COMMUNITY-LED MONITORING OF HEALTH SERVICES

BUILDING ACCOUNTABILITY FOR HIV SERVICE QUALITY

WHITE PAPER

This paper reviews the concepts behind community-led monitoring of health services—a practice that combines systematic and routine data collection by communities with evidence-based advocacy to improve accountability, governance and quality of HIV and health services.

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CONTEXT

The effectiveness of the HIV response is today highly variable—between populations and geographies. Some countries, communities, and populations are doing well against the 90-90-90 treatment goals, achieving high levels of community viral suppression, while others are far behind.[1] At a global level neither deaths nor new HIV infections are on track to reach the 2020 UN goals. Key populations are, in most of the world, far behind in the treatment cascade.[2] Hundreds of thousands of people living with HIV continue to die due to the disease each year.

"Loss to follow up" rates in most programs remain unacceptably high as people initiate treatment but are not effectively retained in care—either because they die or because they are not supported to sustain ART. The South African AIDS response, for example, has lost approximately 1.3 million people in recent years.[3] In Haiti, meanwhile, the number lost represents nearly half of the number of people newly enrolling on treatment in the last three years.[4] In Uganda, between the first and third quarters of 2019 nearly 100,000 people were lost from HIV programs.[5] These retention figures reflect a major problem in the quality and acceptability of HIV services, and availability of medicines and commodities. Particularly in a context of people living with HIV starting ART earlier in the course of the disease, retaining people on treatment requires high quality services, accessibility of treatment without massive burdens like long wait times or stock-outs, facilities suitable for public use, and professional and non-discriminatory health care workers. Evidence shows that facilities differ greatly—not only in the quality of services, but in their life-saving outcomes. A study in Zambia, for example, showed that some clinics had over 10-times the mortality rates of the best performing facilities.[6] HIV testing and HIV prevention services face similar challenges and urgency in improving quality. Meanwhile, evidence shows that developing models of care and differentiating them based on feedback from communities can be highly effective—as seen in recent programs in Kwa Zulu Natal , South Africa that achieved high levels of viral suppression through that model.[7]

ACCOUNTABILITY & DEMOCRATIC DEFICITS

Political accountability deficits are a major reason quality of services differs so dramatically. It has long been shown that the provision of public goods is directly linked to the information and the accountability structures for officials making decisions about those goods.[8,9] In HIV, decision-makers are rarely also users of the HIV and health services over which they exercise control and, in many cases, are not directly accountable to those who are. In many contexts people living with and affected by HIV are low in the priority list of decision-makers—particularly the users of public services and marginalized and criminalized populations. There is correspondingly little information about and accountability for delivering programs that work. In countries with the highest rates of HIV, aid agencies including PEPFAR and the Global Fund provide a significant portion, sometimes most, funding for HIV. In this context, implementing entities in the public and NGO sector are often responsible, most directly, to funders. When decisions are made in Geneva or Washington, D.C., it is very hard for frontline communities to convey information about the quality of services they receive to decision makers and even harder to hold those decision-makers accountable for improving quality.

DEFINING COMMUNITY-LED MONITORING

Addressing continuing challenges in the quality of and access to services is inextricably linked to addressing this accountability deficit in the HIV response. Community-led monitoring offers an opportunity to address both.

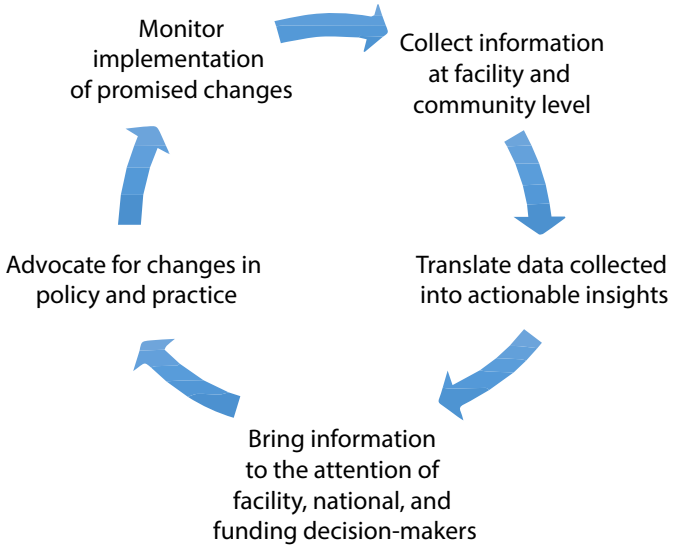
Community-led monitoring trains, supports, equips, and pays members of directly affected communities to themselves carry out routine, ongoing monitoring of the quality and accessibility of HIV treatment and prevention services. Monitoring focuses on collecting quantitative and qualitative data through a wide variety of methods that reveal insights from communities about the problems and solutions to health service

quality problems at the facility, community, sub-national, national, and even international levels. Another key to the concept of community led monitoring—separating it from other modes of quality improvement—is the full integration of evidence-based advocacy into a cycle that brings new information to the attention of decision makers and holds them accountable for acting on that information.

METHODS & CYCLES OF MONITORING

Community-led monitoring can be thought about in a general cycle in five parts characterized by data collection, analysis and translation, engagement and dissemination, advocacy, and monitoring. The effort shares important methodologies with research—and can generate research-ready information—but is distinct in that it is focused on a goal of improving service quality rather than generating generalizable knowledge.

Information gathering—or data collection—occurs through a wide range of qualitative and quantitative methods. These include direct observation of the conditions of services by community monitors, interviewing or surveying clients at facilities, interviewing staff and managers at facilities, conducting focus groups and door-to-door surveys in areas served by clinics, and other methods. These efforts are systematic and rigorous, but focused on the key outcome of creating change, community-led monitoring puts the priority on generating actionable information over scientifically collected data that may be of less utility in the short term. In this sense information generated by individual stories or idiosyncratic observations, for example, can in some cases be important than routine data captured across large numbers of observations, if it brings out an important unaddressed problem.



Information gathered must then be analyzed and translated into actionable insights—a process where community-led efforts provide unique value. This includes a two-step process: First, monitors must group and interpret the information gathered from the diverse methods described above to identify specific problems with facilities. These problems are, themselves, useful information to bring to light. However, community led monitoring goes beyond simply identifying problems to connecting those problems to solutions. Here, the value of having affected communities leading the work is that they bring local knowledge and insights to bear—which in turn generates ideas that might not occur to external actors and eliminate solutions that would be unacceptable to communities. For example, there were recently questions about whether adherence clubs were effective in South Africa—but it was not until communities engaged with decision-makers that it became evident that most of the clubs that were seen as ineffective were not actually functioning. Aggregating data from facilities into local, regional, and national level information is also important to identify issues that need to be tackled at different levels of the health system. District public health managers, for example, need to know which clinics are doing well and which are doing poorly. National decision-makers may need to know that a given province is experiencing a real crisis. International funders may need to know that some implementing agencies are experiencing fewer problems and tackling them quicker than others.

Dissemination of the findings is the next step in community-led monitoring—meaning sharing the insights gathered with a wide range of stakeholders. Results may be disseminated to facility managers, government officials from local to national level, to management of NGOs engaged in service delivery, to international funding agencies, and to broader civil society networks. In many quality-improvement efforts the results are often shared only among insiders or a small group, based on the belief that this can support trust and limit tension. These approaches have value, but also limits.

Community-led monitoring instead brings the insights gathered by communities to a wide public audience—based on the believe that pressure is needed to affect change and that transparency can lead to accountability, particularly in response to problems that have been unresponsive to traditional approaches. In reality both approaches can and do co-exist. Community-led monitoring is, from the start, public in that it simply gathers what is well known by the users of health services at a given facility and makes that knowledge available to wider audience. This complements more internal quality improvement efforts that may be based on insider knowledge and performance data and can work to head-off issues before they are widely experienced by communities.

Advocacy is an integral part of effective community-led monitoring—going beyond simply gathering data to working to change the problems that are identified. This advocacy is the lynchpin of addressing accountability deficits. This occurs at multiple levels—starting at the facility itself where community monitoring efforts can help make health facility managers aware of issues they may not be aware of, ask them to make specific changes, and hold them accountable for doing so. Far from creating a hostile environment for managers, effective community accountability efforts can provide an avenue to address problems that move beyond upset (or even violent) individuals. Often effective advocacy at this level can also support managers to take action with the backing of the community to address issues and to elevate problems that may be out of their control to higher levels of power. Meanwhile, advocacy in community monitoring moves beyond the clinic to address district-level, provincial-level, and national-level actors. International funding agencies such as the Global Fund and PEPFAR are also key targets for advocacy—holding them accountable for how they allocate resources, to which organization, and for which priorities through processes such as the PEPFAR Country Operational Planning Process. Efforts may include meetings, reports, engagement with media, protest, and a variety of tactics—scaled to the level of urgency and receptivity of the decision-maker.

Finally, monitoring commitments by decision-makers is key. At each level where advocacy has been effective, specific commitments are made by decision-makers to address the problems identified. Community-led monitoring is then a key tool to collect information about whether the commitments made are being implemented in practice and, critically, whether these commitments are having the desired outcome. For example, communities may discover that a commitment to build new consultation rooms in a facility to reduce wait times, is not executed because of staff shortages—necessitating further advocacy.

ESSENTIAL ELEMENTS OF THE MODEL

There are several key requisites to making community-led monitoring an effective intervention for improving both quality and accountability.

First, community-led monitoring must be owned and led by communities. People directly affected by a weak, failing, or unaccountable HIV response have the greatest stake designing and monitoring health services and policies that aim to improve treatment and prevention outcomes. Communities are often the first to detect and diagnose problems. Monitoring gives community capacity to share what they know with decision-makers and fight to ensure their needs are met.

Second, organized communities are required for effective monitoring. Individuals could be hired one-by-one from communities to collect data—as is common in research projects. This, however, does not allow for the later steps of translating data into action and creating cycles of advocacy and accountability. The most effective community-led monitoring efforts are based out of organizations or coalitions with organized groups or branches in communities—bringing multiple voices at the local level together to build power—and a central structure capable of managing the effort and connecting it with sub-national and national policy processes. Funders willing to support community-led monitoring must invest resources (financial and technical) to build the necessary community systems. A monitoring effort run by an organization that is itself unaccountable or lacks capacity has the potential to undercut accountability rather than building it.

Third, a focus on generating political-will and accountability is key. Information alone is critical for decision-makers—and too often missing. But information alone often leads to problems being effectively

diagnosed but then left unresolved or made worse. Telling a clinic manager repeatedly about stock-outs of medicines, for example, will have little effect when the problem is a poorly functioning supply chain or fraud in the procurement process. Problems exist for a reason, with root causes often tied to technical, political, and budgetary factors. A real political analysis is needed to address them.

FILLING AN URGENT GAP

The idea of community monitoring is not new—communities throughout the world have long held decision-makers accountable for delivering high quality healthcare and public health efforts. People living with and affected by HIV have been at the forefront of this—demanding action by governments to halt discrimination, provide effective programs to fight HIV, and where these demands failed starting organizations to fill the gaps.

What the current data about the HIV pandemic tell us, though, is that there are urgent issues of quality that have to be addressed. Community-led monitoring, if effectively implemented and sufficiently resourced, can be a key intervention to correct poor retention in HIV treatment that many countries and communities are facing. As some middle-income countries face transition away from donor financing and other countries struggle to get ahead of large numbers of young people newly living with HIV, supporting community-led efforts to hold decision makers accountable for delivering services that actually work for the people they are intended to reach is needed now more than ever.

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