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CITIZENS VOICE NEWSLETTER

"I have authority to tell my fellow duty bearers to address problems faced by my subjects when accessing health services.

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MANERELA+

ITPC INTERNATIONAL TREATMENT PREPAREDNESS COALITION

Contents

Foreword

Dennis Mseu, Executive Director

Welcome to this maiden edition of Citizens Voice Newsletter from Malawi Network of Religious Leaders Living with or Personally or Affected by HIV and AIDS (MANERELA+) with warm heart greetings and blessings from the creator as you enjoy reading. The Newsletter profiles Citizens Science-Community Led Monitoring and Advocacy (CS-CLMA) project which MANERELA+ is implementing with financial and technical assistance from International Treatment Preparedness Coalition (ITPC) since 2018.

CS-CLMA is led and implemented by the community members in their diversity of Adolescent Girls and Young Women (AGYW), Young People living with HIV (YPLHIV), Men and Women Living with HIV (MLHIV), (WLHIV), Female Sex Workers (FSWs), Male Sex Workers (MSW), Men who have Sex with Men (MSM), Transgender, Faith Leaders Living or Affected by HIV and Health Care Workers (HCWs) . The project has 4 core areas of Education, Evidence Building, Engagement and Advocacy. Before we go further, I would like to share with our esteemed readers about MANERELA+'s profile.

Malawi Network of Religious Leaders living with or Personally affected by HIV and AIDS is a faith based organization founded in 2001 with a network membership of over 10000 religious leaders and faith community members spread across all the 28 districts in Malawi. MANERELA+ works towards providing response and support to the HIV and AIDS pandemic through Community Mobilization, Education and Awareness, Capacity Building, Demand Creation, Evidence Based Research, Advocacy and Lobbying.

Our Strategic areas of programme intervention are premised on HIV, TB, Malaria, Sexual Reproductive Health and Rights (SRHR), Gender and Human Rights, Maternal Health, Lesbian Gender Bisexuals Transgender Queers and Intersex (LGBTIQI) programming from Human Rights perspective, Key Populations (KP) programming from Public Health approach, Nutrition, Food Security, Livelihood and Emergency Response.

MANERELA+ is governed by the Board of Directors with its secretariat based in Lilongwe and headed by the Executive Director. The organization's values are principled on Sanctity of all human lives, transparency and accountability, integrity, commitment, inclusiveness, non-discrimination, equality and equity.

Having curtain raised about CS-CLMA and MANERELA+, it is my pleasure to highlight that this publication serves as a platform for sharing our citizen science experiences, lessons, best practices as well as opportunities and challenges in line with the project's objectives and goals. It is my sincere hope that you will find this edition valuable and worth sharing widely. To know more about MANERELA+ and CS-CLMA, visit our social media and online platforms: www.manerela.org and our facebook page: Manerela or visit our offices in Area 14/136, Lilongwe.

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CS-CLMA Feature | About CS-CLMA, with Carolyn Kassam

Citizens Science-Community Led Monitoring (CS-CLMA) is a process whereby 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; analysing results and sharing the insights with wider groups of stakeholders for targeted action and to co-create solutions. Under CS-CLMA, qualitative and quantitative data is systematically collected and analyzed to monitor trends along the HIV cascade for targeted action that will improve the quality of HIV services. The process is led by an organized group of community members or recipients of care (ROC) by acknowledging 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 leading hence promoting data democracy.

MANERELA+ established Community Monitoring platforms in Malawi for People Living with HIV (PLHIV) from the communities to take part in monitoring of HIV services along the prevention; treatment and Care cascade amidst the COVID 19 Pandemic as of 2020. The CS-CLMA platforms, were established in 2 districts of Dedza and Kasungu where 15 health facilities (10 in Kasungu and 5 in Dedza) were targeted in Phase 1. A total of 30 field researchers were recruited from the PLHIV and Key Populations (KPs) communities and trained on data collection, analysis and management. Data is collected on monthly basis from the health facilities using a questionnaire with health care workers (HCWs) as respondents while from the ROC, data is collected through Focus Group Discussions (FGDs) and one on one interviews.

The first phase of the CS-CLMA was implemented from November 2020 to December 2021. CS-CLMA implementation by MANERELA+ in Dedza and Kasungu distrits, registered success by linking ROC with health care workers (HCWs) and clinic managers, district health officials, and showing effectiveness in the collection and sharing of evidence and co-creation of solutions at grassroots and sub-national level. Through the CS-CLMA, MANERELA+ witnessed decline in rates of HIV testing among men who have sex with men (MSM) and female sex workers (FSW) and documented a 73% increase in loss to follow up among adolescent girls and young women aged 15-24 years across 15 health facilities from late 2020 to early 2021.

MANERELA+ and community partners also facilitated meetings involving recipients of care, community leaders, and the Ministry of Health and managers in 15 government health facilities to identify strategies to bring people back into care and mobilise them to undergo HIV test. By linking people to services and empowering communities to demand competency and quality in those services, the CS-CLMA activities resulted in KPs, PHIV, FSW, and MSM to have a greater voice in advocating for health systems to respond to their needs. Community-led monitoring across the 15 health facilities also generated evidence about the successful expansion of multi-month dispensing (MMD) during 2020, in which half of all PLHIV across 15 clinics had received 3-month refills of HIV treatment and another third of PLHIV had received 6-month refills of HIV treatment. The CS-CLMA data also showed where intensified effort is needed to increase the rates of PLHIV offered 6-month refills, and to ensure adequate management of medicine supplies and prevention of medicine stock outs.

For the second phase of the CS-CLMA implementation which commenced in January 2022, MANERELA+ continues to build on the work that started across Dedza and Kasungu districts since 2020. The project continues to monitor the availability and quality of HIV services accessed by the recipients of care and also focus on building relationships with stakeholders. MANERELA+ has partnered with JONEHA to document, disseminate and publicise CS-CLMA. The project has scaled down to 14 facilities (8 in Kasungu and 6 in Dedza) bringing on board community led facilities apart from already targeted government health facilities. The project also continues to use the community treatment obsertory (CTO) model which is guided by the principles of Evidence, Education, Engagement and Advocacy.

Under Evidence building, MANERELA+ identified and trained 28 community members in their identification of PLHIV and KP as field researchers to lead in data collection processes. Data collection for the current phase commenced in May 2022 after seeking approval on re-newal of our ethical approval from the National Health Research Sciences Committee (NHRSC). Retrospective quantitative data was collected from January while qualitative data through in depth interview and focus group discussions was collected from May 2022. The illustrations beside demonstrates steps under the 4 quadrants of the CS-CLMA.

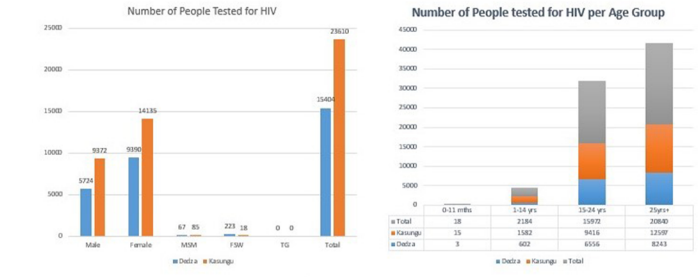
MANERELA+ up the game on Evidence Building

By Harold Kachepatsonga

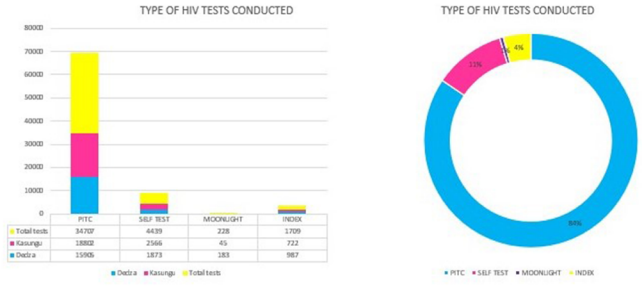
Evidence building is primarily concerned with generation and utilisation of qualitative and quantitative data that in turn shapes the implementation of project's advocacy goals. Methods of reinforcing the synthesis of mixed method is complementary to each other as quantitative data quickly brings out thematic issues to light such decrease in the numbers of PLHIV accessing Results of Viral Load Turnaround Time (RVLT) while the qualitative data illuminates the factors and reasons underlying such. The triangulation of this complementarity forms holistic picture in broader context. Basically, data is collected through Recipients of Care (ROC) in depth interviews Focus Group Discussions (FGDs), Key Informants Interviews (KII) with Health Care Workers (HCWs) and facility quantitative questionnaire.

Between January and June 2022 data collection period, data collectors managed to collect data and monitored 14 health facilities, conducted 28 in depth interviews, conducted 42 Focus Group Discussions (FGDs) and produced 84 monthly health facility quantitative reports in Kasungu and Dedza project impact districts respectively. After data collection and analysis, the CS-CLMA findings revealed among others that availability and uptake of HIV testing increased to 39,014 from 33,610 as of previous quarterly report, Only 11% accessed self-testing, low uptake of HIV testing among young people below 14 years below, majority (84%) still accessing HTS through PITC, less than 1% of the total tested are KP and moonlight services almost non existence at Family Planning Association of Malawi (FPAM).

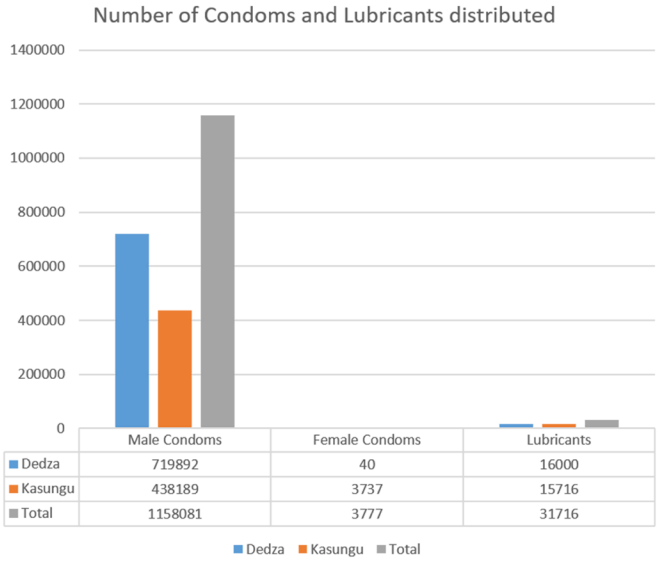
Availability and accessibility of HIV Prevention Services



Access to differentiated HIV Testing Services

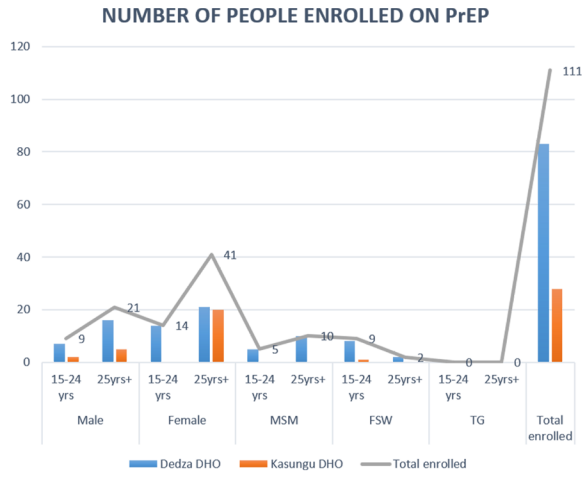


Availability and Uptake of Condoms and Lubricants



- Low demand and uptake of female condoms (0.3%)
- 62% of the condoms distributed in Dedza while 38% Kasungu
- Lubricants only accessed through FPAM

PrEP Uptake



- 3 out of the 14 facilities offering PrEP
- Low demand and uptake of PrEP among the priority population
- Bua Facility has not managed to enroll any client since roll out
- Knowledge gaps among Health Care Workers (HCWs) and Recipients of Care (ROC) around PrEP

Availability and Uptake of Voluntary Medical Male Circumcision (VMMC)

VMMC only offered at 2 facilities Kasungu District Hospital (KDH) and Dedza District Hopital (DHO), Low demand for VMMC, Dedza so far has only managed to reach 3.3% of the consigned annual VMMC target (5834), National circumcision rate at 20.7% (MoH data, 2022)

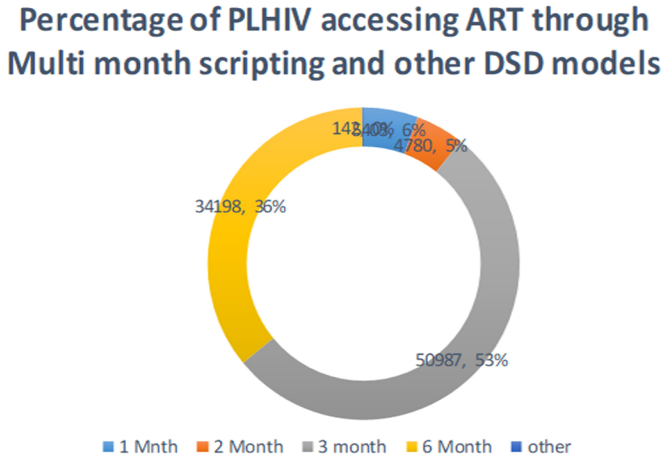
Duration of Results of Viral Load Test (RVLT) Turn around time

- 40.7% within a month,
- 36.3% did not get their results
- 6.7% within 3 months
- 15.9% > 3 months

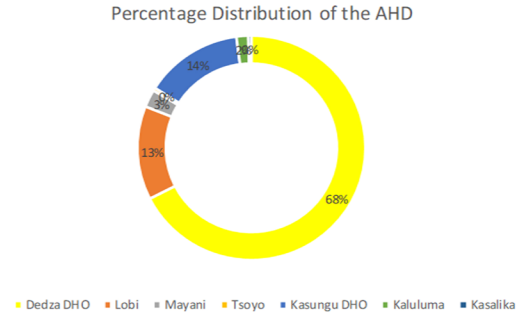
Number of PLHIV Defaulting ART

- 1138 PLHIV (6%) defaulted ART
- Incomplete documentation and the upload of the EMR data
- Distance to the health facilities
- Unreported transfers by clients.
- Individual reasons linked to forgetfulness of refill appointments
- patient fatigue to continue medication
- perceived self stigma and not wanting to be seen accessing ARVs
- Financial barriers related to costs incurred to access ARV.

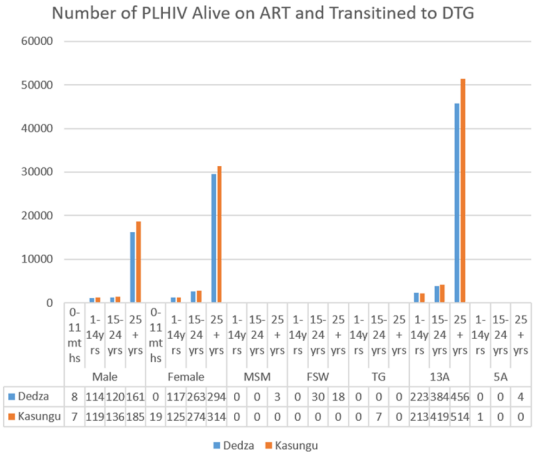
ART Access through Differentiated Service Delivery (DSD) models



Advanced HIV Disease (AHD)



ART Retention; Transition to DTG



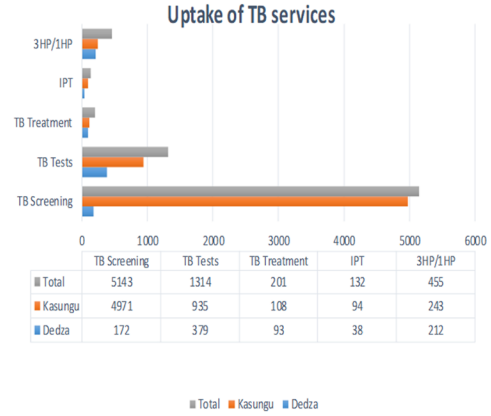
Duration of Results of Viral Turnaround Time (RVLT)

- 40.7% accessed results within within a month
- 36.3% did not get their results
- 6.7% within 3 months
- 15.9% > 3 months
- Turnaround time gaps attributed to distance to testing labs
- Poor sample collection
- Halting of the testing services at the testing labs

Access and Uptake of RVLT

- Lowest uptake as compared to the previous phase only 2226 accessed RVLT against a cohort of over 50000 PLHIV alive on Care
- Acute shortage of DBS kits
- Shortage of cartilage and other necessary equipment within the central testing labs

Uptake of TB services



	TB Screening	TB Tests	TB Treatment	IPT	3HP/1HP
Total	5143	1314	201	132	455
Kasungu	4971	935	108	94	243
Dedza	172	379	93	38	212

Gender Based Violence (GBV) Service Uptake

low data on Sexual Gender Violence (SGV),
Poor documentation as well as linkage to other referral services within the clinical settings,
Challenges with coordination with other support systems and institutions such as welfare of the police victim units where one stop services are not present, Capacity gaps among Health Care Workers (HCWs) on Gender Based Violence (GBV)

Senior Group Wimbe Convinced with Dialogue Meeting Outcome

By Staff Reporter


Senior Group Wimbe

My name is Lusia Msiska. I am Senior Group Wimbe. I would like to report that I am delighted with the outcome of the advocacy engagement accountability where all concerned parties were present in their diversity as Chiefs, Religious Leaders, Health Care Workers (HCWs) Area Development Committee (ADC) and Health Center Management Committee (HCMC) representatives, School Governance Structure representative and the Recipients of Care (ROC). The meeting really achieved its aim of gauging accountability processes and appreciate how services are being offered at Wimbe Health Center as a result of Community Led Monitoring (CLM) findings. As a Chief, I am satisfied with the outcome because all parties committed to resolve the problems along the given timeframe. Should the committed resolutions not going to be implemented, I have powers to summon all gate keepers within my jurisdiction area because the Recipients of Care (ROC) are my subjects. As such, I have authority to tell my fellow chiefs, community gate keepers and duty bearers in my jurisdiction area to do the needful so as to address the problems being faced by our subjects whenever accessing health services at Wimbe Health Center.

Shortage of HCWs Affecting Delivery of Health Services at Chamwabvi Health Center

By Edward Phiri


Fostina Banda,
Chamwabvi Health Centre Incharge

Chamwabvi Health Center serves a population of over 26 thousand people with 1 Clinician against the required benchmark of 6 Clinicians, 2 Nurses against the requirement of 16 Nurses. This situation compromise provision of quality services as a result of shortage of Human Resource for Health (HRH). The Health Facility is also confronted with a small and non-confidential ART consultation with shortage of staff as well. The situation lenders to provision of non-confidential ART services and contributes to high default rate. Meanwhile the facility, is not providing teen club services and Viral Load Testing has not been routinely provided for the past 6 months (January to June 2022) due to unavailability of HIV Diagnostic Assistant (HAD) and Dried Blood Spots (DBS) Kits.

In an interview with CLM media and documentation team, Health Facility Incharge namely Fostina Banda, said that “CLM has created a space for dialogue between Ward Councilor, Chiefs, Community Members, Recipients of Care (ROC), Health Care Workers (HCWs) and Duty Bearers to discuss on hitches affecting Recipients of Care when accessing services and thereafter agree on solutions.”

Charles Mndinda, Ward Councilor for Chibophi area, said there are short term and long term solutions. For example issues to do with scarcity of battery for ART weighing scale, we have agreed that we are going to request community members to contribute money to buy batteries, whereas, long term solutions, we are going to escalate the issues to the Member of Parliament who is also Minister of Health, Honourable Khumbize Kandodo Chiponda and the Director of Health and Social Services (DHSS) to consider construction of ART consultation room, finish construction of HCWs Houses, allocate additional HCWs and, we are also going to do community awareness and sensitization on the rights of People Living With HIV (PLHIV) so as to address stigma and discrimination prevailing at the facility due to unavailability of confidential infrastructure while awaiting for long term solution.


Charles Mndinda
Chibophi Ward Councilor

HCWs Oriented on SOGIE in Dedza and Kasungu Districts

By Harold Kachepatsonga

As part of ensuring that Key Populations (KP) in Dedza and Kasungu districts are ably accessing improved, quality and affordable services within the predicaments of universal health coverage lines and values of KP friendly health services and ensuring that no one is left behind in the Malawi HIV and AIDS response amidst existing inequalities and emerging pandemics, MANARELA+ undertook orientation trainings on Sexual Orientation, Gender Identify and Expression (SOGIE) targeting Health Care Workers (HCWs) in Dedza and Kasungu districts. The primary objective of the training was aimed at equipping HCWs with knowledge and skills on how best to serve KPs in a friendly manner.

The training among other areas equipped HCWs to understand the difference between sex, gender identity, gender expression and sexual orientation, provided knowledge and information on how gender norms and other societal norms affects us all and contribute to stigma and discrimination against KPs when accessing services and the activity went a mile further to enhance their awareness of why it is important for HCWs to be part of the solutions to preventing and responding to violence that occurs among KPs.

In an interview with Citizens Science-Community Led Monitoring and Advocacy (CS-CLMA) media and documentation team MANERELA+ Project Officer, Harold Kachepatsonga reported that as one way of improving access to services among KPs, health facilities have assigned a Health Care Worker (HCW) responsible for handling and assisting Key Populations (KP).

“As we cross the bridge to the other side, it is expected that access and utilisation of services by KPs will increase in Dedza and Kasungu districts in the targeted health facilities in so doing contributing to the achievement of 95-95-95 global targets. Kachepatsonga adds.

MANERALA+ Drills ROC on Treatment Literacy

By Carolyn Kassam

Education is a key project component of the Citizens Science whose focus hinge on human rights specifically the right to health, ensuring all people are aware of the standards of care they are entitled to receive. Implementation of education is designed based on knowledge gaps gathered and evidence that emanates from Citizens Science-Community Led Monitoring (CS-CLMA) findings that mainly centers on treatment literacy training and awareness and sensitization on HIV and AIDS, TB, COVID 19 and other related care and support issues.

It is against this background that MANERELA+ conducted a series of Treatment Literacy trainings targeting Recipients of Care (ROC) on HIV and related co-morbidities, guidelines and standard of care. The events were held from 18th to 30th of September 2022 reaching a total of 280 ROCs in the diversity of Adolescent Girls and Young Women (AGYW), young people, People Living with HIV (PLHIV), Female Sex Workers (FSWs), Men who have sex with Men (MSM), Male Sex Workers (MSM), Transgender and Faith Leaders and Religious Leaders Living with or Personally Affected with AIDS in 14 targeted health facilities in Dedza and Kasungu districts respectively.

The capacity building training was architectured to increase self-empowerment, feelings of self-confidence and personal control over the management and treatment of HIV, increase understanding of the science around HIV to foster informed decision making around personal health, to demand for ROC rights in the event of absence of proper care and increase understanding of the reasons for optimum adherence to treatment coined around improved health outcomes and longevity.

MANERELA+ Program Director Carolyn Kassam ascertained that treatment literacy information helps PLHIV to act, remain healthy and to hold government accountable on access to the right drugs. Treatment literacy work is essential to the development of empowered activists who become important allies for HIV programmes and support the implementation of collaborative efforts.

The Recipient of Care (ROC) who are the primary beneficiaries of the trainings also testified that the training was beneficial to them. Miriam Kibu, a ROC at Mayani Health Centre from Traditional Authority Tambala said that, she learnt new information on the Science around HIV, ART current regimens and HIV protocols and treatment adherence monitoring protocols. “With the training we have received, I will reach out to fellow ROC with the information so that they get tested for Viral Load (VL) in a bid to ensure that they live healthy. Lastly, I would like to appeal to MANERELA+ and other organizations to continue to organize treatment literacy trainings so as to reach many ROC.” Kibu Said.

Numeri Chagalamuka, Faith Leader

CLM Findings Spotlights Barriers Suffocating HIV and AIDS Fight in Kasungu

By Edward Phiri

Community Led Monitoring (CLM) findings have spotlighted knowledge gaps on Pre-Exposure Prophylaxis, Voluntary Male Medical Circumcision (VMMC), Female Condoms and Lubricants as main barriers in the fight against HIV and AIDS in Kasungu district.

This was disclosed at Bua Health Centre during an advocacy meeting organized by the Malawi Network of Religious Leaders Living with or Personally Affected by HIV and AIDS (MANERELA+).

The purpose of the meeting was to enable HIV and AIDS Recipients of Care (ROC) to present CLM findings to duty bearers and other stakeholders and agree on how to resolve the issues with given timeframe.

This follows the introduction of PrEP, VMMC, Female Condoms and Lubricants by the Ministry of Health and Population as one way of curbing the further spread of HIV towards the attainment of epidemic control through the last mile by 2030.

During the meeting, ROC lamented lack of awareness about services the health facility is providing to prevent new HIV infections. Other challenges cited included lack of knowledge on Tuberculosis (TB) screening and preventive therapy, delays of Viral Load (VL) testing results, lack of documentation for sexual gender-based violence and knowledge gaps on the changes of provision of bactrim drugs as part of cotrimoxazole preventative therapy (CPT).

Numeri Chagalamuka, a representative of faith leaders at the meeting, said despite VMMC services being available at Bua Health center, a larger population of the residents is not accessing them because of myths that circumcision is for Muslims.

Chagalamuka said there is a need to triple efforts aimed at demystifying such myths in order to address the problem.

In her contribution, Fanny Kamchamcha, a member for Tithokoze Support Group, pleaded with Health Care Workers (HCWs) to start targeting all ART clients with TB screening services.

Lena Kalinga, ART Nurse

The health facility's nurse and ART provider, Lena Kalinga, encouraged communities to embrace health seeking behavior, stressing that this is key in preventing or treating diseases.

Kalinga asked community and religious leaders to help in educating and sensitizing people through health talks and community sensitization meetings.

MANERELA+ Director of Programs, Caroline Kassam, said her organization is ready to provide support for training the newly elected Health center Management Committee (HCMC) on its roles and responsibilities.

MANERELA+ is a network of Religious Leaders Living with HIV or Personally Affected with HIV and AIDS. Established in 2004, the organization advocates for policies that mitigate the impact of the pandemic and curb further spread of the virus.

With membership from both Christian and Muslim Community, Faith Leaders take a leading role in advocating for the elimination of factors that lead to further spread of the virus including child marriages.