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

From Insights to Evidence

A guide for translating program and policy priorities into **qualitative and quantitative measures** for Community-Led Monitoring

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

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Purpose of This Document

Routinely collecting, analysing and using high quality evidence is the core of community-led monitoring (CLM). With evidence, communities can tell their stories, document successes, and bring attention to issues that impact them. This document provides practical considerations for selecting qualitative indicators (which describe characteristics, experiences and situations), and quantitative indicators (which describe amounts or numbers), an essential part of CLM of HIV, TB and malaria (HTM) programs.

Drawing from the growing body of experience on CLM, we propose a stepwise approach for translating strategic priorities into qualitative questions and quantitative indicators. This document serves as a companion to the International Treatment Preparedness Coalition (ITPC) publication, ***How to Implement Community-Led Monitoring – A Community Toolkit***. It is designed for community and civil society organizations using CLM to monitor access to, continuity, and quality of HTM programs during the COVID-19 pandemic.

Rationale

Data collection is a critical component of CLM, though it is not actually the starting point. Communities must define their strategic priorities first, and then carefully select appropriate qualitative and or quantitative measures that will build the evidence base necessary to inform advocacy and policy change. Thoughtful, careful and deliberate selection of indicators can greatly enhance the value of the evidence from CLM by ensuring that the data is more meaningful and effective.

Though traditional program monitoring approaches may focus on quantitative indicators, qualitative data is considered fundamental to community-led monitoring. Qualitative data provides a unique, often untapped, opportunity to document first-hand experiences of community members and to routinely engage recipients of care in offering solutions. This document contains an initial introduction to qualitative data collection for CLM that will be expanded upon in a forthcoming publication.

COVID-19 has changed how data can be collected (due to public health measures including social distancing and lockdowns), as well as how we think about what kinds of data to collect. Although this guide is developed with an emphasis on monitoring in the context of COVID-19, communities may find it useful in the post-pandemic period, as these approaches remain relevant to community monitoring systems.

Who Should Read This Guide

- → **All current implementers of CLM**
- → **Civil society and community groups who are interested in establishing or strengthening CLM mechanisms in the context of COVID-19**
- → **Technical assistance providers supporting CLM initiatives**
- → **CLM partners (Ministries of Health, government agencies, multilateral and bilateral funders, health center management teams, health facility staff)**

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Abbreviations and Acronyms

AGYW	Adolescent Girls and Young Women
ANC	Antenatal Care
ART	Antiretroviral therapy
ARV	Antiretroviral(s)
CLM	Community-led Monitoring
CLM & A	Community-led Monitoring and Advocacy
COVID-19	Coronavirus Disease 2019
C19RM	COVID-19 Response Mechanism
DTG	Dolutegravir
GF	Global Fund for HIV, TB and Malaria
HIV	Human Immunodeficiency Virus
HTM	HIV, TB and Malaria
IRB	Institutional Review Board
ITPC	International Treatment Preparedness Coalition
KP	Key population
LMIC	Low- and Middle-Income Countries
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer and + in recognition of all non-straight, non-cisgender identities
MMD	Multi-Month Dispensing
M&E	Monitoring & Evaluation
MER	Monitoring, Evaluation & Reporting
MoU	Memorandum of Understanding
PEPFAR	President's Emergency Plan for AIDS Relief
PLHIV	People living with HIV
PrEP	Pre- Exposure Prophylaxis
PWUD	People Who Use Drugs
RDT	Rapid Diagnostic Test
ROC	Recipient of Care
RVLM	Routine Viral Load Monitoring
SARS-COV-2	Severe Acute Respiratory Syndrome Coronavirus 2
SW	Sex Worker(s)
TB	Tuberculosis
TG	Transgender
TLD	Tenofovir/ Lamivudine/ Dolutegravir
WHO	World Health Organization

Background

The COVID-19 pandemic has had a devastating impact globally. Confirmed cases surpassed 330 million by the end of January 2022, and over five million lives have been lost.[1] The pandemic has highlighted and exacerbated inequities in access to healthcare, education, and employment. People who are the most vulnerable — due to co-existing medical conditions and/or poverty — are at higher risk of severe illness from COVID-19 and bear a disproportionate burden of the pandemic's health and socio-economic impact.[2, 3, 4] Key populations (KP) — men who have sex with men (MSM), sex workers (SW), people who use drugs (PWUD), and transgender people (TG) — are even more vulnerable to these pandemic consequences.

In May 2020, researchers at Imperial College London published findings from a study aimed at quantifying the impact of COVID-19 mitigation measures on the epidemics of HIV, tuberculosis (TB) and malaria. By estimating the combined impact of reduced access to prevention services, strained health system capacity and reduced access to treatment, the team predicted five-year increases in HIV-, TB- and malaria-related deaths of 10%, 20% and 36%, respectively.[5] The study considered several factors, estimating that the highest impact for low- and middle-income countries (LMIC) would be seen where access to antiretroviral (ARV) treatment was interrupted for people living with HIV (PLHIV), where timely diagnosis of persons with TB declined, and where bed net campaigns to support malaria prevention were disrupted.

(1) World Health Organization (2022) COVID-19 Dashboard. Available online at [https://covid19.who.int/].

(2) Liao TF, De Maio F. Association of Social and Economic Inequality With Coronavirus Disease 2019 Incidence and Mortality Across US Counties. *JAMA Netw Open*. 2021;4(1):e2034578. Available online at doi:10.1001/jamanetworkopen.2020.34578

(3) Treskova-Schwarzbach, M., Haas, L., Reda, S. et al. Pre-existing health conditions and severe COVID-19 outcomes: an umbrella review approach and meta-analysis of global evidence. BMC Med 19, 212 (2021). Available online at https://doi.org/10.1186/s12916-021-02058-6

(4) Woodward M, Peters SAE, Harris K. Social deprivation as a risk factor for COVID-19 mortality among women and men in the UK Biobank: nature of risk and context suggests that social interventions are essential to mitigate the effects of future pandemics. *J Epidemiol Community Health* 2021;75:1050-1055. Available online at https://jech.bmj.com/content/jech/75/11/1050.full.pdf

(5) Hogan AB, Jewell V, Sherrard-Smith E, et al. The Potential Impact of the COVID-19 Epidemic on HIV, TB and Malaria in Low- and Middle-Income Countries. Imperial College London (01-05-2020). Available online at doi: https://doi.org/10.25561/78670.

Within the first year of the pandemic, reports showed erosions of important gains in HIV, TB and malaria programs. The evidence pointed to significant declines in the uptake of diagnostic and clinical management services, which threaten recipient of care outcomes and further compromise achievement of global HIV, TB and malaria targets. In their 2021 report, the Global Fund to Fight AIDS, Tuberculosis and Malaria (GF) highlighted declines across their partner countries – the largest of which occurred in delivery of prevention services that depend on population mobility. In 2020, the number of people accessing HIV testing and voluntary medical male circumcision declined (by 22% and 27%, respectively); the number of people accessing TB treatment declined by a million, and the number of people who were suspected to have malaria who accessed diagnostic testing declined by 4.3%, as compared to 2019.[6]

The COVID-19 response has required an unprecedented effort to reduce transmission and prevent mortality, while maintaining essential health services. In resource-limited settings, countries have had to redirect human, technical and financial resources to support their COVID-19 responses, which has had a negative impact on the delivery of routine health and social services. Quantifying the impact of COVID-19 from the perspective of recipients of care (ROC) is an important step in addressing these widening gaps. Empowering communities with the tools and expertise to document their experiences through community-led monitoring (CLM) is a way for them to engage with other stakeholders to co-create solutions during (and after) the COVID-19 pandemic.

When analysed, CLM data becomes evidence, which is used to engage a range of stakeholders to co-create and implement solutions and to inform advocacy campaigns when necessary.

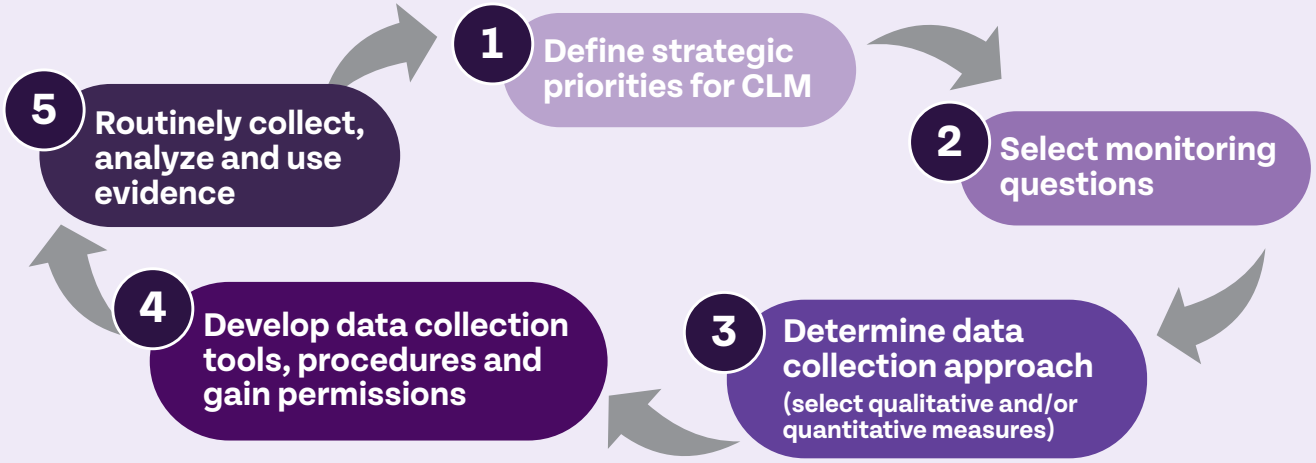
CLM is a process in which people who use health services take the lead in identifying and routinely monitoring the issues that matter to them. After communities identify priority areas, they select appropriate indicators and use them for routine data collection. When analyzed, CLM data becomes evidence, which is used to engage a range of stakeholders (including: national program staff, facility personnel, academic institutions and policymakers) to co-create and implement solutions, and to inform advocacy campaigns when necessary. (Refer to Figure 1). CLM has been used in several countries to monitor HIV services. More recently, it has been adapted to document the impact of COVID-19 on HIV and TB programs.[7]

Between September and December 2020, ITPC supported the implementation of a demonstration project that monitored HIV and TB services in high-volume, urban facilities in China, Guatemala, India, Nepal and Sierra Leone, using "COVID-19 sensitive" indicators.

(6) Global Fund to Fight AIDS, Tuberculosis and Malaria (2021) Results Report 2021. Available online at [https://www.theglobalfund.org/media/11304/corporate_2021resultsreport_report_en.pdf].

(7) Rafif N, Oberth G, Hodes R, et al; International Treatment Preparedness Coalition (2021) Community-led monitoring of COVID-19's effects on service delivery and lived experiences of people living with HIV and TB in China, Guatemala, India, Nepal and Sierra Leone. 2021. Poster presented at ICASA. Available online at https://itpcglobal.org/wp-content/uploads/2021/12/COVID-and-PLHIV-5-Cities.pdf

FIGURE 1 Roadmap for Generating and Using Evidence for Community-led Monitoring



The project, called "5 Cities", used quantitative indicators and complementary qualitative questions to assess priority issues. As a result of the "5 Cities" project, community advocates were able to signal the disruption of viral load monitoring, identify declines in HIV testing and show how COVID-19 mitigation measures have negatively affected access to services.[7] This CLM project also allowed communities to document stories of innovation, such as where treatment interruptions were prevented through community services. This initiative added to a growing body of evidence documenting the impact of COVID-19 from the perspective of recipients of care. Drawing from these experiences and ongoing CLM initiatives, this guide provides communities with a stepwise approach for identifying strategic priorities and selecting quantitative and qualitative measures to monitor them. Box1 defines key terms used for CLM and throughout this brief.

BOX 1 Defining Key Terms

Quantitative data is information that can be counted or measured. For CLM, quantitative data give insight into the number of persons reached by a program, negatively impacted by a service gap, or the duration of an issue.

Qualitative information is non-numerical and describes attributes or qualities. CLM qualitative data allows community members to describe the full scope of an issue that is affecting their health, without being limited to a set of specific numeric data.

Measure is used throughout the document as an umbrella term that includes indicators (qualitative or quantitative) and a series of qualitative questions which provide necessary data for CLM.

(7) Rafif N, Oberth G, Hodes R, et al; International Treatment Preparedness Coalition (2021) Community-led monitoring of COVID-19's effects on service delivery and lived experiences of people living with HIV and TB in China, Guatemala, India, Nepal and Sierra Leone. 2021. Poster presented at ICASA. Available online at https://itpcglobal.org/wp-content/uploads/2021/12/COVID-and-PLHIV-5-Cities.pdf

Section 1

An Overview of Data Collection for Community-Led Monitoring

Community- led monitoring is a process in which communities, particularly people who use health services, take the lead in identifying and routinely monitoring the issues that matter to them, and capture information on stigma, discrimination and access to and quality of services for certain groups of people, particularly key populations. As part of this process, communities select appropriate methods to capture the information that is needed to identify and monitor priority areas (Box 2).[8]

BOX 2 Key Steps for Generating and Using Evidence for CLM

1. **Define Strategic Priorities for CLM:** These should take the form of brief statements that are specific, measurable and determine short-term (1-2 year) intentions for your organization or specific programmatic area.

2. **Select Monitoring Questions:** Monitoring questions summarize the information you need to know to assess the status of the program, or policy areas linked to your strategic priorities

3. **Identify Appropriate Data Collection Approaches (Select Qualitative and or Quantitative Measures):** In this step, you specify the data that will be routinely collected to answer your monitoring questions and provide "evidence" for your CLM. Depending on your information needs, you might opt to collect qualitative or quantitative data (or both). Qualitative questions provide in-depth information on a specific issue. Quantitative indicators are specific, objective, reproducible measures that are used to assess implementation of a policy or program. Indicators can measure program inputs, outputs, outcomes or impact.

4. **Develop Data Collection Tools, Procedures and Permissions:** Once you have defined the information you would like to collect, you need to establish procedures for securely collecting, cleaning, and storing the data. Receiving approval to collect the data from the relevant sources is an important part of this process.

(8) This guide covers Steps 1 to 3 and provides guidance to get started with data collection by covering some aspects of step 4. Please also see ITPC's companion guidance documents on data analysis and data quality assurance.

5 **Routinely Collect, Analyze and Use the Evidence:** With permissions in place, you can routinely collect your CLM data. You will need to incorporate steps for quality assurance to ensure the evidence you collect is high quality, since you will be generating evidence from the review, analysis and interpretation of the data. Data analysis includes interpretation of the information within the local context, and the implications of its results for your advocacy actions. This could lead to identifying programmatic gaps or areas of success. Working with decision-makers, CLM implementers can then use this evidence to influence and support program improvement.

The Goal of CLM

Program improvement, which translates to improved health and quality of life for recipients of care, is the end goal of CLM. It may be possible to immediately co-create solutions with program leads and implementers when you review or disseminate CLM data. In other instances, **advocacy actions** may be necessary to raise awareness and garner support or resources for program improvement. When needed, these advocacy actions are the specific steps your organization will take to address the gaps or issues highlighted by the evidence.

When analyzed, CLM data becomes evidence, which is used to identify and implement solutions for program and service delivery improvement and inform advocacy when necessary. Ultimately, these changes improve health and quality of life outcomes for recipients of care.

Defining strategic priorities is an important first step in CLM (and advocacy). In this document, we outline a stepwise process to take you from identifying your strategic priorities for CLM to selecting high-impact measures. While you may find this process useful for many other health and social issues, we have focused on selecting CLM indicators for monitoring HIV, TB and malaria services in the context of COVID-19.

Your CLM strategic priorities (or objectives) are internally driven, rooted in your organization's mandate and come from the communities that you represent. Since the objective is to improve health and quality of life outcomes, CLM priorities for HIV, TB and malaria programs are also informed by international standards of care, national guidelines, national policies and or emerging evidence. As an example, Figure 2 describes priority areas for CLM of HIV services.

Once defined, your CLM strategic priorities inform development of monitoring questions, which in turn, will guide your approach to data collection. Monitoring questions summarize the information needed to determine the status of program or policy areas linked your CLM objectives. After outlining your monitoring questions, you may decide to focus on qualitative data collection. Alternatively, based on your information needs, you may opt for a combination of quantitative indicators and qualitative questions for a mixed-methods approach. As the CLM data is reviewed and analyzed, the evidence generated is used to identify gaps or shortfalls and co-create solutions to address them. Evidence from CLM also supports development of new and/or more specific advocacy actions that lead to improved services and outcomes.

FIGURE 2 Illustrative Framework with Select Components of the HIV Response that Highlight Possible Strategic Priorities for CLM

Community Led Monitoring – Priority Areas for HIV

Improving access to, and the quality of prevention, diagnostic, treatment, psychosocial and mental health services

Creating a Supportive Social, Legal & Policy Environment

POLICIES

1. **Anti-discrimination and decriminal-ization legislation** protecting PLHIV, and Key Populations (KPs)
2. **Inclusion of reasonable accommodation** in workplace policies

Strengthen Health & Social Systems

SYSTEMS

1. **Capacity and referral networks** for HIV diagnosis, CD4, viral load and surveillance of drug resistance
2. **Reliable supply chain** for HIV medication, diagnostic reagents and commodities
3. **Referral systems** for psychosocial & mental health services
4. **Strategic information systems** to support surveillance, monitoring and evaluation (M&E)

Prevention

1. Educational programs on HIV transmission
2. Combination prevention services (e.g. Pre-Exposure Prophylaxis (PrEP), Sexually transmitted infection (STI) testing, Voluntary Medical Male Circumcision (VMMC) for key populations (e.g. Adolescent Girls and Young Women (AGYW), MSM, SW, TG, PWUD)
3. Provision of condoms, lubricants and vaginal rings
4. Harm reduction programs for PWUD

Early Diagnosis

1. HIV counselling and testing for all pregnant people at antenatal care (ANC) visits
2. HIV self-testing
3. Partner services
4. Accessible facility and community-based HIV and STI testing for key populations

Timely Referral & Treatment Initiation

1. Same-day referral and treatment initiation
2. TB and STI screening and treatment for PLHIV
3. Timely initiation of Antiretroviral Therapy (ART) (including dolutegravir)
4. Adherence support and referral for psychosocial and mental health services

Improve Treatment Outcomes

1. Routine viral load monitoring (RVLM)
2. Multi-month dispensation of Antiretrovirals (ARV)
3. Adherence support for retention on ART
4. Timely and appropriate medication switching
5. HIV drug resistance testing per national protocol

Section 2

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

In addition to the morbidity and mortality it causes, COVID-19 has had a devastating impact on health systems and the delivery of essential health services globally, with LMIC disproportionately affected.

In the context of HIV, TB and malaria programs, the pandemic's impact on health systems has been seen at multiple levels. Production, shipping and supply chain disruptions have led to shortages of reagents and other commodities, while at the local level, limited human resource capacity and lack of dedicated laboratory equipment has led to redirection of resources to support COVID-19 diagnostics and clinical monitoring. As an example, molecular testing platforms (e.g. GeneXpert) have been prioritized for SARS-CoV-2 testing, making them less available, or un-available for HIV viral load testing, TB diagnosis and detection of multi-drug resistant TB.

Outlining the key policy and programmatic components of HIV, TB and malaria programs (as summarized for HIV programs in Figure 2), allows us to identify critical services, points of potential attrition and areas – and groups of people, such as key populations – likely to be directly or indirectly impacted by COVID-19. Measures implemented in response to COVID-19 that restrict movement can affect the availability of services, and the ability of recipients of care to travel to health facilities. Concerns about COVID-19 infection can impact decision-making on seeking healthcare, causing delays in accessing care. CLM data can signal these changes in service provision and uptake. Table 1 provides examples of COVID-19's impact on uptake of prevention, diagnostic and treatment services.

Outlining the key policy and programmatic components of HIV, TB and malaria programs allows us to identify critical services, points of potential attrition and key popluations likely to be impacted by COVID-19.

TABLE 1 Indicative Framework for Identifying Critical Components of the HTM Response, Nature of Disruption(s) and Potential Impact of COVID-19

	Critical Area of HTM Services	Potential Impact of COVID-19 or Mitigating Measures	Impact on Health Service Delivery or Patient Outcomes
Health System Capacity and Resources for Health	→ Personnel for phlebotomy (drawing blood) and diagnostic services → Clinical personnel that provide treatment services → Adequate clinic space and operational hours	→ Reduction in clinic opening hours (including discontinuation of evening or weekend clinics) → Long wait times at clinic → Increased duration between clinic appointments	→ Declines in the number of persons accessing prevention, care and treatment services → (e.g. Declines in total clinic visits or % of clinic appointments kept)
Laboratory Capacity	→ Smear microscopy for TB and malaria → X-ray capacity for TB testing → Molecular diagnostic testing for HIV, TB	→ Limited availability of diagnostic tests → Decline in frequency of testing (less frequent than standard of care, limited to urgent cases)	→ Declines in the number of new tests performed → Declines in the % of persons with suspected malaria and TB receiving a test → Increase in turnaround time for laboratory results
Supply Chain	→ Reliable supply of reagents for CD4, viral load, HIV testing	→ Stockouts of reagents/ commodities for diagnostic tests and clinical monitoring	→ Increase in number and or duration of medication stock-outs
	→ Reliable supply for multi-month dispensation of HIV and TB medication	→ Stock out of medication for treatment	→ Reduction in medication dispensation amounts

	Critical Area of HTM Services	Potential Impact of COVID-19 or Mitigating Measures	Impact on Health Service Delivery or Patient Outcomes
Prevention	→ Distribution of insecticide-treated bed nets → Seasonal medication to prevent malaria (chemoprevention)	→ Limited access to malaria prevention services	→ Increase in number of new infections (e.g. malaria and HIV) – *which may remain undiagnosed initially, due to disruption in diagnostic services or declines in testing uptake*
Diagnosis	→ KP-friendly testing sites → Routine screening programs in antenatal care clinics (HIV, malaria)	→ Decline in number of persons tested for HIV → Decline in number of persons receiving test results and increase in turnaround time for test results	→ Decrease in number of KPs tested for HIV → Decrease in the number and/or % of PLHIV tested for TB → Decrease in the number and/or % of people with TB tested for HIV → Decrease in the number and or % of persons with suspected HIV, TB or malaria receiving a diagnostic test
Treatment	→ Same-day treatment initiation → Directly Observed Treatment for TB (DOTS) → Reliable supply of medicines	→ Delays in initiation of treatment for newly-diagnosed persons → Interruption of treatment due to stock-outs or late drug pick ups	→ Declines in same-day treatment initiation → Increased treatment interruption, leading to risk of HIV/TB drug resistance and treatment failure → Reduction in number of persons completing TB treatment
Clinical Monitoring	→ HIV routine viral load monitoring (RVLM) → TB drug resistance testing	→ Delays in returning results/ increased turnaround time → Decline in number of new viral load tests and increase in number of people in whom viral load testing is overdue	→ Delays in identifying treatment failure, leading to poor health outcomes, development of drug resistance, and potential increases in HIV transmission

Monitoring the Impact of COVID-19

While it is not possible to directly measure the impact of COVID-19 by simply comparing data, a comprehensive description of the trends (in the context of local epidemiology of, and responses to COVID-19) is an important first step. For this type of descriptive analysis, you may consider:

1. **What component of the service was affected?**
2. **What was the reported data for the service during the period?**
3. **What are the historical trends?**
4. **How do the CLM data during periods of restricted movement compare to data from the pre-COVID era?**
5. **How do historical data compare to reports during periods of a rapid increase in COVID-19 cases?**
6. **What details from personal experiences can recipients of care, service providers and program leaders provide that will give insight into the impact of COVID-19?**

Section 3

Getting Started with CLM

STEP 1

Define Your Strategic Priorities

Articulating the priority area, scope and strategic focus of your CLM will allow you to develop clear priorities, which is an important first step to guide your data collection.

Brainstorming CLM Strategic Priorities

Your CLM strategic priorities should take the form of brief statements that are specific, measurable and determine your short-term (one- to two- year) intentions. The objectives will clearly state the priority area, scope and strategic focus of your CLM.

Work with your program team and community members to brainstorm on the programmatic and policy areas that you consider important for improving the health and quality of life outcomes in. your community. These may be policy or program-related issues for a specific target group, and/ or geographic location. A generic framework is provided as a guide in Figure 3. A stepwise process for defining strategic priorities (including prompts!) follows after Figure 3, and will help you to: 1) identify your priority areas; 2) define the scope, and 3) the strategic focus of your CLM activities.

Stepwise Process for Defining Strategic Priorities

1. Define your technical or programmatic focus:

What is the technical/ programmatic focus of your organization/ program? What are the priorities of your community/ constituents?

- Is your priority human rights, policy development, legal reform, health or the enabling environment?
- Is your focus on the program or service delivery level?

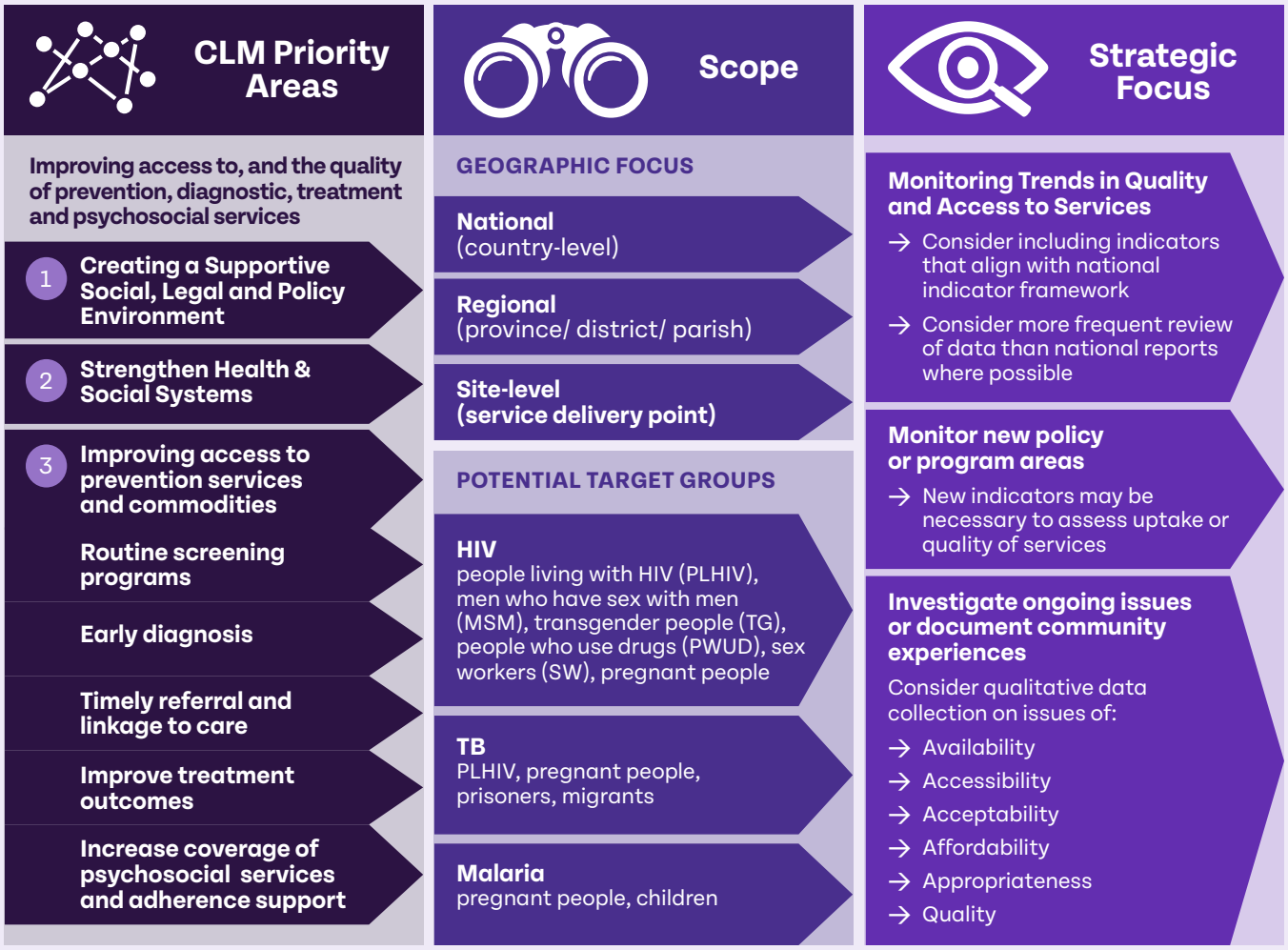
2. Identify what should be monitored:

What are the key elements that should be monitored to assess the status of your priority areas?

- **If your focus is on policy**, what are the three major programmatic/policy issues that define success for your CLM objective? Availability of a particular service? Access to a particular service? Integration of a specific best-practice into national policies or guidelines? What is the status of implementation of the national policy?

FIGURE 3

Framework for Outlining the Priority Areas, Scope and Strategic Focus of CLM Activities on HIV, TB and Malaria



- **If your focus is on program implementation**, what are the CLM priorities linked to your programmatic interests? Is your focus on prevention? Access to treatment? Monitoring treatment outcomes?

3. Clarify your scope

What is the scope of your interest? Is your focus national or subnational? Will you review all services or a specific intervention? Is your focus national or sub-national?

4. Outline your strategic focus:

What is the strategic focus of your CLM activities?

- Investigating or better understanding an ongoing issue (e.g. availability of services, low uptake of a service by a specific community)?
- Monitoring implementation of a new intervention or policy?
- Monitoring trends in service quality or access?

STEP 2

Selecting Monitoring Questions

MONITORING QUESTIONS summarize the information you need to assess the status of the program or policy areas linked to your advocacy objectives. In this section, we take a closer look at CLM priorities and use the parameters outlined in the previous section to develop monitoring questions.

Developing Monitoring Questions

Your monitoring activities should be guided by specific questions that translate to measurable qualitative or quantitative attributes. These questions should closely reflect the priority areas, scope and strategic focus of your CLM. Rather than starting with an exhaustive list, it is better to select one or two monitoring questions for each priority area. **This exercise could ultimately result in a total of 10 – 12 measures, which could be qualitative questions or quantitative indicators (or a combination of both).**

Priority Setting for Monitoring

It might be difficult to choose just three issues for monitoring, and when you start selecting your measures, it may be tempting to include a very long list to monitor many issues. Priority-setting can be difficult, especially when you support a diverse number of community groups or hope to address many programmatic areas. In addition to the questions provided (see Table 2), you may want to consider what data will possibly result in a quick win or have high impact. This process may help you to "right size" your CLM activities, or simply provide a starting point from your list of monitoring questions. To help with this, you may consider:

1. **Will the data highlight an underserved region or population?**
2. **Will you be able to correlate or contrast CLM data with data from other sources?**
3. **Will CLM data provide new information or highlight issues that are not routinely documented?**
4. **Will advocacy will be needed to support program improvement?**
5. **Will the data be usable for advocacy?**

TABLE 2 Developing Monitoring Questions

Guiding Question	Probe/ Sample HIV* Monitoring Question **For related examples on TB and Malaria, please refer to Annexes B2 and B3*
1. What are three major programmatic/ policy issues that, if addressed, would lead to improved health and quality of life outcomes among the community?	**TIP:** In selecting your top three monitoring questions, consider any actions/ initiatives that would, if removed, compromise health and quality of life outcomes. For example, an organization focused on improving treatment access and outcomes for people living with HIV may select: **1. Treatment Initiation:** Ensuring timely treatment initiation for persons newly diagnosed with HIV **2. Continuity of Treatment:** Ensuring anyone on ART has reliable and continuous access to their medication **3. Treatment Outcomes:** Improving clinical outcomes among people on ART by providing RVLM
2. What is the internationally recognized standard for each of the three issues identified above? **Is there emerging evidence of difficulties with access to services?**	**TIP:** Consider World Health Organization (WHO) guidelines in assessing the standard of care; also consider emerging local evidence that points to gaps in service access and/or quality or could lead to poor health and/ or quality of life outcomes. For the three areas identified above, WHO recommends the following:[9] **1. Treatment Initiation:** ART should be initiated for all people living with HIV regardless of WHO clinical stage and at any CD4 cell count. Rapid ART initiation should be offered to all people living with HIV following a confirmed HIV diagnosis and clinical assessment. ART initiation should be offered on the same day to people who are ready to start. **2. Continuity of Treatment:** People established on ART should be offered ART refills lasting three to six months, preferably six months if feasible. **3. Treatment Outcomes:** RVLM can be carried out at six months and at 12 months after starting ART, and then every 12 months thereafter, if the person is clinically stable on ART.

(9) Source: World Health Organization (2021) Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment, Service Delivery and Monitoring. Available online at https://apps.who.int/iris/rest/bitstreams/1357089/retrieve.

Guiding Question	Probe/ Sample HIV* Monitoring Question **For related examples on TB and Malaria, please refer to Annexes B2 and B3*
3. What is the implementation status of the national policy or program?	**TIP:** If the national policy does not align with WHO guidelines, your first point of intervention could be to advocate for updates to the policy. If the national policy aligns with WHO guidelines and is being implemented, then program data should reflect these changes. If this data is not available in existing program reports, CLM may provide new or complementary data to help you assess the level (or outcome) of implementation. The relevant monitoring questions for these three areas include: **1. Treatment Initiation:** → What percentage of newly diagnosed PLHIV start ARV treatment on the same day as their diagnosis, versus within a week, or more than a week after diagnosis? → Are PLHIV initiated on ART regardless of their clinical stage and/or CD4 cell count at diagnosis? → What is the length of time between diagnosis and treatment initiation at the facility? **2. Continuity of Treatment:** → What percentage of all persons on ART are receiving a multi-month supply (three months or more) of their medication? → What challenges do community members face with adherence to treatment? → What support services do community members consider helpful for supporting their adherence to treatment? **3. Treatment Outcomes:** → In the last 12 months, what percentage of all PLHIV on ART (for at least six months) had a viral load test, and received their results? → What percentage of PLHIV on ART are virally suppressed (according to their most recent test)?

STEP 3

Identify Appropriate Data Collection Approaches: Selecting Quantitative Indicators and Qualitative Questions

When CLM objectives and monitoring questions are clearly defined, it is easier to identify appropriate measures (qualitative questions or quantitative indicators).

Following the activities in the previous sections will provide you with enough information to develop monitoring questions that respond to your community's priorities, and enough detail for you to include relevant disaggregates (such as by age, gender, key population group). This section provides more specific guidance on translating your monitoring questions into quantitative indicators, qualitative questions and tips on how to select indicators that are "COVID-19 sensitive."

It is important to decide whether you need qualitative data or quantitative data (or a combination) to address your monitoring questions. This largely depends on your focus. In short, if you want to document trends or count the number of persons impacted, quantitative data are needed. If you want to explore the nature of an issue or gain a more in-depth understanding of changes in service delivery, you need qualitative data (Box 2).

BOX 3 Quantitative vs Qualitative Data

It is common for CLM to use a combination of qualitative and quantitative data points; when taken together, this data can provide a holistic picture of the issues being monitored. Quantitative data can give insight into the number of persons reached by a program, negatively impacted by a service gap or the duration of an issue. When there is an established norm (i.e. WHO Guidelines on same-day treatment initiation for people who are diagnosed with HIV), quantitative data can be very powerful for measuring whether those standards are being met. Qualitative information gathering is more open-ended, enabling community members to articulate the full scope of an issue that is affecting their health, without being limited to a set of specific measurable indicators. For this reason, qualitative questions can be the "golden ticket" that helps reveal and unpack complex and interconnected issues.

Quantitative Data

If your monitoring question focuses on the number of people who are accessing a service, or quantifies the duration of a procedure, quantitative indicators are needed. Quantitative questions allow you to specify the volume and duration of the issue:

→ **How many people were impacted?**

→ **How many people have been reached?**
→ **How long was the service suspended?**
→ **How many facilities in the province provide the service (i.e. ART, RVLM)?**

Qualitative Data

If your monitoring question focuses on describing the extent and nature of an issue by detailing who is affected and the impact of the experience on individuals or communities, qualitative data is needed. Qualitative data allow us to describe the "what" and "why" of the issue. It is especially powerful for gaining insight into underlying barriers or facilitators for the Availability, Accessibility, Acceptability, Affordability, Appropriateness and Quality of services. Qualitative data helps you to answer:

→ **What underlying issues are driving the challenges?**
→ **Why do we experience the identified challenges?**
→ **What is the impact of this issue on community members?**

Selecting Quantitative Indicators

Qualities of a Good Indicator

Indicators specify the data that should be routinely collected to answer your monitoring questions and provide the "evidence" for CLM. An indicator is an objective, reproducible quantitative or qualitative measure used to assess policy or program implementation. Indicators are used for monitoring the entire program cycle and may measure inputs, outputs, outcomes, or impact.

In selecting quantitative indicators, you want to choose a combination that will provide the details to address your monitoring questions. In making your final selection, it is important to consider the feasibility of collecting the data and the available data sources. The qualities of good indicators are summarized in Box 3.

BOX 4 Qualities of a Good Indicator

Valid: the validity of a measure means that it will measure the attribute that it is designed to measure.

Meaningful: This means the information from the indicator tells you something important and it can provide information for action (e.g., policy development or program improvement).

Reliable: Reliable indicators will capture data that change with the attribute being measured and will therefore detect trends, gaps and successes. This means that consistent results are obtained for the same period, regardless who is assessing them.

Reproducibility: Good indicators are clear and easy for all assessors to use or reproduce. This means that the data retrieved from an information source would be the same if different people completed data collection.

Feasible: This refers to the ease of collecting data. Feasibility is closely tied to the availability of the required data sources. Feasibility may also be related to the resources available to conduct data collection for a specific indicator - or all of selected your indicators. If indicator data are readily available in paper or electronic data systems, this information may be more feasible to collect than data that require large, resource-intensive surveys, access to medical records, or through individual interviews and focus groups. In the COVID-19 era, feasibility includes ability to collect data even with public health measures (such as social distancing, etc) are in place.

Anatomy of an Indicator

Indicator details are important to ensure clarity and that all users consistently interpret and collect the expected information in the same way. The indicator description, data sources and methods of measurement are important components of each indicator, which are outlined in an indicator reference sheet or summarized in the monitoring and evaluation (M&E) framework (see Table 3). As you develop your indicators, be sure to include a level of detail that provides the components of each indicator. Please see Annex A for more on indicator frameworks

TABLE 3 Key Components of Indicators

Component	Description	Example (reproduced from WHO)[10] *For examples on TB and Malaria, refer to Annexes B2 and B3*
Indicator code & Title:	Indicators may have a short code in addition to the full indicator title	HIV pre-exposure prophylaxis (PrEP) 1: Percentage of eligible people who initiated oral HIV PrEP during the last 12 months.
Numerator:	Enumerates the result or total reached for an indicator	Number of eligible MSM who initiated oral PrEP during the reporting period

(10) WHO (2018) Implementation Tool for Pre-Exposure Prophylaxis (PrEP) of HIV Infection – Module 5 – Monitoring & Evaluation. Available online at https://apps.who.int/iris/bitstream/handle/10665/279834/WHO-CDS-HIV-18.10-eng.pdf?ua=1

Component	Description	Example (reproduced from WHO)[10] *For examples on TB and Malaria, refer to Annexes B2 and B3
Denominator	Enumerates the total population or cohort (if relevant); coverage indicators include denominators and results are often expressed as a percentage	→ Number of eligible MSM who were newly offered PrEP during the reporting period → Coverage indicator (%) = → numerator (# receiving PrEP) → denominator (# newly offered PrEP)
Disaggregates	Define the relevant subpopulations accounted for by the numerator and denominator	→ People who received PrEP for the first time in their lives → Age (15–19, 20–24, 25–49 and 50+ years → Gender (male, female, transgender or gender non-binary) → Key population (MSM, SW, TG, PWUD and people in prisons and other closed settings → Geographic and other areas of importance.
Frequency of Reporting	This provides details on how often the data are aggregated and reviewed	Data should be collected continuously at the facility level, aggregated periodically and aligned with the reporting frequency of other routinely collected indicators (often on a monthly or quarterly basis). These data should then be combined for annual reporting.
Definition/ Description	This provides additional details on what the indicator is intended to measure	This indicator is key to assessing uptake of PrEP among those who are eligible. People who initiated oral PrEP includes those who started PrEP for the first time and those who may have discontinued PrEP and restarted PrEP in the reporting period.
Data Source & Method of Measurement/ How to Collect	The source for the information could vary, and includes facility/program records, interviews with service users – this will depend on the nature of the indicators and what is available in existing health	**Data Source: Program Records** The numerator is generated by counting the number of people who initiated oral PrEP during the last 12 months among all of the people who were newly offered PrEP during the reporting period. The numerator includes people who received PrEP for the first time,

Component	Description	Example (reproduced from WHO)[10] *For examples on TB and Malaria, refer to Annexes B2 and B3
Data Source & Method of Measurement/ How to Collect	information systems. Consulting with program, M&E and other experts to understand the data flow and where information is available is helpful for this step. Defines the calculations and sources used to report the data; this ensures consistency and comparability with all users of this indicator	and those who had previously discontinued PrEP and restarted it during the reporting period. Regular PrEP users who are continuing on PrEP should be excluded from both the numerator and denominator. The numerator should count each individual only once in a given reporting period. All people who received oral PrEP through national programs, demonstration projects, research or through private means and are taking it according to WHO/UNAIDS standards should be included. The denominator is generated by counting the number of people who were newly offered PrEP after meeting eligibility criteria. An individual should only be counted once in a given reporting period, even if they initiated PrEP more than once after a period of discontinuation. Age is defined as the age at the time the person initiates PrEP. If a person identifies as belonging to more than one key population, all of their responses should be recorded. This means that the sum of the data disaggregated by type of key populations can be greater than the total number of people. Data on transgender people can also be disaggregated by different gendered groups: male, female and non-binary.

Types of Indicators

There are several ways to categorize indicators (based on the level in the results chain – input, output, outcomes, impact, etc. or type of data they represent). For the purpose of this guide, we will describe indicators in two ways, based on whether they include denominators (coverage indicators) or whether they focus solely on numerators (output indicators) (Table 5).

Output Indicators: These indicators capture numeric values. Output indicators provide a count of the number of events (or individuals) during a specified timeframe or meeting certain criteria. As an example, they provide an absolute value for the number of persons receiving a service in a defined period (total number of persons tested for malaria in 2020). Output indicators are useful for analyzing trends in different services that are provided at the same location. In some instances,

output indicators are sufficient. However, because denominators are not included, they do not give a full picture of quality of services or reach within a target population.

Coverage Indicators: Coverage indicators capture numeric values. They include two components, a numerator and a denominator, usually reported as a percentage. The denominator makes it possible to assess gaps in the continuum of diagnosis, care and treatment services. In many instances, the denominators are known (total number of individuals reached at the previous stage of the program), and this information allows programs to quantify both access and gaps. Caution should be used when denominators are estimated, as the quality of the estimated denominator could impact whether coverage is determined to be high or low. Caution should also be used with interpreting coverage data when denominators change significantly, as this results in an artificial change in the percentage. Consider reviewing trends in both the numerator and percentage for coverage indicators.

TABLE 4 Key Components of Indicators

Output Indicator	Coverage Indicator
Consider output indicators for: → Capturing numeric values → Assessing trends in uptake of a service → Describing the magnitude of an issue	**Coverage indicators are best when you need to:** → Determine coverage gaps → Provide an indication of the quality of service.
Number of persons newly initiated on TB treatment	Number and percentage of people who are newly diagnosed TB initiated on treatment
Number of persons on ART who are virally suppressed	Number and percentage persons on ART who are virally suppressed
Number of persons tested for malaria	Number and percentage of people with suspected malaria receiving diagnostic testing[11]

(11) Please see Annex B.1 for more details on output vs coverage indicators.

TABLE 5 Scenarios and Recommended Indicator Types

Scenario	Indicator Type	Explanation
During early stages of implementation	Output	During early stages of implementation, output indicators are useful to track existence of a service (e.g., to count the number of labs providing a specific test). Tracking this allows you to describe trends and signals at the start of policy or program implementation.
To describe the magnitude of an issue	Output (or both)	Using a percentage on its own doesn't tell us the size of the population in need of a service or the magnitude of the gap. An output indicator can tell us that 12,000 persons did not receive a service which could represent 2% of antenatal clinic attendees. Often this means collecting and reporting both the numerator and denominator for a coverage indicator.
To describe trends within a fixed location or site	Output	If the denominator (e.g. number of sites) remains the same, output indicators are very useful for monitoring trends in the number of people accessing a service. All things being equal, major changes in data (positive or negative) could signal the effect of an intervention (such as extending clinic hours or an external event [e.g. COVID-19]).
To describe program coverage	Outcome	Assessing levels of access or determining disparities in access, requires knowing the size of the community that should be receiving the service (denominator), and the number who currently receive the service (numerator). Describing an increasing trend, such as where the number of people accessing a service doubled from 1,500 in 2010 to 3,000 two years later may be compelling (and the first part of the story), but demonstrating that this represents only 15% (in 2010) and 30% (in 2013) of a known population of 10,000 people who use drugs- shows both progress, and the gap in coverage, since 70% of those who need a service are not currently receiving it.
To provide an indication of the quality of service	Outcome	

Developing Qualitative Questions

Qualitative data enable CLM implementers to gather information about the wider context in which HIV, TB and malaria services take place. Data collectors find out about lived experiences and begin to identify the issues (both positive and negative) that shape individuals' engagement with health systems. Through interviews with health providers and decision-makers, qualitative data also allows in-depth exploration of service delivery approaches and bottlenecks that affect the quality of services that communities receive.

Unlike quantitative indicators, which have a fixed (numerical) response (i.e. length of wait time at the clinic, number of TB tests conducted, stock-out durations and types of medicines that are unavailable), qualitative data collection uses open-ended questions or prompts that can help illuminate the full story of a recipient of care's lived experience; it helps reveal why certain healthcare-seeking (or healthcare-avoidant) behaviors might be taking place. For example, some recipients of care may visit a clinic with longer wait times if a trusted provider of lesbian, gay, bisexual, transgender, queer and + (in recognition of all non-heterosexual non-cisgender identities; LGBTQ+)- friendly health services is known to practice there. While quantitative data would show differences in the number of key populations accessing services at the clinic, it is through qualitative data collection that the reason (in this case, positive experiences with the provider) would be documented.

In short, context matters, and qualitative data collection is a powerful tool for identifying, understanding and beginning to address underlying drivers for availability, accessibility, acceptability, affordability, appropriateness and quality of services. Well-constructed, qualitative questions and prompts can help reveal new issues that were previously not captured by other data collection processes. Qualitative data are typically collected through semi-structured interviews, where guiding questions are used during one-on-one (key informant) interviews or focus group discussions with a maximum of 10 participants (Box 4).

BOX 5

Qualitative Interview Techniques Commonly Used in CLM

Key Informant Interviews: Key informant interviews are one-on-one interviews with individuals who are knowledgeable on a specific issue. In the context of CLM, this could be an interview with a community member who is knowledgeable about issues of access to care, acceptability of services or community experiences. Qualitative interviews for CLM may also include interviews with healthcare workers involved in service provision (or management), who are able to provide explanations for service delivery or health system-related issues based on their respective roles.

Focus Group: Focus group discussions are qualitative interviews that bring together several key informants (8-10 persons) with similar backgrounds (e.g., SW, PWUD, young people). The group

session is facilitated by an interviewer, who is able to encourage a discussion on specific topics that provide in-depth information. In the case of CLM, group discussions have included community members who would be comfortable sharing issues (and possible solutions) in a group setting.

Semi-structured Interview: Semi-structured interviews are conducted using a list of topics or sample questions with optional prompts. The interviewer covers all questions or topics in the guide but may ask them in a different sequence based on the natural flow of the discussion with different key informants, or based on the dynamics of the focus group.

Qualitative Interviews Are Particularly Useful When:

- **You are exploring a new issue** and would like key informants to give you a sense of the main factors that are impacting them
- **The issue is layered and complex,** and it cannot be fully understood from a quantitative data source (or you would like to understand the context driving the quantitative data you are seeing)
- **You want to gain an in-depth understanding** of the experiences and needs of communities
- **You want to uncover the reasons why issues have happened** (such as stock-outs or treatment)) interruptions by discussing the experience with the respondent(s)
- **You would like to understand the context** that is driving the quantitative data you are seeing

Determining Whom to Interview

Your interview is a unique opportunity and should maximize the time you have with participants. Therefore, it is important to recognize who is the best placed to speak on the issue. For example:

- The pharmacist might recognize that several persons are late in collecting their medication but may not be able to say why. Interviewing recipients of care who experienced interruptions in their treatment would give in-depth information on reasons for delays in completing medication refills.
- A person working in phlebotomy (blood-drawing) services at the facility may recognize that results are returned late, but might not be able to say why. The laboratory manager would be better placed to explain delays in processing samples and challenges with timely return of results.

Therefore, select participants who:

- Are experts based on their lived experiences and first-hand knowledge of issues affecting their communities
- Are directly responsible for service delivery or related systems

Tips for Developing Qualitative Questions:

1. **Select questions that are related to your strategic priorities (HIV prevention), relevant to your scope (e.g., urban cities) and population focus (e.g., MSM)**
2. **Pose questions that would allow you to gain more insight into the issues covered by your quantitative indicators**
3. **Always provide open-ended questions that allow the respondent to tell their story or share their experience.** Although it is fine for a few close-ended questions to be included, limit questions that garner a simple yes or no response; these will not give the details that you need.

   EXAMPLE OF AN OPEN-ENDED QUESTION: "How have the clinic's opening/closing hours affected the way you seek healthcare?" or "Could you please describe any ways in which services are delivered that have affected (or might affect) the way you seek healthcare"? (Instead of close-ended questions, such as "do the clinic's new hours make it difficult for you to get an appointment?" do use open-ended questions, because they enable the respondent to speak freely about their own experience.)

4. **Qualitative questions are not intended to lead the respondent to a choose a set answer. The answers should not be given (i.e. as multiple choice options), nor should questions be leading.**

   EXAMPLE OF A LEADING QUESTION: "Would you say that the clinic's early closing time on Fridays discourages people from seeking care on that day?" (Avoid leading questions, because they set up the respondent to give a certain answer: "Yes, the early closing time has discouraged me from seeking care.")

   PROMPTS: If you get a "yes" or "no" response, or a very short response, follow up with a 'prompt': a related question that seeks to gather more detailed information. For example, if a respondent says "yes, I have delayed seeking care", ask them to describe why, and offer prompts such as: "Was your delay in care-seeking related to opening hours, location of services, clinic days or another reason?" or, "What caused you to delay seeking care?"

5. **As you develop your questions, think of how you will use and act on the possible data that comes from the question.**

   E.g., Could the information be used to tailor how services are provided to improve affordability or accessibility? Could services offer additional support to recipients of care to improve access (e.g., transport stipends, medication delivery)

6. **Start with general questions (that are easier to answer) to build rapport and then progress to more challenging or sensitive topics**

7. **Separate your questions and pose one question at time**

8. **Collate your questions by respondent, for example – collate all questions you intend to ask PLHIV, or youth, or nurses, in a single tool.**

FOR EXAMPLES OF QUALITATIVE QUESTIONS, PLEASE REFER TO ANNEX B.

BOX 6 Is Your Data Collection A Duplication of Effort?

CLM data collection is an intensive task that requires significant time and commitment from a team of data collectors, data managers, data analysts and other partners – so it is important to be efficient with your resources and strive to avoid collecting unnecessary information.

If another entity – such as the Ministry of Health, a large health implementation partner such as a PEPFAR-funded organization, or the health facility itself – is already collecting data on a certain indicator (such as # of people newly diagnosed with HIV per month) you may want to consider setting up a formal agreement to gain access to this data instead of using community data collectors to go about collecting the same information. **There are exceptions, however:**

(a) **Community reports do not align with existing data** – for example, if your community is reporting consistent stock-outs of essential medicines, but your local health facility's records indicate that stock-outs have not been occurring, it is vital to gather community-generated data to document the situation and substantiate claims that could otherwise be dismissed as "anecdotal evidence." In this case, the community is not setting up a 'parallel system'; instead, it is trying to triangulate data from a variety of sources to get closer to the truth.

(b) **The data exists, but is not shared in a transparent, routine, or timely manner** – While another entity may be collecting this data, there are sometimes circumstances in which the stakeholder with ownership over the data refuses to share the information. This sometimes occurs if the data owner (such as the health facility, or Ministry of Health) feels that communities will use this information to shame or criticize the data-owner, rather than to work together to identify problems and to co-create solutions.

Selecting "COVID-19 Sensitive" Measures

As described in Section II, COVID-19 has directly impacted the capacity of health systems to deliver services. The modalities and frequency of service delivery have also changed. As clinic visits became less frequent, virtual consultations and telemedicine have been scaled-up, and community-based service delivery has also increased. The impact of COVID-19 can therefore include changes in number of people who can be seen at facilities, and the type and nature of services that are available in facility and community settings. **To ensure that your measures are responsive to these dynamics, it may be helpful to consider:**

Describing the Effect of COVID-19 on the Lives of Recipients of Care

Using qualitative data, you can seek to determine the nature of the impact on COVID-19 on the day-to-day lives of recipients of care, specifically:

1. How COVID-19 has impacted areas beyond health – Has COVID-19 directly or indirectly impacted income-earning opportunities, access to food, mobility, and other basic needs? Are there new needs created or exacerbated by COVID-19 (or mitigation measures) that are not being addressed (e.g. access to education)?
2. How have COVID-19 mitigation measures altered the ways and methods of accessing health services? Have the types of services available changed? Are services available where people would normally access them? Are there provisions for traveling to new places for services? For those on long-term medication, has adherence been impacted?
3. How COVID-19 (or the response to it) may have resulted in a positive impact: Are there new ways of accessing services that are (more) acceptable to the community?

Describing how COVID-19 Has Impacted Service Delivery from the Perspective of Providers

Through qualitative interviews, you can explore:

1. How new policies or directives impact the way in which services are provided – health care providers are well placed to describe how shifts in service delivery change the way they work. Do new policies limit opening hours or the times that services are provided? Who can be seen at the clinic? Are there positive outcomes from any changes or new interventions?
2. Whether longstanding issues may be exacerbated by challenges faced at the clinic level, and what solutions may be helpful.

Quantifying the Change in Access to Services

Using quantitative data, you can seek to enumerate the effect on access to services by tracking:

1. The monthly trends in the number of people accessing a service compared with pre-COVID,

pre-surge or pre-lockdown periods. This means selecting an indicator and a measurement method that is consistent with national or facility information systems or historical data.

2. The length of time or timing for provision of services. This could involve measuring the spacing of appointments to capture a reduction in frequency of clinic visits or documenting the turnaround time for laboratory results.

3. The emergence of new interventions or service delivery points. This could include a shift to community-based services. For example, in the case of HIV, a shift away from facility-based pharmacy pick-up of medication refills to community ART delivery.

TABLE 6 Measuring the Impact of COVID-19

Domain	Suggested Monitoring Approaches
1. Service Uptake: Document trends in uptake of services	**TIP:** Consider tracking the number of people or community members accessing a service, and compare this data to pre-COVID periods. Include disaggregation by sub-population to assess whether the profile of people accessing the service has changed. **QUANTITATIVE:** Monitoring the total number of people who were tested for HIV by age group, key population, gender **QUALITATIVE:** Ask recipients of care and community members what barriers (or facilitators) to care exist now because of COVID-19
2. Disruption of Services: Document disruption in availability of services, commodities, and medication	**TIP:** Consider tracking stock-outs and the duration of disruption in access to essential services and medications. **QUANTITATIVE:** Monitoring the occurrence and duration of disruptions in availability of TB diagnostic tests **QUALITATIVE:** Ask healthcare workers how the disruptions have impacted the services provided at the facility, and what preventative measures can be put in place.
3. Delays in Delivery of Services: Highlight delays in provision of services	**TIP:** Consider the turnaround time for services, duration/length/frequency of appointments for people at higher risk of experiencing interruptions to their treatment (for example, due to social distancing measures that prevent immunocomprimised people from attending health clinics in person to collect their monthly dispensation of medication). These data can be quantified from service logbooks and through the experiences of service users which can be gathered through qualitative interviews with recipients of care. **QUANTITATIVE:** Monitoring the turnaround time for HIV viral load test results **QUALITATIVE:** Ask recipients of care about their personal experiences with awaiting results, and the personal impact of delays

Domain	Suggested Monitoring Approaches
4. Service Quality: Monitor changes in coverage of an essential component of services	**TIP:** Consider comparing the percentage of the population receiving a clinical service, compared to data from pre-COVID periods. Including qualitative data collection can offer insight into community experiences and barriers to accessing programs. **QUANTITATIVE:** Assessing the percentage of antenatal clinic attendees receiving a malaria test or an HIV test. **QUALITATIVE:** Ask recipients of care about their personal experience to assess whether they received tests, and to assess their understanding of the importance of these tests.
5. Differentiation of Service Delivery: Document emerging solutions or interventions, including scale-up or introduction of new modalities or service delivery points	**TIP:** COVID-19 could impact where services are being accessed. This may include changes to service delivery points, partnerships with community groups or greater emphasis on service delivery approaches that are less likely to be affected by COVID-19 restrictions. **QUANTITATIVE:** Documenting the number and percentage of persons on ART, disaggregated by the amount of medication that was dispensed to them. **QUALITATIVE:** Discuss emerging good practices or positive experiences with recipients of care, and how these new experiences can help with improving their health and quality of life beyond COVID-19.

STEP 4

Developing Data Collection Tools, Procedures and Permissions

If you have followed the stepwise approach, by now you have clearly outlined what you want to monitor and have selected a combination of measures to allow you to do so. Developing the procedures to guide your data collection would be your next step. These procedures will provide a clear structure for collecting, managing and using your data. This guide covers key steps for data collection. In-depth guidance on data quality assurance and data analysis are provided in separate documents.[12]

1. PLANNING: Data Collection Tools, Protocols and Resources for Implementation

Develop your data collection tools and protocols based on the data you intend to collect and your intended data sources. Ensure your tools allow you to collect the level of disaggregation that you will need. It is also important to separate your tools by the intended source, or in the case of qualitative interviews, by participant type (for example, health facility staff, key and vulnerable population group, etc).

In the COVID-19 era, factor in additional considerations for data collection and tools. For example, if interviews cannot be conducted face-to-face, consider adapting by using online or virtual tools and ensure that your data collection tools are adjusted for online and virtual data collection.

Develop data management guidance that outlines the procedures that your team will follow. This includes whether data collection will be paper-based, or if information will be entered directly into an electronic data management platform. These procedures also need to include steps that are used throughout the process to maintain the quality and confidentiality of the information.

Determine your resource needs for routinely conducting data collection. You will likely need to assemble and train a team of data collectors, a data supervisor and include data entry and analysis personnel on your team. You may also consider collaborating with an academic institution to support your data analysis and dissemination.

(12) ITPC (2022) Precision in a Pandemic (Data Quality Assurance Guide) – *in press*; ITPC (2022) CLM Data Use Guide – *to be released in mid-2022.*

2. PERMISSION: Approval for Data Collection and Informed Consent

Very often, data collection for CLM involves reviewing facility or program records that are not managed by CLM implementers. Formally engaging program or facility leaders to obtain permission prior to commencing data collection is essential. Requirements for obtaining permission can vary based on context — ranging from a memorandum of understanding (MoU), an Institutional Review Board (IRB — or ethics) approval, which are usually needed if partners want to publish data later on.

Obtaining permission from the relevant authority will allow you to review records and document the information you need, and/or to do qualitative interviews. The approval process often involves submitting a copy of your data collection protocol with the relevant data collection tools. You should keep this in mind as you are developing your implementation timeline.

Before starting your interviews with recipients of care and healthcare workers, it is also essential to confirm their permission for you to record and use their responses. This process of explaining the purpose of the interview and how the information will be used is referred to as informed consent. If consent is not obtained for recording, the interviewer could ask if it is still ok to proceed, only by taking notes.

3. PILOTING: Testing your Tools and Refining your Processes

Testing your data collection tools is an important step, so that you can assess the length of time data collection will take and whether the information is available in the format that you need. Following the steps that you have outlined in your data collection protocol when pre-testing paper tools and electronic databases could reveal errors in the tools or gaps in availability of information in your data sources.

Piloting also helps determine if you need to:

- Delete any questions (i.e., because they are redundant or unnecessary);
- Add any questions (i.e., because you are not getting the information you need);
- Re-word any existing questions (i.e., because the wording of the question may be confusing, or too long, or consistently results in responses that don't give you information about the actual topic you want to learn about);
- Scale-down the CLM effort to fewer and more focused questions (i.e., because the volume of information you are collecting is too vast to be analyzed effectively)
- Address any language issues that are hampering effective data collection (i.e., because the tool must be translated into a local language, or because the wording of certain questions needs to be simplified, or because some words need to be put into more general or simpler 'layman's' terms).
- Therefore, piloting or field testing your tools allows you to refine both tools and collection procedures before starting their full implementation.

4. PROTECTION & PRIVACY: Ensure Confidentiality and Secure Storage of Information

Ensuring confidentiality and security of information is important throughout the data collection process. The measures taken to protect data confidentiality should be explained to interviewees as part of the informed consent process. Safeguards include limiting the collection of personal identifiable information (such as names and birthdates). In this way, sensitive data on health status and sexual orientation are not linked to details that can be used to identify individuals. Securely storing records in locked cabinets (paper-based) or on password protected databases and electronic devices is also an important aspect of data security. Even if names are excluded from the databases, it ensures that only those who have permission to access the data are able to (Box 6).

BOX 7 Data Sources, Ethical Approval, Privacy and Security

As mentioned above in Box 4, sharing data is often a key component of CLM, especially where data sets already exist which contain information that communities want to monitor.

As a routine part of setting up any CLM program, we recommend setting up a formal agreement at the outset of the work with such data-holders – be they health facilities, or the Ministry of Health, or program implementers (such as PEPFAR or others). These agreements could take the form of an MoU, a letter of agreement/and or formal authorisation, etc. IRB approval in the context of collaboration with academia is only required prior to conducting any data collection that you hope to publish in a peer-reviewed research journal.

It is important for all parties to agree upon how the data will be shared, how often, through what channels, whom will have access to the data, and to ensure compliance with all privacy laws. There are many reasons for this, including – and especially – the safety and privacy of individual recipients of care, whose health records often contain highly sensitive and private information (such as HIV status, information relating to sexual orientation or gender identity, etc.). Unique identifiers that protect a recipient of care's name and identity can often enable general information to be shared without compromising the person's safety or privacy. Furthermore, formal agreements about routine data sharing can help ensure an on-going flow of information, even if there are moments of tension between different stakeholders in the CLM network (i.e., if the health facility feels criticized and wants to begin withholding data from health facility records).

There should be clear guidelines established about data disposal (to ensure that it is disposed of carefully, without compromising security or privacy) and data destruction, including how long data will be kept in storage before it is destroyed.

A Final Note

As you design your CLM programs, it may be tempting to immediately start by selecting indicators and developing interview questions. We encourage you to start by setting your priorities, defining your monitoring questions, and then identifying indicators and qualitative questions.

This guide provides an approach to get you started; a few examples of our stepwise process are available for reference (see Annex B). Pointers on conducting qualitative interviews are included in Annex C, page XX, and more detail will be provided in a forthcoming publication. To get a sense of what is being monitored in the broader global landscape of indicators for HIV, TB and malaria programs beyond CLM, we have included links to monitoring frameworks from other international programs in Annex D.

Annexes

Annex A

Sample Indicator Framework for Community-Led Monitoring

Highlighting Quantitative Indicators and Related Qualitative Questions

Category	This allows you to group related indicators	HIV Prevention
Indicator	Include your indicator description here. You can also provide clarification on numerators and or denominators (as relevant)	Number of people receiving oral pre-exposure prophylaxis (PrEP) for the first time
Frequency of Reporting	This specifies how often you would review the data- typically monthly for many CLM indicators but could also be quarterly or annually (for measures that are not likely to change on a monthly basis)	Monthly
Disaggregation	This specifies how the data would be separated to provide information about subgroups within the total population that the data represent	By age group By sex By key population
Quantitative Data Source	Indicate the source you would review to collect the information	Health facility records
Qualitative Question	Where you have selected qualitative questions that are related to the quantitative indicator, you can choose to include them here	How did you first learn about PrEP? What prompted you to get PrEP?
Qualitative Data Source	Specify here who would be your key informants or focus group participants for the qualitative questions	MSM Trans Women

Annex B1

Example of Quantitative Indicators and Qualitative Questions for HIV Services

Organization's Mandate	Improve access to high quality treatment for people living with HIV.
National Policy	Newly diagnosed PLHIV should be rapidly initiated on ART, regardless of their clinical stage or CD4 cell count at diagnosis. Dolutegravir (DTG) should be used as part of first-line treatment.
Emerging Evidence	Larger treatment sites have been slow to transition to same-day ART initiation (possibly due to stock management concerns)
Strategic Priority for CLM	Supporting timely initiation on ART for all newly diagnosed PLHIV. Supporting transition to dolutegravir-based first- line treatment for all treatment-naïve recipients of care.
Scope	All PLHIV at site, with disaggregation by age group, key population, and sex.
Monitoring Questions and Indicators	1. **MONITORING QUESTION:** Did newly diagnosed PLHIV start treatment on the same day as they received a positive HIV test result? **INDICATOR**: Number and percentage of newly diagnosed PLHIV initiated on treatment 2. **MONITORING QUESTION:** Is DTG-based first-line treatment provided routinely to recipients of care who are newly initiated on ART? **INDICATOR:** Number of persons newly initiated on ARV, disaggregated by antiretroviral regimen
Demonstrating the Value of Denominators and Coverage Indicators	Note the difference between the proposed indicator for monitoring question 1 and the two options provided below (for output and coverage indicators). Since there is a known population of interest (all newly diagnosed PLHIV), it would be better to use a coverage indicator to assess implementation of the policy. Also note that the indicators will capture the quantitative data, and qualitative interviews may be helpful in explaining the data you see.

INDICATOR:
Number and percentage of newly diagnosed PLHIV initiated on treatment within 24 hours of diagnosis

MONTH	SITE	NUMERATOR	DENOMINATOR	PERCENTAGE
1	Facility A	11,192	19,277	58%
2	Facility A	13,405	21,821	61%
3	Facility A	15,920	20,955	76%
1	Facility B	1,670	1,710	98%
2	Facility B	1,200	1,255	96%
3	Facility B	970	1,004	97%

Using a coverage indicator, we can determine the percentage of PLHIV who were initiated on ART on the same day as they were diagnosed. Despite lower numbers, a higher proportion of persons at Facility B are rapidly initiated on ART. Considering the policy is to rapidly initiate persons on treatment (or in the case of DTG-based ART, using it as first-line treatment), Facility B has demonstrated better policy implementation. Facility A may still be using clinical criteria for initiating recipients of care on treatment, despite apparent increases in absolute counts and percentages of PLHIV who initiated treatment on the same day.

FINAL INDICATOR:
Number and percentage of PLHIV newly initiated on treatment (disaggregated *by timing – within 24 hours of diagnosis; within a week of diagnosis, more than 7 days since diagnosis*)

Qualitative Data Collection	Documenting the reasons for low rates of same-day initiation could be possible through qualitative data collection, interviews with physicians and other clinical staff at the site (a few sample questions are included below). These would form part of a larger tool that targets physicians.
Qualitative Source	Key informant interviews with physicians
Sample Questions	• Please describe any steps or criteria that are used to determine when newly diagnosed recipients of care start treatment. • Please describe any challenges you encountered with rapidly initiating recipients of care on treatment. • How is the prescription length or dispensation amount determined for persons on ART at the facility?

Sample Questions (CONTINUED)	• The national policy recommends initiation of DTG-based regimens as first-line, please describe your experience with roll-out of this policy. Please describe any barriers and possible solutions as you see them. • What are the impacts of COVID-19 on the availability of medicines and commodities on the facility? Probes: How has this affected initiation of new recipients of care on ART; continuation of persons on ART?
Additional Notes	• Disaggregation by sex, key population, age group may provide more insight into disparities by sex, key population or age group. • **NOTE:** a different indicator is needed to address the second monitoring question – though there is overlap, the two questions are different and have different denominators

Annex B2

Example of Quantitative Indicators and Qualitative Questions for Malaria Services

Organization's Mandate	The organization is focused on improving maternal health outcomes for underserved women. The organization advocates for improved quality of antenatal services in regions with high rates of malaria and HIV.
National Policy	The national policy includes commitments to WHO recommendations for malaria testing, specifically: in all settings, when malaria infection is suspected, it should be confirmed with a parasitological test (by microscopy or rapid diagnostic test). The results of parasitological diagnosis should be available within a short time (less than two hours) after the recipient of care presents. In settings where parasitological diagnosis is not possible, a decision to provide antimalarial treatment must be based on the probability that the illness is malaria. Malaria treatment guidelines[13] recommend prompt parasitological confirmation by microscopy or with a rapid diagnostic test (RDT) for all recipients of care with suspected malaria before treatment is started.
Emerging Evidence	There are stockouts of commodities in a geographic location with high malaria transmission rates. Tests and treatment for malaria have not been consistently available. There are delays in receiving malaria test results and treatment initiation for pregnant people.
Strategic Priority for CLM	Supporting timely testing and treatment for malaria amongst pregnant people. Ensuring a consistent supply of appropriate medications, including for treatment of malaria in pregnancy.
Scope	Antenatal clinic attendees
Monitoring Questions and Indicators	1. Have pregnant people with symptoms suspected to be caused by malaria received a test? 2. Have clinics experienced stock-outs in commodities for testing and treatment of malaria? 3. Have persons with malaria received treatment?

(13) World Health Organization (2021) WHO Guidelines for Malaria. Available online at [https://apps.who.int/iris/rest/bitstreams/1361724/retrieve].

INDICATOR 1: Number and percentage of suspected malaria cases that receive a parasitological test. Disaggregated by age, type of test, by clinic (ANC attendees, males, females, transgender people and gender non-binary people).
INDICATOR 2: Number and percentage of pregnant people attending antenatal clinics who received three or more doses of intermittent preventive treatment for malaria
INDICATOR 3: Number and percentage of malaria cases (presumed and confirmed) that received first-line antimalarial treatment at public sector health facilities
INDICATOR 4: Number of facilities experiencing a stock-out of one or more commodities (by type)

Qualitative Data Collection	It may be helpful to include interviews or focus group discussions with providers at the facility to understand the issues and challenges around stock management and service provision. A few sample questions (which would be part of a larger tool), are included below. These questions complement the information from indicator #4.
Qualitative Data Source	Key informant interviews with head pharmacist or senior staff responsible for procurement
Sample Questions	• What are the impacts of COVID-19 on the use of medicines, commodities and equipment in your facility? • What types of preventative actions do you think would address potential stock-out issues at your facility (or prevent recent ones from recurring)?

Annex B3

Example of Quantitative Indicators and Qualitative Questions for TB Services

Organization's Mandate	The organization is focused on advocating for implementation of evidence-based policies and programs for TB diagnostics and treatment services, and, ultimately, TB elimination. The organization works at the policy level to advocate for improvements in national health policy and health system improvement.
National Policy	The country's national policy has not yet been updated to include WHO recommendations which were published in 2021 .[14]
Emerging Evidence	The organization has learned from partners on the ground that TB services have been disrupted and deprioritized because of the ongoing COVID-19 pandemic. Some community-led organizations have reported a decrease in funding. This has led to delays in access to diagnostics and treatment for the communities they serve.
Strategic Priority for CLM	Supporting continued allocation of resources for TB screening, diagnostics and treatment. Improvement of national policy to ensure it is fully aligned with WHO recommendations.
Scope	All persons with TB, including subpopulations at higher risk (PLHIV, people in closed settings including prisons)
Monitoring Questions and Indicators	1. Have funding disbursements/allocations for TB programs changed since the COVID-19 pandemic? 2. Are PLHIV routinely provided with TB screening?

INDICATOR 1: Total amount of funding allocated to TB programming -disaggregated by program area and province/ parish where available.
INDICATOR 2: Number of persons screened for TB – disaggregated by key population

(14) World Health Organization (2021) WHO Consolidated Guidelines on Tuberculosis Screening. Available online at: https://apps.who.int/iris/rest/bitstreams/1336771/retrieve.

INDICATOR 3: Percentage of PLHIV who received TB screening at most recent clinic visit
INDICATOR 4: Number of facilities experiencing a stock-out of one or more commodities (by type)

NB – Collecting historical data will be important to demonstrate the change in the funding allocation and program delivery. It would also be important to consider the experience at service delivery points

Qualitative Data Collection	Interviews with people living with HIV, to assess their experiences with accessing care and treatment for TB or interviews with recipients of care would provide complementary data. Sample questions for interviews with healthcare workers have been included. These complement the data from indicator 4.
Qualitative Data Source	Healthcare worker
Sample Questions	• How has COVID-19 affected your facility's TB testing and treatment programs? • What are the impacts of COVID-19 on the use of medicines and medical equipment in your facility? • What suggestions do you have to prevent these issues from recurring?

Annex C

Conducting Qualitative Interviews

The general steps for conducting qualitative interviews, whether they involve one on one discussions with key informants or group interviews, are similar. Specific pointers for group discussions are also included below.

Key Steps for Conducting Qualitative Interviews

Planning/ Design	**Translate your qualitative questions into an interview guide.** This would serve as the data collection tool for your semi-structured interview. The questions or topics would provide some structure for data collection but the order or sequence in which they are addressed, or the way the questions are asked during execution, may vary with each interview. In developing your tool: → Be sure to include a section with basic information on each informant (e.g., for healthcare workers – the cadre of staff and organization). Identifying information such as names and contact details (if needed) should be stored separately from the tool with the responses. → Separate your questions based on the expected respondents (e.g., include all questions for clinicians in a single tool or all questions for MSM in a single tool → The sequence of your questions is important, remember to start with general topics first and progress to more sensitive questions.
Execution	**Introduction** Greet the participant(s) by introducing yourself and the organization(s) conducting the CLM activities. State the goal of the interview, its duration, the measures in place to ensure confidentiality and data security, and the intended use of the information obtained. **Informed Consent** Clearly state the topic and the context for the interview; remind respondents (s) about their option to decline participation or their right to decline responding to specific questions. Explain how their open and honest sharing will be beneficial to achieving the end goal of CLM (improve health and quality of life outcomes). Explain where this information will be stored and what privacy and security measures are in place (i.e. stored in a computer with a high security password, how many individuals will have access to the data?) Obtain consent before proceeding with the interview. If you will be recording the interview, be sure to explain the process and obtain consent before beginning the recording.

Execution (continued)	**During the Interview** Take care not to influence the informant. If topics have already been addressed by responses before your questions are asked – summarize the responses for the informant and ask if they would like to share any additional reflections. Allow for silences and pauses while the informant gathers their thoughts. Do not rush on to the next question until you have gotten the information you need; use follow-up prompts for very short or incomplete answers. **With group interviews** Encourage all participants to share their thoughts, be on the look-out for opinion leaders who may dominate the discussion, to balance this, it may be necessary to call on those who have not shared and encourage them to do so.
Conclusion	Summarize the discussion to ensure all the themes have been addressed. Thank the informant(s) for their time and the information provided. You could conclude by reminding them of how the information will be securely managed, analyzed and used.

Annex D

M&E and Indicator Guidance Documents

All sources in this publication were accessed in April 2022.

HIV

UNAIDS (2022). HIV Indicator Registry.

AVAILABLE ONLINE AT: https://indicatorregistry.unaids.org/

World Health Organization (2020). Consolidation HIV Strategic Information Guidelines.

AVAILABLE ONLINE AT: https://www.who.int/publications-detail-redirect/9789240000735

Global Fund for HIV, TB and Malaria (2020).HIV Indicator Guidance Sheet.

AVAILABLE ONLINE AT: https://www.theglobalfund.org/media/5189/me_indicatorguidancesheets-annexa-hiv_sheet_en.xlsx

Tuberculosis

Global Fund for HIV, TB and Malaria (2020). Tuberculosis Indicator Guidance Sheet.

AVAILABLE ONLINE AT: https://www.theglobalfund.org/media/5192/me_indicatorguidancesheets-annexa-tb_sheet_en.xlsx

Public Health England (2022). TB Strategy Monitoring Indicators.

AVAILABLE ONLINE AT: https://fingertips.phe.org.uk/profile/tb-monitoring/data#page/1

One Impact (2021). Monitoring and Evaluation Plan.

AVAILABLE ONLINE AT: https://stoptbpartnershiponeimpact.org/resources/M&E/M&E/STP%20CLM%20OneImpact%20M&E%20Plan.pdf

TB Data Impact Assessment and Communications Hub (2021). Navigating Tuberculosis Indicator.

AVAILABLE ONLINE AT: https://www.tbdiah.org/wp-content/uploads/2021/10/Navigating-TB-Indicators-A-Guide-for-TB-Programs-MS-21-197-TB_508_Final.pdf

Malaria

Global Fund for HIV, TB and Malaria (2020). Malaria Indicator Guidance Sheet.

AVAILABLE ONLINE AT: https://www.theglobalfund.org/media/5195/me_indicatorguidancesheets-annexa-malaria_sheet_en.xlsx

MEASURE Evaluation. (2020). Surveillance, Monitoring, and Evaluation of Malaria Programs: Online Course. Chapel Hill, NC, USA: MEASURE Evaluation, University of North Carolina.

AVAILABLE ONLINE AT: https://www.measureevaluation.org/resources/publications/ms-20-184.html

World Health Organization (2018) Malaria surveillance, monitoring & evaluation: a reference manual. Geneva: World Health Organization; 2018. Licence: CC BY-NC-SA 3.0 IGO.

AVAILABLE ONLINE AT:
https://apps.who.int/iris/bitstream/handle/10665/272284/9789241565578-eng.pdf

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

Watch What Matters

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About ITPC

The International Treatment Preparedness Coalition (ITPC) is a global network of people living with HIV and community activists working to achieve universal access to optimal HIV treatment for those in need. Formed in 2003, ITPC actively advocates for treatment access across the globe through the focus of three strategic pillars:

- **Build Resilient Communities (#TreatPeopleRight)**
- **Intellectual property and access to medicines (#MakeMedicinesAffordable)**
- **Community monitoring and accountability (#WatchWhatMatters)**

About Watch What Matters

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

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

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

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