

You Can't Demand What You Don't Know!

A model for community-driven demand creation
for routine viral load testing

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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.

#TreatPeopleRight

#MakeMedicinesAffordable

#WatchWhatMatters

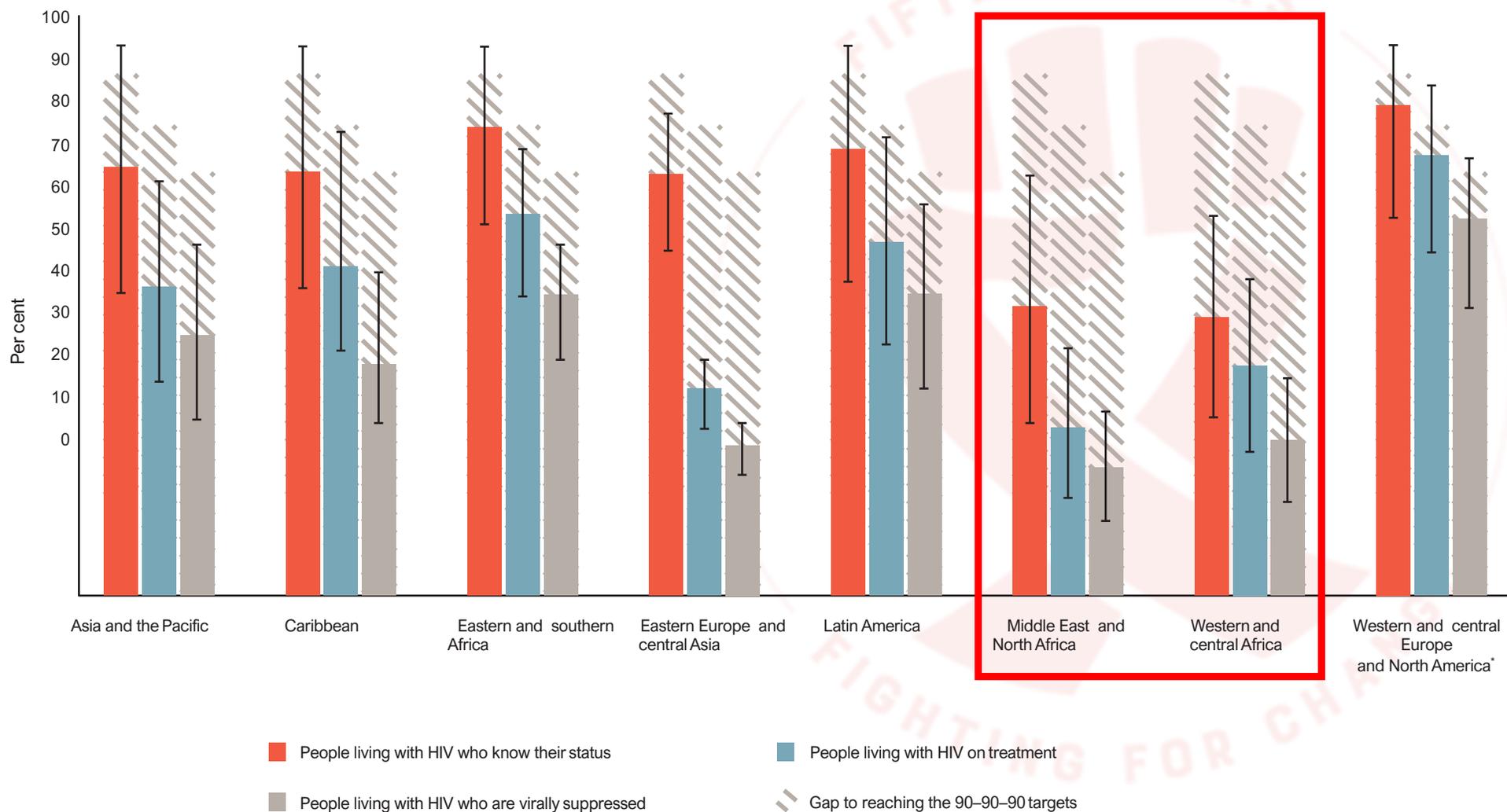
*Global community voice
on treatment access!*

The Problem



Latest Global Statistics on Viral Suppression Rates (UNAIDS)

Knowledge of HIV status, treatment coverage and viral load suppression among people living with HIV, 2017¹



* Cascade for western and central Europe and North America region is for 2016.

Source: UNAIDS special analysis, 2018; see annex on methods for more details.

Countries that have Achieved the 90–90–90 Targets/Near

	First 90	Second 90	Third 90	100% N YE	Viral load suppression among all people living with HIV
Achieved (90% or greater)	Czechia Eswatini Greece Lithuania Malawi Namibia Portugal Romania Serbia Singapore South Africa Thailand	Algeria Austria Botswana Burundi Cambodia Comoros Congo Democratic Republic of the Congo Denmark Eswatini Ethiopia Italy Lesotho Luxembourg Maldives Mauritania Mexico Mozambique Namibia Netherlands Niger Rwanda Saudi Arabia Zimbabwe	Botswana ● Brazil Cambodia Chile Czechia Denmark Germany Hungary Ireland Kuwait Lao People's Democratic Republic Lesotho ● Luxembourg Malaysia Montenegro Myanmar Nepal Netherlands Pakistan Portugal Saudi Arabia Serbia Singapore Slovenia Sri Lanka	Achieved (73% or greater)	Botswana Cambodia Denmark Eswatini Namibia Netherlands
Nearly achieved (85–89%)	Austria Botswana Bulgaria Burkina Faso Cambodia Denmark Germany Ireland Italy Luxembourg Netherlands Slovakia Zimbabwe	Argentina Croatia Germany Kuwait Mongolia Nigeria Portugal Singapore Slovakia Togo Uganda	Armenia Croatia Eswatini ● Georgia Honduras Malawi ● Namibia ● Suriname Thailand The former Yugoslav Republic of Macedonia Viet Nam	Nearly achieved (65–72%)	Germany Ireland Italy Lesotho Luxembourg Portugal Singapore

* Data are for 2017, except as follows. 2016: Austria, Czechia, Denmark, Germany, Italy, Luxembourg, Netherlands, Portugal, Serbia, Slovenia. 2015: Croatia and Hungary. Estimates are for citizens of the country only for Kuwait and Saudi Arabia.

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Source: UNAIDS special analysis, 2018; see annex on methods for more details.

COMMUNITY PERSPECTIVES FROM ITPC's WORK

- **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 (2015)

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

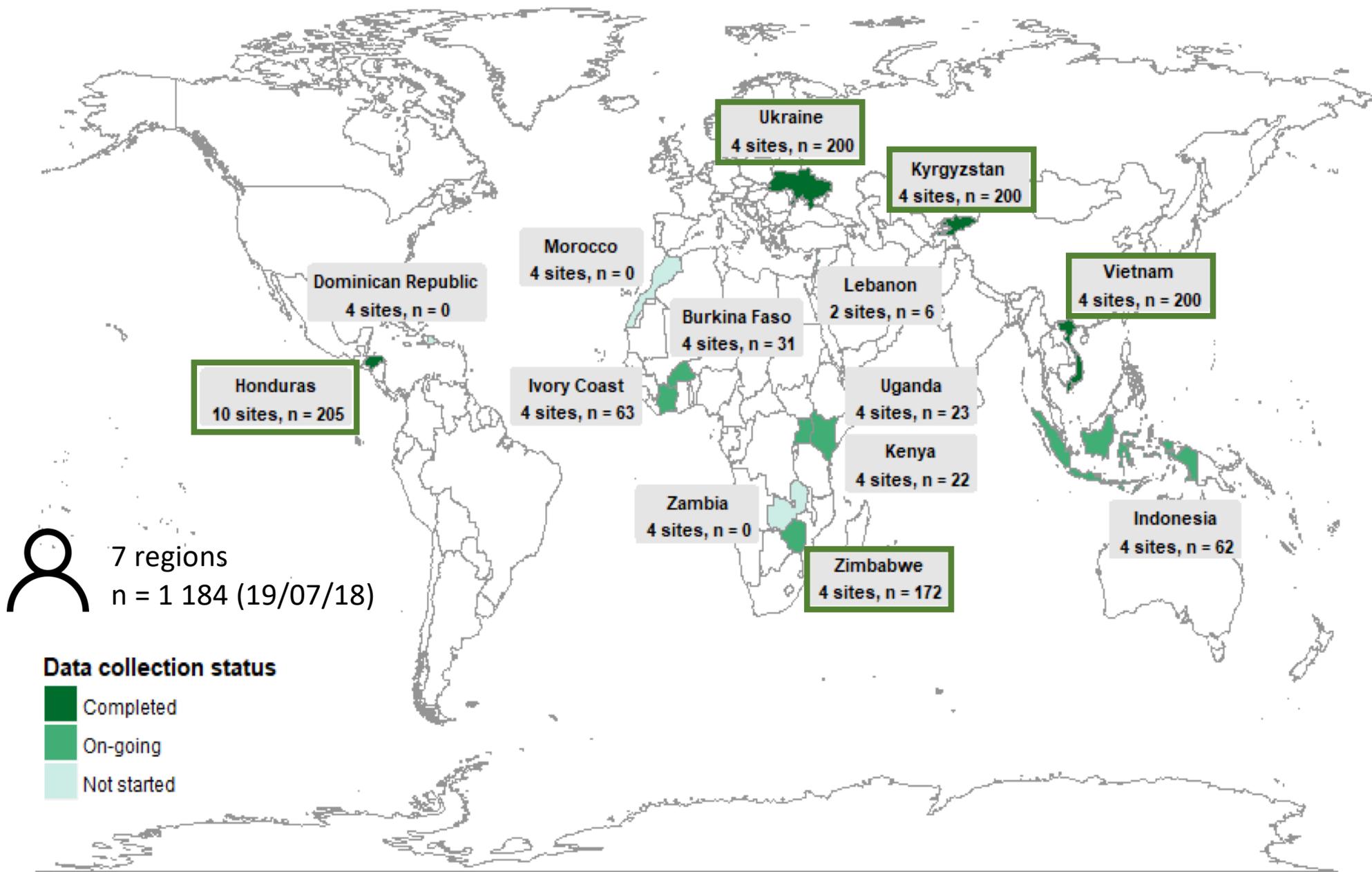
- The time it takes to receive VLT results varies by country ranging from 1 to 5 weeks to several months
- **All countries report stock outs of test kits and/or commodities related to VL testing within the past 12 months**
- Surveys report that countries suffer from delays in results due to staff leave, 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 (2015)

- 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 (1000, 200, U=U)

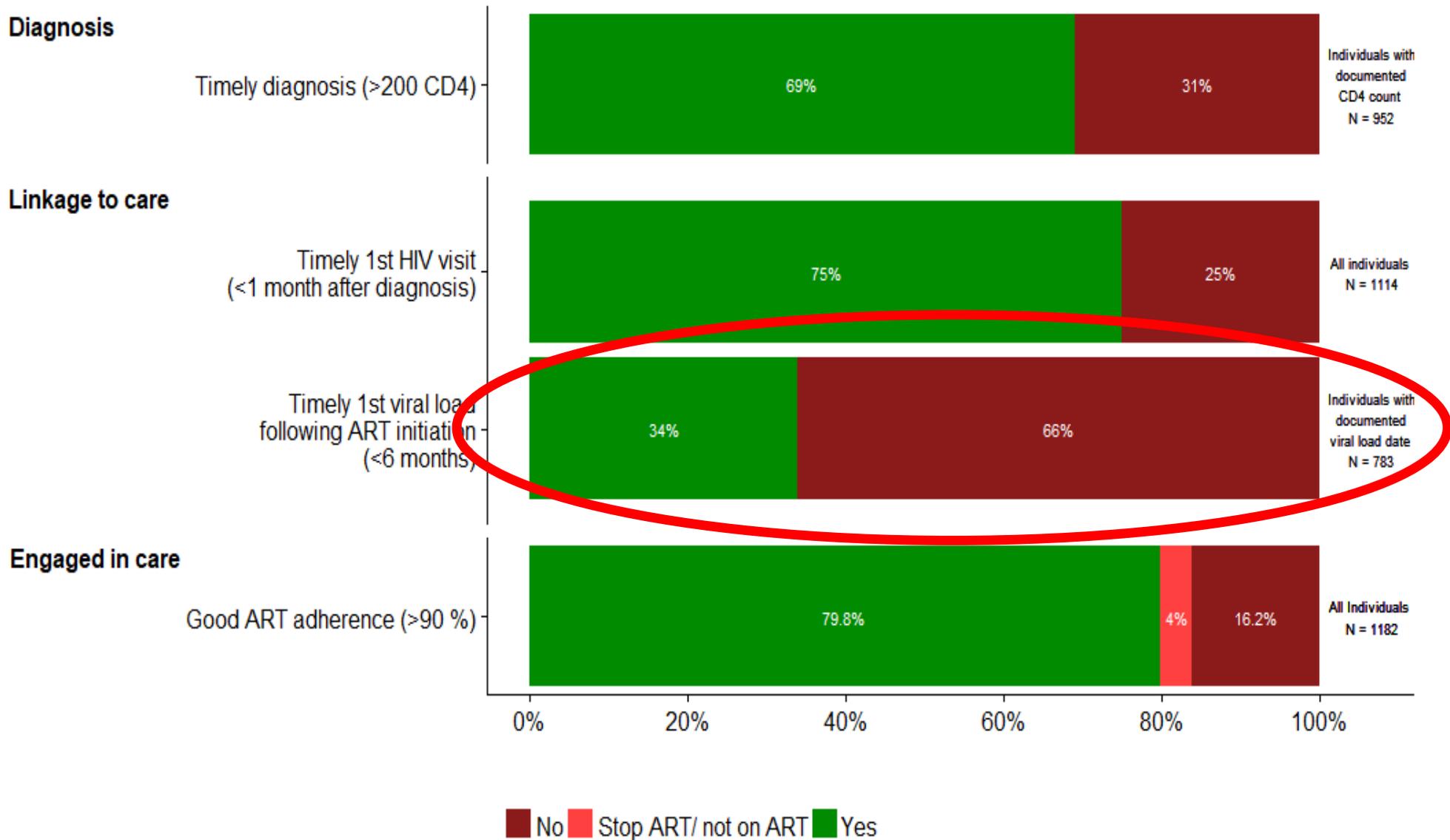
INSIGHTS on Viral Load Testing (2015)

- 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)



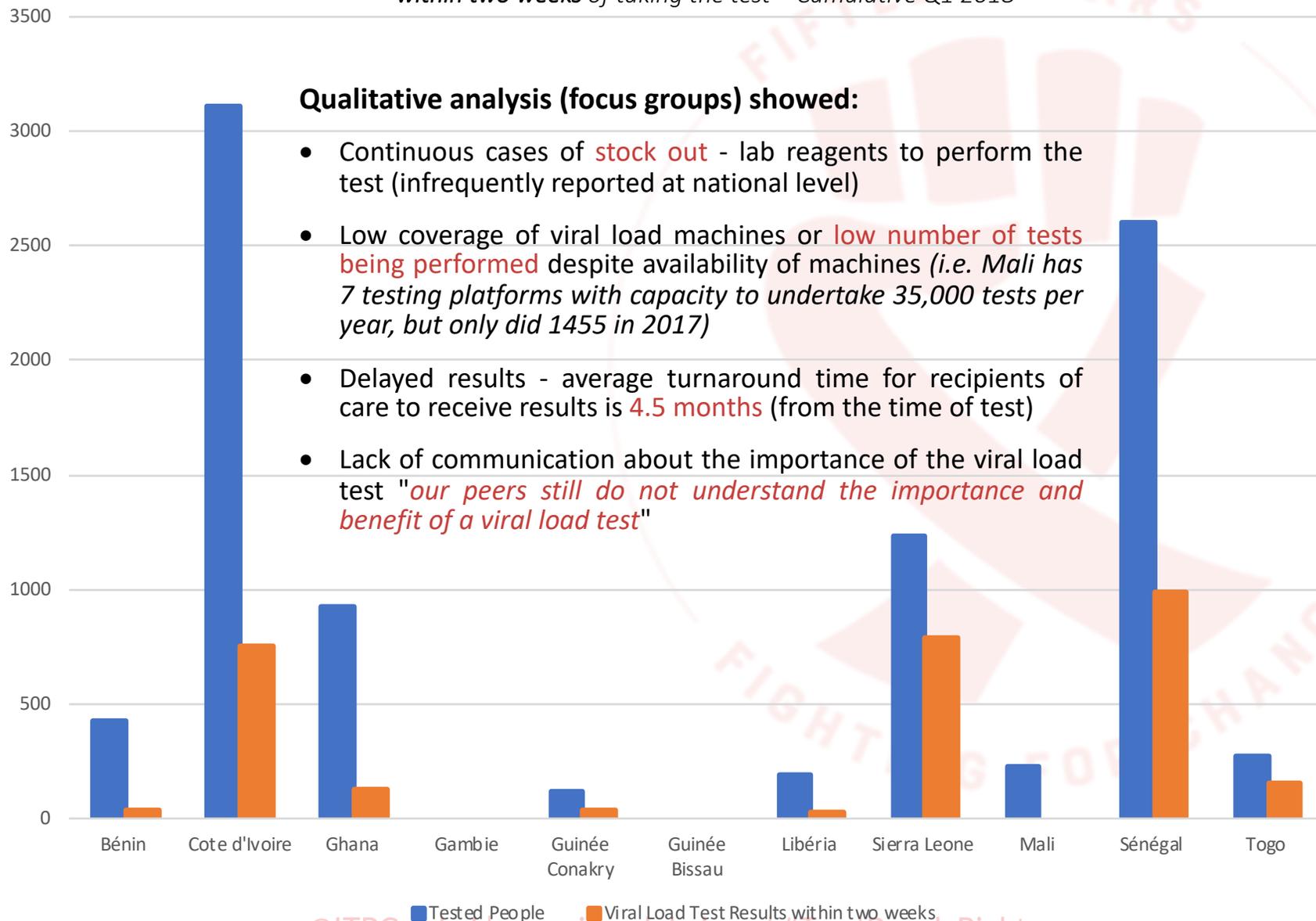
“Assessing Access to Quality HIV/AIDS Treatment: Achievements and Remaining Challenges”
ITPC Global Survey 2017-2018

Timely 1st Viral Load After ART Start



Regional Community Treatment Observatory Data on Viral Load Test Result Turnaround Time in West Africa

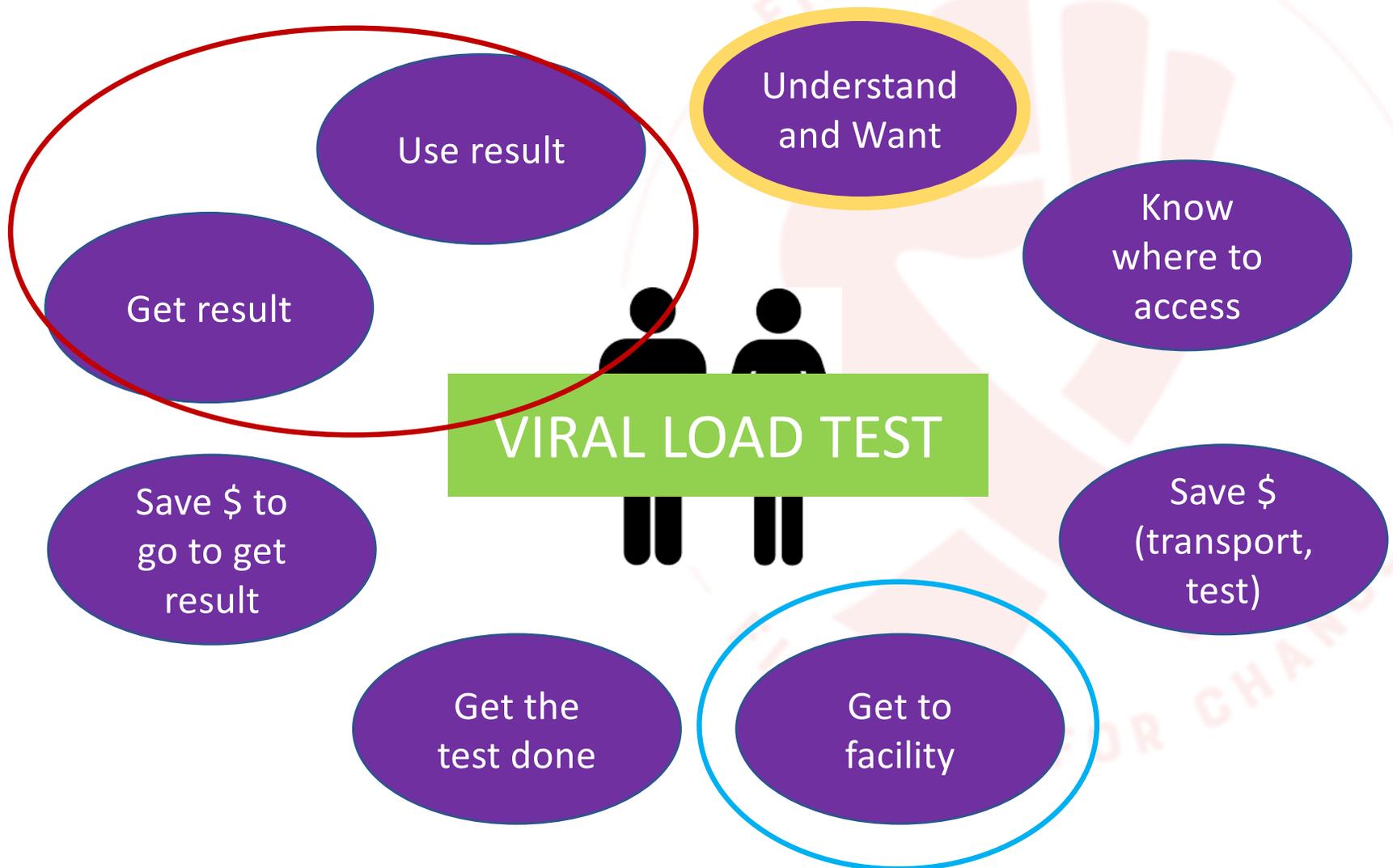
Number of PLHIV that have *done a viral load test* compared with the Number of PLHIV that *received their viral load test result within two weeks* of taking the test – Cumulative Q1 2018



Qualitative analysis (focus groups) showed:

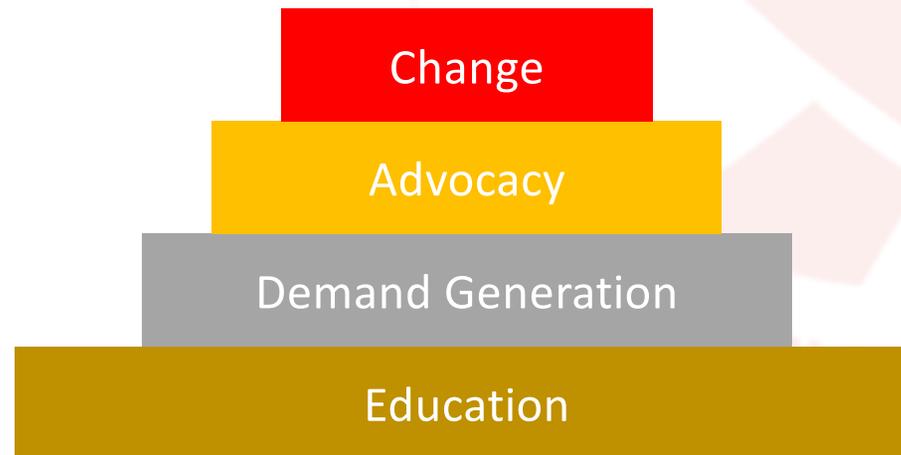
- Continuous cases of **stock out** - lab reagents to perform the test (infrequently reported at national level)
- Low coverage of viral load machines or **low number of tests being performed** despite availability of machines (*i.e. Mali has 7 testing platforms with capacity to undertake 35,000 tests per year, but only did 1455 in 2017*)
- Delayed results - average turnaround time for recipients of care to receive results is **4.5 months** (from the time of test)
- Lack of communication about the importance of the viral load test "*our peers still do not understand the importance and benefit of a viral load test*"

What VL testing means for communities



DEMAND CREATION

The bedrock of ALL demand creation is EDUCATION (knowledge building).



Perspectives

*“We are thinking now that people are taking blood to make money because I have had HIV for 18 years now, and had my blood taken 3 times and **never** gotten a result for my viral load test. We have no clue what is going on!”*

Leader in PHLIV Network, The Gambia.

*“I don’t know what you are talking about. Third line? The third line is the **graveyard!**”* **Leader in PHLIV Network, The Gambia.**

WE SHALL NEVER REACH THE 3RD 90 IF...

“...in the absence of the use of RVLT ... we will continue fighting HIV in the dark!”

An Adolescent LHIV from Jinja Uganda

“People’s blood samples are taken but people don’t know for what”

Sibongile from Western Cape South Africa

“...we travel from far to have blood drawn, go through the pain of a needle prick only to have the blood sample discarded because the lab has ran out of reagents...”

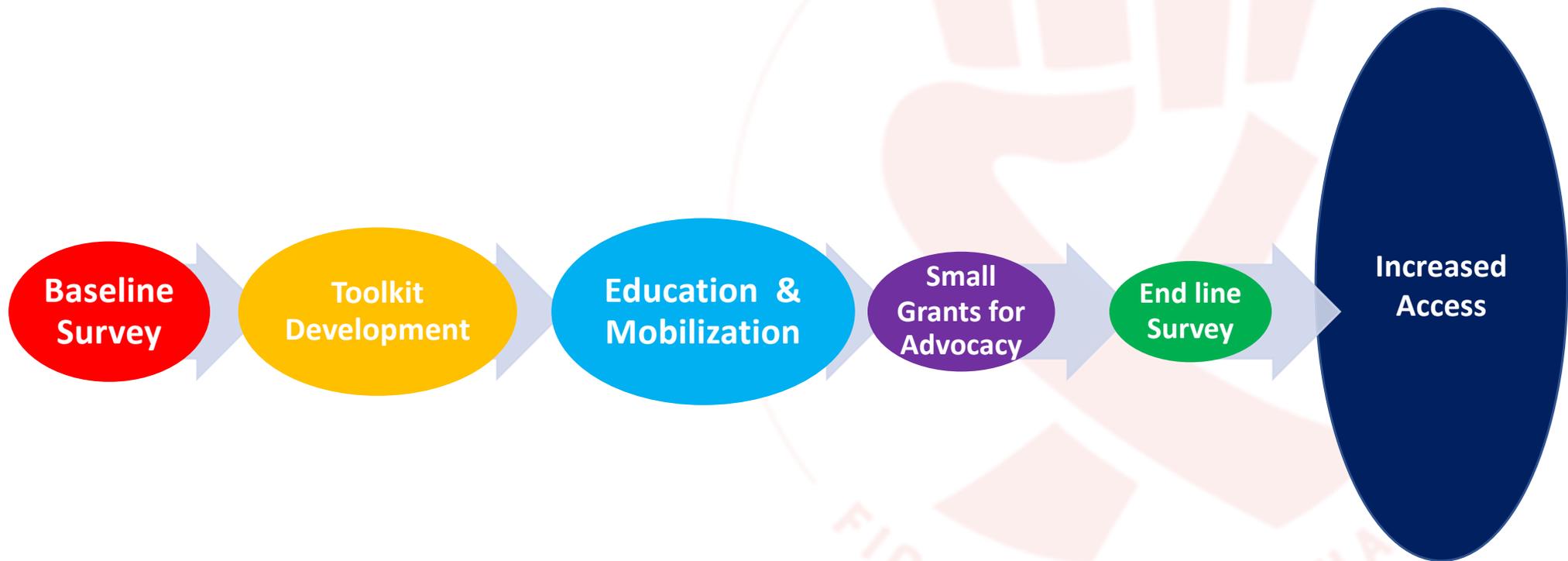
PLHIV mother of 3 from Mafikeng in Lesotho

THE POWER OF IGNORANCE & KNOWLEDGE

“In my experience, those knowledgeable on HIV Treatment are able to confidently interact with the health care workers and ask for things like VLT. What about those living in rural areas who aren’t knowledgeable? Due to their lack of knowledge they are not able to ask for these services”.

*Nellie a community health worker
from Blantyre in Malawi*

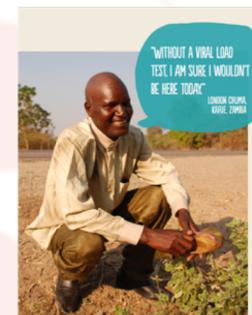
ITPC's Demand Creation Model



How to Create Demand for RVLT

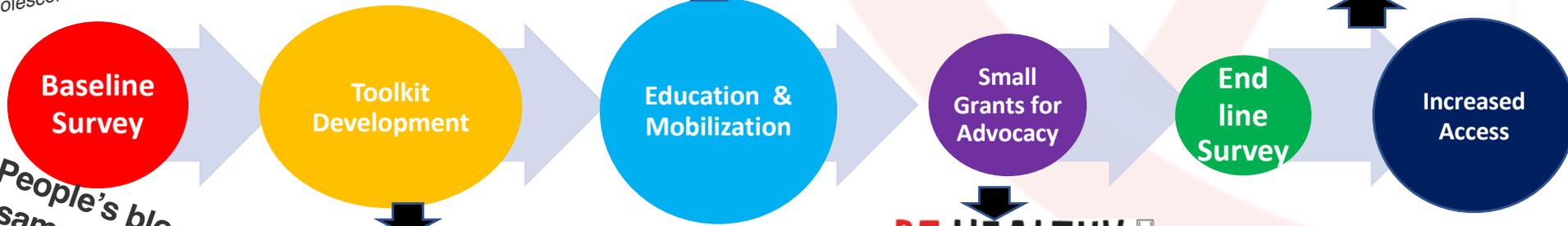
"...in the absence of the use of RVLT ... we will continue fighting HIV in the dark!"

An Adolescent LHIV from Jinja Uganda



"People's blood samples are taken but people don't know for what"

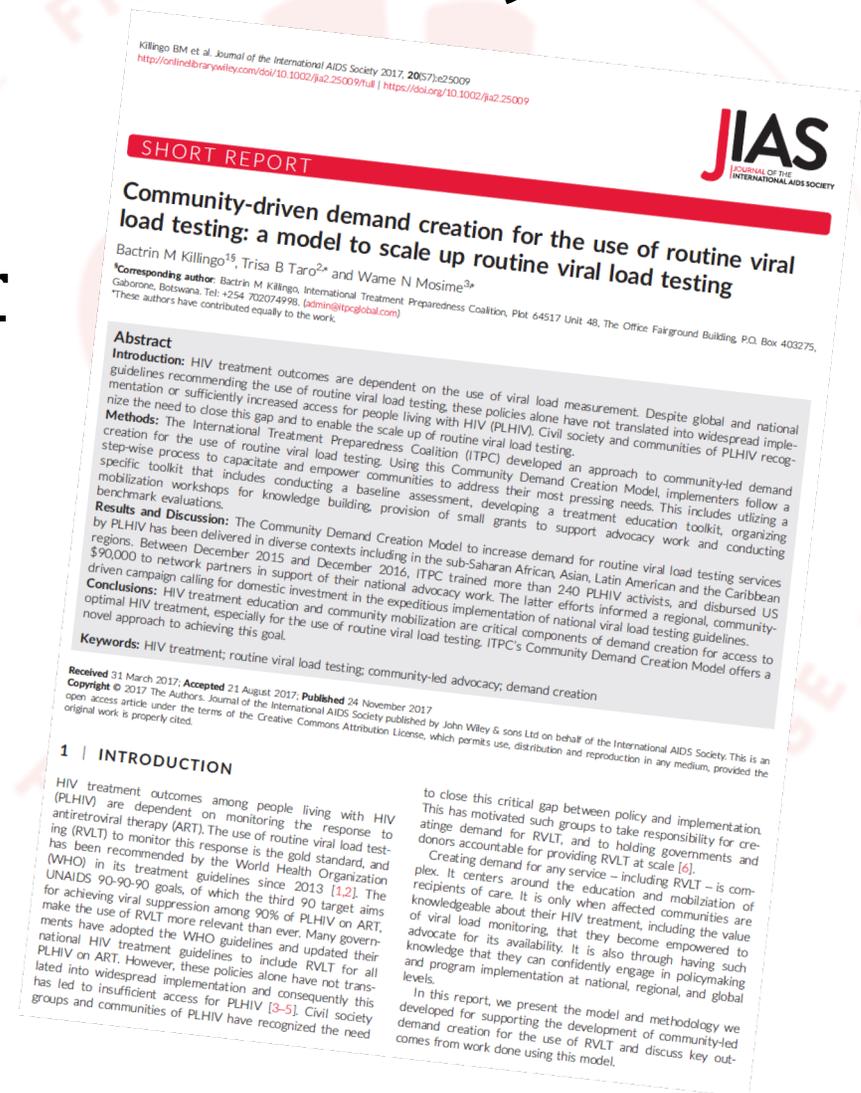
Sibongile from Western Cape South Africa



Demand Creation Model for RVLT of ITPC published in JIAS

Step-wise process to capacitate and empower communities to address their most pressing needs.

- Baseline assessment
- Tool (toolkit, video, etc.)
- Workshops for knowledge building
- Small grants to support advocacy work
- End-line evaluations.



DEMAND CREATION CAMPAIGNS

BE HEALTHY 
KNOW YOUR **VIRAL LOAD**

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 #KnowYourViralLoad

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www.knowyourviralload.org



Summary

- 90-90-90 = **463** days to go!!!!
- **VL is gold standard for knowing If your treatment is working**
- NOT READY to say less frequent VL, especially in the context of U=U and NTDs
 - Governments will this as an excuse to not scale RVL as they are already struggling.
- **HIV treatment education and community mobilization** are critical components of demand creation for access to optimal HIV treatment, especially for the use of routine viral load testing. ITPC's Community Demand Creation Model offers a novel approach to achieving this goal.
- Success must be measured by **getting to all** who need it (age band, population) – Rural populations, distance to health centers?
- Focus and investments must be on Health Systems Strengthening, **COMMUNITY** Systems Strengthening Approach
- See *Recipients of Care* as part of solution!



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