


What will it take to achieve the sexual and reproductive health and rights of women living with HIV?

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Abstract

This article outlines progress in realizing the sexual and reproductive health and rights of women and girls living with HIV over the last 30 years from the perspective of women living with HIV. It argues that the HIV response needs to go beyond the bio-medical aspects of HIV to achieve our sexual and reproductive health and rights, and considers relevant Joint United Nations Programme on HIV/AIDS (UNAIDS), World Health Organization, United States President's Emergency Plan for AIDS Relief (PEPFAR), Global Fund and other guidelines, what engagement there has been with women living with HIV and whether guidelines/strategies have been adopted. It has been written by women living with HIV from around the world and a few key supporters. Co-authors have sought to collate and cite materials produced by women living with HIV from around the world, in the first known effort to date to do this, as a convergence of evidence to substantiate the points made in the article. However, as the article also argues, research led by women living with HIV is seldom funded and rarely accepted as evidence. Combined with a lack of meaningful involvement of women living with HIV in others' research *on us*, this means that formally recognized evidence from women's own perspectives is patchy at best. The article argues that this research gap, combined with the ongoing primacy of conventional research methods and topics that exclude those most affected by issues, and the lack of political will (and sometimes outright opposition) in relation to gender equality and human rights, adversely affect policies and programmes in relation to women's rights. Thus, efforts to achieve an ethical, effective and sustainable response to the pandemic are hindered. The article concludes with a call to action to all key stakeholders.

Keywords

advocacy for global policy change, convergence of evidence, meaningful involvement of women living with HIV, sexual and reproductive health and rights, women living with HIV

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Introduction

This article is a *cri-de-coeur*, a heartfelt plea to all researchers, policy makers, programme creators, donors and service providers, to uphold the sexual and reproductive health (SRH) and rights (SRHR) of women and girls living with HIV in all our diversity, in line with all the global evidence we have of what works to achieve an ethical, effective and sustainable response to the global HIV pandemic.

It charts the progress made in relation to women and HIV over the past 30 years, against a background of ceaseless activism (much of it unpaid), often unheeded or silenced by policy makers, of women living with HIV around the world, to advance and demand our SRHR.

Despite significant biomedical advances in the HIV response, we argue that progress on our SRHR has lagged behind and there remains much unfinished business. Our SRHR are consistently questioned, ignored, violated, deprioritized, opposed¹ and eroded. We ask what it takes to achieve the effective, ethical and sustainable response to the HIV pandemic for women that we all want, to enable our SRHR to be upheld and so as to make best use of these bio-medical advances.

The 'Methods' section provides a brief description of our methods for compilation and review of the global literature of materials produced by women living with HIV regarding our SRHR. The section 'Where are we now' discusses what women living with HIV demanded in 1992, and how these demands relate to the current context. The section 'Accelerating SRHR: what needs to change?' charts what needs to change for our rights to be realized. The section 'Limitations of this review' discusses some limitations of this article. These include the challenges of writing this article, based on the paucity and/or geographical patchiness of peer review journal-based research on our SRHR, despite the global wealth of relevant so-called 'grey-literature' cited here. The section 'Conclusion and call to action' concludes with a call for action to hold our global leaders to account, to make all our collective efforts worthwhile.

The whole article is accompanied by illustrations of artwork created by women living with HIV, who use art as activism to promote our SRHR.

Methods

We conducted a global literature review of English-language materials using a purposive sampling method of collective compilation of digital archival materials² that draws on virtual snowball sampling.³ This included reaching out to global networks of women in different key populations as well as global, regional and a few national networks of women living with HIV, in an attempt to ensure that key relevant documents published by each population group were included. Criteria for selection included (a) historical materials produced by women living with

HIV dating from 1992 when the International Community of Women living with HIV/AIDS (ICW) first began; (b) materials produced by women living with HIV and/or women from key populations that are especially affected by HIV (including women who do sex work, women who inject drugs, lesbian/bisexual women, trans and/or gender non-conforming women; (c) materials related to specific age groups and/or life stages of women living with HIV (including adolescent girls and young women living with HIV, women who have grown up with HIV, women experiencing pregnancy, women ageing with HIV); (d) materials, where possible, from different regions of the world, especially lower- and middle-income countries (LMICs). To our knowledge, this article represents the most complete global archive collection of these materials to date.⁴ The co-authors (women from Western Europe, North America, Eastern Europe, Africa, Asia Pacific and Latin America) worked together virtually to compare the current situation in terms of SRHR of women living with HIV with the positions and advocacy messages contained in the archival materials compiled.

Where are we now

ICW and the 12 statements

Thirty years ago, in 1992, inaugural members from around the world launched ICW at the Amsterdam International AIDS Conference, where women were not on the agenda. They presented 12 statements from the plenary stage.⁵ These were prescient and far-reaching in content. They did not include young women growing up with HIV, nor women with HIV ageing with the menopause: both were unimaginable in pre-treatment days. Furthermore, it was before there was a good understanding of the significant effects of HIV on trans people, or the importance of recognizing and respecting non-binary gender identities. Nonetheless, they provide a unique benchmark to compare where we started in 1992, 10 years into the pandemic, as the first global movement of women activists, with where we are now.

In some key biomedical ways, there has been immense change. As one leading activist, Susan Cole-Haley, recently explained,

The reality is that today people on effective treatment can live as long as anyone else, have children born free of HIV and it's impossible to pass HIV onto our sexual partners!⁶

These fundamental biomedical advances have all happened since 1995 and are greatly welcomed. Yet they cannot alone solve the complex realities of HIV for women. Even in countries where access to HIV care, treatment and support is generally good, women still experience violations of SRHR, and where women experience intersecting inequalities (because of race, age, ethnicity, disability, gender identity, sexual orientation, drug use, sex

Table 1. ICW 12 statements, 1992.⁵

International Community of Women living with HIV/AIDS (ICW)
 Twelve statements read out at the 1992 International AIDS Conference, Amsterdam
 To improve the situation of women living with HIV and AIDS throughout the world:

1. WE NEED encouragement and support for the development of self-help groups and networks.
2. WE NEED the media to portray us realistically and not stigmatize us.
3. WE NEED accessible and affordable health care (conventional and complementary) and research into how the virus affects women.
4. WE NEED funding for services to lessen our isolation and meet our needs. All funds directed to us need to be supervised to make sure we get it.
5. WE NEED the right to be respected and supported in our choices about reproduction. This includes the right to have children and the right not to have children.
6. WE NEED recognition of the right of our children and orphans to be cared for and of the importance of our role as parents.
7. WE NEED education and training of health care providers and the community at large about women's risk and our needs. Up-to-date, accurate information concerning all issues about women living with HIV/AIDS should be easily and freely available.
8. WE NEED recognition of the fundamental human rights of all women living with HIV/AIDS, particularly women in prisons, drug users and sex workers. These fundamental rights should include the right to housing, employment and travel without restrictions.
9. WE NEED research into female infectivity including woman to woman transmission, recognition of and support for lesbians living with HIV/AIDS.
10. WE NEED decision making power and consultation on all levels of policy and programmes affecting us.
11. WE NEED economic support for women living with HIV/AIDS in developing countries to enable them to be self-sufficient and independent.
12. WE NEED any definition of AIDS to include symptoms and clinical manifestations specific to women.

work, immigration status, socioeconomic status or other factors of minoritization), these violations can become more serious. In the context of these persistent violations of our SRHR, the 12 statements (Table 1), which all highlight issues beyond bio-medical aspects of HIV, are as relevant now as they were in 1992. So, where are we now in addressing the unfinished business of our SRHR?

Where are we now? Beyond the WHO 2017 guidelines on SRHR

In 2014, after decades of advocacy around SRHR from networks of women living with HIV, WHO commissioned a global values and preferences study (GVPS) led by and for women living with HIV.⁷ Violence against women featured repeatedly throughout the study report, which documented the survey findings from 945 women from 94 countries.

WHO's 2017 Consolidated Guideline on SRHR of women living with HIV⁸ was informed by the study and is woman-centred, rights-based and gender-equitable, in line with the GVPS findings. WHO Director-General, Dr Tedros Adhanom hailed the collaborative Guideline development process as a first for WHO and one for WHO to replicate in future.

However, since WHO's 2017 Guideline publication, its content, and the participatory process used to develop it, have largely been ignored by United Nations (UN), policy-makers and others alike.⁹

COVID-19

The COVID-19 pandemic has shaken the world, revealing the stark and deep socio-economic and political dimensions

of poverty and ill-health. The UN Secretary General has likened COVID-19:

to an x-ray, revealing fractures in the fragile skeleton of the societies. . . . while we are all floating on the same sea, it's clear that some are in superyachts while others are clinging to the floating debris.¹⁰

The combined health crisis and state restrictions have made the community responses of networks of people living with HIV and civil society all the more important, yet all the more difficult. The crises have also revealed clear disparities and socioeconomic barriers that many women experience daily. A recent Lancet article confirmed the global impact of COVID-19 on mental health, especially of women and young people,¹¹ citing women's heightened pressures of domestic violence and disproportionate duties as carers during the pandemic as contributory factors. This echoes our own research findings, which assessed the effects of lockdown on our lives, and documented our self-help responses.¹²

A 2020 ICW Latina Youth Area study held focus group discussions to identify emerging needs of young women living with HIV in Latin America. The identified needs were rooted in existing socioeconomic inequalities, which were only made evident through the effects of COVID-19: lack of decent employment, access to education for children and the right to daily food, and the great need to create psychological support structures for young women who are mothers and who have not been able to disclose their diagnosis to their families due to self-stigma.

Among the many lessons of COVID-19, we see, from many reports from around the world, just how essential the

knowledge and experience of networks of women living with HIV are to responding to unmet community needs across the pandemics. These include ensuring women living with HIV can access nutrition and treatment, as well as demanding access to SRH care.^{13–22}

2021: a year of global strategies

2021 has been a significant year for HIV. It is 40 years since HIV was first identified in the United States;²³ nearly 30 years since ICW was created; 30 years since the first annual 16 Days of Activism Against Gender-Based Violence;²⁴ and 20 years since the Global Fund for AIDS, TB and Malaria was launched.²⁵ Furthermore, in 2021, there have been seven global processes regarding women and/or HIV: the Joint United Nations Programme on HIV/AIDS (UNAIDS) Global AIDS Strategy;²⁶ the UN High Level Meeting Political Declaration on HIV/AIDS (HLM);²⁷ the Global Fund's strategy development process for 2023–2028;²⁸ WHO's Department for HIV, viral hepatitis and STIs draft strategy;²⁹ the Generation Equality Forum and Global Acceleration Plan for gender equality;^{30,31} draft strategy by the United States President's Emergency Plan for AIDS Relief (PEPFAR) and UNDP's draft health consultation, respectively.^{32,33}

The UNAIDS Global AIDS Strategy development process included a global consultation process, coordinated by Women 4 Global Fund.³⁴ UNAIDS also supported ICW and others to host a series of consultations with women living with HIV, including a special focus on women living with HIV from key populations to inform the Global AIDS Strategy.³⁵ However, other processes did not engage women living with HIV meaningfully at all. WHO's consultation and draft strategy,³⁶ PEPFAR's draft strategy and the Generation Equality Forum^{37–39} all omitted to make specific efforts to meaningfully involve or centre the priorities of women living with HIV. This is a significant oversight, particularly considering that 53% of all people living with HIV globally are women and girls,⁴⁰ and the clear evidence that women living with HIV experience significant inequality at the intersections of gender, HIV status, violence, bodily autonomy, SRHR, economic dependence and other factors. Incalculable time and funds have gone into these and other strategy development processes over the decades. Yet, as we explain throughout this article, we consider that progress on achieving our SRHR remains uneven and still lacks momentum, investment and political will. Our concerted advocacy efforts around all the processes have been almost wholly unfunded, depending once again on women's unpaid work, and a determination by women's networks to mobilize to ensure they are heard in these processes.

A big-picture review of the non-governmental organization (NGO) statements and outcome documents do reveal some positive signs that our efforts have borne some fruit, including strong commitments in the 2021 HLM to human rights, particularly SRHR.²⁷ Within the Global AIDS

Strategy, dedicated results areas focused on community-led interventions, human rights and stigma and discrimination reduction, gender equity and gender-based violence reduction.²⁶ While the earlier draft of the WHO strategy was disappointing on these key issues, coordinated advocacy appears to have produced some progress, with the current draft (as of December 2021) including promising indicators on gender equality and human rights.⁴¹ However, it still omits key issues including the need to recognize that VAWG upon or after HIV diagnosis, both at home and in healthcare settings, is a significant factor in women's lives around the world, with considerable consequences for their SRHR, including capacity to access health services.⁴²

We also see how other worrying gaps persist. Lacking in particular, are specific investments to transform the underlying structural determinants of gender inequalities,⁴³ that are widely documented to lead to girls', adolescents' and women's vulnerability, to HIV, to early child marriage, to other forms of violence and other sexual and reproductive rights violations, like obstetric violence⁴⁴ and coercive practices and all their consequences.^{45,46} Another gap we identify is lack of focus and investment in women's unique health care priorities across the lifespan, beyond our reproductive capacity.^{47–50} Our priorities from high-income countries (HICs),⁵¹ as well as LMICs also include violence reduction, mental health and support for women ageing with HIV. Efforts to collect disaggregated data that will allow us to understand women and gender diverse individuals' unique experiences are still rare.³⁴ Significantly, there has been much rhetoric in various draft policy documents about human rights and specifically reduction of stigma and discrimination as drivers of the epidemic. Yet there remains scant practical investment: in efforts to reduce stigma and discrimination against women;⁵² in comprehensive, integrated, rights-based, respectful health services that include SRHR; or in support to networks of women living with HIV to undertake advocacy to realize their full human rights, including SRHR.^{53,54}

Overall, it is heartening that our global advocacy has led to positive improvements in the UNAIDS, HLM, Global Fund and some action coalitions of the Generation Equality Forum;³⁰ and that the WHO and PEPFAR versions of the draft strategies current at the time of writing have some improvements. However, even strong commitments are toothless tigers if they do not have adequate prioritization, investment and political will. Meanwhile, the current versions of the draft WHO and PEPFAR strategies^{36,45} and the other Generation Equality action coalitions still contain key gaps.^{37–39}

Accelerating SRHR: what needs to change?

So, what needs to change, to transform commitments into reality and realize effective, ethical and sustainable programming to respect, protect and fulfil our SRHR, and to

Table 2. Our checklist for change.

Our checklist for change: What we want and look for in strategies, policies and programmes, to achieve our SRHR	What we regularly see and get
<p>Woman centred Rights based and trauma-aware</p> <p>Gender equitable or transformative Integrated, holistic, comprehensive Across the lifespan</p> <p>Respecting intersectional identities of women, trans and non-binary people in all our diversities; and alliance building around shared experiences in relation to power inequalities Real consideration of girls and young trans and non-binary people in all our diversities as well as meaningful engagement across the work</p>	<p>Disease focused Emphasis on meeting targets: not enough focus on human rights principles Gender blind or exploitative or male-oriented Siloed, bio-medical specific, piece meal Event specific (mainly perinatal); focused on adolescent girls and young women in certain geographies Focus on key population groups in ways that address only one aspect of identity, or that classify people into one group (e.g. drug use) without regard to other (e.g. gender inequitable) aspects of their lives Girls mentioned as an add-on, or 'AGYW' policies, strategies and programmes that do not consider the diversity, priorities, rights and leadership of girls and young trans and non-binary people; or address issues of age of consent and service access; or ensure support for their organizations</p>
<p>Meaningful involvement throughout in design, delivery and evaluation of policies, programmes and services</p>	<p>Policies, programmes and services designed, without involvement of women living with HIV, as 'one size fits all'; women shamed and blamed if they do not attend</p>
<p>Research priorities defined, investigated and validated with/by women Meaningful, collaborative involvement throughout, including co-funding, co-authorship, co-presentation Use of mixed-methods research, combining formal and participatory, quantitative and qualitative methods on gender norms, HIV and various types of VAW Qualitative and quantitative outcomes ('how' and 'why' as well as 'what')</p>	<p>Research priorities defined, investigated and validated by outsiders with no engagement of communities Women and girls treated as 'beneficiaries', targets of 'interventions' and 'subjects' or 'objects' of research Research hierarchy approach, placing RCT as gold standard, dismissing 'grey literature'</p>
<p>Inclusion of gender- and age-disaggregated indicators and data collection, that ensures visibility of women and girls living with HIV and speaks to the nuances of our lives Services for women and gender-diverse people across workplaces, other situations and intersections, recognising our full humanity and supporting us as sexual beings Enabling and protective environment – cultures, faith environments, laws, policies and programmes and health services that protect communities and women in all our diversities</p>	<p>Outcomes based only on quantitative data ('how many'). Sometimes no data are even collected that would enable outcomes to be monitored. National indicators for people with HIV that are not disaggregated by age, sex or gender, and just relate to targets</p>
<p>Inclusive peer-driven support models Funding for us and our organizations, and long-term investment in our priorities Substantial national funding that can make a difference to our lives Women seen as part of the solution and as active change makers with expertise through lived experience Respectful inclusive language</p>	<p>A good woman / bad woman dichotomy that blames women for acquiring HIV, blames sexuality, wants to take away sexual control from women and desexualises women Punitive environment – cultures, faith environments, laws, policies and programmes and health services that punish communities and women</p> <p>Top-down service delivery models Zero to near-zero funding for our priorities. Funding for donor priorities, and short-term externally defined targets Not enough national funding and at the right scale to make a real difference Women are seen as 'the problem' to be solved</p> <p>Blaming objectifying language</p>

SRHR: sexual and reproductive health and rights; AGYW: adolescent girls and young women; VAW: violence against women; RCT: randomized controlled trial.

create a truly gender-transformative response?⁵⁵ Time and again, our global and regional networks give the same feedback, and repeat the same points in our advocacy. The new table created for this article (Table 2) illustrates what we have constantly stressed are our priorities, compared to

what we repeatedly see in policies, programmes and funding. It also reflects the fundamental approach, principles and recommendations of WHO's 2017 Consolidated Guideline on SRHR of women living with HIV, based on responses from 94 countries.⁷

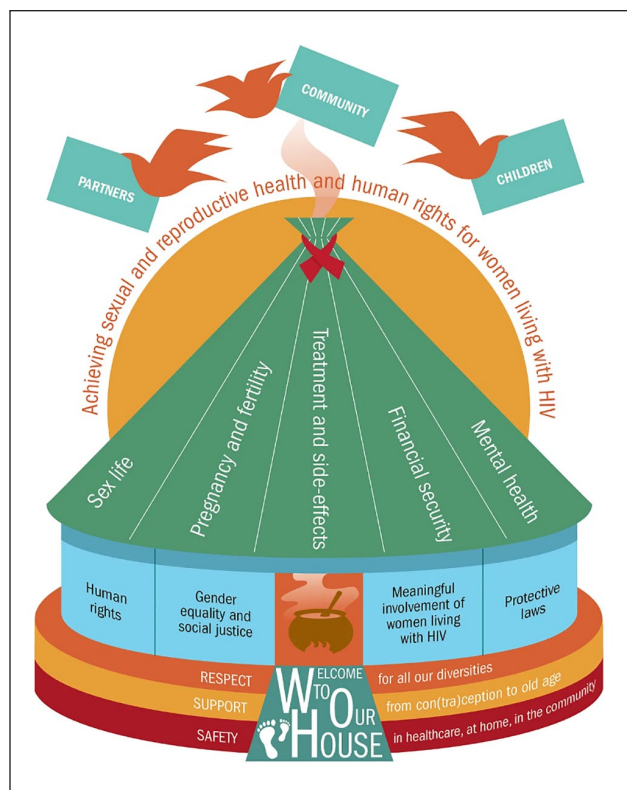


Figure 1. The safe house model.⁷

The safe house model

This section reviews what has been achieved and what is still missing from women's SRHR. It is based on a model of a safe house (Figure 1) created from the findings of the GVPS conducted by women living with HIV and our supporters in 2014.⁷

A safe house model may look nice. But what does it take to enable the house to be safe? The model was created to illustrate our values and preferences: in effect our own priorities in our lives, and what we consider it will take to achieve our SRHR; and ultimately to contribute to an effective, ethical and sustainable response to HIV. It first appeared in the report of the WHO-commissioned GVPS, to inform WHO's guideline published in 2017.⁸ Study extracts appear throughout the resulting guideline.

The model also identifies research areas prioritized by women rather than by researchers, clinicians or policy makers. It portrays how we have many different, complex interconnected dimensions to our lives, identified by the study's respondents that shape and influence our SRHR: and that hinder or facilitate achieving them. Although we cannot discuss them all here, we explore some key research areas, prioritizing those which especially influence other areas.

The foundation layers: safety, support and respect

Safety: in healthcare, at home, in the community. Safety and freedom from all kinds of violence against women

and girls (VAWG), including fear of violence, is a fundamental part of upholding and protecting the SRHR of women living with HIV. This is why it forms the bottom foundation layer of this 'safe house' image and was mentioned throughout the Guideline. Women living with HIV have long raised concerns about the links between VAWG and acquiring HIV, and about how violence against them can often start or worsen on diagnosis.^{56,57} The 2018 Gutmacher Lancet-Commission Report also put women's safety and freedom from violence at the core of its evidence of an 'unfinished SRHR agenda'.^{58,59}

WHO in 2005 established that violence against women from a sexual partner increased vulnerability to HIV and other STIs in high prevalence countries by 1.5 times.^{60,61} The GVPS findings reflect this, showing also how violence could either start or increase for many women upon diagnosis. This was especially noticeable in healthcare settings, and all levels of violence were even worse for women from key populations around the world.^{62,63}

Women living with HIV around the world have documented how they experience violence in many settings.⁵⁷ at home, from intimate partners, other family and community members, or at school, work, or in places of worship; in the realm of the law, where criminalization of women with punitive laws against sex work,⁶⁴ drug use or LGBTI+ rights, as well as laws against HIV transmission, are widespread globally;⁶⁵ and in healthcare settings.^{66–68} The latter, at worst, has included obstetric violence,^{70–72} and forced sterilizations in multiple countries.^{72–74} Violence is also known globally to be triggered by pregnancy,⁷⁵ and can worsen menopause symptoms.⁷⁶

These grim findings were echoed in a UN Women-commissioned global treatment access barriers review. Women living with HIV from Bolivia, Cameroon, Nepal, Tunisia, Kenya, Uganda and Zimbabwe, researching with peers, all consistently described chronic physical, sexual, financial and psychological violence and abuse, at home and in healthcare settings. Again, this was exacerbated for women in key populations.^{77,78} Sex workers and trans communities have also documented diverse barriers to comprehensive SRH services in diverse settings.^{79–81}

ICW Argentina's 2021 study on violence and HIV concluded that violence against women with HIV is a multi-situated phenomenon, transversal throughout life and with different actors involved. The needs of women with HIV in relation to the approach, care and follow-up of situations of violence are focused on a process of empowerment that requires prior processes of information, awareness and education, mainly provided by women peers, and then aiming at a more structural level, influencing public policies and making visible an agenda for women with HIV (Figure 2).^{82,83}

Yet the October 2021 draft WHO strategy barely acknowledges this.⁸⁴ Indeed, it is disheartening and



Figure 2. “Me, You, Us”, Footprints of violence and of AIDS on the bodily state and identity of women living with HIV, sex workers and trans women of three cities in Bolivia: an example of body mapping from Bolivia.⁸³

distressing to see how the latest draft PEPFAR strategy (November 2021) states:

Gender inequality also impacts boys’ and men’s access to HIV testing and treatment services. Across the PEPFAR program, boys and men are less likely than girls and women to know their HIV status, initiate or remain on lifelong treatment, or attain viral suppression⁸⁵

citing the MenStar Coalition.⁸⁶ This is frustrating because it does not also explain that girls and women are ‘targeted’ for HIV testing (and we use ‘targeted’ advisedly), largely because of the skewered focus on females as potential vectors and vessels of HIV transmission, with resulting testing during pregnancy (as a recent GFATM/WHO report rightly points out)⁸⁷ as part of elimination-of-mother-to-child-transmission (‘eMTCT’) programmes, rather than through any gendered, that is, women’s *rights*-focused, lens. While more men undoubtedly need to be tested, and have every right to quality care, it is just misleading to describe this as a ‘gender inequality’ issue, when so many women living with HIV are still experiencing abuse and violence if they try to access perinatal or other care in healthcare settings.⁴⁴

Girls and young women in sub-Saharan Africa are especially vulnerable to acquiring HIV: they are 2.4 times more likely to acquire HIV there than young men.⁸⁸ A UNICEF-hosted consultation report confirms other forms of violence, such as early child marriage, and girls’ and young women’s HIV acquisition have shared causes, rooted in the power imbalances caused by gender inequalities.⁸⁹

Yet there is still limited understanding among researchers, policy makers, programmers or donors of the links between VAWG and HIV, or of the importance of addressing VAWG for effective SRHR/HIV programming and vice versa. The 2018 Global Partnership to end all stigma and discrimination, for example, has yet to deliver for women.⁵²

A 2020 evaluation commissioned by UNAIDS on the work of the Joint Programme to address the linkages between HIV and VAWG found that while there are pockets of good practice, inadequate attention is being paid to transformative approaches to address the structural and root causes of gender inequality, HIV and VAWG. It concludes that

Both targeted and mainstream approaches to addressing the intersections of HIV and VAWG were in evidence in the case study countries but they are unsystematic and not clearly focused on the different types of violence experienced by women and girls living with HIV in their diversity nor on tackling the root causes of this violence.⁹⁰

Intimate partner violence (IPV) is preventable and women living with HIV have done much work themselves on this. Social support has been found to be an important factor in mitigating and moderating the consequences of IPV and improving health outcomes, including closely related mental health challenges.⁹¹ In addition, networks of women living with HIV advocate for trauma-informed care, reducing stigmatizing behaviour among health care providers,⁹² and funding for peer support,⁹³ to make women and girls feel safer in healthcare settings,⁹⁴ in communities and at home. The demand is there: policies need to be in place to make them happen and to fund them properly.⁹⁵ Yet the current PEPFAR funding criteria and Global Fund grant-making structure do not allow for proper use of these evidence-based programmes to reduce IPV effectively in communities.

Support: from con(tra)ception to old age. The WHO 2017 Guideline called for lifelong SRHR support for women living with HIV. Anyone facing challenges in life, women and girls living with HIV included, needs and has the right to support from those around them (Figure 3). However, policy makers’ focus on women’s SRH has long been narrowly focused on pregnancy and prevention of vertical transmission.⁹⁷ This has left multiple gaps in services, omitting SRH services for girls who were born with HIV, those who acquired HIV through child marriage and sexual abuse, those transitioning to adult services, women of all ages who choose not to or cannot have children, as well as women beyond their reproductive years. The priorities



Figure 3. Love positive women.⁹⁶

of all these women are still barely addressed. It is no wonder to us that so many young women struggle to take their antiretroviral drugs (ARVs).^{98–100} Yet young women are barely consulted around their own diverse SRHR priorities,^{42,101} including the challenges they face, for instance, in healthcare settings, with obstetric violence.⁴⁴

For example, in 2020, the youth area of ICW Latina conducted a situational report on perspectives of women with HIV in Argentina, Chile, Honduras and Nicaragua.¹⁸ One key study finding was that there are no data on how many young women with HIV aged 15–29 years have developed cervical cancer; how many have had access to human papillomavirus (HPV) vaccines; or to pap smears in Chile and Argentina. In Central America, it is also impossible to find research about young women with HIV that goes beyond HIV prevalence and diagnosis statistics.

These findings reflect our urgent and repeated call for women to be involved in meaningful research processes across the lifespan and for all data to be gender- and age-disaggregated.

Respect: for all our diversities. The safe house third foundation layer is respect. Women living with HIV everywhere work to support each other, irrespective of our differences.^{56,102} We see our diversity as a strength and celebrate our differences. Women living with HIV from key and other populations are doing extraordinary work in the face of extra stigma and discrimination.

For example, work on drug use rights and harm reduction specifically in relation to women is conducted in Tanzania by Salvage, a sister organization of Tanzanian Network of People who Use Drugs (TaNPUD), coordinated by Happy Assan.^{103–106}

In Indonesia, Women and Harm Reduction International Network (WHRIN),¹⁰⁷ in partnership with the International Women's Right's Action Watch (IWRAP)¹⁰⁸ Asia, supported two internships for Indonesian WHRIN members. The WHRIN interns assisted with the research and development of an Indonesian shadow report on the situation of women who use drugs in Indonesia.¹⁰⁹ Recommendations were subsequently made by the Committee to 'eliminate discrimination, violence and stigma against women [who use] drugs'.¹¹⁰ This recommendation requires activity and a response from the Indonesian government within 4 years.

Phelister Abdalla, National Coordinator of KESWA¹¹¹ and Board Member of the Global Network of Sex Work Projects campaigns tirelessly for the rights of sex workers, in Kenya and globally, to work safely and to be able to access supportive health and other services, including during COVID lockdowns.^{112,113}

Some women in trans communities and women who use drugs, as well as young women who have grown up with HIV, have all augmented the WHO SRHR Guideline work, to develop their own advocacy around SRHR in their own regions.⁹ In Ukraine, Positive Women in coalition with Legalife-Ukraine (sex workers), Svitank Club

(women using drugs) and Insight (Lesbian, Bi-, Trans-Queer, Intersex (LBTQI) Group) developed Committee on the Elimination of all forms of Discrimination Against Women (CEDAW) shadow reports (2017 and 2020)^{114,115} to hold the Ukrainian Government to account around its lack of support for women's rights, including in the context of harm reduction and VAW. This work has since led to women joining the Global Fund Country Coordinating Mechanism and accessing Global Fund grants for Positive Women's work.

Yet women who are lesbian, bisexual or queer also feel invisible, ignored or considered not vulnerable to HIV, criminalized and/or subjected to 'conversion' therapies, increasing their vulnerability to VAW. Organizations of women living with HIV and allies working on this include GALZ,¹¹⁶ Rawo,¹¹⁷ Pakasipiti¹¹⁸ in Zimbabwe; Positive Young Women's Voices in Kenya; and the Sophia Forum in United Kingdom.^{119,120} Yet all face extremely limited funding, thus their services are just in limited urban areas.

All these examples highlight the critical work conducted by women in all our diversity, with chronic lack of funding and often in highly punitive environments. They reflect our ongoing call for protective laws and sustained long-term investment in community-led responses.

The walls: rights and accountability. The safe house walls include human rights, gender equality and social justice, meaningful involvement of women living with HIV in all decisions that affect our lives¹²¹ and protective laws. These issues are, again, inextricably entwined.

Realizing human rights and in particular SRHR has been recognized as essential to achieving the last mile in the HIV response in the majority of multilateral strategies.^{122,123} Yet, this has not translated into consistent and long-term investments in achieving gender equality and ensuring meaningful engagement of women living with HIV, or into key pieces of human rights infrastructure that are needed to advance rights or to hold governments accountable to their obligations to respect, protect and fulfil women's SRHR. Networks of women living with HIV are often on the frontlines of confronting human rights violations, yet remain underfunded and undervalued.

To ensure that women living with HIV are able to achieve our SRHR, women must know their rights and be able to claim them. Governments, healthcare systems and other institutions must respect those rights for all women, including women from key populations. Women must be able to access remedy and redress when their rights are violated. There is also lack of recognition of the SRHR of trans people who are assigned female at birth and the need for them to have safe access to all the SRH services.

Human rights work ending coercive practices in focus. ICW member networks around the world have been at the forefront of identifying and documenting stigma, discrimination

and human rights abuses experienced by women living with HIV.⁷³ In a younger women's dialogue on SRHR held by ICW and the Namibia Women's Health Network (NHWN) in Namibia in 2008, young women shared their experiences of forced sterilization. This ultimately resulted in successful litigation to confront the practice of coercive sterilization of women living with HIV.^{124,125}

Since this time, ICW networks have continued advocating against documenting and challenging forced and coerced sterilization all around the world. In Kenya, the work of local networks of women living with HIV culminated in the Robbed of Choice⁷⁴ report and ongoing litigation on behalf of women who had experienced coerced sterilization and obstetric violence, brought by Kenya Legal & Ethical Issues Network on HIV and AIDS (KELIN) in the Kenyan High Court.¹²⁶

In 2015, ICW, ICW Southern Africa and allies filed a strategic complaint with the South African Commission on Gender Equality (SA-CGE) on behalf of women living with HIV who were sterilized without informed consent. The resulting investigation confirmed that women living with HIV in KwaZulu-Natal and Gauteng were sterilized without their informed consent in public hospitals on the basis of discrimination related to their gender and HIV status, and that the women experienced a range of human rights violations of the rights to equality; to dignity and bodily integrity; to the highest attainable standards of health including sexual and reproductive rights; and that ultimately they were 'subjected to cruel, torturous or inhuman and degrading treatment'.¹²⁷ The complaint has opened an important avenue for dialogue with the National Department of Health.

Most recently, in December 2021 ICW Young Advocates Media Team released the #NowWeKnow video campaign on obstetric violence based on the stories of women living with HIV in their communities. In this, young women living with HIV from Kenya, Nigeria, South Africa, Indonesia, and Kyrgyzstan, powerfully describe young women's experiences of obstetric violence, disrespect and abuse in maternity services, forced and coerced abortion and sterilization of women living with HIV, and call for action to address these issues.⁴⁴

There have been a number of high level and important condemnations of coercive practices, notably the 'Eliminating forced, coercive and otherwise involuntary sterilization interagency statement'.¹²⁸ However, an increase in longer term and sustainable investments in capacity for women's networks, and political will from global funding entities are needed, to ensure governments take action to confront persistent human rights violations experienced by women living with HIV.

Protective laws. Eliminating criminalization of HIV transmission is critical to create an enabling environment for women to realize their SRHR and to hold governments accountable for the obligations to protect against human rights abuses. There is now global consensus



Figure 4. Sheep made for the Catwalk 4 Power programme.¹³²

that criminalization is counterproductive, undermines evidence-based health strategies, discourages women living with HIV from accessing care, and increases the risk of violence against them.^{129,130} In Uganda, for example, there have been high profile cases of women living with HIV who have been falsely and sensationally accused of transmitting HIV to children, under provisions of the HIV Prevention and Control Act, 2014. The widely reported cases of Sylvia Kuomhangi and Rosemary Namiburu, women living with HIV who were falsely charged with transmitting HIV to children in their care under an overly broad interpretation of the penal code, continue to discourage people who know they have HIV from sharing this information with their potential sexual partner, and others, through fear of criminalization and sexual related violence.¹³¹

The roof – social and economic quality of life and good health. The house roof consists of our rights to safe and pleasurable sex, if we want it, pregnancy and fertility, choice and discussion of treatment and side effects – and our rights to bodily autonomy and informed choice regarding all these (Figure 4). The roof also includes financial security and mental health issues. We focus here on some key points.

Pregnancy and fertility. This is a vast topic but much has been written elsewhere so we just include some key references regarding women's work on this topic around the world, including by women in key populations.^{119,133,134} Here again, women have long led a drive away from top-down bio-medical disease-prevention-based 'elimi-

nation-of-mother-to-child-transmission' approaches to a woman-centred, rights-based gender-equitable approach to 'ensure our SRHR'.^{73,135,136} In particular, women in HICs are pushing for the right to informed infant feeding choice including breastfeeding, which is still not recommended in some HICs.^{137–139}

Treatment and side-effects. This part of the GVPS was the least well reflected in the 2017 WHO Guideline. Women have long called for their rights to informed choice regarding if, when and how to take HIV medication, but this has been an ever-challenging issue, with women often being blamed and shamed if they do not adhere to medication (Figure 5).^{141,142}

For example, there was an outcry from women around WHO's HIV Department 2018 global alert¹⁴³ in relation to Dolutegravir and its potential effects on a foetus, which did not specify women's rights to informed choice, as established by the WHO Guideline in 2017. Consequently, many countries issued a blanket ban on Dolutegravir by all women aged 15–49 years.¹⁴⁴ The issues have now been resolved, to some extent, but not without a lot of dismay en route.¹⁴⁵

There are other unaddressed concerns about lack of rights to informed choice around different HIV treatment regimens and side effects. In most LMICs, women living with HIV do not have any treatment choices, but have to make compromises with what is available. For example, in Kenya, an Efavirenz-based regimen for everyone on treatment was forcefully phased out and replaced with a Dolutegravir-based regimen.¹⁴⁶ Yet Dolutegravir has led to



Figure 5. Chair made of empty ARV bottles, Barnara Kemigisa.¹⁴⁰ Photo © Evelyn Lirri. Barbara writes: ‘The bottles in a chair form give fresh relevance and value to something disregarded by society including those that get life from it. We all chose what we want to make out of other people’s brokenness and I chose restoration and these bottles give me the belief that people can be anything regardless of how society sees us’.

weight gain for many women and girls living with HIV, with little apparent concern from health workers. Joyce Ouma, a 24-year-old living with HIV from Kenya shares her frustrations over this in a powerful recent blog.¹⁴⁷

Financial security. This is another huge topic that can only be touched on here. Linkages between gender inequities, financial insecurity, climate change,¹⁴⁸ food, water, fuel, education, healthcare, unplanned pregnancies, VAW and mental health abound. Pregnant women living with HIV who cannot afford scans may die from treatable complications. Women having HIV with abnormal smear tests may not afford treatment.¹⁴⁹ Poverty has taken an especially heavy toll on women living with HIV during the COVID-pandemic.¹² Again women continue to call for a recognition of the intersectionalities of our lives and the need for effective multi-dimensional responses.

Mental health. Women living with HIV have long known the significant mental health challenges of an HIV diagnosis, compounded by other factors in their lives. The responses to the GVPS¹⁵⁰ closely mirrored the findings about violence described above. They confirmed that some women had already experienced mental health challenges before diagnosis; and that these either increased or, for some women, started upon diagnosis.¹⁵¹ Again, women from key populations experienced par-

ticular challenges.

Thankfully there is now growing recognition that an HIV diagnosis can be a traumatic event that can cause post-traumatic stress, which can result in shame and self-stigma,¹⁵² and make it hard for women to access services.^{153–155} Similarly, women who have grown up facing adverse childhood experiences (ACEs) can also find it hard to access services.¹⁵⁶ In both cases, this can be especially difficult if the services themselves are stigmatizing or discriminating or have institutionalized violence.^{67,77} Women have too often been blamed, shamed and exposed by providers, accusing them of ‘failure to adhere’ or ‘failure to disclose’ and being ‘defaulters’ and ‘lost to follow-up’, instead of receiving respect, care and support when it is most needed. Understanding these causal links can help women and their clinicians alike to overcome the challenges and build respect, dignity and resilience.

It is refreshing to see how a growing number of service providers are now emphasizing the need for training in trauma-aware care, so that women do not have to explain their absences or challenges with attending clinic or taking medications regularly. Women living with HIV have trained healthcare providers to understand more clearly the diverse challenges facing the women who access their services.¹⁵⁷ Trauma-aware care training and a welcoming women-friendly, clinic environment with integrated services, to support women living with HIV in all their diversity across

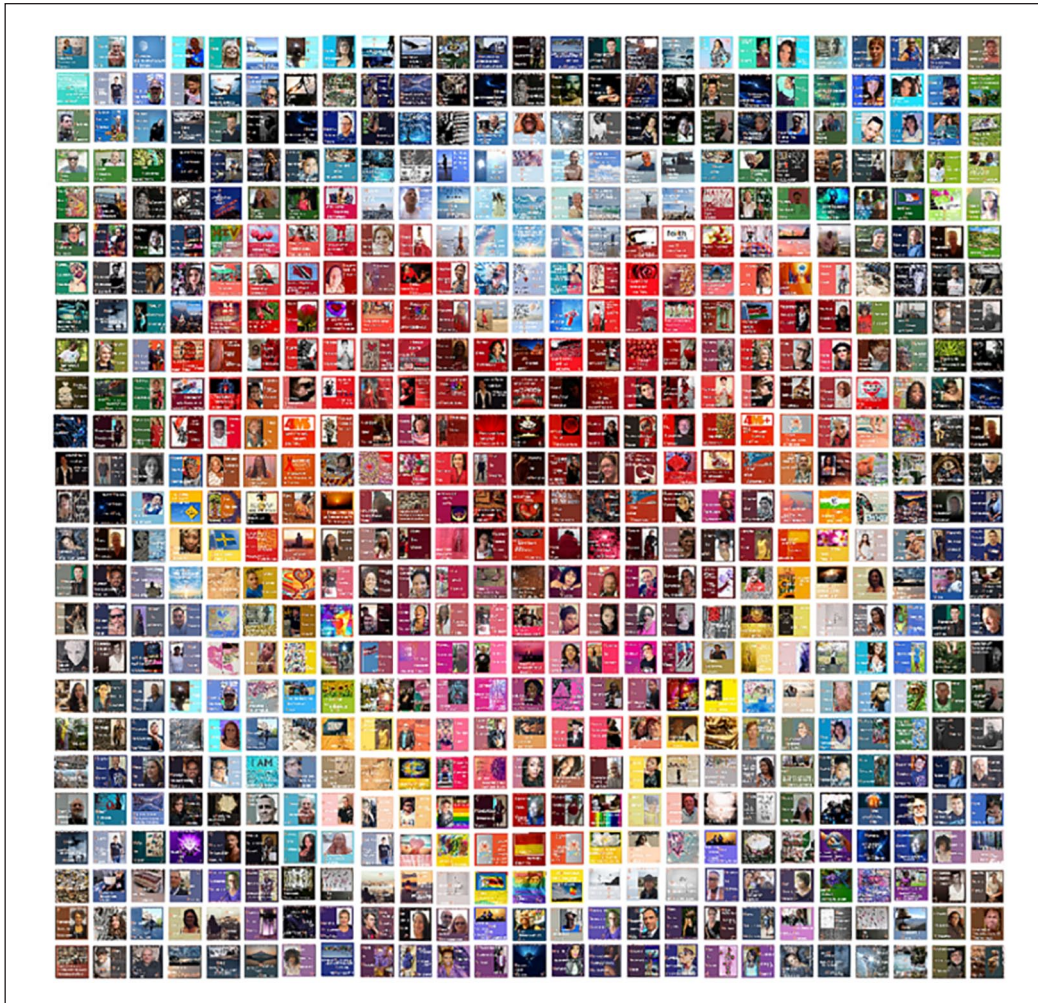


Figure 6. Love positive women, Mel Rattue.¹⁶⁴

the lifespan, need to become standard minimal practice globally, to uphold women's quality of life.^{44,153,158–160} We do note and appreciate that PEPFAR has now included this in its draft strategy.

Women living with HIV have also addressed mental health. One inspiring example is the use of art and mindfulness work to promote positive health and well-being.^{161–163}

This section illustrates how women know what their priorities are, what is needed to address them, and are leading extraordinary initiatives to overcome them, with minimal support (Figure 6). Once more, the right policies, long-term funding for, and other investment in our networks, peer support and SRHR can transform the status quo.

Supporting others

Supporting partners, children and community. Above the safe house are three birds, depicting how women support others around us. Women living with HIV of course have an intrinsic right to have their own rights upheld. But all too often and for far too long, this statement has been con-

tested and the world has assumed that women's primary role in life is an instrumental one: to support and protect others around them. In the world of HIV, this is reflected especially in the 'eMTCT' mantra, which focuses primarily on ending transmission of HIV by women to their children or partners, rather than on ensuring first and foremost that their own SRHR and well-being are upheld.¹³⁵

Nonetheless, women living with HIV have done their utmost to care for their partners and children, as well as many other family and community members. In the case of male partners, this can also often be in the context of IPV which, as explained earlier, is closely linked to HIV causes and consequences for many women. It is also increasingly recognized that women who experience violence and men who perpetrate it have often experienced and/or witnessed violence from childhood. These ACEs can have a lifelong impact on people's lives, affecting their choices, or lack of them, their resilience in the face of later challenges, their capacity or not to seek health and/or social care, and life-cycles of violence.¹⁵⁶ But VAWG is preventable.¹⁶⁵ Some examples of initiatives led by women living with HIV

show how specifically focusing on working with male partners of women living with HIV and working with children living with or affected by HIV and AIDS can effect real change.^{158,166–173} In relation to supporting communities too, women living with HIV have led the way in creating peer support networks^{97,174} and radical models of ‘collective care’.¹⁷⁵ Yet once more peer support and collective care models need sustained funding to realize their full potential.

Ageing with HIV and the unending comorbidities. As women are growing older with HIV, menopause is an area of growing concern and interest. In 2018, the PRIME Study (Positive Transitions Through the Menopause) explored how the menopause impacted the health and well-being of women living with HIV.¹⁷⁶ Sophia Forum has also done much work on the menopause.¹⁷⁷ Around the world there has been high demand for their menopause booklet, and translations are now being produced in Portuguese, Hindi, Bengali, Urdu, Spanish and Russian to make the information available to more women.¹⁷⁸ ICW has also addressed the issue of ageing with HIV, including through a Gender Matters webinar in November 2021 featuring Martha Tholanah in Zimbabwe, Diana Weekes from the Caribbean, Sita Shahi from Asia Pacific, and Jane Shepherd and Rebecca Mbewe from the United Kingdom.¹⁷⁹ In Zimbabwe and South Africa, there has also been work on the menopause, including reference to women living with HIV, with two respective booklets published in multiple languages.¹⁸⁰

Many comorbidities as well as non-communicable diseases in the context of women and HIV are also of concern but are beyond the word limit of this review.

Research: methods, data, involvement

Women living with HIV have had a long-standing research programme, using multiple media over the years. For example, from its foundation in 1992, ICW conducted participatory research in Africa, Asia, Latin America and Europe, on SRHR, access to care, treatment and support, and the priorities and experiences of young women, women who use drugs, refugees and others.¹⁸¹ Research on fertility desires of Zimbabwean women living with HIV appeared in 2002,¹⁸² and the report ‘Oh! This one is infected!’ appeared in 2004.⁶⁹ However, our collective research is often described as ‘grey literature’ and, despite repeatedly raising the same issues over the decades, thereby forming a clear global ‘convergence of evidence’ about the importance of our SRHR to our quality of life and ongoing SRHR violations, it has not been recognized as the robust and valuable source of rich information it is by policy makers, programmers or academics. This has meant that where our SRHR are most violated, there is an ongoing ‘formal evidence’ vacuum: yet our own voices

and views have not been heard and our own research priorities, which often differ from those who conduct research *on* us rather than *with* us, have not been examined (Figure 7). By contrast, research conducted by others, about us, normally does not include us as co-researchers, prioritizes biomedical concerns over our own, often does not disaggregate by gender, age or diversity¹⁸⁴ and prizes quantitative over qualitative indicators. Such measures may produce the ‘what’ but rarely describe the ‘how’ or ‘why’, leaving women living with HIV often overstudied but little understood.^{183,185–187} A separate article in this collection about meaningful involvement of women in clinical trials discusses this in more detail.^{57,183,188–194}

There are some notable recent examples of formal or academic researchers who have specifically reached out to include priorities of women living with HIV, such as Medeiros et al.⁵¹ and Tariq et al.¹⁷⁶ However, these are still very much the exception rather than the rule. Over the years, the ATHENA Network has sought to ensure the meaningful involvement of women in all it has done since its inception in 2005, with women living with HIV on its steering group and involved in its diverse research, training and advocacy activities and co-publications.¹⁹⁵ There have also been some positive recent examples of the meaningful involvement of women living with HIV in good practice guidelines and evaluations. The 2021 UNAIDS evaluators of the Joint Programme’s work to prevent and respond to VAWG in relation to HIV⁹⁰ established the accountability advisory group to ensure women living with HIV were shaping the evaluation and fully involved in the evaluation team. They concluded after this experience that

the concept of ‘independent evaluation’ needs to be revisited. Women who are active in their communities have a wealth of knowledge about what works and what does not, and evaluation practice should be centred around this, ensuring this knowledge and expertise is recompensed and recognised.¹⁹⁶

Also in 2021, Frontline AIDS produced a new Good Practice Guide to gender-transformative approaches to HIV, using a process of meaningful involvement of, and piloting by, a wide diversity of women living with HIV, sex workers, trans women, gender non-conforming people and young women.⁵⁵ Such ways of working, based on co-creation, collaboration and inclusivity, are welcome, long overdue, still rare and can be hard to fund.

Language

A webpage about the power of language states: ‘Language matters. It shapes the way we feel, think, act and react. It also has a physiological effect on our bodies which, in turn, has an effect on all our vital organs’.¹⁹⁷ We have written much about the use of language over the years, reflected also in the WHO Guideline, and space restricts us here (Figure 8). However, the issue is still of

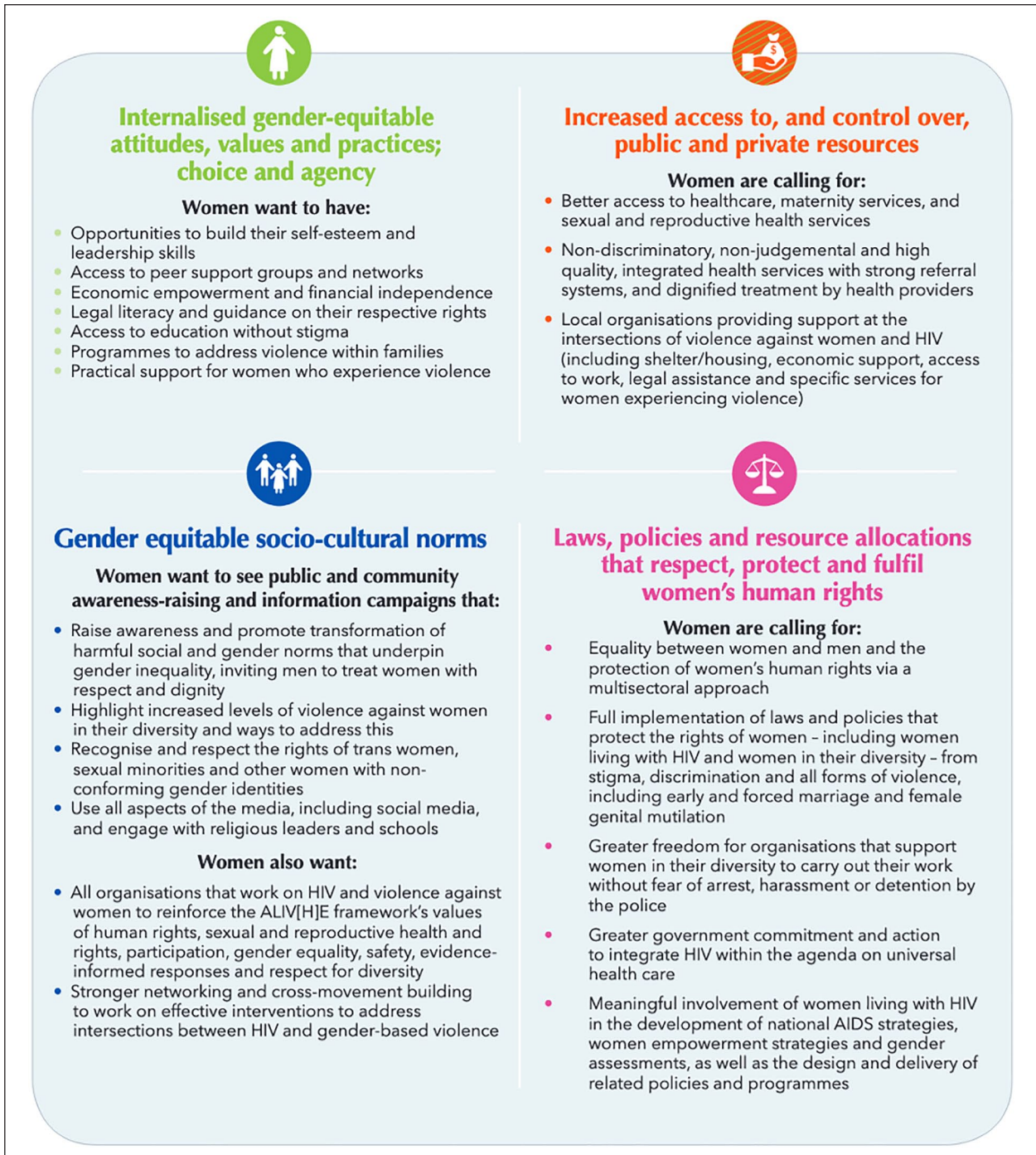


Figure 7. MENA Rosa change matrix.¹⁸³

major concern. We are heartened to see physicians¹⁹⁸ now taking up our concerns and look forward to real positive movement on this,^{8,135,199–208} but there remains room for improvement.^{209,210}

Funding for all our work

The funding challenge has been our constant refrain for decades. In 2003, ICW raised this as a global network of

women living with HIV. In 2011, networks of women and girls around the world signed a global call to action on funding.²¹¹ Overall, funding for women's rights' work has grown ever worse over the years.^{212–220} Generation Equality has a vision that:

By 2026, feminist leaders and activists, women's human rights defenders, and their movements and organizations, including, but not limited to those led by trans, intersex and

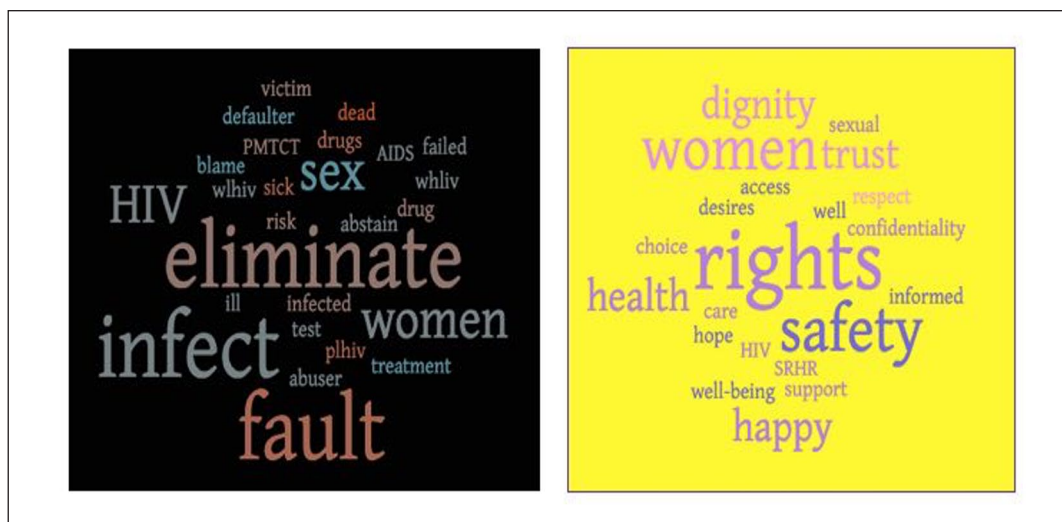


Figure 8. Wordclouds depicting the power of language.¹⁹⁸

nonbinary people, racialized people, indigenous women, women and persons with disabilities, women and persons living with and affected by HIV, young feminists, girls, sex workers and other historically marginalized people, regardless of their status before the law, are fully resourced and supported to become sustainable, can carry out their work without fear of reprisal, and advance gender equality, justice, peace, and human rights for all from an intersectional approach.²²¹

COFEM's 2021 report also highlights what we all seek – sustained funding for our work for transformative change.²²² Change is needed.

Limitations of this review

This review has been written on a wholly voluntary basis across multiple time zones by women living with HIV and some key supporters, who are overwhelmed with their own work commitments, often with limited power, computer or Internet access,²²³ and some dealing with illness, poverty and disabilities, holiday and/or other family commitments. In addition, none of us has access to academic software to support automatic bibliography construction, which done manually is extremely time-consuming. These are not ideal circumstances to produce research articles. However, this is the norm for the women concerned. Many issues were omitted owing to word count but we hope to discuss them in more depth elsewhere. Many women were also excluded from the process owing to limited translation capacity.

The references that we have included, through our virtual snowball method of collective compilation of materials created by women living with HIV, are certainly not exhaustive. However, we are not aware of any other document to date that has tried to gather this amount of (mainly)

English language 'grey-literature' produced by women living with HIV over the decades, or that includes such a globally diverse range of references. In places, there is a surplus of UK-sourced materials used to reference a point. This reflects global funding inequities, based on language, on the United Kingdom's HIC status, and on the existence of a basic welfare state in the United Kingdom, which does give women some basic income and time, therefore, to be involved in some research on an almost entirely voluntary basis. However, funding for research by or with women living with HIV on our own priorities is scant, both in the United Kingdom and globally.

Conclusion and call to action

In conclusion, we welcome and appreciate the opportunity to contribute this review to this special collection on women's health.

Toothless tigers are widespread in the world of global commitments, as current efforts to reduce climate change make all too clear. Yet we believe change can happen. The #metoo, #blacklivesmatter, #refugeeswelcome and #decoloniseaid movements all speak to a deep yearning to shift the needle towards a new point of the compass, so we can all listen to, learn from and build on the experiences and insights of those most affected by global inequalities. Those who have much traditional power, wealth and authority rarely have personal, hands-on experience of the multiple intersectional challenges, which can act as such barriers to achieving quality of life for the majority world.

For women living with HIV, we are potentially on the verge of seismic change, with strong new commitments around our SRHR from UNAIDS, the Political Declaration, the Global Fund, some encouraging signs from WHO's and PEPFAR's latest HIV draft strategies,

and global commitments to accelerate action on gender equality, gender-based violence, SRHR and feminist movements through Generation Equality. There is also some momentum towards universal health coverage for all, including people in key populations.⁷⁹

So what will it take to turn this potential into reality?

As ever, it comes down to political will. Academic researchers, clinicians, donors and those in other powerful roles are seeing the growing need to shift the status quo to follow the evidence, connect and engage more with those whom they are seeking to support. We trust that they too will embrace the left side of the table we presented in the section 'Accelerating SRHR: what needs to change?', which describes the world we want to see; and reject the status quo of the older order.

Clinicians and researchers alike, we need you to do the following:

Move beyond the top-down, disease-driven siloed, target-oriented responses, which have failed so many and which are no longer fit for purpose.

Place women living with HIV in all our diversities, at the centre of research and prioritize our own diverse SRHR issues as these research goals.

Ensure that all research you conduct meaningfully involves women living with HIV throughout.

Check that all platforms you speak from have included women living with HIV meaningfully in their planning – and that women and their own agendas are included in the discussions.

Ensure that all your service delivery meaningfully involves those in your care in design, delivery and accountability controls.

Stand with women living with HIV to engage with donors and other policy influencers to turn evidence into policy – and make change happen.

Join us in celebrating your successes once you see these new approaches flourishing.

Donors, governments and the United Nations, we need you to do the following:

Be courageous in driving through your commitments to investing in our work, organized by us.

Stand firm in your commitment to effecting the structural changes required to create, respect and enact the policies we want to see.

Ensure the involvement, expertise and rights of women in all their diversity as equal partners and influencers at national level, to dispense your funds justly.

Ensure that evaluations are guided by and fully involve women living with HIV – women who are active in their communities, have a wealth of expertise and knowledge about what works and what does not, and that this should be valued beyond being interviewed as key informants or engaged in a tokenizing way.

Ensure safe access to SRH for all, regardless of gender identities.

Fund research on SRH needs for gender minorities.

Remember that it is in your gift to influence the future direction of millions of women's and girls' lives.

An effective, ethical and sustainable response to the AIDS pandemic is possible. Violence is preventable. Mental health and SRHR can be ameliorated with trauma-aware care. The power of peer support is immeasurable. Lives can change. Hope can be restored. Resilience can be built. Rights can be upheld.

The evidence is there. Together we can all do it. Let's go.

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