

# HIV and Ageing

# Terrence Higgins Trust

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# Latest HIV data

# HIV testing in older adults

- Sexual Health Services (SHSs) tested 57,085 people aged 50 and over in 2021, representing **5.4%** of all people tested
- In 2021, 50,842 people aged 50-64 tested for HIV, **26% less than in 2019** (68,852)
- The difference was greater in people aged 65 and over, with 6,243 people tested, **41% fewer than the 10,605 people tested in 2019**
- In both age groups the decline in HIV testing between 2019 and 2021 was more apparent in women, with **32%** fewer tests in women aged 50-64, and **51%** fewer tests in women aged 65 and over

# New and late diagnoses in older adults

In England, **23%** (4

- **26%** (145) of wo
- **21%** (312) of me

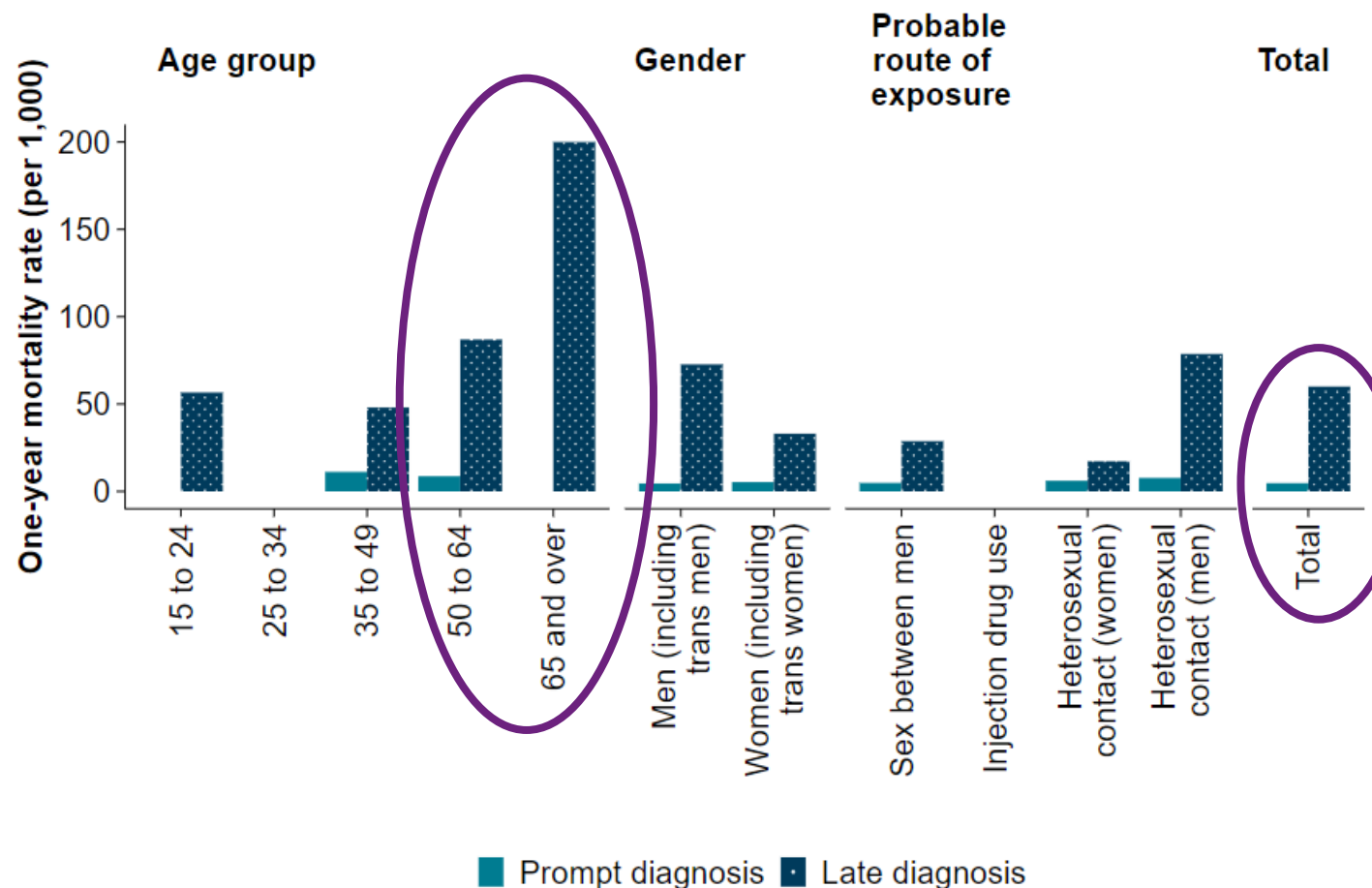
Compared to an o

- **59%** of people
- Almost three q

Late HIV diagnosis  
higher mortality rate

- The one year m  
**1,000 people**, a

Figure 8. One-year mortality (per 1,000) among adults newly diagnosed with HIV, by diagnosis stage, age, gender and probable route of exposure: England, 2021



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# An ageing HIV population in the UK

Within a decade the percentage of people living with HIV in the UK aged 50 and over has grown from 25% in 2012, to 48% in 2021

Nation	UK	England	Scotland (2019 data)	Wales	Northern Ireland
Total living with HIV	94,133	90,587	4,920	2,158	1,325
50-64	37,150 (39%)	35,835 (40%)	1,834 (37%)	819 (38%)	466 (35%)
65 and over	7,581 (8%)	7,274 (8%)	331 (7%)	199 (9%)	101 (8%)
Total 50 and over	44,731 (48%)	43,109 (48%)	2,165 (44%)	1,018 (47%)	567 (43%)

# HIV populations in England

Population	Gay and bisexual men	Women	People of Black African ethnicity who acquired HIV through heterosexual contact	People of White ethnicity who acquired HIV through heterosexual contact	Trans and gender diverse people*	People who inject drugs
Total living with HIV	41,139	28,583	24,273	10,128	167	1,346
50-64	15,792 (38%)	10,690 (37%)	11,152 (46%)	3,989 (39%)	Data not available	572 (42%)
65 and over	3,513 (9%)	1,580 (6%)	1,203 (5%)	1,591 (16%)	Data not available	62 (5%)
Total 50 and over	19,305 (47%)	12,270 (43%)	12,355 (51%)	5,580 (55%)	53 (32%)	634 (47%)

# Ageing at Terrence Higgins Trust



# Post-pandemic review of Ageing services

- Pandemic provided an unexpected opportunity to accelerate the increase in access to our services wherever people live in the UK
- Successful transition of our **Before 96** long-term diagnosed support group from an in-person/London only service, to a national offer. Increased membership, and more women now access this support group
- Our peer-led ageing research (Uncharted Territory, 2017) and UKHSA (then PHE) Positive Voices 2017 survey (2020) were published prior to the pandemic
- Summer 2021, utilising co-production principles and involving people with HIV aged 50 and over, THT began a review of the unmet needs of older adults accessing our services



# Methodology

- Data was collected via an online survey which produced a return of 168 usable responses
- Seven group discussions were held via Zoom, with 53 attendees in total, including sessions for specific demographic groups: women (including trans women), racially minoritised communities and those living long term with HIV.
- 16 one-to-one telephone interviews
- Special discussion events with Africa Advocacy Foundation and Macfarlane beneficiaries
- Data and findings were tested with a variety of internal and external stakeholders
- A User Involvement drop-in session was organised to discuss findings internally
- A Stakeholder evening was organised to discuss the findings with those who had contributed

# Key Findings

Overwhelmingly across all demographics the top three priorities were Emotional and Mental Wellbeing, Physical Health and Social Connectedness

Emotional and Mental Wellbeing	Physical Health	Social Connectedness
High levels of anxiety and depression and other negative impacts on emotional wellbeing	Need for accessible, reliable, up to date information about the physical impact of growing older with HIV, comorbidities and poly pharmacy	Support needed to (re)connect with friends and family
Support needed to start new or grow romantic relationships and have healthy sex lives	Support needed to increase physical activity in a safe, sustainable and healthy way	Desire to provide peer support for others living with HIV
Significant levels of self-stigma and experiences of discrimination	Frustration at the lack of coordinated or joined up care	To meet others living with HIV in a fun, engaging and empowering way to combat loneliness and isolation



# Emotional and Mental Wellbeing

- **46%** of respondents replied that HIV had a slight, moderate or significant negative impact on their emotional and mental wellbeing
- **51%** of respondents saying that HIV had a negative impact on romantic and sexual relationships
- **39%** of respondents saying that HIV had a negative impact on relationships with family, **32 %** with friends and **19%** with work colleagues
- **over two thirds** reporting experiencing depression and **67%** experiencing anxiety
- **35%** reported experiencing self-stigma, **27%** experiencing discrimination from others
- **Three-quarters** of respondents had previously accessed counselling support, whilst **70%** expressed an interest in accessing counselling in the future
- **51%** would like more support to address self-stigma

# Physical Health

- **26%** responded with negative feelings towards their current physical health
  - This was higher in people with long-term diagnosed HIV
- **67%** would like to be more active but aren't sure how to go about it
- **Over two-thirds** reported living with at least one other long term health condition
- Only **28%** felt they were well informed about living well physically as they grow older with HIV

# Social Connectedness

- **54%** of respondents reporting loneliness, **51%** reporting isolation, and **52%** of respondents reporting living alone
- **59%** of respondents saying they would like more connection from social groups and clubs
- The highest demand for social connection was with those long-term diagnosed
- **50%** are currently accessing online events, groups or other activities, HIV-related and not. **80%** planned to continue accessing online events
- **69%** wanted to see a return of in-person events

# Recommendations

Everyone is growing older with HIV, to respond to the increase in older adults living with HIV, Terrence Higgins Trust need to:

- Ensure our living well services are accessible and marketed to those growing older
- Provide specific services for 50+
- Provide specific services for those living long-term with HIV

## What happened next?

- In-person activities resumed May 2022
- Sought funding to develop future ageing pilot programmes
- Recruitment of HIV and Ageing Manager

# Existing Ageing Services

- Commitment to national offer of the Before 96 support group, whilst reviewing how to further diversify attendance, supported by promotional activity
- Review of our 50+ social activities in London after a year of in-person events and activities
- Ensuring existing Living Well (HIV support) services are inclusive and welcoming for people with HIV aged 50 and over
- Exploring how we develop future partnerships
- Co-production approach, involving existing and potential people accessing our services



# Development of Pilot Programmes

Secured funding to develop two pilot programmes looking to:

- Improve physical health for people growing older with HIV
- Improve healthy romantic and sexual and relationships for people growing older with HIV

This funding also providing resource to develop a self-directed, e-learning training package for the social care workforce. This work is building on previous '*Can't Pass It On for healthcare professionals*' training.

March – May 2023, facilitated nine workshops with 13 people living with HIV aged 50 and over. Mix of long-term diagnosed and those who have been living with HIV more recently. Majority of people recruited through existing services.

Recruitment of peer co-facilitator volunteers June 2023.

Delivery of initial programmes from July 2023.

# Learning from co-production workshops

- Anxiety about the future – in particular with regards to potential need for support, loss of independence and HIV stigma within health and social care system
- Lack of confidence in primary care and other non-HIV specialist clinicians to be able to manage HIV with other comorbidities
- Language which HIV sector and clinicians take for granted only understood by a minority of adults growing older with HIV, e.g. 'comorbidities', 'polypharmacy' etc. (we have adapted to use terms including 'multiple conditions', 'multiple medications' etc. when engaging the groups)
- Acceptance of virtual and online services is dependent on the type of activity
  - Discussions, peer-led group support still popular
  - Fatigue around any 'instructional' video content
- Additional, often more complex unmet needs identified for women ageing with HIV

# Experiences from Black and migrant communities

Early this year we supported Africa Advocacy Foundation to produce a series of workshops focused on specific needs of people growing older with HIV from Black and migrant communities.

## Health

- Accessing general information about growing older with HIV
- Understanding what health checks and routine tests are needed as you age with HIV

## End of life decisions

- Funeral plans and repatriation to their country of birth/country their children live in

## Finances

- Understanding financial products such as life insurance

## Social care

- Uncertainty on pathways/decision making for future care needs
- Specific anxieties, such as access to Black and African hair stylists

# Accessing our HIV Support Services



[www.tht.org.uk/livingwell](http://www.tht.org.uk/livingwell)  
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