

Supplemental Materials

I.	Background questions	Page 2
II.	Interview guide: Phase one	Pages 3-6
III.	Topics for phase two interviews	Page 7
IV.	Interview guide: Phase two	Pages 8-10

I. Background questions

Questions sent by email ahead of interview and discussed at the start of each interview

- a. In what city or geographic region was/is the program?
- b. What is the approximate population size of the catchment area(s) covered?
- c. About how long was the program planning process before screening started?
- d. When did screening start?
- e. Did the program end or is it ongoing?
- f. If it ended, how long did it run for?
- g. How babies were, or have been, screened in total?
- h. How many birth centers were/are involved in the program?

II. Interview guide: Phase one

INTRODUCTION

Thank you for speaking with me today. My name is [name here]. As I mentioned in our email exchange, we are doing a study to inform success of newborn screening programs in Africa by assessing enablers and barriers to these programs by learning from the experiences of programs that had been established in the past and programs that are ongoing.

Over the next few months we aim to speak with representatives from various programs. Our plan is to distill the learnings into a format that can be used practically by various stakeholders including health workers, policy makers, NGOs, and others. We anticipate a publication, which we would invite you to review and take part in.

Note that this project received Institutional Review Board (IRB) exemption from the Boston Children's Hospital. We won't be asking for any patient information.

Today, I'd like to learn about your experience with the SCD newborn screening program in [country]. By agreeing to this interview, it is understood that you are in a position to comment on the newborn screening program that took place there and have the necessary authorization to speak on behalf of the program.

Would it be ok for me to audio-record the interview? That will help be sure we don't miss anything when we do the analyses. In the write-up, we won't attribute any specific statements to you unless we get your permission for that.

Any questions or comments?

Thank you so much again. Ok—let's get started with the interview, which will take about 45 minutes.

INTERVIEW

1. Email survey questions

If any email survey questions not answered or need clarification—ask those first. If all have been answered, then move on to next section.

2. Partners

- Who were all the partners involved in the program?
[Govt, MOH, University, teaching hospital, NGO, professional societies, consultants, other]
[Categorize: local partner vs international partner]
- Which partner or partners would you say had the biggest role in planning the program? Can you describe their role?
- Which partner or partners would you say had the biggest role in running the program? Can you describe their role?

- What were the main roles of the other partners?
[Ask specifically about role of government/MOH]
- What was it like to get buy-in from the other partners? What was your approach? Could you tell me more?

3. Planning

- How did the idea for the program come about in the first place?
- What helped the program most in the planning phase?
- What was the biggest challenge you faced in the planning phase?
- Was it envisioned at the start as a “pilot” program with a defined endpoint? Could you tell me more about that?

4. Launch

- Was there some sort of launch event when screening started?
- If so, was that important? What did the launch event consist of? Could you tell me more about that?

5. Logistics

- Who managed the day-to-day operation of the program?
[Profile of managers (nurse, doctor, etc), team composition (how many), full-time/part-time]
- Was there a “headquarters” for the newborn screening program? If so, where was it located?
- Could you describe the birth centers where newborn screening took place?
[Clinics, hospital, urban, rural]
- Were babies screened before leaving facility, or did they return for screening at a later date? How do you think this affected the success of the program?
- Who did most of the heelsticks? About how many participated in the program?
[Want to learn how many nurses and/or other health workers were trained/participated in the program in the various birth centers where screening took place]
- Was there a consent process for families before obtaining heelstick? If so, could you please describe it?
- Could you briefly describe the sample collection and transport process from the point of heelstick to the screening laboratory? Were there any major problems in handling the samples?

- *How did patient information get to the screening lab? How did results get back to patients? Did you use a specific computer program to manage information—if so, which one? Were there any major problems in collecting or managing data/information?*
- *What in your opinion were the most important factors that led to success in day-to-day operation of the program?*
- *What were the biggest challenges in day-to-day operation of the program?*
- *Were modifications to the way the program ran made over time?*

6. Laboratory

- *Was a SCD screening lab newly set up in conjunction with the screening program, or was an already established SCD screening lab used? Was the lab located in the same facility where screening occurred? How did that affect success?*
- *Who worked in the laboratory to analyze the samples?
[Profile of staff (techs, etc), team composition (how many), full-time/part-time]*
- *Did the lab have equipment problems? Staffing problems? Could you tell me more? [How did this affect how the lab ran?]*
- *What method was used to conduct the screening test?
[For example, isoelectric focusing]*
- *Do you happen to know what specific equipment was used in the lab?
[E.g., brand name of isoelectric focusing machine]*
- *What was the most important factor in the successful running of the lab?*
- *What was the biggest barrier to running the lab?*

7. Notification and follow-up

- *If a baby screened positive, how were the parents notified? Who did that communication? What messages were delivered?*
- *What was the process for babies that screened positive—for example, did they get enrolled in a clinical management program? Could you tell me more about that? [Seeking details of the sickle cell management program, if there was one]*

8. Funding

- *How was the program funded? Were the costs shared by different parties?*
- *What were/are the parts of the program that are most expensive?*
- *Would you be comfortable sharing the approximate cost of the program?
[Start-up costs, annual running costs]*

- How did costs affect the program? [*were activities, services, scale, sustainability etc. affected for financial reasons?*]

9. Program disposition

- **If the program has ended**—did it end when planned, go for longer than planned, or end prematurely? What do you think were the main reasons for this?
- **If the program is ongoing**—has it remained stable size, grown, or diminished in size? What do you think have been the main reasons for this?

10. Perceptions

- How did you and the other leaders of this program define [and measure] success?
- Could you comment on how families viewed the program? Could you tell me more about that? [*if viewed negatively, how did the program deal with that?*]
- What was your own biggest learning in doing this program?

11. Closing

- Are there any reports or publications about the program that could be shared with me?
- Is there anything else that you think I should know that we didn't talk about?
- Based on the interviews, we'll be writing a report summarizing the findings and we would like to acknowledge your contribution. Is that ok? We will share the report with you when it's ready and it would be great to get your feedback.
- In addition to you, we have also spoken with Dr. [name] from [country], Dr [name] from [country], etc. Are you aware of other newborn screening programs in Africa and contacts that we haven't yet connected with?

Thank you very much for speaking with me.

Bye!

III. Main topic categories for phase two interviews

For each, discussing how it impacted success, challenges, enablers, and other lessons learned.

- Cultural issues (among providers and community)
- Sustainability
- Balance of involvement between external and local partners
- Notification and follow up

IV. Interview guide: Phase two

INTRODUCTION

Thank you for speaking with me today. My name is Natalie. As I mentioned in our email exchange, we are doing a study to inform success of NBS programs in Africa by assessing enablers and barriers to these programs by learning from the experiences of programs that had been established in the past and programs that are ongoing.

Over the next few months we aim to speak with representatives from various programs. Our plan is to distill the learnings into a format that can be used practically by various stakeholders including health workers, policy makers, NGOs, and others. We anticipate a publication, which we would invite you to review.

Note that this project received Institutional Review Board (IRB) exemption from the Boston Children's Hospital. We won't be asking for any patient information.

Today, I'd like to learn about your experience with the SCD newborn screening program in [country]. By agreeing to this interview, it is understood that you are in a position to comment on the NBS program that took place there and have the necessary authorisation to speak on behalf of the program.

Would it be ok for me to audio-record the interview? That will help be sure we don't miss anything when we do the analyses. In the write-up, we won't attribute any specific statements to you unless we get your permission for that.

Any questions or comments?

Thank you so much again. Ok—let's get started with the interview, which will take about 45 minutes.

INTERVIEW

1. Email survey questions

If any email survey questions not answered or need clarification—ask those first. If all have been answered, then move on to next section.

2. Partners

Who were the partners involved in the program?

- What was the role of local leaders and champions in the program?
- What was the role of external partners?
- What was the role of the government?
- How did they affect the success of the program?
- What lessons learned or recommendations do you have about working with partners?

3. Logistics

- Can you please walk me through the entire screening process for one baby starting with how the baby is identified through how the parents are notified?
 - Probes: data management systems, equipment and supplies needed, getting results back to patients
- What in your opinion were the most important factors that led to success in day-to-day operation of the program?
- What were the biggest challenges in day-to-day operation of the program?
- What lessons learned or recommendations do you have about running the day to day operations of the program?
- Probe: challenges and facilitators for running the lab, recommendations

4. Program disposition

- **If the program has ended**—did it end when planned, go for longer than planned, or end prematurely? What do you think were the main reasons for this?
 - What would be needed in order to have a sustainable program?
- **If the program is ongoing**—has it remained stable size, grown, or diminished in size? What do you think have been the main reasons for this?
- Who pays for it?
- What recommendations do you have for other programs in the planning and implementation phase that can set them up to be sustainable?

5. Perceptions

- Could you comment on how families and the community viewed the program? Could you tell me more about that? [*if viewed negatively, how did the program deal with that?*]
 - Probes: stigma, need for education
- How did this impact the success of the program?
- What was your own biggest learning from the program?

6. Closing

- Are there any reports or publications about the program that could be shared with me?
- Is there anything else that you think I should know that we didn't talk about?
- Based on the interviews, we'll be writing a report summarizing the findings and we would like to acknowledge your contribution. Is that ok? We will share the report with you when it's ready and it would be great to get your feedback.

Thank you very much for speaking with me.

Bye!