

THE CITIZEN VOICE

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Newsletter

DEDZA DISTRICT HOSPITAL BENEFITTING FROM INTEGRATED ONE STOP SERVICE DELIVERY

Dedza district Hospital benefitting from one stop intergrated service delivery.



FOREWORD



D. Moen

EXECUTIVE DIRECTOR

Greetings and blessings from the Creator as you enjoy reading the second edition of Citizen Voice Newsletter from Malawi Network of Religious Leaders Living with or Personally Affected by HIV and AIDS (MANERELA+). The newsletter profiles CitizenScience Community Led Monitoring and Advocacy (CS-CLMA) project, which MANERELA+ is implementing with financial and technical assistance from the International Treatment Preparedness Coalition (ITPC).

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 (MSWs), Men who have Sex Men (MSM), Transgender, Faith Leaders Living or Affected by HIV and Health Care Workers (HCWs). The project has four guiding principles in areas of Education, Evidence Building, Engagement and Advocacy.

Before we go further, I would like to share with you; our esteemed readers about MANERELA+'s profile. Malawi Network of Religious Leaders living with or Personally Affected by HIV and AIDS (MANERELA+) is a faith-based organization founded in 2001, with a network membership of over 15000 religious leaders and faith community members spread across the 28 districts in Malawi. The network 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, Networking, Advocacy and Lobbying.

Our strategic areas of programme intervention is premised on HIV, TB, Malaria, Sexual Reproductive Health and Rights (SRHR), Gender and Human Rights, Maternal Health, Lesbian, Gay, Bisexual, Transgender, Queers and Intersex (LGBTIQ) programming from Human Rights perspective, Key Populations (KPs) programming from Public Health Approach, Nutrition, Food Security, Livelihoods and Emergency Response.

The Board of Directors govern MANERELA+ 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 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.

EDITORIAL

Welcome to the second edition of Citizen Voice newsletter. We continue to learn from your valuable feedback. During this quarter, we had an opportunity to learn more about how poor infrastructure affect privacy, confidentiality and treatment adherence, benefits of integrated service delivery, recipients of care advocacy around delays by ministry of health to approve Community ART Groups as one of the differentiated service delivery models and how support groups are helping in contributing to keeping people in care by bringing those who interrupt treatment back to care.

The Malawi 2018, HIV and AIDS Prevention and Management Act part 5 says a person living with HIV has the right to privacy, dignity, physical integrity and confidentiality with regard to information concerning his/ her HIV status. In addition, the Act says that when operating an ART clinic; there is need for consideration of strategies to ensure that privacy and confidentiality is preserved. However, in Kasungu and Dedza districts; infrastructure has hindered some people living with HIV from receiving treatment resulting in registering higher rates of those who interrupt treatment at the facility. Despite having multi-months refill, some people do not feel comfortable coming in an open place for ART services.

Integrated service delivery (one-stop center) assist people living with HIV with the entire spectrum of care, often including services for non-health-related issues and other barriers to care in order to address the needs of their specific populations. The integrated service delivery model makes it easier for people to access needed services and support by limiting the number of locations they need to travel to. On a positive note; in both Kasungu and Dedza, where CS-CLMA project is being implemented, some facilities have adopted the model which has resulted in an increase in the uptake of services and reduction in stigma and discrimination.

In 2012 Community ART Groups (CAGs), a community-based differentiated Service Delivery (DSD) model of antiretroviral therapy (ART) was piloted in Thyolo District in Malawi as a way to overcome recipients of care barriers to accessing treatment, and to decrease healthcare workers' workload. CAGs are self-formed groups of recipients of care on ART taking turns to collect ART refills for all group members from the health facility. One of the components in CS-CLMA project is sensitizing the masses on differentiated service delivery models. In both Kasungu, and Dedza recipients of care and HCWs speak favorably about the practical benefits of CAGs. Benefits for recipients of care include a reduced frequency of clinic visits, resulting in reduced transportation costs and timesaving. HCW benefits include a reduced workload. Additionally; peer support is perceived as a benefit of the CAGs allowing not only sharing of the logistical constraints of drug refills, but also enhanced emotional support. However, recipients of care bemoan delayed approval of CAGs as a DSD model.

On the other hand; support groups linked to each health center is critical to provide counselling and support services to people prior to testing, post testing, pre-treatment, and those struggling on treatment or re-engaging in care. This is especially true for key populations who are at higher risk of facing stigma and discrimination in this process. The number of key populations who disengage from care continues to be high as they become "treatment fatigued", stop ARVs, and even die. Much more needs to be done to provide counselling, psycho-social support and other mental health services to prevent this "pill fatigue" from taking place. Through Citizen Science Community Led Monitoring and Advocacy (CS-CLMA) project implemented in Kasungu and Dedza districts, Female Sex Workers (FSW) at Family Planning Association Malawi (FPAM) clinic in Kasungu district facilitated establishment of a support group called "Titukulane-Tokha FSWs" to advocate for HIV testing and bringing back to care those who interrupt treatment.

We therefore join hands with other civil society organizations in Malawi to advocate for increased effective participation of the people living with HIV community in decision making to ensure that health services recognize their rights and respond to their needs. It is our hope that government through the Ministry of health will continue to address issues raised by communities through the CS-CLMA project in the country.

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ONE STOP CENTER: BENEFITS OF INTERGRATED SERVICE DELIVERY

BY CHRISTER KALUKUSHA

In many parts of the world, stigma associated with HIV hinders recipients of care from seeking health care and the support they need from health facilities. Despite HIV being known in Malawi in 1985, some people still have a negative attitude towards people living with HIV which discourages recipients of care from publicly or freely accessing healthcare services out of fear of being discriminated.

To create an environment where recipients of care are without fear when it comes to accessing Anti Retroviral Treatment (ART) services, an integration of services is being adopted in some parts of the health sector. This is an approach that aims at providing comprehensive care and increasing uptake of services by combining different health services under a single roof, or facility. Common integrated services include HIV care services, Family Planning, Tuberculosis (TB), Sexually Transmitted Infections (STI's), Malaria and Non-communicable diseases such as Diabetes.

When it comes to HIV, Anti Retroviral Treatment (ART) is offered together with other HIV care related services like Sexually Transmitted Infections (STI's), Tuberculosis, Cervical Cancer and Family Planning to create a sense of confidentiality for the stigmatized.

Family Planning Association of Malawi (FPAM) Health Facility in Dedza district



Integration provides room for privacy-Gama

is one of the facilities that adopted this service at its facility. One of the service providers, Steven Gama describes integrated service delivery model of offering health care including ART as a preferable approach that comes with a number of benefits.

“All our services are provided in one room and that includes; Sexual Reproductive Health Services, STI's diagnosis and treatment, malaria diagnosis and treatment as well as ART, we feel this is time saving because recipients of care do not need to move from one room to another to access a service if they are looking for various services. Integration is also much helpful to recipients of care and key population because it creates a room for privacy to them because some prefer not to be known

that they are on ART,” said Gama.

A study conducted by United States Agency for International Development (USAID) in 2022 on “achieving equitable access to end AIDS” indicates that key populations have inequitable access to safe, effective and quality HIV services and face disproportionate levels of stigma and discrimination among others that prevent them from getting the care they need hence having an integration of health care services; helps to minimize their concerns.

A Key population affiliated to Female Sex Workers Association (FSWA) who is also a recipient of care at FPAM health facility in Dedza explained how she favours integrated service delivery.

“Being a sex worker, it is always difficult for us to openly declare our HIV status for fear of putting our business at risk. We do not wish people to know our HIV status especially our clients because we put ourselves at risk of losing customers. Therefore, I had to transfer from one health facility where ART had a special room and everyone could judge about your HIV status if they see you entering that room. So, I started receiving treatment here at FPAM because I was assured of privacy and confidentiality that I needed when it comes to my HIV status. I also do not want the public to know why I’m visiting the health facility because us sex workers have so many health care services that we seek from health facilities and having rooms of such services far apart makes it hard for us to feel free in accessing all the services for fear of being seen by others,” she said.

Mwayi Kholiyo, an expert client at Dedza District Health Office (DHO) and a Young People Living with HIV (Y+) member added that having related health services such as HIV Testing Services (HTS), ART, TB, STI’s, Viral load testing and cervical cancer screening under a single roof helps them to be helped easily and quickly.

“We do not need to move up and down for viral load testing, TB or ART because these services are provided in one building at the DHO and this saves our time and we are easily helped for the other services even when the sole purpose of visiting the hospital was for ART only but because the rooms for the other HIV care services are adjacent to each other we get the chance to seek for those as well without being lazy,” said Kholiyo.

Dedza District Hospital ART Coordinator, Hiva Mheviwa said having HIV care services in one building helps service providers to assist recipients of care accordingly.

“Before these services were provided in a single building, it was hard for us to provide the adequate care needed to the recipients of care in the sense that when referred to go for TB testing or viral road most of them never went to get that service. Once they go out of the ART room they would leave for home for fear of being observed by many and this made us feel inadequate as service providers that we are not providing enough care to recipients of care,” said Mheviwa.



Idah Katimba



We do not need to move up and down for viral load testing, TB or ART because these services are provided in one building...

TO PG. 8

CCG LEADER WARNS HCWS THAT ADDICTION TO SMART PHONES CAN COST PEOPLE'S LIVES

BY STARPHEL SITHOLE

The Chairperson of the Community Consultative Group (CCG) in Kasungu Billie Msokera has pointed out that while smartphones enhance efficiency of Health Care Workers (HCWs) they can on the other hand; if not handled carefully distract them from focusing on saving people's lives especially when they become so addicted to the gadgets.

"It pains when you see very ill recipients of care waiting for too long to be attended to by a service provider who is wasting his or her time on petty personal conversations or keeping scrolling on social media instead of serving recipients of care," said the chairperson at the CCG meeting held at Kasungu Boma on 22nd June 2023.

The CCG is a governance structure initiated by the Citizen Science-Community Led Monitoring and Advocacy (CS-CLMA) project which is jointly being implemented by the Malawi Network of Religious Leaders Living with or Personally Affected by HIV (MANERELA+) and Network of Journalists Living with HIV (JONEHA). The project is funded by the Bill and Melinda Gates Foundation through the International Treatment Preparedness Coalition (ITPC). The CS-CLMA is being implemented in Kasungu and Dedza districts; targeting 14 facilities.



Kasungu CCG Chairperson.



28% surveyed admitted to perusing social media

A 2021 study on Improving Access to Services in Malawi by Robert Msokwa says timely access to health care can substantially reduce mortality. It highlights the United Nations Sustainable Development Goal 3, target eight which recommends that provision of quality care to all must include usually underserved groups by 2030. On barriers to seek health services, poor health workers' attitude at (5%) is mentioned

in addition to others such as lack of drugs and medical supplies (35%), long distance (25%), lack of health care workers (25%) and poor hospital facilities (10%).

Another survey performed by the Screen Education shows that employees waste, on average, more than two hours per day using their phones and that 14% of respondents said workers' distracted by mobile devices

at some time caused workplace accidents, many of which resulted into injury or even death.

A 2017 study by Robert Half Talent Solutions and Office Team uncovered just what employees are doing on their phones instead of their workplace responsibilities: Most are using their mobile device to check their personal email, while an additional 28% surveyed admitted

to perusing social networks. Sports or entertainment sites, mobile games and online shopping are among the other things workers admitted they use their mobile devices for on the clock.

The study observes that given people's attachment to their phones, it is hardly surprising that these devices are such a common source of distraction at work

"It's understandable that employees may occasionally use their mobile devices or attend to personal tasks during business hours, but these activities can easily become big distractions," said Brandi Britton, Executive Director for Robert Half's contract finance and accounting group, in a statement when the survey was released.

FROM PG. 6

Benefits Of Intergrated Service Delivery

Dedza DHO provides partial integration services where related services are supplied in a single building but in distinct rooms. Mheviwa therefore said the hospital has also incorporated Differentiated Service Delivery (DSD) for those who still feel infringed with the partial integration of services.

According to the International AIDS Society, DSD is a client centred approach that simplifies and adapts HIV services across the cascade to reflect the preferences, expectations and needs of people living with and vulnerable to HIV, while reducing unnecessary burdens on the health system.

Malawi Network of Religious Leaders Living with

or Personally Affected by HIV (MANERELA+) through its project; Citizen Science Community Led Monitoring and Advocacy (CS-CLMA) aims at improving HIV service delivery and uptake by targeted populations with DSD being one of the approaches of increasing uptake of services.

CS-CLMA is being implemented in selected health facilities in Dedza and Kasungu districts. Dedza DHO being one of the health facilities where the project is being implemented, the ART Coordinator said DSD helps to reduce number of visits of recipients of care to the hospital.

"We offer teen clubs and Male Adherence ART clinic (MAAC) as part of DSD where a grouping of people within the same age group receive care together which is usually conducted over the weekend once a month to ensure privacy and reduce the number of visits to the hospital," He said.

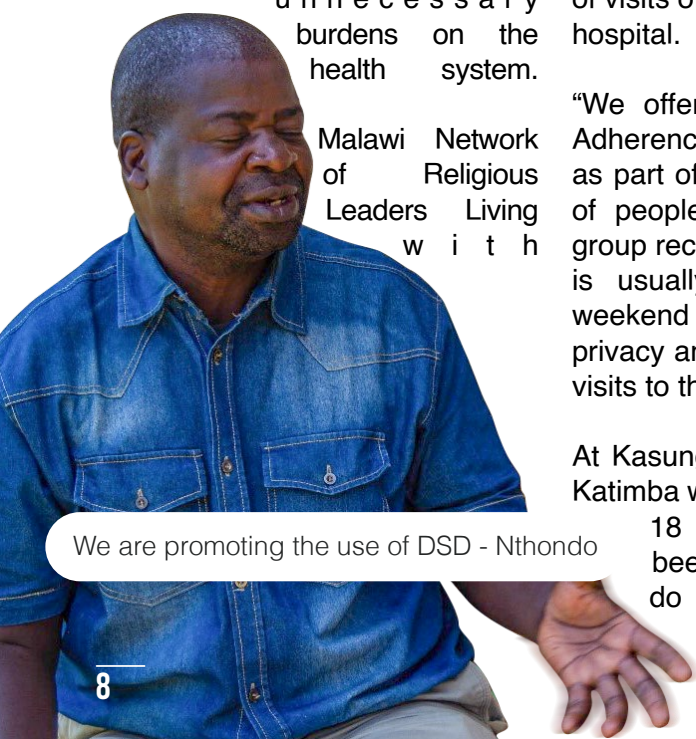
At Kasungu district hospital, Idah Katimba who has been on ART for 18 years said DSD's have been a life saver to those who do not want other to know

they are on ART since ART has a special space at the DHO where everyone can observe who is going there hence DSD's help to relieve them from their fears of being known to be on ART through frequent visits to the hospital.

Twaibu Chipwere, Clinical Officer at Kasungu District Hospital added that, having both integrated and DSD models of providing care is ideal in helping to address stigma and discrimination as they both ensure privacy of recipients of care in one way or the other.

CS-CLMA supervisor in Kasungu Joseph Nthondo said MANERELA+ is promoting the use of DSDs through the project.

"We are mobilising support groups so that they should know the different types of DSDs and choose the ones which are convenient to them. We also engage with health workers because many of them are aware of these DSDs but are not offering them in their respective facilities. So, we engage them so that they should arrange with the recipients of care and begin offering the services," said Nthondo.



We are promoting the use of DSD - Nthondo

A DECLINE IN ART DEFAULTING ACHIEVED DESPITE LONG DISTANCE AND OTHER CHALLENGES

BY JOSEPH GANTHU

There has been a recorded decline in number of people living with HIV on ART defaulting from 1,138 between January and March to 757 in April and May 2023 in Kasungu District where Citizen Science-Community Led Monitoring and Advocacy (CS-CLMA) project is working. This is a positive contribution to the National Strategic Plan 2020-2025 (NSP 2020-25) which among others; aims at increasing the number of people kept on care and

at 12 months from 72% in 2019 to 85% in 2025. The Monitoring and Evaluation (M & E) Officer Tayana Tembo from the Malawi Network of Religious Leaders Living with or Personally Affected by HIV (MANERELA+) on 22nd June, 2023 told the Community Consultative Group (CCG) meeting at Kasungu Boma that the achievement was realized through various interventions such communities and health service providers.

people living with HIV and key populations at district level.

Among several factors that contributed to defaulting between January and March the M & E Officer cited long distance to health facilities, unreported self-transfers by recipients of care, individual reasons linked to forgetfulness of refill appointments, recipients of care fatigue to continue medication, perceived self-stigma like not wanting to be seen



Community Consultative Group (CCG) meeting at Kasungu Boma

treatment through the ART program among adults, adolescents and children which is called retention and adherence. The NSP is has targeted keeping 1,015,000 people living with HIV on care and treatment by 2025, increasing children's ART coverage from 68% to 85% and improving retention in HIV care and treatment

The meeting which was conducted by MANERELA+ with funding from the Bill and Melinda Gates Foundation through the International Treatment Preparedness Coalition (ITPC). brought together 15 representatives from relevant institutions and groups such as health facilities, Civil Society Organizations (CSOs), implementing partners,

accessing ARVs and financial barriers due to out of pocket costs incurred when accessing free ARVs.

The challenge of long distance as a barrier to accessing ART has been well noted by the PEPFAR Country Operational Plan 2023 (COP 23); as it quotes a study by Lam and Eaton, 2021 on Priority locations

for consideration of additional ART sites to reach people living with HIV who have long travel time to existing facilities. The report shows that there were an estimated total of 207,000 people living with HIV residing in greater than a 60-minute walk from an existing ART facility and 74,000 people living with HIV having to travel a distance of greater than 90 minutes from an existing ART facility.

COP 23 therefore recommends the PEPFAR program to scale up the T=T interventions and

dissemination of messages in high burden districts with limited interventions, community ART distribution, community ART Pick up points and support implementing Partners interventions towards bringing Differentiated Service Delivery (DSD) closer to recipients of care such as through Community ART Groups. Tizirombo tochepe = Thanzi (T=T) is a nationally contextualised framework based on the undetectable equals un-transmittable (U=U) global concept that promotes viral

load testing, treatment literacy and adherence with an aim of reducing new infections to achieve epidemic control through viral suppression. The T=T Campaign Strategy (2022-2026) was launched in Malawi by the Minister of Health in Balaka district on 19th June 2022.

CS-CLMA project is being jointly implemented by MANERELA+ and the Network of Journalists Living with HIV (JONEHA) at 14 facilities in Kasungu and Dedza districts.

FROM PG. 8

Benefits Of Intergrated Service Delivery

A 2021/22 study called “Getting to the Heart Of Stigma in Malawi” commissioned by the International AIDS Society noted that people living with HIV, Service Providers and Policy makers agreed that integration helped to reduce stigma and discrimination. However; despite joint calls by the WHO and Ministry of Health in Malawi

as per the 2019 Review Report; Malawi is yet to fully integrate. This is so because currently; integration is adhoc, unstructured and un-coordinated efforts by some health facilities. One service provider respondent said it all about Malawi’s status on integration and known benefits:

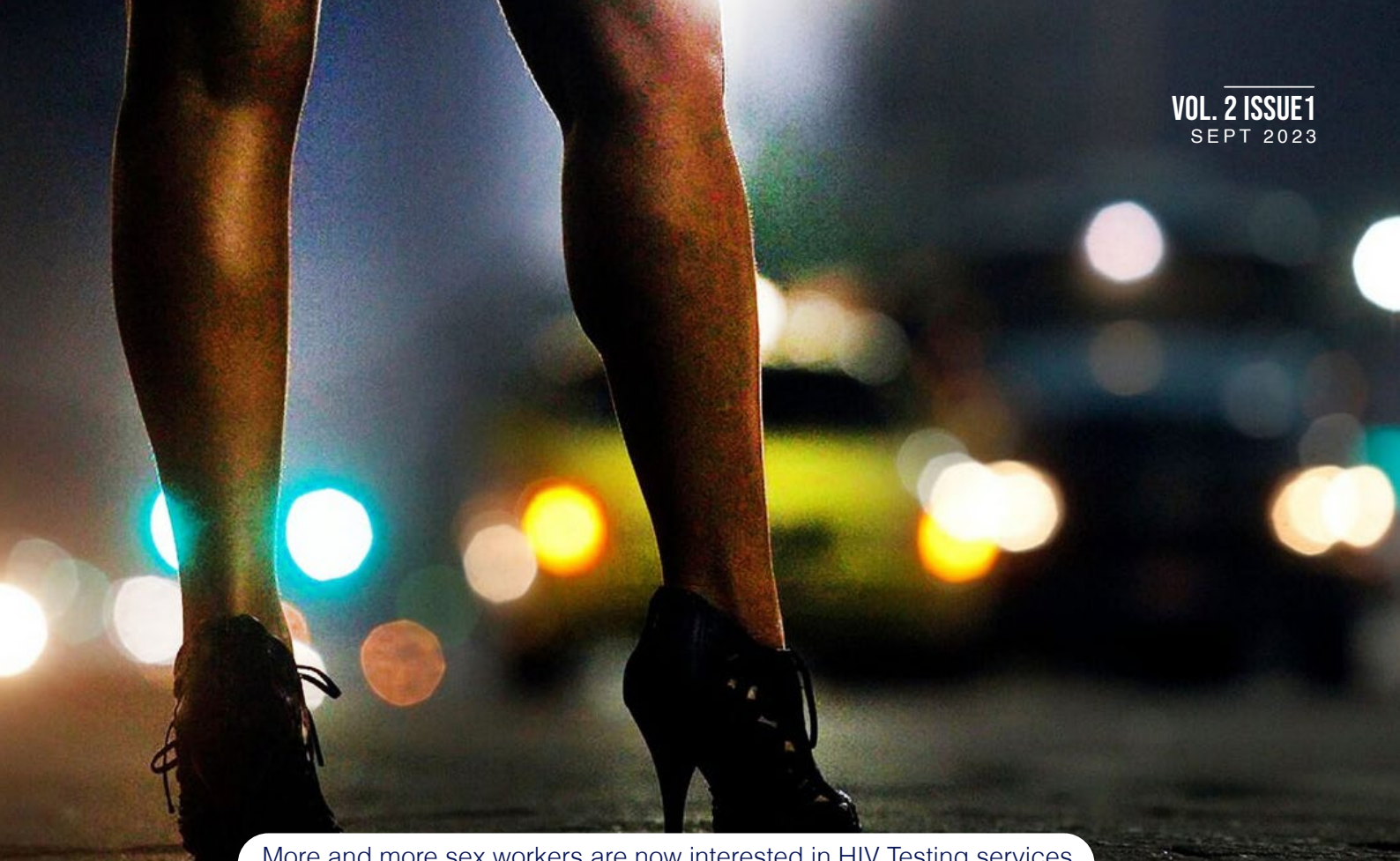
“Since we are moving towards integration; cases of stigma have reduced. But unfortunately we have not yet fully integrated, we are doing it in a staggered approach. There are a few health care facilities that have adopted the system”.

SEX WORKERS DEVELOP AN INTEREST IN HIV TESTING SERVICES

BY JOHN FOLENA

Female sex workers (FSWs) in Kasungu particularly around health facilities where Citizen Science-Community Led Monitoring and Advocacy (CS-CLMA) project is working have developed a strong interest in HIV Testing Services (HTS) as demonstrated by an increase from 18 between January and March to 189 in April to June 2023 according to a report presented and validated at the Community Consultative Group (CCG) meeting on 22nd June 2023 at Kasungu Boma.

The Chairperson of Kasungu CCG Billie Msokera attributed the appetite for HTS among sex workers to sensitization exercises by the CS-CLMA in collaboration with other partners on the benefits of HTS and formation of sex workers support groups. He expressed pleasure over the rising number of people accessing the service; pointing out that doing so reduces chances of transmitting the virus.



More and more sex workers are now interested in HIV Testing services

However, the Monitoring and Evaluation (M & E) Officer Tayana Tembo from the Malawi Network of Religious Leaders Living with or Personally Affected by HIV (MANERELA+) bemoaned the non-existence of HTS among young people aged below 14.

MANERELA+ and the Network of Journalists Living with HIV (JONEHA) are jointly implementing CS-CLMA project with funding from the Bill and Melinda Gates Foundation through the International Treatment Preparedness Coalition (ITPC) at 14 selected facilities in Kasungu and Dedza.

On male versus female populations in accessing the services; the meeting observed that males lagged miserably behind females; a situation that demands advocacy targeting males. The meeting also identified the need for reviving Moonlight and Index Testing Services

as part of the Differentiated Service Delivery (DSD) in the HTS program to reach other groups such as key populations including female sex workers.

The Malawi National Strategic Plan (NSP) for HIV and AIDS of 2020-25 says HTS aims at increasing the number of people living with HIV identified and linked to timely prevention, care and treatment services. The NSP indicates that the proportion of unidentified people living with HIV in the population is estimated to be at 2% and to expand case finding, Malawi will have to scale up active index testing and assisted HIV self-testing using community-based cadres.

Among other strategic interventions the NSP cites strengthening of integrated and targeted facility and community testing of all key and priority populations, improving the quality of HTS diagnoses through better planning, management,

and quality assurance systems, strengthening linkage of HTS clients to comprehensive prevention and treatment services.

The NSP is targeting men, children, FSWs and their clients, Men having Sex with Men (MSM), refugees, migrant workers, prisoners, students of higher education institutions and colleges, and people in uniform in a differentiated manner. It says to reach these key and priority populations, HTS will be fully integrated with Sexual Reproductive Health (SRH) and other key health services.

POOR INFRASTRUCTURE AFFECTING PRIVACY AND CONFIDENTIALITY

BY STARPHEL SITHOLE

Among other factors associated with non-adherence from antiretroviral therapy (ART); is the fear of disclosing an HIV status to prevent stigma and discrimination. Stigma and discrimination can be facilitated by a health infrastructure whose service space is not spacious for privacy and confidentiality. Recipients of care ask for addressing the problem in health facilities where it exists.

Kaluluma Health Center located in the north of Kasungu district is one of the facilities under the Citizen Science Community Led Monitoring Advocacy (CS-CLMA). The facility has inadequate space for offering services which is affecting privacy and confidentiality of recipients of care on ART; the same with Kasalika Health Center in the same district.

According to Kaluluma Health Centre Clinical Officer Gift Chilangiza, a spacious room is needed for the provision of Anti Retro-viral treatment (ART) and other HIV services since the current space is small and some people do not find it comfortable standing on a queue which sometimes extends outside due to lack of space.



Small space and open ART waiting area f

“Infrastructure has hindered people living with HIV from receiving treatment resulting into registering higher defaulter rates at the facility. Despite having multi-months refill some people do not feel comfortable coming on an open place for ART services.” Said Chilangiza.

A Female Sex Worker at Kaluluma Health Center, who seeks health care at the facility concurred with the health worker saying, the issue of privacy is very crucial when it comes to ART due to the nature of their work.

“Kaluluma Health Center does not have a fence. On top of that the waiting space for ART is too small which gets us exposed as the facility has specific days for ART clinic and many people come at once in large numbers, prompting them to wait outside for long.

So, being sex workers, we do not want to be seen on an ART line hence this leads to treatment interruption as many of us do not like to be exposed,” she said.

Kelvin Banda a youth from Titha Youth Club a member of men having Sex with men at Kasalika Health Center bemoaned inadequate ART room at the facility as it also affects the services.

“I am one of the men having sex with men and a recipient of care which makes me a frequent visitor to the health facility. However, when I come to the facility, I have to wait for hours outside which exposes me to the public. This makes me feel stigmatized and stop coming to the facility for the services.” Banda narrated.

The Malawi 2018 Act on HIV and AIDS Prevention and Management part 5 says a person living with HIV has the right to privacy, dignity, physical integrity and confidentiality with regard to information concerning his/ her HIV status. In addition; the Act says that in implementing the ART clinic there is a need for consideration of strategies to ensure that privacy and confidentiality is preserved.



for HIV services at Kasalika Health Centre

AFTERMATH OF COVID 19 - STILL BITING SOCIALLY AND ECONOMICALLY

BY JOSEPH GANTHU

While Malawians are celebrating a long silence of COVID 19 as a deadly disease that has claimed thousands of lives in the country and as millions of people around the globe succumbed to the pandemic, its aftermath is still socially and economically being felt by community members across the country as reported by Sandra, a Kasungu based participant in the ongoing three-year project called Citizen Science Life Maps.

Citizen Science Life Maps is a three-year qualitative, longitudinal research project being implemented in South Africa and Malawi under the International Treatment Preparedness Coalition (ITPC)

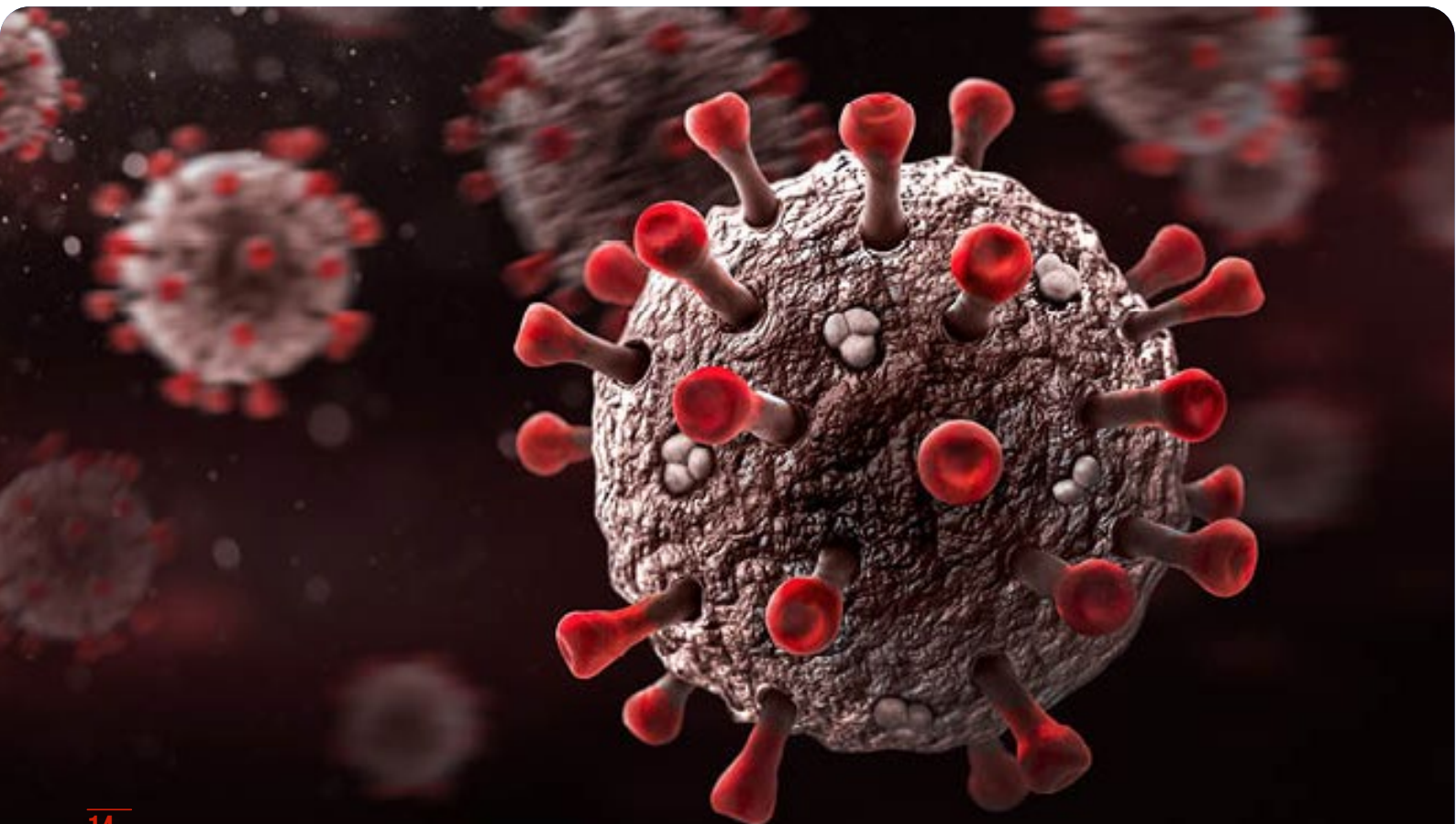
with funding from the Bill and Melinda Gates Foundation. Specifically, Life Maps is a community-based project that uses participatory activities to empower recipients of care to report directly on their needs and experiences while seeking healthcare access and provisions.

Sandra recalled that prior to the pandemic as a person living positively with HIV she was in one of the support groups in which she spiritually and physically got support from colleagues within the group. She bemoaned that the group disappeared following COVID 19 prevention guidelines that barred social gatherings like physical meetings.

Chairperson for the Network of Journalists Living with HIV (JONEHA) David Mhango called on Civil Society Organisations (CSOs), Implementing Partners (IPs), Health Officials, and people living with HIV to revive support groups in communities as an intervention among others that can contribute towards reducing high defaulter rates.

Mhango observed that based on personal experiences shared by People Living with HIV at various meetings; it has shown that members who participate in support groups are hardly categorized as defaulters

[TO PG. 17](#)



SUPPORT GROUPS HELPING TO BRING BACK DEFAULTERS TO CARE

BY STARPHEL SITHOLE

An HIV diagnosis can be very isolating as people frequently hide themselves from the world after testing positive, due to stigma and discrimination associated with such. This effectively prevents people living with HIV from accessing quality services or interrupt treatment.

Through Citizen Science Community Led Monitoring and Advocacy (CS-CLMA) project implemented in Kasungu and Dedza districts, Female Sex Workers (FSW) at Family Planning Association Malawi (FPAM) in Kasungu district facilitated and formed a support group called “Titukulane-Tokha FSWs” to advocate for HIV testing and bringing back defaulters to care. The support group was formed in the fourth quarter of the project in the year 2022 through the initiative of Malawi Network of Religious Leaders personally affected and infected with HIV (MANERELA+) data collector.

The data collector organized the support group to help other key populations because they are at a high risk of contracting the virus, and to advocate for HIV preventive measures and trace defaulters.

“Being a sex worker, there are many things that hinders us from accessing HIV services such as change of hot spots, fear of meeting our clients at the facility and excess drinking of beer. Understanding these factors, when MANERELA+ came in, it explained to us how our friends help each other to remain on care and this made me adopt the idea of forming a support group with the aim of encouraging each other and help bringing back to care our fellow female sex workers and others who have defaulted so that we can all live a healthy life. This support group is also helping to achieve the goals and objectives of the CS-CLMA project.” She narrated.

The FPAM Clinical Officer In-charge for Kasungu district, Anthony Phiri commended the newly formed support group as it has helped reduce defaulter rate.

“We were surprised when we heard about the support group because as a facility, we never initiated it. This group has so far reduced defaulters at our facility through its door-to-door follow-up and it directly works with us through their chairperson. I will also commend the CS-CLMA project as it has empowered recipients of care and they are now taking lead in finding solutions to the challenges faced in the facilities. As we speak this group has brought back to care 5 people living with HIV who defaulted and of that number 4 are FSW and 1 is a youth in two months.” Phiri narrated.

LIFE MAPS TO LINK UP WITH CLM FOR ADVOCACY ON PRIVACY AND CONFIDENTIALITY AT ART CLINIC

BY STARPHEL SITHOLE

The Citizen Science Life Maps (CS-LM) will link up with the Citizen Science Community Led Monitoring and Advocacy (CS-CLMA) initiative to advocate for an implementation of ART clinics that consider aligning with the protection of privacy and confidentiality at Dedza District Hospital.

The CS-LM Manager Ruby Ng'ong'ola Zolowere made the sentiments in response to some of the issues that emerged during an interview between a journalist from the Network of Journalists Living with HIV (JONEHA) and 3 Dedza based participants of the Life Maps as a project that aims at documenting the perspectives of recipients of care on the impact of COVID-19 on their lives as it relates to their access to HIV and TB testing, prevention and treatment services within the context of the COVID 19 pandemic.

The Life Maps participants told the journalist that as recipients of care on ART they feel betrayed because an environment without privacy could easily subject them to stigma and discrimination in a society. The CS-CLMA is being implemented jointly by the Malawi Network of Religious Leaders Living with or Personally

Affected by HIV (MANERELA+) and the Network Of Journalists Living with HIV (JONEHA) with funding from the Bill and Melinda Gates Foundation through ITPC. Similarly, the CS-LM is getting its funding from the Bill and Melinda Gates Foundation through ITPC.

Citizen Science Life Maps is a three-year qualitative, longitudinal research project conducted in South Africa and Malawi under the leadership of ITPC. Specifically, Life Maps is a community-based project

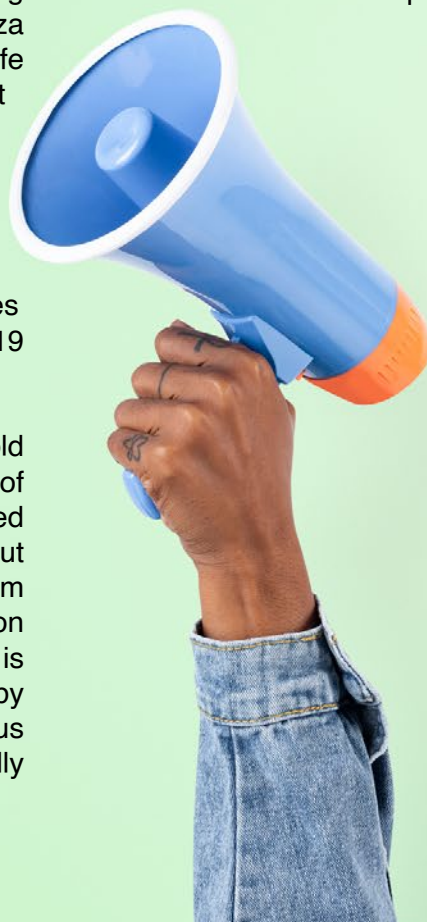
that uses participatory activities to empower recipients of care to report directly on their needs and experiences while seeking healthcare access and provisions.

Baton, a Life Maps participant observes that despite being assisted by very friendly health care workers; the absence of privacy and confidentiality at the ART clinic is a stumbling block to a successful treatment and care initiative. He concludes that such an unfriendly environment can lead many of them into defaulting.

“The door of the ART clinic at Dedza District Hospital is positioned in such a way that all recipients of care waiting for examination and treatment look directly at the entrance; a situation that tempts people into visibly discussing you,” says Baton.

Key Population Coordinator for Dedza District Hospital Walter Chambwe, said that service providers are working hand in hand with the MANERELA+ on the CS-CLMA to engage other stakeholders to intervene on the matter.

In 2021 CS-CLMA successfully advocated for a construction of a modern ART infrastructure



at Kasungu District Hospital following demands of the community members and recipients of care through the community empowerment and engagement meetings brought by the Citizen Science Community Led Monitoring and Advocacy project.

The HIV and Management Act of 2018 section 9 of part 5 explains that a person living with HIV has the right to privacy and confidentiality with regard to information concerning his status and that it is the duty of every health service provider to strictly observe confidentiality in handling all medical information concerning a person living with HIV.

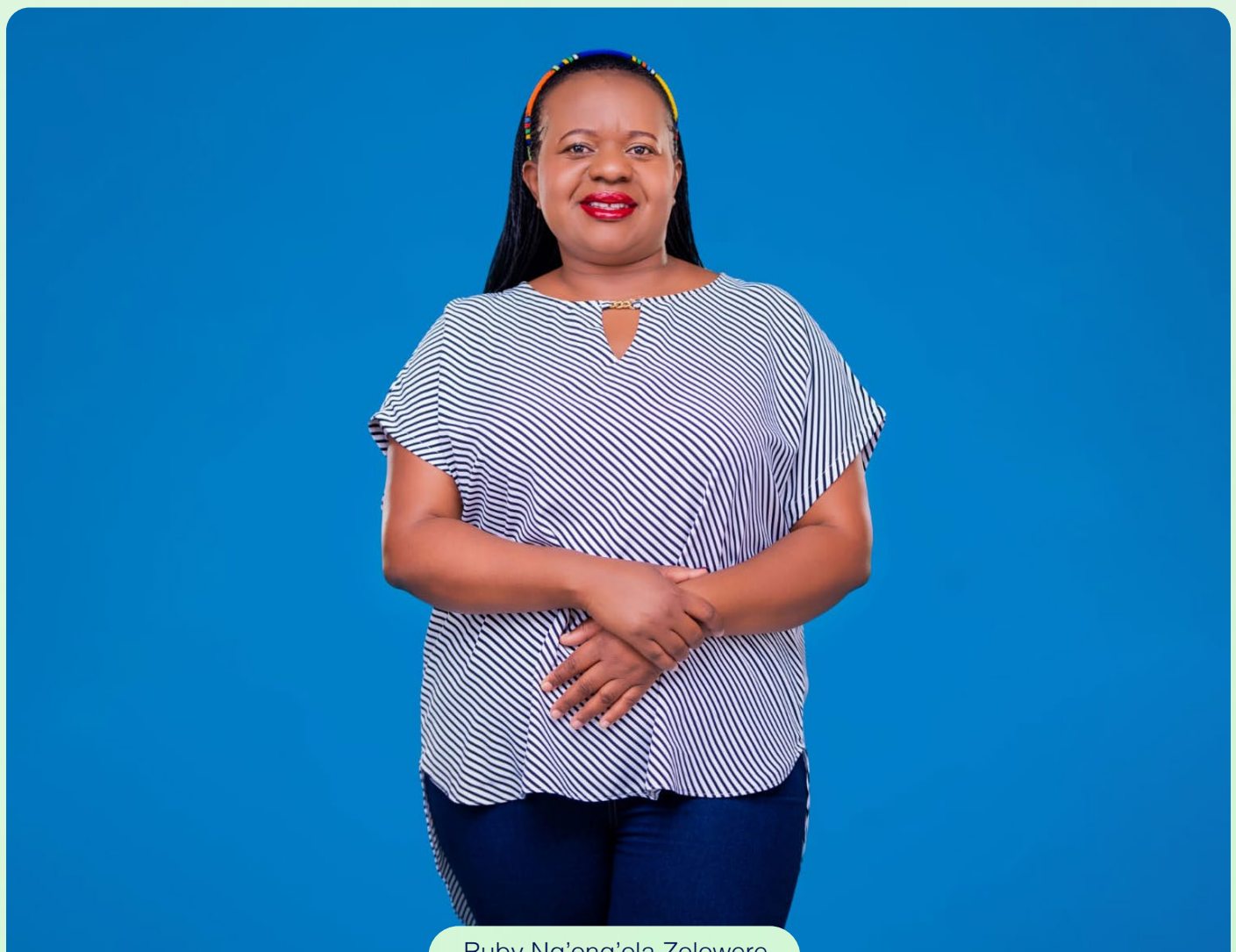
According to a research article published by BMC Public Health

on 28 October 2019 titled Factors Influencing Adherence to ART treatment Among Adults Accessing Care from Private Health Facilities in Malawi concludes that the main reason for defaulting from ARVs was fear of disclosing an HIV status to avert potential stigma and discrimination.

The report adds that in implementing ART clinics due consideration and strategies need to be adopted to ensure that privacy and confidentiality is preserved.

In collaboration with its community partners, Malawi Network of Religious Leaders Living with or personally affected with HIV and AIDS (MANERELA+)

in Malawi and Networking HIV and AIDS Community of Southern Africa (NACOSA) in South Africa, the ITPC recruited a group of 40 Life Maps participants who are recipients of care living with HIV or belong to key or vulnerable populations, including (Lesbians, Gay, Bisexual, Transgender, Queer) LGBTQ+ people and young people. Participation for all was based on their informed consent and so participants were trained in how to use mobile devices to record and capture their everyday life experiences.



Ruby Ng'ong'ola Zolowere

TB TESTS AND TREATMENT INCREASING AS CS-CLMA INTENSIFIES ITS CAMPAIGN IN DEDZA AND KASUNGU

BY FORTINA KAZEMBE

Tuberculosis (TB) tests and treatment is increasing as the Citizen Science Community Led Monitoring and Advocacy (CS-CLMA) Project intensifies its campaign around selected health facilities in Kasungu and Dedza districts according to reports presented at the Community Consultative Group (CCG) meetings held in the two districts on 22nd and 23rd June 2023.

On TB tests conducted between January and March and from April to June 2023 in Dedza respectively; it was reported that sputum Smear microscopy tests increased from 119 to 171, TB urine Lam tests increased from 168 to 339 and tests through GeneXpert increased from 65 to 150 representing an overall improvement in the general uptake of TB services. Kasungu reported a total of 4,111 though with a decrease from 4,971. From January to March there were 365 while April to June of 2023 recorded 935 people living with HIV who underwent TB tests.

In Dedza TB treatment have also improved if we compare the 95 people recorded in January to 153 in March 2023. On the other hand, people accessing TB Prevention Therapy (TPT) increased from 5 to 11 during the same period while

the number of those accessing 3HP or 1HP decreased from 187 to 148. In Kasungu the number of people receiving TB treatment also increased from 108 to 172 and for those accessing TPT growth was from 94 to 189.

“In Kasungu the number of people who managed to access 3HP or 1HP has highly increased from 243 to 364,” commented the Monitoring and Evaluation Officer from the Malawi Network of Religious Leaders Living with or Personally Affected by HIV (MANERELA+) at the Kasungu Boma CCG meeting. MANERELA+ and the Network of Journalists Living with HIV (JONEHA) are jointly implementing CS-CLMA project with funding from the Bill and Melinda Gates Foundation through the International Treatment Preparedness Coalition (ITPC) at 14 selected facilities in Kasungu and Dedza.

The CCG meetings in both Kasungu and Dedza noted that amid the reported successes; there were some challenges in the TB services such as no clear documentation on TB screening among people living with HIV, low uptake of 3HP or 1TPT, access to TB treatment remains a challenge for people living with HIV, stigma and discrimination around people living with HIV or TB recipients



of care and low adherence to TB TPT.

The PEPFAR Country Operational Plan of 2023 (COP 23) points out that the CLM by Civil Society Organizations and HIV and TB affected communities continue to play a pivotal role in identifying gaps and challenges on access and delivery of health services. COP 23 says through quantitative and qualitative data collection, analysis and interpretation, civil society and communities are able to bring to light the challenges behind different program outcomes as well as

provide recommendations for program improvement.



Dedza CCG members pose for a photo after the meeting.

THE COVID 19 MARRED HEALTH WORKER- RECIPIENT OF CARE RELATIONSHIP RESTORED AT FACILITIES

BY JOSEPH GANTHU

Christina; one of the people living with HIV participating in a research project being implemented by a project called Citizen Science Life Maps on the impact of COVID 19 on HIV services in Malawi expresses happiness over restoration of the relationship between communities and healthcare workers.

She recalls that numerous misconceptions which were abundant; some of which dubbed health personnel as killers hired by donors, marred the relationship hence so much so that even recipients of care for other illnesses

TO PG. 20

COVID 19 Still Biting Socially & Economically

because they constantly spiritually and socially support each other as opposed to those outside this supportive structure.

The World Health Organisation acknowledges support groups as an intervention to address retention and adherence among People Living with HIV receiving ART. A systematic review on the impact of support groups for People Living with HIV concluded that as an intervention they are expected to have a high impact on morbidity and retention, a moderate impact on mortality and quality of life.

A review of evidence and implementation strategies in Malawi titled 'Engaging the community to reach 90-90-90' jointly published by UNAIDS, NAC and MSF in 2015 says support groups have been instrumental in the management of HIV positive individuals in Malawi.

This community-based intervention, which is implemented nationwide,

aims to ensure that People Living with HIV have comprehensive knowledge on HIV, lead productive lives, access essential services and that the number of new HIV infections is reduced.

On the economic impact the Life Maps participant observes that since 2020 when the pandemic picked up, she has been experiencing skyrocketing prices in food, transport, health and education industries just to mention a few.

"The unbearable prices of food has negatively affected our survival as you know people on ART are supposed to eat well to support the effective results of medication but as it is it's really a faraway dream," complained Sandra.

A 2022 study by Camelia Munteanu and Betty Schwartz titled: The relationship between nutrition and the Immune System published online on 8 December by PMC Pubmed Central

have shown that proper nutrition helps in strengthening the immune system, managing opportunistic infections and contributing to slowing the progression of the disease. Hence maintaining consumption of adequate food with appropriate nutrients which helps to meet nutritional needs of the people living with HIV is therefore important.

In collaboration with its community partners, Malawi Network of Religious aff MANERELA+ in Malawi and NACOSA in South Africa, the ITPC recruited a group of 40 Life Maps participants who are recipients of care living with HIV or belong to key or vulnerable populations, including (Lesbians, Gay, Bisexual, Transgender, Queer) LGBTQ+ people and young people. Participation for all was based on their informed consent and so participants were trained in how to use mobile devices to record and capture their everyday life experiences.

Health Worker - Recipient Relationship Restored.

were afraid to visit health facilities as rumors were common that recipients of care were secretly stabbed with a lethal injection. Another myth was that every woman who gets a jab of COVID 19 would become infertile hence a number of women traditionally and culturally shunned the health facilities even if they were suffering from other ailments than the pandemic for fear of losing their marriages. Christina recalls that even the healthcare workers too lived in fear of communities

because in most areas' health workers were looked at as enemies, a situation which has now eased because members of the community can now freely interact with them. She says she observes the cordial relationship through day-to-day interactions between healthcare workers and recipients of care. "When I want to inquire something related to HIV services both to a health worker or an ordinary recipient of care the response has now been always positive," says the Life Maps participant.

On 23 April 2020 the Voice of America (VoA) News reported that Malawi health workers were facing stigma and discrimination over COVID-19. The article said while health workers fighting the coronavirus around the world were cheered in public, in Malawi they complained of insults, stigma and discrimination. The VoA News added that as health workers were presumed to carry the virus they were shunned in public, refused access to public transport and even evicted from rented homes.



The relationship has been restored - Christina

Local main stream and social media in Malawi also reported that due to misconceptions; health care workers were on several occasions attacked when they wanted to bury those who died from COVID-19. This was so because communities could not understand that the burial service by the health workers was meant to prevent spreading of the coronavirus since the health guidelines asked them to assist in escorting and burying the remains for safety of the public.

Citizen Science Life Maps is a three-year qualitative, longitudinal research project conducted in South Africa and Malawi under the leadership of the International Treatment Preparedness Coalition (ITPC). Life Maps is one component of the larger Citizen Science Community Led Monitoring and Advocacy (CS_CLMA) project and aims to support and enhance information collected using Citizen Science's Community-Led Monitoring and Advocacy approach.

Specifically, Life Maps is a community-based project that uses participatory activities to empower recipients of care to report directly on their needs and experiences while seeking healthcare access and provisions.

In its collaboration with its community partners

Religious Leaders Living with or personally affected with HIV and AIDS (MANERELA+) in Malawi and Networking HIV and AIDS Community of Southern Africa (NACOSA) in South Africa, the ITPC recruited a group of 40 Life Maps participants who are recipients of care living with HIV or belong to key or vulnerable populations, including LGBTQ+ people and young people.

Participation for all was based on their informed consent and so participants were trained in how to use mobile devices to record and capture their everyday life experiences.



...response has now been always positive

PASTOR SABINA TO SPREAD U=U OR T=T BEYOND HER COMFORT ZONE

BY JOSEPH GANTHU

A recipient in care on antiretroviral therapy (ART) whom we will call Sabina (not her real name), also a participant in the ongoing three-year project called Citizen Science Life Maps says now she will comfortably spread messages of Undetectable equals Un-transmittable (U=U) global campaign locally contextualized as Tizirombo tochepa = Thanzi (T=T). She expressed a sigh of relief after quitting a church whose elders openly stigmatized and discriminated her for living with HIV.

Sabina made the revelation on 23rd August, 2023 in an interview held in Kasungu with a media crew from the Network of Journalists Living with HIV (JONEHA) that she has for years been subjected to stigma and discrimination looking at how unfair she was treated as an HIV positive pastor. She said she was viewed as the most sinful person in the church who was rightly punished by God.

As a person with multiple medical conditions; she needed to be working near a health facility that meet her needs. Contrary to the aforementioned background the church elders though fully aware of her health status gave her a transfer notification to a remote area without a health facility for regular medical check-ups and treatment. She tried to plead with the elders for consideration regarding her status but to no

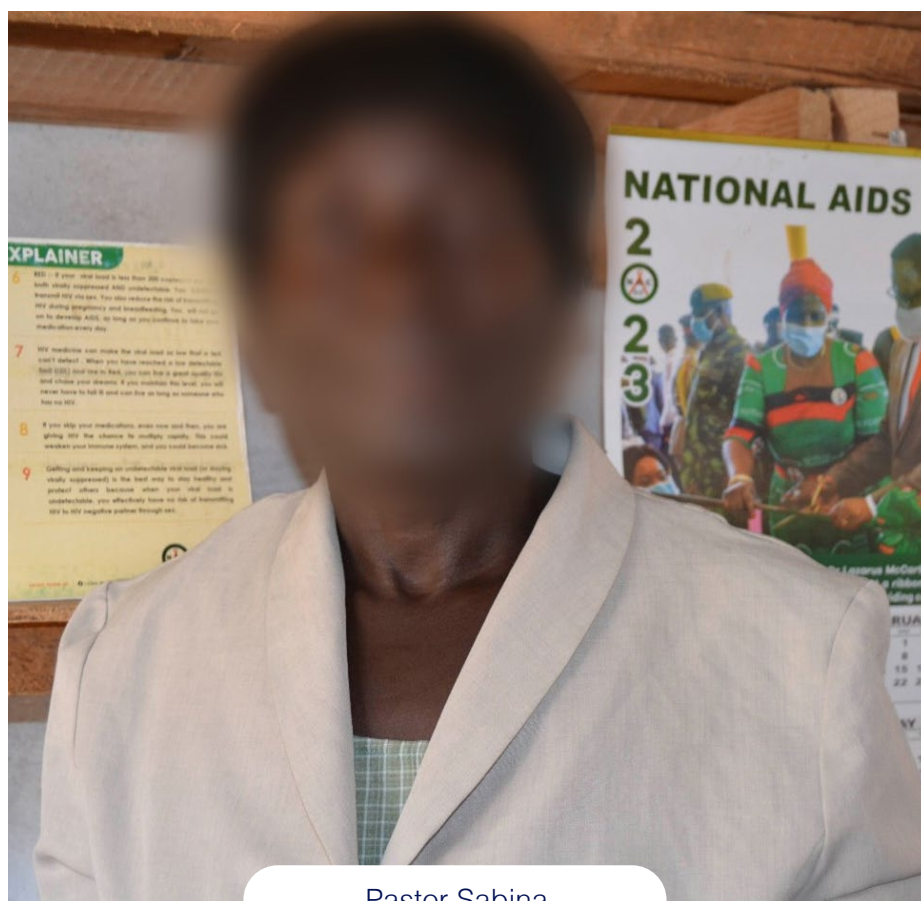
avail and they just brought in another pastor without any formal handover and left her unattended to. The development prompted her to look for a different church.

“Now I have just joined a new church whose elders look friendly despite having shared with them my HIV positive status,” said Sabina indicating that she will as well use the pulpit in spreading the U=U to encourage Malawians that are on ART to adhere to treatment thereby enhancing prevention to end HIV and AIDS

as a public health threat in addition to spiritually leading the flocks to heaven.

Through the Life Maps project, Sabina has an opportunity to interact with the health service providers where she is able to get knowledge on U=U.

U=U or T=T as it is known in Malawi is a campaign that aims at reducing new infections and HIV related deaths by focusing on the three areas of treatment literacy, viral load monitoring



Pastor Sabina

and adherence to treatment for people living with HIV to achieve viral suppression to undetectable levels of HIV medically called viral suppression. T=T in Malawi is part of the global U=U campaign. It is based on the science that when an HIV positive person on treatment reaches viral suppression; he/she cannot transmit the virus sexually. So, it is being promoted as an HIV prevention strategy but also to improve the quality of life for people living with HIV on treatment.

The Country Operational Plan (COP 23) is recommending Presidents Emergency Plan for AIDS Relief (PEPFAR) Malawi to scale up U=U or T=T interventions including dissemination of messages in high burden districts with limited interventions, community ART distribution,

community ART Pick up points and support implementing partner interventions towards bringing Differentiated Service Delivery (DSD) models that bring services closer to recipients of care such as the Community ART Groups (CAGs).

The National HIV and AIDS Policy 2022-2027 Policy Statement 1 declares that the Policy will ensure increased access and uptake of high-quality ART, STI, TB and other health services are promoted in order to reduce mortality by enhancing adherence to treatment and retention in care among People Living with HIV.

Citizen Science Life Maps is a three-year qualitative, longitudinal research project being implemented in South Africa

and Malawi under the guidance of the International Treatment Preparedness Coalition (ITPC). In collaboration with its community partners, Malawi Network of Religious Leaders Living with or personally affected with HIV and AIDS (MANERELA+) in Malawi and Networking HIV and AIDS Community of Southern Africa (NACOSA), the International Treatment Preparedness Coalition (ITPC) recruited a group of 40 Life Maps participants who are recipients of care living with HIV or belong to key or vulnerable populations, including LGBTQ+ people and young people with funding from the Bill and Melinda Gates Foundation.

COMMUNITY ENGAGEMENT-A TOOL TO FIGHT DEFAULTER RATE

BY STARPHEL SITHOLE

Stakeholders have advised and encouraged Malawi Network of Religious Leaders Living with or Personally Affected by HIV (MANERELA+) to adopt a community engagement approach and utilize the implementing partners for the facilities to address issues in the Citizen Science Community Led Monitoring and Advocacy (CS-CLMA) project funded by the Bill and Melinda Gates Foundation through the International Treatment Preparedness Coalition (ITPC).

MANERELA+ conducted a CCG (Community Consultative Group) meeting at Thope Lodge in Dowa district on 15th March 2023. 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 Center for the Development of People (CEDEP), Family Planning Association of Malawi (FPAM), national stakeholders like the department of HIV and AIDS (DHA), The Joint United Nations Programme on HIV and AIDS (UNAIDS) and National AIDS Commission (NAC).

During the meeting, MANERELA+ analyzed the year 2022 data which indicated that there are still issues in ART adherence influenced by stigma and discrimination and unreported deaths. These issues contribute significantly to high defaulter rates in project implementation districts of Kasungu and Dedza.

MANERELA data supervisor for Dedza district, Clement Phiri said that Lobi Health Center located in the border with Mozambique is one of the facilities that has high defaulter rate caused by migration, unregistered transfers, unreported deaths, stigma and discrimination. The Executive Director for Network of Journalists Living with HIV (JONEHA) who is also a CCG member David Kamkwamba said the challenges met during the project implementation can easily be tackled by the education process through engaging people who influence change in the community.

'Issues of defaulter rates are mostly community driven and the community is in a good position to bring the needed change. JONEHA for example had registered tremendous reduction of defaulter rate through engaging the community by bringing

together the traditional and faith leaders, recipients of care, youths, implementing partners and health providers who consultatively explore solutions. They further each take relevant roles in addressing the identified issues.'

'Our first experience was at border Mpala Health Centre in Mulanje in May 2020 where to our disbelief; defaulter rate was as high as 47.2%. But through community engagement led by the Director of Health and Social Services in the district Dr. Alinafe Kalanga supported by Baylor; we witnessed defaulter rate reduced to 1.5% by December 2021. Even in a different setting at Jenda Health Centre and Vibangalala Health Centre; upon conducting community engagement led by the office of the Director of Health and Social Services in Mzimba South represented by Dr. Rita Chipeta Zgambo and supported by the Light House; defaulter rate has significantly reduced from 44.9% in April 2020 to -11% at Jenda Health Centre and 13% to -31% at Vibangalala Health Centre respectively by February 2022', Kamkwamba narrated.

Ministry of Health Programs Officer at the Department of HIV, STIs and

Viral Hepatitis Brown Chiwandira commended the application of community engagement as a way of advocacy at that level in addressing some of the challenges experienced.

'Some of the things experienced in the field cannot be fixed by the national health system alone but communities have to play their role to achieve change and attain the intended goal. Advocacy has to wear multiple faces and CS-CLMA should bring together all the stakeholders and challenge them to play their role in trying to address the problem. CS-CLMA should go beyond communities and health providers and sensitize all that are concerned including implementing partners and structures for the affected populations around the facilities so that everyone can commit to play their role in fighting HIV.' Chiwandira emphasized.

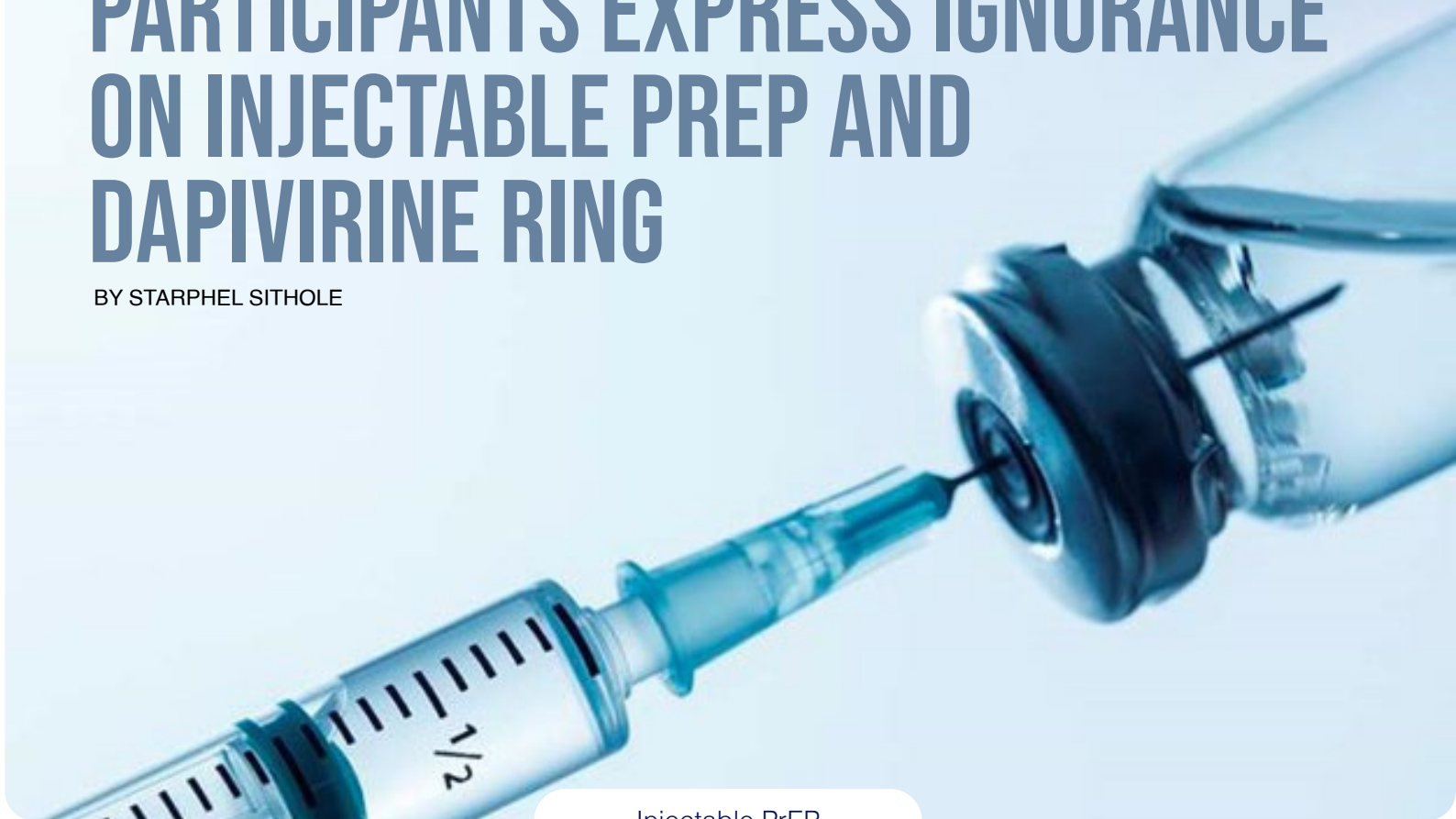
Chiwandira further advised that the CS-CLMA not to be used as a vehicle for fault finding but a way of giving feedback to health service providers that will bring change. He added that CLM is a great feedback system in the country. He concluded by wishing the roll out of CLM across health facilities in Malawi.



CCG Committee

PARTICIPANTS EXPRESS IGNORANCE ON INJECTABLE PREP AND DAPIVIRINE RING

BY STARPHEL SITHOLE



Injectable PrEP

Interviews conducted by the Network of Journalists Living with HIV in Dedza and Kasungu districts on 22 and 23 August respectively have revealed that participants in the Citizen Science Life Maps project are not aware of the recent development in the area of prevention in which injectable Pre-Exposure Prophylaxis (PrEP) and Dapivirine ring have been introduced as options to existing prevention products.

The participants told the journalists that they are very much aware of the oral PrEP and said they would really appreciate learning more about it pointing out that as persons with an advocacy background they can easily take it to communities to enhance HIV prevention. They said this would as well apply to the dapivirine ring which is another new prevention method to offer for community choices.

Life Maps is a community-based project that uses participatory activities to empower recipients of care to report directly on their own needs and experiences while seeking healthcare access and provisions. In collaboration with its community partners, Malawi Network of Religious Leaders Living with or personally affected with HIV and AIDS (MANERELA+) in Malawi and Networking HIV and AIDS Community of Southern Africa (NACOSA) in South Africa, the International Treatment Preparedness Coalition (ITPC) with funding from the Bill and Melinda Gates Foundation recruited a group of 40 Life Maps participants who are recipients of care living with HIV or belong to key or vulnerable populations, including Lesbian Gay Bisexual Transgender, Queer (LGBTQ+) people and young people.

Malawi with financial support from Bill and Melinda Gates Foundation and technical support from the Georgetown University has just embarked on a pilot project on the injectable prep in Lilongwe and Blantyre targeting key populations such as female sex workers, men having sex with men, transgender at drop in centers, adolescent girls and young women, adolescent boys and young men at Sexually transmitted infection (STI) clinics, women of reproductive age, pregnant and breast feeding women at family planning and sexual & reproductive health clinics or entry points at public health centers and for men or women with willingness to pay for access to the services at private clinics.

TO PG. 28

DATA COLLECTOR BECOMES CCG CHAIR

BY CHRISTER KALUKUSHA

Malawi Network of Religious Leaders Living with of personally Affected by HIV (MANERELA+) in partnership with Network of Journalists Living with HIV (JONEHA) is implementing a 5-year project (2020-2024): Citizen Science Community Led Monitoring and Advocacy (CS-CLMA) in 6 health facilities in Dedza and 8 in Kasungu district. The project has an inclusive advisory body of stakeholders which is known as Community Consultative Group (CCG), composed of population groups such as people living with HIV (recipients of care), Key populations, academicians, implementing Non-Governmental Organisations (NGOs) like Family Planning Association of Malawi (FPAM), national stakeholders like the department of HIV and AIDS (DHA), UNAIDS and National AIDS Commission (NAC). The CCG discusses data collected in health facilities where the project is implemented, providing strategic guidance, prioritizing advocacy issues and pointing towards next steps to be taken to inform CS-CLMA implementation. One of the data collectors in Dedza was chosen as the CCG chair and let's get to know him.

May I know you?

I'm Daniel Namate, born on 19 March 1993, I've grown up in Dedza and my home village is Kapamula Traditional Authority (T/A) Kachere, Dedza. In Citizen Science Community Led Monitoring and Advocacy I am one of the Key Population (KP), a data collector at Lobi Health Centre and recently I was elected as a Chairperson for Community Consultative Group (CCG).

What do you mean when you say KP's?

These are people who are most vulnerable to contracting HIV due to the nature of their work, for example Female Sex Workers (FSW), Men having sex with Men (MSM), just to mention a few. I belong to MSM as one of the KP's in this project.

When did you become a CCG chair and how were you chosen?

I became CCG Chair this year; thus, in April 2023, people saw it that I qualify for the position because for one to be a Chair in CCG, you need to have a background knowledge about HIV which I have and must come from the community as one of the principles of CS-CLMA is that it targets and recognises the citizens from the local community as experts on issues that affect them.

How did you take it being an MSM and data collector to be elected as CCG chair?

I was excited because this means that MANERELA+ is indeed working on empowering those who are vulnerable and ensuring that they have the capacity to bring positive change by giving them a platform to voice out their needs as well as challenges. Being the chairperson gives me more power to work on advocating for the rights of KP's when it comes to accessing health care at a larger scale because as a data collector, I had limitations but with this position I am able to do more.

As CCG chair how will you contribute to the success of CS-CLMA project?

I will continue to work with support groups as recipients of care, enlightening them on the new person-centred ways of receiving treatments what we call Differentiated Service Delivery (DSD) which make them feel free to choose what is convenient for them to adhere to treatment. I will also reach out to fellow KP's and raise their awareness about HIV prevention, use of condoms and lubricants as well as advocating for the availability of Pre-Exposure Prophylaxis (PrEP) in a number of health centres since most of them do not offer PrEP services so that these vulnerable groups in communities should have access to them to achieve the project's goal of making health services available to all who need them.

I will also use this platform to get solutions on the challenges that the target population face in the communities from the CCG meetings as it involves different stakeholders with expertise in health services especially HIV.

How far would you wish the project to go?

There are many MSM out there who need assistance, so if resources are available, I would like to see the project expanded to include more health facilities than the current six. More MSM need to know that they too have the right to quality health services regardless of being MSM and I'm excited with the progress the project has made in the facilities that it is being implemented. Based on the data that we collect it shows that recipients of care are adhering to treatment and are following proper procedures when transferring to another health facilities. Therefore, this means that by 2030 we may be able to win the fight against HIV.

FROM PG. 15

Ignorance on Injectable PrEP and Dapivirine ring

On 1st September 2023 at Likuni Boys Sports Ground in the area of traditional authority Maliri in Lilongwe District, Malawi launched the long-acting Injectable PrEP whose administration will begin with Lilongwe and Blantyre targeting 38 health centers. According to the Deputy Minister of Health Halima Daudi who officially launched the product she said it is a two-year project expected to reach 10,000 people in the two districts.

PrEP is for persons who are HIV negative and are at risk of being infected with HIV. Injectable PrEP with CAB is highly effective at protecting people from HIV acquisition and is for People who are at high risk including adolescents and breast-feeding mothers. To access injectable PrEP you must at least weigh 35 kg.

The main advantage of injectable PrEP is that it reduces the frequency of one going to the hospital, it also helps on adherence as it is hard to be consistent with Oral PrEP as users hardly remember taking the pills. The switch from oral pills to injectable gives autonomy for options to individuals over their PrEP choices. Individuals can easily maintain adherence which helps to improve effectiveness of HIV prevention from PrEP.

Dapivirine Ring is designed as a long-acting form of HIV prevention for at-risk women, particularly in developing nations such as sub-Saharan Africa. The ring is made of silicone and is easy to administer by bending and inserting in the vagina. The ring works by releasing the antiretroviral drug dapivirine from the ring into the vagina slowly over 28 days.

The Departmental news of 26 January 2021 reports that WHO recommended that the dapivirine vaginal ring (DVR) may be offered as an additional prevention choice for women at substantial risk of HIV infection as part of combination prevention approaches.

While the Dapivirine ring was registered as a medicine by the Pharmacy and Medicines Regulatory Authority (PMRA) in Malawi in February 2021; the Ministry of Health is yet to introduce the product as a prevention method in the country. Responding to Malawi's concept note for the NFM4 Global Fund application for January 2024 to June 2027; the Technical Review Panel (TRP) asked Malawi to consider Dapivirine ring as a missed opportunity for an effective prevention option for women. Thus; the country policy decision is awaiting the cost analysis study to be undertaken.



Dapivirine ring

RECIPIENTS OF CARE BEMOAN ABSENCE OF CAGS AS A DSD MODEL

BY STARPHEL SITHOLE

Despite bringing ART to some health facilities, many recipients of care continue to face difficulties in accessing ARVs. Recipients of care in Kasungu and Dedza districts under CS—CLMA project have called for Ministry of Health (MoH) to approve the Community ART Group (CAGs) as one of the Differentiated Service Delivery (DSD) Models to help in curbing other challenges.

The Ministry of Health approved a CAG pilot in 2021 but have not yet included it in the 2023 National DSD Operational Manual as one of the DSDs in Malawi. Malawi Network of Religious Leaders Affected and Infected with HIV (MANERELA+) under the Citizen Science Community Led Monitoring Advocacy (CS-CLMA) funded by Bill and Melinda Gates Foundation through International Treatment Coalition (ITPC) sensitize recipients of care (RoC) on various DSD models that are available.

One of the project beneficiaries in Dedza district, Gift Kholiyo, an expert client for Young People Living with HIV (Y+), who has been on ART for 26 years commended CAGs as it helps in reducing transport costs and stigma and discrimination.

“During literacy trainings through the CS-CLMA I was introduced to a different and better DSD model which is more effective and cost saving, (CAGs) where one person collects for the other 5 people. To my understanding, if government can endorse the model,



Gift Kholiyo-Expert Client

it can benefit both recipients of care and service providers thereby addressing barriers of accessing treatment. To recipients of care, HIV-related stigma persists and CAGs are seen as an active strategy to reduce exposure to discriminatory labelling by community members. With CAGs there is reduced frequency of clinic visits resulting in reduced transportation costs and time saving for both provider and recipient of care.” Narrated Kholiyo.

Kenius Paulo, chairperson for Nyangawira Support Group in Kasungu district says the model

reduces waiting time linked to time lost for doing economic activities.

“The groups are excellent. If I visit the health facility this month, I’ll return in five months. I can use this time to focus on my work undertakings like watering the vegetables in the garden” Paulosaid.

Kasungu Clinical Officer and ART facility lead, Twaibu Chipere said CAGs are more beneficial to service providers by reducing and lessening workload.

TO PG. 31

UPTAKE OF FEMALE CONDOMS GROWS BY 30% IN CS-CLMA AREAS

BY JOSEPH GANTHU

As Malawi strives towards prevention goals required to end HIV as a public health threat in the next decade, an uptake of female condoms in Kasungu has increased from 0.3% (3,737) between January and March 2023 to 30% (17,614) according to findings by the Citizen Science-Community Led Monitoring and Advocacy (CS-CLMA) project covering 8 selected health facilities in the district.

The Monitoring and Evaluation (M & E) Officer Tayana Tembo from the Malawi Network of Religious Leaders Living with or Personally Affected by HIV (MANERELA+) presented a report of the findings on 22nd June 2023 at a Community Consultative Group meeting where the findings were also validated. The MANERELA+ and the Network of Journalists Living with HIV (JONEHA) are jointly implementing the CS-CLMA project with funding from the Bill and Melinda Gates Foundation through the International Treatment Preparedness Coalition (ITPC) at 14 selected facilities in Kasungu and Dedza.

“In the previous quarter of January-March 2023 the uptake gaps on female condoms were linked to gender norms and lack of empowerment of women to initiate safer sex but our advocacy initiatives have improved the perspective,” said Tembo who expressed concern over the scarcity of female condoms in public health facilities and described the situation as an element that was dragging the pace towards ending HIV through prevention. She bemoaned that in all the health facilities that includes Kasungu District Hospital

where the CS-CLMA is working it was only FPAM providing lubricants.

On Condom and Lubricants; the National Strategic Plan (NSP) for HIV of 2020-25 says the aspiration is that 80% of all sexual acts are condomized by 2025. As it stands 155 million male condoms and 675,000 female condoms and 1.25 million lubricants are distributed annually. Also 85% of women and 90% of men aged 15-49 know that consistent and correct use of condoms reduces the risk of HIV acquisition.

While the NSP recognizes linkage and adherence to treatment as important components of an effective prevention strategy; it however points out that ART alone will not be enough to achieve Malawi’s prevention goals as transmission also occurs from those who are not yet aware of their HIV status or experience treatment failure or have issues with adherence. Hence Malawi must not focus only on treatment for people living with HIV who can transmit but also on protecting those who can be infected.

The CCG meeting also expressed concern that only 3 health facilities in Kasungu were providing Pre-Exposure Prophylaxis popularly called PrEP; an antiretroviral medication that reduces the risk of infection for people who are uninfected. The NSP recommends PrEP as a prevention method that can be used independently of the choices of one’s sexual partner which presents a promising opportunity to fill the gap in effective prevention methods available to key and vulnerable populations.

An HIV Diagnostic Assistant at FPAM, Angella Sitima reported that her office has PrEP but cannot administer it because of limited capacity due to un-availability of laboratory equipment and inadequate staff to run initial creatinine and Hepatitis B screening tests and conduct quarterly monitoring tests for negative side-effects.

The PEPFAR Country Operational Plan of 2023 (COP 23) points out that community data shows that barriers to PrEP use are still persistent. The COP 23 says while Centre for Disease Control (CDC) guidelines indicate that people on PrEP should be monitored for side effects and be tested for HIV, the Government of Malawi has not yet scaled up laboratory investigations and structures on Creatinine and hepatitis test before initiation of PrEP. In addition; follow up measures for those on PrEP has been a challenge.



The female condom

FROM PG. 29

Recipients Bemoan Absence of CAGs as DSD Model

“Having only one person collecting the ARVs for a group of 4 to 6 means a reduced congestion in the facility and the work load for the health workers is decreased. Hence, we have more time for the individual recipient of care (RoC). There is also a decrease in the need of tracing the RoC as community members update the service providers of the whereabouts of other CAG members and possible deaths.” Chipwere Narrated.

A journal published by International AIDS Society in 2017 “We Are Part of a Family”. Benefits and Limitations of Community ART Groups (CAGs) in Thyolo, Malawi

states that CAG model has shown to be an acceptable model of ART delivery, for people on ART and healthcare workers providing ART services. Through the development of a patient-centered model of ART refill, it was possible to address the main barriers to access ART for patients, with the majority valuing the practical benefits of CAGs in reducing the frequency of clinic visits and the associated transportation costs.

However, during the DSD stakeholder’s coordination meeting held at Ministry of Health on 14th June 2023 which aimed at building consensus

on the validated DSD operational manual and identifying priority research areas in DSDs, CAGs were not included as it is still under pilot to draw lessons on how RoC will access routine services and viral load services. The delegates present from different organizations such as Malawi Network of People Living with HIV/AIDS (MANET+), Coalition of Women Living with HIV and AIDS (COWLHA) and Clinton Health Access Initiative (CHAI) agreed to include the model soon after the pilot.



CAGs have proved to lessen service providers workload-Chipwere

CS-CLMA FACILITATES CHANGE AT KASUNGU DISTRICT HOSPITAL

BY STARPHEL SITHOLE

There has been a construction of a modern ART infrastructure at Kasungu District Hospital following demands of the community members and recipients of care as a result of community empowerment and engagement meetings with duty bearers facilitated by Citizen Science Community Led Monitoring and Advocacy (CS_CLMA) project.

Kasungu District Health Office is one of the health facilities in the central region of Malawi which had a small ART room resulting in extended queues for recipients of care waiting outside the facility. This led to lack of privacy, confidentiality and stigma hindering quality HIV services at the facility. Limited or poor infrastructure is one of the bottlenecks for accessing quality services in Malawian health facilities.

In May 2021 Malawi Network of Religious Leaders infected and affected by HIV (MANERELA) conducted an engagement meeting with service providers, recipients of care, religious leaders, chiefs and other implementing partners in the district aimed at understanding the gaps

hindering quality health services. Among the problems mentioned and discussed was privacy due to small ART infrastructure.

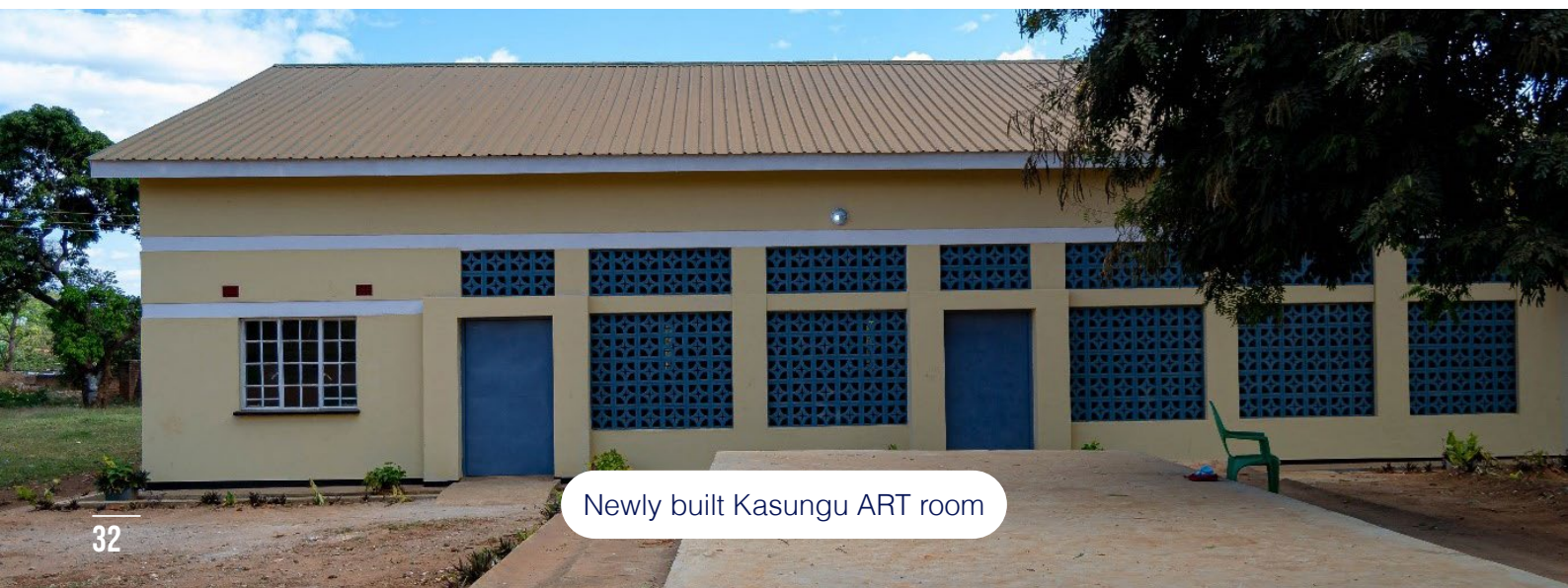
The ART Coordinator promised to convene a meeting and contact other implementing partners. This was after the meeting noted the need for enough space and rooms because the ART room was too tiny to carry out its intended service purpose properly. Kasungu ART Coordinator Mirriam Mkangala commended the coming of the CS-CLMA project which has empowered recipients of care to take the lead in raising issues they encounter during treatment for addressing by duty bearers.

'At our facilities, this project has resulted in numerous improvements. For example; recipients of care now know their role at the facility and they are able to voice out their needs and concerns which leads to problems being addressed. Just after the project commenced in 2021, one of the recipients of care who is also a data collector in the project voiced out the need for a bigger room for ART; as many people living with HIV were

interrupting treatment due to lack of privacy and confidentiality. Through the project we noticed the need and acted accordingly by calling on other partners to render help. Fortunately, Partners in Hope with funding from USAID successfully constructed the modern structure.' Mkangala narrated.

Mkangala further said that the newly built structure will help in enrolling integrated service delivery which will also assist in solving privacy and confidentiality issues at the facility.

'The new modern building which is double the old ART will now provide enough space for one stop service for almost all HIV related services. We are planning to include TB, Cervical cancer screening and viral load testing which will make it easy for recipients of care. When recommended to go for viral load testing, which is done outside the ART room, many recipients of care choose to instead sneak out to their homes since they feel their privacy will be infringed upon by the clinic's obviously small size. A private and confidential atmosphere, essential for any healthcare institution, is anticipated



Newly built Kasungu ART room

anticipated to be created by the new, roomy infrastructure with several rooms.' Mkangala explained.

According to a 16 January 2019 PEPFAR Solutions Platform report, integrated tuberculosis and HIV services in Eswatini led to better and improved individual and population health outcomes.

Idah Katimba, 60, who has been on ART for 18 years and a beneficially

of CS-CLMA project describes the new building as a life saver as it will reduce defaulter rate at the facility.

'There are some people who do not want to disclose their HIV status despite being on ART for so long, I was one of them. Due to the lengthy waiting time and overcrowded ART rooms that forced us to wait in an open area where people occasionally pointed fingers and made fun of us,

I once interrupted treatment and considered switching to a distant facility where no one would recognize me. However, this new building will prevent many in my situation from doing so because we are confident that our privacy will be protected hence reducing defaulting from ART'. Said Katimba.

CS-CLMA CONTRIBUTES TO INCREASED HEALTH SERVICES DEMAND

BY CHRISTER KALUKUSHA

Citizen Science Community Led Monitoring and Advocacy (CS-CLMA) project is largely contributing to a growing demand of health services including pre-exposure prophylaxis (PrEP) by key populations in health facilities in Kasungu and Dedza districts.

CS-CLMA is a project being implemented in Kasungu and Dedza districts by Malawi Network of Religious Leaders Living with or Personally Affected by HIV and AIDS (MANERELA+) in partnership with the Network of Journalists Living with HIV (JONEHA). It is funded by the Bill and Melinda Gates Foundation through the International Treatment Preparedness Coalition (ITPC) with an aim of improving health service delivery and uptake of services by the target populations.

Clinical Officer at Kasungu District Hospital, Twaibu Chipwele said MANERELA+ through CLMA has been conducting community engagement meetings which is an eye opener for key populations

on the rights they have when it comes to accessing health services.

"People in communities never realized that they have the right to access health services because there was no platform for them to learn about these rights. But with CLMA they have been empowered to ask for a service at the hospital they feel they are in need of. For example, we have been having about hundred people asking for PrEP compared to when the year had just started when only twenty or thirty were asking for it," said Chipwele.

However, despite the growing demand for PrEP, some health facilities are unable to meet the demands due to unavailability of the commodity in their facilities and lack of training of the health care workers to start providing it.

Authorities at Kaluluma and Kasalika Health Centres in Kasungu, Mayani Health Centre in Dedza said they do not issue PrEP at their facilities because they have not yet been trained for it.

"The District Hospital offers PrEP but here at the Health Center we do not have it. So we are still waiting to be trained by the Ministry of Health (MoH) and have the drugs supplied at the facility because people are usually asking for it", said Gift Chilangiza, Clinician at Kaluluma Health Centre in Kasungu.

PrEP is the use of antiretroviral medication to reduce the risk of infection for people who are HIV negative. Especially for key populations like Female Sex Workers (FSWs) who face inequities to negotiate consistent condom use with clients. Therefore, the World Health Organisation (WHO) recommended the use of PrEP in 2015 to populations at substantial risk of HIV infection.

CLMA Data Supervisor in Kasungu, James Nthondo said not only do the communities go to ask for medication. They also request for appropriate health service structures where they see there's need.

CS-CLMA IMPROVES SERVICE DELIVERY FOR KEY POPULATIONS IN KASUNGU

BY STARPHEL SITHOLE

Often times, people who are at high risk of HIV like key populations which includes men having sex with men (MSM), Female Sex Workers (FSW), Transgender (TG), are not properly assisted when it comes to health care in health facilities due to their sexual orientation. MANERELA+ through the Citizen Science Community Led Monitoring and Advocacy (CS-CLMA) project started addressing this challenge in 2021.

Jane Zanda, a FSW in Kasungu district, said, as sex workers they have been facing a lot of challenges to accessing health care, but things have changed with the coming of the project.

“We used to get harsh treatment when seeking health care and we sometimes shied away from seeking health care from the hospital, afraid of being called ‘whores’ by health care workers. But now through CS-CLMA we have a good relationship with service providers and no longer get insults,” said Zanda.

District Manager at Family Planning Association of Malawi (FPAM), Anthony Phiri described CS-CLMA as a game changer by bringing new initiatives for providing health care.

“The project has created a platform through engagements with targets; key populations, religious as well as traditional leaders for us to get feedback

on how we are providing services at the health facility and get insights on how we can improve on where we are not doing right,” He said.

He further said FPAM provides a differentiated service delivery known as moonlight to FSW in their respective hot-spots.

“This service is provided at night in areas where FSW are found. We visit them and provide condoms, lubricants, treatment for Sexually Transmitted Infections (STI’s) as well as HIV testing,” he said.

According to the World Health Organisation (WHO), quality health services must be people-centered, which means providing care that responds to individual preferences. It must be safe; avoiding harm to people whom the care is intended, it must be equitable; providing care that does not vary in quality on account of age, sex, religion gender, race, ethnicity, geographical location, socioeconomic status or linguistic or political affiliation, it must also be effective; providing evidence-based health-care services to those who need them.

Joseph Nthondo, CS-CLMA Data Supervisor for the project, said MANERELA+ is working to bridge the gap between health care workers and recipients of care, which includes key populations, so that everybody should know their right to access health services

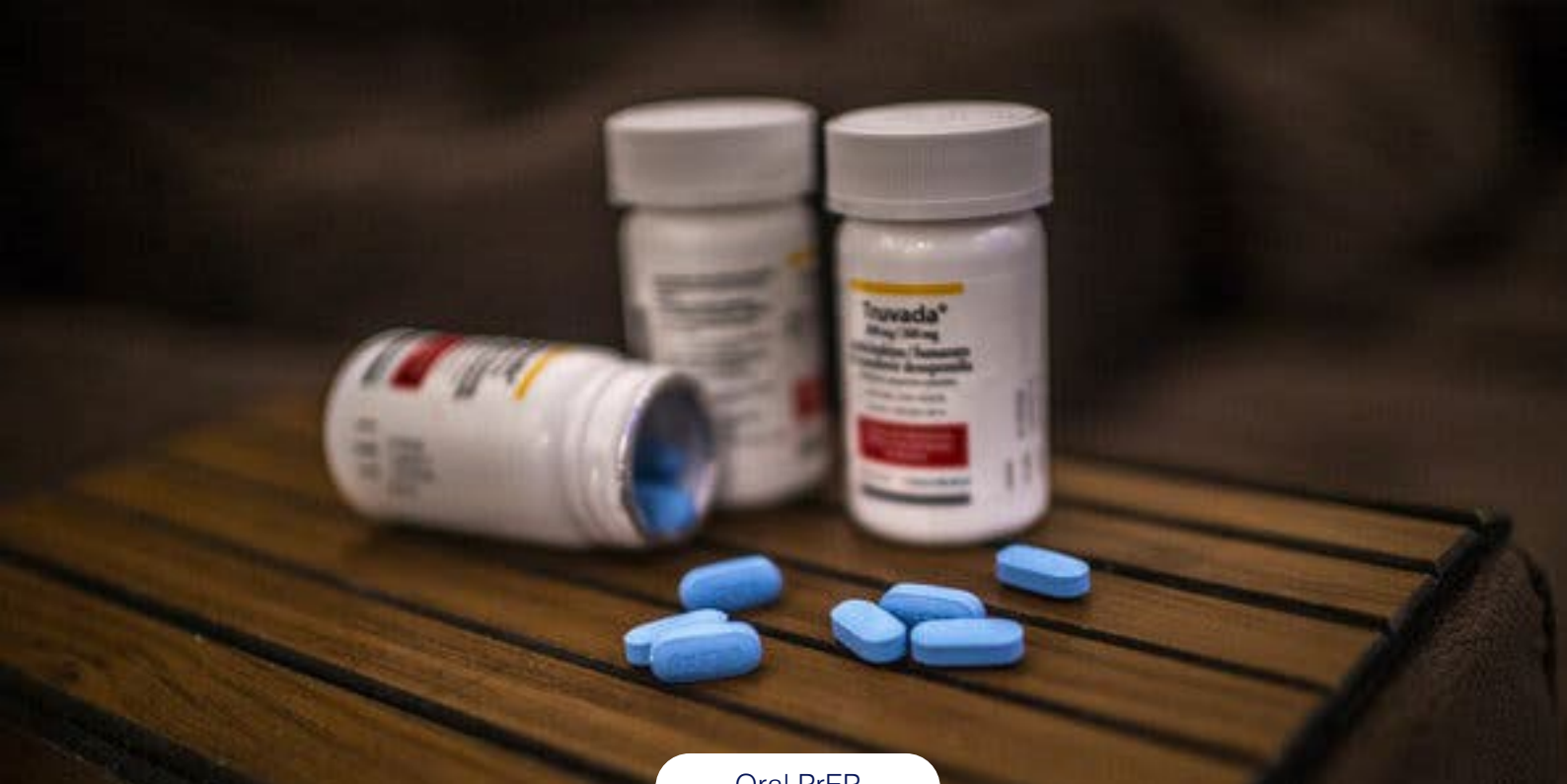
and for health workers to know what services to provide and how.

“We have data collectors in this project who are there to generate evidence through data collection from various health facilities where the project is being implemented on how services are being provided in those facilities and the type of services. Through this data, we conduct interface meetings between recipients of care, including key populations and duty bearers, so that identified problems are addressed.” said Nthondo.

Clinical officer at Kasungu district hospital, Twaibu Chipwele, commended MANERELA+ for the project as it has helped them to address problems that were presented by key populations and other recipients of care. So, there is hope that our country will win the fight against HIV through quality health service delivery.

Malawi is being guided by the UNAIDS fast track strategy of ending AIDS by 2030 through achieving 95:95:95 targets. This means 95% of people HIV-infected individuals to know their status, 95% of recipients of care who know their status to have started and adherent on ART and 95% of recipients on ART to be virally suppressed by 2030 to win the HIV fight.

CS-CLMA is one of the interventions fighting for HIV and it is implemented by MANERELA+



Oral PrEP

in partnership with the Network of Journalists Living with HIV (JONEHA) in 8 facilities in Kasungu district namely; Kasungu District Hospital, FPAM, Kaluluma, Bua, Chamwabvi, Kasalika, Mnyanja and K2-TASO Health Centres with funding

from the Bill and Melinda Gates Foundation through the International Treatment Preparedness Coalition (ITPC). The project seeks to assess and generate evidence on service access gaps and HIV service barriers for people living with HIV/

key populations in the context of COVID 19 and to improve HIV service delivery and service uptake by the target populations amidst the COVID 19 pandemic.

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CS-CLMA Contributes to Increased Health Services Demand

“In one of our engagements with these groups in 2021, a recipient of care requested for an ART structure which has now been built at the District Health Office because they felt privacy was being compromised at the district hospital due to having a small space where ART was offered,” said Nthondo.

CLM seeks to improve quality of health service delivery in facilities by engaging both target populations, health workers and other duty bearers in meetings to help address concerns between parties around health service delivery.

The demand for improved quality of services by different population groups demonstrates knowledge on health as a right for life to everybody irrespective of status, race, gender, religion etc. The right to health is well protected in international human rights instruments like Article 25 of the Universal Declaration of Human Rights (UDHR) and Article 12 of Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) protect health rights.

The Committee on Economic, Social and Cultural Rights (CESCR) interprets it as the right to have access to health care services with a corresponding state duty to make such services accessible to all. It also includes an entitlement to a system of health that provides “equality of opportunity for people to enjoy the highest attainable level of health.”

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Newsletter



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