

# Improving Communication between Doctors and Parents after Newborn Screening

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## ABSTRACT

**Background:** Newborn screening (NBS) enables early treatment, and some consider it a natural vehicle for genetic screening. Bioethicists argue for caution since families of infants with carrier status can develop psychosocial complications. This paper describes the methods and feasibility of Wisconsin's statewide project for quality improvement of communication and psychosocial outcomes after NBS.

**Methods:** When NBS identifies carrier status for cystic fibrosis or sickle cell, we contact primary care providers (PCPs), answer questions, and invite them to rehearse informing the parents. Three months later, we telephone the parents, assess knowledge and psychosocial outcomes, provide counseling, and assist with self-referral to further resources. Afterward, evaluation surveys are provided to the parents, to be returned anonymously.

**Results:** Birthing facilities provided accurate PCP names for 73% of 817 infants meeting inclusion criteria; we identified PCPs for 21% more. We reached 47.3% of PCPs in time to invite a rehearsal; 60% of these accepted. We successfully called 50.2% of eligible parents; 61% recalled a PCP explanation, and 48.5% evaluated the explanation favorably. Evaluations by parents with limited health literacy were less favorable.

**Conclusion:** It is feasible to follow parents for psychosocial outcomes after NBS. Preliminary data about communication is mixed, but further data will describe psychosocial outcomes and investigate outcomes' associations with communication.

## INTRODUCTION

This paper describes the methods, feasibility, and early experience of a statewide, multifaceted quality improvement project designed to assess and improve the quality of provider-parent communication after newborn screening (NBS) identifies het-

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erozygous ("carrier") status for cystic fibrosis (CF) or sickle cell hemoglobinopathy (SCH).

NBS is a population-scale public health program in which newborn infants' blood specimens are applied to a special filter paper, dried, and tested at a centralized laboratory for a panel of genetic and metabolic diseases.<sup>1</sup> CF and SCH are included on NBS panels because the diseases' risk of death and disability can be reduced if the disease is identified before becoming symptomatic.<sup>2-4</sup>

CF is a metabolic disease in which abnormal secretions lead to lung disease, nutritional problems, and dangerous losses of salt in sweat.<sup>2</sup> SCH is a blood disorder in which a hemoglobin mutation (S) is associated with painful crises, life-threatening infections, and vasculopathy, leading to problems like stroke.<sup>3</sup>

Both CF and SCH are autosomal recessive conditions, and carrier infants are identified in far greater numbers than infants with the actual diseases. Infants with carrier status for CF and SCH do not develop the actual disease, but their children may develop the disease if the other parent is also a carrier. Unfortunately, many families of carrier infants develop psychosocial complications after NBS, ranging from clinical levels of parental anxiety and depression to impaired parent-child bonding and the vulnerable child syndrome.<sup>5-10</sup> NBS programs have developed materials for education and support of families, but first conversations can be critical, and the quality of primary care providers' (PCPs) communication about NBS has been criticized by parents and NBS officials.<sup>11,12</sup> Psychosocial problems after carrier identification are cited by bioethicists and others as grounds for delaying or discontinuing some NBS activities.<sup>7-9,13,14</sup> To ensure the continuation of successful NBS programs and reduce harm from psychosocial complications, we developed the Wisconsin

Project on Improvement of Communication Process and Outcomes after Newborn Screening (the Project). We adapted our methods from quality improvement techniques used for medical record review, simplified telephone follow-up, and patient tracking, so that the Project would be affordable and sustainable after research funding ended and replicable by other NBS programs without major budget increases. Eventually, it is hoped that these types of methods may be useful for other genetic conditions, as well as for false-positive results of metabolic screening tests.

The purpose of this paper is to describe the initial workings of the Project, ranging from feasibility of identifying NBS results and PCPs, to preliminary findings from evaluation surveys.

## METHODS

At its core, the Project is designed to be a quality improvement effort by the NBS program of the Wisconsin State Laboratory of Hygiene and the Department of Health Services, with the Medical College of Wisconsin as a contracted agent. Methods and materials are approved by Institutional Review Boards at the Medical College of Wisconsin and University of Wisconsin–Madison.

### Setting

When NBS identifies either CF or SCH, the NBS laboratory communicates by telephone with the infant's PCP and subspecialists to facilitate identification, treatment, and follow-up. The NBS laboratory obtains PCP contact information from the birthing facility's specimen collection card. Anecdotal experience shows that the clinician listed on the NBS card occasionally is incorrect, and the baby's full name may not be listed (eg, "Baby Boy Smith"). When the clinician's name is not the PCP, the listed clinician often is expected to forward the results to the actual PCP or to take temporary responsibility for the infant. When the baby's full name is incorrect, the clinician or the NBS laboratory must backtrack to the birthing facility to connect the result with the correct infant and PCP.

Usual practice is somewhat different when NBS identifies heterozygous carrier status for CF and SCH, which occurs in far greater numbers than results indicating true CF or SCH. SCH carrier results (defined by the presence of fetal, adult, and sickle hemoglobin, or "FAS") are mailed to the PCP because these results are not medically urgent. Note that NBS also identifies carriers for other hemoglobinopathies (eg, Hemoglobin C, D, and E), but the Project is limited to hemoglobin S to focus its analyses on the most common condition.

CF carrier status in NBS is defined by a blood spot showing an elevated immunoreactive trypsinogen and a single CF-associated mutation, followed by a normal sweat chloride

test. The most common CF-associated mutation is  $\Delta F508$  but there are many others.<sup>2</sup> The sweat test is done because up to 2% to 5% of infants with a single mutation have an unmeasured second mutation that results in actual CF.<sup>2</sup> It has been recommended to have the sweat test before 8 weeks of age to have the benefit of early identification,<sup>4</sup> so the NBS laboratory faxes results to PCPs and tracks whether sweat tests have been done. The Project uses the term "likely CF carrier" for infants who had an elevated immunoreactive trypsinogen and a single CF-associated mutation, but who have not yet had a sweat chloride test.

### Project Design

The Project expands the standard NBS methods for telephone follow-up to serve the typical number of about 900 infants born each year in Wisconsin with SCH carrier status or likely CF carrier status (Figure 1). An initial telephone call is conducted with the infant's PCP immediately after the abnormal NBS result is found. A second call is conducted with the infant's parents when the infant is between 3 and 5 months old, allowing sufficient time for infants to have at least 1 well-child visit during which the NBS result could be discussed. Scripts for telephone calls are similar to those that might be used for purely clinical follow-up, but have some additional research questions embedded in them. After telephone calls to the PCP and parent, an anonymous evaluation survey is distributed. The survey's questions are described in the Results section.

### Participants

The main participants in the Project are the infants' parents, although data also are collected about the infants and their PCPs.

To reduce confounding effects of other factors that might cause potential anxiety or correlate with other psychosocial issues, we exclude infants when the NBS report (1) lists more than 1 abnormality, (2) states that the gestational age was <35 weeks, or (3) states that the calendar age at the time of specimen collection was >180 days of age. We also exclude infants if we discover the infant required either (1) >5 days in a neonatal intensive care unit, (2) hospitalization after discharge from the nursery, or (3) evaluation for some other medical abnormality. During the PCP call, we ask the PCP to identify parents who do not speak English and other contraindications to contacting the family by asking, "Can you think of any reason why it would not be appropriate to contact this family later this year?"

Prior to the parent call, a second exclusion criterion is implemented when we use NBS laboratory tracking data to exclude parents of infants who had non-normal sweat test

results (ie, results indicating the presence of CF).

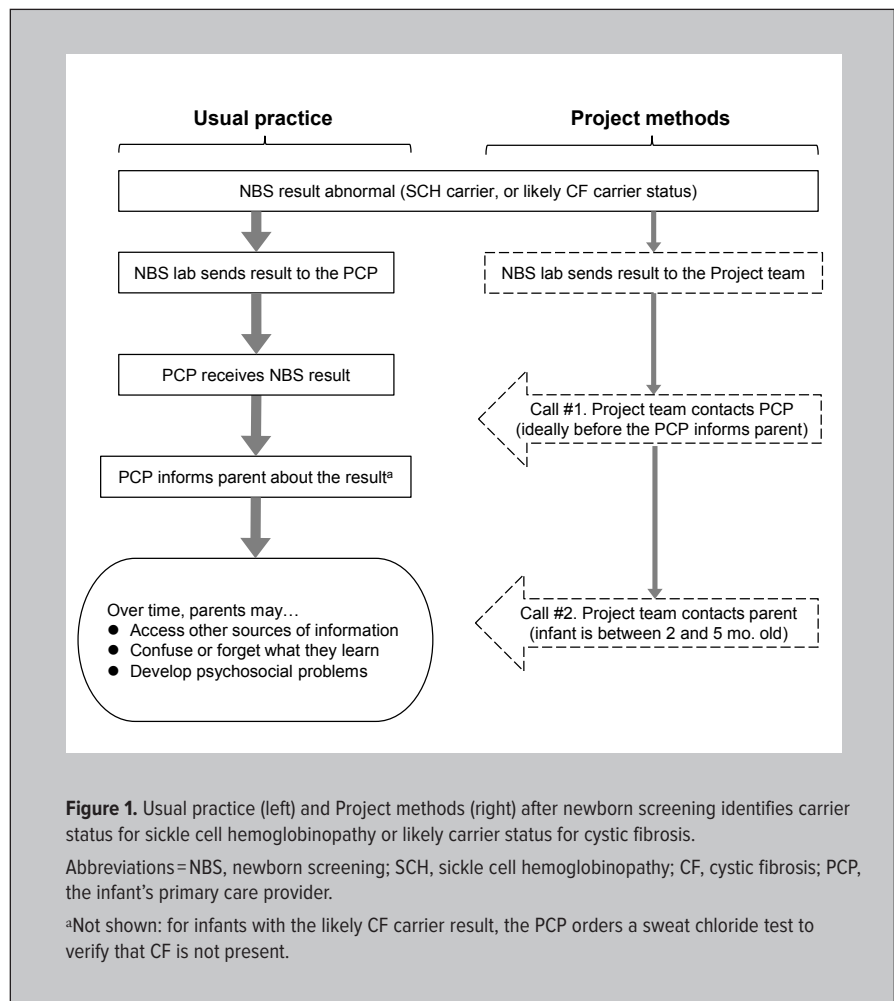
Parents are offered a \$20 gift certificate to more than 200 local or Internet merchants as a gratuity for their participation.

**Procedures**

*Protocol for locating PCPs.* The Project’s first goal is to ensure that the NBS laboratory report has reached the provider who has actual primary care responsibility for the infant. We begin by sending an introductory fax and a copy of the NBS result to the clinician listed by the birthing facility, using information from a directory maintained by the NBS laboratory. A Project caller then telephones the clinician’s office and asks if the clinician is the infant’s PCP. If the clinician does not know the infant or denies a PCP relationship, the Project caller attempts to find the PCP by asking the clinician for advice, and then by contacting the birthing facility or its medical record department. If these methods are not successful in finding the PCP, in a few days the Project team contacts the listed clinician again to see if the infant’s parents have made an appointment. IRB stipulations disallow the Project team from contacting families directly.

When the Project caller reaches the PCP, he or she asks if the PCP has questions about the NBS result or its implications, and describes the Project goals and the parent call. If time allows, the Project caller invites the PCP to rehearse how he or she will inform the infant’s parent(s) about the result. Project callers exercise judgment in deferring the rehearsal invitation if the PCP is hurried due to being contacted between patients. When the PCP does agree to rehearse, that portion of the call is audiotaped, transcribed, and de-identified for future analysis.

*Protocol for locating parents.* If neither the NBS laboratory report nor the PCP identify a reason for exclusion, the parents are mailed an initial contact letter when the infant is about 3 months old. The letter purposely does not mention the infant’s NBS result, in order to avoid confusion or distress for parents who have not heard their child’s results or may not fully understand the implications of the results. Also included is a “decline of contact” card to give the parents an opportunity to decline participation without becoming fully informed about the Project.



**Figure 1.** Usual practice (left) and Project methods (right) after newborn screening identifies carrier status for sickle cell hemoglobinopathy or likely carrier status for cystic fibrosis.

Abbreviations=NBS, newborn screening; SCH, sickle cell hemoglobinopathy; CF, cystic fibrosis; PCP, the infant’s primary care provider.

<sup>a</sup>Not shown: for infants with the likely CF carrier result, the PCP orders a sweat chloride test to verify that CF is not present.

Approximately 10 days after the initial contact letter is mailed, a Project caller telephones the parents. Parents are asked if they recall the letter and if they are willing to complete the call. They are given the opportunity to discontinue the phone call if it is an inconvenient time or if they simply are not interested. The Project caller follows a carefully designed script that weaves together components of informed consent, discussion about the screening result, open-ended survey questions, and fixed answer questions from established scales to assess psychosocial outcomes such as parental anxiety and perceptions of the child’s health.<sup>15-18</sup>

Project callers have a clinical background, so they have the expertise to perceive emotional distress or confusion over the phone. If serious distress or confusion becomes evident, the Project caller has the option of bypassing the research questions, transitioning to a purely clinical intervention. Regardless of whether a parent completes the entire call, the conversation ends with a debriefing effort to ensure there is no lingering confusion, and to provide assistance with self-referral to additional resources.

## Analysis

Both the PCP and parent calls are audio-recorded, transcribed, de-identified, and abstracted for quantitative data. Descriptive data, including the majority of data for this paper, are stored in a Microsoft Access database (Redmond, Washington) and analyzed using JMP software (SAS Institute, Cary, North Carolina). A separate series of papers will report analysis of psychosocial data from the parent calls and communication data from the PCP calls following our communication quality indicator approach. The communication quality indicators follow our previously published techniques for jargon usage,<sup>19,20</sup> assessments of understanding,<sup>21</sup> organizing behaviors,<sup>22</sup> communication about potential emotions,<sup>23</sup> and inclusion of key content messages.<sup>24,25</sup>

## RESULTS

During the Project's first 14 months, the Project team received 929 NBS results from the NBS laboratory; 709 showed SCH carrier status and 220 showed likely CF carrier status. In 141 of the 220 likely CF carrier results, the  $\Delta F508$  mutation was seen (64.1%), while the other 79 infants had 1 of 18 other mutations from the 23 included on Wisconsin's screening panel. Gender was evenly distributed (49.1% male).

Information included on the NBS laboratory report, gestation age and the presence of multiple conditions, was sufficient to exclude 112 infants (12.1%) without the need for a PCP call. The remaining 817 infants who constitute the main sample for this analysis were submitted by 70 different birthing facilities and 4 home births. The median number of results listed for a facility was 36 (SD 26.1). The facilities listed a total of 414 clinicians for their infants. The highest number of infants logged for a single PCP was 13.

### Information about PCPs

*Accuracy of PCP listing provided by the birthing facility.* For 58.8% of infants, the birthing facility listed the accurate PCP, and the NBS laboratory had accurate contact information (Figure 2). For 14.2% of infants, the birthing facility had listed a clinical partner of the correct PCP, so the NBS laboratory's contact information was accurate even if the responsible PCP had not been listed. For the other 27% of infants, the information provided by the birthing facility was not sufficient for the NBS result to automatically reach the PCP. For 20.9% of the 817 infants, we found the PCP by following the protocol described in the Methods section. For 7.3% of the 817 infants, the birthing facility had provided the correct PCPs name, but the PCP had changed locations recently enough that the NBS report was faxed or mailed to an old address. PCPs of infants with likely CF carrier results were more likely to have moved than PCPs of infants with SCH carrier status ( $\chi^2$ ,  $P=0.03$ ).

We were unable to identify a PCP for 50 infants with SCH carrier reports (6.1% of 817). In summary, using our contact procedures, we were able to identify PCPs for 767 infants, or 93.9% of the 817 infants without exclusion criteria.

*PCPs' description of results communication.* Of the 767 infants for whom we identified and reached a PCP during the Project's first 14 months, in 41 cases (5.4%) the PCP reported that he or she had not received the NBS result fax. For the other 672 infants, 130 PCPs reported already informing the parent in person (19.4%), 134 had already told the parent via telephone or planned to do so that day (19.9%), 377 planned to tell the parent at the next scheduled appointment (56.1%), 3 planned to send a letter or an e-mail to the parent(s), and 16 PCPs had not decided how to inform the parent. Only 3 PCPs planned to schedule a special appointment to discuss the NBS result.

PCPs were more likely to wait until the next appointment if the infant had an SCH carrier result than a likely CF carrier result (73% vs 43%,  $\chi^2$ ,  $P<0.001$ ).

When we asked PCPs if they had questions about the NBS result or its implications, PCPs for 33 infants (4.9% of the 672) asked for an explanation. PCPs were more likely to request an explanation about likely CF carrier results than SCH carrier results (13.3% vs 3.0%,  $\chi^2$ ,  $P<0.001$ ).

Many PCPs were willing to rehearse telling the infant's parent(s). Of the 414 individual PCPs identified, we invited rehearsals from 196 PCPs (47.3%) who had not yet informed the parent(s). Of these, 118 agreed to rehearse (60.2%). Another 42 PCPs (21.4%) indicated willingness to rehearse for another infant but deferred rehearsal for the current infant because of time limitations. There were no significant differences by PCP gender or clinical specialty with regard to availability for invitation or agreement to rehearse.

The PCPs who rehearsed supplied some demographic information. The average number of years since graduation from training was 16.7 (SD 10.4 years), with a maximum of 44 years. The average number of months since the PCP last discussed genetic carrier status with a patient was 12.8 (SD 24.7 months).

*Project Acceptability by PCPs.* By the end of the 14-month period analyzed for this paper, we received 79 anonymous evaluations from PCPs who rehearsed with us. We asked, "Was the information you obtained during the telephone call useful?" and gave them 3 options: "very useful" (27/79 respondents), "somewhat useful" (44/79 respondents), and "not at all useful" (8/74 respondents). We asked: "Was the amount of time spent on the interview appropriate?" and gave them 3 options: "just right" (71/79 respondents), "too long," (6/79 respondents), and "too short," (0/79 respondents). Two left the response choices blank. As shown in Table 1, slightly

more than half of the PCPs reported that being notified about the NBS result or having the opportunity to rehearse had influenced their interaction with parents.

### Parent Information

Of the 767 infants for whom we identified and reached a PCP, we were told of contraindications to us contacting the parents for a follow-up call in 54 cases (7%), including 29 infants whose families did not speak English. Seventeen were excluded due to non-normal sweat test before the parent call.

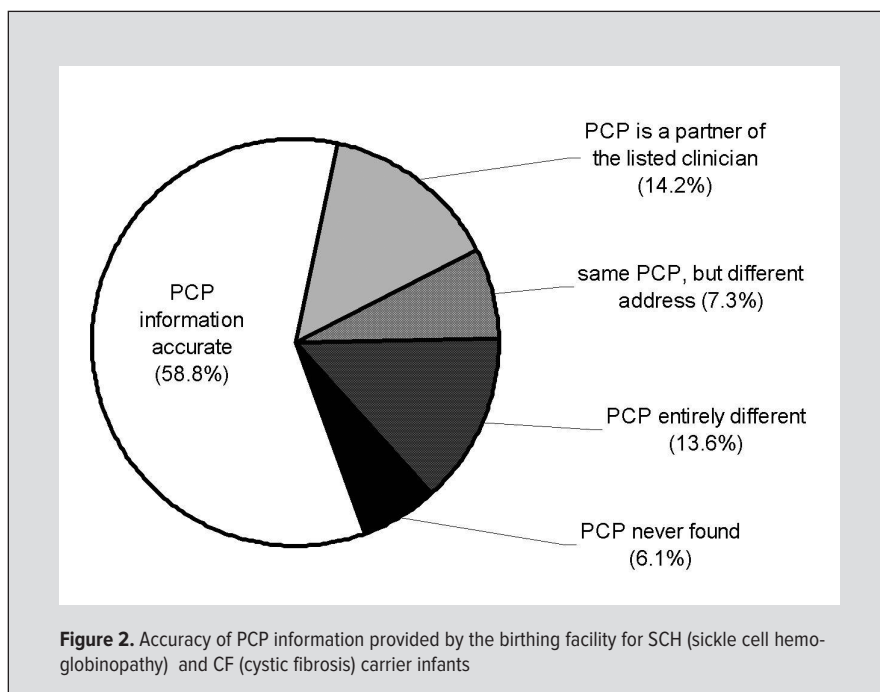
The outcomes of our attempts to reach the remaining 696 infants with SCH carrier results and likely CF carrier results are listed in Table 2. Overall, we were able to complete a call for 297 parents, or 50.4% of eligible parents. The infants' average age at the time of the call was 107.5 days old.

Most of the called parents were mothers, but 8 fathers (2.7%) were called. The average age of parents called was 26.7 years (SD 6.6). The youngest person we called was a 14-year-old mother; the oldest was a 46-year-old mother. We asked most parents their ethnic background in an open-ended question; 54% reported African American, 37% Caucasian, 4% Latino, and 5% reported a combination, such as African American and Latino.

Results of the 3-item health literacy screener identified 25 parents with the potential for a significant limitation in health literacy (9%). Another 83 parents (29.9%) answered the screening questions with intermediate-range answers consistent with occasional health literacy problems.

*Parents' description of communication with the PCPs.* The parents of 38.5% of the SCH carrier infants did not recall an explanation from the PCP. All of the parents of likely CF carrier infants recalled an explanation except for one, despite that infant having gone through the sweat testing process, which includes meeting with a genetic counselor, prior to our phone call.

When asked how well the PCP had explained the result, 48.5% of parents responded "well" or "very well." Responses were similar to a question about general satisfaction with the NBS experience. Parents were more likely to be satisfied if they remembered an explanation or if they evaluated the PCP's explanation favorably ( $\chi^2, P < 0.01$ ). There was no apparent difference in satisfaction of parents of likely CF carrier infants versus SCH carrier infants, but parents were more likely to



evaluate PCP explanations unfavorably if their health literacy was marginal or inadequate ( $\chi^2, P = 0.04$ ).

*Acceptability of the Project for the parents.* By the end of the 14-month period, we received 70 anonymous parent evaluations. When asked: "Was the information you obtained during the telephone call useful?", 50 replied "very useful" (71.4%) and 17 replied "somewhat useful" (24.3%). Three respondents said the information was "not at all useful" (4.3%). When asked: "Was the amount of time spent on the interview appropriate?", 63 said that the time was "just right" (90%), and 7 said it was "too long" (10%). No one responded that the call was "too short."

### Time and Labor Involved

One of our main research questions at this point was the amount of time and labor needed to do follow-up on communication processes and psychosocial outcomes in a typical sample of nearly 900 families per year.

To facilitate planning for similar programs in the future, we tracked time and expenses for clinical and research aspects of the Project. Not counting IRB-required activities necessary for research, we estimate that telephone calls to PCPs and related administrative needs occupied half of each weekday for 1 staff person, or about 20 hours per week. Parent calls take longer, requiring almost 40 hours per week of staff time for calls and documentation. Because of the research and IRB needs for the Project, the call workload was spread out over several members of our lab's team, including a genetic counselor, 3 nurses, a coordinator, and the project director (a pediatrician).

**Table 1.** PCPs' Opinions about the Influence of Being Called by the Project Team

Opinion	"Yes"	"Somewhat"	"No"
	n (%)	n (%)	n (%)
"Being notified about the result influenced my interaction with..."			
... this parent."	14 (17.9)	29 (37.2)	35 (44.9)
... all parents."	12 (15.6)	30 (39)	35 (45.5)
"The rehearsal session influenced my interaction with..."			
... this parent."	13 (17.6)	23 (31.1)	38 (51.4)
... all parents."	11 (15.1)	27 (37)	35 (47.9)

**Table 2.** Recruiting Experience with Parents

Outcome of parent recruiting effort	Parents of infants with NBS results showing...	
	SCH carrier status	Likely CF carrier status
	n (% for result)	n (% for result)
Unable to find reliable contact information	102 (19.0%)	5 (3.1%)
No response to voicemails	183 (34.1%)	46 (28.8%)
Parent reached by telephone but declined	45 (8.4%)	18 (11.3%)
Parent called	206 (37.4%)	91 (56.9%)
Total number of eligible infants	536	160

## DISCUSSION

Decades of experience have shown that NBS effectively can identify diseases before they become symptomatic, but also that NBS can be followed by serious psychosocial complications.<sup>5-10</sup> These complications and other communication problems are found across entire states, so we have developed a population-scale, quality improvement approach to addressing them.

We were pleased at the generally favorable reactions to our calls by PCPs and parents. Some of the busiest PCPs were annoyed to be telephoned directly, but our evaluation data and PCP calls indicated that most PCPs either were grateful or neutral. To improve acceptability for PCPs with large numbers of infants, we developed a protocol for relaying communications through office staff or fax machines. We were impressed by the number of PCPs who were willing to rehearse with us. We hope eventually expand to our service to parents who require English-language translation.

Our most troubling experience has been difficulty locating physicians willing to assume clinical responsibility for some carrier infants. This difficulty stands in sharp contrast to the urgency with which subspecialists and PCPs take action when presented with NBS reports for a life-threatening illness. For NBS to result in more good than harm, some of that urgency needs to be extended to parents of carrier infants. A casual attitude to carrier results may be partially to blame for the psychosocial complications seen in many previous studies.

## Limitations

The Project methods are elaborate in order to integrate into usual-practice NBS, but some limitations are inevitable. Some selection bias may be present despite our response rate and status as a quality improvement project. Due to IRB restrictions and NBS legislative rules about contacting parents directly, we have little or no reliable data about many of the parents who were not reachable via the 2 protocols described earlier. In addition, the use of survey methods may be associated with the social desirability and Hawthorne effects, a change in participant behavior due to a sense of observation. Further study may be needed to know whether it is reasonable to generalize our findings about infants with carrier status for CF and SCH to other types of carrier states and to false positive NBS results.

## CONCLUSION

To ensure that NBS and associated interventions consistently lead to more good than harm, clinicians need to assume responsibility and provide high-quality care for carrier and disease-affected infants. Future reports will comment on the psychosocial data we have gathered which indicates that parents do experience real psychosocial effects of poor communication about NBS results. The role of communication quality assurance and centralized follow-up will be to support PCPs and parents as they deal with positive and false-alarm NBS results. We further hope that the Project and forthcoming papers will serve as models for other population-scale efforts to improve the quality of communication in many other areas of health care.

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