Community-Led Monitoring and Advocacy

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What Community-Led Monitoring & Advocacy is **NOT**

- **Not**... *community-based service delivery*
- **Not**... the monitoring of *community-based service delivery*
- **Not**... the monitoring of *communities* by service providers or governments
- **Not**... M&E that includes some community-centered indicators
- **Not**... periodic *community-check ins* by facilities/HCPs to ensure that services intended to serve communities are doing so effectively
Community-Led Monitoring & Advocacy

- Monitoring of services **BY communities**, where they are the end-user.
- Monitoring can be **routine or at a point in time**.
- Monitoring is of **indicators that are relevant** to that community in order to improve services (quality, type of service etc.).
- Monitoring provides an evidence-informed platform for the all-too-often missing **voice** in the response to advocate for change.
What is Community-Led Monitoring & Advocacy

Community-based Monitoring – “A process by which service users or local communities gather and use information on service provision or information on local conditions impacting on effective service provision, in order to improve the responsiveness, equity and quality of services and hold service providers to account. “Top-down” approaches to monitoring focus on macro level targets and financial accountability and are inadequate to highlight local realities in communities and remain slow in responding to needs of individuals within those communities. CBM extracts essential information which quantitative monitoring cannot. It determines the quality and suitability of services delivered with the consideration of local realities and highlights barriers to accessing services.”

“Observatories play two roles: mechanisms to monitor and evaluate health systems that complement top-down approaches to monitoring; and citizen movements that give a voice to patients.

• They are centered on local, community and citizen involvement
• They aim to sound the alarm on problem areas and to collect valid information on the state of access and quality of health services, which they disseminate on a regular basis at various different levels
• They create dialogue between stakeholders and strengthen advocacy at all levels of the health pyramid
• They contribute to improving health systems by highlighting the accountability of all actors
• They are located within the health system and provide a complementary alternative to institutional information systems.”

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Who is THE community?

UNAIDS Meeting June 2019:

“Community-led organizations, groups, and networks, irrespective of their legal status, are entities for which the majority of governance, leadership, staff, spokespeople, membership and volunteers**, reflect and represent the experiences, perspectives, and voices of their constituencies and who have transparent mechanisms of accountability to their constituencies. Community-led organizations, groups, and networks are self-determining and autonomous, and not influenced by government, commercial, or donor agendas. Not all community-based organizations are community led.”

“Community-led responses are actions and strategies that seek to improve the health and human rights of their constituencies, that are specifically informed and implemented by and for communities themselves and the organizations, groups, and networks that represent them. Community-led responses are determined by and respond to the needs and aspirations of their constituents. Community-led responses include advocacy, campaigning and holding decision-makers to account; monitoring of policies, practices, and service delivery; participatory research; education and information sharing, service delivery; capacity building, and funding of community-led organizations, groups, and networks. Community-led responses can take place at global, regional, national, subnational, and grassroots levels, and can be implemented virtually or in person. Not all responses that take place in communities are community led. “

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The Power of **BIG DATA** in the Hands of Activated Communities

- **11** Countries
- **2** Years of monitoring
- **84** Data collectors
- **125** Health facilities
- **1781** Quantitative reports
- **631,863** HIV tests performed
- **105,435** People on ART
- **81,380** VL tests performed
- **1501** Interviews
- **143** Focus groups
- **98,651** Young people reached
- **35,577** Key populations reached

A statistically significant sample size for the entire West and Central African region (95% confidence interval).
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>Percentage</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>Percentage</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 Health 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>Number</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>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>
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A Country Perspective – SIERRA LEONE

Idrissa D.M. Songo MOR
Executive Director
Network of HIV Positives in Sierra Leone (NETHIPS)
Overview of the HIV Response in Sierra Leone

Adult prevalence is 1.5%

- Spectrum estimate of PLHIV in Sierra Leone (June 2019) - 73,870
  - Sex workers - 8.5%
  - Gay men and other men who have sex with men - 14%
  - People who inject drugs - 8.5%
  - Prisoners - 2.2%

HIV services

- Number of PLHIV on ART - 31,825 (Sept. 2019)
  - 708 testing sites
  - 305 treatment sites
  - 157 sites collect viral load samples
  - On average 500 samples collected monthly
  - Turn around time for viral load results is between 7 – 14 days
How the Government and the Community Work Together

- Data is collected from public health facilities based on MoU signed with National AIDS Control Programme.

- NETHIPS monitors services using a Community Treatment Observatory (CTO). Findings, especially on stock outs, are immediately shared with government for action through advocacy efforts.

- Government representation is part of the “Community Consultative Group – part of the CTO model used and includes the National AIDS Secretariat, National AIDS Control Programme and the District Health Management Team.
Key Results Achieved through the Government and CTO Partnership

Based on health facilities (17) and drop-in centers (3):

- Tested – 60,959
- HIV + – 3,423
- Initiated on treated – 3,007
- # tested for Viral Load – 1,984
- Virally suppressed – 940
Data For A Difference: The Story of CLM & DSD in Sierra Leone

SIERRA LEONE

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.

Key Lessons Learned

- MoU signed with the National AIDS Control Programme helped to remove barriers to collect data from public health facilities
- Community-led monitoring is an effective way to monitor service uptake including DSD
- Community-led monitoring also leads to improved access to quality HIV services
- Evidence-informed advocacy leads to trust and ownership
Key Challenges

- Data collection is paper-based affecting timely collation, analysis and reporting (would like to move to electronic data collection)

- Stockout of HIV drugs and other commodities is a major challenge that affects service uptake

- Need to mobilize resources for continuation of the CTO Project

- High demand to scale up the CTO project nationwide but no resources
LESSONS LEARNED, Challenges and Success Factors

✓ **Strong leadership is critical.** The more successful observatories had strong leadership within the national network, and high-level political buy-in. In Benin, the Community Consultative Group (CCG) was chaired by the Office of the Presidency. Initiatives must invest in the strength of the host organization as well as feedback mechanism (like the CCG) for the community treatment observatory to be successful.

✓ **The model must be embedded in the national response.** Working closely with governments and other key national stakeholders was vital. Rather than finger-pointing, the treatment observatories created a culture of collective problem solving among health care workers, decision-makers, and recipients of care. Governments came to see PLHIV networks as an asset and an ally in the response.

✓ **Moving from ad hoc alerts to systematic monitoring is key.** This enabled the observatories to be proactive instead of reactive. By monitoring services along the entire cascade, other issues were unearthed, such as stigma and discrimination as a barrier to access, and gender-related health inequities.

✓ **Different observatories function at different levels.** The differences in geographic coverage and the varying capacities of the national networks presented challenges. ITPC developed an accreditation tool, classifying the observatories into tiers. This improved the efficiency of the support provided.

✓ **Data-driven advocacy works.** Results and analysis from the Côte d’Ivoire observatory caught the eye of Ambassador Deborah Birx, the United States Global AIDS Coordinator. This observatory is now being funded by PEPFAR in COP19 and has successfully advocated for the removal of user fees in the country.
Value of **Effective** Community-Led Monitoring

- **Forces investments in health/treatment education** – you can’t effectively monitor if you don’t know the standard.

- 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. Data that informs national health plans and frameworks is often **void of information from the recipients of care**.

- In addition to the standard indicators collected by health information management systems, CTOs collect **qualitative data** (not collected by the government) that gives **nuance and insight into the data** and tell the story on the **implications of bad quality service for recipients of care**.

- In some instances, communities have **access to data that is not** collected nor analyzed as part of the nationals HMIS (i.e. KP data).

- CLM has led to communities **finding issues** in the site-level data! CLM is a win for everyone and the whole system.

- The UNAIDS GAM (Global AIDS Monitoring reports) show that community data is **rarely** collected and analyzed at country level – this is due to **lack of capacity and incentive** at national level (based on discussions with UNAIDS). CLM demonstrates an **opportunity to build a system that can contribute to national data systems – with community participation in those processes**.
Community-Led Monitoring and DSD: Some Key Questions

- Is DSD working? Impact?
- Are we doing enough with community data to figure out WHERE and HOW to best intervene?
- To what extent can community-led monitoring support CQUIN/country efforts to ensure implementation success?
- Are we assuming that business as usual will ensure that DSD will be effective?

Of the 289 persons who were virally suppressed, only 76 were enrolled in a mainstream model; that’s 6%!