Ensuring Efforts to Scale up, Strengthen and Sustain HIV Responses:

Developing reporting mechanisms for
community-based HIV service delivery in Kenya

Hosted by the Joep Lange Institute and the Kenya National AIDS Control Council (NACC)

22–23 February 2018
Nairobi, Kenya

What's in this meeting report

Section 1 provides:
- An **introduction of the overall initiative**
- Background analysis as to the **rationale for the meeting**: **the importance of community-based services in the HIV response, and lack of viable HIV or health reporting mechanisms for communities.** Although this meeting focused on Kenya, many of the same challenges, including about reporting, exist elsewhere. It is hoped and assumed that the outcomes from this meeting and the Kenya experience overall will be useful and instructive in other countries where resourcing for vital HIV services provided by civil society and communities remains uncertain and constrained by structural, political and other barriers

Section 2 **summarizes the current situation**, including lagging HIV prevention efforts nationally and existing reporting tools that have proved to be inadequate in capturing communities' input.

Box 1 **highlights some of the vital services that community-based groups have been providing** in Kenya since the beginning of the HIV epidemic.

Section 3 considers some **factors, considerations and principles that could influence new reporting structures**, such as integration with non-communicable diseases (NCDs) and reflecting the contribution of faith-based organizations.

Section 4 provides extensive **summaries of preliminary input at the meeting about suggested options and solutions**, including:
- adding *qualitative indicators* and other general suggestions; and
- feedback from thematic working groups that discussed *what data is currently missing in existing reporting mechanisms and how it might be gathered* (including challenges). The four working groups focused on the following: human rights, prevention, social services support, and linkage and treatment.

Section 5 summarizes comments and input about **advocacy actions and priorities moving forward** that can help speed and promote movement on what came out of the meeting.

1. Introduction and Overview

1.1. About the overall initiative

Ensuring Efforts to Scale up, Strengthen and Sustain HIV Responses is an initiative launched in April 2017 by the Joep Lange Institute. The initiative's overall objectives are to describe challenges to meeting current HIV targets and articulate an approach for the HIV response that takes sharp aim at:

- reducing the number of new HIV infections, with a focus on key populations, adolescents and young adults;
- streamlining and improving service delivery to sustain the overall quality of treatment;
- efficiently targeting the use of resources; and
- building new and more sustainable approaches for funding.

A total of seven consultations will anchor the initiative's agenda. A comprehensive report and findings from those meetings will be launched at the International AIDS Conference in Amsterdam, July 2018. That report will be preceded and accompanied by additional work products to highlight research, communications and advocacy needs and strategies.

Three of the seven meetings are larger-scale, bringing together at least 35 participants from across a range of sectors—including government, donor, research/science, multilateral and technical agencies, and civil society. One of those three, held in September 2017, centred on the potential impact of reduced funding for HIV on countries' efforts and ability to scale up their responses and how limited resources can best be used effectively and responsibly. The second meeting, held in October 2017, considered approaches and strategies to make responses more efficient, with an emphasis on differentiated service delivery (DSD) and HIV prevention efforts for highly vulnerable populations. A third large-scale meeting, on innovative financing options and opportunities, took place in February 2018.

The 22–23 February 2018 meeting, **Developing reporting mechanisms for community-based HIV service delivery in Kenya,** is the second of four additional meetings that will further contribute to the overall process. This meeting is one of three that were planned and organized to respond to priority areas of more intensive work, as identified by participants at the first two larger meetings. The first of these three side meetings, on HIV incidence measurement, was held in January 2018. The third, to be held by the middle of April 2018, will centre on primary prevention, especially from the perspective of key and vulnerable populations. The seventh contributing meeting, held in mid-March 2018 and organized by the Joep Lange Institute (JLI) and the World Health Organization (WHO), focused on strategies and advocacy to address growing rates of HIV drug resistance.

Presentations from each of these meetings will be available through a dedicated page on the JLI website. Exceptions may include situations in which presenters have asked not to make their presentations publicly available for one reason or another.

1.2 Rationale for meeting: the importance of community-based services in the HIV response, and lack of viable HIV or health reporting mechanisms for communities

The value and importance of scaling up community-based services was raised at all the meetings. Despite a long history of providing effective community mobilization, education, prevention, social support and human rights protections, community-based HIV services have

never been fully funded by governments, nor have these service delivery approaches been given the respect they deserve in their ability to create demand for and sustain engagement in health and social services.

The Kenyan government prioritized universal health coverage (UHC) in the so-called Big 4 agenda unveiled near the end of 2017, which means it has set a goal of achieving it by 2030. This plan is hastening the integration of HIV into the broader health and development sectors. There is a real danger, though, that the community-based groups and the critical services they provide for people living with and vulnerable to HIV in Kenya, including key populations, could be overlooked and insufficiently supported.

This concern is magnified by the heightened emphasis by the government and other funding sources (e.g., external donors) on evidence of impact and efficiency. Such an emphasis, while welcome in general, puts most community-based and other civil society groups involved in HIV support and service delivery at a disadvantage. Much of the work they do is not easily translated and filtered into existing reporting systems that the government uses to collect HIV and other health information and to evaluate impact. The result is a **lack of viable reporting mechanisms vis-à-vis community-based service delivery, which has the effect of minimizing communities' value and deprioritizing their access to funding**.

This problem and its various causes are not likely to be overcome without targeted, specific coordination by relevant government entities and civil society and community groups. One important positive sign is that the Kenyan government, through the National AIDS Control Council (NACC), has signalled its interest in working with communities to create a strengthened and mutually acceptable reporting system. The February 2018 workshop in Nairobi represented a first step in this process. It is hoped and assumed that the outcomes from this meeting and the Kenya experience overall will be useful and instructive in other countries where resourcing for vital HIV services provided by civil society and communities remains uncertain and constrained by structural, political and other barriers.

2. The Current Situation: Lagging Prevention Results and Inadequate CAPR

Bringing communities back into and central to Kenya's HIV response, and its UHC response, is partly a priority based on current and future need and partly on historical trends. In the view of many from the Kenyan civil society and community sector, a lot has been 'lost' since HIV programming and funding in Kenya began focusing heavily on treatment scale-up and treatment numbers—a trend that was hastened by PEPFAR prioritization. Funding for communities and civil society groups dropped as the focus shifted toward a highly biomedical approach. This precipitated the diminished availability of critical client-centred support services, with many community-based organizations (CBOs) closing down.

Evidence, observations and common sense underline the need for rethinking this approach. Declining civil society engagement of this sort means that more people are 'missing' from the HIV response because they do not have the kind of support and information they need, which often can only be offered by CBOs and other civil society groups with the patience, experience and community knowledge necessary to have the desired impact. Kenya's inability to make extensive and consistent headway in reducing new HIV infections—a challenge it shares with most other countries—is due in part to the relative failure of underfunded and under-prioritized prevention programming and resourcing. The country's future overall HIV and UHC efforts themselves will fail unless this trend is reversed. **Headway on prevention as well as**

treatment can only be made with greater, sustained participation and leadership by communities.

The majority of Kenya's HIV response is donor-funded, with most of that money used for treatment purposes (e.g., to purchase ARVs and other treatment-related commodities, such as diagnostics). The government and most other stakeholders, including civil society, agree on the need to move to greater domestic financing in the interests of sustainability and integration within the overarching UHC and development environment. This in turn requires greater integration of CBOs and other civil society groups, including in recognizing and reporting their impact, monitoring their efforts and being monitored in return, and financing their work more systematically.

What is missing now, though, is a system that effectively and comprehensively collects routine data, based on agreed indicators and with links to outcomes. All of this ideally should be within a framework through which planning and reporting are structured, captured and sustained. **The government and civil society need to come up with a better way for the civil society sector to describe what it is doing and have those community interventions reflected more fully and accurately. If this is not done, it will be difficult if not impossible for the government to directly or indirectly finance CBOs or other civil society groups**. (One underlying reason is the government's strict emphasis on decision-making based on evidence of impact and accountability.)

Such reporting challenges are not new, but they have not been adequately addressed. The NACC currently has a *community-reporting tool known as CAPR (Community AIDS Programs Reporting).* It was designed to help standardize systematic data collection of activities and services that are outside of the mainstream health system but which contribute directly to it.

The current CAPR is a checklist with 31 indicators divided among the following categories: training of community resource persons (3 indicators); prevention (3 indicators); care and treatment (2 indicators), stigma and discrimination (2 indicators); home and community-based care for referral (8 indicators); school-based HIV prevention programs (1 indicator); information, communication and education (2 indicators); sexual and gender-based violence (5 indicators); and condom program (5 indicators). Each of the indicators refers to a number to be recorded, such as "number of individuals reached with treatment literacy" (indicator number 7) and "number of households referred to youth-friendly services" (indicator number 26). Short descriptions for each indicator are included to provide some detail about how to calculate each number.

Although the CAPR has some important and relevant indicators (including from the perspective of many civil society representatives), the tool reportedly has not been used extensively. A bigger concern is that it is missing some other important indicators that could reflect more extensively and accurately the full scope of HIV-relevant services, especially those offered by communities. The current tool's focus solely on numbers is also limiting because it does not provide opportunities for community groups to describe the bulk of their work that cannot be easily recorded in a strict quantitative manner.

Other structures intended to guide and integrate the work of CBOs in the HIV response include, at the national level, the NACC's key population guidelines for programming and the Kenya AIDS Strategic Framework. Moreover, the country's 47 counties have substantial financial and programmatic responsibility for health as part of a devolution and decentralization strategy over

the past several years. While in some context and instances this may have helped bring services closer to the people, it also has made it more complicated and challenging for data to be reported, gathered and analysed.

Box 1. What communities do and why they are important

Listed below are some of the vital services that community-based groups have been providing in Kenya since the beginning of the HIV epidemic, across areas including prevention, linkage and treatment, social services support and human rights protection. Collectively, these services highlight communities' role and value, especially in 'person-centred' work that can be difficult to capture in standard reporting mechanisms that focus on quantitative inputs such as number of people served, etc.

Efforts to improve, let alone maintain, levels of treatment and prevention effectiveness will be fruitless without much of this support work. Communities' centrality to many of these interventions--many of them peer-led—is a key reason that they should be involved in designing, implementing and monitoring outcomes (and especially of all aspects of prevention programmes).

- Treatment literacy and preparedness
- Adherence counselling
- Tracking people who default on ART and helping to bring them back to care
- Accompanying and supporting during clinic/facility visits
- Stigma reduction (including self-stigma)
- Support group facilitation
- Drop-in centres and safe spaces
- Monitoring and advocating on human rights violations, e.g., confidentiality and privacy
- Monitoring and advocacy on gender-based violence
- Outreach and provision of prevention services (e.g., condoms and information) to criminalized and marginalized populations
- Youth-friendly HIV awareness and support provided by young people
- Nutritional advice and food support
- Localised ARV delivery
- Harm reduction and syringe exchange programs
- Monitoring the quality of health care delivery

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3. Looking to the Future: Factors that Could Influence New Systems

There is little debate that much of what communities do in the overall Kenyan HIV response currently is not being captured or reported. Many of the reasons cited are that such work is not measurable, as per existing systems, because there are no relevant indicators. Communities are not often able to report on outcomes as well as outputs. For example, outcome indicators that could show the impact of such work might be whether the quality of service delivery has improved and whether people have been able to improve their adherence.

It is also currently difficult to capture the full scope and impact of support work that, by its nature, requires a lot of time and relationship building. A community member could

spend a full day talking with a young woman, earning her trust, calming her fears and only then successfully encouraging her to get an HIV test, which might include going with her to the facility and counselling her after she gets the results. That is not easy or simple to document. Neither is it usually possible to adequately document everything that a CBO member has done for one client over a period of time, e.g., multiple counselling sessions (in-person and via telephone) and home visits, provision of transport, etc. Current reporting systems typically would highlight solely or primarily that 'one' person was reached, which signals minimal impact—with the work needed to help the client engage more effectively in the HIV response not reflected at all.

A tool (or tools) that captures the complexity of this work, something not accomplished through the current CAPR, could go a long way to giving a more accurate illustration of all the parameters of Kenya's HIV response. Summarized below are other issues and concepts that deserve consideration when determining what constitutes a more effective reporting tool and approach:

- Any solution(s) aimed at improving reporting mechanisms should ensure a *standardized way of reporting*. Structures should be in place as well to help ensure that CBOs and other civil society groups do not miss crucial data. Also important from communities' perspective is *building and retaining the relevant advocacy and monitoring skills* to ensure that the data gathered is seen and reviewed by decision makers and actually influences investments.

- In developing reporting mechanisms about client outcomes and provider performance, it is *important to strike a balance that ensures relevant and thorough data collection but does not overburden the service provider*. Training and sufficient work time should be scheduled so that the data collection and recording can be done without interfering with the primary responsibilities of serving clients.

- *Trust* is an important issue. It is closely linked with *security and confidentiality*. Communities must have a full understanding of why they are collecting all of the data they are being asked to collect—including where it will go, who has access to it and how it will be used. Communication is needed on a regular basis to build and sustain trust as CBOs and other parts of the civil society sector are integrated into national HIV and UHC responses.

- To better embrace shared roles and responsibilities in a more integrated approach that is based on domestic resourcing, *communities have work to do as well to make the case that they are equal, capable partners*. This might include communities showing that they can be trusted to fulfil the tasks and expectations that come with more responsibility (and more money).

- UHC and the government's increasing attention to *non-communicable diseases (NCDs)* underscore the importance of having reporting mechanisms that can easily and effectively measure integrated service provision and delivery. Improved care for NCDs requires community-based service delivery for HIV to also gather information on NCDs and to help ensure referrals for appropriate care. Community groups may need to be involved in helping clients disclose their HIV status, for example, when presenting for care for diabetes—as such information could expose potential medicine interactions or influence advice on a client's diet. Community-run home-based HIV testing programs

have already begun to incorporate additional monitoring for NCDs in their home visits, including glucose monitoring and blood pressure tests.

- Religious institutions are a large component of both communities and HIV responses overall. *Faith-based organizations (FBOs)* account for about 40% of health service delivery in Kenya, and with more than 90% of the population describing themselves as religious, there is and will be a big role for them as HIV and UHC scale-up continue. Some specific considerations regarding reporting and data capturing among FBOs might include ensuring that religious groups' values and preferences do not limit their ability or will to collect strong, reliable data across all populations living with and vulnerable to HIV, including criminalized key populations.

- *A balance may need to be struck between the government's obligation to abide by laws and communities' commitment and right to work with, support and protect members of criminalized groups*. Any loss of communities' voice as advocates on behalf of key populations and against discriminatory laws and policies (e.g., HIV criminalisation laws) would compromise their effectiveness and, by extension, the effectiveness of overall HIV responses. Reporting processes that do not reflect such advocacy work or the direct provision of services to people breaking the law (e.g., a man who regularly has sex with other men) are insufficient.

- Some CBOs have not had the *capacity* or ability to provide the type and kind of data currently requested for government systems. This suggests the importance of identifying the reasons behind such capacity gaps and possible solutions before moving forward with any new or revised process. One possibility is that it is not the capacity that community group are missing, but simply that they are burdened by massive reporting and documentation demands from various donors and other sources of funding.

- The role and expectations of *community health volunteers (CHVs)* deserve more attention in any efforts to enhance reporting mechanisms and bolster response scale-up. CHVs are already expected to do so much, and they are already part of systems that are expected to report. Adding on to their burden without sufficient support and training should be a huge concern.

- *Digital tools and technology offer opportunities worth exploring*. Mobile phone penetration tops 90% in Kenya. New and innovative approaches might be able to leverage technology, including the implementation and use of tools that report not only on numbers, but on communities' efforts 'behind the scenes'.

- *Quality considerations should take precedence in all decisions*. Standards for quality should be discussed in advance and agreed in a coordinated, collaborative manner. They should reflect the requirement to provide essential, judgment-free, confidential, detailed information that can accurately indicate trends and developments in HIV responses and suggest the way for future decision-making with policies and resources. No indicators or other reporting-related measurements or conditions should be accepted for future use and implementation if they do not meet such minimum standards.

4. Suggested Options and Solutions: Preliminary Input from Meeting

This section summarizes ways to improve reporting mechanisms for community-based service delivery as proposed at the February 2018 meeting in Nairobi. All represent the beginning of a process that participants hope will result in coordinated, collaborative solutions that can be implemented as quickly and efficiently as possible.

4.1 Adding qualitative indicators and other general suggestions

All reporting mechanisms should include qualitative indicators and measures in addition to quantitative ones. Such indicators are needed to better capture the work of community service providers, which therefore helps to give a better understanding of the value of that work in reaching out to, engaging with, and supporting people to get tested for HIV; helping them make and follow through on treatment decisions; provide access to the full range of prevention tools; and offer information that is relevant to their specific risks and needs of their clients. Much of this work cannot be captured effectively, if at all, by with purely quantitative indicators.

A system that allows for the documentation of qualitative components of interventions could be transformative. By offering a window on behavioural aspects such as accepting a diagnosis, challenges with consistent access to or use of condoms, and staying (or not staying) adherent, it could help policy makers and service providers from all sectors design better prevention and treatment strategies and interventions. Differentiated responses that more effectively target discrete populations and risk factors could be developed based on systematically collected qualitative observations and information. Another benefit of qualitative data is that it provides important information on the quality of care and the impact and experiences on the lives of people living with HIV. Current tools do not capture such quality-related issues. Community members are best placed to collect information that would be relevant for any indicators seeking to assess such things.

One potential downside is that qualitative data typically is more complicated and difficult to analyse and assess. It cannot be easily fit into an Excel spreadsheet along with numbers reflecting quantitative indicators. Addressing this concern is partly a training issue both with providers (civil society groups) and recipients (government systems) of reporting data. Higher-quality results could also likely result from working with social scientists to develop qualitative data collection and analysis methods.

Another potentially useful approach might be to **have the 'stories' influence indicator development from the very beginning**. Practically speaking this would require extensive, direct dialogue and engagement between monitoring and evaluation (M&E) personnel who will design new reporting mechanisms and communities before any new indicators are proposed. Such discussions can make it easier for communities to understand what kind of indicators and tools they really want and need, and believe are essential. And in return, the M&E staff would have a better idea of what kind of information can be reasonably expected and how indicators can be best phrased and positioned to elicit the fullest scope possible of communities' HIV-related work.

Revising the CAPR tool is a suggested approach, as indicated below. Some participants have suggested revisiting and reintroducing a different reporting mechanism, the **Community Based Programme Activity Report (COBPAR)**. This tool was used to report on progress to the World Bank's Total War Against HIV and AIDS (TOWA) initiative, which ran in Kenya from 2008–2014. According to some meeting participants with experience with this tool, the COBPAR included more comprehensive and nuanced indicators and reporting specifications.

4.2 Feedback from thematic working groups

In a series of working groups, participants at the Kenya meeting discussed the specific kinds of data, qualitative and quantitative, that they believe is needed to adequately and accurate describe the work of communities within reporting mechanisms. They were then asked to consider which of the data points or components are currently available or are 'missing', and then how all needed data should be collected (e.g., methodology).

The participants considered these questions in working groups that focused on four different areas: prevention, linkage and treatment, social services support and human rights protection. This sub-section summarizes the outputs from those working groups, which were preliminary brainstorming sessions aimed to prompt more in-depth discussion among all Kenyan stakeholders as discussions continued about reporting mechanisms.

One generally accepted approach was to use the current CAPR as a starting point. Revising this tool was seen as one way—perhaps the quickest and thus most useful in the short term at least—to gather more and better information about communities' work across the HIV response. For the CAPR to have the desired impact, it would not only need to be revised, but it also must be used more widely and regularly (by communities entering information) and reviewed and proactively utilized to guide decision-making in HIV financing and policy (by the government).

CAPR revision should be a joint process, as its initiative development reportedly was. In terms of process, strong consideration should be given to allowing space for communities to come up with a preliminary list of revisions (including proposed new indicators and language), with subsequent collaborative discussions flowing from there. This approach would guarantee that revising would be a community-led process, which makes sense since it is CBOs that are doing much of the current work on HIV prevention and other support service areas that are not reflected in the existing tool.

The CAPR tool is only one of a number of possible solutions. **Better and more sustainable options might include developing an entirely new reporting system and structure, including one that more broadly reflects and is closely linked with integrated health and development reporting in the overall UHC drive in Kenya.** To achieve the desired impact, follow-up discussions on specific tools and mechanisms must be based on government, civil society and other relevant stakeholders working together as equal partners with a shared interest in outcomes that enable high-quality, comprehensive HIV services to be accessible to all people living with and vulnerable to HIV.

A. Human rights

Data and information are needed at both the individual and macro levels. The individual level might include, for example, informed consent, legal services for sex workers and confidentiality protections. The macro level might include changing laws and training health workers, with an overall objective that all people know their rights (and that health care workers understand clients' rights as well).

Some *potential areas around which to develop indicators and obtain desired data*:
  • Numbers of health care workers, law enforcement personnel, members of the judiciary, community leaders, and community members themselves trained on human rights issues of working with key populations and people living with HIV. Such training should include the

provision of stigma-free services, and training curriculums for all these groups should include human rights issues that are both specific to and beyond HIV.
- Documentation of human rights violations reported, and how many were addressed to conclusion
- Inclusion of human rights in workplans
- Monitoring the availability and use of legal services
- Gender inequality and gender-based violence, both of which are major human rights issues for people living with HIV, key populations and women and girls (who are uniquely vulnerable)

Also needed are mechanisms for collecting data on human rights violations at the community level and for reaching people with awareness and information about what they have the right to receive when seeking services at a facility. Such issues are related to the *quality of services* as well. Listed below are some of the useful questions to ask clients that would be associated with the kind of qualitative indicators that do not currently exist in the CAPR, such as:
- Did you get services confidentially? (This question is useful because, e.g., sometimes people living with HIV are treated in a separate room or wing, which means everyone visiting a facility that day knows who has the virus.)
- Were you treated with dignity and respect?
- Did you get the services you were looking for?

The findings from such questions could be analysed and compiled to create numbers, percentages and similar information for indicators—such as, 'only 10% of clients were treated with dignity' or 'only 20% got the services they were looking for.'

In terms of **methodology** (gathering such data), the existing human rights indicators in the CAPR are not adequate. One reason is that those in the current tool are mostly limited to stigma and discrimination. It should be broadened to more effectively cover other aspects of human rights such as criminalization. People with disabilities are also missing from the current CAPR. As noted in Box 2, expanded and improved human rights indicators in the CAPR could help to make the HIV Tribunal achieve its intended potential to monitor and obtain redress for HIV-related human rights violations.

The CAPR and any other reporting mechanisms used to gather HIV-related service delivery data from communities also should have clearly defined ways to *account for multiple entries*. For example, a young gay man who engages in sex work has multiple risk factors but is just one person. Current reporting forms make it difficult to fully capture such a situation and have all the work and need reflected adequately. One step might be for CAPR and other forms to have both vertical and horizontal totals.

Box 2. Raising the profile and effectiveness of the HIV Tribunal

One existing structure that several meeting participants referred to, particularly in consideration of human rights, was the HIV and AIDS Tribunal of Kenya. Established in 2009, as stipulated in the HIV and AIDS Prevention and Control ACT (HAPCA), the HIV Tribunal is the only HIV-specific statutory body in the world with the mandate to adjudicate cases relation to violations of HIV-related human rights. It is widely considered by civil society and community advocates as a wonderful idea that has yet to have the desired impact, partly due to insufficient resourcing for it and partly because of limited awareness of its existence and what it can and should do among communities.

Nairobi meeting participants in a human rights working group agreed that although the HIV Tribunal has great potential, it must have stronger leadership, wider oversight and more financial and human resources. To be the truly national institution it is designed to be, ***the Tribunal should to be decentralized***, as it is currently only based in and visible in (to a too-limited extent) in Nairobi. There is also a ***need to increase knowledge about its existence and role,*** including among people living with and vulnerable to HIV, all key populations and community groups across the country that work in all HIV and health areas.

A revised CAPR could help to monitor impact of such awareness-raising efforts, such as by collecting information about how many people are reached with information about the Tribunal and what (if anything) they know about what might constitute human rights violations and how such violations can be redressed through the Tribunal.

B. Prevention

Based on a quick review of the existing CAPR tool, members of the prevention working group concluded that reasonably sufficient information about a series of 10 notable 'direct service delivery' areas ***currently is captured through the CAPR***, ranging from number of individuals reached with HIV prevention information to PrEP.[1]

The group found that the following is ***missing from this tool***:
- Stigma-reduction activities – module; trainings conducted (for people living with HIV but supports prevention)
- Peer-to-peer support on stigma and disclosure
- Positive health and dignity prevention—peer-to-peer messaging on prevention, treatment, stigma reduction and other health needs
- Community-led HIV messaging in school and out-of-school settings (differentiated based on age)
- Sexuality education for HIV prevention targeting parents and caregivers of 10-24 years old
- Community sexuality health education—only communities are running the programme
- Mapping of community services
- Key performance indicators (KPIs) to which civil society organizations (CSOs) and facilities are reporting against
- Data on community systems are not captured
- Supportive interventions from the community – they are not identified

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[1] The other 8 are: # of individuals reached with HIV prevention information with abstinence & delayed sexual debut (targeting youth), # of individuals reached with HIV prevention information reached thru peer-to-peer, school-based HIV messaging, condom promotion, VMMC, PEP – provided via interventions linked to sexual abuse, # of individuals referred for youth-friendly services, and testing.

- Data on quality of services

Listed below are identified **challenges and observations** with collecting current data, and potential future (and different) data referred to above:
- Tools are paper-based, which works for community health workers but can be a challenge for the youth. Data collection through technologies such as mobile phones would be more convenient, efficient and reliable method.
- Issue with making triplicate data and how cumbersome it is
- Cost entailed in printing the tool; also, it is bulky. Fewer mistakes if data-gathering is digitized.
- Challenge on how the entire health system is gathering data, and whether digitization can be done for HIV alone
- There were sexual health programmes that digitized data-gathering from community providers, and they led to an increase in report submission from youth
- A model is needed to cost services delivered by communities
- PEPFAR has a costing model, but it is not clear how community interventions are costed. It is also costing for PEPFAR interventions and not for the country.
- Facilities do not report on referrals that were successfully delivered by community organizations
- Outreach work on stigma reduction has been effective and earlier could be captured through the CAPR. But now, HIV messaging is through digital media and is more difficult to capture.
- How do we capture data from prevention activities that are outside facilities, especially those that are delivered by community groups. Some groups are reporting using their donors' tools based on simple indicators (how many reached, how many tested), but most do not.

Listed below are the group's verbatim recommendations:
- Digitization of the tools is needed to minimise mistakes and make it easier for the community. Mobile technology should be optimized to collect real-time data.
- Accurate costing information on all prevention activities
- Investment case needed for Kenya that covers prevention activities from communities
- Review of all service delivery tools from the perspective of the community
- To map community groups: check registration documents to develop a database of which organization is doing what kind of service delivery
- Improve data-gathering in facilities to make sure that community interventions are given weight and recognised.
- Data analysis needs to be disaggregated to be clear about attribution – civil society, private sector, government
- Advocacy is needed in different levels to improve tools – with national government, among CSOs, the World Health Organization (WHO), Global Fund
- To fund a coordinating platform for HIV CSOs that can have self-regulatory functions, including to consolidate report.
- Capacity-building for the community is needed to develop their own M&E expertise
- Convene an M&E TWG [technical working group] for all programme implementers to push for the inclusion of community-specific data. Review the tools to reflect community specific data.

C. Social services support

In addition to the CAPR, some other tools are useful for collecting some data and information of relevance to communities' HIV work, including the Community Health Information System (CHIS) and Child Protection Management Information System (CPMIS).

The working group concluded that **the current CAPR captures** the following vis-à-vis social services support:
- treatment literacy
- adherence promotion
- education and knowledge sharing

- psychosocial support
- number of home visits
- cash transfer programmes for vulnerable
- legal support through the community avenues and the HIV Tribunal
- training and capacity building
- nutritional support
- youth-friendly services

The tool **does not capture** the following:
- Economic empowerment and support. This refers to, for example, tracking the extent to which people are supported in terms of health and access to services.
- Health insurance subsidy for the poor. This refers to, among other things, finding out who is or is not covered by the National Hospital Insurance Fund (NHIF) at community level.

Some **challenges regarding data collection** in the social services area include the following regarding support groups:
- The lack of standardized tool for qualitative data makes it hard to analyse the data
- Focus group discussions (FGDs) require higher level of capacity to collect
- Most if not all community data systems use numerical/quantitative data as basis for analysis. Analysis of qualitative data would require adjustment or total change of the entire system.
- The risk of being biased/subjective when data is obtained through observation

The following challenges are in regard to social protection and safety nets challenges:
- Lack of age-sex disaggregated data
- Identification of correct beneficiaries is always a challenge (e.g., nepotism is common)
- Inadequate resources to support facilitators of FGD groups, as currently most are expected to volunteer

The group suggested the following in terms of how to collect needed data (**methodology**):

Systematic focus group discussion
- Define clear, measurable, indicators
- Develop FGD schedule/guide with clear questions to be tracked
- Develop a standard

Observation
- Noting and recording of events through prescribed tools
- Leverage on existing tools and adopt them to obtain the required data.
- Non-judgmental, concrete descriptions of what has been observed.

Individual interviews/exit interviews
- Should be periodic (e.g., annually)
- Used in measuring efficiency (perceived quality of service, areas of improvement)

Another proposed methodology was *'significant change stories'*, which refer to beneficiaries sharing stories about their personal experiences. For example, a client could discuss in her own words that at one point her viral load was high, but after a lot of visits and encouragement from community peers, she was able to achieve viral suppression. Such stories could be inspiring if well-documented in a systematic way and then somehow integrated into a reporting mechanism.

D. Linkage and treatment

Essential data related to linkage and treatment is needed about communities' activities that are associated with all three components of the 90-90-90 target areas. One refers to those who have tested positive who are then referred to treatment. Another is the number of people (clients) started on ART, which could be a proxy for community-provided support services. *Also needed is data on the following* that can be linked back to community services:

- Adherence
- Peer support
- Number positive and referred for linkage to treatment.
- Newly started on ART
- HIV treatment literacy
- ART retention
- Viral load suppression
- Number of defaulters traced and brought back to treatment
- Number clients enrolled into a HIV support group in the community

Methods to gather such data could include a *short adherence questionnaire* through the CAPR tool. Some of the information that is fed into this questionnaire could come from the results of *self-adherence checklists* compiled by clients. A different sort of checklist might also be useful to gauge impact of treatment literacy, with the results then being reported in the CAPR tool.

A *monthly focus group discussion* could be a method to capture important data associated with peer support, including: number of clients enrolled in a support group, number of support groups attended in a month, and number of individuals reached through one-on-one peer support. A focus group discussion could help to capture information that can feed into various linkage indicators, such as by asking participants when the last time was that they went to the clinic.

A referral form with a *complementary questionnaire* could be tool used to measure things such as the number people who test positive and then are linked to care. Such a questionnaire might also be used in areas such as covering stock-outs and assessing linkages for NCDs.

Participants in this working group identified the following as some of the **challenges** associated with collecting data:

- Too much paperwork.
- Concerns about integrity of what is reported, in terms of accuracy and honesty.
- Inadequate resources—including human resources, logistical support and basics such as stationary
- High burden of work, due in part to wide geographical areas to cover
- Documentation and technical skills in reporting (e.g., to adequately fill in the CAPR tool).
- Obtaining real-time data. One way to help overcome this challenge, and to make the overall data-gathering effort easier, is to *use innovative/new technology for data collection and transmission*.

5. Guiding Approaches: Advocacy Actions and Priorities for the Next Steps

The overarching assumption from meeting participants from all sectors is that investing in communities is the right thing to do, and therefore it is important to show the value of such investment on health outcomes and quality of life. This section summarizes results from a discussion at the end of the meeting on **advocacy actions and priorities moving forward** that could help speed and promote movement on what came out of the meeting. The input below refers to several respondents' comments on what is needed to strengthen and implement community-based service delivery in Kenya, including to build a community-based model that contributes to a comprehensive, improved prevention programme.

- In Kenya, there are both national and county responsibilities and programs vis-à-vis health and HIV. As a result, there are different targets and expectations. An important task would be to **map the overall situation and do some analysis.** The mapping ideally should cover all the entry points for communities to provide relevant services, from whom or what they receive funding (e.g., county and national health ministries), and to whom or what they are expected to report results and impact. It should also include all the programmatic and funding options at these levels that communities are not currently accessing, or doing so only in a limited way. The goal would be to use analysis of the mapping as background evidence and information for future engagement, including as part of an effort to broaden and standardize reporting.

- A **community-based technical working group (TWG),** or multiple TWGs, should be set up to create standards, systems and influence in different areas such as monitoring and evaluation (M&E), prevention, human rights, etc.

- A very **clear framework is needed as what communities want and expect to achieve**, including in regard to funding. And then, consideration should be given to which tools would help to achieve the desired framework. Such a framework could be developed by a civil society regulatory board of some sort, which would give the sector the space to coordinate and set its own targets, monitor its impact, and hold itself accountable.

- **Further and more extensive analysis should be done of the existing CAPR**. It should be reviewed carefully to ensure deliberative discussion and agreement on how and where it might be added to or changed in other ways.

- There is a clear understanding of the need to **agree on indicators** for existing and future tools and mechanisms that can measure qualitative and quantitative outputs and outcomes that are community priorities. This step requires finding and being supported by people who are experts in developing such indicators. Decisions on which stakeholders to bring on board should be based on the type, scale and scope of indicators that community groups agree on collaboratively.

- **A better case should be built for community engagement**. One important step could be a *cost-benefit analysis*. Some work has already been done in this area. The Ministry of Health (MoH) reportedly has completed an investment case analysis that shows a favourable return on investment for community engagement in the HIV response. One top-level finding reportedly is that for every $1 spent on community-based service delivery, up to $6 comes back—a huge net gain.

- **Strong efforts should be made to stop perpetuating the 'separation' between the community and institutions** (such as the government at county and national levels). It is important for communities to work with the institutions from the very beginning when determining what the communities are asking and demanding for. Input from institutions also would be useful when the community is developing its preferred tools and indicators.

- All involved should keep in mind that this conversation is much bigger than just developing indicators for civil society and communities, or about service delivery. It is

about ***responding to the needs of communities in broader areas such as social justice and rights***. And it is also about ***trust and power-sharing***—and therefore, power-sharing should be integrated into advocacy undertaken around these mechanisms.

- Similarly, ***all work and efforts should be conceptualized around the quality of lives of people living with and affected by HIV, not just about capturing data for targets***. This is important regarding how communities think about and respond to highly publicized targets such as the 90-90-90 targets, which emphasize speed and getting people onto treatment. ***These targets can do a lot of harm*** if the relevant support systems and infrastructure best offered by communities are not in place and effective, such as treatment literacy, adherence support, monitoring drug supplies and stock-outs, etc.