

ADVOCACY
TRAINING FOR
WOMEN LIVING
WITH HIV

WOMEN INSPIRE SUPPORT AND EMPOWER TO UNLEASH POSITIVE POTENTIAL

WISPE



EXECUTIVE SUMMARY

MANCHESTER, UK // 20- 22 JUNE 2014

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Sophia Forum is a UK network of women and organisations, and part of the UNAIDS-coordinated Global Coalition on Women and AIDS. Sophia Forum's core objectives are the protection and promotion of the good health of women, particularly women who are living with HIV or who are at risk of sexually transmitted diseases including 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 2014, 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 extremely weak. The few women who are active and open about their status tend to be older, and community representation in decision-making bodies is still largely dominated by men.

Within this context, the Sophia Forum decided that a key strategic intervention would be 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. Sophia Forum was successful in securing funding from the Awards for All programme of the Big Lottery Fund for WISE UP+ (Women Inspire Support and Empower: Unleashing Positive Potential). The organisation and delivery of the workshop was undertaken in collaboration with Positively UK.

The WISE UP+ workshop was delivered over three days in Manchester and with 24 participants, ranging between 20 to 64 years. 20 women identified themselves as black and minority ethnic (83%) and seven as white. Six women came from Liverpool, seven from Leicester, 10 from other parts of England and one woman from Wales. Their time of diagnosis ranged from three months to over 20 years.

The workshop was facilitated by Silvia Petretti, Positively UK Deputy CEO, and Alice Welbourn, Sophia Forum Co-Chair. It included sessions on:

- Understanding human rights
- Understanding the role of the meaningful involvement of women living with HIV
- Understanding gender-based violence and how HIV, gender, race and class affect women with HIV
- Reflecting on our stories and how our experiences of dealing with HIV can help us to be advocates
- Introduction to advocacy
- Understanding NHS structures for participation
- Identifying our advocacy goals and taking first steps in our advocacy strategy
- Poetry and activism
- Sex and pleasure for women living with HIV
- Yoga

UNDERSTANDING THE LIVES OF WOMEN LIVING WITH HIV IN THE UK

- › Women living with HIV face complex issues
- › Women may face barriers to accessing or maintaining HIV treatment
- › Women-centred research is lacking
- › Women living with HIV in leadership roles are rare



WISE +UP

"I have learnt to air my views without feeling embarrassed. To be an activist with pride."

The feedback evaluation showed that over 95% of participants found the sessions good or excellent (70% excellent, 25% good, 5% satisfactory). By the end of the workshop, most of the women expressed that they wanted to be activists and advocates in their communities to improve the quality of life of all women living with HIV and overcome stigma. However, they pointed out that they need ongoing support and opportunities to meet, to ensure they can continue advocating in their communities.

The workshop shed more light on the issue of gender-based violence and HIV, which has been under-researched in the UK. 19 out of 24 (79%) participants had experienced gender-based violence. It was clear that violence was extremely painful and difficult to address. More support and training will be needed to develop an advocacy strategy in this crucial area.

The workshop highlighted that many women are experiencing issues with their antiretrovirals (ARVs) but communication with their doctors was sometimes very difficult. Moreover, understanding of HIV in healthcare settings, outside of HIV services, was poor. One of the most shocking stories was of a woman who was not provided with ARVs for eight days while sectioned in a mental health unit. As a consequence she developed resistance to her medication, with a significant negative impact on her treatment options.

"My coming to this workshop was one of the best decisions I have made. I have really enjoyed every session, it was a totally new experience and I learnt a lot. This is by listening to others who have been through a lot and have had a lot of experience with living with HIV. My insight living with HIV has been enlightened and I have clarified a lot on gender-based violence."

IN PARTICIPANTS' WORDS

"The NHS has all these structures but it's not easy for them to involve/integrate everyone"

"It's been a wonderful two days of my life."

"I do feel different after coming to WISE UP+. I now know how to deal with the problems we get. Am more aware of my rights. The workshop has been very educative and empowering. My confidence has been boosted up."

"I will try as much as possible to make a change in my local community and if I need a more empowered advocate, I know where to go for advice."

"I now feel confident to become an active advocate. I have all the 'pointers' and tools to help me."

"Helps us to meet other women and share experiences which gives you confidence to live with HIV."

ADVOCACY AGENDA

At the end of the workshop, women identified four 'advocacy asks' to improve the lives of women living with HIV in the UK:

- Increasing healthcare workers' understanding of issues facing women living with HIV, in order to improve quality of care
- Increasing involvement of women living with HIV within NHS participation structures
- Promoting a holistic and integrated approach to the health of women with HIV
- Ensuring the media portray women living with HIV in a more positive light

KEY RECOMMENDATIONS

- Women living with HIV need ongoing support and opportunities to meet, to ensure they can continue advocating in their communities.
- More work needs to be done so that women develop the strength and confidence to develop an advocacy agenda around gender-based violence and HIV
- In order for the 'advocacy asks' to be heard they need broader support from non-governmental organisations in the HIV sector as well as from other activists within broader social justice movements.

♀ WISE + UP

"The lesson really opened my mind in a way I never expected. Really awakened the dead brain cells and certainly stimulated my passion for writing in general."

"This course is very important. It's also vital to get the views of people from different backgrounds and cultures with common issues."

"I hope we are going to break through all the barriers which affect women living with HIV."

"Quite intense, but extremely involving. I like the fact that everyone participated and I've certainly come out with better knowledge in this topic."

"Found it very educative and will pass on the information to other women in my job as a Mentor Mother."

"Stand up for ourselves and be heard. To have our voices heard and express our views and rights in most areas."

"We need to wise up so that we know our rights and it is empowering and educating women to deal with life's challenges."

"Listening to others made me realise that there are worse stories than mine. Made me look at my situation from a different point of view."

"I have learnt about my freedom of choice and my human rights, which I never thought of."

"Now I have the knowledge of how to advocate on behalf of other people."

"Inspirational and enlightening"