

Access to sexual and reproductive health and rights for women and girls living with HIV

Introduction

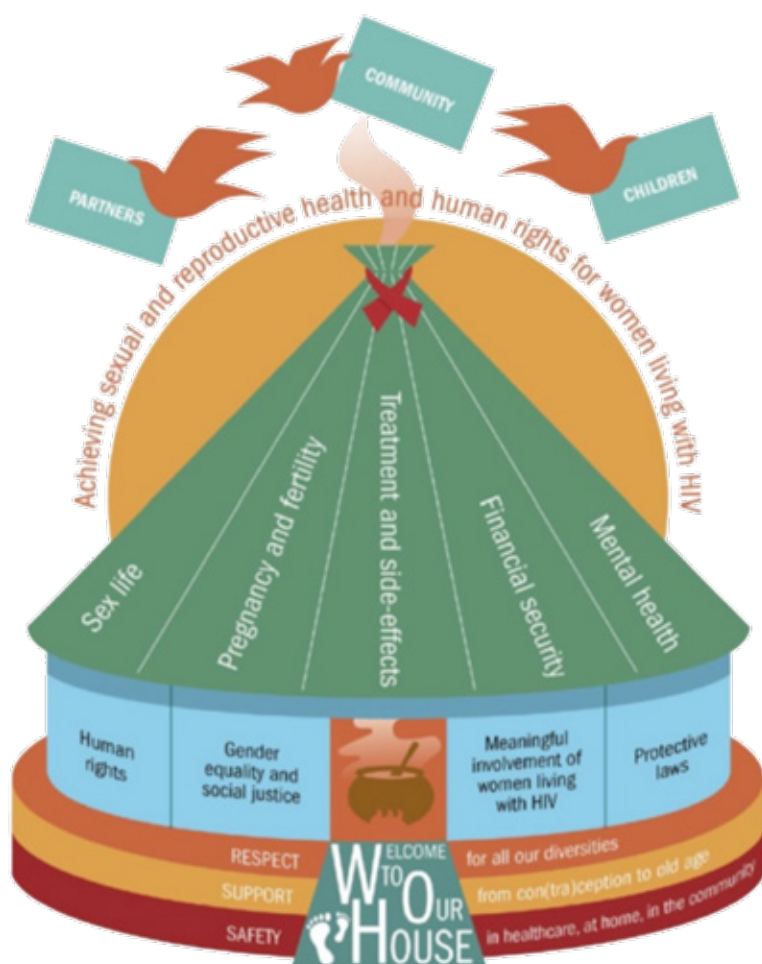
The WHAVE is a podcast series by and for women living with HIV around the world, talking about our sexual and reproductive health and rights. This is the 2nd of four briefs based on this series.

This brief

In this brief, we focus on access to sexual and reproductive health and rights and HIV services for women and girls living with HIV.

The WHO Consolidated Guideline on Sexual and Reproductive Health and Rights of Women living with HIV (WHO, 2017¹) stipulates that services must be women-centred, accessible, acceptable and affordable, and based on human rights, gender equality and the meaningful involvement of women living with HIV in all programmes and policies that affect their lives. It does so in full recognition that women living with HIV face unique challenges and human rights violations related to their sexuality and reproduction within their families and communities, as well as from the health-care institutions where they seek care.

The WHAVE contributors speak in some detail about these challenges, many of which are included in the diagram below. This diagram depicts all the different elements which contribute to achieving SRHR, as described by women living with HIV in a global survey which informed the WHO guideline².



1 World Health Organisation, 2017, Consolidated guideline on sexual and reproductive health and rights of women living with HIV. <https://apps.who.int/iris/bitstream/handle/10665/254885/9789241549998-eng.pdf?sequence=1>

2 Salamander Trust, 2014, 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. WHO, Geneva. <https://salamandertrust.net/wp-content/uploads/2016/09/BuildingASafeHouseOnFirmGroundFINALreport190115.pdf>

What are sexual and reproductive health and rights (SRHR)?

- A state of complete physical, mental and social well-being in all matters relating to the reproductive system. It implies that people are able to have a satisfying and safe sex life, the capability to reproduce, and the freedom to decide if, when, and how often to do so (UNFPA³).
- SRHR include women's rights to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence. Equal relationships between women and men in matters of sexual relations and reproduction, including full respect for the integrity of the person, require mutual respect, consent and shared responsibility for sexual behaviour and its consequences' (Beijing Declaration and Platform for Action, 1995, Paragraph 96⁴).
- SRHR are essential for sustainable development because of their links to gender equality and women's wellbeing, their impact on maternal, newborn, child, and adolescent health, and their roles in shaping future economic development and environmental sustainability (Guttmacher-Lancet Commission, 2018⁵).

The WHAVE key message: Much more is required to create enabling environments for women living with HIV to access their sexual and reproductive health and rights

While the scientific potential to keep women living with HIV alive and well has come a long way, the experiences shared and the views expressed by women contributors to The WHAVE produce an overarching key message. **There is still much more work to be done to secure the sexual and reproductive health and rights of women living with HIV around the world.**

The podcast contributors and their colleagues are all doing unstinting work to create a more enabling environment around their sexual and reproductive rights. This includes feeling safe and well enough physically and mentally. For example, they are working to address: out of date HIV laws and ARV stock-outs (Argentina); government decisions to restrict access to Dolutegravir for women of reproductive age (Kenya); high rates of violence against women (Argentina, Malaysia); work to make services more adolescent-friendly (Uganda); delivering training in women-centred care for medical students (Spain); sharing information that people living with HIV who have an undetectable viral load cannot transmit HIV (known as U=U, or Undetectable = Untransmittable) (UK); perinatal peer support for women living with HIV (UK); peer support to women facing coerced abortion and sterilisation (Malaysia); access to cervical cancer screening and treatment (Zimbabwe); and support for women living with HIV to realise and claim their rights to pleasurable sex lives (Puerto Rico). Women are doing all this in the face of a chronic lack of funding for peer support (see The WHAVE Podcast Paper #1), little acknowledgement of their contribution, and multiple other barriers to the meaningful involvement of women living with HIV in decisions that affect their sexual and reproductive lives.

Contributors to The WHAVE describe a significant lack of focus on the sexual and reproductive health and rights of women and girls living with HIV (and indeed women and girls in general). In their experience, the sexual and reproductive health services on offer must adapt in a number of ways in order to fulfil the WHO Consolidated Guideline. These ways are explored in more detail below.

3 UNFPA, no date. <https://www.unfpa.org/sexual-reproductive-health>

4 Beijing Declaration and Platform for Action, 1995. https://www.un.org/en/events/pastevents/pdfs/Beijing_Declaration_and_Platform_for_Action.pdf

5 Guttmacher-Lancet Commission on Sexual and Reproductive Health and Rights, 2018, Accelerate progress: Sexual and reproductive health and rights for all. https://www.guttmacher.org/sites/default/files/page_files/accelerate-progress-executive-summary.pdf

1. Women and girls living with HIV must be trusted to make informed decisions about their own sexual and reproductive health

According to the WHO Consolidated Guideline, 'Interventions on self-efficacy and empowerment around SRHR should be provided to maximise health and fulfil rights' (WHO Guideline Rec B1). However, The WHAVE contributors describe a widespread lack of trust in women's and girls' ability to make decisions about their own sexual and reproductive health.

'When [healthcare workers] go to the workplace and deal with patients, they don't realise that patients know things. And if they don't have this awareness, the professionals think they have to tell us what to do, instead of listening to us and deciding together what to do. They see themselves as professionals and the patient as someone who knows nothing. They don't value patients as equals.'

(MariJo Vázquez, Spain)

A lack of trust in women also seems to affect whom healthcare professionals decide to share information with about the fact that people with undetectable viral loads cannot transmit HIV (Undetectable = Untransmittable, or U=U).

'And it's one thing for the U=U message to be made available to the general member of the public, who knows nothing about HIV. That's very cool and I'd advocate for that definitely - there need to be more national campaigns. But where there could be even a possibility that an HIV positive person finds out about it for the first time on an advert on a bus, or at a bus stop, -

and that they are finding out about it like that because their doctor hasn't trusted them with that information, that's not acceptable. I think for me it ultimately comes down to who is considered trustworthy, who can be trusted with information, and it really frustrates me.'

(Bakita Kasadha, UK)

The trust theme continues with decisions by various governments to issue 'restrictions' or bans denying access to the antiretroviral drug Dolutegravir (or DTG) for women of reproductive age after early results of a study in Botswana, which linked it to possible neural tube defects in infants (Salamander Trust, 2019⁶). This appears to have been based on an assumption that women would not be able to make their own informed personal decisions about treatment, contraception and pregnancy.

In the case of Kenya, Lucy Wanjiku Njenga talks about the lack of consultation with organisations of women living with HIV before imposing the restriction. Similarly, in Cameroon, Francine Nghanhale explains that women living with HIV were informed that decisions about DTG would be made by technical and scientific 'experts', with no acknowledgement of the expertise obtained through living with HIV, and no meaningful involvement of women living with HIV in the discussions.

The WHAVE contributors believe that access to and delivery of sexual and reproductive health and rights must be improved by trusting in and respecting women's informed choices, autonomy and rights, and ensuring the meaningful involvement of women living with HIV in decisions, policies and programmes that impact their lives.

'As women, we need answers, and we need solutions. This is why we say let's sit together at the table, let's discuss and hear us, and stop calling our issues "anecdotes".'

(Martha Tholanah, Zimbabwe)

6 Salamander Trust and partners, 2019, Our Rights – Our Lives – Our Decisions! A brief about ARV choices for women and girls living with HIV as a human right, with dolutegravir as a focus, Second edition, October 2019. <https://salamandertrust.net/project/the-dolutegravir-debate/>

2. Holistic approaches across sectors are important

Services are rarely able to take a holistic approach that can address other issues women may be facing which can also affect their sexual and reproductive health and rights. As the house image above illustrates, these can include mental health, intimate partner violence, worries about employment and money, or challenges around migration and legal status. Gender inequality underpins these issues.

'In our context, gender equality is really on the rocks. We are in a society where women are always relegated to the background, no matter how hard they try. According to custom in some of our countries in our sub-region, women do not even have the right to speak when men are present. They have no right to inheritance. They are not entitled to this. They are not entitled to that.'

(Francine Nghanhale, Cameroon)

The WHAVE contributors describe the links between these issues and sexual and reproductive health and rights, and the importance of supporting women and girls in the various aspects of their lives.

'I'm seeing in my community the issues that are happening. I am always talking about TB, and also domestic violence for women, girls and children. We have legal issues. Most of the women are denied the right to access property. Others can't even find a job to sustain themselves, they don't have enough food in their house, they don't know whether their children will go back to school. Added to that is the disclosure part of it. It's very hard for them to disclose because they feel like when they disclose they will be rejected. Most

of them are dependent – actually they are dependent because they didn't complete school and they can't find a job because it's very competitive. They don't think they will have a bright future. [...] I integrate to always address each and every key aspect they can be affected by – HIV, TB, malaria, and other sexual and reproductive health issues - so that at least they can get the full package of what they need.'

(Resty Nalwanga, Uganda)

These are the kind of issues that peer-led organisations are very well placed to provide support with.

'The second day [of the Pregnancy Journey Workshop] is around creative writing and peer support [...]. We provide a safe creative space for women to explore their emotions and their experiences. That's one of the sessions women rated really highly. [...] When people start to talk, you start to hear about mental health, violence, so it's a good way to have the conversation around those things and provide support for the women, and by the second day people are more relaxed and able to share, and once people share those stories there is that bond and it creates that sense of community.'

(Longret Kwardem, UK)

Contributors feel this is an extremely important aspect of their work, yet it is one that appears to be all but invisible to most service providers, and goes unacknowledged, unfunded and unsupported by health services. Peer support has a really important part to play in supporting women with the range of issues that affect sexual and reproductive health and rights, in improving well-being, and in helping to live well with HIV.

3. HIV and sexual and reproductive health services must be better integrated

There is widespread recognition of the importance of integrating HIV and sexual and reproductive health services, yet this often does not happen effectively, meaning that critical aspects of sexual and reproductive health and well-being can fall between the gaps (see for example ECHO, 2019⁷).

Cervical cancer: Contributors to The WHAVE highlight access to cervical cancer services as a key challenge.

‘While the HPV vaccination is available in Zimbabwe, and there is free screening for cervical cancer for women living with HIV, this is not free for HIV-negative women, and if follow-up treatment is needed it must be paid for. Furthermore, the cost of transport to clinics can be prohibitive, particularly for women living in rural areas. As a result, many women delay screening and treatment until cancer is in the later stages. Some families – already struggling – are sinking into poverty by selling property to pay for treatment.’ (Martha Tholanah, Zimbabwe)

Cervical cancer disproportionately affects women living with HIV⁸. While it is almost always caused through acquiring the human papilloma virus (HPV), cervical cancer is classified as a non-communicable disease (NCD). The lack of funding for networks and organisations of people living with HIV can be an obstacle to good understanding of the evidence and knowledge of the statistics – as

illustrated in Zimbabwe, where some organisations of people living with HIV have in the past demanded that the National AIDS Council should not focus on NCDs. Women activists continue to urge the National AIDS Council and Ministry of Health to keep a spotlight on NCDs including cervical cancer, and there has been some progress in terms of information dissemination, though more progress is needed to ensure that women living with HIV have better access to cervical cancer screening and treatment, and that women who cannot afford it are not turned away. It is also vital that women’s civil society organisations and networks, in all their diversity, are an integral part of all the programmes, particularly regarding awareness and literacy.

Menopause: Contributors to The WHAVE also talk about poor integration of support around menopause.

‘If you need clinical attention, we have a good system. But other integrated aspects of sexual and reproductive health are not taken into account. I go to the hospital for HIV but the walk-in for sexual and reproductive health, so there is a bit of me in each place. No-one talked to me about menopause – not the HIV clinic or the gynaecologist. It is addressed, but only from a purely clinical perspective, not the emotional or social aspects. I don’t think gynaecologists know much about HIV and HIV specialists don’t talk about menopause.’ (MariJo Vázquez, Spain)

For women and girls of all ages, better integration of HIV and SRHR services is important and needs to happen.

7 ECHO, the Evidence for Contraceptive Options and HIV Outcomes Trial Consortium, 2019, HIV incidence among women using intramuscular depot medroxyprogesterone acetate, a copper intrauterine device, or a levonorgestrel implant for contraception: a randomised, multicentre, open-label trial. The Lancet, 2019; 394: 303–13. [https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(19\)31288-7.pdf](https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(19)31288-7.pdf)

8 Salamander Trust and partners, 2019, WOMEN ENGAGE! LIVING WITH HIV AND CERVICAL CANCER: A guide to our involvement in its Prevention, Screening and Early Diagnosis, Treatment and Research, Second edition, November 2019. <https://salamandertrust.net/project/women-living-with-hiv-and-cervical-cancer/>

4. Contraception is central to gender equality

Women's ability to decide if and when to have children, and access to appropriate and affordable contraception, is central to gender equality. Yet the options available are often limited or unaffordable.

'It's not like contraceptive is readily available. We find in Kenya we have limited choices. There are so many women in the world, half the population, but we have limited choices of contraception. [...] And if there were more choices, there would be more power given to women.'

(Lucy Wanjiku Njenga, Kenya)

Inaccurate information about contraception is widespread, and women's autonomy to decide often limited.

'You find that women don't even have the full choice, their spouses have a say in it, the myths and misconceptions have a say in it, and the woman at the end of the day is confused.' **(Lucy Wanjiku Njenga)**

Young women may face particularly judgemental attitudes when trying to act responsibly by accessing contraception.

'In addition to that, the young mothers who have to get family planning, they tend to get chased away because of their age, or they tend always to be judged. So these are some of the issues these young women face. Most of them they even fear to go back to the health centres because of their brush with the health workers, so we have to break the space between the young people and the health workers, so that they understand. Most of them are sexually active, and they have not to be denied their right to SRHR. We make them

realise they have a right, and we bring the health workers on board and tell them about the rights of young people.'
(Resty Nalwanga, Uganda)

Even when contraceptives are available, the cost and the limited options available may mean women have to make very difficult choices.

'I have an implant, a 3 year contraceptive, and when I went I was thinking I would pay around \$5, but it turned out it was around \$20, and I had not budgeted for it, and I was thinking 'this is not cheap' – it's around 2000 KSH, and if I'm a woman from the community I come from, Dandora, 2000 is equivalent to house rent, so will you be paying house rent or will you be taking contraceptive? Or sometimes you go to the facility and the choices are only three – injection, IUD or pills, and you are told you can only choose from these three, and then you may say you want the IUD and you are told, we don't have it at the moment but you can come next week. So imagine that you come back next week and you are already pregnant – it beats the whole purpose'
(Lucy Wanjiku Njenga, Kenya)

For women living with HIV, contraceptive use may be a condition of access to ARVs.

'I remember towards the last days before WHO approved that DTG was safe for women, there was this conversation when doctors would tell their clients to prove that they were on effective contraception, and for them 'effective contraception' meant having your womb removed or your tubes tied, those were the two 'effective measures' to them, which is very weird because we have many other forms of contraception. This also brought about things we have

already fought, like coerced sterilisation that happened in the past, and Kenya being one of the countries where that happened.’ (Lucy Wanjiku Njenga, Kenya)

Lucy Wanjiku Njenga sums up the issues women and girls face around contraception.

‘So because of all the myths and misconceptions around contraceptives, men and partners of these women are not eager to have the contraceptive in place for their partners, and if women go behind their backs to have it, it brings out violence. [...] I know many women who are on contraceptives but it’s a secret, and this should not be the case. This is a right for every woman to have, and we still have a lot of gaps that we need to fill to ensure women can access contraceptives when they need it, how they want it, and for how long they want it, and as cheaply as they can, without having to worry what will their spouse say, or how will they be treated at the facility. If you are a 15 year old girl and you are going to the facility, are you able to access contraceptives, or will you be chased and told you are too young to even be thinking about sex?’ (Lucy Wanjiku Njenga, Kenya)

5. Pregnancy-related services should be friendly and welcoming, and focus on the woman not just the baby

Not only are women not trusted to make their own decisions: reproductive health services often fail to focus on the woman herself and there is still considerable institutional violence.

‘A lot of the time when it comes to pregnancy, the focus is on the baby, and

not on the woman, so we keep the focus on the woman herself first.’

(Longret Kwardem, UK)

Mistreatment, disrespectful attitudes and obstetric violence from reproductive health service providers are in direct contravention of human rights and the WHO Guideline. Yet coerced and forced abortion and sterilisation is still a reality for women living with HIV in Malaysia, including among sex workers and women who use drugs.

‘If an HIV-positive woman is trying to get pregnant or she is pregnant, she will be subjected to all kinds of pressure. She will be asked to go for abortion, or if it’s too late for abortion, upon delivery she will be asked to go for sterilisation. When I accompanied [a woman] to hospital, she cried each time at her obstetrics and gynaecology appointment because she was pressured, and told, “OK, after delivery you should have your tubes tied”, and when she said “No, no, I don’t want this, I still want to have babies”, they said, “Oh so you are trying to contribute to the HIV statistic?”’

(Rahayu Rahmat, Malaysia)

Services should be there to support women, not to coerce them.

‘Regardless of being women who are HIV positive or not, they should be allowed to have babies, and not be subjected to the pressure of being forced to go for an abortion or sterilisation.’ (Rahayu Rahmat, Malaysia)

This is particularly disturbing, since Malaysia is one of the few countries in the world officially recognised to have ‘eliminated’ vertical transmission of HIV (WHO, 2018⁹). But at what cost to the women concerned?

⁹ WHO, 2018, Malaysia eliminates mother-to-child transmission of HIV and syphilis. <https://www.who.int/westernpacific/news/detail/08-10-2018-malaysia-eliminates-mother-to-child-transmission-of-hiv-and-syphilis>

6. Denial of services and stock-outs continue and must be addressed

The denial of sexual and reproductive health services for girls and young women have far-reaching consequences. Adolescent girls and young women are often denied access to sexual and reproductive health services and information, yet they are disproportionately affected by HIV. In eastern and southern Africa in 2017, 79% of those who acquired HIV among 10–19-year-olds were girls and young women (UNAIDS, 2019¹⁰).

Contributors in Uganda and Kenya describe the difficulties for girls and young women in accessing family planning, maternity, and other sexual and reproductive health services, and in staying engaged in care, particularly after giving birth. These are also concerns for women living with HIV of all ages and diversities of experience, including sex workers, women who use drugs, and others, as expressed by contributors from the UK, Spain, Puerto Rico and Malaysia.

Medication shortages, lack of reagents, and worsening vertical transmission rates are all a concern for The WHAVE contributor Mariana Iacono of Argentina

'In Argentina, the situation for people with HIV really was very bad because there was a shortage of medication which was worse than any other time in the last 15 years. It was so bad we had to take to the streets and mobilise and reconnect with all civil society organisations [...]. We also have to continue to work to eliminate vertical transmission – the latest national report for Argentina shows that there has been an increase in vertical transmission.'
(Mariana Iacono, Argentina)

These shortages and stock-outs must be addressed, and women and girls in all diversity and of all ages must be able to access services. Gender equality and holistic and integrated approaches that are based on human rights are vital to enable this to happen.

7. Addressing violence against women and girls is fundamental to achieving sexual and reproductive health and rights

Violence against women profoundly affects women's sexual and reproductive health and rights. Contributors talk about violence against women and girls in many diverse settings, including in relationships, families and communities, as well as in health services. The links between violence and gender inequality, violence experienced in relation to contraceptive access and use, obstetric violence, and institutional violence in health care settings are all mentioned in previous sections.

Latin America has high rates of femicide, as well as other forms of violence against women. A recent 7-country study by and for women living with HIV documents the widespread and severe forms and experiences of violence of 955 women, with a particular focus on Indigenous, Afro-descendent and young women in the region¹¹. Recognition of the links between HIV, sexual and reproductive health and rights, gender equality and violence against women have led ICW Latina (the International Community of Women living with HIV) to link their campaigns to the wider women's movement, rather than keep their demands siloed in HIV.

10 UNAIDS, 2019, Women and HIV: A spotlight on adolescent girls and young women. https://www.unaids.org/sites/default/files/media_asset/2019_women-and-hiv_en.pdf

11 Luciano D, Negrete M, Vázquez M, Hale F, Salas J, Álvarez-Rudín M, Arends M, Cano A, Iacono M, Sánchez M, Cabezas M, Chete B, Flores G, García F, Ferreira M, López L, Ramírez B, Soto M (2019). Estudio Regional sobre Violencia y Mujeres con VIH en América Latina. ICW Latina, Hivos, Development Connections y Salamander Trust <https://salamandertrust.net/project/estudioregional/>

'Latin America is the region that has the highest rate of violence and femicide in the world towards women. So in this framework, both in Argentina and in ICW Latina, we have a strong feminist position, strong street mobilisations, and we work beyond HIV to incorporate other agendas. Our work focuses on HIV, and we join with the entire feminist movement throughout Latin America to work on other agendas.. [...] There is still so much to do, and many organisations and sectors which work on violence but have not made the connection between HIV and violence, and that is a priority.'
(Mariana Iacono, Argentina)

8. Sexual and reproductive healthcare must be rights-based, which includes a focus on pleasure

The WHO Consolidated Guidelines states: 'Women living with HIV in all their diversity should be supported in their choice to have safe and fulfilling sexual relationships and sexual pleasure as they age. Women living with HIV who choose not to be sexually active should also be supported in their choice. (GPS A.2)'

Yet women's sexual pleasure is often a taboo subject.

'Something very common is that, when a person acquires HIV they do not have sexual intercourse for a long time, not only because they are managing their diagnosis, but because they are often very afraid of transmitting HIV to another person. And there are other things tied up in that that are not necessarily related to HIV, but are related to violence, patriarchy, homophobia, taboos around talking about sexuality. And also because women's sexuality is seen as something that is not for our pleasure, but about

men's pleasure, or reproduction.'
(L'Orangelis Thomas, Puerto Rico)

This is particularly the case for women living with HIV.

'Many times our sexuality is about the degree to which we protect other people and very rarely from ourselves, about our pleasure and about our enjoyment and comfort.' **(L'Orangelis Thomas, Puerto Rico)**

In health settings, this translates into questions from health providers that are often judgemental and usually focused on how we as women living with HIV protect others. They are very rarely about women's pleasure, enjoyment and comfort.

'If there were more places or more interventions that focused on the pleasure of people living with HIV, maybe this could significantly transform the way we handle our diagnosis and our sexuality.'
(L'Orangelis Thomas, Puerto Rico).

U=U has the potential to transform feelings about sexual relationships among people living with HIV. However, The WHAVE contributors are concerned about the potentially stigmatising effects of U=U messaging on those who are not undetectable. This could disproportionately impact women, including women of colour and trans women.

'I just wouldn't want anyone who is still detectable to feel they cannot also go out and date, especially as the people who are more likely to be detectable are women living with HIV, especially black and brown women living in the global South, actually particularly trans women rather than cis women [...] The framing of this message just needs to be really considered to make sure we don't marginalise women especially who are already marginalised enough as is it.'
(Bakita Kasadha, UK)

9. Women living with HIV should be supported and resourced to provide accurate, up-to-date information on sexual and reproductive health and rights to other women and girls

There is a lack of emphasis on, or funding for, peer support since the advent of ARVs. This undermines the ability of women to provide accurate information to each other. However, the WHAVE contributors emphasise how much information provided through peer support is critical to women's effective engagement. Participation in peer support and community groups enables women living with HIV to access accurate information about sexual and reproductive health and rights and a range of other related issues. Much of this work involves the need to counteract out-of-date, confusing or stigmatising messaging from health professionals.

'Among communities, people like me and fellow advocates and activists need to keep ourselves informed. [...] I compare with the time before ARVs in Zimbabwe, and when people got sick we had this system of supporting each other particularly with information, and information is the power that made a lot of us live.' (Martha Tholanah, Zimbabwe)

Some contributors suggested that while the kind of vital information on sexual and reproductive health and rights included in the WHO Consolidated Guideline is often not available to frontline health workers, women living with HIV are generally well-informed about issues affecting them, thanks to ongoing efforts by women living with HIV to share information amongst themselves.

'Whenever there's a convention or a seminar it's always the professionals who attend, but the information is not being channelled to the front line, and as I can see it is not being practised. Most of our women activists they knew about

[the WHO Consolidated Guideline]. We always impart this information among our community. But if it's just only us [who know], it doesn't make a difference.' (Rahayu Rahmat, Malaysia)

10. Women living with HIV should also be supported and resourced to provide direct support to women and girls living with HIV who are let down by sexual and reproductive health services

It is women living with HIV in communities who provide care for women and girls unable to access timely and effective sexual and reproductive health services. Yet they often have to offer this critical safety net with little or no funding.

For example, The WHAVE contributor Resty Nalwanga set up Tendo's World, a grassroots organisation in Uganda, which empowers young women, those who are pregnant, and do not know where to go. She also teaches girls how to make reusable sanitary pads to enable them to stay in school.

In Malaysia, Rahayu Rahmat founded Sinar Sofia, an organisation providing a safe haven and support for women living with HIV, sex workers and women who use drugs.

MariJo Vázquez promotes women-centred approaches in her training work with medical and nursing students in Spain, addressing the power imbalances between health care professionals and patients that lead to health providers thinking they know best about their patients' needs and wants.

In the UK, 4M Mentor Mothers Network provides vital perinatal peer support to women living with HIV, before, during and after pregnancy.

Further examples of the extraordinarily important efforts by women living with HIV in their communities, countries and globally to address and claim their sexual and reproductive health and rights, include the advocacy by women in

Kenya to lift the ban on Dolutegravir for women of reproductive age, advocacy by women living with HIV in Argentina for a new HIV law, efforts by women living with HIV in Zimbabwe to improve access to cervical cancer screening and treatment, work to address stigma, violence and abuse against women living with HIV and raise awareness of damaging gender norms and policies in Cameroon, and work with communities and health care providers to increase access

of young women to contraceptives and sexual health services.

In all these cases, women living with HIV are spending their time, energy and often their own money doing something that is not being offered elsewhere, to plug gaps that they have personally experienced and to facilitate access to sexual and reproductive health and rights for women and girls living with HIV.

What changes The WHAVE contributors want

- **Full dissemination and implementation of the WHO Consolidated Guideline on sexual and reproductive health and rights of women living with HIV. *Although this was published in 2017 many healthcare policy-makers and providers globally are still unaware of its existence.***

The Guideline clearly recommends the following elements of an effective, ethical and sustainable response to women's sexual and reproductive health, rights and well-being. Yet all the podcast contributors aired their ongoing challenges in these areas:

- **Meaningful involvement** of women and girls living with HIV in decision-making related to sexual and reproductive health policy, programming and service delivery. Aligned with this,
- **Recognition of the expertise** of women living with HIV, and trust in women and girls in all our diversities, including those of us living with HIV, to make decisions about our sexual and reproductive health, rights and lives.
- **Safe, friendly and non-judgemental services**, an end to institutional violence of all forms, and an end to forced and coerced abortion and sterilisation everywhere.
- **Better support and resourcing** for women living with HIV and their organisations who do vital work to ensure sexual and reproductive health and rights for women and girls.
- **Support from funders for unexpected and/or emergency events** (eg the response to the DTG restrictions, or the current COVID-19 crisis), and for work carried out by women living with HIV to respond to felt and pressing needs and priorities.

Post-script: As COVID-19 overwhelms us all globally, it is all the more important that women living with HIV are meaningfully involved in the all decisions made around our SRHR. We are learning daily of increased intimate partner violence facing women in communities in lock down, of limited access to contraceptive goods and services, including condoms, of reduced access to abortion (with concomitant future increases in maternal morbidity and mortality). ARV stockouts will also no doubt ensue. We are also yet to learn about the effects of COVID-19 on women living with HIV across the life span, including during pregnancy, as well as the effects on the baby in-utero or post-partum. One thing that more than three decades of global community HIV activism has taught us, as well as the women's rights movement, is that there will be no ethical, effective, sustainable response without meaningful community engagement to uphold our SRHR.¹²

¹² Htun, M., & Weldon, S. 2012, The Civic Origins of Progressive Policy Change: Combating Violence against Women in Global Perspective, 1975–2005. *American Political Science Review*, 106(3), 548-569. doi:10.1017/S0003055412000226

In addition to the material already cited, here is some additional suggested reading:

ALIV[H]E in Action: Key examples of the Action Linking Initiatives on Violence Against Women and HIV Everywhere (ALIV[H]E) Framework (2019) https://salamandertrust.net/wp-content/uploads/2017/11/ALIVHE_in_Action_FINAL_Salamander_et_al_March2019.pdf

The call to action for SRHR-HIV linkages (Amsterdam AIDS 2018) <https://apps.who.int/iris/bitstream/handle/10665/273148/WHO-RHR-18.13-eng.pdf?ua=1>

Community-led responses: https://www.unaids.org/sites/default/files/media_asset/world-aids-day-2019-communities-make-the-difference_en.pdf

Global treatment access review: <https://www.hhrjournal.org/2017/12/in-womens-eyes-key-barriers-to-womens-access-to-hiv-treatment-and-a-rights-based-approach-to-their-sustained-well-being/>

Zero-discrimination in healthcare: https://www.unaids.org/sites/default/files/media_asset/2019_Zero-Discrimination_Brochure_en.pdf

Time to realise our sexual and reproductive health and rights. Anam F, Chung C, Dilmitis S, Kenkem C, Matheson-Omondi R, Moroz S et al. The Lancet Global Health. 2018. [https://doi.org/10.1016/S2214-109X\(18\)30352-8](https://doi.org/10.1016/S2214-109X(18)30352-8)

WHO launch of the Checklist for implementation of the WHO 2017 Guideline on the SRHR of women living with HIV. BMJ Sexual & Reproductive Health blog BMJ Sexual & Reproductive Health blog. 2019: <https://blogs.bmj.com/bmjshr/2019/07/29/who-launch-of-the-checklist/>

WHO 2019, Translating Community Research Into Global Policy Reform For National Action: A Checklist For Community Engagement To Implement The WHO Consolidated Guideline On The Sexual And Reproductive Health And Rights Of Women Living With HIV. <https://apps.who.int/iris/bitstream/handle/10665/325776/9789241515627-eng.pdf?ua=1>

The WHAVE, Women living with HIV, Advocates, Voice, Empowered. Salamander Trust 2019 - 2020

<https://podcasts.apple.com/gb/podcast/salamander-trust-the-whave-podcasts/id1453316451>

The WHAVE is a series of podcasts by and for women living with HIV, talking about our sexual and reproductive health and rights.

- In English: The WHAVE <https://salamandertrust.net/project/podcasts/>
- In Spanish: La Ola <https://salamandertrust.net/project/salamander-trust-podcasts-en-espanol/>
- In French: La Vague <https://salamandertrust.net/project/salamander-trust-podcasts-en-francais/>

Salamander Trust (2019-2020)

- #1 (English) Lucy Wanjiku Njenga, Kenya. Why restrict access to the antiretroviral drug Dolutegravir for women of reproductive age?
- #2 (French) Francine Nghanhale, Cameroon. The importance of peer support for women living with HIV in the Democratic Republic of Congo.
- #3 (Spanish) L'Orangelis Thomas, Puerto Rico. Women living with HIV, sexual health and pleasure.
- #4 (Spanish) MariJo Vázquez, Spain. Learning from women living with HIV: training for medical students.
- #5 (English) Resty Nalwanga, Uganda. Peer mentoring for young mothers living with HIV.
- #6 (English) Martha Tholanah, Zimbabwe. 'Why am I even being screened if I have no recourse if I need further treatment?' Cervical cancer and women living with HIV.
- #7 (English) Bakita Kasadha, UK. Research with us, not about us: meaningful involvement of people living with HIV.
- #8 (English) Bakita Kasadha, UK. Undetectable = Untransmittable: transforming the way we feel about ourselves as women living with HIV.
- #9 (English) Lucy Wanjiku Njenga, Kenya. A success story for collective campaigning: overturning the 'restriction' on Dolutegravir for women of reproductive age.
- #10 (English) Rahayu Rahmat, Malaysia. Women living with HIV, sex workers and women who use drugs: challenges in accessing sexual and reproductive health and rights.
- #11 (Spanish) Mariana Iacono, Argentina. Women living with HIV in Argentina, our priorities.
- #12 (English) Longret Kwardem, UK. 4M Mentor Mothers: where is the funding?
- #13 (English) Longret Kwardem, UK. Peer research and meaningful involvement of women living with HIV, an ongoing challenge.

BACKGROUND ON THIS PAPER

Podcasts are increasingly popular, can be produced and edited with basic equipment, and are accessible to people around the world with a smartphone or computer. In each episode of Series 1 of The WHAVE, a contributor tells a story of advocacy, organising, or peer support work by and for women living with HIV. In this way, contributors from Africa, Asia, Latin America and Europe share their perspectives, expertise and current priorities, in episodes in English, French and Spanish.

Some issues come up time and again in different episodes. These are now brought together in this collection of thematic papers to support the dissemination of key messages arising from The WHAVE podcast:

- **Paper #1:** Funding for organisations of women living with HIV
- **Paper #2:** Access to sexual and reproductive health and rights and HIV services for women and girls living with HIV
- **Paper #3:** Equal partners: recognising the expertise of women living with HIV

We expect these papers to be of interest to relevant teams in UNAIDS, WHO and other technical partners, Ministries of Health, NGOs, networks and associations of people living with HIV, and others involved in addressing HIV and/or sexual and reproductive health and rights of women and girls living with HIV.

A fourth paper is for women living with HIV who are interested in recording a podcast:

- **Paper #4:** A how-to guide to making a podcast for women living with HIV

To access all the briefs, please click [here](#).

Suggested Citation: Salamander Trust (2020) The WHAVE Podcast Paper #2. Access to sexual and reproductive health and rights for women and girls living with HIV

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