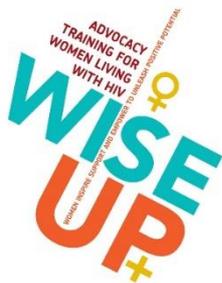




WISE UP+ Ageing with HIV

4th-6th October 2019

Workshop Report



About WISE UP+

WISE UP+: Women Inspire Support and Empower to Unleash Positive Potential is a structured series of workshops designed and led by women living with HIV with the aim of building a dynamic community of female HIV advocates.

The objectives of WISE UP+ programme are:

- ✓ to alleviate isolation - where there is no/low access to services, addressing unmet needs in service design and delivery;
- ✓ to increase knowledge and power – so that women are involved in healthcare decision making, dialogue with health professionals, becoming activists;
- ✓ to meet the needs of ALL HIV+ women - exploring health disparities specific to culture, age, marginalised groups and intersectionality;
- ✓ to provide a safe space where women can share experiences, be creative and develop advocacy messages to inform policy and commissioning decisions;
- ✓ to endorse positive sex messages so that women can work towards the lives and relationships they want.

About Sophia Forum

Sophia Forum is a national UK charity which promotes and advocates for the rights, health, welfare and dignity of women living with HIV through research, raising awareness and influencing policy. Its work reaches women with different ethnic, faith and gender identities, sexual orientations, ages, immigration status and relationships with the criminal justice system.

Women represent roughly a third of people living with HIV in the UK. However, for a variety of reasons, women living with HIV remain extremely under-represented in medical trials, programmes, policy and research. They also often face complex issues, including violence, stigma and poorer mental health. Moreover, trans women are often invisible in the response to HIV and experience far greater intersectional difficulties when accessing healthcare and meaningful engagement in HIV spaces.

Sophia Forum ensures that women living with HIV are meaningfully involved in all its work and is led by a collective of women of diverse ethnicity, age, gender identity and sexual orientation.

Recent work has included partnering with the Terrence Higgins Trust (THT) to deliver ground-breaking research revealing the challenges faced by women living with HIV in the UK. Further work with THT and Public Health England will inform policy and planning moving forward. Sophia Forum has also been instrumental in ensuring that women are included in the debate around the availability of Pre-Exposure Prophylaxis (PrEP) and that information specifically tailored to women is available.

Other activities include:

- an advocacy programme;
- bringing together information and research on issues affecting women living with HIV;
- creating partnerships with organisations and individuals delivering services;
- building relationships with policy makers.

WISE UP+ Ageing with HIV

WISE UP+ Ageing with HIV was a weekend retreat for women aged 45 and over who are living with HIV. The WISE UP+ programme engages with women in all our diversity, in mixed workshops and, through a new strategy initiated in 2019, in age-specific groups focused on shared issues at different life stages. WISE UP+ Ageing with HIV was the first workshop delivered within this strategy.



Sessions at this workshop included:

- Recent research updates on ageing with HIV
- Managing menopause, co-morbidities and HIV
- Mental health and wellbeing
- Addressing loneliness and isolation
- Priorities for developing a support group for women in the menopause
- Co-developing patient and clinician resources on HIV and menopause
- Developing an advocacy agenda for older women living with HIV.

The workshop was funded by an educational grant from Gilead Sciences Ltd and hosted at the offices of Terrence Higgins Trust. We are grateful to both for their support.

The workshop content, lead facilitation, and evaluation were delivered by Jacqui Stevenson, with support from Sophia Forum trustees.

Workshop objectives:

- ✓ To alleviate isolation for older women living with HIV, creating a safe space for women to share their lived experience, creating bonding and friendship.
- ✓ To create a space for women to learn about recent research findings specifically relating to ageing with HIV, the menopause, and co-morbidities.
- ✓ To better understand the diverse needs of women reaching middle age and beyond to help inform commissioning with a gendered lens.
- ✓ To develop an advocacy agenda that can be implemented into direct action beyond the weekend retreat.
- ✓ To provide women with tools to look after their health and wellbeing beyond biomedical interventions.

Workshop overview

The WISE UP+ Ageing with HIV workshop was held in London from Friday 4th to Sunday 6th October 2019. The weekend opened with an informal drop-in session on Friday evening, to provide space for participants to get to know each other. A group meal was shared on Saturday evening at a local restaurant, a welcome opportunity to relax and get to know each other outside the workshop setting.

Workshop sessions ran all day Saturday and Sunday, including group work, presentations and co-productions of advocacy messages and resources. Mindfulness and yoga sessions were also included, led by a workshop participant. Content and feedback from core sessions are described in this report.

Participants

23 women living with HIV, most aged over 50, attended the workshop. Women interested in attending were asked to complete an application form, detailing their interest, what they hoped to gain from participating and demographic details. The event was advertised through the Sophia Forum website, mailing list, social media and through direct contact with HIV sector organisations throughout the UK. Participants from across the UK were diverse in their length of diagnosis with HIV, ethnicity, age and other experiences.

Co-facilitation

WISE UP+ methodology importantly centres on the leadership of women living with HIV. For this workshop six women living with HIV were recruited as co-facilitators for the weekend as a pilot initiative, providing a platform for them to grow and to develop facilitation skills.

Some had significant experience of facilitation but had stepped back from the HIV sector, so welcomed an opportunity to refresh their skills. Others had previous training but had not had access to opportunities to put their skills into action, while some had no previous training and were keen to build new skills. Co-facilitators were provided with an informal training session on Friday evening, covering key facilitation skills and their own priorities, a detailed discussion of the workshop aims and agenda, and then had the opportunity to co-facilitate sessions, lead group work and document sessions throughout the workshop, based on their own preferences. Co-facilitators were provided with an honorarium as acknowledgement of their contribution. All gave positive feedback on this Sophia Forum pilot which will be expanded in future WISE UP+ programming.



Shared aims and expectations

The WISE UP+ methodology aims to create a safe space of community and connection, through which shared aims and expectations are defined to shape the workshop experience. Through this, the experiences, priorities and stories of all participants are centred and explored. Consequently, the weekend started with group discussion to share and agree aims and expectations, with everyone able to contribute and reach consensus. The shared objectives are listed below. These shaped the workshop and were discussed through different sessions. As part of the closing session, participants reviewed the objectives and discussed what had been addressed successfully and what should be carried forward to future activities.

Our aims and objectives:

- Networking, including linking to clinics and sharing information on opportunities like this workshop.
- Explore how to get clinics and others to engage with Sophia Forum.
- Online networking.
- Strategy for funding and supporting this work, and for engaging ethically with pharmaceutical companies.
- Address how HIV is talked about in media and social media.
- Thinking about where gaps are and how these can be addressed, for example in GP knowledge or drug interactions, and be clear on next steps.
- Follow up to this workshop, putting skills to use and engaging women after the training.
- Link to other organisations, networks etc. to bring women's voices and experiences in.
- Connections between women, with different experiences, diagnosis journeys etc.
- Address isolation and share information e.g. on U=U.

Building community and advocacy

In this session, participants were invited to share their ideas around what community is, what advocacy means, and what makes an effective advocate.

Community was defined as including:

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|------------------------------------|------------------------------------|
| ✓ Sharing ideas | ✓ Finding each other's strengths |
| ✓ Common interests | ✓ Shared information |
| ✓ Mentoring | ✓ Communication |
| ✓ Peer support | ✓ Inclusive – belonging |
| ✓ Connection of minds | ✓ Participation and involvement |
| ✓ Common good | ✓ Empowering each other and others |
| ✓ Networking using different tools | |

Participants also considered how they could build community, sharing ideas including recognising themselves as experts in their own lives, feeling a shared sense of ownership and building links and connections. Creating space for new people to bring in new opportunities and ideas was also considered to be important, as were clear messages, valuing different voices and authenticity.

In small groups, women considered two scenarios:

- Scenario 1 - Your friend is a woman living with HIV. She keeps going to her GP with health problems, but her GP brushes her off saying that it's probably related to her HIV. How would you support her?
- Scenario 2 - Your friend is a woman living with HIV. She recently started dating and she is trying to figure out how and when to tell her partner about her HIV status. How would you support her?

In their groups, participants discussed how they would support their friend in each scenario, and then reflected on what advocacy skills their actions would involve. The aim of this activity was to situate advocacy in real life, and to define advocacy within a broad, feminist definition of personal and community change as well as political change and action.

A group discussion about advocacy followed, with women sharing their ideas to define advocacy. These included: empowering others; being a voice for the voiceless; representation; being an ambassador for ideas you believe in; influence; fighting for a solution to a problem; and, being knowledgeable.

Participants identified the skills and attributes the ideal advocate would have:

- ✓ Listening and communication skills
- ✓ Reliable, dependable and approachable
- ✓ Speaks up with knowledge
- ✓ Has up-to-date and relevant information – knowledge is power
- ✓ Reaches out to others to build knowledge
- ✓ Learns from mistakes
- ✓ Resilient
- ✓ Able to prioritise
- ✓ Confident enough to make mistakes
- ✓ Trained about key issues
- ✓ Knows limits
- ✓ Smiley face
- ✓ Non-judgemental and empathetic
- ✓ Passion for the subject
- ✓ Prepared to learn
- ✓ Understand privilege
- ✓ Seeks help and asks for support
- ✓ Focused
- ✓ Diverse and inclusive
- ✓ Uses appropriate language
- ✓ Signposting to different organisations
- ✓ Active listening
- ✓ Confidentiality
- ✓ Good time management
- ✓ Facial expression, tone of voice and body language
- ✓ Quick thinking
- ✓ Sensitivity
- ✓ Respect for boundaries
- ✓ Able to break big things down into small manageable chunks

Participants then worked in small groups to do a force field analysis activity, sharing their thoughts in response to the question: “As a woman growing older with HIV, what makes it easier to have a voice and have your needs met? And what makes it harder?” Some example responses are included in the table below:

Makes it easier to have a voice and have our needs met	Makes it harder to have a voice and have our needs met
<ul style="list-style-type: none"> ● Confidence ● Life experiences ● Networking ● Social media ● Sense of belonging ● Training ● Peer support ● Consistency of care 	<ul style="list-style-type: none"> ● Memory loss ● Complacency ● Body changes ● Too much information ● Changes of consultant ● Limited time with healthcare professionals ● Not having concerns taken seriously ● Immigration status

<ul style="list-style-type: none"> ● Knowledge of own body ● GIPA and spaces like this ● Women's spaces and leadership ● Access to information ● Diversity ● Healthcare – physical, mental and emotional ● Faith 	<ul style="list-style-type: none"> ● Invisibility ● Life challenges ● HIV sector directed by men and modelled by men – excluding women ● Lack of dialogue around end of life issues ● Political will/political landscape ● Lack of support structures ● External stigma and self-stigma ● Racism, classism, sexism
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Research updates

In this session, presentations were given on two recent research projects on ageing, HIV and women and participants had time to ask questions and share their reflections. Danielle Solomon presented on PRIME, a national mixed methods study on menopause and HIV. Her presentation included the methodology, findings and implications of PRIME, and was highly informative. Jacqui Stevenson then presented on her doctoral research: *“I’m Still Here” – women’s experiences of ageing with HIV.* This qualitative study used creative and participatory methods to explore women’s experiences. This provided the foundation for an advocacy campaign co-created at this workshop, *“We Are Still Here.”*



Clinical updates

HIV consultant and menopause expert Dr Nneka Nwokolo led a session on clinical updates on ageing, co-morbidities, and menopause. The session was an open and highly interactive Q&A, with women asking a range of detailed questions based on their own experiences. A particular learning and shared outcome from this session was the challenge women face in accessing accurate, up-to-date and personalised information on menopause and HIV. Many women felt that both the GP and HIV consultant lacked comprehensive information and described being sent back and forth between primary care and the HIV clinic. Dr Nwokolo’s expertise was hugely appreciated, and many women described feeling more informed and confident as a result of the session.

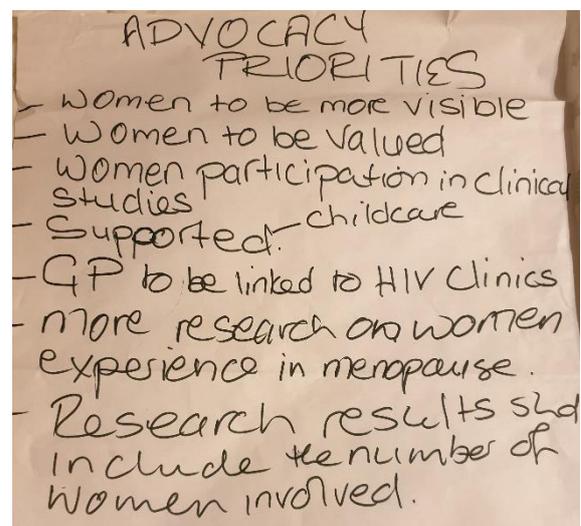
Developing an information resource

Building on the research and clinical sessions, participants co-developed an outline for an information resource, to be funded by the same grant as the workshop. Women described targeted information on menopause for women living with HIV as hard to access and often insufficient, and in particular felt that the opportunity to ask questions had been hugely valuable. Based on this, it was collectively agreed that the resource should be engaging, accessible and made available in clinical and support settings as well as online providing a clear and comprehensive overview of key issues with an FAQ style. Questions would be gathered through both workshop participants and a menopause support group run by Sophia Forum, and answered by an HIV and menopause expert. This resource is currently under development and will be published in 2020 both in print and online at www.sophiaforum.net.

Developing an advocacy agenda – We Are Still Here

We Are Still Here is based on a collaboration between Sophia Forum and Dr Jacqui Stevenson, who carried out research exploring women's experiences of ageing with HIV in London. Using participatory and creative methods, Dr Stevenson involved women living with HIV in each stage of the research, adopting an advocacy approach to generate new evidence on the experiences of women ageing with HIV.

The We Are Still Here campaign was co-developed with participants at this workshop, who developed advocacy priorities and key asks based on their own experiences and the research. In small groups, participants discussed changes they most wanted to see which would benefit older women living with HIV. These priorities were then fed back to the whole group, who agreed shared priorities, resulting in the six key asks listed below.



The campaign aims to highlight the experiences and priorities of older women living with HIV, and calls for:

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

Through the **We Are Still Here** campaign, older women living with HIV are making six 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) Research that involves older women living with HIV, explores issues that are relevant to our lives and addresses barriers to our participation. Clinical research, including HIV treatment, and social research, should meaningfully involve older women. All research results should be disaggregated by sex and gender and report under-representation of women where this is the case.
- 4) Full information about HIV treatment side effects and drug interactions, and support to manage them, should be provided.
- 5) Improved collaboration, coordination and communication between GPs, consultants, other healthcare professionals and HIV clinics.
- 6) Treatment advocacy and peer support training tailored to women, including menopause mentors.

Evaluation and participant feedback

I have told so many people about the weekend and especially Sunday and all the information about the menopause. I'm hoping to organize some talks about the menopause for the women of [my city] for next year around International women's day/week.

I might have also convinced my sister to get more advice about the benefits of HRT and I see my HIV Consultant in January and will definitely be asking her about it benefiting my health.

What you created enabled some emotional beautiful moments of support and connectedness and it was a privilege to be part of it. If I am honest I have felt like an outsider in terms of the HIV sector for a very, very long time and I did not think I would ever feel connected again, but I really did!

I've sent out information about menopause to work colleagues and lido swimmers and I've have had loads of conversations with women. It's been great to have informed conversations and places to sign post for more information.

All participants were invited to complete a pre and post-workshop questionnaire. The pre-questionnaire was completed during the registration session on the first day, and the post-questionnaire in the closing session. Participants were asked to rate their knowledge, skills and confidence, so that a comparison before and after the workshop could be evaluated. Participants were also asked to share their objectives and feedback. All monitoring data was evaluated and will be used to shape future programmes.

The pre questionnaire asked participants to share their objectives for the workshop. Participants highlighted their desire to make friends, build connections and network. Learning about HIV, ageing and menopause were also common priorities, as was building confidence. Other responses included:

- Build stronger network
- Meet new people
- Re-connect with old friends
- More information on advocacy for women
- Learn about WISE UP+ and HIV updates
- Learn more about how women are coping ageing with HIV
- Understanding of other women's experiences both shared and not
- Ideas for what the key themes are for women with HIV who are ageing
- The beginnings of how we might get our voices heard with key messages
- Inspiration from other women living with HIV
- Re-empowerment around my HIV status
- Build confidence in entering back into the HIV community after many years

The pre-questionnaire also asked what skills participants hoped to develop, with many focusing particularly on communications skills, information gathering and accessing support. Responses include:

- Communication
- Facilitating
- Research
- Advocating for others
- Learn from women from rural areas
- Confidence
- Build confidence in communicating about HIV
- Advocating wellbeing when positive
- Ability to reach out to isolated women with HIV especially in rural areas
- Increase knowledge/ confidence/ advocacy
- Co-facilitating
- Leadership
- New ways to get ideas
- Framework for gathering and sharing information
- Confidence on disclosure in public arena
- Boosting self-esteem
- How to access support
- How to access information
- Learn how to properly use my voice and what I can achieve by doing so
- Build on the skills that I have already knowing that I find that my passion lies within the HIV field for the future

In addition, participants were asked if they had any concerns or if there were aspects of the workshop they were unsure about. The lead facilitator reviewed these responses in the first break so issues were addressed, either through sharing information with the whole group, or individually if appropriate.

Participants ranked their own knowledge, skill and confidence in key areas before and after the workshop. The table below shows the average scores. All areas of knowledge, skill and confidence showed improvement after the workshop, with particularly marked improvement in knowledge about menopause and about ageing with HIV, skills in setting objectives and planning advocacy activities, and confidence in speaking up on important issues.

The participants' rankings indicate that the WISE UP+ Ageing with HIV workshop was successful in meeting its objectives for supporting and enhancing the knowledge, skills and confidence of participants. Participants ranged from those who described themselves as new or fairly new to activism and this type of training to others with past experience, including some women who had stepped back from involvement with HIV activism. For this reason, the starting point for participants varied greatly, with some having skills and experience but hoping to build confidence. This mix of experience and background added an important element to the workshop, with participants describing the opportunity to re-connect with activism and refresh their skills as a key highlight.

	Average pre-workshop	Average post-workshop
Skilled at active listening	3.45	4.1
Confident in building relationships	3.41	3.74
Knowledgeable about menopause	2.43	4.15
Skilled at setting objectives	2.82	3.85
Knowledgeable about ageing with HIV	2.82	4.15
Confident about speaking up on issues that matter to you	3.55	4.4
Confident at participating in meetings or conferences	3.64	4.3
Confident in representing your community	3.45	4.15
Skilled at planning advocacy activities	2.86	3.9
Confident in motivating and inspiring others	3.41	4
Skilled in using social media	3.05	3.5
Knowledgeable about research	2.50	3.6
Confident in leading discussions	2.95	3.85

The post-questionnaires were completed by participants during the final session. Participants were asked to reflect on all aspects of the workshop and to consider their experience in the context of their aims and expectations. Feedback was overwhelmingly positive, with participants particularly appreciating the organisation, practical support, expert speakers and the space and time to connect and re-connect with other women living with HIV. Many participants highlighted the relative lack of other opportunities to connect and spend time with women and appreciated the opportunity the workshop provided for this.

Participants were asked what they liked best about the workshop, and gave answers including:

- "All of it! It was amazing, and all about women."
- "Networking. Reacquainting self with old faces and meeting new ones. Feeling re-energised around HIV advocacy. Meditation! Inspirational women. Presentations re research."
- "The way it [was] delivered was so brilliant and I felt included in the workshop. Picking six co-facilitators added that this was delivered with the women."
- "Sharing stories of our experiences on the menopause journey and how much we learned."
- "Everything. Very well-informed presentations. Being with HIV+ women. Great demographic - really thought out regionally. Plenty of time for everyone to be involved. The meditation and yoga workshops - fabulous."

Women were also asked what skills they had developed through participating, which elicited a broad range of responses that often spoke to individual goals. Responses included:

- "Networking, advocacy, knowledge from presentations."
- "Leadership skills that I can co-facilitate and work with fellow facilitators."

- "Team work and group discussion - all to promote our wellbeing and to be heard nationally and globally."
- "More confidence. An opportunity to re-engage as a co-facilitator. Re-energised and re-engaging in activism."
- "Self-awareness, empathy, compassion, listening."

Asked if the workshop had met their aim and expectations, all responded positively, with only one suggestion for a missing element, included in the examples below:

- "Yes!!! As always"
- "Above and beyond. The menopause part was just epic."
- "Fully met and exceeded my expectations. Initially I thought I just wanted to get out of my house and be with other women, especially because all my expenses were being paid for, but the workshop made me realise that I now need to return to activism and mentoring using my research skills and public health background."
- "Yes. Very much so, because I had no idea that I could be involved in my treatment [for] HIV."
- "Exceeded - was wary of coming because I haven't interacted with women regularly."
- "Only bit missed out - health policy and lobbying those in power to change things in NHS."

In keeping with the WISE UP+ focus on activism, participants were asked what actions they would take as a result of the workshop. All respondents committed to at least one action, informed by personal goals as well as the workshop content. Some examples include:

- "Stop trying to do everything myself."
- "I am going to lobby for menopause support in my HIV clinic. I will speak to CCG about a proposal to support HIV [positive] menopausal women in my borough."
- "Share the knowledge I've gained here with peers in [city]. Pursue training in research."
- "Be more involved with Sophia Forum and WISE UP+ activities/campaigns etc. Hopefully help in some way to develop a UK network."

Finally, we asked if participants had any other comments. Responses included suggestions for future workshops, such as more free time to explore the local area, separate rooms for group work to manage noise levels, and more time to rest before the group dinner.

Next steps

Community and connection were highly valued outcomes of the workshop, and so a mailing list for participants has been created to ensure continuity and create a space to share information and opportunities. Immediately after the workshop, a follow-up communication was sent to all participants with links to organisations, information and opportunities that had been discussed during the workshop, along with attachments with presentations from the research and clinical updates sessions. The email also linked to an online survey to review and validate workshop outputs including the six key asks and an outline for the information resource. This survey also asked women to share their questions on menopause and HIV, which will form the content of the information resource.

The 'We Are Still Here' campaign will launch in 2020, with social media and hard copy campaign materials shared with workshop participants. In addition, a second phase of WISE UP+ Ageing with HIV has secured an educational grant from Gilead Sciences Ltd and will also be delivered in 2020. This will build on the first workshop, and in particular create space for women to build on and further develop their skills as advocates.

