INVESTING IN COMMUNITIES
ANNUAL REVIEW 2016

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Protest at International AIDS Conference targeting Gilead on high price of drugs
MISSION
Our mission is to enable people in need to access optimal HIV treatment.

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

VALUES
ITPC’s work is guided by our understanding that access to HIV treatment is a human right.

Our 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.

ITPC-led regional workshop to mobilize demand for routine viral load testing, with MSF, in Johannesburg.
The world changed in 2016. Things were difficult before, but a whole new level of challenge has unfolded for people living with HIV and for civil society as a whole. The populism sweeping Europe and the US is resulting in a new kind of politics that is rescinding on environmental commitments, closing down borders, and reducing aid spending. Already, funding and political will to end AIDS was withering on the vine. Now there is a palpable sense of crisis.

In July, having blocked key population organizations from attending the negotiation process for the "Fast Track to End AIDS" declaration, member states defended their positions based on prejudice and discrimination. Governments that were leading the way on ‘access to medicines’ are now actively working against civil society in India, Thailand, Russia, Argentina and Brazil. Stock outs of antiretroviral drugs are threatening the right to health in many countries, including the entire West African region, where three in four people do not have access to life-saving HIV medicines. Since 2010, there have been no declines in new HIV infections among adults, and every year since then, about 1.9 million adults have become newly infected with HIV. We are a long way from 90-90-90 with fewer than half of people living with HIV on treatment, and even further away from ending AIDS if these trends persist.

How do we respond? Despite how it may look, the true power to influence the changes needed ultimately lies with those people most affected by HIV. The more knowledgeable and engaged people become, the better they can fight to change the systems that oppress them, hold duty-bearers to account, and improve their own health. Now, more than ever, is the time to invest in these communities and strengthen their capacity to demand, monitor, and work with others to achieve their right to optimal health. We made impressive progress empowering communities in 2016:

- Globally, we directly strengthened the advocacy capacity and HIV treatment knowledge of over 270 activists in 36 countries; and these treatment activists went on to mobilize peers and galvanize policy makers to improve access to routine viral load testing.
- With ITPC regions and partners, we conducted training, coordinated community research, and supported advocacy through 125 interventions in over 75 countries.
- Our intellectual property interventions contributed to projected combined annual savings of almost US$700 million for national health budgets in Argentina, Brazil, Ukraine, and Thailand.

ITPC achieved these wins in a harsh environment, with depleting resources and a very small, but dedicated and creative team. We would not have been successful without the support of our amazing and progressive donors who know the value and impact of strengthening the capacity of affected communities.

Our niche is clear. Our work investing in communities is more relevant than ever. When we educate people living with HIV about their rights, we light a fire that fuels a demand for justice.

Solange Baptiste
Executive Director

INVESTING IN COMMUNITIES NOW MORE THAN EVER

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#TreatPeopleRight

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2016 was a year of consolidating, catalyzing and achieving incredible results, for ITPC. We pursued our strategic objectives: to mobilize demand for optimal HIV treatment; we supported civil society to challenge unfair barriers that limit access to essential HIV drugs; and we laid the ground for scaled up community monitoring of HIV treatment services. Our approach, of educating communities, and supporting community-based research and advocacy, informs all our programs.

In 2016, we began new projects to educate communities and mobilize them to demand routine viral load testing, as part of our Be Healthy – Know Your Viral Load campaign. Through 13 regional and national workshops we strengthened the capacity of 270 activists from 36 countries. Training included the science of HIV, HIV treatment monitoring and advocacy. National partners went on to sensitize communities on the need for routine viral load testing, and lobby policy makers to adopt and implement the latest WHO guidelines on treatment monitoring.

We began to see dramatic results from the ITPC-led consortium working together to make HIV medicines more affordable in middle-income countries. As a result of policy and media engagement by our four national consortium partners, we saw the prices of key antiretroviral drugs tumble. The projected combined savings on medicines in the four countries is almost US$700 million per year. The lower prices will mean cash-strapped health budgets in the four countries can afford to treat many more people (see page 16). The Make Medicines Affordable campaign expanded to include 28 countries and five regions.

Increasingly in demand, ITPC provided technical assistance to civil society partners and UN agencies on interventions to counter intellectual property barriers.

In 2016, the Global Fund recommended ITPC for a grant to support the implementation of 11 national Community Treatment Observatories in West Africa. In preparation for the Global Fund grant ITPC underwent a system overhaul, strengthening organizational and financial procedures, as part of the rigorous pre-grant processes. All the intense preparation paid off when the Global Fund Board confirmed the decision to fund ITPC and its 11 sub-recipients. The grant worth €3.6 million runs for three years, from January 2017 to December 2019.

In 2016, ITPC participated in critical policy meetings and conferences to present community-based research, influence international policy and amplify the voices of the communities we represent. At the International AIDS Conference in July 2016, we led, co-hosted and participated in sessions to communicate our message that Optimal Treatment is Not a Dream! Through staff, and partners, we contributed to the consultations and submissions organized by the United Nations High Level Panel on Access to Medicines. We also engaged in civil society submissions to, and advocacy around, the UN High Level Meeting on Ending AIDS.

We continued to forge new partnerships over the year in our efforts to strengthen advocacy and bring the community perspective to a wide range of policy makers and implementers. New partners included ICAP at Columbia and International AIDS Society. We consolidated existing partnerships with a more comprehensive grouping of community networks and HIV focused NGOs to strengthen our joint advocacy, on shared goals.
GLOSSARY

ITPC and Regions

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<tr>
<th>Acronym</th>
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<tbody>
<tr>
<td>ITPC</td>
<td>International Treatment Preparedness Coalition</td>
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<td>ITPC CA</td>
<td>ITPC Central Africa</td>
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<td>ITPC China</td>
<td>ITPC China</td>
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<td>ITPC EA</td>
<td>ITPC East Africa</td>
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<td>ITPCru</td>
<td>ITPC Eastern Europe and Central Asia</td>
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<td>ITPC LATCA</td>
<td>ITPC Latin America and the Caribbean</td>
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<td>ITPC MENA</td>
<td>ITPC Middle East and North Africa</td>
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<td>ITPC SA</td>
<td>ITPC South Asia</td>
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<td>ITPC WA</td>
<td>ITPC West Africa</td>
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Abbreviations & Acronyms

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<thead>
<tr>
<th>Acronym</th>
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<tr>
<td>ABIA</td>
<td>Associação Brasileira Interdisciplinar de AIDS</td>
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<td>ART</td>
<td>antiretroviral therapy</td>
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<td>ARV</td>
<td>antiretroviral</td>
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<td>ARASA</td>
<td>AIDS and Rights Alliance for Southern Africa</td>
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<td>BONELA</td>
<td>Botswana Network on Ethics, Law and HIV/AIDS</td>
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<td>CCM</td>
<td>Country Coordinating Mechanism</td>
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<td>CEDEP</td>
<td>Centre for the Empowerment of People, Malawi</td>
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<tr>
<td>CDC / ICAP</td>
<td>Center for Disease Control / ICAP at Columbia University</td>
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<tr>
<td>CEGAA</td>
<td>Centre for Economic Governance and AIDS in Africa</td>
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<tr>
<td>CSO</td>
<td>civil society organization</td>
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<tr>
<td>EFV</td>
<td>efavirenz</td>
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<td>EMRO</td>
<td>Eastern Mediterranean Regional Office</td>
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<td>FGEP</td>
<td>Fundación Grupo Efecto Positivo</td>
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<td>FTC</td>
<td>emtricitabine</td>
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<td>Global Fund</td>
<td>The Global Fund to Fight AIDS, Tuberculosis and Malaria</td>
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<td>HCV</td>
<td>hepatitis C</td>
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<td>IAC</td>
<td>International AIDS Conference</td>
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<td>IAS</td>
<td>International AIDS Society</td>
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<td>I-MAK</td>
<td>Initiative for Medicines, Access, and Knowledge</td>
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<td>LGBTI</td>
<td>men who have sex with men, people who inject drugs, transgender people, sex workers, prisoners, refugees and migrants, people living with HIV, young people, orphans and vulnerable children, women and girls</td>
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<td>MOH</td>
<td>Ministry of Health</td>
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<td>MSF</td>
<td>Médecins sans Frontières</td>
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<td>MSM</td>
<td>men who have sex with men</td>
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<tr>
<td>NGO</td>
<td>non-governmental organization</td>
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<td>PEPFAR</td>
<td>President’s Emergency Plan for AIDS Relief</td>
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<td>TRIPS</td>
<td>Trade-Related Aspects of Intellectual Property</td>
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<td>TB</td>
<td>tuberculosis</td>
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<td>TDF</td>
<td>tenofovir disoproxil fumarate</td>
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<td>TDF/FTC</td>
<td>tenofovir disoproxil fumarate /emtricitabine</td>
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<td>TDF/FTC/EFV</td>
<td>tenofovir disoproxil fumarate /emtricitabine / efavirenz</td>
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<td>UN</td>
<td>United Nations</td>
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<td>WHO</td>
<td>World Health Organization</td>
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**HIGHLIGHTS OF 2016**

**JANUARY**
ITPC East Africa joins partners to raise concerns about the World Bank’s re-classification of Kenya. The re-classification from a low to middle income country is set to reverse progress on HIV/AIDS.
Read Rose Kaberia’s blog post

**FEBRUARY**
ITPC Central Africa alerts policy leaders to sustained drug stock-outs in health facilities in Congo-Brazzaville. A climate of fear pervades, with informants only prepared to share information anonymously.
Read the statement

**MARCH**
ITPC South Asia (ITPC SA) urges European Union to stop threatening access to affordable medicines, as it resumes negotiations with India.
Read about ITPCSA’s action

Regional Director of ITPC SA highlights three issues to improve access to medicines, at an expert consultation organized by the UN in Bangkok. Read Loon Gangte’s blog post

ITPC and consortium partners contribute to consultations organized by the UN High Level Panel on Access to Medicines in London and Johannesburg.

**APRIL**
Othoman Mellouk, ITPC’s Intellectual Property and Access to Medicines Lead, speaks at the Civil Society Hearing as part of the UN Assembly High Level Meeting on Ending AIDS. See facebook post

New Activist Toolkit from ITPC supports advocacy for routine viral load monitoring.
Read the statement and download the toolkit

**MAY**
The Global Fund recommends grant to enable ITPC to extend community-based monitoring of HIV treatment to eleven countries in West Africa. Find out more

**JUNE**
ITPC expresses deep disappointment with the outcome of the Political Declaration “On the Fast-Track to End the AIDS epidemic” by the UN Assembly at the High-Level Meeting on Ending AIDS. Read the statement

Partners in Southern and East Africa highlight grave concerns about how they have been side-lined in the implementation of programs intended to benefit their communities. Read the statement
HIGHLIGHTS OF 2016

JULY
At the AIDS conference in Durban, ITPC leads, co-hosts and participates in many sessions to raise the flag for optimal HIV treatment. Every day, ITPC leads Satellite Sessions, Skills-Building Workshops, protest actions and the two Networking Zones. Read a summary of our activities

AUGUST
ITPC and ARASA run two intensive ‘Video for Change’ training courses for leaders and activists of key population networks in Malawi and Botswana. Read a blog post about the training

SEPTEMBER
ITPC welcomes, with reservations, the report from the UN Secretary-General’s High Level Panel on Access to Medicines. It is regrettable that voluntary mechanisms were recommended as a first option given their known limitations. Read the statement

OCTOBER
Following action by consortium partner ABIA, dolutegravir becomes part of the national HIV program in Brazil. Dolutegravir has better efficacy and fewer side effects than comparable drugs. Read Othman Mellouk’s blog post about the news

NOVEMBER
The revised, updated and expanded Advocacy for Community Treatment (ACT) Toolkit was launched at regional workshops in Panama and South Africa. Read the statement and download the toolkit

Alongside over 30 organizations, ITPC issues a call for action and global solidarity to address the irresponsible and destructive declines in HIV and TB funding in middle-income countries. Read the statement

ITPC LATCA with partners from across Latin America and the Caribbean raise grave concerns for people living with HIV in Venezuela. The statement highlights interruptions in supply of key antiretroviral drugs. Read the statement

DECEMBER
Make Medicines Affordable partners, and allies from around the world, write an open letter to the WHO Director General. We urge her to give the UN Secretary-General’s High Level Panel on Access to Medicines. Report, and recommendations, the attention they deserve. Read the open-letter
REACH AND RESULTS

With our regions, networks and partners, we ran projects to improve access to optimal HIV treatment in these countries in 2016

- **Training delivered to increase capacity on HIV treatment, rights and advocacy**
  - Armenia, Belorussia, Georgia, Kazakhstan, Latvia, Moldova, Kyrgyzstan, Russia, Tajikistan, Ukraine

- **Treatment activists mobilized to demand routine viral load testing**
  - Bangladesh, Belize, Burundi, Cambodia, China, Costa Rica, Djibouti, Dominican Republic, Democratic Republic of Congo, Ecuador, El Salvador, Ethiopia, Guatemala, Honduras, India, Indonesia, Jamaica, Kenya, Lesotho, Malawi, Mozambique, Myanmar, Nepal, Nicaragua, Pakistan, Panama, Peru, Rwanda, Sri Lanka, South Africa, Swaziland, Tanzania, Thailand, Uganda, Vietnam, Zimbabwe

- **Groundwork laid for expanded community monitoring**
  - Benin, Côte d’Ivoire, The Gambia, Ghana, Guinea Bissau, Guinea Conakry, Liberia, Mali, Pakistan, Senegal, Sierra Leone, Togo

- **Improved HIV treatment services following community monitoring**
  - Guatemala, Honduras

- **Patent oppositions filed**
  - Argentina, Brazil, Egypt, Russia, Thailand, Ukraine

- **Patent opposition successful**
  - Argentina, Brazil

- **Training delivered on intellectual property and access to medicines**
  - Russia, Ukraine, Armenia, Belorussia, Moldova, Kazakhstan, Kyrgyzstan, Georgia, Egypt

- **Community-based research conducted**
  - Armenia, Azerbaijan, Belorussia, Cameroon, Cote D’Ivoire, Egypt, Estonia, Georgia, Guatemala, India, Kazakhstan, Kenya, Kyrgyzstan, Latvia, Lithuania, Malawi, Moldova, Morocco, Russia, Tajikistan, Tanzania, Tunisia, Ukraine, Uzbekistan, Zambia

- **Advocacy to improve accountability, and increase funding for key populations**
  - Algeria, Argentina, Armenia, Botswana, Cameroon, Costa Rica, Dominican Republic, Egypt, Ethiopia, Indonesia, Kenya, Lebanon, Malawi, Mauritania, Moldova, Morocco, Nepal, Philippines, Sierra Leone, South Africa, Suriname, Tanzania, Thailand, Tunisia
MOBILIZE DEMAND

MOBILIZE DEMAND for Optimal Treatment

In line with ITPC’s Strategic Objective 1, we intensified our efforts on treatment education as the first critical step towards mobilizing communities to advocate for optimal HIV treatment. The focus of this work in 2016 was on:

- Mobilizing demand for routine viral load testing and newer more optimal HIV drugs;
- Updating and expanding our toolkit to support community leaders and newly empowered activists to educate and strengthen the advocacy capacity of their peers.

ROUTINE VIRAL LOAD TESTING

The World Health Organization (WHO) recommendation that people on HIV treatment have viral load tests at least once a year is far from reality for many, especially children and adolescents. Most countries do not have clear data on how many people on antiretroviral treatment are accessing the viral load test regularly, or what the country’s viral suppression rates are. From ITPC’s work with communities, we know that many people on antiretroviral treatment are not aware of the need for, or importance of, routine viral load testing.

“As a person living with HIV, on antiretroviral therapy for many years, I never had a viral load test. I was pained to learn today that there are 10 viral load test machines in Malawi. Who are they for?”

Esnat, a community advocate from The Coalition of Women Living with HIV at a workshop in Malawi.
WE MOBILIZED DEMAND for Routine Viral Load Testing

As part of a project supported by UNITAID and Médecins sans Frontières (MSF), we designed and ran one regional, and nine national workshops in East and Southern Africa: South Africa, Swaziland, Lesotho, Mozambique, Zimbabwe, Malawi, Kenya, Uganda and the Democratic Republic of Congo. A total of 210 participants, representing communities of key populations and networks of people living with HIV, attended the three-day workshops. ITPC led and facilitated the training sessions alongside representatives from the Ministry of Health and the national laboratory viral load testing units. Participants came from both rural and urban settings, and were of diverse ages and gender. Here is a comment from Violet, a young activist at a workshop in Malawi.

"It’s common to see health workers challenge people who ask for a viral load test. They mock and ask, ‘When did you become a doctor to ask for a test’ and then refuse to provide a test.”

Through providing science and support for advocacy, the training empowers activists to challenge such negative attitudes by health workers.

ITPC EAST AFRICA’S STORY: An Example of Community Activism

As in many other countries in the region people living with HIV in Kenya had limited information on the critical role of routine viral load testing for their health. Low awareness extended to county health committees and healthcare workers at the facility and community level. The same was true of many policy makers responsible for health.

Kenya Adopts WHO 2015 Guidelines on HIV Treatment Monitoring

To address this, we organized training on routine viral load testing for people living with HIV and government stakeholders in seven counties. The training included health workers, county health committees and journalists. Activists put pressure on the government to scale up the use of viral load testing, and public awareness was increased through the media, including radio talk shows.

“It appreciate the work ITPC EA is doing with communities and especially the routine viral load testing campaign,” said Faith Ndung’u, from AIDS Healthcare Foundation. “It is one of a kind, and empowers communities to demand treatment and monitoring.”

As a result of these education and advocacy activities, there is now a national movement of civil society organizations mobilized on the issue of routine viral load testing. We were invited to join the Technical Working Group developing HIV Treatment Guidelines.

The new official Kenyan HIV Treatment Guidelines, now includes the latest WHO 2015 recommendations for routine viral load testing.

“"For the first time, I heard of things I have never heard before about testing and HIV in general,” said Duncan Gitonga, an FM Radio presenter after interviewing Rose Kaberia, the Regional Director. “ITPC EA and other experts should provide frequent radio talks, because I realized that between information and listeners there is a big gap, like darkness and light.”

Rose Kaberia, ITPC EA Regional Director, in radio interview about HIV and role of routine viral load testing.
COMMUNITIES ADVOCATE for Routine Viral Load Testing

As part of the joint UNITAID/MSF project, we provided small grants to enable nine national partners to carry out the advocacy and awareness-raising plans they developed during the workshops. The plans included peer-to-peer education, media and policy engagement. The focus of policy dialogue was on including routine viral load testing in national HIV Treatment Guidelines and ensuring robust strategies to support implementation.

The nine national partners used a wide range of creative methods to sensitize people living with HIV and health service providers, and to lobby policy makers. Some achievements include:

- **420 champions identified, recruited and trained to promote viral load testing in 20 districts in Malawi**
- **460 people living with HIV and policy makers engaged in dialogue meetings, in 10 provinces in Zimbabwe**
- **2,000 people living with HIV sensitized in two radio talk shows, and social media used extensively, in Uganda**
- **Three meetings with the Ministry of Health, leading to viral load being included as a key indicator in the Zimbabwe Population Based HIV Impact Assessment**
- **Almost 2,000 people living with HIV sensitized on the need for routine viral load testing in the Democratic Republic of Congo. To achieve this, materials were translated, adapted and popularized for the audience**
- **The Kenyan government updated its HIV Treatment Guidelines to include the latest recommendations for routine viral load testing, based on the 2015 WHO Guidelines**

Mobilizing Demand in Asia, Latin America and Africa

Also in 2016, with support from the Robert Carr civil society Networks Fund, we ran three-day workshops in three regions to increase demand for routine viral load testing services. Over 60 activists from 36 countries attended the training in Sub-Saharan Africa, Asia and Latin America and the Caribbean. Participants represented national networks of people living with HIV, key populations and youth groups. The training strengthened participants’ knowledge and capacity so they could mobilize their communities to advocate for routine viral load testing in their respective countries.

The workshops provided space for participants to develop national awareness raising and advocacy plans, to scale up the use of routine viral load testing, as part of the ’Be Healthy – Know your Viral Load’ campaign led by ITPC and ARASA.

“I was not aware of routine viral load testing until ITPC EA trained us,” said David Mbwana, an activist from Tanzania. “Now, I can monitor my treatment and demand testing, as well as teach others on the importance of viral load testing, using the toolkit. The training was very comprehensive and enriching.”

Now, I can monitor my treatment and demand testing, as well as teach others on the importance of viral load testing.”
CREATING DEMAND
for New Hepatitis Therapies and Optimal HIV Antiretroviral Drugs

In addition to our work improving access to medicines by challenging intellectual property barriers (see next chapter), ITPC and our regional networks have been creating demand for newer, more optimal treatment.

In 2016, we ran workshops to educate communities and national stakeholders about new direct-acting antivirals for hepatitis treatment (HCV), and dolutegravir for HIV treatment, as a first option for better efficacy and fewer side effects. Our regional networks in Eastern Europe and Central Asia, and the Middle East and North Africa, ran training and capacity building workshops to create demand for these new therapies. In some cases, we worked with national governments to set ambitious targets for HCV testing and treatment during the development of national strategic plans. For example, in Morocco, the country adopted ITPC MENA’s recommendations, and declared a target of “Eliminating HCV by 2030”.

Working with our partners in Argentina and Brazil, we organized two national technical meetings which brought together government and civil society stakeholders that are engaged in the access to medicines movement. The focus here has been on informing participants about the potential of new drugs, such as dolutegravir, that were coming onto the market. Our initiatives pushing for early introduction of dolutegravir in Ukraine and Morocco were successful. Building on this, we are planning to launch a global campaign to increase access to dolutegravir in 2017.

Jose Maria Di Bello, F-GEP’s Secretary General, speaking at meeting in Buenos Aires, as part of Make Medicines Affordable campaign.
NEW TOOLKITS AND MODULES for Activists

In 2016, ITPC revised its Activist Toolkit, by including new sections and updating content. We also created two new stand-alone modules, one to facilitate advocacy on routine viral load testing, and the other to support optimal HIV treatment for children and adolescents.

New Toolkit Mobilizes Demand for Routine Viral Load Testing

The findings from a baseline awareness survey were used to inform the development of ITPC’s Routine Viral Load Activist Toolkit. ITPC created a new comprehensive toolkit covering the science of HIV, HIV treatment and the role of viral load testing. The toolkit features examples of advocacy case studies that can be used by activists to inspire their strategies to create demand for routine viral load testing. The toolkit was launched at a regional workshop in Johannesburg, in February 2016, as part of the ‘Be Healthy – Know your Viral Load’ campaign.

“In my experience those knowledgeable can confidently interact with health care workers and ask for things like a viral load test,” said Nellie a community health worker from Blantyre, in Malawi. “What about those who don’t know, in the rural areas? Due to their lack of knowledge they are not able to ask for these services. This toolkit will really help empower people out there.”

Second Edition of Advocacy for Community Treatment (ACT) Toolkit

Following the release of the WHO 2015 Guidelines on HIV treatment, ITPC revised the content of the Advocacy for Community Treatment (ACT) Toolkit.

WHO’s new recommendations on treatment and treatment monitoring were integrated in the updated ACT Toolkit 2.0.

The ACT Toolkit 2.0 includes a chapter on HIV Co-Morbidities with a focus on tuberculosis, hepatitis C, and non-communicable diseases (cancer, hypertension and diabetes). The chapter on non-communicable disease was included, as we had identified a knowledge gap amongst people on antiretroviral therapy, who are increasingly facing such health challenges.

“ITPC EA is doing such amazing work to support sex workers and people who use drugs,” said Monica Carriere from Mainline. “Your training tool is great.”

New Community Treatment for Children and Adolescents Toolkit

Most toolkits, information and advocacy materials on HIV and treatment are developed with the needs of adults in mind. It was clear that an activist toolkit was required to support advocacy for optimal HIV treatment for children and adolescents. In 2016, we developed a toolkit that covers the science of HIV treatment and treatment access issues that influence the health outcomes of children and adolescents. We will launch the toolkit in 2017.
DEMAND ACCOUNTABILITY

Decision-Makers on Optimal Treatment: A Focus on Health Systems and Trade Related Barriers

To fulfill our Strategic Objective 2, we pursued three main priorities in 2016:
- We empowered civil society and governments to challenge unmerited patents and use legal reform to make medicines affordable;
- We enabled communities to monitor HIV treatment services and demand improvements from policy makers;
- We supported key population networks to secure meaningful representation to realize their rights in HIV and health programming.

This section covers our progress on these three themes.
MAKING MEDICINES AFFORDABLE

We built on our multi-partner project to make HIV treatment affordable in four middle-income countries. The project, which started in 2015, and is supported by UNITAID, challenges intellectual property barriers that block access to medicines in middle-income countries. Our work aims to remove, and deter the awarding of, unmerited patents.

The interventions we use include targeted legal interventions, policy dialogue and law and policy reform. Such strategies facilitate the introduction of competition from generic manufacturers, thus leading to significantly lower prices for antiretroviral (ARV) drugs in our target countries. By achieving price reductions, these countries can purchase more ARVs and provide treatment to more people who need it.

In 2016, our country partners in Argentina, Brazil, Thailand and Ukraine\(^1\) engaged their governments on intellectual property law reform, despite the difficult political contexts they face. Several draft amendments to intellectual property laws were submitted to the governments of the four countries. Consequently, we are now considered key players in intellectual property reform. Our work has also significantly contributed to increased transparency of patent information, generating useful data about patents. This is not only useful for our work, but it helps other organizations who are working to tackle the high price of medicines.

Engaging with patent offices in patent application examination processes is proving to be effective in all four countries. We have been successful in building strong formal and informal relationships with patent offices in these countries, as well as in countries outside our scope of intervention. Engaging with the Ministry of Health and procurement agencies in the focus countries, has successfully resulted in reductions to the prices of antiretroviral drugs.

\(^{1}\) Fundación Grupo Efecto Positivo, Associação Brasileira Interdisciplinar de AIDS, AIDS Access Foundation and All Ukrainian Network of People Living with HIV/AIDS. Legal expert is Initiative for medicines, Access, and Knowledge.
PROJECTED SAVINGS OF US$696m
for Public Health Budgets in Four Countries

Since the start of project, we filed seven patent oppositions in the four countries. We also pursued two patent oppositions that were filed prior to start of the project. As a result of an opposition we filed in Brazil, the patent application on the antiretroviral drug TDF/FTC was rejected in early 2017. This will mean that other companies can manufacture and sell the drug in Brazil, thus increasing competition and bringing down prices. The outcomes of the other patent oppositions are still pending.

When comparing the latest antiretroviral prices with prices before our interventions, and considering the number of people currently on treatment, we have secured combined projected annual savings of US$696.44 million in the four focus countries.

These significant savings are linked to our work challenging unmerited patents, whilst engaging with health authorities, patent offices and procurement agencies.

Example from Argentina
Our partner, Fundación Grupo Efecto Positivo (FGEP) filed pre-grant patent oppositions on two drugs: TDF/FTC/EFV (Atripla®) and TDF+FTC (Truvada®). This action, combined with sustained meetings with policy makers and suppliers, resulted in the procurement of generic versions of these drugs from the manufacturer Cipla and a local generic producer. This in turn meant price reductions of 68% on TDF/FTC and 95% on TDF/ FTC/EFV. These price reductions are now generating combined annual savings of US$50.8 million in Argentina.

See our full infographic about the impact of our interventions in Argentina.
Expanding the Make Medicines Affordable Campaign

Our Campaign “Make Medicines Affordable”, supported by a multilanguage website and a strong online presence, is now recognized to be among the key players in the intellectual property and access to medicines movement. While the campaign initially included only the four countries supported by our UNITAID funded project, other civil society groups joined the campaign in 2016. To accommodate this, we expanded the website from the four original countries in 2015, to 28 countries by the end of 2016. These include India, Kyrgyzstan, Malaysia, Peru and other countries organized in five regions: Asia Pacific, Eastern Europe and Central Asia, Latin America, North Africa and Southern Africa.

Providing technical assistance

After a year of implementing the project, the consortium has received several requests from different countries and organizations to provide technical support, thus fulfilling one of our original objectives. When we set out, we aimed to share experiences and lessons from our four counties to inspire civil society to challenge intellectual property barriers that impede access to medicines, and thus create a snowball effect. Examples of technical support requests include 1) compulsory license strategies, 2) patent oppositions on anti-HCV medicines, and 3) patent oppositions for Pre-exposure prophylaxis (or PrEP). These requests for support come from civil society, as well as UN organizations, such as WHO/Eastern Mediterranean Regional Office (EMRO). ITPC supported EMRO by helping them to develop the capacity of EMRO Hepatitis National Focal Points in intellectual property.

ITPCru’s Story: An Example of Community Activism

Our work has contributed to price reductions and improved access to medicines throughout Eastern Europe and Central Asia. We have achieved this through price monitoring and advocating for price reductions, intellectual property interventions and putting pressure on pharmaceutical companies. In 2016, we also engaged the government on issues around price reduction, and increased the capacity of communities on medicine prices and intellectual property. We did this by providing training and supported partners to learn by doing.

Twelve Times More People get Tenofovir in Russia

One of the problems for people living with HIV in Russia was lack of access to the essential HIV drug, tenofovir. In 2015, only four thousand people received tenofovir-based regimens in Russia. Over the course of three years, we put pressure on the government and pharmaceutical companies to take specific steps to improve access to tenofovir. For example, we urged the government to include tenofovir in the Essential Medicines List, and we lobbied pharmaceutical companies to decrease its price.

As a result of our activities, the price for tenofovir fell dramatically. This has meant that, in 2016, almost 50,000 people received tenofovir-based regimens in Russia.

“Thanks to these guys we always have access to information about auctions in our region and tools to use if we need to do advocacy,” explains Denis from Kemerovo in Russia. “They help us to be specific in our negotiations with the AIDS clinic and the local authorities.”
Developing a Tool for Comparing Intellectual Property Laws

Building on work in 2015, ITPC Global provided technical support to ITPC MENA to develop an easy and reliable tool to measure the impact of intellectual property laws on public health and access to medicines. The data collection tool and methodology analysis that came out of this research has been successfully tested in the three initial countries (Morocco, Egypt and Tunisia). In 2016, we shared the tool with partners from the Make Medicines Affordable campaign and engaged partners from nine countries to conduct research on their national laws. We expect to publish the data and analysis in 2017.

ITPC MENA’s Story: An Example of Community Activism

Dolutegravir is promising new antiretroviral drug for HIV. The company that owns the patent, ViiV Healthcare, granted a voluntary license so that most African countries had affordable access to the treatment. However, they left out four North African countries: Algeria, Libya, Morocco and Tunisia. Incensed by this, ITPC MENA launched a regional campaign to secure affordable access to the drug in these countries.

Activism Results in Affordable Access to Dolutegravir in Morocco

We urged the Ministry of Health in Morocco to use its right to issue a compulsory license. This would lift the patent protection on the drug, open the door to importing generic versions of the drug, and thus open up market competition and force a reduction in price. Since the launch of its campaign at the end of 2015, ITPC MENA and partner organizations have engaged in intensive advocacy and dialogue with the company. We had several meetings with the Ministry of Health in Morocco, supported by a backdrop of media scrutiny and increased public awareness.

In April 2016, ViiV Healthcare finally announced that its voluntary license would be expanded to Morocco.
ITPC South Asia’s Story: An Example of Community Activism

As a result of our advocacy work in India, the third-line regimen dolutegravir is finally registered, and a generic version is now available on the Indian market. After decades on HIV treatment, second-line regimens are beginning to fail for many people in India and until now there simply wasn’t another option available.

New Drugs Registered and Available
Working with the Delhi Network of Positive People and Médecins sans Frontières Access Campaign, we urged the Drug Control General of India to register the drug dolutegravir. Our campaign kicked off with a letter to the organization in March 2016. Because of our efforts, there is now a generic version of dolutegravir manufactured by Emcure, and launched in February 2017. “This is something we are proud of,” explained Loon Gangte. “Without this treatment people who fail second-line regimens wouldn’t have another option.”

ITPC South Asia also successfully lobbied for a waiver of an unnecessary clinical trial on the HCV drug daclatasvir, so that drug is now also available on the Indian market.

ITPC LATCA’s Story: An Example of Community Activism

We set out to address the anomaly of a decreasing HIV/AIDS budget against the reality of an increase in the number of people living with HIV in Guatemala. We conducted a study of legal and intellectual property barriers and how they affect the acquisition of, and access to, antiretroviral drugs. Based on procurement projections for the single and fixed-dose drug lopinavir/ritonavir (200 mg/50 mg tablet) our study estimated the cost of treatment at almost US$2.5 million which would represent 41% of the entire annual budget for all antiretroviral drugs. If the same quantity and quality of generic lopinavir/ritonavir was bought at prices available on the international market the government could save almost US$1.7 million. These savings could be used to extend coverage of treatment to more people who need it.

Potential Savings of US$1.7 million for Overstretched HIV Budget

In partnership with the Intellectual Property Technical Panel, we urged the government to declare lopinavir/ritonavir of high therapeutic value and non-commercial use. Such categorization would enable the government to secure cheaper access to this essential medicine. In September 2016, we presented the Constitutional President of the Republic of Guatemala with a Memorial to highlight the consequences of ignoring our appeal.
COMMUNITY MONITORING OF HIV TREATMENT SERVICES

ITPC believes that community-driven monitoring of HIV treatment services at national and regional levels is critical to securing access to optimal HIV treatment.

ITPC Seeks to Upscale Community Monitoring of HIV Services
Community-based monitoring offers the potential of increasing domestic oversight and advocacy to demand improvements to HIV treatment, particularly as it affects key populations. While affected communities make up most users of HIV treatment services, they often lack the necessary capacity and information they need to participate meaningfully in decision-making.

ITPC’s pioneering treatment observatories in West Africa and Latin America, shows that our work successfully empowers people to seek and demand better health and justice. In 2016, ITPC submitted major new proposals to facilitate the expansion of community treatment observatories.

ITPC Secures Global Fund Grant
In December 2016, our application to the Global Fund for a Regional Community Treatment Observatory in West Africa was granted. The goal of the project is to increase access to treatment in the 11 West African countries: Benin, Côte d’Ivoire, Gambia, Ghana, Guinea, Guinea Bissau, Liberia, Mali, Senegal, Sierra Leone and Togo. To head up the Global Fund project we successfully recruited experienced HIV treatment leader, Alain Manouan. After completing the intense pre-grant processes throughout 2016, the Global Fund approved our three-year grant from January 2017 to December 2019.

ITPC and ITPC West Africa hosted a regional pre-grant implementation planning workshop with representatives from all 11 focus countries. It was the first time all country partners came together to plan the execution of the project, since the regional consultation that informed the original concept note in 2015.

Under this grant, key activities at the country level will include support to establish and strengthen national Community Treatment Observatories. These Observatories will regularly collect and analyze data to improve access to services across the continuum of HIV prevention, care and treatment.

ITPC and partners from the eleven countries meet to make plans for community monitoring.
Andrey Calls Out Treatment Stock-out and Gets His Pills

Andrey from the Altai Region, in Russia, was unable to get his antiretroviral drugs. There was a change in the way the regional authority procured antiretroviral drugs, which led to a drug shortage. Andrey was one of the patients who were denied access to their HIV treatment. He reported the problem by filling in a form on pereboi.ru – a website set up by ITPCru for people to report stock outs of antiretroviral drugs, and CD4 and viral load tests.

On getting the alert, ITPCru contacted Andrey and helped him to raise the issue in the media, and to pressurize the local authorities. Because of the pressure, the region allocated the extra money needed to purchase antiretroviral drugs, and Andrey got his pills.

Andrey's report was one of over 300 messages about treatment stock-outs on the website in 2016. Each message was responded to by ITPCru, with every person receiving some support to help address the issue. Most people who reported stock outs, got the pills they needed.

See the video about ITPC's model of community monitoring of HIV treatment services.

In addition, data around important policy areas, such as the adoption and implementation of the WHO 2015 Guidelines will be collected. This national level data will be used to inform advocacy priorities, strategies and activities at national and regional levels. It will enable people living with HIV to engage in opportunities to influence the HIV treatment agenda, through the development of policy briefs and funding proposals, and the revision of National Strategic Plans.

At the regional level, national data from the observatories will be compiled and analyzed to track progress, and it will be compared with other African regions. The aggregated data will be used to inform regional advocacy.
Financing for Key Population HIV and TB Services

In 2016, we completed a project that aimed to increase financing for HIV and TB health services for key populations. Led by AIDS and Rights Alliance for Southern Africa (ARASA), the project was supported by a special grant from the Robert Carr civil society Networks Fund and the Global Fund. The project successfully strengthened the capacity of leaders and activists of 11 networks of key populations and people living with HIV in Botswana, Malawi and Tanzania.

As a result of the project, country partners secured better representation for inadequately served populations on national decision-making bodies. This meant key population leaders were in a better position to secure improved allocations of national budgets for the communities they represent.

Better Representation Led to More Funds for Key Population Health Programs

During the two years of the project significant achievements were secured in all three countries:

**BOTSWANA**

Key milestones include:
- A 15% increase in the government health budget;
- The network of people living with HIV became a Sub-Recipient of the Global Fund grant, and key population organizations became Sub-Sub-Recipients;
- An increase from zero to US$2.9 million allocation for key populations in the three-year Global Fund grant, channeled through BONELA as a Sub-Recipient;
- The allocation of around US$680,000 for key population programming under PEPFAR.

**TANZANIA**

Key milestones include:
- Involvement in the drafting of the governance manual of the Country Coordinating Mechanism (CCM). This enabled the partners to secure a Full Member and Alternate Member to directly represent key populations;
- Direct representation of key populations on the CCM for the first time;
- US$800,000 allocated to key population programming under the Global Fund grant.

**MALAWI**

Key milestones include:
- Establishment of the ‘Female Sex Workers’ Association’, a sex worker led and independent organization;
- Secured US$1.2 million by a key population group to implement the MSM module of the Global Fund grant;
- Sex workers represented on the CCM for the first time.
Financing for Key Population HIV and TB Services

See the video about the impact of the project
Strengthened Capacity of Key Populations to Demand Health Services

In 2016, ITPC led participatory communications with program partners in Botswana and Malawi, to help strengthen their capacity to hold decision makers to account. Participatory communication is an extension of ITPC’s rights-based approach.

“With empirical data you can question the data. Here you have real people. The stories have a human face.”

It enables communities to create visual communications to bring about the change that they want to see. In partnership with the NGO WITNESS, we provided ‘Video for Change’ training to members of eight key population networks and NGOs. The intensive training lasted three days in both countries, and included follow-up support.

Participants were trained in the core aspects of making an advocacy film, including filming and the development of storyboards. Taking an average across all six elements they received training in, participants doubled their levels of knowledge, skills and confidence. All groups went on to make an advocacy film. When reflecting on the exercise afterwards partners felt their films would work well with their intended audiences.

“To advocate for policy change we need evidence, and the film provides that,” explained Thatayolthe Junior Molefe from Men for Health and Gender Equality in Botswana. “Action speaks louder than words. So, watching the video might change people’s minds on how they see MSM.” Gift Trapence, CEDEP Director in Malawi, echoed these words when he said, “It will work with our decision makers because it is based on evidence....With empirical data you can question the data. Here you have real people. The stories have a human face.”
STRENGTHEN PARTNERSHIPS AND INFLUENCE

Strengthen and Explore Linkages with Allied Social Justice Movements, and Influence Policy

NEW COLLABORATIONS IN 2016

In 2016, we continued to forge new partnerships in our efforts to strengthen advocacy and bring the community perspective to a wide range of policy makers and implementers.

Bactrin Kilingo (ITPC) speaking at session hosted by UNITAID and MSF at International AIDS Conference, Durban.
International AIDS Society – Researching Community Perspectives

Working with International AIDS Society (IAS), ITPC and ARASA researched community perceptions of differentiated models of antiretroviral therapy (ART) delivery. The IAS is working on a two-year project to support the implementation of responsive and appropriate ART delivery. By providing such models of care, the health system can refocus resources to those most in need. The underlying principle of Differentiated Care, is to provide ART delivery in a way that acknowledges diversity and preferences in how people living with HIV access ART services. To support IAS, and working with ARASA, we conducted research to: understand community perceptions, as well as challenges around differentiated models of ART delivery; and gauge the ‘readiness’ of networks and communities to transition to differentiated models of ART delivery.

We aim to support a longer-term goal of promoting community demand of patient-centered models of care amongst national governments in Africa. Moving into 2017, ITPC will lead a second phase of the project, mobilizing communities to implement differentiated models of ART delivery.

Supporting Learning with ICAP at Columbia University

Recognizing the need to share program implementation solutions related to the rapid scale up of viral load services, ICAP at Columbia convened a multi-day workshop. ITPC was invited to provide the community perspective alongside other community leaders at “Reaching the Third 90: Implementing High Quality Viral Load Monitoring at Scale”. The workshop in Mbabane, Swaziland, brought together more than 100 program planners, implementers, laboratorians, and representatives of people living with HIV, to advance the scale-up of viral load services. The meeting aimed ultimately to improve the quality of HIV treatment – by providing the opportunity for expert dialogue and practical south-to-south exchange. ITPC used the opportunity to highlight the importance of community-led initiatives like the ‘Be Healthy – Know your Viral Load’.
A New Wider Collaboration of Existing Partnerships

In 2016, we joined a new process to strengthen the advocacy impact of organizations representing and supporting networks of people living with HIV and key populations working on the HIV response. The collaboration brings together partners of three existing collaborations: 1) Free Space Process Platform - ten international networking organizations with a focus on HIV/AIDS and international civil society support; 2) PITCH - a strategic partnership between Aidsfonds, the International HIV/AIDS Alliance and the Dutch Ministry of Foreign Affairs; and 3) STOP AIDS Alliance - a group of donors, multilateral agencies and academic organizations.

The new expanded grouping of the three existing partnerships brings the added value of the partners to a larger audience. It will help us recognize and benefit from each other’s comparative advantages, boosting efficiency, improving information sharing, building trust and fostering greater solidarity. One of our ultimate aims of working together is to improve our combined advocacy clout, benefitting from the presence of the Stop AIDS Alliance partners in key policy hubs.

Stronger Advocacy Partnership

We also entered into a new and stronger partnership with the Bridging the Gaps alliance members to strengthen our combined voice to advocate on our shared goals. In 2016, we agreed on a framework for developing a joint advocacy strategy on four priority issues: 1) sustainable funding; 2) meaningful engagement; 3) violence and repressive environments; and 4) the shrinking civil society space for key populations.
United Nations High Level Panel on Access to Medicines

The ITPC-led consortium working on intellectual property, actively engaged during the consultation process leading to the publication of the UN High Level Panel on Access to Medicines Report. Consortium members contributed seven submissions to the Panel. Individuals from consortium members, ITPC, I-MAK, ABIA and FGEP contributed to the two dialogues organized by the Panel in London and Johannesburg, in March 2016. Following the launch of the report, ITPC and its regional networks have referenced the publication and helped disseminate it to relevant stakeholders at national level. Together with our partners we are working to ensure that relevant institutions implement the report’s recommendations. For example, we coordinated a request, which was backed by 27 partners, to the WHO Executive Board. We urged the WHO Board to include the Panel’s recommendations as a specific agenda item in their January 2017 meeting.

UN High Level Meeting on Ending AIDS

In April and June 2016, ITPC global staff and regional coordinators from West Africa, Middle East and North Africa, and Latin America and the Caribbean were selected to represent civil society at the United Nations Assembly at the High-Level Meeting on Ending AIDS. Together with over 80 civil society organizations, ITPC expressed its profound dissatisfaction with the political declaration “On the Fast-Track to End the AIDS Epidemic,” which refused to give accreditation to 22 organizations representing LGBT, sex workers, youth and people who use drugs.

The declaration negotiation process has been marked with polarization of member states defending extreme positions based on political, religious and cultural values rather than science and evidence-based interventions. The UN used a “silence procedure” which allowed us, along with other activists, to lobby moderate member states to “break the silence” and reopen the negotiations of the political declaration. ITPC members worked closely with friendly country missions at the UN, and played a key role to moderate the position of the African countries bloc.

During the High-Level Meeting, ITPC and its partners contributed to civil society advocacy by lobbying to defend the use of TRIPS flexibilities in the final declaration to be adopted by member States. ITPC representatives spoke in various side events organized in parallel, and we contributed with content on intellectual property language in different briefing documents prepared by the Civil Society Task Force.
International AIDS Conference 2016, in Durban

At the International AIDS Conference (IAC) in July 2016, we had one clear message for delegates “Optimal Treatment is Not a Dream!” This was the topic of a Satellite Session hosted by ITPC with a strong line-up of experts and community representatives. We led, co-hosted and participated in numerous sessions to keep this message front and center. On every day of the conference, ITPC had a role hosting, or presenting at, satellite sessions and skills-building workshops, leading and supporting protest actions, and leading the Treatment Networking Zone. ITPC also co-hosted and participated in side sessions with the World Health Organization (WHO), Médecins Sans Frontières (MSF) and others. As a result, ITPC, and our two campaigns were featured prominently in IAC’s conference video.

Read more about our activities at the conference.
GLOBAL INFLUENCE AND VISIBILITY

In 2016, ITPC participated in meetings and conferences to present community-based research, influence international policy and amplify the voices of the people we represent.

Over the next two pages, we describe three of the most significant events for us during the year. We also show in the table here the policy fora and process meetings we participated in to ensure that the community perspective is heard.
ITPC continued to represent excellent value for money in 2016. Over the year, we spent 62% of our overall budget pursuing our strategic objective 1 - to mobilize demand for optimal HIV treatment. We spent 32% of our budget on objective 2 - to hold decision makers to account with an emphasis on health systems and challenging unfair trade barriers. Given our commitment to being lean and flexible, only 6% of our funds was spent on operations (administration, finance, development and communications).

Out of the total spent on programs in 2016, we transferred over half (54%) in grants to regional networks and consortium partners. The remaining 46% was spent on global programs which contributed to: coordinating community research and regional campaigns, providing training and technical support, consulting partners and engaging in advocacy at regional and international levels.

94 CENTS of every dollar goes to programs

VALUE FOR MONEY

ITPC EXPENSES

Operations

Demanding Accountability

Mobilizing Demand

62%

6%

32%
DONORS

We are very grateful to our progressive and dedicated donors who continue to believe in our vision and make our work possible. In 2016, ITPC benefited from the generous support of:

- Aidsfonds
- Dutch Ministry of Foreign Affairs - Bridging the Gaps II Alliance
- Levi Strauss Foundation
- Médecins sans Frontières - Belgium
- Open Society Foundations
- Robert Carr civil society Networks Fund
- The Global Fund to Fight AIDS, Tuberculosis and Malaria
- UNITAID
- ViiV Healthcare

THANK YOU

ITPC GLOBAL ADVISORY BOARD

We would like to thank our Global Advisory Board for their continued support and guidance.

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Nompumelelo (Mpumi) Gumede
South Africa

Polokoetsile Pedro Motau
Gaborone, Botswana

Ben Plumley
United States (until November 2016)

John Rock
Sydney, Australia

ITPC GLOBAL STAFF

Without the dedication and abilities of our global team we wouldn't be able to achieve the goals we set ourselves.

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Educating, mobilizing and supporting communities to address their priorities delivered clear, sustainable results in 2016.

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