



# Prenatal Education Initiative

**Developing and Implementing a Multifaceted approach to NBS  
Education: Equitable Access to Newborn Screening Education**

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# Agenda

- **Share WHO we are.** *Who is Expecting Health and the Navigate Newborn Screening Program?*
- **Discuss the WHAT.** *What is the Newborn Screening prenatal education pilot?*
- **Highlight the WHY.** *What are the key results and why does this matter?*
- **Plan for the FUTURE.** *How can we continue to grow this initiative and bring this education to more families?*



Expecting Health is made up of key leaders in health communication with a strong passion for **bridging scientific information with the everyday realities of parenting experiences and family lives.**

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A close-up photograph of a woman with dark hair, smiling warmly as she holds a newborn baby. The baby is wearing a white onesie and is being held against the woman's chest. The background is softly blurred, showing what appears to be a home interior with a lamp.

## VISION

All families have equitable access to newborn screening information and have confidence to participate in the newborn screening system.

## GOAL

Within 5 years, create a comprehensive newborn screening training program for families that provides them with the information they need to self advocate, discover resources, and serve as leaders in the newborn screening system.

# Meet families where they are



- Use different methods to educate families about newborn screening:
  - *Social media*
  - *Print materials*
  - *Online modules*
  - *In person*
- Newborn Screening Education Pilot

# Why Do We Need Prenatal NBS Education?



Receiving NBS information prenatally and from a health care provider increases parent satisfaction.<sup>1</sup>



Parents state that NBS education should start prior to labor and delivery.<sup>2,3,4</sup>



Prenatal NBS education is recommended by experts, including ACOG.<sup>5,6</sup>



Prenatal NBS education is not common practice among prenatal care providers.<sup>7</sup>

# Prenatal NBS Education Pilot Program

*An initiative to advance equitable access to newborn screening education*



# 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



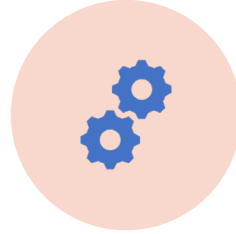
# Key Strategies Used in Pilot Design



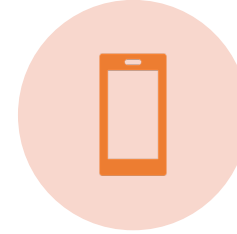
UNDERSTAND CULTURAL  
PERSPECTIVES



LEVERAGE TRUSTED  
HEALTH CARE PARTNERS



INCORPORATE INTO  
EXISTING WORKFLOWS



USE PRACTICAL  
MATERIALS & RELATABLE  
EDUCATIONAL MATERIALS



BE TRANSPARENT TO  
BUILD TRUST



# WHAT DID WE DO?

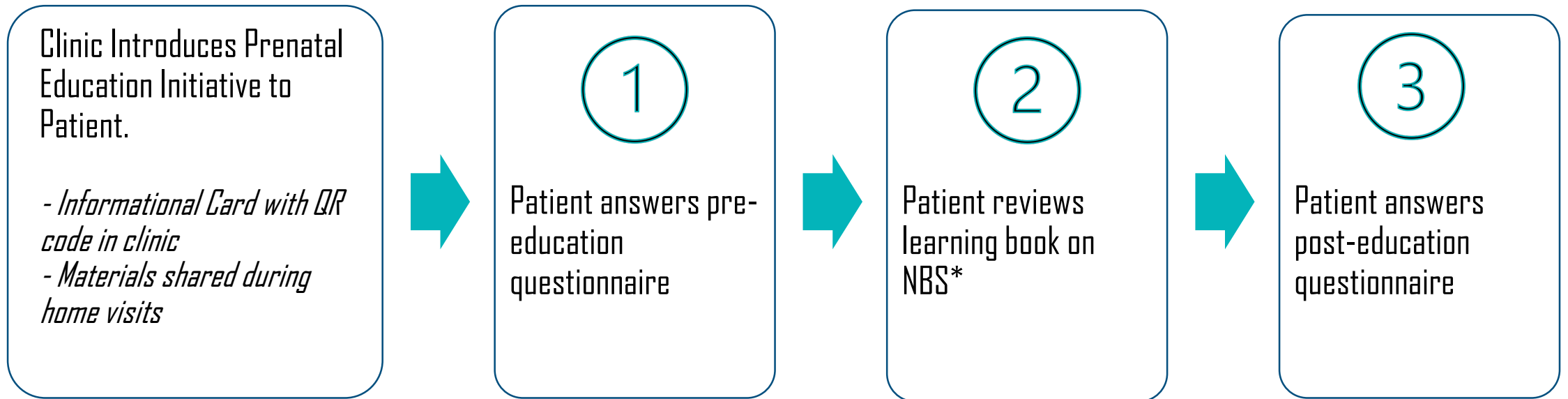
Target & partner with a medically underserved community-based prenatal groups

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)*

# How does it work?



*\*Materials and flipbook available in printed or digital formats in both English and Spanish*

# Patient Information Card

## LEARN MORE ABOUT NEWBORN SCREENING!

We have partnered with **Navigate Newborn Screening** to help our patients learn more about newborn screening with a **free**, online educational book. This book will teach you more about what newborn screening is, how it works, and why it's important.

### How does it work?

To access the book, scan the code in the corner with your camera. Before you are taken to the book, you will be asked a few questions about your knowledge of newborn screening. After you view the book, you will be asked a few questions about what you learned. This information will help us create tools and resources to educate families about newborn screening.

### Do I have to participate?

Participation in this educational opportunity is completely voluntary. Your choice to participate (or not participate) will not change the care you or your baby receive.



Scan here to get started

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant #UK5MC32105

## APRENDA MÁS SOBRE LA EVALUACIÓN DEL RECIÉN NACIDO

Nos hemos asociado al trabajo realizado con el módulo Navegando por la evaluación del recién nacido para ayudar a nuestros pacientes a aprender más sobre la evaluación del recién nacido con un libro educativo gratuito en línea. Este libro les enseñará más sobre qué es la evaluación del recién nacido, cómo funciona y por qué es importante.

### ¿Cómo funciona?

Para acceder al libro, escanee con su cámara el código que aparece en la esquina. Antes de darle acceso al libro, se le harán algunas preguntas sobre sus conocimientos referentes a la evaluación del recién nacido. Después de que vea el libro, se le harán algunas preguntas sobre lo que ha aprendido. Esta información nos ayudará a crear instrumentos y recursos para educar a las familias sobre la evaluación del recién nacido.

### ¿Cómo participo?

La participación en esta oportunidad educativa es completamente voluntaria. Su opción de participar (o de no participar) no cambiará el cuidado que reciben usted o su bebé.



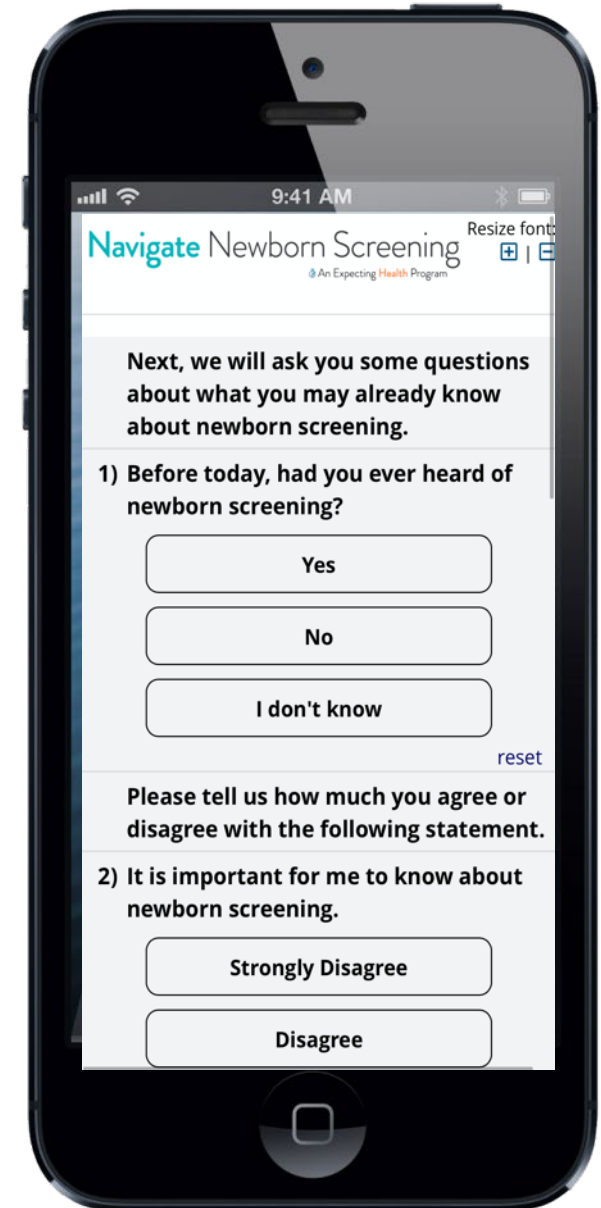
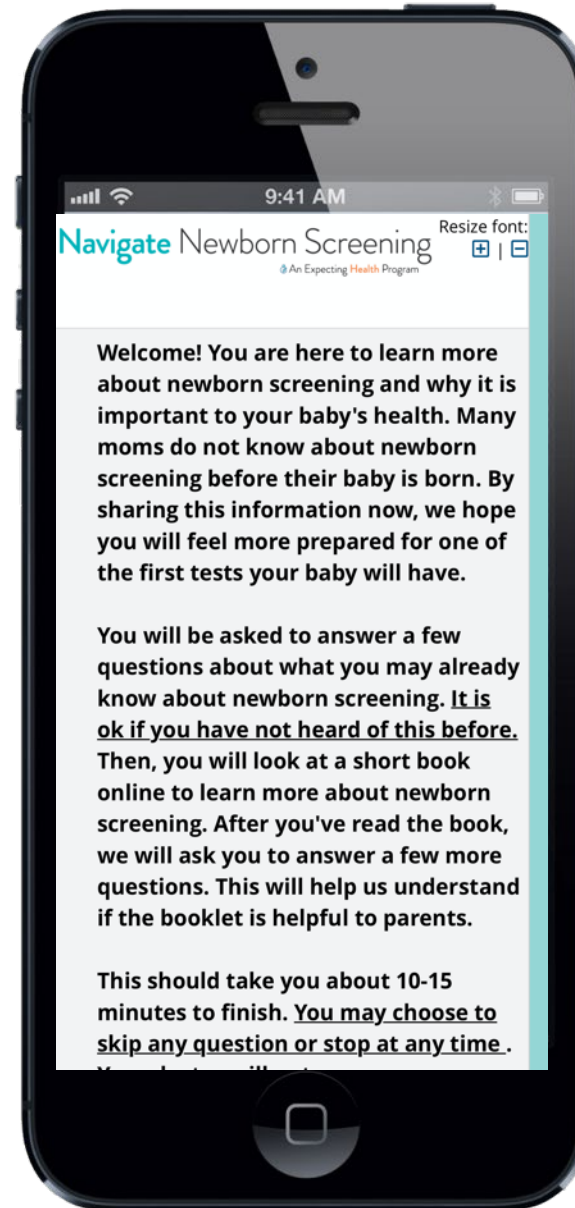
Scan here to get started

Este proyecto se realiza con apoyo de la Administración de Recursos y Servicios de Salud (Health Resources and Services Administration, HRSA) del Departamento de Salud y Servicios Humanos de los Estados Unidos (U. S. Department of Health and Human Services, HHS) dentro de la subvención #UK5MC32105.



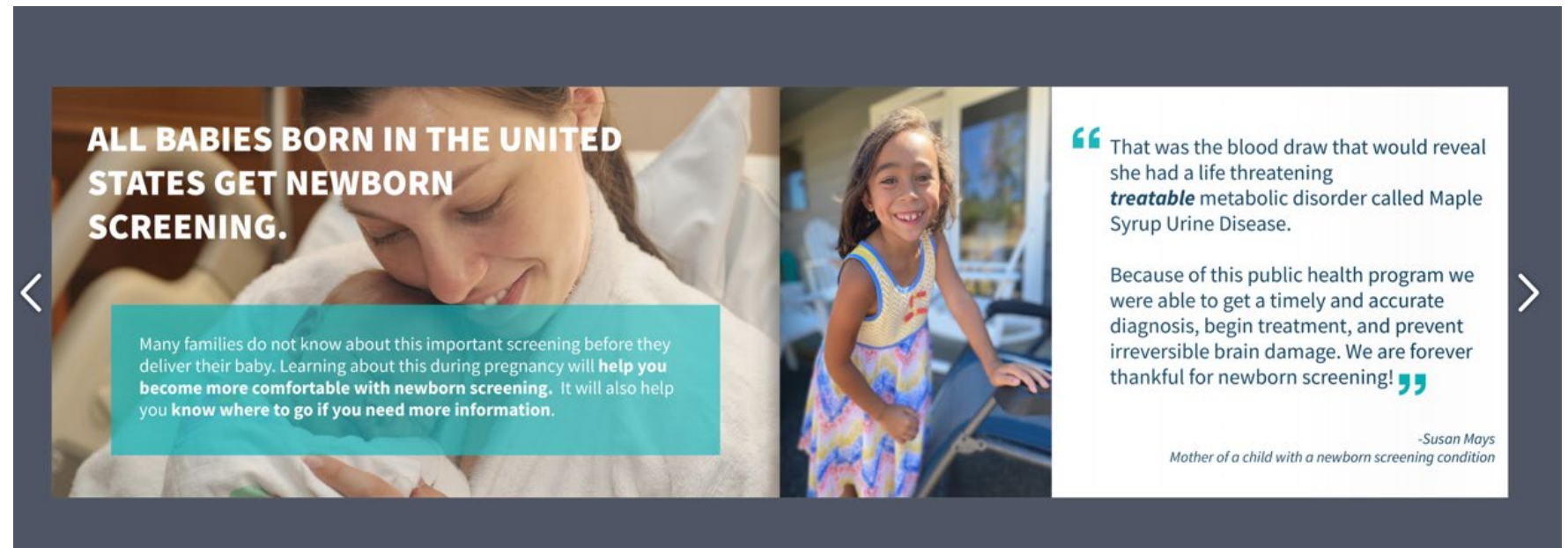
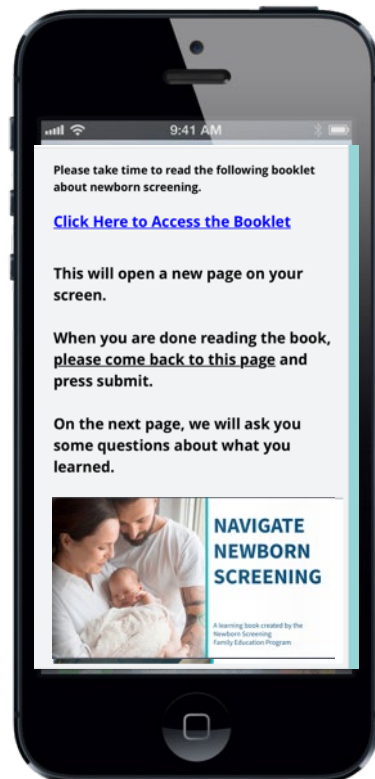
# Awareness & Knowledge Assessments

- Collaborative workgroup effort
- Clear expectation of purpose-to learn & prepare for NBS
- Provided validation that it was OK if they were not aware
- Simple design (mostly true/false or Likert scale)



# Learning Book

- Culturally representative images throughout
- Utilized literacy software to assess reading levels
- Tested for feedback with >25 Spanish and English-speaking families



<https://www.flipsnack.com/navigatenewbornscreening/copy-of-demo-flipbook/full-view.html>



# Staff Training & Tools

- Held In-service over lunch for clinic staff
- Nurses were offered the opportunity to go through the patient experience
- Developed “talking points” to support the clinic staff

## Navigate Newborn Screening @ An Expecting Health Program

### TIPS for Nurses Handing Out Cards

- Pilot cards should be given to third trimester patients-only!
- Patients only have to do this once--when they come back for subsequent appts, if they say they've already done it, they don't need to do again
- If they start and stop (because resident/doctor comes into the room), they don't need to restart UNLESS they close the window.
- Nurses/staff, please **do NOT** click on QR code with your device, it creates a record in the data.
- If patients have trouble opening the QR code you can try:
  - Check Camera settings in phone: QR code reader needs to be turned ON
  - If doesn't work, please give paper book to patient to take home
- Any patient is welcome to have a paper copy of the book
- Please put note under appointment notes section that states “patient given NBS pilot card”

### Navigate Newborn Screening Pilot Program “Script”

- We have put together a free, online educational booklet for expecting parents about what newborn screening is, how it works, and why it's important.
- Your doctor would like for you to read this book to learn more about newborn screening before you deliver.
- Newborn screening is important because:
  - All babies in the US are screened, but many families are unaware of what the tests consist of.



# The Results

# Successes-Spanish/Houston Population

- Over 10 weeks, a total of **56 participants completed** the initiative and **79 participants read through the learning book**.
- Approximately **90% completed the initiative digitally**.
- The mean time spent reading the book was **2.5 minutes**.
- There was a **statistically significant difference in the percent of correct answers** pre and post test.

**Increases in awareness and knowledge of newborn screening**

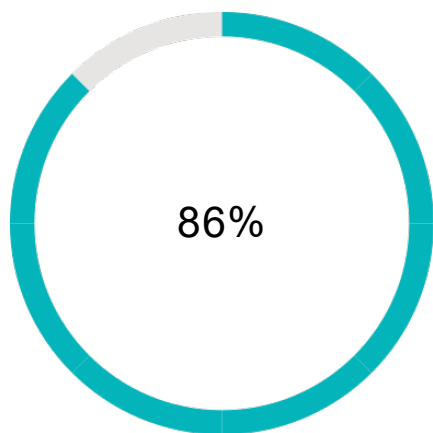
# Success: Plain Population

- Over 10 weeks, a total of **27 participants completed** all 3 parts of the initiative.
- All participants **completed the initiative on paper and in English.**
- There was a **statistically significant difference in the percent of correct answers** pre and post test.

**Increases in awareness and knowledge of newborn screening**

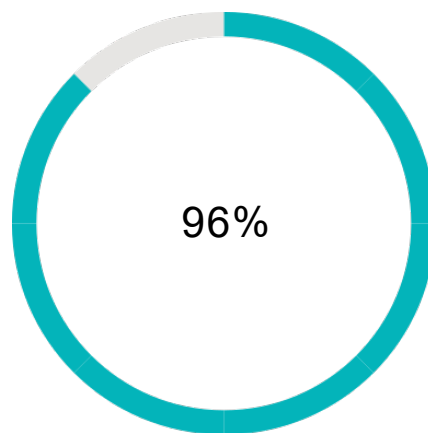
# RESULTS FROM INITIAL PILOT PROGRAM AT LBJ

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



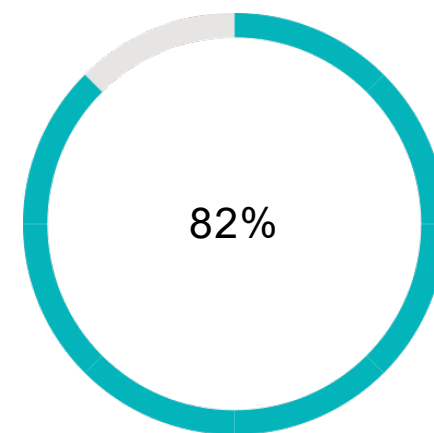
## CORRECTLY DEFINED NBS

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.

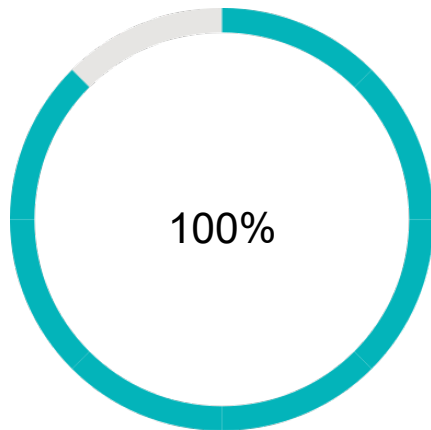


## RECOGNIZED MEANING OF AN ABNORMAL RESULT

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.

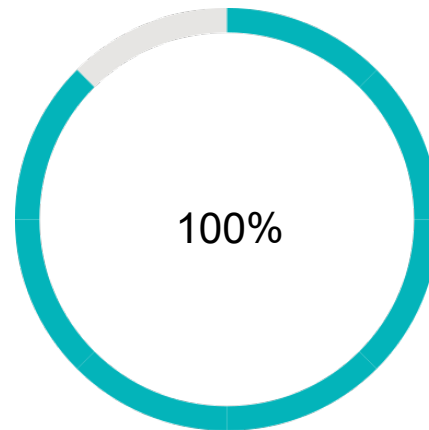
# RESULTS FROM INITIAL PILOT PROGRAM AT ICHC

Correctly **Defining NBS** went from 60% to 100% post intervention



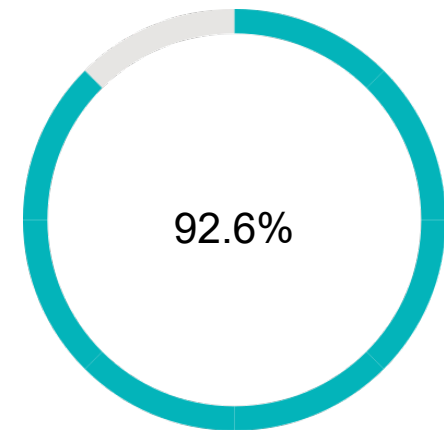
## CORRECTLY DEFINED NBS

Prior to reading the book, 16 (60%) participants correctly identified the definition of NBS while 27 answered correctly after reading the book.



## IDENTIFIED THAT THERE ARE 3 PARTS TO NBS

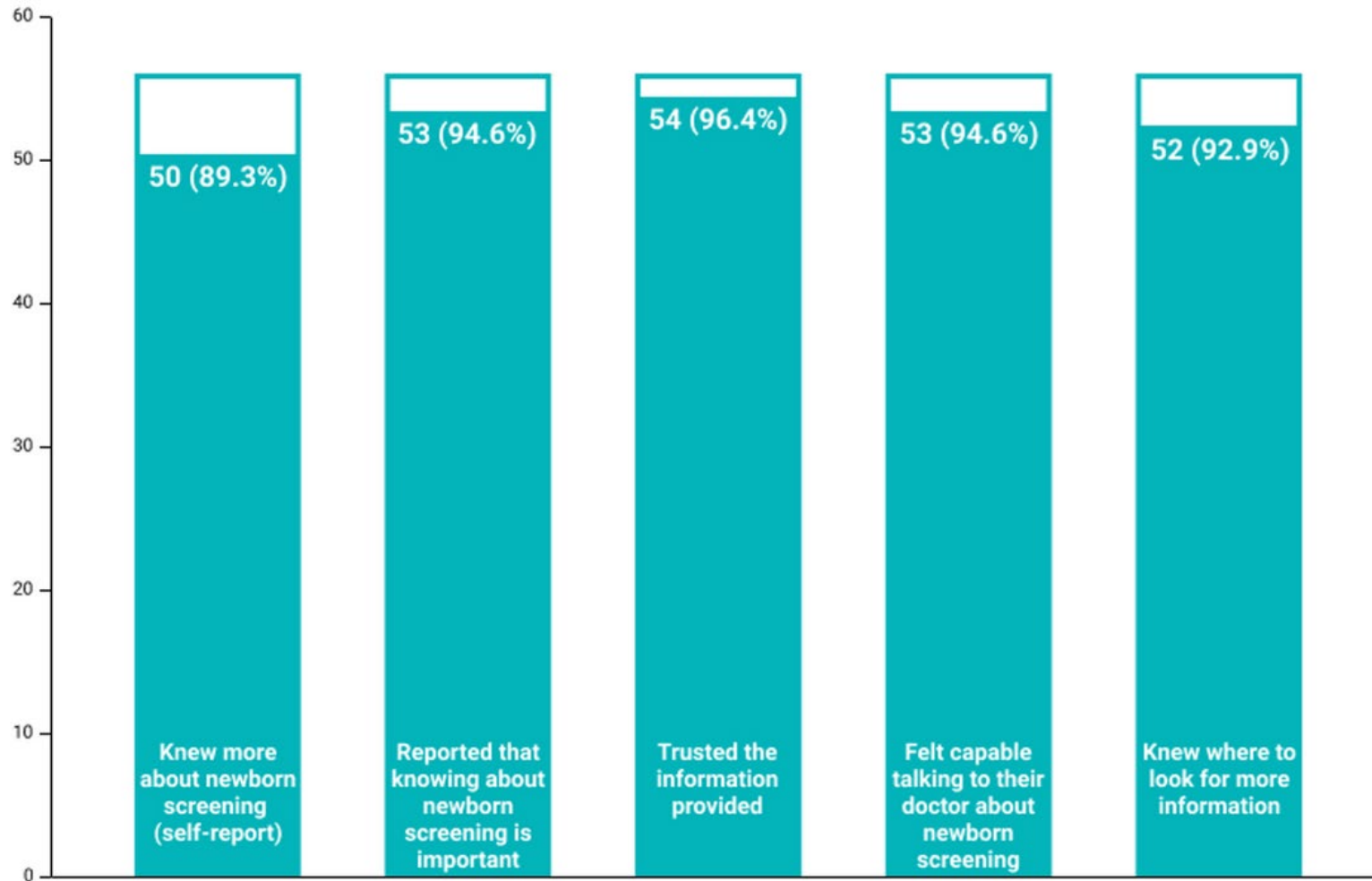
Prior to reading the book, 9 (33%) of participants were aware of the 3 parts to NBS, while 27 correctly answered after reading the book.



## RECOGNIZED MEANING OF AN ABNORMAL RESULT

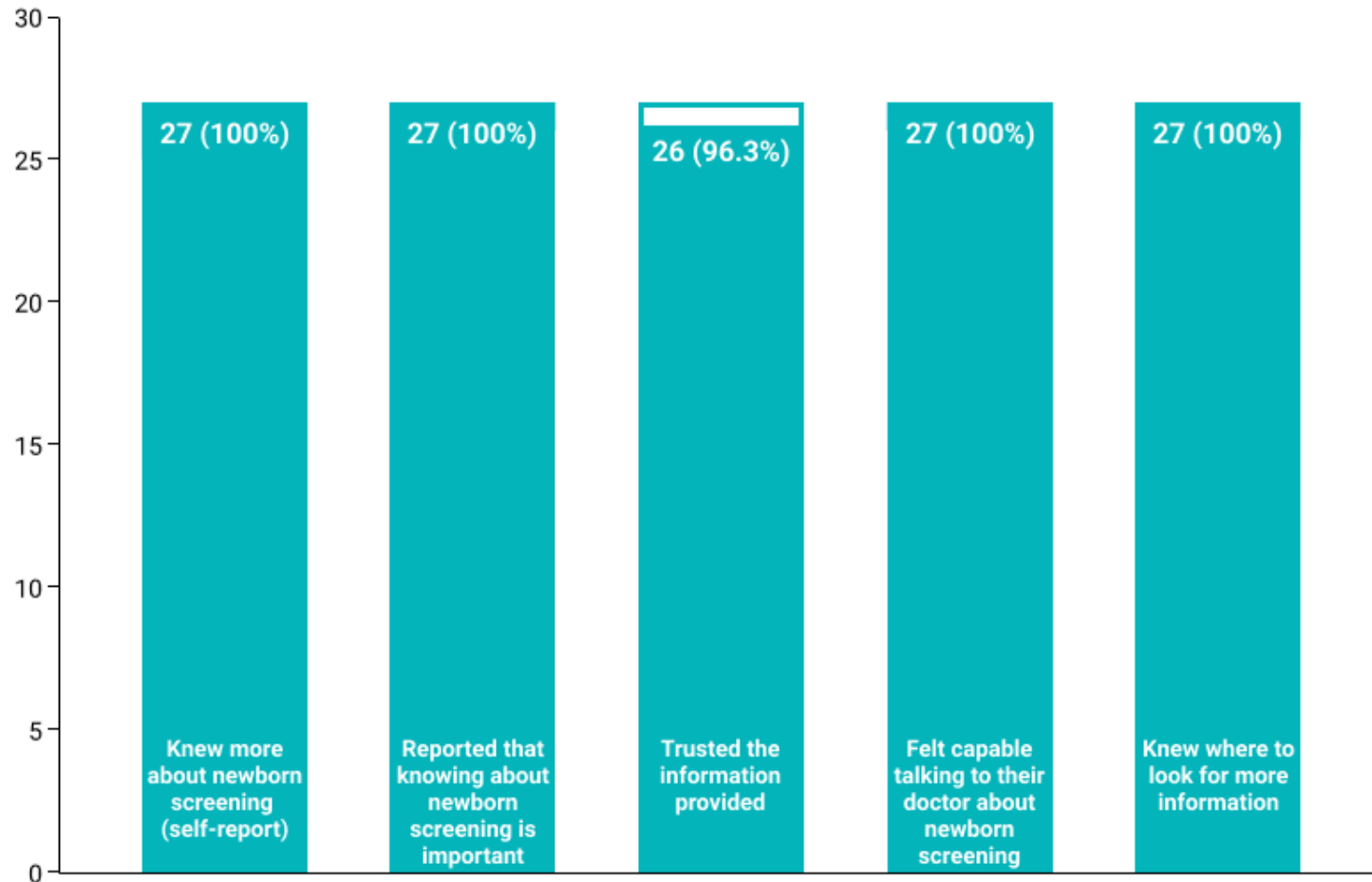
Prior to reading the book, 21 (77.8%) of participants recognized that an abnormal NBS result does not always mean there is something wrong with their baby, while 25 correctly answered after reading the book.

## 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).

## RESULTS FROM INITIAL PILOT PROGRAM AT ICHC



- **96% or more** reported **increases in awareness, knowledge, confidence and skill** to lead and advocate for newborn screening and their families (N=27).

# Key Takeaways

- Flipbook is a successful tool to raise awareness and increase knowledge of newborn screening.
  - *Integrating into existing workflows is key*
  - *Leveraging relatable mechanisms for learning was also important*
- Prenatal groups AND state laboratories have shown interest in increasing efforts to educate families about newborn screening during pregnancy.
- Long term studies are needed to demonstrate impact of education on the system.





# Join our Partnership Network!

- **Connect** to implement and utilize this resource with your patients!
- Receive **implementation tools** and support to begin using this model in your practice
- Ongoing **quality improvement process** and data sharing to support growth and learning
- **Community of practices** with other partners
- **Access** to additional newborn screening resources



## *Stay Connected*

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## *Follow Us*



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# Discussion Questions

- How do you feel about the flipbook?
- How do you think the families you work with will feel about the flipbook?
- Do you see potential benefits/barriers to implementing an initiative like this in your community?
- Other questions & comments?

# NBS Awareness Pilot Workgroup:

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LBJ OB Clinic Staff