



Baby's First Test: What is offered, Who we Reached, What we've Learned

Advisory Committee on Heritable Disorders in
Newborns and Children

November 1, 2018

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The 'Why' In Newborn Screening Education

“Why do you need to educate about newborn screening? It just happens – parents don’t have to do anything or ask for it.”

“Thankfully, we were quickly educated about MCADD by both our pediatrician and some incredible genetic and metabolic specialists at Children's Hospital... He is going to be fine because everyone knows how his body works differently and can factor that knowledge into his care.”

– Kay Kelly, 2013 Consumer Task Force member & mom to 2 boys, one of whom has MCADD

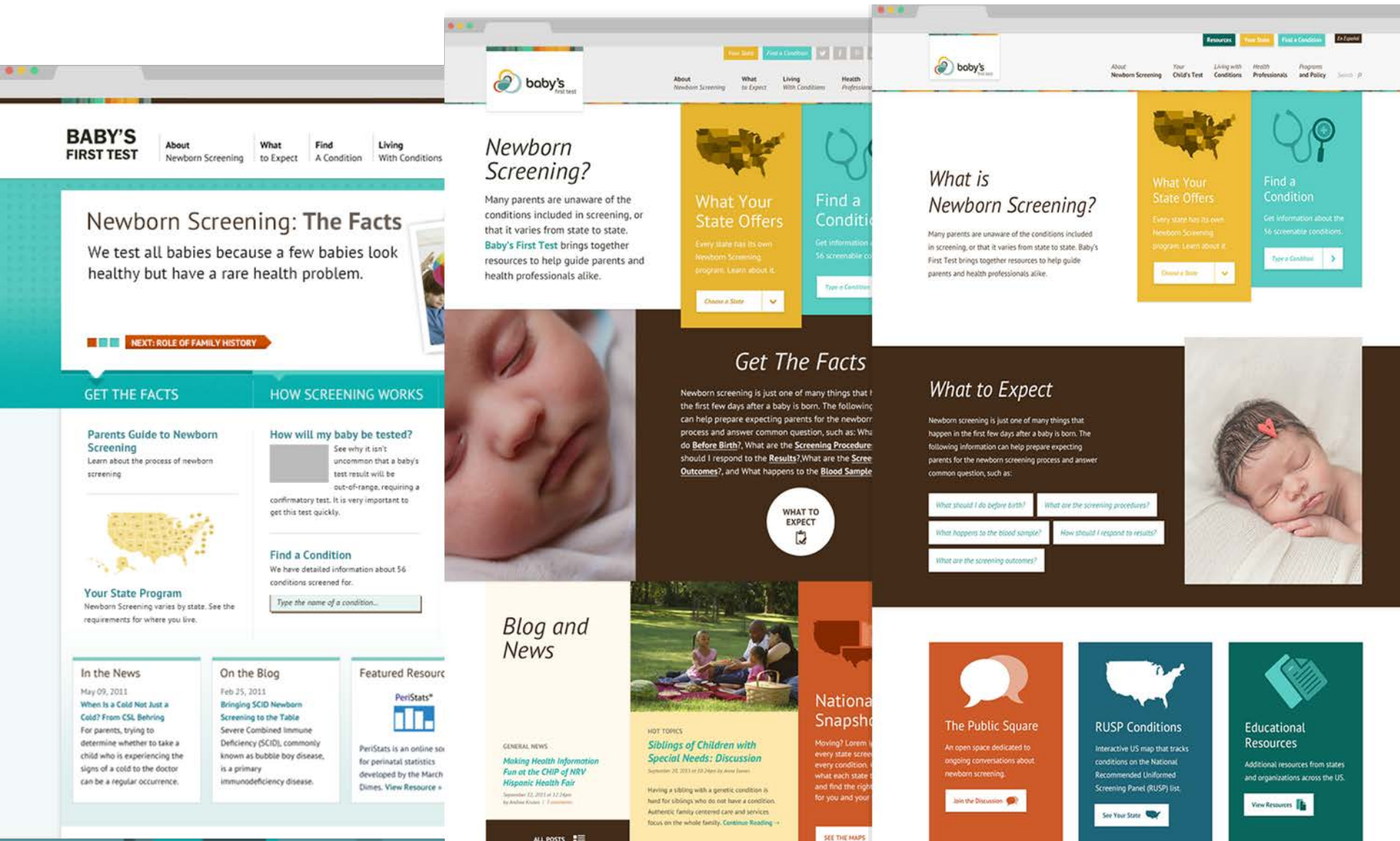


Baby's First Test is a national newborn screening resource center (known as the Clearinghouse until Aug 2018).

Baby's First Test informs and supports millions of families and healthcare professionals throughout the newborn screening experience.

BabysFirstTest.org:

Primary Platform for Increasing Knowledge & Awareness



BabysFirstTest.org since 2011...

2.8 Million Visitors

3.4 Million Sessions

5.2 Million Hits

1:29 average session duration

1.64 pages per session

88% unique user vs 12% returning user

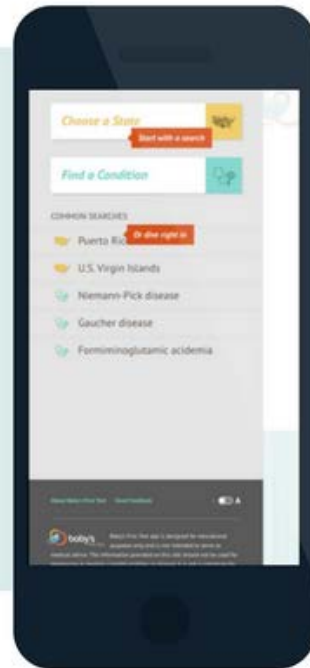
~86% of users are of reproductive age (18 – 44)



Looking to Learn about Newborn Screening in Your State?

Screening in Your State?

(There's An App For That)



Search State Information

Search Condition Information

Save Your Searches

Download for Free



Interactive National Map

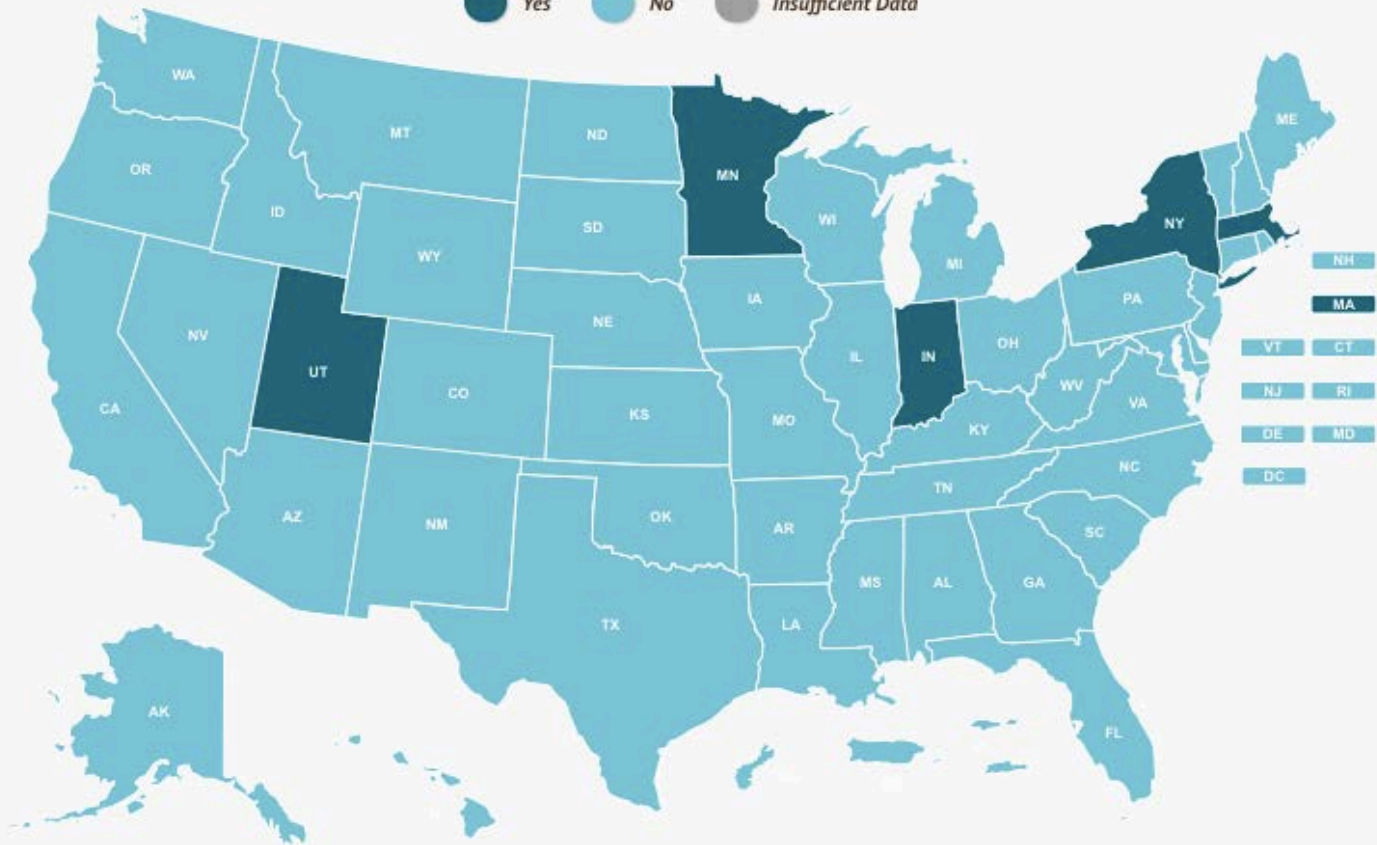
UPDATE

On July 2, 2018 Spinal Muscular Atrophy was added to the RUSP, bringing the total number of conditions on the list to 35.

Spinal Muscular Atrophy

LAST UPDATE - 10/24/2018

● Yes ● No ● Insufficient Data





Newborn Screening Education and Training Resources

Looking for educational materials about [newborn screening](#)? Starting in September 2016, Baby's First Test will be featuring fact sheets, videos, promising practices, and educational tools from states and organizations across the United States. Simply filter by resource type or audience, or search by keyword, to find resources that match your interest.

Interested in adding your educational resource, or not finding what you are looking for? Email resources@babysfirsttest.org for more information.



FILTER BY: [Clear Filters](#)



Type

- Fact Sheet
- Video
- Webinar
- Educational Tool

Created For

- Expecting Parents
- General Public
- Health Professionals
- Parents
- Policy Makers

Resource Key

-  Created by Baby's First Test
-  Created by a State Program

What Your State Offers

- Select State -



Find a Condition

Type a Condition



About Prenatal & Newborn Screening



Prenatal Screenings ensure you and your baby are on track for a healthy pregnancy. They also prepare parents for potential health conditions and treatments before birth.

Newborn Screening is a state public health program that tests for serious and treatable conditions. Babies who test positive for treatable conditions are able to start treatment before harmful effects occur.



Blood Test

A small blood sample is taken from the baby's heel, placed on a newborn screening card, and sent to the state laboratory for analysis.



Hearing Screens

Determines if the ear and auditory brain stem respond to sound. No response can indicate hearing loss.



Pulse Oximetry Test

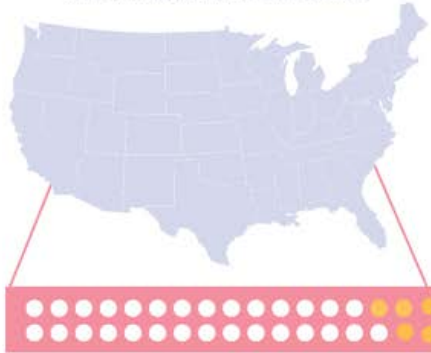
A sensor measures oxygen in the blood and can detect Critical Congenital Heart Disease (CCHD).

Why is screening so important?

Babies who appear healthy and come from healthy families can still have serious medical conditions. Newborn screening helps health professionals identify and treat conditions before they make a baby sick. Most babies identified at birth are treated early and grow up healthy.



Nearly **4 million babies** are born every year in the United States



Most states screen for 29 out of 34 recommended health conditions

Each year, 12,000 babies with serious, but treatable conditions grow up healthy, thanks to newborn screening



Every baby born in the United States can undergo newborn screening.



More than 1 in 300 newborns have a condition detectable through newborn screening



About 1 in 125 newborns have a Congenital Heart Defect



All newborns should be screened between 24-48 hours after birth



According to the Centers for Disease Control and Prevention

One Mother's Perspective

"Newborn screening saved my son's life. Although he appeared perfectly healthy and our family has no history of any disorders, his screening came back positive for a metabolic condition called MCADD. Thanks to the information we gained through his newborn screening, he is a perfectly healthy little boy and we know how to care for him to keep him that way.

I urge all new parents to learn about the life-saving potential of newborn screening and to thank the hospital staff who perform this very important test to ensure the health and safety of your newborn."

- A Grateful Mother in Colorado

Spanish.BabysFirstTest.org

The screenshot shows the website's header and main content area. The header includes the 'baby's first test' logo, navigation links for 'Su estado', 'Condiciones', and 'English', and a search bar. The main content area features three large panels: a white panel with the question '¿Pruebas de Detección en Recién Nacidos?', a yellow panel with a map of the US and the text 'Qué ofrece su estado', and a teal panel with a stethoscope icon and the text 'Busque una condición'.

baby's first test

[Su estado](#) [Condiciones](#) [English](#)

[Las pruebas en recién nacidos](#) [Pasos a seguir](#) [Vivir afectado por una condición](#) [Profesionales médicos](#) [Blog y noticias](#)

¿Pruebas de Detección en Recién Nacidos?

Muchos padres no conocen sobre las condiciones incluidas en las pruebas de detección, o el hecho que varían de estado

Qué ofrece su estado

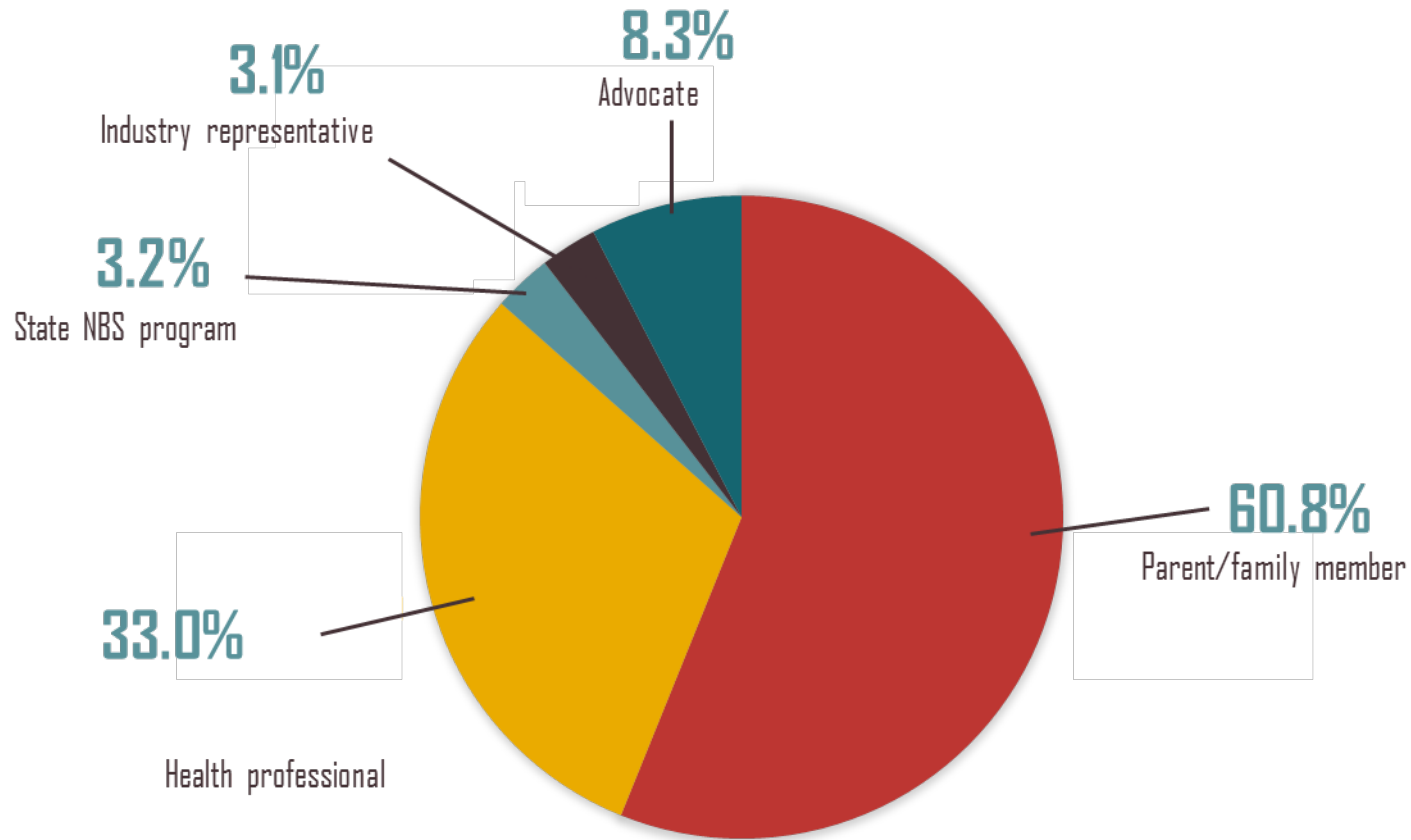
Cada estado tiene su propio programa de

Busque una condición

Obtenga información sobre 77 condiciones que


- Launched in **2015**
- Ongoing process to update site to be reflective of feedback and our audience: *adaptation, not translation*

Spanish.BabysFirstTest.org



*1,162 responses, current as of April 25, 2018

Educational Materials in Spanish



El abecé de las pruebas de detección en recién nacidos

¿Vas a tener un bebé? ¡Felicidades! Cuando se te hagan las pruebas de detección, recuerda el abecé.

A Verifica con tu doctor o proveedor de atención médica, sobre cuáles son las condiciones que se están haciendo las pruebas de detección en recién nacidos en tu estado. También podrás utilizar la información en la página de First Test, busca el perfil de tu estado.

B Busca y encuentra! Es buena idea darle seguimiento al resultado de las pruebas de detección de tu bebé, llámale a tu doctor o proveedor de atención médica. ¡Se proactivos!

C Conéctate con nosotros! Ve a Spanish.BabyFirst.org para obtener información completa sobre las pruebas de detección en todos los estados, DC, y Puerto Rico. Así como se hacen las pruebas de detección y obtén apoyo.

Las pruebas de detección son un componente básico para asegurar que tu bebé tenga un futuro feliz y sano.

Lista para las pruebas de detección

Primer trimestre

- 11-14 semanas: Prueba de sangre materna (MSAFP)
- 15-20 semanas: Prueba de sangre materna (MSAFP)
- 15-20 semanas: Prueba de sangre materna (MSAFP)
- 15-20 semanas: Prueba de sangre materna (MSAFP)

Segundo trimestre

- 15-20 semanas: Prueba de sangre materna (MSAFP)
- 15-20 semanas: Prueba de sangre materna (MSAFP)
- 15-20 semanas: Prueba de sangre materna (MSAFP)
- 15-20 semanas: Prueba de sangre materna (MSAFP)

Tercer trimestre

- 28-32 semanas: Prueba de sangre materna (MSAFP)
- 28-32 semanas: Prueba de sangre materna (MSAFP)
- 28-32 semanas: Prueba de sangre materna (MSAFP)

Pruebas de detección en recién nacidos

- 28-32 semanas: Prueba de sangre materna (MSAFP)
- 28-32 semanas: Prueba de sangre materna (MSAFP)
- 28-32 semanas: Prueba de sangre materna (MSAFP)



¿Sabes sobre las nuevas pruebas que harán a tu bebé?

En los Estados Unidos, nacen casi 4 millones de bebés. Muchos de ellos nacen con condiciones genéticas. Estas condiciones pueden presentarse en cualquier momento y no tienen un historial médico de estas condiciones.

Las pruebas de detección para recién nacidos ayudan a que los profesionales de la salud investiguen y traten estas condiciones antes de que el bebé salga del hospital.

Los tests de detección pueden hacerse a cabo 24 horas después del nacimiento del bebé y antes de que el bebé salga del hospital.

No tienen que solicitar que le hagan las pruebas de detección a tu bebé. Es un procedimiento de rutina que se hace en el hospital.

Las condiciones que se tratan de detectar varían según el estado. En la mayoría de estados, se hacen pruebas para detectar 29 de las 34 condiciones recomendadas por el Ministerio de Salud y Servicios Humanos.

Habla con tu profesional de la salud sobre las pruebas de detección para recién nacidos.

Para más información visita Spanish.BabyFirstTest.org

LAS EVALUACIONES DE LOS RECIÉN NACIDOS: ¿CUÁLES SON LAS VENTAJAS?

¿Sabes así que... las evaluaciones de los recién nacidos son una de las iniciativas más exitosas de la salud pública a nivel nacional.

Más de 1 DE CADA 300 RECIÉN NACIDOS tienen una condición detectable mediante una evaluación médica.

Las evaluaciones médicas ayudan a mantener la salud de tu bebé mediante una PRUEBA DE AUDICIÓN Y LA OXIMETRÍA DEL PULSO.

¡AHORA YO SOY LA PRUEBA de tu bebé!

29 de 35 CONDICIONES MEDICAS RECOMENDADAS

- Housed on Baby's First Test Resource Center
- Available for order



Usability & Experience with BabysFirstTest.org

Evaluating Baby's First Test

Methods

Buckets of Evaluation

1. Google Analytics

Reach of
BabysFirstTest.org

2. User Survey

User Engagement

3. Evaluation with RTI

- New & Expecting Parents
- Healthcare Professionals
- Partners

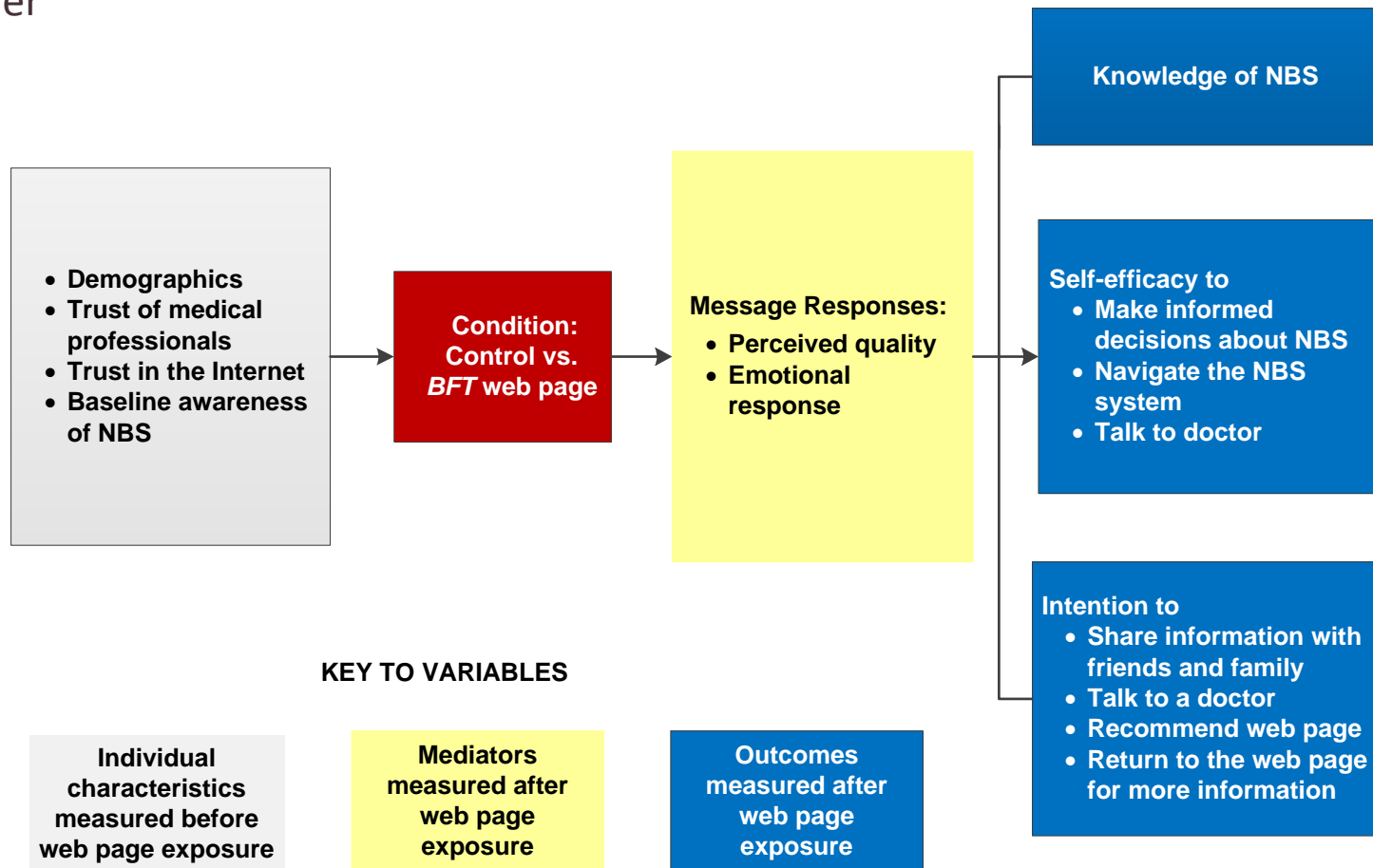
User Knowledge &
Awareness

Partnerships

Website Evaluation with Parents

Methods and Conceptual Model

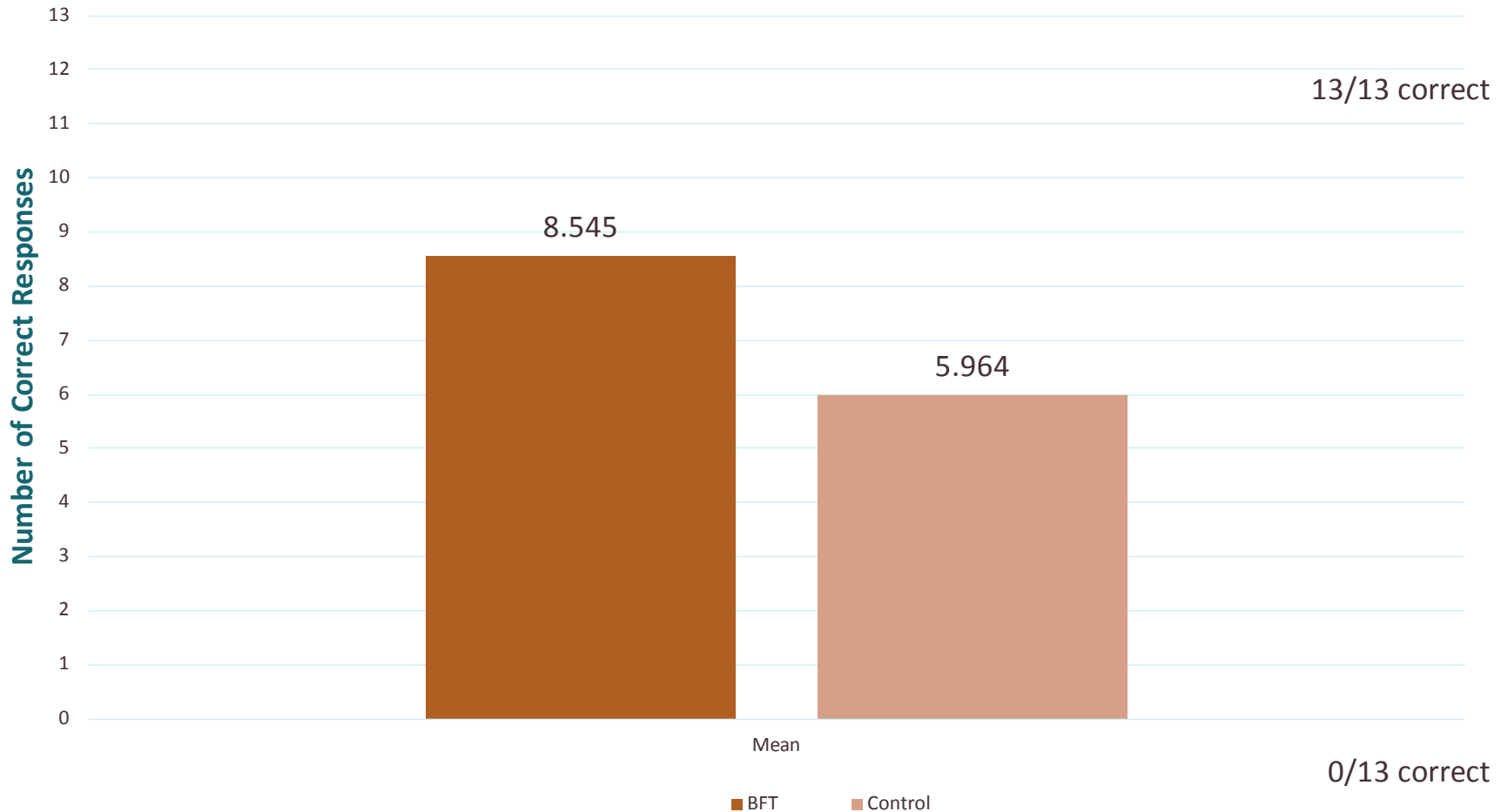
- 777 women and men planning a pregnancy or currently pregnant or with a pregnant partner



Awareness of Newborn Screening

- Prior to viewing any stimuli, **two-thirds of the participants** (66%) reported having heard of the term “newborn screening.”
- When asked to identify the accurate definition of “newborn screening” from three statements, only about **one-third of the participants** chose the correct definition (36%).

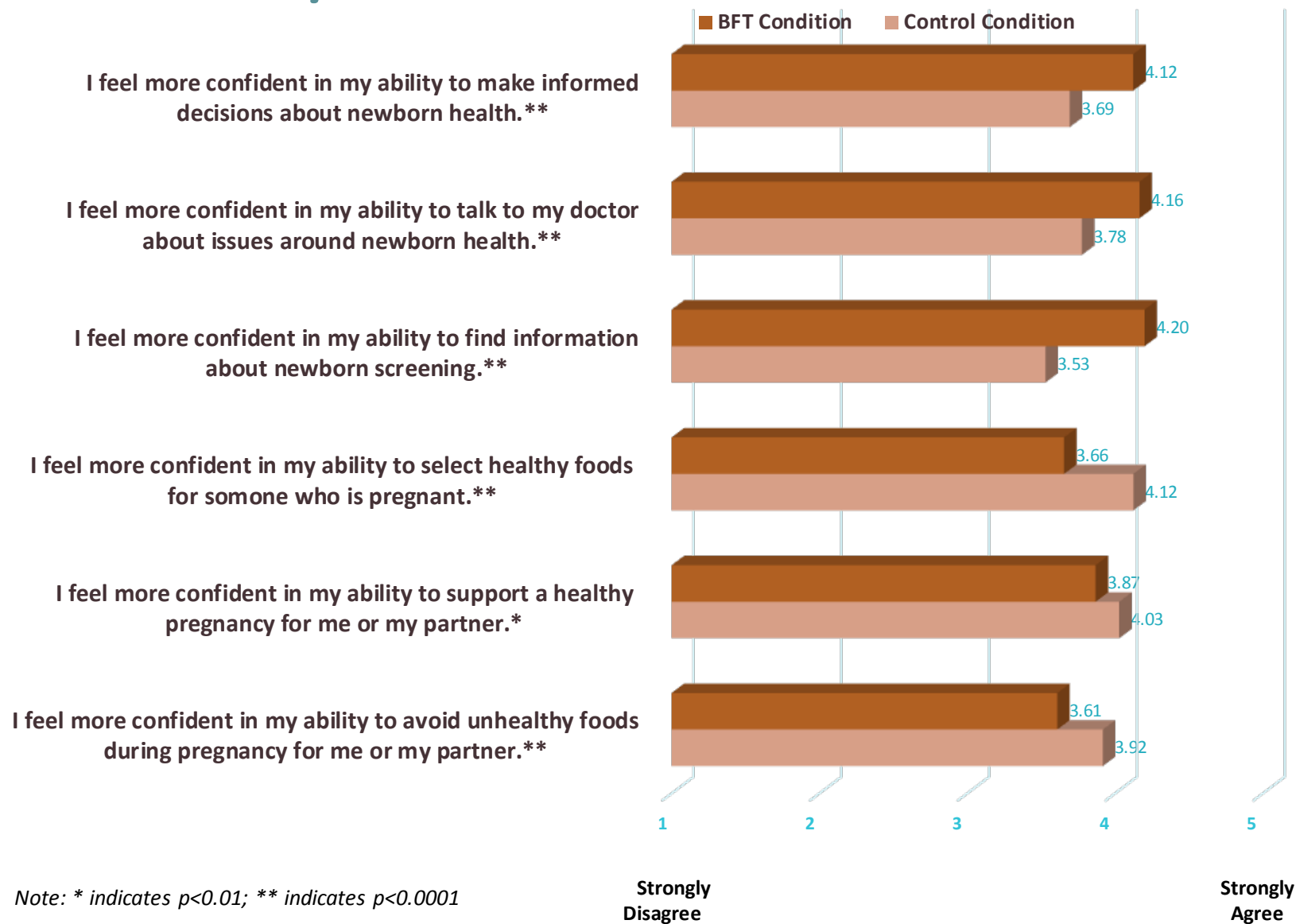
NBS Knowledge Index



The knowledge score for each group is the mean number of correct responses out of a possible 13.

Statistically significant difference between BFT and control group (<0.05)

Self-Efficacy



Implications

Rigorous design: an experimental design allowed us to thoroughly answer the research question: *does BFT increase knowledge about NBS among parents/families?*

NBS knowledge: This evaluation went beyond typical website evaluation measures to concretely assess changes in knowledge, self-efficacy, and behavioral intentions.

Effective Tool: Results from this evaluation suggest that individuals in the perinatal period do not know what NBS is, but exposure to even one web page on the babysfirsttest.org significantly increased their levels of knowledge about NBS.

Healthcare Professional Usability Testing

Methods

		Number (N=12)
Specialty	Medical Doctor (Pediatrician)	6
	Midwife	1
	Physician Assistant	1
	Nurse	3
	Nurse Practitioner	1
Gender	Male	3
	Female	9
Region	South	3
	Northeast	4
	Midwest	4
	West	1

User Needs

- Communication with parents about **newborn screening is not a priority topic** for these HCPs.
- Participants reported being **comfortable talking about newborn screening** in general.
- HCPs may need **extra information about rare conditions or in cases of abnormal test results.**
- Participants were **not necessarily seeking out a resource like this**
- **None of the participants had ever seen BabysFirstTest.org before.**
- **Most HCPs found it very useful** that this information is available.
- Participants said **an ideal website would educate both themselves and parents** about NBS.

Website Perceptions

- When looking at the *Baby's First Test* homepage, **HCPs thought the purpose of the website was:**
 1. **To educate and provide expectant parents with comprehensive information about NBS**
 2. **To provide HCPs with information about conditions screened through NBS**
- Participants saw **expectant parents as the primary target of the site's content and language**
- They also reported that **the site contained information that would help them do their job.**
- **All of the participants had a positive impression of the website content, commonly describing the content as “very informative” and “comprehensive” or “thorough.”**

Outcomes

- **About half of the participants reported learning something new**, with the main value of the website being that that they would:
 - Share and review information from the website with parents
 - Direct parents to information on the website
 - Provide printed materials to parents
- **Participants mentioned a range of reasons for which they would use the website**, including:
 - Returning to the website to learn more upon receipt of an abnormal test result for a patient
 - Providing useful resources to parents of newborns
 - Using the website to self-educate about tests and conditions.
- The majority of participants enthusiastically indicated that they are **highly likely to visit the website again**.

Implications

- **HCPs find the site useful, but are unaware of the site.**
 - **Promote the [BabysFirstTest.org](https://www.babysfirsttest.org) to HCPs** through channels that reach them.
 - **Provide concrete next steps on abnormal test results**, possibly via a separate tab for providers that combines all information about abnormal results in one place.
 - **Increase content that facilitates connections to support networks** for more of the conditions.

Partner Evaluation

Evaluation Questions

- How many and what types of partnerships have been formed?
- What have been the benefits/value-added to partnering with federal and non-federal organizations?
- What has resulted from these partnerships?

Methods

Partner Inventory:

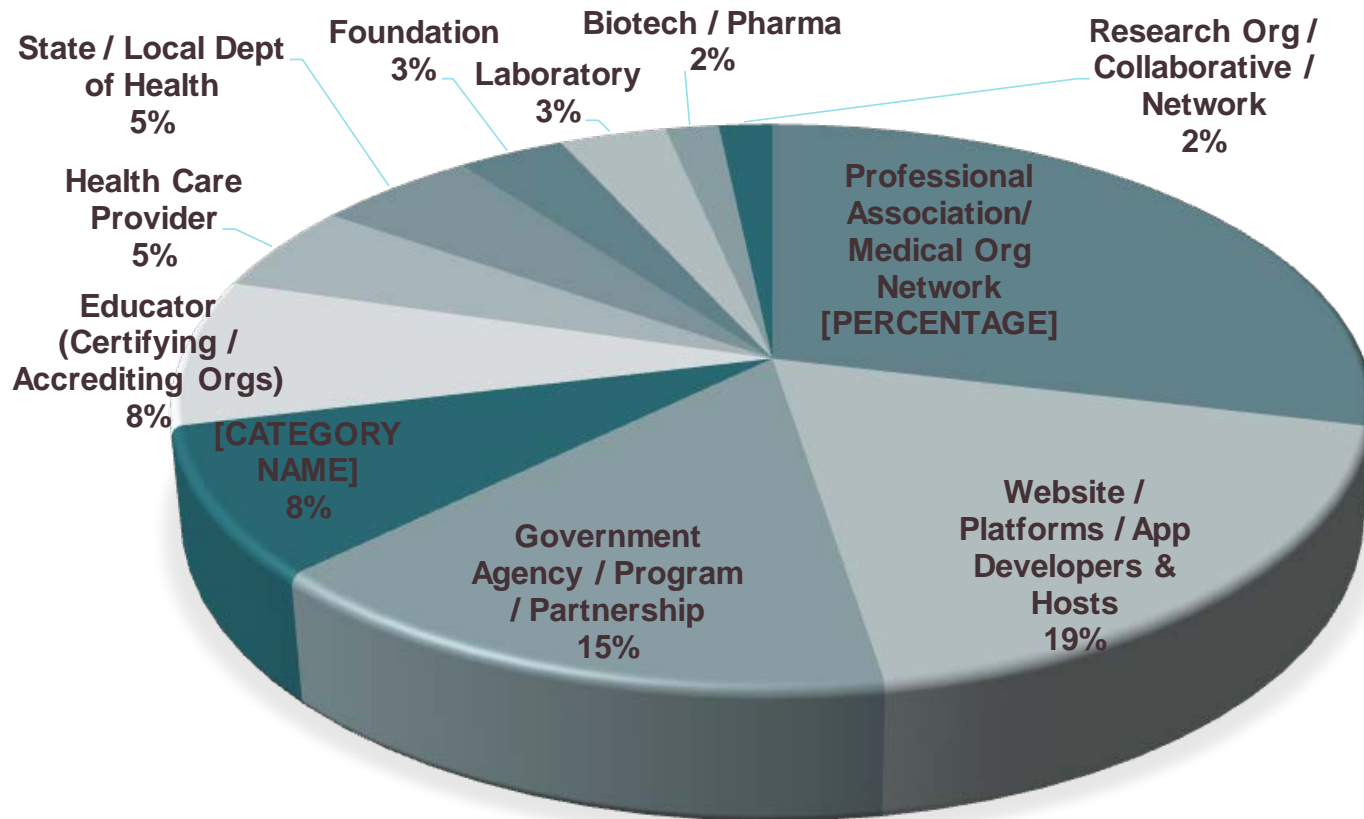
- Categorized partners according to key domains, such as type of organization and stage of partnership in an Excel database.

Partner Survey

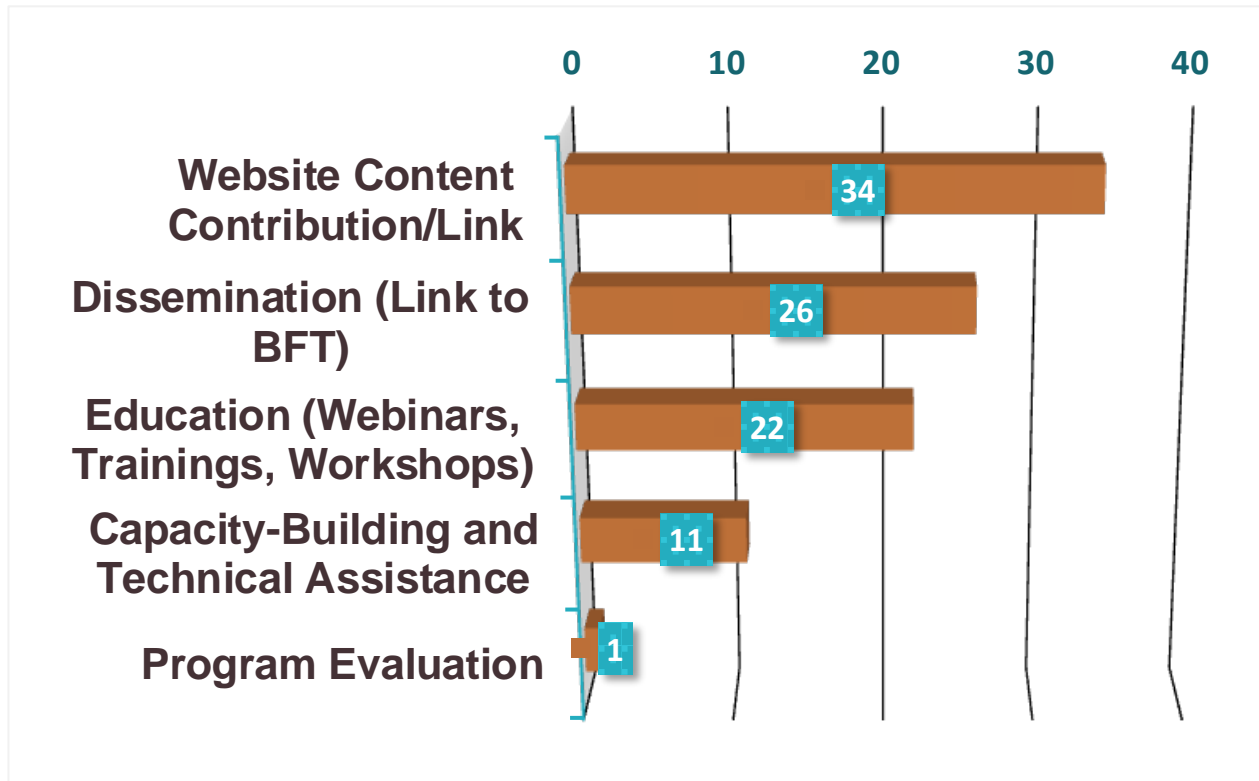
- Selected 15 partners that represented key audiences for BabysFirstTest.org.
- Conducted web-based survey.

Number and Types of Partner Organizations

- By the final year of the program, *Baby's First Test* partnered with **59** organizations.



Partner Roles and Activities



Value of Partnership

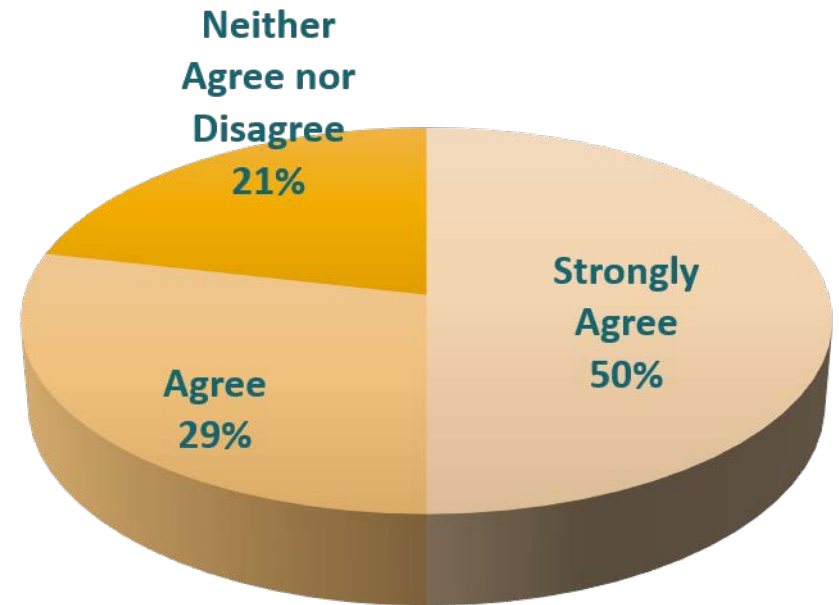
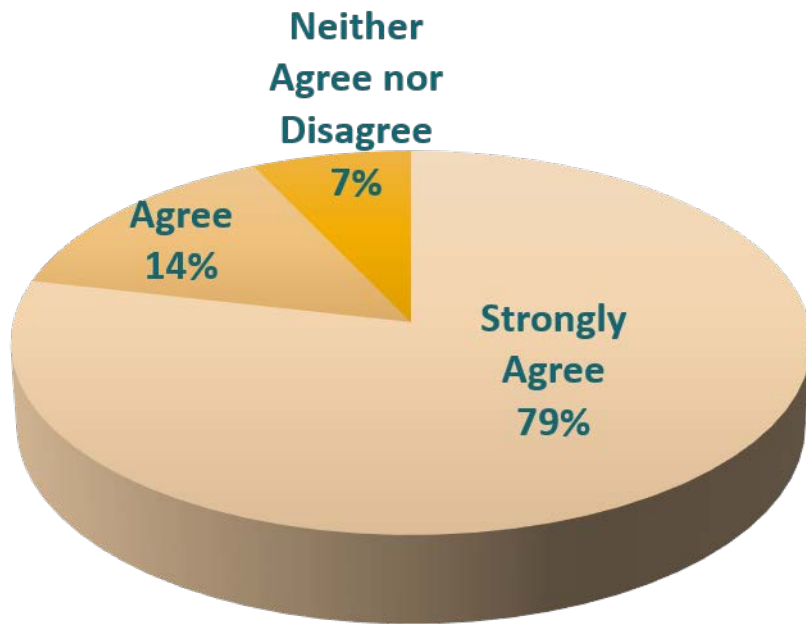
- When asked what value, if any, this partnership brings to their work, almost every Partner Survey participant emphasized the value of their access to knowledge, information, or education developed and provided by *Baby's First Test*.
- Many partners described the ways in which access to Baby's First Test increases their capacity.

"Baby's First Test provides evaluated and robust educational materials and resources that we often do not have the time or expertise to create ourselves. Additionally, Baby's First Test has raised the bar for programs in terms of their educational outreach... I cannot stress enough the value of this partnership in improving our overall program and its relationship to our stakeholders, including the public."

Benefits of Partnership

“Compared to other organizations we partner with, Baby’s First Test is a valuable partner.”

“The partnership with Baby’s First Test is essential to my organization/agency accomplishing its education and outreach goals.”



Future Partnership Plans

- **Ease of partnership:**
 - Essentially all of partners regarded partnering w/ as easy (n=3) or very easy (n=10).
- **Future Partnerships Likely:**
 - All Partner Survey respondents reported that is it either very likely (n=12) or likely (n=2) that they will continue to partner with Baby's First Test next year.
 - The majority of participants consider activities related to continued external funding for NBS education/outreach to be important (36%) or very important (50%).
- **Recommendations:**
 - Expand the number of partnerships with advocacy/health promotion groups, educators, health care providers, and state/local departments of health to further extend reach;
 - Prioritize activities related to continued external funding for NBS education/outreach; and
 - Assess which partners feel strongly about developing written goals for the partnership and a more formal partnership agreement and implement accordingly.



Lessons Learned

What We've Done

- ✓ Responsive Website(s)
- ✓ Mobile App
- ✓ Share & Collect Family Experiences
- ✓ Trained Families
- ✓ Educational Resources
- ✓ Interactive Map & Forum
- ✓ Ask an Expert
- ✓ Social Media Campaigns
- ✓ Webinars
- ✓ Newsletters
- ✓ Animated Videos
- ✓ Billboards (yes, really)
- ✓ Awareness Building (Google Adwords, BabyCenter)
- ✓ Exhibits/Conferences
- ✓ Presentations
- ✓ Hosted Meetings
- ✓ Focus Groups
- ✓ Needs Assessments
- ✓ Message Testing
- ✓ Trainings to State Advisory Groups
- ✓ Evaluation
- ✓ Partnership Building
- ✓ Technical Support
- ✓ Review Educational Campaigns
- ✓ Create & Co Brand Materials

**And much, much
more...**

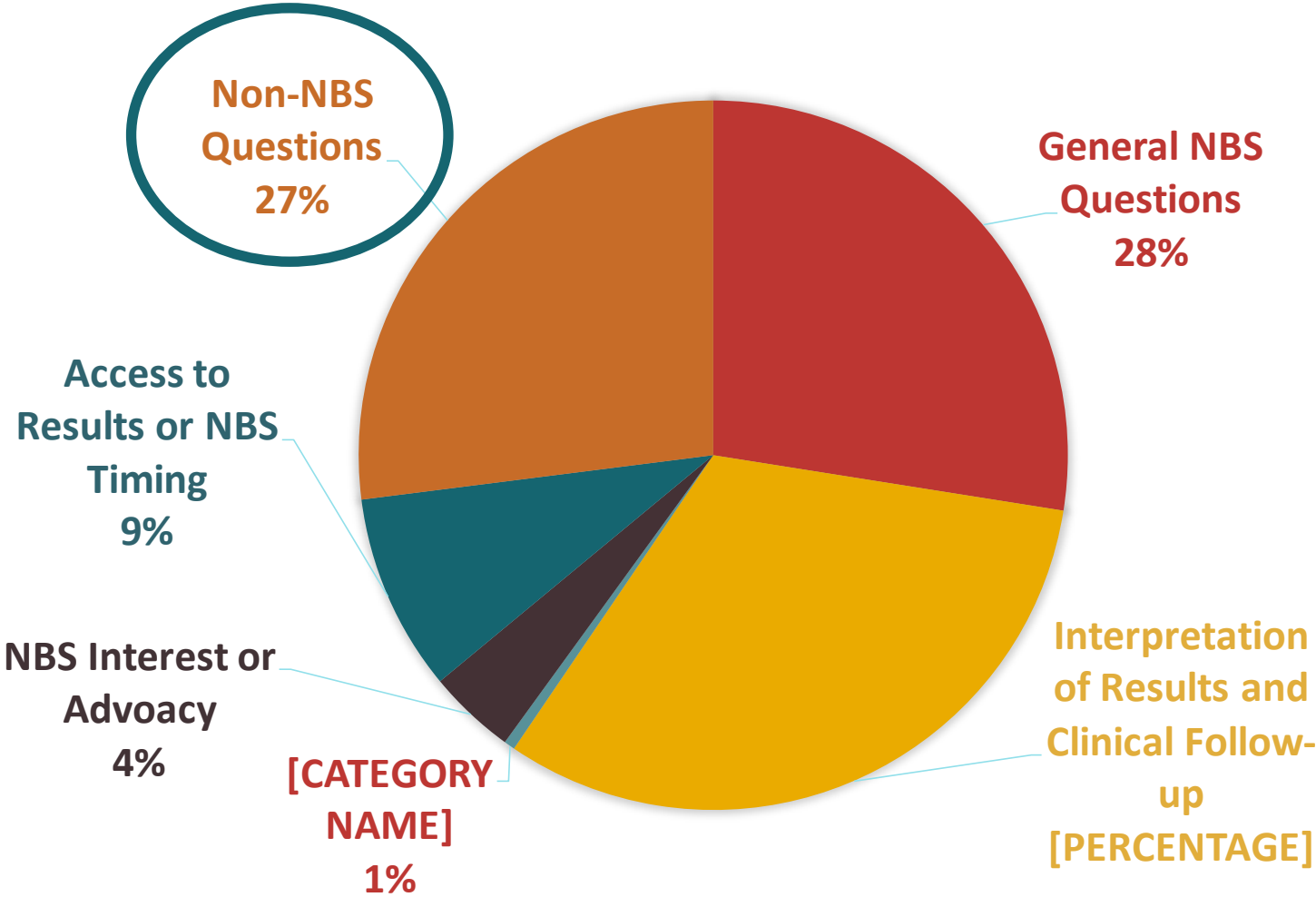
Continuum of NBS Information Touchpoints

THESE ARE NOT **SYNONYMOUS!**

- **Awareness:** Exposure to information
- **Education:** Imparting fundamental knowledge and tools that can be used to grow and expand the concept
- **Training:** Imparting “how to” knowledge
- **Engagement:** Bidirectional process of collaboration

"How incredibly grateful I am for the materials you've provided me with--you've made doing what I do so much easier. From the bottom of my heart, thank you!!"

Ask an Expert



*2016-2017 Data

What Do They Want To Know?

Parents

1. **The Why**
 - Importance of newborn screening
2. **The What**
 - Screening procedures
3. **The What Now?**
 - Copy of results
 - Talk to your health professional

HCP

1. **The Why**
 - Importance of newborn screening
2. **The What**
 - Screening procedures
 - State requirements
 - Newborn screening conditions
3. **The What Now?**
 - Communication tools
 - Messaging
 - Responding to Results
 - Resources





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- **MCHB, Health Resources and Services Administration**



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“At first, I was scared and I cried, but after months of testing and careful follow-up, we now know what to look for, when and what Tristan should be eating since his body can’t fully process protein. To be honest, if it wasn’t for his newborn screening, I don’t know where we would be today. I’m grateful. Tristan is a super happy, healthy boy.”

Tristan was born Jan. 21, 2016 with Methylmalonic Acidemia Minus (Mut-). Story shared by Tristan’s mother, Christine Camacho.

#2018NBS



BabysFirstTest.org