COPPER
Communities in Pandemic
Preparedness & Response

A COMMUNITY GUIDE

DEVELOPING COMMUNITY-LED MONITORING INDICATORS FOR PANDEMIC PREPAREDNESS RESPONSE

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WHAT IS THIS GUIDE ABOUT

This guide helps provide direction to community actors to assess readiness of the country's health system in responding to disease outbreaks and pandemics. It specifically guides community-led monitoring (CLM) implementers and other stakeholders through PPR indicator development, revision and integration into existing CLM projects while aligning with International Health Regulations and the Joint External Evaluation (JEE) domains.

WHAT IS COMMUNITY-LED MONITORING

It is an intervention that empowers communities to hold donors and governments accountable for the quality of health services. It is implemented as a regular cycle:

01 Starts with defining the community’s priority issues to be monitored,

02 followed by designing data collection tools to capture data on these priorities,

03 then gathering of data from service users and providers in healthcare facilities, community delivery sites, and surrounding neighborhoods

04 Data is then reviewed and analyzed to identify key problems and suggest practical evidence-based solutions.

The findings inform advocacy for change. Some problems are quickly fixed at clinic level while others require long-term advocacy at regional and national levels.

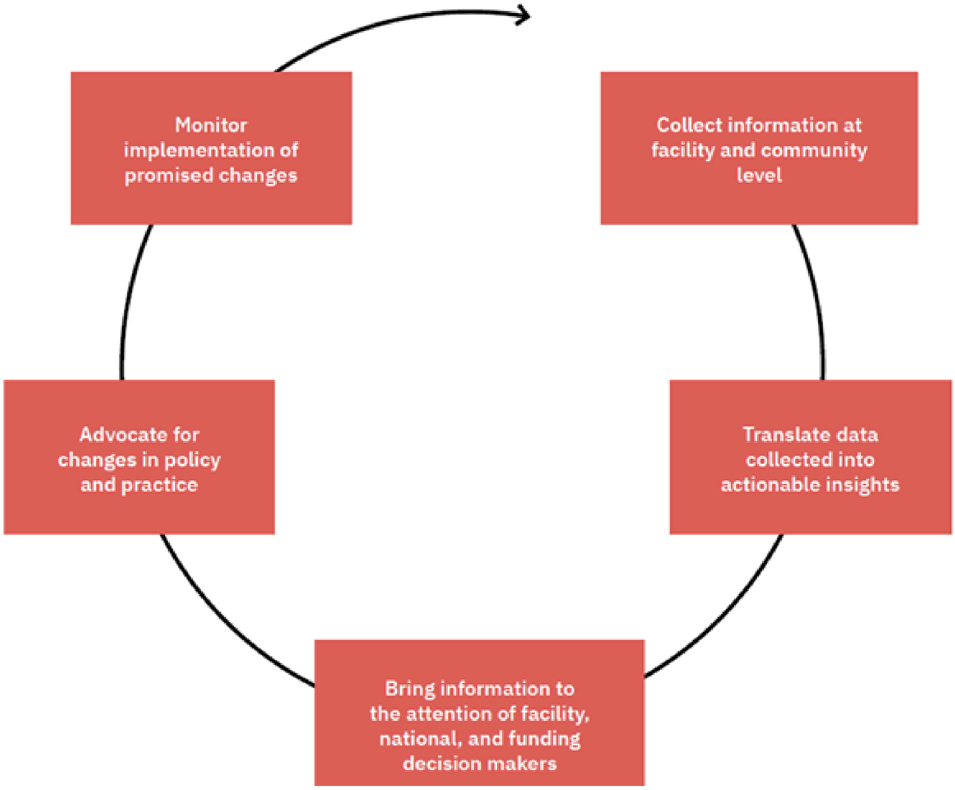
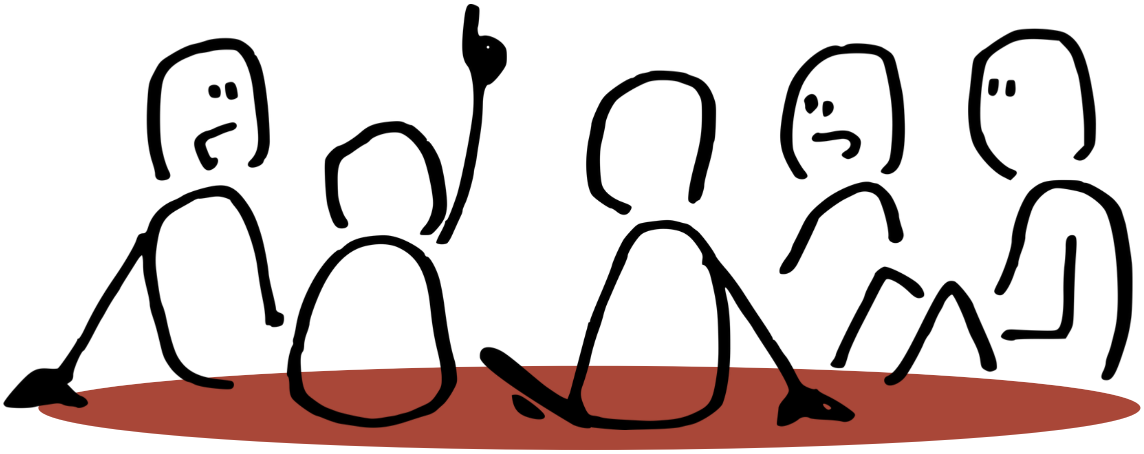


Figure 1. The CLM cycle

WHY DOES IT MATTER FOR PANDEMIC PREPAREDNESS RESPONSE (PPR)

During a disease outbreak or a pandemic, communities are hard-hit first, yet they usually receive help last. Think about a recent outbreak in your community – who got sick first, who first noticed challenges with the health service delivery, and who was the last to be heard in decision making processes? You will realize one common response to all these issues – communities! However, with the flexibility and responsiveness of the CLM model, communities are able to gather their own data in a timely and accurate manner to inform their demand for immediate actions.



STEPS IN DEVELOPING HIGH-IMPACT CLM INDICATORS FOR PPR

Step 01

Build a team of community experts and advocates

Step 02

Sensitize Community Experts on PPR Concepts and Frameworks

Step 03

Define the Community's public health needs and advocacy priorities

Step 04

Plan your evidence strategy

Step 05

Develop data collection questions for your surveys

Step 06

Pilot and refine your data collection tools

STEP 1: BUILD A TEAM OF COMMUNITY EXPERTS AND ADVOCATES

Bring together a group of local community experts and advocates who live in the community and understand the community needs and priorities.

These will include:

- Community-led organizations and networks involved in PPR, health security, human rights, social accountability, budget advocacy.
- People most affected by disease outbreaks and emergencies including PLHIV, Key populations and other vulnerable groups.
- Civil society organizations providing health services and those involved in community mobilization and sensitization.
- Organizations involved in advocacy for PPR at sub national, national, regional and global levels.

Key CLM principles to uphold at this stage include:

- Community ownership

- Community independence

- Inclusivity.

➔ Keep this team independent from non-community stakeholders including health facility staff, government officials and any other representatives of institutions that will be monitored –this protects the integrity and findings of your work. However, Ministry of Health officials, donors and other technical experts may be consulted but not included in decision making processes about what to monitor, how and by whom.

GOLDEN RULE

People most affected by health emergencies should lead the monitoring exercise, and not just participate but rather be in charge since they know the community needs better than anyone else.

STEP 2: SENSITIZE COMMUNITY EXPERTS ON PPR CONCEPTS AND FRAMEWORKS

Your team must be taught basic concepts and technical areas in PPR as well as related frameworks and processes.

Key technical areas to emphasise include:

- disease surveillance,
- laboratory systems,
- infection prevention and control,
- emergency response coordination
- and supply chain management.

Important frameworks to focus on include:

- the International Health Regulations (IHRs),
- Joint External Evaluations (JEEs),
- Strategic Plans for Advancing Real-Time Surveillance (SPARS)
- and your country's National Action Plan for Health Security (NAPHS)

→ Use simple, friendly training sessions in a local language that all participants understand referencing real examples from recent health emergencies in your community. It is helpful to compare your country's official JEE scores with the realities in your community to identify discrepancies that should be monitored. Consider site visits to facilities and points of entry so your team can experience various processes firsthand such as infection prevention control, isolation and disease reporting among others.

Conduct training sessions a simple, friendly format, using a local language understood by all participants. Make sure everyone feels comfortable with the basics.

GOLDEN RULE

Conduct training sessions in a simple, friendly format using a local language that is understood by all participants.

3

STEP 3: DEFINE THE COMMUNITY'S PUBLIC HEALTH NEEDS AND ADVOCACY PRIORITIES

Prioritise the community's public health pandemic preparedness challenges to be monitored.

Start by asking five questions:

- Which technical areas from the pandemic preparedness frameworks are most relevant?
- Which of these can actually be measured at community level?
- -Which services are you interested in monitoring?
- Are there these services Available, Acceptable, Affordable, Accessible and of Quality (AAAQ)
- Which populations, groups, or regions are most affected?

Use the AAAQ framework to breakdown problems:

- Are supplies in stock (Availability)
- Can people afford the services (Affordability)
- Is the way the services are being provided acceptable to the community (Acceptability)
- Do people know where to receive emergency services? (Accessible)
- Are services meeting medical standards? (Quality)

Refer to your National Action Plan for Public Health Security and the pandemic cycle to determine the gaps.

Reflect on how the data collected will be used for specific advocacy asks to decision-makers. Avoid collecting and analyzing data that will not inform advocacy.

IMPORTANTLY:

Monitor 2-3 priority areas really well rather than trying to monitor everything. Remember to reflect on how the data collected will be used for specific advocacy asks to decision-makers. Avoid collecting and analyzing data that will not inform advocacy.

4

Step 4: Plan your evidence strategy

At this stage, it’s important to deeply consider the kind of data that will be used for advocacy.

Advocacy is the strongest when you can not only describe the challenges happening in and with the healthcare system’s preparedness, but also when you can share data about what the duty-bearer can do to fix it. To get here, we need to consider two types of evidence:

- **‘What’** → describes the problem and the context,
- **‘Why’** → explains the cause.

For example, **80% of community health workers** report they have no clear mechanism to alert authorities about unusual illness patterns (The ‘What), and 92% of all community health workers surveyed reported that the most common reason for not reporting is lack of training for most common signals to look for. These questions help you propose solutions such as: *“Establish a simple reporting system using several platform options – WhatsApp, phone call, email, in these communities where no reporting mechanism exists.”*

The best indicators are those where you can convert your data into percentages rather than counts. For example, if you ask 20 people if they received a point of care diagnostic test for any pandemic such as COVID-19, and 5 of them say “no”, you can easily report that “25% of those surveyed had not had a point of care diagnostic test for COVID-19.” Percentages are much easier to interpret as they give context, allow you to make comparisons and are easier to understand!

The best indicators are those where you can convert your data into percentages rather than counts

Before collecting new data, check if it already exists as it may already be recorded by te MoH, GF, District Health Departments and other public and donor agencies. CLM data should not duplicate but rather add the community perspective -- user experiences and quality of health services.

Note:

Think backward from your specific advocacy goal: imagine what statistic or fact would help you build the strongest argument with facility managers or government officials. Then design indicators and questions to capture exactly that evidence.

5

STEP 5: DEVELOP DATA COLLECTION QUESTIONS FOR YOUR SURVEYS

Once you know the evidence you need and have determined the technical area of focus, create survey questions that will give you the evidence required.

Key considerations:

- ***Who will you survey ? will they be service users, facility managers, nurses, community health workers or district officials?*** Importantly, community-based data collection can also be useful to capture the experiences of those who no longer use or feel welcome at health facilities because of past experiences.
- ***Which site should you survey?*** –at the health facility, in the community, or through snowball sampling so that one respondent leads you to another?
- ***Which type of question will provide the best information?*** – single choice questions work for simple "**Yes/No**" questions or rating scales like "**Always/Sometime/Never**" and "**Strongly Agree/Agree/Disagree/Strongly Disagree"**. It's also important to include an option for "**None of the above"** or "**Other**" to make sure people are able to select a response that applies to them. Multiple choice allows people to select several options but it's advisable to keep the list under 8 options/items to maintain quality, and open-ended questions allow free responses rather than pre-specified responses although it's advisable to use them sparingly since they are time-consuming to analyze? And for complicated topics, consider interviews or focus groups rather than open-ended questions.
- ***Which PPR technical area will be the focus***?– for example, is it Antimicrobial Resistance, Immunization, Human Resources, Emergency Preparedness, or Health services Provision among others?

Community-based data collection can also be useful to capture the experiences of those who no longer use or feel welcome at health facilities because of past experiences.

Always prioritize ethics by:

01 Avoid asking individual questions and focus on asking health systems and services-related questions. For example, rather than asking "Have you had side effects from the use of certain antibiotics?" you might ask, "Do you think you would be provided antibiotics at this facility if your doctor prescribed them?"

02 Never collect personally identifiable information like names, phone number, identification numbers etc.

03 Do not ask people to disclose sensitive and/or embarrassing personal experiences. In such instances, you may include options like "prefer not to answer" or do not make the questions required.

04 Never photograph medical records and always start surveys with informed consent explaining who you are and how data will be used. But you may take pictures of service users if they have given you consent.

05 Keep surveys under 30 minutes because long surveys tire people out and reduce data quality. Finally, remember to refer at sample questions from other CLM programs for inspiration.

Always	Never
Seek informed consent explaining wo you are and how data will be used	Ask people to share personal health information
Protect respondednts privacy – do not ask for identifiable information like name, phone number or ID number	Take photos of medical records
Give freedom for one to skip a question or stop participating at any time	Force anyone to participate
Use data to advocate for improvements	Share a respondent's personal information without their consent.

Four golden rules for writing questions:

Clear **–** Use simple language that everyone understands

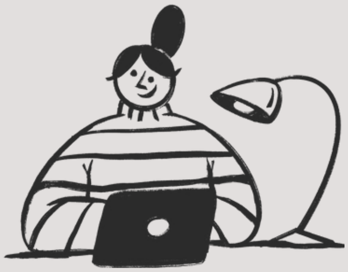
Specific **–** Ask about one thing at a time

Timeframe **–** Provide a time period like "in the last 6 months"

Neutral **–** Don't lead people to answer a certain way. For example, ask "do you face challenges accessing healthcare" with a "none" option, and not "which challenges do you face?" This basically assumes that challenges exist.

Good Question:
"In the last 6 months, has this facility had adequate emergency supplies like gloves and masks?"

Poor Question:
"Don't you think this facility struggles with emergency supplies because of poor planning?"



6

Step 6: Pilot and refine your data collection tools

Before collecting real data, always test your tools to make sure they are working perfectly in the real-world. Pre-test your questions so you can determine how long the questionnaire will take, clarity on both data collector and respondent's side, and identify any confusing elements.

There are two strategies for pre-testing data collection tools:

- **Data collectors pair off and practice interviewing each other** –this is good for determining length of the questionnaire, and clarity of questions.
- **Cognitive interviewing** –test important questions with potential survey respondents. Ask them if there are any words they do not understand or if they can rephase the question in their own words.

Refine data collection tools with the completion of more cycles to adjust for any changes. This may be done by:

- **Review advocacy priorities** to ensure you have exhausted all that you need to be covered and have indicators for each of them. Do no just add indicators as this will lengthen the tool. Consider deleting an irrelevant indicator for every new one added. To delete irrelevant indicators, think about indicators you haven't used at all during your advocacy engagements in the last year.

- **Improve existing questions:** work backwards from your advocacy ask, if the question doesn't give you the required response, revise it accordingly. Also, ask data collectors if there are questions confusing to respondents and clarify them. If the same question has several 'prefer not to answer' or 'other' or 'don't know' responses for many respondents, it's a red flag that the question is not clear or the response menu provided doesn't align with people's experiences. Adjust the response menu accordingly.

KEY TAKE AWAYS

Ensure community leadership –the right team of community stakeholders = successful monitoring

Think backward from your specific advocacy goal to determine the data you want to collect and therefore the PPR technical area(s) and questions to focus on

Ensure community independence – free from non-community stakeholders to protect the integrity and findings of your work.

Avoid collecting and analyzing data that will not inform advocacy.

Use a widely understood local language for any community stakeholders' empowerment sessions

Keep adapting --refine data collection tools with the completion of more cycles to adjust for any changes

Quality over quantity –better to monitor a few things so well than many things poorly

Determine upfront, what success should look like and celebrate any wins irrespective of their measure. This motivates the team.

The best indicators are those where you can convert your data into percentages rather than counts

Pre-test data collection tools in a real-world setting to ensure correctness and relevance.

For further details on each of the steps mentioned above, please refer to the 'Comprehensive Practical Guide for Developing Community-Led Monitoring Indicators for Pandemic Preparedness Response'.

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