Evaluation of the Florida Newborn Screening Program Education Campaign

Mirine Richey * , Cynthia B. Wilson , Minna Jia , Travis Galbraith

Posted Date: 14 January 2025

doi: 10.20944/preprints202501.1081.v1

Keywords: newborn screening; focus groups; survey; perceptions; parental awareness

Article

Evaluation of the Florida Newborn Screening Program Education Campaign

Cynthia B. Wilson [1], Mirine Richey [2]*, Minna Jia [3] and Travis Galbraith [4]

1. Florida State University, The Florida Center for Prevention Research, 2200 Old St. Augustine Rd, Tallahassee, FL 32301 cbwilson2@fsu.edu
2. Florida State University, Center for Prevention and Early Intervention Policy, 1339 E Lafayette St. Tallahassee FL 32301 m.richey@fsu.edu
3. Florida State University, FSU Survey Foundry, 296 Champions Way, #6147 University Center, Tallahassee, FL 32306 minna.jia@fsu.edu
4. George Washington University, Milken Institute School of Public Health tgalbraith@gwmail.gwu.edu

* Correspondence: Mirine Richey, m.richey@fsu.edu

Abstract: Florida's Newborn Screening Program campaign aims to increase awareness and participation of birthing facilities, providers, and parents. This evaluation aimed to determine the effectiveness and reach of the Newborn Screening Program (NBS) Statewide Educational Campaign to pregnant women through surveys and focus groups. The online survey, conducted throughout Florida in English, Spanish, and Haitian Creole, evaluated the reach and effectiveness of educational materials such as paid advertisements and brochures. The surveys also served to recruit participants for in-person focus groups throughout the state. The findings showed that 85.3% of the mothers had discussions with health professionals about the screening program, while others did not hear about if from health professionals. More than 50% of the respondents learned about the program through health facilities, with additional exposure from media platforms such as television, radio, and friends. The study shows the need for increased outreach of the campaign and better communication and education from medical professionals to increase awareness.

Keywords: 1**;** newborn screening 2; focus groups 3; survey 4; perceptions 5; parental awareness

1. Introduction

Newborn screening refers to the testing carried out on infants immediately after birth to ensure they are safe and healthy through the early detection and treatment of health issues. The screening is done to identify infants at risk for specific medical conditions that may threaten the child's health, development, and well-being. Screening is usually performed within the first 24- 48 hours after birth. The disorders targeted by the screening are generally those that, without intervention, would cause significant morbidity, mortality, or intellectual disability[1] . The Florida Department of Health (DOH) oversees the Newborn Screening Program (NBS), which is performed in the birth facility, physician's office, or at home for planned homebirths. As of 2023, it comprises three primary tests: blood spot screening tests to check the baby's blood for selected conditions, pulse oximetry screening to check for any heart abnormalities, and a hearing screening test to detect hearing levels.

All babies are tested since even babies who appear healthy may have some complications and benefit from early referral. Within the Florida primary tests, there are screenings for 35 core conditions, following the Recommended Uniform Screening Panel (RUSP) in the United States[2], and 22 secondary conditions [3]. The core conditions include hearing loss, endocrine disorders, and metabolic disorders. Metabolic disorders make up the bulk of diseases being screened for, with fatty acid oxidation disorders and amino acid disorders among the conditions identified. In most instances, symptoms of inborn metabolic disorders may appear in early infancy, although some may become more apparent in late childhood.

 doi:10.20944/preprints202501.1081.v1

The hearing test and pulse oximetry, to screen for critical congenital heart defects (CCHDs), are non-invasive painless tests carried out at the facility prior to discharge and then results are received through the provider once they are ready, to ensure prompt referral and care. The program is funded through a joint effort, where hospitals and birthing facilities pay $15 for every live birth. Medicaid and private insurance companies are billed for the tests and the state covers the costs for uninsured families[3].

The program has a significant impact in reducing the risk of genetic, metabolic, and other congenital conditions that may affect the infant after birth. The Florida NBS program established a benchmark goal that less than 1% of all specimens received at the laboratory be unsatisfactory. However, the current unsatisfactory rate in Florida ranges between 1.0% to 1.5%. Another benchmark goal set by the NBS program is that all specimens be received at the laboratory no later than 3 days after collection, although not all specimens are received within this timeframe. These performance benchmarks are monitored and reported to the submitting facilities monthly, with quarterly grades posted on the NBS program's public-facing website (floridanewbornscreening.com).

The screening program tests over 225,000 samples annually, and of these, over 700 babies are identified as having a condition that will benefit from early detection and treatment. Many newborn conditions such as phenylketonuria, cystic fibrosis, and sickle cell disease managed through the program and linkages with Children's Medical Services , with some leading to subsequent tests such as X-linked adrenoleukodystrophy (X-ALD), which require a response within a critical timeframe to increase positive outcomes [4]. The screening continues to expand as more conditions are added to the screening list, including one new secondary condition as of 2024 (Cytomegalovirus).

Parents can opt out of the newborn screening, which should include a written refusal that will be included in the medical record[3]. Research on parent willingness, attitudes, and beliefs show that some parents would refuse to participate in newborn bloodspot screening to avoid pain for the baby due to their previous experiences with healthcare services, the thought that the tests are unnecessary, religious reasons, and not trusting the government with the child's DNA[5]. It is crucial to consider factors concerning the parent and child data and how they are handled, and how this will impact the decision to take part in the blood screening. Previous studies have investigated parental psychosocial impacts on newborn screening results, including true positives and inconclusive results[5].

Healthcare providers, while mandated to offer newborn screening to all parents, may influence parent decision-making or parent perceptions [6]. Because of potential healthcare provider influence on newborn screening success rates, previous studies have demonstrated that various educational messaging be available from different sources including public information campaigns aimed at parents[7]. Florida's NBS program provides healthcare provider education and a public campaign aimed at pregnant women and families to address gaps in the Florida screening rates.

The NBS program also reports on hospital, obstetrician, and midwife screening performance measures based on samples received in quality and time-sensitivity to the Bureau of Public Health Laboratories in Jacksonville. The performance measures provide the public with information to make an informed decision on the provider and location. The aims of this study are to a) evaluate how well the Florida NBS education campaign reached the target parent audience, b) how and if new and expectant mothers in Florida interacted with the NBS educational campaign, and c) how the campaign influenced the attitudes, knowledge, and intent regarding the screening of their newborn. The campaign aims to increase awareness of the importance of newborn screening and the conditions covered in Florida.

2. Materials and Methods

A mixed methods approach was used for this evaluation, including an online survey and focus groups. The survey included only quantitative (closed-ended) questions. Focus groups aimed to provide a more comprehensive picture of what possible influence the Newborn Screening Program (NBS) educational campaign may have had on the target population. The survey and focus group questions were designed to complement one another. That is, the survey question asked the "what" questions, while the focus groups questions asked the "how," "when," and "why" questions to elicit a better understanding from participants. In addition to collecting demographic information, survey

 doi:10.20944/preprints202501.1081.v1

and focus group questions determined whether participants saw the NBS educational campaign, the medium from which they saw the campaign (different information sources), knowledge and facts about newborn screenings, and how the education materials influenced their decision to screen their newborns or plan to screen their newborns within the recommended timeframe. The target population for the survey and focus groups included pregnant women currently residing in Florida and women who had given birth in Florida during the campaign evaluation period of 2023.

2.1. Recruitment Procedures

Survey Recruitment. The Florida Center for Prevention Research (FCPR) developed a recruitment flyer for interested participants to access and complete the online survey. The flyer was posted in English, Spanish, and Haitian Creole and included an overview of the study, an invitation to participate, and a description of incentives. Participants could access the survey either through a scannable QR code on the survey or a shortened website URL. The Center for Prevention and Early Intervention Policy (CPEIP) collaborated with Florida home visiting programs, Florida Women, Infants and Children's (WIC) programs, Florida Healthy Start programs, and other maternal and child health (MCH) outreach in Florida to disseminate recruitment materials to the target population. CPEIP requested the groups post the flyer in print, in all available languages, at their offices and on their social media. Programs within the focus group target counties assisted in passing the information to the women they serve within their agencies. Other recruitment efforts included communicating with the doctors' offices where the Florida Department of Health (DOH) had previously placed the brochures, posters, and other NBS educational materials to assess their willingness to be part of the recruitment.

Additionally, sponsored Facebook ad posts focused on reaching the target audience were done to reach a broader demographic. Although this did yield a significant number of responses, it should be noted that there was an unexpectedly high number of responses that, upon further investigation, were determined to be invalid responses. Therefore, those survey responses were eliminated from the dataset. The target completion rate for the online survey was 600 respondents. This sample size was based on the number of responses needed to provide enough data for meaningful analysis and to draw reliable conclusions. To encourage a higher response rate, an incentive of a $5 Amazon gift card was offered to the first 600 verified participants.

Focus Group Recruitment. Participants in the online survey were invited to participate in a 45-to-60-minute in-person focus group. Participants were informed that they would receive a $25 Amazon gift card for participating in the focus group. At the end of the online survey, using a separate link that could not be matched to their survey responses, interested participants were prompted to share their names, emails, phone numbers, and the best time to reach them. Upon receiving the information of potential participants, FCPR contacted them via email and text message to share more details about the focus group and confirm their willingness to participate. Once they confirmed, information on each focus group was sent to participants two weeks before the date. Several reminders were sent to participants, including one week prior and one day prior, via email and text message.

FCPR and CPEIP worked diligently to recruit participants from diverse backgrounds to the focus groups, including women from the state's rural, urban, and suburban areas. Focus groups were conducted from seven target regions throughout Florida (Leon, Jackson, Dade, Duval, Orange, Palm Beach, and Hillsborough counties). Focus groups were hosted in collaborating MCH program offices in each county. Due to the low attendance rate at the in-person focus groups and the number of requests received for virtual focus groups, FCPR attempted to hold additional virtual focus groups for those who could not attend in person. However, although many women registered, no one participated, and this was determined to be an attempt to fraud FSU for the incentive money. The target number of focus groups was six, with an average of ten people per group. A total of seven in-person focus groups were held. The actual number and characteristics of focus group participants are discussed further in the Results section.

2.2. Data Collection

 doi:10.20944/preprints202501.1081.v1

Survey Instrument. In a collaborative effort that began in March 2023, the DOH Children's Medical Services (CMS) team and all three collaborating research centers meticulously designed the survey questionnaire (Appendix A). This collaboration aimed to create a tool that was both comprehensive and sensitive to the nuances of public health messaging. The final instrument consisted of 21 multiple-choice questions, carefully formulated to gauge the public's awareness of the campaign and its effectiveness. The survey was developed using an online survey platform (Qualtrics), which could easily be accessed with a shortened web address or scannable QR code. The survey included English, Spanish, and Haitian Creole language options, significantly broadening accessibility and inclusivity for Florida's diverse populations. Questions focused on assessing participants' awareness of the Florida Newborn Screening Program, their engagement with the Educational Campaign, and their knowledge of newborn screening procedures and benefits. The survey was designed to be clear, concise, and user-friendly, ensuring respondents could provide accurate and meaningful responses. Data security and respondent privacy were prioritized throughout the survey design. No personally identifiable information was collected from respondents. Before data collection, a Human Subjects Determination form was submitted to the Florida State University Institutional Review Board (IRB).

It was determined that this study protocol qualified the study for exemption; therefore, approval to proceed was given by the FSU IRB.

Survey Administration. The FSU Survey Foundry (FSUSF) administered the online survey between November 1, 2023, and December 9, 2023. The survey was strategically deployed during high engagement times to maximize respondent participation and ensure robust data collection. Since a complete sampling frame was unavailable, the survey employed a convenience sampling strategy, as discussed in the Recruitment section above. This approach facilitated rapid data collection from a readily accessible population subset.

Focus Group Instrument. FCPR developed and approved focus group questions for DOH, the funding agency, to ensure the evaluation aligned with the department's objectives (Appendix B). These questions guided the focus group discussions at each session, although the participants were free to provide additional feedback.

Focus Group Implementation. Focus groups were between 45-60 minutes in length. Sign-in sheets were collected at each session, including the date of the session, participant's name, and signature. Participants were asked to complete a Focus Group Participant Info form to gather information needed to have complete contact information for sending incentives. Sessions began by thanking participants for coming, introducing our team, and introducing the purpose of the focus group. Participants were then shown a series of NBS campaign materials, including print materials, a screenshot of the NBS website, and a brochure. Next, they were shown each NBS education campaign video (30 and 60-second versions) and the radio advertisement. Participants were given a Public Education Campaign Material Review form to record whether they recalled seeing any of the items shown (available through floridanewbornscreening.com). All focus groups were audio-recorded and transcribed. No personally identifiable information was recorded on the audio recording or transcriptions, so responses would not be connected to individual respondents. Instead, participants were labeled as "participant" on the transcript. Focus groups were only held in English due to staff limitations.

2.3. Data Analysis

Surveys. Survey data was analyzed using descriptive statistics and cross-tabulations, to answer the research questions outlined in this Evaluation Plan. This included providing demographic data of respondents, assessing the level of awareness and knowledge among the respondents, and comparing responses according to age, ethnicity, and education.

***Focus Groups*:** Focus group recordings were transcribed using Descript. Transcriptions were then verified by manually confirming the transcription against the audio recording. A thematic approach was employed to summarize each focus group's key themes. To contextualize themes identified in the data, axial coding was used to identify connections among major code categories

 doi:10.20944/preprints202501.1081.v1

from the data across all focus groups. Two separate researchers conducted independent coding to ensure inter-rater reliability.

3. Results

3.1. Survey Respondent Characteristics

From a total of 1,406 responses, we validated and analyzed 628 responses. The remaining responses were excluded after rigorous screening identified instances of "bot" activity, fake accounts, and other anomalies, which were removed to maintain data quality and accuracy. Detailed demographic characteristics that are vital for understanding the campaign's reach and impact were summarized.

Survey respondents (65%) were between 20 and 30 years old, followed by 33% in the 30-40 age group. Only 1% of respondents were over 40 years or under 20 years. Notably, mothers under the age of 30 made up over half of the respondents, a demographic particularly relevant to the objectives of the Newborn Screening Program Campaign.

In terms of racial and ethnic composition, 57.3% of participants identify as White, while 33.3% identify as Black or African American. Smaller proportions include 3.5% American Indian or Native Alaskan, 1.9% Asian, and 2.4% Native Hawaiian or Pacific Islander.

Educational attainment among respondents shows the largest proportion (37.6%) having completed a 4-year college degree. This is followed by 23.4% who have completed 2 years of college and 17.7% with some college education. Fewer respondents reported having a professional degree or technical school education (9.9%), a high school diploma (8.4%), or less than a high school education (2.2%).

The breakdown of responses by language is as follows: 19 in Haitian Creole, 3 in Spanish, and the remainder in English.

3.2. Summary of Key Survey Themes

The following summarizes key themes identified from the survey, followed by relevant tables that outline the survey data. Appendix C includes a complete set of all data tables . Relevant tables to the overall results and discussion are included in the main text. Notably, 85.2% of the mothers surveyed reported discussing the Newborn Screening Program with healthcare professionals at various stages of their maternity journey, highlighting effective communication channels (see Table 1). While 69.3% were given the option to opt out of the screening, 17% were not given this option, and 12.9% were unaware of it, indicating areas where patient education could be improved (see Table 2).

Table 1. Did any medical professionals talk to you about the purpose and benefits of the Florida Newborn Screening Program before, during, or after pregnancy?

Response	Frequency	Percent
Yes	535	85.2
No	61	9.7
I'm not sure	31	4.9
Total	627	99.8

Table 2. Were you given the option to refuse newborn screening?

ponse	Frequency	Percent
Yes	435	69.3

 doi:10.20944/preprints202501.1081.v1

No	107	17.0
I'm not sure	81	12.9
Total	623	99.2

3.3. Awareness of the Campaign.

Medical professionals (doctor's office, clinic, or hospital) informed more than half (58%) of the respondents about the Newborn Screening Program, underscoring the critical role that hospitals and clinics play in disseminating information. Traditional media outlets such as TV (15%) and radio (9.6%), as well as personal networks including family and friends (9.6%), also contributed to spreading awareness, indicating a well-rounded outreach strategy (see Table 3).

Table 3. How did you learn about the Newborn Screening Program?

Response	**Frequency**	**Percent**
TV	94	15.0
Radio Station	60	9.6
Doctor's office or Clinic	160	25.5
Hospital	204	32.5
Family and friends	60	9.6
Other (Please Specify)	12	1.9
Total	590	94.1

Overall, 75.3% of respondents recalled seeing the NBS program advertisements, with variations by age suggesting the campaign reached its intended audience. Of those who recalled seeing the advertisements, 97.6% reported that the information was easy to understand, reflecting the campaign's success in engaging its audience.

3.4. Importance of the Newborn Screening

The overwhelming majority (91.5%) recognized the importance of Newborn Screening, responding that it was either "very important" or "important" underlining the program's perceived value among new and expecting mothers and reinforcing the public health message's penetration and acceptance. Only a minimal fraction (1.7%) did not consider the screening important, suggesting widespread support for the initiative. In general, the higher the education, the higher awareness of the importance of the newborn screening.

Most Trusted Information Source. The survey also explored trust in information sources, with results indicating a strong preference for digital platforms among mothers. Social media and online resources emerged as the most trusted channels, pointing to the importance of maintaining robust, clear, and scientifically accurate online content.

3.5. Focus Group Participants

A total of 164 individuals located in regions convenient to the location of the focus groups indicated their interest in participating in a focus group on the online survey. All 164 individuals were contacted via email and text with details about the focus group, a reminder of the incentive, and a request to register for an upcoming focus group in their area. The registration process intended to gather information to ensure they met the inclusion criteria and to gather additional contact

 doi:10.20944/preprints202501.1081.v1

information. Multiple messages were sent to these individuals to encourage them to register. A total of 35 individuals registered for a focus group. Once they registered, additional emails and text messages were sent with specific details for the focus group that they registered for, with a request to confirm their attendance. Only 12 individuals confirmed attendance. In the end, a total of 13 individuals participated in the focus groups across all regions. Although this number was significantly less than the target number of participants, the responses were still enlightening and provided helpful qualitative data.

Summary of Key Focus Group Themes. Appendix D summarizes key themes from each focus group including a summary table of responses, including some quotations, of each question asked during the focus groups. The following provides a brief synthesis of key themes summarizing all the focus groups cumulatively.

Focus Group Participants. Participant Demographics: Focus groups included both first-time mothers and those with multiple children, providing diverse perspectives.

General Awareness of Newborn Screening

Mixed Awareness: Participants showed varying levels of awareness about newborn screening. Most focus group participants (75%) had heard about newborn screening, while a few others learned about it during the focus groups. One common theme was that many mothers did not have a name for the Newborn Screening Program, but after explaining the screening procedures, they recalled this happening after childbirth.

Sources of Information: Information was sporadically provided by medical professionals. Some participants did not receive detailed discussions on newborn screening during previous pregnancies.

Notable quote:

"I think we're just overwhelmed with so much information when we're pregnant, especially for the first time, that we see a lot of it. We take a lot of it in, but at least I know I didn't really have much register."

3.6. Effectiveness of Educational Campaign Materials

Recognition: There was mixed recognition of campaign materials like logos, posters, brochures, and radio/television advertisements. The sources with the highest rate of recognition included Facebook, posters, and the NBS brochure. The source with the lowest rate of recognition was the television advertisements, with only a few reporting hearing the radio ads.

Participants indicated that television and radio ads were less impactful due to consumption habits of women in their 20s and 30s. They noted that they typically stream their television media without ads, or if they are listening to the radio, they change the channel as soon as an ad comes on.

Participants communicated limited exposure to campaign materials, a total of 8 of the 13 participants (62%) reported seeing at least some of the NBS campaign materials. This underscores the importance of utilizing various dissemination channels for future campaign materials to increase the chances that materials will reach the target audience.

Design and Content: Participants gave positive feedback on the use of bright colors and engaging visuals (especially pictures of babies). Participants preferred straightforward messages about the importance of newborn screenings. When shown a screenshot of the NBS webpage, respondents provided positive feedback about the design and ease of navigation.

Preferred Media: Participants preferred social media, posters, and brochures with bright colors and engaging visuals (especially pictures of babies). Videos were appreciated but less frequently encountered. Participants indicated the videos were well done, but most stated they mostly watch television and listen to music on streaming services, so they do not encounter television or radio advertisements.

Suggestions for Improvement: Participants suggested greater visibility and distribution of materials in hospitals, clinics, and Healthy Start offices, and inclusion of detailed, easy-to-understand information in brochures. One notable suggestion was to place video advertisements on televisions in hospital rooms or in provider's waiting rooms. They suggested more focus should be given to target the intended audience through social media rather than traditional television and radio ads. They also recommended including more diversity in images.

 doi:10.20944/preprints202501.1081.v1

3.7. Experiences in Hospitals

Varied Experiences: Hospitals provided varied information about newborn screening. Some participants received detailed explanations and experienced reassurance from the information they received, while others received minimal information during the actual screening or with their discharge papers. One participant recalled receiving login information to check results after discharge and appreciated this being communicated by the hospital. A general sentiment was that newborn screening seemed to be a common, routine experience during childbirth, so they did not question it. In fact, not one focus group participant questioned the necessity of newborn screening.

Communication with Medical Professionals: Direct discussions with doctors and nurses were valuable but inconsistent across healthcare facilities, with some participants stating the nurses explained the procedure while it was being done, while others had very little information given to them. Sources of information included obstetricians, nurses performing tests, childbirth classes, and hospital tours. A common theme from mothers was that more information may have been shared with them, but because there is so much information coming at them so quickly, they may have not retained the information.

The reported experiences from focus groups were slightly different from the surveys. Over 85% of survey respondents recalled a medical professional communicating with them about newborn screening, either before, during, or after childbirth. In comparison, 9 of 12 (75%) focus group participants who responded to this question indicated that a medical professional had spoken with them about newborn screening. Since the focus groups had a limited sample size, results are not generalizable and variations from surveys with a larger sample size are to be expected.

Notable quotes:

"It just seemed routine and expected, the medical professionals didn't say much before doing it."

"Everybody was amazing and…explained what was going on…. She was like 'she passes!'"

"It made me glad that they were doing it. Especially as a first-time parent, you don't know what to expect…so having them come in and explain what was happening...reassures us."

4. Discussion

Participants expressed high levels of trust in medical professionals for health information but noted a desire for more detailed and accessible explanations. Several participants, particularly those from rural areas, indicated the need to seek care outside of their county, in larger cities. This highlights the need for targeted rural outreach, a strategy shown to be effective in previous NBS campaigns that combined healthcare provider engagement with social media platforms like Facebook and Instagram to reach medically underserved areas [8, 9]

While friends' advice was valued, participants considered it secondary to professional guidance, particularly when the friend lacked personal experience with childbirth. Trust in digital sources, such as Google and social media platforms, varied widely. Social media emerged as a preferred and frequently used medium for information, with many participants citing it as their first exposure to the NBS program. However, concerns about the inconsistency of information from Google searches led participants to cross-reference multiple websites, such as Baby Center, to verify accuracy. Despite ongoing efforts to improve the reliability of online health information [10] the burden of determining accuracy remains on the user.

Participants provided actionable suggestions for enhancing future NBS campaigns, including increased use of social media and streaming services like Spotify for public service announcements, as these were seen as more effective than traditional media such as cable TV or radio. They also recommended earlier integration of focus group feedback in the development of educational materials to ensure relevance to the target audience. For example, several participants emphasized the need for materials featuring more diversity and cultural representation.

Focus group discussions further highlighted the importance of diversity in communication and dissemination channels. Materials with the highest recognition rates included Facebook posts, posters, and brochures, while video and audio advertisements were less effective in reaching the

 doi:10.20944/preprints202501.1081.v1

target audience. Participants recommended that future campaigns prioritize a mix of formats to ensure broader reach and impact.

Despite recognizing hospitals and physicians as primary sources of education about NBS, participants emphasized the need for more proactive and transparent communication during prenatal and postnatal care. They expressed a desire for detailed information about the purpose and scope of NBS, as well as timely access to screening results. As one participant noted, "I need to know what exactly they're screening for, and not just being told we're gonna prick your heel… and not really know why." This feedback underscores the need for more thorough patient education and engagement before and during hospital stays. Finally, participants identified gaps in healthcare provider communication, suggesting that future evaluations may want to include Florida's provider dashboard data and grading scale to provide a more robust illustration of the gaps among healthcare and birth facilities. While this falls outside the scope of the current evaluation, such measures could enhance trust and satisfaction in future initiatives.

5. Conclusions

The collaboration to better understand the level of awareness of the Florida Newborn Screening Program (NBS) and the effectiveness of the Statewide NBS Educational Campaign through quantitative and qualitative measures found that overall, there is a general awareness of the Florida NBS, although many respondents reported a lack of detailed knowledge about the purpose and scope of newborn screening.

While the majority of survey and focus group respondents reported having discussions with healthcare professionals about the NBS at various stages of their maternity journey, misunderstandings about the process remain. Survey respondents and focus group participants were consistent in how they learned about NBS, with their top two ways of learning being the hospital (during prenatal tours or childbirth classes) or their obstetrician/clinic.

In terms of reaching the primary target audience of pregnant women and new mothers with the NBS educational campaign, findings were mixed between the survey and focus groups, however, there is a general awareness of the NBS.

The high recall rate of advertisements and their clarity underscore the campaign's success in engaging and educating its audience. The overwhelming recognition of the importance of newborn screening among respondents highlights the campaign's impact on public perception and acceptance.

Despite the challenges encountered with online surveys, such as the need for the elimination of duplicate survey responses and the low attendance rate in some focus groups, the study achieved a robust data collection.

The mixed methods approach enabled an evaluation that included both breadth and depth. However, it should be noted that while focus group data offers valuable insights into the collective perspectives and experiences of participants, it is essential to recognize its inherent limitations. The findings are often context-specific, influenced by group dynamics, and may not be generalizable to broader populations.

Additionally, the subjective nature of qualitative data analysis can introduce potential biases. Despite these limitations, the focus groups provided a powerful tool for exploring nuanced issues surrounding the experiences with NBS and the reach of the educational campaign that complemented the online survey.

Based on these findings, we concluded that the Florida NBS Educational Campaign demonstrated moderate effectiveness in increasing awareness and understanding of the importance of newborn screening, contributing to the health and well-being of infants across the state. Future efforts should focus on enhancing communication strategies to better reach the target audience by addressing the barriers identified during the evaluation, including broader dissemination of educational materials to ensure the intended target audience is exposed to information about newborn screening. Continued collaboration and rigorous evaluation will be essential in sustaining and improving the impact of the Florida NBS educational campaign.

 doi:10.20944/preprints202501.1081.v1

Author Contributions: Conceptualization, C.W. M.R., M.J.; methodology, C.W..; software, M.J.; validation, C.W., and M.J.; data analysis, M.J., C.W., T.G.; writing—original draft preparation, C.W., M.R., T.G.; writing—review and editing, M.R., T.G.; visualization, M.J.; funding acquisition, C.W. All authors have read and agreed to the published version of the manuscript.

Funding: This research was funded by The Florida Department of Health (FDOH) Division of Children's Medical Services (CMS), contract numbers C1643E and C2708F.

Institutional Review Board Statement: Ethical review and approval were waived for this study due to being determined as exempt (tests, surveys, interviews, or observation) by the Florida State University Office for Human Subjects Protection, June 21, 2023 **(Study ID 00004291)**.

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Data Availability Statement: The original contributions presented in this study are included in the article/supplementary material. Further inquiries can be directed to the corresponding author(s).

Conflicts of Interest: The authors declare no conflicts of interest.

Appendix A

Survey Questionnaire

The Florida Department of Health (FDOH) is conducting a survey to assess the effectiveness of the Newborn Screening (NBS) Program educational campaign. The Department encourages your participation in this survey. If you have questions, please call the Florida State University Survey Foundry at 1-888-585-4933.

1. Do you currently live in Florida? Yes No
2. What year were you born?
3. Which race best describes you?

- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Other
- Prefer not to answer

4. Which ethnicity best describes you?

- Hispanic
- Not Hispanic
- Prefer not to answer

5. What's your highest education level?

- Less than high school
- High school graduate
- Some college
- 2 year degree
- 4 year degree
- Professional degree/technical degree
- Doctorate

6. How many people are in your household?
7. How old is your youngest child?
8. Did you give birth within the past 12 months? Yes No
9. What is your most trusted method of receiving information?

- TV (Networks, cable stations, etc.)
- Social Media (Facebook, Twitter, Instagram etc.)
- Online (Website, Pandora, etc.)
- Radio
- Newspapers or Magazines

 doi:10.20944/preprints202501.1081.v1

- Others (Please specify)

10. Have you seen or heard advertisements for the Florida Newborn Screening Program? Yes No I am not sure

11. How did you learn about the Newborn Screening Program?

- TV
- Radio Station
- Doctor's office or Clinic
- Hospital
- Family and friends
- Never heard of Newborn Screening
- Other (Please specify)

12. Have you visited the Florida Newborn Screening Program website? Yes No

13. Did any medical professionals talk to you about the purpose and benefits of the Florida Newborn Screening Program before, during, or after pregnancy? Yes No I am not sure

14. Were you given the option not to have your newborn screened? Yes No I am not sure

15. If you chose not to have your newborn screened, which of the following factors influenced your choice?

- I did not have enough information
- My newborn was screened
- Other (Please specify)

16. Did your pediatrician discuss your baby's newborn screening results with you? Yes No I am not sure

17. Were you given a copy of your baby's newborn screening results? Yes No I am not sure

18. To the best of your knowledge, how important is newborn screening?

- Very important
- Important
- Neutral
- Somewhat important
- Not important

Appendix B

Focus Group Instrument

The following questions will be used during all Focus Groups:

1. Do you recognize any of the screenshots or advertisements? (Paired with a package of screenshots, video and radio PSA, and educational materials for visual prompts)
2. What is your most trusted mode of receiving information? (TV news, Facebook, internet ads, etc.)
3. Would you trust information concerning your health or your baby's health from a friend or a medical professional before, during or after childbirth?
4. Have you heard about newborn screening and how?
5. Did any medical professionals talk to you about newborn screening either before, during, or after pregnancy?
6. Did the information received from those medical professionals change your feelings on the screening process?
7. If you did see any of the newborn screening ads, did it increase your knowledge or curiosity about the newborn screening program?
8. Did your primary care physician discuss the newborn screening results with you after the baby was born?
9. How old is your youngest child?
10. What specifically did you enjoy about the presented newborn screening advertisements/screenshots?
11. Have you visited the Florida newborn screening website? What information provided on the website did you find to be most beneficial/interesting?

 doi:10.20944/preprints202501.1081.v1

12. Have you received any information regarding newborn screening from attending a class or health fair/event?
13. Were you given a copy of your baby's newborn screening results? Given to you by pediatrician or who?
14. Is there anything specifically that you wish you had known about the newborn screening program at the time of your baby's birth?
15. During your pregnancy or hospital stay, were you educated on the newborn screening program? How was the information provided to you? (Verbally or brochure/pamphlet-educational material)
16. GENERAL QUESTION (for additional feedback) Is there anything discussed today you would like more information on, do you have anything to add/share regarding the newborn screening program?

Appendix C

Complete Figures and Tables

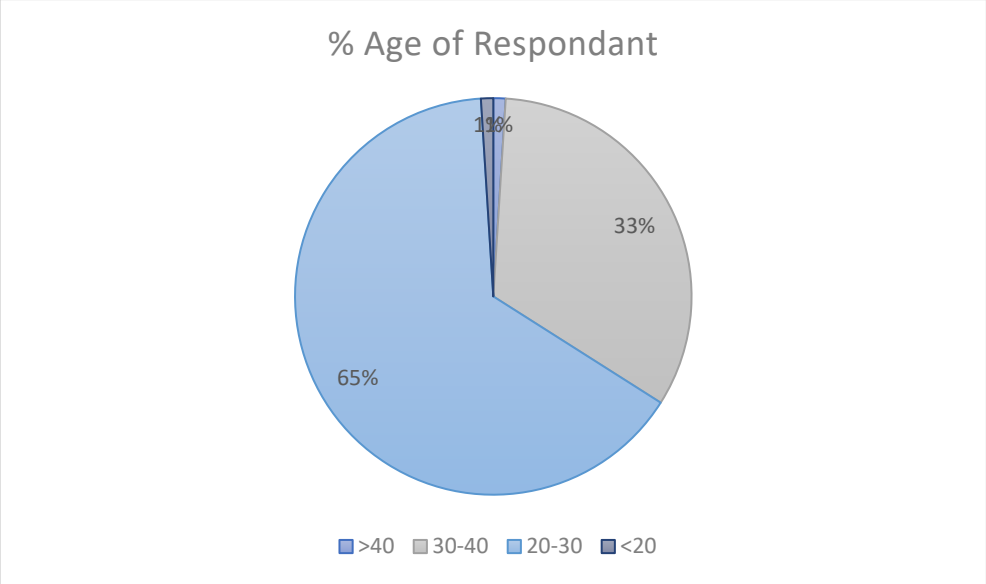

Figure 1. Survey Age Distribution.

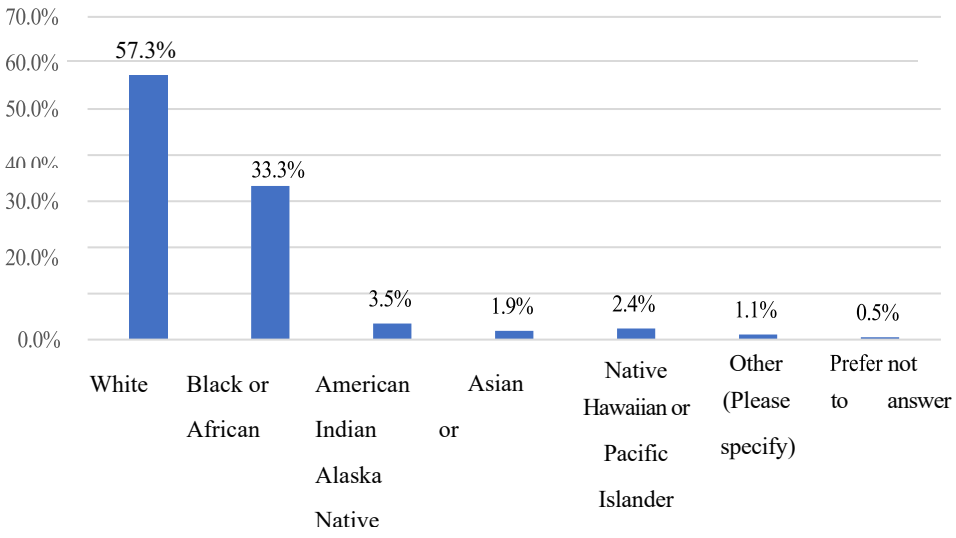

Figure 2. Survey Respondents by Race.

 doi:10.20944/preprints202501.1081.v1

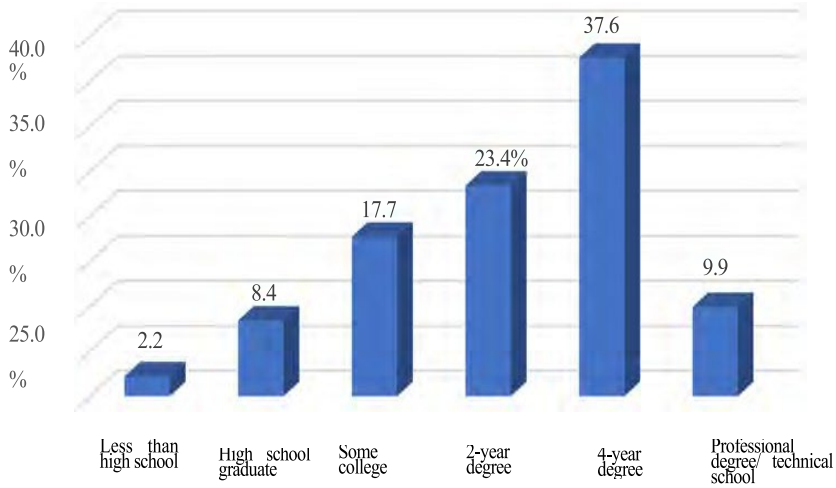

Figure 3. Survey Respondents by Educational Level.

Table 1. Did any medical professionals talk to you about purpose and benefits of the Florida Newborn Screening Program before, during, or after pregnancy?

Response	Frequency	Percent
Yes	535	85.2
No	61	9.7
I'm not sure	31	4.9
Total	627	99.8

Table 2. Were you given the option to refuse newborn screening?

ponse	Frequency	Percent
Yes	435	69.3
No	107	17.0
I'm not sure	81	12.9
Total	623	99.2

Table 3. How did you learn about the Newborn Screening Program?

Response	Frequency	Percent
TV	94	15.0
Radio Station	60	9.6
Doctor's office or Clinic	160	25.5
Hospital	204	32.5
Family and friends	60	9.6

 doi:10.20944/preprints202501.1081.v1

Other (Please Specify)	12	1.9
Total	590	94.1

Table 4. Have you seen or heard advertisements for the "Florida Newborn Screening Program"? * Age by group: Crosstabulation.

		Younger than 20 years old	20 to 30 years old	30 to 40 years old	Older than 40 years old	Total
Yes	Count	5	286	142	2	435
	% within Age by group	62.5%	75.1%	75.9%	100.0%	75.3%
No	Count	3	95	45	0	143
	% within Age by group	37.5%	24.9%	24.1%	0.0%	24.7%
Total	Count	8	381	187	2	578
	% within Age by group	100.0%	100.0%	100.0%	100.0%	100.0%

Table 5. Was the information easy to understand? (only those who reported seeing the NBS advertisements responded to this question).

Response	**Frequency**	**Percent**
Yes	440	97.6
No	11	2.4
Total	451	100.0

Table 6. To the best of your knowledge, how important is newborn screening? * Age by group Crosstabulation.

		Younger than 20 years old	20 to 30 years old	30 to 40 years old	than 40 years old	Total
Very important	Count	5	277	124	2	408
	% within Age by group	55.6%	71.6%	65.6%	100.0%	69.5%
Important	Count	2	77	50	0	129
	% within Age by group	22.2%	19.9%	26.5%	0.0%	22.0%
Neutral	Count	2	26	12	0	40
	% within Age by group	22.2%	6.7%	6.3%	0.0%	6.8%
Unimportant	Count	0	6	3	0	9
	% within Age by group	0.0%	1.6%	1.6%	0.0%	1.5%
Very	Count	0	1	0	0	1

 doi:10.20944/preprints202501.1081.v1

	unimportant						
		% within Age by group	0.0%	0.3%	0.0%	0.0%	0.2%
Total		Count	9	387	189	2	587
		% within Age by group	100.0%	100.0%	100.0%	100.0%	100.0%

Table 7. Importance * What is your highest education level? Crosstabulation.

		Less than high school	High school graduate	Some college	2-year degree	4-year degree	Professional degree/ technical degree	Doctorate	Total
Important / Very Important	Count	11	45	93	135	221	56	5	566
	%	78.6%	88.2%	85.3%	92.5%	95.3%	93.3%	100.0%	91.7%
Unimportant / Very Unimportant	Count	1	1	5	0	3	0	0	10
	%	7.1%	2.0%	4.6%	0.0%	1.3%	0.0%	0.0%	1.6%
Neutral	Count	2	5	11	11	8	4	0	41
	%	14.3%	9.8%	10.1%	7.5%	3.4%	6.7%	0.0%	6.6%
Total	Count	14	51	109	146	232	60	5	617
	%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Table 8. Importance * Which ethnicity best describes you? Crosstabulation.

			Hispanic	Not Hispanic	Total
Importance	Important / Very Important	Count	135	425	560
		% within Q4 Which ethnicity best describes you?	88.2%	92.8%	91.7%
	Unimportant / Very Unimportant	Count	5	5	10
		% within Q4 Which ethnicity best describes you?	3.3%	1.1%	1.6%
	Neutral	Count	13	28	41
		% within Q4 Which ethnicity best describes you?	8.5%	6.1%	6.7%
Total		Count	153	458	611
		% within Q4 Which ethnicity best describes you?	100.0%	100.0%	100.0%

Table 9. Focus Group Participation Numbers.

County where Focus Group Held	**Counties included in recruitment list**	**Location of Focus Group**	**Number indicating interest in online survey**	**Number Registered for focus group**	**Number Confirmed**	**Number Actually Attended**

 doi:10.20944/preprints202501.1081.v1

Dade	Miami-Dade	United Way, Miami	55	14	7	0
Duval*	Duval, Nassau, Clay, St. Johns	Northeast Florida Healthy Start Coalition, Jacksonville	9	1	1	2
Hillsborough	Hillsborough, Manatee, Polk, Sarasota, Pinellas,	Children's Board of Hillsborough County, Tampa	23	6	1	1
Jackson	Jackson, Gadsden	Healthy Start, Marianna	5	2	0	4*
Leon	Leon	Florida Center for Prevention Research, Tallahassee	2	3	2	3
Orange		Orange County DOH, Ocoee	24	6	0	2*
Palm Beach	Palm Beach, Broward, Martin	Children's Services Council of Palm Beach County, Boynton Beach	46	3	1	1
TOTAL			**164**	**35**	**12**	**13**

Table 10. Focus Group Participant Demographics.

County	White	Black	Hispanic	Total
Dade	0	0	0	0
Duval	0	2	0	2
Hillsborough	1	0	0	1
Jackson	3	1	0	4
Leon	3	0	0	3
Orange	2	0	0	2
Palm Beach	0	1*	0	1
Total	**9**	**4**	**0**	**13**

Table 11. General Awareness of Newborn Screening (Focus Groups).

Question	Duval	Jackson	Orange	Palm Beach	Leon	Hillsborough
Have you heard about newborn screening?	Yes-1 No-1	Yes-2 Vaguely-1	Yes-2	No-1	Yes-3	Yes-1
How did you hear about newborn screening?	Hospital, Friends	OB checkups, childbirth class WIC	Hospital	N/A	Birthing class, friends and family, Hospital	OB, Hospital

Table 12. Public Education Campaign Material Review Summary.

	Responses to question, "Do you recognize any of these materials?"

 doi:10.20944/preprints202501.1081.v1

Item Description	Yes	No	Not Sure
NBS Logo	3	7	3
NBS Website	1	11	1
Facebook Post #1 (dated December 10)	4	8	1
Facebook Post #2 (dated January 6)	5	7	1
Poster-Pregnant woman with Sonogram image	4	7	2
Poster-Redhead with Sonogram image	1	9	3
Poster-Baby	4	7	2
NBS Brochure	4	6	3
NBS Screening Radio ad (audio)	2	8	3
Blood Spot FFI Video 30 sec		10	3
Blood Spot FFI Video 60 sec		11	2
Compilation FFI 30 sec		10	3
Compilation FFI 60 sec		11	2
Hearing FFI 30 sec		9	12
Hearing FFI 60 sec	1	9	2

Table 13. Experiences in Hospitals.

Question	Duval	Jackson	Orange	Palm Beach	Leon	Hillsborough
Did any medical professionals talk to you about newborn screening either before, during, or after pregnancy?	Yes-2 After birth	Yes-2 OB, folder from hospital	Yes-2 After childbirth	Not sure-1	Yes-2 No-1 Nurse who did test explained it, during hospital tour	Yes-1 After childbirth
During your pregnancy or hospital stay, were you educated on the newborn screening program? If so, how was the information provided to you?	Maybe-1 No-1	No-1	Yes-2 In childbirth class, hospital tour, during hospital stay	Yes In hospital (handout)	No	A little (brochure)
Did the information received from those medical professionals change your feelings on the screening process?	No, but it helped them understand it better.	No, it seemed routine and expected (all agreed)	They were glad they were doing the screening.	Not answered	Just thought it was a normal part of having a baby.	No

Appendix D

Summary of Key Focus Group Themes

Research Questions	Participant Summary Coder #1	Participant Summary Coder #2

 doi:10.20944/preprints202501.1081.v1

1. Do you recognize any of the screenshots or advertisements? (*Paired with a package of screenshots, video and radio PSA, and educational materials for visual prompts)*	Newborn logo- Yes, not sure Website- Not sure, Yes, no Social media post- Yes, yes, yes Social media post- Yes, yes, yes Poster- No, Not sure, yes Poster- No, Not sure, not sure Poster- Yes, Not sure, not sure Pamphlet- Yes, Not sure, yes Audio- Yes, Yes, no Video- No, No, no Video- No, No, no	
2. What is your most trusted mode of receiving information? *(TV news, Facebook, internet ads, etc.)*	TV news Health care provider and social media. Social media Social media websites local newspaper local news affiliates	Jax: social media, Social media Marianna: One said they don't trust the internet (especially Google searches)), but they trust doctors; other said they may google and compare across sites (e.g. Baby Center); but friends may steer you wrong so internet better. Orange: News, social media, websites Palm Beach: Healthcare and social media Tally: Internet news/websites of local newspaper or local news affiliates; news app on phone, internet, word of mouth Tampa: TV news
3. Would you trust information concerning your health or your baby's health from a friend or a medical professional before, during or after childbirth?	Trust medical professional more than a friend A friend and a doctor A friend Medical professionals	Jax: Medical professional more than friend because they are trained. (both agreed) Marianna: Some friends if they've earned trust and have experience/multiple children, but still fact check; some are skeptical of "old school" doctors who are "stuck in their old ways"; didn't trust local rural doctor so traveled to Tallahassee.
		Orange: Friend friend (depends on the friend-only those who've had other children) Palm Beach: Yes, friends and a doctor Tally: Yes, all of the above, but trust doctor more Tampa: Medical prof

 doi:10.20944/preprints202501.1081.v1

4. Have you heard about newborn screening and how?	Yes No Yes No "my OB, and the hospital when I had her". Brochure "The hospital cause she had to get screened" "birthing class"	Jax: No, Yes From where: Hospital, other friends Marianna: Vaguely, Yes, I think so; Yes-During checkups, childbirth class (two said this), WIC office, Yes Note: Some mothers changed responses once they had more information about what newborn screening was, as they didn't have the terms for it. Orange: Yes-once it was happening; Yes but didn't know what it was called at the moment Palm Beach: No Tally: Yes, Yeah, Sure, birthing class, friends and family, hospital tour Tampa: Yes, from OB and hospital during delivery
5. Did any medical professionals talk to you about newborn screening either before, during, or after pregnancy?	"Yeah, when she was born. It was just brought up just in passing, before." No After pregnancy Yes during the pregnancy "Only when it was happening"	Jax: Yes, Yes After birth Marianna: OB, not yet (currently pregnant), remembers child receiving the screening and got a folder with info, but there is a lot coming at you after birth. Orange: Yes, "everybody was amazing and…explained what was going on….She was like 'she passes!'" Yes, after baby was born. Palm Beach: I don't know Tally: No; Nurse doing test, now wonder if the information was in the discharge packet; Yes during hospital tour Tampa: Yes after childbirth
6. Did the information received from those medical professionals change your	No Yes "It just made me glad that they were doing it"	Jax: No, but I understand it better (both participants agreed). Marianna: It just seemed routine and expected, the medical professionals didn't say much before doing it. All

 doi:10.20944/preprints202501.1081.v1

feelings on the screening process?	No, "just make me more aware of what is expected".	mothers stated it just seemed to be the routine part of delivery so they didn't question it. Orange: "It made me glad that they were doing it. Especially as a first time parent, you don't know what to expect…so..havin them come in and explain what was happening...reassures us." Palm Beach: The doctor Tally: No, just thought it was part of it, part of having a baby; yeah. Tampa: No
7. If you did see any of the newborn screening ads, did it increase your knowledge or curiosity about the newborn screening program?	"Definitely getting little bit more information". "Not curiosity but increased reassurance"	Jax: Yes, they increased my knowledge Marianna: No, she saw on FB but she didn't question its validity, was matter of fact, normal, status quo, didn't know it was an option Orange: "Definitely reassurance that it was happening and that I knew that there would be screening. I think we're just overwhelmed with so much information when we're pregnant, especially for the first time, that We see a lot of it. We take a lot of it in, but at least I know I didn't really have much registers." Palm Beach: She didn't understand Tally: Only saw posters in pediatrician's office after Tampa: Yes,definitely getting little bit more information
8. Did your primary care physician discuss the newborn screening results with you after the baby was born?	The neonatologist did Yes No "I guess no news is good news" "The nurse that did the test was like, oh, she passed"	Jax: Yes (hospital doc did); Yes (with 2nd child) Marianna: No, but they didn't know they should be asking; one mother recalled being given login info to hospital to see results. Orange: Yes, the hearing immediately; yes, that everything was good." Palm Beach: She didn't know Tally: Nope; nurse that did the test said she passed; Yes, that everything looked normal, "no news is good news". Tampa: Neonatologist

 doi:10.20944/preprints202501.1081.v1

9. How old is your youngest child?	5 months 9 months 11.5 months 13 months 15 months 16 months	Jax: 3 mo, 6 yrs Marianna: expecting (3), 5 mo Orange: 9 mo, 6 yrs (currently expecting) Palm Beach: 5 mo Tally: 16 mo old (also expecting); 12 mo, 15 mo Tampa: 11 month
10. What specifically did you enjoy about the presented newborn screening advertisements/screenshots?	Getting more knowledge, "to know what exactly they're screening for, and not just being told we're gonna prick your heel, and we're gonna do this, and not really know why". Brochure/ pamphlet, website Poster, video The logo and the 3 icons	Jax: Bright colors, important info, symbols/icons Fave poster: 5 (pregnant woman holding sonogram); brochure is helpful Marianna: Facebook ads, posters with photographs (especially one with baby) Videos-liked the cute baby boy, preferred 30 second version Orange: Loved the logo, very well done; poster with baby was favorite; videos were really good but never saw them because they don't watch much TV, but they were impactful, videos with kids were cute. About videos: It's reassuring knowing that if something goes wrong like if there is a challenge with a test result that They will take care of it, you know, they'll help provide you with options. Palm Beach: Preferred brochure and website Tally: Poster with baby; brochure; logo For videos: one participant did not like the phrase "as a dad", feeling like it was too gendered, but otherwise felt like videos were very well done, cute kids, good storytelling approach. Felt radio ads were "pointless." For radio ad: Stated that younger childbearing age is not listening to the radio or if they do, they switch channels if ad comes on. They thought billboard would've been better seen. Suggested Spotify ads, which is where people are. Tampa: Getting more knowledge, "it's nice to know what exactly they're screening for…really having the why, on why everything is being done."

 doi:10.20944/preprints202501.1081.v1

11. Have you visited the Florida newborn screening website? What information provided on the website did you find to be most beneficial/interesting?	No No No No	Jax: No, But liked the clarity, design, easy to navigate Marianna: No Orange: No, No Palm Beach: No Tally: No; One participant said it was "white centric"/lacked diversity, liked the three icons and layout Tampa: No, "I think I've seen it, but I don't think I have actually browsed it."
12. Have you received any information regarding newborn screening from attending a class or health fair/event?	No No Yes, in a pregnancy class	Jax: No, Maybe Marinna: Childbirth class (2) Orange: Yes at pregnancy class Palm Beach: No Tally: Birthing class Tampa: No
13. Were you given a copy of your baby's newborn screening results? Given to you by pediatrician or who?	Yes Yes Yes No, I think you have to request in writing The hospital The hospital The hospital	Jax: Probably in discharge papers, yes Marianna: given part of brochure Orange:Yes (hearing result, given by hospital) Palm Beach: Yes (by hospital) Tally: Might be in the take home folder, recall maybe seeing test results; given in discharge papers Tampa: I believe so, by the hospital
14. Is there anything specifically that you wish you had known about the newborn screening program at the time of your baby's birth?	I don't think so. Like I said, "I would've liked to know a little bit more of things that were screened for, and exactly why they're doing it. Everything is so quick when you're in the hospital". I don't know	Jax: All of this information; it depends how long you stay at hospital-longer stays get more info Marianna: Wish they would've been given results right at birth; what to look for, more information, wish they would've known more about NSP Orange: What they're screening for Palm Beach: I don't know Tally: No, because I just thought it was part of the process." Tampa: "I would've liked to know a little bit more of things that were screened for, and exactly why they're doing it."
15. During your pregnancy or hospital stay, were you educated on the newborn screening program?	A little. Yes	Jax: No, maybe Marianna: No Orange: Yes, Yes, in childbirth class, hospital tour, during hospital stay

 doi:10.20944/preprints202501.1081.v1

How was the information provided to you? (Verbally or brochure/pamphlet-educational material)	A brochure. "I definitely would have liked a little bit more verbal explanation" A brochure, no verbal explanation A brochure	Palm Beach: Yes, the hospital (gave handout but didn't explain it) Tally: No. One person questioned whether or not it was even optional, could you opt out of it; other wondered if the results would be helpful to other doctors/future medical decisions Tampa: A little, not as much as I would've liked to have seen. It was a brochure.
16. GENERAL QUESTION (for additional feedback) Is there anything discussed today you would like more information on, do you have anything to add/share regarding the newborn screening program?	I don't think so. No "I kind of wish that like I had heard a little bit more of more than she's good"." if you're going to do radio ads, like. Spotify ads" "no diversity on the website, all white" "white centric"	Jax: wanted website address to search (both) Marianna: Asked if newborn screening was an automatic thing after birth; pregnant women are flooded with so much info after birth, its hard to keep track of everything, new parent brain; "if I'm the most important thing to my baby, then they should make an effort to make sure that I have that information, make sure I know that this is what you're putting in the folder, help me to have an understanding." They suggested that the ads should be playing in the hospital room on the TV in rooms. There was more emphasis on postpartum depression. They'd like to know even if the baby passed with "flying colors". Need more focus on patient education and care. Orange: "I kind of wish that like I had heard a little bit more of more than she's good. I also know people are pressed for time and I'm a new mom, I'm not gonna remember everything, but like, it still would be interesting to hear." Just a high level of what they are testing for. Tally: Reiterated lack of diversity in ads; wish they would've understand their rights to request results Tamps: No

References

1. Dubay, K.S. and T.L. Zach, *Newborn Screening*, in *StatPearls*. 2024: Treasure Island (FL).
2. HRSA, Recommended Uniform Screening Panel, in Advisory Committee on Heritable Disorders in Newborns and Children 2023.
3. Florida Department of Health. *Florida Newborn Screening*. 2023; Available from: floridanewbornscreening.com

 doi:10.20944/preprints202501.1081.v1

4. Zoullas, S., et al., Initial evaluation of newborn screening for X-linked adrenoleukodystrophy in South Florida. Genetics in Medicine Open, 2023. **1**: p. 100399.
5. van der Pal, S.M., et al., Parents' views on accepting, declining, and expanding newborn bloodspot screening. PLoS One, 2022. **17**(8): p. e0272585.
6. Hayeems, R.Z., et al., Informing Parents About Expanded Newborn Screening: Influences on Provider Involvement. Pediatrics, 2009. **124**(3): p. 950-958.
7. Franková, V., et al., *Factors Influencing Parental Awareness about Newborn Screening*. Int J Neonatal Screen, 2019. **5**(3): p. 35.
8. Raia, M.H., et al., One Size Does Not Fit All: A Multifaceted Approach to Educate Families about Newborn Screening. International Journal of Neonatal Screening, 2024. **10**(3): p. 44.
9. Center., P.R. *Social Media Fact Sheet*. 2024; Available from: https://www.pewresearch.org/internet/fact-sheet/social-media/.
10. Daraz, L., et al., Assessing Credibility: Quality Criteria for Patients, Caregivers, and the Public in Online Health Information-A Qualitative Study. J Patient Exp, 2024. **11**: p. 23743735241259440.