University of Cincinnati

Date: 4/18/2014

I, Sarah Ossler, hereby submit this original work as part of the requirements for the degree of Master of Science in Genetic Counseling.

It is entitled:
Attitudes and Beliefs toward Expanded Newborn Screening in Colombia

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Abstract

Introduction: Population based dried blood spot newborn screening (NBS) is designed to identify disorders before clinical symptoms develop, and allow intervention during a narrow window of therapeutic opportunity. Colombia began an optional expanded NBS pilot program at Fundación Cardiovascular de Colombia (FCV) in Bucaramanga, Colombia in January of 2013. The purpose of this study was to identify attitudes and beliefs about the expanded NBS. Differences in the attitudes and beliefs towards the expanded NBS between those who intended to receive NBS for their child and those who did not were expected.

Methods: Participants were pregnant women coming to FCV for an office visit with their obstetrician. The women were offered a survey that measured attitudes and beliefs towards the expanded NBS. The study was conducted from September 2013 to January 2014. Results: Overall, there was moderate interest in the expanded NBS but low awareness, where 53.8% of participants intended to receive the expanded NBS for their child and 80.0% of respondents indicated they had no previous awareness of the expanded NBS. Timing and education may influence parental decision-making and attitudes and beliefs towards screening. Participants who had suboptimal timing to receive the expanded NBS for their child (indicated that their due date was prior to survey administration) or were part of the lowest education group were less likely to express intent to receive the expanded NBS. Though not statistically different, trends were observed, where pregnancy timing and education level may influence the decision making process to receive expanded NBS. However, there was strong consensus overall that the expanded NBS provides benefits to newborns and the participants trusted the healthcare providers offering the expanded NBS. Conclusion: There is moderate interest in the expanded NBS, but low awareness. More education is warranted to increase awareness of the newly available expanded NBS in Colombia.
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**Introduction**

Population based newborn screening (NBS) is a public health measure designed to identify disorders before clinical symptoms develop and to allow intervention during a narrow window of therapeutic opportunity. (Thompson, Ahrens, LeRoy, Brown, & Berry, 2005; Trotter et al., 2011). In general the conditions tested for are rare, but if detected early, treatment can change the outcome for the child. In the United States more than 5,000 children are identified through NBS to have a serious disorder which can be treated (Fleischman, Lin, & Howse, 2009).

An example of a demonstrated benefit of early detection is the effective treatment plan for Phenylketonuria (PKU). PKU is a metabolic disorder that if untreated can cause severe cognitive impairment. Treatment includes immediate implementation of a special diet with modified phenylalanine intake. If a diet low in phenylalanine is followed, the cognitive impairments associated with untreated PKU can be avoided (Guthrie & Susi, 1963, 1982; Williams, Mamotte, & Burnett, 2008). The conditions included on the NBS can be detected later in life as well, but are included on the NBS due to the documented benefits of early detection and early onset of symptoms (Farrell et al., 2001; Lindner et al., 2011; Trotter et al., 2011; Williams et al., 2008). As this is a screen, abnormal values may identify patients who warrant further testing, but are usually not specific enough to confirm a final diagnosis. There is some risk for false positive results, which may increase the anxiety in the families of children who are not affected. The conditions tested for vary not only between countries but also within countries.
While there are clear public health benefits, many countries in the world have no NBS program, and many others are just in the beginning stages of implementing a NBS program (Borrajo, 2007; Padilla, Therrell, & Working Group of the Asia Pacific Society for Human Genetics on Consolidating Newborn Screening Efforts in the Asia Pacific, 2012). The absence of NBS may be due to the fact that a successful NBS program requires a coordinated system of testing, communication of results, and access to treatment. Further, economic factors may be a barrier to implementing a NBS program due to shortage of funds to provide screening universally as well as the ongoing costs of treatment (Borrajo, 2007).

Latin America is very diverse with respect to race, ethnicity, socioeconomic status, geography, birth rate, and other factors including NBS. In Latin America, the countries that currently have an established NBS program include Chile, Argentina, Brazil, Costa Rica, and Mexico. However, many other countries in Latin America do not have NBS. Implementation of NBS may be difficult in Latin American countries due to several factors, including other healthcare issues that compete for healthcare dollars. In Colombia, the only condition that is mandated by the government to be screened for is congenital hypothyroidism, through a decentralized NBS program funded by the health care system (Borrajo, 2007).

There are few studies that examine the benefits of education on the uptake of NBS. Dhondt et al conducted a study in France of the newly initiated Cystic Fibrosis screening in 2005 on the effects of informed consent on refusal rates for the screen. They concluded that the informed consent process decreased the number of refusals from 0.8% at the beginning of the study to 0.2% at the end of the first year of
implementation of informed consent (Dhondt, 2005). Michie et al conducted a study in the United Kingdom to determine if different educational interventions about prenatal screening for Down Syndrome had an effect on several different variables, including test uptake. There was no difference found in any of the variables measured between the groups that receive a simple leaflet regarding testing, a simple leaflet and a video, an expanded leaflet, or an expanded leaflet and a video (Michie, Smith, McClennan, & Marteau, 1997).

Prenatal education is a recommended component of most NBS programs in North America. Indeed, desire for prenatal education for NBS has been demonstrated in several retrospective studies that utilized surveys or focus groups to measure parents’ attitudes towards the NBS (Araia et al., 2012; Tu, He, Chen, Shi, & Li, 2012). However, true informed consent is rare. Parents have noted that they heard about the NBS when they were still in the hospital following birth or when the NBS blood specimen was being collected (Tluczek, Orland, Nick, & Brown, 2009). The busy postnatal recovery period is not an optimal time to discuss newborn screening with parents, given the number of care instructions for the mother prior to being discharged to return home with her newborn child (Araia et al., 2012). As a result of the timing of NBS education, parents in the United States and Canada report that they received little or no information about the test; still others do not even know that their child was ever tested (Araia et al., 2012). Education is not only helpful, but parents also expect to be given information about the NBS by a trusted healthcare provider (Araia et al., 2012).
Few studies have explored why parents accept or reject the NBS. Nicholls and Southern (2013a), conducted qualitative interviews with 18 parents who had given birth in the past two years and accepted NBS in the United Kingdom. They found that attitudes toward the healthcare system and previous experiences with NBS are two important factors that parents think about when deciding whether or not to receive the NBS for their child. A key motivator for parents to accept NBS for their child was the perceived benefits the child would receive due to the screening. Participants were also more likely to draw on past experiences and trust in healthcare providers established with prior children to help decide whether to accept or decline testing (Nicholls & Southern, 2013b).

As there are few studies that have examined the attitudes and beliefs toward NBS at the beginning stages of implementation of a NBS program, there is little guidance for countries seeking to establish a NBS program. Thus, the purpose of this study is to identify attitudes and beliefs about the expanded newborn screening program recently available in Colombia and to elicit reasons that study subjects gave for accepting or declining the screen. As Colombia only recently began their expanded NBS pilot program in January 2013, the results from this study could be valuable to understanding the barriers and facilitators of expanded NBS in Colombia. In addition, assessing the opinions, attitudes, and reasons for opting in or out of the NBS may provide unique insight into and help facilitate educational efforts and policies surrounding the implementation of NBS in regions where it is not currently being offered.
**Methods**

*Study Location*

The hospital named Fundación Cardiovascular de Colombia based in Bucaramanga, Colombia is the largest referral center for congenital heart disease in Colombia. The hospital has 200 beds for management of pediatric and adult patients with a wide range of medical problems. Within the Fundación Cardiovascular de Colombia is the Centro de Medicina Genómica y Metabolismo (Center of Genetic Medicine and Metabolism), which is a center for development of genetic and metabolic tests to improve early diagnosis of treatable conditions and the leading institution for newborn screening in Colombia. The center also takes care of about 1000 patients with rare diseases for medical management. Newborn screening for congenital hypothyroidism is already in place as part of a national effort in Colombia. Cord blood analysis was the mandated practice for national NBS for congenital hypothyroidism through the Colombian government.

*Expanded Newborn Screening Program*

The hospital recently implemented a pilot expanded NBS program in January of 2013. This expanded NBS pilot program included phenylketonuria, galactosemia, congenital adrenal hyperplasia, cystic fibrosis, hemoglobinopathies, biotinidase deficiency, and glucose 6 phosphate dehydrogenase deficiencies (Table 1). The pilot expanded NBS program utilized heel stick collected dried blood spots as opposed to cord blood analysis for their screening practices. The expanded NBS was offered at obstetricians’ offices within Fundación Cardiovascular de Colombia to women who had regular appointments when the expanded NBS pilot program began in January.
of 2013. Of note, the obstetricians were in a separate department than the Centro de Medicina Genómica y Metabolismo.

Study Design

A quantitative cross-sectional comparison study was carried out at the hospital Fundación Cardiovascular de Colombia in Bucaramanga, Colombia. The study was conducted from January 2013 through January 2014.

Inclusion and Exclusion Criteria

Participants were females who were recruited during their prenatal and postnatal visits to the hospital. Participants were excluded if they had a pregnancy loss or termination or did not have the intellectual capacity to complete the survey.

Study Methods

During their visit to the obstetrician’s office, eligible participants were informed of the expanded NBS offered at Fundación Cardiovascular de Colombia by a separate healthcare provider (nurse or general practitioner) who had been trained to discuss the expanded NBS to patients, and a brochure about the expanded NBS was provided for additional information. The healthcare provider also provided education about the expanded NBS.

The brochure provided to participants, “Tamizaje Neonatal” (newborn screen) described the process of the newborn screen and provided a list of the conditions screened for by the expanded NBS. The brochure informed the reader
when to expect the expanded NBS to take place, and explained to the reader that they must indicate intent to receive the screen for their child; the screen will not be administered without consent from the parents. The conversation with the healthcare provider included the same information that was in the brochure “Tamizaje Neonatal”, but the purpose of the conversation with the healthcare provider was to answer participants’ questions the expanded NBS. After the patient received the brochure, they were invited to complete a survey about their interest in receiving the NBS, as well as their attitudes and beliefs regarding the expanded NBS. The participants were provided with a questionnaire, which was developed in English and translated into Spanish through the translational services at Cincinnati Children’s Hospital Medical Center. The surveys were completed without any identifiers, only including a coding number at the top of the survey to keep track of how many participants had completed the questionnaire. Completion of the questionnaire was considered implied consent to participate in this study. Completed questionnaires were sent to the University of Cincinnati for entry into a REDCap database and for subsequent data analysis. Institutional Review Board approval was obtained from both Cincinnati Children’s Hospital Medical Center and Fundación Cardiovascular de Colombia.

Questionnaire

The questionnaire was given to participants to measure interest in and attitudes and beliefs towards the expanded NBS pilot program at the hospital FCV. The questionnaire ascertained whether or not the participant wished to receive the
expanded NBS for their child and elicited their attitudes and beliefs towards the expanded NBS. The readability of the original English questionnaire using the Flesch Reading Ease test was 62, and the Flesch-Kinkaid grade level was 10.

Intent to participate in the NBS was measured by the question, “Do you plan to have your child undergo the expanded Newborn Screen?” Previous awareness and impressions about the NBS were measured by the questions, “Before today, had you heard of the expanded newborn screen (NBS)?” “If yes, when did you first hear about the expanded NBS?” “Where have you heard or read about the expanded NBS?” “Have you heard positive things about the expanded NBS?” “Have you heard negative things about the expanded NBS?” Participants’ attitudes and beliefs about the expanded NBS were measured using a set of 12 questions with likert scale response options. Response options ranged from 1-10, with 1 being strongly agree and 10 being strongly disagree. Clarity of information provided was measured by the question, “The information in the “Tamizaje Neonatal” brochure is clear.” Helpfulness of the information provided was measured by the questions, “The information in the “Tamizaje Neonatal’ brochure will help me to make a decision about the expanded NBS”. Perceived level of being informed was measured by the question, “I feel informed about the expanded NBS”. Cost was measured by the question, “I feel that the cost of the expanded NBS is fair”. Family role in the decision was measured with the question, “My family plays an important role in my decision”. Risk perception due to health of previous child/children was measured by the question, “My previous child/children are healthy”. The role of religion was measured by the question, “My religion plays an important role in my decision”.
Pregnancy complications were measured by the question, “I have had an uncomplicated pregnancy”. Fear of bad results was measured by the question, “I am afraid to receive bad results from the expanded NBS”. Fear of a blood draw was measured by the question, “I do not want my baby to have a blood test”. Trust in healthcare providers was measured by the question, “I trust the doctors who want to perform the expanded NBS”. Perceived benefits were measured by the question, “This screen will provide benefits to my child”. Other attitudes and beliefs measured in this study included pressure to receive the expanded NBS, measured by the question, “When offered the expanded NBS, did you feel pressure from your doctor or any other healthcare provider to accept the expanded NBS?”. Attitudes about government mandated NBS were measured by the question, “If the expanded NBS were mandated by the government, would that change your decision?” The role of the father in the decision to receive the expanded NBS was measured by the question, “What role did the father of your child play in deciding whether or not to have your child undergo the expanded Newborn Screen?”

The questionnaire also measured demographics, including race, age, number of pregnancies, education level, type of insurance, religion, due date, comorbidities, and socioeconomic level, or estrato level. Estrato are a typical characterization of the socioeconomic strata a participant identifies with in Colombia, where estrato 1 is the lowest and estrato 6 is the highest. Education level was collapsed into two groups. The first group included participants who indicated they received a grammar school education or no education. The second education group was participants who indicated they had received a high school education or higher. The
survey is included in Appendix I: English version and Appendix II: Spanish translated version.

The survey was intended for pregnant women; however, the pilot expanded NBS program is offering the expanded NBS to newborns up to one year of age in order to capture as many individuals as possible. The respondents were asked to provide their due dates to determine the pregnancy status of the participant.

**Derived NBS Timing Variable**

NBS timing was defined by the variables due date and survey completion data. Individuals who completed the survey prior to their reported due date were considered optimal timing. Individuals who completed the survey after their reported due date were considered to have suboptimal timing, and individuals who did not list a due date were considered unknown timing.

**Statistical Analysis**

Prior to data analysis, we evaluated the distributional characteristics of the likert scale responses. The data were non-normally distributed with an excess number of observations clustering at the response option “1”, strongly agree. Thus, non-parametric statistics were used when analyzing the likert responses. Frequencies were used to describe the population based on the demographic characteristics.

To characterize the interest in and awareness of the expanded NBS, frequencies were reported for intent to have the expanded NBS and their previous
awareness of the NBS. The likert scale responses were further used for perceived benefit. To compare the rates of intent to have the expanded NBS between groups (timing and education), Fisher’s exact test was used, given the small cell numbers.

To characterize the attitudes and beliefs toward NBS, medians and interquartile ranges were utilized. Further to understand if these attitudes and beliefs were associated with intent to have NBS, pregnancy timing, or educational level, Wilcoxon rank sum analyses was used.
Results

Description of the Study Participants

Fifty-five respondents completed the questionnaire (*Table 2*). The average age of the participants was 26.2 (+/- 6.8) years. Overall, participants were of low socioeconomic status with 54.0% of participants in estrato 1, the lowest socioeconomic level. Of note, no participants responded that they occupied the highest two estrato levels (5 and 6). Additionally, 18.9% of participants reported an education level of grammar school (11.4%) or no education (7.5%). The participants who indicated they had received a grammar school or lower education mostly responded that they occupied estrato 1, and no participant in the lower education group indicated they occupied higher than estrato 2. The majority of respondents identified as mestizo (mixed race), but 20% of participants identified as gypsies, who are a group of people who typically travel frequently and may not be exposed to stable healthcare or education.

Importantly, the majority of participants (50.9%) completed the survey with suboptimal timing (Figure 1). Only six participants were pregnant at the time the survey was administered, and a large proportion (38.1%) had unknown timing.

Interest in the expanded NBS was moderate, but awareness was low

Over half of respondents (53.8%) expressed interest in having the expanded NBS for their child. Participants demonstrated strong agreement (median of 1) of perceived benefit of having the expanded NBS for their child. The majority of respondents, 80.0%, had no prior awareness of the expanded NBS until it was
offered to them at their office visit. Of the nine respondents who answered that they had prior awareness of the expanded NBS, 33.3% (n=3) heard about the screen more than one year ago (Table 3).

**Attitudes and Beliefs**

With respect to the attitudes and beliefs surrounding the expanded NBS, there were a variety of responses for each question, spanning the full range of available answers (1-10, 1 is strongly agree and 10 is strongly disagree). Overall, the median scores reflected moderate to strong agreement (response range of 1 to 3) for all but two questions: the attitudes and beliefs surrounding the role of religion (median 6.5, moderate disagreement) and the fear of a blood draw (5, neutral). Importantly, participants expressed strong agreement that they trusted the healthcare provider who offered participants the expanded NBS (median of 1) (Figure 2).

When testing whether the intent to have NBS was associated with the participants’ attitudes and beliefs measured by the 12 likert scale response questions (Figure 3), only the question, “The information in the “Tamizaje Neonatal” brochure will help me to make a decision about the expanded NBS” was significantly different between those who did and did not intend to have the NBS (p = 0.012). Participants intending to have the expanded NBS had higher agreement (median 1, Inter Quartile Range [IQR] 1-1) that the brochure would help them make a decision about the NBS than participants who did not intend to have the expanded NBS (median 2, IQR 1-8.25). However, the overall trend was that individuals who
intended to receive the expanded NBS were more likely to agree with questions which were positively framed (e.g. cost, clarity of information, and previously healthy children) and less likely to agree with questions which were not positively framed (e.g. fear of bad results and fear of a blood draw).

**Impact of Pregnancy Status on Interest and Attitudes and Beliefs**

A high proportion of individuals who responded to the survey had suboptimal timing for the NBS. Thus, we then tested whether NBS timing (suboptimal, optimal, or unknown) was associated with the intent to have NBS or the attitudes and beliefs toward NBS. While not statistically significant ($p = 0.40$), individuals with optimal timing reported intent to have NBS (80%) more often than those with suboptimal (54 %) or unknown timing (47%; Figure 4).

For the majority of attitudes and beliefs, there were similar responses by timing (Figure 5). However, participants with suboptimal timing were more likely to agree (median 1, IQR 1-1) that their family played an important role in the decision making compared to participants who had unknown timing (median 3, IQR 1-10; $p = 0.005$) and participants with optimal timing (median 2, IQR 1-10; $p = 0.09$). Participants with unknown timing showed a high variability in their agreement that their family played a role in their decision. Additionally, several trends were noted. For the factor of cost ($p = 0.15$), participants with optimal timing agreed that the cost of the expanded NBS was fair (median 3.5), where participants with unknown timing disagreed that cost was fair (median 7). Participants with suboptimal timing disagreed (median 7.5) that they were fearful of receiving bad
results from the expanded NBS compared to participants with optimal timing (median 1) or unknown timing (median 1.5; p=0.15). Lastly, participants with optimal timing disagreed (median 10) that they did not want their child to receive a blood draw, where participants with unknown timing agreed (median 1; p=0.12) that they did not want their child to receive a blood draw.

**Trends in Education level and attitudes and beliefs toward the expanded NBS**

In this study, 18.9% of participants received grammar school or less education (11.4% received grammar school education, 7.5% received no education). It was hypothesized that lower education levels may impact the intent to have NBS. Participants who indicated that they received a grammar school education or less showed a lower intent to have the expanded NBS, with 33.3% of respondents indicating intent for the expanded NBS compared to 56.1% of participants with at least some high school education (Figure 6). However this difference was not statistically significant (p = 0.28).

Attitudes and beliefs were compared to the two groupings of education (one group consisted of grammar school or less education, the other consisted of at least some high school education and above). There was general consensus between the two groupings of education levels for the twelve likert scale questions measuring attitudes and beliefs with a few exceptions; cost, religion, and fear of a blood test (Figure 7). For the variable of cost (p = 0.26), the group with at least some high school education showed moderate agreement that the cost of the test was fair (median of 3.5, IQR 1- 7.75) compared to the grammar school or less group, which
showed disagreement that the cost of the test was fair (median of 8, IQR 1-10). For the likert scale question measuring the role of religion in decision-making (p = 0.10), participants with at least some high school education or higher disagreed (median 8.5, IQR 1.25-10) that religion played a role in their decision making while participants with grammar school or less education tended to agree (median 1, IQR 1-9) that religion played a role in their decision-making. For the variable measuring fear for their child to have a blood test influencing the participants decision to receive expanded NBS (p = 0.053), individuals with at least some high school education or higher tended to be neutral (median 5, IQR 1-10) compared to individuals with less than a high school education who tended to strongly agree (median 1, IQR 1-3.25) that they were fearful for their child to receive a blood test.
**Discussion**

This study sought to identify barriers and facilitators associated with broadening access to the expanded NBS program by measuring attitudes and beliefs about the expanded NBS in an effort to understand where education is warranted. Overall, this study demonstrated a moderate interest in the expanded NBS, but low awareness about the screen. Pregnancy timing and education may influence parental decision making for NBS. Participants who were at a suboptimal time to receive the expanded NBS for their child or were part of the lowest education group were less likely to express intent in the expanded NBS. However, there was strong consensus overall that the expanded NBS provides benefits to newborns and that the participants trust the healthcare providers offering the expanded NBS. Our finding that higher intent to receive the expanded NBS in the group of participants who indicated they had at least some high school education or higher may be important to countries that are working to implement a NBS program. Countries may be able to direct educational efforts to lower education groups to increase uptake of the NBS based on the results from this study on the impact of education and NBS intent. Additionally, participants that were at the optimal time to receive the expanded NBS were more likely to express interest in the screen. This information suggests that the Columbia and other countries developing a NBS program should strive to offer it during the optimal time when NBS has the greatest potential to improve health outcomes.

**Moderate interest in the expanded NBS, but low awareness**
As noted above, there was a moderate interest in receiving the expanded NBS but low awareness. We found that slightly over half the participants were interested in the expanded NBS (53.8%). It is difficult to compare the interest in the NBS in Columbia which uses an opt-in approach compared to other countries, such as the United States, which uses an opt-out approach.

Prior awareness was low, with 80% of participants not having heard of the expanded NBS before their office visit when the survey was administered. The low awareness is consistent with Davis et al findings from a focus group of parents in the United States, where most parents did not know what the NBS was (Davis et al., 2006). It is important to note that while many mothers had no awareness of the expanded NBS before being informed about the screen at their office visit, the pilot expanded NBS program in Colombia used an informed consent process. In general, participants felt that the material helped facilitate their NBS decision. This information sharing is in contrast to the United States, where parents have indicated that they would like providers to discuss the NBS, and provide information on what conditions are included on the screen as well as the timing of results (Tluczek et al., 2009). The information about the NBS desired by parents in the study by Tluczek et al is provided to patients at Fundación Cardiovascular de Colombia prior to delivery. The sharing of the information prior to delivery is critical as mothers in the U.S. who received informed consent just prior to discharge from the hospital had a lower understanding about the NBS than mothers who consented to the screen at an earlier time (Holtzman, 2004). Although not measured in our study, it is possible that participants may have better awareness of the screen in the long term because
of the materials provided and may be more likely to pursue NBS with subsequent children. However, long-term awareness of the expanded NBS was not measured in this study.

The lack of awareness of the expanded NBS suggests more education and marketing can be done to increase awareness of the expanded NBS available in Colombia. The expanded NBS has only been implemented for less than a year, so it is not surprising that more education is warranted due to the program’s age. Many studies have cited the desire from parents to receive more information about the NBS in the United States (Araia et al., 2012; Tu et al., 2012). Bombard, et al concluded that public education and discourse bring awareness to the NBS and the benefits and risks associated with the screen (Bombard et al., 2012). Previous studies suggest a strong desire for education about screening options (Dhondt, 2005; Michie et al., 1997). Providing detailed information about what the expanded NBS screens for, how it is performed, and what results can be expected are examples of information that patients are interested in learning. More education about the expanded NBS in Colombia that includes the aforementioned variables as part of the consent process may increase awareness and therefore assist in increasing uptake.

**Attitudes and Beliefs**

Overall, the participants who completed the questionnaire showed high agreement with the likert scale questions that were used to measure different variables surrounding attitudes and beliefs about the expanded NBS. The majority of respondents strongly agreed that they trusted the healthcare professional that
offered them the expanded NBS, and also strongly agreed that the screen would provide benefits to their child/children. Nicholls and Southern reported that important factors in parents’ decision to undergo screening is based on attitudes towards the healthcare system and perceived benefits from the NBS in the United Kingdom (Nicholls & Southern, 2013b). Since participants feel a great deal of trust in their providers, the information and advice that providers provide to their patients about the expanded NBS may sway the patients’ decision to receive screening, though the impact of the healthcare providers’ conversation with the participant on their decision to receive or decline the expanded NBS was not measured in the study.

**Impact of Timing on Interest and Attitudes and Beliefs**

Many of the study participants had suboptimal timing for the expanded NBS. The proportion of mothers who did not have optimal timing was not surprising, as the expanded NBS is being offered to newborns up to one month following birth. Many of the conditions included on the screen (Biotinidase Deficiency, Congenital Hypothyroidism, Congenital Adrenal Hyperplasia, Galactosemia, Glucose 6 Phosphate Dehydrogenase Deficiency, Thalassemias, and Phenylketonuria) may have an onset from a few days after birth to a few months after birth. Therefore, newborns who undergo NBS outside of the recommended therapeutic window of 24-48 hours may still receive benefit. For example, Biotinidase Deficiency has a variable onset, where affected individuals can experience onset of symptoms from several months of age to several years of age (Wolf et al., 1998). Therefore,
screening outside of the therapeutic window may still be valuable to patients who have not begun to exhibit symptoms, or have begun to exhibit symptoms but are undiagnosed. Other conditions, like Congenital Hypothyroidism (CH), do not come to medical attention until months after birth, though affected individuals encounter morbidity early on in life. Individuals with CH have the best outcome when identified early, and Smith et al concluded that the critical period for identification of affected individuals is during the newborns’ stay in the newborn nursery, so that treatment can be administered in a timely manner (Smith, Klein, Henderson, & Myrianthopoulos, 1975). Screening for CH outside of the therapeutic window may be less beneficial than screening during the therapeutic window.

Cystic Fibrosis is a condition where detection outside of the window recommended for NBS has conflicting evidence of benefit. Waters et al conducted a long term observational study of two cohorts of children; one cohort was born before cystic fibrosis was included on the NBS in Sydney, Australia, and the other cohort were children who were born three years after the implementation of cystic fibrosis NBS. In the cohort identified to have cystic fibrosis through the NBS, height and weight were higher than the cohort of children identified to have cystic fibrosis later in life. Additionally, there were no differences found in pulmonary health based on X-Rays between the two groups (Waters et al., 1999). The data presented in this study may indicate that there are benefits to early detection of cystic fibrosis, but patients who are identified outside of the NBS window can still have improved health. The aforementioned conditions can have effective treatment plans if they are detected in a child after the therapeutic window for NBS; however, when the
conditions included on the expanded NBS are detected through this screen, the greatest benefit can be received through treatment.

Interest in receiving the expanded NBS for their child was lower in the suboptimal timing group than in the optimal timing group. One explanation for this difference is that the mothers that indicated they had suboptimal timing may not intend to receive the expanded NBS for their child as their child may seem perfectly healthy after birth; therefore the NBS may seem unnecessary. Our speculation is supported by the fact that participants with suboptimal timing were not fearful of bad results, whereas participants with unknown or optimal timing were fearful of bad results. Although fearful of receiving bad results from the NBS, participants with optimal timing were still very interested (80.0%) in receiving the expanded NBS for their child. Little information is known about fear of abnormal results from a NBS in the United States due to the opt-out system of screening and lack of sufficient education; many parents are simply unaware that their child will or has had the NBS. However, identification of a condition through NBS may actually help lessen parental stress in the long run. In a study measuring the effects of expanded NBS on parental stress, researchers reported that parents of a child who had a genetic condition identified by NBS within the past 5-30 months had overall less stress on the Parental stress index than those parents of children who had a genetic condition identified through clinical analysis (Waisbren et al., 2003).

Participants with unknown timing disagreed that they thought the cost of the expanded NBS was fair, whereas those with suboptimal timing or optimal timing agreed that they cost was fair. It is difficult to interpret what these results may mean
for the expanded NBS program. Participants that had government subsidized healthcare had their expanded NBS paid for by the hospital if they chose to receive the screen for their child. Of the participants who had unknown timing, all but four had government subsidized insurance (n=15) and would therefore have the expanded NBS paid for by the hospital. It is unclear what the results of fairness of cost mean in the context of this study.

Participants who had unknown timing agreed that they were fearful of a blood draw for their child. Nicholls and Southern surveyed parents about their decision making process for the NBS, and parents indicated that the potential for distress in their child due to the blood draw for the NBS was a concern. However, this concern was lessened after education was provided about the cognitive ability of the child at the time of the blood draw; it was noted that the child would not be able to remember the NBS blood draw (Nicholls & Southern, 2013b). It may be beneficial to provide additional education to any parent who is fearful of a blood draw for their child. Education could include the low risks associated with a blood draw, which may lessen the concern of a blood draw for the parent.

**Trends in Education level and attitudes and beliefs toward the expanded NBS**

Lower education group (grammar school and below group, n=10) were less likely to want to receive the expanded NBS for their child (33.3%) than the group with at least some high school education and higher (n=43) (56.1%). In a survey of 2137 mothers at the University of North Carolina Hospitals regarding the uptake of NBS of the *FMR1* gene, Skinner et al found that as education level decreases,
willingness to receive the NBS decreases (Skinner et al., 2011), suggesting that educational barriers also exist in the uptake of the NBS in the United States. The lower intent to receive the expanded NBS among participants a grammar school education and below suggests that education surrounding the expanded NBS may be most impactful in terms of increasing uptake of the NBS if targeted toward patients with less formal education.

Participants who responded that they had a grammar school education or less also strongly agreed that they were afraid for their child to receive a blood draw, suggesting fear of a blood draw may be one of the reasons for less interest in NBS among those with less education. Educational efforts targeted to those with less education need to address this fear (Nicholls & Southern, 2013b).

**Limitations**

There were several limitations present in the study. Based on the characteristics of the respondents, it is likely that the study population is not representative of the Colombia population who might be offered the expanded NBS. Participants tended to be of a lower socioeconomic status (68% of participants responded that they occupy either estrato 1 or 2), resulting in a biased representation of Colombian mothers. Further, no participants in the study occupied the highest two estrato levels, which contributed to the study population being biased. There were 18.9% of participants who responded that they had an education level of grammar school or no education, and the survey used in the study had a Flesch-Kincaid grade level of 10. The readability of the survey used may have been
too difficult for some participants, and future surveys should have a lower readability score to aid in the understanding for more participants. The sample size for the research project was 55 participants, which meant that the study was not sufficiently powered to find statistically significant results. Additionally, many of the surveys received were not fully completed and participants’ characteristics or attitudes and beliefs may not have been fully captured. The survey was originally intended for pregnant mothers, however many respondents noted that they had a due date prior to survey administration, which may indicate that participants who answered in this way had already given birth. The study only examined attitudes and beliefs for Colombian women at the hospital Fundación Cardiovascular de Colombia, and the results of the study may not be generalizable to all of Colombia.

**Conclusion**

More education surrounding the expanded NBS in Colombia is warranted. Although awareness about the expanded NBS was low, there was moderate interest in receiving the screen demonstrated by the participants in the study. The factors of timing and education may influence the participants’ decision-making toward the expanded NBS as well as their attitudes and beliefs about the screen. The finding that more education is needed surrounding the expanded NBS is not surprising, as the expanded NBS program has only been in place for about one year. As more patients are educated about the expanded NBS and more marketing is done, more people will gain a better understanding of the expanded NBS and the benefits that it can provide to their child or children. More education may also
increase awareness about the optimal timing for receiving the expanded NBS which would offer the most therapeutic benefits. Data obtained during the implementation stage of a pilot NBS program is rare and may provide valuable information to the many other countries of the world that still do not have a NBS program or are working to implement one. Indeed, there are many countries worldwide that have not implemented a NBS program (Borrajo, 2007; Padilla et al., 2012). Education about the NBS and the benefits of NBS is recommended. The benefits and risks associated with expanded NBS should be discussed with patients prior to giving birth to allow time to make an informed decision about screening. The education should include when to receive testing, what conditions are screened for, how results will be delivered, and when results will be deliver, among other details about the expanded NBS. This education is currently being provided to patients who wish to learn more about the expanded NBS at Fundación Cardiovascular de Colombia, but in order to reach the most people who may benefit from this screen national education would be ideal. This education could be provided at various hospitals in Colombia to let patients know they can receive the expanded NBS at Fundación Cardiovascular de Colombia, which may in turn increase the uptake of NBS and potentially improve health outcomes for children.

References


### Table 1: Conditions Included on the Expanded NBS in Colombia with their Corresponding Analyte, Incidence, and Intervention

<table>
<thead>
<tr>
<th>Condition</th>
<th>Analyte</th>
<th>Incidence</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biotinidase Deficiency</td>
<td>Biotinidase (presence)</td>
<td>1 in 50,000 Births</td>
<td>Biotin</td>
</tr>
<tr>
<td>Congenital Hypothyroidism</td>
<td>Thyrotropin, Thyroxine</td>
<td>1 in 3,500-5,000 Births</td>
<td>Levothyroxin Treatment</td>
</tr>
<tr>
<td>Congenital Adrenal Hyperplasia</td>
<td>Deoxycorticosterone, Deoxycortisol, Hydroxyprogesterone, Androstenedione, Cortisol</td>
<td>1 in 15,000 Births</td>
<td>Pharmaceutical treatment based on type</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>Immunoeactive Trypsinogen</td>
<td>1 in 25,000 Births</td>
<td>Pharmaceutical and Therapeutic Treatment based on stage of disease and organ involvement</td>
</tr>
<tr>
<td>Galactosemia</td>
<td>Galactose-1-phosphate Uridyl Transferase</td>
<td>1 in 60,000 Births</td>
<td>Lactose/galactose-restricted diet</td>
</tr>
<tr>
<td>Glucose 6 Phosphate Dehydrogenase Deficiency</td>
<td>Glucose 6 Phosphate Dehydrogenase</td>
<td>Prevalent in Africa, Asia, and Mediterranean</td>
<td>Treatment of jaundice and avoidance of precipitants of hemolysis</td>
</tr>
<tr>
<td>Hemoglobinopathies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sickle Cell Disease</td>
<td>Hemoglobin</td>
<td>1 in 500 Black or African American Births</td>
<td>Penicillin prophylaxis begun by age 2 months</td>
</tr>
<tr>
<td>Thalassemias</td>
<td>Hemoglobin</td>
<td>3-5% depending on ethnic group</td>
<td>Folate supplements, blood transfusion</td>
</tr>
<tr>
<td>Phenylketonuria</td>
<td>Phenylalanine, Phenylalanine/Tyrosine ratio</td>
<td>1 in 10,000 Births</td>
<td>Dietary restriction on Phenylalanine</td>
</tr>
</tbody>
</table>
Table 2. Participant Demographics

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Responses</th>
<th>Percentage of Total Respondents</th>
<th>Number of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td>Gypsy</td>
<td>20.0%</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Hispanic</td>
<td>12.0%</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Unsure</td>
<td>8.0%</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Mestizo</td>
<td>52.0%</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>Caucasian</td>
<td>8.0%</td>
<td>4</td>
</tr>
<tr>
<td>First Child</td>
<td>No</td>
<td>41.8%</td>
<td>23</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>58.2%</td>
<td>32</td>
</tr>
<tr>
<td>Education</td>
<td>Grammar School and Less Education</td>
<td>18.9%</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>At Least Some High School Education and Higher</td>
<td>81.1%</td>
<td>43</td>
</tr>
<tr>
<td>Rural/urban</td>
<td>Rural</td>
<td>34.7%</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Urban</td>
<td>65.3%</td>
<td>32</td>
</tr>
<tr>
<td>Estrato</td>
<td>1</td>
<td>54.0%</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>14.0%</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>20.0%</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>12.0%</td>
<td>6</td>
</tr>
<tr>
<td>Insurance</td>
<td>Contributory</td>
<td>30.8%</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>None</td>
<td>1.9%</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Prepaid</td>
<td>1.9%</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Subsidized</td>
<td>65.4%</td>
<td>34</td>
</tr>
<tr>
<td>Religion</td>
<td>Adventist</td>
<td>1.9%</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Catholic</td>
<td>70.6%</td>
<td>36</td>
</tr>
<tr>
<td></td>
<td>Christian/Non-Catholic</td>
<td>25.5%</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>1.9%</td>
<td>1</td>
</tr>
</tbody>
</table>

1 Race measured the race the participant identified with. First child measured whether or not the participant had previous children. Education measured the highest level of education completed by the participant. Rural/Urban describes the area in which the participants’ lives. Estrato level describes the socioeconomic status of the participant, where 1 is the lowest level and 6 is the highest level. Insurance was measured to determine the type of insurance the participant possessed, with four possible options being available in Colombia, including Contributory, None, Prepaid, or Subsidized. Contributory is where the participant helps contribute some of the expense of medical care and their insurance contributes the rest, subsidized is insurance provided by the government, and prepaid is where the participant pays a certain amount in order to cover all medical expenses. Religion measured the religion that the participant identifies with.
Table 3. Expanded NBS Awareness and Attitudes

<table>
<thead>
<tr>
<th>Likert Scale Question</th>
<th>Response</th>
<th>Percentage of Total (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intent to Receive Expanded NBS</td>
<td>No</td>
<td>23.1% (12)</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>53.8% (28)</td>
</tr>
<tr>
<td></td>
<td>Unsure</td>
<td>23.1% (12)</td>
</tr>
<tr>
<td>Participants Recollection of Previous Expanded NBS Education</td>
<td>No</td>
<td>80.0% (44)</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>16.4% (9)</td>
</tr>
<tr>
<td></td>
<td>Unsure</td>
<td>3.6% (2)</td>
</tr>
<tr>
<td>When the Participants First Heard of the Expanded NBS</td>
<td>Six Months to One Year Ago</td>
<td>22.2% (2)</td>
</tr>
<tr>
<td></td>
<td>Greater than One Year Ago</td>
<td>33.3% (3)</td>
</tr>
<tr>
<td></td>
<td>Unsure</td>
<td>22.2% (2)</td>
</tr>
<tr>
<td></td>
<td>Less than Six Months Ago</td>
<td>22.2% (2)</td>
</tr>
<tr>
<td>Where the Participant Heard about the Expanded NBS</td>
<td>Physician</td>
<td>44.4% (4)</td>
</tr>
<tr>
<td></td>
<td>Family Member</td>
<td>11.1% (1)</td>
</tr>
<tr>
<td></td>
<td>Friend</td>
<td>11.1% (1)</td>
</tr>
<tr>
<td></td>
<td>The Internet</td>
<td>33.3% (3)</td>
</tr>
<tr>
<td>The Participant Heard Positive Things about the Expanded NBS</td>
<td>No</td>
<td>11.1% (1)</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>88.9% (8)</td>
</tr>
<tr>
<td>The Participant Heard Negative Things about the Expanded NBS</td>
<td>No</td>
<td>88.9% (8)</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>11.1% (1)</td>
</tr>
<tr>
<td>The Participant Felt Pressure from a Healthcare Provider to Receive the Expanded NBS</td>
<td>No</td>
<td>78.3% (36)</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>2.2% (1)</td>
</tr>
<tr>
<td></td>
<td>Unsure</td>
<td>19.6% (9)</td>
</tr>
<tr>
<td>The Participant would Change Their Decision to Receive the Expanded NBS if the Government Mandated the screen</td>
<td>No</td>
<td>58.8% (3)</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>11.8% (6)</td>
</tr>
<tr>
<td></td>
<td>Unsure</td>
<td>29.4% (15)</td>
</tr>
<tr>
<td>What Role the Father Played in the Decision</td>
<td>The father made the decision</td>
<td>2.9% (1)</td>
</tr>
<tr>
<td></td>
<td>It was a joint decision</td>
<td>38.2% (13)</td>
</tr>
<tr>
<td></td>
<td>The father was not involved</td>
<td>32.4% (11)</td>
</tr>
<tr>
<td></td>
<td>The father supported the decision</td>
<td>26.5% (9)</td>
</tr>
</tbody>
</table>

The column "likert scale question" refers to the 12 likert scale questions included in the questionnaire. The response column includes the available response in the questionnaire. The percentage of total refers to the percentage of the total responses for that particular question, and the n is included for each question as not every respondent answered all questions.
Figures

Figure 1: Distribution of participants with optimal, suboptimal, and unknown pregnancy timing

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3 Optimal timing is defined as a reported due date that is after survey administration, suboptimal timing is when the participant provided a due date that was prior to survey administration, and unknown timing is when the respondent did not provide their due date.
The plot above corresponds to the twelve likert scale questions provided on the questionnaire. The labels on the X axis correspond to the variable measured in the questions. The level of agreement is from 1-10, with 1 being strongly agree and 10 being strongly disagree.
Figure 3: Attitudes and Beliefs by intent to have NBS

The plot above corresponds to the twelve likert scale questions provided on the questionnaire. The labels on the X axis correspond to the variable measured in the questions. The level of agreement is from 1-10, with 1 being strongly agree and 10 being strongly disagree.

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5 The plot above corresponds to the twelve likert scale questions provided on the questionnaire. The labels on the X axis correspond to the variable measured in the questions. The level of agreement is from 1-10, with 1 being strongly agree and 10 being strongly disagree.
Figure 4: Intent to have NBS by Timing

---

6 Optimal timing is defined as a reported due date that is after survey administration, suboptimal timing is when the participant provided a due date that was prior to survey administration, and unknown timing is when the respondent did not provide their due date.
The plot above corresponds to the twelve Likert scale questions provided on the questionnaire. The labels on the X axis correspond to the variable measured in the questions. The level of agreement is from 1-10, with 1 being strongly agree and 10 being strongly disagree.
Figure 6: Intent to Receive Expanded NBS by Education
The scale of the levels of agreement to the twelve likert scale questions included on the questionnaire were that 1 corresponded with strongly agree and 10 corresponded with strongly disagree. The plot above corresponds to the twelve likert scale questions provided on the questionnaire. The labels on the X axis correspond to the variable measured in the questions. The level of agreement is from 1-10, with 1 being strongly agree and 10 being strongly disagree.
Appendix

Appendix I: English Version of Survey

Dear Participant,

This survey is designed to collect feedback for the expanded Newborn Screening (NBS) program in Colombia. Your answers and opinions provided in the questions below will be used to help improve education about the expanded NBS program so that parents can make informed decisions about expanded NBS for their child.

Your participation in this survey is completely voluntary. There is no right or wrong answer to any of the questions. Please answer the questions honestly. If you decide to participate, you may choose to stop your participation at any time. The information you provide in this survey will be kept confidential.

Thank you for your time.

1. Do you plan to have your child undergo the expanded Newborn Screen?
   Yes
   No
   Undecided

2. Before today, had you heard of the expanded newborn screen (NBS)?
   Yes
   No
   Don’t know

   2a. If yes, when did you first hear about the expanded NBS?
       Less than 6 months ago
       6 months to a year ago
       More than a year ago
       I don’t remember

   2b. Where have you heard or read about the expanded NBS?
       Expanded NBS seminar
       Television
       Newspaper
       Internet
       Healthcare Provider
       Friend
       Family Member
       Don’t remember

   2c. Have you heard positive things about the expanded NBS?
       Yes
       No
I have not heard anything about the NBS.

2d. Have you heard negative things about the expanded NBS?
   - Yes
   - No
   I have not heard anything about the NBS

3. When offered the expanded NBS, did you feel pressure from your doctor or any other healthcare provider to accept the expanded NBS?
   - Yes
   - No
   - Don’t know

4. If the expanded NBS were mandated by the government, would that change your decision?
   - Yes
   - No
   - Don’t know

5. What role did the father of your child play in deciding whether or not to have your child undergo the expanded Newborn Screen?
   - He made the decision
   - We made the decision together
   - He supported my decision
   - He was not involved in the decision

6. Please circle the number indicating your level of agreement about the expanded NBS based on the following statements (where 1 indicates you strongly agree and 10 indicates you strongly disagree):

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. The information in the “Tamizaje Neonatal” brochure is clear</td>
<td>1 2 3 4 5 6 7 8 9 10 NA</td>
</tr>
<tr>
<td>b. The information in the “Tamizaje Neonatal” brochure will help me to make a decision about the expanded NBS</td>
<td>1 2 3 4 5 6 7 8 9 10 NA</td>
</tr>
<tr>
<td>c. I feel informed about the expanded NBS</td>
<td>1 2 3 4 5 6 7 8 9 10 NA</td>
</tr>
<tr>
<td>d. I feel that the cost of the expanded NBS is fair</td>
<td>1 2 3 4 5 6 7 8 9 10 NA</td>
</tr>
</tbody>
</table>
7. Please rank the five most important reasons behind your decision to have your child undergo the expanded newborn screen, with 1 being the most important reason and 5 being the least important reason:
   1.
   2.
   3.
   4.
   5.

8. Is there anything else you would like to tell us about the expanded NBS?

9. Under which racial background do you identify yourself? Please choose one.
   - Hispanic
   - Mestizo
   - Indigenous
   - African
   - Asian
   - White
   - Middle eastern
   - Don’t know

10. What is your age?

11. Is this your first child?
    - Yes
    - No

12. What is your level of education?
    - None
Grammar school  
High school  
Some college  
Bachelor's degree  
Master's degree  
Doctoral degree  
Professional degree (MD, JD, etc.)  
Other:

13. Which of the following areas best describes where you live?  
a.  
Urban  
Rural  
b.  
Estrato 1  
Estrato 2  
Estrato 3  
Estrato 4  
Estrato 5  
Estrato 6

14. What type of social security do you have?  
None  
Contributory  
Subsidized  
Prepaid

15. What religion do you identify with?  
Christian/Catholic  
Christian/Non-Catholic  
Christian/Adventists  
Jewish  
Muslim  
Buddhist  
Atheist  
Agnostic  
Other

16. What is your due date?

17. Has your physician diagnosed you with any of the following conditions?:  
Gestational diabetes  
Preeclampsia (high blood pressure caused by pregnancy)  
Disorders in the ultrasound that indicate a concern with the baby  
Abnormal laboratory test results during the first trimester of pregnancy  
Abnormal laboratory test results during the second trimester of pregnancy
Appendix II: Spanish Translated Version of Survey

Estimada participante:

El objetivo de esta encuesta es recolectar información para el programa de evaluación para recién nacidos llamado Tamizaje Neonatal ampliado en Colombia. Sus respuestas y opiniones en las preguntas a continuación se usarán para mejorar la educación sobre el programa Tamizaje Neonatal ampliado, de manera que los padres puedan tomar decisiones informadas sobre las evaluaciones ampliadas de recién nacidos para sus hijos.

Su participación en esta encuesta es totalmente voluntaria. No existe ninguna respuesta correcta o equivocada para las preguntas. Por favor responda las preguntas con sinceridad. Si decide participar, puede dejar de hacerlo en cualquier momento. La información que proporcione en esta encuesta se mantendrá en forma confidencial.

Gracias por su tiempo.

¿Tiene planeado realizar el Tamizaje Neonatal ampliado a su hijo/a?
  Sí
  No
  Indecisa

18. Antes de hoy, ¿había oído sobre el Tamizaje Neonatal ampliado?
   Sí
   No
   No sé

   a. Si contestó “sí”, ¿cuándo oyó hablar por primera vez sobre el Tamizaje Neonatal ampliado?
      Hace menos de 6 meses
      Entre 6 meses y un año atrás
      Hace más de un año
      No recuerdo

   b. ¿Dónde oyó hablar o leyó sobre el Tamizaje Neonatal ampliado?
      Seminario de Tamizaje Neonatal ampliado
      Televisión
      Periódico
      Internet
      Proveedor de atención médica
      Amiga/o
      Familiar
      No recuerdo

   c. ¿Ha oído comentarios positivos sobre el Tamizaje Neonatal ampliado?
      Sí
No oí nada antes sobre el Tamizaje Neonatal ampliado.

d. ¿Ha oído comentarios negativos sobre el Tamizaje Neonatal ampliado?
   Sí
   No

19. Cuando le ofrecieron el Tamizaje Neonatal ampliado, ¿se sintió presionada por su médico o por cualquier otro proveedor de atención médica para aceptar?
   Sí
   No
   No sé

20. Si el gobierno obligara a hacer el Tamizaje Neonatal ampliado, ¿eso cambiaría su decisión?
   Sí
   No
   No sé

21. ¿Qué rol asumió el padre de su hijo/a con respecto a realizar o no el tamizaje neonatal ampliado en su hijo/a?
   Él tomó la decisión
   Tomamos la decisión en conjunto
   Él apoyó mi decisión
   Él no se involucró en la toma de la decisión

22. Con respecto a las siguientes afirmaciones, por favor encierre en un círculo el número que indique su nivel de acuerdo sobre el Tamizaje Neonatal ampliado (donde 1 es estar totalmente de acuerdo y 10 totalmente en desacuerdo)

<table>
<thead>
<tr>
<th></th>
<th>Totalmente de acuerdo</th>
<th>Totalmente en desacuerdo</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. La información en el folleto “Tamizaje Neonatal” es clara.</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>No corresponde</td>
</tr>
<tr>
<td>b. La información en el folleto “Tamizaje Neonatal” me ayudará a tomar una decisión sobre el Tamizaje Neonatal ampliado.</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>No c.</td>
</tr>
<tr>
<td>c. Siento que estoy informada sobre el Tamizaje Neonatal ampliado.</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>No c.</td>
</tr>
<tr>
<td>d. Creo que el costo del Tamizaje Neonatal ampliado es justo.</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>No c.</td>
</tr>
<tr>
<td>e. Mi familia tiene un rol importante en mi decisión.</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>No c.</td>
</tr>
<tr>
<td>f. Mi hijo/a o hijos anteriores son sanos.</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>No c.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>g. Mi religión tiene un rol importante en mi decisión.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>h. Tuve un embarazo sin complicaciones.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>i. Tengo miedo de recibir malos resultados de las pruebas del Tamizaje Neonatal ampliado.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>j. No quiero que le hagan una prueba de sangre a mi bebé.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>k. Confío en los médicos que quieren hacer el Tamizaje Neonatal ampliado.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>l. Este tamizaje será beneficioso para mi hijo/a.</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

23. Indique los cinco motivos más importantes que la llevaron a tomar la decisión de hacer el tamizaje ampliado en su hijo/a, donde 1 es el motivo más importante y 5 es el motivo menos importante:

1. 
2. 
3. 
4. 
5. 

24. ¿Hay algo más que le gustaría decirnos sobre el Tamizaje Neonatal ampliado?

25. ¿Dentro de cuál grupo racial se identifica? Por favor elija una opción.

Hispano
Mestizo
Indígena
Africano
Asiático
Blanco
Medio Oriente
No sé

26. ¿Qué edad tiene?

27. ¿Este es su primer hijo/a?

Sí
No

28. ¿Cuál es su nivel de escolaridad?

Ninguno
Escuela primaria
Escuela secundaria
Escuela técnica (tecnología)
Algo de educación universitaria
Título profesional univerisitario
Título de maestría
Título de doctorado
Otro:

29. ¿Cuál de las siguientes áreas describe mejor el lugar donde vive?
   a. Urbana
      Rural
   b. Estrato 1
      Estrato 2
      Estrato 3
      Estrato 4
      Estrato 5
      Estrato 6

30. ¿Qué tipo de seguridad social tiene?
    Ninguno
    Contributivo
    Subsidiado
    Prepagada

31. ¿Con cuál religión se identifica?
    Cristiana/Católica
    Cristiana/No católica
    Cristiana/Adventista
    Judía
    Musulmana
    Budista
    Atea
    Agnóstica
    Otra:

32. ¿Cuál es su fecha de parto?

33. ¿Ha sido diagnosticada por su médico con alguna de las siguientes condiciones?:
    Diabetes gestacional
    Preeclampsia (hipertensión inducida por el embarazo)
    Alteraciones en la ecografía que indiquen alguna preocupación con el bebé
    Anormalidades en las pruebas de laboratorio realizadas durante el primer trimestre del embarazo.
    Anormalidades en las pruebas de laboratorio realizadas durante el segundo trimestre del embarazo.