ITPC

CLM SUMMIT

THE FUTURE IS COMMUNITY-LED

8–9 OCTOBER 2024 • **JOHANNESBURG, SOUTH AFRICA**

SUMMIT REPORT

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EXECUTIVE SUMMARY

The CLM Summit organised by ITPC – International Treatment Preparedness Coalition – took place in Johannesburg, South Africa, on 8 and 9th October 2024. The summit aimed to explore and expand the role of Community-Led Monitoring (CLM) in driving accountability, improving health services, and enhancing community engagement across various sectors. Sessions were dynamic, designed to maximize content in a limited time, allowing participants to explore a broad range of topics and perspectives on CLM's applications.

The first day centred on understanding CLM's core principles and its value in empowering communities. Sessions highlighted CLM's ability to create actionable data feedback loops that help governments make informed decisions, especially in health sectors such as HIV, TB, and malaria. Stakeholders explored CLM's unique potential to impact cross-sector areas beyond health, stressing the importance of community-led data in guiding policies and funding.

The second day centred on maximizing the strategic use of community-driven data for systemic change. Sessions highlighted the scientific, technological, and cross-sector possibilities of CLM, with discussions on the integration of Artificial Intelligence, data triangulation, and affordability solutions. Expert panels demonstrated CLM's adaptability to diverse fields, from climate resilience to development financing, underscoring its capacity to enhance sustainable impact beyond health. Interactive Café Conversations empowered attendees to develop actionable strategies for embedding CLM within their respective sectors, reaffirming a shared commitment to community-led accountability and empowerment.

The summit's fast-paced, targeted structure enabled rich discussions on CLM's value proposition and underscored its potential to address both sector-specific and global challenges through sustainable, community-driven initiatives. The summit advanced a collective understanding of CLM as a transformative tool, fostering collaboration among a wide range of stakeholders to scale CLM and support both immediate community needs and long-term systemic resilience.

KEY TAKEAWAYS

The CLM Summit highlighted actionable insights and set the stage for sustained progress. **Key outcomes include:**

1 The Summit showcased CLM's measurable impact in the health sector.

2 The discussions emphasized the importance of multi-stakeholder collaboration across sectors and created a basis for initiating or strengthening partnerships.

3 Participants reinforced the potential of CLM to expand beyond health, bridging gaps between policy and implementation and ensuring that decision-making reflects lived realities in diverse sectors including climate resilience and gender equity.

4 Decision-makers can better harness CLM to make informed decisions through the integration of community-generated data into policy frameworks, enabling real-time, localized insights to guide resource allocation, service delivery improvements, and accountability mechanisms.

The Summit reinforced CLM's potential as a catalyst for systemic change, emphasizing its relevance across multiple sectors and its power to amplify community voices in decision-making processes.

BACKGROUND

In today's world of increasingly complex global challenges, from health disparities to geopolitical and environmental crises, governments often fall short in effectively addressing the real-lived challenges faced by people. Communities must do more than just notify authorities of issues; they need to actively engage and apply pressure to drive systemic change. Empowering communities to be part of the solutions to the challenges they face is crucial. CLM is a powerful tool to achieve this, particularly in the health sector.

CLM is a science-based accountability innovation that puts communities first. It is a process where communities, particularly the end users of public health and social services, take the lead in identifying and routinely monitoring the issues that matter to them. They create indicators, collect and analyse data, and engage with stakeholders to co-create solutions. When problems uncovered through CLM cannot be resolved, communities conduct evidence-based advocacy until corrective actions are implemented. CLM also documents positive innovations and effective practices that can be implemented with greater consistency and scale.

The implementation of CLM is rapidly proliferating around the globe, particularly in addressing HIV, tuberculosis, and malaria. Major global health financing mechanisms, such as The Global Fund and PEPFAR, have made significant investments in CLM interventions. As implementation progresses and existing programs mature, CLM is becoming a recognized discipline for generating evidence for targeted action, which can be applied to a diversity of fields beyond health. This Summit aimed to explore and expand these applications, leveraging the power of CLM and broader community-generated data to address a wide range of global challenges.

PURPOSE OF THE CLM SUMMIT

ITPC brought together an action-oriented group of 87 stakeholders from 18 countries, of the following varied backgrounds:

→ Experienced CLM implementers

→ Subject matter experts across key disease areas (HIV/TB/Malaria) as well as sectors primed for potential CLM implementation

→ Broad representation across strategic geographic regions

→ Private sector organizations and foundations

→ Key partners from (a) mature CLM implementation countries, (b) nascent CLM implementation countries who aspire to learn more from their peers, (c) donor nations seeking to learn more about best practices in CLM investment and support

→ Multilateral funding partners

→ Research and academic partners

The CLM Summit aimed to highlight the progress of CLM in the health sector and to encourage collaborative discussions on the next steps, focusing on the following objectives and outcomes:

OBJECTIVES OF THE SUMMIT	ANTICIPATED OUTCOMES
To master CLM as a transformative approach to illuminate community needs, fuel data-driven strategies, and unlock innovative solutions across sectors.	Build a shared understanding of CLM as a transformative approach, including its principles, methods, and proven impact across multiple sectors, among diverse stakeholders.
To explore and share insights on CLM applications beyond the health sector, demonstrating its potential for measurable and lasting cross-sector impact.	Create a cross-sector platform for open discussions on CLM applications beyond health, fostering innovation and collaboration among various fields.
To exchange knowledge and experiences on leveraging CLM data for strategic decision-making, policy advocacy, and multi-stakeholder collaboration.	Develop strategies for maximizing CLM data utilization and multi-stakeholder collaboration to increase impact, sustainability, and inform policy decisions across sectors.
To discuss scaling CLM from local initiatives to national and global levels, outlining strategies for future development of mature CLM models.	Outline an action plan to scale CLM impact from local to global levels, including strategies for mature CLM models to address complex, cross-sector challenges.

THE VALUE PROPOSITION OF COMMUNITY LED MONITORING

> " Think of communities not as passive recipients but as technology: innovative, adaptive, and capable of driving change.
>
> — SOLANGE BAPTISTE

The first day of the summit was divided into **four sessions**, focusing on setting the stage for Community-Led Monitoring, discussing its core principles, showcasing its diverse impact across various sectors, and exploring the value proposition of CLM through multi-stakeholder engagement.

Dr. Nompumelelo Gumede, Chair of ITPC Board, welcomed the participants and reflected on ITPC's beginnings at the 2000 AIDS Conference in Durban and the 2003 summit in Cape Town, where activists unified around a shared mission: securing AIDS treatment worldwide.

Krista Lauer, Citizen Science Lead at ITPC, outlined four summit goals: to learn, to stretch into new sectors like climate, to strategize for improvement, and to explore the future of CLM. She reminded attendees of the urgency needed to tackle the world's challenges through Leonard Bernstein's words: "To achieve great things, two things are needed: a plan and not quite enough time."

In her keynote address, **Solange Baptiste, Executive Director of ITPC Global**, emphasized that Community-Led Monitoring is essential for achieving sustainable, cross-sector impact amidst global crises. She highlighted the failure to meet SDG targets, widening inequality, and how financial power increasingly influences global decision-making. Solange pointed to the proven power of community movements, like Jubilee 2000 and Black Lives Matter, in effecting real change. She urged participants to view communities not as passive recipients but as adaptive, resilient sources of innovation, CLM being essential for harnessing real-time, community-specific data to inform and direct resources effectively, enabling communities to drive resilient, adaptive solutions in health and beyond.
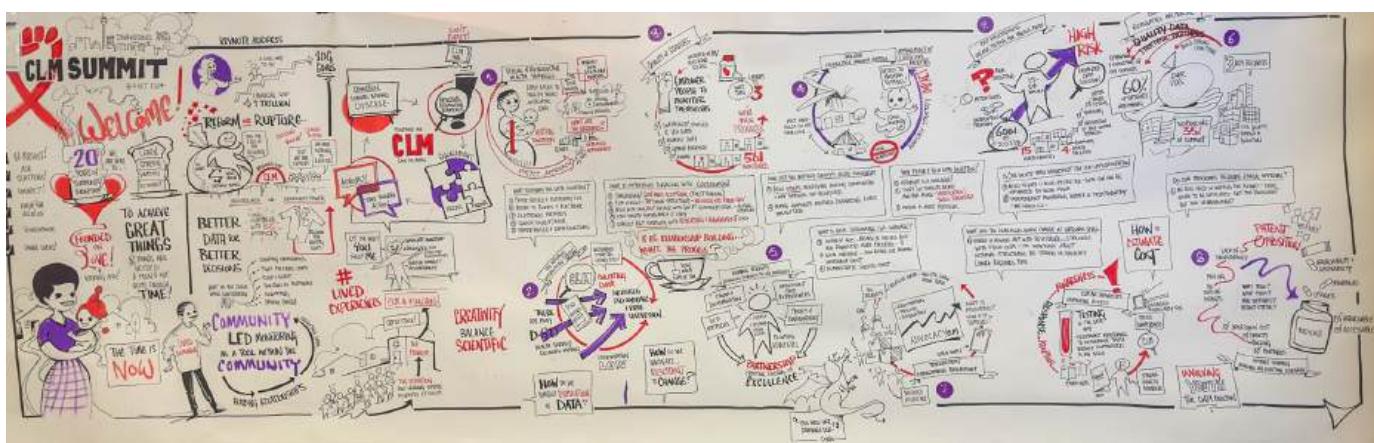
KEY TAKEAWAY

CLM is a paradigm shift that places communities at the centre of decision-making, enabling real-time responses to pressing challenges and fostering systemic resilience.

A short movie was screened: **"We dare you to find a problem that can't be solved by communities"** highlighting CLM as a powerful tool to drive meaningful change.

Jelena Bozinovski, Project Manager at ITPC Global, **introduced CLM** as a global health innovation. At ITPC, CLM emerged in 2015 as an organized response to recurring medicine stockouts in HIV clinics across West Africa, where community members documented shortages to identify trends and present data to decision-makers. This grassroots, accountability-driven approach enables communities to monitor issues consistently, define indicators, and collaborate with stakeholders to find sustainable solutions. Jelena mentioned that CLM's success is rooted in the community's leadership and ownership of data, transforming monitoring from simple data collection into a dynamic, solution-oriented process. CLM is now expanding beyond health to other sectors, using education, evidence collection, engagement, and advocacy as pillars.

TAKE TARGETED ACTION to work with policy makers to fix or improve the services, systems, laws or practices that underlie problems

LEARN ABOUT THE SCIENCE BEHIND THE DISEASE(S) and normative standards for optimal prevention, treatment, care and support interventions, including on COVID-19

EDUCATION

CLM

ADVOCACY

EVIDENCE

ENGAGEMENT

DISCUSS THESE FINDINGS with a wider group of stakeholders, such as a Community Consultative Group (CCG) or other existing group, to co-create solutions

DOCUMENT COMMUNITY EXPERIENCES accessing health services, compile that information, and identify trends and problems

KEY TAKEAWAY

CLM's strength lies in its grassroots approach, enabling communities to collect and analyse data, co-create solutions, and advocate for sustainable impact.

Lightning Panel on The Diverse Impact of CLM

The first part of the session, led by **Krista Lauer**, presented five perspectives on CLM effectiveness across various health sectors.

1. Sexual and Reproductive Health Services
Enhancing HIV service uptake through integrated services

**Melikhaya Soboyisi,
Citizen Science Project,
NACOSA, South Africa**

THE ISSUE	CLM ACTIONS	THE IMPACT
While early antenatal care (ANC) is critical for prevention of mother to child transmission, ANC attendance rates varied significantly by facility, ranging from 50% to 87%.	Collected data on antenatal care timing, engaged health workers to address barriers, collaborated with facility managers, and encouraged outreach teams to con-duct health talks for women.	Early ANC increased from 71% in the first half of 2023 to 75% in the second half at monitored sites. Pregnant women at monitored sites were nearly twice as likely to deliver in a health facility.

2. HIV Outcomes
Promoting differentiated service delivery models to improve health outcomes

**Harold Kachepatsonga,
Citizen Science Project,
MANERELA+, Malawi**

THE ISSUE	CLM ACTIONS	THE IMPACT
Low enrolment in Differentiated Service Delivery (DSD) models in Malawi. Only 27% of ART users (2,936 of 10,837) enrolled in DSD by January 2023; gaps exist in both supply and demand.	Monitored DSD enrolment, collaborated with health facilities to increase enrolment opportunities and patient awareness, secured funding for DSD support, trained peer educators, and implemented community scorecards and client satisfaction surveys.	DSD model enrolment at intervention sites is 6.79 times higher; and viral sup-pression is 2.34 times higher at the DSD strengthening sites vs. non-DSD.

3. Quality of Services
Using CLM data to improve quality of health service delivery

**Ngqabutho Mpofu,
Ritshidze, Treatment
Access Campaign,
South Africa**

THE ISSUE	CLM ACTIONS	THE IMPACT
Need for improved HIV, TB, and broader health services in South Africa.	Gathered patient feedback on service quality in 561 facilities, led advocacy for increased staffing, and collaborated with facilities to reduce waiting times and ensure better PrEP coverage.	Staffing increased to 42%, 3-month+ refills rose to 47%, PrEP coverage at facilities reached 98%; average wait times decreased from six to three hours on average.

4. Malaria
Enhancing malaria control: the impact of community-led monitoring

Laure Moukam,
Impact Santé,
Cameroon

THE ISSUE	CLM ACTIONS	THE IMPACT
Pregnant women and children under 5 in vulnerable groups lack access to malaria supplies in Cameroon (orphanages, dis-placed women and children).	Collected evidence on community needs and engaged local government, parliament, and malaria programs to prioritize insecticidal net distribution in orphanages and among displaced people.	Seven orphanages in Douala fully covered for LLINs; ongoing advocacy through NMCP-CS4ME and parliamentary caucus for wider LLIN access.

5. Human Rights
Expanding services to reach more young sex workers living with HIV

Kacey Sbusiso Biza,
Citizen Science Project,
Life Maps, South Africa

THE ISSUE	CLM ACTIONS	THE IMPACT
Key populations face stigma, discrimination, and lack of privacy, leading to refusal of health services.	Collected data among the community and collaborated with the department of Health to train health care workers on key populations.	Relaunched Krugersdorp Central Clinic as a "Center of Excellence" for vulnerable populations, boosting ART initiation and engaging some as community support ambassadors.

In the second part of the session, **Nadia Rafif** expanded the discussion, highlighting CLM's transformative impact on policy, medicine access, and procurement, particularly for key and underserved populations.

6. Procurement
Strengthening procurement systems in Eastern Europe through community-led monitoring

Denis Godlevskiy,
ITPC Eastern Europe
and Central Asia, Russia

THE ISSUE	CLM ACTIONS	THE IMPACT
ARV, CD4, and viral load stock-outs occurred in Russia during the transition to national fund-ing. Regulatory barriers within the Eurasian Economic Union also affected access to essen-tial drugs.	Documented stock-outs, en-gaged with policymakers to re-duce regulatory barriers, and demonstrated the cost savings achievable through optimized procurement practices.	Achieved $90.3M in HCV drug savings (2022–2024), improved essential medicine procurement in lower-income countries, and demonstrated savings in upper-middle-income coun-tries.

7. Cost Effectiveness
Targeted HIV testing for young people saves money

Colleen Wagner,
Citizen Science Project
NACOSA, South Africa

THE ISSUE	CLM ACTIONS	THE IMPACT
Youth aged 15–24 in South Africa face high HIV risk, with poor targeting of adolescent girls and young women and a need for sustainable programming amid rising healthcare costs.	Promoted HIV and contraceptive service integration, provided refresher training for 100+ healthcare workers, and established after-hours testing at one facility.	CLM sites achieved a 46% higher HIV diagnosis rate for young women, reducing tests and lowering costs to $2,852 per case versus $4,154 at non-CLM sites.

8. Diagnostics
Improving access to diagnostics through community-generated data

Martin Ellie,
NETHIPS,
Sierra Leone

THE ISSUE	CLM ACTIONS	THE IMPACT
Challenges include diagnosing the remaining 17% of people with HIV, monitoring viral suppression for 62%, and issues like test kit stock-outs, machine failures, and HIV-related stigma hindering service uptake.	Identified stock-outs and equipment issues, engaged facility and district health teams, led a press conference with 10 civil society groups on HIV stock-outs, and collaborated with Sierra Leone's judiciary and health committee on HIV and human rights.	National system established with firms for viral load management; expedited supply chain policy adopted by the government for medical supplies delivery.

9. User Fees
Eliminating the malpractice of user fees for HIV services in Cote d'Ivoire

Innocent Laison,
ITPC West Africa,
Cote d'Ivoire

THE ISSUE	CLM ACTIONS	THE IMPACT
User fees continue to be a barrier to HIV services in Côte d'Ivoire, despite policies mandating free access in public facilities.	Collected data showing 6% of HIV patients paid extra fees; reported to PEPFAR, leading to a 35% funding suspension; formed a coalition to demand free HIV services, anti-stigma enforcement, and death tracking.	Minister of Health issued a circular with 8 actions for free HIV services enforcement, with sanctions for violations; increased CLM investment

10. Market Shaping
The role of communities in Making Medicines More Affordable

Dr. Othoman Mellouk, Make Medicines Affordable Consortium, ITPC

THE ISSUE	CLM ACTIONS	THE IMPACT
Intellectual Property rights and patents create monopolies, raising medicine prices and limiting access to essential medicines in many countries	Monitored procurement data to identify inefficiencies and advocate for more transparent and equitable systems; filed 95 patent oppositions with achieving a 26% success rate.	Improved transparency, price reductions, and increased availability of generics; e.g., Argentina saw a 2.6x price drop, saving $353M (2016–2022)

SHOWCASE

Life Maps Exhibition,
Ruby Tionenji Ng'ong'ola and Khokhelwa Zokwana, ITPC

The Citizen Science Life Maps initiative by ITPC, launched in 2021, uses citizen journalism to document the qualitative experiences of HIV and AIDS care recipients during and post-COVID. The data collected feeds advocacy efforts at district and national levels through CLM partnerships and has been promoted via radio, newspapers, and an **online photo exhibition**, bringing visibility to participants' stories and driving change in healthcare access.

KEY TAKEAWAY

CLM drives measurable improvements in service delivery, equity, and policy across health sectors, proving its adaptability to tackle diverse challenges and achieve systemic change.

This session co-moderated by **Solange Baptiste and Dr. Charlene Omrawo from ITPC**, brought together a multi-stakeholder panel. Each panellist shared their perspectives on the transformative potential of CLM and its diverse applications across health and development sectors.

Dr. Rose Nyirenda from the Malawi Ministry of Health highlighted how CLM has contributed to address service quality and drive health system investments in Malawi. CLM has created an ongoing feedback loop that allows governments to make data-driven decisions, particularly at the district level. Rose emphasized that an enabling environment is essential for CLM's success. She shared that a community-produced video showcasing the challenges faced by rural people living with HIV prompted a policy change, enabling a six-month ARV supply plan. She concluded that governments must be willing to listen and respond to community input.

Saira Qureshi from PEPFAR, discussed the high value PEPFAR places on CLM data, citing its timeliness, flexibility, and adaptability. Unlike traditional data systems, CLM allows for quick feedback, enabling PEPFAR and other stakeholders to respond to community needs in real time. This responsiveness provides insights that hold implementing partners and governments accountable. Saira also emphasized that CLM should be an integral, long-term accountability mechanism within healthcare systems.

Keith Mienies, from the Global Fund, underscored CLM's potential in building resilient health systems across HIV, TB, and malaria programs. He pointed out that CLM empowers communities by helping individuals understand their rights and encouraging them to demand quality services. This empowerment aspect fosters a collaborative approach to health improvement. For the Global Fund, CLM facilitates meaningful engagement and promotes health equity.

Prof. Elvin Geng, from the Washington University in St. Louis, explained that while quantitative data might measure physiological metrics, only qualitative feedback can capture patient satisfaction and healthcare experiences. Therefore, CLM offers an invaluable perspective on healthcare effectiveness. He advocated for CLM's role as a structured dialogue platform between the healthcare system and its users, helping health systems evolve from transactional service delivery to responsive, people-centred models.

Nelson Otwoma from NEPHAK, Kenya, provided insights into how CLM benefits recipients of care, particularly people living with HIV in Kenya. NEPHAK's work involves facilitating dialogue between patients and providers to resolve issues at the facility level before they escalate. Nelson highlighted that CLM fosters a structured way for communities to provide feedback on service quality and unmet needs. He also pointed out that CLM helps addressing health issues beyond HIV, as communities face growing needs related to non-communicable diseases as they age with HIV.

Dr. Alexandra Plowright from Anglo American discussed the accountability benefits of CLM for businesses, particularly in ensuring companies are held accountable to the communities they impact. Anglo American, as a corporate partner, uses CLM data to align its community impact strategies with the health and well-being of mining communities. She highlighted CLM's potential for business accountability, where transparent data from CLM allows corporations to demonstrate their responsiveness to community needs and measure their social impact.

Ntefeleng Nene, from Bridgespan Group, shared findings from Bridgespan's research into community-driven change, which aligns with CLM principles. Her research found that community-driven change strengthens communities' power and assets, which leads to equitable, sustainable impact. When communities identify their own needs, co-create solutions, and own the decision-making process, it results in transformative development.

Panellists discussed **funders' hesitation to invest in CLM due to challenges in quantifying long-term benefits**. Unlike direct interventions with immediate, measurable outcomes, CLM's impact is seen in strengthened systems, community empowerment, and capacity-building, which lack short-term metrics. Consolidated evidence of CLM's effectiveness across contexts could aid broader adoption. From a civil society perspective, advocacy is essential for CLM's integration at the national level, particularly through Country Coordinating Mechanisms (CCM). The panel noted that, although CLM is now referenced in the Global Fund's information notes on HIV, TB, and Malaria, its implementation hinges on proactive engagement with ministries. Many CCM members are unfamiliar with CLM, and its reliance on government-monitored programs creates conflicts of interest, contradicting CLM's independent monitoring principles. A bottom-up approach is crucial to ensure that initiatives like CLM gain traction at the country level. Finally, the panel addressed funders' challenges in justifying investments in CLM's qualitative, system-wide changes. The focus on immediate targets often leads to resistance within funding bodies, where there is little support for community-led, long-term impacts. To address this, the panel suggested that restructuring funding frameworks to prioritize sustainable, system-strengthening approaches like CLM is necessary to secure ongoing support for these initiatives.

On the topic of funding independence, the panel discussed the importance of balancing community priorities with donor and government agendas to create sustainable CLM models. They examined strategies to enhance funding independence through a "stakeholders' triangle": communities seek funding to address local issues, donors bring their own priorities, and governments may sometimes resist community feedback. They questioned how CLM can be institutionalized to balance these perspectives: securing government support, enabling communities to set priorities, and aligning donor assistance with genuine community needs. Participants noted the dependency challenge, with communities often reliant on donor funding, which can limit autonomy. Steps toward self-sustaining CLM models, such as independent business plans by some PEPFAR partners, were highlighted as a path toward true community independence. The need for sustainable local funding solutions was emphasized, as external support may decline, especially in broader healthcare beyond HIV, TB, and malaria. Sustainable CLM requires trust-based funding, where funders show flexibility and faith in community organizations, with the COVID-19 pandemic showing the effectiveness of this approach.

The private sector's role in CLM was also explored, with examples like Anglo American's partnerships in Southern Africa. Rather than simply donating, Anglo American collaborates with health ministries to drive systemic, place-based changes, supporting subnational and national health initiatives that reduce reliance on traditional donors and promote sustainable community-led efforts.

Then, panellists discussed **the distinction between community-based and genuinely community-led CLM efforts**. True community leadership means allowing communities to make decisions, not merely provide input, with resources flowing directly to community structures to enable authentic, sustainable leadership. Participants expressed concerns that, despite initial goals to empower communities, external funders often impose strict protocols that sideline community voices. They highlighted that funding often favours those able to produce formal proposals, leaving many community groups unsupported. They advocated for investing in systems that support true community leadership, ensuring that communities can effectively lead CLM.

Aligning CLM with global frameworks, such as the Sustainable Development Goals, was discussed as a strategy to expand CLM's impact by addressing the broader social determinants of health. Panellists emphasized that CLM should address broader economic and social factors influencing health outcomes, encouraging donors to support holistic, community-led solutions across diverse areas such as gender and livelihoods. Research demonstrates that community-driven approaches are most effective when addressing a range of needs rather than isolated issues. Participants also raised the issue of CLM ownership, questioning whether it serves the interests of communities or funders, especially when multiple funders impose distinct tools and requirements. This misalignment can shift CLM focus to meeting funder needs rather than addressing community priorities. The panel suggested consultative groups to align community and funder expectations, stressing that high-level discussions are essential to streamline CLM initiatives for genuine community impact and sustained support.

To effectively measure system change, a shift in research methods may be necessary. Traditional frameworks often prioritize individual health outcomes, which can overlook broader systemic improvements, such as increased integration, better staff morale, and more patient-centred care. For CLM to drive meaningful, system-wide progress, research models should evolve to value process refinement as evidence of change. CLM brings added value by balancing qualitative and quantitative data, reducing social desirability bias, and empowering communities to provide more genuine feedback. This shift encourages a power dynamic that promotes honest insights, supporting a more comprehensive understanding of health systems' strengths and challenges. Integrating these community-based perspectives into scientific standards will validate and amplify the impact of community-led research.

FIGURE 1. GRAPHIC RECORDING OF SESSION 4 OF THE CLM SUMMIT

The panel emphasized that **high data standards are essential in CLM to protect community credibility**, as inconsistent data can quickly undermine efforts. They discussed the importance of building community capacity, particularly in quantitative data, to overcome scepticism from experts and sustain CLM's impact. Some argued that community-led data collection can match traditional data quality if designed around local priorities, enhancing relevance and reducing errors. Participants suggested partnerships with academic institutions to strengthen data rigor, ensuring that community data provides nuanced insights often missing from large datasets. The panel also recognized the value of rapid-response data for urgent issues, noting that strict quality requirements could exclude valuable grassroots insights. They advocated for flexibility in data standards to include diverse community contributions in broader monitoring and advocacy. Finally, they stressed the importance of keeping CLM genuinely community-led to empower local voices in both data collection and advocacy, ensuring the model's authenticity and impact.

To increase CLM's relevance, suggestions included strengthening CLM data to meet traditional validity standards for broader stakeholder appeal and focusing on health financing as funding sources shift. Panellists emphasized the need to communicate CLM's catalytic role to gain wider support and to integrate CLM as a core health program element. The panel also proposed adopting flexible, nonlinear measurement frameworks to expand CLM's impact and exploring its application in other sectors to empower communities. Sharing success stories more widely, especially with non-traditional stakeholders like the private sector, was highlighted as a way to foster greater buy-in.

In conclusion, Solange emphasized that the mindset of "this is just the way it is" for frameworks like those of the Global Fund and PEPFAR needs challenging. "There is no alternative" (TINA) should be replaced by "TAPAs": There Are Plenty of Alternatives.

KEY TAKEAWAY

Effective CLM relies on community leadership, cross-sector collaboration, and responsive data systems to create sustainable, equity-driven impact at all levels.

HARNESSING THE FULL POTENTIAL OF COMMUNITY DATA

> "One of the things I find most exciting about CLM is its potential to drive real change in communities. But to do that, we need to be willing to experiment, to adapt, and to let go of what no longer works.
>
> — **GARY GRAHAM**

The second day of the CLM Summit was divided into **five sessions**, with a focus on broadening the scope of CLM data for decision-making, harnessing its full potential for sustainable impact, and fostering connections among multi-sectoral stakeholders for co-created action and impact.

Broadening the scope of CLM: Key considerations for reinvention

Gary Graham, from 3iii Consulting, South Africa, drew a parallel between an individual's unique gait and each organization's distinctive "way of walking". Both are shaped by various factors, making it unsustainable to replicate others' paths. With the concept of "Titanic Syndrome" (characterized by arrogance, attachment to the past, and resistance to new realities), Gary highlighted the pitfalls of rigidly following outdated methods, warning against complacency and urging adaptation to remain relevant. He encouraged organizations to stay agile, identify the right success metrics, and focus on creating impactful changes, particularly in areas where rapid responses could prevent crises. Stressing the need for short sprints over long marathons, Gary advised prioritizing quick wins, integrating reflection, and embracing failure as a learning tool. Gary used a compelling example involving bacteria to illustrate the urgency of adapting to change before it's too late. He described how a single bacterium, doubling every minute, could fill the Pacific Ocean in just 89 minutes, with 50% of the ocean remaining seemingly empty until the minute before. This rapid growth emphasized the risk of waiting too long to address emerging challenges. Gary urged participants to recognize trends early, as unchecked issues could escalate faster than expected. As systems face unprecedented rates of change, he urged CLM practitioners to experiment, question existing practices, and continually adapt. In this way, CLM could remain effective, relevant, and influential in a rapidly evolving landscape.

SHOWCASE

Moving CLM ahead: The use of CLM for water sustainability

Emmanuel Simon and Dr. Charlene Omrawo demonstrated how community-led monitoring can enhance water sustainability efforts. In a typical system, it can take 2 to 3 weeks from the first illness for a cholera outbreak to be officially declared, as only a pattern of cases at hospitals signals a public health issue. Reducing this delay relies on empowering communities through CLM. By educating communities to track health indicators, real-time data collection can combine with traditional systems to detect trends sooner and improve service delivery, making CLM essential for achieving sustainable development goals.

KEY TAKEAWAY

Agility and adaptability are vital for CLM to remain relevant and impactful. By recognizing trends early, prioritizing quick wins, and empowering communities to track real-time data, CLM can address emerging challenges and drive sustainable development outcomes.

Moderated by **Krista Lauer, ITPC**

Science and the CLM Model: A scientific approach to CLM, its greater potential and CLM 2.0

Dr. Gemma Oberth, from the University of Cape Town, South Africa, emphasized the scientific potential of CLM, likening it to various scientific fields: social, political, citizen, implementation, and program sciences. She highlighted how CLM uniquely combines overlooked data sources, which could strengthen program science. Gemma presented six traditional models of community and scientist interactions, adding a seventh where communities are active scientists in the process, advocating for a shift towards inclusive, community-driven data science. She criticized the profit-driven nature of academic publishing, noting CLM's role in promoting accessible, democratic data. Additionally, Gemma encouraged a scientific, iterative approach in CLM, focusing on refining specific, evolving questions for impact, instead of broad, costly data collection.

INTERVENTION FROM THE FLOOR: The role of community data in shaping informed decisions, and a vision for the future of CLM

Yogan Pillay from The Bill & Melinda Gates Foundation advocated expanding CLM's scope beyond monitoring to emphasize response and accountability. He suggested that CLM could benefit from tools addressing both health determinants and broader, sustainable community needs. Pillay also emphasized refining data metrics to capture underserved populations, noting that lived experiences should be treated as valid scientific data.

Diverse perspectives on strategic data use: The current data landscape and leveraging strategic information for decision-making

Susan Perez, from AIDS Strategy Advocacy and Policy (ASAP), addressed **the inefficiencies in CLM data**. CLM data collection usually involves paper-based methods, making retrospective analysis difficult. Susan praised the digital model of Ritshidze, which organizes data by site, district, and period for easier access and reporting. She outlined key gaps in current CLM practices: Data is often not in a usable format for government needs; community priorities frequently clash with governmental or donor expectations; and CLM programs sometimes gather excessive or irrelevant data, leading to inefficiencies, errors, and delays. She proposed adding a readiness stage to secure community buy-in, budgets, and expectations before data collection. Emphasizing continuous learning, Susan advocated for frameworks that capture indirect outcomes, such as community engagement and empowerment, with monitoring and evaluation embedded throughout the CLM cycle to ensure adaptability and effectiveness.

Saira Qureshi, from PEPFAR, South Africa, outlined PEPFAR's commitment to integrating CLM with a focus on routine data collection, analysis, and sharing with a foundation in scientific rigor and community insights. She highlighted the importance of transparency and accountability, as demonstrated by Ritshidze's accessible data for policymakers. PEPFAR stresses confidentiality and data security, advocating for strong governance policies. CLM findings should support collaboration and equity, particularly for underserved groups, rather than punitive actions. Saira reinforced PEPFAR's guiding values of respect, transparency, and humility throughout the CLM process.

INTERVENTION FROM THE FLOOR: The role of community data in driving sustainability

Jeffrey O'Malley, from UNDP, South Africa, emphasized that CLM should align with sustainable health and development goals, leveraging its potential for cost savings and impact in HIV, TB, and malaria responses. Given funding limits, he advocated "right-scaling" by using existing data. Jeffrey proposed that CLM should also monitor social determinants, such as punitive laws and stigma, aligning with global 10-10-10 targets. According to him, CLM's strength lies in linking data to policy, driving accountability and sustained impact across sectors.

The potential of Artificial Intelligence: Harnessing AI in for community data and safeguards for integrating AI into the CLM model

Emmanuel Simon from Heureo Labs, South Africa, **described AI as a tool that reflects the user's intent**, carrying both promise and power. He likened its unrealized potential to an unfilled water bottle, symbolizing current use and future possibilities. Emmanuel outlined AI's three key functions: prediction, pattern recognition, and process automation, noting that academia and big tech currently harness its promise. With AI becoming more accessible to communities, new opportunities emerge for CLM to enhance data analysis, communication, and storytelling. He encouraged participants to experiment with AI to make CLM efforts more effective.

Natalie Maricich, from Audere, South Africa, **illustrated AI's potential to enhance CLM through Audere's AI toolkit**, which supports HIV prevention in South Africa via a WhatsApp-based AI companion. This tool provides a stigma-free, conversational platform where community members safely share data, receive guidance, and engage in personalized care. It could offer stakeholders a real-time view of service delivery and community insights, supporting targeted interventions, reducing stigma, and improving response times. Natalie encouraged participants to explore AI's potential to make CLM more impactful and inclusive, particularly through tools that are accessible, safe, and tailored to community needs.

A Modeler's Perspective: Could CLM be the "information unicorn" that mathematical models need for improved decision-making?

Prof. Sharmistha Mishra, from the University of Toronto, Canada, highlighted mathematical models' role in health for estimating unseen trends, predicting outcomes, and guiding resources for infectious and non-communicable diseases. Models explore "what if" scenarios, aiding decision-makers from local to global levels. Starting with a research question, models summarize data from multiple sources and calibrate to observed patterns. Sharmistha emphasized the need to integrate CLM data, which is often absent, to improve models' accuracy, in particular in areas like intervention coverage, network dynamics, and quality-of-life impacts. She cited community-driven modelling examples in Kenya with MSM populations and Canadian First Nations, showing that including lived experiences enhances models' relevance, accountability, and decision-making inclusivity.

KEY TAKEAWAY

Scientific rigor and tools like AI amplify CLM's impact, ensuring community-driven insights inform policy, enhance data quality, and support sustainable decision-making.

Moderated by **Dr. Gemma Oberth University of Cape Town, South Africa**

Dr. Gemma Oberth introduced the session by challenging participants to consider sustainability from a different perspective: instead of asking how to sustain CLM, she prompted them to explore how CLM contributes to the long-term sustainability of the HIV response.

The Importance of Data Triangulation: Utilizing tools to strengthen cooperation between local data collection sites and national monitoring systems

Giten Khwairakpam, from TreatAsia, AmfAR, Thailand, emphasized **the potential role of CLM** in advancing treatment literacy, addressing social justice, and increasing data transparency in healthcare. Launched in Asia in 2021 with ITPC's support, CLM efforts evolved from paper-based to digital systems, improving data transparency and accountability through public dashboards. To address facility-specific needs, CLM adapted data collection by separating HIV and hepatitis indicators, responding to feedback from facility managers who requested tailored reporting. Beyond health facilities, CLM initiatives also uncover human rights issues, such as limited accessibility for the differently-abled, and increase awareness of policies like India's HIV/AIDS Act. Moving forward, democratizing data access remains critical, enabling communities to influence policy and enhance service quality across sectors.

Boitumelo Langa, from the West Rand Department of Health, South Africa, shared insights on **integrating CLM with NACOSA and ITPC during COVID-19**. The pilot project highlighted gaps in government data, especially in community engagement and addressing key populations. Initially focused on quantitative data like clinic headcounts, the approach shifted to open-ended questions, gaining richer insights into community needs. CLM then revealed issues with PrEP uptake, ineffective condom use, and challenges faced by the LGBTIQ community and people who use drugs. It also helped triangulate data on rising gender-based violence in the context of COVID-19, qualitative data being essential alongside quantitative metrics for informed planning and impact.

Affordability: How community monitoring of pricing and subsequent advocacy leads to sustainable supply chains for Middle-Income Countries (MICs)

Sergey Golovin from ITPC EECA, shared how in Eastern Europe and Central Asia (EECA), **financial and pricing monitoring for treatment access** began with tracking stockouts and expanded to cover pricing, logistics, and budget constraints, all crucial for consistent access to essential medicines. Starting reactively, the approach evolved to prevent supply disruptions proactively by monitoring data on pricing and procurement. This strategy helped countries like Moldova and Kyrgyzstan cut costs and improve access. According to Sergiy, key principles for success include continuous monitoring, cross-country comparisons, transparency, advocacy, data quality, and capacity building. Simple but powerful messages are then extracted to present to policy-makers, so as to promote optimization and sustainable solutions.

KEY TAKEAWAY

CLM data enhances transparency, supports social justice, and tailors community solutions, driving cost-effective, informed policymaking across sectors.

Moderated by **Dr. Anna Grimsrud, IAS**

The panel on extending CLM beyond health covered perspectives from development financing, climate change and action, integration services and community leadership, exploring how CLM principles can apply in various sectors.

Harpinder Collacott, from Global Public Investment Network (GPI), stressed that development finance often overlooks community voices, and proposed a more inclusive financing model where "all contribute, all benefit, all decide." This shift proposed by GPI would integrate community input into decision-making, ensuring funds are used effectively and equitably. This is however controversial, as funders usually prefer to maintain control.

Lillian Mworeko, from ICW East Africa, explained how challenging effective CLM can be for criminalized or stigmatized communities. Lillian described the obstacles faced by NGOs in Uganda due to government scrutiny, which complicates partnerships and funding for CLM efforts. Lillian called for more inclusive conversations to ensure CLM engages broader societal structures for a sustainable impact.

Seon Mi Choi, from the Global Fund, emphasized that despite rising needs, less than 0.5% of multilateral climate funding is allocated to health, widening the adaptation gap. Seon Mi discussed Locally Led Adaptation (LLA), a model developed to empower local communities in deciding, implementing, and monitoring climate resilience strategies. LLA closely aligns with CLM by promoting local agency, accountability, and integrated national and global knowledge-sharing.

According to **UNAIDS' Raquel Palomino**, there is still much to be done in the HIV field, where lessons learnt can be applied to other fields. For a more effective CLM, she underlined the need to move away from narrow health metrics and toward an integrated strategy that addresses gender equality, human rights, and policy challenges. Encouraging active citizenship is essential for involving marginalized groups and taking significant action in spite of shrinking civic spaces. Raquel emphasized the importance of the need for robust local community-led strategies and demand-creation from the governments' side.

Panellists were then asked to consider **what changes are needed within their respective ecosystems to strengthen and take CLM to the next level**. Harpinder Collacott emphasized the need for development finance to integrate genuine community voices into decision-making. While funders sometimes bring NGOs into proposal reviews, there's still a gap in truly representing the most marginalized communities and their concerns. Lillian Mworeko suggested that implementers should take a more targeted approach by focusing on fewer facilities or districts, chich would help going deeper and lead to more actionable insights. In the view of Raquel Palomino, there's a need for optimization and harmonization across donors and sectors, while maintaining CLM's community-led essence. Balancing standardization and flexibility is essential to keep CLM responsive to local needs while making the most of available resources.

Panellists were then invited to reflect on **threats and opportunities for the future of CLM:**

THREATS

→ Shrinking development finance, with funds being increasingly directed toward climate and humanitarian crises, often at the expense of community-led initiatives.

→ Concerns about localization, as government-led funding might jeopardize the independence of community groups, particularly those facing criminalization

OPPORTUNITIES

→ CLM's community-driven model is well-positioned to address broader global challenges and resilient in managing crises beyond health.

→ CLM's role in resource efficiency and early issue detection.

→ CLM's growing credibility, proven cost-effectiveness and impact.

KEY TAKEAWAY

CLM's community-driven model can tackle global challenges beyond health by integrating marginalized voices, maintaining flexibility, and leveraging its proven impact and efficiency.

Connecting Multi-Sectoral Stakeholders for Co-Created CLM Action and Impact
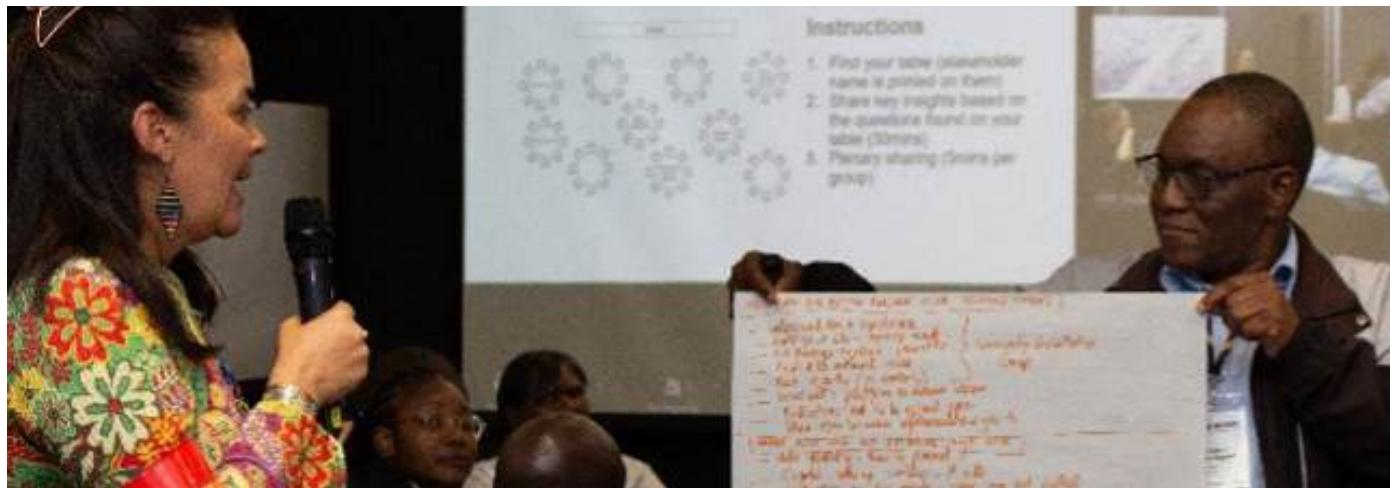
Facilitated by **Nadia Peerun, ITPC**

This session involved an interactive series of Café Conversations where delegates explored the applicability of CLM in their respective fields of work and shared key takeaways on how to engage communities more effectively. The discussion was broken into different tables for various sectors: donors, private sector, government, research, and implementers. Each table had specific questions to reflect on.

DONORS AND PHILANTHROPY

The discussion centred on aligning CLM with national priorities for credibility and sustainability, considering how to motivate governments to support CLM as donor funding decreases. A minimum viable CLM model was suggested to maintain cost-efficiency without compromising effectiveness.

PRIVATE SECTOR

Participants emphasized finding common purposes that align stakeholders' values for sustainable collaboration. Deliberate planning and engagement were identified as key to integrating CLM effectively.

GOVERNMENT AND MULTILATERAL AGENCIES

The focus was on coordinating external funding with existing national strategies, defining stakeholder roles, and ensuring alignment to avoid duplication. The need to educate sectors unfamiliar with CLM on its benefits was highlighted, alongside accountability for those monitoring CLM.

RESEARCH AND ACADEMIA

This table discussed institutionalizing CLM through partnerships, mobilizing resources, and building trust between communities and researchers. Continuous communication and understanding each partner's values were deemed crucial for collaboration.

IMPLEMENTERS

Key themes included better engagement with decision-makers, avoiding duplication by aligning indicators, improving data quality, and focusing on fewer but more impactful indicators. Sustainability was addressed through capacity building and embedding CLM into routine practices, with the potential to expand CLM beyond health to other sectors.

Common themes revolved around trust building, data quality and coordination, advocacy and sensitization of governments and partners on the value of CLM.
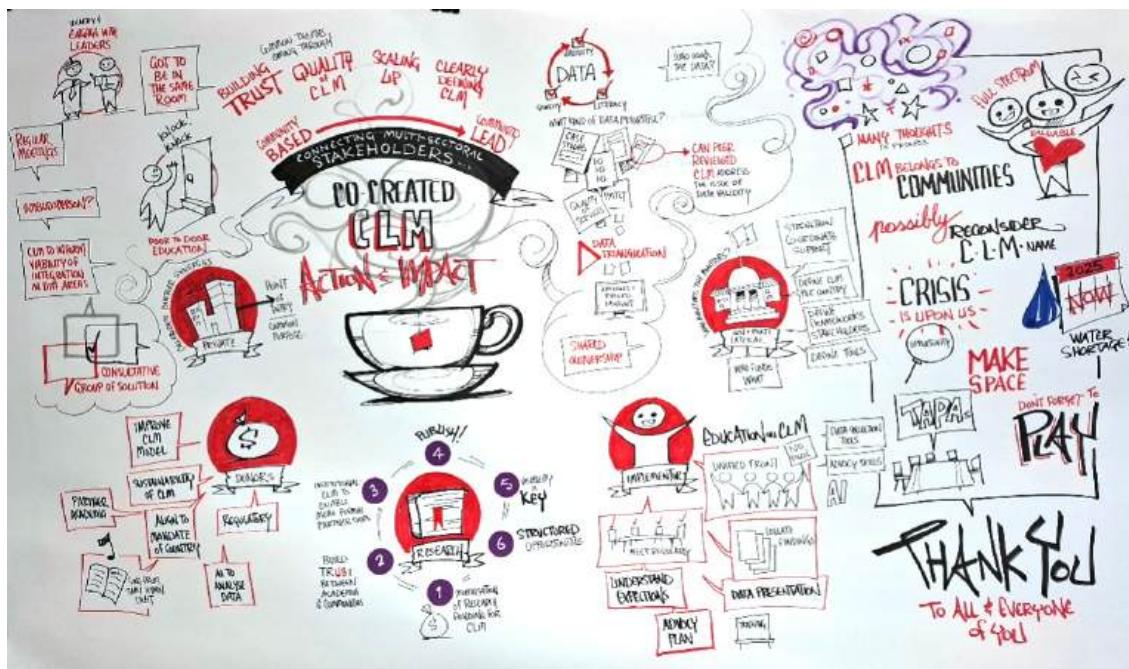
FIGURE 2. GRAPHIC RECORDING OF SESSION 9

KEY TAKEAWAY

Cross-sector collaboration is key, with a focus on trust, data quality, advocacy, and sustainable integration into national systems and beyond health sectors.

CLOSING REMARKS

SOLANGE BAPTISTE

CLM is community-owned, not confined to any single health sector. It should focus on advocacy as well as monitoring. In times of crisis, such as the climate crisis or pandemics, the value of community involvement is crucial. Solange stressed the importance of challenging the status quo, advocating for community voices, and refusing to accept a lack of representation or power in decision-making spaces.

Additional audience questions and detailed responses are available in the **Q&A document**. During the summit, participants engaged with speakers in a live Q&A session, with questions submitted via the Menti App. This interactive format allowed for in-depth discussions where experts addressed a diverse range of inquiries related to CLM.

Topics covered in the Q&A include data collection and tools, government engagement and support, civil society and community involvement, challenges and barriers, sustainability and funding, training and capacity building, as well as the relevance and adaptation of CLM.

Read the Full Q&A Document >

POST-SUMMIT REFLECTIONS AND STEPS FORWARD

The CLM Summit successfully advanced its mission to position community-led monitoring as a transformative force for global change. Grounded in the keynote's call to recognize communities as adaptive, resilient innovators, the Summit showcased CLM's potential to drive systemic change across health, climate, and development. The emphasis on reinvention—letting go of outdated practices and embracing innovation—resonated throughout sessions, inspiring actionable ideas such as CLM for water, leveraging AI, triangulating data for impact, and integrating CLM into broader frameworks. The overarching message was clear: the future is community-led, but realizing this vision requires sustained commitment to adaptability, co-creation, and scaling solutions beyond traditional boundaries.

DELEGATES FEEDBACK

Participants expressed strong satisfaction with the Summit, with the majority affirming that its objectives and outcomes were effectively achieved. Key successes included the creation of a cross-sector platform for open discussions on CLM applications beyond health, fostering innovation and collaboration. Scores reflected positive delegate experiences, particularly regarding logistics, session design, and facilitation. The absence of significant variations in satisfaction across sectors demonstrated the Summit's broad appeal and effective approach. Areas for improvement included venue setup, interactivity levels, and time allocation.

Delegate reflections further highlighted their appreciation of the Summit:

→ **TECHNICAL PARTNERS:**
"Hearing the value proposition of CLM from private sector and opportunities for academia to engage with communities was fascinating. The Summit had thought-provoking discussions, out-of-box thinking and pushed boundaries, within an incredible community. We need to further engage duty bearers through south-south learning to promote acceptability and buy-in."

→ **PRIVATE SECTORS AND DONORS/PHILANTHROPY:**
"Thank you for the inclusion, this was an insightful session and looking forward to taking the conversation and engagements further."

→ **CLM IMPLEMENTERS:**
"Our key takeaways as CLM implementers was that we are not passive recipients, and we need to take actions, while keeping in mind the Titanic Syndrome – avoid being arrogant, let go of excessive attachment to the past and embrace innovation, so that we are capable of driving change."

→ **GOVERNMENT:**
"One key take away was how as government, we can maximize the use of CLM data for decision making when addressing challenges in our area of work."

KEY TAKEAWAYS AND NEXT STEPS

The Summit identified actionable opportunities and provided a foundation for sustained progress:

1   **The Summit showcased CLM's measurable impact in the health sector.**

"Community-led action transforms health systems from the inside out."

ITPC will continue to strengthen the role of CLM in the health sector by providing capacity building, technical assistance, emphasizing the value of community-driven monitoring in improving health systems, and encouraging broader adoption of CLM principles by stakeholders in the health sector.

2   **The discussions emphasized the importance of multi-stakeholder collaboration across sectors and created a basis for initiating or strengthening partnerships.**

"Partnerships thrive when driven by shared purpose and mutual accountability."

ITPC will deepen collaborations with diverse stakeholders, including governments, donors, private sector, technical partners and the community to build a collective commitment toward scaling CLM and embedding it into broader governance and accountability frameworks.

3   **Participants reinforced the potential of CLM to expand beyond health, bridging gaps between policy and implementation and ensuring that decision-making reflects lived realities in diverse sectors including climate resilience and gender equity.**

"Communities innovate solutions by working within their unique contexts and resources — CLM unlocks this power."

Building on the Summit's discussions, ITPC will continue to explore new applications of CLM in areas beyond health, positioning it as a versatile tool for systemic challenges. Discussions will continue with stakeholders to pilot projects on designing sector-specific indicators, partnerships, and advocacy strategies to expand CLM's applicability while ensuring its core principles remain intact.

4   **Decision-makers can better harness CLM to make informed decisions through the integration of community-generated data into policy frameworks, enabling real-time, localized insights to guide resource allocation, service delivery improvements, and accountability mechanisms.**

"Real accountability happens when communities ask the questions and set the agenda."

ITPC will continue to promote participatory governance and ensuring that CLM insights translate into tangible systemic improvements, while sustaining efforts to build trust and collaboration between communities and decision-makers, ensuring that interventions are sustainable and impactful.

RECOMMENDATIONS

Sector-specific recommendations:

FOR IMPLEMENTERS:

→ Focus on fewer, high-impact indicators to avoid data fatigue and enhance actionable insights.

→ Pilot CLM in new sectors, document best practices, and establish academic partnerships.

→ Leverage AI and digital tools to streamline data collection and analysis.

→ Advocate for evidence-based policy changes and foster cross-sector collaborations.

FOR DONORS:

→ Create flexible funding streams prioritizing long-term, community-led outcomes that rely on community data.

→ Showcase CLM's impact through multi-stakeholder platforms to strengthen buy-in.

→ Invest in tailored capacity-building programs for community data collection.

FOR THE PRIVATE SECTOR:

→ Partner with communities to align corporate responsibility initiatives with CLM goals.

→ Provide technical support and sustainable funding models, such as community-business partnerships.

FOR GOVERNMENTS:

→ Integrate CLM into national strategies

→ Establish funding mechanisms for community-driven initiatives.

Cross-cutting recommendations and questions for future consideration:

Building on the Summit's insights, the following recommendations and questions aim to guide stakeholders in advancing the impact and scalability of community-led monitoring through reflection, strategic planning, and cross-sector collaboration.

THEMES AND QUESTIONS	RECOMMENDATIONS
Reinforce long-term sustainability and address funding and equity challenges: How can CLM not only become a self-sustaining model less dependent of donor funding but also contribute to the sustainability of broader health and social systems?	→ Build and communicate the investment case for CLM as a path to sustainability. → Embed CLM into existing health and development systems as a routine practice rather than as a time-limited project activity. → Develop business models for CLM to reduce donor dependency, including local funding mechanisms. → Advocate for funding frameworks that value qualitative, long-term outcomes alongside quantitative metrics. → Suggest collaborative funding models that align donor and community priorities without compromising community independence.
Expand sectoral applications: What steps are required to adapt CLM for emerging sectors while safeguarding its core principles?	→ Explore pilot programs in non-health sectors like climate resilience, education, or gender equity to demonstrate CLM's adaptability. The Summit highlighted CLM's potential beyond health. → Foster cross-sector partnerships to leverage shared data and resources.
Enhance data quality and utilization: How can CLM achieve a balance between rigorous, standardized data collection and the flexibility to adapt to diverse community needs?	→ Invest in capacity-building for communities to improve data quality and analysis, ensuring credibility and stakeholder trust. → Create user-friendly, accessible dashboards for real-time data sharing to increase data transparency. → Explore and leverage AI and other digital platforms for more efficient data collection, analysis, and dissemination — a tool for CLM implementers to make community intelligence more impactful.
Advocate for policy change: How can CLM be integrated into national systems while retaining its community-led principles without compromising independence?	→ Highlight the importance of building community capacity for evidence-based advocacy to influence policies at local, national, and global levels. → Encourage the creation of consultative groups that align funder, government, and community expectations for sustained CLM impact.
Increase awareness and advocacy: How can CLM expand its visibility and influence through strategic communication and advocacy efforts?	→ Propose regular, high-profile forums or summits to showcase the impact of CLM across sectors and geographies. → Develop communication strategies to share success stories with broader audiences, including non-traditional stakeholders.

As the Summit concluded, one unifying message stood out: **real, lasting change happens when communities lead.** With continued and immediate commitment to this principle, CLM can evolve into a cornerstone for addressing global challenges, amplifying community voices, and ensuring equitable, sustainable solutions for generations to come.

ANNEX 1

LIST OF PARTICIPANTS

NAME	COUNTRY	ORGANISATION
Aditi Radhakrishna	South Africa	Akhile Management Consulting
Dr. Alex Plowright	South Africa	Anglo American
Andrew Gasozi Ntwali	Rwanda	UNAIDS
Anele Yawa	South Africa	Treatment Access Campaign
Dr. Anna Grimsrud	South Africa	International AIDS Society
Anna Maalsen	Switzerland	Global Fund
Boitumelo Langa	South Africa	Gauteng Department of Health & Wellness
Candice Oberholzer	South Africa	ITPC Global
Dr. Charlene Omrawo	South Africa	ITPC Global
Christoforos Mallouris	South Africa	UNAIDS
Colleen Wagner	South Africa	NACOSA
David Black Kamkwamba	Malawi	JONEHA
David Mnkandla	South Africa	NACOSA
Denis Godlevskiy	Russia	ITPC EECA
Dennis Mseu	Malawi	MANERELA+
Deo Mutambuka	Rwanda	RRP+
Elsie Ayeh	Ghana	CAN
Prof. Elvin Geng	USA	Washington University in St. Louis
Emmanuel Simon	South Africa	Heureo Labs
Dr. Farana Boodhram	South Africa	Women in Mining
Florence Riako Anam	Kenya	GNP+
Fred Misumbi Chungu	Zambia	NZP+
Gary Graham	South Africa	3iii Consulting
Dr. Gemma Oberth	South Africa	University of Cape Town
Giten Khwairakpam	Thailand	amfAR
Gloriah Moses	South Africa	ITPC Global

NAME	COUNTRY	ORGANISATION
Grace Nyarath	Kenya	CAN
Harold Kachepatsonga	Malawi	MANERELA+
Harpinder Collacott	United Kingdom	Global Public Investment Network
Harry Grainger	South Africa	The Health Foundation
Helen Etya'ale	USA	Washington University
Hossam Bahgat	Egypt	Egyptian Initiative for Personal Rights
Innocent Laison	Côte d'Ivoire	ITPC West Africa
Dr. Jane Harries	South Africa	University of Cape Town
Jeffrey O'Malley	South Africa	UNDP
Jeffrey Walimbwa Wambaya	Kenya	ISHTAR
Jelena Bozinovski	Malawi	ITPC Global
Kacey Sbusiso Biza	South Africa	ITPC Life Maps Participant
Keith Mienies	Switzerland	Global Fund
Khokhelwa Zokwana	South Africa	ITPC Global
Krista Lauer	South Africa	ITPC Global
Larissa Donald	South Africa	ITPC Global
Dr. Laura Schaefli	Switzerland	International AIDS Society
Laure Moukam	Cameroon	Impact Santé
Dr. Laurence J. Gunde	Malawi	ASLM
Lawrence Khonyongwa	Malawi	MANET+
Lillian Mworeko	Uganda	ICW East Africa
Makoti Salome Lekabe	South Africa	ITPC Life Maps Participant
Martin Philip Ellie	Sierra Leone	NETHIPS
Masilo Marumo	South Africa	PEPFAR
Matthew Black	Switzerland	Unitaid
Melikhaya Soboyisi	South Africa	NACOSA
Nadia Peerun	Mauritius	Consultant
Nadia Rafif	USA	ITPC Global
Natalie Maricich	South Africa	Audere Now
Nelson Juma Otwoma	Kenya	NEPHAK

NAME	COUNTRY	ORGANISATION
Ngqabutho Mpofu	South Africa	Treatment Access Campaign
Nicolay Vako	Côte d'Ivoire	CAN
Nkechi Anthonia Okoro	Nigeria	Centre for Citizens with Disabilities
Dr. Nkhensani Nkhwashu	South Africa	Public Health Consultant
Dr. Nompumelelo (Mpumi) Gumede	South Africa	ITPC Board
Nonkumbulo Ntozakhe	South Africa	South African National AIDS Council
Ntefeleng Nene	South Africa	Bridgespan Group
Dr. Othoman Mellouk	Morocco	ITPC Global
Pholokgolo Ramothwala	South Africa	ITPC Life Maps Participant
Pragashnee Murugan	South Africa	Akhile Management Consulting
Raquel Palomino González	South Africa	UNAIDS
Rehmeth Ally	South Africa	NACOSA
Dr. Rose Nyirenda	Malawi	Ministry of Health, Malawi
Ruby Ng'ong'ola Zolowere	Malawi	JONEHA
Saira Johnson-Qureshi	South Africa	PEPFAR
Seonmi Choi	Switzerland	Global Fund
Sergey Golovin	Ukraine	ITPC EECA
Prof. Sharmistha Mishra	Canada	University of Toronto
Dr. Sibongile Kubheka	South Africa	Healthcare Practitioner
Sinokuthaba Mukungwa	South Africa	ITPC Life Maps Participant
Siobhan Malone	USA	Consultant
Solange Baptiste	South Africa	ITPC Global
Susan Perez	USA	AIDS Strategy Advocacy and Policy (ASAP)
Thanduxolo Doro	South Africa	TAC
Vuyo Lwana	South Africa	ITPC Global
Wokie Cole	Liberia	Ministry of Health, Liberia
Yankho Banda	Malawi	JONEHA
Yogan Pillay	USA	Bill & Melinda Gates Foundation

ITPC
CLM SUMMIT AGENDA
THE FUTURE IS COMMUNITY-LED
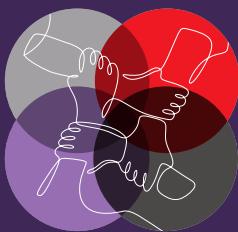
DAY 1
THE VALUE PROPOSITION OF COMMUNITY-LED MONITORING

TIME	ACTIVITY
08:00 – 08:45	**ARRIVAL AND BADGE COLLECTION** (Coffee and light refreshments served)
09:00 – 09:45	**SESSION 1** **Welcome and Setting the Scene** **Introduction to ITPC** **Welcome Address** Nompumelelo Gumede, ITPC Board **Introduction to CLM Summit** Krista Lauer, ITPC **Keynote Address** Solange Baptiste, ITPC
09:45 – 10:15	**SESSION 2** **Introduction to Community-Led Monitoring** *Facilitated by Jelena Bozinovski, ITPC* **Introduction to CLM** Jelena Bozinovski, ITPC **CLM Core principles and Approach** **Brief Q&A** Krista Lauer, ITPC
10:15 – 11:05	**SESSION 3 — PART 1** **Lightning Panel On The Diverse Impact Of CLM** *Moderated by Krista Lauer, ITPC* **ROUND 1** **Sexual and Reproductive Health (SRHR) Services:** Enhancing HIV service uptake through integrated services Melikhaya Soboyisi, Citizen Science Project NACOSA, South Africa **ROUND 2** **HIV Outcomes: Promoting differentiated service delivery models to improve health outcomes** Harold Kachepatsonga, Citizen Science Project MANERELA+, Malawi **ROUND 3** **Quality of Services: Using CLM data to improve quality of health service delivery** Ngqabutho Mpofu, Ritshidze, Treatment Access Campaign, South Africa **ROUND 4** **Malaria: Enhancing malaria control: the impact of community-led monitoring** Laure Vartan Moukam, Impact Santé, Cameroon **ROUND 5** **Human Rights: Expanding services to reach more young sex workers living with HIV** Kacey Sbusiso Biza, Citizen Science Project, Life Maps, South Africa **Q&A** Facilitated by Krista Lauer, ITPC

TIME	ACTIVITY
11:05 – 11:20	**SHORT BREAK**
11:20 – 12:30	**SESSION 3 — PART 2** ## Lightning Panel On The Diverse Impact Of CLM *Moderated by Nadia Rafif, ITPC* **ROUND 6** **User Fees:** Eliminating the malpractice of user fees for HIV services in Cote d'Ivoire Innocent Laison, ITPC West Africa, Cote d'Ivoire **ROUND 7** **Procurement:** Strengthening procurement systems in Eastern Europe through community-led monitoring Denis Godlevskiy, ITPC EECA, Russia **ROUND 8** **Market Shaping:** The role of communities in Making Medicines More Affordable Dr. Othoman Mellouk, Make Medicines Affordable Consortium, ITPC **ROUND 9** **Cost Effectiveness:** Targeted HIV testing for young people saves money Colleen Wagner, Citizen Science Project NACOSA, South Africa **ROUND 10** **CLM For Diagnostics:** Improving access to diagnostics through community-generated data Martin Ellie, NETHIPS, Sierra Leone **Q&A** Facilitated by Nadia Rafif, ITPC **Reflections and discussion** Facilitated by Krista Lauer & Nadia Rafif, ITPC
12:30 – 12:45	## Showcase of the Life Maps Exhibition Ruby Tionenji Ng'ong'ola and Khokhelwa Zokwana, ITPC
12:45 – 13:45	**LUNCH AND NETWORKING**
13:45 – 16:15	**SESSION 4** ## Perspectives – The CLM Value Proposition *Co-moderated by Solange Baptiste and Dr. Charlene Omrawo, ITPC* Multi-stakeholder panel engagement on the diverse value proposition of Community-Led Monitoring: perspectives from government, donors, bilateral agencies, private sector, social impact advisory, academia and community. **PANELISTS:** Rose Nyirenda, Ministry of Health, Malawi Ntefeleng Nene, Bridgespan Group, South Africa Keith Mienies, Global Fund, Switzerland Saira Qureshi, PEPFAR, South Africa Dr. Alexandra Plowright, Anglo American, South Africa Prof. Elvin Geng, Washington University in St Louis, USA Nelson Otwoma, NEPHAK, Kenya
16:15 – 16:30	## Closing Reflections Krista Lauer, ITPC
17:00 – 18:30	**NETWORKING RECEPTION BY THE POOL**

TIME	ACTIVITY
08:00 – 08:45	**ARRIVAL** (Coffee and light refreshments served)
08:45 – 09:15	**SESSION 5** ## Exploring The Full Potential Of Community Data *Facilitated by Charlene Omrawo, ITPC* **Recap and reflections on Day 1, introduction of agenda and outcomes of Day 2** Krista Lauer, ITPC **Broadening the scope of CLM: Key considerations for reinvention** Gary Graham, 3iii Consulting, South Africa **Showcase: Moving CLM ahead: The use of CLM for water sustainability**
9:15 – 10:50	**SESSION 6** ## The Science Of CLM & Data For Decision-Making *Moderated by Krista Lauer, ITPC* **Science and the CLM Model:** A scientific approach to CLM, its greater potential and CLM 2.0 Dr. Gemma Oberth University of Cape Town, South Africa **Intervention from the floor:** The role of community data in shaping informed decisions, and a vision for the future of CLM Yogan Pillay, The Bill & Melinda Gates Foundation, USA **Diverse perspectives on strategic data use:** The current data landscape and leveraging strategic information for decision-making Susan Perez, AIDS Strategy Advocacy and Policy (ASAP) and Saira Qureshi, PEPFAR, South Africa **Intervention from the floor:** The role of community data in driving sustainability Jeffrey O'Malley, UNDP, South Africa **The potential of Artificial Intelligence:** Harnessing AI in for community data and safeguards for integrating AI into the CLM model Natalie Maricich, Audere, South Africa and Emmanuel Simon, Heureo Labs, South Africa **A Modeler's Perspective:** Could CLM be the "information unicorn" that mathematical models need for improved decision-making? Prof. Sharmistha Mishra, University of Toronto, Canada **Q&A and reflections** Facilitated by Krista Lauer, ITPC
10:50 – 11:05	**SHORT BREAK**
11:05 – 12:05	**SESSION 7** ## Use Of CLM Data For Co-Created Sustainable Impact *Moderated by Dr. Othoman Mellouk, ITPC Global* **The Importance of Data Triangulation:** Utilizing tools to strengthen cooperation between local data collection sites and national monitoring systems Giten Khwairakpam TreatAsia, amfAR, Thailand and Boitumelo Langa, Department of Health West Rand, South Africa

TIME	ACTIVITY
11:05 – 12:05	**Affordability:** How community monitoring of pricing and subsequent advocacy leads to sustainable supply chains for Middle-Income Countries(MICs) Sergiy Golovin, ITPC EECA **Q&A and reflections** Facilitated by Dr. Othoman Mellouk, ITPC Global **Intervention from the floor:** Monitoring and advocacy in the context of climate change Hossam Bahgat, Egyptian Initiative for Personal Rights (EIPR), Egypt
12:05 – 12:55	**SESSION 8** **CLM & Community Data As A Means To Sustainability** *Moderated by Dr. Anna Grimsrud, IAS* Facilitated panel engagement around the application and usefulness of CLM and related models beyond the health sector: *perspectives from development financing, climate change and action, integration services and community leadership.* **PANELISTS:** Harpinder Collacott, Global Public Investment Network, United Kingdom Seon Mi Choi, Global Fund, Geneva Raquel Palomino, UNAIDS, South Africa Lilian Mworeko, ICW East Africa, Uganda
12:55 – 13:00	**Special Announcement** Keith Mienies, Global Fund, Switzerland
13:00 – 14:00	**LUNCH AND NETWORKING**
14:00 – 15:00	**SESSION 9 — PART 1** **Connecting Multi-Sectoral Stakeholders For Co-Created CLM Action And Impact** *Facilitated by Nadia Peerun, ITPC* An interactive series of Café Conversations around the applicability of CLM to delegates' fields of work and their take-aways on engagement with communities
15:00 – 15:15	**SHORT BREAK**
15:15– 16:25	**SESSION 9 — PART 2** **Connecting Multi-Sectoral Stakeholders For Co-Created CLM Action And Impact** *Facilitated by Nadia Peerun, ITPC* An interactive series of Café Conversations around the applicability of CLM to delegates' fields of work and their take-aways on engagement with communities
16:25– 16:45	**Wrap Up / Closing Remarks** **Q&A and reflections** Facilitated by Krista Lauer, ITPC **Closing Remarks** Solange Baptiste, ITPC