

## **MANERELA+ Scaling up Advocacy Through Citizen Science-Community Led Monitoring**

*By Christer Mercy Kalukusha*

Stakeholders in the fight against HIV have advised Malawi Network of Religious Leaders Living with or Personally Affected by HIV (MANERELA+) to scale up its advocacy by raising the profile of phase two of the four-year (2020-2024) Citizen Science Community Led Monitoring and Advocacy (CS-CLMA) project which it is implementing in partnership with the Network Of Journalists Living with HIV (JONEHA). The project is funded by the Bill and Melinda Gates Foundation (BMGF) through the International Treatment Preparedness Coalition (ITPC). Stakeholders provided the advice during a Community Consultative Group (CCG) meeting held at Thope Lodge in Dowa district on 27<sup>th</sup> August 2022.



Carol Kassam Director Of Programs and CS-CLMA Project Lead at MANERELA

Citizen Science Community Led Monitoring and Advocacy (CS-CLMA) is an initiative adopted from the ITPC model that moves from models of “data extraction” to “data democracy” by combining community led interventions including Community Led

Monitoring (CLM), implementation Science and a novel methodology called “Life mapping”. Citizen Science acknowledges that people are experts in their own lives. It pivots away from the notion that academic research and analysis is the only legitimate knowledge creation method. The name signals democratization of data collection and analysis, empowering participants and respecting their expertise.

Community Led Monitoring 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 result and sharing the insights with wider groups of stakeholders. CS-CLMA systematically collects and analyses qualitative and quantitative data. The data is used for monitoring trends along the HIV Cascade and to inform targeted action that will improve the quality of HIV services. The data is collected by an organized group of community members on various aspects of HIV prevention, Testing, Care and Treatment services.

During the meeting it was learnt that the data collected from the project which is being implemented in Kasungu and Dedza districts showed that there is still a knowledge gap among recipients of care which is affecting their uptake and demand of HIV services.

Director of Programs and CS-CLMA Project Lead at MANERELA+ Carol Kassam said for example this shows that a lot of people haven't been taking PrEP despite the medication being made available to them.

“In Kasungu, despite PrEP being rolled out last year the uptake and enrolment by recipients of care has been low because we do not have enough initiatives around demand creation within communities, so there is still a lot of knowledge gap affecting uptake,” she said.

She further said that from January 2022 to June 2022 there has also been a lot of issues to do with routine viral load testing when COVID-19 affected the availability of testing kits because there was low production against demand and transportation challenges globally. “We therefore agreed that this was also an advocacy issue where we seriously need to engage the Ministry of Health (MoH) and other stakeholders that support the procurement of testing kits and other equipment,” said Kassam.



*Dr. Damson Kathyola Chairperson of the CS-CLMA Project CCG*

Chairperson for the CCG, Dr. Damson Kathyola said this will help to ensure that the organizations implementing the CS-CLMA project will be seen to be trusted partners in strengthening the national HIV service delivery system. The collaboration between the project and its partners needs to include relevant institutions like Ministry of Health as policy maker and main service provider, the National AIDS Commission (NAC) as Coordinator of the National HIV response in Malawi, funders like the Presidents Emergency Plan For AIDS Relief (PEPFAR) and Global Fund, UNAIDS as global link to the National HIV response, academic institutions, legislature and other Non-Governmental Organizations providing HIV services or implementing CLM. He emphasised need to scale up CS-CLMA to a level of being a national program than the project status which it currently has. By bringing in funders; CS-CLMA financial needs at national program level will be met. In addition; the Chairperson emphasised need for developing an advocacy strategy which prioritises issues and reflects stakeholder interests. Again; among the various implementers; CS-CLMA needs to be coordinated at the national level irrespective of diversity of implementation approach and reach. Above all CS-CLMA in Malawi needs improved documentation and increased media coverage.



*CS-CLMA Project CCG In Session*

CCG is an inclusive advisory body of the CS-CLMA project in Malawi which meets quarterly. It is composed of population groups such as people living with HIV, Key populations, academicians, implementing NGOs like CEDEP, FPAM, national stakeholders like the department of HIV and AIDS (DHA), UNAIDS and NAC. The CCG is guided by Terms Of Reference. The TORs include discussing findings from the presented data and providing guidance in terms of giving a locally contextualised definition of CLM, prioritizing advocacy issues and pointing towards next steps to be taken to inform CS-CLMA implementation.