Community-Led **Monitoring** of HIV, TB and Malaria Services in the Context of COVID-19

Precision in a Pandemic

A **Data Quality Assurance Guide** for Community-led Monitoring During COVID-19

JUNE 2022

ITPC
INTERNATIONAL TREATMENT
PREPAREDNESS COALITION

Purpose of This Document

This guide lays out the principles and dimensions of data quality for communities implementing community-led monitoring (CLM). It includes information on generating, analyzing and using data on characteristics, experiences and situations (called qualitative) and amounts or numbers (called quantitative) in the context of COVID-19. This guide aims to support CLM initiatives in passing the "credibility test", and promotes the use of CLM data for decision-making by health authorities and policy-makers.

Rationale

CLM is a relatively new approach to community engagement with governments, donors, health facilities and other stakeholders, which is gaining recognition for its valuable role in improving HIV, TB and malaria service delivery. Successful CLM requires strong data collection systems. Otherwise, communities face data quality challenges, which hamper their ability to use CLM data for influencing decision-making, policy and programming changes. Without a strong data collection system, the accuracy and/or credibility of CLM data can be called into question, and communities cannot confidently defend their positions.

? Who Should Read This Guide

→ **All current implementers of CLM**

→ **Civil society and community groups who are interested in establishing or strengthening CLM mechanisms in the context of COVID-19**

→ **Technical assistance providers supporting CLM initiatives**

→ **CLM partners (Ministries of Health, government agencies, multilateral and bilateral funders, health center management teams, health facility staff)**

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Abbreviations and Acronyms

AGYW	Adolescent Girls and Young Women
ACC	AIDS Care China
ART	Antiretroviral therapy
C19RM	COVID-19 Response Mechanism
CCG	Community consultative group
CLM	Community-led monitoring
COVID-19	Coronavirus disease 2019
CTO	Community treatment observatory
DMC	Designated microscopy center
HIV	Human immunodeficiency virus
ITPC	International Treatment Preparedness Coalition
MANERELA+	Malawi Network of Religious Leaders Living with or Personally Affected by HIV and AIDS
MMD	Multi-month dispensing
NACOSA	Networking HIV & AIDS Community of Southern Africa
NETHIPS	Network of HIV Positives in Sierra Leone
PEPFAR	The United States President's Emergency Plan for AIDS Relief
PrEP	Pre-exposure prophylaxis
RMAP+	Malian Associations of People Living with HIV
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
VOT	Video observed therapy
WHO	World Health Organization

Background

Introduction

The devastating effect of COVID-19 on the response to HIV, TB and malaria

The COVID-19 pandemic has had a devastating effect on the fight to end HIV, tuberculosis (TB) and malaria. Since the pandemic began, fewer people have been tested for HIV – and the number of people starting anti-retroviral treatment in 2020 has declined in 80% of countries.[1] TB diagnoses have declined 18% between 2019 and 2020, while TB-related deaths have increased by 7%.[2] After steadily declining over 2000-2019, malaria case incidence rose 5% and malaria deaths increased 12% in 2020. About 47,000 (68%) of the additional 69,000 deaths were due to service disruptions from COVID-19.[3] In short, fewer people are being tested and treated, and more people are falling ill and dying.

COVID-19 adaptations to improve the response to HIV, TB and malaria

COVID-19 has hastened the adoption and scale-up of more person-centered services. Among 21 PEPFAR countries, coverage of multi-month dispensing (MMD) of antiretroviral therapy (ART) grew from 49% at the end of 2019 (pre-COVID) to 72% in the second quarter of 2020.[4] Almost all the 28 HIV Prevention Coalition countries reported providing MMD of condoms, and more than two thirds of them also provided MMD of HIV pre-exposure prophylaxis (PrEP).[5] Eight countries adopted MMD of needles and syringes for people who inject drugs, and seven are providing take-home doses of opioid substitution therapy.

In the TB response, 23 countries reported COVID-19 adaptations, including the use of video-observed treatment (VOT) in Brazil, Eswatini, Guatemala, India and Uruguay; integrated TB/COVID-19 screening in Ethiopia, Nigeria, South Africa; using community health workers to aid in specimen collection and transportation and home delivery of TB medicines, and transporting sputum specimens for TB testing along with the COVID-19 specimens.[6,7]

Specific adaptations to mitigate disruptions in malaria case management were rolled out, including delivery of kiosks to facilitate fever screening and triage in Kenya and Malawi, and packages to sustain care seeking and antenatal clinic attendance in Kenya and Nigeria.[8] In addition, countries implemented training programs on the safely preventing COVID-19 transmission during the deployment of community health workers, and during the implementation of surveys.
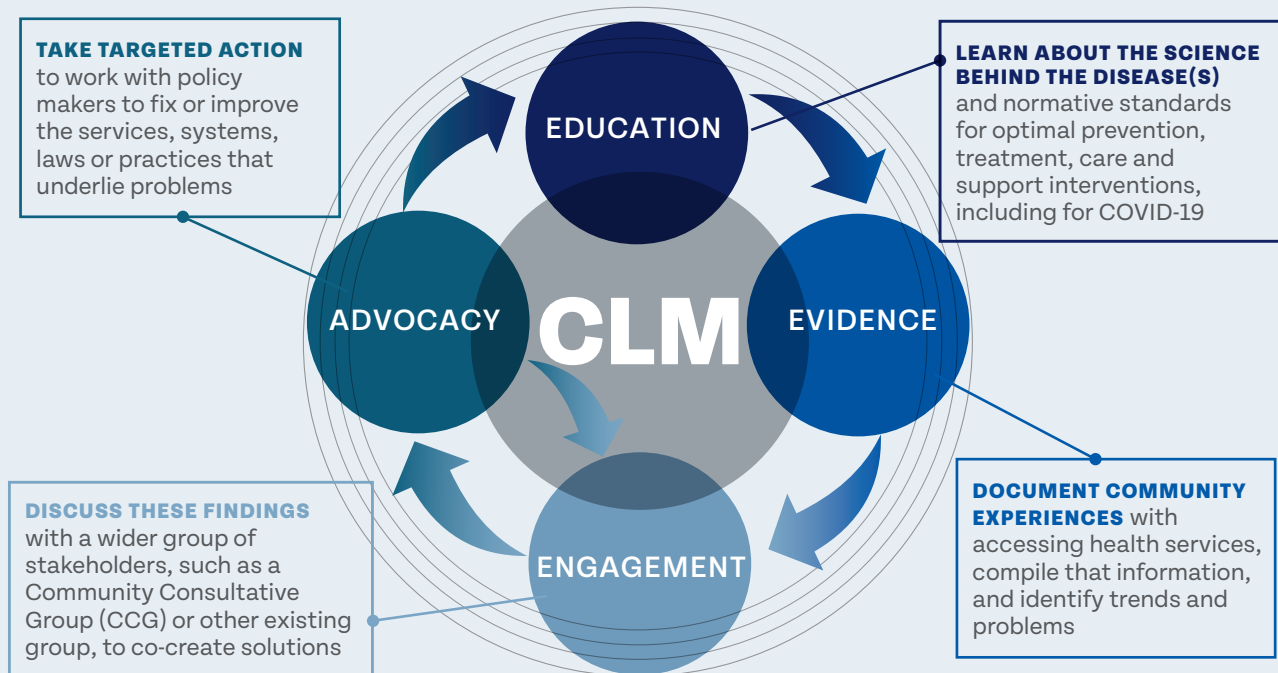
Community-led monitoring (CLM) for improved health service delivery

CLM is an accountability mechanism for health responses at different levels, led and implemented by local community-led

organizations of people living with HIV, TB survivors, networks of key and vulnerable populations, or other affected groups. CLM has been shown to improve service delivery at facility-level and health outcomes among recipients of care.[9,10] It uses a structured platform and rigorously trained peer monitors to systematically and routinely collect and analyze qualitative and quantitative data on HIV, TB and malaria service delivery — including data from people in community settings who might not be accessing health care — and for establishing rapid feedback loops with program managers and health decision-makers (see Figure 1).[11] Successful CLM models are also collaborative, continuous and systematic, and incorporate advocacy and community education.[12]

FIGURE 1 International Treatment Preparedness Coalition (ITPC) Community-led Monitoring Model

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

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

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

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

EDUCATION

ADVOCACY

CLM

EVIDENCE

ENGAGEMENT

Community-led Monitoring in the Context of COVID-19

Adaptations to community-led monitoring in times of COVID-19

In the context of COVID-19, CLM is ever-more critical for supporting recovery from service disruptions, and for urging scale-up of successful adaptations. CLM data collection uses indicators to specify the data that should be routinely collected - this is the "evidence". An indicator is an objective, reproducible quantitative or qualitative measure used to assess policy or program implementation. Indicators are used for monitoring the entire

program cycle and may measure inputs, outputs, outcomes, or impact. See ITPC's CLM Indicator Guide for more information (forthcoming).

Duplication or triangulation? The debate about CLM indicators

It is worth noting that there is some debate about selecting CLM indicators that health facilities may already be collecting, such as the number of people tested for HIV, or the number of people treated for TB. The U.S. President's Emergency Plan for AIDS Relief (PEPFAR) **2022 Country and Regional Operational Plan Guidance** says that "[Community-led] monitoring data should be additive and not duplicate collection of routine data already available to PEPFAR through MER" (pg. 145). On the other hand, *__UNAIDS' 2021 Guidance, Establishing Community-led Monitoring of HIV Services__*, says that clinic record surveys are a useful quantitative data collection method, since "this information supports and triangulates with other CLM data rather than replicating pre-existing monitoring" (pg. 21). **The Stop TB Partnership's guidance** promotes a mix of both types of indicators – those that are unique to CLM implementers, and those that health facilities presumably also have, such as the percentage of people diagnosed with TB who do not start treatment (pg. 10).

ITPC's community-led monitoring guidance emphasizes the importance of communities taking the lead in identifying and monitoring the issues that matter to them — something all partners ultimately agree on. Where health facilities do not readily or timeously share their data with communities, or the data is not trusted by communities to reflect their lived experience, CLM often involves the collection of certain routine data points that are needed to contextualize other information on barriers to access.

Selecting the right indicators is important for eliciting the best quality information for CLM initiatives. If the wrong questions are asked, we won't get the information that is needed. "COVID-blind" indicators will yield data that will not provide much insight into key questions about the pandemic. It is important to use "COVID-sensitive" indicators (see Table 1) and to examine the specific effects of the pandemic itself, as well as its effect on HIV, TB and malaria responses.

When selecting indicators, it is important to ask yourself: **"will the information I get from this indicator identify gaps and allow me to advocate for better care in the context of COVID-19?"** For example, in Jamaica, as part of the country's Global Fund COVID-19 Response Mechanism (C19RM) Grant (2021-2023), community-led organizations are conducting pill counts at treatment sites and in people's homes, including among people living with HIV, people with TB, and people who have other comorbidities. The aim is to monitor stock-outs and supply chain issues and flag issues for urgent action.

In South Africa, the PEPFAR-funded Ritshidze project is operating in 400 health facilities, monitoring the government's commitment to "accelerate decanting to external pick-up points" and "implement multi-month dispensing for all chronic patients" as part of its strategy to continue HIV/TB services in the context of COVID-19.

TABLE 1 **Examples of "COVID-blind" and "COVID-sensitive" CLM indicators**

	Example of "COVID-blind" indicator	Example of "COVID-sensitive" indicator	Explanation
Quantitative	Number of people on ART	Number and percentage of people on ART receiving multi-month dispensing of ART	Multi-month dispensing is a key COVID-adaptation, to decongest health facilities.
	Number of people tested for HIV	Number of people tested for HIV, disaggregated by modality: e.g. (a) facility-based testing, (b) community-based testing, (c) self-testing	Expansion of differentiated HIV testing services is a priority in the context of COVID-19, to decongest health facilities.
	Number of people screened for TB	Number of people screened for both TB and COVID-19	Integrated and bi-directional TB/COVID-19 screening is a key COVID adaptation, due to overlapping symptoms and the possibility of co-infection with TB and COVID-19.
	Number of people tested for TB	Number of people tested for TB disaggregated by type of test (e.g., using a World Health Organization (WHO)-recommended rapid molecular test (GeneXpert) or other methods (specify)	GeneXpert machines are sometimes repurposed for COVID-19 testing, which has deprioritized HIV viral load and TB testing, leading to delays.
Qualitative	How would you rate the quality of care you received here?	How has COVID-19 affected the quality of care that you receive here? *Probe 1: Are some things better since COVID?* *Probe 2: Are some things worse since COVID?*	COVID has impacted health care both positively (e.g., multi-month dispensing) and negatively (e.g., staff burnout).

Elements of CLM Data Collection

Timeframes

To effectively monitor the effect of COVID-19 on HIV, TB and malaria services, it is important to collect current data on health services, as well as pre-pandemic data for comparison.

→ For example, the WHO *Monitoring And Evaluation Framework For The COVID-19 Response in the African Region* guides countries to track the percent change in the number of people living with HIV on ART, by comparing the number of people on ART now with the number of people who were on ART in the same month in 2019.[13]

Education

Information about COVID-19 i should be integrated into the community education done as part of the CLM.

Approaches

Social gathering restrictions may mean that some of the CLM needs to be done virtually, such as key informant interviews and focus group discussions. It is critical to ensure the safety of all CLM participants; data collectors should be provided with personal protective equipment.

Flexibility

COVID-19 is a fast-changing pandemic. When doing CLM in the context of COVID-19, it is important to remain nimble and aware of changes to health policy, normative guidance, waves of new infections, and other relevant landscape shifts.

What is Data Quality and Why is it Important?

What is data quality?

Data quality is a measure of the completeness, timeliness, accuracy, reliability and relevance of information.
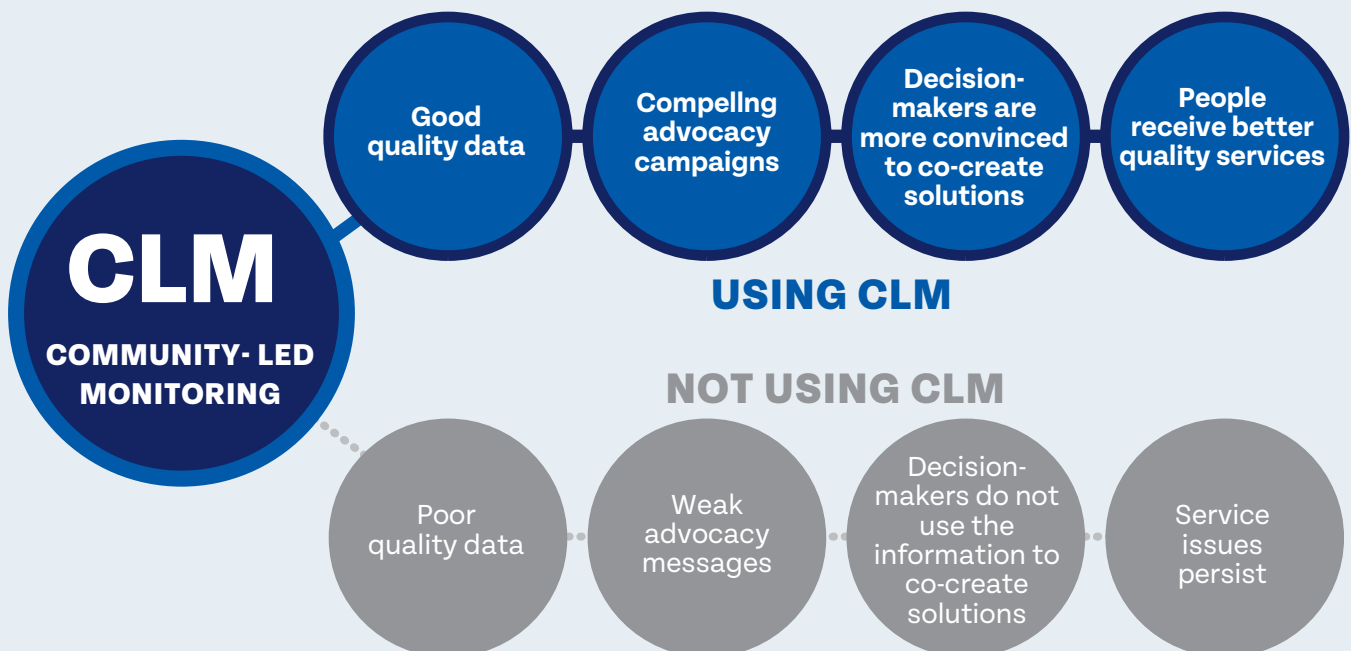
What is data quality assurance?

Data quality assurance is the set of procedures or processes used to routinely and regularly review data, correct errors and remove anomalies.

Why is data quality assurance important for community-led monitoring?

Data quality, although critical to CLM, isn't an end in and of itself – it supports the ultimate goal of CLM by informing decision-making by officials, co-creating solutions, and when needed, advocacy for improved health outcomes. A rigorous data quality assurance process allows you and other data users to have confidence in your data.

FIGURE 2 The link between data quality and health outcomes in the context of CLM

CLM COMMUNITY- LED MONITORING

USING CLM

Good quality data → Compellng advocacy campaigns → Decision-makers are more convinced to co-create solutions → People receive better quality services

NOT USING CLM

Poor quality data → Weak advocacy messages → Decision-makers do not use the information to co-create solutions → Service issues persist

Data quality is important because:

→ High-quality data support the ultimate aim of CLM: improving the health, quality and length of life among people living with HIV, TB and malaria.

→ High-quality data is essential for providing an accurate picture of issue and trends

→ High quality data may be more compelling, and more likely to convince decision-makers to act

→ Low quality data may negatively affect the credibility of your constituency or your organization

→ High quality data is ready and usable for a range of analyses and reporting, including trend analyses, benchmarking, and even statistical analysis and geocoding.

→ When CLM data is not of good quality it can negatively affect community-led organizations' ability to effectively advocate for change. Poor quality data can also affect the sustainability of CLM, if results are not achieved.

EXAMPLE How Uncertainties with Data Quality Can Negatively Affect CLM Advocacy

"The National TB Program acknowledged the [CLM] data, but they just said some technical issues may not be right. For instance, drug side effects, stigma and discrimination, they are not sure if the questions were asked properly or if it was actually aligned to the guidelines." **– CAMBODIA**

"When we presented the CLM results to the district or provinces, they asked, 'ok can you specifically go to this facility and tell us the major problems coming from this facility'? We were not able to do that because we could not disaggregate our data to that level. We needed to be able to pin-point the facility and give that specific local-level feedback." **– MOZAMBIQUE**

CLM data quality assurance in the context of COVID-19

Data quality assurance is critical for all CLM initiatives. However, there are special considerations in the context of COVID-19:
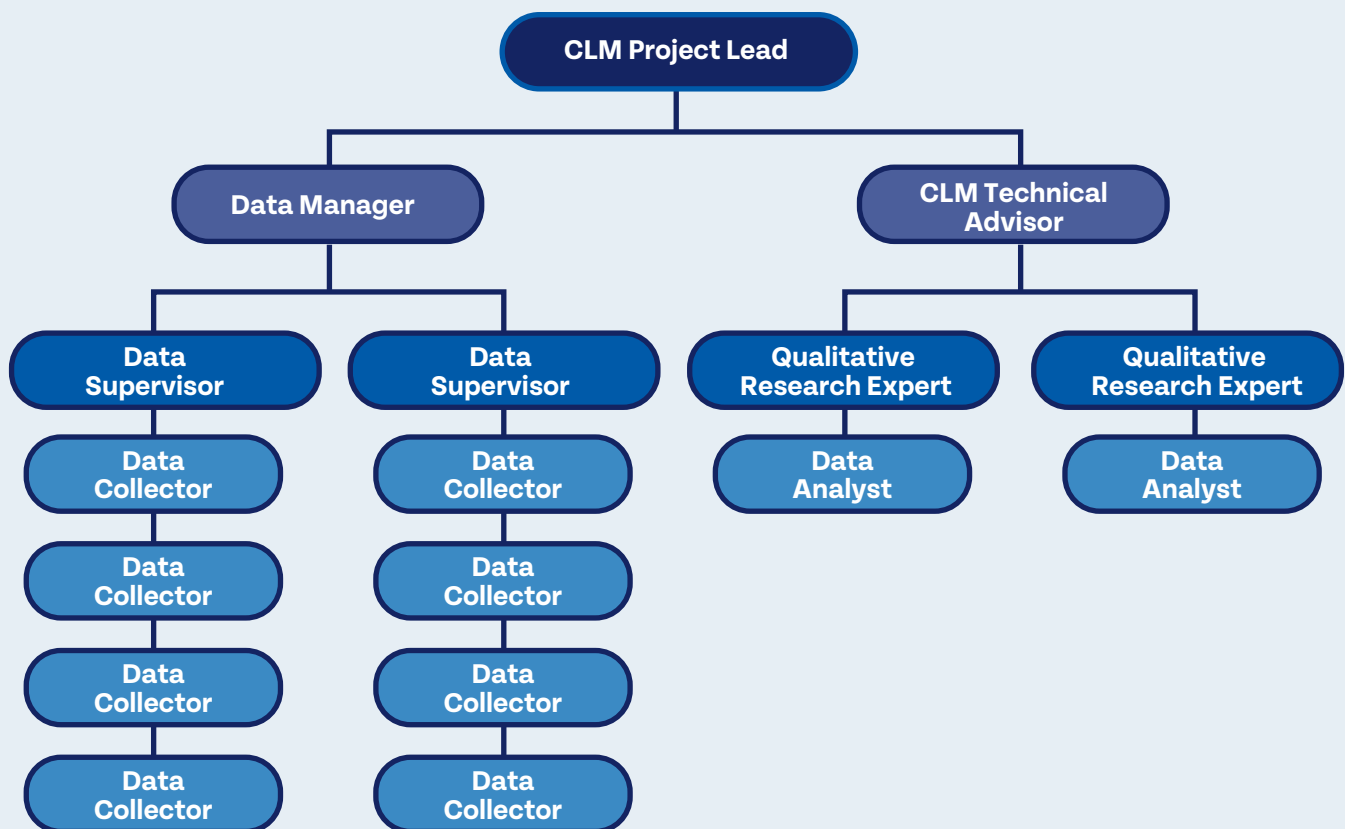
→ Good data for decision-making is even more important in times of crisis or emergency, since there is often less room for error.

→ There is a heightened sensitivity to misinformation related to COVID-19. It is even more important for CLM data to be of high quality, so that it is not perceived to be inaccurate or misleading.

→ With such a fast-moving and fast-changing pandemic, there may be a need for more regular data quality assurance checks.

Members of a data quality assurance team

The structure of data quality assurance teams may vary from one context to another. Below is an illustrative example that may help CLM implementers consider how to structure theirs.

FIGURE 3 Illustrative data quality assurance team for a community-led monitoring project

CLM Project Lead

Data Manager

CLM Technical Advisor

Data Supervisor

Data Supervisor

Qualitative Research Expert

Qualitative Research Expert

Data Collector

Data Collector

Data Analyst

Data Analyst

Data Collector

Data Collector

Data Collector

Data Collector

Data Collector

Data Collector

Factors Affecting CLM Data Quality During COVID-19

Data quality can be affected during data collection *and* during data analysis. Some of the most common factors than can affect data quality include:

Inadequate sample size

Adequate sample sizes for CLM are important. Having a sufficient number and frequency of observations allows you to detect what is truly there. It also allows you to be able to say something meaningful about wider trends. This includes both quantitative sample size (e.g., number of health facilities monitored) and qualitative sample size (e.g., number of interviews with recipients of care). During COVID-19, some facilities may not allow CLM data collectors inside, limiting potential sample size. Other facilities may change their access policies during implementation and suddenly bar access for data collectors, causing the sample size to drop. For qualitative data, health facilities may be short-staffed due to COVID-19, making healthcare workers less likely to agree to interviews with data collectors. Recipients of care, especially people who are immunocompromised, may not agree to an in-person interview if they are trying to avoid COVID-19.

See page 21 of ITPC's "The Community Treatment Observatory (CTO) Model

Explained" for recommended CLM sample sizes that are representative of the population.[14] However, sample size should not be a barrier to starting CLM. Do the best you can with available resources, and always be sure to describe results in context.

Human error

Human error may occur during data entry by CLM data collectors, who may collect data via paper checklists or data collection forms by hand, then enter them into an electronic database on a computer.

During COVID-19, CLM data collection teams may be overstretched, leaving them more prone to errors. There are strategies to help avoid or minimize such errors; for example, data collectors can take a photo of their own work so they have a digital copy of paper records, and data supervisors can also spot check and scrutinize data before it goes into the system.

Machine error

Errors can also occur after data is entered and stored into a computer or laptop. Files can be corrupted, hard drives can crash, programs can misread data, file types can be incompatible, and more. During COVID-19, more CLM data may be digitized, and

people may prefer to use tablets instead of paper-based tools to reduce the risk of COVID-19. Interviews may be done virtually through WhatsApp or Zoom. Paper copies of questionnaires or forms may still be useful as back-up options, in case digital data collection tools (such as tablets) run out of charge in the field or there is no internet access.

Interview style and technique

Ensuring that people who are interviewed have enough space and time to respond in detail is key to acquiring quality qualitative data. Probing and asking follow-up questions is also important. During COVID-19, interviewees and data collectors may be in an added hurry to shorten interviews. to minimize COVID-19 risk, or due to pressing need to move on to other tasks. Another quality issue with interview style can occur when the interviewer asks leading questions instead of open-ended ones. This can be due to the tool itself and the way the questions are worded, or the data collector inserting bias into the interview.

Bias

Bias in data collection can result in information that is not truly representative of the situation you are trying to investigate. For example, did CLM only monitor the experience of people attending services, or did it also collect perspectives from individuals in marginalized communities who otherwise avoid health services and health surveys? If you only collect data from recipients of care, you may not get an accurate picture of the barriers to accessing health services, since the people you spoke with have been able to overcome them to a certain extent.

Bias can be prevented by carefully planning the data collection process Data quality may be enhanced by training data collectors to be aware of their own biases, and by designing indicators, data collection tools, and data collection methodologies to minimize bias.

Data collection frequency

Effective CLM relies on data collection efforts that take place on a recurring basis (weekly, monthly, or quarterly, etc.) in order to reveal changes or trends over time. Rapidly shifting COVID-19 protocols including lockdowns, curfews, or crowd-reduction measures (such as limiting personnel who can be present in a health facility) may disrupt the frequency of regular data collection efforts. This can break the continuous chain of data that underpins credibility of CLM data or weaken the analyses that can take place.

A Framework for CLM Data Quality Assurance in COVID-19
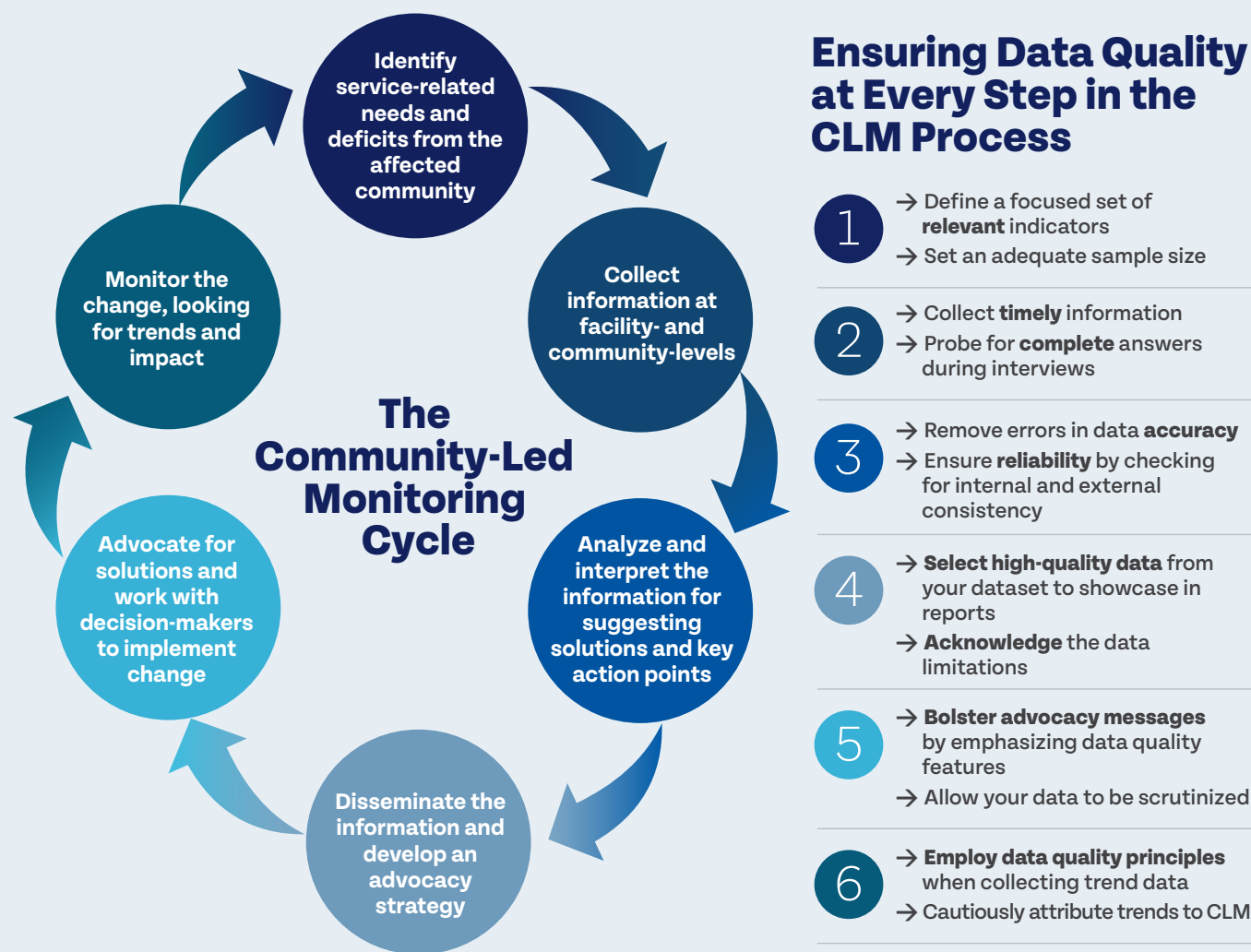
Overview of the Framework

A quality assurance framework can be used to avoid common pitfalls and optimize the quality of CLM data. This framework is simple to follow and can be easily adapted to any CLM project. In this example, special attention is given to the context of COVID-19 throughout the quality assurance framework.

The principles and dimensions of data quality assurance presented in this section are adapted from various existing guides, including those from Harvard University, WHO, and the Global Fund to Fight AIDS, Tuberculosis and Malaria.[15,16,17]

TABLE 2 **Framework for CLM Data Quality**

DIMENSION	ASK YOURSELF
RELEVANCE	Is the data really needed?
TIMELINESS	Is the data up to date?
COMPLETENESS	Are all the data values present?
ACCURACY	Is the data free from errors?
RELIABILITY	Is the data consistent with itself and other trusted sources?

FIGURE 4 Roadmap for Data Quality Assurance Through Each Stage of the CLM Cycle[18]

The Community-Led Monitoring Cycle

- Identify service-related needs and deficits from the affected community
- Collect information at facility- and community-levels
- Analyze and interpret the information for suggesting solutions and key action points
- Disseminate the information and develop an advocacy strategy
- Advocate for solutions and work with decision-makers to implement change
- Monitor the change, looking for trends and impact

Ensuring Data Quality at Every Step in the CLM Process

1
→ Define a focused set of **relevant** indicators
→ Set an adequate sample size

2
→ Collect **timely** information
→ Probe for **complete** answers during interviews

3
→ Remove errors in data **accuracy**
→ Ensure **reliability** by checking for internal and external consistency

4
→ **Select high-quality data** from your dataset to showcase in reports
→ **Acknowledge** the data limitations

5
→ **Bolster advocacy messages** by emphasizing data quality features
→ Allow your data to be scrutinized

6
→ **Employ data quality principles** when collecting trend data
→ Cautiously attribute trends to CLM

DIMENSION 1

Relevance (Do you really need this information?)

Selecting "COVID-sensitive"r indicators

Defining the right indicators for CLM data collection is an important step for assuring better data quality later on. One of the most important adaptations to CLM initiatives in the context of COVID-19 is defining "COVID-19 sensitive" indicators; this is key to assuring the relevance of CLM data.

CLM indicators should always be developed in in consultation with, and agreed upon by key stakeholders, including healthcare facilities and affected communities to ensure openness, transparency and collaboration in the CLM process and project. In the context of

COVID-19, it may be helpful to consult specific actors who are vulnerable to COVID-19 as well as HIV, TB or malaria, such as people with diabetes, pregnant women, the elderly, and healthcare workers.

A fast-changing environment such as COVID-19, may make indicators become irrelevant quickly; new ones may need to be included. For example, in the early days of the pandemic, most CLM focused on monitoring COVID-19-related disruptions of HIV, TB and malaria services. In 2022, this information may be less relevant, as many lockdowns have eased and most service provision has resumed. It may be more strategic now to focus on monitoring the coverage of COVID-19 adaptations, such as MMD or virtual services.

Disaggregating data

Having data that is disaggregated by age, sex and population is a very important for data quality. The relevance of the data that has been collected can depend on how much disaggregation is possible. For example, it may be that the proportion of people living with HIV receiving ART at a given facility is 90%, overall (Figure 4). However, when disaggregated by age and sex, one can see how that average of 90% is reached – some population groups are doing well, while others are not (Figure 4-5).[19]

FIGURES 5 & 6 **Hypothetical data to demonstrate the difference between aggregate and disaggregated data analysis**

FIGURE 5. Illustrative CLM Data on the proportion of PLHIV receiving ART at a Hospital from October–December 2020, aggregated

FIGURE 6. Illustrative CLM Data on the proportion of PLHIV receiving ART at a Hospital from October–December 2020, disaggregated by age and sex

90%

MEN

AGED 0-14 YEARS **99%**

AGED 15-24 YEARS **90%**

AGED 25+ **78%**

WOMEN

AGED 0-14 YEARS **99%**

AGED 15-24 YEARS **77%**

AGED 25+ **99%**

Data disaggregation is also important for qualitative data. For each person you interview, it is important to write down their age, sex, gender identity, job title (if interviewing a healthcare worker), population group, service being sought (if interviewing a recipient of care), among other characteristics that may be relevant for data interpretation later on. For example, in one CLM initiative, the qualitative data all seemed to have very little depth. During data quality assurance, it was discovered that the data collectors were mostly interviewing data entry clerks at the health facilities, not doctors or nurses. This data quality issue was identifiable because CLM tools required data collectors to note the position of the person being interviewed.

Avoiding oversaturation of data

How much data is too much data?

It is important to keep the end goal of CLM — influencing policy and program change — in mind when deciding what data to collect. It is important to set principles at the outset of the work to determine what issues you are hoping to track, and therefore which specific indicators are the best way of soliciting that information. Focusing CLM on what is new, and not already known to communities, health facilities, and policy makers can ensure the relevance and impact of data.

A common mistake in CLM initiatives is for implementers try to collect data on as many different indicators as possible, or to conduct as many interviews as possible. The end result is often an overwhelming amount of CLM data that is unmanageable, making it very difficult to do meaningful analysis, pull out trends, identify issues, and craft policy and advocacy messages. Just because you can measure anything, doesn't mean you should measure everything.

Oversaturation of data can also occur when CLM implementers conduct qualitative interviews or focus group discussions. Having hundreds and hundreds of interview

TABLE 3 Tips and traps" that will likely affect data quality for qualitative CLM data collection

TIPS: Likely to yield higher quality data	TRAPS: Likely to yield lower quality data
Fewer, targeted questions are best (especially if they can be collected in a recurring, uninterrupted manner)	Ask as many questions as possible; you want to be thorough
A smaller number of long qualitative interviews will actually give you better quality data	Aim for a large number of short qualitative interviews

transcripts is often not necessary, and certainly unmanageable when it comes time for analysis. It is usually possible to identify key trends and themes from a few dozen good discussions using open-ended questions, i.e. "what are the main barriers to service delivery?". It can be good to ask yourself: *"Am I learning something new from each interview?"* If the answer is no, then you may have reached

qualitative data saturation. You may have spoken to all the key healthcare workers at the facility, or spoken to most to enough recipients of care, to understand the major challenges there. In this scenario, it is best to stop collecting data and start analyzing what you have. For data quality, it is better to conduct fewer, more in-depth interviews.

EXAMPLE More is not always better – too many interviews in Malawi and South Africa

In one multi-country CLM initiative in Malawi and South Africa, oversaturation of qualitative interviews was a data quality challenge. Over the course of a year, local CLM implementers conducted 98 key informant interviews in Malawi, and 88 in South Africa. But there was not a lot of new information in each transcript. Part of the challenge was that many interviews were very short (about 10 minutes) and had brief or incomplete responses. Ultimately, just 47 transcripts from Malawi (48%) and 24 from South Africa (27%) were deemed useful for analysis – which is not the best use of time or resources, The CLM implementers reflected on this data quality challenge, and resolved to conduct fewer, more in-depth interviews in the second phase of the project.

Key actions to assure CLM data relevance

→ **Select "COVID-sensitive" indicators (both quantitative and qualitative)**

→ **Always disaggregate quantitative data by age and sex**

→ **Always capture relevant characteristics about qualitative interview subjects, including age, sex, population group, job description, or other relevant information.**

→ **Aim for fewer, more in-depth interviews and focus group discussions (quality over quantity)**

Timeliness
(Is the data up-to-date?)

Using the most recent data for advocacy

With certain CLM data (such as medicine stock-outs or critical service disruptions), collecting and using the most recent data is critical, and this is especially true during COVID-19, when the situation can change from day to day, CLM implementers should try to not to let their data get too old before using it to inform advocacy, or it may become less impactful. It. For example, if there is a stock-out of dihydroartemisinin-piperaquine (a common second-line treatment for uncomplicated malaria) this information needs to be shared with district/provincial health management teams and the central medical stores, the national malaria control program, and other key decision-makers, as soon as possible. If the information is only shared weeks later, the stock-out may have already been resolved, and CLM implementers will not appear credible. Or worse – it may be too late for decision-makers to act and prevent unnecessary deaths.

Keeping tabs on policy changes

COVID-19 is a fast-changing pandemic, making timeliness an extremely important element of data quality. It is important to regularly reassess whether or not the data you are collecting is up-to-date? Does it reflect the current pandemic situation and your country's response? For instance, a "COVID-sensitive" qualitative CLM indicator may be asking people: "How is the COVID-19 lockdown affecting your ability to access health services?" This data may be useful during the lockdown period, but it is not useful after restrictions have been lifted.

Collecting retrospective data for comparison purposes

When doing CLM in the context of COVID-19, it may be strategic to collect data from the current time period, as well as retroactively - from a pre-COVID point in time - and compare the two. This is especially true if the CLM initiative aims to draw inferences about COVID-19's effect on HIV, TB or malaria services (the WHO Monitoring And Evaluation Framework For The COVID-19 Response in the African Region recommends this approach).[20]

Comparing pre-COVID and COVID-era time periods in South Africa

From November 2020 to October 2021, the Networking HIV and AIDS Community of Southern Africa (NACOSA) collected CLM data from 14 health facilities in the West Rand District of Gauteng Province. The CLM project, called "Citizen Science", was funded by the Bill and Melinda Gates Foundation, and had a specific focus on the impact of COVID-19 on HIV prevention. NACOSA also collected data from these same health facilities retroactively, for the period between November 2018 and October 2019, enabling a pre-COVID comparison. This pre-COVID comparison data improved the quality of the current CLM data, by giving it context. For example, the CLM revealed that births to adolescent girls living with HIV increased by 10% during the COVID-19 period, and that this was linked to a 73% decline in family planning services compared to the pre-COVID period.

Key actions to assure CLM data timeliness

→ **Use data for advocacy as quickly as possible.**

→ **Monitor changes in the COVID-19 pandemic and the policy response to it, and tailor CLM to reflect the most recent situation.**

→ **Collect current CLM data, as well as retrospective data for a pre-COVID time period, and compare the two.**

Completeness (Are all the data values present?)

Covering the entire sample

Ensuring data completeness includes ensuring data is collected from all the health facilities in the sample, and that enough interviews, with the right people, are conducted to give a representative sense of the situation.

In the context of COVID-19, there may be disruptions to CLM data collection due to lockdowns, curfews, or other restrictions. Health facilities may close with little notice, if high rates of COVID-19 transmission occur, making it hard to collect data. Similarly, changing social gathering rules may make interviews or focus group discussions difficult. It is likely that the concept of a "complete" dataset, in terms of both quantitative and qualitative data, may need a flexible approach.

Be sensitive to the fact that data collectors may contract COVID-19 and may not be able to work for certain periods of time. This could affect the completeness of CLM datasets, underscoring the fact that there may be a need to be flexible. Sometimes, you may be able to assess trends despite the dataset being incomplete and

determine that this is satisfactory. In other instances, you may prefer to pause data collecting for a time, and start collecting the missing data when data collectors are well again. Implementing COVID-19 protocols for CLM data collectors can minimize this threat to data quality. This includes health monitoring for all data collectors on daily basis (e.g., temperature check, symptom screen), provision of personal protective equipment, referrals to COVID testing sites and vaccination opportunities, among other measures.

It can be a good idea to plan a slightly larger sample size that you really need, just in case COVID-19-related measures or illness cause the sample size to shrink during implementation.

It is also critical to speak to the right people during qualitative data collection (i.e., interviews, focus group discussions) as this can affect data quality (such as happened in the example presented earlier in this guide, where a CLM project interviewed data entry clerks rather than doctors or nurses, which led to poor quality responses to questions asked health service delivery).

EXAMPLE CLM data collectors catch COVID-19 in Nepal, unable to complete work

From October-December 2020, Dristi Nepal – a network of women who use drugs – was implementing a rapid CLM project in three hospitals in Kathmandu: Bir Hospital, T.U Teaching Hospital, and Sukraraj Tropical and Infectious Disease Hospital. During Nepal's first wave of COVID-19, cases peaked on 21 October 2020, reaching a total of 5,743. Unfortunately, several of the Dristi data collectors contracted COVID-19 during this time. CLM data collection had to be stopped for about a month. Once the data collectors were well again, they were able to get back on track by collecting the missing data retroactively.

Ensuring data availability

Data availability impacts data completeness. There is not yet consensus on what standardized indicators are in the context of COVID-19 (versus HIV, TB and malaria, where these standards exist). It is often unclear what COVID-19 data is — or is not — being routinely collected at health facilities. Collaborating with the health care providers for defining or developing COVID-sensitive indicators will contribute to data completeness.

If communities define a "COVID-sensitive" indicator that cannot be collected, their data can be incomplete. For instance, in Sierra Leone, communities wanted to track the number of people living with HIV who tested positive for COVID-19, but realized that COVID-19 testing is done at separate facilities which do not share this information with ART facilities; as a result, this this indicator remained blank in monthly records.

CLM implementers should be flexible and consider dropping or altering CLM indicators that are not routinely available. It is always a good idea to review and possibly revise indicators at the end of the pilot phase of any CLM project, and thereafter at least on a yearly basis. In some cases, this may also present an opportunity for CLM implementers to advocate for the inclusion of new indicators in routine M&E systems at health facilities.

EXAMPLE Difficulty collecting COVID-sensitive TB indicators In Malawi

In April 2020, the Ministry of Health in Malawi issued the **second edition of its COVID-19 Guidance for HIV Services**. This guidance urged healthcare workers to implement rigorous, active, intensified case finding for TB, documenting all recipients of care with any of four symptoms (cough of any duration, weight loss, fever, night sweats) as "TB suspected" in the ART patient record. The Government of Malawi felt this record-keeping would provide valuable routine data for COVID-19 surveillance. MANERELA+, a community-based organization, is implementing a COVID-sensitive CLM project in 15 health facilities in two districts. They decided to see if health facilities were actually doing this intensified TB screening, while challenging stigmatizing language ("TB suspect"). As it turned out, this data was not being routinely collected and recorded in ART registers, despite the circular. MANERELA+ decided instead to track the number of people screened for TB during COVID-19.

Getting the full answer

When conducting qualitative CLM interviews, it is important to ensure that the responses people give are complete. During COVID-19, healthcare workers may be more stressed, stretched, and overworked than usual. The same may be true for CLM data collectors. This may tempt both parties to rush CLM interviews. It is important not to do this, as it can negatively affect CLM data quality.

EXAMPLE Allowing time for healthcare workers in India to elaborate on their responses

The Global Coalition of TB Advocates implemented a CLM project in two health facilities in New Delhi in 2020: TB Alert India Designated Microscopy Center (DMC) in Burari, and TB Alert India DMC in Mukundpur. Their qualitative data provides a good example of data completeness.

Example of low-quality data (incomplete answer):

DATA COLLECTOR: "How has COVID-19 affected your ability to provide TB services to people?"

HEALTHCARE WORKER: "COVID-19 has made my job very difficult."

Example of high-quality data (complete answer):

DATA COLLECTOR: "How has COVID-19 affected your ability to provide TB services to people?"

HEALTHCARE WORKER: "COVID-19 has made my job very difficult. [pause] Since the COVID test became mandatory, many patients go back home without testing for TB, though they were coughing for more than two weeks. The patients also notice long queues, which has discouraged them from going for TB tests."

Key actions to assure CLM data completeness

→ Plan a slightly larger sample size than you actually need.

→ Be flexible if data is not available for certain indicators; they can be adapted or removed.

→ Encourage health facilities to track new "COVID-sensitive" indicators.

→ If data is incomplete for one month, collect that data retroactively the next month.

→ Probe interview subjects and give them enough time and space to give full answers.

Accuracy (Is the information free from errors?)

Minimizing human and machine errors

There are often questions about whether to use paper-based or digital data collection tools for CLM. Using both is often a good idea; paper-based data collection tools can be useful for checking data that is later entered into a digital database. If using paper-based data collection, it is a good practice to take   photos of completed data collection tools as a back-up, in case the papers are lost or destroyed.

Human errors during CLM interview transcription are common. CLM data collectors may forget to write down something that a person said, or they may mishear the person and capture the information incorrectly. During COVID-19, it may be more common to collect qualitative CLM data (interviews or focus group discussions) virtually, through

WhatsApp voice notes or through platforms such as Zoom or Teams; these platforms create an opportunity to use technology for recording the sessions and using software to check for human errors in transcriptions. For instance, artificial intelligence software such as otter. ai will transcribe an audio recording for you, word for word. But machines make errors too, so it's always a good idea for to consider the transcription a draft, and review it against the audio recording to make corrections.

Cleaning the data

Data "cleaning" is the process of correcting and deleting inaccurate records from a CLM database. Data cleaning should be done after CLM data is collected and before it is analyzed. This process includes removing duplicate entries, deleting entry errors, spell-checking interview transcripts, converting

Illustrative Steps in a Data Cleaning Process

→ **STEP 1: Ensure that data field names are in a consistent and readable format**

→ **STEP 2: Ensure that all values are in a consistent format (e.g., checking numerical formats, spellings, etc.)**

→ **STEP 3: Eliminate duplicate copies of the same data point**

→ **STEP 4: Check for missing data entries and add them in manually if you spot them**

→ **STEP 5: Delete obvious errors in the dataset (e.g., a person arriving for care after the health facility is closed)**

→ **STEP 6: Do a spell check of the dataset**

→ **STEP 7: Have a peer repeat the data cleaning exercise to see if you arrive at the same or similar conclusions.**

→ **STEP 8: Have a data supervisor check your work when you are finished**

numbers stored as text into numerals (in Excel), and other techniques. When cleaning or manipulating datasets, it is good practice to always maintain a backup or a copy of the data for reference, and to keep version control. It is equally important to keep a record of the steps and rules used for data cleaning, so that these steps and rules are applied consistently. It can also be helpful to keep track of the number of errors or issues identified and corrected during this process, as this gives you an idea of the level of data quality before and after the exercise.

Interrogating the veracity of responses

The way qualitative data is collected can sometimes lead to data accuracy issues if it is misinterpreted, or not properly interrogated. Not all responses that people provide during interviews will conform to the facts of the situation. People provide responses based their comprehension, their needs, motivations, social norms, perceptions of what the interviewer is seeking, and more. It is important to use this data quality lens during the data analysis part of CLM.

EXAMPLE Unlikely claims from healthcare workers in China

AIDS Care China (ACC) was implementing a rapid "COVID-sensitive" CLM project in late 2020. In one qualitative interview, an ART case manager said that *"None of the patients treated in our hospital died, and none of the medical staff were infected. The clinical diagnosis and treatment techniques and methods have been recognized by the outside world."* This statement seemed implausible to the community-led monitoring team, given how COVID-19 was spreading in the area. The political sensitivity of COVID-19 control in China may have led this healthcare worker to convey something that was not accurate. It is important to be alert to such accuracy issues in qualitative data collection.

Key actions to assure CLM data accuracy

→ **Use a combination of paper-based and digital data-capturing techniques, which is useful for cross-referencing later, to help identify errors.**

→ **Always clean CLM data after it is collected and before it is analyzed**

→ **Interrogate CLM data, especially qualitative data, to check if respondents were being truthful.**

Reliability (Is the data consistent with itself and other trusted sources?)

Checking for internal consistencies

Another way to think of this data quality measure is to ask, *"does the data contradict itself"?*

To assure data reliability, review your CLM database and check for coherence between the same data items at different points in time. Do you see the number of people on ART MMD increasing steadily from one month to the next, in line with the government's COVID-19 protocols, then does it suddenly decline for one month, then return to previous levels? This could indicate an error. In this situation, it is a good idea to review the data point against the primary data source and ensure that it is correct.

Another internal consistency check is to look for coherence between related data items in the CLM dataset. For instance, are the number of people testing positive for HIV higher than the number of HIV tests performed? This may be a data reliability issue and should be further examined.

Finally, check for coherence between your quantitative and qualitative CLM data. Are facilities reporting no stock-outs of medicines, yet all recipients of care are saying they cannot get refills on time? This points to a possible reliability issue and should be questioned with key stakeholders and during ongoing data collection.

Checking for external consistencies

Review your CLM database and do a comparison of your data in with trusted national statistics. Are the figures similar, or dramatically different? For example, if a district health management report shows 80% of people living with HIV are

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EXAMPLE Doing a "common Sense Check" of CD4 cell count data in Sierra Leone

To reduce health facility traffic, many programs adjusted their protocols to implement rapid ART initiation during the COVID-19 pandemic and urged same-day initiation of ARVs when not medically contraindicated. In this context, the Network of HIV Positives (NETHIPS) in Sierra Leone was interested in tracking the number of people who received a CD4 cell count before being initiated onto ART as part of a rapid, "COVID-sensitive" CLM exercise conducted between September and December of 2020.
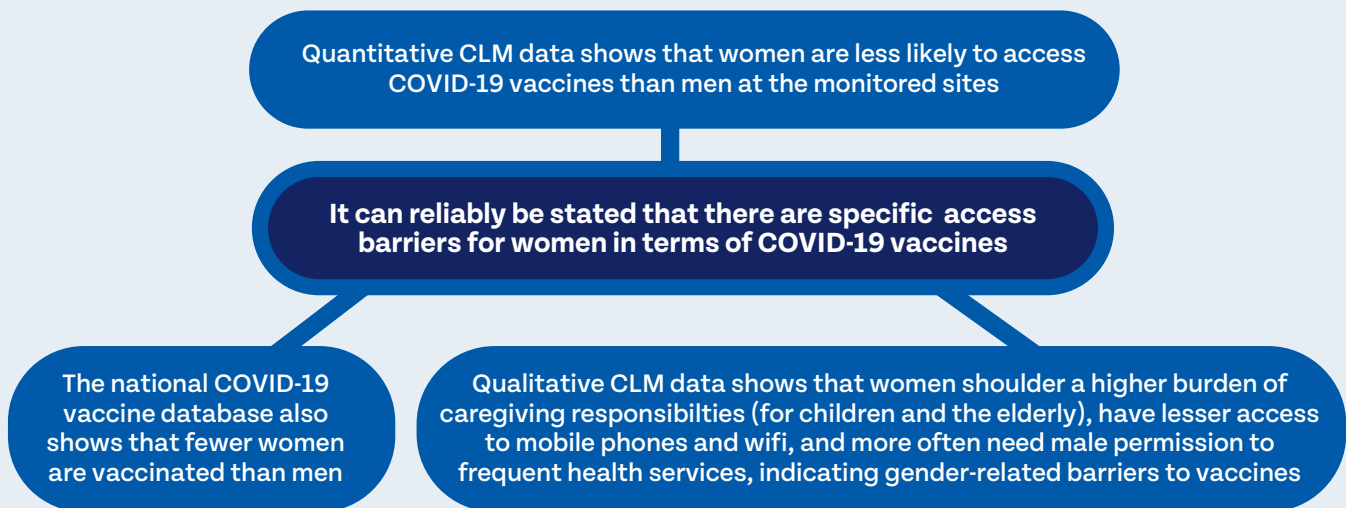
When they analyzed their data at the end of the first month, something wasn't adding up: there were more CD4 cell counts performed than ART initiations — indicating a problem with coherence between related data items.

on ART, but your CLM data shows that only 10% of people at your monitored facilities are on ART, this may indicate an issue with your CLM data collection, your analysis, or a problem with the national data. It is unlikely that the two data points would be so different. You can also compare your CLM data with other types of sources (surveys, studies) to see if the findings are reasonably similar.

Triangulating data

To have increased confidence that CLM data is an accurate reflection of true reality, it can be useful to "triangulate" data with other sources. This is where you will compare three different sources of similar data, including your CLM data, to conclude that your CLM data is reliable.

FIGURE 7 **Hypothetical example of CLM data triangulation to reinforce the credibility of the central claim from three different data sources**

Quantitative CLM data shows that women are less likely to access COVID-19 vaccines than men at the monitored sites

It can reliably be stated that there are specific access barriers for women in terms of COVID-19 vaccines

The national COVID-19 vaccine database also shows that fewer women are vaccinated than men

Qualitative CLM data shows that women shoulder a higher burden of caregiving responsibilties (for children and the elderly), have lesser access to mobile phones and wifi, and more often need male permission to frequent health services, indicating gender-related barriers to vaccines

Key actions to assure CLM data reliability

→ Check for internal consistency, such as coherence between the same data items at different points in time, coherence between related data items in the CLM dataset, and coherence between your quantitative and qualitative CLM data.

→ Check for external consistency, comparing CLM data with trusted national statistics, or other types of sources (surveys, studies).

→ Triangulate CLM data with at least two other sources to be confident the data is reliable.

Process to Assure CLM Data Quality During COVID-19

COVID-Sensitive CLM Data Quality Assurance Checklist

Consider using a checklist — such as the one below, which summarizes each data quality element — to assure the quality of your CLM data.

DIMENSION	QUESTION	STATUS	
		YES	**NO**
RELEVANCE	1. Have you selected "COVID-sensitive" indicators (both quantitative and qualitative)?	☐	☐
	2. Have you disaggregated quantitative data by age and sex and population?	☐	☐
	3. Have you captured relevant characteristics about qualitative interview subjects, including age, sex, population group, job description, or other relevant information?	☐	☐
	4. Have you aimed for fewer, more in-depth interviews and focus group discussions (quality over quantity)?	☐	☐
TIMELINESS	5. Have you used data for advocacy as quickly as possible?	☐	☐
	6. Have you monitored changes in the COVID-19 pandemic and the policy response to it, and tailored your CLM to reflect the most recent situation?	☐	☐
	7. Have you collected current CLM data, as well as retrospective data for a pre-COVID time period, and compared the two?	☐	☐

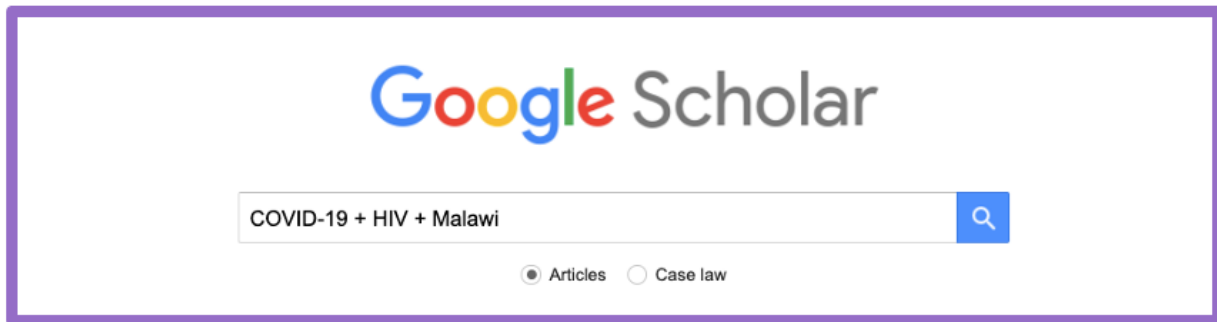| DIMENSION	QUESTION	STATUS	
COMPLETENESS	8. Have you planned a slightly larger sample size than you actually need?	YES ☐	NO ☐
	9. Are you being flexible if data is not available for certain indicators, in adapting or removing them?	YES ☐	NO ☐
	10. Are you encouraging health facilities to track new "COVID-sensitive" indicators?	YES ☐	NO ☐
	11. If the data is incomplete for one month, are you collecting that data retroactively the next month?	YES ☐	NO ☐
ACCURACY	12. Are you using a combination of paper-based and digital data-capturing techniques?	YES ☐	NO ☐
	13. Have you cleaned your CLM data after it is collected and before it is analyzed?	YES ☐	NO ☐
	14. Have you interrogated your CLM data, especially qualitative data, to check if respondents were being truthful?	YES ☐	NO ☐
RELIABILITY	15. Have you checked for internal consistency? This exercise should include:	YES ☐	NO ☐
	16. Coherence between the same data items at different points in time	YES ☐	NO ☐
	17. Coherence between related data items in the CLM dataset	YES ☐	NO ☐
	18. Coherence between your quantitative and qualitative CLM data	YES ☐	NO ☐
	19. Have you triangulated your CLM data with at least two other sources to be confident the data is reliable?	YES ☐	NO ☐
CROSS-CUTTING	20. Have you conducted regular data quality audits to assure the relevance, timeliness, completeness, accuracy and reliability of your data?	YES ☐	NO ☐
TOTAL DATA QUALITY ASSURANCE SCORE				20

Other Data Quality Measures

Partnering with an academic institution

If possible, it is a good idea to identify an academic affiliation, preferable allying with a local professor or university department that is doing work on COVID-19 and its effects on HIV, TB and malaria services. The kind of partnership you form will depend on your context; it is important to note that this may not be feasible in all settings. Some CLM projects have formal relationships with universities, through memoranda of understanding. Others have more informal ties with local researchers, who take an interest in the CLM data and can help to improve data quality through ongoing mentorship and support.

If you don't know where to begin, try going to on Google Scholar (**scholar.google.com**) and searching for "COVID-19 + HIV/TB/malaria) + [country]" and see who is publishing on the topic. Find their contact details. Then, you can approach these professors to seek a partnership.

Developing a data quality protocol

Developing a data quality protocol is a good idea. You can use the dimensions in this guide, and even include the checklist. Your protocol should describe all the quality checks that are in place.

Conducting data quality audits

In addition to the routine data quality review and analysis conducted by the data supervisor(s) and focal point lead, it is critical to conduct formal data supervision and quality assessments. This process involves field visits, where the implementing team can spot check and troubleshoot any issues that would lead to inaccurate, incomplete and/or unreliable data.[22]

Validating data with a diverse group of experts

Lastly, validation of your data is an important way to assure data accuracy, reliability, and relevance. Always include data quality assurance in the agenda for Community Consultative Group[23] meetings or other feedback meetings with stakeholders where you present your CLM data to a trusted circle of advisors. Ask them to scrutinize the data and tell you if it looks like it makes sense.

Balancing the need for data quality and data security

Some believe there are necessarily trade-offs between data quality and data security.[24] The principle of data security, especially confidentiality and integrity, is to protect data against unauthorized access.

However, implementing a data quality assurance system requires flexible read and write access to all data. For instance, data de-duplication is an important step in data quality assurance, yet, if data is encrypted – a key data security measure – it makes deduplication very difficult – if not impossible. The strengthening of data security mechanisms at the expense of data quality processes, or relaxing certain security measures to improve data quality, are two strategies that require careful balance and arbitration. Informed consent by participants in a CLM project, as well as the overall importance of assuring privacy and confidentiality in health settings – particularly for stigmatized and often criminalized groups, including people living with HIV and key populations – are fundamental to assuring the safety, well-being and human rights of stakeholders across CLM work.

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About 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. Formed in 2003 ITPC actively advocates for treatment access across the globe through the focus of three strategic pillars:

→ **Build Resilient Communities (#TreatPeopleRight)**

→ **Intellectual property and access to medicines (#MakeMedicinesAffordable)**

→ **Community monitoring and accountability (#WatchWhatMatters)**

To learn more about ITPC and our work, visit itpcglobal.org.

About Watch What Matters

Watch What Matters is a community monitoring and research initiative that gathers data on access to and quality of HIV treatment globally. It fulfills one of ITPC's core strategic objectives, to ensure that those in power remain accountable to the communities they serve.

Watch What Matters aims to streamline and standardize treatment access data collected by communities – helping ensure that data is no longer collected in a fragmented way and that it reflects the issues and questions that are most important to people living with and affected by HIV. It relies on a unique model that empowers communities to systematically, routinely collect and analyze qualitative and quantitative data on access barriers and use it to guide advocacy efforts and promote accountability.

To learn more about Watch What Matters and our community-led monitoring work, visit www.WatchWhatMatters.org or send us an email at admin@itpcglobal.org.

Acknowledgements

ITPC thanks and acknowledges those who have supported our work in this critical area of community-led monitoring, including:

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