

“You are kind of left out there in a field on your own, and you have to figure it out yourself.”

Responding to the needs of women ageing with HIV

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Why is this work needed?

- In 2019, approximately 10,000 women living with HIV aged 50 years and over attended HIV care in the UK.

Who was involved?

- The GROWS project is a multi-sector collaboration between three HIV charities (Sophia Forum, Positively UK, and NAM) and University College London’s Institute for Global Health.

What was the point?

- GROWS aims to:
 - develop a tailored, sustainable, holistic programme of support for women ageing with HIV
 - provide policy and practice recommendations



What did we do?

- We analysed qualitative data from two existing studies:
 - The PRIME (Positive Transitions Through the Menopause) Study (n=20)
 - “I was not meant to be here, and I’m still here” (n=14 interviews/3 workshops)
- This analysis was supplemented with interviews with:
 - 5 key stakeholders
 - 3 focus group discussions with women aged ≥40 living with HIV in London (n=24)
 - WhatsApp group consultation
- Data were analysed thematically, and a codebook developed through consensus by the team.

Results

We identified five key themes arising from women’s experiences of ageing with HIV presented in Table 1.

Table 1: Key themes

| Themes based on workshops | Quotes |
|---|--|
| Intersecting experiences of ageing | “The good side is like, I think that we have blood tests regularly [...] the blood tests can pick up things that perhaps are not known about, [...] for other people they'll, maybe miss it but for us, it will be more likely to get caught [...].” |
| HIV and stigma | “I mean, I came out of a long-term relationship last year, and HIV played a significant role in the end of that relationship.” |
| Uncertainties around physical and social impacts of ageing with HIV | “...and the worry of future financial security. Who will look after me - will I afford a reasonable care home? Will the care home cater well for all my needs and fussiness?” |
| Gender-specific information for healthcare providers and women | “...where's the research? It's improving, but the research on the impact of the antiretrovirals on women's bodies?” |
| Importance of professional and personal support | “[...] my doctors said: We don't have women as old as you that we've done research on. So you are kind of left out there in a field on your own, and you have to figure it out yourself.” |



Conclusion

- The GROWS project has prioritised research to inform policy design and advocacy, involving women living with HIV throughout the entire process.
- We have created a body of informational resources, including seven videos hosted by NAM, to raise awareness of ageing in women living with HIV among key stakeholders.
- Based on findings from our qualitative analysis, we wrote a policy report and informed the development of a peer-mentor training programme (Phase 2) for women ageing with HIV, due to be rolled out in London in 2022.
- For the first time anywhere in the world, this innovative peer support programme specifically for women ageing with HIV, will be an important and sustainable resource, empowering women to maintain their health and wellbeing as they age.



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