



GROWS

Key findings from research with women ageing with HIV



GROWS is a collaborative project by:



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Foreword

Jane Anderson
Co-chair, London Fast
Track Cities Initiative

As I know only too well from my own clinical and research experience the complex requirements of women who are living with HIV and getting older are often poorly understood and frequently overlooked.

With ever better HIV treatments and increased life expectancy there are more and more women in this situation, making this important and timely report from the Growing Older Wiser Stronger (GROWS) project particularly welcome.

The project has been carried out through collaborative working by experts from separate organisations and different disciplines and exemplifies effective partnership working. The combination of voluntary sector skills in peer support, peer led research and advocacy, specialist clinical knowledge, and academic know-how, coupled with the expertise of lived experience make this work particularly powerful.

This report, the first of several GROWS project outputs, synthesises existing knowledge through a secondary analysis of existing high-quality academic research and tailored primary qualitative research with women living with HIV in London.

The themes that emerge highlight the uncertainty faced by older women living with HIV about their health and wellbeing which stems from a lack of information and poor communication. HIV associated stigma continues to blight lives and is a barrier to service access and best care. The power of effective professional and peer support to make a real and positive difference comes through loud and clear as a key factor in enabling women to live well. The next stages of the GROWS project takes these themes forward, developing and evaluating improvement approaches.

These research findings provide a robust foundation for authoritative recommendations directed towards those with the power to make a real difference. With today's emphasis on integrated, person-centred, place-based care and as new Integrated Care Systems begin to take shape GROWS is an excellent example of how voluntary and statutory services can come together to ensure holistic person-centred care, and provides a worked example of collaborative, evidence-based partnership working.

GROWS is one of a collective of 13 projects that bring together 22 organisations, both statutory and voluntary, as an innovative improvement collaborative across London, carrying out novel partnership working between the NHS and the voluntary sector. All have been funded for a three-year term through London's HIV Fast Track Cities Initiative and have been supported to develop and use quality improvement approaches. GROWS is an excellent example of an effective, robust collaborative method for tackling complex problems. The GROWS project approach is an exemplar that can and should be widely applied across many conditions and many population groups.

It has been a privilege to work with the GROWS project team within the Fast Track Cities Initiative and to witness the expertise, hard work and dedication that has gone into this undertaking. I hope that the results of GROWS work will enable progress to be made, leading to the needs of older women with HIV being both recognised and addressed.





Foreword

Julie Reynolds
GROWS Peer Mentor

Advances in Antiretroviral Therapy have improved the life expectancies of Women living with HIV and there are more than 10,000 of us over the age of 50 according to the latest Public Health England data. This longevity is welcome but women's experiences of growing older living with HIV can still be challenging.

We are the first generation of women to grow older with HIV. For or those of us who have been living for decades with HIV, we may already experience affects from taking medications long term, with increased risk of osteoporosis/ osteopenia, weight gain, and cardiovascular disease.

In addition to HIV, we may have other health issues and the menopause brings additional challenges that can impact us. We also know that women living with HIV experience poorer mental health, with Black African and Caribbean women experiencing greater health disparities.

Our personal lives may also bring conflicting challenges to manage. Poverty, stigma, immigration problems, gender based violence, caring responsibilities not just for children, but also grandchildren and aging parents intersect and all have an impact on our physical and mental wellbeing and quality of life. We may desire intimate relationships, but changes in our bodies and energy can affect our feelings about the relationships we are in. Those of us not in

sexual relationships may still want sex and to experience intimacy but can feel undesirable or invisible once we are beyond child bearing age. Women of our generation were often raised with our value being measured by what we can be to others. We were taught to put others needs first at the cost of our own. Most of us were brought up in a culture where views were deeply sexist and went unchallenged. Language and metaphors used promiscuity and deviance as the reason why women experienced sexual violence and also the ultimate cause of our HIV. The echoes of this still resonate and can leave women carrying trauma, the burden of blame and the shame of stigma.

Historically charitable, grassroots and women's sectors have all played a key role improving the lives of those most marginalised and with the least power. These are services that are striving for equity in health and human rights. They work to reduce poverty and discrimination, provide peer support, advocate and mobilise for change and equality. More than a decade of government disinvestment has left many of these services, including HIV support for women, struggling or gone.

More so than not, the dominant narrative on HIV excludes women, despite this we have always known how to harness our collective power to push to get our voices heard and to become visible. However, women living with HIV can often be left isolated by services that are not designed with our needs in mind and that we struggle to relate to. We are not just one homogenous group, our lives and identities are multidimensional.

We need space where we can celebrate our resilience and develop our self-efficacy and agency. By acknowledging and embracing our differences with curiosity and compassion we can challenge dominant narratives and reveal the intersectional nature of our lives.

GROWS offers women growing older with HIV an exciting opportunity to, share experiences, get accurate accessible information and gain the skills and knowledge to become peer mentors. A role that offers a safe space where women's stories of growing older can be shared and heard, so that challenges can be successfully faced and supported.

We know how liberating, inspiring and empowering peer-led support can be. We grow in confidence as we share, have our experiences of living with HIV acknowledged and validated and our networks grow stronger and wider.

By sharing and collecting our stories we can paint a fuller picture of our diverse lives and experiences and this exposes gaps in existing support and data. Research that is rooted in the reality and diversity of our lives will help to identify those gaps that need closing and to help address our needs and improve our lives. The more participatory, the more powerful our stories become as our collective knowledge and experiences can be the channel for positive change. We have so much to offer to each other and that can speak to a broader agenda than HIV. With time and support we and all women can embrace and revel in growing older and wiser.

Key Messages

1

In 2020, over 11,000 women aged 50 and over attended for HIV care in the UK, a ten-fold increase over 10 years.

6

Women living with HIV expressed both negative and positive aspects of growing older with HIV.

2

Addressing the needs of the growing population of women ageing with HIV is of increasing importance in HIV practice and policy.

7

There is a rich wealth of knowledge and experience among women growing older with HIV which can be shared with women newly-diagnosed with HIV and those already living with HIV who are younger.

3

The GROWS Project is the first global initiative focused on developing information resources and a peer mentor training programme for women growing older with HIV.

8

Stigma continues to have a huge impact on women's lives in relation to telling others about HIV, accessing treatment, adherence and navigating relationships.

4

Primary research was carried out with women aged >40 living with HIV, supplemented with secondary analysis of prior studies. Both have been used to inform policy and advocacy in the GROWS project.

9

Peer support is potentially a key source of support for women growing older with HIV.

5

Discussions with women ageing with HIV highlighted five main areas of concern: multidimensional challenges of ageing with HIV: psychological, physical and social; HIV and stigma; uncertainties around physical and social impacts of ageing with HIV; gender-specific information for healthcare providers and women; and, importance of professional and personal support.

10

Our recommendations include: prioritising research focused on women ageing with HIV; developing holistic support and care models; including HIV awareness in training for all professionals within health and social care; building links between the HIV sector and other ageing and healthcare organisations; and ensuring long term, sustainable funding for grassroots organisations delivering HIV support and education.

Summary

Advances in HIV treatment have meant that the number of people living longer and growing older with HIV has increased. In the United Kingdom (UK), the number of those living with HIV aged 40 and over have trebled over the last decade.

Women, who make up a third of this population, are increasingly reaching middle age and beyond. Data from the UK Health Security Agency (UKHSA, formerly Public Health England)¹ reveal that over 11,000 women aged 50 and over¹ attended for HIV care in the UK in 2020. Therefore, it is important that the needs of women living with HIV in their middle and later lives are addressed.

The GROWS project is a collaborative response between the Sophia Forum, Positively UK, National AIDS map (NAM) and University College London's Institute for Global Health. Grounded in real-world experiences of ageing with HIV, and/or supporting women living with HIV as they age, we seek to map current areas of need among this group, and develop feasible, effective, sustainable, and holistic solutions that will improve the quality of life of women living with HIV aged over 40 in London.

The GROWS Project will achieve this through:

1. Raising awareness of issues relating to ageing in women over 40 living with HIV among their healthcare teams and other stakeholders who may be involved in decisions about their health, care and wellbeing, to help inform further research needs, service development and policy reform.
2. Developing information resources for women living with HIV on issues affecting women growing older with HIV.
3. Developing a peer-mentor training programme for women ageing with HIV (the first of its kind globally).

4. Training and supporting the professional development of women ageing with HIV.

We have analysed qualitative data from two existing studies focusing on women ageing with HIV in England: *The PRIME (Positive Transitions Through the Menopause)* Study led by Dr Shema Tariq at University College London, which explored menopause among women living with HIV, and *"I was not meant to be here, and I'm still here"*; a feminist, participatory and assets-based exploration of women's experiences of ageing with HIV in London (I'm Still Here study), led by Dr Jacqui Stevenson at the University of Greenwich, which explored both positive and negative experiences of women aged over 50 living with HIV. Dr Stevenson's research identified the tools, strengths, and strategies that women have and use to be able to live well.

We also conducted our own primary data collection, holding three focus group discussions with women aged over 40 living with HIV and based in London, and a WhatsApp group consultation. We supplemented this with interviews with five key stakeholders: an HIV healthcare provider, a commissioner, two voluntary sector professionals and a representative from Public Health England.

Through analysis of our primary data and secondary analysis of PRIME and I'm Still Here data, we generated five key themes relating to ageing with HIV as a woman:

1. Intersecting experiences of ageing
2. HIV and stigma
3. Uncertainties around physical and social impacts of ageing with HIV
4. Gender-specific information for healthcare providers and women
5. Importance of professional and personal support.

1. The GROWS project focuses on women aged over 40, but this does not align with the age bands used by the UK Health Security Agency to present national HIV statistics.

Background

Advances in HIV treatment have resulted in the number of women with HIV aged 50 and over in the UK increasing three-fold to approximately 10,000 in the last decade. It is therefore important that the needs of women living with HIV in their middle and later lives, are addressed.

In a recent study on menopause in women living with HIV in Englandⁱⁱ, women reported that they were under-prepared for the menopause, with participants highlighting the value of peer-led support (support from someone with the same condition as you). A national study of the experiences of people living with HIVⁱⁱⁱ found that over two-thirds of women with HIV consider community support services as very important.

Older women with HIV face a number of challenges including high levels of menopausal symptoms and difficulties accessing menopause care^{iv}, increased risk of other age-related conditions such as osteoporosis (brittle

bones) and heart disease^v, and high levels of stigma (often as a result of the intersection between HIV status, older age, being a woman, and often being of racially minoritised status). Over 20% of women with HIV aged 50 and over have not spoken to anyone outside their health care team about their HIV status^{vi}. Additionally, women living with HIV are disproportionately affected by mental health issues and socioeconomic challenges including poverty, gender-based violence and immigration problems^{vii}. Despite these challenges, the *'I'm Still Here'* study^{viii}, describes findings of women's persistence, participation and resilience in successfully meeting the specific challenges of living with HIV. It highlights how important connecting with other women and belonging to a community of people with similar experiences is for living and ageing well with HIV, thus playing a vital role in building coping skills and resilience.

About the GROWS project

In recognition of and in response to the needs outlined above and grounded in our own real-world experiences of ageing with HIV and/or supporting women living with HIV as they age, we have established the Growing Older Wiser and Stronger (GROWS) Project.

GROWS is a collaboration between two leading HIV charities, the Sophia Forum and Positively UK, and is supported by UCL's Institute for Global Health, and National AIDS Map (NAM).

The Sophia Forum exists to empower all women living with HIV to reach their full potential, and to ensure their voices are heard and their needs prioritised within the health sector and wider society through advancing research, influencing policy and providing peer support projects.

Positively UK is a national charity which aims to protect the health and well-being of people living with HIV through tailored peer support, promoting positive attitudes and equitable access to health for people living with HIV.

NAM is one of the world's leading sources of independent, accurate and reliable information on HIV and AIDS.

UCL's Institute of Global Health is a leading academic institute focusing on public health issues globally and is supporting the research and evaluation components of the project.

The GROWS project is part of the FTCI improvement collaborative, one of 12 selected projects from 22 applications. Their quality improvement methodology is something new to the HIV sector, which has provided much learning and reflection and has created a space for training and community collaboration allowing us to explore current ways of working on an individual project and sector level.

The GROWS Project is working to address gaps in knowledge and understanding of the impact of ageing on the health and well-being of women with HIV. Growing older with HIV is a relatively new phenomenon; GROWS will build on existing initiatives to focus on developing information resources and a peer mentor training programme to support women growing older with HIV.

As well as aiming to improve the quality of life of women living with HIV aged over 40 in London through a tailored, sustainable, holistic programme of support (developed and led by women with HIV for women with HIV), it is intended that the findings from the GROWS research will also inform policy and influence commissioning decisions. We will map current areas of need among this group and explore potential ideas for interventions with women living with HIV and their care providers. By the end of the project, we aim to deliver the following outputs:

- GROWS Policy report based on analysis of existing and new data (this report)
- Multimedia information resources on HIV and ageing, and specific topics such as menopause, stigma and other psychosocial issues
- A peer mentor training programme for women ageing with HIV (including training manual and resources)
- A 'Train the Trainers' manual to train existing peer mentors (women living with HIV aged over 40) to train and support other women to become peer mentors
- Professional development among women ageing with HIV through the level 3 City & Guilds qualification in Education and Training for peer mentors on the GROWS training programme.

The GROWS project builds on previous work and recommendations conducted by our team, including Sophia Forum's We Are Still Here campaign^{ix}, in collaboration with Dr Jacqui Stevenson.

The We Are Still Here campaign is advocating for eight advocacy asks prioritised by women growing older with HIV. These are:

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.

GROWS responds directly to these asks, by ensuring that older women living with HIV are visible, included and represented in research and campaigns (1), by providing menopause information and support (2), and by training peer supporters for menopause and other aspects of ageing (8). The GROWS research was conducted by trained peer researchers (3) and was designed with meaningful participation of women living with HIV to ensure its relevance (4).

The GROWS Project comprises three stages (Figure 1):

Stage 1: Research including focus group discussions, WhatsApp consultation, stakeholder interviews, and secondary analysis of existing research (PRIME and I'm Still Here). Analysis and policy report.

Stage 2: Development of peer support training programme and manual and deliver peer mentor training to 45 women. Development of multimedia information resources and advocacy material.

Stage 3: Development of the Train the Trainer programme/workbook, and final report of three-year project.

This report focuses on Stage 1, which was completed in the first 18 months of the project.

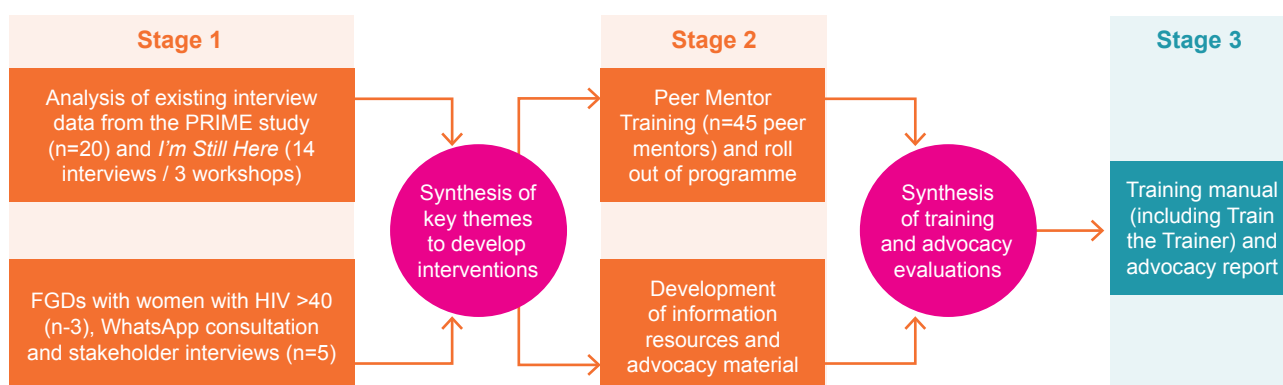


Figure 1. GROWS project research and development stages.

Methodology

We have used a range of approaches to develop this project, and ensured it is informed by robust evidence and guided by women living with HIV at all stages.

We have analysed qualitative data from two existing studies focusing on women ageing with HIV in England: the PRIME (Positive Transitions Through the Menopause) Study at UCL led by Dr Shema Tariq, which explored menopause among women living with HIV (20 semi-structured interviews with women living with HIV aged between 45 and 60 years conducted in 2016-2018); and the “I was not meant to be here, and I’m still here” (I’m Still Here) study; a feminist, participatory and assets-based exploration of women’s experiences of ageing with HIV in London, by Dr Jacqui Stevenson at the University of Greenwich. This study explored both positive and negative experiences of women aged over 50 living with HIV through 14 life story interviews and 3 workshops with 18 participants, and looked at the tools, strengths and strategies and resilience that women have and continue to use to be able to live well with HIV. Data from both studies were shared with the GROWS team. We also conducted our own qualitative work running three focus group discussions (FGDs), a WhatsApp consultation and five semi-structured interviews (SSIs) with key stakeholders. All FGDs and interviews were audio-recorded (with consent) and transcribed using professional transcription software, Otter.ai (confirmed to be secure and compliant with data protection guidelines).

Stage 1

All data (both primary and secondary) were manually coded using a thematic approach by both research coordinators, and emerging themes discussed with the wider project team. Stage 1 work has ethical approval from UCL’s Research Ethics Committee (Ref: 6698/003). A more detailed breakdown of each component of Stage 1 work is provided, as follows:

a. Focus Group Discussions

We held three Focus Group Discussions (FGDs) with women living with HIV aged over 40 based in London between October and November 2020. The discussions explored women’s experiences of getting older with HIV and their ideas for a support programme for women living with HIV as they grow older. A total of 20 participants were recruited over all three focus groups. Recruitment was carried out by Sophia Forum and Positively UK by word of mouth (snowball sampling), existing mailing lists, newsletters and social media channels, and was targeted specifically at women living with HIV aged over 40 who live or access HIV care in London. We provided participants with information sheets (PIS) and obtained informed consent prior to each FGD. Due to the ongoing COVID-19 pandemic, all FGDs were conducted online via Zoom to ensure safety of participants and team members. Each FGD was coordinated and facilitated by the two project coordinators, both of whom also have lived experience of HIV, one taking on the role of lead facilitator and the other providing 1:1 support if required, taking notes and helping manage the group.

b. Key Stakeholder Interviews

We conducted interviews with five stakeholders: one healthcare professional from a leading London NHS Trust, two voluntary sector professionals from two London HIV charities, one academic from Public Health England and one local authority commissioner. All stakeholders were recruited through the project team’s extensive professional networks within the HIV health and social care sector. Informed consent was obtained prior to interviews being undertaken. Due to COVID restrictions, all interviews were conducted online, and audio recorded. All interviews were conducted over a period of four months between December 2020 and April 2021.

c. WhatsApp consultation

The WhatsApp consultation was facilitated across a full day, from 10am to 10pm, on a scheduled date in October 2020, to enable asynchronous engagement. A new WhatsApp group was established specifically for the purposes of the consultation, hosted by a secure work mobile. A total of 11 women, recruited through collaborating organisations' contacts and networks, participated in the group consultation. The women were aged over 40, living with HIV and either based in or accessing their care within London. A PIS explaining the research and how the WhatsApp consultation would be conducted was provided and consent was obtained prior to the group being set up. Research questions were posted intermittently throughout the day giving participants an opportunity to post their responses.

The WhatsApp group was monitored throughout the day by the two project co-ordinators, who took turns to post questions and facilitate the discussion. The consultation was promptly closed at 10pm, responses collated, and the WhatsApp group deleted immediately the responses had been exported and saved onto a secure device.

The project was initiated in 2020. The COVID-19 crisis inevitably affected the delivery of the project, which was initially intended to be delivered and conducted in-person. The team faced challenges in recruiting women for the study during lockdown and due to the need to use virtual methods. The response time and management of the recruitment process took longer than anticipated due to delayed responses from women.

Limitations

Due to the COVID-19 response measures, including lockdowns, focus group discussions which would normally be held face to-face, were delivered online. Organising these created some challenges as many participants had to be supported around IT skills, and this was time consuming and caused delays.

Factoring in the part-time working patterns of the project workers, as well as project funder requirements (i.e., Quality Improvement training sessions) added to time constraints requiring adjustments to project timelines.

Although we know from other research that women with HIV are disproportionately affected by Intimate partner violence and domestic abuse, this did not come out in the discussions, although it was mentioned in one of the stakeholder interviews. It is possible that the remote platforms used during COVID-19 were not perceived by women as a safe space and inhibited them from open discussion on this sensitive and potentially trauma-triggering topic. Moreover, women who experience violence may be less likely to access online services, or not have access to private spaces and devices.

The focus groups included cis women with HIV only and did not include trans women living and ageing with HIV. More needs to be done to include all women with HIV in their diversity in research like this.

Participant characteristics - FGDs and WhatsApp consultation

The age range of participants was 43 - 65 years. The majority of participants were aged 50-59. A total of 31 engagements were recorded across all the FGDs and WhatsApp consultation. It is important to highlight that nine of the eleven women who took part in the WhatsApp consultation also participated in one of the three FGDs.

Findings

Over half of the participants recruited for both the FGDs and WhatsApp consultation were of black African ethnicity, reflecting the epidemiology of HIV among women in the UK. The majority of the women were diagnosed after the year 2000. The majority of the women were not in employment at the time of the focus group discussions. There was almost an even split with a ratio of 8:12 between women who were married and those who were single possibly as a result of stigma, one of the main themes that emerged from FGD with regard to relationships.

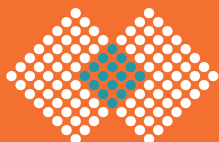
Age	7 aged 40-49, 19 aged 50-59, 5 aged 60+
Ethnicity:	18 Black African, 3 Black Caribbean, 5 White British, 3 White Other, 2 unknown
Year of diagnosis:	1 1980s, 13 1990s, 14 2000s, 3 2010s, 0 2020s
Employment status:	18 employed, 2 self-employed, 8 unemployed, 3 unknown
Relationship status:	8 married, 1 widowed, 12 single, 10 unknown

Experiences, priorities and needs of women ageing with HIV

Our analysis identified five themes relating to the experiences, priorities and needs of women ageing with HIV is set out on page 16.

1

Multidimensional challenges of ageing with HIV: psychological, physical and social



"The good side is like, I think that we have blood tests regularly, which perhaps someone who doesn't have our situation doesn't get. So the blood tests can pick up things that perhaps are not known about, you know what I mean, for other people they'll, maybe miss it, but for us, it will be more likely to get caught, you know, like get seen."

"The biggest challenge I have had is navigating through comorbidities and additional medication especially when I have had to switch and deal with side effects for both ARV and the blood pressure."

2

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."

"And I've, like, lost complete confidence of going into a relationship at the moment, because I just don't feel like I can put myself into that potential situation again."

3

Uncertainties around physical and social impacts of ageing with HIV



"A big impact is being an immigrant in another country. Yeah. More than living 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?"

"But growing older, with HIV, we are growing older with comorbidities, like arthritis and fatigue, tired, isolation, those are most important."

4

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?"

Having specialists, both informal and formal, giving information and advice would be helpful. And discussing different issues from HIV perspective. Or even having an available directory of where to get such support (not sure how much is already available but not accessed by myself).

5

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."

"HIV has given me a network of friends for life who take me as I am, no judgement!"

"I love the way that I'm able to help people, other women, especially women, that are my age. Especially people that have just been diagnosed [with HIV]."

Research themes



Multidimensional challenges of ageing with HIV: psychological, physical and social

When asked what the overlapping issues of growing older with HIV were for them, the women reported a wide range of lived experiences, both positive and negative. What remained constant was the physical and psychological impact that ageing with HIV had on women diagnosed with HIV. Physical symptoms women described included fatigue, joint pain, weight gain, with concern over whether HIV, ageing or a combination of both were the cause.

“The biggest challenge I have had is navigating through comorbidities and additional medication especially when I have had to switch and deal with side effects for both ARV and the blood pressure.”

“I like keeping calm but as I get older these experiences have been very distressing. Especially when ‘unheard’. The arthritis, knee pain, impaired hearing now for both ears, weight gain. I can’t do my hourly morning walk because of the cold weather. I believe my weight gain is related to my recent switch to new meds. Yes, HIV has had a negative impact.”

“I’ve got aches and pains in my muscles, my joints, my shoulders all over my body. Very stiff. Sometimes I get up and when I’m sitting in a chair and I get up. I can’t walk.”

While there were a lot of negative factors relating to ageing with HIV, the women pointed out some positive experiences of growing older with HIV. They described these as being able to access full health screening for other health conditions such as for bone density, kidney function, and liver tests which they would otherwise not have been offered routinely were they not living with HIV. Others spoke of being grateful for being able to see their children grow and for some even being around to witness the birth of their grandchildren – an experience they thought would not be possible when they received their diagnosis.

“...For me, the biggest positive is being able to see my children grow. When we were getting diagnosed, so many years ago, that wasn’t even an option. You didn’t even think about having more children. And even then you were being prepared, you know, memory boxes for your children, because you weren’t expected to live that long.”

Women also experienced psychological symptoms, most commonly anxiety and depression. Sources of anxiety ranged from concerns about the long-term physical impact of anti-retroviral therapy, to worries about symptoms – uncertainty around whether what they were experiencing was related to HIV or general ageing. Memory loss featured highly as a concern for women, again not knowing whether to attribute it to long term HIV, prolonged treatment or general ageing. The women were particularly worried about not being able to remember to take their antiretrovirals which is key in maintaining an undetectable viral load.

“Ageing process doesn’t apply to the body alone, but also in the mind. We all age differently, with me, I tend to forget a lot every day, comparing to when I was younger.”

“I sometimes forget the times to take medications, so I have write it in a piece of paper to remind me. I sometimes forget to switch my heating off or my cooker off, unless I write a note on a piece of paper to remind me. All these affects my every day of life.”

For many women, there were social and economic factors that further complicated the process of ageing with HIV. For example, being a migrant or having different cultural and religious influences compounded challenges of growing older with and HIV diagnosis. Migrant women have had to deal with other social factors as well such as learning how to navigate the healthcare system or living in a constant state of fear and uncertainty whilst they negotiated their immigration status. This sometimes meant not being able to work or have access to social support which meant they experienced a lot of anxiety and affected their mental health. Cultural background also influenced how a woman engaged in healthcare i.e. difficulties in communicating or articulating their symptoms because of language barriers and lack of confidence to express their needs if symptoms persist. This impacts how women interact with health and social care professionals making them feel less confident to ask questions or challenge negative statements.

“Being an immigrant and English not my mother tongue set my career backwards to the beginning. It took me 15 years in UK to regain again that position.”

HIV and Stigma



Stigma was a concern for many women in this study. It was a particular concern in relation to relationships and sharing their HIV status with others i.e., family and friends. It often affected the women’s choices around intimate relationships. The women described lacking confidence to discuss their HIV status with potential partners for fear of being judged.

“What I find challenging is having to constantly counter other people’s negative perceptions of what someone like me is supposed to be.”

“...so the stigma and the discrimination, I think would be just ongoing. It’s ongoing around that. I mean, I came out of a long-term relationship last year, and HIV played a significant role in the end of that relationship.”

Some women in the focus groups stated that faith and religion were very important to them. However, fear of stigma and ignorance created barriers to accessing support from faith communities. For some participants in our peer research, this was an area they felt they were no longer able to engage in, because of lack of knowledge within faith communities or stigma and for fear of being judged. This often left women feeling more isolated. Despite wanting to be more engaged with their faith.

“Most of it is my Community as a Muslim I find difficult to share my status with Imam in the Mosque because they don’t have knowledge.”



Uncertainties around physical and social impacts of ageing with HIV

Lack of research, episodic health impacts and the long-term effect of HIV and medication led to a great deal of uncertainty among women in this study. This was in part attributed to the lack of clarity over whether particular symptoms or physical challenges were linked to HIV or to ageing. It was also described in relation to socioeconomic concerns, including having enough money to live on, housing and care in their later years.

Security, whether in the form of financial stability or the certainty of having a roof over one's head in their later years is what many strive for. However, for women ageing with HIV, lack of security is a pressing concern. Women were not only worried about their health, but also about social care and their financial security in later years.

Some had left employment after having been diagnosed with HIV, voluntarily or otherwise, believing that they did not have long to live. Others became ill and could no longer work, thus losing out on pension schemes and using up savings.

With the advent of effective treatment, many women were willing to return to work. However, returning to employment was difficult as they had lost skills and confidence. Moreover, many had used up all their savings, and pensions packages, if they had one, were too small to live off, resulting in poverty. Consequently, women worried about whether they would have enough money for future care needs. Even those in employment, could often only cover their basic needs, and were unable to save or plan for things such as pensions and care packages. The option for insurance was not possible until recently and even then, premiums are very high for low coverage.

“...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?”

‘It has made me think more of the future and wanting to put things in place to have a good future. Thinking about my job now and whether in 5 or 10 years time I could be physically able to do this job and if not what job could and would I do until retirement.’

Gender-specific information for healthcare providers and women



Women were keen to understand what the impact of long-term treatment might be on their bodies and on their quality of life but identified huge knowledge and information gaps both within and outside of the HIV sector, particularly around HIV and ageing. There was a sense that there was insufficient information and resources in general for women, and also for professionals providing health and social care for women living and growing older with HIV. For instance, women did not know where to find information about the menopause, bone health or heart health in the context of HIV. Women told us they relied on HIV support organisations and HIV specialists for any information about HIV, but now found themselves in uncertain territory when it came to HIV and ageing. The women alluded to this more through questions and suggestions of how more information and resources could be made available. They also had questions around the impact of being diagnosed with HIV for a long time, feeling that this was also a relatively new phenomenon even for the specialist HIV teams who were dealing with an ageing cohort for the first time in history.

“Another of the challenges is as we mentioned before about the health professional, not knowing exactly if this HIV related or not and not taking responsibility.”

“I would also like to have information regarding approaches in research on the technical aspects, alongside more research to find out possible outcomes for conditions. Having a go to place where there is solid information delivered in a supportive way would be fantastic.”



Importance of professional and personal support

Women expressed how important both professional and personal (peer) support was to them. They indicated that the professional support received within their HIV healthcare teams was of a very high standard and where they felt most of their needs were met. However, the process of ageing with HIV requires care from other health care settings as more age-related health issues arise. This leads to more interaction with primary care, as the coordinator and route to referrals for other secondary care. The women reported that it is within this area where they felt professional support was lacking. Women often felt as though they were neither listened to nor heard by their GPs, who often related all concerns to HIV and referred them back to HIV specialist services. This phenomenon is often referred to as ‘ping-ponging’, a term used when women felt as though they were being ‘bounced’ back and forth between their HIV consultants and other healthcare professionals. It often left the women feeling frustrated and unsupported professionally. For example, when women saw their GP about issues linked to menopause, they may assume it is HIV related and send women back to HIV care. The following quote below reflects this.

“I think a female doctor to relate with would help because many of the GPs are not female...”

In areas where the women were referred to other specialities i.e. cardiovascular, kidney or pain management clinics, the awareness and knowledge of HIV was very low. The women pointed out that they were having to ‘educate’ these professionals about HIV and felt this was not their responsibility. Women also reported that more recently, they sometimes felt unsupported by their HIV specialist healthcare teams in trying to understand some of their health concerns. This may be because this is fairly new ground that is still being uncovered and researched. However, this did not detract from the women feeling unsupported professionally as cited below.

“I spoke to my doctors about it, they said: We don’t know because nobody’s been down this road before. 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.”

Another issue that was frequently raised was the lack of peer support. Women raised the huge value and importance of being part of a group of women living with the same condition - it was extremely helpful in dealing with their HIV as well as ageing. Being able to access a peer support network, whether on a one-to-one basis or in a group, meant they felt less isolated, and it also enabled them to navigate the challenges of HIV and ageing. It made a big difference to women knowing they were not alone, increasing their confidence and self-esteem and helping to build resilience.

“For we, the HIV women, I think the charity should try and look into doing more for us, educating us, helping us deal with the symptoms, emotionally, physically and medication...”

Women emphasised the value of peer support and how this has been instrumental in helping them deal with HIV and related issues such as isolation and stigma and navigating relationships. This has been especially true when they have engaged with women who are living well with HIV and are happy to share their experiences of doing so.


“I have built a good network with people who are part of my family.”

“Peer support, I wouldn’t be here today, if it wasn’t for peer support, I wouldn’t have met you [F1], I wouldn’t have met you, [P4], wouldn’t have met you [P2]”

“I am aware that there are things I will never have control over and have become more realistic in my ambitions. I am grateful for the amazing HIV care I get in the UK, a strong support network of friends and continuing to be a productive individual.”

Women also indicated that as a result of having lived so long with HIV, they had a wealth of knowledge, expertise and experiences which women who are more recently diagnosed did not have; they were prepared to pass this on to the younger generation that were also growing older with HIV.

“I have gained knowledge and experience of living well and positive. It also builds my confidence to be able to educate others.”



The QI approach has helped me to identify organizational cultures, apply structure to teamwork, and innovate the ways we use data. It has supported developing the collaboration by fostering shared values and building trusting relationships.


Sophie Strachan CEO

QI has been so valuable in equipping us to alter our approach to designing and delivering project outputs in order to get the most possible impact from them; and has empowered us to try something new, when we have been working to often quite inflexible models prior to our involvement in the QI collaborative. The freedom to try to succeed differently has been a learning experience for us and something we will look to replicate in all of our funder relationships going forward.

Susan Cole-Haley, NAM aidsmap

Part of my learning is devising processes and procedures that work for the partnership, whilst considering the needs of the participants in the programme, and the capabilities of each organisation.

Sarah Fraser



The quality improvement collaborative has been instrumental in helping us visualize our project by using the driver diagram tool and the PDSA cycles, enabling us to identify the best method of promoting our videos on social media to reach our target audience. In our initial GROWS research we were able to conduct our own primary data collection through our focus group discussions , and through further analysis of our primary data and secondary analysis of PRIME and I'm Still Here data, we were able to generate the key themes relating to ageing with HIV as a woman as highlighted in this report.

Juddy & Rebecca GROWS Project leads

Being part of this research gives me an opportunity to share and learn from my peers. The outcome of this research will raise awareness and address the medical and social issues of women, and help improve our experiences as we age with HIV.

FGD Participant

This project has embodied the core value of 'meaningful involvement' which in turn has helped narrow the existing gender gap in HIV research. It has made me feel represented. I hope the findings can now be translated into service delivery to meet our needs as we age as women living with HIV.

FGD Participant

Conclusion

The GROWS project highlights the considerable challenges encountered by women growing older with HIV, as well as capturing their strengths and resourcefulness. We have heard directly from women about the physical, social and psychological impact of growing older with HIV, and how that experience is gendered. Support and information are critical in improving women's health and wellbeing, but more needs to be done in terms of provision especially in services outside the HIV health and social care sectors. The role of community organisations can't be overstated, and it is important that they are supported to provide services to women ageing with HIV and innovate in this sector. However, it is important to emphasise that, while women described challenges, there were also positive aspects of ageing with HIV. For example, women were presented with opportunities to meet people or work in areas that they would not have otherwise been able to. For some, their diagnoses had been accompanied by the fear that being diagnosed with HIV meant a shortened life. Growing older with HIV removes that fear, providing hope (and often the experience) of being able to see children and/or grandchildren grow. They also valued opportunities to pass on their knowledge and experience to the younger generation or those newly diagnosed as well as using this expertise to inform policy and advocacy.

We hope that our work on the GROWS project continues to build on existing conversations on how we holistically address the needs of women as they grow older with HIV. If we are to provide equitable care and support, it is vital that we engage with the intersection of gender, HIV and age and that we put the voices of women living with HIV at the centre of policy and service design.

Next Steps

Following completion of stage 1 of the project plan, the research themes and recommendations have been used to inform the development of a pilot peer mentor training programme, with the first pilot training session having been successfully delivered in February 2022. The pilot training was evaluated and used to further develop the programme, which has been delivered twice more (one virtual, one face-to-face). Further trainings are planned for the second half of 2022. The aim is to train a total of 45 women as peer mentors to support other women >40 ageing with HIV. We also plan to develop information resources and further advocacy materials to support the programme.

The final stage will include building on the research to develop further materials in the form of a Peer Mentor Training Manual, Train the Trainers Manual and further advocacy reports.

Recommendations

As a result of the research, we make the following recommendations to better address the priorities, needs and experiences of women ageing with HIV, in all their diversity:

Academics and Researchers

- Work with older women with HIV to ensure they are meaningfully involved in all aspects of research, including setting research questions, conducting research as peer researchers, and analysing data.
- Carry out research that responds to the experiences and priorities of women ageing with HIV. Priority areas of research women have identified include how age-related co-morbidities affect women with HIV, and the long-term effects on women of living with HIV and taking antiretrovirals.
- Address significant data gaps in this population, ensuring that data are disaggregated by sex, age, ethnicity, gender identity to ensure that all women with HIV, in our diversity, are represented in research.
- Work with older women with HIV and the voluntary sector to translate research findings into accessible and accurate information resources around all aspects of ageing and women with HIV.

Health Care Providers

- Improve links between HIV specialist services, primary care, and other health services, providing clear pathways, communication channels, and lines of accountability to minimise the burden on women living with HIV.
- Develop woman-centred, holistic, and trauma-informed care models for and with women living with HIV aged over 40, informed by the findings in this report.
- Invest in the provision of peer support in HIV clinical settings that will support engagement and retention in care.

Commissioners & Funders

- Commission peer-led services, which are essential in reducing isolation, fostering confidence and self-esteem, and improving well-being of women ageing with HIV.
- Prioritise long term sustainable funding for third sector/grassroots organisations to provide meaningful, impactful, and cost-effective interventions.
- Safeguard funding for specialist woman-focussed HIV research, support and education.

Training and Education

- Embed HIV awareness and education in training for all professionals working in health and social care settings including nursing homes, hospices, and other specialist medical settings.
- Train healthcare workers in caring for older women with HIV using a trauma informed approach, addressing intersectional issues including gender disparities, violence, stigma, being a migrant and navigating an unfamiliar and sometimes hostile system, mental health issues, and economic hardship.

Voluntary Sector

- Encourage and support collaborative links and partnership working between the HIV sector and other ageing and healthcare agencies.
- Continue to develop peer-led programs that offer older women with HIV the opportunity to work and volunteer, to share their skills and lived experiences with others, and feel that they are useful and valued members of their communities.
- Provide spaces for peer and community support. Women ageing with HIV really value spaces where they can gather with peers and share strategies, solutions and support, and inspire each other in shared communities around growing older with HIV.

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Glossary of abbreviations

FGD	Focus Group Discussions
FTCI	Fast Track Cities Initiative
GROWS	Growing Older Wiser Stronger
HIV	Human Immunodeficiency Virus
NHS	National Health Service
PIS	Patient Information System
SSI	Semi-Structured Interview
UKHSA	United Kingdom Health Security Agency (formerly Public Health England)



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