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 care and management, and awareness of HIV, the average age of people living with HIV has increased. 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 backdrop behind them.

The vision for Fifty Over 50 was 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 experiences. Resulting contributors ranged from the age of 50 to 90, 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 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. However, 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 HEALTHCARE 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 described fear of living in a care home, particularly with stigma, prejudice and a lack of understanding from staff members on the management and medicine regime 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. 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 stigmas and discrimination, 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. 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 widespread use of measurement tools (such as HIV-related PROMS) as part of routine clinical practice to facilitate greater person-centred and individualised care for people with HIV.

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. 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. 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.

Commissioning should be person-centred to end fragmentation of service delivery and care, and ensure funding follow 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 commission and provided, in line with a person’s individual care plan.

Tools to drive progress and measurements to monitor progress should be immediately implemented – and mandated through national policies. These should include:

1. The widespread use of measurement tools (such as HIV-related PROMS) as part of routine clinical practice to facilitate greater person- and individualised care for people with HIV.

2. Continuation of work to monitor improvements through national surveys such as the Positive Voices Survey.

3. 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.

Leadership and accountability for driving national improvements should be spearheaded by national/HIV quality of life of the 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 SAOG Clinic at the Royal Free London, for example.

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 as it occurs locally: in the community and in primary care. As a result of this project, a detailed set of recommendations that can be used by the HIV community as a blueprint to drive change was developed.

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.

Authors: Mike Newman, Denis Onyango, Dr Tristan Barber, Dr Nadi Gupta, Matthew Hodson, Cheryl Gowar, Parminder Sekhon, Garry Brough, Sophie Strachan, Jim Fielder, Alex Sparrowhawk

A Merck Sharp & Dohme (UK) Limited, & Africa Advocacy Foundation, eBASHI, eBASHH, eNAF, Foundation AIDS Trust, gNAZ, gPositively UK, Sophia Forum, Terrence Higgins Trust, UK-CAB

*The Whole Person Care Partnership