

Recipients of Care Engagement Working Group Pre-meeting Report



HIV Differentiated Service Delivery Opportunities and Challenges for TB Prevention and Care

Lusaka, Zambia

March 26, 2019

1. BACKGROUND

Since its launch in March 2017, engagement of people living with HIV has been central to the CQUIN learning network. The [CQUIN Dashboard](#) includes a simple standardized metric with which to track community engagement, and network countries continue to flag this domain as one which needs improvement. In response, CQUIN convened the Recipient of Care Community Engagement Working Group in November 2018, to continue promoting the involvement of people living with HIV in the design, delivery and evaluation of Differentiated Service Delivery (DSD). This community of practice meets virtually every two months, and in person in advance of CQUIN network workshops and meetings.

CQUIN organized the second in-person Recipient of Care Engagement Working Group meeting in Lusaka, Zambia on March 26, 2019. The meeting was attended by 13 representatives from national groups and associations of people living with HIV from 8 CQUIN member countries - Eswatini, Kenya, Malawi, South Africa, Tanzania, Uganda, Zambia and Zimbabwe. Participants discussed common barriers, challenges, opportunities for meaningful engagement of people living with HIV in DSD policy development, program design, planning, implementation, monitoring and evaluation.

The objectives of the meeting were to:

- Identify opportunities for co-creation of solutions to promote meaningful, proactive and sustainable engagement of people living with HIV for DSD demand creation
- Review and discuss the staging of the CQUIN Dashboard “Community Engagement” domain
- Identify common key barriers and challenges related to meaningful engagement of people living with HIV in TB/HIV services
- Prepare communication strategies, recommendations and key “takeaway messages” for the [CQUIN TB/HIV meeting](#) starting the next day

2. SUMMARY OF MEETING

The meeting was facilitated by Dr. Bactrin Killingo, from ITPC, Dr. Peter Preko, CQUIN Project Director, and Ms. Siphwe Shongwe, CQUIN Clinical Advisor. Participants included 13 representatives from national networks of people living with HIV. The participant list is included as Appendix A and the meeting agenda is included as Appendix B. Key takeaways from the meeting included:

A. Defining Community Engagement: Noting that principles of CE should include inclusivity (all people living with HIV and recipients of care), meaningfulness, consistency, transparency, structure, equity, support, practicality and accountability, meeting participants deliberated about the most useful definition of “community engagement” as it relates to DSD.

CoP members agreed on the following definition: ‘A structured, supported, meaningful, and accountable process that ensures that people living with HIV have a both seat at the table and a voice in decision-making, planning, implementation, monitoring and evaluation in order to achieve access to quality HIV care for all’.

B. Feedback on the CQUIN DSD Dashboard CE domain: Key recommendations for the CQUIN CE domain were;

1. The dashboard would be more nuanced if CE was defined at different levels; 1) policy, 2) programming and planning and 3) implementation. Currently all three levels are combined, with a focus on policy and planning.
2. The dashboard includes both civil society organizations (CSO) and people living with HIV, but the group felt that beneficiaries and supporters should be scored separately. Because the CE definition that the CoP developed includes only people living with HIV, the group's recommendation was that the domain should include people living with HIV only.
3. Because critical decisions are made at sub-national levels, it would be optimal for the dashboard to capture the element of decentralization – recipients of care should be engaged at regional/provincial level, not just national level.

C. Messages and recommendations for the subsequent TB/HIV meeting: The group reviewed the agenda for the upcoming three-day meeting on DSD and TB/HIV services. Their main take-away messages include:

1. Community engagement is critically important for both TB/HIV and DSD programs
 - a. The group recommends that CQUIN and its member countries adopt the CE definition above
 - b. Ongoing engagement with RoC is necessary – not just “lip service” during meetings
 - c. The CoP wants to be engaged in the development of agendas for CQUIN meetings
 - d. DSD models seem to be defined by providers – RoC need to be more engaged in model development, evaluation, and adaptation
2. TB treatment literacy lags behind HIV treatment literature, and needs to improve
 - a. Despite high levels of TB/HIV coinfection, RoC are more knowledgeable about ARVs compared to TB treatment
 - b. There is very little information about TB disseminated for recipients of care (RoC) especially about TB medication
 - c. TB information needs to be simplified and messages need to be piloted in the community – this has been done for HIV, why not for TB?
 - d. Organizations of people living with HIV can improve TB/HIV treatment literacy if they are properly resourced. They have the capacity, but not the funding!
 - e. Information is the first step towards empowering TB/HIV patients to demand high quality services
3. Successful TB/HIV integration should start from donors & implementing partners
 - a. Funding for TB and HIV is siloed, leading to siloed programs
 - b. Need for leadership within MoH and RoC to advocate for TB/HIV service integration
4. Existing TB screening tools and strategies are suboptimal
 - a. Symptom screening may not be sufficiently sensitive
 - b. Point-of-care TB testing (GeneXpert, LAM) has not been taken to scale

5. Language! Service providers should communicate appropriately when addressing RoC. They are not clients, nor subjects, maybe patients (when they are unwell). RoC is the perfect term to address PLHIV.

3. NEXT STEPS

- Develop a community engagement monitoring tool specific to DSD
- Develop a framework for in-country community engagement in relation to DSD and CQUIN
- Provide a platform for learning exchange within the Recipients of Care Engagement Working Group

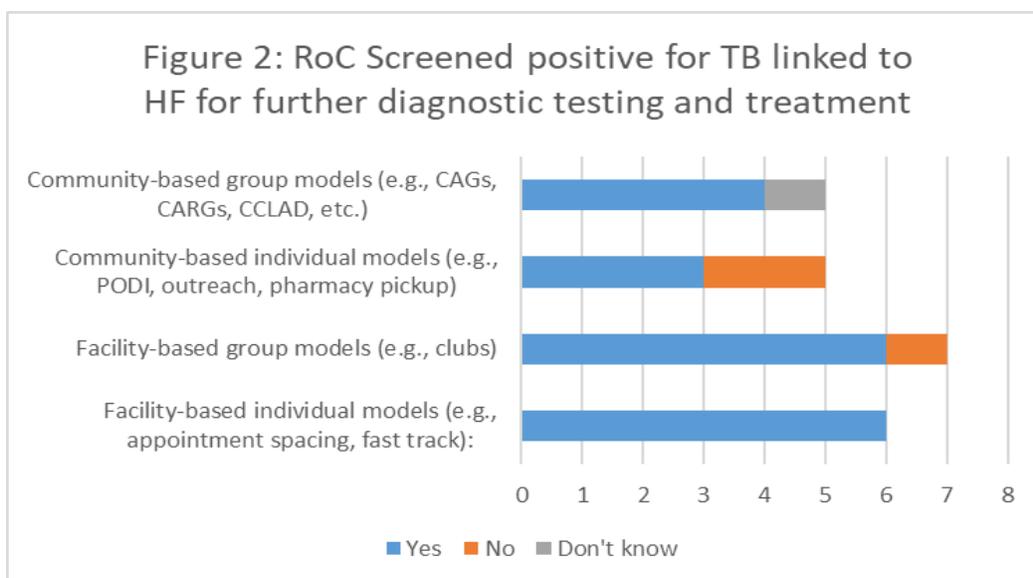
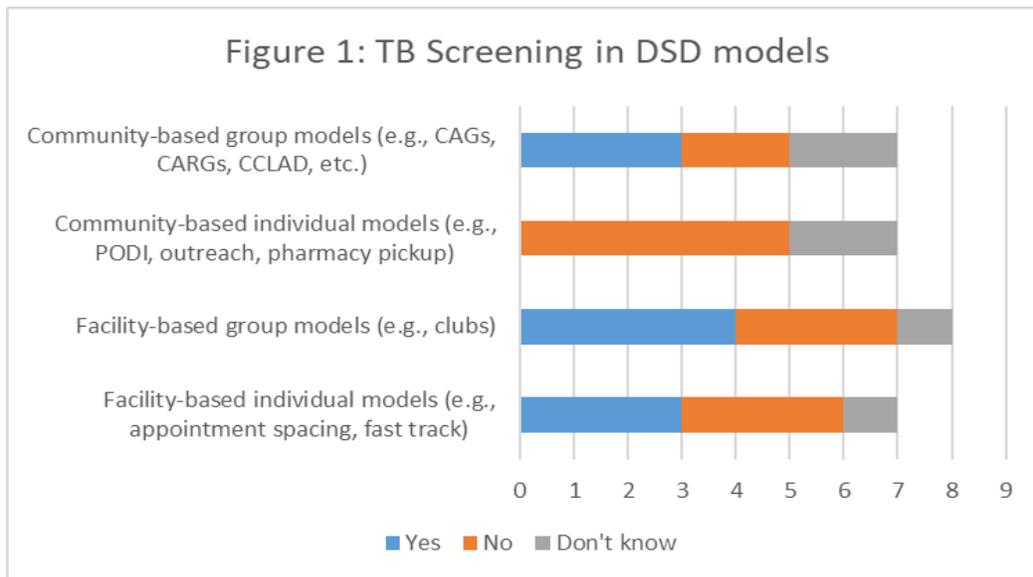
4. PRE- AND POST-MEETING SURVEY RESULTS

A. Pre-meeting survey results

The pre-meeting survey was sent to 10 RoC CoP members. Nine out of ten responded. Despite the small sample size, the results provided interesting entry points for discussion throughout the meeting. The following are a summary of results:

- Eight out of 9 respondents (89%) reported a good/high knowledge of DSD in their country context.
 - Representatives stated that their Ministries of Health have engaged RoC or civil society organizations in DSD, mainly through DSD TWG meetings and in developing guidelines, SOPs, job aides and training manuals.
 - Only one respondent mentioned that there was RoC involvement in DSD implementation.
 - One participant stated that they were not aware of any form of RoC engagement in DSD planning, implementation and evaluation.
 - Several challenges/instances where MoH failed to engage RoC/PLHIV/civil society were stated. These include poor to no engagement of RoC at provincial/regional level, where service delivery takes place and no engagement during implementation and evaluation of DSD.
- Respondents were also asked whether RoC are routinely screened for TB in different DSD models (Figure 1).
 - TB screening was reported to be relatively common in facility-based DSD models.
 - 71% of respondents responded that RoC are not screened for TB in community-based *individual* models (such as outreach, PODI or pharmacy pick-up).
 - 43% of the respondents reported that TB screening does occur in community-based *group* models, such as CAGs and CCLAD.
- Respondents felt that a majority of RoC who screen positive for TB who screen positive for TB are effectively linked to health facilities for further diagnostic testing and treatment, especially those in facility-based models (Figure 2).

- In relation to TB preventive therapy (e.g. INH), respondents (n=3) agreed that it is offered to RoC in conventional models, whilst only one responded that it is also available for RoC in DSD models, and the rest (n=3) did not know.
- Respondents stated that they would like to learn about meaningful involvement and engagement of RoC in DSD.
 - Some respondents mentioned interest in learning how other countries have managed to engage MoH to ensure that resources are made available for implementing different models.
 - Respondents also expressed an interest in learning how other countries were monitoring TB and Health Information System Management for DSD.



B. Post meeting evaluations

A post-meeting evaluation survey was sent to all participants. Only 6 of 13 participants have completed the survey to date; all found the RoC pre-meeting to be useful and said they plan to share ideas and information on return to their home countries.

Participants felt it was helpful to learn from other countries, especially about challenges related to DSD implementation and scale up. They appreciated the fact that the pre-meeting provided a platform for participants to interact and discuss both community engagement and TB/HIV services in relation to DSD.

All six participants who completed the survey stated that they plan to share ideas and information discussed during the pre-meeting back in their home countries whilst five out of six felt that their organizations and countries will be able to apply ideas and information discussed during the pre-meeting to improve engagement of ROC with DSD policy makers and program managers. The lessons to be shared includes TB/HIV service integration in DSD models and how TB/HIV services can be integrated as well as the meaning/definition of community engagement.

Key changes that would be recommended following the pre-meeting includes; TB screening and TB preventive therapy in DSD models, integration of TB/HIV services in DSD models, harmonization of TB and HIV guidelines, and addressing TB prevention and treatment literacy among ROC in DSD models. Other comments and feedback from respondents were about appreciation for the CQUIN network to provide a platform for RoC to learn from each other and share experiences in regards to DSD scale up.

Appendix A: List of Participants

	First name	Last name	Title	Affiliation	Country Team	Email
1.	Mr.	Mathew	Kawogo		National Council of People Living with HIV/AIDS	Tanzania mathewk@nacopha.or.tz
2.	Mr.	Lawrence	Khonyongwa	Executive Director	Malawi Netowrk of People Living with HIV	Malawi lawrencekhongyonya@yahoo.co.uk
3.	Mr.	Luckyboy	Mkhondwane	National Treatment Literacy Coordinator	TAC	South Africa luckyboy@mail.tac.org.za
4.	Ms.	Stella	Kentutsi	National Director	NAFOPHANU	Uganda stella.kentutsi@nafophanu.org
5.	Mr.	Gavin	Khumalo		SWANNEPA (Swaziland Network for PLHIV)	Eswatini khumalogavin@gmail.com
6.	Mr.	Nelson	Otwoma	Coordinator	Kenya National HIV Association	Kenya notwoma@nephak.or.ke
7.	Mr.	Felix	Mwanza	Director	Treatment Advocacy Literacy Campaign (TALC)	Zambia felimwa@yahoo.com
8.	Mr.	Tonderai	Mwareka	Program Manager	ZNNP+	Zimbabwe mwarekatm@gmail.com
9.	Ms.	Lillian	Mworeko	Executive Director	ICWEA	Uganda lmworeko@icwea.org
10.	Ms.	Robinah	Babirye		AY+	Uganda brobinah13@gmail.com
11.	Mr.	Owen*	Mulenga		Treatment Advocacy Literacy Campaign (TALC)	Zambia owenmulenga@gmail.com
12.	Mr.	Fred*	Chungu	Executive Director	ZNP+	Zambia fredchungu@gmail.com
13.	Ms.	Caroline*	Nawina		Coalition of Global TB Activists	Zambia carolnawina@gmail.com

Appendix 2: Pre-meeting Agenda

Pre-Meeting for Organizations of People Living with HIV

Radisson Blue Hotel, Lusaka, Zambia

March 26, 2019

9:00 a.m. – 4:00 p.m.

9:00 – 9:30	Registration <i>Ms. Siphive Shongwe</i>
9:30 – 10:00	Introductions & Setting the context <i>Dr. Bactrin Killingo</i>
10:00 – 10:30	Survey Summary Common Successes, Challenges, and Discussion <i>Ms. Siphive Shongwe</i>
10:30 – 11:00	Tea break
11:00 – 11:45	Forming the CoP CoP ToRs, Co-creation of resources <i>Dr. Bactrin killingo and Peter Preko</i>
11:45 – 12:30	Define community engagement <i>Dr. Bactrin killingo and Dr. Peter Preko</i>
12:30 – 1:00	Summary, next steps and commitments <i>Dr. Bactrin killingo</i>
1:00 – 2:00	Lunch
2:00 – 2:15	Review of TB/HIV meeting agenda and goals <i>Dr. Peter Preko</i>
2:15 – 3:30	Key Recommendations Take Home Points for Larger Meeting <i>Dr. Bactrin Killingo</i>
3:30 – 4:00	Closing Remarks