



The Good, the Bad, and the Unfinished Business

Addressing the Impact of COVID-19 on HIV and TB Services in Malawi and South Africa Through a Community-Led Monitoring Initiative

JUNE 2022

ABOUT ITPC

The International Treatment Preparedness Coalition (ITPC) is a global network of people living with HIV and community activists working to achieve universal access to optimal HIV treatment for those in need. Formed in 2003, ITPC actively advocates for treatment access across the globe through the focus of three strategic pillars:

- ▶ Intellectual property and access to medicines (#MakeMedicinesAffordable)
- ▶ Community-led monitoring and accountability (#WatchWhatMatters)
- ▶ Activism and capacity building (#BuildResilientCommunities)

To learn more about ITPC and our work, visit www.itpcglobal.org.

ABOUT WATCH WHAT MATTERS

Watch What Matters is a community monitoring and research initiative that gathers data on access to and quality of HIV treatment globally. It fulfills one of ITPC's core strategic objectives: to ensure that those in power remain accountable to the communities they serve.

Watch What Matters aims to streamline and standardize treatment access data collected by communities. It helps ensure that data is no longer collected in a fragmented way and reflects the issues and questions that are most important to people living with and affected by HIV. It relies on a unique model that empowers communities to systematically, routinely collect and analyze qualitative and quantitative data on access barriers, and use this data to guide advocacy efforts and promote accountability.

To learn more about Watch What Matters and our work, visit www.WatchWhatMatters.org.

ABOUT CITIZEN SCIENCE

COVID-19 continues to profoundly impact global health, particularly in low- and middle-income countries, where the struggle for equal access to health care has never been more important. As COVID-19 blurs traditional boundaries between journalism, advocacy, research, and policy development, ITPC has launched COVID-19 Citizen Science, a ground-breaking, community-led project documenting real-time perspectives, experiences and advocacy priorities among people living with HIV in Malawi and South Africa. Citizen Science moves from models of “data extraction” to “data democracy” by combining community-led monitoring, operational research, and an innovative research methodology that we have called Life Mapping, which uses collaborative and participatory visual media tools.

ABOUT THIS PUBLICATION

In this publication, we share “**the good**” (the scaling of COVID-related adaptations to HIV and TB services and increased people-centeredness), “**the bad**” (continued COVID-related service disruptions and quality of care issues), and “**the unfinished business**” (emerging advocacy priorities and change agendas) from a year of community-led monitoring of 29 health facilities in Malawi and South Africa.

FOR MORE INFORMATION

Please contact us at admin@itpcglobal.org.

ACKNOWLEDGEMENTS

ITPC thanks and acknowledges those who have supported our work in this critical community-led monitoring project. In particular, we recognize the tireless efforts of our partners in Malawi (MANERELA+) and South Africa (NACOSA, Access Chapter 2, and Rotanganedza Community Care), especially the 58 data collectors who steadfastly visited health facilities and communities, day in and day out, in the midst of a pandemic, watching what matters on the ground. We also commend the efforts of the 20 Life Maps participants, who shared intimate details of their lived experiences in order to improve access to health services in their communities.

We are grateful to our research partners in the School of Public Health and Family Medicine, and the Center for Social Science Research, at the University of Cape Town, South Africa.

ITPC also acknowledges support from the Bill & Melinda Gates Foundation.

Dr. Gemma M. Oberth, Independent Consultant, is the lead author of this report. ITPC would like to thank reviewers for their feedback and comments on earlier drafts.

ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CLM	Community-led monitoring
COP	Country Operational Plan
COVID-19	Coronavirus disease 2019
DHIS2	District Health Information System
GBV	Gender-based violence
HCW	Health care worker
HIV	Human immunodeficiency virus
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
PEPFAR	The U.S. President's Emergency Plan for AIDS Relief
PPE	Personal protective equipment
PrEP	Pre-exposure prophylaxis
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

CONTENTS

- 6 SUMMARY**
Citizen Science in Brief
- 7 CONTEXT**
The Impact of COVID-19 on HIV and TB Services in Malawi and South Africa
- 9 CITIZEN SCIENCE**
A New Community-Led Monitoring Methodology that Promotes Data Democracy
- 17 THE GOOD**
Findings on the Scale-up of COVID-19 Adaptations and Improved Person-Centeredness
- 24 THE BAD**
Findings on COVID-Related Service Disruptions and Quality of Care Challenges
- 31 THE UNFINISHED BUSINESS**
Data for Decision-Making, Emerging Change Agendas, and Ongoing Advocacy Actions
- 34 NEXT STEPS**
Preparing for the Next Three Years of Citizen Science

SUMMARY

Citizen Science in Brief

When the COVID-19 pandemic began, many predicted a looming catastrophe for HIV and TB responses. In high-burden settings, it was estimated that HIV- and TB-related deaths over five years may be increased by up to 10% and 20%, respectively, due to the COVID-19 pandemic.¹ Major multi-lateral organizations recommended community-led monitoring in the context of COVID-19 to help report service disruptions, commodity stock-outs, and human rights violations.²

In September 2020, the International Treatment Preparedness Coalition (ITPC) began Phase 1 of Citizen Science, a local-level community-led monitoring project focused on addressing the impact of COVID-19 on HIV and TB prevention and treatment services. We monitored 29 health facilities (two hospitals, 24 clinics, and three community health centers) in Dedza (Malawi), Kasungu (Malawi), and West Rand (South Africa), together serving a catchment of 884,000 people. Data was routinely collected for one year (October 2020 to September 2021) and retroactively collected for a pre-COVID comparison (November 2018 to October 2019).

Our findings reflect several positive trends in the scale-up of COVID-19 adaptations and improved person-centeredness (“**the good**”). In Malawi, six-month dispensing of antiretroviral therapy (ART) rose from 6% in the pre-COVID period to 31% during-COVID. Three- and six-month dispensing of pre-exposure prophylaxis (PrEP) was similarly scaled up in South Africa, from 0% in November 2020 to 53.7% by August 2021. To promote further scale-up of multi-month dispensing, advocacy should focus on improving knowledge of health care workers and quickly resolving stock-outs of medicines. We also found greater differentiation in HIV testing, with self-testing now comprising nearly a third (28.6%) of all tests in Malawi. Condom distribution increased three-fold in South Africa, thanks in part to innovative community distribution strategies. TB screening was intensified in both countries during COVID-19. There were several examples of health care workers going the extra mile, including delivering condoms and medicines at the clinic gates and paying home visits to people who missed appointments.

We also found examples of COVID-related service disruptions, human rights violations, and quality of care challenges (“**the bad**”). While HIV testing declined by 25.4% during COVID-19 for the general population, sex workers and men who have sex with men experienced decreases of 79.5% and 52.8%, respectively. Mask mandates emerged as a new barrier to access, at times being used to deny people treatment. COVID-19 exacerbated stigma and discrimination against people living with HIV, health care workers, and key populations—all of whom the general public perceived as being “COVID-19 carriers”. Before the pandemic, 23% of viral load test results in Malawi took more than three months to be returned to the recipient of care. During COVID-19, this figure rose to 39%. COVID-related food insecurity made ART adherence a challenge, and limited contact left people feeling uncared for at facilities. Better record-keeping and communication tools for health care workers would help improve the situation. During COVID-19, the number of gender-based violence survivors who walked through facility doors tripled in South Africa. In Malawi, sex workers reported police and military violence.

Using these data, ITPC and its partners are leading several ongoing advocacy actions (“**the unfinished business**”). We are helping bridge the feedback gaps in health facilities by creating regular dialogue spaces where health care workers and recipients of care can discuss our data and co-create solutions. Health care workers report that this model is motivating for them, both to address challenges and scale up good practices. We are also working to improve data sharing among departments of health and social development to improve joint services that address gender-based violence and mental health.

Using a control group scenario of eight facilities where no community-led monitoring took place but where similar data was collected, we aimed to isolate the effect of the Citizen Science project. Our intervention likely had a positive effect on mitigating the negative impact of COVID-19 on HIV testing services, translating to 10,845 more HIV tests at our monitored sites compared with the control.

Results of Phase 1 were used to inform the design and continuation of the Citizen Science project. Phase 2 is set for implementation from January 2022 to December 2024. ITPC and its partners will continue to focus on HIV prevention in South Africa and the treatment and care cascade in Malawi. New priorities, such as HIV drug resistance, community ART delivery, and new forms of PrEP, will be monitored. A costing study will also be done to support more adequate resource mobilization for such initiatives.

CONTEXT

The Impact of COVID-19 on HIV and TB Services in Malawi and South Africa

The COVID-19 pandemic

As of May 2022, South Africa has registered 3.9 million COVID-19 cases and more than 100,000 deaths. Malawi registered nearly 86,000 cases and 2,637 deaths.³

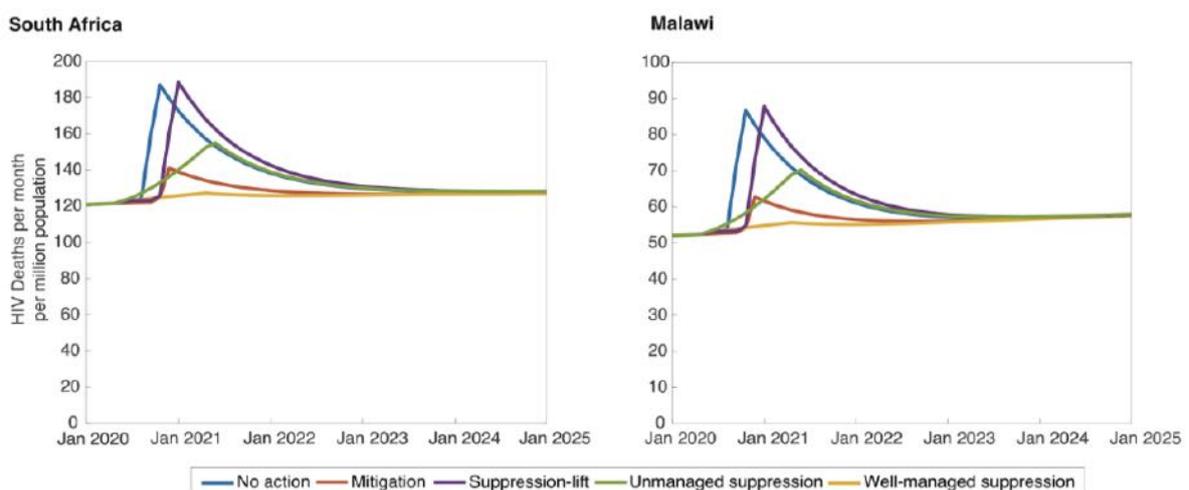
South Africa was under a state of disaster for 750 days, with varying restrictions on movement and services. There was a hard lockdown from 27 March to 30 April 2020 when people were not permitted to leave their homes. Malawi implemented an international travel ban, school closures at all levels, cancellation of public events, decongesting workplaces and public transport, mandatory face coverings, and a testing policy covering symptomatic people.⁴ In both countries, access to health care facilities for non-COVID-19 conditions was limited and resources for HIV and TB control were diverted.

COVID-19 is the fifth documented global pandemic since the 1918 Spanish flu. HIV was the fourth. For activists, researchers, and health care providers whose work has spanned these two most recent pandemics, every aspect of pandemic response presents a challenge and opportunity in using the lessons of the past to inform future work.

The impact of COVID-19 on HIV and TB

With COVID-19, many predicted a looming catastrophe for HIV and TB responses. One study estimated that in high-burden settings, HIV- and TB-related deaths over five years may be increased by up to 10% and 20%, respectively, due to COVID-19 (Figure 1).⁵ Another study suggested that as many as 230,000 excess HIV-related deaths in South Africa and 32,000 in Malawi were possible over a one-year period (2020-2021), depending on the level of treatment disruptions due to COVID-19.⁶

Figure 1. Total HIV-related deaths per million in South Africa and Malawi, by COVID-19 scenario⁷



The impact of the COVID-19 pandemic was surely felt on the delivery of HIV and TB services. A national survey (n=19,330) in South Africa found that 13.2% of people were unable to access medication for their chronic disease during the COVID-19 lockdown.⁸ Monthly TB notifications decreased by more than 50% between March and June 2020 in South Africa. In Malawi, more than 8,000 people living with HIV missed appointments within a two-week period and 30% transferred to other clinics without informing their doctors.⁹ COVID-19 was associated with an overall decrease in persons presenting with presumptive pulmonary TB (45.6%) in Malawi and in those registered for TB treatment (19.1%).¹⁰

The national policy response

In response to the crisis, both countries took swift action to issue new policy guidance. Malawi's Ministry of Health published the first edition of its COVID-19 Guidance for HIV Services on 3 April 2020—one day after the first COVID-19 case was recorded in the country.¹¹ The guidance suspended voluntary HIV testing, routine scheduled viral load monitoring, voluntary medical male circumcision, new initiations onto pre-exposure prophylaxis (PrEP), and condom distribution to walk-in clients. The guidance also noted that clinics must be open seven days a week and serve recipients of care immediately (where possible). Six months of antiretroviral medicines were to be dispensed to all people living with HIV who are stable on treatment.

Malawi also developed a National COVID-19 Preparedness and Response Plan.¹² The plan includes people living with HIV among its target populations, noting the effect of COVID-19 on people living with HIV, both health-wise and economically. There are protective policy measures for the secondary impact of COVID-19, including several aspects with clear links to HIV and TB, such as mental health, social protection, and risk mitigation of gender-based violence.¹³

South Africa's provincial Departments of Health took varying approaches, some promising two months' supply of chronic medication to reduce facility traffic and others committing to three.^{14,15,16} The Gauteng provincial Department of Health encouraged people to use "Pele Boxes" (ATM-style pick-up points) for the collection of medicines. It also issued a statement on 22 March to say that Thuthuzela Care Centres (one-stop centers for post-violence care) would extend themselves beyond providing forensic services.

The community response

Countries that engaged community-led networks and organizations in response to COVID-19 and empowered those most affected by pandemics have been more successful at ensuring the continuity of health services and protecting the rights of vulnerable people.¹⁷

In Malawi, community activists led COVID-19 awareness-raising sessions, mobilized young people to become volunteers, and engaged in district committees to ensure an effective response.¹⁸ In South Africa, civil society formed the Community Constituency COVID-19 Front and developed a Strategy to Mitigate COVID-19 through Coordinated Advocacy, Communication & Social Mobilization.¹⁹ It mobilizes the 18 sectors of the South African National AIDS Council's Civil Society Forum for multi-sectoral coordination of the COVID-19 response.

Guidance from major multi-lateral organizations recommended community-led monitoring in the context of COVID-19 to help report service disruptions, commodity stock-outs, and human rights violations.²⁰ Within the context of COVID-19, community-led monitoring provides an additional level of information on the rapidly shifting situation in countries as the pandemic progresses.

COVID-19 is the fifth documented global pandemic since the 1918 Spanish flu. HIV was the fourth.

For activists, researchers, and health care providers whose work has spanned these two most recent pandemics, every aspect of pandemic response presents a challenge and opportunity in using the lessons of the past to inform future work.

CITIZEN SCIENCE

A New Community-Led Monitoring Methodology that Promotes Data Democracy

In September 2020, ITPC began a project called “Addressing the impact of COVID-19 on HIV and TB prevention and treatment services through community-led monitoring in South Africa and Malawi”, branded “Citizen Science”. The goal of this project is to improve access to, and quality of, HIV prevention and treatment and services in the context of COVID-19, with an ultimate goal of yielding better health outcomes.

Five key activities help get us there:

1. A rapid landscape analysis, which was used to inform the design and approach of the project
2. Community-led monitoring
3. Life Maps
4. A community advocacy network
5. Operational research

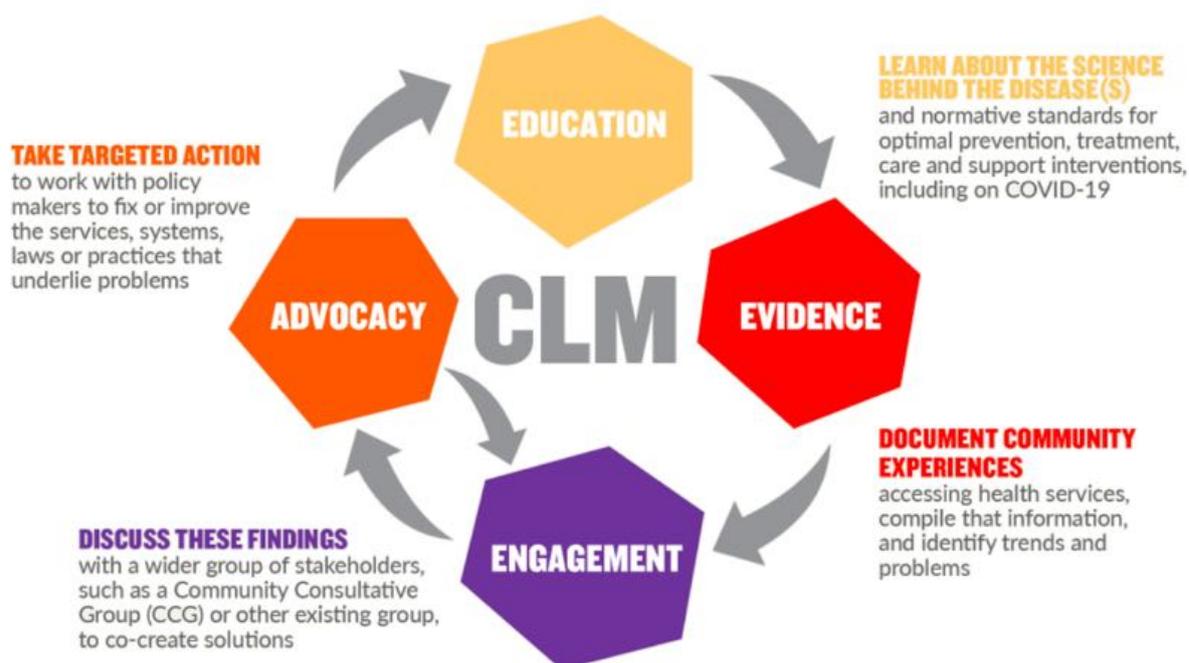
This report focuses on the findings and analysis from the community-led monitoring, Life Maps, and operational research activities.

Approach to community-led monitoring

Our approach to community-led monitoring covers four key areas: education, evidence, engagement, and advocacy (Figure 2). It is grounded in education and based on human rights, including the right to health, to ensure that all people are aware of the standard of care they are entitled to receive.

Our methods reinforce the importance of collecting and analyzing both quantitative and qualitative data. Each approach offers different but complementary insights: the quantitative data quickly brings thematic issues to light (such as decreases in the number of HIV tests administered); and the qualitative data illuminates the underlying factors (such as diversion of health resources and personnel away from HIV toward COVID-19). The triangulation of this complementary data forms a holistic picture of the full context, enabling activists to more precisely identify problems and take the advocacy action required.

Figure 2. The International Treatment Preparedness Coalition’s approach to community-led monitoring



Life Maps

Citizen Science moves from models of “data extraction” to “data democracy” by combining community-led monitoring, operational research, and a novel methodology we call “Life Mapping”, which maps the lived experiences of people using collaborative and participatory visual media tools. We provided participants with mobile phones, data, and training, enabling them to document their experiences and share their perspectives before and during the COVID-19 pandemic, including access to HIV and TB prevention and treatment services and their expectations for the future. Life Maps participants are then empowered to use their own data to advocate for real-world changes, such as improved quality of care and social support.

Project partners

In Malawi, ITPC partners with the Malawi Network of Religious Leaders Living with or Personally Affected by HIV and AIDS (MANERELA+) for the Citizen Science project. In South Africa, ITPC partners with the Networking HIV & AIDS Community of Southern Africa (NACOSA), which collaborates with Access Chapter 2 and Rotanganedza Community Care on implementation.

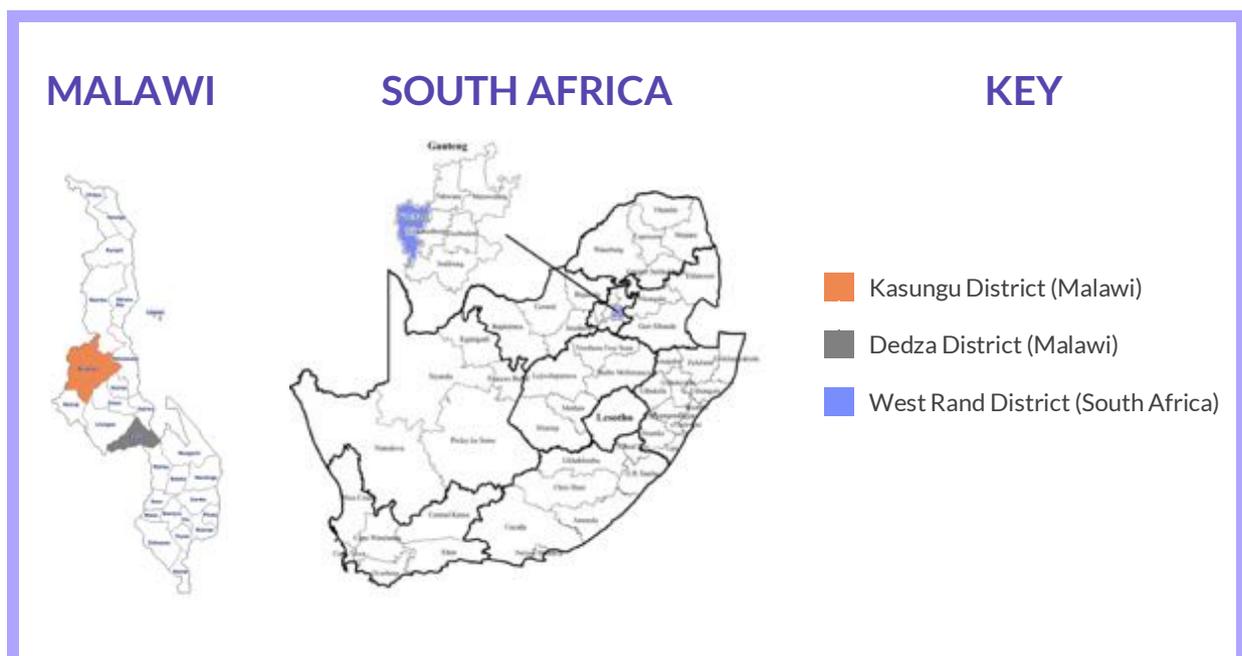
Implementing partners have formed strong partnerships with local health authorities in the areas where they collect data. NACOSA has a memorandum of understanding with the Gauteng Department of Health and has built relationships with the West Rand District Chief Director and Chief Director of District Health Services. MANERELA+ works closely with District Health Offices during district-level planning, which starts in April each year. Partnerships with the 29 health facilities have also strengthened in both countries.

The project is funded by the Bill & Melinda Gates Foundation.

Site selection

Geographically, Citizen Science focused on three districts: Dedza (Malawi), Kasungu (Malawi), and West Rand (South Africa) (Figure 3). Districts were selected based on contextual factors. For example, West Rand is an under-resourced mining community and Kasungu has had a history of famine and cholera outbreaks—factors that exacerbate HIV and TB challenges. Districts were also chosen to avoid duplication by ensuring that the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis and Malaria were not currently funding community-led monitoring there.

Figure 3. Locations of the ITPC Citizen Science community-led monitoring project



We monitored 29 health facilities in total (five in Dedza, 10 in Kasungu, and 14 on the West Rand) (Table 1), including two hospitals, 24 clinics, and three community health centers. Together, they served a catchment area of 884,000 people. Four facilities were in urban locations, nine in peri-urban locations, and 16 in rural areas. In Malawi, six of the sites offered specific services to key populations. In South Africa, one site (Carletonville Central Clinic) was certified as an “Ideal Clinic”, a national benchmarking initiative that began in July 2013. All sites had existing Health Advisory Committees that included key and vulnerable populations; however, in Malawi, these committees were not active.

Data were collected on a routine and systematic basis for one year, from October 2020 to September 2021. Some data were also collected retroactively, from November 2018 to October 2019, enabling a pre-COVID comparison.

Relationships with researchers at the University of Cape Town helped ensure robust methods data quality.



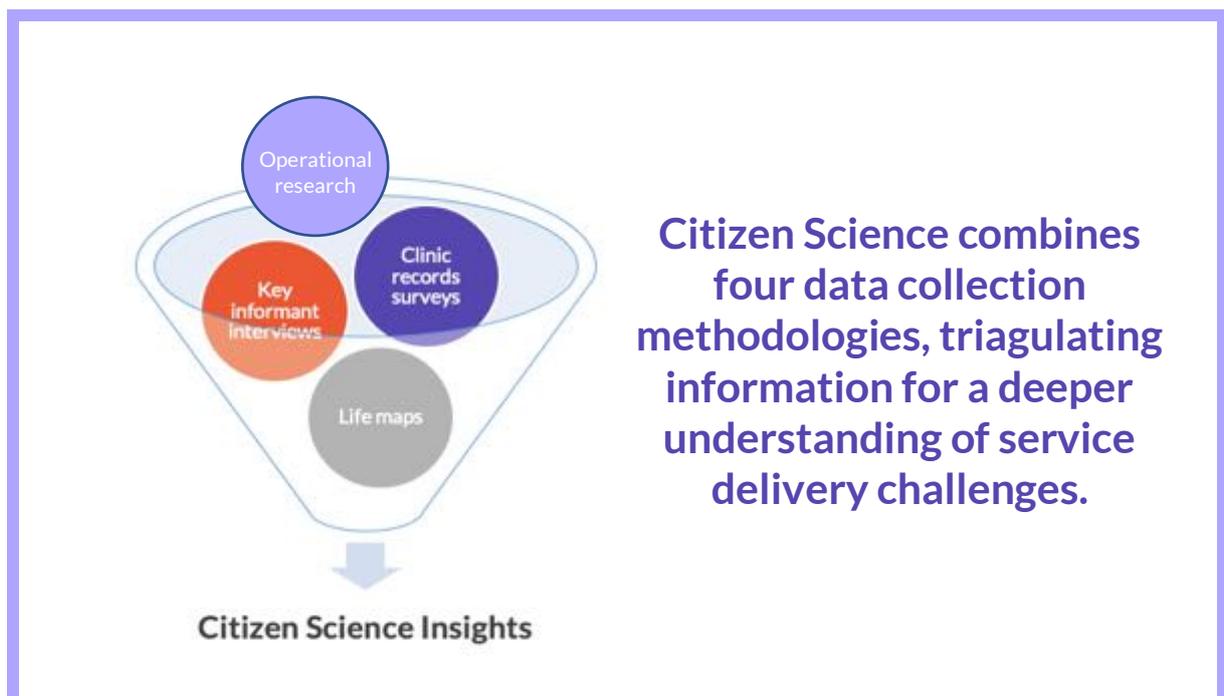
Table 1. Health facilities monitored in ITPC’s Citizen Science community-led monitoring project

Facility name	District	Facility type	Location	Catchment area
MALAWI				
Dedza District Hospital	Dedza	Hospital	Urban	28,906 people
Mayani Health Centre	Dedza	Health center	Rural	29,122 people
Tsoyo Health Centre	Dedza	Health center	Rural	22,653 people
Kaphuka Health Centre	Dedza	Health center	Rural	30,855 people
Lobi Health Centre	Dedza	Health center	Rural	27,570 people
Kasungu District Hospital	Kasungu	Hospital	Urban	98,812 people
Bua Health Centre	Kasungu	Health center	Rural	54,716 people
Mnyanja Health Centre	Kasungu	Health center	Rural	30,916 people
Santhe Health Centre	Kasungu	Health center	Rural	24,472 people
Dwangwa Health Centre	Kasungu	Health center	Rural	36,026 people
Chamwabvi Health Centre	Kasungu	Health center	Rural	42,248 people
Mziza Health Centre	Kasungu	Health center	Rural	28,839 people
Chulu Health Centre	Kasungu	Health center	Rural	38,652 people
Mtunthama Health Centre	Kasungu	Health center	Rural	20,702 people
Kaluluma Health Centre	Kasungu	Health center	Rural	19,818 people
SOUTH AFRICA				
Carletenville Central Clinic	West Rand	Primary health care clinic	Urban	19,023 people
Khutsong CHC	West Rand	Community health center	Peri-urban	22,834 people
Thusanang Clinic	West Rand	Primary health care clinic	Peri-urban	19,548 people
Dr Martinez Ramirez	West Rand	Primary health care clinic	Peri-urban	38,096 people
Krugersdorp Central Clinic	West Rand	Primary health care clinic	Urban	35,873 people
Tartlon Clinic	West Rand	Primary health care clinic	Rural	19,777 people
Mogale Clinic	West Rand	Primary health care clinic	Rural	23,467 people
Odirileng Maponya Clinic	West Rand	Primary health care clinic	Peri-urban	38,401 people
Eric Ndeleni Clinic	West Rand	Primary health care clinic	Peri-urban	38,401 people
Maki Legwete Clinic	West Rand	Primary health care clinic	Peri-urban	38,069 people
Badirile Clinic	West Rand	Primary health care clinic	Rural	11,313 people
Mohlakeng CHC	West Rand	Community health center	Peri-urban	39,474 people
Bekkersdal West CHC	West Rand	Community health center	Peri-urban	31,779 people
Zuurbekom Clinic	West Rand	Primary health care clinic	Peri-urban	17,302 people

Mixed methods for better data triangulation

Citizen Science combines four data collection methodologies: (1) surveys of clinic records, (2) key informant interviews, (3) Life Maps, and (4) operational research. These data are then layered and combined, helping to triangulate information and deepen understanding of service delivery challenges.

- ▶ **Surveys of clinic records:** Using a data collection tool with pre-defined indicators, ITPC and its partners collect quantitative data on a monthly basis from anonymized health facility records. In Malawi, the tool has 26 indicators, focused on differentiated service delivery along the treatment cascade. In South Africa, the tool has 13 indicators, focused on HIV prevention. A total of 637 monthly clinic records surveys were completed: 330 in Malawi and 307 in South Africa. ITPC uses clinic records surveys to gather data about specific points of service quality to support and triangulate our other community-led monitoring data (rather than replicating pre-existing government monitoring).²¹
- ▶ **Key informant interviews:** ITPC and its partners conducted 167 key informant interviews in Malawi (83 health care workers and 84 recipients of care) and 151 interviews in South Africa (55 health care workers and 96 recipients of care). Different questions were asked of health care workers versus recipients of care. Questions focused on understanding barriers to access and ways that services could be improved.
- ▶ **Life Maps:** 20 people living with HIV (10 in each country) were engaged in life mapping, a ‘citizen journalism’ approach to documenting how COVID-19 impacts daily life. We provided participants with mobile phones, airtime/data, and training, enabling them to document their experiences and share their perspectives. Every few weeks, a new topic was introduced to the group, using a prompt (for example, “Tell us how COVID-19 has impacted your mental health”) covering themes like access to HIV and TB services, gender-based violence, and expectations for the future. Participants shared photos, voice notes, text messages, and other media in response to the prompts.
- ▶ **Operational research:** We observed and engaged with 19 health workers at Dedza and Kasungu facilities in Malawi in November and December 2021 to better understand the “know-do gap”—why health care workers do not do in practice what they say they will do in clinical vignettes. (In other words, they do “know” the standards of care when given a hypothetical clinical scenario, but they do not actually “do” them while engaging with a real recipient of care.)²²



The Citizen Science dataset at a glance



2 countries

Malawi and South Africa



3 districts

Dedza (Malawi), Kasungu (Malawi), and West Rand (South Africa)



29 health facilities

3 hospitals, 3 community health centers, and 24 clinics
5 in Dedza, 10 in Kasungu, 14 on West Rand



58 data collectors

16 men (including 5 men who have sex with men and 7 men living with HIV)
41 women (including 4 young women, 5 sex workers, 2 lesbians, 1 trans woman, and 9 women living with HIV)
1 gender non-conforming person



884,000 beneficiaries

Total catchment area of the monitored health facilities



1 year of continuous monitoring (October 2020 – September 2021)

Plus, retroactive data collection for a pre-COVID comparison (October 2018 – September 2019)



637 surveys of quantitative clinic records

330 in Malawi and 307 in South Africa, with a total of 32 indicators monitored



318 qualitative interviews

138 with health care workers and 180 with recipients of care



20 Life Maps

Citizen journalist approach to documenting how COVID-19 affects daily life for people living with HIV



19 health care workers observed in operational research

Gaining better understanding of the “know-do gap” – why knowledge and practice do not always align.

The central role of Citizen Science data collectors

The central role of data collectors in the Citizen Science project cannot be overstated. Data collectors are those individuals tasked with gathering community-led monitoring information on a recurring basis. Usually, this means that data collectors enter health facilities, often on a daily basis, with clipboards to fill out checklists of quantitative indicators (for example, surveying clinic records to monitor the number of HIV tests conducted at that clinic each month or documenting the specific medications that are out of stock at a given time). They also gather information about qualitative indicators (for example, by conducting qualitative interviews with service users about their experience accessing health services and with health care workers about their experiences providing care).

Critically, our data collectors are all from the local communities that are served by the health facilities they monitor. The data collectors are uniquely motivated to pay close attention to issues of service access and quality as these directly affect their lives and the lives of their friends and families. While collecting this information, data collectors gain trust and often build good working relationships with both clinical staff and recipients of care.

We also purposefully engaged data collectors from key and vulnerable populations. More than two-thirds of our data collectors—40 out of 58—are from these groups. Specifically, our data collection team is comprised of four young women (<25 years), five men who have sex with men, five female sex workers, two lesbian women, one trans woman, one gender non-conforming person, six young people living with HIV, seven men living with HIV, and nine women living with HIV. This helps sensitize health care workers and reduce stigma.



40 of our 58 data collectors are from key or vulnerable population groups. This helps empower communities, sensitize health care workers, and reduce stigma.

Out of 58 Citizen Science data collectors:



9 are women living with HIV



7 are men living with HIV



6 are young people living with HIV



5 are men who have sex with men



5 are female sex workers



4 are young women aged 18-24 years



2 are lesbian women



1 is a trans woman



1 is a gender non-conforming person

Skills-building and gainful employment for these communities is part of the Citizen Science project's empowerment approach. Data collectors received training on community-led monitoring, quantitative and qualitative research methodologies, data management, monitoring and evaluation, advocacy techniques, treatment literacy, key populations, gender-based violence, and current HIV and TB guidelines and standards. In South Africa, data collectors also received technical systems training on the District Health Information System (DHIS2) and TIER.net (the national HIV e-register where data can be found) from the sub-district Department of Health coordinator. In some cases, data collectors were able to leverage their new skills to find additional work. Some are now working in the health facilities doing administrative tasks and helping with the sorting of results and recording of the blood bank.

The Citizen Science principle of going from data extraction to data democracy means that data collectors are not just gathering information—they are also change agents within the health facilities and communities, using their own data for improved accountability. The data collectors regularly interact with the health facility staff about their findings and analysis, co-creating solutions to problems they see. They also share their data with the wider community, engaging them in the advocacy agenda.



Citizen Science data collector Makhatzle Engie Tiba (left) with local government HIV secretariat member Lulu Kotobe Sosibo (right) at the Badirile Clinic in West Rand, South Africa (February 2022)

COVID-sensitive community-led monitoring

Doing community-led monitoring during the COVID-19 pandemic requires special considerations.

We tailored the indicators for the surveys of clinic records, questions for the interviews, and themes for Life Maps to HIV and TB in the context of COVID-19. Indicators were defined by the community-led organizations implementing the project, with technical support from ITPC and guidance from research experts at the University of Cape Town.

We also purposefully collected some facility data for a retroactive period before COVID-19 (November 2018 to October 2019), a practice recommended in the World Health Organization's (WHO's) "Monitoring and evaluation framework for the COVID-19 response in the African Region".²³ This approach of evaluating data from before and during COVID-19 allowed us to see the impact that COVID-19 may have had on certain services.

Personal protective equipment was provided to all data collectors and Life Maps participants. Data collection was sometimes tailored to be sensitive to social distancing regulations (for example, sitting 1.5 meters apart for interviews or doing interviews virtually). In some instances, data collection was paused during intense waves of new infections or when data collectors themselves fell ill.

Harnessing technology

ITPC's partners use a mix of paper-based and digital data collection tools (tablets), depending on the location. Once collected, data are entered into a centralized online portal. This database is accessible to data supervisors anywhere in the world, allowing for real-time quality assurance. ITPC and its partners can also access up-to-date data at any time, ensuring that advocacy opportunities are never missed.

Data protection

To ensure the safety of digital data collection, ITPC developed a Data Security Policy. This policy outlines considerations on data management to navigate confidentiality and data security of data collected. The policy was finalized towards the end of Phase 1 of the Citizen Science project and will be used to strengthen data integrity among the implementing partners in Phase 2.

Ethical considerations

Clearance for the Citizen Science project was sought from the administrative authorities where data collection was done. Different approaches were taken in the two countries based on local requirements for community-led monitoring projects. In Malawi, ethical clearance was received from the National Health Science Research Committee. In South Africa, a letter was provided by the provincial Department of Health in Gauteng to allow for data collection within health facilities.

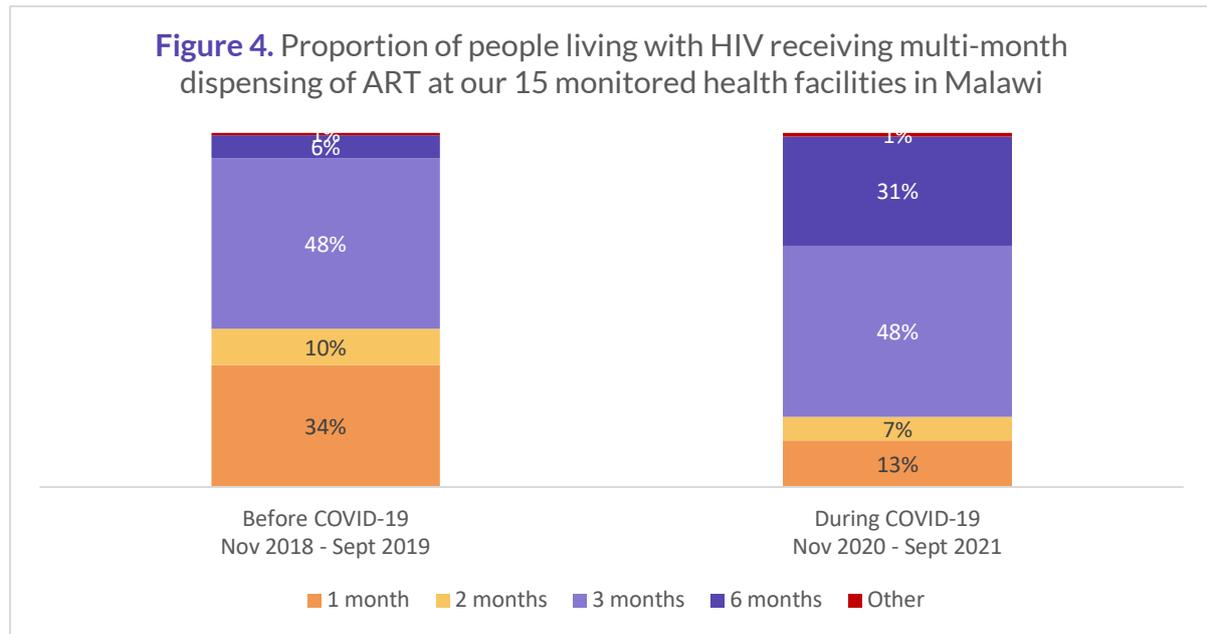
Data is anonymized to the extent possible in all of ITPC's community-led monitoring to protect the confidentiality and privacy of participants. Data collectors conduct the clinic records surveys from anonymized systems, such as DHIS2 and TIER.net. Health facility names do not appear on data collection tools or in the centralized database; they are replaced with code numbers. The same process is followed for data collectors' names; initials are used. All participants sign informed consent forms before participating in the project.

THE GOOD

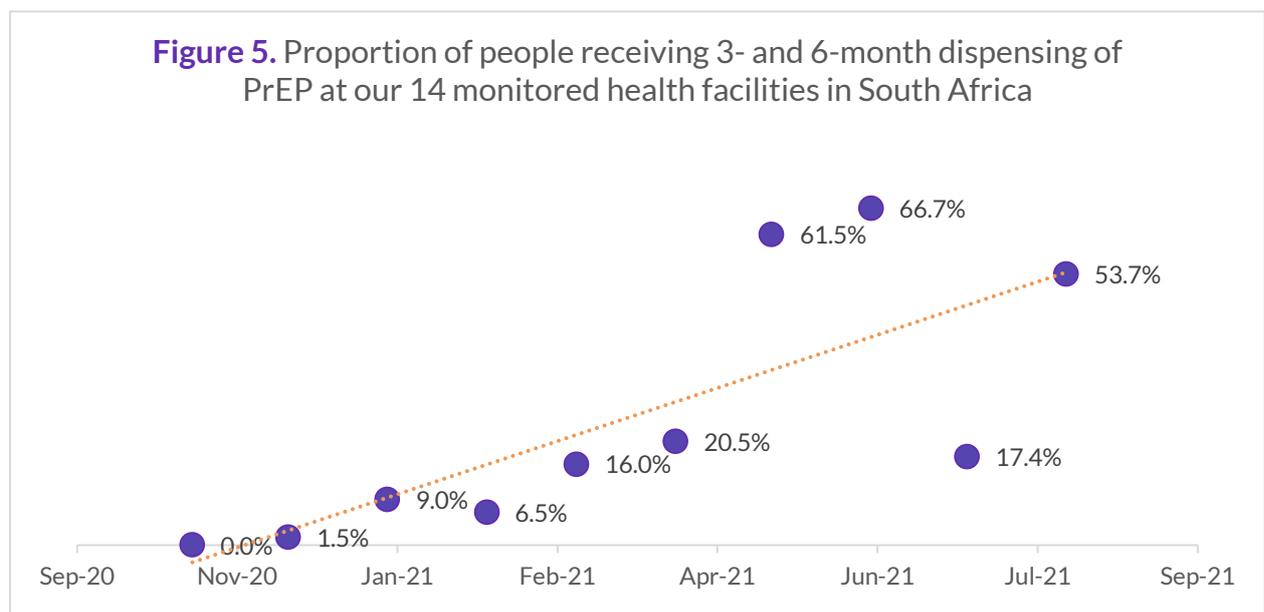
Findings on the Scale-up of COVID-19 Adaptations and Improved Person-Centeredness

Expansion of multi-month dispensing

Our data show how COVID-19 has hastened the change in the delivery of HIV treatment services in the 15 monitored facilities in Malawi. Using multi-month ART refills is a protocol in which people living with HIV are able to collect multiple months' worth of medication at one time, rather than needing to return to the clinic for refills each month. Multi-month refills are now much more widely implemented, although WHO has recommended them since 2016. At our monitored sites in Malawi, six-month ART dispensing rose from 6% in the before COVID-19 period to 31% during COVID-19 (Figure 4).



In South Africa, our data show similar positive trends towards greater access to multi-month dispensing. Here, our project is focused on HIV prevention, so we are monitoring access to and uptake of PrEP rather than ART. Our data show that three- and six-month dispensing of PrEP was scaled up from 0% in November 2020 to 53.7% by August 2021 (Figure 5).



When community-led monitoring drives the global conversation on data

ITPC and its partners started collecting data on multi-month dispensing of ART in September 2020 because it was particularly relevant to people living with HIV in the context of COVID-19. A year and a half later, in February 2022, UNAIDS added multi-month dispensing of ART as a brand-new indicator in Global AIDS Monitoring.²⁴

Ways to promote further scale-up of multi-month dispensing

Despite these positive changes, barriers to further scale-up of multi-month dispensing were identified in both countries. Our data suggest that to promote further scale-up of multi-month dispensing, advocacy should focus on improving health care worker knowledge and resolving stock-outs of medicines.

Improve health care worker knowledge

During interviews with health care workers in Malawi, some expressed reluctance to offer multi-month dispensing of ART for fear of losing clinical oversight: *“Some of the programs have been affected [by COVID]. For instance, people living with HIV are given six months of medication, which is very difficult for health personnel to make a follow-up if he or she is facing any problems with their medications”*. A recent cluster-randomized trial in Malawi demonstrated that clinical visits with ART dispensing every six months is non-inferior to standard-of-care and three-monthly ART dispensing.²⁵ Our partners in Malawi are advocating for health care worker training to include this updated information.

As in Malawi, health care workers in South Africa raised concerns about multi-month dispensing without adequate monitoring and counseling of recipients of care. An enrolled nurse in South Africa said: *“Patients are just taking medication and leaving without consulting with a doctor or nurse.”* Similarly, a health educator and advocate said: *“... most cases, they prepack their medication. They don't monitor them or educate them about the medications, and you will never know if they take the medicine properly”* (Studies in South Africa have shown that contrary to concerns about the responsibility of recipients of care to manage larger quantities of ART, those receiving six-month refills were highly motivated and did not face challenges in transporting, storing, or adhering to treatment.²⁶

In South Africa, data collectors noted that *“health care workers had no idea why some people are getting one month, some are getting three months, and some are getting six months. They just know they must give PrEP.”* NACOSA will start offering PrEP training to health care workers in the second phase of Citizen Science.

Our data show that COVID-19 had a direct effect on health care worker knowledge by limiting refresher trainings and other technical updates. One health care worker in Malawi said: *“We used to have meetings where we were updated on different health issues but now due to COVID, we no longer hold the meetings, so we are mostly left in the dark”*. This helps explain why health care worker knowledge on multi-month dispensing has not kept pace with the science.

The operational research component of Citizen Science found that ITPC's partners can play an important role in helping fill knowledge gap among health care workers. One health care worker said: *“MANERELA+ should continue frequent sensitizations and trainings, both at facility and community levels. The trainings for health workers are useful. Not all health workers know enough about HIV treatment, HIV prevention, or issues such as confidentiality and discrimination and how to engage key populations.”*

“We used to have meetings where we were updated on different health issues but now due to COVID, we no longer hold the meetings, so we are mostly left in the dark.”

– Health care worker, March 2021, Kasungu, Malawi

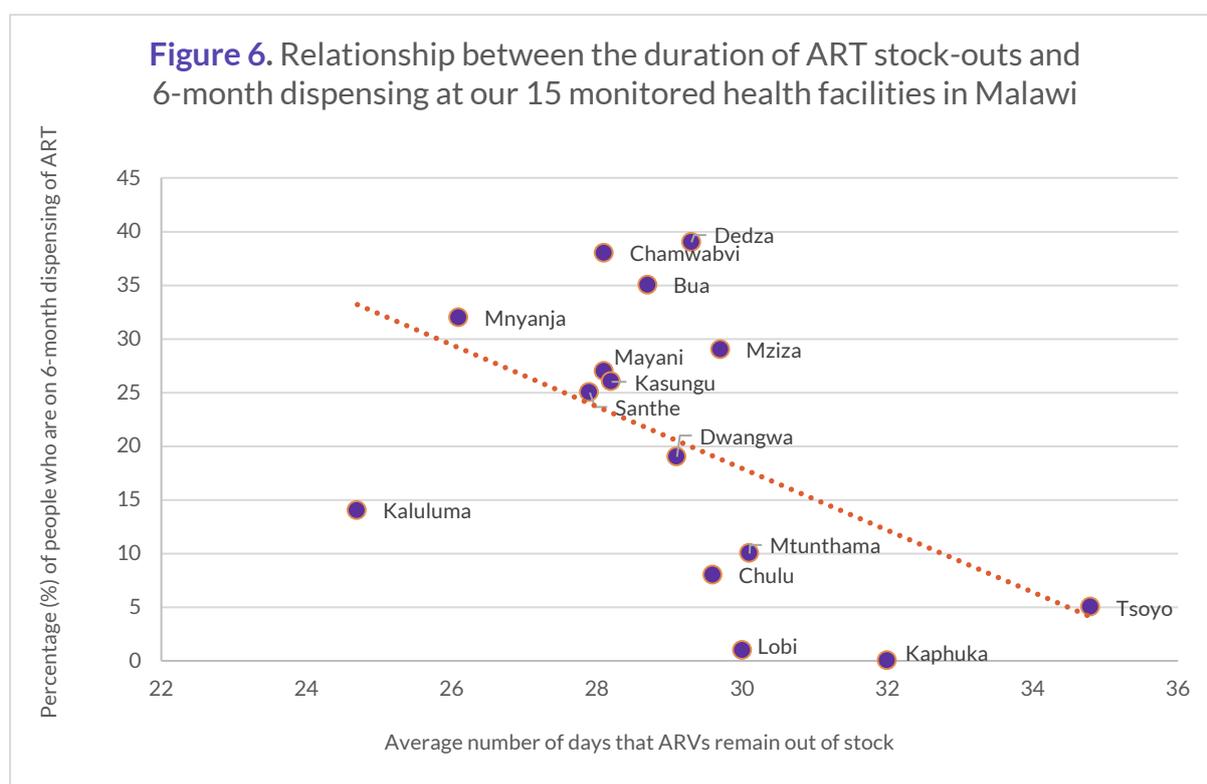
Quickly resolve any stock-outs

A sub-analysis of our quantitative data in Malawi—down to the facility level—revealed that the duration of ART stock-outs at a given clinic can predict the proportion of people there who are offered six-month dispensing ($r\ 0.50$; $p\ 0.057$); the longer ART remained out of stock, the fewer people were offered six-months of ART (Figure 6).

Malawi’s guidelines say that health care workers should confirm sufficient stocks at the facility before expanding six-month dispensing.²⁷ However, what is particularly interesting is that the frequency or type of stock-out was not related to dispensing patterns. In other words, the main bottleneck for six-month dispensing is not whether stock-outs occur, but rather, how quickly they are resolved. Our partners have therefore focused their advocacy on ensuring that there are rapid alert and response systems to stock-outs at facilities.



Our data show that the main factor delaying further scale-up of six-month dispensing is not whether stock-outs occur, but rather, how quickly they are resolved.

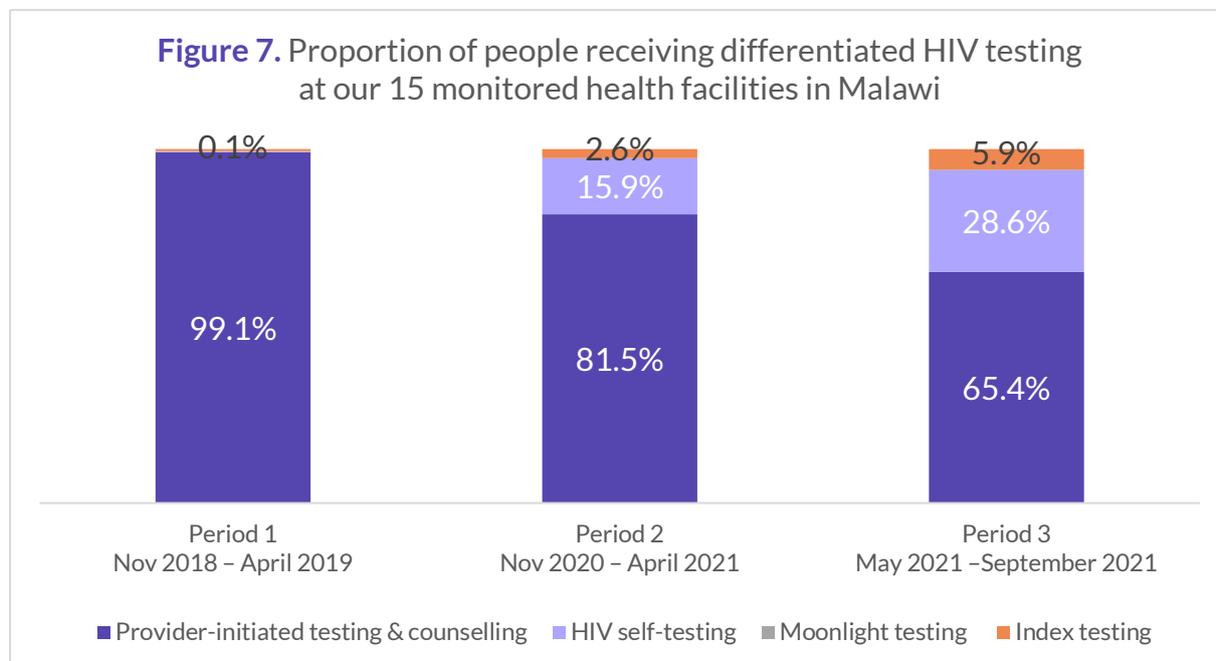


In South Africa, stock-outs of PrEP were also said to hamper scale-up of multi-month dispensing. In October 2020, one Global Fund implementer said: “We have had severe problems with PrEP. We had to really decrease. At times we didn’t even have one bottle of pills to give. There were very big stock-out problems. We had to make loans from this one and give to that one. There was no way we could hand out three months of pills to anyone.” Data collectors also cited a lack of PrEP availability at facilities. One said: “The clinic has no PrEP; it is supposed to start anytime now”. Another said: “There was no PrEP, it was initiated only this March”.

The national Department of Health committed to making PrEP available at all community health centers and primary health care clinics in South Africa by end September 2020. Yet, by January 2021, just 36% were providing the pills.²⁸

Greater differentiation in HIV testing services

Surveys of clinic records show a rapid scale-up of HIV self-testing at the 15 monitored sites in Malawi. As a proportion of all HIV tests performed, self-testing rose from 0.1% in 2018/2019 to 15.9% in 2020/2021 and 28.6% in 2021 (Figure 7). Malawi’s guidelines say that health care workers should consider HIV self-test kits for outpatient department clients to minimize contact.²⁹ WHO has recommended HIV self-testing since 2016. COVID-19 appears to have accelerated its roll-out.



When asked, “Has COVID-19 impacted access to HIV testing?”, Life Maps participants in South Africa noted increased self-testing due to perceived risk of COVID-19 infection at clinics and limited clinic access. As a participant said: “A lot of people were taking tests at home. They were HIV testing at home. They would buy those tests, those home test kits, so they don’t have to go to the clinic because of the queue, and because they were scared they would be infected by COVID”.

Improved same-day treatment initiation rate

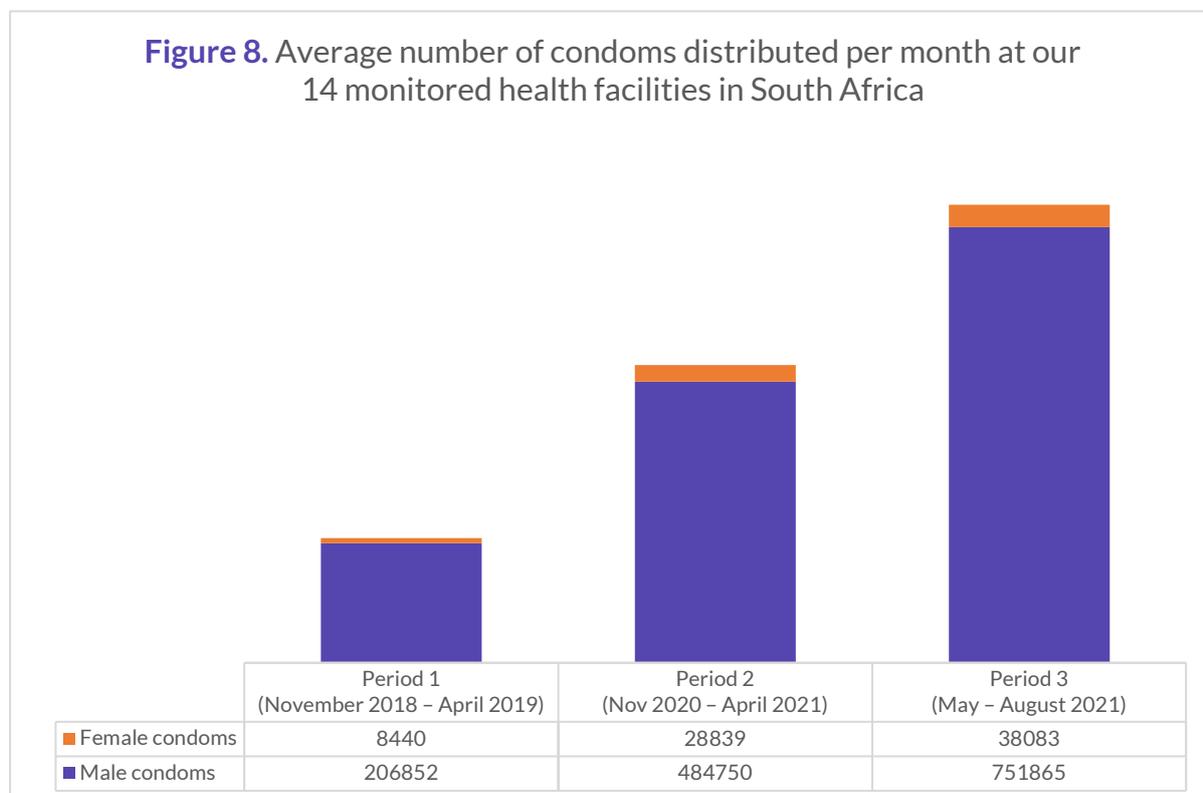
We found improved rates of same-day treatment initiation for people newly diagnosed with HIV at our 15 monitored facilities in Malawi (Table 2). Pre-COVID, 83.6% of people newly diagnosed with HIV were started on HIV treatment that same day. During COVID-19, this figure rose to 91.1%.

In accordance with WHO recommendations and to reduce traffic at health facilities, many countries adjusted their protocols to implement rapid ART initiation during the COVID-19 pandemic and urged same-day ART initiation when not medically contraindicated.^{30,31} In Malawi, approximately 13% of individuals who test positive for HIV fail to initiate treatment, even though Malawi adopted a universal treatment policy in July 2016 and prioritizes same-day ART initiation.³²

Table 2. Same-day treatment initiation rate at our 15 monitored health facilities in Malawi			
Time period	Number of HIV-positive test results	Number of people initiated onto ART same day as HIV-positive test result	Same-day treatment initiation rate
Before COVID-19 November 2018 – September 2019	3,428	2,866	83.6%
During COVID-19 November 2020 – September 2021	2,179	1,986	91.1%

Increased condom distribution

At our 14 monitored health facilities in South Africa, we saw a more than three-fold increase in the average number of male condoms distributed each month compared with pre-COVID-19 times (Figure 8). For female condoms, monthly distribution increased more than four-fold. South Africa’s amended COVID-19 lockdown regulations placed condoms on the essential goods list, helping ensure sustained access.³³



UNAIDS recommends supplying 30–50 condoms per male per year in high-prevalence countries like South Africa.³⁴ Based on the catchment areas served, our 14 monitored facilities should be distributing between 5,817,750 and 9,696,250 condoms per year or between 484,813 and 808,021 per month. Before COVID-19, they were falling short of this benchmark. A year into the pandemic (Period 2), the lower estimate of the condom need was being met. By August 2021, our facilities were nearly at the upper estimate.

Our qualitative data shed light on the innovative ways that health care facilities ensured condom distribution during COVID-19. One enrolled nurse said: “*We put the condoms outside there by the guards. If you can go now, we have lots of condoms there.*” Clinics also partnered with local community-based organizations to distribute condoms outside of health facilities (photo below).



Community-based organization distributing condoms at a busy intersection and truck stop in Randfontein, West Rand, South Africa (February 2022)



Life Maps submissions showing availability of condoms in Malawi (left) & South Africa (middle & right)

In Malawi, average monthly condom distribution at the 15 monitored sites decreased from 219,627 before COVID-19 (November 2018-April 2019) to 95,181 during COVID-19 (November 2020-April 2021), but has since begun to rebound again, climbing to 134,562 during May-September 2021. Malawi's guidelines suspended condom distribution to walk-in recipients of care during the first wave of COVID-19.³⁵ Since we have observed that distribution is on the rise again, we consider this good news. Life Maps participants in Malawi noted that condoms are once again accessible: *"Condoms are available, both male and female condoms"*.

Ensuring that a condom distributed is a condom accessed

Some important learning from this project is that a condom distributed does not necessarily mean a condom accessed by an individual. In South Africa, data collectors learned that health facilities count a condom as "distributed" when it leaves the storeroom. From there, the condoms may go to clinic waiting rooms, bathrooms, local community-based organizations, or other access points. Whether or not people who need condoms actually receive them is another question.

One Life Maps participant in Malawi noted that condoms are available at the facilities, but people are not going to collect them due to fear of COVID-19: *"They're receiving enough packages of these condoms, but the only challenge is that there are a lot of defaulters at the clinic who missed their appointments due to fear of being tested for COVID-19. As a result, there are a lot of condom packages to be distributed."* Another Life Maps participant spoke about how COVID-19 testing modalities created a barrier to condom access for some: *"(COVID-19) has a negative impact as COVID tests are done outside the clinic premises in a tent to limit possible infections. This then limits access to condoms, as limited to no condoms are put in the tent for temperature"*. Recipients of care at the health facilities in South Africa noted that those with a preference for getting condoms through the private sector—which is about a quarter of people³⁶—had limited access: *"COVID came with the lockdown procedures and shops were closed. They couldn't go buy condoms"*.

In Phase 2 of the Citizen Science project, ITPC and its partners aim to further triangulate condom distribution data with information on condom access and condom use to get a better understanding of the situation.

Intensified TB screening

In South Africa, our data show a dramatic increase in TB screening at our 14 monitored health facilities. The number of people screened for TB more than tripled compared with the before COVID-19 baseline (Table 3). The increase in TB screening is less pronounced for children under five years of age, who experienced a 2.5-fold increase. Integrated COVID-19 and TB response strategies may explain this trend.

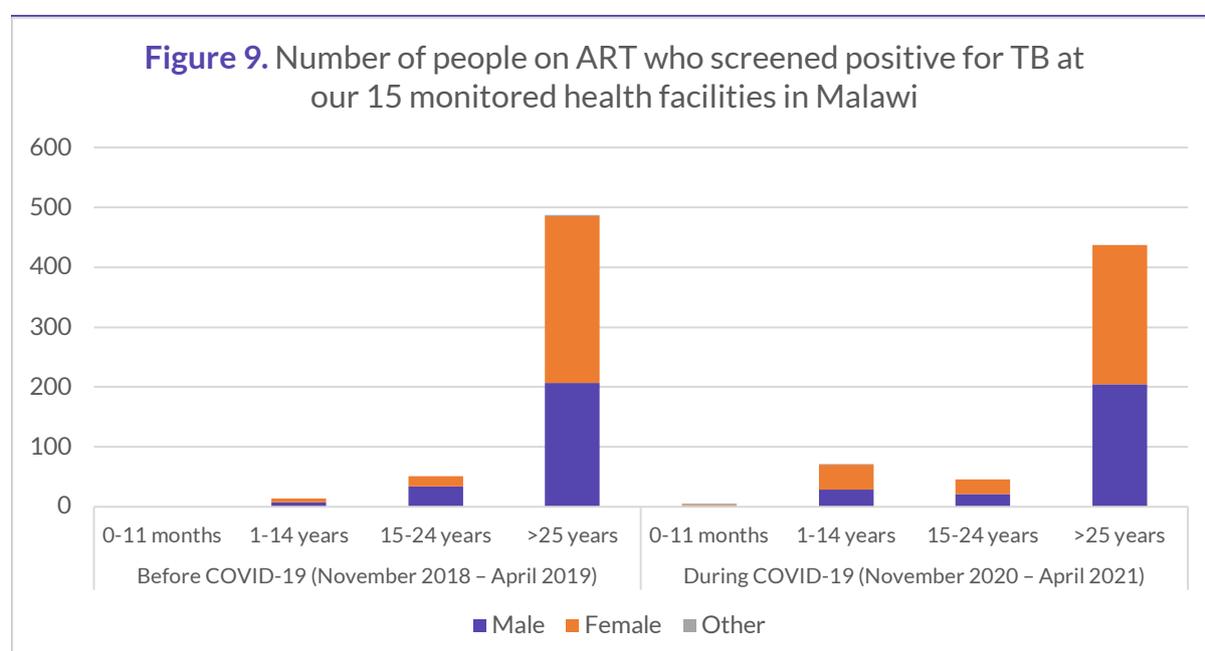
Several COVID-19 adaptations in South Africa may help explain this trend. In September 2020, South Africa started experimenting with combined and bi-directional TB and COVID-19 screening.³⁷ South Africa has also begun leveraging digital technologies for TB screening, launching the TB Health Check app in February 2021. Virtual innovations were accelerated in the context of COVID-19, making some HIV and TB services more accessible.

Table 3. Number of people screened for TB at our 14 monitored health facilities in South Africa

Age	Period 1 Before COVID-19 (Nov. 2018 – April 2019)	Period 2 During COVID-19 (Nov. 2020 – April 2021)	Period 3 During COVID-19 (May – August 2021)
<5 years of age	23,502	26,459	58,971
≥5 years of age	78,531	125,198	276,980
Total	102,033	151,657	335,951

In Malawi, from November 2020 to April 2021, 559 people on ART screened positive for TB, a very slight increase from 552 in the pre-COVID period (November 2018 to April 2019) (Figure 9). However, given that far fewer people were presenting at the health facilities during COVID-19, this increased detection is noteworthy and suggests a much larger trend of TB-symptomatic people in the community who are not being screened, tested, and treated at clinic level.

Malawi’s COVID-19 guidance urges health care workers to implement rigorous active intensified case finding for TB, noting that this will also provide valuable routine data for COVID-19 surveillance.³⁸ Such intensified screening may have helped detect TB that would be missed in a more relaxed context. Of concern, just 306 people on ART screened positive for TB from May to September 2021 (compared with 559 people from November 2020 to April 2021) at the same facilities. Again, the decrease in TB-presumptive people living with HIV is more likely to be the result of lower clinic attendance rates in the context of COVID-19 rather than due to an actual decrease in TB incidence. Qualitative data from Life Maps and key informant interviews can help us continue to triangulate answers.



Health care workers going the extra mile

There were examples of health care workers going the extra mile during COVID-19, providing medicines “from the gate” (at the entrance to facilities) and delivering medicines to people’s homes. Two recipients of care noted that if you missed your appointment during COVID-19, health care workers would pay home visits: “There are caregivers, because the clinic has your information they come at your home. The clinic sends them and they fetch you.”

THE BAD

Findings on COVID-Related Service Disruptions and Quality of Care Challenges

Mandatory mask-wearing as a new barrier to access

The absence of personal protective equipment (PPE) for both health care workers and recipients of care created new COVID-era barriers to access. Providers felt vulnerable not having access to adequate PPE, placing themselves and recipients of care at risk. A health care worker explained: *“There was a time when we ran out of PPEs. A service provider cannot perform services without them.”*

Health care workers also noted how economic inequalities created further divides in access to health care during COVID-19. Financial constraints meant that some recipients of care were not able to purchase facemasks and were subsequently turned away from health facilities without receiving treatment. One Health Surveillance Assistant in Malawi explained: *“Some people are failing to go to the facility just because they do not have money to buy personal protective equipment. [...] They have been affected because when a person comes without wearing a mask, we send them back without accessing medication even if it happens that the person has run out of medication.”*

A recipient of care echoed this experience from their perspective: *“Now, when you go to the health facility, they cannot assist you if you don’t have a mask. If you don’t have money to buy the mask, it means you are not assisted.”*

Another elaborated: *“People do not understand when we talk about masks, they think that the facility distributes masks, yet the situation now requires people to have their own masks, this especially those that come from typical village, are finding it hard to understand why service providers send them back without medical attention when they do not wear masks.”*

Recipients of care noted that mask mandates also impacted their ability to earn a living, creating a kind of vicious circle: *“As heads of families, they have financial difficulties, plus work is a challenge. [For example,] A bicycle taxi being asked to wear a mask—it really is a challenge to perform.”*

Mandatory mask-wearing was not found to be a barrier to access in South Africa as it was in Malawi. However, one social worker in South Africa described how the mask mandates compromised the quality of care they were able to provide: *“Things are done differently now, and we have to put on masks all the time and somehow it’s disadvantaging me when I have clients with a low voice. It has affected me in terms of work because there are now boundaries between a health worker and client which is a shield between us.”*

Life Maps participants in South Africa reported discomfort with the lack of adherence to mask-wearing in public transport: *“I have to travel on public transport using a taxi. It is very uncomfortable as mostly people are not using masks.”* It may have discouraged people from going to health facilities if the journey is perceived as an added layer of risk.

“Some people are failing to go to the facility just because they do not have money to buy personal protective equipment. [...] They have been affected because when a person comes without wearing a mask, we send them back without accessing medication, even if it happens that the person has run out of medication.”

– Health care worker, June 2021, Kasungu, Malawi

Heightened stigma and discrimination

There were reports of increased severity of stigma and discrimination in the context of COVID-19. People living with HIV were understood to be at greater risk of severe infection and death from COVID-19 while also perceived to be vectors of the disease. People with HIV were “shunned” by their families and community members. They were called “dead man walking” or “last drop”.

“From the messages we hear every day on COVID-19, we are told that those with underlying illnesses such as HIV are at increased risk of being infected and dying from COVID-19. This is not an easy thing to bear [...] What makes it worse is the stigma and discrimination that as people living with HIV we are experiencing now with the pandemic. People have misinterpreted the messages of being at an increased risk to thinking that people living with HIV have the coronavirus and are infecting others.”

Key populations experienced heightened stigma and discrimination due to COVID-19. One Life Maps participant from Malawi, who is a sex worker, noted: *“Us, as sex workers, people were talking bad rumors that we are spreading the disease COVID-19 because we meet with different people by the time we’re doing our work.”*

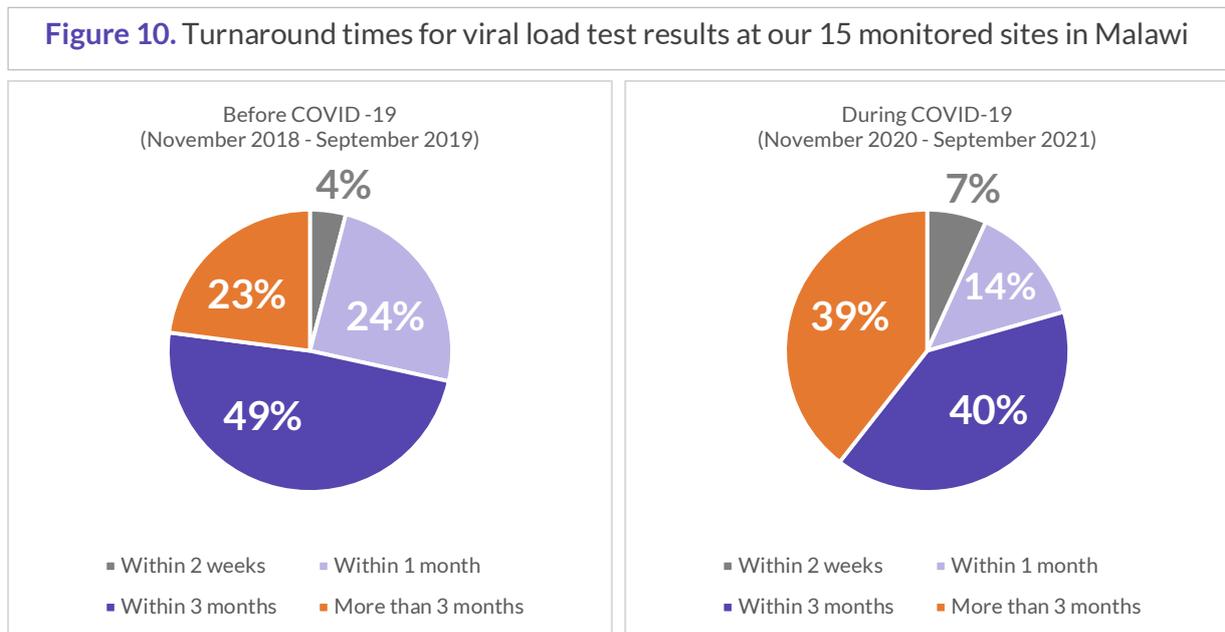
Our data show that health care workers also experienced heightened COVID-related stigma, which impacted their ability to provide HIV and TB services: *“When I try to deliver my service in a community, people sometimes discriminate against me, saying that it is service providers who are spreading COVID-19 because they are mostly close to COVID-19 patients.”* There were also reported incidents of health care workers being harassed or refused transport for fear of COVID-19.³⁹

“What makes it worse is the stigma and discrimination that as people living with HIV we are experiencing now with the pandemic. People have misinterpreted the messages of being at an increased risk to thinking that people living with HIV have the coronavirus and are infecting others.”

– Recipient of care, Malawi

Poor quality viral load monitoring

COVID-19 had a clear negative impact on the quality of viral load monitoring. Before the pandemic, 23% of viral load test results at our 15 monitored health facilities in Malawi took more than three months to be returned to the recipient of care. During COVID-19, this figure rose to 39% (Figure 10). There are some indications of the situation improving slightly in the most recent months of monitoring. If one looks at May-September 2021, 32% of test results took more than three months to be returned.



Life Maps participants spoke about reduced lab capacity due to the strain of processing COVID-19 tests (which use the same machines as viral load testing). There was also a delayed shipment for viral load controls due to COVID-19, leading to a viral load testing backlog.⁴⁰

Our qualitative data show that a lack of communication channels is sometimes the reason for a delayed return of results. *“Oftentimes the results come when it is not the appointment date for the clients and to communicate to them is a challenge as we are not supported with airtime to communicate on the phone, so we wait for the clients’ next refill date which is often 3 months or 6 months,”* a health care worker in Malawi said.

A Life Maps participant in Malawi said that COVID-19 brought unexplained changes to where people needed to go to receive results, which for some, meant not receiving them at all:

“The routine check-ups didn’t change, they do them every 6 months. What has changed is they are taking long for us to receive the results, like more than 6 months, and other people are being told to go to another area (Khamenya) without transport or food, and without those, they will not go to have their viral load results, that is the challenge we are meeting here.”

In Phase 2 of the Citizen Science project (January 2022-December 2024), we will be adding a fifth category to our viral load turnaround time monitoring: results that were never returned at all. Many recipients of care indicated that this had happened to them, requiring advocacy attention.

In South Africa, our data do not show a disruption to viral load testing the same way as in Malawi. However, there was a 3.4% decrease in viral load suppression (under 400 copies/ml at six months) when comparing the before COVID-19 and during COVID-19 periods. Many Life Maps participants described food insecurity during COVID-19, which contributed to ART adherence challenges.

Several data collectors recorded field observations about the poor quality of viral load data management at our 14 monitored health facilities in South Africa. This could contribute to sub-optimal outcomes for people living with HIV.

One said: *“The ART viral load is information that is not available at the facility. They say I can only get it from the Department of Health office.”* Another noted: *“ART viral load under 400/ml at 6 months stats were only given from April 2020 and the rest of the stats could not be found in their system; they do not record or upload”.* A third commented that the data was not recorded at all: *“The clinic did not have daily data capturing for ART viral load.”*

One Life Maps participant in South Africa reflected on the key difference in viral load testing services since COVID-19; nobody asked her how she was doing.

“This month was my blood [viral load] month. It was very different from the way they did things before COVID, because firstly, when I had to go take bloods at the clinic I used to go, weigh, and then see a sister and then the sister will see how am I doing. [This time] when I went back to her all she did was give me my new appointment card for June. It was very strange for me because I even asked ‘why are they doing it this way’ and they were saying ‘no, they trying to eliminate time spent at the clinic’.”

– Catwoman, Life Maps participant, South Africa

Reduced privacy and confidentiality

COVID-19 also created new challenges for maintaining privacy and confidentiality. Our data show that these were often compromised due to social distancing measures, further compounded by limited physical space in health care facilities, resulting in people waiting outside facilities where they were exposed to the elements and visible to other community members and passers-by. A Health Surveillance Assistant in Malawi said:

“We are serving a few people at a particular time and most people wait outside. The challenge is most people have not come out in the open, they think a relative might pass by and see them on the line, so to hide, they force themselves to sit inside the room. As a result, they are complaining that there is no privacy in the facility, hence we do not know how to help them. In the past, we used to allow all people to get inside the room and assist them all together and counsel them together, but now with COVID-19, that is not the case.”

Life Maps participants in South Africa noted the same challenge: “Because of COVID-19 people are not allowed to wait inside.” This participant shared a photo to illustrate the effect of this COVID-era policy on the lack of privacy (photo below).



Life Maps submissions showing lack of privacy in South Africa from COVID-19 policy of queuing outside

Recipients of care reported intensified triaging in the context of COVID-19, which reduced privacy and confidentiality: “Now it’s obvious you can see that the person is HIV and this one is for what. It’s obvious, you understand? Because you don’t have to ask questions, because you will see nurses saying; ‘chronic this side and pregnancy this side’, so come on [it’s that obvious].”

Limited access to HIV testing services, especially for key populations

In Malawi, the total number of HIV tests performed at the 15 monitored sites declined from 80,595 in the pre-COVID period (November 2018-September 2019) to 60,008 post-COVID (November 2020-September 2021)—a 25.5% decrease.

COVID-19 had a disproportionately negative effect on key populations’ access to HIV testing services. At our 15 monitored health facilities in Malawi, HIV testing fell by 25.4% among the general population compared with 52.8% among men who have sex with men and 79.5% among sex workers (Table 4).

COVID-19 had a disproportionately negative effect on key populations’ access to HIV testing services. In Malawi, testing fell by 79.5% among female sex workers and 52.8% among men who have sex with men compared with 25.4% for the general population.

Table 4. Number of HIV tests performed at our 15 monitored health facilities in Malawi, by population

	Before COVID-19 (November 2018 – September 2019)	During COVID-19 (November 2020 – September 2021)	% CHANGE
Number of HIV tests among the general population	80,215	59,864	Testing fell by 25.4%
Number of HIV tests among men who have sex with men	248	117	Testing fell by 52.8%
Number of HIV tests among female sex workers	132	27	Testing fell by 79.5%

When COVID-19 arrived, Malawi’s guidelines suspended all voluntary HIV testing services until further notice.⁴¹ When COVID-19 eased and regular service delivery returned, the demand for those services did not. The disruption to HIV testing as a result of COVID-19 has had a lasting negative effect on health-seeking behavior.

“COVID has been one of the things that they prioritize, and when it comes to HIV testing, you don't get those mobile clinics or those tents anymore. Most of them, they focus on COVID testing. You might find that once in a week, there are tents that do HIV testing, but other than that, it's been COVID and COVID and nothing else but COVID.”

– Life Maps participant, South Africa

Our qualitative data suggest that the fear of COVID-19 hampered provision of HIV testing services. One health care worker in Malawi said: *“We are working under panic because service providers and patients fear each other as either of them could be a COVID-19 carrier.”*

In Malawi, most Life Maps participants reported a reduction in HIV testing due to the stigma of COVID-19 (and fear of testing positive for COVID-19 due to that stigma) and the perceived risk of COVID-19 infection at clinics: *“Testing for HIV nowadays is becoming a problem since COVID-19 has started. Mentality of most people is that when they fall sick, they should not go to the hospital to avoid being tested for COVID-19. As a result of this, the turn up of people coming for HIV testing is decreasing.”*

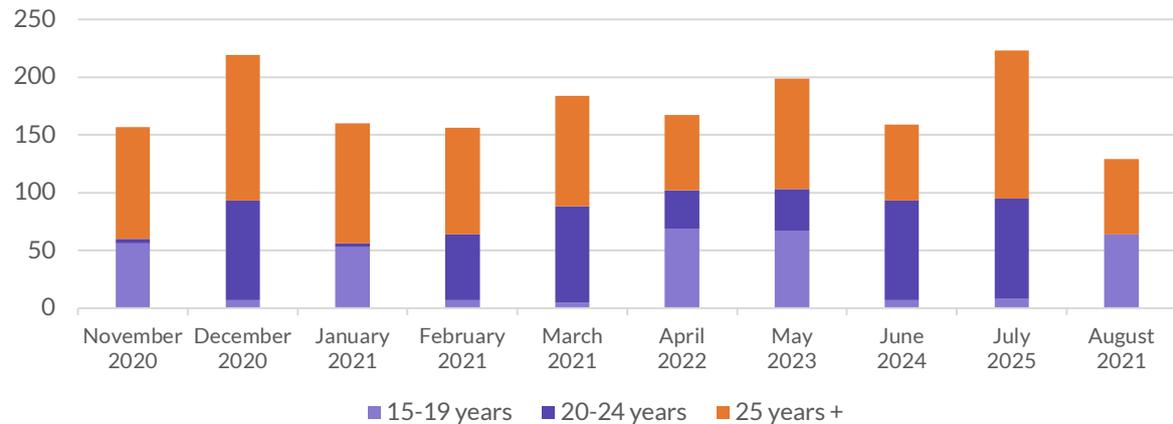
Qualitative data also point to a feeling of HIV (especially testing) being “side-lined” by COVID-19. During an interview with a health care worker in Malawi, she said: *“We ask government not to side-line people living with HIV. Some of the HIV services have ceased. Government’s focus has shifted to the COVID-19 pandemic. HIV testing points such as outpatient departments have been closed due to COVID-19.”*

In South Africa, Life Maps participants said that COVID-19 testing had supplanted HIV testing, taking over former access points.

Spikes in teenage pregnancies

The effects of COVID-19 on pregnancies are apparent in our quantitative data (Figure 11). The highest overall number of births was in December 2020—exactly nine months after the first hard lockdown in South Africa. The effects of subsequent COVID-19 waves are also visible in the data. The highest number of live births to teenage mothers was in April (n=69) and May (n=67), which follows exactly nine months after the twin peaks of South Africa’s third wave in July and August 2020. COVID-related barriers to accessing condoms and other contraceptive methods may be particularly acute for adolescent girls.

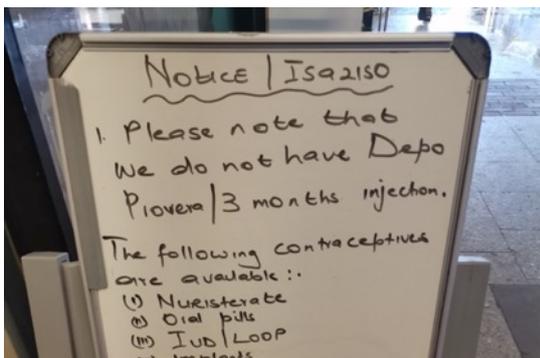
Figure 11. Number of live births at our 14 monitored health facilities in South Africa



These increases in live births map onto other data in our clinic records surveys, which show a decline in family planning services offered to young people aged 15-24 years. Before COVID-19, in the November 2018-September 2019 period, 61,177 young people received family planning services at our 14 monitored facilities in South Africa. During COVID-19, between November 2020 and September 2021, this figure dropped to 51,269—a 16% decrease.

Life Maps participants in South Africa reported stock-outs of contraceptives during COVID-19 (photo below). In Malawi, one noted how COVID-related lockdowns contributed to spikes in teenage pregnancies: “During this period, we have witnessed as a nation of over 20,000 teenage pregnancies through coercion or by default falling prey to prevailing circumstances at the time. This ‘pregnancy boom’ was a result of induced school break for six months.”

In one data collector’s field notes, they made a point on the apparent lack of provision for adolescents and young people: “Family planning is being accessed by persons over the age of 24 years.” Others noted that some facilities simply did not keep records at all on this indicator, suggesting that it is not viewed as important: “The clinic’s data capturers had no statistics on the number of young people provided with family planning services.”



Stock-out of Depo Provera, South Africa.

“The clinic’s data capturers had no statistics on [the] number of young people provided with family planning services.”

– Data collector’s field notes, May 2021, South Africa

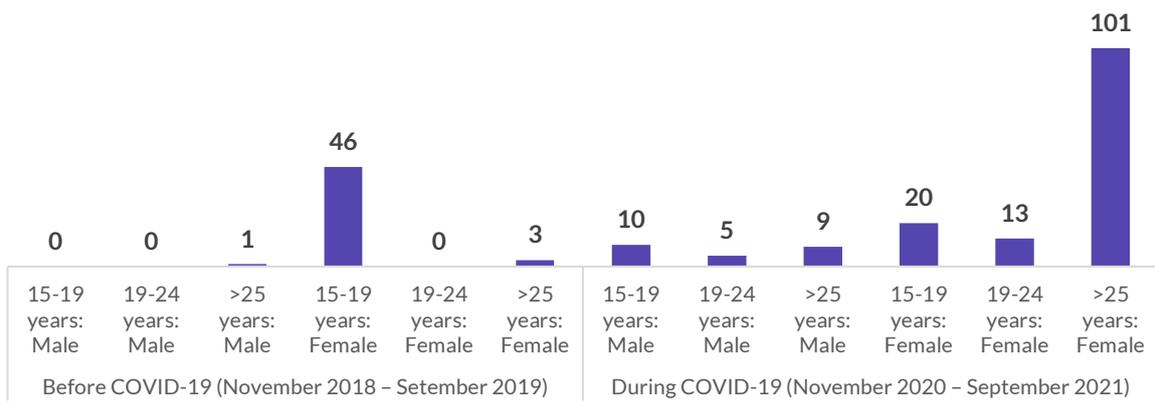
Increased gender-based violence

COVID-19 is associated with increased gender-based violence. Before the COVID-19 pandemic began, about one in three women experienced physical or sexual violence, mostly by an intimate partner. A UN Women survey found that since COVID-19 began, 65% of women reported ever having experienced a form of violence against women or knowing another woman who experienced it.⁴²

Data from our 14 monitored health facilities in South Africa show a similar upward trend. Before COVID-19, 50 people accessed gender-based violence services over an 11-month period. Over the same period two years later, 158 people accessed these services—a 216% increase linked to COVID-19.

We saw surges in violence in November and December 2020 (28% of services were provided during South Africa’s second wave of infections) and during August and September 2021 (33% of services were provided during South Africa’s third wave of infections). During these waves, the government repeatedly banned and unbanned the sale of alcohol, leading to dips and spikes in incidents of trauma.⁴³

Figure 12. Number of people provided with gender-based violence services at our 14 monitored health facilities in South Africa



Life Maps participants in Malawi pointed to increased state-sponsored violence as a particular threat during COVID-19: “Police and military and other security forces were also involved in GBV because they used force by beating people who do not get tested and do not wear masks.” Another also spoke about violence from uniformed officers: “The police and the military were enforcing the COVID-19 protocols and prevention measures. People were harassed, beaten with baton sticks for not wearing masks, and taken to court.”

ITPC and its partners believe that these data do not reflect the true extent of violence in the West Rand community. This is due to data quality issues (more on this in the “Unfinished Business” section) and the fact that many people do not present for care. One Life Maps participant in South Africa said: “Here in my community, I have never heard of gender-based violence-related services [...] I don’t know how people who are being abused or victims of gender-based violence, how do they get help?”. ITPC’s partners couple community-led monitoring with information sessions to try to bridge some of these knowledge gaps (photo below).



Talk with young people about gender-based violence at Badarile Clinic, South Africa, February 2022

THE UNFINISHED BUSINESS

Data for Decision-Making, Emerging Change Agendas, and Ongoing Advocacy Actions

Harnessing the power of dialogue to co-create solutions with communities and health facilities

Our operational research revealed how the Citizen Science project contributed to some of the improvements we saw (“the good”) and helped address challenges (“the bad”). Importantly, we learned that by bridging the feedback gap, we can help improve the actions taken by health care workers. In our experience, health care workers yearn for information that can help them improve their performance.

“The inclusion of recipients of care into data collection and focus groups helped the clinic staff work as a team to address the needs of patients. Before, we were just seeing patients and prescribing medicines. Now, there is a space to interact with the patients to hear their concerns. As health workers, we are awakened and activated to work together.”

– Health care worker participating in Citizen Science operational research, Malawi

“CLM enlightens us on what we did not know. The process collects data and shows evidence about gaps, which we then discuss. This gives space for potential changes and improvements.”

– Health care worker participating in Citizen Science operational research, Malawi

The way in which feedback is provided is important. There is a deliberate effort to provide feedback at local levels. A solid planning process and ongoing multi-stakeholder engagement is critical, bringing recipients of care and health care workers together to co-create solutions: *“MANERELA+ is a small organization, but unlike many other organizations, it has partnered with the Ministry of Health to work for the communities. They involve the community and the government, and do not simply come straight to the health workers to plan and improve things.”*

As a result of the trust established with health facilities, data collectors often provided auxiliary support in clinics. Some additional tasks that the data collectors reported doing included registration and data capturing. This was particularly crucial during COVID-19-related staff shortages.

Another health care worker noted: *“MANERELA+ conducts briefings and meetings with key populations along with religious leaders and other local community leaders, and they involve health workers in those meetings. They also bring these community members to the clinics for dialogue about needs and services.”*

We also learned that it can be effective to triage advocacy issues—knowing when to feedback what. Data collectors began to put issues into two buckets: (1) those that require urgent action right now; and (2) those that can wait and be shared during the regular quarterly feedback sessions. This has shown early promise as a useful practice, which will be further refined and explored over the next two years.

Triaging advocacy issues into those requiring urgent action vs. those that can wait for the quarterly feedback session helped focus the attention of health facilities.

Involving recipients of care in the data feedback sessions with health care workers helped with motivation and accountability.



Bua task force team after meeting to follow up on advocacy issues raised at their facility, Bua Health Center, Kasungu, Malawi

Strengthening key population-friendly services

Only five of our 15 monitored facilities in Malawi keep data on key populations. However, by virtue of having key population data collectors in Malawi, their peers report feeling more emboldened to open up about their sexual orientation and gender identity when visiting health facilities.

Health care workers who participated in our operational research said that this helped improve service delivery: *“This community-led monitoring effort changed the mindset of people in the communities towards TB and HIV and helped people to talk with health workers about how to improve services.”* Such empowered communities helped contribute to the inclusion of key population-friendly services at the Dedza, Kasungu, and Kaphuka sites.

Improving government data quality and monitoring

Our community-led monitoring in South Africa showed a significant gap in gender-based violence data, which was not readily available at many of the health facilities. Data collectors’ field notes repeatedly said things like *“They receive women and men who are being beaten up or who want to report gender-based violence but they transfer them to the police station”*, and *“The facility does get gender-based violence from women and [men] but they tell them to go to the police station. They do help them if they are injured but they don’t keep their record.”*

Communication with facility managers indicated that gender-based violence information was not captured as they felt that this was the responsibility of the Department of Social Development. However, the Department of Social Development provided incomplete and/or anecdotal information, which could not be effectively analyzed. NACOSA consulted with both the Department of Health and the Department of Social Development to consider strategies to improve on gender-based violence reporting. Such strategies included training, linkages with other service providers, such as Thuthuzela Care Centres, and ensuring that health care workers understand their policies regarding gender-based violence.

As a result of this ongoing advocacy, in February 2022, a district Department of Health began sharing its complete social work data with ITPC and its partners, seeking collaboration in how it could improve its record keeping. From this exercise, we learned that the Department of Health keeps data on several violence-related categories, including gender-based violence, child abuse, emotional abuse and trauma, and clinical forensic medical services for sexual abuse. These appear to be counted separately.

Influencing national resource mobilization processes

While Citizen Science is a local-level project, it also influences national-level decisions. In South Africa’s most recent Global Fund application, submitted in August 2021, Citizen Science data and methodology

is explicitly referenced.⁴⁴ This helped rationalize a five-fold increase in funding for community-led monitoring (from \$318,221 in the 2019-2022 grant to \$1,578,691 in the 2022-2025 grant). In the 2022 Country Operational Planning (COP) process for PEPFAR programs in Malawi, ITPC’s partners used Citizen Science data to advocate for increased funding for viral load testing, including for additional sites and to speed up turnaround time to no more than 14 days. They also pushed for an increase in funding for community-led monitoring, from \$694,898 in COP21 to \$1.08 million in COP22.⁴⁵ The upcoming Global Fund allocation period for 2023-2025 presents an opportunity for both countries to use Citizen Science data to further influence HIV and TB resourcing decisions.

Measuring the impact of our community-led monitoring on health outcomes

Measuring the impact of community-led monitoring is complex. It is often difficult to draw a straight line from the intervention to health outcomes. One way to try to isolate the effect of community-led monitoring is to compare what happened at other health facilities where communities were not doing regular monitoring, providing feedback to health care workers, and holding decision-makers accountable for improvements. This allows for a kind of “intervention” versus “control group” analysis.

We found one study in Malawi that allows us to (crudely) do this (Table 5).⁴⁶ At our 15 monitored health facilities in Dedza and Kasungu, where data was regularly fed back to health care workers and discussed, HIV testing services fell by 25.5% during COVID-19. At eight other health facilities in Lilongwe, where no community-led monitoring mechanism was in place, HIV testing fell by 39.0% over a similar period.

While the presence of community-led monitoring is likely not the only factor at play, the comparison of these two groups of facilities suggests that our intervention likely had a positive effect on mitigating the negative impact of COVID-19 on HIV testing services. If we assume that testing could have fallen by 39% without our intervention, this means that the Citizen Science project may have contributed to an additional 10,845 HIV tests being conducted during COVID-19.

Table 5. Isolating the effect of our community-led monitoring – the counterfactual

Group	Location	# of facilities	CLM in place	Data source	Time periods examined	Change in HIV testing
Intervention	Dedza & Kasungu Districts, Malawi	15	Yes	Citizen Science project	Before COVID-19: November 2018 – September 2019 During COVID-19: November 2020 – September 2021	25.5% fewer tests due to COVID-19
Control	Lilongwe District, Malawi	8	No	Thekkur, et al. (2021) ⁴⁷	Before COVID-19: March 2019 – February 2020 During COVID-19: March 2020 – February 2021	39.0% fewer tests due to COVID-19

Our intervention likely had a positive effect on mitigating the negative impact of COVID-19 on HIV testing services, translating to 10,845 more HIV tests at our monitored sites compared with the control group scenario.

Ideally, such comparisons should be done in a randomized study setting, eliminating other factors that may contribute to differences. Control versus intervention group comparisons should also be triangulated with other data sources, such as health care worker testimonials about how the intervention may have helped. To be sure, measuring the impact of community-led monitoring on health outcomes is “unfinished business”. Ongoing implementation science in Phase 2 of the Citizen Science project will continue to examine ways to demonstrate the attribution of community-led monitoring to improved service provision.

NEXT STEPS

Preparing for the Next Three Years of Citizen Science

The Citizen Science project will continue for a second phase of implementation from January 2022 until December 2024 (three years). Several strategic shifts are planned.

New indicators

Reflecting on the data collection tools that were used in Phase 1, several adjustments will be made to the indicators (both quantitative and qualitative) in Phase 2. These changes are driven by the implementing partners in-country, based on consultations with communities and health authorities.

In Malawi, data will now be collected on HIV drug resistance, following concerns raised by communities about the longer-term effects of disruptions in treatment during COVID-19. We will also begin to measure uptake of differentiated service delivery models for ART. Screening for intimate partner violence will also be monitored. Interview questions include a more focused examination of the challenges around ensuring quality viral load testing services.

In South Africa, new indicators will measure uptake of different forms of PrEP, including the dapivirine ring. Implementers will also begin to systematically monitor stock-outs of contraceptives. TB is elevated as a priority, with the project now tracking rapid molecular testing and turnaround times for results. Interview questions zoom in more closely on understanding barriers to service access for young people.

New sites

Phase 2 of Citizen Science will expand to monitor 31 sites (up from 29 in Phase 1). A key change in the site selection for Phase 2 is the inclusion of seven community service delivery points (three in South Africa and four in Malawi) where we will monitor HIV and TB services delivered by non-governmental organizations. In addition, the project will double the number of Life Maps participants (from 20 in Phase 1 to 40 in Phase 2) to gather even more personalized stories that add such vital contour and depth to the data.

Harnessing the skills of data collectors

As part of the operational research component of Citizen Science, an analysis was conducted of 32 data collectors' CVs. Most of the data collectors have capacities that are not fully tapped by the project. Many have been expert clients, mentor mothers, peer counsellors, and leaders of community groups. They also have technical skills in community education, caregiving, HIV testing, treatment adherence, service navigation, and nutritional support. Some have prior experience in adjacent fields, such as being a classroom teacher, adult literacy tutor, marketing and sales agent, and event promoter.

In Phase 1 of the Citizen Science project, some data collectors were assigned additional responsibilities that served to reinforce engagement with health services, though this was not done in a systematic way. They organized and facilitated health education and treatment literacy trainings and provided support for contacting and re-engaging people who had missed clinic appointments. Some were involved in direct provision of basic health services, such as counselling people, providing treatment adherence support, measuring people's weight and providing nutrition counselling, and facilitating support groups.

In Phase 2 of Citizen Science, the project will more intentionally harness data collectors' capacities. They will be provided with more opportunities to work with recipients and health care providers to advance the change agendas that their data generates. Additionally, seven of the data collectors from Phase 1 will also be engaged as Life Maps participants in Phase 2.

Costing study

Starting in 2022, ITPC will be working with Avenir Health to determine the average and range of costs per site of providing community-led monitoring services, including the average cost for a minimum package of services and an extended CLM package that includes additional effective services.

Understanding “what works” in community-led monitoring

The operational research component of Citizen Science will evolve in Phase 2 of the project. Where Phase 1 tried to understand the “know-do” gap, Phase 2 will broaden the scope of the operational research to try to understand different data feedback mechanisms and how these influence change. In particular, we will examine the different ways in which community-led monitoring data is shared with decision-makers and which methods are more or less effective at compelling action.

The operational research in Phase 2 will also ask questions like “How do you (more) confidently attribute positive changes to community-led monitoring?” and “What level of community-led monitoring coverage is enough?”

Longer-term advocacy agendas

There are advocacy issues that emerged during Phase 1 that require a more long-term vision for change. These advocacy agendas will carry over into Phase 2 of the project.

For example, the roll-out of community-based ART in Malawi has long been a priority for people living with HIV. As of 2022, only a few health facilities in the south of the country have accepted that community ART refill groups may be implemented. These groups are donor-funded, and the government views them as demonstration projects. The scale-up of community ART models is an ongoing advocacy agenda in Malawi.

Ongoing access to government data is a priority in both countries. In Malawi, MANERELA+ has recently gained access to the national dataset. In South Africa, NACOSA now receives the West Rand health dataset from the Department of Social Development. These are both significant indications of the trust built between Citizen Science partners and local health authorities. However, gaps remain. NACOSA does not yet have access to TIER.Net unless they are physically collecting data from within health facilities. Ideally, health facilities will share their entire anonymized datasets with community-led monitoring implementors in order to make the completion of clinic records surveys more efficient.

Accessing this information in a more convenient way remains on the agenda in South Africa.



REFERENCES

- ¹ Hogan, A. B., Jewell, B. L., Sherrard-Smith, E., Vesga, J. F., Watson, O. J., Whittaker, C., ... & Hallett, T. B. (2020). Potential impact of the COVID-19 pandemic on HIV, tuberculosis, and malaria in low-income and middle-income countries: a modelling study. *The Lancet Global Health*, 8(9), e1132-e1141. Online at <https://www.thelancet.com/action/showPdf?pii=S2214-109X%2820%2930288-6>
- ² Global Fund (2020) COVID-19 Guidance Note: Community, Rights and Gender. Page 3. Online at https://www.theglobalfund.org/media/9648/covid19_communityrightsgender_guidancenote_en.pdf
- ³ World Health Organization COVID-19 Dashboard. Online at <https://covid19.who.int/>
- ⁴ Mzumara, G. W., Chawani, M., Sakala, M., Mwandira, L., Phiri, E., Milanzi, E., ... & Squire, B. (2021). The health policy response to COVID-19 in Malawi. *BMJ global health*, 6(5), e006035. Online at <https://gh.bmj.com/content/6/5/e006035>
- ⁵ Hogan, A. B., Jewell, B. L., Sherrard-Smith, E., Vesga, J. F., Watson, O. J., Whittaker, C., ... & Hallett, T. B. (2020). Potential impact of the COVID-19 pandemic on HIV, tuberculosis, and malaria in low-income and middle-income countries: a modelling study. *The Lancet Global Health*, 8(9), e1132-e1141. Online at <https://www.thelancet.com/action/showPdf?pii=S2214-109X%2820%2930288-6>
- ⁶ Jewell, B. L., Mudimu, E., Stover, J., Ten Brink, D., Phillips, A. N., Smith, J. A., ... & HIV Modelling Consortium. (2020). Potential effects of disruption to HIV programmes in sub-Saharan Africa caused by COVID-19: results from multiple mathematical models. *The Lancet HIV*, 7(9), e629-e640. Online at [https://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018\(20\)30211-3/fulltext](https://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018(20)30211-3/fulltext)
- ⁷ Hogan, A. B., Jewell, B. L., Sherrard-Smith, E., Vesga, J. F., Watson, O. J., Whittaker, C., ... & Hallett, T. B. (2020). Potential impact of the COVID-19 pandemic on HIV, tuberculosis, and malaria in low-income and middle-income countries: a modelling study. *The Lancet Global Health*, 8(9), e1132-e1141. Online at <https://www.thelancet.com/action/showPdf?pii=S2214-109X%2820%2930288-6>
- ⁸ Human Sciences Research Council (HSRC) (2020) HSRC responds to the COVID -19 outbreak. Online at: <http://www.hsrc.ac.za/uploads/pageContent/11529/COVID-19%20MASTER%20SLIDES%2026%20APRIL%202020%20FOR%20MEDIA%20BRIEFING%20FINAL.pdf>
- ⁹ PEPFAR (2020) Malawi Q2 POARTHIV Program Implementation in a Post COVID-19 Environment. Slide 105.
- ¹⁰ Thekkur, P., Tweya, H., Phiri, S., Mpunga, J., Kalua, T., Kumar, A., ... & Harries, A. D. (2021). Assessing the Impact of COVID-19 on TB and HIV Programme Services in Selected Health Facilities in Lilongwe, Malawi: Operational Research in Real Time. *Tropical Medicine and Infectious Disease*, 6(2), 81. Online at <https://www.mdpi.com/2414-6366/6/2/81>
- ¹¹ Malawi Ministry of Health (2020) Guidance on HIV services with COVID-19, Edition 1. 3 April 2020. Online at <https://bit.ly/2ZTIW5i>
- ¹² Malawi Ministry of Health (2020). National COVID-19 Preparedness and Response Plan March-June 2020. Online at <https://bit.ly/2EiFeKh>
- ¹³ Malawi Ministry of Health (2020). National COVID-19 Preparedness and Response Plan March-June 2020, pp. 40. Online at <https://bit.ly/2EiFeKh>
- ¹⁴ Gauteng Provincial Department of Health (2020) "Gauteng Health Strengthens COVID-19 Response in Health Facilities", Media Statement 22 March 2020. Online at <https://bit.ly/2RGrp1H>
- ¹⁵ North West Provincial Department of Health (2020) "Suspension of Routine Activities in the District Due to COVID-19 Emergencies" directive, 19 March 2020. Online at <https://bit.ly/3hJdwUt>
- ¹⁶ Kwazulu-Natal Provincial Department of Health (2020) Novel Coronavirus (COVID-19) Provincial Response Plan 18 March 2020. Online at <https://bit.ly/2ZTrxc2>
- ¹⁷ UNAIDS (2021) Holding the line: communities as first responders to COVID-19 and emerging health threats. Online at https://www.unaids.org/en/resources/presscentre/featurestories/2022/january/20220128_communities-first-responders
- ¹⁸ UNAIDS (2021) Holding the line: communities as first responders to COVID-19 and emerging health threats. Page 29, 40 & 41. Online at https://www.unaids.org/en/resources/presscentre/featurestories/2022/january/20220128_communities-first-responders
- ¹⁹ Online at <https://communityconstituency.org.za/>
- ²⁰ Global Fund (2020) COVID-19 Guidance Note: Community, Rights and Gender. Page 3. Online at https://www.theglobalfund.org/media/9648/covid19_communityrightsgender_guidancenote_en.pdf
- ²¹ UNAIDS (2021) Establishing community-led monitoring of HIV services. Page 21. Online at https://www.unaids.org/sites/default/files/media_asset/establishing-community-led-monitoring-hiv-services_en.pdf
- ²² Mohanan, M., Vera-Hernández, M., Das, V., Giardili, S., Goldhaber-Fiebert, J. D., Rabin, T. L., ... & Seth, A. (2015). The know-do gap in quality of health care for childhood diarrhea and pneumonia in rural India. *JAMA pediatrics*, 169(4), 349-357. Online at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5023324/>
- ²³ WHO (2020) Monitoring and evaluation framework for the COVID-19 response in the WHO African Region. Page 24. Online at <https://www.afro.who.int/publications/monitoring-and-evaluation-framework-covid-19-response-who-african-region>
- ²⁴ UNAIDS (2022) Global AIDS Monitoring 2022: Indicators and questions for monitoring progress on the 2021 Political Declaration on HIV and AIDS. Page 106. Online at: https://www.unaids.org/sites/default/files/media_asset/global-aids-monitoring_en.pdf
- ²⁵ Hoffman, R. M., Moyo, C., Balakasi, K. T., Siwale, Z., Hubbard, J., Bardon, A., ... & Rosen, S. (2021). Multimonth dispensing of up to 6 months of antiretroviral therapy in Malawi and Zambia (INTERVAL): a cluster-randomised, non-blinded, non-inferiority trial. *The Lancet Global Health*, 9(5), e628-e638. Online at [https://www.thelancet.com/journals/langlo/article/PIIS2214-109X\(21\)00039-5/fulltext](https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(21)00039-5/fulltext)

- ²⁶ Keene, C. M., Zokufa, N., Venables, E. C., Wilkinson, L., Hoffman, R., Cassidy, T., ... & Isaakidis, P. (2020). 'Only twice a year': a qualitative exploration of 6-month antiretroviral treatment refills in adherence clubs for people living with HIV in Khayelitsha, South Africa. *BMJ open*, 10(7), e037545. Online at <https://bmjopen.bmj.com/content/10/7/e037545.abstract>
- ²⁷ Malawi Ministry of Health (2020) COVID-19 Guidance for HIV Services. Page 4. Online at https://differentiatedservicedelivery.org/Portals/0/adam/Content/dGLU8P8dhkOEMHjU8ZRqiA/File/Malawi_Guidance%20on%20HIV%20services%20with%20COVID-19Edition%202version%202.pdf
- ²⁸ Spotlight (2021) HIV prevention pill available at 36% of public healthcare facilities, says Health Department. Online at <https://www.spotlightnsp.co.za/2021/02/02/hiv-prevention-pill-available-at-36-of-public-healthcare-facilities-says-health-department/>
- ²⁹ Malawi Ministry of Health (2020) COVID-19 Guidance for HIV Services. Page 3. Online at https://differentiatedservicedelivery.org/Portals/0/adam/Content/dGLU8P8dhkOEMHjU8ZRqiA/File/Malawi_Guidance%20on%20HIV%20services%20with%20COVID-19Edition%202version%202.pdf
- ³⁰ Mendelsohn, A. S., & Ritchwood, T. (2020). COVID-19 and Antiretroviral Therapies: South Africa's Charge Towards 90-90-90 in the Midst of a Second Pandemic. *AIDS and Behavior*, 24 (10), 2754-2756. Online at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7191543/>
- ³¹ Radix, A. et al. (2020). Guidance: Rapid Antiretroviral Therapy (ART) Initiation During COVID-19. New York State Department of Health AIDS Institute Clinical Guidelines Program. Online at <https://www.hivguidelines.org/antiretroviral-therapy/rapid-art-covid-19/>
- ³² Malawi Ministry of Health (2016) Malawi Clinical HIV guidelines. Lilongwe, Malawi, as cited in Phiri, K., McBride, K., Moucheraud, C., Mphande, M., Balakasi, K., Lungu, E., ... & Dovel, K. (2021). Community and health system factors associated with antiretroviral therapy initiation among men and women in Malawi: a mixed methods study exploring gender-specific barriers to care. *International health*, 13(3), 253-261. Online at <https://academic.oup.com/inthealth/article/13/3/253/5897140>
- ³³ Spotlight (2020) COVID-19: What the lockdown means for sexual and reproductive health services. Online at <https://www.spotlightnsp.co.za/2020/04/22/covid-19-what-the-lockdown-means-for-sexual-and-reproductive-health-services/>
- ³⁴ UNAIDS (2016) UPDATE Condoms. Online at https://www.unaids.org/en/resources/presscentre/featurestories/2016/october/20161002_condoms
- ³⁵ Malawi Ministry of Health (2020) COVID-19 Guidance for HIV Services. Page 3. Online at https://differentiatedservicedelivery.org/Portals/0/adam/Content/dGLU8P8dhkOEMHjU8ZRqiA/File/Malawi_Guidance%20on%20HIV%20services%20with%20COVID-19Edition%202version%202.pdf
- ³⁶ Bolarinwa, O. A. (2021). Factors associated with access to condoms and sources of condoms during the COVID-19 pandemic in South Africa. *Archives of Public Health*, 79(1), 1-9. Online at <https://archpublichealth.biomedcentral.com/articles/10.1186/s13690-021-00701-5>
- ³⁷ DevDiscourse (2020) Provinces experimenting with combining TB and COVID-19 screening. Online at <https://www.devdiscourse.com/article/health/1197889-provinces-experimenting-with-combining-tb-and-covid-19-screening>
- ³⁸ Malawi Ministry of Health (2020) COVID-19 Guidance for HIV Services. Page 3. Online at https://differentiatedservicedelivery.org/Portals/0/adam/Content/dGLU8P8dhkOEMHjU8ZRqiA/File/Malawi_Guidance%20on%20HIV%20services%20with%20COVID-19Edition%202version%202.pdf
- ³⁹ PEPFAR (2020) Malawi Q2 POART HIV Program Implementation in a Post COVID-19 Environment. Slide 140.
- ⁴⁰ PEPFAR (2020) Malawi Q2 POART HIV Program Implementation in a Post COVID-19 Environment. Slide 143.
- ⁴¹ Malawi Ministry of Health (2020) COVID-19 Guidance for HIV Services. Page 4. Online at https://differentiatedservicedelivery.org/Portals/0/adam/Content/dGLU8P8dhkOEMHjU8ZRqiA/File/Malawi_Guidance%20on%20HIV%20services%20with%20COVID-19Edition%202version%202.pdf
- ⁴² UN Women (2021) Measuring the shadow pandemic: Violence against women during COVID-19. Page 7. Online at <https://data.unwomen.org/sites/default/files/documents/Publications/Measuring-shadow-pandemic.pdf>
- ⁴³ van Hoving, D. J., van Koningsbruggen, C., de Man, M., & Hendrikse, C. (2021). Temporal changes in trauma according to alcohol sale restrictions during the south African national COVID-19 lockdown. *African journal of emergency medicine*, 11(4), 477-482. Online at <https://www.sciencedirect.com/science/article/pii/S2211419X21000586>
- ⁴⁴ South Africa Country Coordinating Mechanism (2021) TB/HIV Funding Request Form: Allocation Period 2020-2022. Pages 4, 30, 51 & 60. Online at <https://data.theglobalfund.org/location/ZAF/documents>
- ⁴⁵ Health GAP (2021) Liu Lathu Mu: COP22 Our Voice Malawi. PEPFAR Country Operational Plan 2022 Community Priorities. Page 21 & 25. Online at <http://pepfarwatch.org/wp-content/uploads/2022/03/Liu-Lathu-Mu-COP22-Malawi.pdf>
- ⁴⁶ Thekkur, P., Tweya, H., Phiri, S., Mpunga, J., Kalua, T., Kumar, A., ... & Harries, A. D. (2021). Assessing the Impact of COVID-19 on TB and HIV Programme Services in Selected Health Facilities in Lilongwe, Malawi: Operational Research in Real Time. *Tropical Medicine and Infectious Disease*, 6(2), 81. Online at <https://www.mdpi.com/2414-6366/6/2/81>
- ⁴⁷ Thekkur, P., Tweya, H., Phiri, S., Mpunga, J., Kalua, T., Kumar, A., ... & Harries, A. D. (2021). Assessing the Impact of COVID-19 on TB and HIV Programme Services in Selected Health Facilities in Lilongwe, Malawi: Operational Research in Real Time. *Tropical Medicine and Infectious Disease*, 6(2), 81. Online at <https://www.mdpi.com/2414-6366/6/2/81>