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HIV and the menopause (patient perspective)

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HIV and the menopause - patient perspective

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CEO Sophia Forum

Conflict of Interest

In relation to this presentation I declare that I have no conflict of interest

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We Are Still Here

We Are Still Here is a campaign by older women living with HIV. Our aim is to highlight our experiences and priorities. We are calling for:

- Opportunities to pass on our experiences
- Peer networks for older women
- Holistic services and standards of care

OLDER WOMEN WITH HIV: OUR JOURNEY



RESILIENCE



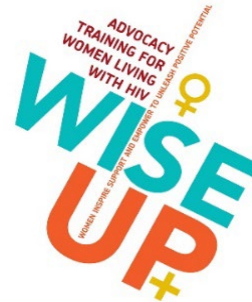
SUPPORT



SELF-CARE

We Are Still Here

- Method
- Sophia Forum used our long-standing WISE-UP methodology developed by and for women living with HIV, creating communities of women living with HIV, building advocacy skills and peer support to run a weekend workshop on Ageing with HIV.
- During one workshop we ran an interactive update session ran by researchers and a clinician specializing in HIV and the menopause that enabled women to ask questions relating to this subject and what they would like to see in a resource



We Are Still Here Advocacy Asks

We have eight key asks:

1. Visibility, inclusion and representation of older women living with HIV in research, funding, decision-making and campaigns.
2. Accurate, accessible and comprehensive menopause information and support in HIV clinics.
3. Meaningful involvement of older women living with HIV in research, including clinical, social and treatment research.
4. Research that explores issues that are relevant to our lives and addresses barriers to our participation.
5. Research results that are disaggregated by sex and gender and report under-representation of women where this is the case.
6. Full information about HIV treatment side effects and drug interactions and support to manage them.
7. Improved collaboration, coordination and communication between GPs, consultants, other healthcare professionals and HIV clinics.
8. Treatment advocacy and peer support training tailored to women, including menopause mentors.



WISE UP+ Ageing with HIV was a weekend retreat for women aged 45 and over, living with HIV. The WISE UP+ programme creates spaces for women living with HIV to build advocacy skills, form networks and co-develop advocacy and information resources



2. Accurate, accessible and comprehensive menopause information and support in HIV clinics

A GUIDE TO
MENOPAUSE
FOR WOMEN
LIVING WITH HIV



WE
ARE *still*

OMEN WITH HIV

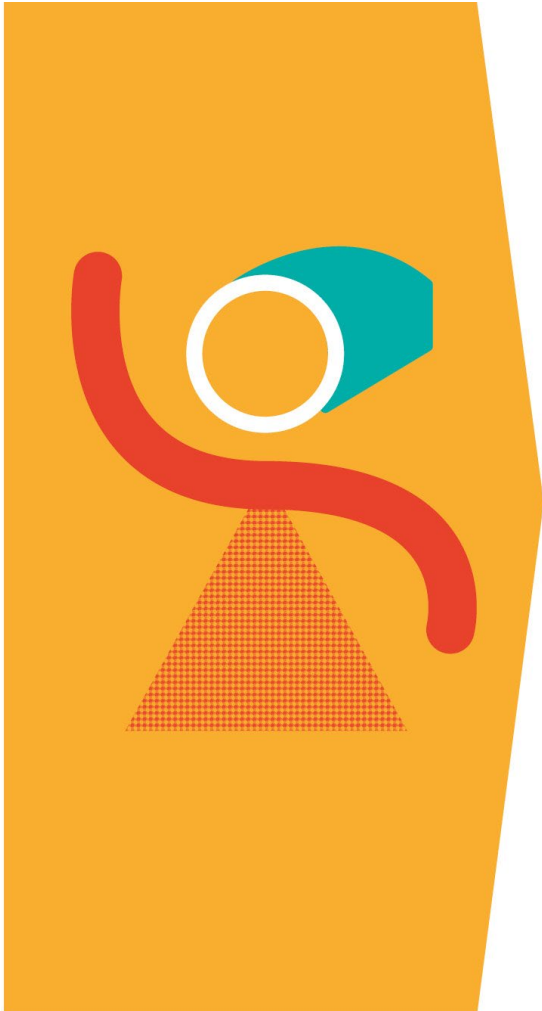
www.nhivna.org



We Are Still Here

Results

- The workshop was attended by 23 women
- Topics highlighted as important included health risks related to menopause, treatment menopause treatment and sex and relationships
- Women requested that any resource developed should be in a simple, engaging question and answer format
- We collaborated with Newson Health Menopause and Wellbeing Centre in co-creating this guide, which was made available in 2020 both online and in printed versions
- Women reported after reading it they felt included, able to have informed conversations and comfortable asking about support with symptoms relating to the menopause
- Demand for the guide has been high, it is available throughout the UK, globally and has been translated into Shona, Swahili, Xhosa and Russian. More translations coming



8. Treatment advocacy and peer support training tailored to women, including menopause mentors

GROWs



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.

GROWS

Themes based on workshops	Quotes
Intersecting experiences of ageing	<i>"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 [...]."</i>
HIV and stigma	<i>"I mean, I came out of a long-term relationship last year, and HIV played a significant role in the end of that relationship."</i>
Uncertainties around physical and social impacts of ageing with HIV	<i>"...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?"</i>
Gender-specific information for healthcare providers and women	<i>"...where's the research? It's improving, but the research on the impact of the antiretrovirals on women's bodies?"</i>
Importance of professional and personal support	<i>"[...] my doctors said: We don't have women as old as you that we've done research on. <u>So</u> you are kind of left out there in a field on your own, and you <u>have to</u> figure it out yourself."</i>





- **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.

**ROCK
THE RIBBON**
WORLD AIDS DAY
WEDNESDAY 1 DECEMBER 2021

BEARDED & FLUSHED

1 DEC 2021
7.00 PM
FREE

Sisters living with HIV
share menopausal
stories!

NAZ
SOPHIA
POSITIVELY UK
4MS Network
My health, My choice, My child, My life

www.nhivna.org

ARE YOU LIVING WITH HIV & THE MENOPAUSE?

BEARDED AND FLUSHED

CREATIVE WRITING WORKSHOPS

Aim

- To develop a performance based body of work that enables women living with HIV to give creative expression to the intersection of HIV and the Menopause and improve access to information and physical and psychological wellbeing.

Objectives

- To bear witness and profile the lived experience reality of women living with HIV approaching and living through the menopause journey.
- To amplify voices of women living with HIV experiencing the menopause articulating what would help and reducing isolation.
- To further advocate the support and information needs of women living with HIV and for those approaching the menopause over the life course.

Voices of workshop participants

- *“This creative process was emotionally emancipating and unlocking my potential... emotional roller-coaster and a personal transformation”*

focus group participant

- *“The creative writing workshops have been life changing in unlocking my creative potential and boosting my confidence. It has enabled me to speak my truth and be unapologetically authentic!”*

participant from Cohort 1

Thank you

- To all the women who have given their time and lived experience without which, our work cannot happen.
- Our collaborators for HIV menopause resource
- Dr Jacqui Stevenson, Dr Louise Newson, Dr Nneka Nwokolo
- GROWS Project collaboration with - Positively UK, NAM, UCL Global Health
- Project Leads - Juddy Otti and Rebecca Mbewe
- Bearded and Flushed collaboration NAZ, 4M, Sophia Forum and Positively UK