About ITPC

• Birthed in South Africa in 2003 when < 500,000 people had access to ART given that it cost more than $10,000 per person per year.
• **Mission**: To enable people in need to access *optimal* treatment.

Global community voice on treatment access!
Selected Partners & Donors

- People living with HIV orgs. across the globe (individuals, CBOs etc.)
- ARASA (*DSD, Treatment Education and Advocacy*)
- Linkages/FHI 360 (*PrEP, Treatment Education*)
- Global Fund (*Community Monitoring and Advocacy*)
- IAS (*DSD, Community Monitoring, Treatment Education and Advocacy*)
- ICAP (*DSD, Treatment Education and Advocacy*)
- M.A.C AIDS Foundation (*PrEP, Treatment Education and Advocacy*)
- MSF (*Demand Generation, RVLT and Advocacy*)
- Pharmaceutical Industry (*Community Advisory Boards – CABs, global and regional and national Treatment Education*)
- Unitaid & Project Consortium Partners  (*IP & A2M interventions*)
- West African Pharmaceutical Association (WAPMA)- Civil Society Member
Global health and impact on individual people’s life:

What does delayed access really mean?

Solange Baptiste
Executive Director
International Treatment Preparedness Coalition
July 24, 2018
Access Discussions

Health System
Lived Realities

• “Global Policy, Local Disconnects”
• “Routine for You, but not for Me”
• “What you don’t know can hurt you!”
• Missing the Target (Reports 1-11)
COMMUNITY PERSPECTIVES

• **Community survey** of 12 countries on access to **viral load** testing. [2015]

• Rapid assessment on ‘readiness’ of patients and communities to advocate for **differentiated models of ART delivery**. [2016]

• Three (3)-day consultation with 75 **PLHIV leaders** from all CQUIN countries on barriers to DSD scale up and RVLT access. [2017]

• A five (5)-day intensive **community workshop on RVLT/DSD** with 30 activists across 12 countries from seven (7) networks of people living with HIV in **Asia and Africa**. [2017]

• **Baseline results** on RVLT access from Global Fund project in 11 West African countries. [2017]

• Preliminary findings from **Global Treatment Survey** in 15 countries. [2018 On-going]

• **15 years of experience** across 9 Regional ITPC Networks, Global & Regional CABs, Global Community Consultation on PrEP [2017], Community Global IP Summit [2017] and over 4000 CBOs.
INSIGHTS ON:

• Viral Load Testing

• Who we are leaving behind

• HIV Self-Testing

• HIV Surveillance
INSIGHTS on Viral Load Testing

GOVERNMENT POLICY WITH NO IMPLEMENTATION
- Two thirds of the 12 countries (8) surveyed, reported the existence of a government policy that mandates providers to conduct routine viral load testing as part of HIV treatment monitoring but only 3 countries were reported to have routine viral load testing.

LOW HEALTH CARE PROVIDER INITIATIVE
- Almost 60% of countries were reported to have viral load tests that are patient driven (not from health care providers).

NOT FREE
- Greater than half of the countries surveyed reported that patients accessing VL are asked to pay for the service.
- Most countries reported that patients also have to pay for genotype testing if available.

UNCLEAR HOW TO GET A TEST
- The steps involved in viral load testing vary widely within and among countries and remain unclear.

INCONSISTENT RESULT TURNAROUND TIME
- The time it takes to receive VLT results varies by country ranging from 1 to 5 weeks to several months.
- All countries report stock outs of test kits and/or commodities related to VL testing within the past 12 months.
- Surveys report that countries suffer from delays in results due to staff leave, and stock outs.
- 11 out 12 countries do not use electronic or mobile technologies to relay readiness of results to patients.
INSIGHTS on Viral Load Testing

• VL testing is often not routine. It is scarce, and expensive.

• VL load availability is only part of the equation – it must be implemented, and implemented with treatment education and adherence support:
  • Patients need to and have a right to understand what their viral load tests mean
  • Poor support (counseling, social/community/peer) will likely have implications for adherence and ultimately resistance

• Confusion among health care workers and recipients of care about:
  • use of and need for CD4, VL,
  • meaning of detectable vs suppression,
  • switching when your treatment is working (do people have a choice?)
  • what to do when pregnant etc.
INSIGHTS on Viral Load Testing

- Access still largely concentrated in major urban centers, with patients facing long delays in obtaining results.
- Communities need more machines and in non-urban centers for communities (example of project OPP-ERA and access to viral load in community-based organizations in Burundi) and need faster access to innovation (e.g. DBS).
- Some countries still overpay for tests despite initiatives in place (such as Roche, UNAIDS, Unitaid, PEPFAR and GF joint program giving access to US$9.40 VL tests to 77 countries).
  - Partners should provide clear guidance and do follow up to ensure effective access to these prices for countries (https://aidsfree.usaid.gov/sites/default/files/roche_gai.pdf)
90% of all PLWH will know their HIV status

90% of all PLWH who know their status will receive sustained antiretroviral therapy

90% of all PLWH receiving antiretroviral therapy will have durable suppression

90%

Know status

81% On ART

73% VS

526 days!

@ITPCglobal | www.itpcglobal.org | #TreatPeopleRight
90% Know status
81% On ART
73% VS
HIV is estimated to be the number one cause of death among adolescents (10-19) in Africa.

Perinatally infected adolescents (fatigue, manipulation of meds)

DTG does not make a person adherent!
INSIGHTS on HIVST

• Most communities of PLHIV (partners, families, friends impact) and those in high risk contexts don’t know about self-testing.

• Global view is that uptake is rapid but unequal depending on regions: e.g. in MENA, HIVST still totally absent from testing strategies
  • Regulatory barriers
  • Low investment from international donors in MICs
  • Prohibitive prices: current prices prevent use of domestic funding in HIVST and prevents demand creation especially in small markets

• Vicious circle: prohibitive prices => low demand => small volumes => continuation of high prices

• Need for companies to work on lowering prices.

• HIVST and RDT use the same technology, HIVST might cost more to produce due to individual packaging but nothing can explain such huge price difference (US$ 0.50 for RDTs, between US$22 and $48 for HIVST in private sector, $7.50 and $15 in public sector)
INSIGHTS on HIVST

• “Need to change from the donor funding towards a more sustainable private market”

• Access to communities.
  • In many countries, key populations are still criminalized and in need of targeted, complementary testing strategies

• HIVST is one of them as it provides total confidentiality and anonymity.

• If we want HIVST to achieve global health impact it needs to be made available through community based approaches and for free (Southern African through STAR Initiative)
INSIGHTS Surveillance

• IDEAL: Once impact has been demonstrated, implement
• Communities rely on governments for robust surveillance
• It is not happening
• Pilotitis leads to death
• Notification vs surveillance (policing)
• Trust issues – data privacy, very different contexts
• TB in India – pharmacy stockout
• Stigma
Countries or Markets ≠ PLHIV
Tool is not the End!
RAPID ACCESS TO NEW TECHNOLOGY

• Not always rapid
• Not always reaching the people who need the innovation
• Not always used in the best way, appropriate uptake (systemic, policy and regulatory issues)
• Not always used sustainably
• Product going into a system not to a “market” which is often weak!
We Advocate for...

- Test and offer (respect human rights)
- Test and offer ALL (Governments & KPs)
- RVLTr (non-urban)
- A focus on children and adolescents
- DSD – including communities, regulatory issues, multi-month prescriptions
- Community Monitoring (using proxy indicators) on Resistance
  - Sub-optimal quality in service delivery is predictive of drug resistance
We Advocate for...

- Treatment education investments
- Adequate **funding** for diagnostics (Vietnam case)
- **Affordability** of diagnostics: GF teeth, patent offices waking up, law reform, parliamentarians understanding TRIPS flexibilities and having the political gumption to use it, lower prices!
- **Scale-up metrics** that are not just about volumes/# but also **quality** of service
- Clear **country guidance on how** to switch
- **Funding for innovative community approaches** to service delivery
- **Sustainable response** ($, demand creation)