CASE STUDY

Sickle Cell Foundation of Ghana

CommCare for Mitigating Child Deaths from Hereditary Disease

dimagi NOVARTIS Ghana Health Service Your Health Our Concern MINISTRY OF HEALTH REPUBLIC OF GHANA | A HEALTHY POPULATION FOR NATIONAL DEVELOPMENT

OVERVIEW

Every year, upwards of 400,000 children are born with Sickle Cell Disease (SCD), a genetic disease that stiffens red blood cells and distorts their normal round shape, causing many complications including, frequent episodes of pain, acute lung injury, stroke, overwhelming infection, and chronic organ damage. Three-quarters of these children live in sub-Saharan Africa. Further, the World Health Organization (WHO) estimates that 70% of deaths associated with SCD are preventable with simple, cost-effective interventions, such as early detection through newborn screening and the subsequent provision of comprehensive care. Since 2017, Dimagi has partnered with the Sickle Cell Foundation of Ghana (SCFG) to support the National Newborn Screening Program (NNSP) by digitizing its paper forms and serving as a job aid to its users. To date, more than 12,500 newborns have been registered through the mobile application at six sites across two districts in Ghana.

SUMMARY

LOCATION

Ghana

SECTOR

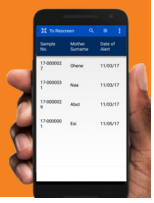
Disease Treatment, Maternal & Child Health

PARTNERS

Novartis, Ministry of Health (Ghana), Ghana Health Service, Sickle Cell Foundation of Ghana

FEATURES

Offline Case Management, Multimedia, Validation Conditions, Custom User Properties, Case Sharing (between four User Types), Module Filtering by User Type, Case List Filters, Automatic Case Closure (closes negative cases after 3 months of test result date)



NUMBER OF USERS (TO DATE)

- 40 Nurses
- 3 Lab Technicians
- 1 Nurse Coordinator
- 3 Project Staff for Supervision

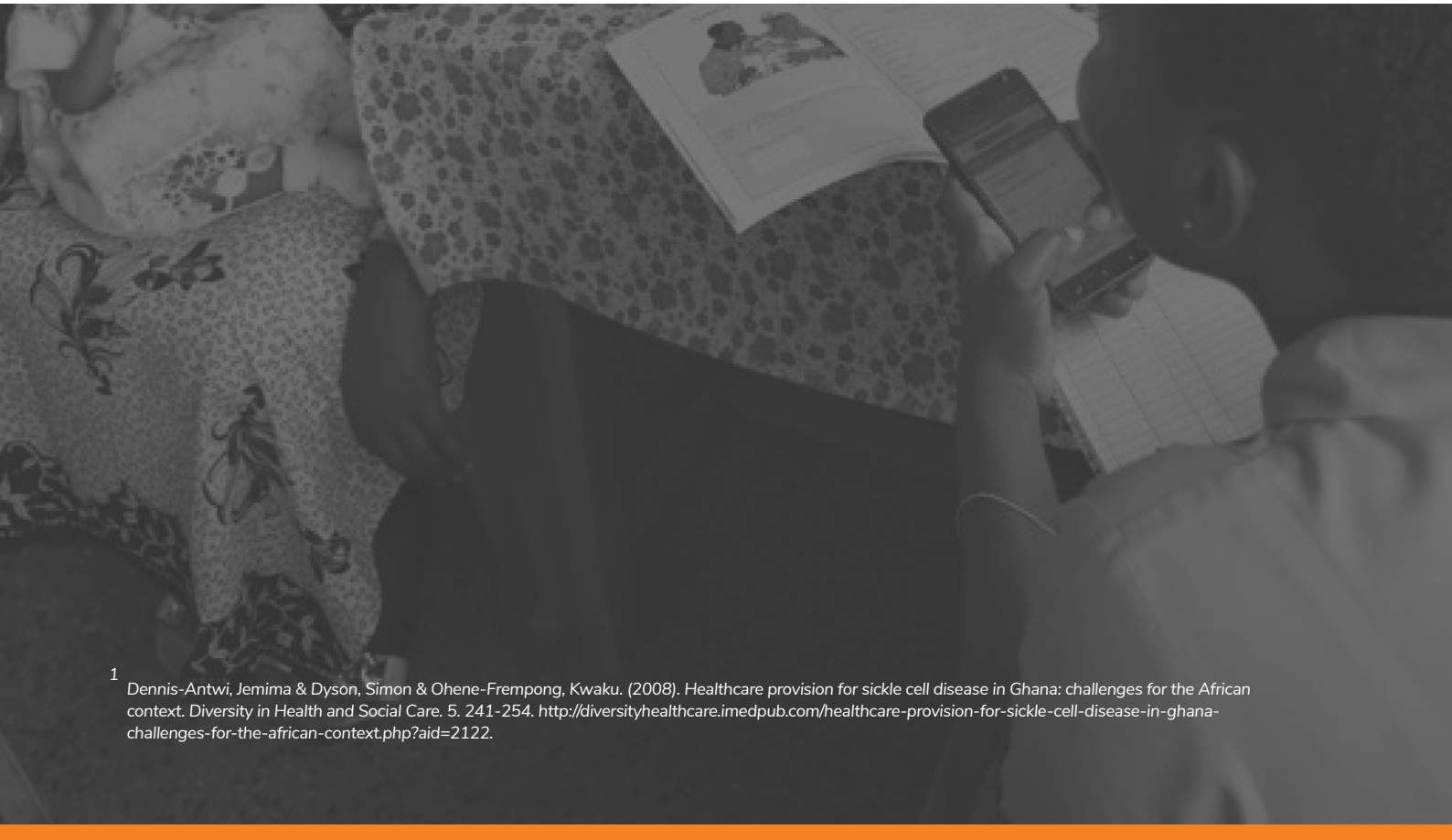
PROBLEM

Each year, upwards of 400,000 children are born with SCD, a genetic disease that stiffens red blood cells and distorts their normal round shape, causing many complications including, frequent episodes of pain, acute lung injury, stroke, overwhelming infection, stunted growth, and chronic organ damage. The WHO estimates that as many as 75 percent of newborns with SCD live in sub-Saharan Africa, but that 70 percent of the associated deaths in the region are actually preventable with simple, cost-effective interventions such as early detection through newborn screening and the subsequent provision of comprehensive care.

The majority of babies born with SCD start to experience their first symptoms – such as the swelling of their hands and feet – when they're about five to six months old. But in countries across Africa, 50-90 percent of undiagnosed children will die before the age of 5 without ever being treated for the disease.

Today, two percent of Ghanian babies are born with SCD. Ghana is one of the few countries in sub-Saharan Africa that has a newborn screening program, but according to Prof. Kwaku Ohene-Frempong, President of the SCFG, there's not a single country in Africa that tests all their children for SCD. In Ghana, "screening is currently established at 40 sites, but reaches only about 4 percent of all newborns," he said.

According to a pair of studies carried out in 1997 and 2007, "clinical care in health facilities at the district level is basic and sometimes lacking, despite the fact that 25% of the population are carriers and 2% of all babies born, that is 1 in 50 live births, have a form of SCD." [1] However, the studies also found that in one city that implemented the first newborn screening program in Africa, treated patients survived 95% of the time.



[1] *Dennis-Antwi, Jemima & Dyson, Simon & Ohene-Frempong, Kwaku. (2008). Healthcare provision for sickle cell disease in Ghana: challenges for the African context. Diversity in Health and Social Care. 5. 241-254. http://diversityhealthcare.imedpub.com/healthcare-provision-for-sickle-cell-disease-in-ghana-challenges-for-the-african-context.php?aid=2122.*

SOLUTION

Realizing large-scale, universal screening could save the lives of up to 9 million newborns in sub-Saharan Africa before 2050, the SCFG established a partnership of organizations aimed at preventing SCD child deaths in Ghana through the expansion of universal newborn screening and improved treatment.

Prof. Kwaku Ohene-Frempong hopes the partnership will "bring awareness to sickle cell disease, especially in Africa where it's most prevalent and where governments have ignored the disease for a long time, while many people see that it is worth fighting for."[2]

As part of this partnership, Dimagi worked with the Foundation to support the NNSP by digitizing its paper forms and developing a mobile job aid for its users.

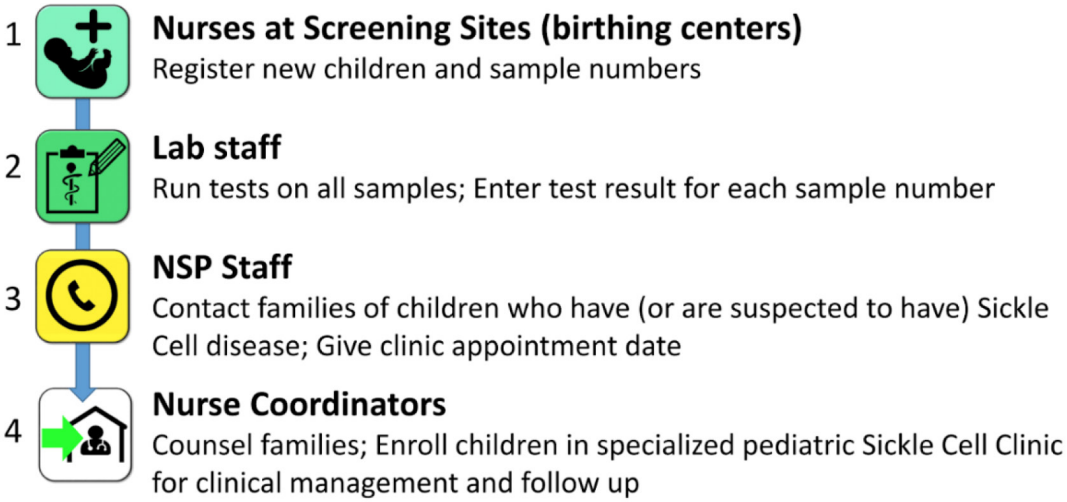
[2] *Donback, Natalie. "Improving the Lives of People with Sickle Cell Disease in Ghana." DevEx, Novartis, 20 May 2019, evex.shorthandstories.com/sickle-cell-disease-in-Ghana/.*

APP OVERVIEW

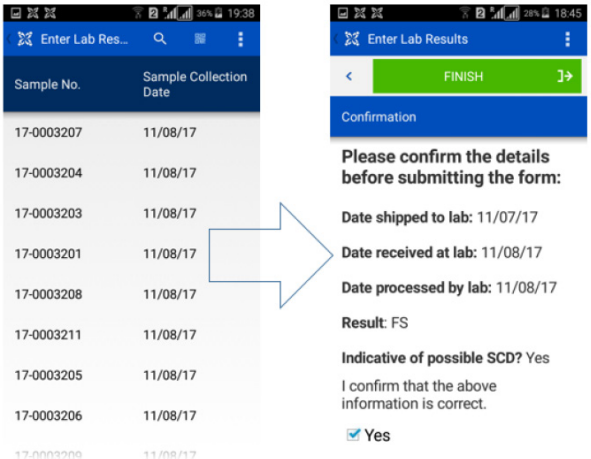
The SCFG developed a CommCare-based application to support the NNSP by replacing the use of older paper forms in a number of different areas:

- Registration of samples and family contact information, bypassing paper forms
- Tracking of samples from screening sites to the lab in Accra
- Entering of lab results and real-time distribution of results
- Contacting, following up and enrolling children with presumptive SCD (P-SCD) into the specialized pediatric clinic at Komfo Anokye Teaching Hospital
- Reliable monitoring of children through a specialized workflow involving the doctors,

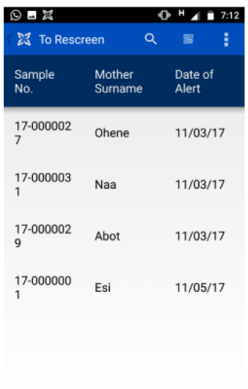
The SCFG developed a CommCare-based application to support the NNSP by replacing the use of older paper forms in a number of different areas:



Enter Lab Results



To Rescreen



List of babies screened at this facility who need to be brought back in to take a second sample

- Sorted most recent to oldest
- Includes contact info (mother's address; phone numbers of mother, father, landlord)

View Screening Results

List of babies screened at this facility whose results have been released

- Sorted most recent to oldest
- Negative results close out from the phone automatically after 3 months

FEATURE HIGHLIGHT

Case List Filtering for Improved Clinic Enrollment Rates

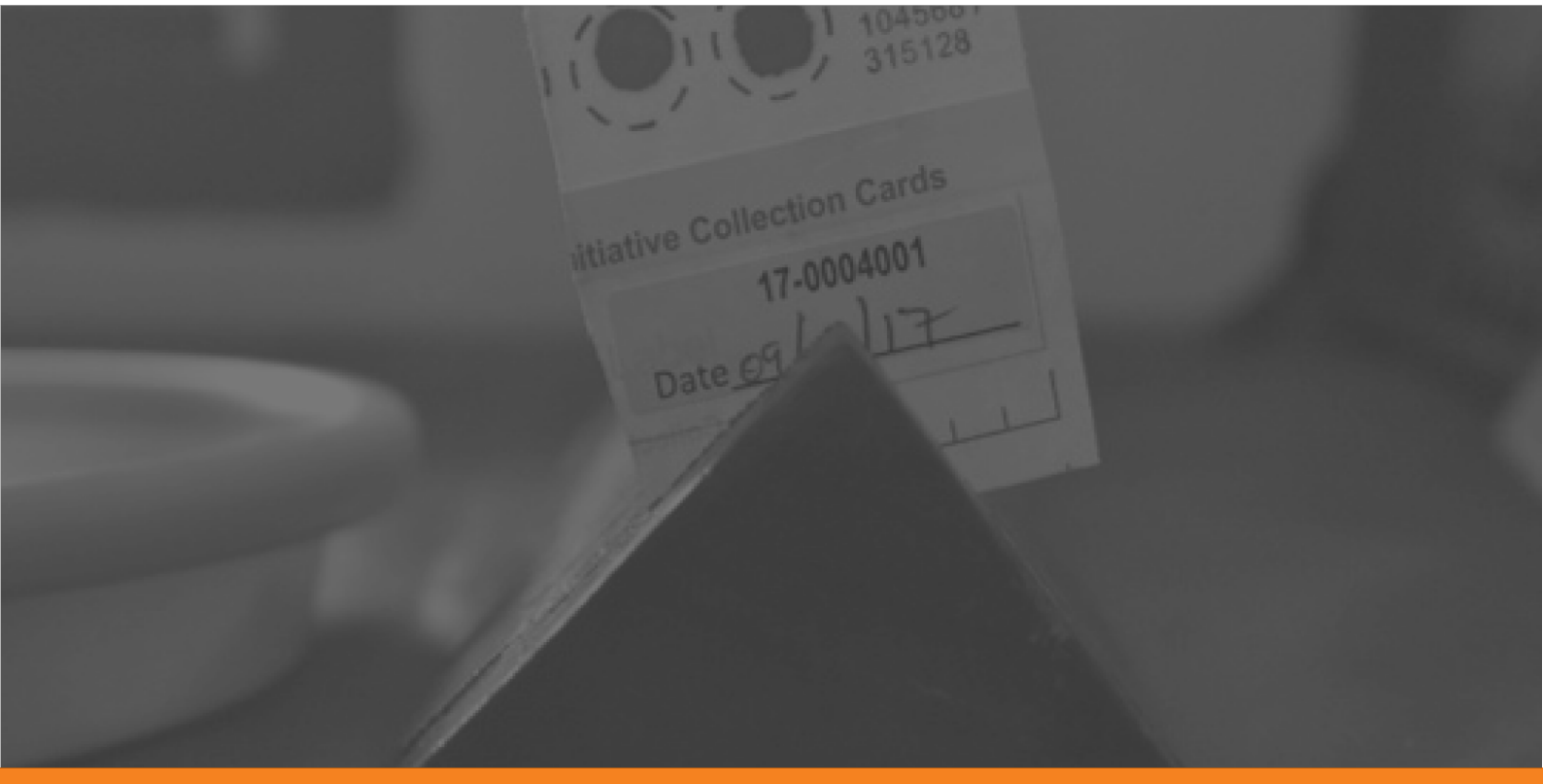
At the Ghana newborn screening sites, babies born in a health facility or at home are screened for Sickle Cell Disease before they leave the facility or at their first immunization visit, respectively. The difficult part is locating them again once their lab results are in.

Maternity or community health nurses record as many pieces of information about the mother and father as possible: full names, up to three phone numbers, home address, landmark near home, place of work, occupation, landlord name, landlord's phone number. These pieces of information help, but locating the family is still not always straightforward. While there are some "extreme" cases of incorrect phone numbers or addresses provided, it's more often that phones are out of service or the users have switched the SIM card.

With a paper-based system, it was difficult to know how well tracking and follow-up was being handled and cases would fall through the cracks if the patient couldn't be found quickly. To combat this, the team at the SCFG added a "smart agenda" to their application, which ensures that the health workers follow through with every child.

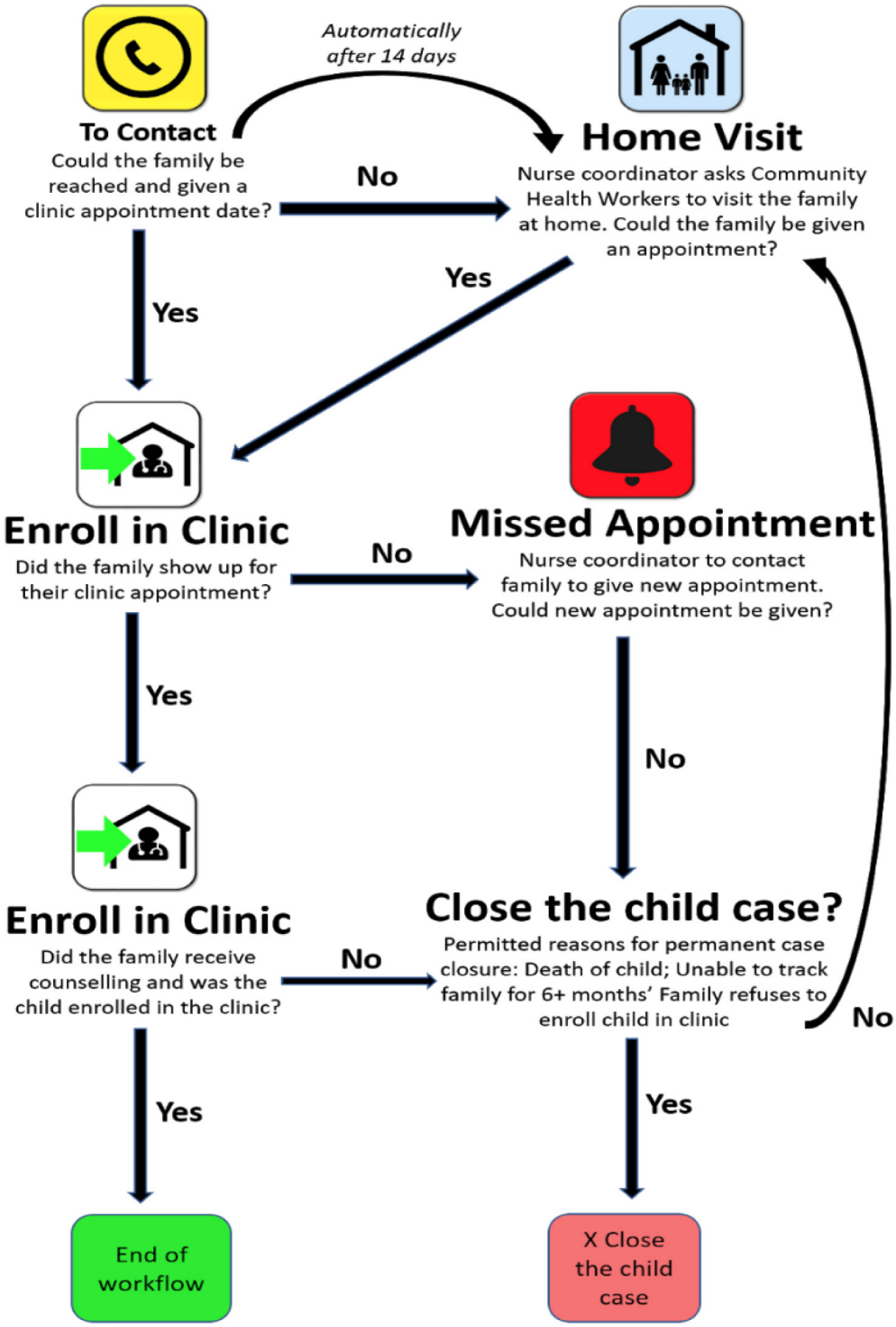
The application helps remove any uncertainty around questions such as:

- How many times would a family be called before noting them as "unable to be tracked"?
- Over what time period would a family be contacted before noting them as "unable to be tracked"?
- What percentage of "wrong number" and "non-response" cases pass through to the Home Visit stage? Since it should be 100%, is there a log of such cases?
- What percentage of families are given a second appointment date if they miss their first? Is there a log of these cases?



Because a verified person must manually close each case and specify the reason, each case is always listed somewhere and cannot get lost at the bottom of a stack of papers.

The app has numerous built-in checks, which do not allow for a case to be falsely marked as “lost.” For instance, a user cannot select the “lost to follow up (family could not be contacted or tracked for 6+ months)” option unless 6 months have passed from the date of the test result.
The application follows the following logic:

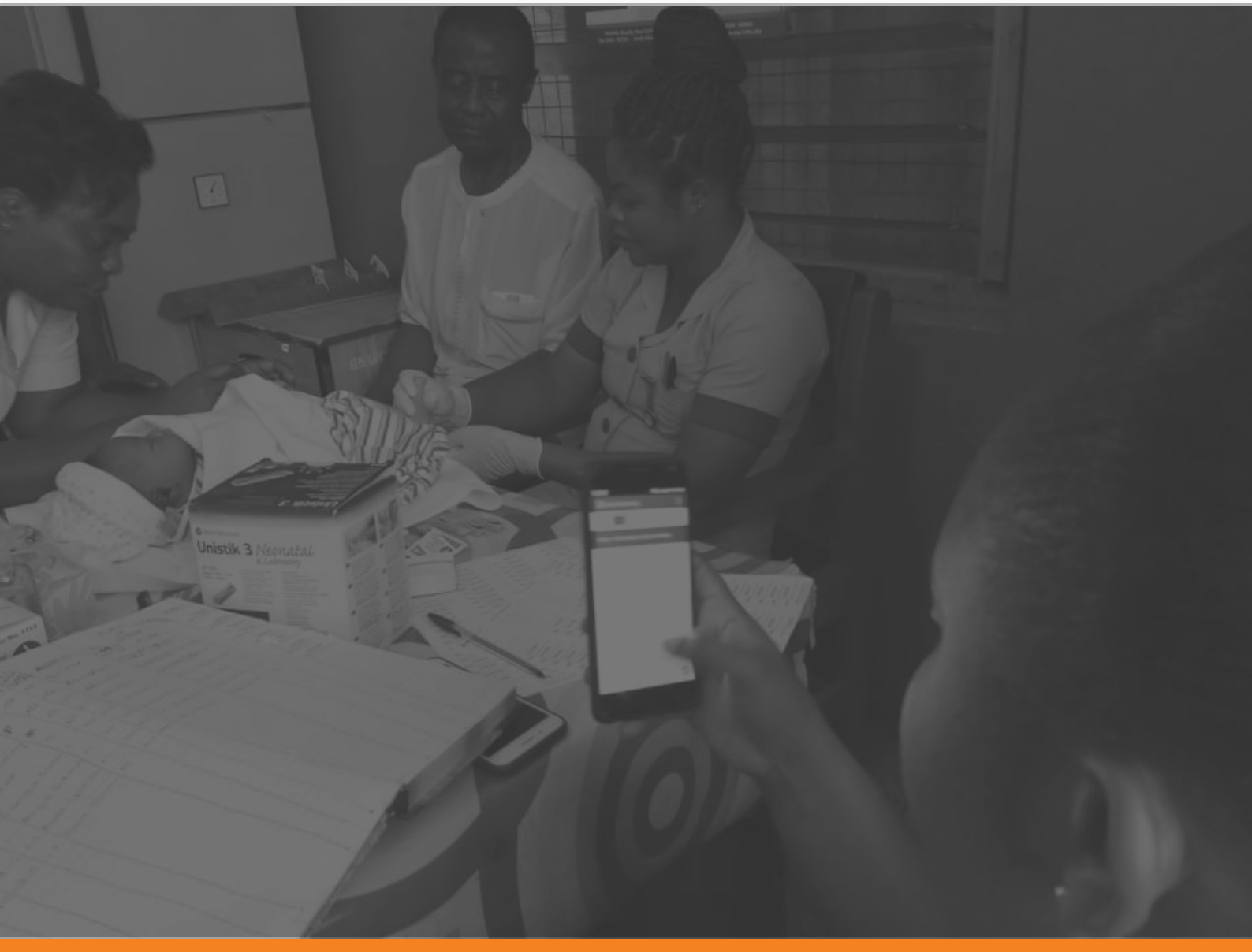


IMPLEMENTATION

The app was launched in November of 2017 and is being used in birth centers in two regions of Ghana. In the future, it is expected to become part of a comprehensive set of SCD applications for use throughout Ghana to facilitate patient management and hydroxyurea treatment, and provide targeted educational materials about the disease and treatment to patients and their caregivers.

IMPACT

A brief review after 18 months in action shows high and steady usage of the CommCare-based application. To date, more than 12,500 newborns have been registered through the app with more added every day.



WITH THANKS TO

Prof. Kwaku Ohene-Frempong
President, Sickle Cell Foundation of Ghana

Augustine Kwabena Asubonteng
Research Officer, Sickle Cell Foundation of Ghana

Dimagi Inc.
585 Massachusetts Ave, Suite 4,
Cambridge, MA 02139
+1 617.649.2214
+1 617.274.8393