20 YEARS
CHAMPIONING COMMUNITY LEADERSHIP · ITPC ·

ITPC
INTERNATIONAL TREATMENT
PREPAREDNESS COALITION

COMMUNITY-LED ACTION IS THE CRUCIAL COUNTERMEASURE

20 YEARS

ITPC ✊ CHAMPIONING COMMUNITY LEADERSHIP

ITPC

INTERNATIONAL TREATMENT
PREPAREDNESS COALITION

ABOUT

The International Treatment Preparedness Coalition (ITPC) is a global coalition of people living with HIV and community activists working to achieve health and social justice for all through robust community engagement. Formed in 2003 by a group of 125 HIV activists from 65 countries at a meeting in Cape Town, ITPC actively advocates for treatment access in eight regions across the globe. ITPC believes that the fight for treatment remains one of the most significant global social justice issues. ITPC is an issue-based coalition. **It actively advocates for treatment access through three strategic focus areas:**

#MakeMedicinesAffordable

#WatchWhatMatters

#BuildResilientCommunities

TO LEARN MORE ABOUT ITPC, VISIT ITPCGLOBAL.ORG

The **#Make Medicines Affordable (MMA)** consortium works to bring down the prices of medical products for HIV, TB, HCV, and COVID-19 medicines by removing intellectual property (IP) and other access barriers. The MMA consortium is led by civil society organizations from over 20 countries. It includes people living with HIV, people living with HCV, people living with TB, lawyers, health experts, and activists, all choosing to challenge the IP measures that support profit but not people.

#Watch What Matters is a community monitoring and research initiative that gathers data on access to and quality of HIV treatment globally. It fulfills one of ITPC's core strategic objectives: to ensure that those in power remain accountable to the communities they serve. It relies on a unique model that empowers communities to systematically and routinely collect and analyze qualitative and quantitative data on access barriers, and to use this data to guide advocacy efforts and promote accountability.

Regarding **#Build Resilient Communities**, the progress made to date in access to HIV treatment and improvements in the quality of HIV services is based on communities self-organizing and demanding their right to health. ITPC understands the importance of creating meaningful partnerships within the movement to form broader coalitions to fight for social justice.

SUGGESTED CITATION

ACKNOWLEDGEMENTS

ABBREVIATIONS

AAF	AIDS Access Foundation
ADP	Activists Development Program
ARV	Antiretroviral
CAB	Community Advisory Board
CCGs	Community Consultative Groups
CLM	Community-led monitoring
CTO	Community Treatment Observatory
DHIS	District Health Information System
DNP+	Delhi Network of People Living with HIV
DRV	Darunavir
DTG	Dolutegravir
EECA	Eastern Europe and Central Asia
JEE	Joint External Evaluation
GPI	Global Public Investment
HIC	High-income country
HMIS	Health Management Information Systems
ITPC	International Treatment Preparedness Coalition
MMA	Make Medicines Affordable
MCM	Medical countermeasures
M&E	Monitoring and evaluation
MENA	Middle East and North Africa
MIC	Middle-income country
MMD	Multi-month dispensing
NAC	National AIDS Commission
NGO	Non-governmental organizations
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PrEP	Pre-exposure prophylaxis
RCTO-WA	Regional Community Treatment Observatory-West Africa
SDGs	Sustainable Development Goals
TB	Tuberculosis
TDF/FTC	Tenofovir/emtricitabine
TLD	Tenofovir/lamivudine/dolutegravir
TNP +	Thai Network of People Living with HIV
UHC	Universal health coverage
UN	United Nations
VMMC	Voluntary medical male circumcision
WHO	World Health Organization

TABLE OF CONTENTS

EXECUTIVE SUMMARY

EXECUTIVE SUMMARY

A COUNTERMEASURE IS A CORRECTIVE, A REMEDY, OR A CURE. In a medical context, a countermeasure is "critical for minimizing morbidity and mortality in the event of a large-scale public health emergency."[1] Community-led action meets these criteria. It always has.

Through advocacy, engagement, education, and evidence-gathering — the core elements of community-led action — this countermeasure makes communities healthier, health systems more effective, and societies better able to continue essential health services before, during, and after crises, including climate events, conflicts, and outbreaks.

In this report, ITPC presents the evidence for the impact of this community-led action. We share the data on how community-led monitoring at health facilities is linked to resilience and return to full capacity after COVID-19; how ongoing work to secure affordable medicines drives cost savings that allow countries to make scant budgets go further; and how communities are the first to respond in crises, with astute analyses and actions that address and avert service disruptions and emergencies for community members in close to real time.

From this evidence, we move to the argument that community-led action must be considered a crucial countermeasure to address current health issues and prevent future outbreaks. To secure this access, community-led action must be understood and embraced beyond the HIV-impacted communities where it has been honed and practiced for years as part of transformative, fearless transnational activism.

Twenty years ago, people living with HIV fought for and won access to affordable antiretrovirals (ARVs). ITPC was founded by activists who knew that communities must be involved in every aspect of a health response, from understanding the science to designing the services to setting the policies. We put preparedness into our name and our mission — and we took action.

In HIV and TB, there's widespread, though incomplete, recognition of the impact of community leadership. As such, funding is allocated for community-led monitoring (CLM) — a critical component of this action cycle — and well-articulated systems for community engagement and education exist.

THIS REPORT IS A ROADMAP AND AN ADVOCACY TOOL FOR MOVING TO A GLOBAL ACCESS PLAN FOR COMMUNITY-LED ACTION

TREAT PEOPLE RIGHT

In contrast, the approach of other arenas, including pandemic preparedness and response and universal health coverage (UHC), is much less consistent. Community engagement gets referenced in high-level documents, but it isn't resourced adequately or rigorously defined. While individual countries, communities, and/or programs are developing innovative approaches to collaboration in many other settings, those with the most valuable insights and greatest need are left out of high-level decision-making processes.

This has to change. **This report is a roadmap and an advocacy tool for moving from a piecemeal approach to a global access plan for community-led action.** It includes recommendations for a global access plan for community-led action, such as securing high-level political commitment, robust, reliable funding for activist "technology transfer" to ensure equitable global access, and an innovation agenda. All lead to necessary and transformative change.

MEET THE COUNTERMEASURE

An analysis of ITPC data and insights from 2019 to 2022 makes it abundantly clear that community-led action contributes to core pandemic preparedness and response outcomes. Honing in on the past three years — encompassing the COVID-19 pandemic, the Russian invasion of Ukraine, and numerous local and global climate-related crises and outbreaks — **we can clearly demonstrate that community-led action was a crucial countermeasure that has mitigated crises.** Where it was in place, it delivered the highest level of impact possible in the International Health Regulations' Joint External Evaluation (JEE) indicator, which is used to measure community engagement. As Figure 2 shows, the JEE is a voluntary, collaborative multi-stakeholder assessment of country progress

toward pandemic preparedness and response. The metrics for community engagement aren't perfect. We know that communities have insights into more than socio-behavioral issues, but they are a starting point for justifying investment and measuring progress. These JEE metrics include:

→ **Active involvement in and co-design of emergency response initiatives**

→ **Systematic stakeholder mapping and engagement**

→ **Collection and analysis of community feedback and socio-behavioral data to inform the public health response**

Our data tie these activities to impact.

Community-led action increases health system resilience by:

→ **Mitigating service disruption**

→ **Identifying and addressing acute (and entrenched) problems**

→ **Pinpointing where to put available resources**

→ **Speeding resumption of and demand for services**

For example, as described in more detail on page 24, ITPC EECA has, since 2020, helped people living with HIV to continue accessing their ARVs when COVID-19 lockdowns and the Russian invasion of Ukraine cut off access to public clinics. In India, the ITPC South Asia Regional Coordinator and co-founder of the Delhi Network of People Living with HIV (DNP+), Loon Gangte, started planning for ART access under lockdown before the restrictions even began (see page 19).

MAKE THE PLAN

We call for a global access plan of community-led action. Expanding global coverage of community-led action benefits the communities who engage in the action. But it isn't just about helping these communities, which are often viewed as "beneficiaries" of aid and investment. When community-led action is in place, everyone benefits: governments, funders, researchers, and private-sector stakeholders, as well as societies and countries.

COMMUNITY-LED ACTION ACCESS PLAN

ACCESS PLAN PILLAR	RECOMMENDATION
High-level political commitment	**Include clear, consistent commitments** to comprehensively define community-led action in all health-, climate-, and development-related declarations, accords, and guidance.
Robust, reliable funding for activist "technology transfer" to ensure equitable global access	**Establish a global hub for accessing funding and activist expertise** in gathering, analyzing, and taking impactful action that drives change. This hub can also track global progress on access to community-led action worldwide.
An innovation pipeline	**Develop a community-led action research and innovation agenda** that includes an ideas incubator, operational research, and piloting and scaling of impactful strategies and approaches.

ACCESS PLAN ACTIONS TO UNLOCK IMPACT

IMPACT AREA Mitigating service disruption

ACTIONS

→ **Map and use additional investments** to ensure sufficiency of specific funding policies and reserves to support rapid response systems aimed at preventing service disruptions during a crisis, especially at large government-backed donors, such as the Global Fund to Fight AIDS, Tuberculosis and Malaria, the Pandemic Fund, UNITAID, and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR).

→ **Develop crisis response systems and decision-making bodies** that include communities, and support delegation and outsourcing of key functions to non-governmental organizations (NGOs) in emergency. These systems,

inclusive of community leadership, should be in place before new crises emerge.

→ **Resource and prioritize partnerships** between governments and grassroots communities and their organizations to address health system and disease-specific issues on an ongoing basis, recognizing this as an investment in pandemic preparedness and response.

→ Community organizations should **invest resources into documenting and promoting their rapid response systems.**

IMPACT AREA Identifying and addressing acute (and entrenched) problems

ACTIONS

→ **CLM of routine health services should be a required component** of excellent (level 4) performance for the Joint Evaluation Exercise "community engagement" evaluation area.

→ **Governments should embed CLM in national processes,** using innovative approaches (such as Ministry of Health national accreditation systems) for health facilities that demonstrate excellence in addressing problems that have been identified by CLM data.

→ **Community-designed rapid assessment tools and measures should be in place in grassroots groups before crises,** with policy support, such as travel permits, channels for feeding back information and avenues, and funding for accessing emergency supplies. Groups that mobilized during COVID-19 should lead the development of these context-specific readiness programs.

IMPACT AREA Putting available resources to optimal, equitable use

ACTIONS

→ Health system shifts and innovations, including product introduction plans for new treatments, preventive strategies, diagnostics, and integration initiatives (such as HIV and primary healthcare), should **include earmarked resources for community-led action at a subset of facilities.**

→ **Funders of civil society advocacy and activism should structure grants with the flexibility and scope to support work on access to medicines and monitoring of health sites and systems.** These complementary areas require different skill sets and activities. Civil society groups need to have sufficient unrestricted or flexible resources for taking action on multiple levels and for adjusting nimbly to changing contexts.

IMPACT AREA Speeding resumption of and demand for services

ACTIONS

→ Investments in community-led action that gathers qualitative and quantitative data at the facility level and engages health workers and community members in

discussion and action **should be part of any risk mitigation strategy for pandemics, outbreaks, and other shocks.**

Each of these components maps directly to the current approach to building support for and supplies of other countermeasures that are most commonly deployed in health crises. We recognize that this language is embedded in and derives from a market-driven, capitalist, extractive economy. We also understand the

need to pursue justice and global health equity in the short-, mid-, and long-term. At this time, it is essential to incorporate community-led action into the current paradigm, using the principles, approaches, and concepts prevailing in global health. We believe that this short- and mid-term work will lead to long-term systemic change.

LETTER FROM THE EXECUTIVE DIRECTOR

TIME IS SHORT. THE WORLD IS IN CRISIS. SO I WILL GET RIGHT TO THE POINT:

Community-led action is a countermeasure that matters every bit as much as vaccines, new health technologies, tests, and treatments in responses to current — and future — outbreaks and pandemics.

In fact, it may matter more.

Yet, shockingly, this crucial countermeasure isn't a cornerstone of global plans, agendas, strategies, and financing mechanisms for improving pandemic preparedness and overall health for all.

We're choosing our words deliberately here. A countermeasure is an evidence-based strategy for quickly and effectively responding to an outbreak or pandemic. In the past year, the World Health Organization (WHO) launched a taskforce on ensuring access to "medical countermeasures" (MCMs); they are a hot topic in many forums.

AIDS activists know all about MCMs: ARVs are a medical countermeasure. So are HIV and viral load testing, TB testing and treatments, and many other diagnostics, medications, and vaccines used to prevent, treat, and care for people during these ongoing pandemics.

And because of our experience with the fight for health justice, we also know that the best MCMs in the world don't get to the people who need them without community-led action. It's that simple. Investments in commodities will be wasted, for example, due to the exorbitantly high prices of medical products, due to patent monopolies that keep them out of reach, or due to stigma and discrimination-related barriers in the absence of community-led action in plans, strategies, budgets, and programs.

That's why we're calling community-led action a countermeasure: lives depend on it. These are the lives of people living with and vulnerable to HIV and/or TB, the lives of people displaced by climate disasters and conflicts, and the lives of people in the community where the next outbreak happens.

Countermeasures must be in the right places, at the right time, in the right quantity, and with the right quality. Community-led action is no different.

TO MAKE REAL CHANGE, COMMUNITY-LED ACTION MUST BE AVAILABLE AND IMPLEMENTED ON A GLOBAL SCALE

To make real change, community-led action must be available and implemented on a global scale. That's why we need an access plan for this essential countermeasure — now.

Expanding access to community-led action is just one step towards a world that works differently. We are living at a time of unprecedented inequity and rising authoritarianism. The gaps between rich and poor are greater than ever. Progress towards achieving the Sustainable Development Goals (SDGs) has been slowed or stalled by the COVID-19 pandemic and the current global economic downturn. As climate crises and conflicts are destabilizing households, communities, and society, everyone is being forced to do more — with less.

The world needs to work differently. We need a paradigm shift in how financing flows, how — and by whom — decisions are made, and how impact is measured.

As we discuss in the conclusion of this report, that paradigm shift can be achieved with a global embrace of Global Public Investment (GPI – see page 13). This is a framework for moving foreign aid away from a charity-based approach that diminishes the autonomy and resources of low-income countries and communities, and to a model in which everyone contributes, benefits, and decides. Faced with global challenges of every form, GPI and community-led action should be a source of optimism. It isn't a vaccine or a cure, but it is a potent and necessary countermeasure for the current reality of colliding pandemics and poly-crises. We've put the proof of impact in these pages, along with a clear-eyed analysis of where we and our closest allies have to grow and change. **We're ready for the hard work of fighting for a more just and healthy future for all.**

Are you?

IN SOLIDARITY,

SOLANGE BAPTISTE
EXECUTIVE DIRECTOR, ITPC

WHAT IS GLOBAL PUBLIC INVESTMENT?

Global Public Investment (GPI) is a new approach to raising money to solve the world's problems and spending it in a way that is fair and equitable. In more technical terms, GPI is concessional, international public financing based on three principles that support a horizontal, equitable approach to addressing the world's challenges.

The three principles are:

1. **All contribute**
2. **All decide**
3. **All benefit**

Applying these principles to global financing will change how the world uses and benefits from a limited pool of monetary resources. By centering communities in the **"all decide"** principle, GPI will expand the aims of "aid" (such as how to spend the money and use the resources), from narrow, paternalistic, donor-driven poverty-reduction plans to community-driven agendas that take on challenges of inequality and sustainability. **"All benefit"** means exactly that – prioritizing support for the communities that bear the brunt of climate, health, and economic crises actually benefits all of us. This means moving away from the (disproven) idea that initiatives that benefit high-income countries (HICs) and communities will "trickle down" and moving toward solutions put forward by communities on the frontlines of inequalities, resulting in powerful and systemic change.

"All contribute" means that all countries will put resources into a shared pool, not just rich countries pledging money (which is what usually happens); low- and middle-income countries will make contributions, as well. It acknowledges that non-monetary offerings (such as knowledge, ideas, and in-kind support) are contributions that are just as valuable as financial resources. When all three principles are in place, the world will be able to take action and allocate resources for a shared agenda for lasting change.

TO LEARN MORE ABOUT GPI, VISIT GLOBALPUBLICINVESTMENT.NET/WHAT-IS-GPI/

PART 1
MEET THE COUNTERMEASURE

MEET THE COUNTERMEASURE

THE COMPONENTS

Countermeasures work when they contain all of the high-quality components needed for impact. Many effective vaccines contain an antigen that teaches the immune system what to look for and an adjuvant that enhances the immune reaction to the vaccine. Take away the adjuvant or the antigen, and your vaccine doesn't offer the same level of protection. This doesn't stop companies from making and consumers from buying drugs, tests, and shots that lack the quality and consistency needed to protect health and save lives.

Today, one of the main threats to community-led action is a glut of look-alike approaches and concepts. As we discuss in Part II, current drafts of United Nations (UN) high-level declarations on pandemic preparedness and response, TB, and UHC make mention of community engagement and involvement, but they stop short of naming and prioritizing the specific type of community-led action needed to transform the global health landscape.
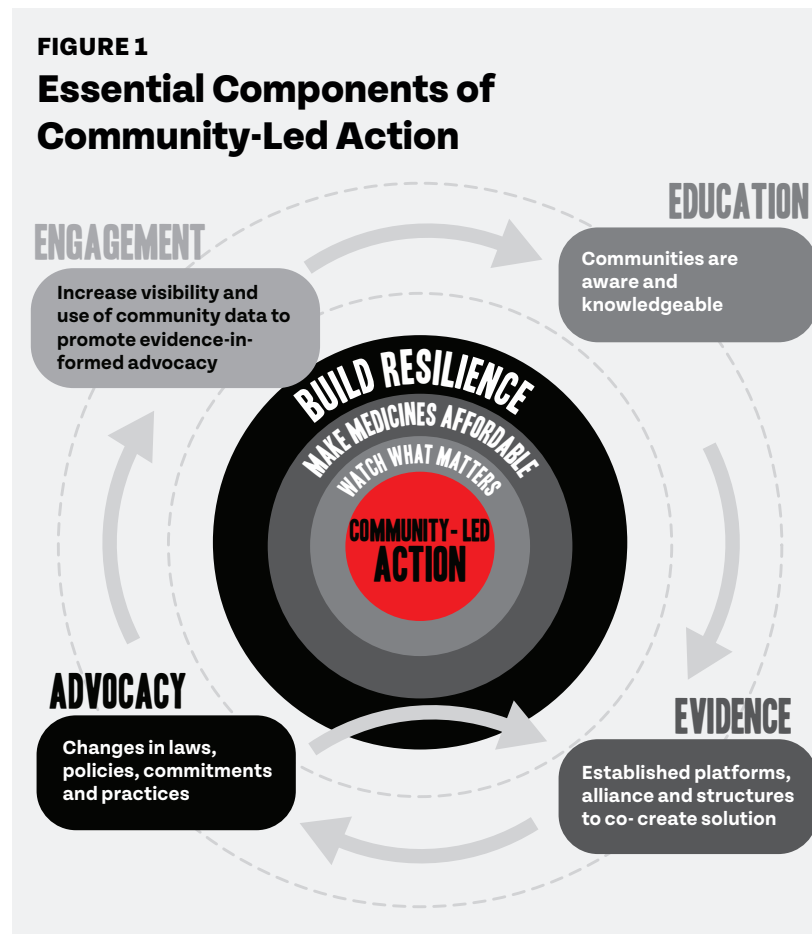
Community-led action that includes all of the components shown in Figure 1 is a cycle of change, driven by the insights, actions, and abilities of communities. This work benefits everyone, everywhere. Community-led action addresses the budgets, policies, social norms, and global frameworks that drive inequities. It is a countermeasure that addresses diseases and health problems – and the forces that create and feed them. Bringing this vision to life requires activists to be clear, consistent, and uncompromising in our language, the design of strategies, and the execution of our campaigns. This is hard.

FIGURE 1
Essential Components of Community-Led Action

ENGAGEMENT
Increase visibility and use of community data to promote evidence-informed advocacy

EDUCATION
Communities are aware and knowledgeable

BUILD RESILIENCE
MAKE MEDICINES AFFORDABLE
WATCH WHAT MATTERS
COMMUNITY-LED ACTION

ADVOCACY
Changes in laws, policies, commitments and practices

EVIDENCE
Established platforms, alliance and structures to co-create solution

Funds are limited. Civil society spaces for organizing are shrinking as crises multiply. We need housing, food, education, and the funds to keep the lights on, so sometimes we take resources that reflect donor priorities, even if they don't mirror our own.

While acknowledging these challenges, no one can afford to compromise on the quality of community-led action – not funders, governments, health workers, policy makers, or activists.

We all need the countermeasure in its most effective form, which includes four crucial components (Figure 1):

→ **Education**

→ **Evidence**

→ **Engagement**

→ **Advocacy**

There isn't a set recipe for these elements. The relative importance of investing in and undertaking education, engagement, evidence-gathering, and advocacy changes over time, depending on epidemiology, local and national priorities, new technologies, and, unfortunately, emergent crises. But each element must be in place, or the benefits to individuals, systems, and societies aren't delivered. Table 1 summarizes what, why, and how things can go wrong for each element.

TABLE 1 **Core Components of Community-Led Action**

	WHAT	WHY	WHERE IT CAN GO WRONG
Education	These are health literacy workshops, discussion groups, trainings, and materials that explain the science of specific diseases in community-friendly, accessible language. Likewise, information about public health and policy-making that affect issues that communities care about should be clear and straightforward.	Health systems, like societies, are based on trust. Trust is built on clarity, transparency, and a common understanding of what matters to people and what can be done to change conditions. Community health literacy is the most efficient, sustainable way to build confidence in and demand for systems and strategies that work.	Plenty of education efforts pay community groups (or outsiders) to offer information about services or tools that the community hasn't prioritized. The education is intermittent, often crisis-based, and tells people what should matter, rather than listening to their priorities.
Evidence	Document experiences, conditions, outcomes, and the "root causes" of a problem.	Health system data can identify some problems. But it can't say why the problem is happening or what to do to fix it. Communities can. This practice is formally called "community-led monitoring." Local problems also stem from global agreements such as patents, price structures, funding approaches, trade, and other policies. Gathering the evidence that explains inequities is also essential.	Simply collecting data doesn't drive change. Programs that focus on documentation and don't have the resources for long-term follow-up don't yield results. Monitoring and advocating for budgets, procurement procedures, and prices of medical countermeasures is complementary to monitoring at the health facility level. This may be done by the same groups or by groups working with coordinated agendas (see ITPC MENA case study on page 32).
Engagement	Hold dialogues and meetings within communities and between communities, decision-makers, and duty-bearers to look at data and figure out what to do next.	Engagement is where evidence gets put to use. Community-led action can turn evidence into impact – if, and only if, there are adequate time, space, and resources for problem-solving to happen, and all parties are involved in equal dialogue and consultation.	Engagement is often used to describe one-off consultations or one-way conversations, where the community is invited to hear about plans, programs, or products they had no part in developing or is given a limited role to simply validate pre-determined plans and ideas.
Advocacy	Embark on targeted action to make a change in the conditions impacting people's lives.	Some problems exist because the people with power don't want to solve them. Advocacy redistributes power and enables solutions.	Advocacy takes time, its impact isn't always obvious, and it is not always comfortable. Advocacy is a specific skill that requires adequate resourcing and patience.

THE EVIDENCE

Within the field of HIV, community-led action has support from normative agencies, with dedicated documents, guidelines, and funding streams. Although there isn't always enough money, and there's always more to be done, support has been institutionalized. CLM – which is just one component of community-led action – is a priority intervention of the Global Fund's 2023-2028 Strategy[3] and has been funded through numerous country grants. Since 2020, PEPFAR has made country-level CLM a condition for funding.[4] UNAIDS has developed a guide on principles and best practices and has, with a range of other partners, supported technical assistance and shared learning around the world.[5]

The funding flows because community-led monitoring makes programs, communities, and systems better.

There's plenty of evidence for this. But it hasn't translated into earmarked funding and prioritization of other arenas, including pandemic preparedness and response and UHC. The first USD 338 million in grants from the Pandemic Fund[6] will go to countries that were encouraged to engage communities in proposal development, but they are not required or incentivized to incorporate community-led action as a priority intervention.

Compared with other diseases and health issues, HIV has been defined by transformative, fearless, transnational activism, led by and for those most impacted. It has, because of this ceaseless fight, received large amounts of funding compared with many other diseases. These hard-fought successes sometimes get used as an excuse to set aside approaches and systems

COMMUNITY-LED ACTION INCREASES HEALTH SYSTEM RESILIENCE

developed in the context of HIV. Then, there's the fact that the HIV pandemic is decades old. It's not an outbreak or a new emergency. Its relevance to pandemic preparedness and response may not be immediately clear.

An analysis of ITPC data and insights makes it abundantly clear that community-led action contributes to core pandemic preparedness and response outcomes. Honing in on the past three years – encompassing the COVID-19 pandemic, the Russian invasion of Ukraine, and numerous local and global climate-related crises and outbreaks – we can clearly demonstrate that community-led action was a crucial countermeasure. Where it was in place, it delivered the highest level of impact possible in the Joint External Evaluation indicator[7] used to measure community engagement (see Figure 2), including:

→ **Active involvement in and co-design of emergency response initiatives**

→ **Systematic stakeholder mapping and engagement**

→ **Collection and analysis of community feedback and socio-behavioral data to inform the public health response**

Our data tie these activities to impact. To put it succinctly: **community-led action increases health system resilience.**

FIGURE 2

How We Can Measure Community Engagement in Pandemic Preparedness

JEE stands for "Joint External Evaluation." It's a voluntary external assessment that countries do to measure their progress in fulfilling the International Health Regulations, the globally endorsed framework for preventing and responding to pandemics threats. *** SPAR is the "State Party Self-Assessment Annual Report"** that countries undertake to measure their progress against IHR indicators, including community engagement.

LEVELS OF ADVANCEMENT / SPAR* INDICATORS

1 — **Mechanisms for community engagement in public health emergencies, including guidelines and/or SOPs, are in development.** Community engagement activities are largely one-way information-sharing activities and limited to disease control programmes — such as maternal and child health, malaria, tuberculosis, HIV and AIDS, polio, and neglected tropcial diseases. Community enagement efforts are not systematically linked to the emergency response.

2 — **Mechanisms for systematic community engagement in public health emergencies, including guidelines and/or SOPs, have been developed.** Community engagement activities involve some community participation, including consulting and gathering their feedback on decisions and actions.

3 — **Communities are actively involved in emergency response and co-design emergency response initiatives.** Stakeholders, such as community leaders, faith-based organizations, and civil society are mapped but only engaged on an ad hoc basis. Formal or informal community feedback mechanisms, such as hotlines and social-behavioural research, are established and used to inform emergency responses. Commuinity engagement coordination mechanisms exist at national, intermediate, and community levels.

4 — **Communities are actively involved in emergency response and co-design emergency response initiatives.** Stakeholders, such as community leaders, faith-based organizations, and civil society are mapped and systematically engaged. Emergency responders are trained and surge capacity mechanisms for community engagement are in place and operational. Collection and analysis of community feedback and socio-behavioural data at national, intermediate, and primary public health response level are conducted on an ad hoc basis.

JEE and SPAR indicators are a key way that countries measure and report progress against pandemic preparedness goals. The new Pandemic Fund's results framework is based on progress against JEE and SPAR indicators. The community engagement indicators aren't perfect – RCCE, or risk communication and community engagement often involves asking communities to report data that matters to public health authorities. This data may not be a priority for communities. But these indicators and the funds that support work towards them can be used to drive investments and actions that show the true impact of community-led action as a crucial countermeasure.

There are many ways to define resilience. One framing for health systems is the ability to prepare for, adapt to, absorb, and learn from shocks.[8] Shocks can be environmental and epidemiological (drought, fire, flood, outbreak), but they can also be triggered by changes in policies, political regimens, funding conditionalities, conflicts, and military invasions.[9]

Establishing resilience is a top priority. Take just one of many recent and current shocks: COVID-19. Between late 2020 and late 2021, more than 90% of WHO Member States responding to a global assessment reported disruptions to at least one essential health service. Across countries, in this period, nearly half of 29 essential services were disrupted.[10] In late 2022, 84% of countries participating in the WHO survey continued to report that at least one essential health service was disrupted.[11]

The future depends on building systems that function better – and community-led action has to be part of these systems. One meta-analysis of health system function in fragile and conflict-affected countries concluded: "Community engagement in response to shocks reduced the risk of trust issues, and enhanced health systems' ability to adapt to changing situations."[12] ITPC's own data support this conclusion, as described in the case studies below.

From 2020 to 2023, community-led action contributed to resilience in direct, quantifiable ways that warrant its inclusion as a required component of risk-mitigation investments in health systems.

Our website, ITPCglobal.org, has reports and documentation spanning decades of work. Below, we've summarized core findings about this crucial countermeasure and its impact on:

→ **Mitigating service disruption**

→ **Identifying and addressing acute (and entrenched) problems**

→ **Putting available resources to optimal use**

→ **Speeding resumption of and demand for services**

MITIGATING SERVICE DISRUPTION

When crises hit, health services have to continue. People need routine and critical care, prevention, and treatment. Interruptions cause cascading problems that last well beyond the initial crisis. Community-led action can ensure continuity from the outset. Over the past three years, ITPC and partners used community-led action, including evidence gathering, education, engagement and advocacy with government, industry, other NGOs, and recipients of care to rapidly set up systems for continuing essential services.

KEY FINDINGS

Using pre-existing relationships with government, industry, other NGOs, and communities, activists prevented service disruptions:

→ **More than 1,000 people living with HIV continued to access ARVs during COVID-19 lockdowns and after the Russian invasion of Ukraine.**

→ **An estimated 700 people living with HIV in India continued to receive ARVs during the first months of lockdown.**

AVERTING HIV AND HCV TREATMENT INTERRUPTIONS DURING LOCKDOWN: A CASE STUDY FROM INDIA

In March 2020, ITPC South Asia Regional Coordinator Loon Gangte knew what was coming. India hadn't yet locked down, but China and other countries had. He wrote out a message that was posted in the window of all of the 11 ARV and HCV treatment centers in Delhi. The message was simple: "Due to COVID-19, there could be an emergency or lockdown. So if you are in need of HCV or HIV medications, please call." He included four or five cell phone numbers with his own. Then he and his fellow activists wrote a letter to the National AIDS Commission (NAC). "Our adherence is non-negotiable," they declared.

At first, the NAC brushed off the concerns. But within days, Gangte and two of his colleagues from DNP+ were spending every waking hour crisscrossing Delhi, Uttar Pradesh, and Punjab to collect medications and lists of recipients of care from hospitals, then traveling up 300 kilometers by motorcycle to deliver them. Ultimately, this three-person team reached 700 people over about six weeks. They stopped only when the state shifted its policy so that people living with HIV and people living with HCV could access their medication in the nearest treatment center during lockdown, even if that wasn't their regular clinic site.

The response was possible because Gangte and his comrades had:

→ **Cooperation from government leaders and hospital officials**

→ **Trust from the community they were supporting**

→ **Commitment to and resources for acting during a crisis**

Years of engagement, education, activism, and advocacy put these building blocks in place. Long-term work laid the foundation for rapid action. As Gangte noticed, the people willing to take on the risk of delivering the medications were also directly impacted by the problem.

"Before COVID, there were lots of people and lots of organizations working on HIV. After COVID, there are lots of people working on HIV. But I keep thinking, 'I never saw you in those COVID days. To me, that is the essence of community. We work for ourselves.'"

"THAT IS THE ESSENCE OF COMMUNITY. WE WORK FOR OURSELVES."

ACCESS PLAN ACTIONS

→ **Map existing investments and fill any gaps identified** to ensure sufficiency of specific funding policies and reserves to support rapid response systems aimed at preventing disruptions during a crisis, especially at large government-backed donors, such as the Global Fund, the Pandemic Fund, UNITAID, and PEPFAR.

→ **Develop systems for delegating and outsourcing key functions to NGOs in emergencies and have this delegation system running before new crises emerge.**

→ **Resource and prioritize partnerships between governments and communities** to address health system and disease-specific issues on an ongoing basis in recognition that this is an investment in pandemic preparedness and response.

→ **Community organizations should invest resources into documenting and promoting their rapid response systems.**

IDENTIFYING AND ADDRESSING ACUTE (AND ENTRENCHED) PROBLEMS

Impact by Crisis

Global crises have local impacts. The specific needs differ by community, and the most vulnerable people often are the last to be involved in setting priorities or receiving relief. Community-led action pinpoints these and other acute problems and helps address them.

In March 2020, when Nepal's lockdown began, Dristi Nepal, an advocacy organization of women living with HIV who use drugs, went into "crisis mode," providing emergency food and toiletries to members. As word of Dristi's support spread through the community, more requests came in. ITPC and Dristi developed a rapid needs assessment tool for women in need of emergency support and used this information to inform the government and other partners about the most urgent needs. The activists were able to secure the necessary permits to visit extremely vulnerable

women and provide emergency health services and food aid, which prevented these women from getting ill or starving.[13]

ITPC worked with women of diverse identities living with or affected by HIV and groups who were working with women and girls living with HIV to understand their experiences of accessing sexual and reproductive health and rights services. This work, which began just prior to COVID-19,[14] continued during the pandemic,[15,16] with virtual and in-person evidence collection and engagement. This identified immediate needs for food, income, and resources to address gender-based and intimate partner-based violence. It also yielded concrete recommendations for funders seeking to provide support about how to structure grants and aid to reach the people who need it most. This kind of information reduces the risk that limited resources will be wasted.
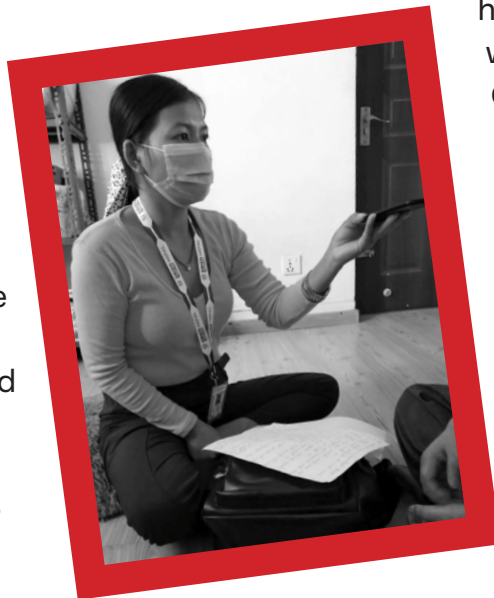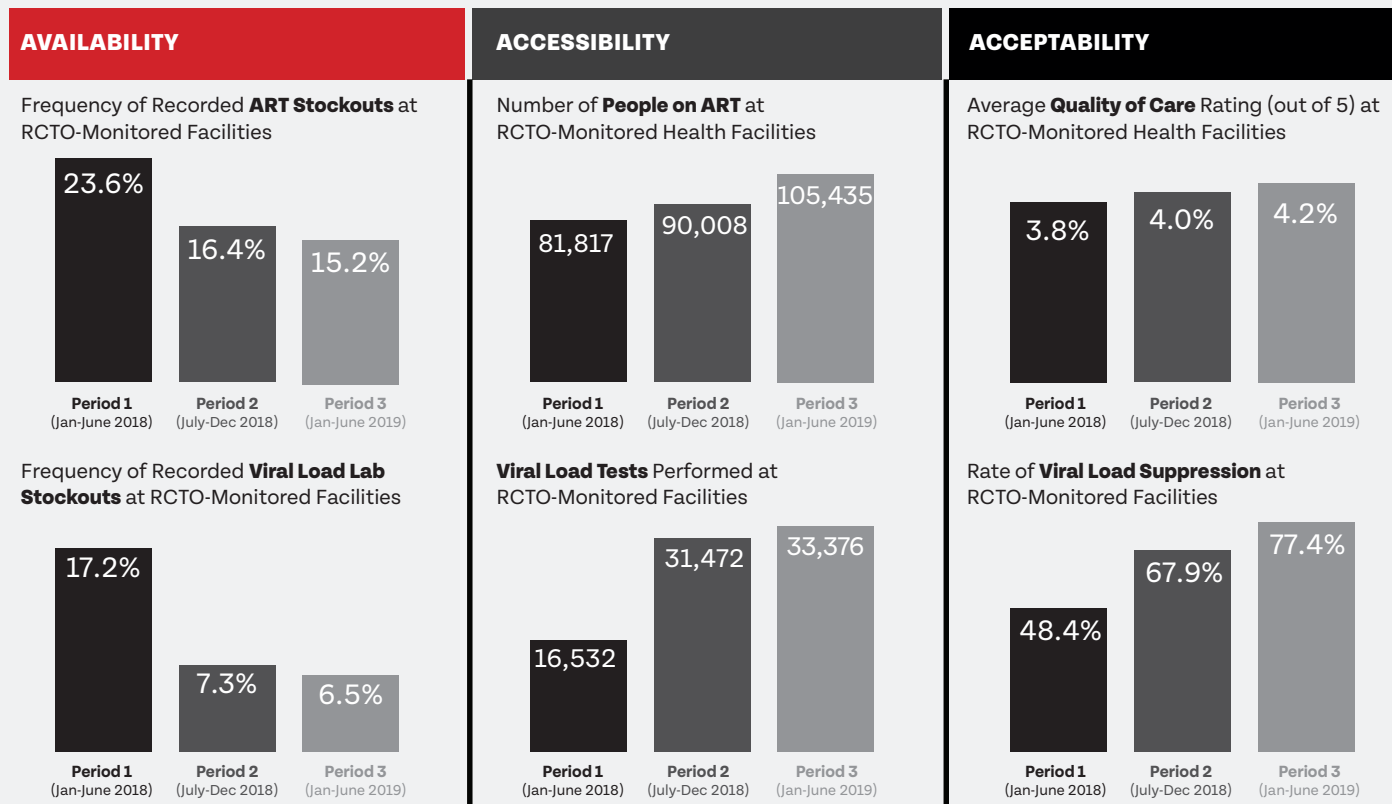
FIGURE 3

Community-led Action Led to Improvements at Sites Monitored by the West Africa Regional Community Treatment Observatory (RCTO)

AVAILABILITY	ACCESSIBILITY	ACCEPTABILITY

AVAILABILITY

Frequency of Recorded **ART Stockouts** at RCTO-Monitored Facilities

- 23.6% — **Period 1** (Jan-June 2018)
- 16.4% — **Period 2** (July-Dec 2018)
- 15.2% — **Period 3** (Jan-June 2019)

Frequency of Recorded **Viral Load Lab Stockouts** at RCTO-Monitored Facilities

- 17.2% — **Period 1** (Jan-June 2018)
- 7.3% — **Period 2** (July-Dec 2018)
- 6.5% — **Period 3** (Jan-June 2019)

ACCESSIBILITY

Number of **People on ART** at RCTO-Monitored Health Facilities

- 81,817 — **Period 1** (Jan-June 2018)
- 90,008 — **Period 2** (July-Dec 2018)
- 105,435 — **Period 3** (Jan-June 2019)

Viral Load Tests Performed at RCTO-Monitored Facilities

- 16,532 — **Period 1** (Jan-June 2018)
- 31,472 — **Period 2** (July-Dec 2018)
- 33,376 — **Period 3** (Jan-June 2019)

ACCEPTABILITY

Average **Quality of Care** Rating (out of 5) at RCTO-Monitored Health Facilities

- 3.8% — **Period 1** (Jan-June 2018)
- 4.0% — **Period 2** (July-Dec 2018)
- 4.2% — **Period 3** (Jan-June 2019)

Rate of **Viral Load Suppression** at RCTO-Monitored Facilities

- 48.4% — **Period 1** (Jan-June 2018)
- 67.9% — **Period 2** (July-Dec 2018)
- 77.4% — **Period 3** (Jan-June 2019)

Established in 2017, the West Africa Regional Community Treatment Observatory included partners and monitoring programs in Benin, Côte d'Ivoire, Gambia, Ghana, Guinea-Conakry, Guinea-Bissau,* Liberia, Mali, Senegal, Sierra Leone, and Togo

Impact in the Context of Routine Service Delivery

Governments, funders, and program implementers collect, analyze, and share information on a wide range of indicators. These data point to problems, such as people not being tested for HIV or other conditions or not receiving treatment. The data can sometimes show issues with equity, for example, young people, key populations, women, migrants, and many other groups having less access than the general population. But while health system data can point to problems, it can't reliably identify solutions. It can say what's happening – but not why. Health system data doesn't routinely include the experiences of recipients of care or health workers and other qualitative information. Community-led action brings clarity to the scientific and policy contexts that shape health services (education), sets priorities for collecting data (evidence), works to understand it (engagement), and uses it to solve problems and shape outcomes at health facility and systems level (advocacy).

Figure 3 gives one of many examples of how this works. Over 12 months, from 2018 to 2019, ITPC's Regional Community Treatment Observatory-West Africa (RCTO-WA) recorded positive changes in six key areas of HIV service delivery.[17] The positive trends reflect the impact of feedback loops between the RCTO-WA data collectors and community members, health

facility staff, and government officials. A culture of collective problem-solving led to a range of changes that, together, shifted performance in the right direction. These changes included: shifts in how viral load data were reported to central databases in Mali; successful advocacy for additional viral load machines in Gambia; and development of differentiated service delivery manuals and policies in Ghana and Sierra Leone to better reach key populations and move towards improvements in procurement, supply, and management of HIV and TB medicines and commodities.[18] Some problems were solved on the spot in conversations at the facility level; other findings were discussed at quarterly meetings of Community Consultative Groups. These multi-stakeholder forums are typically chaired by high-level political officials and have garnered strong support from government, evidenced by inclusion in Global Fund grant proposals, PEPFAR funding, and requests from health ministries for scale up.

Across countries where Community Treatment Observatories have been in action, government demand for community insights into health services has increased over time. In South Africa, the West Rand provincial health authority has given community data collectors access to their District Health Information System data to facilitate access to certain quantitative indicators, freeing up more time for more in-depth discussions and monitoring on community-identified pain points. The West Rand health department also used CLM data to work with clinics to improve policies and protocols for multi-month dispensing (MMD) of HIV pre-exposure prophylaxis (PrEP) and condom distribution.[19]

KEY FINDINGS

→ **Research and mutual aid are highly compatible – even in a crisis.** Community-embedded groups can combine mutual aid and emergency assistance with rapid assessments that generate usable information about acute issues to guide government and NGO action, almost in real time. For example, during the COVID-19 pandemic, more healthcare facilities implemented MMD of ARVs, something that people living with HIV and their advocates had long been fighting for. Rapid assessments highlight the need to strengthen supply chain management since several facilities reported stockouts of essential medicines and commodities.[20]

→ **Community-generated insights are additive to government data.** Community findings enrich government and program data. In Togo, the service supervisor at a major teaching hospital uses community data to cross-check information on prevention of HIV vertical transmission in the central database. Managers at Malawi's Ministry of Health used CLM data to justify expansion of working hours at public hospitals and to increase resources for HIV testing during the COVID-19 pandemic. Government officials at the Ministry of Health in Zimbabwe used CLM data to corroborate their own findings, and then took action that shortened the duration of ARV and HIV test kit stockouts.

→ **A focused program can lead to national solutions.** Community-led action, based on problems identified at selected sites, prompts policy changes that improve the performance of national HIV services. In Côte d'Ivoire,[21] the Ministry of Health used CLM data to eliminate user fees paid by people living with HIV and to improve health sector governance, laboratory

systems, Health Management Information Systems, and monitoring and evaluation (M&E). In Gambia, Community Treatment Observatory (CTO) data has been used to shine a spotlight on facility-level needs for quality improvement. High-level, data-driven advocacy has resulted in two specific commitments from the country's National Assembly Health Select Committee. First, the committee promised to engage the Ministry of Health and National AIDS Secretariat on performance improvement plans for health facilities. Second, the committee promised to engage the Ministry of Finance on additional budgetary allocation to the HIV response.[22] In India, the CLM project yielded valuable data on TB and HIV services from the perspectives of recipients of care and healthcare workers: it inspired real-time advocacy and rapid responses to identified needs, including providing ART to refugees from Myanmar who were stranded on the border with China, together with mental healthcare, adherence support, linkage to HIV services, and advocacy to roll out video-observed TB treatment.[23]

ACCESS PLAN ACTIONS

→ **CLM of routine health services should be a required component of excellent (level 4) performance for the JEE "community engagement" area of evaluation.**

→ **Community-designed rapid assessment tools should be in place with grassroots groups before crises,** with policy supports, such as travel permits, channels for feeding back information, and avenues for accessing emergency supplies, established in advance. Groups that mobilized during COVID-19 should lead the development of these context-specific readiness programs.

MITIGATING HEALTH SERVICE DISRUPTIONS DURING MULTIPLE CRISES: A CASE STUDY FROM ITPC EASTERN EUROPE AND CENTRAL ASIA

During the first year of the COVID-19 pandemic, lockdowns and travel restrictions prevented many people from reaching health services. For people living with HIV, as for people living with many other conditions, this lack of access was life-threatening: interrupted access to ARVs, TB treatment, and other medications can lead to drug resistance, which is associated with return of illness and increased risk of death. In addition, interruptions in HIV and TB treatment can increase the risk of onward transmission, as well as negatively impact mental health by exacerbating stress and anxiety.

In numerous countries, when it became clear that people living with HIV were losing access to medications, ITPC EECA implemented a rapid response system that allowed people living with HIV to access ARVs when they were not able to obtain them from public clinics, such as for Russian-speaking people who could not return home due to travel restrictions, or foreign citizens in Russia facing the same problem.

ITPC EECA already had extensive experience in dealing with drug stockouts. It collaborated with the Patients in Control movement to build a website (**pereboi.ru**) to receive and respond to requests for help obtaining antiretrovirals. To respond, ITPC EECA and collaborators needed an emergency drug stock and a vast network of contacts abroad.

ITPC EECA mobilized a network of pre-existing relationships and capacities. It relied on its market research analyses to identify the most-needed drugs, reached out to respective companies for donations, and reassigned
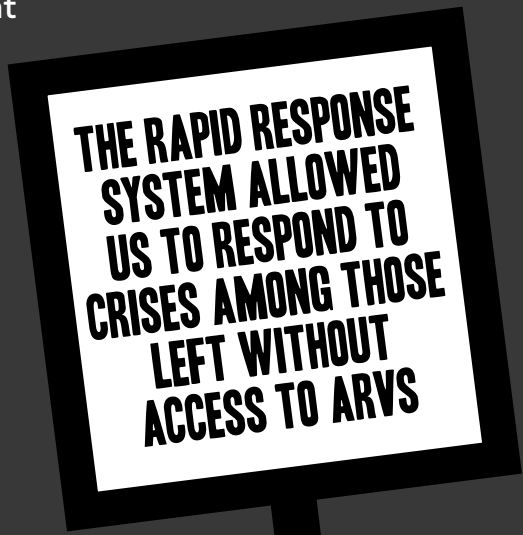
staff to coordinate drug shipments and referrals for people abroad; it also worked via a partnership agreement with an NGO that had a pharmaceutical license (which was essential for complying with the drug circulation regulations). Later, the same system was used during the war in Ukraine, with a specific website (**helphiv.ru**) created to collect messages from refugees in need of medications.

The rapid response system allowed ITPC-EECA to identify and respond to crises among foreign citizens who were left without access to ARVs. For over four and a half months in Russia, from May to September 2020, 449 foreign citizens from 19 countries, mostly in EECA, received at least a one-month emergency supply of ARVs. In total, over 1,000 monthly courses of ARVs were distributed, representing donations provided from five organizations, including originator and generic pharmaceutical companies and an NGO. An additional 232 people, who were stuck abroad in 47 countries, received referrals to partner organizations or healthcare facilities in the respective countries; this part of the project was implemented in collaboration with Life4me+. In most cases, coordinators helped establish contacts with a local NGO or healthcare facility, sometimes assisting with booking appointments. Drawing from this experience, ITPC EECA and its partner organizations built a database of contacts in various countries to deal with emerging treatment access issues. In total, from the beginning of the pandemic until 31 December 2020, almost 700 people were covered by the rapid response project. Almost all the work was done using existing expertise and resources, except for medicine donations.

In 2022, ITPC EECA and partner organizations relied on the experience of the COVID-19 response to help refugees fleeing from the war in Ukraine get ARVs in other countries. By 31 December 2022, 383 people living with HIV in Russian territory, 93% of them Ukrainian citizens, had received emergency ARV supplies, which were donated by four pharmaceutical companies. During the project, **helphiv.ru** helped reach even more people living with HIV: in total, over 900 monthly ARV courses were distributed. Some people came to ITPC EECA to refill their supplies as the process of enrollment in the government treatment program turned out to be lengthy and cumbersome, with challenging requirements for documentation to establish eligibility. People also received free testing and counseling support from friendly healthcare professionals when their ARV regimen was switched or treatment was interrupted, or, for example, they were treated for new comorbidities and ARV side effects. In other countries, 14 people were counseled and referred to partner organizations or healthcare facilities as of 31 December 2022.

The absolute number of people covered may seem comparatively small, but the scope largely depends on the available resources as the system can be easily expanded by recruiting more coordinators to reach people in need of medications – and by simultaneously investing in the system's visibility. An essential element of the proposed approach is support from pharmaceutical companies in the form of drug donations or funds to purchase medications. **Donors and governments need to join with civil society in holding companies and other stakeholders accountable.**

> THE RAPID RESPONSE SYSTEM ALLOWED US TO RESPOND TO CRISES AMONG THOSE LEFT WITHOUT ACCESS TO ARVS

PUTTING AVAILABLE RESOURCES TO OPTIMAL, EQUITABLE USE

The current global economic downturn cuts across high-, middle-, and low-income countries. It is exacerbating inequities in all settings and forcing countries, communities, households, and individuals to do more with less. In this context, every investment – of time, energy, and money – has to deliver as much as it can. All too often, people who are directly affected by policy decisions and who have valuable insights about where and how to use available resources have little or no input on setting priorities at local, national, or global levels. As discussed in the introduction, the GPI framework is a concrete plan for transforming the terms and outcomes of decision-making and resource allocation. Community-led action makes resources work better and more equitably at all levels.
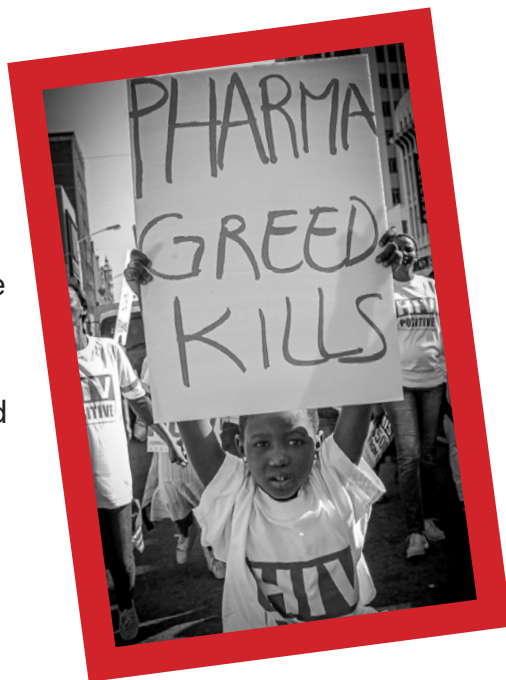
THE FINDINGS

→ PrEP, ART initiations, and HIV testing yield[24] (the percentage of tests administered that come back positive) have increased at sites with community-led monitoring, education, and engagement (see Figures 4, 5, and 6).

→ Data from our RCTO-WA and community-led monitoring efforts in Malawi showed low rates of HIV testing and service usage among key populations, who have a disproportionate burden of HIV. Local engagement and problem-solving helped bring more key populations into clinics[25] (see Figure 7).

→ Civil society coalitions have led countless campaigns to protect and expand access to affordable medications with results that save money for health systems. The campaigns and commodities vary by country. Here are some examples:

→ In Argentina, activists challenged patent applications that would have allowed monopoly owners to set high prices for tenofovir and emtricitabine (TDF/FTC), ARVs used to prevent and treat HIV, and sofosbuvir, a direct-acting antiviral medicine that is part of the cure for HCV. The challenge worked. The patents were withdrawn, and several manufacturers were able to produce these drugs at lower costs. Government procurement from a local generics manufacturer resulted in annualized savings of USD 14 million for TDF/FTC and USD 7.5 million for sofosbuvir.[26]

→ In Thailand, the AIDS Access Foundation (AAF) and Thai Network of People Living with HIV (TNP+) successfully opposed a pending patent application from a drug company (Toyama/Fuji) on favipiravir, an antiviral drug initially used to treat COVID-19. As the result of tireless advocacy, including policy dialogues with the Director General of the Department of Intellectual Property, legal filings, and community organizing, AAF and TNP+ played a key role in the Thai government's rejection of the patent application.[27]

→ In Ukraine, 100% LIFE used research and analysis to determine that there were pathways to procurement of generic darunavir (DRV) in the country. 100% LIFE tested its research and analysis in 2020 when, as a recipient of a Global Fund grant with responsibility for purchasing ARVs, it sought proposals and awarded a contract for generic DRV, the first such procurement in Ukraine. In late 2020, the Ukraine state procurement agency allowed generics manufacturers to participate in a call for proposals for ongoing DRV supply, and three generics competitors submitted bids. Generic competition has reduced the price for DRV, from USD 7.25-7.50 to USD 2.5 per tablet, generating an estimated annualized savings of USD 803,000.[28]

FIGURE 4

Community-led Action Helped Improve the Average Number of New PrEP Initiations (per month) at 33 Facilities in Malawi and South Africa Monitored as Part of ITPC's Citizen Science Project
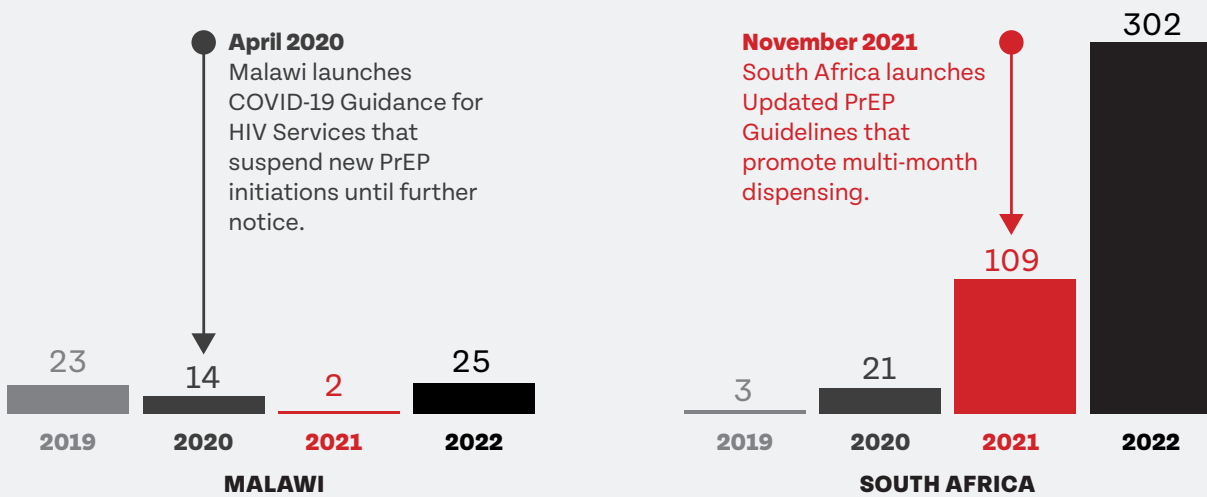

April 2020
Malawi launches COVID-19 Guidance for HIV Services that suspend new PrEP initiations until further notice.

November 2021
South Africa launches Updated PrEP Guidelines that promote multi-month dispensing.

MALAWI: 23 (2019), 14 (2020), 2 (2021), 25 (2022)

SOUTH AFRICA: 3 (2019), 21 (2020), 109 (2021), 302 (2022)

FIGURE 5

Community-led Action Speeds Return of Demand for VMMC at CLM-Monitored Sites as Compared to National Averages

% change from 2020 to 2021: 126%, 156%

% change from 2020 to 2021: DATA NOT YET AVAILABLE, 60%

% change from 2019 to 2020: -64%, -66%

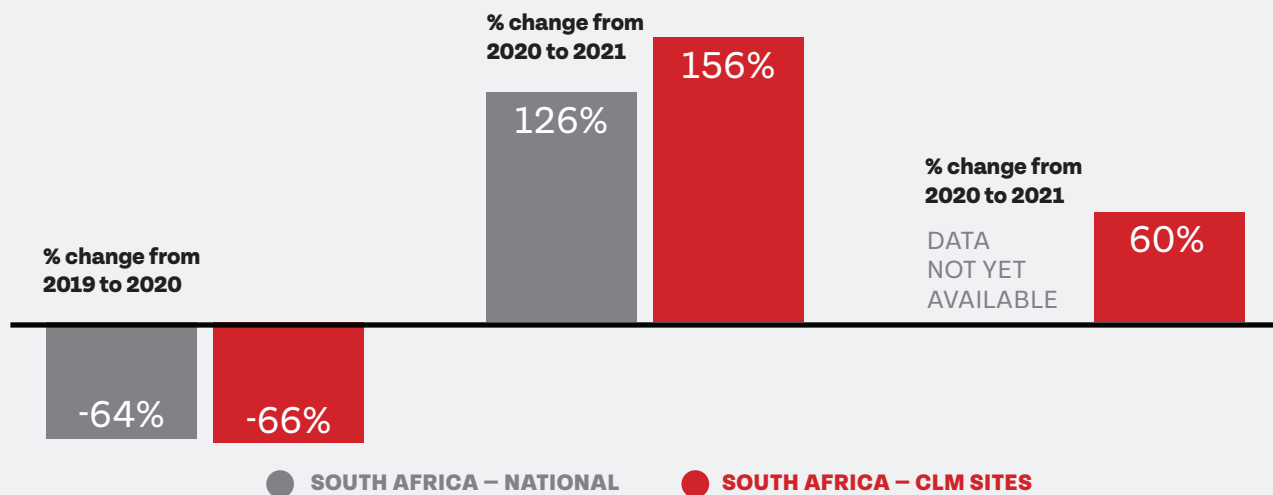● SOUTH AFRICA – NATIONAL   ● SOUTH AFRICA – CLM SITES

FIGURE 6

Community-led Action Increased New ART Initiations at at Monitored Sites in Malawi versus Nationally

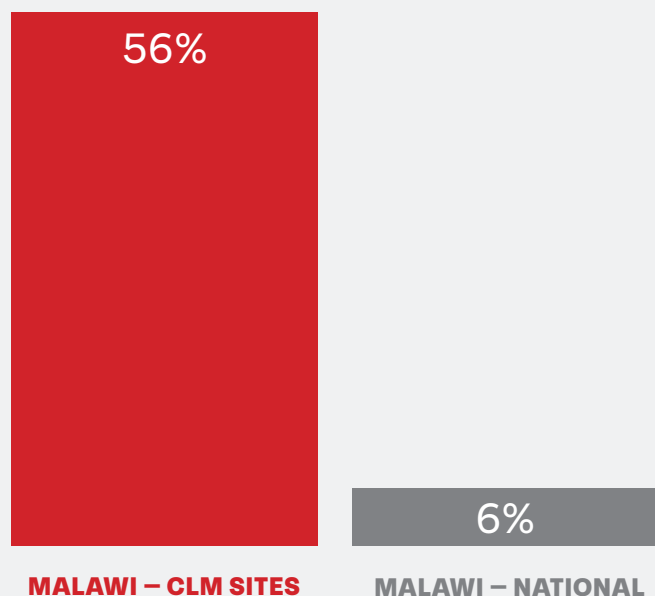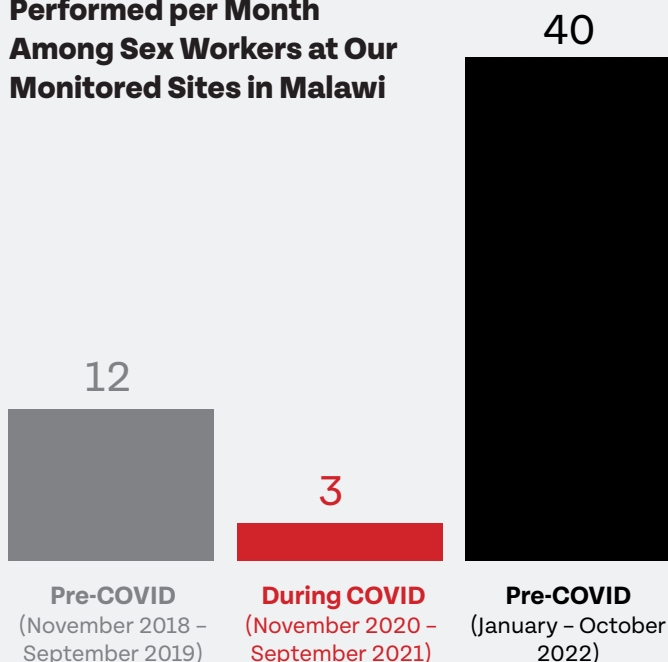**Percent Change in New ART Initiations in Malawi, 2020–2021**

56%	6%
MALAWI – CLM SITES	**MALAWI – NATIONAL**

FIGURE 7

Community-led Action Improved Access to HIV Testing Services for Priority Populations

Average # of HIV Tests Performed per Month Among Sex Workers at Our Monitored Sites in Malawi

12	3	40
Pre-COVID (November 2018 – September 2019)	**During COVID** (November 2020 – September 2021)	**Pre-COVID** (January – October 2022)

ACCESS PLAN ACTIONS

→ **Health system shifts and innovations, including product introduction plans for new treatments, preventive strategies, diagnostics, and integration initiatives (such as HIV and primary healthcare) should include earmarked resources for community-led action at a subset of facilities.** These efforts can include: provision of community-friendly, evidence-based information about the new products; opportunities to pose and answer questions in a peer-to-peer setting; and, potentially, opportunities to conduct monitoring of gaps and barriers in the accessibility, appropriateness, availability, affordability, and quality of services and products.

→ **Funders of civil society advocacy and activism should structure grants with the flexibility and scope to support work on access to medicines and monitoring of health sites and systems.** These complementary areas require different skill sets and activities. Civil society groups need sufficient, unrestricted, or flexible resources to take action on multiple levels.

DEMAND CREATION FOR AFFORDABLE MEDICATIONS: A CASE STUDY ON COMMUNITY-LED ACTION AND ACCESS BEFORE, DURING, AND AFTER CRISES SUCH AS COVID-19

Since 2014, ITPC's Make Medicines Affordable (MMA) campaign has connected activists and advocates around the world in local, regional, and global action. MMA partners work to expand access to medicines by taking on the intellectual property, procurement, and demand creation barriers that drive health inequities worldwide.

In 2021, the MMA network in 17 middle-income countries (MICs) took action on access to and pricing of four COVID-19 vaccines from Johnson & Johnson, Moderna, Oxford-AstraZeneca, and Pfizer/BioNTech. They started with an assessment of the availability and affordability of these four vaccines, gathering information about vaccine supply, donations, pricing, and technology transfer issues. National and regional civil society and community-based groups in all 17 MICs (Argentina, Armenia, Belarus, Brazil, El Salvador, Georgia, Guatemala, Honduras, India, Kazakhstan, Kyrgyzstan, Moldova, Morocco, Russia, Thailand, Ukraine, and Vietnam) helped gather and verify this information. The MMA work unfolded alongside, and informed, rapid mobilizations to assess and mitigate the impact of COVID-19 at community level. Frontline activists worked fast to find out what was needed, including vaccines, tests, treatment, and personal protective equipment.

The collective research documented gaps between MICs and HICs. Of the 11.4 billion vaccine doses supplied as of January 2022, 2.8 billion (approximately 25%) went to these 17 MICs. The average vaccination rate in these 17 countries was approximately 52% far lower than that reported from HIC.

There were significant disparities in terms of vaccines delivered within the 17 MICs. For example, while vaccines delivered to Moldova and Georgia covered 29% and 31% of their populations, respectively, coverage rates were 91% for Brazil and Vietnam and up to 110% for Argentina. Thus, some of the 17 MICs were not even on track to meet the 40% WHO 2021 vaccination target.

Among the 17 MICs, those with smaller markets and weaker purchasing power experienced delays in securing supply contracts for the four COVID vaccines, as HICs had cornered the initial supply. As a result, most MICs relied initially on vaccines from China and Russia. For some of the larger MICs, which were able to attract the attention of HIC vaccine manufacturers, negotiations on issues of indemnity and liability were particularly thorny and held up agreements for several months.

By the time the full report was published in 2023, many of its concerns had been incorporated into the Zero Draft of the Pandemic Accord currently being negotiated at WHO. As the international

community prepares for the next pandemic, it must recognize the crucial role and work, such as this, of national and regional community and civil society groups during the pandemic.

The same MMA coalitions that worked on COVID-19 vaccines also work every day to ensure access to affordable ARVs and treatment for TB and HCV. During the pandemic, they pivoted to address COVID-19 medical countermeasures, drawing from skills honed in other contexts. This is community-led action at its most powerful: a source of insight and advocacy that adapts in real time to emergent crises and a crucial countermeasure whose impact derives from continuous action. This takes financing and recognition of its value, as we describe in our action plan on page 27.[29]

SPEEDING RESUMPTION OF AND DEMAND FOR SERVICES

Launched in 2020, our Citizen Science initiative focused on HIV, TB, and malaria health services at 33 sites serving close to 1 million people in South Africa and Malawi[30,31] (see Figure 8). This ongoing project draws on three years of prospective engagement, education, and data collection, as well as one year of retrospective data and national-level data, which were used for trend analysis and comparison of outcomes at sites with and without CLM.

The Citizen Science initiative monitored TB screenings at 19 sites, witnessing a 158% increase from 2020 to 2022 compared to just a 22% increase nationwide (see Figure 9: Finding More Missing People with TB Through GeneXpert TB Testing).

→ Following a sharp drop in 2020 (during COVID-19), ART initiations recovered 10 times faster at monitored sites in Malawi than in the rest of the country.

THE FINDINGS

→ By 2022 (post-COVID-19), demand for voluntary medical male circumcision (VMMC) services and GeneXpert TB testing had recovered seven times faster at monitored sites than at other sites in South Africa. During COVID-19, diagnostic capacity was diverted, preventive health services such as VMMC were scaled back, and the rate of TB screenings declined in South Africa.

ACCESS PLAN ACTION

→ **Investments in community-led action that gathers qualitative and quantitative data at a facility level and engages health workers and other duty bearers, including national-level stakeholders, in dialogue with community members should be part of any risk mitigation strategy for pandemics, outbreaks, and other shocks.**

FIGURE 8

At a Glance: The Citizen Science Project to Monitor Impact of COVID-19 on HIV and TB Services in Malawi and South Africa
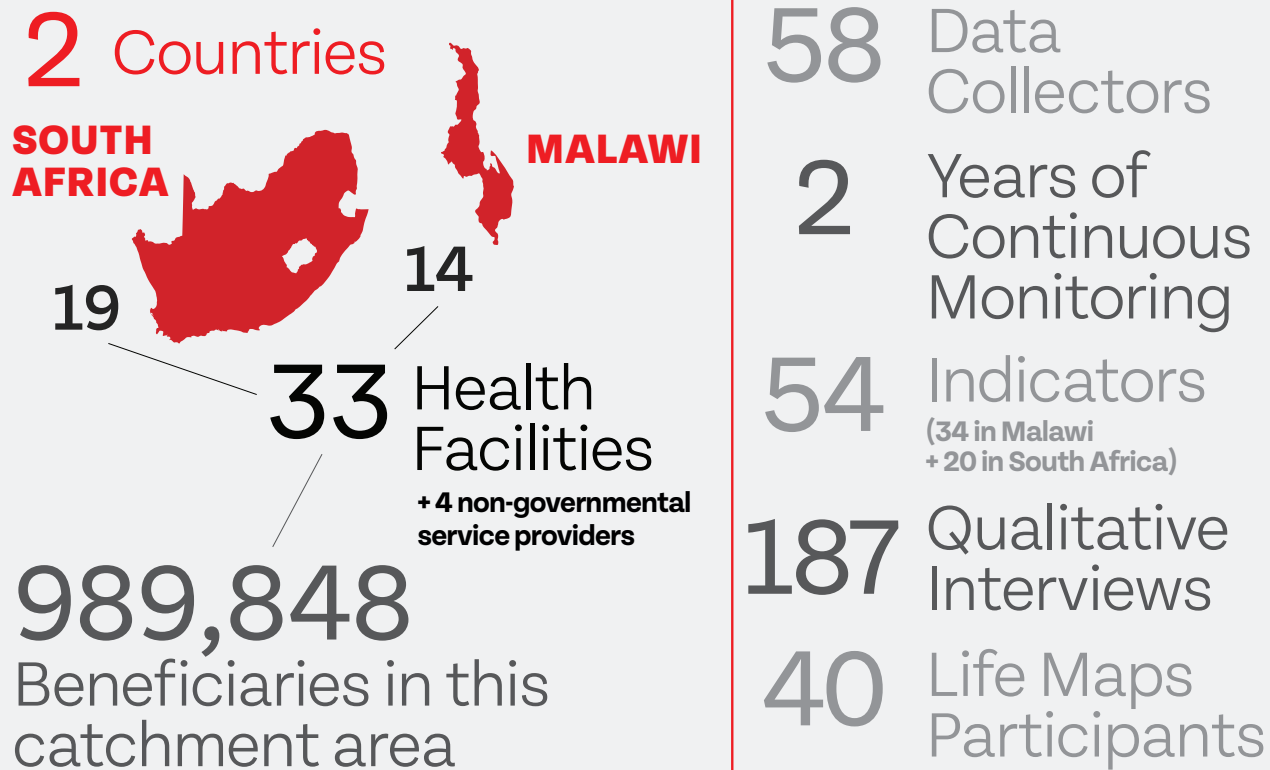
2 Countries

SOUTH AFRICA

MALAWI

19

14

33 Health Facilities

+ 4 non-governmental service providers

989,848 Beneficiaries in this catchment area

58 Data Collectors

2 Years of Continuous Monitoring

54 Indicators (34 in Malawi + 20 in South Africa)

187 Qualitative Interviews

40 Life Maps Participants

FIGURE 9

Community-led Action Helped Find More Missing People with TB Through GeneXpert TB Testing

Number of GeneXpert TB Tests at our CLM Sites in South Africa

9,839

3,813
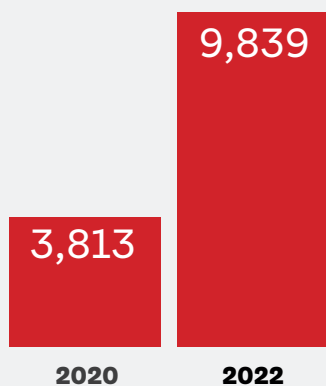
2020

2022

Number of GeneXpert TB Tests Done Nationally in South Africa

2,494,985

2,046,832
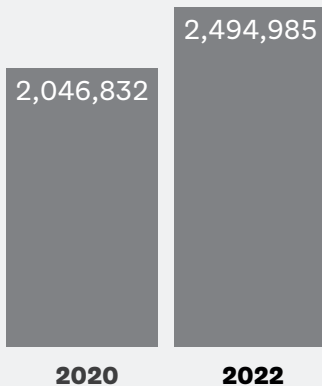
2020

2022

% Change in the Number of GeneXpert TB Tests in South Africa, 2020–2022

158%

22%

2020

2022
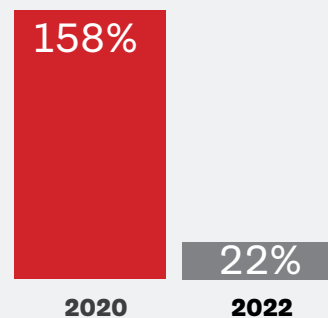
● SOUTH AFRICA – NATIONAL   ● SOUTH AFRICA – CLM SITES

THE INGREDIENTS FOR IMPACT: A CASE STUDY FROM ITPC MENA ON THE COMPLEMENTARY ELEMENTS OF COMMUNITY-LED ACTION

ITPC-MENA shows the power of community-led action in an example that combines all of the elements required for this crucial countermeasure. Like the essential compounds for a vaccine or drug, the core elements of education, evidence, advocacy, and engagement must be in place, resourced, and coordinated. When combined, they offer benefits and results that no one element would provide on its own, which was especially evident during the **COVID-19 pandemic**.

In ITPC MENA, the three pillars are:

→ **The Activists Development Program (ADP)**, a capacity-building initiative aimed at training a new generation of activists by providing them with a comprehensive understanding of health challenges and drug access in the MENA region

→ **The MENA Community Advisory Board (MENA-CAB)**, a space that aims to provide a platform for MENA community members to voice their concerns, provide feedback, contribute to decision-making processes, and engage with government, the pharmaceutical industry, and other stakeholders

→ **The Community Learning and Monitoring Hub (CLM)**, in collaboration with French NGO Solidarité Sida, which trains impacted community members to collect, analyze, and act on data to improve the quality and access to HIV prevention, screening, care, and treatment, particularly for key populations in the MENA region

ITPC ADVOCACY REPORT: COMMUNITY-LED ACTION IS THE CRUCIAL COUNTERMEASURE

Before and during COVID-19, ITPC MENA used these three pillars to drive change across the cycle of activities in community-led action. As Table 2 shows, CLM is just one of the core elements of this crucial community-led countermeasure. Evidence feeds into and strengthens action that is also supported by training, structured engagement, and analysis of access to medicines issues. It takes all the "ingredients" to achieve the power of the intervention.

TABLE 2 ITPC MENA: Community-Led Action Powered by Four Key Elements

	"DOLUTEGRAVIR (DTG) FOR ALL AFRICA" CAMPAIGN	COVID-19 IMPACT MITIGATION
Education	Advocates were trained through the ADP about the ARV, dolutegravir (DTG) when it was identified by WHO as the preferred first-line ARV. They addressed questions about risks, benefits, and the rationale for demanding that countries change their first-line treatment regimens to include DTG.	The ADP program trained 37 advocates on issues related to health services and treatment access in the context of COVID-19.
Evidence	CLM partners gathered data on specific barriers to DTG access in the region.	ITPC-MENA recruited 29 data collectors specifically for the Community Learning and Monitoring hubs through its five regional partners in Egypt, Lebanon, Mauritania, Morocco, and Tunisia; they were trained in protocols and data collection methods, ensuring the quality and reliability of the information they gathered in the field.
Engagement	MENA-CAB presented data from the Community Learning and Monitoring hubs and other sources to representatives of the pharmaceutical industry and their governments to support demands for action.	MENA-CAB convened two meetings between communities affected by HIV, civil society organizations, and 10 representatives from the pharmaceutical industry to present information on barriers to treatment access, stock shortages, and other issues from data gathered by the ADP and the Community Learning and Monitoring hubs. The advocates paired evidence with requests for action to pharmaceutical companies, policy makers, and healthcare professionals.
Advocacy	The activists developed **concrete demands** for ensuring availability and affordability of DTG in the MENA region supported by Community Learning and Monitoring data and market analysis (that is, that Mylan holds the license to produce generic DTG and has a new pharmaceutical facility in Morocco). Discussions were held with the Clinton Health Access Initiative about negotiating the price for the ARV combination of tenofovir/lamivudine/dolutegravir (TLD).	Advocates called for country-specific actions. For example, ITPC Morocco urged the Moroccan government to issue a compulsory license for COVID-19 drugs and technologies to facilitate rapid and affordable access.

PART 2
A GLOBAL ACCESS PLAN FOR COMMUNITY-LED ACTION

A GLOBAL ACCESS PLAN FOR COMMUNITY-LED ACTION

We've summarized the evidence for community-led action as a crucial countermeasure. As with vaccines, medications, and diagnostics, the life-saving, transformative impact of community-led action depends on equitable access. Putting effective vaccines in some places and not in others does nothing to stop the spread of an outbreak or achieve an end to pandemics. Scattering community-led action across geographies or concentrating it in a single disease area, such as HIV, won't achieve the necessary resilience, trust, and effective resource use.

Mentioning community engagement in policies and political speeches isn't enough. Meeting with community leaders once or twice when a plan is being developed isn't enough. Inviting communities to validate pre-written plans isn't enough. Piecemeal investments are not enough. Yet, the current conversations around pandemic preparedness and response and, in some cases, UHC, are going in this direction.

Rather than fragmented efforts, a comprehensive access strategy is required to guarantee effective global community-led initiatives. Governments, funders, researchers, and private sector stakeholders will also benefit from this partnership – where communities are so often configured as the sole beneficiaries.

Each of these components map directly to the current approach to building support for and supplies of other countermeasures. We recognize that this language is embedded in and derives from a market-driven, capitalist, extractive economy. We also understand the need to pursue justice and equity in the short-, mid-, and long-term. At this time, it is essential to incorporate community-led action into the current paradigm using the principles, approaches, and concepts prevailing in global health. We believe that this short- and mid-term work will lead to long-term systemic change.

THIS PLAN SHOULD INCLUDE:

1. **High-level political commitment**

2. **Robust, reliable funding for activist "technology transfer" to ensure equitable global access**

3. **An innovation pipeline**

THE THREE COMPONENTS
OF THE GLOBAL ACTION PLAN

1. High-level political commitment

RECOMMENDATION

Include clear, consistent commitments to community-led action in all health-, climate-, and development-related declarations, accords, and guidance.

These commitments should include:

1. **A statement of evidence-based value:** "Community-led monitoring improves outcomes and accountability"

2. **A statement that links community-led monitoring or action to resources and plans:** "CLM and community groups must be adequately resourced and incorporated into action plans, decision-making forums, etc."

3. **A statement affirming the connection between community-led monitoring and action and the principles of GPI:** "all decide, all contribute, and all benefit." For example, "CLM will support diversified decision-making and mutual responsibility for how international public finance is mobilized and allocated"

KEY CONSIDERATIONS

→ **This language cannot be conditional or aspirational.** Terms like "encourage," "strive," and "aim" leave room for inaction. Community-led action "must" be supported as a key component of comprehensive plans.

→ **This language must be specific.** Community engagement is not the same as community-led action. "CLM" is not inclusive of all community-led action, but it is well-defined and sufficient (and at the very least a good starting point) for many of the documents in question.

→ **This language must be tied to funding and operationalization of high-level goals** since community-led action is integral to impact.

CURRENT TARGETS AND ASKS

→ Forthcoming UN declarations on pandemic preparedness and response, TB, and UHC[32] should contain identical language recognizing the "value of community-led monitoring in improving social accountability" that is supported by clear and programmatic commitments to develop and implement "community-led monitoring" in each declaration in alignment with the focal areas.

→ Article 16, Clause 1 of the Zero Draft of the Pandemic Accord[33] has positive language, which should be changed from a conditional to required formulation, as follows:

*The Parties recognize that pandemics begin and end in communities **and** ~~are encouraged to~~ **should** adopt a whole-of-government and whole-of-society approach, including to empower and ensure communities' ownership of, and contribution to, community readiness and resilience for pandemic prevention, preparedness, response and recovery of health systems.*

→ Article 16, Clause 3, of the same draft should make specific mention of community leadership as follows:

*Each Party shall, in accordance with its national context, promote effective and meaningful engagement of and **leadership by** communities, civil society and other relevant stakeholders, including the private sector, as part of a whole-of-society response in decision-making, implementation, monitoring and evaluation, as well as provide effective feedback opportunities.*

2. Robust, reliable funding for activist "technology transfer" to ensure equitable global access

RECOMMENDATION

Establish a global hub accessing funding and activist expertise and tracking global coverage of community-led action. It will do this, for example, by looking at the presence of community-led monitoring, accountability, and feedback mechanisms for engaging communities in planning and implementing public health strategies and mapping resources for ongoing community-led health literacy.

This hub should provide:

→ **Technology transfer of community-led action.** Technology transfer that distributes the ability to make medical countermeasures is widely understood as essential to global public health. It is also essential for equitable access to community-led action. Technology transfer includes training, support in adapting processes to local conditions, on-site visits and exchanges between teams, and open access to tools, resources, and mechanisms for monitoring, evaluation, and quality checks. This hub must support exchanges between activists, advocates, and other stakeholders working on disease-specific issues, climate, UHC, and pandemic preparedness and response.

→ **Robust, reliable funding.** The quality and impact of community-led action is diminished by project-specific, erratic, and insufficient funding. Groups working on a specific issue, such as HIV, are not resourced to react to emergent crises, including new outbreaks or climate disasters. Engagement in long-term political negotiations and planning processes is often difficult. The current patchwork of funding isn't sufficient for a global supply of high-quality, community-led action.

→ **Coordinated demand creation for access to essential countermeasures and services.** Public health programs turn to communities to raise demand for new medical technologies and strategies by sharing information via trusted channels. That's important. But demand creation doesn't start there. It begins with and depends on community-led action, taking on pricing and IP barriers. Access to medicine issues manifest locally and globally. A coordinated "demand creation" hub for mapping persistent and emergent access gaps and supporting legal cases and community-led advocacy to address them can be efficiently created by a long-term investment to support the linkage of existing stakeholders' efforts.

KEY CONSIDERATIONS

→ **This hub (or an equivalent pooled funding mechanism for community-led action) would help ensure a steady supply of high-quality, community-led action**. It would, in other words, support equitable access to a global public good. The hub should support work across disease and issue areas, and be supported by a range of stakeholders. It is an investment that advances and contributes to the GPI framework (see "What Is Global Public Investment?" on page 13).

CURRENT TARGETS

→ **We propose resourcing this hub through pooled contributions from The Pandemic Fund, private philanthropies, bilateral and multilateral disease-specific and issue-specific funding mechanisms, and government financing.** A foundational funding commitment should be announced as part of the next funding round of The Pandemic Fund, with additional supportive commitments from stakeholders at upcoming G7 and G20 meetings, leading to a formal launch at the 25th International AIDS Conference in Munich in 2024.
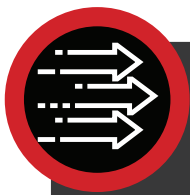
3. An innovation agenda

RECOMMENDATION

Develop a community-led action research and innovation agenda that includes operational research and piloting and scaling impactful strategies and approaches.

This agenda should include:

→ **Linkages between academic groups and individuals and groups engaged in community-led action** to define research questions and approaches that will generate usable information on priority questions.

→ **Resources for challenging, pressing issues,** such as innovations in community-led monitoring to bridge climate and health at community level.

→ **Advance funding commitments to scale effective strategies.** Innovation is driven by need and, often, the potential of additional resources. We cannot expect communities to explore, innovate, iterate, and take risks in community-led action without a commitment to support "experiments" that may fail and invest in those that produce solutions that work.

KEY CONSIDERATIONS

→ **The pressure on CLM to show impact to funders and governments can actually water down the work.** Advocacy and activism take time. Change is incremental, and the direct and indirect impacts of sustained engagement can be difficult to measure. This does not mean that evaluation and research are impossible, but that the standards, priorities, and approaches to learning about community-led action must be defined by practitioners and their communities.

→ At present, there are some investments in elements of this work underway, with a particular focus on HIV-related community-led monitoring. **This is a proposal for a more comprehensive, systematic, and coordinated approach.**

CURRENT TARGETS

→ **Current funders of CLM could support implementing groups in forging linkages with like-minded researchers and other practitioners to develop a comprehensive research and innovation agenda for community-led action.** UNAIDS, WHO, and other UN agencies could support the process of disseminating and implementing this agenda.

CONCLUSION

CONCLUSION

GLOBAL ACCESS TO COMMUNITY-LED ACTION + GLOBAL PUBLIC INVESTMENT = TRANSFORMATIVE CHANGE

ITPC WAS LAUNCHED 20 YEARS AGO IN THE CONTEXT OF MASSIVE GLOBAL INEQUITIES IN THE RESPONSE TO THE DEVASTATING AIDS PANDEMIC. **Today, when we look around, we are saddened but not surprised that the gaps between rich and poor people and nations have widened into a global "crisis of extreme inequality."[34]** Progress toward the SDGs[35] has stalled or backslid in the past few years as COVID-19, conflict, and climate crises have disrupted already fragile social safety nets, supply chains, and much more. Innovations in global financing to provide relief to low- and lower-middle-income countries crushed by debt conditions have yet to materialize in ways that provide meaningful relief. At every turn, the message to households, communities, and countries is to get better at doing more with less. This means making hard choices every day about what gets paid for and what doesn't. This means paying very close attention to who is making these decisions and who is left out.

Who gets to decide what gets funded and at what level? These questions are especially important when it comes to health. As we've described in this report, community-led action transforms the conditions in which these questions are asked, discussed, and answered. By changing who is involved in the decisions, community-led action changes outcomes. Scarce resources go farther, life-saving services are accessed by the people who need them the most, and governments and communities find common ground for constructive problem-solving. Scaling up global access to community-led action is crucial for the future of health investments. Without it, resources will be wasted, services will not be trusted, and the communication systems that support rapid public health responses to new outbreaks will not be as robust as they need to be.

But we can't stop with community-led action focused on health. Today's problems are deeply interconnected. Ending extreme poverty and inequalities, achieving UHC, forestalling further climate destruction — these and other SDGs cannot possibly be achieved in isolation. Global Public Investment is a unifying framework that has the immense potential to revolutionize the way we tackle global issues, from a macro-level view, as well as a community perspective. GPI is a novel approach that aims to diversify decision-making and establish mutual responsibility for how international public

finance for sustainable development is mobilized and allocated.[36] Simply put, GPI is about how public money is used to invest in goods and services that are of global benefit.[37] To make GPI work for civil society — not just certain countries or groups of countries — we must comprehensively apply and widen our understanding of the core principles of "all decide, all contribute, and all benefit."[38] Decision-making has to include affected communities; contributions must go beyond monetary assets; and benefits should reach all people.

Community-led action — including all four elements of education, evidence, engagement, and advocacy — is the pathway to meaningful contributions. GPI is the ideal ecosystem for these contributions to drive real, systemic change. Scaling up global coverage of community-led action through our action plan will create conditions in which GPI will flourish. This is the equation that will help solve many of the interconnected problems facing the world today:

Community-Led Action + GPI = Transformative Change

We could end this report with a call to donors, development banks, and governments. Many of the same stakeholders making decisions about global health today are also involved and implicated in global financing and development assistance.

We urge and demand that you take GPI on as the framework for doing business, reflecting it in the governance structures for every endeavor, from the global to the grassroots.

But our last word is to our closest partners in the HIV activism and advocacy movement. Many of the same communities that are bearing the brunt of inequalities and unfinished business in ending HIV, stigma, gender-based violence, and many other issues are already working on pandemic preparedness, GPI, and other global issues. But we need to do more. The HIV movement, which has generated so much power through its community-led action, needs to find new ways to work smarter — not harder — across disease and thematic areas and to tackle financing for a diverse array of issues head-on.

We need to demand flexible resources that allow us to spend real time — not just the time it takes to fly to and attend a meeting — making connections with environmental activists, financing activists, access to treatment activists, communities working on pandemic preparedness, antimicrobial resistance, and more. We need to reinvigorate the journey to end the AIDS pandemic because the response, too, is under threat and our hard-fought gains could easily be lost. And we need to upend the entrenched power dynamics between the global North and South that make our movement weaker.

We need to do all of this to create the condition where community-led action is everywhere, and GPI is the framework for global financing. It is hard work, but it's wholly possible. We wouldn't call for it — and call ourselves to it — if we didn't believe this. **We have the evidence: in just 20 years, we changed the global health landscape for a single pandemic. We've learned a lot since then. Now, it's time to change the entire world.**

IT'S TIME TO CHANGE THE ENTIRE WORLD

1. Avchen RN, LeBlanc TT, Kosmos C. Medical Countermeasures: Mission, Method, and Management. *Am J Public Health*. 2018 Sep;108(S3):S172. doi: 10.2105/AJPH.2018.304686.

2. World Health Organization (2022.) Joint external evaluation tool: International Health Regulations (2005) – third edition. (https://www.who.int/publications/i/item/9789240051980, accessed 20 August, 2023).

3. The Global Fund. Webpage: "Strategy." (https://www.theglobalfund.org/en/strategy/, accessed 20 August 2023).

4. US Department of State, President's Emergency Plan for AIDS Relief (2020). PEPFAR 2020 Country Operational Plan Guidance for all PEPFAR Countries. (https://www.state.gov/wp-content/uploads/2020/01/COP20-Guidance_Final-1-15-2020.pdf, accessed 20 August 2023).

5. UNAIDS (2021). Establishing Community-Led Monitoring of HIV Services: Principles and Process. (https://www.unaids.org/en/resources/documents/2021/establishing-community-led-monitoring-hiv-services, accessed 20 August, 2023).

6. The World Bank (20 July 2023). "Pandemic Fund Allocates First Grants to Help Countries Be Better Prepared for Future Pandemics." (https://www.worldbank.org/en/news/press-release/2023/07/20/pandemic-fund-allocates-first-grants-to-help-countries-be-better-prepared-for-future-pandemics, accessed 20 August 2023).

7. World Health Organization (2022.) Joint external evaluation tool: International Health Regulations (2005) – third edition. (https://www.who.int/publications/i/item/9789240051980, accessed 20 August, 2023).

8. Sagan A, Thomas S, McKee M, Karankolos M, et all. COVID-19 and Health Systems Resilience: Lessons Going Forward. *Eurohealth* 2020; 26 (2). (https://apps.who.int/iris/bitstream/handle/10665/336290/Eurohealth-26-2-20-24-eng.pdf, accessed 20 August 2023).

9. Topp SM. Power and politics: the case for linking resilience to health system governance. *BMJ Glob Health*; 2020 Jun 5(6):e002891. doi: 10.1136/bmjgh-2020-002891.

10. World Health Organization (2022). Third round of the global pulse survey on continuity of health services during the COVID-19 pandemic: November-December 2021. (https://www.who.int/publications/i/item/WHO-2019-nCoV-EHS_continuity-survey-2022.1, accessed 20 August 2023).

11. World Health Organization (2023). Fourth round of the global pulse survey on continuity of health services during the COVID-19 pandemic: November 2022-January 2023. (https://www.who.int/publications/i/item/WHO-2019-nCoV-EHS_continuity-survey-2023.1, accessed 20 August 2023).

12. Thu, K.M., Bernays, S. & Abimbola, S. A literature review exploring how health systems respond to acute shocks in fragile and conflict-affected countries. *Confl Health* 16, 60 (2022). https://doi.org/10.1186/s13031-022-00484-8

13. International Treatment Preparedness Coalition and Dristi Nepal (2021). *Impacts of COVID-19 on Women Living with HIV Who Use Drugs in Nepal.* (https://itpcglobal.org/blog/resource/impacts-of-covid-19-on-women-living-with-hiv-who-use-drugs-in-nepal/, accessed 20 August 2023).

14. ITPC and Salamander Trust (2020). *Women, HIV and their Sexual and Reproductive Health and Rights: Are We Meeting WHO Guidelines?* (https://itpcglobal.org/wp-content/uploads/2020/09/SRHR-women-and-HIV_20200929.pdf, accessed 20 August, 2023).

15. ITPC and Salamander Trust (2020). *Confined by COVID 19: women and girls, HIV and SRHR.* (https://itpcglobal.org/blog/resource/confined-by-covid-women-girls-hiv-and-srhr/, accessed 20 August 2023).

16. ITPC, GALZ, JSF, PYWV, YP, Making Waves and Salamander Trust (2022). *Are the Sexual and Reproductive Health and Rights of Women living with HIV still confined by Covid-19?: An analysis of then and now.* (https://itpcglobal.org/blog/resource/sexual-and-reproductive-health-rights-of-women-living-with-hiv-still-confined-by-covid-19-analysis/, accessed 20 August 2023).

17. ITPC (2019). *Data for a Difference: Key Findings, Analysis and Advocacy Opportunities from the Regional Community Treatment Observatories in West Africa.* (https://itpcglobal.org/wp-content/uploads/2019/09/Data-for-a-Difference_rev.pdf, accessed 20 August 2023).

18. ITPC (2020). *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.* (https://itpcglobal.org/blog/resource/why-bold-action-against-inequalities-is-needed-to-end-aids-stop-covid-19-and-prepare-for-future-pandemics/, accessed 20 August 2023).

19. ITPC (2022). *The Good, the Bad, and the Unfinished Business: Addressing the Impact of COVID-19 on HIV and TB Services in Malawi and South Africa Through A Community-Led Monitoring Initiative.* (https://itpcglobal.org/wp-content/uploads/2023/01/2022-itpc-the-good-the-bad-and-the-unfinished-business.pdf, accessed 20 August, 2023)

20. ITPC (2021). *Community Pandemic Preparedness: Community-led monitoring of COVID-19's effects on service delivery and lived experiences of people living with HIV and TB in China, Guatemala, India, Nepal and Sierra Leone* UNAIDS, June 2021. https://itpcglobal.org/blog/resource/community-led-monitoring-of-covid-19s-effects-on-service-delivery-and-lived-experiences-of-people-living-with-hiv-and-tb-in-china-guatemala-india-nepal-and-sierra-leone/

21. ITPC (2019). *Data for a Difference: Key Findings, Analysis and Advocacy Opportunities from the Regional Community Treatment Observatories in West Africa.* (https://itpcglobal.org/wp-content/uploads/2019/09/Data-for-a-Difference_rev.pdf, accessed 20 August 2023).

22. ITPC (2019). *Data for a Difference: Key Findings, Analysis and Advocacy Opportunities from the Regional Community Treatment Observatories in West Africa.* (https://itpcglobal.org/wp-content/uploads/2019/09/Data-for-a-Difference_rev.pdf, accessed 20 August 2023).

23. ITPC (2019). *Data for a Difference: Key Findings, Analysis and Advocacy Opportunities from the Regional Community Treatment Observatories in West Africa.* (https://itpcglobal.org/wp-content/uploads/2019/09/Data-for-a-Difference_rev.pdf, accessed 20 August 2023).

24. See citations 17, 18 and 19.

25. ITPC (2022). T*he Good, the Bad, and the Unfinished Business: Addressing the Impact of COVID-19 on HIV and TB Services in Malawi and South Africa Through A Community-Led Monitoring Initiative.* (https://itpcglobal.org/wp-content/uploads/2023/01/2022-itpc-the-good-the-bad-and-the-unfinished-business.pdf, accessed 20 August, 2023).

26. Source: Fundacion GEP.

27. Make Medicines Affordable (2021). "Thailand rejects Fujifilms COVID-19 related patent request, 6 May 2021." (https://makemedicinesaffordable.org/thailand-rejects-fujifilms-covid-19-related-patent-request/, accessed 20 August, 2023).

28. Dmytriiev, Sergii. "Breaking a 'vicious cycle' of overpaying for HIV drugs in Ukraine." Make Medicines Affordable; 3 December, 2020. (https://makemedicinesaffordable.org/opinion-breaking-a-vicious-cycle-of-overpaying-for-hiv-drugs-in-ukraine/, accessed 20 August 2023).

29. ITPC (2022). *The Good, the Bad, and the Unfinished Business: Addressing the Impact of COVID-19 on HIV and TB Services in Malawi and South Africa Through A Community-Led Monitoring Initiative.* (https://itpcglobal.org/wp-content/uploads/2023/01/2022-itpc-the-good-the-bad-and-the-unfinished-business.pdf, accessed 20 August, 2023).

30. ITPC (2023). *Bouncing Back: How a Community-Led Monitoring Initiative in Malawi and South Africa is Supporting the Recovery of HIV Services in the wake of COVID-19.* (https://itpcglobal.org/blog/resource/bouncing-back/, accessed 20 August 2023).

31. United Nations (2023). Webpage: "United Nations: General Assembly High-Level Week 2023)." (https://www.un.org/en/high-level-week-2023, accessed 20 August 2023).

32. An explanation of the process by which the Pandemic Accord is being developed, and links to the Zero Draft in several languages, can be found on the World Health Organization webpage, "INB Process" (https://inb.who.int/home/inb-process#Conceptual%20Zero%20Draft, accessed 20 August 2023).

33. https://equalshope.org/index.php/2023/07/17/setting-serious-goals-to-combat-inequality/

34. United Nations (2023). *Transforming Our World: the 2030 Agenda for Sustainable Development.* (https://sdgs.un.org/2030agenda, accessed 20 August, 2023).

35. Development Initiatives (2022). Webinar Recording: *Global Public Investment: A better way to finance the SDGs.* (https://devinit.org/what-we-do/events/global-public-investment-a-better-way-to-finance-the-sdgs/, accessed 20 August, 2023)

36. McCoy, D. Global Public Investment: Time to build the movement now. United Nations University: International Institute for Global Health; 08 02 2022. (https://iigh.unu.edu/publications/articles/global-public-investment-report-released-time-to-now-build-the-movement.htm, accessed 20 August 2023).

37. Global Public Investment Network. Webpage: *What is GPI* (https://globalpublicinvestment.net/what-is-gpi/ accessed 20 August 2023).

COMMUNITY-LED ACTION IS THE CRUCIAL COUNTERMEASURE TO ADDRESS HIV, TB, HEPATITIS, COVID-19 AND PREVENT FUTURE OUTBREAKS EQUITABLY AND EFFECTIVELY

20 YEARS · ITPC · CHAMPIONING COMMUNITY LEADERSHIP

ITPC
INTERNATIONAL TREATMENT
PREPAREDNESS COALITION

ITPCGLOBAL.ORG

✉ admin@itpcglobal.org   f /itpcglobal   🐦 @itpcglobal

📷 @itpcglobal   ▶ /itpcglobal   in /company/itpcglobal