



ARISE

African Research And Innovative
Initiative For Sickle Cell Education

Train-the-Trainer Workshop Abuja, Nigeria 11th – 13th September 2019

Management of Newborn Screening Data in Ghana

Augustine Kwabena Asubonteng

Research Officer

Sickle Cell Foundation of Ghana

This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No. 824021



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



Sickle Cell Foundation of Ghana



Outline

- Introduction
- Aim of the Mobile Application
- Method of Development
- 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



Management of Newborn Screening Data in Ghana

NBS Sample Form #2

PLEASE PRINT CLEARLY-PRESS FIRMLY
COMPLETE ALL INFORMATION
NEWBORN SCREENING SPECIMEN

NEWBORN SCREENING DATA ENTRY FORM		Sample # No. 07849
Baby's Information:		Parent's Information:
Date of Birth: 18-3-99 <small>Day Month Year</small>	Place of Birth: UST	Mother's Surname: ANSAH ASIAMAH Mother's First Name: OTAVIA Mother's other names: CATHERINE ANSAH ASSIMAH Mother's Home Address Line 1: HOME C I ASAWASTI Mother's Home Address Line 2: Mother's Occupation: HAIR DRESSER Mother's Workplace: ASAWASTI Church/Mosque Mother Attends: PENTECOST Area: ASAWASTI Mother's Landlord: COMFORT MILLS Mother's House Landmark:
Name of Baby: <small>Surname First Name</small>	Sex of Baby: Male YES Female NO Twin? NO	Father's Name: MR. DANIEL A. ASSAIMAH Father's Workplace Line 1: CARPENTER Father's workplace Line 2: NEBA METHO. CHURCH Family Ethnic Group (Tribe) Father: ASHANTE Mother: FANTI Blood collection site: UST Blood collection Date: 19-3-99 Blood drawn by: E. GTAPA Blood collection time: 9:40 AM
Was baby Transfused? NO	Baby's First P/N Clinic, Where: UST	



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




Management of Newborn Screening Data in Ghana

NBS Sample Form #4

Hand-glued Filter paper

Data Form

																				
Sample #	1	2	3	4	5	6	7	8	9	10	BARCODE									
Use ALL CAPITALS, one letter per box; one space between names and words																				
Screening Site: Name										Screening Site: telephone number										
Screening Site: Town																				
Screening Site: District										Screening Site: Region (X)										
Baby's Birthdate (mm-dd-yy)					Birthwt/kg					Sex		Twin?		Twin sex?		Trnsfs/d?				
-					.					F M		Y N		F M		Y N				
Baby's Place and Town of birth																				
Mother's Surname																				
Mother's First & Middle Names (Leave one space between names)																				
Mother's other or previous Names (Leave one space between names)																				
Mother's Mobile tel. number 1							Mother's Mobile tel. number 2													
Mother's Town of living							Mother's Area of Town													
Mother's House Number																				
Mother's House Landmark																				
Mother's Landlord's Full Name (Leave one space between names)																				
Mother's Workplace (e.g. Suntreso Govt. Hosp. Ksi.)																				
Mother's Occupation at workplace																				
Mother's Place of worship (e.g. Suame Catholic, Ksi.)																				
Father's Full Name (First Name and Surname)																				
Father's Mobile tel. number 1							Father's Mobile tel. number 2													
Father's Workplace (e.g. Post Office, Adum, Ksi.)																				
Father's Occupation at workplace																				
Sample Collection Date (mm-dd-yy)							Sample Collection Time													
-							: am pm													
Sample Collector's Full Name (First Name and Surname)																				



Management of Newborn Screening Data in Ghana

NBS Sample Form #5 with Sample Card

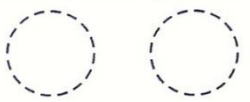
Continual Learning and improvement

Data Form, separated

Design changes out of necessity

National Newborn Screening Programme for Sickle Cell Disease

Paste Sample # Label here		(Bar Code)									
Use ALL CAPITALS, one letter per box; one space between names and words											
Screening Site: Name		Screening Site: telephone number									
Screening Site: Town											
Screening Site: District		Screening Site: Region (X)									
		AS	BA	CR	ER	GA	NR	UE	UW	VR	WR
Baby's Birthdate (mm-dd-yy)		Birthwt/kg		Sex		Twin?		Twin sex?		Trnsl's'g?	
-		-		F M		Y N		F M		Y N	
Baby's Place and Town of birth											
Mother's Surname											
Mother's First & Middle Names (Leave one space between names)											
Mother's other or previous Names (Leave one space between names)											
Mother's Mobile tel. number 1		Mother's Mobile tel. number 2									
Mother's Town of living		Mother's Area of Town									
Mother's House Number											
Mother's House Landmark											
Mother's Landlord's Full Name (Leave one space between names)											
Mother's Workplace (e.g. Sunreso Govt. Hosp, Ksi.)											
Mother's Occupation at workplace											
Mother's Place of worship (e.g. Suame Catholic, Ksi.)											
Father's Full Name (First Name and Surname)											
Father's Mobile tel. number 1		Father's Mobile tel. number 2									
Father's Workplace (e.g. Post Office, Adum, Ksi.)											
Father's Occupation at workplace											
Sample Collection Date (mm-dd-yy)		Sample Collection Time									
-		:		am pm							
Sample Collector's Full Name (First Name and Surname)											

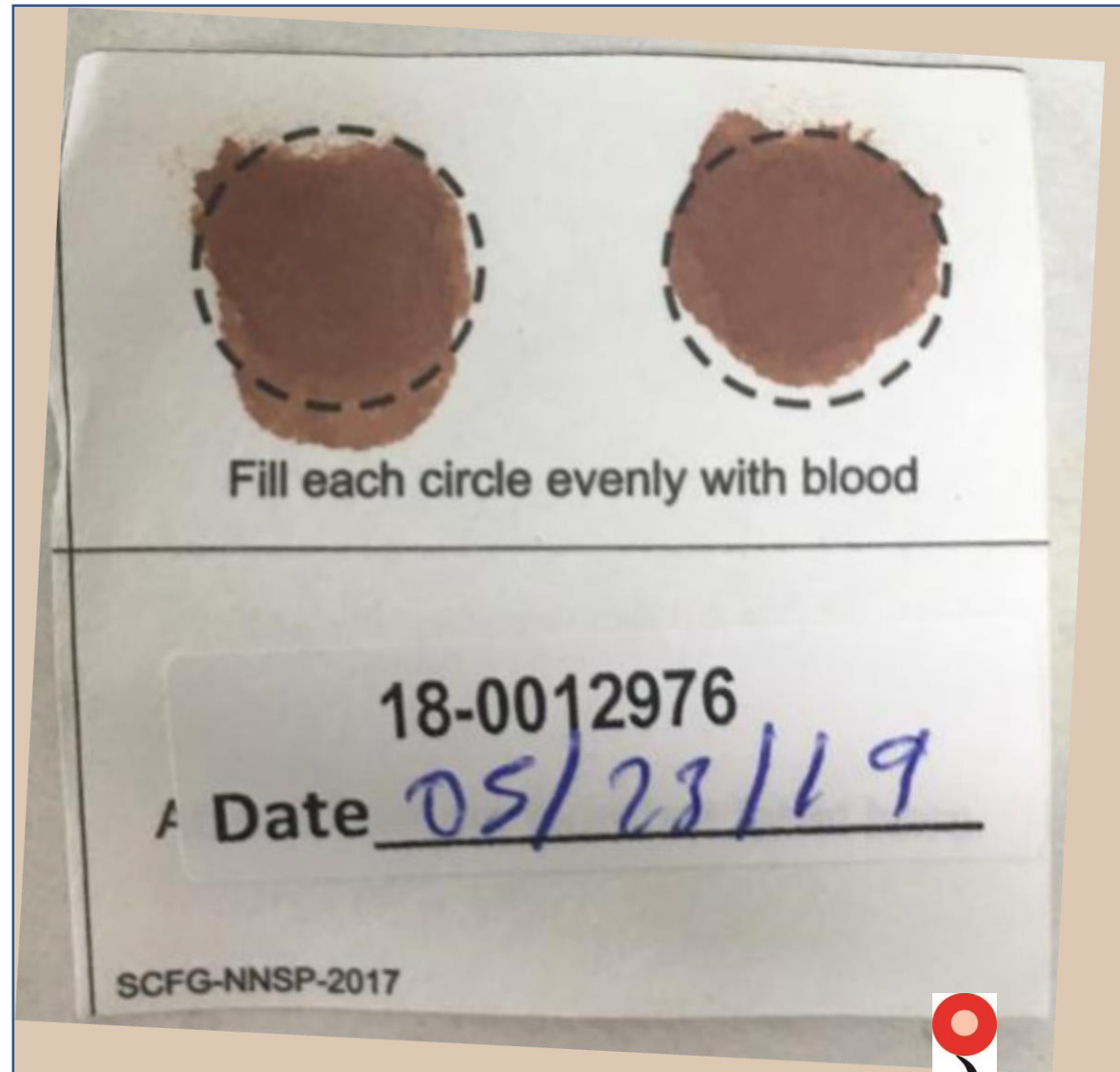

Fill each circle evenly with blood
Attach Sample Number label here
SCFG NSNP 2017

Filter-paper Sample Card



Management of Newborn Screening Data in Ghana

Blood-filled Sample Card



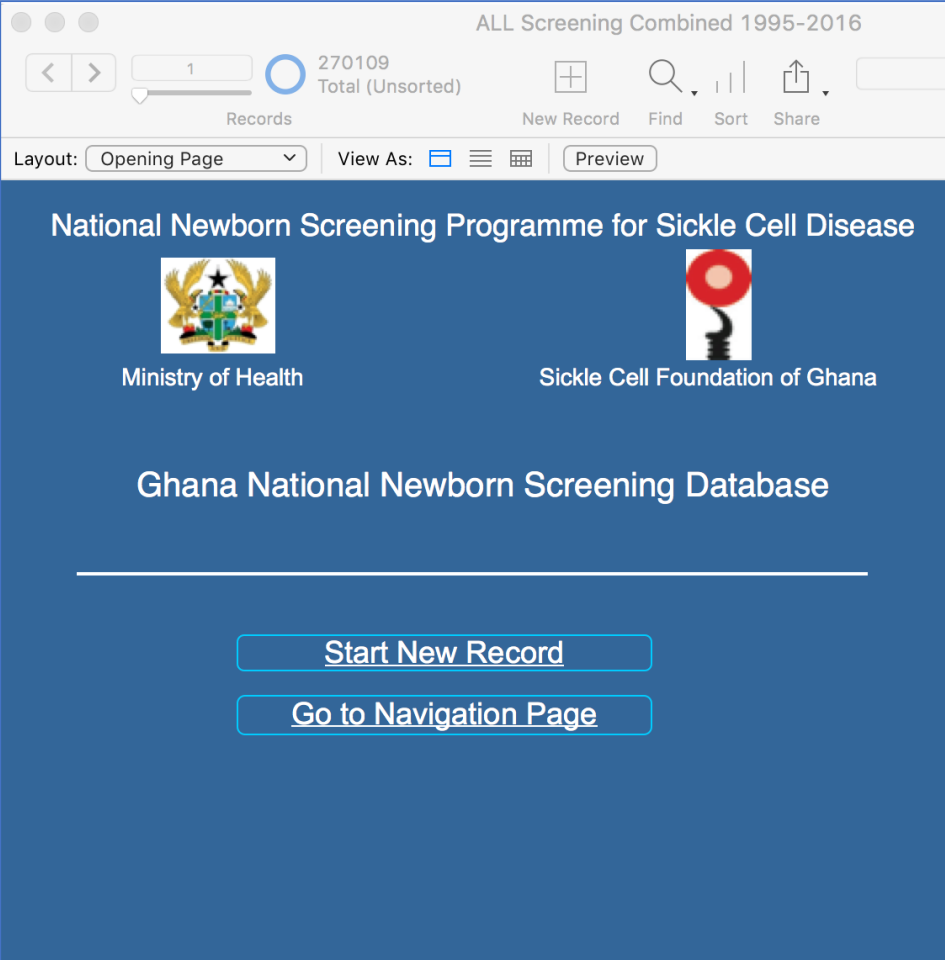
Management of Newborn Screening Data in Ghana

Peeling Sample Number label for Sample Card



Management of Newborn Screening Data in Ghana

Newborn Screening Database



ALL Screening Combined 1995-2016

Records: 270109 Total (Unsorted)

Layout: Opening Page View As: Preview

National Newborn Screening Programme for Sickle Cell Disease

Ministry of Health Sickle Cell Foundation of Ghana

Ghana National Newborn Screening Database

Start New Record

Go to Navigation Page

National Newborn Screening Program -SCD Database:



Management of Newborn Screening Data in Ghana

Newborn Screening Database

**Ghana National Newborn Screening Database
Navigation Page**

To "Find" one or more records, enter "Find" mode >>

Choose "Find" criterion, click in adjacent search field of choice, type in or select whom/what you want to find and press "Return/Enter". You may make requests from more than one field on a single "Find".

<u>Find criteria</u>	<u>Search fields</u>
Find Baby by Sample Number	<input type="text" value="K06-035256N"/>
Find Baby by Baby Surname	<input type="text"/>
Find Baby by First Names	<input type="text"/>
Find Baby by Mother's Surname	<input type="text" value="Darko"/>
Find Baby by Mother's First Name	<input type="text" value="Rose"/>
Find Baby by Birthdate	<input type="text" value="Mon, Jan 1, 2007"/>
Find Baby by Screening IEF Results	<input type="text" value="FA"/>
Find Baby by IEF interpretation	<input type="text" value="No abnormal Hb"/>
Find Baby by Sample collection site	<input type="text" value="KATH"/>
Find Baby by Sample shipment date	<input type="text" value="01/03/2007"/>

To view other layouts:

<input type="button" value="Go to Screening Entry"/>	<input type="button" value="Go to Tracking & Follow-up Form"/>
<input type="button" value="Go to Test Entry"/>	<input type="button" value="Go to Sample Shipment List"/>
<input type="button" value="Go to Tracking & Follow-up Results Entry"/>	<input type="button" value="Go to Screening Results List"/>
<input type="button" value="Go to Sickle Cell Centre Results Entry"/>	<input type="button" value="Go to SCD Center Enrollment Form"/>
<input type="button" value="Go to SCD Centre Enrollment Entry"/>	<input type="button" value="Go to Opening Page"/>

**Ghana National Newborn Screening Database
Screening Entry**

Creation date	<input type="text" value="Apr 29, 2017"/>	Modification date	<input type="text" value="Apr 30, 2017"/>
Shipment Date	<input type="text" value="4-29-2016"/>		
Baby Sample Number	<input type="text" value="K17-1234567"/>	Retype	<input type="text" value="K17-1234567"/>
Screening Site Name	<input type="text" value="Tryp Berlin Mitte"/>		
Screening Site telephone number	<input type="text" value="012-345-6789"/>		
Screening Site Town	<input type="text" value="Berlin"/>		
Screening Site District	<input type="text" value="Berlin1-"/>		
Screening Site Region	<input type="text" value="Berlin-2"/>		
Baby birthdate	<input type="text" value="Apr 28, 2016"/>	Retype	<input type="text" value="Apr 28, 2016"/>
Baby birthweight kg	<input type="text" value="3.5"/>		
Baby Sex	<input type="text" value="M"/>		
Baby is a twin?	<input type="text" value="Yes"/>		
Baby twin's sex	<input type="text" value="F"/>		
Baby transfused?	<input type="text" value="No"/>		
Baby place and town of birth?	<input type="text" value="KATH, Kumasi"/>		
Mother Surname	<input type="text" value="Boafo"/>		
Mother First and Middle Names	<input type="text" value="Ernestina Odi"/>		
Mother other or previous names	<input type="text" value="Adwobi"/>		
Mother mobile telephone 1	<input type="text" value="054-123-4567"/>		
Mother mobile telephone 2	<input type="text" value="023-123-4567"/>		
Mother town of living	<input type="text" value="Kukurantumi"/>		
Mother area of town	<input type="text" value="Asen"/>		
Mother House No.	<input type="text" value="A23/45"/>		
Mother house landmark	<input type="text" value="White mosque"/>		
Mother landlord full name	<input type="text" value="Agya Kwadwo"/>		
Mother workplace	<input type="text" value="Kejetia market"/>		
Mother occupation at workplace	<input type="text" value="Fruit seller"/>		
Mother place of worship	<input type="text" value="Kukurantumi Presvyterian Church"/>		
Father Full Name (First Name and Surname)	<input type="text" value="Kwasi Addai Ohene"/>		
Father mobile telephone 1	<input type="text" value="050-123-4567"/>		
Father mobile telephone 2	<input type="text" value="026-123-4567"/>		
Father workplace	<input type="text" value="KNUST"/>		
Father occupation at workplace	<input type="text" value="Driver"/>		
Baby Screening sample 1 collection date	<input type="text" value="Apr 28, 2016"/>		
Baby Screening sample 1 collection time	<input type="text" value="11:30 am"/>		
Sample collector Full Name (First and Last Names)	<input type="text" value="Afa Owusua"/>		

National Newborn Screening Program -SCD Database:



Management of Newborn Screening Data in Ghana

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 Ohene
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 & Follow-up Entry Form	
BABY'S INFORMATION:	
Baby's Sample Number	K17-1234567 Baby birthdate April 28, 2016
Baby Surname	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 site	
PARENTS' INFORMATION:	
Mother's Full Name	Ernestina Odi Boafo Other Names Adwobi
Mother's House No.	A23/45 Mother's area of town Asen
Mother's occupation	Fruit seller Mother's workplace Kejetia market
Mother's mobile tel. 1	054-123-4567 Mother's mobile telephone 2 023-123-4567
Mother's place of worship	Kukurantumi Presbyterian Church Mother's landlord full name Agya Kwadwo
Mother's house landmark	White mosque
Mother's tribe	
Father's Full Name	Kwasi Addai Ohene Father's tribe
Father's mobile tel. 1	050-123-4567 Father's mobile tel. 2 026-123-4567
Father's workplace	KNUST Father's occupation Driver
BLOOD TESTING INFORMATION AND RESULTS:	
Sample collection site	Tryp Berlin Mitte Noguchi sample receipt date
Sample collector's name	Alia Owusua Initials Baby screening IEF 1 results date
Baby Screening sample 1 collection date	Apr 28, 2016 Baby screening IEF 1 results FS
Baby Screening sample 1 collection time	11:30 am Baby's Screening Results Possible SCD
Baby Screening sample 1 shipment date	Apr 29, 2016
Name of person conducting tracking or follow-up:	
Was mother reached by phone? Yes: <input type="checkbox"/> No: <input type="checkbox"/>	Was father reached by phone? Yes: <input type="checkbox"/> No: <input type="checkbox"/>
1st 4 week expected visit date	Completed with 1st 4 wk visit Yes: <input type="checkbox"/> No: <input type="checkbox"/>
Home visit date	Home visit successful (baby found)? Yes: <input type="checkbox"/> No: <input type="checkbox"/>
Mother's workplace visit date	Mother's workplace visit successful? Yes: <input type="checkbox"/> No: <input type="checkbox"/>
Mother's place of worship visit date	Mother's workshop place visit successful? Yes: <input type="checkbox"/> No: <input type="checkbox"/>
Father's workplace visit date	Father's workplace visit successful? Yes: <input type="checkbox"/> No: <input type="checkbox"/>
Date baby was found	Tracking successful (baby found)? Yes: <input type="checkbox"/> No: <input type="checkbox"/>
1st clinic scheduled date	Followup results: Baby referred to clinic? Yes: <input type="checkbox"/> No: <input type="checkbox"/>
Did baby come to 1st clinic visit? Yes: <input type="checkbox"/> No: <input type="checkbox"/>	Reasons for Tracking/follow up failure:
1st SCD Clinic attended date	Family unknown at targeted house (baby not found) <input type="checkbox"/>
STATUS OF BABY AT END OF SCREENING /TRACKING	
<input type="checkbox"/> Enrolled in clinic	<input type="checkbox"/> Still under follow-up
<input type="checkbox"/> Contacted but not enrolled	<input type="checkbox"/> Never found
<input type="checkbox"/> Lost to follow-up	<input type="checkbox"/> Expired before enrolled
<input type="checkbox"/> Expired after enrolled	
	Wrong house information (baby not found) <input type="checkbox"/>
	Family moved or travelled (baby not found) <input type="checkbox"/>
	Father's workplace wrong (father not found) <input type="checkbox"/>
	Mother's workplace wrong (mother not found) <input type="checkbox"/>
	Mother's workshop place wrong (mother not found) <input type="checkbox"/>

National Newborn Screening Program -SCD Database:



Management of Newborn Screening Data in Ghana



Collecting data on
mobile phone App

CommCare for Newborn Screening



Sickle Cell Foundation
of Ghana



Made possible by



Management of Newborn Screening Data in Ghana

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



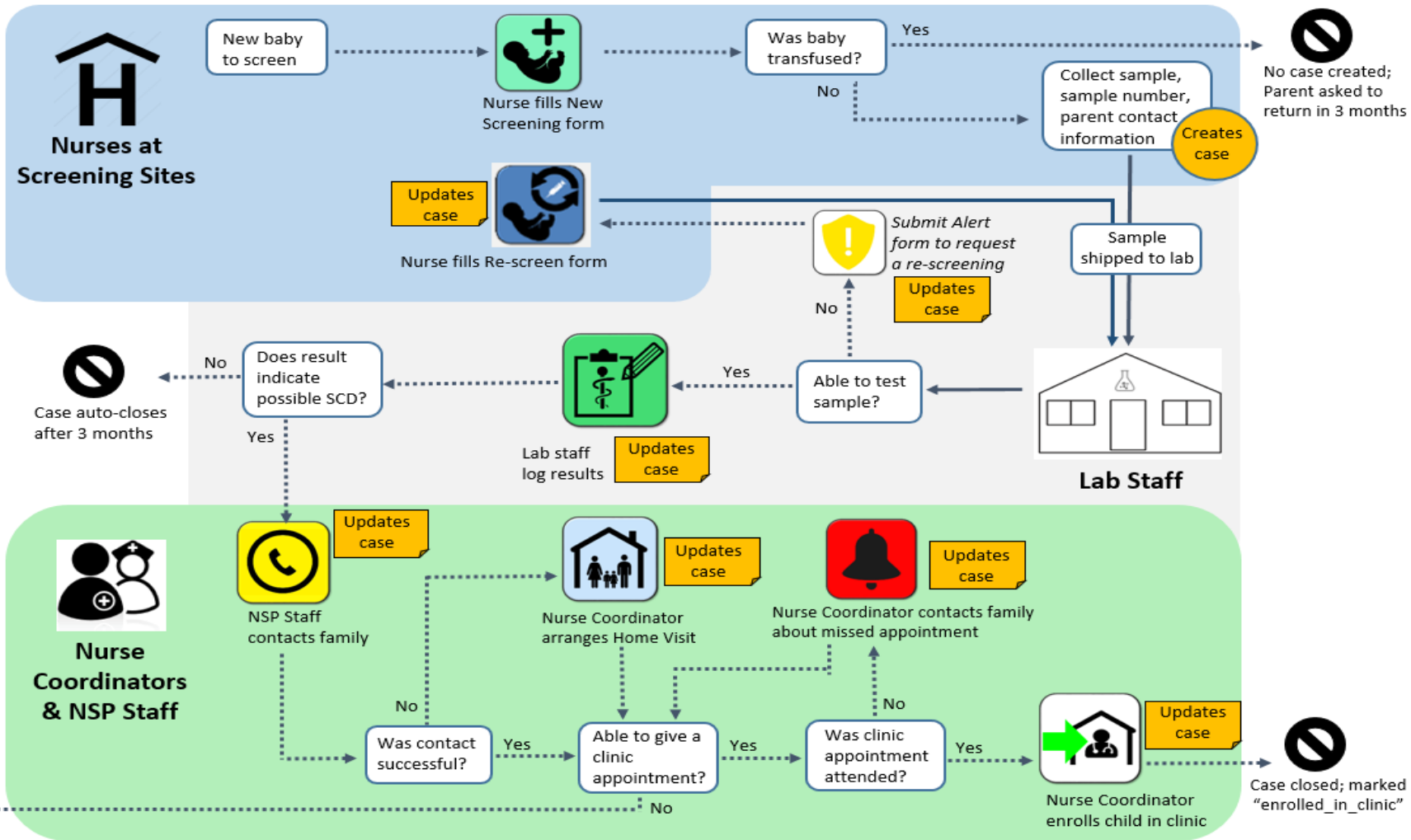
Management of Newborn Screening Data in Ghana

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



Full Workflow Diagram



Management of Newborn Screening Data in Ghana

Ghana Newborn Screening App: 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



Workflow / Role of each of the 4 user types



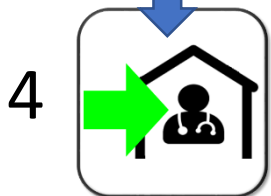
Nurses at Screening Sites (public hospitals)
Register new children and sample numbers



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 up



Management of Newborn Screening Data in Ghana

A Demonstration of the Ghana Newborn Screening Mobile Application



Management of Newborn Screening Data in Ghana

Web-Based interface of the Ghana Newborn Screening App

The screenshot shows a web browser window with the URL `commcarehq.org`. The page title is "Welcome Back to CommCare HQ". The dashboard is organized into two rows of four panels each. The top row contains: "Applications" (listing "Newborn Screening Ghana" and "Village Health"), "Reports" (listing "Augustine Asubonteng", "Monthly Reports", "Pilot Report", and "PSCD for 6 Screening Sites"), "Data" (listing "Alerts", "baby (created 2018-12-21)", "Baby export - all case properties", "Baby export - for import", and "Baby IEF"), and "Users" (with a user icon). The bottom row contains: "Messaging" (with a speech bubble icon), "Exchange" (with a circular arrow icon), "Settings" (with a gear icon), and "Help Site" (with a question mark icon).

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](#).



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.



Management of Newborn Screening Data in Ghana

Thank
You





ARISE

African Research And Innovative
Initiative For Sickle Cell Education

This presentation reflects only the author(s)'s view and the EU Research Executive Agency (REA) is not responsible for any use that may be made of the information it contains.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No. 824021

