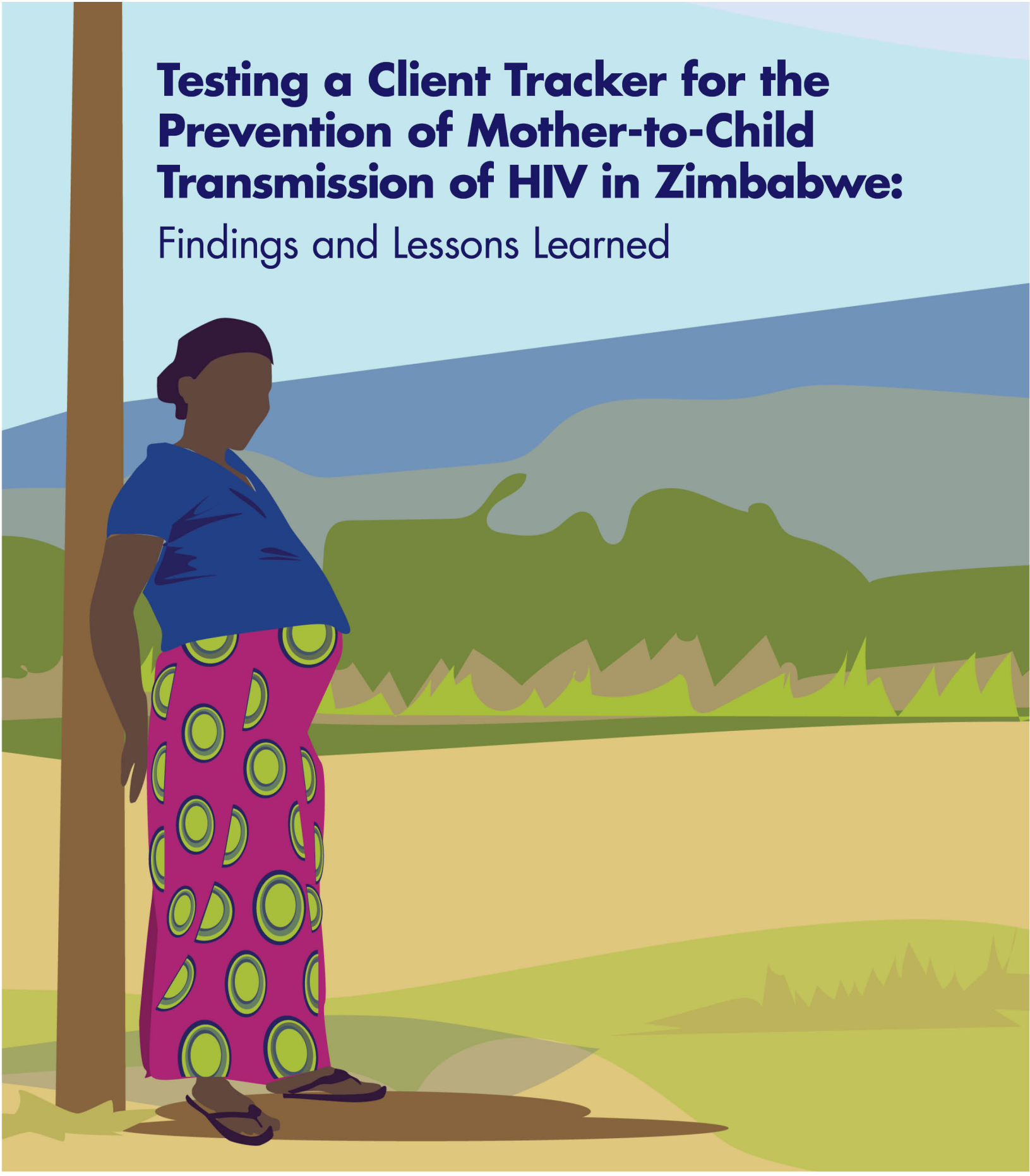
Testing a Client Tracker for the Prevention of Mother-to-Child Transmission of HIV in Zimbabwe:

Findings and Lessons Learned



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Testing a Client Tracker for the Prevention of Mother-to-Child Transmission of HIV in Zimbabwe:

Findings and Lessons Learned

Allison Schmale, MEASURE Evaluation, ICF
Lwendo Moonzwe, MEASURE Evaluation, ICF
Francesca Scott, Qebo, Ltd.
Samuel Johnson, Qebo, Ltd.
Cristina de la Torre, MEASURE Evaluation, ICF

March 2019

MEASURE Evaluation
University of North Carolina at Chapel Hill
123 West Franklin Street, Suite 330
Chapel Hill, NC 27516 USA
Phone: +1 919-445-9350
measure@unc.edu
www.measureevaluation.org

This publication was produced with the support of the United States Agency for International Development (USAID) under the terms of the MEASURE Evaluation cooperative agreement AID-OAA-L-14-00004. MEASURE Evaluation is implemented by the Carolina Population Center, University of North Carolina at Chapel Hill in partnership with ICF International; John Snow, Inc.; Management Sciences for Health; Palladium; and Tulane University. Views expressed are not necessarily those of USAID or the United States government. TR-19-333

ISBN: 978-1-64232-128-9

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ACKNOWLEDGMENTS

We thank the United States Agency for International Development (USAID) and the United States President's Emergency Plan for AIDS Relief for their support of this publication on the prevention of mother-to-child transmission of HIV (PMTCT) in Zimbabwe.

We also thank the many people who assisted in the rollout of this test in Zimbabwe: Major-General (Dr.) Gerald Gwinji (Rtd.) (Secretary for Health and Child Care, Ministry of Health and Child Care), Dr. Portia Manangazira (Director of Epidemiology and Disease Control, Ministry of Health and Child Care), Dr. Angela Mushavi (National PMTCT and Pediatric HIV Care and Treatment Coordinator, Ministry of Health and Child Care), Manes Munyani (Deputy Director Health Information and Surveillance Systems, Ministry of Health and Child Care), Anesu Chimwaza (Monitoring and Evaluation Officer, Ministry of Health and Child Care), Brilliant Nkomo (Data Analysis Specialist, Strategic Information, USAID Zimbabwe), Nurse L. Tsiga (Chitungwiza Central Hospital's Sister-in-Charge, Labor and Delivery Ward Floor), and Nurse Tsvangirayi (St. Mary's Clinic Sister-in-Charge, ANC and Labor and Delivery). They all provided essential guidance and assistance at the ministry and facility level to carry out testing of the PMTCT Tracker.

We thank our local consulting firm, M Consulting Group (registered as M-Care Enterprises Private Limited), including Dr. Brian Maguranyanga, Fungai Chigumbura and Charmaine Rudo Madiro, assisted by Maxine Mpofu, Charlene Murahwa and Rujeko Motsi, for their hard work to set up the PMTCT Tracker and subsequent data collection efforts.

We also thank Emily Bobrow, MEASURE Evaluation, University of North Carolina at Chapel Hill, for her technical guidance regarding prevention of mother-to-child transmission service delivery in low-resource settings.

Finally, we thank Cindy Young-Turner, of ICF, for editing this report and the knowledge management team at MEASURE Evaluation, University of North Carolina at Chapel Hill for editing, design, and production services.

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ABBREVIATIONS

ANC	antenatal care
ART	antiretroviral therapy
MOHCC	Ministry of Health and Child Care
OI	opportunistic infection
PMTCT	prevention of mother-to-child transmission of HIV
USAID	United States Agency for International Development

INTRODUCTION

This brief summarizes the findings and lessons learned from testing a client tracker for prevention of mother-to-child transmission of HIV (PMTCT) programs. MEASURE Evaluation developed the PMTCT Tracker on the DHIS 2 platform based on previously developed guidance.[1] We subsequently tested the PMTCT Tracker in a health clinic in Zimbabwe to identify any issues that needed to be fixed or improved. In this report, we describe the PMTCT Tracker and present findings from the testing exercise. Findings from the testing exercise were used to refine the PMTCT Tracker before making it publicly available.

The PMTCT Tracker

PMTCT programs need improved solutions for tracking clients across the PMTCT continuum of care to increase retention of mothers and their infants through the pregnancy and breastfeeding periods. Many challenges exist in tracking mothers and their infants across the continuum of care, such as cumbersome paper-based systems that rely on multiple registers to track services, the fact that women seek services from different clinics over the course of their pregnancy, and the inability of clinicians to properly identify HIV-exposed infants in child wellness services. To address these and other common challenges that PMTCT clinicians and program managers face, MEASURE Evaluation—funded by the United States Agency for International Development (USAID) and the United States President's Emergency Plan for AIDS Relief—developed a PMTCT Tracker program on the DHIS 2 platform. The PMTCT Tracker was designed to longitudinally track mother-infant pairs in unison, monitor completion of scheduled visits, and rapidly identify clients lost to follow-up. The PMTCT Tracker does the following:

- Tracks clients across providers and facilities
- Differentiates between clients who are lost to follow-up and clients seeking services elsewhere
- Monitors HIV-exposed infants while they continue to breastfeed and ensures that they meet their HIV testing schedule
- Generates reports of clients who are overdue for a visit
- Allows monitoring of client referrals to other clinics
- Sends notifications to clients when appointments are missed

The overall structure of the PMTCT Tracker focuses on managing transitions of care at five key points:

- Initiation of treatment (or treatment status at enrollment, if already on treatment)
- Transition of mother from antenatal care (ANC) to delivery, which often occurs at a different location
- Transition of mother from delivery to postnatal care, to ensure that postnatal care occurs
- Transition of child from delivery to the Exposed Child Program, to link mother and infant records and ensure that testing is done
- Transition of both mother and child from the PMTCT pathway to mainstream antiretroviral therapy (ART), as needed

[1] de la Torre, C., Johnson, S., & Schmale, A. (2018). *Using DHIS 2 software to track prevention of mother-to-child transmission of HIV: Guidance*. Chapel Hill, NC, USA: MEASURE Evaluation, University of North Carolina. Retrieved from https://www.measureevaluation.org/resources/publications/ms-18-127.

Objectives of the Test

The objectives of the test were to observe how the PMTCT Tracker works in a facility setting and identify and resolve any bugs and issues during implementation.

METHODS

MEASURE Evaluation tested the PMTCT Tracker in one health clinic in Chitungwiza Town, in Zimbabwe. This area was selected because it was easily accessible from Harare and was in a USAID-supported district. Using data provided by the Ministry of Health and Child Care (MOHCC), we selected a clinic that had a relatively high number of ANC bookings and institutional deliveries by HIV-positive women. Although funding did not allow testing across a larger number of facilities, we also conducted some data collection at the closest reference hospital, because some women are referred there for delivery from the health center we were studying. The inclusion of the hospital would allow us to test whether two facilities could enter information for the same client and mark each other's scheduled appointments as completed.

Testing the tracker involved the following steps:

1. **Mapping the data elements in the PMTCT Tracker to the relevant registers provided by the MOHCC.** We reviewed the registers associated with the PMTCT continuum of care, which include the ANC register, the labor and delivery register, the postnatal care register, the HIV-exposed infant register, and the client opportunistic infection (OI)/ART booklet. We identified which registers contained the information needed for each step of the PMTCT Tracker, including information needed to register and uniquely identify the woman and her child (Figure 1).

Figure1. Mapping the PMTCT Tracker data elements to the clinical registers

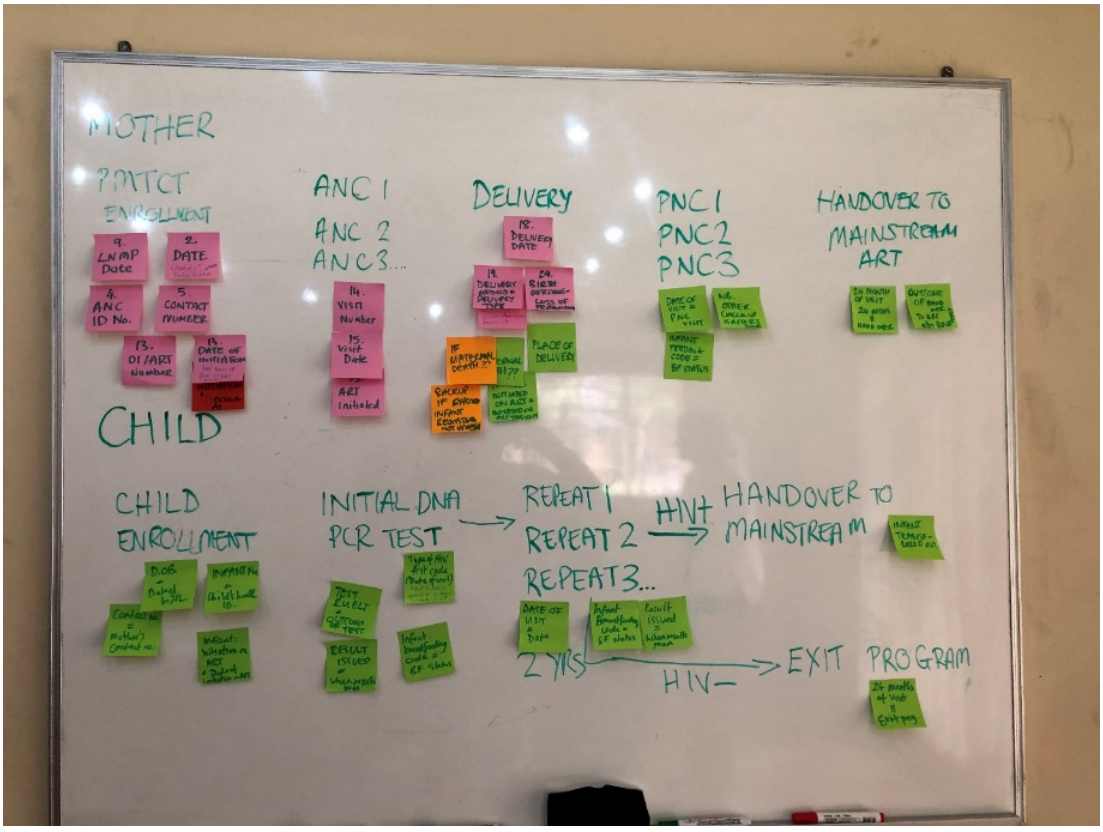
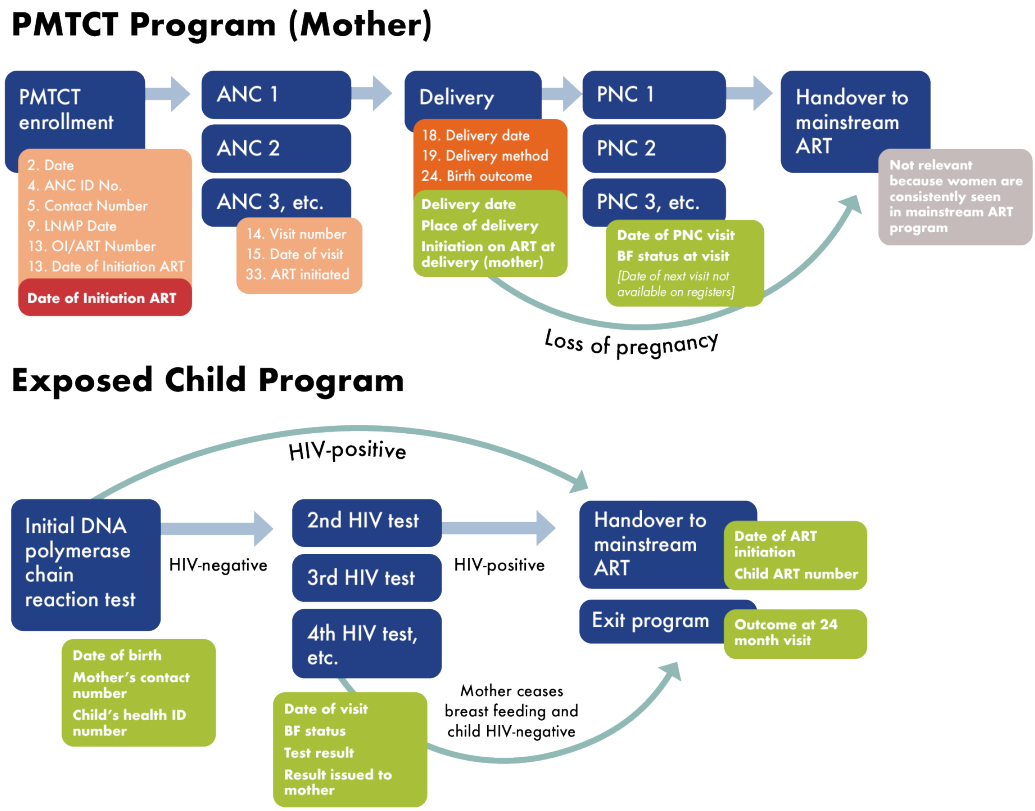


Figure 2. Electronic version of the PMTCT Tracker data mapping exercise



Peach=ANC register. Orange=labor and delivery register. Green=HIV-exposed infant register. Red=OI/ART client booklet. Numbers correspond to column numbers in registers. Not all registers had numbered columns.

Although we were able to successfully map all the needed data elements to specific registers provided by the MOHCC, we later found out that not all the registers were being used at the clinic where we did the testing. Specifically, the HIV-exposed infant register was not available, and the clinic staff was inconsistently documenting the relevant information on the mother's OI/ART booklet. No other client register was in use at the Family Health Services unit. The mother's ART booklet did have room for collecting all the data elements needed in the PMTCT Tracker for the infants, but many were either not filled out, or we were not able to locate them because the mother was registered for ART elsewhere and did not have a booklet on file in this clinic. Thus, we ended up with quite a lot of missing information for infants.

The team had planned to do a preliminary scoping visit ahead of data collection to review all registers and develop new paper tools for use at the facility if needed. However, this was not feasible due to abridged time frame for the testing.[2] As a result, we had to make do with the data that were available at the facility.

2. **Installing the PMTCT Tracker program on a MOHCC server.** The MOHCC granted permission to use a test server for the PMTCT Tracker. The program was successfully installed,

[2] The testing period was abridged because of delays in identifying a country and obtaining concurrence to test the PMTCT Tracker, as well as because of funding requirements.

although some fixes had to be implemented because linkages between the mother and child program did not work after installation. Our team was quickly able to remedy this issue. The MOHCC server stopped operating while we were initiating data collection, so we transferred the test site to a BAO Systems cloud server for the remainder of the data collection.

3. **Training data entry clerks.** MEASURE Evaluation trained five data entry clerks over three days in a classroom setting, followed by four days of continued supervision at the facility. A user manual was developed to help guide the data entry clerks, using screenshots to help the user set up the PMTCT Tracker, register a new client, complete data entry, and view reports. In addition, a demonstration video was used to orient the data entry clerks to the PMTCT Tracker and its functionality. During the training, the data entry clerks were provided with dummy data, which sometimes purposefully contained data errors (e.g., improbable dates or missing values), to teach the clerks how to handle situations such as these that may arise in a clinical setting.
4. **Supplying the necessary equipment.** MEASURE Evaluation provided a laptop and a dongle for Internet collection because all data entry was to be done online directly in the PMTCT Tracker.
5. **Entering data retrospectively for a cohort of women.** We entered data for a cohort of women who had at least one ANC visit on record between August 1, 2018, and March 15, 2019, and were documented as being HIV-positive. We omitted data for 30 women for whom we were unable to calculate an estimated delivery date (because they were missing a last menstrual period date and had no information on symphysis fundal height). In the end, we registered and initiated tracking of 93 pregnant or lactating women.
6. **Tracking the cohort of women longitudinally.** This involved reviewing the registers three times a week to determine whether any new data had been entered for the women we were tracking. We had a two-week window to track women longitudinally, so a few additional visits were identified.
7. **Generating and sharing reports of overdue visits with clinic staff.** After we entered data for the cohort of women, we shared the reports with the clinic staff. Owing to incomplete record keeping at the facility,[3] we had a fair amount of missing data for the mothers and their infants. Nevertheless, we were able to demonstrate how many women were missing records about their deliveries and infant testing and how many were overdue for visits.
8. **Remote monitoring of data entry and data quality.** Because the PMTCT Tracker is online, MEASURE Evaluation was able to log in daily to see progress with data entry, checking the number of records input and which data were available or missing for individual clients. The data clerks also sent the updated intermediary data collection tool daily. MEASURE staff would check the data in the intermediary tool against the data in the PMTCT Tracker to determine whether the data entry clerks were able to keep up with electronic data entry and whether there were data quality issues related to data entry. If issues were identified, we provided prompt feedback to the data entry clerks through email, so that they could either re-check the registers or correct errors.
9. **Establishing a means for reporting and tracking issues related to the PMTCT Tracker.** We set up a WhatsApp group to allow the data entry clerks to notify the developers and the rest of the team of any challenges encountered in real time. The developers could then use this means to help them troubleshoot, or determine whether additional changes to the PMTCT Tracker were needed. In

[3] We discuss this issue more in the Findings section.

addition, we had daily check-in calls with the data entry clerks. We established a Trello board to document and track issues, requests, and lessons learned as we became aware of them.

10. **Debriefing with data entry clerks and clinic staff.** At the end of the four-week testing period, MEASURE Evaluation interviewed the data entry clerks and the clinic staff to learn more about their experiences using the PMTCT Tracker. We used their responses, together with the information we collected in Trello, to develop this report.

RESULTS

Generally, the PMTCT Tracker worked as expected. We were able to register the PMTCT clients, schedule a series of appointments for them based on expected delivery dates, generate reports for women who either missed appointments or lacked data for follow-up appointments, and link the mother and child records to initiate tracking of HIV-exposed infants. We identified a few issues that needed to be fixed in the PMTCT Tracker during implementation and also made a few tweaks to adapt the PMTCT Tracker to the Zimbabwe context. We also identified some situations that would require data entry clerks to make manual changes to the PMTCT Tracker configuration. We summarize these issues in the sections that follow.

Some requirements for implementing the PMTCT Tracker, as described in the PMTCT Tracker guidance previously developed,[4] were not in place in the clinic when we initiated testing, which led to difficulties in obtaining all relevant data from mother and infant pairs. These issues are described as follows:

- PMTCT clients did not have a single unique identifier used across services. Instead each woman is given a different number for ANC and ART, which made it difficult to trace all services received.
- The necessary paper registers were not in use. As noted in the Methods section, the lack of client registers, in general and especially for documenting child wellness visits, impeded our ability to collect the relevant information to populate all date fields in the PMTCT Tracker. Most information regarding services received and scheduled follow-up appointments is captured on mother and infant cards, which the mothers keep and to which data clerks do not have access.
- Because we collected data in a single facility, we did not capture information for services obtained elsewhere. The PMTCT Tracker is designed to capture data across facilities, but our test was limited to only one clinic, and therefore we could not capture all information for the cohort of women being studied.

Over the course of the test, we collected information for 93 women who had been seen at least once for an ANC visit.

- 54 women delivered or should have delivered as of March 15, 2019.
  - 29 had a delivery record in the PMTCT Tracker (6 of these had delivered in the reference hospital and the rest at St. Mary's).
  - 25 were missing delivery information (records not located).
- 39 women were still in ANC as of March 15.
- 39 women had information for more than 1 visit (regardless of type).
- 57 women had ART booklets that were missing or could not be located at St. Mary's.
- 10 infants were identified and linked to mother records, but only two had sufficient information to enter them in the PMTCT Tracker.
- One infant had data on a six-week polymerase chain reaction test.
- No infants had data for subsequent HIV tests.

[4] de la Torre, C., Johnson, S., & Schmale, A. (2018). *Using DHIS 2 software to track prevention of mother-to-child transmission of HIV: Guidance*. Chapel Hill, NC, USA: MEASURE Evaluation, University of North Carolina. Retrieved from https://www.measureevaluation.org/resources/publications/ms-18-127

- Specific data elements that proved difficult to obtain in this context were as follows:
    - Delivery data
    - Data about infant testing
    - Postnatal care visits for women

These issues point to the importance of properly planning for the implementation of a PMTCT Tracker, including aligning clinic registers to the PMTCT Tracker, rolling out a unique ID system, and deploying the PMTCT Tracker across all facilities within a district (at minimum). The guidance document provides detailed information on the preparation phase.

Availability of and Access to Data

Challenges

- The data clerks had limited access to the client registers and ART booklets because these were in use during clinic hours and data clerks could not access the facility after hours. The clerks had to spend long hours at the clinic waiting for opportunities to access the registers.
- Facility staff had limited availability to enter data in the client registers or ART booklets, limiting the amount of information available in the paper-based tools.
- There were duplicate record-keeping and data entry systems at the facility, which burdened clinic staff and led to poor documentation and data quality. For example, the clinicians had to record services provided on the mother and infant cards (which the mothers keep), in client registers, and in the mother's ART booklet (which stays at the facility).
- A woman was sometimes given a new ANC or ART number if her mother card was lost or when she needed to change to a new ART booklet. Although this was not observed in the cohort we were following, this would have created problems, making it impossible to trace the mother's clinical records back to her PMTCT Tracker registration number.

Lessons Learned

- It is imperative to have a solid paper-based system in place, with registers that include all necessary data elements for the PMTRCT Tracker, and for staff to use the registers to properly document all client visits. The PMTCT Tracker was designed to collect minimum data, and the data elements in the PMTCT Tracker are standard and were included on the official MOHCC registers. Making sure that the registers are available and used is critical.
- The PMTCT Tracker requires a date of last menstrual period to schedule all subsequent visits and an estimated delivery date. The last menstrual period date is required to register a woman in the PMTCT Tracker. Multiple women did not know this date, and it was not recorded. However, most had the symphysis fundal height recorded, which can be used to estimate gestational age and working backwards, to estimate the date of last menstrual period. We recommend including symphysis fundal height in the ANC books in countries where the PMTCT Tracker will be deployed. Clinicians also need to be encouraged to estimate a delivery data if a last menstrual period date cannot be ascertained.
- It is important to document the dates of women's follow-up appointments in the register. The PMTCT Tracker defaults to scheduling a follow-up appointment every month (based on the ART

pick-up schedules). In some cases, the woman may be given a different window between appointments. If these dates are recorded in the registers, they can be adjusted in the PMTCT Tracker to avoid false missed appointment notices.

- Data clerks need to schedule data collection around when the registers are most available. Special arrangements should be made to access registers during off hours.
- It was crucial for data clerks to check all possible data sources. Registers and ART booklets often had missing information that was recorded in a different source. As a result, the data clerks needed to check all possible sources to complete data entry for a woman.
- Unique identifiers that are permanently assigned to a woman and that can be used across all services, including ANC, labor and delivery, and ART, are necessary for successful implementation. The PMTCT Tracker is designed to allow a woman to have multiple pregnancy episodes and multiple children all linked to her record by a single unique identifier (ID). A unique ID assigned only for a specific pregnancy makes it more difficult to link files back to existing ART records.
- Using a daily appointment log to record all women who come to the facility for ANC or ART facilitates identifying women whose records need to be updated in the PMTCT Tracker. ANC registers are typically longitudinal, with one client per line, and organized by date of first ANC visit (rather than date of last visit). Therefore, finding new visits in the ANC register entails flipping through many pages and looking at each woman's record to determine who came in on that day.

Design of the Tracker

Challenges

- When the PMTCT Tracker was installed on the server, problems arose in exporting the relationships feature (which links mother and child records). The program code had to be adjusted on the new server. This issue is being fixed.
- When we designed the PMTCT Tracker, we anticipated ANC and ART services to be integrated and scheduled women's visits at monthly intervals based on typical ART pick-up scheduled. In Zimbabwe, these services are not integrated. Tracking only ANC appointments monthly did not make sense in this context, because many women receive ANC only once or twice during their pregnancy. Furthermore, because the follow-up appointment dates were not recorded at the clinic, it was difficult to estimate when the next appointment would be. This could cause an overestimation of overdue events in the PMTCT Tracker and incorrectly identify women as lost to follow-up. Therefore we opted to include all visits for the woman, whether for ANC or ART pick-up, and monitored her across all services.

Lessons Learned

- Initially the PMTCT Tracker required the ANC number to register a woman; however not all women had an ANC number (e.g., a woman did not have an ANC number if she presented after delivery), and some had only an ART number. The PMTCT Tracker was updated so that a woman could be registered either with the ANC or ART number. It would have been preferable to have a unique ID system that cut across all services.
- When ART and ANC services are not integrated, tracking a woman's ART pick-ups and ANC visits may be required. ART pick-up occurs at more regular intervals, and therefore it is easier to predict

scheduling and identify loss to follow-up. The PMTCT Tracker does allow for manual adjustments to date of next visit. Documenting follow-up appointment dates in the registers is recommended for better accuracy.

- The child's HIV testing schedule may need to be aligned with the local guidelines. The PMTCT Tracker has default testing scheduled for 8 weeks, 6 months, 12 months, and 18 months. The timing of these tests can be adjusted. It is also possible to manually add new or unscheduled testing visits that occur between the pre-scheduled dates, without deleting the next scheduled appointment. These instructions need to be added to the User Manual.
- The current version of DHIS 2 (Version 2.30) allows the relationship between mother and child to be visible in only one direction. The child can be seen from the mother's record, but the mother's record cannot be seen from the child's record. For this reason, it is important to capture the mother's unique ID or ANC number in the child's record so that we can easily search for the mother, if need be.
- In our PMTCT Tracker, there was a bug that did not allow the mother's ART number to be entered in the child's record, because the tracker flagged the record as a duplicate. The developers are fixing this issue.
- The PMTCT Tracker needs to be adjusted to handle situations in which test results for child testing are delayed. Currently, the PMTCT Tracker will schedule a subsequent visit only when the previous one is completed. If the visit is marked as completed, it will no longer generate missed appointment reminders. When delays in obtaining test results occur, we prefer to leave the appointment as not completed, to remind the clinic staff to obtain those results. If this is done, however, the subsequent test will not be scheduled and therefore will not be tracked or appear on missed appointment reports in the future. The team is working to identify a solution to this issue.
- For the delivery record, we needed to update the "place of delivery contact" field to include place of delivery options (facility, born before arrival, or home), so that we could indicate if the mother did not have the child at a facility.
- For breastfeeding status, we needed to include an option for "Don't Know" for instances when the breastfeeding status was not recorded. The PMTCT Tracker is designed to keep monitoring children as long as they continue breastfeeding and to schedule one last test for children who cease breastfeeding. We revised the PMTCT Tracker so that "Don't Know" would be treated the same as continued breastfeeding, and the child would be monitored until cessation is confirmed.
- We had to include "Loss of Pregnancy" and "Loss of Infant" as delivery outcomes to indicate if a woman or infant was no longer followed, owing to death or miscarriage.
- The dashboards and indicator estimates were working as planned. We noted small discrepancies between our event reports and the data reported in the dashboards for certain indicators. It turns out this was because a few women were enrolled in the PMTCT Tracker during delivery. These women were missing any information for ANC services and were omitted from the events report. Nevertheless, the indicators were calculated using the correct numerators and denominators.

Data Capture

Challenges

- Lack of unique identifiers at the facility complicated tracing a woman through different services at the facility.
- Occasionally the data entry clerks received error messages when registering women. These error messages did not always specify the cause of error. This required the DHIS 2 experts to explore the back-end code to identify the issue. Data entry for that woman could not continue until this was resolved.

Lessons Learned

- To address the multiple numbers used at different service delivery areas of the facility (including multiple ANC and ART numbers), data clerks resorted to using names to ensure that duplicates were not entered and to verify that they matched the correct woman between the ANC register and the ART booklet.
    - The PMTCT Tracker will automatically alert a user when a number is a duplicate so it cannot be entered. In such cases, the data clerk would double-check ART numbers and clarify any questions with data entry staff at the facility.
- It is crucial for date formats to be standardized to the format in the PMTCT Tracker. If an intermediary tool is used, the data entry staff need to be reminded about the format for entering dates in the PMTCT Tracker (YY/MM/DD), so the dates are transferred from the tool to the PMTCT Tracker correctly.
- Having an intermediary tool was very helpful for gathering information for women across the registers prior to entering it in the PMTCT Tracker. This is particularly helpful when retrospective data are gathered on all clients, to set up an initial cohort of women to be tracked longitudinally. An intermediary data entry tool also allowed for faster extraction of data from the registers.
- It is helpful to develop a troubleshooting list for data entry clerks so they have a resource to try to resolve any issues that come up during data collection.
- The PMTCT Tracker needs good quality data to create meaningful reports for the facility. When a lot of data are missing (owing to improper record keeping), differentiating women who are truly lost to follow-up from those for whom data are missing is impossible.
- Supervisors need to perform continual and daily data checks, to ensure that data entered in the PMTCT Tracker make sense for the program and that data are transferred correctly from the intermediary tool to the PMTCT Tracker. They should also check for overdue deliveries, to alert data entry staff that they need to follow up on a possible delivery.
- If a client is registered in the PMTCT Tracker but not enrolled or commenced on the PMTCT program (to initiate scheduling of ANC visits), the woman will not be visible in the reports. This may give data entry clerks the impression that she is not in the system, but they will get an error message if they try to register her again. Data clerks need to be trained to search for the woman's unique ID number if they get an error message, to determine if she is already in the system.
- The User Manual needs to be updated, to discuss how to delete client records if data are incorrectly entered in the registration form. Conversely, the User Manual should discuss the importance of not

deleting scheduled appointments when data entry mistakes are made, and describe what to do instead.
- Some clients did not have information on the date of enrollment in ART (possibly because they did not remember). Therefore this field was changed from mandatory to optional.

Referrals and Handovers

Challenges

By tracking deliveries between St. Mary's and the reference hospital, our team identified challenges in the current system that made tracking referrals difficult, as follows:

- The facility lacked referral processes and standard operating procedures.
    - There were no forms or documentation of any communications used to refer a woman to other services within the facility (such as ART) or to other facilities for specialized care or transfers. As a result, there was no way to know whether women were lost to follow-up or whether they went to a different clinic.
- Handovers to mainstream ART services were not documented, regardless of whether they were within the facility or to a different facility. This is likely because, in Zimbabwe, women continue in mainstream ART care when receiving PMTCT services.

Lessons Learned

- Without a referral process, it difficult to know which women may be receiving care elsewhere, and it is more likely that women will be lost to follow-up. When the PMTCT Tracker is fully deployed, any clinic can mark the woman as having completed an appointment. Having a formal referral allows the initiating clinic staff to follow up on the status of that client if she becomes overdue.
- Data clerks and supervisors need to understand local protocols for referrals and handovers, which may differ in clinics, especially high- and low-volume clinics, to ensure that they check all relevant data sources.
- All facilities need to be included in the organizational units in DHIS 2 so that referrals and handovers can be properly captured.

Technology Issues

Challenges

- The facility also experienced intermittent electricity, which would go out on a daily basis. This slowed data entry when laptops needed to charge.
- The PMTCT Tracker was easy to export and set up for Zimbabwe, but it needed continual testing to ensure that all the features were working properly. The information technology technical support made fixes when not all features were working.

Lessons Learned

- Having a team of DHIS 2 experts available is critical in the launch phase of the PMTCT Tracker. Direct lines of communication between data entry clerks and the DHIS 2 experts are important for

reporting issues and rapid troubleshooting. Having the DHIS 2 experts available in the same time zone meant that issues could be addressed more rapidly.

- Systematic processes for reporting bugs and documenting and monitoring required fixes was helpful. Our team used a Trello board, which worked very well for this purpose.
- Providing data entry clerks with dedicated laptops and Internet dongles facilitated timely data entry. Having all equipment charged overnight is necessary when electricity is unreliable.
- An alternative server that is in compliance with Ministry of Health rules needs to be available when the Ministry of Health server is down, so that data collection can continue. Data need to be backed up regularly.
- Data clerks need to save daily versions of the intermediary tool, if used, to minimalize loss of data in case of power outages, damage to laptops, or issues with saving data in the PMTCT Tracker.
- Data clerks must also clear the cache in the PMTCT Tracker daily so that any fixes that were made are updated for that day.
- Internet connectivity in Zimbabwe was not always reliable, which could impact data entry and could potentially cause loss of data. In our test, using a dongle worked well.

MEASURE Evaluation
University of North Carolina at Chapel Hill
123 West Franklin Street, Suite 330
Chapel Hill, NC 27516 USA
Phone: +1 919-445-9350
measure@unc.edu
www.measureevaluation.org

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