



"We are united in our belief that more work needs to be done in this area, and that the voices of people who are growing older should be central to this."

Chris, 74

"I tell people about it when I trust them: good friends, and sometimes new friends if it feels right and I feel I can trust them with that information."

Moji, 60

"There is still a long way to go with public education. We've got to get the message out there, we've got to talk about it."

Simon, 57

"It is important to keep raising awareness. People need to be realistic about how this has affected us."

Adrienne, 72

FIFTY OVER 50

A COLLECTION OF INDIVIDUAL REFLECTIONS ON GROWING OLDER WITH HIV

Authors: Mike Newman^a, Denis Onyango^b, Dr Tristan Barber^c, Dr Nadi Gupta^d, Matthew Hodson^e, Cheryl Gowar^f, Parminder Sekhon^g, Garry Brough^h, Sophie Strachanⁱ, Jim Fielder^j, Alex Sparrowhawk^k

^a Merck Sharp & Dohme (UK) Limited, ^b Africa Advocacy Foundation, ^c BASHH, ^d BHIVA, ^e NAM, ^f National Aids Trust, ^g NAZ, ^h Positively UK, ⁱ Sophia Forum, ^j Terrence Higgins Trust, ^k UK-CAB

The Fifty Over 50 project is organised and fully funded by MSD UK and coordinated by communications agency M+F Health with communications support from Jo Josh, communications consultant. The contents of this material are the result of collaboration and discussion between MSD UK and the Whole Person Care Partnership*.

INTRODUCTION

Fifty Over 50 is a unique listening project focused on people who are growing older with HIV. Thanks to advances in clinical development and management, HIV is now largely considered to be a chronic condition and the average age of people living with a diagnosis of HIV is increasing. Yet there is no blueprint for growing older with HIV. Many uncertainties remain about how HIV interacts with the ageing process, and no generation before has had to face the myriad challenges of ageing with this backstory behind them.

The vision for Fifty Over 50 was not to conduct scientific research but to seek meaningful, qualitative accounts of experience, to add to the body of evidence and existing insights on HIV and ageing. Published in the form of both an e-book and hard-copy version, Fifty Over 50 provided a platform for people to share their own personal experiences, bringing to light the range of issues that exist for people living and growing older with HIV.

APPROACH

In order to seek meaningful, qualitative accounts of HIV and ageing, it was important to work in partnership to shape the approach. The Whole Person Care (WPC) Partnership, a coalition between MSD UK and several HIV community and professional organisations, worked to form a framework sympathetic to the diverse nature of those impacted by HIV and their stories. Fifty Over 50 set out to speak with 50 people living with HIV aged 50+ willing to collaborate and share their first-hand accounts. Resulting contributors ranged from the age of 50 to 80, were diagnosed at a range of times, from the 1980s, the 1990s, the 2000s, and most recently in the last decade (2010-2020), and as much as possible represented a balance of genders and a balance of genders and racial and ethnic identities.

There were however some limitations in being able to achieve proportionate representation of people living with HIV aged 50+, notably in regional diversity, representation from the transgender community and from people whose first language is not English, therefore this project should be considered to provide an illustrative, rather than a fully representative sample of experience.

INSIGHTS

Some of the key themes that arose from the interviews included:

ACCESS TO HEALTH CARE AND MANAGEMENT OF COMORBIDITIES:

People growing older with HIV face the prospect of managing multiple long-term conditions in addition to their HIV diagnosis and treatment. Many contributors were concerned about how they would take care of themselves and manage daily tasks, whilst others said there was a lack of support to help people with HIV deal with comorbidities in their daily life.

SOCIAL CARE:

Many people reported concern about whether they would be able to access adequate social care in the future. Some contributors noted fear of living in a care home largely due to stigma, prejudice and a lack of understanding from staff members on the management and medicine regimen associated with HIV.

MENTAL HEALTH AND SOCIAL ISOLATION:

People living with HIV aged 50 and over are likely to experience high levels of loneliness, which may exacerbate mental health challenges.¹ Meanwhile, others noted fears about their future financial stability once they give up working.

STIGMA AND SELF-STIGMA:

People with HIV face the additional challenge of stigma and self-stigma which can exacerbate increased social isolation. UNAIDS issued international commitments to end HIV-related discrimination and stigma. However, as contributors frequently reported, high levels of discrimination are still associated with HIV – not only from members of the public but also from within health care services. Additionally, self-stigma, which affects the way an individual feels about themselves as well as how they perceive and manage external stigma and discrimination,² was prevalent particularly amongst the female contributors, even, in some cases, preventing people from receiving care.

IMPACT ON WOMEN:

Women have long been the invisible face of HIV in the UK: – despite the fact that one third of people living with HIV in the UK are women.³ Fifty Over 50 found that women were more likely to hide their HIV status from family members, with many highlighting the need for more female-specific support groups. There remain many unanswered questions regarding the effects of HIV on women as they grow older – with many contributors highlighting the impact on menopause. The burden of menopausal symptoms alongside managing HIV can lead to additional physical and mental challenges, along with difficulties managing their medication regime and clinical appointments.⁴ Compared with HIV-negative women, women living with HIV are at an increased risk of an acute cardiovascular event and reduced bone mineral density.⁵ This is especially important as both HIV and the menopause can raise the risk of bone issues.

RESULTING POLICY RECOMMENDATIONS

- 1 The UK Governments must formally recognise that the success of any plan to sustainably eliminate new HIV transmissions is linked with enabling people with HIV to live well throughout their life.
- 2 It is encouraging that the Government in England has acknowledged the importance of improving quality of life and addressing stigma within the HIV Action Plan for England.⁶ However, to build on the objectives within the Plan and ensure accountability, 'living well with HIV' targets, such as numbers of people with a personalised care plan or proportion of peer support needs that are met, should be developed in coordination with the HIV community and be formally adopted into the fourth objective of the HIV Action Plan. Quality of life issues with measurable targets should also be included in the Action Plans of both Scotland and Wales.
- 3 Commissioning should be person-centred to end fragmentation of service delivery and care, and ensure funding follows the person so that HIV-related healthcare professionals can provide joined-up, holistic care as people with HIV age. Integrated Care Systems must provide adequate funding to local HIV care and support services to guarantee that services can be both commissioned and provided, in line with a person's individual care plan.
- 4 Tools to drive progress and measurements to monitor progress should be immediately implemented – and mandated through national policies. These should include:
 - The widespread use of measurement tools (such as HIV-related PROMS) as part of routine clinical practice to facilitate greater person-centered and individualised care for people with HIV.
 - Continuation of work to monitor improvements through national surveys such as the Positive Voices Survey.
 - Transparency and clear accountability for progress against these targets should be demonstrated through annual progress reports to Parliament on living well with HIV, including for those over the age of 50.
- 5 Leadership and accountability for driving national improvements should be spearheaded by national HIV quality of life clinical and community champions who can work with regional and local system leaders to ensure services for people growing older with HIV receive adequate investment. Dedicated champions will be responsible for supporting the delivery of integrated care, whilst ensuring that services are able to replicate or adapt innovative best-practice models that have a specific focus on HIV and ageing – as shown by the Silver Clinic in Brighton and the SAGE Clinic at the Royal Free London, for example.
- 6 There are currently too few research projects examining the impact HIV has on the ageing process. Therefore, adequate investment is required to enable more research with a specific focus on HIV and ageing to ensure that stakeholders and the clinical community understand the evolving needs of the ageing population. Key areas to explore include the physical, mental and socio-economic impact of living with HIV and maintaining treatment over the long term, and the impact of health inequalities and intersectional challenges older people with HIV may face. To be meaningful, research must properly involve people living with HIV.



CLOSING REMARKS

As a next step, the WPC partners will be working with stakeholders involved in all levels of commissioning and provision, to craft a detailed set of recommendations that can be used by the HIV community as a blueprint to drive change.

We're looking forward to working together to make this vision a reality.

*The Whole Person Care Partnership



1. Aidsmap. Many older people living with HIV in the UK worried about poverty (v1.0) - Experience of loneliness (p.1) [Accessed September 2022]
 2. National Aids Trust. Tackling HIV Stigma (v1.0) - Self-stigma definition (p.27) [Accessed September 2022]
 3. TH1+ Invisible No Longer (v1.0) - Women absence from HIV narrative implications (p.4) Women living with and affected by HIV have so far been mainly invisible in the narrative and response to HIV in the UK, despite making up [Accessed September 2022]
 4. Sophia Forum. A guide to menopause for women living with HIV. (v1.0) - Menopause and HIV impact on mental health (p.4). [Accessed September 2022]

5. Aidsmap. [Online]. Women living with HIV are under-represented in research, limiting our understanding of co-morbid diseases. 2021. Available at: <https://www.aidsmap.com/news/dec-2021/women-living-hiv-are-under-represented-research-limiting-our-understanding-co-morbid> [accessed September 2022]
 6. GOV.UK. [Online]. Towards zero – an action plan towards ending HIV transmission, AIDS and HIV-related deaths in England – 2022 to 2025. Available at: <https://www.gov.uk/government/publications/towards-zero-the-hiv-action-plan-for-england-2022-to-2025/towards-zero-an-action-plan-towards-ending-hiv-transmission-aids-and-hiv-related-deaths-in-england-2022-to-2025> [accessed September 2022]

Scan the QR code to be taken to the Fifty Over 50 e-book, which is hosted on an MSD UK non-promotional website.

