



World Health
Organization

Consolidated guideline on sexual and reproductive health and rights of women living with HIV



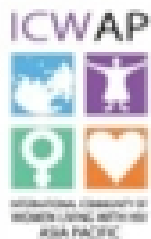
Building a safe house on firm ground

Presentation made at the launch of the new WHO Guideline on
SRH&R of women living with HIV

Co-hosted by the Royal College of Obstetricians and
Gynaecologists and the World Health Organization

London, 20 July 2017

Alice Welbourn, Salamander Trust



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GLOBAL NETWORK OF
PEOPLE LIVING WITH HIV



Transgender Law Center

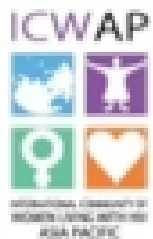
Making Authentic Lives Possible

Building a safe house on firm ground

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

GRG members: Nushinaro 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.

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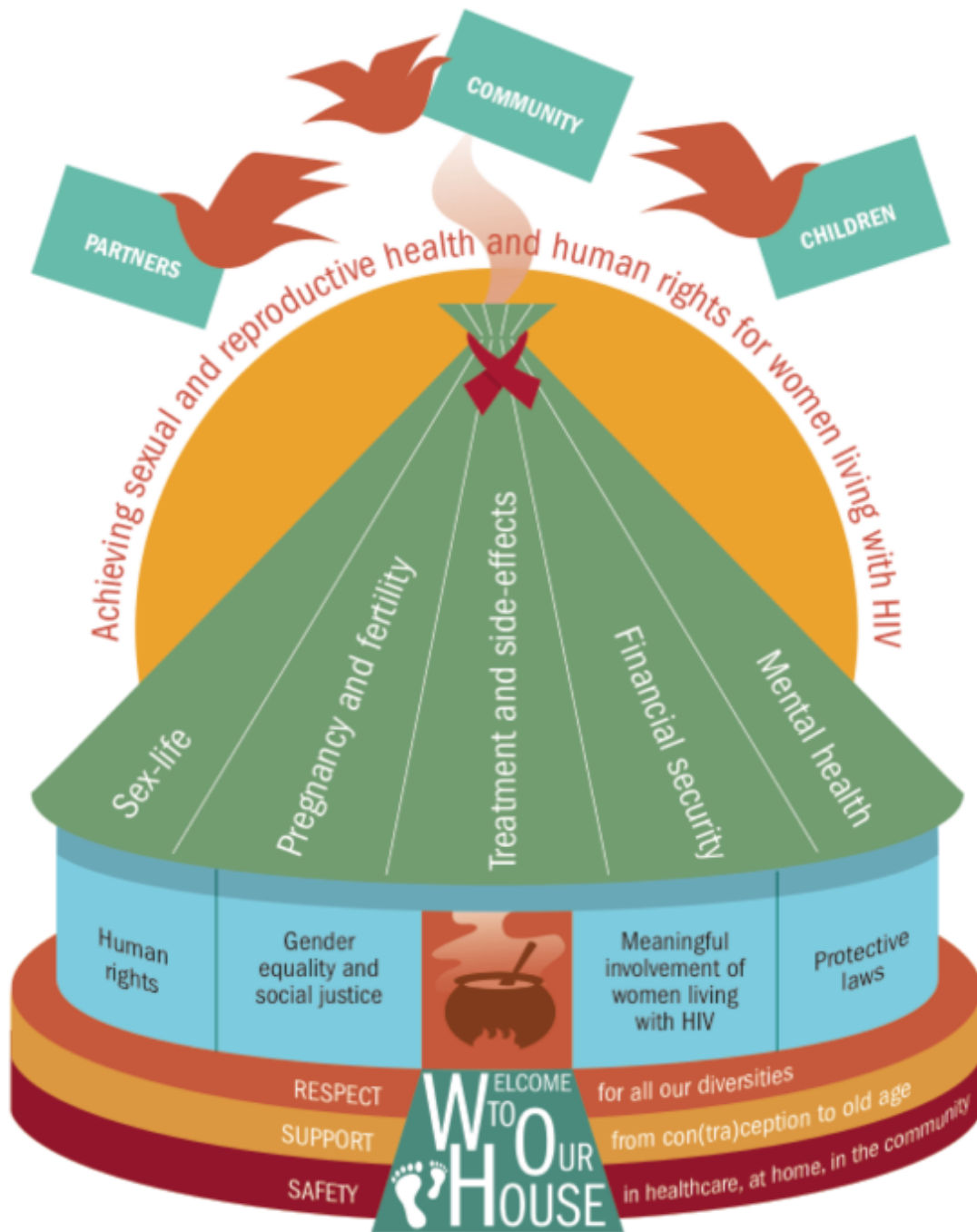
It is my great honour to say something about the background survey which informed this Guideline, and about our allies around world.

The title of our background values and preferences survey is called 'Building a Safe House on Firm Ground'.

You can see at the bottom of the slide above the logos of several different organisations with amazing women behind them.

Key names I'd like to honour are Luisa Orza and Susan Bewley, both members of the core research team: huge thanks to you both.

We are also lucky to have two global reference group members here: Angelina Namiba and Sophie Strachan. You will have seen others of this group in the [slideroll](#) at the beginning: these are all inspirational women to work with.



<http://tinyurl.com/womenHIVSR>
[HR](#)

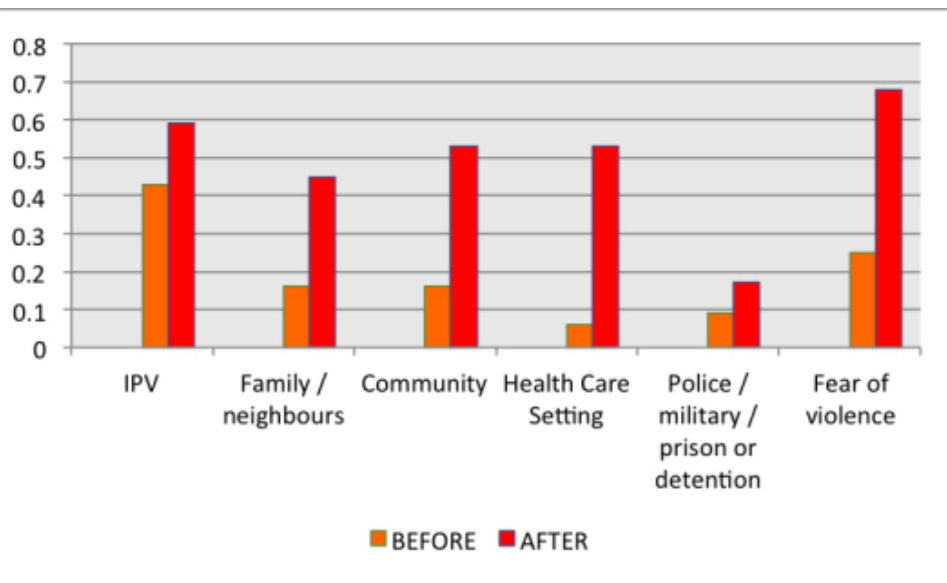
945 respondents from 94 countries aged between 15-72 in all our diversity responded to the survey. The idea was to involve women from many different regions of the world, ethnic variations, indigenous migrants, refugees, women who contracted HIV from all different routes, women from all walks of life: we wanted that diversity to shape the survey and we are grateful for the huge commitment they made. Jane Shepherd, also here tonight, constructed the beautiful image of the safe house on firm ground.

An intrinsic part of the house is that it is a safe shelter, and you can see that it is also made up of so many components. At the bottom we have safety, support, and respect as key foundations. Then we have what makes up the strong walls: human rights, gender equality and social justice, meaningful involvement of women living with HIV and protective laws. Then we have different roof slates: sex life, pregnancy and fertility, treatment and side effects, financial security, and mental health.

Then we have the beautiful sun rising, around which it says 'Achieving sexual and reproductive health and human rights for women living with HIV'. Above the sun there are 3 birds holding cards saying 'partners', 'community' and 'children'. The principle behind the house is that we have complex dimensions to our lives as women living with HIV: at all stages we need to look at this from lifelong perspectives and the complicated things going on in our lives.

The key point about the birds is, if you help us achieve our sexual and reproductive rights, then we, in turn, will be able to support our partners and children and communities: and, just as we are all told on aeroplanes about putting our oxygen masks on first, before we help others, it is absolutely critical that our rights are achieved first.

Results from 58% of 832 survey respondents on Gender-Based Violence (GBV)



- High **IPV** levels before and after diagnosis.
- Higher levels of other violence experienced *post*-diagnosis in **health settings** & in the **community**

- **89%** reported experiencing at least one type of violence
 - (UK 80%)
- Experiences of violence in the health care setting often **worse** for women with *other* socially disadvantaged identities

Orza et al 2015a, [JIAS](#)



One key thing that came up were issues around violence. We know about the work of Charlotte Watts at the LSHTM and her team's work with WHO on the multi-country study – and how intimate partner violence can increase vulnerability to HIV among women by a factor of [1.5](#).

What has not been so clear, and this survey brought it out, is how a lot of women who responded to the survey described violence. Some women had not experienced intimate partner violence (IPV), pre-diagnosis, but then it started after their diagnosis. Some had experienced some pre-diagnosis and it increased post-diagnosis. What is perhaps really shocking, though it had already been reported widely by women living with HIV in 'anecdotal' evidence, is what is happening to women in health care services. Before diagnosis, the level of violence against them in healthcare settings was small, after diagnosis it is high. We are very concerned about this.

Ethics of Guidelines and Research?



- “...we conclude that erroneous justifications were initially given in support of Option B+. We identify tensions that remain in light of these results and argue that future strategies would benefit from a community-focused, human rights-based approach.” *Hodson N and Bewley S. JVE 2017; 3: [163–166](#)*
- “In this review, we found the amount of peer-reviewed literature to directly address human rights and the SRH of women living with HIV to be far more limited than expected in terms of quantity, and what does exist only addresses a few rights in the context of a few areas within SRH.” *Kumar S, et al. JIAS 2015; 18 ([Supp 5](#))*
- “Most studies placed greater emphasis on instrumental health outcomes to prevent HIV transmission than on the intrinsic well-being and SRH of women living with HIV.” *Beres L et al. AIDSCARE [2017](#); 29, 9.*

So there is a big disconnect between policies and research, which are focusing on getting women on treatment as soon as they are diagnosed and getting them to 'disclose' to others, and the realities facing many women once diagnosed . A woman is offered treatment - and it is supposedly a choice but the way the policy has been interpreted by healthcare providers means that it is often *not* a choice. And to start anything on day one after a major diagnosis like this is a huge ask. Then for women who decide *not* to start treatment straight away, they're often labelled as 'defaulters': there is a lot of blame in the language around these issues. As part of my preparation for today's talk, I did a word count of how many times the word 'violen' (ie the stem of 'violent' and 'violence') appeared in the 480 page long 2016 WHO Guideline on [ARVs](#), published by the HIV Department. In this whole document, the word appeared 3 times.

By contrast, in this new women-centred [Guideline](#) being launched here, which is only 1/3 of the length, I gave up counting after the first 200 mentions of the word. As a social anthropologist I see my role as seeking to put our feet into the shoes of others, to see things from different perspectives. I see here therefore a disconnect between policies and guidelines such as this ARV Guideline and the realities of women's lives as we see in the new SRH&R Guideline. We need to bring the ARV Guideline also in line with women's realities and rights. If we *don't* start treatment right away, then there are valid reasons for why women do that, to keep us safe. If women go home with medication or if they are pushed into 'disclosure', when they don't feel safe at home, then they will fear what is going to happen both to themselves and to their children. So *not* taking medication and *not* telling anyone is the safer and rationale decision.

So that is what is great about this new Guideline – being women-centred and based on our own experiences, it puts women's rights – to safety, respect & support, and to everything else in the house image - first.

In conclusion, it was so great to hear Lesley say how the new Guideline could be woven into the new HIV component of the RCOG training materials.

There is so much scope here for a win-win situation - to make life better for women: and then, as women always do around the world, we will *of course* make sure that we are supporting our communities, our children, and our partners, who will then all benefit also.

And healthcare providers will then benefit too. Thank you all so much.