

# THE FUTURE IS COMMUNITY-LED



ANNUAL REVIEW 2019



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## A MESSAGE FROM

Solange Baptiste,  
Executive Director, ITPC Global

## THE FUTURE IS COMMUNITY-LED

It is impossible to look back at ITPC's work in 2019 without reflecting on this new reality we find ourselves in. Mid-way through 2020, we are in the midst of the global coronavirus pandemic. In addition to the hundreds of thousands of lives lost, and an uncounted number of survivors with severe side effects, coronavirus has disrupted our lives and the world as we knew it. From where I am in Johannesburg, South Africa, this has ranged from devastating economic consequences for people who work on the streets to disruptions in essential medicines as global supply chains falter.

**"COMMUNITIES ARE NOT WAITING TO BE INVITED TO THE TABLE OR INCLUDED IN YOUR STUDY, THEY ARE LEADING THE WAY."**

And yet as much as I have experienced moments of fear and anxiety about the consequences of this pandemic, I have also been reminded of why the work that ITPC does is so vital. Communities have never been more important in trying to keep people safe and healthy. As coronavirus demonstrates, while governments play a critical role setting policy and guidelines, it is communities that determine how well these will work in reality. The race for a coronavirus vaccine reminds us that a vaccine will be meaningless if it is out of reach for the majority of the world's population due to patents.

ITPC's work in 2019 reflects our commitment to sustained, community-driven activism. Our groundbreaking Community Treatment Observatory model expanded from West Africa to Southern Africa, resulting in concrete improvements to health facilities for people living with HIV. Our work to challenge unfair intellectual property regimes and make medicines affordable soared, as new patent oppositions were filed around the world and dozens of lawyers were trained to fight

inequitable patent regimes. At the core of our work remains our treatment education, which continued last year to adapt and improve the way people learn about their bodies, medicines and how to stay healthy.

As we look back on the year but also towards the future, it is clear that the lessons learned from community-led HIV advocacy and health programs can inform our broader health responses.

Communities are not waiting to be invited to the table or included in your study, they are leading the way.

**In solidarity,**

**To watch Executive Director's  
Welcome Message, [click here >](#)**



◀ *“The Regional Community Treatment Observatory improved our evidence-based advocacy. We are more credible. We are **relied on.**”* Amen Hlomewoo, Community Treatment Observatory Focal Point, Togo, pictured here receiving the CTO Accreditation at the ITPC CTO Learning Event on October 17 at the UNICEF/UNAIDS Meeting Room, Abidjan, Côte d'Ivoire

*“Everyone talks about ‘Ending the Emergency,’ but without funding for communities that is a distant dream!”* ▶

Blessi Kumar (centre), CEO of the Global Coalition of Tuberculosis Activists, pictured here alongside her GCTA colleagues Priyanka Aiyer and Archana Oinam at the World Lung Conference 2019, Hyderabad, India



▼ *“Communities are at the centre of every action. Communities are defining the indicators and monitoring the trends. Communities are determining the research parameters and leading the science. They are the ones taking the actions, coming up with the solutions, conducting the advocacy and partnering with stakeholders to bring about change.”*

Greg Vergus, Coordinator, ITPC Eastern Europe and Central Asia (ITPCru), pictured in a screenshot from the CTO Impact Film released in October 2019



# A GLOBAL ACTIVIST NETWORK

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

As an issue-based coalition, ITPC actively advocates for treatment access across the globe through the focus of three strategic priorities:

## #TREATPEOPLERIGHT

Treatment education and demand creation

## #MAKEMEDICINESAFFORDABLE

Intellectual property and access to medicines

## #WATCHWHATMATTERS

Community monitoring and accountability

# MISSION

To enable people in need to access optimal HIV treatment

# VISION

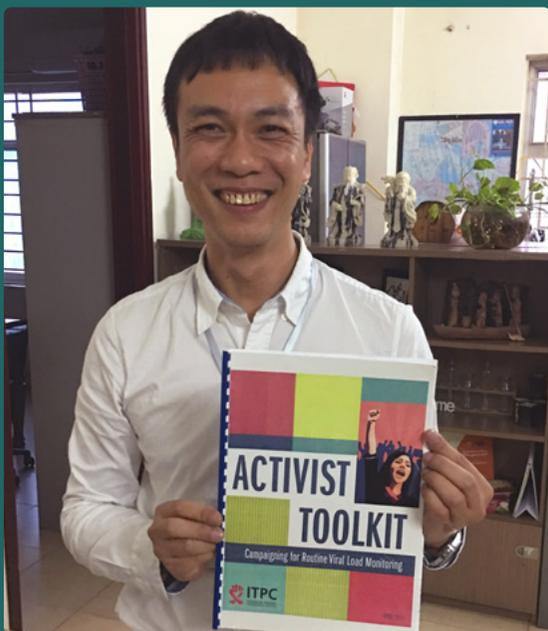
Longer, healthier, and more fulfilling lives for people living with HIV, their families, and their communities

# VALUES

Communities are at the center of the response. There is equity in treatment access. We work together in solidarity as a global movement. We are transparent about our finances and how we work. We are accountable to those we serve

Over the last decade, ITPC has expanded its work beyond HIV by responding to the health priorities of coalition members and advocating for access to medicines and quality health care for TB, viral hepatitis, diabetes and other life-threatening conditions.





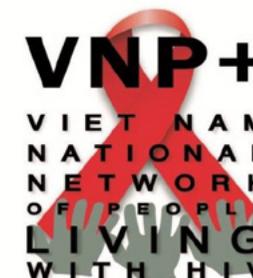
Dong Do Dang holds the first version of the ITPC Activist Toolkit at the Bridging the Gaps Learning Institute, in Hanoi, Viet Nam, April, 2019



## GAN MEMBER PROFILE

### Dong Do Dang

Viet Nam Network of People Living with HIV



Dong Do Dang, 44, is the Chairman of the Viet Nam Network of People Living with HIV/AIDS (VNP+) and a member of the Global Activist Network. Dang is based in Hanoi, where he is involved in leading treatment activism work for the network's 167 groups of people living with HIV. When he's not working, he likes to spend time at home with his family.

#### What first motivated you to get involved with HIV activism?

In 2005, I saw images of late-stage HIV-infected children returning home from the hospital with opportunistic infections, such as oral thrush and pain due to an inability to eat. I then joined a home-based care group helping get treatment for these opportunistic infections to children, at a time when doctors would not treat them. ARVs were not even available in Viet Nam at the time; we had to buy medicines used for adults from Thailand and bring back to Viet Nam.

#### What does a typical day at work look like for you?

Most of my time is spent in meetings with partners. I can work from anywhere, sometimes in the office or late at home.

#### How does VNP+ work with ITPC?

VNP+ works with ITPC as a partner. And the important thing about the relationship for us is that we found common ideal, goals and works in term of supporting people living with HIV.

#### Have you ever been afraid as an activist, and if so, how did you find courage?

No, I've never been afraid to do my activism, because for me activism is not a job or hobby, it is my life. I used to say with my friend that in this HIV war, we have only one target—that is "treatment for all"—but during the process to reach our target we have to do many things that we're not familiar with and haven't been trained in before, but we have to do it.

# GLOBAL TEAM & BOARD



## GLOBAL TEAM MEMBER PROFILE



### Alain Manouan

Community-Led Monitoring Lead,  
ITPC Global”

Alain joined the ITPC community in December 2016 as the Community Treatment Monitoring Project Director. Over the past three years, Alain has worked to improve access to treatment in 11 countries in West Africa), and in January 2020 he became the Community Monitoring Lead for ITPC Global.



*Alain Manouan (third right), speaks at France Expertise session, ICASA 2019, Abidjan, Côte d'Ivoire.*

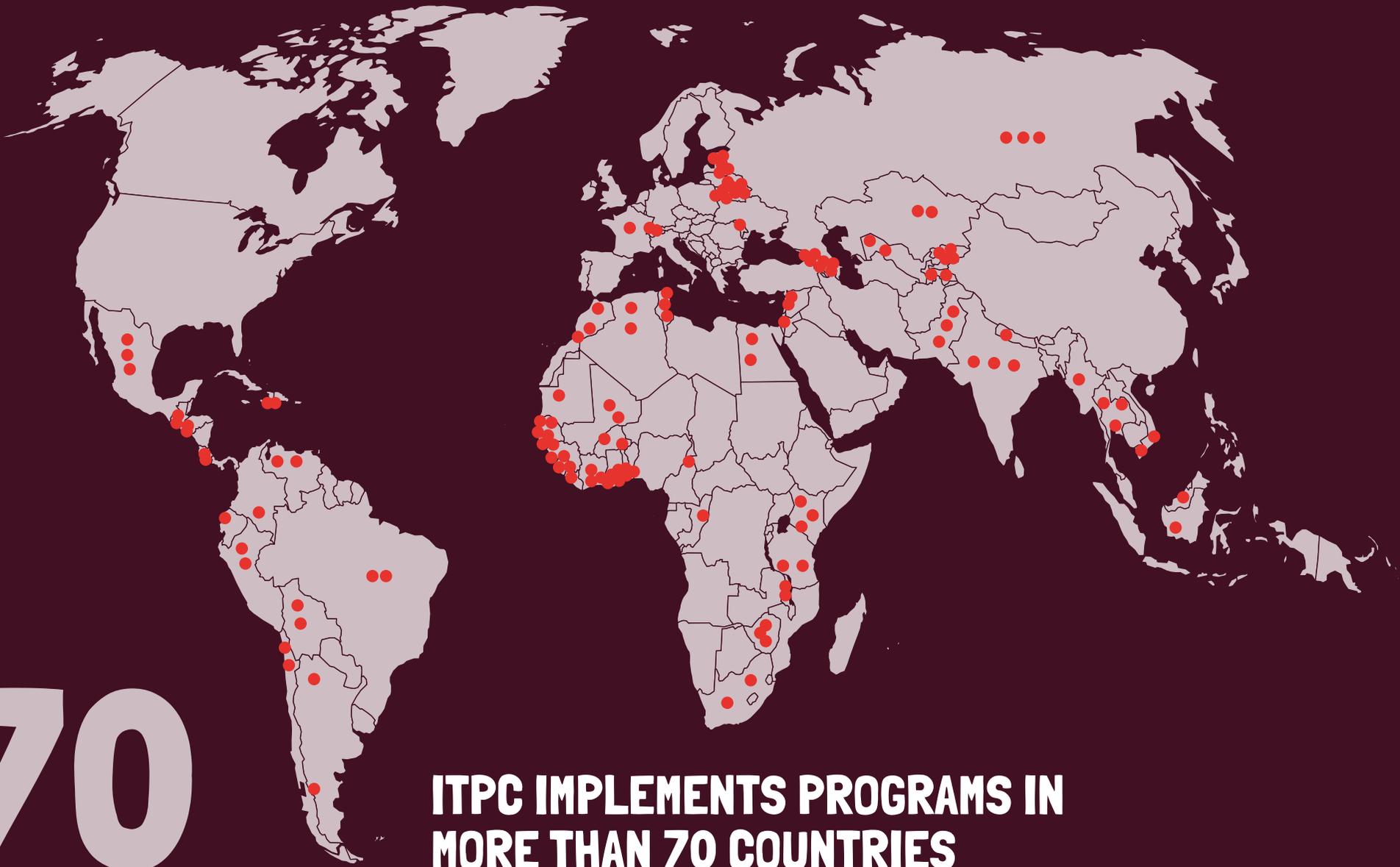
#### **Tell us about your work at ITPC**

I contribute to building the capacity of communities to conduct community-led interventions. Recently, community monitoring and advocacy have been the focus of my work. This work falls under Watch What Matters, which is one of three pillars of ITPC's Global Strategy.

#### **What challenges do you foresee in West Africa as a result of Covid-19?**

West Africa is not immune to the Covid-19 pandemic. Its effects threaten the gains made in the region's Treatment Access agenda. West Africa's public health system could be severely affected and therefore there is a need to build on community systems strengthening.

# ITPC AROUND THE WORLD



>70

**ITPC IMPLEMENTS PROGRAMS IN  
MORE THAN 70 COUNTRIES**



**OUR IMPACT**

# YEAR IN NUMBERS



## COMMUNICATIONS REVAMPED

We revamped our communications, including a new website and animated videos on treatment issues



**REJECTED**

Thailand's patent office rejected the application on raltegravir, a highly priced 3rd line ARV, building on work done in 2018.

**2,777** PEOPLE  
IN   
**14** COUNTRIES

A global treatment access survey launched in April in 14 countries surveyed 2,777 people living with HIV and identified access barriers and gaps in services.

**125**

Health facilities monitored in **11** West African countries

**TO INCREASE ACCESS TO OPTIMAL HIV TREATMENT**

**9**

Health facilities monitored in **3** South African countries

**LAUNCH OF PATENT OPPOSITION ACADEMIES**



To build a cadre of scientists and lawyers:

**62**

community leaders, lawyers and chemists trained from

**13**

countries in EECA and Latin America



**NEW PATENT OPPOSITIONS FILED**

in Argentina, Brazil, India, Thailand and Ukraine

**\$2,696,747**

**GRANTS TO GAN/ REGIONAL NETWORKS AND CONSORTIUM PARTNERS**



**EVIDENCE-BASED RESEARCH REPORTS RELEASED**

# #MAKEMEDICINESAFFORDABLE



*Othoman Mellouk, Intellectual Property and Access to Medicines Lead, ITPC Global, speaks out at a joint protest at the 10th International AIDS Society Conference on HIV Science (IAS 2019) in Mexico City, Mexico.*



*“Not all treatment is equal, yet everyone deserves optimal treatment. Most countries have committed to respect the right to health, but this right is being violated by private companies abusing the patent system, for example, by applying for secondary patents on medicines.”*

**Sergey Kondratyuk, Make Medicines Affordable Campaign Manager**

Over the past year, we continued our work to ensure that essential medicines become affordable in all communities. We focused on legal interventions at the national level that remove intellectual property barriers, while also supporting grassroots campaigns to demand accessible generic antiretrovirals, Hepatitis C treatment, and more.

## Contesting deadly patents

In 2019, following a multiyear legal challenge from ITPC’s partner AAF, Thailand’s patent office rejected the application of Merck & Co’s patent on raltegravir, a highly priced 3rd line antiretroviral. As a result, raltegravir will become available in Thailand as a generic medicine, ensuring that people living with HIV can access it. During the year ITPC’s team also filed seven new patent oppositions in five countries: Argentina, Brazil, India, Thailand, and Ukraine. These

filings represent a critical first step towards ensuring lifesaving drugs are available in these countries for millions of people who need them.

## Monitoring procurement

ITPC Russia produced procurement monitoring reports in [Armenia](#), [Belarus](#), [Kazakhstan](#), [Kyrgyzstan](#), and [Russia](#). Based on this analysis, the countries have identified priority drugs for intellectual property interventions.

## Educating activists on new medicines

ITPC developed two new HCV and TB toolkits to increase activists’ knowledge on new medicines that are entering the market. These educational materials help communities decide which medicines they need to advocate for in national treatment protocols, as well as where activism is needed to make medicines affordable.



*ITPC Make Medicines Affordable campaign hosts Latin American Patent Opposition Academy, Rio de Janeiro, Brazil, September 30 - October 2, 2019*

## Building a cadre of lawyers and scientists

ITPC's new Patent Opposition Academies train professionals to contest intellectual property barriers to medicines. In 2019, ITPC trained 62 community leaders, lawyers and chemists from 13 countries in EECA and Latin America. ITPC's partner in Thailand, AAF, held four workshops on creating patent oppositions, training 40 young pharmacists and lawyers between February and August 2019.

## Increasing national funding for intellectual property activism

Often funding for intellectual property (IP) activism at the community level is woefully inadequate. Organizations need multi-year resources to file patent oppositions and conduct advocacy. In 2019, ITPC launched a global budget advocacy initiative to encourage the Global Fund to Fight AIDS, TB and Malaria grants to include funding

for IP work. This included creating and disseminating a Country Coordinating Mechanism Engagement Toolkit, a budget toolkit, and a global workshop for activists.

ITPC also supported its partner groups in six regions to train community members on IP issues. Some examples:

### Brazil

ABIA/GTPI developed treatment and IP trainings in the cities of Manaus and Cuiaba, building capacity for local groups on treatment education, price monitoring, use of TRIPS flexibilities, and legislative advocacy.

### Thailand

AAF's partner TNP+ organized seven demand creation workshops at the local level with 300 participants, ranging from PLHIV networks to local health authorities and community-based hospitals. Three trainings for community group leaders also took place.

### Ukraine

100 Percent Life organized a workshop on global best practices on HCV treatment in October 2019 with the aim to raise awareness of doctors on the use of generic medicines and to present the WHO Guidelines on Hepatitis C.

## Demanding access to optimal ARVs in 12 countries

In July 2019, following the launch of the new WHO HIV Treatment guidelines, ITPC

launched a global campaign to pressure governments to utilize TRIPS flexibilities to get optimal antiretrovirals and Hep C treatments to their citizens. The campaign included a call for 12 countries to issue compulsory licenses for dolutegravir.

## Connecting grassroots activists to powerful pharmaceuticals

ITPC's Community Advisory Board (CAB) program trains HIV advocates to understand drug development and access issues. It also connects these advocates with pharmaceutical representatives, creating a unique communication channel. In 2019, ITPC convened Community Advisory Board (CAB) forums in Eastern Europe and Central Asia, ECAT, Latin America and the Caribbean, the Middle East and North Africa. In addition, a World CAB was held in Washington, DC.

## Sustained activism through collective organizing

For the past few years, ITPC has worked in collaboration with the Delhi Network of Positive People (DNP+) and other civil society organizations in India to campaign for routine viral load testing (RVTL) for anti-retroviral treatment (ART) ART monitoring and HCV treatment roll-out. India adopted RVLT in 2018 and started HCV treatment roll-out in 2019: showing that multi-year sustained advocacy results in concrete changes. DNP+ has also filed patent oppositions on seven key HIV/HCV drugs.

# #TREATPEOPLERIGHT

At the center of ITPC's work is our commitment to community-led treatment education. We support people living with and affected by HIV to have the knowledge and tools to take charge of their health and futures. Our Treat People Right portfolio continued in 2019 to help activists increase their knowledge around HIV medicines and catalyze grassroots advocacy.



*Alma de León, Regional Coordinator, ITPC Latin America and the Caribbean, centre, stands in joint protest action for dolutegravir to be recognised as the preferred drug in San Salvador, El Salvador, November, 2019*



*Alma de León, Regional Coordinator, ITPC Latin America and the Caribbean, at the United Nations High Level Meeting on Universal Health Coverage, New York, USA, September 23, 2019*

## Navigating the twists and turns around a new antiretroviral

In 2019, we expanded our Treat People Right program to examine the pros and cons of widespread adaptation of the antiretroviral drug dolutegravir (DTG). In 2018, the World Health Organization (WHO) recommended DTG as a preferred first-line treatment regimen.

Shortly afterwards, Botswana's Tsempano study, which follows birth outcomes among women living with and without HIV, reported a higher rate of neural tube defects among babies born to women living with HIV who were using DTG at conception and during the first 12 weeks of their pregnancy. This potential safety

signal led WHO to amend its guidelines pending more information about the risk while some national ministries of health prohibited DTG use among women without consulting them.

ITPC responded to this changing context by working with networks of people living with HIV, WHO and other key global health organizations, and updating its treatment education materials to include this information about DTG. Through ITPC's Global Activist Network, we were also alerted to a new possible side effect of DTG – weight gain. ITPC subsequently organized an online community consultation, bringing together communities with doctors, and shared the discussion outcomes with the WHO.

## Making global treatment guidelines work for communities

ITPC continued its work of assessing how the current WHO treatment guidelines on HIV play out in practice. In December 2019, we organized a consultation at ICASA in Kigali, Rwanda to document community perspectives on these standards. Our forthcoming Community Guide will build on this consultation to offer clear and simple information about WHO treatment guidelines, including about women and DTG. We also conducted an online survey and focus group discussions in 28 countries among women living with and vulnerable to HIV about sexual and reproductive health, with a focus on contraception choices.

## Seeding advocacy and new program models

In 2019, we disbursed \$20,000 in small grants to key population groups in Indonesia, Kenya, Kyrgyzstan, Nepal, and Vietnam to advocate for their treatment needs. Organizations received funds after participating in a regional treatment education training.

## SNAPSHOTS OF ITPC GRANTEES

### VIET NAM G-LINK'S "PARALLEL TREATMENT MODEL"

In Viet Nam, many people trying to access HIV services faced long waiting times in overcrowded government clinics for hours on end. Men who have sex with men also said they did not feel comfortable disclosing their sexual histories and needs to regular practitioners. G-link created a hotline to refer men to other places where they could receive services like PrEP, PEP, and STI treatment. G-link also worked to offer extended clinic hours in some of these locations.

### INDONESIA'S KOALISI SATU HATI

ITPC, in partnership with Bridging the Gaps, supported Koalisi Satu Hati to conduct HCV community awareness in 9 provinces of Indonesia.

### NEPAL

In Nepal, ITPC supported a community organization to provide HIV/HCV/TB treatment literacy to 4,000 inmates in 3 prisons in Kathmandu Valley through 14 trainers and assistant trainers from across all 7 provinces in Nepal.

### KENYA'S SWOP AMBASSADORS

In Kenya, migrant sex workers face extreme marginalization and often are cut off from health services. They are also hesitant to report violence or assault for fear of the police or others checking their immigration status. The SWOP Ambassadors provided grassroots training for migrant sex workers on their rights and how to report abuses. The SWOP Ambassadors educated police officers and local leaders, especially village elders, on the rights of sex workers. The group also pulled together a new crisis response network, so that migrant sex workers could immediately report violence or abuse confidentially and safely, and receive referrals to services.

## Supporting sex workers to access health services

ITPC, in partnership with the Aids Fonds SW project in Zimbabwe, held a training in Bulawayo on how to better cater health services to sex workers.

- **22 people** from sex worker organizations, civil society, and health services providers took part

## Building a new generation of activists: the Activist Development Fellows program

ITPC's Activist Development Fellows program continued to support HIV activists with knowledge, mentoring and leadership development.

- **In Kenya**, Patricia Ochieng led a campaign on DTG access for women of reproductive age and is also leading a "know your rights" campaign for people living with HIV.
- **In Egypt**, Menna-t-Allah M. El-Kotamy worked on eradicating patent barriers to key medicines, and also trained clinicians on the rights of people living with HIV.
- **In Nepal**, Parina Subba focused on HCV advocacy for women who use drugs.



Loon Gangte, Coordinator, ITPC South Asia, (left, front) gathers with activists at the Regional Viral Hepatitis Workshop in Bali, Indonesia, September 19, 2019

## Empowering men who have sex with men to demand and implement PrEP

ITPC collaborated with MPact to organize PrEP demand generation workshops for men who have sex with men and transgender people in Cambodia and South Africa. The meetings devled into the science of PrEP and explored how communities could generate interest and uptake of PrEP in order to further prevent HIV transmission.

- **30 activists** from East, Southern and West Africa participated in South Africa
- **22 activists** from Jamaica, EECA, and Central and South East Asia participated in Cambodia

After the workshop, participants could apply for small grants ranging from

\$5,000 – 10,000 to work in their communities on PrEP demand generation.

- **5 grants issued** to participants in the Cambodia workshop
- **6 grants issues** to participants in the South Africa workshop

*"ITPC has played a major role in the development of my activism. They have provided training, resources, tools and funding. ITPC's wealth of knowledge and platform to move agendas from the grassroots to the national, regional and global is unique!"*

**Patricia Ochieng, GAN member, Kenya**



Umid Shukurov

*"The best help you can expect is from someone that has experienced himself or herself the same conditions. In order to manage the side effects properly you should understand how to take drugs... it was my peers that explained this to me. I was given some good advice, I tried, and I proved it to myself that it was really working out."*

**Umid Shukurov**



## ITPC GRANTEE PROFILE

### Story of change: Umid Shukurov

Peer counseling is a lifeline in Kyrgyzstan

ITPC and ITPCru first began working with Kyrgyzstan's Partnership Network Association, in 2017. Based on community research about treatment adherence gaps, ITPC and GNP+ supported the Partnership Network in 2019 to mobilize resources, resulting in new funding from the Global Fund, PEPFAR, UNAIDS and UNDP for their innovative initiatives.

Umid's story reveals the importance of community-led adherence counseling. Umid learned he was HIV positive in 2009, while he was in a Biskek prison for using drugs. For a long time, Umid did not consider going on HIV treatment, finding the idea of taking pills for a lifetime unpalatable.

When Umid did finally initiate treatment, he experienced terrible side effects from the medication; as a result he frequently took breaks. In early 2019, the Partnership Network's "Rapid Response Teams" matched Umid with a peer counselor. Through this relationship, Umid came to accept his status, and joined support groups, making friends with other PLHIV. As he learned more about ART, he eventually managed to take ARVs without interruptions.

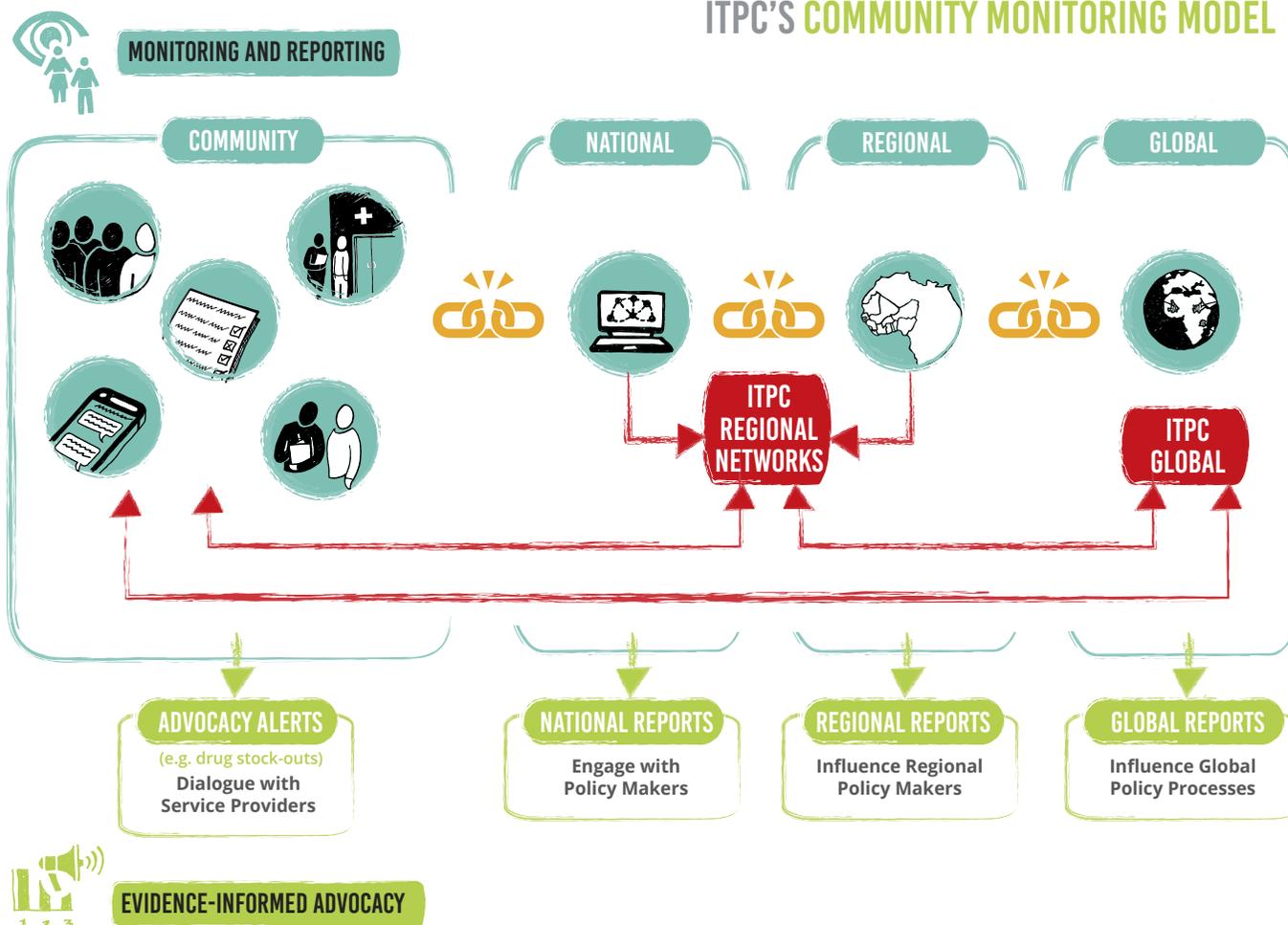
# #WATCHWHATMATTERS

ITPC invests in community-led monitoring and research to gather data on access to HIV treatment and related services globally. We also assess the quality of available treatment and services. Armed with information collected by the community, we advocate for governments to improve the accessibility and availability of high-quality health services.

*“Today ITPC’s Community Treatment Observatory is a well-designed model that moves from treatment education to evidence collection, right into targeted action and wide stakeholder engagement for the co-creation of solutions.”*

**Valentin Keipo, ITPC West Africa**

## ITPC’S COMMUNITY MONITORING MODEL



# Watch What Matters



## Community-led monitoring of treatment services

ITPC's groundbreaking model trains communities to collect and analyze public health data. In 2019, ITPC's West Africa Regional Community Treatment Observatory (CTO) was active in 11 countries assessing the HIV treatment services available at 125 health facilities. As a result of community-led monitoring, issues like stock-outs of antiretrovirals were swiftly identified and remedied. ITPC advocated for specific improvements in different countries. In Cote d'Ivoire, ITPC successfully eliminated fees for HIV testing and treatment. In Sierra Leone, ITPC successfully pushed for the creation of a differentiated service delivery policy to support key populations. Other highlights:

- **The number of viral load tests performed more than doubled** from mid-2018 to mid-2019 in ITPC monitored sites in West Africa, increasing from 16,532 to 33,376.
- **The rate of viral suppression** at these health facilities also increased dramatically, from 48.3% in mid-2018, to 77.4% in 2019.

### Gambia

The national CTO host documented that health service facilities needed improvement. Their report was shared nation-wide including with the ministry of health. As a result, the National Assembly Health Select Committee will engage the Ministry of Health and National AIDS Secretariat on performance improvement plans for health facilities and the Ministry of Finance on related budget needs.

### Mali

The CTO succeeded in getting health facility managers to record viral load patient data by individual rather than in groups, allowing for better tracking of individual health outcomes.

### Ghana

The CTO met with village chiefs and imams after documenting persistent stigma towards people living with HIV and key populations. In 2019, ITPC expanded its visionary Community Treatment Observatory model to Southern Africa. In partnership with the AIDS and Rights Alliance Southern Africa (ARASA), the Southern Africa CTO now monitors 9

health facilities in three countries: Malawi, Zambia and Zimbabwe. From mid-2018 to mid-2019, these CTOs documented issues in real time, such as the stock-outs of HIV testing kits and lack of routine viral load testing machines.

### Malawi

The CTO succeeded in getting health facilities to extend their opening hours so that key populations could more easily access services. The CTO model was included in PEPFAR's Country Operational Plan 2020, and it was integrated into the country's 2020-2025 National Strategic Plans for HIV and AIDS.

### Zambia

The CTO reduced by 13 days the average duration of ARV stockouts at the monitored health facilities. Data from the CTO in Zimbabwe was included in the country's funding request to the Global Fund.

### Zimbabwe

The CTO mobilized communities around differentiated service delivery (DSD), and the Community Initiative for Tuberculosis, HIV/AIDS and Malaria plus related diseases (CITAM+) presented project results during a Country Coordinating Mechanism (CCM) workshop in preparation for the Global Fund 2021/2023 request.



Delegates at ITPC Global's Community Treatment Observatory Learning Event in Abidjan, Côte d'Ivoire, October 2019

### Malawi advocacy alert

Data from interviews and focus group discussions revealed that inconvenient health clinic opening hours were a challenge for truck drivers and sex workers. MANERELA+ targeted policy makers at the Ministry of Health and at the district level, and in 2019 working hours within all public hospitals providing HIV services were extended, greatly improving the accessibility of services for key populations.

CTO data was also key in advocating for changes in the national guidelines for viral load testing. After a tireless advocacy campaign from civil society, the Ministry of Health aligned the country's guidelines with WHO recommendations, from testing every 24 months to every 12 months.

### Community-led research offers concrete program and policy suggestions

Based on its ground-level research, ITPC issued reports to call attention to flaws in HIV programs and policies. In 2019 this included:

- **Global Treatment Access Survey:** 2,777 people living with HIV surveyed in 14 low- and middle-income countries on access to and quality of HIV services and report
- **Data for a Difference report** in West Africa
- **Missing the Target report** for Kyrgyzstan

### Community systems strengthening

In line with the Global Fund to Fight AIDS, TB and Malaria's commitment to funding community systems, ITPC worked to strengthen the ability of communities to participate in health programs.

## DATA FOR A DIFFERENCE

### Regional Community Treatment Observatory-West Africa Key Stats

**2** years

**11** countries

**101** health facilities

**389** interviews & focus groups

**9,357** key populations

**15,442** young people (age 15-24)

**16,491** viral load tests

**78,591** people on ART

**160,689** HIV tests



*“They keep us on our toes. Toes, in the sense that they’ve been putting pressure on us. Whenever there are stock-outs, they give us the alert. Then, we assemble our partners to help us to quickly distribute the drugs.”*

Abdul Rahman Sesay, Director-General, National AIDS Secretariat, Sierra Leone, explaining the national-level impact of that country’s Community Treatment Observatory in ITPC’s CTO Impact Film.

To watch the Community Treatment Observatory Impact video, [click here](#) >

## STORY OF CHANGE

### A young woman’s experience in Zimbabwe

With funding from Bridging the Gaps, ITPC supported the Zimbabwe National Network of People Living with HIV (ZNNP+) and Zimbabwe Young Positives (ZYP+) to create four new community treatment observatories.

After one year of monitoring and dialogue, the four health facilities created more flexible opening hours so that teenagers could attend outside of school hours. They also streamlined health services, so that young people could have their needs met in one visit, and reduced the time it took to receive viral load test results.

Hazvinei, 17, witnessed these changes firsthand. Hazvinei lives in Kunaka village in Mashonaland East, hours away from the closest ART clinic.

*“I go to the clinic for my viral load results and I am told to come back next week. When I get there the next week, still my results are not out. Ah! I will not go back because it’s taking a lot of my money and time,”* she said.

But after the health facility implemented changes, Hazvinei noticed the difference immediately. Her mom can now collect the family’s ARVs in one go. Hazvinei is now more willing to do routine viral load testing, and her results are returned in three weeks, instead of the previous eight.

*“Personally, it has saved me time and for our family, it has saved us money,”* she said triumphantly.

A stylized red fist icon is centered in the background. The fist is clenched, with fingers pointing upwards and slightly to the right. The text 'OUR INFLUENCE' is written in a bold, white, sans-serif font across the middle of the fist. The background is a solid dark red color.

**OUR INFLUENCE**

# KEEPING GLOBAL HEALTH ACCOUNTABLE TO COMMUNITIES

## High-level advocacy

ITPC participated in numerous critical international and regional advisory bodies, donor meetings, and scientific conferences in 2019. ITPC's presence allows community demands to be directly presented to people making decisions about funding, clinical guidelines, and programs. A few of these opportunities last year included:

### International Aids Conference:

In July, ITPC contributed to multiple sessions at the IAC in Mexico City, Mexico, including on differentiated care for HIV diagnosis and tackling HIV stigma. ITPC also campaigned on #MakeMedicinesAffordable, including peaceful sit-ins at drug company conference booths.

### United Nations High-Level Meeting (HLM):

In New York City, US, in September, ITPC shared its networks perspective on universal health care coverage and HIV-related needs to consider.

**PEPFAR:** At PEPFAR's Community Monitoring Meeting in November,

ITPC presented its work running the Community Treatment Observatory in West Africa.

## Building a pathway to public health researchers

ITPC also channeled the community perspective to medical researchers. For example:

### The Conference on Retroviruses and Opportunistic Infections (CROI):

ITPC facilitated a session on the best interventions to support connecting people who test positive to treatment.

**Africa Collaborative to Advance Diagnostics (AfCAD):** At an AfCAD meeting in Johannesburg, South Africa, ITPC advocated for optimizing diagnostic networks across diseases rather than focusing on single disease models.

**African Society for Laboratory Medicine (ASLM):** At the Laboratory Community of Practice meeting, ITPC shared best practices on generating demand for routine viral load testing.



*In 2019, for the first time in over 10 years, a World Community Advisory Board (CAB) included a focus on new, optimal HIV drugs. The World CAB on HIV, Hepatitis C and TB brought together treatment advocates, pharmaceutical companies and producers, and public health institutions. Twenty treatment advocates from 16 countries attended to question the drug industry, present the community perspective and highlight how people are affected by barriers to access. It took place in Washington D.C., USA from November 24-27, 2019.*

## Contributing to research and knowledge

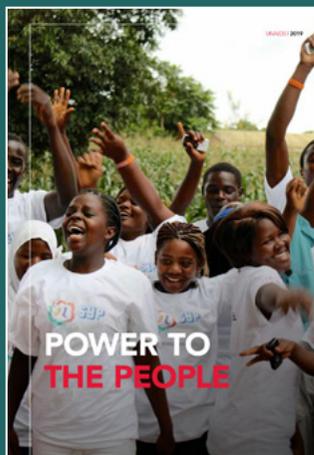
- Andrew Hill, et al. "Comparison of Prices of Hepatitis C Treatments to Average Income Levels in 49 Countries" accepted by the Journal of Virus Eradication.
- [Global Survey on Access to and Quality of HIV Treatment and Care](#)
- [Missing the Target 12 – Full report](#)
- [Data for a Difference](#)
- [The Problem with Patents](#): Access to affordable HIV treatment in middle-income countries
- [Community and activists demand for tenofovir/ emtricitabine or lamivudine/ dolutegravir and routine viral load testing](#) – a review article
- University of Cape Town - Center for Social Science Research (CSSR): Understanding Gaps in the HIV Treatment Cascade in 11 West African Countries: [Findings from a Regional Community Treatment Observatory](#)
- What is DSD? ([Video](#))
- What is a CTO? ([Video](#))

## ITPC's work was also cited in external publications, including:

- [AIDS Data Hub: The Community Treatment Observatory \(CTO\) Model Explained](#)
- [Journal of Health Design](#) - Sierra Leone Community Treatment Observatory



*Wame Jallow, Director of Global Programs and Advocacy, ITPC Global, alongside a delegation of partners from Botswana (civil society, private sector, government, development partners and academia) including the First Lady of Botswana Neo Masisi at ICASA 2019, Kigali, Rwanda*



## ITPC FEATURED IN UNAIDS REPORT

UNAIDS featured ITPC's Activist Development Program in its Power to the People report, as an illustration of how empowered civil society have a role to play in tackling the epidemic. The ITPC Regional Community Treatment Observatory Project was also featured as an innovative model for monitoring and advocating for improved health services. [Download the report: UNAIDS Power to the People – 2019 World AIDS Day Report](#)

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

# VALUE FOR MONEY

*"In 2019, ITPC continued to use our resources in the most effective way possible to advance our mission."*

Collen Ngundu, Director of Finance, ITPC Global



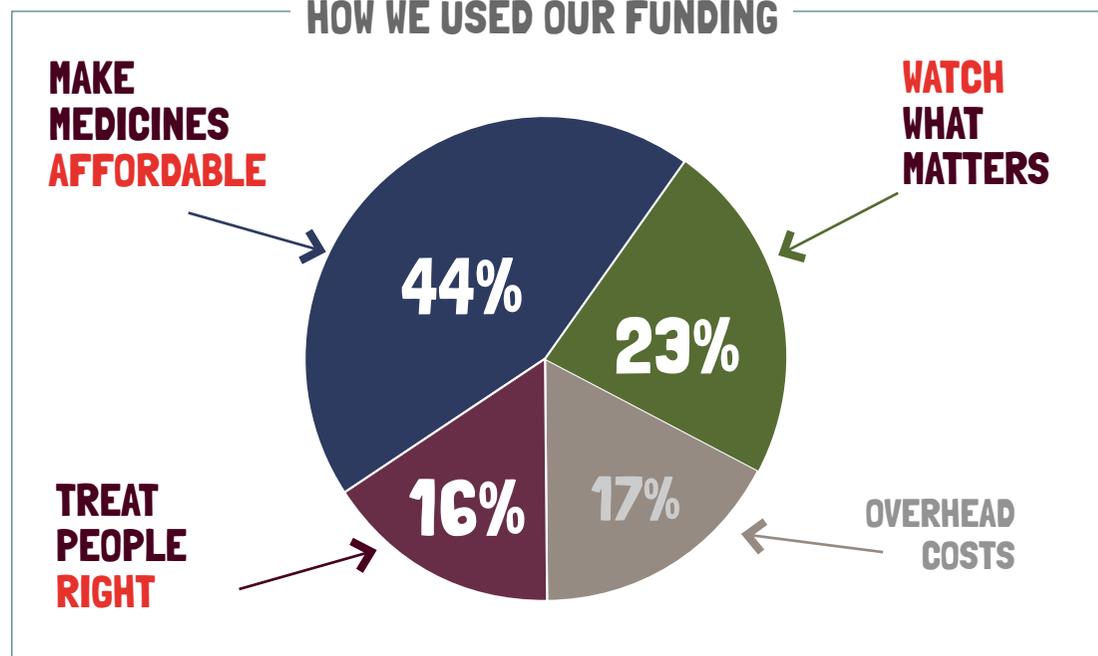
**IN 2019, ITPC HAD A TOTAL OF 5.3M USD IN REVENUE.**

**ONLY 17% OF TOTAL REVENUE GOES TO OVERHEAD COSTS**

## FUNDING SOURCES



## HOW WE USED OUR FUNDING



Out of 5.3 Million USD

**83%** WAS SPENT DIRECTLY ON PROGRAM COSTS TO ADVANCE UNIVERSAL ACCESS TO HIV TREATMENT

Out of ITPC total direct program cost

**61%** WAS SPENT IN THE FORM OF GRANTS TO ITPC REGIONAL NETWORKS AND CONSORTIUM PARTNERS.

To read our 2019 annual audited summary financial statement [click here >](#)



# 2019 HIGHLIGHTS

## JANUARY

ITPC leads a consortium under the Robert Robert Carr Fund with Global Coalition of Tuberculosis Activists, T1International, Mainline International, ITPC MENA, ITPC LATCA, ITPCru, ITPC South Asia, and ITPC West Africa coming together to tackle HIV, Tuberculosis, diabetes, and Hepatitis C.

## FEBRUARY

ITPC and the AIDS and Rights Alliance of Southern Africa (ARASA) launches three new Community Treatment Observatories in Southern Africa.

## MARCH

ITPC publicly applauds the HPTN 071 – Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART) study, which reinforces that community-based approaches for HIV prevention, testing, and linkage to care work.

## APRIL

ITPC releases its report, [Missing the Target 12: Barriers to HIV Treatment Access Among People Who Inject Drugs](#).

## MAY

ITPC hosts an open consultation for women living with HIV on the use of dolutegravir (DTG) and the related issue of weight gain.

## JUNE

ITPC's **animated video** "[What is Differentiated Service Delivery](#)" is now available on YouTube, along with Datos Abiertos from ITPC Latin America.

## JULY

ITPC releases its [Data For A Difference research publication](#) outlining key findings, analysis and advocacy opportunities from the Regional Community Treatment Observatory in West Africa.

## AUGUST

ITPC's new website now has [a searchable community resource database](#) and is multilingual.

## SEPTEMBER

ITPC and partners release [The Problem with Patents policy brief](#).

## OCTOBER

ITPC holds a forum for 100 delegates from across West Africa in Abidjan, Côte d'Ivoire and around the world for joint talks on a community-led approach to improving healthcare delivery and HIV treatment.

## NOVEMBER

ITPC releases a [video highlighting the impact of its innovative Community Treatment Observatory in West Africa](#).

## DECEMBER

ITPC publishes its [Global Survey on Access to and Quality of HIV Treatment and Care](#), focused on barriers to quality HIV care and treatment across 14 low- and middle-income countries covering seven regions of the world.

# THANK YOU

## DONORS

We are grateful to our donors who continue to believe in our vision, invest in the value of communities, and make our work possible. In 2019, ITPC thrived thanks to the generous support of:

**Aidsfonds**

**AJG Foundation**

**Dutch Ministry of Foreign Affairs - Bridging the Gaps II**

**International AIDS Society**

**Levi Strauss Foundation**

**Open Society Foundations**

**Robert Carr Fund**

**The Global Fund to Fight AIDS, Tuberculosis and Malaria**

**Unitaid**

**ViiV Healthcare**

**ICAP - Columbia University Mailman School of Public Health**

**World Health Organization**

## ITPC GLOBAL BOARD

We thank the Global Board for their continued support and invaluable guidance.

**Gregg Gonsalves**, Chair, USA

**Ava Avalos**, Vice Chair, Botswana

**Polokoetsile Pedro Motau**, Treasurer, Botswana

**Nompumelelo Gumede**, South Africa

**Jarasa Kanok**, USA

**Karyn Kaplan**, USA

**Nathaniel Wong**, USA

## ITPC GLOBAL TEAM

We are a small, dedicated team who are proud to commit our energy, expertise, and creativity to this important work each and every day.

**Solange Baptiste**, Executive Director

**Wame Jallow**, Director of Global Programs and Advocacy

**Collen Ngundu**, Director of Finance

**Othoman Mellouk**, Intellectual Property and Access to Medicines Lead

**Alain Manouan**, Community Monitoring Lead

**Bactrin Killingo**, Treatment Education Co-Lead

**Tracy Swan**, Treatment Education Co-Lead

**Helen Etya'ale**, Program Officer

**Gerard Best**, Interim Program Impact Manager

**Pedro Garcia**, Monitoring & Evaluation and Research Manager

**Mercy Motasi**, Executive Assistant

**Khathutshelo Musekwa**, Accountant

**Ilene Boshielo**, Finance and Administrative Assistant

**Sergiy Kondratyuk**, Unitaid Program Manager

**Detrich Peeler**, Unitaid Partnership Officer

**Morgane Ahmar**, Unitaid Partnership Officer

**Leonard Moyo**, Unitaid Grants and Compliance Manager

**Nothando Moabi**, Unitaid Grants and Compliance Officer

**Elizabeth Tejada**, Director of Finance and Administration (Until June 2019)

**Trisa Taro**, Program Impact Manager (until May 2019)

**Norma Masheleng**, Finance Manager (Until March 2019)

**Nigel Ndwekere**, Finance Manager (Until September 2019)



# THE FUTURE IS COMMUNITY-LED

[www.itpcglobal.org](http://www.itpcglobal.org)

