

THE NEWBORN SCREENING FAMILY EDUCATION PROGRAM

MAY 2022



THANK YOU

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OUR VISION

To create a landscape where all families have equitable access to newborn screening information

OUR MISSION

To meet families where they are

THE NEWBORN SCREENING FAMILY EDUCATION PROGRAM



1

FAMILY EDUCATION

Increase by 20% from baseline, the number of parents and families trained and educated on the newborn screening system annually.

2

PARTNERSHIPS

Increase by 15% from baseline, the number of partnerships to increase awareness of newborn screening and to facilitate the dissemination of materials to the target audiences

3

FAMILY ENGAGEMENT & LEADERSHIP

Increase by 20% from baseline the number of families/parents trained that report increased knowledge, skill, ability and self-efficacy to serve as leaders on newborn screening systems-level teams.

4

MEDICALLY UNDERSERVED FAMILIES

Increase by 10% from baseline, the outreach to medically underserved populations and increase by 10% the number of medically underserved individuals that are aware of newborn screening and have access to information on the newborn screening system.

The primary focus of the The Newborn Screening Family Education Program is to educate, engage and train families.



OUR
APPROACH

- Connect
- Convene
- Create
- Collaborate
- Collect
- Communicate



OUR PROGRAM TODAY

234 <i>families trained</i>	25 <i>org & individual partners</i>	12 <i>Ambassadors</i>	>3000 <i>MUP aware of NBS</i>
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The Newborn Screening Family Education Program (Navigate Newborn Screening) is dedicated to developing opportunities for all families to learn about newborn screening and to develop training and educational resources that build confidence for families to become leaders in the newborn screening system.



The NBS Family Education Program

Navigate Newborn Screening
An Expecting Health Program

Education & Training

- ONLINE LEARNING CURRICULUMS
- VIDEOS
- MICROLEARNING
- WEBPAGES/BUNDLES

Awareness Campaigns

- *PRENATAL EDUCATION**
- *SOCIAL MEDIA**

Family Leadership

- NBS AMBASSADOR PROGRAM
- WEBINARS
- COMMUNITIES OF PRACTICE
- DISCUSSION GROUPS

EDUCATION IS MEETING FAMILIES WHERE THEY ARE

WHAT WE HAVE SEEN



WE HAVE INCREASED
AWARENESS &
EDUCATION
OPPORTUNITIES, BUT IT
REQUIRES MULTIPLE
STRATEGIES FOR SUCCESS



BOTH ORGANIZATIONAL
AND INDIVIDUAL
PARTNERSHIPS ARE
CRITICAL TO MEET
FAMILIES WHERE THEY
ARE



INNOVATIVE ONLINE
& IN-PERSON
STRATEGIES ARE
REQUIRED TO REACH
FAMILIES IN MUC

WHY DO WE NEED PRENATAL NBS EDUCATION



Receiving NBS information prenatally and from a health care provider increases parent satisfaction.¹



Parents state that NBS education should start prior to labor and delivery.^{2,3,4}



Prenatal NBS education is recommended by experts, including ACOG.^{5,6}



Prenatal NBS education is not common practice among prenatal care providers.⁷

PRENATAL EDUCATION PILOT

- To increase awareness of the process and importance of newborn screening (NBS) in medically underserved populations by introducing education during routine pregnancy visits.
- To assess accuracy of knowledge regarding how, when and why newborn screening occurs.
- To provide resources for families for additional information regarding newborn screening should their baby have an out-of-range result.



ALL BABIES BORN IN THE UNITED STATES GET NEWBORN SCREENING.

Many families do not know about this important screening before they deliver their baby. Learning about this during pregnancy will **help you become more comfortable with newborn screening.** It will also help you **know where to go if you need more information.**



“ That was the blood draw that would reveal she had a life threatening **treatable** metabolic disorder called Maple Syrup Urine Disease.

Because of this public health program we were able to get a timely and accurate diagnosis, begin treatment, and prevent irreversible brain damage. We are forever thankful for newborn screening! ”

-Susan Mays
Mother of a child with a newborn screening condition



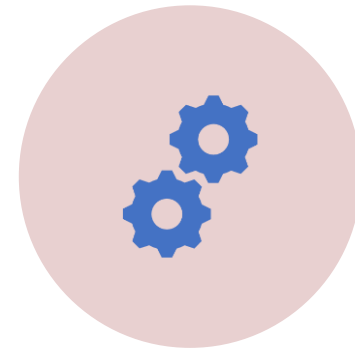
KEY STRATEGIES USED IN PILOT DESIGN



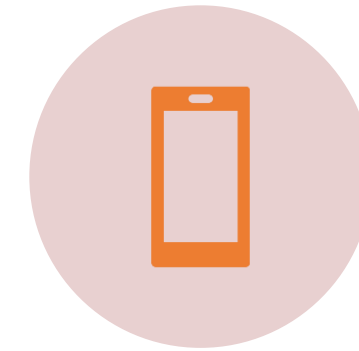
UNDERSTAND
CULTURAL
PERSPECTIVES



LEVERAGE
TRUSTED
HEALTH CARE
PARTNERS



INCORPORATE
INTO EXISTING
WORKFLOWS



USE PRACTICAL
MATERIALS &
RELATABLE
EDUCATIONAL
MATERIALS



BE
TRANSPARENT
TO BUILD
TRUST

WHAT DID WE DO?

Target & partner with
a medically
underserved
community-based
prenatal groups

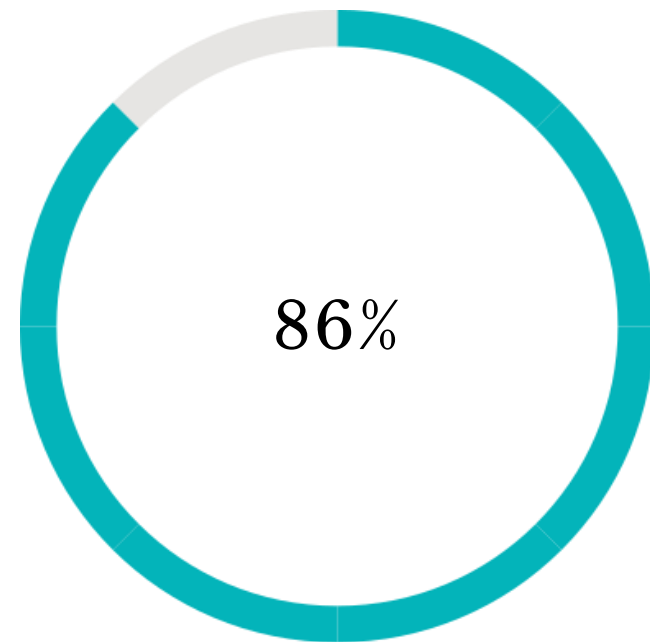
Develop & implement
an educational
initiative for patients

Develop a repeatable
model for other
prenatal care centers
to leverage

1. LBJ Hospital: Latino Community in Houston, TX *(June-Aug 2021)*
2. Indiana Community Health Clinic: Plain Community in Indiana *(Oct 2021-Jan 2022)*
3. Prenatal Tribal Health Clinic: Tribal Community *(launching spring 2022)*

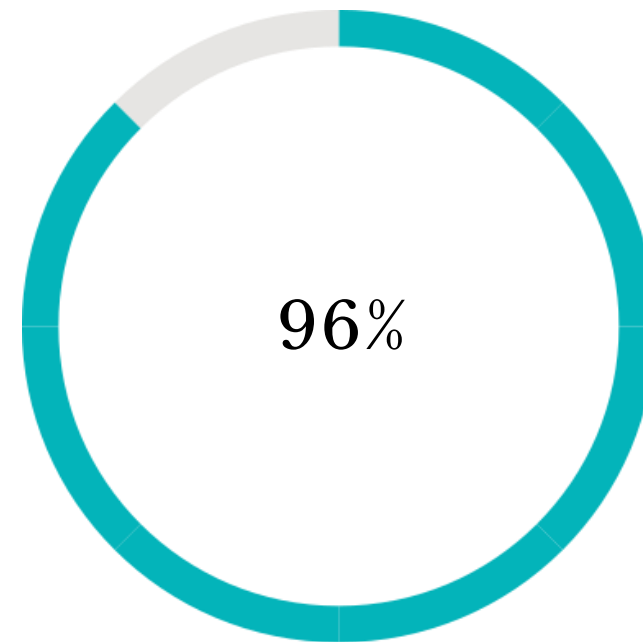
RESULTS FROM INITIAL PILOT PROGRAM AT LBJ

*Correctly **Defining NBS** went from 32% to 86% post intervention*



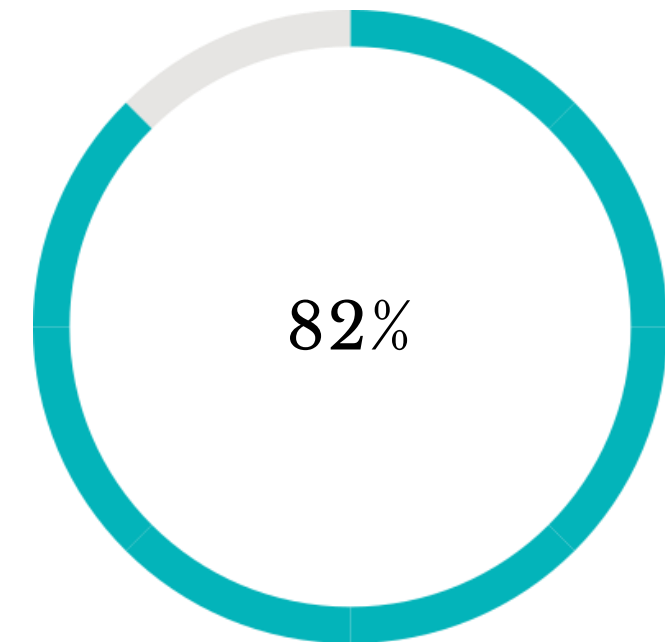
CORRECTLY DEFINED NBS

Prior to reading the book, 18 (32%) participants correctly identified the definition of NBS while 48 answered correctly after reading the book.



IDENTIFIED THAT THERE ARE 3 PARTS TO NBS

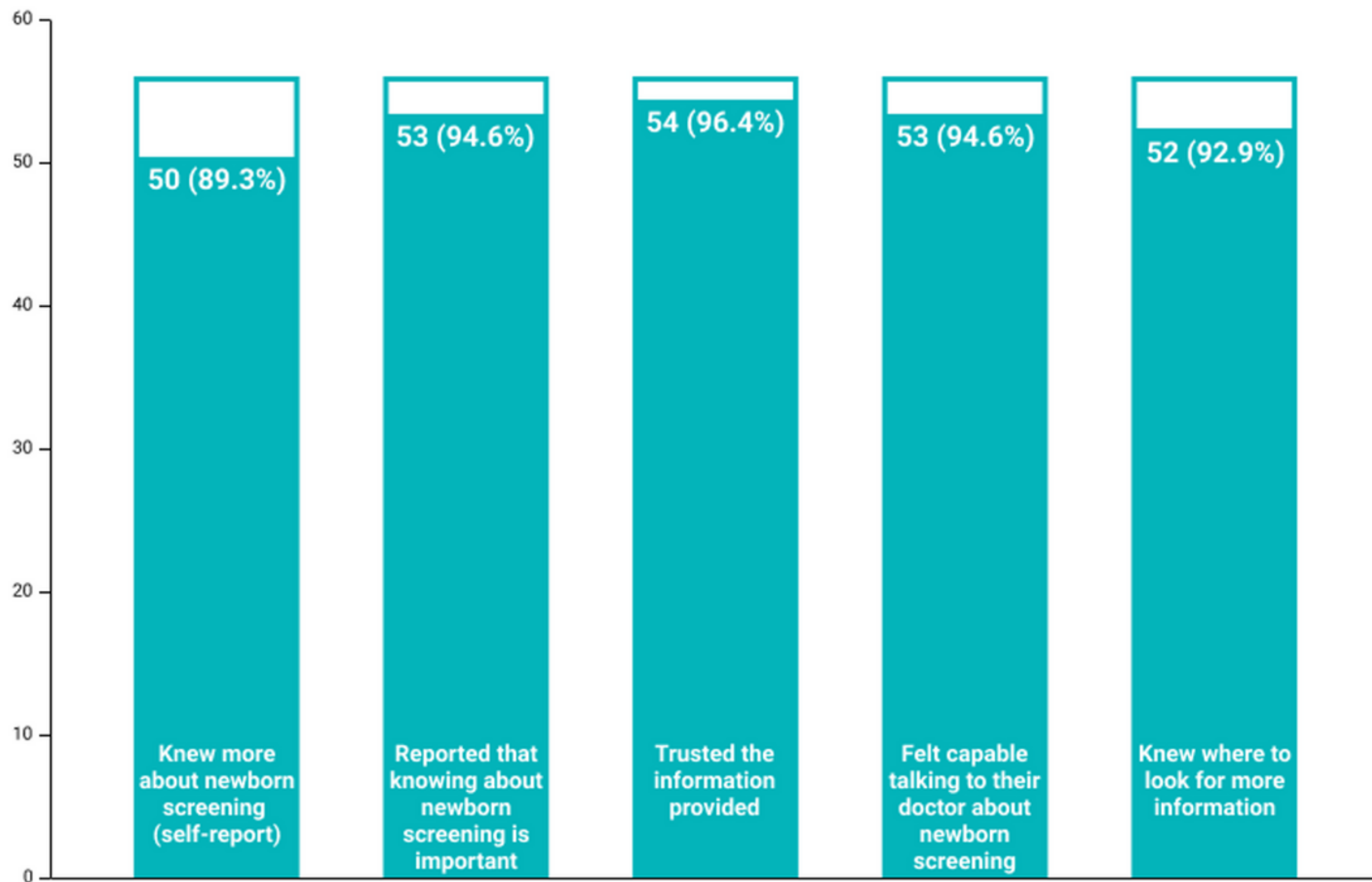
Prior to reading the book, 25 (44%) of participants were aware of the 3 parts to NBS, while 54 correctly answered after reading the book.



RECOGNIZED MEANING OF AN ABNORMAL RESULT

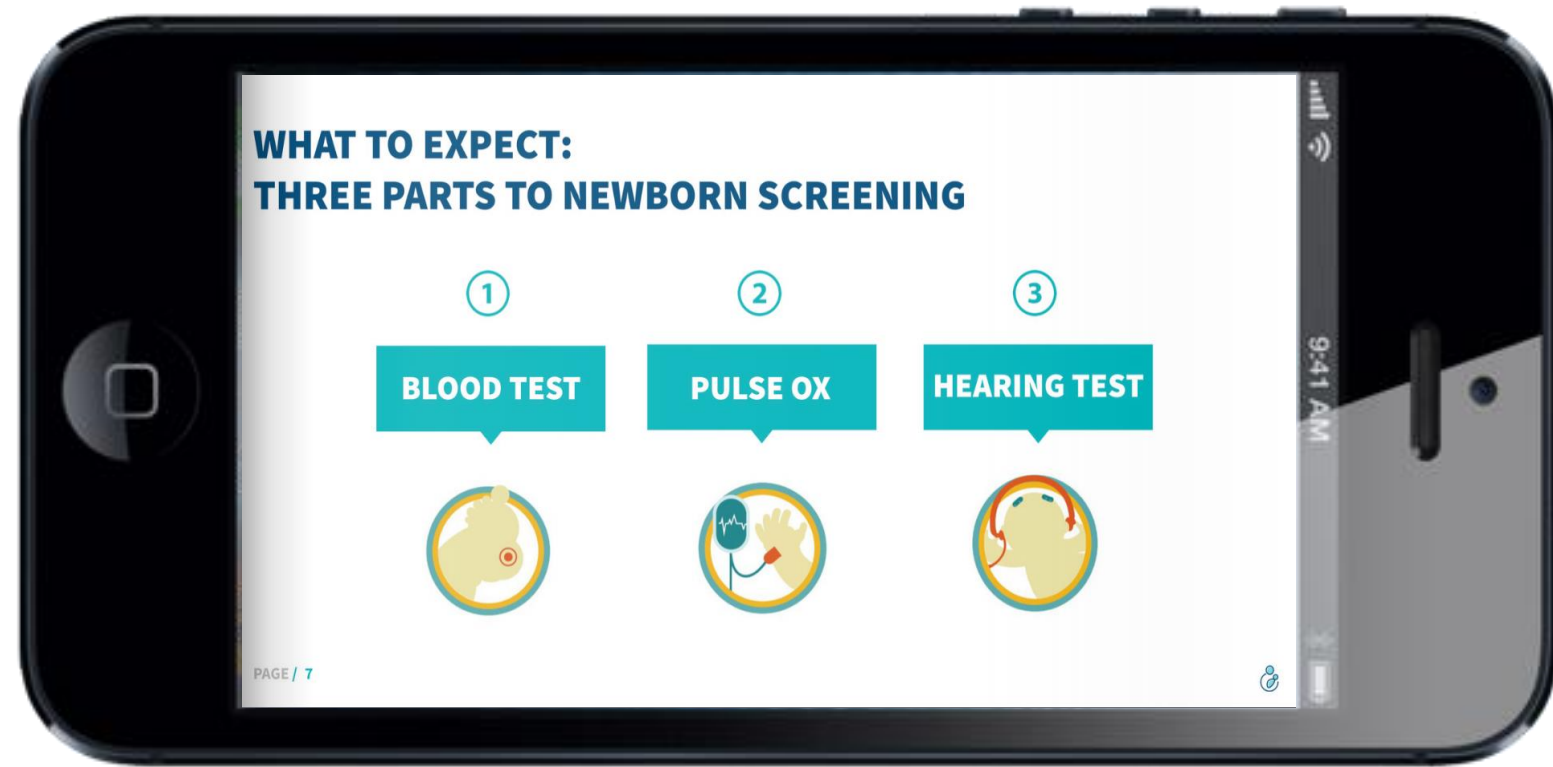
Prior to reading the book, 9 (16%) of participants recognized that an abnormal NBS result does not always mean there is something wrong with their baby, while 48 correctly answered after reading the book.

RESULTS FROM INITIAL PILOT PROGRAM AT LBJ



- *89% or more reported increases in awareness, knowledge, confidence and skill to lead and advocate for newborn screening and their families (N=56).*

SUCCESSES & OPPORTUNITIES



- Integrate into existing workflows
- Leverage relatable mechanisms for learning
- Consistency
- Prenatal groups AND state NBS programs have shown interest in increasing efforts to educate families about newborn screening during pregnancy.
- Longitudinal studies are needed to demonstrate the impact of education on all parts/experiences of the newborn screening system.

SOCIAL MEDIA CAMPAIGN

- Social media is a well known tool for communicating preconception and pregnancy related health topics with over 90% of adults ages 18-24 engaging with some platform (1).
- Multiphase approach utilizing multiple strategies
 - Can we reach a target audience?
 - How does the target audience engage with NBS education?

Know early.
Know now.
Know newborn screening.

Get free information to promote a healthy start for your baby!



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EARLY SUCCESSES

- *Phase 1: August 2021
 - Successful test of our ability to reach a targeted audience
- Phase 2: Launch March 2022
 - Will the targeted audience we reach engage in education about newborn screening?



30

*Day Campaign**

1.9 M

MUP reached

3.7M

Impressions

5000

Clicks

67%

*Ages 18-44
reached*

A photograph of three women sitting together, looking at a laptop screen. The woman on the left is smiling and holding the laptop. The woman in the middle is pointing at the screen. The woman on the right is also looking at the screen. The background is blurred, suggesting an indoor setting.

LESSONS LEARNED

- Increased access to NBS education requires multiple strategies to meet families where they are.
- Implementation requires buy in from multiple stakeholders and capacity at both the local and national levels.
- Education tools must be innovative & engaging, but simple to implement.
- Trusted sources are key connectors to families and may include parent partners & organizations, providers, state programs and social media.



HOW TO
GET
INVOLVED?

PARTNERSHIPS ARE INTEGRAL TO FAMILY EDUCATION

67%

Doulas

Each of these activities highlighted that providers also have gaps in the knowledge and confidence of newborn screening.

ACTIVITY	DETAILS	OUTCOME
Doula Focus Group	9 doulas elected to complete Navigate and join a discussion group	<ul style="list-style-type: none"> • 67% of doulas reported taking the training was a good use of their time
CA Midwives Focus Group & Training	2 midwives joined a discussion group to review prenatal initiative	<ul style="list-style-type: none"> • Midwives rely on the state brochure which will no longer be available
University of GA Undergraduate Course	70 undergraduate students completed Navigate NBS	<ul style="list-style-type: none"> • Unique Opportunity to educate future providers and parents.
Ambassador Task Force	12 Ambassadors participated in quarterly meetings	<ul style="list-style-type: none"> • Some family leaders experience frustration with provider experiences

Thank You



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MEET THE TEAM



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