



Uncharted Territory

A report into the first generation growing older with HIV

January 2017

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.

**Health
& Wealth
Happiness**

Supporting over 50s living with HIV

- 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.

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.

'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.

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.

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

84%

were concerned about future financial difficulties.

88%

had not made financial plans to fund future care needs.



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.

22%

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

58%

of people living with HIV aged 50+ had moderate to high levels of HIV self-stigma.

1/3

of survey respondents were socially isolated.

82%

experienced moderate to high levels of loneliness.

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.

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.

Read the full report at:
www.tht.org.uk/unchartedterritory