



ACKNOWLEDGEMENTS

In this Special Edition 20th Anniversary Annual Review, the International Treatment Preparedness Coalition (ITPC) recognizes the tireless efforts of our founders, community partners, regional teams, global staff, previous members of our Board, executive leadership, and key collaborators in strengthening the HIV movement over the past two decades. We express our particular thanks to all the people living with HIV, health workers, and community activists who were involved in activities implemented and supported by ITPC over the course of our journey to this milestone. We are grateful to everyone who contributed their time, goodwill, energy, and archival materials to the production of this historic and significant publication.





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EXECUTIVE DIRECTOR'S LETTER NOT PITY, PARTNERSHIP: THE RISE OF COMMUNITY LEADERSHIP

DEAR FRIENDS IN THE FIGHT,

As we mark the momentous occasion of our 20th anniversary, my heart swells with pride and gratitude for our remarkable journey. Not Pity, Partnership: The Rise of Community Leadership marks the path from which we came and encapsulates the spirit of our shared mission to achieve health and social justice through robust community engagement. This theme reflects the mission of our global activist network to make space for communities as equal partners in the fight for quality health for all. Today, Community Leadership is a foundational part of the strategies of PEPFAR, the Global Fund, and UNAIDS. But it did not start this way. Every single ounce of visibility, resourcing, and credibility that communities have today was hard-fought and earned.

Two decades ago, we dared to dream of a world where quality health is not a luxury and where communities affected by HIV and AIDS would live long, healthy, and fulfilling lives. In 2001 – just two years before the International Treatment Preparedness Summit that would launch our organization – the US government's Bush administration opposed any extensive use of the life-extending anti-AIDS drugs in Africa. It insisted that the healthcare infrastructure was too primitive and that Africans were incapable of following the regimen as they "don't know what

Western time is ... never seen a clock or a watch their entire lives." Inexcusably, the head of the U.S. Agency for International Development (USAID) said the money raised by a new global fund to fight AIDS should be used almost entirely for prevention services, not for the antiretroviral (ARV) drugs that had been so successful in extending the lives of people living with HIV. He went on to explain that attempting to get treatment drugs to Africans any time soon would not be worth the effort.

It was in this context that ITPC was birthed — in inequity, injustice, morbidity, death, and blow after blow to our collective drive as we watched our friends die. But, together, we defied the odds, increased resource allocations, and changed how governments valued communities. By refusing to accept the status quo and steadfastly pushing for quality medicines for all, everywhere, we changed the course of history and reshaped the discourse around access to treatment and health altogether.

In 2003, even though the AIDS response was moving into a new phase, globally, with growing political commitment (WHO's 3x5 initiative to bring antiretroviral treatment to 3 million people by 2005 would be launched that December) and increasing funding that led to treatment programs shifting into gear and prevention efforts being expanded, ARVs cost more than USD 1,000 per person per year. Less than 500,000 people had access to ARVs, and HIV prevalence in Botswana was a staggering $40\%^2$ – there was no pre-exposure prophylaxis (PrEP), no long-acting injectables, no routine viral load testing, and no strategic initiatives for community-led monitoring.



¹ https://www.nytimes.com/2001/06/11/opinion/in-america-refusing-to-save-africans.html

^[2] https://data.unaids.org/pub/report/2003/2003 epiupdate en.pdf

EXECUTIVE DIRECTOR'S LETTER NOT PITY, PARTNERSHIP: THE RISE OF COMMUNITY LEADERSHIP

This was the backdrop for the start of our global activism. What caused a ragtag group of people across the globe to come together and stay the course, over 20 years? What is in ITPC's DNA that sustains us and pushes us to face the challenges of the future? This Annual Report explores the answers to these questions. Unlike other reports, our 20 Year Anniversary Special Edition not only reflects where have come from, but who we are; it showcases our 2022 work and shares our vision for the work ahead.

The year 2022 marks the second year of work under our current Strategic Plan. This report highlights how we have continued to share knowledge and critical resources with grassroots activists, held decision-makers accountable, and increased the availability and affordability of diagnostics and medicines. In every corner of the world, our community-led efforts have unleashed the potential of ordinary people to bring about extraordinary change. From generating CLM data for the removal of user fees in Cote d'Ivoire to successful patent oppositions in Argentina saving literally millions of dollars and lives, our work has proven time and again that when communities are at the heart of the response, the impact is undeniable.

On this significant milestone, I invite you to review our 2022 Annual Review video, this Special Edition 2022 Annual Report as well as our 20th Anniversary video.

As we think about the future, although we see a dark world filled with colliding crises and yawning equity gaps, we reaffirm our pledge to challenge injustice, dismantle barriers, and amplify the voices of those on the frontlines of the consequences of policies. We commit to evidence-informed advocacy, the elevation of community data, and a grounding in human rights. For ITPC, people

will always be first – before investment cases, before government protocols, before cost-benefit analyses, and before profit. Together, we will continue to push the boundaries of what is possible and foster a world where health equity is the norm, not the exception.

I stand in awe of the relentless passion and commitment of the community leaders, activists, advocates, and allies who have refused to be silenced by adversity – and the camaraderie, humor, and heart that has sustained us through it all. I extend my heartfelt gratitude to each one of you. Our secret formula is no secret: ordinary individuals accomplishing extraordinary feats united under the banner of shared purpose and collective action.

Community leadership is not a footnote; it's the anthem of progress.

WITH UNWAVERING DETERMINATION,





OUR VOICES REFLECTIONS FROM ITPC LEADERSHIP, PAST AND PRESENT

A GROUP OF 125 HIV ACTIVISTS FROM 65 COUNTRIES

met in Cape Town, South Africa, in 2003: they refused to accept a world where people living with HIV were denied access to life-saving treatment. The result was the creation of ITPC. Join us as we take a look back with some key players.

ROOTED IN ACTIVISM

David Barr, co-founder and first Executive Director (2003–2010)

The initial call for global access to HIV treatment was made at AIDS 1998, the 11th International AIDS Conference, in Geneva. The real push for global access – spearheaded by the Treatment Access Campaign – began in Durban at the AIDS Conference in 2000. By the next AIDS Conference in Barcelona in 2002, we knew that the Global Fund was about to be established and there would be an effort to bring treatment to where it was needed most. Around 25 activists gathered informally in Barcelona and we talked about the need to bring treatment activists from around the world together to talk about our role in this next wave of

Those talks culminated in a meeting in Cape Town in 2003. We called it the International Treatment Preparedness Summit — a very clumsy name. I helped draft the agenda and then wrote the meeting report, which recommended continuing the network of treatment activists that we'd started to build. Given the name of the summit, I just started calling this new network the International Treatment Preparedness Coalition. That's how the name of ITPC came about. It was never really discussed; it just kind of stuck. It's a terrible name, but a great organization.

GROWING INTO A GLOBAL PEOPLE'S MOVEMENT

Morolake Odetoyinbo, Board Chair (2009-2014)

From the early days of ITPC, there was a lot of collaboration among community stakeholders. That's what made ITPC strong – people plugged in at different points.

Whatever you were doing, you came to the table with that and this became a global movement. Eventually, through the HIV Collaborative Fund, ITPC started giving grants to support

grassroots activists. Before then, you had grants, but a lot of the grants were for service delivery. Nobody exclusively and expressly supported treatment literacy and activism: that was the role that ITPC played. ITPC supported activists so that they could keep pushing their governments for access to treatment.



the response to HIV.

OUR VOICES REFLECTIONS FROM ITPC LEADERSHIP, PAST AND PRESENT

FACING CONTINUING INEQUITIES

Sarah Zaidi, Executive Director (2010-2012)

Before I joined, ITPC consisted of the HIV Collaborative Fund and two other separate projects: the "Missing the Target" report, which researched how HIV-related targets had been missed; and the World Community Advisory Board, which worked on engaging

the pharmaceutical industry, both generic and name brands, on treatment. We consolidated these projects and leveraged their strengths.

Some of the things that we learned from those early years became so relevant during the COVID-19 pandemic. We saw that vaccines were not affordable for many people living in the Global South. Corporations, and pharmaceuticals in particular, have a lot of control over that. Even though most of the research was done with public funding, we saw that in most countries, the vaccines were either not available or very expensive, especially the ones using newer mRNA technologies.

Pharma controlled pricing and the products remained largely

inaccessible to people in developing countries. Treatment access

rights remain a big issue because of intellectual property rights and trade-related barriers.

CLM IS THE WAY WE DO THINGS

Christine Stegling, Executive Director (2013-2015)

What people now refer to in mainstream conversation as "community-led monitoring" is really the work that ITPC had been doing for so

long. But nobody was really that interested in it and nobody wanted to fund it. ITPC managed to evolve and get that to a different level.

ITPC also helped make discussions about intellectual property issues and access to medicines part of the mainstream conversation. ITPC has evolved over time, but has always found a way to stay true to its principles.

CREATING COMMUNITIES OF ACTIVISM & SUPPORT

Ava Avalos, Board member (2017–2020), Chair (2020)

I don't think a board meeting took place where people were not concerned about how to prevent burnout. Activists are idealists by nature, strong and energetic, but at a certain point, that can also work against you. Perhaps we needed more people on the ground, even though we had a set of heroes who were working non-stop. We weren't always sure that was the best model.

Fundraising became an important part of that picture. The biggest issue was always being able to negotiate how we could get support for positions that were outside of very grant-specific budget lines.

All activists right now across the world are feeling so overwhelmed, and the mental health of community organizers is suffering ... we feel like we're living through a time that we've never experienced before. So, how do we create communities of activism but also communities of support? How do we create networks where self-care is as revolutionary as demands for access to life-saving medication? And how do we bring young people and channel their enthusiasm to fight, not just for other people's well-being, but also for their own?

OUR VOICES REFLECTIONS FROM ITPC LEADERSHIP, PAST AND PRESENT

ADJUSTING TO NEW REALITIES

Gregg Gonsalves, co-founder and Board Chair (2014–2019)

We are in a more perilous situation than we've ever been.
We came out of the third year of the COVID-19 pandemic
with vaccine inequity still rampant across the globe. I think it
speaks to a much more nationalistic, protect-your-own version

of global development: a rapacity from companies like Pfizer and Moderna who refused to share their technology with others during the pandemic, and global leaders who aided and abetted them. I think there are less generous and less forward-thinking politics out there that are quite different from how we started all this work as ITPC. I think we've lost that solidarity that we might have had with people in the early 2000s. In many cases, we're on our own now.

The struggle is going to be a lot harder. I think we have to broaden to pull in new collaborations with other interest groups across the world because we're not just fighting health agencies now. We're talking about whose way of life gets to survive. It's pretty clear that global inequality is expanding, and that's tied to who benefits when the checks are written.

There is a much more fundamental, structural struggle that ITPC needs to be a part of. We can still do our work but I think we have to build bridges with other organizations in allied sectors as we often have the same opponents or the same challenges ahead of us.

BRANCHING BEYOND HIV

Mpumi Gumede, Board Chair (2021 to present)

Through ITPC's community-led activism, we have seen how communities were able to build structures on the ground, which were able to challenge policies and Big Pharma – the

David and Goliath reality – and build infrastructure using the architecure and learnings of HIV movement. When the COVID-19 pandemic hit, we were then able to mobilize those structures quickly. Our communities were able to galvanize and begin to fight for access to vaccines. We now see that model being replicated for other non-commicable diseases like cancer and wider health issues.

STAYING TRUE TO THE ITPC CORE

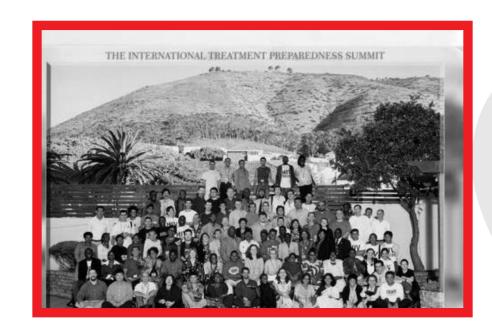
Solange Baptiste, long-standing ITPC staff member and Executive Director (2016 to present)

The thing I would like to say to donors is: I dare you to find a problem that cannot be solved by communities.

Every problem we're facing globally could be solved by communities if we trusted them and funded them and respected them as experts in their own right. The belief in community leadership lies at the core of ITPC, just as it did 20 years ago.



THROUGH THE YEARS







ANDY QUAN: 2003 INTERNATIONAL TREATMENT PREPAREDNESS SUMMIT ATTENDEE

I was at the meeting in Cape Town in 2003 when ITPC was founded and then worked as the Project Manager for South Asia, Southeast Asia, China, and Eastern Europe and Central Asia from 2005 to 2010. I helped facilitate getting small grants out to dozens of community-based organizations for HIV treatment education and improving access to HIV treatment.

ITPC members were great at combining work with pleasure, taking group photos, and telling stories. Those early years had a lot of funding challenges. We knew our work

was vital, important, and effective but how could we convince the funders? Did we have the evidence? Community-based organizations never have an easy time with both funding and stability, so it's a testament to ITPC and all those involved to see it evolve into the dynamic, solid network that it is today.

A big shout-out to my ITPC family and especially all of you who are carrying on the amazing work of the coalition.

THROUGH THE YEARS







MOISÉS AGOSTO: PROGRAM MANAGER (2005-2010)

I was the a Program Manager for the Caribbean, Latin America, and East Africa in the early 2000s. The issues that dominated my time with ITPC were access to HIV medications and treatment education. We needed to educate people living with HIV about the side-effects of these new medications and how to take them.

We were also building a grassroots community grant-making infrastructure that was community led. The community made decisions about what was needed locally and regionally, what proposals were going to be funded. That was groundbreaking work.

My message to ITPC on the organization's 20th anniversary would be to keep up your commitment to communities. Keep up the passion to save lives because ultimately that's what it's all about. Access to healthcare is a human right and you are in a position to directly impact the building of healthy communities.

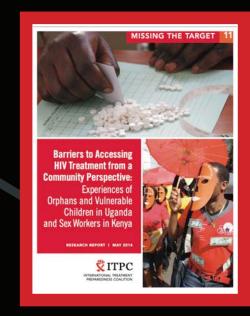
THROUGH THE YEARS MISSING THE TARGET



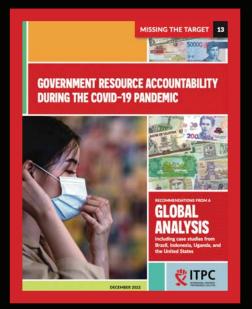






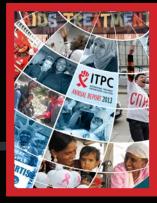






THROUGH THE YEARS PREVIOUS ANNUAL REPORTS



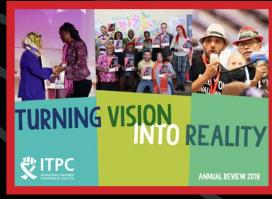




















WHO WE ARE @20

SINCE 2003

The International Treatment Preparedness Coalition (ITPC) has been a global issue-based network of people living with HIV, community activists, and their supporters working to achieve universal access to HIV treatment and other life-saving medicines.

OUR VISION

... is longer, healthier, and more fulfilling lives for people living with HIV, their families, and their communities.

OUR MISSION

... is to enable people in need to access optimal HIV treatment.

AFTER 20 YEARS

The core of our work remains **Treat People Right**. ITPC actively advocates for treatment access through three strategic focus areas: **Build Resilient Communities**, **Make Medicines Affordable**, **Watch What Matters**.

OUR VISION

... is all people realizing their right to a long, healthy, and fulfilling life.

OUR MISSION

... is to achieve health and social justice for all through robust community engagement.



WHAT WE DO

ITPC is committed to renewing its work in four core areas:

- 1 BUILDING RESILIENT COMMUNITIES and community systems
- **EDUCATING PEOPLE** to demand the health services they need
- INCREASING THE AVAILABILITY AND AFFORDABILITY
 OF DIAGNOSTICS AND MEDICINES, with a particular focus on
 access to life-saving medicines for HIV, TB, viral hepatitis,
 and other illnesses
- HOLDING GOVERNMENTS, DONORS, AND OTHER AUTHORITIES ACCOUNT ABLE to globally recognized standards for human rights and public health, with a focus on social justice

OUR VALUES

- Communities of people most affected by a particular disease are at the center of the response.
- There should be equity in treatment access.
- · We work in solidarity as a global movement.
- We are transparent about our finances and how we work.
- We are accountable to the communities we serve.



GLOBAL ACTIVIST NETWORK

BUILD RESILIENT COMMUNITIES

Namibia

Nigeria

Russia

Rwanda

Senegal

Sierra Leone

South Africa

South Sudan

Tanzania

Uganda

Zambia

Zimbabwe

Armenia

Brazil

Burundi

Cameroon

Côte d'Ivoire

DRC

Eswatini

Ethiopia

Ghana

Guatemala

Indonesia

Kazakhstan

Kenya

Kyrgyzstan

Lesotho

Liberia

Malawi

Mozambique

MAKE MEDICINES AFFORDABLE

Argentina

Armenia

Belarus

Brazil

El Salvador

Georgia

Guatemala

Honduras

India

Kazakhstan

Kyrgyzstan

Moldova

Morocco

Russia

Thailand

Ukraine

Vietnam

WATCH WHAT MATTERS

Algeria

Armenia

Belarus

Bolivia

Botswana

Burkina Faso

Burundi

Central African

Republic

Costa Rica

Côte d'Ivoire

Dominican Republic

DRC

Egypt

El Salvador

Ecuador

Guatemala

Honduras

Jamaica

Jordan Kazakhstan

Kenya

Kyrgyzstan

Lebanon

Malawi

Mauritania

Mexico

Morocco

Mozambique

Myanmar

Nigeria

Pakistan

Paraguay

Russia

Rwanda

South Africa

Sudan

Tajikistan

Togo

Tunisia

Ukraine

Uzbekistan

ACTIVIST IN FOCUS SERGIY KONDRATYUK

WORKING TO ENSURE ACCESS TO MEDICINES IN A WAR ZONE

Sleepless winters. Water shortages. Air raid sirens. Power outages. This is life in the war-torn capital that is **Sergiy Kondratyuk's** home. From there, his days are a labor of love as the Program Manager for ITPC's Make Medicines Affordable (MMA) strategic focus area and the global campaign led by ITPC Global.

"When the full-scale Russian invasion started in Ukraine, it brought a lot of deaths, suffering, destruction, and trauma for all Ukrainians. I start trembling whenever I hear loud sounds now," he said.

"I always try to do my best at work. I got used to working from the corridor, or trying to get work done despite being exhausted due to nights of air raids on my city, or trying to work as quickly as I could when

> there was electricity. At times, I tried to save my laptop and mobile phone batteries as much as I could to stay connected during blackouts."

> > "Happy" is how Sergiy described his feelings about the impact of his work.

In 2022, he helped organize the Global Summit on Intellectual Property and Access to Medicines, a three-day gathering of 75 participants from 36 countries working together to improve access to medicines. He muscled through challenges to secure the team's representation at the 24th International AIDS Conference, the world's largest conference on HIV, and he worked alongside ITPC's scientific and legal teams to facilitate filing 20 patent oppositions across seven countries.

"I am very thankful for all my ITPC colleagues' support during this hard period. All your messages after air raid attacks on Kyiv felt so important for me. There were moments when it was hard to answer 'How are you?' because of the lump in my throat ... there were too many things to say."

Other members of the ITPC family also live in Ukraine. Or used to. Many still have family there.

"I think of the people when I think of what's happening in the country of Ukraine," Solange Baptiste, ITPC Executive Director, said.

During the country's Orange Revolution, Solange spent several months in Ukraine working on maternal and child health. "Ukraine holds a special place in my heart. I have a lot of friends there. To see how that country has been torn apart has been heartbreaking," she added.

"Despite everything, there is also beauty in this tragic situation," said Othoman Mellouk, who leads ITPC's MMA strategic focus area.

"People were innovative and demonstrated a great capacity for adaptation, responding to emergencies but not forgetting the core work. We continued to file patent oppositions in Ukraine in the middle of the war."



ACTIVIST IN FOCUS SERGIY KONDRATYUK

With all the hardships, the Ukrainian team of activists at 100% LIFE, the largest organization for people living with HIV in Eastern Europe and Central Asia (EECA), developed and submitted a draft law on intellectual property security waiver in accordance with Article 73 of the World Trade Organization's Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) to the Ukrainian Parliament.

100% LIFE stood firm in advocating against a law "on protection of the interests of persons in the field of intellectual property during the martial law introduced in connection with the armed aggression of the Russian Federation against Ukraine." Such a law provides for illogical and harmful patent term extensions during the war period.

For ITPC leadership, the protracted geopolitical conflict made 2022 a year of complex decisions. "We are seeing Russia, China, and other non-aligned countries forming an alignment, which is shifting away from the traditional one. The Ukraine-Russia conflict saw our regional office, which was previously ITPCru, rebranded as ITPC Eastern Europe and Central Asia," Nompumelelo Gumede, Board Chair of ITPC Global, said.

"Because of the geopolitical issues, beyond the fact that Ukraine as a country is being devastated, the individuals and communities are also affected because they can't access the medicines they need."

ITPC stands in firm solidarity with civil society organizations (CSOs) working to ensure access to healthcare, human rights, and social justice in both Ukraine and Russia and across Eastern Europe and Central Asia.

"We continued to organize and educate people and do community-led monitoring ourselves to ensure that in countries like Russia, Kyrgyzstan, Kazakhstan, Armenia, and others, there is access to diagnostic tools and ARV treatment, and that people

who need care have access to it," Denis Godlevsky, who coordinates ITPC across that region, said.

ITPC EECA also kept track of stockouts of antiretroviral treatment across the region. "We were able to gather more than 600 messages from citizens of various countries, migrants, refugees, who did not receive the care that they were supposed to receive as citizens of their countries. We were able to help them to exercise their human rights," Denis said.

"ITPC was able to not just maintain its regular operations, but also to organize and help hundreds of Ukrainian refugees fleeing from their country, from their homes. We were able to provide them with medications, treatment for HIV and hepatitis C, and vital diagnostics that were essential for them to stay alive," he said.

For Sergiy in Kyiv, the way forward is unequivocal: "I believe we should continue the fight even harder for the rights of communities and against all the injustices that big systems and greed cause to people."

"I really appreciate and honor Sergiy," Solange said. "He is very special to us, and we appreciate the fact that he is able to hold the light and carry the torch in a very dark space."

Sergiy Kondratyuk still lives in Kyiv, Ukraine.



ACTIVIST IN FOCUS LOON GANGTE

42-DAY PEACEFUL PROTEST AGAINST DRUG STOCKOUT IN INDIA

India is the world's largest manufacturer of generic medicines. It supplies over 80% of the ARV drugs used to treat HIV worldwide. **Despite that, in July 2022, a group of**

Indian activists were forced to stage a six-week sit-in dharna

(peaceful protest) over a life-threatening

HIV drug shortage in the country. Here's how their action changed India's health system.

"We were ready to live or die fighting for the cause of our community," **Loon Gangte**, Regional Coordinator of ITPC South Asia and founder of the Delhi Network of Positive People (DNP+), said.

In early 2022, DNP+ members and people living with HIV all over India started witnessing an acute shortage of certain ARVs. Many people depend entirely on ARV medications, which are distributed for free in special antiretroviral therapy (ART) centers. Among the reported drug shortages was dolutegravir (DTG), which is the backbone of ART in India.

Instead of receiving a minimum one-month supply from ART centers, DNP+ members in various states reported that they were getting only five days' supply. Some even said they had been sent back home empty-handed, with ART centers advising them to buy the drugs themselves. ARVs are available at private pharmacies, but many people living with HIV are unable to afford them.

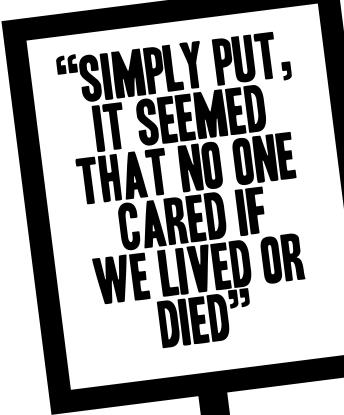
"Simply put, it seemed that no one cared if we lived or died," Loon said.

Stockout reports kept coming in from Assam, Bihar, Chandigarh, Gujarat, Haryana, Himachal Pradesh, Jharkhand, Manipur, Punjab, Rajasthan, Uttarakhand, and Uttar Pradesh. Some people reported that, instead of adult formulations, they had been asked to take multiple doses of pediatric formulations. And when pediatric doses were not available, adult pills were broken or crushed, making adherence challenging for caregivers.

Adherence is a life-or-death issue. An HIV treatment interruption can cause a person's viral load to rise and heighten vulnerability to HIV transmission, drug resistance, and secondary infections, such as tuberculosis.

"We saw that we were left to defend ourselves. So, after several months, we had to do what we didn't want to do," Loon said.

On 21 July, Loon and about 30 members and staff of DNP+ went to the National AIDS Control Organization (NACO) on



ACTIVIST IN FOCUS LOON GANGTE

the sixth floor of Chanderlok Building, Janpath, New Delhi, and started an indefinite and non-stop *dharna*.

"NACO and its allies put us under constant pressure and tried to manipulate us. But we stood firm in our demand: one-month minimum ART supplies for all. This is not just our job; this is our real life. We're fighting for our lives and the lives of the people we serve," Loon said.

Forty-two days later, on 31 August, NACO finally agreed to the demands and DNP+ ended the *dharna*.

IMPACT

3 big wins from the DNP+ dharna:

- **BETTER ACCESS.** "We got our main demand, which was immediate restoration of one-month minimum ART supplies for every person living with HIV in India."
- 2 SYSTEMIC IMPACT. Government officials committed to issuing a two-year ART tender, instead of one year.
- 3 INCREASED VISIBILITY. Almost every day, regional, national, and international media crews, including the BBC, came to the protest site to cover the protest.

LESSONS LEARNED

What communities should know:

- **BE CLEAR ABOUT YOUR GOALS.** Many things are negotiable, but some things must be non-negotiable. Distractions come in all shapes and sizes. Don't get distracted.
- **IF YOU START, DON'T STOP.** Stand firm on what you believe is right even if the whole world thinks you are crazy. If you're going to stop, don't start.
- STAY TRUE TO YOURSELF. But don't be surprised if some friends suddenly become foes, or some allies emerge as enemies. Some people change their colours under pressure.





ACTIVIST IN FOCUS ALMA DE LEÓN

LIBERATING MEDICINE IN LATIN AMERICA

Alma de Leon has led ITPC's operations in Latin America and the Caribbean (ITPC LATCA) since 2007. In that time, ITPC was never able to block any patents in Central America. Until 2022.

"In 2022, we had the opportunity to make interventions in Guatemala, El Salvador, and Honduras," Alma said.

"We are working to make intellectual property rights better for people, and not for pharmacies."

In Guatemala, an ITPC-led team of activists filed a patent opposition against remdesivir. In El Salvador, one annulment request has already been filed and approved. And in Honduras, the activists' struggle to make life-saving medicines more affordable continues.

"This is a great experience for the Latin American hub," Alma said. "Since I have been working at ITPC, it is the first time that the Latin America and Caribbean region has had the opportunity to file a patent opposition. Working with ITPC Global has given us this opportunity."

"In 2022, we continued to file oppositions to patents that we believe are abusive," Othoman Mellouk, ITPC Global's Program Lead for Intellectual Property and Access to Medicines and Diagnostics, said. This patent opposition in Guatemala has been the result of the effort from ITPC to make prices more accessible in the region by training different partners and colleagues in Guatemala, El Salvador, and Honduras, as well as others who are united in this effort.

Alma and her team of Latin American activists' critical role in El Salvador, Guatemala, and Honduras opened up entry into the generic market, similar to what happened in Argentina, where ITPC's interventions made it possible to generate

several hundred million dollars in savings for the national program.

For Alma, the struggle to make even more medicines affordable across the region is the only way forward.

"We still have a lot to do, mainly in Central American countries where more treatment coverage needs to be achieved," she said.





Countries where ITPC projects were implemented

COMMUNITY Leadership 345
Community
activists trained

Stakeholder engagements held

Advocacy initiatives held

IMPACT IN NUMBERS

HIV, HCV, or COVID-I9 products made cheaper

Medicines for which IP interventions have started

2

Countries where CSOs filed oppositions for the first time

ACCESS TO REATMENT USD 232 MILLION

Projected impact in cost savings and efficiencies

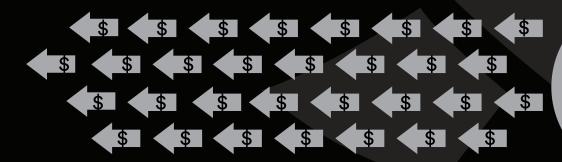
Patent oppositions filed

5

Legal policy amendments made

75

Participants in GSIPA2M 2022 in Istanbul



strategic advocacy grants awarded and dispersed

USD 2,007,523.51

value of grants disbursed



IN 2022, WE CONTINUED TO SUPPORT

increased treatment access through educational initiatives and community-led research and monitoring for stronger national, regional, and global advocacy. We reinforced knowledge on HIV and COVID-19: we developed educational materials and trainings on the HIV cascade and on COVID-19 vaccines, and a COVID-19 guiz and webinars. Empowered and engaged communities are essential for achieving person-centered care. We supported members of the ITPC Community Advocacy Network (CAN) to document the involvement of recipients of care in shaping HIV policy and programming, calling for greater engagement.

We also partnered with communities in efforts to monitor and mitigate the impact of the COVID-19 pandemic and its effects on service delivery and already fragile HIV health systems. Through disbursement of grants and technical input, we enabled communities to gather information to support advocacy on a wide variety of issues, including differentiated service delivery, sexual and reproductive health, and access to diagnostic tests and COVID-19 technologies. This year, ITPC also published its first-ever "Missing the Target" report focused on government resource allocation in response to COVID-19, with insights relevant to the future of pandemic preparedness and responses. We continued to provide communities with adequate tools to safeguard advocacy for corrective action and community participation in decision-making.

OUR IMPACT

- ITPC disbursed small grants to networks of people living with HIV and other key populations in 20 countries to assess the nature of and advocate for increased national-level community engagement in differentiated service delivery decision-making and programming.
- We revamped our educational treatment materials and held virtual educational workshops with community advocates on HIV prevention, treatment and care, and COVID-19 science and advocacy.

- We developed an interactive, COVID-19 educational quiz, a community resource with updated information on SARS-CoV-2. The quiz tests existing knowledge and dispels myths and misconceptions about COVID-19.
- We produced a Missing the Target (MTT) report—in partnership with community research teams from Brazil, Indonesia, Uganda, and the United States—for research that explored government resource accountability during the 2020-2022 COVID-19 pandemic.
- In collaboration with Matahari Global, we adopted a phased approach to track the availability of and access barriers to COVID-19 technologies across 14 countries: Bangladesh, Democratic Republic of the Congo, Haiti, Jamaica, Liberia, Madagascar, Nepal, Nigeria, Perú, Senegal, Somalia (and de facto state Somaliland), Uganda, and Ukraine.
- With the Salamander Trust and women's groups in East and Southern Africa, we assessed whether the sexual and reproductive health of women living with HIV is still confined by COVID-19. Through this research process, we have seen how the COVID-19 pandemic and the responses from governments and donors have further deepened the inequities that women and girls from East and Southern Africa continue to face. The protracted effects of COVID-19 have made recovery an impossible task for most women and girls living with HIV in the region.
- We supported communities to go beyond demand creation to identify gaps in access to routine viral load and CD4 cell count testing (using

BUILD RESILIENT COMMUNITIES

quantitative and qualitative techniques) in two pilot sites in Kenya and Sierra Leone. This study highlighted that the "new" pandemic shone a harsh light on old and enduring problems with supply chains, procurement, repair, transportation, and staff shortages that hinder availability of RVLT, CD4 cell count tests and other diagnostics and treatments.





Regional ITPC networks led local community networks in the monitoring of antiretroviral stockouts and related advocacy. In the Eastern European and Central Asia region, these networks looked at HIV treatment interruption among people living with HIV because of the ongoing conflict between Russia and Ukraine. In Latin America, ITPC Latin America and the Caribbean led advocacy to address financial constraints and legal barriers that were identified as factors in accessibility to HIV treatments and treatment stockouts. ITPC South Asia exposed the reality of ARV stockouts in India and led a 42-day sit-in protest that generated international media coverage and action from the government of India to address this long-standing issue.

BUILD RESILIENT COMMUNITIES

LEARN MORE

Are the sexual and reproductive health and rights of women living with HIV still confined by Covid-19?
An analysis of then and now

Mapping COVID-19 Access Gaps: Results from 14 Countries & Territories

Mapping COVID-19 Access Gaps: Results from 14 Countries & Territories – Media Coverage:

- · The Guardian
- The India Times
- Health Policy Watch
- Politico
- The Hindu Business Line
- · The Business Standard
- · Common Dreams
- Devex

Community Engagement Framework for Differentiated Service Delivery

Missing the Target 13: Government resource accountability during the COVID-19 pandemic: Uganda

Missing the Target 13: Government resource accountability during the COVID-19 pandemic: Indonesia

Missing the Target 13: Government resource accountability during the COVID-19 pandemic: Brazil

Missing the Target 13: Government resource accountability during the COVID-19 pandemic: Global Analysis

COVID-19 Educational quiz

ARV stockouts in India media coverage

Revamped treatment education toolkit - HIV cascade









MAKE MEDICINES AFFORDABLE WORKS TO NCREASE ACCESS to life-saving medicines, diagnostics, and medical

technologies for all who need them. High prices and market monopolies held by multinational pharmaceutical corporations and corrupt governmental policies have led to deadly access gaps for life-saving medicines. ITPC believes that a comprehensive understanding of intellectual property (IP) regulations and flexibilities puts activists in a stronger position to advocate for universal access to affordable diagnostics, medicines, and healthcare. This ultimately leads to savings in health budgets that can be used to provide optimal prevention, treatment, and care for all.

The ITPC-led Make Medicines Affordable (MMA) campaign has been continually working with a consortium of partners across 17 countries (Argentina, Armenia elarus, Brazil, Georgia, Guatemala, El Salvador, Honduras, India, Kazakhstan, yrgyzstan, Moldova, Morocco, Russia, Thailand, Ukraine, and Vietnam) since 2018.

In 2022, the MMA campaign created conditions for significant price reductions for seven HIV, HCV, and COVID-19 medicines in six countries, which contributed to estimated savings of USD 232 million in government funding.

In July, we held our Global Summit on IP and Access to Medicines over three days and brought together 75 participants from 36 countries. It was an opportunity to share experiences and strategies between the consortium members, as well as with other civil society organizations working on IP and access to medicines.

ITPC and our partners continued gathering and maintaining up-to-date patent and market intelligence related to HIV, HCV, TB, and COVID-19 products. Data gathered was used to identify target products, to identify appropriate interventions, and to inform policy dialogue with relevant stakeholders. Eight market intelligence reports covering nine countries (Argentina,

Armenia, Belarus, El Salvador, Guatemala, Honduras, Kazakhstan, Kyrgyzstan, and Russia) were published in 2022.



MAKE MEDICINES AFFORDABLE

OUR IMPACT

Twenty patent oppositions, including seven on potential COVID-19 medicines, were filed during the reporting period in seven countries (Argentina, Armenia, Brazil, Morocco, Russia, Thailand, and Vietnam). First-ever CSO-led patent oppositions were filed in two new countries (Morocco and Armenia).

There were important wins related to our cases on five products, including:

- On 28 April 2022, Thailand's Department of Intellectual Property (DIP) took a
 decision to reject Fuji Film Toyama's appeal against the DIP's first decision to
 reject the patent application on the tablet formulation of favipiravir.
- On 22 March, El Salvador's Department of Patents rejected the patent application on doravirine in El Salvador using alternative patent opposition strategies.
- In Argentina, Fundación GEP's patent oppositions contributed to the forced withdrawal of the patent application on remdesivir (2 June 2022) and to the National Institute of Intellectual Property's rejection of patent applications on Sofosbuvir (July 2022) and tenofovir alafenamide TAF (September 30).







MAKE MEDICINES AFFORDABLE

There were five amendments of legal policies adopted in four countries (Argentina, Belarus, Russia, and Vietnam) with contributions by relevant country teams. Additionally, seven legal and policy amendments have been submitted by MMA consortia to promote the use of TRIPS Flexibilities. Six comments and language submissions took place in three countries to prevent the adoption of TRIPS-plus provisions. At least 10 policy makers made commitments to take action in favor of public health safeguards and against TRIPS-plus measures.

Our Community Advisory Boards at global or regional levels enabled 82 community representatives to meet with 16 pharmaceutical companies to discuss drug development, pricing, and access initiatives.





LEARN MORE

Vaccines Efficacy
Community Resource

Medicines Equality Now

GSIPA2M 2022 - The Pandemic Edition: Reclaiming Access

GSIPA2M - Day 1

GSIPA2M - Day 2

In times of peace and in times of war: 100% LIFE outstanding work in Ukraine

Fighting for access to better TB drugs in Thailand





THROUGH ITPC'S COMMUNITY-LED AND RESEARCH INITIATIVES, such as Missing the Target, Citizen

Science and Community-Led Monitoring (CLM), recipients of care documented emerging health issues, showcased gaps and disparities, and worked with local providers to co-create solutions to overcome barriers to health. These initiatives mean that data is gathered on access to and quality of HIV treatment so that decision-makers and HIV programs are accountable to communities and can tailor prevention and treatment services to real needs. When that happens, more people use services and health outcomes are better with more effective and efficient use of resources.

More specifically, we applied CLM across several health areas, collecting data from recipients of care and their communities on human rights violations and treatment access gaps for HIV, TB, hepatitis C, and COVID-19. CLM enabled people living with HIV, their networks, key populations, and organizations to monitor the quality of health services and medicines. They sound the alarm when drugs are missing or human rights are violated.

WATCH WHAT MATTERS

OUR IMPACT

- ITPC documented CLM's role in catalyzing greater differentiation of service delivery in more than 20 countries, increasing use of communications technology in health services, and improving supply chain management and multi-month dispensing.
- We supported partner organizations to conduct CLM of urban health facilities in China, Guatemala, India, Nepal, and Sierra Leone. These organizations include AIDS Care China, ITPC Latin America and the Caribbean, the Global Coalition of TB Activists, Dristi (Nepal), and the Network of HIV Positives in Sierra Leone.
- We partnered with amfAR's TREAT Asia program, working with the Community Network for Empowerment in India and Peduli Hati in Indonesia, to initiate community treatment observatories (CTOs).
 Country-specific indicators on HIV and hepatitis C services were developed for these CTOs, which collected data from February to December 2021 for health facility sites and entered the data into ITPC-hosted databases. This data will be used to help guide ongoing implementation of CTOs and inform advocacy for HIV and HCV service improvements for people living with HIV and people who inject drugs.

WATCH WHAT MATTERS

 We provided CLM technical assistance in the Democratic Republic of Congo, Jamaica, Nigeria, and Ukraine. We provided short-term CLM support to Belarus, the Central African Republic, Egypt, Kenya, Russia, and Senegal, which face high levels of disruption of HIV, TB, and malaria grant and program implementation due to COVID-19.

We supported the development of CLM resources and tools adapted for COVID-19 for use regionally and globally.

HIGHLIGHTS

In September 2020, ITPC launched COVID-19 Citizen Science, a groundbreaking, community-led project documenting real-time perspectives, experiences and advocacy priorities among people living with HIV in Malawi and South Africa. It combined community-led monitoring, operational research, and a novel methodology we call Life Mapping, which uses collaborative and participatory visual media tools.

We monitored 29 health facilities serving a catchment area of 884,000 people. Data was routinely collected for one year from October 2020 to September 2021. Some data was also collected

retroactively for November 2018 to October 2019, enabling a pre-COVID-19 comparison.

Using this data, ITPC and its partners are leading several ongoing advocacy actions.

We are helping bridge the feedback gaps in health facilities by creating regular dialogue spaces where healthcare workers and recipients of care can discuss our data and co-create solutions.

Healthcare workers report that this model is motivating for them, both to address challenges and scale up good practices. We are also working to improve data sharing among departments of health and social development to improve joint services for gender-based violence and mental health, for example.

LEARN MORE

CLMHub.org

From Insights to Evidence

Precision to Pandemic

Data Analysis Methods in Community-Led Monitoring

Data Management Tools

Guide to Support Community-Led Monitoring in Data Use in Decision Making

Costing Resources





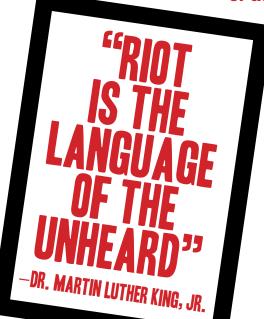
MILESTONE MOMENTS

DELIVERING A PLENARY ADDRESS AT THE INTERNATIONAL AIDS

CONFERENCE IN MONTREAL, Executive Director **Solange Baptiste** showcased ITPC's Community-Led Monitoring (CLM) as an intervention where the communities themselves identify pain points, develop indicators, collect evidence, inform decision-makers, and work with other stakeholders to co-create solutions.

Just two days before, at the conference opening ceremony, Baptiste participated in a joint protest on the event's main stage.

"There's really no such thing as 'voiceless'. There's only the deliberately silenced, or the preferably unheard." – Arundhati Roy



Solange Baptiste, Executive Director, International Treatment Preparedness Coalition (ITPC), and Member of the Global Public Investment Network (GPIN) expert working group, received a certificate from Gargee Ghosh, President of Global Policy and Advocacy at the Bill & Melinda Gates Foundation, outlining a Commitment to Action, during a session titled "Reversing the Global Slide on Poverty: How We Can Scale Up Proven Anti-Poverty Solutions", held at the launch of the Clinton Foundation's Clinton Global Initiative (CGI) 2022 in New York. The Global Public Investment or GPI approach emerged from years of

analysis and advocacy, and has widespread support across the globe for its principles of **All Contribute**, **All Benefit**, **All Decide**.

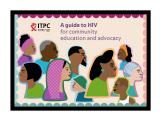
"I'm coming from a place of frustration and GPI provides some hope if I have to be brutally honest. Communities, civil society [are] just absolutely frustrated. The system does not work for us. The system is designed very well for those who have power to retain their power. So, I'm not about fixing the system. I think we need to burn it all down and

build something that works for communities."

- Solange Baptiste



OUR IMPACT PUBLICATIONS



A Guide to HIV for Community

Education & Advocacy





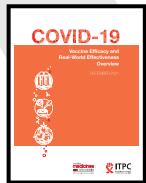
Analysis of Community Treatment
Observatory Data for HIV and
Hepatitis C Virus Services in India
and Indonesia



Are the Sexual and Reproductive
Health and Rights of Women
Living with HIV still Confined by
Covid-19? An analysis of then and
now



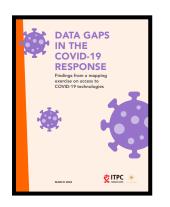
Community-led Monitoring in
Country Proposals for the Global
Fund 2023-2025 Funding Cycle
(NFM4) Information Brief



COVID-19 Vaccine Efficacy and Real-World Effectiveness Overview



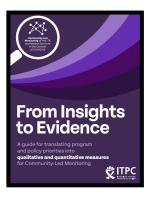
CQUIN Recipient of Care Satisfaction Toolkit



Data Gaps in the COVID-19
Response: Findings from a
mapping exercise on access to
COVID-19 technologies



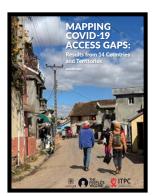
Democratic Republic of Congo Phase II



From Insights to Evidence: a guide for translating priorities into qualitative & quantitative measures for community-led monitoring



OUR IMPACT PUBLICATIONS



Mapping COVID-19 Access Gaps:
Results from 14 Countries &
Territories



Missing the Target: Global
Analysis: Government Resource
Accountability During the
COVID-19 Pandemic



Missing the Target: 14 Countries:
Government Resource
Accountability During the
COVID-19 Pandemic



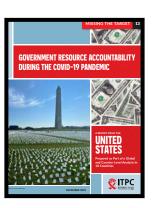
Missing the Target: Indonesia:
Government Resource
Accountability During the
COVID-19 Pandemic



Missing the Target: Brazil:
Government Resource
Accountability During the
COVID-19 Pandemic



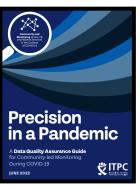
Missing the Target: Uganda:
Government Resource
Accountability During the
COVID-19 Pandemic



Missing the Target: United
States: Government Resource
Accountability During the
COVID-19 Pandemic



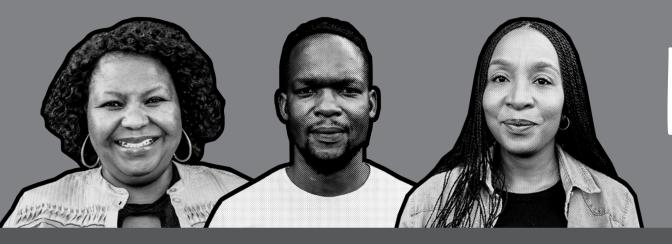
Nigeria Brief Phase II



Precision in a Pandemic



The Good, the Bad, & the Unfinished Business



MAKE YOUR MONEY COUNT

ITPC DELIVERS IMPACT IN PEOPLE'S LIVES, backed by solid expense

management and continued strong resource mobilization. We deliver strong value for money.

In spite of the significant global downturn in the non-profit sector, our financial operations continued with controlled growth, at least in part

because of our focus on enabling communities to build resilience, hold officials to account, and demand what they deserve, as outlined in this annual report. Our online donation portal, launched in November 2022, remains essential to our mission.

The year 2022 was characterized by war in Ukraine, price increases on fuel, energy, and food, and a post-COVID-19 global order that presents existential challenges to our former business model. We expected large budget uncertainties and revenue shortfalls. But holding it together was the ongoing commitment of our staff, Global Activist Network, business partners, Board, and management team. Through our prudent and responsive financial measures, we were able to close the year with an actual operating surplus, close to what was projected.

USE OF FUNDS

We continued to maintain higher costs on implementation of grants. In 2022, our personnel and overhead expenses made up 27% of our overall spending, while program direct cost and strategic granting made up 73%.

For every dollar donated, only 27 cents went towards overheads, making ITPC a high-impact strategic investment.

PEOPLE OVER OVER PROFIT

HOW WE Spent our Money

73%
PROGRAMS

42% DIRECT PROGRAM **21 %**PERSONNEL & OPERATING COSTS

31% STRATEGIC GRANTS



THANK YOU

FUNDERS

ITPC is grateful to current and new donors for their consistent support that enabled us to meet our strategic objectives and core goal of Treating People Right:

Addie Guttag • Bill & Melinda
Gates Foundation • The
Global Fund to Fight AIDS,
Tuberculosis and Malaria •
ICAP at Columbia University's
Mailman School of Public Health

Levi Strauss Foundation

Open Society Foundations •

Robert Carr Fund • UNAIDS •

UNITAID • UNOPS-StopTB •

ViiV Healthcare

"I AM DELIGHTED
TO HAVE BEEN INVOLVED WITH
ITPC SINCE ITS CREATION.
I'M AMAZED BY HOW MANY
LIVES HAVE BEEN SAVED
AND IMPROVED BY THE WORK
OF ITPC, THE STAFF AND
THE COUNTLESS ACTIVISTS
THAT HAVE BEEN INVOLVED
OVER 20 YEARS."

- ADDIE GUTTAG, FUNDER

BOARD

Thanks also to our **Global Board members** for their continued support and invaluable guidance through these tough times:



Nompumelelo Gumede Chair South Africa



Jarasa Kanok
Vice Chair United States of America



Nathaniel Wong
Treasurer United States of America



Cindy Kelemi

Botswana



Nikhil Bumb
United States of America

LET'S WORK TOGETHER



DONORS

If you are a funder, let us know what you are interested in. We have gathered a wealth of insight from over 20 years of activism across the globe.



GOVERNMENTS

If you are a government official, let us work together and create a standout model for effective health systems.



COMPANIES

If you are from the private sector, work with us to express and expand your corporate social responsibility.

LEARN MORE ABOUT ITPC



CONTACT ITPC



GLOBAL TEAM



Solange Baptiste

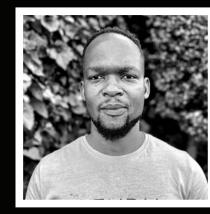
Executive Director



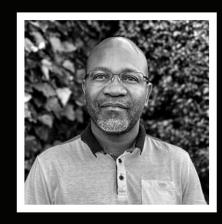
Wame Jallow
Director of Global Programs
and Advocacy



Collen Ngundu Finance Lead



Khathu Musekwa
Accountant



Leonard Moyo
Grants & Compliance Manager



Mpho Sekano
Grants & Compliance Officer



Vuyokazi Lwana
Procurement and Contracts
Officer



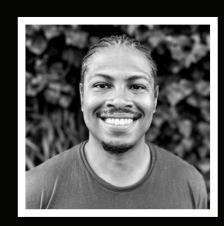
Jacquie Majawala
Finance & Administration
Officer



Othoman Mellouk Intellectual Property and Access to Medicines Lead



Sergiy Kondratyuk Unitaid Program Manager



Detrich Peeler
Unitaid Partnership Officer



Morgane Ahmar
Unitaid Partnership Officer

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Khokhelwa Zokwana Life Maps Officer



Nadia Rafif Advocacy & Influence Lead



Helen Etya'ale
Program Manager



Bactrin Killingo
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