ONLINE WORKSHOP ON
COMMUNITY-LED
MONITORING IN HIV
SERVICES
Key questions for planning

• Where will monitoring happen?
  • In certain geographic areas? At highest burden clinics? Only at PEPFAR sites?

• Which sectors should do the monitoring?

• How will monitors be hired and trained?

• Can multiple organizations be involved and still achieve comparable results?
  • Can a consortium work?

• How will you manage the data? Do you need to buy tablets? Can you use an existing system like those used by TAC or ITPC?

• Will you be able to achieve sufficient scale?

• How will advocacy happen?

• How will you ensure it is truly community-led and owned?

• What kind of capacities are needed that don’t already exist
  • (data systems? Advocacy skills?)
Why Community Led Monitoring is important

Maureen Milanga
Associate Director International Policy and Advocacy
To ensure accountability for all actors including government & aid agencies.

• The provision of health services is directly linked to the information and the accountability structures for officials making decisions about those goods.

• 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.

• Data that informs national health plans and frameworks often lacks of information from the recipients of care.

• CLM demonstrates an opportunity to build a system that can contribute to national data systems AND includes community input.
To highlight gaps in the quality of services provided

- People accessing services are still facing long wait times, stock-outs, bad health facility infrastructure and unprofessional and discriminatory health care workers among others.

- 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.

- "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. Retention figures still reflect major problems in the quality and acceptability of HIV services, and availability of medicines and commodities.

- **NOTE:** When we monitor, we aim to fix the whole health system. HIV services are not provided in a silo. They are provided in the general health clinic where other services are provided e.g. the health workers who cater to HIV also work on other disease in the facility if there is a general shortage in the facility that is going to affect the HIV program. CLM has led to communities finding issues in the site-level data that would otherwise not have been detected or would have taken longer to fix. **CLM is a win for everyone and the whole system.**
To gather evidence for Advocacy

• CLM combines systematic and routine data collection by communities with evidence-based advocacy to improve accountability, governance and quality of HIV and health services.

• The core principle of CLM is that, this is data collected by the users of the service to improve the quality of service they ultimately receive.

• Monitoring provides an evidence-informed platform for communities to advocate for change in the response. Eg. stock outs, lack of health workers, lack of key population services.

• Monitoring by communities ensure focus on key area relevant to communities in order to improve services (quality, type of service etc.). In some instances, communities have access to data that is not collected nor analyzed as part of the national data.

• Monitoring can be done routinely or depending on need to answer immediate questions.
Even donors such as PEPFAR & GF & the French are interested

PEPFAR COP19 /20


The Global Fund:

https://www.theglobalfund.org/media/4790/core_communitysystems_technicalbrief_en.pdf
maureen@healthgap.org
COMMUNITY-LED MONITORING OF HEALTH SERVICES

Building Accountability for HIV Service Quality

Matthew Kavanagh
Georgetown University
O’Neill Institute for National & Global Health Law
Defining Community-Led Monitoring

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.
The cycle of community monitoring

- **Information gathering—or data collection:** direct observation of facilities by community monitors, interviewing or surveying clients at facilities, interviewing staff and managers, conducting focus groups and door-to-door surveys in communities served by clinics.

- **Translate into actionable insights:** Group and interpret the information to identify specific problems and generate potential solutions.

- **Dissemination** to facility managers, government officials from local to national level, management of NGOs engaged in service delivery, to international funding agencies, and civil society networks.

- **Advocacy** is an integral part of effective community-led monitoring—going beyond simply gathering data to working to change the problems that are identified.

- **Monitor commitments** by decision-makers to see if they are implemented and are having the desired outcome.

CLM creates accountability for decision-makers to the communities who use health services
Community-Led Monitoring **one** key piece of the community system

CLM is a piece of the community puzzle—focused on gathering information and building accountability. It provides decision-makers access to information and knowledge only communities have and builds pressure on them to act.

*It is complementary to, but different from, other pieces of an effective community-response*

- Community-led service provision
- One-off rapid surveys
- Peer-support and community outreach efforts
- Research efforts to gather data for scientific papers
Necessary Elements for Community-Led Monitoring

• **Owned and led by communities.** Monitoring gives community capacity to share what communities know with decision-makers and fight to ensure needs are met.

• **Organized communities.** 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. A central structure capable of managing the effort and connecting it with national policy processes.

• **Advocacy to generate accountability.** Information alone often leads to problems being diagnosed but then left unresolved or made worse.

• **Sufficient scale & resources.** Having many small community-monitoring efforts often does not enable comparable, valid information—especially to compare across facilities—so ensuring an organization or consortium is able to bring sufficient scale to the effort is necessary. Analysis of what we find is not automatic—it takes time and skills.
Many resources available:
• White paper
• Guides from Ritshidze & ITPC
• Data collection tools
Community-Led Monitoring

“how we collect data”

International Treatment Preparedness Coalition, ITPC
April 23rd, 2020
Webinar
ITPC’s Community Treatment Observatories (CTO) Model
Structure of a CTO data collection **team**

**Focal point person:** oversees the general operation; conducts data entry and analysis; and serves as liaison for data collectors, CCCs, and AI.

**Data supervisor:** tests data collector's knowledge, checks, and verifies data.

**Data sites:** health facilities (public or private), community-based service delivery facilities, and/or community service points.

**Data collector:** interacts directly with data collection sites and recipients of care to collect qualitative and quantitative data.

**Academic institution (AI):** supports analysis, facilitates institutional review board (IRB), and oversees data quality audit.

**Community Consultative Group (CCG):** serves as a technical advisory board that oversees and guides implementation of the CTO.

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Structure of a CTO data collection **process**

**Advocacy Targets**
- (e.g., policy makers)
- (e.g., national AIDS councils)
- (e.g., UNAIDS)

**Academic Institution (AI):**
- Data entry
- Validation & Verification
- Analysis & Reporting
- Management & Storage
- Data Quality Assessments
- Advocacy Tool Development

**Data collection sites:**
- Data entry
- Data verification
- Data collection

**Focal Point Person:**
- Data supervisor
- Data collector

**Community Consultative Group (CCG):**
- Data entry
- Data verification
- Data collection

*Note: The number of data supervisors and data sites shown here are for example only. In operation, these numbers may vary.*
Structured data

• **Quantitative data**
  - Collected at set intervals at the health facility level
  - Indicators informed by national data & M&E systems
  - *Examples of indicators:* number of people accessing services (prevention & treatment), medicine and commodity stock-out monitoring, number of viral load tests & turnaround times of results to recipients of care, etc.

• **Qualitative data**
  - Collected through short individual interviews and FGDs (with PLHIV, KP, HCW, etc.)
  - *Examples of topics:* reasons for not accessing services, gaps in quality of services, appropriateness of services, etc.

*Left:* Example of paper data collection form approved by ethics committee.
*Left:* Example of electronic data collection form used during interviews or FGDs
*Right:* Community data collector with data clerk at health facility in Harare, Zimbabwe
What do CTOs Monitor?

CTOs collect and analyze data on **availability, accessibility, acceptability, affordability and appropriateness** of HIV care and services – *can be applied in various contexts/disease focus areas*

<table>
<thead>
<tr>
<th>Availability</th>
<th>Accessibility</th>
<th>Acceptability</th>
<th>Affordability</th>
<th>Appropriateness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do the required health services, medicines, commodities and supplies exist?</td>
<td>Are there long travel distances or wait times?</td>
<td>Is there a high quality of care?</td>
<td>Do services require out-of-pocket spending on behalf of the client?</td>
<td>Are services tailored to the specific needs of key and vulnerable populations?</td>
</tr>
<tr>
<td>If so, do they exist when they are needed and in adequate supply?</td>
<td>Are hours of operation convenient?</td>
<td>Are services provided free of stigma and discrimination?</td>
<td>Is the service delivery model(s) efficient?</td>
<td>Are age and gender considered in service packages?</td>
</tr>
<tr>
<td>Are referral processes along the care cascade smooth?</td>
<td>Are the human rights of patients promoted and protected?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

@ITPCglobal | www.itpcglobal.org | #WatchWhatMatters
Unstructured data

• Collecting information from recipients of care and members of the community – “continuum of community perspectives”
  • Informal data collection methods – e.g. WhatsApp groups, Vlogs, social media engagements, etc.
  • Data from project reports, contextual analysis, meetings with stakeholders, etc.
Data Quality and Data Analysis

• DQAs are organized in addition to routine data quality reviews and analysis
• The CCG and academic partners provide operational oversight and important technical assistance.
• Community members can use the data and subsequent analysis to inform the development of advocacy strategies and campaigns
• Advocacy reports identify and include key recommendations for improving quality and coverage of services.
KEY RESULTS of ITPC’s Ongoing Community-led Monitoring

Fig 1. Frequency of Recorded ART Stock-outs at RCTO-WA Monitored Facilities

<table>
<thead>
<tr>
<th>Period</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Period 1</td>
<td>23.6%</td>
</tr>
<tr>
<td>Period 2</td>
<td>16.4%</td>
</tr>
<tr>
<td>Period 3</td>
<td>15.2%</td>
</tr>
</tbody>
</table>

Fig 2. Frequency of Recorded VL Lab Supply Stock-outs at RCTO-WA Monitored Facilities

<table>
<thead>
<tr>
<th>Period</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Period 1</td>
<td>17.2%</td>
</tr>
<tr>
<td>Period 2</td>
<td>7.3%</td>
</tr>
<tr>
<td>Period 3</td>
<td>6.5%</td>
</tr>
</tbody>
</table>

Fig 3. Average Length (days) of ART Stock-outs at RCTO-WA Monitoring Facilities in Côte d’Ivoire

<table>
<thead>
<tr>
<th>Period</th>
<th>Length (days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Period 1</td>
<td>53</td>
</tr>
<tr>
<td>Period 2</td>
<td>33</td>
</tr>
<tr>
<td>Period 3</td>
<td>23</td>
</tr>
</tbody>
</table>

Fig 4. Average Quality of Care Rating (out of 5) at RCTO-WA Monitored Facilities

<table>
<thead>
<tr>
<th>Period</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Period 1</td>
<td>3.8</td>
</tr>
<tr>
<td>Period 2</td>
<td>4.0</td>
</tr>
<tr>
<td>Period 3</td>
<td>4.2</td>
</tr>
</tbody>
</table>

Fig 5. Viral Load Tests Performed at RCTO-WA Monitored Health Facilities

<table>
<thead>
<tr>
<th>Period</th>
<th>Tests (performed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Period 1</td>
<td>16,532</td>
</tr>
<tr>
<td>Period 2</td>
<td>31,472</td>
</tr>
<tr>
<td>Period 3</td>
<td>33,376</td>
</tr>
</tbody>
</table>

Fig 6. Rate of Viral Load Suppression at RCTO-WA Monitored Health Facilities

<table>
<thead>
<tr>
<th>Period</th>
<th>Suppression Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Period 1</td>
<td>48.4%</td>
</tr>
<tr>
<td>Period 2</td>
<td>67.9%</td>
</tr>
<tr>
<td>Period 3</td>
<td>77.4%</td>
</tr>
</tbody>
</table>
The host of the national CTO in Sierra Leone, NETHIPS, has been engaged in sustained advocacy efforts with the government to formally adopt a National Differentiated Service Delivery Strategy. Making use of CTO data that showed the low uptake of services for key populations, NETHIPS has made the case to the National AIDS Control Program of the Ministry of Health and Sanitation that such a strategy is needed in order to reduce barriers to accessing services and to achieve the 90-90-90 targets. On 4 March 2019, at the National HIV/AIDS Control Program conference hall, NETHIPS turned CTO data into an advocacy win, securing a commitment from the government to develop a DSD policy for Sierra Leone. The policy was signed by government and the National AIDS Secretariat in May 2019. As next step, NETHIPS will now work closely with key partners to mobilize the resources needed to implement Sierra Leone’s new DSD policy.
Building Data Systems

Brian Honermann
Keep Purpose of CLM in Mind

Data and Data Dashboards on their own don’t fix things and can cost a lot of money and time to develop, fix, and maintain.

Focus should be on getting data analysed so that it can be acted on.

Simpler, flexible tools.
## Electronic vs Paper Based Data Collection

<table>
<thead>
<tr>
<th></th>
<th><strong>Electronic</strong></th>
<th><strong>Paper</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Best suited for large-scale or longer term CLM projects</td>
<td>May be appropriate for smaller rapid-assessments</td>
</tr>
<tr>
<td><strong>Data Collection</strong></td>
<td><strong>Pro:</strong> Quicker to implement, more reliable, provides safer data storage</td>
<td><strong>Pro:</strong> Low cost and may require less capacity to design and implement</td>
</tr>
<tr>
<td><strong>Data Aggregation</strong></td>
<td><strong>Pros:</strong> Fast, simple, often automatic with electronic collection tools</td>
<td>****Very time consuming and prone to errors for large projects **</td>
</tr>
</tbody>
</table>
Electronic Data Collection:

**Commonly used data collection tools:**

- Each have pros and cons concerning functionality, price, available tech support, and usability
- **Tips:** Ask for a free trial so you can test out the platform before purchasing.

- Open Data Kit: http://www.opendatakit.org/
- Kobo Toolbox: https://www.kobotoolbox.org/
- Ona: https://company.ona.io/
- CommCare: http://www.commcarehq.org/
Phases of Data:

**Phase 1: Data Collection**
- Getting the questions right.
- MUST make sure you know how you want to analyse data when developing your tools
- *Phase 3 is part of Phase 1!*

**Phase 2: Data Centralization / Cleaning**
- All data need to be checked for errors and cleaned.
- Data cannot just live where they were collected.

**Phase 3: Data Analysis / Visualization**
- Don’t get too fancy and don’t over-promise
- Different audiences:
  - **Program manager**: to see where data have and have not been collected
  - **Data Analysis**: Identify where there are problems.

Think through and plan for each of these phases separately!
Other Things to Consider

Approach to Qualitative Data
- Qualitative data is important for making quantitative data real. Fills in stories and provides details otherwise missed
- Tools can collect some of this, but also needs different approach to analyse
- More isn’t necessarily better

Photos
- Photos as really powerful. Develop plans on how monitors can submit and file photos so that they can be used
Community collected data shows the problems.

So what next?
DATA COLLECTION by Community Monitors

Data compilation (through online app) & ANALYSIS & published (through data dashboard)

Use the information to GENERATE SOLUTIONS

State of health report developed and used for ENGAGING DUTY BEARERS at relevant levels

If there is no change, it is time to develop an activist CAMPAIGN
Moving from problems to solutions

Generating solutions can take many forms. In Ritshidze we think of them in three big groups:

1. Monitoring Team generated solutions
2. Community generated solutions
3. Solutions beyond the immediate clinic
Engaging duty bearers

28 Jun 2018

TAC RELEASES PROVINCIAL STATE OF HEALTH REPORTS

The Treatment Action Campaign (TAC) has today released a series of reports in the provinces in which we work that highlight the state of public healthcare services. Each TAC branch has adopted a primary healthcare facility local to them and have been monitoring the state of services at these facilities since November 2017. The results highlight a number of critical concerns with regard to the state of services at clinics and community healthcare centres. The full reports, data sets and summary of demands can be found at the links below:

Accountability Meetings

Bringing people together who have been affected by identified challenges in a public hearing or community meeting to hold duty bearers accountable is an important advocacy tactic to showcase the findings from data collection, raise people’s own stories, and put pressure on our targets to implement our proposed solutions.
When is it time for activist campaigns?

So you’ve gathered evidence, analysed the data, generated solutions, politely engaged duty bearers — and yet nothing has changed.

What next?

It is time to build a campaign strategy to address the challenge.
<table>
<thead>
<tr>
<th>Role</th>
<th>Team</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minister of Health and Director General, National Department of Health</td>
<td>National team</td>
</tr>
<tr>
<td>PEPFAR Coordinator, PEPFAR CCM, Global Fund</td>
<td></td>
</tr>
<tr>
<td>Premiers/Mayors, AIDS Councils</td>
<td>PLHIV Sector</td>
</tr>
<tr>
<td>MEC of Health and Head of Department, Provincial Department of Health</td>
<td>Provincial teams</td>
</tr>
<tr>
<td>PHC Director and District Director, District Department of Health</td>
<td>District teams</td>
</tr>
<tr>
<td>Facility Manager, Clinic Committee</td>
<td>Community Monitors</td>
</tr>
</tbody>
</table>
State of Clinic, district, province reports
People’s COP
Writing letters
Meetings
Engaging with Clinic Committees
Engaging in AIDS Councils
Organising Public hearings
Exposing issue in media
Publications
Sign on letters
Accountability meetings
Social media
Vigil
Pickets
Vigil
March
Sit ins

Level of escalation – as we exhaust options
What if you need a rapid resolution?
1. Can the facility manager fix the situation?
   If no: Contacting district, provincial, or national government or PEPFAR duty bearers may be necessary to resolve the situation. If so, consult quickly with national project staff to make a plan.

   If yes then ask:

2. Is the facility manager or other managers aware of the situation?
   If no: consider bringing the situation to their attention.
   If yes: If the facility management is aware, but has not resolved the situation make a plan about how you can help resolve the situation. It may require escalation to higher levels.