

A group of young women, likely members of a youth group, are captured in a moment of joy and celebration. They are wearing white t-shirts with a colorful logo and the letters 'SYP' printed on them. Many of the women have their arms raised high, some holding mobile phones, suggesting they are taking photos or videos. The background shows a lush green field, possibly a cornfield, under a bright sky. The overall atmosphere is one of empowerment and community.

# POWER TO THE PEOPLE

Cover photo credit: UNFPA/Swiss Agency for Development and Cooperation

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Melody, a sex worker from Epworth, Zimbabwe, prepares herself for work. Melody receives support from Katswe Sistahood, an organization which advocates for women's full attainment of sexual and reproductive rights in Zimbabwe. Credit: UNAIDS/C. Matonhodze



**POWER TO  
THE PEOPLE**

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# FOREWORD

The struggle to end the AIDS epidemic continues to be inextricably linked with the struggle to end human rights violations, including discrimination and violence against women and girls and the marginalization and criminalization of key populations—sex workers, people who use drugs, gay men and other men who have sex with men, transgender people and prisoners.

In 2018, more than half of all new HIV infections were among key populations. Globally in 2018, 6000 adolescent girls and young women became infected with HIV every week. In sub-Saharan Africa, four in five new HIV infections among adolescents aged 10–19 years are among girls. Young women aged 15–24 years are twice as likely to be living with HIV than men of the same age.

As the people worst affected by the virus, young women and adolescent girls and key populations need to have the power to shape the response to HIV as it changes and evolves.

This means giving young women and girls access to the knowledge, information and HIV prevention tools that give them the power to protect themselves from infection, to social interventions that keep them in school longer and improve their life chances and to policies and programmes that end their exposure to gender-based violence, which fuels the epidemic.

The world needs a feminist approach to HIV that will equalize power and transform the health and development agenda for women and girls and all key populations.

Key populations must be able to enjoy their rights as equal citizens in every country.

Global citizenship confers rights on each of us to have equal access to essential services, such as health and education. Universal health coverage should become the foundation of the right to access health. Every human being has the right to be treated with respect and dignity, and yet every day we witness people paying the price and becoming infected with HIV because they face stigma and discrimination, are marginalized and criminalized.

To end the AIDS epidemic, denial of citizenship rights must end.

To break the grip of the virus and end the cycle of transmission we must ensure that people have access to regular HIV testing services and that, if necessary, they are linked to treatment or prevention services as quickly as possible.

When a person living with HIV is on effective antiretroviral therapy, they can no longer transmit the virus. This is the power to know and the power to thrive.

While the world has made great progress in reducing the number of children born with the virus by expanding treatment to pregnant women living with HIV, there remain alarming gaps in treatment for infants and older children living with HIV. It is shameful that children living with HIV are less likely to have access to treatment than adults. We are leaving children behind.

HIV is more than a health issue. It is an issue of development and social justice, which cuts across so many of the Sustainable Development Goals.

We stand on the threshold of a new decade. The world must make it a decade of delivery to bring the 2030 Agenda for Sustainable Development to life for everyone.

**Winnie Byanyima**

UNAIDS Executive Director







# INTRODUCTION AND SUMMARY

*Power is traditionally defined as the ability of an individual or group to convince others to do things that they would not otherwise do (2). Such power often appears to concentrate in the hands of a few wealthy, strong and charismatic individuals—such as monarchs, presidents, tycoons and media stars. This unequal distribution of power has been described as one of the most pervasive facts of political life (3).*

This report argues that power in fact rests in the hands of the people, as can be seen in countless local, national and international movements to redistribute power and bring greater attention to neglected issues.

Mass movements to redistribute power often have humble beginnings, born out of desperate need or simmering injustice. Sparks of frustration light infernos of change. In the early days of the HIV response, grossly insufficient leadership and medical care ignited a global civil society movement. It was the loud and persistent voice of people living with HIV and key populations at high risk of infection that accelerated the pace of research on antiretroviral medicines and drove down their prices, and it is that same determination that continues to expand the provision of affordable, life-saving treatment to millions of people around the world living with HIV.

*Fatma Khamis, a youth reporter from the Zanzibar Association of People Living with HIV/AIDS, records a radio show in Zanzibar, United Republic of Tanzania.*

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**“THE GREAT ILLUSION OF POLITICS IS THAT POWER FLOWS DOWNWARD FROM THE RULER THROUGH THE ELITE TO THE MASSES, WHEREAS IN ACTUAL FACT THE PROCESS IS PRECISELY THE REVERSE. . . POWER CAN ONLY FLOW UPWARD.”**

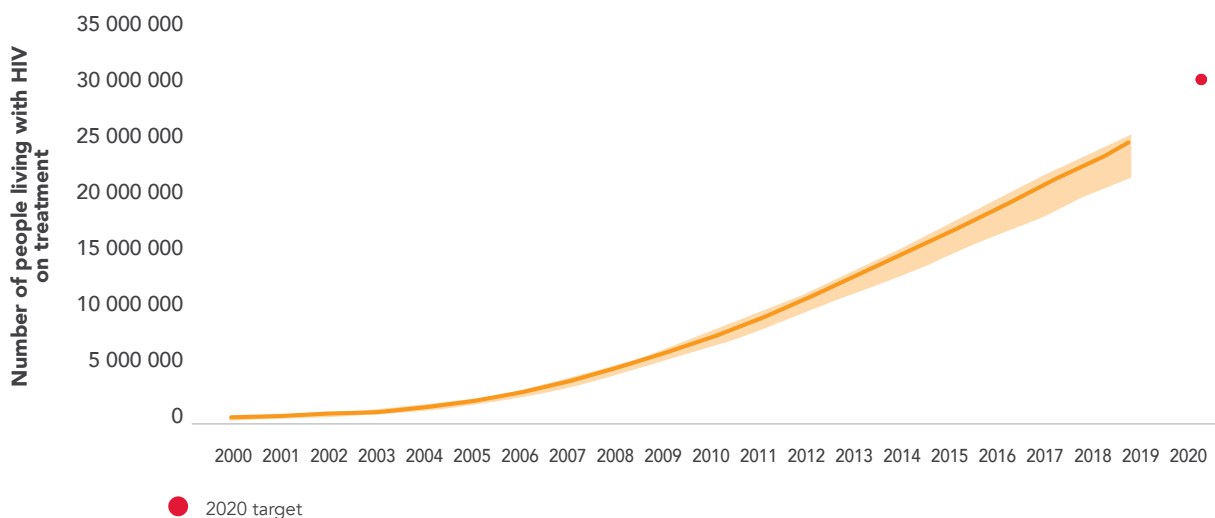
*Lucian Pye (1)*

The number of people living with HIV who are on treatment continues to rise, with an estimated 24.5 million [21.5–25.5 million] receiving antiretroviral therapy in mid-2019—more than double the number on treatment in 2012 (Figure 1.1). Strong progress has been made towards the 90–90–90 testing and treatment targets in several regions.<sup>1</sup> However, gaps across the HIV testing and treatment cascade have left the world short of the 2020 goal of 30 million people on treatment, and nearly half (47%) of people living with HIV in 2018 had unsuppressed viral loads.

<sup>1</sup> The 90–90–90 targets call for 90% of people living with HIV to know their HIV status, 90% of people who know their HIV-positive status to be accessing treatment and 90% of people on treatment to have suppressed viral loads by 2020.

FIGURE 1.1

**Number of people living with HIV on treatment, global, 2000 to mid-2019**



**Source:** UNAIDS Global AIDS Monitoring, 2019 (see <https://aidsinfo.unaids.org/>) and UNAIDS special analysis, 2019 (for more details please see Annex on methods in *Communities at the centre: defending rights, breaking barriers, reaching people with HIV services*. Geneva: UNAIDS; 2019).

**Power imbalances leave people behind**

Where communities are able to participate in decision-making and service delivery, outcomes and impacts have generally improved. Conversely, where stigma and discrimination and criminalization have shut out communities, HIV responses struggle to provide services to those who need them most. As a result, annual HIV infections and AIDS-related deaths continue to rise in dozens of countries.

The marginalization of key populations is holding back efforts to achieve the 90–90–90 targets in several regions. For example, among gay men and other men who have sex with men living with HIV in sub-Saharan Africa, knowledge of HIV status appears to be considerably lower than it is among men as a whole (4).

There also are large gaps in knowledge of HIV status among young people and men living with HIV. Outmoded conceptions of masculinity—combined with relatively less interaction between men and the health system compared to women—result in

long periods of time between infection and diagnosis among men. For example, only one in four young men (aged 15–24 years) and one in three older men (aged 25 years and older) in Mozambique were diagnosed within one year of infection, compared to more than half of women (Figure 1.2).

Lower knowledge of HIV status and treatment coverage among men combines with gender inequalities that sanction the subordination of women and girls to perpetuate HIV epidemics. Special efforts are needed to address the barriers that men living with HIV face when it comes to knowing their HIV status and suppressing their viral loads, and holistic efforts are needed to tackle the gender inequalities, patriarchal norms and practices, violence, discrimination and other rights violations that women and girls face every day.

For example, population-based survey data from five eastern and southern African countries show considerable variation in the use of modern contraception methods and access to family planning among adolescent girls, although the unmet need tends to be especially high among those who are

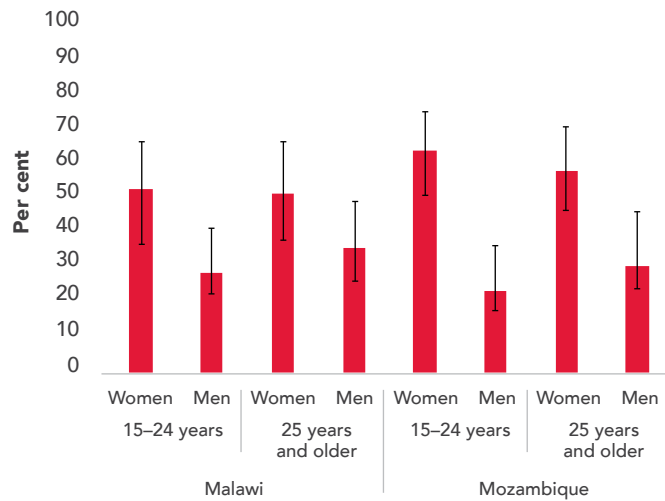


sexually active but unmarried (Figure 1.3). Achieving the Sustainable Development Goals (SDGs) will be impossible as long as women and girls are denied control over their bodies and their sexual and reproductive lives.

The recent Evidence for Contraceptive Options and HIV Outcomes (ECHO) trial in Eswatini, Kenya, South Africa and Zambia highlighted the ongoing need for evidence-informed and women-centred interventions—biomedical, social and economic—that protect the health and lives of women, especially young women and adolescent girls. Despite regularly accessing health services during the trial that included HIV prevention, participants in all three trial arms had a high incidence of HIV infection (about 3.8%) (5).

FIGURE 1.2

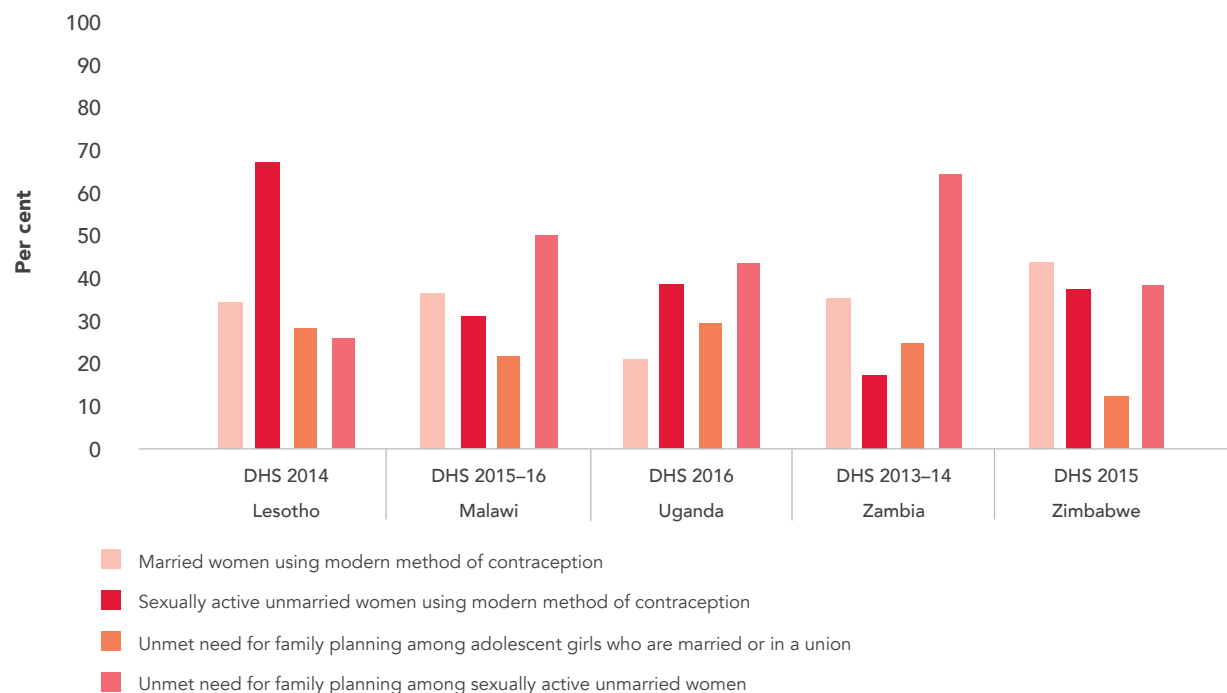
**Per cent diagnosed within a year of HIV seroconversion, by age and sex, selected countries, 2018**



**Source:** Estimates shared in personal communication from K Giguère, JW Eaton, and M Maheu-Giroux, October 2019. For more details on the estimation method, see National HIV testing and diagnosis coverage in sub-Saharan Africa: a new modeling tool for estimating the “first 90” from program and survey data. Maheu-Giroux, M, Marsh K, et al. bioRxiv 532010; doi: <https://doi.org/10.1101/532010>.

FIGURE 1.3

**Modern method of contraceptive use and unmet need for family planning among married and sexually active unmarried adolescent girls and young women (aged 15–19 years), five selected countries in eastern and southern Africa, 2014–2016**



**Source:** Demographic and Health Surveys, 2014–2016.

Efforts aimed at redressing gender inequalities and socioeconomic inequities can mitigate factors that fuel the HIV epidemic (6). Providing cash incentives to young people, especially girls, to stay in school longer and do better in their studies has been shown to have a positive impact on monetary poverty, school attendance and performance, health, nutrition (especially for children) and empowerment (7–9). Other evidence indicates that cash grants that enable girls to continue their schooling also delay their sexual debut, increase their use of health services, and reduce teen pregnancies and early marriage, and that they can promote safer sexual behaviours (7, 10).

Staying in school longer has also been linked with reduced HIV risk (11–13). A three-year cluster randomized controlled trial in Eswatini, the Sitakhela Likusasa study, has shown that cash transfers are improving school attendance and reducing the risk of HIV infection among adolescent girls and young women. Study participants who received cash transfers had a 25% lower risk of acquiring HIV, and participants who both received cash transfers and an additional raffle incentive had a 38% reduction in HIV risk (14).

### **Demanding removal of legal barriers**

Community organizations are at the vanguard of efforts to change laws that criminalize key populations or discriminate against people living with HIV. In Botswana, for example, LEGABIBO (The Lesbians, Gays and Bisexuals of Botswana) was at the centre of efforts to strike down a law criminalizing same-sex sexual intercourse as unconstitutional (15). In several countries in Latin America, community activists successfully campaigned for the promulgation of protective gender identity laws (16). In 2017, after years of campaigning by Girasoles, a local organization, Nicaragua became the third central American country to formally recognize a sex workers' union (17).

Age of consent laws are a major barrier to HIV testing for older children and adolescents. In countries where the age of consent for testing is 15 years or younger,

adolescents aged 15–18 years were 74% more likely to have taken an HIV test in the previous year than in countries where the age of consent for testing is 16 years and older.

In the face of multiple barriers to sexual and reproductive health and rights and HIV services, young people are coming together to demand their rights and hold authorities accountable. In Zambia, Tikambe ("Let's Talk"), a youth accountability project run by Restless Development, raises civic awareness of the rights and responsibilities of young people and encourages them to take action and hold government to account for the provision of accessible and adequate youth-friendly health services (18, 19). In India, Know Your Body Know Your Rights is a youth-led programme that aims to empower young people to advocate for and access information on human rights, HIV, gender, sexuality, sexual and reproductive health, and youth-friendly health services (20). #uproot, an audit and accountability scorecard developed by and for young people, informed South Sudan's first-ever National Youth Conference on HIV, sexual and reproductive health and rights, and gender equality (21).

### **Community-led services for hard-to-reach populations**

Structural change can be slow. Laws can take decades to change, as was the case in India, where a 2018 Supreme Court decision to overturn a colonial-era law that criminalized consensual same-sex sexual activity came after 20 years of campaigning and organizing by lesbian, gay, bisexual, transgender and intersex (LGBTI) community groups and local nongovernmental organizations.

HIV-related stigma and discrimination—often reinforced by age-of-consent laws, structural inequities and the criminalization of HIV transmission and key populations—interferes with the ability of people to access the testing and treatment services they need. Community-led and community-engaged efforts are combining service provision with safe spaces, individual empowerment, advocacy and broader learning opportunities that mitigate the negative impact of threatening

environments. For example, peer and other forms of community support enable women to make positive health-care decisions, including taking an HIV test and, if necessary, starting antiretroviral therapy. Mentoring and peer support, and the support of partners and other family members, are especially effective for strengthening the retention of women in HIV care (22).

Community-led groups and other civil society organizations are at the forefront of changing drug policies and providing services to reduce the harms associated with drug use, including HIV. In 2018, civil society organizations were operating needle-syringe programmes and/or opioid substitution therapy programmes in 47 countries in all regions.

Combining services with community empowerment activities among female sex workers has been shown to increase consistent condom use with clients and reduce HIV infection rates (23).

Community-led support has also proven highly effective among gay men and other men who have sex with men for promoting safer sex, popularizing the use of oral pre-exposure prophylaxis (PrEP), advocating for its use, increasing HIV and sexually transmitted infection (STI) testing rates, and supporting treatment adherence (4, 24).

Community-led and community-engaged efforts also are increasing access to HIV self-testing. In Zimbabwe, men valued the privacy and confidentiality afforded them when community mobilizers offered self-testing kits, giving many who otherwise would not visit health facilities the opportunity to know their HIV status (25). Peer-mobilized self-testing has increased HIV diagnoses and linkage to care among female sex workers and gay men and other men who have sex with men in Burundi, and transgender women in India have shown a preference to access self-testing in peer-supported, community-based settings (26, 27).

*Young activists from the Teenergizer movement meet in Kiev, Ukraine. Teenergizer brings together adolescents born to mothers living with HIV and other young volunteers from Georgia, the Russian Federation and Ukraine who are advocating for adolescents' sexual and reproductive health and rights.*





*Mukiibi Grace Nickolas, a doctor at the Uganda Harm Reduction Network's drop-in centre in Mukono, Uganda, administers an HIV test for a client, Kenigisa Sandriano.*

Credit: UNAIDS/E. Echwalu

### **PrEP: an empowering additional prevention method**

Oral PrEP has shown considerable impact in reducing HIV infections when provided as an additional HIV prevention choice to gay men and other men who have sex with men, transgender persons and sex workers. Despite this, PrEP is not a “magic bullet” for HIV prevention: it is a component of a robust combination HIV prevention programme that tackles the contextual factors that put people at risk of HIV infection and prevent them from accessing services.

PrEP is now being rolled out in sub-Saharan Africa for serodiscordant couples and adolescent girls and young women who are at high risk of HIV infection (28–31). Uptake is high when community-level stigma and misconceptions are addressed, when women and girls are provided with accurate and relevant messaging about PrEP (including compelling explanations of

its benefits), and when PrEP is framed as an empowering prevention method and a positive life choice (32, 33).

PrEP has high efficacy when it is taken regularly (34). In South Africa and Zimbabwe—where steps were taken to facilitate peer support, publicize the benefits of PrEP and engage community stakeholders more closely—retention was 88% at six months (35).

### **Defining and expanding community-led responses**

The importance of community-led responses was enshrined in the United Nations (UN) General Assembly's 2016 Political Declaration on Ending AIDS. The Declaration recognizes the role that community organizations play and commits to expanding community-led



service delivery to cover at least 30% of all service delivery by 2030. It also calls for increased and sustained investment in the advocacy and leadership role, involvement and empowerment of community-based organizations and people living with, at risk of and affected by HIV.

Despite that commitment, progress was never adequately measured, in part because community-based organizations were not well-defined. This led the UNAIDS Programme Coordinating Board to request the formation of a task team with broad representation to standardize

the use of definitions (36). In June 2019, representatives of people living with HIV, women living with HIV, young women, young people, gay men and other men who have sex with men, transgender people, sex workers, people who use drugs, women's organizations, treatment activists, and people living with tuberculosis from across the world came together to define what "community-led response" means (see below). The consultation was informed by an online survey of community members and a consolidation of definitions from other sources (37–41).

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## DEFINITIONS FOR COMMUNITY-LED HIV RESPONSES

**Community-led organizations, groups, and networks,**<sup>2</sup> irrespective of their legal status, are entities for which the majority of governance, leadership, staff, spokespeople, membership and volunteers,<sup>3</sup> reflect and represent the experiences, perspectives, and voices of their constituencies and who have transparent mechanisms of accountability to their constituencies.

Community-led organizations, groups, and networks are self-determining and autonomous, and not influenced by government, commercial, or donor agendas.

Not all community-based organizations are community-led.

**Community-led responses** are actions and strategies that seek to improve the health and human rights of their constituencies, that are specifically informed and implemented by and for communities themselves and the organizations, groups, and networks that represent them.

Community-led responses are determined by and respond to the needs and aspirations of their constituents. Community-led responses include advocacy, campaigning and holding decision-makers to account; monitoring of policies, practices, and service delivery; participatory research; education and information sharing; service delivery; capacity building, and funding of community-led organizations, groups, and networks. Community-led responses can take place at global, regional, national, subnational, and grassroots levels, and can be implemented virtually or in person.

Not all responses that take place in communities are community-led.

**Note:** "Community-led" is an umbrella term that includes people living with HIV, key populations, women, youth, and all self-organized groups. Community experts attending the consultation shaped the definition and tested it to be sure it was inclusive of each of their constituencies. While the definition of community-led is inclusive of key population-led and of women-led, there was a call among participants for specific sub-definitions for these two types of responses. Those for key population-led were elaborated at the June 2019 meeting. In order to engage a wider diversity of women, the group recommended an additional meeting be called to develop the sub-definition for women-led organizations and responses. This will take place in early 2020, with the participation of communities of women living with and affected by HIV in all their diversity, who are a crucial part of the HIV response and face multiple impacts of gender discrimination and gender-based violence that fuel the HIV epidemic.

**Source:** What is a community-led organization? Geneva: UNAIDS; 2019

<sup>2</sup> Including collectives, coalitions and other ways that people self-organize.

<sup>3</sup> Organizing and capacity-building support was provided to Angola, Antigua, Bangladesh, Botswana, Brazil, Cambodia, China, Colombia, Ecuador, Eswatini, the Gambia, Georgia, Guyana, Indonesia, Jamaica, Kazakhstan, Kenya, Kyrgyzstan, Mexico, Mongolia, Myanmar, Nepal, Peru, Suriname, Trinidad and Tobago, Ukraine, Viet Nam and Zimbabwe. Please see: <https://robertcarrfund.org/networks/2016-2018/sex-worker-networks-consortium>



## Civic space must be protected

In several countries, the political climate for civic activism and community organizing is becoming less hospitable, especially for organizations that challenge inequalities and inequities or those that promote the rights of minorities.

The CIVICUS Monitor, a global civil society research collaboration that tracks the state of basic freedoms in 196 countries, has reported that almost 60% of those countries maintain major restrictions on people's fundamental freedoms of association, peaceful assembly and expression (42). According to the Global Commission on HIV and the Law, 60 countries passed approximately 120 laws restricting the activities of nongovernmental organizations (NGOs) between 2012 and 2015. More than one third of those laws affected the ability of organizations to receive foreign funding (43). This weakens HIV responses and the many intersecting efforts to build healthier societies that are more inclusive and just.

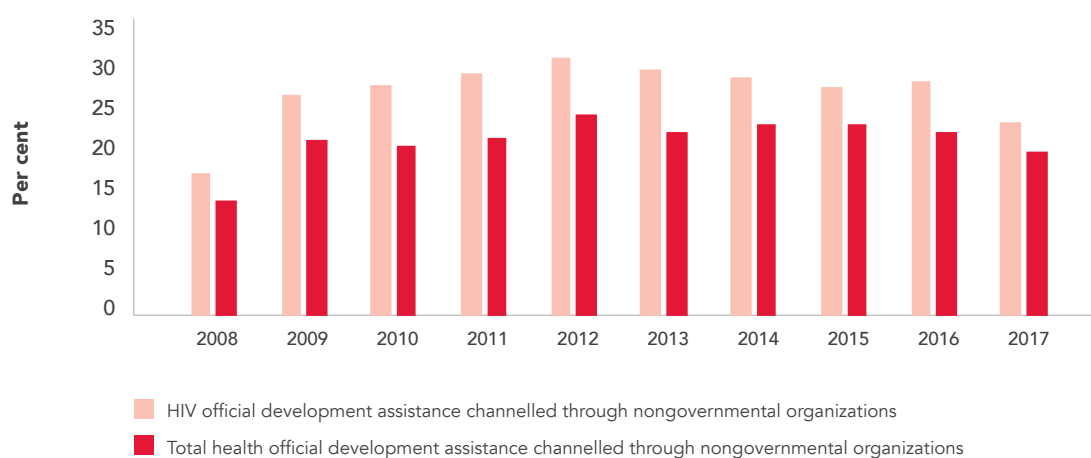
Communities of key populations in some countries in Africa have been unable to register their organizations, forcing them to

work as loose groupings or register under different guises (44). A recent assessment of conditions in Ethiopia, Kenya and Uganda, for example, found that the criminalization of key populations was used to justify restrictions on civil society activities relating to HIV, with some organizations unable to open bank accounts or hold public meetings (45).

The amount of HIV funding channeled through NGOs and civil society entities has been relatively flat in recent years despite their growing importance to HIV responses. Data on official development assistance (ODA) for HIV programming from the OECD's Creditor Reporting System show that funding for HIV channeled through nongovernmental organizations globally totaled US\$ 1.8 billion in 2017, a little higher than the US\$ 1.7 billion in 2015. An estimated 23% of ODA expenditures for HIV were channeled through NGOs and other civil society entities, compared with 28% in 2015. ODA for NGOs and civil society working on health, by comparison, has been more stable over the same period (Figure 1.4).

FIGURE 1.4

### Percentage of international resources for HIV and health channelled through nongovernmental organizations and civil society, 2008–2017



Source: Creditor Reporting System. In: stats.oecd.org [Internet]. OECD; c2019 (<https://stats.oecd.org/Index.aspx?DataSetCode=CRS1>, accessed 30 October 2019).

# CASE STUDY

## Making change together: Zimbabwe's National Key Populations HIV and AIDS Implementation Plan 2019–2020

Zimbabwe has shown how the engagement of diverse communities by national authorities can lead to a more effective approach to the HIV epidemic. Together, government and communities recently developed a landmark national HIV plan that puts key populations centre stage in the country's HIV response.

The National Key Populations HIV and AIDS Implementation Plan 2019–2020 showcases the concerns and rights of key populations, lays out the necessary interventions and describes the legal and policy framework that is needed to facilitate those actions. HIV interventions for key populations now have the support of Zimbabwe's National AIDS Council and the government (46).

The Plan was developed in consultation with key populations in December 2018 and January 2019, including through stakeholder meetings. Local organizations lobbied hard for the initiative and helped craft the process for developing the plan. They included the Gay and Lesbians of Zimbabwe (GALZ), the Zimbabwe Civil Liberties and Drug Network (ZCLDN), SAfAIDS, the Sexual Rights Centre, the Zimbabwe National Network of People Living with HIV (ZNNP+) and the Batanai HIV and AIDS Service Organisation (BHASO).

The participating organizations ensured that the exercise was guided by an accurate understanding of the importance of key populations to the HIV epidemic and response in Zimbabwe. Epidemiological briefings were provided, as were clear definitions of various key populations and discussions of their experiences and needs. The process of crafting the Plan included steps to guarantee confidentiality and protect delegates against possible harm related to their participation.

Subgroups examined specific issues (e.g., those relating to LGBTI persons, sex workers, refugees, people who use drugs or prison officials) and provided detailed recommendations, such as on specific activities, proposed partners, monitoring and evaluation indicators, and capacity needs. This was fed into the drafting process. Afterwards, an electronic questionnaire was circulated to gather additional inputs.

Written in plain language, the 10-point implementation plan includes timelines, target indicators, milestones and an overview of roles and responsibilities, with key populations assigned central roles. Supplementing this is an investment case that sets out the epidemiological, public health, economic and political arguments for implementing the recommendations.

The Plan stresses the need for continued cooperation between key population communities, civil society organizations, the National AIDS Council, government structures, health providers, donors and community leaders. It makes provisions for the meaningful involvement of key populations and their organizations in implementing projects, delivering services, collecting and analyzing community-level data, and monitoring the Plan's roll-out. It also recognizes the need for funding and training so that key populations can participate effectively.

## Power together

Communities are at their most effective when they are able to link up and join together as networks, alliances or even temporary partnerships. Networks and consortia make it possible to align and amplify the demands and activities of individual organizations, enabling skills, resources and lessons to be shared between organizations and across sectors and borders. Grassroots activism is transformed into global leadership.

The International Treatment Preparedness Coalition (ITPC), a global network of community activists and people living with HIV, is an example of the power of cross-border partnerships. The ITPC's Activist Development Programme trains and supports health activists around the world in advocacy and hands-on networking so they can push for greater access to HIV treatment and other life-saving medicines.

The Sex Worker Networks Consortium also reaches across boundaries to link often-beleaguered sex worker organizations that are striving to protect the health and human rights of sex workers.<sup>4</sup> This global consortium links six regional networks of sex worker organizations, helping to develop their management and programming capacities, provide fundraising support and back cross-border activities. Recent campaigns have focused on confronting violence against women, supporting survivors and ensuring that relevant national and international policies reflect sex worker health and rights. The Consortium has trained sex worker-led organizations in more than a dozen countries to use the Sex Worker Implementation Tool (SWIT) for HIV and STI programming, and it provides guidance for advancing the sexual and reproductive health and rights of sex workers.<sup>5,6</sup> This has enabled sex worker-led



**"ALL TOO OFTEN, ACTIVISM PITS 'US' VERSUS 'THEM,' BUT OUR COMMUNITY TREATMENT OBSERVATORY MODEL FOSTERS A CULTURE OF COLLECTIVE PROBLEM-SOLVING AMONG HEALTH-CARE WORKERS, DECISION-MAKERS AND RECIPIENTS OF CARE. THE BEAUTY OF THIS PROCESS IS THAT WE CHANGED THE WAY PEOPLE LIVING WITH HIV WERE PERCEIVED. CLINICS WERE NOW CALLING ON COMMUNITY DATA COLLECTORS FOR HELP WITH MONITORING. WHAT STARTED OUT AS A REGIONAL PROJECT IN 11 WEST AFRICAN COUNTRIES HAS BECOME A MODEL FOR COMMUNITY-BASED MONITORING ANYWHERE IN THE WORLD."**

*Solange Baptiste, Executive Director, ITPC Global*

organizations to push successfully for significant policy changes in Guyana, Kazakhstan, Kyrgyzstan, Mexico, Mongolia, Myanmar, Peru and Suriname. In Mexico, sex worker-led organizations now meet with health authorities to deal with medicine stock-outs.

The Caribbean Vulnerable Communities Coalition is a regional coalition of about 40 grass-roots civil society groups that work with marginalized populations who are especially vulnerable to HIV due to

<sup>4</sup> Organizing and capacity-building support was provided to Angola, Antigua, Bangladesh, Botswana, Brazil, Cambodia, China, Colombia, Ecuador, Eswatini, the Gambia, Georgia, Guyana, Indonesia, Jamaica, Kazakhstan, Kenya, Kyrgyzstan, Mexico, Mongolia, Myanmar, Nepal, Peru, Suriname, Trinidad and Tobago, Ukraine, Viet Nam and Zimbabwe. Please see: <https://robertcarrfund.org/networks/2016-2018/sex-worker-networks-consortium>

<sup>5</sup> The trained organizations were in countries that included Angola, Bangladesh, Botswana, Georgia, Guyana, Kenya, Kyrgyzstan, Mexico, Mongolia, Myanmar, Nepal, Papua New Guinea, Suriname, Ukraine and Zimbabwe.

<sup>6</sup> The SWIT is based on recommendations developed by the United Nations Population Fund (UNFPA), World Health Organization (WHO), UNAIDS and the Global Network of Sex Worker Projects. It provides practical guidance on effective HIV and STI programming for sex workers, as well as evidence of the positive impact of decriminalization of sex work and the involvement of sex workers in developing policies and promoting practices that are rights-based.

socioeconomic exclusion, punitive laws and policies, and high levels of violence and stigma and discrimination.<sup>7</sup> In addition to providing training and support for community organizations, the Coalition has launched a Shared Incident Database in which 34 community organizations in 11 countries catalogue human rights violations, including more than 2000 cases that merited potential pro bono legal assistance. It also has sponsored community education, advocacy and media work to advance human rights through the region, including community education related to high-profile legal cases in Belize, Guyana, Jamaica and Trinidad and Tobago. This support to country-level activism is making an impact. For example, high-profile legal challenges have led the High Courts of Belize and Trinidad and Tobago to strike down national laws criminalizing same-sex sexual relationships.

Similar alliance-building is underway in the Middle East and North Africa, where SIBA, a new youth-led network, has been set up to reshape policy-making on HIV and sexual and reproductive health and rights. The first entity of its kind in that region, SIBA emerged from a regional consultation in August 2019 on the role of youth in the region's HIV response. It hopes to emulate some of the success of the Teenergizer movement of young people in eastern Europe and central Asia, which has successfully campaigned for the creation of new youth-friendly HIV testing and peer counselling services.

### *Community participation is a win-win for governments and communities*

Community engagement and empowerment is a win-win scenario: communities are supported to claim their human rights, and governments are able to accelerate their efforts to achieve HIV, health and development goals. Country reporting to UNAIDS shows that women living with HIV, sex workers and gay men and other men who have sex with men are participating in the development of national policies, guidelines and/or strategies relating to their health (Figure 1.5). Participation is lower for transgender people, however, and people who inject

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**COMMUNITY ENGAGEMENT AND EMPOWERMENT IS A WIN-WIN SCENARIO: COMMUNITIES ARE SUPPORTED TO EXERCISE THEIR POWERS TO CHOOSE, KNOW, THRIVE AND DEMAND, AND GOVERNMENTS ARE ABLE TO ACCELERATE THEIR EFFORTS TO ACHIEVE HIV, HEALTH AND DEVELOPMENT GOALS.**

drugs and current and former prisoners are often left out of crucial strategic decision-making.

A recent example of progress is Zimbabwe, where a landmark national plan for reaching key populations with HIV services was developed with broad civil society participation (see case study below).

### **Four powers of the people**

Community-led action continues to drive the HIV response—from treatment monitoring groups in western and central Africa to LGBTI rights activists in India, from women's organizations working to end gender-based violence to regional youth networks campaigning for safe access to HIV services. Community organizations confront rights abuses, combat stigma and discrimination, challenge habits and norms, demand equality, campaign for legal change, manage community dialogues, advocate for policy reform, deliver services when other systems fail, run support groups, perform research and monitor programmes.

In short, they are the backbone of the HIV response. This report celebrates their power and their contribution to the global response to HIV, focusing on four themes:

- **The power to choose:** game-changing new HIV prevention options such as PrEP are bolstering the power of people to choose among options that best fit their needs. One size does not fit all.

<sup>7</sup> For more on the Coalition, please see: <https://robertcarrfund.org/networks/2016-2018/caribbean-vulnerable-communities-coalition>

FIGURE 1.5

**Countries with community participation in the development of national policies, guidelines and/or strategies relating to their health, global, most recent available data**

UNAIDS policy monitoring includes separate reports from national authorities and civil society. The below pie charts show the proportion of responses from each set of these reports regarding whether various affected communities participate in the development of national policies, guidelines and/or strategies.



Source: UNAIDS National Commitments and Policy Instrument, 2017 and 2019 (see <http://lawsandpolicies.unaids.org/>).

- **The power to know:** knowledge is essential to ending the HIV epidemic—including knowing how to prevent the acquisition and transmission of HIV, knowing your HIV status and, if living with HIV, knowing that reducing your viral load to undetectable levels will keep you healthy and ensure you do not transmit the virus to others. Undetectable = untransmittable, or U = U.
- **The power to thrive:** the rights to health, education, work and a standard of living adequate for health and well-being are among those that must

be upheld if people at risk of HIV and those living with HIV—from birth to adolescence to adulthood—are to thrive and reach their full potential.

- **The power to demand:** the power of communities and individuals to participate in the decisions that affect them—to raise their voices, be heard and have all of their inalienable human rights respected.

When these powers are exercised, the global target to end AIDS as a public health threat by 2030 can be reached.







## AT A GLANCE

Getting on track to reach the 90% reduction in HIV infections by 2030 requires not only making combinations of prevention options available and accessible to the people who need them, but doing so in ways that fit their different needs and realities.

Holistic efforts are needed to tackle the gender inequalities, patriarchal norms and practices, violence, discrimination and other rights violations they face.

Women also need improved integration of contraceptive services with HIV and STI testing, prevention and care options, as well as strengthened community-level prevention outreach for women and men.

PrEP is emerging as an empowering prevention option for women and girls who are at high risk of HIV infection.

Community-led groups and other civil society organizations are at the forefront of changing drug policies and providing services to reduce the harms associated with drug use, including HIV.

Data from recent population-based surveys from 10 countries show that male circumcision rates are consistently higher in urban areas.

# POWER TO CHOOSE

*Different people in different situations have different needs. They require different options to fill those needs. A young woman in southern Africa, a gay man in South-East Asia and a person who injects drugs in the Middle East all face different challenges that put them at risk of HIV. Effective prevention options exist for them. They need the power to choose among them.*

When used consistently and correctly, condoms are highly effective at preventing HIV and other sexually transmitted infections (STIs). Comprehensive harm reduction, including the provision of sterile injecting equipment, can quickly halt HIV outbreaks among people who inject drugs (1, 2). People living with HIV who successfully suppress their viral load to undetectable levels with antiretroviral therapy do not transmit the virus to anyone else. Pre-exposure prophylaxis (PrEP) can virtually eliminate the risk of acquiring HIV, and antiretroviral medicines also prevent vertical transmission of HIV to babies. Voluntary medical male circumcision provides lifelong partial protection against female-to-male HIV transmission (3).

Over the past two decades, efforts to expand the use of these prevention options have seen the number of people globally who acquire HIV each year fall from a peak of 2.9 million [2.3–3.8 million] in 1997 to 1.7 million [1.4–2.3 million] in 2018 (Figure 2.1).

*A lay provider from the Rainbow Sky Association of Thailand discusses PrEP with a client. Rainbow Sky is one of the five community-based organizations in Thailand providing PrEP under the Princess PrEP Project.*

Progress has been strongest in eastern and southern Africa, where the annual number of new HIV infections has declined by 28% since 2010. The incidence of HIV among adolescent girls and young women (aged 15–24 years) in the region has declined by 42% since 2010 and by about two thirds since 2000 (Figure 2.2).<sup>1</sup> Rapid population growth in the region, however, means that the number of new infections in this subpopulation decreased by only 28%.

Outside of eastern and southern Africa, new infections declined by just 4% between 2010 and 2018 (all ages) and in some regions, they have increased. The annual number of new HIV infections rose by 29% in eastern Europe and central Asia during that same period, by 10% in the Middle East and North Africa, and by 7% in Latin America. Globally, the annual number of new infections since 2010 has declined by just 16%, and year-on-year declines have slowed in recent years. This is largely because key populations and their sexual partners are still acquiring HIV at an alarming rate: they accounted for almost two thirds of new HIV infections in western and central Africa in 2018 and for at least three quarters of new infections in Asia and the Pacific, Middle East and North Africa, eastern Europe and central Asia, and western and central Europe and North America.

<sup>1</sup> The incidence of HIV infection is the estimated number of people acquiring HIV infection per 100 uninfected people per year.

Getting on track to reach the 90% reduction in HIV infections by 2030 that the United Nations (UN) General Assembly pledged to achieve requires not only making combinations of prevention options available and accessible to the people who need them, but doing so in ways that fit their different needs and realities. It also requires

community-level changes that remove the social and structural drivers of the HIV epidemic, including gender inequalities, gender-based violence and the persecution of marginalized populations. In other words, people must have the power to choose—and use—the options that work best for them.

FIGURE 2.1

**New HIV infections, global versus eastern and southern Africa and remaining regions, 1990–2018**

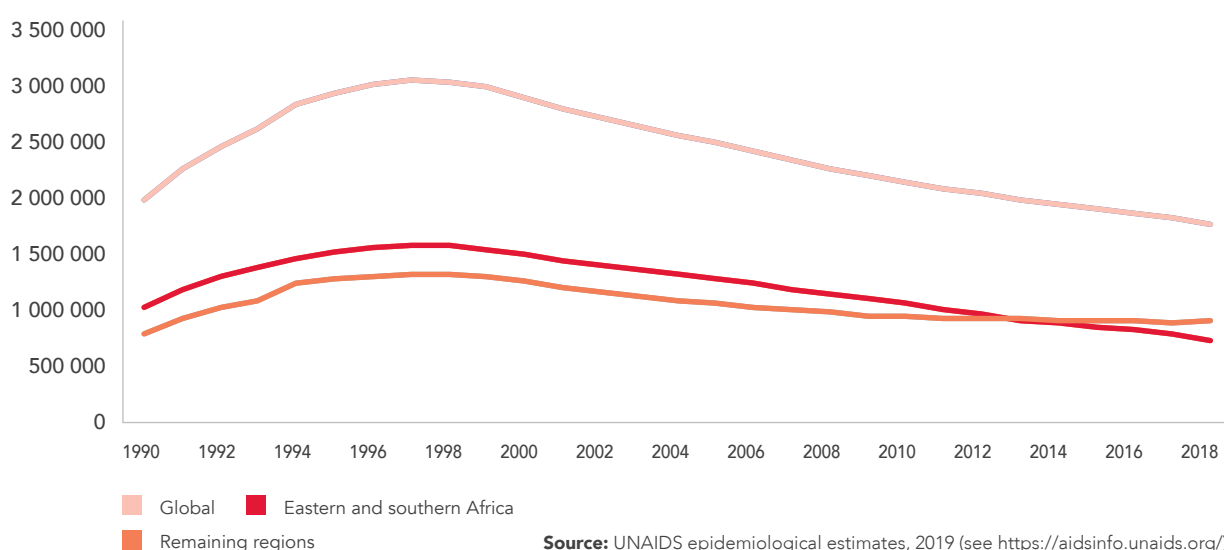
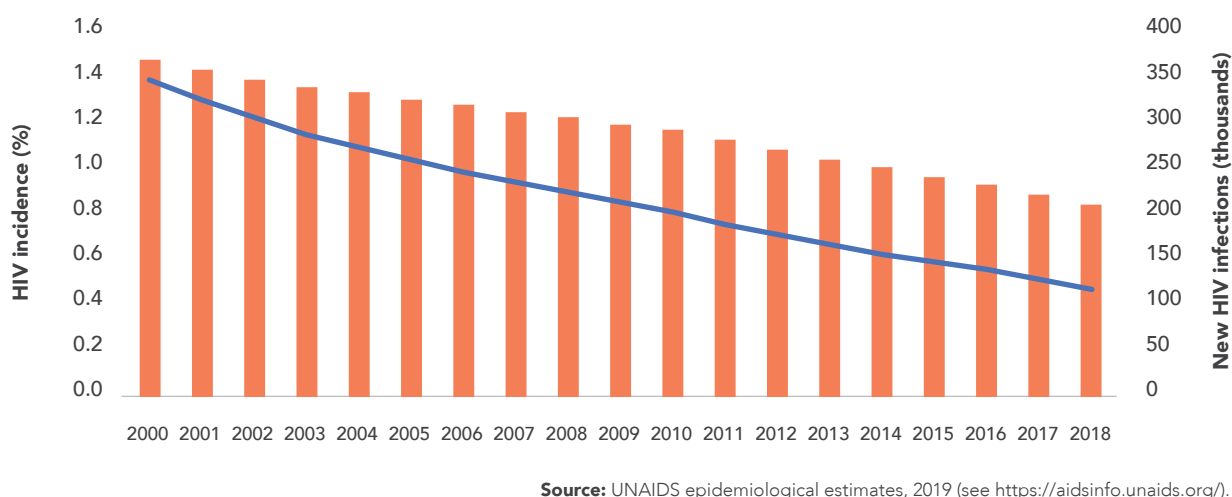


FIGURE 2.2

**HIV incidence and new HIV infections, young women (aged 15–24 years), eastern and southern Africa, 2000–2018**





*Melody and Trish, sex workers from Epworth, Zimbabwe, deliver condoms to the club where they work. The condoms are provided by Katswe Sistahood, an organization which advocates for women to fully attain their sexual and reproductive rights in Zimbabwe.*

Credit: UNAIDS/C. Matonhodze

## **Women-centred approaches to sexual and reproductive health and rights**

Adolescent girls and young women continue to be at risk of HIV infection, particularly in sub-Saharan Africa. Gender inequalities, patriarchal norms and practices, violence, discrimination and other rights violations, and limited access to comprehensive sexuality education and sexual and reproductive health services still badly compromise their attempts to protect their health and improve their well-being. In eastern and southern Africa, for example, almost three times as many adolescent girls and young women (aged 15–24 years) acquired HIV in 2018 compared to their male peers. Among those aged 15 to 19 years, that ratio was even greater: girls were almost five times more likely to acquire HIV than boys.

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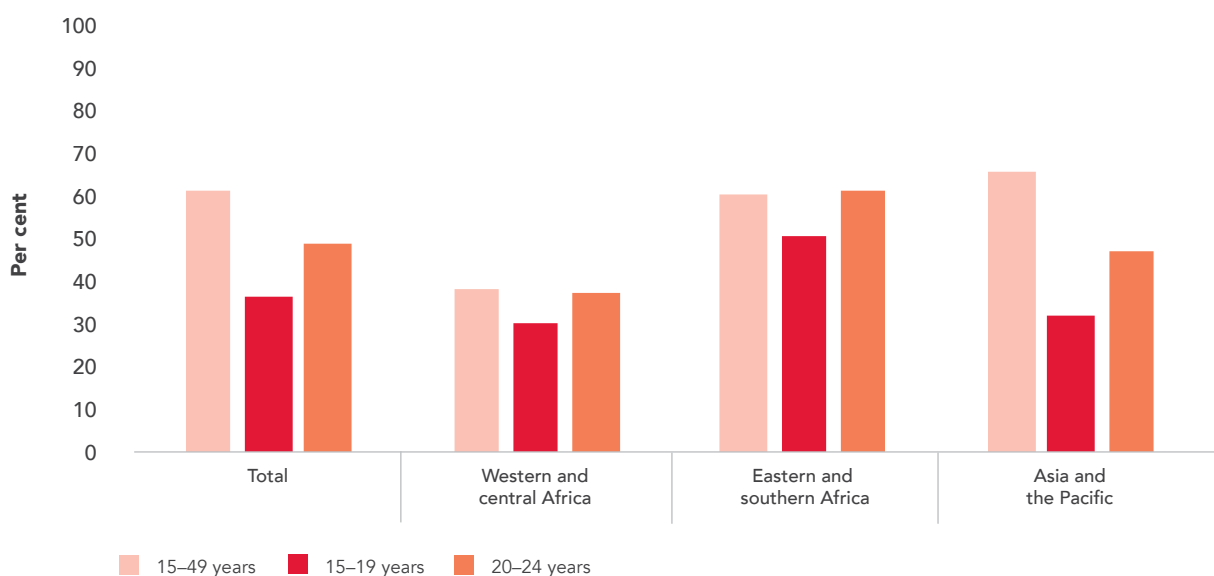
## **EACH WEEK, AN ESTIMATED 6000 YOUNG WOMEN (AGED 15–24 YEARS) ARE INFECTED WITH HIV**

Achieving the Sustainable Development Goals (SDGs)—including ending the AIDS epidemic as a public health threat—will be impossible as long as women and girls are denied control over their bodies and their sexual and reproductive lives, and are prevented from fully claiming their human rights. The importance of this challenge was evident in the recent Evidence for Contraceptive Options and HIV Outcomes (ECHO) trial in Eswatini, Kenya, South Africa and Zambia. The results highlighted the ongoing need for evidence-informed and women-centred interventions—biomedical, social and economic—that protect the health and lives of women, especially young women and adolescent girls.



FIGURE 2.3

Women's demand for family planning satisfied by modern methods, by age, 2013–2018



**Note:** Data coverage of aggregates: Total: 46 countries; western and central Africa: 13 countries; Asia and the Pacific: 10 countries; eastern and southern Africa: 13 countries. Data included refer to all women, except for Afghanistan, Bangladesh, Jordan and Pakistan; those data refer to currently married women only.

**Source:** Demographic and Health Surveys, 2013–2018.

The ECHO trial spanned the intersecting issues of contraception, sexual and reproductive health, HIV and human rights. It was primarily designed to assess the impact of three different contraceptive options on the HIV risk of women, most of them younger than 25 years. All three contraceptive methods studied were found to be effective, and the participants wanted and were willing to use a range of contraceptive methods (4).

However, despite regularly accessing health services during the trial that included HIV prevention, participants in all three trial arms had a high incidence of HIV infection (about 3.8%)(4). Incidence was highest among women younger than 25 years. These results highlighted the fact that even women and girls who were accessing services had limited ability to avoid acquiring HIV.

The ECHO trial underlined the substantial need in sub-Saharan Africa for sexual and reproductive health services (including modern contraception) that are woman-centred, youth-friendly and grounded in informed choice (5). Overall, almost 50% of women (aged 15–49 years)

**THE ECHO TRIAL RESULTS SHOWED THAT EVEN WOMEN AND GIRLS WHO WERE ACCESSING SERVICES HAD LIMITED ABILITY TO AVOID ACQUIRING HIV.**

in sub-Saharan Africa have unmet needs for modern contraception, and that gap is even higher (almost 60%) among adolescent girls aged 15–19 years (Figure 2.3) (6).

Improving HIV and other sexual and reproductive health outcomes for women requires changes to make services responsive to their needs. All women must have safe and effective choices for contraception and HIV and other STI prevention—and they should be able to exercise those choices freely. Women need improved integration of contraceptive services with HIV and STI testing, prevention and care options, as well as strengthened community-level prevention outreach for both women and men. There also remains an urgent need for a broader range of effective HIV prevention options, especially for adolescent girls and young women who are at high risk of HIV infection.



*Dr. Magreth Mayala counsels a client on family planning at a clinic in Vijibweni Hospital.*  
Credit: UNAIDS/D. Msirikale

# CASE STUDY

## PEER-LED PROTECTION FOR SEX WORKERS in South Africa

Sex workers in South Africa work and live in hostile environments where sex work is illegal, violence is commonplace, social stigma is rife and police harassment is a constant risk (7). This limits their ability to protect themselves against HIV infection and other dangers.

Extraordinarily high levels of HIV infection have been reported among sex workers in South Africa: a large survey conducted in 2014 found that HIV prevalence was 72% in Johannesburg, 54% in Durban and 40% in Cape Town (8). It has been estimated that as many as one in five new infections annually in South Africa may be associated with sex work (9).

The Networking HIV and AIDS Community of South Africa (NACOSA) sex work programme is a peer-led initiative grounded in the country's National Sex Worker Plan and its National Strategic Plan 2017–2022, both of which emphasize the protection of human rights (10, 11). NACOSA, a southern African network of civil society organizations focusing on HIV- and tuberculosis-related activities, used the UN-supported Sex Worker Implementation Tool (SWIT) to develop a programme that aims to enable sex workers to claim their human rights and access the information and services they need to protect their health (12).

The programme is peer-led, with former or current sex workers across 14 districts in eight provinces acting as peer educators and filling other roles. It uses a microplanning methodology, in which educators work closely with their peers in specific areas over long periods. This builds consistency and trust, allows for more personalized support and has led to increased and more regular use of health services.

Since 2016, the programme has reached more than 71 000 sex workers with a range of services, including risk reduction counselling, basic health and human rights information, and psychosocial support. Along with distributing condoms and lubricants, the programme offers advice on negotiating condom use, and it supports increased access to primary health-care services, including for sexual and reproductive health and HIV testing and treatment (Figure 2.4). Of the almost 40 000 sex workers (about 94% of whom were women) who took an HIV test, three in four were HIV-positive, and the programme succeeded in starting 84% of those women on HIV treatment. A small PrEP component will soon be expanded countrywide.<sup>2</sup>

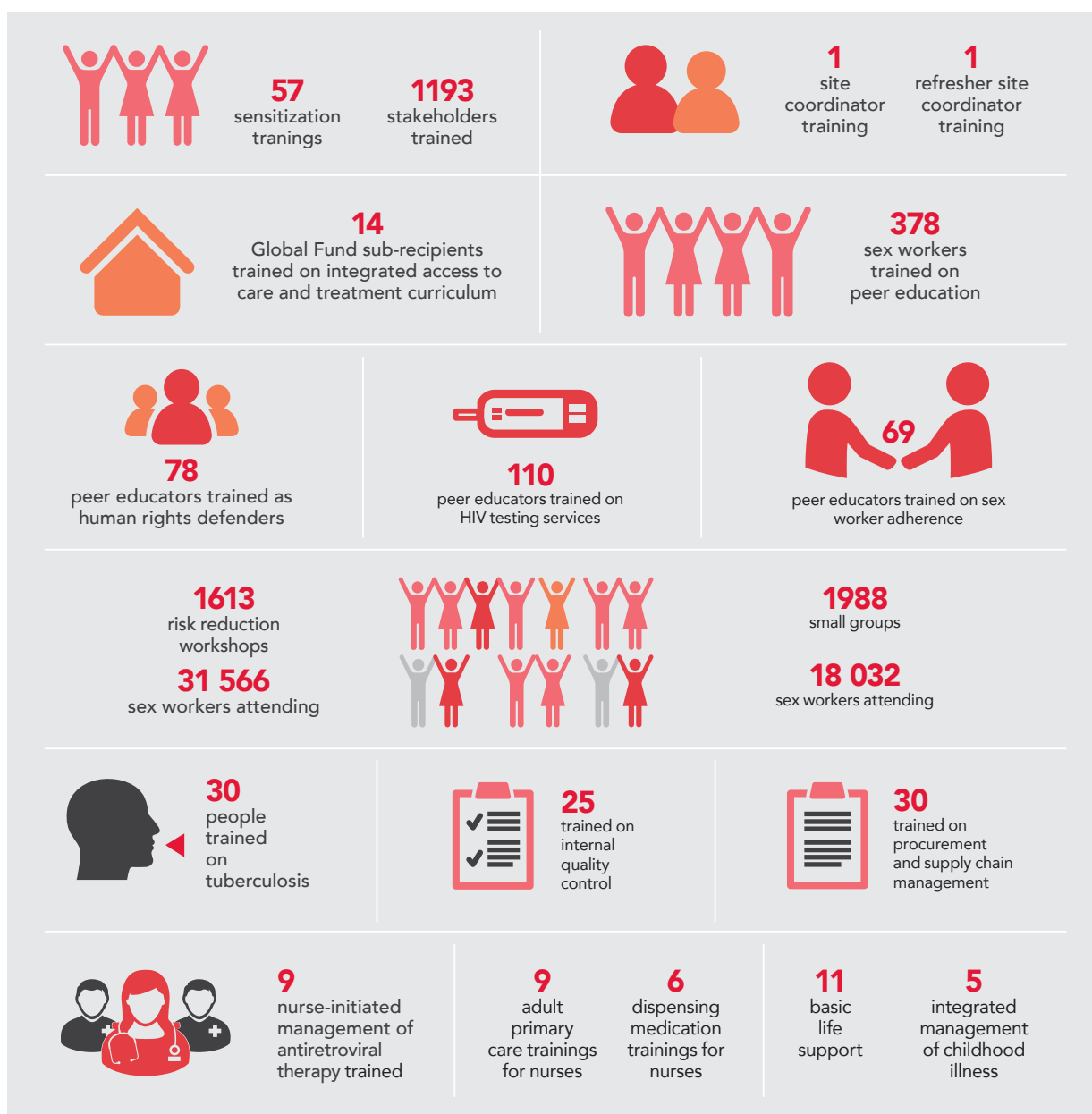
Officially, sex work remains illegal in South Africa, and stigma and discrimination against sex workers is still rife, although sensitization training for police and health-care and social workers is making a difference in some districts: there are usually fewer reports of rights violations against sex workers after the training. When those violations do occur, however, peer educators document them and, when possible, arrange legal assistance for the affected sex workers.

*People who engage in sex work are entitled to the same rights and freedoms as everyone else.*

<sup>2</sup> PrEP is available to sex workers through other channels. According to Global AIDS Monitoring 2019 data, about 4100 sex workers in South Africa used PrEP at least once in 2018.

FIGURE 2.4

**A snapshot of the capacity-building and training in South Africa's peer-led sex worker programme, 2016–2019**



Source: NACOSA report, 2019.



## PrEP: an additional HIV prevention choice

Oral PrEP is an HIV prevention choice that is increasingly in demand in industrialized countries, and by early 2019, at least 20 countries globally were managing national PrEP programmes. A further 40 were operating pilot or demonstration projects. Several programmes that have focused on gay men and other men who have sex with men, transgender persons and sex workers have shown considerable impact, and PrEP is now being rolled out in sub-Saharan Africa as an additional prevention choice for serodiscordant couples and adolescent girls and young women who are at high risk of HIV infection (13–16).

The United States of America has led the world in the roll-out of PrEP, with more than 130 000 current users in mid-2019. More than 55 000 additional people were accessing PrEP in western and central Europe and other parts of North America (17).<sup>3</sup> By the

end of 2018, more than 30 000 people had used PrEP at least once in the past 12 months in Kenya, as had more than 8000 in South Africa, more than 7000 in Lesotho and more than 8000 in Brazil. Further global expansion of PrEP requires countries to address regulatory issues and other barriers that are stopping people who want to use PrEP from doing so (Figure 2.5).

### Getting the most out of PrEP for women and girls

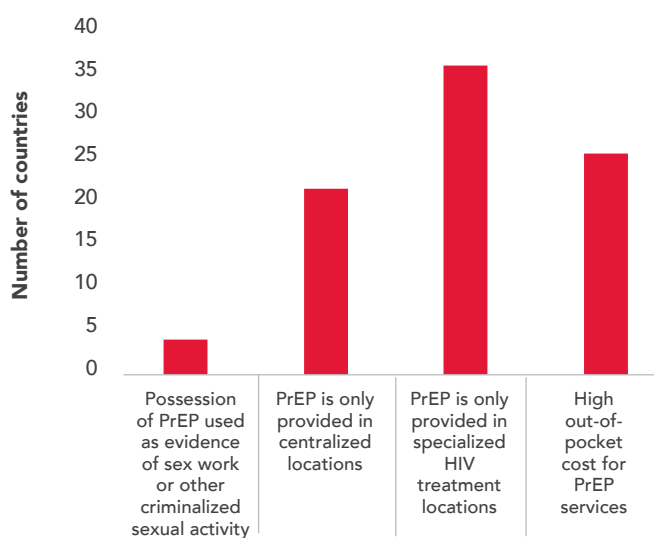
PrEP is emerging as an empowering prevention option for women and girls who are at high risk of HIV infection, and countries in sub-Saharan Africa have begun rolling out PrEP for these women. Practical and social considerations for successful and sustained use are being grappled with as PrEP availability expands (27, 28).

Knowledge about PrEP has grown enormously among women and girls in Africa in the past year. Community-level stigma and misconceptions sometimes surround PrEP's introduction (29). Women and other PrEP users in Kenya, for example, have reported that PrEP use is associated with sexual promiscuity, or that it is believed within their communities to be unsafe for one's health or an indication that a person is HIV-positive (30). Such misconceptions can be barriers for adolescents and young adults (31). In a recent study in Kenya, South Africa and Zimbabwe, health-care providers supported providing PrEP for young women, but they had reservations about doing so for adolescent girls, citing concerns about negative reactions from the parents or partners of the girls (32).

Uptake is high when women and girls are provided with accurate and relevant messaging about PrEP, including compelling explanations of its benefits, and when PrEP is framed as an empowering prevention method and a positive life choice (28, 33). In the Eswatini PrEP demonstration project, for example, women said that PrEP boosted their sense of protection, relieved their fear of acquiring HIV and facilitated sexual enjoyment (34). Uptake is also high in projects that integrate PrEP into youth-friendly health services and family planning clinics, and when it is separated from HIV treatment (28, 35).

FIGURE 2.5

### Countries reporting barriers that limit access to pre-exposure prophylaxis (PrEP), global, 2019



**Note:** Data correspond to 56 countries that reported at least one barrier (of the 69 countries that reported that PrEP was available).

**Source:** UNAIDS National Commitments and Policy Instrument, 2019 (see <http://lawsandpolicies.unaids.org/>).

<sup>3</sup> An unreported number of people in the region are accessing PrEP through private means, including online purchases.





## COMMUNITY VOICES

### “WE HAD TO DO SOMETHING” TO GET PREP NOW

**When Greg Owen first heard about a pill that could keep people from acquiring HIV, he didn't believe it. He asked around in London, where he lives, and discovered that PrEP was only available in the United States and in a clinical trial in England.**

“I finally got hold of PrEP via a friend in August 2015,” he recalls. “The next day I went for an HIV test and it came back positive.” He'd acquired HIV infection in the preceding months, while he was desperately trying to get hold of PrEP. It felt as if the system had failed him.

“We decided we had to do something,” Mr Owen says. He and a friend gathered as much information as they could about PrEP, including where to obtain it, how to take it and other advice. They set up a website, IwantPrEPnow ([www.iwantprepnw.co.uk](http://www.iwantprepnw.co.uk)), to share the information and campaign for wider PrEP access. The site went live in October 2015. With a little money and a lot of research and advocacy, IwantPrEPnow attracted a growing audience. “There was a clear need for drug advice in the community,” Mr Owen says.

As awareness about PrEP grew, demand rapidly increased. In England, more than 10 000 people have access to PrEP through the PrEP Impact Trial, while in Northern Ireland, Scotland and Wales, it is available through public sexual health clinics (25). Many people also obtain PrEP online.

“PrEP has been a game changer,” Mr Owen believes. “We have already stepped up regular testing, we're encouraging increased condom use and starting people on treatment as soon as possible—PrEP completes that combination prevention picture.”

In the past two years, new HIV diagnoses among gay men and other men who have sex with men in the United Kingdom of Great Britain and Northern Ireland have decreased by more than 30% (26). But Mr Owen believes that PrEP's benefits go beyond preventing HIV infections. People feel liberated again, he says, freed from the blame and shame associated with having sex without condoms.

IwantPrEPnow continues its work to increase access to PrEP for everyone who needs it, particularly women, transgender people and communities of colour. “A community means no one is left behind . . . no one gets turned away—that's a real community,” says Mr Owen.

# CASE STUDY



## ROYAL BACKING FOR PrEP in Thailand

A combination of royal patronage and grass-roots engagement has seen PrEP in Thailand move from a key population-led pilot to being provided free under the country's universal health coverage benefits package to everyone at increased risk of HIV infection.

Her Royal Highness Princess Soamsawali Krom Muen Suddhanarinatha, who has championed Thailand's breakthrough Princess PrEP project, presided over the launch of the national PrEP programme in October 2019.

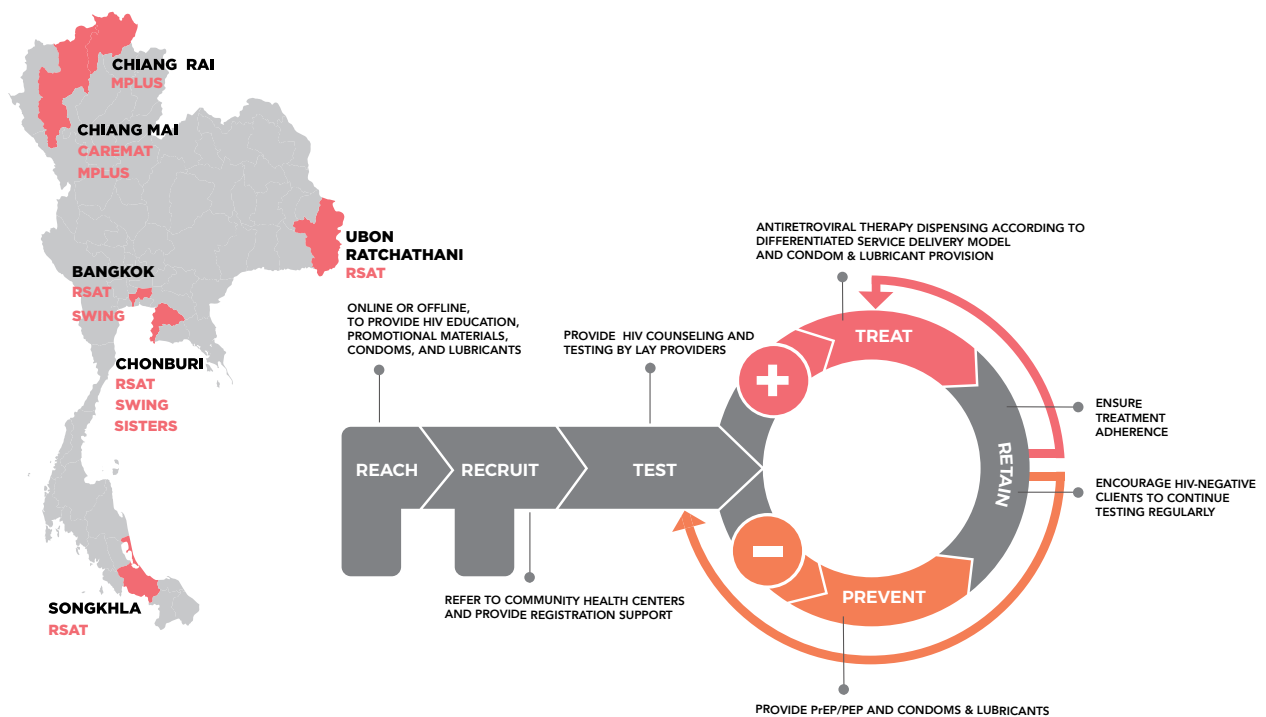
Established in 2016 as a three-year demonstration project, Princess PrEP's main purpose was to generate evidence to support calls for the Thai government to allow PrEP to be dispensed by trained community health workers who belong to key populations (18). The project is a prevention partnership that includes the Royal Thai Princess, the public (via a donation fund), the United States Agency for International Development (USAID) LINKAGES project, the Thai Government Pharmaceutical Organization and two pharmaceutical companies (Hetero and Mylan). In 2019, the partnership provided free PrEP services to thousands of people in six Thai provinces (Figure 2.6).

About 4000 people were accessing PrEP through the project in mid-2019, more than half of the 7200 people using PrEP in Thailand at the time. Another quarter of Thai PrEP users were accessing it through the fee-based PrEP-30 and PrEP-15 projects, which have a large proportion of non-Thai users (19). More than 80% of PrEP users in the Princess PrEP project are gay men and other men who have sex with men; transgender women make up a further 15%. These two population groups account for more than half of new HIV diagnoses in Thailand each year (20).

The project adopted Thailand's key population-led health services model, in which members of key populations identify and meet the HIV and other health-related needs of their peers (21). Community

FIGURE 2.6

**Examples of community health centres participating in the Princess PrEP programme, and the reach–recruit–test–treat/prevent–retain cascade used in the programme**



Source: Termvanich, Krittaporn. Princess PrEP: key population-led PrEP service delivery in Thailand. Thai Red Cross AIDS Research Centre and USAID LINKAGES Thailand (31 October 2019).

health workers—who belong to the key populations they serve—provide same-day services that include risk assessment, counselling and an HIV test. Depending on the outcome of that test, they also provide a referral to antiretroviral therapy or an in-depth discussion about taking PrEP and a one-month supply of pills—all in a nonjudgmental and supportive atmosphere (20).

A programme review published in a 2018 study reported that the total number of key population clients receiving PrEP under a key population-led health services model was six times higher than at government facilities (22). Retention has been highest among gay men and other men who have sex with men (especially those older than 25 years and with tertiary education) and lowest among transgender women. The latter show strong interest in taking PrEP but find it more difficult to continue using those services: concerns about potential interactions between PrEP and hormone therapy and discomfort about accessing PrEP through services designed for men may be discouraging factors (21, 23).

Options that are being explored to improve retention and adherence include adapting some health-care support for online platforms, an approach that has been effective for HIV treatment linkages but has not yet been applied to PrEP services. Enhanced counselling for first-time users is also being considered (24).

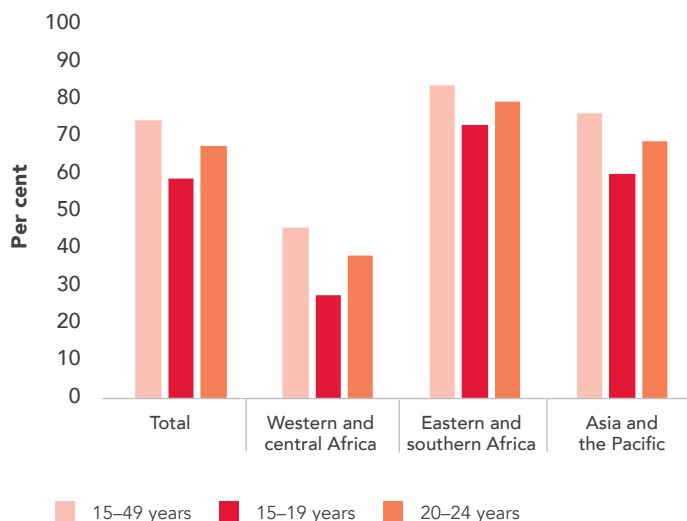




Mahlapane Lipholo, a voluntary community advocate from Jhpiego Lesotho, shares information on the benefits of PrEP with young women employees of the Glory International Textile factory in Maseru, Lesotho.  
Credit: UNAIDS/M. Hyoky

FIGURE 2.7

**Percentage of currently married women who say that they make decisions on their health care alone or jointly with their husband, by age, 2013–2018**



**Note:** The aggregated total refers to data from 45 countries, the western and central Africa total to data from 12 countries, the Asia and the Pacific total to data from 10 countries, and the eastern and southern Africa total to data from 13 countries.

**Source:** Demographic and Health Surveys, 2013–2018.

Lesotho’s PrEP roll-out is also showing that proactive community-led demand creation works well, and that PrEP user clubs and social media-based group support can help reduce early drop-out rates. More than 12 000 people enrolled during the first 18 months of the USAID-funded TSEPO programme, and more than 80% of new PrEP users are adolescent girls and young women or members of key populations (36).

Some research has highlighted male partners as a potential barrier, which is too often the case for women seeking health care (Figure 2.7) (35). A study from KwaZulu-Natal province in South Africa reported that although PrEP was acceptable to women, many of their male partners opposed its use (37). Partnerships between health-care providers and community groups will be important to improve understanding of PrEP (including among partners), foster demand and support adherence (27, 38).

Adherence is important to PrEP’s success as an HIV prevention tool (39, 40). Some early PrEP trials showed high adherence and



impact, while others reported steep drop-off rates among adolescent girls and young women after the first few months of use (26, 41–45). Similar drop-off rates have been seen more recently in Project PrEP in Kenya and South Africa (46).

It is clear that efficacy is high when high adherence is achieved (47). When the HPTN 082 PrEP trial in South Africa and Zimbabwe added steps to facilitate peer support, publicize the benefits of PrEP and engage community stakeholders more closely, retention was 88% at six months (48). Younger users benefit from boosted adherence support or frequent contact with health providers, and support from peers, partners and family is especially important (28, 49).

It's not unusual for adolescent girls and young women who stop taking PrEP to restart a few months later. The interruptions are often intentional (e.g., during periods of abstinence)—a reminder that perceived risk is a significant factor in the decisions that women and girls make to start and keep taking PrEP (50). In studies from East Africa, for instance, women were much more likely to continue using PrEP—and to do so for long periods—if they knew their partners were HIV-positive (51, 52).

PrEP is not a “magic bullet” for HIV prevention: it is a component of a robust combination HIV prevention programme. As well as making multiple prevention options available, programmes must tackle contextual factors that put people at risk of HIV infection and prevent them from accessing services. Improved syndromic case management of STIs should be part of PrEP provision, as should screening and support for gender-based violence and mental health issues, and interventions that boost the autonomy of women and girls (28, 53).

### Community-based harm reduction

The world is still failing to protect the health and human rights of the majority of people who use drugs. National drug policies have regressed in recent years, with repressive strategies finding renewed favour in countries such as Bangladesh, Indonesia, the Philippines and Sri Lanka, and continuing in many others (54). People who use drugs across the world face violence, criminalization and exclusion, and they are routinely denied access to basic health and other services (55).

Only a small minority of people who inject drugs live in countries with adequate coverage of both needle-syringe

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## SOME BASIC STEPS TO FACILITATE ACCESS TO PREP FOR WOMEN AND GIRLS

- Remove or reduce legal and policy barriers (such as age of consent requirements) that block access to PrEP, sexual and reproductive health services, and HIV services for young people and women.
- Eliminate licensing and regulatory constraints for PrEP use.
- Integrate PrEP into health services that sexually active adolescents and young adults are likely to use.
- Involve young women and men in the development of PrEP services and service promotion.
- Foster demand by presenting PrEP as a highly effective prevention method that women and girls can control.
- Increase awareness and understanding about PrEP among potential users and peers, partners, parents and the wider community.
- Sensitize and train health-care providers to integrate PrEP with sexual and reproductive health services and to provide respectful, age-appropriate services.
- Back PrEP provision with peer support and interventions that address legal (e.g., age of consent constraints), social (e.g., gender-based stigma and discrimination, and threats of violence) and affordability barriers.<sup>4</sup>

<sup>4</sup> The recommendations in this list are compiled from various references cited in this chapter.



programmes and opioid substitution therapy, despite the well-documented public health benefits of harm reduction programmes (56–60).

The most recently available data from national health authorities show that needle–syringe programmes were operational in only 54 out of 135 reporting countries, and that opioid substitution therapy programmes were operational in 48 of 134 reporting countries. The scale and quality of those services varied widely. It is under these conditions that the incidence of HIV infection among people who inject drugs appears to have risen over the past decade, from 1.2% [1.0–1.3%] in 2011 to 1.4% [1.2–1.5%] in 2017 (61).

Community-led groups and other civil society organizations are at the forefront of changing drug policies and providing services to reduce the harms associated with

drug use, including HIV. In 2018, civil society organizations were operating needle–syringe programmes and/or opioid substitution therapy programmes in 47 countries in all regions.

Examples include a community-driven project in Myanmar’s Kachin State that focuses on providing women-specific harm reduction services. Gender disparities, poverty, intimate partner violence and unsafe sex work environments all contribute to the vulnerable condition of women who use drugs (61). Women are nominally able to access harm reduction services at regular drop-in centres, but stigma surrounding drug use and sex work is a deterrent, and it stops many women from receiving medical and psychosocial support (63). To address this, a women’s drop-in centre largely run by women who use drugs provides free harm reduction services (including sterile injecting equipment and condoms) and counselling

*At the UPAM addiction centre in M'bour, Senegal, mentors and peer educators provide information and link people who use drugs to opioid substitution therapy. UPAM provides decentralized services in collaboration with the Dakar Addiction Centre, the first publicly funded harm reduction centre in West Africa. It's an example of how state structures and civil society groups (including community organizations) can work together to provide harm reduction services to people who use drugs, and support them to reintegrate into society (62).*



for individuals and couples about safer sex and drug injecting practices. It also offers basic primary health care and reproductive health services. The centre serves 30–40 women each day and reaches another 500 with outreach services (63).

The Karisma Recovery Society's shabu harm-reduction outreach project in Jakarta, Indonesia, is filling another common gap.<sup>5</sup> Established in 2016, it was the first harm reduction project in South-East Asia to focus on users of methamphetamine. Outreach workers and peer educators in the project provide drug users with information on

how to reduce the harm associated with stimulant drug use. It is a valuable service in a country where harsh drug laws and police harassment deter drug users from accessing health-care information and services (64).

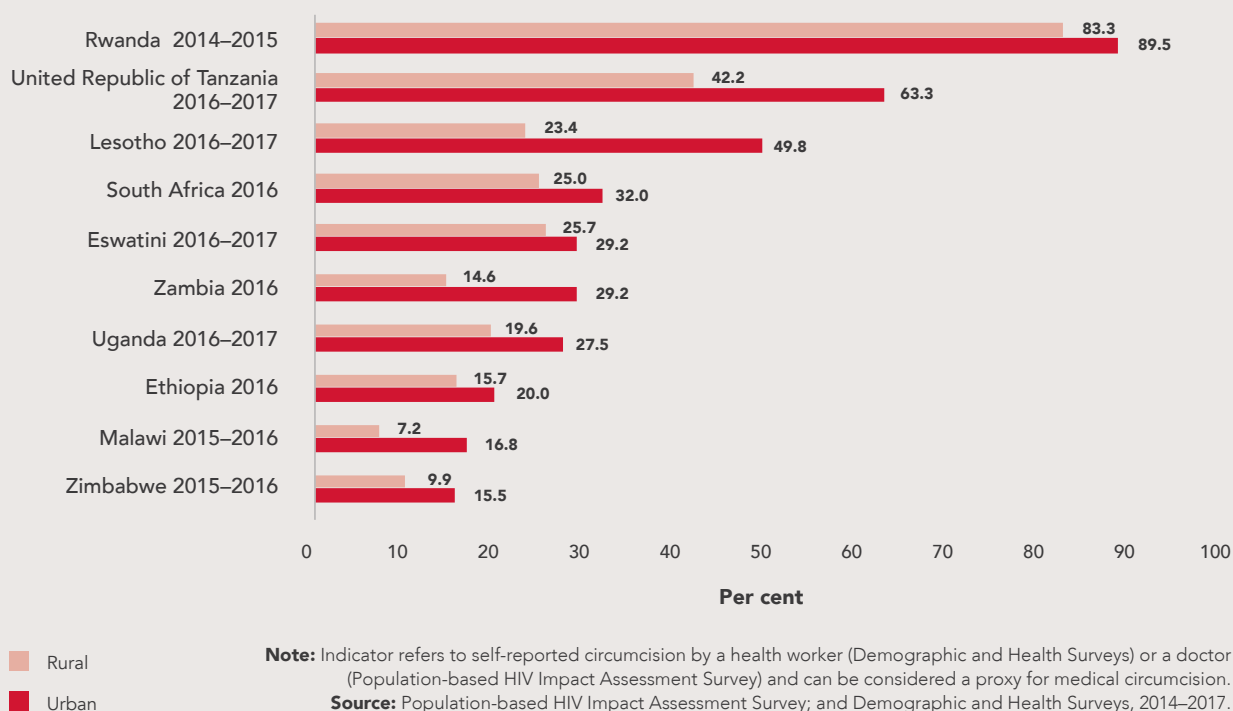
Despite these successes, community-led projects remain the exception to the rule in too many places, stymied by a lack of funding, counterproductive legal and regulatory environments, and the hostile practices of law enforcement officials and health-care providers. Until these conditions improve, the full potential of community-driven initiatives will not be realized.

## RURAL GAP IN MALE CIRCUMCISIONS


There has been progress towards the 2020 target of 25 million additional voluntary medical male circumcisions for HIV prevention. About 11 million have been performed in 15 priority countries in eastern and southern Africa since the beginning of 2016, including more than 4 million in 2018. Data from recent population-based surveys from 10 of these countries show that medical circumcision is consistently higher in urban areas (Figure 2.8). There is a need to strengthen community outreach services, including through the use of mobile clinics, to bring voluntary medical male circumcision to underserved rural areas.

FIGURE 2.8

### Percentage of medical male circumcision, by residence, selected countries, 2014–2017



<sup>5</sup> Shabu is a slang term for methamphetamines that is used in certain parts of the Asia–Pacific region.



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## AT A GLANCE

There has been strong progress towards the 90–90–90 targets. However, there often are large disparities in knowledge of HIV status, both geographically and by subpopulation.

HIV self-testing is an important, discreet addition to facility-based approaches. Community-led and community-engaged efforts are empowering people to choose for themselves the circumstances in which they take an HIV test.

All young people have a right to comprehensive, age-appropriate sexuality education that is relevant to their needs and experiences.

Community monitoring is a form of public oversight that can be used to hold health systems accountable for providing quality services. Information collected by community data collectors is being used to advocate for health service improvements.

HIV-related stigma and discrimination—often reinforced by laws and structural inequities—interfere with the ability of people to access the testing and treatment services they need. Community-led and community-engaged efforts are combining service provision with safe spaces and advocacy that mitigate the negative impact of threatening environments.



# POWER TO KNOW

*The power to know is essential to ending the HIV epidemic—including knowing how to prevent the acquisition and transmission of HIV, knowing your HIV status and, if living with HIV, knowing your viral load. It is the power to understand one's options and to take steps to ensure one's health and well-being.*

Women, girls, men, boys and members of key populations all face distinct barriers to acquiring the knowledge they need. Many adolescents are denied access to sexuality education and youth-friendly services and face age-related legal restrictions. Gender inequality is at the root of multiple barriers faced by women and girls, and men can be trapped by gendered expectations around masculinity that make them less likely to seek health care. Key populations face criminalization and multiple levels of stigma and discrimination related to behaviours and status that prevent or deter them from accessing the services they need.

The power to know also includes knowledge about HIV epidemics and responses. In many places, a lack of data and resource constraints mean that programmes are not adequately monitored and deficiencies are left unaddressed. Such knowledge is not just for health systems and programme managers: communities require that knowledge in order to hold duty bearers accountable for meeting their commitments to the people they serve.

*Members of the New Men and Women of Panama Association (AHMNP) accompany peers to a LGBTI-friendly clinic in Panama City, Panama.*

Credit: Vía Libre/Ramón Lepage

## **The power to know and the 90–90–90 targets**

HIV testing gives people the knowledge they need to make choices about their lives and their health. Where people are empowered to access HIV testing and discover their HIV status, those who test negative can seek out ways to remain so. Those who test positive can access treatment and services that support them to achieve durable viral suppression that safeguards their health and protects others from infection.

The 90–90–90 targets have inspired progress towards these outcomes: they call for 90% of people living with HIV to know their HIV status, 90% of people who know their HIV-positive status to be accessing treatment and 90% of people on treatment to have suppressed viral loads by 2020. At the end of 2018, nearly four in five people living with HIV globally knew their serostatus, 78% [69–82%] of people who knew their status were on treatment and 86% [72–92%] of those on HIV treatment were virally suppressed. However, gaps across the HIV testing and treatment cascade have left the world shy of the 2020 goal of 30 million on treatment, and nearly half (47%) of people living with HIV in 2018 had unsuppressed viral loads.

*Late knowledge of HIV status perpetuates epidemics*

There often are large disparities in knowledge of HIV status, both geographically and by subpopulation. In eastern and southern Africa, for example, young people and men living with HIV are much less likely to be aware of their status: while 90% [88–92%] of women living with HIV aged 25 and above knew their status in 2018 (thanks in large part to the success of efforts to prevent mother-to-child transmission), that was the case among only 80% [77–83%] of men of the same age, 66% [62–71%] of young women (aged 15–24 years) and 50% [46–54%] of young men (aged 15–24 years). In western and central Africa, the gaps are even larger (Figure 3.1).

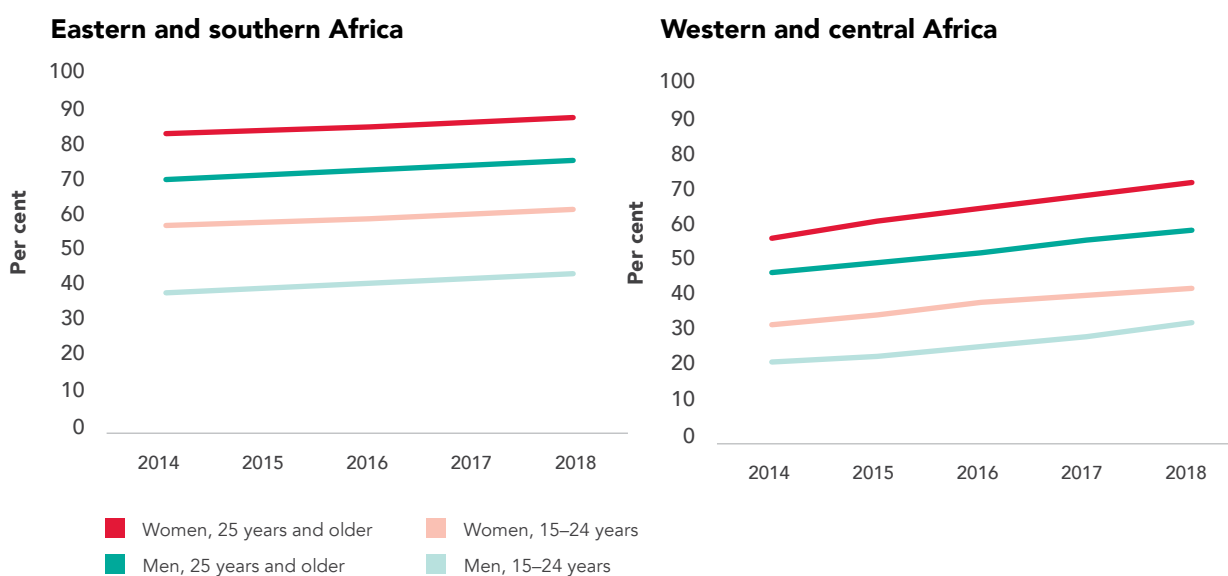
A special analysis of data from two countries in eastern and southern Africa reveals longer durations between infection and diagnosis among men compared to women, and among young people compared to older adults. In Malawi, the average time to diagnosis was twice as long for men than women; in Mozambique, young men (aged 15–24 years) living with HIV were on average diagnosed more than four years after infection, compared to one year for young women living with HIV (Figure 3.2).

These estimates reflect that young men and adult men generally interact with the health system far less than adult women. In high-prevalence settings, lower knowledge of HIV status and treatment coverage among men combines with gender inequalities that sanction the subordination of women and girls, magnifying their HIV risk. As a result, 59% of new adult HIV infections in eastern and southern Africa in 2018 were among women. Special efforts are needed to address the barriers faced by men living with HIV to know their HIV status and suppress their viral loads, and holistic efforts are needed to tackle the gender inequalities, patriarchal norms and practices, violence, discrimination and other rights violations that women and girls face every day (see *Power to thrive* chapter).

**LOWER KNOWLEDGE OF HIV STATUS AND TREATMENT COVERAGE AMONG MEN COMBINES WITH GENDER INEQUALITIES THAT SANCTION THE SUBORDINATION OF WOMEN AND GIRLS TO PERPETUATE HIV EPIDEMICS.**

FIGURE 3.1

**Number of adults living with HIV who know their HIV status, by age and sex, 2014–2018**



**Source:** Estimates shared in personal communication from K Giguère, JW Eaton, and M Maheu-Giroux, October 2019. For more details on the estimation method, see National HIV testing and diagnosis coverage in sub-Saharan Africa: a new modeling tool for estimating the “first 90” from program and survey data. Maheu-Giroux, M, Marsh K, et al. bioRxiv 532010; doi: <https://doi.org/10.1101/532010>.



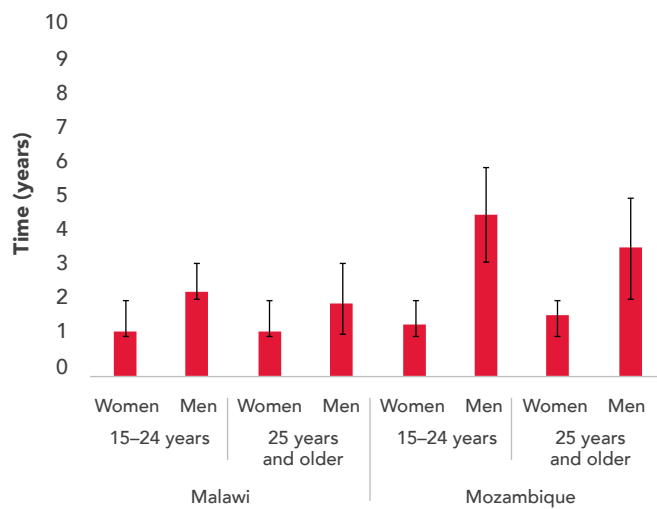
## Comprehensive sexuality education: a foundation for adolescents and young people

Knowledge of HIV among young people is alarmingly low in many regions. In countries with recently available survey data, just 23% of young women (aged 15–24 years) and 29% of young men (aged 15–24 years) have comprehensive and correct knowledge of HIV. In sub-Saharan Africa, where the risk of HIV acquisition for young people is greatest, young women and men have slightly higher knowledge (31% and 35%, respectively) (2).<sup>1</sup>

All young people, including young people from key populations and other vulnerable communities, have a right to comprehensive, age-appropriate sexuality education that is relevant to their needs and experiences. Comprehensive sexuality education lays a basic foundation for empowering young people, especially adolescent girls and young women, to understand and claim their health rights, make informed choices, have pleasurable and safe sex lives, and enjoy mutually respectful relationships.

FIGURE 3.2

### Average time between infection and diagnosis, by age and sex, selected countries, 2018\*



\* Includes competing risk of HIV death.

Source: Estimates shared in personal communication from K Giguère, JW Eaton, and M Maheu-Giroux, October 2019.

For more details on the estimation method, see National HIV testing and diagnosis coverage in sub-Saharan Africa: a new modeling tool for estimating the “first 90” from program and survey data. Maheu-Giroux, M, Marsh K, et al. bioRxiv 532010; doi: <https://doi.org/10.1101/532010>.

## BARRIERS FACED BY WOMEN AND GIRLS

Structural factors—such as poverty, economic security and lack of decision-making power—affect women’s access to health and resources, including those related to HIV. Women and girls living with HIV face multiple barriers to prevention, testing, treatment and viral suppression that are rooted in gender inequality. Gendered roles and responsibilities can prevent women from seeking out and benefiting from services: they may have to ask permission from husbands or other family members, or their caregiving responsibilities may interfere with their ability to attend clinics. Access to treatment is also impeded by violence, including in the home, the community and health facilities.

Violations of the rights to privacy, confidentiality and bodily integrity in health-care services may disproportionately affect women, and they may resist treatment due to its side effects, including changes in body shape that do not adhere to gender norms and expectations for women’s bodies and sexuality. Livelihood challenges—including food security, nutrition and housing—also present barriers to service access.

All of these factors interact with the common taboos and misconceptions that surround HIV, leading to multiplied fears and experiences of stigma and discrimination. These in turn contribute to status non-disclosure, lower adherence, depression, low self-esteem and self-worth, and other mental health problems (1).

<sup>1</sup> Data from population-based surveys conducted between 2013 and 2018 were available for young women in 68 countries globally and 31 countries in sub-Saharan Africa, and for young men in 54 countries globally and 30 countries in sub-Saharan Africa.



*A sex worker prepares to self-test for HIV at her home in Kazo, Uganda.*  
Credit: UNAIDS/E. Echwalu

United Nations (UN) agencies have recently updated their guidance on sexuality education based on extensive evidence showing that sexuality education—in or out of schools—does not lead to increased sexual activity, sexual risk-taking or higher infection rates for HIV or other sexually transmitted infections (STIs) (3).

Sexuality education is especially powerful when it confronts inequities that skew people's lives and prospects. For example, sexuality education that addresses gender inequality and power imbalances in relationships is up to five times more effective at reducing STIs and unintended pregnancies than standard approaches that neglect those issues (4, 5).

In most countries around the world, school curricula and education policies include some form of sexuality education, although implementing these policies remains a

major challenge, as does the quality of the education provided. Involving young people in the development and implementation of policies has been shown to improve their effectiveness. Incorporating referrals to age-appropriate, gender-responsive sexual and reproductive health services (including for STIs and HIV) can also improve their impact (4, 6).

### **Expanding HIV testing options**

Accessing HIV testing, particularly in facilities, can be difficult for people who belong to key populations (particularly where they are criminalized) and adolescents (particularly where age-of-consent laws are in place). Concerns about privacy and confidentiality, long travel distances and inconvenient clinic opening hours also discourage use.

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**“THE BEST WAY TO COMMUNICATE  
WITH MEN IS THROUGH THEIR PEERS.”**

*David Mawejje, International Labour  
Organization National Officer,  
Uganda (13)*

Innovative approaches that expand the ways in which people can test for HIV increase the likelihood that people living with HIV will know their status early, thus allowing timely treatment and reducing the rate of new infections. For example, the International Labour Organization (ILO) VCT@WORK campaign increases access to voluntary testing, counselling and treatment for workers, their families and communities (12).

VCT@WORK expanded in 2019 to reach 20 000 Ugandan workers in the male-dominated economic sectors of road construction and transport. A campaign for male champions has trained 46 men to serve as HIV peer educators, including by challenging gender-related attitudes around masculinity that can drive high-risk sexual behaviours (such as low condom use or having multiple partners) and poor health-seeking behaviours. ILO, UNAIDS and the United Nations Entity for Gender Equality and the Empowerment of Women (UN Women) are also organizing HIV awareness and testing events during boxing tournaments, with messages about testing on video screens and HIV service providers on site to offer HIV counselling and testing to the men who come to watch the fights. Unions and employer organizations, Uganda’s AIDS Commission and health-care providers are also working together to promote early HIV testing, including through workplace health fairs that provide HIV testing and prevention and refer workers for further counselling and treatment (13).

### **HIV self-testing**

Self-testing is an important, discreet addition to facility-based approaches, empowering people to choose for themselves the circumstances in which they take an HIV test. Since a second test is needed to confirm diagnosis, self-testing policies must include measures

to link self-testers to confirmation testing, diagnosis and treatment where necessary.

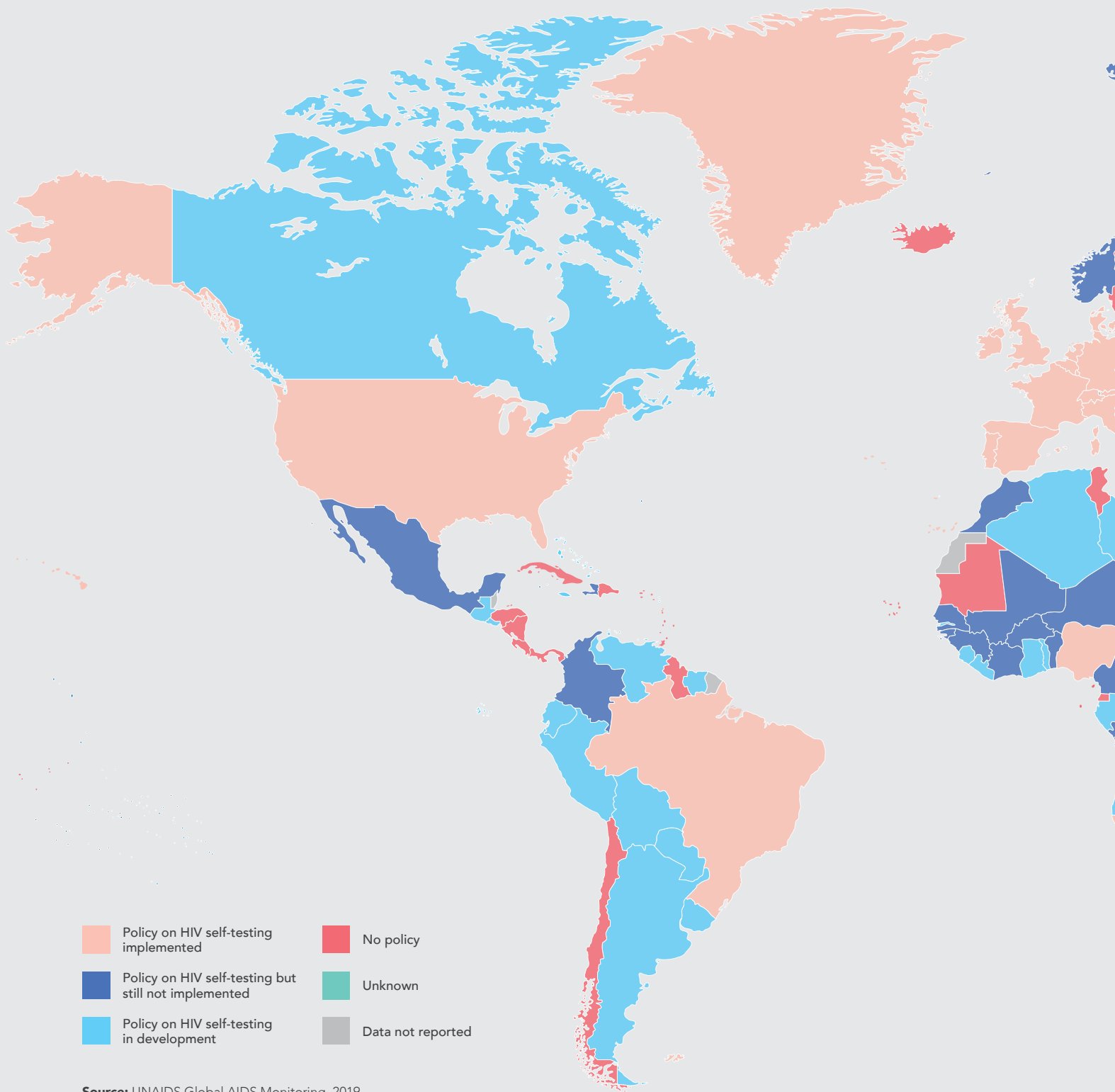
According to a 2017 systematic review, HIV self-testing increases the uptake of HIV testing among both individuals and couples, especially men (14). Demonstration projects in Malawi, Zambia and Zimbabwe found that when HIV self-testing was delivered at scale, it reached high proportions of men, young people and first-time testers (15). Studies in several African countries also indicate that when pregnant or postpartum women deliver HIV self-testing kits to their male partners, acceptability and uptake is high among the men (16, 17). This enables the woman to know whether she is at heightened risk of acquiring HIV, indicates to her partner if he should seek treatment and helps the couple take the necessary preventive precautions. In a roll-out of self-testing in Zambia, more men than women accessed HIV self-testing, although men were still much less likely than women (32% compared to 68%) to immediately link to care if they tested HIV-positive (18).

Community-led and community-engaged efforts increase access to self-testing. In Zimbabwe, men valued the privacy and confidentiality afforded them when community mobilizers offered self-testing kits, giving many who otherwise would not visit health facilities the opportunity to know their HIV status (19). In Burundi, peer-mobilized self-testing increased HIV diagnoses and linkage to care among female sex workers and gay men and other men who have sex with men, with linkage to care especially high among the women (97% compared to 74% among men) (20). In India, transgender women found self-testing acceptable, preferring to access kits provided in community-based settings and be assisted by a peer to use the kit for their first try (21).

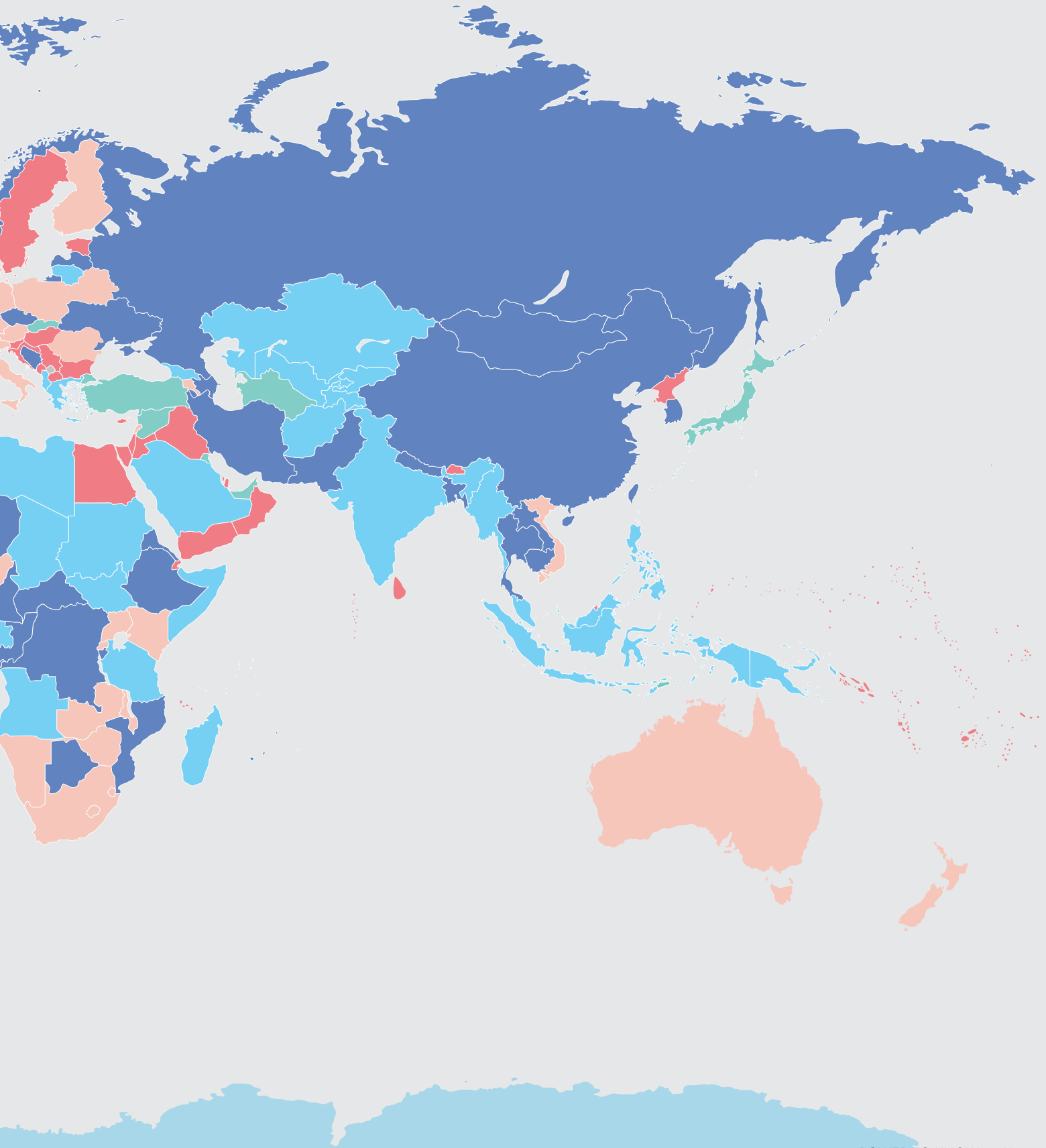
Regulatory barriers appear to be limiting the availability of HIV self-testing. Just 77 countries reported in 2019 that they have an HIV self-testing policy; among those, only 38 were implementing the policy. Another 47 countries reported that a policy was under development, and 33 reported that they are piloting HIV self-testing (Figure 3.3).

FIGURE 3.3

National policies on HIV self-testing, as of July 2019



**Source:** UNAIDS Global AIDS Monitoring, 2019 (see <https://aidsinfo.unaids.org/>); and World Health Organization (WHO) HIV Country Intelligence Tool.





# CASE STUDY

## SAFEGUARDING YOUNG PEOPLE in southern Africa

*The Safeguard Young People programme uses a range of approaches to reduce HIV transmission among adolescents and young people in eight southern African countries. Project data suggest that school dropout rates, early marriages and teenage pregnancies have decreased, and that drop-outs are returning to complete their educations.*



The Safeguard Young People programme by the United Nations Population Fund (UNFPA) is working in eight southern African countries with high HIV prevalence to reduce HIV transmission among adolescents and young people. The focus is on improved access to high-quality out-of-school, rights-based and gender-equitable comprehensive sexuality education and sexual and reproductive health and rights services.

Safeguard Young People uses a range of approaches, including community-based comprehensive sexuality education delivery, the TuneMe mobile site ([www.tuneme.org](http://www.tuneme.org)) and edutainment through songs and music videos. Especially significant are engagements with community leaders and traditional chiefs to ensure that factually correct HIV and sexual and reproductive information is available during initiation rites and at community events. By the end of 2018, the programme had reached almost 6.7 million young people.

UNFPA has developed the Regional Comprehensive Sexuality Education Resource Package for Out-of-School Young People to help ensure consistently high standards across the interventions (7). The resource package, which is designed for flexible use in and outside formal classroom settings, includes an observation and monitoring tool, the iCAN life skills package for young people living with HIV and a set of animated videos for youth aged 10–14 years (8, 9). Sexuality education materials for young people with disabilities are also being piloted.

A recent evaluation of Safeguard Young People found that it has helped create the preconditions for reducing new HIV infections and for improving the sexual and reproductive health status of young people. Project data



Credit: UNFPA

suggest that school dropout rates, early marriages and teenage pregnancies have decreased, and increasing numbers of girls who have dropped out of school are returning to complete their educations (10).

### **TuneMe: putting sexuality education in the hands of young people**

In southern Africa, “tune me” is slang for “tell me.” It’s also the name of a mobile health (mHealth) tool that is reaching large numbers of adolescents and young people with accurate information on their sexual and reproductive health and rights. Part of the Safeguard Young People programme, TuneMe was designed to be accessed on mobile telephones in settings where high data charges and poor network coverage limit people’s access to online services. It is available in Botswana, Eswatini, Lesotho, Malawi, Namibia, Zambia and Zimbabwe (11).

The content in TuneMe focuses on equipping young people with knowledge and skills they can use to safeguard their health, well-being and dignity. It also seeks to help them have respectful social and sexual relationships, and to consider how their choices affect their own well-being and that of others.

TuneMe’s appeal is the confidential access it offers to content and features that speak to the lives of young people. This helps overcome some of the barriers that adolescents encounter when seeking information on sexual and reproductive health, such as judgmental attitudes among health-care workers and legal impediments like age of consent laws. Since December 2015, TuneMe has run 219 Facebook campaigns, a radio campaign and numerous mobile web banner campaigns. Its Facebook page has had more than 3 million unique users, at least 60 000 likes and more than 345 000 clicks.



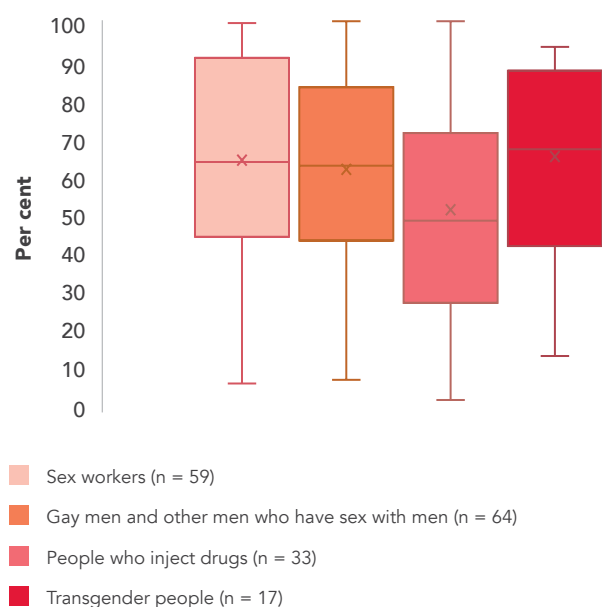
## Ensuring key populations are not left behind

The full achievement of the three 90s is being held back in part by a lack of attention to key populations. Survey data show that, on average globally, more than one third of sex workers, gay men and other men who have sex with men and transgender people do not know their HIV status; that rate rises to approximately one half among people who inject drugs (Figure 3.4). These data may even underestimate the knowledge gap, since surveys of key populations are typically conducted in areas where HIV testing services are available and therefore do not account for those who do not have access to testing.

Among gay men and other men who have sex with men living with HIV in sub-Saharan Africa, knowledge of HIV status appears considerably lower than among men as a whole. Pooled estimates indicate that between 2011 and 2017, the proportion of HIV-positive gay men and other men who have sex with men who were aware of their status was just 19% [13–25%], compared to 61% [58–64%] among all men aged 15 and over in 2014 (Figure 3.5) (22). While treatment coverage and viral suppression rates among HIV-positive gay men and other men who have sex with men who knew their HIV status were similar to those among all adult men, the initial gap in knowledge of HIV status means that only a small fraction of gay men and other men who have sex with men living with HIV in the region are accessing the treatment they need to stay healthy. Furthermore, researchers found statistically significant lower rates of HIV testing and status awareness within this population in countries that have severe legislation against lesbian, gay, bisexual, transgender and intersex (LGBTI) people or behaviour (22).

FIGURE 3.4

### Knowledge of status among key populations, global, 2016–2018



**Note:** Data shown come from surveys, which are typically conducted in areas that have services available and may not be nationally representative. Contrary to the usual representation of the 90–90–90 targets, “knowledge of status” includes members of key populations who have been tested in the past 12 months and know that their results are negative.  
**Source:** UNAIDS Global AIDS Monitoring, 2019 (see <https://aidsinfo.unaids.org/>).

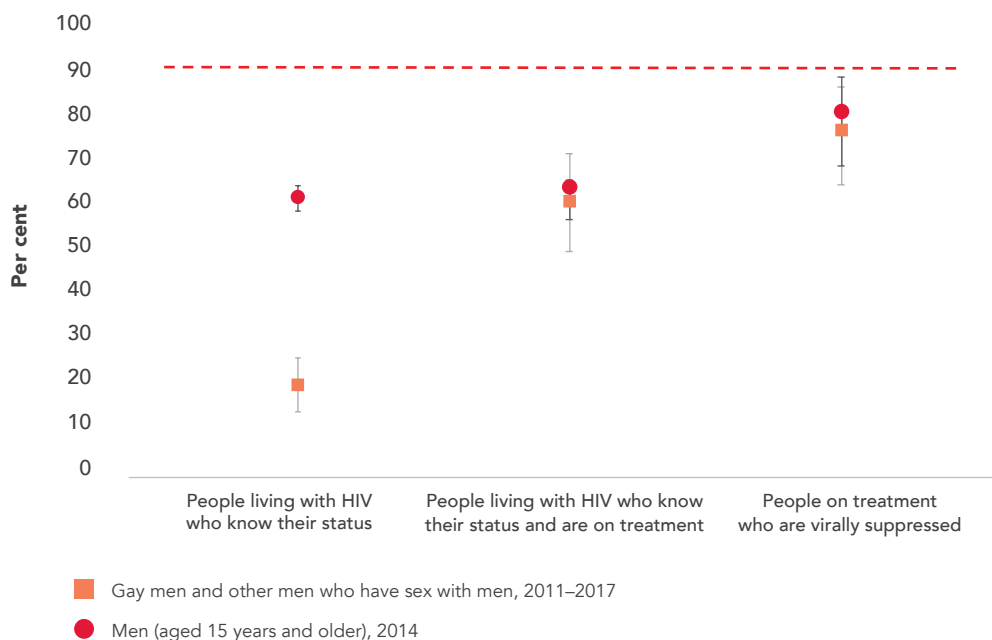
### Holistic approaches combine services with efforts to fight discrimination

HIV-related stigma and discrimination—often reinforced by criminalization of key populations and HIV transmission, age-of-consent laws and structural inequities—interfere with the ability of people to access the testing and treatment services they need. Community-led and community-engaged efforts are combining service provision with safe spaces, individual empowerment, advocacy and broader learning opportunities that mitigate the negative impact of threatening environments.

In Kenya, for instance, gay men and other men who have sex with men face homophobia, criminalization, and stigma and discrimination within health-care settings. Low HIV testing levels coupled with high-risk sexual behaviours mean that the population accounts for up to 15% of the country’s total new HIV infections (23). Despite this, Kenya still lacks a national health programme that specifically addresses the needs of gay men and other men who have sex with men.

FIGURE 3.5

**Progress towards 90–90–90 targets, adult men compared to gay men and other men who have sex with men, sub-Saharan Africa, 2011–2017**



**Note:** Data for men (aged 15 years and older) on treatment who are virally suppressed is from 2015 because 2014 data are not available.

**Source:** Gay men and other men who have sex with men, 2011–2017: J, Dale E, Elmes J, Staunton R, Beyrer C, Mitchell KM et al. HIV testing and engagement with the HIV treatment cascade among men who have sex with men in Africa: a systematic review and meta-analysis. *The Lancet HIV*. 2019;6(11):E769-E787. Knowledge of status among men (aged 15 years and older): Estimates of knowledge of status shared in personal communication from K Giguère, JW Eaton, and M Maheu-Giroux, October 2019. For more details on this estimation method, see National HIV testing and diagnosis coverage in sub-Saharan Africa: a new modeling tool for estimating the “first 90” from program and survey data. Maheu-Giroux, M, Marsh K, et al. *bioRxiv* 532010; doi: <https://doi.org/10.1101/532010>. All other estimates: UNAIDS epidemiological estimates, 2019 (see <https://aidsinfo.unaids.org/>).

“EVERYONE IS FROM THE COMMUNITY—FROM THE RECEPTIONIST, THE NURSE, EVEN THE HEALTH-CARE PROVIDER. WE WERE HAPPY THAT WE WERE THE FIRST COMMUNITY HEALTH CLINIC THAT GAVE SERVICES RUN BY THE COMMUNITY AND FOR THE COMMUNITY. PEOPLE ARE COMFORTABLE [COMING TO US] BECAUSE THE THINGS THEY ARE GOING THROUGH ARE THE SAME THINGS WE ARE GOING THROUGH. WE UNDERSTAND THEIR ISSUES” (26).

*Peter Njane, Director, Ishtar*

ISHTAR is a community-based organization that defends the sexual health rights of its 4200 members, reduces stigma and discrimination by creating awareness, and advocates for the rights of members to access health care, including HIV- and STI-related services (24). In 2014, it opened a community wellness centre in Nairobi that provides free, confidential and nonjudgmental routine HIV and STI testing and treatment for gay men and other men who have sex with men and transgender women (25).

The centre is open seven days a week and is complemented by outreach HIV prevention and treatment services provided by trained peer educators and outreach workers at selected hotspots in Nairobi and the surrounding areas. The model has been supported by the Kenyan Government and adopted as best practice for key population programmes (25).



*Members of the Panamanian Association of Trans People (APPT) reach out to their peers on the streets of Panama City, Panama, and offer them rapid HIV tests.*

Credit: Vía Libre/Ramón Lepage



In the Philippines, the 1110-strong volunteer-based community organization LoveYourself aims to empower gay men and other men who have sex with men and transgender women to increase their sense of self-worth and access services at six community centres in Metropolitan Manila and Cebu City (27). The centres provide peer education on HIV, sexual orientation, gender identity expression and health-related human rights, as well as condoms and lubricants, HIV counselling and testing, referral to care and adherence support. LoveYourself was responsible for 40.1% of HIV diagnoses in Metropolitan Manila (15.1% of those nationwide) in 2018 alone, and 3800 of its clients are currently being provided with treatment, making it the third largest HIV treatment hub in the Philippines (27). LoveYourself is also making PrEP available at two centres, while a third centre offers free hormone management and pre-gender-affirming surgery assessment and counselling (28).

In Zimbabwe, where same-sex sexual relationships are criminalized and legislation is in place that actively discriminates against LGBTI people, mental health problems among community members are common (29). In 2018, Gays and Lesbians of Zimbabwe (GALZ) established three counselling drop-in centres in Harare, Masvingo and Mutare with the support of the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund). Their clients often arrive with signs of depression, suicidal tendencies, paranoia, anxiety and other mental health challenges. They are given psychiatric assessments and advice, and individual, couple, family or group counselling therapy sessions are available. GALZ staff also conduct community visits to check on clients (30).

The GALZ drop-in centres also serve as safe spaces for LGBTI community activities. The GALZ Centre in Harare, for instance, hosts social events for LGBTI people and their friends and allies. It also has a library and video club that offers books, magazines, journals, research studies and films on LGBTI-related themes and health and human rights issues (31).





## SANADI: AN ANTI-STIGMA SUPERHERO

Virtual communities in cyberspace are helping key populations improve access to services. In 2017, the M-Coalition launched Sanadi, a website designed to facilitate access to HIV services by harnessing the knowledge of communities.<sup>2</sup> M-Coalition is the health department of the Arab Foundation for Freedoms and Equality (AFE), the only regional advocacy network specifically devoted to the needs of LGBTI people in the Middle East and North Africa.

Sanadi, which means “my support” in Arabic, seeks to improve the quality of services and fight stigma by guiding users to friendly, discrimination-free services. The website maps HIV service providers across the Middle East and North Africa region, allowing community members to filter the results by HIV service (including testing, prevention and treatment). It also more broadly links users to other health services, including for mental health, hepatitis B and C, harm reduction, vaccination, social and accessibility services, and those specific to the LGBTI community.<sup>3</sup> Users thus have increased power to decide for themselves what they want and choose an appropriate service.

Although the Sanadi website was originally developed with LGBTI people in mind, it will be broadened in upcoming iterations to include all key populations, with added filters that cover a wider range of needs and services for the health and well-being of its users. This includes additional filters for accessibility, services for people living with disabilities, and sexual and reproductive health services.

Sanadi also allows users to rate each facility across three criteria: LGBTI and gender sensitivity; how well the centre protects privacy; and cleanliness. This feature not only allows community members to know where they can go for services, but also how stigma-free those environments are. The intention of the reviewing feature is twofold: it empowers communities by encouraging them to evaluate the services they need and use, thus directly contributing to increasing access to quality care; and it provides service providers with a real-time metric that shows where they can improve their care to better meet the needs of communities and counter stigma and discrimination. M-Coalition reports that a number of providers have already done so.

Sanadi activities go beyond the website, with an ongoing media campaign that features the superhero Sanadi, a member of the community who educates other community members about HIV. A recent video links with the Undetectable = Untransmittable (U = U) campaign, revealing that the superhero is living with HIV and taking his medication, and that he has an undetectable viral load (32).

<sup>2</sup> For more information, please see the M-Coalition website (<http://m-coalition.org>) and the Sanadi website (<https://sanadi.org/>).

<sup>3</sup> A two-year mapping exercise of service providers was carried out in 165 testing centres across Algeria, Jordan, Lebanon, Morocco, Tunisia and Yemen. There are plans to expand to eight new countries in 2020 (including Kuwait, Qatar, Saudi Arabia and the United Arab Emirates).



## Harnessing the power to know for service improvement

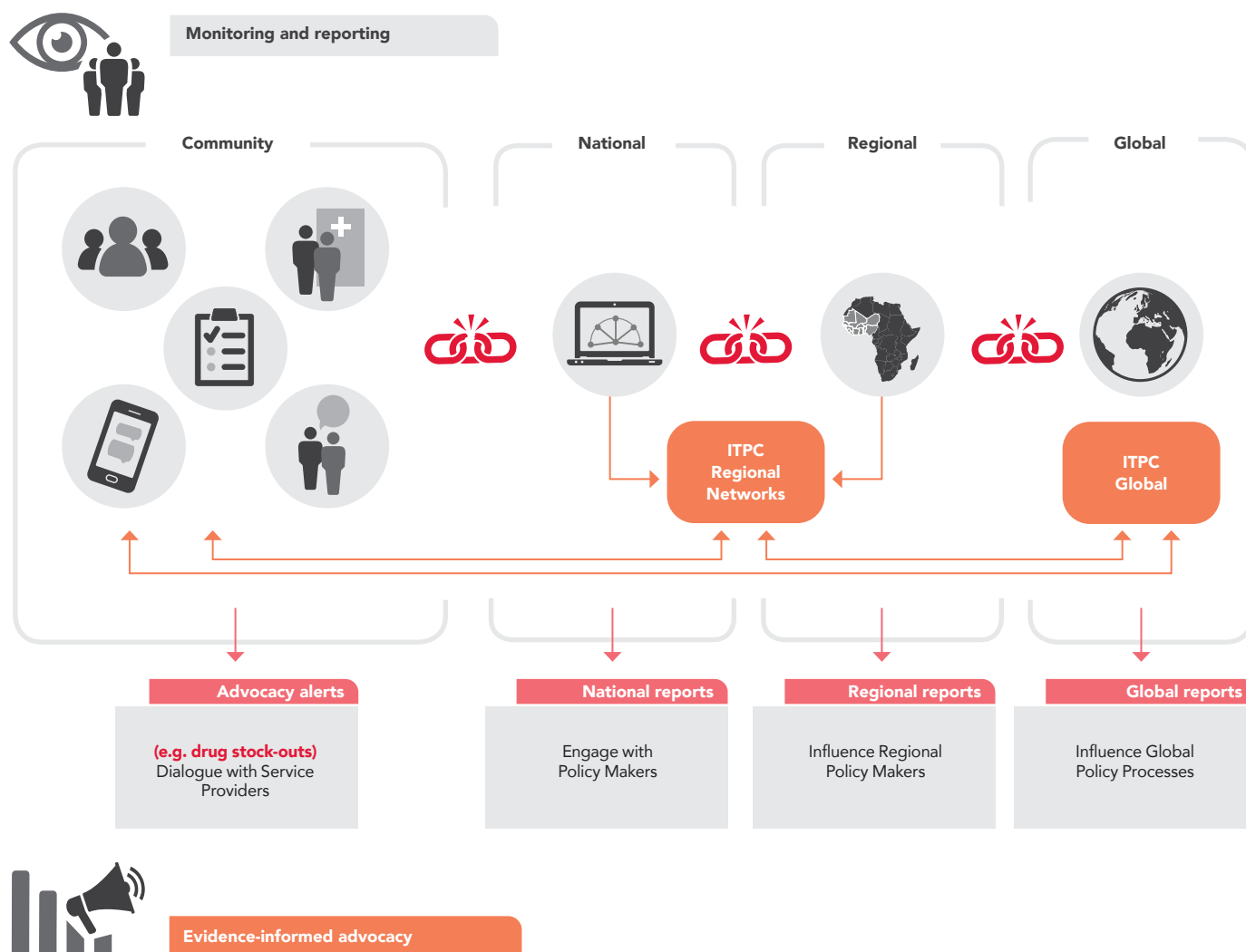
Community monitoring is a form of public oversight that can be used to hold health systems accountable for providing quality services (33). For example, a large part of the success of India's treatment programmes lies in the central role that communities of people living with HIV played in establishing and managing 350 care and support centres through the Vihaan consortium (34). Vihaan includes Alliance India and 17 state-level networks of people living with HIV and nongovernmental organizations that in turn partner with district-level networks and other

organizations to deliver care and support services in communities (34). Vihaan uses community monitoring and reporting to: (a) ensure that diagnosed individuals are linked to treatment and other social protection schemes; (b) track the availability of commodities to avoid stock-outs; (c) monitor the quality of treatment services; and (d) empower individual people living with HIV through peer-delivered treatment literacy programmes (35).

Since 2017, Vihaan has been further strengthened by the use of the eMpower mobile application (developed in collaboration with IBM Global Services

FIGURE 3.6

### ITPC Community Monitoring Model



Source: International Treatment Preparedness Coalition (ITPC). *The Community Treatment Observatory (CTO) model explained: how communities can collect and analyze health data to ensure accountability and drive change.* 2019.

and with support from the Global Fund) to support client management (36). The tablet-based application uses images to help patients and staff who have limited literacy, and it includes multiple language settings to accommodate local dialects. Tablets with the application installed are provided to community outreach workers, who prioritize clients based on needs and vulnerability, provide a range of services (including HIV testing and referral to treatment), and monitor services, supplies and client adherence. More than 2 million patients across India had benefited from eMpower by September 2019. The technology has helped find more than 400 000 people lost to follow-up, improving access and adherence to HIV treatment (37). The follow-up rate also has increased—from 42% before the use of the tablet to 52% with the tablet—and HIV testing of partners and family members, health monitoring and tuberculosis screening have all improved dramatically.

*Watching what matters: community-led monitoring in West Africa*

Western and central Africa is lagging behind the rest of sub-Saharan Africa in efforts to achieve the 90–90–90 targets (33). To accelerate progress, the UNAIDS Western and Central Africa Catch-Up Plan calls for the establishment of community monitoring systems for commodity stocks, service fees and quality of care (38).

Since 2017, the three-year Regional Community Treatment Observatory in West Africa (RCTO-WA) project, led by the International Treatment Preparedness Coalition (ITPC) and supported by the Global Fund, has worked to increase access to optimal HIV treatment in 11 West African countries (39).<sup>4</sup> Community treatment observatories systematically and routinely collect and analyse qualitative and quantitative data using the ITPC Community Monitoring Model (Figure 3.6). This enables them to monitor trends and variations along the HIV care cascade and within the health system over time (40). As a result, activists can document the availability, continuity and quality of all aspects of HIV service delivery, potentially alerting procurement systems when commodities (e.g., drugs and

diagnostics) reach critically low levels. They can then develop recommendations and advocate for action, creating a culture of collective problem-solving among people living with HIV, health-care workers and policy-makers (41).

The RCTO-WA focuses on five populations: gay men and other men who have sex with men, sex workers, people who inject drugs, pregnant women and young people (39). Between January 2018 and June 2019, RCTO-WA data collectors conducted 1781 monthly monitoring visits to 125 health facilities across the 11 countries. The quantitative data collected were bolstered by 1501 interviews and 143 focus group discussions held quarterly with patients and health-care workers (40). These data, along with a baseline study, highlight both disproportionate gaps in the HIV care cascade for key populations and specific issues within certain critical areas. It is clear that stigma and discrimination, lack of knowledge and awareness about HIV, and procurement failures prevent key populations from accessing the prevention and treatment services they want and need (39, 41).

Despite a number of significant improvements recorded during the reporting period, the RCTO-WA found that the time taken to resolve stock-outs of medicines remained unacceptably long. Similarly, the average turnaround for viral load test results is more than four months, limiting the usefulness of the test results for adherence counselling or a regimen change (39).

*Knowledge in action: using data for accountability and to advocate for change*

The information collected by community data collectors is being used to advocate for improvements. In Côte d'Ivoire, data collected by the Ivorian Network of People Living with HIV highlighted user fees as a key barrier, especially for young and pregnant women. This advocacy contributed to the Government of Côte d'Ivoire announcing in April 2019 that it would eliminate user fees for HIV testing and treatment services (40).

<sup>4</sup> The 11 countries are Benin, Côte d'Ivoire, the Gambia, Ghana, Guinea, Guinea-Bissau, Liberia, Mali, Senegal, Sierra Leone and Togo.

Similar successes have been realized throughout the region. Advocacy by the Network of HIV Positives in Sierra Leone (NETHIPS) using community treatment observatory data resulted in the signing of a national differentiated service delivery strategy in May 2019 (40). In Benin, a meeting with the Benin Network of People Living with HIV (REBAP+) that revealed a chronic lack of lab reagents and critical treatment monitoring services resulted in the National AIDS Control Programme in that country stocking Bethesda Hospital

in Cotonou with reagents. As a result, no stock-outs have been recorded at RCTO-WA-monitored facilities in Benin in 2019 (40). Nurses at the Gabriel Touré University Teaching Hospital in Bamako, Mali, responded immediately (and without waiting for official instruction) to advice from the Malian Network of People Living with HIV (RMAP+) to transfer viral load results to the central database by patient rather than in groups, thus improving data quality and treatment monitoring (40).

*Two young women living with HIV, Wansama Johnson (left) and Pili Ramadhan (right), support a client at a care and treatment clinic in Kigamboni, Dar es Salaam, Tanzania.*

Credit: UNAIDS/D Msirikale







## COMMUNITY VOICES

### U = U: TRANSFORMING THE LIVES OF PEOPLE LIVING WITH HIV

**Dr. Carrie Foote, a professor at the Indiana University–Purdue University Indianapolis (IUPUI) School of Liberal Arts in the United States of America, is a member of the Prevention Access Campaign Founding Task Force that started the U = U movement. She was once a homeless injecting drug user, and she learned that she was living with HIV in 1988.**

U = U (undetectable = untransmittable) is a global movement started by the Prevention Access Campaign and people living with HIV to disseminate a revolutionary scientific fact: people living with HIV receiving effective antiretroviral treatment cannot sexually transmit HIV.

U = U is transforming our lives by liberating us from HIV stigma and its numerous harms. As the message spreads, people living with HIV are empowered! We no longer feel shameful or a danger to others. Depression fades and suicidal thoughts disappear. Many of us have emerged from social isolation to become activists, determined to share this life-changing message.

Fear of passing on HIV is a deeply destructive barrier to relationships for so many of us living with HIV. U = U breaks down that fear, opening up social, sexual and reproductive lives that we never thought would be possible. It is changing the way we see ourselves, the way others see us, how we are treated in provider settings, and the way policy decisions are made about us. U = U encourages testing and treatment adherence, and it provides a strong public health argument for eliminating barriers to universal access to advance the well-being of people living with HIV and prevent new transmissions.

Phrases such as “greatly reduces risk” or “virtually impossible” incorrectly convey the possibility of risk and perpetuate stigma. U = U should be described in easy-to-understand ways that inspire

confidence and avoid unnecessary doubts, such as “can’t pass it on,” “no chance” or “zero risk.”

All our messaging, including when we are advocating for universal access and ending HIV criminalization, must be morally neutral regarding viral load. This is to avoid a viral divide in which those currently undetectable are valued more than those who are not. Everyone should be treated the same in our services and under the law, regardless of viral load status, especially as structural barriers to care—such as stigma, poverty and violence—undercut access. This is especially true for the most oppressed communities among us who may be subject to racism, homophobia, transphobia and criminalization.

It is also important to acknowledge that treatment is a very personal decision and not a public health responsibility. Support people living with HIV to start treatment whenever they are ready to do so. We are not prevention tools. Use U = U as a public health argument to advocate for health equity for all.

U = U is a game changer because it empowers people living with HIV. It is a key to ending the HIV pandemic. It’s imperative to share this message at every opportunity with providers, policy-makers and people living with HIV. Where barriers to sharing exist, rest assured that our U = U community voices are loud, clear and persistent, and we will carry the message for you!





## AT A GLANCE

Peer support and other forms of community support are enabling women to make positive health-care decisions, including taking an HIV test and, if necessary, starting antiretroviral therapy.

As efforts to diagnose vertically infected infants improve, the paediatric treatment gap is shifting to older children who went undetected as babies and survived without treatment. Adolescents can struggle to access services designed primarily for adults. Age-of-consent laws are barriers to many.

UNAIDS is supporting countries to use their data to pinpoint the remaining gaps in their programmes to prevent vertical transmission, and to direct fresh efforts and solutions to those areas.

Providing cash incentives to young people, especially girls, to stay in school longer and to do better in their studies has been shown to delay sexual debut, increase use of health services, reduce teen pregnancies and early marriage, and reduce HIV-related sexual risk behaviour.

The Sitakhela Likusasa study in Eswatini has shown that cash transfers can reduce the risk of HIV infection among adolescent girls and young women.

HIV-related stigma and discrimination interferes with the ability of people to access the services they need. Community-led efforts are combining service provision with safe spaces, individual empowerment, advocacy and broader learning opportunities that mitigate the negative impact of threatening environments.

# POWER TO THRIVE

***The 1948 Universal Declaration of Human Rights includes the rights to health, education, work and a standard of living adequate for the health and well-being of the individual and family. These are among the rights that must be upheld if people at risk of HIV and those living with HIV are to thrive and reach their full potential.***

Infants exposed to HIV require rapid HIV testing and return of results, and all children living with HIV must be provided with antiretroviral therapy. Adolescents and young people require age-appropriate and comprehensive sexuality education to protect themselves from HIV and to safeguard their sexual and reproductive health and rights (see *Power to know* chapter). Broader education is critical to achieving the economic security needed to control one's own destiny, and universal health-care schemes and social protection programmes provide the safety nets that people need to guard their health and well-being.

## **Enabling mothers with HIV and their children to flourish**

Efforts to provide pregnant women living with HIV with antiretroviral medicines have led to a steep decline in the annual number

of children newly infected with HIV: from 280 000 [190 000–430 000] in 2010 to 160 000 [110 000–260 000] in 2018, a 41% decrease. However, progress has been uneven, and some key challenges require additional attention.

The collection and analysis of more detailed data is helping countries to identify and focus on their particular challenges. UNAIDS is supporting countries to use their data to pinpoint the remaining gaps in their programmes to prevent mother-to-child transmission, and to direct fresh efforts and solutions to those areas. In Nigeria, for example, the biggest challenge is low coverage of antiretroviral therapy among pregnant and breastfeeding women living with HIV. A significant number of women also are infected by their sexual partners while breastfeeding and then pass the virus on to their babies. In Zimbabwe, where antiretroviral therapy coverage is higher, mothers and babies acquiring HIV during breastfeeding is also a challenge, and a large proportion of vertical infections occur because pregnant and breastfeeding women living with HIV are not retained in care, pointing to the need for additional adherence support programming (Figure 4.1).

*A woman living with HIV and her baby attend a routine checkup with a peer mother at Mildmay Hospital in Kampala, Uganda. The peer mother programme at the hospital helped ensure the baby was born HIV negative.*

Credit: UNAIDS/E. Echwalu

Countries are using this textured information to introduce a range of improvements, among them the wider use of community-based approaches to protect the health of women, their infants and their partners (1, 2). Peer and other forms of community support are proving to be key for enabling women to make positive health-care decisions, including taking an HIV test and, if necessary, starting antiretroviral therapy. Mentoring and peer support, and the support of partners and other family members, are especially effective for strengthening the retention of women in HIV care (3).

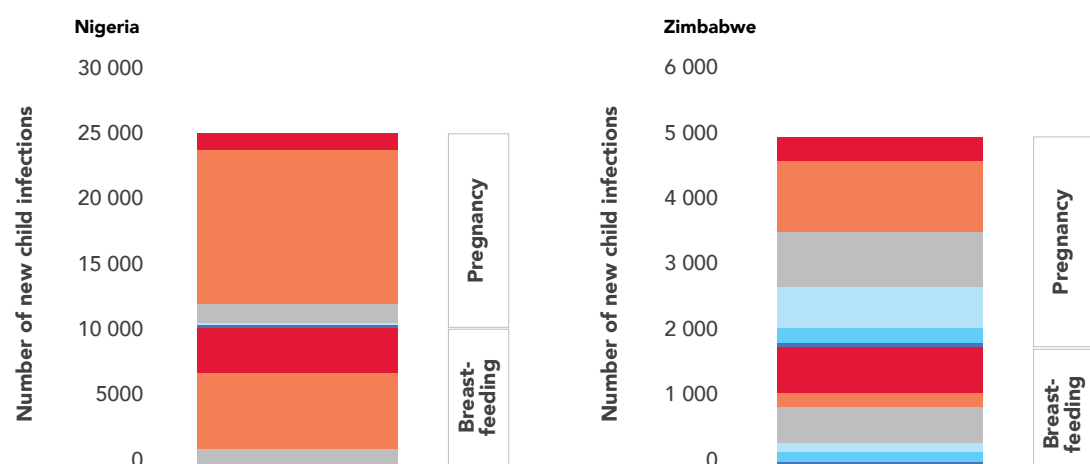
Voice of Women is one of more than 40 community groups in Sierra Leone providing

peer psychosocial support to women living with HIV. The group's Mother-to-Mother (M2M) programme carries out home visits throughout the country to help pregnant women stay on treatment. In the first half of 2018, M2M volunteers brought back into care more than 300 pregnant women living with HIV who had been lost to follow-up (4).

In the Democratic Republic of the Congo, a similar approach—the Mentor Mothers (mère-mentors) programme—has been combined with what is known as “papa antenatal care,” which takes the form of education sessions for couples or men-only discussion groups for male partners that provide information about pregnancy, antenatal care, HIV testing and infant health (5).

FIGURE 4.1

**Distribution of new HIV infections among children, by service gaps for preventing vertical transmission of HIV, Nigeria and Zimbabwe, 2018**



Nigeria		Zimbabwe		
1170	370			Mother infected during pregnancy; child infected during pregnancy
11 060	1010			Did not receive antiretroviral therapy during pregnancy; child infected during pregnancy
1450	800			Mother dropped off antiretroviral therapy during pregnancy; child infected during pregnancy
80	610			Started antiretroviral therapy late in the pregnancy; child infected during pregnancy
150	180			Started antiretroviral therapy during the pregnancy; child infected during pregnancy
60	90			Started antiretroviral therapy before the pregnancy; child infected during pregnancy
3320	670			Mother infected during breastfeeding; child infected during breastfeeding
5620	190			Did not receive antiretroviral therapy during breastfeeding; child infected during breastfeeding
940	510			Mother dropped off antiretroviral therapy during breastfeeding; child infected during breastfeeding
20	140			Started antiretroviral therapy late in pregnancy; child infected during breastfeeding
140	140			Started antiretroviral therapy during pregnancy; child infected during breastfeeding
70	80			Started antiretroviral therapy before pregnancy; child infected during breastfeeding

Source: UNAIDS epidemiological estimates, 2019.

Some men who attend these sessions go on to serve as peer educators. Local pastors, chiefs and teachers assist in encouraging greater male involvement, and some clinics have modified their opening hours to make it easier for working men to join their wives or girlfriends on antenatal care visits. In one year in North Kivu province, more than 66 000 pregnant women and 21 000 male partners took HIV tests, and 1100 antenatal care kits were distributed to couples who jointly attended clinic appointments (5).

The Better Life Guri Foundation (Fondation Guri Vie Meilleure) in Niger works with networks of people living with HIV to recruit community facilitators at 20 primary health-care centres in the Niamey region (6). All of the facilitators are either living with HIV or directly affected by HIV. They counsel and assist women to take an HIV test and, if the results are positive, to agree for their children to be tested. They then arrange for the women and their children to receive appropriate care.

Within eight months, the project enabled every pregnant woman visiting one of the health facilities to take an HIV test. More than 92% of all pregnant women reached by the programme who tested HIV-positive were started on antiretroviral therapy (compared to a national average of 78%), and two thirds of the pregnant women who had been lost to follow-up were brought back into the treatment programme (6). Ensuring that infants exposed to HIV are tested remains a challenge, however, even though the programme has more than doubled the 2018 national average of 22% of HIV-exposed infants tested (6).

### *Doing better at diagnosing HIV-exposed infants*

If infants who have acquired HIV in the womb or at birth are not diagnosed early and linked to effective treatment and care, 50% will die before their second birthday. Peak mortality is two or three months of age (7–9). Too many infants are identified only when they present with HIV-related symptoms, which badly compromises their chances of survival and a healthy childhood (10). Early infant diagnosis and prompt linkage of HIV-positive children to treatment could



*Peer counsellor Rose Mekinda weighs a baby at the Ebolowa Regional Hospital in Cameroon.*  
Credit: UNICEF

have avoided many of the estimated 100 000 [64 000–160 000] AIDS-related deaths in 2018 among children (aged 0–14 years).

A major hindrance is the need for time-consuming and logistically challenging virological testing for HIV-exposed infants (11). It is estimated that more than 40% of test results for infants are never received by the caregiver, contributing to high loss to follow-up, poor linkage between testing and treatment, and high infant mortality (12). Globally, only 59% [48–78%] of HIV-exposed children in 2018 were tested before two months of age.

Greater use of point-of-care platforms for early infant diagnosis would make a huge difference. These technologies drastically improve and speed up the return of test results to caregivers (13). Fifteen countries in Africa have already adopted this technology with support from a range of international partners.<sup>1</sup> The Innovation to Scale Initiative for West and Central Africa by the United Nations Children's Fund (UNICEF), which launched in September 2019, is supporting the expansion of

<sup>1</sup> The 15 early adopter countries are Cameroon, Côte d'Ivoire, the Democratic Republic of the Congo, Eswatini, Ethiopia, Kenya, Lesotho, Malawi, Mozambique, Rwanda, Senegal, Uganda, the United Republic of Tanzania, Zambia and Zimbabwe.



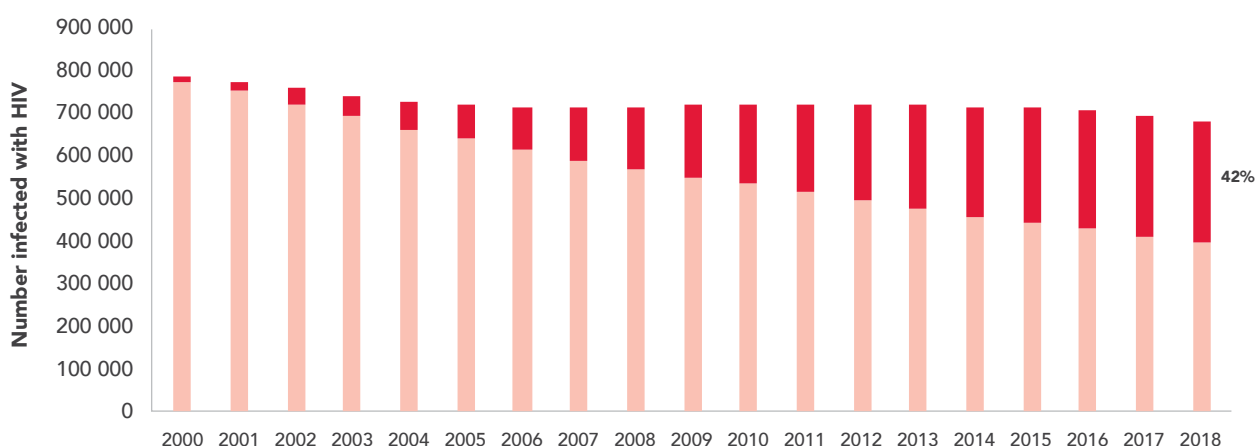
point-of-care systems to 10 additional countries in western and central Africa by 2021.<sup>2</sup> In Cameroon, coverage of early infant diagnosis increased from 51% of HIV-exposed infants in 2017 to 69% in 2018 after point-of-care platforms were phased in (14). That rate is more than double the 29% HIV testing rate across western and central Africa in 2018 for HIV-exposed infants within two months of birth.

There also are opportunities to use the same diagnostic platform to test for different health conditions. In a pilot in Zimbabwe in 2017 and 2018, integrated HIV and tuberculosis testing not only had benefits for early infant diagnosis of HIV, but it also provided cost-savings for the tuberculosis programme (15). As point-of-care platforms are rolled out, it will remain important to adapt the approach to the needs, capacities and limitations of diagnostic systems in different settings.

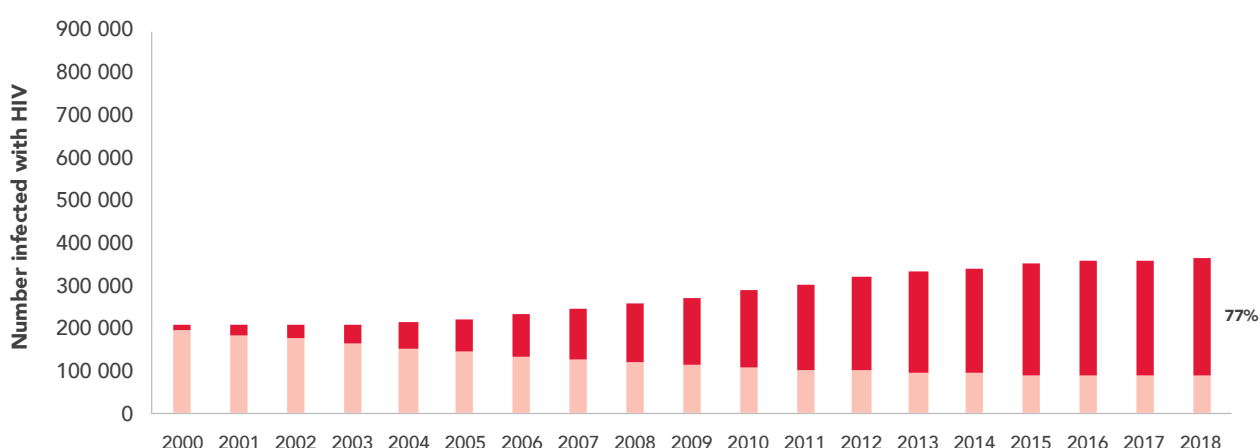
FIGURE 4.2

**Distribution of young women and young men (aged 15–19 years) living with HIV who were infected vertically and horizontally, global, 2000–2018**

**Women**



**Men**



■ Horizontally infected  
■ Vertically infected

Source: UNAIDS epidemiological estimates, 2019.

<sup>2</sup> The 10 additional countries are Burkina Faso, Cabo Verde, Central African Republic, Chad, the Congo, Equatorial Guinea, Gabon, Ghana, Mali and Nigeria.



## Reaching older children and adolescents with HIV services

There has been a significant rise in the proportion of adolescents living with HIV who acquired their infection vertically: in 2018, they accounted for 42% of adolescent girls (aged 15–19 years) living with HIV and 77% of adolescent boys (aged 15–19 years) (Figure 4.2). Differentiated strategies are needed to support these adolescent girls and boys to know their HIV status, start treatment and remain in care. Adolescent girls living with HIV are more likely to be identified through strategies linked to sexual debut, while adolescent boys living with HIV are more likely to be identified through strategies such as family testing.

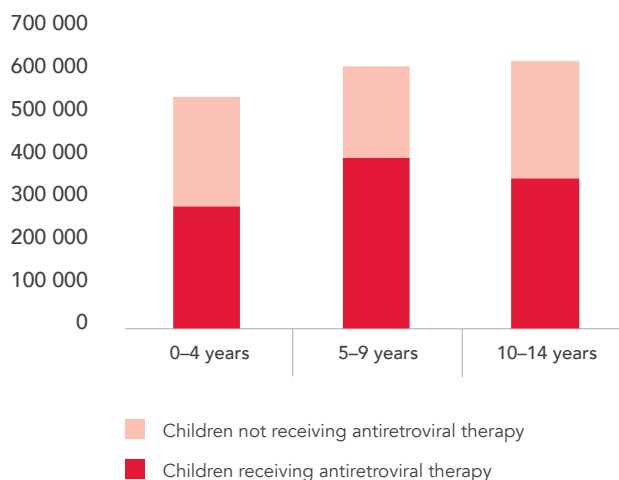
Children and adolescents living with HIV generally have lower rates of HIV diagnosis, antiretroviral therapy initiation and viral suppression than other age groups. As efforts to diagnose vertically infected infants improve, the paediatric treatment gap is shifting to older children who went undetected as babies and survived without treatment. Age-disaggregated estimates of antiretroviral therapy coverage globally suggest that the treatment gap among older children (aged 10–14 years) is similar to the gap among infants and young children (aged 0–4 years) (Figure 4.3).

More proactive screening protocols at health facilities can assist in identifying undiagnosed children and adolescents. For example, adolescents who have lost a mother or both parents—or those whose mother was living with HIV—were 2–3 times more likely to be living with HIV than other adolescents, according to survey data from sub-Saharan Africa (16). Point-of-care case-finding can be focused at health services where there is a high potential for identifying children and adolescents living with HIV, such as in tuberculosis clinics, paediatric inpatient wards or therapeutic feeding centres (17). Children who receive orphan and vulnerable children services should also be assessed for HIV testing.

For adolescents, accessing services designed primarily for adults is often an intimidating experience (17, 18). Simple adjustments can change that, and adolescents should be meaningfully engaged in efforts to make and evaluate those adjustments. Training

FIGURE 4.3

### Children living with HIV receiving antiretroviral therapy, by age, global, 2018



Source: UNAIDS epidemiological estimates, 2019.

health-care personnel to be more considerate and less judgmental towards adolescents has important benefits, as does extending certain services to after-school hours a few days a week, making them free of charge, and ensuring that privacy and confidentiality are respected (19). In Malawi, for instance, adolescent-only clinics are open on weekends at some health facilities, and group peer support is available to teens while they wait for their appointments (20).

HIV self-testing can also help sidestep some stigma-related barriers that are major deterrents for children and adolescents (21–23). In a recent study from Malawi, testing uptake was considerably higher when adolescents were offered counselling and self-testing kits (24). Community-based testing approaches also have shown good results, especially when they are well-targeted and linked with other health services (25). Similarly, social media platforms can be used to promote testing among adolescents: in Nigeria, a recent youth-focused social media campaign to promote HIV self-testing reached more than 3.5 million people (26, 27).

Adolescents are less likely to drop out of care when they receive peer support (28–31). Data from eastern and southern Africa show that adolescents receiving peer support had viral suppression rates seven

times higher than the average regional rate (32). The Community Adolescent Treatment Supporters approach used in the Zvandiri programme in Zimbabwe has proven effective for increasing uptake of HIV testing, linkage to care, treatment adherence and retention in care, and for providing services related to sexual, reproductive and mental health to adolescents (33). When treatment support is linked with access to food security, social protection and economic empowerment, the survival rates among adolescents and young adults living with HIV also improve (34).

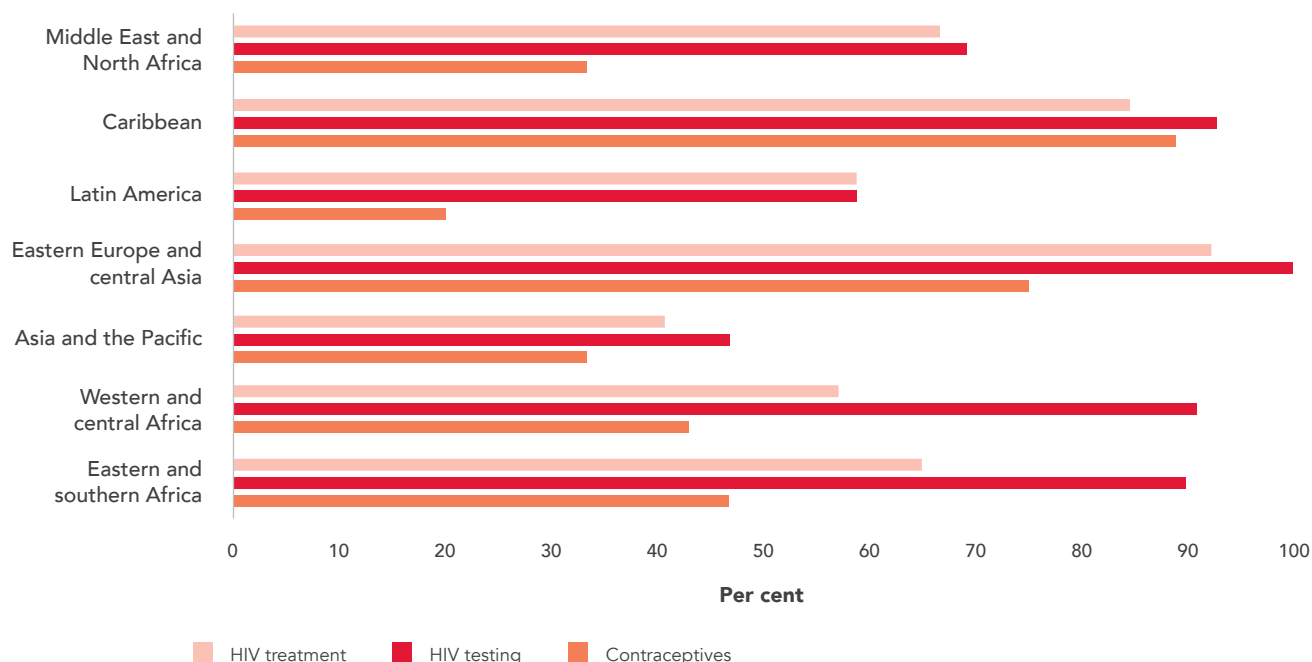
#### Legal and policy barriers

Age of consent stipulations can be a major barrier for older children and adolescents. In 2019, 105 of 142 countries with available data required parental or guardian consent for adolescents to access HIV testing, including 90% of reporting countries in eastern and

southern Africa. Similarly, 86 of 138 countries with available data required parental or guardian consent for HIV treatment, including 65% of countries in eastern and southern Africa. Parental consent for contraceptives was required in 41 of 90 countries, including 75% of reporting countries in eastern Europe and central Asia and 89% of reporting countries in the Caribbean (Figure 4.4). Removing such legal barriers can be extremely beneficial, especially for girls, according to a recent analysis of data from national population-based surveys from 15 countries in sub-Saharan Africa (35). In countries where the age of consent for testing is 15 years or younger, adolescents aged 15–18 years were 74% more likely to have taken an HIV test in the previous year than in countries where the age of consent for testing is 16 years and over. The difference was even higher for girls than boys.<sup>3</sup>

FIGURE 4.4

### Percentage of reporting countries with laws requiring parental or guardian consent for adolescents to access contraceptives, HIV testing and HIV treatment, by region, 2017–2019



**Source:** UNAIDS National Commitments and Policy Instrument, 2017–2019 (see <http://lawsandpolicies.unaids.org/>); National guidelines for prevention and management of HIV and STIs. Kigali: Ministry of Health (Rwanda); 2016 ([https://aidsfree.usaid.gov/sites/default/files/rw\\_national\\_guidelines\\_hiv.pdf](https://aidsfree.usaid.gov/sites/default/files/rw_national_guidelines_hiv.pdf), accessed 30 October 2019); Sexual Rights Initiative [database]. Sexual Rights Initiative; c2016 (<http://sexualrightsdatabase.org/map/21/Adult%20sex%20work>, accessed 30 October 2019); National HIV testing and counselling policy. Port of Spain (Trinidad and Tobago): Ministry of Health (Trinidad and Tobago); 2006 ([www.health.gov.tt/downloads/DownloadItem.aspx?id=258](http://www.health.gov.tt/downloads/DownloadItem.aspx?id=258), accessed 30 October 2019); Republic of Djibouti. Décret N° 2008-0182/PR/MS portant Institution des Normes et Directives en Matière de Conseil Dépistage Volontaire du VIH/SIDA en République de Djibouti. Article 19 ([http://www.ilo.org/wcmsp5/groups/public/---ed\\_protect/---protrav/---ilo\\_aids/documents/legaldocument/wcms\\_126992.pdf](http://www.ilo.org/wcmsp5/groups/public/---ed_protect/---protrav/---ilo_aids/documents/legaldocument/wcms_126992.pdf), accessed 30 October 2019).

<sup>3</sup> In countries where the age of consent is under 15 years, an average of 31% of girls aged 15–18 years took an HIV test in the previous year (compared with 17% in countries with an age of consent greater than 16 years). For boys, the corresponding percentages were 19% and 12%, respectively.



*Young medical school students attend a week-long course on HIV in Moscow, Russian Federation. Age-of-consent laws are a barrier to HIV services in most countries in eastern Europe and central Asia.*

### **Confronting gender inequality**

Almost one third of all new HIV infections each year are among young people (aged 15–24 years). In 2018, an estimated 510 000 [300 000–740 000] people globally in that age group acquired HIV, the majority (51%) of whom were adolescent girls and young women living in sub-Saharan Africa. Their disparate HIV risk is tied to a variety of factors that routinely threaten their health and well-being and narrow their chances of fulfilling their potential. These factors include entrenched gender discrimination and inequality, impoverishment, gender-based violence (especially by intimate partners), harmful norms of masculinity, and the social customs and institutional provisions that perpetuate those injustices.

#### ***The double harm of violence and HIV***

Gender-based violence remains an everyday threat to women and girls everywhere. It is estimated that one in three women worldwide has experienced physical and/or sexual violence at some point in her life (36). Great harm is done to the physical and mental health of these woman and girls,

and the violence can also magnify their HIV risk (37, 38). In the recent Sitakhela Likusasa study in Eswatini, for example (see below), adolescent girls and young women who experienced gender-based violence were 1.6 times more likely to acquire HIV than those who did not (39). Among women living with HIV, intimate partner violence can reduce antiretroviral therapy use and adherence to HIV treatment (40, 41).

Enforced zero tolerance policies and laws are important for reducing gender-based violence, as are sustained social interventions that confront and reshape the norms and relations that permit such violence. Community-based organizations often lead the way, such as Uganda’s SASA!, which works with a network of volunteer community activists and tackles unequal power relations.

Some behavioural interventions to prevent intimate partner violence and reduce HIV risk have seen success, especially in southern Africa, but they appear to be less effective among adolescents and young women (42–45). According to a new analysis, the lack of meaningful involvement of both

young women and young men in these kinds of interventions is a prime reason they are not successful: they are not always well-informed by local perspectives and realities (45). Another drawback appears to be an emphasis on individual risk factors rather than wider social and structural conditions. The recommended way forward is to develop interventions for preventing intimate partner violence and HIV jointly with youth—particularly young women—in a genuinely participatory process of research, design and implementation (45). Young women, the analysis emphasizes, are best placed to understand their gendered world and to how to transform their lives.

### *Making social protection work for women and girls*

Efforts aimed at redressing gender inequalities and socioeconomic inequities can mitigate factors that fuel the HIV epidemic (46). Social protection schemes are an increasingly popular tool for improving people’s well-being and health, and for supporting a range of Sustainable

Development Goals (SDGs). For example, providing cash incentives to stimulate access to education and other essential services is an increasingly popular form of social protection (47). Programmes that provide noncontributory cash payments to individuals now reach more than 1 billion people across more than 130 countries (48). In 2019, 47 countries were implementing cash transfer schemes that focused on young women: 22 in sub-Saharan Africa and 13 in Latin America and the Caribbean (Figure 4.5).

According to extensive reviews of evidence, cash transfer schemes can have a positive impact on monetary poverty, school attendance and performance, health and nutrition (especially for children), and empowerment (48–50). Cash transfers therefore can contribute to several SDGs. For example, one South African study found that cash-based and care-oriented social protection for adolescents reduced: (a) hunger (SDG 2: Zero Hunger); (b) HIV risk behaviours, mental health risks, and

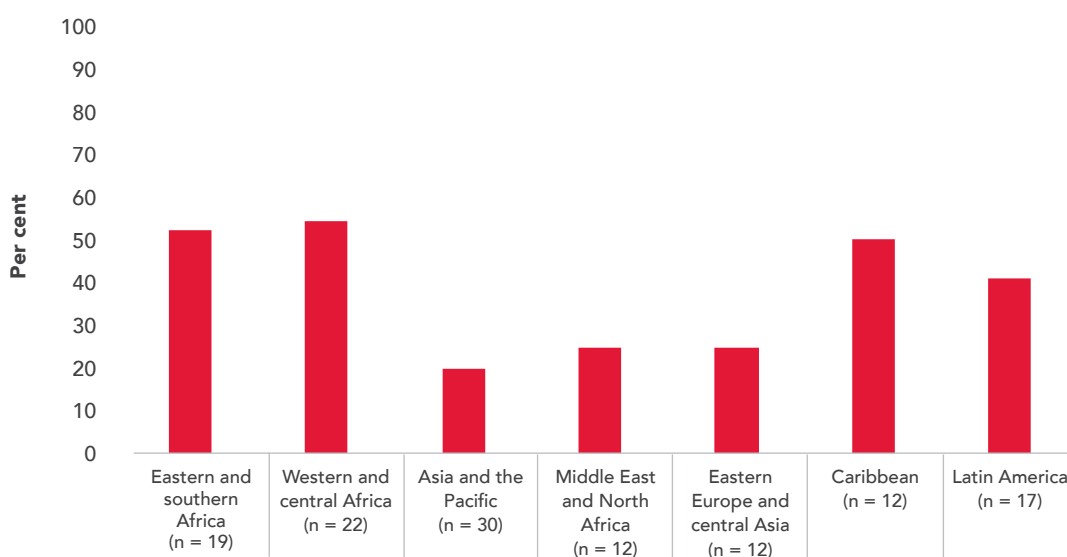
*A young woman buys groceries from a vendor in Kampala, Uganda. The vendor is a member of a local savings club that economically empowers women in the community.*

Credit: UNAIDS/E. Echwalu



FIGURE 4.5

**Percentage of reporting countries that are implementing cash transfer programmes for young women (aged 15–24 years), by region, 2017–2019**



Source: UNAIDS National Commitments and Policy Instrument, 2017–2019 (see <http://lawsandpolicies.unaids.org/>).

substance or alcohol misuse (SDG 3: Good Health and Well-Being); (c) school dropout rates (SDG 4: Quality Education); (d) sexual exploitation of and violence against girls, and improved access to sexual and reproductive health (SDG 5: Gender Equality); and (e) perpetration of violence by boys (SDG 16: Peace, Justice and Strong Institutions) (51, 52).

Studies from Eswatini, Lesotho, Malawi and the United Republic of Tanzania show that cash transfers help young people, especially girls, stay in school longer and do better in their studies (39, 53–55). Other evidence indicates that cash grants that enable girls to continue their schooling also delay their sexual debut, increase their use of health services, reduce teen pregnancies and early marriage, and can promote safer sexual behaviours (48, 52).

Staying in school has been linked with reduced HIV risk. When Botswana extended compulsory secondary education, researchers discovered that each additional year of schooling after Year 9 was associated with an 8% reduction in the risk of HIV infection (and a 11.6% reduction among girls) (56). While it

**CASH TRANSFERS HELP YOUNG PEOPLE, ESPECIALLY GIRLS, STAY IN SCHOOL LONGER. STAYING IN SCHOOL HAS BEEN LINKED WITH REDUCED HIV RISK.**

stands to reason that cash transfer programmes that keep young people in school should reduce their HIV risk, a recent systematic review concluded there was limited evidence that cash transfers reduce HIV infection rates (57). More encouragingly, however, it found that some programmes affect HIV-related outcomes. For example, structural cash transfer programmes (run by the state or as trials) have been successful in delaying sexual initiation and reducing high-risk sex among adolescent girls (57).

Challenging the systematic review’s findings are the results of a major new study conducted in Eswatini, which found that cash transfers reduced the risk of acquiring HIV by 25%, and that cash transfers plus a raffle reduced the risk of acquiring HIV by 38% (see case study below) (39).



# CASE STUDY

*In the Sitakhela Likusasa study, the odds of the recipients of education incentives becoming HIV-positive were 25% lower than for people who were not eligible for the incentives. Participants who both received the financial incentives to remain in education and were entered into a raffle if they remained free of STIs were 38% less likely to acquire HIV.*



## LINKING CASH PAYMENTS TO SCHOOL ATTENDANCE REDUCES HIV INFECTIONS in Eswatini

Do cash transfers help protect adolescent girls and young women against acquiring HIV infection? Evidence to date has been mixed. The Sitakhela Likusasa study, a three-year cluster randomized controlled trial in Eswatini, was designed to test whether improved school attendance and greater financial independence would reduce the risk of HIV infection among adolescent girls and young women. Sitakhela Likusasa was conducted under the leadership of the National Emergency Response Council on HIV and AIDS (NERCHA) and involved several partners.<sup>4</sup>

The study recruited almost 4400 adolescent girls and young women aged 15–22 years, the majority of them from rural areas. Half of the girls and women were already in school or another educational institution, while the other half were not enrolled in any form of education. Participants assigned to education incentives received about US\$ 100 a year for enrolling in and attending school, while tuition fees of up to US\$ 200 were paid for out-of-school participants in the final year of the study. Young women could also receive up to US\$ 100 a year for enrolling in, and completing, tertiary education or vocational short courses. Half the participants were also eligible for a raffle prize if they tested negative for syphilis and trichomonas vaginalis (Figure 4.6).

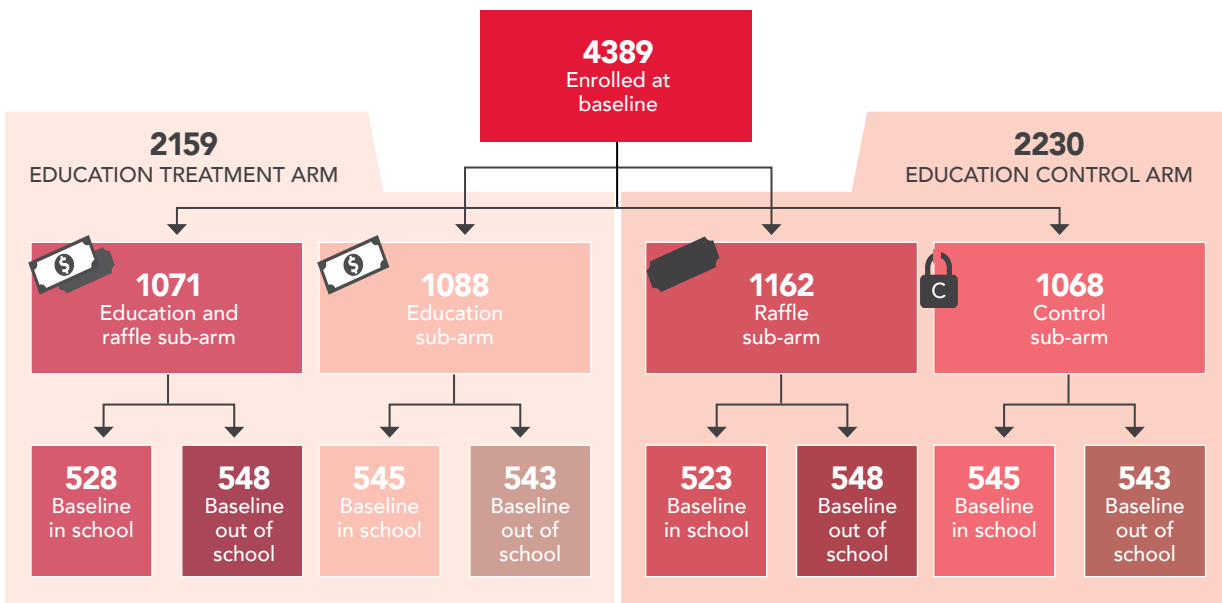
<sup>4</sup> The study partners included IHM Southern Africa, the Eswatini Ministries of Education and Health, and the Swaziland Action Group Against Abuse. It received technical assistance from the World Bank and cofinancing from the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) and the United Kingdom of Great Britain and Northern Ireland's Department for International Development (DFID).



FIGURE 4.6

Structure of the Sitakhela Likusasa Impact Evaluation, Eswatini, 2016–2018

	▶ RAFFLE TREATMENT ARM	▶ RAFFLE CONTROL ARM
▶ EDUCATION INCENTIVE TREATMENT ARM	Sub-arm 1 EDUCATION & raffle	Sub-arm 2 EDUCATION only
▶ EDUCATION CONTROL ARM	Sub-arm 3 RAFFLE only	Sub-arm 4 NO intervention



Source: The World Bank, 2019.

**TABLE 4.1**

**HIV incidence and odds of acquiring HIV over the study period, by raffle and education incentive status, Sitakhela Likusasa study, Eswatini, 2016–2018**

	HIV incidence over the study period	Adjusted Odds ratio [95% confidence interval]	Reduction in Risk (%) [95% confidence interval]	P-value
No intervention	8.84%	1	–	
Raffle only	7.38%	0.84 [0.60, 1.18]	(not statistically significant)	0.310
Education only	6.87%	0.77 [0.54, 1.09]	<b>25%</b>	0.142
Education and raffle	5.79%	0.62 [0.43, 0.89]	<b>38%</b>	<b>0.010</b>

Source: The World Bank, 2019.

The odds of the recipients of education incentives becoming HIV-positive were 25% lower than for people who were not eligible for the incentive (Table 4.1). For participants involved only in the raffle (for which they were eligible if they remained free of sexually transmitted infections), the reduction in odds of acquiring HIV was not statistically significant. However, participants who both received the financial incentives to remain in education and participated in the raffle were 38% less likely to acquire HIV. Those reductions were on par with those achievable through biomedical interventions (39).

The incentives also contributed to reductions in teen pregnancies and enabled more pregnant participants to return to school after giving birth (39). Their main reasons for not enrolling in school were pregnancy and lack of money for school fees. This underscores the positive ways in which HIV intervention can intersect with people’s lived realities.

Those are important results in a country that has the highest HIV prevalence in the world: 27% among adults aged 15–49 years. Adolescent girls and young women (aged 15–24 years) are five times more likely to be living with HIV than their male peers.

The findings are strikingly different from those made by some other studies in the same region, such as the HPTN 068 study in South Africa’s Mpumalanga Province and the CAPRISA 007 study in KwaZulu-Natal, South Africa, both of which found little or no impact from similar interventions (58, 59). A big difference between those studies and the Sitakhela Likusasa study, however, is that the latter paid the cash transfers directly to the women and girls rather than to their households.

The Sitakhela Likusasa results demonstrate the interconnectedness of interventions in health, education and economic well-being, and they provide evidence that keeping adolescent girls and young women in some form of education significantly reduces their chances of acquiring HIV. The results highlight both the importance of including such measures in HIV responses and the need for client-centred, holistic responses that integrate nonmedical interventions and advance the goal of taking HIV out of isolation.



## Addressing stigma and discrimination through community empowerment

Stigma and discrimination divides communities, licenses harassment and violence, and legitimizes injustice. The effects on people's health, well-being and dignity are pernicious, especially in the context of the HIV epidemic. Bringing those experiences into the open and challenging them within health-care settings (see *Power to know* chapter) and within laws and policies (see *Power to demand* chapter) has been a long-standing priority for HIV responses.

By providing guidance and camaraderie, community-led interventions help build a sense of belonging and community that is vital for people's well-being and health. A systematic review has shown the big difference that community empowerment activities among female sex workers can make: the odds of consistent condom use with clients was almost three times higher, and the odds of HIV infection were 32% lower (60). Community-led support has also proven highly effective among gay men and other men who have sex with men for promoting safer sex, popularizing the use of PrEP, advocating for its use, increasing HIV and STI testing rates, and supporting treatment adherence (61, 62).

Transgender persons are subjected to discrimination in every sphere of life, including education and employment. It occurs to such an extent that, according to a 2016 International Labour Organization (ILO) study, only about 10% of transgender persons work in the formal economy. Such exclusion drives people towards livelihoods and personal behaviours that can be unhealthy and dangerous, placing them at high risk of substance misuse, violence and HIV infection.

Community activism has brought long-overdue attention to the rights and realities of transgender people in recent years. Some of the most exciting progress is being made in Latin America: health services have been adapted for transgender women in Mexico; community and health workers are jointly operating clinics in Argentina that are welcoming to lesbian, gay, bisexual, transgender and intersex (LGBTI) people; and social services have

been adapted to strengthen social inclusion in Uruguay (63).

Self-stigma is especially challenging. It drains people's confidence, weakens their sense of agency and damages their health and well-being (64, 65). High levels of self-stigma among people living with HIV have been reported through People Living with HIV Stigma Index surveys in many countries. However, social empowerment, economic support and cognitive-behavioural therapy have been shown to reduce self-stigma among people living with and affected by HIV. Collective activities also appear to be much more effective than individual-level interventions (e.g., focusing on health behaviour change or coaching people about dealing with stigma) when it comes to reducing HIV-related self-stigma (66).

## Integrating mental health into HIV services

Even though an estimated 16% of people globally experience mental health issues, mental health continues to be misunderstood and stigmatized, including in the context of the HIV epidemic (67). People living with HIV often experience mental health conditions; this can be especially challenging for adolescents living with HIV (68). A systematic review of studies from sub-Saharan Africa found that about 31% of people receiving antiretroviral therapy displayed significant depressive symptoms, and that 18% showed signs of major depression (69). A synthesis of 125 studies from 38 countries found that an average of 15% of adults and 25% of adolescents living with HIV reported that depression hindered antiretroviral therapy adherence (70). Poor mental health is also associated with HIV disease progression, independent of its effects on adherence to care (71).

Opportunities for integrating mental health services into HIV programmes exist across the prevention and care continuum. Psychosocial interventions should be offered as part of an integrated package of services, in collaboration with community organizations. In one meta-analysis of study data, the odds of adhering to HIV treatment were 83% better for people receiving mental health care (71).





*Psychologist Ahmedjanov Dior works with children living with HIV at Osh Oblast AIDS Centre, Kyrgyzstan.*

These interlinked challenges have been attracting increased attention and action in recent years. The SEEK-GSP (Social, Emotional, and Economic empowerment through Knowledge of Group Support Psychotherapy) project has successfully treated mild depression in persons living with HIV in northern Uganda (72). Before the project's implementation, cultural perceptions of depression were explored through focus group discussions, and health workers were trained in active learning techniques, such as role play (73). Since then, the project has supported about 3000 people living with HIV, and it is being implemented at 30 primary health-care facilities (74).

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**15% OF ADULTS AND 25% OF ADOLESCENTS HAVE REPORTED THAT DEPRESSION HINDERED THEIR TREATMENT ADHERENCE.**

Living Positive with HIV is an online self-help programme that is being implemented across the Netherlands for people living with HIV who are experiencing symptoms of depression. A randomized controlled trial found the programme could be effective for reducing depressive symptoms and improving people's quality of life (75). The programme is now being piloted in Botswana.

## BUILDING NETWORKS BEHIND PRISON WALLS

Bringing together people who are incarcerated and isolated in different facilities is very difficult—even more so when, as in many states within the United States of America, incarcerated people are not allowed to correspond with their counterparts in other prisons.

The Sero Project, a network of people living with HIV that is fighting stigma and criminalization, has taken on this challenge by building a network that can support incarcerated people living with HIV, hepatitis or other chronic and stigmatized health conditions, helping to provide them with a collective voice. In addition to being at the forefront of the advocacy movement to end HIV criminalization, Sero has created *Turn it up: staying strong inside*, a magazine-format wellness and resource guide for this scattered community.

*Turn it up* is written, edited and illustrated primarily by people who are or have been incarcerated, which accounts for its authentic voice and special appeal. Sero coordinates the project and acts as liaison between the contributors so they can share practical information and help forge a sense of community (76).

The magazine provides a forum for currently or formerly incarcerated people to share experiences and lessons for dealing with stigma, accessing treatment, managing the “pill line” and other issues that are relevant to people living with chronic health conditions while incarcerated. It also covers advocacy campaigns run by prisoners, features profiles on individuals, and provides a listing of health and wellness-related resources for incarcerated persons.

The second edition of the magazine, published in April 2019, was sent to 30 000 incarcerated individuals and shipped in bulk to prison clinics and facilities that are used by formerly incarcerated people (76).

*The cover of the second edition of Turn it up! magazine, an HIV resource guide made by prisoners for prisoners in the United States.*







## AT A GLANCE

Community organizations are at the vanguard of efforts to change laws that criminalize key populations or discriminate against people living with HIV.

Accountability and community oversight mechanisms can stop rights violations before they occur, and legal aid provides communities with redress when rights violations occur.

Communities are collecting data to inform their advocacy for rights protections and quality services.

In the face of multiple barriers to sexual and reproductive health and rights and HIV services, young people are coming together to demand their rights and hold authorities accountable.

#uproot, an audit and accountability scorecard developed by and for young people, has been used in national youth consultations in at least 18 countries, and advocacy road maps based on the results have been developed in nine countries.

# POWER TO DEMAND

***The power to demand is the power of communities and individuals to participate in the decisions that affect them, to raise their voices and be heard.*** Across the world, civil society puts neglected issues onto agendas, proposes solutions, mobilizes action and leads by example. Communities also monitor service provision and hold duty bearers accountable for their commitments—these are fundamental aspects of human rights and key to establishing laws, policies and services that reflect the views of the people they are meant to serve.

Despite this, many civil society organizations operate in precarious circumstances. They rely on limited numbers of committed but overburdened staff and volunteers, and they typically function with minimal funding and other resources. They must contend with legal constraints, funding restrictions and regulatory barriers, and in many countries, they operate in hostile, authoritarian environments.

These are harmful, counterproductive circumstances that deprive dozens of national HIV responses of the knowledge, dynamism and determination of organized communities, disconnecting them from the populations most affected by the epidemic. Recent analysis has found that the proportions of people living with HIV who know their HIV status tend to be larger in countries with high measures of democracy. Researchers believe this is due to the increased capacity of civil society organizations and the opportunities they

have to advocate for the health care needs of their communities and engage in health care delivery for them (1).

## **Demanding legislative change**

Laws that criminalize key populations or discriminate against people living with HIV undermine efforts to prevent HIV infections and AIDS-related deaths in dozens of countries across all regions (Figure 5.1). Such laws include: (a) the criminalization of drug use, sex work and same-sex sexual behaviour; (b) criminalization of HIV non-disclosure, exposure or transmission; and (c) mandatory HIV testing or HIV status disclosure for entry, residence, work and/or study and marriage permits, or for certain groups of people (such as pregnant women).

Crackdowns or restrictions on lesbian, gay, bisexual, transgender and intersex (LGBTI) groups and campaigns have been reported in numerous countries. Similarly, organizations of sex workers and people who inject drugs remain subject to harassment and violence. Where people fear discovery and arrest—and where violence, discrimination, aggressive law enforcement and harassment are enabled by national and local legislation—the people most in need of services cannot access them (2–4).

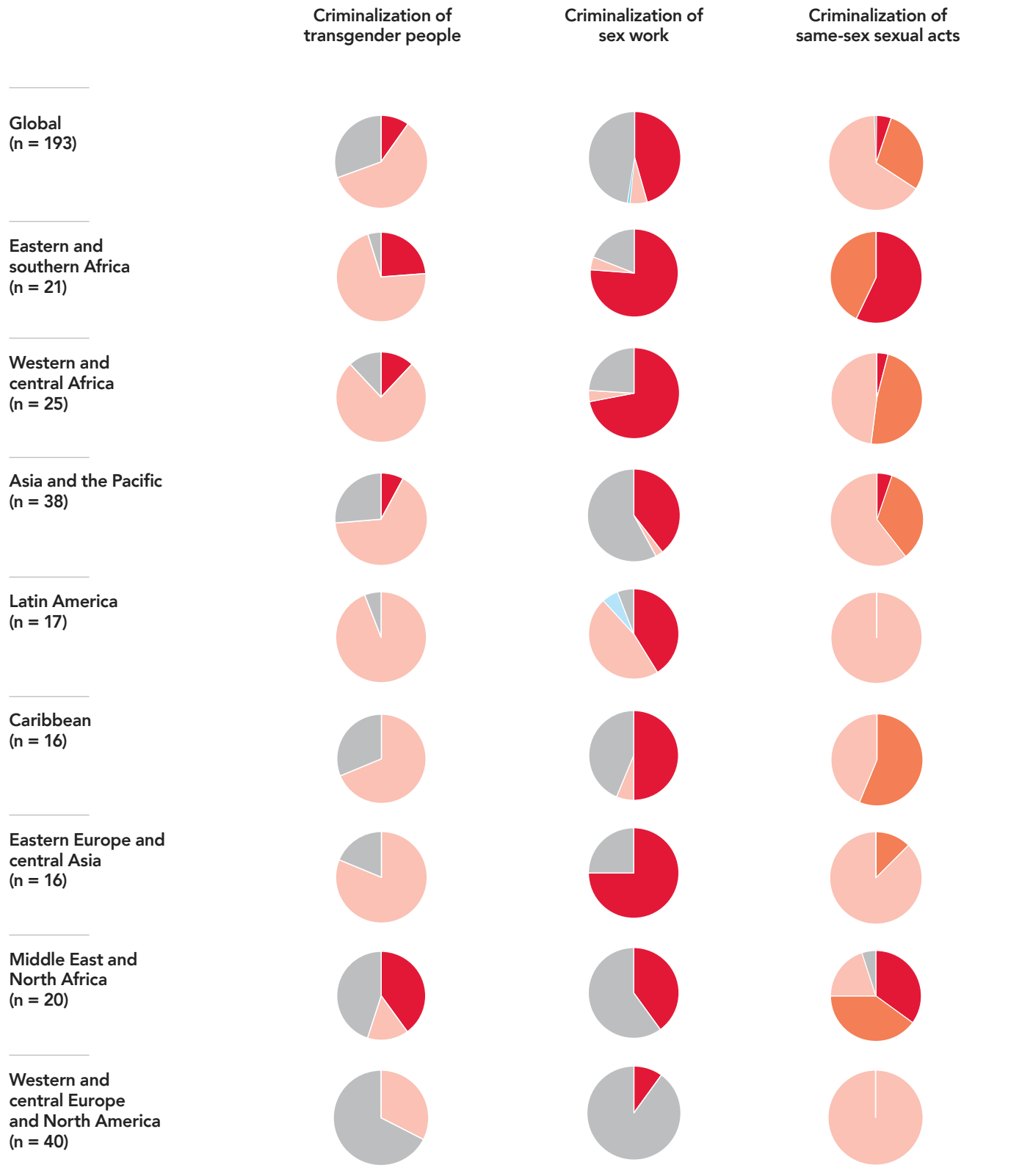
*Tello Hlao and Tumelo Mandoro participate in a Pride event in Maseru, Lesotho, organized by People's Matrix Association, an advocacy group that campaigns for the rights and dignity of LGBTI people in Lesotho.*

Credit: UNAIDS/M. Hyoky



FIGURE 5.1

Laws and policies, global and by region, 2019



**Source:** UNAIDS National Commitments and Policy Instrument, 2017 and 2019 (see <http://lawsandpolicies.unaids.org/>); supplemented by additional sources where noted (see references for this chapter).

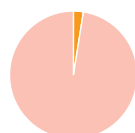
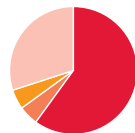
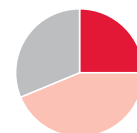
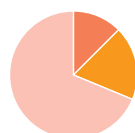
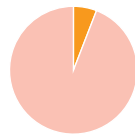
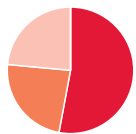
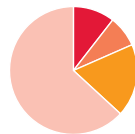
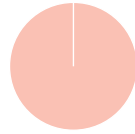
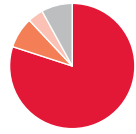
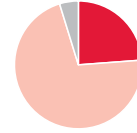
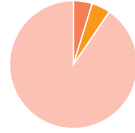
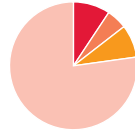
- Criminalized and/or prosecuted
  - Neither criminalized nor prosecuted
  - Data not available
- Any criminalization or punitive regulation of sex work
  - Sex work is not subject to punitive regulations or is not criminalized
  - Issue is determined/differs at the subnational level
  - Data not available
- Death penalty
  - Imprisonment (14 years–life, up to 14 years) or no penalty specified
  - Laws penalizing same-sex sexual acts have been decriminalized or never existed, or no specific legislation
  - Data not available

**Drug use or possession for personal use is an offence**

**Laws criminalizing the transmission of, non-disclosure of, or exposure to HIV transmission**

**Laws or policies restricting the entry, stay and residence of people living with HIV**

**Mandatory HIV testing for marriage, work or residence permits or for certain groups**



- Drug use or consumption and/or possession of drugs for personal use is specified as a criminal offence
- Drug use or consumption and/or possession of drugs for personal use is specified as a noncriminal offence
- No
- Data not available

- Yes
- No, but prosecutions exist based on general criminal laws
- No
- Data not available

- Deport, prohibit short- and/or long-stay and require HIV testing or disclosure for some permits
- Prohibit short- and/or long-stay and require HIV testing or disclosure for some permits
- Require HIV testing or disclosure for some permits
- No restrictions

- Yes
- No
- Data not available



*Members of the Alliance of Women Advocating for Change (AWAC) promote the decriminalization of sex work on the sidelines of a National Sex Workers Dialogue in Kampala, Uganda.*

Credit: UNAIDS

These clampdowns also make it difficult, even dangerous, for community organizations to function, but they are not silenced. In Botswana, for example, LEGABIBO (The Lesbians, Gays and Bisexuals of Botswana) was refused permission to register as a nongovernmental organization in 2012. It took four years of legal challenges and campaigning before the Court of Appeal of Botswana ruled in 2016 that the decision was unconstitutional (5). That victory enabled LEGABIBO to mount and win a court case in 2019 challenging a law criminalizing same-sex sexual intercourse as unconstitutional (6).

Similar tenacity elsewhere has also yielded victories. In several countries in Latin

America, for instance, community activists successfully campaigned for the promulgation of protective gender identity laws, while The Inter-American Court of Human Rights issued a landmark advisory ruling in July 2018 affirming the rights of transgender persons and same-sex couples (7).<sup>1</sup> In 2017, after years of campaigning by a local organization, Girasoles, Nicaragua became the third central American country to formally recognize a sex workers' union (8).

### **Removing restrictions for marginalized populations**

A host of marginalized populations—including people living with disabilities, migrants, refugees, and other displaced

<sup>1</sup> Other countries in the region that have seen protective gender identity laws enacted include Argentina, Chile, Mexico, the Plurinational State of Bolivia and Uruguay.

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**“WHILE THE COMMUNITIES HAD THEIR DIFFERENCES OF OPINION, PERSPECTIVES, POLICIES AND IDEAS, THE OBJECTIVE OF GETTING RID OF THE LAW BROUGHT EVERYONE TOGETHER. THEY WERE ABLE TO UNIFY, TO MAINTAIN AND RESPECT THEIR DIFFERENCES WHILE ACHIEVING THE OUTCOME.”**

*Tripti Tandon, Lawyers Collective, India*

or mobile people—are denied access to health services and placed at higher risk of HIV infection and HIV-related illnesses by structural factors, including social exclusion, restricted or discriminatory provision of health-care services, and the lack of protective laws. For example, restricting the entry, stay and residence of individuals on the basis of their HIV status can discourage migrants from seeking HIV testing, prevention and treatment for fear of being deported. HIV-related immigration restrictions also violate the human rights to health and privacy, while mandatory HIV testing is in contravention of internationally agreed standards relating to informed consent, confidentiality and counselling. Laws specifically targeting people living with HIV increase stigma attached to HIV more broadly, discouraging everyone—not only migrants—from accessing HIV testing and treatment (13).

The number of Venezuelans seeking refugee status worldwide has increased by 8000% since 2014: around 4.5 million Venezuelans now live outside of their country (14). As of 2018, an estimated 7700 Venezuelans living with HIV in host countries were in need of antiretroviral therapy, while many more Venezuelan refugees and migrants required information on and consistent access to combination HIV prevention and voluntary counselling and testing services (15).

A multistakeholder campaign in Panama demonstrates the power of advocacy to demand and achieve change in HIV-related

immigration restrictions (13). In 2018, Carmen (not her real name), a Venezuelan woman living in Panama, was detained by Panamanian immigration authorities when she was diagnosed with HIV at a health clinic. She awaited deportation to Venezuela for eight months; for more than two months, she had no access to antiretroviral therapy. Following a legal campaign spearheaded by the Panamanian Ombudsman Office and the Committee on Human Rights for Key Populations, Carmen was released (16). The Panamanian Ministry of Health published a resolution stating that it would no longer automatically inform immigration services about migrants who are diagnosed with HIV, and that it would not require them to be detained or deported on the grounds of their HIV status (13).

### **Demanding the enforcement of laws**

Laws and policies that explicitly protect the human rights (including the right to health) of people living with HIV and members of key populations must be more than words on paper. When legislative change is not followed by efforts to raise public awareness and ensure enforcement, stigma and discrimination, violence and injustice can remain ingrained within institutions and among duty bearers, including judges, law enforcement officers, policy-makers, parliamentarians and health-care workers.

Legal aid services are a key element of accountability. People living with HIV and members of key populations can lack sufficient knowledge of their rights and the mechanisms available to protect them. They often are unable to afford the legal support they need to seek remedies when their rights are violated, even where they are aware such an option exists.

In 2016, United Nations (UN) Member States committed to having national AIDS strategies that empower people to know their rights and access legal services in order to prevent and challenge violations of human rights. In 2019, 69 countries reported to UNAIDS that they had legal aid systems applicable to HIV casework, and 30 reported the existence of legal clinics providing legal services. Civil society reports differed in some countries, with some disagreeing with the government’s assertion that legal

FIGURE 5.2

**Number of countries that report having mechanisms in place for accessing affordable legal services, global, 2019**



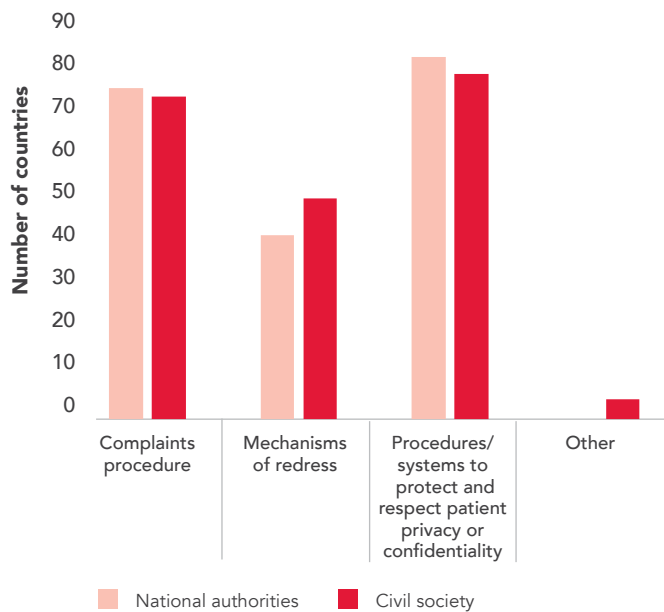
Source: UNAIDS National Commitments and Policy Instrument, 2019 (see <http://lawsandpolicies.unaids.org/>).

aid systems were in place, and others suggesting that the government may not be aware of available free or subsidized legal aid (Figure 5.2).

Accountability and community oversight mechanisms can stop rights violations before they occur, and they can ensure that communities receive redress when they do. Such mechanisms should be developed with community involvement, as in Ghana, where a web- and SMS-based discrimination reporting system developed by community organizations and the government links people living with HIV, members of key populations and the civil society organizations that support them to legal services (17). In 2019, 84 countries reported to UNAIDS the existence of systems to protect and respect patient privacy or confidentiality in health-care settings, 77 reported the existence of complaint procedures and 43 reported the existence of mechanisms for the redress of human rights violations (Figure 5.3).

FIGURE 5.3

**Number of countries reporting the existence of accountability mechanisms in relation to discrimination and human rights violations in health-care settings, global, 2019**



Source: UNAIDS National Commitments and Policy Instrument, 2019 (see <http://lawsandpolicies.unaids.org/>).





Members of MENA-Rosa, a regional network of women living with or affected by HIV, participate in a community dialogue. The women shared their experiences, documented gender-related stigma and discrimination and explored the underlying causes of violence and HIV in their communities.

Credit: UNAIDS/G. Eid

## BURKINA FASO: LEGAL AID FOR PEOPLE LIVING WITH HIV AND KEY POPULATIONS

In Burkina Faso, mobile technology is helping to widen the reach of legal aid services for sex workers, people living with HIV, and gay men and other men who have sex with men who are victims of stigma and discrimination or rights violations (18).

The nongovernmental organizations Kasabati and CICDoc have contracted a legal firm, JurisExpress, to provide services to beneficiaries from across the network of community-based organizations they support. Field lawyers in Ouagadougou and Bobo Dioulasso specialize in HIV and human rights and are familiar with key populations and the problems they face.

JurisExpress offers awareness raising and information for key populations on their rights, as well as legal advice, legal defence and counsel. Beneficiaries can access the services through telephone calls, SMS, WhatsApp groups, legal clinics at the law firm or at the premises of community-based organizations, or even through home visits. The use of phone technologies has helped to widen the reach of the programme. The service has seen a wide range of requests: inheritance and child custody disputes from women living with HIV; labour contracts, property expulsion or paternity testing from sex workers; and instances of physical violence, arbitrary detention, and stigma and discrimination from sex workers and gay men and other men who have sex with men. The vast majority of requests (71%) come from women, and the Ouagadougou team has recruited a woman member to deal with cases that are more difficult to discuss with a man (18).

In the first 15 months of the programme, nearly 1000 people living with HIV, sex workers and gay men and other men who have sex with men benefited from JurisExpress information sessions. In addition, 629 people received legal advice and 197 received longer term legal assistance, while 72 cases required oral or written defense arguments prepared by JurisExpress lawyers. More than 100 people were referred to other services, including social welfare services. Most cases have been solved through mediation, with very few (29 cases) referred to law enforcement. None have been referred to the courts. The number of requests from all methods of access tripled in a little over a year (18).

# CASE STUDY

## THE TWO-DECADE FIGHT AGAINST SECTION 377 in India

The power to demand can be a long, incremental process, in which the community voices, power and engagement gained along the way can be as important as the legislative outcomes.

On 6 September 2018, India's Supreme Court unanimously overturned Section 377 of the Indian Penal Code, a colonial-era law that criminalized consensual same-sex sexual activity, ruling that discrimination on the basis of sexual orientation is a fundamental violation of human rights (9). The change was the result of a sustained effort by community groups—20 years of campaigning and organizing—during which time the communities involved grew in strength and activism.

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"TODAY WE NO LONGER HAVE SECTION 377, INSTEAD WE HAVE THE FREEDOM OF THE QUEER MOVEMENT AND A NEW PATHWAY FOR LGBTI PEOPLE TO SEEK THEIR RIGHTS, PROTECT THEIR DIGNITY AND ACCESS HEALTH CARE. WE ARE THANKFUL TO INDIA'S SUPREME COURT BUT WE MUST NOT FORGET THE SACRIFICES OF MILLIONS OF LGBTI LEADERS WHO FOUGHT SHOULDER-TO-SHOULDER OVER THE YEARS AND MADE THIS DREAM COME TRUE. WE ARE QUEER AND WE ARE FREE."

*Abhina Aher, India HIV/AIDS Alliance (10)*

The first effort to roll back Section 377 came in 1994, when the AIDS Bhedbhav Virodhi Andolan (ABVA, or AIDS Anti-discrimination Movement) challenged an order that condoms should be prohibited in a prison (11). The writ was dismissed in 2001. In that year, the Naz Foundation, a sexual health nongovernmental organization working with gay men and other men who have sex with men—supported by the legal nongovernmental organization Lawyers Collective—filed a public interest litigation in the Delhi High Court, challenging the constitutionality of Section 377 and calling for the legalization of homosexuality. The legal battle over Section 377 went back and forth for several years, with India's LGBTI and HIV communities (including Voices Against 377, a coalition of nongovernmental organizations) playing a high-profile role as advocates against the legislation. In 2013, the Supreme Court overturned a Delhi High Court decision to strike down Section 377. This major setback galvanized the LGBTI community, and a "global day of rage" was observed across the country and other parts of the world protesting the decision (12).

Several key legal developments paved the way for the 2018 decision to overturn Section 377. These include: (a) the passing of the Protection of Children from Sexual Offences Act (2012); (b) expansions of the definition of rape under criminal law (2013); (c) the passing of the 2017 HIV and AIDS Prevention and Control Act and Mental Healthcare Act; and (d) the Supreme Court's recognition of the fundamental right to gender identity (2014), its decision that privacy is a constitutionally protected right (2017) and its affirmation of the right to choose one's partner as an integral component of the right to life (2018).



*Abhina Aher, a transgender woman working with the India HIV/AIDS Alliance, speaks at a UNAIDS Programme Coordinating Board meeting in 2017.*





*Mercy Kyando, a programme officer of the Tanzania Youth Alliance, trains peer educators on combination prevention for adolescent girls and young women.*  
Credit: UNAIDS/D. Msirikale

### **Bringing community data to the table**

Epidemiological data, behavioural surveys and service coverage data are the building blocks of the strategic information that guides efforts to improve the response to HIV. As well as programme managers and health-care providers, communities need data to advocate for their rights, access testing and treatment, and seek support for adherence and other services.

In the eastern Caribbean, networks of sex workers, gay men and other men who have sex with men and transgender people came together in partnership with government officials and social science researchers to implement biobehavioural surveys for their

respective communities on six islands. The surveys were undertaken to address a severe lack of data on these communities, with previous attempts to collect data stymied by an inability to reach populations due to fears among community members of disclosure and stigma and discrimination. The surveys used participatory action research, with community members serving as paid co-owners of the project. The results demonstrated that community-based organizations and activists can collect high-quality and reliable data on issues faced by hidden subpopulations. The data were used to advocate for and make decisions about programming and allocation of resources that directly benefited these groups (19).

The People Living with HIV Stigma Index survey is another way for communities to hold their countries accountable for commitments to eliminate HIV-related stigma and discrimination. The surveys have been carried out in more than 100 countries as of 2019, with two goals: (1) to increase the evidence base on HIV-related stigma and discrimination; and (2) to empower people living with HIV and their communities to engage in advocacy around the HIV response.<sup>2</sup> While there is no question about the success of the first goal, it has been harder for communities to achieve the second.

In Kazakhstan, a Stigma Index survey was undertaken in 2015 as part of a regional initiative that also included Kyrgyzstan and Tajikistan. Based on the findings of the survey, the Kazakhstan National Plan against Stigma and Discrimination for 2018–2019 was adopted and co-signed by the leader of the national network of people living with HIV and the head of the Republican AIDS Centre. The plan included specific objectives relating to further research, legal analysis (including of labour rights violations), social contracting for community activities against stigma and discrimination, and information campaigns and training for medical staff. Communities of people living with HIV have been monitoring the implementation of the National Plan against Stigma and Discrimination, raising concerns over a lack of adequate funding and its slow implementation.

As part of this monitoring process, Kazakh community organizations used the Stigma Index survey data for a shadow report to the Committee on the Elimination of Discrimination against Women (CEDAW) (20, 21). The report was presented by Kazakh women living with HIV at the CEDAW pre-session meeting in March 2019. As a result, the list of issues and questions from CEDAW to the Government of Kazakhstan contained the following:

Please provide information on measures taken to eliminate discrimination and violence against women living with HIV and women who use drugs, including in prisons, and to ensure their access to adequate health services, including sexual and reproductive

health services, drug dependency treatment and HIV treatment. (22)

The Government of Kazakhstan responded to these in its formal reply to the list and at the 74th session of CEDAW in October 2019 (23, 24).

An updated and improved version of the People Living with HIV Stigma Index was launched at the end of 2018. This Stigma Index 2.0 reflects changes in the HIV epidemic and aims to provide more detailed information about the prevalence and character of HIV-related stigma and discrimination. It probes the experiences of specific populations in more detail, as well as the impact of stigma on health-care services generally. Stigma Index 2.0 also uses digital data collection, one of several improvements that make the survey easier to conduct. In Brazil, organizations of people living with HIV, supported by UNAIDS, were able to swiftly collect data in seven cities, conducting 1800 interviews in two months (25).

### **Young people call for change across continents**

In the face of multiple barriers to sexual and reproductive health and rights and HIV services, young people are coming together to demand their rights and hold authorities accountable.

In Zambia, Tikambe (“Let’s Talk”), a youth accountability project run by Restless Development, raises civic awareness of the rights and responsibilities of young people and encourages them to take action and hold government to account for the provision of accessible and adequate youth-friendly health services (27, 28). It also provides peer-led training for student teachers on young people’s sexual and reproductive health and on rights protection mechanisms for pupils, encouraging these future teachers to act as positive role models and share their knowledge in schools and communities (28). The Tikambe Youth Resource Centre opened in March 2019, providing a safe space for young people to meet, connect and share experiences with each other, and to develop advocacy strategies on issues that affect their

<sup>2</sup> For more information, please see the People Living with HIV Stigma Index website: [www.stigmaindex.org](http://www.stigmaindex.org)



well-being. The Centre focuses on young people both in and out of school, supporting their access to information (including on the prevention of HIV, gender-based violence and child marriages), comprehensive sexuality education and youth-friendly health services. It also offers supportive counselling, including on employment and educational opportunities (29).

In India, Know Your Body Know Your Rights is a youth-led programme that aims to empower young people to advocate for and access information on human rights, gender, sexuality, sexual and reproductive health, HIV and youth-friendly health services. Three-quarters of its youth leaders and outreach staff are young women, among whom leadership, self-confidence and negotiation skills have increased (30). The campaign has reached around 1.9 million people, with more than 12 000 people engaged through grass-roots partner organizations (26).

The Know Your Body Know Your Rights programme runs comprehensive sexuality education workshops and outreach in diverse locations (including urban slums, institutional care homes, schools, colleges and vocational training centres). It provides young people with leadership opportunities, such as developing and facilitating the peer-education model and advocating with policy-makers. Youth leaders also conducted an assessment of access to youth-friendly health services, with the data from their research used in multistakeholder consultations at the district and state levels and in constructive dialogues between youth leaders and front-line health workers, doctors, and representatives of government and nongovernmental organizations (31).

Other efforts are providing young people with monitoring and evaluation tools. #uproot, an audit and accountability tool developed by and for young people, was launched in 2016 by The PACT, a coalition of more than 80 youth organizations (32). The #uproot scorecard is used to assess progress made by countries on the issues that matter to young people and affect them most, including the commitments on young

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**“WHEN NOBODY IS READY TO LISTEN OR WILLING TO PROVIDE INFORMATION, THEN THE ADOLESCENTS HAVE TO START THEIR OWN MOVEMENT.”**

*Zafreen Neha, Project Coordinator,  
Centre for Social Equity and Inclusion,  
India (26)*

people in the 2016 Political Declaration on Ending AIDS (33). It uses both quantitative and qualitative data to assess progress in five areas: laws and policies, participation, partnerships, beneficiaries and leaders (34). The scorecard is intended to be the starting point for youth-led advocacy at the national level to hold governments and decision-makers accountable for their commitments on HIV, sexual and reproductive health and rights, and gender equality (32).

#uproot scorecards have been finalized and validated through national consultations in at least 18 countries.<sup>3</sup> They have been implemented with youth leaders and networks and the participation of more than 400 young people, including those living with HIV and those representing key populations (34). Advocacy road maps based on scorecard results have been developed in nine countries.

In August 2019, the findings of the #uproot scorecard informed South Sudan's first-ever National Youth Conference on HIV, sexual and reproductive health and rights, and gender equality (35). The conference brought together 22 youth-led organizations and more than 100 young people from across the country, including young people living with disabilities, refugees and internally displaced people. Participants took part in skill-building sessions and discussions on a broad range of issues, including the widespread and systematic

<sup>3</sup> The 18 countries are: Cambodia, Egypt, Fiji, Ghana, India, the Lao People's Democratic Republic, Mali, Mexico, Myanmar, Nigeria, Panama, the Philippines, the Russian Federation, South Sudan, Sri Lanka, Ukraine, the United Republic of Tanzania and Zambia.



*Teenergizer activists in Kazan, Russian Federation, pose for a selfie. Teenergizer brings together adolescents born to mothers living with HIV and other young volunteers from Georgia, the Russian Federation and Ukraine who are advocating for adolescents' sexual and reproductive health and rights.*

incidence of conflict-driven rape and other forms of sexual and gender-based violence in South Sudan. They also discussed stigma and discrimination, barriers to accessing services and information on sexual and reproductive health and rights, early and forced marriage, menstrual health, and comprehensive sexuality education for in-school and out-of-school youth. The conference concluded with the adoption of a youth compact on sexual and reproductive health, HIV and gender equality. An operational plan to support national authorities in implementing the compact is being developed (35).

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**"#UPROOT IS A CHANCE TO SHOW THAT WE'RE BEING LEFT BEHIND, AND THIS ISN'T AN ACCIDENT—IT'S BECAUSE OF POLITICAL CHOICES ON WHO AND WHAT TO INVEST IN, AND BECAUSE OF STIGMA AND FEAR AROUND YOUNG PEOPLE'S SEXUALITY."**

*Hayley Gleeson, ACT!2030 Project Coordinator, The PACT (33)*



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## Source for Figure 5.1:

### Criminalization of transgender people

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