

ADVOCACY  
TRAINING FOR  
WOMEN LIVING  
WITH HIV

WOMEN INSPIRE SUPPORT AND EMPOWER TO UNLEASH POSITIVE POTENTIAL

**WISE UP+**


WISE UP+ WORKSHOP  
REPORT 2019

## WISE-UP+: WOMEN INSPIRE SUPPORT AND EMPOWER TO UNLEASH POSITIVE POTENTIAL

WISE-UP+ 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 the WISE-UP+ programmes 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 UK national 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.

## AIMS OF 2019 WISE UP+

- ✓ To create and facilitate a community building space for women to connect, upskill and realise and/or refresh their activism skills.
- ✓ To enable participants to feel more confident to go out into the world as community organisers and activists

## OVERVIEW OF THE 2019 WISE UP+ WORKSHOP

The WISE UP+ 2019 workshop ran over two days in London and was attended by 13 women from different parts of England. These women ranged in ages, with one aged 20-25 years, three aged 25-35 years, two aged 35-45 years, and seven aged over 50 years. There was also a range in ethnicity, with three women identifying as white and 10 identifying as black and minority ethnic. The workshop was facilitated by Bakita Kasadha and supported by Sophia Forum trustees. The WISE UP+ 2019 workshop focused on fostering participants' confidence to go out into the world as community organisers and activists. At the beginning of the workshop, participants were invited to discuss what brought each of them to the workshop and what they are striving for. While everyone had their own unique aim, there was a group consensus that they were all striving to be heard as HIV positive women. This theme of women living with HIV taking up space and using their voice was one that characterised the rest of the weekend.

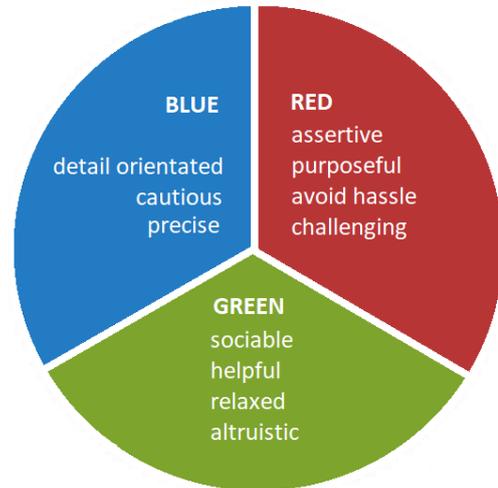


## ACTIVITIES DURING THE WORKSHOP INCLUDED:

### Colour Communication and Team Building

Participants learned different communication styles and explored their own communication using colour assessment.

Three different colours were used to represent different types of people: blue for those who are detail-orientated, red for those who are goal-orientated and green for those who are more emotionally driven. Participants identified which colour they felt best represented them and reflected on the differences in communication, styles for the different colours, and what conflicts or synergies they might present. This activity was well-received, with participants often referring to their colours throughout the weekend.



### Expressing Yourself and Importance of Self-care

During the weekend participants were invited to share how they personally express themselves. Examples include poetry, dance, music, singing, sex, art, fashion, body language, charity work, and political involvement. This led to discussions about mental health and practising self-care, as participants reflected on the importance of learning how to express themselves effectively, in order not to bottle up their feelings. An analogy of an overflowing cup was used to illustrate what could happen if feelings were not expressed in some way. Participants then shared their own self-care methods and discussed the importance of setting personal boundaries.



## Creative Expression

To explore methods of self-expression, participants wrote poems and pieces of creative writing. This session was broken into two parts, which gave participants the opportunity to express themselves creatively both individually and collectively. During the first half, participants worked in groups to create a group poem, on the theme of using your voice. The first person wrote one line, folded the paper over so that only the one preceding line is seen, and then passed it to the next person. This was repeated until everyone had written a line. When the resulting poems were read out there was an air of excitement and pride at the results, with the activity being the first time that many participants had ever tried doing poetry. There were also some emotional reactions with the poems being very poignant and representative of the shared experiences of some of the participants.

### Example of Group Poem

To come here today was only a few short steps, but in my head it was a journey of a thousand miles.

Every journey starts with the first step and many have walked the route before to show the path.

I'm in my stride, looking left and right but my direction is forwards.

I know that what happened to me is good. What happened to me is sometimes hard.

One day I will overcome it.

And then I will be free.

For the second part of the session everyone was given the opportunity to write and perform their own poem or spoken word piece. As shown in the above photograph some participants took the opportunity to illustrate their thoughts. These were shared with the entire session ending on a high note with a strong and empowering spoken word piece.

## Introducing Advocacy

During this session participants were encouraged to talk about what skills they thought were needed to be an advocate. Skills included: patience, compassion, confidence, resilience, empathy and being informed. Following on from this discussion participants were encouraged to realise their own ability and skills to be advocates. This was achieved through group work: groups were asked to discuss how they would support a woman in two different 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?

The groups shared their reflections on the scenarios, and it was highlighted that the skills the groups had used in the scenarios were the same skills it took to be a good advocate. Participants reflected on how they could use their own experiences as

women living with HIV to help others, with one participant commenting that women living with HIV were “experts in our own lives”. Participants also emphasised that they had had similar experiences to those featured in the scenarios. This included discussions around relationships, with some of the women talking about how they’d previously experienced fears of being reduced to just their HIV status within a relationship, and how important it was to know that living with HIV does not make you undeserving of love. There were also discussions around experiences of accessing healthcare, with some women discussing how they had experienced worries about disclosing their status to their GP, with one woman commenting how she’d only told her GP a few weeks prior to attending the event.

## **Understanding Participation and Taking Action**

Participants discussed different forms of participation, agreeing that bottom up, co-produced and self-organised participation were of particular importance. Working in groups, participants identified issues facing women living with HIV that they felt require more advocacy, and considered how they would achieve change. Five issues were identified:

- combatting stigma through social media
- reproductive rights of women living with HIV, including better sex education in schools
- heterosexual people living with HIV, including access to PrEP for women
- people diagnosed before combination ARVs were introduced
- needs of people living in isolation

This session encouraged and excited a lot of participants, with some expressing an interest to keep in contact with each other to try to advocate for the issues they had identified.

## **Expressing Gratitude**

The final session ended the workshop on a note of celebration with participants given the time and space to encourage and appreciate each other. Everyone was given a piece of paper with their name on it. This was passed around the room and everyone wrote one line about what they appreciated about that person. When everyone received their own paper back, there were intense positive emotions as they read their comments, with all of the women expressing the desire to keep in touch with each other. Participants were also asked to describe how they felt at the end of the workshop, comments included:

- Hoping to take back what I’ve learned to what I’m already doing in advocacy role
- The training was solar powered energy for the HIV soul
- Felt more in control and inspired to do something about that in the future
- The best training I’ve ever been to
- It’s the first time I’ve interacted with an HIV group; I feel energised
- I’m so grateful for this and for being able to share
- I will treasure this experience
- Nothing’s changed in 30 years BUT I’m hopeful
- I want to make a difference as an advocate
- Together we can make a difference and I feel blessed to be here

The word cloud below illustrates the emotions participants described experiencing at the end of the event, with the size of words representing the frequency with which it was said.



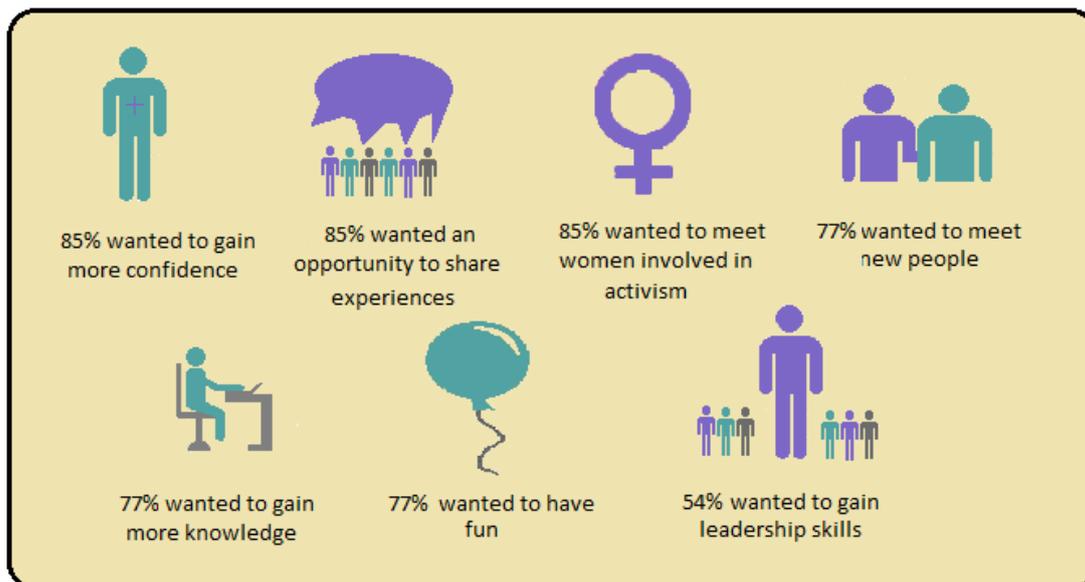
## EVALUATION METHODS

Participants were sent pre-evaluation forms prior to the workshop or asked to complete at the start of the workshop, and post-evaluation forms were completed after the workshop. This allowed participants' expectations to be captured and enabled a better understanding of whether participants felt the workshop had improved their confidence and met their objectives. All participants returned their pre-evaluation forms and 11 participants returned their post-evaluation forms. To view both evaluation forms, please see Appendix 1.

## FEEDBACK

### Expectations

Prior to the workshop, participants were asked about their expectations of the WISE UP+ 2019 workshop. The most common expectations were to gain more confidence, meet women involved in activism and to have an opportunity to share experiences, while the least common expectation was to gain leadership skills (as highlighted below). Following the workshop 82% of participants felt that their expectations had been met.



### Rating the Workshop

Following the workshop participants were asked whether they had enjoyed the workshop, what particular aspects they liked or disliked, and were also asked to rate the overall workshop. 100% of participants responded that they had enjoyed the workshop, in particular the creative expression and colour communication sessions were singled out as high points of the weekend. 100% of participants found the weekend to be either excellent or good (82% rated the workshop as excellent and 18% rated the workshop as good). It is also notable that 100% of participants expressed that they would be interested in attending or assisting with future Sophia Forum events.

### Improving Confidence

Prior to the workshop and again afterwards participants were asked to rate their confidence in a number of roles: being in a leadership role, participating in social and political activities such as campaigning or volunteering, and being an advocate in their community. Prior to the workshop 15% of participants felt very confident about being in a leadership role and after the event 55% reported feeling very confident being in a leadership role. In terms of participating in social and political activities, 46% of participants felt very confident prior to the workshop and 55% felt very confident after the workshop. Prior to the workshop 46% felt very confident being an advocate in their community and after the event 73% felt very confident. Participants were also asked to self-report whether they felt their overall confidence had been improved by the workshop with 82% reporting that they felt more confident.

## Participant Comments and Recommendations

Qualitative feedback from participants also reflected the event's impact on some participants' confidence levels:

*"The event was amazing. Very much needed for women living in isolation due to the stigma attached with HIV. The workshop gave me the confidence to live my life to its full potential. I felt inspired by meeting so many other women from different walks of life - and I learned a lot from their experiences within the sector. This workshop was literally one of the best workshops I've been to for a long time. It's given me the confidence to want to work in the sector and support other women to do so."*

*"Events like this directly improve my quality of life, in that they build confidence and give the opportunity to network. I hope there will be many more."*

There was an overall positive response, with a number expressing an interest in attending a similar event in the future and suggesting a need for more regular events.

*"Have events like this more often. Maybe four times a year. Have an email list that informs every one of campaigning events all over the UK"*

*"I would like to thank everyone who was involved in organising this Forum. I would like to see more over 50+ and long-term survivor forums in the future"*

## FINAL COMMENTS AND IMPACT

Overall the 2019 WISE UP+ workshop succeeded in meeting its aims, and provided a setting where women living with HIV could express themselves, educate each other, problem solve together, and strengthen their advocacy skills. The workshop was clearly valued by participants and may have lasting effects on their confidence and ability to be advocates in the HIV sector. This was especially apparent when the women attending the workshop expressed a desire to try to stay in contact and investigate advocating for the issues they'd identified during the weekend. It was also reflected in participants' feedback, particularly through qualitative comments describing increased confidence.

## ACKNOWLEDGEMENTS

The WISE UP+ 2019 workshop was facilitated by Bakita Kasadha and organised and supported by members of the Sophia Forum Board of Trustees. This report was prepared by Emma Louise Craig.