UNAIDS 2021

Establishing community-led monitoring of HIV services

Principles and process

Contents

Why this document?

This technical guidance is a living document that builds on guidelines and reports of the UNAIDS Joint Programme. The definitions contained herein are working definitions that are subject to change. Updates will also be added further to the work of the multistakeholder Task Team on community-led AIDS responses that was recently established by the UNAIDS Executive Director and the UNAIDS Joint Programme, and which will conclude its task in December 2021.

Communities affected by HIV have been providing feedback on the quality of health service provision since the early days of the HIV epidemic. Gathering, collating and using this information, however, has not necessarily been systematic *(1)*. Consequently, decision-makers often lack data and analysis from the perspective of service users, and interventions may not accurately respond to community priorities and experiences. This imbalance of knowledge and power in service design and provision particularly penalizes minority and stigmatized groups *(2)*.

Global support is growing for communities of people living with and affected by HIV to collect and use their data to improve their health and broader societal situations and to hold decision-makers and service providers accountable for reaching their HIV commitments *(3)*. Such an approach is the essential core of community-led monitoring (CLM) and redressing knowledge and power imbalances. The experiences of CLM from people living with and affected by HIV can inform a wide range of services that affect community health and well-being, particularly of marginalized and underserved people.

The goal of this document is to describe the principles of CLM, outline an approach to establishing CLM activities and explore the factors that facilitate and hinder CLM effectiveness. It should contribute to establishing in-country platforms whereby CLM can provide data principally related to HIV service provision. The framework outlined also gives structure to facilitate engagement by external partners.

The document is intended for use by networks of people living with HIV and members of affected communities—including key and other priority populations—when establishing, implementing and leading CLM programmes. It also will be relevant for others collaborating in using CLM, including those involved at different levels of service planning and provision, and for funders and other CLM sponsors.

The Introduction defines CLM and its place in improving service provision. The first section lays out the context in which CLM is increasingly promoted, supported by lessons learned from active CLM programmes. Following this is more detail on the suggested stages in establishing community-driven and community-led monitoring, including collaborative management, data security, customization of methods and capacity-building. Finally, the implementation of CLM in challenging environments is explored and some responses proposed. Extensive annex material details the principles of CLM and its unique contribution to comprehensive service evaluation that can be used in advocacy. It also considers possible situational analyses for CLM in different settings.

How this document was developed

The content of this document is based on a range of inputs, including:

- CLM meetings, including those organized by UNAIDS (September 2019 and February 2020) and the Global Fund to Fight AIDS, Tuberculosis and Malaria (The Global Fund) (February 2020). Participants included representatives of key populations and HIV civil society advocates, donors, technical agencies, governments, United Nations agencies and other stakeholders.
- A literature review of documents on the concepts of CLM.
- A review of documents describing CLM initiatives, including methodological descriptions, results reports and evaluations.
- Interviews with key informants involved in implementing CLM initiatives.

Introduction

What is community-led monitoring?

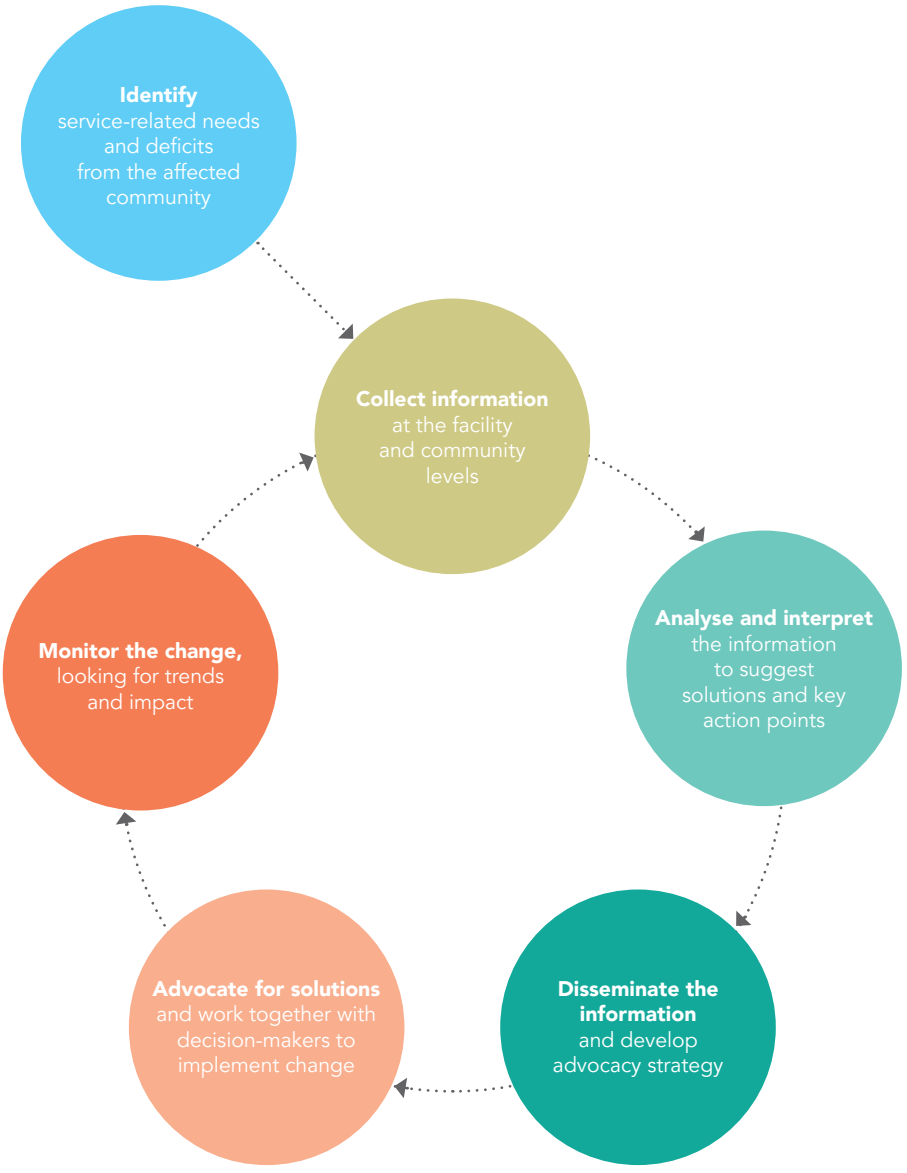
HIV community-led monitoring (CLM) is an accountability mechanism for HIV responses at different levels, led and implemented by local community-led organizations of people living with HIV, networks of key populations, other affected groups or other community entities. CLM uses a structured platform and rigorously trained peer monitors to systematically and routinely collect and analyse qualitative and quantitative data on HIV service delivery—including data from people in community settings who might not be accessing health care—and to establish rapid feedback loops with programme managers and health decision-makers (Figure 1). CLM data builds evidence on what works well, what is not working and what needs to be improved, with suggestions for targeted action to improve outcomes.

Through the CLM process, community-led organizations and key population groups increase their technical capacity to gather, analyse, secure, use and own data. The data collected complement local and national monitoring and provide key information to fill critical gaps in the decision-making process that leads to evidence-informed action to improve services. CLM provides a platform from which to strengthen relationships with other partners in the HIV and AIDS response around a shared understanding and response to service enablers and barriers.

CLM can be used to monitor trends of service quality within other disease areas (such as tuberculosis and sexual and reproductive health), humanitarian situations, challenging environments, and for social and structural health interventions, including combination prevention and human rights compliance, promotion and protection.

As the purpose of CLM is to serve as a surveillance and accountability community mechanism (i.e., a watchdog function) for health services, CLM should not be confused with community-based HIV service delivery or with the routine collection and reporting of internal programme data by community-led organizations.

Figure 1.
Integration of community-led monitoring into service review and improvement



Source: Adapted from: O'Neill Institute, Treatment Action Campaign, Health Gap, ITPC, ICW, Sexual Minorities Uganda (SMUG) et al. Community-led monitoring of health services: building accountability for HIV service quality (https://healthgap.org/wp-content/uploads/2020/02/Community-Led-Monitoring-of_Health-Services.pdf).

Community-led monitoring in context

Why now for community-led monitoring?

The recent development of CLM is partly due to recognition by programme planners and donors of the unique value of community data in responding to high levels of antiretroviral treatment interruptions for people living with HIV *(4)*. Services need to adapt to become more user-friendly for the increasing numbers of people who are being diagnosed with HIV and starting treatment, including people starting antiretroviral treatment early *(5)*. Other priority groups that are often poorly served are those with continued high levels of HIV infection who have been excluded, either systemically or through stigma and discrimination faced at health centres. Including user priorities and health care experiences when creating quality services is a key part of creating health services that engage affected communities and respond to their needs *(6)*.

CLM is not new, however: forms of CLM are already used by communities seeking to address antiretroviral medicine stock-outs and shortages, service attitudes, high prices and shortages of medicines used to treat coinfections (including tuberculosis and viral hepatitis).

Recognition of CLM's unique contribution to making health services fit for purpose has led to increased investment in and active promotion of CLM by international funders, including the United States President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) *(7, 8)*. United Nations (UN) agencies are also actively promoting CLM as a way to voice equity and rights issues in HIV programmes.

Well-funded support can enable community-led organizations and networks to demonstrate the value of their expertise in a formal way, and to translate the intimate knowledge, trust and understanding of affected communities into concrete programme improvements. Global and normative adoption of CLM also encourages decision-makers to bring the valid contributions of affected populations into the process of improving service quality and livelihoods more broadly.

The COVID-19 pandemic and the resulting responses have highlighted the barriers that exist to the collection and flow of data from service users to facilities, thus reinforcing the need for quality and systematic community data collection and analysis. Trends of service quality within other disease areas can be monitored through CLM, such as tuberculosis, mental health, HIV primary prevention or sexual and reproductive health. CLM can be used by communities in humanitarian situations and other challenging environments, and in monitoring related societal and structural interventions, including improving the legal environment, human rights promotion and protection, or action against stigma and discrimination. In these ways, CLM can promote integrated rights-based and people-centred health systems and more accountable supply chains beyond HIV.

CLM can contribute to shaping effective health services and influence policy changes that are part of the drive to achieve universal health coverage and tailored health care. Universal health coverage aims for all individuals and communities to receive the health services that they need without suffering financial hardship *(9)*, while tailored health care is the improved design and provision of a health services response that is shaped by factors that include location, health-seeking behaviour, disease prevalence and structural environments *(10)*.

Experience with community-led monitoring

Some CLM programmes are already established, and many community-based activities contain elements of routine community-led data collection and use. Across a range of issues, CLM has already delivered benefits to communities through policy and practice change at the local and national level.

The Ritshidze Project is a model of CLM in South African communities, covering nearly half of the population living with HIV in the country *(11)*. The focus is on sites with large treatment cohorts that have low rates of linkage to care and insufficient continuation on antiretroviral treatment. The project is the result of collaboration between groups and organizations of people living with HIV of the South Africa National AIDS council (SANAC) Civil Society Forum with the Treatment Action Campaign (TAC) as the host organization, and the Department of Health at the national and subnational levels, supported by UNAIDS and funded by PEPFAR through the United States Centers for Disease Control and Prevention (CDC) and USAID grants. Technical support was from Georgetown University, Health GAP (Global Access Project) and amfAR, the Foundation for AIDS research. The community teams present and discuss their findings, including through a dashboard, with the facility management trying to find solutions. Communities retain ownership of the data and control their use and sharing. Changes that have already been observed include improvements in access to medicines with multi-month dispensing, staffing levels and reduced stigmatization of people who miss appointments.

Two regional groupings of community treatment observatories that were set up to establish CLM in western and southern Africa are also active, sharing successful methods, tools and experience. The Data for a Difference project in western Africa links 11 country observatories led by networks of people living with HIV in the region through the Regional Community Treatment Observatory *(12)*. Amalgamated regional data show decreases in stock-outs of antiretroviral medicines and viral load tests, and an improvement in viral load suppression rates. Specific successes include securing a differentiated service delivery policy in Sierra Leone, changes to viral load monitoring data collection in Mali, evidence-informed dialogue leading to a strategy on human rights and addressing gender-related barriers in Ghana, and the lifting of user fees in Côte d'Ivoire *(13, 14)*.

Results and impact from South Africa (through the Ritshidze Project) and western Africa were instrumental in proving the concept of CLM and encouraging expanded global interest and funding in the approach *(15, 16, 17)*.

Lessons learned from these early CLM experiences include the following:

- Building trust between all those involved, including government, service providers, community groups and sponsors, is a critical factor in the success of CLM. This requires transparent, consistent, and broad-based communication, policy development and practice.
- Early engagement with departments of health is essential. The top policymakers should be convinced that CLM is a useful tool for reaching the HIV-related goals and targets. Local health service managers need to see CLM as a partner in delivering on their responsibilities.
- Although CLM is often responding to service deficits, the approach should not be to apportion blame for those shortcomings. Rather, the goal should be to have a full analysis of contributing factors, and to share in identifying solutions that satisfy user needs.

- Formal collaboration between different networks of people living with HIV and community-led organizations from affected communities is the most suitable and efficient CLM model to ensure systematic processes and appropriate data collection.
- Early agreement between members of the CLM coalition on the topics of data collection will provide the foundation and framework for developing future activities.

- Tailored and ongoing training for data collectors is important for ensuring their confidence and competence in the use of all data collection tools.
- Data collectors and others community members involved in conducting CLM should be remunerated in line with national practices and standards.
- The burden of establishing CLM can be eased by sharing validated and appropriate standardized tools. There are established tools that could be adapted to local contexts, and UNAIDS is working to initiate a central resource repository of resources.
- CLM can deliver useful data and beneficial action even without being formally incorporated in the national monitoring platform. However, CLM data should eventually develop to become part of the broader information structure without compromising community leadership.

- Communities must be the leaders of CLM and be equal partners when decisions are made about service quality. Non-community members with technical expertise can support and advise, as requested.
- Acceptance and integration of CLM in decision-making processes and negotiations with local authorities, funders and other external supporters depends on collaborative efforts towards problem-solving and credibility. Credibility comes from valid and useful data, combined with demonstrated community leadership and civic participation.
- A structured long-term plan for capacity-building, supervision and performance feedback for data collectors, analysts and advocates will optimize the results and impact of CLM.

- A structured, long-term advocacy plan that builds buy-in and ownership among stakeholders such as health-care workers will facilitate consistent and iterative progress in service improvement.

- CLM is not a stand-alone activity. Rather, it is an essential component of a larger framework of community-led responses to health and well-being. CLM is most effective when it is included in national policy and has other concrete signs of long-term and sustainable support.

Note on "community-led" definitions *(18)*

Community-led organizations, groups and networks—whether formally or informally organized—are entities for which the majority of governance, leadership, staff, spokespeople, membership and volunteers reflect and represent the experiences, perspectives and voices of their constituencies, and which have transparent mechanisms of accountability to their constituencies.

Community-led responses are actions and strategies that seek to improve the health and human rights of their constituencies. They are specifically informed and implemented by and for communities and the organizations, groups and networks that represent them.

Community-led monitoring is one type of community-led response. CLM for HIV is ultimately an accountability mechanism for the quality of HIV responses, led and implemented by community-led organizations of people living with HIV, networks of key populations, other affected groups or other community entities.

Community-led monitoring in practice

CLM can be quickly initiated where there is existing community capacity, and by drawing on experience from active CLM projects. It is imperative that any initiative be rooted in community-led decision making and collaboration from the start.

Early demonstration of capacity and CLM feasibility through rapid generation of preliminary data will encourage further development of CLM and can make a first contribution to service evaluation.

Establishing CLM needs to strike a balance between maintaining standards and avoiding being overburdened by the process. Sharing resources across CLM projects, such as data collection tools, model consent forms and data security frameworks is encouraged to ease the process burden.

A template for action: five community-led stages to establish community-led monitoring

The flow chart (Figure 2 and Table 1) lay out a series of possible stages for affected communities establishing CLM. Objective outcomes are proposed for each stage. This represents a comprehensive conceptual framework for the establishment and integration of CLM in routine health service monitoring and improvement. Depending on the readiness of communities to start CLM, not all of these stages may be needed.

The order and content of each stage is not rigid or prescriptive and the actual steps taken to establish CLM need to be tailored to fit the specific context of resources and capacity already available. In every case it will be the community leadership group that makes decisions and guides the process.

As CLM develops, the stages will overlap. For example, new tools can be developed and piloted at the same time as a memorandum of understanding is being updated. The staged approach is detailed here to encourage the anticipation of challenges and simplify the complex mix of stakeholders and different contexts involved.

Ethical standards should be maintained across all CLM activities. Ethical data collection essentially means that the approach is inclusive, unbiased, relevant to the issue under investigation and trustworthy. For these reasons, the choice of data to be collected and the plan for analysis should be open to scrutiny and agreed on by the community-led coalition. Attempts should be made to gather responses from a representative selection of the community, including those not usually engaged with health services.

Figure 2.
Suggested stages for affected communities establishing community-led monitoring

Table 1.
Essential components and community actors for each stage

Stage	Activities				Outcome
Stage 0 Community assessment of resources, context and implementation of CLM	Presentation of CLM aims and objectives to the full range of affected community members	Deliberative process that may include a formal or informal situational analysis of strengths, weaknesses, opportunities and threats (see Annex 3)	Identify and describe CLM-related funds and other resources available or likely to become available	Finalize and confirm funding and other available resources. Engage with the department of health at the highest possible level.	Community-led call to pursue CLM
Stage 1 Establish the budgetary, workplan and collaboration foundations for CLM	Establish the local and/or national coalition of community-led groups, or assure broad community approval for leadership by an existing network. Agree on a bureau with leadership and collaborating roles and defined responsibilities.	With consultation across its networks, the bureau oversees the development of a workplan, including terms of reference for different posts	Bureau develops a clear budget and seeks consensus from community-led groups and funders	Bureau makes efforts to secure political engagement in a memorandum of understanding.	Agreed organization, budgets and workplans recorded in a memorandum of understanding between community-led groups and the government that includes the flow of funds and a conflict resolution process
Stage 2 Develop a robust data and information framework with trained monitors	Members of the coalition of community-led organizations lead outreach to community members to provide information on standards in health services, and the structural enablers and barriers to accessing them. This is followed by consultation and community-led identification of priority concerns for monitoring.	Design and test data collection tools in response to priorities identified, adapting those already validated, where possible. Establish data security at all stages of collection use and storage (see Box 1). Prepare a robust monitoring and evaluation system for CLM activities.	Hear from facility managers about how data are collected and used in service evaluation, and plan how to integrate CLM	Recruit and train those conducting CLM and introduce them to communities and facilities	A trained team of community members with confidence and competence in evidence-informed tools and secure data management systems that are ready to pilot CLM
Stage 3 Community members use analysis, advocacy and shared decision-making to improve services	Finalize the data collection, analysis and advocacy workplan. Incorporate monitoring and evaluation of CLM and other internal quality controls.	Pilot the data collection, analysis and advocacy workflow, and adapt as necessary	Move to routine data collection. Share and analyse data as agreed by the community, and develop advocacy messages.	Present data in the service review and improvement process. Propose and advocate for solutions, with others involved in the service review, and agree on changes.	Evidence-informed CLM advocacy is used for shared decision-making to improve services
Stage 4 CLM transparently integrated with the health service evaluation and decision-making process	Monitor the commitments to change and any resulting innovation, looking for trends and impact	Provide regular feedback to the community and the clinic	Continue listening and acting on points of concern, enlarging the data collection strategy, if necessary	Consolidate capacity and strengthen available expertise	Community members receive improved services, free of stigma and discrimination, without interruptions due to stock-outs, and without long delays or undue hardships. The service evaluation cycle has no gaps, engagement is maintained and CLM has led to changes that improve health.

Expanding on the stage components

Stage 0. Community assessment of resources, context and implementation of CLM

The call to establish CLM should come from the affected community, even when it is the availability of funding that makes the initiation of CLM possible. Despite an imbalance of financial and political power with funders and other stakeholders, CLM will only function properly and to the benefit of affected communities when they are the ones leading the decision to proceed. Building trust between different community groups, funders and stakeholders is vital.

1. **Presentation of CLM aims and objectives by and to community members.**

- Community leaders present the concept and practice of CLM for members of the community in an impartial and objective manner.
- Ensure that this information is disseminated widely and collaboratively by and across all key and other affected populations and groups.

2. **Deliberative process that may include a formal or informal situational analysis of strengths, weaknesses, opportunities and threats (see Annex 1).**

- Allow time for discussion through verbal and written formats.
- Community-led and objective discussions will contribute to building trust.
- Consideration of CLM could benefit from affected communities conducting a situational analysis to describe strengths, weaknesses, opportunities and threats (also known as a "SWOT" analysis; examples can be found in Annex 3). If a situational analysis has already been undertaken, then it can serve as a checklist to tailor CLM along the way.

3. **Include information and assessment of existing and potential CLM-related funds and other resources available or likely to become available.**

4. **Finalize and confirm funding and other available resources. Engage with the department of health at the highest possible level.**

- If funding sources have not already been identified, then communities will need to identify and engage potential donors in exploratory discussions around CLM funding options.

Stage 1. Establish the budgetary, workplan and collaboration foundations for CLM

1. Create a coalition of community-led groups to lay the foundations for CLM.

- Community-led organizations map local community groups and civil society organizations and networks by the following: (a) populations represented; (b) technical capacity and any ongoing CLM; and (c) geographical location.[1]
- Through discussion and negotiation between these organizations, build a coalition of interested community-led bodies.
- Ensure that groups or members of the key and marginalized populations (sex workers, gay men and other men who have sex with men, transgender populations, people who use/inject drugs and other priority populations depending on the situation) are strongly represented in the coalition.
- Install a transparent and collaborative process for free and fair decision-making.
- A process for conflict resolution should be described that prioritizes open communication and early resolution of issues.
- Build consensus to identify one organization to be the lead community implementer for managing the coalition, and fill other bureau posts (administration, workplan and budget development, and preparation of agreements) according to capacity.
- Prioritize consensus without losing the momentum for action to start CLM.

2. Develop a workplan and draw up terms of reference for different posts.

- Fit the workplan to the CLM cycle (Figure 1), potentially liaising with a local health facility manager where data are to be collected.
- Identify the different skills required to deliver the workplan, and define a clear and fair hiring process that promotes the employment of people from the affected communities.
- Identify early the gaps in the workplan that cannot be filled by community-led groups, and seek the necessary technical assistance. For example, this might include the development of monitoring tools, preparation of analyses or ensuring end-to-end data security.
- Contact and contract the groups that can support or provide this technical support.

3. Develop a clear budget in consultation with key stakeholders.

- In line with any funding agreement, the bureau should describe the flow of funds and finance responsibilities, including clear reporting requirements on the use of funds.
- Where possible, community-led groups should be prioritized as the recipients of funds, and in all cases, there should be agreement on funding flows that provide the maximum amount of external funds to the community.
- Identify all paid posts, including data collectors, and other resource needs. This includes data platforms and Internet or other communications access.
- Draw up terms of employment, including salaries, that are in line with country norms.
- Consider involving a neutral broker (e.g., UN organizations and registered auditors) to establish funding flows, reporting schedules and payment methods in a legally sound, fair, transparent and accountable way.

[1] To maintain objectivity, community implementers of service delivery should not conduct CLM on their own performance.

4. Secure political engagement in a memorandum of understanding.

- The lead community implementer should try and achieve real political commitment to CLM at the local, district and national levels, and establish a collaborative approach to service improvement. In case of difficulties, strategic support from a neutral broker with no engagement or interest in the services may be valuable.
- Explain to decision-makers and authorities the selection of issues to be monitored and how the use of data will be guided by the affected communities. Give examples of what this might include.
- Be as inclusive as possible in these discussions. Depending on the level of data collection and advocacy envisaged, those involved could include facility managers, programme managers, and monitoring and evaluation teams.
- Obtain written assurance that community monitors can have access to facilities to collect the monitoring data and information, and conduct their work safely and free from interference.
- Share the data security protocol (Box 1).
- Share the budget and workplan with government authorities, and draw up one or more memorandums of understanding between the community-led coalition and the government authority.

Box 1.
Data security and community-led monitoring

Human rights and relevant ethical and privacy principles apply to all aspects of CLM data collection, storage, analysis and use. The principles of consent, confidentiality and data security apply equally for all community members, service providers, authorities or decision-makers who may provide information. It should be clear at each step how data are being processed and what security challenges may exist.

Data protection arrangements will be documented in a data management protocol as part of Stage 1. It will be important to be able to report what was done to maintain data and personal safety and to uphold the principles of CLM throughout the process.

Consent for participants

Informed consent for data collection and use is required. It should be possible for participants to opt out at any time. The language of consent should be expressed in a manner that is widely and easily understood, and any consent form will be kept separate from the interview data after completion of the interview.

Confidentiality and protection of data

Data collection will be performed by trained community members (known as "monitors"). All staff working on any component of CLM will sign confidentiality agreements as part of their employment contracts.

All data should be anonymous, and no information that could allow individual identification will be shared. This is particularly relevant for very small populations of respondents where it is easy to link behaviours to individuals, even though respondents are not named.

Completed paper surveys, audio recordings, digital data gathering devices and digital data will need to be securely stored and/or password protected. Data transfer by any means should be similarly secured.

Data ownership

The lead community implementer holds the data on behalf of the coalition and oversees data management, with the responsibility of ensuring that the data security protocol remains fit for purpose.

Data transfer and analysis

A data transfer agreement will need to be established with collaborators and agreed in the protocol prior to any data transfer taking place. Standardized protocols for data entry, transfer and storage are being developed by implementers.

CLM programmes are increasingly using hand-held mobile data platforms, and they should wait to have a secure connection before uploading. The use of standardized protocols and instruments is encouraged to facilitate CLM start-up, promote comparison across populations and locations (at least in-country), and avoid duplication of efforts.

Data entry and analysis will occur through secure software and be accessible for monitoring staff and collaborators. Building analytical capacity is a priority for maintaining trust that the data cleaning and processing is not being used to suppress some information. Only designated data stewards will have access to the data files.

Technical capacity

Arrangements to have the necessary technical expertise available to assure data security are part of the security protocol defined in Stage 1. The choice of data collection and transfer platform will depend in part on the technical capacity available. Capacity-building should be ongoing to enable the lead implementer and others in the coalition to eventually take on technical support.

Systematic guidance on data security can be found in the *Privacy, confidentiality and security assessment tool* from UNAIDS (available at: https://www.unaids.org/sites/default/files/media_asset/confidentiality_security_assessment_tool_en.pdf).

Stage 2. Develop a robust data and information framework with trained monitors

1. Identify issues of concern from affected communities.

- Inform the community about standards for HIV services, and structural enablers and barriers.
- Identify priority concerns for monitoring through focus group discussions, one-on-one interviews and questionnaires.
- Special effort is required to ensure representation of the key population and the most marginalized groups in these discussions.
- Provide feedback to the community about the priority themes that will be monitored. The focus of CLM is mainly on collecting data that are not collected elsewhere (Box 2), including data with improved age and gender disaggregation.

2. Recruit and train those conducting CLM.

- Keep recruitment standardized and transparent. Tailor recruitment profiles and criteria to local needs and contexts.
- Produce standardized curriculum and training manuals in an appropriate language.
- Include skills validation, with ongoing evaluation, mentoring and feedback mechanisms.
- Use trusted community leaders to present the CLM team and their work in the community and at the facilities.

3. Design and test the data collection tools.

- Clearly define the information required and identify the appropriate method to collect it (see Box 3).
- If possible, use digital data collection tools that increase data quality and reduce data collation and analysis time. However, make sure that there are always updated and accessible non-digital tools when the situation is not conducive for using digital ones.
- Consult available standardized tools and take technical advice as necessary to adapt them. High-quality monitoring tools will increase credibility, improve user-friendliness of data collection tools, and ease integration into an analysis and evaluation feedback cycle.
- Ensure that the language or languages used in the data collection tools are appropriate.
- Become completely familiar with any applications being used and integrate the necessary improvements.
- Establish data security at all stages of collection, use and storage. Be especially mindful of data anonymization and secure storage and transfer (see Box 1).

4. Be informed how data are collected and used in service evaluation.

- Create a working relationship with facility and other decision-making staff, emphasizing mutual problem-solving for the improvement of services and the benefit of the affected community.
- Consider how data will feed into the formal facility or other monitoring and evaluation systems.
- Small amounts of well-focused local data with short feedback loops are a useful entry point.
- Work towards involving and empowering care providers in creating alliances and work procedures.

Box 2.
Examples of topics that can be routinely evaluated through community-led monitoring, and that may not be captured elsewhere

Service quality

- Real-time availability of medicines, diagnostics and HIV prevention tools.
- Accessibility of services, their opening hours and the time required to reach the facility.
- Acceptability of services, including culture- and gender-appropriate staff attitudes and behaviour.
- Affordability of services, including unofficial user fees or other hidden charges.
- Other factors that encourage the uptake of services and frequency of attendance (e.g., security and wait times).

Service provision

- People receiving prevention services according to their need.
- Testing availability and the process for returning results.
- Viral load and CD4 measurement availability, lag time and results response.
- Multimonth dispensing roll-out.
- Level of integration of additional services (e.g., tuberculosis or sexual health services).

Structural and policy enablers of effective HIV responses

- National legislation on behaviour- and gender-related barriers to services.
- Local legislation environment and experience with local law enforcement.
- Equitable access to quality education.
- Allocation and utilization of financial resources that affect services for people living with HIV.
- Respect for human rights in services and polices.

Box 3.
Examples of methods of quantitative and qualitative data collection at facilities and in the broader affected community

CLM is complementary and conducted separately to other reporting, such as that embedded in the health programme by the Ministry of Health or collected through an external funder's data stream. Findings from different programmes can be triangulated to strengthen the evaluation.

Choice of tools and methods depends on the goals of each CLM programme.

All CLM data are routinely anonymized.

Based in affected communities

Community dialogue: Meeting of community members to discuss and assess an issue or need that was identified as requiring routine evaluation.

User survey: Conducted among people living with HIV who attend or do not attend the service in question. Structured questionnaires tailored to underlying factors in health-seeking behaviour, such as experiences of stigma and discrimination and health provider attitudes.

Focus group discussion: Group discussion that is conducted among selected service users or those who are not engaging with the service. This should be structured around an agreed framework with consistent topics to identify solutions and trends.

Door-to-door survey: A more open-ended approach that is designed to engage people who are not using services and other members of the affected community. The survey questions may lead with the health service experience generally and proceed to cover HIV services, thus avoiding stigmatization of directly approaching people living with HIV at home.

Facility-based

Observational survey: Monitoring aspects of different types of service (e.g., fixed, drop-in or mobile) by on-site observation of specific points.

Interview of service users at facilities: Tailored quantitative and qualitative questions to assess user experience (e.g., waiting times, safety at different times, sufficiency of staff, and availability of medicines and diagnostics for HIV, other sexually transmitted infections and tuberculosis).

HIV treatment facility leader survey: As the previous point, with additional questions about the context of any identified problems.

Facility-supported adherence club survey: Baseline data on the number of clubs and individual members, the frequency of meetings and the assessment of functionality. Supplemented by individual or focus group discussions.

Clinic records survey: Covers specific points of service quality. This information supports and triangulates with other CLM data rather than replicating pre-existing monitoring. This is only possible if data anonymity is assured, and after clearance by a recognized ethics authority.

Facility-based focus group discussion: Group discussion that is conducted among selected service users and/or providers. This should be structured around an agreed framework with consistent topics.

Community scorecards and citizen report cards: These monitoring and feedback tools, developed by communities and their health-care providers, are already in use in many settings and are a forerunner of CLM. They can be adopted into the routine CLM process.

Stage 3. Community members use analysis, advocacy and shared decision-making to improve services

1. **Finalize the data collection and analysis plan.**

- Establish an analysis and advocacy group from members of the coalition.
- Plan to analyse the cause of the problem and the environment that enables it, rather than apportioning blame.
- Understand the practical and data needs of service providers and decision-makers.
- Practice analysis and presentation that is clear and best demonstrates a problem and/or solution.
- Check that the data collected will enable analysis and identify advocacy messages and points for intervention and change. Involve technical expertise, if necessary.

2. **Pilot routine monitoring with standardized questions at the facility and community levels.**

- Put safety and security of data collectors first.
- Prepare to phase in CLM, adapting tools as necessary.
- In parallel with piloting the routine data collection, establish a mechanism for urgent feedback and response, where necessary.
- Evaluate and report to the coalition to prepare monitors and resources for routine CLM.
- Identify and respond to any weaknesses in the presentation of data or linkage to analysis and advocacy messages. Revise accordingly.

3. **Move to routine data collection. Analyse data and develop advocacy messages.**

- Group and interpret the information to bring out key findings.
- Identify uncertainties and avoid looking only for information that supports pre-held opinions.
- Disseminate the information first to the community and then to decision-makers (e.g., facility managers and government officials).
- Identify possible solutions and action points with the community.
- Collaborate with those who have experience in feasible solutions and implementation requirements.

4. **Work with partners to establish a dedicated seat at the relevant forums where related health sector data are presented and discussed.**

- Find such forums at the local, regional and national levels.
- Find allies within and outside of government to advocate for the importance of CLM data.
- Check that methods of data presentation are useful and appropriate for different forums.

5. **Present data in the service review and improvement process.**

- Present arguments step-by-step, along with context and insight.
- Be prepared to explain sources of data and methods of collection to establish credibility.
- Propose solutions and seek support from service providers and others involved in strategy.
- Work together to implement change at the appropriate level.
- Agree and standardize the analysis of the impact of any future interventions.

Stage 4. CLM transparently integrated with the health service evaluation and decision-making process

1. **Monitor the commitments to change, looking for links between intervention and impact.**

- Focus on capturing trends, linking interventions to outcomes over time.
- Outcomes can be health outcomes, service access, service quality or policy change.

2. **Provide regular feedback to the clinic and the community.**

- Implementation of decisions and their effects are transparently reported back to service providers, decision-makers and communities to maintain accountability.

3. **Continue listening, gathering and acting on points of concern.**

- Enlarge the data collection strategy as required to include a wider range of community members or to capture information at different levels of decision-making.

4. **Consolidate capacity and strengthen available expertise.**

- Self-evaluation to identify needs for capacity-building or refinement of the management structure.
- Standardized assessment of impact as established in the analysis and monitoring plan.
- Ensure continuity while seeking ways to expand the use of CLM.

Community-led monitoring in challenging environments

Societal and structural barriers to community-led monitoring

Some environments are challenging for affected communities; achieving and maintaining CLM poses particular difficulties in such contexts. CLM data monitors should take measures—through their professional level of working and their personal identification and experience—to protect the safety, dignity, human rights and welfare of all respondents and their data, and to prevent discrimination or prejudice. Although the protection of respondents is strengthened through anonymous participation, those conducting CLM have increased public exposure and are particularly at risk of prosecution or other harm. There should be a regular review of the consequences of CLM for data collectors, and their working practices can be altered in response to associated safety considerations.

This risk to data collectors and others who are more visible can be mitigated by supporting strong partnerships with government health ministries and local authorities from the start of CLM planning. This risk to data collectors needs further attention and planning by all involved CLM donors and UN agencies, particularly as CLM expands beyond settings that are more easily accessible.

Not all communities are in a position to establish CLM. Where the communities are disenfranchised and in vulnerable situations due to marginalization, criminalization and discrimination, then it is delicate and potentially dangerous to demand accountability. It is not realistic to expect governments to fund or welcome external funding for populations that are suppressed. While local authorities can be prepared to form partnerships with the CLM coalition as they see beneficial, it might be necessary to identify civil society organizations trusted by the community to receive and manage the CLM funding.

Outsourcing CLM activities should be a last resort, occurring only when community-led work is not feasible and when called for by community members. Any outsourcing should be concurrent with ongoing efforts to strengthen the existing empowerment and mutual aid of marginalized and criminalized populations. In a similar way, data may very rarely be collected by people other than the community members, such as by health workers or external trusted employees working for the CLM.

In these situations, having CLM sponsors—whether financial sponsors or those with political influence or neutral power (such as UN agencies)—can help to establish and reinforce memorandums of understanding. Neutral promoters of CLM could be needed to champion the transformative approach and constructive new ideas generated through CLM, and to navigate power imbalances and define working relationships between the different stakeholders. A neutral sponsor can also be called upon to uphold human rights, advise on ethical issues and promote internationally agreed standards of service.

Humanitarian and migrant contexts

CLM is highly applicable to humanitarian situations. Organization around community-led structures is organic in such settings because people are often fending for themselves, with only their peers and fellow community members for support.

Forcibly displaced and highly disadvantaged populations find it difficult to have their needs heard, but organized groups can have more autonomy and influence in humanitarian readiness and responses. The ability to generate standardized data about points of concern identified by the community is a powerful way to represent needs. Any standardized measurements will provide an important framework for service providers to support affected communities and a basis for ongoing conversation and review.

Resource provision with strong advocacy on the part of international agencies is critical. There is already experience with fund transfer from credit and cash transfers systems that are used widely in humanitarian contexts as a means to sustain social development.

Advocates should remember that in emergencies or isolated locations without power supply and with very limited technology, data collection is often based on paper support. An effective humanitarian response depends on the rapid delivery of such findings through trusted community sources, including by SMS or verbally. Data security is an important consideration, and if the physical document cannot be securely stored, then proper actions should be taken to prevent records being misused.

Conclusion

CLM provides the structure and mechanism through which community data can have a sustainable impact on service quality. Decision-makers seldom use the same services as most people living with HIV, and solid mechanisms for their direct accountability are often not established. Affected communities hold the information and expertise that, when validly captured and drawn upon, can link directly to accountability structures in joined-up ways that have not previously been achieved. Many affected communities are already undertaking CLM, and the existence of effective CLM is a marker of community capacity.

CLM should document the diverse experiences that impact health and quality of life beyond trends in local health service provision. Systematic evidence collected over time is crucial for mapping key enablers of effective interventions. This includes equitable access to quality education and health care, policies to prevent and manage stigma and discrimination and gender-based violence, and laws and justice systems that protect the rights of the most marginalized within society. But evidence alone cannot solve deeply divisive and repressive problems: it must be coupled with the necessary policy changes and mechanisms to balance power in a solutions-oriented approach that feeds into the political process and decision-making.

The investment currently going to CLM with rapid scale-up means that there are high expectations of delivery and results in 2021. The transformative approach of CLM should be embraced and incorporated, expanding from convening actors around HIV-related services into broader related fields. Now is the moment of opportunity for multiple different actors to pull together to realize the potential of CLM.

Annexes

Annex 1. The principles of community-led monitoring

Certain principles underpin all CLM activities and should be maintained throughout the stages of the process.

Community-led and community-owned

CLM is specifically informed, led, implemented and used by and for HIV-affected communities. This includes special attention to those community members who are marginalized and the most underserved. Ownership of the CLM process, including decisions about dissemination and use of the data generated, remains with the community from which they were drawn. Special effort should be made to ensure representation of organizations and groups affected by HIV in any coordinating body.

Focus on action and accountability

Collection and analysis of data are through a lens of community need, focused on removing barriers to good health, identifying solutions and holding decision-makers accountable for their implementation.

Independent

CLM is conducted independently and autonomously, without being directed or interfered with by other stakeholders (e.g., the government or a donor). For example, independence is reflected in the choice of data collected, the shaping of monitoring tools, and decisions about when and with whom to share CLM data.

Collaborative

Promoting good partnerships between all those involved in the service monitoring and improvement cycle—including the Ministry of Health, local health authorities, facilities and service providers—is critical to CLM success. Bringing in the necessary technical expertise while building community capacity can ensure a strong and effective CLM process. All collaboration should be based on mutual respect for the integrity of other actors, with recognition of the unique role of each contributor in improving health.

Routine and systematic

CLM should be developed and funded in a sustainable manner to allow for ongoing data collection that can monitor trends over time. Data collection for surveys, research, ad hoc troubleshooting and the like are all important, and may complement CLM. But such intermittent interventions are not part of the regular and methodical data collection, advocacy and accountability that are the core of CLM.

Shows results

The intended outcome of CLM is to achieve improvements collaboratively that respond to the community's priorities and improve health outcomes. Most of the iterative and continuous approach to quality improvement and building partnerships will be at the local level. As its capacity and contribution grows, CLM can broaden the range of topics covered and enable the comparison of standardized data from different groups. Findings from CLM may eventually be collated for advocacy and funding proposals at the national level, but without compromising the community leadership.

Annex 2. Advocating for community-led monitoring

At any point in the service delivery chain, CLM is a mechanism for unique input from communities into the monitoring and improvement process.

Elements missing frwom current service monitoring and evaluation	The unique contribution of CLM
View of services from the user perspective, especially in challenging circumstances	**Insight:** CLM can bring valid and nuanced understanding of the experience, needs and contexts of people living with HIV and other affected communities, including those who are marginalized. CLM can be the only way to hear from and respond to the affected community, especially in circumstances of low engagement (e.g., where criminalization is a barrier), poor access (e.g., centralized services or those for migrant populations) and when exacerbated by the COVID-19 pandemic.
Service improvement shaped by the experiences of service users	**Responsiveness:** CLM can help ensure that action is taken through short feedback loops that engage the appropriate service providers, programme managers and other decision-makers. With greater autonomy, communities can initiate improvements with service providers without waiting for external approval. This is especially relevant for communities in isolated sociopolitical situations where there is a large degree of local power. Standardized monitoring is a mechanism for service users to be heard.
Developing and harnessing skills of service users and their communities	**Empowerment:** Training, support and other capacity-building are all necessary for the implementation of CLM. The skills that are developed equip communities to capture and use valid data that apply to the service-related issues that matter to them. In turn, this motivates greater engagement with—and use of—the services available, for their benefit.
Collaboration between service providers, service users and other authorities	**Joint problem-solving:** CLM can contribute to a multisectoral approach to service quality improvement, with responsibility, accountability and joint problem-solving. Information can be shared with the community or service users, enabling both to contribute to change and improvement. Relationships based on trust and respect foster the generation of solutions. CLM can be used for other health services, such as tuberculosis or sexual and reproductive health.

Annex 3. Examples of strengths, weaknesses, opportunities and threats (SWOT) analyses

A SWOT analysis considers themes such as cultural aspects, local capacity, financial support, policy/political support, other stakeholder views and pressures, health system context and the perception of usefulness. The SWOT analysis should be conducted by and within the affected community.

In a hypothetical setting, with a relatively supportive structural environment and a source of external funds, a SWOT analysis might look like the following.

Strengths

- Communities are internally well-organized, with common purpose.
- Local authorities are already engaging with communities on service provision.
- Monitoring tools are ready to be adapted from existing CLM programmes.
- Government committed to evidence-informed HIV programme planning.
- National legislation promotes equality and outlaws discrimination.
- Neutral, skilled and trusted technical support is available.

Weaknesses

- No existing organizational framework.
- External funding is unsustainable.
- Community technical capacity needs building.
- Diverse languages and cultures challenge communication.
- Geographic dispersion and isolation of some communities with inadequate communication.
- Local law authorities threaten and harass some key populations.
- Commitment of facility decision-makers is variable.
- High turnover of facility staff.
- Community coalitions may have a higher level of privilege that can lead to a degree of elitism.

Opportunities

- Funding is available.
- Neutral institutions are ready to broker arrangements.
- Common purpose stimulates the creation of partnerships and sharing of resources.
- Global interest.
- Political will is open to increased collaboration.
- Technical support for capacity-building is available.
- Affected communities are knowledgeable about health service standards and structural enablers and barriers.

Threats

- Historical friction and hierarchies of funding between different community groups.
- Change of government could derail the process.
- Competing priorities (e.g., drought and COVID-19 restrictions) may lead to the drop-out of trained monitors.
- Existing civil society organizations may not accept a CLM coalition or activities.
- Rapid scale-up with external pressure may lead to weak CLM foundation.
- Misuse of systems and data.

In a challenging situation, the SWOT analysis could resemble the following.

Strengths

- Communities have strong identities and are internally supportive.
- Monitoring tools are ready to be adapted from existing CLM programmes.
- Growing global momentum for a people-centred HIV response.
- Technical capacity exists in the country.

Weaknesses

- Affected communities cannot be legally acknowledged.
- No existing organizational framework.
- No history of effective engagement with facilities.
- No government policy that is favourable to CLM.
- No funding available or it is complicated to receive funding.
- Community technical capacity needs building.
- Diverse languages, culture and isolation challenge communication.
- Systemic stigma and discrimination.
- Commitment to engagement among facility decision-makers is rare and fragile.
- Potential monitors have moved away from their community.

Opportunities

- Some local health facilities are ready to engage with communities on service improvement.
- Some local law enforcement agencies are open to dialogue with affected communities.
- Common purpose could stimulate the creation of partnerships and sharing of resources.
- There are pockets of knowledge on health service standards and structural enablers and barriers.

Threats

- Increased risk of exposure to sanctions for those involved in CLM and their communities.
- Necessary access to services for affected communities is severely limited.
- Competing priorities (e.g., insecurity and COVID-19 restrictions) may lead to the drop-out of trained monitors.
- Existing civil society organizations may take control.
- High turnover of facility staff.
- Partner institutions do not comply with the principles of neutrality.
- Choosing to engage with CLM may be perceived as a betrayal to other community groups working in the same context and lead to the breakdown of mutual support and collaboration.

References

1. Molokele D, Mohammed Y, Matika W. Mapping report of civil society and access to medicines in Southern Africa. Stockholm and Cape Town: AIDS Accountability International; 2015 (http://www.aidsaccountability.org/wp-content/uploads/2016/09/AAI-SARPAM-Access-to-Medicines-Scorecard-Mapping-Report.pdf).

2. Poteat T, German D, Kerrigan D. Managing uncertainty: a grounded theory of stigma in transgender health care encounters. Soc Sci Med. 2013 May;84:22-9. (https://www.sciencedirect.com/science/article/abs/pii/S0277953613001019?via%3Dihub).

3. O'Neill Institute, Treatment Action Campaign, Health Gap, ITPC, ICW, Sexual Minorities Uganda (SMUG) et al. Community-led monitoring of health services: building accountability for HIV service quality (https://healthgap.org/wp-content/uploads/2020/02/Community-Led-Monitoring-of_Health-Services.pdf).

4. PEPFAR 2021 Country and Regional Operational Plan (COP/ROP) guidance for all PEPFAR countries. Washington (DC): PEPFAR; 2020 (https://www.state.gov/wp-content/uploads/2020/12/PEPFAR-COP21-Guidance-Final.pdf).

5. WHO consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. Second edition. Geneva: WHO; 2016 (https://apps.who.int/iris/bitstream/handle/10665/208825/9789241549684_eng.pdf;jsessionid=023EB69A41A9CC051D94F6C047540AAD?sequence=1).

6. Ending AIDS: progress towards the 90–90–90 targets. UNAIDS: Geneva; 2017 (https://www.unaids.org/sites/default/files/media_asset/Global_AIDS_update_2017_en.pdf).

7. Community-led monitoring tools. In: PEPFAR Solutions Platform (Beta) [Internet]. 17 March 2020. Washington (DC): PEPFAR; c2021 (https://www.pepfarsolutions.org/tools-2/2020/3/12/community-led-monitoring-implementation-tools).

8. Technical Evaluation Reference Group: position paper—thematic review on resilient and sustainable systems for health (RSSH). Geneva: The Global Fund; July 2019 (https://www.theglobalfund.org/media/8793/terg_resilientsustainablesystemsforhealthreview_paper_en.pdf?u=637319004264830000).

9. Universal Health Coverage. In: World Health Organization [Internet]. 24 January 2019. Geneva: WHO; c2021 (https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-(uhc)).

10. Holmes C, Rabkin M, Ford N, Preko P, Rosen S, Ellman T et al. Tailored HIV programmes and universal health coverage. Bull World Health Organ. 2020;98:87-94. (https://www.who.int/bulletin/volumes/98/2/18-223495/en/).

11. The Ritshidze Project's background and reports are available at https://ritshidze.org.za/

12. The international Treatment Preparedness background and reports are available at itpcglobal.org

13. Data for a difference. Key findings, analysis and advocacy opportunities from the Regional Community Treatment Observatory in West Africa. ITPC; June 2019 (https://itpcglobal.org/wp-content/uploads/2019/06/RCTO-WA-Data-for-a-Difference-Advocacy-Paper.pdf).

14. Baptiste S, Mamouan A, Garcia P, Etya'ale H, Swan T, Jallow W. Community-led monitoring: when community drives implementation strategies. Curr HIV/AIDS Rep. 2020;17(5):415-21.

15. Yawa A, Rutter L. OPINION: community-led monitoring is a breakthrough in our HIV response. In: Spotlight [Internet]. 3 March 2020. Cape Town: Spotlight; c2021 (https://www.spotlightnsp.co.za/2020/03/03/opinion-community-led-monitoring-is-a-breakthrough-in-our-hiv-response/).

16. People's COP20. South Africa. Community priority recommendations (https://healthgap.org/wp-content/uploads/2020/02/Peoples-COP20-South-Africa.pdf).

17. Les observatoires communautaires en santé. L'initiative 5%; 2019 (https://www.initiative5pour100.fr/sites/default/files/ressource-doc/2019-10/Observatoires-communautaires-en-sant%C3%A9-capitalisation.pdf).

18. Report of the Task Team on Community-led AIDS Responses to the 47th PCB 15 December 2020 *[Language in this document is under final review]* (https://www.unaids.org/en/resources/documents/2020/PCB47_Report_Task_Team_Community-led_AIDS_Responses).

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