

A report on WISE UP+ Young Women Rising

A retreat weekend for young women 18 - 27 living with HIV



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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.

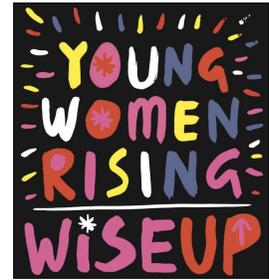
Sophia Forum ensures that women living with HIV are meaningfully involved in all its work and is led by a collective of women of diverse ethnicity, age, gender identity and sexual orientation.

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.

About WISE UP+

WISE UP+ is an ongoing workshop series 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 and 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.

Since WISE UP+ began, each weekend has explored a different topic or worked with a particular demographic. Young women rising 2020 was targeted specifically at young women aged 18 – 27.

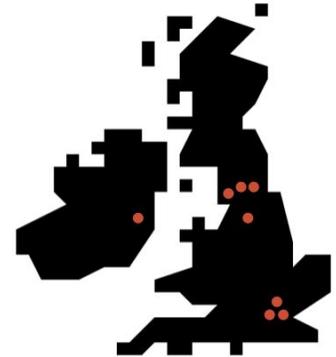
The decision to target this particular group for the 2020 WISE UP+ weekend was reached by understanding that intersectionality impacts on individuals' experiences and that young women living with HIV are a particularly marginalised group.

Aims of WISE UP+ Young Women Rising

- ⊕ To create and facilitate a community building space for young 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.

Participants

The WISE UP+ weekend was aimed at young women aged 18 - 27 living with HIV from across the UK. Eight people attended from the UK and the Republic of Ireland. There was a clear demand for the event with more than 10 formal applications received. More than 70% of applicants said they had not attended any similar events before.



Volunteers

It is important for Sophia Forum that the volunteers can relate to the experiences of the participants and that there are opportunities for participants to be involved in future events in a meaningful way. At WISE UP+ Young Women Rising, the event was led by a young woman living with HIV. There were three other facilitators living with HIV who also led workshops and supported over the weekend, one of whom had participated in earlier facilitation training provided by Sophia Forum. There was significant interest from participants in potential engagement in future events and training opportunities.



Methodology and approach

The weekend was developed by Sophia Forum Co-Chair, Mercy Shibemba, in collaboration with Project Consultant, Camilla Gordon, and structured so that each session led to the next, creating a safe space for all participants. The weekend took a participatory approach which focused on creative activities to explore challenging topics and questions. The programme was developed to be as inclusive and accessible as possible for participants with different needs, abilities and learning styles.

Accessibility

Accessibility and inclusion is a key objective for the WISE UP+ weekends. As part of WISE UP+ Young Women rising there was a participant who is profoundly deaf. In order to make sure the space was as accessible as possible for her, three British Sign Language (BSL) interpreters were engaged to support over the weekend. All games and activities were appropriately adjusted and all workshop materials were made available in advance to the interpreters. Two interpreters were on site at all times over the weekend and worked closely with facilitators to ensure the best possible engagement.



Breakdown of the weekend

The programme was structured so that each session progressively built on previous sessions, and so that a safe space was created for all participants. The topics covered ranged from identity and empowerment, to advocacy and sexual health. There were a number of themes that came up over the weekend in a range of different sessions. This part of the report will explore key workshops, their outcomes and the conversations they generated.

To welcome participants there was a pamper evening with products generously donated by LUSH. This provided a space for participants to come together to meet and connect. With a small group, this space provided time for strong bonds to be formed at the beginning of the weekend.

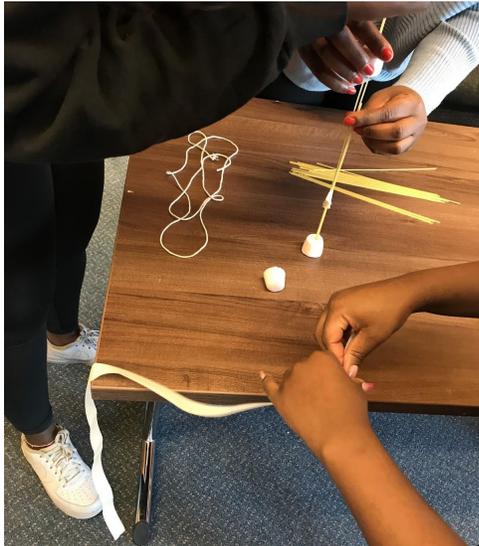


Opening

The weekend was opened with an introduction to WISE UP+ training and the Sophia Forum, discussing why it was set up and what it hoped to achieve. This prompted discussion straight away, with participants asking: **“Where are the spaces for women living with HIV?”** and **“Where’s our story being told? There is no acknowledgement that we exist.”** Almost all participants noted that this was the first time they had been in a space solely dedicated to women living with HIV and commented on the power that this space had created. One participant talked about how the people in the room knew her better than many in her ‘regular life’ because of the experiences they shared.

This led into a session exploring hopes and expectations. A set of guiding principles were developed by the group to set the ‘ground rules’ for the weekend.

Marshmallow challenge



To conclude the opening session, a final activity was a marshmallow challenge, in which participants had to build a tower out of spaghetti that would support the weight of a marshmallow.

At the end there was a facilitated discussion about how this challenge might relate to everyday life. The discussion focused around how, at the beginning of the challenge, the marshmallow seems light and fluffy but by the end its weight is obvious and that it is challenging to balance it on the spaghetti.

When this was explored further one participant said:

“The marshmallow is me, the spaghetti is all the people around me. As soon as you rely on someone it

breaks.” Another commented: **“The marshmallow is the life people see me leading and it looks easy from the outside. But they don’t see all the support networks that have got me to where I am. It’s what builds you up but it can also be knocked over so easily. When one part or piece of spaghetti breaks it all falls over.”**

Who am I? Who are you? Who are we?

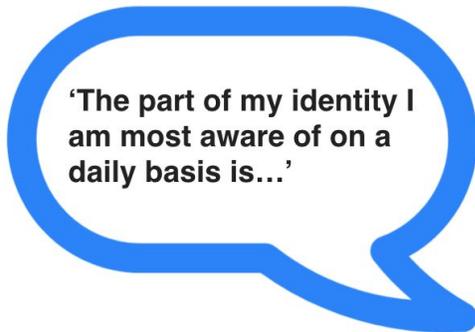
The next session looked at identity, exploring the different parts that make up who a person is. It looked at what part of people's identity they relate to at different times in their life and what that meant for the group as a whole. A number of themes came up throughout the session and participants noted the reality that everyone's situation is individual but also connected, leading to a discussion on intersectionality. A significant and consistent theme was the impact of family and cultural pressures on the participants' everyday life.

One activity asked participants to answer incomplete statements by standing next to one of the following words or phrases

- National origin
- Immigration status

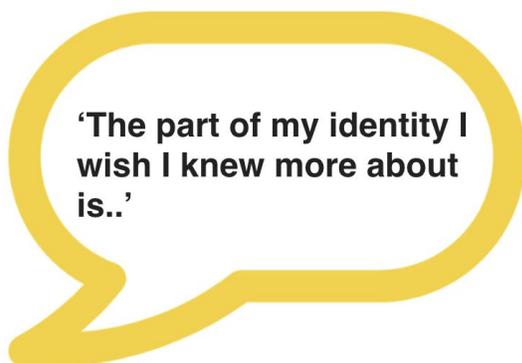
- HIV Status
- Physical attributes
- Race
- Class
- Age
- Gender
- Sex
- Something else

Presented below are three of the statements with the number of participants who selected each answer.



5 participants selected **physical attributes**; 2 selected **race**; 1 selected **national origin**.

There was a consensus that the pressure of how to look was affecting their daily lives, with particular pressure coming from family members. **“Other women in my family - aunties and that - they might say ‘oh you are putting weight on’ I think it’s a projection of what they think about themselves.”** When discussing why they had picked “race” participants said: **“I am one of 3 black people in my office”** and **“When I was working at the hospital I was the only black woman.”** There was recognition of the different experiences of participants from different parts of the UK and Ireland, with many coming from areas with a lower proportion of BAME representation, and how this affected individuals’ experiences of their identity.



2 selected **national origin**; 1 selected **HIV status**; 4 selected **something else**; 1 selected **gender**.

The conversation around this statement focused largely on national heritage and the loss of identity that came from feeling disconnected from a part of this heritage. One participant said: **“I feel like I’ve become very British. I don’t even know about my Malawian heritage.”** This was echoed by other participants expressing the challenges of being part of multiple cultures at the same time and the loss of cultural heritage such as language and food. One participant picked HIV status and discussed the challenges of owning her own story. Commenting that **“When you are born with HIV you are not just disclosing for you, you are disclosing for your parents too”**.

‘The part of my identity I feel is difficult to discuss with others who identify differently is..’

All 8 participants picked **HIV status** in answer to this statement. There were a range of reasons for this with many relating to experiences of sharing their status with partners and friends. There was a focus around the burden of educating someone and whose responsibility that was. There were stories shared of negative experiences and having to reassure people who don’t always know how to respond but also those who respond negatively. One participant said:

“There is stigma around being racist but not if someone says something about HIV.”



NAT - My HIV and the community

Led by NAT, this session focused on what rights people living with HIV have, how to recognise discrimination and what to do about it in the workplace, using case studies to understand the different types of discrimination and what the implications might be.

Many of the participants could clearly identify examples of when they had been discriminated against and could relate to the situations outlined in the case studies. One participant asked what to do if they saw someone else being discriminated against and another asked if there was a time limitation on making a claim.

Participants said: **“I found it very informative. I learnt about different forms of discrimination against PLWH”** and **“I liked the lesson on the Equality act (2010) that everyone, including PLWH should be treated with fairness.”**

More than 70% percent of participants said they found the session very useful, with feedback suggesting the session could have been made more interactive using role play to help understand how to deal better with situations.

An example of one of the case studies:

Sara is studying medicine at university and moves into halls of residence. As she is anxious being away from home for the first time she shares her HIV status with a mentor. Her mentor says he will need to make both the residence manager and the medical school aware of her HIV status as it poses a risk to other students.

HIV Empowering Me

This session, led by Mercy, explored advocacy through a lens of empowerment. The session started by exploring empowerment, looking at when participants felt empowered or disempowered. Through the conversation the idea of what empowerment is and how we can define it was explored.

When did you feel most empowered?

- Going to the doctor on my own
- Coming out as HIV, standing up for myself when family disagree
- When I changed my attitude, tone and way I shared my HIV
- Getting a job after so many rejections
- Becoming a mother, giving life to someone
- Being told I would make a great PLWH nurse
- Graduation because I worked so hard
- I felt empowered watching 'How to get away with murder' watching Viola Davis and Kerry Washington fight for justice. Strong, black, educated and powerful women



The group then went onto to create a fictional character who they used to explore situations that felt empowering and disempowering. This character was representative of the group as a whole but not too close to any one participant, giving them space to explore the challenges she might face.



Empowering situations Lyla might find herself in...

- Good relationships
- Going out with friends and feeling connected
- When she has been taking her medicines every day without a reminder and has reached an undetectable viral load
- Empowerment and having self growth
- Attending an HIV+ workshop and meeting other women
- Getting a husband through Hinge (dating app)

Disempowering situations Lyla might find herself in...

- Being rejected because of HIV status
- Financial stress
- Feeling stuck
- Sharing her experiences with her friend and not feel supported
- No peer support
- Isolation
- Bad friendship
- Hospital appointment with unempathetic professionals
- Having a bad relationship because of opening up about her status
- Change in meds.



While these situations were in relation to a fictional character, they were also representative of the experiences of the participants. As the scenarios were shared participants frequently remarked that they could relate to scenarios and shared similar stories with the group.

A question that came up through the weekend was around how to be an advocate? Many of the participants wanted to be advocates but were concerned this meant they had to be living openly. This led to a discussion around the role of advocates and opportunities to advocate in a range of different ways. In particular the idea of self-advocacy was discussed, exploring the idea that being an advocate for themselves was just as important as being any other kind of advocate. Working to challenge 'negative self-talk' and to combat the self-stigma they experience.

Examples of this kind of self-talk became apparent over the weekend with participants saying things such as: **"Sometimes I feel undeserving of a good life"** and in relation to living with HIV and relationships: **"It makes me doubt things. Doubt things will be good for long."** These comments were closely related to the ideas raised in the discussion around empowerment: how

empowering situations moved people more towards being confident to be self-advocates while disempowering situations moved them further away.



Sexual reproductive health & relationships

The sexual health and contraception workshop was led by Kim Leverett, an advanced nurse practitioner and Sophie Strachan, a sexual health advisor, and co-chair of the Sophia Forum. The first part of the session looked directly at different types of contraception, how they work and potential side effects. A range of different contraceptives were discussed, including different types of “The Pill,” long-acting reversible contraceptives and male/female condoms.



There was a consensus that conversations around sexual health had been mainly focused on the importance of not passing on HIV, rather than on what was right for them and their bodies. This meant condoms had been promoted above and beyond other forms of contraception. A number of participants also commented that they hadn't had a formal introduction to sexual health care until they transitioned into adult care, with five participants giving ages over 16 for their first in depth conversation around sexual health care and contraception.

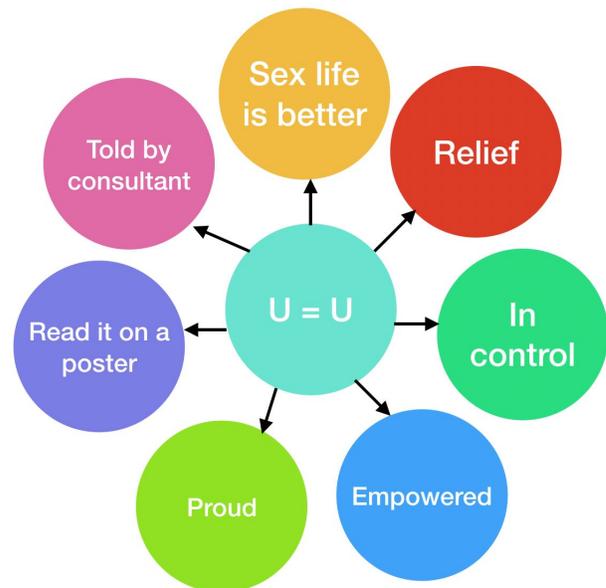
When discussing relationships, the pressure of telling a potential partner about your status was discussed, with a difference of opinion about when to tell a partner. One participant remarked: **“If you know what you want it's easier, but if you're not sure then it can be more difficult and uncomfortable to discuss what you want out of your sex life.”** This led to a discussion around the challenges of casual dating and relationships. Another participant said: **“You feel like you have to be in a relationship and casual sex isn't really an option.”** Overall the feeling was that the burden of responsibility to educate a potential partner fell to them, which made the prospect of telling a partner so much more overwhelming.

“That's why I don't bother telling people as they're never going to go out and find the right information about it and I have to do the legwork.”

U = U

All participants agreed that sex life is better after U = U but most also recognised that the most important part of U = U is keeping themselves healthy. Only two participants had found out about U=U from their consultants, with one participant only having found out about it the week before. One participant noted even understanding U=U, she still feels paranoid and uses condoms just in case.

“I choose to share so that people can understand me more and know me more and are able to see that part of me.”



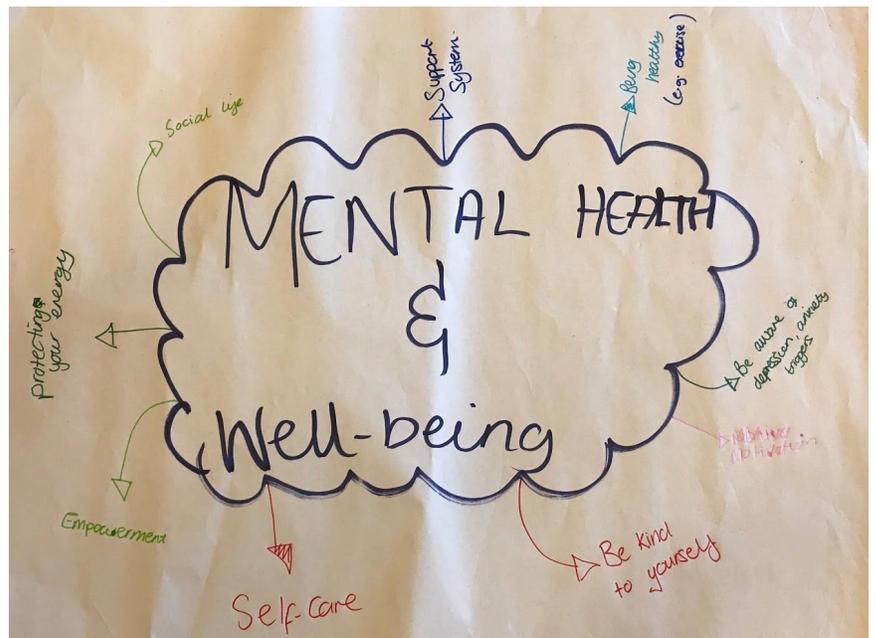
Mental Health

The mental health session was run by a participant who had taken part in a previous WISE UP+ weekend and who specialises in mental health and wellbeing. Topics explored included what mental health meant to participants and there was a particular focus around sharing stories and how participants can look after themselves through the process of sharing their status.



Some of the key questions asked were...

- “How do you respond when people ask you how you got it?”
- “How did you find separating your story from someone else’s?”
- “Do you find that you make a bigger deal of it than people do when you tell them?”



Another participant went onto remark **“When you share your story, it becomes theirs too as you are letting them come on the journey with you.”**

As the group explored what mental health meant to them, they recognised that it encompassed both physical and mental wellbeing and that medication is part of their wellbeing.

They then discussed the importance of resilience, and that **“Self stigma is a thing, you need to be resilient”**. This then led to another participant noting that **“It’s about trial and error with us”** in relation to the fact that there isn’t a generation that has lived with HIV all their lives before and so the impacts are still largely unknown, and how this might impact their mental health and wellbeing in the future.

“It’s a muscle, everyone has a muscle and you either work on it or you don’t”

As a final activity in this session participants were each given a jar to fill with affirmations and positive thoughts for each other. When they are struggling or feeling low they can open up their jars and be supported by this community.

Closing

To close the weekend there was a focus on reflecting back but also in looking forward. Participants had the opportunity to write themselves a letter to be sent to them in six months time - exploring where they are now and reminding themselves of what they want to be feeling when they open their letters.

Skills development

Skills development is a core aim for WISE UP+ and an important part of developing the advocacy element of the weekend. Communication and confidence were the two skills most commonly referred to in the feedback. 86% of respondents noted an improvement in skills relating to planning advocacy activities. 86% also recorded an improvement in feelings of empowerment with 57% recording an improvement in self-confidence.

Feedback and evaluation

To evaluate the weekend two questionnaires were developed, one to be completed before the weekend and one to be completed at the end of the weekend. Through the workshops and sessions questions were also asked to gather dynamic feedback over the course of the weekend with responses to activities and discussions also forming the basis for this report. There were eight participants at the WISE UP+ weekend, providing a small data set.

The overwhelming response to the weekend was positive with 100% of respondents reporting that WISE UP+ had met their aims and expectations.

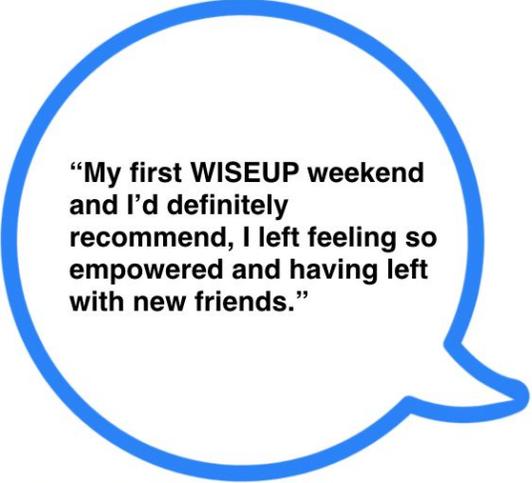
The alleviation of isolation is a key aim for WISE UP+, and building community and new friendships is crucial in achieving this aim. 88% of the participants listed new friendships and community as something they hoped to gain from the weekend. Not only were friendships made over the weekend but 100% of respondents reported an increase in confidence in forming relationships at the end of the weekend.

Another key aim for WISE UP+ is to provide a safe space for women to come together, share experiences and grow together. 100% of respondents said they felt safe and supported over the weekend with one saying **“The space we were able to have was so comfortable and inclusive”**.

A challenge faced by WISE UP+ was in relation to recruitment. Over the course of the weekend a number of participants mentioned friends they felt would benefit from a WISE UP+ weekend. Some said that the information hadn't been shared widely enough within the networks they were already a part of. 100% of participants said they would recommend WISE UP+ to a friend. When asked how would they describe WISE UP+ they said



“An amazing open and safe environment to meet people with similar experience to you where you can talk freely and bond but also learn and understand new things. A very freeing experience.”



“My first WISEUP weekend and I'd definitely recommend, I left feeling so empowered and having left with new friends.”



“A weekend with an amazing girl gang and unpacking what it is to be a young woman living with HIV in a safe space.”

Areas for Improvement

When asked for feedback on the weekend as a whole, the areas mentioned for improvement were around key workshop areas, such as workshops on personal finances and pensions, and including more practical sessions such as yoga, dance or drama or even a long walk to get out into nature. One participant noted as the only deaf participant, it would have been good to have met another deaf person living with HIV at the event. Participants also asked when the next event would be and many were interested in leading sessions at future events.

Final thoughts

Overall the weekend was deemed a huge success with the participants giving excellent feedback on both the programme and the weekend as a whole. This was the first Young Women Rising event but there was a commitment made to deliver more WISE UP+ weekends for this age group and potentially for combined events with other WISE UP+ groups. Many thanks to the volunteers for giving their time to make this event possible and to Mercy Shibemba for leading the weekend.

