

Welcome !

ALIV[H]E Webinar # 3
Participatory Approaches in Research
10 November 2016



The recording of this webinar can be found [here](#).



COWLHA ALIV(H)E UPDATE

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Project Background

Project Goal:

- To reduce HIV and GBV incidences in three Traditional Authorities (TAs) of Zomba District in Malawi

Objectives:

- **Objective 1:** Strengthen community by-laws that promote women's safety and SRHR in the context of HIV and GBV developed and implemented in three TAs of Zomba District by February 2016
- **Objective 2:** Support men and boys to contribute to a safe environment for women and girls and ensure gender equality in three TAs in Zomba
- **Objective 3:** Increase open communication among couples, women and men around HIV, gender equality and address GBV in three TAs
- **Objective 4:** Strengthen monitoring and evaluation systems for data and information generation.

How the *Stepping Stones* Methodology was being Utilized

- **Step 1:** Conducted a baseline study using formal quantitative and qualitative methods to understand the issues to be focused on during trainings.
- **Step 2:** Putting Research into practice: Adapt the *Stepping Stones* methodology to highlight the issues of the target communities.
- **Step 3:** Conduct a training of trainers of couples to facilitate community *Stepping Stones* workshops.
- **Step 4:** Rolling out of community workshops by trained couples/ facilitators

3

How We Promoted Participation

- We worked with traditional leaders to help us in mobilising community members (men, women, boys and girls) to participate in the program
- Support groups of people living with HIV (men and women) took lead in facilitating community

Challenges encountered in using participatory approaches

- Some community members thought the program is specifically for People Living with HIV and as such were not willing to participate at first for fear of being labelled as a Person Living with HIV
- It took longer for some community members to appreciate the importance of inclusiveness and respecting the views of everyone as a way of promoting participation. This was particularly the case with men due to patriarchy

Advantages seen with the *Stepping Stones* approach

- We managed to reach out to more community members because of having an all-inclusive participatory approach with something for each peer group. In total 10,023 women, 3939 men, 1311 girls and 1203 boys were reached.
- Making the community peer groups to identify and discuss issues within their peer groups before discussing with the larger group made the approach more interactive, participatory and relevant to the community members in relation to gender equality and HIV.
- Focus on improving communication has reduced incidents of GBV and enhanced cooperation among couples. Case studies are available to prove this

Action Linking Interventions on VAW and HIV Everywhere ("ALIV[H]E") Framework

UNAIDS-commissioned HEARD led consortium, with Salamander Trust, AIDS Legal Network, ATHENA Network and Project Empower



Principles of Participation

A. INTRINSIC RIGHTS

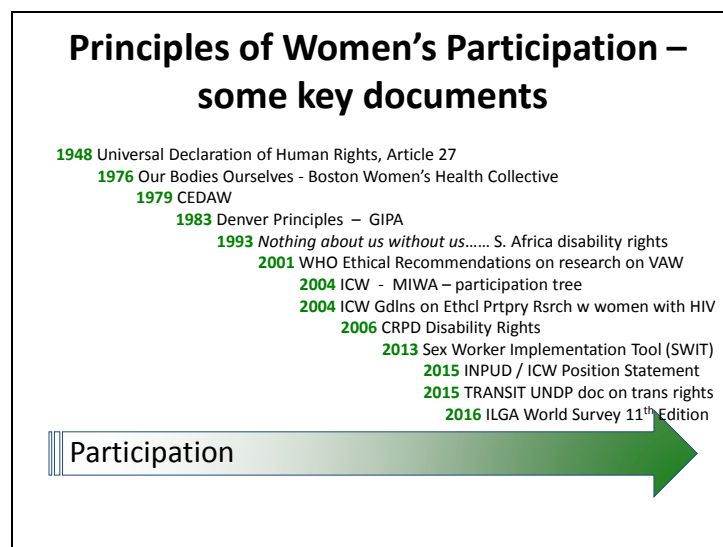
Universal Declaration of Human Rights 1948: Article 27

1) *Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.*

This gives us the right to participate in research - which is scientific advancement

2) *Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.*

This gives us the right to meaningful involvement & ownership of the information that we provide



Putting women first: ethical and safety recommendations for research on domestic violence against women [Internet]. WHO; 2001 [cited 2015 Nov 10]. Available from: <http://www.who.int/gender/violence/womenfirtseng.pdf>

Guidelines on ethical participatory research with HIV positive women [Internet]. ICW; 2004 [cited 2015 Nov 10]. Available from: <http://www.icw.org/files/EthicalGuidelinesICW-07-04.pdf>

Universal Declaration on Human Rights 1948

Our Bodies Ourselves - Boston Women's Health Collective 1976

Denver Principles - GIPA 1983

Nothing about us without us..... S Africa 1993 disability rights

WHO ethical guidelines - 2001

ICW - MIWA 2004

ICW Ethical Guidelines - 2004

Disability Rights - CRPD 2006

SWIT Tool

Harm reduction

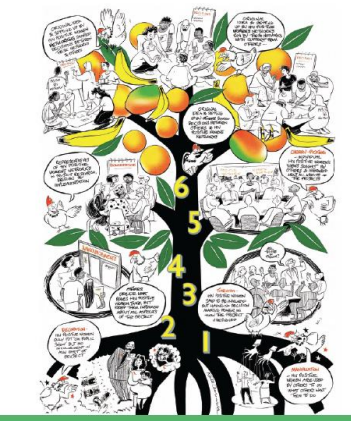
ILGA

Trans rights: The first time ever trans women were included was in 2010 in the CEDAW Shadow report

(http://tbinternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/ZAF/INT_CEDAW_NGO_ZAF_48_10363_E.pdf) written by Masimanyane Women's Support Center.

The TRANSIT document (<http://www.undp.org/content/undp/en/home/librarypage/hiv-aids/implementing-comprehensive-hiv-and-sti-programmes-with-transgend.html>) was published in 2015 and the African Trans Feminist Charter

<http://tsq.dukejournals.org/content/3/1-2/272.extract> was published beginning 2016.



What is 'meaningful participation'?

Not just:

- Answering questions
- Recruiting respondents
- Data collectors
- Qualitative methods

Includes being *involved* in:

- ✓ Design, delivery, implementation, analysis, ownership of research process - and findings
- ✓ Formal and participatory, quantitative & qualitative methods
- ✓ Co-authorship of reports, articles etc.
- ✓ Co-presenters at conferences
- ✓ Long-term sustained partnerships between NGOs, academics, community members, etc.
- ✓ Funding

IS YOUR ORGANISATION BEARING FRUIT?
 ENSURE MEANINGFUL INVOLVEMENT OF WOMEN AND GIRLS LIVING WITH HIV

See eg <http://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-015-1949-1>

A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects

Principles of Participation

B. INSTRUMENTAL BENEFITS

- If people want to have programmes which are acceptable, accessible, affordable, sustainable, then the sooner they involve those most affected by the issue in the programme design, development, implementation, monitoring and evaluation, the better.

Gradual realisation of the importance of this.

- **Eg the WAVE Study:** 2011-3, Johns Hopkins Bloomberg School of Public Health
 - 5-city international project on young people 15-19 years
 - quantitative questionnaire developed first
 - conducted the qualitative work (photo-voice, community mapping and IDIs.)
 - Qualitative study made them rewrite the quantitative questionnaire
- **Eg Julia Kim: (Raab and Stuppert):** "Participation also tended to deepen the evaluators' understanding of the intervention and its participants.
- Eg - **Chicago presentation R4P** 2016 - Most of studies on VAW are in Africa but only 15% of researchers are African.

See eg <http://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-015-1949-1>

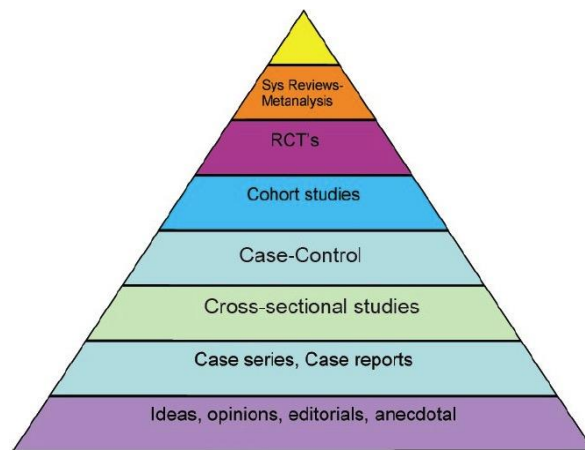
A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects

Eg the WAVE Study: 2011-3. 5-city international project on young people 15-19 years by Johns Hopkins Bloomberg School of Public Health: they developed the quantitative questionnaire first and then conducted the qualitative work (photo-voice, community mapping and IDIs.) Their results from the qualitative study made them realise they needed to tear up the quantitative questionnaire and re-write it.

Eg Julia Kim: (Raab and Stuppert): "Participation also tended to deepen the evaluators' understanding of the intervention and its participants: *'I think there is a kind of paradigm that research must be something that should be kind of kept at arm's length in order to be objective but [...] there is [another] way to conduct research that is rigorous and objective. [...] to some extent researchers actually do need to get in there and understand the situation in some way in order to really understand what it is that they are studying'* (Kim 2009 #3).

Raab M, Stuppert W. Review of evaluation approaches and methods for interventions related to violence against women and girls (VAWG), [Internet]. Department for International Development; 2014. Available from: http://r4d.dfid.gov.uk/pdf/outputs/misc_gov/61259-Raab_Stuppert_Report_VAWG_Evaluations_Review_DFID_20140626.pdf

Questioning the hierarchy of evidence



Questioning the hierarchy of evidence





Webinar 3: Empowering Participatory Approaches for women with disabilities

Betty Kwagala
TASO, UGANDA
10th Nov. 2016



A programme I felt most involved in

- In 2000 I was selected for a six-week participatory Learning approaches training facilitated by Community Development Resource Network (CDRN) - organized by DFID representing National Union of Disabled persons of Uganda
- We selected a community for participatory Learning approaches practical work in the District of Masindi Uganda to look at different diverse groupings in that community based on gender, age, socio economic wellbeing, and disability.

Techniques Used

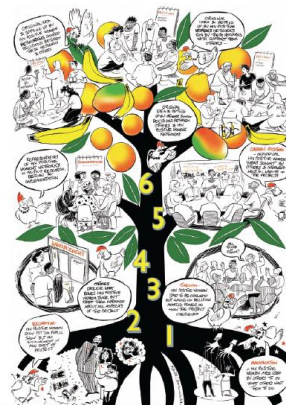
- Situational Analysis
- Participatory problem identification and planning.
- Participatory monitoring, management and evaluation.
- Participatory mapping
- Transect walk
- Seasonal calendars
- Daily activity chart

How participation enabled success?

- The community where we practiced participatory learning approaches was able to identify the challenge of dirty water which was the source of poor health and high level of poverty.
 - 5 protected wells were built with funding from DFID and community contribution
 - The skills acquired helped young people with disabilities to get more knowledge about HIV and AIDS, and how to access accessible services and information.
- I was able to analyze and document policies, attitudes, accessibility of services for people living with disabilities, by family members and the community at large
 - What happened?
- During Participatory Learning Approaches practical work I was able to speak with hard-to-reach group
 - parents of children with disabilities
 - Other vulnerable children example children of parents with disabilities.

The ICW Participation Tree:

Extent of participation



**IS YOUR ORGANISATION
BEARING FRUIT?**

ENSURE MEANINGFUL INVOLVEMENT OF WOMEN
AND GIRLS LIVING WITH HIV

Webinar 3: The Personal is Political

Silvia Petretti


Positively UK

November 10, 2016



Women
Inspire
Support
Empower

Unleashing
Positive Potential
A workshop to nurture
new women activists!



Sophia



The River of Life

- Spend 15 minutes drawing the river of your life as a woman living with HIV and how this river arrived where we are now in Wise UP.
- Think about your HIV diagnosis and your life with HIV. Where did you find obstacles? Where did you find strength and inspiration?
- Imagine when the waters were calm and when they were rough.
- Where there were bridges that helped you to cross.
- Where dams contained the waters, What were the banks like, green dry etc

Identify:

3 main obstacles in your life with HIV

3 things that helped you overcoming some of the obstacles.

In small groups

- How was your HIV diagnosis?
- What helped you?
- What would have made it easier that was not available?
- What do you need to live well with HIV?
- Does anything need to change (change within you / or change in outside world), to allow you to live well ?
- What skills and qualities have you developed from dealing with your diagnosis and living with HIV?



How does what you have learned from your HIV diagnosis, and living with HIV apply to be an activist and an advocate for the rights of women living with HIV?



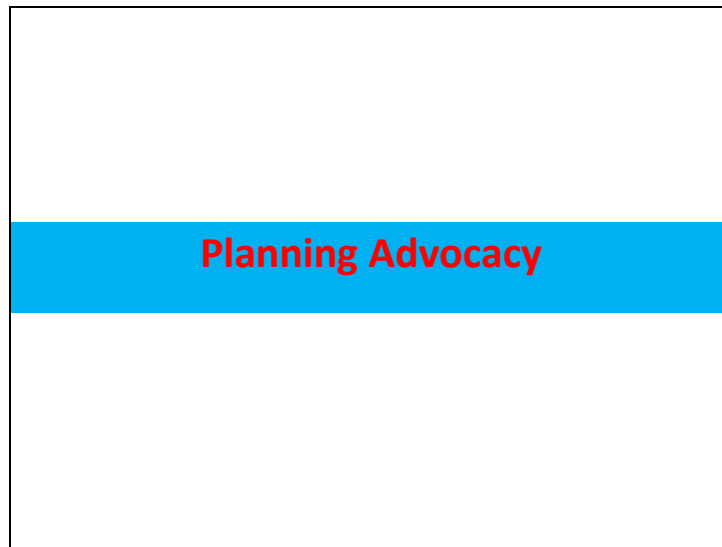
Our Dreams, Hopes and Aspirations

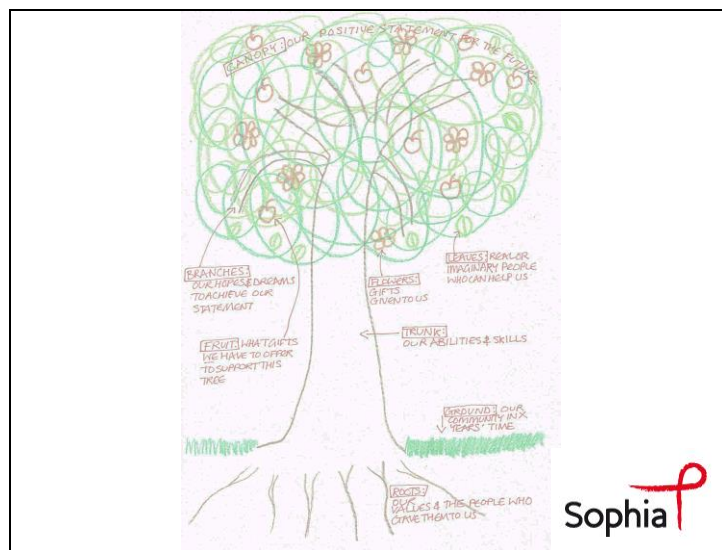


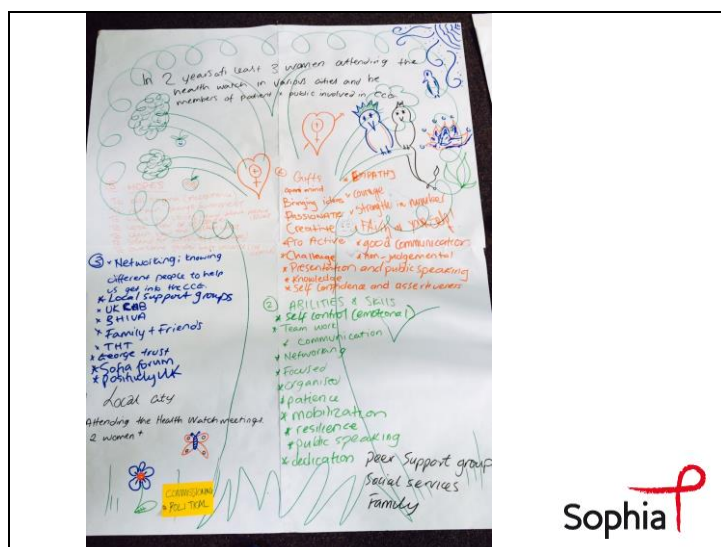
The River of Life Goes On

- Try to imagine and draw where you want your River of Life to go
- A river estuary can have many branches: you may want to think about several directions for yourself: personal, family, as an activist, professionally .

This exercise is for yourself. You will not have to share it, unless you want to.







Sophia

Trans Women & Participatory Research Processes

Trans Women and Participatory Research Processes
Leigh Ann van der Merwe
10 November 2016



Research Streams, Themes and Resources

- The HIV discourse among researchers on trans women has been useful but also harmful - it shifted the other health needs and challenges that face trans women
- Too many assumptions are made when it comes to trans women, which tells us that it's time to rethink our methodologies
- Balancing our uniqueness as a population with (rigid) scientific methodologies
- What counts as research? Is it only research because its documented using a rigid method?
- Only a few countries that document the demographic patterns of trans people or trans women

Engaging Trans women in Research

- Trans women's needs have been served through interventions for other key populations e.g. sex work, men who have sex with men and people who inject drugs
- “Trans women are a hard to reach population” It cant be that hard to find us if you are really looking
- Research environments are often not “trans friendly”
- Trans people can conceptualize research, collect data, interpret data, write up and disseminate findings

Recommendations

- Transgender cultural competency training
- Creating trans-friendly environments
- True partnerships with local trans-friendly organizations and health care providers
- Protocols that focus on transgender specific issues
- Data collection and tracking of transgender individuals
- Trans women can conceptualise research, we can collect and manage data; we can write up their findings; and we can disseminate our own findings

