#WatchWhatMatters

About PLHIV Community Monitoring in West Africa

Session 6:Plenary Presentation | Fostering Engagement and Generating Demand

Solange Baptiste, Executive Director

Mbabane, Swaziland | June 26-29, 2018

Empowering Health for 15 years ICAP Columbia University Mailman School of Public Health

HIV LEARNING NETWORK
The CQUIN Project for Differentiated Service Delivery

The Science & Practice of SCALE-UP

Watch What Matters

ITPC INTERNATIONAL TREATMENT PREPAREDNESS COALITION

ITPC & Community Monitoring

- In 2003, ITPC was founded in South Africa on the principles of ***justice and accountability***
  - How could people in the global north have access to medicines while their counterparts in the global south were dying?
- ITPC is ***issue-based***
  - We use treatment access as an entry point to ensure the right to health.
- ITPC works with and for ***humans***
  - ITPC works to guarantee optimal treatment as a right for all people living with HIV, particularly for disenfranchised and marginalized populations.
- ITPC supports ***communities*** to define their own research questions, conduct their own research and carry out targeted evidence-informed advocacy

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

Key Relevant Publications

- *"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*


ITPC

JULY 2016

WHAT YOU DON'T KNOW CAN HURT YOU!

BASELINE SURVEY ON LEVEL OF AWARENESS & KNOWLEDGE OF ROUTINE VIRAL LOAD TESTING IN SUB-SAHARAN AFRICA

BACKGROUND

WHAT DID WE FIND?

CD4 STILL PREVAILS OVER VLT

AWARENESS IS NOT ENOUGH

THE MOST VULNERABLE ARE NOT BEING REACHED

FIGURE 1. AWARENESS & KNOWLEDGE OF RVLT IN 8 SUB-SAHARAN AFRICAN COUNTRIES

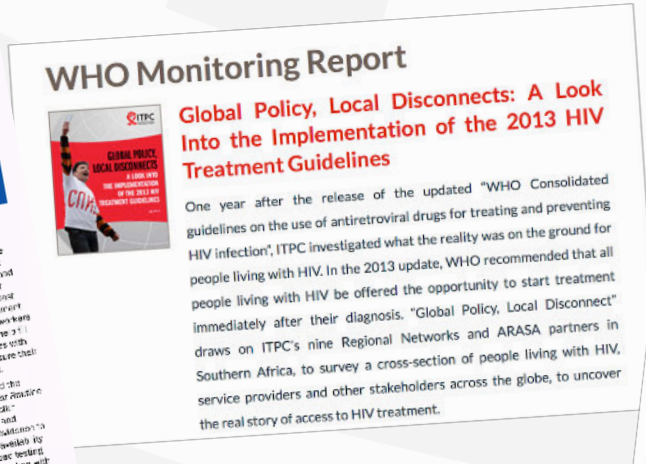
ACTING ON THE RESULTS

www.itpcglobal.org

www.knowyourviralload.com


Missing the Target 11 Documents Trea Barriers

The International Treatment Preparedness Coalition (ITPC)'s new Missing the Target 11: Barriers to Accessing HIV Treatment Community Perspective: Experiences of Orphans and Vuln Children in Uganda And Sex Workers in Kenya, documents pro affecting access to treatment for people living with HIV in communities in East Africa. Learn more in our short video.


WHO Monitoring Report

Global Policy, Local Disconnects: A Look Into the Implementation of the 2013 HIV Treatment Guidelines

One year after the release of the updated "WHO Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection", ITPC investigated what the reality was on the ground for people living with HIV. In the 2013 update, WHO recommended that all people living with HIV be offered the opportunity to start treatment immediately after their diagnosis. "Global Policy, Local Disconnect" draws on ITPC's nine Regional Networks and ARASA partners in Southern Africa, to survey a cross-section of people living with HIV, service providers and other stakeholders across the globe, to uncover the real story of access to HIV treatment.


ROUTINE FOR YOU BUT NOT FOR ME

July 18, 2015 | by ITPCglobal | in Latest News

Routine for you but not for me

A Sobering Review of Access to Routine Viral Load Testing in 12 Countries in Africa

International Treatment Preparedness Coalition (ITPC) and AIDS and Rights Alliance for Southern Africa (ARASA) coordinated a review of access to Routine Viral Load (RVL) Testing across 12 African countries. The results suggest limited availability of RVL and low levels of awareness of the value of RVL amongst people living with HIV and service providers.

Over the last two decades, treatment coverage has increased, in part, thanks to effective community treatment activism across the globe. Despite these gains, close to half of those in need of treatment still have no access to life-saving medicines. It is also not clear how many people

ISSUE BRIEF | ROUTINE FOR YOU BUT NOT FOR ME

ITPC Global Fund RCTO Project At-a-Glance

APPLICANT: ***ITPC***

APPLICANT TYPE: ***Regional***

Sub-recipients: ***11 PLHIV national organizations***

COMPONENT: ***HIV***

TOTAL FUNDING: ***~EURO 3,6million***

FOCUS COUNTRIES: ***11*** *(*Benin, Cote d'Ivoire, The Gambia, Ghana, Guinea Conakry, Guinea-Bissau, Liberia, Mali, Senegal, Sierra Leone, Togo)

TIMELINE: ***January 2017 to December 2019***

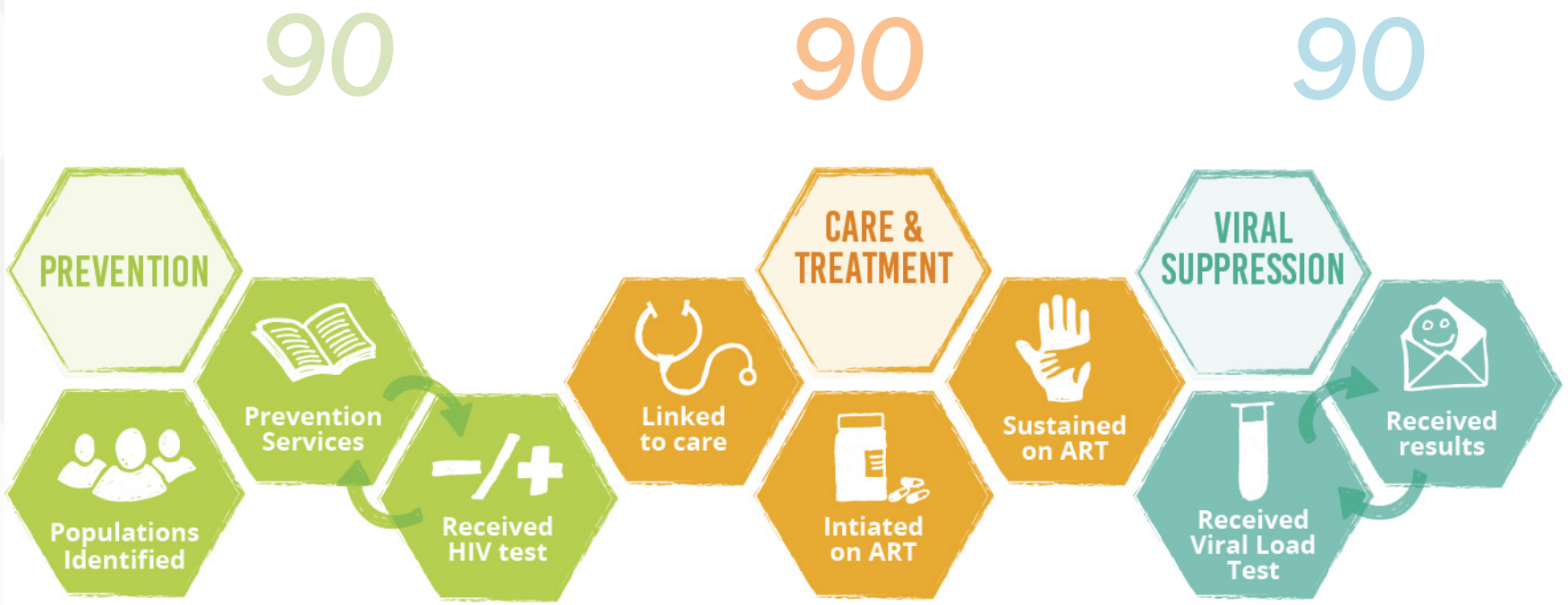
GOAL: **Increase access to antiretroviral treatment for people living with HIV (PLHIV) in 11 West African countries through regional advocacy using data from community treatment observatories.**

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

COMMUNITY MONITORING

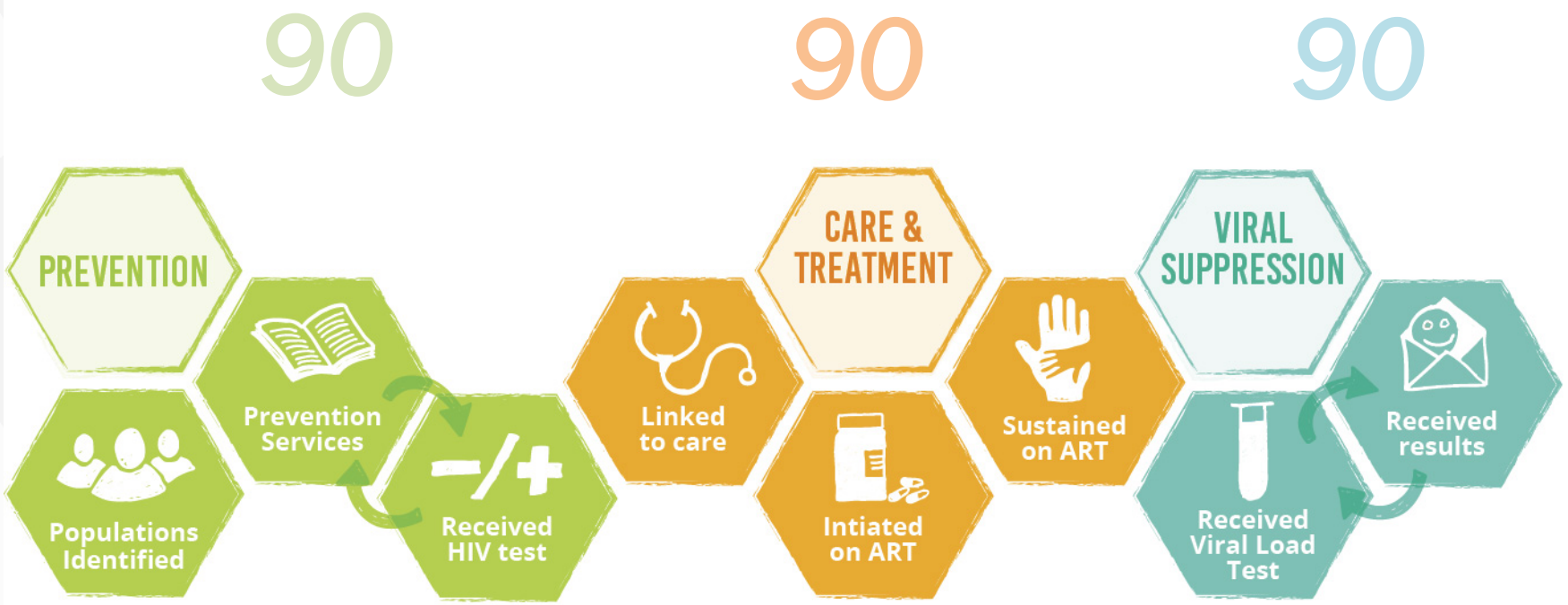
Along the HIV Continuum of Prevention, Care and Treatment



ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

COMMUNITY MONITORING

Along the HIV Continuum of Prevention, Care and Treatment

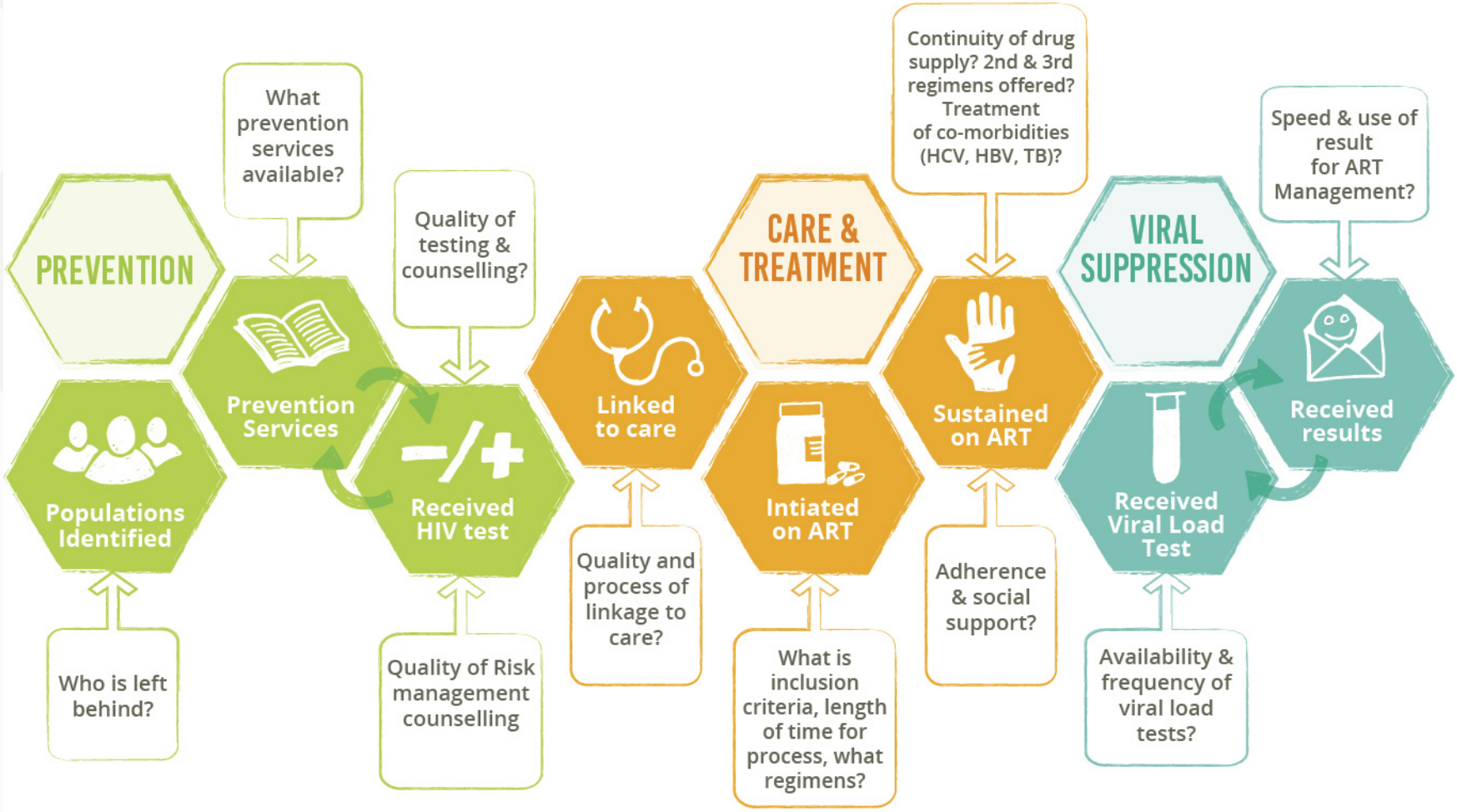


What does this picture look like by **sub-population**?
What does this picture look like by **age disaggregation**?
What does this picture look like by a **rights-based focus / lens**?
What does this picture look like by **region or geographical location**?
What does this picture look like by **investment, policy, skill and interest?**

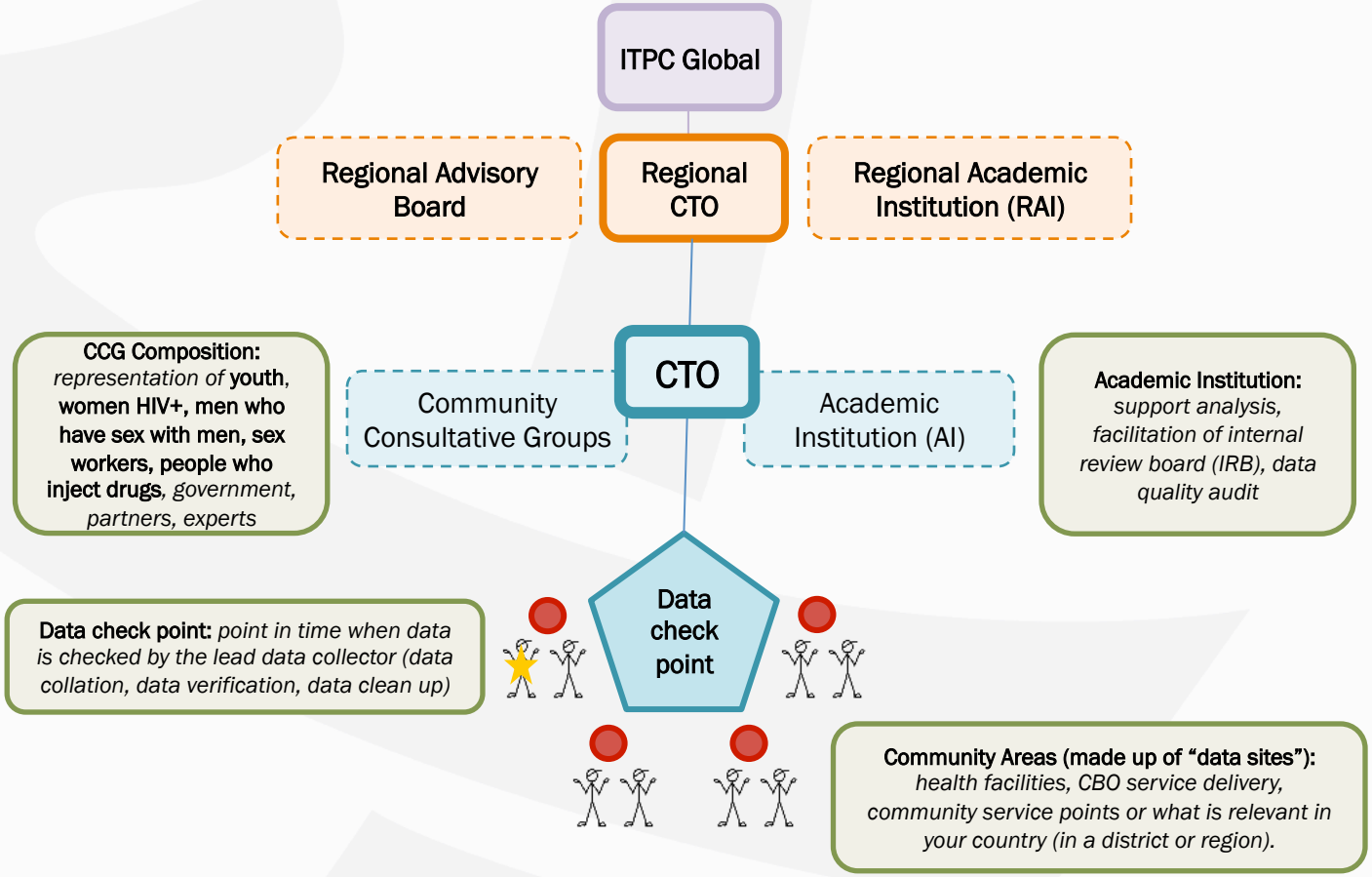
ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

COMMUNITY MONITORING

Along the HIV Continuum of Prevention, Care and Treatment

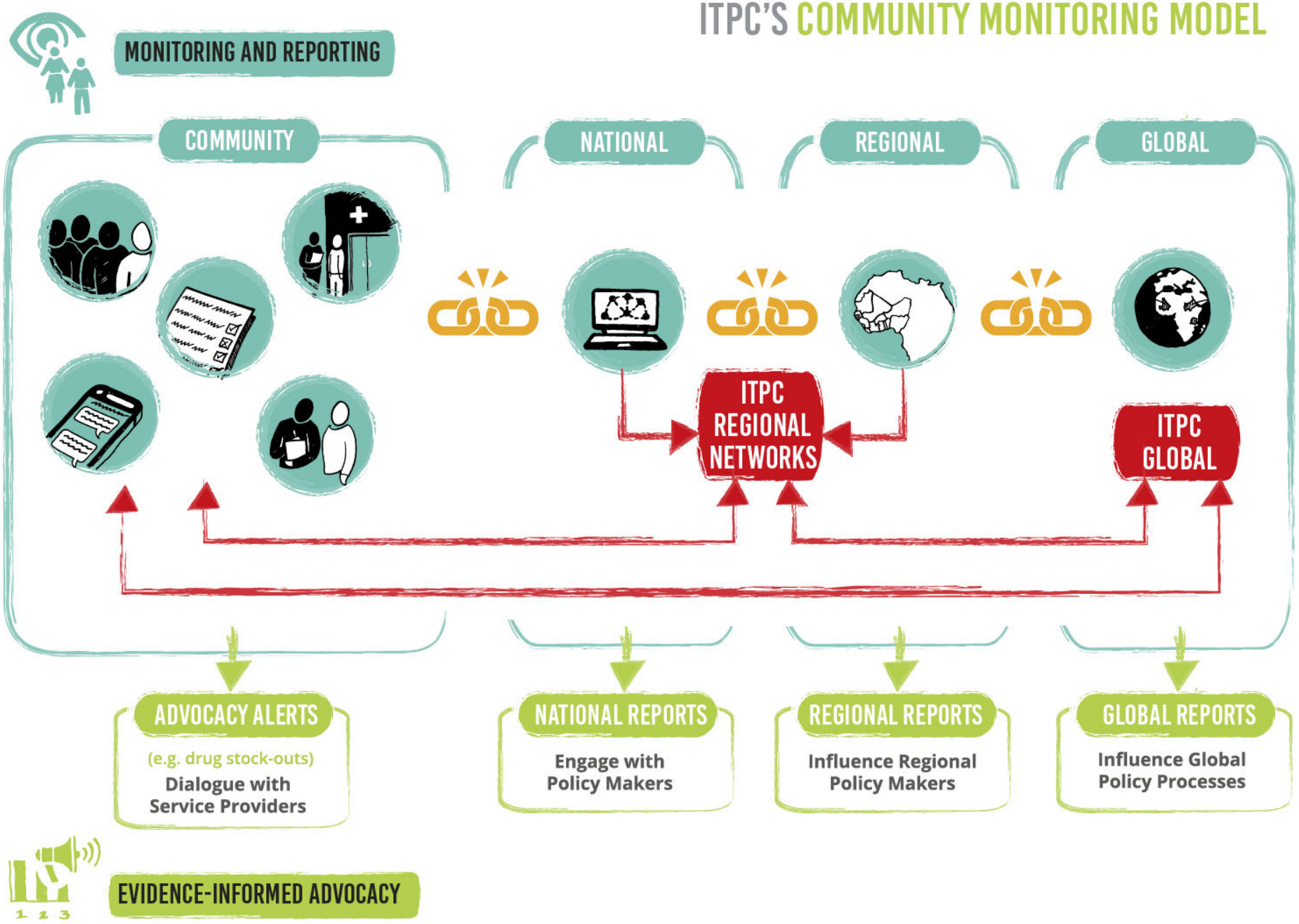


Structure of a Community Treatment Observatory (CTO)



ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

ITPC'S COMMUNITY MONITORING MODEL



Benefits of the CTOs

- Collection of **qualitative data** from the perspective of the recipients of care:
  - Helps to provide in-depth context for trends observed in quantitative data, collected at health facility level
  - Helps to provide context on quality of service and not just quantity
- Builds the **capacity of communities** on data ownership, management and processing: "building the practice of data collection, entry, analysis, and validation"
- Gives **credibility** and supports community organizations to **contribution to national** indicators and data systems
- Facilitates **evidence-based advocacy approaches** (by communities/recipients of care) to inform improvements of policies, programs and services
- Provides opportunity to develop **appropriate demand creation strategies**

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

Categories of CTO Coverage

Category	CTOs in Progress	District level CTOs	National level CTOs
Criteria and Countries	Data collection in the capital city area Criteria for site selection: representation of target groups and high number of PLHIV receiving services Guinea-Bissau Liberia Benin Mali	Data collection at district level Criteria for site selection: High prevalence in the districts (+2%) covered. Data collection should not be in more than one region/province. The population covered by the data collectors should be a minimum of 10% of the total PLHIV receiving services in the country. The Gambia Guinea Conakry Ghana	Data collection at provincial/ regional level Criteria for site selection: High prevalence in the provinces/ regions (+2%) covered. The population covered by the data collection should be minimum of 20% of the PLHIV receiving services at national level Possibility to cover more than 2 regions/provinces as long as they have the 20% representativity condition Sierra Leone Senegal Cote d'Ivoire Togo

Number & Type of Sites by country

Quantitative data collection (monthly) by site and country

Countries	Category	Public health facilities	Community services
Bénin	CTO in progress	1	-
Guinée Bissau	CTO in progress	7	1
Mali	CTO in progress	3	1
Libéria	CTO in progress	14	-
Ghana	District level CTO	7	-
Guinée Conakry	District level CTO	6	2
The Gambia	District level CTO	12	-
Cote d'Ivoire	National level CTO	13	2
Sierra Leone	National level CTO	14	6
Sénégal	National level CTO	10	1
Togo	National level CTO	6	1

Qualitative data collection (quarterly) by country

Countries	Total number of persons *(Q1 2018)*
Bénin	47
Cote d'Ivoire	50
Ghana	45
Guinée Conakry	49
Guinée Bissau	-
Libéria	47
Gambie	42
Sierra Leone	50
Sénégal	50
Togo	50
Mali	42

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

Examples of Key Indicators

PREVENTION

- 2.1ai — Number of people who received an **HIV test**
- 2.1.aii — Number of people who received an HIV test and know their **result**
- 2.1b — Number of eligible people provided with pre-exposure prophylaxis (**PrEP**)
- 2.1c — Number of eligible people provided with post-exposure prophylaxis (**PEP**)

CARE & TREATMENT

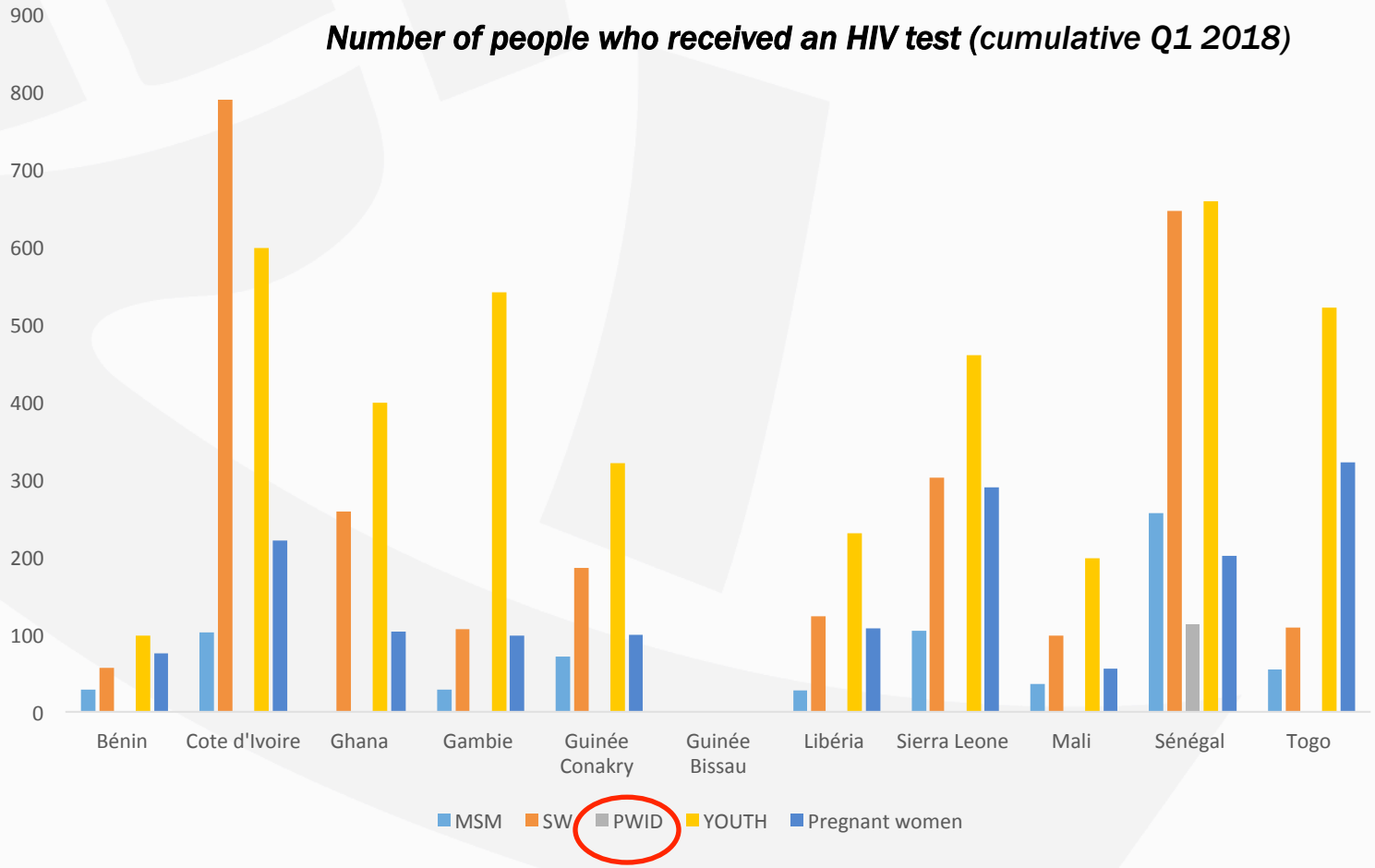
- 2.2a — Number of PLHIV **initiating** ART
- 2.2b — Number of PLHIV currently receiving ART
- 2.2c — Number of PLHIV known to be on ART 12 months after initiating

VIRAL SUPRESSION

- 2.3a — Number of PLHIV that have **did a viral load test**
- 2.3b — Number of PLHIV that received their viral load test **result within two weeks** of taking the test
- 2.3bi — Number of PLHIV that received their viral load test result between fifteen days and three months of taking the test
- 2.3c — Number of PLHIV on ART who have achieved viral suppression (<1000 copies/ml)

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

Prevention

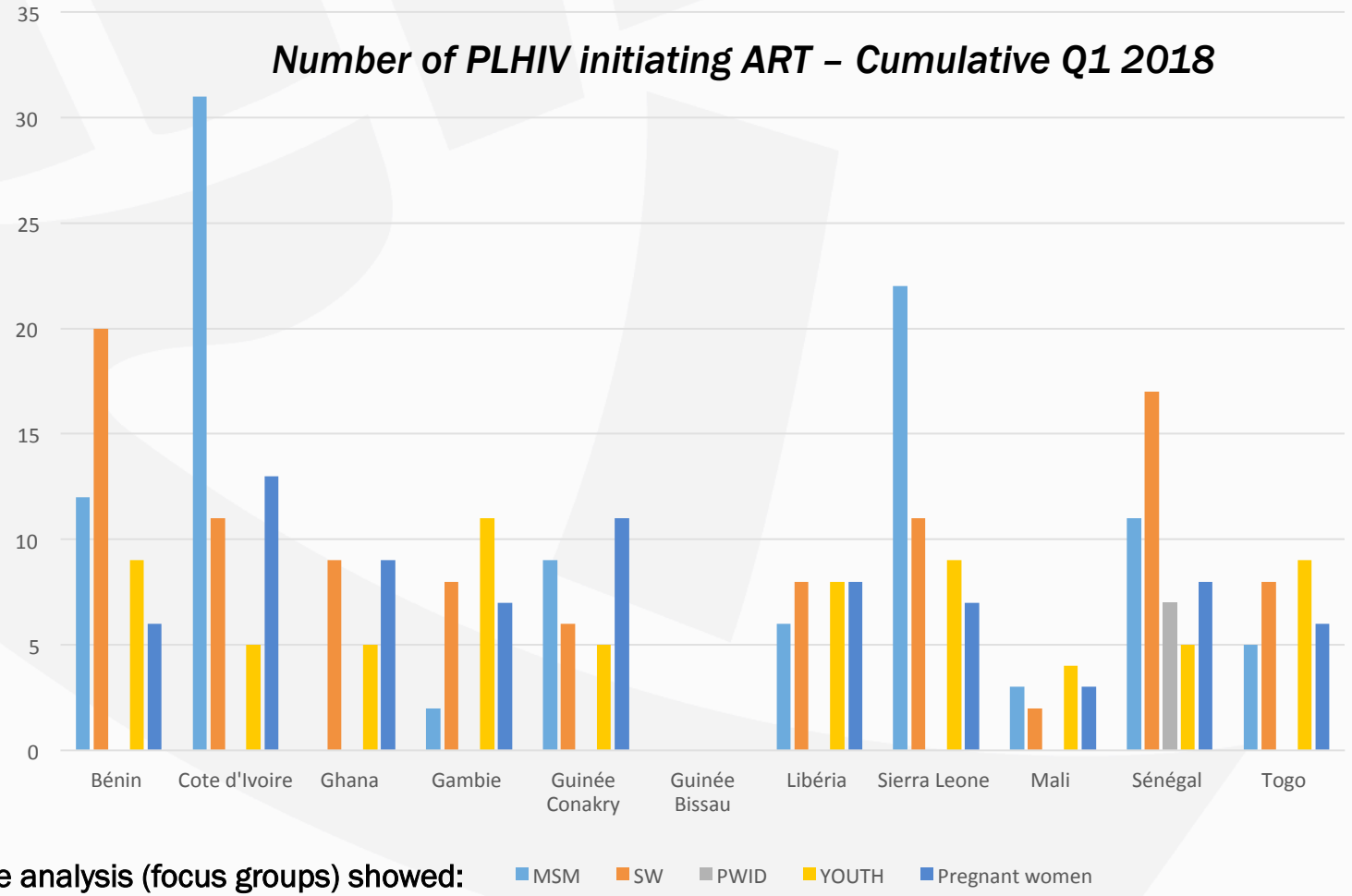


Q1 Qualitative analysis (focus groups) showed:

- In some countries there are low proportions of KPs testing or KPs test but do not self-identify at the health center, due to high stigma that still prevails within the health facilities.
- Where there is data on key populations: KPs preferred to access services from KP-friendly sites

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

Care & Treatment



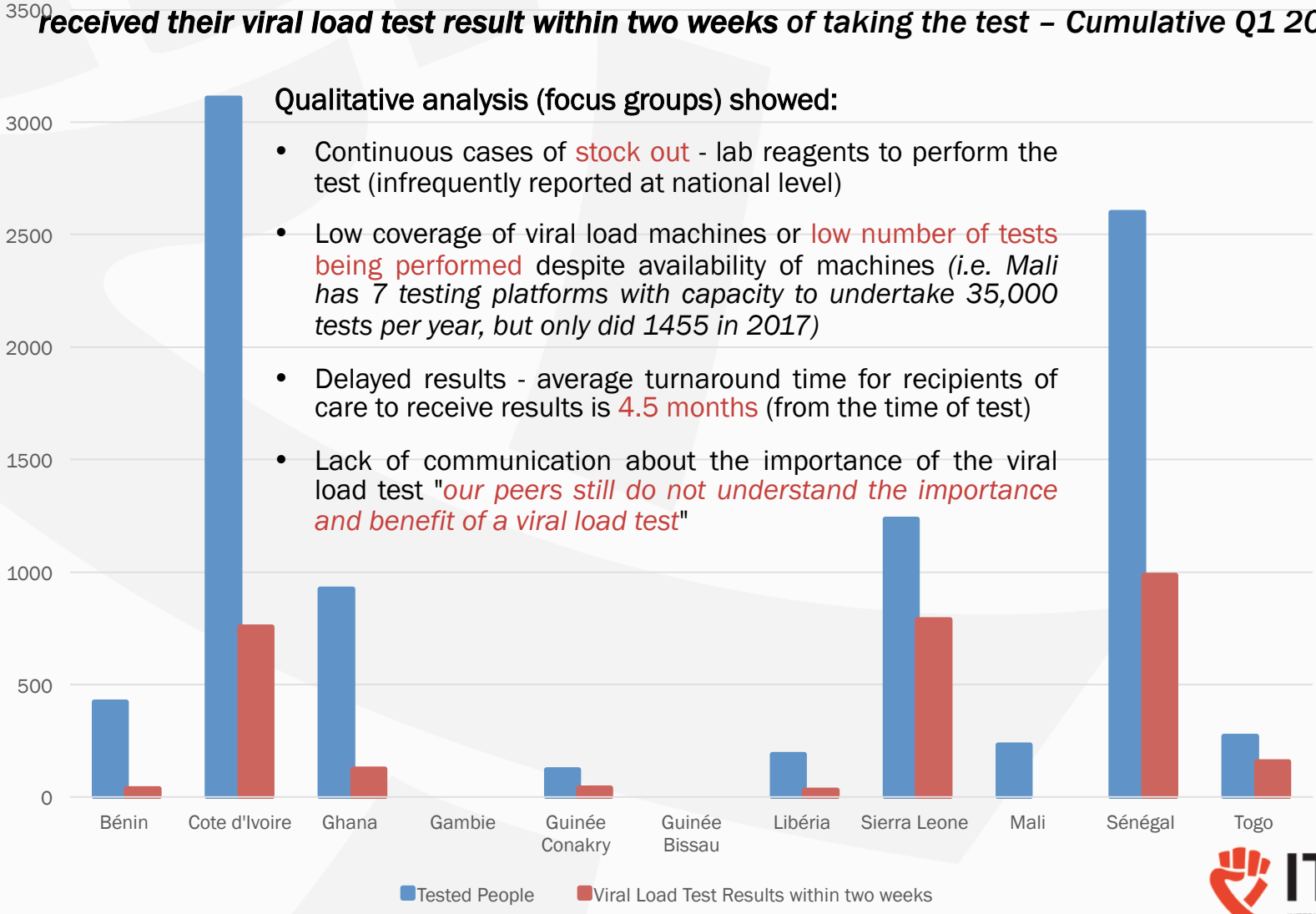
Qualitative analysis (focus groups) showed:

- Despite current "Test and Treat" policy, slow uptake of treatment due to:
  - Location of health centers (being far away), and cost of transportation prohibits travel to health facility
  - Stigma still prevails in many health centers, therefore recipients of care prefer to travel to other regions and areas to access services (fear of disclose or being identified) = loss to follow up
  - Lack of access to continuous nutrition in order to take medicine

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

Viral Suppression

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*"

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

Next steps on Data

- Compare with National Data
  - Challenges
    - Access to data (right to information)
    - Disaggregation
    - Timing (about 2-year lag)
    - Integration of community-led data and/or processes into national data - political (**DSD is an excellent entry point for this**)
- Resolve issues raised from data quality audit
  - Challenges
    - Accountability mechanisms
    - Capacity building
- Focus intensely on CTOs working at district and national level for the remainder of the project (vs those in progress)

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

What else have we heard?

VIRAL LOAD TESTING

- *Limited knowledge and availability of routine viral load testing*

  3 regional trainings (Asia, Africa, LATCA) 60 participants & survey conducted in 9 countries, 2,250 PLHIV respondents

  - Respondents didn't know that the RVLT existed
  - Awareness, knowledge and uptake of VLT was low and generally eclipsed by awareness/knowledge and uptake of CD4 testing
  - Cost of RVLT was a significant issue

- *Stock-outs still a persistent issue*

  Global survey, 764 respondents

  - West & parts of Southern Africa - regular CD4 and viral load testing were often unavailable for patients due to frequent stock-out of lab reagents

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

Perspectives

"*We are thinking now that people 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.

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

Other Key Observations

- Governments remain hesitant to invest in communities and key population programming, despite evidence of the public health impact
  - These interventions were mainly funded by bilateral or multilateral donors
- Frequent human rights violations
- Key population organizations and small community NGOs still struggle with legal registration
- Stock outs/Shortages (lab commodities), artificial stockouts, poor forecasting, delivery etc. – sitting in stores).
- Fragile health systems (Ebola)

DSD is an opportunity in WA

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

ITPC Global Fund Project in W. Africa

Community System Strengthening

Monitoring/Data

Regional Advocacy

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

ITPC Global Fund Project in W. Africa

Community System Strengthening

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

So what's the Link to DSD?

- Can't effectively scale DSD without:
  - robust **COMMUNITY MONITORING**: to monitor quality and access of services along the HIV cascade
  - understanding how to scale/improve **QUALITY** (not just #s)
  - building **COMMUNITY SYSTEMS**
  - truly supporting the shift to more **COMMUNITY-LED & PROVIDED SERVICES**
  - funding **COMMUNITY ADVOCACY**: to ensure there is a strong community voice

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION