

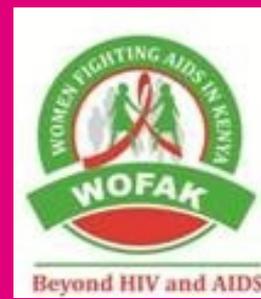
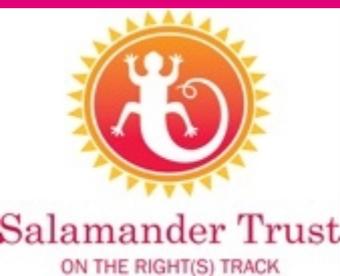
Background introduction to the WHO Guideline on the SRHR of women living with HIV

Alice Welbourn

Salamander Trust

Nairobi Implementation Workshop

April 2018





I was diagnosed in 1992
when I was expecting a baby.

I am still fit and well, and am
about to turn 60.

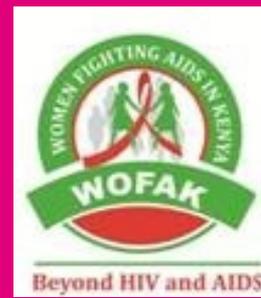
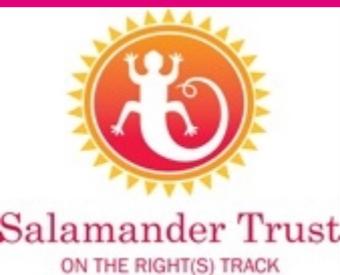
All women living with HIV
should have the same
access to our SRHR as I have
been privileged enough to
enjoy.



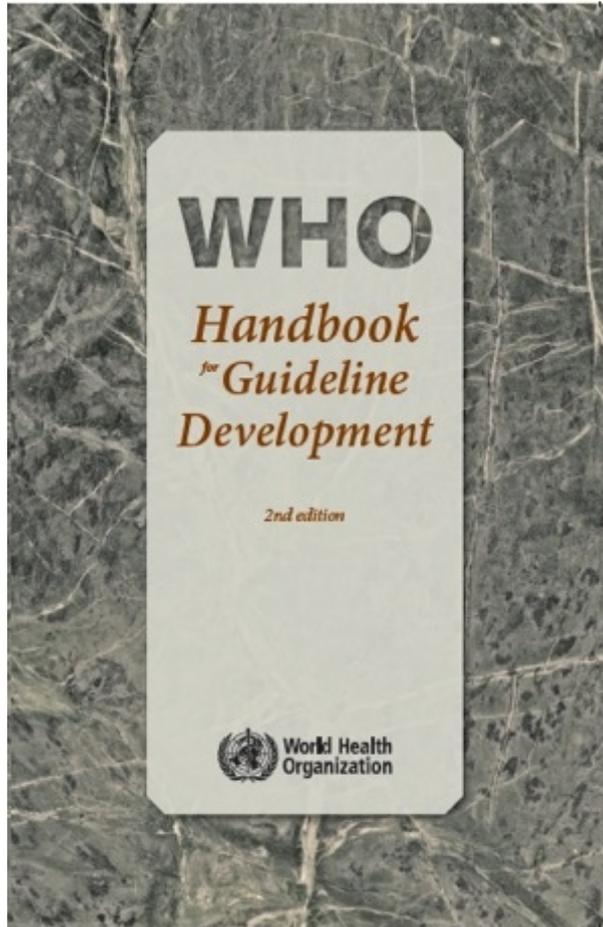
World Health
Organization

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

What do sexual and reproductive health and rights mean to *you*?

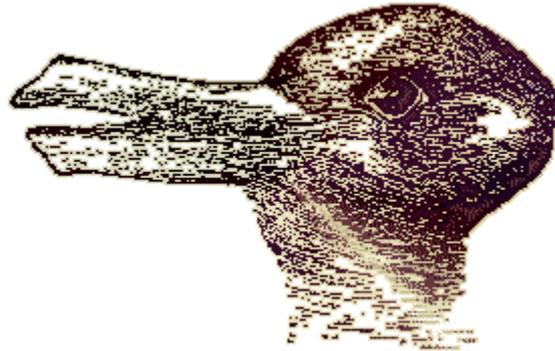


What is a WHO guideline?



- “A **WHO guideline** is any document, whatever its title, that contains WHO recommendations about health interventions, whether they be clinical, public health or policy interventions.”
- “A **recommendation** provides information about what policy-makers, health-care providers or patients should do. It implies a choice between different interventions that have an impact on health and that have ramifications for the use of resources.”

Different viewpoints.....



Some people can only see one, some people can only see the other.....
We need to help one another to see both.....



Salamander Trust
ON THE RIGHT(S) TRACK

Guiding principles



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

TIMELINE – some key dates so far:

October 2013: WHO contracted Salamander Trust to conduct survey

2014: Global survey conducted through survey monkey & with FGDs

Jan 2015: Global meeting in WHO Geneva to present & discuss [report](#)

Dec 2015: Published JIAS Special [Edition](#) on SRH&R of women living with HIV

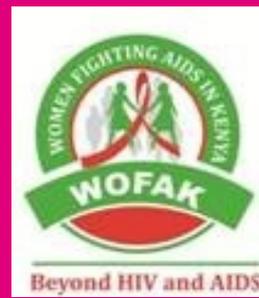
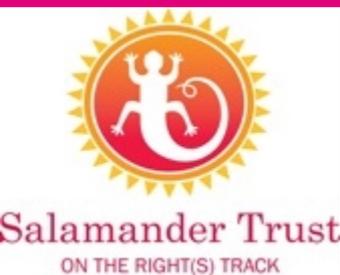
April 2016: Guideline Development Group meets, Geneva

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)



Survey Report: Building a safe house on firm ground

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.

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

WHO: Manjulaa Narasimhan



GLOBAL NETWORK OF
PEOPLE LIVING WITH HIV

Transgender Law Center

Making Authentic Lives Possible

This was a huge collaborative effort, as you can see from all the logos along the bottom of this slide.

Our Global Reference Group was made up of women living with HIV in all our diversity – some have grown up with HIV, others through various other routes of transmission, some of us are still young, others rather older, from all corners of the world. We wanted to ensure this diversity of experience, insight and perspectives on purpose.

Huge thanks especially to Luisa Orza and Susan Bewley, Tyler Crone of ATHENA Network and former ICW Chair Marijo Vazquez, who were all part of the CORE TEAM- and also to all the Global Reference Group members- and to Jane Shepherd, our Graphic Designer, who created the beautiful house image for us.

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 here the logos of several different organisations with amazing women behind them.

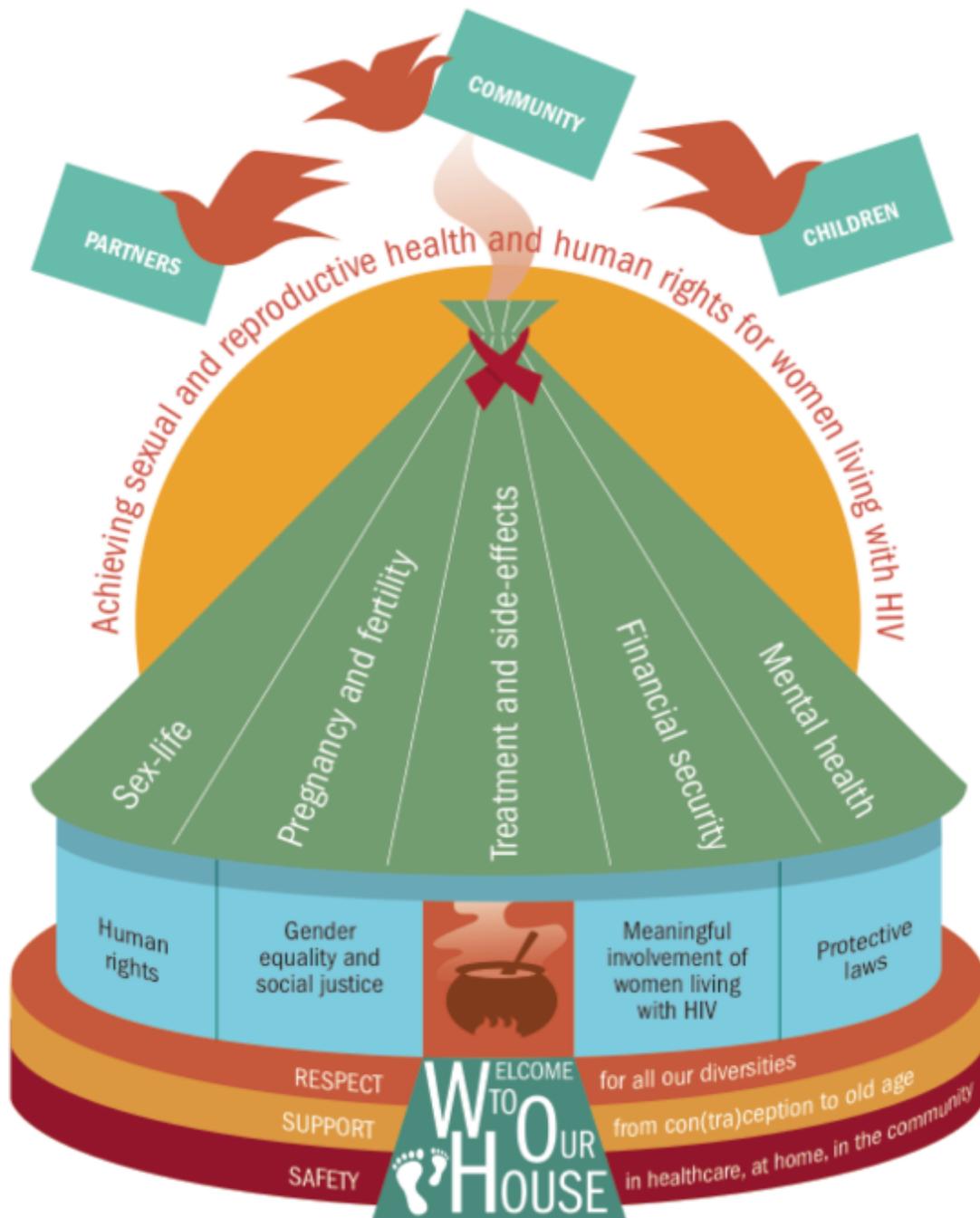


GLOBAL NETWORK OF PEOPLE LIVING WITH HIV



Transgender Law Center

Making Authentic Lives Possible



<http://tinyurl.com/womenHIVSRHR>

And here above is the famous **house** we created - you can see it is a house of many parts - from the foundation layers - right through the walls and the roof parts.

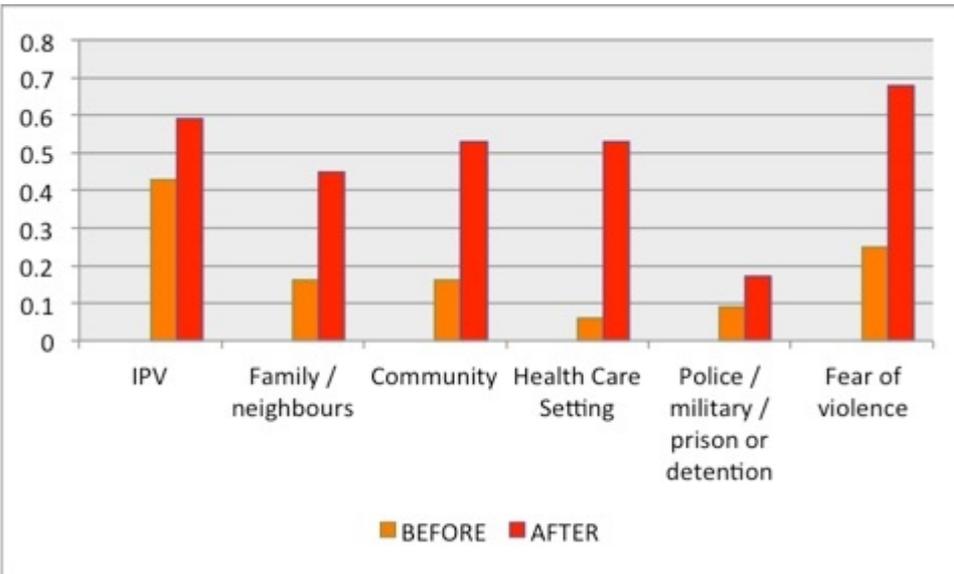
We had 945 responses altogether. 832 respondents from 94 countries aged between 15-72 in all our diversity responded to the online survey. A further 113 contributed through FGDs using the same questions in different countries where they didn't have access to the internet. The idea was to involve women 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, another woman living with HIV, 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 for example, sex life, pregnancy and fertility, treatment and side effects, financial security, mental health. Then we have the beautiful sun, and it says 'Achieving sexual and reproductive health and human rights of women living with HIV'. Above the sun there are **3 birds holding placards** 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 in our lives. The key point about **the birds** is, if you help us achieve our sexual and reproductive rights, we in turn will be able to support our partners and children and communities: and, like we are all told about putting our oxygen masks on first on aeroplanes, 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
- Experiences of violence in the health care setting often **worse** for women with *other* socially disadvantaged identities



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

- One key thing that came up were issues around violence. We know about the work of the LSHTM and its with WHO on the multi-country study – and how partner &/or sexual 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 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.
- Orza L et al. Journal of the International AIDS Society 2015, 18(Suppl 5):20285
- <http://www.jiasociety.org/index.php/jias/article/view/20285> | <http://dx.doi.org/10.7448/IAS.18.6.20285>
- <http://salamandertrust.net/project/salamander-trust-survey-sexual-reproductive-health-human-rights-women-living-hiv/>



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

Journal of Health & Human Rights Dec 2017



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

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**. On the one hand there are policies and research, which are focusing primarily on getting women on treatment as soon as they are diagnosed, on their 'disclosure' to partners, and seeking to reduce the possibility of onward transmission to partners and children.

However **from women's perspectives these priorities may be provoking violence**, which can be dangerous both for the women themselves and their children, given the realities facing many women once diagnosed.

For example, WHO's current policy is for a woman to start treatment for life on the day she is diagnosed. So she 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.

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 right first.

Different viewpoints.....



Some people can only see one word, some people can only see the other.....
We need to help one another to see both.....

DISCRIMINATION-FREE HEALTH-CARE SETTINGS

IS YOUR HEALTH FACILITY FREE FROM DISCRIMINATION? MINIMUM STANDARDS HEALTH-CARE SETTINGS COULD USE TO ENSURE A DISCRIMINATION-FREE ENVIRONMENT FOR PATIENTS AND HEALTH-CARE PROVIDERS INCLUDE THE FOLLOWING:

01.

THE HEALTH-CARE CENTRE SHOULD PROVIDE TIMELY AND QUALITY HEALTH CARE TO ALL PEOPLE IN NEED, REGARDLESS OF GENDER, NATIONALITY, AGE, DISABILITY, ETHNIC ORIGIN, SEXUAL ORIENTATION, RELIGION, LANGUAGE, SOCIOECONOMIC STATUS, HIV OR OTHER HEALTH STATUS, OR ANY OTHER GROUNDS.

02.

INFORMED CONSENT IS REQUESTED FROM THE PATIENT BEFORE ANY TESTS ARE CARRIED OUT OR ANY TREATMENT IS PRESCRIBED. FURTHERMORE, PATIENTS ARE NOT FORCED TO TAKE UP OR REQUEST ANY SERVICES.

03.

HEALTH-CARE PROVIDERS RESPECT THE PATIENT'S PRIVACY AND CONFIDENTIALITY AT ALL TIMES.

04.

HEALTH-CARE PROVIDERS ARE REGULARLY TRAINED AND HAVE SUFFICIENT CAPACITIES AND COMPETENCIES TO PROVIDE SERVICES FREE FROM STIGMA AND DISCRIMINATION.

05.

THE HEALTH-CARE CENTRE HAS MECHANISMS IN PLACE TO REDRESS EPISODES OF DISCRIMINATION AND VIOLATION OF THE RIGHTS OF ITS CLIENTS AND ENSURE ACCOUNTABILITY.

06.

THE HEALTH-CARE CENTRE ENSURES THE PARTICIPATION OF AFFECTED COMMUNITIES IN THE DEVELOPMENT OF POLICIES AND PROGRAMMES PROMOTING EQUALITY AND NON-DISCRIMINATION IN HEALTH CARE.

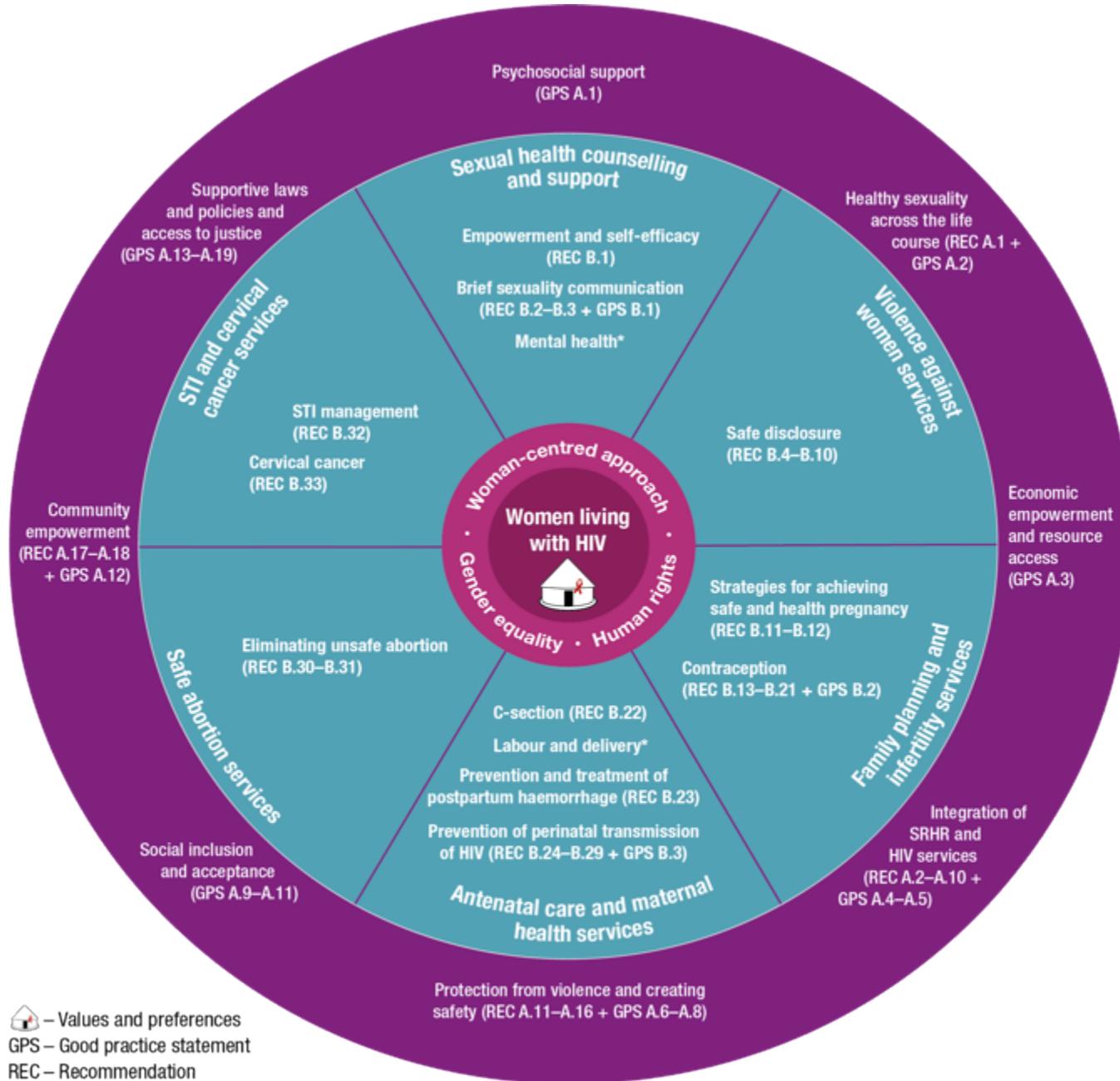
AGENDA
FOR ZERO
DISCRIMINATION
IN HEALTH-CARE SETTINGS



New Recommendations and Good Practice Statements....



This diagram is from the 2017 WHO Guideline on the SRHR of women Living with HIV



C-section: caesarean section; SRHR: sexual and reproductive health and rights; STI: sexually transmitted infection.

* For sections on "Mental health" and "Labour and delivery", this guideline does not include any RECs or GPSs but refers to existing WHO guidance.

Table 10.1. Factors that determine the direction and strength of a recommendation

Factor	How the factor influences the direction and strength of a recommendation
Quality of the evidence	The quality of the evidence across outcomes critical to decision-making will inform the strength of the recommendation. The higher the quality of the evidence, the greater the likelihood of a strong recommendation.
Values and preferences	This describes the relative importance assigned to health outcomes by those affected by them; how such importance varies within and across populations; and whether this importance or variability is surrounded by uncertainty. The less uncertainty or variability there is about the values and preferences of people experiencing the critical or important outcomes, the greater the likelihood of a strong recommendation.
Balance of benefits and harms	This requires an evaluation of the absolute effects of both benefits and harms (or downsides) of the intervention and their importance. The greater the net benefit or net harm associated with an intervention or exposure, the greater the likelihood of a strong recommendation in favour or against the intervention.
Resource implications	This pertains to how resource-intensive an intervention is, whether it is cost-effective and whether it offers any incremental benefit. The more advantageous or clearly disadvantageous the resource implications are, the greater the likelihood of a strong recommendation either for or against the intervention.
Priority of the problem	The problem's priority is determined by its importance and frequency (i.e. burden of disease, disease prevalence or baseline risk). The greater the importance of the problem, the greater the likelihood of a strong recommendation.
Equity and human rights	The greater the likelihood that the intervention will reduce inequities, improve equity or contribute to the realization of one or several human rights as defined under the international legal framework, the greater the likelihood of a strong recommendation.
Acceptability	The greater the acceptability of an option to all or most stakeholders, the greater the likelihood of a strong recommendation.
Feasibility	The greater the feasibility of an option from the standpoint of all or most stakeholders, the greater the likelihood of a strong recommendation. Feasibility overlaps with values and preferences, resource considerations, existing infrastructures, equity, cultural norms, legal frameworks, and many other considerations.

GRADE =
Grading of
Recommendations
Assessment,
Development and
Evaluation

This table is from
the WHO
Guideline
Development
Handbook, 2nd
Edition,
November 2014

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

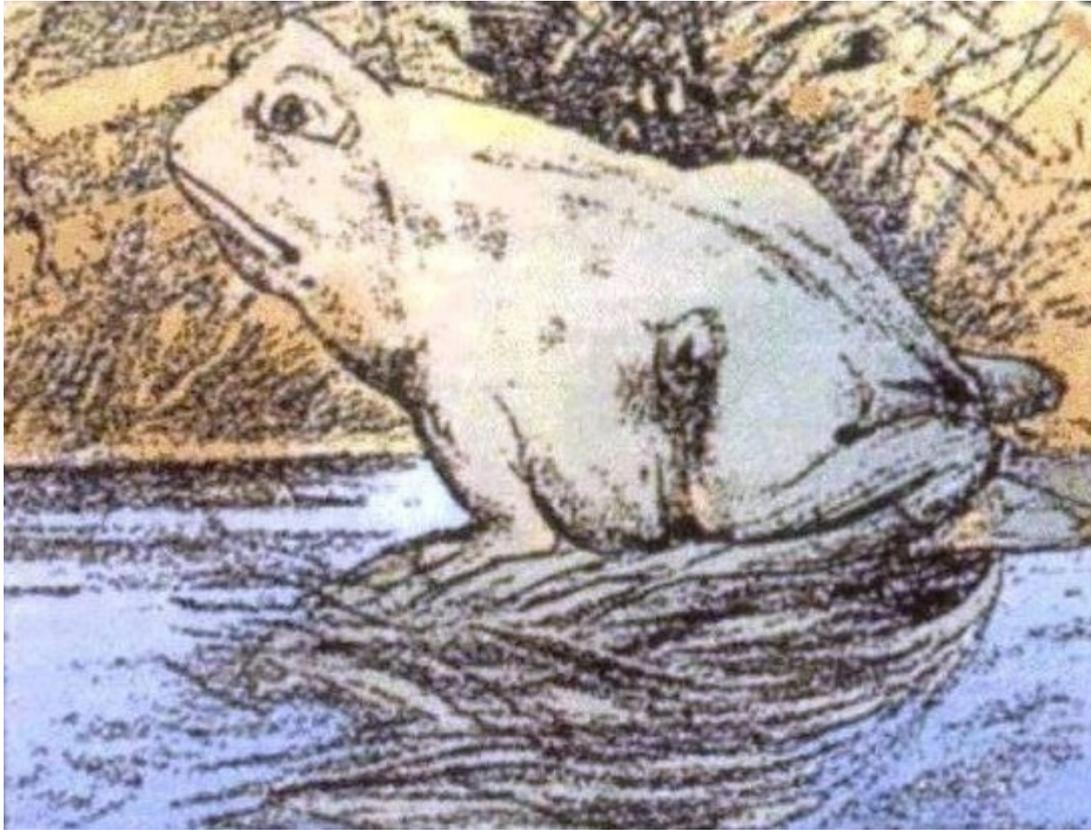
6.2.1 Women living with HIV as equal partners in research

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.

WHO SRH&R Guideline 2017:

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

Different viewpoints.....



Some people can only see one, some people can only see the other.....
We need to help one another to see both.....

Effective Implementation

A pair of hands, one from a darker-skinned person and one from a lighter-skinned person, are shown holding a small green plant with soil. The background is a soft, warm gradient of yellow and orange. The plant has several green leaves and a thin stem. The hands are positioned as if they are gently supporting the plant, symbolizing care, growth, and collaboration.

Action on the recommendations in this guideline requires a strategy that is informed by evidence, appropriate to the local context, and responsive to the needs and rights of women living with HIV.

In conclusion, it is so great to be here listening to how you plan to weave this new Guideline into existing Kenyan policies and practices. 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!

Slides acknowledgements:

Thank you to Dr Manjulaa Narasimhan, Dept of Reproductive Health and Research, WHO for slides no. 3,5,7,16 and 23

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