

TOOLKIT

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





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MATAHARI GLOBAL SOLUTIONS is a global health MATAHARI consultancy firm focusing on global health solutions with local relevance. Registered in Kuala Lumpur and with consultants based globally, our work has covered a wide

range of global health issues using robust and inclusive methodologies. This includes: work to develop the African Union Health Workforce Compact in consultation with African Member States; market/critical path analyses on syphilis/gonorrhea assays and novel non-sputum diagnostics; in-depth research on transgender legal recognition and impact on access to healthcare; an evaluation on impacts of civil society advocacy on paediatric TB; the evaluation of multi-country HIV projects across Africa, Asia, Eastern Europe and Central Asia, and Latin America; and research on COVID-19 access gaps with ITPC.



The INTERNATIONAL TREATMENT PREPAREDNESS COALITION (ITPC)

is a global network of people living with HIV and community activists working to achieve universal access to optimal HIV treatment for those in need. ITPC is an issue-based non-profit organization working to

achieve health and social justice for all through robust community engagement. ITPC actively advocates for health access across the globe through its focus on three strategic pillars: intellectual property and access to medicines (#MakeMedicinesAffordable); communityled monitoring (CLM) and accountability (#WatchWhatMatters); and activism and capacity building (#BuildResilientCommunities).

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ABBREVIATIONS

МОН

NACOSA

Ministry of Health

Networking HIV and AIDS Community of Southern Africa

AAAQ	Accessibility, Acceptability, Availability, and Quality	NAPHS	National Action Plan for Health Security
AAR	After Action Review	PABS	Pathogen access and
ACHIEVE	Action for Health Initiatives		benefit sharing
AFRICA CDC	Africa Centres for Disease Control and Prevention	PASTB	People Affected by Tuberculosis Philippine Alliance to Stop TB
AMALGAM	African Movement for Access to Long-Acting Medicines and	PBSB	Philippines Bureau for Social Progress
	Generics for All in HIV, TB, and Malaria	PEPFAR	President's Emergency Plan for AIDS Relief
ART	Antiretroviral treatment	PHEIC	Public health emergency of international concern
ARVs	Antiretrovirals	PHSM	Public health and social
CBS	Community-based surveillance	РПЗМ	measures
СВО	Community-based organization	PPE	Personal protective equipment
ССМ	Country Coordinating Mechanism	PPPR	Pandemic prevention, preparedness, and response
CE	Community engagement	PrEP	Pre-exposure prophylaxis
CHW	Community health worker	PWA	Asia Pacific Women's Alliance
CLM	Community-led monitoring		for HIV/AIDS
COPPER	Communities in Pandemic Preparedness and Response	SADC	Southern African Development Community
cso	Civil society organization	SANARELA+	Southern Africa Network of
рон	Department of Health		Adolescents and Young People Living with HIV
GHSA	Global Health Security Agenda	SimEX	Simulation Exercise
нтм	HIV, tuberculosis, and malaria	SPAR	States Parties Self-Assessment
EAR	Early Action Review		Annual Reporting
ECOWAS	Economic Community of West	TA	Technical assistance
	African States	TAC	Treatment Action Campaign
ERR	Emergency Response Review	тв	Tuberculosis
IAR	Intra-Action Review	TBDOTS	Tuberculosis directly observed
ICESCR	International Covenant on		treatment short courses
	Economic, Social and Cultural Rights	UHC	Universal health coverage
JEE	Joint External Evaluation	UNICEF	United Nations International Children's Fund
Health GAP	Global Access Project	USAID	United States Agency for
IHR	International Health Regulations		International Development
IHR-MEF	International Health Regulations	WASH	Water, sanitation and hygiene
	Monitoring and Evaluation Framework	WHO	World Health Organization
LGBTQ	Lesbian, Gay, Bisexual, Transgender, and Queer (sometimes also "Questioning")	WHO AFRO	World Health Organization African Region

INTRODUCTION



This Toolkit was developed against the backdrop of a changing operating environment for global health that was not anticipated at the May 2024 inception meeting of the Global Fund **Communities in Pandemic Preparedness** and Response (COPPER) initiative. It is one in a series of technical assistance products meant for communities, civil society, and community-led monitoring (CLM) implementers exploring the synergies of their health work with pandemic preparedness, prevention, and response (PPPR). Even before the shift in global funding for health, communities and civil society working in global health were faced with an evolving landscape. In the aftermath of the COVID-19 pandemic, stakeholders in the global health architecture have been discussing new governance instruments, such as a Pandemic Agreement, amended the International Health Regulations (IHR), and set up a new multilateral funding mechanism, the Pandemic Fund. At the same time, communities, civil society, and CLM implementers have gained new expertise in conducting CLM throughout the COVID-19 pandemic, Ebola and mpox outbreaks. With their expertise comes valuable data that can and should influence PPPR decisions on health.

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

This toolkit aims to provide HIV, TB and malaria (HTM) actors with information that will allow them to find suitable entry points for their monitoring and advocacy.

CLM has been an important mechanism for deeper understanding of how health systems work, and for accountability, on a local, subnational, and national level. In the world of HIV, TB, and malaria (HTM), communities and civil society have utilized CLM to assess the health system in terms of the Availability, Acceptability, Accessibility, and Quality (AAAQ) framework.

This work has been critical in identifying the myriad impacts of the COVID-19 pandemic on key populations, that is, those most affected by HTM. Yet, engaging PPPR actors in strategic CLM data-based advocacy requires knowledge of the ecosystem and processes that govern PPPR policymaking. This toolkit aims to provide HTM actors with information that will allow them to find suitable entry points for their monitoring and advocacy. It will map relevant government, organizational, and coalition actors at the national, regional, and global levels and explain what parts of major PPPR instruments, such as the IHR and its Monitoring Evaluation and Learning Framework (IHR-MEL), are relevant for those working on CLM. Based on community feedback, this Toolkit will also explore some areas that CLM-PPPR can map (and in some cases, has mapped).

^[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.

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But why is it important for communities and civil society organizations (CSOs) working on HTM to consider PPPR as part of their work? To answer this, let's look at one definition of PPPR,² which reads as follows:

"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. However, some technical knowledge and the processes through which PPPR works will likely be new to you. Yet, 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 life with dignity and realize their human rights, including the right to health (ICESCR Art. 12)3 and right to science (ICESCR Art. 15).4 CLM has proven to be a great tool for better understanding how health systems perform (or don't perform) on the local, national, or/and regional levels.

Community-based surveillance (CBS), according to a WHO consensus, is "the systematic detection and reporting of events of public health significance within a community by community members." 5 CBS is often a part of the

TABLE 1: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."	Usually, part of the national public health system

^[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/.

^[3] United Nations. International Covenant on Economic, Social and Cultural Rights. 16 December 1996. https://www.ohchr.org/en/instruments-mechanisms/instruments/ international-covenant-economic-social-and-cultural-rights.

^[4] Ibid.

^[5] 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/.

^[6] 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/.

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national public health system routine to keep informed about the incidence and spread of infectious diseases, but it can also record other health-related incidents. In PPPR, CBS can be used as part of the One Health framework⁷ to count incidents of animal and human health. Community under CBS can be understood, for example, as the people in a specific geographic region, people who are part of a profession (for example, farmers), or an ethnic group within a country. It refers to data collection on the community level or collection of data from a specific community.

In CLM, the meaning of community refers to who is collecting the data and who is leading the overall work, that is, members of a specific community design the project, lead the project, and use the collected data for improving access and quality of health services that their community needs. CLM may also look at specific disease incidents, but unlike in CBS, this is part of understanding the operating environment in order for communities to advocate for a policy change or the implementation of existing policies. In some cases, CLM works closely with and informs local health system stakeholders. However, CLM is

not a routine part of the health system itself – yet.8 However, evidence shows that when CLM is integrated into the health infrastructure, it has a positive impact on the health system.9

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 as one of the interviewees for the development of this Toolkit said, "You can't make good decisions without having good data." 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.

This Toolkit will 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 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

^[7] See definition of One Health here: who.int/health-topics/one-health.

^[8] Find more on CBS in the Further Reading section of the Annex.

^[9] See e.g., UNAIDS. Community-led monitoring in action. 2023. https://www.unaids.org/sites/default/files/media_asset/JC3085E_community-led-monitoring-in-action_en.pdf.

A shorter version of this Toolkit, the Community Guide, is available here [LINK]. These resources can be used jointly or separately, depending on what your circumstances require. You can use the Toolkit and Community Guide in several ways:

- → As reference handbooks: This Toolkit provides basic knowledge that will get you started on mapping how to use CLM for your advocacy as it relates to PPPR. The Further Reading section, as well as the footnotes throughout, provide you with additional sources to deepen your knowledge and understand World Health Organization (WHO) requirements that countries are obligated to fulfill, as well as official guidelines and processes.
- → As personal learning resources: At your own pace, explore the connection points for CLM and PPPR. Connect your expertise to the information in this Toolkit and use the Reflection Questions throughout the text as thought exercises. The IHR sections will introduce you to the official wording and obligations that are commonly referred to in official global and domestic PPPR documents.
- → As teaching material: Depending on the needs of your community or organization, develop a workshop or study group to tackle the content of this Toolkit. Several of the figures and tables can be the starting point for better understanding your specific environment and jointly increase your community's expertise in PPPR and CLM against the backdrop of global public health practices and concepts.

- → As advocacy and project development resources: The structure of this Toolkit follows the steps of developing a project on CLM for the PPPR space, which requires you to:
 - O Know the operating environment of PPPR, including legal requirements, official documents and processes, and the different stakeholders.
 - O Understand how CLM and PPPR intersect and what examples and/or findings already exist that you can use to explain the significance of your project.
 - O Define which of the overlapping parts of PPPR and HTM are most important for your community and how you can use the AAAQ framework to advocate for a better health system through CLM data that advances the HTM response and PPPR at the same time.
 - O Map the specific stakeholders that are important collaborators and advocacy targets for your advocacy goal and decide how and when you will approach them.
 - O Choose which national processes, if any, you can contribute to with your CLM data and learn what documents will show you the national priorities that your government has defined as part of its International Health Regulations Monitoring and Evaluation Framework (IHR-MEF) work.

All these steps are part of developing your successful CLM mechanism. While none of them teach you how to conduct CLM (see Further Reading on page 56 for that), these steps are important because CLM always connects to an advocacy goal. Situating your project within the broader PPPR and HTM systems and knowing who to approach, when to use your data, and how to use it will set you up for a stronger journey in connecting PPPR and HTM work.

What Went Wrong in the COVID-19 Pandemic? What Can We Do Better in the Next Pandemic?

The COVID-19 pandemic saw numerous inequities due to inadequacies in prevention, preparedness, and response; the failure to adequately account for human rights; insufficient participatory expertise; nationalism that prevented equal access to pandemic products, such as personal protective

equipment (PPE), tests, treatments, and vaccines; interruptions to routine health services; and insufficient social protections. In adequately designing a CLM-PPPR intervention that captures community priorities, it is a valuable step to consider these experiences, as well as those from Ebola or mpox.

TABLE 2: 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 strategies¹⁰
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) ¹¹	 → 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 ¹²	 Participatory PPPR policymaking Gender-disaggregated data, for example, on how many men, women, and gender-diverse people are accessing pandemic products, such as vaccines 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

^[10] Recommended in https://journals.plos.org/plosmedicine/article/figure?id=10.1371/journal.pmed.1003666.t001.

^[11] 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/.

^[12] 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.

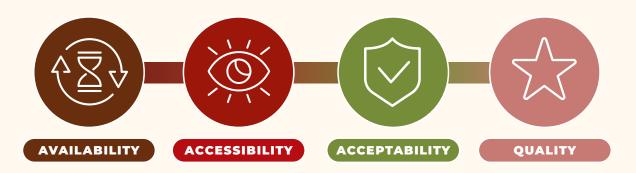
WHAT WENT WRONG IN THE COVID-19 PANDEMIC?

WHAT WENT WRONG IN THE COVID-19 PANDEMIC?	PREVENTION AND PREPAREDNESS INTERVENTIONS
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 ¹³	 → 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 ¹⁴	→ 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

 $^{[13] \}quad \text{International Treatment Preparedness Coalition. How to Implement Community-Led Monitoring: A Community Toolkit. December 2021.} \\ \underline{\text{https://itpcglobal.org/wp-content/opensional Treatment Preparedness Coalition.}}$ $uploads/2021/12/1205_ITPC_CLM_Design_FullReport06_compressed.pdf.$

^[14] 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.

FIGURE 1: PPPR and Human Rights



Human rights are integral to every person's life. They apply to everyone, everywhere, always, except if temporarily restricted following a legal process during a state of emergency, which a pandemic could constitute. One example of this is when the freedom of movement is suspended during lockdowns. As you know, human rights have been integral to the HIV response for a long time and a human rights-based response is now also more common in TB programs. But what about other pandemics? Human rights still apply, but with each pandemic, activists have had to remind governments of their human rights obligations, which stem from international law. Human rights

are interdependent and indivisible, which means that if you positively affect one right, your actions will also have benefits for other human rights. You cannot separate one human right from the other and address them in isolation. Human rights that can be majorly affected in pandemics include: the right to life; the right to health with its framework of Availability, Accessibility, Acceptability, and Quality (AAAQ), as well as the underlying determinants of health; the right to science (that is, the government's obligation to develop, diffuse, and conserve the tangible and intangible results aka products of science); and the right to nondiscrimination.

What Does PPPR Entail?

The following table shows some of the components of PPPR and some examples of how these are implemented.

This will give you additional parameters for understanding the aspects of PPPR that might be interesting for CLM and provide a starting point for mapping the stakeholders involved in that component of PPPR.

TABLE 3: Components of PPPR

COMPONENT	TOPIC	DEFINITION	IMPLEMENTATION
	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
	One Health interventions	Strategies that recognize the interconnectedness of human, animal, and environmental health in preventing zoonotic spillover , that is, when diseases jump from animals to humans	Includes zoning policies that separate human settlements from high-risk animal habitats, vaccinating livestock to prevent disease reservoirs, and monitoring for unusual morbidity/mortality events in wildlife and livestock
PREVENTION	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
X X X X X X X X X X	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
PREPAREDNESS	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

COMPONENT	TOPIC	DEFINITION	IMPLEMENTATION
<u> </u>	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
PREPAREDNESS	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
	Early detection	Rapid and accurate identification of new disease cases or unusual symptoms that may indicate a pandemic event	Establishing responsive surveillance systems, enhancing laboratory capacity for diagnostic testing, and facilitating direct case reporting to health authorities
~~ <u>~</u>	Case isolation	Separating affected individuals with the disease or those thought to have the disease to prevent transmission to others	Setting up isolation facilities, arranging safe medical transportation, and providing necessary medical care according to established health protocols
RESPONSE	Appropriate medical care	Providing effective care to individuals with the disease to improve recovery chances and reduce disease severity	Coordinating care teams, providing intensive care facilities, and ensuring access to medications and therapies recommended by health authorities
	Clear risk communication	Conveying timely, accurate, and trustworthy information to the public about health risks, preventive measures, and the latest developments related to the pandemic	Utilizing diverse communication platforms, such as mass media, social media, and direct outreach sessions to ensure optimal public understanding and engagement
	Interagency coordination	Cross-sector and interagency collaboration to effectively coordinate pandemic responses, including logistics management, information dissemination, and strategic decision-making	Facilitating regular meetings, forming emergency response teams, and implementing clear command and control structures to minimize barriers in handling crisis situations

Who is Involved in PPPR?

Advocacy Targets and Entry Points at the Local, National, Regional, and Global Levels

One important aspect of CLM is to involve decision-makers from the beginning. However, some of the decisionmakers may not yet be part of your advocacy network. This chapter will present you with the overall structure of who is involved in PPPR, especially, but not only, on the health side. In this chapter, you will see the main actors on the global, regional, national, and subnational/local levels.

Keep in mind that at the national or subnational level, specific agencies may have different names, but someone will serve that kind of function. On the local level, it is quite possible that the focal point for PPPR-related work also has other responsibilities — and you may already know them. A stakeholder analysis or a power analysis conducted in your context will be helpful in mapping stakeholders relevant to your context.

FIGURE 2: Power Analysis

Power analysis is a type of stakeholder mapping used to identify who has the power to create change and what information, data, or tactics it will take to get them to use their power in support of your advocacy goal. One approach to power analysis looks at where the power lies within a specific community. Other power analysis approaches differentiate between the types of power that you can map out to decide where to focus your advocacy:



POWER OVER An institution or person that has the power to directly influence the

behavior of others



POWER TO

The realization that everyone holds power to do certain things and power can be built through learning skills and action



POWER WITH

The power that comes from collective based on shared priorities



POWER WITHIN

The sense of confidence that you build, for example, through realizing that you have the ability to do something

Power analysis can not only help you identify who your primary advocacy target should be, but also if and how you can gain additional advocacy targets that will advocate on your **behalf.** Read more about power analysis here:

- Analysis. https://belonging.berkeley.edu/ power-analysis.
- → National Education Association. Power Mapping 101. https://www.nea. org/professional-excellence/studentengagement/tools-tips/powermapping-101.
- → Othering and Belonging Institute. Power → The Commons Social Change Library. A Guide to Power Analysis in Community Organising. https://commonslibrary.org/aguide-to-power-analysis-in-communityorganising/.

As you read through this chapter, consider the following:

- 1. What are the national committees working on epidemics and diseases in your country? Use this information to identify them.
- 2. What are their respective roles in PPPR and/or HTM?
- 3. Who could you involve in the CLM planning and implementation process? In some cases, this might include primary and secondary advocacy targets.
- 4. Who do you already know? How will you build engagement with those advocacy targets you do not yet know?

The following diagram provides an overview of who is involved in PPPR at local, national, regional, and global levels. We also provide a more detailed description of major PPPR actors and their roles in the following pages.

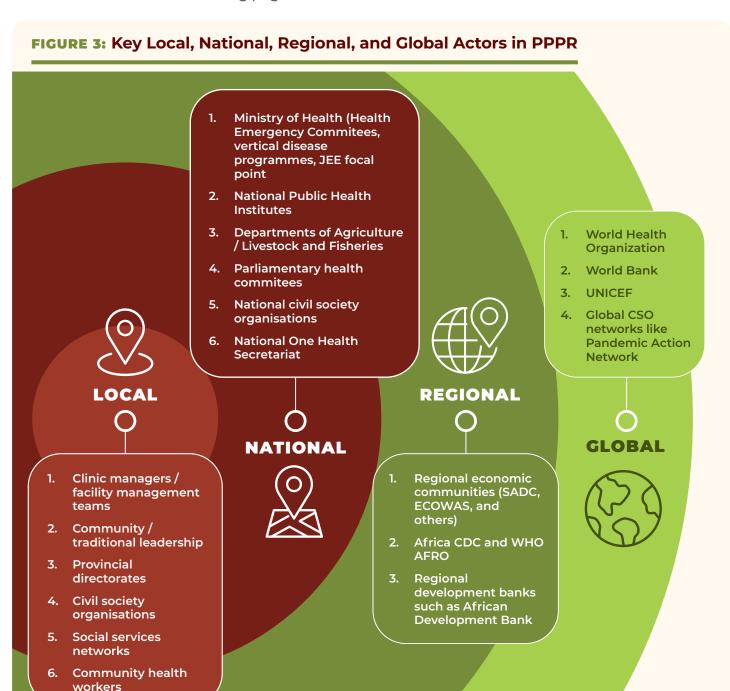


TABLE 4: Key Local, National, Regional, and Global Actors in PPPR

LEVEL	ACTOR/ADVOCACY TARGET/ENTRY POINT	ROLE IN PPPR AND RELEVANCE FOR CLM
	Clinic managers/facility management teams	Understand how clinics feed into reporting systems, need to implement hygiene and safety protocols, as well as emerging PPPR protocols during pandemics.
	Community leadership	Depending on your country's administrative system, there can be several political, administrative, and community organization positions of leadership. They can be part of the official political system and reporting to the next higher level. Their division of responsibility can mirror the provincial or national level. In some cases, one person can hold more than one reporting responsibility. These positions are part of the official PPPR hierarchy and are tasked with implementation and monitoring of policies. Local life also has social leadership positions, such as other community-based organizations (CBOs) and civil society organizations or structures. These people can hold considerable social and political influence, as well as expertise. Consider how collaborating can enhance your project effectiveness, reach, and impact.
LOCAL	Traditional/religious leadership	Traditional leaders play a vital role in pandemic response efforts due to their authority, influence, and deep connection with local communities. Their relevance is particularly pronounced in rural and underserved areas where formal government structures may have limited reach. Traditional leaders are trusted figures within their communities, making them effective at disseminating information about health crises and enforcing control measures. Many traditional leaders actively enforced government policies at the community level. In Malawi, leaders mandated mask-wearing, restricted large gatherings, and established hand-washing stations. You can share your CLM findings with traditional leaders, and because they often act as intermediaries between governments and local populations, this allows these leaders to advocate for necessary changes based on your CLM data.
	Provincial directorates	Depending on your country's bureaucratic/administrative system, provincial, state, or other subregional entities are the connecting pieces between the local and the national healthcare system. They are also important entry points when you are trying to address similar issues across more than one or two clinics, for example.
	Civil society organizations	Coalition building is an important cornerstone of effective advocacy. New advocacy goals can require building out your network with CSOs from other regions or communities: those that have complementary skills or that can amplify your work. Depending on your country, academics or think tanks can also be effective civil society partners.

^[15] Management Sciences for Health. Malawi's Traditional Leaders Key to COVID-19 Response. Leadership, Management, and Governance, Pandemic Preparedness and Response (blog). 16 June 2022. https://msh.org/story/malawis-traditional-leaders-key-to-covid-19-response/.

LEVEL	ACTOR/ADVOCACY TARGET/ENTRY POINT	ROLE IN PPPR AND RELEVANCE FOR CLM
LOCAL	Social services networks	Understanding the formal and informal networks that provide social services in your community and country prepares you for responding quickly to your community's needs in the next pandemic. Social services networks provide food and psychosocial support and may even provide financial assistance to communities that your CLM data has identified as being in need. You can use your COVID-19 experience to identify necessary services, such as access to food aid, and see what official and informal channels exist to get access for your community, and also to consider building a coalition.
LOCAL	Community health workers/healthcare workers	As in one of the case examples below, healthcare workers and community health workers are important stakeholders for CLM and also for PPPR. During COVID-19, stronger recognition, especially of unpaid community health workers, emerged, which can be an important entry point to support PPPR-related advocacy and also to gain recognition for the contributions of key populations and community peer support during pandemic and non-pandemic times.
	Ministry of Health → IHR focal point → Disease programmes (such as the national TB programme) → Emergency response directorates/ departments	These entities have official designations and responsibilities within the IHR Monitoring and Evaluation Framework that are activated during an emerging pandemic and, in some cases, in non-pandemic times. They are in charge of developing policies and programs and often also of implementing WHO recommendations in your country context.
NATIONAL	National One Health secretariats/ One Health coordination platforms	One Health coordination platforms are often multi-agency bodies that work across the human-animal-environment interfaces to prevent zoonotic spillover (that is, the transfer of pathogens from animals and the environment into humans). If you are logging within your communities that there are unexplained animal deaths, this platform will need to know, and you can report this data to these platforms.
	Departments of Agriculture/Livestock	During emergencies, these departments are important for maintaining food supply and handling subsidies for people and the sector, and are part of recovery processes. They are usually also part of the One Health and community-based surveillance structures for reporting disease outbreaks that may have pandemic potential. For example, they could be part of national One Health platforms that monitor and report unexplained animal deaths and potential zoonotic spillover. It can be useful for your planning and advocacy to understand their role and focus during COVID-19 to assess how you may be able to collaborate with them in your CLM and/or a future pandemic outbreak.

LEVEL	ACTOR/ADVOCACY TARGET/ENTRY POINT	ROLE IN PPPR AND RELEVANCE FOR CLM
\bigcirc	Civil defence and disaster authorities	COVID-19 has shown us that decision-makers are more likely to consult emergency response players and security forces (such as police) than communities. If these authorities understand your added value and you can build a relationship with them, you might be able to influence that dynamic on a local level and advocate that your community's priorities are included in emergency responses, especially when there are no public participation channels.
NATIONAL	National public health institutes/national centers for disease control	National centers for disease control (or similarly named public health agencies) are the main units for protecting public health, including through scientific research, surveillance mechanisms, policy responses, preparation and planning for emergencies, and communicating disease prevention and control measures to the public during a public health emergency. They are also tasked with ensuring that recommendations and policies that keep the public as healthy as possible are in place. These institutions are the main national bodies for protecting public health and, therefore, at the forefront of managing PPPR in your country. They have a variety of departments that are in charge of different programs. These departments are where you should be able to locate information, guidelines, and emergency plans, which makes them a central target or partner for your CLM advocacy.
REGIONAL	Africa CDC → Community health delegate → Division of Emergency Preparedness and Response (EPR)	The Africa Centres for Disease Control and Prevention is a regional body that, among other areas, focuses on overarching policy development, such as health workforce and other health system strengthening approaches. It works across countries to highlight positive experiences and support countries in working towards stronger PPPR. If you are working on a national level and require additional expertise or peer pressure for your advocacy to be recognized, working with a regional entity can be useful.
	World Health Organization	WHO is the norm-forming body for PPPR, including the IHR, the IHR-MEF, and the Pandemic Fund. The structures and health system responses that your country is supposed to implement derive from the WHO framework that your country has (most likely) signed in agreement.
GLOBAL	World Bank → Pandemic Fund	The Pandemic Fund currently does not fund communities directly, but it does fund programs that could be run by or, at minimum, include community and CSO participation. Already, efforts are underway to advocate with the Pandemic Fund to adjust its funding to the new global health financing context. One important requirement of the Pandemic Fund is the "additionality" of its funding. As what gets funded has significantly changed with the exit of US funding, the Pandemic Fund should step up to include funding for CLM. Inclusion of CLM in the funding request supports social accountability across the three pillars (laboratories, workforce, and surveillance). CLM can, for instance, help better understand human resources or rapid response gaps of PPPR systems and policies.

WHO IS INVOLVED IN PPPR?

LEVEL	ACTOR/ADVOCACY TARGET/ENTRY POINT	ROLE IN PPPR AND RELEVANCE FOR CLM
	UNICEF	In many countries, UNICEF is a big supporter of vaccination and deployment of other health countermeasures.
GLOBAL	Pandemic Action Network	This is a global network of CSOs and other civil society actors to share information, update each other on campaigns and findings, collaborate on advocacy related to PPPR, and amplify the role of civil society in PPPR.

Where your data is most useful for advocacy depends on the change you want to create and who has the power to make that change. Based on your power analysis, that may be one of the institutions listed above. In many cases, you may not be able to influence your advocacy target directly, and you may need to channel your advocacy through allies and/or someone who has the respective influence over your target. For example, if your mapping shows that other community groups or civil society organizations are already plugged into the advocacy platform that you want to use, strategize with them on how to get your data in front of the key decisionmakers. You may also consider working in coalition with them, especially when you are advocating

for community priorities that would also benefit their advocacy goals and communities. In the end, better PPPR is good for all communities, and building coalitions increases the strength and reach of your advocacy.

If you do not have the contacts, networks, and/ or relevant connections, you will need to discuss with others who they think would be relevant. The following is a case study from Burkina Faso based on the experiences of Réseau Accès aux Médicaments Essentiels (RAME).

FIGURE 4: PPPR Stakeholders for CLM Data Advocacy: Burkina Faso Case Study

According to Hamidou Ouédraogo of RAME, the national IHR focal point is the Population Health Protection Department of the Ministry of Health and Hygiene. Burkina Faso has also received support for PPPR from various partners, including in the development of its 2025-2029 National Action Plan for Health Security, through a workshop held on 3-7 September 2025. This plan is not presently publicly available, but stakeholders consulted in this process would be relevant for CLM data advocacy.

Additionally, the NGO Davycas International, headquartered in Burkina Faso's capital, Ouagadougou, organized a training session

for data managers from the Departments of Prevention through Vaccination and Population Health Protection for deployment of Version 2.0 of STELab (an application for monitoring the traceability of epidemiological data and laboratory samples). The application is deployed in all health districts and regions and in national and reference laboratories and hospitals. If CLM data from Burkina Faso showed, for example. that laboratory services were not sufficiently accessible to communities, CLM data could be shared with Davycas International, data managers, health district facilities, and national and reference laboratories.







DAVYCAS INTERNATIONAL



NATIONAL & REFERENCE **LABORATORIES**



HEALTH DISTRICT FACILITIES



MOH DATA MANAGERS

Hence, relevant stakeholders would include:

- → Ministry of Health, Population Health **Protection Department**
- → Davycas International

- → National and reference laboratories
- → Health district facilities
- → Data Managers in the MOH

WHO IS INVOLVED IN PPPR?

Besides the direct entry points for advocacy using your CLM-PPPR data, you can also use your CLM-PPPR data for advocacy with global health stakeholders that you already know. Here is a list of some that you might want to consider:

- 1. Your Global Fund CCM members: Country Coordinating Mechanisms (CCMs) are an important governance mechanism of Global Fund grants, and its members need to have up-to-date data to make smart decisions. For example, consider how you are connecting with CCMs on oversight visits. Are you engaging them on your PPPR work? And are you sharing your PPPR data so that you can advocate for community priorities and they can make informed decisions? This is important throughout the grant cycle as there are times when funding is reprogrammed.
- 2. National AIDS Council: National AIDS Councils coordinate the AIDS response in many countries. Because community participation has been an important part of the HIV and AIDS response, there should be existing community participation pathways that you can utilize or may have already utilized for your advocacy.
- 3. HIV Sustainability Roadmap: For those working on HIV (and TB to some extent), understanding if your country is part of the 30 countries that take part in the UNAIDS HIV Sustainability Roadmap could be key. These countries are already engaged in HIV-specific health system reforms and working on integrating HIV services into primary healthcare services, for example. Your CLM-PPPR data may provide them with a critical understanding of how current PPPR policies are or are not working for key HTM communities, and you may have the data-backed suggestions on strengthening the health system that they need.
- 4. UHC: Organizations and stakeholders focused on universal health coverage (UHC) are also looking at how the health system is working and which health services are available for which communities. Ensuring that HTM communities can access essential health services during a pandemic is relevant for HTM, PPPR, and UHC. CLM data can provide recommendations for all of these.16

^[16] For references on PPPR and UHC, see, for example, WHO, "Universal health converage (UHC)" https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-(uhc). 26 March 2025.

FIGURE 5: Case Study - How KHANA in Cambodia Identified Stakeholders for CLM in PPPR



Photo Courtesy of KHANA

In Cambodia, KHANA has been implementing CLM for TB since 2018, using the OneImpact platform by the Stop TB Partnership. As a partner of the COPPER project, KHANA has worked on PPPR and community engagement, with plans to integrate CLM-PPPRintoits existing CLM platform. To facilitate learning and coalition building around PPPR, KHANA has been convening a new national COPPER PPPR platform, modeled after previous CLM platforms. This platform includes multiple stakeholders, including government agencies. The multistakeholder nature of the platform was purposely selected to ensure that all government stakeholders, as well as civil society partners, are equally informed about COPPER and PPPR-related initiatives. KHANA started the platform with existing government contacts in health,

including the national disease control body under the Ministry of Health, and has since been exploring how to include additional government agencies that are focused on PPPR and not yet part of their network, such as the National Disaster Authority. KHANA has also been building its COPPER platform through its participation in PPPR-related processes, specifically the Cambodia JEE in 2024. In Cambodia, information related to national security, including national health security, remains tightly controlled by the government and is not easily accessible by external organizations, making the establishment of a multistakeholder PPPR communication platform led by civil society an important mechanism for the mutual sharing of information.

What are the International **Health Regulations and Why Are They Relevant for Communities?**

The International Health Regulations international (IHR) an instrument aimed at preventing, protecting against, controlling, and providing a public health response to the international spread of diseases in ways that are proportionate to public **health risks.** A total of 196 countries are parties to the IHR. This includes all 194 WHO Member States, as well as Liechtenstein and the Holv See. Centrally governed via the WHO system, the IHR and the accompanying IHR Monitoring & Evaluation Framework (IHR-MEF) govern the obligations that your country's government is supposed to fulfil for PPPR. The IHR-MEF includes the Joint External Evaluation (JEE) and the States Parties Self-Assessment Annual Reporting (SPAR).

While you may have some understanding of what constitutes preventing, preparing, and responding to a pandemic - after all, HIV, tuberculosis and malaria are each pandemics -

much of the terminology used by PPPR systems and stakeholders might be different. Much like you learned new language skills when you began your work in HTM advocacy, implementing CLM for PPPR and successfully using it within PPPR systems will require some learning of technical terms so that you and your advocacy targets have a joint language and you can integrate your lived experience and expertise into the existing system.

The following table summarizes some key areas of the IHR and the JEE, what these mean for communities, and what advocacy messages communities can use based on CLM data. How should this table be read? Column 1 summarizes what the text is about. Column 2 includes the exact text extract of the IHR. Columns 3 and 4 are most important for communities: Column 3 breaks down the legal text into what this means for you; and Column 4 provides advocacy messages that you can use and which are linked to international legal obligations in the IHR.

TABLE 5: Summary of IHR Obligations and What These Mean for Communities

SUBJECT AREA OF IHR OBLIGATION	IHR VERBATIM TEXT	WHAT THIS MEANS FOR COMMUNITIES	ADVOCACY MESSAGE
Obligations of states to develop and maintain core PPPR capacities	Annex 1, 2. Each State Party shall assess, within two years following the entry into force of these Regulations for that State Party, the ability of existing national structures and resources to meet the minimum requirements described in this Annex. As a result of such assessment, States Parties shall develop and implement plans of action to ensure that these core capacities are present and functioning throughout their territories as set out in paragraph 1 of Article 5, and paragraph 1 of Article 13 and subparagraph (a) of Article 19.	The state must have a process and plan for maintaining and developing core capacities related to public health emergencies.	The state must use CLM to assess core capacities at the local and national levels. The state is contravening international obligations by not developing laboratory expertise, for example.

WHAT ARE THE INTERNATIONAL HEALTH REGULATIONS?

SUBJECT AREA OF IHR OBLIGATION	IHR VERBATIM TEXT	WHAT THIS MEANS FOR COMMUNITIES	ADVOCACY MESSAGE
Obligations of states to develop and maintain core PPPR capacities	Annex 1.A.1. At the local community level and/or primary public health response level (hereinafter the "Local level"), each State Party shall develop, strengthen and maintain the core capacities: a. to detect events involving disease or death above expected levels for the particular time and place in all areas within the territory of the State Party; and b. to report all available essential information immediately to the appropriate level of health-care response. At the community level, reporting shall be to local community health-care institutions or the appropriate health personnel. At the primary public health response level, reporting shall be to the intermediate or national response level, depending on organizational structures. For the purposes of this Annex, essential information includes the following: clinical descriptions, laboratory results, sources and type of risk, numbers of human cases and deaths, conditions affecting the spread of the disease and the health measures employed; c. to prepare for the implementation of, and implement immediately, preliminary control measures immediately; d. to prepare for the provision of, and facilitate access to health services necessary for responding to public health risks and events; and e. to engage relevant stakeholders, including communities, in preparing for and responding to public health risks and events.	The state is obligated to report all available essential information about the outbreak in communities to WHO. The state must engage communities in both preparedness and response to public health emergencies.	The government must report events of disease and death beyond expected levels in a timely manner and must deploy emergency responses in a timely manner. Communities must be engaged and consulted in preparing and responding to public health risks.

SUBJECT AREA OF IHR OBLIGATION	IHR VERBATIM TEXT	WHAT THIS MEANS FOR COMMUNITIES	ADVOCACY MESSAGE
Obligations of states to coordinate with the local level on laboratory diagnostics, implementation of control measures, access to health services and products, and addressing disinformation and misinformation	ANNEX 1.A.2. At the intermediate public health response levels (hereinafter the "Intermediate level"), where applicable, each State Party shall develop, strengthen and maintain the core capacities: a. to confirm the status of reported events and to support or implement additional control measures; and b. to assess reported events immediately and, if found urgent, to report all essential information to the national level. For the purposes of this Annex, the criteria for urgent events include serious public health impact and/or unusual or unexpected nature with high potential for spread.; and c. to coordinate with and support the Local level in preventing, preparing for and responding to public health risks and events, including in relation to: i. surveillance; ii. on-site investigations; iii. laboratory diagnostics, including referral of samples; iv. implementation of control measures; v. access to health services and health products needed for the response; vi. risk communication, including addressing misinformation and disinformation; vii. logistical assistance (e.g. equipment, medical and other relevant supplies and transport);	States must coordinate with stakeholders at the local level to ensure that tests are accessible and results are returned from laboratories in a timely manner. States must support stakeholders at the local level in relation to access to health services and products; they must ensure that local health services are not interrupted and that health products can be accessed. States must support the local level on risk communication, including addressing disinformation and misinformation at the local level.	Tests must be accessible to communities and results must be returned in a timely manner. Routine health services should not be interrupted, and the national government must support local health facilities. All pandemic products must be available to communities. Disinformation and misinformation must be in a language that communities at the local level understand and must occur via the medium most relevant to communities.
Financing for PPPR at the local level	Does the local/regional public entity (such as district or provincial leadership) have a budget allocation in place for activities related to responding to public health emergencies? [P] [Question P2.2, JEE]	Budgets at the local level mean that responses can occur more quickly instead of waiting for national-level budgets to trickle down. Local budgets that are deployed quickly and informed by local needs mean that communities can be protected quicker.	 Local authorities must have budgets set aside for emergencies. Local authority budgets must explain how it can be deployed quickly to serve PPPR efforts in communities.

WHAT ARE THE INTERNATIONAL HEALTH REGULATIONS?

SUBJECT AREA OF IHR OBLIGATION	IHR VERBATIM TEXT	WHAT THIS MEANS FOR COMMUNITIES	ADVOCACY MESSAGE
Participatory approaches in pandemic risk communications	Do the risk communications approaches utilise a "whole-of-government" approach including international and national partners, media and influencers, and are appointed spokespersons are trained in risk communication? [R] [Question R5.2, JEE]	Communication should happen in multiple ways so that everyone will get the necessary information, regardless of how they consume media. Messages from the state should be offered in the different languages spoken in the country and be easily understood. Communities should be one of the partners in sharing and tailoring the messages. If messages are lacking information or are not reaching parts of the community, that information should be shared with the state so that adjustments can be made.	 Messaging on pandemics and how communities protect themselves must reach communities through the most used or convenient medium. Development of risk communication materials must meaningfully involve all relevant partners.

What Can CLM Track in PPPR?

Community-led monitoring (CLM) takes place when the community itself decides which issues should be tracked, creates indicators, and collects facility- and community-level data. 17 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 guite 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
- → Limited community involvement in decisions that impact their lives
- → Lack of support and resources for underserved communities to address their health challenges

When you consider which aspects are of most urgency or priority for your community, you can apply the concept of intersectionality in your process. Kimberlé Crenshaw, who coined the term "intersectionality" as part of US legal studies, defined it as follows: "Intersectionality is a lens through which you can see where power comes and collides, where it locks and intersects. It is the acknowledgement that everyone has their own unique experiences of discrimination and privilege." 18 Intersectionality can be a combination of identities based on such factors as race, ethnicity, gender identity, class, language, religion, ability, sexuality, mental health, age, and education. This means that you must consider how your CLM-PPPR model, for example, views a woman from an ethnic minority who has not had access to formal education, or LGBTQ people who live in remote areas, or individuals who speak a minority language and who live with disabilities. This is what intersectionality is.

The following mind map provides some illustration of what can be tracked by CLM in PPPR, drawing upon key informant interviews, the IHR Joint External Evaluation Tool, the UN Women minimum requirements for gender equality in the COVID-19 socioeconomic response, the Gender Equality Working Group's COVID-19 gender and vaccine deployment checklist,19 and the Human Rights Watch COVID-19 checklist.20

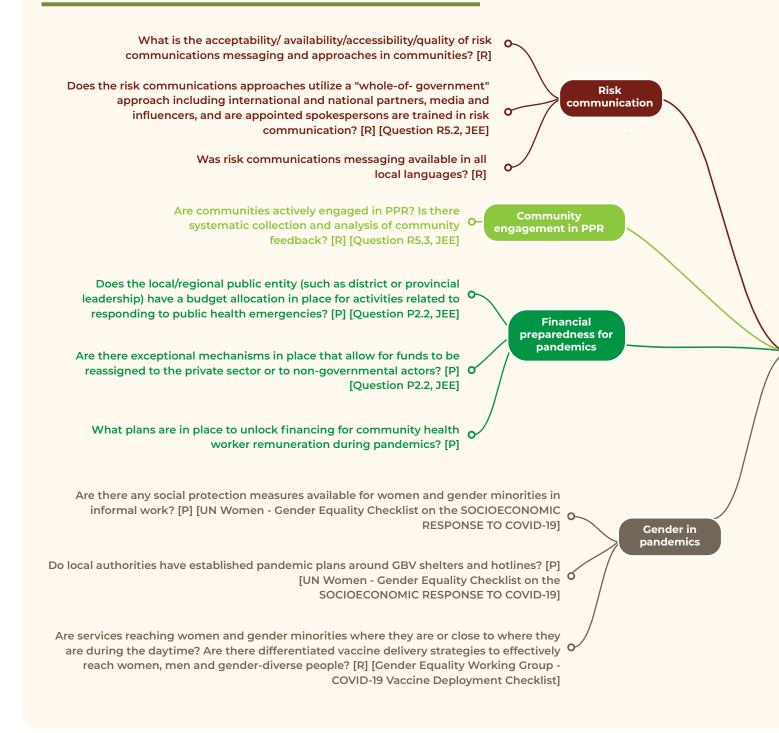
^[17] ITPC. White Paper. Community-led Monitoring. Best practices for strengthening the model. https://itpcglobal.org/wp-content/uploads/2022/12/CD4C-CLAW-EANNASO-ATAC-APCASO-Community-led-Monitoring-Best-practices-for-strengthning-the-model.pdf (accessed 9 April 2025).

Relay Resources. Intersectionality and Disability. https://relayresources.org/blog/intersectionality-and-disability.

 $[\]hbox{[19]} \quad \underline{\text{https://www.genderhealthhub.org/wp-content/uploads/2021/03/COVIDVAX-English_6August.pdf)}. \\$

^[20] https://www.hrw.org/news/2020/04/14/covid-19-human-rights-checklist

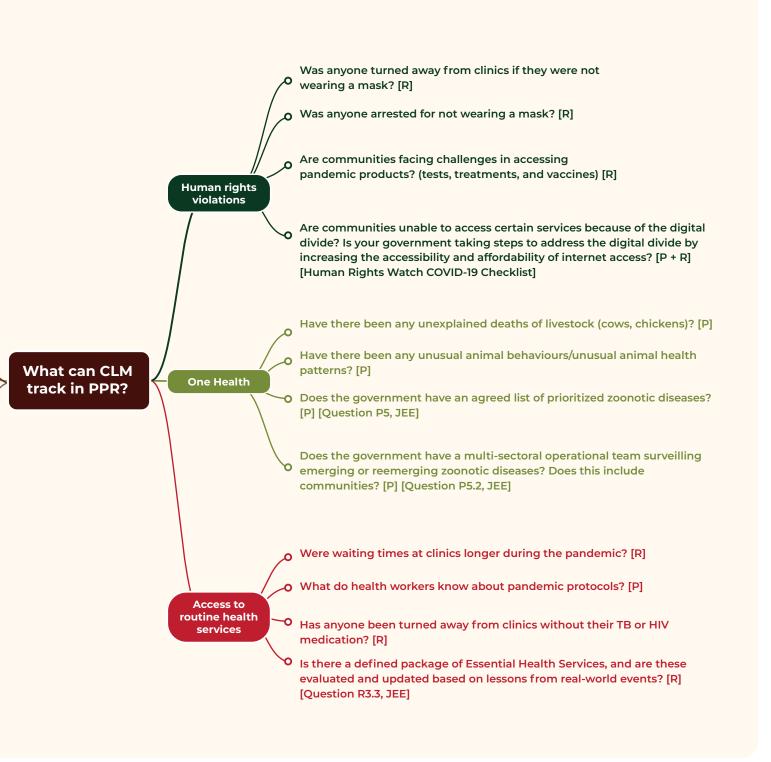
FIGURE 6: What Can CLM Track in PPPR? A Mind Map



Your decision on what aspects of PPPR you want to track with your CLM will depend on what resonates with you, what your community's existing priorities are, and the particular problem you want to address. If you can identify an area where there is synergy between what is relevant to PPPR and what is already important to your community, your advocacy strategy will expand in a way that mutually reinforces the benefits for your community. If you have the resources

to expand your work into something important but less related to existing priorities and ongoing work, it might still be fruitful if you decide that this is the best use of your resources. As you read this chapter, consider:

- 1. What resonates with you and your community?
- 2. Are you already working on immunization of the health workforce? Both are part of the JEE, though under different processes.



- 3. What does your lived experience from COVID-19, mpox, and Ebola tell you are challenges with AAAQ for your communities?
- 4. With which stakeholder and in which areas have you already established your "CLM soft power"? And how can you use your CLM now to establish the necessary soft power that you will need for the next pandemic?

CLM uses the AAAQ framework to understand and gather data. 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.

TABLE 6: 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." "I heard that pathogens are being cultivated in a district laboratory, and that the staff are not vaccinated against that pathogen. I'm not sure that they have received adequate biosecurity training."
	Respect for hygiene, infection control, and safety standards	Local clinics observing WASH standards

Modeled after: https://itpcglobal.org/wp-content/uploads/2023/02/0113_CLM_NewTool_full_B2.pdf page 18/table 4

WHAT CAN CLM TRACK IN PPPR?

During the COVID-19 pandemic, there were ongoing CLM initiatives in several countries. CLM in PPPR facilitates social accountability, information sharing, and awareness raising. Based on our experiences during this recent pandemic, other examples of CLM that took place during COVID-19 or that could have taken place include the following:

- 1. In Malawi, CLM documented the successful expansion of multi-month ART expansion during COVID-19 and resulted in advocacy to include strategies for continuing this trend in healthcare worker trainings. CLM data also showed that "the main factor delaying further scale-up of six-month dispensing is not whether stockouts occur, but rather, how quickly they are resolved."21
- 2. CLM in South Africa showed a three-fold increase in TB testing at the clinics involved in CLM (as compared to the pre-COVID baseline), which the implementers suggested may have been a result of clinical changes during COVID-19 because in 2020. "South Africa started experimenting with combined and bidirectional TB and COVID-19 screening."22
- 3. CLM documented the impact that PPE stockouts had on healthcare providers and the resulting disruption of services.²³

^[22] https://itpcglobal.org/wp-content/uploads/2023/01/2022-itpc-the-good-the-bad-and-the-unfinished-business.pdf.

^[23] Ibid.

CLM in Real Life Examples and Lessons from Malawi, South Africa, and USAID Defunding

Long-term CLM is an opportunity to build strong partnerships between the local health system, including clinics and healthcare workers, and CBOs and CSOs. These three examples highlight how collaboration can make systems stronger and more effective.

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 found that awareness of gender-based violence was crucial to improve HIV prevention, CHWs campaigned together to educate their community.
- 3. 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 in the number 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.²⁴

This experience shows the many ways in which CLM implementers can collaborate with CHWs and other stakeholders. This kind of collaboration strengthens 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 important in the next pandemic, as well as for prevention and preparedness.

CLM ON HIV FUNDING CUTS IN MALAWI

CLM can be an effective tool in a situation that requires a rapid response. The freezing of US foreign aid beginning in early 2025 presents us with an opportunity to show how CLM can be used in an emergency situation that is still evolving, that is, a situation with some parameters that are similar to an emerging pandemic. In Malawi, the Network of Journalists Living with HIV (JONEHA), in partnership with NACOSA (South Africa) and ITPC, repurposed its existing CLM structures to collect information in three districts to understand the early effects of US foreign aid cuts. The team conducted 11 focus groups across both countries, with 30 healthcare workers and 123 people living with HIV.

The resulting report exemplifies how CLM can inform stakeholders about the specifics of a newly developing crisis. Findings published in the report illustrate: how different stakeholders received different kinds of information from different sources; the many ways in which the unclear or incomplete official donor and government guidance impacted HIV prevention and treatment; and what this signifies about gaps and challenges for the health system. Analysis of the CLM data allowed the team to formulate seven recommendations to national-level health administrators and to advocate for community inclusion in policymaking.

This example holds lessons for CLM as a useful tool for rapid data gathering and sharing in PPPR:

- 1. Existing CLM data collection structures, experience, and partnerships are the basis for the ability to quickly develop joint tools and data collection methods, thereby gathering data without much delay.
- 2. A focus on individual-level and clinic-level data allows stakeholders to understand the local situation more rapidly than a national statistical effort, which takes longer to set up and evaluate. Quick access to data means quick access to analysis and the ability to rapidly develop and share advocacy messages with advocacy targets at different levels.
- 3. CLM builds trust relationships between clinics, healthcare workers, and affected communities so that access and approval for new work or to new sites may be given quickly and that respondents are likely to share their experience comprehensively.

The data and resulting recommendations from this rapid CLM exercise allowed communities and local knowledge to contribute to a broader understanding of an evolving emergency situation, which in turn enables participation in formulating a policy response that ultimately should strengthen the health system. In a pandemic situation, community expertise in CLM can contribute to a better health system response and also influence recovery, prevention, and preparedness for the next epidemic.²⁵

^[24] 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/.

^[25] International Treatment Preparedness Coalition. Sounding the Alarm. Effects of Funding Cuts in Malawi and South Africa. April 2025. https://itpcglobal.org/wp-content/ uploads/2025/04/Sounding-the-Alarm-effects-of-funding-cuts-in-Malawi-SA-ITPC-April-2025.pdf

COVID-19 SHIFTS IN HIV CLM MODELS

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 recipient 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 Toolkit:

"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



PHOTO 1: Anele Yawa, General Secretary, Treatment Action Campaign, and lead of Ritshidze

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."

CLM DATA OWNERSHIP, INTEGRITY, AND GOVERNANCE FRAMEWORKS

CLM implementers need to consider who holds and owns the data. Data ownership decides how the data is secured, as well as who gets to use the data, who decides when the data is used, how the data is used, and how long the data is kept.

(USAID) also holds lessons for data security, data ownership, and data governance for any CLM or similar data collection efforts by communities. Any form of data collection that involves human beings must include a protocol for data security. This is not just for ethical reasons, but also for the privacy and security of the persons who trust you with their information. Especially in HTM, stigma and discrimination can have intensely negative consequences, for example, for individuals whose health status is revealed. In places where some behaviors are criminalized, data security is imperative to protect the people involved in the research and also to retain the trust and access necessary to continue to improve prevention, diagnostics, and treatment of infectious diseases.

The cessation of the United States Agency for International Development

CLM implementers need to consider who holds and owns the data. Data ownership decides how the data is secured, as well as who gets to use the data, who decides when the data is used, how the data is used, and how long the data is kept. In the first quarter of 2025, in conjunction with the funding and spending cuts at USAID, one CLM implementer in Asia and one in Sub-Saharan Africa that provided information for this Toolkit lost access to the data they had collected because they were not directly holding the data themselves. When funding for the organization that was holding the data was withdrawn due to the US foreign aid freeze, the online data collection tool and the data were no longer available for use by the CLM implementer. In a similar example, the US foreign aid cuts in 2025 impacted the use and availability of the online tool, OneImpact, developed and shared through the Stop TB Partnership. In Cambodia, CLM with OneImpact stopped.²⁶ Online tools have many advantages, such as immediate updates to the database, central holding of data to manage access to data, decentralized data collection; however, technological tools also require dedicated funding. Paper collection of data is onerous and data can easily get lost or misplaced, but it can be quite cost-effective.

^[26] Stop TB Partnership. Rapid assessment on the Impact of US Government Funding Freeze on TB Responses in selected High TB Burden Countries. https://www.stoptb.org/ sites/default/files/documents/Impact%20 of%20 funding%20 freeze%20 report.pdf.

CLM IN REAL LIFE

Best practices in CLM include assessing and planning for risks, including on data access and ownership. This can include formal agreements between whoever holds the data and those organizations that collect the data and those that want to use the data. These agreements should include privacy measures taken to protect the people who share their data and also decide on access to data and when and how data will be destroyed.²⁷ Your data and risk management plan should also prepare for scenarios in which you lose access to existing data or new data gets lost before it is included in your database, for example. Servers that host data must also be located in countries that are politically stable and have low risk for data compromise. Many best practices for CLM are documented in this ITPC Guide to Support CLM Data Use in Decision-Making.²⁸ They are fully applicable to CLM for PPPR. In fact, some figures in this Toolkit were adapted from there.

REFLECTION QUESTIONS

These examples illustrate how long-term CLM, as well as short-term or rapid assessment CLM, can play a role in PPPR. As you consider if and how to incorporate CLM for PPPR, these and other examples of CLM or community-led qualitative research can support your development process. Use the following questions to start considering how your existing networks, relationships, CLM experience, and HTM expertise can help you adapt CLM for PPPR:

- How could your existing network and research expertise have been leveraged to understand the challenges for your community during COVID-19? Which relationships could you have incorporated into your CLM methodology, for example, for data gathering or advocacy?
- 2. If you conducted CLM or similar research during the COVID-19 pandemic, how did your focus shift and how did you decide what to focus on?
- 3. Which parts of the CLM methodology and implementation were, or would be, easy to adjust, leverage, or copy to be utilized for a newly emerging pandemic or other health emergency so that you may advocate for your community?

^[27] See resources on handling data and data ownership in the Further Reading section of the Annex.

 $[\]hbox{[28]} \qquad \underline{ https://itpcglobal.org/wp-content/uploads/2023/02/0113_CLM_NewTool_full_B2.pdf.}$

Tools for CLM Advocacy

ADVOCACY LOG

You may already have tools to track CLM-driven advocacy. If you need to supplement these, here are two assets you can use. The first is an advocacy log, which serves as a consolidated record of all the advocacy you have done through time, constitutes a database for contact details for advocacy targets, is a tool that enables teams to plot next steps linked to CLM data in a structured way, and can be used as proof of activities for monitoring and evaluation reports to donors. The tool, however, must be frequently updated to be meaningful.

Here is an example of what an advocacy log should look like. It logs the change that you want to see, who your target is, links it to the CLM data that you have collected, and logs the outcome of your advocacy. The following example shows that you have logged that 550 people with disabilities are unable to travel to access PCR testing and details several approaches in advocacy that you can use.

Example of an Advocacy Log that Can Track What You Do with Your CLM Data

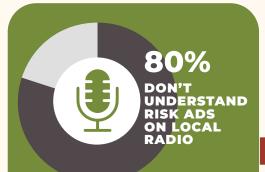
Change You Want to See	Relevant CLM Data Gathered	Date of Event / Meeting	Advocacy Target	Contact Details of Advocacy Target	Medium of Advocacy	URL / Link to Relevant Materials	Outcome of Event	Next Steps Required
Self-tests provided for free to people living with disabilities	550 people with disabilities 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 impli- cations	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 Linke- dln, 103,000 impressions, journalist en- quired about the social media post	Set up a TV appearance to discuss CLM data on access to self-tests

TOOLS FOR CLM ADVOCACY

Always remember to use the advocacy medium that suits your context the best — and that can help amplify your message in a clear way. Here are some examples on how you can fill in the column, "Next steps required", based on the CLM data you have generated.

FIGURE 7: Examples of Next Steps Based on CLM Findings

CLM FINDINGS



80% of people living in the vicinity of District A and B health facilities report not understanding the risk communication advertisements on local radio

NEXT STEPS REQUIRED

- 1. Conduct focus group discussions with communities on challenges in understanding risk communication materials and what can be changed.
- 2. Write up two-page brief in English and local language on findings.
- **3. Disseminate two-page brief** to Ministry of Health, facility managers in District A and B, traditional leadership, and local radio stations.
- Request a meeting with MOH risk communication team and IHR focal point.

In summary, here are the instructions on using the advocacy log:

- 1. Every few days, **fill in details** of relevant CLM data that you have, who you've had advocacy meetings with, their contact details, the outcome of the meeting, and the next steps required.
- 2. Also **review the "next steps" column** to see if you've missed any follow-up actions that you should be doing. Mark if the steps are no longer relevant.
- 3. Remember to **include the impact of any social media advocacy** that you've done.
- 4. At the end of the year, **you can generate useful statistics from the advocacy log**, for example, to calculate how many letters you've sent and how many social media posts there have been and you'll have qualitative excerpts on the impact of your work.

SOCIAL MEDIA

Secondly, use of social media to amplify your CLM data should be succinct and compelling. Below and at this link, we have provided an example of a social media graphic that you can use to amplify your CLM data. You should also include text for the social media post and tag your advocacy target with your ask. Here are examples of good and bad text that can accompany your graphic.

Example of Social Media Post to Amplify Your CLM Messages



Examples of Good vs. Bad Social Media Posts

GOOD 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:

- Shows where the data is coming from
- Tags the advocacy targets so they receive social media notifications

BAD TEXT

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:

- Is too long and will lose the reader
- Does not tag advocacy targets no one will receive notifications and journalists will not know who you are targeting your message to

GOOD TEXT

NEW REPORT A finds that 452 PLHIV did not receive ARVs in [Country X] because of lockdowns. Read more at this link: <a href="http://<URL">http://<URL @MOH @DrTedros

EXPLANATION:

- 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

BAD TEXT

We released a new report on CLM.

EXPANATION:

- 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

List of Relevant PPPR Resources and Document Summaries

TABLE 7: List of Relevant PPPR Resources

WHO PANDEMIC AGREEMENT

URL/MAIN LINK

https://inb.who.int/ and https://www.who.int/news-room/questions-and-answers/ item/pandemic-prevention--preparedness-and-response-accord

DESCRIPTION

The Pandemic Agreement is an international legal agreement agreed to by WHO Member States. It covers such topics as prevention of pandemics, biosafety and biosecurity, technology transfer, One Health interventions, pathogen access and benefit sharing (PABS), and research and development of pandemic products. (See also: COPPER Lessons #229 for a video discussion of the Pandemic Treaty and a brief on key issues in the Pandemic Treaty.30) Negotiations were launched through the WHO Intergovernmental Negotiating Body³¹ to bring about a global agreement on PPPR against the backdrop of COVID-19, and the agreement was adopted at the World Health Assembly in May 2025. While negotiations will have to continue on the specifics of the PABS system, the Pandemic Treaty will provide a new benchmark on how governments need to collaborate and independently act with regards to potential future pandemics. The Agreement establishes a Conference of the Parties that will sit every five years to discuss progress on treaty obligations. Advocacy for civil society participation was ongoing at the time of writing (2025).

FAQs on the next steps for the Pandemic Agreement and how to stay informed are available from WHO: https://www.who.int/news-room/questions-and-answers/item/ pandemic-prevention--preparedness-and-response-accord.

REFLECTION QUESTIONS

- → How was your country involved in the Pandemic Agreement negotiations?
- → What were its main positions?
- → Was it part of any negotiating groups?
- What does that tell you about your country's priorities with regards to PPPR?
- What are your country's plans to sign and ratify the Agreement?
- When and how will it be debated in your Parliament?
- Will you host discussions with local MPs on what they should say and champion?

^[29] https://www.youtube.com/watch?v=G8ykDuAcu8Q

 $^{[30] \}quad \text{https://copper.apcaso.org/download/article-2-key-issues-in-the-pandemic-accord-highlighted-in-second-lessons-webinar/}.$

^[31] https://inb.who.int/.

GLOBAL HEALTH SECURITY AGENDA (GHSA)

URL/MAIN LINK

www.globalhealthsecurityagenda.org

DESCRIPTION

The GHSA was launched in February 2014 and is now in its third cycle, called Agenda 2028 (1 January 2024-31 December 2028). It is a voluntary group, currently made up of over 70 countries, international organizations, nongovernment organizations, and private sector companies that aim for "a world safe and secure from global health threats posed by infectious diseases." The GHSA is not a pandemic response entity, but rather a framework to build on and an initiative focused on supporting countries to become better prepared to respond to health emergencies, including pandemics, through capacity building. As we know, the COVID-19 pandemic exposed underlying structural and operational challenges at different levels in many countries. The GHSA could be a unique multisectoral platform for addressing gaps and needs in global health security and strengthening the evolving global health security architecture. However, there is a need to improve further stakeholder engagement under GHSA and leverage GHSA as a communication mechanism and forum of experts to inform the global health security architecture.

The 2028 targets for GHSA include:

- Over 100 countries that have completed an evaluation of health security capacity will have undergone planning that includes identifying resources to support plan components to address post-pandemic gaps and will be in the process of implementing and monitoring activities to achieve impact.
- O Demonstrate improvements in at least five technical areas to a level of "Demonstrated Capacity" (per IHR-MEF tools).
- Develop sustainable financing mechanisms.

REFLECTION QUESTIONS

- → Is your country involved in the GHSA?
- → How is your country involved and what commitments has it made?
- → Is there any evidence that your country has followed through on its commitments?

INTERNATIONAL HEALTH REGULATIONS (IHR)

URL/MAIN LINK

https://www.who.int/health-topics/international-health-regulations#tab=tab_1 and https://www.who.int/publications/i/item/9789241580496

DESCRIPTION

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

DESCRIPTION

The IHR was established through the WHO World Health Assembly in 2005. New amendments, decided at the Assembly in 2024, go into effect on 19 September 2025. One important aspect of the IHR is that it determines a process by which and when something becomes a public health emergency of international concern (PHEIC), which is a technical designation that requires WHO and its member countries to respond in a specific way, including through the National IHR Focal Point that each country should designate. Find more on the importance of IHR in the dedicated chapter above [include chapter and page #].

WHO describes the implementation of the IHR in 10 steps:

- Know the IHR and its purpose, scope, principles, and concepts.
- Update national legislation in accordance with IHR.
- Recognize shared realities and the need for a collective defense.
- 4. Monitor and report on the IHR implementation progress.
- 5. Notify, report, consult, and inform WHO.
- 6. Understand WHO's role in international event detection, joint assessment, and response.
- 7. Participate in the PHEIC determination and WHO recommendation-making processes.
- 8. Strengthen national surveillance and response capacities.
- 9. Increase public health security at ports, airports, and ground crossings.
- 10. Use and disseminate IHR health documents at points of entry.

The IHR also gives WHO the opportunity to establish emergency committees when necessary. Several emergency committees are currently operating, including the Poliovirus IHR Emergency Committee, the COVID-19 IHR Emergency Committee, and the Mpox IHR Emergency Committee.

REFLECTION OUESTIONS

- → Who is your IHR National Focal Point?
- → Has it established links and coordination mechanisms with existing national health emergency committees and mechanisms, within and outside the health sector, and is the information on those committees and mechanisms available to you?
- → Is there evidence that your country is working towards implementing the new IHR amendments?

IHR MONITORING AND EVALUATION FRAMEWORK (IHR-MEF)

URL/MAIN LINK

https://www.who.int/emergencies/operations/international-health-regulationsmonitoring-evaluation-framework

DESCRIPTION

The IHR-MEF works just like other monitoring and evaluation frameworks in that it establishes 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. The different parts of the IHR-MEF are described below, and you will see that each of them includes indicators or benchmarks for the different PPPR categories. In English, a three-minute video explains the IHR Monitoring and Evaluation Framework.

LIST OF RELEVANT PPPR RESOURCES AND DOCUMENT SUMMARIES

REFLECTION OUESTIONS

- Is information on the IHR-MEF available in your preferred language and additional languages that your community may require?
- → Which parts of the IHR-MEF has your country completed?
- → Are the processes publicly announced, or how can you become aware of the next opportunity to feed into an IHR-MEF process?

NATIONAL ACTION PLAN FOR HEALTH SECURITY (NAPHS)

URL/MAIN LINK

https://www.who.int/emergencies/operations/international-health-regulationsmonitoring-evaluation-framework/national-action-plan-for-health-security

DESCRIPTION

The NAPHS is described as a country-owned, multi-year planning process that is meant to accelerate the implementation of IHR core capacities. It does so by applying an approach that focuses on One Health and working across whole-of-government and whole-of-society. Therefore, this is one entry point to understand what your country's processes are and what opportunities for participation may already exist. It defines national priorities for health security and must incorporate multiple sectors to be successful. It is also utilized to allocate appropriate resources for capacity development for health security and PPPR. The second edition of the NAPHS country implementation guide was published in January 2025 and is available here. 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 should develop a fiveyear strategic plan and a one- to two-year operational plan that focuses on improving in at least 19 prioritized areas from their Joint External Evaluation (JEE).

REFLECTION QUESTIONS

- → What information in the implementation guide for NAPHS could be of interest for your advocacy with your CLM-PPPR data?
- → What should the whole-of-society approach look like, and what entry points might support your advocacy?
- → How are these processes broken down into subnational and local levels?

JOINT EXTERNAL EVALUATION (JEE)

URL/MAIN LINK

https://www.who.int/emergencies/operations/international-health-regulationsmonitoring-evaluation-framework/joint-external-evaluations

DESCRIPTION

The JEE is 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: 1) a country self-evaluation using the WHO JEE tool and country implementation guide, which should be completed by the country with multisectoral engagement, that is, there should be avenues for community and CSO participation; 2) JEE subject matter experts review the self-evaluation data to understand the country's baseline health security capabilities; 3) The IHR review committee recommends a combination of self-evaluation, peer review, and external evaluations involving domestic and independent experts; 4) JEE subject matter experts conduct country visits for in-depth discussions of the self-reported data and participate in structured site visits and meetings organized by the host country, which should also provide opportunities for community and CSO participation; and 5) The JEE team drafts a report to identify status levels for each indicator and presents an

LIST OF RELEVANT PPPR RESOURCES AND DOCUMENT SUMMARIES

DESCRIPTION

analysis of the country's capabilities, gaps, opportunities, and challenges. The JEE is divided into 19 technical areas with a total of 56 indicators. These indicators can be quite interesting to look at in detail - it will give you some idea of existing synergies and overlaps between HTM and PPPR work, for example, around drug-resistant TB.

REFLECTION OUESTIONS

- → When did your country last conduct a JEE?
- → If it was before the COVID-19 pandemic, are there currently plans to conduct another one soon?
- → If so, what are your opportunities to participate and use your CLM data and knowledge?
- → As you review the JEE, which areas of interest to your community is your country doing quite well in and which has it made less progress in?
- → How can your CLM-PPPR data contribute to the understanding of JEE technical areas?
- → Which areas have synergies, that is, require more progress and are also areas of community or CSO expertise and where CLM data could fill knowledge gaps?

STATES PARTIES SELF-ASSESSMENT ANNUAL REPORT (SPAR)

URL/MAIN LINK

https://www.who.int/emergencies/operations/international-health-regulationsmonitoring-evaluation-framework/states-parties-self-assessment-annual-reporting

DESCRIPTION

The SPAR is an annual report based on a questionnaire for governments to use to assess their status across the 15 IHR capacities using 35 indicators. Each indicator measures progress for the capacities. Usually, the SPAR process is launched each year after the World Health Assembly. The National Focal Point submits their reporting online via the e-SPAR page (https://extranet.who.int/e-spar/). Indicators are scored on a scale of 1 to 5, calculated as a percentage along the scale. The capacity level is measured as an average overall percentage of the indicator scores related to this capacity. Each country's information should be published on the WHO e-SPAR website and the IHR SPAR website.

REFLECTION QUESTIONS

- → What is the status of your country's SPAR?
- → What has its progress been in technical areas that are of interest to your communities?
- → Do you have or would you want to gather complementary CLM data that can provide further evidence of what needs to be done for your communities?

SIMULATION EXERCISE (SIMEX)

URL/MAIN LINK

https://www.who.int/emergencies/operations/simulation-exercises

DESCRIPTION

A Simulation Exercise is what it sounds like, that is, it simulates an emergency to validate and enhance preparedness and response plans, procedures, and systems for all hazards and capabilities. The WHO website provides a detailed Toolbox and online training modules. These include discussion-based exercises and operations-based exercises, such as drills, functional exercises, and field/full-scale exercises.

REFLECTION OUESTIONS

- → What information about any of your country's SimEx is available for you to better understand your country's progress?
- → Were any recommendations made, and do they have relevance for your community or CSO priorities that could provide entry points for connecting your HTM work with CLM and PPPR?

EMERGENCY RESPONSE REVIEWS (ERRS)

URL/MAIN LINK

https://www.who.int/emergencies/operations/emergency-response-reviews

DESCRIPTION

There are three types of ERRs, and their names are based on when they take place. These are the Early Action Review (EAR), Intra-Action Review (IAR), and After Action Review (ARR). These qualitative reviews look at actions in response to a public health event or following a project or a public health intervention. They are meant to identify and document best practices and challenges with the response actions. These reviews should be undertaken at each phase of managing a public health event to identify what worked well, what worked less well, and why. They can demonstrate the functionality of national capacities in preparing for, detecting, and responding to a public health event or identify corrective actions and ways to adjust emergency management for a better response the next time. They may also be used to address any challenges that were uncovered during an AAR.

REFLECTION QUESTIONS

- → What information about any of your country's EER is available for you to better understand your country's progress?
- → Were any recommendations made, and do they have relevance for your community or CSO priorities that could provide entry points for connecting your HTM work with CLM and PPPR?

WHO BENCHMARKS FOR STRENGTHENING HEALTH EMERGENCY CAPACITIES EXPANDED TO INCLUDE PUBLIC HEALTH AND SOCIAL MEASURES (PHSM)

URL/MAIN LINK

https://www.who.int/news/item/02-02-2024-the-updated-who-benchmarks-forstrengthening-health-emergency-capacities-expanded-to-include-public-healthand-social-measures-(phsm)

DESCRIPTION

The Benchmarks offer another tool to implement the IHR, specifically by providing a list of benchmarks and ways in which these benchmarks can be reached. This is meant to strengthen PPPR, as well as the resilience of the health system, and offer suggestions on how a country can improve its scores in a JEE or SPAR, for example. A second updated edition of the Benchmarks was published in early 2024, based on COVID-19 learnings. This update contains a new technical area: public health and social measures (PHSM). According to the WHO definition, PHSM are actions "by individuals, communities, and governments to reduce the risk and scale of epidemicand pandemic-prone infectious diseases transmission. Examples of PHSM include hand washing, mask-wearing, physical distancing, school and business measures, modifications of mass gatherings and international travel and trade measures." These actions are important in addition to medical responses, as seen during COVID-19, for example. This is not only because they can happen quickly, but also because they are less expensive and can provide protection while medical countermeasures are in development or governments negotiate access. It is the goal that these PHSM are

LIST OF RELEVANT PPPR RESOURCES AND DOCUMENT SUMMARIES

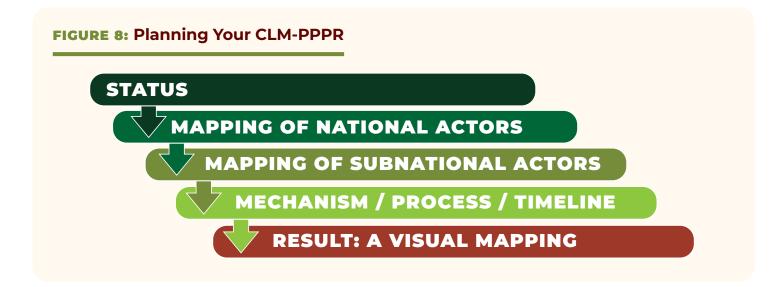
DESCRIPTION	integrated into PPPR plans and are accounted for in budgets. These Benchmarks can be interesting for identifying and fine-tuning CLM-PPPR indicators as well. WHO has additional complementary documents, for example, a dedicated document with a checklist for PPPR for a pandemic caused by a respiratory pathogen. This document could be very interesting for those working on TB, for example.					
REFLECTION QUESTIONS	 → Are there any areas of the Benchmarks that are of interest to your community and that complement your community or CSO priorities? → Can any of the Benchmarks help you further understand the technical areas of PPPR that you are interested in adding to your CLM? → What do the Benchmarks, together with your country's JEE or SPAR, tell you about areas where CLM-PPPR data would be highly beneficial? 					

Next Steps

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.

Below is an exercise that can help you with proceeding with the next steps and move from PPPR knowledge towards planning your PPPRfocused CLM.



MAPPING EXERCISE

NOTE: This exercise can be done with your own organization, as part of a coalition-building workshop, or with multiple stakeholders. Feel free to adapt the set-up to fit your specific needs and circumstances. You could even do this alone and find another way to validate your ideas and results with your community.

PURPOSE

This is a longer small-group exercise for participants to collectively develop a deeper understanding of the SPAR and JEE (you could substitute any other PPPR frameworks). That should involve some time for looking at the WHO websites, documents, and research of where the country is with regards to each of these frameworks. Participants work in small groups to begin mapping out their country's PPPR status and process. How deep participants go will depend on the time that the facilitator can allocate to this exercise.

SET-UP

If you are doing this as part of a workshop or any other group activity, the facilitator should divide participants into at least two groups, for example, one group for SPAR and one group for JEE. Even better would be more than one group per instrument, so that there is an opportunity for comparison.

TASKS

- 1. Small groups first check the status of their country's engagement to understand where their country is in terms of PPPR. If the country has, for example, not recently conducted a JEE, that is okay. This is also an opportunity to build expertise on what the country COULD and SHOULD be doing.
- 2. Each group should map out the different levels of actors that WERE involved and/or SHOULD be involved; note any gaps in participation; and map when and how community participation might be possible. This is not to determine where they must engage, but rather to present options to participants. .
- 3. If they find that there is very limited opportunity, participants can discuss if that is adequate or an area for potential change (consider that maybe participation does not happen in the formal process, but rather through passing information to allies in the MOH).
- 4. This exercise should result in visual maps and not just words, so remind participants to use their creativity and provide them with such items as posters, colored markers, and sticky notes to spark their creativity.

REVIEW

Small groups should present their findings to everyone. The resulting posters should be hung in the meeting room so that everyone can understand the situation in detail and leave comments via sticky notes.

END

The facilitator summarizes the findings and supports participants in deciding on next steps and a timeline for implementing those steps.

Once you understand the status of IHR-MEF implementation in your country based on one or more of the above-described instruments, you will have a clearer idea of the progress and needs of your country with regards to PPPR and also a deeper understanding of who the specific stakeholders in your country are. Taking that together with your community's expertise and priorities, deciding on an area to explore with CLM that has relevance for PPPR should be much easier. With that area of exploration decided, you can move on to defining your indicators, which is the subject of another COPPER resource/guide.

CONCLUSION

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

We hope that this Toolkit will be useful in your deployment of CLM-PPPR models and tools in your context. This Toolkit 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 Toolkit 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. You are now prepared to use CLM data for advocacy.

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.



CASE STUDY

BUILDING COALITIONS FOR CLM IN THE PHILIPPINES: A CONVERSATION WITH ACHIEVE³²

Action for Health Initiatives, Inc. (ACHIEVE) was founded in 2000 and works on mobility and health, with a focus on sexual and reproductive health and rights, and HIV and AIDS vulnerability of migrant workers and their families. ACHIEVE uses rights-based, gender-responsive, and participatory approaches that directly involve communities in the planning, implementation, monitoring, and evaluation of this work. ACHIEVE is a COPPER CE partner. In this case study, notice how ACHIEVE uses relationship-building towards new partnerships, collaboration with existing partners, and integration of new COPPER components into existing work.

QUESTION: How did you identify the stakeholders for the PPPR processes? How did you approach them initially and how did you continue your conversations?

RESPONSE: The COPPER CE team at ACHIEVE identified stakeholders for the PPPR processes by determining which government agencies have PPPR programming. We invited these stakeholders to attend our COPPER CE Project Inception Forum to showcase their PPPR work. We introduced the COPPER Project and held initial partnership conversations as side meetings throughout the event. After this initial exchange, our team continued to engage with them, for example, at the National Stakeholders Meeting: Responsive and Resilient Health Systems: Community-Led and Community-Centered.

QUESTION: How are COPPER CE and COPPER CLM partners collaborating?

RESPONSE: We are part of the COPPER Coalition Philippines, a group of 27 CBOs working on TB, HIV, public transportation (for example, the Tricycle Operators and Drivers Association), women's rights, youth, and migrant worker issues that wants to amplify local voices to shape effective PPPR strategies. After ACHIEVE's CLM Integration Inception Meeting in November 2024, five members of the COPPER Coalition started to collaborate with existing CLM initiatives, while some became members of the existing CLM-Community Advisory Board. Together, we are building a long-term partnership to integrate PPPR, TB, and HIV CLM across the Philippines.

QUESTION: What was your experience with participating in JEE and/or NAPHS processes?

RESPONSE: The COPPER Coalition had planned to participate in the Joint External Evaluation (JEE). However, the JEE is a high-level government meeting and was scheduled in advance of our project's implementation. Instead, we will participate in the consultation on the JEE results and the subsequent planning activities for the National Action Plan for Health Security (NAPHS). One of the main challenges in participating in the JEE and NAPHS processes is the recent USAID funding freeze. Funding for the

^[32] Answers may have been lightly edited for clarity and style consistency.

ANNEX: ACHIEVE CASE STUDY

Philippines' NAPHS was provided by a USAID project, which has been terminated. Discussions about which organization or agency will take over the task of funding the NAPHS are ongoing. The NAPHS, which follows the JEE completion, will then serve as the basis for domestic pandemic funding. As of writing, the Department of Health (DOH) Epidemiology Bureau and DOH Health Emergency Management Bureau are leading the efforts on JEE results and NAPHS development.

QUESTION: What new partnerships did you develop through your participation in the process?

RESPONSE: While advocating for our engagement in the JEE and NAHPS processes, we have established new partnerships and collaboration with the top agencies working on PPPR, including the Office of the Civil Defense, the National Disaster Risk Reduction and Management Council, the DOH Epidemiology Department and Health Emergency Management Bureau, the Research Institute for Tropical Medicine, and the Department of Social Welfare and Development. We have new or renewed collaboration with: 1) epidemiology departments of local government units (for example, in Quezon City, Manila, and Pasig City); 2) NGOs and INGOs working on PPPR (such as Cullion Foundation, Philippines Red Cross, Médecins Sans Frontiéres MSF, and PBSP); 3) Philippine Country Coordinating Mechanism for the Global Fund; and 4) an academic institution, the University of the Philippines National Institutes of Health. The COPPER CE Coalition Philippines also includes community organizations that ACHIEVE has not worked with before.

QUESTION: How have you been able to use existing CLM data in these processes?

RESPONSE: In 2023, People Affected by Tuberculosis Philippine Alliance to Stop TB (PASTB) published Towards a People-Centered TB Response in the Philippines – A Community Report by People Affected by Tuberculosis. This document is based on CLM and data analysis to transform data into actionable recommendations towards the government to decrease TB program vulnerabilities documented during COVID-19. The COPPER Coalition Philippines used these recommendations in a workshop on integrating TB and PPPR advocacy goals. Based in CLM findings, our advocacy goals now include: 1) Not limiting TB service availability by diverting GeneXpert diagnostics for COVID-19 testing; 2) Training TB community leaders and service providers in disaster preparedness, including contact tracing and the continued delivery of services; 3) Adapting programs for home-based service delivery, strengthening telemedicine, and introducing new diagnostic tools, such as the TBLAM test; and 4) Implementing the TBDOTS rider program, which includes specimen transport and recipient of care transportation to healthcare facilities. Also, the ACHIEVE COPPER team actively participated in the National TB Planning Process. TB is a major issue in our country, and it is important that the National TB Program incorporates PPPR principles and mechanisms. Combining community expertise from different disease programs demonstrates our commitment to building partnerships and will strengthen our evidence to advocate for stronger, community-driven solutions.

QUESTION: What are your plans moving forward?

RESPONSE: The COPPER Coalition and the ACHIEVE-CLM integration team are working on further integrating CLM-PPPR. Our project will gather data from selected health facilities by 120 CLM monitors. This CLM feedback on Availability, Accessibility, Acceptability, and Quality of health services in the context of PPPR will be analyzed and utilized to strengthen our advocacy.

FURTHER READING

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ITPC. Community-led monitoring of COVID-19's effects on service delivery and lived experiences of people living with HIV and TB in China, Guatemala, India, Nepal and Sierra Leone. https://itpcglobal.org/resource/ community-led-monitoring-of-covid-19s-effectson-service-delivery-and-lived-experiencesof-people-living-with-hiv-and-tb-in-chinaguatemala-india-nepal-and-sierra-leone/.

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