THE GLOBAL FUND

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

Stop TB Partnership

hosted by UNOPS

ABOUT THE STOP TB PARTNERSHIP

The Stop TB Partnership brings together expertise from a broad spectrum of country, regional, and global partners in our shared mission to revolutionize the TB space and end TB by 2030.

Founded in 2001, the Stop TB Partnership is a United Nations hosted organization that takes bold and smart risks to serve the needs and amplify the voices of the people, communities, and countries affected by TB.

We work to: advocate, catalyze, and facilitate sustained coordination and collaboration among partners; support the development, replication, and scale-up of innovative approaches and tools; and facilitate equitable access to TB diagnostics, treatment, and care for all in need. We believe that our comprehensive range of strategic and technical expertise and our willingness to push boundaries are crucial factors in reaching the targets set forth by the TB community at large.

To learn more about The Stop TB Partnership , visit www.stoptb.org

ABOUT THE GLOBAL FUND TO FIGHT AIDS, TUBERCULOSIS AND MALARIA

The Global Fund is a worldwide movement to defeat HIV, TB and malaria and ensure a healthier, safer, more equitable future for all. The Global Fund raises and invests US$4 billion a year to fight the deadliest infectious diseases, challenge the injustices which fuel them and strengthen health systems in more than 100 of the hardest hit countries.

To learn more about The Global Fund, visit www.theglobalfund.org/en/

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: Make Medicines Affordable, Watch What Matters, and Build Resilient Communities.

#Watch What Matters is an ITPC 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 and www.clmhub.org

This guidance document was developed with support from the Global Fund to Fight AIDS, Tuberculosis and Malaria and was coordinated by Stop TB Partnership, with the technical support of ITPC.

TABLE OF CONTENTS

LIST OF FIGURES AND TABLES

ABOUT THIS GUIDE

This guide supports the use of data generated by community-led monitoring (CLM) for decision-making and action to improve services, programs and policies. It focuses primarily on use of CLM data about services and programs related to HIV, tuberculosis (TB), and malaria. Much of the content is also applicable to the use of CLM data related to other health priorities, human rights and gender equality, and other social, economic and development issues.

Rationale for this guide

CLM is a mechanism through which communities and service users monitor the delivery of health services and implementation of programs. CLM is also used to monitor stigma, violations of human rights, delivery of programs to inform and empower people about their rights, and access to services such as psychosocial support and legal aid.[1] CLM empowers community organizations and recipients of care to work alongside service providers and other decision-makers to use CLM-generated data to improve the availability, accessibility, acceptability, affordability, and quality of health services, leading to greater program impact.[2,3] **As a community-led effort that leverages the unique perspectives and experiences of communities and service users,** CLM is a valuable strategy to engage them directly in identifying and solving practical issues in program quality, particularly at service locations, and promote people-centered care.

In the context of the response to HIV, TB, and malaria, CLM is being used in an increasing number of countries to gather data related to the availability and experience of health and support services, stigma, and human rights violations at clinic, community, and district levels. As of 2022, CLM initiatives are being implemented in more than 60 countries across every region of the world (see Figure 3). CLM is also now a standard program activity funded by the Global Fund to Fight AIDS, Tuberculosis and Malaria, the United States Agency for International Development (USAID), the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), Expertise France/L'Initiative, GIZ Backup Health, and other international funders.

It is not enough for CLM implementers to collect and report data on service statistics and user experiences. CLM implementers and decision-making authorities need to have the capacity to understand the data and translate findings into action to improve services, programs and policies.

(1) This guidance understands CLM as an important mechanism for monitoring human rights. Thus, this guidance uses the term "services" to refer to both health and rights-centered interventions delivered to beneficiary populations, and "programs" to refer to broader health and human rights promotion and related plans, policies, standards, management, and coordination.

(2) The Global Fund. Community-based monitoring: An Overview. 2020. (https://www.theglobalfund.org/media/9622/core_css_overview_en.pdf)

(3) ITPC. How to Implement Community-Led Monitoring: A community toolkit. 2021. (https://itpcglobal.org/blog/resource/how-to-implement-community-led-monitoring-toolkit/)

In practice, the widespread use of CLM data has faced several challenges to date, on the side of both CLM implementers and decision-making authorities.[4]

To address this need, with support from the Global Fund's Strategic Initiative for Data, the Stop TB Partnership and the International Treatment Preparedness Coalition (ITPC) coordinated the development of this guide on data use for decision-making. As part of this process, ITPC facilitated stakeholder consultations in March 2022 on the barriers to CLM data use. ITPC and the Stop TB Partnership also organized meetings in South Africa and the Democratic Republic of Congo in August and November 2022 respectively, to share the content of this guide and collect inputs. In these consultations and meetings, participants confirmed that CLM data are not yet being utilized to their full potential because of various barriers along the data journey, and affirmed that new guidance focused on CLM data use would be useful.[5,6]

By supporting the use of CLM data, the guide also contributes to the shared vision and achievement of the Global Fund Strategy 2018-2022 and its new Strategy 2023-2028.[7,8] It also addresses the recommendation of the Global Fund Technical Evaluation Reference Group to scale up and strengthen CLM systems[9] and the recommendation of the Global Fund Technical Review Panel to allocate sufficient funding for CLM and for national efforts to respond, integrate, and systematically use CLM data for different purposes.[10]

CLM data are not yet being utilized to their full potential because of various barriers along the data journey.

Focus of this guide: Data use for decision-making

With its focus on data use, this guide addresses the final steps in the CLM data journey (Figure 1).

At the start of the CLM data journey, or the **design** stage of a CLM initiative, the right indicators are selected in relation to the needs and priorities of communities. During **implementation**, data are collected, managed, and stored, with processes to assure their quality, privacy, and security.

This guide focuses on the use of data that have been generated through CLM. It provides checklists and recommendations to turn data into actionable information by cleaning it, making it accessible to different stakeholders,

(4) The Global Fund. Towards a Common Understanding of Community-based Monitoring and Advocacy. 2020. (https://www.theglobalfund.org/media/9632/crs_2020-02cbmmeeting_report_en.pdf)

(5) ITPC. Report on Key Findings from CLM Guidance Feedback Process. 2022.

(6) Reports of the South Africa and Kinshasa meetings will be posted at www.clmhub.org

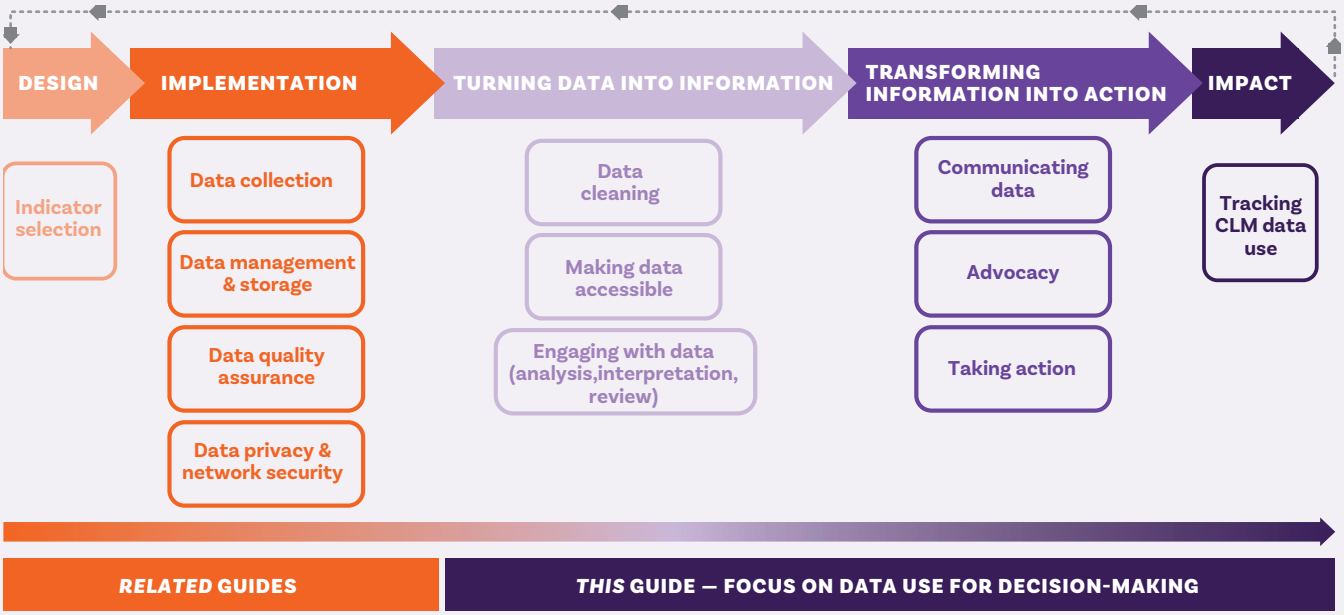
(7) The Global Fund. The Global Fund Strategy 2017-2022: Investing to end epidemics. 2017. (https://www.theglobalfund.org/media/2531/core_globalfundstrategy2017-2022_strategy_en.pdf)

(8) The Global Fund. Fighting Pandemics and Building a Healthier and More Equitable World: Global Fund Strategy 2023-2028. 2022. (https://www.theglobalfund.org/media/11612/strategy_globalfund2023-2028_narrative_en.pdf)

(9) Technical Evaluation Reference Group: Position Paper - Thematic Review on Resilient and Sustainable Systems for Health (RSSH). July 2019.

(10) The Global Fund: 2020 Technical Review Panel Lessons Learned (https://www.theglobalfund.org/media/10771/trp_2020-lessonslearned_report_en.pdf)

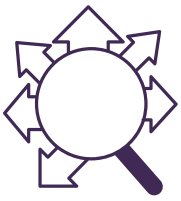
FIGURE 1 CLM data use in the context of the CLM data journey



analyzing and engaging with the data, and communicating it effectively. It also presents the steps to transform the information into actions for improvement, and approaches to accountability to track whether agreed actions have been fulfilled and issues resolved.

Who should read this guide?

CLM data are used by various stakeholders for different purposes (Figure 2).

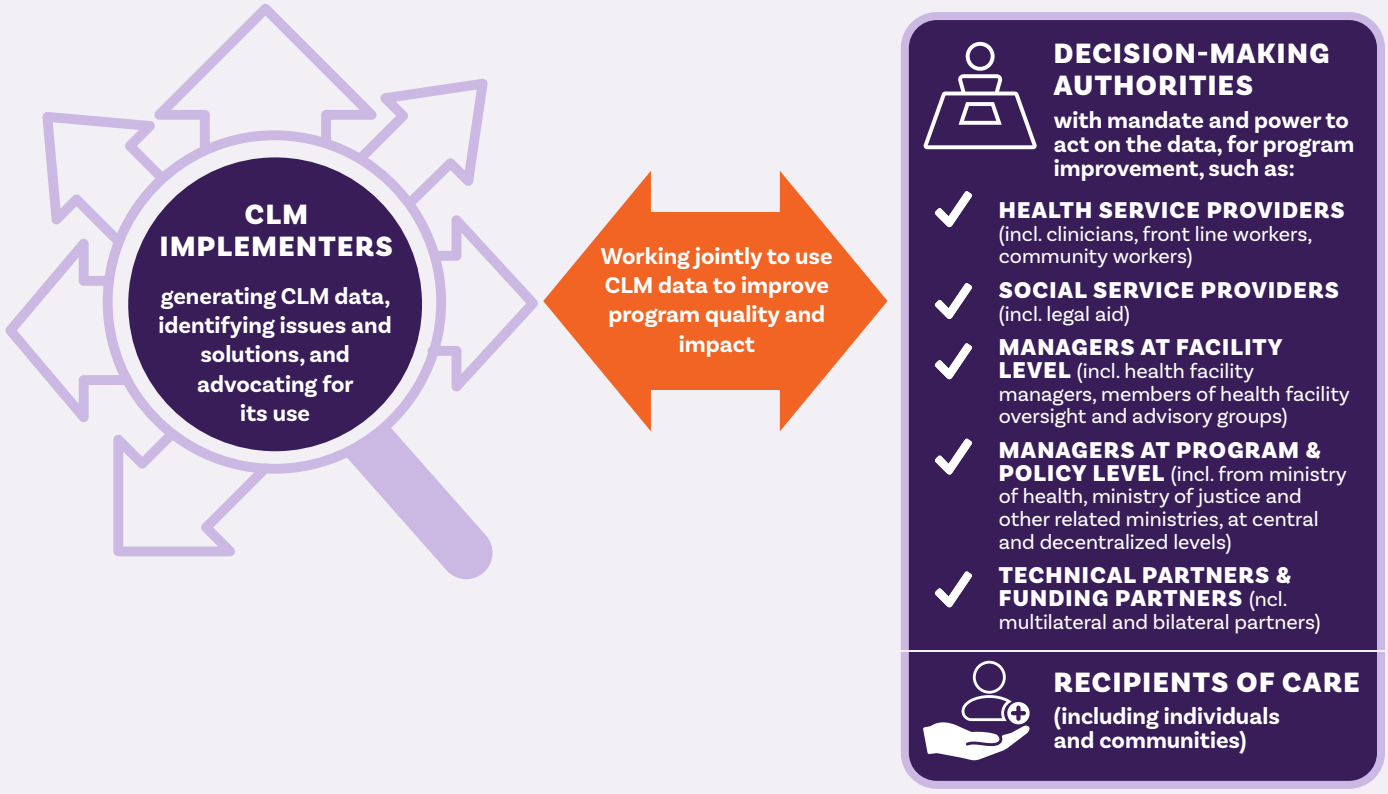


CLM implementers (including community organizations directly involved in implementing CLM and other community advocates) are users of CLM data themselves. Based on their analyses of these data, CLM implementers can identify potential solutions to bottlenecks and barriers, promote the use of CLM data, mobilize advocacy efforts towards various stakeholders, and continually adjust and improve their CLM approach. CLM data can also be used by lawyers and advocacy groups representing the interests of communities, protecting the rights of community members, and advocating for change.

Decision-making authorities, that is, the various institutions and individuals who have the mandate and the authority to take decisions to improve health programs and services and to protect and promote human rights, use CLM data for an enhanced understanding of program gaps and barriers, and act upon these data to bring about change.

Finally, **recipients of care** also use CLM data to make better informed choices for their own health. Although this guide is not directly targeted to recipients of care, it provides a reference for CLM implementers to

FIGURE 2 Users of CLM Data



communicate findings to them in formats and through channels that would be useful to them.

CLM is not just about airing complaints; it is about working together to fix problems. The guide is based on the premise that to be effective, CLM implementers and decision-making authorities should engage early in the CLM process to ensure that data can be used in a collaborative manner with mutual accountability. The guide thus aims to **facilitate mutual understanding of CLM data and its use among CLM implementers and decision-making authorities,** appreciating the value added of CLM data to national health programs, and addressing any negative perceptions of a "watchdog"-type role of CLM.

Expected outcomes of this guide

With this guide:

CLM implementers will gain capacity to:

→ Understand concepts and components of CLM data use

→ Reflect on how CLM data might be shared for program improvement decisions at different levels

→ Assess readiness, capacity, and resource needs for CLM data use and plan to address gaps

→ Communicate CLM data and advocate for its use

→ Assess, track, and report on the use of CLM data

- → Further improve CLM design and implementation to maximize data use in decision-making

Decision-making authorities will gain capacity to:

- → Understand the scope, importance, and value added of CLM data to national health programs
- → Reflect on how CLM data might be accessed and used for program improvement decisions at different levels
- → Assess readiness, capacity, and resource needs for CLM data use and plan to address gaps
- → Assess, track, and report on the use of CLM data
- → Consider CLM as a key contribution to national M&E systems and program review processes

Related guides and training materials

This guide complements other available guides related to CLM design, CLM implementation, and CLM-related advocacy. With the focus on data use, this guide also specifically complements documents that address the data-related steps *preceding* data use, including the selection of CLM indicators, CLM data collection, data management, and data quality assurance (Table 1).

This guide is accompanied by training materials, accessible at **www.clmhub.org**.

TABLE 1 Related CLM guidance

GENERAL RESOURCES ON CLM:

The Global Fund. Information note: Resilient and Sustainable Systems for Health (RSSH) Allocation Period 2023-2025. 2022.
https://www.theglobalfund.org/media/4759/core_resilientsustainablesystemsforhealth_infonote_en.pdf

The Global Fund. Community Systems Strengthening (CSS) Technical Brief. 2022.
https://www.theglobalfund.org/media/4790/core_communitysystems_technicalbrief_en.pdf

UNAIDS. Establishing community-led monitoring of HIV services – Principles and process. 2021.
https://www.unaids.org/en/resources/documents/2021/establishing-community-led-monitoring-hiv-services

Stop TB Partnership. OneImpact CLM implementation framework. 2021
https://stoptbpartnershiponeimpact.org/resources/Conceptual%20Framework/OneImpact%20CLM%20Conceptual%20and%20Implementation%20Framework%20FN.pdf

Stop TB Partnership. OneImpact CLM Dashboard. 2022
https://stoptbpartnershiponeimpact.org/dashboard/login

PEPFAR. 2022 Country Operational Plan Guidance. 2022.
https://www.state.gov/2022-country-operational-plan-guidance/

IAS – the International AIDS Society. A guide to support inclusion of CLM in funding requests to the Global Fund. 2022.
https://www.differentiatedservicedelivery.org/wp-content/uploads/IAS-CLM-Guide-final.pdf

GENERAL RESOURCES ON CLM:

PEPFAR. Community-Led Monitoring Tools. 2020.
https://www.pepfarsolutions.org/tools-2/2020/3/12/community-led-monitoring-implementation-tools

Expertise France. Community health observatories. 2019.
https://www.initiative5pour100.fr/sites/default/files/ressource-doc/2019-10/Community-health-observatories-capitalization_0.pdf

ITPC. How to Implement Community-Led Monitoring: A community toolkit. 2021.
https://itpcglobal.org/blog/resource/how-to-implement-community-led-monitoring-toolkit/

ITPC, EANNASO, Health Gap, and Anglophone Africa Regional Platform. Integrating community-led monitoring (CLM) into Global Fund C19RM funding requests. 2021.
https://itpcglobal.org/blog/resource/integrating-community-led-monitoring-clm-into-c19rm-funding-requests/

Health Gap, O'Neil Institute, TAC et al. Community-led monitoring of health services: Building accountability for HIV service quality. White paper. 2020.
https://healthgap.org/wp-content/uploads/2020/02/Community-Led-Monitoring-of_Health-Services.pdf

EANNASO, Anglophone Africa Regional Platform, Frontline AIDS, and the Stop TB Partnership. Community-led monitoring: A technical guide for HIV, tuberculosis, and malaria programming. 2021.
https://stoptb.org/assets/documents/resources/publications/acsm/CBM%20Guide%20Report_Final%200309_compressed.pdf

RESOURCES RELATED TO CLM DATA COLLECTION, MANAGEMENT, QUALITY ASSURANCE, AND USE:

Stop TB Partnership. OneImpact Data Privacy and Network Security User Manual. 2021.
https://stoptbpartnershiponeimpact.org/resources/Training Tools/OneImpact CLM Data Privacy and Network Security User Manual.pdf

ITPC. Data for a Difference. 2019.
https://itpcglobal.org/wp-content/uploads/2019/06/RCTO-WA-Data-for-a-Difference-Advocacy-Paper.pdf

ITPC. From insights to evidence: A guide to qualitative and quantitative measures for CLM. 2022.
https://itpcglobal.org/blog/resource/from-insights-to-evidence-a-guide-for-translating-priorities-into-qualitative-quantitative-measures-for-community-led-monitoring/

ITPC. Precision in a pandemic: guidance on CLM data quality assurance. 2022.
https:// itpcglobal.org/blog/resource/precision-in-a-pandemic/

CLAW Consortium. Community Evidence to Create Change. 2022.
https://healthgap. org/wp-content/uploads/2022/09/CLAW-Advocacy-for-Change.pdf

RESOURCES RELATED TO CLM DATA COLLECTION, MANAGEMENT, QUALITY ASSURANCE, AND USE:

World Health Organization. Data Quality Assurance. Toolkit. 2021.
https://www.who.int/data/data-collection-tools/health-service-data/data-quality-assurance-dqa

WHO. Analysis and use of health facility data. Toolkit. 2020
https://www.who.int/data/data-collection-tools/analysis-use-health-facility-data

MEASURE Evaluation. Data Demand and Information Use in the Health Sector: Conceptual Framework. 2011.
https://www.measureevaluation.org/resources/publications/ms-06-16a/at_download/document

UNECE. Making Data Meaningful. Four practical guides. 2009.
https://unece.org/statistics/making-data-meaningful

1. INTRODUCTION

Progress towards the 2030 Agenda for Sustainable Development requires not only further investments, but also improved policies and programs that protect and promote human rights and advance universal health coverage. It requires greater accountability by all decision-makers to remove access barriers faced by populations in need, and to deliver people-centred services that leave no one behind.

In programs focused on HIV, TB, and malaria, far too many people remain undiagnosed and untreated or are not returning to services in a timely way. People routinely report avoiding or not seeking care because of quality concerns, including experiences of long wait times, negative and stigmatizing interactions with health care providers, unexpected fees, and stockouts of key tests and medicines. People affected by HIV, TB, and malaria also experience human rights violations when seeking health care. This includes discrimination, infringements of their privacy and confidentiality, and failure to fulfill their right to health.

Such issues prevent people from accessing the services they need and contribute to and exacerbate poor health outcomes. Greater accountability for these and other concerns is key to ensuring the availability, accessibility, acceptability, and quality (AAAQ) of health and support services, and the protection and promotion of human rights.

The importance of CLM in advancing universal health coverage

Community-led monitoring (CLM) is monitoring of services, programs and policies that is conducted by service users and local affected communities, with the intention of improving them achieve better outcomes and impact.[11,12] CLM is a community-led effort that fills data gaps in national health information systems by leveraging the unique perspectives of affected communities and service users. It makes services more responsive by engaging communities and service users to identify and solve practical issues in program quality, and advances participation, equity and human rights.

Recognizing the potential of CLM to improve the quality of HIV, TB, and malaria services, **CLM is now being funded by many international partners**, including the Global Fund, PEPFAR, Expertise France/L'Initiative, and others as a standard program activity. As of 2022, CLM initiatives are being implemented in more than 60 countries across every region of the world (Figure 3).

(11) The Global Fund. Community-based monitoring: An Overview. 2020. (https://www.theglobalfund.org/media/9622/core_css_overview_en.pdf)

(12) ITPC. How to Implement Community-Led Monitoring: A community toolkit. 2021. (https://itpcglobal.org/blog/resource/how-to-implement-community-led-monitoring-toolkit/)

FIGURE 3 Community-led monitoring in the world today

CLM data are not being used to their full potential

While the scope and geographic spread of CLM initiatives is increasing, and large amounts of valuable information are being generated, CLM data are not yet being utilized to their full potential for program improvements and other actions to address the needs of affected communities. Stakeholder consultations revealed that both CLM implementers and decision-making authorities face challenges in CLM data use at different levels through the data journey (Table 2).[13]

(13) ITPC. Report on Key Findings from CLM Guidance Feedback Process. 2022.

TABLE 2 Barriers and challenges related to CLM data use

In March 2022, ITPC facilitated a process to gather feedback on barriers and challenges related to CLM data use. The consultation started with a broad survey disseminated via Alchemer to 157 stakeholders, including CLM implementers and government authorities; of whom 46 responded. Following the survey, ITPC held focus group discussions and key informant interviews to gather in-depth feedback. Of the 20 stakeholders who expressed interest in contributing to these, 14 were able to participate and represented the regions of West Africa (Côte d'Ivoire, Sierra Leone), Southern Africa (Malawi, Botswana), Asia (India, Nepal, Indonesia), and Latin America and the Caribbean (Guatemala, Jamaica).

The stakeholders noted the following barriers and challenges to CLM data use:

→ **CLM implementers do not have adequate capacity for CLM data use:** CLM implementers may not have adequate capacity to successfully undertake the different steps of the CLM data journey, such as data collection, analyses, visualization, and communication. Further, they face a lack of financial resources to build their capacity or to procure this expertise externally, which creates a challenge for long-term sustainability of CLM efforts and the integration of CLM into the broader health information system. CLM implementers themselves may lack knowledge of local and national decision-making processes, be inadequately remunerated, and face lack of time and infrastructure to sustain their efforts.

→ **CLM implementers may not communicate data effectively:** CLM implementers face gaps in data analysis capacity and, as a result, CLM data may not be organized in an understandable way or well packaged in a visual, clear, and easily digestible format. Key messages may not be distilled and expressed clearly. Further, there may not be an adequate framework for dialogue with health authorities, to discuss findings and develop solutions together.

→ **CLM implementers may not target data at the right level:** CLM data and advocacy efforts may not be pegged at the right level of influence or decision-making. For example, while some data may be actionable by a nurse or a health clinic at the local level, other data may need to be targeted at a higher administrative level, such as to influence policy changes at a national level.

→ **Decision-making authorities are not familiar with CLM:** CLM is a relatively new and growing field in program monitoring, and many stakeholders note that it remains unknown, undervalued, and unfunded. In particular, decision-makers may not have training or understanding of the importance or value of qualitative data. As a result, CLM data, which include a significant qualitative component, are rarely considered in the development of program policies, guidelines, and planning.

- **Decision-making authorities have concerns about data quality:** Government and other decision-making authorities often express concerns about the quality of data generated by CLM processes and question its legitimacy, reliability, and representativeness on grounds that collection processes may not be systematic or rigorous. In some instances, decision-makers may dismiss CLM data, raising questions regarding whose data counts and whose voice is heard.
- **Service providers show resistance to use CLM data:** At the local level, service providers may perceive CLM with suspicion due to its "watchdog"-type role and may feel that the process implicitly criticizes them or their work, rather than viewing CLM as a process where communities and service providers would work together to improve services for recipients of care.
- **CLM focus areas and indicators may be misaligned with those of national programs, donors, and partners:** CLM implementers find that where CLM indicators are not aligned with national program targets, this results in a missed opportunity to use CLM data to identify the underlying barriers and root causes of missing these targets (for example, stigma impacting treatment adherence). CLM areas of focus, indicators, and reporting requirements may also not align with those of donors and partners. CLM implementers feel frustration that their voices may not be adequately heard in instances where donors show inflexibility about using these data.

The challenge of inadequate data use is not unique to CLM. The Global Fund's Strategic Framework for Data Use for Action and Improvement at Country Level recognizes that there has been much improvement in the overall availability and quality of health data over the past several years, but the use of data for planning, resource allocation, and program improvement remains a challenge.

The Global Fund supports efforts to ensure that good quality data are regularly analyzed and used at all levels and stages of a program cycle. By providing practical tips for improving the use of CLM data, this guide contributes to the broader global objective of promoting data use for decision-making in health and human rights.)[14]

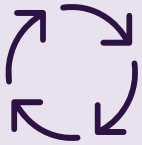
(14) The Global Fund. The Global Fund Strategic Framework for Data Use for Action and Improvement at Country Level (2017-2022). 2017. https://www.theglobalfund.org/media/8362/me_datauseforactionandimprovement_framework_en.pdf

2. CONTEXT & DEFINITIONS

2.1 What are CLM data?

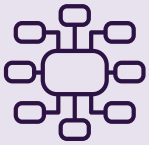
CLM data refer to **quantitative data (statistics) and qualitative data (observations, experiences, and descriptions**, for example in the form of text, photographs, audio, and video recordings), collected by service users and local affected communities about services, programs and policies related to health and human rights. (Table 3). The scope of CLM includes health services, support services, stigma, discrimination and human rights violations, and their impact.

TABLE 3 Common terms related to CLM data



Monitoring is a process of continuous observation, documentation, and tracking. This differentiates CLM from more periodic surveys, assessments, and evaluations.

Indicators are measures, providing signals and evidence of what is happening. Those measures can be quantitative (numerical) or qualitative (descriptive). **Quantitative** data refers to information that can be counted or measured (such as the number of persons reached by a program, or negatively impacted by a service gap. **Qualitative** information is non-numerical and describes attributes or qualities (such as descriptions or narratives of user experience in a health facility).



The resulting **CLM data** are the accumulated measures and observations. For example, a CLM data set might include a total of 2,000 observations collected for five indicators and/or qualitative measures, at 20 locations during each month.

Once the data set has been cleaned and examined, it will be **translated into usable information** (with analyses and synthesis), targeted to various audiences including decision-making authorities, and presented in formats, language and terminology familiar to the users of these data. For example, key findings and messaging should be tailored the needs of diverse audiences such as health and social service providers, managers at facility level, managers at program and policy level (at central and decentralized levels), technical partners and funding partners, or recipients of care.

CLM data use also relies on decision-maker trust in the **quality of the data**. This requires ensuring relative objectivity and **control of bias** (or systematic errors) in CLM data collection, including efforts to reduce biases of data collectors (such as selection bias, information bias, and confounding) and respondents (such as recall

bias, acquiescence bias, and social desirability bias). Data quality also refers to the **power** of the data (sufficient number and frequency of observations to detect what is truly there), its **validity and accuracy** (how closely the data represents what is truly there), **reliability** (consistency when repeated), and **significance** (broad applicability). However, some data points, such as documentation of human rights violations, discrimination, or privacy violations, in and off themselves require immediate action.

For more information, see:

The Global Fund. Information note: Resilient and Sustainable Systems for Health (RSSH) Allocation Period 2023-2025. 2022.
https://www.theglobalfund.org/media/4759/core_resilientsustainablesystemsforhealth_infonote_en.pdf

The Global Fund. Community Systems Strengthening (CSS) Technical Brief. 2022.
https://www.theglobalfund.org/media/4790/core_communitysystems_technicalbrief_en.pdf

ITPC. From insights to evidence: A guide to qualitative and quantitative measures for CLM. 2022.
https://itpcglobal.org/blog/resource/from-insights-to-evidence-a-guide-for-translating-priorities-into-qualitative-quantitative-measures-for-community-led-monitoring/

ITPC. Precision in a pandemic: guidance on CLM data quality assurance. 2022.
https:// itpcglobal.org/blog/resource/precision-in-a-pandemic/

WHO. Voice, agency, empowerment – handbook on social participation for universal health coverage. 2021.
https://www.who.int/publications/i/item/9789240027794

MEASURE Evaluation. Data Demand and Information Use in the Health Sector: Conceptual Framework. 2011.
https://www.measureevaluation.org/resources/publications/ms-06-16a/at_download/document

2.2 What do CLM data look like and where are they collected?

CLM data can cover **various topics** related to availability, accessibility, acceptability and quality of services related to health and human rights (Table 4). They can be collected and reported by recipients of care and affected communities from **various locations**. This includes data collected by recipients of care and affected communities at points of service delivery (such as hospitals or clinics) or outside of service settings (such as places of employment and other social settings, through community mobilization and participation, through crowdsourcing of CLM data directly from affected communities, and through periodic data collection by CLM implementers).

CLM data are typically collected and recorded **on paper or in digital form** using hand-held phones or tablets. They are then **compiled** in spreadsheets or databases, and finally synthesized and presented in reports, documents, in-person presentations, and wider dissemination channels.

TABLE 4 Examples of CLM data

Examples of CLM data topics	Examples of insights that can be gathered
AVAILABILITY	
Availability of services and products	*"I have MDR TB and I do not have access to MDR-specific drugs"* *"The local health center did not have molecular testing for HIV or TB, and I did not receive a referral".* *"I am a migrant worker and the designated treatment center denied me an appointment"*
Availability of comprehensive and accurate health information	
Discrimination or denial of services based on various factors	
ACCESSIBILITY	
Physical accessibility (e.g. distance, safety)	*"I am not able to get tested for HIV because my health facility is far away and the route is not safe."* *"I was asked to pay for a malaria rapid diagnostic test but it should be available free of cost."* *"I am a sex worker. I am moving to a new district and my TB treatment center has not transferred my file."*
Financial accessibility (e.g. user fees or other expenses)	
Opening hours and administrative procedures	
Other barriers such as inadequate access to social protection, stigma, discrimination, violence	
ACCEPTABILITY	
Experiences of stigma, discrimination or human rights violations	*"My health centre is staffed by male health workers only, which makes me uncomfortable to seek care"* *"I did not receive information in a language I understand."* *"The service provider told my family about my HIV diagnosis without my consent."*
Reasons people do not seek or utilize the health services they need, such as gender norms and social acceptability of male/female health care providers	
Preferences of users and affected communities in relation to the patient-provider interaction, such as the language used, cultural beliefs, etc.	

Examples of CLM data topics	Examples of insights that can be gathered
QUALITY	
Relative wait times or turnaround times to receive test results	*"It has been more than 2 weeks since I tested for TB but have not received the test results yet."* *"I have a drug side effect from my HIV treatment but my service provider does not have the knowledge and resources to manage my condition."* *"Medicines are not being stored properly at my health centre."* *"The nurses are rude and make me feel uncomfortable when I go to pick up my HIV medicines, because I am transgender."*
Referral mechanisms to other services	
Skills and competencies of providers	
Respect of clinical protocols	
Respect of hygiene, infection control and safety standards	
Experiences of stigmatizing or disrespectful treatment by service providers	
Use of services from unlicensed providers	
Individual health outcomes in relation to information and services received	

2.3 What is the added value of CLM data for a national health response?

CLM is complementary to other data used by decision-making authorities for program planning and improvement. It adds value to national health information systems in the following ways:

→ **Filling a gap in national health information systems by helping understand the underlying barriers that prevent national programs from achieving targets:** CLM tracks and reports information on the diverse barriers to availability, accessibility, acceptability, affordability, and quality of health services faced by affected communities. These can include long wait times, negative and stigmatizing interactions with health care providers, unexpected fees and stockouts of key tests and medicines, or human rights violations, such as discrimination and infringements of their privacy and confidentiality. By doing so, CLM provides

crucial data that national health information systems do not have access to. CLM helps to understand the underlying factors that prevent national programs from achieving their targets for core program indicators such as screening, testing, treatment, and treatment outcomes. It also complements other country quality management and improvement efforts to advance programmatic goals. CLM data are collected continuously, usually every month or every three months, alongside routine health management information systems (HMIS) and periodic population surveys. CLM data can be triangulated with national program key indicators to analyse and act upon the factors that may prevent national programs from achieving their targets.

Put another way: CLM data use is not just about airing complaints; it is about working together to fix problems.

→ Delivering people-centered services by making them more responsive to community needs: CLM data includes open-ended qualitative monitoring, adding nuance and detail about how health systems do and do not respond to people's needs. Recipients of care speak more freely to community members about the quality of the services they receive, enabling CLM to track the perspectives of recipients of care about their experience of programs and services (such as their concerns about stigma and discrimination, their perceptions of provider competency, and protection of privacy and confidentiality). Such information is essential to promote people-centered services and may not be captured by standard data collection categories.

→ Promoting evidence-based decision-making by bringing community voices and enhancing social participation: As a community-led effort, CLM provides decision-making authorities with independent and continuous evidence about the experience of recipients of care and affected communities. By engaging recipients of care in qualitative assessments of services and finding solutions to address barriers, CLM data overcome biases in health system reporting caused by hierarchies, organizational interests, or professional interests, and pave the way to improvements.

→ Promoting equity by helping reach key and affected populations: Data from routine HMIS and health surveys may not adequately capture all affected population groups. CLM tracks perspectives from key populations for HIV (including sex workers, men who have sex with men, people who inject drugs, trans persons, and people in prisons and other closed settings), as well as populations that may be marginalized or hard to reach (such as mobile and migrant populations). CLM can help service providers understand their reasons for avoiding or not benefitting from available services, and identify actions to reach key and affected populations and promote equity.

→ Protecting and promoting health-related human rights by documenting violations and breaches: CLM data captures information about people's health-related human rights, including the rights to health, non-discrimination, information, and privacy and confidentiality. CLM data about the

availability, accessibility, acceptability, and quality of health services directly relates to the fulfillment of communities' right to health. CLM data reveal discrimination in health care settings against members of particular groups or based on individuals' health status, which violates the right to be free from discrimination. CLM data document the failure to provide people with accurate and comprehensive information about their health and health services, which constitutes a failure to fulfill the right to information. CLM data also demonstrate breaches of confidentiality or privacy in health care settings or elsewhere, which violate the rights to privacy and confidentiality. By collecting and responding to human right violations, CLM can protect and promote the rights of the affected populations.

→ **Building collaboration between communities and decision-making authorities:** CLM data are collected through an empowerment approach, which informs and organizes communities for engagement in health and health systems and responses, and brings recipients of care into dialogue with clinic staff and other providers to identify and solve practical issues in program delivery. Put another way: CLM data use is not just about airing complaints; it is about working together to fix problems.

2.4 What do we mean by data use for decision-making?

Data are used when stakeholders explicitly consider information — including both positive and negative findings — in one or more steps in the process of policymaking, program planning and management, service provision, addressing barriers to service access, and the protection and promotion of human rights. Data use thus involves two key elements: those who make decisions; and the decisions they make. The actual information that is used may differ among decision-makers; the important issue is whether they are aware of all available information and are able to apply it in their decision-making processes. The more positive experiences a decision-maker has in using information to support a decision, the stronger their commitment to support the data collection systems – in other words, increased data use in turn stimulates greater demand for data.[15]

A decision is a choice. People make choices all the time, for themselves as individuals, as professionals, or as members and leaders of organizations. In health, decisions can range from daily individual behavioral choices related to health and health-seeking behaviour, to major decisions by managers, policy-makers and other decision-making authorities that have an impact on the health of communities and countries.

Decision-making is not always based on objective facts. People make decisions based on:

- → Past experience and the current situation of engrained practices and routines
- → Expectations and values about what is possible and what is acceptable
- → Economic considerations of what is possible and what benefits economic interest
- → Institutional and organizational considerations of hierarchy and levels of authority

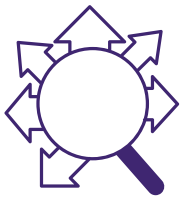
(15) MEASURE Evaluation. Data Demand and Information Use in the Health Sector: Conceptual Framework. 2011.

- → Subjective factors, such as instinct and opinion, power and influence, ideology, or other interests
- → Biases and discriminatory attitudes and beliefs about certain groups of people or kinds of behaviors

The World Health Organization (WHO) and other global normative agencies strongly recommend evidence-based decision-making in health with the meaningful engagement of populations, communities, and civil society in national health decision-making processes.[16] Evidence-based decisions rely upon data and information from multiple sources that include qualitative data on the perspectives, needs, challenges, and expectations of people and communities themselves.

2.5 How can stakeholders use CLM data for decision-making?

Different stakeholders will require and use different types of data to take various decisions and actions (Figure 4).



Community organizations, advocates and lawyers, including CLM implementers, can use the data to educate and empower communities; represent community interests; advocate for improving services, programs and policies; identify issues, barriers and bottlenecks faced by communities; and hold decision-making authorities accountable.

Decision-making authorities (health and social service providers, and managers at facility and program levels) can use the data to understand local service quality and access issues that are preventing programs from achieving their goals; adjust services, programs and policies; and protect and promote human rights.

Decision-making authorities (technical partners and funders) can use the data to obtain a more complete picture of the quality and impact of programs alongside other data sources; and allocate resources to address the issues.

Recipients of care (including individuals and communities) can use the data for self-empowerment, making better informed choices related to health and health-seeking behaviour; and holding decision-making authorities accountable.

(16) World Health Organization. Voice, agency, empowerment – handbook on social participation for universal health coverage. 2021, (https://www.who.int/publications/i/item/9789240027794)

FIGURE 4 Stakeholders can use CLM data for taking various decisions

AVAILABILITY e.g. the local health centre does not have drugs to treat MDR-TB

- *I will alert my district health officer immediately* — CLM IMPLEMENTER
- *I will conduct a spot-check and request for an emergency delivery of stocks* — DISTRICT HEALTH OFFICER
- *I will check on the commodity forecasting and quantification data, and the delivery schedule of the next order* — FUNDING PARTNER
- *I will obtain information on the next nearest health facility where the drugs may be available* — TB PATIENT

ACCESSIBILITY e.g. a fee is being charged for a malaria test, contrary to national policy

- *I will verify the issue and raise it at the next facility data review meeting* — CLM IMPLEMENTER
- *I will take corrective action and enforce application of national policy* — FACILITY MANAGER
- *I will formally engage relevant authorities for reimbursement* — LAWYER REPRESENTING COMMUNITY INTERESTS
- *I am now aware of my rights and will inform my peers* — COMMUNITY MEMBER WHO WAS CHARGED A FEE

ACCEPTABILITY e.g. service uptake has decreased due to complaints of discrimination at health facilities

- *I will gather additional qualitative information to understand and document the experiences, and provide information to community members on peer support groups* — CLM IMPLEMENTER
- *I will introduce a formal complaints mechanism, and request funding for a refresher training of all staff on providing non-discriminatory care* — FACILITY MANAGER
- *I will support the delivery of a refresher training for all health care staff in the district* — TECHNICAL PARTNER
- *I am now aware of my rights and will reach out to a peer support group for help* — COMMUNITY MEMBER WHO EXPERIENCED DISCRIMINATION ON ACCOUNT OF SEXUAL ORIENTATION

QUALITY e.g. there are long waiting times to receive test results, resulting in treatment delays

- *I will analyse the data and present them at the next district data review meeting, at which I represent my organization* — CLM IMPLEMENTER
- *I will triangulate this information with routine program data and seek solutions for timely sample transportation to the district laboratory and return of results by SMS* — DISTRICT CHIEF MEDICAL OFFICE
- *In the next funding request to a funding partner, I will seek funding for a new laboratory sample transportation and information management system* — NATIONAL DISEASE PROGRAM MANAGER
- *I will disseminate this analysis through social media and other communication channels to advocate for change* — COMMUNITY ORGANIZATION

3. BUILDING READINESS, CAPACITY & SUSTAINABILITY FOR CLM DATA USE

The readiness to use CLM data depends on familiarity with CLM and its objectives, the value added of these data, and the availability of skills and resources to apply these data and take action. Both CLM implementers and decision-making authorities need a range of capacities and resources to ensure effective data use.

Table 5 provides checklists for these capacities. It is useful to assess and build these capacities early with the start of CLM activities. Further, CLM implementers should engage with decision-making authorities early in the CLM design and implementation process in order to secure their buy-in for CLM activities and address negative perceptions that these authorities may have about CLM. In general, the more positive experiences users have in applying CLM data to support a decision, the stronger their commitment to continue engaging with and supporting the strengthening of those data systems.[17]

Financial sustainability is an important consideration for ensuring the routine implementation of CLM over the long term. For CLM to be regularly

TABLE 5 Capacities for CLM data use

CHECKLIST FOR CLM IMPLEMENTERS

INDIVIDUAL CAPACITIES	TECHNICAL CAPACITIES	ORGANIZATIONAL CAPACITIES
I can: ✓ Explain concepts and categories of CLM data ✓ Explain the value and use of CLM data ✓ Review, analyse and synthesize CLM data (or procure these skills externally as needed)	**I have access to:** ✓ Basic equipment such as smart phone, tablet, computer and connectivity ✓ Software, such as spreadsheets and databases, shared files, and data analysis and presentation programs, to review, analyse and interpret CLM data	**My organization has:** ✓ Staff time and resources allocated to access, review, share and communicate CLM data (e.g. M&E officer, IT support) ✓ Clear internal processes for CLM data use, including authorizations for data access and sharing; and dealing with conflicting information from CLM and other data

(17) Measure EVALUATION. Data Demand and Information Use in the Health Sector: Conceptual Framework. 2011. (https://www.measureevaluation.org/resources/publications/ms-06-16a/at_download/document)

CHECKLIST FOR CLM IMPLEMENTERS

INDIVIDUAL CAPACITIES	TECHNICAL CAPACITIES	ORGANIZATIONAL CAPACITIES
I can: ✓ Understand the human rights implications stemming from CLM data related to services and programs ✓ Understand human rights concerns around data privacy and security, and take appropriate measures	**I have access to:** ✓ Regional or national platforms where CLM data be shared, including technical interoperability of databases where needed ✓ Robust technical protections for CLM data privacy and network security	**My organization has:** ✓ Mechanisms to prioritize issues to raise with decision-making authorities; and anticipating actions ✓ Capacities for sharing CLM data findings and engaging in advocacy efforts ✓ Clear policies for data privacy and network security; and addressing breaches or misuse in that security ✓ Adequate financial resources for sustaining CLM over time, and an analysis of resource needs and gaps

CHECKLIST FOR DECISION-MAKING AUTHORITIES

INDIVIDUAL CAPACITIES	TECHNICAL CAPACITIES	ORGANIZATIONAL CAPACITIES
I can: ✓ Understand the value and use of CLM data ✓ Review, analyse and use CLM data in my decision-making ✓ Understand the human rights implications stemming from CLM data related to services and programs ✓ Understand human rights concerns around data privacy and security, and take appropriate measures	**I have access to:** ✓ Basic equipment such as smart phone, tablet, computer and connectivity ✓ Software, such as spreadsheets and databases, shared files, and data analysis and presentation programs, with which to access and triangulate CLM data with other data sources ✓ Robust technical protections for CLM data privacy and network security	**My organization has:** ✓ Staff time and resources allocated to access, review and apply CLM data (e.g. M&E officer, IT support) ✓ Clear internal processes and protocols for review and use of CLM data by program/data experts within national programs ✓ CLM indicators reflected as part of national M&E plans ✓ Capacities for using CLM data findings in program decision-making ✓ Clear policies for data privacy and network security; and addressing breaches or misuse in that security

used for decision-making, it needs to be fully funded. It is also important that CLM efforts do not rely exclusively on external donor support, technical assistance, or other support. Community implementers should have the capacities and resources to be able to maintain data collection efforts and undertake data analyses, sharing, communication, and advocacy (Table 6).

TABLE 6 Planning and budgeting for CLM data use capacity

The Global Fund supports CLM as one of the four priority interventions to strengthen community systems and integrate human rights and gender considerations into programming for key and vulnerable populations.[18]

The Global Fund also supports investments in data systems towards which CLM can contribute. This includes the maintenance and strengthening of health information systems, program quality assessments, data quality review and improvements, and capacity building for data analysis and use.[19] Various resources are available to help CLM implementers and other stakeholders ensure that the funding required for CLM data use is adequately integrated in funding requests, implementation plans, and budgets for activities related to M&E and community systems supported by the Global Fund and other funders and partners.

For more information, see:

The Global Fund. Community Systems Strengthening (CSS) Technical Brief. 2022.
https://www.theglobalfund.org/media/4790/core_communitysystems_technicalbrief_en.pdf

IAS – the International AIDS Society. A guide to support inclusion of CLM in funding requests to the Global Fund. 2022.
https://www.differentiatedservicedelivery.org/wp-content/uploads/IAS-CLM-Guide-final.pdf

ITPC, EANNASO, Health Gap, and Anglophone Africa Regional Platform. Integrating Community-led Monitoring (CLM) into Global Fund C19RM Funding Requests. 2021.
https://itpcglobal.org/resource/integrating-communityled-monitoring-clm-into-c19rm-funding-requests

ITPC. How to Implement Community-led Monitoring: A community toolkit. 2021.
https://itpcglobal.org/blog/resource/how-to-implement-community-led-monitoring-toolkit/
(section on Resourcing and financing of CLM, page 37)

EANNASO, Anglophone Africa Regional Platform, Frontline AIDS, and the Stop TB Partnership. Community Led monitoring: A Technical Guide for HIV, Tuberculosis and Malaria Programming. 2021.
https://stoptb.org/assets/documents/resources/publications/acsm/CBM%20Guide%20Report_Final%200309_compressed.pdf (section on Integrating CLM into funding requests to the Global Fund, page 10)

The Global Fund. Considerations for Global Fund Support to the COVID-19 Response, including Health and Community System Strengthening, and Mitigation of COVID-19 effects on HIV, TB and Malaria Services and Programs. 2021.
https://www.theglobalfund.org/media/10749/covid19_c19rm-technical_informationnote_en.pdf

The Global Fund. Guidance Note on Essential Monitoring and Evaluation Investments. 2020.
https://www.theglobalfund.org/media/6501/me_essentialsetdatasysteminvestments_guidance_en.pdf

(18) The Global Fund. Community-based monitoring : An Overview. 2020.

(19) The Global Fund. Guidance Note on Essential Monitoring and Evaluation Investments. 2020.

4. CLM DATA USE IN DECISION-MAKING

Data use can be thought of in three parts (Figure 5).

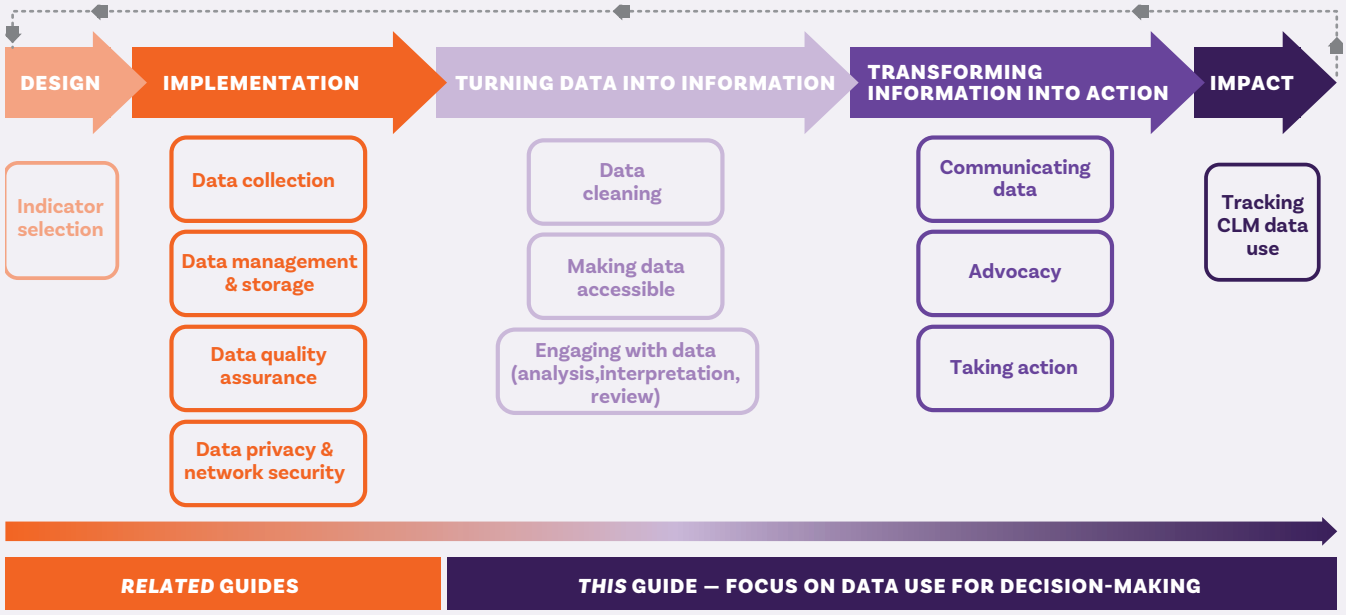
Turning data to information: The CLM implementers first have to clean the raw data. Once this has taken place, implementers analyze the data. The cleaned, de-identified and anonymized data can also be made available to other stakeholders, who may analyze it at their end. Once analyzed, the findings are turned into actionable information; in other words, the findings are interpreted to identify issues and potential solutions, and communicated to decision-making authorities.

Transforming information to action: Once the information is available to decision-making authorities, CLM implementers advocate for change, and decision-making authorities identify actions to be taken.

Achieving impact through joint action and accountability: Finally, the competent decision-making authorities take the actions that have been agreed upon, and progress is jointly tracked to ensure mutual accountability.

CLM implementers and decision-making authorities each have roles to play at the different steps of data use, as described in the sections below. It should be noted that the protection and promotion of people's rights to privacy and data confidentiality is central in each step of the data journey. [20]

FIGURE 5 CLM data use in the context of the CLM data journey



(20) Stop TB Partnership. Data Privacy and Network Security User Manual. https://stoptbpartnershiponeimpact.org/resources/Training Tools/OneImpact CLM Data Privacy and Network Security User Manual.pdf

4.1 Turning data into information

4.1.1 Data cleaning

What does this step involve?

Data collected through CLM efforts need to be cleaned as close as possible to the time and place of data collection, to catch and remedy errors in data collection and to catch and respond to problems described in services and programs.

Typically, CLM implementers clean the raw data to make them usable. In some cases, they may engage the support of another entity, such as an external technical assistance or service provider. Ideally, raw data will not include any personally identifiable information, but if it does, raw data containing such information should never be shared with government authorities or private enterprises.

It should be noted that some CLM data provide alert signals that need to be acted upon in real time to address bottlenecks faced by individuals and affected communities in the cascade of care.

CHECKLIST FOR CLM IMPLEMENTERS

- ✓ Are there real-time data that provide alerts for immediate action at the individual, community or program level? If yes, what action can we take?
- ✓ Has the raw CLM data set been cleaned?
- ✓ Do we have the capacity (skills and resources) to conduct the data cleaning in-house? If not, who will conduct the data cleaning? Have we planned for this?
- ✓ If the data cleaning is done by another entity, have we ensured that the raw data set is de-identified and anonymized?
- ✓ If the data cleaning is done by another entity, do we have access to the cleaned data set?
- ✓ Do we have protections in place for confidentiality and privacy of individual community members?

CHECKLIST FOR DECISION-MAKING AUTHORITIES

- ✓ Are there real-time data that provide alerts for immediate action at the individual, community or program level? If yes, what action needs to be taken?
- ✓ Is a cleaned, de-identified and anonymized CLM data set available to us?

Data are initially available as "raw data", that is, in the form in which they have been collected. CLM implementers "clean" the raw data to make them usable for analysis (Table 7). Even the raw data must include robust protections for the confidentiality and privacy of individual community members. In particular, strict role-based access controls must be in place to ensure that raw data containing personally identifiable information (PII) of community members, if collected, is never accessed or shared with anyone outside a small and limited group of CLM managers. Ideally, CLM data will not include PII, but if it does, raw data containing PII should never be shared with government authorities or private enterprises.

TABLE 7 Checklist of steps to clean raw data sets for analysis

A "raw" CLM data set, made up of the primary data as they were collected, must be cleaned, a process that refers to assessing and converting the "raw" data set into a form that is suitable for analysis.

Data cleaning typically involves the following steps:

- ✓ Removing all personal identifying information by de-identifying or anonymizing the data
- ✓ Assessing the completeness and timeliness of the data
- ✓ Ensuring completeness of data reported across all sites and for agreed reporting periods
- ✓ Ensuring that data field names are in a consistent readable format (guided by a data dictionary)
- ✓ Ensuring that all values are in a consistent format (such as checking numerical formats, spellings)
- ✓ Ensuring readability especially for qualitative data collected via paper form
- ✓ Removing duplicate values
- ✓ Correcting entry errors and removing erroneous or irrelevant observations
- ✓ Addressing missing values (for example, indicating no reporting or data not available)
- ✓ Removing outliers and anomalies

The source data may be collected in paper or electronic forms. The raw data are then commonly compiled in MS Excel, which provides a number of functionalities for data cleaning and analysis. Many other data analysis software and tools are also available to manage and analyze large data sets. These include STATA, SAS, SPSS, and Epi Info for quantitative data analyses, NVIVO or Atlas for qualitative analyses, and Tableau for data visualization.

When cleaning or manipulating data sets, it is good practice to always maintain a backup or a copy of the data that can be reverted to when necessary 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 can be written up and applied consistently. It is a good idea to keep track of the number of errors that are identified and corrected during this process as this gives an idea of the level of data quality.

For more information, see:

ITPC. Precision in a pandemic: guidance on CLM data quality assurance. 2022.
https:// itpcglobal.org/blog/resource/precision-in-a-pandemic/

MEASURE Evaluation. Data Demand and Information Use in the Health Sector: Conceptual Framework. 2011.
https://www.measureevaluation.org/resources/publications/ms-06-16a/at_download/document

UNECE. Making Data Meaningful. Four practical guides. 2009.
https://unece.org/statistics/making-data-meaningful#:~:text=Four%20practical%20guides%20to%20help,strategies%20for%20improving%20statistical%20literacy

4.1.2 Making data accessible

What does this step involve?

Once data have been cleaned and secured, CLM implementers need access to the cleaned data sets for analysis. They may also provide decision-making authorities or external service providers with access to the data for analyses. In this case, they determine the formats and channels through which the data will be made available, keeping in mind that the protection and promotion of people's rights to privacy and data confidentiality is paramount.

CHECKLIST FOR CLM IMPLEMENTERS

- ✓ Do we have access to the cleaned CLM data set to proceed with internal analysis?
- ✓ In cases where the cleaned CLM data set is also made available to other stakeholders prior to internal analyses, have we de-identified or anonymized all data so that the personally identifiable information (PII) of individual community members has been fully removed?

CHECKLIST FOR DECISION-MAKING AUTHORITIES

- ✓ Do we wish to access the cleaned CLM data set for our own data triangulation and analyses?
- ✓ If yes, which data, in which format, and through which channel do we wish to access the CLM data in order to be able to take action? Are the data available to us in formats that are readily usable?

CHECKLIST FOR CLM IMPLEMENTERS

- ✓ Which data will be shared, and with whom? Have we established agreements and processes for sharing CLM data? Do we have policies in place to ensure data privacy and security?
- ✓ Do we know the right timing to share CLM data to facilitate analysis and use alongside other health data being generated in the country (for example, national HMIS reporting cycles, and timing of key partner coordination meetings, such as Global Fund Country Coordinating Mechanism meetings)?
- ✓ Are we sharing the data in formats that will be compatible with other relevant data sets?

CHECKLIST FOR DECISION-MAKING AUTHORITIES

- ✓ Have we established agreements and processes for accessing CLM data? Do we have policies in place to ensure data privacy and security?
- ✓ Have we informed the CLM implementing organization of national data reporting and analyses schedules?

CLM implementers can make data accessible in various formats and through different channels (Figure 6).

FIGURE 6 Formats and channels through which cleaned CLM data can be made available to data users

	RAW DATA →	PRELIMINARY ANALYSES →	KEY MESSAGES AND RECOMMENDATIONS
Purpose	Data cleaning	Data analysis (key findings and synthesis)	Data interpretation (identifying issues and potential solutions)
User	CLM implementers	CLM implementers and/or other stakeholders, such as health and social service providers, managers at facility level, data/M&E experts, partners	CLM implementers and/or other stakeholders, such as managers at policy and program level, data/M&E experts, partners, community advocates, recipients of care
Channel through which the data are accessed	CLM databases (such as Excel or other data management software) with raw data	• Direct access to cleaned data sets (for example, through web portals) • Periodic data sharing (for example, sharing spreadsheets or database extracts) • Sharing preliminary analyses in reports and presentations • Interactive database queries	• Presentations • Communications via listservs, media, and social media
Data privacy and security measures	De-identifying and anonymizing data during data cleaning	Establishing written agreements to ensure that CLM data ownership rests with CLM implementers and to ensure data privacy, network security, role-based access, and confidentiality	Human rights and ethical norms and standards to frame and highlight key findings

There are **specific considerations related to sharing CLM data with the broader national health information system,** such as the engagement of decision-making authorities, the process for sharing the data, the ownership of the data, privacy, network security, timing of data reporting and reviews, and compatibility of data formats (Table 8).

TABLE 8 Considerations for CLM implementers when sharing CLM data with decision-making authorities

- **Engage decision-makers early in the CLM process and establish data-sharing processes:** To enable and encourage decision-makers in the government sector to use CLM data, CLM implementers should engage them early in the CLM design and implementation process and agree (through dialogue and formal agreements) on policies or processes for sharing these data. For example, a CLM implementer can develop a formal data-sharing agreement or a CLM/human rights data-sharing platform with a Ministry of Health, a Global Fund Country Coordinating Mechanism (CCM), or a PEPFAR country office in connection with international grant performance reviews. Early engagement also ensures that decision-makers in the government sector can use CLM data to understand and respond to programmatic gaps, and fulfill their responsibility to make quality health services available, accessible, acceptable to all free from stigma and discrimination.
- **Ensure CLM data ownership, data privacy, network security, role-based access, and confidentiality agreements:** In negotiating agreements for data sharing, it is important to establish - through written agreement - that the ownership of CLM data rests with the CLM implementers. As noted above, it is also critical to ensure that all PII, if collected during CLM, is removed from any data shared outside of the CLM implementing organization. In practice, this means that CLM data must be de-identified or, preferably, anonymized, before it is shared. Protocols and technologies should be used to ensure the security of the computer network used to collect, store, transfer, and process CLM data. These include strong password policies to access any kind of CLM data, multi-factor authentication to access any computer or device on the network, role-based access controls, anti-virus software, use of virtual private networks for remote access to the network, data encryption for all data in transit and at rest, and network segmentation for any sensitive data. For role-based access, CLM implementers should designate specific roles with designated duties within an established hierarchy to which corresponding data access authorizations are granted. The underlying principle is to restrict access to the CLM network and data unless access is required for a specific role to effectively perform its duties. CLM implementers should develop and require all personnel involved in the project to sign a confidentiality agreement. The agreement should prohibit all personnel from disclosing, releasing, or using in any other unauthorized way any information collected during CLM on penalty of disciplinary or legal action, depending on the severity of the transgression.
- **Align CLM data reporting schedules:** Typically, data from the national health information system are consolidated and reported upwards to higher administrative levels on a monthly and quarterly basis, within four to six weeks of the end of each reporting period. The data are then reviewed by national disease programs and other units and also reported further to technical partners, funding partners, and others. It is useful for CLM implementers to be aware of these schedules so that they can make CLM data available at the right times in the country's health information management cycle.

→ **Prepare for key instances of national data review and use:** CLM implementers should be aware of the key national milestones for data review and use and, specifically, where it would be important to share CLM data. These milestones include preparation of national strategic plans, new funding requests for the Global Fund or annual Country Operational Plans for PEPFAR, national program reviews, and service quality assessments.

→ **Promote compatibility of indicator definitions and data formats:** For CLM data to be easily analyzed and used along with other data generated by national health information systems, it is important to ensure that the indicator definitions being used are aligned with national indicator definitions, so that data can be easily triangulated and cross-analyzed. It is equally important that CLM data are being gathered, stored, and managed in formats and with field names that align with country standards for health data (for example, including ethical and data security considerations).

→ **Promote compatibility in the use of digital technology:** The use of technology influences all steps of the data journey, starting with data collection, data management and storage, data analysis, and data use. For example, the use of community-focused digital interventions that allow affected communities to directly report challenges and provide feedback in a crowd-sourced manner can help mobilize community voices in real-time and help CLM implementers and first responders to act promptly upon the data and community needs. It is useful for CLM implementers to be aware of the data platforms that are being used by the national routine health information system to ensure that systems can be compatible or interoperable as needed. The users of CLM data should also have access to the right technology to be able to access CLM data and conduct analyses. This includes compatibility with data security considerations and ethical considerations.

For more information, see:

ITPC. How to Implement Community-Led Monitoring: A community toolkit. 2021.
https://itpcglobal.org/blog/resource/how-to-implement-community-led-monitoring-toolkit/
(section on Technology Integration, page 22)

Stop TB Partnership. Data Privacy and Network Security User Manual. 2021.
https://stoptbpartnershiponeimpact.org/resources/Training Tools/OneImpact CLM Data Privacy and Network Security User Manual.pdf

4.1.3 Engaging with data (analysis, interpretation, review)

What does this step involve?

CLM implementers interrogate, analyze, interpret and review the data in-house. This may be done with internal staff or or with support from technical assistance or external service providers. Decision-making authorities who have access to CLM data may also conduct such analyses themselves, for example, to triangulate CLM data with data from national program reporting. In this case, the analyses should be shared with CLM implementers.

What does this step involve?

Once the data have been analyzed, CLM implementers and decision-making authorities both need to determine possible courses of action to respond to the issues raised.

CHECKLIST FOR CLM IMPLEMENTERS

ANALYSIS:

- ✓ What kinds of analyses are required to gather insights from the data?
- ✓ Do we have the capacity (skills and resources) to undertake data analyses in-house? If not, who will analyze the data? If additional resources (such as technical assistance, training, engaging an external service provider) are needed, do we have the resources to procure this expertise?
- ✓ Have we thought about ways to build capacity for data analyses within the CLM implementing organization?

INTERPRETATION:

- ✓ What do the data tell us? Do the findings suggest anything new? Are the data of adequate quality?
- ✓ Do the findings correlate with other evidence and experience?
- ✓ What further data or analyses may be needed?
- ✓ Which key findings are most relevant? How can we drive change? At which level? What actions can we take?

REVIEW:

- ✓ Have we scheduled a meeting to review the data jointly with all stakeholders?
- ✓ Which decision-makers should be part of the CLM data review meeting? What is the right timing of the meeting? Which findings will be shared at the meeting?
- ✓ What challenges do we anticipate around sensitive data or issues and how best can we prepare to handle them?

CHECKLIST FOR DECISION-MAKING AUTHORITIES

ANALYSIS:

- ✓ Have we allocated resources to cross-analyze and triangulate CLM data with data from other sources?
- ✓ How will we share our analyses with the CLM implementers?
- ✓ If the CLM implementing organization requires additional skills and resources for this, can we support capacity-building efforts?

INTERPRETATION:

- ✓ What do the data tell us? Do the findings suggest anything new? Are the data of adequate quality?
- ✓ Do the findings correlate with other evidence and experience?
- ✓ What further data or analyses may be needed?
- ✓ Which key findings are most relevant? How can we drive change? At which level? What actions can we take?

REVIEW:

- ✓ Have we scheduled a meeting to review the data jointly with all stakeholders?
- ✓ Are we aware of the next meeting when the findings from CLM data will be reviewed by stakeholders? Do we see the meetings as a joint opportunity to review the key issues and barriers faced by communities in order to take appropriate action at our level?

ANALYSIS

A deeper understanding of the data requires analyses to uncover useful insights (Table 9). It is helpful to prepare a data analysis plan to ensure that the "right" information is being collected from the start and that data can be collected and organized in a way that makes sense and can still account for any unintended consequences or unexpected findings that arise during collection.

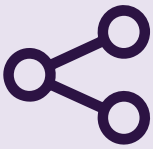
TABLE 9 Some basic concepts related to data analyses

QUANTITATIVE DATA ANALYSES

Trend analysis: This refers to comparisons of data over a period in order to understand changes or patterns over time, for example, trends over time in: antiretroviral therapy same-day initiation; TB diagnostic waiting times; real-time availability of malaria treatment; and experiences of stigma and discrimination for key populations or young people at health facilities.

Benchmarking: These refer to comparisons of data in relation to established standards or averages to understand how results compare with those from another comparable context and to understand gaps in performance. Examples are, for a reporting period: analyzing data on HIV testing in a community with the national aggregate value to assess whether the results for the community are above or below the national average and exploring underlying reasons; and comparing data on the proportion of people living with HIV who are screened for TB with the national target for this intervention.

Disaggregation: This refers to analyzing the data by sub-population categories, such as by age group, sex, gender, geographic location, other demographics and identities, or other variables to identify differences in patterns of service availability, accessibility, affordability, and quality. Examples are: analyzing the percentage of people reached with HIV prevention programs for different key populations; and analyzing the barriers to retention in TB treatment for various populations.



Comparison with other data sources and triangulation: This refers to comparing the data with other data sources to provide further insights, validate findings, and interpret results in the context of the wider context. An example is cross-analyzing data on the number of people living with HIV who experience treatment failure with data on stock availability of antiretroviral medicines for the same community and time period.

Advanced statistical analyses: While the analyses mentioned above are primarily descriptive, statistical analyses methods can also include more

advanced analysis types, such as regression analyses that track how changes in one variable affect changes in another. An example is analyzing the impact of demographic or social variables on the level of knowledge, attitudes, and practices related to HIV, TB, or malaria.

QUALITATIVE DATA ANALYSES

This refers to the analysis of non-numeric information, such as observations of health sites and services or interviews and focus group discussions with health workers or recipients of care. Qualitative data are collected in the form of notes, interview transcripts, and recordings. The analysis of such qualitative observations requires methods to categorize and code these observations, identify common themes, patterns and relationships, and summarize the findings. Qualitative data help explore in depth the underlying reasons for pertinent issues that arise in quantitative findings. Qualitative data analyses can thus be combined with quantitative data analyses to understand the full picture.

ANALYSES RELATED TO HUMAN RIGHTS AND LEGAL ISSUES

CLM data can be reviewed and analyzed to identify human rights and legal issues experienced by community members. For example, if users are experiencing stigmatizing treatment in health facilities, an analysis could be done to determine whether this is legal discrimination under applicable national or local law. If community members report concerns around privacy or confidentiality, a legal analysis could determine whether the incidents violate national or local laws protecting privacy or confidentiality of health information.

For more information, see:

ITPC. How to Implement Community-Led Monitoring: A community toolkit. 2021.
https://itpcglobal.org/blog/resource/how-to-implement-community-led-monitoring-toolkit/
(section on Data use for advocacy)

WHO. Analysis and use of health facility data. Toolkit. 2020
https://www.who.int/data/data-collection-tools/analysis-use-health-facility-data

MEASURE Evaluation. Data Demand and Information Use in the Health Sector: Conceptual Framework. 2011.
https://www.measureevaluation.org/resources/publications/ms-06-16a/at_download/document

UNECE. Making Data Meaningful. Four practical guides. 2009
https://unece.org/statistics/making-data-meaningful#:~:text=Four%20practical%20guides%20to%20help,strategies%20for%20improving%20statistical%20literacy

With the different types of data analyses, CLM implementers and decision-making authorities will interrogate the data to answer different types of questions (Table 10).

TABLE 10 Interrogating the data

1. Are the data valid and reliable?	
CLM implementers might ask:	**Decision-making authorities might ask:**
→ Do I trust the source of this information? → Do my peers trust it? → What is the quality of the data?	→ What are data sources and methods? → What is the quality of the data?

2. What do the data tell us?	
CLM implementers might ask:	**Decision-making authorities might ask:**
→ What are the key themes and concerns that emerge from the data? → What do the data tell us about service gaps and barriers faced by the community? → What do the data tell us about human rights and legal issues? → Are there any new and compelling findings that might be relevant to the needs of my community?	→ What are the key themes and concerns that emerge from the data? → How can CLM data complement and explain gaps in facility or program targets? → How do intended beneficiaries perceive and experience services and programs? → Are there any new and compelling findings that can complement what is known from other data, e.g. gaps in the service cascade or service quality, equity in service access by population or geography, stigma, discrimination and other structural barriers for missing cases along the care cascade and loss to follow up? → What are the specific needs and challenges experienced by key populations and other affected populations?

3. How do the findings correlate with other evidence and experience?

CLM implementers might ask:

- Does this information align with other information in the community, including personal experience or that of the community?
- What commonalities are present across the experiences of different kinds of community service users?

Decision-making authorities might ask:

- How do these CLM data compare with other data? e.g.:
- How do CLM findings about wait times, fees, and provider availability correlate with health facility reporting?
- How do CLM stockout reports correlate with country supply chain management data?
- How do drug adverse events correlate with pharmacovigilance data?
- How do CLM findings about people's utilization of community testing and prevention services correlate with reporting from community-based providers?
- How do CLM findings about people's experience of poverty, malnutrition, housing, violence, and stigma and discrimination based on gender or other demographics correlate with other social and demographic data?

4. Are the findings relevant and broadly applicable?

CLM implementers might ask:

- Does this information help with the challenges or needs of the community right now?
- Does this information help understand what the peers and community are experiencing?

Decision-making authorities might ask:

- Are the findings within my or my department's responsibility or purview?
- Are these findings potentially relevant to current initiatives to improve program and service performance?
- Are the findings potentially applicable to program and staff management and funding?
- Any applicability to law, policy, and guidelines development?
- How representative are the data of service delivery in the wider community, district and/or country?

5. What are the potential implied decisions or advocacy priorities?

CLM implementers might ask:	Decision-making authorities might ask:
→ Which stakeholders do we need to engage for action on these data? → What kinds of technical, financial or other support is needed to move this forward?	→ What are the potential decisions considering current policies, programs, and practices, current budgets, management capacity, and scope of authority? → What does the local committee or advisory group (such as the community consultative group) recommend? → Where can funding and technical assistance best assist the country in achieving its aims?

6. What further data or analyses are needed?

CLM implementers might ask:	Decision-making authorities might ask:
→ What more do we need to know in order to act? → What should we follow up on or look further into?	→ Are any further analyses or studies needed? → Are there questions to add to program quality assessments, facility monitoring, patient record reviews, or country population surveys? → How can future CLM tell us more?

INTERPRETING FINDINGS AND EXAMINING POSSIBLE ACTIONS

CLM implementers, decision-making authorities, and other data users will then interpret key findings and determine which actions they could take at which level to achieve intended improvements. Figure 7 provides some examples of how the different stakeholders may use the data to take action. In addition, Annex 1 provides a more comprehensive list of the types of findings and potential actions that would be relevant for different stakeholders.

FIGURE 7 Examples of findings and possible actions by different stakeholders

	Which findings could be relevant?	What kind of actions could be taken?
 CLM IMPLEMENTER	**e.g.** → x% of facilities reported a stock-out of an essential medicine in the last quarter (or real-time alert of a stock-out) → x% of key population community members reported stigma and discrimination in health facilities	**e.g.** ✓ advocate at local level for immediate action on the stock-out and ensuring reliable supplies in the long-run ✓ work with local service providers to address issues of stigma, and protect and protect human rights ✓ orient and organize communities to improve awareness and for advocacy ✓ document stigma and discrimination and formally engage institutions or authorities
 CIVIL SOCIETY & COMMUNITY GROUPS, INCLUDING LAWYERS	**e.g.** → x% of migrants report human rights violations in health facilities (or real-time alert of a violation) → x# qualitative reports of breaches of privacy or confidentiality of health information received	**e.g.** ✓ support CLM implementers and communities to document human rights violations and formally institutions or authorities responsible for rights violations through legal and other channels ✓ represent the interests of communities, protecting the rights of community members
 HEALTH & SOCIAL SERVICE PROVIDERS	**e.g.** → x% of service users report a negative experience at the facility → x% increase in rates of treatment interruption	**e.g.** ✓ review and adjust staffing assignments and protocols to provide comprehensive services in relation to people's needs ✓ improve coordination and collaboration across programs and sites ✓ review availability of health and human rights information in appropriate languages

	Which findings could be relevant?	What kind of actions could be taken?
MANAGERS AT FACILITY LEVEL	**e.g.** → # qualitative reports of challenges in service referral to secondary or tertiary levels → # qualitative reports of lack of adequate and easily understandable information available to the community	**e.g.** ✓ adjust services and program delivery across sites to address identified disparities ✓ expand the delivery of differentiated services that are tailored to meet the needs of population groups ✓ improve coordination and collaboration across programs and sites ✓ in funding proposals and plans, allocate resources to address inequities and improve quality
MANAGERS AT POLICY AND PROGRAM LEVEL (INCLUDING HEALTH PROGRAM AND DATA/M&E EXPERTS, AND OTHER SECTORS)	**e.g.** → variability in rates of retention or treatment success across sites or districts, which can be partly explained through CLM qualitative data findings on service availability → disparities in access by sex, age, key population or other population variables, which can be partly explained through CLM qualitative data findings on service acceptability	**e.g.** ✓ adjust services and program delivery across sites to address identified disparities ✓ expand the delivery of differentiated services that are tailored to meet the needs of population groups ✓ improve coordination and collaboration across programs and sites ✓ in funding proposals and plans, allocate resources to address inequities and improve quality
TECHNICAL & FUNDING PARTNERS	**e.g.** → triangulating CLM data alongside other data sources for a complete picture of program quality and impact	**e.g.** ✓ provide funding and technical assistance to support quality and effectiveness of existing services and programs and to fund new targeted initiatives to address identified gaps, disparities, and population needs.
RECIPIENTS OF CARE	**e.g.** → individual or community experience of service availability, accessibility, acceptability, quality	**e.g.** ✓ gain awareness of patient rights regarding access to quality health services ✓ gain awareness on what is available and seek out further information and services based on new knowledge ✓ access programs and services at different locations or with greater advance knowledge to achieve intended outcomes.

REVIEW

Once the key findings have been assessed, CLM implementers will determine the **forum and process through which CLM data can be jointly reviewed, validated, and discussed** (Table 11). It is important that these discussions take place in an environment that promotes open dialogue and discussion, including of negative findings. Key levels of meetings include:

- Community meetings
- Facility-level meetings, such as management and advisory committees, including CLM-specific data review meetings and community consultative group (CCG) meetings
- District or regional meetings with government health managers and advisory committees
- National meetings, including partner coordination mechanisms, such as Global Fund CCMs, National Stop TB Partnership Platforms, regular PEPFAR country meetings, or OneGroup meetings[21]

TABLE 11 Preparing a CLM data review meeting

A standard four-part sequence for a regular 60-minute meeting agenda may include the following:

- **A data report** by the CLM implementer with any summary patterns and limitations
- **Discussion of findings** to note what might be new, relevant, or applicable
- **Clarifications and validation of the findings**
- **Discussion of actions, including:**
  - local actions to immediate verify and resolve issues
  - next steps specific to the CLM initiative or other program monitoring and research
  - next steps to further share CLM data and related findings/ recommendations with other stakeholders

(21) OneGroups are defined in the OneImpact CLM model as a national network of experts and CLM decision-makers who use reported CLM data to provide oversight of the CLM initiative and findings to CLM partners. See the Stop TB OneImpact CLM Framework at: https://stoptbpartnershiponeimpact.org/resources/Conceptual%20Framework/OneImpact%20CLM%20Conceptual%20and%20Implementation%20Framework%20FN.pdf

4.1.1 Communicating data

What does this step involve?

CLM implementers develop the key messages emerging from the data, and communicate these to decision-making authorities and to the wider community, using effective data visualization and communication techniques, and respecting human rights and ethics.

CHECKLIST FOR CLM IMPLEMENTERS

- ✓ What are the key messages emerging from the data analyses?
- ✓ How will we present these to the relevant decision-making authorities to generate positive influence?
- ✓ What norms and standards should we use to frame and highlight key findings, such as human rights, ethics, and national law?
- ✓ How widely do we want to disseminate the findings of CLM data? To whom and how frequently? What are our objectives (what do we hope to achieve?) by sharing CLM data more widely beyond local and national stakeholders? What human rights and ethical concerns might arise and how should we handle them?

CHECKLIST FOR DECISION-MAKING AUTHORITIES

- ✓ Do we understand the key findings and messages that are being presented to us?
- ✓ Do we have enough background information to interpret these data in their context?
- ✓ How regularly do we receive information updates from CLM implementers?

To proceed towards the use of data for decisions and action, CLM implementers need to communicate the findings effectively to decision-making authorities and the wider community (Table 12). It is important for data users to feed the data back to the community that participated in the CLM process, in order to raise awareness that the participation of the community has resulted in follow-up and to prepare communities for their engagement with service providers and other decision-making authorities.

TABLE 12 Telling the story

To facilitate data use, the data need to be presented and communicated in ways that are meaningful for the users and will positively influence their decision-making. Those who are preparing the data for presentation to decision-making authorities should keep the following considerations in mind:

Respecting human rights and ethics: CLM data are a powerful source of information to make community voices heard, get experiences understood, and to amplify community involvement. It is important to use communication tools and products that tell the stories of people in the communities and the barriers and challenges that they face, but these should be told with their informed consent and with due respect to protecting rights to privacy, confidentiality, and security. The ownership of the materials created must remain with the community organizations with the permission of affected communities.

Tailoring to the audience: The different information needs of different categories of data users should be considered to ensure that the information presented is tailored to the audience, with the appropriate level of detail and complexity – keeping in mind the role of the user, their prior level of knowledge, their level of data literacy, and their information needs.

Using effective formats for data presentation and visualization: Data may be presented in various formats, including tables, charts or graphics, maps, and newer techniques, such as infographics and dynamic visualizations. The use of graphics is always an effective communication tool. An effective graphic should have a clear, visual message, and elements of a graphic should be used consistently to facilitate user understanding.

Messaging: The key findings and key messages emerging from the data should be communicated clearly, precisely, concisely, and as simply as possible to make maximum impact. The findings and conclusions should be in line with the scope, size, and representativeness of the collected data. For example, if data have been collected at a small number of service provision sites in a geographical area, then recommended actions cannot be proposed at the national level.

Placing the data in context: Adding narrative around the data with examples, comparison statistics, or real-world stories can provide additional perspective and influence how effectively the data are absorbed and retained. It is also important to be aware of contextual issues, such as the role, prior experience, or opinions and beliefs of decision-making authorities that may create bias and influence understanding.

Disseminating the findings: The findings can be disseminated through various channels, such as reports, briefings, slide decks, media articles, case studies, and social media. It is important to assess and select the right channels to reach the desired audience. It is critical that the data are communicated back to community members first, so that they can be part of advocacy and mobilization efforts and help build momentum for the change they seek.

CLM data also may be further disseminated to a wider audience (Table 13).

TABLE 13 Options for sharing CLM data more widely

(BY LENGTH AND COMPLEXITY IN DESCENDING ORDER)

- Long-form data reports, including from academic partners
- Short reports
- Policy and data update briefings
- Peer review journal publications
- Presentation slide decks
- Fact sheets
- Media articles
- Case studies
- Inclusion of data summaries and key messages in funding proposals
- Email and listserv updates
- Dashboard screen shots
- Infographics
- Regular messaging via mobile phone applications

4.2 Transforming information into advocacy and action

4.2.1 Advocacy

What does this step involve?

CLM implementers engage and negotiate with decision-making authorities and advocate for CLM data use to address the issues identified.

CHECKLIST FOR CLM IMPLEMENTERS

- ✓ To whom do we need to advocate and with which objectives?
- ✓ Do we have the capacity (skills and resources) for evidence-based advocacy?
- ✓ If additional resources (such as technical assistance and training) are needed to build this capacity, then do we have the resources to procure this expertise? Have we thought about ways to build capacity within the CLM implementing organization?

CHECKLIST FOR DECISION-MAKING AUTHORITIES

- ✓ Are we willing to engage with CLM implementers to co-create solutions to address the identified barriers and challenges?

To drive action, CLM implementers need to engage with decision-making authorities through **evidence-based advocacy** efforts to find joint solutions and drive action to change norms, guidelines, standards, policies, and practices to improve program quality and impact (Table 14). Advocacy is a specialized skill, and it is important to plan and budget for capacity building in advocacy for community-based organizations.

TABLE 14 Using CLM data use as part of advocacy efforts

Advocacy is the active promotion and defense of an opinion, a cause, a policy and/or a group of people. It is, at its essence, an effort to communicate with and influence those who hold power, and not only creating and defining obligations but also holding those in power to be accountable to those obligations.

CLM data are used in advocacy in several ways:

- → **Provide insights for potential advocacy priorities.** For example, CLM data can document disparities in access, human rights violations in health care settings, the role of social determinants in access, and potential improvements to be made in the accessibility, affordability, and quality of programs, thereby shaping priorities for advocacy about program improvements.
- → **Help to focus discussions with program implementers.** For example, advocates can attend regular CLM data review meetings at health facilities and use CLM data to work with health workers to improve service availability, accessibility, acceptability, and quality.
- → **Engage communities and build constituency support for issues and actions.** For example, where CLM data reveals needs to improve programs and services for specific key and vulnerable populations, that data can bring new visibility and allies to advocacy efforts.

→ **Help to frame and support arguments for changes in policies and laws, and can help to convince international donors of the need for increased and targeted funding.** For example, advocates can use CLM data findings in meetings of national health programs, national legal and human rights groups, and CCMs.

For more information, see:

CLAW Consortium. Community Evidence to Create Change. 2022.
https://healthgap. org/wp-content/uploads/2022/09/CLAW-Advocacy-for-Change.pdf

ITPC. How to Implement Community-led Monitoring: A community toolkit. 2021.
https://itpcglobal.org/blog/resource/how-to-implement-community-led-monitoring-toolkit/

ITPC, EANNASO, Health Gap, and Anglophone Africa Regional Platform. Integrating Community-Led Monitoring (CLM) into Global Fund C19RM Funding Requests. 2021
https://itpcglobal.org/resource/integrating-communityled-monitoring-clm-into-c19rm-funding-requests

4.2.2 Taking CLM-informed action

What does this step involve?

Decision-making authorities identify potential solutions in collaboration with CLM authorities, define concrete actions, and allocate adequate resources to implement those actions.

CHECKLIST FOR CLM IMPLEMENTERS

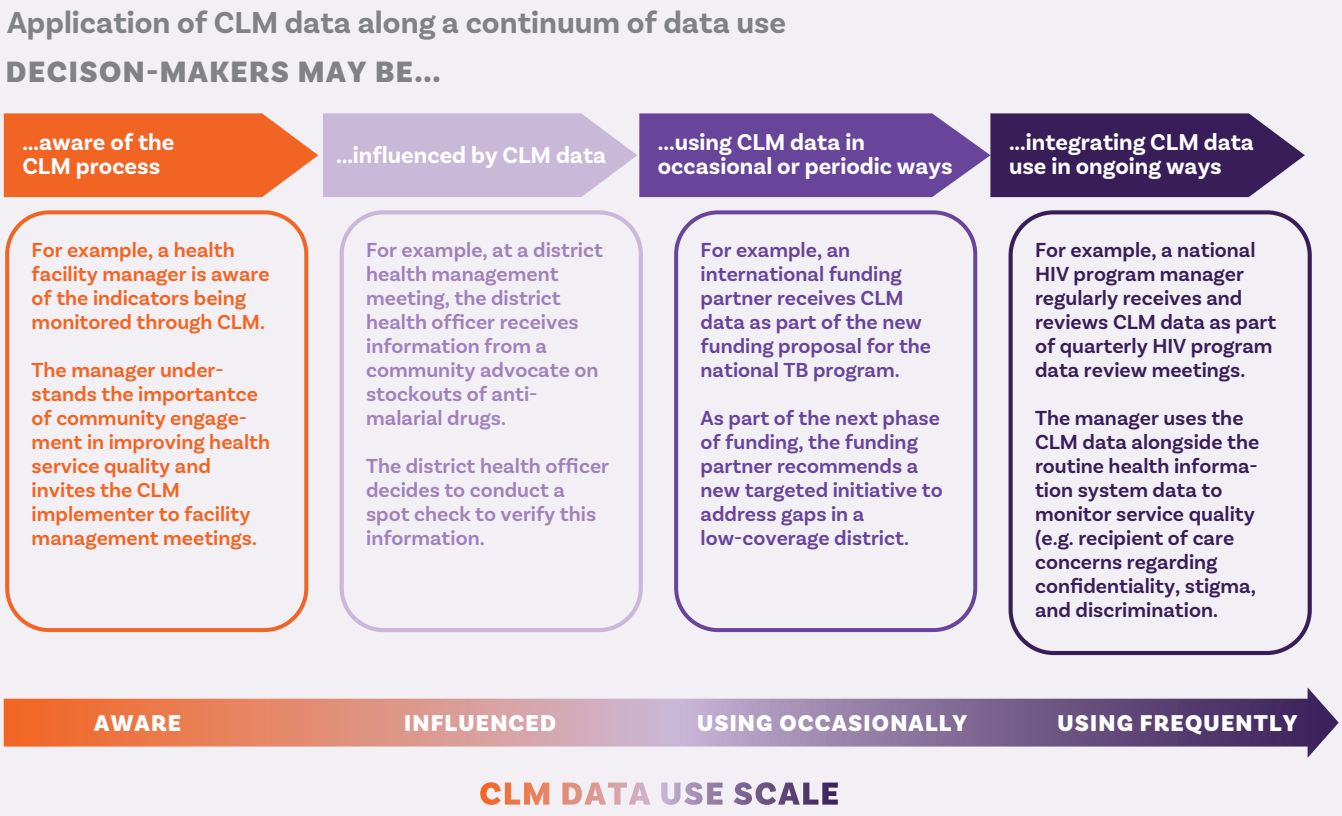
- ✓ What is the willingness and capacity of the relevant decision-making authorities to use CLM data for concrete action?
- ✓ What can I do to promote the use of CLM data in regular and ongoing ways?

CHECKLIST FOR DECISION-MAKING AUTHORITIES

- ✓ What is our willingness and capacity to use CLM data for concrete action?
- ✓ What are our barriers to the use of CLM data in regular and ongoing ways? how can these be overcome?

The extent to which decision-making authorities will use data for action depends on their willingness and capacity to do so. Data use can be thought of incrementally along a continuum of data use (Figure 8). For example, at a minimum, decision-making authorities may be simply aware of CLM data and influenced indirectly by the CLM process. Further along the continuum, decision-making authorities may be influenced by the findings and start to use CLM data in occasional or periodic ways, leading eventually to the integration and use of CLM data in their work on a regular and sustained basis.

FIGURE 8 A continuum of data use



Once the need for action has been identified, decision-making authorities should work with CLM implementers to assess options for the course of action, and translate these into concrete planning and budgeting of time and resources.

For example, for health program managers, CLM data use can result in the following types of decisions:

Resource allocations, for example:

- → Adjustments to service provision and program delivery to improve engagement, retention, and positive outcomes for recipients of care
- → Adjustments to resource allocations in country funding proposals, such as Global Fund-supported and PEPFAR-supported proposals, and plans to achieve greater quality and effectiveness of existing services and programs and create new targeted initiatives
- → Reallocations of funding and technical assistance to support quality and effectiveness of existing services and programs and fund new targeted initiatives to address identified gaps, disparities, and population needs

Program standards, protocols, and education and training, for example:

- → Meetings of service providers and service recipients to help solve identified challenges

- → Targeted education and organizing of communities to improve awareness and engagement
- → Adjustments to staffing protocols and improvements in staff and program management and trainings to improve performance toward intended outcomes.
- → Improvements in coordination and collaboration across programs and sites to address specific challenges
- → Sensitization and training for service providers to promote non-stigmatizing, culturally- and gender-sensitive, people-centered care, focusing on the concerns raised by community members in CLM data, particularly for key and vulnerable populations

Policies and research, for example:

- → Adjustments and improvements in HMIS, monitoring and evaluation, and community-led monitoring to further inform and drive program improvements
- → Reforms and improvements to laws, policies, programs, and services to address identified gaps, disparities, and population needs

4.3 Achieving impact through joint accountability

4.3.1 Tracking CLM data use

What does this step involve?

CLM implementers and decision-making authorities should jointly monitor the commitments made by decision-making authorities to address the problems identified by CLM.

KEY QUESTIONS FOR CLM IMPLEMENTERS	KEY QUESTIONS FOR DECISION-MAKING AUTHORITIES
✓ How will we track whether the agreed actions have been implemented by decision-making authorities?	✓ How will we track whether we have implemented the agreed actions?
✓ How will we assess the outcomes and impact of these actions?	✓ How will we assess the outcomes and impact of these actions?

Tracking the use of CLM data involves collecting information about whether the commitments made are being implemented in practice and, once implemented, whether these commitments are having the desired outcome (Table 15). To be effective, the tracking should be done jointly by the CLM implementers and the relevant decision-making authorities who are responsible and accountable for taking action.

It is helpful to track CLM data use for various purposes:

- → To document whether and how CLM data are influencing advocacy, services, policies and programs
- → To follow dynamics and trends in CLM data use to better understand how to share and communicate data
- → To explain the value of CLM as a source of evidence for advocacy, services, policies, and programs

TABLE 15 How can CLM data use be tracked?

There are a number of ways in which the use of CLM data may be tracked:

- → **Monitoring where and how CLM data are shared:** CLM implementers can monitor how frequently CLM data and related findings are shared with decision-making authorities and the communities that provided the data.
  - → **Key measure(s), for example:**

    Percentage of health service delivery sites with a community-led monitoring mechanism in place

    Number of community-based monitoring reports presented to relevant oversight mechanisms (such as Country Coordination Mechanisms)
- → **Monitoring who and how many accessed the information:** CLM implementers can also monitor who accessed the data and the feedback they receive about the use of data (for example, asked for more, signed up for more, said they learned something new, used in education, used in advocacy, contributed to solutions)
  - → **Key measure(s), for example:**

    Number of decision-making fora where CLM data are presented and discussed

    Automated updates on numbers of people accessing a web page, requesting access to a web portal, list serv, or other.
- → **Monitoring the decisions made and actions taken following CLM data use:** CLM implementers and decision-making authorities can jointly keep track of the decisions or commitments that are made, the timeframe, and the follow-up action undertaken. Community-based organizations that are part of national committees and processes for the development of national program strategies and funding proposals can also ensure that CLM data are reflected in the analyses in these documents.
  - → **Key measure(s), for example:**

    Tracking logs with information on commitments made, roles and responsibilities, timeframe, and follow-up

    References to CLM data and corresponding actions in funding proposals, national disease program strategies, and reports

    Integration of CLM data into national M&E plans, program performance dashboards, and other monitoring systems

→ **Monitoring the results in terms of improved program quality and impact: CLM implementers and decision-making authorities should jointly define how the success of the CLM action will be measured. This can include: improvements in availability, accessibility, acceptability, and quality of services; reduced barriers (including through greater affordability, improvements in services, systems, laws, policies, or practices that underlie identified problems); and improved quality of programming for health and greater respect for human rights, especially for key and vulnerable populations.**

→ **Key measure(s), for example:**

Routine service coverage and impact indicators, disaggregated by age, sex, and other relevant variable, or special studies, surveys (such as satisfaction surveys and scorecards), or evaluations.

Comparisons of evidence generated through CLM efforts (such as community scorecards and community treatment observatories] with national standards.

For more information, see:

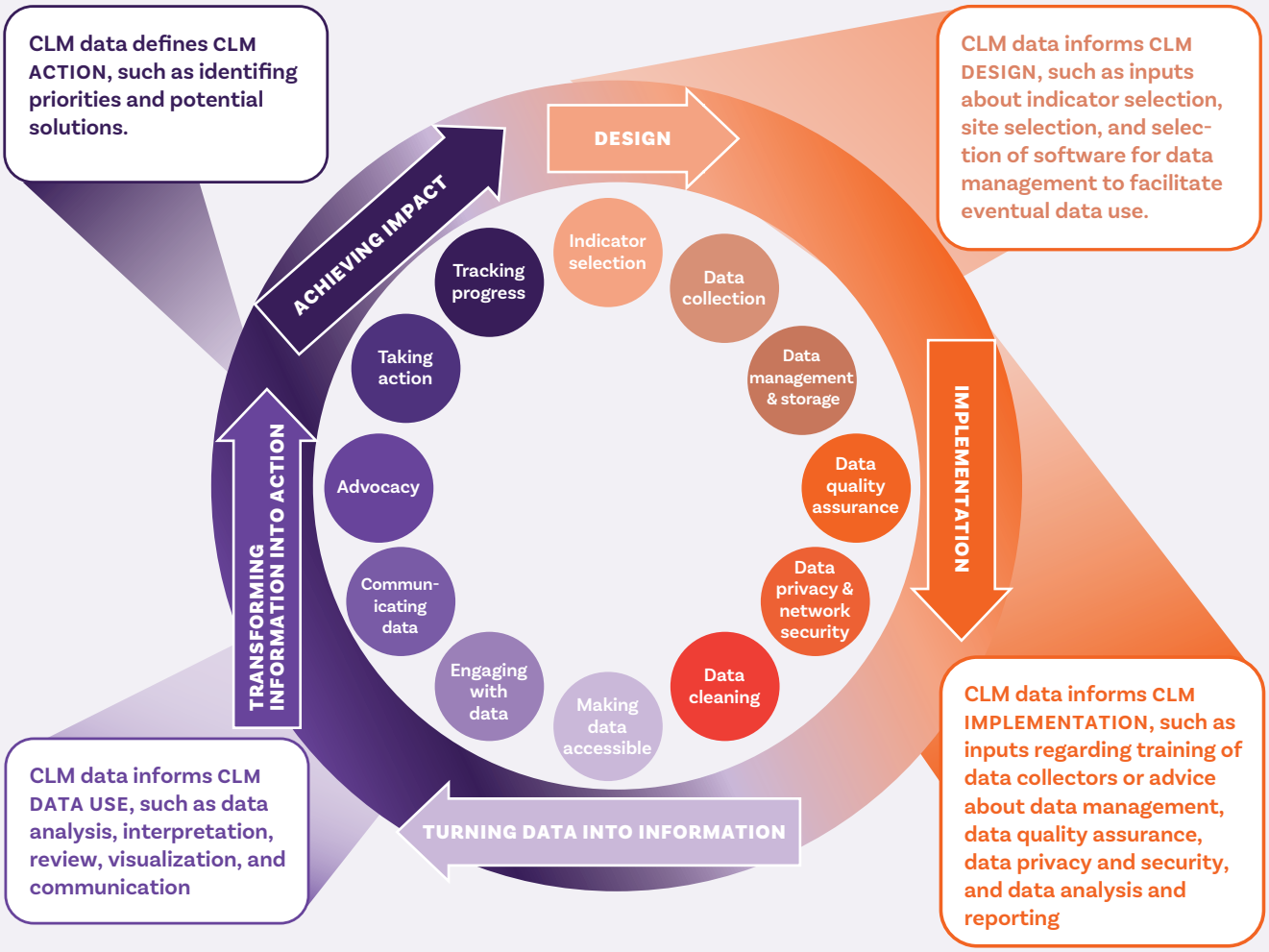
Stop TB Partnership. OneImpact Monitoring and Evaluation Plan. 2020.
https://stoptbpartnershiponeimpact.org/resources/M&E/M&E/STP%20CLM%20OneImpact%20M&E%20Plan.pdf

4.4 Bringing it all together

Finally, CLM data not only informs improvements in program quality and outcomes, but its use can also inform improvements in the design and effectiveness of CLM itself across the implementation cycle.

CLM implementers can use CLM data for continuous improvement in CLM design, implementation, data analysis and use, and action across the cycle of the CLM data journey (Figure 9).

FIGURE 9 Using CLM data to improve CLM implementation along the data journey



ANNEXES

ANNEX 1 EXAMPLES OF DATA FINDINGS & ACTIONS FOR CLM DATA USERS

COMMUNITY ORGANIZATIONS AND COMMUNITY ADVOCATES

CLM DATA USER	WHICH TYPES OF FINDINGS ARE MOST RELEVANT?	AT WHICH LEVEL COULD THEY DRIVE CHANGE?	WHAT KINDS OF ACTIONS COULD THEY TAKE?
CLM implementers	→ How can CLM data complement and explain gaps in program targets? How can they confirm or add nuance to other country data about programs and services? → What are current gaps and barriers in programs and services? → What human rights issues are community members facing? → How can programs and services be improved to better meet community needs?	**Community/local** **Program/central**	✓ Advocate at local and central levels for specific improvements in programs and services. ✓ Work with service providers to help solve identified challenges including human rights issues related to discrimination, information, and privacy and confidentiality that may affect availability, accessibility, acceptability, and quality. ✓ Orient and organize communities to improve awareness of health issues, gender, and human rights, and engage them in CLM data analysis and advocacy. ✓ Seek support from lawyers to document human rights violations or formally engage institutions or authorities responsible for rights violations through legal and other channels. ✓ Adjust and improve community-led monitoring to further inform and drive program improvements.
Lawyers, civil society, and community groups	→ What human rights and legal issues are community members facing? → Are there national or local laws protecting privacy or confidentiality of health information?	**Community/local** **Program/central**	✓ Support CLM implementers and communities to document human rights violations or formally engage institutions or authorities responsible for rights violations through legal and other channels. ✓ Represent the interests of communities, protecting the rights of community members, and advocating for programmatic change.

DECISION-MAKING AUTHORITIES

CLM DATA USER	WHICH TYPES OF FINDINGS ARE MOST RELEVANT?	AT WHICH LEVEL COULD THEY DRIVE CHANGE?	WHAT KINDS OF ACTIONS COULD THEY TAKE?
Health and social service providers	→ How do the intended beneficiaries perceive and experience services and programs? → Are there specific needs and challenges experienced by women or people from vulnerable or marginalized communities? → How can providers improve quality to meet identified needs and challenges? → Are sufficient protections in place for the privacy and confidentiality of service users at both the operational and infrastructural levels?	**Community/local**	✓ Improve local service quality issues to address immediate barriers related to service availability, accessibility, acceptability, quality, cost and affordability, and concerns about confidentiality, discrimination, human rights violations, and gender issues. ✓ Sensitize or train service providers on non-stigmatizing, culturally- and gender-sensitive, people-centered care. ✓ Adjust or decentralize service provision and program delivery to improve engagement, retention, and positive outcomes for all, including marginalized and vulnerable populations and all genders.
Managers at facility level	→ How can CLM data complement and explain gaps in facility level targets? How can they confirm or add nuance to other country data about programs and services? → How do people access and navigate multiple services within our facility? → How do people receive and understand health and human rights information, such as information provided by facility staff or in printed form? → Are people missing or avoiding needed services for any reason? → How can the facility be managed to better meet people's needs?	**Program/central**	✓ Adjust policies, programs and service provision at the intermediate and central levels – for example, adjust staffing assignments, trainings, protocols, and staff and program management to improve performance toward people's positive experience and toward intended program outcomes. ✓ Sensitize or train service providers on non-stigmatizing, culturally- and gender-sensitive, people-centered care. ✓ Improve coordination and collaboration across programs and sites.

DECISION-MAKING AUTHORITIES

CLM DATA USER	WHICH TYPES OF FINDINGS ARE MOST RELEVANT?	AT WHICH LEVEL COULD THEY DRIVE CHANGE?	WHAT KINDS OF ACTIONS COULD THEY TAKE?
Managers at policy and program level (including health program and data/M&E experts, and other sectors)	→ How can CLM data complement and explain gaps in program targets? How can they confirm or add nuance to other country data about programs and services? → Across multiple service delivery sites, where are the greatest challenges in the availability, accessibility, acceptability, and quality of services? → Which sites are most effective, and which need remedial action? → Where do services need to be scaled up, differentiated, or decentralized? → Are there disparities and access or specific needs disaggregated by sex, age, key populations, and locations? → Are service users experiencing human rights violations in health facilities?	**Program/central**	✓ In country funding proposals and plans, allocate resources to achieve greater equity, quality, and effectiveness of existing services and programs and to create new targeted initiatives. ✓ Improve coordination and collaboration across programs and sites. ✓ Develop and mandate sensitization and training programs for service providers to ensure non-stigmatizing, culturally- and gender-sensitive, people-centered care. ✓ Adjust policies, programs, and services to address identified gaps, disparities, and population needs.
Technical partners and international funders	→ How can CLM data complement and explain gaps in program targets? How can they confirm or add nuance to other country data about programs and services? → How do community-generated CLM data confirm or add nuance to other country data about programs and services? → How can CLM frameworks and technologies be improved based on the feedback of CLM implementers? → Where can funding and technical assistance best assist the country in achieving its aims?	**Program/central** **International**	✓ Provide funding and technical assistance to support quality and effectiveness of existing services and programs and to fund new targeted initiatives to address identified gaps, disparities, and population needs.

RECIPIENTS OF CARE

CLM DATA USER	WHICH TYPES OF FINDINGS ARE MOST RELEVANT?	AT WHICH LEVEL COULD THEY DRIVE CHANGE?	WHAT KINDS OF ACTIONS COULD THEY TAKE?
Individuals	→ What services are available? → Are there fees and wait times? → What is the individual's experience and the experience of peers about availability, accessibility, acceptability, quality of services, and stigma and discrimination?	**Individual** **Community/local**	✓ Gain awareness of their rights regarding access to quality health services. ✓ Gain awareness on what is available and seek out further information and services based on new knowledge. ✓ Access programs and services at different locations or with greater advance knowledge to better navigate and achieve intended outcomes. ✓ Seek support from lawyers to document human rights violations or formally engage institutions or authorities responsible for rights violations through legal and other channels.

ANNEX 2 EXAMPLES OF TOOLS & TEMPLATES FOR CLM DATA USE

1. Data reporting and visualization

EXAMPLE 1
Data dashboard from OneImpact

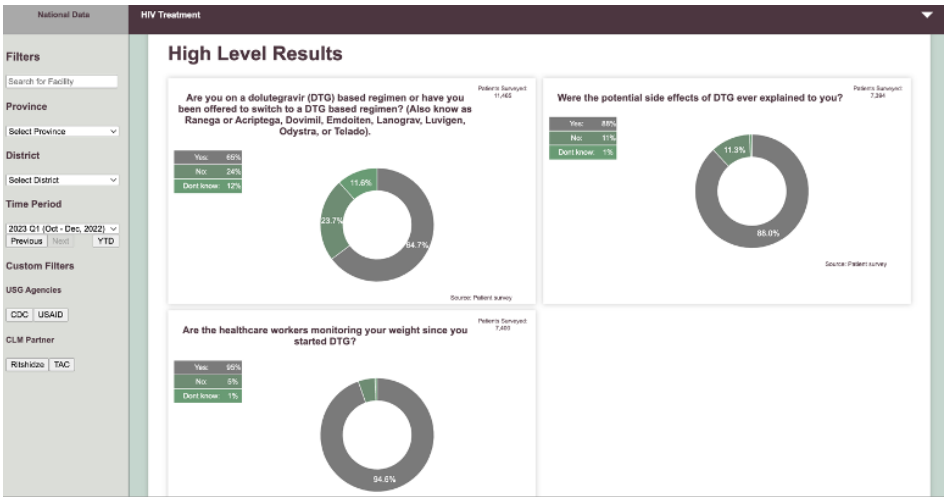
SOURCE: Stop TB Partnership and OneImpact.

(https://stoptbpartnershiponeimpact.org/#community-dashboard)

EXAMPLE 2
Data dashboard from Ritshidze

SOURCE: Ritshidze. Data Dashboard.

(http://data.ritshidze.org.za/ZA/reports?lang=en)



EXAMPLE 3

Data summary report from Ritshidze

SOURCE: Rithidze. Quarterly Facility Report

(http://data.ritshidze.org.za/ZA/reports?lang=en)

2. Data advocacy and use

EXAMPLE 1

Advocacy log from CLAW Consortium

SOURCE: Community-Led Accountability Working Group (CLAW Consortium). Community evidence to create change. 2022

(https://healthgap.org/wp-content/uploads/2022/09/CLAW-Advocacy-for-Change.pdf)

ADVOCACY LOG TEMPLATE

Name of the Organization: _____
Name of advocate: _____

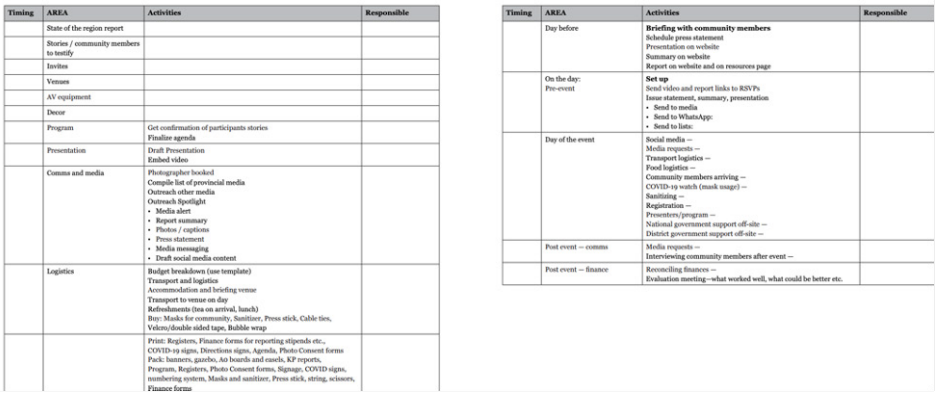
A) Advocacy Ask/ Result	B) Date (DD/MM/YYYY)	C) Advocacy target	D) Significant change (Triggers/Turning Point/Blockages)	E) Useful context or other comments	F) Next Steps/ Follow Up
Instructions: Insert the advocacy ask, or a theme if beyond advocacy asks, e.g, reflection on evidence collection, etc.	Instructions: Insert the date when the entry happened	Instructions: Include the name/ organization targeted with the advocacy. Leave blank in case of capacity building	Instructions: Describe the significant change that was experience and activities that might have contributed to the change	Instructions: Add any other comments or information	Instructions: Insert the next steps or things to be followed up by you and others

EXAMPLE 2

Community accountability checklist from CLAW Consortium

SOURCE: Community-Led Accountability Working Group (CLAW Consortium). Community evidence to create change. 2022

(https://healthgap.org/wp-content/uploads/2022/09/CLAW-Advocacy-for-Change.pdf)



Timing	AREA	Activities	Responsible
	State of the region report		
	Stories / community members to testify		
	Invites		
	Venues		
	AV equipment		
	Decor		
	Program	Get confirmation of participants stories Finalize agenda	
	Presentation	Draft Presentation Embed video	
	Comms and media	Photographer booked Compile list of provincial media Outreach other media Outreach Spotlight • Media alert • Report summary • Photos / captions • Press statement • Media messaging • Draft social media content	
	Logistics	Budget breakdown (use template) Transport and logistics Accommodation and briefing venue Transport to venue on day Refreshments (tea on arrival, lunch) Buy: Masks for community, Sanitizer, Press stick, Cable ties, Velcro/double sided tape, Bubble wrap	
		Print: Registers, Finance forms for reporting stipends etc., COVID-19 signs, Directions signs, Agenda, Photo Consent forms Pack: banners, gazebo, A0 boards and easels, KP reports, Program, Registers, Photo Consent forms, Signage, COVID signs, numbering system, Masks and sanitizer, Press stick, string, scissors, Finance forms	

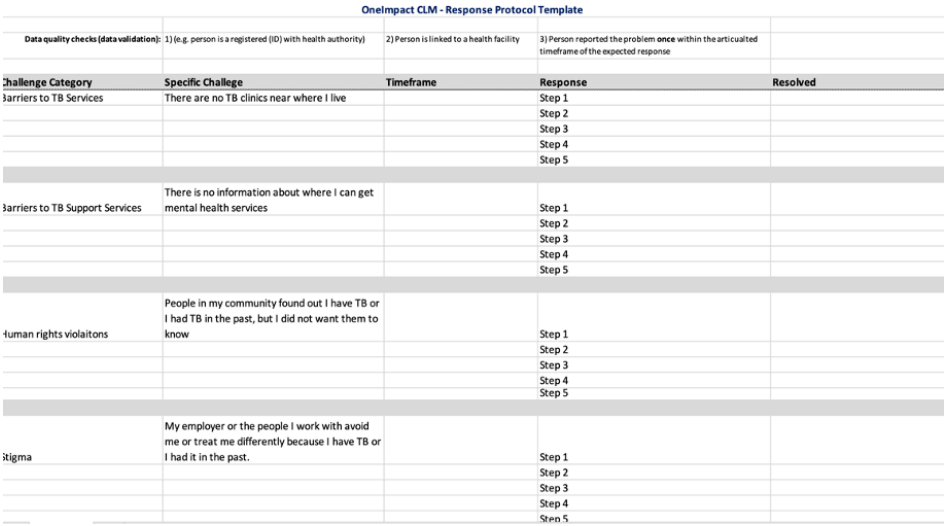
Timing	AREA	Activities	Responsible
	Day before	**Briefing with community members** Schedule press statement Presentation on website Summary on website Report on website and on resources page	
	On the day: Pre-event	**Set up** Send video and report links to RSVPs Issue statement, summary, presentation • Send to media • Send to WhatsApp: • Send to lists:	
	Day of the event	Social media – Media requests – Transport logistics – Food logistics – Community members arriving – COVID-19 watch (mask usage) – Sanitizing – Registration – Presenters/program – National government support off-site – District government support off-site –	
	Post event – comms	Media requests – Interviewing community members after event –	
	Post event – finance	Reconciling finances – Evaluation meeting –what worked well, what could be better etc.	

EXAMPLE 3

Response protocol template from OneImpact

SOURCE: Stop TB Partnership and OneImpact

(https://stoptbpartnershiponeimpact.org/#community-dashboard)



OneImpact CLM - Response Protocol Template

Data quality checks (data validation):	1) (e.g. person is a registered (ID) with health authority)	2) Person is linked to a health facility	3) Person reported the problem **once** within the articualted timeframe of the expected response	
Challenge Category	**Specific Challege**	**Timeframe**	**Response**	**Resolved**
Barriers to TB Services	There are no TB clinics near where I live		Step 1	
			Step 2	
			Step 3	
			Step 4	
			Step 5	
Barriers to TB Support Services	There is no information about where I can get mental health services		Step 1	
			Step 2	
			Step 3	
			Step 4	
			Step 5	
Human rights violaitons	People in my community found out I have TB or I had TB in the past, but I did not want them to know		Step 1	
			Step 2	
			Step 3	
			Step 4	
			Step 5	
Stigma	My employer or the people I work with avoid me or treat me differently because I have TB or I had it in the past.		Step 1	
			Step 2	
			Step 3	
			Step 4	
			Step 5	

ANNEX 3
ABBREVIATIONS

AAAQ	CLM data use in the context of the CLM data journey
CCG	Community consultative group
CCM	Country coordinating mechanism
C19RM	COVID-19 Response Mechanism (Global Fund)
CLM	Community-led monitoring
COVID-19	Coronavirus disease 2019
CSS	Community systems strengthening
HMIS	Health management information system
ITPC	International Treatment Preparedness Coalition
M&E	Monitoring and evaluation
NGO	Non-governmental organization
PEPFAR	President's Emergency Plan for AIDS Relief
PII	Personally identifiable information
PREP	Pre-exposure prophylaxis
STI	Sexually transmitted infection
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

ACKNOWLEDGEMENTS

This guidance document was developed with support from the Global Fund to Fight AIDS, Tuberculosis and Malaria and was coordinated by Stop TB Partnership, with the technical support of ITPC.

The development of this guide was led by a Core Team, guided by an Advisory Group. It was pilot tested by community-led monitoring implementers and national HIV, TB and malaria programs. The Core Team acknowledges and thanks all those who have supported the development of this guide.

LEAD AUTHORS: Sam Avrett and Parijat Baijal

CORE TEAM: The Global Fund (Keith Mienies, Nnamdi Nwaneri, Susan Perez, Isabelle Yersin), Stop TB Partnership (Caoimhe Smyth, Viorel Soltan), ITPC (Jelena Bozinovski, Helen Etya'ale, Ayesha Mago, Nadia Rafif, Jalpa Sha)

ADVISORY GROUP: Roll Back Malaria (RBM), UNAIDS, Expertise France, German Agency for International Cooperation (GIZ), National Empowerment Network of People living with HIV / AIDS in Kenya (NEPHAK), TBpeople Ukraine, Innovations for Community Health Philippines, Civil Society in Malaria Control Immunization and Nutrition (ACOMIN).

PILOT TESTING TEAM SOUTH AFRICA: The Networking HIV and AIDS Community of Southern Africa (NACOSA), Access Chapter 2, Rotanganedza Community Care, Ritshitse/Treatment Action Campaign (TAC), TB/HIV Care, TB Proof, Ubunye Foundation Trust, South African National AIDS Council (SANAC), Beyond Zero, Aids Foundation South Africa (ADSA), Ubunye Foundation Trust, National Department of Health, West Rand Department of Health.

PILOT TESTING TEAM DEMOCRATIC REPUBLIC OF CONGO: L'Union Congolaise des Organisations des Personnes Vivant avec le VIH (UCOP+), Fondation Femme Plus (FFP), Club des Amis Damien (CAD,) Conseil national des ONG de la Sante (CNOS), Réseau National des ONG pour le Développement de la Femme (RENADEF), Ligue Nationale Antituberculeuse et Antilépreuse du Congo (LNAC), Coordination Nationale de Renforcement du Système Communautaire (CNRSC), Word Production, Programme national de la Lutte contre le paludisme, Programme national de Lutte contre le VIH/Sida, Programme National Multisectoriel de Lutte contre le Sida (PNMLS,) Programme National de Lutte contre la Tuberculose (PNLT), The United States President's Emergency Plan for AIDS Relief (PEPFAR), Médecins Sans Frontières (MSF Belgique), Organisation catholique de secours et d'aide au développement (CORTAID), Soins de Santé Primaires en Milieu Rural et urbain (SANRU Asbl).

DESIGN AND ILLUSTRATIONS BY: Trevor Messersmith / 80east Design