



# Community-led monitoring in a changing world

**A pre-conference at AIDS 2024, the 25th International AIDS Conference**

Sunday, 21 July 2024

Messe München, Munich, Germany

# Executive summary

The pre-conference, "Community-led monitoring in a changing world", convened by IAS – the International AIDS Society – had four main objectives:

- 1. To celebrate community-led monitoring (CLM) successes to date**
- 2. To explore how CLM can be strengthened and sustained**
- 3. To discuss what is working, what is needed and what is next for collaborations with governments in the broader context of sustainability in the HIV response**
- 4. To identify key considerations, priorities and next steps towards strengthening CLM as a social accountability mechanism moving forward**

Session 1 focused on setting the scene, covering CLM core principles, the role of CLM in centring community leadership and solutions to protracted global problems, and key successes of CLM on HIV, TB and malaria responses to date. The session was designed to orient audiences less familiar with CLM to the CLM methodology and why it matters while sharing diverse examples of evidence of CLM-driven improvement in healthcare delivery across global regions.

Session 2 foregrounded CLM implementers' insight and experiences in the sustainability debate and concentrated on what is needed to strengthen and sustain CLM as a vital social accountability mechanism moving forward. Following a plenary presentation on the experiences of Ritshidze in South Africa, one of the largest and longest-running CLM programmes globally, a panel of CLM implementers from Haiti, Indonesia, South Africa and Tanzania delved into priorities for CLM strengthening.

The third pre-conference session heard from government representatives in India, Malawi, Namibia and the Philippines on collaborations with communities on CLM. Presentations highlighted what is working, what is needed and what is next for CLM in presenters' respective countries. This was followed by questions and answers.

Session 4 explored in-depth what sustainability means – and looks like – for CLM. Leaders in the HIV and AIDS response shared their thoughts towards a sustainability agenda for CLM in a moderated discussion, followed by questions and answers.

The final pre-conference session summarized key takeaways from the day's discussion and heard from CLM implementers from India and Zimbabwe on priorities and challenging questions for the future. The session closed with an interactive exercise with audience members and a networking reception.

## Background, aims and objectives

Community-led monitoring (CLM) is a social accountability mechanism for communities to identify and articulate and advocate for action to address the health issues, service issues and/or inequalities they face. Communities engage directly with services and service recipients, analyse findings, and advocate and engage with stakeholders in government and other sectors to identify and implement solutions based on the findings. CLM programmes are underway in over 60 countries<sup>1</sup>; they address issues related to quality of HIV, tuberculosis, malaria and COVID-19 services and abuse of human rights<sup>2, 3</sup>.

Today, the context in which CLM takes place includes competing health system priorities, such as pandemic preparedness, outbreak response and universal health coverage. While issues of inequality, stigma, discrimination and fragile services and systems endure, the HIV response is increasingly focused on sustainability after 2030 – the UNAIDS deadline for achieving the end of HIV as a public health threat.

IAS – the International AIDS Society – convened the full-day pre-conference, “CLM in a changing world”, at AIDS 2024, the 25th International AIDS Conference. The aim was to identify and explore the strengths and needs of CLM in the current environment to ensure its continuity and efficacy moving forward.

The pre-conference created a space for exchange about the application of CLM principles, models and experience to ensure quality and accountability in the HIV response and in other health and development priorities. Through dialogue and case studies, the pre-conference aimed to deepen understanding and foster cross-sectoral collaboration that values, strengthens and sustains CLM in a changing world.

### The pre-conference had four main objectives:

1. **To celebrate CLM successes to date**
2. **To explore how CLM can be strengthened and sustained**
3. **To showcase what is working, what is needed, and what is next for collaborations with governments**
4. **To identify key considerations, priorities and next steps towards strengthening CLM as a social accountability mechanism moving forward**

The pre-conference was held at the Messe München in Munich, Germany, on 21 July 2024 and brought together 28 speakers from 16 countries<sup>4</sup>. Session moderators and speakers included representatives of community-led organizations implementing CLM, advocacy networks of people living with HIV, and global normative and funding agencies, including UNAIDS, The Global Fund to Fight AIDS, Tuberculosis and Malaria, PEPFAR and WHO (see Annex 1: Agenda). Each of the five pre-conference sessions was organized thematically and followed by questions and answers.

The pre-conference was designed collaboratively. A working group, comprised of IAS CLM programme Steering Committee members and external experts, was convened in January 2024 and met monthly through April. The discussion began with a mapping of challenges in the CLM field, which informed the identification of pre-conference priorities and the agenda (see Annex 2: List of working group members).

# Session 1: Celebrating CLM to date: Impact, outcomes and role in the HIV/TB/malaria response



"The path to equity means elevating community data and community-led interventions."

**Solange Baptiste**  
Executive Director of the International Treatment Preparedness Coalition (ITPC), South Africa

The purpose of the pre-conference opening session was to highlight the successes of CLM on HIV, tuberculosis (TB) and malaria responses to date. By delivering a clear sense of what CLM is and its impact as a vital social accountability mechanism, the first session set the scene and laid the groundwork for future sessions.

The session was opened by co-chairs Kenneth Ngure (Jomo Kenyatta University of Agriculture and Technology, Kenya) and Lillian Mworeko (International Community of Women Living with HIV, Uganda). They welcomed participants, provided an overview of community-led monitoring, and laid out the agenda for the day.

In a plenary presentation, Solange Baptiste (ITPC Global, South Africa) highlighted ongoing inequities in the HIV response and the role of community-led interventions in identifying and addressing persistent issues in healthcare delivery. CLM is a routine intervention led by those best placed to identify cracks in national healthcare systems. It provides data granularity that can guide decision making to improve prevention and treatment retention and address inconsistent and low-quality services, discriminatory laws and stigma, and prohibitive pricing of medications and other commodities.

For example, in West Rand, South Africa, in 2023, people who visited one or more of 19 CLM sites were 32% more likely to initiate PrEP following PrEP-related CLM feedback sessions with facility managers than those visiting non-CLM monitored sites<sup>5</sup>. In Kasungu District, Malawi, in 2022, CLM identified that clinics needed support to implement national differentiated service delivery (DSD) guidelines. Following





DSD strengthening interventions at seven health facilities, people accessing ART at these facilities were six times more likely to be on a DSD model and twice as likely to be virally suppressed compared to those accessing ART at other facilities<sup>5</sup>.

The second half of the session focused on deep dives into CLM successes in three countries and regions: Mongolia, eastern Europe and central Asia, and Lesotho. RD Marte (APCASO, Thailand) shared that in Mongolia, over 80% of people living with TB are undiagnosed. A high level of stigma and the near absence of organized networks of TB survivors and affected communities have meant that people living with TB are excluded from decision making. Following CLM orientation and capacity building and the establishment of a TB CLM coordinating committee and strategy, TB CLM was officially included in Mongolia's TB National Strategic Plan and its funding request to the Global Fund under GC7. This set a strong foundation for the further strengthening of TB health services.



Sergey Golovin (ITPC EECA) highlighted how community-led monitoring of HIV, HCV and TB drug availability in Moldova and Kyrgyzstan led to price reductions of key medications. Likewise, community-led interventions during the tendering process for dolutegravir contributed to price drops in Belarus and Kazakhstan.

Makeneuoe Fako (Bacha re Bacha Youth Forum, Lesotho) described how CLM data collection revealed the absence of stigma- and judgement-free spaces where adolescent girls and young women could seek health services. Following discussions with the Quthing district health facility, space was allocated and tailored to the needs of adolescent girls and young women.

## The question-and-answer period focused on:

- Processes for involving technology to collect, analyse and present CLM data
- Experiences in communicating with stakeholders, such as district pharmacies
- The role of CLM as fact finding rather than fault finding
- The importance of ensuring that impacted communities are empowered leaders of CLM programmes
- Analysing CLM data to show progress towards UNAIDS targets
- Opportunities to establish a common set of core CLM indicators



# Session 2: What does CLM need to survive and thrive in a changing world?

"CLM is not an apolitical tool that is used as a reporting mechanism. It is the sustained change of community leadership and solutions that is needed at a time when the world is facing a polycrisis."

**Vuyiseka Dubula**  
 Head, Community, Rights and Gender,  
 the Global Fund



The second pre-conference session sought to answer the question: how will CLM impact continue in a complex future? It was moderated by co-chairs Vuyiseka Dubula (the Global Fund, Switzerland) and Geoff Garnett (Gates Foundation, USA). In this session, CLM experts considered how CLM can be strengthened and sustained going forward. After a framing presentation by Ndivhuwo Rambau (Treatment Action Campaign, South Africa), a panel explored challenges and opportunities in the design, resourcing and implementation of CLM programmes that lead to impact for and with communities and the health services they need. The panel was made up of CLM implementers Georges Casimir (ODELPA, Haiti), Marineus Mutongore (Key and Vulnerable Population Forum, Tanzania), Caroline Thomas (Peduli Hati Bangsa, Indonesia) and Ndivhuwo Rambau.

Ndivhuwo Rambau began the session with an overview of the Ritshidze project in South Africa, which monitors over 400 clinics and community healthcare centres across 29 districts in eight provinces. In 2024 so far, Ritshidze has interviewed 74,933 public healthcare users, 37,991 people living with HIV, 11,440 young people (under the age of 25) and 1,415 facility managers. A central challenge for CLM at this scale is automation – electronic data platforms and collection tools are critical for generating clinic-specific insights quickly, yet are often not funded. Likewise, CLM funding often does not include support for advocacy and implementation of community-led solutions to programmatic gaps and policies. Ensuring community leadership in defining indicators to track is critical, as is recognition of the importance of partnerships and collaboration, especially with governments, to strong CLM programmes.

Vuyiseka Dubula and Geoff Garnett invited each panellist to begin the moderated discussion with a statement on what they see is needed for CLM to survive and thrive.

Caroline Thomas emphasized that while technical assistance is sometimes needed to establish data collection processes, strengthening community capacity to conduct data analysis is vital. For Georges Casimir, strengthened coordination between donor organizations is required to expand CLM nationally in Haiti. Marineus Mutongore highlighted the importance of ensuring that CLM is led by key populations (men who have sex with men, trans people, people in prisons and other closed settings, people who inject drugs, and sex workers and their clients). In many countries, key populations are criminalized and key population-led organizations cannot officially register and so are excluded from donor funding. Yet key populations can play a central role in identifying gaps in health service delivery, both at the clinic level and in health groups to identify reasons why people do not go to clinics. Donors need to be cognizant of country-specific social and political realities and adapt the conditions on which partner organizations are selected accordingly. Police also need to be sensitized about HIV services for key populations.

The panel discussion focused on how panellists see their work evolving over time, the importance of funding the full cycle of CLM from data collection to advocacy, strategies for managing donors' expectations around independence, and the value of aggregating CLM data across donors and programmes.



## The question-and-answer period focused on:

- The extent to which conditions monitored by CLM programmes, including stockouts, stigma, and poor-quality services, have not changed, even as priorities for public health funding shift
- Experiences in building collaborations and sharing data with governments
- How Global Fund and PEPFAR CLM programmes can be harmonized and lessons learnt shared
- Building community leadership to monitor beyond health areas
- How CLM processes can also be used to address systemic issues, such as poor remuneration of health workers

# Session 3: Government as a CLM partner: What's working, what's needed, what's next?



"CLM data needs to be used in real time – it doesn't make sense to wait six months to respond to a stockout."

**Shobini Rajan**  
Deputy Director General, Ministry  
of Health and Family Welfare,  
Government of India

CLM requires collaboration and communication with government. The purpose of Session 3 was to explore duty bearers' views on CLM to date and going forward. Representatives of national and local governments shared their experiences in building partnerships with CLM implementers, identifying best practices, and exploring the urgent question of how CLM can support health system strengthening and long-term, sustainable HIV programmes.

The session was co-chaired by Greg Millett (amfAR, USA) and Maureen Luba (IAS, Malawi). It focused on what is working, what is needed and what is next for CLM-government collaborations in four countries: India, Malawi, Namibia and the Philippines.

Julieth Karirao (Ministry of Health and Social Services, Namibia) began the session by noting the strengths of the CLM governance structure in Namibia. This included the establishment of a steering committee with representation from the Ministry of Health and Social Services and the Quality Assurance Division, and regular engagement of duty bearers in reviewing CLM findings and co-developing solutions. Current needs include the establishment of an advanced database for online and offline data capture, data visualization and reporting, and development of an advocacy and dissemination strategy and strengthened feedback mechanisms to the ministry to ensure rapid response. Future work will focus on the institutionalization of CLM so that data can be used for real-time responses at the facility level.



For Rose Nyirenda (Ministry of Health, Malawi), the current strengths of CLM-government collaboration in Malawi include political will, regular policy and performance dialogues, health service monitoring and reporting, and collaborative problem solving. In communities, the need is for:

- Improved knowledge and alignment with government vision, priorities, strategies and systems
- Expand CLM to other disease areas beyond HIV
- Increased capacity in data for decision making

In the government, the need is for increased engagement and implementation of reforms and capacitating duty bearers in CLM at all levels of the healthcare system. Going forward, the priorities will be:

- Strengthening civil society leadership
- Ensuring that government engages with civil society beyond HIV, TB and malaria programming
- Collaborative development of roadmaps based on CLM priorities, with community leadership
- Supporting civil society to interface with communities on priority health issues through cost-effective models

Rolando Cruz (Department of Health, Quezon City, the Philippines) highlighted the utility of CLM data to advocate for policy changes at local and national levels, how community involvement builds trust between community members and healthcare providers, and the role of CLM in identifying tailored solutions. Key needs include sustained and consistent data collection and analysis across healthcare facilities, simplified CLM questionnaires, monitoring of key action items and agreements, and clearer linking of CLM outcome indicators to improvement of the HIV treatment cascade.



Shobini Rajan (Ministry of Health and Family Welfare, India) outlined current strengths in CLM pilot programmes, including the development of an accountability mechanism and platform for communities to share findings and contribute to addressing the issues raised, and the use of technology for data collection and analysis. However, data should be collected more frequently to allow for quicker responses to identified issues, the questionnaires should be simplified, and community resource groups could be better leveraged to improve accountability across the health system. Priorities moving forward will be to consolidate learnings from the pilot phase towards finalization of a CLM implementation framework, development of strategies for CLM rollout in HIV high-priority districts, orientation of service providers on CLM, and technological developments to support data collection.

## The discussion focused on:

- Panellists' perspectives on the gaps that CLM is effective in addressing
- What is needed from government to make partnerships effective
- The role that CLM can play for key populations
- Increasing community accessibility through simplification of data collection tools
- Data ownership
- Sharing of government data and systems with CLM implementers
- Given the broader context of sustainability, how power differentials between government and community will be addressed



# Session 4: How can CLM be sustained and strengthened as part of HIV-focused sustainability agendas?

"When we put people at the centre of our healthcare systems, it is not as beneficiaries but as drivers of better health outcomes."

**Bience Gawanas**  
Board Vice Chair, the Global Fund



The HIV response is increasingly focused on sustainability. Session 4 explored what sustainability means – and looks like – for CLM. Sustainability encompasses a range of topics, from financing to political will, and programme design to data storage and use. In this session, leaders in the HIV and AIDS response shared their thoughts about reaching a sustainability agenda for CLM.

Naiké Ledan (Health GAP, USA) and Matthew Kusen (Health Equity Matters, Thailand) co-chaired the session. It comprised a panel discussion with Florence Anam (Global Network of People Living with HIV, GNP+), Winnie Byanyima (UNAIDS, Switzerland), Erin Eckstein (PEPFAR, US Department of State) and Bience Gawanas (the Global Fund, Switzerland).

The session began with a question to all panellists on what sustainability for CLM looks like.

Erin Eckstein noted that PEPFAR is moving to ensure sustainability of political leadership, programmatic oversight and funding in its partner countries. Within that context, CLM remains important as a mechanism for civil society to engage with and ensure accountability from government. This requires a measured and considered approach that is tailored to the unique contexts of each PEPFAR-supported country. Eckstein emphasized that the priority is on protecting healthcare clients – PEPFAR will still aim to be funding programmes in countries where government is not ready to incorporate CLM into health systems. Overall, the work ahead lies in hearing from governments what their vision of sustainability looks like and then defining how to work together to achieve it. For PEPFAR, emphasizing and protecting equity is a priority, particularly for people living with HIV and key populations.



Equity is a key pillar of a sustainable HIV response, and this involves civil society routinely engaging with governments to identify issues and make recommendations for programme improvement. Many elements must be thought through and strengthened: how CLM is funded; ensuring the primary leadership of communities; how to fortify governance structures; how to develop a CLM workforce that is trained and compensated fairly; and how to institutionalize CLM feedback systems so that issues can be addressed rapidly.



Florence Anam spoke from the perspective of a grassroots organization. She noted the power differential in these discussions – communities have often found themselves in processes that are not designed by them, yet must create spaces to engage anyway because they will be affected. For Anam, sustainability means that community work is understood as a process, not an activity with an end date. We have an opportunity now to identify what has worked in CLM and what can be taken to scale. Communities must be centred in these discussions with strong resource support.

Bience Gawanas emphasized that putting people at the centre of healthcare systems necessarily means that people are drivers, not beneficiaries. When we ask what sustainability means for CLM, we are going to the fundamentals of how communities demand better health services. This begs the question: how do we build leadership in communities to hold governments accountable for better health services? Are there systems and processes in place to sustain programmes to continue what has been done? The hope is that people take charge and ownership over the long term. CLM has gained momentum because communities have pushed, and this is part of a broader shift in which communities have said: nothing about us without us.



Winnie Byanyima noted that “sustainability” is time-related and so raises the question of why we are having these discussions now. In 2015, the world came together to agree on the Sustainable Development Goals (SDGs) with a time horizon of 2030. So, now we are considering what those targets mean. As not everyone will be cured of HIV, what does it mean for people living with HIV to live healthy lives? Byanyima outlined four key pillars (Box 1).



#### **Box 1. Winnie Byanyima's four key pillars for CLM sustainability**

- 1. Financing – the gap between what is available and what is needed is large. How do we ensure that all countries have resources to prevent, test and keep people on treatment?**
- 2. Programming – in many countries, there are parallel health programmes for HIV due to donor funding. We need to integrate programmes into national health systems for continuity. HIV changed global health by putting people at the centre and bringing care out of facilities. Other healthcare does not work that way; how do we combine these different models of healthcare delivery?**
- 3. Access – if countries start paying for health systems out of their own taxes, they need to be able to procure and produce locally and regionally. Technology transfer is key.**
- 4. Political will – governments must recognize the human rights of all people.**

Bience Gawanas noted that CLM is essential to Global Fund investments and has clear linkages to strengthening health systems. The Global Fund embeds CLM data in country programming to inform sustainability discussions. Looking to challenges, Gawanas shared that CLM is about something we don't talk about enough: solidarity. She emphasized that community leadership is key and it is important to consider what criteria are being used to ensure community leadership.



Florence Anam was asked about the red flags she sees, as a leader of a grassroots network, regarding government involvement in CLM. She responded that HIV has changed a lot of things, including shifting healthcare dynamics to centre people living with HIV as partners in their own health. Community work has been a central part of that shift. Given that civic space is shrinking globally, will CLM be able to provide an environment for community leadership? If the aim is to improve health service delivery, it is vital to reflect on the role of communities who conduct advocacy with governments; how are they protected against backlash? There is a risk that community-led work will be diluted. We must not lose sight of the fact that donors have played a role in getting us to where we are.

Winnie Byanyima was asked how CLM can be sustained and strengthened in the current context of criminalization of key populations and shrinking civic space. She responded by asking how CLM can also challenge these contexts. Byanyima noted that UNAIDS is deeply involved in supporting CLM through normative guidance and technical assistance. Ultimately, CLM must be more integrated into the health system to support improved inclusion, guarantee of human rights, and efficiency and cost effectiveness of services; this is a key aspect of engaging with governments. CLM also has the potential to be broadened to address systemic issues. For example, stockouts are related to medicine access and availability of the full range of treatment and prevention tools; this can be a key part of the CLM commentary. Byanyima highlighted the depth of knowledge of communities and the enormous capacity to grow this expertise. The work lies in showing governments the value of this.

Erin Eckstein was asked how data on key populations can be secured in an increasingly digital world. In response, Eckstein highlighted the need for tailored tools to address the stigma, discrimination and criminalization facing key populations. CLM programmes require leadership by key populations to best determine what is appropriate use of data and how to protect sensitive data.

Questions from the audience included how to proceed on issues regarding stockouts and access to medicines, given that many governments will not fund a system that holds them to account. They also focused on how to ensure that community-led recommendations on stigma, for example, are incorporated into donor programmes and experienced by communities, and how to ensure that in the context of sustainability, national data systems include key population data.

# Session 5: Safeguarding social accountability: Toward a consensus statement on CLM in a changing world

"CLM is to show the injustices that happen in our communities."

**Yvette Raphael**  
Co-founder and Executive Director,  
Advocacy for Prevention of HIV and AIDS  
(APHA), South Africa



CLM has strengthened social accountability worldwide. The last session of the day asked: where to from here? The session highlighted priority issues and actions arising from CLM implementers' experience and the day's discussion and concluded with an interactive session with audience members on what is next needed for CLM.

The session began with summary remarks from co-chairs Yvette Raphael (APHA, South Africa) and Antons Mozalevskis (WHO, Switzerland) on the discussions so far. Yvette and Antons noted that throughout the pre-conference, people spoke about the sources of change, such as HIV integration with national primary healthcare systems and funding cuts, and about what hasn't changed: stockouts and health inequities that impact specific segments of the population. Discussions also centred on many definitions of sustainability and different ideas about what challenges CLM faces in this context. Another cross-cutting theme was the importance of data for advocacy, including stories and qualitative information, and the need to simplify and customize to adapt monitoring for specific populations.

The co-chairs noted that overall, many of the issues facing CLM are also those facing the HIV field more broadly. However, we have also seen how CLM can help answer some of these questions, both through the information it provides and in the relationships it forges between health workers and communities. The question is less about how CLM can survive and thrive in a changing world, and more about how the CLM methodology can help a changing world – and people impacted by health inequities – survive and thrive.

The session then turned to presentations from Loon Gangte (Delhi Network of Positive People, India) and Janet Tatenda Bhila (Zimbabwe Young Positives) with their respective must-haves and challenging questions for CLM moving forward.





Loon Gangte emphasized the importance of full funding for the CLM cycle and independence from government, highlighting that the responsibility of government lies in instituting mechanisms to identify problems and respond effectively to issues raised. Other needs include protections for whistleblowers, increased transparency and access to information, and sustained and efficient use of resources through direct funding of community organizations.

### **Government and policy makers**

How can we ensure that community feedback leads to tangible policy changes and improvements in service delivery that benefits the community?

What measures can be put in place to protect and support whistleblowers and community monitors?

### **Donors and funding agencies**

How can funding mechanisms be designed to support long-term social accountability initiatives, rather than short-term projects?

What strategies can be adopted to ensure that funding reaches directly the grassroots level?

### **Civil society organizations**

How can we build and maintain trust with the communities we serve, ensuring that their voices are genuinely heard and acted upon?

### **Communities**

What are the most effective ways to mobilize and sustain community participation in monitoring and accountability processes?

How can we ensure inclusivity and representation in community-led monitoring, especially for marginalized groups?





Janet Tatenda Bhila highlighted that data that represent the experiences of – and support advocacy for – children and adolescents are currently missing in the HIV response. Secure, streamlined and digitized data collection and visualization systems are key to addressing this gap, as is fair remuneration of data collectors. CLM models must be adapted to diverse contexts, and more opportunities are needed to share evidence and best practices.

Yvette Raphael and Antons Mozalevskis then introduced the interactive exercise. Audience members were invited to respond to three poll questions:

1. What is your must-have for CLM to survive and thrive in a changing world?
2. What is your challenging question about the future of CLM?
3. What is one word for CLM moving forward?

Trends in the poll results focused on: the importance of centring community leadership, particularly of key populations; the need to fund the full cycle of CLM; who is responsible for ensuring the sustainability of CLM; and how to ensure CLM independence.

Audience members were then invited to elaborate on their poll comments. The discussion centred on the need to adapt advocacy strategies to the issues identified. For example, stigma and discrimination require different approaches than stockouts. Additional topics included: how to protect whistleblowers from government, especially around sensitive issues like medication shortages and stockouts; the need to adapt CLM funding models to allow rapid response to issues identified; and the importance of funding community-led organizations directly, rather than through governments.

Audience members also highlighted: the need for fair remuneration for CLM work; the role of donor support in ensuring protection for communities; and the need and potential for CLM to encompass monitoring of systemic issues, such as the shrinking space for advocacy and the fact that this pre-conference was taking place in a space that was not accessible for many advocates.

Yvette Raphael closed the session with a reminder that we all have a duty to highlight and respond to the injustices that happen in our communities. Raphael and Mozalevskis thanked the session speakers and extended an invitation to all to join the networking reception following the session.

# Annex 1

## Community-led monitoring in a changing world

Sunday, 21 July, 08:00-16:30 local time (CET), Munich, Germany, and virtually

### Agenda

**08:00 - 09:00 Session 1: Celebrating CLM to date: Impact, outcomes and role in the HIV/TB/malaria response to date**

#### Opening and welcoming remarks

Kenneth Ngure, Associate Professor, Jomo Kenyatta University of Agriculture and Technology, Kenya, & Lillian Mworeko, Executive Director, International Community of Women Living with HIV East Africa (ICWEA), Uganda

#### Community-led monitoring as a means to lasting change

Solange Baptiste, Executive Director, International Treatment Preparedness Coalition (ITPC), South Africa

#### Celebrating CLM: Success stories in the Asia-Pacific region

RD Marte, Executive Director, APCASO, Thailand

#### Celebrating CLM: Success stories from Eastern Europe and Central Asia region

Sergey Golovin, consultant, ITPC-EECA

#### Celebrating CLM: Success stories from Lesotho

Makeneuoe Fako, Monitoring and Evaluation Manager, Bacha re Bacha Youth Forum, Lesotho

#### Question and answer

**09:30 - 11:00 Session 2: What does CLM need to survive and thrive in a changing world?**

#### Welcome and opening remarks

Vuyiseka Dubula, Head, Community, Rights and Gender, The Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), Switzerland, & Geoff Garnett, Bill & Melinda Gates Foundation, USA

#### Challenges to sustaining and strengthening CLM in a changing world: Examples from Ritshidze

Ndivhuwo Rambau, Project Coordinator, Treatment Action Campaign, South Africa

#### Moderated panel discussion: What does CLM need to survive and thrive in a changing world?

- Marineus Mutongore, Chairperson, Key and Vulnerable Population Forum, Tanzania
- Caroline Thomas, Founder, Peduli Hati Bangsa, Indonesia
- Georges Casimir, Data Assistant, ODELPA, Haiti
- Ndivhuwo Rambau, Project Coordinator, Treatment Action Campaign, South Africa

11:30 - 12:30

### Session 3: Government as a CLM partner: What's working, what's needed, what's next?

#### Welcome and opening remarks

Gregorio Millett, Vice President and Director Public Policy, amfAR, USA, & Maureen Luba, consultant, International AIDS Society, Malawi

#### CLM in Namibia: What's working, what's needed, what's next?

Julieth Karirao, Deputy Director in the Directorate of Special Programmes, Ministry of Health and Social Services, Namibia

#### CLM in Malawi: What's working, what's needed, what's next?

Rose Nyirenda, Director: HIV, STIs, Hepatitis, Ministry of Health, Malawi

#### CLM in Quezon City: What's working, what's needed, what's next?

Rolando Cruz, Quezon City Health Department, Philippines

#### CLM in India: What's working, what's needed, what's next?

Shobini Rajan, Deputy Director General, National AIDS Control Organization, Ministry of Health and Family Welfare, India

#### Question and answer

13:30-14:30

### Session 4: How can CLM be sustained and strengthened as part of HIV-focused sustainability agendas?

#### Welcome and opening remarks

Naiké Ledan, Director of International Policy and Advocacy, Health GAP, Haiti, & Matthew Kusen, Senior Technical Advisor, Health Equity Matters, Thailand

#### Moderated panel discussion

- Florence Riako Anam, Co-Executive Director, the Global Network of People Living with HIV (GNP+), Kenya
- Winnie Byanyima, Executive Director, the United Nations Joint Programme on HIV/AIDS (UNAIDS), Switzerland
- Erin Eckstein, Team Lead, Key Populations, Human Rights, and Community, PEPFAR, US Department of State, United States
- Bience Gawanas, Vice-Chair, Board of the Global Fund to Fight AIDS, Tuberculosis and Malaria, Switzerland

15:00-16:30

### Session 5: Safeguarding social accountability: Toward a consensus statement on CLM in changing world. Followed by CLM networking event

#### Summary remarks and welcome

Yvette Raphael, Executive Director, Advocacy for the Prevention of HIV and AIDS (APHA), South Africa, & Antons Mozalevskis, Technical Officer for Key Populations, Global HIV, Viral Hepatitis and STIs Programmes, World Health Organization, Switzerland

#### Loon's "must haves" and challenging questions

Loon Gangte, Executive Director, Delhi Network of Positive People (DNP+), India

#### Janet's "must haves" and challenging questions

Janet Tatenda Bhila, National Coordinator, Zimbabwe Young Positives, Zimbabwe

#### Question and answer

**Interactive session** Yvette Raphael

#### Closing remarks

# Annex 2

## AIDS 2024 CLM pre-conference working group members

Focal point	Affiliation	Country of residence	IAS CLM programme Steering Committee member
Beatrice Ajonye	International Community of Women Living with HIV Eastern Africa (ICWEA)	Uganda	Yes
Emily Bass	International AIDS Society	USA	IAS Secretariat
Ayibatari Burutolu	PEPFAR, Bureau of Global Health Security and Diplomacy	USA	No
Vuyiseka Dubula (alternate: Keith Mienies)	Global Fund	Switzerland	No
Erin Eckstein	PEPFAR, US Department of State	USA	No
Anna Grimsrud	International AIDS Society	Switzerland	IAS Secretariat
Brian Honermann	amfAR	USA	No
David Kamkwamba	Network of Journalists Living with HIV (JONEHA)	Malawi	Yes
Julieth Karirao	Ministry of Health and Social Services, Tanzania	Tanzania	No
Siobhan Malone	Gates Foundation	USA	Yes
Imelda Mahaka	Pangaea Zimbabwe AIDS Trust (PZAT)	Zimbabwe	No
Rosemary Mburu	WACI Health	Kenya	No
Mtisinge Mikaya	Malawi Network of AIDS Service Organizations (MANASO)	Malawi	Yes
Kenneth Ngure	Jomo Kenyatta University of Agriculture and Technology / Department of Global Health, University of Washington	Kenya	Yes
Yvette Raphael	Advocacy for Prevention of HIV and AIDS (APHA)	South Africa	No
Laura Schaefli	International AIDS Society	Switzerland	IAS Secretariat
Andy Seale	World Health Organization	Switzerland	No
Laurel Sprague	UNAIDS	Switzerland	No



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