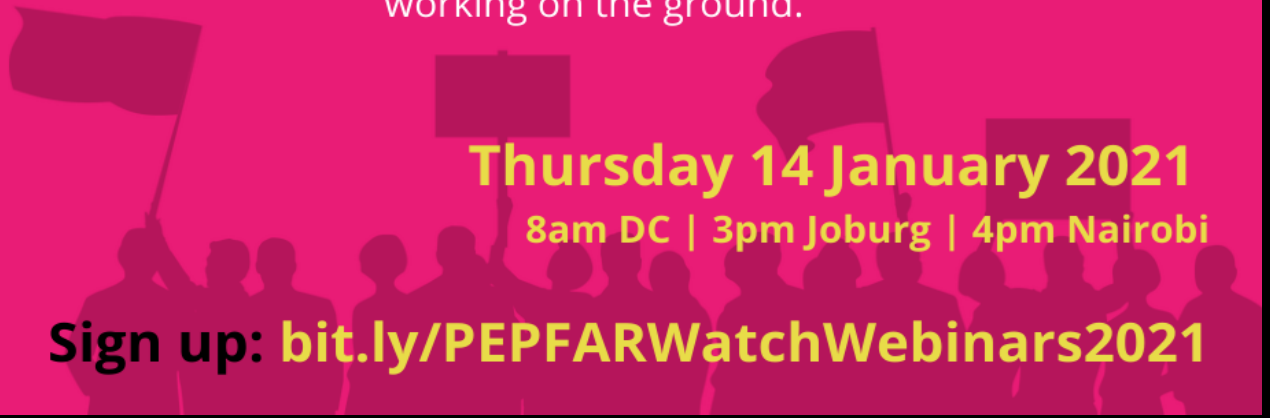
PEPFAR Watch

WEBINAR: Improving HIV retention — how do we get more people to start and stay on treatment?

People with HIV are being lost in several places between testing HIV positive & initiating on treatment, & interrupting treatment between initiation & long-term retention. As we prepare for COP20 — join us for a webinar to unpack what *is* and what *is not* working on the ground.



Thursday 14 January 2021

8am DC | 3pm Joburg | 4pm Nairobi

Sign up: bit.ly/PEPFARWatchWebinars2021

AGENDA

Speakers:

1. Ken Mwehonge HEPS— Uganda

The reality on the ground, sharing the experience from the Uganda CLM efforts

1. Anna Grimsrud — International AIDS Society (IAS)

What countries should consider demanding for to improve retention

1. Maureen Milanga — Health GAP

Using the checklist model what should we ask for in COP21?
How can we win it?
What to do when PEPFAR says "no"?

Moderator:
Matt Kavanagh — O'Neill Institute, Georgetown University

PEPFAR Watch

Gaps that Lead to Reduction in Retention from CLM

Uganda: Iraka Ly'Abantu

Highlights on Retention from Pilot Phas
January 14th 2021

PEPFAR Watch

Model and Approach

Goal of Iraka Ly'Abantu (Runyakitara for "the People's Voice"): Improved quality and accessibility of HIV services for people living with HIV and people most affected by HIV. **We achieve this through:**

- ➔ Independent, routine monitoring of the quality and accessibility of prevention and treatment services provided at PEPFAR-supported clinics and in our communities;
- ➔ Analysis of data;
- ➔ Generating solutions that respond to the evidence collected;
- ➔ Engaging duty bearers & advocating to make ensure solutions are implemented

OBJECTIVES OF THE ASSESSMENT/SURVEY

- To generate and compile community level views on the barriers and enablers to HIV/TB services at PEPFAR supported sites

- To provide constructive feedback from communities to stakeholders and service providers on the quality of HIV/TB service delivery and benefits of health interventions.

- To generate recommendations aimed at enhancing social accountability for HIV/TB services

CLM Survey Design

- ➔ Adopted a quantitative and qualitative approach
- ➔ Collected at facility and non-facility levels
- ➔ Conducted in-depth interviews and Focus group discussions
- ➔ Used standard assessment tools:
  - ◆ PLHIV patients survey tool
  - ◆ Facility manager survey tool
  - ◆ Focus Group discussion check-list
  - ◆ Data capture survey tool
  - ◆ Implementing mechanism survey tool
  - ◆ Observation guide
  - ◆ Facility based support group survey tool
- ➔ Themes of Assessment: HIV & TB services, Human resources for health and data management systems.

CLM Survey Methodology: Site Selection

- **Criteria for site selection during learning phase:**
  - Representation across all Implementing Mechanisms (IMs)
    - Rationale: IMs have a divergent approaches to cross-cutting problems such as LTFU
  - Selected poor performing sites as measured by relevant PEPFAR MER indicators, such as retention of newly enrolled people living with HIV and VL suppression
    - Minimum of 2 facilities per IM; field-based changes in 2 cases due to COVID-19
  - RRHs generally have access to more funding, staff and commodities; they tend to report better program performance to PEPFAR so were not selected (exception: Mubende RRH)
    - We assume PEPFAR's approach (focusing first on the highest volume TX_CURR sites) can create vicious cycle of leaving smaller sites behind because they 'matter less' if the focus is numbers
    - While our combined TX_CURR represented by our pilot CLM sites wass relatively small, we feel we identified commonly overlooked challenges among communities whose needs have been consistently ignored

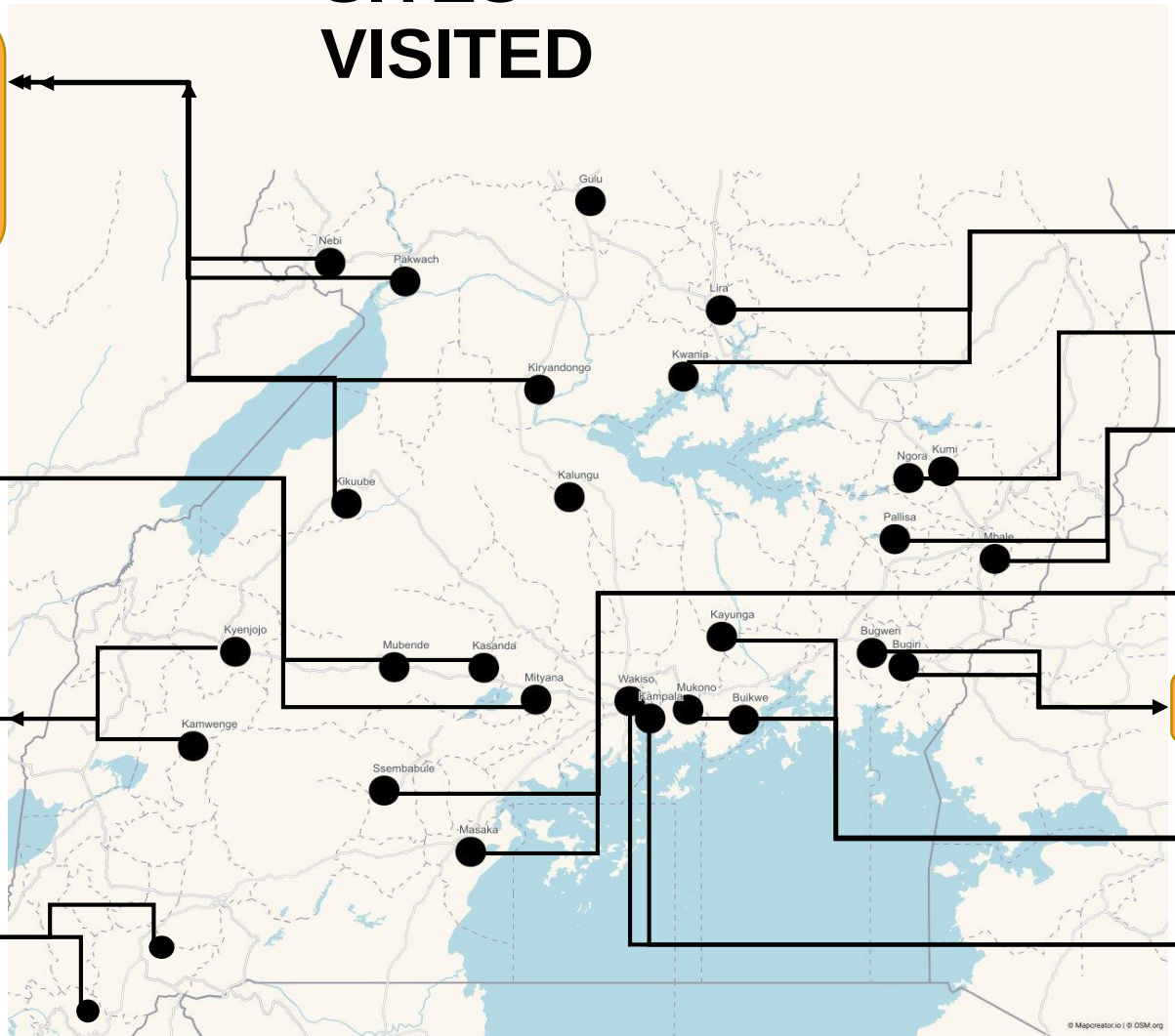
SITES VISITED

IDI / Scaling up HIV services in Western and West Nile
Kikuube –Kabwoya HCIII
Kiryandongo-Panyadoli HC III
Nebbi-Nebbi Hospital
Pakwatch-Panyimur HC III,Pakwatch HCIV

Mildmay/Mubende Region
Kassanda- Musozi HCIII
Mubende-Mubende Reg Hospital
Mityana –St.Jacinta

Baylor / Fort Portal Region
Kamwenge –Ntara HCIV
Kyenjojo –Butiti HC III

EGPAF / RHITES
Kabale –Kamukira HC IV
Ntungamo –Kitwe HC IV



RHITES-LANGO
Lira-Barapwo HCIII,Amach HCIV
Kwania-Inomo HCIII

TASO/SOROTI Region
Ngora-Ngora Ngo Hospital
Kumi-Kumi HCIV

RHITES-E
Mbale-Namatala HCIV
Palisa-Pallisa Hospital

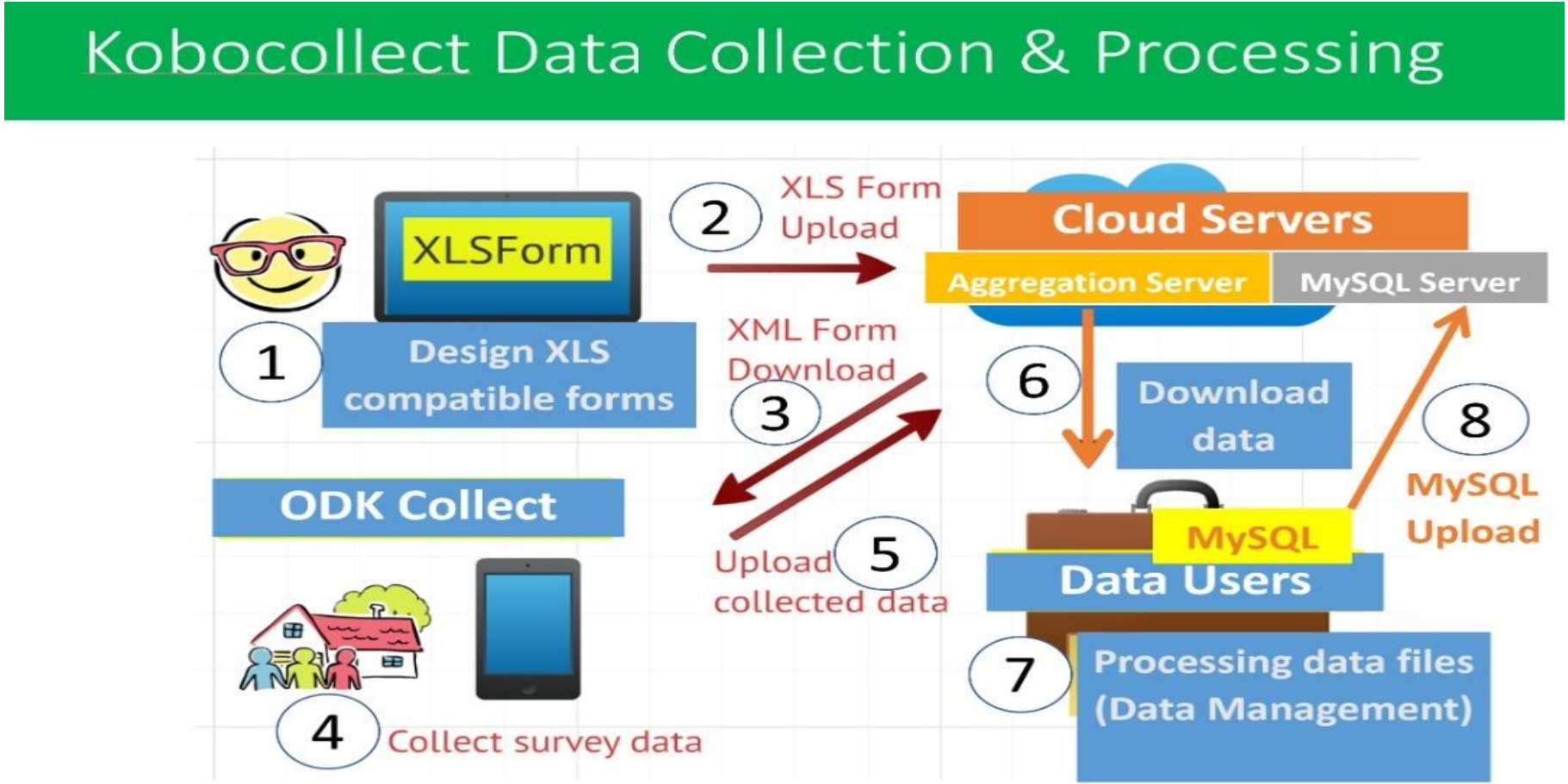
Rakai Health Sciences Program/ Masaka Region
Kalungu-Kalungu HCIII
Masaka –Bukakata HCIII
Sembabule-Ntuusi HCIV

RHITES – EC
Bugiri-Bugiri Hospital
Bugweri-Busembatia HCIII

WALTER REED/MUWRP
Kayunga –Bbale HCIV
Mukono –Mukono T.C HCIV
Buikwe-Ssi HCIV

IDI/Kampala Region
Kampala -Hope Clinic Lukuli HC II
Wakiso -Kajjansi HC III

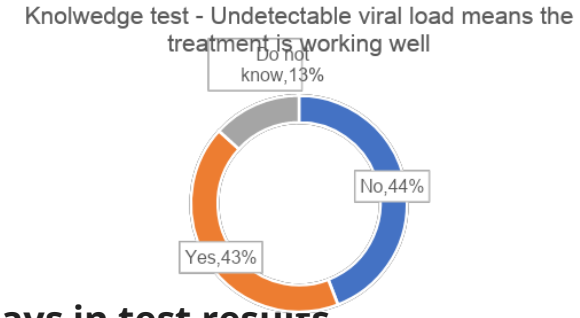
Country-specific CLM Hard- & Software System-Kobo toolbox

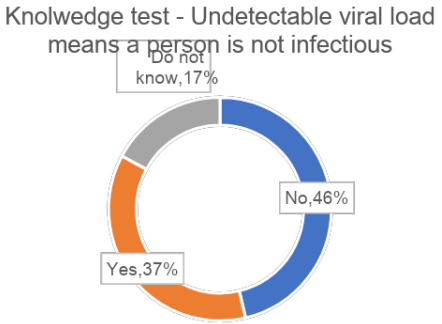


KEY FINDINGS

Findings: Community-Led Monitoring

Theme 1: TREATMENT: What did the evidence show?
Low levels of treatment literacy, low levels of demand for services (Viral load)





- **Delays in test results**
  - Long TAT for EID; **Barapwo HCIII**: **Inomo HCIII:** delayed by >2 months April - August; **Ntuusi, Bukakata HCIII;** Kamukira
  - Long TAT for V.L
  - Loss of viral load samples was common practice; for example in **Ntaara HCIV, Ntuusi, Bukakata**

Findings: Community-Led Monitoring

Theme 2: RETENTION IN CARE: What did the evidence show?

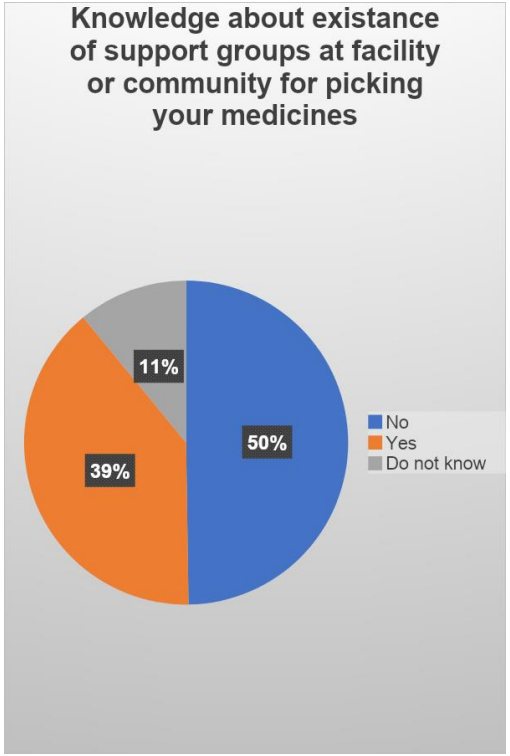
➔ **Staff attitudes and staffing levels having major impact on retention and quality**

- Inadequate HRH having implication on patient waiting times e.g **Amach HCIV:** only 2 ART technical staff (ART clinic in-charge and counselor) for TX_CURR of 2,312;
- **Poor staff attitudes reported to included** health workers berate and humiliate people; sex workers report fear, discrimination preventing them from collecting ART at clinic; youth report staff unfriendly, judgemental **e.g Kabwoya HCIII: Bukakata HCIII, Kitwe HCIII, Bugiri Hospital. In contrast, Ssi-Bukunja HCIII, Mukono Hospital**: staff attitudes reported "good"
- Practice of bribing health workers to get services: **Kabwoya HCIII, Mubende RRH, Ntaara HCIV**
- Denial of patient transfer requests and turning away patients from care. E.g a case of a woman in **Panyandoli HCIII** arriving as clinic closed, needed 6weeks PCR being turned away
- **In contrast:** a good practice for retention was reported in Ssembabule-Ntuusi Health Centre IV. The facility is has CBOs affiliated to it for example D&D CBO and they do follow ups and linkage, operate DiC and offer counselling and facilitate groups for those on Dreams programs

Findings: Community-Led Monitoring

Theme 2: RETENTION IN CARE: What did the evidence show?

- ➔ **Facility-based support groups exist in name only**
  - Generally, staff reported support groups; but patients were largely unaware of their existence; also support groups typically run by clinic staff rather than community
  - **Kabwoya HCIII** patients had self-organized with no facility support, started savings group; **Kumi HCIV** adherence clubs inactive—no funds
  - **In contrast;** the Ariel support groups for AGYW and Paediatrics in Kabale were working well and headed/facilitated by young people
- ➔ **Treatment literacy**
  - **Unfunded, sorely needed, stated as a focus in PEPFAR COP20 but will it happen?**



Thank you for Listening

International Community of Women Living with HIV Eastern Africa

UGANET
Justice for Health HIV and Gender

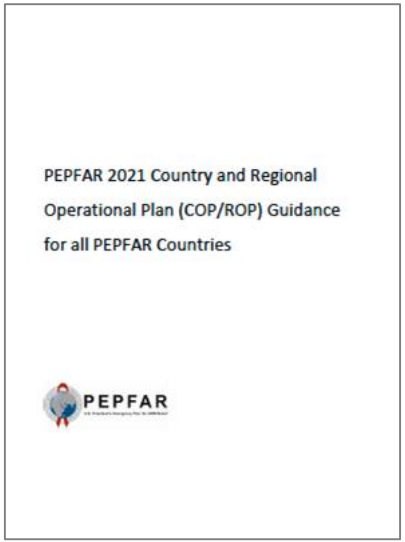
Improving retention on HIV treatment: Ensuring programmes support people to start and stay on treatment

14 January 2021

Anna Grimsrud, International AIDS Society

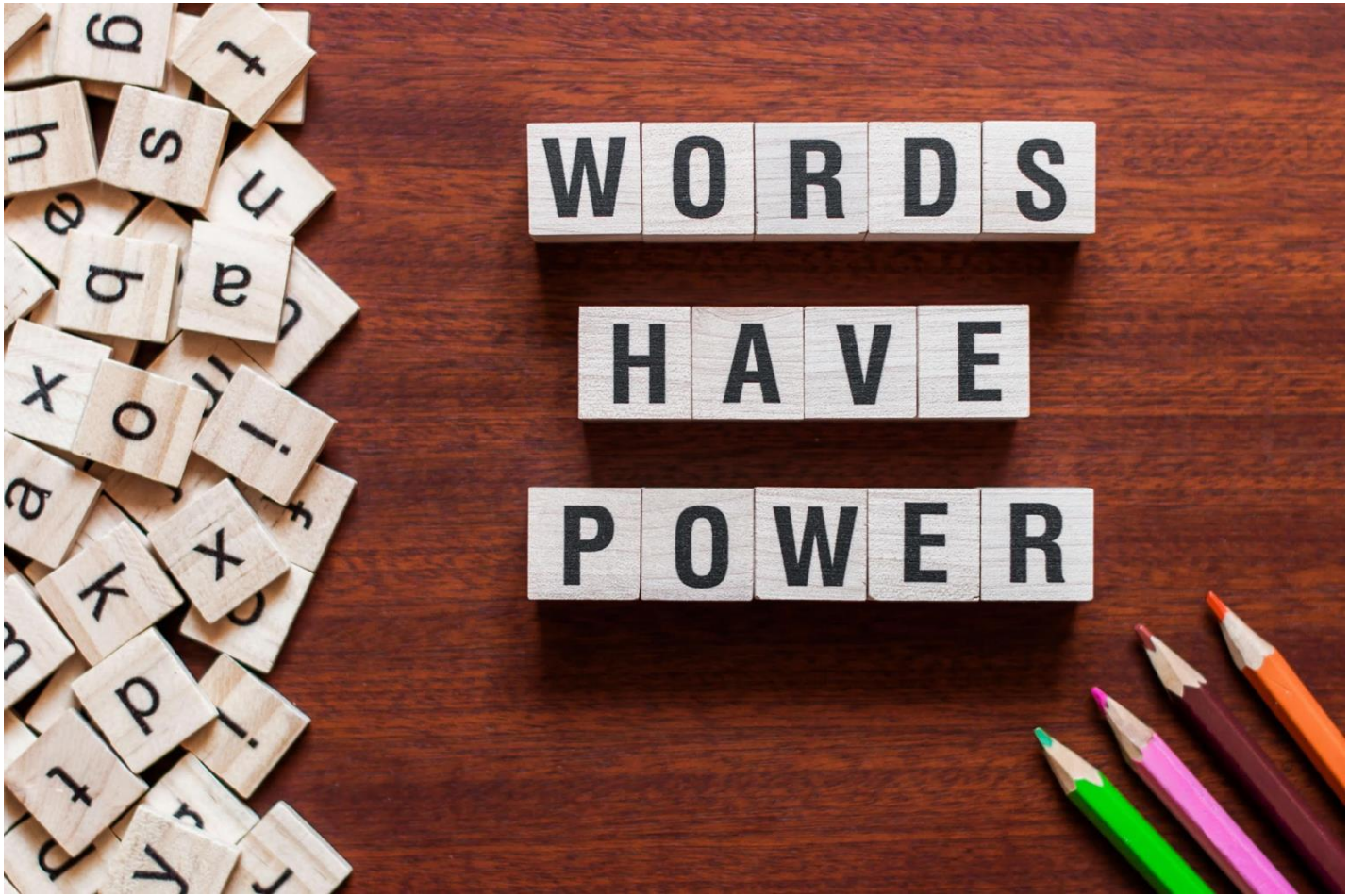
PEPFAR Watch Webinars 2021

Retention and COP21



- What does the PEPFAR 2021 COP guidance say about retention
  - Initiation
  - Retention
    - Specific populations
    - Returning to care
- What should civil society demand around retention


WHATS NEW?


WORDS
HAVE
POWER

COP21 guidance shifts language with:

“continuity of treatment” replaces “retention”

and

“interruption in treatment” replaces “loss to follow up” (LTFU)

Improving continuity of treatment
Ensuring programmes support people to start and stay on treatment

Anna Grimsrud
International AIDS Society

PEPFAR Watch Webinars 2021

"COP21 guidance reinforces clients' agency (i.e., ability to choose and act), focusing on the therapeutic alliance"

“Multi-month dispensing (MMD) and decentralized drug delivery (DDD) accelerated by COVID-19 adaptations should continue”

COP21 “Minimum program requirements” (related to continuity of treatment)

1. “Adoption and implementation of Test and Start, with demonstratable access across all age, sex, and risk groups, and with direct and immediate (>95%) linkage of clients from testing to treatment across age, sex, and risk groups.”
3. “Adoption and implementation of differentiated service delivery models for all clients with HIV, including six-month MMD, DDD, and services designed to improve identification and ART coverage and continuity for different demographic and risk groups.”

2.3.1 PEPFAR's Number 1 Treatment Priority: Supporting Clients by Facilitating Continuous ART

- Recognize the agency of clients—their right to make their own choices
- Providers strive to enter a therapeutic alliance that honors the needs, preferences, and motivations of a client along with their family and/or significant others
- Emphasize privacy, dignity, and voluntary participation.
- The vision … make it as easy as possible for clients to remain on uninterrupted ART across the lifespan and across changing life circumstances.

PEPFAR-supported site requirements for client centered-services

Consistent, affirmative "Welcome back" messaging, expedited timeline to access MMD and DSD models

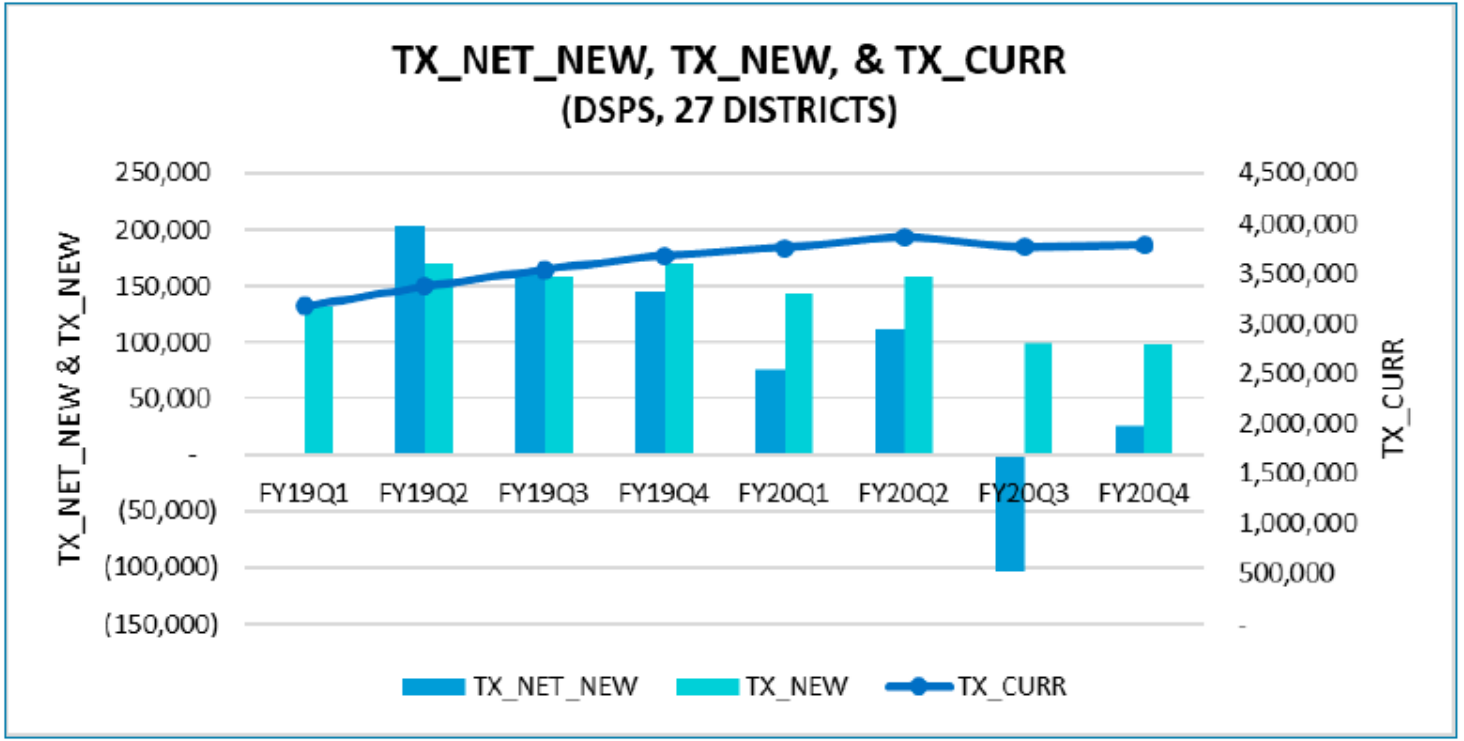
Multi-month dispensing and separation of drug dispensing from clinical care, community-based treatment initiation, peer-supported services, measured wait times, extended hours, more convenient places

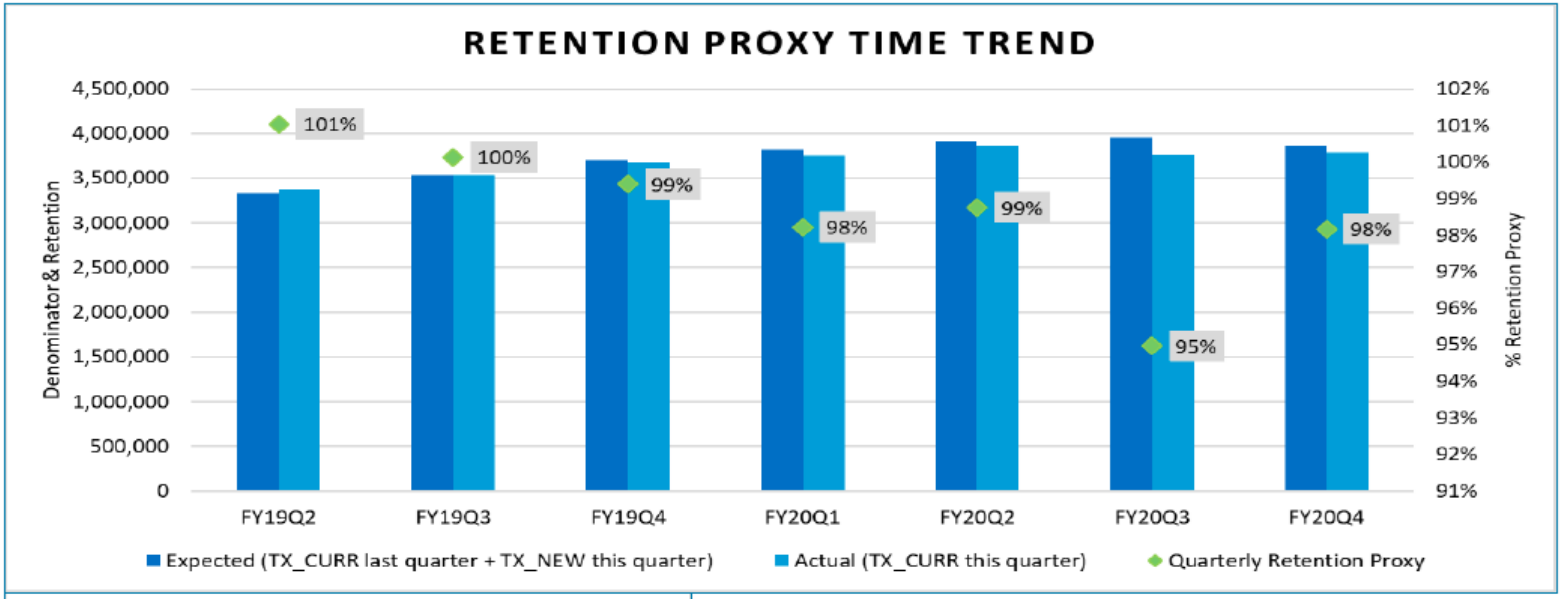
Service referral and linkage, peer outreach, tracking, system for pre-appointment reminders

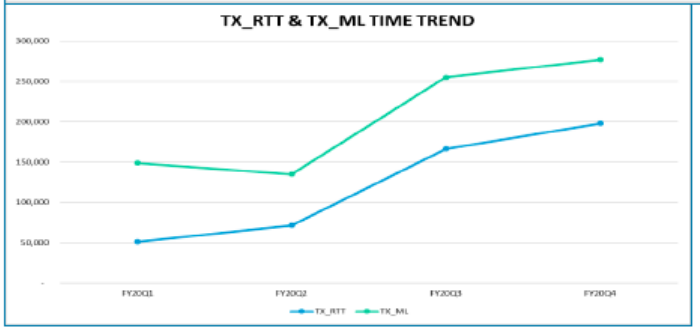
MER indicators related to continuity of treatment (“retention”)

- TX_CURR
  - Disaggregated by ARV dispensing quantity
- Retention*
  - *Proxy indicator calculated from TX_NEW & TX_CURR
- TX_NEW
- TX_NET_NEW
- TX_ML (treatment interruption)
  - Disaggregated by recently initiation on ART (<3 months), established on ART (3+ months)
- TX_RTT

Example 1: Treatment indicators, South Africa



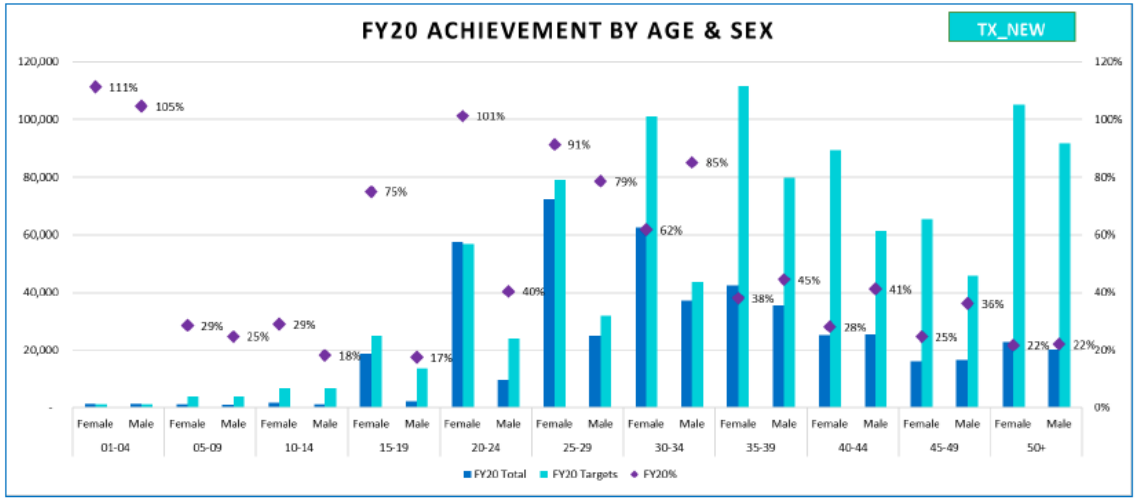




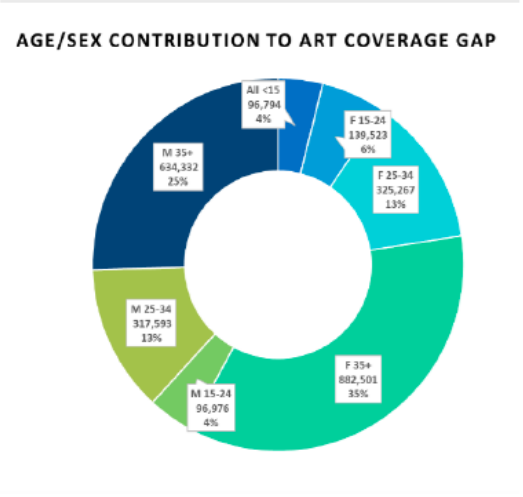
- Proxy retention reached 98% in Q4
- The number of patients returned to treatment reported in TX_RTT (blue line) have been steadily increasing since FY20Q1

Quarterly Retention Proxy: *[TX_CURR end of quarter]/([TX_CURR last quarter] + [TX_NEW this quarter])*

Where are the gaps?



Source: *DATIM PSNU x IM dataset, accessed Nov 17 (27 Focus Districts)*



- Total treatment initiations and target achievement are highest among young women (20-34yrs)
- Target achievement is lowest among males ages 10-19yrs, whereas ART coverage gap is largest in males and females 35 years of age and older; however, TX_NEW is lagging in these age groups

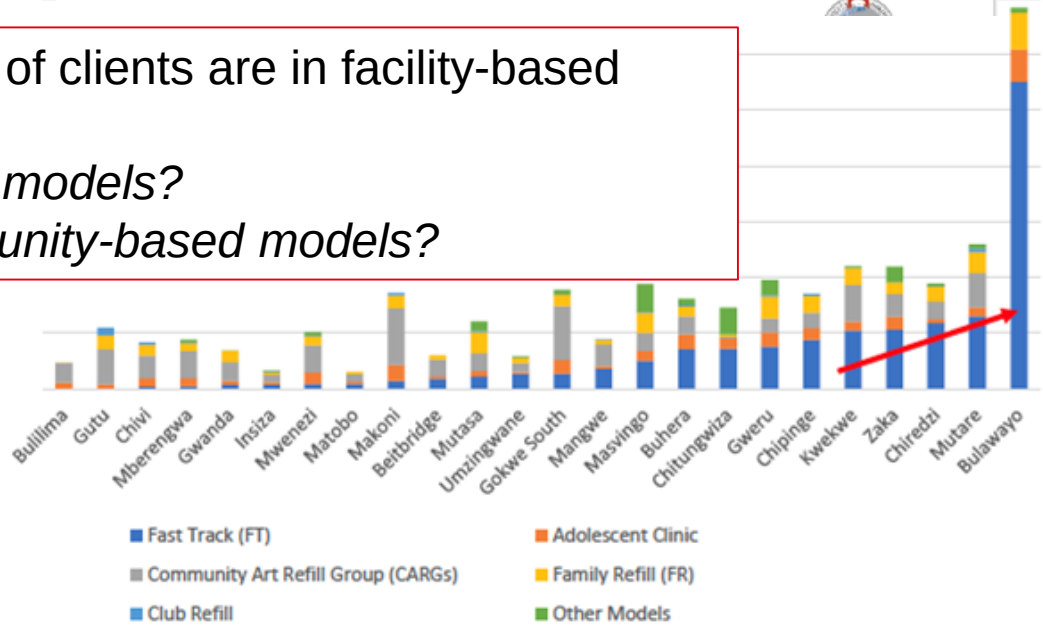
Example 2: POART Q3, Zimbabwe (1)

- There were variations in dominant DSD models across the 24 districts
- Fast track is more dominant in Urban districts whilst CARGS are dominant in Rural districts.

The large majority of clients are in facility-based individual models

What about group models?

What about community-based models?



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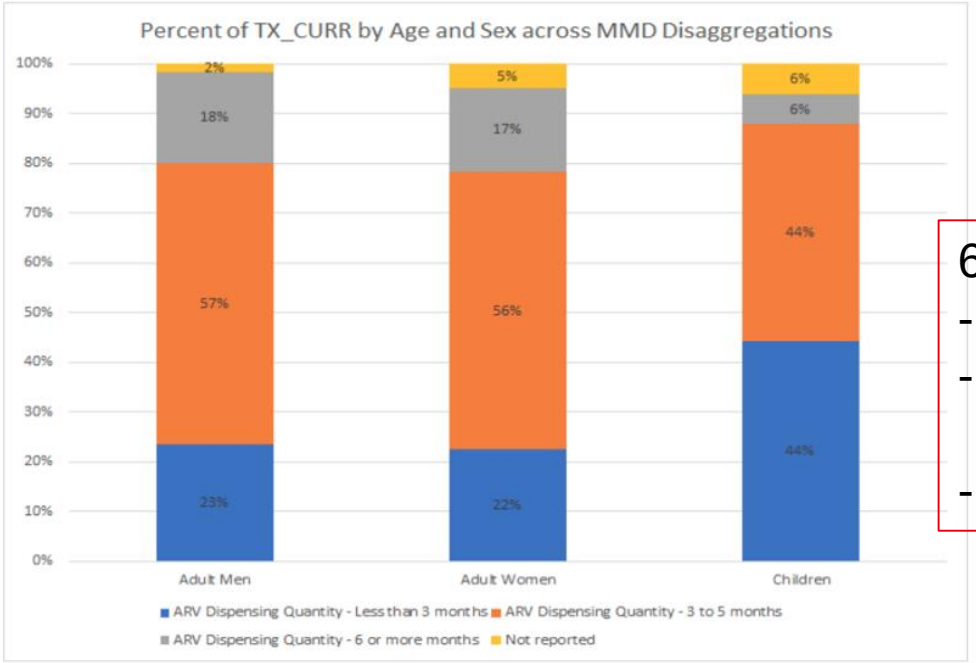
U.S. President's Emergency Plan for AIDS Relief

Example 2: POART Q3, Zimbabwe (2)

By age? By sex? By location?

PEPFAR Global Q3 2020 (April to June 2020)

Duration of multi-month dispensing by age and sex*



6MMD (grey bars)
- 18% adult men
- 17% adult women
- 6% of children

PEPFAR

17 YEARS OF SAVING LIVES THROUGH AMERICAN GENEROSITY AND PARTNERSHIPS

#AIDS2020Virtual

*Excluding South Africa

What does the PEPFAR guidance say on treatment initiation?

- Community initiation
- Same-day and rapid ART
- Rapid ART initiation for key populations should be offered at various points of entry, meeting the client where they can best be served, including at community testing sites, drop-in centers, STI clinics, private clinics, primary care clinics, and hospitals

Building blocks of treatment initiation

Same day and rapid ART initiation

Comprehensive case management teams – including peers

Community-initiation, meeting the client where they can best be served, including at community testing sites, drop-in centers, STI clinics, private clinics, primary care clinics, and hospitals

Package of services – with variable intensity. Can also include MMD.

DSD to support treatment continuation (1)

PEPFAR supports four models of DSD for HIV treatment

DSD to support treatment continuation (2)

- Explicitly notes the separation between clinical services and drug delivery
- Highlights that MMD can be part of any of the models
- Emphasizes the importance of DDD – so these are models outside of the health facility
- Highlights DSD for all populations including children, adolescents, pregnant and breastfeeding women, and key populations
- Emphasizes that medications, including TB preventive therapy (TPT) and others can be incorporated and within these models

Summary of PEPFAR guidance on continuity of treatment

- PEPFAR guidance is strong on continuity of treatment
  - Client agency and therapeutic alliance
- Question is more around resourcing and ensuring investment in strategies that are client-centered
  - Where are the gaps?
  - Is community resourced – both for treatment literacy and to support provision of services?
  - That targets should not dictate which model needs to be scaled – rather should reflect client choice

WHAT SHOULD COUNTRIES CONSIDER DEMANDING TO SUPPORT AND IMPROVE CONTINUITY OF TREATMENT?

Supply chain

DSD is more than just MMD!

1. Investment needed to strengthen supply chain systems BOTH to fully enable MMD *and* ensure uninterrupted supplies

Can civil society demand an analysis of the supply chain to identify weakness and understand what is needed for support scaling up of 6MMD and decentralized drug distribution?

Human resources for health

2. “Lay workers play an important role in differentiated service delivery and should be recognized and sufficiently funded in order to scale DSD models.”

- For group models
- To support initiation
- For services provided by peers

Targets

3. Targets beyond MMD

- % facilities offering a group model and out-of-facility/DDD model option? Or at least more than one DSD option? Otherwise not a choice.

4. Targets for DSD coverage

- sharing DSD coverage data with civil society (possibl
reporting to clinic committees available DSD for HIV treatment options?)

Inclusivity, access and choice

5. Ensure all populations are eligible and have DSD models that work for them

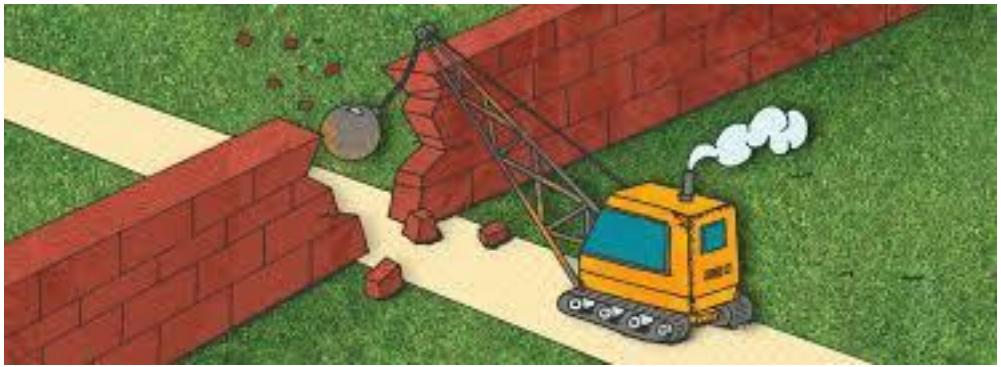
- Children over 2 years of age have access ideally to the same models as their caregiver
- Adolescents also qualify for longer drug refills
- Pregnant women have a choice of where to receive their HIV care during the pregnancy and post-partum
- Key populations programming includes HIV treatment
- Where possible, hours to collect ART refills are extended

Treatment initiation

6. Sufficient investment for *quality* community treatment initiation
   - Not measured just on % who initiate on the same day
   - Appropriate support for same-day, community-based ART initiation

Re-engagement/Return to care

7. “Re-engagement service delivery algorithms… an expedited timeline to access MMD and DSD models”
   – Support accelerate access to DSD after re-engagement – want to remove barriers to being retained



In summary

What should countries consider demanding to support and improve continuity of treatment?

1. Strengthened supply chain to ensure scale-up of extended ART refills *and* decentralized drug distribution/community-based models of ART delivery
2. Recognition of lay workers as DSD providers (funding and sustainability plan)
3. Targets to include % with a group model and % with an out-of-facility/DDD model (more than just MMD)
4. Targets for DSD coverage to be shared and discussed with civil society
5. Access to DSD for all populations – with specifics
6. Resourcing for quality community, rapid, treatment initiation
7. Accelerated access to DSD for those who re-engage

DEMAND BETTER

Visit: www.differentiatedservicedelivery.org

Email: dsd@iasociety.org

How to make your retention(continuity of treatment) asks using the checklist?

Maureen Milanga
Health GAP

PEPFAR Watch

What you need to know?

1. What does your country data say about retention?

- Review quarterly data. Amfar Data and PEPFAR Data
- Review the latest SDS from your country
- Speak to communities of people living with HIV and activists
- Read the COP guidance
- Read the PEPFAR planning level letters

PEPFAR Watch

Adding your retention recommendations to the checklist

Area	CSO Priorities	What PEPFAR is doing in 2019 (see COP19 + data)	What exactly should PEPFAR do in COP20 **(include specific language for the COP +budget)**	Target for COP20	Agreements in COP20
EXAMPLE	Establishing adherence clubs + stronger system for linkage and tracing those lost to follow up. This requires PEPFAR to fund community health workers for linkage and adherence.	**Quarter 4 Data** shows 80% retention rates have not changed since last year. Especially poor retention rates in KZN and Eastern Cape provinces. Language from COP18: "In COP19 PEPFAR will support CBO's, Ward Based Outreach Teams (WBOTS), community health workers (CHW), and (for KPs) peer navigators to serve as community linkage officers to assure PLHIV newly diagnosed in the community are successfully referred to the nearest facility, where the facility linkage and retention officers will ensure enrollment in care and treatment." (p49) In COP19 PEPFAR will … promote a choice of ART delivery options such as facility-based fast track and community- led models of ART provision, including community adherence groups (CAGs), community-led adherence clubs, and community drug delivery through the CCMDD where feasible (p55) **No clear information: How many HCW does PEPFAR currently support? Where are they based? What % are formally paid?**	We request the following be in the COP: In COP20, PEPFAR will partner directly with government to fund a cadre of CHWs in line with the government's CHW Policy. Every PEPFAR-supported facility with more than 500 people on ART will be linked with a cadre of community health workers supported by PEPFAR through the public sector. These CHWs will be formally paid, trained, capacitated, and equipped with communications and transportation needed to be effective. PEPFAR will also fund a cadre of supervisors of the CHWs at ratios based on best practices. In addition, in COP20, 100% of PEPFAR-supported sites will have adherence clubs established and functioning that enable groups of PLHIV stable on ART to meet and pick up medicines together via short (no longer than 1-2 hours) trips to the clinic. PEPFAR will support the staffing needed to establish and maintain these programs including community health workers and additional clinical staff. In addition, in each of the 27 PEPFAR-supported districts community-based adherence clubs will also be set up and staffed by PEPFAR supported clinical and community health workers. There are approximately 2,300 PEPFAR sites with more than 500 people on treatment. On average sites need 3-4 facility based CHWs and 4 or more based at the facility but who spend their time in communities to do outreach. So minimum numbers to be funded in COP19 should be: 6,900 facility-based and 9,200 outreach CHWs. This is in addition to outreach team leaders. We anticipate the direct-cost for salaries about R3,500/month, R42,000/yr (US$3,600) per HCW plus US$1,500 in supplies and communications. So total cost is US$45 million additional for new outreach workers.	COP20 will fund 6,900 facility-based and 9,200 outreach CHWs in in addition to outreach team leaders. 100% of PEPFAR sites will have an adherence club model for ART delivery as well as support groups running by end of COP20 and will report portion of patients in adherence groups.	

https://docs.google.com/document/d/1fokp3d84kAby8Ci0bG9Aa27A8QD_skYpRswt3iTmNeM/edit

What is the area of concern?

Continuity of care (retention)

What is the CSO priority?

Answers the question what do you want PEPFAR to fund with its continuity of care allocation eg. Increase the number of support groups at the facility funded by PEPFAR.

What is PEPFAR doing in 2020? (refer to the SDS and Quarterly data)?

Review and cite PEPFAR data.

Target for COP 21?

Be as a specific as you can in the recommendation. COP 21 will fund 200 new support group in Kampala

Agreements in COP21?

Note down your wins from the COP process

How to Win!

1. Start working on your recommendations early and send them to PEPFAR teams early.
2. Present your recommendations as many times as you can in the most detail you can so they know it is important. Before the planning meetings make sure PEPFAR knows your major priorities and ask that they be included in the agenda for the meeting.
3. Be as detailed as you can about the most critical request but no shopping lists.
4. Use data to inform your recommendations. (Guidance, Quarterly data, country data)
5. Have pre-meetings with all civil society organizations to make sure your representatives are well prepared to represent all of your priorities
6. Send your best, boldest advocates well prepared to push for your priorities; please email **info@pepfarwatch.org** to share the names of those who will be going!
7. Liaise with the international activists likely to be part of your planning meeting to strategize together. Send an email to **info@pepfarwatch.org** of you need help Identifying them.
8. Ask the PEPFAR team to send you the data and presentations for the planning meetings in advance.
9. If possible, Consider also doing a pre-meeting with government and implementers to gather information.
10. Consider inviting the PEPFAR team to a meeting hosted by civil society to discuss priorities.

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