and AIDS



Foreword

HIV in the UK 'is not over'. Without question great progress has been made in the treatment of HIV, however this has led to society at large acting like it's old news – people don't want to talk about it anymore.

This included me, until in February 2016 aged 63 I was diagnosed as HIV positive.

Following a friend's suggestion this led to me getting involved with Terrence Higgins Trust and volunteering to help with the peer research that this report covers. I have to say my motivation was mainly for selfish reasons, trying to make sense of what had happened and what the future held. The messages I was getting from the medical profession and others was that great improvements in medication meant I would have a near-normal life, probably with as great a life expectancy as the general population. Despite this positive message, what I wasn't prepared for was the subsequent mental and social impact.

By taking part in this research I became aware that the focus on the medical success around HIV can lead to complacency and we risk overlooking a myriad of issues. Not least ongoing stigmatisation, the impact of HIV on mental health and a sense of loneliness or even abandonment.

This brought to mind the words of journalist Tom Sutcliffe – presenting a show on BBC Radio 4 in November 2016 entitled: *AIDS Activism and Surviving a Plague*. He suggested that progress and success meant having to 'survive the surviving' as well.

The reader of this report should bear in mind that even with great medical progress, we are still seeing high numbers of people being diagnosed with HIV – including in individuals aged 50 and over. The ongoing need for support for older people living with HIV will continue – and indeed will increase – in the face of diminishing NHS and social care resources.

I felt humbled by having heard the stories shared in this research by so many people, and an admiration for the resilience of many.

However, I also fear that through complacency we may fail to recognise the emerging needs of those growing older with HIV. We must work together to make sure this does not happen.

David Rogers

Peer Researcher, Terrence Higgins Trust

Executive Summary

More than 30 years on from the start of the HIV and AIDS epidemic in the UK, the reality of living with HIV is unrecognisable. While stigma and discrimination unfortunately still remain, the availability of effective HIV treatment means that an HIV diagnosis is now no longer the fatal health condition that took the lives of many – far too many – individuals in the prime of their lives.

We are seeing the first wave of individuals who have been on antiretroviral therapy (ART) for a substantial period of time and who are ageing with HIV. We are also seeing a new phenomenon as more people than ever before are diagnosed with HIV aged 50 or over. The result is that the proportion of people living with HIV who are aged 50+ will continue to rise.

This is uncharted territory.

While there are many unanswered questions about the interplay between HIV and ageing, an ever increasing volume of academic and clinical research is starting to determine the physical, mental and social impact of growing older with HIV.

In 2010, Terrence Higgins Trust, Age UK and The Joseph Rowntree Foundation released a groundbreaking piece of research, *A National Study of Ageing and HIV (50 Plus)*, that explored the needs and experiences of over 400 people living with HIV aged 50 and over. Much has changed since then and this research aims to update the evidence based on the findings of 2010. This will provide the call to action needed for the HIV community and other advocates to push for change to ensure the needs of people ageing with HIV are fully met.

Methodology

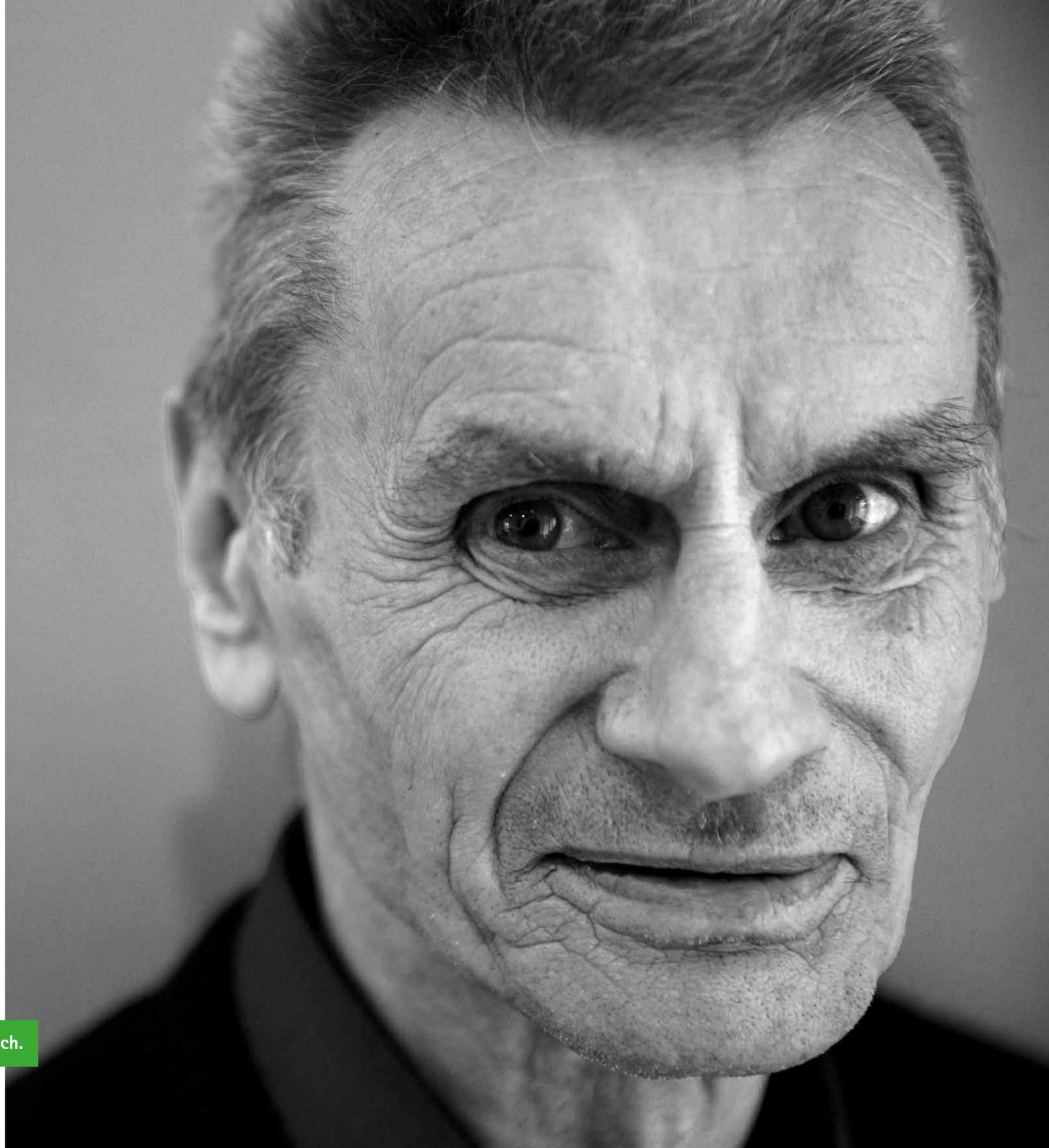
This research project utilised a peer-led research design model. The inclusion criteria for this project, either as peer researcher or as participant, was that the individual must be aged 50 or older, be living with HIV and live in the UK.

The first stage of data collection included a survey of 55 questions on topics including health, financial situation and emotional wellbeing.

- A total of 246 completed surveys were analysed.
- Respondents lived across the UK – 10% in Scotland, 3% in Wales and the remaining 87% in England.
- Respondents' ages ranged from 50 to 82 years old, with a median age of 55. Women made up 22% of respondents to the survey.
- The date of HIV diagnosis represented in the survey respondents ranged from 1982 – 2016 and age ranged from 18 to 74 years old at diagnosis.
- 32% were diagnosed with HIV before effective treatment was available in the UK in 1996.

A total of 30 interviews and six workshops with individuals living with HIV aged 50 or over were conducted by the peer researchers. The interviews were designed under the life history model of qualitative interviewing. The workshops consisted of group discussion and activities inspired by deliberative event methodologies.

307 people living with HIV aged 50+ participated in this research.



The main limitation of this research project is that the trans community is unfortunately totally unrepresented in this research. It is essential that further research is undertaken to fully understand how transgender individuals living with HIV are affected by HIV as they grow older.

It is important to state that this report does not make the assumption that all people living with HIV aged 50 and over have the same experiences, current and future concerns or the same needs. The personal situation, needs and experiences of people who took part in this research ranged from individuals who have no current and no defined future need and who have a positive experience of living with HIV, to individuals who face a myriad of current and future challenges.

The impact of the availability of HIV treatment

Unsurprisingly, our study has highlighted that there is a difference in needs and experience depending on whether an individual was diagnosed with HIV before or after the availability of effective antiretrovirals (ARVs) in the UK in 1996.

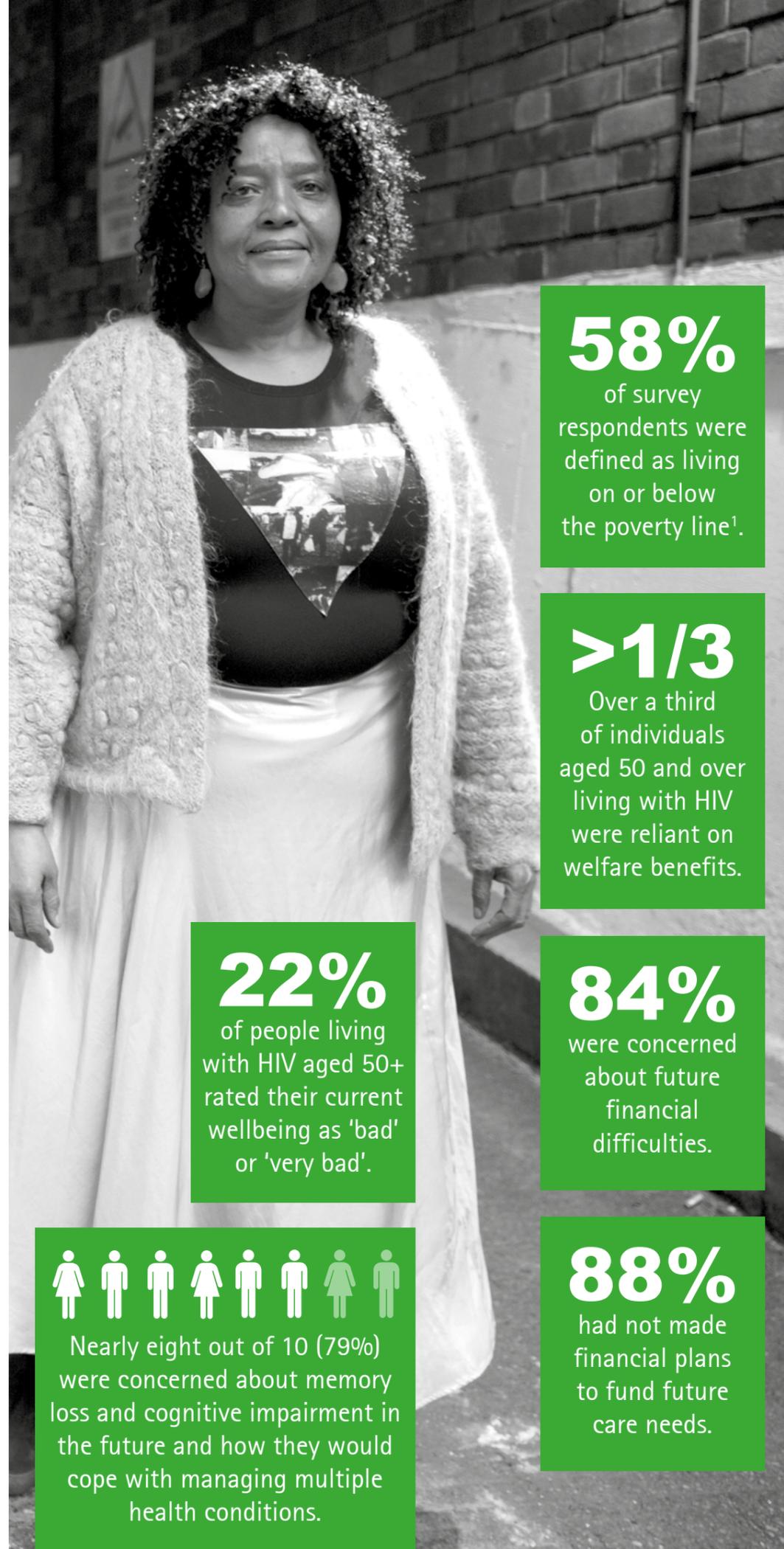
Individuals diagnosed before 1996 were more likely to be dependent on benefits as their sole or main source of income. They were less likely to be in employment (full- or part-time). Individuals diagnosed before treatment was available were more likely to have three or more additional health conditions.

'50+' is not one category

The research found a divide between individuals aged 50-60 and those aged 65+, whereas individuals aged 61-64 see a mixed picture. Individuals in these age groups had very different needs and different experiences.

People living with HIV aged 50-60 - of working age - were concerned about seeking or retaining employment and benefits. In total, 36% of those aged 50-60 were solely reliant on benefits compared to 9% of those aged 65+. People living with HIV aged under 60 and receiving benefits spoke of the anxiety of being reassessed, or the threat of benefits being stopped at any time.

Of respondents aged 65 and over, 77% rated their wellbeing as 'good' or 'very good' compared to a third (34%) of those aged 50-60. The older a person living with HIV got the happier they felt, the better their wellbeing, the lower their levels of HIV self-stigma.



58%
of survey respondents were defined as living on or below the poverty line¹.

>1/3
Over a third of individuals aged 50 and over living with HIV were reliant on welfare benefits.

22%
of people living with HIV aged 50+ rated their current wellbeing as 'bad' or 'very bad'.

84%
were concerned about future financial difficulties.



Nearly eight out of 10 (79%) were concerned about memory loss and cognitive impairment in the future and how they would cope with managing multiple health conditions.

88%
had not made financial plans to fund future care needs.

Poverty is impacting people living with HIV aged 50 and over

58% of survey respondents were defined as living on or below the poverty line¹. The situation has deteriorated since 2010 when 48% of respondents to Terrence Higgins Trust's HIV and Ageing survey were found to be living in poverty. Statistics available for the general population indicate that levels of poverty seen in people living with HIV aged 55+ are double those seen in the general population.

Over a third of individuals aged 50 and over living with HIV were reliant on welfare benefits. A third had not made financial plans for the future and 84% were concerned about future financial difficulties. The situation has deteriorated since 2010 with more people living with HIV aged 50+ having concerns about future finances compared to seven years ago.

Social care is not currently meeting the needs of people living with HIV

People growing older with HIV face the prospect of managing multiple long-term conditions that are made more complex by their interactions with HIV. Of people living with HIV aged 50 and over, 81% were concerned about how they would take care of themselves and manage daily tasks in the future. A quarter said they would have no one to help them if they ever needed support with daily tasks.

Altogether, 82% of over 50s living with HIV were concerned about whether they would be able to access adequate social care in the future and 88% had not made financial plans to fund future care needs.

Even when people living with HIV have been able to access social care services they have faced discrimination from social care professionals due to their HIV status, including in residential care homes. This is unacceptable. People living with HIV in care homes should not be treated differently from their peers. Instead, these actions are fuelling myths and stigma around HIV and further isolating older residents living with HIV in residential care.

Co-ordinated long-term condition management, with support to self-manage, is essential for people living with HIV aged 50 and over

Our survey found that 22% of people living with HIV aged 50+ rated their current wellbeing as 'bad' or 'very bad', with an additional 39% rating it as 'fair'.

Over 50s living with HIV had on average three times as many long-term health conditions compared with the general population. Survey respondents reported lower levels of wellbeing with increasing numbers of co-morbidities and increasing numbers of daily medications needed.

Many people reported that they were already struggling to remember to take multiple medications, as well as remember the multiple healthcare appointments their health conditions demanded. Nearly eight out of 10 (79%) were concerned about memory loss and cognitive impairment in the future and how they would cope with managing multiple health conditions.

¹ Poverty threshold in the UK is currently defined at: £283.8 per week.



1/3
of survey
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The reality is that clinically HIV is a long-term condition and, with the increased risk of co-morbidities that an HIV diagnosis brings, co-ordination is essential across all aspects of care and support. Strong support from primary care professionals is key. Effective, co-ordinated, holistic long-term condition management is essential for individuals growing older with HIV who are having to cope with health conditions related to HIV, ageing and the interaction of HIV with the ageing process.

GPs need to step up to the mark in supporting people living with HIV aged 50 and over

The role of specialist HIV clinical staff will remain fundamental to the support of people as they grow older with HIV. Yet HIV clinical services are not the 'one-stop-shops' they once were and some survey respondents were concerned about what will happen once their HIV consultant - who they have often got to know over decades of HIV treatment and support - retires. There is a clear need for someone to play a co-ordination (clinical) support role to ensure people living with HIV are getting the co-ordinated long-term condition management they need.

GPs are key. Most people (87%) aged 50+ living with HIV had told their GP about their HIV status. But progress is needed as GPs often lack knowledge around HIV and ageing - for one in five (19%) survey respondents their GP had never given them the information they wanted on HIV and ageing.

Many people living with HIV aged 50 and over face social isolation and loneliness

A third of survey respondents were socially isolated and 82% experienced moderate to high levels of loneliness. People living with HIV aged 50 and over were at least three times more likely to experience high levels of loneliness than the general population. Wellbeing decreased with increased social isolation. The situation has deteriorated since the 2010 Terrence Higgins Trust 50+ research when 61% of people living with HIV aged 50+ were concerned about loneliness in the future - that figure is now 76%.

People living with HIV aged 50 and over experience HIV self-stigma

58% of people living with HIV aged 50+ had moderate to high levels of HIV self-stigma. HIV self-stigma decreases with increasing age. It is less common in gay men living with HIV than in heterosexuals living with HIV. There was an observed trend of increasing self-stigma with decreasing financial income. HIV self-stigma also increased with increasing social isolation and loneliness.

Research participants expressed difficulties in telling family and friends about living with HIV. This was particularly acute in those diagnosed more recently. The lack of any recent national HIV campaign aimed at the general population, and the perpetuation of HIV myths and stigmatising language in the media, has led to a lack of up-to-date knowledge and understanding of HIV.

Older women are also affected by HIV

Women have long been the invisible face of HIV in the UK. Yet over a third of people living with HIV in the UK are women and women account for a quarter of all new HIV diagnoses.

Throughout this research women made clear that they have specific concerns and experiences related to HIV and ageing. Women reported lower levels of wellbeing than men – 28% of women rated their wellbeing as 'very good' or 'good', compared to 41% of men. When it comes to financial stability women were on average on lower incomes than men.

There remain many unanswered questions regarding the effects of HIV on women as they grow older – including the impact on menopause. Analysis shows that women were more concerned about all aspects of growing older with HIV than men. Women were most concerned about the long-term effects of HIV and ART as well as how they would manage co-morbidities. Caring for family came out as a strong concern of women across all aspects of the research.

This research did not explore the needs of people aged 50+ who are at risk of HIV. With increasing numbers of older people newly diagnosed with HIV, further discussion needs to occur on how HIV (and other sexual ill-health) prevention and health promotion programmes can adapt to meet the needs of this group.

Conclusion

We are entering uncharted territory.

A new generation of people living with HIV are living into older age. A very diverse generation.

While many will continue to live without the need for additional health and social care services or financial support, the 307 people involved in this research have shown that just as often this isn't the case. There is a major cohort of individuals growing older with HIV who, now and in the future, require significant levels of support.

Many support needs are not unique to people living with HIV – the welfare and social care systems across the UK are failing many. However, we have found that living with HIV adds an extra level of need – additional necessities that go beyond the 'standard' experiences of ageing.

With reducing NHS, public health and social care budgets the future is uncertain.

But the opportunity exists to ensure that the needs of people ageing with HIV are central to discussions, policy change and structural change that is currently happening.

People living with HIV aged 50 and over must be at the heart of this action – the voices of older people living with HIV have too often been absent.

Together we can be the generation that pushes for change to ensure that all people living with HIV have a positive experience of ageing.



Recommendations

Recommendation: HIV support services aimed at people living with HIV aged 50 and over should carefully consider the diversity of needs of service users and consider tailoring different support packages to 50–60 year olds, 61–64 year olds and to individuals aged 65+.

Recommendation: Support services for older people provided by older person's/ageing organisations and charities should carefully consider the diversity of needs and experiences of service users living with HIV and consider tailoring support to ensure specific needs are met.

Recommendation: HIV organisations must continue to engage in the development of the benefits systems across the UK and ensure that current and future benefits systems understand and deliver the needs of people living with HIV aged 50 and over who are unable to work or work full-time.

Recommendation: The Department for Work and Pensions must improve the quality and consistency of information and guidance it provides to people living with HIV. Continual training of welfare benefits advisers across the UK is essential. All training packages should be written in collaboration with HIV organisations and individuals directly affected by HIV.

Recommendation: The Department for Work and Pensions must ensure that both welfare benefits advisers and staff of Job Centres provide consistent information around access to benefits for people living with HIV.

Recommendation: HIV organisations, working with older people's organisations and mainstream advice services, should ensure that information, advice and support is available to people living with HIV aged 50 and over in relation to access to benefits, housing and financial planning. They should be clear on the rights that individuals have in regard to these areas.

Recommendation: HIV organisations and charities, alongside individuals living with HIV, must actively engage in policy and commissioning discussions about the future provision of social care across the UK, ensuring that the needs of people living with HIV are fully met.

Recommendation: Skills for Care alongside Health Education England, the Scottish Social Services Council and the Care Council for Wales must ensure that HIV and ageing is a mandatory part of all entry-level training and induction for social care workers.

Recommendation: Social care providers should ensure continued professional development for staff around HIV, using key awareness days such as World AIDS Day and utilising local and national HIV organisations to ensure all activities are based on up-to-date evidence.



Recommendation: HIV organisations should actively engage with local and national social care providers to provide up-to-date training on HIV – including HIV and ageing. Educational resources should be co-produced with people living with HIV. Ideally, positive speakers should be supported to facilitate training and awareness.

Recommendation: HIV charities and organisations should work with older person's/ageing charities that regularly interact with social care providers to ensure that they have up-to-date knowledge around HIV and feel confident to support older people living with HIV who are accessing social care.

Recommendation: The British HIV Association (BHIVA), the British Association for Sexual Health and HIV (BASHH), the Royal College of General Practitioners (RCGP) and the Royal College of Physicians (RCP), working in collaboration with people living with HIV aged 50 and over, should agree clear care pathways and ways of working. These will ensure that everyone aged over 50 who is living with HIV receives co-ordinated care for all health conditions.

Recommendation: All stakeholders involved in supporting people living with HIV aged 50 and over must ensure adequate information, tools and resources are available to enable individuals to play a greater role in managing their own health and wellbeing.

Recommendation: BHIVA, BASHH and the RCGP should ensure that HIV (including a focus on HIV and ageing) is a compulsory part of all GP training as well as of ongoing professional development.

Recommendation: RCGP should work with BHIVA, BASHH, HIV charities and people living with HIV to provide training and support to current GPs to increase their understanding of HIV and its interaction with ageing.

Recommendation: HIV organisations and charities should work with older person's/ageing organisations to understand how to address social isolation and loneliness in older people living with HIV, acknowledging the role that HIV stigma and discrimination plays.

Recommendation: Public Health England, Public Health Wales and Health Protection Scotland – working in collaboration with HIV charities and people living with HIV – should actively seek opportunities to increase accurate awareness of HIV among the general population. This should include through compulsory Sex and Relationships Education (SRE)/Relationships, Sexual Health and Parenthood education (RSHP) in schools, interventions aimed at the media, and opportunities to support people living with HIV to become Positive Speakers in local communities.

Recommendation: HIV and older person's/ageing charities should offer services that support the emotional and mental health needs of older people living with HIV and in particular address the issues underpinning HIV-related self-stigma.

Recommendation: HIV organisations and organisations providing services for older women should work with HIV-focused charities, (such as Sophia Forum) as well as women living with HIV themselves, to design services and interventions that best meet the needs of women as they age with HIV.



Introduction

The changing face of HIV

More than 30 years from the start of the HIV and AIDS epidemic in the UK, the reality of living with HIV is unrecognisable. While stigma and discrimination unfortunately still remain, the availability of effective HIV treatment means that an HIV diagnosis is now no longer the fatal health condition that took the lives of many – far too many – individuals in the prime of their lives.

Effective antiretroviral therapy (ART) allows individuals living with HIV who were diagnosed early to look forward to the same life expectancy as their peers who are HIV negative. This has resulted in a shift in the demographics of people who are living with HIV in the UK. In 2015, there were 29,960 people aged 50 and over in the UK living with diagnosed HIV – 34% of all people accessing HIV care². This has significantly increased since 2010 when 21% of people living with HIV were 50 or over and will continue to rise as we see more people living into older age with HIV.

But we are also seeing a new phenomenon as more people than ever before are diagnosed with HIV aged 50+. In 2015, 1,018 individuals aged 50 or older were diagnosed with HIV in the UK – one in six of all HIV diagnoses that year. This has increased by 12% since 2010.

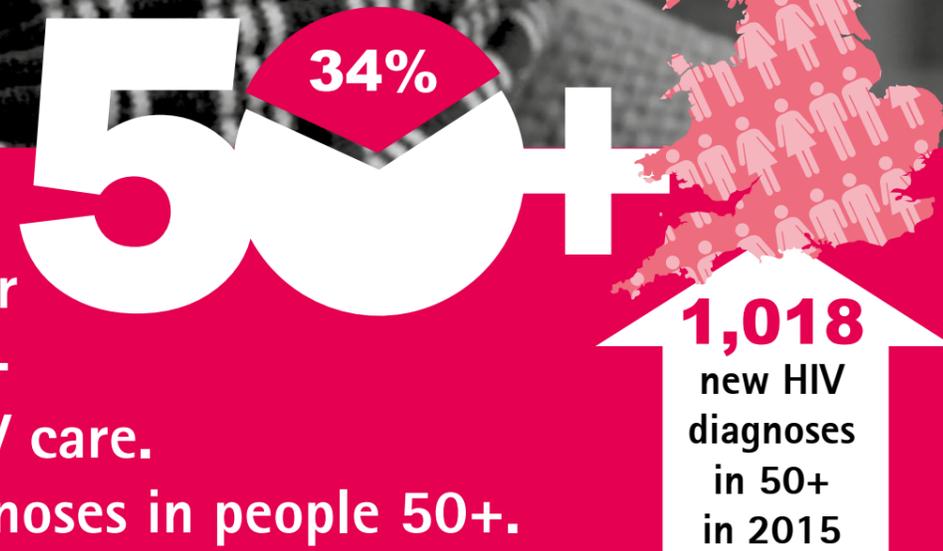
Older individuals of all genders and sexualities are being diagnosed with HIV. In 2015 in the UK, 26% of new diagnoses in the over 50s were in women with the remaining 74% in men.

Late diagnosis of HIV³ is associated with significantly worse clinical outcomes including a tenfold increase in the risk of death within one year of diagnosis. In 2015, people aged 50+ saw worrying levels of late HIV diagnoses. While 39% of HIV diagnoses across all ages were late, over half (55%) of 50-64 year olds and 63% of individuals aged 65+ were diagnosed late. The health impacts of late diagnosis are also found to be even more pronounced, with the increased risk of death in the first year being 16 times more likely in the 50+ age group⁴.

It is not only HIV that is increasingly being diagnosed in older individuals. In 2015, there were 30,055 new sexually transmitted infections (STI) diagnoses in people aged 45 and older, this is up 19% from 2011. A total of 72% of these new diagnoses were in men. The increase is largely due to a rise in the number of diagnosed cases of syphilis (up 109%), gonorrhoea (up 108%) and chlamydia (up 75%)⁵.

In 2015:

- 29,960 people aged 50 and over in the UK were living with HIV – 34% of all people accessing HIV care.
- There were 1,018 new HIV diagnoses in people 50+.



² Great Britain. Public Health England (2016) HIV diagnosis, late diagnoses and numbers accessing treatment and care: 2016 report [Online]. Available at: www.gov.uk/government/uploads/system/uploads/attachment_data/file/561098/HIV_diagnoses_late_diagnoses_and_numbers_accessing_treatment_and_care_NB181016v4.pdf

³ Defined as a CD4 count <350cells/mm3.

⁴ Great Britain. Public Health England. (2016) HIV in the UK: 2016 report [Online]. Available at: www.gov.uk/government/uploads/system/uploads/attachment_data/file/574667/HIV_in_the_UK_2016.pdf

⁵ Great Britain. Public Health England (2016) New STI diagnoses and rates by gender, sexual risk and age group, 2011 to 2015 (Table 2) [Online]. Available at: www.gov.uk/government/statistics/sexually-transmitted-infections-stis-annual-data-tables

Into the unknown

It is a phenomenal achievement that individuals living with HIV can now live a full life expectancy – but what does it mean to grow older with HIV? What are the long-term impacts of ART? What are the health impacts on those individuals who took early HIV treatments like AZT and DDI during the early stages of the HIV epidemic? What are the differences in quality of life of individuals living with HIV diagnosed in the 1980s and 1990s 'versus' those diagnosed in more recent years? How does HIV function as a long-term condition? What relationship is there between HIV and other age-related co-morbidities?

We are seeing the first wave of people who have been on ART for a substantial period of time and who are ageing with HIV. This is uncharted territory.

While there are many unanswered questions about the interplay between HIV and ageing, an ever increasing volume of academic and clinical research is starting to determine the physical, mental, and social impact of growing older with HIV.

Research has shown that people living with HIV may experience a multitude of related health conditions, in many cases earlier in life than their HIV negative peers. HIV 'ages' people more rapidly and the chances of many other long-term, often life threatening, health conditions are significantly higher in an individual living with HIV. These include:

- premature onset of cardiovascular disease⁶
- higher risk of diabetes⁷
- bone and joint disorders⁸
- hypertension⁹
- kidney disease¹⁰
- dementia and other neuro-cognitive impairments¹¹.

Updating the evidence

But what does this actually mean for people living with HIV and what needs to change to ensure that individuals ageing with HIV have their needs met in the ways that best work for them?

In 2010 Terrence Higgins Trust, Age UK and The Joseph Rowntree Foundation released a groundbreaking piece of research, *A National Study of Ageing and HIV (50 Plus)*, that explored the needs and experiences of over 400 people living with HIV aged 50 and over. The research found that people living with HIV aged 50+:

- Have twice as many long-term conditions as their peers.
- Are poorer, less economically active and less likely to have savings for old age.
- Are less likely to be homeowners.
- Are worried about their future social care, health care and financial safety.
- Are as likely to experience age discrimination as HIV discrimination.

⁶ Vance, DE., et al. (2011) Ageing with HIV: a cross sectional study of comorbidity prevalence and clinical characteristics across decades of life. in *J Assoc Nurses AIDS Care* 2011;22: 17-25.

⁷ *ibid.*

⁸ Brown, TT., et al. (2006) 'Osteopenia and osteoporosis in patients with HIV: a review of current concepts.' In *Curr Infect Dis Rep* 2006;8:162-170.

⁹ Bonnet, F., et al. (2016) 'HIV patients today and 10 years ago: do they have the same needs? Results from cross-sectional analysis of ANRS CO3 Aquitaine cohort.' At International Congress on Drug Therapy in HIV Infection (HIV Glasgow), Glasgow, abstract 0212.

¹⁰ *ibid.*

¹¹ Becker, JT., et al. (2004). 'Prevalence of cognitive disorders differs as a function of age in HIV virus infection.' In *AIDS*. 2004 Jan 1;18 Suppl 1:S11-8.

The most common concerns for the future for those over 50 in the study were:

- financial difficulties (79%)
- inability to care for self (76%)
- mental health issues or depression (73%)
- inability to access proper healthcare (69%)
- social stigma & discrimination (66%).

The research led to the establishment of the first support programme targeted solely at people living with HIV aged 50 and over – Terrence Higgins Trust's Health, Wealth and Happiness project.

However, much has changed since 2010.

- The health and social care system in England is unrecognisable, with the Health and Social Care Act 2012 fundamentally changing structures and responsibilities for HIV services as well as other health and social care services accessed by older people.
- Health and social care policy has changed in Scotland and Wales and all three countries are seeing continued strain on national and local NHS budgets as well as a deprioritisation of HIV in political agendas.
- The changing epidemiology of HIV has led to an increase in the proportion of people living with HIV who are aged 50 and over, as well as increasing numbers of over 50s newly diagnosed with HIV.
- More is known (although questions remain) about the biological impact of ageing with HIV.

This research aims to update the evidence based on the findings of the 2010 study. HIV and ageing is a key policy priority for Terrence Higgins Trust but it is essential that all policy work is based on up-to-date evidence.

A multitude of services, interventions and organisations are needed if the needs of people growing older with HIV are to be met. This is reflected in the recommendations of this report which are aimed not just at national and local policy and decision makers, but also at organisations in the ageing sector, as well as HIV organisations.

We hope that this research, alongside excellent recent research – including the HIV in Later Life (HALL) study and research still to be published (including by a PhD researcher at the University of Greenwich) – will provide the evidence and call to action needed for the HIV community and other advocates to push for change to ensure the needs of people living with HIV aged 50+ are fully met.

Methodology

Peer research

This research project utilised a peer-led research design model. Peer research is a 'bottom-up' approach which has developed from field participatory community-based research, where members of the community play an active role in the research process. Shared use of language and shared experience allow research participants to relax and open up to peer researchers, increasing the quality of information gathered compared to traditional approaches^{12 13}.

We recruited a team of 12 volunteer peer researchers from across the UK. The inclusion criteria for this project, either as a peer researcher or a participant, was that the individual must be aged 50 or older, be living with HIV and live in the UK. All recruited peer researchers either had prior experience in research or transferable skills. Peer researchers completed mandatory training in research design and data collection methods. The team was involved in all stages of the research process from question design, data collection and analysis to final interpretation of findings.

Survey responses

The first stage of data collection included a survey of 55 questions. The survey included questions on health, financial situation and emotional wellbeing. Key questions from the 2010 Terrence Higgins Trust HIV and Ageing survey were repeated in order to allow comparison over the subsequent seven year period. Additional questions were included to reflect the changing landscape since 2010. The survey was developed by the project team and reviewed by the peer researchers. The peer researchers were responsible for ensuring that the wording of all questions was appropriate and understandable and also that all relevant topics were covered. The survey was then piloted by three service users to ensure all questions made sense and were understandable to those outside of the research project.

The survey, available online and as paper copy, was disseminated to Terrence Higgins Trust members, services users, the wider HIV community and more broadly through health and social care networks.

A total of 250 completed surveys were received, 246 of which were taken forward for analysis. The remaining four were excluded due to the respondents being aged younger than 50.

The respondents lived across the UK - 10% were in Scotland, 3% in Wales and the remaining 87% were in England. The majority of respondents (85%) lived in an urban area, with 8% in a semi-rural area and 7% rural¹⁴. Respondents' ages ranged from 50 to 82 years old, with a median age of 55.

¹² Roche, B., Guta, A., Flicker, S. (2010) 'Peer research in action: Models for Practice' Community Based Research Working Paper Series [Online]. Available at: www.wellesleyinstitute.com/wp-content/uploads/2011/02/Models_of_Practice_WEB.pdf

¹³ O'Keeffe, C., Senior, P., Monti-Holland, V. (2011) 'Barriers to employment, training, and education in prison and beyond: a peer-led solution' in Sheehan, R., McIvor, G., Trotter, C. (ed.) What works for woman offenders. Routledge, pp 241.

¹⁴ Defined as being in a settlement with a population <10,000 (Great Britain. Office of National Statistics. (2013). Urban and Rural Area Definitions for Policy Purposes in England and Wales: Methodology (v1.0) [Online]. Available at: www.gov.uk/government/uploads/system/uploads/attachment_data/file/239477/RUC11methodologypaperaug_28_Aug.pdf

¹⁵ Great Britain. Public Health England. National HIV surveillance data tables (Table 10) [Online]. Available at: www.gov.uk/government/statistics/hiv-annual-data-tables

Breakdown of research participants

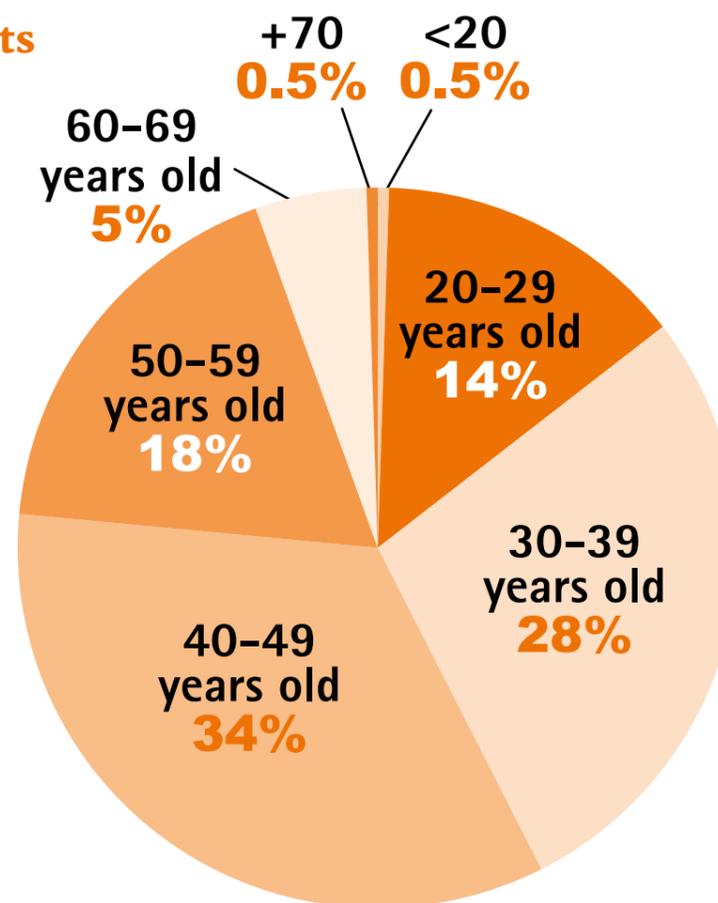


In terms of gender, women made up 22% of respondents to the survey. In 2015 women made up 24% of those individuals aged 50 and over seen for HIV care¹⁵, indicating that survey responses are representative in terms of gender. Of the 193 male respondents 88% were men who have sex with men (MSM), 9% were heterosexual and the remaining 3% chose not to define their sexuality.

Altogether, 75% of survey respondents described themselves as white British, 9% as black African and 5% as other white background. The remaining 11% included people describing themselves as black British, mixed race, black Caribbean and Asian Indian.

The date of HIV diagnosis represented in survey respondents ranged from 1982 to 2016. In total, 32% of survey respondents were diagnosed with HIV before effective treatment was available in the UK in 1996. Survey respondents' age at HIV diagnosis ranged from 18 to 74 years old, with a median age of 42.

Survey respondents age at date of HIV diagnosis



Interviews and workshops

The initial results from the survey were used to inform the design of the qualitative phase of the research. The interviews were designed under the life history model of qualitative interviewing, which involves structuring the interview to document the interviewee's life or an aspect of it which has developed over the course of time. This technique allows the researcher to understand in greater detail the experiences of that person rather than focusing on a restricted topic area. The semi-structured interview guide covered the participant's life before their HIV diagnosis, the circumstances of their diagnosis, what life has been like since then, their current situation and how they feel about the future.

A total of 30 interviews with individuals living with HIV aged 50 or over were conducted by the peer researchers. Interviews took place in London, Manchester, Coventry, Glasgow, Cardiff and Brighton. Participants' ages ranged from 50 to 83 years old. Seven women and 23 men were interviewed.

The interviews were audio recorded and professionally transcribed. The qualitative analysis of the interview transcripts was based on the pre-defined themes identified in the 2010 Terrence Higgins Trust HIV and Ageing research to allow for comparison, but scope was also left in the coding framework to identify emergent themes not identified in 2010.

In addition to the qualitative interviews, six group workshops were conducted, each facilitated by two members of the peer researcher team. Participants' ages ranged from 50 to 78 years old. In total 19 women and 22 men took part in the workshops.

These workshops were designed by the peer team to be more participatory and solutions-based than traditional focus group events. The workshops consisted of group discussion and activities inspired by deliberative event methodologies. In a deliberative workshop, the participants have a facilitated discussion about a complex topic which they look at in-depth. There are many elements, options and trade-offs to be considered when assessing possible solutions. The purpose of the workshops was to identify which aspects of life were most impacted by both HIV and growing older, how things are likely to change in the future and what can be done to improve the quality of life for different people as they grow older with HIV.

A total of 41 people took part in six workshops across five geographical locations (two in London, one each in Manchester, Birmingham, Glasgow and Brighton). In order to address the under-representation of women in the interview stage, one all-female workshop was conducted with the support of George House Trust in Manchester. Recognising the lower representation of the black African communities in other aspects of this research, a workshop with particular focus on these communities was organised in partnership with Body and Soul in London.

In total, 307 people living with HIV aged 50 and over participated in this research.

Interpreting findings

Following the data collection and initial analysis a data summit was held with the team of peer researchers. This data summit involved a review of the data analysis looking at what chimed and what conflicted with the peer researchers' own experiences and the experiences of the participants they had spoken to in the qualitative phase of the research. The findings were then considered in the 'real world' context - what did they mean for peoples' lives? Finally, consideration was given to what could realistically be done to alleviate the challenges highlighted in the research.



Limitations of the research

The main limitation of this research project is the under-representation of a certain section of the over 50s population who are particularly affected by HIV. The trans community is unfortunately totally unrepresented in this research. Further research is required to fully understand how transgender individuals living with HIV are affected by HIV as they grow older. This report can therefore not say whether the identified support needs and recommendations made are relevant to the trans community.

Other under-represented groups in this research include heterosexual men and the black African community.

Paper copies of the survey were accessible through HIV services for individuals who did not feel confident completing the survey online. Individuals who are not engaged with HIV services and could not access the online survey are likely to have been missed and are therefore absent from this research.

This research did not explore the needs of people aged 50 and over who were at risk of HIV. With increasing numbers of older people newly diagnosed with HIV, further discussion needs to occur on how HIV (and other sexual ill-health) prevention and health promotion programmes can adapt to meet the needs of this group.



Results and recommendations

People living with HIV aged 50 and over are a diverse group

It is important to state that this report does not make the assumption that all people aged 50+ living with HIV have the same experiences, current and future concerns or the same needs.

People living with HIV aged 50 and over, like people living with HIV of all ages, are a diverse community of individuals. There was a 32 year age range between the participants in this research – from individuals aged 50 to those aged 82. What 'unites' these individuals is their HIV status and the biological impact of HIV on the ageing process. What differs is everything else – job status, financial stability, family and social relationships, time since HIV diagnosis, where they reside (from inner city to the most rural of areas), and of course gender.

The personal situation, needs and experiences of people who took part in this research ranged from individuals who have no current and no defined future need and who have a positive experience of living with HIV, to individuals who face a myriad of current and future challenges.

The wide-ranging situations of over 50s living with HIV

Health

Wealth

Happiness

“Phil” male, 51, white British, gay.

Phil was diagnosed in the 1980s. At the time he was in a well paid job that he really enjoyed and was in a stable relationship. For several years he was given early HIV treatments including AZT and DDI. His health rapidly declined in the mid-1990s when he spent some time in hospital and had to give up work. He started ART in 1996, but has continued to suffer from poor health, side effects from the medication, reduced mobility and chronic fatigue ever since.

Phil's partner died in the mid-1990s and he has been single since then. He has never been able to return to work due to his poor health and is dependent on benefits. Phil struggles to cope financially and in particular worries about being able to afford to have his heating on during the winter.

Phil has lived in a housing association flat for many years. Over the past few years he has begun to feel more vulnerable due to the antisocial behaviour of his neighbours, but he feels he will never be able to move. He fears his neighbours will find out about his HIV status. He has never told any of his family his HIV status and is not close to them. He used to have a strong social network of friends he could rely on for support. However, he has gradually felt more and more isolated from them due to not being able to afford to ever go out and socialise. In addition, his reduced mobility and fatigue makes leaving the flat more and more difficult – he spends most of his time home alone.

Phil's fears for the future are that his health and mobility will deteriorate even further, which would lead to even greater social isolation. Phil would prefer to move into a care home or supported housing, but with no savings and only a basic state pension in the future he is unlikely to be able to afford this.

“Mercy” female, 52, black African, heterosexual.

Mercy has only recently been diagnosed. She was diagnosed very late and was very ill in hospital for some time. Her health is now much improved and she has returned to work, but with fewer hours due to having reduced and fluctuating energy levels. She feels her health is unlikely to last and feels her life expectancy is much reduced due to her HIV status.

All of Mercy's family, including her children, live in another country and she has not told them her HIV status. She has made a few friends in the UK but has not told anyone apart from her employer about her HIV diagnosis. She does not really socialise very much and finds that HIV has become a barrier to both romantic relationships and friendships. This barrier is mainly due to the stigma surrounding the issue and her fear that people will find out about her HIV status.

She is trying to accept her diagnosis and not let it affect her life. However, it is currently affecting her financial situation as she is unable to work as much as she used to. She receives Housing Benefit but this is not enough to cover her rent. That her Housing Benefit might get taken away in the future is a constant worry.

Mercy's main concerns for the future are that her health will once again deteriorate and she will not be able to work enough to support her children.

“Catherine” female, 62, white European.

Catherine was diagnosed with HIV four years ago, she was unwell at the time of her diagnosis but since starting treatment her health has improved and she has few side effects from the medication. Since being told her viral load is undetectable (and it has been explained to her what this means) she has been able to accept her diagnosis and now sees it as any other long-term manageable condition.

Catherine has a couple of unrelated health conditions, her HIV medication occasionally complicates their treatment, but overall she is in good health. She has a good relationship with her GP who manages her care well.

She is single but has a strong relationship with her family and children. She has a good network of friends in her local area. They all know her HIV status and are very supportive.

Catherine had to give up work a couple of years ago and is dependent on disability benefits. She has little spare money but, as she lives with her daughter, she has enough to meet her basic needs and feels secure in her housing situation.

Her main concern for the future is what will happen when her GP and HIV consultant retire – what will her care be like with new clinicians? Will they know enough about HIV and her other health conditions? She also worries that her benefits will be taken away and she will become a burden on her family.

“Mike” male, 56, white British, gay.

Mike was diagnosed with HIV 10 years ago, his health when he was diagnosed was very bad. However, since then his health has stabilised and he suffers few side effects from the medication.

He has a long-term partner and their relationship has not been affected by his diagnosis. They own their own home together and feel financially secure for the future, with savings and private pensions.

Mike actually describes his diagnosis as, although upsetting initially, ultimately a positive thing as it allowed him to take stock of his life and realise what was really important. This led to a career change and he is now doing a job he really loves. He also volunteers on a regular basis for various HIV organisations, supporting people who have been recently diagnosed, which he finds very fulfilling.

Mike's main concerns for the future are based around general fears about getting older. He says his HIV is no more worrying than any other long-term manageable condition.

The impact of the availability of HIV treatment

Unsurprisingly, our study has highlighted that there is a difference in needs and experience depending on whether an individual was diagnosed with HIV before or after the availability of effective ARVs in the UK in 1996. Before this, HIV often progressed to AIDS with many individuals diagnosed pre-treatment being told that they were likely to die within a matter of years. This is especially true for MSM who were particularly affected in the early years of HIV and AIDS.

'Back then when they told me, they told me I had a maximum of five years to live, they were quite blatant about it. So that was the thing that stuck in my mind "FIVE YEARS". I didn't really care about anything for a while, I didn't care about what people thought, about what my life could be, those five years were always there in the back of my mind. But even though I'm still here now, those five years have never left me ...in that respect the damage has been done from that early diagnosis.'

(Male, 52, white British, gay, diagnosed in 1985)

'In 1993 there was still a lot of stigma, particularly with this. There were still a lot of people dying from AIDS. All of a sudden in the 1980s there was this GRID and "gay cancer" and all the rubbish in the newspapers, and every way you looked there was stigma and violence and just ...the world was not a happy place to be.'

(Male, 60, mixed race, gay, diagnosed in 1993)

'The hospital I was diagnosed in, that hospital was just ...oh my God ...there were all these young gay guys in wheelchairs ...you don't see that any more ...they looked like skeletons ...beautiful boyfriends pushing their skeleton boyfriends in wheelchairs ...horrendous. And then in the waiting rooms they said to me: "Don't take the medication they want to give you, a lot of people die from it." But the doctors didn't have anything else to say to you. I felt sorry for them really - the doctors - because they didn't know what to do, all these people dying and they didn't know what to do ...that stays with you.'

(Female, 63, white European, heterosexual, diagnosed in 1992)

'I mean I have nothing, the money has gone. That's all gone. But I mean we'd spend our holidays having fun thinking we were going to just spend up until we died. I didn't bother with pensions or savings, what was the point? But now ...my partner died, but I lived. So I'm lucky, but I struggle with money, we spent it all.'

(Male, 63, white British, gay, diagnosed in 1990)

A third (32%) of individuals who completed the survey were diagnosed pre HIV treatment¹⁶, with the remaining 68% diagnosed with HIV after the availability of HIV treatment in the UK. Individuals diagnosed post-treatment¹⁷ were nearly twice as likely to rate their wellbeing as 'very good' or 'good'.

Individuals diagnosed before 1996 were more likely to be dependent on benefits as their sole or main source of income. They were less likely to be in employment (full- or part-time) and, when in employment, were more likely to have additional forms of income to supplement their wage (possibly indicating they are on lower wages).

Individuals diagnosed before treatment was available were more likely to have three or more additional health conditions. People diagnosed with HIV after treatment was available were more likely to have none to two additional health conditions.

Many individuals diagnosed with HIV since effective treatment has been available have a very different experience of being diagnosed and subsequently living with HIV.

'It's a controllable infection. Pop a pill a day and you'll be fine.'

(Male, 56, white British, gay, diagnosed in 2006)

As with all things, it is not a clear-cut picture. Some individuals, no matter what their year of diagnosis, see HIV simply as a long-term health condition. And vice versa some individuals, diagnosed across all decades, continue to struggle with living with HIV including the external and self-stigma their HIV diagnosis has brought them.

'Getting diagnosed ...it just feels like a little blip in life now looking back. At first you think ...everyone remembers all the horror stories of the 80s, the tombstones and all that ...but it's not like that now really. So, at the hospital, he just said: "Look, your CD4 is this. Your viral load is this. So, you are quite stable." They said I could go back to work.'

(Male, 52, British Asian, gay, diagnosed in 2004)

The situation also differs between MSM, the black African community and heterosexual men and women living with HIV. For the African community, AIDS is still a reality for many friends and relatives living in sub-Saharan African countries where access to good quality ART is not a given. While the early HIV epidemic in the UK was seen to affect mainly MSM, black African and heterosexual individuals were diagnosed, and continue to be diagnosed, with HIV. A recent HIV diagnosis for some remains traumatic.

'I mean, I was aware of it, I've even done training on it but it never entered my head as a condition that I could get. No one tells you, there's nothing out there ...it was a nasty moment, I felt suicidal. I don't tell anyone, no one knows, I couldn't cope if my friends or family found out.'

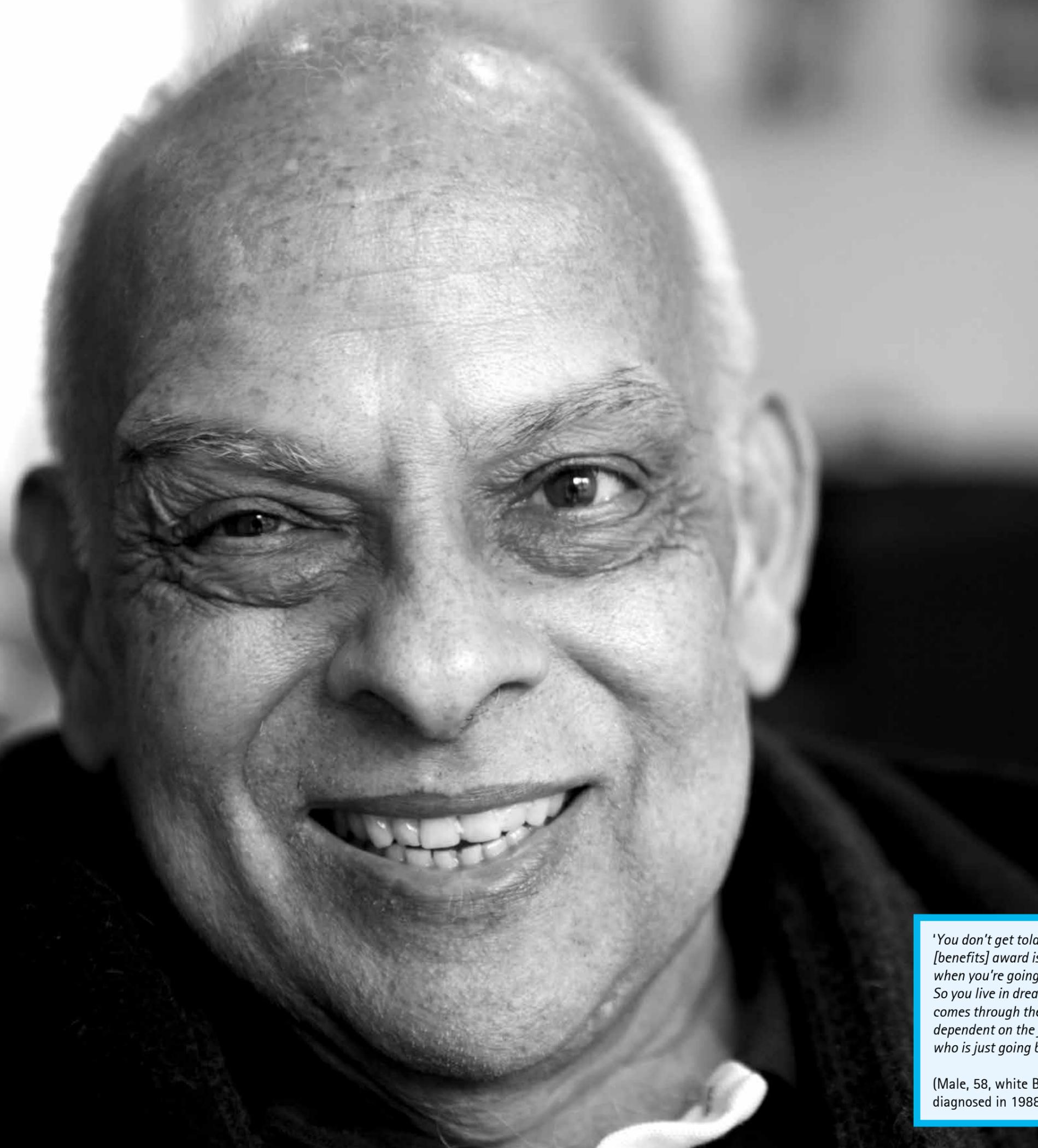
(Female, 56, white British, heterosexual, diagnosed in 2011)

'When people find out they think things about you, that you're a loose woman, that you have sold sex. They think lots of things and that's not me ...but I know they think it and it affects me.'

(Female, 52, black African, heterosexual, diagnosed in 2002)

¹⁶ Before 1996

¹⁷ From 1996 onwards



'50+' is not one category

- People living with HIV aged 50-60 - of working age - were concerned about seeking or retaining employment and benefits.
- 77% of respondents aged 65 and over rated their wellbeing as 'good' or 'very good', compared to 34% of those aged 50-60.
- The older a person living with HIV gets the happier they feel, the better their wellbeing, the lower their levels of both age- and HIV-related self-stigma.
- Individuals aged 65+ tended to see their GPs as having more knowledge about HIV, about growing older and about growing older with HIV.

For many people in the UK - no matter what their HIV status - 50 is not old! It is perhaps the beginning of another phase in an individual's life but many people will still be of working age with 10 or 15 years left to work before retirement.

For people living with HIV who can now look forward to a full life expectancy, the outlook is similar. The research found a divide between individuals aged 50-60 and those aged 65+, whereas individuals aged 61-64 see a mixed picture. Individuals in these age groups had very different needs and different experiences.

50-60 years of age

Individuals in this age group are still of working age. Society deems that they should still be able to work. Research participants in this age group raised issues related to employment and benefits:

- There were examples of broken career histories due to time off work with HIV-related ill-health.
- Loss of early careers due to an HIV diagnosis.
- Having to retrain and pursue an alternative career as they are no longer physically able to carry out the job they were doing pre HIV diagnosis.
- The difficulty of competing in the job market against younger people being made extra difficult when a fluctuating condition such as HIV is added to the mix.

Concern was also shared about the impact of the ever-rising age of retirement on people living with HIV who are physically ageing earlier because of their HIV diagnosis.

A total of 36% of individuals aged 50-60 were solely reliant on benefits compared to 9% of those aged 65+. People living with HIV aged under 60 receiving benefits spoke of the anxiety of being reassessed for benefits, or the threat of benefits being stopped at any time. The lack of understanding of HIV in those who assess benefit claims came out as a major issue in research participants. Conflicting information was given by Job Centre employees and the benefits office.

'You don't get told how long that [benefits] award is for. You don't get told when you're going to be reassessed again. So you live in dread of everything that comes through the letterbox...your life is dependent on the judgement of somebody who is just going by tick boxes on a form.'

(Male, 58, white British, gay, diagnosed in 1988)

'The assessment is awful, so degrading - they try to trick you to make you give something away that would show you are pretending. Why would you pretend? I don't want to be like this...they don't seem to understand HIV at all, no two days are the same, one day I am fine and could work, tomorrow I can't get out of bed.'

(Female, 55, black African, heterosexual, diagnosed in 2000)

When thinking about the future, 45% of people living with HIV aged 50-60 were very concerned about retaining or seeking employment. This figure was 0% in those aged 65+, with 65% of individuals aged 65 and older also reporting that they are totally unconcerned about future employment.

This is reflected in the type of services that survey respondents said they would like to access. Half of all people aged 50-60 wanted advice around employment, as opposed to only 18% of individuals aged 65 and older. In total 63% of individuals aged 50-60 would like financial advice, compared to 55% aged 65+.

We also heard that people aged 50-60 often had increased care responsibilities for parents, partners and children and the added pressure this brings.

People living with HIV aged 50-60 (in common with their peers not living with HIV) are often still planning for the future. Research participants had many unanswered questions about what the future holds – financially, health-wise and socially. When thinking about the future they were notably more concerned than their peers aged 65+ about how they would access adequate healthcare and social care, how they would be able to care for themselves, how they would manage multiple health conditions, the uncertainty of the long-term impact of HIV and ART, memory loss, future mental health issues and loneliness.

'It's so hard to find work I can do, I am so up and down, there will always be somebody younger and who isn't sick who they would rather give the job to. No one wants to employ someone my age, not someone with HIV. I need part-time work, I can't do full-time, I wouldn't cope - but when they assess whether you can work at all they say you should work full-time. They don't help you find a job you can actually do.'

(Female, 57, Indian, heterosexual, diagnosed 2004)

'The big worry for the future is this social care thing ... I think that is the big issue which we need to start exploring. What is needed? And do I as a gay man need something different? Do I as someone with HIV need something different? I don't have any kids of my own ... I don't have that [safety net].'

(Male, 59, white British, gay, diagnosed in 1982)

'I also fear what illnesses lie ahead ... you're getting older and there's no way around that ... but wondering how HIV plays out. I mean, I've already had cancers cut out of my face. I had them cut out and they said we don't normally see this until people are in their 70s and 80s.'

(Male, 58, white British, gay, diagnosed in 1988)

'I think it's how this illness is affecting us long-term. It damages your organs ... those things I worry about. Is that the illness or the medication for the illness? Both, I think ... growing old worries me. I wonder how it is going to affect me. What kind of illnesses and diseases will I get from it?'

(Female, 51, white British, heterosexual, diagnosed in 2015)

'I can feel myself not thinking as well, not remembering things that I should, even today I couldn't remember where to come even though I knew I knew it. That worries me, that I'm losing my marbles - I'm too young to be going dotty ... I worry that my partner and my friends will get sick of me ... I worry I'll be alone.'

(Male, 51, white British, gay, diagnosed in 2011)

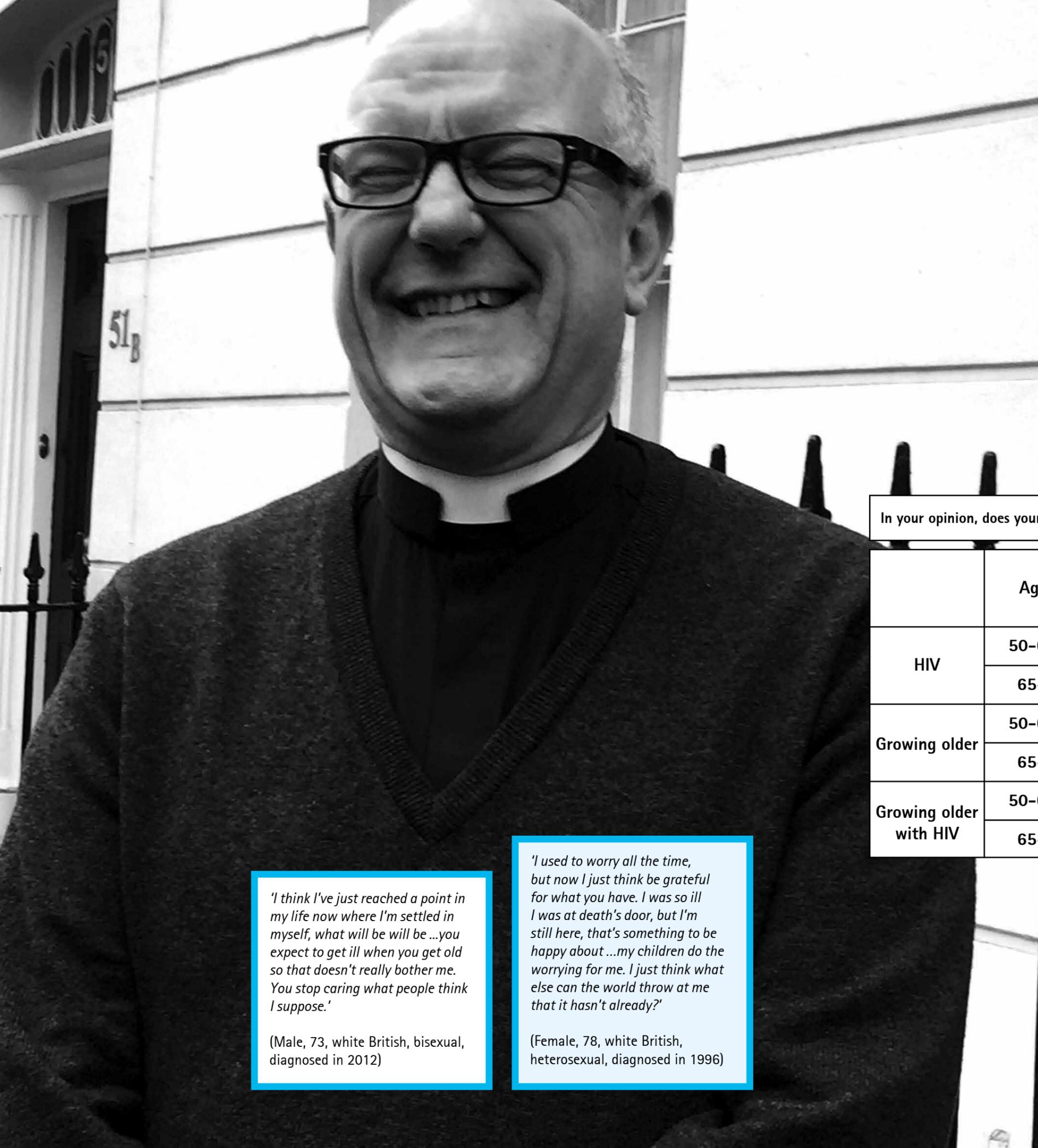


Individuals living with HIV aged 50-60, some of whom had only recently been diagnosed with HIV or other long-term conditions, were also still trying to navigate the healthcare system.

HIV self-stigma was higher in those individuals aged 50-60. Nearly three times as many 50-60 year olds had the highest score for HIV self-stigma compared to those aged 65+. Of individuals aged 50-60, 16% had no HIV self-stigma – this is double (32%) in their peers aged 65+. Those aged 50-60 were also more likely to experience moderate to high age-related self-stigma – 31% experience moderate to high age-related self-stigma compared to 18% of individuals aged 65+. Conversely, just under half (45%) of 50-60 year olds experienced no age-related self-stigma compared to 64% of their peers aged 65+.

When thinking about the future, individuals aged 50-60 were also twice as likely to be concerned about finding or retaining a partner compared to those aged 65 and older.

The research found a mixed picture for people living with HIV aged 61-64. It was often a transition period with individuals who were employed retiring or planning their retirement in the near future.



'I think I've just reached a point in my life now where I'm settled in myself, what will be will be...you expect to get ill when you get old so that doesn't really bother me. You stop caring what people think I suppose.'

(Male, 73, white British, bisexual, diagnosed in 2012)

'I used to worry all the time, but now I just think be grateful for what you have. I was so ill I was at death's door, but I'm still here, that's something to be happy about...my children do the worrying for me. I just think what else can the world throw at me that it hasn't already?'

(Female, 78, white British, heterosexual, diagnosed in 1996)

65+

In contrast, survey responses indicated that the older a person living with HIV gets the happier they felt, the better their wellbeing and the lower their levels of HIV self-stigma.

Altogether, 77% of respondents aged 65 and over rated their wellbeing as 'good' or 'very good', compared to 34% of those aged 50-60. Of individuals aged 50-60, 25% reported their wellbeing as 'bad' or 'very bad', compared to only 5% aged 65 or older.

People living with HIV aged 65+ were less reliant on benefits, more likely to feel that they have enough money to meet their basic needs, and were also unsurprisingly less likely to be working than their younger peers. Of people living with HIV aged 50-60, 28% had a full-time wage compared to 5% of those aged 65+. All in all 9% of individuals aged 50-60 had a private pension as their main form of income, compared to 69% of people aged 65 and older. Nearly three times as many (25%) individuals aged 50-60 'never' or 'rarely' had enough money to meet their basic needs, compared to just 9% of individuals aged 65+. A third of individuals aged 50-60 'always' had enough money compared to 45% of those aged 65+.

Relationships with health professionals are key to people living with HIV aged 65 and older. This age group tended to see their GPs as having more knowledge about HIV, about growing older and about growing older with HIV.

In your opinion, does your GP know enough about the following health related topics to be able to help you?

	Age	Yes always	Sometimes	No but refers me	No never	I don't ask
HIV	50-60	14%	30%	25%	13%	19%
	65+	45%	30%	15%	5%	5%
Growing older	50-60	21%	28%	9%	6%	36%
	65+	50%	25%	5%	5%	15%
Growing older with HIV	50-60	7%	16%	15%	21%	42%
	65+	28%	28%	23%	9%	14%

However, this age group was also more likely to access social care, including residential care, and experience discrimination and prejudice by social care staff.

Recommendation: HIV support services aimed at people living with HIV aged 50 and over should carefully consider the diversity of needs of service users, and consider tailoring different support packages to 50-60 year olds, 61-64 year olds and to individuals aged 65+.

Recommendation: Support services for older people provided by older person's/ ageing organisations and charities should carefully consider the diversity of needs and experiences of service users living with HIV and consider tailoring support to ensure specific needs are met.

Poverty is impacting people living with HIV aged 50 and over

- Over half of people living with HIV aged 50+ are living in poverty.
- Levels of poverty are double those seen in the general population.
- Over a third of over 50s living with HIV are reliant on welfare benefits.
- A third of people living with HIV aged 50 and over have not made financial plans for the future.
- 84% of over 50s living with HIV are concerned about future financial difficulties.
- The situation has deteriorated since 2010 with more people living with HIV aged 50 and over having concerns about future finances compared to seven years ago.

Poverty

In total 58% of survey respondents were defined as living on or below the poverty line¹⁸. The situation has deteriorated since 2010 when 48% of respondents to Terrence Higgins Trust's HIV and Ageing survey were found to be living in poverty. Statistics available for the general population indicate that 30% of individuals aged 55 or older are living in poverty¹⁹. As 58% of over 55s living with HIV are living in poverty this is double that seen in the general population.

'Finances ... well I don't have any, well nowhere near what I need to be healthy, to be secure. To be healthy, for the medication to work properly, you need to eat well - but eating well, eating enough, costs money, money I don't have. Friends as well, how do you see your friends with no money?'

(Male, 52, white British, gay, diagnosed in 2001)

'If I spend what little money I have on one thing, I can't spend it on something else, it's always a trade-off, that's a stress, a worry. My flat is damp and it's not good for my chest - I think I'm more ill and that's why. I should have the heating on to help the damp but it's so expensive. I worry about how cold a winter it will be, how much will I have to have the heating on.'

(Male, 51, white British, gay, diagnosed in 1989)

Under half (45%) of people living with HIV aged 50 to 64 years old were economically active (full-time, part-time or self employed). In comparison, in the UK population, 72% of 50 to 64 year olds are economically active²⁰.

Welfare benefits

A third (32%) of those over 50 living with HIV were solely reliant on benefits to live. An additional 5% rely on benefits as the major source of their income. Reliance on benefits is more common in individuals diagnosed pre HIV treatment - when an HIV diagnosis was considered terminal and individuals often used any financial savings (including cashing in pensions) to enjoy the few years they had left to live.

¹⁸ Poverty threshold in the UK is currently defined at: £283.80 per week.

¹⁹ Great Britain. Department for Work and Pensions (2016) Households below average income: 1994/95 to 2014/15 (Supporting table 3.22ts) [Online]. Available at: www.gov.uk/government/statistics/households-below-average-income-199495-to-201415

²⁰ Great Britain. Nomis and Office of National Statistics. (2016) Annual Population Survey - households by combined economic activity status (2004 - 2015) [Online].

Available at: www.nomisweb.co.uk/query/select/getdatasetbytheme.asp?opt=3&theme=&subgrp=

But many individuals did not die and instead, without savings, employment or good health, were placed on Disability Living Allowance and other forms of benefits. This situation persisted for many people living with HIV who, for physical or mental health reasons, were not able to work and remained reliant on benefits. The number of individuals living with HIV aged 50 and over who are reliant on benefits has not changed over time with 32% of respondents to Terrence Higgins Trust's HIV and Ageing research in 2010 also reliant.

'The idea that someone would take me on after I've been out of work for so long, about 23 years now, that my skills would be relevant, you know, that somebody would want to take me on with this health condition? Who's going to want to employ somebody like that?'

(Male, 58, white British, gay, diagnosed in 1988)

'I'm living on benefits because I can't work at the moment. I want to get back to work, I want to get fit enough to get back to work. Every time when I get better, something else hits me. Especially at the time of life when you didn't think this would ever happen to you.'

(Female, 51, white British, heterosexual, diagnosed in 2015)

'I had to give up work when I got ill, I was in hospital so I couldn't work ...I did try going back to work part-time, doing three days a week. And that was far too much. I was literally passing out at work. I was ill for years, always just ill, ill, ill. I've never been able to go back to work I still get every bug going and am fatigued all the time.'

(Male, 51, white British, gay, diagnosed in 1989)

Dependence on welfare benefits is particularly seen in individuals of working age. In total 36% of individuals living with HIV aged 50-60 were solely reliant on benefits compared to 9% of those aged 65+. Half (51%) of survey respondents aged 50-60 wanted to access services that provided employment advice, and 63% would like financial advice.

The survey found that individuals who were receiving benefits (of any amount) had the lowest reported levels of wellbeing and the highest levels of HIV self-stigma. Much is currently changing

in the national benefits system in England and many individuals told us that the stress of benefit reassessments (or the threat that they may be reassessed at any time) had a direct impact on their physical and mental health. Similar correlations were seen in the recent HALL study²¹ with people who were living with HIV aged 50 and over and receiving benefits seeing the lowest levels of quality of life.

The lack of understanding of HIV in those who assess benefits came out as a major issue for research participants. Conflicting information was given by Job Centre employees and the benefit office.

'It's so confusing, the benefit office tells you one thing, the Job Centre people tell you another. If you do one thing that might help you get a job, you then get told that if you do that your money will get taken away. One says try for something part-time because of your HIV, the other says if you can work at all then you don't deserve your benefits. What are you supposed to do? Who do you listen to?'

(Male, 57, black African, heterosexual, diagnosed in 2007)

²¹ Rosenfeld, D., et al. (2015) Social support, mental health, and quality of life among older people living with HIV: Findings from the HIV and later life (HALL) project [Online] Available at: www.keele.ac.uk/hall

'There is a definite attitude that if your life is dependent on Government money, then your life is less valued than those people who are working ...and I get very resentful about that.'

(Male, 58, white British, gay, diagnosed in 1988)

Good health and housing

Good health is key to financial stability. Individuals who were diagnosed early after infection with HIV (ie, with a CD4 count of 500 cells/mm³ or higher) were more likely to be in higher income brackets. Conversely, individuals diagnosed very late with HIV (CD4 <200 cells/mm³) were more likely to be in the lowest two income brackets.

Alongside financial stability, housing was also a key concern. Two thirds (62%) of people who responded to the survey did not own their own home. This is deterioration from the 2010 HIV and Ageing research when 47% did not own a home. In the 2016 survey individuals instead resided in housing association accommodation (19%), privately rented accommodation (17%) or council property (15%). Insecurity around current and future housing was a key theme emerging from the research workshops and interviews. Participants felt a lack of power over where they live, no ability to move or change accommodation and a fear that at any time their housing may be taken away from them or they will have to leave the community in which they live. Over half of respondents wanted to access advice on housing.

Over 50s living with HIV were over three times more likely not to own their home than their HIV negative peers. Recent Age UK statistics have shown that 20% of individuals in the UK aged 50 and over do not own their home²². However, Age UK research also found that nearly a quarter of the general population in the UK in their early 50s were concerned about being forced to leave their home because of mortgage/rent payments²³.

'I fear that I will get too ill to work and we will lose our family home.'

(Male, 53, white European, heterosexual, diagnosed in 1991)

'My main concern for the future is the inability to provide myself with an independent roof, food and heating.'

(Male, 50, white British, gay, diagnosed in 1992)

'Fear of becoming too ill to work as long as I wish to. This would compromise my finances and my ability to pay the rent and service charges on my shared ownership property.'

(Female, 55, white British, heterosexual, 2011)

Planning for the future

Again it is important to stress that not all people living with HIV aged 50+ live in poverty. However, worryingly, a third of survey respondents had not made any financial plans for the future. Some shared concerns that their health would deteriorate and they would have to retire early – before they had saved enough money to live on in retirement. Others who were still in their 50s worried that they would not have enough money once they retire to have anything resembling a good quality of life.

In total 84% of over 50s were concerned about future financial difficulties and over half (56%) were concerned about their ability to find or sustain paid employment in the future. A theme from the research was that many individuals wanted to prepare for the future but could not afford to, or had no spare money to save – especially with the threat of benefit reductions. This is a deterioration from 2010 when the HIV and Ageing survey saw 79% of older people living with HIV concerned about future financial difficulties.

Recommendation: HIV organisations must continue to engage in the development of the benefits systems across the UK and ensure that current and future benefits systems understand and deliver the needs of people living with HIV aged 50 and over who are unable to work or work full-time.

Recommendation: The Department for Work and Pensions must improve the quality and consistency of information and guidance it provides to people living with HIV. Continual training of welfare benefits advisers across the UK is essential. All training packages should be written in collaboration with HIV organisations and individuals directly affected by HIV.

Recommendation: The Department for Work and Pensions must ensure that both welfare benefits advisers and staff of Job Centres provide consistent information around access to benefits for people living with HIV.

Recommendation: HIV organisations, working with older people's organisations and mainstream advice services, should ensure that information, advice and support is available to people living with HIV aged 50 and over in relation to access to benefits, housing and financial planning – being clear about the rights that individuals have in regard to these areas.

²² Age UK (2016) Later life in the United Kingdom [Online]. Available at: www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true

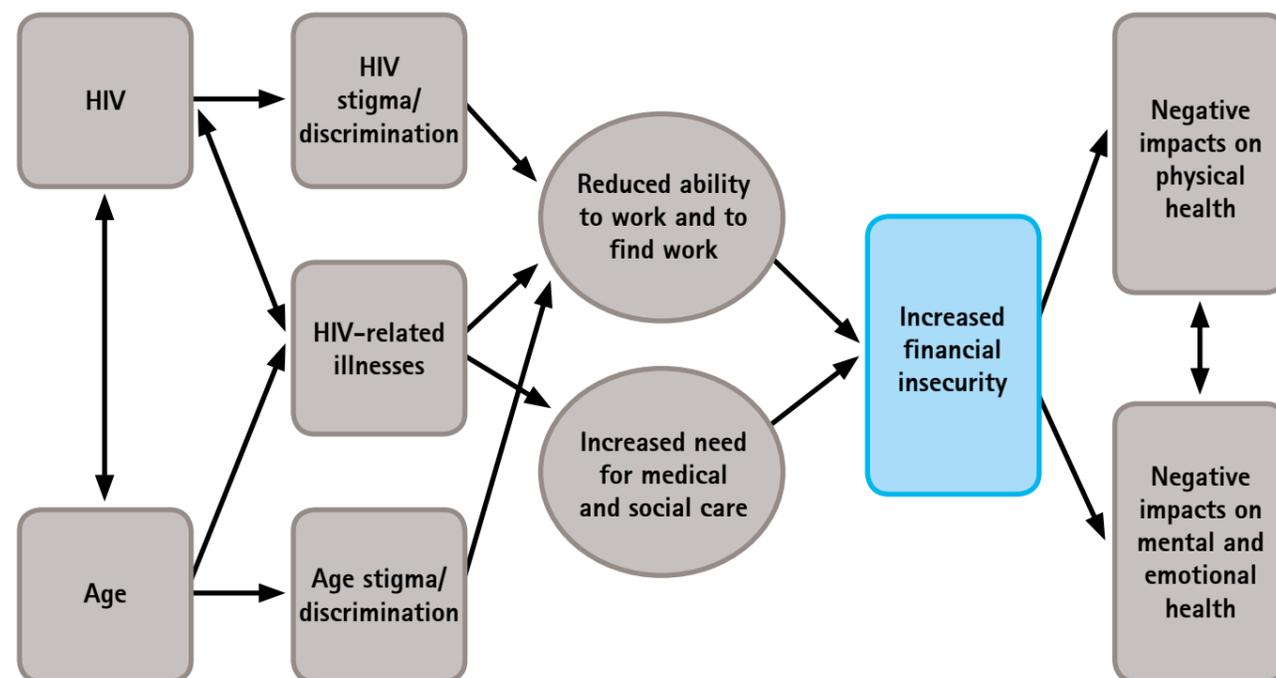
²³ Age UK (2013) Economic Tracker [Online].

Available at: www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Economic%20Monitor%20Report%20Summer%202013.pdf?dtrk=true

It all comes back to finances

- £ In nearly all areas that were explored in this research, there is a direct link with finances and income.
- £ Wellbeing decreases with decreasing income. In contrast wellbeing increases with the frequency at which people say they have enough money to purchase essential items including housing, food and fuel.
- £ Social isolation increases with decreasing income. Some respondents were concerned that if their financial situation got any tighter in the future socialising would be the first cost they would cut – leaving concerns on what this means for social isolation.
- £ HIV self-stigma is lowest in people who are employed, and highest in people reliant on benefits.
- £ Age-related stigma increased with decreasing financial income.
- £ Loneliness increased with decreasing income.

Process chart on HIV, age, money, health and work



Illustrating the complex relationships between HIV, age and stigma in impacting money, health and work. Taken from *Terrence Higgins Trust – A National Study of Ageing and HIV (50+)*, 2010.

Social care is not currently meeting the needs of people living with HIV

- People living with HIV aged 50 and over have faced discrimination from social care professionals due to their HIV status.
- 82% of over 50s living with HIV are concerned about whether they will be able to access adequate social care in the future.
- 88% of people living with HIV aged 50+ had not made financial plans to fund future care needs.

People growing older with HIV face the prospect of managing multiple long-term conditions that are made more complex by their interactions with HIV. In total 81% of people living with HIV aged 50 and over were concerned about how they would take care of themselves and manage daily tasks in the future. A quarter (22%) of survey participants also told us that they have no one to help them if they ever needed support with daily tasks.

Affordability of social care

A fundamental concern that was highlighted in the research was the fear that individuals would not be able to access social care – that financial barriers would prevent them being able to afford the care that they need. Those aged 50 and over felt a lack of agency and control over their future social care and support, with a lack of financial freedom limiting (or eliminating entirely) their ability to choose a residential care setting.

These concerns are well-founded and relate to all older people – not just those living with HIV. The inability to access a social care sector in crisis is unfortunately already a reality for many older people. The English Care Quality Commission's (CQC) 2016 report, *The State of Care*²⁴, warns that adult social care 'is approaching a tipping point' while the UK Parliamentary Select Committee on Health in a recent inquiry²⁵ highlighted that: '[English] Local Authorities have responded to budget pressures by reducing the availability of social care ...in June 2015, some 400,000 fewer disabled and older people received social care than in 2009–10.'

People living with HIV aged 50+ in our research shared experiences of seeing the impact of poor quality care on their own parents – understanding the reality that you 'get what you pay for' when it comes to social care. Yet social care is now getting more expensive, access to financial support to fund social care ever more scarce. We also now know from this research that over half of people living with HIV aged 50 and over are living in poverty and 88% have not made any financial plans for their future care. For these individuals, securing quality social care that meets their needs will be of immense difficulty.

²⁴ Care Quality Commission, *The state of health care and adult social care in England*, 2016 2015/16 www.cqc.org.uk/sites/default/files/20161013_stateofcare1516_summary.pdf
²⁵ Health Select Committee, *Impact of the Spending Review on health and social care*, 2016 www.publications.parliament.uk/pa/cm201617/cmselect/cmhealth/139/13902.htm

While we would have liked to include a recommendation within this report of a 'silver-bullet' that will solve the social care crisis in the UK, the predicament and complexity of the situation is such that a ready solution is unfortunately not possible. However, this does not prevent a range of actions being taken to improve the quality of life of people living with HIV accessing social care, and to advise individuals as they seek entry to social care. The HIV sector – both policy and service provider organisations – must also actively seek to be part of the conversations on the future of social care. We must actively engage with, and see how we can support, Local Authorities, the NHS and social care providers in ensuring the needs of people growing older with HIV are considered.

Recommendation: HIV organisations and charities, alongside individuals living with HIV, must actively engage in policy and commissioning discussions about the future provision of social care across the UK, ensuring that the needs of people living with HIV are fully met.

Discrimination and confidentiality

Social care provides personal and practical support to help individuals with their physical needs. Social care should be centred around independence – enabling individuals to remain in control of their lives. Even when physical and mental ill-health prevents an individual from living independently, all social care should be provided with dignity and respect.

Yet research participants who had direct experience of social care reported a gross lack of understanding and awareness of HIV among social care professionals – often manifested as prejudice and discrimination. One participant had their HIV status revealed to their brother when somebody delivering mobility equipment left a document mentioning the participant's HIV status visible. This led to a complete loss of relationship with the participant's brother. Another participant had their HIV status revealed to a friend when a home care support worker mentioned her HIV status in conversation in front of the visiting friend.

This is reinforced by multiple experiences of discrimination that Terrence Higgins Trust has seen regarding to people living with HIV aged 50 and over accessing social care.

Case study - Wales

A man living with HIV was an inpatient on a ward in a hospital in Wales. The individual had been diagnosed late with HIV and had experienced complications with his health. However, his HIV treatment had resulted in his HIV viral load becoming undetectable. He needed to be discharged into a residential care home to support his general care needs. The first care home contacted refused to take him, knowing he was living with HIV, stating that 'we don't deal with people like that'. A second care home was approached. They also refused to take the individual on the grounds of 'infection control' and 'risk to staff'. In response, HIV awareness training was delivered in the care home, but even after the training the care home refused to take the individual. A third care home agreed to take him but said that residential fees would be doubled to compensate for the extra 'burden' of care his HIV diagnosis would bring. After at least four months the gentleman was still on the hospital ward – with no move to a residential care home in sight

Case study - London

A resident living with HIV in a care home in London was encouraged to spend as much time in her room as possible to avoid contact with other residents. If the individual did sit in the residents' lounge, she was only allowed to sit on one particular chair. The TV remote was taken away when she tried to use it and wiped down with antibacterial wipes. Care staff were told to double up their gloves when changing her bed sheets.

This is unacceptable. People living with HIV in care homes should not be treated any differently from their peers. Instead, these actions are fuelling myths and stigma around HIV and further isolating older residents living with HIV in residential care.

Examples of HIV discrimination in social care for older people are now starting to be better known in the HIV community, leading to concerns for the future for individuals as they age with HIV. Research respondents who do not currently access social care, but who foresee that they will have to in the future, reported concerns with staff not knowing how to care for someone with HIV. There was also concern that they would experience stigma and homophobia from other residents and that discrimination from staff could lead to poorer quality care.

The experience of Terrence Higgins Trust's Health, Wealth and Happiness project has been that social care professionals generally discriminate against people living with HIV. This is not because of deep-rooted maliciousness, but because of a lack of up-to-date information and knowledge on what it means to live with HIV in 2016.

Social care professionals are not routinely provided with training on HIV as part of basic inductions, and are not required to remain up-to-date with HIV as part of their professional development. Social care providers have a duty to ensure that the services they provide promote equality, respect and are based on up-to-date evidence and best practice. In England, induction training as part of the Care Certificate does not include HIV. Yet there are opportunities to incorporate learning on HIV – whether it be through the Care Certificate standard on privacy and dignity, on equality and diversity, or busting some HIV myths while teaching the standard on infection prevention and control²⁶. In Wales, the change brought about by the Social Services and Well-being (Wales) Act provides an opportunity to examine the degree to which social care staff are trained and supported to care for someone living with HIV. The Scottish Social Services Council has a key role to play in ensuring that care staff are equipped with the ongoing knowledge they need around HIV including ageing with HIV.

In reality, sustainability will only be achieved if all social care professionals are taught about HIV as a matter of routine during basic training. All training materials should be co-produced with over 50s living with HIV and, as with the National AIDS Trust guidance²⁷, cover basics around HIV. For example how HIV is transmitted, Treatment as Prevention (TasP) and undetectable viral load – as well as information related to the specific needs of people living with HIV aged 50 and over.

All training must clearly set out the legal requirements for confidentiality around an individual's HIV status.

²⁶ Skills for Care, Skills for Health, Health Education England. The Care Certificate Standards www.skillsforcare.org.uk/Documents/Learning-and-development/Care-Certificate/The-Care-Certificate-Standards.pdf

²⁷ The National AIDS Trust, HIV: A Guide for Care Providers, 2015.

Recommendation: Skills for Care alongside Health Education England, the Scottish Social Services Council and the Care Council for Wales must ensure that HIV and ageing is a mandatory part of all entry-level training and induction for social care workers.

Our understanding of the impact of HIV on ageing (and of HIV more broadly) is changing constantly. Social care professionals, as part of their professional development, must continue to keep up-to-date with evidence and best practice around meeting the needs of individuals growing older with HIV. Social care provider organisations must keep HIV in their thoughts when it comes to staff training and development. National HIV health professional organisations, HIV charities and community groups can play a key role in upskilling social care providers in the basics of HIV as well as the needs of people living with HIV aged 50 and over. It is fully acknowledged that the financial constraints currently facing HIV organisations will mean that training can only be provided if additional resources are secured.

There are already resources available and established good practice that can be used to design and implement ongoing training for social care staff. The National AIDS Trust's 2015 *Guide for Care Providers*²⁸ provides practical guidance to domiciliary and residential care staff. It provides basic information on HIV, busts HIV myths and includes clarity on confidentiality and the rights of people living with HIV.

Sahir House, National AIDS Trust and Terrence Higgins Trust all currently provide training to residential care providers – in some cases proactively, in other cases as an outcome of reported HIV discrimination by a social care worker.

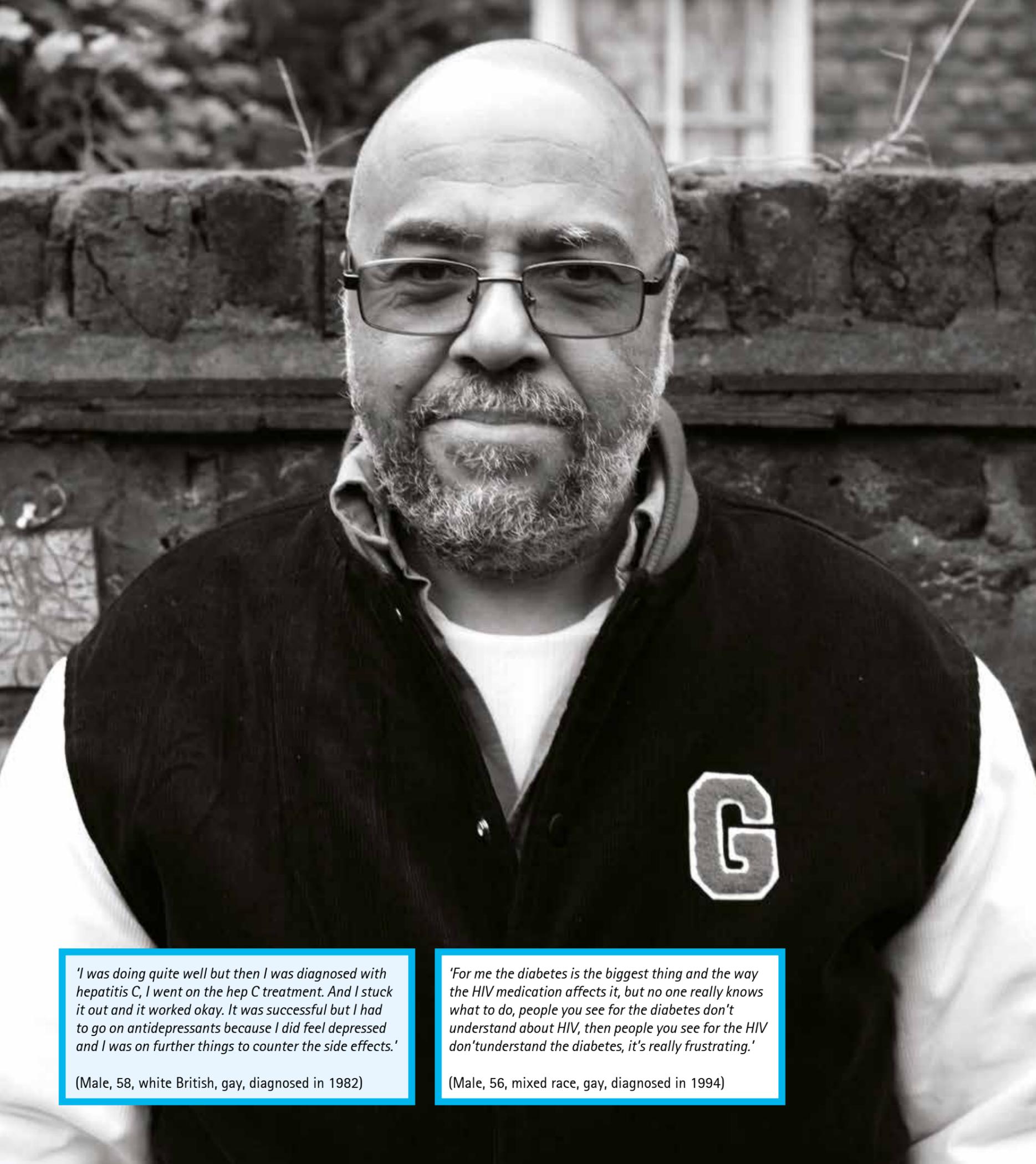
Recommendation: Social care providers should ensure continued professional development for staff around HIV, using key awareness days such as World AIDS Day and utilising local and national HIV organisations to ensure all activities are based on up-to-date evidence.

Recommendation: HIV organisations should actively engage with local and national social care providers to provide up-to-date training on HIV including HIV and ageing. Educational resources should be co-produced with people living with HIV. Ideally, positive speakers should be supported to facilitate training and awareness.

Recommendation: HIV charities and organisations should work with older person's/ ageing charities that regularly interact with social care providers to ensure that they have up-to-date knowledge around HIV and feel confident in supporting older people living with HIV who are accessing social care.



²⁸ The National AIDS Trust, *HIV: A Guide for Care Providers*, 2015



Co-ordinated long-term condition management, with support to self-manage, is essential for people living with HIV aged 50 and over

- People living with HIV aged 50 and over have on average three times as many long-term health conditions as the general population.
- 84% of people living with HIV aged 50 and over were concerned about how they will manage multiple health conditions in the future.
- 80% of survey respondents were worried about the uncertainty of the impact of living with HIV long-term.
- 79% of people living with HIV aged 50 and over were worried about the impact of taking ART long-term.

Wellbeing

Our survey found that 22% of over 50s rate their current wellbeing as 'bad' or 'very bad', with an additional 39% rating it as 'fair'. However, in contrast, 39% felt their wellbeing was 'good' or 'very good'.

Survey respondents reported lower levels of wellbeing with increasing numbers of co-morbidities and increasing numbers of daily medications needed. Altogether, 90% of respondents with no other health conditions rated their wellbeing as 'good' or 'very good', compared to only 5% of people with five or more conditions. No one with no additional health conditions rated their wellbeing as 'bad' or 'very bad'. In comparison half (51%) of those with five or more health conditions in addition to HIV rated their wellbeing as 'bad' or 'very bad'.

A total of 45% of people living with HIV aged 50 and over had experienced depression and 39% anxiety-related disorders. Three quarters (77%) are concerned about experiencing mental health issues or depression in the future.

Multi-morbidities

People living with HIV aged 50+ who responded to the survey live with up to 11 co-morbidities. This ranges from 8% of individuals who do not have any health conditions other than HIV, to 28% of respondents who live with five or more health conditions in addition to HIV.

This group had on average three times as many long-term health conditions (in addition to HIV), compared to the general population^{29,30}. In total 92% of our survey respondents had at least one long-term health condition (in addition to HIV). This is compared to 58% of the UK's population of over 60s and 14% of the UK's population aged over 40³¹.

29 Barnett, K., et al. (2012) 'Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross sectional study' in *The Lancet Volume 380, Number 9836* p37-43.
30 Beach, B. (2015) *Serious illness in the over 50s* published by The International Longevity Centre.
31 The King's Fund (2013) *Long term conditions and multi-morbidity* [Online]. Available at: www.kingsfund.org.uk/time-to-think-differently/trends/disease-and-disability/long-term-conditions-multi-morbidity

'I was doing quite well but then I was diagnosed with hepatitis C, I went on the hep C treatment. And I stuck it out and it worked okay. It was successful but I had to go on antidepressants because I did feel depressed and I was on further things to counter the side effects.'

(Male, 58, white British, gay, diagnosed in 1982)

'For me the diabetes is the biggest thing and the way the HIV medication affects it, but no one really knows what to do, people you see for the diabetes don't understand about HIV, then people you see for the HIV don't understand the diabetes, it's really frustrating.'

(Male, 56, mixed race, gay, diagnosed in 1994)

The reality is that many of those over 50 living with HIV are taking a large number of different medications daily and have their care managed by a large number of different health professionals. Drug interactions between ART and other medications are common.

In total 65% are taking medication for health conditions in addition to HIV. The amount of medication (in addition to ART) that an individual took daily ranged from none up to eight additional medicines.

Many people reported that they were already struggling to remember to take multiple medications as well as remember the multiple healthcare appointments their health conditions demanded. Nearly eight out of 10 (79%) were concerned about memory loss and cognitive impairment in the future and 84% were concerned with how they would cope with managing multiple health conditions.

'I worry about early dementia, I'm OK now, but that's a worry. I live alone. How will I cope if that happens?'

(Male, 51, white British, gay, diagnosed in 2012)

People aged 50+ living with HIV reported having to visit up to six locations for their healthcare. In total 11% regularly visited four or more locations.

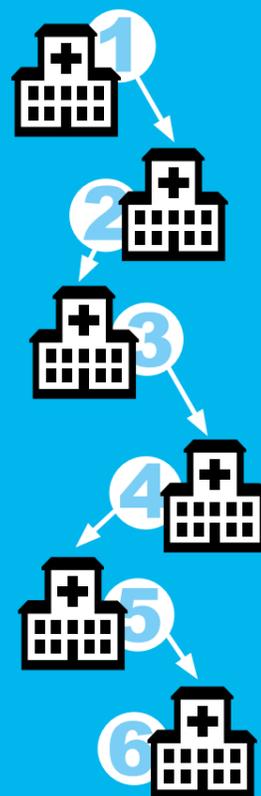
A common theme that came out of discussions was the sadness that HIV clinics are no longer 'one-stop-shops'. Participants reported very high levels of satisfaction with their HIV clinical team – the UK has excellent, high quality HIV clinical care with incredibly short waiting times. However, whereas in the past many HIV clinics treated the needs of people living with HIV holistically – including providing low-level, non HIV-specific care such as influenza vaccines – people living with HIV (of all ages) must now visit other health services including primary care to access these interventions.

As will be discussed in the next chapter, the reality is that clinically HIV is a manageable long-term condition, and with the increased risk of co-morbidities that an HIV diagnosis brings, co-ordination is essential across all aspects of care and support. Strong support from primary care professionals is key. Effective, co-ordinated, holistic long-term condition management is essential for people living with HIV who are having to cope with health conditions related to HIV, ageing and the interaction of HIV on the ageing process.

65%
are taking medication for health conditions in addition to HIV.



People aged 50+ living with HIV reported having to visit up to six locations for their healthcare.



'It just gets on top of you all these different medications and side effects and medications for the side effects, statins, ART, insulin, stuff for my stomach ...it goes on and on. I think my arthritis is the hardest thing to cope with, that makes everything difficult - going to the shops, going to hospital appointments - the more appointments the more my arthritis bothers me.'

(Male, 61, white British, diagnosed in 1990)

'It just gets so confusing - there are so many appointments. I have to go to four different hospitals ...before I have remembered the correct time but gone to the wrong hospital. I try to have coping mechanisms - to write everything down - but its not always foolproof.'

(Female, 52, black African, heterosexual, diagnosed in 2003)

Health & Wealth & Happiness

Supporting over 50s living with HIV

Terrence Higgins Trust's Health, Wealth and Happiness project offers workshops and information sessions for older people living with HIV. The project offers treatment update sessions, menopause workshops, men's health sessions – all with the express purpose of helping people to manage their own health and care.

There is a way to go to for this to be a reality. Survey respondents reported a lack of communication between the various health professionals that manage their healthcare. People living with HIV aged 50 and over also experienced multiple instances of non HIV-specialist health professionals having no understanding of HIV and any potential impact it might have on other health conditions.

'At first my GP knew nothing about HIV, he was obviously quite flustered by it. But he's getting better, he's trying.'

(Male, 56, white British, gay, diagnosed in 1997)

'My GP knows very little, the nurses seem to understand more. I used to be a doctor so I find out what I can myself, the GP is no help.'

(Male, 54, black African, heterosexual, diagnosed in 2005)

There is a desire by many people living with HIV (of all ages) to play a greater role in their own care management. There is a need for support to allow individuals to self-manage their health and wellbeing. In total 86% of respondents wanted information on health and treatment issues for people living with HIV aged 50 and over – making it the most common service/intervention requested.

'Just someone telling you the dos and don'ts, what you don't need to worry about, where to find information, that can be hugely powerful, makes a real difference.'

(Male, 62, white British, gay, diagnosed in 2009)

Recommendation: BHIVA, BASHH, RCGP and RCP, working with people living with HIV aged 50 and over, should work together to agree clear care pathways and ways of working that ensure all people living with HIV aged 50 and over receive co-ordinated care for all health conditions.

Recommendation: All stakeholders involved in supporting people living with HIV aged 50 and over must ensure adequate information, tools and resources are available to ensure individuals can play a greater role in managing their own health and wellbeing.

'I think one thing that I would like to see happen [for] the HIV community is some kind of information campaign - Government-driven information campaign - which has been sorely lacking. The Newly Diagnosed Groups - the guys that come along to those groups are either misinformed or under informed - they don't know it's a controllable infection, pop a pill a day and you'll be fine. There's little acknowledgement of the psychological impact of a diagnosis. So these guys that come to the Newly Diagnosed Group, the one thing they all have in common is fear when they turn up.'

(Male, 56, white British, gay, diagnosed in 2006)

GPs need to step up to the mark in supporting people living with HIV aged 50 and over

The potential role of GPs

As discussed in the last chapter, people growing older with HIV often experience a number of complex long-term conditions in addition to HIV. This results in contact with multiple health professionals in various locations – all giving different medication and advice on how to manage each different health condition.

The role of specialist HIV clinical staff will remain fundamental to the support of people ageing with HIV. Yet HIV clinical services are not the 'one-stop-shops' they once were and some survey respondents were concerned about what will happen once their HIV consultant – that they have often got to know over decades of HIV treatment and support – retires. There is a clear need for someone to play a co-ordination (clinical) support role in ensuring people living with HIV are getting the long-term condition management they need.

GPs are key.

Most people (87%) who responded to the survey had told their GP about their HIV status. But GPs are often lacking knowledge around HIV and ageing – for one in five (19%) people their GP had never given them the information they wanted around this. GPs are better at providing information on ageing – a quarter of people living with HIV aged 50 and over said that their GP always gave them the information they needed around this.

'Every health problem you go to your doctor about, they always say: "Oh it's because you're HIV positive" or: "Oh it's because of your age". But no one can ever tell you what to expect because of these two things.'

(Female, 59, black African, heterosexual, diagnosed in 2010)

It is not being suggested that GPs should become experts in all aspects of HIV (as well as the other health conditions an individual may experience). But it is key that a GP is adequately equipped to be able to have oversight and pull together all of the strings of a person's healthcare. It is also essential that they are able to fulfil the information requests of a patient living with HIV – either themselves or via other health professionals. Only 22% of survey respondents said that their GP does not know about HIV but that they do refer the person living with HIV on to someone who does know (whether that is an HIV clinical specialist or HIV charity).

Consistency is crucial. There were frustrations among some people who could never get an appointment with the same GP so ended up having to re-tell their HIV history over and over again.



'It was just easier when you saw your HIV consultant for everything. You knew them, you had a relationship. With the GP you see a different person each time, so you have to go through your entire medical history, which for me is quite long, by the time you've done that the appointment's over.'

(Male, 62, white European, gay, diagnosed in 1988)

Using expertise in the community

A total of 59% of survey respondents said that they currently speak to HIV support organisations about concerns they have about growing older with HIV. A further 38% speak to someone they consider a peer who is also living with HIV. Consideration needs to be given to how GPs can best use the expertise of HIV organisations and peer-led services – and vice-versa – how HIV charities and community groups can best support GPs to, in turn, support their patients who are growing older with HIV.

Those over 50 living with HIV said that they wanted to see a greater understanding of HIV from their GPs and be equipped with the information they need to play a key role in self-managing their own health needs.

Recommendation: BHIVA, BASHH and RCGP should ensure that HIV (including a focus on HIV and ageing) is a compulsory part of all GP training as well as of ongoing professional development.

Recommendation: RCGP should work with BHIVA, BASHH, HIV charities and people living with HIV to provide training and support to current GPs to increase their understanding of HIV and its interaction with ageing.

Many people living with HIV aged 50 and over face social isolation and loneliness

- A third of people living with HIV aged 50 and over were socially isolated.
- 82% of over 50s living with HIV experienced moderate to high levels of loneliness.
- People aged over 50 living with HIV were at least three times more likely to experience high levels of loneliness than the general population.

Isolation and loneliness, although often used interchangeably, are in fact separate experiences. Age UK considers that: 'Isolation refers to separation from social or familial contact, community involvement or access to services. Loneliness, by contrast, can be understood as an individual's personal, subjective sense of lacking these things to the extent that they are wanted or needed.'³²

Social isolation

Our survey showed that over a third of respondents were socially isolated³³ with 3% experiencing severe isolation³⁴. As ever, it is a mixed picture as a fifth of survey respondents are not in any way socially isolated.

'I am lucky I have my family and friends, I am very open about my status - I think getting involved in the HIV community has really helped me. I am in a much better place because of that I think.'

(Female, 67, white British, heterosexual, diagnosed in 2007)

'So there's that aspect of becoming more and more socially...isolated is the only word you can use. I used to spend a lot more time on my hobbies...I lost interest. Just let the depression come through, you know, it's all part of that. So if I could get onto antidepressants I might find my interest in life revived. I don't expect to be in a long-term relationship ever again. I no longer pursue sexual relationships.'

(Male, 58, white British, gay, diagnosed in 1988)

We found that wellbeing decreased with increased social isolation. Research has also shown the impact of social isolation - a lack of social connections - on health is as damaging to an individual's health as smoking 15 cigarettes per day³⁵.

³² Age UK (no date) Loneliness and Social Isolation: Evidence review [Online]. Available at: http://www.ageuk.org.uk/documents/en-gb/for-professionals/evidence_review_loneliness_and_isolation.pdf?dtrk=true (no date)

³³ Social isolation was measured and given a score using the Social Isolation Index developed by UCL for use in the English Longitudinal Study of Ageing (ELSA), Shankar, A., et al. (2011) 'Loneliness, social isolation, and behavioral and biological health indicators in older adults.' In Health Psychology Volume 30(4), Jul2011, p377-385

³⁴ Severe social isolation is defined as when a person receives the highest scores on the social isolation index scale. This score is based on whether they are cohabitating with a partner/spouse, frequency of contact with family and friends, and participation in organisations or social groups.

³⁵ Holt-Lunstad, J., et al. (2015) 'Loneliness and social isolation as risk factors for mortality: a meta-analysis review' in Perspectives on Psychological Science Volume 10(2), p227-237.



HIV social support services:

These services, often peer-led, provide a 'safe space' and opportunities for people living with HIV to interact and socialise with other people from the HIV community.

HIV specialist support services:

These services include HIV specialist advice (eg, welfare benefits or housing advice), advocacy and HIV specialist counselling.



'There's always this question. There's this kind of secret. A lot of people still don't know that I have this illness and don't know about my situation, why I don't work or that I don't work. I have a lot of shame about not working. So, my neighbours never knew that I have HIV. I always felt I needed to guard myself. So, there's always been this guard. I have had some relationships since then ...I noticed I was very guarded. I would never have gone with them without telling. I found it hard.'

(Female, 63, white European, heterosexual, diagnosed in 1992)

Some participants pointed to the loss of local HIV social support groups as one reason why social isolation is increasing. It was felt that this situation will only get worse as more funding cuts mean fewer and fewer HIV social support services.

'I worry about the future - about being alone. A place to go and socialise is important, but with all the cuts I don't think there will be many groups to go to, there just isn't the money.'

(Male, 59, white British, gay, diagnosed in 1982)

Loneliness

Using the UCLA Three Item Loneliness Scale, half (51%) of people living with HIV aged 50 and over responding to our survey were defined as experiencing high levels of loneliness³⁶. An additional 31% of individuals experienced 'moderate loneliness' and 17% experienced no loneliness.

'I have friends but I can't afford to see them, I can't work, I can't afford hobbies, plus my health makes getting out hard. I feel very alone. I see my family but they don't really like talking about my HIV, so there's a separation.'

(Male, 58, white British, gay, diagnosed in 2000)

'I don't let people know about my condition. I've found I've lost friends because being ill, people just get bored and I just found it very lonely and isolating. I don't talk about my HIV ...I feel terribly isolated. But it's because you can't ...and even if I did tell a friend, which I don't, how do you talk to them about it? Because they don't ...you can't understand how it feels until you have it.'

(Female, 51, white British, heterosexual, diagnosed in 2015)

A recent Campaign to End Loneliness report³⁷ has shown that research suggests between 5-16% of the general population in the UK is lonely. Estimates on loneliness vary widely with the findings from the English Longitudinal Study of Ageing (ELSA) study^{38, 39}, showing that only 2% of the general population in England aged 50 and over experience the highest levels of loneliness and 50% experience no loneliness at all.

Some respondents felt that living with HIV makes meeting new people and forging new friendships more challenging.

'I could only really be friends with other people who are HIV positive. They're the only people I really feel comfortable with, but with all the support groups closing down there are less and less places to meet positive people.'

(Male, 60, mixed race, gay, diagnosed in 1993)

The situation has deteriorated since the 2010 Terrence Higgins Trust 50+ HIV and Ageing survey. In 2010 a total of 61% of over 50s living with HIV were concerned about loneliness in the future; that figure is now 76%.

³⁶ Defined as a score of 7-9 on the scale (Hughes, M E., et al. (2004) 'A short scale for measuring loneliness in large surveys: results from two population based studies' in *Research on Ageing Volume 26(6)*, p655-672.
³⁷ Campaign to End Loneliness (2015) Hidden Citizens: How can we identify the most lonely older adults? [online] Available at www.campaigntoendloneliness.org/wp-content/uploads/CEL-Hidden-People-Exec-Summary-final.pdf
³⁸ Shankar, A., (2012) Social Isolation and Loneliness [Online].

Available at: www.ifs.org.uk/conferences/AShankar_ELSA_Presentation.pdf

³⁹ Banks, J., Nazroo, J., Steptoe, A. (2012) *The dynamics of ageing: evidence from the English Longitudinal Study of Ageing 2002-10 (Wave 5)* [Online]. Available at: www.elsa-project.ac.uk/reportWaves

Addressing social isolation and loneliness

People said they wanted 'opportunities for social engagement'. There was a desire for HIV social support services to be available locally. A common theme emerged in 2010 when 77% of survey respondents said they wanted social support or networking opportunities.

Terrence Higgins Trust's Health Wealth and Happiness project runs social support groups in each of the five centres where it operates

**Health
& Wealth
& Happiness**

Supporting over 50s
living with HIV

after identifying that isolation was a major concern for service users. These range from discussion groups to skills workshops and organised outings to places of interest. Attendees report that they enjoy sharing experiences with others who understand what it means to live with HIV as well as having the opportunity to try new things.

'I really look forward to coming to this group because I get lonely and miserable. Here I see people who speak the same language.'

'I'm happy to meet other people with the same problems. Now I have power to live my life.'

'Being with and talking to others improves my self confidence.'

HIV social support services are not statutory – there is no impetus on the NHS or Local Authorities to provide these services. Yet our research, backed up by the HALL study and others, suggests that social isolation and loneliness are important factors in the ongoing physical and mental health and wellbeing of people living with HIV aged 50 and over.

Social isolation and loneliness are, of course, not confined to people living with HIV. However, those over 50 living with HIV see both social isolation and loneliness as significant concerns – both now and for the future. It is therefore essential that HIV organisations, as well as health and social care professionals, consider how isolation and loneliness can be alleviated in older people living with HIV.

We do not need to reinvent the wheel. HIV organisations are already providing HIV social support services. We can also learn from the practical experience and resources of others working to alleviate social isolation and loneliness. The Campaign to End Loneliness has released a report that: 'Provides adult social care, clinical commissioning groups and public health teams practical guidance on planning how to address the loneliness experienced by older people in their local populations'. The guidance includes a 'Loneliness Framework' that sets out the role that all stakeholders – including community-based organisations, health professionals, families and friends – can play to support someone facing loneliness.

Recommendation: HIV organisations and charities should work with older person's/ageing organisations to understand how to address social isolation and loneliness in older people living with HIV, acknowledging the role that HIV stigma and discrimination plays.





People living with HIV aged 50 and over experience HIV self-stigma

- 58% of over 50s living with HIV have moderate to high levels of HIV self-stigma.
- HIV self-stigma decreases with increasing age.
- HIV self-stigma is less common in gay men living with HIV than in heterosexuals living with HIV.
- HIV self-stigma increased with increasing social isolation and with increasing loneliness.
- HIV self-stigma increased with decreasing financial income.

Self-stigma is defined by the Stigma Index as: 'Negative self-judgement resulting in shame, worthlessness and blame'⁴⁰. In our research we looked at HIV self-stigma – self-stigma related to an individual's HIV diagnosis.

Nearly half of all survey respondents were defined as having moderate levels of HIV self-stigma. In addition, 11% of people living with HIV aged 50 and over had high levels of HIV self-stigma. As always, there is variation as 20% of survey respondents did not have any self-stigma related to their HIV status. HIV self-stigma was linked to age – self-stigma decreased as individuals got older.

'At first, it's like your blood is definitely tainted. And maybe there's something I could've done that would've stop me getting this.'

(Female, 51, white British, heterosexual, diagnosed in 2015)

'I used to feel like a time bomb, so scared that I would infect someone else. But since I have become undetectable that has really lifted. Being undetectable and understanding what that means has made such a difference.'

(Female, 63, white European, heterosexual, diagnosed in 1992)

There was an observed trend of increasing self-stigma with decreasing financial income. HIV self-stigma increased with decreasing financial income. HIV self-stigma also increased with increasing social isolation and loneliness.

Research participants expressed difficulties in telling family about HIV. This was particularly acute in those diagnosed more recently. Many individuals felt that the accepted narrative of HIV among the UK general population was that of 'AIDS' – the tombstone adverts of the 1980s still informing the views of many people, including friends and family of people living with HIV. The lack of any national HIV campaign since then, aimed at the general population, and the perpetuation of HIV myths and stigmatising language in the media, has led to a lack of up-to-date knowledge and understanding.

⁴⁰ Stigma Index (2015) The People Living With HIV Stigma Index [Online]. Available at: www.stigmaindex.org/news/oct-2015/we-are-change-dealing-self-stigma-and-hiv-aids-experience-zimbabwe

'When I told my family they totally freaked, I had to have separate towels, separate cutlery kept in a separate drawer, they were so scared. But it's not their fault, they didn't know, all they know of it was the 80s, the tombstone adverts. There's been nothing since so why would they think anything has changed?'

(Male, 51, white British, gay, diagnosed in 2014)

HIV-related self-stigma was more pronounced than age-related self-stigma. Nearly half (47%) of people living with HIV aged 50 and over did not experience any self-stigma related to age and only 2% had high levels of age-related self-stigma. Age-related stigma decreased with increasing age. Age-related self-stigma was higher in older gay men living with HIV – in comparison to HIV-related self-stigma when gay men reported lower levels than heterosexual men and women.

Both age- and HIV-related self-stigma were higher in individuals who reported experiencing depression and/or anxiety. In total 71% of older people living with HIV who had reported that they experience depression, and 75% anxiety experienced moderate to high levels of HIV self-stigma.

Recommendation: Public Health England, Public Health Wales and Health Protection Scotland – working with HIV charities and people living with HIV – should actively seek opportunities to increase accurate awareness of HIV among the general population. This should include through compulsory SRE in schools, interventions aimed at the media and opportunities to support people living with HIV to become Positive Speakers in local communities.

Recommendation: HIV and older person's/ageing charities should offer services that support the emotional and mental health needs of older people living with HIV, and in particular address the issues underpinning HIV-related self-stigma.



Older women are also affected by HIV

- A quarter of individuals living with HIV aged 50 and over in the UK are women.
- Women were more concerned about all aspects of growing older with HIV than men.
- Women reported lower levels of wellbeing than men.

Women have long been the invisible face of HIV in the UK. Yet over a third of people living with HIV in the UK are women and women account for a quarter of all new diagnoses.

In 2015, a total of 7,169 women aged 50 or older were living with diagnosed HIV – this is a quarter of all those aged over 50 with diagnosed HIV. Altogether 260 women aged over 50 were diagnosed with HIV in 2015 – again a quarter of all those diagnosed aged 50 or older.

Over a third (35%) of individuals who took part in research workshops and one-to-one interviews, and 22% of respondents to the survey, were women⁴¹.

Throughout this research women made it clear that they have specific concerns and experiences related to HIV and ageing. Women reported lower levels of wellbeing than men – 28% of women rated their wellbeing as 'very good' or 'good', compared to 41% of men. When it comes to financial stability women were on average on lower incomes than men.

'I just worry about providing for my children, that I can't earn enough money, that I will get too sick to work. I worry about my health and money a lot.'

(Female, 52, black African, heterosexual, diagnosed in 2016)

There remain many unanswered questions regarding the affect of HIV on women as they grow older – including the impact of menopause. We found that 53% of women wanted information and support regarding the menopause and how it is affected by HIV.

Analysis shows that women were more concerned about all aspects of growing older with HIV than men. Women were most concerned about the long-term effects of HIV and ART as well as how they would manage co-morbidities.

Caring for family came out as a strong concern of women across all aspects of the research. Some women were concerned that a change in their financial situation or a deterioration of their health will lead to uncertainty about who would look after their children. More than double the number of women than men reported that they were very concerned about taking care of family members in the future.

Recommendation: HIV organisations, and organisations providing services for older women, should work with HIV and women-focused organisations – such as Sophia Forum – and women living with HIV themselves, to design services and interventions that best meet the needs of women as they age with HIV.

⁴¹ However, as mentioned earlier, this research did not engage with any women from the trans community – a community at high risk of HIV where much more focus on HIV and ageing is needed.





Conclusion

This is uncharted territory.

A new generation of people living with HIV are living into older age. A very diverse generation.

While many will continue to live without the need for additional health and social care services or financial support, the 300 plus people involved in this research have shown that just as often this isn't the case. There is a major cohort of individuals growing older with HIV who, now and in the future, require significant levels of support.

Many support needs are not unique to people living with HIV – the welfare and social care systems across the UK are failing many. However, we have found that living with HIV adds an extra level of need, additional necessities that go beyond the 'standard' experience of ageing.

With reducing NHS, public health and social care budgets the future is uncertain.

But the opportunity exists to ensure that the needs of people ageing with HIV are central to discussions, policy change and structural change that is currently happening.

People living with HIV aged 50 and over must be at the heart of this action – the voices of older people living with HIV have too often been absent.

Together we can be the generation that pushes for change to ensure that people living with HIV have a positive experience of ageing with HIV.

The HIV and sexual health charity for life

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