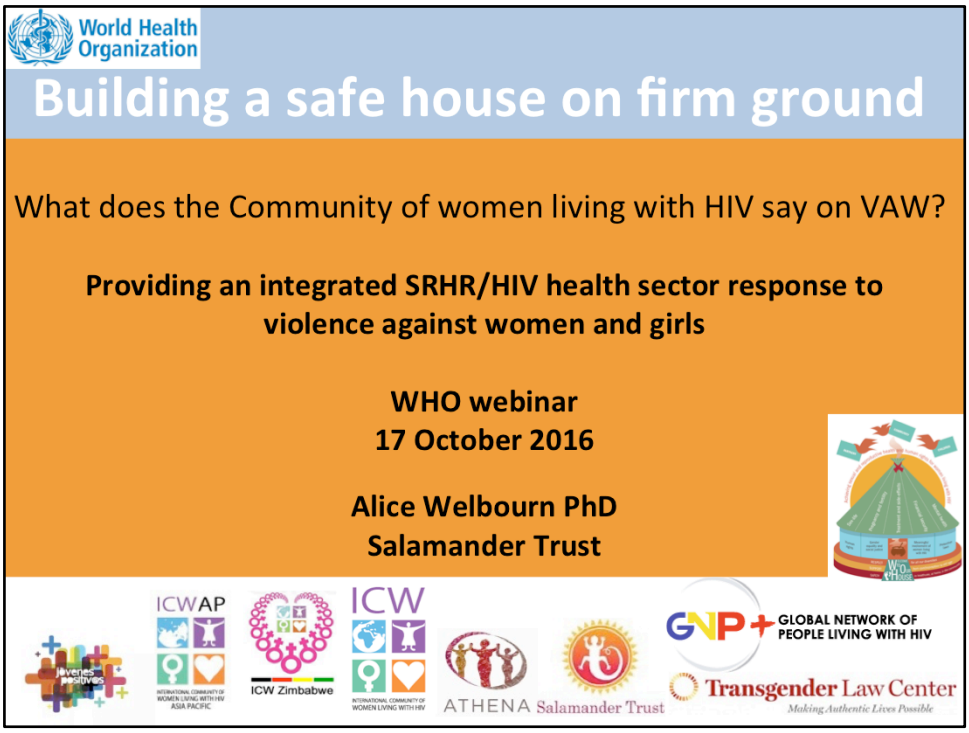


Thank you Ian for welcoming me and thank you to all for inviting me to present today.

I'm sharing today some findings on violence against women (VAW) living with HIV from a global survey which we conducted in 2014.

This was a huge collaborative effort, as all the logos show at the bottom of this slide. Two of us in the core team, Marijo Vazquez and myself, are women living with HIV. And all 14 of our Global Reference Group (GRG) members are leading women living with HIV around the world. They have diverse ages, are from diverse regions, have diverse routes of HIV acquisition and diverse other identities. We sought from the outset to develop a sense of inclusivity in this survey, reflected by the diversity of the GRG. We also worked closely with Dr Manjulaa Narasimhan of WHO, who commissioned us to conduct this survey, which was a values and preferences survey to inform the new guidelines on sexual and reproductive health and rights (SRHR) of women living with HIV, which is due to be published shortly.

Background: WHO survey

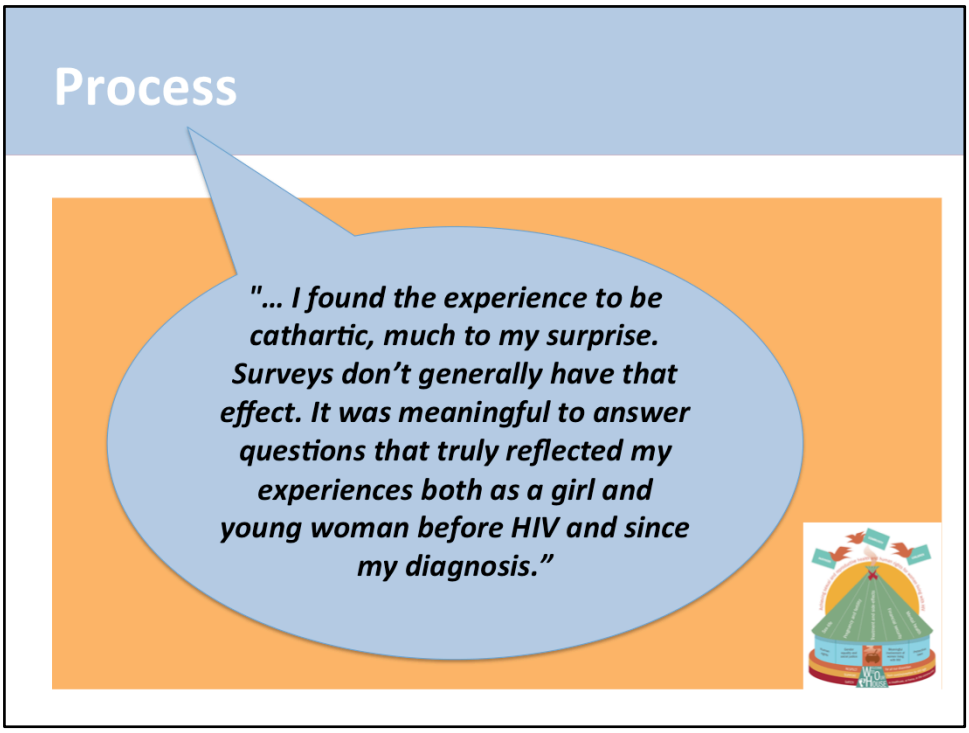
- Values and Preferences Survey to update SRH & HR **guidelines**
- Led by a **Global Reference Group** of 14 women living with HIV
- User-led, **participatory**, community-based research
- 7 **languages** & 5 more through Focus Group Discussions
- Used positive, future-oriented "**appreciative inquiry**"

✧ **945** women living with HIV from **94** countries

✧ Aged **15-72**, women with HIV in all their **diversities**

➢ **Largest** global survey of women living with HIV

To explain a bit more the background to the survey: the GRG guided and shaped the survey content. The survey was user-led, participatory and community based. It used positive, future oriented "appreciative inquiry" language − and we will say a bit more about this shortly.

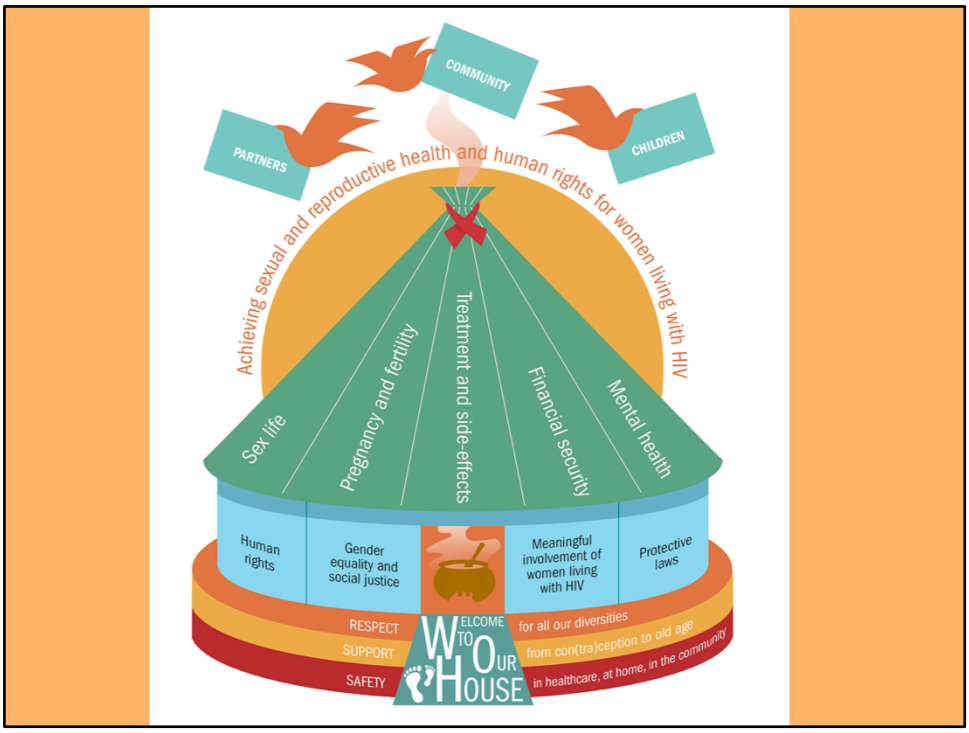


Here is one quote from one respondent. Surveys themselves can be violent. They can retraumatise women, throwing them back to memories of dark times and places. So we were anxious to ensure that this survey would not do that and observed both WHO's own ethical guidelines on research with women who have experienced domestic violence; and guidelines we developed at the International Community of Women living with HIV back in 2004, on ethical involvement of women living with HIV in research.

So we were glad to see this comment from one respondent. For more on the methodology see below.

Narasimhan, M., Orza, L., Welbourn, A., Bewley, S., Crone, T. and Vazquez, M. (2016). Sexual and reproductive health and human rights of women living with HIV: a global community survey. ***Bulletin of the World Health Organization*, 94(4), pp.243-249.**

Namiba, A., Orza, L., Bewley, S., Crone, E., Vazquez, M. and Welbourn, A. (2016). Ethical, strategic and meaningful involvement of women living with HIV starts at the beginning. ***Journal of Virus Eradication***, [online] 2, pp.110-111. Available at: http://viruseradication.com/journal-details/Ethical,_strategic_and_meaningful_involvement_of_women_living_with_HIV_starts_at_the_beginning/ [Accessed 10 May 2016].



Here we have the image of a house that we used to present the survey report, which we entitled “Building A House on Safe Ground”. There are different key elements of a house, similar to different key elements of a woman’s life. You need all these elements to make a house stand up firm and strong − all are important, all are needed. The house reflects the holistic nature of the survey, where we explored the psycho-social, sexual, physical, material and spiritual well-being of women’s lives across the life-span, from conception to death.

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

- **89%** reported experiencing at least one type of violence
  - From an **intimate partner**: 59%
  - From **family or neighbours**: 45%
  - In the **community**: 53%
  - In the **health care setting**: 53%
  - From **police / military / prison or detention**: 17%
  - **Fear** of violence: 68%
- High IPV levels before and after diagnosis. Higher levels of violence experienced ***post***-diagnosis in **health settings** & in the **community**
- Experiences of violence in the health care setting often ***worse*** for women with *other* socially disadvantaged identities

Here are the results about GBV from the survey. The survey had 1 mandatory and 8 optional sections. GBV was highlighted in responses to *all sections* of the survey.
58% of the 832 on-line participants responded to the GBV section. Of these, 89% reported experiencing at least 1 type of violence.

While reported IPV was already high at 43%, pre-diagnosis, it rose to 59% after diagnosis.

The most marked increases were GBV from family or neighbours and from the community, which rose from 16% each pre-diagnosis to 45% and 53% respectively.

The highest increase was in relation to violence experienced by women in healthcare settings, which jumped from 6% pre-diagnosis to 53% after diagnosis.

Examples of GBV in healthcare settings included: * Breach of confidentiality; * Coerced testing; * Coerced disclosure to partner and in-laws, which can trigger violence from *them;*

- Coerced treatment initiation; * Coerced abortion; *Coerced sterilisation; * Coerced long-term contraceptives; * or Withdrawal of contraceptive services on the basis that women should not be having sex or children;
- Verbal abuse; * Lack of support during delivery; * And women reported even worse experiences if they were sex workers, lesbian, trans or women who used drugs or who had other disabilities than HIV.

These experiences resulted in women: avoiding health services if possible; fearing to start treatment; and resulting in poor health outcomes in many ways, both for themselves and their children.

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

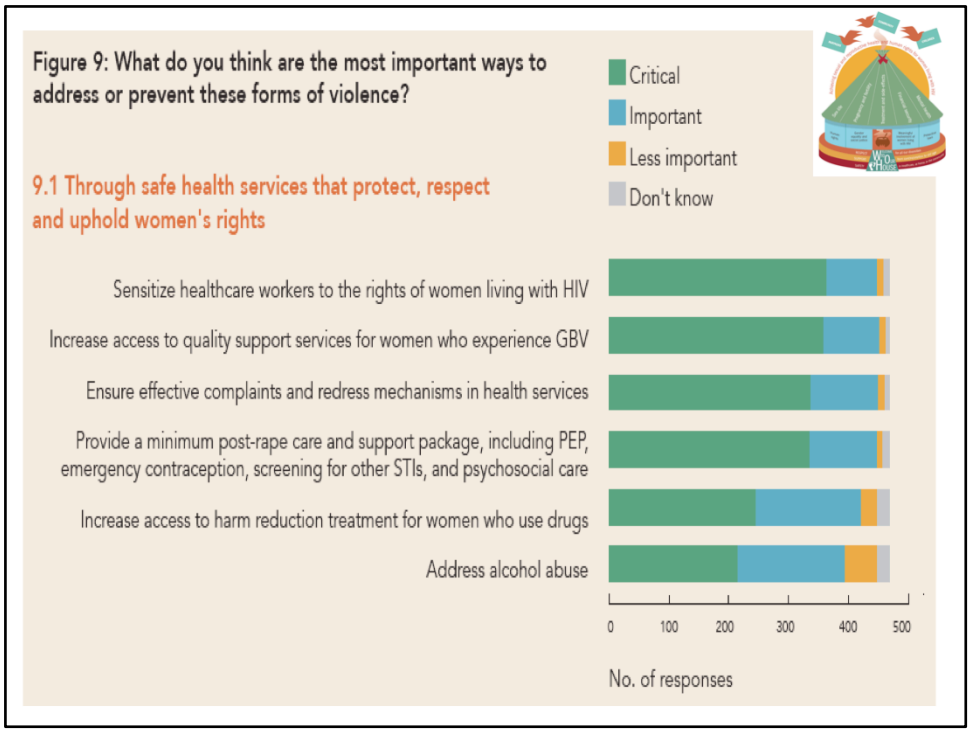
"Violence against women with HIV"

"any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV."

Hale and Vazquez 2011

There are various definitions of VAW. We used this one which, so far as we know, is the only one specific to women living with HIV. This includes structural violence, as explained below.

Hale and Vazquez definition – see also Galtung J 1969 and Farmer P et al 2006 regarding structural violence, which includes psychological violence



As explained earlier, we were anxious not just to focus on negative experiences but also to present a forward-looking, positive solution-focused report. The top three lines shown here were identified by 95% of respondents as critical or important.

http://tinyurl.com/BuildingASafeHouse

Results from 59% of 832 survey respondents on Mental Health*

- **82%** reported depression; **78%** rejection
- 1/5 reported MH issues *before* diagnosis
- This increased by **3.5 times *after*** diagnosis
- 45.8% had multiple 'socially disadvantaged identities' (SDIs)
- More SDIs ⇔ More mental health issues
- MH affected ability to enjoy SRH and to access services
- MH included: depression, rejection, social exclusion, sleep problems, intersectional stigma, challenges with sexual & intimate relationships, substance use, sexual risk, repro health barriers, human rights (HR) violations

Respondents recommended psychological support & counselling, funding for peer support & interventions to challenge GBV and to promote HR

** Thanks to Carmen Logie for additional analysis of quantitative responses*

One-fifth reported mental health issues before HIV diagnosis. Respondents reported experiencing a 3.5-fold higher number of mental health issues after diagnosis (8.71 vs 2.48, t[488]23.00, pB0.001). Nearly half (n224; 45.8%) had multiple identities which can make them socially disadvantaged (SDIs), in addition to HIV. The number of 'SDIs' was positively correlated with experiencing mental health issues (pB0.05). Women described how mental health issues affected their ability to enjoy their right to sexual and reproductive health and to access services. These included depression, rejection and social exclusion, sleep problems, intersectional stigma, challenges with sexual and intimate relationships, substance use and sexual risk, reproductive health barriers and human rights (HR) violations. Respondents recommended that policymakers and clinicians provide psychological support and counselling, funding for peer support and interventions to challenge gender-based violence and to promote HR. **Orza L et al. Journal of the International AIDS Society 2015, 18(Suppl 5):20289 http://www.jiasociety.org/index.php/jias/article/view/20289 | http://dx.doi.org/10.7448/IAS.18.6.20289**

Some questions for today:

- How can healthcare providers best be supported to develop a more ***holistic, women-centred*** approach to care of women living with HIV?
- How can healthcare providers recognise and address high levels of ***VAW*** experienced by many women living with HIV *in* ***healthcare settings***?
- How can we share examples of ***good practice*** in healthcare settings more effectively (eg Neema et al 2012, McLeish & Redshaw 2016)?
- How can donors and policy-makers promote more ***joined-up thinking across service providers***?
- How can donors and policy-makers promote more coordinated action between ***healthcare providers and community-based*** programmes to reduce VAW?

Here are some questions for today. It is great that WHO has developed the materials to promote healthcare providers' support for women who have experienced intimate partner and/or sexual violence. These are very welcome and much needed. It will also be great when the violence experienced by women living with HIV in healthcare settings themselves, which can be so detrimental to their health, can become history.

For particular examples of good practice in relation to young women living with HIV, see page 34 of our report. 7% of our survey respondents (70) were young women living with HIV aged 15-25.

To see indicators and other M&E materials related to these issues, see the forthcoming WHO guidelines on SRH&R of women living with HIV.

No doubt there are many examples of good practice that those of you listening today could share. It would be great to disseminate them so they could be replicated

Here are two examples of Good Practice, one from Uganda and one from the UK: Neema S et al 2012 **Using a clinic based creativity initiative to reduce HIV related stigma at the Infectious Diseases Institute, Mulago National Referral Hospital, Uganda** African Health Sciences 2012; 12(2): 231 - 239 http://dx.doi.org/10.4314/ahs.v12i2.24; McLeish J and Redshaw M. 2016 '**We have beaten HIV a bit': a qualitative study of experiences of peer support during pregnancy with an HIV Mentor Mother project in England** *BMJ Open 2016;6:e011499 doi:10.1136/bmjopen-2016-011499* http://m.bmjopen.bmj.com/content/6/6/e011499.full

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http://tinyurl.com/BuildingASafeHouse

Salamander Trust

Building a safe house on firm ground

KEY FINDINGS FROM A GLOBAL VALUES AND PREFERENCES SURVEY REGARDING THE SEXUAL AND REPRODUCTIVE HEALTH AND HUMAN RIGHTS OF WOMEN LIVING WITH HIV