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

Web annex: Community-led strategies for implementation

Consolidated guideline on sexual and reproductive health and rights of women living with HIV. Web Annex: Community-led strategies for implementation.*

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* The full guideline is available at:
www.who.int/reproductivehealth/publications/gender_rights/srhr-women-hiv/en/

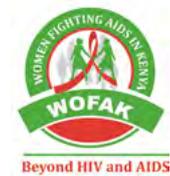
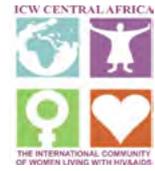


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Consolidated guideline on sexual and reproductive health and rights of women living with HIV

Web annex: Community-led strategies for implementation



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Background information for this publication was researched by **Sophie Dilmitis** (Salamander Trust Associate) and **Alice Welbourn** (Salamander Trust Founder and Director). The work of this report was overseen by Salamander Trust with contribution from **Jaya Shreedhar**, independent consultant, and the women whose work has contributed so richly to this publication.

The publication is dedicated to all the inspirational women living with HIV in all their diversity – both living and past. These women have paved the way for those who continue to act as bold defenders of sexual and reproductive health and rights.

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The Checklist and the WHO Consolidated guideline it supports can be found on the WHO website: <https://www.who.int/reproductivehealth/topics/en/>

Abbreviations and acronyms

ART	Antiretroviral therapy
ARV(s)	Antiretroviral(s)
CCM	Country Coordinating Mechanism
CEDAW	Convention on the Elimination of all Discrimination Against Women
EWNA	Eurasian Women's Network on AIDS
FGD	Focus group discussion
Global Fund	Global Fund to Fight AIDS, TB and Malaria.
GDG	Guidelines Development Group
GVPS	Global Values and Preferences Survey
GBV	Gender-based violence
HIV	Human immunodeficiency virus
ICW	International Community of Women living with HIV/AIDS
IPV	Intimate partner violence
LGBT	Lesbian, gay, bisexual, transgender
LGBTQIA+	Lesbian, gay, bisexual, transgender, queer/questioning, intersex, asexual. The + stands for sexualities, sexes, and genders that are not captured by the letters.
MIWA	Meaningful involvement of women living with HIV
NACC	National AIDS Control Council
NGO	Non-governmental organization
PEPFAR	President's Emergency Plan for AIDS Relief
STI	Sexually transmitted infection
SRH	Sexual and reproductive health
SRHR	Sexual and reproductive health and rights
PR	Principal Recipient (of Global Fund grants)
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on AIDS
VAWG	Violence against women and girls
WGNRR	Women's Global Network for Reproductive Rights
WHO	World Health Organization
WOFAK	Women Fighting AIDS in Kenya

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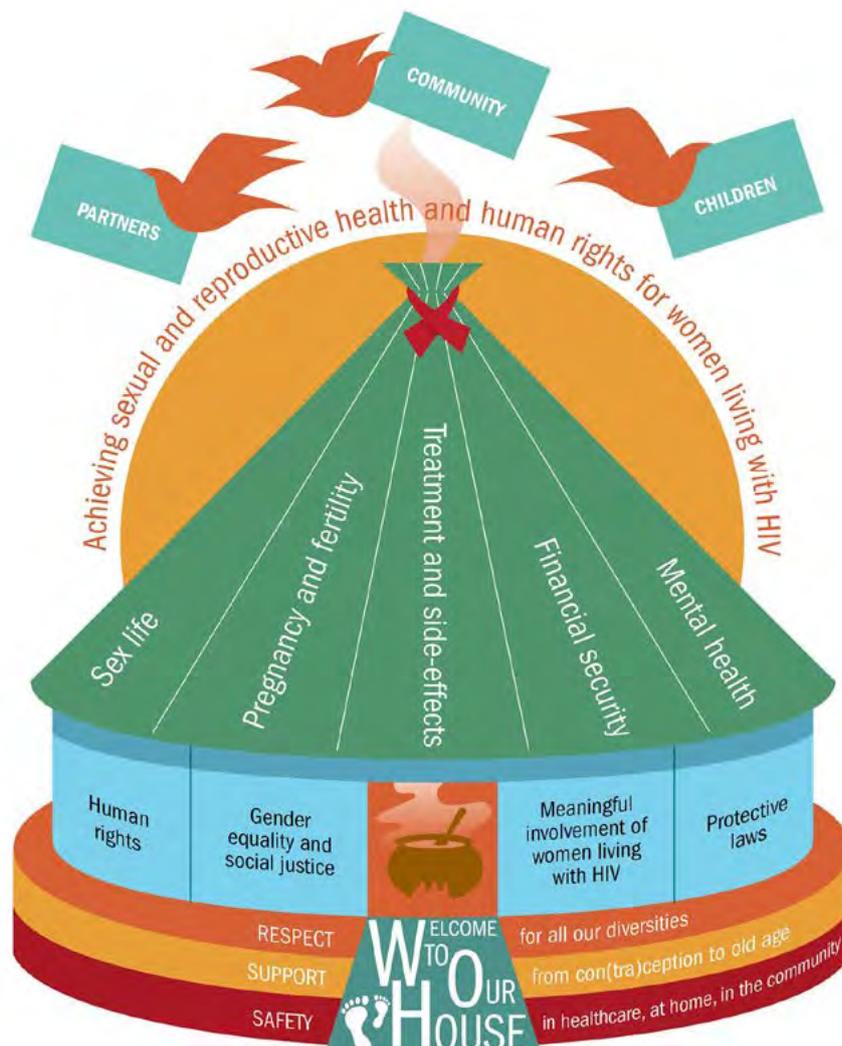
1. Foreword



Celebrating our circus tent: reaching high for our rights

Alice Welbourn

In 2015 we submitted an article to the WHO Bulletin describing the participatory process that informed the Global Values and Preferences Survey (GVPS). We were surprised at a critical comment made by one of the peer reviewers about the house image which describes our survey results. S/he asked, “What’s with the circus tent?” We didn’t know whether to laugh or to cry when we read this. On the one hand, we felt deep dismay at such a scathing and disparaging remark, which seemed to dismiss with one blow all the huge body of personal knowledge that 945 women globally had contributed to the survey. On the other hand, we laughed because the house image does indeed look a bit like a circus tent, which could stand to celebrate our deep resilience and our rich and diverse global experiences, insights and contributions to an effective, ethical and sustainable response.



So, a circus tent it is. This document celebrates the wealth of fierce activism around our SRHR led by inspiring women living with HIV who are cracking the whip for the changes we want, which are long overdue. This work is characterized by being poorly funded, unrecognized and rarely documented in peer-reviewed journals. The women involved are constantly juggling many complex and challenging issues in their lives, as BAKITA:KK has described in her formidable poem, Numbers Game¹. Yet it is ground-breaking, vibrant and world-class work, which all policy-makers and programme coordinators would be wise to listen to, engage with and learn from.

What other circus tents can look like

Policy-makers who work on other complex issues, such as smoking, obesity and excessive alcohol use (all of which also have a gender dimension), recognize the importance of not just saying “*don’t*”. They recognize the value of engaging with their clients in order to understand why, when and how they feel able to change or not. This creates trust between the healthcare provider and client, which enables a shared understanding around the stressors and/or other factors that prompt the activity which the healthcare provider is seeking to change. They recognise the importance of not only understanding what they want the individual to do, but also of understanding how and why the client smokes, eats or drinks to excess². If the client wants to change, this shared understanding supports the client to reduce the stressors or their effects, and enables change to happen. Healthcare providers also understand that each client is not just an individual actor but is deeply embedded in a web of social and systems structures, often quite traumatic, which can make it extremely challenging for them to change their behaviour. How a healthcare provider approaches and engages with a client plays a significant role in health outcomes.

In the lions’ den

However, when it comes to activities conducted by people whom society condemns, such as women who use drugs, there is far less understanding or support for the clients’ own feelings, perspectives and challenges. Instead, “*don’t*” is the only mantra promoted by many. Criminalization of such activities often makes this approach even more entrenched. So, it is hardly surprising that many programmes fail, since they only focus on the priorities of lawmakers and healthcare providers and negate or exclude the experiences, priorities and rights of those whose activities they want to change.

This is often the experience for women living with HIV. The women featured in this publication repeatedly describe how biomedical priorities have been paramount, whilst our lives, experiences, priorities and rights have been negated or ignored. As L’Orangelis Thomas explains: “Conversations on sexual practices between healthcare providers and women living with HIV usually start with a question ‘Are you having sex?’ And the next question is ‘Do you use protection?’ This is not much of an introduction and does not affirm our right to be having sex and to enjoy it or to question if our sex is consensual.”

Dorothy Onyango describes how women are “told not to have sex, not to have children, told to stick to ARVs” and how services are not confidential, rights-sensitive, or convenient. To make matters worse, Dorothy describes how in Kenya there is compulsory partner testing and notification, rendering women exposed to potential violence from partners and/or other community members, and possibly costing them their children, homes and jobs.

This must stop.

Walking the tightrope

What happens in healthcare settings affects and sometimes reinforces what happens in the home. As the GVPS shows, when women are diagnosed with HIV some may already be experiencing IPV, whilst for others this starts upon receiving their diagnosis. Policies like partner notification, lack of confidentiality in HIV clinics,

and women being told to use condoms are potentially highly dangerous for women. We walk a tightrope between being told what to do by healthcare providers and knowing that if we follow their directions it can make our lives much more dangerous. So many women wisely choose *not* to return to health centres rather than expose themselves to potential violence at home.

For many women this violence and the associated anxieties that accompany it are their day-to-day norm. It is often so ingrained that it doesn't get mentioned. As L'Orangelis puts it, "Seeing oneself solely as a source of 'infection' to others and living with this internalized negative view of the self is the reality for many young women living with HIV. It is often what the outside world mirrors back to us. Often, many of us experience guilt when we do experience sexual pleasure, yet, it is the most natural thing for human beings".

This is why it is especially important for health policies and practices to uphold rights-based, women-centred approaches in order to care, respect and support every client in their care.

Cecilia Chung describes how, "For the majority of transgender people living with HIV, a priority need is not HIV care, but care related to sexual transition, mental health and gender-affirmation. Despite assumptions made by health care providers, our number one priority is not our viral load and HIV care but, more importantly, it is feeling respected and treated with dignity and to have our gender affirmed. If transgender communities do not feel this, we are likely to drop out of care".

Fire-breathing policies

Policy-makers have much to reconsider here. Women and girls living with HIV, in all our diversity, have the right to informed choice regarding access to life-saving antiretroviral therapy (ART) and related care, respect and support. This is embedded in numerous human rights, including the rights to the highest attainable standard of health, to life, to privacy, to be free from discrimination, and to gender equality. Yet our right to bodily autonomy is constantly at risk. Practices which directly or indirectly affect our choices, such as how we are treated by healthcare providers, access to ARV treatment options or contraceptive choice, or a combination of these, undermine human rights and have grave consequences, not only for our mental and physical health but in every sphere of our lives^a.

The contributors explain how "90 90 90", "getting to zero" and other such blinkered slogans actually fuel the flames of the many complex challenges they face rather than ameliorate them. As Svitlana Moroz explains, "UN agencies continue to chant mantras like '90-90-90' with no acknowledgement of how this connects to the social determinants of health-seeking behaviour. Our challenge, as women living with HIV, is to convince society and those in power about the intersectionality of deprivation, violence and community health. We cannot stop HIV without sexual and reproductive health and rights and gender equality as a minimum starting point".

Cecilia comments, "current policies ... continue to disenfranchise some of the most marginalized communities such as immigrants, people of colour and the transgender communities".

L'Orangelis adds, "Our ability to protect others from HIV cannot and should not be the sole focus of the discussions at the clinic. Many of us face sexual violence and are forced to have sex, but gender perspectives and this sensitivity are yet to find their way into all health services".

^a Adapted from 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, 2019, Salamander Trust and partners, <https://salamandertrust.net/project/the-dolutegravir-debate/>

Building the big top

But there are also encouraging stories emerging from each contributor's experience, where different actors are joining hands, connecting and reaching for more. In so doing, healthcare providers and policy-makers are now, also, starting to realize that the meaningful involvement of women living with HIV in issues that deeply affect our lives is not only our intrinsic right, but also makes *all* our lives easier and leads to better health outcomes for all.

Dorothy described how in Kenya “previously there had been a lack of health staff training – but now they have welcomed the women advocates. Now advocates for this guideline are both the recipients and the providers of care. The healthcare providers in two counties offered us room in their offices, asking us to come and work with them from there. In Kenya women living with HIV are becoming members of community committees to address their SRHR, which are being set up for the 1st time”.

In the US, Cecilia explains, “We have created a participatory process led by the community for the community where we invite researchers to come talk to us to learn of our needs and our interests in what we would like researched about ourselves. And so far, it seems to work very well. We are changing some of the relationship dynamics between researchers and communities, as well as funders and the communities. More funders now are open to funding organizations that are led by transgender people for transgender people”.

In Ukraine, Svitlana and her team collected stories, explaining, “The coordinators gathered 40 stories from women living with HIV, which presented the diversity of experiences. Positive stories showed how health support enhanced the quality of some lives, while other stories described the far-reaching impact of stigma and discrimination experienced in the health care system”.

And in her work in Latin America and Southern Africa, L'Orangelis explains, “My effort is to focus on working with women living with HIV, rather than on public policy. Even when Sexual and Reproductive Health and Rights policy for women living with HIV is adopted by the country, it's crucial for women to compare what the policy entitles them to, against what they receive in the field and connect the policy to what women actually know or have, so that we can work towards ensuring that the policy gets implemented”.

There are many different ways to create the magic of the circus for us all, young and old alike, in all our diversity around the world. But circuses are often ephemeral – here today, gone the next. What we want is to build a lasting big top for us all, to uphold and protect all our safety and to ensure that the SRHR of us all are achieved, throughout our lives, with health workers as our advocates and allies not our foes. Just imagine what proper funding and strong political will could achieve by building on initiatives such as those described here.

Welcome to our circus tent. We hope you find the stories shared here as inspiring as we have. There is so much to learn inside.

2. Meaningful engagement with communities of women living with HIV

WHO's working definition of community engagement states that "Community engagement is a process of developing relationships, characterized by respect, trust and purpose, that enable stakeholders to work together to address health-related issues, including emergencies, and promote well-being to achieve positive health impact and outcomes".³

Stakeholders comprise multiple communities, including community members, patients, health workers, researchers and policy-makers. While many key partners in the health sector are systematically engaged and have formed strong collaborations in WHO's work, gaps do exist. Not all policies, programmes and services engage women in ways that take into account their own preferences, needs, and priorities in order to build trust and ensure that health outcomes are reached. This is particularly true for women who are vulnerable and part of key populations. All technical partners need to do more to strengthen partnerships, especially given the changing global health architecture.

The identity of the community in community engagement depends on the activity. Given the global impact of the WHO's work, the definition of community goes beyond geographical location. It refers to a group of people that share some common identity, interest, experience or challenge. Within communities there is diversity, and often the perspectives of the most marginalized are the hardest to acquire in community consultation processes.

Furthermore, community engagement is different from community involvement. Engagement implies a more active role and participation in the process, rather than communities being passive recipients of guidelines and interventions, involved in a fragmentary, tokenistic or non-meaningful way, and only involved when

convenient, and often only at the very end of the process.^{4,5,6} As articulated in [Working with Individuals, Families and Communities to Improve Maternal and Neonatal Health](#) (WHO, 2010), "the former promotes social support and has a goal of individual and community empowerment, rather than a focus on achieving a desired behaviour... The assumption is that knowledge is developed and obtained through a process of critical reflection and deliberation where new knowledge is linked to existing knowledge".⁷

Describing community engagement as 'meaningful' is a response to lacklustre attempts at involving community members. Meaningful community engagement refers to actively seek the participation of members of a community in the process of understanding and taking actions to improve their health.⁸ It is sometimes erroneously taken to mean enlisting community in implementing or supporting interventions that have

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"It is only fair to ensure that those who benefit from the Guideline be involved in its earliest stages of evolution to its subsequent development. It's up to us, as key stakeholders, to lead from the front to ensure effective implementation. That is, when the implementation of the guideline shall commence, it is only prudent that the local stakeholders are involved outright from the inception so as to put into action the input given during the formation."

– Dorothy Onyango, Chief Executive Officer, Women Fighting AIDS in Kenya (WOFAK)

already been developed without their involvement or input. It is an approach which recognizes community members as experts on the lived experience of issues challenging their health, and solicits that expertise when making decisions regarding identifying and combatting those issues.^{9, 10, 11}

Meaningful engagement, as is evident in Section 4 of this document, is planned, and done frequently, openly, and intentionally to give a community the opportunity to express their views in significant planning and decision-making procedures that affect their lives.¹⁰

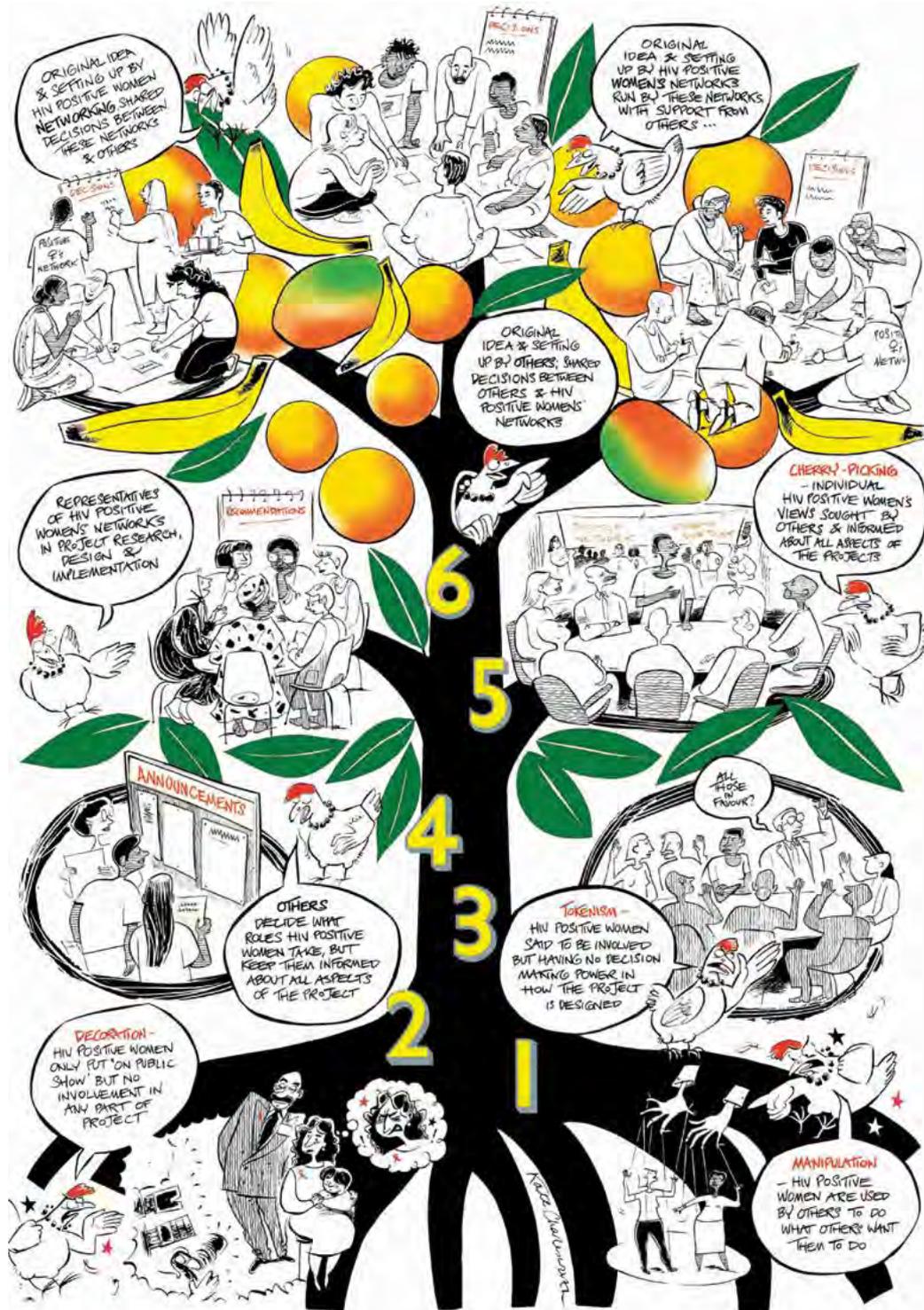
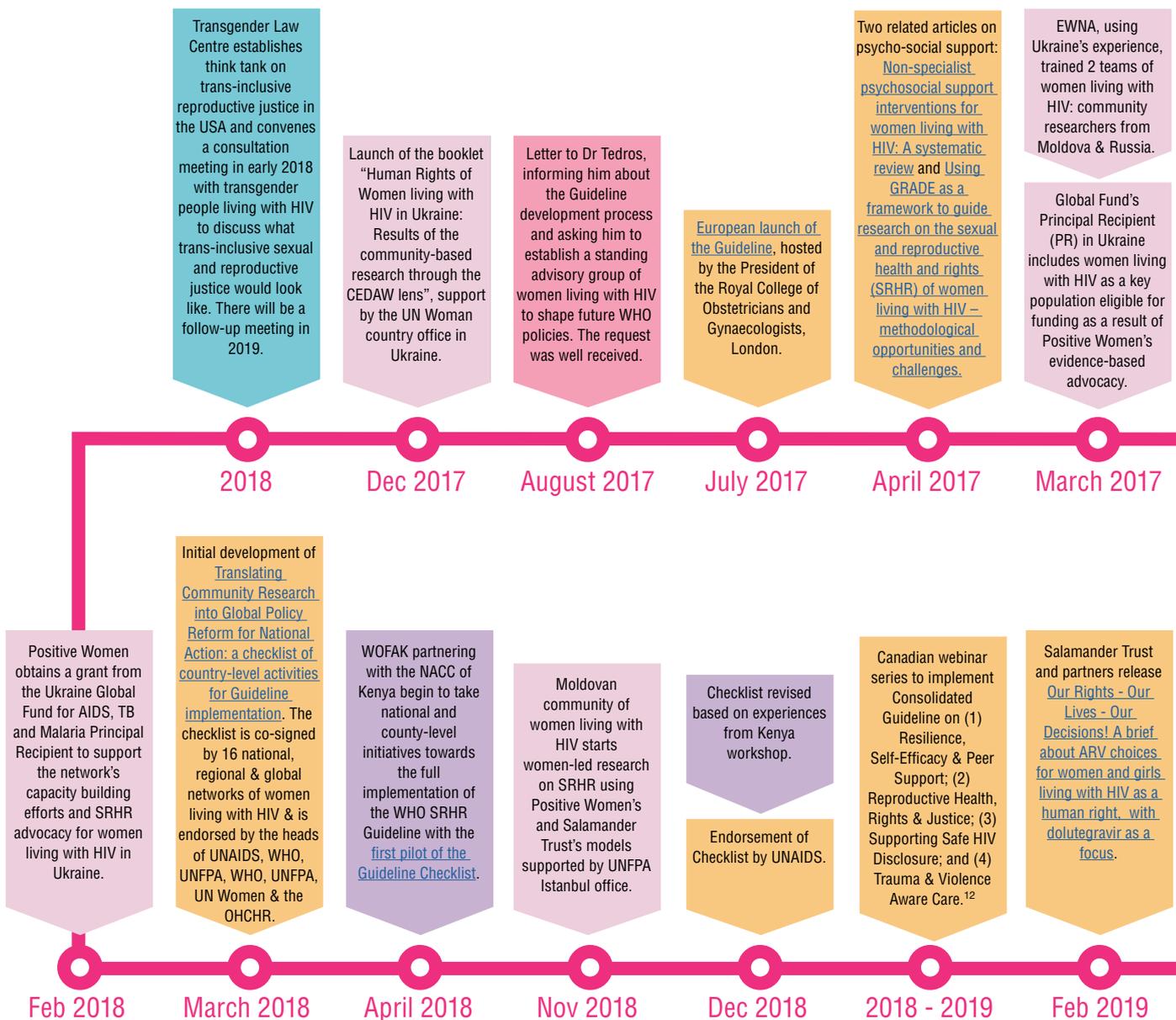
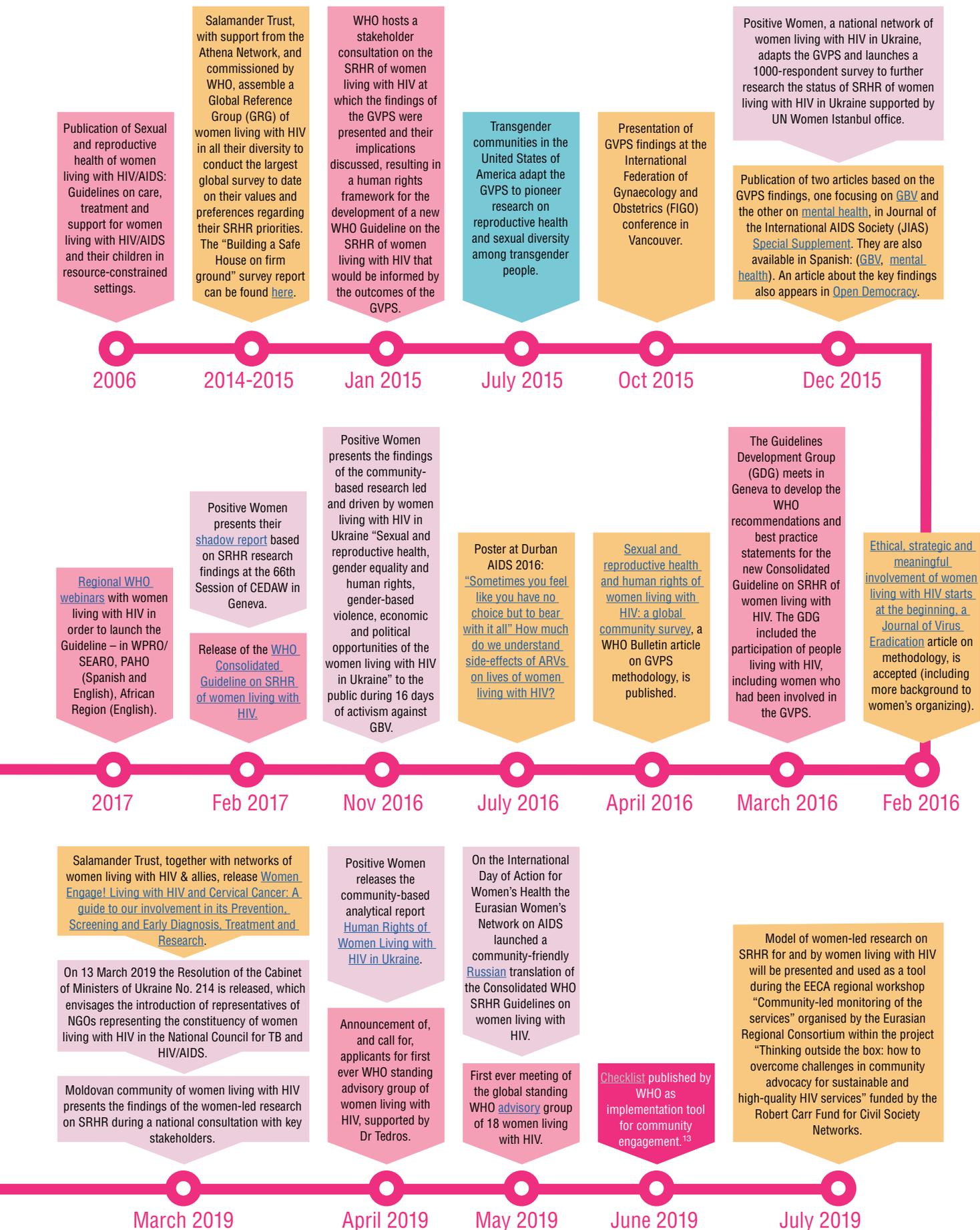


Illustration: Participation tree © International Community of Women with HIV/AIDS (ICW), 2004.⁴

3. A timeline of meaningful engagement: Women working towards enjoying their sexual and reproductive health and rights

This timeline sequences key events related to the highlighted case studies. It is not intended to be exhaustive. Parallel initiatives by other women living with HIV and their supporters have taken place in many other settings and countries.





4. Women leading the way: Communities in action

Women the world over have had to advocate to enjoy the same human rights as men, and any gains made need to be protected.

Women living with HIV have the right to full SRHR services alongside other women, irrespective of their HIV status, sexuality, identity, and across the life course. This includes, among others, access to prevention, care, treatment and support for cancers of the reproductive organs, and access to assisted reproductive technologies.

We define our sexual and reproductive rights as follows:

Sexual rights are the rights of all people to decide if, when, where, how and with whom we choose to have sexual experiences, including exploring our own bodies. We require information about how to protect ourselves and freely express our own sexuality and identity. Sexual rights include mutual respect, consent from both parties and equality.

Reproductive rights afford us the right to make informed and educated choices about starting a family or not. It is our right to choose if we would like to have children, how many we would like to have, and when and how to have them. Enshrined in this is our freedom and right to make our own educated decisions about contraception and/or birthing methods.

A. Advocating for the full implementation of the WHO SRHR Guideline (2017) with women living with HIV in Kenya: a win-win for women and service providers alike



“As gatekeepers of health services, health care providers have a right to guidance on gender and human rights to better understand and respond to the needs and priorities of women living with HIV. Their understanding and acceptance of the WHO SRHR Guideline is crucial to the way they are applied in the field.”

Dorothy Onyango, Chief Executive Officer, Women Fighting AIDS in Kenya (WOFAK)

About WOFAK

[WOFAK](#) is a non-governmental organization (NGO) in Kenya established in 1994 by a group of women, most of whom were living with HIV. The founding group created a forum for mutual support and empowerment at a time when women experienced extreme HIV-related stigma and discrimination. Since then, WOFAK has seen significant growth and contributes to the national HIV response. WOFAK also supports the provision of comprehensive care and support for women, youth and children living with and affected by HIV.

My inspiration

If living with HIV for over 25 years has taught me anything, it is that the quality of our lives is determined by our sense of self-worth. WOFAK’s work, since inception, has centred on inspiring self-respect and building emotional strength and coping skills among women living with HIV. Even in the early stages of our work it became clear that to reduce HIV-related discrimination we needed to support men and opinion leaders to recognize women living with HIV as citizens of value. Today that includes anyone who has influence over policy that improves the quality of our lives as women living with HIV, young people, children and older people.

Our context

In Kenya, access to information has had a positive impact on HIV-related stigma, yet HIV-related prejudice resurfaces at critical points in our lives. This happens when we seek support to conceive and are told not to have a child; when we seek counselling on sexual health and are told not to have sex but instead to maintain our antiretrovirals; when we are denied the assurance of services that are confidential, rights-sensitive and convenient; and, most of all, when we face different forms of violence in our homes – often so ingrained in our lives that it is dismissed as the norm for women and girls. The challenges of living with HIV are compounded by all these constraints, which impede the realisation of our right to enjoy our sexual and reproductive health. Additional layers of restrictions cripple women who choose to express a different gender orientation or identity, including those who are lesbian, gay, bisexual, transgender or sex workers.

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We face different forms of violence in our homes, yet often this is so ingrained in our lives that it is dismissed as the norm for women and girls.

Moving our agenda forward

When the 2017 WHO Consolidated Guideline on the SRHR of women living with HIV was launched, I was excited. I knew that despite it incorporating our concerns, the Guideline could do little if it remained only on paper. It was then that WOFAK learned of the Generic Checklist of actions developed by the Salamander Trust. We seized the opportunity when UNAIDS offered to support us to pilot the Checklist in Kenya. Twenty-five women living with HIV from high-burden counties in Kenya came together in Nairobi in April 2018.

This process supported us to advocate the full implementation of the Guideline in Kenya. It was timely, as we were in the process of updating our own national SRHR Guideline for women living with HIV. We strategically invited the Ministry's Division of Reproductive Health to our workshop.

WOFAK and the Salamander Trust jointly worked through the Checklist to ensure that women who participated had a solid understanding of what is in the Guideline. We developed a statement which included recommendations to the Ministry of Health and the National AIDS Control Council (NACC):

- Review the existing national Guidelines on SRHR to identify gaps in service provision.
- Align all Kenyan HIV policies and strategies with the recommendations and good practice statements outlined in the Consolidated Guideline.
- Involve women living with HIV to help shape policies and programmes that would enable the full implementation of the Guideline.
- Review prevailing attitudes among healthcare providers.

“

We work within the federal structure in Kenya which is made up of forty-seven county governments under a national government. Counties receive about 15% of the country's revenue for development and health and they decide on programmatic priorities and allocations. Established technical working groups conduct activities to support the sectors within that county. In addition to this, various health programs at the county level are supported by additional donors. As far as women living with HIV are concerned, it is counties who take the responsibility to work with us at the community level.

The Checklist enabled us to assess the conceptual and practical gaps in the existing services for women living with HIV. Operating from this informed position empowered us to negotiate policy that supports and promotes our rights to sexual and reproductive health services.

Soon after the workshop we began preparations to take the Checklist to the counties. Of the 47 counties in Kenya, six are most in need of maternal, newborn and adolescent health services. These include Marsabit, Wajir, Mandera, Lamu, Isiolo and Migori. WOFAK partnered with the NACC, who linked us to key networks of women in the three counties that were identified as a starting point (Lamu, Isiolo and Migori), given the available budget. Together with NACC field coordinators, we identified 10 women living with HIV activists from each county who had influence with their local authorities and had established relationships with their county governments.

Women from each county directed the advocacy, given that each county presented its own challenges. For instance, in regions that practise a certain faith we could not talk openly about HIV, so our entry point was to work with a few women who were open about their HIV status.

By December 2018, we had taken women through the Checklist in three counties (Lamu, Isiolo and Migori). WOFAK also shared the WHO Guideline with the county networks of women living with HIV, and many requested that the Guideline be translated into Swahili and additional local languages. Healthcare providers are key to women living with HIV being able to enjoy our SRHR. The reality is that in the three counties we

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In other counties, issues around testing the partners of people living with HIV are a huge concern, given that PEPFAR (a major funder) insists on partner testing and government notification. In such counties, people hesitate to seek healthcare due to the fear of their HIV status being disclosed.

On understanding the recommendations in the Guideline, a number of them expressed huge disappointment and now know the gap between what they are receiving and what they should be accessing in terms of treatment and services related to their sexual and reproductive health. They had not been aware that they had the right to seek information from healthcare providers. They said, “Now that we know, we feel like we have more voice to question health personnel and let them know that as women living with HIV, we have a stake in what services are given to us”.

”

found that community workers did not have any information on how best to work with women living with HIV. From the outset, the Ministry of Health, the NACC and key NGO partners participated in the workshops. As gatekeepers of the health services, their understanding and acceptance of the Guideline is crucial to the way it is applied in our communities.

Healthcare providers in the counties were exceedingly receptive and grateful for the information that they received through engaging with us. In Migori and Isiolo, where WOFAK does not have a presence, they were happy to offer us a desk so that we could work as a team. This gesture sprang from their realisation that having a representative from the community would make a difference. In a centre in Lamu, the health provider said that prior to our arrival they had no information on how to handle issues related to sexual and reproductive health, but were now better equipped to implement key recommendations in the Guideline.

Service providers and the Ministry of Health have for too long been missing from our advocacy. It is easy to find fault, but they were working according to the policies that directed them. A key lesson learned is that we have to work together to influence different levels: from policy, to insisting on health services that are sensitive to and respond to the SRHR of women living with HIV. So now our advocates include both the recipients and providers of care. Both groups now have the means to champion awareness among women living with HIV and among the communities of service providers.

In most places, community members and service providers requested that we include them in meetings to promote the effective implementation of the Guideline. In each county, those who participated in the workshop are now part of technical working groups at the county, sub-county, or community level. They are going to ensure that they sit together with members of the community to discuss issues affecting women living with HIV. They are equipped to give their input and share the statement from our workshop as champions in the regions that they work in.

“For the very first time, women living with HIV in Kenya are members of community committees devoted purely to respond to our sexual and reproductive health!”

Another concept note has been submitted to UNAIDS to conduct the Checklist in the remaining three counties. We are also developing a local language, pocket-size version of the Guideline.

In June 2019, the Checklist was published by WHO as an official UN document.¹³

B. Pioneering research on reproductive health and sexual diversity among transgender people



“Transgender people are the most under-researched and ill understood among communities. The GVPS inspired us to research, introspect and reflect upon our realities. By incorporating the vital concerns of transgender communities, the survey enhanced the inclusivity and responsiveness of the WHO SRHR Guideline.”

Cecilia Chung, Transgender Law Centre, United States of America

About the Transgender Law Center

The [Transgender Law Center](#) (TLC) is the largest national trans-led organization advocating self-determination for all people in the United States of America (USA). Grounded in legal expertise and committed to racial justice, the TLC employs a variety of community-driven strategies to keep transgender and gender-nonconforming people alive, thriving, and fighting for liberation.

In 2015 the Transgender Law Center launched Positively Trans, a project to develop self-empowerment and advocacy by and for transgender people living with HIV. Positively Trans operates under the guidance of a National Advisory Board (NAB) made up of people living with HIV across the USA. The project recognises the distinct groups within our communities and accords high priority to fighting discrimination against transgender people living with HIV. This group faces the double stigma of being transgender as well as being HIV positive. Positively Trans is a bid to instead represent ourselves as doubly powerful and to give a human face to those among us who feel too stigmatised to raise their voices.

My Inspiration

I am a transgender woman living with HIV in North America and I work with the global network of transgender women living with HIV. As the co-chair of the Global Network of People Living with HIV (GNP+) in 2014, I participated in the Global Reference Group (GRG) set up to disseminate the Global Values and Preferences survey (GVPS) in connection with the development of the 2017 WHO Consolidated SRHR Guideline for women living with HIV.

The survey was an inclusive process that incorporated many questions and concerns of vital import to transgender communities. We are among the most under-researched and ill-understood communities and the survey highlighted the immense value of collecting evidence from communities to support our concerns.

Our Context

Whilst transgender people living with HIV have distinct needs and concerns, we also share some of the values of the women’s movement on reproductive health and rights, such as bodily autonomy. We believe that we have the right to make decisions about our own bodies. We believe that the care we receive from health providers should be with our informed consent. We believe that those of us who desire a family, to raise children, should be supported in this. We believe we have the right to safe and accessible sexual and reproductive health services that respect us.

As the Positively Trans network continues to grow, we often revisit these values to ground our discussions and decisions. The values also enable us to frame mental health, violence and trauma in trans-inclusive ways. For example, we conduct a digital story workshop that supports transgender people living with HIV to develop their own stories, script a screenplay and produce a video in their own voices. A number of videos in our repository of stories speak of sexual violence faced by both transgender men and transgender women and how it impacts their relationships with the community and with health providers.

More and more, transgender and gender non-conforming people are learning to be their authentic selves. The idea of one's true sexuality, one's authentic sexual self, emerges from being able to abjure the identities that one was conferred with at birth or was forced to live out in public. Someone who was assigned the male gender at birth and later in life discloses that they identify as a woman, attracts stigma, ridicule and harassment from families, at the workplace and even from their social circles. Transgender people often out themselves late in life and when they do, they feel a strong sense of relief and pride that comes with breaking free. They realize that it is liberating to be able to speak the truth about who they are and make their own decisions based on a gender they identify as and not one that was assumed for them by others.

Moving our agenda forward

The Transgender Law Center adapted the GVPS to the national context and specifically for the trans communities. An important starting point was to explain our survey results to our communities before planning any further research of our own. We then created our own tools to survey violence experienced by transgender people living with HIV. This included various forms of violence, including sexual violence perpetrated by intimate partners.

The findings showed that most transgender people living with HIV had experienced at least one form of violence. This included being harassed on the street, physically assaulted, rejected by family, sexually assaulted, and assaulted by intimate partners. This motivated us to continue researching violence against and within the transgender and gender non-conforming communities. It is well known that violence against transgender women is high, but we wanted to create opportunities for transgender men to share their experiences of violence too. Our preliminary surveys suggest that transgender men experience just as much violence as transgender women, but do not talk about it within the community. Findings like these strongly affirm the need for discussions about our safety and wellbeing.

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Unlike the in academic world, where most research findings do not get shared with the researched community until after peer review and publication, we immediately offer survey results back to the communities before they are shared any further. It's important for community members who lead advocacy efforts to fully digest research data and equip themselves to tell their stories in their own voices. Sharing the research findings sooner also gives funders opportunities to pursue mutual areas of interest with us and have conversations with either us or the community members who have been represented either from our project, or from communities who have worked very closely with us.

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“For the majority of transgender people living with HIV, a priority need is not HIV care, but care related to sexual transition, mental health and gender-affirmation. Despite assumptions made by healthcare providers, our number one priority is not our viral load and HIV care but more importantly it is feeling respected and treated with dignity and to have our gender affirmed. If transgender communities do not feel this, we are likely to drop out of care.”

In the summer of 2015 we carried out an online needs assessment to identify community needs and advocacy priorities. We have since updated the survey tool focusing on three geographical sites, including one among under-served communities. Some of the findings were consistent with our national survey.

Based on both of our surveys among transgender people, we developed the following recommendations for anyone working to uphold human rights:

- Support institutions that provide legal, rights-based advocacy training programmes.
- Support systems for transgender people who have experienced discrimination or who anticipate discrimination to be able to access care and services without fear of mistreatment.
- Identify and develop economic initiatives to relieve financial barriers and stresses that limit access to care.
- Promote anti-discrimination initiatives and training in gender-affirming care in healthcare facilities, healthcare; along with service provider education and support to address the mental health needs – including the effects of trauma – on transgender people living with HIV.

“All of these recommendations run counter to current policies which continue to disenfranchise some of the most marginalised communities such as immigrants, people of colour and the transgender communities.”

Discrimination faced by people living with HIV is among the factors that drive the HIV epidemic, but the work that we do, telling our stories, is gaining traction to push back against the status quo. The National HIV Prevention Conference at the Centers for Disease Control has introduced a track on storytelling for providers and affected communities, recognizing that data and evidence are important but need to have a human face to effect important changes that lead to better health outcomes.

Funding for and interest in research exploring the health of under-researched communities such as transgender people has exploded in recent times. For example, there is research on how the presence or absence of a supportive environment affects the health of young lesbian, gay, bisexual and transgender (LGBT) people of colour.^b As a result, people have become aware of intersectional issues and how they drive HIV epidemics.

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“We have created a participatory process led by the community for the community where we invite researchers to come talk to us to learn of our needs and our interests in what we would like researched about ourselves. And so far, it seems to work very well. We are changing some of the relationship dynamics between researchers and communities, as well as funders and the communities. More funders now are open to funding organizations that are led by transgender people for transgender people.”

Oftentimes the research findings take a long time to reach the public domain. We strongly believe that awareness is empowerment. The transgender community needs to be researched and we encourage our own community to examine how we drive that research.

At about the same time as we were carrying out our surveys and advocating with funders, the International Transgender Fund was created with a start-up pool of US\$ 20 million to concentrate on supporting trans-led organizations globally, particularly in developing countries. When we talk about hard-to-reach populations – which sometimes includes transgender people of colour, transgender men living with HIV, those who have not transitioned physically to the gender they identify with, and those who do not identify with the gender binary – we need to engage members from their social network in order to connect with them. The fund has a review process

² Family Acceptance Project, familyproject.sfsu.edu, <https://familyproject.sfsu.edu>

in place to ensure that there is equity in the funding distribution. It is hoped that the fund becomes the tipping point for transgender rights to move forward at a global level.

In 2018, representatives from trans communities gathered to discuss trans-inclusive reproductive justice in the USA. Establishing a think tank on trans and SRHR is a priority for a trans-inclusive reproductive health and rights movement. Transgender and gender non-conforming communities are diverse, and it's important for us to reach a consensus on the language that we use to enable us to move forward as a collective.

We are sometimes asked to review reproductive health documents and we often recommend more gender-neutral language when possible. This is a real challenge given that we are not able to be more specific ourselves. We are in the process of developing a glossary that can support and improve the language by including more inclusive gendered terms in the reproductive health movement.

Often the broad-brush language we find in the Guideline on SRHR, say for women and girls or for men who have sex with men, excludes those communities upon whom the impact of these issues is greatest, such as transgender women living with HIV or transgender men who have sex with other men. We have yet to discuss such concerns.

For example, transgender men are often invisible in the current reproductive health and rights milieu. The terminology to describe a transgender man expecting a child does not yet exist because most transgender men do not identify themselves to the child as “mother”. It is crucial for transgender men who are expecting, or transgender women who need to access sperm freezing facilities, to be able to access reproductive consultations at their health facilities, yet this right is not afforded to us. We are unaware of the trends in pregnancy and childbirth among transgender men in general. Stigma deters transgender people from revealing themselves, and in many countries, such as those in sub-Saharan Africa, transgender men often don't feel safe disclosing their gender identity. Also, transgender men may not openly identify as trans while they are pregnant.

It is time that key donors start to leverage their influence to change anti-LGBT attitudes in many of the countries that depend on foreign aid. Many countries continue to uphold laws that criminalize people who are lesbian, gay, bisexual or transgender. In some instances, when donors decide not to re-grant the same proposals, those programmes are forced to lay off staff. What those programmes need assistance with is to develop sustainable strategies that support and strengthen communities, not a band-aid approach or pulling funding altogether. Donors should invest more in community-led interventions, ensure community members are actively participating in the decision-making process, and support leadership from the community to ensure safe access to the full range of sexual and reproductive services without fear, even in countries that continue to criminalize people based on their gender identity and/or sexual orientation.”

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“Slogans such as ‘Getting to zero’ or ‘90-90-90’ are exclusionary by definition and the 10% who are missing are exactly those communities that are the hardest to reach. Such targets imply that people should submit to testing whether they are ready or not. Such targets also imply that it is acceptable to discriminate and so, as a matter of course, the smallest groups are left out.”

C. Mobilizing funding for women living with HIV through evidence-based advocacy in Ukraine, Eastern Europe and Central Asia



“The WHO Guideline presents us with a potent advocacy tool to help us realize our sexual and reproductive health and rights. It’s value stems from the fact that they are rooted in the existential constraints of women living with HIV.”

Svitlana Moroz, Eurasian Women’s Network on AIDS

About EWNA

The [Eurasian Women’s Network on AIDS](#) (EWNA) unites women leaders from 12 countries in Eastern Europe and Central Asia. It is the region’s only organization dedicated to protecting the rights of women living with HIV and vulnerable to HIV, developing and strengthening their potential, as well as making women’s stories and voices visible and meaningful in decision-making processes at various levels.

My inspiration

I am a member of the EWNA, which is the first women’s network to emerge in Eastern Europe with SRHR at the centre of its advocacy agenda. EWNA has over 55 members from 12 countries across Eastern Europe and Central Asia.

As a fairly young network and a community of women living with HIV, we are strengthening our advocacy. It is clear that many of our concerns and challenges reach beyond HIV, extending to gender inequality and negative gender norms that many women globally continue to face in a strongly patriarchal society such as Ukraine’s.

In 2014, I was invited by the Salamander Trust to coordinate the GVPS on SRHR in Eastern Europe and Central Asia. We mobilized 100 women from our region to participate in the online survey (in Russian) and their feedback was subsequently translated into English for wider access.

The 2017 WHO Consolidated Guideline is a powerful advocacy tool to lobby our governments to realize our rights. Given the total absence of data in Ukraine on the experiences of women living with HIV with regard to reproductive and sexual health, I felt compelled to adapt the survey to collect more data from Ukraine.

Applying the same methodology as the GVPS, we as a national network of women living with HIV, Positive Women, formed a reference group of five women living with HIV, who represented diverse groups in our community. At the end of 2015, with support from UN Women, we launched the survey through the local coordinators and members of national networks of women living with HIV as well as women from key populations. We followed the same women-oriented, participatory approach as the original survey, and incorporated questions that highlighted the economic and political challenges facing women living with HIV.

We felt this research was essential, and we were ready and able to be the first to care enough to build the body of evidence that we so desperately needed. This was momentous, as it was the first time that research had been conducted by women living with and affected by HIV in Ukraine. We had two objectives: 1) To map

the extent to which women living with HIV were able to realize their SRHR; 2) To allow research findings to inform our agenda.

Traditionally, our advocacy agenda is sometimes dictated by donors, but this research would enable us to speak and be taken seriously. This is also linked to a lack of understanding around the Guideline itself. Many progressive recommendations from the WHO do not engage or reach communities. This is because they are mostly written in a language and style that communities do not easily understand. We have plans to adapt the full Guideline into a community-friendly version in Russian, focusing on context-specific areas. This work also enabled women to develop their own understanding of what is in the Guideline and what they ought to be able to access.

A key example of the gap between what is recommended in the Guideline and what we are told in the Ukraine is around the guidance on breastfeeding for women living with HIV. Presently, doctors advise women living with HIV to avoid breastfeeding, citing the national policy, but WHO's guidance differs. This was discovered when EWNA's Russia representatives tried (unsuccessfully) to gather evidence on the prevalence of HIV transmission through breastfeeding among women on antiretroviral medications. Advocating for our national guidelines to change to reflect the latest scientific findings is now part of our advocacy agenda in Ukraine. If we want to, we should be allowed to breastfeed our babies if our viral load is undetectable. This is just one example of the many areas that require change. In this regard the support of WHO and other UN agencies is crucial, but we have almost no relationship with WHO – even at the global level – and no country representative. UN agencies continue to chant mantras like “90-90-90” with no acknowledgement of how this connects to the social determinants of health-seeking behaviour. Our challenge as women living with HIV is to convince society and those in power about the intersectionality of poverty, violence and community health. We cannot stop HIV without respecting all human rights and upholding equity as a starting point.

Moving our agenda forward

Our survey design was approved by the National Reference Group of women living with HIV and the Sociological Association of Ukraine. The research, analysis and documentation following the survey took almost a year to complete.

With the help of four regional coordinators and representatives from the community, we reached 1000 women living with HIV in 26 provinces. The coordinators were women leaders and activists with access to communities. The questionnaires were printed and completed in person because many lack access to the internet. The exercise was not only about gathering information but about building awareness. We provided information about reproductive health and created space for women to talk and ask questions.

We additionally conducted community-level consultations with 57 service providers who were also women living with HIV. To us this was critical, as they are better equipped to analyse the state of our access to services and related laws.

Our findings provided us with detailed information on the human rights violations experienced by women living with HIV and how our right to sexual and reproductive health services is systematically and consistently denied. For example, there are rules that prohibit women living with HIV from adopting a child or seeking the help of assisted reproduction technologies, such as in-vitro fertilization, to conceive.

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“The coordinators gathered 40 stories from women living with HIV, which presented the diversity of experiences. Positive stories showed how health support enhanced the quality of some lives, while other stories described the far-reaching impact of stigma and discrimination experienced in the health care system.”

As our own sensitivities grew, we began to work in synergy with the other women’s rights groups advocating for SRHR. Based on research findings, and together with other women from key populations, we submitted a shadow report to CEDAW providing recommendations advocating non-discriminatory provision of services for women living with HIV, sex workers, women who use drugs, women who have sex with women, bisexual women and transgender people. The report also carried recommendations to address stigma, and sexual and other forms of violence, including police violence, and the denial of reproductive and parenting rights. The report was, in short, the familiar tale of marginalized communities everywhere.

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“Another key finding was that generally women living with HIV are not aware of their rights or the laws that affect their lives.”

We submitted the document as a [shadow report](#) at the 66th CEDAW Session in Geneva, Switzerland, in 2017, which was attended by marginalized groups, soon after the publication of the WHO 2017 Consolidated Guideline. After this, things began to change for us. The findings had bolstered our resolve and voice with facts and figures, and provided us with a platform to lobby for the Ukrainian government to adopt and implement the recommendations.

The findings provided the evidence we needed to lobby for women living with HIV to be included in the Global Fund funding request from Ukraine. Earlier attempts had failed, as we are not seen as a key population, which is where Ukraine has chosen to focus their attention. In the Communities Mobilisation Working Group, we successfully advocated for funds to be channelled to address violence experienced by women. In addition to this historic investment – the first of its kind – the representation of women living with HIV in the Country Coordinating Mechanism (CCM) since July 2019 has been officially declared and is working.

In 2018 the support of the Global Fund enabled us to train service providers in 10 regions of Ukraine to address the impact of gender-based violence among women living with HIV. We have started new community-led research to monitor GBV among HIV-positive women in HIV prevention, care and support programmes in 10 Ukrainian regions.

EWNA is using the Ukraine experience to promote similar research at a regional level. With UNFPA support, we are carrying out a values and preferences survey in Moldova. On the International Day of Action for Women’s Health we launched a [community-friendly Russian translation](#) of the Consolidated WHO Guideline on sexual and reproductive health and rights of women living with HIV.¹⁴

On 4 June 2019, after two years of advocacy, an order of the Ministry of Health came into force, which allows for the provision of IVFs to women living with HIV who have undetectable viral load.

D. Allowing healing and improving young women's self-worth in Puerto Rico



“The GVPS and the WHO SRHR Guideline are powerful instruments that have helped us understand the scope of our rights. We - as women living with HIV - have embraced these ideas, converted them into practical tools that we use in the field, and are transforming our lives.”

L'Orangelis Thomas Negrón

About L'Orangelis

L'Orangelis Thomas Negrón works to ensure that women living with HIV – especially young women living with HIV – have better quality of life and can live free of stigma, especially self-stigma. Before L'Orangelis turned 30, she was part of the Latin-American and Caribbean Positive Youth Network. L'Orangelis was previously a board member of the Global Network of People Living with HIV (GNP+).

L'Orangelis was born HIV-positive in San Juan, Puerto Rico, where she resides and works with Pangea – a positive youth group that she co-founded in 2017 after Hurricane Maria. L'Orangelis is also part of El Hangar en Santurce, a queer and trans feminist cultural space. Besides this, L'Orangelis collaborates with the HIV Howler, an art printed newspaper around HIV, art and activism. Fluir Más, is a personal project where she uses her menstrual blood as paint to represent the ongoing healing processes around the cycles that we are connected with, and to start a conversation around HIV, menstruation and its taboo. L'Orangelis is still working with the Women's Global Network for Reproductive Rights (WGNRR).

My inspiration

It was in my capacity as a member of the Latin America & Caribbean Positive Youth Network that I engaged with Salamander Trust as a member of the Global Reference Group to develop the GVPS. I was interested in developing the Guideline because it directly links to my work building community-level discussions around sex, sexuality and sexual pleasure.

I began focusing on SRHR because biomedical responses to HIV prevention and treatment literacy to maintain undetectable viral loads (again also for prevention purposes) have been the overwhelming focus of global efforts to “support” people living with HIV.

Our context

As women living with HIV, it feels like when people speak to us about sex and sexuality it's never about how we are affected by this or how much we enjoy it. It is more about someone else's sexuality and how we can protect them.

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“Our ability to protect others from HIV cannot and should not be the sole focus of the discussions at the clinic. Many of us face sexual violence and are forced to have sex, but gender perspectives and this sensitivity are yet to find their way into all health services.”

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Conversations on sexual practices between healthcare providers and women living with HIV usually start with the question “Are you having sex?” And the next question is “Do you use protection?”

This is not much of an introduction and does not affirm our right to be having sex and to enjoy it or to question if our sex is consensual. Any further limited instructions on how to use and negotiate condoms and how to prevent transmission do not address any of the key emotional challenges that come with living with HIV as a sexually active being.

“If women living with HIV feel comfortable with their sexuality, they will be more able not only to protect themselves, but to protect others.”

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Conversations about sex should be an important part of our own journeys as women living with HIV and should come naturally, but questions such as “what do you do in bed when you have sex?” or “was the experience enjoyable?” are rarely asked by healthcare providers, nor discussed among women living with HIV.

Women living with HIV should enjoy sex, otherwise why do it? We need to explore what we do and don’t enjoy, and we need to be clear about the barriers that prevent us from enjoying sex. I encourage women living with HIV to start speaking about their autonomy over their bodies and the pleasure that we have the right to enjoy when we have sex.

Women living with HIV have the right to fulfilling sex lives and should not have to live in a constant state of fear. Many women abstain from sex for years after they are diagnosed, and are not able to speak about it. In almost all cases no one even tries to talk to them about it. Goodness forbid anyone should be seen to promote sex for women living with HIV!

Seeing oneself solely as a source of infection to others and living with this internalized negative view of the self is the reality for many young women living with HIV. It is often what the outside world mirrors back to us. Often many of us experience guilt when we do experience sexual pleasure, yet it is the most natural thing for human beings.

Moving our agenda forwards

In my work I speak about positive sexuality. I focus on helping women living with HIV to realize that it’s perfectly healthy and natural to have good feelings about sex. Shifting our views on sex is critical to expanding our self-confidence. This begins with the determination to stop thinking and talking about sex from a position of fear. Positive sexuality is an aspiration that we must work together to realize.

Many communities are now in conversation about sexuality, but we need to expand this circle to include discussions specifically with women living with HIV. There is a great body of evidence, including from the GVPS, about the barriers we face. For example, there are many sex-related issues that women living with HIV do not want to talk about. One of them is partner violence, where many feel they don’t have the opportunities to negotiate sex or safer sex. When you say “Hey, a large group of young women are having those experiences – what about you?” some begin to identify with those issues. Others realize that we have certain rights over our bodies and the way we are treated. The GVPS and the Guideline have presented women living with HIV with a unique opportunity to have informed community discussions around SRHR and to share our experiences with each other.

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“In my work, I focus less on the importance of adhering to treatment, because that’s all we ever hear about from health care providers.”

The Guideline also provides a starting point to encourage discussions on topics that are not spoken about by health providers. For example, the Guideline includes information on the [side-effects of antiretroviral medications](#) that women report to have. We are aware that many of the women living with HIV are on treatment but may not necessarily adhere to it. Instead we speak about whether medication affects our sex lives, and the ways in which this might happen. Does the medication give you a headache? What do you do if you want to have sex and you feel ill because of the medication? What do you do when your partner wants to have sex and you know you often don't take your medication to avoid its side effects?

Health services follow protocols aimed at ensuring safe pregnancy and childbirth among women living with HIV, but Puerto Rico has no policies on the SRHR of women living with HIV.

The first steps towards transformation have taken place in safe spaces where in workshops we educate ourselves about SRHR and sexuality. My focus is on working with women living with HIV, rather than on public policy. Even when SRHR policy for women living with HIV is adopted by the country, it's crucial for women to compare what the policy entitles them to, against what they receive to connect the policy to what women actually know or have, so that we can work towards ensuring that the policy gets implemented. With this goal in mind, I have developed a series of workshops which can be conducted in order or experienced separately.

The first workshop is about the body and the experience of being diagnosed with HIV. We explore how we feel about our bodies living with HIV and the changes in the messages that we hear – and send ourselves – about our value now that we live with HIV. This includes taking women through guided meditations and opening up space for safe and unjudged conversations. Each participant is given a card to visually express their feelings and to share their personal journey towards empowerment. Art workshops are a valuable exercise because painting is a comfortable way to express ourselves freely. The process also provides support as participants speak to each other while painting. By listening to each other's stories, women become more comfortable and secure with each other. The workshop usually results in making us feel that we are part of a safe, supportive community.



The second workshop is more of a conversation about knowing oneself and one's body. Sometimes I use 3D printed models of the female sexual anatomy and explain it. I also initiate conversations about the physiology of sexual pleasure. An important part of the workshop is to carry out a self-examination of the vagina. This is a powerful act, not only for woman living with HIV, but for every woman. When we talk about autonomy over our bodies, we need to realize that it begins by knowing our bodies. Often the healthcare providers know our bodies better than we do. I provide a speculum so that they can explore their vagina in the privacy of their homes, and sometimes we do this as a group. We also discuss gender-based violence and mental well-being at the workshop.

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“In one instance, a participant was able to seek care for cancer because she found a lesion when conducting the vaginal examination.”

I have conducted workshops in Argentina, Perú, México, South Africa and Zimbabwe, and found that there is a difference between how African and Latin American women respond to the discussions. I have so far not been able to run the vaginal self-exam session in South Africa and Zimbabwe, as they were more comfortable expressing their ideas through painting. It is much harder to have conversations around sex with young woman in Southern Africa, and this may be partly due to traditionally conservative patriarchal cultures and stigma. In Latin America, conversations on sexuality are common and many young women believe in gender equality and identify as feminists. In Southern Africa our conversations are more along the lines of the support that women living with HIV need, whereas in Latin America women bring up issues related to female orgasm without encouragement from me.

A key factor that deters frank discussions on sexuality is being born with HIV. In Latin America the participants include many young women who acquired HIV through sex as well as some who were born with HIV. For those who contracted HIV at birth, they have sometimes had to deal with the death of their parents. The fear of transmitting HIV to someone is ingrained from birth, and when one is ready to become sexually active that fear needs to be explored and resolved.

In the workshops in Puerto Rico I have largely focused on working with young women. Outside of the workshops I often see young women at clinics and would like to establish a communication network so that we can support each other more. Young people living with HIV are trying to organize themselves into groups across the island. As women living with HIV, we would like to build our own networks so that we don't feel alone. The workshops offer the opportunity to connect with each other and to discuss policies that have an impact on our lives. Although we are all different, some of us are more conservative than others and have unique perspectives – speaking with one voice in Puerto Rico will take time to realize. I plan to create a manual to equip other women to conduct similar workshops elsewhere in the country in order to reach more women living with HIV, because forming networks of like-minded people is important to create solidarity. We need to build these relationships before we begin to advocate for a national policy on SRHR. In Mayagüez on the west coast of Puerto Rico I am creating youth groups.

We plan to adapt some of the workshops for transgender, queer and non-binary people, following a request from a transgender man. He wished to be part of the workshop because although he identifies as a man, he has a vagina and brought valuable insights to the discussions. Many transgender people have no access to health services and especially to any sexual health service because they don't feel respected or comfortable at the clinics. Transgender people living with HIV have access to HIV services, but for those who do not have HIV, trans-friendly services are simply not available.

Over the last year a physical forum to work on culture and sexuality, called El Hangar en Santurce (The Hangar in Santurce), has been established in Puerto Rico. Over the course of 2018 we developed a youth

network called [PANGEA](#), and I also collaborated with feminist groups on other reproductive rights issues, such as the right to have safe abortions and to be able to access post-abortion care.

We have been working with lesbian, gay, bisexual, transgender, queer, trans, asexual and non-binary communities and others (LGBTQIA+) on SRHR, and this is really my passion. The right to sexual and reproductive health belongs to everyone, including people living with HIV in all our diversity. It is important for people, irrespective of their sexual orientation or gender identity, to be well informed on their sexual and reproductive health and rights. Specific communities need to discuss their concerns and identify basic concepts regarding sexual identity and their specific needs and desires. For example, someone who identifies as transgender or non-binary may want to learn about abortion.

The GVPS and the Guideline are powerful instruments that have enabled us to understand the scope of our rights. As women living with HIV, we have embraced these ideas and converted them into practical tools, which we are leveraging to transform our lives. We have protocols for pregnant women which has helped to end vertical transmission since 2008. Sometimes we just need financial support to sustain the gains and scale up what we know is working. Among our challenges is the absence of UNAIDS or other technical partners, so we have to find our own way to bring about the changes we desire.

The collective years of work with women living with HIV have had an impact on their lives. I believe this has been a better investment than spending time and energy trying to change policy only. It is practical interventions among women living with HIV that will eventually have the knock-on effect of shaping meaningful policies. We need to recognize the good practices that women living with HIV have been implementing and build demand for more of these programmes and services. Clearly, the vision that we bring to the table has a potential that extends far beyond SRHR.

I believe that in Puerto Rico we need to converse among ourselves so that as a community we can understand which issues affect us the most and why. Policy and action move in a continuous circle. Therefore, we need to have conversations on sexuality and inform and empower ourselves as communities. We need to then channel that information to shape policies that promote healthy sexuality. And we need to transform those policies into tools that can concretely change our lives for the better, and feed the beneficial impact of the implementation back into a knowledge pool that can expand our choices.



5. Guiding principles for meaningful partnership with civil society

The [UNAIDS guidance for partnerships with civil society, including people living with HIV and key populations](#)¹⁵ contains several key principles, including:

- human rights
- evidence-informed and ethical responses
- people living with HIV as leaders
- genuine partnership
- equality
- country ownership
- responsibility of the entire Joint UN Programme on AIDS
- strategic impact
- mutual respect, cooperation, transparency and accountability
- recognition of the autonomy and diversity of civil society.

These key principles are also relevant to WHO's engagement with communities in securing the rights of all women – especially their sexual and reproductive health and rights. Meaningful community engagement means recognizing the influence of many stakeholders across sectors who may have varying levels of prestige and social power. The diversity in stakeholders' experiences is key in identifying and understanding the contexts, challenges, and opportunities around a given issue¹⁶ in order to figure out the right course of action. This understanding is essential to developing a holistic approach to ensuring evidence-informed and ethical responses that promote and uphold a woman's SRHR. Women in communities should be recognised for their expertise, autonomy, and diversity, which enrich the discussion and facilitate the ownership of the health agenda. Opportunities need to be created for collaboration between national and international leadership, civil society, and communities in SRHR, including vulnerable and marginalized populations. This should utilise an enabling environment approach that includes human rights, gender equality, empowerment and a people-centred approach.

In the context of a human rights-based approach, the intended beneficiaries of programmes and policies should be active participants in the decisions that will affect their lives, specifically in scientific advancement, as enshrined in [Article 27 of the Universal Declaration on Human Rights](#), which states that “everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits”. Gender equality is particularly relevant in that it enables women, girls, adolescents and gender and sexual minorities to claim their rights. Gender and other inequalities have led to gaps in: meaningful engagement; research on issues affecting their health; age of consent; recognition that sex work is work; and a lack of disaggregated data.¹⁷ Engaging communities around their fundamental rights and freedoms is a way to increase gender equality while also providing opportunities for self-empowerment.¹⁸ Empowerment is a process that allows women to acquire more control over their lives. Through this increased control they establish, implement, and defend their rights, reduce inequities, and make changes in their communities. The process of meaningful community engagement seeks to support women to empower themselves to change the social forces around them.¹⁹

People-centred approaches recognize people as powerful decision-makers in their own health. The autonomy of every woman should be considered essential to ensuring successful health outcomes. This shift in ideology would allow communication between individuals and the health system to be open and clear, and would facilitate informed health choices. As active participants in the health system, the perspectives of women in communities are a key influence on how services and interventions are delivered to respond to their priorities, concerns and rights.¹⁹ In this framework, health systems respond to their priorities, rights and preferences in humane and holistic ways. This requires that all people – especially women – are empowered through education and support to make and enact decisions in all aspects of their lives, including in relation to sexuality and reproduction.

6. WHO's role in securing sexual and reproductive health and rights for women

The WHO's work on SRHR covers a broad range of issues, including to:

- identify gaps and priorities and shape the global SRHR research agenda;
- provide leadership on matters critical to improving SRHR through knowledge generation, synthesis and management;
- support national research, strengthen technical capacity and engage in relevant partnerships;
- articulate ethical and evidence-based options for policy formulation and programme development to improve SRHR, in collaboration with WHO Regional and Country Offices;
- monitor and evaluate SRHR situations and trends, advocacy, thereby catalysing change and supporting healthcare delivery; and
- develop WHO guidelines: clinical standards, norms and related policy and technical guidance documents.

Each of these key areas can be strengthened by reinforcing and expanding partnerships with women in communities in order to advance SRHR and drive progress towards the Sustainable Development Goals (SDGs), in particular target 3.7 to ensure, by 2030, universal access to sexual and reproductive healthcare services, including for family planning, information and education, and the integration of SRHR into national strategies and programmes.^{20, 21}

Meaningfully engaging women in all their diversity in core functions can foster acceptable and relevant approaches, as well as end-to-end, integrated connections between country-level priorities and the needs of women. Thoughtful, innovative and creative approaches for applying the principles of meaningful community engagement can include:

Identifying gaps and priorities, and shaping the global SRH research agenda

Engaging women to identify and assess their own priorities highlights the gaps or inequities that are important to the community itself instead of imposing perceived needs.¹¹ As highlighted by the GVPS, this reveals priorities, needs and preferences that were previously unidentified or undervalued by investigators, and need to be researched further.⁸ As a research agenda setting organization, WHO has a responsibility to set research priorities that will make progress in filling the gaps in health services that are important to the population being served.

Providing leadership on matters critical to improving SRHR through knowledge generation, synthesis and management

The impact of community engagement at the research level has been demonstrated to improve the effectiveness, acceptability, user satisfaction, and cost-effectiveness of interventions. However, much of the existing research is on community engagement in the US and Canada.^{22, 23} WHO can generate a body of evidence around meaningful community engagement, especially in low- and middle-income countries (LMICs), where it is sorely lacking. The remaining core functions concern research, policy, monitoring and evaluation, and guideline development. Although these four areas are very different processes, the most

effective way of involving communities in each of them is universal. Communities should be approached early in the process, involved in as much of the process as possible, and treated respectfully as partners, not as a resource. This enables the engagement to be an empowering process so that communities might be better equipped to voice their perspectives in the research and policy fields in the future.¹¹

Community engagement that promotes the empowerment and human rights of those involved must be done with multisectoral humility. Concerted efforts to respect communities and their autonomy should include to:

- choose how they are represented and by whom;
- choose how they are engaged in the process;
- choose whether to participate;
- address barriers to participation, should they desire to be meaningfully engaged; and
- have an equal voice in how partnerships are managed.²⁴

For both sides to benefit fully from engagement, community partners must remain in a position to engage in future partnerships and to build the capacity of their communities. This is a key role that technical partners, such as UN agencies and donors, can play to ensure that civil society participates with appropriate and adequate funding and resources. However, many of the groups are vulnerable in their home environments. For them to remain engaged for prolonged impact, WHO can also have a role to play in capacity building. Efforts should be made to avoid community members being brought in for consultation and then sent away without being given a chance to learn from the engagement process, and with fragmentary use of their expertise. Communities should therefore be invited to participate in ways that are sustainable in their home environments and be empowered with knowledge and skills to make changes upon their return.²⁵

Supporting national research, strengthening technical capacity and engaging in relevant partnerships

Evidence supports early and continuous community involvement in setting the scope, objectives, and outcomes of the research in order to improve its cost-effectiveness, relevance, and translation into practice.⁸

In addition to improved research, WHO can also help improve a country's technical capacity by supporting community engagement. Community members actively involved in the research process have the opportunity to learn from it. Their involvement and understanding contributes to a trusting relationship with the scientific community, facilitating future cooperation and contribution to research.²⁵

Community engagement in SRHR policy formulation results in a policy more grounded in the realities of the people it affects. It also empowers the people engaged to voice and defend their interests in future policy creation.²⁶

Monitoring and evaluation of SRHR situations and trends, advocacy, thereby catalysing change and supporting intervention delivery

The [WHO Evaluation Practice Handbook](#) recommends a participatory approach to evaluation to identify relevant evaluation questions, improve programme performance, empower participants, build capacity, develop leaders and teams, and sustain organizational learning and growth.²⁷ As described in the handbook, community members have experiential insight that can be powerfully beneficial for monitoring and evaluation problem-solving, and can be trained to conduct community monitoring and evaluation programmes in order to increase ownership of the programme and strengthen capacity and accountability.

WHO can provide technical support for implementing meaningful community engagement in intervention delivery by integrating meaningful community engagement guidance into existing implementation tools, as

well as by producing tools specifically for community engagement-based interventions. The Innov8 approach is a health programme review process developed by WHO to integrate equity, human rights, and gender-responsive elements into existing programmes. In the review and redesign process laid out by Innov8, a multidisciplinary review team considers why some populations are not being adequately served by a programme and how to improve the situation. Intersectoral action and social participation is identified as a key step in improving programme performance for underserved populations.²⁶

Developing of WHO guidelines: clinical standards, norms and related policy and technical guidance documents

The procedures laid out in the 2014 WHO handbook for guideline development dictate that “the process of developing guidelines is multidisciplinary and includes all relevant expertise and perspectives, including input from stakeholders”.²⁸ Those affected by the guidelines both as end users and the intended beneficiaries are to be represented in the Guideline Development Group (GDG) because the value of their expertise is recognized for ensuring that the developed guidelines are asking the right questions and considering those affected in the context of their lives. It is not possible to accurately balance the benefits and harms of an intervention without considering its impact across all aspects of the intended beneficiaries’ lives.^{8, 28} The WHO-INTEGRATE framework for the Guideline Review Committee (GRC) that is currently being developed emphasizes the perspectives of the intended beneficiaries. They must be considered when evaluating an intervention’s impact on various health outcomes, and its acceptability and feasibility. If the population of relevance to an intervention does not find the intervention acceptable or feasible, and does not value the intended outcomes, the intervention is not serving the needs of the population, and hence will not be taken up. The opportunities for meaningful community engagement described in this brief help one to consider values and preferences by bringing in the voices of intended beneficiaries, thereby achieving this goal of the framework.

The Consolidated Guideline on sexual and reproductive health and rights of women living with HIV was developed with the input of the Global Values and Preferences Survey (GVPS).²⁹ Women living with HIV were involved from the beginning in survey development, implementation, and analysis. Their involvement included two positions in the expert coordinating team, comprising the entirety of the Global Reference Group, as well as being focus group leaders and surveyors.³⁰

Through the survey, women living with HIV were given a voice to share their concerns, experiences, and priorities, not only with the investigators but also with each other. The women reported this as an empowering experience for them both as individuals and as a community.³⁰ This guideline development approach has been recognized as a best practice.

“I welcome the innovative and participatory approach taken in the development of this guideline and the evidence-based approaches to sexual and reproductive health and rights of women living with HIV. We must make sure these guidelines reach health workers and users of health services to eliminate stigma and discrimination against women in health care, through attention to and fulfilment of their rights, roles and responsibilities.”

Dr Tedros Adhanom Ghebreyesus, Director-General, World Health Organization

7. The gains of community-driven/owned approaches

The meaningful engagement of women living with HIV from diverse geographies, backgrounds and circumstances at every stage of the development of the 2017 WHO Consolidated Guideline signifies the beginning of a larger movement within WHO to support rights-based access to better health choices for all communities on the margins.

This process has been a powerful demonstration of how WHO is able to leverage its mandate to uphold human rights and dignity and respect meaningful engagement of community members as equal stakeholders, working towards the attainment of health for all.

Meaningful community participation began with the GVPS on the SRHR of women living with HIV. This was not an afterthought but was intentionally conceived, and the mandate was given to women living with HIV to conduct.

”

“The process that was followed in the development of this guideline is an approach that we hope we can replicate elsewhere as a best practice for the Organization.”

- Dr Flavia Bustreo, Assistant Director-General, Family, Women's and Children's Health, WHO

- The process of self-reflection through the Global Survey was both revealing and healing. It created space and opportunity for women to assess their own lives. As they engaged, they also received information. This process was reflective and empowering, and mirrored for some the reality of their lives, especially around violence. Of the 58% of women who completed an optional section related to VAW, 89% reported that they had experienced violence or fear of violence before, since or because of their diagnosis. The right to exercise sexual and reproductive health choices can be fully realized only when the social determinants of health – which lie mainly beyond the traditional confines of the health sector – are duly acknowledged and addressed by all.
- The global survey and process inspired actions in several countries, four of which are highlighted in this publication. These include adaptations of the GVPS for sensitive and ethical research in the USA and Ukraine; the pilots of the generic Checklist for the Guideline's implementation in Kenya; and the inspiring work with young women on sexuality in Puerto Rico. All of these examples demonstrate how women living with HIV have generated their own simple and practical tools to support their communities in order to translate global policy language into their lived realities and to stimulate transformational action. The adapted national surveys in Ukraine and the USA produced data where none existed and revealed the stark daily realities, priorities and needs of key affected women living with HIV in their efforts to attain their SRHR.
- The qualitative evidence collected has reached beyond mere numbers to influence and shape SRH policies, and to garner funding for the community. Women are also demanding more accessible information on SRHR in their own local languages, in order to build a better understanding of their SRHR and to enable themselves to hold duty bearers accountable.

- Women living with HIV are also growing more aware of their bodies, desires, priorities and rights, and of what does or does not exist in global guidance. In addition to this, women are more alert to what governments should be providing and where the gaps are. This outcome has enabled women to find common ground and build community solidarity. This is an important step towards being able to claim their rights and advocate for policy that will make a difference in their lives.
- Healthcare providers, researchers and policy-makers are starting to recognize and respect the invaluable insights that women living with HIV bring to these issues. They are now realizing increasingly that listening to and working with women is critical to the production of ethical, effective and sustainable approaches to achieving the SRHR of women living with HIV, resulting in good health outcomes for the women, and in positive working experiences for health workers. Meaningful engagement with women living with HIV in all their diversity can help healthcare professionals to better understand what priorities and preferences are revealed by adopting a woman-centred approach in an SRHR-friendly environment in healthcare settings. In Kenya, for example, healthcare workers have welcomed the immense potential of this approach by offering women office space in their health centres so as to work alongside them.
- And last, but very far from least, the processes described here show how funding is critical. The engagement of women living with HIV in developing this Guideline and all of these outcomes are because key staff at WHO and its technical partners, such as UNAIDS, have strategically or purposefully invested in the very communities that are affected by the policy that aims to better their lives. Yet such investments are still small and rare. With funding, the inspiring initiatives of women living with HIV described here could be widely replicated elsewhere. We need to overcome the politics of marginalization experienced by women living with HIV by means of powerful strategies that can dismantle disempowerment, irrespective of age, location, sexual orientation, gender identity or profession etc. The work described here has informed policy, highlighted the gaps, and set the direction that policy-makers and donors need to take to help us realize the SRHR of women living with HIV in all their diversity.

8. Conclusion

Promoting the health and well-being, particularly of women who are vulnerable and part of key populations, requires approaches that are responsive to the priorities, needs and preferences of affected individuals and communities. Traditional approaches to engaging service users, families and local communities have broadly focused on three aspects of community engagement: better information provision and the improvement of communication skills; empowering people, families and communities to be more literate in using and navigating the health system; and improving accountability of health systems. However, many women are simply not engaged, and often their engagement around the policies and programmes that directly affect them is tokenistic, and the quality of healthcare they receive is often affected by this lack of meaningful engagement.

The perception of quality of care is shaped by relational and contextual factors, and not necessarily the efficacy or safety of clinical or technical interventions alone. Quality of care can also be compromised when countries struggle to balance human rights-based principles and approaches with public health. In addition to this, factors such as compassion, empathy and trust are important attributes of acceptable and quality care. Important opportunities to improve quality of care are missed by ignoring how culture and context shape not only the relationships between people, but also how the outcomes of these relationships and human interactions influence the way that health services and healthcare are organized, delivered and experienced. Consequently, patient–provider interaction, particularly for vulnerable populations, continues to be suboptimal across, high-, middle- and low-income countries.

Because of this, women in communities have picked up the load in different ways to support community health systems. Many have actively taken the initiative to engage meaningfully with health workers by encouraging their peers to use health services, thereby strengthening the ability of health workers to do their work, and making sure that women are able to talk to people who deeply understand their realities. All of this peer support enhances women’s capacity to adhere to treatment and to remain in care that keeps them healthy. Meanwhile, some of these and other women also work on the outside demanding health services that are fit for purpose. They advocate for human rights, for appropriate services and options, and for programmes and services to be scaled to match the need.

It is timely to better support the role of non-traditional health systems, including supporting women to shape the delivery of quality health services that are safe, effective, efficient, equitable, people-centred and that integrate multiple kinds of care.³¹ Engagement and empowerment of health service users and community members has re-emerged as a core strategy in the [WHO Framework on Integrated People-Centred Health Services](#), which was formally adopted by Member States in 2016.³² Although consensus is lacking on who the community is, what community engagement means, who is responsible for this engagement and how it is done and measured, it is acknowledged that quality, integrated, people-centred and resilient health services can be attained through meaningful community engagement.¹⁶

Purposefully engaging with relevant communities entails the inclusion of the planning, budgeting, development, implementation, and monitoring and evaluation stages. In some instances, it also means developing remedial action if community partners are not meaningfully engaged. Early and continuous

involvement of a community may serve as an ongoing check that the activity is respecting community identities, values, preferences, concerns, and rights. It helps a community to be empowered to advocate for their own interests, and it builds capacity to understand the mandate of WHO's work.³³

As health behaviours and incidence of illness are rooted in the physical and social environments of individuals³⁴, community engagement allows the task at hand to be influenced by the real experiences of the people directly affected. A community is the expert on the experience of the social forces shaping its own health. These individuals are a valuable source of information as experts on their own lives and physical and social environments.^{35, 8, 36}

Community engagement describes the relational aspect of the health system and could be practised to its fullest extent in all core activities of WHO, as it is relevant, feasible and can contribute to advancing SRHR.

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