CITIZEN SCIENCE

Insight, Influence & Impact

10 Big Change Stories from the Citizen Science Community-led Monitoring Project in 2023

ITPC

NACOSA

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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 its focus on three strategic pillars:

- → **Build Resilient Communities (#TreatPeopleRight)**
- → **Intellectual property and access to medicines (#MakeMedicinesAffordable)**
- → **Community monitoring and accountability (#WatchWhatMatters)**

To learn more about ITPC and our work, visit 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 collect and analyze qualitative and quantitative data on barriers to access, systematically and routinely. This data is then used to inform advocacy efforts and promote accountability.

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

About Citizen Science

COVID-19 had a profound impact on global health, particularly in low- and middle-income countries, where the struggle for equal access to healthcare has never been more important. As COVID-19 blurred traditional boundaries between journalism, advocacy, research, and policy development, ITPC 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 is now being applied to other health conditions, documenting the gaps between globally recognized standards of care and services on the ground. Citizen Science moves from models of "data extraction" to "data democracy" by combining community-led monitoring (CLM), operational research, and an innovative research methodology that we have called Life Mapping, which uses collaborative and participatory visual and textual media tools.

About This Publication

This publication is the third in a series of reports from ITPC's Citizen Science project. In the first report, titled ***The Good, the Bad, and the Unfinished Business***, we shared community-led monitoring data from 2020 and 2021 and compared it with data from 2018 and 2019. The purpose was to gain insight into how COVID-19 affected HIV and TB services in Malawi and South Africa, informing strategic advocacy messages. The second report, titled ***Bouncing Back***, shared data and advocacy outcomes from 2022. It told an optimistic story of recovery and resilience, highlighting how community-led initiatives can help restore health services in the aftershock of a crisis like COVID-19. This report, ***Insight, Influence, and Impact***, shares 10 big change stories from the project in 2023, showcasing the potential of CLM to contribute to tangible improvements in health outcomes.

For More Information

Please contact us at admin@itpcglobal.org.

Acknowlegements

ITPC thanks and acknowledges those who have supported our work in the Citizen Science community-led monitoring project. In particular, we recognize the tireless efforts of our partners. In Malawi, these are the Malawi Network of Religious Leaders Living with or Personally Affected by HIV and AIDS (MANERELA+) and The Network of Journalists Living with HIV (JONEHA). In South Africa, they are the Networking HIV & AIDS Community of Southern Africa (NACOSA), Access Chapter 2, and Rotanganedza Community Care. We especially recognize the 66 data collectors, who steadfastly visited health facilities and communities, day in and day out, watching what matters on the ground. We also commend the efforts of the 39 Life Maps participants, who shared intimate details of their lived experiences in order to improve access to health services in their communities.

Dr. Gemma M. Oberth, Independent Consultant, is the lead author of this report. Data collection and initial analysis were carried out by MANERELA+ (Malawi) and NACOSA in partnership with Access Chapter 2 and Rotanganedza Community Care (South Africa), complemented by further interpretation by the ITPC team. **Krista Lauer, Jelena Bozinovski, Solange Baptiste, Melikhaya Soboyisi, and Harold Kachepatsonga** provided feedback and comments on earlier drafts.

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Abbreviations

AC2	Access Chapter 2
AIDS	Acquired immune deficiency syndrome
ANC	Antenatal care
ART	Antiretroviral therapy
ARV	Antiretroviral
CAB-LA	Long-acting cabotegravir
CCM	Country coordinating mechanism
CI	Confidence interval
CLM	Community-led monitoring
COVID-19	Coronavirus disease 2019
DHIS2	District Health Information Software 2
DSD	Differentiated service delivery
DVR	Dapivirine vaginal ring
FPAM	Family Planning Association of Malawi
HAST	HIV, AIDS, STIs, and TB
HIV	Human immunodeficiency virus
IEC	Information, education, and communication
ITPC	International Treatment Preparedness Coalition
JONEHA	The Network of Journalists Living with HIV
MANERELA+	Malawi Network of Religious Leaders Living with or Personally Affected by HIV and AIDS
MGFCC	Malawi Global Fund Coordinating Committee
MSC	Most Significant Change
NACOSA	Networking HIV & AIDS Community of Southern Africa
NHLS	National Health Laboratory Service
OR	Odds ratio
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PHIA	Population-based HIV Impact Assessment
PrEP	Pre-exposure prophylaxis
RCC	Rotanganedza Community Care
STI	Sexually transmitted infection
SVS	Stock Visibility System
TB	Tuberculosis
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
VMMC	Voluntary medical male circumcision
WHO	World Health Organization

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Executive Summary

The Citizen Science community-led monitoring project observes HIV and TB service at 33 health facilities in Malawi and South Africa, serving almost a million people (914,383). It uses both quantitative (clinic records surveys) and qualitative (key informant interviews) methods. Information is analyzed and fed back to facilities and communities, and solutions are co-created with all stakeholders involved.

As community-led monitoring (CLM) projects mature, it is important to track the changes that occur and look for trends and impact. The Citizen Science project is now in its fourth year of implementation, and the work is contributing to tangible health improvements. In this paper, we employ a "Most Significant Change (MSC)" technique to capture 10 big change stories from the Citizen Science community-led monitoring project in 2023.

Change Story 1 (SOUTH AFRICA)

We found low uptake of pre-exposure prophylaxis (PrEP) among young women in the West Rand, South Africa. Interviews pointed to limited knowledge of the prevention option. We engaged facility managers to encourage healthcare providers to offer PrEP. In 2023, there were 2,520 new PrEP initiations at our monitored sites. People who visited our monitored sites were 32% more likely to initiate PrEP following an HIV test compared with people visiting other West Rand facilities (1.32 OR 95% CI 1.27-1.38).

Change Story 2 (SOUTH AFRICA)

Older men are less likely to test for HIV. Our CLM data suggested a strong preference for community-led HIV testing among this group. We also saw that community-led testing was underutilized as a strategy (20.4% of tests in 2022). We promoted community-led testing, including strategic placement of mobile testing sites at truck stops to reach older men. In 2023, community-led testing surpassed the UN target (30%), constituting 33.6% of all HIV tests at our monitored sites in the West Rand. As a result, more older men living with HIV were diagnosed. According to the Naomi model, the percentage of men living with HIV aged 25-34 years in the West Rand who knew their status increased from 86.8% in 2022 to 88.9% in 2023.

Change Story 3 (SOUTH AFRICA)

We identified a disproportionate challenge with stockouts of TB medicines at two high-volume health facilities, as well as a link to poor treatment initiation. Reactive approaches to stock management were identified as a root cause. We worked with the pharmacists at these facilities for better stock monitoring. The total cumulative number of days that TB medicines remained out of stock at our monitored sites steadily declined from 120 days in both Q4 2022 and Q1 2023, to 26 days in Q2 2023, to just six days in Q3 2023. In 2023, our monitored sites had a TB treatment success

PICTURE: A group of women during a Citizen Science focus group discussion in facility MW04, Dedza, Malawi

rate of 91% (up from 88% in 2022), surpassing the End TB Strategy target of 90% by 2025.

Change Story 4 (SOUTH AFRICA)

We discovered a high proportion (29%) of women attending their first antenatal care (ANC) visit after 20 weeks. The World Health Organization (WHO) recommends the first visit take place within 12 weeks. Interviews with healthcare workers pointed to difficulties in finding and engaging cross-border recipients of care. We engaged Clinic Committees to help find solutions. We promoted enhanced use of the NHLS LabTrak system to follow up foreign nationals. We also worked with facility managers to start documenting reasons for late ANC visits in the files of recipients of care. Early ANC visits rose from 71% in the first half of 2023 to 75% in the second half. Pregnant women at our CLM sites were twice as likely to deliver in the health facility (1.99 OR 95% CI 1.51-2.62) compared with pregnant women at non-monitored sites.

Change Story 5 (SOUTH AFRICA)

In 2023, we found a moderate association between HIV testing and the provision of contraceptive services among adolescent girls and young women aged 15-24 years ($r = 0.36$, $p < 0.001$), suggesting that service integration may promote uptake of both. We encouraged HIV and family planning service integration at our monitored sites. In 2023, our CLM sites were 46% more likely to find and diagnose adolescent girls and young women living with HIV than non-CLM sites (1.46 OR 95% CI 1.28-1.66). Based on the number of HIV tests needed, the cost to diagnose one adolescent girl and young woman living with HIV at our CLM sites was USD 2,852 compared with USD 4,154 at non-CLM sites.

Change Story 6 (MALAWI)

In January 2023, our CLM data showed that just 2,936 people were enrolled in a differentiated service delivery (DSD) model out of 10,837 people on ART at our 14 monitored sites (27% coverage). We used our CLM data to mobilize additional funding from ViiV Positive Action to implement DSD strengthening interventions in seven of our 14 monitored sites. By December 2023, people accessing ART at facilities with DSD strengthening intervention were six times more likely to be in a DSD model (6.79 OR 95% CI 6.04-7.63). As a proportion of total viral load tests done, people at the DSD strengthening sites were twice as likely to be virally suppressed than people at sites without DSD strengthening (2.34 OR 95% CI 2.16-2.54).

Change Story 7 (MALAWI)

Young sex workers have high HIV prevalence and low knowledge of their status. In 2022, 456 HIV tests were conducted among female

sex workers at our monitored sites, of which 217 were among 15-24 year olds (48% of tests). We engaged with government hospitals about creating safe spaces for sex workers, as well as appointing key population focal points to encourage service uptake. In 2023, 808 sex workers tested for HIV at our monitored sites, of whom 434 were young sex workers (54% of tests). An increase in HIV-positive testing yield was recorded overall (2.4% in 2022 to 3.1% in 2023), which was mostly driven by increased identification of young sex workers living with HIV (1.7% vs. 2.4%).

Change Story 8 (MALAWI)

From July to December 2022, 1,841,472 condoms were distributed at our monitored sites; only 3,870 of these were female condoms. Quantification suggests that 50,348 female condoms are needed. Many recipients of care spoke about difficulties accessing female condoms. As members of the National Condom Committee, we shared our CLM data, calling attention to the issue of access to female condoms. We then engaged District Condom Coordinators and trained condom distributors, sensitizing them to access issues with female condoms. In 2023, there was a 23.4% increase in total condom distribution and a more than five-fold increase in female condoms. The number of new HIV acquisitions in the two districts fell from 868 in 2022 to 632 in 2023, according to Naomi.

Change Story 9 (MALAWI)

In 2022, 589 TB tests were conducted at our 14 monitored sites, but just 108 (18%) of these were done using GeneXpert. Data collectors' field notes indicated a lack of health equipment as the main reason for limited GeneXpert testing. We engaged in Global Fund-related processes and secured a commitment from the Malawi Global Fund Coordinating Committee (MGFCC) for 50 new 10-color GeneXpert machines to be installed before the end of the year and a commitment to increase GeneXpert coverage to 40% at TB registered sites. The proportion of TB tests that were done using GeneXpert increased to 39% in 2023 at our monitored sites. The number of people diagnosed with TB and enrolled onto treatment nearly tripled, from 320 in 2022 to 907 in 2023.

Change Story 10 (MALAWI)

In 2022, 23% of all circumcisions at our monitored sites were among boys aged 14 years and younger, and 77% were among men and boys aged 15 years and older. Evidence suggests greater impact and cost-effectiveness if voluntary medical male circumcision (VMMC) efforts are aimed at boys aged 15 years and older. Interviews pointed to inconsistent mobile service provision as a limiting factor. We engaged the District Health Management Team about increasing the number of static sites offering VMMC, successfully lobbying for two additional static sites in 2023 (in addition to the two district hospitals). The proportion of circumcisions among men aged 15 years and older increased from 77% in 2022 to 82% in 2023. According to the Naomi model, there were 205 new HIV acquisitions among men in this age group in the two districts in 2023, down from 284 in 2022.

Citizen Science CLM is contributing to demonstrable improvements in health systems and health outcomes. It is associated with improved service uptake, improved service quality, cost savings, and key impact indicators, such as fewer new HIV acquisitions and greater viral load suppression. CLM helped our sites meet and exceed global targets. The model should be integrated into routine monitoring and evaluation and quality improvement systems so that impact may continue after the project ends.

Introduction

While many community-led monitoring (CLM) initiatives identify problems and barriers to care, few focus on how identifying these problems is linked to advocacy and concrete changes.[1] As CLM projects mature, it is important to track the changes that occur and look for trends and impact.[2]

The Citizen Science project is now in its fourth year of implementation. Relationships with facility managers and district health offices have been built. Communities trust us as sources of feedback and information about health services. We are now focused on follow-up to ensure that commitments from duty-bearers are enacted.[3]

Technical experts agree that requiring impact evaluation for CLM as a measure of success at this nascent stage of global rollout is not realistic nor justified, even while early results are seen in some countries.[4] Yet, there are other methods that provide an indication of a project's impact, which possess similar scientific rigor.

In this paper, we employed a "Most Significant Change (MSC)" technique, which is a form of participatory monitoring and evaluation.[5] It involves the collection and selection of stories of change, produced by program or project stakeholders. This method is appropriate for CLM since it is not always possible to precisely predict desired changes, and it is therefore difficult to set pre-defined indicators of change.

While MSC is primarily a qualitative method, we combined this with statistical analysis, such as odds ratio calculations, linear regression, and district-level epidemiological modelling.

In consultation with our project partners, we identified 10 big change stories from the Citizen Science Project in 2023—5 from South Africa, and 5 from Malawi. The change stories suggest that a properly resourced sub-national CLM project can have concrete and significant impact on health outcomes.

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The Citizen Science Project

The Citizen Science Project is a community-led monitoring demonstration initiative implemented by the International Treatment Preparedness Coalition (ITPC), in collaboration with three partners in South Africa—Networking HIV & AIDS Community of Southern Africa (NACOSA), Rotanganedza Care Center (RCC), and Access Chapter 2 (AC2)—and two partners in Malawi—the Malawi Network of Religious Leaders Living with or Personally Affected by HIV and AIDS (MANERELA+) and The Network of Journalists Living with HIV (JONEHA).

With support from the Bill & Melinda Gates Foundation, we have routinely and systematically collected quantitative and qualitative data from 33 health facilities in Malawi and South Africa since November 2020. We also work with 39 Life Maps participants, whose results are reported separately. Life Maps, part of the Citizen Science Project, uses participatory activities to empower recipients of care to report on their own needs and experiences in seeking healthcare access and provisions.

In 2023, there were some exciting new developments in the project. We began monitoring four community-led clinics in the West Rand (South Africa), using an adapted CLM tool with 25 indicators. We also monitor one community-led clinic in Dedza (Malawi) and another in Kasungu (Malawi).

In the past year, we began tracking HIV testing in South Africa, as well as coverage of differentiated service delivery models in Malawi. Both new indicators contributed to a change story.

Our partners in South Africa secured a data-sharing agreement with the West Rand District Health Service. Specifically, designated login and password credentials have been assigned to our Program Manager, enabling full access to DHIS2. Through this access, we can review data from all health facilities in the West Rand reporting on the system, including community sites. It is important to note that our primary focus and agreement revolve around strengthening outcomes at our 19 monitored sites. Where data remains aggregated by age and sex in DHIS2, we continue to collect information directly at the health facilities. Access to DHIS2 for the entire district allows us to compare outcomes at our 19 monitored sites with the other 69 sites in the district, strengthening CLM attribution.

We have also begun analyzing district-level modelling data (Naomi)[6] to try to draw inferences about our project's impact.

TABLE 1 The Citizen Science Project in 2023

	Malawi	 South Africa
PARTNERS	MANERELA+ and JONEHA	NACOSA, RCC and AC2
DISTRICTS	Dedza and Kasungu	West Rand
MONITORED SITES	14 (12 government, 2 community)	19 (15 government, 4 community)
CATCHMENT AREA	559,427 people	354,956 people
QUANTITATIVE INDICATORS	34	23
QUALITATIVE INDICATORS	11	13
DATA COLLECTORS	28	38
INTERVIEWS WITH RECIPIENTS OF CARE	52	149
FOCUS GROUP DISCUSSIONS WITH RECIPIENTS OF CARE	23	03
INTERVIEWS WITH HEALTHCARE WORKERS	24	87
CLINIC RECORDS SURVEYS	167	228

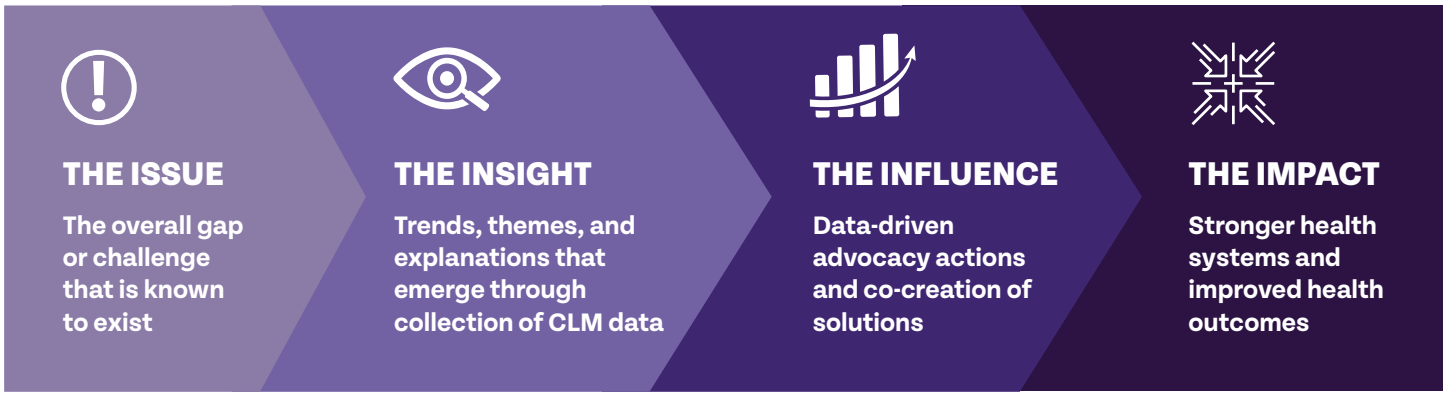
Community-Led Monitoring Change Stories

The following CLM change stories are presented as mini case studies. They unpack how data collected by communities led to actions that improved the uptake and quality of health services and contributed to improved health outcomes.

Each change story contains four sections:

1. **"The Issue"** presents the overall gap or challenge that is known to exist. These are the major problems with health service access and quality that community-led monitoring seeks to address.
2. **"The Insight"** refers to the specific piece(s) of information—often trends or themes—that came to light through the collection of CLM data. It provides additional information on the locations and populations where the issue may be concentrated, as well as why it may be happening.
3. **"The Influence"** indicates the action(s) taken. It describes how Citizen Science project implementers made use of CLM data to engage duty-bearers and other key stakeholders to co-create solutions and address the issue.
4. **"The Impact"** examines improvements to health systems and health outcomes as a result of data-driven action. To the extent possible, we make inferences about the project's contribution to tangible improvements in key epidemiological indicators.

Logic Model for Documenting Citizen Science CLM Change Stories



CHANGE STORY 1

Initiating More Young Women onto Pre-exposure Prophylaxis by Engaging Facility Managers and Mobilizing Communities

THE ISSUE

In 2022, 248,020 people received oral pre-exposure prophylaxis (PrEP) for the first time in South Africa. The country has ambitious targets to increase this to 410,827 annually by 2024.[7]

THE INSIGHT

Our 2022 CLM data show that 20-24 year olds had the lowest PrEP uptake among women despite having the highest HIV incidence rate. From January to October 2022, just 333 young women (aged 20-24 years) initiated PrEP at our monitored sites, compared with 527 15-19 year olds and 849 women aged 25 years and above.

Since our CLM database enables sorting by age and sex, we performed a sub-analysis among 69 transcripts from interviews with young women aged 20-24 years to understand their PrEP barriers. Many showed limited to no understanding of PrEP (especially new forms), and most had never been offered the service. Two said they were offered it only during their pregnancy.

"I think PrEP is mostly for those partners where one partner tested positive and another partner is negative."

– FEMALE, 23, FACILITY ZA15, 27 JULY 2022

"I don't know what PrEP means. I think we need education because in my community, we don't know."

– FEMALE, 21, FACILITY ZA13, 25 JULY 2022

"So, the way I think I understand it, it's sort of something you take, pre-exposure, I think when you feel you will be exposed to the virus. I know about them, but I have never gone to enquire."

– FEMALE, 24, FACILITY ZA14, 3 APRIL 2022

THE INFLUENCE

We conducted feedback sessions with facility managers to share these findings. The focus of the feedback sessions was on how to increase PrEP initiations, especially among young women.

We also conducted health education sessions to generate demand for PrEP services. On 24 February 2022, we convened a PrEP information session at facility ZA11 with 60 in-school adolescents. About 80% of them said this was the first time they learned about PrEP. We also collaborated with the Department of Health to distribute approved PrEP information, education, and communication (IEC) materials[8] in Badirile and Randfontein.

On 13 April 2022, we called a meeting with the Chief Directorates of HIV, AIDS, STIs, and TB (HAST) and District Health Officials, which took place at the West Rand Health Services Department. There was a positive response from the Department of Health, demonstrating acceptance and willingness to engage in the Citizen Science CLM program. The department acknowledged challenges related to PrEP scale-up, particularly in 2021, and committed to addressing these challenges by focusing on increasing awareness and uptake of PrEP in the future. Directly following this meeting, the department sent out new PrEP targets to the facilities, which had a noticeable effect on increased PrEP initiations.

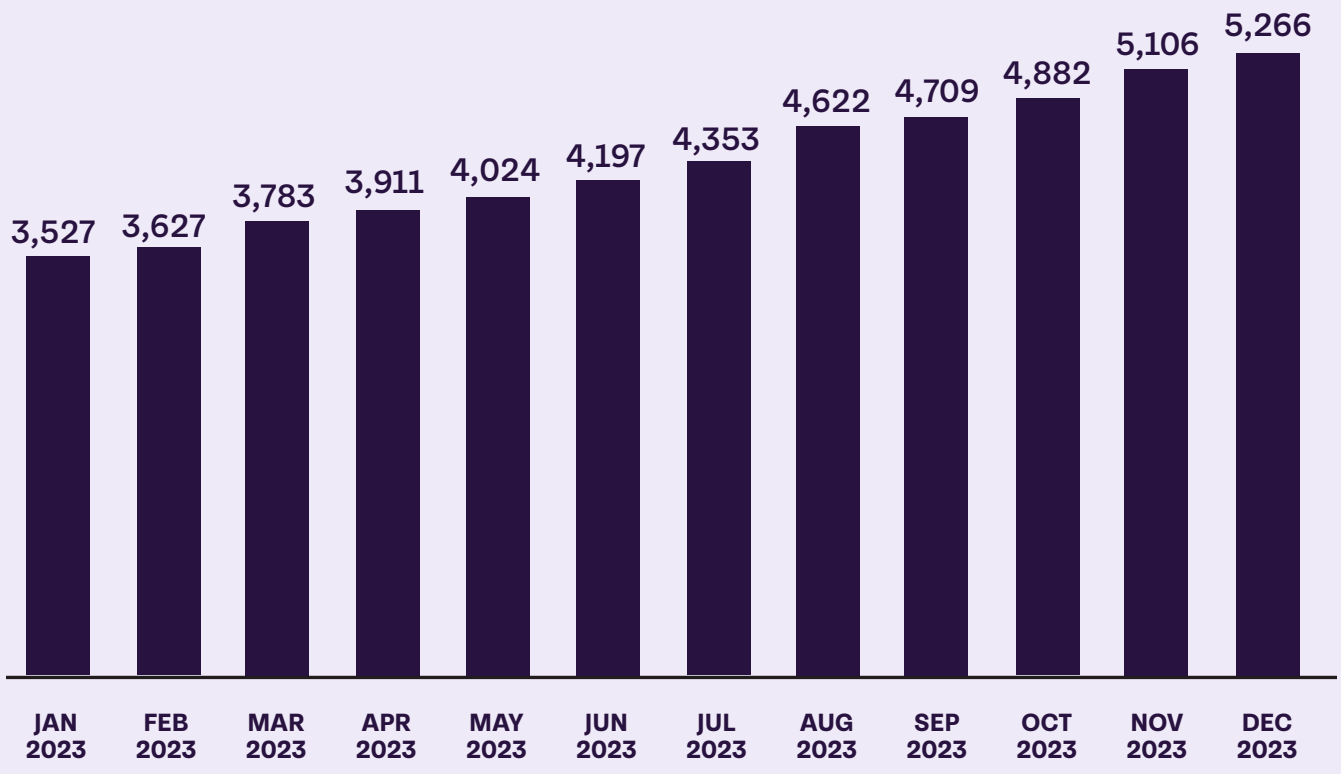
We also conducted three PrEP-related refresher trainings, reaching 105 healthcare workers, Facility Managers, and District Managers from our monitored sites. These sessions took place on 18-19 July 2022, 16-19 August 2022, and 22-23 August 2023.

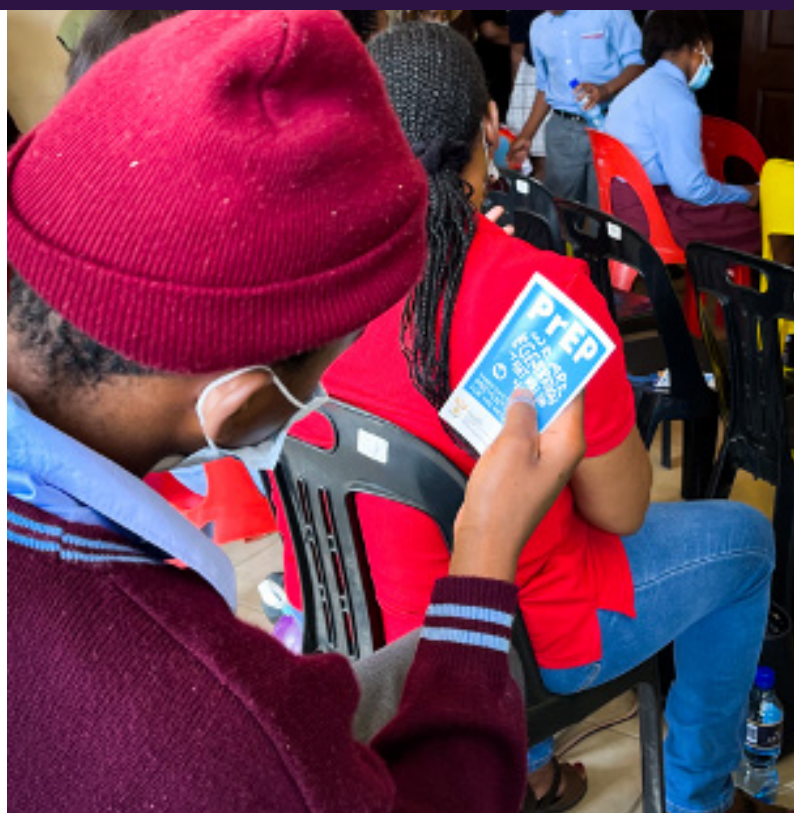
Finally, during the 149 interviews conducted with recipients of care, we asked questions about PrEP knowledge and provided PrEP information. This included information about new forms of PrEP, such as the dapivirine vaginal ring (DVR) and, as of November 2023, long-acting cabotegravir (CAB-LA).

THE IMPACT

The total number of people remaining on PrEP grew steadily at our monitored sites, from 3,527 in January 2023 to 5,266 in December 2023, with a total of 2,520 new PrEP initiations in 2023

FIGURE 1 Total Remaining on PrEP at our 15 Monitored Sites in the West Rand





PICTURES: Citizen Science CLM implementing partner distributing PrEP information to in-school adolescents at facility ZA11, February 2022

(Figure 1). Of these, 368 were among young women aged 20-24 years, up from 333 in 2022. Following our actions, we see evidence of stronger PrEP performance at our CLM sites compared with others in the district. In 2023, people who visited our monitored sites were 32% more likely to initiate PrEP following an HIV test compared with other West Rand facilities (1.32 OR 95% CI 1.27-1.38) (Table 2).

TABLE 2

Odds Ratio for PrEP Initiation at CLM vs. non-CLM sites in the West Rand, 2023 (1.32 OR 95% CI 1.27-1.38)

	CLM sites (n=18 facilities)	**Non-CLM sites** (n=70 facilities)
Initiated PrEP following an HIV test	2,520	10,563
Did not initiate PrEP following an HIV test	157,718	874,722

CHANGE STORY 2

Diagnosing More Men Living with HIV Through Early Achievement of the 2025 Targets on Community-led Service Delivery

THE ISSUE

Men aged 25 years and older have a poor treatment cascade compared with other age and sex cohorts.[9] Low ART coverage and viral load suppression among men in their early 30s have been shown to perpetuate a cycle of HIV transmission to adolescent girls and young women.[10] To achieve epidemic control, it is critical to increase testing, treatment, and viral suppression among this group.

THE INSIGHT

Through our CLM, we discovered a strong preference for community-led HIV testing services among men aged 25 years and older. At our monitored government sites, just 5.6% of HIV tests in 2022 were among men aged 25 years and older compared with 35.5% of tests at our monitored community-led sites (Figures 2 and 3).

We also discovered that community-led testing was below target across our monitored sites: just 20.5% of HIV tests in 2022 were done by community-led implementers, below the UN target of 30% by 2025.

FIGURE 2 HIV Tests By Age and Sex at 15 **Government Health Facilities** in West Rand, 2022 (n=98,410 tests)

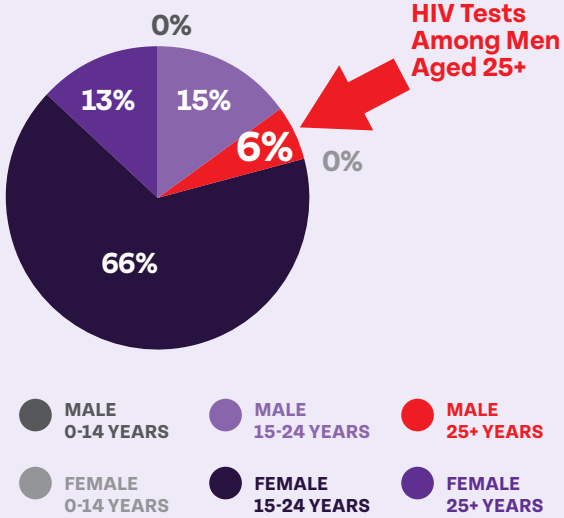
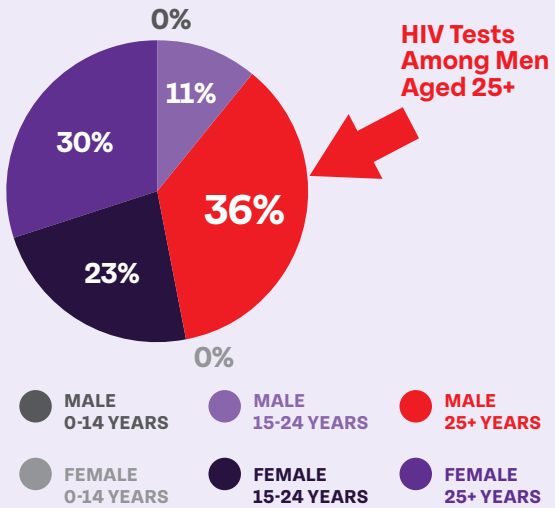


FIGURE 3 HIV Tests By Age and Sex at 4 **Community-led Health Facilities** in West Rand, 2022 (n=20,191 tests)



PICTURE: Citizen Science CLM implementer, Caroline Tiba (Rotanganedza Community Care) (left) with local government HIV secretariat member Lulu Kotobe Sosibo (right) at a community-led HIV testing site near CLM facility ZA11 in the West Rand, South Africa (February 2022)

We performed a sub-analysis of the 47 interview transcripts among men aged 25-34 years to understand their barriers to HIV testing. Participants expressed views that the non-governmental organizations were "specialists" in HIV testing, so they preferred to go there (male, 30, ZA14, 19 July 2022). Increasing community-led testing appeared to be a good strategy to reach and diagnose more men living with HIV.

THE INFLUENCE

We used our CLM data to further promote community-led HIV testing among older men, recommending the strategic placement of community-led testing sites along busy transport routes to reach long-distance truck drivers. We collaborated with the Department of Health to conduct site mapping exercises to determine suitable locations for reaching this target group.

We advocated for the Department of Health to provide HIV testing commodities to community-led organizations. Rotanganedza Community Care now receives 360 HIV test kits (Toyo Anti-HIV 1/2 boxes) and 40 boxes of diabetes strips from the government every month. Every six months, the Department of Health collaborates with community partners to review the targets set for these initiatives. Data from Rotanganedza Community Care and other community-led HIV testing initiatives are fed into DHIS2. Recipients of care are referred to fixed sites for confirmatory testing, as well as treatment and prevention services, such as PrEP and ART.

We also collaborated with the Department of Health to conduct men's health campaigns. The department hosted a Men's *Imbizo* (gathering) on 18 March 2023 to address the CLM-identified barriers that prevent men from testing for TB, HIV, and STIs. We worked closely with the Men's Sector of the Civil Society Forum to help mobilize people for these HIV testing campaigns.

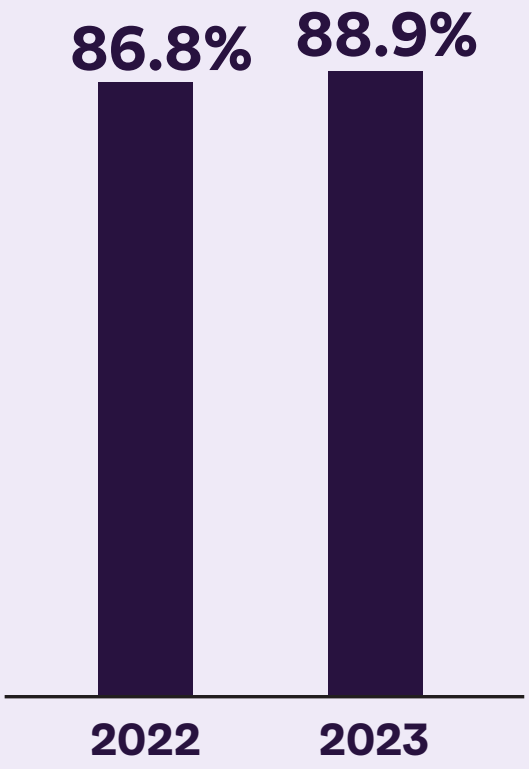
THE IMPACT

The district prioritized community-led testing in 2023. The number of HIV tests at community-led sites more than doubled, from 20,191 in 2022 to 46,891 in 2023, while testing at government sites declined slightly, from 98,410 in 2022 to 89,896 in 2023. In other words, community-led testing at our monitored sites increased from 20.5% in 2022 to 33.6% in 2023 (Figure 4). This demonstrates early achievement of the UN target of 30% by 2025.

As a result, more older men accessed HIV testing services. Naomi estimates that the percentage of men living with HIV aged 25-34 years in the West Rand who know their status increased from 86.8% in 2022 to 88.9% in 2023 (Figure 5).[11]

FIGURE 4 Percentage of HIV tests Delivered by Community-led Organizations, West Rand (CLM data)

FIGURE 5 Percentage of Men Aged 25-34 years Living with HIV who Know their Status, West Rand (Naomi Model)



CHANGE STORY 3

Curing More People with TB by Alleviating Stockouts of Medicines

THE ISSUE

South Africa's TB treatment success rate (79.0%) remains below the End TB Strategy target of 90% by 2025. The West Rand has the highest TB treatment success rate in the country, but remains below the goal, at 88.9%.[12] Many factors affect TB treatment success.

THE INSIGHT

Our CLM identified a disproportionate challenge with stockouts of TB medicines at facilities ZA12 and ZA13. These two clinics are important. In 2023, ZA12 and ZA13 treated more than a quarter (121/466) of all people receiving TB treatment at our 15 monitored sites. ZA12 and ZA13 experienced stockouts of four different TB medicines in 2022 for a cumulative 210 days (Table 3). The problem continued into early 2023, when ZA12 experienced 42 stockouts of 17 TB medicines lasting 139 cumulative days and ZA13 had two stockouts lasting 60 days. ZA03 was the only other facility to record a TB stockout, lasting 30 days in January 2023. All other monitored sites had no TB medicine stockouts.

TABLE 3

Stockouts of TB Medicines at Facilities ZA12 and ZA13 in 2022

FACILITY ZA12			FACILITY ZA 13		
Month	**TB Medicine**	**Out of Stock**	**Month**	**TB Medicine**	**Out of Stock**
September	Rifampicin, INH 150&75mg tablet, 84 tablet pack	30 days	**June**	Rifampicin, INH 75&50mg tablet, 84 tablet pack	30 days
	Rifampicin, INH 75&50mg tablet, 84 tablet pack	30 days			
October	Rifampicin, INH 150&75mg tablet, 56 tablet pack	30 days	**October**	Rifampicin, INH 150&75mg tablet, 84 tablet pack	30 days
	Rifampicin, INH 75&50mg tablet, 84 tablet pack	30 days		Rifampicin, INH 300&150mg tablet; 56 tablet pack	30 days
		TOTAL: 120 days			**TOTAL: 90 days**

PICTURE: Healthcare workers at one of our Citizen Science monitored sites in the West Rand

We identified a link between stockouts of TB medicines and poor treatment initiation. The treatment initiation rate was 86.1% at ZA13 in 2022 compared with 88.4% across all our monitored sites. At facility ZA12, where stockouts were most severe, treatment initiation was just 50% in February 2023. The Citizen Science CLM tools emphasize the importance of data collectors' direct observations by including a space after each indicator for field notes. This creates an added layer of critical insight. The field notes for ZA12 indicated a reactive, rather than a proactive, approach to stock management, acting on a supply issue only when the facility had already run out of medicines: "*When a stockout occurs in the TB room, then they order at the main pharmacy*" (data collector TT's field notes, August 2023).

THE INFLUENCE

We alerted the Facility Managers and the District Health Office about the challenges with stockouts of TB medicines at ZA03, ZA12, and ZA13. We worked with the pharmacist at ZA12 to encourage a proactive approach to stock monitoring, including forecasting, so that orders are placed before stockouts occur.

Through negotiations with the Department of Health, we gained access to the government's web-based Stock Visibility System (SVS). We cross-referenced our CLM data on recorded stockouts at the health facilities with what was uploaded to the online SVS system, making sure that the District Health Office was aware of any supply issues.

THE IMPACT

The total number of days that TB medicines remained out of stock at our monitored sites has steadily declined, from 120 days in both Q4 2022 and Q1 2023 to 26 days in Q2 2023 and to just six days in Q3 2023 (Figure 6). The TB treatment success rate at our monitored sites continued to improve, sitting consistently above the national average (Figure 7). In 2023, our monitored sites had a TB treatment success rate of 91%, surpassing the End TB Strategy target of 90% by 2025.

FIGURE 6 Total Stockout Days of TB Medicines at our Monitored Sites, West Rand

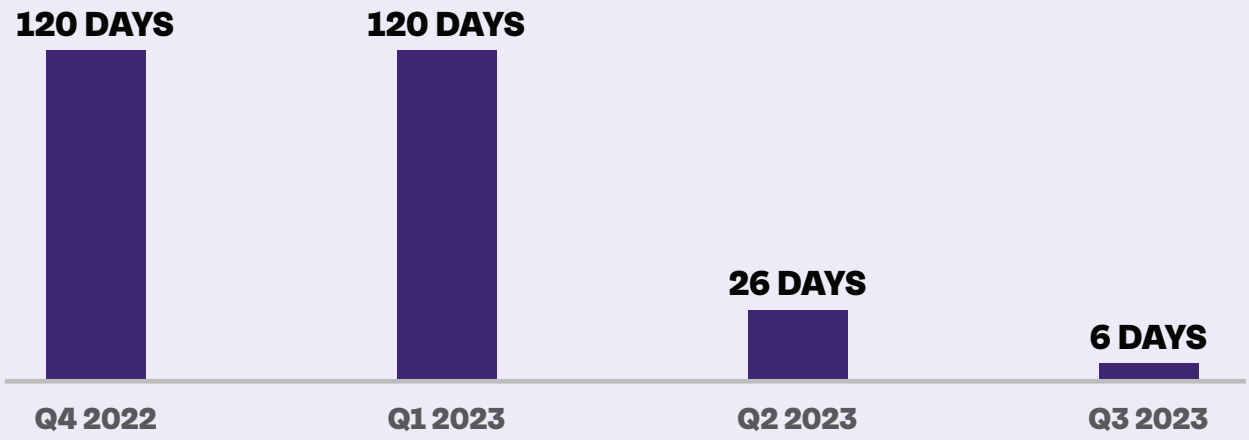
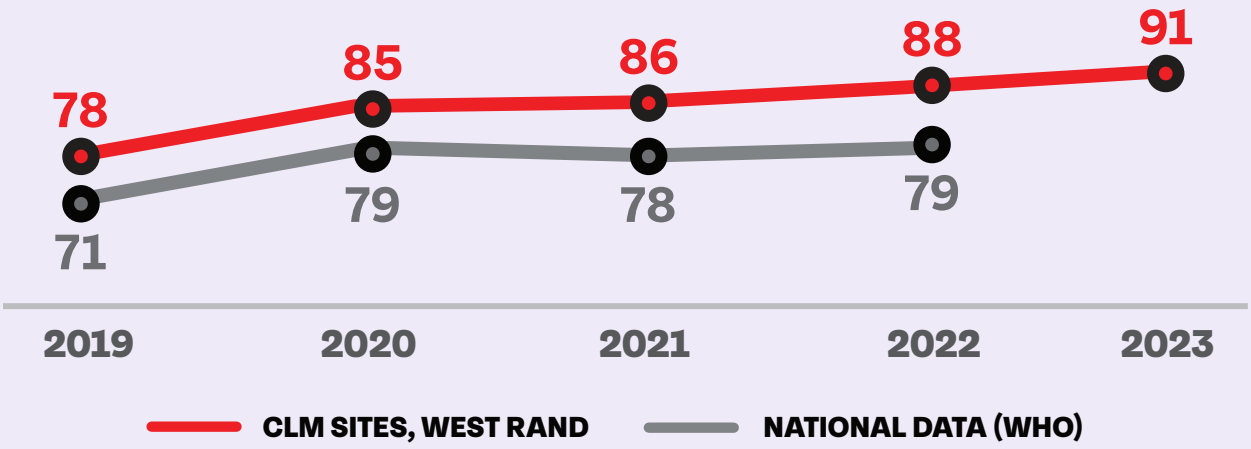


FIGURE 7 TB Treatment Success Rates (%) at our Monitored Sites (West Rand) and in South Africa, 2019-2023



CHANGE STORY 4

Preventing Vertical Transmission of HIV Through Promoting Early Access to Antenatal Care and Delivery at the Health Facility

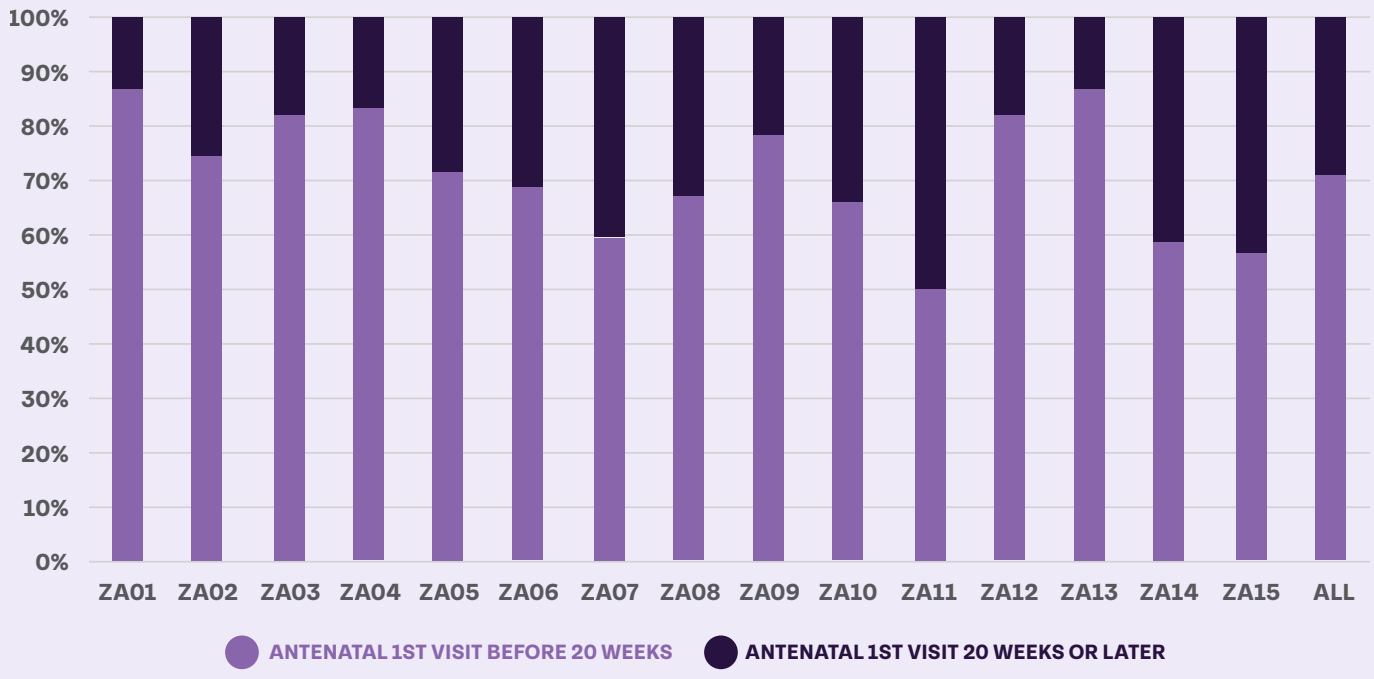
THE ISSUE

Early access to facility-based antenatal care (ANC) is important for optimal prevention of vertical transmission, including ART for pregnant women living with HIV. Women who deliver outside of health facilities are less likely to receive ART and quality obstetric care and may suffer complications leading to vertical transmission of HIV. [13] In South Africa, about 4% of births occur at home.[14]

THE INSIGHT

We began closely monitoring prevention of vertical transmission indicators after South Africa joined the Global Alliance to end AIDS in Children in February 2023.[15] From January to June 2023, 71% of pregnant women attended their first antenatal visit before 20 weeks[16] at our CLM sites, with wide variation by facility, from 50% at ZA11 to 87% at ZA01 (Figure 8). We conducted interviews with healthcare workers to understand the barriers to timely care. A major issue emerged with cross-border follow-up.

FIGURE 8 ANC Attendance Before and After 20 weeks at our 15 Monitored Sites in the West Rand, January-June 2023



PICTURE: The maternity ward at one of our Citizen Science monitored health facilities, 20 April 2023

"Late reporting is associated with foreign nationals."
– HEALTHCARE WORKER, ZA13

"Women attending the clinic for ANC are often not from the local area."
– HEALTHCARE WORKER, ZA03

"Foreign nationals tend to present late, with some specifically delaying booking and delivery."
– HEALTHCARE WORKER, ZA09

"There are also challenges in tracing foreign nationals who borrow IDs."
– HEALTHCARE WORKER, ZA05

"Situated at a cross-border location, this clinic faces challenges with people from North West booking late. Language barriers among foreign nationals and undocumented individuals also contribute to delayed ANC"
– HEALTHCARE WORKER, ZA07

THE INFLUENCE

We worked with clinics to strengthen systems and strategies to improve follow-up and retention in care. It should be noted that tracing individual recipients of care who are lost to follow-up is not part of the Citizen Science Project's mandate.

We engaged Clinic Committees to help us find solutions. A Clinic Committee typically serves as a governing body or advisory group for a local clinic. Its primary purpose is to facilitate community involvement, ensure accountability, and promote the delivery of quality healthcare services within the clinic's catchment area. These committees may include community leaders, representatives from community-based and community-led organizations, recipients of care, and other community members.

Through Clinic Committees, we encouraged Ward-based Outreach Teams to conduct health talks for women of childbearing age.

We also advocated for the enhanced use of the NHLS LabTrak—a system used to telephonically trace unreachable recipients of care—to monitor foreign nationals visiting the clinics.

Finally, we worked with facility managers to begin implementing a practice of documenting reasons for late ANC visits in medical files.

THE IMPACT

Early ANC presentation at our monitored sites increased from 71% in the first half of 2023 to 75% in the second half. At our monitored sites, 91% of pregnant women living with HIV were on ART at their first ANC visit compared with 90.3% at the non-CLM sites. Pregnant women at our monitored sites were twice as likely to deliver in the health facility (1.99 OR 95% CI 1.51-2.62).

FIGURE 9 Proportion of Pregnant Women With HIV on ART at First ANC Visit in the West Rand, CLM vs. non-CLM sites, 2023

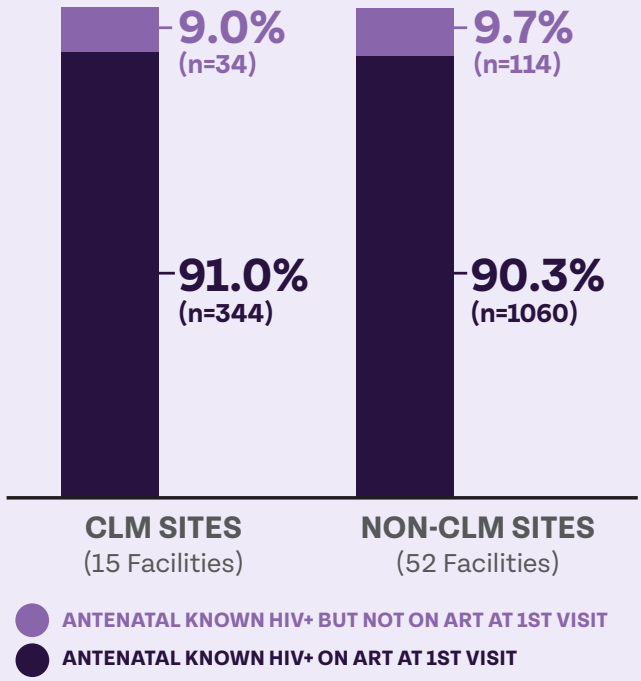
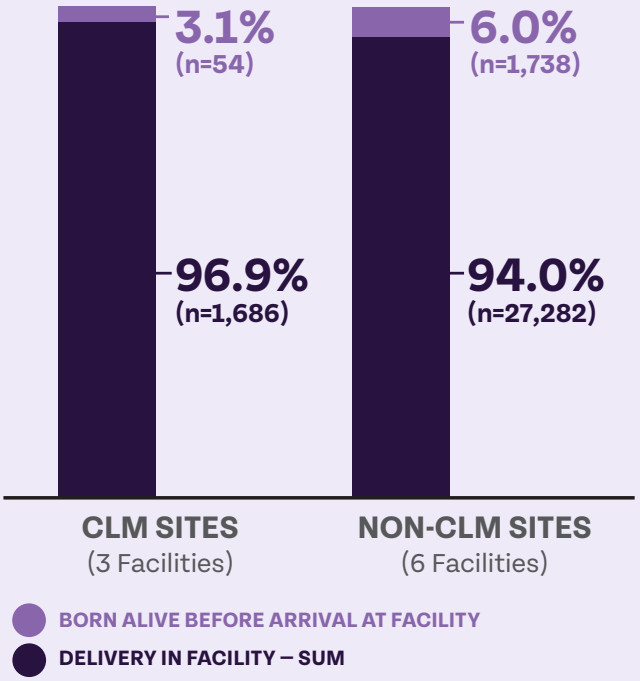


FIGURE 10 Proportion of Pregnant Women Delivering in the Health Facility in the West Rand, CLM vs. non-CLM sites, 2023



CHANGE STORY 5

Enhancing Cost-Effectiveness Through More Targeted and Integrated HIV Testing Among Adolescent Girls and Young Women

THE ISSUE

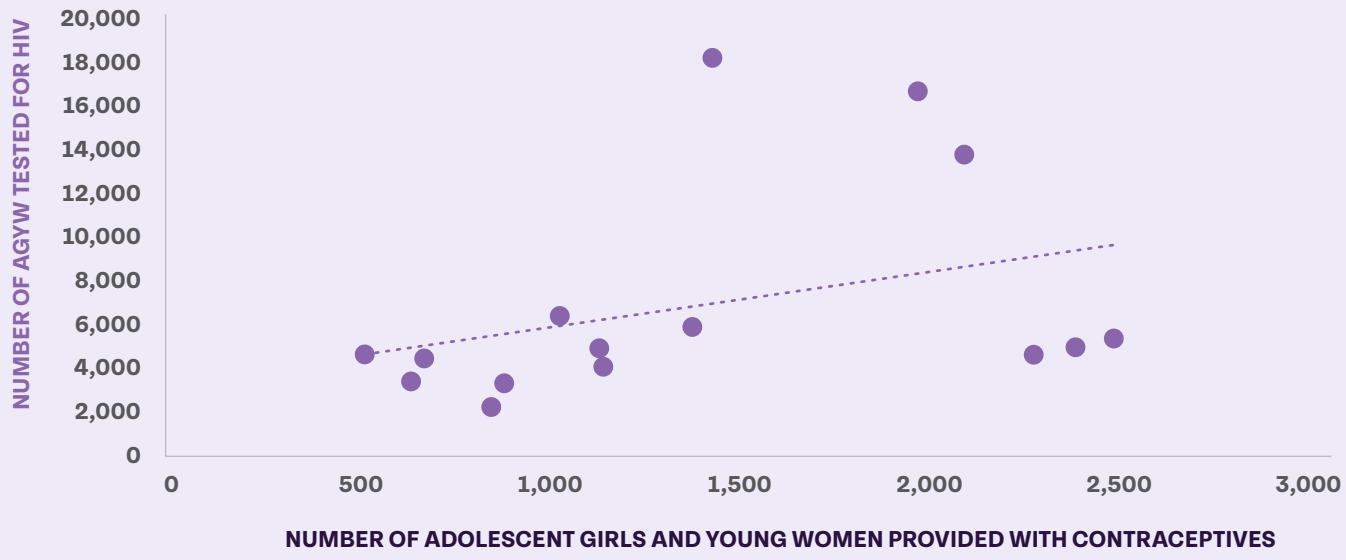
South Africa's response to HIV, TB, and STIs is estimated to cost as much as ZAR 60 billion by 2027/28. The most recent National AIDS Spending Assessment (2019/20) showed expenditure of ZAR 37.5 billion.[17] There is a need for greater domestic ownership of health overall, and HIV prevention programming in particular.[18] Increasing the sustainability of South Africa's HIV program is essential.

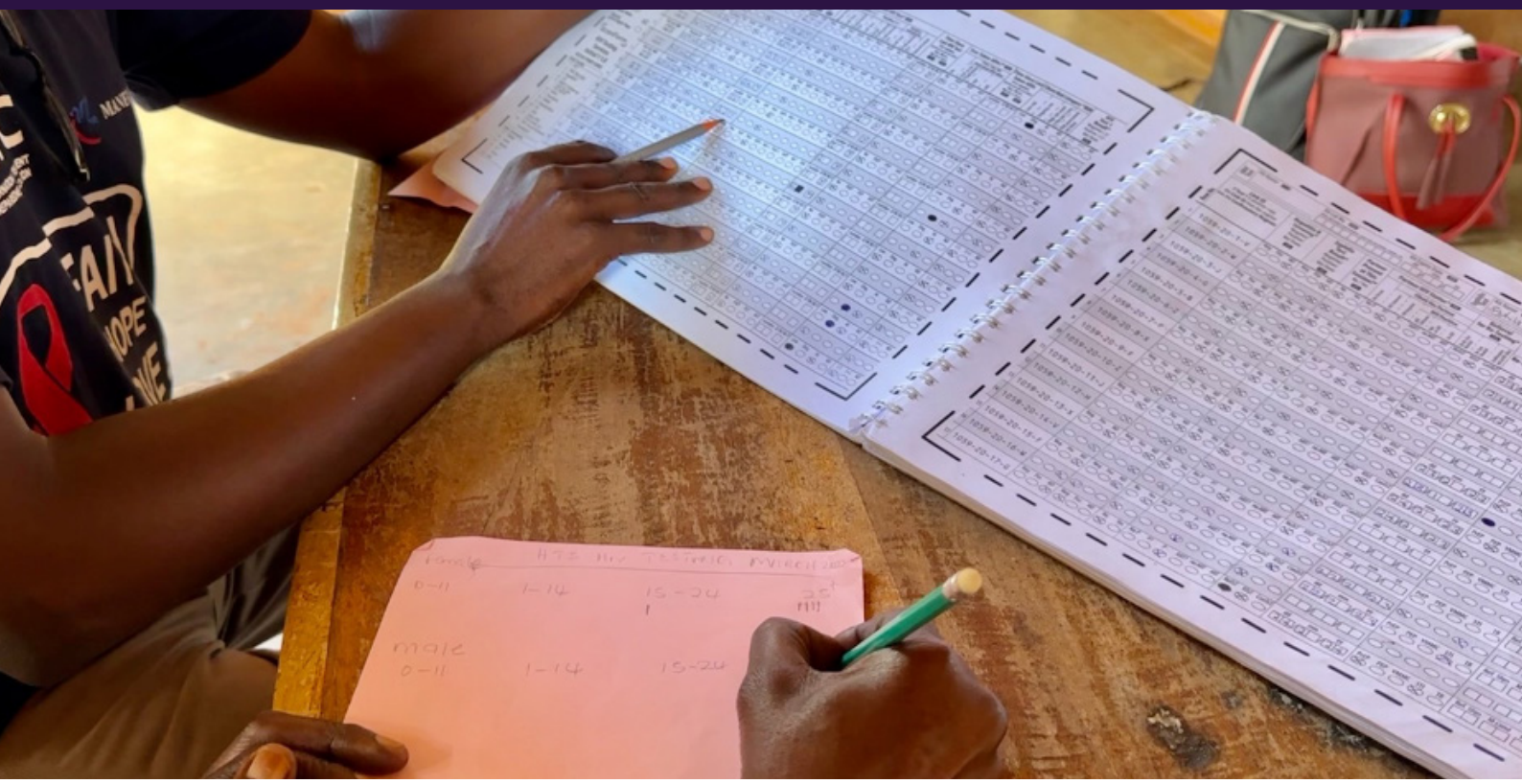
THE INSIGHT

Our CLM data showed poor targeting (low HIV positivity) among young women, suggesting inefficient use of resources. Then, in 2023, we found a moderate correlation between the provision of contraceptive services and HIV testing among adolescent girls and young women aged 15-24 years at our CLM sites in 2023 ($r = 0.36$, $p < 0.001$), suggesting that service integration may promote uptake of both (Figure 11).

We also realized that our facilities were not offering any after-hours or "moonlight" testing services, which have been shown to appeal to young people who spend most of their day in school.[19]

FIGURE 11 Relationship Between Provision of Contraceptive Services and HIV Testing Service among Adolescent Girls and Young Women Aged 15-24 at CLM Sites in West Rand, 2023 ($r = 0.36$, $p < 0.001$)





PICTURE: Citizen Science CLM data collectors analyzing an HIV testing register, 20 April 2023

THE INFLUENCE

We encouraged integration of HIV and family planning services at our monitored sites throughout the year. We offered refresher training sessions to more than 100 healthcare workers at our monitored sites in July 2022, August 2022, and August 2023; these included information on how to integrate HIV testing and the offer of contraceptives.

Since adolescent girls and young women preferred accessing services outside of school hours, we also advocated for after-hours testing at our monitored sites. We were successful in establishing after-hours ("moonlight") testing at one facility (ZA06), which constituted 6.7% of all tests at our CLM sites in 2023.

THE IMPACT

In 2023, our CLM sites were 46% more likely to find and diagnose adolescent girls and young women living with HIV than non-CLM sites (1.46 OR 95% CI 1.28-1.66) (Table 4). There are many benefits to more targeted testing, including diagnosing and treating more people, as well as providing prevention services to people who are most vulnerable to HIV.

More targeted HIV testing is also more cost-effective. In 2023, our 19 CLM sites needed to do 92 HIV tests among young women aged 15-24 years to diagnose one living with HIV. The remaining 69 non-CLM West Rand sites had to do 134 tests for the same result. With a unit cost of USD 31,[20] the cost to diagnose one adolescent girl or young woman living with HIV (in terms of numbers needed to test) at our CLM sites was USD 2,852 compared with USD 4,154 at non-CLM sites (Figure 12).

FIGURE 12 Cost to Diagnose One Adolescent Girl or Young Woman Living with HIV, West Rand, CLM vs. non-CLM sites, 2023

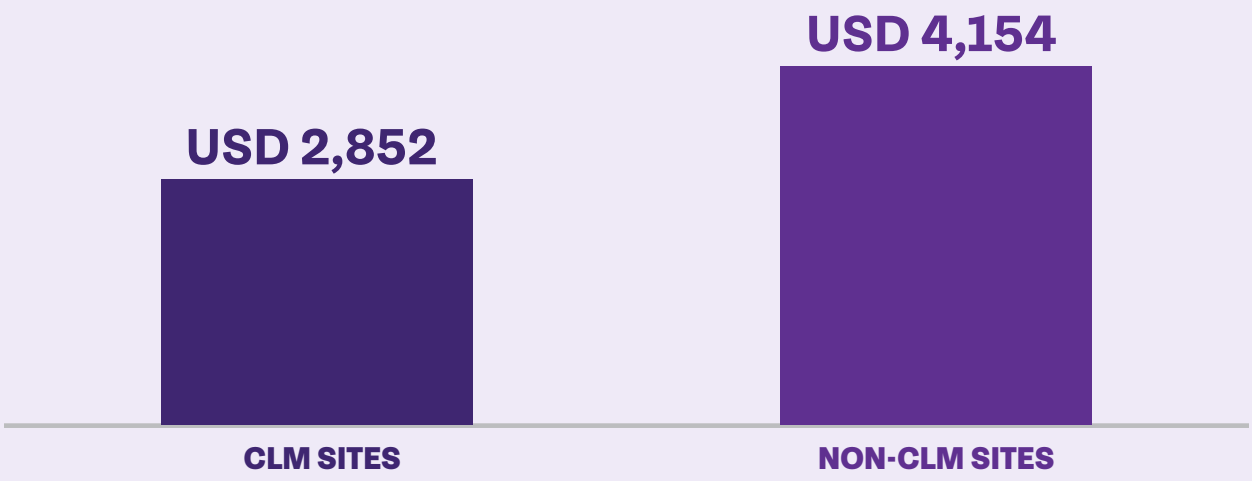


TABLE 4
Odds Ratio for HIV Positivity in Adolescent Girls and Young Women 15-24 years CLM vs. non-CLM sites, West Rand, 2023 (1.46 OR 95% CI 1.28-1.66)

	CLM sites (n=19 facilities)	**Non-CLM sites** (n=69 facilities)
HIV positive	293	1,093
HIV negative	26,945	146,451

CHANGE STORY 6

Increasing Viral Load Suppression by Promoting Differentiated ART Service Delivery Models

THE ISSUE

Differentiated service delivery (DSD) models have been shown to improve viral load suppression.[21] In Malawi, DSD guidelines exist, but coverage of DSD models remains low.

THE INSIGHT

We monitored people accessing ART through DSD models, including six-month dispensing, teen clubs, after hours, and alternative pick-up points. In January 2023, just 2,936 people were enrolled in a DSD model out of 10,837 people on ART at our 14 monitored sites (27% coverage).

Despite being part of Malawi's HIV Clinical Guidelines since 2018, one healthcare worker told us in May 2022, "*We have not started providing services by using differentiated service delivery*" (male, 48, healthcare worker, MW03, 25 May 2022). Another spoke about avoidance of healthcare: "*This has also affected DSD as we are failing to reach the targeted groups*" (female nurse, 23, MW08, 7 October 2022). There were clearly gaps on both the supply and demand side for DSD and a need to strengthen this approach.

THE INFLUENCE

We used our CLM data to mobilize an additional GBP 300,000 from ViiV Positive Action for a three-year project ending in April 2025. The project is implemented by MANERELA+ in partnership with the Universal Health Coverage Coalition and the Civil Society Advocacy Forum. Its focus is on increasing access to DSD for adolescent mothers living with HIV. The ViiV project is complementary to Citizen Science community-led monitoring.

With this additional funding, we supported three DSD strengthening interventions in seven of our 14 Citizen Science CLM sites (Table 5). We supported the establishment of 14 community-level platforms aimed at gathering the views of people living with HIV on various DSD models, organized 25 trainings for peer educators and people living with HIV on DSD, and implemented eight community scorecards and/or client satisfaction surveys for DSD.

PICTURE: Facility MW08, where we implemented community scorecards and client satisfaction surveys for DSD from January to March 2023. Here, two DSD models are implemented: teen clubs and multi-month dispensing. Photo taken on 20 April 2023

TABLE 5 Targeted Interventions to Strengthen Differentiated Service Delivery at 7 CLM Sites in Malawi

FACILITY	DSD STRENGTHENING INTERVENTIONS	
	#	Description
MW03	1	Community scorecard of a DSD model
MW04	1	Community scorecard of a DSD model
MW07	13	Community platforms established to gather views of people living with HIV on DSD models
	8	DSD trainings for people living with HIV and peer educators
	3	Community scorecards of DSD models
MW08	1	Community scorecard of a DSD model
MW09	2	Community scorecards of DSD models
MW10	13	DSD trainings for people living with HIV and peer educators
MW14	1	Community platforms established to gather views of people living with HIV on DSD models
	4	DSD trainings for people living with HIV and peer educators

THE IMPACT

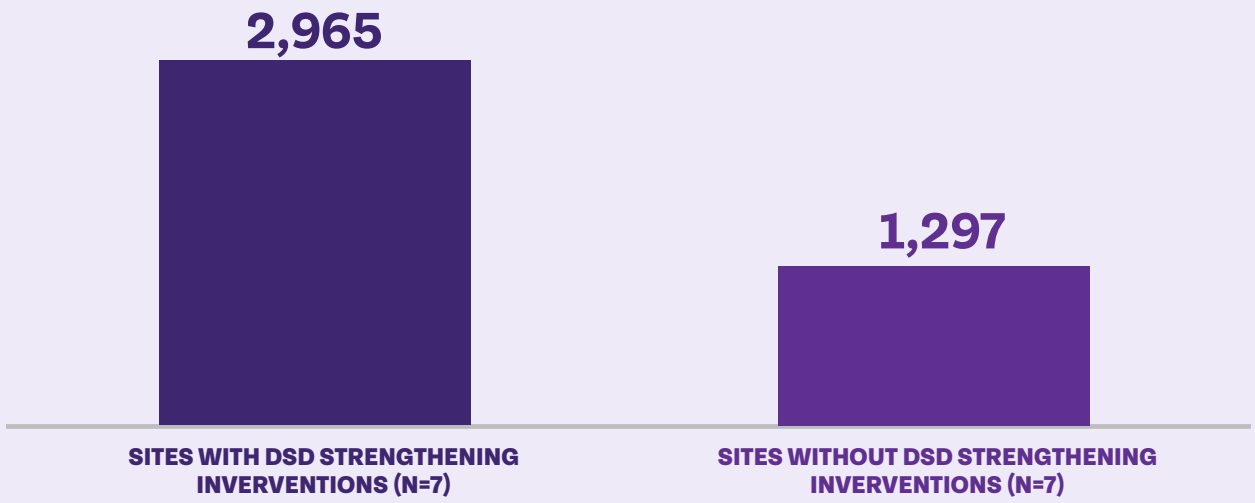
We compared health outcomes at the seven sites with the DSD strengthening interventions to the other seven sites where no intervention was implemented. By December 2023, people accessing ART at facilities with DSD strengthening interventions were six times more likely to be in a DSD model (6.79 OR 95% CI 6.04-7.63) (Table 6). As a proportion of total viral load tests done, people at the DSD strengthening sites were twice as likely to be virally suppressed than at sites without DSD strengthening (2.34 OR 95% CI 2.16-2.54) (Figure 13).

TABLE 6

Odds Ratio for DSD Access Based on Exposure to DSD Strengthening Interventions, December 2023 (6.79 OR 95% CI 6.04-7.63)

	Facilities with DSD strengthening Interventions	Facilities without DSD strengthening Interventions
People accessing ART though a DSD model	2,290	334
People accessing ART through standard care	17,389	17,221

FIGURE 13 Number of People who were Virally Suppressed (<0-199 copies/ml or undetectable) at CLM Sites with and without DSD Strengthening Interventions, 2023



CHANGE STORY 7

Reaching More Young Sex Workers Living with HIV by Creating Safe Spaces and Removing Barriers to Access

THE ISSUE

In many parts of Africa, studies have documented the existence of very young sex workers, many in adolescence, including those exploited into sex work.[22] In Malawi's most recent integrated biological and behavioral survey among sex workers, 18.1% of 15-19 year olds and 21.5% of 20-24 year olds tested positive for HIV for the first time during the survey. Identifying and treating young sex workers living with HIV is essential to leaving nobody behind.[23]

THE INSIGHT

Five of our 14 monitored sites have data available on services provided to key populations (MW01, MW05, MW06, MW07 and MW11). Two of these are District Hospitals, two are non-governmental service delivery sites, and the fifth is a rural health center. In 2022, 456 HIV tests were conducted among female sex workers; 217 of these were tests among young girls exploited into sex work (aged 15-17 years) and young sex workers aged 18-24 years (48% of tests) (Figure 14). Of the 11 positive HIV test results, 27% (n=3) were among young sex workers (Figure 15).

FIGURE 14 HIV Tests Done Among Sex Workers at 5 Sites in Malawi, by Age, 2022

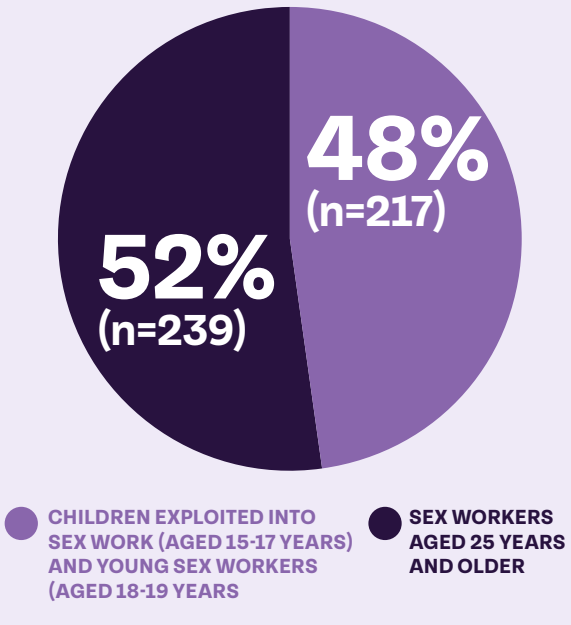
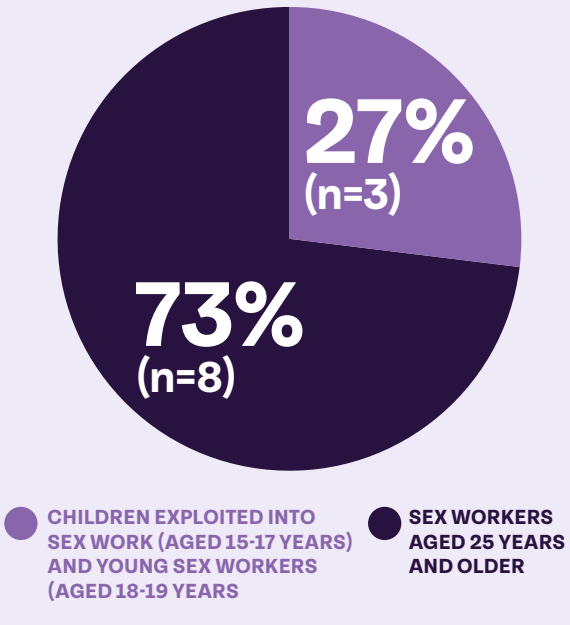


FIGURE 15 Positive HIV Test Results Among Sex Workers at 5 Sites in Malawi, by Age, 2022



PICTURE: A Citizen Science project CLM team member (left) who also works as an outreach worker for sex worker programs at the Family Planning Association of Malawi (FPAM), photographed here at Citizen Science CLM facility MW08 on 20 April 2023. Her presence in the health facility helps reduce stigma and discrimination and promote health service uptake among sex workers.

THE INFLUENCE

In April 2022, we organized an engagement meeting with officials from the Department of Reproductive Health, Department of HIV/AIDS, National AIDS Council, members of civil society, and representatives of the Diversity Forum (the key population networks umbrella body). The aim was to discuss CLM data on service provision for key populations and advocate for safe spaces for key populations at facilities and key population-friendly services. During this meeting, we secured a commitment from government to introduce key population focal points in every health facility. These focal points are specifically trained in providing stigma-free services for key populations.

In November 2022, we trained healthcare workers in all 14 Citizen Science CLM facilities on sexual orientation, gender identity, and expression to strengthen key population-friendly service provision. This training was organized by MANERELA+ in collaboration with the District Health Management Team and the Center for the Development of People, an organization implementing Global Fund-supported key population programs in Dedza.

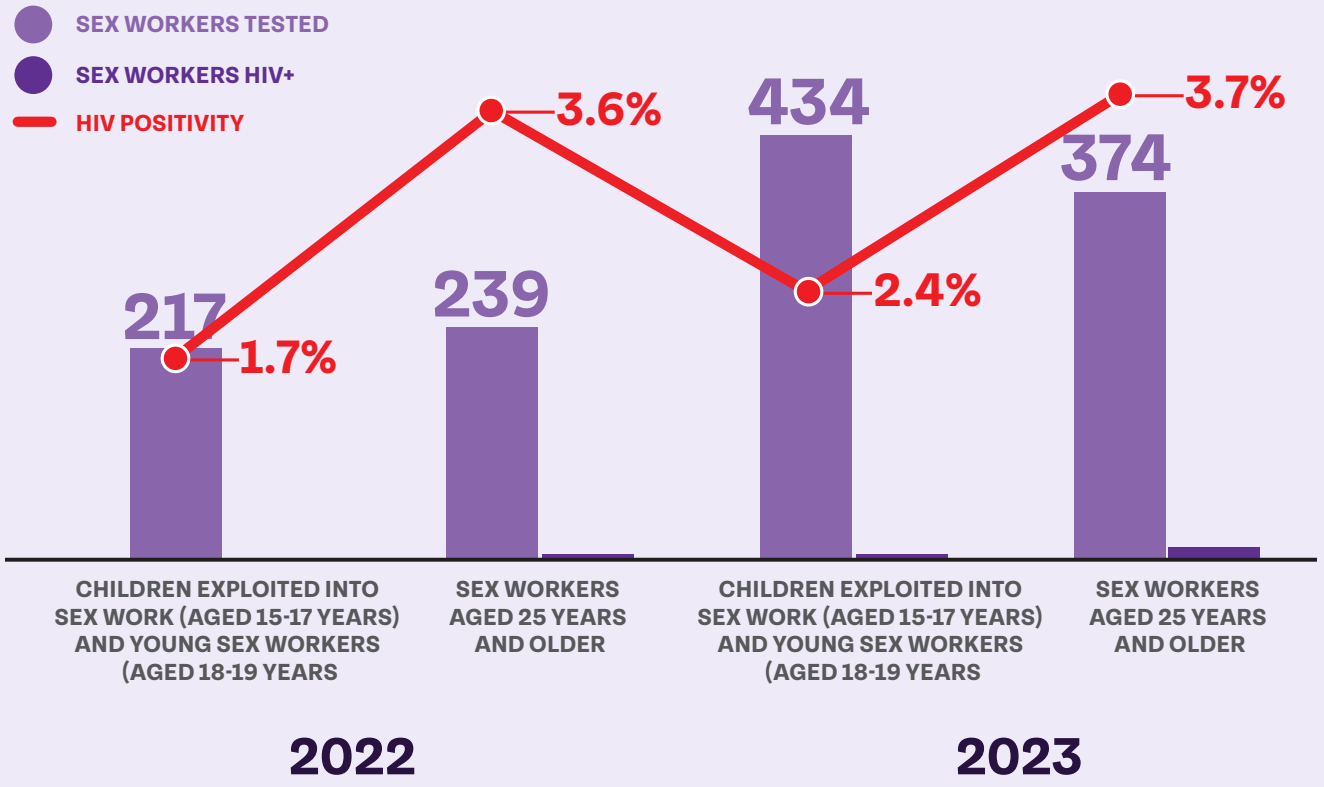
We also engaged with government hospitals about creating safe spaces for sex workers to encourage service uptake. In May 2022, we secured a commitment from a nursing officer at a district hospital: "*We have a room where we help female sex workers, which we intend to turn into a key populations clinic*" (male, age 34, MW01, 31 May 2022).

Finally, we hired five sex workers as CLM data collectors, encouraging their peers to seek healthcare.

THE IMPACT

In 2023, 808 sex workers tested for HIV at our monitored sites, up from 456 sex workers in 2022 (Figure 16). Of these, 434 were young sex workers in 2023 (54% of tests), up from 217 in 2022 (48% of tests). An increase in HIV-positive testing yield was recorded overall (2.4% in 2022 to 3.1% in 2023), but this was mostly driven by increased identification of young sex workers living with HIV (1.7% vs. 2.4%), suggesting better targeting of the most vulnerable sex workers at our monitored sites.

FIGURE 16 Testing Coverage and HIV Positivity Among Sex Workers by Age at 5 Monitored Sites in Dedza and Kasungu, 2022-2023



CHANGE STORY 8

Reducing New HIV Acquisitions by Engaging Condom Committee and District Condom Coordinators to Increase Access to Condoms

THE ISSUE

Malawi's 2015/2016 Demographic and Health Survey found large disparities between condom use among men (55.8%) and women (18.5%).[24] Evidence suggests that provision of female condoms can decrease the number of unprotected sex acts in a population.[25]

THE INSIGHT

In the last half of 2022, 1,841,472 condoms were distributed at our monitored sites, only 3,870 of which were female condoms. According to UNFPA, advisable distribution is 450 female condoms per 10,000 people for a three-month period.[26] The catchment area of our 14 facilities is home to an estimated 559,427 people. This means that the ideal distribution should have been more like 50,348 female condoms. Many recipients of care that we interviewed spoke about difficulty accessing female condoms.

"The hospital doesn't order female condoms they only stock male condoms, so we also got tired of asking for them when we come to the hospital."

– FEMALE, 42, MW08, NOVEMBER 2022

"For male condoms there is no problem. They are there, but female condoms are not available."

– MALE, 43, MW08, OCTOBER 2022

"No female condoms at facility; only male condoms available."

– FEMALE, 25, MW12, 9 MAY 2023

"There is a shortfall of female condoms."

– FEMALE, 15, MW12, 9 MAY 2023

"There are no barriers in accessing male condoms, but (for) female condoms we don't have access."

– HEALTHCARE WORKER, ZA07

THE INFLUENCE

The Citizen Science partner, MANERELA+, is part of Malawi's Condom Committee, which is defined in the country's National Condom Strategy,[27] as well as the District Condom Coordinating Committees in Dedza and Kasungu. We shared our CLM data through these committees, calling attention to the issue of condom access, especially female condoms.

We held engagement meetings with the Ministry of Health, advocating for the inclusion of key population-led organizations and networks of people living with HIV in the National Condom Committee. Mobilizing key populations was a critical strategy for increasing condom distribution.

We engaged the Dedza and Kasungu District Condom Coordinators and the condom focal points in each facility we monitor. Through the District Condom Coordinators, we trained 163 female sex workers and 98 adolescent mothers living with HIV to serve as condom distributors to their peers (see Table 7). The aim was to increase condom distribution and female condom distribution in particular.

TABLE 7 Number of Community Condom Distributors Trained at Priority CLM Sites in 2023

FACILITY	TRAINED COMMUNITY CONDOM DISTRIBUTORS	
	#	Description
MW01	25	Female sex workers
	27	Adolescent mothers living with HIV
MW02	12	Female sex workers
	42	Adolescent mothers living with HIV
MW03	29	Adolescent mothers living with HIV
MW04	15	Female sex workers
MW05	35	Female sex workers
MW06	20	Female sex workers
MW08	8	Female sex workers
MW09	12	Female sex workers
MW11	24	Female sex workers
MW14	12	Female sex workers

With resources leveraged from Viiv Positive Action (see Change Story 6), we also established safe space "hubs" where young people can access condoms more discretely than in public health facilities.

Finally, CLM data collectors alongside service providers in all 14 sites took the lead in disseminating messages on condom use within support groups for people living with HIV. In particular, they discussed and dispelled myths about female condoms.

PICTURES: Female condoms distributed at one of our monitored sites in Malawi

THE IMPACT

In the second half of 2023, 2,272,597 condoms were distributed at our 14 monitored sites, including 21,593 female condoms (Figure 17). This represents a 23.4% increase in total condom distribution and a more than five-fold increase in female condom distribution. We believe that these efforts are contributing to increased condom use and fewer new HIV acquisitions in the districts where we work. In 2022, the Naomi model estimated that there were 423 new acquisitions in Kasungu and 445 in Dedza. In 2023, the model estimates that there were 305 new acquisitions in Kasungu and 327 in Dedza (Figure 18).[28]

FIGURE 17 Total Condom Distribution at our 14 Monitored Sites in July-December 2022 vs. July-December 2023

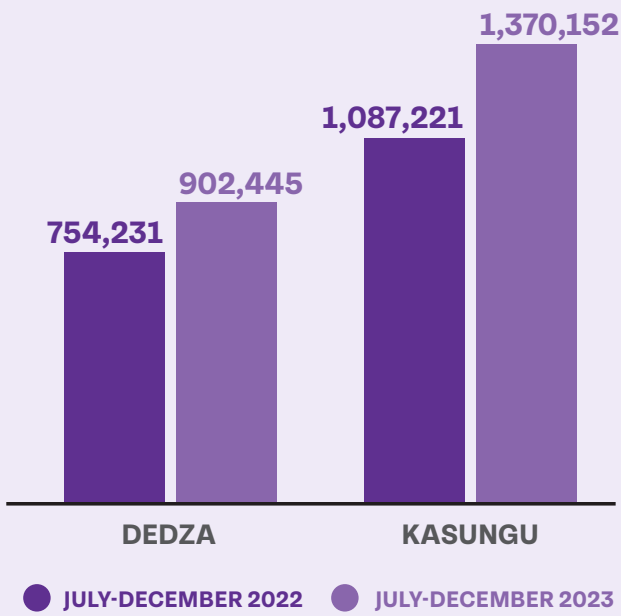
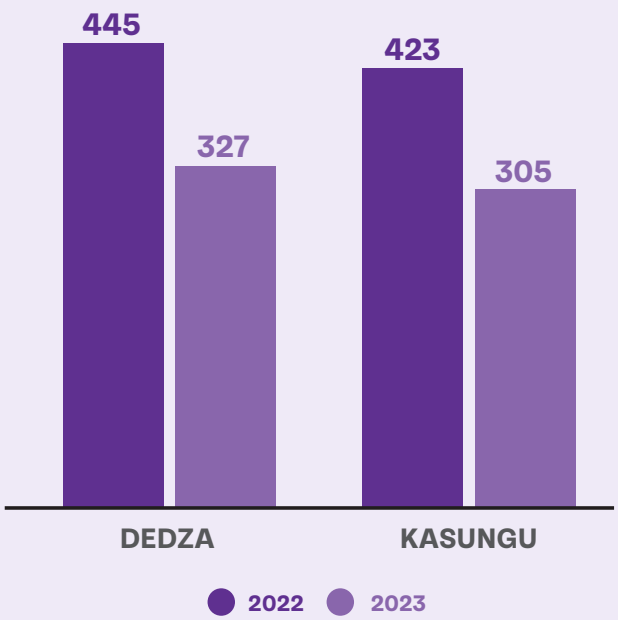


FIGURE 18 Number of New HIV Acquisitions in Dedza and Kasungu, 2022 vs. 2023 (Naomi Model)



CHANGE STORY 9

Finding Missing People with TB and Initiating Them onto Treatment by Engaging Donors to Increase Access to Rapid Molecular Testing

THE ISSUE

In 2022, Malawi had a total TB incidence of 25,000, but only 18,255 individuals were notified, leaving 6,745 missing people with TB.[29] It is important to detect and treat these people, both to save their lives and to eliminate reservoirs for transmission in the community. The World Health Organization (WHO) recommends that TB programs transition from microscopy as the initial TB diagnostic test to rapid molecular diagnostics, such as GeneXpert and Truenat.[30] Malawi's National Strategic Plan for TB 2021-2025 acknowledges limited access to new diagnostic technologies, with about 45% of notified bacteriologically confirmed TB cases being diagnosed using rapid molecular tests.[31]

THE INSIGHT

In 2022, there were 589 TB tests at our 14 monitored sites, but just 108 (18%) of these were done using GeneXpert. Data collectors' field notes shed light on the reasons. A total of 24 out of 58 clinic records surveys indicate a lack of health equipment as the main reason for limited GeneXpert and Urine LAM testing. One data collector recorded that *"healthcare workers have been trained for Urine Lam and are waiting for equipment for the service"* (data collector EK, MW08, September 2022).

THE INFLUENCE

We engaged in Global Fund-related processes in Malawi to advocate for investment in GeneXpert Machines, cartridges, and Urine LAM strips. We have several direct inroads for Global Fund advocacy, which we harness to share CLM data and advocate for change. One of MANERELA+'s board members sits in the Malawi Global Fund Coordinating Committee (MGFCC), representing key populations. We share CLM information and priorities with her and she takes them to country coordinating mechanism (CCM) level. Further, one of the Citizen Science Project partners, JONEHA, is also a member of the MGFCC, representing the Civil Society Advocacy Forum.

During Grant Cycle 7 funding request development in early 2023, we pushed for Global Fund resources to be prioritized for TB diagnostics. We engaged in the national dialogue for the funding request on 18 January 2023, sharing our CLM data.

In the MGFCC meeting on 13 March 2023, we secured a commitment for the number of GeneXpert sites in Malawi to be increased from 147 in 2022 to 197 by the end of 2023. This would be done through the installation of 50 new 10-color Xpert machines, procured through the old Global Fund grant. We also secured a commitment from the MGFCC for GeneXpert testing coverage to reach 40% among TB registered sites.[32]

PICTURE: MGFCC meeting on 13 March 2023 where a commitment was secured to increase the number of GeneXpert sites in Malawi from 147 in 2022 to 197 by the end of 2023 and for GeneXpert testing coverage to reach 40%[33]

THE IMPACT

The proportion of TB tests that were done using GeneXpert increased from 18% (n=108/589) in 2022 to 39% (n=609/1,544) in 2023 at our monitored sites (Figure 19).

We also saw a significant increase in Urine LAM testing, from 20% in 2022 to 42% in 2023.

Linked to more precise testing, we can also see steady increases in the number of people diagnosed with TB and initiated onto treatment, with a particularly large increase in the second half of 2023 when the 50 new machines were installed (Figure 20).

In 2022, 320 people were diagnosed and enrolled onto TB treatment at our 14 monitored sites. In 2023, this number nearly tripled, reaching 907.

FIGURE 19 Proportion of TB Tests Done Using Various Diagnostics at our 14 Monitored Sites, 2022 and 2023

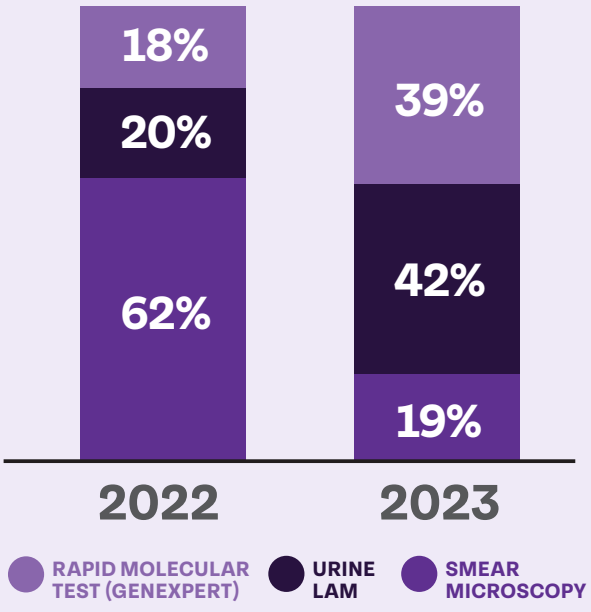
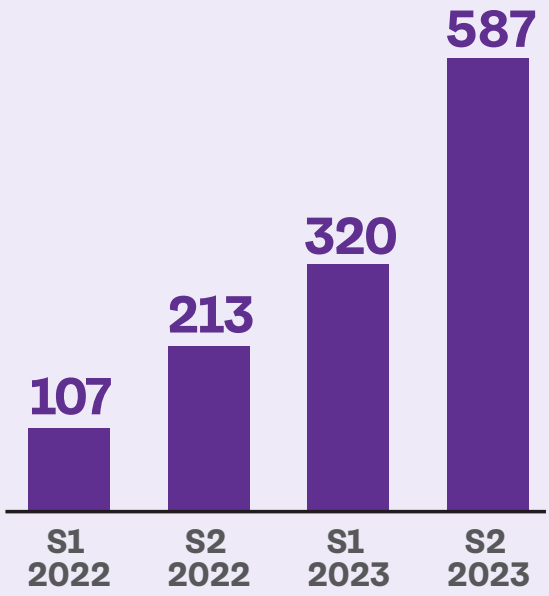


FIGURE 20 Number of People Diagnosed and Initiated onto TB Treatment at our 14 Monitored Sites, by Semester



CHANGE STORY 10

Preventing New Acquisitions and Increasing Cost-Effectiveness by Age Targeting Voluntary Medical Male Circumcision

THE ISSUE

It is more cost-effective for voluntary medical male circumcision (VMMC) programs to target men aged 15 years and older.[34] In Malawi, VMMC programs are modelled to have the greatest reduction in HIV incidence over a 15-year period if they focus on adolescent boys and young men aged 15-24 years.[35] Malawi's latest Population-based HIV Impact Assessment (PHIA) (2020-2021) indicates that 66.6% of men aged 15 years and older and 62% of those aged 15-24 years remain uncircumcised.[36]

THE INSIGHT

In 2022, 23% of all circumcisions at our monitored sites were among boys aged 14 years and younger and 77% were among men and boys aged 15 years and older (Figure 21). We realized that VMMC services were limited to the two District Hospitals (MW01 & MW07), with the others providing VMMC only through mobile clinics that rely on donor funding and availability of the project implementing partners. For example, one healthcare worker said, *"VMMC, we had a provider who was doing this but as of now we don't have one"* (female, 42, MW08, 26 November 2022). Another said, *"As of now, we are no longer doing VMMC, but it used to happen in the past"* (healthcare worker, male, 32, MW06, 15 May 2022). Our data suggested that demand for VMMC services was not properly matched with supply, which was impacting negatively on client experiences and deterring clients from referring their peers for circumcision. This is especially true for older men, who may have taken time off work to seek a service that is suddenly no longer offered.

THE INFLUENCE

We used the CLM data to engage District Health Management Teams about increasing the number of static sites offering VMMC. In 2023, we were successful in lobbying for two additional sites. Now, MW02 and MW14 also offer VMMC, alongside MW01 and MW07. In these two additional facilities, there were already trained personnel for VMMC, making it easy for the facilities to add this service. We also encouraged age targeting in these new sites. We took the opportunity during interviews and focus group discussions with older men to promote VMMC service uptake at these sites.

We engaged government to try to mobilize domestic resources for VMMC. Historically, VMMC in Malawi is a donor-funded initiative, predominantly supported by the World Bank and other partners. We are engaging the councils, which serve as Local Government Units,

PICTURE: A Citizen Science focus group discussion among men at facility MW03 in Dedza in 2023. During these sessions, we shared VMMC information and promoted service uptake.

to mobilize resources at district level for these services. In Dedza, we helped convene a meeting about domestic funding for VMMC on 11 December 2023 with the District AIDS Coordinating Committee, the Principal Nutrition HIV and AIDS Officer, the District Council, and HIV implementing partners. In Kasungu, we convened a similar session on 15 December 2023 in partnership with I-TECH, Partners in Hope, the District Council, and the Ministry of Health. At these meetings, there was consensus that advocacy for funding must be taken up to the national level.

THE IMPACT

The expansion of reliable, fixed-site VMMC services has increased the proportion of men aged 15 years and older seeking the service. The proportion of circumcisions among this age group increased from 77% in 2022 to 81% in 2023 (Figures 21 & 22). These, alongside other prevention efforts, are contributing to reduced numbers of new HIV acquisitions among the target group. In 2023, there were 205 new HIV acquisitions among men aged 15 and over in the two districts, down from 284 in 2022 (Figure 23).

FIGURE 21 Proportion of VMMCs Done at our Monitored Sites in 2022, by Age

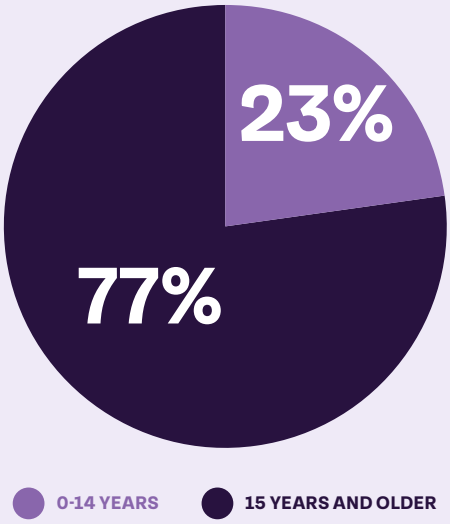


FIGURE 22 Proportion of VMMCs Done at our Monitored Sites in 2023, by Age

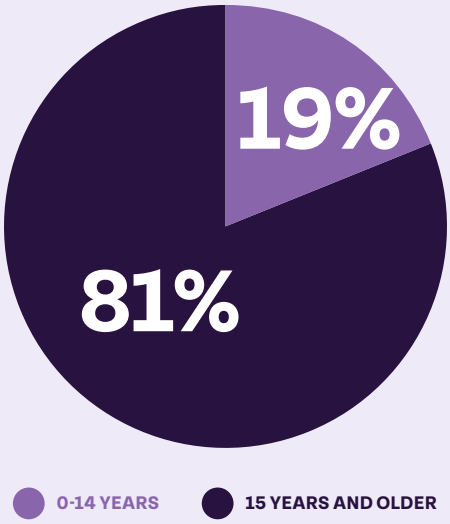
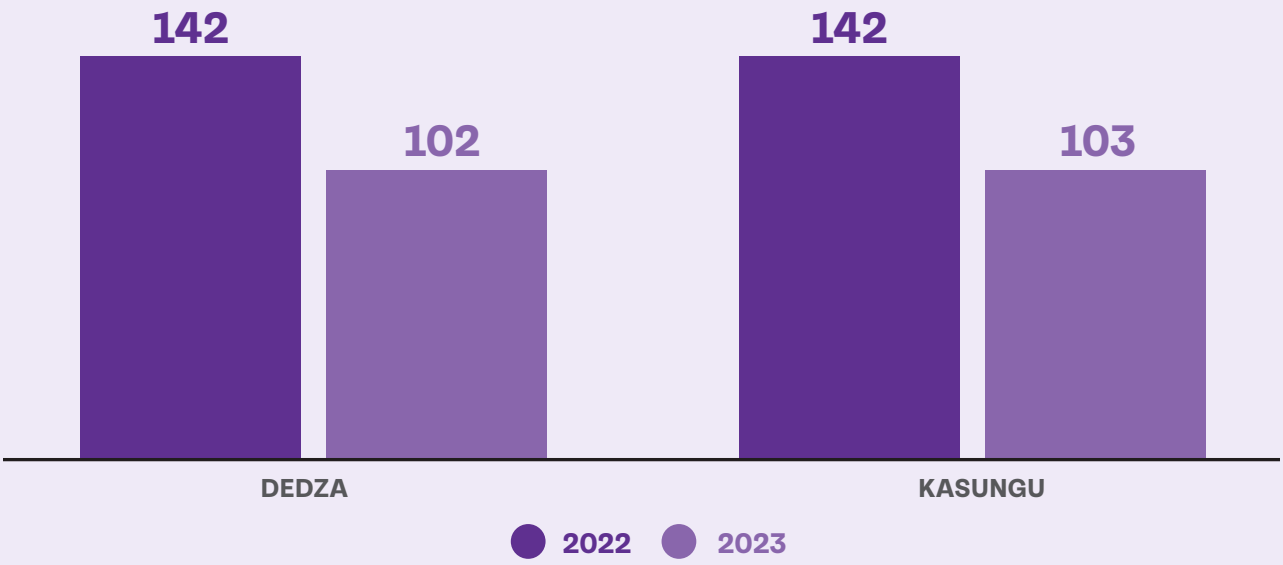


FIGURE 23 Number of New HIV Acquistions Among Men Aged 15 Years and Older in Dedza and Kasungu, 2022 and 2023 (Naomi Model)



Conclusion

This report provides compelling evidence that a well-resourced, multi-year CLM program can contribute to demonstrable improvements in health systems and health outcomes. Citizen Science CLM is associated with improved service uptake, improved service quality, cost savings, and key impact indicators, such as fewer new acquisitions and greater viral load suppression. In several instances, CLM helped our monitored sites meet and exceed global health targets.

These improvements would not be possible without community leadership, data, and expertise.

The implications of these findings are multi-pronged:

1. **Community-monitored sites fare better**
When compared with non-monitored sites, health facilities that undergo community monitoring have better health outcomes and lower costs and implement improvements quicker. CLM models should be integrated into routine monitoring and evaluation and quality improvement systems on an ongoing (rather than project-based or temporary) basis.

2. **The rigor of CLM implementation matters**
The outcomes described in this report were made possible via the hard work of all implementation partners, as well as many other factors, one of which is the rigor of implementation. As the two largest bilateral and multilateral funders in the global HIV response (PEPFAR and the Global Fund, respectively) invest significantly in the implementation of CLM, it is important that efforts hew to a proven model.

3. **Trust between community and government partners + data transparency = impact**
The scope of the findings described in this report was made possible thanks to data-sharing agreements with government data systems, including access to DHIS2. The impact of CLM is difficult to measure without comparison to non-monitored sites, and only through data transparency agreements with governments were we able to thoroughly analyze and quantify the impact of CLM. These data agreements are not a given and rely on a long and steady process of building trust between community and government partners. This aspect of

CLM—diplomacy, communication, relationship building, coordination, compromise, and mutual respect—is often unfunded and the nature of the work is difficult to articulate in a project plan. But it is nonetheless essential to the success of the effort. The next wave of CLM implementation will hinge significantly on strengthening this aspect of the work.

4

Impact takes time

The Citizen Science project is a rare multi-year investment in CLM. All too often, support for CLM ends after the start-up phase or is short-term in nature. Our experience shows that real impact is only possible if CLM is embedded in health facilities, communities, and district review mechanisms. Sometimes, trends in the data emerge only after several iterations. Advocacy actions must be followed up and tracked. Evidence of impact may only be visible several years later. Funders, implementers, policymakers, and governments must understand CLM in the context of making a long-term investment in the quality of their health systems and adjust their cost-benefit models accordingly.

These encouraging signs of CLM impact also spark additional questions:

- → ***What is the optimal coverage and intensity of CLM to achieve this impact?***
- → ***Once impact is achieved, (how) should the CLM model be adjusted?***

Inquiry into the sustainability of CLM and its associated impact is the prime focus of Citizen Science in 2024—the final year of the project.

We have begun working with the Clinic Committees at our monitored sites, involving them very closely in the CLM process. These committees, which include recipients of care, may be a viable way to maintain CLM when projects taper.

We are also initiating conversations with District Health Officials about ways to ensure ongoing community engagement in health service monitoring, including routine quality improvement initiatives.

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