
Towards a Common Understanding of Community-based Monitoring and Advocacy

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Acronyms and abbreviations

| | |
|---------------|---|
| CBM = | community-based monitoring |
| CBO = | community-based organization |
| CSO = | civil society organization |
| Global Fund = | Global Fund to Fight AIDS, Tuberculosis and Malaria |
| JLI = | Joep Lange Institute |
| NGO = | non-governmental organization |
| PEPFAR = | US President's Emergency Plan for AIDS Relief |
| SDG = | Sustainable Development Goal |
| UHC = | universal health coverage |
| WHO = | World Health Organization |

1. Purpose and process of the meeting

The Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) is committed to scaling up community-based monitoring and advocacy (CBM) as a means to improve the responsiveness, effectiveness and impact of grants and country disease responses. To help advance this agenda, the Global Fund sponsored a meeting on 20–21 February 2020 at the Global Health Campus in Geneva, Switzerland that brought together (1) representatives from global, regional and national community-based and other civil society organizations; (2) Global Fund staff, including from the Community, Rights and Gender (CRG) department; and (3) representatives from other donors and multilateral technical agencies that work closely with the Global Fund at the Secretariat and implementing country levels.

The meeting was coordinated by the Joep Lange Institute (JLI) and co-sponsored by the Stop TB Partnership and Expertise France. The World Health Organization (WHO), the Joint United Nations Programme on HIV/AIDS (UNAIDS) and Unitaid also participated in meeting coordination and agenda development. The February 2020 meeting was part of a broader consultation and series of discussions on community engagement in health involving the civil society sector, donors, technical agencies, governments and other stakeholders.

The objectives of the February 2020 meeting, defined in advance, were the following:

- Support the uptake of CBM, especially in Global Fund funding requests, by increasing awareness of the purpose and added value of CBM as well as the development of guidance and tools on CBM as an effective way to monitor the performance of treatment, diagnostic and prevention services, better understand the needs of recipients of care, and provide evidence for advocacy to improve services and health outcomes
- Share the models, experience, results and learning from treatment observatories and other CBM approaches from a range of implementers, technical partners and donors
- Discuss key principles for CBM and community-led monitoring and advocacy

The meeting consisted of a combination of presentations and plenary discussions. The majority of the presentations were devoted to examples of various types of activities and programmes performed by civil society organizations (CSOs) at local and regional levels that were characterized as CBM. The intention of this wide variety and scope was to highlight the many opportunities for such work in different contexts and for different objectives.

An ongoing discussion theme at the meeting was how to conceptualize and define CBM and what that might mean from the perspective of Global Fund grant-making and more broadly across health and development environments. Near the end of the meeting, participants brainstormed about the principles that drive community monitoring, the essential components that shape it, and what is needed to scale up and resource community monitoring and advocacy. Those preliminary ideas and proposals – described in this report – are the basis for the further discussions among the Global Fund, donors, technical partners, and civil society representatives on how to better ensure that funding, technical assistance and other kinds of support that meet the needs and standards of communities and other civil society groups working in implementing countries are made available more extensively, consistently, and sustainably.

Near the end of the meeting, participants discussed **opportunities to get CBM activities funded in the Global Fund's ongoing funding cycle**, including options for technical support and assistance both within the Global Fund and from several governmental and civil society partners. The tight deadlines in the next few months make this an urgent priority for many community and civil society groups.

This report provides a summary of discussions at the meeting on 20–21 February 2020. It is not intended to be a comprehensive, in-depth account of all proceedings. Annex 3 contains a list of participants. Summaries of the CBM examples presented and discussed at the meeting are included in Annex 1.

2. Introduction and overview: why community-based monitoring?

The importance of community-driven activities in health systems everywhere in the world has been signalled for decades, including when community engagement was highlighted as a central component of primary health care at the landmark International Conference on Primary Health Care in Alma-Ata in 1978.¹ Today, more than four decades and countless health guidance documents and frameworks later, the promise has yet to be realized, largely because community and other civil society groups have never been adequately respected, funded or integrated into health systems. This lost opportunity can only be rectified through more extensive community systems strengthening (CSS) that covers the full range of what communities can and should be doing in current and future health responses.

CBM is one aspect of the overall community engagement spectrum. It has a critical role to play in identifying and effectively addressing issues and bottlenecks in engaging and retaining people along the prevention and treatment continuums for HIV, TB and malaria. This is done through mechanisms that monitor the availability, accessibility, acceptability, equity, and quality of services. Advocacy based on the evidence and observations gathered is an essential final activity of most community monitoring initiatives. As one civil society representative noted at the meeting, “There’s no point in doing monitoring if you’re not using it. Monitoring should always be done for advocacy purposes.” This underscores the importance of advance planning to do the necessary advocacy, including by ensuring there is adequate funding – which remains one of the biggest challenges to this vital monitoring component of overall community engagement in health systems.

For the Global Fund and other stakeholders, CBM can help to collect and assess data and observations – both quantitative and qualitative input – that are essential for programme 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 CBM, which is often quite different from the results of monitoring undertaken or controlled by governments.

Of particular note, **working with community-based organizations (CBOs) and other civil society groups in this area is vital to recognize and respond to human rights and gender barriers that weaken programmes and systems.** For the Global Fund, that kind of knowledge is needed to gauge its own accountability, as well as that of its partners, to one of its four strategic objectives: To promote and protect human rights and gender equality (Strategic Objective 3). In every context or programme, whether or not the Global Fund is involved, failure to safeguard human rights and address gender-related obstacles severely undermines the quality and effectiveness of efforts to protect and support people living with or otherwise affected by HIV, TB or malaria. This represents a major danger to the health, safety and overall well-being of the individuals, families and communities who are supposed to benefit from programmes and services focused on the three diseases.

Awareness and interest within the Global Fund for finding more and better ways to support CBM have been growing, including because a high-profile Technical Evaluation Reference Group (TERG) report in 2019 concluded that CBM is underutilized and urged the following: “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.”² Increased interest in CBM and community engagement more broadly also has been seen in many other donors and Global Fund partners. The COP20 guidance for the US President’s Emergency Plan for AIDS Relief (PEPFAR), for example, states the following: “In COP 20, all PEPFAR programs are required to develop, support and fund a community monitoring platform in close collaboration with civil society organizations and host country governments.”³

For the Global Fund and other partners to fully seize the opportunities of CBM, it is important first of all that they be in harmony with CBOs and other CSOs. This means having a shared understanding of what

¹ www.who.int/publications/almaata_declaration_en.pdf

² Technical Evaluation Reference Group: Position Paper - Thematic Review on Resilient and Sustainable Systems for Health (RSSH), July 2019. Available at: <https://bit.ly/3d1ztNr>

³ <https://bit.ly/3a0kUb6>

constitutes CBM (and, as necessary, what CBM is *not*); basic principles and guidelines of CBM, including how the underlying concept should be framed and termed; and how and why to ensure the leadership and independence of CBOs and CSOs engaged in monitoring and advocacy. The 20–21 February meeting was a step toward building and formalizing this common understanding and, ultimately, driving more resources for community monitoring worldwide.

3. Defining and describing CBM: what criteria should guide it and what should it be termed?

The term 'community-based monitoring' has been used, and continues to be used, to refer to a wide range of activities and processes that differ substantially in areas such as what is involved, who is involved, and the purpose of the monitoring itself. At the broadest level, CBM is usually assumed to cover any type of monitoring that involves communities – whatever the monitoring activities, approaches and models comprise, and whether the monitoring consists of communities assessing their own activities or services and systems implemented by other entities. This heterogeneity is why there are many different definitions, even in regard to organizations and institutions focusing only on health-related CBM.

In defining CBM, one key differentiation is made between monitoring efforts that utilize community members in data collection (or just collect data from community members) and efforts that are developed and led by community organizations that usually work outside of the health system. This 'community-led monitoring' was the focus of much of the Geneva meeting discussion. Most participants prefer the 'community-led' approach, arguing that in order for it to be valid and acceptable, CBM must be entirely independent and driven by CBOs and CSOs and that the activities should be coupled with advocacy to act upon the results of the monitoring in efforts to improve access to and the quality of health care. The use of a strict definition of this sort, however, would exclude other types of monitoring that involve communities but are not necessarily led or directed by them – such as health systems, working closely with communities, seeking feedback from people getting services.⁴

Both approaches have value. Most meeting participants, however, stressed the need to tip the balance more in favour of 'community-led' approaches because they face the greatest and most persistent challenges to getting funded and taken seriously. Therefore, in the opinion of most civil society representatives and the meeting, **to ensure legitimate community engagement, funding and support for community monitoring from the Global Fund and all other stakeholders should be primarily directed toward organizations and other stakeholders that meet basic criteria of independence.** The core of these criteria should include communities being in control of the design, implementation, messaging, results and subsequent advocacy. This should be the basic underlying platform, regardless of the specific monitoring activities, models or approaches or the term used by the Global Fund and other funders of community-oriented monitoring of HIV, TB and malaria responses. Acceptable monitoring, however it is termed, would be 'by' communities and not 'of' communities.

For the distinction to be relevant to both funders and implementers, most participants also agreed that **greater clarity is needed on what would and should constitute legitimate community monitoring for**

⁴ The Global Fund and other stakeholders directly engaged in funding civil society groups to undertake monitoring or supporting them in other ways have different definitions of CBM that guide their work. But these definitions tend to have similar parameters and priorities. They typically stress the value of CBM and community participation more generally in helping to increase access to quality HIV, TB and malaria services by mobilizing communities and holding the institutions and mechanisms themselves – and government health systems at all levels – accountable to their commitments and values. Communities therefore can play different roles in CBM, acting as 'watchdogs' and as partners depending on the circumstances. (The Global Fund's current definition of CBM is as follows: '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.' The French government's 5% Initiative focuses on the term 'observatories' and calls them 'mechanisms to monitor and evaluate health systems that complement top-down approaches to monitoring; and citizen movements that give a voice to patients.')

health. This could be essential for better coordination, increased funding, and ‘routinizing’ community monitoring in the processes and structures of many donors.

Communities establishing minimum standards is one option toward this type of clarity. Some concern was expressed, though, that standardizing community monitoring could undermine or inadvertently side-line some great work done by communities, other civil society groups and even governments themselves to collect data and make changes that improve responses. Similar caution was expressed in regard to avoiding any ‘one-size-fits-all’ scenarios, since what can be done and works well in Senegal, for example, is different from that in India. The political, social and epidemiological context in each country will affect how CBM is shaped and implemented, as will the capacity of civil society to perform such work.

4. How CBM adds value

Several examples of community monitoring and advocacy were presented at the meeting by representatives of CBOs and other CSOs involved in designing and implementing them. (Annex 1 contains summaries of all the examples.) They differ in terms of tools, models and approaches; training, skills and expertise needed and deployed; geographic range; type and extent of data and observations gathered; and partnership and collaboration arrangements, among many other factors. Yet despite the differences, all examples refer to efforts by communities to assess the scope and quality of health services and obtain information that can improve access, care and support for all in need. Often the emphasis is on highlighting gaps and challenges in health service delivery – and especially for the most vulnerable and stigmatized populations – and then using the data as the basis for advocacy activities to directly address those shortcomings.

Independent budget monitoring by communities is another increasingly valuable activity in countries that are moving from external to domestic financing for their HIV programmes, such as countries transitioning from eligibility for funding from the Global Fund and other major financing mechanisms and institutions. Through close, detailed review of budget documents, civil society groups playing a close ‘watchdog’ role seek to determine if promised domestic funding for HIV and other health services is actually allocated and spent on the services that national or sub-national budgets indicated it would be spent on.

The examples listed in Annex 1 showcase many of the values of CBM to overarching efforts to build, improve and sustain health care services and outcomes, including HIV, TB and malaria programmes that reach all in need. These examples show how CBM can contribute to improving the quality of and access to services by encouraging providers to be more responsive to the needs and preferences of care recipients. Some general examples of value added of CBM that were cited at the meeting include the following:

- Brought the **right to participation and meaningful engagement of clients and communities** to the TB response, which has primarily been focused on service delivery and extension of the health system. Now, for many donors and technical partners, engaging people affected by HIV and other community members is a priority at country level in designing, implementing and monitoring TB programmes.
- Contributes to **embedding and advancing human rights** in programme responses from global, regional and national perspectives.
- Provides essential **feedback into global guidelines processes**. For example, community monitoring and advocacy contributed to WHO revising its HIV treatment guidelines in 2019 to recommend that all women be given equal access to dolutegravir (DTG) despite some small risks indicated for pregnant women.
- Provides **data on communities from a client perspective** that could not be gathered efficiently or effectively by national or global programmes. This information helps to boost the quality of programmes by giving them input to make them more accessible and acceptable for end users. Such data also can shine a light on social determinants of HIV, TB and other diseases, and thereby prompt targeted action to understand and address them.
- Gives government health officials and policy makers an “**outside the room**” view, in the words of one meeting participant, which is critical for any successful efforts to make services more client-

centred. Community monitoring is also **vital for governments' accountability**, so that, for example, a ministry is "doing what it said it was going to do".

- Documents more effectively and realistically **which populations are being overlooked** or otherwise not being reached, which differs by context, disease and specific services.
- **Improves the quality of quantitative data** by being one of the ways that governments and technical agencies can triangulate their data. For example, when reviewing quantitative data generated through CBM work, representatives from other sectors can consider whether they are reaching the same results and conclusions from similar data that they collect.
- **Improves overall data quality by 'humanizing' it with qualitative data.** Often, the qualitative aspects of CBM implementation – e.g., client surveys about access – give insight into barriers that are not evident in the numbers, but which are a factor in overall quality.
- **Brings solutions to the table.** Community monitoring is not just about 'pointing the finger'. CBM initiatives often have sensible, realistic and excellent ideas and recommendations for how to improve health service quality and delivery. Recognizing this collaborative component is helpful among health facilities, CCMs, governments, and other stakeholders.

Another additive-value reason cited for supporting, funding and promoting community monitoring is that it can help to **'shift power' from those implementing programmes to those most affected** (e.g., people living with or otherwise affected by HIV, TB or malaria and other communities). Shifts are often needed to block or reform potentially harmful policies and programmes and to ensure that the interests and needs of communities are more influential in decision-making. For example, index testing is a strategy now being promoted to improve HIV case finding. But there are major human rights concerns when a person living with HIV is 'asked' – which could mean 'forced' – to bring into care others who might be at risk. CBM could provide valuable information about the effect of index testing on people's attitudes and willingness to test for HIV and about the impact that contact tracing might have on incidences of domestic violence and HIV-related discrimination.

A more positive example of power shift can be seen regarding the process of eliminating vertical transmission of HIV. As a result of community advocacy and pressure, women living with HIV are required to participate in the WHO validation process. This can help to ensure that validation is not occurring as a result of, or in spite of, systematic human rights and other violations against women living with HIV.

5. Notable challenges to more widespread CBM

Although many donors and other stakeholders might acknowledge the value of community monitoring, several challenges exist to it being better respected, funded and reflected in disease programming. **A major challenge is around concerns about the credibility of data collected through CBM.** Addressing this persistent challenge requires efforts to increase awareness of the value of CBM (as described in Section 5) as well as changing mindsets.

Also, experts and officials WHO and other influential institutions, including those engaged in the area of setting normative guidelines, often have no training in or understanding of the importance and **value of qualitative data** in designing and supporting effective HIV, TB and malaria programs. As a result, many of the main barriers to service delivery are not recognized or addressed. Yet despite this gap in knowledge, **data from CBM are rarely accepted or recognized for guidelines development and national-level programme evaluation and planning.**

Other challenges centre around capacity and funding constraints, including among CBOs and other CSOs at national level that want to do monitoring work. Some of these obstacles could be removed fairly easily and consistently with more information and resources made available from the Global Fund, other donors and other stakeholders that are interested in promoting CBM. These challenges include the following, among others:

- Capacity and training needs of monitors
- Lack of consistency and sustainability of funding

- Lack of funding for the advocacy work associated with monitoring
- Difficulties with health facilities providing access to clients and data, even when the monitoring activities have been formally approved and clients expressing strong interest in participating
- Ensuring independence in monitoring activities when receiving funding from or being overseen by an entity that is being monitored or is otherwise engaged in work associated with the monitoring. This could be the case, for example, with a sub-recipient in a Global Fund programme and the Principal Recipient.

6. Key additional considerations about CBM

The values and challenges associated with CBM influence other considerations about what community monitoring can and should do, as well as how it might be more formally incorporated into the work of donors and technical agencies. The following refer to some issues and considerations that were discussed at the meeting:

- **Who actually is authorized, or should be authorized, to represent communities** – to speak on behalf of them, to advocate for them, etc. This can be a difficult issue to discuss or resolve in many contexts.
- **Diversity in monitoring can yield the most diverse and valuable results.** Communities as a whole are more likely to accept and engage with monitoring that is led by, supported by and responsive to the voices of women, key populations and young people.
- **Potential problems with governments** should not be overestimated. Most problems relate to suspicion with ‘watchdog’-type monitoring that government officials often believe is aimed to embarrass or otherwise criticize them. These assumptions can lead governments to harass monitors or obstruct the work in other ways, including by attempting to block access to data and clients. Often, such problems can be dealt with upfront through strategies to build trust and to develop the ‘right’ kind of CBM models. This could mean, for example, positioning the monitoring as a form of partnership aimed at achieving the same overall goals of improving health services, including by identifying gaps and challenges that can be collaboratively addressed.
- **Protecting people who are involved in community monitoring** can be difficult in many contexts, including when they are from or supporting criminalized populations or focused on human rights violations that put them at high risk for harassment or abuse. But the security risks are more wide-ranging, because organizations involved in CBM are often disliked and threatened with closure. This limits their ability and inclination to be ‘watchdogs’ or act independently in other ways.
- The **security, confidentiality and ownership of the data collected through community monitoring** already are, and will continue to be, major issues for all organizations involved in CBM. Ideally, in principle, data are owned by those who give the data, which means the information should not be freely or easily available elsewhere. This points to a major priority of CBOs and CSOs to protect data, especially as digital systems and structures become more prominent and necessary in all their work. Community groups also need to consider how or if they agree to provide data to be integrated in national systems.

Data collected through CBM programs should be **incorporated into normative guidance** by WHO and other technical partners engaged in HIV, TB, malaria and broader health responses. This is seen as a crucial factor in increasing respect for, acceptance of, and funding of this type of monitoring by donors and governments in Global Fund implementing countries and more broadly.

Concerns about the legitimacy of community-provided data and input remain the key obstacle among most normative bodies in general. According to a WHO representative at the February meeting in Geneva, for example, the most critical thing for that global body is that communities have processes around data and development of evidence that are clear and well-documented and in the public domain. This is the baseline for legitimacy by WHO standards and for consideration for normative guidance. For WHO, the evidence also must be relevant, of high quality, and compliant with human rights standards.

WHO participants at the meeting also observed that there is often a time lag between what communities experience and instinctively understand collectively and when that is evidence that is taken seriously by large institutions and organizations such as WHO. There are some indications of change, however. WHO always includes community members on guidelines development teams, which is one way that diverse community experiences, voices and priorities can be leveraged. Another opportunity more recently became available because, starting in 2020, WHO must have public consultations for all guidelines-related changes or decisions. How that will work in practice reportedly had not yet been formalized by the time of the meeting, but it is assumed that such consultations will be largely online.

7. Digital solutions as opportunities

Making community monitoring faster, less expensive, and more precise can be beneficial to the organizations implementing the monitoring, those funding such work, and those utilizing the collected data. Improvements in these areas can support CBM at a larger scale and across a wider range of models and community partners.

Mobile technology and other digital platforms offer promise in boosting the efficiency and effectiveness of data collection, analysis, and reporting of all kinds, including that gathered through community monitoring. Their added value and benefits can be based on factors such as the following:

- Mobile phone technology and Internet accessibility continue to increase steadily everywhere in the world, including low-income settings, which means that digital platforms are technologically feasible in a growing number of places.
- Digital options for scaling can supplement human capacity, for example, and also allow new options for gathering both structured and non-structured (e.g., qualitative) data.
- Smartphones, which are increasingly ubiquitous throughout much of the world now, continue to get cheaper and more powerful. Many new tools and apps are fit for monitoring because they are not only able to gather and store huge amounts of data in easily accessible ways via smartphones but are also available with security and encryption tools and applications.
- New technologies can be used to gather client feedback in a variety of ways (audio, visual, social media, etc.), thereby tapping into the ‘wisdom of the crowd’, and to offer incentives for monitors (e.g., remuneration via mobile phones) that could further improve the quality of the data gathered.

An example of how and where mobile technology might be useful for community monitoring can be seen in **OneImpact, a digital solution for monitoring of the TB response developed by the Stop TB Partnership**. The goal of the smartphone-based tool is to improve overall TB responses, including by increasing accountability by further engaging with the TB-affected community to report barriers preventing them from being diagnosed, treated and reported. Reporting evidence-based challenges is one of the four main modules of the tool, with the others providing information and messaging about TB, the location of treatment and care facilities, and opportunities to chat among community members (peer-to-peer) or with a community support group.

Since early 2019, OneImpact has been introduced in six implementation phases, including feasibility, adaptation, solution development, training and launch, maintenance, and monitoring and evaluation (M&E). As of February 2020, nine countries were at various stages along those implementation phases.⁵ As implementation progresses, the Stop TB Partnership is assessing the value of the app in areas such as ease of use, impact at community level, how the community data were used (e.g., advocacy, dissemination of findings), and how or whether the data were responded to at national level, including by national TB programmes.

⁵ Cambodia, Democratic Republic of the Congo (DRC), Indonesia, Kenya, Mozambique, Nigeria, Tajikistan, Tanzania, and Ukraine.

Best practice observations to date indicate that OneImpact can be easily adapted to different local settings to meet community needs while also conforming to national TB guidelines, protocols and priorities. It can also be flexibly introduced and used, including in places with limited cell phone coverage. Moving forward, the Stop TB Partnership intends to scale up gradually, to ensure that the results of M&E can be leveraged adequately.

8. Next steps and commitments: short and longer term

Several steps and activities were proposed to promote an increase in funding for and expansion of CBM work. Some were priorities in the relative short term, to take advantage of imminent opportunities, while others were relevant over a longer horizon. Summaries of discussions regarding several of the proposed actions and approaches are listed below.

Definitions and parameters of community monitoring. Several meeting participants strongly supported establishing a common understanding of how CBM should be defined, as well as what its processes and outcomes should be. In their view, this could help CBOs and CSOs to think more strategically about what the data collected are used for, which could also help clarify the added value of community monitoring. Efforts to achieve consensus among communities on the definition and specific term used also could include consideration of potential minimum standards to which the definition would apply. That could be useful for the Global Fund, PEPFAR and other donors as they consider how they can better support such initiatives. [NOTE: Preliminary steps toward minimum standards are discussed in Box 2 and Annex 2.]

Closer collaboration with governments about core indicators. Governments are likely to be more supportive of community monitoring and to value its results when monitoring covers indicators of health responses (or, as relevant, for HIV, TB and malaria responses more specifically) that they have designated as priority. Many of these core indicators are things that governments need to know about to assess their efforts, and through their monitoring communities can provide important information about whether the services associated with the indicators are working well. Aligning with governments in this way is not a threat to independence because it does not mean that CBOs and CSOs cannot also select and monitor what they consider important.

8.1 Global Fund actions, approaches and entry points for CBM funding and technical support

There is a sense of urgency regarding the 2020–2022 funding cycle because Window 1 – the first deadline for submission of country proposals – closes 23 March 2020 and Windows 2 and 3 are not far behind. Representatives from both the Global Fund and civil society at the meeting stressed the importance of noting gaps in community engagement and identifying ways to increase CBM opportunities in proposals and build allies on the issue at the country level.

One strategic observation was that “if it’s not in the grant, it can’t be funded”. Thus, it is important to get ‘community monitoring’ or other language that self-evidently refers to CBM into one or more of the modules – such as the treatment, key populations, and adolescent girls and young women modules (for example). At the same time, it is also essential to provide some budget figures for this work. Later in the process, it will likely be useful for someone to be in the room during grant-making discussions to help ensure that the monitoring interventions are clearly defined and left in, and that the budgets for each one are included and make sense.

More generally regarding CBM, the Global Fund’s Community, Rights and Gender (CRG) department will consider the issues raised at this meeting in its internal engagement. In addition:

- Potential activities by the CRG to raise awareness of CBM and how it might be funded could include targeted engagement with country teams and identifying other ways to support community engagement at all levels of the funding cycle.
- Internally, the CRG is preparing a guide to CBM for the Global Fund’s Secretariat and partners.

- Taking advantage of the TERG report's conclusion that CBM is underutilized (see Section 2 of this report), the Technical Review Panel (TRP) will be engaged to encourage that more community monitoring is included in grant proposals and ultimately funded in grant agreements.
- The new Global Fund Strategy development process will present important opportunities for civil society to build momentum for CBM to be more fully integrated into Global Fund investments in the future.

Some **civil society representatives** indicated that their groups were or would be **supporting efforts to get CBM into proposals** in various countries and contexts. For example, MPact Global Action for Gay Men's Health and Rights plans to issue policy and technical alerts regarding community monitoring that will highlight the importance of bringing it up at specific entry points in proposal-writing processes. The organization will also include community monitoring as part of the technical assistance it is providing on behalf of the Global Fund in proposal development. African Men for Sexual Health and Rights (AMSHeR) is contacting its members who sit on CCMs as key population representatives about the importance of CBM and who might be allies. Open Society Foundations (OSF) already includes community monitoring in its strategy and funding plans and contributes to efforts to get it funded in Global Fund grants and through other donors.

One donor at the meeting, **Expertise France** (which oversees the French government's 5% initiative), is supporting such efforts by adopting a strategy that includes a focus on observatories. The French Ministry of Foreign Affairs reportedly has given orders to ambassadors to participate in meetings about CBM as a way to make them aware of what observatories are and how and why they might provide or influence funding for them.

Representatives from CBOs and other CSOs also had **requests and suggestions for the Global Fund**. They included the following:

- Less money going to the 'largest' organizations and institutions in a country, and more going for advocacy overall.
- Funding for human rights and community systems strengthening (CSS) often goes through governments, which means that it is often defined and used as governments want it to be. This limits the value of the initiatives and often excludes work that is essential from communities' perspective, but which governments want to restrict.
- Funding for 'practical' activities in and around proposal development would be helpful. Dedicated resources – perhaps from the CRG – could be made available to help local civil society groups gather allies in the sector by explaining CBM and how and why it should go into grants. In some cases, there have been insufficient funds to have pre-meetings among civil society about the sector's top priorities for grants and how to monitor the process throughout the funding cycle.
- Additional options for funding than from the Principal Recipient, which often will not fund activities (e.g., some kinds of monitoring) that could expose problems with grants.
- It would send a huge signal about the value of CBM if the TRP were to return proposals for reworking if CBM and other key community engagement activities are not included sufficiently.

8.2 Preliminary steps toward setting standards and principles

The lack of clear guidance or consensus on what CBM is or should be – or even which terms should be used for community monitoring, and in which instances – prompted a preliminary effort to identify some principles and essential components that could serve as the basis for developing some standards acceptable across communities. A process to move this forward has yet to be determined, but there was interest in taking additional steps toward 'formalizing' in a way that ensures flexibilities for context, capacity, and focus area, among other factors.

Brainstorming for this preliminary work resulted in the feedback presented in full in Annex 2. The suggestions there – which were not prioritized or discussed further after being proposed – were based on responses to

three questions: (1) What are the **principles that drive** community-based monitoring? (2) What are the **essential components that shape** effective community-based monitoring? (3) What is **needed to scale up and resource** community-based monitoring and advocacy?

Listed below are some of the main **priority CBM principles proposed by participants** during the brainstorming session. As noted above, the full preliminary list is included in Annex 2.

- Independence: To the fullest extent possible, CBM activities should be community-owned, community-led, and implemented and supported by end users, beneficiaries and people living with, affected by or at risk of what is being monitored
- Responsive to the needs of the community
- Accountable to communities and to end users of services
- Grounded in human rights
- Advocacy-oriented, as all monitoring activities should feed into advocacy plans
- Training and capacity building ingrained so that competencies are transferred widely across communities and the civil society sector

9. Annex 1. Community Monitoring in Action: Diverse Examples from National and Regional Levels

Listed below are summaries of the community monitoring examples formally presented and discussed at the Geneva meeting, with selected input about methodology, results, impact and lessons learned for most of them. The information available for inclusion in each summary varies based on what was mentioned during the meeting and the detail provided in background documents that ranged from one-page 'posters' to multi-slide PowerPoint presentations.⁶

9.1 *Client satisfaction in Ukraine*

- **Name of initiative:** Community-led survey of client satisfaction with opioid maintenance therapy (OMT) services
- **Organization(s) undertaking the monitoring:** Eurasian Harm Reduction Association (EHRA)
- **Geographic scope:** Kyiv, Ukraine and Kyiv oblast region
- **Timeframe:** 2019
- **Reason for project (e.g., gaps or challenges observed):** Request from Ukrainian community to help evaluate OMT programme
- **Goals/objectives:** Identify key factors in OMT programmes that are important for client satisfaction and self-reported quality of life
- **Methodology:** Two main components were used: a qualitative one, involving 16 semi-structured interviews with OMT programme participants, and quantitative one involving data sampling in which 376 OMT clients took part. To help make the arguments stronger – and ensure that data from the community are accepted by the state – EHRA involved professional researchers from the beginning. Working together with representatives from national community organizations, those researchers helped to develop a tool to assess treatment satisfaction. Communities were involved in all stages, including development of the tool, data collection, analyzing the results, and formulating advocacy messages.
- **Results/impact:** A key finding of the research was that clients base their satisfaction primarily on one factor: access to and availability of the medicines. They see their own enrolment in OMT as an opportunity to obtain medication rather than to access an integrated set of services, which are often available for them now as well. Similarly, the services outside of the provision of medicine did not improve clients' quality of life.

The findings were presented to the government, with officials responding that they would consider them. No actions had been taken as of February 2020.

- **Lessons learned:**
 - The process had several challenges, including difficulties in identifying and recruiting the research team and data collection that took longer than expected. EHRA also experienced resistance from the community to accept the relatively complicated model (especially the sampling component) and to find the required respondents. This suggests the need for more careful consideration of what is acceptable and possible from the community perspective, which likely differs by context.
 - It is often difficult to get governments to take communities seriously even when they have taken extra efforts to be professional – such as by bringing in independent researchers.

⁶ The summary examples were not formally validated with the organizations implementing the activities. However, all meeting attendees were given an opportunity to review the input and suggest revisions.

9.2 ART retention in Indonesia

- **Name of initiative:** Peer-led on tracking of lost to follow-up (LTFU) PLHIV
- **Organization(s) undertaking the monitoring:** Jagarin Indonesia Positif
- **Geographic scope:** Central and South Jakarta, Indonesia
- **Timeframe:** July–December 2019
- **Reason for project (e.g., gaps or challenges observed):** Lost to follow-up (LTFU) rates of more than 20% every year among people living with HIV (PLHIV) on ART in Indonesia
- **Goals/objectives:** Identify and trace PLHIV who are lost to follow-up and (1) encourage and motivate them 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).
- **Methodology:** Identification and tracking those lost to follow-up was done through peer-led approaches. This included developing standard operating procedures (SOPs) for the outreach work 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/impact:** The initiative was seen as 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.
- **Lessons learned:** Some of the main self-reported lessons learned were the following:
 - Peer-led approaches are effective to track LTFU clients because peers have strong motivation, ability and communication skills – due to their personal experiences and the supportive training – in working with the health facilities.
 - Collaboration with the provincial health offices was one of the determining factors in the success of the programme because it made health facilities more willing to open their data regarding PLHIV clients who had been lost to follow-up.
 - Completeness of client data greatly influences the success of the tracing process. Therefore, it is important for health services to improve data collection systems for all clients.
 - Contact efforts seemed to work best when peers first called a target individual or family. If necessary, that could be followed up by an in-person visit. The assignment letter from health facilities appeared to have a positive impact on participation and return to care.
- **Additional observations:** Different districts in Indonesia have different contexts, which strongly suggests that one template cannot work for all of them. This points to a problem with developing proposals for the Global Fund, which has one standard template. Effectively reflecting and addressing the local context requires that proposals be developed more from the bottom-up than be top-down.

9.3 Quality health services in South Africa

- **Name of initiative:** Ritshidze (‘Saving Our Lives’)

- **Organization(s) undertaking the monitoring:** Five local civil society groups: Treatment Action Campaign (TAC), Positive Women's Network, Positive Action Campaign, SANERELA+, the National Association of People Living with HIV/AIDS (NAPWA)
- **Geographic scope:** South Africa
- **Timeframe:** Ongoing since September 2019; planned to conclude one year later
- **Reason for project (e.g., gaps or challenges observed):** Lack of quality or consistent HIV services for all in need; lack of accountability on the part of the government
- **Goals/objectives:** To monitor the country's HIV and TB response, with the data and observations collected used to help support efforts for health systems strengthening
- **Methodology:** A mixed-method approach involving both qualitative and quantitative methods. Trained community monitors are using several rigorously designed tools to gather data and observations from health care workers, people living with HIV and other clients. The two-month and six-month surveys at the heart of the monitoring work are a patient survey, a PLHIV survey, a data capturer survey, an observational data survey, a facility manager survey, an adherence club facility survey, a door-to-door survey, an individual testimony form, and a reflection form. The project, which is supported by PEPFAR, started at 23 sites and has since expanded to more than more than 400 HIV clinics and community health centres across the country.
- **Results/impact:** Preliminary findings are based on data collected from 23 sites in three districts during the second half of 2019. Challenges identified included long waiting times to be seen at many clinics, not enough staff (clinical or non-clinical) to meet the needs of clients at many facilities, missing or unreliable equipment, and poor infection control, which among other things means that people can contract TB at the clinic.

Results, observations and information about Ritshidze are regularly updated online, including on TAC's website. At the end of the project, a detailed advocacy-focused report on the findings will be published. It will include proposed solutions generated by the monitoring.

9.4 TB programme challenges in Sierra Leone

- **Name of initiative:** Community Based Monitoring and Feedback on National TB Service Delivery
- **Organization(s) undertaking the monitoring:** Civil Society Movement Against TB – Sierra Leone (CISMAT-SL)
- **Geographic scope:** 16 districts in Sierra Leone
- **Reason for project (e.g., gaps or challenges observed):** Persistent challenges in the implementation of an effective TB programme in the country
- **Goals/objectives:** To assess the performance of national TB service delivery; to recommend actions to improve the situation; to accelerate community engagement in all aspects of TB-related service delivery
- **Methodology:** The core of the work consists 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 has recruited 16 district coordinators who supervise data collection at the district level and submit forms and information to CISMAT-SL headquarters for analysis.
- **Results/impact:** The data collected, analyzed and used for advocacy purposes show the following, among other things: 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. The information from the monitoring work is made available, along with suggestions for improvement and changes, to government officials and other key stakeholders in the TB response.

Positive impacts seen 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.

9.5 *Accountability in Cameroon*

- **Name of initiative:** Treatment Action Watch (TAW)
- **Organization(s) undertaking the monitoring:** Positive Generation
- **Geographic scope:** Cameroon
- **Timeframe:** Ongoing since 2009
- **Reason for project (e.g., gaps or challenges observed):** Need for independent citizen monitoring to hold the government and other stakeholders accountable for critical health programmes
- **Goals/objectives:** To serve as a consistent, trusted 'watchdog' that can support improved health service delivery
- **Methodology:** Quantitative and qualitative data are collected by specially trained observers from health service users and health facility staff associated with more than 70 health facilities across Cameroon. The focus is on clients' experiences accessing HIV, TB, malaria and hepatitis C services. Community peers working in the health system, called *sentinelles*, are heavily involved in the data-gathering process. TAW staff collate and analyze the data, with reports on findings published periodically.
- **Additional observations:** TAW is an observatory supported by the French government's 5% Initiative.

9.6 *HIV treatment access in West and Central Africa*

- **Name of initiative:** Regional Community Treatment Observatory in West Africa (RCTO-WA)
- **Organization(s) undertaking the monitoring:** 11 local civil society groups overseen by the International Treatment Preparedness Coalition (ITPC)
- **Geographic scope:** 11 countries in West and Central Africa
- **Timeframe:** January 2017 to December 2019
- **Reason for project (e.g., gaps or challenges observed):** Better understanding of the gaps and challenges in HIV treatment service delivery
- **Goals/objectives:** Improve access to ARVs for people living with HIV in the 11 participating countries
- **Methodology:** Community treatment observatory (CTO) model developed by ITPC. For this initiative, funded as a grant programme by the Global Fund, the structure put in place involved recruiting and training 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. The facilities that were monitored were selected by the local civil society implementers in each country.

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 and more than 35,000 key populations and engaged with a total of 105,435 people on ART.

- **Results/impact:** The information across multiple indicators over time offered vital information about the quality of service delivery that formed the basis of community groups' advocacy in the 11 countries and globally. 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.

- **Lessons learned:** It is important to be embedded in the national response, but also to remain independent. This is necessary to allow community monitors to be supportive of health systems strengthening by acting in a partner role while also being able to highlight shortcomings from a 'watchdog' perspective.

9.7 *Viral load suppression in Zambia*

- **Name of initiative:** 6X6 HVL Network
- **Organization(s) undertaking the monitoring:** Centre for Infectious Disease Research in Zambia (CIDRZ)
- **Geographic scope:** Senanga General Hospital, Western Province, Zambia
- **Timeframe:** March – September 2019
- **Reason for project (e.g., gaps or challenges observed):** Low levels of viral suppression among ART clients
- **Goals/objectives:** To understand barriers to viral suppression and introduce interventions to help overcome them
- **Methodology:** CIDRZ, an NGO, used a targeted community monitoring approach to identify and respond to findings that more than 400 of 2,850 clients at the hospital were not virally suppressed – nearly 10 percentage points below a 95% goal. The approach centred on educating community members with links among the client population about the importance of viral suppression and asking them to try to find out what the barriers were (e.g., difficulties in adherence) and what might be done to address them. The trained community members also asked those they reached for specific suggestions for improvement. An associated step involved providing 324 clients who were not suppressed with comprehensive viral load education. This intervention resulted in the site achieving 98% viral load suppression within six months.
- **Results/impact:** Through this 'chain' method, CIDRZ was able to identify some key gaps and then develop five indicators associated with them: long queues and waiting times among clients; long turnaround times for viral load testing results; poor communications by health care workers around viral load and CD4 tests; poor community sensitization/stigma; and poor referral systems. These indicators formed the basis of actions aimed at addressing these obstacles and the development of a scorecard that was used to assess change over time. Within a few months, there was extensive improvement in all five indicators.

These improvements and the intensified viral load education resulted in the site achieving 98% viral load suppression within six months. CIDRZ subsequently began scaling this type of community monitoring in other facilities.

9.8 *Challenges with ART access in Mozambique*

- **Name of initiative:** JAM: Together for Access to Meds
- **Organization(s) undertaking the monitoring:** Médecins Sans Frontières (MSF)
- **Geographic scope:** Tete province in Mozambique
- **Timeframe:** Started July 2015 [results analysis available for work through March 2018]
- **Reason for project (e.g., gaps or challenges observed):** Stock-outs of ARVs

- **Goals/objectives:** To increase client engagement in reporting and responding to shortages of medicines
- **Methodology:** Two of four components of an overall strategy to address recurring stock-outs focused on feedback and involvement from community members. One component was a 'patient empowerment' aimed at informing clients of their right to access to medicines and provide them with information so they could take greater control over decisions involving their health. Patient empowerment activities included health talks, trainings, radio programmes, door-to-door campaigns and a range of other communications materials and approaches that involved community members and were made available in local languages.

The second component was a hotline for clients, health workers and other community members to report problems with accessing medications. Anyone could contact the hotline by calling or messaging one of the free numbers from the three phone operators available in Mozambique.

- **Results/impact:** The patient empowerment component contributed to the hotline one, as the number of reports about problems with access to medications increased on a monthly basis over the course of the project. Out of 1,015 reported cases received through the JAM hotline between July 2015 and March 2018, 75% (760) were confirmed as stock-outs in a health centre. In the remaining 255 reported cases (25%), it was confirmed that the medicines were available in the health centre, but not accessible to the clients. This important finding highlighted ongoing barriers associated service delivery even when the supply chain appeared to be working and medications were available. The most common reasons for clients' failure to obtain the desired medications were related to the absence of the person in charge of the pharmacy or the presence of the drug in a stockroom or other storage place but not in the pharmacy where the dispensation was made for clients.

The initiative had success in resolving problems at both an individual and systems level. Each report received by JAM via the hotline prompted a series of steps including confirmation of whether the medication was in fact available – in which case the client was instructed to return to the health centre to access it – and an 'escalation protocol', which was a series of steps to determine the reasons for the problem along the supply chain, with the goal of finding a solution at the lowest-level possible.

- **Lessons learned:** Repeated exposure to messages and information was the most effective strategy for engaging and empowering clients. Activities focused on treatment literacy, explaining how the medical supply chain worked from the beginning to reaching the end user, peer testimonials to reinforce adherence, and raising awareness of the role clients can play in improving their access to medicines. Other lessons learned included the following:
 - The main factors that prevent access to medication include lack of communication in the system, lack of adequate distribution to the 'last mile', and lack of organized strategies to respond to shortages and lack of medication.
 - Community-based monitoring programmes are essential to complement efforts in improving visibility and transparency of the supply chain, by offering feedback from bottom-up.
 - Empowered clients will continue to report stock-outs through any available channel. Strategies focused on health talks and training proved to be the most effective way to empower patients.

9.9 *Barriers to HIV and TB services in DRC*

- **Name of initiative:** Observatory on the Quality of Care HIV/TB
- **Organization(s) undertaking the monitoring:** Congolese Union of People Living with HIV Organizations (UCOP+)
- **Geographic scope:** Three provinces in the Democratic Republic of the Congo [started initially in one province]
- **Timeframe:** Ongoing since 2013; has been funded by the Global Fund since 2016
- **Reason for project (e.g., gaps or challenges observed):** Stock-outs of essential medicines; reports of clients paying for services that were supposed to be free; and other barriers to HIV and TB

services including stigma and discrimination and inaccessibility of facilities (e.g., lengthy travel times to reach them)

- **Goals/objectives:** To monitor gaps and in HIV and TB services and report on barriers to quality services
- **Methodology:** Client questionnaires. They are now available via mobile phones, which makes it easier to get data and to have the information submitted and reviewed more quickly. AlertPlus, a new application for smartphones, is expected to make the work even more efficient by allowing information to be gathered in real time from users.
- **Results/impact:** Results from the most recent calendar year (January to December 2019) indicate the type of impact the observatory project has continued to have where it operates. For example, stock-outs of ARVs in Kinshasa were 16% in December compared with 39% in January. TB medication stock-outs, as high as 95% at the beginning of the year, were just 5% in December. Significant reductions in stock-outs also occurred in North Kivu province. Advocacy with service providers was a major factor in user fees for ARVs being reduced to \$15 to just \$2 in North Kivu.
- **Lessons learned:** Project personnel report having had a difficult time initially being accepted by the government and some other stakeholders involved in HIV and TB responses. The perception was that the implementers were “acting as policemen”. In response, UCOP+ and other partners in the observatory focused on convincing the sceptics and opponents that their efforts were helping them work better, including by improving HIV and TB services and results. Over time, governments and other initially suspicious institutions and individuals reportedly have come to accept the monitoring work, with many now reporting themselves on stock-outs.

9.10 *Key populations in Africa*

- **Name of initiative:** African Key Populations Scorecard
- **Organization(s) undertaking the monitoring:** African Men for Sexual Health and Rights (AMSHeR)
- **Geographic scope:** Countries where AMSHeR has members
- **Timeframe:** Recently launched
- **Reason for project (e.g., gaps or challenges observed):** Gaps in human rights and access to health care among key populations
- **Goals/objectives:** Need to improve accountability to African key populations in health responses
- **Methodology:** Community scorecard that is based on one developed initially for men who have sex with men (MSM) that has been used in Côte d'Ivoire, Kenya and Nigeria. That model has since been revised to be a broader key populations scorecard that can be customized for different groups in addition to MSM, including sex workers, people who inject drugs, incarcerated individuals, and young people within all key populations. AMSHeR trains community data collectors so they understand how to use the tool, analyze results, and present and use the findings. To increase the rigor and value of the collected data, the scorecard specifically measures accountability to key populations against the World Health Organization's Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations and other relevant guidance documents, as well as UNAIDS implementation toolkits.
- **Results/impact:** Current plans are for an assessment based on the scorecards' input to be done two years after launch.
- **Additional observations:** AMSHeR is implementing the key populations scorecard initiative in partnership with Accountability International, an African-led civil society group that will serve as the technical partner.

9.11 *Treatment inequality in Kenya*

- **Name of initiative:** Kenya National HIV, TB and Human Rights Training and Advocacy Country Programme
- **Organization(s) undertaking the monitoring:** Kenya Legal & Ethical Issues Network on HIV and AIDS (KELIN), in collaboration with local partners
- **Geographic scope:** 5 counties in Kenya
- **Timeframe:** 2 years [now ended]
- **Reason for project (e.g., gaps or challenges observed):** Continued inequality in the treatment of marginalised communities (people living with HIV, TB survivors and key populations) that impedes access to health services; weak health and community systems that are not responsive to the needs of marginalised communities
- **Goals/objectives:** To promote access to HIV, TB and sexual and reproductive health (SRH) services and access to justice among communities of persons living with and affected by HIV and TB, and key populations in the target counties. Approaches undertaken toward this goal included enhancing the capacity of CSOs, CBOs and communities to advocate for and create demand for HIV, TB and sexual and reproductive health (SRH) services and strengthening the legal environment through review of laws, policies and practices that act as a barrier of access to services.
- **Methodology:** Data collection was undertaken by 30 community health advocates (CHAs) specially trained on health, human rights and access to justice in general and more specifically for the Kenya context. The work was structured around action plans that guided the CHAs' research and work in areas such as collecting evidence on barriers to access to health services, increasing awareness in communities around their rights regarding health services, and creating linkages between communities and health facilities. CHAs reported monthly on the activities undertaken and data collected.
- **Results/impact:** Reported results over the two years through training and continuous follow-up included the following: (a) 29,066 people reached through dissemination forums on human rights, TB and HIV; (b) 14,755 people reached through advocacy activities initiated, participated, and conducted on TB, HIV and human rights; and (c) 757 case referred for legal support to network of pro bono lawyers or to the HIV Tribunal.
- **Lessons learned:**
 - Investing in community health services is necessary to improve services overall, because communities can help to direct and drive more people to the overall health system and the services available there.
 - Informing people of their rights and what they are missing can help ensure they will respond to community-delivered monitoring and information-raising activities.

9.12 *Human rights-advancing tool worldwide*

- **Name of initiative:** Rights - Evidence - Action (REAct)
- **Organization(s) undertaking the monitoring:** Frontline AIDS and national civil society partners
- **Geographic scope:** 22 countries⁷ used REACT between 2014–2018; for the 2019–2020 period, more than 20 countries⁸ are expected to be involved
- **Timeframe:** Ongoing since 2014

⁷ Bangladesh, Botswana, Burundi, Egypt, India, Kenya, Lebanon, Lesotho, Malawi, Mozambique, Myanmar, Namibia, Nigeria, Senegal, South Africa, Sudan, Eswatini, Tunisia, Uganda, Yemen, Zambia, Zimbabwe.

⁸ Botswana, Burundi, Georgia, India, Jordan, Kyrgyzstan, Lebanon, Lesotho, Malawi, Myanmar, Moldova, Morocco, Mozambique, Namibia, Nigeria, Senegal, South Africa, Swaziland, Tajikistan, Tunisia, Uganda, Ukraine, Zimbabwe. Also in the process: West Africa regional

- **Reason for project (e.g., gaps or challenges observed):** Violence and human rights violations in communities that were impeding access to HIV services
- **Goals/objectives:** Use data collected in monitoring processes to inform quality human rights-based HIV programming, policy and advocacy at national, regional and global levels
- **Methodology:** REAct is a community-based and -owned rights and HIV monitoring and response system. It is based on semi-structured interviews carried out by specially trained community monitors known as 'REActors'. A REAct training package is the basis for training and supporting them and their local civil society groups to document human rights violations. It includes modules on introducing basic human rights theory to participants, and providing training on the information management tool used within REAct. 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/impact:** Selected results from 2014–2018 phase of REAct include 234 community representatives consulted and trained on REAct and on human rights-based HIV monitoring and response; (b) nearly 50 CBOs and Frontline AIDS partners providing direct emergency responses to human rights and violence related needs among community members; and (c) 686 cases of violations documented, responded to, or referred to other services. Selected impact examples from the same period include the following:
 - 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 Tunisia.
 - 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 successfully 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.
- **Additional observations:** The REAct system is compatible many national tools and systems, which means it can be used to document human rights violations as well as for other monitoring purposes. It is also flexible enough to be scaled up and embedded into monitoring systems at higher level.

9.13 Stock-outs of ARVs in Latin America

- **Name of initiative:** Community Mobilization to increasing Access to HIV Treatment in Guatemala and Nicaragua
- **Organization(s) undertaking the monitoring:** ITPC-LATCA (Latin America and the Caribbean regional branch of the International Treatment Preparedness Coalition)
- **Geographic scope:** Guatemala and Nicaragua (2 of 6 priority countries in the region)
- **Reason for project (e.g., gaps or challenges observed):** Stock-outs of HIV drugs and commodities as well as other service interruptions in HIV programmes
- **Goals/objectives:** The overarching goal of this community monitoring initiative is to contribute to the achievement of the 90-90-90 targets by influencing governments and other programme implementers to improve access to quality, consistent HIV treatment and care services. Other goals include supporting enhanced community engagement and influence in HIV responses more generally. One workstream in this area centres around strengthening the role of CCMs in both countries by establishing alliances between community treatment committee (CTCs) and local HIV organizations and key populations, which are part of the CCMs of Guatemala and Nicaragua.

ITPC-LATCA established these CTCs in six priority countries in Latin America – including Guatemala and Nicaragua – as coordinated, collaborative groups of community observers who follow HIV responses, with particular attention to access to HIV treatment, as well as health systems service delivery more generally.

- **Methodology:** Questionnaires are used by activists and other community members, including those associated with CTCs and key population groups, to gather quantitative and qualitative data from clients and other key stakeholders. They primarily monitor stock-outs of ARVs and diagnostic tests for viral load and CD4. ITPC-LATCA now has an online tool to collect survey information as well. Based on the results of the questionnaires, CTCs define priority problems and identify advocacy focus areas. As part of the advocacy and influencing work, reports generated by the surveys are sent to CCMs and national HIV programmes for consideration.

More broadly through this work in Guatemala and Nicaragua, ITPC-LATCA trains community treatment activists to better understand the risks related to the management of ART and aims to reinforce their knowledge and technique to make CTCs operational and successful.

- **Results/impact:** Examples include: In Guatemala, survey results revealed that many people living with HIV had not had a CD4 or viral load test for at least two years. In Nicaragua, the community monitors discovered (and reported) that ARV stock-outs in many places persisted and that they were due to uncoordinated logistics. This is the kind of information that is used to inform advocacy and develop recommendations for improving services overall.

Also, by strengthening civil society groups, the monitoring work has helped to build a strong local knowledge base that can better support HIV programming and services when Global Fund assistance is no longer provided.

- **Lessons learned:** The monitoring initiative and the model behind it have helped to introduce a different working culture in many CSOs because they now recognize the importance of generating and using information as a basis to achieve their objectives, and thereby are doing more to contribute to the national epidemic response.

9.14 Strengthening communities and civil society in West Africa

- **Name of initiative:** Strengthening the involvement of civil society in the monitoring and governance of policies to strengthen health systems
- **Organization(s) undertaking the monitoring:** Observatoire Citoyen sur L'Accès aux Services de Santé (OCASS)
- **Geographic scope:** Burkina Faso, Guinea, and Niger
- **Timeframe:** Ongoing
- **Reason for project (e.g., gaps or challenges observed):** Gaps in quality health service delivery
- **Goals/objectives:** Helping to improve the performance of health systems by strengthening the effectiveness of contributions of civil society and community actors in the health sector. The overall objectives are not just to undertake monitoring, but also act on it – via advocacy – to influence and change the situation. Making users aware of their rights and good practices can serve as the basis for opening important political dialogues.
- **Methodology:** Observatory that operates through Health Democracy and Citizen Involvement Platforms (DES-ICI), which are groups of community members trained in strategic monitoring of health services. Different types and levels of monitoring are undertaken, including monitoring availability of and access to services; budget monitoring; and monitoring the efficiency and effectiveness of governance. Local and regional civil society groups have been involved in training DES-ICI members, including Réseau Accès aux Médicaments Essentiels (RAME).

10. Annex 2. Proposed principles, components and resourcing needs of community monitoring

Listed below are the collaborative inputs from meeting participants during a brainstorming exercise. The entries are listed below as they were mentioned at the meeting, and thus have not been coordinated, aligned or prioritized. The suggestions are intended to be a preliminary step in a longer-term process to develop some broadly accepted community monitoring standards and guidelines.

What are the principles that drive community monitoring?

- Community training, transfer of competencies
- Independence – community-owned, community-led. Implemented and supported by end users, beneficiaries and people living with, affected by or at risk of what is being monitored
- Responsive to the needs of the community. Monitoring must be grounded in human rights; should be service-oriented (including prevention and treatment)
- Facilitating local action – so the data feed back into the system; communities are co-problem solvers with implementers
- Accountability and feedback on campaign data and results. (Mechanism needs to be accountable at all levels, including to service users and to service providers.)
- Information must be owned and used by the community (those affected)
- Should represent most underserved, marginalized populations (including within key populations)
- Credibility and transparency. Communities doing the monitoring must be credible to those they represent and to decision-makers
- Accommodate professionalism; should be supervised and incentivized
- Advocacy-oriented; should feed into advocacy plans
- Ethical use of data and data protection (especially for people who provided info for monitoring)
- Clear and transparent methodology of data collection
- Should be done in a way that's sustainable and regular (not just one off)
- Diversity in information sources; should rely on multiple sources to be able to triangulate and cross-check input
- Monitor effective governance and accountability
- Quality assurance and improvement frameworks
- Ensure recipients of services can articulate their expectations
- Should be conducted by and not on communities

What are the essential components that shape effective community monitoring?

- Capacity strengthening
- Consistency; should be an ongoing process and long-term commitment
- Routine data collection on availability, accessibility and quality of services
- Training of community (e.g., their rights), of data collectors and of duty bearers
- Partnership and stakeholder engagement – including perhaps with government, other NGOs, etc.
- Validation process on reliability and quality of information
- Surveys or studies on specific problems and issues – including in addition to routine data collection
- Watchdog element – to be able to both inside and outside
- Resourcing and evaluation of intervention itself; should be adequately resourced re time, money and people
- Safety and security provisions for individuals and organizations
- Tied to standards of international guidance
- Rewarding of good practice
- Leaving behind materials and tools to support duty bearers and service providers
- Include follow-up measures
- Transparency; data should be as open and publicly available as possible
- Accountability to the people information was collected from
- Community mobilization
- Influence and advocacy

- Acceptance of 'unpolished' data and input
- External review to help ensure credibility; could include partnerships to help deepen and strengthen results

What is needed to scale up and resource community monitoring and advocacy?

- For adequate resourcing: donor that pays, and/or government working with, and/or self-generation of income to do the work
- Monitoring should be a real pillar of programming
- Demand creation and literacy around monitoring
- To get GF grants: case studies, best practices to show evidence, have champions on CCMs
- Revising GF funding models to accommodate community monitoring opportunities, including by incorporating more useful/accessible funding lines
- Integration of community monitoring model in all GF program departments
- Clear normative guidelines, definitions and framework are needed; should ensure ability to capture full range of monitoring that communities want to do and have been doing
- Should be standardized to enable scale-up
- Independent financing
- Evidence that it works is needed; prove impact
- Clarity to what is being done with and through monitoring
- Community monitoring to accommodate program impact assurance
- Open up to unstructured data collection
- Digitization of tools and how we collect and share data
- Buy-in and movement building
- In addition to financing for specific monitoring project, need other kinds of support for mechanisms to be sustainable (e.g., core funding for organizations); also useful is support to confront other risks and challenges to organizations' operations and strength
- Multi-donor financing to avoid dependence on one donor

11. Annex 3. List of participants

The individuals in the list below attended all or part of the 20–21 February meeting in Geneva, Switzerland on defining and mobilizing for community-based monitoring and advocacy. Participants are listed in alphabetical order by last name. The country specified is where the participant is currently based.

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