

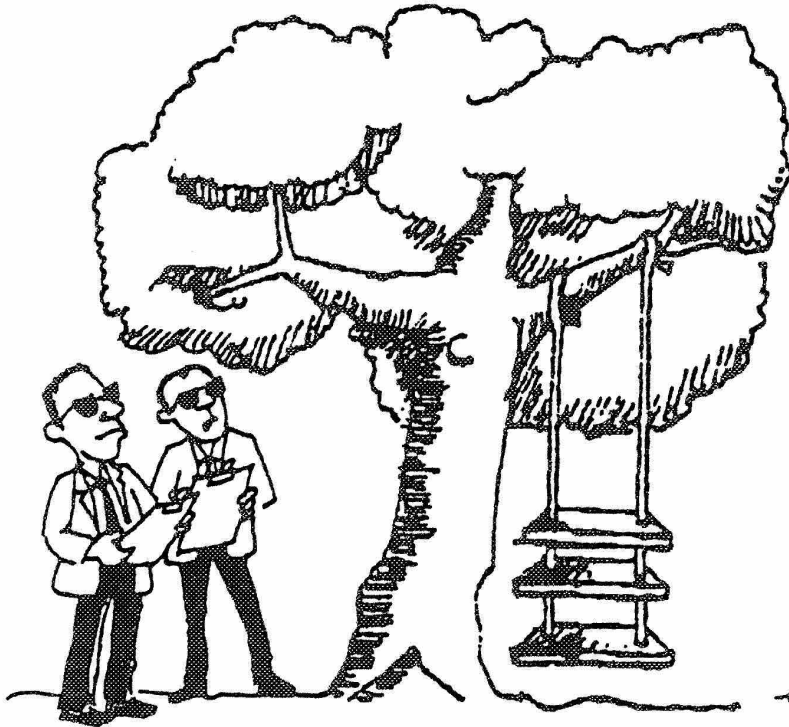
**Women LEAD:  
Community Participatory Research-based Advocacy towards  
Policy and Programs that impact Women and Girls**

**ICW Satellite  
International AIDS Conference  
24 July 2018 | Amsterdam**

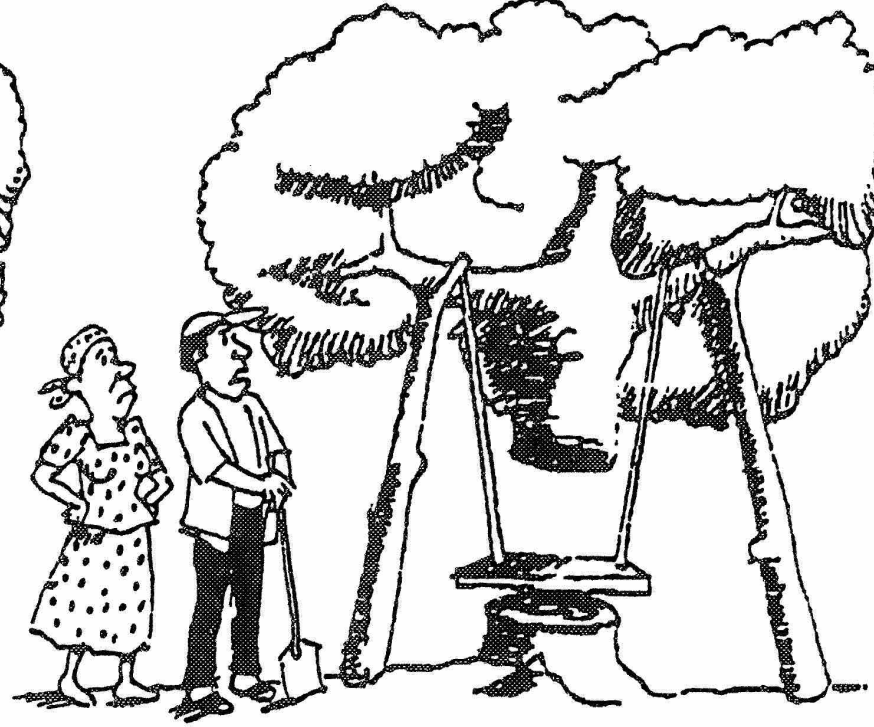
Alice Welbourn | Salamander Trust



# Making a case for women-led research to inform Policy and Programs.....



What the experts designed



What the people got



What the children wanted

# Making a case for women-led research to inform Policy and Programs.....

## Roger Hart's Ladder of Young People's Participation

Created by The Firechild Project - <http://firechild.org>

Rung 8: Young people & adults share decision-making

Rung 7: Young people lead & initiate action

Rung 6: Adult-initiated, shared decisions with young people

Rung 5: Young people consulted and informed

Rung 4: Young people assigned and informed

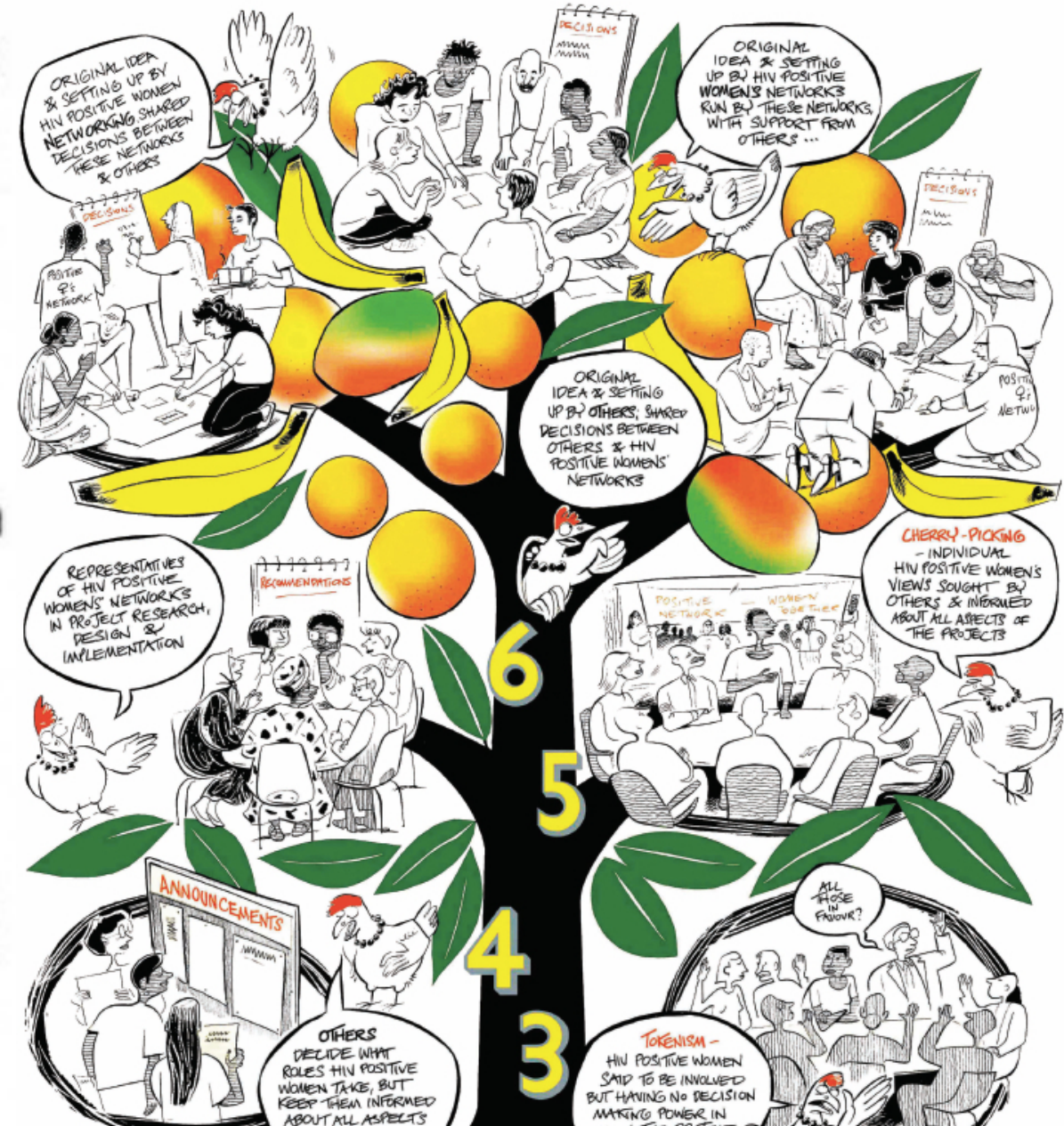
Rung 3: Young people tokenized\*

Rung 2: Young people are decoration\*

Rung 1: Young people are manipulated\*

\* Note: Hart explains that the last three rungs are non-participation

Adapted from Hart, R. (1992). *Children's Participation from Tokenism to Citizenship*. Florence: UNICEF Innocenti Research Centre.



# Principles of Women's Participation – some key documents

**1948** Universal Declaration of Human Rights, Article 27

**1976** Our Bodies Ourselves - Boston Women's Health Collective

**1979** CEDAW

**1983** Denver Principles – GIPA

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

**2001/16** WHO Ethical Recommendations on research on VAW

**2004** ICW - MIWA – participation tree

**2004** ICW Gdlnes on Ethcl Prtrpry Rsrch w women with HIV

**2006** CRPD Disability Rights

**2013** Sex Worker Implementation Tool (SWIT)

**2015** INPUD / ICW Position Statement

**2015** TRANSIT UNDP doc on trans rights

**2016** ILGA World Survey 11<sup>th</sup> Edition

**2017** WHO Gdlne on SRH&R of women living with HIV



Participation

Making a case for women-led research to inform Policy and Programs.....

## Our RIGHTS.....

- Universal Declaration of Human Rights, Article 27

## In WHO 2017 SRHR Guideline.....

### 6.2.1 Women living with HIV as equal partners in research

Research about women living with HIV should be conducted with, by and for women living with HIV, as equal research partners. Research that is pursued and funded in this area should include justification for why it is important to women living with HIV.

## A win-win for us.....

- Holistic programmes, designed by, *with* and fit *for* women rather than disease-focused narrowly siloed vertical interventions – a moral *and* economic imperative

***“There is no such thing as a single-issue struggle because we do not live single-issue lives.”***

Audre Lourde (1934-1992) African-American-lesbian-feminist-activist-woman....

***"Am I 'lost to follow up' or am I bullied out of care?"***

**"GLOBAL PLAN TOWARDS THE ELIMINATION OF NEW HIV INFECTIONS AMONG CHILDREN BY 2015 AND KEEPING THEIR MOTHERS ALIVE 2011-2015"**

*or*



COMMENTARY

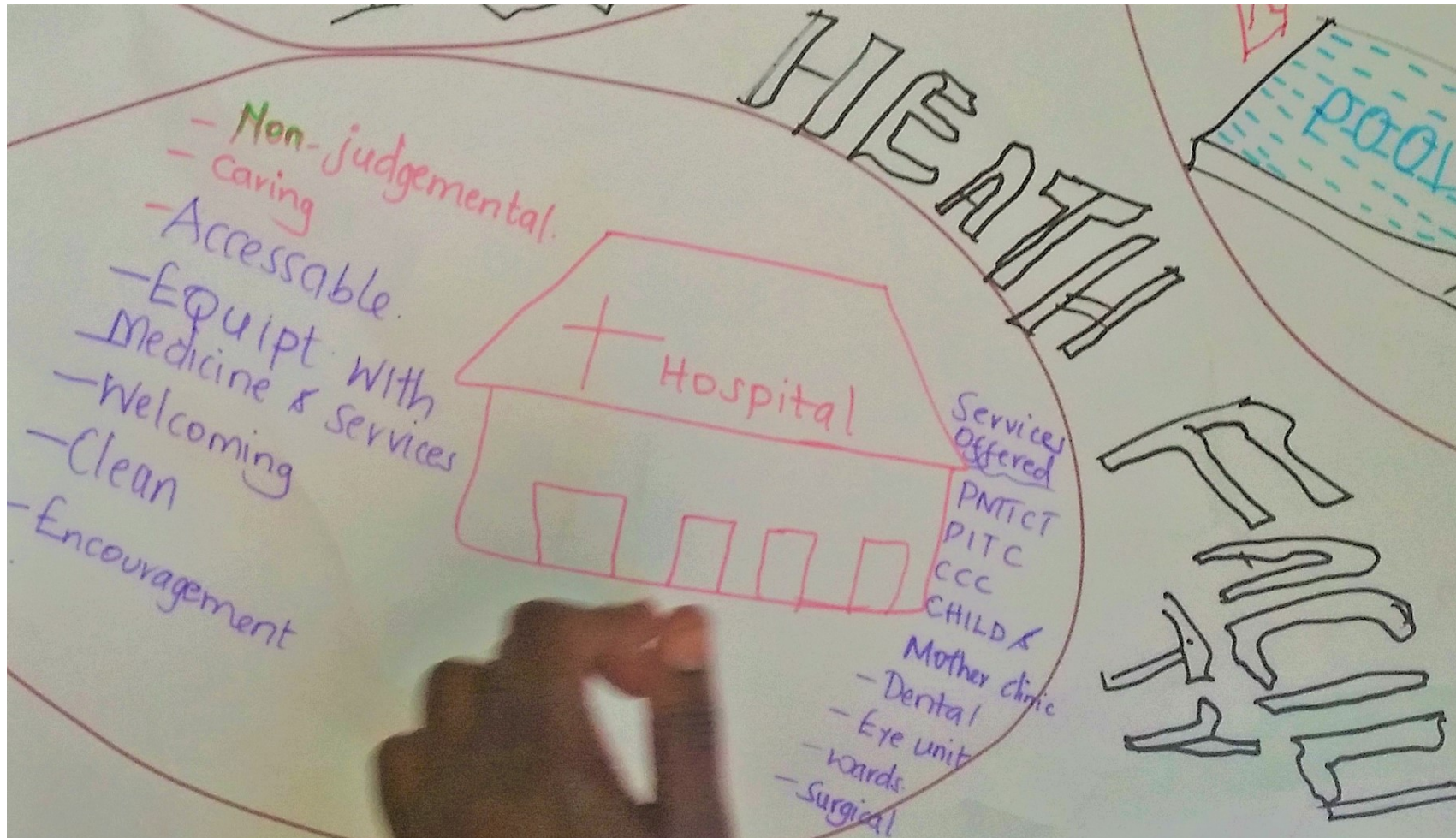
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## **Towards an HIV-free generation: getting to zero or getting to rights?**

Amina Chitembo,<sup>a</sup> Sophie Dilmitis,<sup>b</sup> Olive Edwards,<sup>c</sup> Carrie Foote,<sup>d</sup>  
Leasuwan Griffiths,<sup>e</sup> Svetlana Moroz,<sup>f</sup> Lydia Mungherera,<sup>g</sup> Lillian Mworeko,<sup>h</sup>  
Jo Manchester,<sup>i</sup> Shari Margolese,<sup>j</sup> Angelina Namiba,<sup>k</sup> Susan Paxton,<sup>l</sup>  
Gracia Violeta Ross,<sup>m</sup> Sita Shahi,<sup>n</sup> Susan,<sup>o</sup> Alice Welbourn<sup>p</sup>

Peri-natal peer support led by, with & for women living with HIV:

**4M = My Health, My Choice, My Child, My Life**



<https://tinyurl.com/4MIWD2018>



**MOTHERS AND  
INFANTS  
THRIVING**

#PADHIV #PositiveAffirmationDay 2<sup>nd</sup> December #PAD2017



**Salamander Trust**  
ON THE RIGHT(S) TRACK

## VIEWPOINT

## Eliminating Mother-to-Child Transmission of HIV by 2030: 5 Strategies to Ensure Continued Progress

Alexandra C. Vrazo,<sup>a</sup> David Sullivan,<sup>a</sup> Benjamin Ryan Phelps<sup>a</sup>

To keep up momentum in preventing mother-to-child transmission we propose: (1) advocating for greater political and financial commitment; (2) targeting high-risk populations such as adolescent girls and young women; (3) implementing novel service delivery models such as community treatment groups; (4) performing regular viral load monitoring during pregnancy and postpartum to ensure suppression before delivery and during breastfeeding; and (5) harnessing technology in monitoring and evaluation and HIV diagnostics.

# VIOLENCE as a barrier to Treatment:

## Global Treatment Access Review



KEY BARRIERS TO WOMEN'S  
ACCESS TO HIV TREATMENT:  
A GLOBAL REVIEW



"I am living with HIV since 2007; married and I've got two sons. After several years of marriage, my husband was very ill and his health deteriorated so much, we went to the hospital and after doing lot of tests and analyses proved to us that he was infected with the virus, and a few days after his death, doctors have conducted tests for me and my sons. I was shocked to discover my disease and since started my journey with the torment of society that does not have mercy on the one hand and on the other hand, **his family refused to accept us, me.** It did not stop at that, even **my sister accused me of moral corruption** because of the virus and then **she and my brothers kicked me off** from my father's house, where I didn't go there since. I was also exposed to many cases of stigma and discrimination, for example; while I had to stay in hospital for several days, and specifically in the Department of Rheumatology **the medical team put a banner reading: "'Beware sick with AIDS'."**

*Respondent from Tunisia*



Salamander Trust  
TRANSFORMING THE WAY WE THINK ABOUT HIV



See: <https://cdn2.sph.harvard.edu/wp-content/uploads/sites/125/2017/12/Orza.pdf>

And <http://genderandaids.unwomen.org/->

/media/files/un%20women/geha/resources/key%20barriers%20to%20womens%20access%20to%20treatment-v4.pdf?vs=3230

# REFRAMING the hierarchy of evidence: *from a pyramid.....*

Figure 4: Conventional hierarchy of evidence



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Figure 4: Conventional hierarchy of evidence

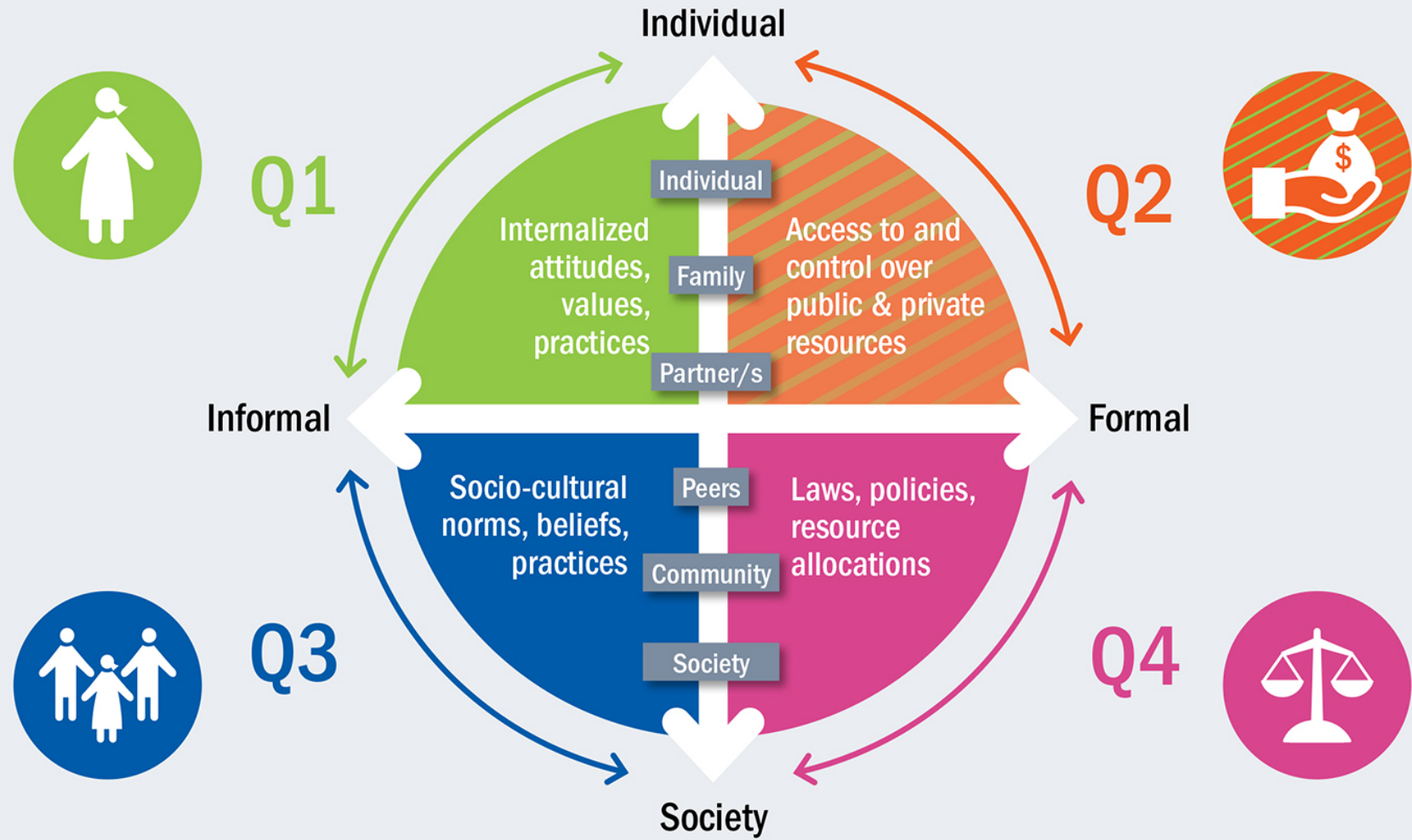


# REFRAMING the hierarchy of evidence: *from a pyramid.....*

Figure 4: Conventional hierarchy of evidence



Figure 5: The change matrix<sup>65</sup>



**AIDS  
LEGAL  
NETWORK**



**UNAIDS**



## “Targets for 2015:



- \* 90 % reduction of new HIV infections among children
- \* 50 % reduction in AIDS-related maternal mortality
- \* Start all pregnant and breastfeeding women on Option B+ (tx for life)
- \* World Health Organization's (WHO's) aptly named “Treat All” guidelines”

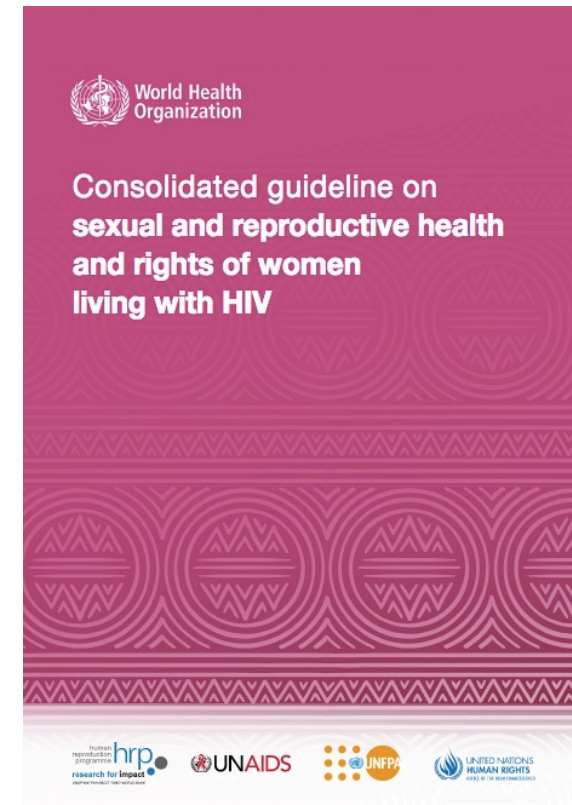
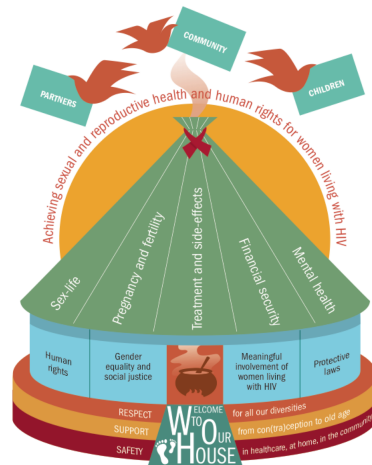
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6024627/>

## Q1: Internalized *gender-equitable* attitudes, values and practices

- More women and girls, in all their diversity, know about their rights and have the skills and knowledge to claim them.
- More women and girls can recognize, name and reject different forms of violence and know where to seek redress if they experience any of these.
- More men and boys individually recognize and uphold women's and girls' rights, and encourage, support and facilitate women and girls to claim their rights.
- More women can make and enact decisions about their healthcare, including avoiding unwanted pregnancies and sexually transmitted infections (STIs), and access harm reduction and HIV services.
- More women living with HIV can choose when and whether to have relationships and start a family or have more children.
- More women feel they can start a conversation about sex with their partners and children.
- More women and men make joint decisions about and share domestic responsibilities such as chores and childcare.

# WHO 2017 Consolidated Guideline on SRHR of Women Living with HIV: the process so far....

Oct 2013.....Jan 2015.....Feb 2017.....>>>>>>>



## TIMELINE – some key dates so far:

- Oct 2013: WHO contracted Salamander Trust to conduct survey
- 2014: Global survey conducted (survey monkey & FGDs)
- Jan 2015: Global meeting WHO Geneva to discuss [report](#)
- Dec 2015: Published JIAS Special Edition on SRH&R of women living with HIV with findings on [VAW](#) and [MH](#)
- April 2016: Guideline Development Group meets, Geneva
- Feb 2017: New WHO [Guideline](#) on SRHR of women living with HIV
- 2017: WHO Regional [Webinars](#) to disseminate the new Guideline
- 2018: Generic [Checklist](#) for Implementation Developed (funded by WHO)
- April 2018: Kenya Pilot Checklist Workshop (funded by UNAIDS)
- July 2018: Guideline and checklist [webinar](#) (funded by UNAIDS)
- July 2018: Checklist edition 2 [released](#) (funded by UNAIDS)

# Survey Report: Building a safe house on firm ground

**Global Reference Group members:** Nukshinaro Ao, Cecilia Chung, Sophie Dilmitis, Calorine Kenkem, Svetlana Moroz, Suzette Moses-Burton, Hajjarah Nagadya, Angelina Namiba, L'Orangelis Thomas Negrón, Gracia Violeta Ross, Sophie Strachan, Martha Tholanah, Patricia Ukoli, Rita Wahab.

**Core Team Members:** Luisa Orza, Alice Welbourn, Susan Bewley, E. Tyler Crone, Marijo Vazquez

**WHO:** Manjulaa Narasimhan



# Survey Process

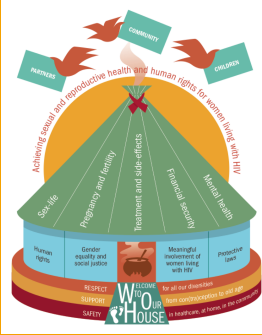
- Content developed *by and with GRG*
- Affirmative, solution-focused, forward thinking
- Conducted in 7 languages (English, Spanish, French, Russian, Chinese, Bahasi, Portuguese)
- 945 responses altogether: 832 respondents online,  
113 in 11 Focus Group Discussions
- from 94 countries
- Respondents aged between 15-72
- Respondents women living with HIV in all our diversity

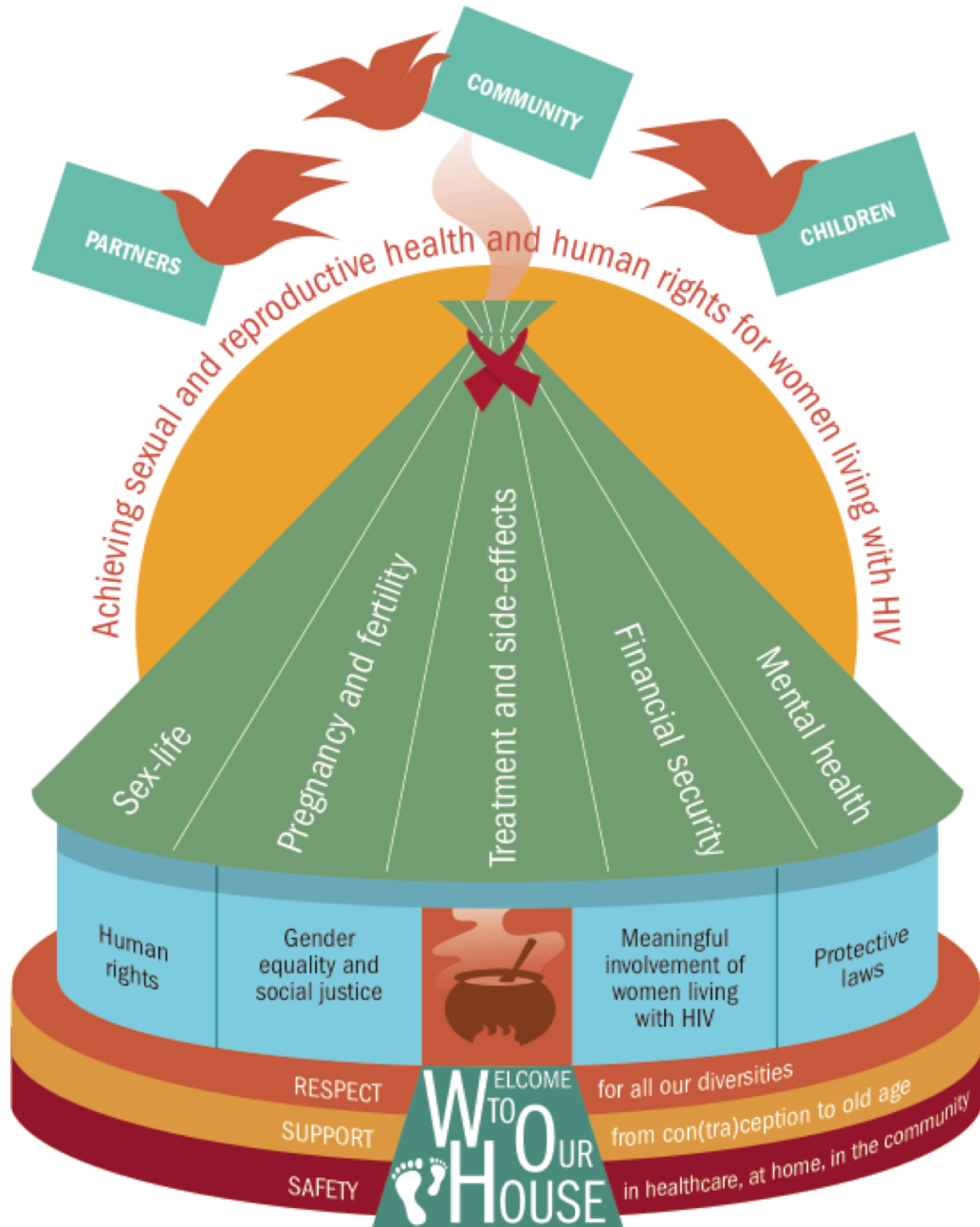
<http://tinyurl.com/womenHIVSRHR>

<http://www.who.int/bulletin/volumes/94/4/14-150912.pdf?ua=1>

<http://viruseradication.com/journal->

[details/Ethical,\\_strategic\\_and\\_meaningful\\_involvement\\_of\\_women\\_living\\_with\\_HIV\\_starts\\_at\\_the\\_beginning/](http://viruseradication.com/journal-details/Ethical,_strategic_and_meaningful_involvement_of_women_living_with_HIV_starts_at_the_beginning/)





## SOME KEY FINDINGS:

Close **similarities** in issues reported by women around the world

Multiple **complex** issues – see house model

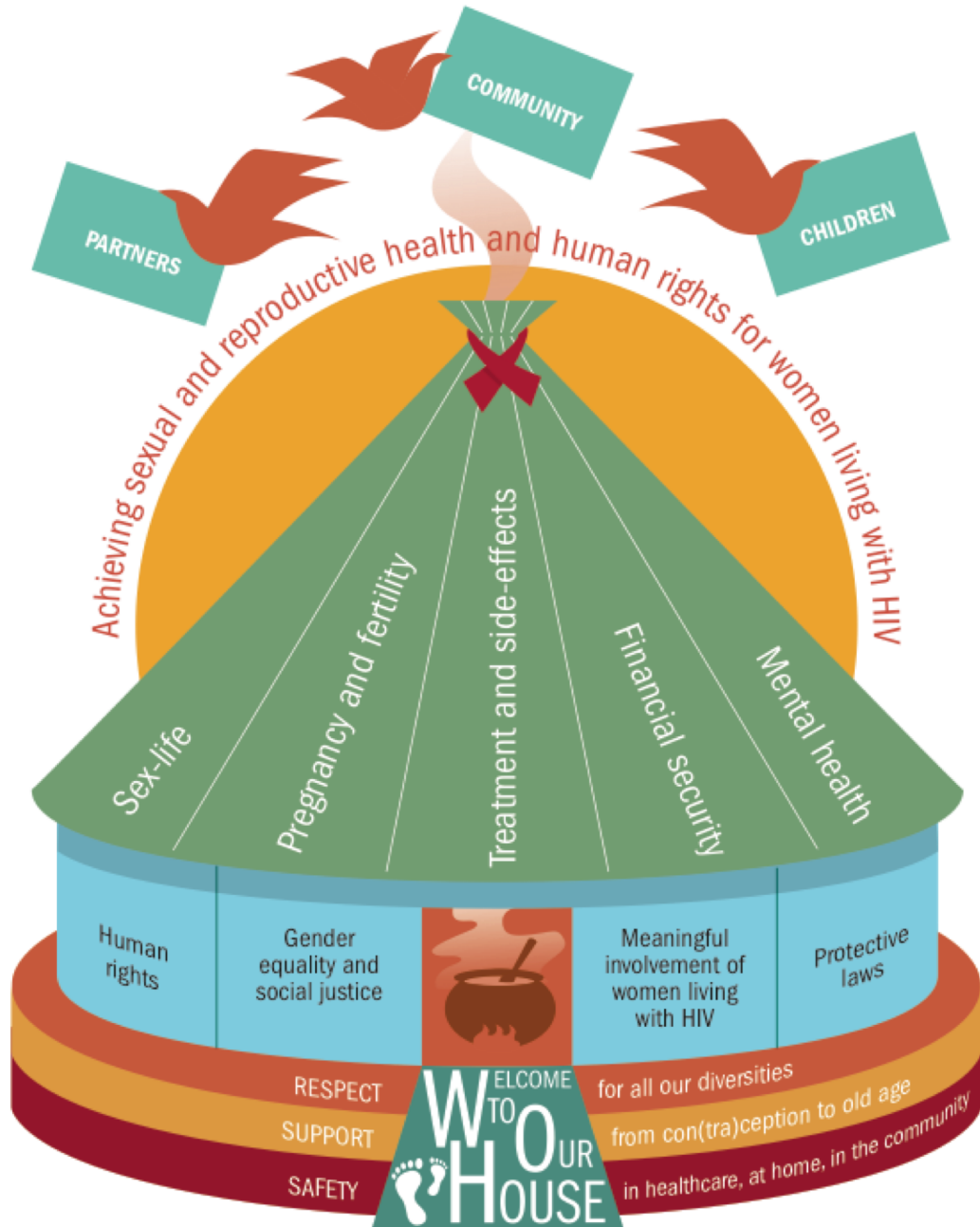
Marked *increase* in **VAW** in health care settings especially

Marked *increase* in **mental health** issues

Both the above *exacerbated* in women who also had *additional marginalised* identities

Huge call for issues facing women *across the lifespan* to be addressed

<http://tinyurl.com/womenHIVSRHR>



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# Guiding principles



- Woman-centred approach
- promotion of human rights
- gender equality

## Excerpt from Guideline - i

### **Box 4.3: A human rights-based approach to antiretroviral therapy (ART)**

All ART should be prescribed using a human rights-based approach. This means that the pregnant or breastfeeding woman receives full information and medical guidance that is appropriate to her situation, and is supported to make voluntary choices around medical therapy initiation, continuation and adherence/retention in care, as applicable. Health workers must help women to appropriately address their health-care needs and those of their children.

WHO SRH&R Guideline 2017:

<http://apps.who.int/iris/bitstream/10665/254885/1/9789241549998-eng.pdf?ua=1>

## Excerpt from Guideline - ii

### Values and preferences

Survey respondents emphasized the importance of: access to information relating to positive sexuality and sexual pleasure (including addressing gender norms and sexual taboos); access to psychosexual counselling; trust between intimate partners and also between clients and SRH providers; provision of support with regard to disclosure; and access to SRH providers who are sensitized and well informed about the SRH needs of women in same-sex relationships and transgender women (37).



WHO SRH&R Guideline 2017:

<http://apps.who.int/iris/bitstream/10665/254885/1/9789241549998-eng.pdf?ua=1>

## Excerpt from Guideline - iii

### **6.2.1 Women living with HIV as equal partners in research**

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THANK YOU!

Alice Welbourn | Salamander Trust | [www.salamandertrust.net](http://www.salamandertrust.net)

