



ADVOCACY BRIEF

Are the sexual and reproductive health and rights of women living with HIV *still* confined by Covid-19?

An analysis of then and now

Southern and East Africa
SEPTEMBER 2022



ABOUT ITPC

The International Treatment Preparedness Coalition (ITPC) is a global network of people living with HIV and community activists working to achieve universal access to optimal HIV treatment for those in need. Formed in 2003, ITPC actively advocates for treatment access across the globe through the focus of three strategic pillars: Make Medicines Affordable, Watch What Matters, and Build Resilient Communities.

ABOUT BRC

The progress we have seen in access to treatment and improvements in quality HIV services are based on communities self-organising and demanding their right to health. ITPC understands the importance of creating meaningful partnerships within the movement, in order to form broader coalitions to fight for social justice. To find out more about our Building Resilient Communities focus area, click [here](#).

ABOUT GALZ

GALZ is an association of LGBTIQ+ people In Zimbabwe. Our vision is that of a just society that promotes and protects human rights of LGBTI people as equal citizens in Zimbabwe. GALZ's mission is to promote, represent and protect the rights and interests of lesbians, gays, bisexuals, transgender, intersex and queer people. GALZ works with other LGBTIQ+ oriented CSOs, Individuals and the broader CSOs to promote inclusion through advocating for social affirmation of sexual minorities and the repeal of existing homophobic legislation. GALZ is currently operating guided by an ambitious strategic plan LEADING WITH LOVE! which runs from 2021 to 2025. As the oldest LGBTIQ+ organization in Zimbabwe (formed in 1990), GALZ has supported the growth and formation of various LGBTIQ+ CSOs. GALZ's mission includes strengthening its capacity as an institution to continuously evolve and that of its partners towards meaningful engagement in national processes. GALZ leads nationwide research on marginalized communities and develops evidence-based policy position papers.

ABOUT The Jacquelyne Ssozi Foundation

The Jacquelyne Ssozi Foundation is registered with the Uganda Registration Services Bureau with registration number 80020002550007. We are currently based in Luweero District. To date, we have supported about 150 women, of whom 60% are women living with HIV, 30% are Adolescent Girls and Young Women, and 10% are women of old age. Our vision is to support women to feel confident and empowered to participate in and influence society. Our mission is to provide a conducive environment for vulnerable people especially Adolescent Girls and Young Women (AGYW) and children living with and affected by HIV, including those with disabilities in our communities to live a better and healthy life. Our goal is to have a society in which the visually impaired Adolescent Girls and Young Women (AGYW) and vulnerable children have opportunities for living healthy and productive lives. Our values are integrity, honesty, and recognizing our unique contribution. We welcome all equally, we are accountable and promote quality through continued reflection and improvement, We use a person-centered approach, realizing individual potential.

ABOUT Positive Young Women Voices

Positive Young Women Voices (PYWV) is a community-based organization duly registered in Kenya by the Department of Gender and Social Services. Started as a self-help group in 2014, but later registered as a community-based organization in 2017. PYWV harnesses the power of volunteerism, where young women from the community are at the forefront of implementing our project interventions.

Founded as a safe space to amplify the voices of underprivileged girls and women, including those living with HIV in Dandora slums of Nairobi, Kenya, Positive Young Women Voices works towards the vision of humanizing young women and adolescent girls in all their diversities. PYWV exists to mentor and advocate for young women and adolescent girls in all their diversities to advance their rights through access to inclusive healthcare, advocacy and social and economic empowerment.

ABOUT YOUNG POSITIVES SOUTH SUDAN

Young Positives South Sudan (YPSS) is a national Non-Governmental and not-for-profit organisation which brings together adolescent girls/boys and young men and women living with HIV in South Sudan to accelerate the prevention, care and support services. YPSS was born on the pertinent need to promote better quality of life of young people living with HIV/AIDS and to address issues of vulnerability, stigma and discrimination among the youth population, to enable young positives to speak up their stories. It is also designed to engage young positives to take charge, lead the process and protect their human rights for greater and meaningful involvement. It is on this ground that Young Positives South Sudan was formed to have unique and tailored approaches to young positives. YPSS was registered by the Relief and Rehabilitation Commission as a national Organisation in December 2019.

ABOUT MAKING WAVES

Making Waves is an international, intergenerational, intersectional feminist collective of women working together for common aims around gender equality, gender-based violence, HIV and sexual and reproductive rights, and for mutual exchange, collaboration and amplification of the work done by networks and organisations led by women, girls and gender-diverse people everywhere.

Making Waves amplifies the advocacy work women, girls and gender-diverse people are doing around the world through collaborating and documenting the priorities and perspectives that come from our global collective expertise.

ABOUT SALAMANDER TRUST

The aim of Salamander Trust is to protect, promote and enhance the health and rights of people marginalised by societies worldwide as a result of their gender, HIV status or sexual and reproductive health issues.

Our approach is holistic, inclusive and people-centred, based on gender- and child- rights.

ABOUT THIS REPORT

This report was prepared by Salamander Trust Associates and Making Waves members, with contributions from the women listed below, who also reviewed and commented on the draft paper.

ACKNOWLEDGMENTS

Lead writer: Joyce Ouma

Lead researchers:

Lucy Wanjiku Njenga and Joyce Ouma in Kenya
Jacquelyne Alesi in Uganda
Nunu Diana Alison in South Sudan
Martha Tholanah in Zimbabwe

Editing support:

Emma Bell, Fiona Hale and Alice Welbourn (Salamander Trust); Tracy Swann (ITPC).

Design: Sarah Sills, Gerard Best

Original artwork: Jane Shepherd

Thank you to all the women and girls living with HIV who shared their experiences and thoughts with our researchers. We also would like to thank all the people who support sexual and reproductive health rights (SRHR) advocates living with HIV: whether colleagues, friends or family.

SUGGESTED CITATION

ITPC, GALZ, JSF, PYWV, YP, Making Waves and Salamander Trust (2022) *Are the Sexual and Reproductive Health and Rights of Women living with HIV still confined by Covid-19?: An analysis of then and now.*

COPYRIGHT

© 2022 ITPC, GALZ, JSF, PYWV, YP, Making Waves and Salamander Trust.

[Click to download this publication \(PDF\)](#)

Contents

Background	1
Introduction	4
Summary of findings	5
Normal is not always good	5
Two years on: what's changed?	6
1. Women's access to HIV and SRH services	7
2. The vital work of women and girls living with HIV	12
3. Women's access to food and money	15
4. Privacy and confidentiality	18
5. Violence against women and girls	21
6. Digital communications	24
7. Funding for women- and girl-led HIV organisations	28
8. Additional findings	31
Key messages and recommendations	35
Conclusion	39
Endnotes	41

Abbreviations & acronyms

ART	Antiretroviral Therapy
ARV	Antiretrovirals
CARG	Community Antiretroviral Therapy Group
COVID-19	Coronavirus disease (2019)
CROI	Conference on Retroviruses and Opportunistic Infections
DSD	Differentiated service delivery
HIV	Human Immunodeficiency Virus
ICW-EA	The International Community of Women Living With HIV—East Africa
ITPC	International Treatment Preparedness Coalition
LGBTQI+	Lesbian, gay, bisexual, transgender, queer and intersex, and other sexuality, sex and gender diverse people
NGO	Non-governmental organisation
PEP	Post-exposure prophylaxis
PEPFAR	President’s Emergency Fund for AIDS Relief
PPE	Personal protective equipment
PrEP	Pre-exposure prophylaxis
SMS	Short message service
SRH	Sexual and reproductive health
SRHR	Sexual and reproductive health and rights
STI(s)	Sexually-transmitted infections
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
VAWG	Violence against women and girls
WHO	World Health Organization

Background

This is the third in a series of research programmes regarding the sexual and reproductive health and rights (SRHR) of women living with HIV, conducted by Salamander Trust and Making Waves for the International Treatment Preparedness Coalition (ITPC). The first, published in March 2020, was prepared for the Conference on Retroviruses and Opportunistic Infections (CROI), to ascertain whether health services were meeting the SRHR of women living with HIV, in accordance with World Health Organization (WHO) Guidelines.^{1,2}

The process for the first report is as follows: we consulted with 198 women in 28 countries through an online survey (ITPC), interviews (Salamander Trust) and focus group discussions (ICW East Africa and AfricAid), and Salamander Trust conducted a rapid literature review. The interviews and focus groups included women from Kenya, Namibia, South Africa, South Sudan, Uganda, Zambia and Zimbabwe. However, the survey was open to women in all countries, and responses were received from: Angola, Australia, Bangladesh, Brazil, Canada, Ecuador, Egypt, El Salvador, Germany, India, Indonesia, Kazakhstan, Kenya, Kyrgyzstan, Malawi, Namibia, Nepal, Netherlands, Nigeria, Rwanda, South Africa, South Sudan, Switzerland, Uganda, UK, USA, Zambia and Zimbabwe.

In August 2020, ITPC then commissioned and supported Salamander Trust alongside the Making Waves network to document the impact of the COVID-19 pandemic on women, HIV, and their SRHR. Salamander Trust and the Making Waves Network consulted 30 women

who are community leaders and advocates, in all their diversity, from 10 countries in East and Southern Africa (Botswana, Kenya, Namibia, South Africa, South Sudan, Swaziland, Tanzania, Uganda, Zambia, and Zimbabwe). These women were living with or affected by HIV, or working with women and girls living with HIV. They ranged in age from 17 to 54, and lived in urban, rural or peri-urban areas. They included adolescents living with HIV, young women, pregnant women, women who have children and women who don't, women who are married, partnered and single, women living with disabilities and co-morbidities, women who are engaged in sex work, women who use drugs, LGBTQI+ women and women who experience racism.

The interviews for this report—which included consultation on the digital divide and how it excluded women—were mainly conducted online or via telephone, since COVID-19 was at its peak at the time. Different countries in the region experienced the COVID-19 pandemic differently. However, it was clear that all women across the region faced many similar cross-cutting issues, including gender inequalities, violence, and economic injustices. They mentioned that COVID-19 deepened the inequalities and revealed fractures within systems when it came to addressing women's HIV and SRHR needs. It was also evident that women and girls continued to support each other during the unprecedented COVID-19 times.

The feedback from the respondents in 2020 was consolidated into seven key findings:³

1. Women's access to HIV- and SRH-related services was severely undermined and deprioritized due to COVID-19.
2. The vital work of women and girls living with HIV on SRHR, HIV and COVID-19 in their communities is being ignored by governments and donors.
3. Women's access to food and money has been devastated by the pandemic.
4. COVID-19 restrictions have brought serious privacy and confidentiality concerns for women and girls living with HIV.
5. COVID-19 has led to increases in violence against women and girls (VAWG).
6. Digital communications leave out many women and girls.
7. Before and during this crisis, funding has been in very short supply for organizations led by women and girls living with and affected by HIV.

The seven key findings were used to create a call to action to donors and governments to redress the immense imbalances exacerbated by the COVID-19 pandemic:

1. **Uphold our SRHR as essential!**
SRHR should never be deprioritized, even in a pandemic. Continuing to ensure provision of SRHR and HIV services during a pandemic is not negotiable, and this must be done in ways that feel safe for women and girls living with HIV.
2. **Urgently recognize and support the vital work of women and girls and their organizations in their communities.**
Be flexible! Allow funds to be re-orientated towards a more holistic, integrated

response to COVID-19 that embraces women's and girls' SRHR and vice versa.

3. **Ensure everyone has enough to eat, and women and girls living with HIV do not have to take antiretrovirals (ARVs) on an empty stomach**

Governments and non-governmental organizations (NGOs) must ensure women and girls have enough to eat, through emergency food provision and/or financial support. They must support and fund women-led organizations that are already distributing food and money to our peers, as well as advocating for economic empowerment. Beyond the current situation, ongoing economic empowerment and sustainability must be in place to enable women and girls to weather future crises, realise our potential and thrive.

4. **Ensure COVID-19 responses respect privacy and confidentiality for women and girls living with HIV.**

Ensure that all COVID-19 adaptations to HIV and SRHR service delivery and transport arrangements for accessing such services fully respect privacy and confidentiality, offer women and girls choice about how to access services, and ensure we are not left without ARVs and contraception. Consult with women and girls on more innovative ways of providing essential services without breaching privacy and confidentiality.

5. **COVID-19 responses must address and prevent violence against women and girls (VAWG).**

Fund VAWG response services and prevention activities, and consult with women and girls on more innovative ways of providing essential services without breaching our rights. This includes

consulting us on conducting VAWG work with men and boys. Check with women- and girl-led organizations to ensure COVID-19 policies do not increase or exacerbate potential violence against women and girls in all our diversities, in the community and elsewhere, or expose us to new sites of violence or vulnerability. Ensure that addressing VAWG is integrated into your institutions and the programmes you support.

5. Our digital inclusion is vital—but make sure you meet our other priorities too!

Donors, governments and international organizations, please recognize that our face-to-face community work is still vital, including provision of basic needs like food and medicine. Ask us what our priorities are! Further, if you are supporting digital services, involve women's and girls' organizations as we understand better how to engage our peers. Budget to provide devices, digital skills training and ongoing (advance) payments for data bundles for women and girls and our organizations. This will ensure we can connect, coordinate and feed into policy and programme discussions, and bring our community expertise and lived experience to all COVID-19 responses. In the longer-term, country-wide provision of free public internet services would help address the gender digital divide.

7. Provide flexible, creative, accessible funding for organizations led by women and girls during and beyond this COVID-19 crisis.

We call on funders to recognize that women-led and girl-led organizations are doing vital work during this crisis, and we call on feminist funders to recognize that women living with HIV are a key part of the feminist response to COVID-19.

The 2020 advocacy report asks all funders to:

1. Provide core funding that is flexible and long-term, to support work led by us as women and girls in our diversity. Avoid providing project-only funding that does not recognize the work that goes into building and maintaining organizations.
2. Fund our organizations, even those that are not necessarily legally registered or formally constituted.
3. Recognize that representation requirements for boards and governance structures may feel like an expectation that community members must work for free (as Trustee positions are not paid roles). Women do enough unpaid work!
4. Think creatively about how you can support organizations that do not have a bank account.
5. Fund new organizations, without a requirement of years of existence.
6. Be accountable to communities of women and girls living with and affected by HIV.

The findings of #ConfinedbyCovid were disseminated in video reports, presentations, an advocacy report, and an advocacy webinar chaired by ITPC featuring women living with HIV, UNAIDS, and WHO.⁴

Our new report now revisits the situation in the region in 2022, to research how the landscape relating to these issues has changed over time, and to determine whether women and girls living with HIV are still confined by COVID-19.

Introduction

Women and girls share with all people the inherent right to the highest attainable standard of health, regardless of their identity, sexuality, or health status. In an ideal world, all women and girls should have access to HIV- and SRH-related services in an equitable manner, and these services should be accessible, affordable, available, and acceptable.

Before the pandemic, the SRHR of women and girls, including women and girls living with HIV were not given the priority they warranted.⁵ With the onset of COVID-19, women's right to the highest attainable standard of HIV and SRH services was further compromised. The adverse effects of the pandemic have had a significant, on-going impact on the lives and health of women and girls who are living with or affected by HIV.

It has been widely documented by ourselves and others that lawmakers and programmers overlooked the importance of women- and girls-centred policies and programming for women-focused interventions during the pandemic.⁶ There has also been a dramatic rise in an anti-gender movement that opposes the rights of women, girls and gender-expansive people including SRHR.^{7,8,9,10,11} Laws and policies continue to restrict our SRHR, particularly for young women, as recently evidenced by Kenya's ten-year **National**

Reproductive Health Policy 2022-2023, which enforces parental consent for adolescents under the age of 18.¹² Even where services are available, the focus is on ensuring commodity availability at the clinics and rarely addresses barriers faced at household and community level for many women and girls.¹³ Yet women- and girls-led networks still do not have adequate access to funding for continuing the critical work that they do to counter inequities and rights abuses and support the SRHR of the women, girls, and others in their communities.

In this 2022 phase of **#ConfinedbyCovid** research, Making Waves members in four countries consulted women living with HIV in their diversity to take stock of the current situation, and engage directly with policy-makers locally, nationally, and globally. A total of 99 women were engaged in this round of consultations in mid-2022: 39 from Kenya, 8 from South Sudan, 26 from Uganda and 26 from Zimbabwe.

This 2022 research was conducted when the whole world was experiencing unforeseen disasters such as the Russia-Ukraine war, the cyclone in Zimbabwe, and the increasingly evident impacts of climate change. These human-made events, on top of the global pandemic (likely also fuelled by climate change), have led to a cost-of-living crisis, which has severely affected the most marginalised people.¹⁴

Summary of findings

Normal is not always good

At first glance, much appears to have changed since the height of the COVID-19 pandemic, with decreases in COVID-19 lockdown regulations. The numbers of people acquiring COVID-19 or dying from it have clearly reduced significantly across the board.

During lockdowns, however, women and girls had many of their rights taken away, by movement restrictions, job losses, inaccessibility of sexual and reproductive health (SRH) information and services and stockouts of essential medicines. Many of these rights are yet to be reinstated.

In addition to an increase in existing SRHR violations during COVID-19 (such as greater levels of gender-based violence), women and girls encountered various shadow pandemics. These included commodity stockouts, and economic instability. For example, Kenyan women described how they experienced catastrophic commodity insecurity, including for contraceptives, HIV pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP), ART, reagents for viral load testing—and even condoms—as all became unavailable. These stockouts were a major barrier to essential SRH services during COVID-19.

Many would suggest that life is now returning to 'normal'. Women described the current situation as 'post-COVID-19'.

“Things are not the same anymore since COVID-19 struck. It is still tough, and I am in a dilemma of what to do next because I am yet to recover from it.”

YOUNG WOMAN FROM KENYA

These restrictions may have eased somewhat, but women and girls are now living with their consequences and a global cost-of-living crisis, caused in part by COVID-19, in part by climate change and in part by the war in Ukraine. The physical and economic impacts are worsened by resulting stockouts, combined with mental health issues¹⁵, arising from uncertainty, fear, as well as the lasting impact of rights violations and unplanned pregnancies brought by the pandemic.

Women and girls were clear that COVID-19 has deeply affected their HIV and SRHR needs and priorities, and they are understandably sceptical about whether or not 'normal' is acceptable. These women and girls are slowly recovering some of their rights to autonomy which were removed during the pandemic. Although governments have lifted some COVID-19 measures, their impact is still felt. On top of violence against women and girls and other SRHR challenges already present before COVID-19 arrived—which worsened during the pandemic—the several parallel crises described above which also emerged have challenged women living with HIV. In sum, the consultations with the women make it clear that the protracted effects of COVID-19 are still being felt over two years after the onset of the pandemic. The progress in responding to COVID-19 continues to be slow, and governments and funders are still deprioritizing the HIV and SRH priorities of women and girls.

Two years on: what's changed?

Since March of 2020, the world has experienced various waves of COVID-19, driven by the emergence of new variants. After more than two years of living with COVID-19, most of the world has relaxed restrictions and limited COVID-19-related services.

According to the WHO COVID-19 dashboard, the number of people acquiring COVID-19 and dying from it in the countries covered in this report has declined over time, due to immunity from past infection and/or vaccines, compared with two years ago, (when our COVID-related research was first conducted. Most of the world has relaxed or eliminated restrictions—and limited COVID-19-related services.

COVID-19 Country contexts. All four countries have experienced at least three waves of COVID-19. As of August 2022, cases in these four countries are much lower than they were during the height of the pandemic.

Country	Waves of COVID	Current official new COVID numbers reported daily	COVID-related officially reported deaths by July 2022	Vaccinations per 100
KENYA	6	50-150	5,670	17.34
SOUTH SUDAN	3	4-25	138	13.14
UGANDA	3	13-95	3,627	27.18
ZIMBABWE	3*	14-36	5,568	31.64

Source: <https://www.worldometers.info/coronavirus/>

* (+ a few miniwaves)

We now look at our seven findings from two years ago, and consider to what degree they still apply.

1 WOMEN'S ACCESS TO HIV AND SRH SERVICES

"I got pregnant after getting a three-month injection from the facility. After giving birth, I went there and they still insist on me using the three-months injection that did not work, and they were talking to me rudely."

YOUNG WOMAN FROM KENYA



IN GENERAL

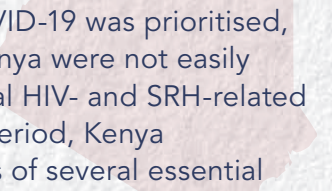
Access to HIV- and SRHR-related services was heavily compromised when narrowly defined, ungendered policies regarding 'essential' COVID-19-related services took priority over them, and excluded them. Donors shifted funding to try to address COVID-19, but the lack of a gendered lens in their funding meant that services relevant to women were eroded. Although access to and provision of services are now better than they were at the height of the pandemic, two years down the line, women and girls' needs and priorities are still not being fully met.

There appears to be a top-down approach to SRH in some contexts, which was also prevalent before the pandemic. This approach has tied women's access to SRH and HIV services to unreasonable demands. For example, there are concerning reports from Kenya and Zimbabwe about access to ARVs being contingent upon cervical cancer screening; women and girls of reproductive age who are living with HIV are being coerced to undergo cervical cancer screening before they are given access to life-saving ARVs. Although this policy might appear to be well-intentioned, it violates their right to bodily autonomy. Furthermore, there is a chronic lack of services to treat abnormal pap smears.

Access to information on SRHR and HIV at some health centres is still a problem, particularly among women and girls in rural settings, who reported lack of access to comprehensive information on SRH commodities or available services. This lack of information has left people living with HIV feeling unable to address their SRHR and in fear of the unknown, although the situation has been improving for some since lockdowns have been lifted. For example, some participants explained that they were able to access information through social media

platforms, such as Twitter and Facebook posts and via live conversations.

KENYA



Two years ago, as COVID-19 was prioritised, women and girls in Kenya were not easily able to access essential HIV- and SRH-related services. During this period, Kenya experienced stockouts of several essential commodities, such as ART and viral load testing supplies, leaving women living with HIV without access to SRH and HIV services and commodities. Support groups and feeding programmes were halted at facilities, because of pandemic-related restrictions and priorities. HIV treatment was disrupted, and treatment outcomes were compromised, as many were not able to access facilities or even the WHO-recommended essential package of care for SRHR of women living with HIV. Some facilities had a limited number of health care providers because attention was shifted to COVID-19. Wards and clinic setups were converted to isolation zones, and the number of available hospital beds was reduced. These unmet HIV and SRH-related needs led women and girls to seek services at alternative unregulated sites, whose commodities cannot be trusted.

"I got pregnant after getting a three-month injection from the facility. After giving birth, I went there and they still insist on me using the three-months injection that did not work, and they were talking to me rudely"

YOUNG WOMAN FROM KENYA

Many girls and women reported unplanned pregnancies. With alarming cases of teenage pregnancies being reported across the

country, some women reported having accessed services at unlicensed facilities that issued counterfeit commodities that were also administered unprofessionally.

Abortion is illegal in Kenya (and the other countries included in this research). Respondents reported that some young women were forced to seek backstreet abortions or undergo pregnancy and give birth to children whom they were unable to take care of.

More girls and women acquired HIV and/or other sexually transmitted infections (STIs). VAWG increased during COVID-19, which heightened women's and girls' vulnerability to acquiring HIV and other STIs and exacerbated SRH problems for women living with HIV.

'I don't have access to most products that I need to practise safe sex, no one cares about my rights because I am queer.'

YOUNG QUEER WOMXN FROM KENYA

Factors such as VAWG greatly affected those who are already marginalized, such as Queer womxn, who experience challenges accessing HIV testing, care and treatment and other services. [NB the womxn interviewed preferred to be identified as womxn]. A lack of commodities and services designed for Queer women in health facilities hinders most of them from being able to practise safer sex and access essential SRH services.

There are some areas of improvement to hold on to. The country gradually lifted COVID-19 restrictions that posed barriers to HIV- and SRH-related services and, as of July 2022, 'normality' is almost restored.

Some of the women and girls in all their diversity noted and appreciated some improvement in services during their

interviews. In Kenya, they mentioned fast-tracking at health facilities, which reduced queues and waiting time for appointments, and differentiated service delivery (DSD) models that were implemented (such as Community Antiretroviral Therapy [ART] Groups for people living with HIV, in which members took turns picking up ARVs for the whole group, which saved time and out-of-pocket expenditures for everyone. They would like these improvements to be retained, to enhance the quality of HIV- and SRH-related services that they receive from these facilities.

SOUTH SUDAN

In **South Sudan** however, where access to HIV- and SRH-related services and commodities is free, due to family norms, most young people do not have access to these services—and they are not age-appropriate. Sometimes service providers are older, with their own perceptions of young people and how they should behave. They ask young people a lot of questions when they come for contraceptives or other SRH services. This was the situation before COVID-19 and it remains the case. Two of the eight young women living with HIV who were interviewed are now living with AIDS due to their distance from health facilities and a lack of education on adherence to medications. Young Positives South Sudan are supporting them to take their medication.

UGANDA

In **Uganda**, there has been an improvement in the availability of SRH-related services since the height of the pandemic and HIV-related services are now running as normal. However, the rise in fuel prices has impacted the ability for women to travel and access these services. Further, in the community where the interviews for this research took place, two clinics are merging, which is causing huge service disruptions for people on ARVs. The COVID-19 vaccine has also been prioritised at the expense of other health services, such as those related to SRH for women living with HIV. These include outreach services. Activists have had to work hard to get local councils to include other services as part of the councils' community outreach.

There is a continued lack of information about SRHR and HIV, including a misconception that ARVs act as a form of family planning. Funding for community engagement services has been drastically cut as a result of the pandemic, which has worsened this problem. For example, before COVID-19 there was a counsellor who came to talk to women about various SRHR issues as part of their access to HIV-related services, but now the worst of COVID-19 has abated, donors have removed the budget for the counsellor. Now, discussions where women were exploring disclosure, stigma, treatment, contraception, and other issues no longer take place.

Women still feel the impact of the pandemic on SRHR-related services and lack of information. For example, in 2020, when Jacquelyne visited the women she interviewed, a number of the women were then pregnant. When she returned to speak to them again [in June 2022] for this follow-up research, the women had small babies and were pregnant again. It was agreed by the women and Jacquelyne together that this was because

of the lack of access to services and the related lack of information about SRH service availability during the pandemic restrictions.

ZIMBABWE

In **Zimbabwe**, during the pandemic, activists focused on ensuring access to services rather than service *quality*. There has been some improvement in access to and availability of SRH-related service, and there is an emphasis on how to provide services safely. So, there is some relief now, since women are able to go to services without fear of getting COVID-19.

Commodities such as contraceptive pills and condoms are largely provided by the Zimbabwe National Family Planning Council, which is a parastatal, and NGOs, with support from Population Services Zimbabwe, so access has returned to normal. However, SRHR services for women living with HIV in Zimbabwe are quite poor.

COVID-19 has led to some improvements in accessing ART. For example, people living with HIV were given six months' supply instead of a three-month supply as done before the pandemic.

“In my community, we managed to form CARGs, which help[ed] us a lot as people living with HIV, since in these groups we are normally given six months ARVs supply and we rotate to go and refill our medication, this saves time and money.”

WOMAN FROM ZIMBABWE

However, one size never fits all: some people did not feel comfortable joining a CARG or they do not have one that is close enough to join, so this is not an option for them.

Meanwhile, clinics are returning to providing only three months of ARVs at a time, instead of maintaining the positive lockdown-era strategy that some people living with HIV benefitted from.

Furthermore, ARVs are still distributed outside in the open air because of continued COVID-19-related adaptations to service delivery, which creates dangerous challenges to confidentiality for some women. Viral load testing is still done once a year, but it is not yet clear whether the timeline for delivering results has improved. In our 2020 report, we found that not all results were delivered, and some facilities made people wait until the following year to re-test and hope the results will be delivered.

2

THE VITAL WORK OF WOMEN AND GIRLS LIVING WITH HIV

"Most of the time, the women don't have time or the means to document the resources they have used to support their peers. The only documentation they have is on their phones and the experiences of those they have supported yet this is not considered documentation by donors."

PARTICIPANT FROM ZIMBABWE



IN GENERAL

As our previous report highlighted, the work done by women and girls is essential in ensuring access to services and psychosocial support. Women- and girls'- led networks, despite having minimal resources, continued to support their peers and wider communities during the height of COVID-19 and beyond. Since the start of the pandemic, women living with HIV and their organisations and networks have, among other things, supported other women and girls living with HIV by providing emotional support, food baskets, dignity packs (including, for example, sanitary products), and cash transfers. They have risked their lives, often working without access to personal protective equipment (PPE) or transport, to respond to the pandemic, driven by their passion and experience to put their peers first.

However, due to stringent COVID-19 measures, these responses from women were impeded and not prioritised in governmental responses. Women volunteers were not regarded as essential community or health care workers, and were not supported to continue their work. Where possible, these women continued their community support work, but, during the height of the pandemic, support groups were closed down because of government restrictions, so they did what they could through online communications. Many support groups have not been revived.

KENYA

In **Kenya**, when COVID-19 emerged, the work done by women- and girl-led networks was disregarded and deprioritised—and it was not considered essential. The country's HIV and SRH funding landscape has shrunk, because of the global prioritisation of COVID-19. The vital

work done by women- and girls-led networks continues not to receive much recognition and support. In situations where the women- and girls-led networks are engaged by donors and governments for the COVID-19 response, it is on a short-term basis that has no sustainable plan. This has impacted these networks, especially those operating at the community level. Yet major donors such as PEPFAR have already begun conversations around their transition out of Kenya, as they report that their own targets have been met.

SOUTH SUDAN

In **South Sudan**: Young Positives South Sudan holds a monthly forum led by young women, and for young women living with HIV, where they share key messages about why it is important to access SRH- and HIV-related services and adhere to HIV treatment. They have mental health sessions, because many people were affected by COVID-19. Young people were traumatised because schools were closed; they were confined to their homes and could not socialise with others, which affected their mental health. So Young Positives has a strong focus on self-care and group support. There is also a support group in the hospital, which is led by young people living with HIV. This enables people living with HIV to discuss their experiences, including their worries about relationships. Yet the efforts of Young Positives are not adequately recognised or supported by others working on HIV and SRHR.

The eight young women who were interviewed for this report—and the previous 'Confined by COVID-19' -report said that being interviewed really helped them air their experiences and build their confidence.

UGANDA

In **Uganda**, the cut in donor budgets for community engagement activities has really affected the efforts of women and girls living with HIV to support their peers and communities. Women are still helping women and girls living with HIV in the community largely 'in silence', without recognition and funds. Jacquelyne Alesi, for example, has set up a WhatsApp group for women to share support and information about services, as well as providing in-person support. She has also worked with local councils to persuade them to take the SRH of women living with HIV seriously.

ZIMBABWE

In **Zimbabwe**, women living with HIV continue to support their communities and are called on by the Ministry of Health to help, but no one reimburses them for their efforts and they have to spend their own money to deliver services and help each other.

'Most of the time, the women don't have time or the means to document the resources they have used to support their peers. The only documentation they have is on their phones and the experiences of those they have supported yet this is not considered documentation by donors'

PARTICIPANT FROM ZIMBABWE

When a community member needs financial help, for example US \$20, to access a service, other community members chip in US \$1 each. The small organisations that help women in such ways do not attract funding, and they are not documenting the vital support they offer, because documentation takes time, and

the women are busy helping others and their families—so their work is invisible.

Martha Tholanah, the lead researcher in Zimbabwe, supports women and girls living with HIV directly with monthly stipends; she also covers medical expenses and supports their education when she can. Before COVID-19, it was easier for women and girls living with HIV to access some funds through organisations or the Department of Social Welfare, but now people make appeals directly as individuals through WhatsApp groups. Organisations have no funds—or they have closed.



It is notable that women and girls, despite the many barriers presented by the pandemic, stepped up to support each other, advocate, and deliver community responses to their peers without any support and resources. Their experiences illustrated that there will be no ethical, effective, sustainable response to COVID-19 without women being at the centre of decision-making around their SRHR.

3

WOMEN'S ACCESS TO FOOD AND MONEY

"I noticed that some of the women who actually used to have two meals, have reduced to one meal a day, the cost of living is currently very high."

JACQUELYNE FROM UGANDA



IN GENERAL

The COVID-19 pandemic led to a global economic crisis, as instability reigned. This greatly affected women and girls, such as small business owners, those not or under-employed, and those living in rural areas, who were already experiencing economic turmoil. Women reported the loss of jobs and livelihood under measures imposed by the Government (such as social distancing, lockdowns, curfews, and business closures) to curb the spread of COVID-19. These measures led to unstable and inadequate income, that largely affected women and girls in all their diversity, and continue to this day due to the global cost of living crisis

“People lost jobs. Now they cannot rise back, as the economy still is dwindling.”

WOMAN FROM ZIMBABWE

This has lowered their living standards and resulted in deteriorating physical and mental health.

‘I hooked up with multiple people as a means of surviving. I practised sex work to get a little money’

YOUNG WOMAN FROM KENYA

The women we interviewed reported that the pressure on women to secure a livelihood led to increased transactional sex and increased exposure to STIs. The situation is worse for women living with HIV, who are often juggling time, money and energy needed to manage a range of health issues.

KENYA

In Kenya, the struggles for everyone, including women and girls living with HIV, regarding food and livelihood, has worsened with inflation and the spiralling cost of living. Many people lost opportunities, jobs and businesses when COVID-19 hit. People are still struggling to return to their jobs or find new sources of income.

“I am employed. But I’m still feeling the pains of the inflation because for 1 kg, for example, one of our staple meal used to go for KES100 [ca.US\$1]. And now it is about KES225 [almost US\$2.5]. And this is something that has become very difficult for us to even continue to support others, because now you have to think about yourself.”

YOUNG WOMEN PARTICIPANT FROM KENYA.

COVID-19 has exacerbated the cost-of-living crisis; everything has almost doubled in price. As Joyce, the lead researcher from Kenya put it, ‘once the cost of living goes up, it never comes down.’ COVID-19 has exposed the country’s inadequate economic and health structures. It is one of a number of different factors that impacts people’s lives, including those of women and girls living with HIV: for instance, 2022 is an election year in Kenya, which also negatively impacts prices.

However, some young people have developed careers during this time. For example, some are now getting paid to do videos on TikTok, and use this or other social media to advance their livelihoods in some way.

SOUTH SUDAN

In South Sudan, it was a struggle for everyone to access food during the pandemic, since much of the food comes from Kenya, Sudan and Uganda and borders were closed. There were restrictions on food provided in the markets and it was very expensive, which made it a huge struggle to obtain food during COVID 19. The only people who were given food during the pandemic were elderly or living with disabilities. South Sudan also has ethnic divisions; it was reported that food was given to those favoured by the leaders.

Now that the pandemic has subsided, for people living with HIV, there is food in the hospitals—but only for people who have AIDS, and it is only a small amount once a month. Some people will not collect the food because it is given out in an open space in the hospital, there is no privacy or confidentiality, and they will be discriminated against if they are seen.

UGANDA

In **Uganda**, the cost of living crisis has been exacerbated by COVID-19. It is really affecting people including the women we interviewed, who said it is affecting their lives more than COVID-19 itself.

“I noticed that some of the women who actually used to have two meals, have reduced to one meal a day, the cost of living is currently very high.”

JACQUELYNE FROM UGANDA

The stipend that was offered to women for their interviews was welcomed, but the women really need help with developing skills and income-generating projects. Currently they struggle to afford more than one meal a day.



The women who have been helped in the past to develop income-generating skills have been able to stabilise their economic lives since the pandemic and weather better the current cost-of-living crisis. With such skills they can provide food for their family and access services. This is clearly an area that needs proper attention and funding.

ZIMBABWE

In **Zimbabwe**, many women have not been able to recover from the economic devastation that COVID-19 brought. Zimbabwe’s economy was already very precarious when COVID-19 ‘pulled the rug from under women’s feet’, as they were no longer able to move around to fend for their families and many opportunities remain restrained or closed to women and girls. Before COVID-19, it was fairly easy for women to get stalls in fresh produce and flea markets. Women were able to travel to different cities, and to farming, rural, mining areas, and across borders, where they would procure and trade various wares. But this ended with the first lockdown in March 2020. Now, with the appearance of “normalcy post-COVID”, trading is not as easy as it was, because markets are now highly regulated. There is a thin line between COVID-19 prevention and political control as the country moves towards elections in 2023. In national discussions about the economic crisis, there is very little discussion about the lives of women and girls, or about how they have been impacted and can be helped to access food and money.

4 PRIVACY AND CONFIDENTIALITY

"She unfortunately left. She's now in her parents' home, because she was really traumatised. She couldn't handle the pain she got, the people she trusted, disclosed the problem she was going through."

JACQUELYNE FROM UGANDA



IN GENERAL

The various country-level COVID-19 regulations and restrictions meant that women living with HIV were forced to disclose their HIV status to access HIV- and SRH-related services, and were unable to access related services in a confidential environment. The lifting of restrictions has somewhat ameliorated these privacy and confidentiality concerns. However, some countries still have COVID-19 related requirements and/or service delivery systems that can lead to breaches. Further, violations of confidentiality have lasting impact as once somebody knows about your status they can not then 'unknow' it.

KENYA



In **Kenya**, restrictions have been lifted, so many of the past findings are no longer relevant. However, women and girls living with HIV are still living with the impact of the possible exposures of their status that they experienced during the pandemic.

"This is a sort of coerced disclosure because you feel you need it, and you want to take care of yourself and you want to be safe, but you're not ready to tell people about your status."

YOUNG WOMAN PARTICIPANT FROM KENYA

Women living with HIV also have had a dilemma when seeking their COVID-19 vaccination. When the vaccine first was rolled-out it went to prioritised populations, including people living with HIV, and so people had to explain why they felt they were eligible.

"I was afraid to get the vaccine shots as I was unsure of the contents and how they interacted with my ARVs. I had to disclose to the health care worker administering the vaccine, who seemed not to know the answer."

YOUNG WOMAN PARTICIPANT FROM KENYA.

Currently, people living with HIV are understandably worried about (so far unevidenced) potential adverse interactions between the vaccine and HIV, as well as with ARVs, so they said that they can also feel a pressure to disclose to health care workers administering vaccines.

SOUTH SUDAN



In **South Sudan**, there was no privacy or confidentiality at health facilities, as everyone goes to the same service provider. It is very hard for young people seek services from the facilities, as they fear stigma and discrimination. Women, including young women, are asked to come with their partners, despite our advocacy with health care providers (which has tried to explain that this contravenes our rights to confidentiality and bodily autonomy).

During COVID-19, private facilities for young people and people living with HIV were all used for quarantining people with COVID-19. It was very difficult for young people to access safe spaces where they could take their medication, since families often live together. It was very hard for people living with HIV who had not disclosed to family members to take their medication at home during the pandemic. However, with the lifting of various regulations, ARV adherence levels have notably improved.

UGANDA

In **Uganda**, lifting of COVID-19 regulations has lessened some impacts on privacy. However, in one facility, counsellors see 50-70 people in one day and work with different groups, which may heighten the risk of breaches of confidentiality. Although this may not be directly related to COVID-19, it is clear that confidentiality breaches continue to cause much suffering among women living with HIV.

One woman said she realised that almost all the nurses at the facility she went to, for her HIV treatment, knew about her status—and some of the other clients too. This woman approached Jacquelyne to help her change her facility.

“She unfortunately left. She’s now in her parents’ home, because she was really traumatised. She couldn’t handle the pain she got, the people she trusted, disclosed the problem she was going through.”

JACQUELYNE, UGANDA

ZIMBABWE

Zimbabwe: Some facilities are yet to rescind the COVID-19 regulations. For example, some are still distributing ARVs outside, in the open air. At one of the clinics women use, there is no appointment system and everybody is asked to come at 7am. This has implications for people’s confidentiality. Others distribute ARVs in a tent, but the thin walls mean that people can hear what is being said inside.

“Many local health authorities are using structures donated by PEPFAR as the HIV clinic.

Whereas before COVID-19, people living with HIV accessing the clinic would sit on benches outside and each person entered for a private and confidential interaction with the staff, now no-one is allowed inside. The staff bring out a chair and table to the veranda and attend to each client in full view and earshot of everyone else waiting their turn.”

WOMAN FROM ZIMBABWE

5

VIOLENCE AGAINST WOMEN AND GIRLS

"Maintaining relationships have become a major challenge to an extent of divorce, since most of the families didn't have money to pay rent and food; this also affected children which also result (s) in child marriages, sexual abuse, and drug abuse."

YOUNG WOMAN FROM KENYA



IN GENERAL

Violence against women and girls is a major challenge faced by women and girls in all their diversity, even before COVID-19 and now. Women's experience of lockdown exacerbated their pre-pandemic situations. During COVID-19, women and girls found themselves trapped at home with their abusers. The stress brought about by restrictions, including not having any source of income, led to greater tensions in the domestic sphere, thereby increasing both women and girls' fear of violence, and the actual violence they experienced. Increase in drug and alcohol use during curfews and lockdowns further exposed women and girls to domestic and interpersonal violence.

“Maintaining relationships have become a major challenge to an extent of divorce, since most of the families didn't have money to pay rent and food; this also affected children which also result (s) in child marriages, sexual abuse, and drug abuse.”

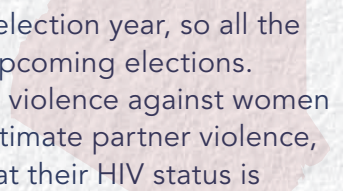
YOUNG WOMAN FROM KENYA

Most of these cases went unreported because of the stigma associated with rape and other sexual abuse, fear of the unknown, and inaccessible and protracted national justice systems. This sexual abuse and the strong stigma associated with it are both widely prevalent and thus 'normalised'. This normalisation in itself acts as a major barrier: to halting both the stigma and the abuse; to funding care and support services for those affected; and to holding perpetrators to account.

Of course, violence against women and girls as well as gender diverse people, is endemic globally. It is important to remember that it is gender inequality and harmful gender norms, upheld by formal and informal rules that

drive violence against women. Such violence remains firmly rooted in society and is further entrenched by crises such as COVID-19, which inevitably exacerbate it. This is why a strong and vibrant feminist movement is all the more needed in these challenging times.

KENYA



In Kenya, 2022 is an election year, so all the focus has shifted to upcoming elections. Respondents felt that violence against women and girls, including intimate partner violence, where women feel that their HIV status is used by partners as a reason to abuse them emotionally and physically, has remained prevalent before, during and after COVID-19. However, it is no longer spotlighted as it was during the pandemic.

“And now the situation is back to where it was—not that this is not happening, but we are back to being silent about it. We are back to keep quiet about it. Because there is no COVID to blame it on. There is no lock down to blame it on, or anything else that we would like to blame it on. Like now, we don't have the media focusing so much on this. But we have people who are still being, you know, women and girls, we're still being exposed.”

YOUNG WOMAN FROM KENYA

Intimate partner violence is so rampant that it is also referred to as 'bedroom bullying' in informal settlements in Kenya. The respondents were not confident that cases of violence against women and girls have gone down after the height of the pandemic; they felt that cases were just not being

reported on the mainstream media due to the elections—and also because survivors fear being stigmatised. For instance, Queer and masculine-presenting women do not report cases of abuse and violence, such as intimate partner violence, because of feeling ashamed about being masculine. Their sense of shame is related to toxic heteronormative masculinity, which belittles and shames masculine-presenting and other diverse groups, such as non-binary people as ‘not real men’.

SOUTH SUDAN

In **South Sudan**, the pandemic led to increases in violence against women and girls. South Sudan had high numbers of rape cases, including among girls. Young girls below the age of 18 got pregnant because, when they were confined to their homes in lockdown, they did not have access to information about their bodies and their SRHR. There have also been increased reports of forced and early marriages.

Women spoke about the intimate partner violence they experienced because of stress brought by COVID-19, as well as harassment from in-laws. One respondent spoke about the difficulties of being confined with her husband when previously she had gone out to work. They had many disagreements about money.

Since the regulations have been lifted and schools have opened, participants reported that the rate of forced and early marriages has gone down.

UGANDA

In **Uganda**, there was a lot of violence against women and girls during COVID-19, and it is ongoing.

“The violence, like I said, is still happening. The violence, some of them have overcome what happened to them. Some of them are still clicking to the fact that they were really hurt and they need justice.”

YOUNG MOTHER 24YRS FROM UGANDA

Women spoke about being left by men during the pandemic; when they were pregnant, the men, on their return, denied paternity, making accusations and being abusive. In one example, a counsellor supported the man over the woman, violating her confidentiality and exacerbating the violence the woman faced. The psychological and emotional violence and subsequent trauma is significant. Women still suffer the impact from the trauma they experienced during COVID-19 restrictions, and it has been difficult to get support and legal redress.

ZIMBABWE

In **Zimbabwe**, there is still a lot of violence against women and girls since the pandemic started, including intimate partner violence. There are reports of women being killed by partners due to economic, health or relationship issues.

People (including the police) are still using supposed violations of COVID-19 restrictions as an excuse to perpetrate violence against those attending gatherings, even gatherings related to HIV and health information and peer support sessions. There is a fear by the authorities that people are gathering to discuss politics.

6

DIGITAL COMMUNICATIONS

“Digital space and access is expensive. You need data to stay online.”

YOUNG WOMAN
FROM SOUTH SUDAN



IN GENERAL

In the previous report, women reported feeling left out of the digital era, as they had limited access to digital devices, data bundles and the skills to use the devices. Some respondents felt that the digital era had left out a big number of women and girls, since digital technologies were available only to the privileged few with access to smartphones, electricity, and data bundles. They noted that one needs hands-on digital skills to use the platforms effectively, which still remain inaccessible to most women and girls especially in rural areas and among older women and those from low-income backgrounds. Thus, the pandemic has exacerbated the pre-pandemic digital divide.

“Digital space and access is expensive. You need data to stay online.”

YOUNG WOMAN FROM SOUTH SUDAN

Rumours and false information about COVID-19 and its impact on people living with HIV spread through social media, during the pandemic. Many women and girls without access to smartphones have had to rely on information shared with them by friends and neighbours who did have smartphones and access to the internet. This led to so much fear and panic among communities of people living with HIV.

As the pandemic progressed, the world gradually adapted to the digital era, which has led to positive and negative impacts. The adoption of technologies provided opportunities for many women and girls in all their diversity and it has brought people from different areas together on various platform, where they can interact and share their experiences. Some women were able to continue conducting their meetings virtually and some support groups also were able to transition to the virtual space. A few women

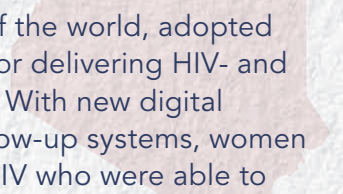
also earned a living by creating online content. Some women who sell sex adopted the digital platforms, and their work thrived in it. School lessons were offered virtually and this ensured continuity in the syllabus for girls and young women who had access to digital technologies.

“As a content creator, digital space was home to some of us that provided new opportunities.”

YOUNG WOMAN FROM KENYA

Although some digital platforms provided useful information and the means to exchange it, they were criticised for lacking the human contact and intimacy required for effective engagement with existing or new support groups for women and girls.

KENYA



Kenya, like the rest of the world, adopted digital technologies for delivering HIV- and SRH-related services. With new digital appointment and follow-up systems, women and girls living with HIV who were able to access digital services could reduce the time it took to access services by using digital platforms to book and set appointments—and even to receive results. (However, digital health is not without its potential confidentiality and related challenges. See, for instance, WHO’s *Global Strategy on Digital Health 2020-2025*).

Although they were virtual, support groups were maintained during COVID-19. Some facilities adopted technological advancements, even in the ‘post- peak COVID-19 era’, as mentioned above. But very minimal action has been taken to address the digital divide that still largely affects women and girls, who cannot access online services.

SOUTH SUDAN

In **South Sudan**, young women have realised that becoming more familiar with digital communication was a positive side to COVID-19. They learned how to use digital communication and learned some key

knowledge through email, WhatsApp and Zoom meetings and they became much more reliant on what they could access through the internet; before the pandemic, many of them did not know they could access information through their phones.



Many young women are still not literate when it comes to technology. The pandemic highlighted this gap—but it also ushered in activities to address the gap through training women in digital technologies. For example, Young Positives trained young women on how to use phones and pass information through WhatsApp. They have WhatsApp groups for young women in different regions of South Sudan. Women and girls in the network are now equipped to communicate on WhatsApp but the barriers still remain. This vital channel of information faces the challenge of an unstable internet, expensive devices and tariffs for young women who do not have access to money.

UGANDA

In **Uganda**, women and girls are being left behind as the world shifts to a digital era. Digital communication and reliance on online tools to channel information on SRHR and HIV information are leaving women, particularly in rural areas, behind. Many do not know how to use phones—or even have access to a phone.

“Most women do not know much about digital technologies, they feel left out of everything.”

JACQUELYNE FROM UGANDA

It is important for women to have smart phones, airtime and training on digital communications that would enable women to access information on SRHR and HIV—but there is a lack of funds to offer this. Jacquelyne set up a WhatsApp group for those who had phones, to send messages to encourage them; and would call those who needed to speak to someone. However, this was a short-term solution, as Jacquelyne lacked resources to sustain the women’s internet access, or buy devices for them.

ZIMBABWE

In **Zimbabwe**, digital communications have provided welcome flexibility for women who need to be looking after their children while working and, for some women in chronic pain or with mobility difficulties, digital communications enable them to work in more comfortable positions, or without the hassle of trying to find suitable transport to the office and to meetings. Some employers have embraced a hybrid model, where employees can choose to connect to the office virtually or attend in person. However, there are still some issues if virtual meetings are the only option.

Some women have been bullied online, and now tend to shy away from interacting online. Further, many women still cannot afford devices, the data, and still need digital

training; they are getting left behind from access to information. During the height of the pandemic in Zimbabwe, data charges went up 100%, and this cost has not been reduced, even as the pandemic subsided. This severely constrains women's ability to link, share information, and support each other. It remains important to share information face-to-face and in print, but organisations need to invest in smart phones for women and support with data. Some organisations do not think to provide data costs for women they work with, or if they do cover data costs, they expect the women to pay up front.

7

FUNDING FOR WOMEN- AND GIRL-LED HIV ORGANISATIONS

“There is increased competition around funds and much of the funding for work on HIV goes to key populations...There is an absence of funding to address the specific needs of women and girls living with HIV.”

WOMAN FROM UGANDA



IN GENERAL

The pandemic and current global cost of living crisis has led to funding cuts, deepening the lack of resources available for organisations led by women and girls living with HIV.

“There is increased competition around funds and much of the funding for work on HIV goes to key populations. This has led to pressure on women-focused organisations to change their mandates and focus. Other women-focused organisations have had to close, or are inactive because of the lack of funds. For example, the national network of women living with HIV has struggled financially. There is an absence of funding to address the specific needs of women and girls living with HIV.”

WOMAN FROM UGANDA

KENYA

In **Kenya**, during the peak COVID-19 period, women- and girls-led networks continued to be under-funded; some networks had no funds at all. Women and girls were not engaged in COVID-19 response management and planning and, as a result, these initiatives did not include a clear focus on women and girls. With shrinking financing options for non-biomedical approaches to the HIV and COVID-19 response, work done by organisations of women and girls was not recognized or regarded as important. Only the government and bigger networks received funding from donors for COVID-19 responses. Post COVID-19, women and girls-led organisations continue to miss out on key funding opportunities, as they are deemed to lack the capacity to implement major grants such as from the Global Fund to Fight AIDS, Tuberculosis and Malaria.

SOUTH SUDAN

In **South Sudan**, during the peak of COVID-19, the focus was entirely on the pandemic, and health responses to COVID-19. Women- and girls-led networks were left out of funding opportunities before, during, and even after the pandemic's peak. Access to funding remains a big challenge, due to the convoluted due diligence processes and requirements put in place by donors, such as three-year audit reports, effective governance structures, registration status and other criteria.

After the peak COVID-19 era, reports have emerged about funds allegedly being dispersed to women-led organizations in exchange for sexual favours; these organisations are reported not to get funding if representatives of these organisations refuse. Further, there are individuals within funding organisations (intermediaries) who reportedly expect a percentage of the funds as a bribe, which means there is little left for organisational activities to support girls and young women living with HIV. In addition, some funders perceive Young Positives to be promoting immorality, because sexual transmission of HIV is widely recognized.

UGANDA

In **Uganda**, there are organisations that continue to do great work in the community, others that focus on policy change and those who do both. Unfortunately, there are some organisations that claim to help women and girls but do not, which has a considerable impact on the morale of women.

ZIMBABWE

In **Zimbabwe**, funding for organisations led by women and girls living with and affected by HIV is still very scarce. Even before the pandemic, the funding landscape was dominated by stronger CSOs who 'snap up' any funding that becomes available—and this remains the case. Very little of this funding trickles to women and girls living with HIV. The process is tokenistic, as only one or two of the women may be called to sit in a meeting where decisions are taken, which is regarded as our 'inclusion'.

8 ADDITIONAL FINDINGS

"I have colleagues, friends and families who died of COVID-19, and it was a very traumatising period for me."

YOUNG WOMAN FROM KENYA



Ill-health from COVID-19: Women and girls were directly and indirectly affected by COVID-19. Some lost relatives and others fell ill, without access to treatment options. The combination of having to manage the health and financial costs of HIV and COVID-19 for themselves or relatives was really difficult, and the emotional impacts are still being felt.

Some women continue to suffer symptoms. Yet these symptoms of long-COVID are not being taken seriously by doctors—or women do not fully understand the symptoms they are experiencing. When they fell ill or relatives did, they faced stigma and discrimination associated with the illness. Other women spoke about their fear of contracting the virus. Some people understandably believed that people living with HIV are more susceptible to COVID-19 (although people living with HIV are not more likely to acquire COVID-19, they are more likely to fall seriously ill from it than HIV-negative people; maintaining an undetectable viral load may reduce the risk of severe illness from COVID-19, but lockdowns complicated access to ART).¹⁶ Fear of getting COVID-19 led people to avoid available services; this might have caused negative impacts on their health over the short-, medium- and long-term.

“I went to the facility, registered myself for vaccination and I ran away for fear of getting sick. I also did that for my second jab.”

YOUNG WOMAN FROM SOUTH SUDAN

Getting COVID-19 can have multiple impacts on health and livelihood.

“I looked for laundry jobs but no one could offer me due to fear of infecting family members. I had to put my household stuff in my friend’s house and then go to my rural home.”

-YOUNG WOMAN FROM KENYA

One participant from Kenya was admitted with COVID-19 to the intensive care unit, and isolated for 21 days. This had an impact on her family; one of her sons had to stop his schooling while the other was terminated from work, due to the fear that they might have also acquired COVID-19, and her insurance could not settle the bill.

The fear of contracting COVID-19 was very dominant among the populations of people living with HIV across all of the countries included in this report, particularly among those who did not have insurance that covered COVID-19 health expenses.

The networks of people living with HIV in Kenya decided to collaborate to acquire an insurance scheme that would cater for COVID-19, in case any of them acquired it.

“We were all afraid, COVID-19 attacked the strongest amongst us and left them financially paralysed. We had to contribute. The group insurance was an affordable way to take action and be prepared as people living with HIV.”

OLDER WOMAN FROM KENYA

The vaccine roll-out: In Kenya and Zimbabwe, people living with HIV were prioritised for the vaccine, but this meant that they had to disclose their status while waiting in queues.

In Zimbabwe, people were initially told that the vaccine was not good for people living with HIV, nor for pregnant women. Now, health authorities are stating that everyone should have it. However, the consequences of these original messages still have to be countered. Women living with HIV are concerned about the impact of the vaccine on their health and their HIV treatment. There is significant vaccine hesitancy. When women living with HIV go to get vaccinated now, they feel obliged to disclose their HIV status to healthcare

providers, out of an understandable fear of interactions between vaccines and their ART (although, to date, none has yet been reported by global researchers and there is no reason to think that this will occur; in fact, ART improves immune health, and therefore, responses to vaccination—a message that needs to be shared widely).

In sum, there is still a lot of fear of the vaccine, and much to learn from HIV treatment literacy campaigns in communities.

The impact of climate change: The respondents alluded to global climate change, referring to heat waves and unusual weather patterns. The response to the pandemic has also had implications for those experiencing the negative effects of climate change. For example, during COVID-19, governments emphasised regular hand-washing as one way of controlling the virus. However, some areas were already experiencing drought and there was inadequate water supply. In areas where water (and indeed firewood) is scarce, women had to travel kilometres away from their homes to collect it. This, in turn, exposed them to violence, contaminated water, or, in rural areas, attacks from wild animals. Because of the distances involved, those who could afford it opted to buy water, but this raised the challenge of whether to buy food or water.

“I have been affected by floods and climate patterns have changed. My people were affected, so I had to help them with food since their crops were washed away with heavy rains at a time when I was also suffering, not even managing my own life.”

- YOUNG WOMAN FROM ZIMBABWE

Women living with HIV in semi-arid areas, whose livelihood depended on agriculture, are also adversely affected by unfavourable

weather changes, and could not cope with the high cost of living. In Kenya, most parts of the country are affected by drought. Many people did not have enough harvest, because of insufficient rain in the past year, which has led to food and water insecurity; it also makes malnutrition a challenge to HIV care and treatment. Participants described how climate change has led to many deaths.^{17,18}

Commodity security and stock-outs:

Countries such as Kenya have experienced acute shortages of essential, life-saving commodities such as ART and reagents for viral load testing. Without essential viral load monitoring, women and girls are not sure of their treatment progress and outcomes.

People living with HIV have therefore been forced to incur high out-of-pocket expenditures (ie extra transport costs and the time involved) to seek HIV- and SRH-related services at uneven intervals, while being issued ARVs in small portions. Sometimes they had to attend clinic as often as every two weeks to access ARVs.

Key messages and recommendations

Below we present key messages and recommendations to uphold the rights of women and girls living with HIV and achieve well-being in the current context of COVID-19, climate change, and the global cost-of-living crisis.

The following overarching messages and recommendations are based on the findings from all the participants consulted. They are directed to all stakeholders and duty bearers. They are by no means comprehensive, but offer an overall indication of the many and complex challenges which women living with HIV are still facing, post-COVID, and the opportunities that they are identifying clearly to overcome them.

Our messages and calls to action:

1 Normal is not always good

There has been much talk of getting 'back to normal', but **normal is not always good**. Women living with HIV were not well supported before COVID-19, and nothing has improved.

RECOMMENDATION

Make supporting women and girls living with HIV in all our diversity the new normal. Treat women and girls living with HIV as stakeholders, not just as beneficiaries, and involve us in decision-making spaces. Provide an equal platform for representatives of women- and girls – led networks to engage and inform decisions.

2 Sustain our SRHR

Because **the SRHR of women living with HIV** was not prioritised before the pandemic, governments and donors did not consider SRHR an essential part of the response, and so were ill-prepared to ensure SRHR were met during the pandemic.

RECOMMENDATION

Uphold our SRHR as essential—even in a pandemic. Disaster and emergency preparedness is key, to minimise the impact of disasters on the SRHR of all women and girls, including women and girls living with HIV, by ensuring that support, with a minimum package of SRHR embedded within it, is delivered.

3 Maintain our mental health

Women are also now dealing with **the ongoing impact on mental and physical health** of the multiple traumas and lack of access to SRH and other services faced during the pandemic. Women living with HIV (or family members) who had COVID-19 have also experienced health and financial impacts. Supply chains were affected and this has led to commodity and drug stock-outs which have also affected the health and SRHR of women living with HIV.

RECOMMENDATION

Recognise and address the ongoing impact of the pandemic and cost of living crisis on our lives. Fund peer support,

which is a proven way to support anyone, and reduce the trauma in their lives. Funding peer support of women living with HIV is a crucial way of enabling us to support one another not to fall through the immense gaps in services. Recognise and consider the diversities of women and girls, cease from criminalising us as women living with HIV, those amongst us who are in key populations, immigrants, etc., and ensure each person acquires the highest attainable standard of health. Employ human-centred and trauma-informed strategies into programming for HIV- and SRH-related services and involve women living with HIV in training healthcare providers to improve the quality of SRH care.

4 Ensure our education

Access to SRH and HIV services as well as **information and education** that would support young women and girls living with HIV have been set back considerably by the COVID-19 pandemic, including because of school closures during COVID-19 restrictions.

RECOMMENDATION

Whenever possible, keep students in school during country disaster periods. Schools need to be recognised as critical social protection zones for girls and young women including those living with HIV. Schools should also ensure age-appropriate Comprehensive Sexuality Education from the age of five years upwards, which includes the SRHR of women and girls living with HIV. Schools can support menstrual health management among girls, when sanitary towels are available and free. Build in better support for catch-up for those who have had to miss out on their schooling, to minimise their disadvantages.

5 Validate our vital work

The **vital work of women and girls** living with HIV on SRHR, HIV and COVID-19 in their communities is still being ignored by governments and donors. Women are still doing it against all the odds, and many are experiencing burn-out.

RECOMMENDATION

Urgently support the vital work of women and girls in their communities. We can promote and engage in knowledge-sharing and linking and learning sessions in regional and global platforms, to strengthen the capacity of women- and girls-led rights organisations.

6 Secure our livelihoods

Women's **access to food and money** was devastated by the pandemic and continues to be so due to the global cost-of-living crisis caused by the combination of the economic consequences of the pandemic, climate change, and conflict. Women who have had some support with income generation before and during the pandemic have fared better than others.

RECOMMENDATION

Support the livelihoods of women living with HIV and ensure everyone has enough to eat. Fund skills to promote income-generation. Women who were funded to acquire some income-generating skills in Uganda fared better during the pandemic than those who did not receive this training.

7 Protect our privacies

COVID-19 restrictions have brought **serious privacy and confidentiality concerns** for women and girls living with HIV and while pandemic related restrictions have largely (though not fully) been lifted, women are still living with the consequences of these breaches and those brought about by the ongoing and increasing financial squeeze on services. For some women, the COVID-19 vaccine roll-out has caused more privacy concerns.

RECOMMENDATION

Ensure *all* health services respect the privacy and confidentiality for women and girls living with HIV. Equip health care service providers with knowledge and skills in providing appropriate, non-judgemental, respectful and confidential advice and services, to recipients of care, whenever they seek any HIV- and SRH-related services at the facilities.

8 Safeguard our safety

COVID-19 led to **increases in violence against women and girls** and this received international condemnation. Women are still living with the psychological and physical consequences of the violence they faced. The pandemic shone a spotlight on VAWG as endemic before and during the crisis, and yet the spotlight has shifted away from VAWG now that the COVID-19 crisis is seen as over.

RECOMMENDATION

Fund effective, ethical and sustainable, evidence-based, gender-transformative VAWG programmes in communities, which are led by women living with

and/or affected by HIV and VAWG. Ensure that policies and programmes are in place to prevent VAWG as well as intersections with HIV-related stigma and discrimination, in our communities and across all government sectors—and to hold perpetrators to account.

9 Invest in our digital inclusion

Digital communications are still leaving out many women and girls. However, there are examples of women living with HIV adapting to online ways of working, communicating and supporting their peers.

RECOMMENDATION

Face to face is still really important—don't forget it in the reliance on digital. Even so, our digital inclusion is vital. Make internet access a human right. Fund women's organisations to provide training for women on how to use the internet and how to access accurate and reliable information on smartphones. Women in South Sudan who received this training benefitted from their new-found skills. Fund skills, devices, connectivity and data.

10 Fund what we want

Before and during this crisis, **funding remains in very short supply** for organisations led by women and girls living with and affected by HIV. There is a focus in the HIV response on supporting key populations but this approach often fails to recognise the gendered implications for women and girls living with HIV. There is also an overwhelming critical issue for us all—namely that there is still so much donor emphasis on top-down bio-medical issues related to HIV and women, rather

than on all the other quality of life issues facing women living with HIV beyond our diagnoses in our daily lives. The findings shown here reflect the rich diversity of women's lives, way beyond the specific physical details of dealing with the HIV virus. It is these complex psycho-social, sexual, physical, financial and legal issues which combine either to undermine, deny us and violate our SRHR—or access, uphold and ensure them.

RECOMMENDATION

Provide flexible, creative, accessible funding for organisations led by women and girls living with HIV during and beyond this COVID-19 crisis. Fund women-led, rights organisations to

continue the critical work that they do, including support for core costs. Modify your eligibility criteria for funding women- and girls-led rights networks, and use flexible funding mechanisms. We entirely support your funding for key populations, which also include many women who urgently need funds. At the same time, ensure that women and girls living with HIV whose issues are *not* addressed by organisations of key populations are also funded. It is shaming for us all to have to compete for your funding. Lastly, fund *what we want* to have funded, to support *our own priorities* instead of what you think are our 'needs'. We know what works for us. Listen to us. Believe us.

CONCLUSION

Are women and girls still confined by COVID-19?

“The simple answer is Yes! Women and girls are still affected by the effects of the COVID-19 pandemic.”

LEAD RESEARCHER, JOYCE OUMA.

Through this research process, we have seen how the COVID-19 pandemic and the responses from governments and donors have further deepened the inequities that women and girls from East and Southern Africa continue to face. The protracted effects of COVID-19 have made recovery an impossible task for most women and girls living with HIV in the region.

The worrying responses received by the co-researchers indicate clearly that women and girls continue to be confined by more than just COVID-19. They are confined by the on-going patriarchy, oppression, gendered inequities and injustices which we described in our original report for ITPC in early 2020.¹⁹ When the world shifted its focus to respond to the pandemic, it maintained these confinements in its strategies. These responses led to many shadow pandemics, such as healthcare commodities stockouts, increased violence against women and girls in all their diversities, and loss of income sources, which led to increased financial constraints and mental health issues.

The COVID-19 pandemic and its social and economic impacts have created a global crisis unparalleled in our history, which faces us all, and one which requires a whole-of-society response to match its sheer scale and complexity.

The chronic prevalence of VAWG across all the countries is also a deeply challenging parallel pandemic, which needs urgent attention at global, national and provincial levels.²⁰ Violence is a fundamental challenge to our mental as well as physical and sexual health and well-being. Violence is also preventable—yet it continues to be considered the norm—and, as such, is dismissed. Yet its effects on so many women’s and girls’ lives across the life-course presents a fundamental barrier to ever achieving our SRHR. This status quo remains entirely unacceptable.

Yet this report has also shown, once again, that women living with HIV continue to shift the norms. It shows what we are highly capable of doing for ourselves—and what an immense difference appropriate policies and funding do—and could make—to what we are able to do. The women in Uganda who had had skills training were better able to re-start earning an income for themselves post-lockdown. The women in South Sudan who had received IT training were better able to navigate online accurate information, funding and other resources. Some women in Kenya have started to use social media to earn an income and developed community ART collection and distribution groups. Women in Zimbabwe continue to offer each other collective financial support when they are in need, and also organised the CARGs for collecting ARVs. These are simple solutions which are community-led and driven.



There is a great thirst amongst us all to make use of our own skills and efforts to support ourselves and one another—and yet it is *still* so hard to access even basic funding to acquire these skills and pool these initiatives. Just imagine what we could do if the right policies and funds were in place.

All stakeholders, at global, national and provincial levels, should be intentional in addressing the issues affecting women and girls, both within and beyond the COVID-19 context. They should invest in comprehensive pandemic preparedness to ensure that health systems are resilient and prepared for all the multi-faceted upheavals of COVID-19 and other climate-related challenges. Global and national health systems need to future-proof the SRHR of women and girls living with HIV, both for our own good and for the public good of countries in which we live. The only way to do this is to invest in, regard, and uphold the political, economic, legal, social, technological, environmental and ethical leadership of women and girls, so that our needs and priorities are infused throughout policies, programmes, processes, evaluations—and results. Together we *can* still all do this. The time to act is *now*.

Endnotes

- 1 Salamander Trust and ITPC. Women, HIV and their Sexual and Reproductive Health Rights: Are We Meeting WHO Guidelines?: A focus on contraceptive rights, inclusion, access research in the context of HIV. Some voices from the community. Advocacy Brief. 2020. Available from: https://itpcglobal.org/wp-content/uploads/2020/09/SRHR-women-and-HIV_20200929.pdf
- 2 The World Health Organization (WHO) (2017) Consolidated guideline on sexual and reproductive health and rights of women living with HIV
- 3 Salamander Trust and ITPC. Confined by COVID-19: women and girls, HIV and SRHR The challenges, the responses and calls to action: Advocacy Brief. 2020. Available from: https://itpcglobal.org/wp-content/uploads/2020/12/SRHR-Women-and-COVID-19_12-10_v2.pdf
- 4 Salamander Trust. How COVID-19 is affecting the lives of women living with HIV. Webinar. 21 January 2021. Available from: <https://vimeo.com/505743729>
- 5 Guttmacher.org: ACCELERATE PROGRESS: Sexual and Reproductive Health and Rights for All. 2018. Available from: [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(18\)30293-9/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)30293-9/fulltext)
- 6 Organisation for Economic Co-operation and Development. Women at the core of the fight against COVID-19 crisis. 2020. Available from: https://read.oecd-ilibrary.org/view/?ref=127_127000-awfnqj80me&title=Women-at-the-core-of-the-fight-against-COVID-19-crisis.
- 7 European Parliamentary Forum for Sexual and Reproductive Rights. Tip of the Iceberg: Religious extremist - Funders against Human Rights for Sexuality and Reproductive Health in Europe 2009- 2018. Intelligence Brief. 15 June 2021. Available from: <https://www.epfweb.org/sites/default/files/2021-08/Tip%20of%20the%20Iceberg%20August%202021%20Final.pdf>
- 8 JASS. Defending Rights in Hostile Contexts: Understanding and Confronting the Crackdown Against Activists and Democratic Space in Southern Africa. December 2019. Available from: https://justassociates.org/wp-content/uploads/2020/08/defending_rights_in_hostile_contexts_insights_from_southern_africa.pdf
- 9 The Observatory on the Universality of Rights. <https://www.oursplatform.org/>
- 10 Denkovski D, Bernarding N, Lunz K. Power over Rights: Understanding and Countering the Transnational Anti-Gender Movement. Center for Feminist Foreign Policy. 2021. Available from: <https://centreforfeministforeignpolicy.org/power-over-rights-understanding-and-countering-the-antigender-campaigns>
- 11 Martínez J Duarte, A, Rojas MJ. Sentido (Colombia). Manufacturing Moral Panic: Weaponizing children to undermine gender justice and human rights. Report. Elevate Children Funders Group. 2021. Available from <https://globalphilanthropyproject.org/wp-content/uploads/2021/04/Manufacturing-Moral-Panic-Report.pdf>
- 12 Aoko E. The Kenya National Reproductive Health Policy 2022-2032: Until when will we have to fight for our Sexual and Reproductive Health and Rights? Making Waves. 2022. Available at: <https://makingwaves.network/2022/08/05/kenyas-national-reproductive-health-policy-2022-2032/>
- 13 Nowshin N, Kapiriri L, Davison C, et al. Sexual and reproductive health and rights of “last mile” adolescents: a scoping review. Sex Reprod Health Matters. 2022; 30(1): 2077283. Published online 2022 Jun 6. doi: 10.1080/26410397.2022.2077283
- 14 C-CHANGE/ Harvard T.H. Chan School of Public Health. Coronavirus, Climate Change, and the Environment. A Conversation on COVID-19 with Dr. Aaron Bernstein, Director of Harvard Chan C-CHANGE. Undated. Available from: <https://www.hsph.harvard.edu/c-change/subtopics/coronavirus-and-climate-change/>
- 15 WHO World Mental Health report: transforming mental health for all 2022 <https://www.who.int/publications/i/item/9789240049338>
- 16 UNAIDS. People living with HIV at higher risk of COVID-19 illness but have lower access to COVID-19 vaccines, 2021. Available from: https://www.unaids.org/en/resources/presscentre/featurestories/2021/october/20211011_people-living-with-hiv-covid19

- 17 Logie CH, Toccalino D, Reed AC, et al, Exploring linkages between climate change and sexual health: a scoping review protocol *BMJ Open* 2021;11:e054720. doi: 10.1136/bmjopen-2021-054720
- 18 Women Deliver. The link between climate change and sexual and reproductive health and rights, 2021. <https://womendeliver.org/wp-content/uploads/2021/02/Climate-Change-Report.pdf>
- 19 Salamander Trust and ITPC. Women, HIV and their Sexual and Reproductive Health Rights: Are We Meeting WHO Guidelines?: A focus on contraceptive rights, inclusion, access research in the context of HIV. Some voices from the community. *Advocacy Brief*. 2020. Available from: https://itpcglobal.org/wp-content/uploads/2020/09/SRHR-women-and-HIV_20200929.pdf
- 20 World Health Organization. RESPECT women— Preventing violence against women. Report. 2019. Geneva. Available from: <https://www.who.int/publications/i/item/WHO-RHR-18.19>

All references were cited in August 2022.



Salamander Trust
ON THE RIGHT(S) TRACK



Making Waves



itpcglobal.org



@ITPCglobal



facebook.com/ITPCglobal



ITPC Global