

ARISE Virtual Teaching

Management of Newborn Screening Data in Ghana

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Sickle Cell Foundation of Ghana

Application of Mobile Digital Solution in Management of Newborn Screening Data in Ghana



Sickle Cell Foundation of Ghana

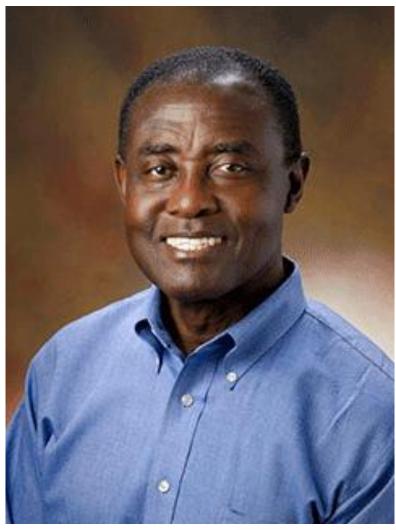
Mobile App for NBS Data Management in Ghana

<u>Outline</u>

- Pre-Lecture Test
- The Ghana Newborn Screening App
- App Demonstration
- Class Discussions/Activity
- Conclusion
- Post-Lecture Test
- **♦**Q & A
- Feedback



Before I begin



Prof. Kwaku Ohene-Frempong, MD

Mobile App for NBS Data Management in Ghana



The Newborn Screening App

- ►Introduction
- ➤ Aim of the Mobile Application
- ➤ Method
- **≻**Results
- **≻**Conclusion

Introduction: A brief history of NBS Sample Forms in Ghana

NBS Sample Form #1

- Designed in Ghana
- Printed in USA
- Triplicate form
- Glued 5-circle filter paper
- Expensive > \$1/form

NBS Sample Form #2

| | NEWBORN SCREENING DATA ENTRY FORM | Sample # 07849 |
|---|--|---|
| COMPLETE ALL INFORMATION NEWBORN SCREENING SPECIMEN | Place of Birth Name of Baby: Name Sex of Baby: Mother's Home Address Line 2: Mother's Home Address Line 2: Mother's Occupation: HAIR DE Mother's Occupation: HAIR DE Mother's Landlord: Mother's House Landmark: Father's Name. Mother's Home Address Line 2: Mother's Name First Name Mother's Name Mother's Home Address Line 2: Mother's Name Mother's Name Mother's Name Mother's Home Address Line 2: Mother's Name Mother's Name Mother's Name Mother's Home Address Line 2: Mother's Name Mother's Name Mother's Home Address Line 2: Mother's Name Mother's Name Mother's Home Address Line 2: Mother's Name Mother's Home Address Line 2: Mother's Name Mother | SSER Mother'S Workplace. ENTECOSTAREA SAWAST OF THE A ASSAUMANT APT METHO CHURCH TASHAMTE Mother: TAMATA Blood drawn by ENTAPA |

NBS Sample Form #2

- Designed in Ghana
- Printed in Ghana
- Triplicate form
- Pressure-sensitive duplicates
- Stapled; no-circle filter paper
- Manually completed
- Inexpensive < \$0.50/form

NBS Sample Form #2: Challenges

- Manually assembled
- Triplicate sheets attached with staples
- Sample Number mismatch
- Hand-filled
- Errors not noted until data entry into database; often too late for correction

NBS Sample Form #4

Hand-glued Filter paper

Data Form

| _ | _ | | | | | _ | _ | | | | | | | | | _ | | | | | | | |
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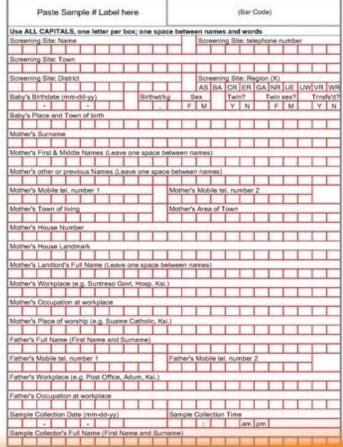
NBS Sample Form #5 with Sample Card

Continual Learning and

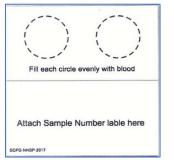
Continual Learning and improvement

Data Form, separated

Design changes out of necessity



National Newborn Screening Programme for Sickle Cell Disease



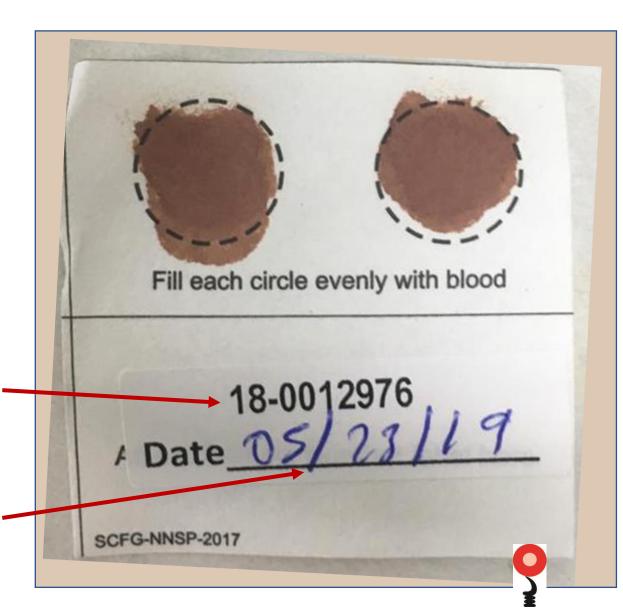
Filter-paper Sample Card



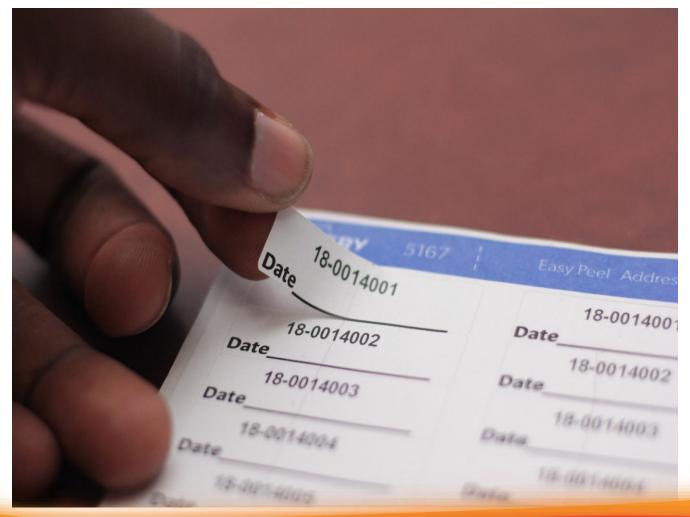
Blood-filled Sample Card

Unique Sample Number

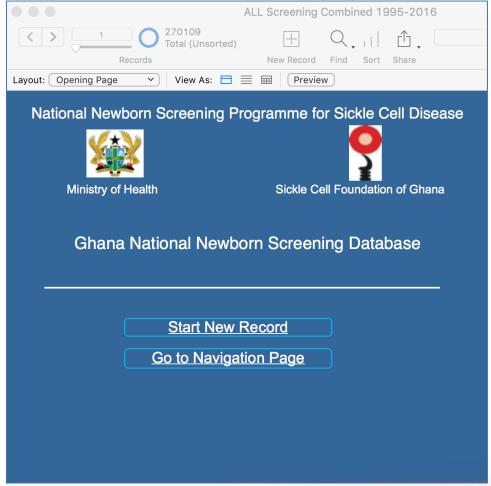
Date Sample Taken



Peeling Sample Number label for Sample Card



Newborn Screening Database



National Newborn Screening Program -SCD Database:

Newborn Screening Database

| Ghana National Newbo Navigat i | | Ghana National Newborn S Screening E | | | |
|---|-------------------------------------|--|--|--|--|
| To "Find" one or more records, enter | "Find" mode >> Enter Find mode | Creation date Apr 29, 2017 | Modification date Apr 30, 2017 | | |
| Choose "Find" criterion, click in adjacent s whom/what you want to find and press "R from more than one field on a single "Find | eturn/Enter". You may make requests | Shipment Date Baby Sample Number Screening Site Name Screening Site telephone number | K17-1234567 Retype K17-1234567 Tryp Berlin Mitte | | |
| Find criteria | Search fields | Screening Site Town | Berlin | | |
| | | Screening Site District | Berlin1- | | |
| Find Baby by Sample Number | K06-035256N | Screening Site Region | | | |
| Find Baby by Baby Surname | | | Apr 28, 2016 Retype Apr 28, 2016 | | |
| Find Baby by First Names | | Baby birthweight kg | | | |
| Tilld baby by First Names | | Baby Sex | M Yes | | |
| Find Baby by Mother's Surname | <u>Darko</u> | Baby twin's sex | | | |
| Find Baby by Mother's First Name | Rose | Baby transfused? | | | |
| , , | | Baby place and town of birth? | | | |
| Find Baby by Birthdate | Mon, Jan 1, 2007 | Mother Surname | Boafo | | |
| Find Baby by Screening IEF Results | FA | Mother First and Middle Names | Ernestina Odi | | |
| Find Dahm has IFF intermedation | | Mother other or previous names | Adwobi | | |
| Find Baby by IEF interpretation | No abnormal Hb | Mother mobile telephone 1 | 054-123-4567 | | |
| Find Baby by Sample collection site | <u>KATH</u> | Mother mobile telephone 2 | 023-123-4567 | | |
| Find Baby by Sample shipment date | 01/03/2007 | Mother town of living | Kukurantumi | | |
| Find baby by Sample Shipment date | 01/03/2007 | Mother area of town | Asen | | |
| To view other layouts: | | Mother House No. | A23/45 | | |
| | | Mother house landmark | | | |
| Go to Screening Entry | Go to Tracking & Follow-up Form | Mother landlord full name | Agya Kwadwo | | |
| Go to Test Entry | Go to Sample Shipment List | Mother workplace | Kejetia market Fruit seller | | |
| O to rest tility | OO to Campio Onipmont List | Mother occupation at workplace Mother place of worship | Kukurantumi Presvyterian Church | | |
| Go to Tracking & Follow-up Results Entry | Go to Screening Results List | Father Full Name (First Name and Surname) | Kwasi Addai Ohene | | |
| Go to Sickle Cell Centre Results Entry | Go to SCD Center Enrollment Form | Father mobile telephone 1 | 050-123-4567 | | |
| Go to Sickle Cell Certife Results Entry | Go to GOD Genter Enrollment Form | Father mobile telephone 2 | E. H. C. | | |
| Go to SCD Centre Enrollment Entry | Go to Opening Page | Father workplace | KNUST | | |
| | | Father occupation at workplace | Driver | | |
| | | Baby Screening sample 1 collection date | | | |
| Go to Opening Page | Go to Navigation Page | Baby Screening sample 1 collection time | 11:30 am | | |
| Go to Opening Page | GO to Navigation Page | Sample collector Full Name (First and Last Names) | Afia Owusua | | |

National Newborn Screening Program -SCD Database:

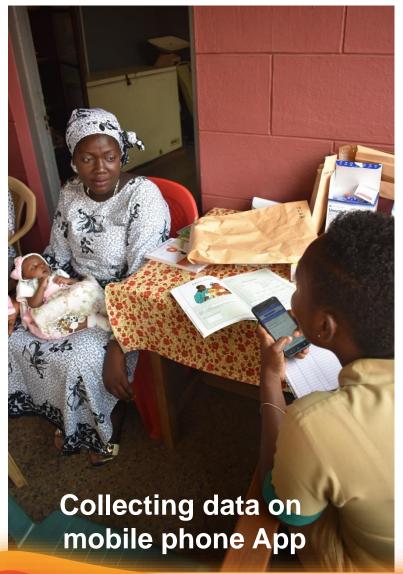


Newborn Screening Database

| Ghana National Newborn Screening Database Test Results Entry | | | | | | | | | |
|--|-----------------|------------------------|--|--|--|--|--|--|--|
| Sample Number | K17-1234567 | Retype K17-1234567 | | | | | | | |
| Baby birthdate | Apr 28, 2016 | Retype Apr 28, 2016 | | | | | | | |
| Baby First and Middle Names | | | | | | | | | |
| Baby Surname | | | | | | | | | |
| Baby place and town of birth | KATH, Kumasi | | | | | | | | |
| Baby Screening sample 1 collection date | Apr 28, 2016 | Age at test, wk. | | | | | | | |
| Baby screening IEF 1 results | FS | Re-enter FS | | | | | | | |
| Baby IEF 1 Hb phenotype | FS | | | | | | | | |
| Baby Screening IEF 1 interpretation | Possible SCD | | | | | | | | |
| Baby Screening sample 2 collection date | Apr 27, 2017 | Age at test, wk. 52.00 | | | | | | | |
| Baby screening IEF 2 results | SFA2 | Re-enter SFA2 | | | | | | | |
| Baby IEF 2 Hb phenotype | SFA2 | | | | | | | | |
| Baby Screening IEF 2 interpretation | | | | | | | | | |
| Baby Confirmatory sample 1 collection date | | Age at test, wk. | | | | | | | |
| Confirmatory IEF 1 results date | | _ | | | | | | | |
| Baby confirmatory IEF 1 results | FS | | | | | | | | |
| Baby Confirmatory sample 2 collection date | | Age at test, wk. | | | | | | | |
| Baby Confirmatory IEF 2 results date | | _ | | | | | | | |
| Baby confirmatory IEF 2 results | SFA2 | | | | | | | | |
| Baby HPLC sample collection date | | Age at test, wk. | | | | | | | |
| Baby HPLC results date | | _ | | | | | | | |
| Baby HPLC results | | | | | | | | | |
| Baby HPLC Hb phenotype | | | | | | | | | |
| Baby Hb Genotype Final Interpretation | | | | | | | | | |
| Father Full Name (First Name and Surname) | Kwasi Addai Ohe | ne | | | | | | | |
| Father IEF date | | _ | | | | | | | |
| Father IEF results | | | | | | | | | |
| Father Hb phenotype | | | | | | | | | |
| Mother First Name | | | | | | | | | |
| Mother Surname | Boafo | | | | | | | | |
| Mother IEF date | | _ | | | | | | | |
| Mother IEF results | | | | | | | | | |
| Mother Hb phenotype | | | | | | | | | |

| | Ghana National Newborn Screening Database | | | | | | | | |
|--|--|--|--|--|--|--|--|--|--|
| | Tracking & Follo | ow-up Entry Form | | | | | | | |
| BABY'S INFORMATION: Baby's Sample Number Baby Surname | K17-1234567 | Baby birthdate April 28, 2016 Baby First and Middle Names | | | | | | | |
| Baby place and town of birth | KATH, Kumasi | Baby Sex M | | | | | | | |
| Is Baby a twin? | F | Has Baby Been Transfused? No | | | | | | | |
| Baby's 1st Postnatal Clinic si | ite | | | | | | | | |
| PARENTS' INFORMATION: | | | | | | | | | |
| | tina Odi Boafo | Other Names Adwobi | | | | | | | |
| Mother's House No. A23/4 | | Mother's area of town Asen | | | | | | | |
| Mother's occupation Fruit s | | Mother's workplace Kejetia market | | | | | | | |
| | 4-123-4567 Moth kurantumi Presvyterian Church | ner's mobile telephone 2 023-123-4567 Mother's landlord full name Agya Kwadwo | | | | | | | |
| Mother's house landmark W | • | Mouner's landiord full frame Agya Kwadwo | | | | | | | |
| Mother's tribe | | | | | | | | | |
| Father's Full Name Kv | vasi Addai Ohene | Father's tribe | | | | | | | |
| Father's mobile tel. 1 05 | 0-123-4567 | Father's mobile tel. 2 026-123-4567 | | | | | | | |
| Father's workplace KN | UST | Father's occupation Driver | | | | | | | |
| Sample collector's name Afi Baby Screening sample 1 co | ollection date Apr 28, 2016 | Noguchi sample receipt date Baby screening IEF 1 results date Baby screening IEF 1 results FS Babv's Screenina Results Possible SCD | | | | | | | |
| Sample collector's name Afi | a Owusua Initials Dilection date Apr 28, 2016 Dilection time 11:30 am | Baby screening IEF 1 results date | | | | | | | |
| Sample collector's name Afi Baby Screening sample 1 or Baby Screening sample 1 or Baby Screening sample 1 st Baby Screening sample 1 st Name of person conductin Was mother reached by 1st 4 week expecte Home | a Owusua Initials Initials Initials Initials Initials Initials 2016 Silection time 11:30 am Initials Apr 29, 2016 Initials Init | Baby screening IEF 1 results date Baby screening IEF 1 results FS Baby's Screening Results Possible SCD Was father reached by phone? Yes: No: Home visit successful (baby found)? Yes: No: Home visit successful (baby found)? Yes: No: | | | | | | | |
| Sample collector's name Afi Baby Screening sample 1 or Baby Screening sample 1 or Baby Screening sample 1 or Baby Screening sample 1 st Name of person conductin Was mother reached by 1st 4 week expecte Home Mother's workplace | a Owusua Initials Ini | Baby screening IEF 1 results date Baby screening IEF 1 results FS Baby's Screening Results Possible SCD Was father reached by phone? Yes: No: Home visit successful (baby found)? Yes: No: Mother's workplace visit successful? | | | | | | | |
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| Sample collector's name Afi Baby Screening sample 1 or Baby Screening sample 1 or Baby Screening sample 1 st Name of person conductin Was mother reached by 1st 4 week expecte Home Mother's workplac Mother's workplac | a Owusua Initials Ini | Baby screening IEF 1 results date Baby screening IEF 1 results FS Baby's Screening Results Possible SCD Was father reached by phone? Yes: No: Complied with 1st 4 wk visit Yes: No: Home visit successful (baby found)? Yes: No: Mother's workplace visit successful? Yes: No: Father's workplace visit successful? Yes: No: Father's workplace visit successful? Yes: No: | | | | | | | |
| Sample collector's name Afi Baby Screening sample 1 or Baby Screening sample 1 or Baby Screening sample 1 or Baby Screening sample 1 st Name of person conductir Was mother reached by 1st 4 week expecte Home Mother's workplac Mother's workplac Date baby | a Owusua Initials Initials Initials Illection date Apr 28, 2016 Illection time 11:30 am Inipment date Apr 29, 2016 Ing tracking or follow-up: In y phone? Yes: No: divisit date Invisit dat | Baby screening IEF 1 results date Baby screening IEF 1 results FS Baby's Screening Results Possible SCD Was father reached by phone? Yes: No: Complied with 1st 4 wk visit Yes: No: Home visit successful (baby found)? Yes: No: Mother's workplace visit successful? Yes: No: Father's workplace visit successful? Yes: No: Tracking successful (baby found)? Yes: No: | | | | | | | |
| Sample collector's name Afi Baby Screening sample 1 or Baby Screening sample 1 or Baby Screening sample 1 or Baby Screening sample 1 st Name of person conductin Was mother reached by 1st 4 week expecte Home Mother's workplac Mother's place of worshi Father's workplac Date baby 1st clinic sche | a Owusua Initials Initials Illection date Apr 28, 2016 Illection time 11:30 am Inipment date Apr 29, 2016 Ing tracking or follow-up: Ing tracking or follow- | Baby screening IEF 1 results date Baby screening IEF 1 results FS Baby's Screening Results Possible SCD Was father reached by phone? Yes: No: Complied with 1st 4 wk visit Yes: No: Home visit successful (baby found)? Yes: No: Mother's workplace visit successful? Yes: No: Father's workplace visit successful? Yes: No: Tracking successful (baby found)? Yes: No: owup results: Baby referred to clinic? Yes: No: | | | | | | | |
| Sample collector's name Afi Baby Screening sample 1 or Baby Screening sample 1 st Name of person conductir Was mother reached by 1st 4 week expecte Home Mother's workplac Mother's workplac Date baby 1st clinic sche Did baby come to 1st cl | a Owusua Initials Ini | Baby screening IEF 1 results date Baby screening IEF 1 results FS Baby's Screening Results Possible SCD Was father reached by phone? Yes: No: Complied with 1st.4 wk visit Yes: No: Home visit successful (baby found)? Yes: No: Home visit successful (baby found)? Yes: No: Her's workplace visit successful? Yes: No: Tather's workplace visit successful? Yes: No: Down yes workplace visit successful? Yes: No: Tracking successful (baby found)? Yes: No: Down yesults: Baby referred to clinic? Yes: No: Reasons for Tracking/follow up failure: | | | | | | | |
| Sample collector's name Afi Baby Screening sample 1 or Baby Screening sample 1 or Baby Screening sample 1 or Baby Screening sample 1 st Name of person conductir Was mother reached by 1st 4 week expecte Home Mother's workplac Mother's borshi Father's workplac Date baby 1st clinic sche Did baby come to 1st cl 1st SCD Clinic atte | a Owusua Initials Ini | Baby screening IEF 1 results date Baby screening IEF 1 results FS Baby's Screening Results Possible SCD Was father reached by phone? Yes: No: Complied with 1st 4 wk visit Yes: No: Home visit successful (baby found)? Yes: No: Home visit successful (baby found)? Yes: No: Her's workplace visit successful? Yes: No: Tather's workplace visit successful? Yes: No: Down or successful (baby found)? Yes: No: Tracking successful (baby found)? Yes: No: Reasons for Tracking/follow up failure: Family unknown at targeted house (baby not found) | | | | | | | |
| Sample collector's name Afi Baby Screening sample 1 or Baby Screening sample 1 or Baby Screening sample 1 st Name of person conductin Was mother reached by 1st 4 week expecte Home Mother's workplac Mother's workplac Date baby 1st clinic sche Did baby come tofst cl 1st SCD Clinic atte | a Owusua Initials Ini | Baby screening IEF 1 results date Baby screening IEF 1 results FS Baby's Screening Results Possible SCD Was father reached by phone? Yes: No: No: No: No: No: No: No: No: No: No | | | | | | | |
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National Newborn Screening Program -SCD Databases



CommCare for Newborn Screening



Sickle Cell Foundation of Ghana





Made possible by



Aim of the Mobile Application



Aim of the Mobile Application

Decrease time/effort spent on tracking patients

 Decrease clinic enrollment timeline, i.e. the time it takes from discovering a Presumptive Sickle Cell Disease (PSCD) patient to enrolling them in the clinic

 Decrease time/effort of non PSCD results distribution to Screening Sites

Improve re-screening rates at Screening Sites



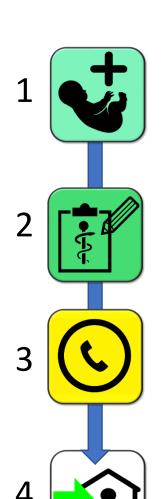
Steps in the Ghana Newborn Screening App Development



Ghana Newborn Screening App: Steps in the Development

- Scoping Visit to have an overview of the workflow of the program May, 2017
- Prototype Development June-July, 2017
- Field Testing in August, 2017
- Final Application Development after feedback from field testing September-October, 2017
- Final Application Launch in November, 2017

Workflow / Role of each of the 4 user types



Nurses at Screening Sites (public hospitals)

Register new children and sample numbers

Lab staff

Run tests on all samples; Enter test result for each sample number

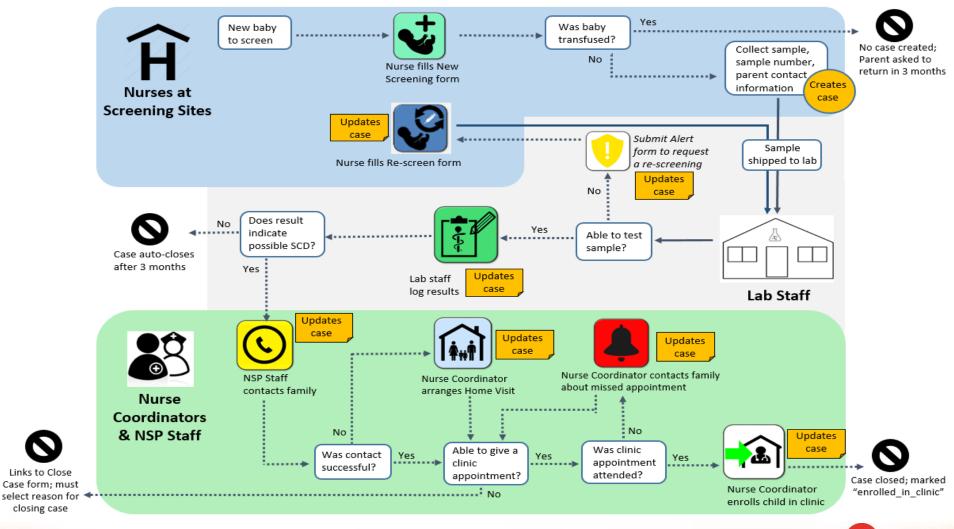
NSP Staff

Contact families of children who have (or are suspected to have) Sickle Cell disease; Give clinic appointment date

Nurse Coordinators

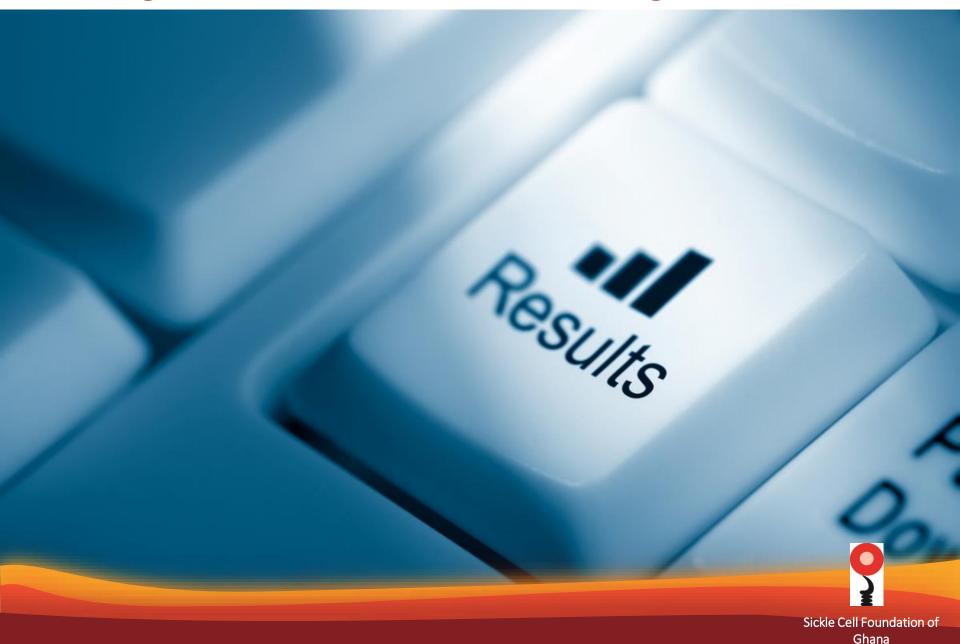
Counsel families; Enroll children in specialized pediatric Sickle Cell Clinic for clinical management and follow:

Full Workflow Diagram



Ghana Newborn Screening App: Key Features

- Android-based mobile devices; also, web-based access
- Data entered in field, stored on mobile devices until synched to servers
- Synched data become available to lab and central management
- Results entered in laboratory and synched become available at screening sites for follow up
- Weekly data summary provided to management



- After the App was developed, it has been used to successfully manage the information of over **17,800** babies.
- ➤ With **13,535** lab results assigned
- **▶228** Presumptive-SCD (**1.68%**)
- >99 enrollment (All Enrollment Done through calls)
- **▶30** contacted but not enrolled
- >2 Deaths





Web Users

SCFG program staff received dedicated, in-person training from Dimagi in November 2017 on relevant sections of CommCareHQ in addition to independently completing

- ✓ CommCare Fundamentals
- ✓ CommCare Application Building for Public Health Students
- ✓ CommCare for Universities

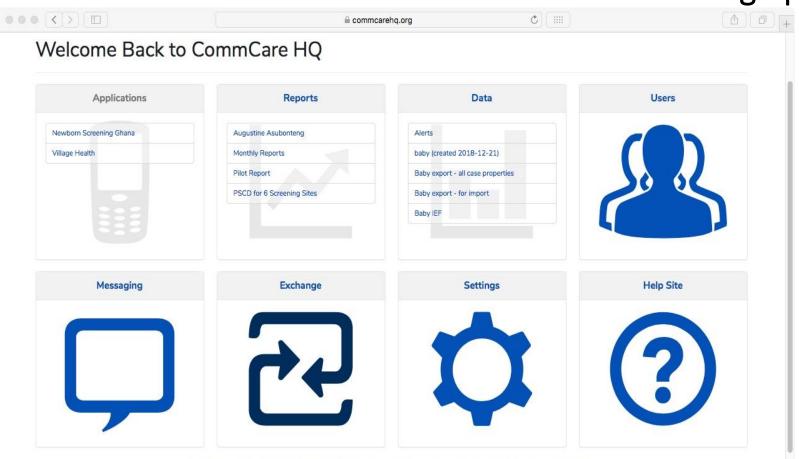
All courses offered by Dimagi Academy

Web Users

Responsibilities include but not limited to:

- ✓ Add and deactivate mobile users as required
- ✓ Add and deactivate web users as required
- ✓ Make changes to the app as desired
- ✓ Set up, modify, and run data exports as needed
- ✓ Access standard reports via the web or by e-mail on mobile user activity, including number, type, and time of form submissions and follow-up rates on patients.
- ✓ Follow-up with low performing mobile users.

Web-Based interface of the Ghana Newborn Screening App



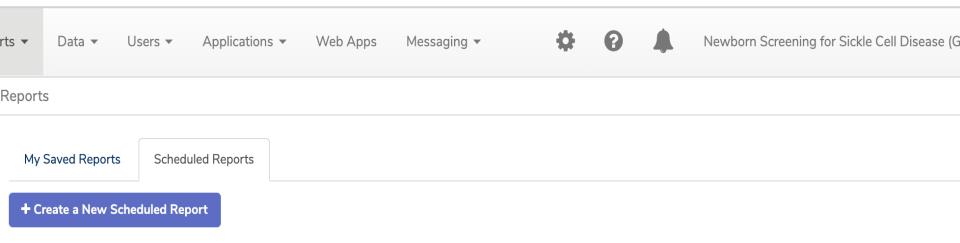
Thanks for using CommCare HQ! If you have questions, suggestions, or other thoughts, we invite you to join the discussion on the CommCare User Forums.

Reporting on CommcareHQ

Worker Activity

| | Form Data | | | Case Data | | Case Activity | | | |
|------------------------------------|---------------------------|----------------------------|-------------------------------------|-------------------------|------------------------|-------------------------------|---|-------------------------------|--|
| ↓ <u>i</u> User | ↓↑ # Forms Submitted � | ↑↑ Avg # Forms Submitted • | ↓↑ Last Form Submission ② | ↓↑ # Cases Created • | ↓↑ # Cases Closed • | ↓↑ # Active Cases ② | ∬ # Total Cases (Owned & Shared) ② | ↓↑ % Active Cases ② | |
| arise_lab "Arise Lab" | 1 | 0 | 2020-07-22 | 0 | 0 | 0 | 0 | | |
| arise_nurse "Arise Nurse" | 0 | 0 | None | 0 | 0 | 0 | 0 | | |
| arise_tracking "Arise Tracking" | 0 | 0 | None | 0 | 0 | 0 | 0 | | |
| Total | 1 | | 1/3 | | | | | | |

Reporting on CommcareHQ



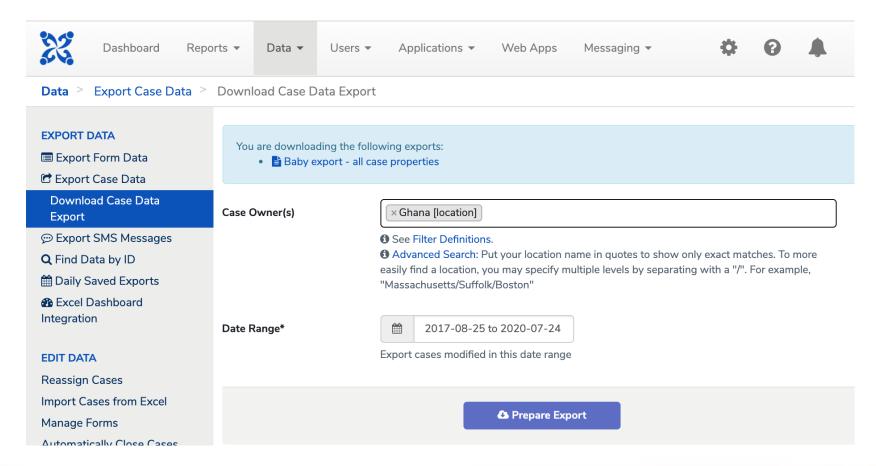
My Scheduled Reports

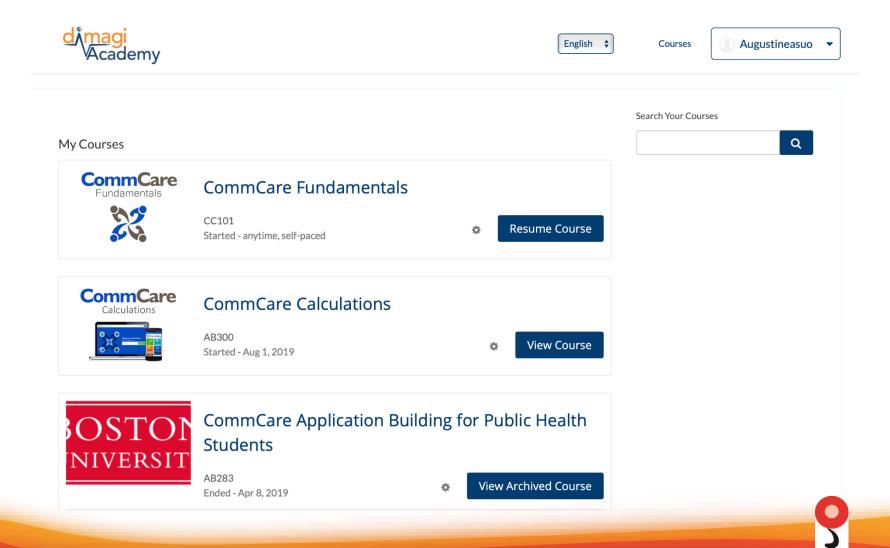
Other Scheduled Reports

| Owner | Reports | Day and Time | Recipients | Actions |
|---------------------------------|---|----------------|---|---------|
| asubontenga@sicklecellghana.org | Augustine Asubonteng (Daily Form Activity) | Monday at 7:00 | asubontenga@sicklecellghana.org, addoe@sicklecellghana.org, amoahe@sicklecellghana.org, ohene@sicklecellghana.org, mealgh2009@yahoo.com | © Edit |
| asubontenga@sicklecellghana.org | Korle-Bu Teaching Report (Daily Form Activity) | Monday at 7:00 | csegbefia@gmail.com, irenekanyoke@yahoo.com | © Edit |
| | | | | 5 |

Sickle Cell Foundation of Ghana

Reporting on CommcareHQ





A Demonstration of the Ghana Newborn Screening Mobile Application

Groupings to brainstorm

- G1. Login as screening Nurses register a baby
- G2. Login as a Lab Technician and enter Lab results.
- G3. Log in as a tracking nurse to track and enroll a Baby

- How to Download Commcare and Install the Ghana NBS App
- Search Commcare at Play store
- Download and install Commcare
- 3. Click enter code
- 4. Enter code: **2WMYBBc**
- 5. Finally click on install

- ➤ You can Login as
- A. As a screening Nurse

Username: arise_nurse

Password: 123

B. As a Lab Technician

Username: arise_lab

Password: 123

C. As a Nurse Coordinator/Tracking nurse

Username: arise_tracking

Password: 123

Groupings to brainstorm

• G1. Make a list of Screening data to be collected in Nigeria

• G2. Data not captured by the Ghana App but may be important in the Nigerian context.

G3. Discuss why the Ghana App can help track PSCD in Nigeria

Conclusion

Conclusion

The Ghana Newborn Screening Application has successfully been deployed and it's fully functioning for:

- Registration of sample and family contact information
- Data analysis
- Transmission of lab results
- Supervision of health workers and program staff
- Overall efficiency in time, cost and efforts.

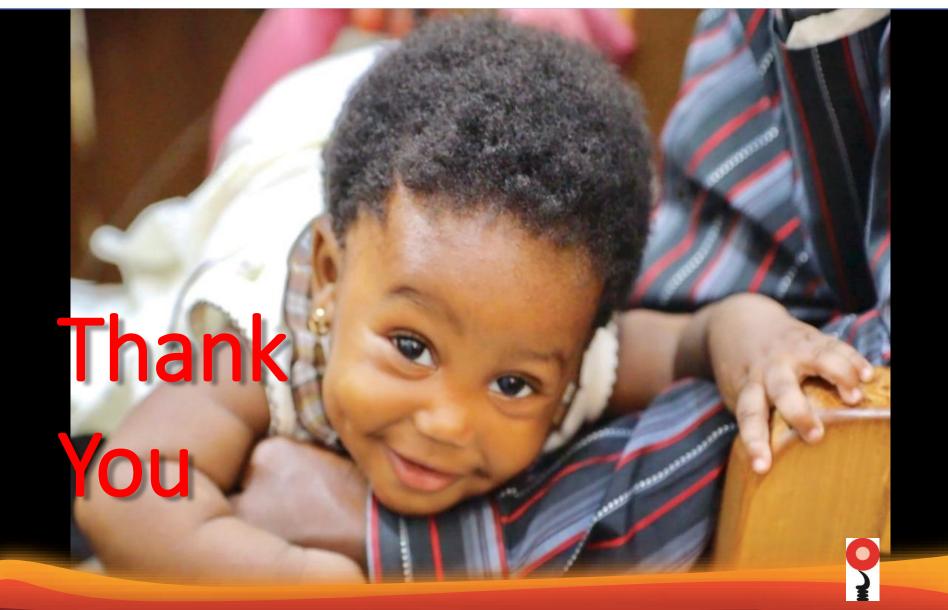
Post Lecture Test





ARISE Virtual Teaching





Sickle Cell Foundation of Ghana



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information it contains.

