Towards an inclusive and integrated approach to care delivery for people growing older with HIV

Introduction

Great advancements have been made to end the HIV epidemic including the launch of the UK's HIV action plan back in 2022[1] which focuses on ending HIV transmission, AIDS and HIV related deaths by 2030.

The efficacy of anti-retroviral treatments has meant that HIV is no longer a life-limiting condition. There is a growing population of people ageing with HIV and an increasing number of older people acquiring HIV. In 2023, 100,063 people were accessing HIV care in England compared to 94,569 in 2022. The average age of people living with HIV in England is getting higher.

Over half (51%) of people receiving specialist HIV care in 2023 were over 50, compared to one in five in 2007[2].

The unmet needs of people living with HIV (PLHIV) are evolving as challenges remain to be addressed, such as the impact of long-term HIV care, health related quality of life, mental health burden and the prevalence of comorbidities on an ageing population. Older PLHIV face a higher risk of conditions such as dementia, diabetes, osteoporosis and certain cancers compared to those without HIV[2]. Specifically, many older PLHIV have experienced the side effects of early anti-retroviral treatment, have been exposed to HIV exceptionalism and carry the psychological burden of historical loss. These people have significant needs which cannot be ignored.

Ageing PLHIV are a diverse population with different needs and may include the following individuals (non-mutually exclusive, non-exhaustive):

- **People who acquired HIV pre-1996:**
  Those who acquired HIV pre-1996, before the availability of highly active anti-retroviral treatments (HAART). These people may be living with comorbidities associated with years of untreated virus and the effects of early treatment[3].
- **Older adults:**
  People over the age of 50 who acquired HIV more recently than 1996, after the advent of HAART[3].
- **Women:**
  Those who identify as women who are over the age of 50 and are living with HIV.

There are different definitions for people growing older with HIV:

- **Ageing People Living with HIV:**
  Refers to those who are experiencing the biological and social processes of ageing, typically starting from around 50 years of age.
- **Older People Living with HIV:**
  Refers to those who have reached a specific chronological age, typically 50 years or older.

From April 2024, commissioning HIV services in England was delegated to Integrated Care Systems (ICS)[4] which is likely to impact how PLHIV access care and has the potential to create variation in the way care is delivered. There is a risk that HIV care becomes further fragmented and deprioritised.

With the government's commitment to a new HIV Action Plan and the HIV Commission's recommendations to shape delivery[5], now is the time to ensure that older PLHIV have access to the care they need to live healthy, happy and fulfilled lives.

KPMG and Terrence Higgins Trust (THT) convened a roundtable, bringing together a group of experts across the HIV care, advocacy, industry and policy landscape to discuss challenges faced by the ageing population living with HIV and what can be done to improve the management and overall quality of life of an older population living with HIV, or with a potential to acquire HIV.

During the discussion, four challenges facing ageing PLHIV were identified. These included:

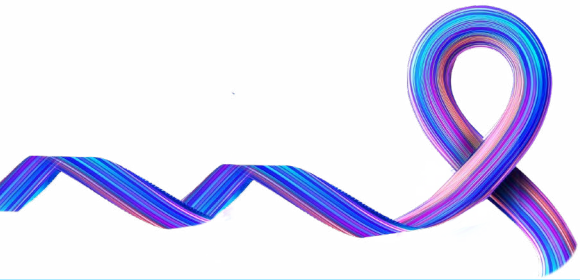
01 Stigma prevents ageing PLHIV from accessing care services contributing to suboptimal health outcomes and disengagement.

02 There is a disconnect between primary and secondary care for ageing PLHIV.

03 Social care does not currently meet the needs of an ageing HIV population.

04 Older Women living with HIV are disproportionately impacted by the complexities of ageing.

The group shared some examples of best practices already being implemented to improve the management and overall quality of life of ageing PLHIV as well as those with a potential to acquire the disease. There was an acknowledgement that progress is being made to address challenges however, opportunities exist to drive further improvements in care.



These have been summarised into three key themes and associated calls to action:

Education and Empowerment

- **Ensure access to HIV training to stakeholders across the healthcare ecosystem:**
  Design tailored training programmes in collaboration with ageing PLHIV, for health and social care professionals who may interact with older adults living with HIV to increase knowledge outside of specialist care.

- **Encourage knowledge sharing:**
  Promote open communication and collaboration between ageing PLHIV and healthcare providers.

Holistic and Person-Centred Care

- **Enhance existing standards to make them age inclusive**:
  To reduce disparities, care standards should be tailored to the diverse needs of ageing PLHIV with a particular focus on women.

- **Ensure joined-up, multi-disciplinary care**:
  An MDT approach is standard of care however this should be mandated to ensure consistency and address the complex and individual needs of ageing PLHIV.

- **Adopt tailored, evidence-based approaches to care for older women living with HIV (OWLH)**:
  Ensure Healthcare Professionals (HCPs) and healthcare providers understand the multifaceted challenges faced by OWLH.

Cascade of care[6] and engagement

- **Maximise opportunities for HIV diagnosis and prevention in older adults:**
  Implement opt-out HIV testing across the UK as part of the NHS over-40 health check.

- **Encourage open communication**:
  HCPs should maintain open and active channels of communication with ageing PLHIV to ensure improved outcomes, reduce stigma and disengagement from HIV care.

This paper details the key challenges facing ageing PLHIV that were identified as part of the roundtable and highlights what more can be done to ensure that no one living with HIV is left behind.

The roundtable participants discussed challenges faced by an ageing HIV population as well as current best practice examples in place to address these.

01 Stigma prevents ageing PLHIV from accessing care services contributing to suboptimal health outcomes and disengagement

Traditionally, HIV specialist services were a one-stop shop. However, over time commissioning and funding models have changed and many older PLHIV will access primary care for support in managing comorbidities. People ageing with HIV may encounter unique challenges that differ from those experienced by younger people, compounded by stigmas.

Older PLHIV are more likely to have had years of untreated virus and have been exposed to early treatments.

Some older PLHIV don't feel comfortable disclosing their HIV status to General Practitioners (GPs) and other healthcare providers. This is largely a result of discrimination experienced in primary care settings following disclosure and prevents PLHIV accessing the treatment they need to manage comorbidities.

Those with years of untreated HIV, or those who experienced early medication, may not have fully restored their immune response.

This group report that they find it hard to get GPs to take this seriously and do not respond appropriately. This can result in a needlessly and prolonged bout of ill health.

Whilst there is peer support available to those diagnosed with HIV, some older adults may struggle to engage because of the assumption that these programmes are created for younger people and the peer support assigned to them is not always age specific. This creates barriers to older, recently diagnosed PLHIV accessing the appropriate support they need following initial diagnosis.

There is also an element of fatigue and frustration for the long-term diagnosed who can find peer support groups repetitive.

Some older adults recently diagnosed in an acute setting (i.e. A&E) are transferred to HIV services but do not re-engage in care. Stigma remains a significant barrier for older PLHIV accessing healthcare which in turn exacerbates poor health outcomes.

For those with a potential to acquire of HIV, older adults can feel uncomfortable disclosing to GPs or other Healthcare Professionals (HCPs) that they are engaging in sexual behaviour which may increase the likelihood of acquiring HIV. This can create barriers to them accessing the appropriate sexual health advice and services.

02 There is a disconnect between primary and secondary care for ageing PLHIV

Care can be fragmented because of the need for ageing PLHIV to access both HIV care and other specialist services to manage comorbidities associated with HIV and ageing.

There is significant variation in the delivery of care for ageing PLHIV. Whilst some services such as the Silver Clinic (Royal Sussex County Hospital, University Hospitals Sussex NHS Foundation Trust) cater specifically to the needs of ageing PLHIV, not all older PLHIV have access to this type of combined HIV-geriatric care. Lack of access to multidisciplinary care can lead to an increased risk of poorer health outcomes and disparities in care.

Some HCPs lack the specific knowledge and skills required to effectively manage HIV in an ageing population. This can leave older PLHIV feeling "stuck between their HIV clinic and GP", unsure of where to turn for appropriate care. Stories were shared of some older PLHIV who have had to educate GPs about their condition, highlighting the need for greater understanding and collaboration between patients and healthcare providers.

There may be disputes between GPs and HIV clinicians, via their patient, on standards of care. For example, BHIVA recommend statins for PLHIV earlier than general population groups. Not all GPs accept this guidance causing anxiety for PLHIV and potential poorer health.

Testing for HIV: Over 40 NHS Health Check in City & Hackney Pilot

As part of a pilot, anyone aged 40 to 74 who undergoes an NHS Health Check were routinely tested for HIV unless they chose to opt out. The initiative sought to identify new cases of HIV as well as those that may have been lost to care.

More information can be found here: **Opt out HIV testing in Primary Care**

There can be a lack of awareness and knowledge amongst some HCPs about potential HIV transmission in older adults. Some HCPs may not routinely test for HIV in older people, assuming they are not sexually active or there is a potential to acquire HIV. This can lead to late diagnoses and missed opportunities for early intervention.

Opt-out testing for HIV in A&E departments has shown the efficacy of testing all ages, having diagnosed an 86 year old.

The Silver Clinic, Brighton:

A combined HIV and geriatric clinic

The Silver Clinic run by Dr Tom Levett, Prof Juliet Wright, Prof Jaime Vera and colleagues at the Royal Sussex County Hospital (University Hospitals Sussex NHS Foundation Trust) combines HIV and geriatric care.
The clinic adopts a holistic approach to improve both physical health as well as mental and emotional wellbeing. Patients can be referred onto the service from any healthcare professional involved in HIV care including GPs, as well as identifying individuals through proactive annual frailty screening. Individuals complete an HIV specific patient reported outcome measure (PROM) tool to identify medical, social or mental health issues.
A multidisciplinary team including a HIV consultant, geriatric consultant, HIV nurse specialist and HIV pharmacist discuss each case before a dual consultation with a HIV and geriatric consultant is conducted.

An individualised management plan is generated to ensure a comprehensive and inclusive approach to HIV care for an ageing population. High levels of acceptability amongst those using the service as well as HCPs has been reported[8]. A randomised controlled trial is ongoing to evaluate the feasibility of screening for frailty and providing a comprehensive geriatric assessment, delivered via outpatient HIV services[9].

More information on the Silver Clinic can be found here: **The Silver clinic (Frailty) – Brighton SHAC.**

03 Social care does not meet the needs of an ageing HIV population

Ageing PLHIV face unique challenges in accessing appropriate social care. Care homes may lack the necessary knowledge and understanding of HIV leading to stigma and discrimination against residents. Residents may be reluctant to disclose their status due to fear of judgement. Additionally, many care workers may have limited knowledge of HIV transmission leading to inappropriate, unnecessary practices such as "double gloving" when caring for PLHIV.

The support needed by ageing PLHIV extends beyond medical care. There is a lack of appropriate social housing to meet the needs of this population. Ageing PLHIV may require adaptations to their living spaces such as grab rails and wet rooms to support them to navigate day-to-day living. Ageing PLHIV may require assistance with job applications and tailored support to address loneliness, social isolation and depression.

Ageing well: Supporting PLHIV over the age of 50 in Manchester and Liverpool

George House Trust provides support for older PLHIV through their ageing well programme which since 2021 has supported approximately 2,700 PLHIV over the age of 50. Services include 1-to-1 support including assistance with housing and personal independence payment applications as well as events and activities including a fortnightly knit and natter group, information sessions on frailty prevention and aqua aerobics.

The following feedback has been gathered from project attendees during evaluation (year 1) of the service:

- Older People Living with HIV were particularly positive about the project's overall approach, describing it using words like dignity, non-judgemental and honest. Project participants and partners frequently commented on the warmth of the project staff and the welcoming atmosphere they nurtured across all the activities.
- Social connections and meeting people was the main highlight for people attending Ageing Well activities.
- Being active and developing skills were also mentioned by project attendees. People valued the support and therapeutic aspects of the project but also saw it as a place to come together to learn new things and develop skills.

More information can be found here:
Ageing Well

HIV awareness and training for residential care homes

George House Trust and Terrence Higgins Trust deliver training to residential care homes, domiciliary care providers, and other organisations to increase knowledge and understanding of HIV and reduce stigma and discrimination that may be experienced by older PLHIV. The Can't Pass It On training for social care provided by Terrence Higgins Trust aims to increase awareness and understanding of HIV, how it is passed on and the Undetectable = Untransmittable message.

Between February 2024 and February 2025 the project has delivered:

- 11 HIV awareness training sessions with 135 attendees.
- Training in 5 local authority areas: Liverpool, Salford, Stockport, Trafford and Wigan.
- Sessions are co-delivered with a positive speaker aged 50+.

More information can be found here:
Can't Pass It On training for social care | Terrence Higgins Trust

04 Older Women living with HIV are disproportionately impacted by the complexities of ageing

Historically, women have been poorly represented in clinical trials for HIV[7], and ART medication may not be titrated for women, compromising optimal health and wellbeing. Older women living with HIV can experience a range of side effects from treatment including weight gain, sleep disturbances and neuropathy.

A growing number of women living with HIV are experiencing menopause and its aftermath. These women may experience earlier onset of the menopause, and some shared their challenges accessing hormone replacement therapy (HRT). There can be a lack of awareness and understanding outside of specialist care about HIV and the menopause particularly in primary care.

Factors such as the impact of HIV on mental health, relationships in older age and the intersection of ageism, gender and HIV-related stigma may impact the psychosocial wellbeing of Older women living with HIV (OWLH). There can be societal stigma surrounding older women's sexuality, making it difficult for them to talk openly about their sexual needs and concerns.

GROWS: Women with HIV Growing Older Wiser and Stronger

The GROWS project provides peer led support, accurate and accessible information and networks and spaces to help ageing women with HIV embrace growing older. The project is developing a support programme for women who are growing older, training women peer mentors and raising awareness through advocacy/policy and scientific report publication.

More information can be found here: **GROWS | Positively UK – HIV Peer Support, Advocacy and Information**

Recommendations

Whilst the headline goal of eliminating new HIV infections by 2030 is crucial, we must not lose sight of those ageing with HIV by continuing to educate society on their needs. Data will be important to understand the cascade of care for older PLHIV including stratifying the 95:95:95 target[10] by age to identify gaps that need to be addressed.

Multidisciplinary stakeholder collaboration both within and outside of HIV is required to raise awareness and advocate for the needs of ageing PLHIV.

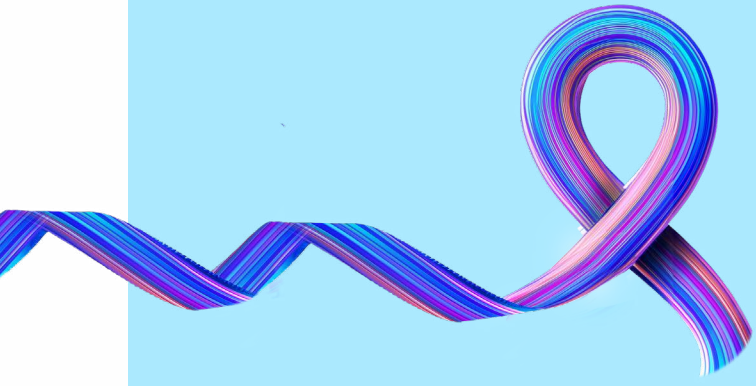
A new HIV National Action Plan, a government committed to its implementation and a growing focus on ageing, presents a critical opportunity to address the needs of ageing PLHIV and ensure they are not left behind.

A call for an inclusive and integrated approach to care for people growing older with HIV.

The roundtable participants acknowledged that progress has been made to address challenges in care for an ageing HIV population however, there are opportunities to drive further improvements which can be summarised into three key themes and associated calls to action:

Education and Empowerment

- **Ensure access to HIV training to stakeholders across the healthcare ecosystem**
  Design tailored training programmes in collaboration with ageing PLHIV, for health and social care professionals who may interact with older adults living with HIV. This education should extend to HCPs who are in training e.g., trainee doctors and nurses as well as nursing and domiciliary care providers. This education should be designed to increase knowledge and understanding of HIV outside of specialist care, educate on the diverse needs of an ageing HIV population and reduce stigma. Existing training programmes provided by Terrence Higgins Trust and George House Trust can be leveraged to deliver on this action.
- **Encourage knowledge sharing**
  Promote open communication and collaboration between ageing PLHIV and healthcare providers. Ensure knowledge transfer from HCPs in HIV specialist care to those working in primary care. The expertise and lived experience of ageing PLHIV should be valued, ensuring they feel comfortable to disclose their status and can be actively involved in their own care.



Holistic and Person-Centred Care

- **Enhance existing standards to make them age inclusive**
  To reduce disparities, care standards should be tailored to the diverse needs of older PLHIV, in particular women. Age specific guidelines should reflect the different service users. Enhancement of standards must involve the HIV community (e.g., BASHH, BHIVA, NHIVNA, THT, GHT), the government (e.g., Integrated Care Systems) (ICSs)) as well as non-HIV related bodies (e.g., the Kings Fund) to ensure the needs of an ageing population more broadly is considered.
- **Ensure joined-up, multi-disciplinary care**
  MDTs should be mandated and offer enhanced access to physiotherapists, occupational therapists and social workers who are often needed but rarely part of current MDT-based approaches.
- **Adopt tailored, evidence-based approaches to care for OWLH**
  Ensure HCPs and healthcare providers understand the multifaceted challenges faced by OWLH to address disparities and ensure equitable access to care. The impact of intersectional identities (HIV, gender, age) on health outcomes in OWLH should not be underestimated. Evidence-based interventions should be developed and informed by the experiences of OWLH.

Cascade of care and engagement

- **Maximise opportunities for HIV diagnosis and prevention**
  Implement opt-out HIV testing across the UK as part of the NHS over-40 health check. This could help avoid missed diagnoses and lead to earlier identification and intervention in older adults. This is vital to ensure the 2030 target of zero transmissions is reached.
- **Encourage open communication**
  HCPs should maintain open and active channels of communication with ageing PLHIV to reduce stigma and disengagement from HIV care. Sexual intercourse should be more openly discussed as part of routine health assessments for older adults, particularly those with a potential to acquire HIV.

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KPMG UK

KPMG in the UK is a leading provider of professional services such as audit, tax and advisory, leveraging extensive industry knowledge and a multi-disciplinary approach to help clients address challenges and seize opportunities. With over 150 years of experience, KPMG builds trusted relationships through a deep understanding of clients' businesses and sectors, offering unique insights, innovative thinking, and advanced technology. Our Advisory team is recognised for expertise in technology, data, and global capabilities, supporting clients from strategy and transactions to transformation and compliance. We lead community projects with purpose to strengthen our society, and work collaboratively with schools, charities, community groups and other businesses to ensure they create a lasting impact, for better.

Terrence Higgins Trust

Terrence Higgins Trust is the UK's leading HIV and sexual health charity. Their mission is to ensure 'there will be no new HIV cases in the UK' and 'everyone living with HIV will be diagnosed, in treatment and care, free from stigma, and able to take advantage of life's opportunities'. The services they provide range from HIV testing to hardship support, return to work workshops, counselling and peer support.

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