

UNEQUAL, UNPREPARED, UNDER THREAT

WHY BOLD ACTION AGAINST INEQUALITIES IS NEEDED TO END AIDS, STOP COVID-19 AND PREPARE FOR FUTURE PANDEMICS



CONTENTS

FOREWORD

PREFACE

INTRODUCTION AND SUMMARY

4

5

7

21

30

38

47

58

CHAPTER 1: Community-led and community-based infrastructure _

CHAPTER 2: Equitable access to medicines, vaccines and health technologies

CHAPTER 3: Supporting workers on the pandemic front lines

CHAPTER 4: Human rights at the centre of pandemic responses _____

CHAPTER 5: People-centred data systems that highlight inequalities

FOREWORD

This report is a wake-up call on the AIDS emergency, and on the urgency of addressing our multiple pandemic challenges together. It highlights why we can't afford *not* to end AIDS, and powerfully illustrates the need for leaders to take the courageous steps that will save lives today and make us more prepared for pandemics of the future.

The AIDS pandemic could kill millions in the coming years if we do not act with urgency.

In this time of COVID-19, there is a significant risk that political attention to and financing for HIV will drift. If we do not take the steps needed to tackle the inequalities driving HIV today, not only will we fail to end the AIDS pandemic, we also will leave our world dangerously unprepared for future pandemics.

As the report notes, an effective package of measures needs to include community-led services, affordable access to cutting-edge medical technology, human rights, protections for health and essential workers, and data to reveal inequalities.

Too often, such key issues are pushed to the periphery. But the transformative measures required to end AIDS are core to good pandemic preparedness and response. This report illustrates the need for the comprehensive approach to pandemics called for by the Independent Panel for Pandemic Preparedness and Response.

As this report notes, pandemics find space to grow in the fractures of divided societies.

The amazing scientists, doctors, nurses and communities who work to end pandemics cannot succeed unless world leaders take the steps that will enable them to do so.

We must be open-eyed about the risks of business as usual. Without bold action to end inequalities, the trajectory we are on will consign us to be trapped with multiple colliding pandemics. It will leave us at risk and fearful. It will undermine progress, peace and prosperity.

The report highlights two important reasons for hope. First, we have strong evidence of approaches that work. We now need to apply those lessons at scale, everywhere. Second, we have a global plan, agreed at the United Nations General Assembly's High-Level Meeting on Ending AIDS earlier this year. If put into practice, the measures agreed by the General Assembly will enable the world to end the inequalities which drive HIV and AIDS, and pave the way to pandemic preparedness.

Hope depends on courageous action by leaders now. We cannot wait. Pandemics don't just go away by themselves. They are beaten by determined action, or they beat us.

We can win the fight to end pandemics, but only if we are bold enough to end the inequalities which drive them.

It is vital that all governments heed the message of this report, and follow through with deeds not words.

End inequalities. End AIDS. End pandemics.



Helen Clark

Co-chair of the Independent Panel for Pandemic Preparedness and Response, former Prime Minister of New Zealand, and former Administrator of the United Nations Development Programme

PREFACE

We can end AIDS by 2030. Some countries are making remarkable progress, showing us what is possible. But globally, we are simply not bending the curves fast enough to stop the AIDS pandemic.

In this report the Joint United Nations Programme on HIV/AIDS (UNAIDS) issues a stark warning. The red light is flashing. Progress against AIDS, which was already off track, is now under even greater strain as the COVID-19 crisis continues to rage, disrupting HIV prevention and treatment services, schooling, violence-prevention programmes and more.

Analysis in this report shows that millions of lives will be lost from AIDS-related causes if we carry on as we are—if we do not rapidly expand coverage to stop new infections and deaths and bring the pandemic to end.

And make no mistake: AIDS remains a pandemic. To stop it we urgently need a bolder view of pandemic response that is capable of tackling the inequalities prolonging the AIDS pandemic. Many of these missing pieces to fight HIV are also allowing the COVID-19 pandemic to continue and leaving us dangerously unprepared for pandemics of the future.

Leaders took a major step forward this year at the United Nations General Assembly when they agreed to a bold plan to tackle those inequalities. Making that plan a reality depends now on determined and rapid follow-through.

By acting boldly together, leaders are bringing together cutting-edge science, services that meet people's needs, the protection of human rights, and sustained financing. These actions are making AIDS-related deaths and new HIV infections rare. But this is only the case *in some places and for some people*.

World leaders must work together urgently to tackle these challenges head-on. We have a very clear sense of the right direction. But right now, in too many cases, we are not heading in it fast enough. Some are even heading in the wrong direction.

Through fighting the AIDS pandemic, we have learned a lot about what is needed to successfully confront AIDS and all pandemics. The world must not choose between ending the AIDS pandemic that is raging today and preparing for the pandemics of tomorrow. The only successful approach will achieve both. As of today, we are not on track to achieve either.

The good news is that inequality-busting approaches have been proven to work, even in the most challenging contexts. Now they need to be rapidly applied at scale everywhere.

WE HAVE REACHED A FORK IN THE ROAD. THE CHOICE FOR LEADERS TO MAKE IS BETWEEN BOLD ACTION AND HALF-MEASURES. THE DATA IS CLEAR: IT IS BEING TOO GRADUAL THAT IS THE UNAFFORDABLE CHOICE. This report examines five critical elements from the Global AIDS Strategy that must urgently be universalized, and which are also critical but under-funded and under-prioritized for pandemic prevention, preparedness and response.



We have reached a fork in the road. The choice for leaders to make is between bold action and half-measures. The data is clear: it is being too gradual that is the unaffordable choice.

We can win this, but only if we are courageous, and only if we act together.

On my recent visit to Senegal, I saw the power of leadership in driving down new HIV infections. In Dakar I met with the inspirational Mariama Ba Thiam, a peer educator at a harm reduction programme for people who inject drugs. The programme helps them protect their health and to secure economic independence. Mariama's approach works because it starts by considering the whole person, connecting the medical with the social. It rejects the failed punitive and stigmatizing approaches taken by so many, and it instead respects the dignity of every person. It succeeds because it involves frontline communities in service provision and in leadership, and because it recognizes that access to the treatments grounded in the best science is a human right and a public good. We know what success looks like, and it looks like Mariama. Thousands of Mariamas worldwide have shown the way by walking it.

Every minute that passes, we are losing a precious life to AIDS. We don't have time.

End inequalities. End AIDS. End pandemics.



Winnie Byanyima UNAIDS Executive Director



COLLIDING PANDEMICS

Humanity is threatened by an expanding list of pandemics. AIDS is colliding with COVID-19 to deadly effect because much of the world remains dangerously under-prepared and under-resourced to confront the pandemics of today and tomorrow.

Over four decades, advances in science, human rights and public health investment have driven remarkable success against AIDS for some locations and populations. This progress has shown what is possible when countries and communities work together against a deadly contagion.

Considerable gaps remain. Entrenched inequalities stand in the way of further progress against AIDS and leave the world vulnerable to future pandemics. The colossal new challenges created by COVID-19 threaten the gains made thus far.

Just six months before this year's World AIDS Day, United Nations (UN) Member States agreed to a new approach—to address inequalities, to close gaps in HIV service access by 2025 and to get on track to the global goal of ending AIDS by 2030. Those agreed actions are not being made at the required speed and scale.

UNAIDS data show that the curves of HIV infections and AIDS-related deaths are not bending fast enough to end the pandemic. A failure to build on the gains made thus far would result in 7.7 million AIDS-related deaths during this decade.¹ Most of those deaths can be avoided if the world follows the Global AIDS Strategy 2021–2026 and achieves the 2025 targets agreed by the UN General Assembly.

There is no time to spare. Health systems and communities are now being pushed to the breaking point by a coronavirus pandemic that the world was woefully unprepared for, despite clear warnings by infectious disease experts and even Hollywood blockbuster films. Worse yet, two years of the COVID-19 crisis has so far failed to inspire a unified global response to the new pandemic: wealthy nations hoard vaccines and struggle to convince sufficient proportions of their populations to get vaccinated, while low- and middle-income countries are left exposed to the full force of the next wave of SARS-CoV-2 infections.

What is at stake is bigger than AIDS. The actions and interventions that need greater political leadership, policy attention and funding to end AIDS are also critical for turning the tide against COVID-19. As world leaders and the major economies within the G20 work to establish a global framework for pandemic prevention, preparedness and response, the hard-won successes and bitter failures from the response to AIDS have experiences to share. These experiences reveal that critical elements of the Global AIDS Strategy are largely missing from pandemic preparedness efforts and plans—things that must not be neglected if the world is to make good on its pledge to end AIDS within the next decade, to swiftly defeat COVID-19 and to proactively confront the pandemics of tomorrow.

THE CURVES OF HIV INFECTIONS AND AIDS-RELATED DEATHS ARE NOT BENDING FAST ENOUGH. A FAILURE TO BUILD ON THE GAINS MADE THUS FAR WOULD RESULT IN 7.7 MILLION AIDS-RELATED DEATHS DURING THIS DECADE.

Five critical elements of the Global AIDS Strategy that are needed to strengthen global pandemic prevention, preparedness and response architecture

Community-led and community-based infrastructure. Where public health systems have engaged community-led networks and organizations and empowered those most affected by pandemics, they have been more successful at countering disinformation, ensuring the continuity of health services, and protecting the rights and livelihoods of the most vulnerable.

Equitable access to medicines, vaccines and health technologies. It took decades for HIV tests and medications to become widely available and easily affordable for all who need them. Millions of lives were lost along the way. The vaccine inequalities of today's COVID-19 pandemic echo the treatment inequalities of the early AIDS response. At the beginning of November 2021, just 2% of people in low-income countries were fully vaccinated against COVID-19, compared to 65% in high-income countries (1). In mid-November, the daily number of boosters administered globally (largely in high-income countries) was six times larger than the daily number of primary doses in low-income countries in the 1990s and early 2000s led to the establishment of mechanisms that make generic versions of cutting-edge HIV technologies quickly affordable and accessible. These mechanisms must be strengthened further to ensure that all urgently needed medicines, vaccines, diagnostics and other health technologies are considered as public goods.

Supporting workers on the pandemic front lines. Health workers, social workers, teachers and unpaid caregivers are the heroes of pandemic responses, risking their health to provide care and ensure that basic goods and services remain available. Yet they often work in unsafe and exploitative working conditions, they are chronically underpaid and under-resourced, and they are underappreciated during all but the most acute phases of crises. Elevating essential workers and providing them with the resources and tools they need is critical to keeping them on the job.

Human rights at the centre of pandemic responses. Rights violations undermine trust and drive people away from public health measures. This continues to be a barrier to ending AIDS in many places, and a lack of respect for rights is also undermining COVID-19 measures. Conversely, evidence and experience show that advancing human rights improves public health. Key elements of rights-based pandemic responses that build public trust include limiting the use of criminal law to enforce public health measures, identifying rights violations where they happen, effective judicial and human rights institutions, and independent civil society groups capable of holding governments and other actors accountable.

People-centred data systems that highlight inequalities. In a world awash in data, it is easy to pick and choose the data points that reinforce biases and protect personal and political interests. Pandemic responses should be shaped by the objective triangulation of a wide range of data. The collection, analysis and use of both quantitative and qualitative data—in a way that is ethical and maintains the confidentiality of individuals' private information—is critical to understanding who is most affected during disease outbreaks, who is being reached with services, who is not being reached and why.



A Cambodian man living with HIV has his hands sanitized before a medical check-up. Credit: UNAIDS/S. Dara

A FIVE-YEAR STRATEGY FOR ENDING INEQUALITIES AND ENDING AIDS

Efforts to safeguard and re-energize the global HIV response achieved two major milestones in 2021: the development of a five-year global AIDS strategy and approval by the UN General Assembly of the strategy's focus on inequalities alongside a comprehensive set of global targets for 2025.

The Global AIDS Strategy and the 2025 global targets recognize that HIV thrives on the fault lines of inequalities within and across societies, and they make addressing these inequalities the centrepiece of efforts to banish AIDS to the history books. HIV is not alone in this regard: underlying inequalities are at the heart of the unequal impacts of COVID-19, tuberculosis, malaria, Ebola, cholera and other infectious diseases.

Several key populations—including sex workers, people who inject drugs, prisoners, transgender people and gay men and other men who have sex with men—are at heightened risk of HIV and other life-threatening infections due to their marginalized status in society, the discrimination and violence they experience, and the laws that seek to punish their actions. A new analysis done by UNAIDS shows that the data reported by many countries appear to underestimate the size of key populations, leaving tens of millions of people in greatest need virtually invisible to national HIV plans and programmes (see Chapter 5).

HIV THRIVES ON THE FAULT LINES OF INEQUALITIES WITHIN AND ACROSS SOCIETIES. ADDRESSING THESE INEQUALITIES MUST BE THE CENTREPIECE OF EFFORTS TO BANISH AIDS TO THE HISTORY BOOKS.

In sub-Saharan Africa, adolescent girls and women still far outnumber men and boys among people acquiring HIV infection. However, men in this region are less likely to be reached with HIV testing and treatment services. Poverty and lack of schooling are additional formidable barriers to health and HIV services. Substantial evidence shows that empowering adolescent girls and young women can not only reduce their HIV risk but also confer a broad array of lifelong health and social benefits. Education, in particular, reduces HIV vulnerability while helping build strong, resilient societies, underscoring the importance of national investments in education systems generally—and specifically in measures to help keep girls in school.

The Global AIDS Strategy incorporates decades of experience and evidence into a comprehensive framework of transformative actions to: maximize equitable and equal access to HIV services and solutions; break down barriers to achieving HIV outcomes; and fully resource and sustain efficient HIV responses and integrate them into systems for health, social protection, humanitarian settings and pandemic responses.

Many aspects of the Global AIDS Strategy are also important to help prevent and respond to the pandemics of the future.



The Global AIDS Strategy 2021–2026. Credit: UNAIDS.

ADAPTATIONS AND RESILIENCE GUARD CRITICAL HIV PROGRAMMES

The damage done to HIV programmes by COVID-19 varies across countries. There have been substantial setbacks, particularly during the first six months of the crisis, and people living with HIV are at elevated risk of COVID-19-related morbidity and mortality (see box). There have also been many inspiring examples of adaptation and resilience.

Harm reduction services for people who use drugs, which are the cornerstone of HIV prevention measures among this key population at higher risk of HIV infection, were disrupted in nearly two thirds (65%) of 130 countries surveyed in 2020 (3). Voluntary medical male circumcision (VMMC) programmes were also badly disrupted in 2020, with some countries suspending the procedures altogether. The targets set for VMMC in 15 priority countries in eastern and southern Africa were missed by a large margin, but as social restrictions were relaxed, these programmes encouragingly showed signs of recovery towards the end of 2020 (4). Pre-exposure prophylaxis (PrEP) programmes expanded in 2020, but PrEP access remains far off global targets for this relatively new HIV prevention option.

The pace of HIV testing declined almost uniformly, and available evidence shows that HIV diagnoses decreased and fewer people living with HIV initiated treatment in 2020 in 40 of the 50 countries that reported those data to UNAIDS.

The biggest disruptions were in the first half of 2020, when many countries were in their first lockdowns and HIV programmes were scrambling to adapt. The number of people living with HIV receiving antiretroviral therapy increased by just 1.9% between January and June 2020, from 25.5 million people to 26.0 million people (Figure 1). This was followed by an accelerated 4.9% increase from July 2020 to December 2020, reaching 27.3 million people, and then a 3.4% increase during the first six months of 2021. At the end of June 2021, there were 28.2 million people living with HIV on treatment globally.²

THE BIGGEST DISRUPTIONS TO HIV SERVICES WERE IN THE FIRST HALF OF 2020, WHEN MANY COUNTRIES WERE IN THEIR FIRST LOCKDOWNS AND HIV PROGRAMMES WERE SCRAMBLING TO ADAPT.

FIGURE 1. Percentage change in the number of people living with HIV on antiretroviral therapy, global, January 2019–June 2021



Source: UNAIDS special analysis, 2021.

In many places, the upheaval caused by COVID-19 has summoned the inventiveness and resilience that have become hallmarks of the HIV response. Programmes that are well-resourced, willing to adapt and anchored in strong community involvement have tended to cope the best. COVID-19 movement restrictions necessitated an acceleration of multimonth dispensing by national HIV treatment programmes, and the approach has been a resounding success, enabling people to continue taking their HIV medicines despite service disruptions. Similarly, take-home doses for opioid substitution therapy in the United Kingdom of Great Britain and Northern Ireland have decreased stigma and improved treatment adherence for people who inject drugs (5).

Trusting affected communities has consistently proved to be a winning strategy. HIV treatment and other critical services were preserved by shifting to community-centred and other forms of differentiated services, and using telehealth and virtual platforms for information and support. Community pick-up schemes and sites were set up, home delivery services were arranged and treatment support was shifted online.

In seven eastern and southern African countries, for example, 2500 HIV treatment sites supported by the United States President's Emergency Plan for AIDS Relief (PEPFAR) serving 1.8 million people living with HIV provided antiretroviral medicine refills at community facilities, dispensed greater amounts of the drugs to cover longer periods of treatment (typically six months rather three months), and established social distancing and other preventive measures at clinics (6).³ In six of the seven countries, these adjustments actually reduced the percentage of patients who experienced treatment interruptions. Across all seven countries, in the quarter before the lockdowns, 23% more patients experienced treatment interruptions than was the case during lockdowns, while in the quarter after the lockdowns, treatment interruptions declined a further 10% from the number of interruptions during lockdowns.

In Uganda, a combination of community-centred approaches was used, including multimonth dispensing of antiretroviral medicines, community drug pick-up points and communal drug collection (where people form small groups and alternate collecting everyone's antiretroviral medicine) (7). In western and central Africa, Nigeria's Antiretroviral Therapy Surge initiative succeeded in boosting HIV treatment coverage and quality despite COVID-19 disruptions (see feature story).

Prior to the COVID-19 crisis, many countries resisted World Health Organization (WHO) recommendations for multimonth dispensing of antiretroviral medicines, arguing that they were too complex and risky to implement. This hand-wringing and foot-dragging echoed unfounded concerns expressed decades earlier, when antiretroviral medicines were cruelly withheld from sub-Saharan Africa and other low-income settings over fears that their health systems were too weak and their patients too uneducated and undisciplined to manage the daily dosing of HIV treatment.

COVID-19-related disruptions to the production and distribution of antiretroviral medicine threatened to cause stock-outs and constrained the expansion of multimonth dispensing in some countries. Customs data from India show that there were significant reductions in shipments of generic antiretroviral medicines to low-income and lower-middle-income countries in March–June 2020, when many countries were in their first lockdowns. The volumes of exports from India recovered and increased in late 2020 (8). The impact of COVID-19 in 2020 and the emergence of the SARS-CoV-2 Delta variant in India and its global spread in 2021 appeared to change patterns and levels of orders for generic antiretroviral medicines from low- and middle-income countries compared to previous years, but it did not impact the delivery of orders that were placed in the first eight months of 2021 (8).

Mounting evidence that people living with HIV face higher COVID-19 risks

A fuller picture is emerging of the interplay between HIV infection and SARS-CoV-2 infection, and of COVID-19 vaccine response in people living with HIV. A strong body of evidence—from South Africa, the United Kingdom and the United States of America—indicates that people living with HIV who acquire SARS-CoV-2 infection are at heightened risk of serious illness and death (9–15). The risk is especially high for people who are not controlling their HIV infection with antiretroviral therapy (16, 17).

A recent large study based on data from 5.8 million people at 54 clinical sites in the United States addressed potentially confounding factors by adjusting for comorbidities, demographic characteristics and lifestyle factors. It found that living with HIV was associated with a 20% higher risk of being hospitalized for COVID-19 infection and a 29% higher risk of COVID-19 mortality (*18*). The finding is broadly echoed in a meta-analysis of 84 studies from Africa, Asia, the Americas and Europe (*19*).

There is also growing evidence that the risk of adverse outcomes among people living with HIV is highest among those who have low CD4 cell counts or detectable HIV viral loads (18, 20–22). This underscores the importance and multiple benefits of successful HIV treatment. Of note, though, are findings from another study, indicating that people living with HIV and with low CD4 cell counts may be at higher risk of poor COVID-19 outcomes even if they are virally suppressed (23). This suggests that people who have recently started HIV treatment or those who have experienced low CD4 cell counts for long periods may need closer observation if they acquire COVID-19. The United States Centers for Disease Control and Prevention recommends a COVID-19 vaccine booster for people with advanced or untreated HIV (24).

There is no evidence that HIV infection may be associated with adverse reactions to current COVID-19 vaccines. There is conflicting study evidence, however, on whether people living with HIV may have weaker vaccine-induced antibody responses. Several studies have found no such difference (25–28). However, a recent study from the United States has reported a lower vaccine-induced antibody response in people living with HIV than in HIV-negative people, with the effect seeming to differ depending on the vaccine (29). The response was poorest in people with unsuppressed HIV infections. Antibodies, though, are not the only determinant of vaccine response, and this study did not measure T-cell responses.

COVID-19 CRISIS AGGRAVATES INEQUALITIES

While many HIV programmes have proved resilient during the COVID-19 crisis, the wider damage done by the pandemic—most acutely felt by populations that are already disadvantaged—threatens to undermine global efforts to end the AIDS pandemic by 2030.

COVID-19 has pushed back gender equality by at least a generation, according to the World Economic Forum. Based on current trends, it will take nearly 136 years to close the global gender gap, up from 100 years before COVID-19. Job and income losses during the pandemic have been higher among women, and their unpaid care burdens have increased (30). Dozens of studies have documented increases in violence against women and girls during the pandemic; that increased violence—along with physical and emotional harm—is also associated with increased risk of HIV infection and worse health outcomes for women living with HIV (31–33). A rapid assessment of the impact of the COVID-19 pandemic in six countries in 2020 revealed that access to sexual and reproductive health rights services had been disrupted (34).⁴ Schooling also has been interrupted at some point for most children in the world, and it is projected that 11 million girls may never return to school following the COVID-19 pandemic (35).

Social protection was temporarily expanded in many countries as entire employment sectors were shut down, but the assistance missed many of the poorest and most vulnerable people. As incomes plummet and food prices rise, food insecurity is increasing: around one in three people globally (2.4 billion people) did not have access to adequate food in 2020, an increase of 320 million people in one year, according to the UN Food and Agriculture Organization (*36*). Food insecurity also negatively impacts people living with HIV, including HIV treatment adherence (*37*).



A staff member from the civil society organization Diálogo Diverso hands out condoms to migrants from the Bolivarian Republic of Venezuela. Based in Quito, Ecuador, Diálogo Diverso works on the protection and promotion of human rights, with an emphasis on gender and lesbian, gay, bisexual, transgender and intersex (LGBTI) people. Credit: UNAIDS

PANDEMIC PREPAREDNESS AND RESPONSE LESSONS

The task of ending the AIDS pandemic has grown during the past two years. The challenges faced during the COVID-19 crisis and efforts to overcome them have also highlighted some of the core elements of success for pandemic responses. The course corrections called for in the Global AIDS Strategy will not only end AIDS by 2030; they are also needed to protect the world against future pandemics. The AIDS strategy's focus on inequalities recognizes that the people and communities at highest risk must be placed at the centre of pandemic responses. No one is safe until everyone is safe.

History also underscores the fundamental importance of having enough reliable funding to manage and sustain effective pandemic responses. The most resilient HIV programmes during the COVID-19 crisis have been the ones with dependable funding and a strong core of public health professionals who work closely with community leaders. More, not less, ambitious health spending is a priority if the world is to bring the COVID-19 pandemic under control and end the HIV and tuberculosis pandemics (*38*).

There is a stark danger of once again repeating the mistakes of the past, where short-term economic growth, the market shares of corporate giants and personal political futures of government leaders are prioritized over the greater long-term good that can be achieved when public health systems are given the resources and support they need to respond to health crises, and where communities are constructively engaged to confront inequalities and ensure that no one is left behind by the responses to AIDS, COVID-19 and other pandemics.

As pandemic prevention, preparedness and response negotiations continue in 2022, five critical elements of the Global AIDS Strategy require greater attention by world leaders: (1) community-led and community-based infrastructure; (2) equitable access to medicines, vaccines and health technologies; (3) supporting workers on the pandemic front lines; (4) human rights at the centre of pandemic responses; and (5) people-centred data systems that highlight inequalities. The stakes for people living with HIV and those at elevated risk of infection are incredibly high. They are among the most vulnerable, but they are not alone: the rapid spread of SARS-CoV-2 and the broad impacts of COVID-19 are a global tragedy affecting almost everyone. This crisis, however, is also an unprecedented opportunity to learn from past mistakes and mobilize the leadership and investment needed for a comprehensive global framework that can end inequalities, end AIDS and end pandemics.

COVID-19 IS A TERRIBLE CRISIS. IT IS ALSO AN UNPRECEDENTED OPPORTUNITY TO LEARN FROM PAST MISTAKES AND MOBILIZE THE LEADERSHIP AND INVESTMENT NEEDED FOR A COMPREHENSIVE GLOBAL FRAMEWORK THAT CAN END INEQUALITIES, END AIDS AND END PANDEMICS.

FEATURE STORY: AGILE ADAPTATIONS DURING TREATMENT SURGE IN NIGERIA

The COVID-19 pandemic hit Nigeria in the middle of an intensive effort to accelerate coverage of antiretroviral therapy among people living with HIV. What happened next was an inspiring example of how a robust, community-centred HIV programme can steer around disruptions associated with the COVID-19 pandemic.

The PEPFAR-supported Nigeria Antiretroviral Therapy Surge initiative began in April 2019 with an 18-month objective of increasing by 500 000 the number of people living with HIV in 10 Nigerian states and territories receiving PEPFAR-supported treatment (*39*).⁵

Diagnosing people living with HIV has been a particularly big challenge in Nigeria's treatment programme due to low health facility attendance, especially in low-income rural settings. To overcome this challenge, the Surge used recent national survey data to focus on areas with large numbers of undiagnosed people living with HIV, an HIV risk-screening tool and index testing to accelerate HIV diagnoses, and several supportive strategies to rapidly link the newly diagnosed to treatment (40).

Community-based testing, active linkage to care, immediate treatment initiation and provision of 30-day "starter packs" of antiretroviral medicines achieved impressive gains within a short period of time. In the 10 states and territories, the weekly number of HIV tests conducted increased by 518% from April 2019 to March 2020, the weekly number of positive test results increased by 239%, and the weekly number of newly identified people living with HIV who initiated treatment increased by 272% (Figure 2) (41). The total number on treatment in the 10 states and territories increased by 43% during the first year of the Surge, to a total of 559 488 (41).



Health-care workers braving treacherous terrains to deliver services to clients in hard-to-reach locations, en route to General Hospital, Ngo, Andoni Local Government Area (LGA), Rivers State, Nigeria. Credit: PEPFAR Nigeria

When COVID-19-related restrictions began affecting health facility attendance in early 2020, Surge programme managers doubled down on community-centred approaches. Outreach teams worked with local community organizations to tailor HIV education, screening, counselling and testing to comply with COVID-19 restrictions, and to make it easier to receive and stay on HIV treatment (42). People starting HIV treatment were given 90-day supplies of antiretrovirals to reduce health facility visits. Additional community pick-up points were set up for antiretroviral distribution, and people were sent mobile phone messages with refill reminders and the addresses of nearby collection points. Multimonth (three to six month) dispensing of antiretrovirals was also expanded to everyone already on HIV treatment. COVID-19 mitigation measures included the provision of face masks for staff members, enhanced hand hygiene by staff members and clients during clinical visits, and physical distancing measures (43). Most of the adaptations were in place by April 2020 (44).

The proportion of people diagnosed in their communities (rather than at health facilities) grew from 67% in March 2020 to 80% in September 2020, 90% of people on treatment had multimonth prescriptions for antiretroviral medicines, and almost all medication refill pick-ups were on time (41). By May 2020, Surge activities returned to pre-pandemic levels (i.e., prior to late March 2020) and they have continued to increase: during the period of April to September 2020, 161 444 people initiated treatment and the total number of people on treatment increased by a further 29% to 720 932 (41).





Week of antiretroviral therapy initiation

Newly identified people living with HIV who initiated antiretroviral therapy

Note: Nine Nigerian states participated in the Antiretroviral Therapy Surge Initiative: Akwa Ibom, Benue, Delta, Enugu, Gombe, Imo, Lagos, Nasarawa and Rivers. One territory also participated: the Federal Capital Territory.

Note: On 27 February 2020, the Nigeria Centre for Disease Control confirmed the first confirmed COVID-19 case. It activated an Emergency Operations Center on 28 February. Following that, the Government of Nigeria implemented COVID-19 mitigation efforts, including school closures (beginning 19 March), international travel bans (beginning 23 March) and statewide stay-at-home orders (beginning 30 March).

Source: Dirlikov E, Jahun I, Odafe SF, Obinna O, Onyenuobi C, Ifunanya M et al. Rapid scale-up of an antiretroviral therapy program before and during the COVID-19 pandemic—nine states, Nigeria, March 31, 2019–September 30, 2020. MMWR Morb Mortal Wkly Rep. 2021;70(12):421–6.

REFERENCES

- 1. Our World in Data [database]. Our World in Data; c2021 (https://ourworldindata.org/covid-vaccinations).
- 2. Kutlu O. WHO head says there is "scandal" in global coronavirus vaccine inequity. In: Anadolu Agency [Internet]. 13 November 2021. Anadolu Agency; c2021 (https://www.aa.com.tr/en/health/who-head-says-there-is-scandal-in-global-coronavirus-vaccine-inequity/2419607).
- 3. The impact of COVID-19 on mental, neurological and substance use services [Internet]. Geneva: WHO; 2020 (https://www.who.int/publications/i/item/978924012455).
- 4. Peck M, Ong K, Lucas T, Kiggundu V, Thomas A, Chandler S et al. Characterizing the effect of the COVID-19 pandemic on PEPFAR-supported voluntary medical male circumcision services, 2020. International AIDS Society Conference, 18–21 July 2021. Abstract 760.
- 5. EuroNPUD. Take home opiate substitution therapies. Advocacy brief. 2020 (https://www.dropbox.com/s/s0y4hrvacf4q1f2/EuroNPUD%20Take%20Home%20 OST%20Advocacy%20Brief%20UK.pdf?dl=0).
- 6. Mehta N, Stewart A, Fisher K, Ghosh S, Santos L, Harvey P et al. Impact of COVID-19 on HIV treatment interruption in seven PEPFAR countries, April–June 2020. International AIDS Society Conference, 18–21 July 2021. Abstract 2641.
- 7. Zakumumpa H, Makobu K, Ntawiha W, Maniple E. A mixed-methods evaluation of the uptake of novel differentiated ART delivery models in a national sample of health facilities in Uganda. PLoS One. 2021;16(7):e0254214.
- 8. UNAIDS analysis of Indian customs data obtained from Seair Exim solutions, 2020–2021.
- Western Cape Department of Health in collaboration with the National Institute for Communicable Diseases, South Africa. Risk Factors for Coronavirus Disease 2019 (COVID-19) Death in a Population Cohort Study from the Western Cape Province, South Africa. Clin Infect Dis. 2021 Oct 5;73(7):e2005-e2015.
- Sabin C, Raya R, Curtis H, Water L, Chadwick D; BHIVA COVID Registry Working Group. Coronavirus (COVID)-19 in people with HIV in the UK: initial findings from the BHIVA COVID-19 Registry. Fifth Joint Conference of the British HIV Association and the British Association for Sexual Health and HIV, 19–21 April 2021. Abstract 08.
- 11. Bhaskaran K, Rentsch CT, MacKenna B, Schulze A, Mehrkar A, Bates CJ et al. HIV infection and COVID-19 death: a population-based cohort analysis of UK primary care data and linked national death registrations within the OpenSAFELY platform. Lancet HIV. 2021;8(1):e24-e32.
- 12. Geretti AM, Stockdale AJ, Kelly SH, Cevik M, Collins S, Waters L et al. Outcomes of COVID-19 related hospitalization among people with HIV in the ISARIC WHO Clinical Characterization Protocol (UK): a prospective observational study. Clin Infect Dis. 2020 Oct 5;73(7):e2095-e2106.
- Yendewa GA, Perez JA, Schlick KA, Tribout HA, McComsey GA. Characterizing COVID-19 presentation and clinical outcomes in HIV patients in the US. Conference on Retroviruses and Opportunistic Infections, 6–10 March 2021. Abstract 548.
- 14. Spinelli MA, Brown LB, Glidden DV, Hunter K, Martin-Tuite P, Zheng J et al. SARS-CoV-2 incidence, testing rates, and severe COVID-19 outcomes among people with and without HIV. AIDS. 2021;35:2545-7.
- 15. Clinical features and prognostic factors of COVID-19 in people living with HIV hospitalized with suspected or confirmed SARS-CoV-2 infection. Geneva: WHO; 2021.
- Ambrosioni J, Blanco JS, Reyes-Uruena JM, Davies M, Sued O, Marcos MA et al. Overview of SARS-CoV-2 infection in adults living with HIV. Lancet HIV. 2021;8(5):e294-e305.
- Del Amo J. Does HIV impact COVID-19 susceptibility or severity? Conference on Retroviruses and Opportunistic Infections, 6–10 March 2021. Abstract 31.
 Yang X, Sun J, Patel RC, Zhang J, Guo S, Zheng Q et al. Associations between HIV infection and clinical spectrum of COVID-19: a population level analysis
- based on US National COVID Cohort Collaborative (N3C) data. Lancet HIV. 2021;8(11):e690-e700.
- Wang Y, Feng R, Xu J, Shi L, Feng H, Yang H. An updated meta-analysis on the association between HIV infection and COVID-19 mortality. AIDS. 2021;35:1875-80.
- Nomah DK, Reyes-Urueña J, Díaz Y, Moreno S, Aceiton J, Bruguera A et al. Sociodemographic, clinical and immunological factors associated with SARS-CoV-2 diagnosis and severe COVID-19 outcomes in people living with HIV: a retrospective cohort study. Lancet HIV. 2021;8(11):e701-e710.
- 21. Sigel K, Swartz T, Golden E, Paranjpe I, Somani S, Richter F et al. Coronavirus 2019 and people living with human immunodeficiency virus: outcomes for hospitalized patients in New York City. Clin Infect Dis. 2020;71(11):2933-8.
- 22. Jassat W, Cohen C, Tempia S, Masha M, Godlstein S, Kufa T. Risk factors for COVID-19-related in-hospital mortality in a high HIV and tuberculosis prevalence setting in South Africa: a cohort study. Lancet HIV. 2021;8(9):e554-e567.
- Dandachi D, Geiger G, Montgomery MW, Karmen-Tuohy S, Golzy M, Antar AAR et al. Characteristics, comorbidities and outcomes in a multicenter registry of patients with human immunodeficiency virus and coronavirus disease 2019. Clin Infect Dis. 2021;73(7):e1964-e1972.
- 24. COVID-19 Vaccines for Moderately to Severely Immunocompromised People. In: US Centers for Disease Control and Prevention [Internet]. 18 October 2021. Atlanta (GA): US CDC; c2021 (https://www.cdc.gov/coronavirus/2019-ncov/vaccines/recommendations/immuno.html).
- Madhi S, Koen A, Fairlie L, Cutland C, Baillie V, Padayachee S et al. ChAdOx1 n CoV-19 (AZD1222) vaccine in people living with and without HIV. 2021. Pre-print.
 Frater J, Ewer K, Ogbe A, Pace M, Adele S, Adland E et al. Safety and immunogenicity of the ChAdOx1 nCoV-19 (ZAD1222) vaccine against SARS-CoV-2 in HIV infection. Lancet. 2021;19 April. Pre-print.
- Ruddy J, Boyarsky B, Bailey J, Karaba A, Garonzik-Wang J, Jacqueline M et al. Safety and antibody response to two-dose SARS-CoV-2 messenger RNA vacination in persons with HIV. AIDS. 2021;35(14):2399-401.
- 28. Woldemeskel B, Karaba A, Garliss C, Beck E, Wang K, Laeyendecker O et al. The BNT162b2 mRNA vaccine elicits robust humoral
- and cellular immune responses in people living with Human Immunodeficiency Virus (HIV). Clin Infec Dis. 2021;ciab648.
- 29. Spinelli M. Lower SARS-CoV-2 IgG and pseudovirus neutralization titers post-mRNA vaccination among people living with HIV. IDWeek 2021, 29 September–3 October. Abstract LB8.
- 30. Global gender gap report 2021. Geneva: World Economic Forum; 2021 (https://www3.weforum.org/docs/WEF_GGGR_2021.pdf).
- 31. Bourgault S, Peterman A, O'Donnell M. Violence against women and children during COVID-19—one year on and 100 papers in. A fourth research round-up. Washington (DC): Center for Global Development; 2021 (https://www.cgdev.org/sites/default/files/vawc-fourth-roundup.pdf).
- 32. Global and regional estimates of violence against women: prevalence and health effects of intimate partner violence and non-partner sexual violence. Geneva: WHO; 2013.
- Hatcher AM, Smout EM, Turan JM, Christofides N, Stöckl H. Intimate partner violence and engagement in HIV care and treatment among women: a systematic review and meta-analysis. AIDS. 2015;29(16):2183-94.
- 34. Missing in action: COVID-19 response funding for gender-based violence and sexual and reproductive health in five countries. New York (NY): Global Health Justice and Governance Programme at Columbia University; 2020 (https://www.publichealth.columbia.edu/sites/default/files/multi-country_funding_2-pager_9_april_2021.pdf).
- 35. Addressing the gender dimensions of COVID-related school closures. Geneva: UNESCO; August 2020 (https://unesdoc.unesco.org/ark:/48223/pf0000373379).
- 36. The state of food security and nutrition in the world 2021. Rome: Food and Agriculture Organization; 2021 (https://www.fao.org/3/cb4474en.html).
- 37. McLinden T, Stover S, Hogg RS. HIV and food insecurity: a syndemic amid the COVID-19 pandemic. AIDS Behav. 2020;24:2766-9.
- Korowski C, Evans DB, Tandon A, Eozenou PH-V, Schmidt M, Irwin A et al. From double shock to double recovery: implications and options for health financing in the time of COVID-19. Washington (DC): World Bank; 2021 (https://openknowledge.worldbank.org/handle/10986/35298).
- Jahun I, Said I, El-Imam I, Ehoche A, Dalhatu I, Yakubu A et al. Optimizing community linkage to care and antiretroviral therapy initiation: lessons from the Nigeria HIV/AIDS Indicator and Impact Survey (NAIIS) and their adaptation in Nigeria ART Surge. PLoS ONE. 2021;16(9):e0257476.
- 40. Jahun I, Dirlikov E, Odafe S, Yakubu A, Boyd AT, Bachanas P et al. Ensuring optimal community HIV testing services in Nigeria using an enhanced community case-finding package (ECCP), October 2019–March 2020: acceleration to HIV epidemic control. HIV AIDS (Auckl). 2021 Aug 25;13:839-50.
- 41. Data provided to UNAIDS by the PEPFAR team in Nigeria, 16 November 2021.
- 42. Boyd AT, Ogbanufe O, Onyenuobi C, Mgbakor I, Bachanas P, Olupitan O et al. Scale-up of antiretroviral treatment access among people living with HIV in Rivers State, Nigeria, 2019–2020. AIDS. 2021;35(7):1127-34.
- 43. Dirlikov E, Jahun I, Odafe SF, Obinna O, Onyenuobi C, Ifunanya M et al. Rapid scale-up of an antiretroviral therapy program before and during the COVID-19 pandemic—nine states, Nigeria, March 31, 2019–September 30, 2020. MMWR Morb Mortal Wkly Rep. 2021;70(12):421-6.
- 44. Boyd AT, Jahun I, Dirlikov E, Greby S, Odafe S, Abdulkadir A et al. Expanding access to HIV services during the COVID-19 pandemic—Nigeria, 2020. AIDS Res Ther. 2021;18(1):62.



The social landscapes in which viruses spread and pandemic responses operate are diverse, complex and turbulent. Failures to reach critical parts of the population contribute to outbreaks becoming epidemics, and epidemics becoming pandemics. Top-down deployment of public health measures that are inconvenient, disrupt livelihoods or challenge social mores can be undermined by misinformation, fear, doubts and stigma that paralyze a pandemic response (1).

Civil society and community-based organizations, especially those led by people most often excluded or poorly served, can complement traditional health systems' pandemic responses in three key roles: providing services; bringing community insights to planning and decisions; and supporting accountability.

In both the AIDS and COVID-19 pandemics, national programmes have struggled to contend with rumours, misinformation, mistrust and stigma. In many of the most effective AIDS responses, community-led organizations have been engaged to convey evidence-informed prevention and treatment information relevant to different perspectives, and to set up HIV services for key populations experiencing discrimination. People living with HIV and key populations have secured a seat at the decision-making table, while civil society advocacy and community-led monitoring have improved HIV services. Over time, a patchwork of community organizations have matured into a community-led infrastructure essential to every aspect of the pandemic response.

To get the AIDS response on track, full engagement of this community-led infrastructure must become universal. In 2021, United Nations (UN) Member States committed in the UN General Assembly's Political Declaration on Ending AIDS to increase inclusion in decision-making and the proportion of HIV services delivered by communities, strengthen the community health workforce, and support the collection of community-generated data to protect rights and meet the needs of people living with, at risk of and affected by HIV.

From COVID-19 to Ebola and beyond, this community-led and community-based infrastructure has proved similarly important. It is not a substitute for the state, but rather an effective way to extend the scope and depth of interventions and make pandemic responses more inclusive, equitable and sustainable.

Yet this community-led infrastructure is rarely included in the essentials of pandemic preparedness.

THE MOST SUCCESSFUL AIDS PANDEMIC RESPONSES UNDERSTAND THAT PEOPLE PLACE GREATER TRUST IN THEIR OWN COMMUNITIES THAN THEY DO IN GOVERNMENT AUTHORITIES. ORGANIZATIONS OF AFFECTED COMMUNITIES MUST BE TREATED AS FULL PARTNERS—INVOLVED IN GOVERNING, DESIGNING, PLANNING AND BUDGETING PANDEMIC RESPONSES—AND THEY NEED THE TECHNICAL AND FINANCIAL SUPPORT TO DO SO EFFECTIVELY.

THE HARD LESSONS OF EBOLA AND HIV

During the early days of the 2014–2016 Ebola crisis in West Africa, containment efforts were imposed top-down, without engaging communities. Some of those public health measures were economically harmful and clashed with local social customs, triggering a backlash. Over time, insights from community-level health workers fed back into response strategies, facilitated by networks of social scientists, but precious time and many lives were lost before the epidemic response shifted to more community-engaged—and effective—approaches (2).¹ A more inclusive process that focused on building understanding and trust could have limited the resentment and disarray (3).

Decades earlier, HIV responses faltered when they neglected the realities and rights of affected communities and prioritized patent protections over people. Community-led organizations ultimately forced their way into the decision-making processes and arenas, as ACT-UP did in the United States of America and Europe, and the Treatment Action Campaign did in South Africa. Like their counterparts in other countries, these organizations pressured planners into adopting human rights-based approaches, accelerating drug development and approval, implementing interventions at the community level, and tackling the disabling effects of stigma and discrimination. They ensured that the harsh realities of unaffordable prices and unequal access to life-saving HIV treatment remained centre stage until new pricing deals were struck, patent restrictions were relaxed, manufacturing of less expensive generic drugs increased, and global accountability mechanisms were established.

Today, the active participation of community-led organizations in the governance, planning and implementation of national HIV responses is the rule in many countries. They sit on national AIDS councils and the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) Country Coordinating Mechanisms. Sex workers, transgender people and gay men and other men who have sex with men are engaged in the development of national policies, guidelines and strategies related to their health in the majority of countries that have reported to UNAIDS in recent years. The engagement of other key populations—people who inject drugs and people currently or formerly in prison—is less common (Figure 3). At the global level, community-led organizations and networks are members of the UNAIDS Programme Coordinating Board and the Global Fund Board, and they are engaged in the decision-making processes of the United States President's Emergency Plan for AIDS Relief (PEPFAR), the world's largest bilateral HIV programme.

HIV RESPONSES FALTERED WHEN THEY NEGLECTED THE REALITIES AND RIGHTS OF AFFECTED COMMUNITIES AND PRIORITIZED PATENT PROTECTIONS OVER PEOPLE. COMMUNITY-LED ORGANIZATIONS ENSURED THAT THE HARSH REALITIES OF UNAFFORDABLE PRICES AND UNEQUAL ACCESS TO LIFE-SAVING HIV TREATMENT REMAINED CENTRE STAGE.

1. For more information, see: Jedwab R, Khan AM, Russ J, Zaveri ED. Epidemics, pandemics, and social conflict: lessons from the past and possible scenarios for COVID-19. World Development. 2021;147:105629.

FIGURE 3. Countries reporting participation of key populations in developing national policies, guidelines and/or strategies relating to their health, global, 2017–2021



Source: National Commitments and Policy Instrument, 2017-2021.



Young people gather at a Teenergizer event in Kyiv, Ukraine. Teenergizer provides peer support to adolescents living with HIV and HIV prevention and counselling services to young people in eastern European and central Asian countries. Credit: Teenergizer

A SLOW START TO COMMUNITY ENGAGEMENT DURING COVID-19

National COVID-19 responses risk undervaluing nonhealth and nongovernment expertise that can reveal insights into the challenges, concerns and needs of affected populations.

As much of the world entered its first lockdown in April 2020, a rapid analysis of the governance structures for COVID-19 responses in 24 countries found that civil society was hardly involved in decision-making and response efforts at the national government level (4). The analysis determined that the researchers consulted were largely epidemiologists and virologists, leaving out specialists in areas such as mental health, child health, chronic diseases, preventive medicine, gerontology and other nonhealth spheres. It also found that there were low percentages of female experts on national COVID-19 task forces, despite the fact that the majority of front-line health staff are women (5).

Nearly a year later, a deeper analysis of the COVID-19 responses of nine countries found that some leveraged the potential of civil society and effectively reduced the consequences of the crisis while also increasing a sense of solidarity and belonging within their societies (6). In other countries, the government attempted to play the role of heroic saviour and exclusive problem-solver, grabbing for itself both symbolic gains and an increased concentration of power (6).²



A young man from Let's Walk Uganda prepares supplies. The community-led organization's Jump Start Project is equipping gay men and other men who have sex with men living in three urban slums in Kampala with the necessary skills to start, manage and maintain a social business. Credit: UNAIDS

Approaches that ignore the diverse realities and disparities in societies have blind spots that often trip them up. Lockdowns, masking and social distancing measures for COVID-19 are relatively easy for people who can work from home, who live and work in uncrowded conditions, and who do not rely on public transport. Similarly, avoiding acquiring HIV is easier for people who have ready access to relevant information and prevention services, who control their sexual lives, and who do not face stigma and discrimination in their day-to-day lives. By contrast, those who struggle to make ends meet and who are victimized, harassed and pushed to the margins are often left behind and further marginalized by pandemic response measures.

Community-led organizations are more likely to understand the diverse needs and concerns of local communities. Because they are rooted in and trusted by those communities, they are better placed to develop and introduce effective, collective responses, and to increase the accountability of those responses, especially to those already pushed to the margins (7, 8). They are also crucial for preserving and adapting interventions when other crises hit.

In parts of Africa and Asia, community-led organizations are serving as bridges to marginalized communities (9). They take COVID-19 screening, testing and contact tracing into underserviced areas, perform those services in ways that respect people's different realities and concerns, and link communities to formal health services.

In Malawi and southern Mozambique, community organizations worked with local government authorities to link returning migrant workers to testing services, provide them with food and other support while they were quarantined, and perform contact tracing where necessary (8, 10). In Sao Paolo's Paraisópolis favela, "block presidents" monitored the health and well-being of households, while locally trained volunteers publicized precautionary methods and provided emergency care (11). A review of similar efforts across 14 cities in Latin America found that many of the activities became networked and linked into multilevel alliances between organizations, enabling information, resources and lessons to be shared (12).

AS MUCH OF THE WORLD ENTERED ITS FIRST LOCKDOWN IN APRIL 2020, CIVIL SOCIETY WAS HARDLY INVOLVED IN DECISION-MAKING AND RESPONSE EFFORTS AT THE NATIONAL GOVERNMENT LEVEL. THERE WERE LOW PERCENTAGES OF FEMALE EXPERTS ON NATIONAL COVID-19 TASK FORCES, DESPITE THE FACT THAT THE MAJORITY OF FRONT-LINE HEALTH STAFF ARE WOMEN. For instance, by working through networks of local community groups and leaders, the Philippines Homeless People's Federation compiled local databases of people in need in 14 cities, distributed food supplies and other relief, set up community kitchens, provided information and protective equipment for avoiding COVID-19 infection, and coordinated with local governments to get ill homeless people to health facilities (13, 17). Similarly, Community Action Networks in South Africa organized volunteers to staff community kitchens and prepare winter care packages for homeless people, and they used social media groups to stay in contact with people in need (14). Other initiatives in India and South Africa linked small-scale farmers, community food gardens and local restaurants with volunteer operations delivering food to households in need (15, 16).

The values and approaches of these collective actions—their emphasis on rights, equity and solidarity—are essential to preventing pandemic responses from mirroring and reinforcing existing inequities. But for these admirable efforts to have maximum effect, they have to link and become integrated with overarching pandemic strategies, a feat that distinguishes some of the most effective HIV programmes.



Beneficiaries of the Balaio Project receive provisions at a community-based distribution point. The Balaio Project, an initiative of the Barong Cultural Institute supported by UNAIDS Brazil, provides antiretroviral medicines, food, hygiene kits, fuel and social assistance to people living with HIV in Sao Paulo. Credit: A Bertini

COMMUNITY GROUPS HELP KEEP HIV SERVICES RUNNING IN THE COVID-19 ERA

The quick action and resourcefulness of community-led organizations helped many HIV services adjust to the disruptions of COVID-19 lockdowns. Linking with formal health-care providers, they supplemented and adapted HIV services as health staff were redeployed and hospitals and clinics were overrun with COVID-19 cases.

From Colombia to Côte d'Ivoire, Thailand to the United Republic of Tanzania, community-led groups organized to take antiretroviral and tuberculosis medicine to people's homes or local drop-in centres, delivered condoms and HIV self-testing kits to safe community distribution points, linked people in distress to emergency support, and supplied food and other essentials. They improvised and maintained referrals and linkage to care, shifted in-person peer support to social media platforms and mobile phone communication, and used outreach teams to track and trace patients who may be defaulting on treatment (18–24). These kinds of interventions helped millions of people stay on treatment in Africa, Asia, Latin America and the Caribbean as the COVID-19 pandemic spread. Most of these examples have included some level of cooperation or partnership with state authorities, usually at the city or local level—a reminder of the importance of partnering and combining resources and capacities (8).

The International Treatment Preparedness Coalition adapted its Community Treatment Observatory model to rapidly implement short-term, community-led monitoring and advocacy to assess the impact of COVID-19 restrictions on the access to—and quality of—HIV and tuberculosis treatment, and on other health and human rights provisions (24).

Community groups and networks of key populations in dozens of countries have been working closely with their communities to provide essential supplies, information, and HIV testing and treatment services. Iloilo Pride Team in the Philippines are delivering antiretroviral medicines and providing relief packages for gay men and other men who have sex with men. They are also facilitating referrals to testing centres and treatment hubs for testing and treatment for HIV and other sexually transmitted infections (25). Beirut Tayf, in Lebanon, launched an online mental health clinic, and volunteers equipped with personal protective equipment (PPE) are delivering food baskets and sanitation supplies to gay communities (25). In Peru, Red Trans is providing food baskets for transgender women living with HIV and sex workers, two groups who are impoverished and at greater risk. They are also coordinating home delivery of medicines through a rapid text programme (25).

Trusting affected communities has consistently proved to be a winning strategy for HIV programmes. Under the additional challenges of COVID-19, community-led organizations are again proving their essential role in public health and pandemic responses.

COMMUNITIES AND NETWORKS OF KEY POPULATIONS IN DOZENS OF COUNTRIES HAVE BEEN WORKING CLOSELY WITH THEIR COMMUNITIES TO PROVIDE ESSENTIAL SUPPLIES, INFORMATION, AND HIV TESTING AND TREATMENT SERVICES.

REFERENCES

- 1. Johnson O, Goronga T. Why communities must be at the centre of the Coronavirus Disease 2019 response: lessons from Ebola and human immunodeficiency virus in Africa. Afr J Prim Health Care Fam Med. 2021;12(1):a2496.
- Leach M, MacGregor H, Scoones I, Wilkinson A. Post-pandemic transformations: how and why COVID-19 requires us to rethink development. World Dev. 2021;138:105233.
- Cohn S, Kutalek R. Historical parallels, Ebola virus disease and cholera: understanding community distrust and social violence with epidemics. PLoS Curr. 2016;8:ecurrents.outbreaks.aa1f2b60e8d43939b43fbd93e1a63a94.
- 4. Rajan D, Koch K, Rohrer K, Bajnoczki C, Socha A, Voss M et al. Governance of the COVID-19 response: a call for more inclusive and transparent decisionmaking. BMJ Global Health. 2020;5(5):e002655.
- Women in Global Health. Operation 50/50: women's perspectives save lives, 2020 (https://c8fbe10e-fb87-47e7-844b-4e700959d2d4.filesusr.com/ugd/ ffa4bc_aa83e933b1294558a11df9172afd926a.pdf?index=true).
- 6. Kövér Á. The relationship between government and civil society in the era of COVID-19. Nonprofit Policy Forum. 2021;12(1):1-24.
- 7. Marston C, Renedo A, Miles S. Community participation is crucial in a pandemic. Lancet. 2020;395(10238):1676-8.
- Loewenson R, Colvin CJ, Szabzon F, Das S, Khanna R, Schattan V et al. Beyond command and control: a rapid review of meaningful community-engaged responses to COVID-19. Glob Public Health. 2021;6(8-9):1439-53.
- 9. Community-led package services in response to COVID-19 in high density settlements: resource needs. Geneva: UNAIDS; 2021.
- 10. Black S. Mozambican workers returning from South Africa engaged to check COVID-19's spread. In: iom.int [Internet]. Geneva: IOM; 2020 (https://www. iom.int/news/mozambican-workers-returning-south-africa-engaged-check-covid-19s-spread).
- 11. Osborn C. How Brazil's COVID-19 response has fallen to community leaders. In: The New Humanitarian [Internet]. 27 May 2020. The New Humanitarian; c2021 (https://www.thenewhumanitarian.org/news/2020/05/27/Brazil-coronavirus-response-community-leaders).
- 12. Duque Franco I, Ortiz C, Samper J, Millan G. Mapping repertoires of collective action facing the COVID-19 pandemic in informal settlements in Latin American cities. Environment and Urbanization. 2020;32(2):523-46.
- Carampatana T, Tuazon RA. Community-led COVID-19 response: the work of the Philippines Homeless People's Federation. In: iied.org [Internet]. 9 June 2020. London: International Institute for Environment and Development; c2020 (https://www.iied.org/community-led-covid-19-response-work-philippineshomeless-peoples-federation).
- 14. Scheepers E, Lakhani I, Armstrong K. Making a community action net (work): organising in the times of COVID-19. In: openglobalrights.org [Internet]. 15 May 2020. Open Global Rights; c2020 (https://www.openglobalrights.org/organising-in-the-times-of-COVID-19/).
- 15. Buxton N. Food flow: the initiative that's helping both farmers and families in need. In: Eat Out [Internet]. 16 April 2020. iab.South Africa; c2006–2021 (https://www.eatout.co.za/arti<cle/food-flow-initiative-thats-helping-farmers-families-need/).
- Pol A. In lockdown, Satara farmers' revolutionary new model. In: New Delhi Television [Internet]. 17 April 2020. NDTV Convergence; c2021 (https://www.ndtv.com/opinion/in-lockdown-satara-farmers-revolutionary-new-model-2213476).
- Papeleras R, Gaddi M. Community-led COVID-19 response: an update from the Philippines. In: iied.org [Internet]. 14 July 2021. London: International Institute for Environment and Development; c2021 (https://www.iied.org/community-led-covid-19-response-update-philippines).
- Hong SY, Ashipala LSN, Bikinesi L, Hamunime N, Kamangu J, Boylan A et al. Rapid adaptation of HIV treatment programs in response to COVID-19– Namibia, 2020. MMWR Morb Mortal Wkly Rep. 2020;69(42):1549-51.
- Ensuring that people living with HIV in the Philippines have access to treatment during COVID-19. In: UNAIDS.org [Internet]. 8 April 2020. Geneva: UNAIDS; c2021 (https://www.unaids.org/en/resources/presscentre/featurestories/2020/april/20200408_philippines).
- 20. Nasuuna EM, Alex M, Namayanja G, Shamim N, Paul K, Mwondha RMN et al. Ensuring HIV service continuity during the COVID-19 pandemic in Kampala, Uganda. Conference on Retroviruses and Opportunistic Infections, 6–10 March 2021. Abstract 729.
- Tukei BB, Fatti G, Tiam A, Ngorima-Mabhena N, Tukei VJ, Tshabalala I et al. Twelve-month outcomes of community-based differentiated models of multimonth dispensing of ART among stable HIV-infected adults in Lesotho: a cluster-randomized noninferiority trial. J Acquir Immune Defic Syndr. 2020;85(3):280-91.
- 22. Fatti G, Lopes J, Mabhena-Ngorima N, Tiam A, Tukei B, Pisa P et al. Community multimonth ART provision: pooled analysis of 2 cluster-randomized trials. Conference on Retroviruses and Opportunistic Infections, 6–10 March 2021. Abstract 182.
- 23. Odinga M, Kuria S, Muindi O, Mwakazi P, Njraini M, Melon M et al. HIV testing amid COVID-19: community efforts to reach men who have sex with men in three Kenyan countries. Gates Open Res. 2020;4:117.
- Integrating community-led monitoring (CLM) into C19RM funding requests. Arusha (TZ): The Eastern Africa National Networks of AIDS and Health Service Organizations (EANNASO); n.d. (https://eannaso.org/download/1020/reports/10875/integrating-community-led-monitoring-clm-into-c19rmfunding-requests.pdf).
- Positive living in the time of COVID-19. Breaking the silence. ICW, GNP+, the Global Network of Young People Living with HIV; 15 June 2020 (https:// gnpplus.net/wp-content/uploads/2020/06/June-15th-Newsletter-6th-Edition-Positive-Living-in-the-time-of-Covid-19-Special-edition_-Transgendercommunity-living-with-HIV.pdf).



Pandemic responses fail when health technologies are available to some but are denied to others. It took the HIV response many years and millions of avoidable infections and deaths to learn that lesson, but determined advocacy from civil society, clinicians, and low- and middle-income country governments led to the establishment of mechanisms that help make HIV medicines and diagnostics affordable and available worldwide. There are more than 28 million people living with HIV on treatment today because shared technology and expanded generic production drive down prices, allowing larger quantities of life-saving health technologies to be purchased and distributed to the people who need them.

These mechanisms, however, are under threat. As powerful new technologies for HIV, COVID-19 and other diseases hit the market, intellectual property barriers, restricted sharing and technology transfer, limited locations of pharmaceutical production, weak regulatory capacities and prohibitive pricing are constricting supply for low- and middle-income countries.

About 6% of Africa's population had been vaccinated for SARS-CoV-2 by late October 2021, compared to at least 40% on most other continents and more than 60% in most high-income countries (1, 2). The World Health Organization (WHO) predicts that the COVID-19 pandemic will last at least a year longer than it should because poorer countries are not getting the vaccines they need (3). United Nations (UN) Secretary-General António Guterres has described the rapid development of COVID-19 vaccines and the snail's pace of their global distribution as "a moral indictment of the state of our world. It is an obscenity. We passed the science test. But we are getting an F in Ethics" (4).

It is critical to secure affordable access to new technologies that can help address HIV inequalities, such as new HIV treatment formulations for children and adults, oral preexposure prophylaxis (PrEP) and vaginal rings for HIV prevention, and long-acting antiretroviral medicines.

A range of actions and innovations advocated by the People's Vaccine Alliance can make access to health technologies more equitable. An international agreement that guarantees fair and equitable access to essential health technologies, especially during health crises, is an urgent priority. Without one, people in low- and middle-income countries will continue to be denied their fundamental right to health, and the world will remain unprepared for the pandemics of today and tomorrow.



A SMARTgirl healthcare outreach professional gives an HIV test to a woman during outreach in Phnom Penh, Cambodia. Credit: UNAIDS/T Brown

HIV TREATMENT IS MORE AFFORDABLE, BUT THE FUTURE IS UNCERTAIN

It took a wide range of actions—driven by people living with HIV and their allies—to make life-saving HIV treatments as affordable and accessible as they are today. Governments were pushed to use flexibilities in the World Trade Organization (WTO) agreement on Trade-related Aspects of Intellectual Property Rights (TRIPS) to achieve more affordable prices for low- and middle-income countries. A patent pooling scheme, the Medicines Patent Pool, was set up to negotiate voluntary licensing deals with patent holders to allow for manufacturing of generic HIV, tuberculosis and hepatitis C treatments (5). Greater competition from generic drug producers drove prices lower, and donors stepped up by funding new drug access initiatives and treatment programmes that use generic HIV medicines.

Prices of HIV medicines plummeted in most countries (see Figure 4). HIV treatment regimens in 2000 cost more than US\$ 10 000 per person per year; the current recommended first-line HIV treatment of dolutegravir, lamivudine and tenofovir was available in 2020 for an average price of US\$ 83 per person per year in low- and middle-income countries that reported price data to UNAIDS. Many new HIV drugs now enter the market in more affordable generic formulations. Experts have noted that the public health-oriented management of intellectual property rights, either through the use of the TRIPS flexibilities or voluntary mechanisms, has not undermined the innovation system or the profitability of the world's biggest pharmaceutical companies (6).

But there have been hitches. Even though free HIV testing and treatment are the norm in many low- and middle-income countries, the levying of user fees at clinics and hospitals in some countries still deprives many people, especially those with low incomes, of the benefits of HIV and other health services and medicines (7–9). Some middle-income countries are struggling to access affordable generic HIV drugs, PrEP remains expensive in many countries (due to patent restrictions and regulatory delays), and the affordability of new HIV products that are being developed (such as long-acting antiretroviral medicines and vaginal rings) is by no means guaranteed. The development of child-friendly paediatric treatments, which are not seen as profitable investments, has been very slow.

THE PUBLIC HEALTH-ORIENTED MANAGEMENT OF INTELLECTUAL PROPERTY RIGHTS, EITHER THROUGH THE USE OF THE TRIPS FLEXIBILITIES OR VOLUNTARY MECHANISMS, HAS NOT UNDERMINED THE INNOVATION SYSTEM OR THE PROFITABILITY OF THE WORLD'S BIGGEST PHARMACEUTICAL COMPANIES.





Percentage change in unit price of antiretroviral medicine procurements, 2016–2020

Source: UNAIDS estimates, based on the country reports to Global AIDS Monitoring 2021 and export data from government customs from 69 low- and middle-income countries.



Methadone is dispensed for opioid substitution therapy, Senegal. Credit: UNAIDS

EXPAND PRODUCTION IN LOW- AND MIDDLE-INCOME COUNTRIES

Pandemic preparedness and responses are being stymied by production choke points, vulnerable supply chains and pricing constraints. The COVID-19 pandemic has especially exposed the overdependence of most African health systems on imported pharmaceutical and medical products: as the COVID-19 crisis grew in 2020, Africa was affected by export restrictions in countries of origin and lower access to medicine supplies as a result of shutdowns of manufacturing facilities in China and India (10). For example, significant reductions in shipments of HIV medicines from India to low- and lower-middle-income countries were observed during the second quarter of 2020 (11).

Pharmaceutical value chains are currently concentrated in a very small number of countries. While the European Union, the United States of America and Japan dominate pharmaceutical research and development, China and India are major producers of active pharmaceutical ingredients and pharmaceutical exports.

All African countries are net importers of medical and pharmaceutical products, with most of them importing between 70% and 90% of the drugs they consume (10, 12). The main exceptions are Morocco and South Africa (13). The continent's pharmaceutical industry is evolving rapidly, although mainly in Ghana, Nigeria, South Africa and a few countries in eastern and northern Africa. There are at least 370 drug product manufacturers in Africa, but they are clustered in only nine countries, with about one third of the companies limited to packaging pills and tablets purchased from others. The production of active pharmaceutical ingredients is limited to only three companies in Africa: two in South Africa and one in Ghana (13).

As the world struggles with current pandemics and prepares for future ones, a wider distribution of manufacturing of medical supplies, pharmaceuticals and other health technologies should be prioritized. Localizing manufacturing would reduce the vulnerability of health systems to supply chain disruptions and the hoarding of essential medical products during crises. This could be done by establishing regional value chains, developing subregional hubs in which manufacturers work together in clusters, and harmonizing regulatory arrangements to facilitate and capitalize on cross-border collaboration (13). The recent creation of the African Medicines Agency is an important step towards establishing a continental platform for regulatory decisions (14).

AS THE WORLD STRUGGLES WITH CURRENT PANDEMICS AND PREPARES FOR FUTURE ONES, A WIDER DISTRIBUTION OF MANUFACTURING OF MEDICAL SUPPLIES, PHARMACEUTICALS AND OTHER HEALTH TECHNOLOGIES SHOULD BE PRIORITIZED. Health technologies are global public goods and must be accessible to all; they should not be treated as regular, marketable goods. The following actions would accelerate the global production, distribution and use of medicines, vaccines, diagnostics and other essential health technologies for COVID-19.

Selective waiving of intellectual property rights. In late 2020, India and South Africa proposed to the WTO a temporary waiver for COVID-19 diagnostics, therapeutics, vaccines and other technologies for the duration of the COVID-19 pandemic (*15*). The proposal has been backed by more than 100 WTO members, but some powerful members have withheld their support.

Broader use of the COVID-19 Technology Access Pool (C-TAP). WHO set up the C-TAP in mid-2020 to facilitate the voluntary licensing of technologies in a transparent way. However, large pharmaceutical companies have not yet embraced this mechanism (*16*).

Immediate fulfilment of commitments made by governments and pharmaceutical companies under the COVAX Advance Market Commitment initiative (the vaccines pillar of the Access to COVID-19 Tools Accelerator, or ACT-A).¹ Pooled regional procurement should also be boosted, such as through cooperation between the Africa Centres for Disease Control and the WHO-led UN Supply Chain Taskforce, the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund) and other entities (17).

Wider distribution of manufacturing and production of health products. Prevention of monopolies and increased production capacity for health products across regions is needed to increase competition and reduce the risk of supply chain disruptions during crises (15).



A patient at the Chhouk Sar Clinic in Phnom Penh, Cambodia, gets blood drawn to test for HIV and sexually transmitted infections. This clinic is known as a 'one stop shop' that caters largely to the LGBTI community. Credit: UNAIDS/de la Guardia

 Under the COVAX initiative, high-income countries pledged to ship 1.8 billion vaccine doses to low- and middle-income countries by the end of 2021; about 261 million doses had arrived in those countries by October 2021. Vaccine manufacturers promised an additional 994 million doses, of which 120 million had been delivered. See: Malpanik R, Maitland A. Dose of reality: how rich countries and pharmaceutical corporations are breaking their vaccine promises. London: The People's Vaccine, OXFAM; 2021 (https://app.box.com/s/kygk0i850bo18l33vk5p3qwyq9umk527).

PUTTING DIAGNOSTICS

Every pandemic response hinges upon countries having quality diagnostics to detect and track disease outbreaks and to diagnose people who may need treatment. There have been extraordinary innovations in diagnostic technologies and information systems in the past 10 to 15 years, including point-of-care diagnostics, but the importance of diagnostics for achieving health equity often goes unnoticed, leading to underfunding, regulatory hitches and other problems.

In 2008, the Maputo Declaration on Strengthening of Laboratory Systems highlighted the need for improved access to diagnostic testing. More than a decade later, few if any universal health coverage plans explicitly provide for the financing of diagnostics (18). According to the Lancet Commission on Diagnostics, almost half (47%) of the world's population has little to no access to diagnostics (18).

Access to diagnostics remains uneven in many low- and middle-income countries, with impoverished and rural communities worst affected. In many instances, diagnostics are effectively unavailable outside urban areas (19). Medical laboratories are also unequally distributed across countries. The United States, for example, has 260 000 accredited medical laboratories, while India, with four times as many inhabitants, has 1150 such laboratories. There is also a shortfall in the diagnostic workforce: an additional 840 000 to 1 million diagnostic staff will be needed globally by 2030 (18). This is a huge weakness, both for pandemic responses and routine health care.

During the early months of the COVID-19 pandemic, lack of access to diagnostics was described as the Achilles heel of Africa's response. When genome sequences of SARS-CoV-2 were made available, Asia and Europe started producing in-house tests within weeks. Africa lacked this capacity and had to wait for imports, often being pushed to the back of the line as countries competed to acquire tests from the limited supply (20).

The HIV response has been creating routes around these constraints. It has broadened access to HIV diagnostics by using simplified technologies, including point-of-care tests, that can be decentralized and administered by lay health workers. Although significant proportions of people living with HIV are still undiagnosed in some countries, wider use of community-based case finding and the advent of HIV self-testing kits can reduce that gap further.

Access to screening and testing for cervical cancer, diabetes, blood pressure or syphilis is much lower than for HIV.² The stakes are high: the Lancet Commission estimated that reducing the diagnostic gap for six relatively common conditions from the current 35–62% to 10% would reduce the annual number of premature deaths in low- and middle-income countries by 1.1 million (*18*).³

Reliable and equitable access to quality diagnostics requires long-term prioritization, commitment and investment. Diagnostics should be incorporated into universal health coverage plans, and equitable access to diagnostics should be a key element of pandemic preparedness planning.

An analysis of nationally representative surveys done for lifetime access to cervical cancer screening between 2005 and 2018 in 55 low- and middle-income countries (representing more than 1.1 million women) showed that women who lived in rural areas, had low educational attainment or had low household wealth were generally least likely to self-report ever being screened.

^{3.} The six conditions are diabetes, hypertension, HIV and tuberculosis in the overall population, plus hepatitis B and syphilis among pregnant women.
REFERENCES

- 1. Less than 10% of African countries to hit key COVID-19 vaccination goal. In: WHO Africa [Internet]. 28 October 2021. Brazzaville: WHO Regional Office for Africa; c2021 (https://www.afro.who.int/news/less-10-african-countries-hit-key-covid-19-vaccination-goal).
- Holder J. Tracking Coronavirus vaccinations around the world. In: New York Times [Internet]. 9 November 2021. New York (NY): New York Times Company; c2021 (https://www.nytimes.com/interactive/2021/world/covid-vaccinations-tracker.html).
- 3. Malpanik R, Maitland A. A dose of reality. London: The People's Vaccine, OXFAM; 2021 (https://app.box.com/s/kygk0i850bo18l33vk5p3qwyq9umk527).
- 4. COVID-19: UN Secretary-General says the world has failed an ethics test. In: United Nations in Western Europe [Internet]. 21 September 2021. United Nations; c2021 (https://unric.org/en/covid-19-un-secretary-general-says-the-world-has-failed-an-ethics-test/).
- 5. Medicines Patent Pool [Internet]. Geneva: Medicine Patents Pool; c2021 (https://medicinespatentpool.org).
- 6. Garrett L. Stopping drug patents has stopped pandemics before. In: Foreign Policy. 7 May 2021. The Slate Group; c2021 (https://foreignpolicy. com/2021/05/07/stopping-drug-patents-pandemics-coronavirus-hiv-aids/).
- Ahonkhai AA, Regan S, Idigbe I, Adeniyi O, Aliyu MH, Okonkwo P et al. The impact of user fees on uptake of HIV services and adherence to HIV treatment: findings from a large HIV program in Nigeria. PLoS One. 2020;15(10):e0238720.
- Watson SI, Wroe EB, Dunbar EL, Mukherjee J, Squire SB, Nazimera L et al. The impact of user fees on health services utilization and infectious disease diagnoses in Neno District, Malawi: a longitudinal, quasi-experimental study. BMC Health Serv Res. 2016;16(1):595.
- 9. Yates R. Universal health coverage and the removal of user fees. Lancet. 2009;373(9680):2078-81.
- 10. Banga K, Keane J, Mendez-Parra M, Pettinotti L, Sommer L. Africa trade and Covid-19: the supply chain dimension. London: Overseas Development Institute; 2020 (https://cdn.odi.org/media/documents/Africa_trade_and_Covid19_the_supply_chain_dimension.pdf).
- 11. UNAIDS analysis of Indian customs data obtained from Seair Exim Solutions, 2020–2021.
- 12. Conway M, Holt T, Sabow A, Sun I. Should sub-Saharan Africa make its own drugs? In: McKinsey and Company [Internet]. 10 January 2019. McKinsey & Company; c1996–2021 (https://www.mckinsey.com/industries/public-and-social-sector/our-insights/should-sub-saharan-africa-make-its-own-drugs).
- 13. Bright B, Babalola CP, Sam-Agudu NA, Oneaghala AA, Olatunji A, Aduh U et al. COVID-19 preparedness: capacity to manufacture vaccines, therapeutics and diagnostics in sub-Saharan Africa. Global Health. 2021;17(1):24.
- 14. Ncube BM, Dube A, Ward K. Establishment of the African Medicines Agency: progress, challenges and regulatory readiness. J Pharm Policy Pract. 2021;14(1):29.
- Editorial. A patent waiver on COVID vaccines is right and fair. In: Nature [Internet]. 25 May 2021. Springer Nature Ltd; c2021 (https://www.nature.com/articles/ d41586-021-01242-1).
- 16. Zarocostas J. What next for a COVID-19 intellectual property waiver? The Lancet. 2021;397(10288):1871-2187.
- 17. Kavanagh MM, Erondu NA, Tomori O, Dzau VJ, Okiro EA, Maleche A et al. Access to lifesaving medical resources for African countries: COVID-19 testing and response, ethics, and politics. Lancet. 2020;395(10238):1735-8.
- Fleming KA, Horton S, Wilson ML, Atun R, DeStigter K, Flanigan J et al. The Lancet Commission on diagnostics: transforming access to diagnostics. The Lancet. 2021;S0140-6736(21)00673-5.
- Ndihokubwayo JB, Maruta T, Ndlovu N, Moyo S, Yahaya AA, Coulibaly SO et al. Implementation of the World Health Organization Regional Office for Africa stepwise laboratory quality improvement process towards accreditation. Afr J Lab Med. 2016;5:280.
- Nkengasong J. Let Africa into the market for COVID-19 diagnostics. In: Nature [Internet]. 28 April 2020. Springer Nature Ltd; c2021 (https://www.nature.com/ articles/d41586-020-01265-0).



Front-line workers are the heroes of pandemic responses, risking their health and safety to provide care and ensure that basic goods and services remain available. International and domestic AIDS response resources have been used to hire and train millions of health workers over the decades, enabling the expansion of HIV prevention, testing and treatment service. Especially at the community and primary care levels, these health-care professionals and communities of people living with HIV and key populations do far more than HIV work, and they are now playing a major role against COVID-19.

Despite the addition of these much-needed reinforcements, essential workers are chronically too few in numbers, under-resourced and overburdened. Crises compound those shortages. Often labouring in difficult and unsafe conditions, these workers improvise ways to cope with heavy workloads, equipment shortages and deficient systems. But coping is not the same as resilience: it may avoid disaster in the short term, but it hides deeper flaws and failings that stand in the way of actual resilience (1).

During the COVID-19 crisis, health workers have faced extraordinary burdens, and they are at heightened risk of burnout, mental health distress, illness and death (2, 3). Data from 119 countries indicate that, by October 2021, only two in five health-care workers globally were fully vaccinated. Fewer than one in 10 health-care workers in Africa were fully vaccinated, compared with eight in 10 in high-income countries (4). The World Health Organization (WHO) estimated that COVID-19 had killed between 80 000 and 180 000 health workers by October 2021 (5). Health systems desperately need more health workers, and they need the resources and tools to keep them safe.

Community health workers and community-led organizations have become increasingly important resources, providing basic health care in their communities, acting as vital bridges between communities and health facilities, and supporting the response to HIV, tuberculosis and, increasingly, COVID-19 in many countries (6). Despite their importance, community health workers currently represent only about 3% of the world's health workforce. They also are used very differently across countries, and in many cases, they are poorly trained, paid and integrated into health systems (7). As countries confront current pandemics and prepare for future ones, the ranks of essential workers must be expanded to meet the challenge. As well as sufficient numbers and fair pay, these workers need adequate training, resources and tools for their jobs, and mechanisms for the enforcement of rights as workers. Tangible steps must also be pursued to value the unpaid care work of women.



A patient and his friend wait to see health care staff at Chhuok Sar Clinic in Phnom Penh, Cambodia, 2019. Credit: UNAIDS/T Brown

HEALTH WORKER SHORTAGES UNDERMINE PANDEMIC RESPONSES

It takes strong health systems to manage and overcome pandemics. But those systems are only as strong as the people who make them work.

Arguably the most important element in a pandemic response is the ability to deploy enough health workers for interventions, while keeping standard public health systems functioning smoothly. The COVID-19 crisis has exposed a lingering danger: many countries, including middle- and high-income ones, do not have enough health workers to manage a pandemic. Health workers are inequitably distributed throughout the world, with severe imbalances between high-income and low- and middle-income countries, and within countries with split public and private health systems (Figure 5).

Globally, a shortfall of 18 million health workers is predicted for 2030, due mainly to ageing populations and rising rates of noncommunicable diseases (8). Those projections, made in 2016, did not factor in pandemic crises such as COVID-19. They also hide the dire situation in some regions. For instance, while Africa has 24% of the world's disease burden, it has only 3% of the world's health workers (9). Thirty-one of the 54 African countries have a doctor–patient ratio of about 1 : 10 000, compared to the favourable ratio in high-income countries like Germany (1 : 417) and Italy (1 : 270) (10). Similar disparities occur within countries, especially between urban and rural areas.



A client chats with a visitor at CEPIAD, an integrated drug dependence management centre in Dakar, Senegal. Credit: CEPIAD

FIGURE 5. Density of selected health professionals, per 10 000 population, global and regional, 2013–2019



Nursing and midwifery personnel

Medical doctors

Note: Latest data available (2013–2019).

Source: Global Health Workforce statistics database [database]. Geneva: WHO; c2021 (https://www.who.int/data/gho/data/themes/topics/health-workforce).

TASK-SHARING WITH COMMUNITY HEALTH WORKERS CAN HELP CLOSE GAPS

Health workforces can also be organized more effectively. It has been estimated that more than three quarters of nurses and doctors perform tasks for which they are overqualified (11). By redistributing tasks to health workers with shorter training and fewer qualifications, including community health workers, task-sharing has contributed to major breakthroughs in HIV responses. These adaptations also reduce the workloads of doctors and nurses and allow services and procedures to be decentralized from hospitals to clinics and other facilities, putting them in closer reach of communities (12). Similarly, decisions to allow nurses to prescribe HIV medicines and lay health workers to assist in dispensing the medicines has contributed to rapid increases in the coverage of HIV treatment since the mid-2000s (13–15).

HIV, tuberculosis and immunization programmes underscore the importance of community health workers for both basic health services and pandemic responses, especially in communities that are underserved by health systems (6). For instance, when adequately trained and supported, lay health workers provide quality follow-up care for people living with HIV (16). Across the world, networks of people living with HIV and community support groups have expanded access to HIV services and helped tailor those services to people's varied needs. This differentiated care and support is making it easier for people to avoid acquiring HIV infection and to adhere to HIV treatment.

ACROSS THE WORLD, NETWORKS OF PEOPLE LIVING WITH HIV AND COMMUNITY SUPPORT GROUPS HAVE EXPANDED ACCESS TO HIV SERVICES AND HELPED TAILOR THOSE SERVICES TO PEOPLE'S VARIED NEEDS.

During the COVID-19 pandemic, these groups and networks have taken on vital roles, bringing medicines, food and other support to people in need, linking them to health and social services, monitoring and reporting rights violations, and assisting with COVID-19 screening and contact tracing. As part of the African Union's Partnership to Accelerate COVID-19 Testing (PACT) initiative, groups of people living with HIV in several countries are now being linked with community health workers to assist with COVID-19 awareness-raising and contact tracing and to report HIV service disruptions (17, 18).

In Nigeria, some 50 000 community assistants who had been trained in polio detection were deployed to assist with COVID-19 contract tracing as the pandemic advanced (19). Authorities in Kerala, India, dispatched some 30 000 community health workers to support early detection, contract tracing and risk communication efforts (20). Some 28 000 community health workers in South Africa were redeployed from HIV activities to assist with community screening and contact tracing (21). The United Republic of Tanzania took a similar path (21).

The Africa Centres for Disease Control and Prevention has made community health workers a linchpin in its efforts to bolster COVID-19 programmes in underserved communities. They are doing risk communication work, running surveillance activities for early case identification, performing contact tracing and facilitating referrals for testing and care. By mid-2021, 17 000 newly-trained community health workers working in 24 countries had referred more than 550 000 suspected COVID-19 cases for testing (22). A recent review of evidence from Botswana, Ghana, Nigeria, South Africa, Uganda and Zimbabwe also noted the value of community health workers for delivering medications and other supplies to homes, and for following up with patients who have chronic conditions (23).

These promising examples should not exaggerate the current impact of community health workers, who still represent a tiny fraction of the world's health workforce. In Africa and Asia, for example, there are roughly 0.1 to 1 community health workers for every 1000 adults (24). In some countries, community health workers are poorly paid and trained, inefficiently distributed and underutilized. Health systems are not always geared to link with them effectively and efficiently (7, 23, 25).

Managing current and future pandemics requires training, deploying and remunerating more community health workers, and integrating them into health systems and community structures (24, 26). That also requires more funding. At the moment, community health programmes in most countries rely heavily on donor support, even though they represent a small fraction of development assistance for public health (27, 28).¹

Women bear a disproportionate care burden

Women are especially likely to be found on the front lines of pandemic responses, at work and at home, in roles that increase their risk of infection. They comprise at least 70% of health workers (though a minority of medical doctors and specialists), and they provide health services for some 5 billion people worldwide (29). Studies are finding high rates of mental exhaustion and trauma among female nurses providing COVID-19-related care (30). Women also constitute the majority of community health workers in Africa and Asia. In addition, girls and women bear the brunt of unpaid care work, including childcare and home schooling—all of it typically undervalued and uncompensated. Stay-at-home restrictions have added to the unpaid care workloads of women, and domestic violence has worsened (31).

Women are also overrepresented in the economic sectors hardest hit by pandemic shutdowns (32). According to the International Labour Organization (ILO), the equivalent of 125 million full-time jobs have been lost since the pandemic began, with women disproportionately affected (33). Their employment rates declined by 5% in 2020 (compared to 3.9% for men) (34). Self-employed and informal sector workers (e.g., domestic workers, 80% of whom are women) are very seldom covered by unemployment or health insurance schemes. This leaves them with an unenviable choice between returning to work despite the health risks or being unable to meet their basic needs for survival.

Funding for community health worker programmes globally accounted for approximately 2.5% of total development assistance for health between 2007 and 2017. Most of that funding went to programmes in sub-Saharan Africa, especially those focused on infectious diseases and child and maternal health. Those investment levels have been declining.

CONTRIBUTION OF COMMUNITIES OFTEN UNRECOGNIZED

The 40-year response to the AIDS pandemic has included the establishment and development of community-led organization in every region of the world. Their members have developed substantial knowledge and capacities, and these organizations have come to function as an invaluable part of global public health responses.

In June and July 2020, UNAIDS conducted a survey of community-led organizations run by and for people living with and affected by HIV. This predominantly qualitative survey sought to gain a deeper understanding of the impact that the COVID-19 pandemic was having on the HIV-related work of community-led organizations, and to learn more about their contributions to the COVID-19 response (*35*). A total of 225 community-led organizations from 72 countries responded to the survey. Almost all respondents (92.5%) reported being directly involved in the provision of HIV-related services to their communities.

The survey found that community-led organizations moved swiftly at the onset of the COVID-19 pandemic to mitigate its impact on members of their communities, undertaking a wide range of new activities to help ensure continuity of HIV-related services and bolster their health and well-being (*35*). At the same time, these organizations innovated and undertook new interventions to respond to the COVID-19 pandemic itself. They rolled out COVID-19 awareness-raising and health information campaigns, provided individual counselling and guidance, produced and distributed masks, soap and sanitizers, and provided assistance to survivors of an upsurge in gender-based violence (*35*).

While community-led organizations stretched their existing human and financial resources to the fullest extent possible, they experienced severe funding gaps that left their staff exhausted and working nights and weekends to fundraise, usually unsuccessfully, and turning to their own personal salaries and savings to help their communities (35). Community-led organizations also repeatedly expressed deep concern about the economic impact of lockdowns and travel restrictions on their beneficiaries, as well as on service interruptions to community-delivered services (*35*).

The COVID-19 pandemic has underscored the immense value of having this global community resource ready to deploy at times of crisis. Yet these organizations were frequently left out of COVID-19 response bodies, excluding them from the planning, design and evaluation of interventions, and ultimately failing to recognize them as providers of essential services and insights.



Human rights law allows for the limitation or derogation of some rights for legitimate purposes, such as to protect public health, but there are strict boundaries on when, how and to what extent rights may be limited. Effective pandemic preparedness and response efforts therefore need specific, funded human rights work as an essential component.

KEEPING OTHER ESSENTIAL WORKERS SAFE ON THE JOB

Essential workers extend far beyond the health system, and include teachers, food and agricultural workers, food and beverage store employees, and those providing police and firefighting services, to name just a few. Among those who are critical to preventing wider inequalities between the powerful and the marginalized within societies during pandemics are those who deliver social protection services. Within the response to the AIDS pandemic, for instance, HIV-sensitive social protection measures have increased household income, enhanced food security and nutrition, and improved access to education among people living with HIV and people at elevated risk of HIV infection within poor and vulnerable households (36). During the early months of the COVID-19 pandemic, however, social workers were not consistently being recognized as essential workers, despite their critical role in the delivery of health services and community care (36).

As is the case with health services, community-led organizations play an important supporting role in the delivery of social protection services that are HIV-sensitive and reach people living with HIV and key populations. Marginalized, vulnerable and underserved populations face institutionalized impediments that limit their access to services. For example, as social protection services in Ukraine were expanded to mitigate the impact of COVID-19 restrictions, key populations received little support, mainly because many were unregistered workers. Similar gaps occurred in Nepal because many within key populations did not have citizenship certificates or other official registration. In both cases, community-led networks had to step in to provide food, medicines and other basic subsistence support to as many as they could, but the need far outweighed their resources (*36*).



A client meets with his pre-exposure prophylaxis (PrEP) counsellor at Chhouk Sar Clinic in Phnom Penh, Cambodia. Credit: UNAIDS/de la Guardia

REFERENCES

- 1. Lee BY, Wedlock PT, Mitgang EA, Cox SN, Haidari LA, Das MK et al. How coping can hide larger systems problems: the routine immunisation supply chain in Bihar, India. BMJ Glob Health. 2019;4:e001609.
- 2. Kaushik D. COVID-19 and health care workers burnout: a call for global action. EClinicalMedicine. 2021;35:100808.
- 3. Anzaldua A, Halpern J. Can clinical empathy survive? Distress, burnout, and malignant duty in the age of COVID-19. Hastings Cent Rep. 2021;51(1):22-7.
- Steering Committee for the International Year of Health and Care Workers in 2021. Joint statement on WHO's estimates of health and care worker deaths due to COVID-19. 2021 (https://cdn.who.int/media/docs/default-source/health-workforce/year2021/english_joint-statement-health-care-health-deaths. pdf?sfvrsn=b3527728_50).
- 5. The impact of COVID-19 on health and care workers: a closer look at deaths. Health Workforce Department, Working Paper 1. Geneva: WHO; 2021 (https://apps.who.int/iris/bitstream/handle/10665/345300/WHO-HWF-WorkingPaper-2021.1-eng.pdf?sequence=1&isAllowed=y).
- Gichaga A, Masis L, Chandra A, Palazuelos D, Wakaba N. Mind the global community health funding gap. Glob Health Sci Pract. 2021;9(Suppl 1):S9-S17.
 Gebremeskel AT, Otu A, Abimbola S, Yaya S. Building resilient health systems in Africa beyond the COVID-19 pandemic response. BMJ Glob Health.
- Bigh-level commission on health employment and economic growth: report of the expert group. Geneva: WHO; 2016 (https://apps.who.int/iris/
- High-level commission on health employment and economic growth: report of the expert group. Geneva: WHO; 2016 (https://apps.who.int/iris handle/10665/250040).
- 9. Health workers: a global profile. Geneva: WHO; 2006 (https://www.who.int/whr/2006/06_chap1_en.pdf?ua=1).
- Poppe A, Jirovsky E, Blacklock C, Laxmikanth P, Moosa S, De Maeseneer J et al. Why sub-Saharan African health workers migrate to European countries that do not actively recruit: a qualitative study post-migration. Glob Health Action. 2014;7:24071.
- 11. Health workforce policies in OECD countries: right jobs, right skills, right places. Paris: OECD; 2016 (https://doi.org/10.1787/9789264239517-en).
- 12. Consolidated guidelines on HIV prevention, testing, treatment, service delivery and monitoring: recommendations for a public health approach. Geneva: WHO; 2021 (https://apps.who.int/iris/rest/bitstreams/1357089/retrieve).
- 13. Callaghan M, Ford N, Schneider H. A systematic review of task-shifting for HIV treatment and care in Africa. Hum Resour Health. 2010;8:8.
- 14. Mbeye NM, Adetokunboh O, Negussie E, Kredo T, Wiysonge CS. Shifting tasks from pharmacy to non-pharmacy personnel for providing antiretroviral therapy to people living with HIV: a systematic review and meta-analysis. BMJ Open. 2017;7:e015072.
- 15. Penazzato M, Davies MA, Apollo T, Negussie E, Ford N. Task shifting for the delivery of pediatric antiretroviral treatment: a systematic review. J Acquir Immune Defic Syndr. 2014;65:414-22.
- Kredo T, Adeniyi FB, Bateganya M, Pienaar ED. Task shifting from doctors to non-doctors for initiation and maintenance of antiretroviral therapy. Cochrane Database Syst Rev. 2014;(7):CD007331.
- 17. Partnering to strengthen community engagement in the HIV and COVID-19 responses in Namibia. In: UNAIDS.org [Internet]. 12 October 2021. Geneva: UNAIDS; c2021 (https://www.unaids.org/en/resources/presscentre/featurestories/2021/october/20211012_namibia).
- UNAIDS and its partners implement Partnership to Accelerate COVID-19 Testing in Madagascar. In: UNAIDS.org [Internet]. 18 May 2021. Geneva: UNAIDS; c2021 (https://www.unaids.org/en/resources/presscentre/featurestories/2021/may/20210518_madagascar).
- 19. Nigeria's polio infrastructure bolster COVID-19 response. In: WHO in Africa [Internet]. 4 April 2020. Abidjan: WHO Regional Office for Africa; c2020 (https://www.afro.who.int/pt/node/12495).
- 20. Masih N. Aggressive testing, contact tracing, cooked meals: how the Indian state of Kerala flattened its coronavirus curve. In: Washington Post [Internet]. 14 April 2020. Washington (DC): Washington Post; c2021 (https://www.washingtonpost.com/world/aggressive-testing-contact-tracing-cooked-meals-how-theindian-state-of-kerala-flattened-its-coronavirus-curve/2020/04/10/3352e470-783e-11ea-a311-adb1344719a9_story.html).
- Nachega JB, Grimwood A, Mahomed H, Fatti G, Preiser W, Kallay O et al. From easing lockdowns to scaling up community-based Coronavirus Disease 2019 screening, testing, and contact tracing in Africa—shared approaches, innovations, and challenges to minimize morbidity and mortality. Clin Infect Dis. 2021;72(2):327-31.
- 22. The critical role of community health workers in COVID-19 vaccine roll out. Addis Ababa: Africa CDC; 2021 (https://africacdc.org/download/the-critical-roleof-community-health-workers-in-covid-19-vaccine-roll-out/).
- 23. Ray S, Mash R. Innovation in primary health care responses to COVID-19 in sub-Saharan Africa. Prim Health Care Res Dev. 2021;22:e44.
- 24. Community health workers (per 1,000 people). In: The World Bank Data [database]. Washington (DC): The World Bank Group; c2021 (https://data.worldbank. org/indicator/SH.MED.CMHW.P3).
- WHO guideline on health policy and system support to optimize community health worker programmes. Geneva: WHO; 2018 (https://www.who.int/ publications/i/item/9789241550369).
- 26. LeBan K, Kok M, Perry HB. Community health workers at the dawn of a new era: 9. CHWs' relationships with the health system and communities. Health Res Policy Syst. 2021;19(Suppl 3):116.
- 27. Lu C, Palazuelos D, Luan Y, Sachs SA, Mitnick CD, Rhatigan J et al. Development assistance for community health workers in 114 low- and middle-income countries, 2007–2017. Bull World Health Organ. 2020;98(1):30-9.
- 28. Masis L, Gichaga A, Zerayacob T, Lu C, Perry HB. Community health workers at the dawn of a new era: 4. Programme financing. Health Res Policy Syst. 2021;19(Suppl 3):107.
- 29. Delivered by women, led by men: gender and equity analysis of the global health and social workforce. Geneva: WHO; 2019 (https://apps.who.int/iris/ handle/10665/311322).
- Chen R, Sun C, Chen JJ, Jen HJ, Kang XL, Kao CC et al. A large-scale survey on trauma, burnout, and posttraumatic growth among nurses during the COVID-19 pandemic. Int J Ment Health Nurs. 2021;30(1):102-16.
- 31. Kabeer N, Razavi S, van der Meulen Rodgers Y. Feminist economic perspectives on the COVID-19 pandemic. Feminist Economics. 2021;27(1–2):1-29.
- 32. Wenham C, Smith J, Davies SE, Feng H, Grépin KA, Harman S et al. Women are most affected by pandemics—lessons from past outbreaks. Nature. 2020;583(7815):194-8.
- 33. ILO Monitor: COVID-19 and the world of work. 8th edition. Geneva: ILO; 2021 (https://www.ilo.org/wcmsp5/groups/public/---dgreports/---dcomm/ documents/briefingnote/wcms_824092.pdf).
- 34. World employment and social outlook: trends 2021. Geneva: ILO; 2021 (https://www.ilo.org/wcmsp5/groups/public/---dgreports/---dcomm/---publ/ documents/publication/wcms_795453.pdf).
- 35. Holding the line: communities as first responders to COVID-19 and emerging health threats. Geneva: UNAIDS; 2021 (forthcoming).
- 36. Life-changing HIV and social protection interventions in COVID-19 era. Geneva: UNAIDS; [pre-publication version].



Human rights are central to effective pandemic response strategies. Decades of research have demonstrated that human rights-based approaches address power imbalances and improve public health outcomes, including during the crisis of a pandemic.

In the AIDS pandemic, the odds are stacked against populations that routinely face discrimination and injustice—experiences that increase their risk of acquiring HIV and that make it difficult for them to access treatment and remain in care. Depending on the place and context, these populations include women and girls, gay men and other men who have sex with men, transgender people, sex workers, people who use drugs, prisoners, migrants, refugees and other displaced persons.

Responses to HIV, Ebola and Zika not anchored in human rights have undercut medium- and long-term success against these pandemics.

International human rights law creates obligations for United Nations (UN) Member States to ensure the right to the highest attainable standard of health, and it also requires that states maintain protections for free expression, access to information, and equity and non-discrimination. Failing to overtly consider inequalities in planning and pandemic response efforts undercuts their efficacy. The planning of pandemic strategies should include analyses that recognize the intersecting realities of women and girls in all their diversity, marginalized populations, people living in poverty and other inequality axes. Funding gender-transformative and violence prevention work as part of pandemic response can address gender inequalities while increasing the effectiveness of pandemic responses.

At times, the protection of human rights can seem to be in tension with the enforcement of public health orders. However, past and present pandemics show that human rights and public health are inextricably linked, and that a human rights-based approach is critical to ensure successful public health outcomes. Rights violations, particularly those that can flow from coercive, restrictive or public-security approaches to health, often have direct negative health impacts, undercut trust in public health and undermine pandemic responses, particularly for those who are already in vulnerable or marginalized situations. Conversely, rights-building and enabling approaches can build trust, reduce stigma and enable people and communities to protect their health and wellbeing, including increasing access to testing, prevention and treatment.

While human rights law allows for the limitation or derogation of some rights for legitimate purposes, such as to protect public health, there are strict boundaries on when, how and to what extent rights may be limited (1). Any limitation must be for a legitimate aim and must be proportionate to that aim, necessary (effective and evidence-informed), time-bound, non-arbitrary (non-discriminatory) and according to law (1). Governments should also ensure that any limitations do not result in additional human rights violations, for example by making accommodations and providing additional support for people and communities who are in vulnerable situations.

Effective pandemic preparedness and response efforts therefore need specific, funded human rights work as an essential component. This includes building enabling legal and policy environments, strengthening independent judicial and human rights institutions, and supporting civil society groups capable of holding governments and other actors accountable. This human rights infrastructure ensures that inequalities do not intensify and prolong pandemics, and that pandemics do not exacerbate inequalities.

HUMAN RIGHTS-BASED APPROACHES ADDRESS POWER IMBALANCES AND IMPROVE PUBLIC HEALTH OUTCOMES, INCLUDING DURING THE CRISIS OF A PANDEMIC. EFFECTIVE PANDEMIC PREPAREDNESS AND RESPONSE EFFORTS NEED SPECIFIC, FUNDED HUMAN RIGHTS WORK AS AN ESSENTIAL COMPONENT.

BUILDING HUMAN RIGHTS INFRASTRUCTURE WITHIN PANDEMIC PREPAREDNESS

Rights-based actors are critical partners in building effective pandemic response, helping proactively plan effective public health policies and quickly remedy rights violations in order to restore trust in public health.

When duty bearers overstep their authority, accountability mechanisms are critical to making course corrections and providing recourse to those whose rights are violated. Courts, lawyers and legal services have been critical to ensuring the defense of human rights during pandemics, including for key populations and other vulnerable groups.

In Egypt, for example, a nongovernmental legal rights organization, Al Shehab Foundation for Comprehensive Development, helped encourage HIV testing when they successfully argued in court that people living with HIV cannot be fired by their employers because of their HIV status (2). The National Human Rights Commission of India helped build trust and encourage people living with HIV to engage in care by defending their rights to treatment, and the National Human Rights Commission of Thailand fought against pre-employment HIV screening and other forms of mandatory testing that have been shown to cause people to mistrust public health authorities (3).

FIGURE 6. Percentage of countries reporting that mechanisms exist to record and address individual complaints of HIV-related discrimination, global, 2017–2021





Mechanisms established by the community and/or nongovernmental organizations (n = 70)

Source: National Commitments and Policy Instrument, 2017–2021.

Mechanisms to record and address individual complaints of HIV-related discrimination have been established by governments in 92 of the 130 countries that reported data to UNAIDS. A similar percentage of reporting countries (55 of 70) have mechanisms established by community and/or nongovernmental organizations (Figure 6). One of the key lessons of the HIV response has been that civil society advocacy and public interest legal efforts increase the potential for accountability, provide a platform for authentic community voices and bring critical information to light for governments about what is and is not working to advance public health. Engagement with civil society builds trust, ensures suitability and effectiveness, helps avoid indirect or unintended harms and ensures frequent sharing of information (4).

Civic actors and community organizations around the world have been critical to addressing government violations of human rights in the COVID-19 response, fighting for redress for affected communities and combatting disinformation. In Uganda, for example, pressure from civic groups preceded a government amendment to movement restrictions to allow pregnant women to seek care without official permission—an order that had caused fatalities early in the pandemic. Similarly, Nigeria's National Human Rights Commission set up special hotlines early in the COVID-19 pandemic to receive reports of human rights violations following incidents of extrajudicial killings perpetrated by the police, the military and the Nigerian Correctional Service that had resulted in 18 deaths (5, 6).

Activists have been able to provide critical insights into proposed measures, helping to shape COVID-19 response legislation in ways that protect the rights of citizens and increase the potential for effective pandemic responses. Civic activism has also paved the way for public interest litigation that has buttressed a country's rights-based responses. For instance, Chilean activists helped secure court orders to implement the government's multimonth dispensing policy nationwide, and they have monitored stock-outs of HIV medicines during COVID-19 (4). Kenyan rights leaders were able to ensure that lawyers were designated as essential workers, allowing them to assist those detained for violating lockdown orders—individuals who had otherwise been left to languish in jails at heightened risk of contracting COVID-19 (4).

Investing in human rights and civil society infrastructure should be a key focus of funding and political energy for the response to the AIDS pandemic, and for building broader and more equitable pandemic preparedness and response plans.



A participant at an LGBTI pride event in Maseru, Lesotho, organized by People's Matrix Association. Credit: UNAIDS/M.Hyoky

CURBING THE USE OF CRIMINAL LAW IN PANDEMIC RESPONSES

Criminal laws have repeatedly been shown to do much more harm than good for pandemic responses and advancing public health goals.

The use of criminal law for public health ends is, in most cases, a disproportionate and ineffective response that is vulnerable to arbitrary and discriminatory implementation. Such an approach often drives people away from much needed services, increases the potential risk of exposure or transmission, and undercuts learning by (and empowerment of) all citizens. Enforcement also can also distract limited human resources and budgets away from measures that could more effectively respond to the pandemic, such as citizen education, testing, tracing and treatment.

Criminalization of same-sex sexual relations, sex work, drug possession and use, and HIVexposure, non-disclosure and transmission have been shown to block HIV service access and increase HIV risk. Countries that criminalize key populations saw less progress towards HIV testing and treatment targets over the last five years—with significantly lower percentages of people living with HIV knowing their HIV status and achieving viral suppression than in countries that avoided criminalization (7). Even greater gains were achieved in countries where laws have advanced human rights protections, particularly those that protected rights to non-discrimination and responded to gender-based violence (7). Despite this compelling evidence, discriminatory and punitive laws remain alarmingly common (Figure 7).

FIGURE 7. Number of countries with discriminatory and punitive laws, global, 2021



Yes Data not available

Sources: UNAIDS National Commitments and Policy Instrument 2017–2021 (http://lawsandpolicies.unaids.org/); supplemented by additional sources.

Similar patterns are emerging during COVID-19 responses. Criminalization of sex work, for example, has meant that sex workers are excluded from temporary social protection programmes in many countries, undermining their health and well-being—and their ability to help stop the spread of SARS-CoV-2 (3). Early in the COVID-19 response, some governments instituted gender-specific mobility days during lockdowns, which resulted in violence and discrimination against transgender people out on the "wrong" day (4).

An overreliance on criminal sanctions within the COVID-19 responses of many countries has enabled a raft of human rights violations that not only undermine efforts to curtail the pandemic but also exacerbate pre-existing social challenges of marginalization, discrimination and poverty. A recent study conducted among sex workers in eastern and southern Africa showed that COVID-19 has coincided with a high frequency of police harassment and arrests (almost half the respondents had been assaulted or extorted by police officers), alongside diminished access to health facilities and HIV services (8). People who use drugs also lack safe options for accessing harm reduction services (4). In the United States of America, for example, over 100 000 drug overdose deaths were recorded between April 2020 and April 2021, a 28.5% increase that health authorities have in part attributed to reduced access to evidence-informed medications such as naloxone, an important pillar of comprehensive harm reduction (9).

Gay men and other men who have sex with men and transgender people have also been subject to arrest and abuse. For example, in Uganda, officials arrested at least 23 lesbian, gay, bisexual, transgender and intersex (LGBTI) youth who were living in a safe house in March 2020 (10). Most were charged with committing a "negligent act likely to spread an infectious disease" under the criminal code, allegedly because of the total number of people living in the house. While they were eventually released and all charges were dropped, they were never tested for COVID-19 during their detention, spent weeks in custody with no access to lawyers, and were horrifically brutalized, both by other prisoners and by guards (10).

There is no evidence that incarceration is an effective tool for fighting pandemics. Overcrowding, poor sanitation and ventilation, and denial of condoms, needle–syringes and other tools to prevent sexual and blood-borne infections make prisons and other closed settings ideal environments for infectious disease outbreaks. The prevalence of HIV among prisoners is six times higher than it is among adults in the general population, and SARS-CoV-2 has also spread rapidly and fatally through prisons around the world (11).

CRIMINALIZATION AND PUNITIVE LAWS AND POLICIES BASED ON SEXUAL ACTIVITY, SEXUAL ORIENTATION AND GENDER IDENTITY, DRUG USE AND HIV STATUS FURTHER EXPOSE ADOLESCENT GIRLS AND YOUNG WOMEN FROM KEY POPULATIONS TO EXTREME LEVELS OF VIOLENCE, STIGMA AND DISCRIMINATION. SUCH LAWS AND POLICIES ONLY DRIVE THEM FURTHER FROM ACCESSING THE HIV PREVENTION AND TREATMENT SERVICES THEY NEED, WITH LITTLE IF ANY RECOURSE TO GENDER AND SOCIAL JUSTICE FOR VIOLATIONS OF THEIR RIGHTS.

ADDRESSING DISCRIMINATION IN HEALTH CARE THAT DRIVES PEOPLE AWAY FROM SERVICES

When those most vulnerable to disease transmission avoid health services, pandemics continue to grow. Evidence from UNAIDS and other agencies shows that stigma and discrimination in health-care settings is disturbingly common.

Country data reported to UNAIDS show that the proportions of people belonging to key populations who avoid health-care services due to stigma and discrimination remain disconcertingly high. Across all key populations, at least one in three reporting countries stated that more than 10% of respondents avoided health care, including three in four countries for people who inject drugs. This has negative impacts along the continuum of care, from prevention and testing to treatment.

Non-discrimination is a fundamental precept of international human rights law, and UN Member States have an obligation to protect citizens from discrimination in private and public settings and to repeal discriminatory laws and policies. Both HIV and COVID-19 have shown the very real public health risks stemming from the discriminatory provision of public health services, which drives people away from seeking services and treatments.

One key element of an effective pandemic response is for governments to take immediate action to invest in non-discrimination policies and training for health personnel across health settings. Such work can be buttressed by public messaging campaigns that underscore the importance of addressing stigma and discrimination for improved public health outcomes.



A medical assistant measures the blood pressure of a patient at the Bokhtar City office of AFIF, an organization that provides medical, social and legal services to people living with HIV and key populations in Tajikistan. Credit: UNAIDS/N Kalandarov

PRIORITIZING GENDER-RESPONSIVE PANDEMIC EFFORTS

The impacts of AIDS and other pandemics are often profoundly gendered. Effective pandemic responses require attention to both the gendered impact of disease and the need for equitable, rights-based efforts to combat underlying inequities.

In sub-Saharan Africa, gender inequality contributes to the heightened risk of HIV faced by adolescent girls and young women in the region: six in seven new HIV infections among adolescents (aged 15 to 19 years) in the region occur among girls, and young women (aged 15 to 24 years) are twice as likely to be living with HIV as young men of the same age. Violence can further increase the risk of acquiring HIV infection for women, and violence against women living with HIV has been linked to reduced access and adherence to treatment, lower CD4 counts and higher viral loads (*13, 14*). However, men living with HIV in this region are less likely than women to seek an HIV test and to initiate and adhere to treatment, leading to worse health outcomes.

For COVID-19, men appear to have a higher proportion of hospitalizations, intensive care admissions and deaths (Figure 8), while women and girls face greater socioeconomic impacts (15). Women are being hit especially hard by job and income losses, a growing crisis of unpaid care, and rising levels of intimate partner violence, harmful practices and other forms of gender-based violence, including early, child and forced marriages, teenage pregnancy and maternal mortality (16–18).

Multiple studies investigating the effect of the COVID-19 pandemic on women and children have reported increased violence (19). Women also appear to be experiencing greater adverse mental health effects—including higher levels of stress, anxiety, depression and fear of COVID-19—than men (20, 21). In this context, effective responses have necessarily included ramping up sexual and reproductive health services and anti-violence efforts as a key part of the pandemic response.

WOMEN AND GIRLS FACE GREATER SOCIOECONOMIC IMPACTS FROM COVID-19, INCLUDING JOB AND INCOME LOSSES, A GROWING CRISIS OF UNPAID CARE, AND RISING LEVELS OF INTIMATE PARTNER VIOLENCE, FORCED MARRIAGES, TEENAGE PREGNANCY AND MATERNAL MORTALITY.

FIGURE 8. Gender differences along the COVID-19 clinical pathway, available global data, as of October 2021



Male Female

Note: n = number of countries that reported sex-disaggregated data.

Note: Just two countries (Austria and India) report vaccinations among non-binary people.

Source: The COVID-19 sex-disaggregated data tracker. October update report. Global Health 5050; 2021 (https://globalhealth5050.org/wp-content/uploads/October-2021-data-tracker-update.pdf).

Intersecting inequalities drive disparate pandemic impacts. The Ebola virus outbreaks in West Africa of 2014–2016 upended livelihoods, with women's livelihoods typically taking longer to recover than those of men (22, 23). For example, quarantine measures forced the closure of markets for food and other items, interrupting the livelihoods of traders in Liberia and Sierra Leone, 85% of whom were women, with many in the lowest income groups. Men also lost jobs, but a year after the first Ebola case had been detected, 63% of men had returned to work—compared with only 17% of women (22, 23).

During the Zika outbreak in Latin America in the mid-2010s, women were advised to delay pregnancy. However, the huge unfulfilled demands for sexual and reproductive health services in many countries—which especially affected women and girls in low-income neighbourhoods and those belonging to indigenous communities or racial minorities—undermined the ability of people to implement this advice (25).

Gender-responsive public health design can account for and address inequalities such as these.

Pandemics and poverty

Those living in poverty bear the brunt of many pandemics. Nearly two centuries ago, when cholera first spread across the world, it was quickly recognized as primarily a disease of the poor, and that inequality within societies was associated with poorer societal health outcomes (26).

Large-scale vaccination campaigns have fuelled recent progress against the disease, but long-term solutions require addressing underlying inequalities, including sanitation, hygiene and access to clean drinking water (27). More than 170 years after the first cholera pandemic, cases in high-income countries are extremely rare (and nearly always imported), but cholera remains endemic in dozens of countries, nearly all of them low-income or lower-middle-income (28, 29).

Poverty and lack of schooling are also formidable barriers to HIV services and the ability of women to claim their sexual and reproductive health and rights. For example, survey data from 32 countries show that women in lower wealth and education quintiles are less likely to access the family planning services they need (*30*). Similarly, men in lower wealth quintiles in 11 countries in sub-Saharan Africa with a high HIV prevalence were less likely than men in higher wealth quintiles to undergo voluntary medical male circumcision (VMMC) in order to reduce their risk of acquiring HIV (*31*).



REFERENCES

- 1. UN Commission on Human Rights, The Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights, 28 September 1984, E/CN.4/1985/4 (https://www.refworld.org/docid/4672bc122.html).
- Landmark court ruling in Egypt prohibits HIV discrimination in the workplace. In: UNAIDS [Internet]. 1 July 2016. Geneva: UNAIDS; c2021 (https://www.unaids. org/en/resources/presscentre/featurestories/2016/july/20160713_Egypt).
- 3. Handbook on HIV and human rights for national human rights institutions. OHCHR, UNAIDS; 2007 (https://www.unaids.org/sites/default/files/media_asset/jc1367-handbookhiv_en_0.pdf).
- 4. Rights in a pandemic. Lockdowns, rights and lessons from HIV in the early response to COVID-19. Geneva: UNAIDS; 2020.
- 5. Coronavirus: security forces kill more Nigerians than COVID-19. In: BBC News [Internet]. 16 April 2020. London: BBC; c2021 (https://www.bbc.com/news/ world-africa-52317196).
- 6. National Human Rights Commission press release on COVID-19 enforcement so far report on incidents of violations of human rights. In: National Human Rights Commission [Internet]. 15 April 2020. Abuja: National Human Rights Commission; c2021 (https://www.nigeriarights.gov.ng/nhrc-media/press-release/100-national-human-rights-commission-press-release-on-covid-19-enforcement-so-far-report-on-incidents-of-violation-of-human-rights.html).
- Kavanagh M, Agbla SC, Joy M, Aneja K, Pillinger M, Case A et al. Law, criminalisation and HIV in the world: have countries that criminalise achieved more or less successful pandemic response? BMJ Global Health. 2021;6:e006315.
- 8. A rapid scoping of the impact of COVID-19 on sex worker programmes in east and southern Africa. Pretoria: UNFPA East and Southern Africa; 2020 (https://esaro.unfpa.org/sites/default/files/pub-pdf/covid-19_sex_workers_report-ia.pdf).
- 9. Brooks B, Mishra M. U.S. drug deaths surpass 100,000 for first time, spurred by pandemic. In: Reuters [Internet]. 17 November 2021. Reuters; [updated 18 November 2021] (https://www.reuters.com/world/us/us-drug-overdose-deaths-top-100000-annually-cdc-2021-11-17/).
- 10. Press statement. 21 July 2020. Kampala: Human Rights Awareness and Promotion Forum; 2020 (https://www.hrapf.org/index.php/resources/other-publications/159-20-07-20-press-statement-on-filing-of-the-cosf-case-7/file).
- 11. Global Outbreaks. In: The COVID Prison Project [Internet]. c2021 (https://covidprisonproject.com/additional-resources/global-outbreaks/#:~:text=Of%20 832%20samples%20collected%20from,at%20the%20beginning%20of%20May).
- 12. Gender equality and justice critical for ending AIDS. In: UNAIDS.org [Internet]. 10 June 2021. Geneva: UNAIDS; c2021 (https://www.unaids.org/en/resources/ presscentre/featurestories/2021/june/20210614_gender-equality-and-justice).
- 13. Global and regional estimates of violence against women: prevalence and health effects of intimate partner violence and non-partner sexual violence. Geneva: WHO; 2013.
- 14. Hatcher AM, Smout EM, Turan JM, Christofides N, Stöckl H. Intimate partner violence and engagement in HIV care and treatment among women: a systematic review and meta-analysis. AIDS. 2015;29(16):2183-94.
- The COVID-19 sex-disaggregated data tracker. October update report. Global Health 5050; 2021 (https://globalhealth5050.org/the-sex-gender-and-covid-19-project/the-data-tracker/).
- 16. Global gender gap report 2021. Geneva: World Economic Forum; 2021 (https://www3.weforum.org/docs/WEF_GGGR_2021.pdf).
- 17. COVID-19: a threat to progress against child marriage. New York: UNICEF; 2021.
- Chmielewska B, Barratt I, Townsend R, Kalafat E, van der Meulen J, Gurol-Urganci I et al. Effects of the COVID-19 pandemic on maternal and perinatal outcomes: a systematic review and meta-analysis. Lancet Glob Health. 2021;9(6):e759-e772.
- Petermann A, O'Donnell M. COVID-19 and violence against women and children: a third research round-up for the 16 Days of Activism. Washington (DC): Center for Global Development; 2020 (https://www.cgdev.org/sites/default/files/covid-and-violence-against-women-and-children-three.pdf).
- Krubiner C, O'Donnell M, Kaufmann J, Bourgault S. Addressing the COVID-19 crisis' indirect health impacts for women and girls. Washington (DC): Center for Global Development; 2021 (https://www.cgdev.org/sites/default/files/COVID-Gender-Health-BRIEF.pdf).
- 21. Gender dimensions of the COVID-19 pandemic. Washington (DC): World Bank; 2020 (https://documents.worldbank.org/en/publication/documents-reports/ documentdetail/618731587147227244/gender-dimensions-of-the-covid-19-pandemic).
- 22. Bandiera O, Buehren N, Goldstein M, Imran R, Smurra A. The economic lives of young women in the time of Ebola: lessons from an empowerment programme. Washington (DC): World Bank; 2018.
- 23. Neglected and unprotected: the impact of the Zika outbreak on women and girls in northeastern Brazil. Human Rights Watch; 2017.
- 24. Wenham C, Smith J, Davies SE, Feng H, Grépin KA, Harman S et al. Women are most affected by pandemics—lessons from past outbreaks. Nature. 2020;583(7815):194-8.
- Cabal L. Tackling Zika: have we learned our lesson rights? In: Rewire [Internet]. 15 March 2016. Rewire News Group; c2021 (https://rewirenewsgroup.com/article/2016/03/15/tackling-zika-learned-lesson-rights/).
- 26. Williams AS. The rich man and the diseased poor in early Victorian literature. Atlantic Highlands (NJ): Humanities Press International; 1987.
- 27. Drop in cholera cases worldwide, as key endemic countries report gains in cholera control. In: WHO.int [Internet]. 19 December 2019. Geneva: WHO; c2021 (https://www.who.int/news/item/19-12-2019-drop-in-cholera-cases-worldwide-as-key-endemic-countries-report-gains-in-cholera-control).
- 28. Ali M, Nelson AR, Lopez AL, Sack DA. Updated global burden of cholera in endemic countries. PLoS Negl Trop Dis. 2015;9(6):e0003832.
- 29. World Health Organization. Weekly epidemiological record. 29 November 2019. 94(48):561-80.
- 30. Demographic and Health Surveys, 2015–2020.
- 31. Population-based HIV Impact Assessments, 2015-2019.

PEOPLE-CENTRED DATA SYSTEMS THAT HIGHLIGHT INEQUALITIES

The nearly real-time tracking of SARS-CoV-2 infections, COVID-19 deaths and vaccine coverage by multiple public health websites and major news providers has captivated people around the world over the last two years. The speed of COVID-19 data collection, aggregation and sharing is a remarkable achievement. What is often missing from these data, however, are the details: who is most vulnerable to the impacts of COVID-19, who is being reached, who is not being reached and why.

More granular data are needed to reveal the underlying disparities and inequalities that shape pandemics and their consequences. The global HIV response has built some of the most comprehensive data systems in global health and development, and dozens of countries are using those systems against COVID-19 and other health challenges (1). One of the world's most commonly used health information management systems, DHIS2, which is funded largely through HIV investments, is being used for planning and service delivery improvements for COVID-19 and other health priorities in 73 countries (2).

The HIV response also remains on the vanguard of community leadership and engagement in data collection and use. Community-led monitoring is increasingly being used as an accountability mechanism that empowers networks of key populations, other affected groups or other community entities to systematically and routinely collect and analyse qualitative and quantitative data on HIV service delivery. It reports to HIV programme managers and health decision-makers on what works well, what is not working and what needs to be improved, with suggestions for targeted action to improve outcomes.

Some countries still lack the capacity to collect and effectively use timely, disaggregated health data. Many do not collect sufficient data on priority populations, which can leave important aspects of their epidemics hidden from the response. In many low- and middle-income countries, for example, reliable data on COVID-19 trends remain scarce almost two years into the pandemic. In Africa, the additional burden of dealing with COVID-19 is straining already fragile health systems. They urgently need training, infrastructure improvements, modern equipment and technical support to transition from paper-based to electronic data collection systems (3). High mobile phone penetration can be used much more effectively to gather and share vital data in disease outbreaks (especially if exorbitant airtime costs are reduced).¹ Data stewardship and governance, however, must be enhanced to ensure that health data are collected and used in ways that protect people's privacy and right to confidentiality.



A participant reviews data during a consultation in Phnom Penh, Cambodia, on the Uproot scorecard. This community-led monitoring initiative collects quantitative and qualitative information on countries' efforts to achieve global targets for the AIDS response. Credit: Kyoungmi Kim/UNAIDS

 During the Ebola outbreaks in West Africa in 2014–2016, mobile phone data were used to model travel patterns, and handheld sequencing devices permitted more effective contact tracing and a better understanding of outbreak dynamics. See: Gebremeskel AT, Otu A, Abimbola S, Yaya S. Building resilient health systems in Africa beyond the COVID-19 pandemic response. BMJ Glob Health. 2021;6(6):e006108.

COMMUNITY-LED MONITORING IS TRANSFORMING HIV TREATMENT PROGRAMMES

The defects that hold back health programmes are not always obvious to service providers or to routine monitoring and evaluation processes. By systematically documenting the experience and knowledge of service users, community-led monitoring adds vital missing perspectives and information that can be used to improve the quality and use of health services.

Community-led monitoring is being built into an increasing number of HIV programmes in Africa, Asia and Latin America, as more evidence emerges of the value and impact of this approach. These inclusive monitoring models are improving services and rebuilding public trust by fostering a culture of collective problem-solving with health officials. For instance, health facility committees in Kenya, Peru and Zimbabwe have successfully advocated for reduced user fees, staff increases and other improvements that have led to the increased use of health services. Similarly, the use of community reports or scorecards in parts of Malawi and Uganda have led to more young people and men attending health facilities, shorter waiting times, cleaner facilities and higher rates of child immunization (4, 5).

A pioneering effort is the Regional Community Treatment Observatory in West Africa, which was set up in 2017 by the International Treatment Preparedness Coalition to help improve lagging HIV treatment programmes.² The model involves community members working with a support structure to collect quantitative and qualitative data on access to, and quality of, HIV services. Supervisors collect, verify and validate the data, which is then analyzed and used for advocacy and lobbying to bring about needed changes (6). The innovation has led to important improvements, including reduced drug stock-outs and better service quality, and it has contributed to rising rates of viral load suppression among people on HIV treatment (7).

In South Africa, faltering rates of retention in care are a major problem. A community-led monitoring effort named Ritshidze (which means "saving our lives" in the Venda language) is bringing to light deficiencies at the heart of low retention and finding solutions that enable more people to keep taking HIV treatment (8). Ritshidze collects data at more than 400 HIV treatment sites across the country, focusing on the poorest performing clinics.

In South Africa's Free State province from April to June 2021, for example, Ritshidze highlighted a slew of issues, including chronic staff shortages, long waiting times (five hours on average), unsuitable opening hours, unsafe surroundings, dirty facilities, lack of medicines (including of multimonth prescriptions for antiretroviral medicines) and the inconsiderate conduct of some health staff. Improvements have been proposed for each monitored facility, and health officials at the facility, district and provincial levels are being pressured to implement them (8).

Community scorecards are also being used in Viet Nam to track and improve service quality. Community members and health staff jointly develop a set of indicators, which they use to rate services. Fifteen months after being set up in January 2020, people using monitored facilities reported major improvements in the provision of free HIV prevention products (including condoms and sterile injecting equipment), information and counselling (see Figure 9) (9).

Knowing why people shun health services or resist public health measures is vitally important, as COVID-19 responses have discovered. Almost a year into the roll-out of SARS-CoV-2 vaccines in high-income countries, the reasons for vaccine resistance and hesitancy among substantial proportions of populations are still poorly understood (10).

Community-led monitoring helps bridge the gap between the best-laid plans of health strategies and the unruly ways in which they play out in reality. By tracking the quality and adequacy of services and identifying persistent hindrances and problems, the approach can reveal why some people avoid using health services, skip appointments, interrupt or stop taking medicines, or even refuse to be vaccinated against life-threatening diseases.

Crucially, it also helps strengthen political accountability for health programmes and services (11). Stronger accountability boosts public trust and confidence in health systems, a chronic challenge during pandemic crises.

With community-led monitoring, community members collect information at service sites and from patients. The information is then used in partnership with health providers and programme managers to quickly resolve problems that are identified; it can also be used, when needed, for advocacy to hold governments, donors and health programmes accountable for improving service accessibility and quality (11).

To work well, community-led monitoring requires training, supporting, equipping and paying community-led organizations to routinely monitor the quality and accessibility of health services (11). Community members identify their top priorities and devise indicators or metrics to see whether health services are fulfilling those priorities. They then collect the data, analyze the results, bring their insights to the attention of planners and managers of the services, and pressure officials to make the recommended improvements (12).



A Ritshidze community monitor interviews a client outside Bloemspruit Clinic in South Africa's Free State province. Credit: Ritshidze/R Horn

FIGURE 9. Clinic user ratings of service quality across three rounds of community-led monitoring at clinics in Binh Duong and Thai Nguyen, Viet Nam, January 2020–April 2021



Note: Quality of services: 1 = poorest quality; 10 = best quality.

Source: Nguyen LH, Nhat Thi Dang V, Thi Do P, Pllack T, Tuyet Thi Vo N, Tra Dang M et al. Community-led quality improvement of HIV services using community scorecards in Vietnam. International AIDS Society Conference, 18–21 July 20. Abstract OALD01LB02.

Community-driven monitoring was crucial for shoring up HIV and other health services during the early phases of the COVID-19 pandemic. The community-led Five Cities Project, for example, tracked the pandemic's impact on HIV services in major cities in China, Guatemala, India, Nepal and Sierra Leone. Managed by the International Treatment Preparedness Coalition and other partners, the project identified and publicized tactics to preserve those services (e.g., home deliveries of antiretrovirals and other medicines, use of social media and other digital tools, and multimonth dispensing of essential medicines). As health systems buckled under the impact of the COVID-19 pandemic, similar initiatives kept HIV services running in dozens of countries around the world.



Clients queuing outside Namahali Clinic in South Africa's Free State before the clinic opens. Credit: Ritshidze/R Horn

MILLIONS WITHIN KEY POPULATIONS REMAIN INVISIBLE TO PANDEMIC RESPONSES

A new analysis done by UNAIDS shows that millions of people who are at high risk of HIV infection globally are virtually invisible to many national HIV plans and programmes. Data reported to UNAIDS by many countries appear to underestimate the size of their key populations; as a result, their HIV programmes may be unbalanced, with potentially profound gaps in services for the populations in greatest need of them.

Since 2016, 52 countries have reported to UNAIDS a size estimate for at least one key population that meets standard criteria of quality and scope. For each key population, the median of those nationally adequate size estimates was compared to all the population size estimates reported to UNAIDS in recent years (Figure 10)³. The analysis estimates that more than 15 million people who would benefit from HIV prevention, care and treatment services are unaccounted for in population size estimates of reporting countries. In other words, the total number of female sex workers, people who inject drugs, gay men and other men who have sex with men and transgender women is probably double the current size estimates reflected in the HIV plans and strategies of these countries.

Underestimated population sizes are magnified by other data shortcomings for key populations. Biobehavioural surveys have been supplying the bulk of HIV-related data regarding key populations (13, 14). However, funding constraints and other decisions are causing a reduction in these surveys, with donors and countries now relying more on routine programme data that miss the large numbers of people who avoid health services due to lack of access and experiences of stigma and discrimination and harassment. This can lead to blind spots in countries with substantial HIV and other epidemics (e.g., viral hepatitis and sexually transmitted infections) among key populations (15).

Closing data gaps for key populations is critical to reaching them with the services they need. This must be done in a way that respects their privacy and the confidentiality of their data. Use of health data for other purposes, such as law enforcement, undermines confidence in services and data systems, violates the rights of patients, and reduces the likelihood that comprehensive, accurate data can be collected. Individual information related to key populations and criminalized behaviours should not be included in HIV service registers or reported to subnational or national data management units. National databases also should use unique identifiers rather than names to strengthen the confidentiality and security of data (16).

MANY COUNTRIES APPEAR TO UNDERESTIMATE THE SIZE OF THEIR KEY POPULATIONS; AS A RESULT, THEIR HIV PROGRAMMES MAY HAVE PROFOUND GAPS IN SERVICES FOR THE POPULATIONS IN GREATEST NEED OF THEM.

UNAIDS, WHO and the Global Fund reviewed all population size estimates reported by countries. A population size estimate was considered to be nationally adequate if it was of sufficient quality and scope to be used in the planning and budgeting of a national AIDS response. The median estimate for female sex workers is based on nationally adequate data from 29 countries, reflecting 17% of the global adult female population. The median estimate for gay men and other men who have sex with men is based on data from 29 countries, reflecting 12% of the global adult male population. The median estimate for people who inject drugs is based on data from 29 countries, reflecting 12% of the global adult male population. The median estimate for people who inject drugs is based on data from 29 countries, reflecting 12% of the global adult male population. The median estimate for people who inject drugs is based on data from 29 countries, reflecting 12% of the global adult male population. The median estimate for people who inject drugs is based on data from 29 countries, reflecting 12% of the global adult male population. The median estimate for people who inject drugs is based on data from 29 countries, reflecting 12% of the global adult male population. The median estimate for people who inject drugs is based on data from 25 countries, reflecting 57% of adults globally. The median estimate for is countries that reported size estimates represent the following percentages of the estimated total population: female sex workers within 48% of the adult female population; gay men and other men who have sex within 70% of the adult male population (male and female); and transgender women within 46% of the adult female population. Countries that have not submitted data are presumed to have no official data and are shown in grey in Figure 10.





Population within aggregated reported data

Expected population not represented in nationally adequate country-reported data

Expected population in countries that have not reported

* uses global median which includes 29 countries for sex workers, 29 countries for gay men and other men who have sex with men, 25 countries for people who inject drugs and 17 countries for transgender women.

n = number of countries in the region with nationally adequate size estimates.

Note: A population size estimate was considered to be nationally adequate if it was of sufficient quality and scope to be used in the planning and budgeting of a national AIDS response. The median estimate for female sex workers is based on nationally adequate data from 29 countries, reflecting 17% of the global female population. The median estimate for gay men and other men who have sex with men is based on data from 29 countries, reflecting 12% of the global male population. The median estimate for people who inject drugs is based on data from 25 countries, reflecting 57% of adults globally. The median estimate for transgender women is based on 17 countries, reflecting 17% of the global female population. The number of key populations unaccounted for in reported size estimates apply to 48% of the global female population for gay men and other men who have sex with men, 80% of men and women for people who inject drugs and 46% of women for transgender women. Countries that have not submitted data are presumed to have no official data and are shown separately in the bars. Source: UNAIDS special analysis, 2021.

USING SUBNATIONAL DATA TO ZERO IN ON SERVICE GAPS

Subnational geolocated data are important for focusing interventions where the risk of infection and the need for treatment and care are highest, especially when resources are constrained. As a result, more and more HIV programmes are using these data.

Early in the HIV epidemic, most countries tracked the spread of HIV by setting up sentinel surveillance systems that tested pregnant women attending select antenatal clinics for two to three months every two years. Countries have since transitioned from using that sporadic sentinel surveillance data to using the routine HIV prevalence data collected every time a pregnant woman goes into a clinic for antenatal care. This routine data is available from every clinic in the country, providing essential granular data to help improve understanding of the distribution of the epidemic across a country.

Countries are also increasingly collecting and analysing geolocated programme data in order to fine-tune their HIV responses. In the 2021 round of the UNAIDS-supported HIV epidemiological estimates, 38 countries used the Naomi modelling tool to generate subnational HIV estimates (Figure 11), which the United States President's Emergency Plan for AIDS Relief (PEPFAR) uses in its planning and decisions (17).

As access to subnational data increases, it becomes easier to fine-tune interventions and track and detect variations in results (Figure 11). This information can then be used to enhance the precision and effectiveness of interventions (18, 19).



Two colleagues review data at the Kutabila Call Center in Zimbabwe. The centre, which is run by the Zimbabwe National Network of People Living with HIV, gathers data on client satisfaction, visibility of implementing partners, and trends and patterns of access to services such as HIV prevention, multimonth dispensing of antiretroviral medicines and viral load testing. Credit: UNAIDS





Note: HIV incidence estimated as new HIV infections per 1000 person-years at risk. Note: No data reported for Cabo Delgado province in Mozambique. Source: UNAIDS epidemiological estimates, 2021.

DISAGGREGATED DATA REFINES HIV RESPONSES IN SUB-SAHARAN AFRICA

Sex- and age-disaggregated HIV data are revealing underlying patterns in the AIDS pandemic and reshaping responses, especially in sub-Saharan Africa. For example, country-produced epidemiological estimates and survey data show that women and adolescent girls in sub-Saharan Africa are at considerably greater risk of acquiring HIV than men and boys (Figure 12).⁴ Substantial evidence, however, also demonstrates that empowering adolescent girls and young women can not only reduce their HIV risk but also confer a broad array of lifelong health and social benefits. Education, in particular, reduces HIV vulnerability: data from several sub-Saharan African countries clearly show that staying in school longer reduces the risk of HIV infection, and that increased educational attainment among women is linked with their increased control over their sexual and reproductive health and rights (20–22). These findings underscore the importance of national investments in education systems for building strong, resilient societies, and they have inspired greater efforts to empower women with education and economic opportunities, including cash transfers that help them stay in school.

At the same time, data collected through UNAIDS Global AIDS Monitoring and epidemiological estimates show that men living with HIV in sub-Saharan Africa are less likely than women to be diagnosed with HIV, or to start and stay on HIV treatment (Figure 13). Recognition of this gap has encouraged stronger efforts to improve testing and treatment coverage among men in that region, including the multipartner MenStar Coalition. By September 2021, MenStar had linked nearly 1.3 million men to HIV treatment in southern Africa, with 91% of them suppressing their viral loads to very low levels.⁵



^{4.} While they represent only 10% of the population, adolescent girls and young women (aged 15 to 24 years) accounted for 25% of new HIV infections in sub-Saharan Africa in 2020 (based on 2021 UNAIDS estimates).

^{5.} For more information, please see: https://menstarcoalition.org/about-menstar/.

FIGURE 12. Distribution of new HIV infections and of the population, by age and sex, sub-Saharan Africa, 2020



FIGURE 13. HIV testing and treatment cascade, women (15+) compared to men (15+), sub-Saharan Africa, 2020



Women (aged 15+ years) living with HIV

Men (aged 15+ years) living with HIV



Source: UNAIDS special analysis, 2021.

It is generally assumed that prevailing norms of masculinity encourage higher risk behaviours in men and discourage them from seeking health care (23). But close analysis of facility attendance data is revealing a more nuanced picture and pointing to some simple, practical improvements (24).

Studies from Malawi, for example, show that men in that country actually visit health facilities regularly. They attend outpatient departments for acute care, and they attend other departments, accompanying children or spouses (24, 25). A recent study in 36 villages found that 70% of men in need of HIV testing had visited a health facility in the previous 12 months. In an earlier study, almost one quarter of rural men (22%) had accessed health services for their own health in the previous two months (26). But those men are seldom offered HIV testing services, even in settings where HIV is highly prevalent: in the recent study, only 7% of men who need an HIV test were offered one (26). In addition, most HIV services were organized around reproductive and child health services, a pattern also seen elsewhere (27).

Routine programmatic data have shown that outreach strategies that focus on HIV self-testing, index testing and work-based testing have increased testing rates among men (28). The analysis of data from Malawi suggest that other, currently available options can also be used better. For example, outpatient departments and other facilities can capitalize on men's visits by actually offering HIV testing and by making other basic adjustments, including more convenient operating hours (extending beyond regular workday hours), reduced waiting times, and greater privacy and confidentiality (24, 25). In many cases, these changes would also benefit women.

UNAIDS DATA SHOW THAT MEN LIVING WITH HIV IN SUB-SAHARAN AFRICA ARE LESS LIKELY THAN WOMEN TO BE DIAGNOSED WITH HIV, OR TO START AND STAY ON HIV TREATMENT. OUTREACH STRATEGIES THAT FOCUS ON HIV SELF-TESTING, INDEX TESTING AND WORK-BASED TESTING HAVE INCREASED TESTING RATES AMONG MEN.

REFERENCES

- Achrekar A. Our global plan to fight HIV has been a strategic weapon against COVID. In: The Hill [Internet]. 20 September 2021. Washington (DC): The Hill; c2021 (https://thehill.com/opinion/healthcare/573056-our-global-plan-to-fight-hiv-has-been-a-strategic-weapon-against-covid).
- 2. DHIS2 [Internet]. Oslo: University of Oslo (https://dhis2.org).
- 3. Gebremeskel AT, Otu A, Abimbola S, Yaya S. Building resilient health systems in Africa beyond the COVID-19 pandemic response. BMJ Glob Health. 2021;6(6):e006108.
- Gullo S, Galavotti C, Sebert Kuhlmann A, Msiska T, Hastings P, Marti CN. Effects of a social accountability approach, CARE's Community Score Card, on reproductive health-related outcomes in Malawi: a cluster-randomized controlled evaluation. PLoS One. 2017;12(2):e0171316.
- 5. Danhoundo G, Nasiri K, Wiktorowicz ME. Improving social accountability processes in the health sector in sub-Saharan Africa: a systematic review. BMC Public Health. 2018;18(1):497.
- The Community Treatment Observatory model explained. Summary brief. International Treatment Preparedness Coalition; 2019 (https://www.aidsdatahub. org/sites/default/files/resource/itpc-community-treatment-observatory-model-explained-2019-summary.pdf).
- "They keep us on our toes": how the Regional Community Treatment Observatory in West Africa improved HIV service delivery, strengthened systems for health, and institutionalized community-led monitoring. International Treatment Preparedness Coalition; September 2020 (https://itpcglobal.org/wpcontent/uploads/2020/10/ITPC-2020-They-Keep-Us-On-Our-Toes.pdf).
- Free state of health. Johannesburg: Ritshidze; 2021 (https://ritshidze.org.za/wp-content/uploads/2021/09/Ritshidze-State-of-Health-Free-State-2021.pdf).
 Nguyen LH, Nhat Thi Dang V, Thi Do P, Pllack T, Tuyet Thi Vo N, Tra Dang M et al. Community-led quality improvement of HIV services using community
- scorecards in Vietnam. International AIDS Society Conference, 18–21 July 2021. Abstract OALD01LB02.
 Tufecki Z. The unvaccinated may not be who you think. In: New York Times [Internet]. 15 October 2021. New York (NY): The New York Times Company; c2021 (https://www.nytimes.com/2021/10/15/opinion/covid-vaccinas-unvaccinated.html).
- O'Neill Institute, Treatment Action Campaign, Health Gap, ITPC, ICW, Sexual Minorities Uganda (SMUG) et al. Community-led monitoring of health services: building accountability for HIV service quality. Washington (DC): O'Neill Institute for National and Global Health Law; 2020 (https://healthgap. org/wp-content/uploads/2020/02/Community-Led-Monitoring-of_Health-Services.pdf).
- Yawa A, Rambau N, Rutter L, Honermann B, Norato L, Kavanaugh M. Using community-led monitoring to hold national governments' and PEPFAR HIV programmes accountable to the needs of people living with HIV for quality, accessible health services. International AIDS Society Conference, 18–21 July 2021. Abstract PED453.
- Volkmann T, Chase, M, Lockard AM, Henningham D, Albalak R. Lessons learned from the implementation of biological-behavioural surveys of key populations in the Caribbean. AIDS Educ Prev. 2019;30:528-41.
- 14. Hakim A, Macdonald V, Hladik W, Zhao J, Burnett J, Sabin K et al. Gaps and opportunities: measuring the key population cascade through surveys and services to guide the HIV response. J Int AIDS Soc. 2018;21(S5):e25119.
- 15. Davis SLM. The Uncounted: Politics of Data in Global Health. Cambridge Studies in Law and Society. Cambridge: Cambridge University Press, 2020.
- 16. Consolidated guidelines on person-centred HIV patient monitoring and case surveillance. Geneva: WHO; June 2017.
- 17. PEPFAR 2021 Country and Regional Operational Plan (COP/ROP) guidance for all PEPFAR countries. Washington (DC): U.S. Department of State (https:// www.state.gov/wp-content/uploads/2020/12/PEPFAR-COP21-Guidance-Final.pdf).
- Local Burden of Disease HIV Collaborators. Subnational mapping of HIV incidence and mortality among individuals aged 15–49 years in sub-Saharan Africa, 2000–2018, a modelling study. Lancet HIV. 2021;8:e363-e375.
- Van Schalkwyk C, Dorrington RE, Seatlhodi T, Velasquez C, Feizadeh A, Johnson LF. Modelling of HIV prevention and treatment progress in five South African metropolitan districts. Sci Rep. 2021;11(1):5652.
- 20. Behman JA. The effect of increased primary schooling on adult women's HIV status in Malawi and Uganda: universal primary education as a natural experiment. Soc Sci Med. 2015;127:108-15.
- Pettifor AE, Levandowski BA, MacPhail C, Padian NS, Cohen MS, Rees HV. Keep them in school: the importance of education as a protective factor against HIV infection among young South African women. Int J Epidemiol. 2008;37:1266-73.
- Santelli JS, Mathur S, Song Z, Huang TJ, Wei Y, Lutalo T et al. Rising school and enrollment and declining HIV and pregnancy risk among adolescents in Rakai District, Uganda, 1994–2013. Global Soc Welf. 2015;2:87-103.
- 23. Sileo KM, Fielding-Miller R, Dworkin SL, Fleming PJ. What role do masculine norms play in men's HIV testing in sub-Saharan Africa? A scoping review. AIDS Behav. 2018;22(8):2468-79.
- 24. Dovel K, Dworkin SL, Cornell M, Coates TJ, Yeatman S. Gendered health institutions: examining the organization of health services and men's use of HIV testing in Malawi. J Int AIDS Soc. 2020;23(Suppl 2):e25517.
- Dovel K, Balakasi K, Gupta S, Mphande M, Robson I, Khan S et al. Frequency of visits to health facilities and HIV services offered to men, Malawi. Bull World Health Organ. 2021;99(9):618-26.
- Yeatman S, Chamberlin S, Dovel K. Women's (health) work: a population-based, cross-sectional study of gender differences in time spent seeking health care in Malawi. PLoS One. 2018;13(12):e0209586.
- 27. Chikovore J, Gillespie N, McGrath N, Orne-Gliemann J, Zuma T. Men, masculinity, and engagement with treatment as prevention in KwaZulu-Natal, South Africa. AIDS Care. 2016;28 Suppl 3:74-82.
- 28. Sharma M, Barnabas RV, Celum C. Community-based strategies to strengthen men's engagement in the HIV care cascade in sub-Saharan Africa. PLoS Med. 2017;14:e1002262.

© Joint United Nations Programme on HIV/AIDS (UNAIDS), 2021

Some rights reserved. This work is available under the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 IGO licence (CC BY-NC-SA 3.0 IGO; https://creativecommons.org/licenses/by-nc-sa/3.0/igo/).

Under the terms of this licence, you may copy, redistribute and adapt the work for noncommercial purposes, provided the work is appropriately cited, as indicated below. In any use of this work, there should be no suggestion that UNAIDS endorses any specific organization, products or services. The use of the UNAIDS logo is not permitted. If you adapt the work, then you must license your work under the same or equivalent Creative Commons licence. If you create a translation of this work, you should add the following disclaimer along with the suggested citation: "This translation was not created by UNAIDS. UNAIDS is not responsible for the content or accuracy of this translation. The original English edition shall be the binding and authentic edition".

Any mediation relating to disputes arising under the licence shall be conducted in accordance with the mediation rules of the World Intellectual Property Organization (http://www.wipo.int/amc/en/mediation/rules).

Suggested citation. [Title]. Geneva: Joint United Nations Programme on HIV/AIDS; 2021. Licence: CC BY-NC-SA 3.0 IGO.

Third-party materials. If you wish to reuse material from this work that is attributed to a third party, such as tables, figures or images, it is your responsibility to determine whether permission is needed for that reuse and to obtain permission from the copyright holder. The risk of claims resulting from infringement of any third-party-owned component in the work rests solely with the user.

The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of UNAIDS concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by UNAIDS in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by UNAIDS to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall UNAIDS be liable for damages arising from its use.

UNAIDS/JC3041E

