

# INTRODUCTORY GUIDE ON COMMUNITY-LED MONITORING OF NCD SERVICES



## Acknowledgements

The development of this introductory guide was managed by Charlotte Aberdein with contributions from Prachi Kathuria and Cristina Parsons Perez at NCD Alliance. With thanks to Sally Shackleton, the external consultant with expertise on community-led monitoring (CLM) who supported the development of the publication and facilitated consultations with various civil society organisations and experts in the NCD and HIV space. Special thanks to all people living with NCDs, NCD alliances and civil society organisations with CLM expertise who were involved in consultations and activities. We are grateful for all key informant interviews, focus group discussions and wider consultation with the NCD Alliance network via the completion of a survey to inform this guide.

This work was made possible thanks to NCD Alliance's partnership with The Leona M. and Harry B. Helmsley Charitable Trust.

## Acronyms and abbreviations

<b>NCD</b>	Noncommunicable disease
<b>NCDA</b>	NCD Alliance
<b>LMICs</b>	Low- and middle-income countries
<b>CLM</b>	Community-led monitoring
<b>CSOs</b>	Civil society organisations
<b>HIV</b>	Human immunodeficiency virus
<b>WHO</b>	World Health Organization
<b>ITPC</b>	International Treatment Preparedness Coalition
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>RMNCHA</b>	Reproductive, maternal, newborn, child and adolescent health



© 2023 NCD Alliance

Editorial coordination: Jennifer Bajdan and Sairica Rose

Design, layout and infographics: Mar Nieto



NCD Alliance

31-33 Avenue Giuseppe Motta  
1202 Geneva, Switzerland

[www.ncdalliance.org](http://www.ncdalliance.org)

## Table of contents

<b>1. Introduction to the guide and its scope</b>	<b>4</b>
<b>2. Introduction to community-led monitoring</b>	<b>5</b>
2.1. What is community-led monitoring?	5
2.2. Why is CLM relevant in the context of NCDs?	6
2.3. Principles of CLM for NCD Services	7
<b>3. Community-led monitoring step-by-step</b>	<b>8</b>
<b>STEP 1</b> Planning, consultation and coordination	9
<b>STEP 2</b> Selecting data collection tools and collecting data	13
<b>STEP 3</b> Putting your data to work – awareness-raising and advocacy	16
<b>STEP 4</b> Following up and monitoring solutions and advocacy asks	18
<b>4. CLM in the context of NCDs – Readiness and progression</b>	<b>19</b>
4.1. Adapting current approaches to be more CLM aligned	19
4.2. CLM progression and scale-up	20
<b>5. Conclusion</b>	<b>21</b>
<b>6. Essential reading on CLM for NCD services</b>	<b>22</b>
<b>Annex 1</b> CLM Checklist	23
<b>Annex 2</b> Case studies on CLM in the context of NCDs	24

# 1. Introduction to the guide and its scope

Civil society organisations, people living with NCDs, and community-led efforts all play a fundamental role in driving action on NCDs from local to global level. A strong and coordinated civil society movement, with the active involvement of people living with NCDs, builds the demand for action and accountability, and ensures that policies and programmes are relevant, appropriate and sustainable.

People living with NCDs refers to a broad group of people who have or have had one or more NCD, as well as those who are closely connected to someone with an NCD – such as relatives, close friends, and care partners (sometimes also referred to as carers or caregivers).

The [NCD Alliance \(NCDA\) Strategy 2021-2026](#) includes community engagement as one of its four impact goals, rooted in the belief that the meaningful involvement of communities, civil society and people living with NCDs, are fundamental to achieving progress. Community engagement is a key aspect of advocacy and a critical enabler of other organisational impact goals in prevention, care, and financing.

NCDA addresses community engagement through its capacity development work, strengthening the capacity of NCD alliances at national and regional levels, particularly in low- and middle-income countries (LMICs), and promoting the meaningful involvement of people living with NCDs in the response.

Through its flagship initiatives of the Advocacy Institute and Our Views, Our Voices, NCDA has recently supported community-led monitoring (CLM) activities of NCD alliances in [Ghana](#) and Kenya. CLM is a community-driven, grassroots accountability mechanism used by affected communities to assess the accessibility and quality of health services. Given that CLM is an emerging area of interest and an underdeveloped tool for improving NCD services, NCDA has developed this introductory guide to present the principles, elements and processes of CLM, as they relate to NCDs.

This introductory guide is for NCD alliances, advocates and other civil society organisations who:

- Work with people with lived experience of NCDs to build their capacity to advocate for a people-centred response at all levels of decision-making and service delivery.
- Are monitoring or are interested in monitoring access to and quality of NCD-related health services and who wish to scale up this work.
- Undertake evidence-based advocacy for people-centred NCD prevention and care services.

The guide is informed by NCDA's commitment to the meaningful involvement of people living with NCDs in decisions that affect their lives. This guide draws from CLM in the context of HIV and includes the perspectives and experiences of NCD alliances who participated in focus groups and key informant interviews preceding the development of the introductory guide. This guide is not intended to be an extensive technical resource on CLM for NCDs, but rather an introductory guide to CLM with resources and links to further information.

This introductory guide includes CLM definitions, explores CLM's relevance and potential in the context of NCDs, describes CLM principles, outlines in detail the different steps in the CLM process including tips for implementation and insights from alliances with CLM experience, gives examples of different types of CLM implementation and provides guidance on how to develop CLM from a basic pilot model to institutionalising CLM practices at sub-national and national levels.

## 2. Introduction to community-led monitoring

### 2.1. What is community-led monitoring?

Community-led monitoring (CLM) refers to structured processes led by affected communities, to regularly monitor issues that matter to them to advocate for improvements in prevention, service delivery and care.<sup>1</sup> CLM recognises the crucial role that communities play in responsive, accountable and effective systems for service delivery and disease prevention. While CLM has mostly been used for improving health service delivery, it has also been used to identify and address systemic barriers, gaps in prevention, as well as identify policy and legal gaps that impact people's access to and uptake of health and other services. For instance, in a survey of CLM best practices, 62% of the initiatives surveyed had as their focus human rights.<sup>2</sup> CLM therefore contributes to addressing inequity in health outcomes for marginalised people and groups.<sup>3</sup>

Definitions of CLM by organisations such as UNAIDS, PEPFAR<sup>4</sup> and The Global Fund to Fight TB, HIV and Malaria<sup>5</sup> agree that CLM must:

1. Be owned, led, and implemented by key affected communities.
2. Be systematic in collecting information or data from service users and affected communities on the issues of importance to them.
3. Involve the analysis of data collected, with the goal of identifying issues that prevent access to and use of quality health services.
4. Address these issues with powerholders, with recommendations for solutions.

What makes CLM different from routine monitoring of health care services is that it is an accountability measure led by communities themselves. CLM might also be referred to as community-based monitoring or social accountability.



1 International Treatment Preparedness Coalition. *CLM hub III*. Available from: <https://clm.itpcglobal.org/>

2 Health Gap. *Best Practices of Community-Led Monitoring*. 2022. Available from: <https://healthgap.org/wp-content/uploads/2022/09/CLAW-Best-Practices-in-Community-Led-Monitoring-EN.pdf>

3 NCD Alliance. *Accelerating the NCD response through Health Equity: from ideas to action. A Conceptual Framework for Community Advocates*. Forthcoming – 2024.

4 PEPFAR. *Community-Led Monitoring Fact Sheet*. 2020. Available from: <https://www.state.gov/wp-content/uploads/2020/07/PEPFAR-Community-Led-Monitoring-Fact-Sheet-2020.pdf>

5 The Global Fund. *Technical Brief: Community Systems Strengthening*. 2022. Available from: <https://www.theglobalfund.org/media/4790/core-communitysystems-technicalbrief-en.pdf>

## 2.2. Why is CLM relevant in the context of NCDs?

“CLM is basically about giving power, engaging and then enhancing the capacity of recipients of services to demand what is due to them in terms of care, support and social justice – the right to health – ensuring the community voice is felt and measuring what affects them.”

Ghana NCD Alliance

“CLM should be seen as a core component of meaningful community engagement and involvement.”

Healthy India Alliance

“It’s really making sure that those who are affected have a say in planning, monitoring, evaluation and also holding duty bearers accountable.”

NCD Alliance Kenya

Noncommunicable diseases (NCDs) are persistently a leading cause of premature death around the world, with 41 million people dying from NCDs every year. More than three-quarters of NCD-related deaths occur in lower and middle-income countries, with NCDs being both a cause and a consequence of poverty. Many NCDs are preventable, with two-thirds of NCD deaths linked to tobacco use, harmful use of alcohol, unhealthy diets, physical inactivity, and air pollution.

The 66<sup>th</sup> World Health Assembly endorsed the WHO Global Action Plan for the prevention and control of NCDs 2013–2020 (extended to 2030), which aims to achieve the commitments made by world leaders in the United Nations Political Declaration on the Prevention and Control of NCDs (2018). The plan is organised around six objectives, one of which is to monitor NCD trends and determinants and evaluate progress in their prevention and control through surveillance.

There are several resources that describe how to undertake CLM in the context of HIV, TB and malaria, for instance, the International Treatment Preparedness Coalition has set up a CLM Hub.<sup>6</sup> UNAIDS<sup>7</sup> and the Global Fund have also supported CLM initiatives for HIV, TB, and malaria.<sup>8</sup> CLM resources and initiatives in the NCD response are currently extremely limited and underutilised. Whereas but this is not the case for community-led monitoring of the NCD response. This gap offers an opportunity for civil society organisations and alliances to define what CLM might look like in the context of NCD prevention, treatment and care.

Community-led monitoring of HIV services has demonstrated that it can have positive outcomes for people living with HIV. CLM has also shown that community-generated data can complement government data with insights which more formal data gathering does not cover. Overall, CLM is a win-win for communities and service providers, who work together to find solutions and fix problems.

In the context of NCDs, CLM has the potential to:

1. Gather frontline community insights into the availability, acceptability, accessibility and quality of NCD health services that might be missing from national and sub-national efforts to collect data on NCDs.
2. Include the perspectives of people living with NCDs that are essential to identify, understand and remove structural, policy and other barriers to the prevention and care of NCDs.
3. Identify gaps and other problems with the implementation of existing policies, strategies and plans as well as other national measures to address NCDs.
4. Identify practical and actionable measures that can be taken to address service delivery problems at primary health care level, in partnership with people living with NCDs.

6 International Treatment Preparedness Coalition. *CLM hub III*. Available from: <https://clm.itpcglobal.org/>

7 UNAIDS. *Establishing Community-Led HIV Services: Principles and Processes*. 2021. Available from: [https://www.unaids.org/sites/default/files/media\\_asset/establishing-community-led-monitoring-hiv-services\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/establishing-community-led-monitoring-hiv-services_en.pdf)

8 The Global Fund. *Community Responses and Systems. Related Resources*. Available from: <https://www.theglobalfund.org/en/community-responses-and-systems/>



## 2.3. Principles of CLM for NCD Services

### Drawing from existing practices, CLM should.<sup>9</sup>

#### Community-driven and owned

- Be implemented and led by affected communities, including those left behind and the most marginalised i.e., those left furthest behind.
- Be owned by communities at every stage, including identifying priority issues in the community, defining indicators, establishing preferred channels of communication with key stakeholders and deciding how data is stored, used as well as how and what data is shared.

#### Independent and ethical

- Be independent, protecting against programmatic interference from other actors including donors, national government, and other monitoring and evaluation systems.
- Be ethical – with the collection of data, informed consent, confidentiality, and data security.
- Be verifiable, reliable, conducted in a routine/continuous cycle and collected under a 'do no harm' principle.
- Be inclusive and enabling – with trained, adequately supported and remunerated field workers and monitors.
- Be coordinated by a central, community-owned structure or civil society organisation, in collaboration with national and/or sub-national decision-makers, capable of managing the programmatic, financial, and human resource components of the CLM programme.

#### Driven by a clarity of purpose

- Not re-gather, replace, or duplicate monitoring and evaluation data from existing systems.
- Generate political will and advance a health equity lens on NCD prevention and care.
- Function as a tool to drive improvements in service delivery, and in the prevention and treatment of NCDs.

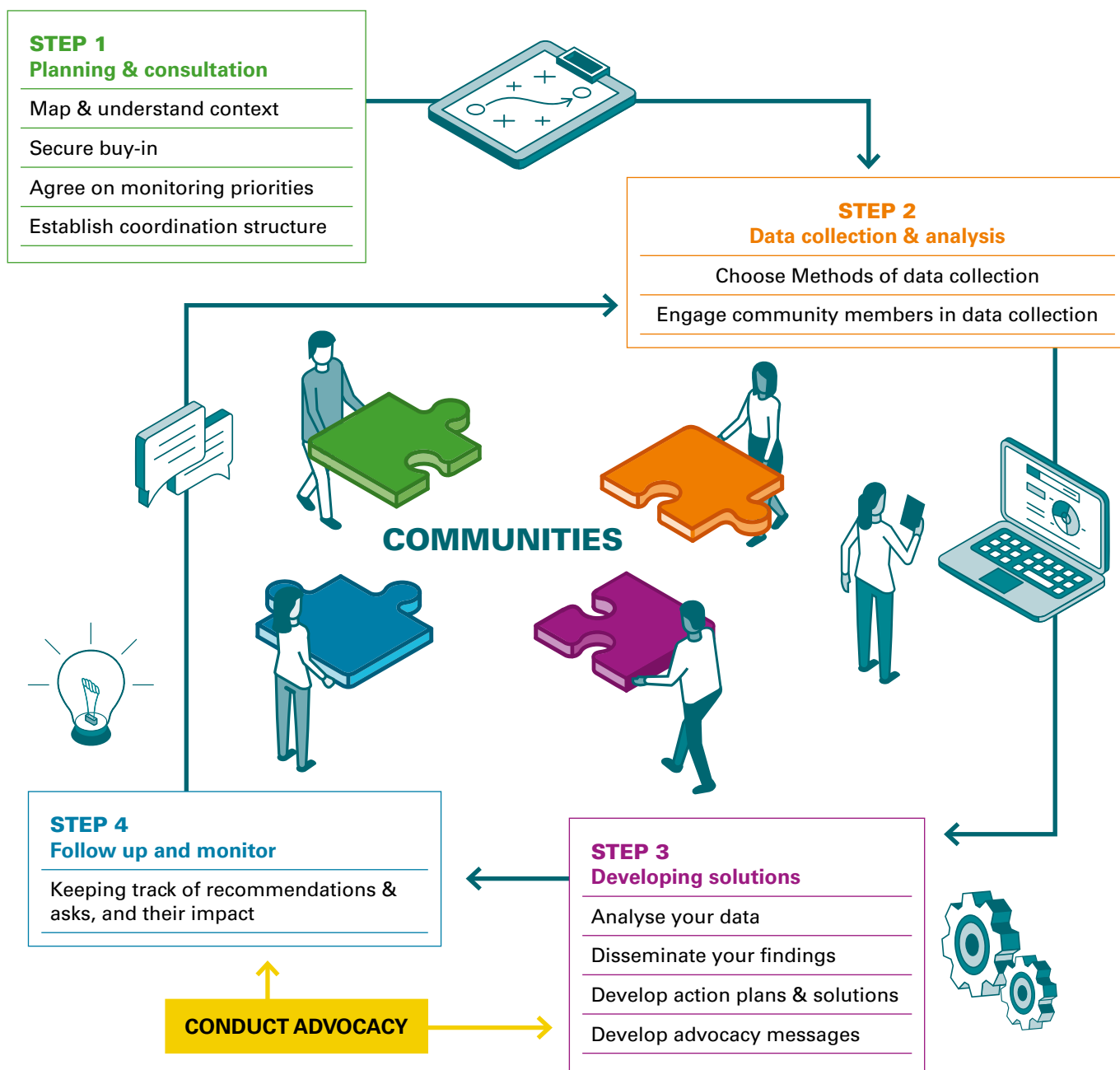


<sup>9</sup> Community Data for Change (CD4C) Consortium. *Community-Led Monitoring. Best Practices for Strengthening the Model (White Paper)*. Available from: <https://oneill.law.georgetown.edu/wp-content/uploads/2022/12/CD4C-CLAW-EANNASO-ATAC-APCASO-Community-led-Monitoring-Best-practices-for-strengthening-the-model.pdf>

## 3. Community-led monitoring step-by-step

The following section guides you on the basic elements and steps to designing and implementing a community-led monitoring project. In the section that follows, we discuss some considerations that may impact your decision-making and your readiness to undertake CLM.

CLM should be seen as a cycle of activities, each action informing the next. The key processes involved in CLM<sup>10</sup> are illustrated in the diagram below:



We include some guidance on the activities in each of these processes below.

10 Ibid, page 6.



## STEP 1

### Planning, consultation and coordination

This is the first phase of your CLM project and lays the groundwork for the CLM cycle. The focus of this phase is on building a common understanding of CLM, establishing partnerships and agreements with stakeholders and very importantly, identifying and agreeing on what you will monitor. The groundwork will include raising funds and developing on-going fundraising efforts to sustain your work.

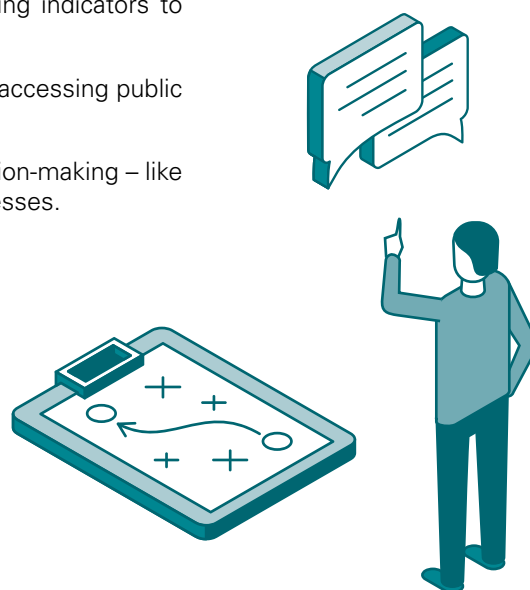
“An on-going relationship with the Ministry of Health set us off on the right footing and also opened doors for us.”  
NCD Alliance Kenya

#### Identifying NCD needs and gaps

To make informed decisions on structuring your CLM project, what and where to monitor, and who to target in your advocacy, it is important to undertake a mapping or research exercise that will clarify your current NCD policy environment, NCD needs and gaps. You can gather information by holding a series of meetings, conducting surveys or consultations and/or doing your own investigation through formal or informal research, depending on your context.

Your mapping or research can include:

- What is known about the disease burden in your context, including any data available on NCD mortality, morbidity, prevalence and incidence, financial burden or other relevant indicators – to identify which NCDs are preventable among which populations?
- What is known (and not known) about barriers to NCD prevention and care in your context, including information about the social and commercial determinants of health?<sup>11</sup>
- Mapping your key stakeholders – this can include organisations and organised groups of people living with NCDs, specialist services run by the government and the private sector etc.
- Your policy environment and the existing service delivery standards that health facilities are expected to meet. Your country may have national plans and strategies related to NCDs and may also have existing indicators to measure prevention efforts and health service delivery.
- The processes and permissions that might be needed for accessing public health facilities and public health data.
- Existing monitoring processes and cycles and health decision-making – like budget cycles and national and sub-national strategy processes.



11 Schram and Goldman. *Paradigm shift: new ideas for a structural approach to NCD prevention. Comment on “How Neoliberalism is shaping the supply of unhealthy commodities and what this means for NCD prevention.”* Int J Health Policy Manag. 2020;9(3):124–127. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7093042/>



## Practical advice

**Acknowledge and understand national and district health planning and implementation cycles.** Timing your CLM activities to coincide with reviews of policy, or budget processes, may help ensure that your recommendations are more easily integrated into revised plans and budget allocations.

Being aware of and realistic about processes and procedures required to gain access to facilities and help secure buy-in from officials is essential. The first step of your CLM process should involve intensive relationship-building and engagement to make sure that when your monitoring cycle starts, you don't run into unexpected delays and barriers. For Ghana NCD Alliance, a community scorecard project that was meant to be completed in six months, took a lot longer because the project was delayed waiting for letters that permitted access to facilities. For Ghana NCD Alliance, the four-month delay in their project was worth it.

"We would not have been able to achieve buy-in and that kind of acceptability from the government had we proceeded without this process."

Ghana NCD Alliance

"...for us to go into a community and even start to speak to them on the importance of CLM on NCDs, we first have to get the buy-in of the communities."

NCD Alliance Malaysia

"What the communities wanted to measure was quite different from the template indicators drawn from international practice. And we have had to redo and revise the indicators to make them from a person with lived experience's perspective rather than something that was top-down and driven by an international entity."

NCD Alliance Malaysia

## Engaging key stakeholders – civil society organisations, networks of people living with NCDs, ministries and official structures

Conducting meetings and other engagements with key stakeholders is important to ensure that CLM is well understood and that there is cooperation and engagement in the monitoring process. Activities related to this may include awareness-raising initiatives using social media and other digital media, holding meetings and consultations in-person and online, and engaging in existing structures that offer an opportunity to present the benefits of CLM.

## Community-led design – agreeing on priorities for monitoring

The process of identifying what to monitor, and the creation of indicators for measurement constitute a complex but critical element of CLM. At this stage, it may be helpful to hold a series of community conversations – defined as structured small group discussions with members of a community designed to better understand views on a particular topic,<sup>12</sup> meetings or workshops with stakeholders who are involved in prevention or service delivery and care and communities of people living with NCDs. You could also consider implementing online surveys and consultations to gather feedback and verify your assumptions of what your monitoring priorities should be.

Global guidance<sup>13</sup> and indicators for monitoring NCDs at health facilities, as well as national and sub-national plans, strategies and commitments, could be used as a starting point for thinking through your monitoring priorities.

CLM should not be confused with routine monitoring of health service delivery or one-off data collection by ministries of health or external agencies engaged in service delivery monitoring and research. It should be complementary to existing monitoring and focus on questions that are not answered by other means, and that will help you understand underlying reasons for persistent and unexplained problems in service delivery or other aspects of the NCD response. Community-led monitoring should gather insights from people living with NCDs and service users themselves to provide information over time that may not be captured by routine monitoring. The CLM focus can be on different aspects of service quality, service provision or structural and policy enablers of an effective NCD response.<sup>14</sup>

12 NCD Alliance. *Community Conversation Guide. Our Views, Our Voices*. 2017. Available from: [https://ncdalliance.org/sites/default/files/OVOV\\_4.pdf](https://ncdalliance.org/sites/default/files/OVOV_4.pdf)

13 WHO. *Noncommunicable Disease Facility-Based Monitoring Guidance. Framework, Indicators, and Application*. 2022. Available from: <https://www.who.int/southeastasia/publications/i/item/9789240057067>

14 UNAIDS. *Establishing Community-Led HIV Services: Principles and Processes*. Page 19, Box 2. Available from: [https://www.unaids.org/sites/default/files/media\\_asset/establishing-community-led-monitoring-hiv-services\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/establishing-community-led-monitoring-hiv-services_en.pdf)

**Key questions that can guide your decision-making include the following:**

- What are the questions that communities of people living with NCDs want answered? For instance, are out-of-pocket costs for accessing care a significant issue for your community?
- Are these major concerns focused on structural issues related to NCDs (such as human rights and health equity, NCD policy development or legal reforms) or are they programme, or service delivery related?
- Which of these concerns would CLM have the biggest impact on? (i.e., is data already being collected on these issues? what is missing in the data?)
- Are there existing targets, plans and budgets for NCD service delivery that are not being measured, or where the perspectives of people living with NCDs are missing?
- Which communities are left furthest behind in policies, plans, strategies, programme implementation and service delivery? Who is most marginalised, most at risk? E.g., people living in poverty, women and girls, ethnic minorities, migrants, indigenous populations, people living with multimorbidity, or with rarer NCDs. These questions could help you determine the geographic and/or target population-related scope of your monitoring.

Using the four elements<sup>15</sup> of the right to health that are enshrined in international and regional human rights treaties illustrated below, could help you decide on your monitoring focus.



Once you have decided on the questions your monitoring will need to answer, you will be able to identify the people and locations to target for your data collection. Keep in mind that your monitoring does not need to be facility-based – your data gathering can be based in affected communities at different levels (e.g., community, household, smaller groups, school-based or in other community spaces).

**Defining your indicators**

After deciding what your monitoring priorities are, it's time to develop your objectives and indicators for data gathering. Your indicators will help you come up with a score or benchmark for the issues or services you want to monitor.

15 WHO. *Fact Sheet No. 31: The Right to Health*. 2008. Available from: <https://www.ohchr.org/sites/default/files/Documents/Issues/ESCR/Health/RightToHealthWHOF32.pdf>

“Some countries have different prevalence of NCDs, some are at different levels of development – indicators and advocacy strategies are customised to respond to these local contexts.”  
NCDCA Kenya

## Project set-up planning and management

When embarking on your CLM project, you will need to set up a structure (sometimes called a Steering Committee) that will enable you to manage and coordinate your efforts at local and/or national level. This is a good time to clarify how decisions will be made in relation to your CLM efforts and agree on a work plan and responsibilities. This should relate to all the steps of your community-led monitoring, from decisions on what to monitor and who does the monitoring to data gathering and analysis, to advocacy and follow-up and budget.

The development of Terms of Reference or a Memorandum of Understanding at this point will help to ensure that all partners involved in your decision-making structure agree on the processes and responsibilities held by each partner.

Your structure must include the representation of people with lived experience of NCDs and make a special effort to ensure the involvement of the most marginalised groups. You could also consider including health officials, donors or other stakeholders in your structure, but be mindful that this could lead to a conflict of interest.



### Practical advice

**In the planning stages of your CLM initiatives, you will need to identify who needs to be consulted with and engaged, and when.** Ghana NCD Alliance engaged health officials, and ensured they were engaged throughout their project, including in formulating recommendations.

“We carried health workers along with us throughout the process, so we had feedback on-hand in the process – so, for instance when we had issues related to the supply of drugs we were fortunate to have the health directorate officers to take note about this and take responsibility for taking action.”

Ghana NCD Alliance



### Useful resources for STEP 1

- **From Insights to Evidence: A Guide for Translating Priorities into Qualitative and Quantitative Measures for Community led Monitoring** (2022) by ITPC is a technical brief on defining your strategic priorities, developing monitoring questions and qualitative and quantitative indicators for use in HIV-related CLM programmes. (It is also available in **French, Russian and Spanish**).
- You can draw on the **facility-based monitoring guidance developed** by WHO,<sup>16</sup> which includes indicators for different diseases, as well as your country’s health indicators.
- **NCDCA’s Civil Society Compass** highlights major gaps in progress in NCD prevention and care, and potential actions that civil society can take.
- Health Indicators for and by People Living with NCDs: A Community Guide by National Cancer Society Malaysia 2023 (pending publication).

16 WHO. *Noncommunicable Disease Facility-Based Monitoring Guidance*. Framework, Indicators, and Application. 2022. Available from: <https://www.who.int/southeastasia/publications/i/item/9789240057067>



## STEP 2

### Selecting data collection tools and collecting data

This phase of your CLM project is when the monitoring cycle begins, its focus is on testing and implementing data-gathering tools and establishing cycles for data-gathering and analysis.

#### Choosing methods for data collection

There are a number of methods for data collection – what you decide on will depend on your context, what you are monitoring, who you collect data from and whether they are based in affected communities or facility-based. The tools you use will also influence who collects the data – the more sophisticated and in-depth the data is, the more training and support will be needed for those collecting the data. You will also need to test or pilot your tools in the field, identifying any adjustments that might need to be made, and ensuring that training on the use of the tools is adequate.

“We often conduct a community conversation with people living with NCDs and NCD focal persons at the health facilities to assess the care gap and know the key asks from people with lived experience.”  
Rwanda NCD Alliance

#### Considering Qualitative and Quantitative Data

##### **QUANTITATIVE data is information that can be counted or measured.**

For community-led monitoring, quantitative data can give insights into the numbers of people negatively impacted by an issue, and the length of time the issue has impacted them. To collect quantitative data, you will need standardised tools for data collection and a thorough process for analysing and verifying the information. Quantitative information is useful to demonstrate the extent of a problem and to measure its evolution over time.

##### **QUALITATIVE information is not focused on numbers – it concentrates on the narrative.**

Qualitative information describes the issues affecting people and the impact this has on their lives. This information can be collected using interviews, focus group discussions, participatory workshops, and through more innovative projects that enable participants to document their own lives and lived experiences. This information can be described in text, audio, video, art and photographs.

Your CLM project can focus on one or both of these kinds of data.



## Examples of data-gathering tools for use in affected communities and at facilities

### Community scorecards

Community scorecards are a social accountability tool that engages communities in formally assessing and measuring the performance of health and other services. Some governments and organisations use community scorecards to monitor services. Community scorecards are implemented in several countries, by Ministries of Health to address gaps in service delivery and quality of care. For instance, Ethiopia, Malawi, Senegal, Burundi and Zambia use community scorecards<sup>17</sup> to monitor various services, including maternal and child health, nutrition, malaria and neglected tropical diseases. In Lesotho, a **community scorecard** tool was used to assess young people's experiences of sexual and reproductive health and rights services, including young people living with disabilities. In Ghana, a **community scorecard** tool is used at health facilities to gather community feedback on nine quality of care indicators, and scores are used to develop action plans to address issues identified. Ghana NCD Alliance used the existing government community scorecard to **monitor care for NCDs**.<sup>18</sup>

### Service user surveys and feedback mechanisms

Tools like telephone hotlines for service users to contact, and online surveys or phone-based feedback assessments for service users could be useful methods for gathering feedback on the acceptability and quality of the service they received, as well as health-seeking behaviour to capture experiences of stigma and discrimination and health provider attitudes. In some CLM initiatives, trained facility-based monitors interview service users (with their consent) about their experiences using standard data collection tools. In South Africa, **surveys** were implemented targeting different groups – facility managers, patients visiting clinics as well as treatment adherence club facilitators.

### Facility-based or community-based focus group discussions

Focus group discussions held regularly with affected communities and/or at facility level could generate useful information on issues affecting service delivery as well as changes over time. Group discussions should be consistent and structured across sites and could be conducted with service users, non-users in the community and service providers.

### Door-to-door surveys

Community door-to-door surveys are a useful strategy to collect data on knowledge, attitudes and beliefs about NCDs. This is a good way of engaging people who are not using services and other people living with NCDs who might be undiagnosed or particularly marginalised. Care should be taken to ensure privacy and to avoid exposing people to stigma. Standardised tools for interviews should be developed for this kind of data collection.

### Direct observation and mystery clients

Monitors, who regularly visit health facilities, could use standardised tools to collect information based on their own observations at a particular facility. For instance, they could note if the facility is accessible for people who have limited mobility, or if the clinic has the necessary equipment, in working order. Mystery clients are trained monitors who assume the role of clients (service users) and use standardised tools to assess their experiences.



## Practical advice

**Community-led monitoring of NCDs can go beyond health facilities** and could, for instance, conduct audits of accessible, open and safe spaces for exercise, or it may mean monitoring how producers and suppliers of food adhere to legal regulations on food labelling (and community understanding of food labels).

17 African Leaders Malaria Alliance (ALMA). *Scorecard Hub website, Scorecard Management Tools*. Available from: <https://scorecardhub.org/scorecards/>

18 NCD Alliance. *Ghana includes NCDs in community healthcare monitoring scorecard*. 2023. Available from: <https://ncdalliance.org/news-events/news/ghana-includes-ncds-in-community-healthcare-monitoring-scorecard>

## Engage community members in data collection

It is strongly recommended that data be collected by people with lived experience of NCDs who are based in communities where monitoring takes place. While this will require an investment in their training, and on-going support, they bring an existing understanding of the history, culture and language of their communities. By using community-based monitors or data collectors, your project will also build local capacity for on-going monitoring.



### Practical advice

**Community monitors or data collectors work in communities and at facilities, making contact with service users or community members and gathering information from them.** Doing this work requires knowledge, training and commitment. Repeat training, and recruitment to replace those that are unable to continue or drop out because of other commitments is essential.

“It requires the right people who want the capacity to provide their time and to be part of the process.”

NCDA Kenya.

**Include compensation of monitors and or data collectors in your budget, as well as support for travel and connectivity costs for data collectors or monitors.** Make sure you manage the expectations of community members who are engaged in your project. NCDA Malaysia provided compensation to volunteer data collectors.

“Providing that sort of compensation or incentive for the community has always been the most effective way for us to encourage participation and involvement”

NCDA Malaysia.



### Useful resources for STEP 2

- South Africa’s HIV CLM initiative Ritshidze developed an **Activist Guide** (2020) that contains useful information on their evidence-gathering processes – including their quarterly monitoring cycle.
- Advancing Partners and Community (APC) **Community Scorecard Toolkit** is a step-by-step guide to community scorecards from concept to implementation of a scorecard in health facilities
- ITPC’s **Guide to Data Analysis Methods in Community-Led Monitoring** explains key concepts and processes in analysing data collected through CLM in the HIV context and is a very useful resource. ITPC’s resource on **data management** for community-led organisations offers guidance on selecting tools based on critical questions about privacy data needs and costs.
- The **Engagement Hub** website includes examples of data collection tools used in different countries from scorecards used in Lesotho to surveys used in different contexts in South Africa.
- Aidsfonds has produced a **toolkit** on using a mystery client methodology for assessing healthcare services for sex workers in the context of HIV – it provides useful and practical ideas for applying this methodology.
- **NCDA’s Guide to Community Conversations** provides all the information and materials needed to organise a community conversation which can be used as a tool for monitoring in affected communities.
- **This ITPC guide** helps communities to introduce CLM data to decision-makers.
- UNAIDS resource on **Establishing Community Led Monitoring for HIV Services** includes useful guidance on tools for data collection, as well as on other aspects of community-led monitoring.
- The use of Ghana’s community scorecard is highlighted in the African Leaders Malaria Alliance (**ALMA Scorecard Hub**), where you can also find resources and examples of the use of community scorecards for Malaria and related diseases.

## STEP 3

### Putting your data to work – awareness-raising and advocacy

This phase focuses on making use of your CLM findings to collectively develop solutions, advocate for change and track the progress in implementing these changes.

#### Analysing and validating your data

The structure you established in Step 1 will have defined a process for validating and analysing the data you have now collected, and the key groups and/or individuals who will participate in the process.

Your data analysis and validation process should include the following elements:

- Responding to any weaknesses or issues identified with your data-gathering tools, methods or processes.
- Identifying trends and grouping data in ways that contribute to understanding – for instance, disaggregating data for type of NCD, gender, age, location or other important data points
- Checking that your analysis is rigorous in avoiding bias or assumptions.
- Documenting the process of analysis to establish its credibility and to ensure you can engage with critical feedback.
- Involving technical experts who can contribute to the credibility and verification of your data analysis – as needed.

#### Disseminating your analysis and developing action plans and solutions

The findings of your CLM efforts (and the data itself) are owned by communities and must be made available to communities first. The structure you established in the first phase of your CLM project (Step 1) now assumes the responsibility of disseminating your analysis to community structures and other stakeholders to develop solutions at different levels. At a local level, for instance, a dissemination meeting with community-based health structures can be organised to discuss the findings and recommend local solutions. **In Kenya, the findings of community scorecards were presented to existing Community Health Management Committees. Ghana NCD Alliance held a multi-stakeholder dissemination event where all stakeholders (including the Ministry of Health and facility managers, as well as community members) participated. In South Africa, HIV CLM findings are made available online, and data analysis is discussed in quarterly clinic review meetings, where a form recording their suggested solutions is finalised and shared for sign-off at district level.**<sup>19</sup>



#### Practical advice

It is essential to implement quality control measures and data verification processes, especially since community generated data isn't always considered reliable. Undertake training for all involved in the collection, storage and analysis of data, which includes ethical considerations of data collection and storage. Ghana NCD Alliance met with some resistance to the findings of their community scorecard in some facilities.

“They wanted us to go verify that the things community members found did exist. The committee stood firm, and I was glad about this. It takes conscious effort – you build capacity, you encourage them, and you say they must own the facility to get the best for the community.”

Ghana NCD Alliance

19 Ritshidze Saving Our Lives. *Activist Guide: Community-Led Monitoring in South Africa*. 2020. Available from: <https://ritshidze.org.za/wp-content/uploads/2020/11/Ritshidze-Activist-Guide-2020-1.pdf>



## Developing advocacy messages

While some solutions can be implemented at local level, others may require that you develop a longer-term action plan or advocacy strategy. Dissemination meetings at local, district and national levels are also a good place to generate and agree on key advocacy messages and solutions where these cannot be solved at the local level. In developing your advocacy messages, you must identify the duty bearers that can bring about the change you want and develop a plan for engaging them.

Here, you might also identify platforms where health (and other) decisions are made or where routine monitoring information is discussed and request a seat on these platforms to present your CLM findings. **For instance, in Ghana, the Minister of Health established the Multisectoral National Steering Committee on NCDs, to bring onboard the non-health sector to understand their role in NCD prevention and control. Persons living with NCDs are part of the Technical Working Groups, and there is a working group on advocacy led by Ghana NCD Alliance.**

Findings from HIV CLM in Malawi were used at a ministerial level, to push for the appointment of key Population Focal Points, resulting in 14 monitoring sites now having a focal point.<sup>20</sup> NCD Alliance Kenya advocated for indicators related to NCDs to be included in selected five-year plans at county level.

**The NCD Diaries** is a project of the NCD Alliance which uses multimedia approaches to share lived experiences that drive change. The NCD Diaries is an example of a qualitative, storytelling project using participatory methods that illustrates individual lived experiences and highlights calls to action on NCDs, by people living with NCDs, on different themes. While the NCD Diaries does not have a monitoring component, it demonstrates how storytelling and narratives using multimedia can be used as a tool to support the advocacy messages developed from the findings of CLM.



### Practical advice

NCD prevention can sometimes mean campaigning for access to safe, open spaces for exercise, or for access to good nutrition and evidence-based policies related to labelling of ultra-processed food. For instance, NCD Alliance Kenya noted that food security was an issue for their community.

“After our community scorecard was implemented, we were able to link communities with other service providers to address issues outside of public health – for instance in one area there were issues with food security, as it was a dry area. The community was linked to the Department of Agriculture in the county, for workshops on food gardens.”

NCD Alliance Kenya



### Useful resources for STEP 3

- South Africa’s CLM programme disseminates its data in the form of an **online dashboard** – this is a useful example of making data accessible.
- ITPC have documented **advocacy case studies and wins** (2017 -2022) related to HIV, TB and Malaria, providing some useful information on what can be achieved through CLM informed advocacy.
- The NCD Alliance’s **Practical Guide to Strategic Advocacy** may help you develop your advocacy plan.
- The NCD Alliance’s **Community Conversation Guide** is a useful resource for hosting communities to discuss advocacy priorities.

20 ITPC Global. Bouncing Back Report. *How a Community-Led Monitoring Initiative in Malawi and South Africa is Supporting the Recovering of HIV and TB Services in the wake of COVID-19*. 2022. Available from: <https://itpcglobal.org/wp-content/uploads/2023/07/2022-ITPC-Bouncing-Back-Report.pdf>

## STEP 4

### Following up and monitoring solutions and advocacy asks

Once you have made recommendations and demanded changes, your monitoring cycle will include keeping track of any changes made and their impact. Ideally, follow-up can be integrated into routine monitoring or management structures at a local, district or national level.

Being able to document the positive impact of the changes you have asked for will be a good way of demonstrating the value of your community-led monitoring project.



#### Practical advice

NCD Alliance Kenya established community-based multi-stakeholder linkage meetings –established to close the monitoring loop, following up on issues identified in the community scorecard, and remedial actions. The meetings involved community members, facility staff and other key stakeholders.

“We have seen that holding duty bearers to account requires a lot of engagement.”

NCD Alliance Kenya

## 4. CLM in the context of NCDs – Readiness and progression

### 4.1. Adapting current approaches to be more CLM aligned

Monitoring progress in the prevention of NCDs and care for people living with NCDs is an essential element of health governance. While organisations, national alliances and community groups have been conducting service delivery monitoring, adopting a CLM approach will require a more systematic approach and a shift towards community leadership. Below are some examples of adaptations from current experiences in the NCD response. These are not exhaustive but do offer some options for either stand-alone NCD CLM, integrating NCDs into existing CLM programmes or using existing CLM data for NCD-specific service delivery improvements and advocacy.

#### Stand-alone CLM of NCD services

In Kenya, the national NCD Alliance leveraged their positive relationship with the Ministry of Health to implement an NCD scorecard. To date, the scorecard has been implemented in six counties and designed to complement the [Advocacy Agenda of People Living with NCDs in Kenya](#) and the Kenya National NCD Strategic Plan. Kenya already uses scorecards in their Reproductive, maternal, newborn, child and adolescent health (RMNCAH), malaria and national vaccine immunisation programme, and more recently a community scorecard was developed for assessing primary healthcare delivery from community perspectives, with a focus on RMNCAH.<sup>21</sup> NCD Alliance Kenya developed a scorecard looking at six elements and 11 indicators specifically related to NCDs, and a process that involved communities in data gathering and interpretation, and in collaborating with healthcare providers to come up with solutions. Taking such an approach will require access to sustainable funding.

#### Integrating NCDs into existing HIV CLM or other social accountability projects

In the Political Declaration on HIV/AIDS (2021), Member States pledged, among other things, full coverage of NCD services for 90% of people living with, at risk of, and affected by HIV by 2025. Given that cardiovascular disease is now one of the leading causes of non-AIDS-related morbidity and mortality among people living with HIV,<sup>22</sup> as well as a higher risk of diabetes and some types of cancer, there is an urgent need to realise this pledge.<sup>23</sup>

In Ghana, the Health Ministry uses community scorecards to gather community perspectives on primary healthcare delivery. NCD Alliance Ghana implemented this community scorecard in six facilities in partnership with the Ministry of Health and Ghana Health Services, using the opportunity to integrate NCDs into the process. They did this by including NCDs in the training programme for teams gathering data, analysing results and developing solutions. They also recruited people living with NCDs into the process. Ghana, along with representatives from Mozambique, Tanzania, Zambia and Zimbabwe joined a workshop supported by WHO and UNAIDS<sup>24</sup> in April 2023 to discuss the integration of NCDs and mental health components into HIV programming – and therefore CLM – supported by the Global Fund.

#### Extracting or applying HIV CLM data related to NCDs for advocacy

Another potential strategy is for NCD organisations to examine existing available CLM data to extract information either relating directly to NCDs, or which has implications for NCD service delivery. For instance, South Africa's [Stop Stockouts Project](#) monitors medicine stockouts, using reports from communities and healthcare workers to a hotline, as well as an annual survey. They monitor medicines related to NCD conditions. The country's HIV CLM [Ritshidze](#) programme joins the Stop Stockouts project in monitoring for medicine shortages. They reported that there were shortages of Cardiac medicines, psychiatric medicines as well as other medicines to treat NCDs.<sup>25</sup>

21 ALMA Scorecard Hub. Kenya RMNCAH Scorecard, Quarter 4, 2022. Oct – Dec 2022. Available from: <https://scorecardhub.org/scorecards/kenya-rmncah-scorecard-quarter-4-2022/>

22 Paraskevi et al. *Cardiovascular disease and risk assessment in people living with HIV: Current practices and novel perspectives*. Hellenic Journal of Cardiology, Volume 71, 2023, Pages 42-54, ISSN 1109-9666. Available from: <https://doi.org/10.1016/j.hjc.2022.12.013>.

23 NCD Alliance. *Long, full, healthy lives: Delivering on the commitment to integrated NCD care for people living with HIV by 2025*. 2021. Available from: <https://ncdalliance.org/resources/long-full-healthy-lives-delivering-on-the-commitment-to-integrated-ncd-care-for-people-living-with-hiv-by-2025>

24 WHO. Press Release. *Zimbabwe Hosts Workshop on Integrating NCD and Mental Health Components in HIV Programming for Global Fund*. 2023. Available from: <https://www.afro.who.int/countries/zimbabwe/news/zimbabwe-hosts-workshop-integrating-non-communicable-diseases-ncd-and-mental-health-components-hiv>

25 Stop Stockouts. *Stockouts Heatmap*. Available from: <https://stockouts.org/Comparison>









## 4.2. CLM progression and scale-up

“Community-led monitoring work is like a wheel: it is ever running, it doesn’t stop.”

NCD Alliance Kenya

Your CLM initiative can start small, and build momentum over time, learning from your experiences and gathering evidence of your impact. The table below is adapted from the UNAIDS CLM progression Matrix and shows how your CLM can grow to be a fully institutionalised initiative.<sup>26</sup>

	→ Basic/pilot	→ Learning & refining	→ Systematisation & consolidation	→ Institutionalisation
 <b>Community leadership &amp; ownership</b>	Initiated with support from technical partners, with communities fully and meaningfully engaged.		Communities lead CLM implementation with limited external technical support.	Local NCD hub for CLM is led by people living with NCDs, with increasing numbers of community CLM implementers year on year.
 <b>Geographical coverage</b>	Adequately resourced and focused where you can have the most impact.		Multiple geographic areas & issues covered, based on transparent criteria identified by communities.	All priority regions/provinces, urban and/or rural areas, covering all priority areas identified by communities.
 <b>Scope of monitoring</b>	Focused on a limited type of service or issue, with priorities set by communities – but not all people living with NCDs.		CLM activities are more comprehensive, monitoring health and non-health service delivery of more groups and with priorities set by communities.	CLM supports the integration of NCDs, focusing on underserved and vulnerable groups with priorities set by communities.
 <b>Dissemination</b>	Locally based with dissemination & solution finding primarily taking place at local level by communities themselves.		CLM is implemented at local, sub-national and/or national level. CLM-data is triangulated with those from national health information systems and CLM (where implemented) is considered an integral part of the national accountability mechanism for health programmes and used on an on-going basis to inform service delivery improvements and/or hold health (or other) system accountable in order to improve the national NCD response.	
 <b>Advocacy</b>	Key advocacy asks are identified for national action and are shared with national alliances for ad-hoc meetings with decision makers’ above local level.		CLM is systematised as part of a regular process of soliciting community feedback, tracking performance against commitments, and delivering this in a routine way to decision-makers through advocacy.	
 <b>Sustainability</b>	Resources and systems for a full CLM cycle are in place with community capacity to lead being supported within a geographic area (including remuneration for community workforce).		CLM is sustainably resourced, with established systems and skilled personnel who are building the capacity of other communities to lead CLM.	CLM activities, where implemented, are fully funded as routine expenditures (including domestic resources), with community expertise and capacity recognised and proactively informing other areas of health service delivery.

26 Community-Led Monitoring Workshop for East and Southern Africa 13-15 June 2023, Johannesburg South African UNAIDS Regional Support Team, ESA, unpublished, undergoing revision based on feedback from communities implementing CLM in different countries in 2023/4.



## 5. Conclusion

Community-led monitoring recognises community-generated data as an essential component of the overall health monitoring landscape.

With the intention of finding and fixing problems that prevent people at risk of and living with NCDs from living healthy lives, CLM can help health systems make important progress in achieving their targets for preventing and controlling NCDs. At the local level, CLM enables evidence-based decision making that can improve the availability, accessibility, acceptability and quality of services, as well as identify non-health related barriers to these services. At sub-national and national levels, CLM findings inform advocacy to address systemic and policy and legal barriers that prevent progress in reaching NCD targets. CLM also has the potential to bridge gaps in data on NCDs – especially data relating to specific populations that are either at increased risk of NCDs or who are being left furthest behind – and therefore address health inequities.<sup>27</sup>

CLM is consistent with the **Global Charter on Meaningful Involvement of People living with NCDs**<sup>28</sup> which demands that people living with NCDs are meaningfully involved in the NCD response, including monitoring and evaluation. The CLM cycle has the potential to operationalise the meaningful involvement of people living with NCDs at a local level, bringing communities of people living with NCDs closer to services.

We hope the steps outlined in Section 3 will provide NCD alliances, civil society organisations and other stakeholders a starting point for thinking about how to make use of CLM to advance a country's NCD response. We have offered some ideas on adapting existing monitoring and advocacy work and pathways for CLM progression in Section 4.



27 NCD Alliance. *Accelerating the NCD response through Health Equity: from ideas to action. A Conceptual Framework for Community Advocates*. Forthcoming – 2024.

28 NCD Alliance. *Global Charter on Meaningful Involvement of People Living with NCDs*. 2021. Available from: [https://www.ourviewsourvoices.org/sites/ovov/files/2021-09/Global%20Charter\\_English\\_Final\\_2%20Sep\\_1.pdf](https://www.ourviewsourvoices.org/sites/ovov/files/2021-09/Global%20Charter_English_Final_2%20Sep_1.pdf)

## 6. Essential reading on CLM for NCD services

**Establishing community-led monitoring of HIV services UNAIDS 2021**

[https://www.unaids.org/sites/default/files/media\\_asset/establishing-community-led-monitoring-hiv-services\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/establishing-community-led-monitoring-hiv-services_en.pdf)

---

**Best Practices for Community-Led Monitoring, Community-Led Accountability Working Group (CLAW) September 2022**

<https://healthgap.org/wp-content/uploads/2022/09/CLAW-Best-Practices-in-Community-Led-Monitoring-EN.pdf>

---

**Community Evidence to Create Change Community-Led Accountability Working Group (CLAW)**

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

---

**Community Data Matters: A Look into Community-led Monitoring. Solange Baptiste, International Treatment Preparedness Coalition, International AIDS Conference 2022**

[https://clm.itpcglobal.org/download/baptiste\\_clm-plenary\\_aids2022.pdf](https://clm.itpcglobal.org/download/baptiste_clm-plenary_aids2022.pdf)

---

**A Community Guide for Introducing Decision-Makers to Using CLM Data, ITPC May 2023**

[https://itpcglobal.org/wp-content/uploads/2023/05/0526\\_CLM\\_CommunityGuide\\_D.pdf](https://itpcglobal.org/wp-content/uploads/2023/05/0526_CLM_CommunityGuide_D.pdf)

---

**How to Implement Community Led Monitoring – A Community Toolkit ITPC 2021**

[https://itpcglobal.org/wp-content/uploads/2021/12/1205\\_ITPC\\_CLM\\_Design\\_FullReport06\\_compressed.pdf](https://itpcglobal.org/wp-content/uploads/2021/12/1205_ITPC_CLM_Design_FullReport06_compressed.pdf)

---

**Integrating the prevention and control of noncommunicable diseases in HIV, tuberculosis and sexual and reproductive health programmes: implementation guide 3 April 2023 WHO**

<https://www.who.int/publications/i/item/9789240061682>

---

## Annex 1

### CLM Checklist

#### STEP 1 Planning consultation and coordination

**GOAL** You know what you want to monitor, why you are monitoring it, and where you will be monitoring

Your monitoring priorities are based on current evidence, realities and context (including your policy context)

The NCD sector and other important stakeholders in your country (or locality) have an understanding of what CLM is, and have been meaningfully engaged

You have established a structure to coordinate and manage your CLM project, which includes people living with NCDs, and all stakeholders in this structure have signed a terms of reference

Your monitoring priorities were jointly agreed on with people living with NCDs and other key stakeholders

You have agreed on indicators that correspond to your monitoring priorities, and these have been communicated to key stakeholders

#### STEP 2 Data collection

**GOAL** Your CLM analysis is based on sound data collection methods and tools, and your analysis reveals constructive and actionable solutions

Your data collection methods are finalised

You have tested your data collection tools in the field

Monitors or data collectors have been trained

The local community and stakeholders have been consulted, and all necessary permissions have been secured for monitoring

You collect data in line with your data collection cycle (which is in line with decision-making cycles and other strategic timelines)

#### STEP 3 Putting data to work

**GOAL** Your CLM data is a part of local decision-making on NCD prevention and care

You have established methods for regularly analysing your data, including enabling the participation of people living with NCDs and other stakeholders

Your findings are disseminated to the structures and people who need to see it

You keep a record of promises and commitments made in response to your CLM

#### STEP 4 Follow-up and monitoring changes

**GOAL** Your CLM data contributes to a positive trend in NCD prevention and care and is considered integral to national plans for achieving NCD targets

You regularly review your CLM findings against commitments and changes implemented



## Annex 2

### Case studies on CLM in the context of NCDs

#### NCD Alliance Kenya

##### Using community scorecards for accountability

NCD Alliance Kenya developed and implemented a community scorecard as part of its Social Accountability Toolkit. The approach empowered communities to ask questions about how public resources were mobilised and to take a leading role in recommending how these resources should be employed. An ongoing relationship with the Ministry of Health meant that NCD Alliance Kenya was able to involve the Ministry in the process from the start of the project, opening doors for the scorecard's implementation and responding to the results. The tool is based on the [Kenya Advocacy Agenda of People Living with NCDs](#), and the Kenya National NCD Strategic Plan (NSP) 2021/22-2025/26.

Once the Social Accountability Framework and scorecard tool was developed, NCD Alliance Kenya engaged people living with NCDs and youth members who are part of county advocacy groups, training them on the social accountability process, and how to implement the community scorecard. NCD Alliance Kenya also engaged with communities of people living with HIV and TB at the county level, where people living with NCDs learned from, and worked with people living with HIV.

Through a consultative process outlined in the Social Accountability Toolkit, those trained engaged with duty bearers to look at NCD prevention and control based on the scorecard's 6 areas of focus. The implementation of the Scorecard meant that information was generated by communities and by healthcare workers in facilities through a self-assessment. The scorecard revealed that in some sites, community members had a different experience than what was ascertained by speaking to facilities or by looking at county plans. The results of the community scorecard were then compared to the outcomes of the Facility-self assessments in a community meeting to develop and agree on an Action Plan that responds to gaps and concerns raised and finalises how this will be presented to service providers and duty bearers. A linkage meeting is held between service users, service providers and duty bearers, where the Action Plan is presented, and joint solutions are agreed on. A committee conducts on-going monitoring of commitments made. The scorecard may be repeated every 6-9 months.

As a result of this work, indicators related to NCDs are now included in some county's five-year plans. NCD Alliance Kenya uses its social accountability work to help inform and guide organisational and programmatic decisions. Lessons from the project are shared with other counties, in their mission to ensure that policymakers prioritise NCD prevention and care and improve financing for NCDs in Kenya.





## Ghana NCD Alliance (GhNCDA)

### An intersectional approach to community scorecards

Ghana's National Community Scorecard was developed to enhance the health sector's ability to gather public feedback on a quarterly basis on the delivery of health services at a primary health level. The Scorecard was integrated into Ghana's Community-Based Health Planning programme and has been implemented since 2018.

After extensive engagement with the Ministry of Health and the Ghana Health Service, Ghana NCD Alliance (GhNCDA) piloted a community-led monitoring intervention using the community scorecard. The project was implemented in six facilities in three districts and was concluded in February 2023.

Using their existing positive relationship with the Ministry of Health and Ghana Health Service, GhNCDA engaged a consultant who also had existing relationships and excellent knowledge of both the Scorecard and the stakeholders involved in it. The project initially hoped to include additional NCD-specific indicators into the community scorecard, but, following engagements with the Ministry and Health services, they focussed on integrating NCDs within the nine existing indicators, and piloted this approach in jointly selected sites where community scorecard implementation was weak or absent. They then trained Community Health Management Committee members and healthcare workers in the selected facilities (of the 95 people trained, 30 were people living with NCDs). Once trained, the Community Health Management Committee members returned to their sites and implemented a National Scorecard, with their newly-gained knowledge of NCDs. Based on their scores, the Community Health Management Committee members engaged with communities to develop a Community Health Action Plan. Agreed actions in the Plans were allocated to a responsible person, stakeholders were identified, and deadlines were set. Action items resulting from the scorecard are recorded and monitored as part of the Community-based Health Planning and Services (CHPS) programme. They also held a multi-stakeholder dissemination event, which engaged stakeholders beyond the health system to respond to the scorecard findings.

Ghana NCD Alliance set out to improve the meaningful involvement of people living with NCDs in improving NCD service delivery at the primary healthcare level. They achieved this goal – by increasing the number of facilities implementing the Community Scorecard and ensuring that NCD considerations and people living with NCDs were integrated into the process at these sites.

Their pilot project also found that NCDs can be effectively integrated into the National Community Scorecard and CHPS programme without additional NCD ear-marking funding. The pilot sites were able to identify NCD-related challenges, develop action plans and implement these within the existing support structure for community scorecards.

Ghana NCD Alliance continues to promote its NCD integrated Community Scorecard approach. Its role in the National Caucus of people living with NCDs which spearheads advocacy initiatives at the national level and is recognised by the Ministry of Health, as representing the views of persons living with NCDs offers an opportunity for presenting the findings of their efforts. Ghana NCD Alliance is focused on raising funds to support ongoing training for people living with NCDs; healthcare workers and Community Health Management Committees on this approach.





**PROMOTE HEALTH. PROTECT RIGHTS. SAVE LIVES.**



**#NCDs @ncdalliance**