



WISE UP

HIV AND
BONE HEALTH
FOR WOMEN
LIVING WITH HIV

Workshop report
March 16–17, 2024

About Sophia Forum

Sophia Forum exists to advance the rights of all women living with and at risk of HIV and we challenge unequal access to services and opportunities based on gender. We do this through our peer led advocacy, research and policy work.

We are a peer-led charity with a clear vision of empowering all women living with HIV and at risk of acquiring HIV to reach their full potential, and ensure their voices are heard and their needs prioritised within the health sector and wider society.

We make sure that women living with HIV are meaningfully involved in all our work.

About the WISE-UP+ programme

WISE-UP+ stands for Women Inspire Support and Empower to Unleash Positive Potential. It 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.

Programme objectives:

- 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* women living with HIV – 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.

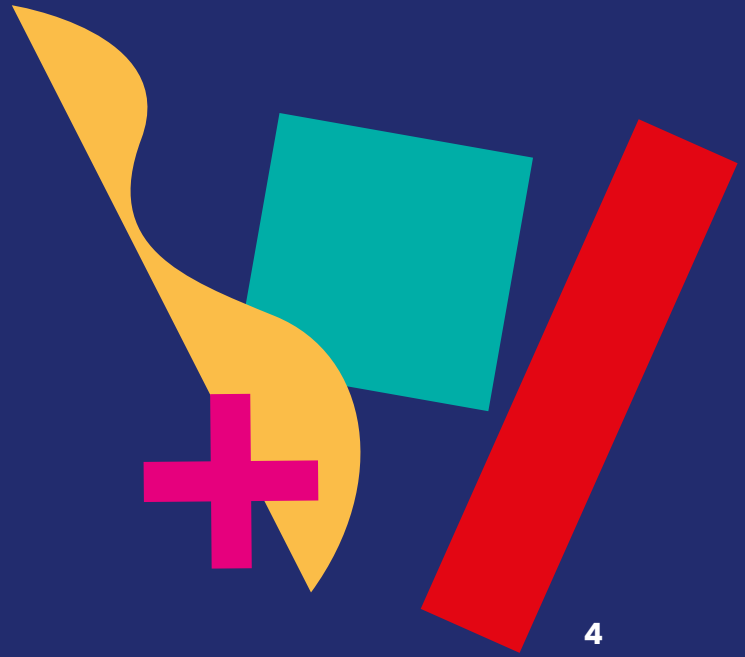
Acknowledgements

Sophia Forum would like to say a massive thank you to all the WISE-UP participants who attended the weekend and shared their experiences. To all our facilitators for giving their time and expertise; Emma Bell, Darren Brown, Fiona Hale, Bakita Kasadha, Dr Nneka Nwokolo, Sophie Strachan, Dr Jacqui Stevenson, and Wezi Thamm.

Thank you also to: Riverhouse Trust for hosting us (www.riverhouseuk.org), Ketchurah Ravindren for food, Paul Chettle for filming and Jane Shepherd for design work.

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WISE-UP+
HIV AND BONE HEALTH
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WORKSHOP REPORT



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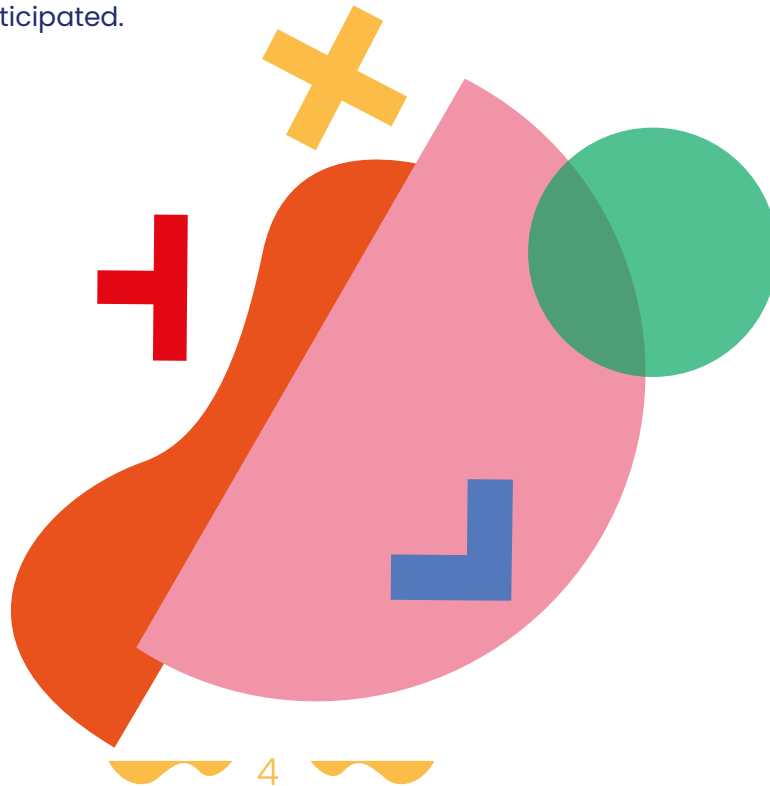
1. INTRODUCTION

The 2024 WISE-UP+ workshop on HIV and bone health was designed and led by women living with HIV and allies with the following aims:

- to improve knowledge about bone health for women ageing with HIV;
- to develop a booklet by and for women living with HIV on bone health and ageing with HIV;
- to improve understanding of the history of HIV-related women's activism;
- to build an advocacy agenda for improving the rights and health of women living with HIV.

The workshop was held at the wonderful River House in Hammersmith over the weekend of March 16–17.

Seventeen women participated.



2. OUR GIFTS, OURSELVES

Facilitator: Sophie Strachan

Activity part 1: Head, heart, hands – understanding our gifts

After introducing the workshop, Sophie took the participants through this simple exercise to help them identify their own gifts and what they have to contribute and to connect with other people with shared interests, and to find out what gifts other participants have to contribute.

The exercise encouraged us to think about gifts in these three categories:

- **Gifts of the head:** knowledge or information we have; things that we know about and would enjoy talking about, or teaching others about, e.g. health, services, community support.
- **Gifts of the hands:** practical skills; things that we know how to do and enjoy doing, e.g. massage, art, dressmaking.
- **Gifts of the heart:** passions or skills; things we care deeply about, e.g. supporting our peers, listening, laughing.

Reflections from Sophie

Some of us found it challenging, but it shows why we need these spaces – to be kind to ourselves. Spaces where we can reflect and really think about what we do as women in the world, what we go out and do every day and face every day, and the resilience and courage we have as women (and the brilliance). We can put ourselves down and don't give ourselves enough recognition. We need to celebrate ourselves more and acknowledge what we've come through, what we live through on a daily basis, what we share with the world and what we might be going through right now.



Comments from the activity's post-it-notes included:

Head



- Life goes on.
- HIV does not stop us.
- Listening, advocating, helping, teaching.
- Always try to do better, never give up, support those who feel they don't have a voice.
- Supporting a friend through grieving.
- Helping those in my community – giving hugs and receiving them back.
- When I was diagnosed doctors said I would die soon but I didn't, I am still living.
- Manager of a charity, showing resilience, sharing how to live with joy.
- I was in a wheelchair for 2.5 years and told I wouldn't walk again. Through determination and will power I walk again.
- Sewing and cooking.
- Young at heart.
- Mentor Mother.
- Part of a team.
- Comforting, hugging, prayer.

Hands



- Yoga.
- Giving massages, including foot massage.
- I like to hug, touch, calm, reassure.
- I write small poems for myself.
- Cooking for myself and others.
- Cooking, cleaning, driving, eating.
- Cooking, writing stories, donating money.
- Good at listening and giving advice.
- Cooking, dusting, ironing.
- Stroking my grandson to sleep.
- Giving big warm cuddles
- Inputting data.
- Demonstrating writing.

Heart

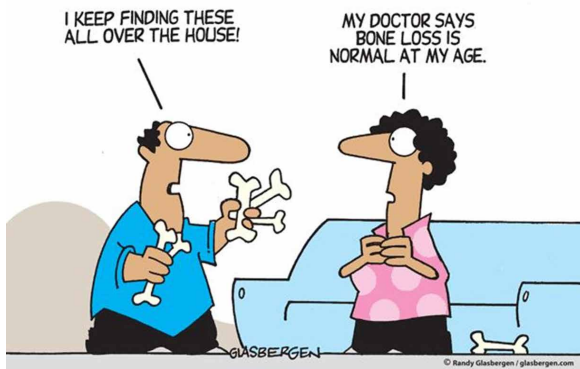


- Being non-judgemental.
- Sensitive.
- Emotional.
- Smoking weed.
- Giving, loving, supporting.
- My children are my heart.
- I love watching the sea.
- Watching movies, dancing.
- Nature, walking in nature, tree hugging.
- I'm proud of me, nursing is my passion.
- I love football – Arsenal is my passion.
- I love my grandkids, my daughters.
- Travel, seeing other countries alone and with others.
- Facilitating peer support to help others.
- Listening, laughing, spending time with others in need.

3. UNDERSTANDING BONE HEALTH

Facilitator: Dr Nneka Nwokolo

Nneka is a consultant at Chelsea and Westminster NHS Foundation Trust. She runs a general HIV clinic and an HIV and menopause clinic, and works part time for ViiV Healthcare. Nneka provided information about bone health and ageing with HIV and participants were welcome to ask questions throughout. A separate booklet based on participants' questions and the information she provided is available.



Comments from participants' feedback on the session included:

- I liked engaging, asking questions and learning from others' experiences, being able to ask menopause/HIV consultation questions.
- The in-depth description of the make-up of our bones and how that decreases over time and what causes this like menopause.
- The session was full of content and enjoyable.

- What an informative session!
- The facilitator was laid back and interactive.
- I learned the different stages of menopause and how it affects the bones, how to reduce the risk of bone decline and the benefits of exercise to increase bone and muscle.
- She answered all questions diligently and honestly – really communicated with us.
- I learned how to talk to my GP about my bones and osteoarthritis.
- I loved information about eating well and expectations of menopause at a certain age and how to request a menopause checkup.

Useful resources

- Guide to menopause for women living with HIV: <https://sophiaforum.net/guide-to-menopause-for-women-living-with-hiv/>
- www.menopausematters.co.uk
- British Menopause Society factsheets: www.womens-health-concern.org
- Premature ovarian insufficiency (POI): Daisy Network, a charity for women with POI, www.daisynetwork.org. Guideline of the ESHRE on the management of women with POI: www.eshre.eu/Guidelines-and-Legal/Guidelines/Management-of-premature-ovarian-insufficiency.aspx
- Gender Inclusion Network: www.genderinclusionnetwork.co.uk/menopause
- www.menopausecafe.net
- Royal Osteoporosis Society: <https://theros.org.uk/information-and-support/support-for-you/fact-sheets-and-booklets/>

4. FEMINIST/WOMEN'S ACTIVISM, GENDER INEQUALITY AND HIV

Facilitators: Fiona Hale and Emma Bell

There has been a long history of loud and quiet activism by women living with HIV over the years, in public and in private. By feminist activism we mean social movements and campaigns for change led by women, girls and transgender people, to claim their rights. Activism is also about building community, and making life better for ourselves and others.

Some of the participants had been involved in this kind of activism over the years. Lots of women do not want to be public about their HIV status. Activism isn't always loud, or public – it can be quiet, for example, like helping a friend.

The facilitators discussed a suggested timeline of women's HIV activism in the UK, for example; 1987 Positively Women was founded, followed by International Community of Women Living with HIV (ICW) in 1992, and the GIPA (greater involvement of people living with HIV) principle in 2004. Participants suggested adding CHIVA, an advocacy and support organisation for young people.

Sophia Forum was co-founded in 2004 by Alice Welbourn as a UK chapter of the UNAIDS developed Global Coalition on Women and AIDS (GCWA). When GCWA was dissolved Sophia Forum's work continued with its strong peer-led policy, advocacy and research focus and is pivotal in bringing a feminist lens to the UK HIV response.

Sophie reminded us that Angelina Namiba was a key member of the 'From Pregnancy to Baby



and Beyond' team at Positively Women. She left in 2016 and co-founded 4M (a project within Salamander Trust until it gained independence as a CIC in 2019).

Participants discussed issues that have been raised in the context of the HIV response.



Other topics mentioned included: research and collaboration, research on breastfeeding, U=U ('we are still struggling with this'), specific gendered programmes like Women with HIV GRowing Older Wiser and Stronger (GROWS) that delivers peer support to women ageing with HIV.

Spotlight on ICW

In 1992, ICW (International Community of Women Living with HIV) was launched in response to the lack of attention given to women living with HIV. In the same year they published 12 statements that were prescient and far-reaching in content.

ICW 12 statements*

To improve the situation of women living with HIV and AIDS throughout the world:

1. WE NEED encouragement and support for the development of self-help groups and networks.
2. WE NEED the media to portray us realistically and not stigmatise us.
3. WE NEED accessible and affordable health care (conventional and complementary) and research into how the virus affects women.
4. WE NEED funding for services to lessen our isolation and meet our needs. All funds directed to us need to be supervised to make sure we get it.
5. WE NEED the right to be respected and supported in our choices about reproduction. This includes the right to have children and the right not to have children.
6. WE NEED recognition of the right of our children and orphans to be cared for and of the importance of our role as parents.
7. WE NEED education and training of health care providers and the community at large about women's risk and our needs. Up-to-date, accurate information concerning all issues about women living with HIV/AIDS should be easily and freely available.
8. WE NEED recognition of the fundamental human rights of all women living with HIV/AIDS, particularly women in prisons, drug users and sex workers. These fundamental rights should include the right to housing, employment and travel without restrictions.
9. WE NEED research into female infectivity including woman to woman transmission, recognition of and support for lesbians living with HIV/AIDS.
10. WE NEED decision making power and consultation on all levels of policy and programmes affecting us.
11. WE NEED economic support for women living with HIV/AIDS in developing countries to enable them to be self-sufficient and independent.
12. WE NEED any definition of AIDS to include symptoms and clinical manifestations specific to women.

The 12 statements did not include young women growing up with HIV, nor women with HIV ageing with the menopause. The 12 statements don't specifically mention transgender women, and don't include any acknowledgement of gender diversity or non-binary gender identities. Nonetheless, they provide a unique benchmark to compare where we started in 1992, 10 years into the HIV pandemic, as the first and only global movement of women activists, with where we are now.**

Since 1992, women with HIV around the world and in the UK have worked to raise their issues and priorities, and increase their visibility. See ICW's latest report on abuse experienced by women living with HIV in reproductive and sexual health services here: <https://www.wlhiv.org/reproductivejustice>

* Source: Manchester (2021) https://www.wlhiv.org/_files/ugd/682db7_1b77cd94cec141e6945111a691083279.pdf

** See also: Dunaway K, Brion S, Hale F, et al. What will it take

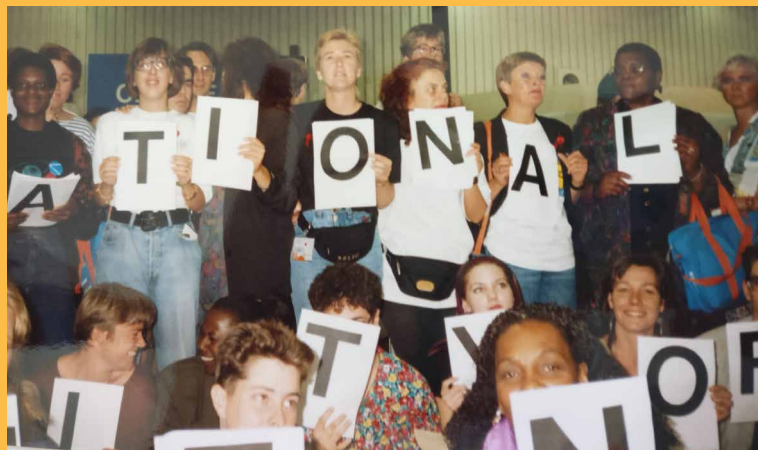
to achieve the sexual and reproductive health and rights of women living with HIV? *Women's Health* (2022): <https://doi.org/10.1177/17455057221080361>

Achievements in feminist/women's activism

- A UK movement focusing on issues identified by women, e.g. Sophia Forum, 4M, Positively UK and others that provide information, support, skills, connect women and influence others. And, globally through the efforts of many women, girls and their networks.
- Treatment and health options for women, e.g. women (including transgender women) taking part in HIV treatment and prevention clinical trials, specific information on women and HIV made **available**.
- Gender-based violence addressed in its own right as a barrier to accessing HIV service. For example, it is one of the key areas within the **Global AIDS Strategy 2021–2026**. Legal cases on forced sterilisation in countries.
- Cognition of sexual and reproductive health and rights (SRHR), e.g. **World Health Organization Guideline on Sexual and Reproductive Health and Rights of Women living with HIV**.
- Ageing with HIV, e.g. the **GROWS** (Growing Older, Wiser and Stronger) project, **booklet on HIV and the menopause** produced through Sophia Forum workshops with women and clinicians. The booklet has also informed other menopause resources in other languages and contexts.
- Research that puts women at the centre, e.g. the **PRIME study**, the **NOURISH study**, 'We are still here' campaign, and many others including how gender inequality influences living with HIV and access to services.
- Policy changes, e.g. UK breastfeeding guidance.
- A recognition and celebration of diversity – one size does not fit all!

Key messages

- It can feel as if we are still asking for the same things 30 or 40 years later! There have been real improvements, but there is still a long way to go. We have to keep plugging away!
- At some times in life, activism is more possible than others. That is fine!
- What we do at a personal level is as important as what is done at a service or policy level, for example, providing a shoulder to cry on can help a woman feel better able to get the service she needs, or asking for what we need in clinic can help a healthcare provider think about the services they offer.



Women living with HIV on the stage at the opening of the International AIDS Conference, Amsterdam, 1992

5. THE LINKS BETWEEN GENDER INEQUALITY AND HIV

Facilitators: Fiona Hale and Emma Bell

What is gender inequality?

Gender inequality is discrimination on the basis of sex or gender causing one sex or gender to be routinely privileged or prioritised over another. Gender equality is a fundamental human right and that right is violated by gender-based discrimination.

Gender inequalities manifest in differences in women's and men's access to resources, status and wellbeing, which usually favour men and are often enshrined in law, justice and social norms and the way our services are set up.

Gender inequality affects us all. Societal oppression conditions how we feel about ourselves and what we do, our achievements.

Other useful terms:

- **Gender norms** are ideas (which are not based on fact) about how women and men should be and act. Internalised early in life and affect how we live our lives.
- **Bodily autonomy** is the ability to make decisions about your own body, life and future, without coercion or violence -

deciding whether or not to have sex, use contraception, or go to the doctor. Bodily autonomy has long been recognised as a fundamental human right.

- **Sexual and reproductive health and rights (SRHR)**: the right for everyone, regardless of age, ethnicity, sexual orientation, HIV status or other aspects of identity, to make informed choices regarding their own sexuality, sexual health and reproduction.

The UK has committed to upholding the rights of women living with HIV through international frameworks that uphold those rights: the [Political Declaration on HIV & AIDS \(2021\)](#) and the [UN Global AIDS Strategy \(2021–2026\)](#) which states that discriminatory laws and practices should be repealed, and the rights of women living with and affected by HIV upheld.

The UK has also committed to the meaningful engagement and leadership of women living with HIV, and SRHR for all, regardless of age, ethnicity, sexual orientation, HIV status or other aspects of identity.



Here are some of the main pathways linking gender inequality and HIV:

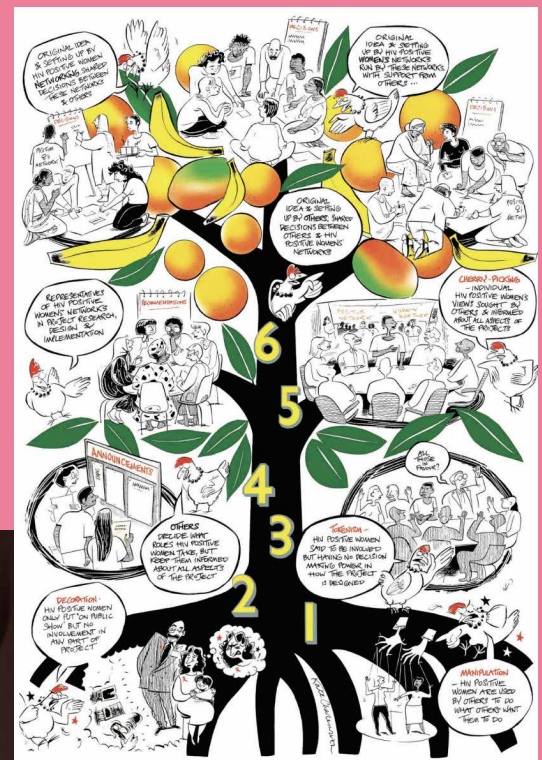
- Gender inequality may increase the possibility of women and girls acquiring HIV.
- Sexual violence and rape (including within marriage) and lack of bodily autonomy in intimate relationships can increase the possibility of acquiring HIV.
- Gender inequality can make it hard to use HIV services and adhere to treatment.
- Gender inequality including discrimination against women and girls can be an outcome of HIV status and disclosure.
- The lack of support for the involvement of women living with HIV and their groups / networks in the HIV response undermines an HIV response that addresses their priorities and needs.

Where change happens



- Ourselves – ourselves and our bodies, our bodily autonomy
- Our communities – sociocultural norms, beliefs and practices – our own, and those of our partner/s, families, communities
- Health services and HIV organisations
- Money, jobs, other services
- Research and evidence (knowledge creation)
- Laws, policies, resource allocations
- Other places that you think are important

Inspired by World Health Organization (2013) 16 Ideas for addressing violence against women in the context of the HIV epidemic. Geneva: WHO.



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GROWS
Women with HIV Growing Older, Wiser, Stronger

Peer Mentor Training Workbook

The Sophia Forum, Positively UK, National AIDS Mod (NAM) and University College London (UCL)

July 2022

4M
4M: My health, My choice, My child, My life

MENTOR MOTHER TRAINERS' GUIDE
to train other women living with HIV as Mentor Mothers

by Angelina Namiba

Volume 1

4M Network
Sulamander Trust

<https://sophiaforum.net/women-with-hiv-growing-older-wiser-and-stronger-grows/>

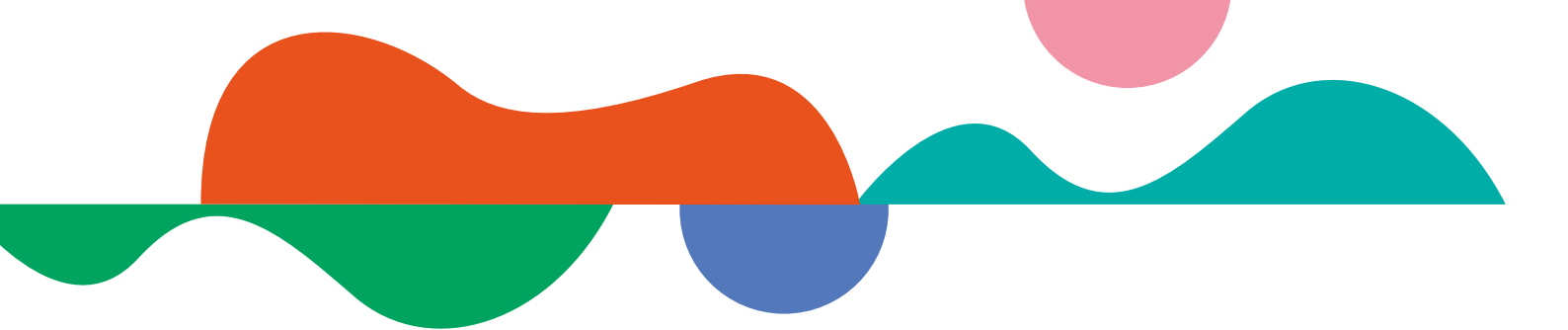
<https://4mmm.org/training-manual/>



©Charity Nyirenda.
<https://positivelyuk.org/c4ptoolkit/>

The facilitators asked the women to take a look at these visuals, illustrating women's HIV activism, and to reflect on the following:

- What do the images make you think about in terms of gender and gender inequality for women living with HIV?
- Why do you think this activism was/is needed?



Women enjoyed thinking about the achievements of women's activism in the response to HIV in the UK, and, for some, thinking about their place within it through the years.

Comments from participants' feedback on the sessions included:

- I liked hearing about the women's stories and positivity.
- I loved that women are taking positive action/taking steps to be a viable and important part of growth and being heard.
- I learned how to take care of myself and also know my rights.
- I liked the pictures as it shows what we as individuals are going through with professionals, they've also helped me to wise-up.
- I learned that research can help with learning and ways to be involved in our care.
- We've got each other and that is very encouraging.
- I liked the display of pictures on the wall and what they presented brought a lot of memories – they show how far we have come as women living with HIV.
- I love the way they delivered the session on women and the issues inequality has caused women.
- Activism can be small or big.
- I learned about feminism through the years and there is still much to do.
- I learned that I am an activist – I never thought of it.
- Seeing how much presence women have in terms of working towards change.
- Women are there doing wonderful things regardless of all the hurdles faced.
- I loved the discovery that women are being activists without realising it.

6. EXERCISE AND BONE HEALTH

Facilitator: Darren Brown

Darren Brown OBE is an HIV Physiotherapist at Chelsea and Westminster Hospital NHS Foundation Trust. He started by opening the floor for questions – there were many questions and personal health stories. Most of the information that Darren provided is in the separate booklet on HIV and bone health. This is a snapshot of questions and advice:

- “I have a chronic lung problem and my oxygen levels drop easily, so I refrain from exercise, but then if I do a little, I suffer even more because I haven’t done it for a long time. So I am trying to find a balance, taking into consideration my oxygen levels, aching all the time, and as well weak bones after 10 years of steroids.”
 - “I have heart failure, back pain, hip pain, even standing cooking for 10 minutes is a challenge, and if I do exercise my breathing gets bad. I’m not really exerting myself, and don’t want to end up worse because I’m not doing exercise. How can I do it safely without repercussions?”
 - “I have fibromyalgia and other things going on – I sometimes wake up in so much pain. The symptoms are invisible so people can’t see. The pain I feel makes me worry about work. I struggle, I don’t sleep properly, and I’m constantly tired. When I go to the GP, they don’t listen when I say how I am struggling. For me, work is tiring and challenging.”
- Darren gave some reflections and useful advice:
- I was invited to talk about bones, but it’s never that simple because I can’t consider bones in isolation when you have a heart problem, for example.
 - Nobody’s experience is the same – everyone’s health challenges are different and unique, yet you have probably been told to ‘just exercise’.
 - There is a mismatch between the group and your needs – it’s really common in groups. Whilst groups can be supportive in many ways, your needs won’t always necessarily be met through an exercise group.
 - Being a woman is the other aspect. Growing older as women, with the onset of menopause and the impact that has. There is a gendered impact on the ability to exercise.
 - We can do something together but it needs to be safe, and something that doesn’t make you feel rotten tomorrow.
 - Exercise is medicine, it needs to be dosed correctly, specific to your needs. It’s not the same for everyone. It might be for joints, bones, flexibility, mental health, mood, just to be with other people... It’s about finding the right thing for you.
 - Getting out, being physically active, exercising – can be used interchangeably. Physical activity is what we do in day to

day life, and it can help if you build up slowly. Exercise is different – it's intentional repetitive movement, and most people with health conditions find it hard.

- When talking about physical activity or exercise it's important to find something you enjoy. You need to find something that doesn't set you back, exacerbate your symptoms. Some movement is better than none, because we are human and we move, that's day to day life.

Useful resources

- Looking online can be overwhelming, lots of people telling you to try different things. The NHS instructor-led exercise videos are a good place to start. They include chair exercises, aerobic exercises, pilates and yoga (www.nhs.uk/conditions/nhs-fitness-studio/). This website is a reliable resource you can have some trust in. It might help you to find something that works for you.
- Chelsea and Westminster has free videos from the Kobler rehabilitation class (www.chelwest.nhs.uk/services/therapy-services/hiv-rehabilitation/kobler-rehabilitation-class). The videos are in chapters, so you can pick what you want to do. There are other links to more information, so you can find the thing you enjoy that is nourishing for your body and doesn't cause you problems.

Darren took the participants through some gentle exercises that can be done at home. These are featured in the booklet on HIV and bone health.

Comments from participants' feedback on the session included:

- I was reminded that I can exercise in a chair.
- I hate exercise but I think I can do these ones.
- You can exercise anywhere, you don't have to go to the gym.
- I like to exercise and go to gym, but I can use this to stretch afterwards.
- A little is better than nothing – maybe I can do this once a day. I'll build on this, and next time you see me ...
- How important simple stretching exercises are, and the need to do more of them at home.
- I've been to physios and they haven't shown me some of these, so I have new moves, which is always beneficial.
- I do exercise and I walk, but recently I didn't have motivation, and this has given me more motivation to do some stretching at home.
- For me this is not exercise at all, like my yoga practice. That reminds me to keep it simple.
- It's starting it – once you start you can enjoy it.
- I used to do exercises, it's not always easy and this has reminded me to get back to it. I usually walk 50 or 60 minutes every few days, but this doesn't stop me from getting fat so what's the point! But it's not about this – it's about keeping my bones healthy.
- I'm happy today – I have a compact room, but these are in a chair so I can do them.

- These reminded me of the exercises I used to do, and I can do them.
- Chair yoga sounds so simple it is not going to be effective, but it is really is.
- I've been trying for months to do a squat, but I can't, but with a chair it's much easier.
- I have had the word 'stretch' on my fridge for so long, but this has really helped me do it. At home it could feel a bit strange – I enjoy group work, but I can try to adapt!
- Stretching has been something I've wanted to bring into my life for years, but having a small space at home – this was a revelation. But I will forget? Can we get a link to the exercise?
- Timed sit and stand for fluctuating energy levels, I like the idea of tracking it.
- How fit or not you are, you still feel something, and something is better than nothing.

7. RECAP OF DAY ONE

On Sunday Bakita Kasadha asked everyone present what they had enjoyed most about Saturday.

Comments from participants' feedback included:

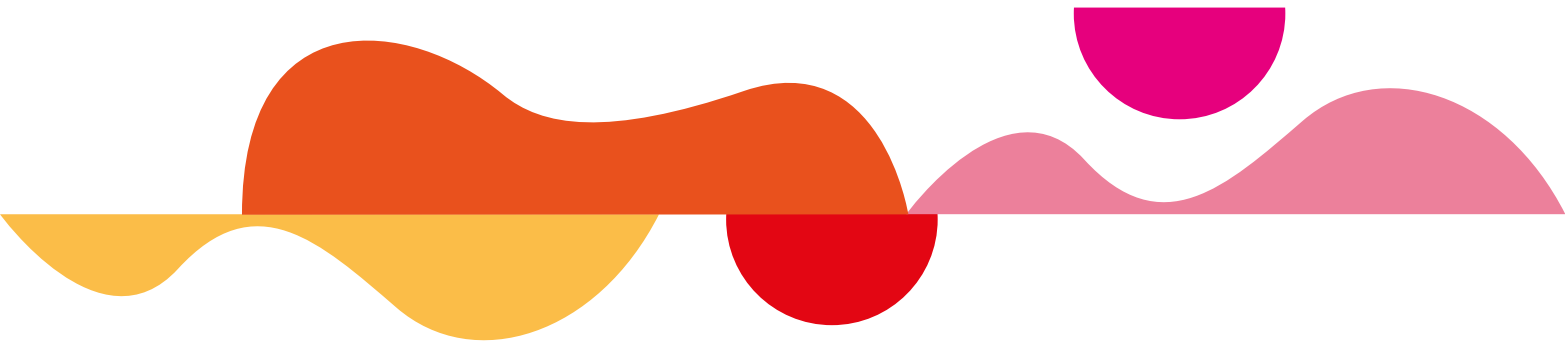
- I learned a lot about bone health.
- Physical activity – learning how to do things in a manageable way.
- I loved going back to activism – we take it for granted but we've come a long way.
- We can't put back the clock, we have to cope with it. I'm allergic to exercise, but I loved it. I loved meeting everyone, old and new.
- I loved all of it.
- I'm paying £30 a month for a gym I never go to. I can do this at home and save the money.
- Meeting everyone.
- I've enjoyed the whole weekend.
- Nneka's presentation about bone health.
- I've enjoyed the whole day, the bone health presentation, the 'what makes me me' exercise.
- Realising that I am part of it, I am an activist. Sometimes we do things without giving ourselves labels, and sometimes you think you have to have a medal, a trophy, go on marches, and I've never done this – but yesterday I came out knowing I am an activist.
- I enjoyed listening to other women's stories. I live so far away.
- I learnt bones are made from collagen.
- All these posters – learning more about women around the world.
- Learning about the connection between oestrogen and sleep.
- Sophie, you've done a great job. And the restaurant yesterday!
- I enjoyed my big salad.
- Yesterday was lovely, meeting new people



and seeing others I haven't seen for a long time. The presentation on exercise – I practised this morning! I know how important exercise is, but it was a reminder.

- Seeing the posters on the walls and reading the stories, seeing how far we have come, things are improving. Sometimes we do activism without knowing, we can do it in our own way.
- A lot of people aren't aware of the issues related to HIV, like U=U. I'm amazed that women have got together to change the narrative on HIV.
- Compliance – I thought I must be the only one messing up, and it's helpful to know I share this with others. I can't believe what I'm learning that I wasn't aware of before. Very glad I came. The exercise as well.
- I enjoyed yesterday – it was my first time at a social gathering since leaving hospital. I learnt a lot about bone health, exercise, I know I can do it at home. It's very very nice.

- I'm happy to be here. It's a very big opportunity for me and I don't take it for granted. The highlight was bone health. I think an advocate should have a lot of information, and I've never come to the point of feeling I had it, but I realised I can be an advocate not just on HIV.
- You have to help yourself to keep fit and keep your bones strong. Thank you Sophie.
- The bit I loved most was the session from Nneka and Darren. It made me realise that exercise is something I can do. It doesn't have to be waking up early and going for a long run.
- Seeing women, reconnecting with some I haven't seen for 10 years. There wasn't a session I didn't enjoy. We didn't give ourselves enough credit, we're in a society that oppresses women, and yesterday we were able to explore that and acknowledge what we do. It warmed me to hear women say, I didn't realise I'm an activist, I'm a feminist, but I didn't know.



8. POETRY/STORYTELLING

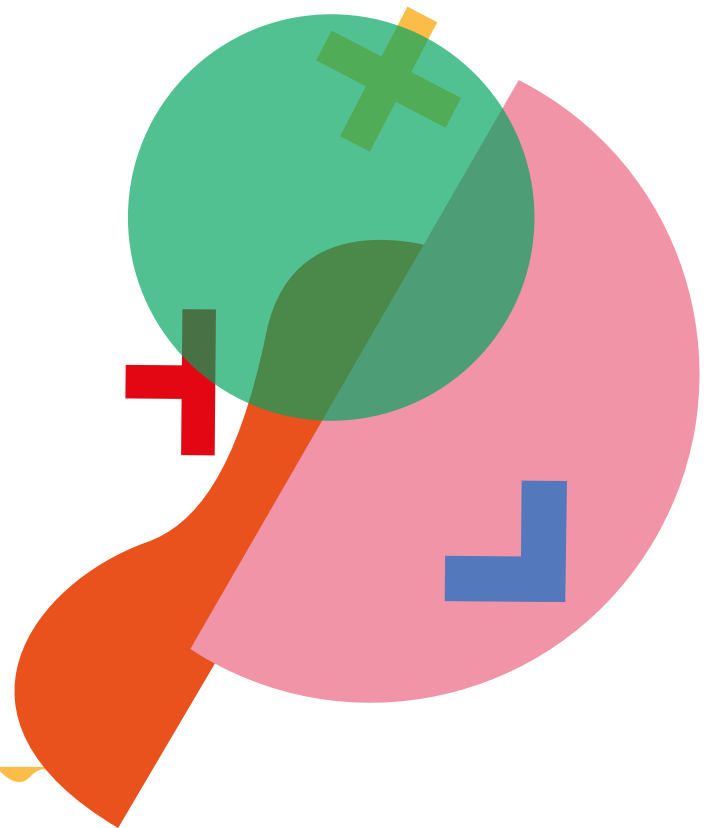
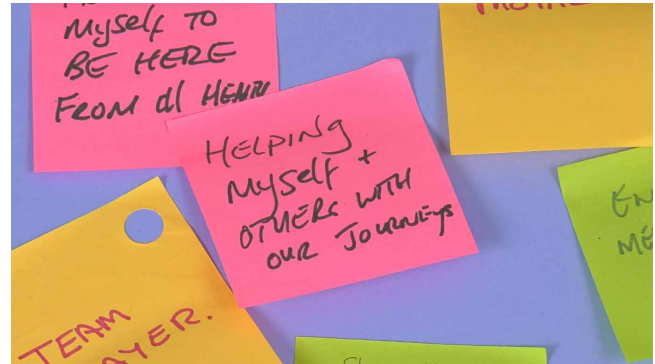
Facilitator: Bakita Kasadha

Bakita facilitated creative activities exploring resilience and the importance of telling our story and for our stories to be heard, especially women living with HIV.

In two large groups, each woman was asked to write 'Words for a woman who needs/wants...' and then asked to complete the sentence before passing the paper around. Each person added a line to the piece of paper, so that everyone (in each group) had contributed to each piece of paper. The aim was to create group messages centring women living with HIV, to capture our range of hopes, choices and experiences.

Comments from participants' feedback:

- I learned about everyone else – amazingly touching!
- The presenter was brilliant, friendly, included everyone – very much enjoyed!!
- I loved writing the sentences for each of us in the group and receiving a 'poem' back.
- I loved the inspiration and creativity.
- I learned how amazing the women in the room are.
- I learned that no matter what we will remain steadfast and positive about our future.
- As individuals we can make up lovely stories of the world.



9. BUILDING AN ADVOCACY AGENDA: MAKING CHANGE HAPPEN

Facilitator: Dr Jacqui Stevenson

Jacqui began the session by asking:

What is advocacy?

- Speaking about something you feel passionately about. Trying to influence change.
- 'Advocacy is putting an issue on the agenda, speaking up for your views and experiences, trying to influence change in policies, practice, attitudes or behaviours.'

How can we be effective advocates?

- knowledge, information, keeping up to date, being a person living with HIV, good listening.
- Enable others to advocate for themselves, giving them tools to advocate for themselves. As advocates we can share our skills and knowledge so others can become advocates – ripple effect. No one person can do everything on their own, and it's not about taking the weight of the world on our shoulders.

Jacqui described how we can take a few steps forward, then get pushback. We need to be a collective, so that we don't get discouraged. Some things just aren't for us – it's important to protect our own energy. It's easy to think about advocacy as a linear process, a journey – and this is how we talk about it. We'll get this policy changed, and that will make things better. But it's not like that – you get the policy, then a

new government comes in, or in the clinic the consultant retires, and you have to start again. It's not a journey with an end point – things can always slip back, but also there's always more we can ask for. It's like having a garden, there's always something to do. You can do everything right, but then there's no rain, or too much rain – and you can bring more energy to it at different points of life than others. There is quiet activism, quiet advocacy, things you do in your own life, or in your community, or on a world stage. There's no one way that is better than the other – they all matter. However you find your way into advocacy and whatever it looks like, it's all important, so there are lots of skills that are important.

What skills do advocates need?

- Organised, enable/help people, knowing the needs of people – bring our own experiences but also know others' experience to be more representative.
- 'Skills may include: being an effective communicator, being influential, being a leader, or being self-confident.'

What advocacy skills do we have already?

Participants were asked to consider the following two scenarios in small groups:

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?

Comments from participants' feedback on Scenario 1:

- Get her to write down questions, offer to go with her, phone the practice manager, etc.
- Bring your own experience, share what you've gone through that's similar, etc.
- She's going to the GP for something else – she could be there for a cold and the GP says 'it's probably related to your HIV, I can't prescribe you anything'. Tell them to go to the Liverpool HIV drug interactions website to check drug and vitamin interactions (www.hiv-druginteractions.org).
- GPs can think everything is related to HIV. But the HIV clinic is specialist – you can't get all your healthcare through the clinic. But women find themselves batted between. It can be hard to find who is responsible for your care for different things.
- People living with a condition are the experts in living with the condition and often have more expertise than doctors. They won't always know to check interactions, or might shy away from prescribing things. But no-one should get substandard care for any other condition they are living with. If you are educating your GP about this, your GP increases their knowledge, you get better care, and the next person does too.
- My GP, HIV clinic, lung clinic all communicate really well, and check interactions between meds for my different conditions. Even my GP will know what

antibiotics I have to avoid because of other medication I take. Some people don't want their GP to know about their HIV status, but for me it works very well, it makes my care better when my GP knows what is happening with me, there is continuity.

- If I go to the HIV clinic for something that isn't for the HIV clinic, they will send you back to the GP because they don't have the funding for it. GPs are the gateways to other services, so it's really important for GPs to be informed and up to date, but they are underfunded and overworked, so they need our help to gently push them.
- In the past it worked well for us to access most things from our clinics. But now we can't, and it's also very hard to get appointments with our GPs. They will only see you for one thing – but you may have a few things disturbing you.
- For people who can't get an appointment, I go online and do the online consultation/ appointment booking.
- Can we advocate for it to go back to all going through the clinic?

Jacqui suggested that this could be an advocacy ask – for women living with HIV it's hard to get access to a GP and the care they need. So we can think about pushing for HIV clinics to take back more of the responsibility, although there is an issue of funding. The apps for online consultations – who is excluded from that? What are the alternative routes? Or is it an issue being on the phone at 7.52am, or missing a GP phone appointment? Are we looking for political change? Should we be conducting general election advocacy if a certain political party has a better offer, or advocacy to our local services, or providing individual peer support?

Comments from participants' feedback on Scenario 2:

- Share information about U=U – but before she does that, she needs to be sure she can trust the other person. Get information leaflets to give to him, find the right time and place, if it's going to be a shock, she might face rejection. Prepare him by asking about HIV – judge from his reaction. If he reacts badly, I wouldn't tell him. If he reacts OK, I'd give info about U=U. She has to be prepared for a negative or a positive response.
- We don't use the word disclosing now.
- There is no right or wrong answer in scenario 2 – it depends on the individual. Do you really need to share?
- Think about the positives and negatives of sharing – and your own experiences if you've been through it yourself. Find a safe space to do it, where you know you're going to come out alive.
- Remember, it's not all about us. They may also have health conditions – CVD, diabetes, needing Viagra. He told me he needed Viagra and it might affect spontaneity. So I took a deep breath and told him about HIV.
- We need to think about the person we are telling. Sometimes we have to put ourselves in their shoes. If someone told me as a friend, how would I feel? Sometimes people's positive reactions turn negative, or vice versa. It's the same with any diagnosis – people don't know how to instantly react.
- We tell someone about our HIV, and they have no-one to tell about it, whereas we have each other.

- It is a heavy load to put on someone. If I was still home in Zimbabwe, wind back 20 years, and found someone who was positive, wanting to love me, I would have run for my life. But now, if I find someone who is positive today and I'm negative, knowing what I know now, I'd be happy to love them. The way people react is how impacted they are – sometimes it's not fair to expect a good reaction all the time.
- Advocacy is about creating space to share our experiences but we need to recognise everyone is different. We need to share information and give people space to use that information.

Further comments from participants' feedback:

- We should be very careful – there is a thin line between us taking responsibility for everything the other person is doing. We are special, we have to be ourselves, don't self-stigmatise and think we are not good enough. Why do I have to worry before I have sex – they need to take responsibility for themselves.
- We all have somebody who is negative who supports us. We have all this safe space and support, but the people who support us don't have anyone. If I had my daughter sitting next to me, my daughter would be able to understand more. If I do an outing or group, I let people invite their loved one or child, it helps the individual to tell more people.

Jacqui introduced a force field analysis – noting that formal advocacy language can be technical and alienating, but all this means is what makes it easier and what makes it harder.

| Easier | Harder |
|--|--|
| Community support | Not being heard |
| Peer support | GP access |
| Financial help | Specific policies |
| Better meds | Discrimination and prejudice |
| Feeling listened to | |
| <i>What kind of asks could support these things?</i> | <i>These are the top level things we want to change.</i> |

Key question

Thinking about this weekend – how much of your advocacy coming out of it will be related to bone health, or will be broader but impacting on bone health, or much more holistic? It's about your priorities.

Previous work we can build on

Previous work gives us some ideas and context on which to build. For example:

- There was a **WISE-UP+** weekend on ageing and the menopause.
- The **'We are Still Here'** campaign from WISE-UP+ which came up with eight key asks.
- Jacqui's work on ageing with HIV.
- The **GROWS** project was a response to one of the eight asks.

Other policy-focused initiatives include:

- **Women and HIV: Invisible No Longer** (2018). A one-year research project led by Sophia Forum and Terrence Higgins Trust, which aimed to set out clear recommendations for policy and service development to ensure that greater focus is given to women affected by HIV.
- The **policy report from GROWS** provided key findings from research with women ageing with HIV (2023).

Jacqui concluded with advocacy can be like pushing a boulder up a hill to make changes really stick. However, when we come together and define collectively what we think is important, it can make things happen.

Comments from participants' feedback:

- I learned about building an advocacy agenda and how important it is in my life.
- I know who to talk to if I have issues.
- As an advocate I'll be able to speak on behalf of people for their voice to be heard.
- I learned advocacy comes in different forms and the importance of working together.
- There's still a lot to do within our community in getting the message out regarding changes.
- Jacqui's passion and positivity in delivering her message is inspiring and uplifting!! Thank you.
- Learning about other projects like GROWS.
- To advocate is not something difficult like I thought it was.

SPOTLIGHT ON 'WE ARE STILL HERE' CAMPAIGN



We have eight key 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. Meaningful involvement of older women living with HIV in research, including clinical, social and treatment research.
4. Research that explores issues that are relevant to our lives and addresses barriers to our participation.
5. Research results that are disaggregated by sex and gender and report under-representation of women where this is the case.
6. Full information about HIV treatment side effects and drug interactions and support to manage them.
7. Improved collaboration, coordination and communication between GPs, consultants, other healthcare professionals and HIV clinics.
8. Treatment advocacy and peer support training tailored to women, including menopause mentors.

The 'We Are Still Here' campaign is a collaboration between Sophia Forum and Dr Jacqui Stevenson, who carried out doctoral research at the University of Greenwich 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 in London. This resulted in the campaign 'We Are Still Here'.

<https://sophiaforum.net/index.php/we-are-still-here/>

10. CIRCLING BACK – WOMEN AND GENDER EQUALITY IN THE HIV RESPONSE

Facilitators: Fiona Hale and Emma bell

This session aimed to support the women to develop an advocacy agenda to inform their (and Sophia Forum's) campaigning and influencing at every level.

Fiona and Emma asked the women to think about what 'asks' they had. In groups the participants were encouraged to:

- review and revitalise the existing asks from the 'We Are Still Here' campaign – as much or as little as they wanted to.
- ensure the learning, priorities and changes identified this weekend are included.
- think about would make things better for you and other women, relating to bone health or whatever your priorities are?

The women's top line ideas

- Everyone should have a DEXA and FRAX scan. We need to know how often and who is responsible for provision as per the BHIVA guidelines.
- Commitment and not lip service – the government has to provide the money.
- More collaboration between health professionals and GPs – they need to take our issues seriously and make it easier to see someone.

- Co-production of research – involve women at all steps of the research that is relevant to our lives and healthcare.
- Representation of women living with HIV at high levels of decision-making.
- Information for young people.

Comments from participants' feedback included:

- I learned how 'asks' are ongoing and need pushing to progress.
- I liked what we do as a community together.
- I learned how to become a better advocate.
- I loved the group working and feeding back.
- I liked the open discussions within our groups and listening to others.
- I loved collaborating with my fellow ladies, laughing and talking was a great medicine for me – thanks.
- The facilitators were amazing – they interact and listen.
- I liked the unity, tenacity, drive and steadfastness of these incredible women.
- I loved meeting lovely people here and listening to women share their experiences.

11. WHAT WOMEN THOUGHT OF THE WEEKEND

Women were asked in their evaluation forms 'on a scale of one to ten how much did you enjoy the weekend?' All gave the workshop a 7 or more.

- Ten gave the workshop a 10 out of 10
- One a 9.5
- One a 9
- Two an 8
- One gave the workshop a 7

Twelve women filled in the detailed pre- and post-workshop questionnaires regarding their skills, knowledge and confidence (three additional women filled in the post-

questionnaire but not the pre-questionnaire so comparisons could not be made).

- 10 of the 15 women who filled out the post-workshop questionnaire gave the workshop 10 out of 10!
- All said they would be interested in attending a future WISE-UP+ workshop.
- All women who filled in the post-workshop questionnaire (n15) said that the workshop had met or exceeded their expectations. Of these, 9 made clear that their expectations had been exceeded.

Number of women who said there was an improvement in skills, knowledge and confidence as a result of the workshop

| Skills, knowledge or confidence | Number |
|--|--------|
| Understanding of feminist activism | 10 |
| Knowledgeable about bone health | 9 |
| Knowledgeable about other aspects of ageing with HIV | 11 |
| Confident in building relationships to support your health and wellbeing | 8 |
| Confident about speaking up on issues that matter to you | 10 |
| Confident at participating in meetings or conferences | 9 |
| Confident in representing your community | 10 |
| Confident in expressing yourself through creativity | 8 |
| Skilled at planning advocacy activities | 11 |
| Confident in motivating and inspiring others | 9 |
| Knowledgeable about research | 10 |
| Confident in leading discussions | 9 |
| Confident in knowing where you can access information and services | 6 |

Comments from participants on the workshop overall

What did you like best?

- Everything – meeting old and new friends, listening to women’s lived experiences and sharing my experiences.
- It helps me to know how to manage my HIV.
- Enjoyed being with other women who could understand what I am going through.
- I cannot single out one thing from the whole.
- Lots of information and the fellowship of the women.
- Bone health talk, physio and storytelling.
- Physio and everything around being a collective.
- Being made aware that more needs to be done.
- The atmosphere, the knowledge I am taking with me and all the facilitators.
- It was well organised and well delivered.
- It was friendly and educational – fun.
- I liked everything about the workshop.
- Community of diverse women sharing experiences.
- That I did not have many expectations and enjoyed the process.
- Working together as a team and all the information shared.

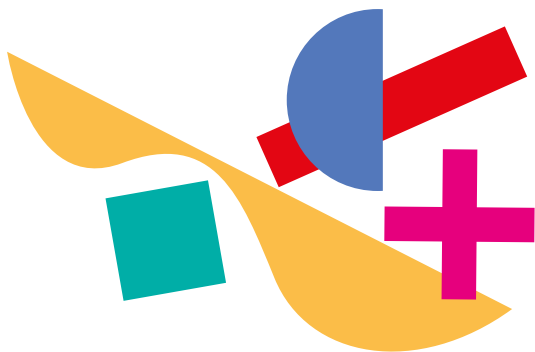
What skills and knowledge have you developed by taking part in this workshop?

- I’ve learned lots about bone health and menopause.
- I acquired more knowledge on bone health and how to do some of the exercises.
- More about my body. This has enabled me to advocate for myself more.
- How to be a better advocate and how exercise can be simple.
- In-depth knowledge on bone health, advocacy and needs.
- How to be an effective advocate.
- Speaking out openly, sharing my opinion with others and talking on a subject.
- Older women = bone health. I previously had septic osteoarthritis. I learnt there is a difference between osteoporosis and osteoarthritis. The need to spread and share information is paramount.
- More knowledge (very useful) about bone health and ‘quiet’ advocacy.
- Bone information – will teach other women. Chair exercises – will practise myself to better my bones and muscles.
- Did a presentation – just a brief one – proud of me.
- More knowledge about advocacy, confident about issues surrounding women, realising I am not alone.
- Learning more about advocacy and opportunity to represent other women though being recorded.

- This workshop has allowed me to have some time away to reflect on working on myself aside from my busy work schedule.
- Working and sharing experiences and the impact this can achieve.

Did the workshop meet your aims and expectations?

- It went above and beyond. I've been laughing all weekend.
- Aw definitely and a lot more.
- Yes and beyond.
- Absolutely.
- This exceeded anything I imagined. In some ways it was sad to realise the struggle still continues.
- Exceeded my expectations.
- Yes it did and more. Just went back to the basics of advocacy and really loved it.
- Yes it did - would love more of these.
- Yes would have liked more information / sharing on diet for bone health, recipes etc.
- The workshop was very valuable in meeting my emotional needs and working together with my peers.



What actions will you take now you have attended the workshop?

- Research, share my experiences, tell people about Sophia Forum, compile a list of questions for my doctor.
- I will be managing my life with HIV and able to educate others with HIV.
- I will be able to share with others, especially with other women and colleagues.
- Watch what the UK's commitment to HIV and how I can challenge them.
- Disseminate information learnt as much as possible, mentoring and peer support.
- Take the initiative to create awareness and speak to my GP about my bone health.
- Dental care.
- Learn more, be more proactive and take pride in the amazing group of women who continue to be the voice of reason.
- I'll apply what I have learned in my private life and when mentoring.
- Will definitely teach other women how important it is to take care of their bones.
- Up my game on exercise and looking after my wellbeing.
- Watching out for my bones, menopause, going back to reflect on all being together.
- Share about the workshop itself, encourage other women to learn and participate. Advocate for myself for my bone health.
- I will follow-up on the helpful information and websites that I will be sent via email.
- Continue advocating and running workshops to support others. Advocate for the vulnerable.

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