

Stakeholder perceptions of community-owned data:

Perspectives from community-led monitoring

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Background

Achieving 95-95-95 targets will require a new effort to close gaps in quality of care and retention, especially for populations that face structural barriers to care.

Community-led monitoring (CLM) has emerged as a critical strategy to addressing these gaps by empowering community to hold duty bearers to account for quality service delivery. CLM consists of ongoing cycles of community-led data collection on health services, analysis of those data, and collective solution generation and advocacy.

Despite growing interest and implementation, little formalized research on CLM exists to date. This work uses qualitative research to characterize the unique challenges and benefits of using community data for advocacy in early CLM implementation.

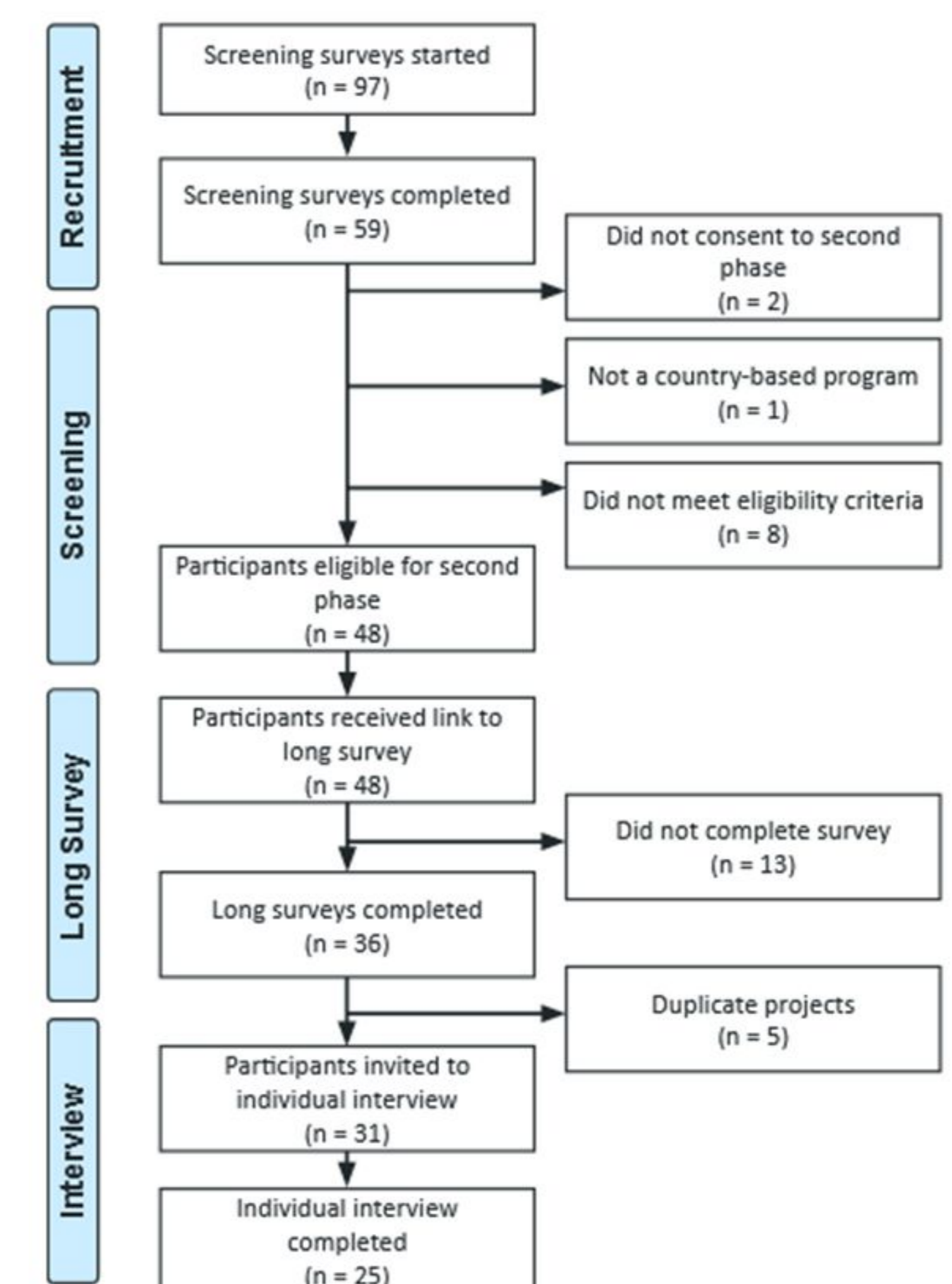
Methods

Participants were recruited from CLM programs focused on HIV, TB, malaria, or COVID-19 health service delivery and/or human rights using a brief screening questionnaire.

Respondents were invited to participate in interviews if they fulfilled at least two of the eligibility criteria: membership in a community organization, affiliation with a data-collecting program, and participation in a program conducting advocacy using those data.

Interviews were translated, transcribed and coded independently by two researchers using deductive hierarchical coding followed by purposeful thematic analysis.

In holding with the principles of CLM, community was centered in this research through collaborative development of survey and interview tools and the use of member checking during data analyses.



Results

Respondents: Twenty-five in-depth interviews were completed with respondents from CLM programs in 21 countries including representation from North Africa, Central Africa, West Africa, Eastern and Southern Africa, Eastern Europe, Central Asia, and Southeast Asia.

Ownership and evolution of data collection tools

Respondents highlighted that data were only useful for advocacy when community truly owned and led the development of the tools to be used for data collection, otherwise they were not reflective of local priorities. Challenges arose where funders and other stakeholder requested harmonized indicators across diverse contexts or had specific indicators they wanted included that communities did not feel were relevant.

"We have started looking at the tools again, as they they've been rolled out in the community, right? Just to see if they are speaking to issues that communities have. So, if they are top-down, basically they remain very structured to the extent that they do not speak to the different conditions that the different communities experience."

Capacitation for data collection

CLM projects noted that projects needed both skilled staff for data management and analysis, but also highly capacitated community monitors for data collection. Community monitors were perceived as being the face of the project, so ensuring they had an appropriate skill set was highlighted as essential. Retention and capacitation of community monitors was particularly challenging given payments or incentives were often delayed or not budgeted for.

"These are the ones at the front. It's different from the generals who are in the offices. They are theorists where they know war, in theory. But [without capacitation] those who face the enemy, the target...they are not armed."

Standards for data

Communities were at times faced with pushback that data were not rigorous enough or sample sizes were not large enough. CLM data was sometimes held to standards of national-level monitoring and evaluation systems. CLM projects also struggled to use qualitative data in a compelling way and when or if their data spoke to issues at beyond a facility level.

So, if you pick up qualitative issues...some of them are critically important for one site, but they are not for another site. But, you know, I think people or stakeholders, and even key advocacy players, are interested in things that affect the majority. So, how do you transmit that information about the minority so that it makes sense? How do you justify that?

The value of community-data

CLM projects highlighted that community data was truly reflective of what community cared about in a way that government and academic data systems were not. The timeliness and ever evolving nature of CLM data and tools was also highlighted as essential for advocacy.

"So, [CLM] creates a world apart from the previous world where community-led monitoring was not available, where we had to rely on surveys, where we had to rely on a situational analysis and all sorts of things that are very...what I can call very academic, very structured in nature. So, it's community-led monitoring, where it is functional, where the information is available, and it's stored and packaged in a manner that speaks to what communities want, creates an opportunity for data that is available, that can be shared at any moment."

Conclusions

- The CLM model is an innovative strategy for the improvement of HIV service delivery, arming civil society with timely and relevant data for advocacy in a way not replicable by traditional monitoring and evaluation tools or academic research.
- However, given the nascency of CLM, challenges remain in reaching consensus on what characterizes high-quality CLM data for both community and other stakeholders.
- Moving forward, CLM funders and technical experts like PEPFAR, the Global Fund, and UNAIDS can play a critical role in clarifying for other stakeholders both CLM's unique model and the associated benefits for health and community systems strengthening.



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