

WISE UP+

WORKSHOP REPORT EXECUTIVE SUMMARY

About Sophia Forum

Sophia promotes and advocates for the rights, health, welfare and dignity of women living with HIV through research, raising awareness and influencing policy. We do this through: developing and delivering our advocacy programme; bringing together information and research on the issues affecting women living with HIV; creating partnerships with organisations and individuals delivering services; building relationships with policy makers; we make sure that women living with HIV are meaningfully involved in all our work.

About WISE UP+

Following the huge success of the first Women Inspire Support and Empower to Unleash Positive Potential (WISE UP+) workshop in June 2014 the Sophia Forum managed to secure further funding from the Awards for All of the Big Lottery Fund and run a second workshop, for a new group of advocates, in October 2015.

The WISE UP+ workshops aim to provide advocacy skills to women living with HIV, as well as an opportunity to meet and collectively analyse their current situation and take the first steps toward developing an advocacy strategy.

The organisation and delivery of the workshops to-date was undertaken in collaboration with Positively UK, a peer lead organisation that provides support and advocacy to people living with HIV in the UK.

About WISE UP+ 2015

The workshop took place in Manchester over 3 days and was attended by 24 women from different parts of England. Women were

Why focus on women living with HIV

In the UK women are substantially affected by HIV. They represent the second largest group of people living with HIV after men who have sex with men (MSM). Sadly, in 2016, women's experience of living with HIV is still exacerbated by gender inequality, high prevalence of gender-based violence, poverty, and a paucity of women-specific research. In recent years funding for women-only services has shrunk enormously, leaving women living with HIV not only lacking in support, but also often invisible and unheard in decision-making processes. The voices and advocacy of women living with HIV in the UK are still weak and community representation in decision-making bodies is largely dominated by men. Further, the few women who are active and open about their status tend to be older.

selected based on their commitment to advocacy and desire to be an activist as well as where they lived in the UK, to ensure geographic representation. The group was diverse, with 18 black African women, 3 black women from the Caribbean, 1 Russian and 1 European (both white). The age ranged from 27 to 58. Time living with HIV ranged from three and a half years to 24 years.

The weekend was facilitated by Silvia Petretti, Positively UK Deputy CEO, Sophie Strachan, Sophia Forum Trustee and Laura Kwardem, former Sophia Forum Trustee and participant of the first WISE UP+ in 2014. The facilitators were all women living with HIV. External speakers were also invited to facilitate specific sessions.

2015 WISE UP+ workshop

This second WISE UP+ workshop highlighted once again the importance of women only spaces for women with HIV to reflect on their lives and develop confidence and skills to move into activism.

The discussions over the three days showed how perceived stigma prevents people living openly with HIV, they fear family members, friends, employers and employees will respond negatively. This, combined with poverty, isolation, issues with unresolved immigration cases, and lack of skills, still create huge obstacles for women's full participation in advocacy. However, throughout the workshop the women explored the myriad ways they drew strength to effect change in their lives and how this could be drawn on to catalyze wider transformations.

Participants' expectations of the workshop are shown in the word cloud below.

Examples of sessions:

✦ **Personal experiences of affecting change**

Participants gave examples of when they confronted an issue in order to effect change, personal or institutional, in the home or the workplace. They also reflected on the impact on themselves. Responses included: disclosure to partners / family members; starting community based organisations and community gardens; advocating for somebody who did not speak English; challenging noisy neighbours; dating after an HIV diagnosis; joining an HIV support group to overcome isolation and challenging family members. Facilitators reflected that all



those actions are forms of activism. 'We all have experiences of trying to achieve change.'

✦ **Dr Margaret Kingston facilitated a session on living with HIV in the UK.**

Participants had the opportunity to ask questions about their health which continue to go answered. For example, 'is it legal for me to have sex?' Kingston explained that there is no law in the UK that criminalises sex for people living with HIV, however intentional transmission of HIV is a crime. A discussion about criminalisation of HIV transmission, including proving or disproving intent to transmit, followed. Participants also discussed issues such as disclosing their HIV status, staying healthy and clinical trials for treatment.

✦ **Human rights**

The session on human rights explored not only what rights women living with HIV have but also what women need in order for rights to grow. Suggestions included shelter and employment, understanding legislation like the Equality Act and housing Act, policies, confidence, funding and networking, legal representation, unity among people who want to know their rights and knowing how to work with religious and faith leaders.

✦ **Power, Control and Women's Resistance with Imkaan**

The session helped women to identify forms of violence beyond physical violence. Following the workshop 22 women out of 24 reported having experienced violence in their lives. Participants explored their experience of being privileged and oppressed. 'Understanding in what way we experience oppression and disadvantage can be important as we advocate for positive changes and challenge oppressive powers and structures.' Participants also shared ideas of how oppression could be challenged.

✦ **The Personal is Political**

The rivers of our lives, how our experiences dealing with HIV can help us to be advocates - Women drew a 'river of life' illustrating their journey with HIV, including where they got strength and inspiration. Self-acceptance, role models and confidence through accessing information and peer support were 3 of the learnings from living with HIV that had helped the women become advocates.

✦ **Introduction to advocacy**

The women agreed that the central theme of advocacy is achieving Change. Amongst other aspects of advocacy participants discussed how they could influence change through NHS participation structures, for example, hospital /HIV clinics patient forums and local Health Watches. They came up with a set of

advocacy goals which are very similar to the 2014 workshop, confirming that those are the most crucial areas for women living with HIV. It was agreed that gender based violence and mental health should be addressed throughout all of the goals.

Advocacy goals

1. Ensure every woman living with HIV has access to peer support.
2. Increase the number of women living with HIV in clinical trials.
3. Educate faith communities on the issues women living with HIV face to tackle stigma and discrimination, and address churches that stop people from taking HIV medications.
4. Women with HIV to lead in educating the public to stop stigma and discrimination with a special focus on health care practitioners.
5. Increase the number of women living with HIV in decision making structures.

✦ Activism and direct action with Faith Taylor Act Up London

Participants were asked whether they would participate in a number of different direct action activities, for example, 'would you join a march in the street against cuts to domestic violence services?' Concerns regarding engaging in direct action included: visa status, impact on profession and fear of unintended disclosure. The women discussed what support they would need to get involved in different forms of direct action, such as education, legal and emotional support, information, knowing our rights, accountability and financial security.

✦ Poetry and Advocacy session – with Dorothea Smart

Dorothea encouraged participants to realise their own ability to create poetry. The women asked each other 'poetic' questions to which they replied with the first thing that came to their mind. Poems by Selina Nwulu and Kim Moore inspired the women to write their own poems. A book of their poems

From Poetry and Advocacy session:

Before the sound of my laugh began to decay
After the HIV diagnosis the life I had, had to be forgotten
After the grieving sensation became too much to bear
After the beautiful rose petals fall in the ground
After the dreams I had were scattered
After reaching rock bottom
After deciding to reclaim my identity
After all the old dreams could not be turned into reality
After looking back
After reaching there were some blessings in all of hell

will shortly be available from the Sophia Forum.

✦ **Sex and Intimacy for women living with HIV – with Rebecca Mbewe**

The aims of the session were to speak openly in a safe space, explore barriers, enhance knowledge, equip women with confidence and have fun. Women discussed barriers to discussing sex as well as what helped them overcome barriers e.g. learning to pleasure yourself first and to be comfortable with yourself. The session was closed with a discussion regarding what gave them pleasure.

✦ **Finally - The women planned ways to stay in touch with each other and Sophia, to keep informed and to stay active.**



What did the WISE UP+ participants think of the workshop?

The evaluation of the workshop was overwhelmingly positive. Participants were asked to evaluate each session individually (scoring from poor, satisfactory, good and excellent). Ninety-nine per cent of all the ratings for the sessions were either good or excellent (67% Excellent 37% Good 1% Satisfactory).

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Qualitative feedback illustrated the powerful impact of the three days for workshop participants:

“The information delivered was very powerful and I am going back home a different woman, full of empowerment and eager to speak out for myself and others to represent other women.”

“It has really changed my life and understanding of many issues. I have just taken up a post as a service user rep and coming here has empowered me so much of knowledge and information. My goal is to take what I have learned to empower other women. Truly I have been changed and transformed.”

“[I] feel more confident but still need more support to get into action or be productive after this workshop.”

“I feel better and know I am not on my own anymore. I have confidence that together we can make ourselves heard, and can trigger changes which we need.”

Fund WISE UP+ to reach more women living with HIV and further build the skills and network of our alumni.

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