ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

STRATEGIC PLAN 2021-2023

GLOBAL HEALTH MATTERS:

THE COLLECTIVE MOVEMENT TO REBUILD OUR WORLD

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ITPC
INTERNATIONAL TREATMENT
PREPAREDNESS COALITION

IF NOT NOW, WHEN?

ITPC was formed in 2003 in Cape Town by a committed group of HIV treatment activists who **refused to accept** a world in which people living with HIV were denied access to life-saving medicine.

As ITPC grew into a global activist network advocating for the needs of communities affected by HIV and TB, it also laid the groundwork for community-driven work extending **beyond singular diseases** and addressing the systemic issues affecting people's health — **exposing and resisting entrenched global power dynamics** that consistently prioritize profit over the right to health and dignity.

In 2020, the coronavirus pandemic revealed why ITPC's approach is critical: improving access to medicines and vaccines, sharpening the ability of communities to organize, and holding those in power accountable, offers a pathway to improve the health outcomes of the majority of the world's citizens. But it also offers us **a new model for how communities can drive change and become more resilient** - whether in response to changing climates, the rise of authoritarian governments or the challenges of new migration.

As we took stock of our work over the previous years, we worked to hone our strategy for the future, laying the foundation to promote and create more equitable and integrated health care beyond HIV. A person living with HIV does not just need a package of pills; and a person seeking to prevent HIV does not only need to be offered an HIV test. **Instead, each individual should be able to access a health system that responds to them as a whole person**. The quality of a country's health system is reflected not only in terms of how they deliver HIV and TB treatment and prevention, but also how well they adapt to meet the needs of the most marginalized in their society.

Therefore, ITPC is **committed to renewing its work in four core areas** from 2021-2023:

- **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 particular focus on access to life-saving medicines for HIV, TB, viral hepatitis, and other illnesses
- **Holding governments, donors, and other authorities accountable** to globally recognized standards for human rights and public health, with a focus on social justice.

2020 was also a year in which the world recoiled from expressions of police brutality, systemic injustice, and racial inequality. Thousands of people demonstrated, including those who had never been politically active. As protestors marched in the streets from Washington D.C. to Mumbai to Johannesburg, they carried one message: We reject the current status quo of inequity, violence and all forms of racism.

We hope that you join us in our collective purpose to realize a more equitable world. If not now, when?

In solidarity,

Solange Baptiste
Executive Director

Ava Avalos
Board Chair

Over the past 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 healthcare for TB, viral hepatitis, and other life-threatening conditions, including hypertension and diabetes.

OUR MISSION

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

OUR VISION

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

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.

ITPC global Team

ITPC regional networks

Individual activist

Community-based organization

NGOs / Partner organizations

ABOUT ITPC

Global Team and Governance

ITPC is led by a global team responsible for managing day-to-day global operations. We work virtually with team members based in Africa, North America, the Caribbean, and Europe. **Our flexible and decentralized model allows us to conserve resources and focus on supporting communities.** Moving forward, we will maintain this adaptable and resilient model to ensure that the majority of our resources support our programs and communities.

ITPC is registered as a non-profit organization in South Africa and Botswana. We are governed by a global advisory board, which oversees all of ITPC's strategic decisions. Our board members collectively represent people who are living with HIV, identify with key population groups, reside in the regions where we work, and possess a range of relevant skills from governance and resource mobilization to advocacy.
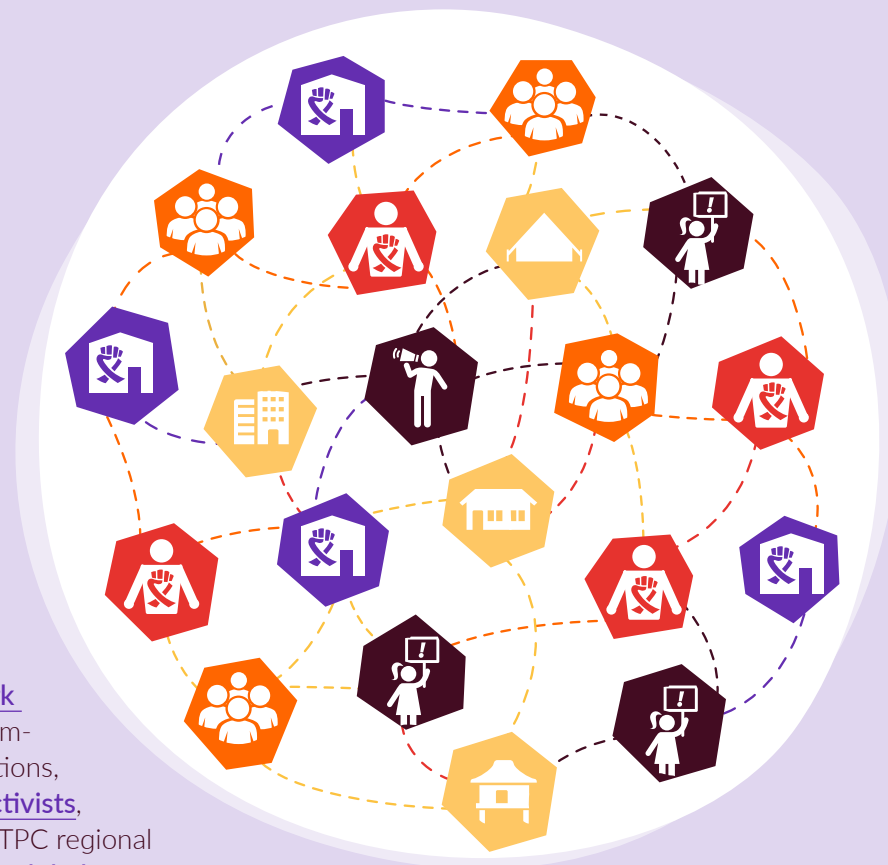
GLOBAL ACTIVIST NETWORK

ITPC is an open and flexible coalition. Our central structure is the Global Activist Network (GAN), consisting of community-based organizations, individual treatment activists, partner organizations, ITPC regional networks, and the ITPC global team.

Our GAN invites and fosters the participation and leadership of hundreds of treatment activists through information sharing, trainings, and meetings, as well as collaborative policy work, community-led monitoring, and advocacy. It also gives ITPC the flexibility and responsiven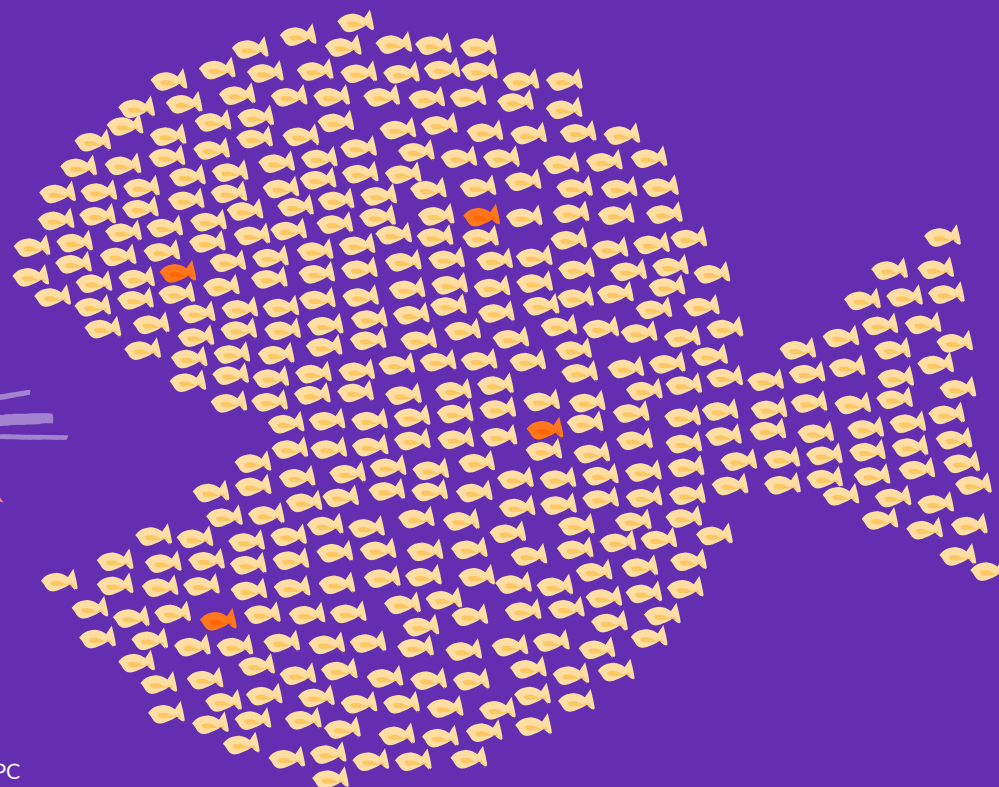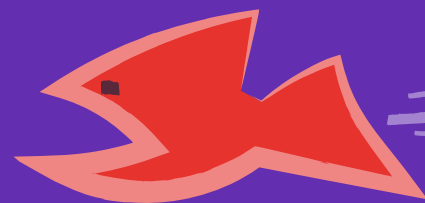ess needed to actively advocate for health issues as they arise across the globe as informed by our routine Global Treatment Access Survey.

We operate around the world and in the world's major languages, including English, French, Spanish, Russian, and Arabic.

DON'T PANIC!

ORGANIZE!

ITPC works to mobilize communities through a Global Activist Network that builds the long-term strength of communities and systems while also supporting partners to undertake data collection, strengthen health programs, and expand advocacy. ITPC uses four strategic pathways to achieve our goals:

- Education
- Evidence
- Advocacy
- Engagement

HOW WE WORK

We **connect** activists and community leaders to tools, resources, grants, policymakers, politicians, and most importantly **to each other.**
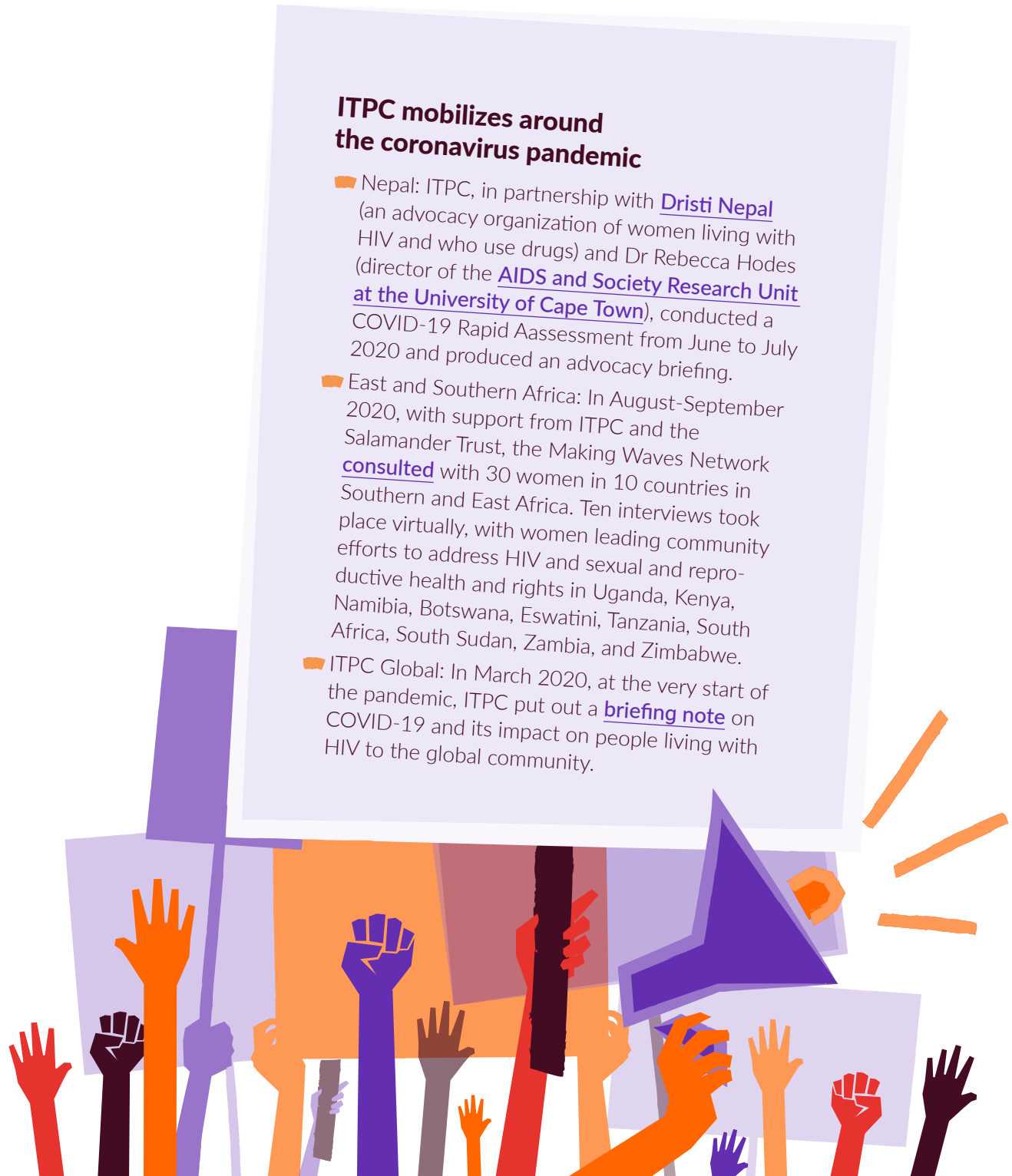
We are **people-centered and community-led:** ITPC was created by communities, for communities, and that value is central to our work. At the end of the day, we care most about our **members** and are accountable to them.

We are **rooted in the global South:** Our organization is based in South Africa, our birthplace, and Botswana. South Africa is the location of our operational hub and Executive Director, and over 80% of our staff lead our programs from the global South.

We are **resilient and adaptable** to emerging public health issues.

ITPC mobilizes around the coronavirus pandemic

☛ Nepal: ITPC, in partnership with Dristi Nepal (an advocacy organization of women living with HIV and who use drugs) and Dr Rebecca Hodes (director of the AIDS and Society Research Unit at the University of Cape Town), conducted a COVID-19 Rapid Aassessment from June to July 2020 and produced an advocacy briefing.

☛ East and Southern Africa: In August-September 2020, with support from ITPC and the Salamander Trust, the Making Waves Network consulted with 30 women in 10 countries in Southern and East Africa. Ten interviews took place virtually, with women leading community efforts to address HIV and sexual and reproductive health and rights in Uganda, Kenya, Namibia, Botswana, Eswatini, Tanzania, South Africa, South Sudan, Zambia, and Zimbabwe.

☛ ITPC Global: In March 2020, at the very start of the pandemic, ITPC put out a briefing note on COVID-19 and its impact on people living with HIV to the global community.

OUR PAST

The HIV movement has resulted in specific wins that translated into progress towards broader health goals. These include the concept of **differentiated service delivery, patent reform, and a more people-centric approach to medicine.**

In addition, the HIV movement also transformed the global health architecture, demanding that people most affected by HIV had seats at the table. ITPC has contributed to these gains through innovations such as:

Community-led research and evidence-informed advocacy: ITPC's Global Survey on Access to and Quality of HIV Treatment and Care is conducted in 14 countries in seven regions, collecting information on the needs of people living with HIV to identify barriers to access and gaps in services. ITPC then prepares targeted advocacy to address them.

Through the ITPC **Regional Community Treatment Observatory (RCTO)** in West Africa, networks of people living with HIV systematically collected quantitative and qualitative data on services across the HIV cascade. The evidence from our data collection was used to support advocacy that led to **improvements in access to and delivery of care,** such as the revision of the central pharmacy dispatching system in Senegal, the adoption of a new differentiated service delivery policy in Sierra Leone, and the elimination of user fees for health services in Côte d'Ivoire.

Treatment education: ITPC's groundbreaking treatment education curricula and trainings have provided people living with HIV, as well as those using medicines like pre- and post-exposure prophylaxis (PrEP and PEP), the knowledge to take control of their health. ITPC has also created community guides to accompany the rollout of World Health Organization (WHO) and other public health guidelines, offering a **trusted source of clear and simple information about new drugs and treatment policies.**

Reducing the cost of ARVs: In 2018, the ITPC-led Make Medicines Affordable consortium catalysed an average **price reduction of 67% across 15 target antiretrovirals (ARVs)** in four countries and contributed to a total annualized financial benefit of $238 million to $345 million.

In the HIV response, ITPC has contributed to:

- 🗨 Building better health systems
- 🗨 Establishing the role of communities in health systems
- 🗨 Innovating around reaching marginalized groups
- 🗨 Reforming clinical research and drug development protocols to include affected communities more
- 🗨 Reducing prices on essential medicines
- 🗨 Shifting the global discourse on patents and intellectual property rights

OUR PRESENT

CHALLENGING INEQUITY

ITPC recognizes that health inequity is a global issue. It is not a matter of fixing or improving the health systems in poor countries; rather, **the entire global health architecture has to be transformed.** Even within rich countries, inequities remain due to class, race, gender, and other factors. Long-term organizing must therefore occur in both poor and rich countries: **to dissolve patent barriers, educate people on their rights, and build resilient and accessible health systems.** We can work to dissolve "North" and "South" divides through collaboration and collective action. We can also take meaningful steps to make sure that our values translate into practice.

"*Despite calls to 'reimagine systems for health', there is no incentive for the established system to relinquish power ... the path to real change lives in the local, people-centered response. If there is no incentive for the established system to relinquish power, it will be taken, by the people.*"
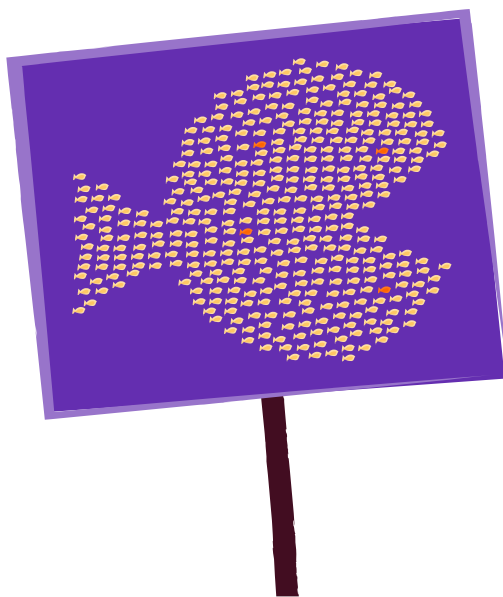
Solange Baptiste, *Executive Director, ITPC Global, 2020*

CULTIVATING RESILIENT HEALTH SYSTEMS

COVID-19 exposes the need for resilient, accessible, and free health systems. What does a resilient health system look like? It is a health system that can adapt quickly to a changing context, that works to meet people where they are, and that puts the lives and well-being of people over profit. **ITPC draws on 20 years of experience to bring these skills to the table in order to foster preparedness.**

COVID-19 shows us that we need to:

- Develop comprehensive and integrated interventions, **rather than COVID-19-specific solutions.**
- Address the non-biomedical, root causes of diseases.
- Tackle stigma and myths surrounding diseases **using interventions based on community-generated evidence,** rather than assuming that simply presenting information or data will sway people's beliefs or behaviours.
- Demand that donors, pharmaceutical companies, and others allow key medical supplies, such as vaccines, diagnostics, and medicines, to be made accessible and affordable, **regardless of World Bank income ranking.**
- Equip communities to be **prepared for more shocks to the system:** in other words, be prepared for the unexpected.

Finally, COVID-19 further emphasizes what HIV has already made clear: quality health-care should **not** be linked to having a job or determined by market forces.

How HIV benefits the whole system (and vice versa)

- Focusing on the structural and socio-economic drivers of HIV also leads to positive outcomes around reducing poverty, increasing access to education, and realizing human rights.
- Addressing HIV is an entry point for also preventing and/or treating COVID-19, viral hepatitis, TB, and non-communicable diseases.
  - For example, in post-apartheid South Africa, townships are hotspots for COVID-19. If we enacted better housing policies, we could more effectively address both COVID-19 and TB.
  - For example, policies to improve the availability of healthy food could save lives, reduce cardiovascular disease and diabetes, and help moderate the effects of diseases.

RESISTING AUTHORITARIANISM

Healthcare systems do not exist in a vacuum. When leaders undermine human rights, attack minorities, and use corruption and violence to stay in power, people's mental and physical health suffers. **Community organizing and action are the backbones of fighting for political change;** they are also the factors that address gaps in government health services during crises or when supply lines falter.
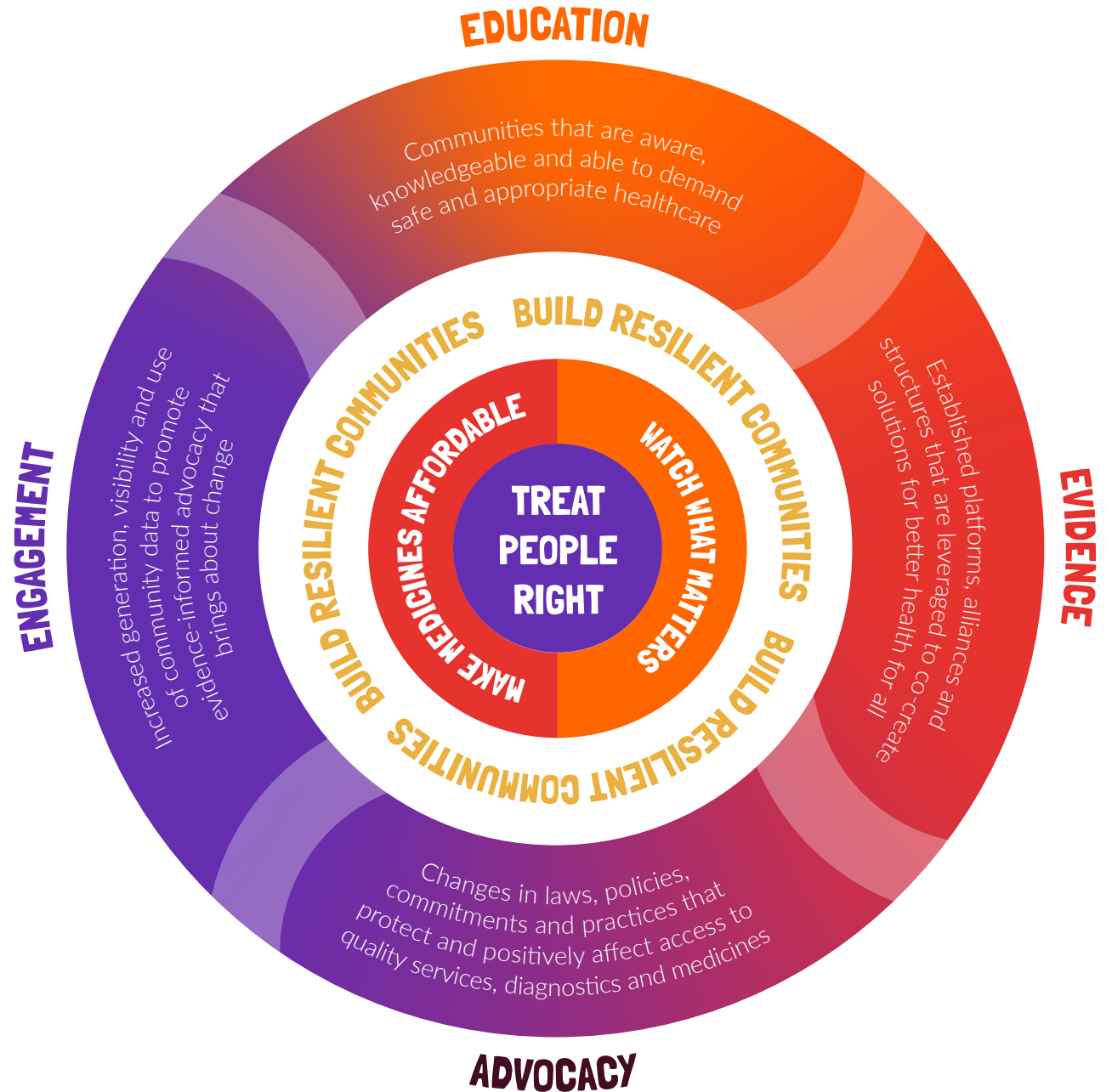
"The drugs are not in the facilities. Nothing is happening and people living with HIV are suffering. Despite COVID-19, we now have no choice and we must take to the streets!"

Patricia Asero Ochieng, *ITPC Global Activist Development Program Fellow, Kenya, 2021*
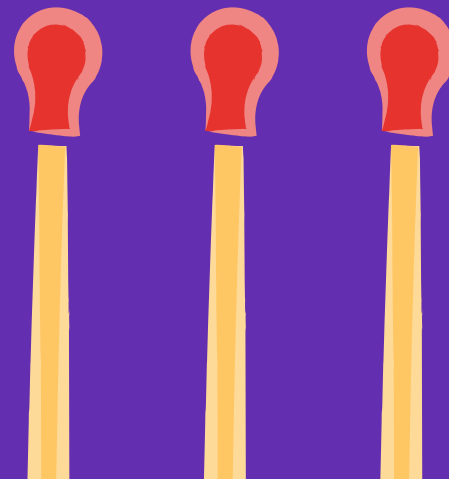
STRATEGIC FOCUS AREAS

OUR FUTURE

Moving into the future, ITPC's Theory of Change will have four strategic focus areas. These four areas intersect in critical ways to create change. **Treat People Right** is the core of ITPC's work, providing information and education to people on an individual basis to understand and take ownership of their health so that they can then advocate for their own needs. Once people are empowered, we fight to ensure that the medicines and services they need are available, free or reasonably priced, and accessible: **Make Medicines Affordable.** Communities also need to monitor in real time the barriers to staying healthy and raise the alarm when there are problems – from medicine stock-outs to discriminatory service providers to human rights issues. We do this through **Watch What Matters.** Finally, none of this is possible without powerful communities that have the capacity to organize, take action, and create the change they desire, so we work collectively to **Build Resilient Communities.**

EDUCATION

Communities that are aware, knowledgeable and able to demand safe and appropriate healthcare

EVIDENCE

Established platforms, alliances and structures that are leveraged to co-create solutions for better health for all

ENGAGEMENT

Increased generation, visibility and use of community data to promote evidence-informed advocacy that brings about change

BUILD RESILIENT COMMUNITIES

MAKE MEDICINES AFFORDABLE

TREAT PEOPLE RIGHT

WATCH WHAT MATTERS

ADVOCACY

Changes in laws, policies, commitments and practices that protect and positively affect access to quality services, diagnostics and medicines

"There is fire in my blood when I see people suffering when they can't get good or even basic healthcare. Look at us in India now, even breathing is a privilege!"

Loon Gangte, *Regional Coordinator, ITPC South Asia, April 2021*

RESILIENT
BUILD
COMMUNITIES
WATCH WHAT MATTERS
MAKE MEDICINES AFFORDABLE
TREAT PEOPLE RIGHT

> *"Even as a lawyer, for me it was important to understand how to work on patent barriers for antiretrovirals, DAAs (direct-acting antivirals) and TB medicines. This training brought a lot of clarity on how to do that, what things to pay attention to and how lawyers and chemists think when preparing patent oppositions. Now I feel prepared to launch similar work in my country."*

Participant, Latin American Patent Academy, El Salvador, 2020

STRATEGIC FOCUS AREAS

MAKE MEDICINES AFFORDABLE

Action: Make life-saving medicines available and affordable

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 HIV 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.

MAKE MEDICINES AFFORDABLE

Results:

- Collected data and intelligence on access to medicine gaps **informs policymakers and drives policy change.**
- New patent oppositions are filed.
- A cadre of IP activists is successfully trained and empowered to **lead campaigns in their countries.**
- Advocacy campaigns contribute to changing the global intellectual property landscape towards one that respects **people over profits.**
- Court wins on patents and other issues help **expand access** to essential medicines in key countries.

Strategy:

- **Create, update, adapt, and deliver trainings and webinars** on IP, access to medicines, and how to advocate for affordable and quality treatment and challenge low-quality, abusive patents.
- **Create educational tools and materials** on IP, including digital toolkits.
- **Provide mentorship and technical support** to activists and other stakeholders, through a "learning by doing" approach.
- **Market and patent intelligence units** that regularly collect data on registration, prices, forecasting, availability, affordability, patent status, and existing licences on key products in countries across the globe.
- **Assess intellectual property law, policy, and practices from patent offices**, including positive and harmful provisions and practices that are likely to have an impact on access to and affordability of medicines.
- **Conduct advocacy workshops and campaigns** to support trained IP activists and organizations in advocating for pro-access laws and policy reform and fighting harmful trade agreements. Campaigns also demand that affordability of HIV, TB, and HCV medicines improve and that people living with HIV and related conditions have access to optimal treatment.

- **Provide small grants** to facilitate advocacy activities related to intellectual property, seeding marginally or rarely funded initiatives.
- **File patent oppositions** on key medicines at intellectual property offices and courts, using legal and scientific evidence to end unfair monopolies, encourage competition, and drive down drug prices, resulting in increased access to medicines for all people.
- Hold intellectual property **community forums** to establish preferences, concerns, and recommendations related to IP and access to medicines globally.
- Collaborate with regional networks to set up **Community Advisory Boards (CABs)**, a formalized mechanism to promote community and civil society engagement and representation in clinical trials, research and drug development and treatment access discussions with pharmaceutical companies. CABs also focus on empowering community activists through capacity development and training.

> *"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, 2019*

STRATEGIC FOCUS AREAS

WATCH WHAT MATTERS

Action: Hold governments accountable for health commitments

If efforts to achieve sustainable progress against HIV and AIDS are to be successful, targets must include who has access to HIV and health services and the actual quality of these services. Additionally, community data (not just from traditional sources) must be collected on these targets. Community-led monitoring is a critical part of data collection, allowing communities to identify real-time gaps in access and provide new insights about the state of a country's HIV and broader health response. **When communities have tools and techniques to collect and analyse their own data, they are able to increase domestic oversight and conduct evidence-based advocacy to improve services for HIV and related conditions.**

Strategy:

- **Create, update, adapt, and deliver trainings and webinars** on community-led monitoring, monitoring and evaluation methods for community-led research, and how to collect and analyze data, generating evidence that can be used to hold governments accountable for improving treatment and service delivery.

- **Create educational tools and materials** on community-led monitoring and research, including digital toolkits.

- **Foster "citizen science"** by democratizing access to information, as well as robust research initiatives, through:

  - **Community-led research and surveys**, which bring power directly into the hands of affected communities, instead of waiting for researchers or development institutions to shed light on particular issues

  - **Supporting the rollout and effective implementation of ITPC's community-ty-led monitoring model, including Community Treatment Observatories** (CTOs) to monitor trends across the HIV care cascade, the wider legal and structural framework for health, and the socioeconomic landscape to inform targeted actions to improve the quality of services for recipients of care.

- Conduct **advocacy workshops and campaigns** to support partners and other key stakeholders in discussing, analyzing, and transforming quantitative and qualitative data into action roadmaps for national, regional, or global advocacy. Conduct campaigns based on data collected from its monitoring and research projects, including CTOs. This work includes planning meetings, workshops, petitions, campaigns, targeted statements, position papers, and protests.

- **Provide small grants** to facilitate community-led monitoring and research for advocacy. Often, our grants seed marginally or rarely funded initiatives.

- Support collaboration with implementing partners in organizing **Community Consultative Group (CCG)** meetings to ensure that monitoring initiatives are responsive to community needs. ITPC's implementing partners work collaboratively with CCGs and provide input and support for the development of data collection tools, data analysis, organizational decisions, and advocacy roadmaps.

- **Attend national, regional, and international meetings and conferences** to showcase our community-led monitoring and research work, reflecting on our results, and engaging with other activists and organizations to push for change.

Results:

- Communities are trained to **collect and analyze data** to inform health responses.

- Communities **conduct evidence-based advocacy** to improve health and social systems.

- Decision makers recognize the **value of community data and integrate this data into their responses.**

- Changes take place in policy, norms, legislation, commitments, and implementation of commitments.

"I leave this workshop empowered. People have so many misunderstandings; they hear that their viral load is undetectable and they believe they are cured. Now that I understand U=U, I now know how to explain to members of my community what that means and what that means for their lives."

Participant in treatment education workshop, Malawi, 2021

STRATEGIC FOCUS AREAS

BUILD RESILIENT COMMUNITIES

Action 1: Generate demand for appropriate and equitable healthcare

When people access reliable information about their health conditions and the impact of HIV (prevention, testing, treatment, and care) on their well-being and quality of life, **they are empowered to seek out quality health services.** Communities that share accurate information are more likely to support each other in reducing harm, accessing services, adhering to HIV treatment, and achieving better overall health outcomes.

BUILD RESILIENT COMMUNITIES

Results:

- 👄 Community-driven advocacy initiatives on treatment access **secure concrete advocacy wins,** such as changes to policies or programs.
- 👄 There are **higher levels of community education** around HIV prevention and treatment.
- 👄 Stronger activist networks and coalitions can **swiftly respond to emerging health threats,** as well as consistently advocate for improved health responses.
- 👄 National and global policies reflect the **realities** and needs of communities.
- 👄 Communities **drive the creation of better local and national health services,** improving the health of individuals and their society more broadly.
- 👄 Communities are **politically engaged** and organized to advocate for their rights and address rights violations, helping create more vibrant democracies.

Strategy:

- 👄 **Create, update, adapt, and deliver trainings and webinars** for people living with HIV and their networks, treatment activists, healthcare workers, community leaders, and other stakeholders to build awareness of and demand for better health services.
- 👄 **Create educational tools and materials** on HIV and its care and treatment, including digital toolkits and community versions of global guidelines.
- 👄 **Provide evidence mapping and community consultations** to identify preferences, concerns, and recommendations for improving access to quality treatment. The methodology may include desk reviews, surveys, thematic focus group discussions, workshops, and/or webinars.
- 👄 **Hold advocacy workshops and campaigns** to improve the skills of advocates, develop strategic partnerships, and collectively identify targets, allies, resources, and action roadmaps to demand increased access to optimal treatment for people living with HIV and related conditions.

- 👄 **Provide small grants** to facilitate advocacy on the treatment access gaps that advocates have identified, seeding marginally or rarely funded initiatives.
- 👄 Lead, organize, and participate in global, national, and community **technical working groups**, drawing attention to community issues and sharing direct experiences from tracking the quality of HIV care and services at the community level.
- 👄 **Develop alliances with key global organizations and institutions** to influence current debates around access to quality HIV treatment and related conditions.
- 👄 **Organize Activist Development Programs (ADPs)**, a competitive, professional training initiative aimed at equipping and empowering activists around the world to fight for better health.
- 👄 **Organize Community Activist Summits (CAS)**, which bring together people living with HIV, activists who are members of key population groups, civil society and community advocates, program implementers, government officials, and other stakeholders to contribute to a global, community-led HIV advocacy agenda.

BUILD RESILIENT COMMUNITIES

"The Regional Community Treatment Observatory improved our evidence-based advocacy. Because of the RCTO work in Togo, we are more credible with the government. We moved from being seen as 'those guys coming to police' to being relied on."

Amen Hlomewoo, Community Treatment Observatory Focal Point, Togo, 2020

Action 2: Strengthen community systems and networks to support health equity

From the beginning, ITPC has focused not just on supporting individual activists, but also on emboldening the networks and organizations that enable sustained activism and engaged communities. **This work is often invisible to donors, but is essential for long-term progress on HIV.** Strengthening community systems and networks includes helping small organizations **secure funding, putting in place management, governance, and financial systems,** and developing leadership so that communities are better equipped to do community-led monitoring, advocacy, and education.

Results:

- Communities have **ownership** over education, monitoring, and advocacy activities, rather than being in service to outside organizations or donors.
- Staff and volunteers of community networks and organizations develop **skills** in data management, monitoring and evaluation, and advocacy.
- Health interventions at the local level are **more appropriate and responsive** to the real needs of communities.
- Communities are able to **continue responding to and advocating** for their needs over the long term.
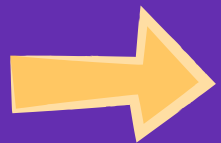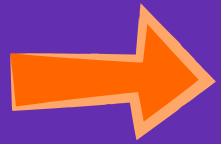
Strategy:

- Hold **Activist Development Programs** (ADPs) in nine countries to build sustainable leadership.
- Provide or create a **range of tailored tools** to support organizations in developing good governance and accountability practices, policies for organizational operations, management, strategic planning, and resource mobilization. These tools include in-person and virtual trainings, one-on-one mentorship, and organizational exchanges and placements.
- Host the Global Activist Network (GAN) to **foster participation and leadership.**
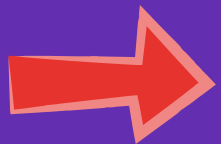- Organize **Community Consultative Groups** (CCGs) to ensure that CTOs are responsive to community needs.

JOIN US

Join our **Global Activist Network** of community-based organizations, individual treatment activists, partner organizations, ITPC regional networks and the ITPC team.

SIGN UP

Subscribe to our newsletter and join hundreds of activists already making an impact in their communities.

DONATE

Whether you make a one-time contribution, or provide ongoing support, **every dollar counts.**

- Donors: If you're a funder, let us know what you're interested in. We have gathered a wealth of insight from over 15 years of activism across the globe.
- Governments: If you're a government official, let us work together and create a standout model for effective health systems.
- Companies: If you're from the private sector, work with us to express and expand your corporate social responsibility.

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