World Health Organization

"Imagine yourself in my place"

Gender-based violence, mental health issues & the sexual & reproductive health & rights of women living with HIV in Eastern Europe and Central Asia

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jóvenes positivos

ICWAP

ICW Zimbabwe

ICW

ATHENA

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GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

Transgender Law Center
Making Authentic Lives Possible

Ladies and gentlemen, thank you very much for inviting me to speak today. The research I am presenting here is based on a global survey commissioned by the World Health Organization on the sexual and reproductive health and human rights of women living with HIV. It was commissioned to inform WHO as it updates its guidelines on this topic.

We conducted this survey in 2014 and on this slide you see all the team members and organisations involved. The report we produced from this survey, entitled "Building a Safe House on Firm Ground" can be found on the Salamander Trust website and four recent articles about the survey methodology and its findings can be found in the Journal of the International AIDS Society, the WHO Bulletin and the Journal of Virus Eradication.

Background: WHO survey

Values & preferences survey to update **WHO guidelines**

Led by a **Global Reference Group -** 14 women living with HIV

User-led, **participatory**, community-based research

7 **languages** in survey, 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

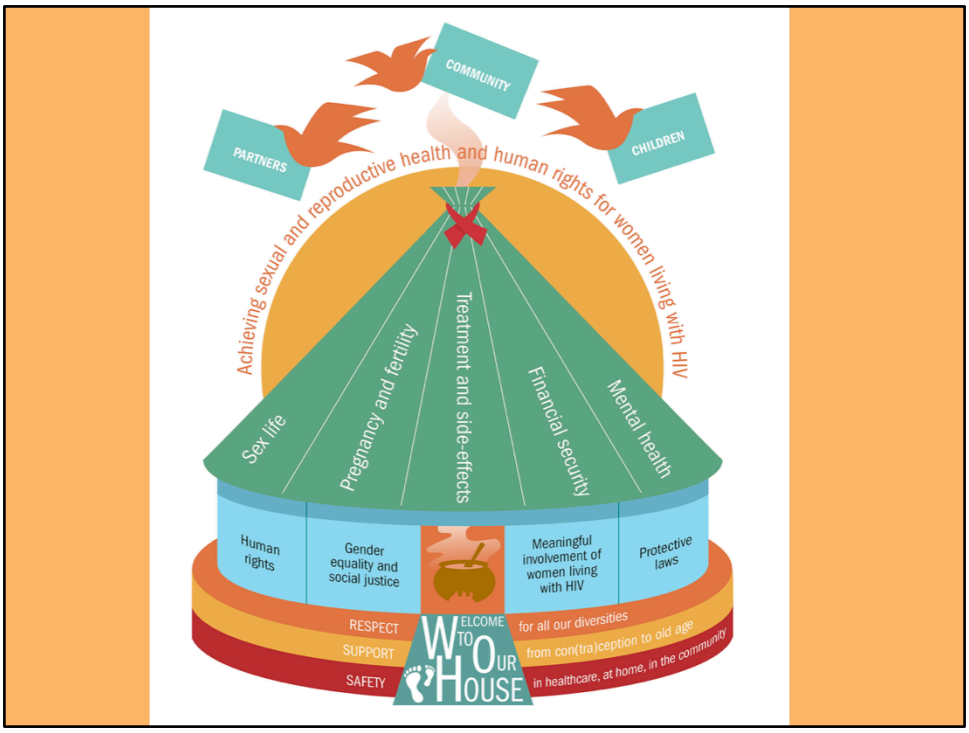
Here is a quick summary of the survey. It was a values and preferences survey, which forms part of the WHO guidelines update process. This normally happens much later in the process but this time WHO decided to conduct this element of the process first. It was led by an expert Global Reference Group of 14 women living with HIV in all their diversities from around the world.

Thus our methodology was a used-led, participatory community-based research process.

We conducted the online survey, using survey monkey in 7 languages; as well as focus group discussions, to triangulate our findings, in 5 separate languages.

We used a positive, future-oriented, "appreciativei inquiry" approach – asking questions such as what respondents find good about services and asking them to prioritise future positive strategies, instead of focusing solely on respondents' negative experiences.

This resulted in 945 women living with HIV from 94 countries worldwide taking part in the survey or focus-group discussions. Their age range was 15-72 and women living with HIV in all their diversities responded.



Here is an image of the “safe house on firm ground” that we created to represent the many and complex issues facing women living with HIV in relation to our sexual and reproductive health and rights. You can see the foundations, the wall panels, the roofing all needing to stand firm together in order that the house may stand safe and strong. If any one component of the house is damaged or missing, the house will be very vulnerable to collapse.

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**: 52%
  - 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

In terms of global results, respondents were asked to respond to 1 mandatory initial section and up to 8 optional sections, one of which was on Gender-Based Violence. Respondents made reference to Gender-Based Violence in *all* optional sections.

58% of 832 on-line respondents responded to the Gender-Based Violence section. Of these, 89% reported experiencing at least one type of violence.

What is key here is that whilst there were high levels of Intimate Partner Violence both before and after diagnosis, as one might expect, there were marked increases in other forms of GBV post-diagnosis, from neighbours, the wider community and healthcare settings. These latter experiences of violence in healthcare settings were even worse for women with identities which are socially disadvantaged in addition to HIV.

[Reference - Don't read this out: See 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]

Global 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*

Another optional section addressed mental health.

Of the 59% of all respondents who filled this section, one-fifth reported mental health issues *before* HIV diagnosis.

Respondents reported experiencing a 3.5-fold higher number of mental health issues after diagnosis [Don't read this out: (8.71 vs 2.48, t[488]23.00, pB0.001).]

Nearly half [Don't read this out: (n224; 45.8%)] had multiple socially disadvantaged identities (SDIs), in addition to HIV.

The number of SDIs was positively correlated with experiencing mental health issues [Don't read this out: (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 a variety of different experiences, as shown here.

Respondents concluded by making clear recommendations about what they needed from policymakers and clinicians.

[Don't read this out: **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]**

Russian language respondents: 99 responses from 11 countries, age 16-53 (60% in their 30s)

Country	Number (%)
Ukraine	53 (57%)
Russia	17 (18%)
Kazakhstan	8 (9%)
Uzbekistan	4 (4%)
Tajikistan	2 (2%)
Moldova	2 (2%)
Transnistria (Moldova)	2 (2%)
Kyrgyzstan	1 (1%)
Belarus	1 (1%)
Georgia	1 (1%)
Estonia	1 (1%)
Armenia	1 (1%)
Total	**93 (100%)**
No response	*6*

Moving on now to the specific results from Russian language respondents.

There were 99 of these, aged 16-53 from the countries shown here.

Comparison Russian language & global data

Identities	Russian language	Global
I have a partner who uses or has used drugs	54%	21%
I have hepatitis C	49%	20%
I use or have used drugs	42%	17%
I have been in detention	17%	7%
I have been in prison	13%	7%
I have or have had TB	10%	13%
I do or have done sex work	8%	13%
I have or have had malaria	0%	15%
I am lesbian, bi-sexual	2%	5.5%
I am transgender	0%	4.5%

This slide highlights the respondents' varied diversities, compared to the global data.

The figures in red are higher than the global figures, with the top four double the global number.

Experiences of services: *disagree/ strongly disagree*

Services	Russian language	Global
I find the **service providers** well-trained and knowledgeable, friendly, and supportive	**71%**	43%
My experience of **accessing** sexual and reproductive health **care** has been good, and I have confidence in the advice and treatment I receive	**64%**	37%
I believe my service provider offers a **full range of choices** for SRH care, including family planning options and prevention, diagnosis and treatment of sexually transmitted infections (STIs)	**66%**	35%
I know my rights and if I experience a rights violation within the health **service I know where I can go** to make a complaint	75%	73%

Here is a comparison between global and Russian language **NEGATIVE** experiences of availability and quality of their healthcare services. The figures above indicate where respondents have disagreed or strongly disagreed with the statements. Again the red figures indicate where there are marked differences between the global response to these statements and the Russian language responses.

Experiences of violence (58% of responses)

Violence	Russian language	Global
I have experienced **at least one** type of GBV	100%	89%
Violence in the **health care setting**	83%	53%
Ever fear violence	81%	68%
In the **community**	69%	52%
Intimate partner violence	54%	59%
Fear of violence **pre-diagnosis**	53%	25%
From **family** or **neighbours**	41%	45%
From **police / military / prison or detention**	41%	17%

This slide shows Russian language respondents' experiences of Gender-Based Violence, compared to the global data shown earlier. You can see how the Russian language responses clearly indicate even higher levels of GBV than those reported globally.

On experiences of violence…

Это болезненный вопрос. Поскольку я в прошлом работник секс бизнеса, то физически насиловали меня не единожды. А вот психологические травмы получаю по сей день: в родах мне боялись оказать помощь из-за статуса, отношение было пренебрежительным, иногда даже оскорбляли.

This is a painful question. Since in the past I was a sex worker, [I was] *physically raped more than once. But I am still traumatized to this day: during labor* [nurses] *were afraid to help me because of my* [HIV] *status, the attitude was dismissive, sometimes even insulting.*

Меня избивали в полицейском участке, по причине того что я употребляла наркотики.

I was beaten at the police station, due to the fact that I used drugs (Ukraine)

Here are some qualitative free text responses regarding experiences of violence. (Please allow a few seconds to enable audience to read them for themselves). **[Skip over this slide if time running short]**

On lack of support….

Один последний раз после того как меня изнасиловали двое молодых мужчин, я в то время проходила реабилитацию от химической зависимости амбулаторно. Я пришла на психотерапевтическую группу и попыталась получить там поддержку, но я не получила ее. Мне просто объяснили, что в этой ситуации виновата я сама. И ничего другого от этого не стоило и ожидать. "Дура! мол сама виновата"

One last time after I was raped by two young men at the time I was an outpatient in rehabilitation for drug use. I came to the psychotherapy group and tried to get support there, but I did not get it. I just explained that I blame myself in this situation. And I should not have expected anything else from it. "Fool! It must be her own fault"

And here is one response regarding lack of professional support. (Again, please allow a few seconds, for the audience to read this for themselves.) **[Skip over this slide if time running short]**

Experiences of MENTAL HEALTH ISSUES: (59% of responses) Russian language respondents

MENTAL HEALTH	Russian language data	Global data
Depression	91%	82%
Rejection	72%	78%

еще до ВИЧ я часто переживала физическое и психологическое насилие от своего парня, из-за этого я не испытываю оргазм и у меня часто было чувство вины, возможно если бы этого не было, я бы не вступила в половой контакт с человеком, заразившим меня ВИЧ

Before HIV I often suffered physical and psychological abuse from my boyfriend because of that I did not have an orgasm, and I often had feelings of guilt, maybe if it was not [for that], I would not have entered into sexual contact with the person who infected me with HIV

Moving on to the mental health section. Here are the Russian language and global figures for depression and rejection, all of which are unacceptably high.

On mental health-related issues…

2 года боялась заниматься сексом - 2 года не имела секса. боялась заразить партнера даже с презервативом.

2 years was afraid to have sex - 2 years did not have sex. Afraid to infect a partner, even with a condom.

Избегала более близкого общения с людьми, поставила на себе крест как маме,жене....и начала сильно употреблять наркотики молясь, чтоб Бог мменя забрал

Avoided close contact with more people, put on a cross as a mother, wife .... And began to heavily use drugs praying for God to take me

And here are a couple of comments from Russian language respondents in this section. **[Skip over this slide if time running short]**

KEY FINDINGS *Russian-language respondents*

In relation to global responses:

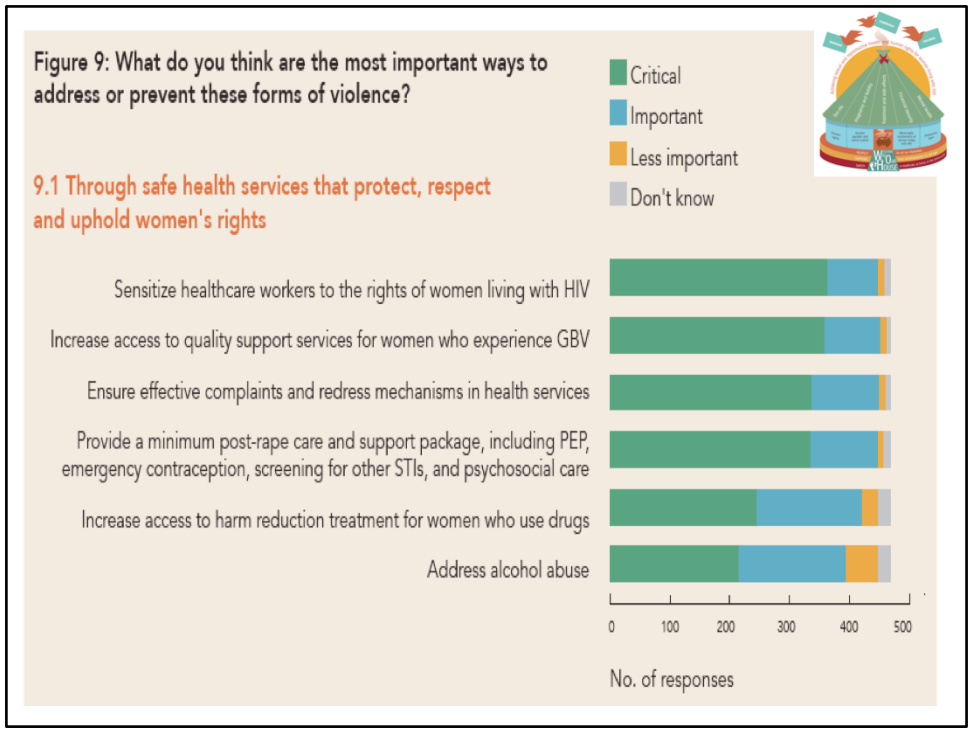
- Women's reported experiences of GBV from healthworkers are even higher
- Women's reported experiences of GBV from police are even higher
- Women's views of healthcare provision and lack of support for GBV are even higher

So comparing the Russian language responses to the global responses, some key findings emerge.

In relation to global responses:

- Firstly, Women's reported experiences of GBV from *healthworkers* are even higher
- Second, Women's reported experiences of GBV from *police* are even higher
- And Third, Women's views of healthcare *provision* and *lack of support for GBV* are even higher

These negative experiences clearly have a knock-on effect on women's abilities to access services for themselves or for their children, and to start or adhere to treatment. If you have a negative experience of professional services, you are highly unlikely to return to them for support in a hurry. There are big policy implications here for us all, which global, regional or national guidelines are yet to address.



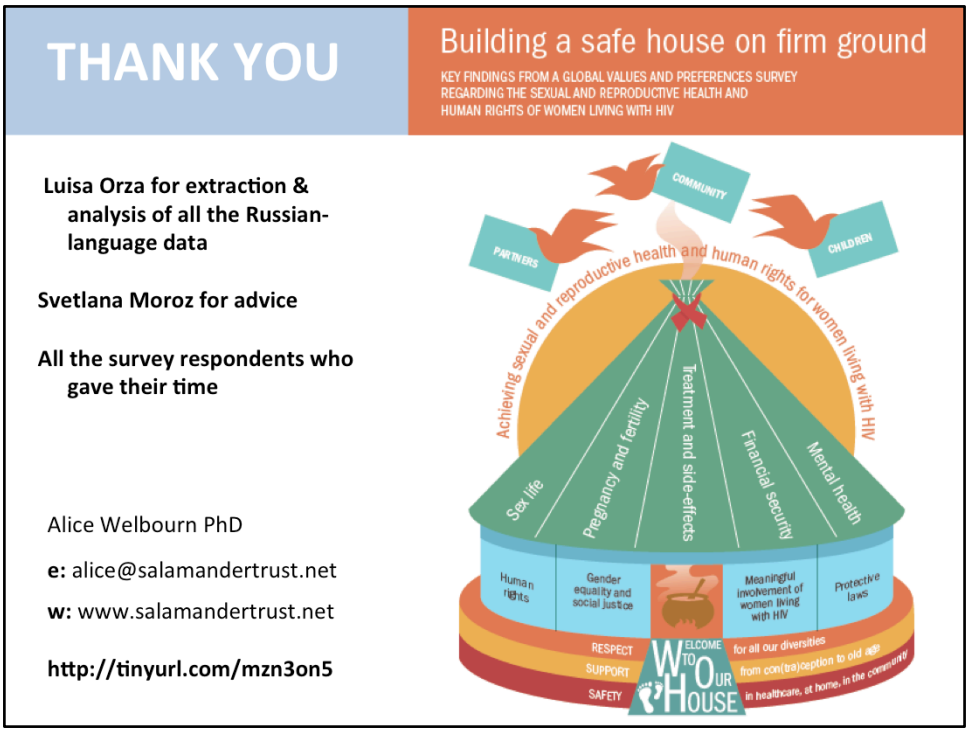
Here though are some clear recommendations from *all* survey respondents for policy makers and clinicians to address, to prevent the GBV reported in this survey.

The chart here shows how all respondents globally prioritised these key recommendations, as proposed by our expert Global Reference Group.

These recommendations should send a clear message to *all* policy makers and clinicians globally – and ***especially*** to those tasked to uphold the human rights of the Russian language respondents, whose experiences are that much worse than the global findings.

Further research, based on this same survey, is currently underway in Ukraine and we welcome women living with HIV in other Russian language speaking countries to make use of this same survey to research further the situation in their countries also.

[http://tinyurl.com/mzn3on5]



WHO is now moving forward with the findings from this survey to update its sexual and reproductive health and human rights guidelines. Not only are our intrinsic human rights at stake here. There is also a strategic instrumental advantage in upholding our rights and maintaining our safety, in terms of treatment uptake, long-term adherence – and our capacity also to support our children, our partners and the wider community.

But as they always say on aeroplanes, before you help others around you, you need to put your *own* oxygen mask on first. It is the responsibility of *all with the power to do so,* to ensure that women with HIV can *access* that oxygen mask, because without ensuring that support for us is in place, these strategies and policies are oxygen-starved.

In conclusion, ladies and gentlemen, women living with HIV in all our diversities, both globally and in this part of the world, *want* to be and *should* be at the heart of a long-term effective strategic response to this pandemic. We hope and trust that WHO and all those with the power to do so ensure that these *rights* can *also* be all our *realities*.