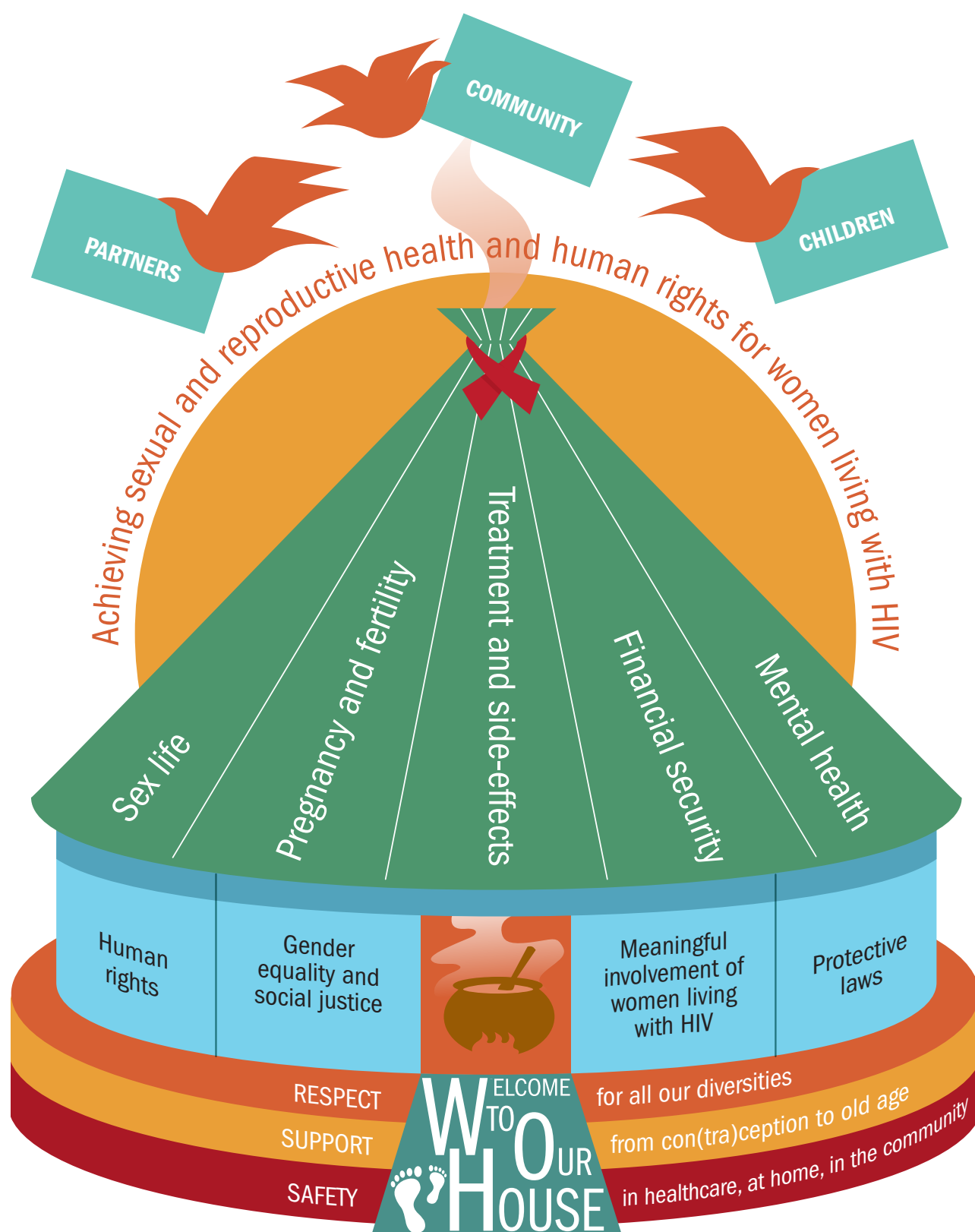


# Building a safe house on firm ground

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



## Lead author

Salamander Trust is a registered UK charity, which seeks to transform the way we think about HIV. It has a strong track record in global advocacy, research and training in relation to HIV, gender and rights, including sexual and reproductive health and rights, and gender-based violence. Its Founding Director, Alice Welbourn, is also a woman living with HIV and a former international chair of the International Community of Women Living with HIV (ICW).

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**Salamander Trust**  
TRANSFORMING THE WAY WE THINK ABOUT HIV

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## Participating entities





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## Abbreviations and acronyms

ART	antiretroviral therapy
ARV(s)	antiretroviral(s)
AIDS	acquired immune deficiency syndrome
CEDAW	Convention on the Elimination of all Discrimination Against Women
CRPD	Convention on the Rights of Persons with Disabilities
FGD	focus group discussion
GBV	gender-based violence
HIV	human immunodeficiency virus
IPV	intimate partner violence
MIWA	meaningful involvement of women living with HIV
MTCT	mother-to-child transmission
PVT	prevention of vertical transmission
STI	sexually transmitted infection
SRH	sexual and reproductive health
TB	tuberculosis
VAWG	violence against women and girls
WHO	World Health Organization

# EXECUTIVE SUMMARY

## BACKGROUND AND PROCESS

- 50–55% of adults living with HIV globally are women.
- The World Health Organization (WHO) 2006 guidelines *Sexual and reproductive health of women living with HIV/AIDS* need to be updated.
- This values and preferences survey was created to inform the Guideline update process.
- The survey was led, informed and run by women living with HIV, including: two of the coordinating team; all 14 of the Global Reference Group;<sup>1</sup> and six of the leaders of the focus group discussions.

## THE SURVEY FORMAT

- The survey used an appreciative enquiry, life course approach, grounded in human rights. It included both quantitative and qualitative sections. It identified what is already working for women living with HIV, in the context of the realities of their lives. It aims to build on these achievements to strengthen the HIV response in relation to the SRH and human rights of women living with HIV.
- A secondary intention was to develop the survey tool as a supportive, informative SRH and human rights framework, which can be used potentially to support women's advocacy at local, national and international levels. The survey platform gives voice to women to tell their stories and reflect on all stages of their lives.

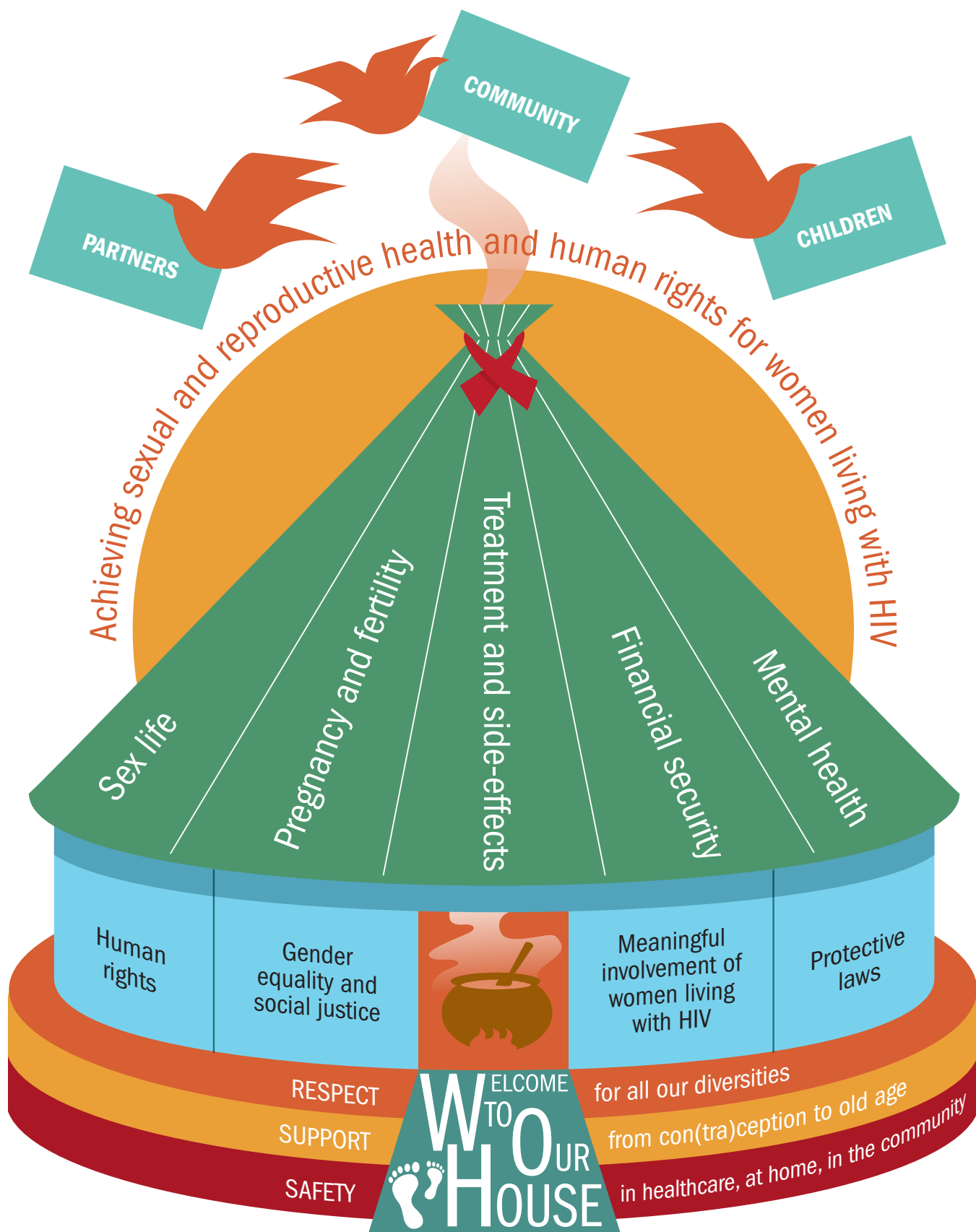
## THE PARTICIPANTS

- With 945 respondents, this is the largest ever survey of women living with HIV (832 survey responders from 94 countries aged 15–72, and another 113 women in focus groups in seven countries).
- Respondents came from a diverse range of backgrounds and experiences, including women who: are heterosexual, use drugs, do sex work, are lesbian, bisexual, trans or intersex, are indigenous, are single, in stable relationships, have been circumcised, have tuberculosis (TB)/malaria/hepatitis C/other co-morbidities, have been incarcerated, are economic or political migrants, have other disabilities, have been detained or who have been homeless.

## FRAMEWORK FOR ANALYSIS OF THE FINDINGS

- A comprehensive pre-consultation process with the Global Reference Group of women living with HIV produced a holistic set of key themes, which shaped the survey framework, content and report structure.
- The online survey and concurrent focus group discussions expanded upon, and endorsed, the key priorities for women living with HIV globally.
- The key themes and priorities are represented as a house (see page 4). This illustrates how each element is needed to build a safe house (or policy, or guideline) that is stable, upright and watertight, and has benefits for the wider community. The concept and basic structure of a house is a universal frame of reference, relevant to all communities and countries.

1. See Annex i for details of the Coordination Team and the Global Reference Group.



## FINDINGS

### The foundations

#### 1. Safety for women living with HIV is paramount

89% of respondents reported that they have experienced violence or fear of violence, before, since or because of their diagnosis. Violence occurs in homes, communities and in institutions, including healthcare settings. Violence, including stigma, forces many respondents to keep their HIV secret from partners, family and health workers.

**Respondents call for safety in healthcare, at home and in the community. Safety within health services and support to address interpersonal violence are viewed as key. Reduction of stigma and discrimination within health services must address human rights violations including mandatory testing, involuntary disclosure, and coerced or forced sterilization and abortion.**

#### 2. From con(tra)ception to old age

Respondents reported sizeable gaps in clinical care, practice, policy and research for girls and women outside the reproductive years and for women who are not having children.

**Respondents request health services to adopt a holistic, women-centred con(tra)ception to old-age approach to sexual and reproductive healthcare, with a comprehensive package of age- and stage-appropriate services.**

#### 3. Diversities

Women living with HIV come from many different backgrounds and have individual experiences, needs and desires. Respondents reported many gaps in care, judgmental attitudes from health staff and even abuses within health settings.

**There was a strong call for stigma reduction by healthcare providers and for them to adopt, uphold and be accountable for respectful policies and practices for women living with HIV in all their diversity.**

### Walls

#### 4. Human rights

Respondents expressed concern about lack of choice in healthcare services. Only 50% of respondents find their service providers well trained and knowledgeable, friendly and supportive. Respondents described a routine lack of inclusion or choice in decision making about their own SRH care and care pathways.

**Principles of human rights need to be embedded in all healthcare policies, practices and training.**

#### 5. Gender equality and social justice

Respondents reported widespread difficulty in decision making around when, how and with whom to have sex, and whether and when to have children. Partners and/or in-laws often make such decisions for women. Family members,

communities, neighbours and health staff alike judge the appropriateness of women's sexual behaviour. These attitudes and practices often affect disclosure of HIV status. Public health policies pressure women to disclose, without protections or support to do this safely.

**Gender equality should be addressed in all healthcare policies and practices as a matter of quality, not merely quantity, of service.**

#### 6. Meaningful involvement

Respondents confirmed that peer support of other women living with HIV is fundamental to their SRH and human rights, but reported very limited availability. Meaningful involvement in decisions which affect the lives of women living with HIV is deeply desired by the women but rarely acknowledged or realized by policy makers or service providers. Respondents are disappointed that the wealth of experiences of women living with HIV remains an immense, largely unacknowledged and untapped resource.

**Health staff should promote and support grassroots-created and -led peer groups of women living with HIV, to work alongside them. Women living with HIV should be encouraged, capacitated and supported to join local, regional, national and international health committees, to shape robust, high quality services based on safety and evidence.**

#### 7. Protective laws

Whilst it was understood that WHO addresses the health sector, respondents reported widespread concerns about punitive and repressive laws, which act as a barrier to the achievement of the SRH and human rights of women living with HIV.

**Decision makers should promote laws and policies that create safe environments for women living with HIV, in order that health systems may effectively reach their targets to reduce HIV and alleviate its impact.**

### Roof

#### 8. Pleasurable and fulfilling sex life

Significant numbers of respondents reported challenges to achieving a pleasurable and satisfying sex life. Only 32% of respondents reported always or usually having a healthy libido or feeling sexual desire. Fear of onward HIV transmission, pregnancy and STIs, linked with difficulties with condom availability and negotiation, and with fears of the impact and consequences of HIV disclosure (including violence) make sex challenging.

**Through its leadership and language on SRH and human rights, WHO can influence attitudes and practices within health systems and amongst the general population to ensure that women enjoy pleasurable and fulfilled sex lives.**

#### 9. Pregnancy and fertility desires

Nearly 60% of respondents had an unplanned pregnancy. Only 40% accessed family planning services. While 72%



received advice on safe conception, only 55% received practical support for this. Even though 70% reported being able to talk to their service provider about their fertility desires, only 50% felt they had received support to realize them. The most prevalent noted fear for women around pregnancy was onward transmission to a child or partner and this was compounded by stigmatising attitudes from healthcare staff.

Compassionate, holistic, unconditional care and support and informed choice should be provided to all women living with HIV in the context of pregnancy and fertility desires.

### 10. Treatment and side-effects

88% of respondents in this section were on HIV treatment. Half had an undetectable viral load. Women living with HIV experience a high burden of treatment: on average they each experienced four different side-effects, which affect their sexual health; only 10% reported no side-effects; and some expressed SRH challenges associated with viral suppression.

The high burden of side-effects from some HIV treatment regimens and consequent impact on quality of life needs further research. Viral load suppression policies should be reviewed in the light of SRH and human rights concerns.

### 11. Financial security

Throughout the survey respondents emphasized the challenges of poverty. Its resulting strain on mental as well as physical and sexual health and its role as a barrier to accessing services and realising human rights was evident. This was despite the majority of respondents – with access to computers, the internet, treatment and care – being better off than the vast majority of women living with HIV globally.

Healthcare for women and girls living with HIV – and related transport and childcare – should be accessible, affordable and available, with provision of integrated SRH, and care and support for SRH and gender-based violence (GBV).

### 12. Mental health

Over 80% of respondents reported experiences of depression, shame and feelings of rejection. Over 75% reported insomnia and difficulty sleeping, self-blame, very low self-esteem, loneliness, body image issues, or anxiety, fear and panic attacks, whether before, as a direct result of, or after, diagnosis. The attitudes and practices of health staff are key to their ability to cope with the diagnosis of HIV, especially when made during pregnancy.

Service providers need training in compassionate care and support for women living with HIV in all their diversities at all times and to ensure that women who struggle with mental health challenges receive the appropriate support and medication.

### 13. Achieving sexual and reproductive health and rights

Women living with HIV have an intrinsic right to all human rights including SRH, which will be achieved if all the above conditions are in place. If the health system upholds and respects the rights of women living with HIV (in all their diversity) women can then reach out to others to enable them to enjoy their rights also.

Safety in healthcare settings is fundamental. Healthcare providers and services should promote, respect and uphold the rights of women living with HIV in their care at all times. Systems need to be in place to redress any violations.

### 14. Supporting the children of women living with HIV

Many respondents referred repeatedly to anxieties about their own and others' children in their care. Women want to provide intergenerational support for their children as they grow into young adults.

Women living with HIV need health staff to provide a variety of comprehensive services for these children and young adults.

### 15. Supporting partners

45% of respondents were in a stable relationship. Many feared onward transmission of HIV to a partner. Others felt unable to start a relationship because of fear of disclosure.

Women living with HIV who are experiencing violence or fear disclosure need health staff to reach out beyond the clinic to promote and provide links to community-based programmes.

### 16. Supporting community

All women living with HIV belong to communities and many want to find ways to promote an effective response to HIV. WHO is in an authoritative position to promote its own life-affirming and holistic definition of health throughout its guidelines.

Service providers should regard women living with HIV as a valuable resource, to build bridges between health services and communities. Such linkages act as a 'win-win', ensuring that policies and practices are grounded in human rights and lived experiences, as well as leading to effective implementation to achieve SRH and human rights, not only for women living with HIV but for all.

Women living with HIV in all of their diversities designed the global consultation. If heard and acted upon, it will assure their support for, and engagement with, the revised WHO guidelines on the sexual and reproductive health and human rights of women living with HIV.



# BACKGROUND AND INTRODUCTION

## WHY PERFORM THE SURVEY?

It is estimated that 50–55%<sup>2</sup> of people living with HIV globally are women. In 2006, the World Health Organization (WHO) issued *Sexual and reproductive health of women living with HIV/AIDS: Guidelines on care, treatment and support for women living with HIV and their children in resource-constrained settings*. These guidelines focused on five key areas; sexual health, family planning, maternal and perinatal health, abortion, and sexually transmitted infections (STIs).

This Guideline needs to be updated due to changes in the biomedical and political aspects of the HIV response, and in internal WHO processes relating to the production of its technical guidelines. The forthcoming Guideline will encompass recommendations for policy, formal health care, and community engagement, and will be embedded in a human rights framework.

## WHO COMMISSIONED THE CONSULTATION?

Salamander Trust was selected to work in partnership with the Department of Reproductive Health and Research at WHO to conduct a global community consultation on the sexual and reproductive health (SRH) and human rights of women living with HIV to inform the Guideline update process and to help determine priorities and outline key content areas for the updated Guideline. See Annex 2 for details.

Women living with HIV designed the global consultation, on which this report is based. By involving and listening to women from the outset, WHO are more likely to produce guidance that authentically addresses what women living with HIV want and need, and thus gain their support and engagement.

The consultation aimed to:

- identify key areas to include in the revised Guidelines in line with priorities expressed by women who live with HIV with diverse geographic backgrounds and experiences
- strengthen capacity among civil society (in general) and women living with HIV (in particular) to understand the purpose and scope of, and to engage with and advocate for, the WHO technical guidelines
- galvanize broad-based support for and likely endorsement of the final guidelines among women living with HIV
- identify key unaddressed areas for future policy, research and action.

## HOW WAS THE SURVEY CONDUCTED?

The survey used an appreciative enquiry, life course approach, grounded in human rights. It aimed first and foremost to identify what is already working for women living with HIV, in the context of the realities of their lives, and to build on these achievements to strengthen the HIV response in relation to the SRH and human rights of women living with HIV. To this end, the Global Reference Group<sup>3</sup> and survey authors intended to reflect on all stages of women's life, from conception to grave, and to give voice to women to tell their stories through the platform of the survey. A secondary intention was to develop the survey tool itself as an informative SRH and human rights framework, which can potentially be used to support women's advocacy at local, national and international levels.

2. See Murray et al 2014 and UNAIDS 2013.

3. See Annex i for membership and biographies of the Coordination Team and Global Reference Group

## PROCESS AND METHODOLOGY

The consultation process took place between February and June 2014. It built on a consultative model developed by the ATHENA Network<sup>4</sup> to increase engagement of women in all their diversity in the 2011 High Level Meeting on HIV and AIDS<sup>5</sup>. The process combined an iterative and piloted design, followed by a global web-based survey collating quantitative and qualitative data in both mandated and optional sections, plus in-depth focus groups in order to obtain breadth and depth of

data and triangulate findings. Details of the process and methodology can be found in Annex iii. Summary findings are presented in each section, with more detail in the annexes. All quotations are taken from survey respondents and presented in italics, giving the country of origin of the respondent. Any quotes not from survey respondents are clearly marked.

## RESPONDENTS' COMMENTS ON THEIR MEANINGFUL INVOLVEMENT WITH THE SURVEY PROCESS

*"Women with HIV should be placed in the driving seat when it comes to our care, support, access to treatment when WE need it and our sexual and reproductive health and human rights. Dignity and respect should lie at the heart of the updated guidelines."*

*It's great that WHO have decided to fund this wide-reaching survey. I really hope that this is just the start of a new way of engaging with women with HIV – and that all our comments will be taken on board and addressed with the depth of thought that has been put into sharing them. Thank you to the creators of this survey!"*

United Kingdom

*"I really want to help women who face problems. As I pointed out in this questionnaire, more information is needed for women with low libido, problems of the body, issues of early menopause and hormonal changes."*

Russia

*"... I found the experience to be cathartic, much to my surprise. Surveys don't generally have that effect. It was meaningful to answer questions that truly reflected my experiences both as a girl and young woman before HIV and since my diagnosis. Even though there were questions about violence and trauma that could have felt difficult, the fact that the survey was written by and for women living with HIV and in a tone that is empowering rather than victimizing, made my participation feel good and made me feel that I could be really honest in my answers. Thank you and kudos to your team."*

United States

4. ATHENA Network is a global network created to advance gender equity and human rights in the global HIV response. <http://www.athenanetwork.org>

5. ATHENA Network (2011) *In Women's Words: Action Agenda*. HLM 2011 survey results available at: [http://wecareplus.net/index.php/page/HLM\\_June\\_2011/en](http://wecareplus.net/index.php/page/HLM_June_2011/en)

## WHO WERE THE RESPONDENTS?

### Number of survey participants

832 women living with HIV from 94 different countries across all regions of the world,<sup>6</sup> and in seven languages completed the survey.<sup>7</sup>

This is the largest ever survey of women living with HIV, based on a 'snowballing' technique via informed networks. This is not a pure 'representative sample' as such, as that would be very difficult to obtain for such a stigmatized condition and within the timescale. The response exceeded the authors' expectations and easily achieved the breadth and depth of intelligence required.

### Age of participants

Participants were aged between 15 and 72 years old, with the majority of responses from women in their 30s and 40s (approximately 30% each). At least 7% (approximately 70 participants<sup>8</sup>) were young women aged 15–25.

### Women in all of their diversity

The survey aimed to be as inclusive as possible of women in particular contexts of risk or marginalization, by connecting through a working group of focal points representing, or with links to, networks of women from different backgrounds and contexts.<sup>9</sup> (See Table 1.)

**Table 1: Survey participants**

Women living with HIV who:	Number	Percentage
are heterosexual	455	63%
are married or in a stable relationship	321	45%
have or had malaria	133	18%
have or had hepatitis C	118	16.5%
have partner(s) who use or have used drugs	100	14%
have done or do sex work	100	14%
are or have been homeless	99	14%
have or had active tuberculosis (TB)	95	13%
are living with disabilities	90	12%
are on opioid substitution therapy	21	3%
have migrated to another country for economic reasons	65	9%
are indigenous women	55	8%
are lesbian, bisexual or other women who have sex with women	40	5.5%
have undergone some form of female genital cutting	39	5%
are or have been in prison	40	5%
are or have been in a detention centre	37	5%
are transwomen	33	4.5%
have migrated to another country for political reasons	19	2.5%
are intersex women	5	0.7%
<b>Total</b>	<b>723</b>	<b>100%</b>

6. Algeria, Angola, Argentina, Armenia, Austria, Australia, Azerbaijan, Belarus, Belgium, Belize, Bolivia, Botswana, Brazil, Burkina Faso, Burundi, Cambodia, Cameroon, Canada, Chile, China\*, Colombia, Costa Rica, Cote D'Ivoire, Czech Republic, Denmark, Democratic Republic of Congo, Dominican Republic, Ecuador, El Salvador, Estonia, Ethiopia\*, France, Gabon, Germany, Ghana, Greece, Guatemala, Honduras, Hungary, India, Indonesia\*, Ireland, Italy, Jamaica\*, Kazakhstan, Kenya\*, Kyrgyzstan, Lesotho, Malawi\*, Mali\*, Mexico, Moldova, Morocco, Mozambique, Myanmar, Namibia, Nepal, Netherlands, New Zealand, Nigeria\*, Norway, Rwanda, Togo, Paraguay, Nicaragua, Venezuela, Peru, Panama, Portugal\*, Republic of Congo, Russia\*, Romania, Serbia, Somalia, South Africa, Spain, Sri Lanka, Sudan, Swaziland, Switzerland, Tajikistan, Tanzania, Transnistria, Turkey, Uganda\*, United Kingdom\*, Uruguay, United States\*, Uzbekistan, Ukraine\*, Viet Nam, Zambia, Zimbabwe. Countries marked with a star had >20 responses. The largest number of responses came from United Kingdom (50), Ukraine (52), and the United States (84).

7. See Annex iii for language breakdown.

8. We are not sure of the exact ages of all the FGD participants, hence this cautious approximation.

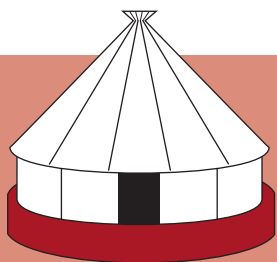
9. Percentages are calculated from the 723 women living with HIV who answered this question (87% of the 832 women who answered the survey).

In addition to the on-line survey, concurrent focus groups discussions (FGDs) were conducted in order to deepen understanding of the experience of women belonging to specific key populations, or who were unable to access the on-line survey due to language or technology barriers. These focus groups facilitated the participation of 113 women from Africa, Asia, and the Caribbean, in addition to those who took part in the on-line survey. (See Table 2.)

**Table 2: Focus group discussions with women living with**

<b>Country</b>	<b>No. FGD</b>	<b>Participants</b>
Ethiopia	1	20 women living with HIV from a rural area (no English language and no internet access)
	1	10 sex workers living with HIV
Senegal	1	20 young women who do sex work
	1	10 women living with disabilities
Nepal	3	10 widows with HIV (husbands were migrant workers), 4 young women who do sex work, and 5 transgender women living with HIV
Myanmar	1	10 young women born with HIV
United Kingdom	1	11 migrant women, three of whom had been in prison or detention
Jamaica	1	8 older women living with HIV
Thailand	1	5 women living with HIV, including 2 women who use drugs
<b>Total</b>	<b>11</b>	<b>113 women</b>

# FINDINGS



## 1. SAFETY FOR WOMEN LIVING WITH HIV: IN HEALTHCARE, AT HOME AND IN THE COMMUNITY

### ***“Violence. Enough already.”***

United States

#### EXPERIENCE

The single most prominent finding was that women living with HIV experience high and intolerable levels of violence that can be situated along, and addressed as, a continuum throughout the life cycle.<sup>10</sup> Women reported HIV-related violence before, because of, and after HIV acquisition and diagnosis – or a combination of the three.

Over half of the total number of survey respondents (480 women) responded to the (optional) survey section on violence against women. Of these, only 58 respondents (11%) said they had *never* experienced violence in any of the six categories: intimate partner violence; violence from family and neighbours; violence within the community; violence within the health sectors; violence within police, in prison or in detention; and, fear of violence. (For more detail, see Annex to Section 1).

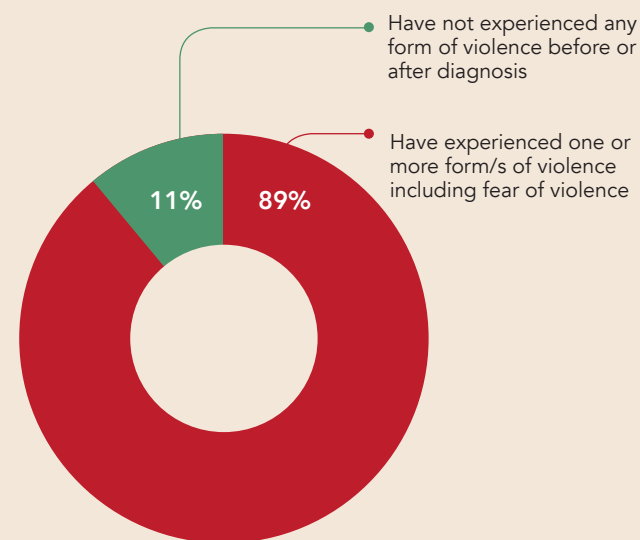
***“Before HIV, I was victim of different types of violence (physical, psychological, financial) besides the impact my partner’s alcoholism and machismo; this lead me to get several STIs, including HIV.”***

El Salvador<sup>11</sup>

Additionally, HIV diagnosis acts as a specific trigger for violence. It also exposes women to new settings of HIV-related violence, including within healthcare institutions, in particular in relation to SRH. Women reported judgmental provider attitudes, assumptions, involuntary disclosure (exposing women to further forms of violence from partners, family and community members), and breaches of confidentiality.

Once diagnosed, women also reported denial of treatment (especially fertility treatment) or being forced or coerced into services they did not freely choose, including abortion or sterilization.

**Figure 1: Consolidated responses to whether respondents had experienced violence**



10. Hale and Vazquez, 2011.

11. Wherever possible, quotes from survey respondents have been used verbatim.

## IMPLICATIONS FOR GUIDELINE WRITERS

Women need to be more aware of the different forms of gender-based violence (GBV) so that they can name it as such, identify it as a 'wrong' and as a violation of their rights, move towards greater agency in the face of violence and seek redress and safety.

*"I would like them to address gender violence because women are suffering in the hands of their husbands. Most women like me stay in the marriage not because I want but because I have nowhere else to go and also the business I do is family business so if I leave I won't have any financial support, so I endure the beatings, insults etc. because I don't have an alternative."* Kenya

Over 80% of respondents agreed that critical or important ways healthcare services can address violence against women living with HIV should include:<sup>12</sup>

- **Sensitizing healthcare workers** to the rights of women living with HIV
- **Increasing access to quality support services** for women who experience GBV (including sexual violence)
- **Ensuring effective complaints and redress mechanisms** in case of rights violations within health services
- **Increasing access to harm reduction-based treatment** for women who use drugs, including overdose provision
- **Addressing inappropriate alcohol use**

- **A minimum post-rape care and support package**, including post-exposure prophylaxis (PEP), emergency contraception, screening for other STIs, and psychosocial care and counselling
- **Advocacy** for women within judicial responses to sexual abuse and rape

In addition, we suggest the following for all women and girls, especially those with HIV:

- **Healthcare staff should be trained and enabled to routinely enquire about GBV and violence against women and girls (VAWG)**, as a part of everyday interactions within healthcare settings
- **Organizations must have formal pathways to advocacy and safety planning** for women who disclose GBV/VAWG<sup>13</sup>
- **Ensure support, treatment and interventions for GBV/VAWG are routine in healthcare**, in order to break down stigma and shame and connect women with the support, care and services they need

Protection from violence needs to occur throughout the entire structure of the 'house' (or policies and guidelines). Safety for women and girls is the foundation and 'firm ground' bedrock of an effective response. This must, at a minimum, include a protective legal environment (see Section 7), economic empowerment and financial security for women and their children (see Section 11), stigma reduction, and safety and human rights protection within health services to address human rights violations including mandatory testing, involuntary disclosure, and coerced or forced sterilization and abortion.

## FURTHER RESEARCH

There is urgent need for more research regarding the experience of violence and interrelationship with SRH across a woman's life cycle, in terms of:

- Women's health, dignity, and welfare
- The interface between violence and HIV exposure, acquisition and impact, and its impact on the SRH of women living with HIV
- The interface between violence and other factors, such as gender identity and gender expression, and its impact on the SRH of women living with HIV

12. See Annex to Section 1 for further details about safety throughout the consultation.

13. For further details, see a review of the best available evidence: NICE 2014 *Domestic violence and abuse: how health services, social care and the organizations they work with can respond effectively*. All healthcare staff should be enabled to support women who disclose violence. There is a lack of clear evidence to support formal 'screening' but health and social care organizations should be able to ask in a more routine way, with training, raised awareness and formal pathways to advocacy and help.



## 2. LIFE-CYCLES FROM CON(TRA)CEPTION TO OLD AGE

***"I think if you are a woman without children and or husband or partner, you are still very low priority."*** Uganda

Girls and women living with HIV change throughout their lives. They encounter different sets of problems and concerns, and have different desires, visions and priorities during different stages of their lives. Initially, there has been an understandable focus on pregnancy and vertical transmission, but this one-dimensional approach risks overwhelming other, equally important women's health and human rights issues, that would enhance women's agency, adherence and the fulfilment of all SRH goals.

***"If we're being honest and critical there are huge gaps in clinical care, practice, policy and research for women in general especially those of us living with HIV ... in menopause and post-menopause, because then the 'threat' of MTCT [mother-to-child transmission] isn't present."*** United States

### EXPERIENCE

The key finding was that there are sizeable gaps in clinical care, practice, policy and research for:

- Girls and young women born with HIV
- Those who acquired HIV through sexual abuse, early sexual debut or child marriage
- Young women transitioning to adult services
- Women who are not having children
- Women beyond the reproductive years

### IMPLICATIONS FOR GUIDELINE WRITERS<sup>14</sup>

A con(tra)ception to old age approach to sexual and reproductive health and sexuality for girls and women living with HIV should be adopted and include:

- **Comprehensive, age-appropriate sexuality education** from age five upwards, for all children, in line with UNESCO guidelines<sup>15</sup>
- **Social protection mechanisms** to avoid child sex abuse, child and teen marriage<sup>16</sup>
- **Access to a full range of information** about body changes, menstruation, sexual maturity and contraception and family planning options for all girls and young women, especially those transitioning from child to adult services, free from judgment, coercion or the need for parental consent
- **Sex and relationships counselling** for girls and women of all ages
- **Support women to have children born free of HIV** with access to information, choice of appropriate conception techniques, and HIV and STI prevention, diagnosis, treatment and care for women of any age

- **Cancer screening and management**
- **Information about HIV and ARVs and the menopause** and appropriate care and support to women going through the menopause
- **Training and sensitization for doctors and other care providers to offer holistic, women-centered and culturally-competent care** throughout the life-cycle, so that the whole girl or woman is considered and not just the virus. Services should be high quality, voluntary, optional, informed, confidential and work for the benefit of each individual. The treatment of girls, unmarried women and those without children should be unbiased and to the same standard of attention and care as those who are married or have children. Information and support should be lifelong.

14. See Annex to Section 2 for further details of these experiences throughout the consultation.

15. UNESCO n.d.

16. See Waring M et al 2013 for example.





### 3. RESPECT FOR ALL OUR DIVERSITIES

***"Women who use drugs are subjected to double or sometimes triple stigma. There are cases of discrimination against these women, even in the HIV service organizations in which they work." Ukraine***

#### EXPERIENCE

Women are not all the same. We all have multiple and interacting identities, lifestyles and circumstances. Some women have particular needs or desires, can face additional barriers, or may experience multiple layers of discrimination, which make it more challenging to access SRH services, and enjoy healthy pleasurable relationships.

Women and girls with HIV from key affected populations – including sex workers, women who use/inject drugs, lesbian, bisexual and other women who have sex with women, trans women, and women with disabilities (among others) – face many of the same challenges that women and girls in general face, based on gender inequalities, assumptions and HIV-related stigma, discrimination and violence. However, gender norms and other societal perceptions and values may also play out within the specific context of their lives to create an additional layer of structural barriers to accessing services and claiming human rights. These are underpinned by criminalization of certain practices (for example, sex work, drug use, same sex practices, migration), absence of protective laws, societal stigma and discrimination (for example, against women who are or have been in prison or detention), taboo (for example, around mental health and disability), and deeply held cultural or religious beliefs about which women are 'eligible' to have sex and start families, and how and when.

***"Social workers and doctors in prisons are well trained so they know about HIV and how to handle it. The problem is provisory detention: a friend of mine almost got raped in a police station when she entered to press charges against a taxi driver who had refused to take her at night. It's very common. If you agree to sleep with them [police officer], you can get out; if you don't then you have to stay until at least the next day. The main issue is that you have to take your medicine while you're there but you don't want the policemen to know about your status because they will breach the confidentiality, so you stay without taking your ARVs." Senegal FGD with sex workers***

Further examples of how SRH services are severely restricted for women living with of different diversities can be found in the Annex to Section 3.

#### IMPLICATIONS FOR GUIDELINE WRITERS<sup>17</sup>

An approach which equitably serves all women living with HIV, in all of their diversities, requires both overarching and specifically tailored measures, first to create an enabling environment in which the needs, rights and desires of all women have equal potential to be fulfilled, and second to address the specific needs of women living with HIV facing particular circumstances. For example, trans women reported facing higher on average levels of violence – especially at the community and health services level – than other women. Trans women also experienced very specific barriers, such as punishments for using the 'wrong' restroom facilities within institutional settings.

***"Being trans and HIV positive makes getting compassionate and comprehensive care very difficult. I have been hospitalized at the University of New Mexico Hospital, Duke University Hospital, and University of Cincinnati Hospital – all places made me feel extremely unsafe. I had to explain my trans identity when I felt it was unnecessary. I felt objectified." United States***

***"As a trans woman, healthcare providers do not have the correct information about my body. I experienced that they are very uncomfortable dealing with a woman who have a penis. Some of them also want to lecture me that what I'm doing – having a male body and having sex with men – are wrong. They always want to preach me about how I will burn in hell. Now I avoid such centres." South Africa***

Similarly, women who inject drugs tend to encounter more societal stigma and disapprobation than men who use drugs, as well as being discriminated against on the basis of their gender within the drug-using community, which puts them at greater risk of HIV acquisition. They also have very specific needs in relation to ante-natal, maternal and child healthcare (such as threats to child custody) to ensure the well-being of both mother and baby.<sup>18</sup>

17. See Annex to Section 3 for further details of these experiences throughout the consultation.

18. See Burns 2009 and WHO 2014d for example.

## Policy and practice recommendations

The policy and practice suggestions listed below were informed by the Global Reference Group, and ranked as critical, important, less important, or not important by the survey respondents (see Annex to Section 3). A minimum of 54% of respondents (and up to 93%), agreed that the proposed measures were critical or important. Where a lower percentage of respondents endorsed measures, there was also consistently a greater percentage of respondents answering 'don't know' (up to 30%) indicating the need for greater awareness raising, accessible information and evidence-informed debate in some of these areas.

### ● Women who use drugs

- > access to methadone or buprenorphine for women living with HIV who inject drugs and are pregnant
- > treatment and support for hepatitis C co-morbidities
- > education on prevention and first aid for overdoses, including access to naloxone

### ● Sex workers

- > interventions to halt and address violence and discrimination against sex workers

### ● Women with disabilities

- > tailored access to information and services for women with disabilities

### ● Lesbian, bisexual, trans women, and other women who have sex with women

- > tailored SRH services
- > introduction of SRH guidelines and policy for trans women
- > access to hormone replacement therapy, sexual reassignment and other gender-affirming surgeries for trans women

### ● Women in prison or detention

- > continuity of treatment access and adherence support for women in prison or detention and women re-entering into society
- > address HIV-related stigma and discrimination among prison staff and inmates
- > consistent implementation of up-to-date practice guidelines in relation to women living with HIV in prison (including prisons' duty of care as outlined in key performance indicators)

### ● All women, throughout the life-cycle

- > comprehensive sexuality education
- > removal of age-restrictive policies
- > treatment and support for TB co-morbidities

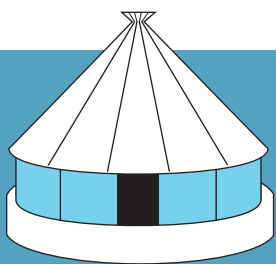
In addition, we suggest human rights protections are strengthened for women living with HIV and women from key populations by:

### ● Repealing laws that criminalize HIV transmission and exposure, and those which criminalize personal drug use, sex work, and same sex practices

### ● Eliminating stigma and discrimination on the basis of HIV, drug use, sex work, sexuality, gender orientation, or age

### ● Ensuring continuity of treatment and holistic care for women in prison or detention

### ● Ensuring that people in authority see it as a part of their duty and role to remove barriers to SRH access for women living with HIV, in all their diversities.



## 4. HUMAN RIGHTS AND EXPERIENCE OF ACCESSING SERVICES

***"Just because I know my rights and where to report violations, doesn't mean I have the confidence to report these."*** Australia

In 2014, WHO produced groundbreaking guidance and recommendations *Ensuring human rights in the provision of contraceptive information and services*.<sup>19</sup> This document clearly articulates the need for contraceptive information and services to be firmly embedded in nine human rights dimensions, namely:

- Non-discrimination
- Availability
- Accessibility
- Acceptability
- Quality
- Informed decision making
- Privacy and confidentiality
- Participation
- Accountability

The principle of choice is especially important to women living with HIV. Respondents described a routine lack of inclusion or choice in decision making about their own SRH care and care pathways.

Only 50% of respondents agreed that they find their service providers well-trained and knowledgeable, friendly and supportive.<sup>20</sup>

### EXPERIENCES

#### Contraception

Respondents reported that they do not have good experiences of contraceptive choice. Many have been told by service providers that they may only use condoms. Conversely, others have been coerced or forced into using long-acting or permanent birth-control methods such as intra-uterine devices (coils), injectable hormonal contraceptives, or tubal ligation (sterilization). Additionally, these methods are often given as a condition to receiving other services, such as safe abortion or antiretroviral treatment. Negative, moralistic and judgemental attitudes continue to be frequently encountered regarding women's 'duty' to protect other people. They are told to abstain

from sexual relationships and forego motherhood. Former ill-treatment has left deep emotional scars on many women living with HIV, especially those who were strongly discouraged or dissuaded from having children, and who now are too old or feel too old to do so.

***"Many doctors say that women living with HIV can't be mothers, or even that they shouldn't have an active sex life because they should be aware of not hurting other people in the world."*** Ecuador

#### Maternity care and obstetrics

Women's choice – whether to test for HIV, and whether, when and how to disclose their status to their partner(s) – has also often been compromised in maternity contexts. The impact of poor, or actively discriminatory, maternity services can be devastating.

***"The moment a woman identifies herself as living positively with HIV, they are neglected, especially during delivery, hence increased number of children born with HIV because women prefer to keep it a secret and be treated like the rest. Others have avoided giving birth from health centres or hospitals because of negligence in those hospitals. They prefer traditional birth attendants."*** Uganda

#### Diversity and wider contexts

No fewer than 30% of respondents find discrimination a challenge in healthcare settings. This is exacerbated for sex workers, lesbians and trans women – in particular with regard to decision making around fertility and access to family planning. Participants commonly experience discrimination – sometimes embedded in policy – with regard to accessing fertility treatment and adoption on the same basis as women who are not living with HIV.

#### Accountability

Globally, most respondents<sup>21</sup> are aware of the SRH services that exist in their countries (80%), are aware of their rights in relation to accessing them (70%), and are able to access those that exist (70%). Many also report a great improvement in SRH services for women living with HIV over the past 20 years.

However, whilst these figures appear encouraging, many survey respondents also said that they would not know where to seek redress in the event of a rights violation, that they would not trust the redress services, and/or that they would be afraid to seek redress for fear of alienating

19. WHO 2014a.

20. Responses revealed great regional variation and the percentage dropped to 24% in Eastern Europe and Central Asia.

21. See Annex to Section 4 for further data. The high level of awareness reported by respondents may be a reflection of respondents' access to emails and the internet.

doctors and service providers with whom they have built up supportive relationships over time. Further, nearly 40% of women still do not feel they have access to good quality care services in which their rights are promoted, protected and upheld. In some regions, including Eastern Europe and Central Asia, these women still constitute the majority.

*"I also know my rights, but if they are violated, I do not know where I can run for redress."* Uganda

Respondents described the importance of building up a good relationship with care providers, but many have had multiple service providers (often specialising in a range of areas) with mixed experiences over time. This is clearly an area for further research.

Inappropriate health staff attitudes ranged from the unkind to abuse and violation of human rights. Here are some examples:

*"I went to the health facility for an IUD which they did willingly but after six months I wanted it removed because I wanted to have a baby. They told me the family planning method I used was for 12 years so they gave me a hard time that I had wasted their IUD, which*

*another person would have used – 'someone who is not like me'. it hurt me so much and I left. So I gave up removing it."* Uganda

*"While you're in labour [the midwives] say to your face that 'when you were making love it was good, so now you just need to open up your legs.'" Senegal*

*"I have also given up complaining about the yellow stickers on all my tests saying 'danger of infection' because I just feel that I am not listened to and I don't want to alienate my HIV doctor."* United Kingdom

*"There have been cases of suicides or attempted suicide as women were scared of what might happen to them if people got to know their status."* Senegal

*"When my mother-in-law found out about my HIV-positive status from hospital nurses, she did everything possible to take away my daughter. She has not deprived me of my maternity rights, but tried to take custody of my daughter by threatening to bribe in the office that decides on the question of custody."* Russia

## IMPLICATIONS FOR GUIDELINE WRITERS<sup>22</sup>

- **Women living with HIV should be at the centre of healthcare workers' considerations** – their values, needs and preferences, and human rights; never coerce women into any course of action (especially pregnancy termination and long-acting or irreversible contraception in the SRH context) whether explicitly without consent, implicitly, or even unwittingly by their words, deeds and information or recommendations.
- **Healthcare institutions should regularly examine their policies, procedures and practices to ensure non-discrimination.** Guideline writers should consider how institutions could be audited to ensure this, e.g. if an institution had a higher rate of procedures for women living with HIV.
- **Perinatal policies that limit women's choices around treatment uptake should be reviewed in light of the SRH and human rights of women living with HIV.** Antenatal HIV testing, along with

the current roll-out of approaches such as 'treatment as prevention', can create an environment where pregnant women – and others – are no longer treated as 'ends in themselves' but as a 'means to an end'. Women face rushed decisions during pregnancy, and coerced or mandatory 'test and treat',<sup>23</sup> contrary to both medical and human rights principles<sup>24</sup>. Concerns about effectiveness, poor follow-up, drug resistance in children,<sup>25</sup> and human rights abuses have been raised.

- **Healthcare institutions should set standards that support the SRH and human rights of women living with HIV who are employees and be safe places for women living with HIV to work.** Over 90% of women living with HIV working as healthcare professionals, have acquired HIV outside these roles.<sup>26</sup> Women often fear losing their jobs if they disclose their status. They may also experience GBV at home and in the workplace. Their SRH and human rights need to be supported, especially if their skills and insights are to be retained and harnessed.<sup>27</sup>

22. See Annex to Section 4 for further details of these experiences throughout the consultation.

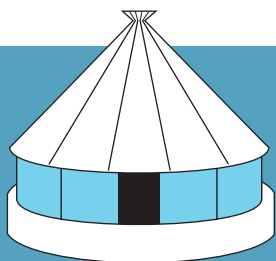
23. Horton 2014.

24. For example, Option B+ is a policy that starts HIV positive pregnant women on treatment for life, rather than a short course of treatment to prevent vertical transmission during pregnancy and infant feeding, and then subsequent treatment as per the general population, thus potentially increasing the burden of taking medication and being singled out (as women and mothers). The policy elides two different purposes (individual and population) and thus may cause unintended harms including to human rights. For more information see Welbourn et al 2014.

25. Kuhn et al 2014.

26. [http://www.who.int/occupational\\_health/topics/hcworkers/en/](http://www.who.int/occupational_health/topics/hcworkers/en/)

27. Odetoynbo et al 2009.



## 5. GENDER EQUALITY AND SOCIAL JUSTICE

**"Men cannot set policy on a woman's body. They have no experience or true idea of that which they speak."**

United States

Gender inequality and other forms of marginalization have long been recognized as structural drivers of the HIV epidemic. SRH and human rights for all women, including women living with HIV and women from key populations, must be embedded in a framework of gender equality and social justice.

### EXPERIENCES

Social relations predicated on gender inequality mean that women – and others deemed to 'deviate' from culturally accepted gender norms and behaviours – are excluded from decision making in all areas of their lives, and have limited access to, or control over, resources. In addition to 'the usual' violence against women and girls, violence related to HIV, sexuality, gender identity, race/caste, age, sex work, drug use, and (dis)ability – among other factors – creates additional layers of structural disadvantage, often manifested in exclusion, marginalization, and more violence.

This severely limits women's ability to exercise agency in relation to SRH, and to claim and realize their human rights.

**"Gender dynamics and societal norms play a strong role in decision making around whether and when to have children. Men are seen as heads of households, especially where women are not formally employed. Financial empowerment can bring about a shift towards more shared household decision making."** FGD, Thai Positive Women's Network

Decision making about sex – when, how and with whom; whether and when to have children – is often based on patriarchal norms, whereby a man is seen as the household head, frequently through his (greater) income.

**"My husband want four child while me, I need two."** Uganda

Financial inequalities, and calls to protect and create economic opportunities for women were raised repeatedly by survey respondents, in relation to their sex life, their fertility desires, their mental health, and their ability to access and utilize health services, including SRH services.

**"As long as a woman is not able to support herself financially the discussion will never end. So train our women and girls then make ways and mean for them to get jobs. I had facilitated a support group for years and the concern has always been being able to support self. Yes we have the information, but that can not pay the bills and dependency does not sit well for everyone."**

Jamaica

Community gender norms are also held by health staff. Family members, neighbours and service providers alike judge 'appropriate' sexual behaviour and motherhood for women. Assumptions are made about the sexuality of girls and young women, older and post-menopausal women, women living with disabilities, and women living with HIV, among others. Women who do not 'fit' into culturally accepted sexual and gender norms (e.g. sex workers, women who use drugs, lesbian and bisexual women, transgender women, trans men who choose to get pregnant) are often seen as unfit for parenthood, and not worthy of the same levels of treatment and care as other women.

**"The anger, hatred and violence against us trans women by the community and the government."** United States

These biases are also often reflected in policies and laws, for example; laws that criminalize same-sex practices. They create barriers, denying access to high quality, appropriate treatment, and holistic care.

**"Remove the FEAR of going to jail for exercising my sexual desires."** United States

Gender inequality also has serious implications for disclosure. As Section 1 shows, women living with HIV experience high levels of violence, including intimate partner violence.

**"We must address the serious gender-based inequalities which render it difficult for women to disclose their HIV status due to the serious repercussions which often await us when we do disclose to sexual partners. The police must also receive training around HIV to reduce their highly discriminatory practices."** United Kingdom

Service providers and public health policies may pressurize women to disclose, without safe protections or support.

**"Service providers should stop forcing women with HIV to disclose to their husbands, they should teach on how to help them to disclose, because if a woman doesn't disclose she is not attended to."** Uganda

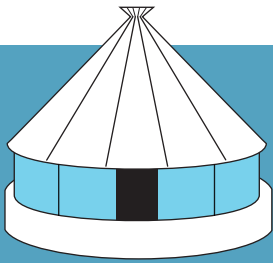


## IMPLICATIONS FOR GUIDELINE WRITERS

The manifestations of gender inequality are structural drivers of the HIV epidemic, especially violence against women and girls, and they perpetuate the two way linkages between HIV and GBV. Women living with HIV want gender inequality to be addressed by.

- **Signing, ratifying and implementing CEDAW<sup>28</sup> and other international instruments** that promote and protect women's human rights, including their SRH.
- **Providing options for women experiencing intimate partner violence**, including mental and physical violence, such as safe houses, income-generating opportunities, etc.
- **Recognizing and providing redress for gender-based violence in institutional settings** against women living with HIV, such as forced or coerced sterilization.
- **Reviewing, amending or repealing all laws that promote, sustain or contain gender inequality** either in their content or implementation.
- **Addressing gender inequality in all healthcare policies and practices** as a matter of quality, not merely quantity, of service.

28. Convention on Elimination of Discrimination Against Women.



## 6. MEANINGFUL INVOLVEMENT OF WOMEN LIVING WITH HIV

***"Connecting with other positive women was the best thing I ever did for myself."*** United States

In addition to political engagement, the support and engagement of other women living with HIV is of fundamental importance to achieving SRH and human rights.

### EXPERIENCES

Survey respondents raised the issue of the meaningful involvement of women living with HIV (MIWA)<sup>29</sup> and peer support in every section of the survey, in particular when:

- dealing with mental health issues, including self stigma, anxiety and isolation
- making decisions about their fertility
- making decisions around disclosure
- understanding their rights
- feeling empowered and confident to enjoy sexual relationships
- seeking redress for violence
- supporting other women as they learn of their HIV diagnosis.

Meaningful involvement of women living with HIV is fundamental to an effective HIV response, grounded in the contexts and realities of women's lives, experiences, hopes and desires.

***"Meaningful involvement is a must. Too often the ones making decisions have not had to live with the many challenges faced by women living with this infection."*** United States

It is especially relevant to the efficient and effective development and implementation of robust policies and programmes around SRH, as these play out and

are contested and negotiated through structures that are often very hostile to women, including those living with HIV and women from key affected populations, and which frequently expose women to violence and fear (see Section 1).

Meaningful involvement can only come from strategic investment in the organizations, networks and support groups of women living with HIV.<sup>30</sup>

***Ensure that there is the funding and recognition of the importance of support services for HIV positive people and women-focused services in particular. These centres that encourage peer support enable the client group to become confident and articulate in demanding their rights and taking an active role in shaping services in accordance with their needs.*** United Kingdom

The Thai Positive Women's Network focus group discussion on SRH and human rights described how participation in trainings, discussions, peer support groups and workshops with other women living with HIV had empowered them to be more aware of their SRH needs and rights, and to talk more openly about their sexual health needs and rights with their partners and care providers, as well as with other women: ***"Spaces to tell stories and share experiences are a vital part of this empowerment process."*** FGD, Thai Positive Women's Network

As well as providing peer support and mentorship at an individual level, MIWA has the potential to challenge traditional structures, gender norms and power relations. It can provide non-traditional leadership and advocacy spaces for women and break down stigma around culturally sensitive or taboo subjects.

***"In a traditional setting, women do not discuss sexuality. Need to empower women. This can be done through developing a pool of well-trained advocates who interface with facility and community healthcare providers."*** Kenya

29. MIWA is based on the principle of the greater involvement of people living with HIV and AIDS (GIPA), coined in 1994.

30. See the ICW Tree of Participation in Annex to Section 6.



## IMPLICATIONS FOR GUIDELINE WRITERS<sup>31</sup>

To ensure the meaningful involvement of women living with HIV:

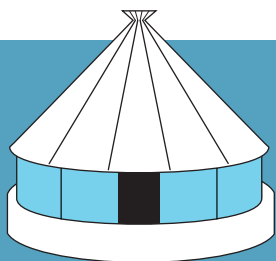
- **Promote and fund support for peer counselling and support, created and led by women living with HIV,** in order to support women newly diagnosed with HIV, women living with HIV who experience violence, and peer support services in general
- **Invest in women's empowerment and leadership development at the community level** as well as in advocacy and policy
- **Protect, create and expand spaces for women living with HIV to learn about and debate policy issues**
- **Encourage participatory dialogues between women living with HIV and healthcare professionals,** and provide opportunities to contribute to mutually supportive care pathways
- **Ensure funding streams for women's rights programmes,** including capacity building in SRH and human rights advocacy for women living with HIV
- **Involve women living with HIV in clinical trials,** both in the design and execution phases as well as participants
- **Create working groups at national level that include women living with HIV in policy and programme design,** budgeting, implementation, monitoring and evaluation
- **Promote good practice examples of realising meaningful involvement** in the context of SRH and human rights, for example; include a minimum of three women living with HIV on all local health committees,<sup>32</sup> ensure grassroots-led peer mentor structures for women living with HIV in all antenatal clinics<sup>33,34</sup>

31. See Annex to Section 6 for further details of these experiences throughout the consultation.

32. Tarr-Whelan 2011.

33. See Salamander Trust 2014 and Knudsen-Strong 2011.

34. Peers for Progress.



## 7. PROTECTIVE LAWS AND FREEDOM FROM CRIMINALISATION

***"Imagine yourself in my place."*** Ukraine

Whilst WHO cannot directly address laws, respondents reported widespread concerns about punitive and repressive laws that act as a barrier to their achievement of SRH and rights and impact on effective health delivery.

### EXPERIENCES

The overarching narrative revealed two major barriers to achieving SRH – a woman's intrinsic fear of onward transmission to a partner and to that of her child. These did not appear to be based on a fear of blame or the law, but rather on respondents' basic humanity.<sup>35</sup>

***"I am afraid to have baby because of the risk of mother-to-infant transmission."*** Cambodia

***"I wanted [motherhood], but could not imagine to bring my unborn baby, and maybe the father too, to get infected and to take that treatment. I decided to renounce to become a mother. Even if it was the dream."*** Switzerland

Nevertheless, punitive laws – those that criminalize the exposure to or transmission of HIV, sex work, drug use, and same-sex practices – create barriers for women living

with HIV to realize their SRH and human rights. Laws that criminalize HIV transmission single out and position those living with HIV as the 'threat' (rather than the recipient of a virus), and legitimize stigma, discrimination and violence.

Rather than creating a threatening and fearful environment, laws should be used to establish an environment where women's fears of, and actual, HIV transmission to children and partners are reduced by the provision of timely and appropriate information, services, care and support and where their desires and rights are protected.

***"They should put up policies and laws that don't criminalize us – for instance the HIV prevention and control bill – because such bills will stop us from accessing treatment."*** Uganda

Laws that criminalize activities that are already high risk for HIV, such as sex work, drug use and same-sex practices, can leave women at greater risk of marginalization and violence (see Section 1). Violence can also be institutional, such as through forced or coerced abortion or sterilization.

***"Understand what HIV is, eliminate stigma and stop criminalization of people living with HIV. Understand human rights, and our basic rights for universal health care."*** Indonesia

### IMPLICATIONS FOR GUIDELINE WRITERS

Respondents said that criminalization acts as a disincentive to test, disclose and access HIV treatment. This also prevents health services from supporting marginalized people. Decriminalization of sex work would have a marked effect on reducing HIV transmission, averting 33–46% of HIV infections in the next decade.<sup>36</sup>

***"Decriminalize HIV. As a human race we look unintelligent in our care of other humans by making a disease a crime. This same principal could be applied to all diseases that have caused a death right down to the common cold. Decriminalize now!"*** United States

Women living with HIV want informed opinion leaders to press legislators to:

- **Strengthen laws and policies to protect the rights of women living with HIV**, including sexual and reproductive rights
- **Strengthen legal protections around all forms of violence against women** including within health services
- **Recognize and address marital rape and 'date rape'**
- **Provide universal access to effective sexual assault referral, forensic and follow up services** including in conflict areas
- **Involve women living with HIV in policy development**
- **Remove laws that criminalize HIV non-disclosure, exposure and transmission**
- **Remove laws that criminalize sex work, drug use and same sex practices**

35. To read views of women living with on this, see UNAIDS 2012.

36. Shannon et al 2014.

## Enabling laws

Enabling laws, based on equality, justice and rights, exist at national and international levels, but are often not well implemented and are unfamiliar to key stakeholders and beneficiaries.

- **Promote and disseminate positive and rights-enhancing laws and policies in SRH and human rights through campaigns and training**, targeting decision makers.

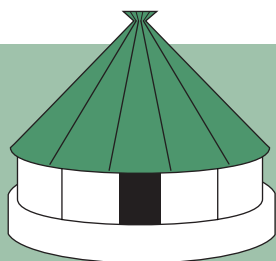
*"You have to adapt the legal framework so that it ensures access to sexual and reproductive health in a holistic way, and then monitor [until] it's fully implemented." Mexico*

- **Allocate laws and policy commitments, which protect the rights of women living with HIV, adequate budgets** or resources, implementation strategies, and accountability frameworks.

*"There exists good policy documents. There is need for strengthening them and to ACT on implementation. Ratify and sign important regional and international human rights instruments especially those specific to women and girls."*

South Sudan

*"Laws may be great, but what happens on the ground is a total different issue. Don't create laws in isolation of others – creating a plan to decrease HIV infection without looking into the issues of gender, economics and education is a waste of time, money and lives."* South Africa



## 8. PLEASURABLE AND FULFILLING SEX LIFE

***"Sexuality is a fundamental dimension of human beings that accompanies us from when we are born till we die. Acknowledging this, for good or bad, our destiny will lie in the policies you put in place."*** Guatemala

### EXPERIENCES

Significant numbers of respondents reported challenges to achieving a pleasurable and satisfying sex life, with lack of decision making powers (e.g. when and how to have sex, use of male and female condoms, and attention to their own sexual pleasure). Only 48% find it easy to climax during sex, and 46% have sex when they want to. Only 32% report always or usually having a strong libido or feeling sexual desire.

***"It is hard for me to reach orgasm so I never enjoy it that much although I fodge orgasm in most cases."*** Uganda

Challenges and barriers include:

- Fear of onward transmission, pregnancy and STIs, and the impact and consequences of disclosure, including violence. ***"A partner used derogatory comments like 'no-one will ever want to touch you!'"*** United Kingdom
- Lack of desire and libido due to: HIV itself; ART and side-effects (including possibly menstrual problems); drugs and alcohol use; sterilization; age and menopause
- Lack of a loving or caring partner, for example: hard to find a partner who will accept HIV status; partner only concerned with their own pleasure; partner has eroded trust in the relationship by being unfaithful.
- Lack of availability and not knowing how to use the female condom. 25% of respondents said they are 'never' able to access or use female condoms and consider this a key concern. Approximately 25% are only 'sometimes' able to access or use them.<sup>37</sup>
- Difficulty in negotiating use of the male condom, resulting in anxiety and reduced pleasure for the woman and/or her partner.
- Broader societal stigma and discrimination, for example; service providers, leading to misinformation or the belief that women living with HIV shouldn't have sex. This results in self-stigma, low self-esteem and feeling 'dirty' or 'guilty'.

- Poverty, which results in stress and reduced libido. Lack of resources make it difficult to go out or look for a new partner (see Section 11).
- Anxieties about body shape, particularly among women affected by lipodystrophy.

Despite the above, many respondents reported enjoying a positive, satisfying sex life, based on trusting, respectful relationships, with good communication – including around HIV status – and informed decision making around onward transmission, contraception, STI prevention, treatment and care. Amongst survey participants, access<sup>38</sup> to such information was high (86%), as was access to related commodities (68%). Similar proportions felt confident to have sex without fear of onward transmission, STIs, or unintended pregnancy (69%, 72% and 75% respectively). Although encouraging, these figures may reflect the well-informed, activist-linked roles of our respondents.

The largest group of enabling factors to achieve a satisfying and enjoyable sex life, raised in about 50% of responses, included:

- Having a partner that accepts your status and is loving and caring
- Being able to talk opening and honestly in a trusting relationship about HIV status and sex and sexual pleasure
- Being able to protect a partner from onward transmission – through the use of condoms, as well as through treatment access and achieving an undetectable viral load.

In addition, the following were considered important for women living with HIV:

- Access to condoms, lubricant and sex toys (and being able to negotiate their use)
- Access to information, training and awareness on SRH and human rights for women living with HIV, awareness of risks and safety (for oneself and partner) as well as on sex and sexual pleasure; there was a strong element of peer-learning, sharing and counselling in this
- Self-acceptance (including acceptance of diagnosis), and self-confidence
- Condoms were seen as both one of the biggest enablers of, and barriers to, a healthy, pleasurable sex life. Not only did respondents comment on sometimes being unable to negotiate their use; many also commented on the negative impact condoms have on their own sexual pleasure. This example highlights once more the complexity of women's lives and experiences.

37. See data in Annex to Section 8 for more details.

38. See also WHO 2012.

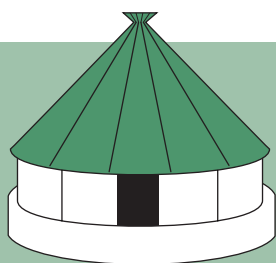
## IMPLICATIONS FOR GUIDELINE WRITERS<sup>39</sup>

- **Leadership on sexual matters** WHO can influence attitudes, particularly amongst the health sector, through its leadership and language. The chances that women will have partners, neighbours, families and communities who accept their status will be directly impacted by the tone the guidelines set.
- **Access to psychological support**, including: for disclosure; on-going psychosexual counselling including with partner/s; psychological care for past traumas; for self-confidence, acceptance and positive body image; know and believe in rights
- **Provision of community-based information and training programmes on HIV, SRH and human rights of women living with HIV**, including reliable information about minimising onward transmission and promoting pleasurable, safer sex. These should be addressed within the wider context of addressing gender inequality, VAWG and negative societal attitudes, stigma and discrimination towards women living with HIV and resultant loss of libido and desire.
- **Provision of programmes and forums in health centres with opportunities to talk positively about sex**, including safe spaces with doctors, other health staff and peer mentors.
- **Easy access to male and female condoms, lubricant and other commodities.**

## FUTURE RESEARCH

Areas for future study include further microbicides research and understanding the interactions of ART adherence on libido and sexual desire.

39. See Annex to Section 8 for further details of these experiences throughout the consultation.



## 9. PREGNANCY AND FERTILITY DESIRES

***"Pregnancy with HIV is possible, desirable and normal!"*** Ukraine

Respondents reported relatively good access to and use of family planning, prevention of vertical transmission programmes, and information and advice around safe conception but there appears to be a disconnection between healthworkers' words and actions in relation to desires and decisions of women living with over whether to have children or not.

### EXPERIENCES

72% of respondents reported receiving advice on safe conception, but only 55% reported receiving practical support for safe conception, suggesting that some services are less available than desired. Similarly, while 70% of respondents reported being able to talk to their service provider about their fertility desires, only 50% felt that they had received support from service providers in realising these desires.

Nearly 60% of survey respondents reported having had at least one unplanned pregnancy. Respondents also indicated limited access to safe abortion, post-miscarriage and post-abortion care, fertility treatment or advice on legal adoption.

There is also a major gap in counselling on family planning and child spacing with only around 40% of women having accessed these services. When asked if they had chosen to test for HIV during pregnancy and were given adequate pre- and post-test counselling, only 35% replied yes. This statistic presents significant concerns particularly where there are global trends to scale up testing during pregnancy –as in many countries this is already viewed (by service users and providers alike) as mandatory for pregnant women.

Reasons for limited choices included:

- Fear of passing HIV onto a child and/or partner, based on a lack of knowledge (see also Section 7). This was the biggest single reported barrier to realizing fertility desires.
- Stigmatizing or judgmental attitudes from service providers, the community at large, and family members. These attitudes were often based on lack of information on HIV treatment and prevention of vertical transmission (PVT) programmes
- Self stigma
- Fear of disclosing to a partner
- Partner is unwilling or fearful about having children
- Financial constraints, especially when combined with unemployment, homelessness or the threat of homelessness (see also Section 11)
- Age, infertility and early menopause (both possibly HIV/ART-related), lack of access to fertility treatments, including for safe conception, and compromised health

Some women described positive experiences of pregnancy and fertility choices. They had access to a full package of support with choices around pregnancy and fertility from: peer counsellors and support groups (80%); partners (70%); doctors and service providers (only 55%); and family and community (only 50%).

***"My HIV doctors have been my greatest supporters when it comes to the choices I have around children and pregnancy. They have armed me with information, giving me the courage to make informed and correct decisions for myself and my partner."*** Uganda

Ability to make an informed choice resulted from access to relevant, up-to-date and trustworthy information on HIV, pregnancy and transmission. Women reported that it is crucial to know that it is possible to have children born HIV free through access to PVT programmes, which include advice and support on delivery and infant feeding options, and access to fertility treatments, if needed.

Self awareness and trust in one's own decisions was also an important factor.

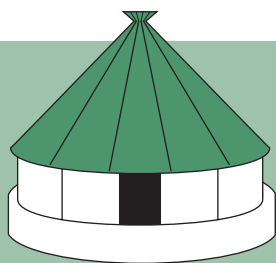
## IMPLICATIONS FOR GUIDELINE WRITERS<sup>40</sup>

*"In 25 years no one ever talked to me about my thoughts or feelings about having a child, wanting a child, adoption, birth control, truly nothing. Oh, when doing pentamidine treatment I signed a paper saying I wouldn't get pregnant." United States*

- **Ensure women have the right to care and support**, which is not conditional on disclosure to partners (see Section 1 on safety)
- **Access to compassionate and holistic care and support in all areas** (financial, psychological, institutional, legal and physical) to enable women living with HIV to realize their pregnancy and fertility desires
- **Normalize 'positive' pregnancy and childbirth** for women living with HIV
- Health staff should initiate **open discussion to demystify sexuality and fertility**
- **Provide education campaigns** on the rights of women living with HIV for families, friends, communities and health providers. Women living with HIV will then feel supported to make and trust their own decisions
- **Offer a package of SRH services** including: family planning; assisted conception and fertility treatment; information on legal adoption rights; breastfeeding and delivery advice; pre and post exposure prophylaxis (PrEP and PEP); sexual relationships and peer counselling; prevention of vertical transmission programmes and pregnancy-related ART

40. See Annex to Section 9 for further details of these experiences throughout the consultation





## 10. HIV TREATMENT AND SIDE-EFFECTS

### ***"Sometimes I don't feel like a woman."*** Uganda

Among 434 respondents to the optional section on treatment, 88%<sup>41</sup> were on treatment, of whom approximately half had an undetectable viral load.

### EXPERIENCES

The survey sought respondents' views on treatment side-effects and having an undetectable viral load. The latter was of interest in the context of Option B+ and the UNAIDS targeted campaign 90-90-90 (both approaches intend to achieve an undetectable viral load in the interests of prevention of onward transmission).

Free text responses revealed that some women felt that an undetectable viral load is desirable as long as there are no problems with safety through adherence (see Section 1 and below), no problematic or disruptive side-effects (see below) and no other unintended adverse consequences.

Some women expressed concerns about having an undetectable viral load, which may have consequences for the implementation of test and treat approaches.

- Having an undetectable viral load could make it harder for a woman to negotiate condom use – given the reduced risk of HIV transmission – leaving her vulnerable to STIs and unplanned pregnancy. ***"It might be easier for a partner to want unprotected sex (without ensuring there is no STI)."*** Nigeria
- Without adequate information and adherence counselling, there is a danger that people with an undetectable viral load may believe they no longer need to take their ARVs, leading to potential future drug resistance. ***"There is no problem but I feel if not communicated well people could stop taking drugs."*** Malawi
- Having an undetectable viral load can cause a false sense of security and mask the fact that all is not well. ***"Despite having an undetectable viral load I feel too overwhelmed and exhausted most of the time in order to manage my life effectively."*** Spain

The data revealed high levels of perceived side-effects from taking ARVs. On average, respondents each experienced four different side-effects. Some respondents, were unsure if these symptoms were caused by their

treatment regimen, HIV, or their age and/or other factors.

Fatigue and tiredness were experienced by over 60% of respondents, mood swings by almost 50%, and loss of libido, headaches and changes of body shape by up to 40%. Only about 10% of respondents experienced no side-effects at all (see Annex to Section 10).

The greatest impact of side-effects on women's SRH is on their ability to enjoy a healthy and satisfying sex life. Low moods, headaches, irritability, and feeling tired results in not wanting to have sex, which is stressful and puts a strain on relationships.

### ***"Husband is not satisfied, I often force myself to have sex."*** Ukraine

Heavy and prolonged menstrual periods, nausea or constipation also make sex uncomfortable. In addition, women often feel undesirable – sometimes due to body changes – and undesired.

### ***"There are times when I have the side-effects and it feels like I am dying, the menstrual [issues] affects my relationship when I want to have sex, the change of body shape if I wasn't a strong person I would be ashamed of my shape, but because I love my self. I have high self esteem."*** Jamaica

### ***"Affect the sex life, self-compassion, looks ugly, unhappy, can not find partners."*** China

### ***"On my sexual health, I feel unwanted."*** Kenya

Side-effects – especially fatigue – also affect work, social activities and activism, leading to mental health problems. Being unable to work can also result in poverty, loneliness and isolation resulting in further anxiety and depression.

### ***"Efavirinz makes me feel like I have been drinking alcohol or taking drugs, I feel tired after I eat it and I am not able to work."*** Nepal

Women often have a lack of information on side-effects especially when they start treatment, and feel that health providers do not take side-effects seriously.

### ***"Sometimes you feel like you have no choice but to bear with it all, our health workers tell us it is better than stopping the drugs and die."*** Uganda

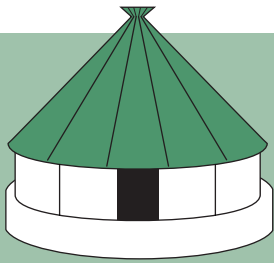
41. For more details by language of respondents, see Annex to Section 10.

## IMPLICATIONS FOR GUIDELINE WRITERS<sup>42</sup>

- **Review guidelines for current and imminent test and treat approaches.** An undetectable viral load may have less positive consequences for women living with HIV in terms of their SRH and human rights.
- If a woman is well with HIV, taking daily medication from the point of diagnosis may serve as a reminder of the virus and lead to poor adherence. Taking medication at a point where symptoms are noticeable may mean that the resulting benefits and associated complications are better tolerated.<sup>43</sup> This is a powerful argument *against* starting treatment for life from a high point of feeling well during pregnancy.
- **There is a need for greater knowledge, understanding and information around perceived and/or real side-effects of ARVs** for women living with HIV and their potential impact on the SRH and human rights of women living with HIV; as well as to support the rights of women living with HIV to make informed decisions on treatment.

42. See Annex to Section 10 for further details of these experiences throughout the consultation.

43. See for example <http://social.eyeforpharma.com/column/make-no-bones-about-it-treatment-adherence-challenge-osteoporosis>



## 11. FINANCIAL SECURITY

***"Most women I know are housewife, unemployed or work as labour. Low education, no skill, afraid to have dream."*** Indonesia

Throughout the survey, responses emphasized the challenges of poverty. Its resulting strains on mental, physical and sexual health were repeatedly highlighted. This is despite the fact that most respondents, with access to computers and the internet, may be better off than the vast majority of women living with globally.

### EXPERIENCES

The greatest single issue raised was employment opportunities for women living with HIV (67%), closely related to stigma and discrimination in the workplace (61%).

***I have days that I feel good, and days I find it hard to get out of bed because of diarrhoea or stomach problems, so I would be a undependable employee. I disclosed my status to an employer, and I know that is why I did not get hired.*** United States

Violence against women living with and affected by HIV creates and exacerbates poverty and financial vulnerability.

***"Spouses/widows of migrants [who have died of AIDS] are expelled from our families and our communities and society then we are alone and living marginalized in the street and then we are very vulnerable anyone can do anything including sexual violence, and we need to survive some may become sex workers to take drugs."*** Nepal

Economic dependence can force women to stay in violent relationships, and also creates a lack of negotiating and decision making power within the relationship, including in relation to sex and child-bearing.

Financial stability also bears on whether and when women living with HIV decide to have (more) children, including the ability to access private fertility services, and private safe abortion services.

***"It was expensive to see the doctors and paying at every point of access was not easy for me."*** Zimbabwe

***"China only one child, and healthcare is not perfect, if the child is unhealthy, a family can not afford the costs associated with treatment."*** China

***"It was difficult to find a maternity hospital, and childbirth services due to HIV were significantly more than 4,000 dollars ... Expensive, since in general the prices are not low, but HIV status increases the price to almost double".*** Russia

Poverty is a major concern for women growing older with HIV, especially for women who do not have children, are widowed or without a partner, or have no access to insurance or pensions. Accessing care in old age is a worry.

For women who are economic migrants, employment restrictions leave them in financial limbo or vulnerable to exploitation and abuse. Women who have been in detention or prison may also face financial constraints upon their release as well as challenges finding employment.

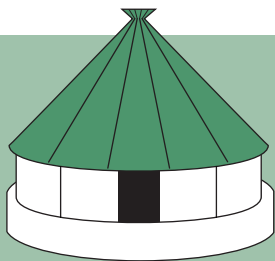
Women living with HIV who also experience discrimination or violence on the basis of their sexuality, gender orientation, sex work or drug use, also often face economic as well as social marginalization as a result of multiple layers of stigma.

### IMPLICATIONS FOR GUIDELINE WRITERS<sup>44</sup>

- **Women want affordable healthcare**, including for HIV testing, treatment and care, sexual and reproductive health, and mental health. To achieve this:
  - > increase the number of health centres offering HIV treatment and care and SRH services in rural areas
  - > enable access to health insurance
  - > offer affordable fertility treatment
  - > ensure transport and childcare costs are not barriers to accessing services
- **The intersectionality of the experiences of women living with HIV calls for multi-disciplinary teams**, including peer mentors, able to work across sectors.

***"Women with HIV need multi-disciplinary teams to support them. HIV is often just the tip of the iceberg in terms of many different social, economic and legal problems facing women."*** United Kingdom

44. See Annex to Section 11 for further details of these experiences throughout the consultation.



## 12. MENTAL HEALTH ISSUES

*"During night you dream things which at times if you wake up you fear even to go out or you think may be you can die."* Tanzania

### EXPERIENCES

Over 80% of respondents reported depression, and feelings of shame and rejection. Over 75% reported experiencing insomnia and difficulty sleeping, self-blame, very low self-esteem, loneliness, body image anxieties, or anxiety, fear and panic attacks – either before, as a direct result of, or after diagnosis.

Impacts of trauma-related mental health conditions, including post-traumatic stress on SRH and human rights for women living with HIV included:

- Loss of sex drive or self-imposed sexual abstinence or increased need for sexual intimacy
- Difficulty committing to sexual or romantic relationships, lack of trust in sexual partners, choosing or staying with a partner who is violent or who has little support to offer
- Reliance on alcohol or recreational drugs to socialize or do sex work which, in turn, prevents formation of close relationships
- Secrecy in relationships with family and friends as well as actual or potential partners
- Anxiety-related sleep disorders and pain
- Overall lack of assertiveness in sexual situations, including lack of ability to negotiate condom use

Respondents' extremely high figures of HIV and mental health co-morbidity, which exceed previously quoted figures<sup>45</sup>, may be provoked by, or have their roots in, a wide range of factors, including GBV – especially sexual violence, stigma (either HIV-related or related to gender identity and sexual orientation – often worsened by punitive legal and policy environments), poverty or financial stress, and homelessness.

The figures highlight the complex realities of women's lives, whereby mental health matters potentially create vulnerabilities to HIV acquisition, and/or result from HIV diagnosis. As a 2014 WHO report states: "mental disorders and other chronic diseases are highly interdependent and tend to co-occur."<sup>46</sup>

While a significant number of women experienced mental health issues pre-diagnosis, the survey data (see Annex to Section 12) and FGDs indicate that HIV diagnosis is, in itself, a flashpoint for immediate and on-going mental health problems, especially depression, feelings of rejection, shame, self-blame, anxiety, insomnia, loneliness, and body image anxieties.

### IMPLICATIONS FOR GUIDELINE WRITERS<sup>47</sup>

Negative responses to a woman's HIV diagnosis by health staff and others around her, may entrench or spark a series of new mental health difficulties. These can be exacerbated if HIV diagnosis is made during pregnancy – normally a time of optimism for any woman – already recognized for potential mental health issues.<sup>48</sup> The consequences of postnatal depression may have a long-term impact on child development.

Certain mental health problems, particularly body issues and insomnia, may be linked to treatment regimens (see Section 10) but all may have an adverse impact on treatment uptake or adherence.

In the context of HIV, additional effects can include: layers of stigma arising from experiencing mental health disorder; fear of disclosure in order to avoid blame, rejection and stress; treatment commencement and adherence issues.

45. WHO 2014b

46. Ibid.

47. See Annex to Section 12 for further details of these experiences throughout the consultation.

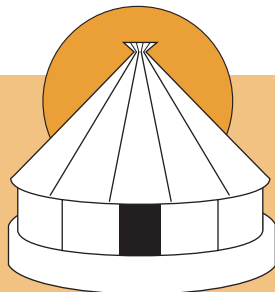
48. WHO 2014c.

## Policy and practice recommendations

- **Women living with HIV need affordable, accessible, continuous, holistic and integrated psychological support and counselling in HIV care** (beyond accepting diagnosis), relationship and sex counselling, and support with disclosure. Healthcare providers should:
    - > understand that post-traumatic stress is a natural psychological response for some people to some experiences
    - > understand that mental health issues are something everyone needs help with – they cannot necessarily be dealt with on one's own
    - > include mental health in holistic care of people living with HIV
  - Identify, work with and build on traditional local prevention and treatment strategies to mental health issues
  - Explore underlying issues and not just HIV
  - Recognize that HIV may be just one manifestation or result of pre-existing mental health issues and traumatic experiences
  - Ensure availability of supportive harm reduction policies and practices
  - Ensure referral pathways and proper linkages exist
  - Access to treatment for psychologically distressing side-effects, e.g. those which affect physical appearance such as weight change and lipodystrophy
  - Provide peer counselling and peer support
  - Create support groups for and led by women living with HIV and spaces for women living with HIV to talk
  - Involve networks of women and people living with HIV
  - Promote respect from healthcare services for people living with HIV, co-morbidities, and mental health conditions
  - Raise health service awareness regarding co-morbidities
  - Rights awareness and training in: legal protection; laws and policies that protect the rights of women living with HIV and remove discrimination
- For financial support, see Section 11.

## FURTHER RESEARCH

Many women living with HIV find mindfulness practices, yoga, acupuncture and related therapies of great value. We suggest further research into the effectiveness of these practices to manage mental health, free of, or in combination with, relevant medication.



## 13. ACHIEVING SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS

### EXPERIENCES

The survey responses and focus group discussions clearly show that achieving SRH and human rights for women living with HIV requires a multi-faceted holistic process with many complex dimensions.

We have created a framework using the metaphor of a house – the inter-dependancy of the foundations, pillars and roof being essential for a well-constructed house. A house is a universal symbol, recognized around the world. We have described each dimension through Sections 1 to 12 of this report.

Section 1 is the primary foundation for this house and is portrayed as safety. This call for safety resonated throughout all sections of the survey. Safety in the home, as well as in healthcare settings – and beyond – is viewed as a fundamental *sine qua non* to achieve women's SRH and human rights.

The widely used Hale and Vazquez definition: "*Violence against positive women is 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.*"<sup>49</sup> confirms that many experiences cited by respondents throughout their responses are violent in nature.

Sections 2 to 12 depend on this primary foundation to be fully achieved and realized. From this foundation, women can look to a brighter future for themselves as well as their families and communities, as discussed below.

### IMPLICATIONS FOR GUIDELINE WRITERS

We recognize that many health systems would not traditionally consider violence as part of their remit. However, the WHO multi-country study highlights the widespread prevalence of violence against women;<sup>50</sup> WHO research demonstrates how intimate partner violence increases women's vulnerability to HIV by 50%<sup>51</sup> and, as our respondents have clearly shown here, there is widespread experience of GBV both since and as a consequence of an HIV diagnosis. In order to uphold the SRH and human rights of women living with HIV, we suggest that it is imperative that the updated guidelines emphasize the critical and acute need to address gender-based violence and concomitant issues experienced by women and girls in all their diversities, including with HIV, in healthcare settings.

Throughout this report we argue that women living with HIV, in all their diversities, should be able to achieve their SRH and human rights in their own intrinsic right to self-determination. However, women around the world are the primary carers of children, partners and the wider community and also have a traditional role as carers, especially when family members get old or sick.<sup>52</sup> The health and well-being of children, including whether or not they acquire HIV, live or die with HIV, or experience GBV as perpetrators or recipients, is very much predicated on whether or not their mothers are safe, happy and well.<sup>53,54</sup>

We, therefore, suggest that there is a secondary instrumental value in women living with HIV achieving their SRH and human rights. This is in order to enable them to; fulfil their traditional roles – if they wish – as nurturers and carers of children; be equal partners in their sexual relationships; and be leaders of change in their communities. Women living with HIV can only achieve these roles effectively if their own SRH and human rights are achieved, and Sections 14–16 address each of these groups in turn.

49. Hale and Vazquez 2011.50. WHO 2005.

50. WHO 2005

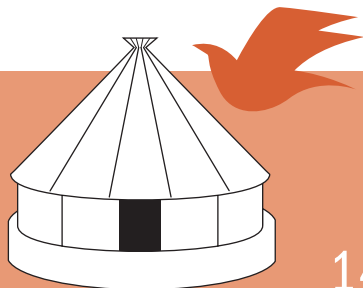
51. WHO 2013.

52. UK Consortium 2012.

53. Gerhardt 2004.

54. UNICEF/Liverpool School of Tropical Medicine 2011.





## 14. SUPPORTING CHILDREN

### EXPERIENCES

Many respondents referred repeatedly to anxieties about their own children and about children in their care throughout the survey and FGDs. These included concerns about:

- the effects of ARVs on women's reproduction and fetal and child development
- the potential contra-indications of hormonal contraception for ARV effectiveness – and consequent family planning effectiveness
- HIV disclosure
- supporting children to start or adhere to treatment
- what and how to tell children about sex and relationships and diversities
- their children's future should respondents get sick or die

*"I do not sleep, all sorts of thoughts go through my head, mostly related to my health. I feel sorry for myself, and for my son. He will be left alone; who will support him? And if during the day I almost never think about it, I'm busy all the time, at night I cannot calm down and often cry." Ukraine*

Women also spoke of the damaging effects on their own lives of having experienced violence, including sexual violence, when they were children themselves.

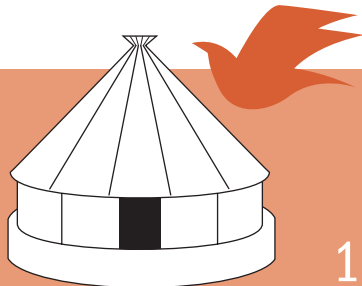
In Myanmar, teenage girls who have grown up with HIV, reported feeling isolated due to over-protection from their parents and guardians. This closes important channels of information and awareness – especially around their SRH and human rights, and even about their own HIV status.

### IMPLICATIONS FOR GUIDELINE WRITERS

Women living with HIV need to feel supported by health systems in providing inter-generational support to their children. This will support women intrinsically, in that it would help to allay anxieties and aid them to achieve their own SRH and human rights. Consequently, it will also enable women to support the children in their care, to achieve SRH and human rights in turn. Support includes:

- **Comprehensive sexuality education, carried out in a wide variety of settings** (e.g. schools, youth clubs, churches/mosques, radio, TV, print media) and include:
  - > Sexual health and basic sex education
  - > Girls and young women are empowered to protect themselves from unwanted sex, pregnancy, HIV and STIs
  - > Education about VAWG and how to address it
  - > Information about SRH and rights including family planning and contraceptives
  - > Information about HIV and normalizing HIV to reduce stigma and discrimination
  - > Promotion of inter-generational dialogue – especially between parents and children – about sex and sexuality, HIV and treatment
- **Sexual relationships counselling for teenage girls and young women** living with HIV that:
  - > Acknowledges and accepts young people's sexuality
  - > Prevents unplanned pregnancy and supports teenage girls and young women when this happens
  - > Increases access to contraception and safe abortion
  - > Provides holistic mental health care
- > Prevents and addresses violence against women (including psycho-social support)
- > Gives advice and support with disclosure for both parents/guardians and children
- > Builds skills to navigate starting new relationships (e.g. disclosure and condom use)
- > Increases access to confidential STI screening
- > Ensures medical privacy
- **Ensure safe and smooth tailored transition from child to adolescent to adult health services** including:
  - > 'Know your rights' information
  - > SRH information and education
  - > Youth-friendly and adequately equipped health centres
  - > Peer support, as well as mentorship and support from older women living with HIV and participation in support groups and networks
- Other important areas for adolescent girls and young women include:
  - > Addressing stigma in schools. Assure confidentiality is respected, protected and upheld, along with all other human rights
  - > Providing funding for support groups and skills building and leadership programmes, and to support the meaningful involvement of girls and young women living with HIV in decision making
  - > Research into influences on and impact of HIV and/or ART adherence on puberty including menstrual issues (late/early; prolonged, very heavy, or very painful bleeding) and the influences on, and impacts of, adherence





## 15. SUPPORTING PARTNERS

### EXPERIENCES

45% of respondents are married or in a stable relationship. Respondents repeatedly stated their anxieties about keeping their partner(s) safe from acquiring HIV. Many respondents also expressed the desire to start a sexual relationship, yet faced anxieties about disclosure, transmission and violence because of their HIV.

The ability to have happy, pleasurable sexual relationship(s) is intrinsic to a woman being able to achieve her SRH and human rights. This was borne out by the significant number of free text responses saying that a supportive partner was the most important factor in achieving a healthy sex life and making decisions around pregnancy and fertility. Once achieved, there is clearly an

instrumental benefit for partners in having strong, resilient and safe women living with HIV by their side.

One of the main barriers for women living with HIV to achieving their SRH and human rights is GBV including IPV (see Section 1). This often arises out of inherited power imbalances in gender-relations, compounded by ignorance and fear based on myths about HIV. Many men have grown up witnessing and experiencing violence from fathers or other male figures, and they too experience fear, need and hurt.<sup>55</sup> As well as dealing with perpetrator responsibility, there is a need to address root causes – including promoting women's economic empowerment and participation in decision making fora – in order to overcome IPV.<sup>56</sup>

### IMPLICATIONS FOR GUIDELINE WRITERS

Health systems do not, and cannot, exist or operate in a vacuum. The 2014 *ABC of Domestic and Sexual Violence*, states: "domestic violence reaches beyond the realms of medical diagnoses and treatments and engages a community-integrated response."<sup>57</sup> Health staff who are systematically encouraged and supported to reach out beyond the clinic door, to work collaboratively with community groups and other local service institutions, will create a more holistic, community-wide response to the many different facets of our 'house'.

In terms of safety, this could mean engaging men and boys through community-based programmes, for example; Stepping Stones and SASA!<sup>58-60</sup> Both have shown to reduce IPV.

In Malawi, the Coalition of Women Living with HIV and AIDS (COWLHA) discovered in a baseline survey that IPV was widespread in communities.<sup>61</sup> It also established that treatment initiation, treatment adherence and

mental health all suffered as a consequence of IPV. Men reported how their partners' visits to hospital for treatment resulted in IPV. Yet, through implementation of Stepping Stones and related community interventions, this IPV has now stopped.<sup>62</sup> Men have now also been tested and are also accessing treatment.<sup>63</sup> Thus, the SRH and human rights of women living with HIV are now closer to being achieved and – through the agency of COWLHA members – those of their partners also.

In life-course terms, such programmes improve harmony within the household and increase chances for girls and boys to grow up to achieve their own SRH and human rights.<sup>64</sup>

**We suggest that guideline writers refer explicitly to the many diversities of women living with HIV and their partners.** All have a right to be treated with equally high qualities of appropriately tailored care by health services, in order for their SRH and human rights to be achieved (See also Section 3). This requires the health sector to work with other organizational partners, in multi-agency, multi-disciplinary ways.

55. See Gilligan 2001 for example

56. See Welbourn 2008 for more on this

57. Bewley and Welch 2014

58. Welbourn 1995

59. <http://www.whatworksforwomen.org/chapters/21-Strengthening-the-Enabling-Environment/sections/59-Addressing-Violence-Against-Women/evidence#s-441>

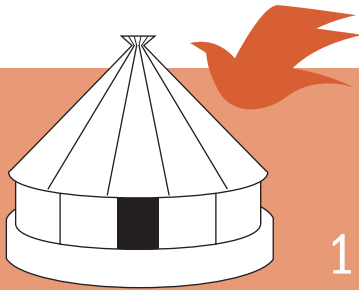
60. Raising Voices n.d.

61. COWLHA 2012

62. Banda 2014

63. Salamander Trust 2013

64. UNICEF/Liverpool 2011; Salamander Trust 2013.



## 16. SUPPORTING COMMUNITIES

Last, but by no means least, women living with HIV come from and belong to communities. By dint of participation, all our respondents – and many more women living with HIV besides – are, or want to become, active members of an effective community response to the HIV pandemic. There is intrinsic value in this, since feeling useful and involved can support women to make sense of what has happened to them, restore their self-esteem, improve their mental health and achieve their own SRH and human rights.<sup>65</sup> Many respondents described how involvement in HIV support groups or organizations had helped them become aware of, and begin to claim, their human rights.

There is also instrumental value<sup>66</sup> in women living with HIV using their experiences and skills to support other younger, or more recently diagnosed, women – and others living with HIV – to achieve their own SRH and human rights. In an effective response to the HIV pandemic, communities have the potential to be either a liability or an asset. Harnessing the experience, drive and skills of women living with HIV can ensure that communities as a whole are an asset.

Each and every woman and girl living with HIV has a unique experience and story. Her experiences may be unfamiliar to her healthcare providers and consequently she may be stereotyped, misunderstood and discriminated against. HIV does not discriminate. It is people and institutions that do. Human rights protect us all.

<sup>65</sup>. See Biros 2014 for example.

<sup>66</sup>. See ATHENA 2011 for example.

## CONCLUSION: BUILDING OUR 'HOUSE'

WHO can use its authoritative position to promote a life-affirming and holistic definition of health throughout its guidelines.<sup>67</sup> The world looks to WHO for positive leadership in acting as an exemplary role-model to promote and uphold safe, supportive and respectful policies and practices in relation to women and girls living with HIV and their SRH and human rights.

WHO Guideline writers have the capacity to 'set a high bar' for healthcare providers worldwide in order to facilitate quality care, positive attitudes and good practice in the treatment and care of women living with HIV.

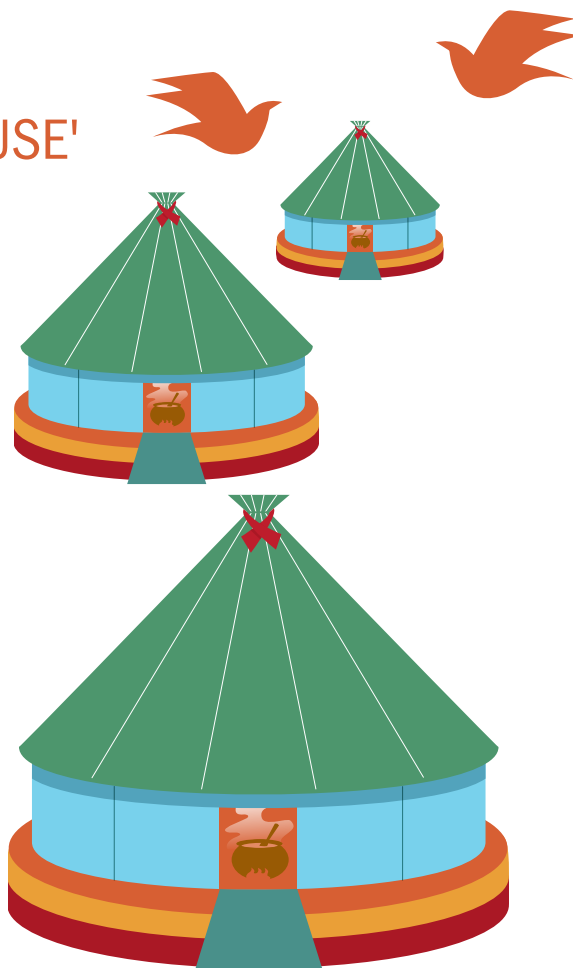
Healthcare providers have a responsibility as respected leaders in their communities. When health staff lead creatively and with humane compassion, community members will follow.

We suggest that the guideline explicitly promotes the meaningful involvement of women living with HIV in all aspects of healthcare, in order to build robust collaborative links between professional healthcare providers and those with lived experience.

Women living with HIV should be consulted, appointed and employed by healthcare providers, as peer mentors to support all women in healthcare settings, from counselling to testing and diagnosis onwards.

WHO guidelines on healthcare and delivery are considered powerful and influential messages by governments and health systems.<sup>68</sup> WHO has demonstrated leadership in promoting MIWA in this review process, and we trust that the updated guidelines will encourage health systems to harness the experiences and desires of women living with HIV, in order that they may both help to shape and also to deliver messages, both within healthcare settings and beyond.

For communication to be successful it needs to be a two-way and interactive exchange, with recipients able to understand, act and respond to information. This is particularly important when human rights are at stake. The participatory design of the guidelines should extend to the management and implementation of them.



Women living with HIV can act as bridges, taking rights- and evidence-based messages into the home and community, reinforced by the authoritative support of healthcare systems and WHO.

These linkages act as a 'win-win': ensuring that policies and practices are grounded in human rights and lived experience; improving job satisfaction for overworked and stressed health workers; and enabling women living with HIV to 'give something back' and take on leadership roles in their communities. Women living with HIV are thus supported to transform their challenging experiences into firm foundations for future safety, respect and support – not only for themselves but the community at large.

The more the WHO Guidelines writers can do to ensure that women living with HIV, their experiences and their willingness to contribute to achieving their SRH and human rights, are woven into the updated guidelines, then the more the guidelines will achieve what they set out to do.

67. WHO definition of health 1948 "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."

68. See also Salamander Trust on integrating GBV and working with men and boys as partners towards gender equality into national strategic plans on HIV. [http://salamandertrust.net/index.php/Projects/GBV\\_Workshop\\_Johannesburg\\_Dec\\_2012](http://salamandertrust.net/index.php/Projects/GBV_Workshop_Johannesburg_Dec_2012)

## ANNEX i

### BIOGRAPHIES OF GLOBAL REFERENCE GROUP AND COORDINATION TEAM

#### Coordination Team



**Alice Welbourn PhD** is the Founding Director of Salamander Trust. Alice works internationally on gender and health. She lived and worked in Africa for several years. Diagnosed with HIV in 1992, she developed *Stepping Stones*, a training package on gender, HIV, communication and relationship skills, now used worldwide. A former chair of the International Community of Women Living with HIV/AIDS (ICW), Alice also sat on the Global Coalition on Women and AIDS Leadership Council. Currently, she is a member of the UNAIDS Global Dialogue Platform of Women living with HIV.



**Susan Bewley** qualified as a doctor in 1982, trained in obstetrics and gynaecology and medical law and ethics. She was appointed consultant and Head of Obstetrics at Guy's & St Thomas' Hospitals in 1994, Clinical Director for Obstetrics for NHS London (2010–13) and is now a Professor of Complex Obstetrics at Kings College London. As well as being the obstetrician in the joint HIV-pregnancy clinic for 17 years, she's written about HIV, served on many expert guideline committees (including the UK's National Institute for Clinical Excellence (NICE)), and is now a trustee of Sophia Forum. Her research focuses on severe maternal morbidity and domestic violence.



**E. Tyler Crone, MPH, JD.** A human rights lawyer by training, Tyler Crone co-founded and directs the ATHENA Network to advance gender equality and human rights through the HIV response. Tyler has been working at the intersection of gender, human rights, HIV, and sexual and reproductive health (SRH) and rights since supporting the U.S. State Department preparations for the 1994 International Conference on Population and Development. Tyler's most recent work has focused on advancing the integration of SRH and rights and HIV through a five country project across Africa and Asia; championing the engagement of young women in all their diversity in shaping the post-2015 development framework; and strengthening the HIV policy framework for women, girls, and gender equality in Southern and Eastern Africa with UN family members, a broad range of civil society stakeholders, and academic partners with specific attention to addressing gender-based violence (GBV).



**MariJo Vázquez** has been working in HIV, gender and community participation for the last 18 years. She is a counsellor and a facilitator of peer-support groups in HIV. She is also a community advocate on women's issues. MariJo has been using storytelling as a tool for working in gender and personal growth, and the fruit of this interest and experience is her project (*Sanar a través de nuestras historias – Healing through our stories*) using life narratives to give voices to HIV positive women in Spain. She is currently a Board member of The Constellation (an international organisation aiming to connect local responses around the world), and she is also part of the Consultancy team of Salamander Trust.



**Luisa Orza's** work over the past ten years has centred around gender and HIV, with a strong focus on the sexual and reproductive rights of women living with HIV; building the leadership and participation of women living with HIV; and on participatory, community-led monitoring and evaluation. She was the Monitoring and Evaluation Officer for the International Community of Women Living with HIV/AIDS (ICW) from 2004–2008, and since 2009 has been working as an independent consultant. She is currently Programme Coordinator for the ATHENA Network as well as a Salamander Trust Associate, and STOPAIDS trustee.

#### Global Reference Group



**Nukshinaro Ao** is 34 years old and has been living with HIV for the last nine years. She is a recovering drug user and is not married. She comes from a very remote and hilly North eastern part of India called Nagaland. Naro is currently working with ICW Asia Pacific and has previously worked as Coordinator of Women of Asia Pacific Plus (WAP+) under APN+ in Bangkok. Prior to this she worked in Nagaland with an NGO, the Eleutheros Christian Society, on HIV and AIDS prevention, care, support and treatment; churches on advocacy for reducing stigma and discrimination; and Nagaland State AIDS Control Society as the GIPA Coordinator.



**Cecilia Chung** is the U.S. People Living with HIV Caucus President, as well as the Senior Strategist of Transgender Law Center, a Health Commissioner and former Human Rights Commissioner of San Francisco and a recognized leader

who advocates for HIV and AIDS awareness and care, LGBT equality, and social justice. Cecilia is currently serving on the executive committee of GNP+ – the first trans woman living with HIV to be elected. Cecilia has dedicated herself to ending stigma, discrimination, and various forms of violence in all communities.



**Sophie Dilmitis** has worked for almost two decades in pioneering grassroots work and top-level policy development focusing on women and young people in developing and developed countries. Born and living in Zimbabwe, Sophie has been HIV positive for 20 years. She has

become a vocal advocate for policies and programmes that work for all women, human rights and programmes that integrate SRH and rights with HIV.



**Calorine Kenkem** is a joyful Cameroonian women living with HIV. She works with the Cameroonian Network of Positive Women. She is very happy to work with the community on HIV issues since 2005.



**Sveta Moroz** is one of the founders of the All-Ukrainian Network of People living with HIV/AIDS (AUN). For 11 years she has run Donetsk local NGO for people living with HIV called Club "Svitanok", which provides comprehensive services for more than 3,500 people living with HIV,

1,000 people who use drugs and 1,000 prisoners annually. In May 2011 Svitlana initiated the creation of Ukrainian Union of Women Infected and Affected by HIV. In 2012 she became a member of AIDS Action Europe Steering Committee. Since June 2013, Svitlana is a Commissioner of the UNAIDS and Lancet Commission: Defeating AIDS – Advancing global health, as well as regional coordinator of newly established Eurasian Women's Network on AIDS.



**Suzette Moses-Burton** joined GNP+ as its Executive Director in January 2014. She comes to the organization with a wealth of experience, and a deep understanding of the HIV sector. As a key advocate and leader for people living with HIV for over 20 years, she brings passion,

creative thinking and new ideas to address the issues that people living with HIV face on an daily basis, particularly in the context of a shifting epidemic and the post-2015 development agenda. Her vision is to take GNP+ in a fresh new direction that builds on the strengths of its existing programmes, while adapting its approaches to meet the needs of people living with HIV in the ever-changing HIV landscape.



**Hajjarah Nagadya** is a member of ICW Eastern Africa, and of the UNAIDS Dialogue Platform for Women Living with HIV. She is an advocate for SRHR and HIV integration, and a champion of the visions, needs, and priorities of young women living with HIV and has represented young women living with HIV in different policy fora to ensure issues concerning them are highly prioritized.



Originally from Kenya, **Angelina Namiba** has over 16 years' experience of working in the HIV sector. She has worked on initiatives ranging from providing one-to-one support to people living with HIV; managing service provision to facilitating, promoting and advocating for

the involvement of women living with HIV in forming and informing local and national strategy and policy. Angelina is passionate about the sexual health and reproductive rights of women living with HIV and currently manages a project aimed at providing information, educational, practical and peer support to pregnant and prospective parents living with HIV.



**Gracia Violeta Ross**, National Chair, Bolivian Network of People Living with HIV and AIDS (REDBOL). Violeta Ross is 37 and from La Paz in Bolivia. Violeta is an advocate, researcher and public speaker on her experience with rape, HIV and gender. Violeta is a member of the TB-HIV

Working Group of the Stop TB Partnership and a Board member for UNITAID.



**Sophie Strachan** is an HIV positive women and activist with passion and total commitment to challenging injustice, stigma and discrimination toward vulnerable people living with HIV. Sophie received her own diagnosis in prison 11 years ago and has been in recovery

from active drug addiction for over 10 years, choosing complete abstinence. Her research into whether the health and social care needs of people living with HIV in UK prisons are met, was presented at AIDS2012, Washington DC. Sophie is an advocate for this key population and for lesbians and bi-sexual women living with HIV. She was invited to present on these issues at the International AIDS Conference 2010, Vienna. Sophie is an advisory member for GNP+, a trustee of The Sophia Forum, and has been appointed as a member of the UNAIDS dialogue platform on rights of women living with HIV 2014–2015.





**Martha Tholanah** is a feminist Zimbabwean woman, mother and grandmother, openly living with HIV. She is a trained family therapy counsellor with over ten years' experience, plus over twenty years' experience as a

medical rehabilitation practitioner. She has also worked in developing and running health programmes in Zimbabwe for people with disabilities, lesbian, gay, bisexual and transgender and intersex (LGBTI) communities, and with people living with HIV, with a particular focus on children, girls and women. She has a passion for community organising and grassroots mobilisation for transformation for social justice and access to basic services.



**L'Orangelis Thomas Negron** is a young free-spirited woman, strengthened by HIV. She is working every day in HIV prevention, and with young people and women so that people living with HIV have a better quality of life and can live free of stigma. L'Orangelis is 25 years old; she

was born HIV positive in San Juan, Puerto Rico where she still lives. On 1 December 2008, publicly shared her HIV status; the following year she became a certified HIV counsellor. L'Orangelis is part of the Latin-American and Caribbean Positive Youth Network.



**Patricia Ukoli** is the Vice Chairperson of the International Treatment Preparedness Coalition West Africa (ITPC-WA) and secretary for ICW West Africa. She has been openly living with HIV for the past 10 years and has worked on HIV and AIDS issues since 2004. She is a treatment

activist, and passionate about young women's SRH and rights. In Nigeria she represents people living with HIV on the Country Coordinating Mechanism of Global Fund, Quality improvement & Assurance (QI/QA) committee, and a focal point on care and support for people living with HIV and AIDS in Nigeria. She is a member of the Pan African Positive Women Coalition, UNAIDS Community support Team.

**Rita Wahab**, from Lebanon, has been a women living with HIV activist since 1995. Rita co-founded a local association of people living with and affected by HIV, Vivre Positif, in December 2007. She assisted in designing and translating *How to be a Positive Trainer* training curriculum for other people living with HIV in the Middle East and North Africa (MENA) region. She is the Coordinator for MENA Rosa (a group of women living with HIV in MENA) since 2010, and works to enhance the quality of life for women living with HIV and their dependants.

## ANNEX ii

### TERMS OF REFERENCE FOR THE STUDY

#### Revision of WHO Guidelines on meeting the sexual and reproductive health needs of women living with HIV: preliminary consultation to determine priorities

#### Terms of reference: Salamander Trust and partners

##### Background

In 2006, the World Health Organization produced “Sexual and Reproductive Health for Women Living with HIV: Guidelines on care, treatment and support for women living with HIV and their children in resource-constrained settings.” These guidelines focus on five key areas: sexual health; family planning; maternal and perinatal health; abortion; and, sexually transmitted infections.

These Guidelines are in urgent need of up-dating, given changes in both the biomedical and political aspects of the HIV response since 2006, and in the internal processes relating to production of technical guidelines within WHO – in particular measurement against the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) standards in research. In addition, the earlier guidelines, whilst welcomed at the time, are now considered to need substantial revision, with a broader focus than just primary clinical care, and on a wider range of settings. It is felt that a new set of guidelines should be developed, encompassing recommendations for policy, formal health care, and community engagement (as per the findings from systematic reviews), and that these should be global in scope, to be adapted to the specific context for application at country level.

Further, many issues relating to the sexual and reproductive health of women living with HIV are addressed through other WHO Guidelines already in existence or currently under development. These include guidelines on the prevention and treatment of STIs; family planning; HIV testing and counselling; and, adolescent sexuality and counselling. A scoping exercise is currently being conducted internally within WHO to determine which areas are already covered. However, gaps remain, including (but not limited to) guidelines and recommendations on medical and surgical abortion for women living with HIV; ageing; sexual and reproductive health among adolescent girls and young women who have acquired HIV peri-natally, as well as through other routes; etc.

On identification of a comprehensive set of content areas, systematic reviews of existing evidence will be undertaken, and recommendations will be made on the basis of the quality of research against GRADE standards. Where no robust data exist, text will be included on the challenges raised without recommendations; in parallel, operational research questions will be developed for further research. All recommendations within the Guidelines will be embedded in a human rights framework.

In the interests of ensuring that the priority areas for women living with HIV are addressed through the Guidelines, and to ensure broad-based support for, and engagement with, the product, WHO has been eager to undertake a preliminary consultation with women living with HIV.

Key areas identified on the basis of this preliminary study will be prioritised further through a technical consultation bringing together the participants of the project, in addition to other stakeholders with technical expertise. It is hoped that participants of the preliminary consultation will remain engaged (eg as members of a technical advisory group) throughout the Guidelines development process, expected to take 2–3 years in total, and beyond, through their dissemination and implementation.

##### Preliminary consultation to determine priorities

Salamander Trust will work in collaboration with ATHENA Network and other partners to conduct a preliminary consultation among women living with HIV – including members of the UNAIDS Dialogue Platform, the International Community of Women living with HIV (ICW) and the Global Network of People living with HIV (GNP+) – to determine priorities for systematic review, and outline key content areas for the Guidelines, and to assure the genuine support and engagement of women living with HIV with the final product. Based on previous experience,<sup>1</sup> we will develop a global on-line survey with additional face-to-face dialogues for broad engagement by women living with HIV across a range of diverse geographic and social contexts.

A core coordination team comprising five members who bring expertise in the following areas give strategic guidance and oversight to the consultation (see short biographical data in Annex i):

- community participation, HIV, sexual and reproductive health rights, gender-based violence
- clinical excellence and guideline development, women's health

1. In particular, the proposed consultation builds on a virtual consultation to build the participation of women living with HIV in the High Level Meeting on HIV and AIDS in 2011, led by ATHENA Network, in collaboration with the Global Coalition on Women and AIDS. For more information, see [http://wecareplus.net/index.php/page/HLM\\_June\\_2011/en](http://wecareplus.net/index.php/page/HLM_June_2011/en) and <http://wecareplus.net/resources/InWomen%27sWordsFinal.pdf>



- human rights, gender and the law
- participatory monitoring and evaluation, HIV, sexual and reproductive health and rights and gender equality

The consultation will further engage a Global Reference Group of 13 regional and technical focal points from among women living with HIV. These will include members of the UNAIDS Dialogue Platform, and networks of women living with HIV including ICW and GNP+. The Global Reference Group will include:

- 8 regional focal points (from Asia-Pacific, Eastern Europe and Central Asia, Middle East and North Africa, West and Central Africa, East and Southern Africa, Western Europe, North America, and Latin America and the Caribbean)
- young women living with HIV (including young women born with HIV)
- women living with HIV who use or have used drugs
- women living with HIV who do or have done sex work
- women living with HIV with experience of prison or detention
- women living with HIV from lesbian, bisexual, trans, queer and intersex communities
- women living with HIV from rural and from urban communities
- women living with HIV who are caregivers
- women who are migrants, asylum seekers and/or refugees
- women with (other) disabilities and co-morbidities
- older women living with HIV
- women living with HIV from a variety of different faiths and none

## Anticipated outcomes

Whilst wanting to ensure that the priorities of women living with HIV are addressed through the guidelines, we also see this as a key opportunity to strengthen institutional capacity and build understanding among women living with HIV on technical areas, including the purpose, scope and utilization of technical guidelines; some understanding of systematic reviews and the GRADE system, and the development and use of research (PICO) questions. This is to ensure not only that priorities are addressed, but that the resulting Guidelines will have maximum potential for implementation, and in doing so, improve the quality of women's lives. This would be in line with UK guidelines published by the National Institute for Health and Clinical Excellence (NICE) which recognises the importance of service-users' involvement and understanding of these processes,<sup>2</sup> and initiatives such as the James Lind Initiative for research priority setting by patients.<sup>3</sup>

With these considerations in mind, the anticipated outcomes of the proposed consultation are:

- Key areas to include in the revised Guidelines on SRH for women living with HIV are identified in line with priorities expressed by women living with HIV from diverse geographic backgrounds and experience
- Capacity among civil society in general and women living with HIV in particular to understand the purpose and scope, and to engage with and advocate for the technical guidelines is strengthened
- Broad-based support for and endorsement of the final guidelines among women living with HIV
- Identification of key unaddressed areas for future policy, research or action

## Outputs and deliverables

The project workplan, budget and strategic approach are established in collaboration with WHO **by end-November, 2013.**

1. The strengthening of two-way capacity building by:

- Establishing a wider advisory group of regional and technical focal points
- Initiating a two-way dialogue between the Coordinating Team and Reference Group for institutional capacity building around the purpose, scope and entry points for engagement of technical guidelines **by end-January 2014**

2. Data-collection tools developed, validated and translated into 3 languages in consultation with coordination team and reference group **by end-February 2014**

3. Data gathered through on-line survey, and email. Also disseminated through the reference group networks to maximise geographical and population specific outreach, and through selected community dialogues for in-depth geographic and population-focused priorities, and in order to reach women, particularly in rural areas, who might not have access to the internet **by mid-April 2014**

4. Data analysed, key themes identified and prioritised **by end May, 2014**

5. Consultation findings shared with all stakeholders **by mid-June 2014**

6. Process documented for learning, replication and accountability **by end June 2014**

2. See for example: <http://www.nice.org.uk/getinvolved/patientsandpublic/patientandpublichome.jsp> (many other references on patient involvement in NICE, as well as evidence on patients' experience of adult care and quality standards are available and can be provided)

3. <http://www.lindalliance.org>

The Global Reference Group will:

- Participate in “open forum” style teleconferences for learning, sharing and shaping the work
- Provide input for the development of the data collection tools (on-line survey and field guide for community dialogues)
- Pilot, review and validate data collection tools
- Disseminate the e-survey through list-servs and networks; in addition to this, where feasible, members will may also help women with limited access to internet to complete

the survey, using paper versions of the survey or conducting small group surveys and reporting collective results.

- Review and validate data analysis and priorities

In addition:

- Several focus group discussions (FGDs) will be held to augment online survey information and to reach out to women with no computer or internet access. These will constitute approximately half-day meetings for up to 30 people to open up the details of specific issues.

## ANNEX iii

### PROCESS AND METHODOLOGY

The consultation process took place between February and June 2014. It built on a consultative model developed by the ATHENA Network to increase engagement of women in all our diversity in the 2011 High Level Meeting on HIV and AIDS.

- Establishment of a 5-member Coordination Group to lead the consultation, bringing together key areas of expertise, namely: clinical practice and policy; human rights law; community engagement and participation; and, participatory monitoring and evaluation. All members brought expertise in gender transformative advocacy and programming. Two Coordination Group members are women living with HIV activists.
- Establishment of a 13-member Global Reference Group of women living with HIV as regional and technical focal points. This group comprised women from Bolivia, Cameroon, India (currently based in Thailand), Jamaica, Lebanon, Nigeria, Puerto Rico, St Marten (currently based in the Netherlands), Uganda, UK, Ukraine, USA, and Zimbabwe. Key affected population-specific perspectives represented on the group included: trans women living with HIV; lesbian, bisexual and other women who have sex with women; women with experience of prison or detention; women who use/have used drugs; older women living with HIV; young women living with HIV (including young women who acquired HIV peri-natally); women with experience of sexual violence or rape.<sup>4</sup>
- We conducted four international teleconferences with the Global Reference Group. These calls included two-way information sharing. Several articles and resources were also circulated among both the coordinating group and the reference group about guideline development, client-provider engagement, and health policy. In this way the reference group members were being informed

about the guidelines before they engaged in identifying themes and developing the survey questions. This was a way of ‘priming the field’ and disseminating the concept of guidelines.

- Comprehensive pre-consultation process led by the Global Reference Group to determine overarching priorities for inclusion and validation in the data collection tool. This utilized a ‘quality of life and well-being’ exercise in which the working group members convened virtual focus groups around particular experiences and the reciprocal and iterative impact on the SRH and human rights of women living with HIV.

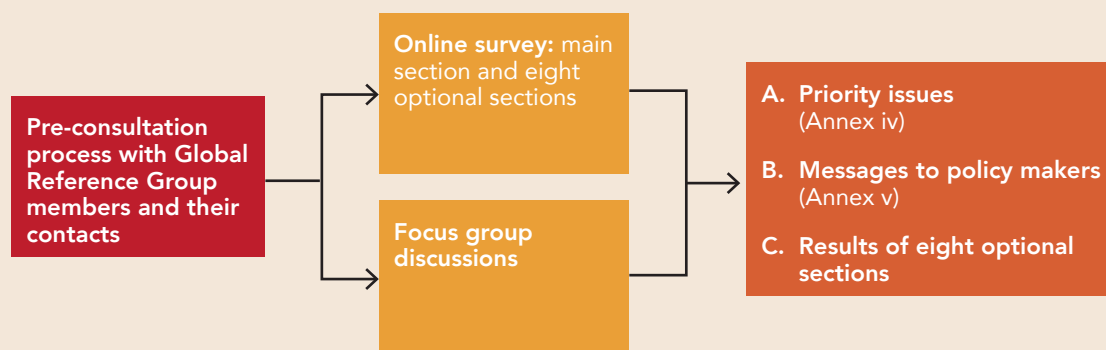
Priority areas included:

- Growing older with HIV
- Drug use and sex work
- Experiences of prison or detention for women living with HIV
- Issues affecting transgender women living with HIV
- Experiences of violence, including sexual violence and rape, in relation to HIV

***"Thank you to those of you who have sent others and me words of support in solidarity – your sisterhood is so appreciated! Sometimes it feels like life is unrelenting but I take comfort in knowing that all things (no matter how hard) pass. This is what keeps me going. Thanks for sharing what you are going through and have gone through – it takes such huge courage to share our own hurt and it is so hard. I have no words of wisdom but just sending you so much love and huge amounts of respect. I feel so privileged to know all of you. Thank you! Thank you!"*** Global Reference Group Member

4. Short biographies of the Coordination Team and Global Reference Group participants are included in Annex i.

**Figure 1: Consultation development process**



The overarching priorities (the first section of the survey), and the menu and content of the eight other key priorities ('optional' sections<sup>5</sup>) emerged as clear human rights priorities from this comprehensive pre-consultation process. The Global Reference Group also piloted and pretested the survey tool, allowing for minor adjustments before launching the survey.

- The main report (Sections 1–16) has drawn on the strong overlapping information from sources A, B and C.
- The Executive summary summarises the synthesised main report.
- More detailed information from source A is in Annex iv and from source B in Annex v.
- Further information from all sources, including charts and responses from free text messages are in the Annexes to relevant Sections.

## Translation

Translation of the on-line survey into French, Spanish and Russian in the first instance. Translations into Portuguese and Bahasa Indonesian were also undertaken by women living with HIV activists on a voluntary basis, due to the perceived importance of the work. Finally, a translation into Chinese was also offered on a voluntary basis by HIV activists.

***"I think [the survey] is very interesting and important. It actually listed all the possible options to make people think from a different perspective to look at HIV. So completing the survey will be another process to learn the knowledge of sexual and reproductive health and human rights."*** Chinese HIV activist, who translated the survey free of charge

## Survey launch and dissemination

The on-line survey was disseminated by the Global Reference Group members and Coordinating team through list-serves, websites, professional and community networks (in particular networks of women living with HIV, networks of key affected populations and networks of clinicians working on HIV), women's groups and support groups, Facebook and Twitter, personal emails and phone calls to individual women and activists with broad networks, emails sent to individual clinicians and doctors who treat women living with HIV, and visits to outreach clinics to engage directly with their clients, among others. Some Global Reference Group members hosted small groups of women to facilitate their responding to the survey, either on-line using office computers or personal laptops, or using hard or electronic Word versions of the survey. The completed forms were then sent by post or email to the coordinator.

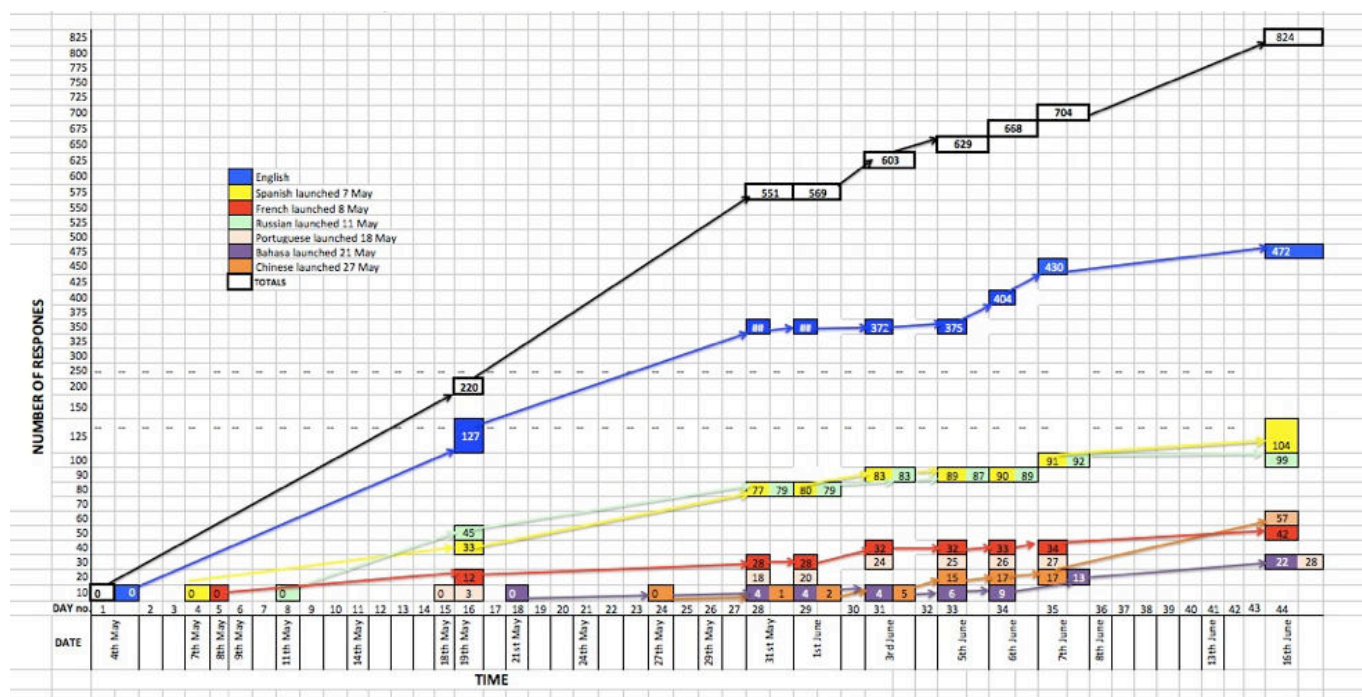
***"I also persuaded some to respond to the survey informing them how important their ideas were and that it was one way their voices would be heard."***  
Global Reference Group Member

We sent out seven initial survey announcements (one for each language). These were followed up with weekly reminders from the Coordination Team.

Emails were sent out to different individuals and institutions. These included colleagues in: the UN; international donors and NGOs; the gender working group listserv of STOPAIDS; a European network of women HIV clinicians; British HIV Association (BHIVA); networks of women living with HIV; and other SRH and human rights networks.

5. Life-long support, diversities, freedom from violence, financial security, overcoming mental health issues, support for pregnancy and fertility desires, treatment choices and side-effects, and healthy sex life.

Figure 2: Responses in different languages over time, from date launched



Emails were also supplemented by Facebook and Twitter alerts. The Chinese twitter alert was even 'favourited' by an international Chinese English language newspaper.

Once the survey was closed and the FGD reports were received, the lead coordinator read through all the transcripts and these were thematically analysed. Quotes were picked to illustrate many recurring themes. However, with the rich wealth of data received, many quotes remain unused.

## Respondents

### Strengths and limitations of the consultation

Many women engaging with the survey are advocates, or have access to networks and support groups; several respondents reported having received training on their SRH and human rights, but believed that this information is not available to all women in all countries. On average, survey respondents – those with access to internet, literate, and who are able to answer the survey in one of the available languages – may be more aware of their rights than the general population of women living with HIV.

***"I am an advocate and my experience is far better than most women I know."*** United States

Table 1: Numbers of survey respondents per language

Language	No. of survey responses <sup>6</sup>	No. of women living with HIV
English	568	480
Russian	135	99
Spanish	128	104
Chinese	80	57
French	46	42
Portuguese	44	28
Bahasa Indonesian	27	22
<b>Total</b>	<b>1,038</b>	<b>832</b>

A further limitation, pointed out by survey respondents, was that while they may have now reached a positive conclusion in relation to current experiences (for example, accessing services), this may be built on years of struggling to access the care women are entitled to. For these reasons, the findings might present a much rosier picture than the reality on the ground.

6. Only responses from women living with HIV were counted in this report. Women were asked whether or not they are living with HIV very early in the survey. They could only continue with the survey if they replied "yes" to this question.

## ANNEX iv

### PRIORITY ISSUES

Priority statements were drawn up by the survey coordinator, on the basis of the pre-consultation process with the Global Reference Group (see source A in Figure 1 in Annex iii). These were ranked through the online consultation, as per the below order in each section, but the vast majority of survey participants agreed that they are priority issues

At least 50% of respondents saw all of them as an absolute must, and at least 90% saw all of them as an absolute must or a high priority.

#### Overarching issues

- Create and expand spaces for women living with HIV to be meaningfully involved in policy-making and programming about our SRH and human rights
- Ensure laws, policy and regulations are grounded in human rights for women and girls with HIV in all our diversity
- Ensure provision of care is grounded in human rights for women and girls with HIV in all our diversity
- Review, reform and amend laws and policies to decriminalize issues related to SRH and HIV (including HIV exposure and transmission, and access to reproductive health and HIV services)
- Provide comprehensive sexuality education and choice of SRH services, which promote women's sexual pleasure, respectful relationships, gender equality, and human rights for all irrespective of sexual identity, gender orientation and HIV status
- Provide integrated HIV and sexual and reproductive health services and referrals
- Expand the evidence base around the linkages between HIV and SRH and human rights for girls or women living with HIV at all stages of our lives

#### Gender-based violence

- Acknowledge and address all health facility-based rights violations against women living with HIV (e.g. stigma and discrimination; provider bias; coerced or forced abortion or sterilization; lack of choice, privacy, or information; etc)
- Address gender inequality in society at all levels (e.g. end harmful gender norms and practices such as child marriage and female genital cutting; ensure equal

employment opportunities and equal pay for men and women; ensure equal property and inheritance rights, etc)

- Address gender-based violence, including intimate partner violence, violence from other family members and violence against women living with HIV who are from key affected populations (including sex work, drug use, same-sex relationships, trans women)

#### Access to clinical care, treatment and support

- Ensure high qualities of dignity, respect and non-discriminatory care of girls and women living with HIV at all stages of the life cycle (including by addressing provider bias, which can act as a barrier to accessing services)
- Ensure Universal Precautions are in place in all health settings (e.g. sterilizing or using new equipment for each patient regardless of the previous patient's HIV status.)
- Understand, support and treat the wide range of mental health issues faced by girls and women living with HIV (including chronic anxiety and depression)
- Understand co-morbidities including TB, malaria, hepatitis C, cancer and other sexually transmitted infections (STIs) in the context of the SRH and human rights of women living with HIV
- Ensure access to a full range of age-appropriate contraceptive choices and services for HIV and STIs
- Understand the interaction between antiretroviral treatment (ART) and family planning options, including safe medical and surgical abortion
- Understand the ways in which HIV and/or ART cause menstrual irregularities, including heavy/irregular/ prolonged/ painful periods and other gynecological disorders including fibroids
- Understand the ways in which HIV and/or ART adherence affect the onset, course and duration of the menopause in women living with HIV
- Understand the impacts of HIV and/or ART on the libido and sexual pleasure among women living with HIV at all stages of our life



## Sexual relationships

- Promote the involvement of sexual partners (men and/or women), in seeking, accessing and utilizing SRH services for women living with HIV. (For example, couple counselling for HIV testing, disclosure, family planning, and mental health issues)
- Promote accurate and up-to-date fertility and conception advice among couples with the same (sero-concordant) or couples with different (sero-discordant) HIV status
- Promote sexual health, well-being, safely and pleasure

## Care and support for children of women living with HIV

- Ensure that women living with HIV are given full support to care for our children, whether or not they are also living with HIV

## ANNEX v MESSAGES TO POLICY MAKERS

In this part of the survey, respondents were asked to state their messages to policy makers using free text messages. Below are the summarised messages in relation to rights, service access, service quality, and sex and sexuality. (See Figure 1 in Annex iii).

*“Put yourself in my shoes” Ukraine*

### Rights

**Develop and implement public policies to promote and protect full enjoyment of SRH and human rights, among women living with HIV, free from religious or moralistic ideologies.**

- Ensure that policies are strongly embedded in human rights principles, especially of equality and non-discrimination on the basis of gender, age, marital status, HIV status or sexual orientation
- Adopt integrated approaches to HIV-related policy
- Ensure policies that address the SRH and human rights of women living with HIV are costed and budgeted, and accompanied by strong accountability, monitoring and evaluation frameworks
- Amend laws that restrict the access, or otherwise violate the rights, of women living with HIV to SRH services, such as laws that criminalize HIV exposure or transmission, same sex practices, sex work, or possession and personal use of narcotic drugs
- Avoid complacency in relation to the bio-medical advances in HIV prevention and treatment, recognizing that HIV continues to affect millions of people, and that without access to treatment, people continue to die of AIDS

- change HIV consideration from 'contagious' to 'transmissible' infection

### Service access

**Generate consensus on universal access to holistic, quality, women-friendly, confidential and non-discriminatory, integrated HIV and SRH services for women living with HIV, including in poor or rural locations, incorporating but not limited to the below:**

- Universal access to ART
- Tailored services for women from key affected populations, including women who have experienced violence (including female genital mutilation/cutting (FGM/C) or early or forced marriage), sex workers, women who use/inject drugs, lesbian, bisexual or trans women, and adolescent girls
- Full range of modern family planning/contraceptive options to all women living with HIV, including young women
- Antenatal care, prevention of vertical transmission, safe delivery options, and infant feeding options
- STI and HIV prevention, diagnosis, treatment and care
- Cervical cancer screening
- Information on treatment and side-effects
- SRH, fertility, and relationships counselling for sero-discordant and sero-concordant couples
- Free and safe abortions
- Fertility treatment (IVF) and legal adoption to be available to women living with HIV on an equal basis with women who are not living with HIV

## Service quality

**Sensitize health providers to eliminate HIV-related stigma, discrimination and violence against women living with HIV in health settings, and to promote and protect human rights of women living with HIV.**

- Ensure non-discriminatory services for women living with HIV (i.e women living with HIV receive the same, and same quality, services as women who are not living with HIV)
- Protect the confidentiality, privacy, and dignity of women living with HIV
- Provide adequate information for women living with HIV to make informed decisions about their care
- Involve women living with HIV in shaping services, and provide peer counselling and support within services
- Ensure the implementation of universal precautions within services, which are up to date and in line with medical standards and guidelines
- Ensure accountability among service providers in the event of rights violations within health facilities
- Ensure standards and guidelines do not discriminate against women living with HIV

## Sex and sexuality

**Acknowledge sexuality as a fundamental dimension of life. Provide comprehensive sexuality education for in- and out-of-school young people, and raise public awareness of HIV, SRH and human rights (including of women and men living with HIV) through media campaigns, advertising TV, radio, social media, and:**

- Promote gender sensitive, lesbian, gay, bisexual and trans (LGBT)-affirming sexual health literacy programmes for young people, including children in foster care
- Celebrate biomedical advances made in HIV treatment and prevention
- Normalize HIV as a health condition that can affect anyone
- Create awareness around living positively and the rights of women living with HIV to enjoy sexual relationships, marry and have children
- Promote sexual pleasure and safe, healthy sex lives
- Ensure comprehensive sexuality education is not based on religious beliefs or morality codes

## ANNEX TO SECTION 1. SAFETY IN HEALTHCARE, AT HOME AND IN THE COMMUNITY

Please read Section 1. Safety in healthcare, at home and in the community first. This annex includes extra information from the consultation.

The survey allowed for women to respond to more than one answer, so if they had experienced violence in the situation described they could choose one or all three of "before", "since" or "because of" HIV diagnosis. Therefore, given the possibility of multiple responses, there is some overlap in the answers.

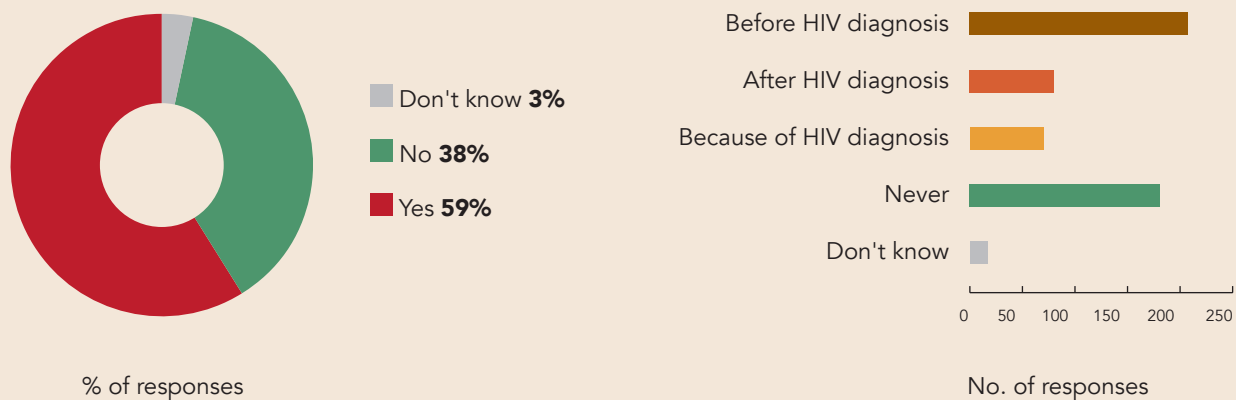
Note: The following bar charts show the number of responses to each option and the pie charts show this expressed as a percentage. Even with the possibility of overlap it is clear that a high proportion of women in the survey have experienced a form of violence at some stage during their lives. Among survey respondents from the Eastern Europe and Central Asia region, all had experienced at least one of the forms of violence mentioned here.

**Table 2: Consolidated responses to whether respondents had experienced violence**

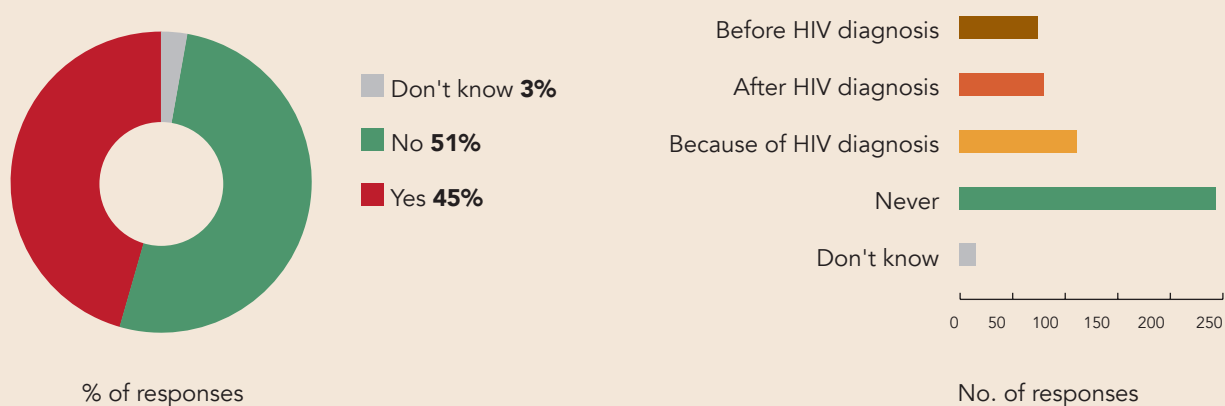
Experience	% No	% Yes	% Don't know
I have experienced violence from a sexual partner or spouse	37.7	58.8	3.5
I have experienced violence from a member of my family/neighbours	51.4	45.3	3.4
I have experienced violence in the community	41.6	53.1	5.3
I have experienced violence in health settings	44.0	53.3	2.7
I have experienced violence from the police/ military/prison or detention services	76.8	16.6	6.6
I have experienced fear of violence	29.6	68.1	2.3



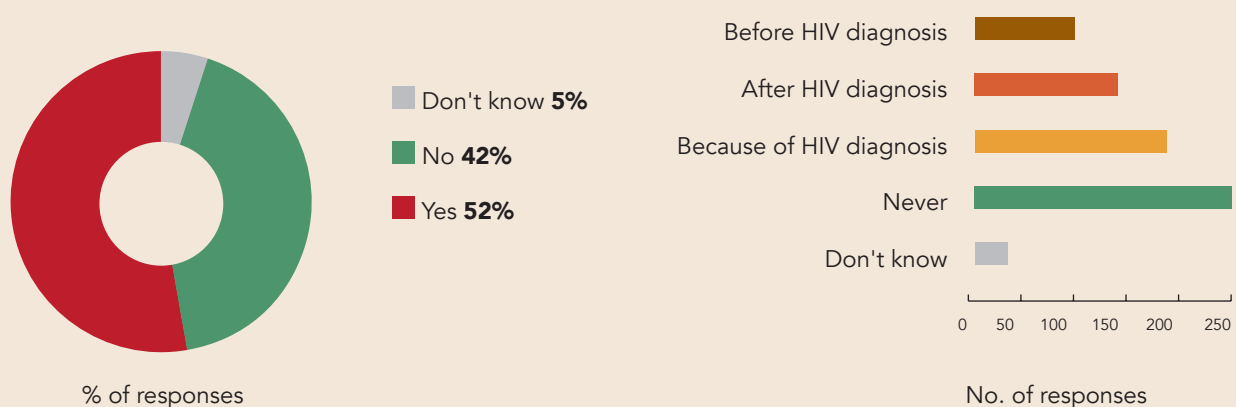
**Figure 3: I have experienced violence from a sexual partner or spouse**



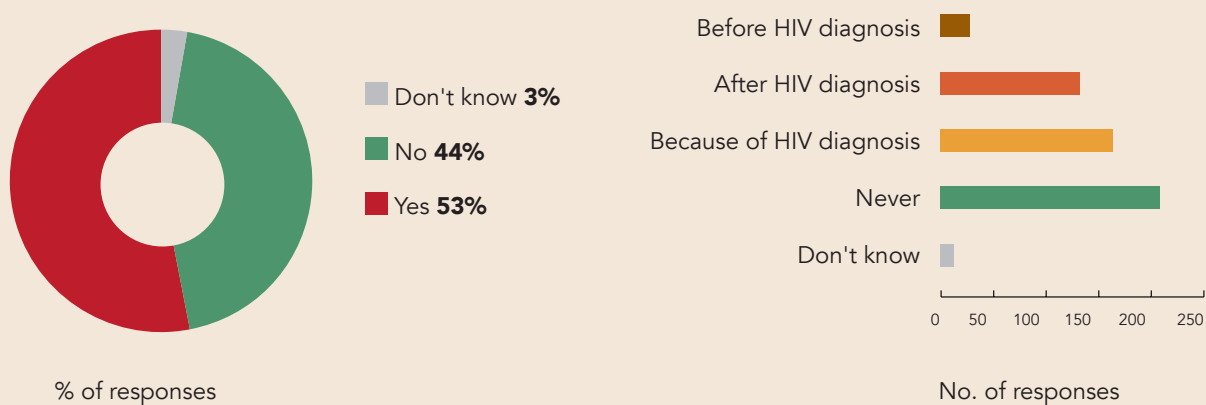
**Figure 4: I have experienced violence from a member of my family/neighbours**



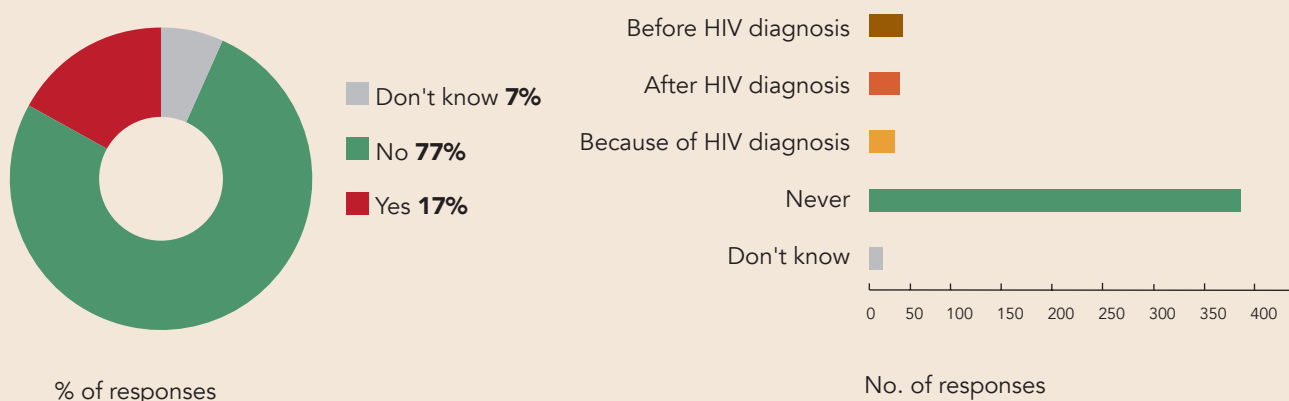
**Figure 5: I have experienced violence in the community**



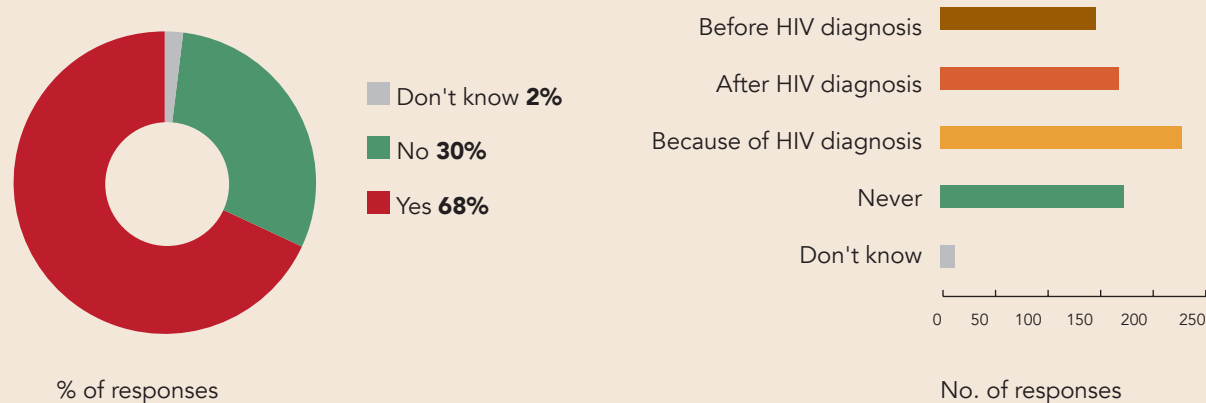
**Figure 6: I have experienced violence in health settings**



**Figure 7: I have experienced violence from the police/military/prison or detention services**

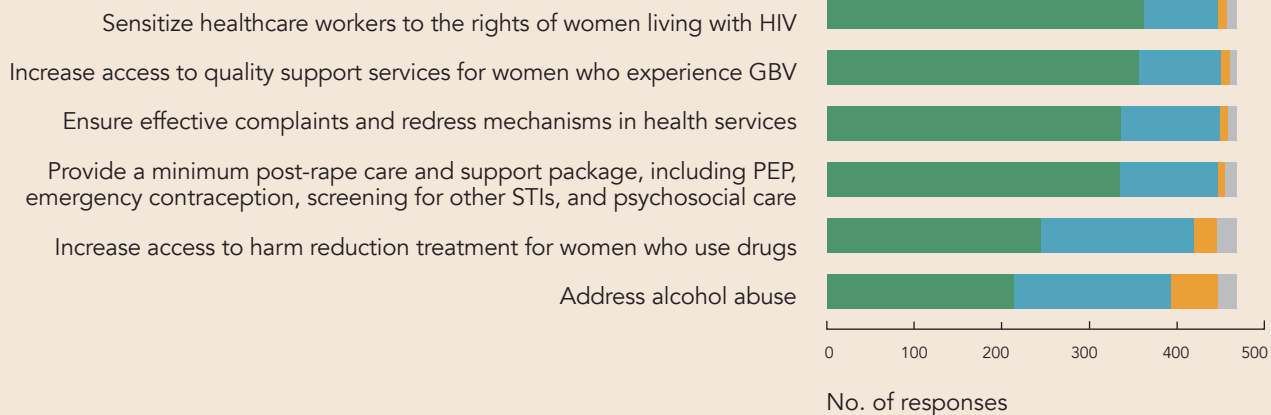


**Figure 8: I have experienced fear of violence**

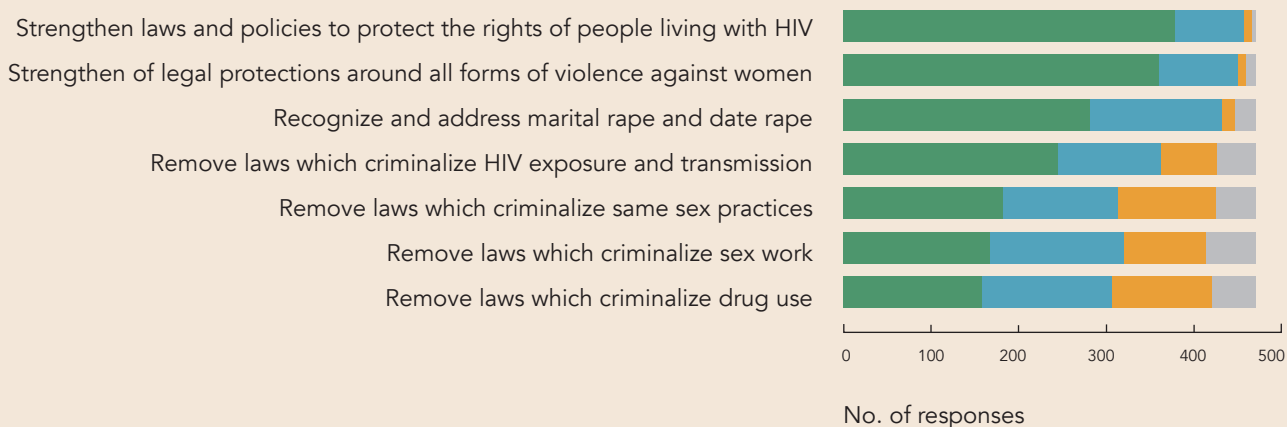


**Figure 9: What do you think are the most important ways to address or prevent these forms of violence?**

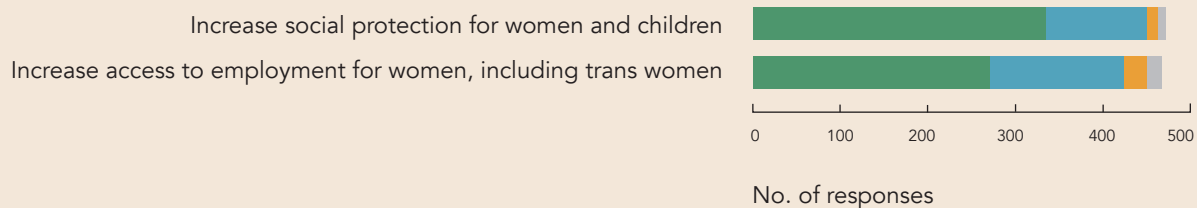
### 9.1 Through safe health services that protect, respect and uphold women's rights



### 9.2 Through a protective legal and policy environment and decriminalisation



### 9.3 Through financial security



## ANNEX TO SECTION 2. FROM CON(TRA)CEPTION TO OLD AGE

Please read Section 2. From con(tra)ception to old age first. This annex includes extra information from the consultation.

Below are specific priorities at different stages of life.

### Health service level

Address stigma, discrimination and judgemental attitudes within services, including:

- Sensitize service providers around the rights of girls and women living with HIV
- Ensure a minimum<sup>7</sup> of three women living with HIV on each local health committee
- Eliminate forced/coerced sterilization and abortion
- Specially train youth friendly health workers and midwives to provide holistic care to girls and women living with HIV
- Fund and train grassroots groups of girls and women living with HIV as peer-mentors
- Promote compassion not blame, and holistic care and support

There is an urgent need for further research across different stages of the life cycle, specifically on:

- Side-effects of ART on reproduction and fetal and child development
- ARV dosage among women at different stages of the life cycle
- Menstrual issues and irregularities, including research on:
  - > Side-effects of ART on the menstrual cycle
  - > Research into influences on and impact of HIV and/or ART adherence on puberty including menstrual issues (late/early; prolonged, very heavy, or very painful bleeding) and the influences on, and impacts of, adherence
  - > Hormonal contraceptive interactions with HIV medication
  - > Interaction of ART with hysterectomy, or treatment for fibroids
  - > Osteoporosis
  - > Influences on ART adherences during old age, including among women with dementia or in care homes

### Childhood and pubescence

#### Main priorities

- Comprehensive sexuality education, carried out in a wide variety of settings (e.g. schools, youth clubs, churches, radio, TV, print media). Include the following:
  - > Educate about sexual health and basic sex (e.g. what are periods?)
  - > Empower young women to protect themselves from unwanted sex, pregnancy, HIV and STIs
  - > Educate about violence against women and girls and how to address it
  - > Inform about SRH and rights including family planning and contraceptives
  - > Inform about HIV: normalizing HIV to reduce stigma and discrimination
  - > Promote inter-generational dialogue – especially between parents and children – about sex and sexuality, HIV and treatment
- Sexual relationships counselling for teenage girls and young women living with HIV including:
  - > Acknowledge and accepting young people's sexuality
  - > Prevent and support women with unplanned pregnancy
  - > Increase access to contraception and safe abortion
  - > Address violence against women and how to overcome it
  - > Advice and support with disclosure for both parents/guardians and children
- Provide holistic mental health care
  - > Build skills to navigate starting new relationships (e.g. disclosure and condom use)
- Ensure safe and smooth tailored transition from child to adolescent to adult health services including:
  - > Know your rights information
  - > SRH information and education
  - > Ensure youth-friendly and adequately equipped health centres
  - > Peer support, as well as mentorship and support from older women living with HIV and participation in support groups and networks
- Other areas important for adolescent girls and young women include:
  - > Address stigma in schools. Assure confidentiality is respected, protected and upheld, along with all other human rights

- > Provide funding for support groups and skills building and leadership programmes, and to support the meaningful involvement of young women living with HIV in decision making
- > Research into influences on and impact of HIV and/or ART adherence on puberty including menstrual issues (late/early; prolonged, very heavy, or very painful bleeding) and the influences on, and impacts of, adherence

## Reproductive years

See also Section 9. Pregnancy and fertility desires.

### Main priorities

- STI information, diagnosis, treatment and management, including:
  - > Risk perception and management
  - > Provider-initiated conversations, as women may not know what to look for or be too shy to ask
  - > Regular check-ups and screening
- Access to full range of birth control methods, enabling:
  - > Access to safe, voluntary abortion and sterilisation
  - > Access to female friendly prevention and treatment female condoms; multi-purpose prevention technologies (MPTs)<sup>8</sup>
  - > Access to ante-natal care, safe delivery, infant feeding options, etc.
  - > Access to fertility treatment
- Reproductive cancers
  - > Provide access to regular screening, especially cervical smears for women living with HIV
  - > Also address oral, breast and anal cancers

## Menopause and post-menopause

### Main priorities

- Provide information and understanding relating to the menopause for women living with HIV. Include research and information on the following:
  - > Bodily changes associated with HIV and the menopause
  - > Management of post menopausal effects, such as support with hormone replacement therapy (HRT)
  - > Interactions with ART, the menopausal process and HRT
  - > Whether HIV brings on early menopause
  - > Issues of misdiagnosis (HIV being diagnosed as menopause; menopause being 'undiagnosed' as an

effect of HIV)

- > The risks involved in pregnancy and child-bearing as women are closer to the menopause
- Sexual relationships counselling for older and post-menopausal women. Include:
  - > Acknowledgement and promotion of sexuality and sexual pleasure among older women
  - > Effect of ART and hormone therapies on libido
  - > HIV awareness and testing for older women
  - > Super-infection and re-infection among sero-same couples
- Tailored services for older women living with HIV, including:
  - > Information and education to service providers on impacts of menopause in women living with HIV, and tailored services to address the issues
  - > Peer support within primary care facilities
  - > Mental health care and counselling
  - > Attention to other health conditions related to menopause, such as bone density, non-communicable diseases (heart disease, diabetes, cancers, including HIV-related cancers – cervical, anal)
  - > Monitor impact of HIV and ART adherence on older women and longer-term survivors

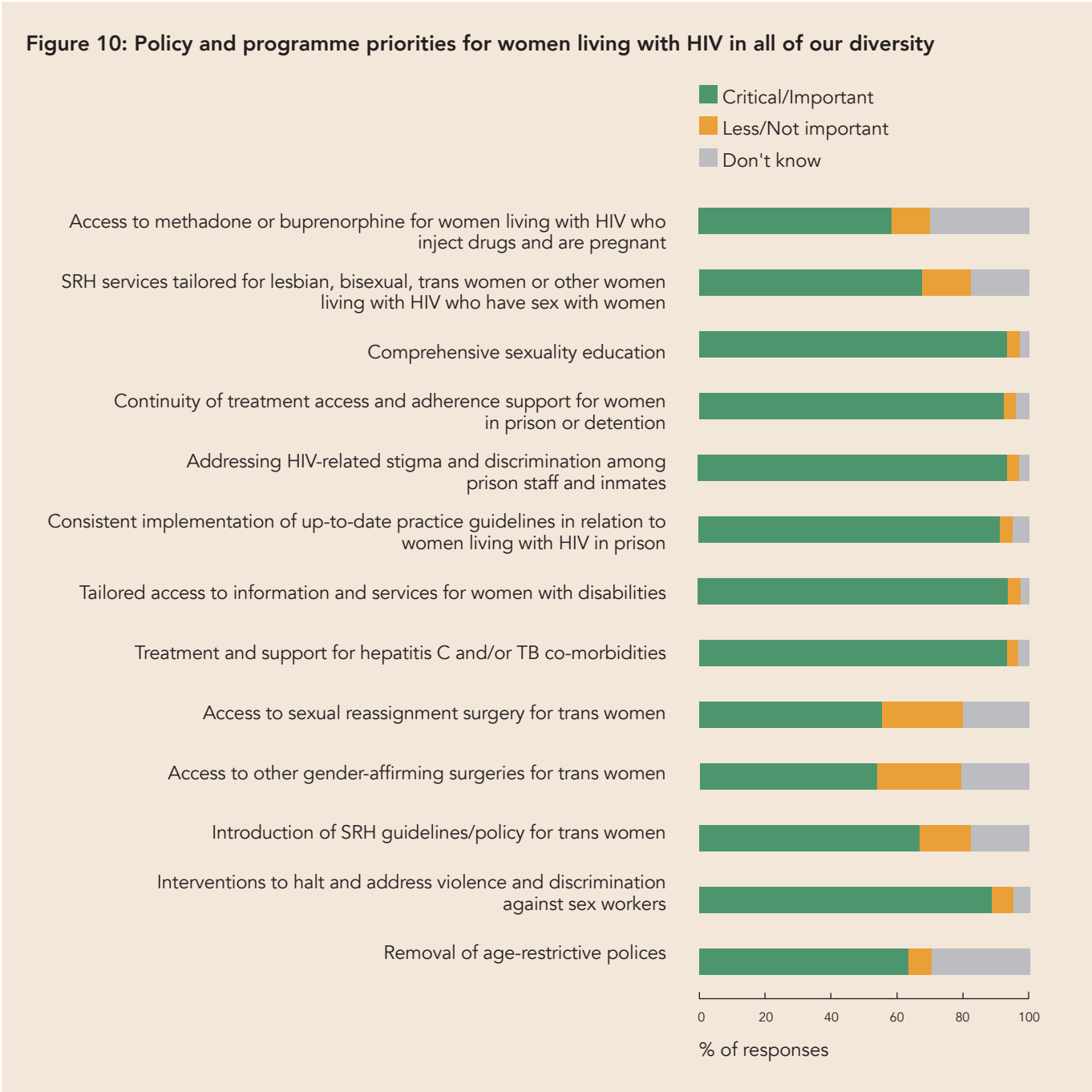
8. Multipurpose prevention technologies (MPTs) are products that combine protection against unintended pregnancy, HIV and other sexually transmitted infections such as HPV, gonorrhea and chlamydia. For more information, see [www.mpts101.org](http://www.mpts101.org) or <http://www.cami-health.org/mpts-video>

# ANNEX TO SECTION 3. RESPECT FOR ALL OUR DIVERSITY

Please read Section 3. Respect for all our diversities first. This annex includes extra information from the consultation.

***"We need to take a much more holistic approach to issues face with women living with HIV than we have to date. Women living with HIV AND dealing with other issues in their lives such as detention, prison, drug use, gender identity, sexual orientation etc have even greater barriers to deal with than I have."***

United Kingdom





The policy and programme priorities (see Figure 10) came out of the pre-consultation exercise, and were endorsed by survey respondents. These are discussed in Section 3 of the main report. Here, we provide supplementary data and issues emerging from the survey's free text responses and FGDs among specific groups of women.

## Trans women

Tailor policies and services to address the extremely high level of stigma, discrimination, harassment and violence against trans women, which increase their vulnerability to HIV acquisition. Ensure:

- Hormonal treatment for trans women
- Specific protocols for trans women living with HIV
- Protection of rights
- Education of health professionals on the specific needs of trans women
- Psycho-social care and support for trans women from a young age

**"Be very clear that being trans is not a mental disease; trans people have enough stigma to deal with. Be very clear that access to trans health care is medically necessary and should not be excluded from public or private insurance. Be very clear in recognizing that the trans community has one of the highest HIV infection rates due to social determinates which result from institutionalized discrimination (homelessness, rape, beatings, unemployment, being underserved in every way)." United States**

**"As a trans woman I have always been gang raped because the society thinks that am a man pretending to be a woman. When I [was] gang raped I called people to give me help instead they beat me up." Uganda**

**"Ensure that trans women who attempt to access help know that it's a safe place – that nobody is going to arrest you when you use the restroom?" United States**

**"For a trans woman living with HIV to have a satisfying and pleasurable sex life is important to first have laws that protect her in third world countries." Peru**

**"There is no respect for trans female identity in any health service and in state services, they violate us, calling us by our legal names; the law of gender identity [is needed for us] to [legally] change our names and have access to health services based on respect." Nicaragua**

**"In the health center before giving me a diagnosis I was already crossed out by someone with HIV, that was increased when I got my diagnosis even asked me to tell my family to take me food to eat because the**

**hospital could not provide me this service. Equally in the penal center, the level of discrimination is high, not only among the authorities but also among detainees. El Salvador**

**"They must make sure that the primary health care system is a safe system for transgender women. Health care providers must receive education regarding transgenderism and transgender specific as well as transgender health care service." South Africa**

**"I access information on sexual and reproductive health and rights from the trainings organised by organisations such as international community of women living with HIV. However, accessing those services from the facilities is not easy for me because of the legal environment which is not friendly in my country and the attitude of the health workers. ... The Anti Homosexuality Act has affected trans women from getting friendly services." Uganda**

**"Allow trans women to adopt children." El Salvador**

**"Basically, think of any service a youth could benefit from and just know that trans kids probably aren't allowed to access it." United States**

## Sex workers

**"When someone has AIDS, they should not be ignored or isolated, people have to put themselves in their shoes. We need to take the person as they are; this is particularly true for health facilities." Sex worker FGD, Senegal**

While relatively little narrative data pertaining to sex workers came out of the survey data, two FGDs among sex workers in Ethiopia (Nikat Association) and Senegal (UNICEF and Karlene) highlighted the following areas for sex workers living with HIV.

The overarching narrative for many sex workers is related to poverty and the need for financial security.

**"Poverty is what triggers all that. You need to help your family and your children. Poverty is responsible of everything. It's poverty that pushes women to go and do the whore. If a client offers to have sex without condom, you will accept because you need money or else you risk to be exposed to violence. If from midnight to 5am you only meet clients who do not want to use condoms you eventually accept even if you have an STI – it's not only about HIV, there are other STDs that might be dangerous for your life." Senegal**

**"It is poverty that pushes most women to sleep anywhere or accept anything, which then increases their risk to be exposed to violence." Senegal**

Stemming from, and clearly related to this narrative, the following experiences emerged. Sex workers living with HIV face often extreme levels of stigma, discrimination and violence. Women in both focus groups expressed fear of violence from clients, family members and the general public, health providers, police and judiciary, and sometimes even from themselves (see below).

Focus group discussion participants in Ethiopia described the impact of the threat of closure of a clinic they have access to where they feel safe and care for, and the dread of having to use government facilities in the future.

**"I went yesterday to the clinic and found that it no longer is providing support – it is closed, I cried in front of the gate, I was so unhappy and asked why good things don't last. I started worrying about my kid and about me."** Ethiopia

Women living with HIV who are involved in sex work risk losing clients if they disclose their status. Among sex workers, HIV status is used as a means to "eliminate" the competition – whether a woman is known to be HIV positive or not.

**"Even in the 'work environment', if someone gets to learn you are HIV-positive you are being denounced by others because they also need money."** Senegal

**"There have been cases of suicides or attempt of suicide as women were scared of what might happen to them if people got to know their status."** Senegal

Lack of protection from law enforcement bodies

**"One night I was coming from work to NIKAT association after finishing my shift and I was robbed. The police officer was standing right there."** Ethiopia

In contrast to this, another woman who had experienced violence and abuse at the hands of a client, was able to seek assistance from the police, was protected, and had the money owed to her reimbursed:

**"Men have to get educated, they need to be informed about being civilized and the police should work on their attitude to protect us. We now have a code to protect ourselves but we can't do it alone."** Ethiopia

Sex workers in Senegal described very great fear of the police in relation to sexual violence, and disclosure of HIV status. The latter is such a huge problem for them that women who are arrested and put into provisory detention overnight will not risk taking their HIV medication for fear of involuntary disclosure and breaches of confidentiality.

**"The main issue is that you have to take your medicine while you're there but you don't want the policemen to know about your status because they will breach the confidentiality so you stay without taking your ARVs."** Senegal

The women also described how they could not file a complaint against the police for maltreatment, because if the judge discovered they were living with HIV and still doing sex work they would be arrested for it.

## Women in prison or detention

The experience of prison can have severe impacts on the mental, financial, and physical health of women living with HIV. In particular, four areas came out strongly in relation to the SRH and human rights of women living with HIV who are or have been incarcerated.

- treatment adherence, and access to regular health care, including treatment for side-effects
- stigma, discrimination and violence from staff and other inmates, and
- fear of/actual loss of custody of children while in prison
- social isolation and financial hardship on reintegration

**"Make sure that incarcerated women and girls have equal access to the same standard of medical information, care and services as unincarcerated women and girls."** United States

## Women who use drugs

**"Women who use drugs are subjected to double or sometimes triple stigma. There are cases of discrimination against these women, even in HIV-service organizations in which they work."** Ukraine

**"I was beaten at the police station, due to the fact that I used drugs."** Ukraine

**"In active addiction I had knives put to my throat, a gun to my head, [was] assaulted numerous occasions."** United Kingdom

Women who use drugs typically face high levels of stigma, discrimination and violence, in particular in relation their reproductive rights. In responding to the survey, women living with HIV who use drugs reported high levels of anxiety especially in relation to having their children taken away from them.

**"When my mother in law found out about my HIV-positive status from hospital nurses, she did everything possible to take away my daughter. She has not deprived me of my maternity rights, but tried to take custody of my daughter by threatening to bribe in the office that decides on the question of custody."** Russia

**"When I was diagnosed, doctors actively discouraged me from having a baby – even if we already knew good interventions to stop vertical transmission. Maybe it was because I was an ex drug user and also had**

**hepatitis C virus ... But it took me many years to even ask again if I could have children and it was too late.**  
Italy

## Women with disabilities

Services need to be tailored to ensure that women with disabilities enjoy the same access to, quality of and benefits from services, and that they are treated with dignity and respect. Without modification, some women need help to access and utilise services, such as delivery beds, which can have a negative impact on both the physical and emotional experience of giving birth, and potentially cause distress to both mother and baby.

Women with disabilities participating through both the survey and a focus group discussion reported high levels

of violence, in particular intimate partner violence before HIV diagnosis (60%), and violence in the community and within health settings both since (35% community 42% health services) and because of diagnosis (40% in both settings).

While some women clearly linked their experience of stigma, discrimination and violence to their disability/ies, (e.g. one woman in the Senegal FGD was made pregnant by her cousin who wanted to marry her, but his parents refused to give their consent), in other cases it was not clear whether violence experienced before diagnosis was related to their disability, or any other factors.

**"A participant shared having been sexually abused twice; first by her cousin and second by the husband of a friend before HIV diagnosis. These two cases of rape in this woman resulted in pregnancies."** FGD, Senegal

## ANNEX TO SECTION 4. HUMAN RIGHTS AND EXPERIENCE OF ACCESSING SERVICES

Please read Section 4. Human rights and experiences of accessing services first. This annex includes extra information from the consultation.

In the first part of the survey, statements were developed to reflect the human rights principles and dimensions below, to ascertain the extent to which women not only had access to services, but also the extent to which services were instrumental in protecting, respecting and fulfilling their human rights. Statements were made in the positive (i.e. affirming the ideal scenario of women's human rights being upheld within and through services), and respondents were encouraged to agree or disagree with the statements according to their recent experience.

### Additional responses

**"I know my rights and responsibilities as a patient, however I feel that all too often there is a power imbalance within healthcare settings which often makes it difficult for patients to advocate for their rights."**  
Ireland

**"I have also given up complaining about the yellow stickers on all my tests saying "danger of infection" because I just feel that I am not listened to and I don't want to alienate my HIV doctor."** United Kingdom

**"When I found out I was HIV+, my Doctor at Planned Parenthood told me I could never have children. That I might infect them and I would be "horrible Woman" to do so. I didn't have children but I have regretted**

**that decision every day of my life since. I did refuse sterilization when it was "encouraged" but still wish I had considered having children as a possibility."** United States

**"Health providers have no experience in dealing with lesbian women especially those living with HIV, who also have both HIV+ and HIV- partners. I have been frowned upon when I went for pap-smear test. Then when to come with my "male partner" I responded that I am lesbian. The clinician never looked at me directly in the eyes again as he was very much disgusted when I revealed my sexual preference. I have never attended that hospital again."** Kenya

**"Because I am a sex worker I am ignored most of the times."** Malawi

**"Not having your choices and inner wisdom respected is annoying and down right inappropriate when you are about to deliver."** United Kingdom

### Messages to policy makers

In one part of the survey, respondents were asked to state their messages to policy makers. Here are the messages in relation to rights, to service access and to service quality.

**Rights:** Develop and implement public policies to promote and protect full enjoyment of SRH and human rights, among women living with HIV, free from religious or moralistic ideologies

- ensure that policies are strongly embedded in human rights principles, especially of equality and non-discrimination on the basis of gender, age, marital status, HIV status or sexual orientation
- adopt integrated approaches to HIV-related policy
- ensure policies that address the SRH and human rights of women living with HIV are costed and budgeted, and accompanied by strong accountability, monitoring and evaluation frameworks
- amend laws that restrict the access, or otherwise violate the rights, of women living with HIV to SRH services, such as laws that criminalize HIV exposure or transmission, same sex practices, sex work, or possession and personal use of narcotic drugs
- avoid complacency in relation to the biomedical advances in HIV prevention and treatment, recognizing that HIV continues to affect millions of people, and that without access to treatment, people continue to die of AIDS
- change HIV consideration from "contagious" to "transmissible" infection

**Service access:** Generate consensus on universal access to holistic, quality, women-friendly, confidential and non-discriminatory, integrated HIV and SRH services for women living with HIV, including in poor or rural locations, incorporating but not limited to:

- universal access to antiretroviral treatment
- tailored services for women from key affected populations, including women who have experienced violence (including FGM/C or early or forced marriage), sex workers, women who use/inject drugs, lesbian, bisexual or trans women, and adolescent girls
- a full range of modern family planning and contraceptive options to all women living with HIV, including young women
- ante-natal care, prevention of vertical transmission, safe delivery options, and infant feeding options
- STI and HIV prevention, diagnosis, treatment and care
- cervical cancer screening
- information on treatment and side-effects

**Figure 11: Experiences of SRH services**





- SRH, fertility, and relationships counselling for sero-discordant and sero-concordant couples
  - free and safe abortions
  - fertility treatment (IVF) and legal adoption to be available to women living with HIV on a equal basis with women who are not living with HIV
- Service quality:** Sensitize health providers to eliminate HIV-related stigma, discrimination and violence against women living with HIV in health settings, and to promote and protect human rights of women living with HIV.
- Ensure non-discriminatory services for women living with HIV (i.e women living with HIV receive the same, and same quality, services as women who are not living with HIV)
  - Protect the confidentiality, privacy, and dignity of women living with HIV
  - Provide adequate information for women living with HIV to make informed decisions about their care
  - Involve women living with HIV in shaping services, and provide peer counselling and support within services
  - Ensure the implementation of universal precautions within services, which are up to date and in line with medical standards and guidelines
  - Ensure accountability among service providers in the event of rights violations within health facilities
  - Ensure standards and guidelines do not discriminate against women living with HIV

## ANNEX TO SECTION 6. MEANINGFUL INVOLVEMENT OF WOMEN LIVING WITH HIV

Please read Section 6. Meaningful involvement of women living with HIV first. This annex includes extra information from the consultation.

### Additional responses

*"To have self help spaces where women living with HIV could share experiences and start a new path together, supporting each other. And also have sensitized health carers, with good knowledge and respectful of HIV related legislation."*

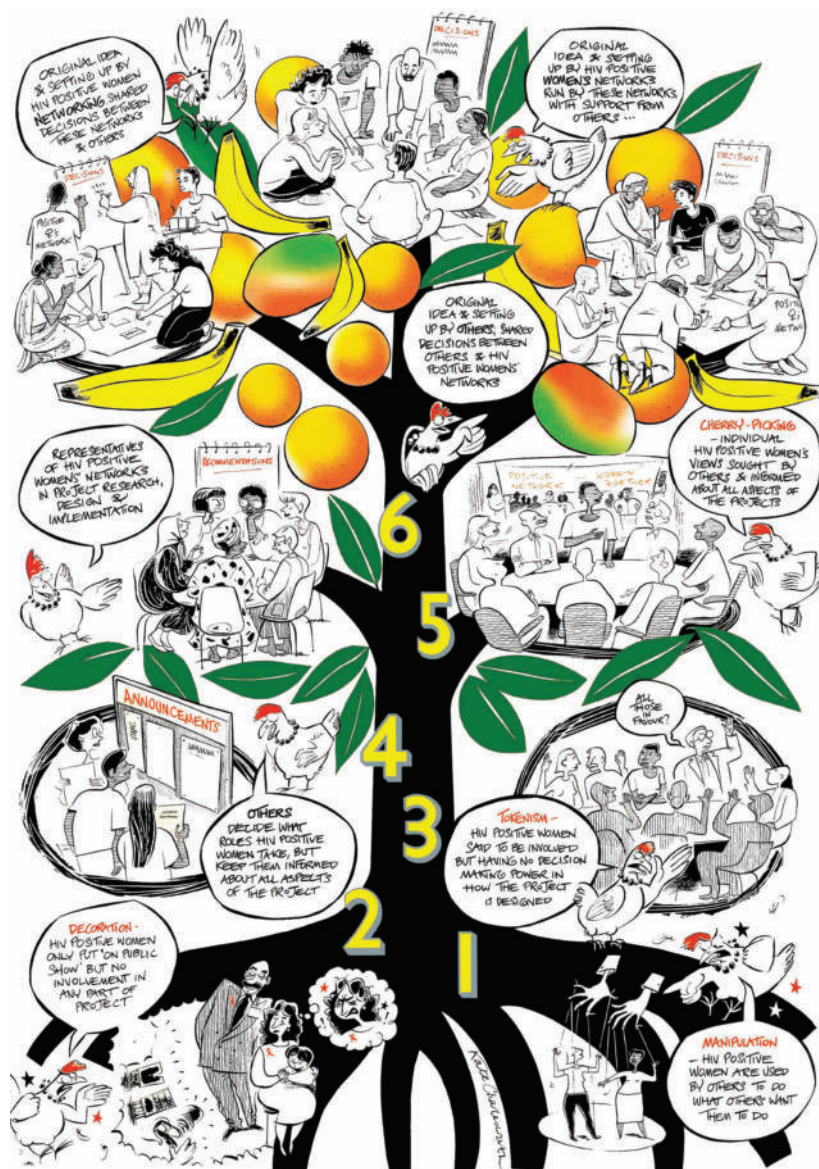
El Salvador

*"The situation regarding HIV diagnosis changed when I met the same people and we have created the All-Ukrainian Network of PLWH, and then I became HIV activist. It helps me survive."*

*"Giving women 'spaces' to be themselves. to talk about what they are going through without judgement."*

United Kingdom

**The Participation Tree: Ensuring the meaningful participation of women living with HIV.** © ICW, 2004. Available at: [http://www.womeneurope.net/resources/Policybriefing\\_ENGJuly2011.pdf](http://www.womeneurope.net/resources/Policybriefing_ENGJuly2011.pdf)



## ANNEX TO SECTION 8. PLEASURABLE AND FULFILLING SEX LIFE

Please read Section 8. Pleasurable and fulfilling sex life first. This annex includes extra information from the consultation. See also Figure 12 on page 61.

### Additional responses

**"Nowadays, every day I need to have sex."** Uganda

**"Before HIV I often experienced physical and psychological abuse from my boyfriend, because I did not have orgasms and I often had the feeling of guilt. Maybe if it was not [the case], I would not have engaged in sexual contact with the person who infected me with HIV."** Russia

### Messages to policy makers

In one part of the survey, respondents were asked to state their messages to policy makers. Here are the messages in relation to sex and sexuality.

- Acknowledge sexuality as a fundamental dimension of life.
- Provide comprehensive sexuality education for young people in- and out-of-school, which is not based on religious beliefs or morality codes
- Promote gender sensitive, lesbian, gay, bisexual and trans (LGBT)-affirming sexual health literacy programmes for young people, including children in foster care
- Raise public awareness of HIV, SRH and human rights (including of women and men living with HIV) through media campaigns, advertising TV, radio, social media.
- Celebrate bio-medical advances made in HIV treatment and prevention
- Normalize HIV as a health condition that can affect anyone
- Create awareness around living positively and the rights of women living with HIV to enjoy sexual relationships, marry and have children
- Promote sexual pleasure and safe, healthy sex lives

## ANNEX TO SECTION 9. PREGNANCY AND FERTILITY DESIRES

Please read the main section on pregnancy and fertility desires first. This annex includes extra information from the consultation. See also Figure 13 on page 61.

### Additional responses

**"Doctors and nurses must be given awareness workshops and more information as patients often know more about this issue. Also find a law that strongly punishes doctors performing forced sterilization and that does not expire, and [provides] time to make a lawsuit if necessary because many times we realize that we were sterilized many years later and we can do nothing"** Puerto Rico<sup>9</sup>

**"In Gabon, it is a problem to decide to have children. Women who choose to do it without their doctor's advice are perceived as women who wish to transmit HIV."** Gabon

**"Stigma. Finding supportive providers. The range of terrible to great is amazing."** United States

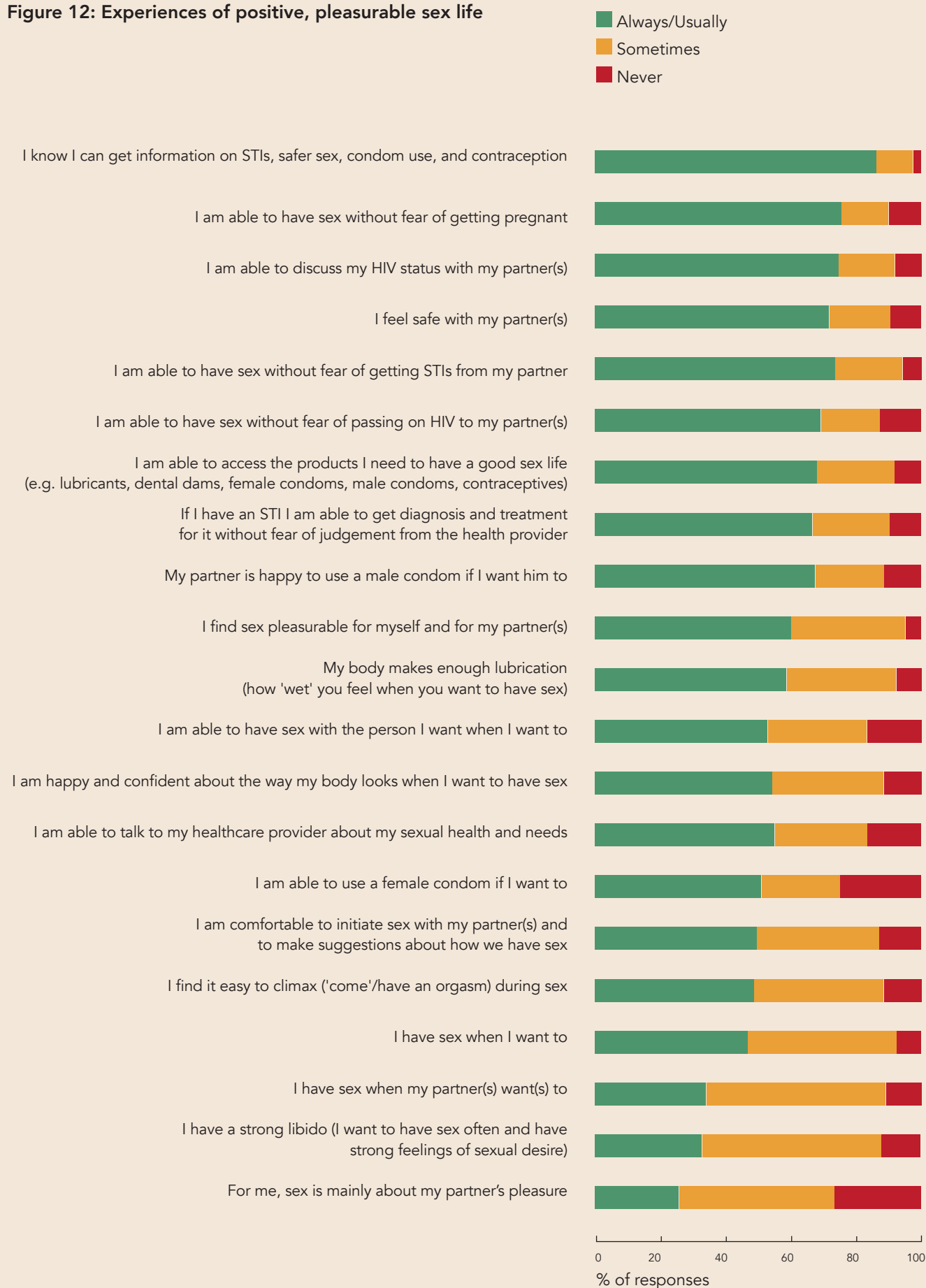
**"I feel my rights are well provided for but my confidence in that is also built on a foundation of being someone who makes a point of informing myself on relevant issues. Being actively involved in forums that provide services to positive people and I do not necessarily take clinicians opinions as gospel. Having lived with the condition for 23 years I trust my own experience above all."** United Kingdom

**"This is NOT a practical answer, but I would love to have the world view HIV/AIDS for what it really is, a virus that can kill you. I feel like people immediately judge me as being "dirty" or diseased. I believe that people have a right to make their own decisions about their bodies, and their desire to have/not have children. There needs to be current, updated information available for women."** United States

**"We know little about the rights, if there was more information to many it would help in the decision, for example, the question: to give birth or not, etc."** Ukraine

9. This quote is particularly apt in the context of the November 2014 Supreme Court ruling in Namibia that found that women living with HIV in Namibia have been forcibly sterilized in public hospitals (see <http://hivlawcommission.org/index.php/news/news/380-news-release-namibia-s-highest-court-finds-government-forcibly-sterilised-hiv-positive-women>)



**Figure 12: Experiences of positive, pleasurable sex life**

**Figure 13: Experiences of decision making around fertility desires**



## ANNEX TO SECTION 10. HIV TREATMENT AND SIDE-EFFECTS

Please read the main section on HIV treatment and side-effects first. This annex includes extra information from the consultation.

Impacts of side-effects on women's sexual and reproductive health and human rights included the following additional issues:

**"Husband is not satisfied, I often force myself to have sex."** Ukraine

**"Affect the sex life, self-compassion, looks ugly, unhappy, can not find partners."** China

**"Hard for me to fully work and feel like a normal person. Every day I am afraid of losing efficiency."** Ukraine

**Figure 14: HIV treatment side-effects**



## ANNEX TO SECTION 11. FINANCIAL SECURITY

Please read Section 11. Financial security first. This annex includes extra information from the consultation.

**"Stronger support for labour market participation: having an adequate income to support myself and family would go a long way to helping me deal with some of the challenges I have experienced."** Canada

**"I have days that I feel good, and days I find it hard to get out of bed because of diarrhoea or stomach problems, so I would be a undependable employee. I disclosed my status to an employer, and I know that is why I did not get hired."** United States

Specifically, the priority issues for policy and practice raised through the survey were:

- Access to economic empowerment and equal and equitable employment opportunities for women living with HIV in all of our diversity, including:

- > Equal opportunities policies (age, gender, sexuality, HIV status), and employment protection
- > Elimination of stigma and discrimination in the workplace; sensitization among employers re: the rights of women living with HIV
- > Gender equality writ large
- > Economic empowerment and income generation projects
- > Equal property and inheritance rights for women
- > Access to loans, credit, start-up capital, business development
- > Right to work for people who have immigrated for economic or political reasons.

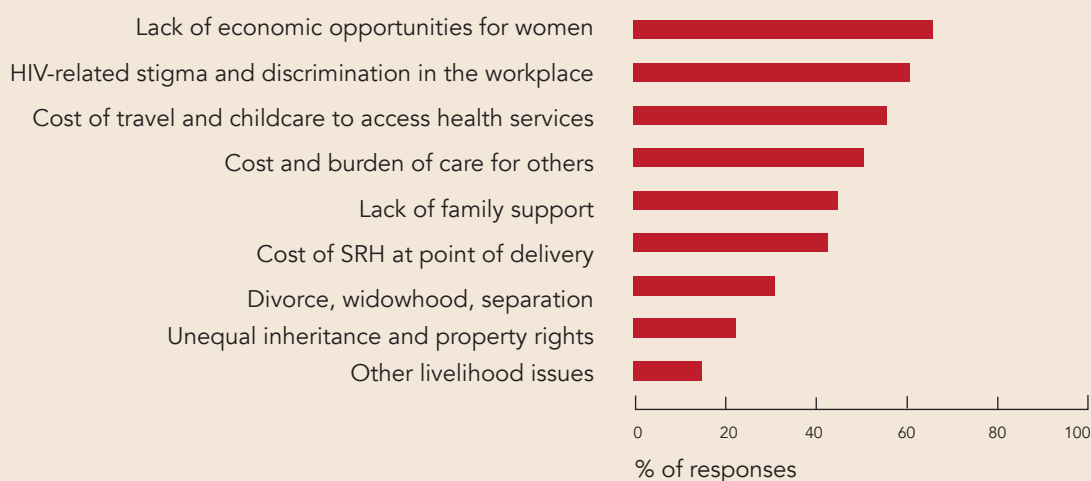
**"Tajik women are very vulnerable as financially dependent on their husbands or partners, to pay attention to education and improving the competitiveness of women in the labor market."** Tajikistan

- Financial support to women living with HIV
  - > Disability allowance, recognizing that living with HIV puts a strain on a person's finances due to the need for multiple hospital appointments, mental health care and other areas of support, all of which have a cost attached to them
  - > Housing allowance and access to affordable housing or accommodation
  - > Nutritional support
  - > Cash transfer or livelihoods<sup>10</sup> programmes, built on prior gender-transformative communications training

***"All other women with HIV facing these times should be given support as of it is a risk to their own life, families or partners."*** Cameroon

- Access to free/affordable vocational training and education
- Implementation of laws, which protect the rights of women living with HIV, including in the workplace
- Funding for women's organizations and projects to support the economic empowerment of women living with HIV

**Figure 15: Financial issues that impact on women living with HIV to access quality sexual and reproductive healthcare and wellbeing**



10. See, for instance HEARD et al 2013

## ANNEX TO SECTION 12. MENTAL HEALTH MATTERS

Please read Section 12. Mental health matters first. This annex includes extra information from the consultation.

### WHO summary on mental health

"Many of these risks to health are also interrelated; for example, low socioeconomic status increases the risk of trauma or neglect during childhood, which in turn increases the risk of anxiety and depression in early life and later in life, which can increase the risk of alcohol or substance abuse, and then increase the risk of exposure to HIV or worsen outcomes in people with diabetes. From this risk factor perspective, the precise biological mechanisms responsible for diseases are less important than the overlapping and consistent influence of behaviour and family characteristics on disease outcomes, both of which are shaped by social factors... Mental disorders also are interwoven with HIV/AIDS. Between 11% and 63% of HIV-positive people in low- and middle-income countries have depression. In the United Republic of Tanzania, for example, one study showed that 57% of HIV-positive women experienced depression at least once during the study period of 6 to 8 years, and that depression was associated with a greater likelihood of disease progression and death.

"Worldwide about 10% of pregnant women and 13% of women who have just given birth experience a mental disorder, primarily depression. In developing countries this is even higher, i.e. 15.6% during pregnancy and 19.8% after child birth. In severe cases mothers' suffering might be so severe that they may even commit suicide. In addition, the affected mothers cannot function properly. As a result, the children's growth and development may be negatively affected as well. Maternal mental disorders are treatable. Effective interventions can be delivered even by well-trained non-specialist health providers."<sup>11, 12</sup>

### Responses in relation to dealing with mental health experiences

**"Dealing with stigma and fear of rejection is a very hard thing to do, but it has to be taken in the context of one's general life, as it is not an isolated issue, so it is difficult to deal with it, if you don't have a support system or have felt rejected anyway, regardless of HIV."** United Kingdom

**"It makes me less assertive and I sometimes give permission to my partner to take advantage of me by doing having sex when I would rather not."** Nigeria

**"Due to diagnosis I never trusted men again; I have been feeling very lonely and do not have anybody to share with."** Colombia

**"I have never disclosed my status to people so they assume I'm just normal like them and hence no stress whatsoever."** Kenya

**"Treat underlying causes. I was an addict and couldn't get better till I gave up all drugs. HIV was a cause/symptom of that rather than the problem."** United Kingdom

**"Family member blaming me for death of my husband, fear disclose to even my mother because she will isolate me from my siblings and use me as an example in every case."** Uganda

**"I have stopped engaging in sexual relationships since being diagnosed. I feel embarrassed and will never disclose to any one."** Nigeria

**"Mental health issues have been much larger for me than I originally realised. When I was diagnosed with clinical depression, I felt ashamed all over again. I have since learnt how widespread this is and now feel OK to talk about it publicly but this took some time."** United Kingdom

**"Be in their shoes. To understand."** United Kingdom

**"1. Let them know they are not alone. 2. Help them (and their providers) to understand they may feel badly AFTER a traumatic experience rather than during it." (Examples: Homeless families that do well while living in a car but fall apart once housed. Women who are resilient through their pregnancy and childbirth, but have confusingly upset feelings after they learn their baby is HIV-negative.) 3. Focus the blame for violence against women on the perpetrators, not the victims. 4. Develop and disseminate models for trauma-informed care (including models that work in resource-poor settings)."** United States

**"HIV clinics should incorporate mental healthcare services for them so that they are supported in a one-stop shop sort of manner."** Kenya

**"Helping them to understand that their reaction is completely normal – that anyone who is given a diagnosis of a chronic illness goes into a sort of shock, followed by depression. Basically by making them appreciate that it is not their fault – it is rather a normal reaction to an abnormal situation."** United Kingdom

11. Accessed November 2014: [http://www.who.int/mental\\_health/maternal-child/en/](http://www.who.int/mental_health/maternal-child/en/)

12. Research by Positively UK found that seven out of ten women with HIV in the UK experienced mental health issues in the past year. Positively UK 2013.

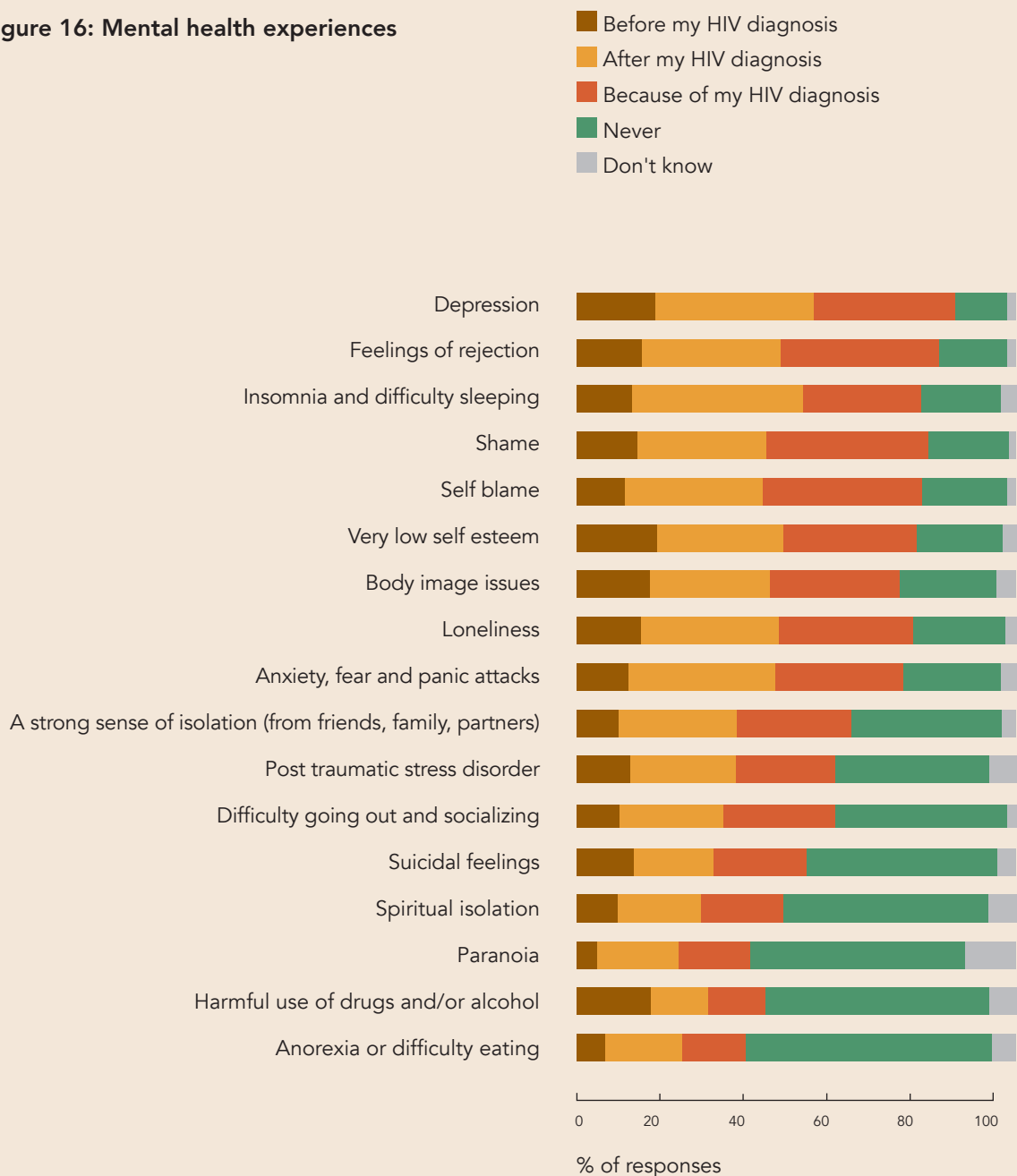
**"Real health policies addressing HIV+ women and girls issues respecting their dignity and human rights." Brazil**

**"End the stigma by all means possible! Policies, laws, education, public information etc. What other way is there?" United Kingdom**

**"Educating society is also important, because if one**

**had to seek help from their spiritual leaders and their mental health condition is not acknowledged, then it becomes even more damaging." United Kingdom**

**Figure 16: Mental health experiences**





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