

Citizen Science Life Maps 2022 Report



Life Maps Annual Report 2022

Introduction

Citizen Science Life Maps (LM) 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 project and aims to support and enhance information collected using Citizen Science's Community-Led Monitoring approach. Specifically, 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 seeking healthcare access and provisions.

Participants

In collaboration with its community partners, MANERELA + and NACOSA, ITPC recruited a cohort 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. All participation was contingent upon informed consent and participants were trained in using mobile devices to record and capture their everyday life experiences. Life Maps participants received personal protective equipment (PPE), including masks and hand sanitizers. Each participant was given a mobile phone for documenting their lived experiences and information enabling them to share their observations and contributions with the project officer and manager. Ten topic areas were explored throughout the three-year project.

KEY POPULATIONS, YOUTH & PLHIV



People Living
with HIV



LGBTQ+



Trans People



Sex Workers

PARTICIPANT SUBMISSIONS VIA PHONE



Audio



Photos



Videos



Text

Project Aim

The project aims to document 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. This project explores the use of collaborative, participatory visual media tools to document people's lived experiences. It aims to empower and enable participant advocacy pathways, moving away from models of "data extraction" to "data democracy". The nature of the project creates the potential for outcomes to be shared in both academic and non-academic settings.

Methodology

A mobile phone is used to document participants' lived experiences during the COVID-19 pandemic. Participants are required to take photographs and videos and record voice notes and provide text messages documenting their lives and experiences as they relate to a particular topic. The data collected is used to assess how COVID-19 has impacted participants' lives. In instances that require taking photographs in health facilities (such as routine blood draw for viral load testing and information posters displayed in clinics), consent will be obtained from the health facility staff in charge. No personal information or photographs of individuals are captured and documented, as stipulated by the South African Protection of Personal Information Act (POPIA). Precautions are taken to ensure that participants' personal information and all project submissions are securely stored for use within the context of the project and, where possible, proxied, aggregated, or anonymized to replace any information that may compromise participants' privacy or safety. Each participant was provided with a pseudonym to protect confidentiality.

Themes

The following themes were explored during 2022:



1. **This is me:** Participants provided biographies of themselves.
2. **COVID-19 diary: This topic explored issues such as** How has COVID-19 affected recipients of care? Document changes in routine, public transport, employment, education, and food security.
3. **Mental health:** How has COVID-19 affected participants' mental health? Has there been an increase in stress, depression, anxiety, or aggression? What access is there to mental health services like social workers or psychologists? Have they felt like a burden to their family? What have they done to take care of your mental health
4. **State violence, violent crime, and gender-based violence:** Document gender-based violence, increased crime or state-sponsored violence from police, military, or other security forces and its impact on health outcomes and access to services.
5. **Economic impact of COVID-19 (cost of living, food security):** Document the economic impact of COVID-19 through photographs of the contents of food cupboards, refrigerators, and daily meals. How has COVID-19 impacted your monthly budget? Participants submit a written budget plan with figures showing cost changes for essential goods and services, like transport and food.
6. **Impact of COVID-19 on HIV services:** How has COVID-19 affected access to HIV services in various health facilities, including treatment supply, clinic opening hours, check-ups and viral load testing, and medication changes due to stockouts or shortages?
7. **Access to HIV prevention services:** How has COVID-19 impacted access to HIV testing, condoms, pre-exposure prophylaxis (PrEP), and voluntary medical male circumcision (VMMC)? Photographs of clinic opening times, condoms available at clinics, PrEP supplied, changes to waiting areas, and COVID-19 PPE signage at clinics will be gathered.
8. **U=U:** Have healthcare providers explained the positive impact of antiretroviral therapy (ART) adherence on participants' health? Have they seen posters mentioning "undetectable equals untransmittable" (U=U)? Have healthcare providers explained that an undetectable viral load means that one cannot transmit HIV?
9. **Living with HIV and TB comorbidities and other chronic diseases during COVID-19:** Participants are living with HIV, hypertension, diabetes, or other chronic diseases, as well as possibly TB, during the COVID-19 pandemic. Has stigma increased? Have they or their family members had difficulty accessing or adhering to treatment for a chronic disease? Have there been drug stockouts?
10. **Water and sanitation:** How has access to clean water and sanitation affected participants' ability to protect themselves, family, and their communities from COVID-19? Do they have access to clean running water? If not, how do they access water? Have they ever suffered from diarrhoea because of lack of access to clean water? How has lack of access to clean water and sanitation prevented them from adhering to their ART, PrEP, TB treatment, or other chronic medication?

Data Collection Period

Data was collected from April to November 2022 and all 10 themes were covered. The data was transcribed and translated verbatim. Participants were able to submit in their preferred language, which included English and Chichewa.

Key Findings and Data Analysis

The data was analyzed manually with the assistance of a professional qualitative analyst and the LM team. The report covers five key themes:

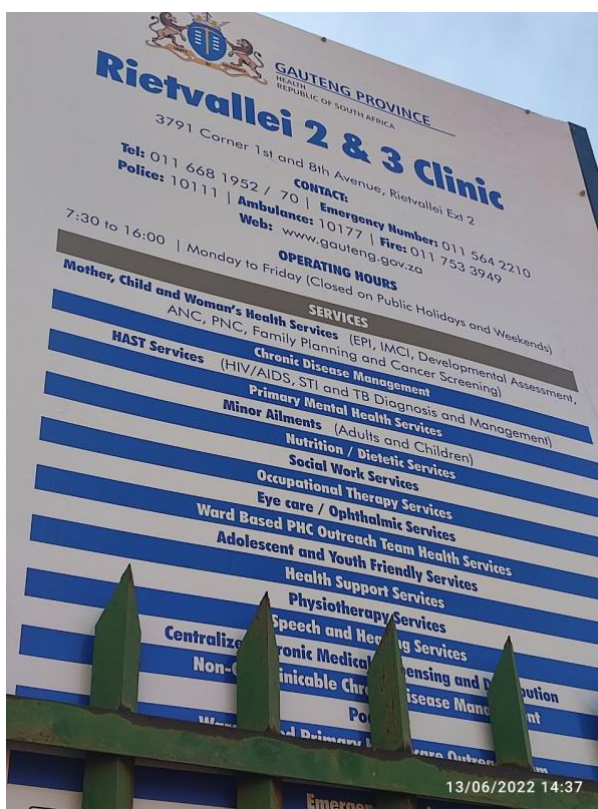
1. Impact of COVID-19 on HIV services
2. Access to HIV prevention services
3. Mental health
4. HIV U=U
5. State and gender-based/intimate partner violence.

THEME 1: IMPACT OF COVID-19 ON HIV SERVICES

a. Clinic opening times and access to healthcare during COVID-19

Most Life Maps participants in South Africa and Malawi reported that clinic opening times had not changed significantly during the COVID-19 pandemic. However, to avoid overcrowding in facilities and adhere to social distancing measures, people had to wait outside to reduce overcrowding. Accommodations were made to reduce the opening times and numbers of people entering clinics to adjust to the subsequent easing of restrictions where “things were now returning to normal.”

“Clinic opening hours at ‘my facility’ had not changed. Blantyre Adventist Hospital is open from Mondays to Fridays from [7:30am to 4:30pm]. And also, being a Private Hospital, it is open 24/7 for other emergency medical issues.” Spiderman, Malawi, 21 June 2022, text sent via Telegram



Caption: A clinic poster showing opening hours in West Rand, South Africa. *Invisible Woman, South Africa, 21 June 2022, photo shared via Telegram*



Caption: A clinic poster showing opening hours in Blantyre, Malawi. Spiderman, Malawi, 06 June 2022, photo shared via Telegram



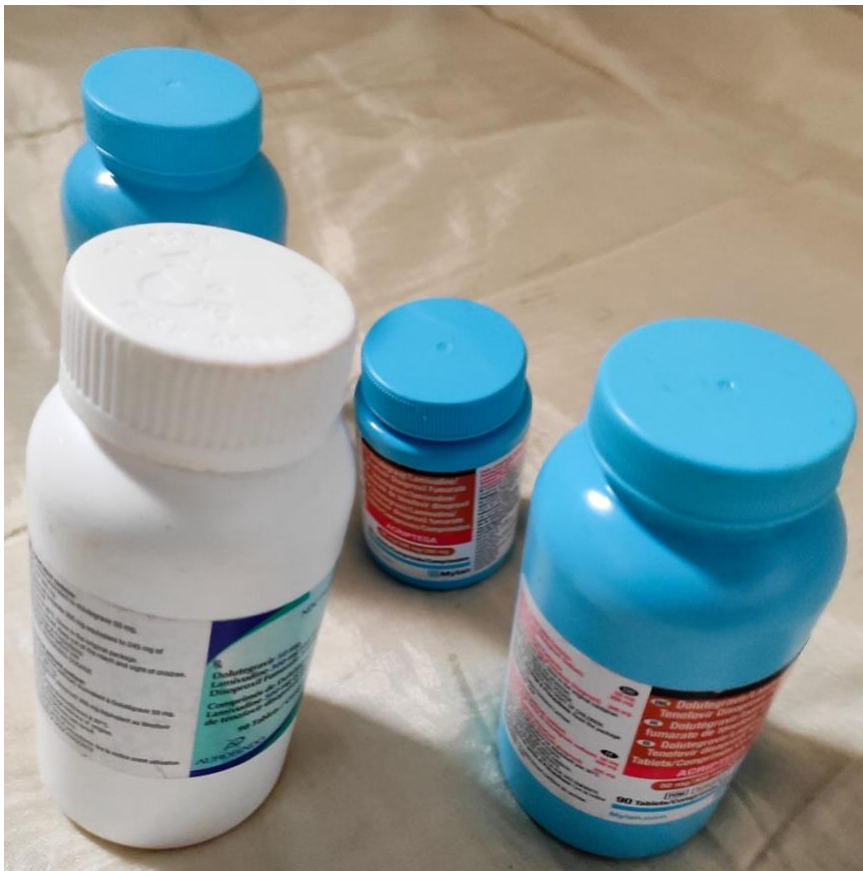
Caption: A clinic poster showing people waiting to register before entering a clinic in South Africa. Hulk, South Africa, 25 May 2022, photo shared via Telegram

b. Supply of antiretroviral treatment

In 2022, most of the Malawi participants stated that they were receiving their supplies of antiretrovirals (ARVs) every six months, whereas before the COVID-19 pandemic (2019) they received their ART every one to three months. The expansion of multi-month dispensation to six months of medication at a time was spurred in large part by COVID-19, as an adaptation to avoid crowding at clinics. However, a few participants mentioned that they were receiving their ARTs every three months and appeared to be dependent on the facility in terms of how ARTs were dispensed. All Malawian participants reported that they were no longer receiving Bactrim. Bactrim is the brand name for trimethoprim/sulfamethoxazole and is a fixed-dose combination antibiotic used to treat a variety of bacterial infections.

“ARV supply has also changed. Before they used to give 1 to 3 months. This would help to know fast if there is a problem, for example, side-effects of ARVs, and they deal with the problem fast. But for now, due to COVID-19, they give 3 to 6 months for one’s next visit. But for Bactrim, [they stop giving for no reason].” **Drax, Malawi, 6 June 2022, text sent via Telegram**

For the South African cohort, ARV supplies during the pandemic were variable and ranged from multi-month dispensing (three-six months) to monthly or two-monthly dispensing, with a few reports of medicine stockouts.



Caption: A photo of ARV medication for Rogue. Rogue, Malawi, 23 June 2022, photo shared via Telegram

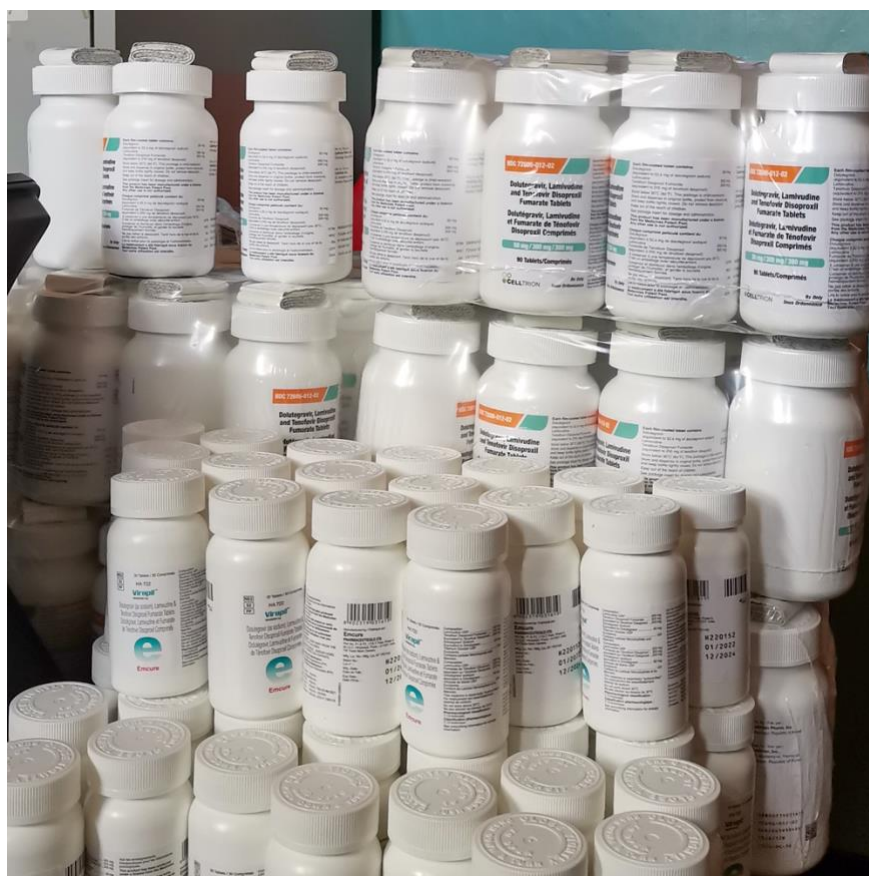
c. ARV access during COVID-19

Numerous delivery methods of ARV and other medications

South African participants reported multiple and new, innovative delivery methods of ART and other medications. These included receiving medications in-clinic, home delivery, mobile pharmacies, access at central private pharmacies, and outreach efforts to communities, such as Ward-Based Outreach Teams.

“For the supply of antiretroviral treatment, they have introduced a new system of people collecting their treatment at Dis-Chem[private pharmacy], which is called a FastTrack. They give this to people who are adhering to their treatment properly.”
Hawkeye, South Africa, 30 June 2022, text sent via Telegram

“In our clinic in the eThekweni Municipality, we have mobile pharmacies that park in the community daily to dispense medication through the Health Systems Trust. On alternate days the mobile pharmacies come in the morning or in the afternoon. Patients only go to the clinic to dispense every 6 months for a check-up.”
Wonder Woman, South Africa, 18 June 2022, text sent Via Telegram



Caption: A photo of ARV drugs at the pharmacy where Iron Man receives his medication. Iron Man, Malawi, 4 July 2022,

d. Viral load testing

Most participants reported that their viral load testing and receiving of results coincided with their three- to six-monthly collection of their ARVs at healthcare facilities. Some participants mentioned shortages of viral load testing kits and priority given to COVID-19 testing.

"We get our viral load results when we come and get our medication which is after 3 months or 6 months." **Colossus, Malawi, 14 June 2022, voice note transcript**

Another participant in Malawi mentioned how he had waited two years to obtain a viral load (VL) test and subsequent result and attributed the delays to the COVID-19 pandemic.

"COVID has affected viral load testing. I have stayed two years without a VL test only to be told that laboratories are busy with COVID-19 services. A sample was taken in March 2022, but the result is not yet out. The reason for delay could be that there are few VL testing machines." **Deadpool, Malawi, 6 June 2022, text sent via Telegram**

Other participants attributed delays in receiving viral load test results to health systems problems, such as missing results and limited viral load testing infrastructure.

"What has changed in terms of viral load testing is the time for receiving the viral load results. But they also say that your results are missing and tell us to do the test again. And it even reaches 3 times without having viral load results after being tested 3 times. In the past, we used to get tested this month and the following month when we go to the clinic, we would have our results ready and even if they gave us medication for 6 months, they would give us an earlier date to get our viral load results." **Angel, Malawi, 6 June 2022, voice note transcript**

In contrast, the South African cohort reported uninterrupted viral load testing and results during COVID-19.



Caption: A poster of viral load sample collection for children and pregnant women at Bua Hospital in Kasungu, Malawi. Black Panther, Malawi, 16 June 2022, photo shared via Telegram

THEME 2: ACCESS TO HIV PREVENTION SERVICES

a. HIV testing

Both in South Africa and Malawi, Life Maps participants reported that during the peak of the COVID-19 pandemic, HIV testing was impacted. However, with the easing of COVID-19 restrictions, HIV testing services have slowly recovered.

Nonetheless, some Life Maps participants reported that people were afraid to access HIV services at healthcare facilities for fear that they might be tested for COVID-19 or given the COVID-19 vaccine. These fears were related to COVID-19 misinformation.

“People are afraid to go to the hospital because they think that if they go to the hospital, they will get vaccinated ... People are afraid to go for tests, especially HIV, because a lot of people think that the time they are getting tested for HIV is the same time the hospital takes advantage of testing people for COVID-19. Lastly, COVID-19 has affected HIV testing. It was last week I went [to] Kanyama and I was distributing HIV self-testing kits, but some people were refusing to take the kit because they were thinking that it was the vaccine for COVID-19.” Iron Man, Malawi, 6 June 2022, voice note transcript



Caption: A clinic poster showing HIV services offered at Dedza District Hospital. Human Torch, Malawi, 27 June 2022, photo shared via Telegram

b. Access to self-testing kits

Both South Africa and Malawi Life Maps participants recounted how initially during the pandemic, HIV testing services were reduced as healthcare providers focused on COVID-19-related prevention protocols but with the easing of restrictions, self-testing kits were readily available.

“In the initial stages, COVID did impact access to HIV testing services due to the new alignment of ‘COVID-19 Prevention Protocols’ ... until people got used to the new guidelines ... HIV self-testing kits are now readily available in many health centres.” Iron Man, Malawi, 4 July 2022, voice note transcript

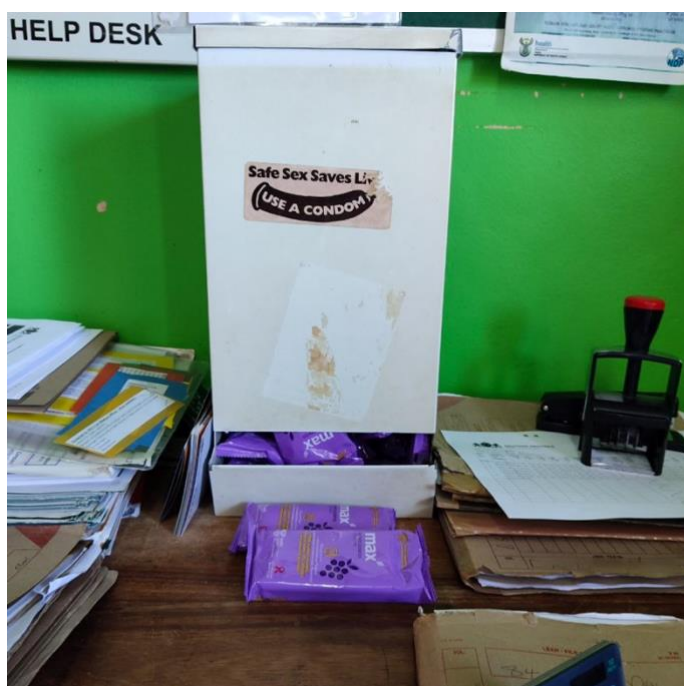
“There has been a problem. The turn up of people has been low at the hospital during COVID [which] has affected the number of clients that have been found to get tested. On the issue of self-testing kits, these were difficult to find during COVID but at least now in other health centres, they are found.” Batwoman, South Africa, 30 June 2022, text via Telegram

c. Condoms

The Malawi and South Africa cohorts reported on the availability of condoms. A few Life Maps participants reported shortages and delays in receiving supplies. Female condoms were also not readily available in most facilities.

Privacy and confidentiality were also viewed as important in the dispensing of male condoms. As a male participant explained and suggested the option of secret condom dispensers which were less visible to others.

“In many instances, men are shy to ask for condoms from female service providers. We would prefer secret condom dispensers.” The Atom, South Africa, 30 June 2022, text shared via Telegram



Caption: This is a box filled with condoms found at Dr. Martinez Ramirez clinic, South Africa. *The Atom, South Africa, 30 June 2022, photo shared via Telegram*

d. Provision of PrEP

Most of the Malawi cohort had basic knowledge of PrEP. They reported that PrEP was available mainly in district and mission hospitals, but during the COVID-19 peak periods supplies of PrEP were interrupted.

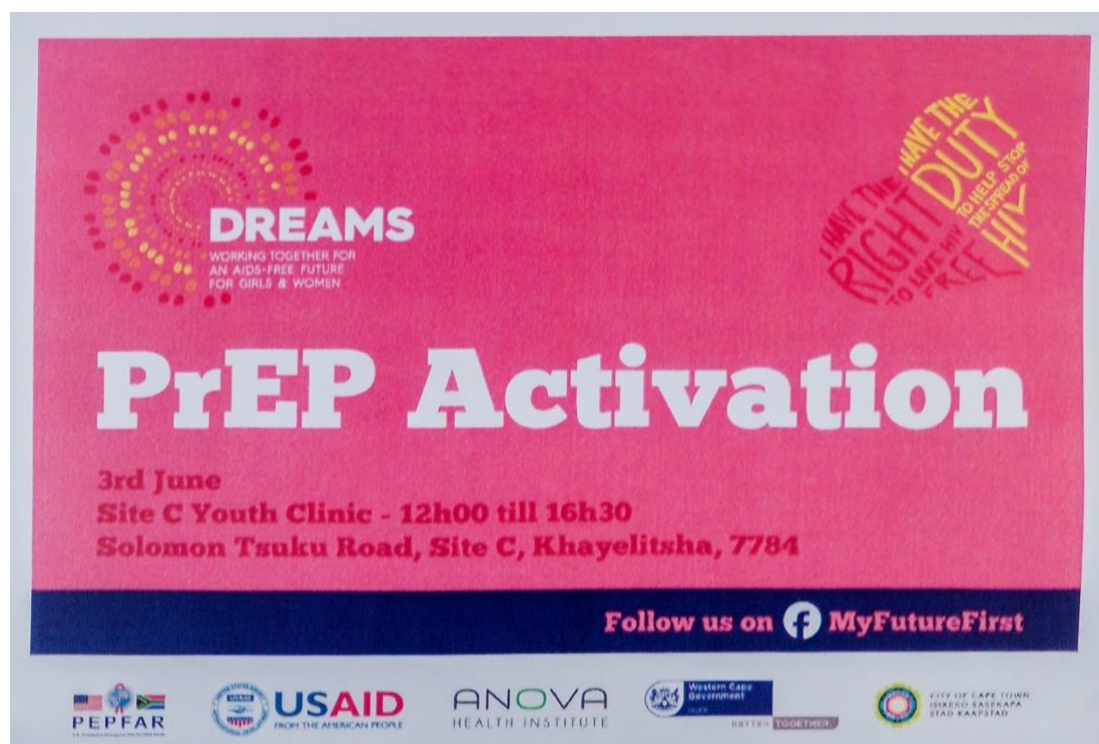
"They don't have any PrEP, but before, they provided PrEP. I think it's because it is said that PrEP can only be provided in district hospitals and mission hospitals. This is because, in smaller facilities they don't have proper tools." **Drax, Malawi, 28 June 2022, text sent via Telegram**

In the same regard, the South Africa cohort had basic knowledge of PrEP, and most participants reported that they were able to access PrEP at their regular health facilities.

It was interesting to note that almost all Life Maps participants in both countries (except for two in South Africa) had not heard about injectable PrEP and the dapivirine vaginal ring. However, they were keen to know more.

"No, I haven't heard about those things [referring to injectable PrEP and vaginal ring] but am willing to go in-depth to do some research about such information which is new to me." **Gambit, South Africa, 30 June 2022, text via Telegram**

"I have not heard or come across any information on injectable PrEP (CAB-LA) or dapivirine, vaginal ring. I will endeavour to learn more about this (new) development. May be new to me, but there might be other users out there." **Spiderman, Malawi, 28 June 2022, text via Telegram**



Caption: A poster showing PrEP activation conducted Nolungile Clinic in Khayelitsha, South Africa, *Superman, South Africa, 08 June 2022* shared via Telegram

e. Voluntary medical male circumcision

Both Malawi and South Africa cohorts reported that VMMC was performed in larger facilities such as district hospitals with the requisite infrastructure. An LM participant in Malawi explained:

“Circumcisions are not taking place in our facility this is because it is a small facility. They don't have materials for male circumcisions. But in district hospitals, they do circumcisions because they have proper materials to do the process.” **Rogue, Malawi, 29 June 2022, text via Telegram**

“No, they refer the patient to Mandela clinic, a 24-hour clinic that is in my location. We have 2 clinics. They just do vitals at East clinic, so that when the patient arrives at Mandela clinic or the hospital, they just continue with the circumcision process on the patient.” **Electra, South Africa 30 June 2022, text via Telegram**

THEME 3: MENTAL HEALTH

There was an overwhelming response to mental health issues recorded by Malawi and South Africa Life Maps participants. These included discussions around anxiety, depression, concerns around livelihoods, fear of contracting COVID-19, especially if living with HIV, and isolation due to quarantine measures. This was further underscored by anxiety and fear of the unknown in the early stages of the pandemic. A participant in South Africa noted that COVID-19 was affecting everyone, including the upper- and middle-income classes, suggesting that those with fewer resources and underlying health conditions were even more vulnerable.

a. Stressors linked to COVID-19

“As a person who is living with HIV and staying in an environment which is not good for my health, I was little bit stressed. The cause of stress to me was that COVID-19 was killing people such as doctors, politicians and other rich people who have all the resources. That is what causes an increase in stress because I did not know what was going to happen to me as a person who already has another health condition.” **Supergirl, South Africa, 25 July 2022, text via Telegram**

Financial difficulties brought about due to the pandemic also impacted interpersonal relationships adding further stress.

“COVID-19 has brought confusion, poverty, and aggression. It ended marriages and employment because of lack of money.” **Drax, Malawi, 19 July 2022, text via Telegram**

A mother in SA explained lengthy personal hygiene measures to protect herself and her family from contracting COVID-19 and the impact it had on people's daily lives.

“There has been stress caused by COVID-19 and the impacts it had on my day-to-day life. When COVID-19 started, it was not easy. I was so scared of living my life and losing the people I love and are close to my heart. I remember during those times, I didn't want to go to the shops or [have] visitors at home. I was not comfortable being around lots of people or to use public transportation. It really caused us to be stressed out. I was also paranoid. I remember after a visitor left, I would quickly sanitize where they were seated and start cleaning all over again. So, it really made us look a bit crazy. Also, when I was from town, I would take a bath again. When my daughter was from school, I made sure would she steam and take a bath, hoping that the germs would go away. So honestly, those were not great times at all. We couldn't even support each other as families during hard times (funerals) because of the number of people who were supposed to attend. So, it really made the situation worse and the pain to be more and the stress and depression to rise. But as for now, things are much better. We have learned more about COVID-19, and we have learned to take precautions and no longer be scared like before.” **Supergirl, South Africa, 27 July 2022, text via Telegram**

b. Stigma and discrimination

Some participants in South Africa and Malawi reported that the focus on the COVID-19 pandemic resulted in less stigma and discrimination towards people living with HIV.

“During this COVID-19 period, there is not a lot of stigma on people living with HIV because people are more concerned with COVID, and those with COVID are the ones stigmatized and discriminated against. Stigma has not increased because people are afraid of COVID-19 disease.” **Black Panther, Malawi, 21 July 2022, text via Telegram**

“I don't think that stigma and discrimination have increased because of COVID-19 because people were more focused on the pandemic and on how they should take care of themselves and their families”. **Night Wing, Malawi, 21 July 2022, text via Telegram**

However, this was not the case for all participants. In the experience of some, the COVID-19 pandemic had increased stigma and discrimination for people living with HIV due to the belief that they were more vulnerable to contracting COVID-19 due to a “weak immune system” and, in some instances, more predisposed to spreading the virus to others.

“During this COVID-19 pandemic, stigma and discrimination have increased against people who are living HIV positive. People are afraid to be close to us because of the news that was circulating that one of the groups of people who are at a high risk of getting COVID-19 are people who are HIV. This happens especially when you have got signs and symptoms of COVID-19 like coughing and fever. Such kind of behaviour is happening to people who have disclosed their HIV status.” **Iron Man, Malawi, 21 July 2022, text via Telegram**

“During this time of COVID, stigma and discrimination amongst us living with HIV and AIDS is much. People say that we are the ones that are spreading the diseases

because our immunity is weak, and they say that we are the ones who can easily get the disease and die.” Valkyrie, Malawi, 17 July 2022, text via Telegram

c. Provision of mental healthcare services

Most participants reported an absence of mental healthcare services at healthcare facilities. Participants sought other ways to deal with their mental health, such as seeking support from religious and social activities, listening to music, dancing, and maintaining a healthy lifestyle through exercise.

“In terms of psychologists, there are not here in Malawi. I have not heard that a person was assisted by professionals when they were stressed. A lot of people go to prophets and pastors to be assisted, but they still have their stresses and worries with them. Not a lot of people can be active on social media, it’s only a few.” Drax, Malawi, 17 July 2022, text via Telegram

“In terms of how to take care of my mental health, I like to listen to music. If something affects me so much, [I] am in deep thoughts and sometimes I cry. I just listen to music of encouragement, gospel music, and I get encouraged. And if am not very worried then I also listen to songs that I dance to, Malawian music. In terms of exercises, I like running and then my body is strong and healthy and then I like stretching myself.” Drax, Malawi, 17 July 2022, text via Telegram

d. Religiosity and resilience in the absences of mental healthcare services

Religion played a significant role in people’s lives in the absence of access to mental healthcare services.

“I do not have any worries because of COVID because I just leave everything in the hands of God.” Kai, Malawi, 24 July 2022, text via Telegram



Caption: Black Panther with choir members at his church. Religion was a stress remover for Black Panther. Black Panther, Malawi, 30 June 2022, photo shared via Telegram

THEME 4: HIV UNDETECTABLE = UNTRANSMITTABLE (U=U)

a. Life Maps Malawi cohort

Almost all the Malawi participants have heard of the term, U=U. They did understand what undetectable viral load and untransmittable meant. One participant, (Deadpool) had not heard about U=U, but after the assignment, enquired at the healthcare facility and was informed about the importance of ARV adherence and the implications of an undetectable viral load for HIV transmission. One participant did not fully understand what an undetectable viral load meant.

"I have not heard of U=U but my friend told me that U=U is a valve in our body and our bodies have 2 different valves. Other valves face upwards and people who have those valves are at a risk of getting HIV. And those that have valves facing downwards are at a lower risk of getting HIV ... In my thinking, I think that those who have valves facing upwards receive a lot of stuff in their body and they are different from those who have valves facing downwards. These people do not easily take in stuff in their body, and it takes from them to get sick and get viruses." **Black Panther, Malawi, 21 September 2022, text via Telegram**

"Undetectable means when a drop of blood is tested in a laboratory to see how many Human Immunodeficiency Viruses are present and the result of the test shows no figures. Untransmittable is when the Human Immunodeficiency Viruses are undetectable by a testing machine meaning that they are all weak and sleepy to do any harm to the human body." **Dr Strange, Malawi, 17 September 2022, text via Telegram**

The process of posing the questions around U=U enabled many participants to engage with the concepts of undetectable viral loads in relation to HIV transmission and elicited conversations around the importance of ARV adherence in the context of HIV transmission to sexual partners. Posing questions around undetectable viral loads and the implications thereof suggests that this was an important information-sharing exercise.

b. Visibility of U=U posters in health facilities

Almost all LM participants in Malawi had not seen posters mentioning U=U at healthcare clinics or hospitals. Only one person (Valkyrie) had seen such a poster but was not able to take a photo of the poster as she did not have permission to take a photo within the healthcare facility. Some participants mentioned that counsellors had shown them posters about U=U online but were still waiting for funding for posters to be displayed in healthcare facilities.

"The U=U posters ... they do not have them at the hospital, but they assured me that they explain this to their clients through the site counsellor and the coordinator. The coordinator explained to me that they have not printed the posters because they work with partners, and they are not yet out. So, they showed a poster on the

internet on which was indeed written U=U. They are waiting on funds from partners who will assist in printing the posters.” **Deadpool, Malawi, 19 September 2022, text via Telegram**

“Since 2014, when I first started taking ARVs, I have never seen a U=U poster.” **Human Touch, Malawi, 22 September 2022, text via Telegram**

“I have seen these posters in other hospitals but at our clinic, we don't have one.” **Wasp, Malawi, U=U, September 2022, text via Telegram**

c. Life Maps South Africa cohort

Half of the South African Life Maps participants had little knowledge of U=U. Data collectors and people living with HIV had some understanding of U=U. Young people had very little to no knowledge.

“Well, I never had that conversation with my doctor or nurse because I am not on ARVs as I know my status and I am HIV negative but kind of have an idea of ARVs as this is a primary teaching to everyone when taught about HIV. You can't transmit HIV if you take ARVs correctly and are virally suppressed. There is zero risk of HIV transmission via condomless sex. Missing doses of HIV medicines can reduce their usefulness and increase the possibility of developing drug resistance, which makes certain HIV drugs lose their effectiveness. A person's viral load is considered 'durably undetectable' when all viral load test results are undetectable for at least six months after their first undetectable test result. This means that most people will need to be on treatment for 7 to 12 months to have a durably undetectable viral load.”

Supergirl, South Africa, 20 September 2022, text via Telegram

“Yes, my healthcare provider emphasizes that it is important to take ARVs regularly because it helps to keep HIV undetectable. The healthcare provider also explained that being undetectable does not mean I should not use protection, because the virus is still there but doesn't have that power because of taking ARVs.” **Superman, South Africa, 16 September 2022, text via Telegram**

“Yes. She explained that the ARV treatment suppresses the virus. When a patient adheres to the treatment, it will sort of be as if the virus is not available and therefore it cannot be transmitted to others.” **Nightcrawler, South Africa, 19 September 2022, text via Telegram**

d. Visibility of U=U posters in health facilities

In the South Africa cohort, some participants confirmed that they had never seen a U=U poster though a few had seen U=U mentioned online. A few participants recalled seeing posters in a few larger public hospitals and at private doctors' offices but not in community-based clinics.

“At Dr. Martinez clinic where I collect data, I have not seen a poster mentioning U=U. I asked about it and they told me to go to a nurse who was responsible for the HIV and AIDS sector. Upon her arrival, she was still busy attending to patients, so I ended

up not finding out if she had a poster mentioning U=U in her space.” **The Atom, South Africa, 19 September 2022, text via Telegram**

“I have seen posters mentioning U=U. In most cases, they are found at the public hospitals and private doctors' places on the waiting room walls. In my local clinic where I fetched my treatment, you can't see any posters like that.” **Superman, South Africa, 16 September 2022, text via Telegram**

e. Knowledge of HIV drug resistance

From the Malawi cohort, there were varying responses to HIV drug resistance and what it meant. Some Life Maps participants understood what it meant and others did not fully understand. This would be important to explore further to support and encourage ART uptake and adherence.

“This means that a person is not taking drugs as prescribed by the doctor. As a result of this, the viral load may be higher, showing that you're not adhering to drugs. In other words, we can say that the drugs you are taking are not responding to the disease.” **Gamora, Malawi, 14 September 2022, text via Telegram**

“Yes, I have heard about HIV drug resistance. These are medications given to HIV person to prolong life, and one is required to take them for the rest of their life.” **Valkyrie, Malawi, 17 September 2022, text via Telegram**

Life Maps participants in South Africa, on the other hand, also yielded varying responses on HIV drug resistance. Some understood what it was and some did not understand.

“HIV drug resistance means that a person has been taking their treatment and then they stopped taking it and their immune system rejected them and it causes them to be at high risk.” **Hawkeye, South Africa, 27 September 2022, text via Telegram**

“Yes, I have heard of drug resistance. According to my knowledge, when you have a partner who is not taking ARV treatment and you are having unprotected sex with her. It can cause problems for her when she has to take ARV treatment because I sleep with her without protection while I'm on ARVs and she is not.” **Superman, South Africa, 16 September 2022, text via Telegram**

“No, I haven't heard about the term, HIV drug resistance. But I think that it's a drug that is used to control HIV in your body. When you use it, your body resists HIV or HIV will be suppressed. That is what I think but I am not 100% sure.” **Nightwing, South Africa, 19 September 2022, text via Telegram**

Regarding sharing viral load results with partners, most responded that they had shared their results with partners “so that they are assured they are protected from HIV, and they know that my immunity is strong.” **Vision, Malawi, 14 September 2022, text via Telegram**

Another participant explained how sharing of viral load results brought “joy” and generated discussions in the family around the implications of the results and possible “remedial approaches.”

“Sharing of my viral load results with my wife brings joy and generates discussion in our family. If the healthcare worker shares the results of suppressed viral load, it brings joy. On the other hand, if he/she raises concern, it brings sadness. As a family, we share and discuss remedial approaches.” **Spiderman, Malawi, 22 September 2022, text via Telegram**

THEME 5: STATE AND GENDER-BASED/INTIMATE PARTNER VIOLENCE

a. South Africa

While not all Life Maps participants in South Africa witnessed or experienced gender-based violence (GBV) during the COVID-19 pandemic, many discussed seeing reports on social media and the news on police brutality relating to lockdown and other COVID-19-related regulations. A participant in South Africa reported that she had seen media reports about COVID-related increases in gender-based and intimate partner violence, underscored by police and military brutality and abuse of power while they were enforcing COVID-19 lockdown regulations.

“I have seen media reports about COVID-19-related increases in gender-based and intimate partner violence. And I think it's because people were locked down and stuck together in their homes. I have also seen COVID-19-related increases in state-sponsored violence from police and the military forces. In this case, these people were abusing their power.” **Batman, South Africa, 18 September 2022, text via Telegram**

b. Access to GBV-related services, including post-exposure prophylaxis (PEP) – South Africa

Another Life Maps participant in South Africa witnessed police brutality first-hand and described what they experienced, including police aggression towards those selling alcohol illegally and not adhering to the imposed curfew. The sale of alcohol, including in restaurants and other public places, was banned in South Africa during the height of the COVID-19 pandemic.

“I saw police and military beating people when they found them on the streets after hours they were not allowed to be on the street. My neighbour, who is selling cases of alcohol now and during the COVID-19 lockdown, was always fighting with police and military because they were taking his alcohol.” **Batman, South Africa, 18 September 2022, text via Telegram**

The questions posed to Life Maps participants around gender-based and state-sponsored violence prompted some LM participants to undertake their own information gathering and, in the process, gain knowledge about HIV treatment and care.

Most participants in South Africa mentioned services available to victims of GBV. These included reporting at police stations, access to social workers at clinics, referral to hospitals for treatment of injuries, support from NGOs, and toll-free lines that provided support to people experiencing GBV. However, there was minimal discussion around the uptake of these services, including the quality of these services and whether people experiencing GBV

were assisted. One participant spoke of “victim empowerment services and a focus on the support of the LGBTQI community.” A few participants also mentioned that local clinics provided PEP services, including counselling and advice to people experiencing GBV. However, one participant did caution that despite these efforts, the justice system was still failing people experiencing GBV.

Another participant spoke about government initiatives, such as the Gender-Based Violence Command Centre, to address the high levels of GBV in South Africa.

“GBV services information is everywhere truly ... social media, TV, radio ... since it is something that is now spreading as a problem in our country. People make sure that the information for help is advertised everywhere where people can easily access it.” **Raven, South Africa, 21 September 2022, text via Telegram**

c. Malawi

Participants in Malawi spoke less about personal experiences of gender-based and intimate partner violence and more about experiences of state-sponsored violence during the COVID-19 pandemic.

“I want to explain about violence during COVID. The violence was there but not much of GBV but violence coming from the police and army.” **Deadpool, Malawi, 19 September 2022, text via Telegram**

Many Life Maps participants reported state-sponsored violence from the military and police in their attempts to enforce COVID-19-related restrictions and public health measures, such as wearing face masks. People were violently punished and beaten and, in many cases, placed in prison for perceived violations of COVID-19 restriction measures.

A participant in Malawi recounted how he was violently beaten for not wearing a face mask and had to pay a bribe to avoid imprisonment.

“Last year, I travelled to Mozambique for business issues ... on that day, I forgot to take the mask. I just saw a policeman come in front of me. He asked me why I am not wearing a mask. I told him that I have forgotten the mask, but I will buy another one. He whipped me with a sjambok [whip] on my back and requested me to pay a sum of 15 thousand Malawi kwacha. He said that if failed to pay the amount of money which he requested, he will send me to prison.” **Iron Man, Malawi, 19 September 2022, text via Telegram**

“Police people are violent when they meet people who are not wearing a mask and instead of telling them to wear a mask. They just hit people and lock them up in cells and demand for them to pay R 10,000 to be released ... And people in those cells are at a risk of getting COVID because there are so many of them in one cell.” **Jean Grey, Malawi, 19 September 2022, text via Telegram**

Overcrowding in police cells exacerbated the spread of COVID-19 and was contrary to containment measures.

Apart from reports of state violence and incarceration, participants also felt that many COVID-19 restrictions, such as being chased out of taxis and refusal of treatment due to not being vaccinated or wearing a mask, were a form of “abuse and violation of their human rights.”

“During COVID, I have experienced violence. We were told by healthcare workers from our area that children of those that did not get the COVID vaccine will not be allowed to enter the under-5 clinic. We were thinking that they were lying but we ended up not being assisted ... So, I saw this as abuse because I was forced to do things I did not want to do and even my children were failing to access under-5 clinic services.” **Jean Grey, Malawi, 19 September 2022, text via Telegram**

There were also reports of violence towards returning migrants from South Africa who were evading quarantine measures and were not vaccinated.

“I have not experienced state violence but sometimes, those who want to go outside Malawi or coming in have been hit because of not getting vaccinated. Or sometimes because they have a fake vaccination card – people are also refused entry into hospital as they have not been vaccinated.” **Human Touch, Malawi, 22 September 2022, text via Telegram**



Caption: Hawkeye attended a gender-based violence dialogue on 18 November 2022, Hawkeye, 22 November 2022, sent via Telegram Malawi

d. Access to GBV-related services, including post-exposure prophylaxis (PEP) – Malawi

Most people knew where to report gender-based violence and the process to follow, which included, reporting instances of domestic or gender-based violence at police stations. People reporting violence were then referred to healthcare facilities for care, including in some cases, receiving PEP if available. All participants reported that there were no safe houses for people experiencing GBV. Some reported that they also went to community leaders to report abuse.

COVID-19 Vaccine: Misconceptions and Myths

While not explicitly explored, discussions around the COVID-19 vaccine would be important to explore, especially in the context of the current COVID-19 trajectory and the availability of the vaccine in Malawi and South Africa. Levels of understanding, beliefs and misconceptions around the vaccine would be important to explore.

A respondent from Malawi raised serious concerns about the vaccine for people living with HIV, believing that it could be fatal for individuals living with HIV.

“Most people say that for us who are HIV positive, we should not get the COVID-19 vaccine because our immunity is already compromised, so if we get it, we can die because of the effects of the vaccine ... It was like that when the vaccine had just rolled out.” – Vision, Malawi, text via Telegram

Conclusion

Life Maps provided nuanced and in-depth insight into communities affected by the pandemic. The project further created an environment for recipients of care to lead in monitoring the delivery and uptake of HIV treatment and services. The Life Maps process facilitated self-education around different treatment modalities.

Moving forward, insights from Life Maps should be applied to the following actions:

- **Community health education.** Community-friendly information and evidence-based health education are lacking. Life Maps participants and CLM data collectors (field researchers) are well positioned to serve as peer educators on COVID-19 prevention and care (including vaccine hesitancy) and to promote HIV and TB service uptake.
- **Connect LM data to advocacy efforts with duty-bearers and decision-makers.** Life Maps helps bring the full data story to light, and more efforts are needed to bring LM insights to bear on policymakers and program implementers. In particular, insights beyond HIV, such as deeper exploration of mental health and social insecurity, should be shared. Statistics on diminishing ARV adherence, for example, are a symptom of a deeper root cause (food insecurity due to inflation).
- **Enhance opportunities to share LM data.** The photos and narratives from LMs are compelling and powerful, but have not yet been shared publicly in a timely manner due to careful and arduous internal processes focused on protecting privacy and ensuring

safety of participants. In 2023 and beyond, the ITPC team will endeavor to find ways to circulate LM photos and narratives in a more rapid – but still careful – manner.

ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CLM	Community-led monitoring
COVID-19	Coronavirus disease 2019
GBV	Gender-based violence
HIV	Human immunodeficiency virus
IPV	Intimate partner violence
ITPC	International Treatment Preparedness Coalition
MANERELA+	Malawi Network of Religious Leaders Living with or Personally Affected by HIV and AIDS
NACOSA	Networking HIV & AIDS Community of Southern Africa
PLHIV	People Living with HIV
PEP	Post-exposure prophylaxis
PrEP	Pre-exposure prophylaxis
POPIA	Protection of Personal Information Act
PPE	Personal protective equipment
TB	Tuberculosis
U=U	Undetectable = Untransmittable
VMMC	Voluntary medical male circumcision

Life Maps uses collaborative participatory visual media tools, enabling participants to document their own experiences, opening advocacy pathways, moving away from models of 'data extraction' to 'data democracy'



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