OPPER
Communities in Pandemic Preparedness & Response

COMMUNITY GUIDE

Using Community-Led Monitoring Data for Pandemic Prevention, Preparedness, and Response Advocacy Toolkit

ITPC

MATAHARI

CREDITS

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ABBREVIATIONS

AAAQ	Accessibility, Acceptability, Availability, and Quality
AFRICA CDC	Africa Centres for Disease Control and Prevention
AFRO	WHO Regional Office for Africa (World Health Organization, Regional Office for Africa)
AMALGAM	African Movement for Access to Long-Acting Medicines and Generics for All in HIV, TB, and Malaria
ART	Antiretroviral Therapy
ARVS	Antiretrovirals
CE	Community engagement
CLM	Community-led monitoring
COPPER	Communities in Pandemic Preparedness and Response
CSO	Civil society organization
ECOWAS	Economic Community of West African States
HEALTH GAP	Global Access Project
HTM	HIV, tuberculosis, and malaria
ICESCR	International Covenant on Economic, Social and Cultural Rights
IHR	International Health Regulations
IHR-MEF	International Health Regulations Monitoring and Evaluation Framework
JEE	Joint External Evaluation
LGBTQ	Lesbian, Gay, Bisexual, Transgender, and Queer (sometimes also “Questioning”)
METAL	Mobilizing Expertise and Technical Assistance for CLM-PPR & Advocacy Leadership
MOH	Ministry of Health
NACOSA	Networking HIV and AIDS Community of Southern Africa
NAPHS	National Action Plan for Health Security
PCR	Polymerase Chain Reaction
PEPFAR	President’s Emergency Plan for AIDS Relief
PLHIV	People Living with HIV
PPPR	Pandemic prevention, preparedness, and response
PREP	Pre-exposure prophylaxis
PWA	Asia Pacific Women’s Alliance for HIV/AIDS:
SADC	Southern African Development Community
SANARELA+	Southern Africa Network of Adolescents and Young People Living with HIV
TAC	Treatment Action Campaign
TB	Tuberculosis
UNICEF	United Nations International Children’s Fund
WASH	Water, Sanitation and Hygiene
WHO	World Health Organization

SUMMARY

This Community Guide accompanies a longer pandemic prevention, preparedness, and response Toolkit [LINK] on mapping advocacy entry points for community-led monitoring data developed by Matahari Global Solutions as part of the METAL Consortium for the Global Fund COPPER initiative. **The Guide and Toolkit can help you identify:**

THE WHO
Actors in CLM-PPPR Advocacy

This Guide — and the comprehensive Toolkit [LINK] it accompanies — is for anyone who would like to grow their knowledge on how to use community-led monitoring (CLM) for advocating on issues that intersect with pandemic prevention, preparedness, and response (PPPR).

Are you already implementing CLM, although on HIV, TB, and malaria (HTM)? This Guide is for you. Do you work on PPPR and would like to start using CLM data in your advocacy? This Guide is also for you. Are you curious and keen to learn more about how CLM, advocacy, and PPPR fit together? Read on!

As a reminder, CLM is defined as:

> *A process in which communities—particularly people living with HIV and those affected by health programs — **routinely collect and analyze data about the quality and accessibility of health services.** This data is used to **advocate for improvements** in the delivery of care, based on **real-time, community-generated evidence**.*[1]

Against the backdrop of an evolving global health landscape and shifting global health threats, communities and civil society organizations working on HTM, for example, should consider taking a closer look at PPPR, which another COPPER manual defines as follows:[2]

> *"Pandemic Prevention, Preparedness, and Response (PPPR) is a **systematic approach** to preventing, preparing for, and responding to pandemics through disease surveillance, health promotion, quarantine policies, contingency planning, medical training, and equipment procurement. The aim is to **protect public health, reduce social and economic impacts**, and **strengthen health systems** and interagency collaboration."*

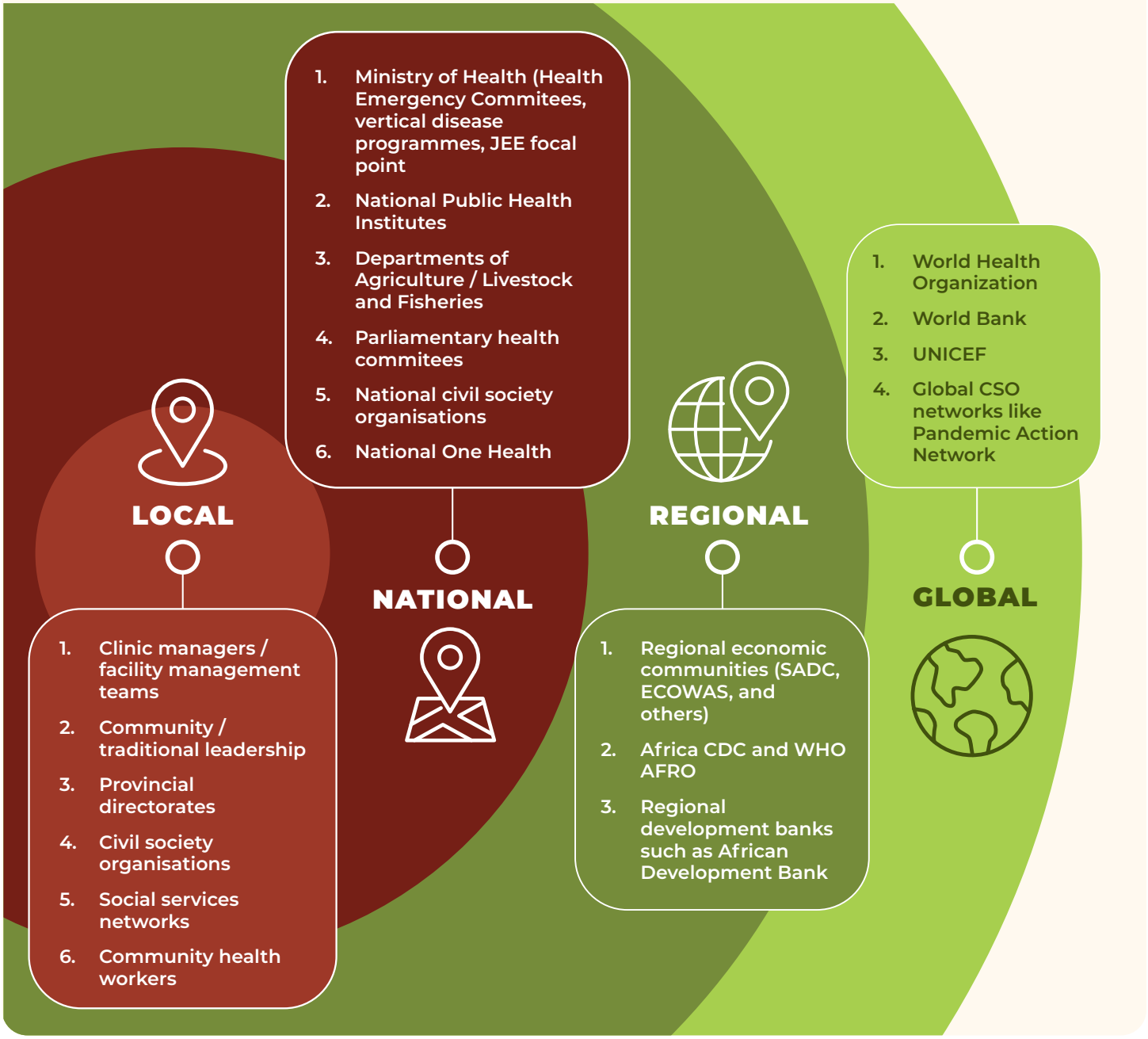
If you are working on HTM, most of this might sound quite familiar to you. It might also remind you of public health responses to mpox and Ebola and your recent lived experience with COVID-19. Indeed, some of the work that you are doing on HIV, TB, or malaria is part of PPPR and/or adjacent to PPPR.

The other side of **Who** applies to who is involved in PPPR on the local, national, regional, and global levels. The following figure introduces key actors, which may have different names in your country, but whose functions should be represented within your political bureaucracy.

[1] International Treatment Preparedness Coalition. How to Implement Community-Led Monitoring: A Community Toolkit. December 2021. https://itpcglobal.org/wp-content/uploads/2021/12/1205_ITPC_CLM_Design_FullReport06_compressed.pdf.

[2] APCASO et al. Training Module. Enhancing Community Capacity for Human Rights and Advocacy in the Context of Pandemic Prevention, Preparedness, and Response. July 2024. https://copper.apcaso.org/download/ppr-101-training-module-english/.

FIGURE 1: Key Local, National, Regional, and Global Actors in PPPR

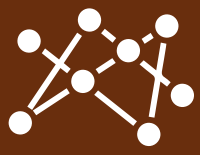


THE WHAT
Content of this Guide and CLM-PPPR Advocacy

This Guide introduces readers to how to map out PPPR advocacy with CLM data. While you may have experience in CLM, some technical knowledge and the processes through which PPPR works may be new to you. If you work on PPPR, the details of how CLM can elevate your work may need further explanations. There is a lot of synergy between these workstreams because they all look at the health system and how it delivers or does not deliver the necessary interventions for all people to live their lives with dignity and realize their human rights, including the right to health (ICESCR Art 12) and the right to science (ICESCR Art 15).

CLM has proven to be a great tool for better understanding how health systems perform, or don't, on the local, national, or/and regional levels. CLM, therefore, is one important way of bringing HTM and PPPR together. COVID-19 and other health events repeatedly show that key populations in HTM are also sidelined during health emergencies. Communities play an important role in shaping appropriate policy responses, and they are closest to wherever policies are insufficient or are not implemented effectively. Yet, they are often sidelined when new health emergencies occur. Their expertise is rarely actively sought out by policymakers and those institutions responding to health emergencies. But you need good data to make good decisions. CLM implementers can bring this data to PPPR policymaking, participate in PPPR processes, and thereby ensure that strategies for future health emergencies are stronger and our health systems more resilient.

FIGURE 2:
Definitions: Community-led Monitoring vs. Community-Based Surveillance

	DEFINITION	DETAILS
 Community-led monitoring	"A process in which communities—particularly people living with HIV and those affected by health programs—**routinely collect and analyse data about the quality and accessibility of health services**. This data is used to advocate for improvements in the delivery of care, based on real-time, community-generated evidence."	**Not a routine part of the national health system**
 Community-based surveillance	"The systematic detection and reporting of events of public health significance within a community, by community members."[3]	**Usually, part of the national public health system**

[3] Technical Contributors to the June 2018 WHO meeting. A definition for community-based surveillance and a way forward: results of the WHO global technical meeting, France, 26 to 28 June 2018. Euro Surveill. 2019 Jan;24(2):1800681. doi: 10.2807/1560-7917.ES.2019.24.2.1800681. https://pmc.ncbi.nlm.nih.gov/articles/PMC6337056/.

This Guide and the Toolkit [LINK] provide communities, civil society organizations, CLM implementers, and those supporting CLM implementation with insights into:

- **Examples from COVID-19 and what that teaches us for CLM and the next pandemic**
- **Who the main stakeholders in PPPR are**
- **What the main international and national processes for PPPR are**
- **Which parts of the International Health Regulations (IHR) are of main interest for HTM and PPPR CLM**
- **Ideas of what CLM can track in PPPR that are meaningful for HTM at the same time**
- **Important PPPR documents, processes, and terminology to understand**
- **How to get started with CLM that combines HTM and PPPR**

CLM takes place when the community itself decides which issues should be tracked, creates indicators, and collects facility- and community-level data.[4] Crucial scenarios in which CLM can have a big impact include fast-moving situations, such as a new pandemic, or rapidly evolving situations, such as the global health funding cuts in early 2025. CLM is a great tool for these scenarios because it can collect useful data in real time. CLM is also quite useful for understanding a situation from the perspectives of healthcare workers or those receiving care because the insights will be different from health facility data that is generated in a top-down manner.

The collective experience with CLM has shown that in the following situations, CLM has proven to be an adequate tool. You will notice that these situations appear in HTM as much as they did during, for example, COVID-19, meaning that they are likely to also be issues in the next pandemic if unaddressed:

- **Inefficient resource allocation**, leading to gaps in services and community development
- **Lack of community-driven data**, resulting in poor decision-making by service providers (especially in a rapidly changing context)
- **Systemic health and social inequalities**, disproportionately affecting marginalized populations and women
- **Limited community involvement** in decisions that impact their lives
- **Lack of support and resources** for underserved communities to address their health challenges

The following excerpt of the mind map in the Toolkit [LINK] provides some illustration of what CLM can track in PPPR:

FIGURE 3: Excerpt from What Can CLM Track in PPPR? A Mind Map

[4] White Paper. Community-led Monitoring. Best Practices for Strengthening the Model. https://itpcglobal.org/wp-content/uploads/2022/12/CD4C-CLAW-EANNASO-ATAC-APCASO-Community-led-Monitoring-Best-practices-for-strengthning-the-model.pdf (accessed 9 April 2025).

In the world of HTM, communities and civil society have utilized CLM to assess the health system regarding Availability, Acceptability, Accessibility, and Quality (AAAQ). The following table is an example of how one of the above examples from PPPR could be further unpacked using the AAAQ framework. CLM can engage well with the "Prevention" aspect of PPPR and, for example, track the implementation of the Prevention module in your community.

FIGURE 4: Examples of CLM-PPPR Data Topics

	EXAMPLES OF CLM-PPPR DATA TOPICS	EXAMPLES OF INSIGHTS THAT CAN BE GATHERED
AVAILABILITY	**Availability of services and products**	*"I went to the clinic to get a COVID-19 vaccine, but there were no more shots available when it was my turn."*
	Availability of comprehensive and accurate health information	*"The information from the health authorities was not available in our local languages and only on the TV and not the radio, which our disability community mainly uses."*
	Denial of services based on various factors	*"I wanted to get a COVID-19 vaccine, but was told by the nurse I could not because I am pregnant."*
ACCESSIBILITY	**Physical accessibility**	*"The clinic that provides vaccines is 5km away. That is too long for us to walk to and we don't have money to take a motor taxi."*
	Financial accessibility	*"I cannot wait in line all day; I need to make sure we have food to eat."*
	Opening hours and administrative procedures	*"There is no way to sign up in advance. Instead, you have to line up at the clinic and you may or may not actually get a shot by the end of the day."*
	Other barriers, such as inadequate access to social protections, stigma, discrimination, violence	*"Community health workers brought TB patients to the clinic, but because the symptoms are similar, they thought it was COVID-19 and told them to go home. These patients did not receive any TB diagnosis services at that time."*

	EXAMPLES OF CLM-PPPR DATA TOPICS	EXAMPLES OF INSIGHTS THAT CAN BE GATHERED
ACCEPTABILITY	**Experiences of stigma, discrimination, or human rights violations**	*"The lines at the hospital are split into men and women. Our trans community gets harassed when we try to line up according to our gender."*
	Reasons people do not seek or utilize the health services they need (for example, gender norms and social acceptability of male or female health care providers)	*"In our community, a woman cannot go see the doctor alone. Unless a man from my family accompanies me, I cannot go to the clinic for a COVID-19 vaccine or test."*
	Preferences of users and affected communities in relation to the recipient of care-provider interaction (such as language used and cultural beliefs)	*"The radio messages about COVID-19 are all in English, not in my local language."*
QUALITY	**Relative wait times**	*"The wait time for a COVID test result is several days. I cannot isolate that long."*
	Skills and competencies of providers	*"The nurse did not seem like she knew how to use a rapid test. She also did not seem to know what the symptoms of this pandemic pathogen could be."*
	Respect for clinical protocols	*"The nasal swab used on me was not unwrapped in front of me – it did not look new."*
	Respect for hygiene, infection control, and safety standards	*Local clinics observing WASH standards*

THE WHERE
Applicability of the Guide and Toolkit

CLM has been an important mechanism for a deeper understanding of how health systems work, as well as for accountability on local, subnational, and national levels. During the COVID-19 pandemic, this work was critical in documenting the myriad impacts of the pandemic on key populations, that is, those most affected by HTM. This Guide, therefore, can be of use throughout the world where communities and civil society seek to bring together CLM for PPPR and HTM advocacy.

This Guide relies on the practical findings from the Global Fund COPPER CLM project and COPPER CE implementers, as well as long-time CLM community experts and PPPR experts. While the case studies describe specific situations, some knowledge is transferable regardless of the location. For example, the following table on learnings from the COVID-19 pandemic includes examples that should sound familiar and which might inspire you to start exploring where your priorities fit the most.

FIGURE 5: What Went Wrong in the COVID-19 Pandemic?

WHAT WENT WRONG IN THE COVID-19 PANDEMIC?	PREVENTION AND PREPAREDNESS INTERVENTIONS
GeneXpert machines normally used for TB displaced to test for COVID-19	→ Preparedness for surge capacity of labs → Integrating TB diagnosis in COVID-19 testing strategies[5]
Routine HIV, TB, and malaria services interrupted (due to lockdowns, facility closures, stock supply disruptions)	→ Policy developed with HIV, TB, and malaria community organizations on remote service/ door-to-door delivery of, for example, drugs and other alternative service delivery options
Self-tests reached the communities in the Global South later than in the Global North (late issuance of WHO guidelines, preventing procurement by countries, Global Fund, and UNICEF)[6]	→ Advocating for increased reliance on regional guidelines, such as from the Africa CDC or the African Medicines Agency → Regional or local production of self-tests
Women and LGBTQ people not factored into responses, resulting in less-than-optimal access to pandemic products[7]	→ Participatory PPPR policymaking → Gender-disaggregated data, for example, on how many men, women, and gender-diverse people are accessing pandemic products, such as vaccines

[5] Recommended in https://journals.plos.org/plosmedicine/article/figure?id=10.1371/journal.pmed.1003666.t001.

[6] Fifa A. Rahman, Brook K. Baker, and Carolyn Gomes. COVID Testing Equity: A Reflection Based on 1.5 Years in the ACT-Accelerator. PLOS Global Public Health (blog). 24 January 2022. https://speakingofmedicine.plos.org/2022/01/24/covid-testing-equity-a-reflection-based-on-1-5-years-in-the-act-accelerator/.

[7] Fifa Rahman and Gisa Dang. COVID-19 and Gender: Best Practices, Challenges, and Lessons for Future Pandemics. Matahari Global Solutions, December 2023. https://matahari.global/wp-content/uploads/2024/01/COVID19_Gender_Report-FINAL.pdf.

WHAT WENT WRONG IN THE COVID-19 PANDEMIC?	PREVENTION AND PREPAREDNESS INTERVENTIONS
Women and LGBTQ people not factored into responses, resulting in less-than-optimal access to pandemic products[7]	→ LGBTQ organizations consulted about the best approach/locations for delivery of pandemic services → Trusted influencers, women's organizations, local leadership, and community health workers actively engaged as agents and experts to increase demand creation
Human rights violations (such as arrests for not wearing masks)	→ Engagement and established protocols with law enforcement and political leaders, including sensitization on impact of arrests on infection risk, the right to health, and the right to family life, among other human rights
People living with HIV and people with TB in informal sectors lost their incomes, resulting in food insecurity and an inability to remain adherent to ART and TB treatments[8]	→ Advocacy highlighting impact of lost income on health and security and the need for a social safety net for the informal sector during pandemic times – including via direct cash payouts → Active adherence support via trained community health workers and digital adherence support technologies
Accessibility of pandemic products limited due to distance from facilities and long queues[9]	→ Mobile services deployed to ensure accessibility to communities, including homemakers, people with disabilities, farming communities, and migrants
Official information flow insufficiently presented in local languages and not frequent/strong enough to counter misinformation	→ MOH emergency teams to include qualified risk communications experts, robust communications budgets, and authority to work across all relevant media channels to ensure agility → Official information to be presented in major local languages → Community and CSO partnership on communication

[8] International Treatment Preparedness Coalition. How to Implement Community-Led Monitoring: A Community Toolkit. December 2021. https://itpcglobal.org/wp-content/uploads/2021/12/1205_ITPC_CLM_Design_FullReport06_compressed.pdf.

[9] Fifa A. Rahman et al. Mapping Access Gaps in COVID-19: Results from 14 Countries and Territories. Matahari Global Solutions. August 2022. https://matahari.global/wp-content/uploads/2022/08/Mapping-Access-Gaps-in-COVID-19.pdf.

THE WHEN
Identifying Your Opportunities

In an ideal scenario, you would read the Guide and Toolkit before you start planning your CLM and PPPR project. You would have sufficient time to understand the main effects that COVID-19, Ebola, and/or mpox has had on your community. You would hold stakeholder meetings that include joint learning and agreement on priorities. You would design and test indicators. You would have an advocacy mapping of what data should be used when, with whom, in what format, and with what follow-up. And you would have sufficient staffing and financial resources.

However, we understand that reality does not always work like that. Even if you have already started your project, you can use this Guide as a reference to check if you have considered all the potential advocacy entry points for your specific goal and use it to prioritize where you want to focus your advocacy engagement. You can use this Guide once you have collected and analyzed your data to see if you have missed any opportunities. If you are in the process of developing your CLM indicators, use the reflection questions in the Toolkit to gain additional knowledge on the IHR and the IHR-Monitoring and Evaluation Framework (IHR-MEF) or other PPPR instruments that could be of use. If you are new to CLM, use the case studies to explore different ways in which CLM can strengthen advocacy and accountability and provide long-term monitoring or snapshots of an emerging situation.

Opportunities within the global PPPR framework are governed largely by the IHR and their accompanying IHR-MEF. The IHR establishes a global surveillance network for rapid information sharing among countries on health emergencies with international implications. It is a legally binding instrument that applies to 196 countries, including all 194 WHO Member States. Similar to other international law (think, for example, of ICESCR for human rights), it establishes rights and obligations between countries. **The IHR work across four main categories:**

DETECT	ASSESS	REPORT	RESPOND
Which requires capable surveillance and labs	Which requires international collaboration on emergencies	Which follows guidelines for specific diseases and potential international emergencies	Which requires action for public health events

The IHR-MEF works just like other monitoring and evaluation frameworks in that it established processes and benchmarks to measure how countries progress in the implementation of the IHR. Importantly, it provides suggested timelines and several instruments or processes that countries should use. These processes provide entry points for community and CSO engagement in PPPR, as well as potential avenues for utilizing CLM data. One such entry point is the Joint External Evaluation (JEE), a voluntary, collaborative, multisectoral process that is meant to assess country capacities to prevent, detect, and rapidly respond to public health risks. The JEE process cycles through five steps and is divided into 19 technical areas with a total of 56 indicators. These indicators can be quite interesting to look at in detail because that will give you some idea of existing synergies and overlap between HTM and PPPR work, for example, around drug-resistant TB.

Another part of the IHR-MEF is the National Action Plan for Health Security (NAPHS), a country-owned, multi-year planning process that is meant to accelerate the implementation of IHR core capacities, which are the eight capacities required of each country per the IHR.[10] It does that by applying an approach that focuses on One Health, which considers the health of humans, animals, and ecosystem as interdependent,[11] and works across whole-of-government and whole-of-society. This is one entry point to understand what your country's processes are and what opportunities for participation may already exist. The NAPHS is a costed plan through which countries can adopt strategies, establish priorities, and implement activities to improve their PPPR and health security. Countries are advised to develop a five-year strategic plan and a one- to two-year operational plan that focuses on improving in at least 19 prioritized areas from their JEE.

[10] WHO. International Health Regulations. https://www.emro.who.int/international-health-regulations/about/ihr-core-capacities.html.

[11] WHO. One Health. https://www.who.int/health-topics/one-health#tab=tab_1.

THE WHY
Understanding the Importance of CLM for PPPR and HTM

Engaging PPPR actors in strategic CLM data-based advocacy requires knowledge of the ecosystem and processes that govern PPPR policymaking. The Community Guide and Toolkit aim to provide HTM actors with information that will allow them to find suitable entry points for their monitoring and advocacy. It maps relevant governmental, organizational, and coalition actors at the national, regional, and global levels and explains what parts of major PPPR instruments, such as the IHR and its Monitoring Evaluation and Learning Framework (IHR-MEF), are relevant for those working on CLM. Based on community feedback, this Guide and the Toolkit [LINK] explore some areas that CLM-PPPR can map and, in some cases, already has, as illustrated by the case studies, two of which are in this Guide.

For example, the chapter on the IHR shows you which obligations your country has regarding PPPR. The Toolkit [LINK] explains which sections of the formal text are relevant to communities and civil society organizations, not only because it shows you where you could participate, but also because it defines the steps your country should take at different levels. The following table, showing two components of PPPR (prevention and preparedness), illustrates why understanding and engaging at the intersection of PPPR and HTM can be a powerful strategy.

FIGURE 6: IHR Obligations for Pandemic Prevention and Preparedness

COMPONENT	TOPIC	DEFINITION	IMPLEMENTATION
PREVENTION	**Disease surveillance**	Active monitoring of disease events conducted systematically to detect changes in disease spread	Includes case monitoring, epidemiological trend analysis, and routine data reporting to support timely decision-making
	Public health promotion	Efforts to raise community awareness regarding the importance of health, as well as educating them about preventive actions that can be taken to reduce the risk of disease spread	Utilizing public campaigns, outreach, and mass education to change community behaviours related to hygiene, vaccination, and other preventive practices
	Quarantine policies	Policies that restrict the movement of people, animals, or goods to prevent the spread of disease from affected areas to not affected areas	Regulating and enforcing quarantine procedures, including health monitoring at entry points, isolating identified cases, and applying appropriate quarantine measures

COMPONENT	TOPIC	DEFINITION	IMPLEMENTATION
PREPAREDNESS	**Contingency plan development**	Detailed planning documents outlining the steps to be taken in response to a pandemic, including resource allocation, standard operating procedures, and crisis management structures	Creating and regularly testing contingency plans, involving key stakeholders to ensure readiness for various potential pandemic scenarios
	Training for healthcare personnel	Education and training processes to enhance healthcare workers' competencies in managing pandemic cases, including symptom identification, isolation management, and appropriate medical care	Conducting regular training, pandemic simulations, and specialized courses to enhance healthcare workers' skills and knowledge in facing public health emergencies
	Procurement of medical equipment	The process of acquiring and preparing necessary medical tools and supplies to respond to a pandemic, such as diagnostic testing tools, personal protective equipment, and vital support equipment	Assessing needs, inventorying stocks, and developing efficient distribution systems to ensure adequate medical equipment availability during a pandemic
	Public education	Delivering information to the public about preventive measures people can take to protect themselves and their families from disease spread	Organizing social campaigns, providing educational materials, and holding community outreach sessions to raise public awareness about pandemics and effective preventive measures

THE HOW
Tools and Case Studies from Communities and CSOs on CLM for PPPR and HTM

ADVOCACY TOOLS

CLM data can be critical in ensuring robust and timely pandemic preparedness and response. For example, if you are recording many unexplained animal deaths in the community, that should be reported to local veterinary systems and the national One Health platform. If you are seeing HTM treatments disrupted as a result of pandemic lockdowns, those incidents and general locations of the disruptions should be logged and reported.

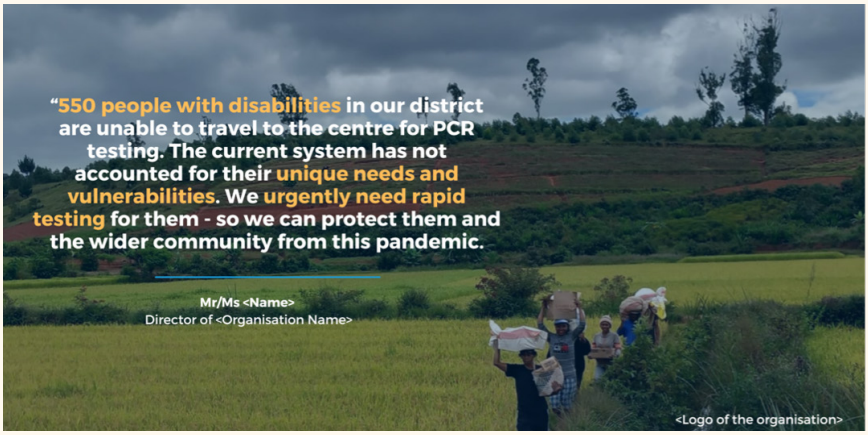
There are several tools that can be deployed in maximizing advocacy from CLM data. An **advocacy log** that tracks the advocacy conversations that you have, as well as effective social media messaging, can effect real change. An advocacy log is a spreadsheet that systematically documents the CLM data that you have, who you want to target, when you targeted them, their response, and what the next steps should be. This helps create a historical log and strategic tool for you to make sure your CLM data reaches those you want to target.

FIGURE 7:
IHR Example of an Advocacy Log that Can Track What You Do with Your CLM Data

Change You Want to See	Relevant CLM Data Gathered	Date of Event / Meeting	Advocacy Target	Contact Details of Advocacy Target	Medium of Advocacy	URL / Link to Relevant Materials	Outcome of Event	Next Steps Required
Self-tests provided for free to people living with disabilities	550 people with disabilities in southern district are unable to travel to facilities for PCR testing	14th April 2025	MOH Emergencies Team	sample@moh.gov	Letter		Response received via Whats-app from MOH stating that they will not be providing self-tests due to cost implications	Request for a meeting with MOH Prepare social media assets based on CLM data to raise support
Increased awareness round our CLM data on self-tests	550 people with disabilities in southern district are unable to travel to facilities for PCR testing	17th April 2025	General Public, MOH Emergencies Team	N/A	Social media	<link>	43,500 likes of the post on LinkedIn, 103,000 impressions, journalist enquired about the social media post	Set up a TV appearance to discuss CLM data on access to self-tests

Social media messaging can be used effectively for advocacy based on your CLM data. At **this link**, we've provided some social media templates that you can use for your work.

FIGURE 8:
Example of Social Media Post to Amplify Your CLM Messages



Not all public engagement is effective for social media advocacy. Consider the following table to spot the differences. As you compare the texts, consider additional ways to edit the bad text into good text. How can you use the example of good text in CLM for PPPR?

FIGURE 9: Examples of Good vs. Bad Social Media Posts

GOOD TEXT	BAD TEXT
Our community-led monitoring data show that people with disabilities are not getting the tests they need. We urge @DrTedros and @WilliamRuto to take action to protect our communities. **EXPLANATION:** 1. Shows where the data is coming from 2. Tags the advocacy targets so they receive social media notifications	Our community-led monitoring data show that people with disabilities are not getting the tests they need. In District X, we interviewed 25 people, in District Y, we had 3 focus groups, and in District Z, we interviewed 40 people, and we would like to collect more data in the next months. Ministry of Health has received our data. **EXPLANATION:** 1. Is too long and will lose the reader 2. Does not tag advocacy targets – no one will receive notifications and journalists will not know who you are targeting your message to
GOOD TEXT	**BAD TEXT**
NEW REPORT 🚨 finds that 452 PLHIV did not receive ARVs in [Country X] because of lockdowns. Read more at this link: **http://<URL> @MOH @DrTedros** **EXPLANATION:** 1. Leads with clear finding, data, or barrier to be addressed 2. Tags the advocacy targets so they receive social media notifications 3. Links to the report	We released a new report on CLM. **EXPANATION:** 1. Provides no information, no links, no context, no advocacy message 2. Does not tag any advocacy targets; therefore, they will not ever know that you have posted this online

CLM has been used effectively elsewhere in PPPR and HTM. The following two case studies from communities illustrate this point. They highlight that long-term CLM is an opportunity to build strong partnerships between the local health system, including clinics, healthcare workers, community-based organizations, and CSOs, showing that collaboration can make CLM, including advocacy, which is the purpose for CLM, stronger and more effective.

CASE STUDY: CLM ADVOCACY WITH COMMUNITY HEALTH WORKERS IN SOUTH AFRICA

As part of the following project, community health workers (CHWs) in South Africa were part of identifying interviewees and collecting CLM data to understand service provision barriers. They shared findings at Community Consultative Group meetings at the subdistrict level. According to the Networking HIV and AIDS Community of Southern Africa (NACOSA):

> *"Our CLM field researchers developed a strong working relationship with Community Health Workers (CHWs), which played a crucial role in correctly identifying Receivers of Care. Through client consent, our field researchers were able to conduct interviews using the Receiver of Care tool to assess service provision at selected public healthcare facilities. This collaboration bridged the gap between the CLM programme and CHWs, enhancing their knowledge and making it easier to work together in implementation. CHWs were also invited to Community Consultative Group Meetings, held at the sub-district level, where CLM insights were shared. CLM organizations and CHWs worked together to address advocacy challenges in the community."*

According to NACOSA, the following impacts and activities were observed:

1. In the West Rand, CLM data from 2022 showed that 20-24-year-olds had the lowest pre-exposure prophylaxis (PrEP) uptake among women. The small number of young women who started to use PrEP was identified as a barrier to HIV prevention. CLM at a number of sites found that knowledge and education about the prevention option was insufficient. After NACOSA and CHWs used this data to inform healthcare facilities and education about PrEP was increased, CLM at these sites documented a significant increase in PrEP uptake.
2. When CLM data suggested that older men preferred community-based testing and that reaching them was a priority, CHWs and CLM implementers joined forces to increase availability of this testing, including through mobile testing sites in community locations. The ongoing CLM documented an increase of older men who knew their HIV status.

Strategic collaboration and long-term monitoring were key to understanding prevention barriers, identifying potential solutions, advocating for the needed changes, and documenting the success of the new approaches. The partnership between CLM implementers and CHWs resulted in a coordinated and impactful approach to using CLM for advocacy and health system strengthening.[12] This experience shows the many ways in which CLM implementers can collaborate with CHWs and other stakeholders. Not only does this kind of collaboration strengthen data collection because of better access to those you want to interview; it also has the potential to strengthen your advocacy. These relationships will also be of importance in the next pandemic, as well as for prevention and preparedness.

[12] International Treatment Preparedness Coalition and NACOSA. Insight, Influence & Impact: 10 Big Change Stories from the Citizen Science Community-Led Monitoring Project in 2023. 26 May 2024. https://itpcglobal.org/resource/insight-influence-impact-clm-report/.

CASE STUDY: COVID-19 SHIFTS IN HIV CLM MODELS

As part of the following project, community health workers (CHWs) in South Africa were part of identifying interviewees and collecting CLM data to understand service provision barriers. The Ritshidze is a civil society-led health monitoring project in South Africa, focused on improving the quality of HIV and TB services in public healthcare facilities. It is led by the Treatment Action Campaign (TAC) and a coalition of networks of people living with HIV, including NAPWA, Positive Women's Network, and SANERELA+, with support from Health GAP and AMALGAM. It was established in 2020 with support from PEPFAR to monitor public health facilities, gather data directly from recipients of care and healthcare workers, and hold the government accountable for improving service delivery through recipients of care interviews, direct observation, and scorecards. It has produced numerous province-specific reports, such as this **2021 report** on Mpumalanga province, finding, inter alia, that 92.7% of health facility managers say their facilities don't have enough staff and that 4 hours 41 minutes was the average waiting time reported by recipients of care.

During the COVID-19 pandemic, Ritshidze had to change its ways of working and modify its CLM tools. According to Anele Yawa, TAC General Secretary, interviewed for this Guide:

"Much changed for Ritshidze during COVID-19. Internally, the pandemic changed our ways of working – personal protective equipment was procured for the teams, and multiple safety trainings were held to give people information on how to protect themselves. Options to stop monitoring (if it felt unsafe to continue) were integrated into our systems, and of course, during the major waves and lockdowns, all monitoring was paused entirely. But it was also critical to monitor our clinics to be able to document the challenges in our already broken healthcare system.

"To do this, additional indicators were included in Ritshidze observation tools, as well as in surveys being conducted with public healthcare users, people living with HIV, and facility staff. These helped us to determine what was arising as a result of the pandemic – such as clinics being closed altogether or having partial disruptions – and the impact this had on people who needed health services or were there to collect ARVs or other chronic medicines. In some places, people were turning up to collect medicines only to find clinics shut – for some, this meant treatment interruptions; for others, having to find taxi fare for extra trips to the clinic to try again, even putting people at extra risk of getting COVID-19. In other instances, we witnessed people being denied entry and medicines being openly passed through clinic fences, violating confidentiality. Adherence clubs were decimated, a key mechanism for people to have peer support and find treatment literacy information; these never recovered.

"On top of that, our existing questions helped us to determine the impact of COVID-19 on waiting times, staffing shortages, ART collection models, and stockouts, for example – and through our public dashboard, we were able to see all these indicators over time to assess the impact. We also monitored specific safety protocols related to COVID-19 prevention, including if people were provided with masks, if windows were being kept open, if sanitizer was available, and [if there was] water and soap to wash hands. Not all facilities had these measures in place, and even staff members at times complained of having to wash masks and re-use because of a lack of resources.

"Critically, through our existing engagement channels with duty bearers at facility, district, provincial, and national levels, we were able to escalate all the challenges we identified for urgent corrective action."

NEXT STEPS AND CONCLUSION

We hope that this Guide and the Toolkit will be useful in your deployment of CLM-PPPR models and tools in your context.

As you plan your CLM-PPPR journey, mapping of advocacy entry points is just one of several steps that you will need to take. To be prepared for the full process, you will not only need to acquire the necessary knowledge and terminology to effectively communicate with your new advocacy targets and participate in PPPR processes. You will also need to retain the necessary means for CLM on PPPR. This includes, for example, locating and securing funding for your CLM research and technology needs. You will need to mobilize and train your data collectors and equip your networks toward building active coalitions.

We hope that this Guide and the Toolkit [LINK] will be useful in your deployment of CLM-PPPR models and tools in your context.

The Toolkit [LINK] has an advocacy log that lets you track who you spoke to about your CLM data last week, last month, last year, last three years, what "next steps" you had planned at the time, whether you followed through, and whether you should reconnect with that advocacy target.

This Guide also contains good examples of who you should target with your CLM data, whether it is One Health coordination platforms, Ministries of Health, or heads of health facilities.

We've also added some social media examples and explanations of the International Health Regulations and what these mean to communities for your review in the Toolkit [LINK].

You are now prepared to use CLM data for PPPR advocacy.

*If you require additional support on CLM, CLM-PPPR integration, setting up CLM systems, or PPPR, consider reaching out to the ITPC team at **Admin@itpcglobal.org**.*

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