

# **CS-CLMA CONTRIBUTING TO MALAWI NATIONAL HIV RESPONSE**

**By Starphel Sithole**

The Revised Malawi National Strategic Plan for HIV and AIDS 2020-2025 says empowerment, involvement and engagement of community structures especially recipients of care and gate keepers in the community such as block leaders and Religious Leaders is one of the core pillars guiding the work towards the fight against HIV (Malawi National Strategic Plan for HIV and AIDS response 2020 to 2025).

Citizen Science Community Led Monitoring and Advocacy (CS-CLMA) a project being implemented in Kasungu and Dedza by MANERELA+ (Malawi Network of Religious Leaders Living with or Personally Affected by HIV and AIDS) in partnership with the Network of Journalists Living with HIV (JONEHA) which is funded by Bill and Melinda Gates Foundation through International Treatment Preparedness Coalition (ITPC) has registered tremendous strides in HIV service delivery by empowering recipients of care to be at the center of advocating for quality services in health facilities.

In achieving the goal of the CS-CLMA project, MANERELA+ uses some guiding stages which include generation of evidence through data collection and analysis to facilitate identification of issues, education follows to increase recipients of care and providers understanding of concepts and issues affecting delivery of quality health services, then the two parties engage for a common understanding on generated evidence leading unto advocacy on implementation of agreed solutions. Following this commonly known as Community Led Monitoring (CLM) cycle; when data is collected by the recipients of care after training; it is validated by the health providers as sources of information along community members. Thereafter, MANERELA+ engages different key stakeholders on how the identified gaps would be addressed with clear action plans. Education forms a critical part of CLM as it is the basis for community empowerment and their ability to engage stakeholders. In this way the knowledge and relationship gap between provider and recipient of care is bridged.

## **Why CS-CLMA project?**

CS-CLMA which started in 2020 and targets People Living with HIV, Health care Workers and Key Populations (KP) is a concept that aims at empowering the community to assess and generate evidence on access gaps and HIV service barriers in the context of COVID 19. Overly; the project aims at improving HIV service delivery and uptake by targeted populations.

James Kamanga 43, a recipient of care at Mnyanja Health Center in Kasungu district who has been living with HIV for 17 years expressed the positive impact of CS-CLMA at the facility. The project has brought a mutual understanding between the health providers and recipient of care. "Before the project started implementation at this facility, we were afraid of approaching Health Service Providers on the gaps we were experiencing like their attitude, the facility not opening by 10am, which led to people going back without being assisted. The worst was that providers used harsh words when talking to us. This made us feel undermined, unwanted and discriminated. For these reasons many were defaulting" Kamanga narrated.



*Kamanga: CS-CLMA has empowered ROC*

"After CS-CLMA started empowering us; we called for the village heads, health providers to dialogue with recipients of care on addressing the gaps we noted. Our village heads took a great role in creating a good relationship between the recipients of care and the health providers. Since then; the facility opening time has changed as a result of engagements that we had, the health providers are now our friends, we interact and ask for better ways on how to take care of ourselves," he added.

MANERELA+ Kasungu District Data Supervisor, Joseph Nthondo explained that the project acknowledges the fact that people are experts in their own lives and take lead in the things that matter to them and where change is needed. "CS-CLMA is a process where communities take lead to routinely monitor an issue that matters to them by identifying their top priorities, creating indicators to routinely track those priorities, collecting data, analyzing results and sharing the insights with wider groups of stakeholders. CS-CLMA systematically collects and analyses qualitative and quantitative data and this data is used for monitoring trends along the HIV Cascade to inform targeted action that will improve the quality of HIV services", he explained.

Nthondo added that the project is aiming at contributing towards the national HIV response of 95:95:95 targets by observing that all the HIV and ART protocols are done with effective community participation.

## How has the project benefitted the key populations (KPs) in the targeted districts?

Jane Zanda a female sex worker and a recipient of care at Family Planning Association of Malawi (FPAM) Health Facility in Kasungu happens to be one of the beneficiaries. She explains how the project has turned their lives around:

“Being a sex worker and living with HIV is a shameful and stigmatizing situation to many. However; this is not the case with me anymore. The coming in of the CS-CLMA project at FPAM has focused so much on the Key Populations. I mean us as sex workers. Through the project we have a focal person at the facility who is also a sex worker and a data collector. So, we run to them whenever we have problems or in need of condoms. Through treatment literacy trainings organized by MANERELA+ we have realized that we are not left out in receiving quality health services at the facility as we had previously believed. We are now aware that we can freely ask for preventive measures such as condoms to protect our sex partners. We also know about pre-exposure prophylaxis (PREP) and post exposure prophylaxis (PEP) drugs which can protect fellow sex workers not living with HIV from contracting the virus” Zanda Narrated.



*we are not left out in receiving quality services- Zanda*

Zanda added that through the support groups that were formed after the introduction of the project, they are now empowered to share information about HIV preventive measures such as PREP, PEP and female condoms to other sex workers. Not only that, the project has helped in reducing defaulter rate amongst KPs as they do not interrupt treatment because they are aware of the negative effects of treatment interruption.

HIV Testing Services Counselor for FPAM, Angela Sitima commended the project. She said through the community awareness; the facility now reports low death rates for

people living with HIV and has now a high uptake of condoms than in the past which indicates that many are having safe sex.



*Sitima: More condoms are distributed at the facility*

“This project has brought so much change at FPAM, I can attest that now more sex workers are coming to collect female condoms and this is because they have a focal person who is also a data collector. This makes them to feel free at the health facility. Before the project commenced in 2020; only 6000 Male and 0 Female condoms were distributed annually. But in 2022 statistics show that 373 002 Male condoms and 11 496 female condoms were distributed. We also now have more people asking for PREP and PEP because of the awareness MANELERA+ has brought to our communities.” She said.

Dan Namate a Data Collector at Kasungu District hospital who is also in the group of Men having Sex with Men (MSM) is another beneficiary of the project. Namate said the project has helped their group to come out freely to the hospital to ask for water-based lubricants and male condoms. “We thought the facility does not have lubricants but the coming in of CS-CLMA opened our eyes during the education session on treatment literacy. Among other reasons, poor relationships with health service providers limited us to go and ask for the lubricants for fear of being disclosed to the public”

Key Population Coordinator at Dedza District hospital, Walter Chambwe said the arrival of CS-CLMA project has bridged the gap between health service providers and Key populations. It has also increased the uptake of water base lubricants and condoms. “MANERELA+ conducts awareness meetings where service providers take lead in educating key populations on how to prevent HIV and the importance of staying in care. Through these education meetings key populations are made aware of the

availability of lubricants at the facility and the benefits of using lubricants. So, they are now coming in large numbers.” Chambwe explained.

### **What has changed in the Health Facilities?**

The CS-CLMA project is being implemented in 8 health facilities in Kasungu and 6 Facilities in Dedza district. In Kasungu; Mnyanja Health Center is one of the facilities under the project.

Mnyanja Health Facility In-charge, Ulemu Banda applauded the project for having empowered people living with HIV who work as data collectors at the facility. She said these data collectors add value to the ART services, as they carry out shifted tasks acceptably saving health providers’ time. They also act as living testimonies of the benefits of ART.

“In the past when we were working alone, we were unable to counsel and provide other necessary information to recipients of care. The coming in of CS-CLMA has lessened our work at the facility, we now work hand in hand with the data collectors in following up with ART defaulters. When we notice people defaulting ART, we consult the data collectors who go in the communities to trace those that have defaulted. So the CS-CLMA initiative has brought many people back to care as in 2020 our facility registered 26 defaulters of the 641 on ART where last quarter of 2022, we registered 12 defaulters of the 884 on ART.” Banda narrated.

“Data collectors provide daily health education talks about HIV, on-the-spot counselling and psychological support to recipients of care who come for review and drug refills. The data collectors also easily create a good relationship with other recipients of care which encourages other recipients to remain on care.” Banda added.

Medical Assistant at Lobi Health Center in Dedza district, Edward Nedi also praised the CS-CLMA project for contributing to reducing stigma and discrimination and defaulters at the facility.

“When MANERELA+ brought in the data collectors we were afraid that they are here to record our wrongs. On the contrary; after the data collectors saw the need for space and privacy at the hospital, they called out to the project which introduced a different Differentiated Service Delivery model (DSD). DSDs are ways of providing flexibilities to service access by promoting recipient of care convenience in access. The Community ART Groups (CAGs) is one of the DSDs preferred by communities on treatment. A CAG is a group of 6 recipients of care who choose one person at a time to go and collect drugs on behalf of others. So, it reduces the frequency of recipients of care to go to the health facility. CAGs have helped in reducing workload for us as Health workers. So, we have more quality time for recipients of care. There is also accurate information on treatment outcomes of recipients of care. CAGs have decreased need for tracing of defaulters. This is so because CAG members update us on their whereabouts. Overly; CAGs have reduced defaulters from 472 in 2021 last quarter to 321 in Q4 2022 as they provide peer support on treatment” Nedi explained.



*CS-CLMA; one of the facilities under the project*

Nedi added that data collectors engage Traditional Authorities and community leaders who have now joined the fight against HIV. The community leaders are taking part by sensitizing people about HIV and ART services. Some Traditional Leaders have further set rules where anyone found discriminating people living with HIV is punished.

According to Communities Deliver, UNAIDS and Stop AIDS alliance of 2015, Community-based advocacy, campaigning and participation has changed the landscape of the HIV and AIDS response worldwide. Communities continue to deliver key changes that enhance the well-being of individuals and their communities. Community-based advocacy and campaigning have: mobilized millions of individuals; influenced policies and laws; improved access to treatment, care, support, HIV testing and other services; challenged stigma and addressed discrimination; enhanced prevention interventions; and created more enabling environments. These changes have in turn supported the achievement of better health outcomes and human rights.