CASE STUDY

# Elizabeth Glaser Pediatric AIDS

## HIV Patient Tracking and Appointment Reminder System


Source: Baylor College of Medicine Children's Foundation

# OVERVIEW

With support from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF)-Lesotho and Dimagi collaborated in Lesotho to develop a CommCare mobile solution to track patients' clinic appointments, send automated SMS reminders of clinic appointment dates, facilitate patient tracking, and report on chosen outcomes as part of a comprehensive HIV, TB, and maternal and child health program. The overall aim of the project, which was later supported in two additional districts by a team at Baylor College of Medicine Children's Foundation, was to reduce missed appointments and the number of patients lost to follow-up, especially those in the target population of pregnant women who are receiving antiretroviral therapy (ART).

The program aimed to reduce the number of patients in HIV, TB, and maternal and child health programs who miss their health facility appointments by sending personalized, confidential SMS appointment reminder messages; to reduce the time and effort required for health facility and client-tracking workers to follow up with patients; and to provide cleaner, more efficient ways to follow up with those patients who miss appointments.

# SUMMARY

## LOCATION

The pilot was carried out in two districts (Berea and Leribe) of Lesotho in 2016 and scaled to the other three lowlands districts (Maseru, Mafeteng, and Mohale's Hoek) in 2017. In 2018 the application was modified to include clinical transfers and group updates for Community ART Group (CAG) members and was rolled out to the remaining five highlands districts (Qacha's Nek, Quthing, Thaba-Tseka, Butha-Buthe, and Mokhotlong).

## PARTNERS

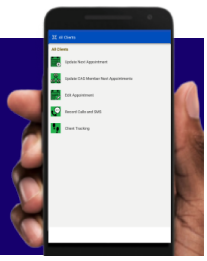
EGPAF-Lesotho, Baylor College of Medicine Children's Foundation Lesotho, Lesotho Network of AIDS Services Organizations (LENASO), and the Lesotho Ministry of Health

## SECTOR

HIV/AIDS

## FEATURES

Case management, SMS reminders, GPS



## NUMBER OF USERS (TO DATE)

**314** Frontline Workers (i.e. records assistants)

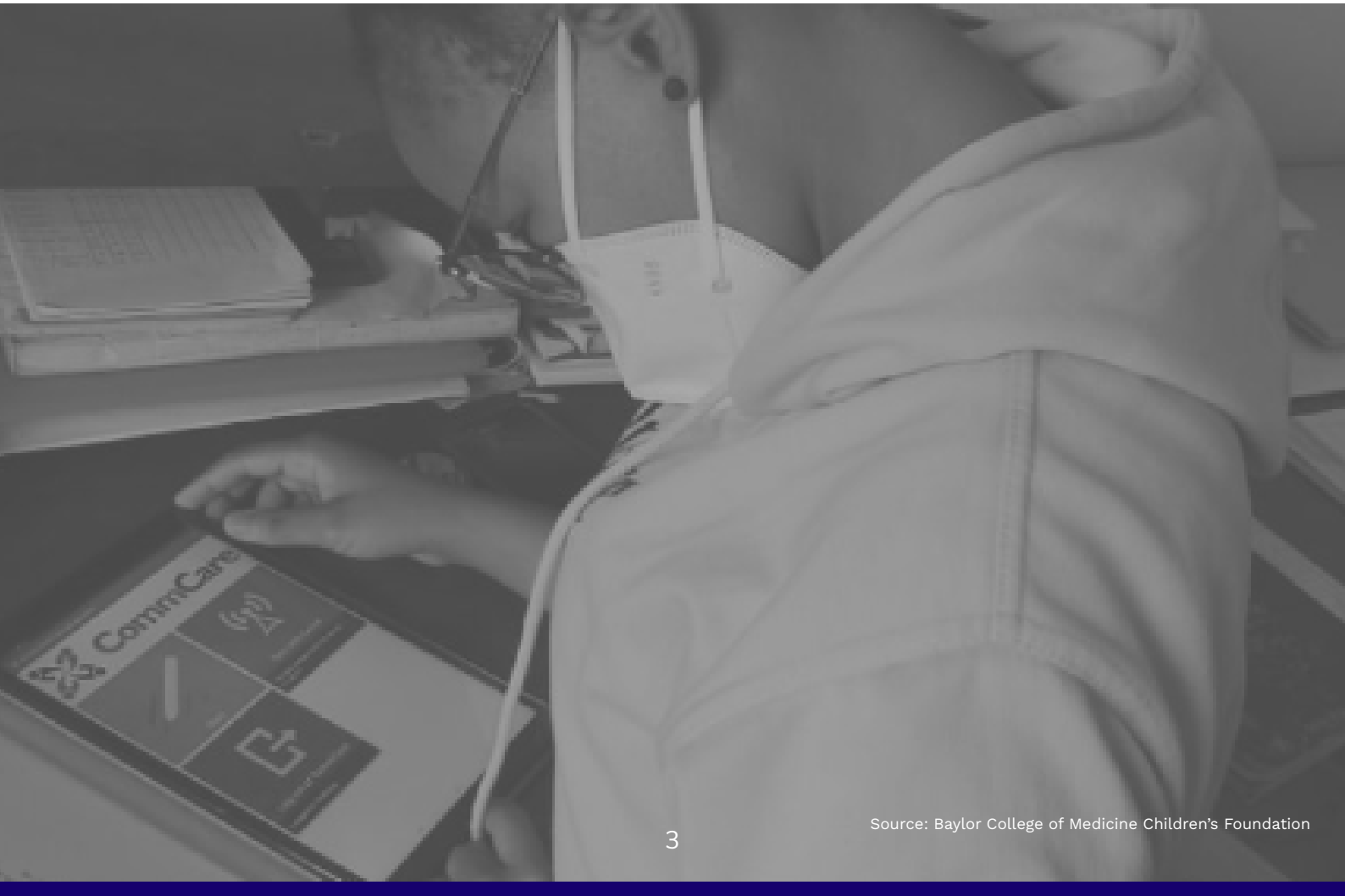
**200** Health Facilities in Lesotho Districts [1]

# PROBLEM

Adherence to HIV and TB regimes is important in improving patient outcomes and preventing the spread of disease. An interruption in ART can be nearly as detrimental to a patient's health as stopping treatment completely[1]. One of the greatest challenges in reducing transmission of HIV, TB, and other communicable diseases is the retention of patients in care. Defaulting prevents effective treatment and results in a patient being virally unsuppressed and more likely to infect other individuals. Defaulting also has a financial burden on health systems: more resources are either needed to track and return patients to care or to address the growing infection rates resulting from non-suppression of viral loads among patients.

Lesotho has one of the highest HIV incidence rates in the world, according to UNAIDS statistics; as of 2018, 340,000 people were living with HIV in Lesotho. Minimizing bottlenecks and leakages in patient follow-up, adherence to treatment, and retention in care are critical areas needing strengthening in order to improve efficiencies in the cascade of care.

The timely identification of patients at high risk of not returning to care was difficult under prevailing circumstances at the time of the project launch. Operational indicators were frequently collected by hand at the point of care, with a significant time lag in delivering data for reporting needs. Another significant issue the country faced was duplicate patient records for ART patients, which doubled patient-tracking efforts. Furthermore, there were few effective examples of real-time data usage and application on the front line, where the impact may be largest.

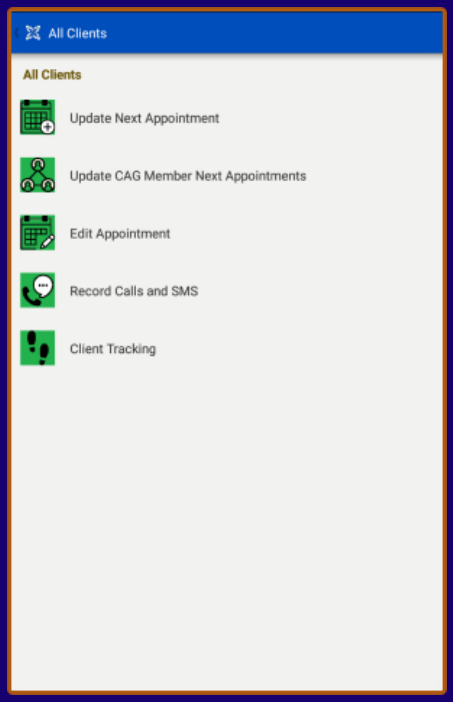


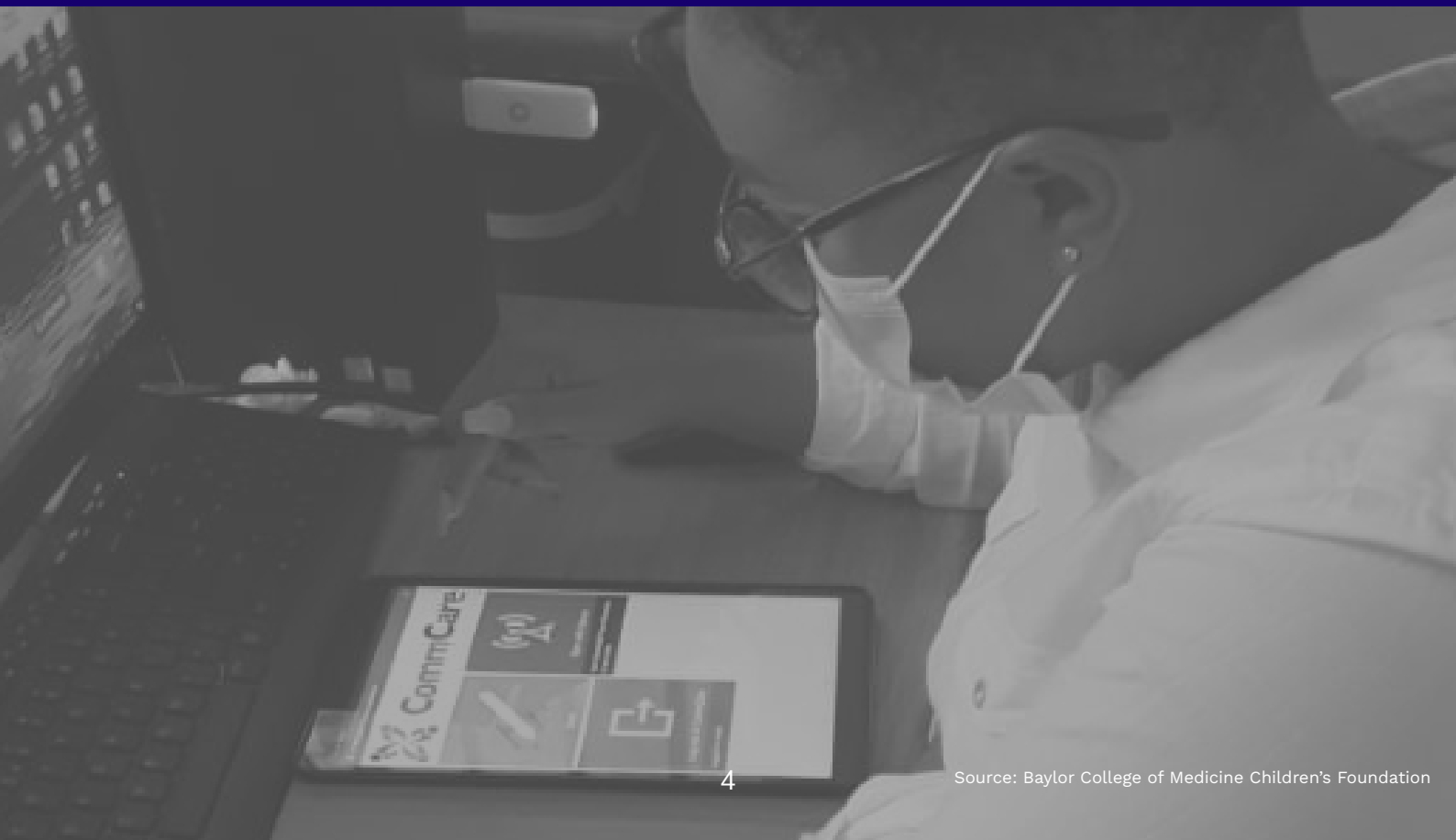

Source: Baylor College of Medicine Children's Foundation

# PROBLEM

Dimagi proposed a digital tool that would promote a better understanding of these gaps in the HIV cascade of care and help programs develop more targeted initiatives to improve adherence and retention. Dimagi's flagship platform, CommCare, is an open-source client case management tool that includes the following relevant features to reduce loss to follow-up:

- **Case management** is used to track individuals with HIV through the care cycle from diagnosis, initiation of treatment, adherence monitoring to end of treatment.
- **Electronic patient registries** employ a GPS integration and patient unique ID features.
- **SMS messages** are automatically sent as reminders for patients three days before an appointment and three days after a missed appointment.
- **Powerful app logic** helps prioritize patients based on adherence, due dates for tests, and missed deadlines for re-testing or appointments.




Source: Baylor College of Medicine Children's Foundation

# SYSTEM OVERVIEW

The Patient Tracking and Appointment Reminder application was developed in partnership with EGPAF-Lesotho. It is used to track clinic appointments, send SMS reminders to patients, facilitate patient tracking (HIV, TB), and record inter-facility and inter-district transfers to reduce the number of missed appointments, defaulting, and patients lost to follow-up in TB, HIV, and antenatal care.

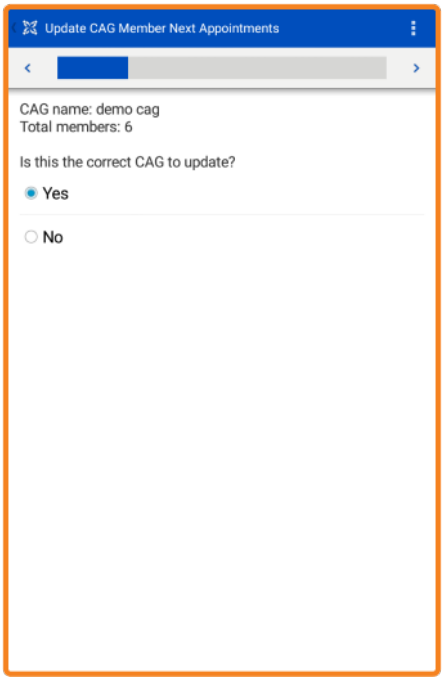
Dimagi has partnered with EGPAF-Lesotho since 2016 and Baylor College of Medicine Children's Foundation Lesotho took over two districts (Botha-Bothe and Mokhotlong) in 2020 to help support those two districts.

# FEATURE HIGHLIGHTS

## Bulk Updates and Referral Tracking

### Bulk updates to more than one case record

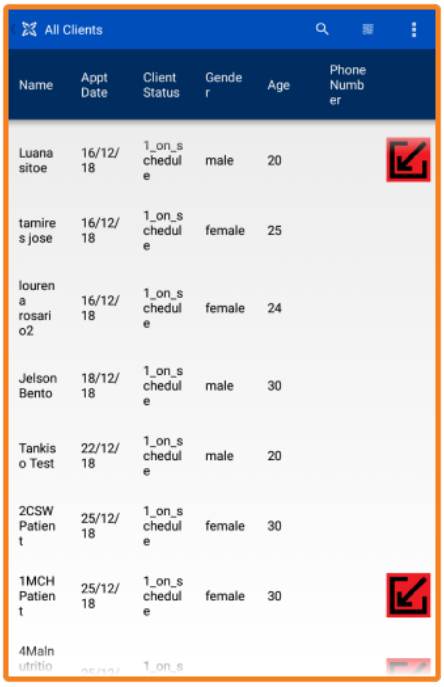
'Repeat group' and 'save-to-case' features are used to update patient info for multiple cases at once and to record the next appointment date and type for the entire Community ART Group (CAG).




Antiretroviral therapy (ART) patients in Lesotho may encounter many barriers accessing treatment[2]. Patients often travel long distances to get their monthly refills, and may have difficulty affording the travel costs; likewise health workers face challenges with large caseloads for ART distribution. Community ART groups aim to facilitate ART distribution; groups of patients from the same area will take turns traveling to the clinic for drug refill and in turn deliver the drugs to their group members in their community, also ensuring peer support.

In the first version of the application CAG group members had to be updated individually in the application and in situations where there was a long queue, patients and front line workers were frustrated with the additional time it took to update multiple client records. In the second version of the application Dimagi worked to create a solution to this problem by adding the ability to update multiple client cases with one form submission, used to record next appointment date and type for each member of the CAG group in one form.

### Transfer/referral tracking across facilities and districts




Large migrant populations that travel periodically for work and self-transfers by patients that wish to seek care at a different facility present challenges to tracking patients, who might be seen as having defaulted when in fact they are in constant care at another facility or in another district (sometimes across the border in South Africa).

The second version of this application, implemented with EGPAF in 2018, was updated to record these "self-transfers" as well as official clinical transfers, and to transfer the relevant application patient records. This feature can be used at a facility that receives a new client from another facility (self-transfer) to notify the original facility of their arrival, or by a facility that wishes to inform another facility to expect a client that has transferred their care.

The feature includes:

- **Transfer client cases to another facility (self-transfer and clinical transfers)**
- **Reclaim transferred client cases (e.g., a client returns to the original facility)**
- **Close transferred client cases (e.g., when successfully transferred to a facility that is not using CommCare or is managed by a different program)**
- **Create a list of patients transferred to a facility who have not yet initiated care**

One limitation of the feature in the current system is that now that two districts are managed by ETHICS and eight districts are managed by EGPAF, it is no longer possible to transfer the application patient records between these two systems. However, users and mHealth coordinators can view a record of patient transfers captured in the respective CommCare systems.

Source: Baylor College of Medicine Children's Foundation

# FEATURE HIGHLIGHTS

The system deployment team managed the versioning of the application carefully and thoughtfully. The first prototype of the appointment reminder system was built in 2016. Two years later, in a second adaptation and revision, the CommCare platform was significantly updated to support new and improved features that were a major upgrade from the initial Version 1 architecture. Specifically, the enhancements involved adding bulk updates to client case records (for CAG members), recording national inter-facility transfers and transferring patient application records, and including additional patient types (such as key populations, mainly used in specific clinics in Maseru).

Dimagi worked with key partners to carefully manage this major upgrade to the updated feature sets in a way that maintained access and minimized impact on existing patient case lists, appointment data, and user and location registration data.

Dimagi and EGPAF-Lesotho recognize that any successful digital health solution implementation requires a clear project management strategy, led by a dedicated in-country project manager or project coordinator. While the intention was to maintain a consistent in-country coordinator and team, the EGPAF-Lesotho team did see staff turnover over the course of four years of the program. This led to some implementation delays and the need to train new members on the new digital solution, the project's goals, and how to use the platform. Dimagi supported the rapid ramp-up of new members, and the system itself was designed to be simple and scalable, requiring limited maintenance over time. Dimagi, EGPAF-Lesotho, and LENASO agreed that throughout the course of the solution design, pilot, and scale-up, the ideal team structure to better assure continuity and long-term success would be to have a consistent implementation team and Dimagi support team that could oversee the digital health transformation and solution deployment.

Despite these challenges, the EGPAF-Lesotho team brought consistent energy and high levels of skill as a technical partner. EGPAF-Lesotho embraced the tool provided by Dimagi and also took on significant ownership and management of the application in the interim period between Dimagi implementations. EGPAF-Lesotho expanded the scope and functions of the application independent from Dimagi and made its own changes and additions to the app, including the following:

- **Additional clinical content (e.g. ability to include viral load results for High VL patients, Client treatment regimen, etc.)**
- **Additional patient lists (e.g. Workplace patients – who prefer to receive medication at their workplace)**

In 2020, the management of the application in two districts (Mokhotlong and Butha-Buthe) was transferred to the ETHICS program of Baylor College of Medicine Children's Foundation Lesotho. Dimagi has partnered with Baylor to transfer client data as well as train Baylor staff to take ownership of and manage the application in these two districts. Baylor has taken on these districts with great rigor and is diving into simultaneously relaunching the application, scaling implementation in these two districts, and providing thoughtful post-deployment support. Despite being new to CommCare, Baylor has taken the lead on implementation monitoring and supportive supervision for users in these two districts.

# IMPACT

The goal of the project was to increase the ease and visibility of patient tracking and reduce defaulter numbers for appointments. This was achieved, as demonstrated by the following data points for 2019

- Usage numbers for the app far exceeded expectations, with 286,808 clients registered and ~**1,520 SMS reminders** sent daily
- Approximately **2,150 forms** submitted daily
- **78% of client appointments** on schedule
- Only **3% of patient**s lost to follow-up
- User feedback, relayed from user-testing trips by Dimagi and ongoing field supervision trips by the EGPAF mHealth project, is that the app was simple and easy to use and is much improved over their previous filing and paper-based system of patient tracking

EGPAF is scaling up and further studying the relationship between Dimagi and adherence. As our use of the technology grows and continues to show positive outcomes, we'll study this relationship to identify its association or causality to improved adherence.

In 2018, Dimagi partnered with EGPAF-Lesotho again to enhance the Patient Tracking and Appointment Reminder application and to expand to the remaining five districts in Lesotho. The intended impact was to make the application easier to use and decrease the effort spent on tracking patients, especially those that self-transfer, and to add additional patient types that could be tracked in the application. Version 2 of the application was launched in January 2019, when EGPAF-Lesotho took on further ownership and management of the app and even developed its own additional content for the application. Feedback from users and from EGPAF-Lesotho indicated that users were very excited to have shorter input times when updating the records of multiple patients in CAGs, to be able to refer patients to other facilities and districts, and to see improved performance times in facilities with high caseloads.

In 2020, Dimagi worked with Baylor Lesotho to transfer the management of two districts, Mokhotlong and Butha-Buthe, to the ETHICS program. Lesotho health care workers were found to be overburdened by high caseloads and significant paperwork; additionally, the CommCare tool had not been used since December 2019 and data were out of date, this was due to the fact that PEPFAR is prioritizing the localization agenda from 2019/2020 financial year hence very limited number of staff were working in this two districts as there was transition from EGPAF-Lesotho to Baylor. High turnover in facilities meant that some health care workers were not familiar with CommCare. In this implementation, Dimagi took care to use a cascading training method so that there would be more than one CommCare expert at a given facility at any given time, and proposed additional solutions that are still under review or in process with Baylor.

The tool developed by Dimagi with EGPAF-Lesotho was reviewed and transferred to Baylor's own project space, and existing patient records and data were migrated to this project space for Baylor's management. Through this partnership with Baylor, Dimagi plans to scale the application to 22 facilities across Mokhotlong and Butha-Buthe districts for an estimated 40 health care workers, including facility-based data clerks and LENASO focal persons conducting tracking activities.

During the national COVID-19 lockdown, data were pulled to provide estimates for drug ordering and to allow multimonth dispensing for all stable patients in order to prevent congestion at health facilities.

Source: Baylor College of Medicine Children's Foundation

# REFERENCES


1 Costs are dependent on number of users with this open source technology. For more information on related costs, visit: https://www.dimagi.com/commcare/pricing/

2 Doctors Without Borders. 2015. Community ART Group Toolkit. [Online]. [01 June 2020]. Available from: https://www.differentiatedservicedelivery.org/wp-content/uploads/cag_toolkit.pdf.

3 Deeks SG, Gange SJ, et al. Trends in multidrug treatment failure and subsequent mortality among antiretroviral therapy- experienced patients with HIV infection in North America. *Clin Infect Dis.* 2009;49(10):1582-1590.



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