

Community-based monitoring: An Overview

May 2020

1. What is community-based monitoring?

Community-based monitoring (CBM) refers to service users assessing the effectiveness, quality, accessibility and impact of health programs and services which they receive. CBM includes any type of monitoring led by communities, however a key principal of CBM is that communities decide what to monitor and act upon the data collected. Unlike monitoring led or undertaken by health systems, advocacy based on the evidence and observations gathered is an essential outcome of community-based monitoring initiatives.

CBM is undertaken through mechanisms that, depending on the specific objectives of the monitoring, service users and communities **gather quantitative and qualitative data and observations to assess the availability, accessibility, acceptability, equity, and quality of services they receive and uses that information to hold service providers and decision makers accountable**. This short [video](#) provides illustrative examples of CBM.

The most effective CBM projects are implemented so that the main concerns of recipients of care are reflected and prioritized from the beginning. Therefore, the work varies by context, goals and objectives, geographic scope, and target population, among numerous other factors. CBM initiatives have monitored a wide range of issues that are associated with effective and responsive HIV, TB and malaria services, with many of the activities centred around the quality of client experience at facilities, the quality of systems (clinic management), the quality of programmes, availability of essential drugs and violations of rights.

CBM models can take different forms and types. For instance, community scorecards used in health facilities, patient satisfaction surveys, complaint and grievance mechanisms, treatment observatories and social audits, resource and budget tracking and monitoring and responding to human rights violations. Many models use pre-determined tools which includes quantitate and qualitative indicators and data.

This document aims to stimulate the inclusion of CBM in Global Fund grants to complement national monitoring systems, identify bottlenecks to improve service delivery and respond to community preferences regarding access, quality and acceptability of services. Furthermore, CBM integrated into Global Fund grants contributes towards a comprehensive strategic information landscape of national HIV, TB and malaria programs.

Global Fund definition of CBM

Mechanisms that service users or local communities use to gather, analyze and use information on an ongoing basis to improve access, quality and the impact of services, and to hold service providers and decision makers to account.

HIV treatment access in West and Central Africa

Regional Community Treatment Observatory in West Africa (RCTO-WA)

To better understand gaps and challenges in HIV treatment service delivery, 11 local civil society groups across 11 countries in west and Central Africa, with support and coordination from the International Treatment Preparedness Coalition (ITPC) rolled out community treatment observatories (CTO) to improve access to ARVs for people living with HIV.

Implementation: The project ran between January 2017 and December 2019 and recruited and trained data collectors (84 in all across the 11 countries) who then reviewed available data and surveyed clients and health workers to fill in periodic reports. Both quantitative and qualitative data were gathered, with the quantitative tool including more than 100 indicators relevant to assessing the overall quality of service delivery. Over the course of the project, data collectors and other personnel conducted more than 1,500 interviews, organized 143 focus group discussions, and visited 125 health facilities. They reached nearly 100,000 young people, more than 35,000 key populations and engaged a total of 105,435 people on ART.

Results: Among the biggest ongoing challenges noted was the lengthy gap in returning viral load test results to clients, as only 25% of results were returned within two weeks. Positive trends were seen in several key indicators as the project progressed, developments due in part to community groups' advocacy based on observatory findings. For example, the frequency of recorded stock-outs at facilities monitored across the project was 15.2% in period three (January-June 2019) compared with 23.6% over the same period the previous year. The rate of viral load suppression improved even more substantially, rising from 48.4% in January-June 2018 to 77.4% during period three the following year. Several notable country-level changes were observed as well in response to the monitoring findings and subsequent advocacy, including improvements in quality of care in health facilities in Mali and the removal of user fees in Nigeria.

Costs: The Global Fund grant was EURO 3.6 million over three years for 11 countries (in three languages). From a national perspective, the estimated annual cost of implementing a CTO in one country with about 15 data collection sites (health facilities) is about US\$350,000.

2. Why support community-based monitoring?

CBM provides a unique opportunity to the Global Fund to improve quality and efficiency of investments, particularly for key and vulnerable population prevention, care and treatment programs. This is echoed in the 2019 TERG report which notes that CBM is underutilized and urged that “**community-based monitoring should be scaled up and community data systems strengthened and linked to the national data systems, in order to improve access and quality of services.**”¹

There has been a long history of CBM in relation to health, particularly HIV, TB and malaria responses. Community-based organizations (CBOs) and other civil society groups have been implementing monitoring activities for decades at local, regional and global levels. More recently, experience and interest in this monitoring model has gained significant traction across the health sector. For instance, in COP 20, all PEPFAR programs are required to develop, support and fund a community led monitoring platform. Similarly, Expertise France and other donors already invest in supporting treatment observatories in Francophone Africa.

¹ Technical Evaluation Reference Group: Position Paper - Thematic Review on Resilient and Sustainable Systems for Health (RSSH), July 2019. Available at: <https://bit.ly/3d1ztNr>

Spotlight on TB program challenges in Sierra Leone

Community Based Monitoring and Feedback on National TB Service Delivery

Persistent challenges in the implementation of an effective TB program in Sierra Leone triggered the Civil Society Movement Against TB (CISMAT-SL) to implement a CBM model to assess the performance of national TB service delivery; to recommend actions to improve the situation and to accelerate community engagement in all aspects of TB-related service delivery in 16 districts.

Implementation: The core of the work consisted of data collection at facilities and among clients on a monthly basis by 160 community TB 'animators' who use a specially designed tool. CISMAT-SL also recruited 16 district coordinators to supervise data collection at the district level and submit forms and information to CISMAT-SL headquarters for analysis. Data collected included where drug stock-outs are occurring and the availability of TB drugs in facilities at the end of every month; infrastructure and staff capacity levels at facilities; stigma, discrimination and human rights violations experienced by TB clients; and TB case notification and lost to follow-up data.

Results: Positive impacts seen from advocacy undertaken in response to the findings include more expedited drug supplies (and thus fewer stock-outs) and efforts to create more TB sites, which reduces travel time and thus makes it easier for clients to access facilities.

Costs: The total cost of this CBM initiative since 2017 was \$290,000 - which covered 14 districts with 2 subsequently added. As of March 2020, the estimated cost to implement across 16 districts for the next 5 years is \$750,000. The cost is estimated to be a bit higher per facility due to the addition of new digital tools and added incentives for community members undertaking the work. Costs includes monitoring activities only and excludes expenses for training workshops and advocacy work.

3. How does CBM add value?

CBM contributes directly to the achievement of three of the four Global Fund's 2017-2022 Strategic Objectives: (1) maximize impact against HIV, TB and malaria; (2) build resilient and sustainable systems for health; and (3) promote and protect human rights and gender equality.

CBM helps to collect, assess and triangulate data and observations – both quantitative and qualitative– that are essential for program oversight and to improve policies and procedures. The immense value of communities collecting data can be seen in the kind of information and observations resulting from independent monitoring activities, which is often quite different from the results of monitoring undertaken or controlled by health systems, other government agencies, academic institutions, and other stakeholders outside of the civil society sector. Recipients of care speak more freely to community members about the quality of the services they receive. It is key to note that CBM is not a substitute for more traditional DHIS systems, instead it compliments and should be used in addition to monitor quality and accessibility of services.

CBM has supported **gathering crucial data that the health system does not often have access to, especially around key populations and other underserved groups.** This ingrained advantage is likely to become even more important in the future because recent trends indicate that national HIV and TB epidemics in all contexts are increasingly concentrated among or closely associated with key populations and other marginalized groups. Similarly, CBM can **fill gaps in issues that cannot be captured by health facility monitoring.** In HIV programming, for example, CBM is uniquely well-positioned to find people who have dropped out of care and to provide insights for how overall retention efforts might be improved.

The costs of CBM implementation are modest in comparison to data collection and data strengthening investments. As a result, the CBM value for money proposition contributes indirectly to the fourth strategic objective - mobilize increased resource. Particularly using the findings from CBM interventions to advocate for additional financial resources for health from governments or other donors.

Human rights-advancing tool worldwide

Rights - Evidence - Action (REAct)

Frontline AIDS and national civil society partners implemented REACT in 22 countries between 2014-2018, anticipating a further 20 countries for implementation between 2019-2020 in response to violence and human rights violations in communities that were impeding access to HIV services. As a result, data collected in monitoring processes were used to inform quality human rights-based HIV programming, policy and advocacy at national, regional and global levels.

Implementation: REAct is based on semi-structured interviews carried out by specially trained community monitors. Each REAct implementing organization owns the data it collects, and is responsible for monitoring, analyzing, and using this data to inform their own programming.

Results: 234 community representatives were consulted and trained on REAct and on human rights-based HIV monitoring and responses along with nearly 50 CBOs and Frontline AIDS partners providing direct emergency responses to human rights and violence related to the needs among community members. Moreover, 686 cases of violations were documented, responded to, or referred. Of particular importance, the following impact was achieved as a result of implementation:

- **Evidence from the cases documented under REAct contributed to the Tunisian parliament passing, in 2019, the Organic Law on the Elimination of All Forms of Racial Discrimination**
- **In 2018, Lebanon passed a law for the protection of people living with HIV. Evidence generated by React was presented in parliament to advocate for the passing of the law. The evidence gathered also helped to influence authorities to regulate and sanction breach of confidentiality and ethical practices at state-run health premises.**
- **REAct informed a research report by Sexual Minorities Uganda (SMUG) called ‘And That’s How I Survived Being Killed’, which documented 264 reported violations and was used in pre-election campaigning to sensitize candidates**

Costs: The total costs of establishing and running the REAct initiative in South Africa, where it is embedded as a component of the national HIV monitoring, were \$255,774 over a three-year period. Indirect costs over the same timeframe totalled \$30,693, resulting in a grand total to \$286,467. The project has also been embedded at a smaller scale in other contexts. The budget for working with 3–4 organizations and focusing on up to 2 key populations is about \$90,000 over two years.

4. How can CBM be embedded in Global Fund grants?

CBM adds value to Global Fund investments, programs and disease responses by **bringing community-led solutions to address program implementation bottlenecks, quality and performance to the table**. CBM initiatives have responsive, realistic ideas and recommendations for how to improve HIV, TB and malaria service quality and delivery. This is especially important at the national and subnational levels – e.g. for CCMs, governments, health care facilities, and civil society stakeholders – where planning and implementation takes place.

Community-based monitoring is one of the four priority community systems strengthening (CSS) interventions in the Resilient and Sustainable Systems for Health (RSSH) module which include workplan tracking measures and indicators for progress monitoring. Furthermore, CBM is an essential component of human rights and gender integration into prevention, care and treatment programs for key and vulnerable populations and provides a secondary opportunity for investment. If there is no existing CBM mechanism in country, the Community, Rights and Gender Department, through the Community, Rights and Gender (CRG) Strategic Initiative (SI) can provide technical assistance to communities and civil society to develop a CBM strategy. Moreover, additional technical assistance is available to a limited number of countries through the RSSH Service Delivery and Innovation Strategic Initiative.

ART retention in Indonesia

Peer-led on tracking of lost to follow-up (LTFU) PLHIV

While observing lost to follow-up rates of more than 20% per year among people living with HIV on ART in Indonesia, the Hagarin Indonesia Positif rolled out CBM in central and south Jakarta to identify and trace PLHIV who are lost to follow-up. The project objectives included to (1) encourage and motivate PLHIV to re-engage with health facilities and go back on ART; (2) record the causes for people abandoning ART and dropping out of care, and (3) monitor treatment compliance for those who re-start ART (adherence).

Implementation: Identification and tracking those lost to follow-up was done through peer-led approaches. This included developing standard operating procedures (SOPs) for the outreach workers and training 10 peers – all PLHIV on ART who had suppressed viral loads – in areas such as motivational interviewing. The project was developed in collaboration with local government and health services and underpinned by memorandums of understanding (MOUs) with provincial and district health offices and individual health facilities. Each peer received a formal assignment letter from health facilities that explained who they were and the objective of their work. Such letters could be shown to individuals and families to help convince them to 'open the door' to the peers.

Results: The initiative was highly effective because it directly contributed to an improvement in retention rates among clients on ART. Health officials view it as an innovation that could be implemented in other facilities and districts, and interest elsewhere in introducing the model reportedly was already strong. Also notable is that the project provided valuable information and observations on why people stopped taking medications or dropped out of care altogether. Two of the top reasons were that they felt healthy and hated the side effects. This type of information based on the experiences of clients themselves is useful for more effective programming, including in adherence support.

Costs: The LTFU tracking initiative costs about \$150,000 per year, which in 2019 covered activities in two districts of Jakarta with 10 peer trackers.

5. Additional Resources

UNAIDS is in the process of creating guidance. Other resources include:

- Expertise France: [Report on Community Health Observatories](#).
- PEPFAR: [Community-Led Monitoring Tools](#)
- The Stop TB Partnership: [Community-based monitoring of the TB response, using the OnelImpact digital platform](#)