HIV Tracing App With the Community Health Toolkit

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In Sub-Saharan Africa (SSA), retention of HIV-infected patients in antiretroviral therapy (ART) is an increasing challenge. With significant healthcare system constraints and formidable healthcare worker (HCW) shortages, ART services in SSA struggle to meet ambitious global targets of 90% retained in care. In research settings, text-based mobile health innovations show promise iin increasing ART retention and reducing viral load (VL). Currently, there is a two-way texting system that reduces Back to Care (B2C) workload significantly. For our project, we focus on adapting the Community Health Toolkit's core framework to help tracers track HIV patients who missed ART visits and bring them back to care.

CCS Concepts: • **Applied computing → Health care information systems**.

Additional Key Words and Phrases: mobile health, community health workers, HIV/AIDs, ART, Tracing

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1 INTRODUCTION

The Community Health Toolkit (CHT) is a project aiming to support the development of digital health solutions in hard-to-reach or low-connectivity communities with the goal of providing equal care for all. The toolkit is currently used by 34,000 healthcare workers to support a million home visits every month. Our team first learned about the CHT through a presentation by Dr. Caryl Feldacker, who teaches in the Department of Global Health and later became our main point of contact for the project. Dr. Feldacker has many years of research experience in improving medical programs in African countries like Malawi and Zimbabwe with healthcare system constraints.

There are many existing apps built using the CHT core framework including contact tracing for infectious diseases, such as COVID-19. A lot of this work is carried out by a nonprofit organization called Medic (https://medic.org/) which serves as the technical steward of the CHT. We got a chance to speak with Isaac from the Medic team earlier this quarter, who gave us some guidance on the technical side of the project and how to get started.

Our team worked on adapting the core framework to the HIV tracing use case to serve the most impacted areas in Sub-Saharan Africa. Over the course of a month, we learned about how to build digital health interventions that meet the countries' health ministry requirements. Our product is four digital forms integrated with the CHT that simplify the workload of health workers and the tracers who go out and trace missing patients to bring them back to care. This is still an ongoing project, and we will talk more about the future work and potential impacts in the later sections.

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2 RELATED WORK

CHT affords a broad set of applications because of it is highly configurable. It's useful for managing decision pipelines for front-line care, smart messaging, actionable analytics for managers, and home visits/follow-ups. Built to be effective with intermittent connectivity and low resources in many "last-mile" places, it works over SMS and smartphones. For example, in Nepal, female health care volunteers (FHCVs) use a CHT-based system to assist with antenatal and postnatal care, immunization, safe deliveries, and improving health for mothers and newborns, via simplifying logistics [3]. The phones are paired with more powerful dashboards on web apps that allow managers to operate more efficiently than without.

More closely related to our project, another example of an existing CHT-based application is COVID-19 contact tracing, which rapidly tracks large numbers of patient cases and contacts to help control outbreaks. The contact tracing works through both SMS and the CHT app. COVID-19 patients will first be entered as data entries in the app. Then a trace request form is completed for every person who has come in contact with the patient. These contacts will each be assigned a tracer who will follow up with them. Both the contact and the tracer will be notified by SMS. The tracers can access information such as self-quarantine responses and incomplete tasks. From there, a series of daily check-ins will happen for 14 days to make sure there are no new symptoms (Figure 2). If the contact is experiencing symptoms, he/she will be referred for care and monitoring. Such use cases help ensure self-isolation and speedy care in order to reduce transmission of the virus. Other features of the application include helping educate the contacts and providing prevention strategies.

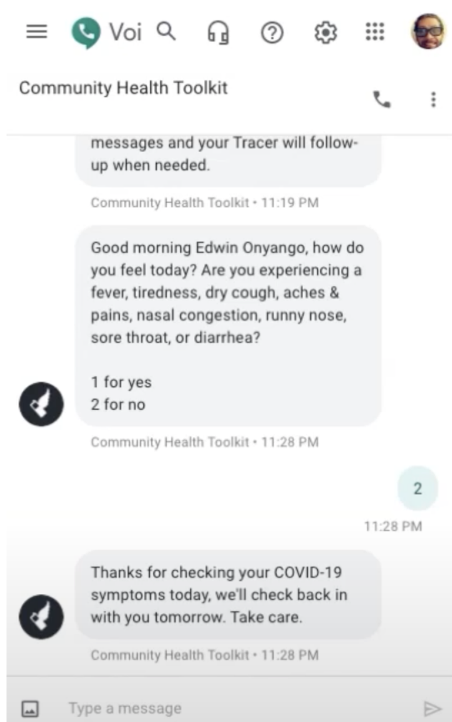

Fig. 1. Tracer performing COVID follow-up

Efforts to use contact tracing for HIV have been ongoing for a long time [2]. Traditional approaches include patient or provider (or hybrid) referral contact tracing (namely, the patient or the care provider tells their partners soon after diagnosis). The common methods are in-person, telephone, and more recently, texts and emails [1]. Contact tracing in this way is mostly determined via tracing chains of partners sharing epidemiological connections. While this is the predominant method, there are newer techniques enabled by fields such as molecular epidemiology. One such method, HIV-TRACE, enables a computational approach; it identifies chains of partners whose viral genetic relatedness imply direct or indirect epidemiological connections [7]. While this may not be immediately useful in the low resource settings we are targeting, they nonetheless can yield benefits (either in terms of offloading human labor where it can, or in terms of providing a research baseline from which low cost techniques can be developed).

There have been studies done which indicate that such efforts could in fact help on multiple axes for HIV [5]. In general, telehealth can reduce stigma-related delays in care by separating patients from healthcare workers. It can improve access to care by removing physical barriers like transportation issues. Additionally, it can ease and make more efficient administrative and financial headaches (on the healthcare provider's side). These benefits seem transferable to HIV contact tracing, especially the first and third. Making the administration of the effort more efficient means fewer people slip through the cracks. Some of the challenges, also mentioned previously, are low resources to run such systems, learning curves, and privacy concerns. At least on the first two points [5] brings up, CHT based apps already have a big advantage here, having been designed specifically with these issues in mind.

3 PROBLEM

Despite the fact that Sub-Saharan Africa only contains about 11% of the world's population, the number of HIV patients in the region is daunting. Adult HIV prevalence is 9% in Sub-Saharan Africa compared to 1.2% worldwide. The most affected countries form an "AIDS belt" in eastern and southern Africa, which accounts for more than 50% of HIV infections worldwide [4]. AIDS is now the leading cause of death in Sub-Saharan Africa, which affects life expectancy and the number of orphaned children. Without rapid prevention efforts, HIV and AIDS will continue to have a profound impact on African development well into the 21st century.

Medical intervention involves proper HIV testing and follow-up care, which is what we focused on. According to the World Health Organization, a steady scale-up of antiretroviral therapy (ART) can effectively reduce AIDS-related deaths [6]. Of 23 million people living with HIV in Sub-Saharan Africa, only around 70% are on antiretroviral therapy (Figure 1). That means over 7.5 million people are out of care, threatening both individual health and HIV epidemic control.

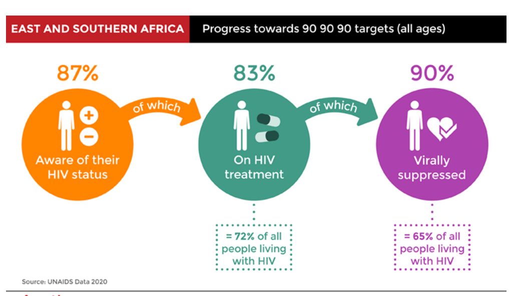

Fig. 2. HIV retention rate in East and Southern Africa

The hospitals in these regions currently use an electronic medical records (EMR) system to provide care. The majority of patients who come in will use EMR. Additionally, the hospitals are staffed with healthcare workers who will text and respond to the patients in case something comes up. One reason for why a digital health solution is preferred is that there are more than 50 thousands patients in antiretroviral therapy (ART) and managing this many appointments is a pain point for healthcare workers.

Right now, healthcare workers rely on hand-written diaries and logs to trace patients who missed visits. They also need to manually update the EMR with tracing outcomes which creates a lot of room for error. Due to high demand and low resources, only 33% of eligible back to care patients are being traced currently. The lack of proper tracing puts more patients out of care, which reduces ART retention and viral suppression for HIV.

The goal of our project is to create a portal to organize missed visits, tasks, and reduce the workload for these tracers and healthcare workers. The tracing outcomes should be synced from the tracking app to the EMR automatically. This will hopefully help improve retention rates for ART and reduce HIV transmission in the hardest hit areas in Sub-Saharan Africa.

4 DESIGN

Currently, there is an existing CHT-based app which can identify patients who have not had visits or responded to texts. After identification, this app imports their phone number from the EMR so that tracers can follow up on the people who haven't responded. The general workflow will be that patients who have access to a mobile device will be enrolled and start receiving automatic 2-way texting (2wT) messages back and forth. These messages include appointment reminders and adherence messages. They may also reschedule or inform medical workers that they transferred to another facility. The nurses will be able to respond to questions and update the records.

After the day of the scheduled appointment, if they didn't show up, then their absence is recorded in the EMR and sent to the CHT framework. Afterwards, a 2wT officer will confirm that the patient didn't show up. From there, the patient information is conveyed to the Tracers through the CHT and the B2C application. By tracing, we mean that the tracer's job is to follow up with the patient on why they didn't know. In the process of following up, they will fill out tracing logs and perform interviews and record tracing outcomes in the Back to Care (B2C) application, which gets synced back to the CHT framework. The ultimate goal is to have the CHT sync information to the EMR, but we aren't that far yet in development, so currently the 2wT Officer has to manually update the EMR with the outcome. Note that the tracers do not directly interact with the CHT framework or the EMR.

Then we move onto the tasks for the tracers. The tracers will see the tasks they have to perform in the B2C tracing app. When they first get the task, they're asked to try to reach out to the patient up to three times via SMS. If they are successful, they would ask them to hop on a call and try to conduct an interview and fill out the tracing outcome. If the three texts fail, they move onto three calls. If a call succeeds, then the tracer can fill out the interview form and the tracing outcome. If the three phone calls fail, then they will try to visit the patient's home in order to interview them in person. This means that the tracer will try to locate them based on the information that they have on where they live in the patient file, which might not be a concrete address, but a relative location. Additionally, the patient might not be home at the time of the visit, so the tracer may need to talk to a neighbor or people living with the patient in order to ascertain when the patient will be back home. If the tracer is successful in contacting the patient, the tracer will be able to fill out the interview form and the tracing outcome. If after 3 times, the tracer is unable to locate the patient, the tracer gives up.

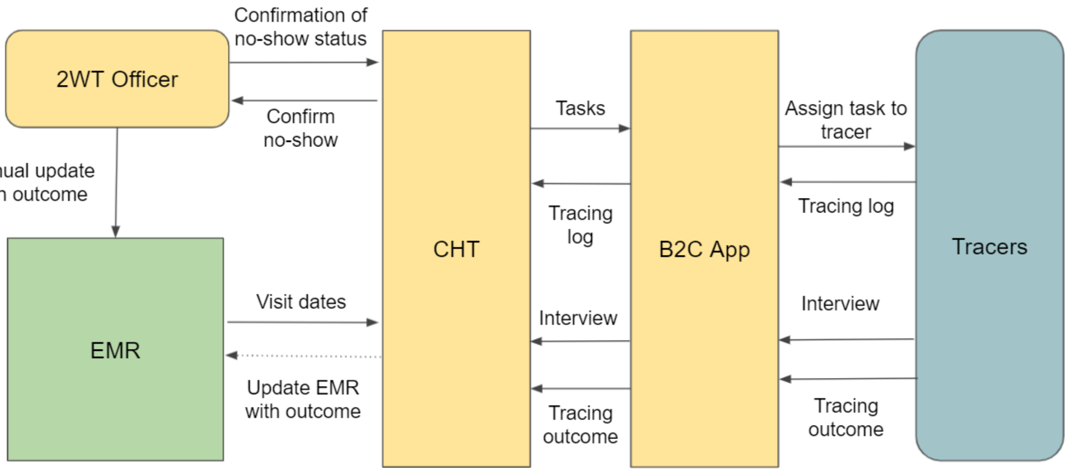

Fig. 3. B2C system workflow

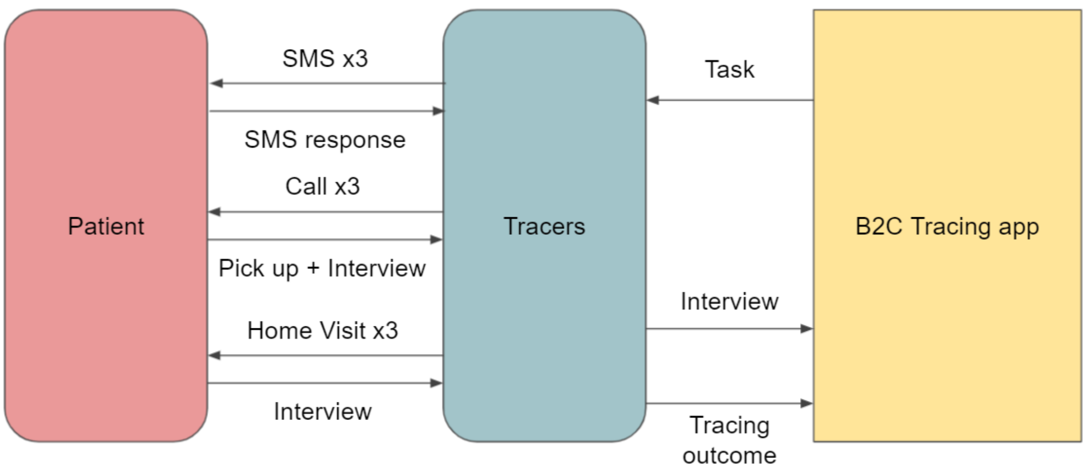

Fig. 4. Tracer interactions

The interview process involves asking for information like how the treatment is going with the ARV pills, reasons for why they didn't show up to the appointment, and if they have intentions to go back to the clinic in the future. There are also many potential tracing outcomes. It's possible that after the patient is confirmed to not have shown up for their appointment, that they could've transferred out, decided to stop the treatment themselves, refused to answer, or have potentially died. The tracing outcome marks the conclusion of the tracer's task for the patient, allowing them to move on to other patients who also need to be traced.

Most of the 2wT design is based on an exiting text flow for ART retention. We will also be using the HIV back to care form to comply with the public health ministry's model. There will be high level design decisions such as the hierarchy in the app which includes different roles and permissions. We are still in the process of further talks with stakeholders to get a better sense of what needs to be adapted and what features need to be added for the setting in which this project will be deployed.

5 IMPLEMENTATION

All of our implementation is based on the Community Health Toolkit (CHT) framework, which is an open-source project mostly written in JavaScript. Since this is an open-source project, the documentation was very well-organized and easy to read for engineers without any background (https://docs.communityhealthtoolkit.org/apps/). Anyone who wants to contribute to their Core Framework can do so through the deployment guides up on the GitHub repository (https://github.com/medic/cht-core). Despite this, there were some small portions missing from the guide that had to be inferred through the examples, like how to set conditions and how parts of the system interact with each other.

CHT-core provides the framework for all of the community health toolkit projects, which are designed to function in low-resource environments, with functionality like syncing data when wifi connectivity is available. The core framework is structured around hierarchies and tasks. Tasks are usually associated with the patients that the logged-in users are in charge of (Figure 5). In our case, it would be the list of people that the tracer needs to trace. These tasks will show up when a missed visit is confirmed and they will disappear when a tracing outcome form is filled out for the patient.

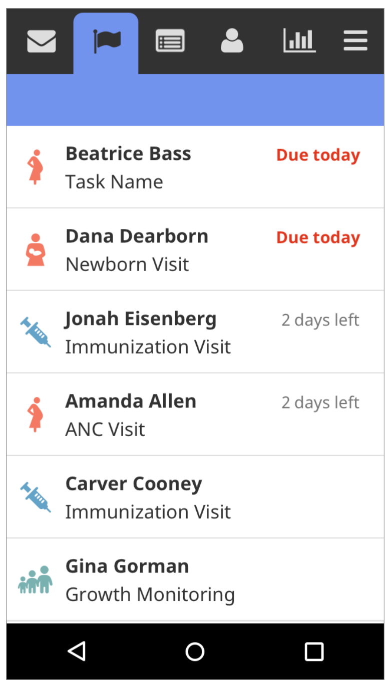

Fig. 5. Upcoming visits or follow up tasks

Forms are another big part of the CHT framework and are milestones that allows tracers to make progress towards a tracing outcome. Instead of the original long form, we have broken down the HIV Back-to-Care form into 4 different forms on the app. The workflow for the application can be found in the previous section.

When the tracer successfully contacts the patient, they will fill out an interview form gathering the status of that patient since the last ARV visit. Figure 5 is a snippet of the interview form with questions like "How many days' supply of ARVs did patient collect on last visit?" or why they missed the appointment. Then these filled out forms will remain on the tracers' device until they can be synced back to the CHT, which may require a visit to the clinic.

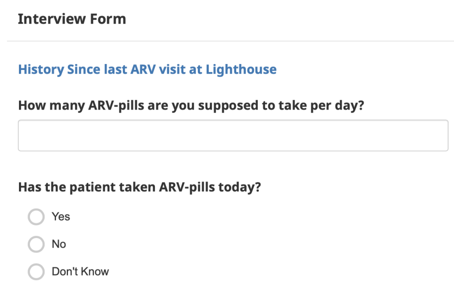

Fig. 6. Snippet of the patient interview form

The process of uploading the forms to the app was fairly straightforward. We first created a XLS file with columns like name, type, and appearance using Excel. On the sheet, we can set up each question with field types like date, string, and define options for selection. When we're done, we had to run a command to convert the forms into xml files and upload them to the app. The tricky bit here was getting the form layout and paths correct. On a paper form, which we were digitizing, one sees all possible question/answer paths, which is fine if someone is used to it, but doing so may be clunky or intrusive when digitized. To this end, we wanted to make sure that only the necessary information was present on the form when displayed in the app, which took some time to get correct. For example, some questions ask for a numeric value (e.g. number of pills, date, etc.), but also allow for a "Don't know" answer. Figuring out how to provide this option, and not resorting to having users input special characters representing the "Don't know" answer (as we are accustomed to doing a la macros in programming), took some time. And, we also wanted to trim unnecessary content, so we had to come up with and properly implement the tree of paths a user could take on the form. We also changed the form as we digitized it, in terms of the questions themselves. This took place when the paper form asked questions like "which of the following reasons apply to ...". Basically, the paper form had a bunch radio buttons for each option (with yes, no options), but we thought it better to convert these to check boxes for a better digital experience.

The tracers can fill out the forms through two different entry points. They can file a new report in the "Report" section, or fill out the form for a specific patient in the "People" section. One issue we ran into was figuring out how to associate the forms with patients. To get the form to show up for the patient on their profile page, we needed to define some form settings outside the form that set constraints for who the form can be filled out for. Another issue we ran into was not being able to associate the form with each patient and have it show up in the profile. We later found out that in the XLS file, we need to add some hidden fields to calculate patient ID based on the patient name selected. Once that was done, each report filed for the patient will show up on their profile (Figure 6).

6 IMPACT

The back-to-care tracing app will greatly reduce the workload of tracers and health workers. For the health workers, instead of working on manual data entry and manually assigning patients to tracers, they will be able to spend time

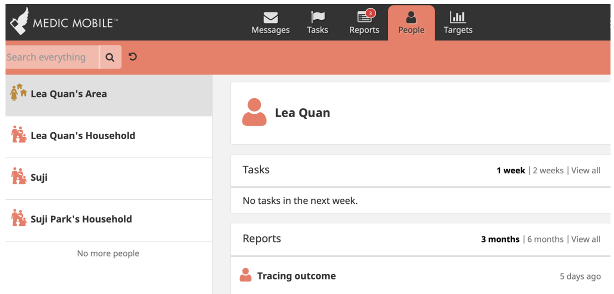

Fig. 7. Tracing outcome form showing up under people tab

performing higher-level tasks like responding to patients' questions or offering consultations. This will make care available for more patients who need it.

For the tracers, they will be able to pull up information about the patient and fill out the forms associated with the patient all in one place. They can do this without needing to bring around stacks of papers everywhere whenever they needed to interview someone. The tasks will remind them about the actions that need to be taken so they don't miss any steps. This reduces error and ensures their time goes towards patients who need care. By bringing more patients back to care, we will hopefully improve retention rates for ART and reduce HIV transmission significantly.

7 FUTURE WORK

For next steps, we are planning to get a few participants from these clinics to evaluate our current implementation and provide some feedback. One of the goals of this project was to reduce the amount of work that the health workers and tracers had to do and to improve their quality of life. Therefore, some kind of qualitative interview will help us gauge whether the application makes tracing patients easier or not. We are still in the process of implementing tasks to link our forms, which is the key to guiding the tracers on the app. We believe it will be a complicated step that requires some technical support from the Medic team.

Another goal of this project is to eventually improve retention rates on ART. However, we won't be able to measure the quantitative impact until some time after the study. By then, we will be collecting data such as # of clients registered, % of clients traced through the app, and the change in workload for medical workers. The result of this study will be measured by different outcome indicators, such as the retention (visits, ART outcomes) and cumulative tracing referrals after 12 months.

A loftier goal, or perhaps hope, is that this work helps more people see the value in these systems and the benefits they can provide, and work towards these ends as well. Specifically, inspire them to use and improve these means. Low-resource computing is ripe with technical, social, and political problems. Advances in technology could help scaling and per-patient care, but we are still a long way away from exceptional, accessible healthcare for everyone.

ACKNOWLEDGMENTS

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