WHAT IS FIFTY OVER 50 AND WHY NOW?

Thanks to advances in science, HIV is now largely considered to be a chronic condition. As such, today the average age of people living with an HIV diagnosis is increasing. However, there is no blueprint for ageing with HIV in the UK, despite the widespread physical, mental, socio-economic and intersectional challenges those who are over 50 and living with HIV currently face.

41,855

people accessing HIV care in 2019 were aged 50 or over.[1]

Whilst the UK holds the ambition to eliminate HIV transmissions within its grasp, people who are growing older with HIV face significant challenges compared to the general population. People living with HIV are likely to develop additional health problems as they age,[2] becoming more vulnerable to 'multimorbidities' such as higher risk of bone frailty, high cholesterol, hypertension, diabetes and 'heart conditions', as well as chronic widespread pain which can impact quality of life and a high rate of disability.[3] Without further research into ageing with HIV, these associated conditions are projected to significantly increase in the ageing HIV population in the decade ahead.[4]

MSD coordinated *Fifty Over 50* in collaboration with the Whole Person Care (WPC) partners – a coalition of HIV patient and professional organisations – to collect first-hand and diverse experiences of people living with HIV who are aged 50 and over. The vision for the listening exercise was to seek qualitative accounts of individual experiences to add to the body of evidence and existing insights on HIV and ageing. By providing a platform for people to share their own personal experiences, *Fifty Over 50* highlights the changes that are needed to support people to live well across the entirety of their life.

The *Fifty Over 50* listening exercise builds on the last collaboration by the WPC partners, *A Declaration on Whole Person Care: HIV Care and Support*; setting out four pillars around which care pathways, service delivery and funding should be based.[5] This included the need to ensure that people living with HIV are at the centre of their care with access to high quality treatment and a clear care plan, whilst ensuring that HIV does not become an 'invisible' condition.

"Whilst we need to celebrate the UK's achievements in reducing HIV transmission, we also need to acknowledge and embrace the challenges that are taking shape in front of us as the picture changes. Now more than ever we need to ensure we remain committed to listening to the communities of people living with the HIV. That is what Fifty Over 50 is all about."

Whole Person Care Partners

KEY THEMES IDENTIFIED IN FIFTY OVER 50 LISTENING EXERCISE

It would be easy to fall into the trap of talking about older people with HIV as one group, but even a cursory glance at the experiences in the e-Book will highlight the folly in that approach. Not only were our contributors diverse in demographics, gender, and sexuality but also in their outlook on life. However, throughout the experiences several themes emerged, providing a clear picture of the key issues that need more consideration from policy makers and those who can influence the commissioning and delivery of services for people living with and growing older with HIV.

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

- **ACCESS TO HEALTH CARE AND MANAGEMENT OF COMORBIDITIES**
  People growing older with HIV face the prospect of managing multiple long-term conditions in additional to their HIV diagnosis and treatment. The Positive Voices survey (2017), which was completed by 4,422 people living with diagnosed HIV, identified one in three (33%) were living with two or more long-term conditions in addition to HIV – such as diabetes, asthma and arthritis.[6] 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.[7] Many contributors noted struggles to manage their mental health, highlighting the importance of effective support services. Meanwhile, others noted fears about their future financial stability once they give up working – due to the historical expectation of short life expectancy once diagnosed, many people with HIV made no long-term pension plans.

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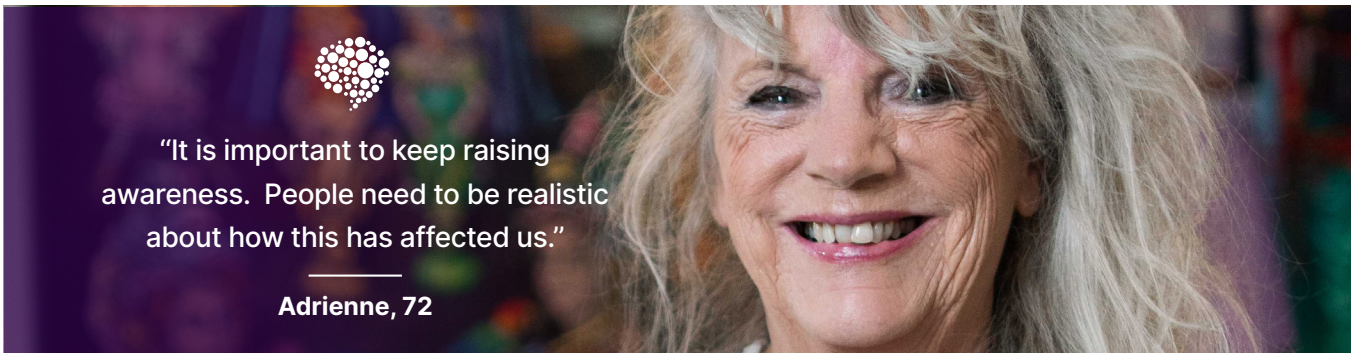
- **STIGMA AND SELF-STIGMA**

  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 the 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,[8] 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.[9] *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 participants highlighting the impact on menopause. The burden of menopausal symptoms alongside managing HIV can lead to additional physical and mental challenges,[10] along with difficulties managing their medication regime and clinical appointments. Compared with HIV-negative women, women living with HIV are at an increased risk on an acute cardiovascular event and reduced bone mineral density. This is especially important as both HIV and the menopause can raise the risk of bone issues.



OUR CALL TO ACTION

The vision of Whole Person Care was developed to drive meaningful and impactful change to support people living with HIV. It is clear from the accounts enshrined in *Fifty Over 50* that significant challenges remain, and for many these basic principles are not being met.

In a policy context which is increasingly focused on the goals of HIV elimination, there is a real danger that HIV will become an 'invisible' condition, with the needs of those who are already living with, and growing older with, a diagnosis of HIV being forgotten, and many unaware of how to seek treatment and support.

It is time that we put people living with HIV at the centre of their care; listening to those who are facing daily challenges, and recognising that national policy must also take account of quality of life and the changing physical, mental, financial and social care needs as people grow older with HIV.

We need to work together to ensure that national policy goes further - to champion a meaningful vision for change - and develop tangible goals to drive progress such as ensuring that all people with HIV have a clear, personalised care plan. Future policy should also identify and address inequalities in access to HIV services so that all people living with HIV have high quality treatment and care services irrespective of their geographical, social or economic background, or their gender, sexuality and ethnicity.

We must make sure that people living with HIV today are not left behind. MSD with the WPC coalition is calling on UK Governments to bridge the current policy gap; making sure ageing well and achieving a good quality of life is fully considered and central to all future HIV related policy.

URGENT CHANGES THAT GOVERNMENTS MUST MAKE TODAY

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 UK Government has acknowledged the importance of improving quality of life and addressing stigma within the HIV Action Plan's fourth objective. 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 in time for World Aids Day 2022.

3. Commissioning should be person-centred to end fragmentation of service delivery and care, and ensure funding follows patients so that HIV-related healthcare professionals can provide joined-up, holistic care as people with HIV age. Local HIV care and support services must be provided with adequate funding to guarantee that services can be both commissioned and provided, in line with a patient's individual care plan.

4. Tools to drive progress and measurements to monitor progress should be immediately implemented – and mandated through National Policy. These should include:
   - The widespread use of measurement tools (such as HIV-related PROMS) as part of routine clinical practice to facilitate greater patient-centric 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 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 – taking examples from the Silver Clinic in Brighton and the SAGE Clinic at the Royal Free London.

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 aging population. Projects should not only explore the physical impact of HIV and treatments, but also engage with people with HIV to consider the long-term mental and socio-economic issues, as well as the impact of the health inequalities and intersectional challenges older people with HIV may face.

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.

Annex

THE WHOLE PERSON CARE VISION FOR CHANGE

Several years ago, the Whole Person Care (WPC) group of Partners came together to develop a Declaration on Whole Person Care: HIV Care and Support. This set out the vision around which care pathways, service delivery and funding should be based. Whole Person Care represents support and treatment that does not simply treat HIV from a medical perspective, but recognises the many other social, economic, employment, and physical and mental health needs that are associated with HIV. Whole Person care can be achieved through adoption of four key principles:

- **Care planning:** Recognising the need for people living with HIV to have a clear care plan which is co-produced/jointly decided with the individual. Discussions on the care plan should include choices around what services are available, with a focus on long term objectives, ensuring the needs of the individual are fully met in a way that works for them.
- **Party of Esteem:** With a recent policy focus geared towards prevention, there is a growing need to ensure that HIV does not become an 'invisible' condition and that those who are diagnosed with HIV are aware of how to seek treatment and support.
- **Addressing care inequality:** There is a need to identify and address inequalities in access to HIV services so that all people living with HIV have access to high quality treatment and care services irrespective of their geographical, social or economic background. This should also include other protected intersecting characteristics, such as gender identity, sexuality, and ethnicity.
- **Patient self-management:** People living with HIV should be at the centre of their care- they are the experts on their own needs and what will work for them. People with HIV must have easy access to the right information and services that allow them to obtain the information they may need. This is important for those who do not speak English as a first language, particularly amongst migrant populations and within Black African communities.

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