

Jacquelyne Alesi UGANDA

My name is Jacquelyne Alesi from Uganda, currently doing my personal work with my foundation as i support women living with HIV in my community.

- 1) Since my dream has always been to become an independent consultant, being part of this group will help increase my knowledge on research but also I would like to continue with my education so I need information.

2) And 2 things you would like us to discuss in the group in future

1. I would like us to discuss Aging with HIV
2. We used to have to peer support group in terms of visiting one another, is it something we can how visiting one another within the country can be refreshed. Because as a Psychologist, the results of a physical visit to one another helps in some acceptability to continue living happily with HIV.



Florence Anam KENYA

Florence Riako Anam is a program manager at the Global Network of people living with HIV (GNP+) based in Kenya. She is a seasoned HIV and Sexual Reproductive Health and Rights (SRHR) advocate with over ten years' experience in Program Management, Advocacy, Policy and Communication for health and social development at national, regional and global levels. Florence has a Masters of Arts degree in Communications studies from Nairobi University. Previously she worked as the HIV/TB Advocacy coordinator for Africa at MSF in Johannesburg, South Africa. Prior to that was the Global Advocacy, Policy and Communication Manager at the International Community of Women Living with HIV (ICW) where she spearheaded the advocacy and communication portfolio amplifying effective representation of women living with HIV and their communities on issues including access to HIV prevention and treatment, maternal health, reproductive rights, equality and social justice, expanded economic and education access for women and girls.



Emma Bell UK

I am a long-time feminist, mum to a wonderful son and living in Hackney, London. I am interested in the links between gender equality, HIV, violence against women and girls and sexual and reproductive health and rights. Six years working with the International Community of Women Living with HIV (ICW) sparked my passion to support movement-building to address these links.

**Cecilia Chung USA**

Cecilia Chung is the Senior Director of Strategic Initiatives and Evaluation at Transgender Law Center, a Health Commissioner of San Francisco and an internationally recognized civil rights leader who advocates for HIV/AIDS awareness and care, LGBT equality, and social justice. An immigrant from Hong Kong, Cecilia has lived in San Francisco for almost 40 years where she has worked locally and internationally to advance equality and justice. During that time, she has broken ground in a number of ways including: being the first transgender woman and first Asian to be elected to lead the Board of Directors of the San Francisco Lesbian, Gay, Bisexual, and Transgender Pride Celebration; the first transgender woman and first person living openly with HIV to Chair the San Francisco Human Rights Commission; and, an architect of the nation's most ambitious publicly funded program addressing economic justice within the transgender community. Her community service spans over three decades.

In 2004, as a founding producer of Trans March, she helped organize one of the world's largest annual transgender events which has since been replicated in cities across the U.S.



In 2005, she became the first Deputy Director of the Transgender Law Center and is widely credited with shaping the organization's mission and programs. In 2004, Mayor Gavin Newsom appointed Cecilia to the Human Rights Commission where she served for seven years before Mayor Ed Lee appointed her to the Health Commission. In 2015, Cecilia founded Positively Trans, a network of trans people living with HIV. Cecilia's life story was portrayed in ABC's miniseries *When We Rise*.

Currently Cecilia serves on the WHO Advisory Council of Women Living with HIV.

I am joining the group because trans women have been underserved and, in some cases, erased from researches.

1. The desegregation of data related to trans and non- binary people.
2. To cultivate more trans women living with HIV in the field or advocacy and research.

Nunu Diana Alison SOUTH SUDAN

Nunu Diana Alison, founder and executive director of young positives South Sudan, an organisation that works with adolescent girls and young women living with HIV.

The reason am joining the power group is to network and gain more knowledge in the field of Gender and HIV.

I would like us to discuss more how get funding for our organizations.



Keren Dunaway HONDURAS

Keren Dunaway is a young feminist consultant whose scope of work reaches regional and global levels, working in the global offices as Gender Equity Officer representing the International Community of Women Living with HIV (ICW) at the International Partnership of the PLHIV Stigma Index, she ensures that all research has a gender perspective. In 2023, Keren was promoted to Global Program Officer where she worked leading Gender Advocacy Toolkit for Research, SRHR advocacy for young women and global advocacy for women living with HIV. She has developed data collection work as the principal investigator for the Situational Analysis on Young People Living with HIV in Latin America, Africa, and Asia for Y+ Global. She is also a team member of the LAC Platform of the Global Fund's CE-SI program. She is also a steering committee member at W4GF to ensure the Global Fund is responsive and accountable to the needs of women living with (& affected by) HIV, TB and malaria.

One of the issues I always bring up in discussion about HIV-related research is that from the We Know We Can project, funded by the IAS, we have been able to see the lack of research focused on adolescent and young women with HIV in the region, as well as the lack of indicators for monitoring service delivery to these populations. How can we begin to influence these issues in order to make a comprehensive diagnosis of young women with HIV in Latin American countries?



Olive Edwards JAMAICA

Olive is the founder of Jamaica Community of Positive Women (JCW+) which was launched in 2010 and legally registered in 2013. For 22 years Ms. Edwards has been a leader in the struggle for HIV treatment access and women's sexual reproductive health and rights.

She has served as a convener, board member, or staff of multiple organizations and networks including the International Community of Women Living with HIV (ICW), Jamaican Network of Seropositives (JN+), Caribbean Regional Network of People Living with HIV (CRN+), Jamaica Country Coordinating Mechanism of the Global Fund to Fight AIDS Tuberculosis and Malaria (JCCM), Jamaica Civil Society Forum, International Treatment Preparedness Coalition (ITPC), and ITPC Caribbean.

Ms. Edwards is involved in community mobilization and representation, at the global, regional, and national levels. Participated in strategic planning exercises, and work plan development, served as PLHIV representative on the Jamaica Country Coordinating Mechanism Executive and proposal review team 2003-2005.

Ms. Edwards is actively involved in EAW advocacy and co-writer of 3 articles on Gender - Ending Violence against women.

Identify training for Community researchers and partners to collaborate on Community research.



[Carrie Foote](#) USA

(Dr. Carrie) is a Professor of Sociology at Indiana University Purdue University Indianapolis, where she teaches courses on HIV, social theory, and qualitative methods. Her current research focuses on HIV criminalization and the 2015 HIV outbreak among people who inject drugs in Scott County, Indiana. Dr. Carrie has served on numerous HIV clinical, care, and prevention advisory boards in Indiana, is a founding member of the Prevention Access Undetectable=Untransmittable Campaign and chairs the [HIV Modernization Movement Indiana](#) - an effort to modernize HIV criminal laws. She received her PhD from the University of Colorado, Boulder in 2002 and has been living with HIV since 1988.



Fiona Hale UK

I'm interested in how research reflects the priorities of the people it's about. I'm especially interested in research by and with (I mean *fully with*, not *tokenistically with*) the people who are most affected. As well as being involved in research and advocacy in relation to gender and HIV in my work, I want to mention my own experience as a 'patient' involved in research. I have Primary Biliary Cholangitis (PBC) - a chronic liver disease which is considered a rare disease - and my mum had it too. When she was diagnosed in 1984, very little was known about PBC, and she was told she probably only had a year to live. This turned out not to be the case, and my mum did a huge amount to raise awareness of PBC. She especially focused on advancing research into the symptom that most affected her - fatigue, which many doctors did not accept as a reality of the condition. My mum was a single parent who left school with no qualifications. On paper she doesn't sound like a researcher, but she most definitely was. By the time she died in 2015, she had spoken at conferences, co-written an article for the BMJ, and given a TedX talk. I've tried to bring her ethos and a little bit of her drive into what I do in my personal life and in my work. I've been involved in a load of studies into PBC, and have sat on national PBC research committees and steering groups. Some of the experiences have been good, others absolutely terrible, where the patient participants were patronised, seen as 'research subjects' with no agency, and given no feedback on the findings. I also had breast cancer, and have been involved as a participant in research into chemo-brain, the lasting effects of cancer treatment, and the impact of cancer on the social and economic lives of 'young adults' (in cancer terms, that's anyone under 50). I draw on that experience in my work life and my commitment to HIV.

One reason why I decided to join this core group: Since I work on HIV but am not living with HIV, I love any opportunity to connect and understand how and if I can contribute (without taking up space from someone else), and learn from other people.

Two things I would like us to discuss in the group in future: How to continue to advance research methodologies that are fully involving. How to make sure women and gender-



diverse people of all ages living with and affected by HIV are authoring/co-authoring and presenting/co-presenting research that involves them.

Bakita Kasadha UK

My name is Bakita Kasadha. I am a health researcher (qualitative), health writer and poet.

I am currently an NIHR Pre-Doctoral Fellow at the University of Oxford and will begin my PhD there in 2023/24. My PhD will focus on the experiences of peer/community researchers in academically-led health research. Previously, I was the lead researcher on the HIV and infant feeding study, NOURISH-UK. I co-edited a special collection on women and HIV (with Dr Shema Tariq). I enjoy turning data into art (especially with visual and poetic inquiry). Beyond academia, I am a freelance writer for NAM aidsmap and The Body/The BodyPro, the Chair of Glitch (a charity focused on improving online safety for Black women and girls) and I am an incoming member of the Fast-Track Cities Leadership Group.

- 1) reason: to connect with other researchers
- 2) discussion points of interest: participatory research, rights-based research and interdisciplinary research



Longret Kwardem UK

Longret Kwardem is a Co-director of the 4M Mentor Mothers Network CIC and a Salamander Trust Associate. She is a peer researcher, public speaker and active community advocate who belongs to several networks including Making Waves, UK Community Advisory Board (UK-CAB) and Supporting Women with HIV Forum and Information (SWIFT).

Longret is passionate about the value of peer support, peer research and the meaningful involvement of People living with HIV. She has a special interest in the sexual and reproductive health and rights (SRHR) of women and girls living with HIV, women movement building, economic empowerment and the sustainable funding of grassroots women-only spaces.

I understand the importance of research in generating evidence and I want to have my voice and that of my community heard. I believe we are better as a group because we have unique skills we can bring to the table and our voice is stronger together. I am interested in using my experience to steer the group

How we can sustain the group at a pace where we do enough to make an impact but not burn out

Have clear objectives of what we want to achieve, for who and why? Do we want to engage in new research or enhance what exists? What outcomes do we want to have and what will be the indicators.? Who are the key players and what is their role? what do we want to change or influence? are there partners we can work with that will enhance our work? It might be helpful to have strategic plans-yearly plans and longer- term plans.



Rebecca Mbewe UK

Rebecca is a mentor, speaker and trainer who has long standing experience of working within the HIV sector and is passionate about gender equality and women's health and sexual rights. Along with many other roles within the HIV community, Rebecca is currently an active member of the UK Community Advisory Board (UKCAB) Rebecca sits on British HIV Association Audit and Standards sub-committee group as a community/patient representative. As well as working with Positively UK at a Training & Policy Coordinator for the (GROWS: Growing Older, Wiser, Stronger) project, Rebecca is an Associate of the Salamander Trust, which aims to protect, promote and enhance the health and rights of people marginalised by societies worldwide as a result of their gender, HIV status or sexual and reproductive health issues. She has recently become one of 3 directors for 4M Mentor Mothers Network CIC (4mmm.org), which developed from a project aimed at mentoring, supporting and training women living with HIV going through the pregnancy journey. Rebecca has lived experience of HIV for 24 years, currently lives in West London and is mother to young men.

Any excuse to join a movement that has members with an impressive track record of making change!!! I know that these are people who put their money where their mouths are - so there is much to learn from them.

Ageing with HIV and better sexual health for people living with HIV.



Svitlana Moroz UKRAINE

Svitlana Moroz is an HIV-positive women's rights activist in Eastern Europe and Central Asia region. From 2011-2016 Svitlana co-founded the national network of women living with HIV “**Positive Women**” and was a lead author of the unique community-based research led and driven by women living with HIV “Sexual and reproductive health, gender equality and human rights, gender-based violence, economic and political opportunities of women living with HIV in Ukraine”. She is co-author of a [Shadow Report](#) on the situation of women who use drugs, women living with HIV, sex workers, and lesbian, bisexual women and transgender people in Ukraine, submitted to the CEDAW sessions. Since 2018 she is organizing community-based monitoring to uphold the human rights of women living with HIV in Ukraine. Svitlana led the **Eurasian Women’s Network on AIDS (EWNA) for 5 years** and advocated effectively to ensure adequate gender equality standards and commitments in HIV response in the region. For example, she drafted the analysis of the existing policy and legislative framework aimed at HIV prevention/response in Kazakhstan and Tajikistan to address gender aspects in the mid- and long-term. In 2014 Svitlana engaged in the values and preferences Global survey on the Sexual and Reproductive Health and Rights of women living with HIV and then was part of the external review of the **WHO Consolidated Guideline on SRHR of Women Living with HIV** launched in February 2017.

- 2) women-led research is an essential part of my professional and activist work
- 3) I’d like to increase my capacity in promotion of community-led research, and particular as community-led monitoring tool



Fungai Murau UK

Fungai Murau is a passionate researcher in the HIV field with special interest in mental health (quality of life for people living with HIV), migration and educating adolescent girls in making informed choices about their sexuality and wellbeing.

Fungai studied at the renowned Institute of Development studies with her MA (poverty and development) dissertation focusing on the mental health of undocumented women living with HIV in the UK. Fungai currently works as an independent consultant focusing on policy, advocacy and project delivery.

Fungai is affiliated with national and international advisory boards. These include, board member at AMAZE, Beyond Stigma, SWIFT (Supporting Women with HIV Information Network) , and a member of the Organising Committee of the annual International Women and HIV Workshop. She is employed part time at Terrence Higgins Trust as Health Inequalities Lead.

I am interested in exploring participatory research: how to be affiliated to an institution as a way of ensuring that the research findings are continuously disseminated, to not only other researchers but to community members who do not know much about research, so they can understand the importance of being involved in research (participant).



| | |
|--|--|
| | |
| Lillian Mworeko Uganda Coming soon | |

Angelina Namiba UK

Originally from Kenya, Angelina has over 24 years' experience of working in the HIV sector on different initiatives ranging from providing one-to-one support, treatment advocacy, managing service delivery to facilitating, promoting and advocating for the involvement of women living with HIV in forming and informing local and national strategy and policy. A founder member of the [4M Network of Mentor Mothers living with HIV](#), Angelina also sits on various national and international advisory boards. These include, as a patron of the [National HIV Nurses Association](#), a lay member of the Women's [Network](#) of the Royal College of Obstetricians and Gynaecologists, a member of the Organizing Committee of the [International Women and HIV Workshop](#), has been a Community Representative for [BHIVA](#), and is a Trustee of the [National AIDS Trust](#) and [SAFE Kenya](#). She has co-authored various articles in peer-review journals and UNAIDS reports.

Reason for joining

Because I am a passionate advocate for the meaningful involvement of women living with HIV in research that is about us. I strongly believe that women should be involved through the lifecycle of both clinical and qualitative studies. From coming up with research questions to being an integral part of the study team as peer researchers, to leading on PPI, being co-authors to disseminating study/trial results at relevant forums including to our own communities.

I would love an update on what qualitative studies or clinical trials members are currently involved in and how they are involved.



Francine Nghanhale Cameroon

I am extremely ambitious and self-motivated as a HIV advocate which has enabled me to contribute positively to my community volunteering to work with people living with HIV in association and all around, even orphans and vulnerable children, tuberculosis and malaria patients in my community.

Through my professional and personal experiences including participation in various work shops on the theme, and at community level, my ability, autonomy and sense of responsibility. Through training, seminars and advocacy meetings, I was able to contribute to the development of advocacy on TB, HIV and malaria . Also make sure the position of secretary in my association allow me to develop skills in communication for the past 10 years. Thanks to my linguistic asset (French and English) and professional experiences, I think I have the skills to communicate and educate.

What do I do:

I am currently the regional coordinator of ICW Central Africa where I join a very passionate team for the rights of women living with HIV. I also have been volunteering as a focal person for Cameroonian network of people living with HIV. I also blog long stories around HIV, Tuberculosis and Malaria issues with advocates for the whole community and especially for people living with HIV. My ambition is to build my capacity to train and empower my community and especially to stand as speaker to champion the work of ICW through women network because of my strategic position in community of civil society. I'm always appointed as a member of UNDAIDS Dialogue Platform on the rights of women living with HIV and part of the community of Cameroonian women living with HIV and AIDS. As a leader of association, I continue to play a central role in the women's leadership initiative, a joint endeavor of the work inside of Global Fund in my country. I learn a lot about issues of women living with HIV in the ICW platform, especially in my country and all over the world. It is also a base from which small regional networks like ICWCA are empowered to grow and make meaningful impact for women and girls in region. My entrance in AFROCAB in 2016 has gave me knowledge of the issues around DTG and which help me to contribute meaningfully to many conversations around HIV and SRH and around cervical cancer in my region.



Lucy Wanjiku Njenga KENYA

- 1) Lucy Wanjiku Njenga founded Sauti Skika in 2015. Sauti Skika is the first network of adolescent and young people living with HIV in Kenya that has become a platform that gives adolescent and young people a voice. Lucy is also the Founder and Executive Coordinator of Positive Young Women Voices and now the Programme Officer for W4GF's Accountability work. Lucy served as the African Delegate in the NGO Delegation to PCB of UNAIDS in 2018 -2020 and is the Alternate Board member in the Kenya Coordinating Mechanism (KCM) to the Global Fund. She has engaged in the developing national funding request submitted to the Global Fund as well as advocating for the Global Fund to advance gender equality across its entire portfolio
- 2) We keep speaking of research not being inclusive and this is an opportunity to do something about it. To make research easy, available and accessible. This platform will make it not look like a mountain of chaos.
- 3) Where and how to start with research that is responsive to our needs and success stories of research done in the past in such a group.



Ayu Oktariani INDONESIA

I am a woman living with HIV, a mother, entrepreneur and also an artist. After living with HIV, I'm joining the national network of Women living with HIV in Indonesia (IPPI). And from 2020, I'm responsible as the national coordinator.

In my hometown Bandung, I open a coffee shop and also doing a lot of art activity, such as workshop. I'm doing art for coping mechanism and healing therapy.



Luisa Orza UK

Luisa is a writer, storyteller and women's rights advocate with 20 years' policy, programming and advocacy experience in gender equality, sexual and reproductive health and rights (SRHR), and gender-based violence (GBV) in the context of HIV. Deeply and consistently committed to building the leadership and meaningful participation of women in all of their diversity, her work focuses on advancing the rights of the most marginalized women, girls and gender non-conforming people, and supporting feminist organizing and movement building. She is experienced in strategy development and planning, policy analysis and advocacy, monitoring and evaluation (including developing and working with theory of change), and facilitating participatory action research. She has been involved in the development and dissemination of knowledge products including toolkits and guides, discussion papers, technical briefs and peer-reviewed publications to deepen the understanding and evidence base around HIV, GBV and SRHR linkages.



Teresia Otieno USA

- 1) I am based in Washington State, but am originally from Kenya. I have been engaged in HIV work for over 16 years. I am currently the Acting Director for the ATHENA Network and also a member of ICW. I am a Steering Committee member of the US People Living with HIV Caucus.
- 2) I love the idea of having a support group that is research related. I also know that I will learn and grow both as a person and professionally.
- 3) Prioritizing on the things we can do and have a plan for what is not achievable now. What has worked in the past and how can we leverage existing opportunities and expertise.

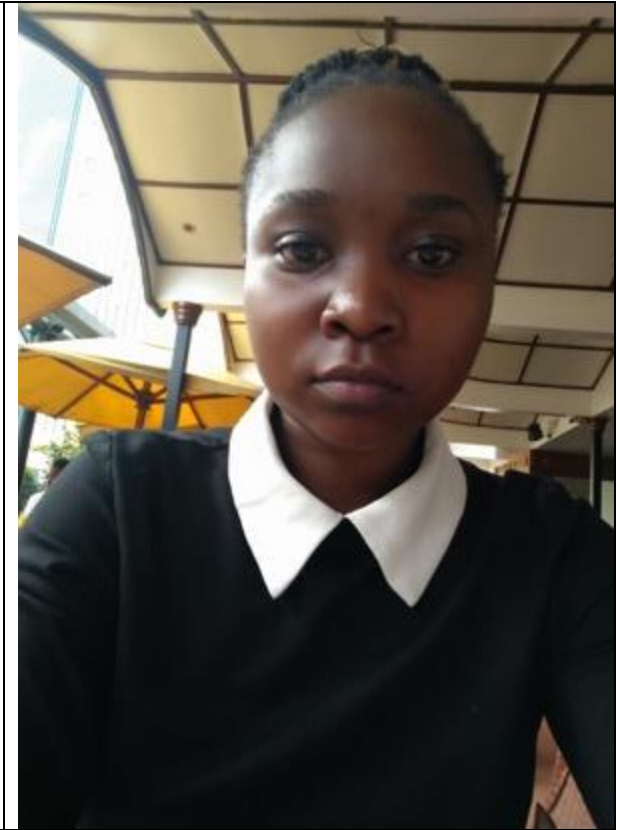


Joyce Ouma KENYA

Joyce Ouma is a young women advocate living openly with HIV from Kenya. She is passionate about the meaningful and ethical engagement of young people living with HIV in all the decision making processes. Most importantly she is an aspiring scholar who has keen interest in pursuing a Masters in Public Health (MPH) and on completion, a doctorate. Joyce is equally passionate about research and adapting community voices and experiences as critical evidence in programming.

The main reason I decided to join the core group is to learn and be prepared for my Master's education. I would really like to know how to work professionally at all stages of research.

Two things I would like the core group to discuss include research approaches that work best, when and research finding analysis.



Silvia Petretti UK

Silvia is Positively UK's CEO, a national charity lead and run by people with HIV, which aims to enable people living with HIV to improve their health and quality of life. Silvia believes that a key tool in defeating HIV stigma is for people with HIV to be heard and visible. She firstly joined Positively UK in 1999 as a volunteer in the organisation Community Development Team providing treatment information to women attending HIV clinics. Soon she became a staff member leading on support for women with drug and alcohol issues and providing outreach in Holloway prison. Since then Silvia has worked in many roles as a manager, from setting up PozFem, the first national women's network, developing new activists through the Taking Part Project and the recent Changing Perceptions campaign. Silvia has also represented people with HIV on the British HIV Association (BHIVA) board, between 2008 and 2011, chaired the UK CAB, and represented the Global Network of People Living with HIV at the United Nations; she currently sits on the World Health Organisation advisory board on women and HIV. Silvia. Silvia has been living with HIV for over 25 years.

I would love to create a space where women with HIV are in the driving seat in terms of research agenda. I am interested in understanding better quality of life from a gender perspective and what works in terms of empowering women to have more control of their lives and not be so limited by what society expect of us. Accessing SRHR throughout our lives.



Nicoletta Policek UK

My name is Nicoletta Policek. I am a senior academic thriving with HIV. This year I have celebrated 40 years in the company of HIV and following the celebration of such an important milestone I have made the decision to leave academia and focus instead on what is most meaningful to me that is sharing my skills and knowledge with my peers.

I will bring with my membership 30 years of extensive professional experience in Higher Education in the field of social and criminal justice and human rights focussing on policy, research, systems thinking, management, education and training. My work experience spans different geographical and legal settings influencing and changing governmental policies and practices in addressing human rights violations, with particular focus on interpersonal violence, sex work, sexual and reproductive rights, prison and migration/statelessness. For example, my latest academic output [Policek, N. Statelessness as a site of fear, *Ibidem*, 2023. ISBN 978-3-8382-1634-8.] addresses issues pertaining to HIV and citizenship as experienced by stateless women and young girls in different EU settings.

With reference to my research expertise and practice which could benefit this group, I am a trainer in Participatory Action Research. I strongly believe that this is the only meaningful opportunity for diverse and dissenting voices to be heard. Indeed, all my research endeavours pay careful attention to power relationships, advocating for power to be deliberately shared between the researcher and the researched: blurring the line between them until the researched become the researchers.

I want to train community members to be research leaders. The principle of nothing about us without us needs to be applied to HIV research where we should not simply have a place at decision-making tables but we could lead as informed stakeholders at every stage of the research process.



Mel Rattue UK

I'm Mel Rattue (say it like statue) I teach mindfulness in schools and communities, which keeps me grounded and grateful. From 2021-2025, I am studying for a part-time MA in Art Therapy at the University of Hertfordshire, bringing together my interests in art, painting, poetry and psychology. I am an advocate for peer support for people experiencing poor mental health and/or living with HIV. I am also currently the Online Peer Support Coordinator for Terrence Higgins Trust.

I decided to join this core group, as who could resist the call to join POWERful women? I have been a UKCAB Rep on the BHIVA guidelines for 5 years and understand how important it is to have peer reviewed, evidence-based studies/research to validate change in policy and secure recommendations for our care.

Alternatives for supporting good mental health for people experiencing multiple disadvantages, in particular approaches that are bottom up and peer led.
How can we involve therapists/psychologists to acknowledge this support works?
How can we research the impact of connection, community and sense of belonging as important to maintaining our well being?



Violeta Ross BOLIVIA

Gracia Violeta Ross is Bolivian; she is a Social Anthropologist with postgraduate studies on Gender, Sexual and Reproductive Health. In 2000, Violeta Ross discovered her HIV positive status and founded the Bolivian Network of People Living with HIV/AIDS (REDBOL) serving as its President in different periods including the present. Violeta led the process for the demand of antiretroviral medications in Bolivia, the elaboration and negotiation of the HIV law and currently leads the demand for inclusion of public funding for the sustainable response to HIV in Bolivia. Violeta Ross represented Bolivia and Latin America in several global bodies. The roles of representation of Violeta include the Developing Countries NGO Delegation to the Global Fund to fight AIDS, TB and Malaria. Violeta was an adviser to the Civil Society Advisory Group for UN Women in Latin America. She was a member in the TB-HIV Working Group for the Stop TB Partnership, the WHO Civil Society Task Force and advised the Experts Advisory Group to the Medicines Patent Pool. Violeta was the Board Member for the Communities Living with the Diseases Delegation in UNITAID board until 2017. Currently, Ross is a Latin America and Caribbean NGO Delegate in NGO Delegation, UNAIDS PCB. Ross is a public speaker, writer and researcher on HIV, gender-based violence, health and human rights, she writes about her experience as a rape survivor and as a woman living with HIV.

2) I would like to strengthen the role of women living with HIV in research, using research as one of the tools for political incidence.

3) 2 things I would like us to discuss in the group in future:
Innovative methodologies of online research based and led by communities.
How to better use research results in advocacy.



Sita Shahi

I am the founder member of the National Federation of women living with HIV in Nepal and founder president of Srijansil Mahila Samuha a community-based organization. Since 2004 I am actively working in the HIV response particularly for access to treatment women's rights and SRHR. I have served as a staff and board member and positioned in multiple levels and organizations. Currently serving as regional coordinator of ICWAP. I have both knowledge on governance and program management. Most importantly I am always keen to learn from others.

Why I would love to be in the core group?

Well, I am so much eager to learn from leaders and working with a team including hearing young people and their diverse ideas. It was a good platform for me when I was nominated into TAAG members that gave me a loads of experience from different country context and how the community-led research work. I am not a magic stick that I can change things suddenly but of course, this will be a great platform to exchange our common ideas and plan what we required to change. Unity is something very important power to change and sisterhood is something about feeling better within the group therefore I would love to join this group.

About the issues:

I am pretty much not sure about the concept of what kind of issues can be discussed but for sure overcoming the challenges while doing research can be one issue for now.



Jane Shepherd UK

I am a graphic designer, artist, writer and peer mentor. I am interested in the stories we tell about our lives as women living with HIV. I have a particular interest in the changing narratives of women who were diagnosed before the advent of HIV treatment. I have a post-graduate certificate in Life History work, including oral history, and more recently a post-grad certificate in Narrative research. Currently, I am working on a self-initiated autobiographical project. But very interested in developing research guidelines/principles by and for people living with HIV who wish to document their histories. I would love to see narrative research used more as a methodology and would be happy to share resources.



Sophie Strachan UK

Sophie is CEO of the Sophia Forum, a UK based women's HIV charity whose vision is a world where nothing stands in the way of all women living with HIV enjoying their rights to a dignified, fulfilled and healthy life.

Sophie has been a committed advocate for women and HIV for 20 years, ensuring gender and health equity in the HIV response, through advancing research and influencing policy. Sophie has provided policy advice to public health organisations, NHS England, NICE, NGOs and academics, advocating both nationally and internationally.

Sophie's work includes advocacy on Pre-Exposure Prophylaxis (PrEP) access for women, is the past Co-Chair of the Women and PrEP sub group for the UK PrEP IMPACT trial. She currently works as a sexual health advisor at Chelsea and Westminster Hospital.

Sophie sits on the HIV Action Plan Oversight Group and the Vision for HIV in London Community Advisory Group. Sophie sits on Public Health England SHARE (Surveillance of HIV Acquired Recently; Enhanced) Advisory Group.

Sophie is the current co-chair of the London Prep Equity working group.

Sophie is co-author on a piece of research looking at the lived experiences of those living with HIV currently incarcerated in UK prisons.

Main reason for joining: to meet and learn with likeminded feminists to build a network of support to strengthen a gendered response in HIV



Wezi Thamm UK

Wezi has a background in teaching and psychology. She has been an HIV activist in community work, prevention, treatment, care, advocacy and training for the past 30 years, and is a longstanding member of ICW (International Community of Women Living with HIV) and a former European Representative of the network.

Wezi is a trustee on the board of HART (Hillingdon AIDS Response Trust), on the SAB of the INTUIT project (intuitproject.org) and a founding member and Chair of the network WECARE+ (Women in Europe and Central Asia Regions plus). Wezi is also a trustee on the Sophia Forum board and GSSG in Germany (Gesellschaft für Sexualität und Gesundheit e.V).

Wezi is a doctoral researcher at Newcastle University and her PhD entitled: A Life course Perspective to Sustainable Employment, investigates the complexities of supporting HIV in the workplace, Ageing and Change and Digital Services. It is cross-disciplinary, drawing on social design and business psychology, and will encompass organisational perspectives alongside individual and community perspectives.

1. **Funding:** How and where to find funders and how to access funding (maybe also how to fund raise).
2. **Research:** A lot in and around research, encouraging women to learn/to do/get involved with/undertake world class HIV women & girls focused research, how to get our research into conferences, peer review journals, how to promote our research effectively so that it actually gets translated into policy change.



Martha Tholanah ZIMBABWE

My name is Martha Tholanah. I am a feminist, health, human rights and social justice activist and advocate. I have been on anti-retroviral treatment (ARVs) since May 2003. Scientific research has fascinated me since then, as when I started, I was surrounded by no hope for survival from the community I lived in, the medical field I looked up to for remedies, and the faith where I thought I would be given encouragement against all odds. In the end, it was science to the rescue. It has been a fascinating journey witnessing how science has ensured a transformation of how people living with HIV thrive and are treated. I have also seen my self-growth, now actively contributing to building scientific evidence. I hope to see an HIV cure successfully developed and distributed in my lifetime.

I like the POWER Group because I am POSITIVE about my having HIV, and I am POSITIVE about research. I am keen on engagement in research as women from the community.

2 things I would like us to discuss in the group in future:

- Ageing with HIV – how we engage with a diversity lens.
- Coping with chronic pain



Marijo Vázquez SPAIN

MariJo lives in Barcelona, has been involved with many wonderful women along her path advocating for HIV+ women's rights (and women in general), and now cooperates in spreading alternative ways of looking at health in nursing training at the UAB (Universidad Autònoma de Barcelona) and community work with The Constellation (international network aiming to support local responses to life challenges).



Alice Welbourn UK

I am a practical anthropologist by training and my PhD was on the social construction of authority, access to and control of goods and resources, based on gender and age in a Kenyan rural community. I then lived and worked in Somalia, supporting: communities with pastoral primary health care, street children, and on sand-dune fixation (regreening the desert) from 1984-89. From 1989-1992, I was involved in the development of the Participatory Learning and Action (PLA) movement, supporting NGO staff to listen to and learn from 'issues of difference' amongst people in communities across East, Southern and West Africa, through participatory democratising approaches which did not demand literacy. These were essentially participatory approaches to research and development, which recognised how their perspectives were influenced by their gender, age and well-being.

I learnt that I have HIV when I was diagnosed in 1992 when I was expecting a baby. This shaped the development of *Stepping Stones* with colleagues in Uganda from 1993-5. I became involved in global advocacy and research processes to advance the SRHR of women living with HIV from 2002 when I joined ICW and learnt at first hand about the power of movements to effect change. Salamander Trust started in 2008 and we have tried to weave together advocacy, research and training agendas to continue to advance the SRHR of women and girls in all their diversity. Salamander Trust is now winding down as I retire.

- 1) I wanted to join this group to pool and share all our insights, experiences and learnings around trying to do research to advance our SRHR.
- 2) I would love to explore ways of getting peer research established as an essential part of all ethical, effective and sustainable policies and programming to ensure and uphold our SRHR.
- 3) I would like to explore the practicalities of who is ready to form the core team to run the group - and how we reach out to other women living with HIV in all our diversity, to ensure inclusion of any who wish to join us and share their learnings and insights.

