



Redefining Public Engagement in Newborn Screening and Its Impact on Education and Policy

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Baby's First Test houses the nation's newborn screening clearinghouse. As the clearinghouse, Baby's First Test informs and supports millions of families and healthcare professionals throughout the newborn screening experience.

*Increasing Newborn Screening **Awareness, Training, and Education** through **Engagement***

Education vs. Engagement: Why Does it Matter?

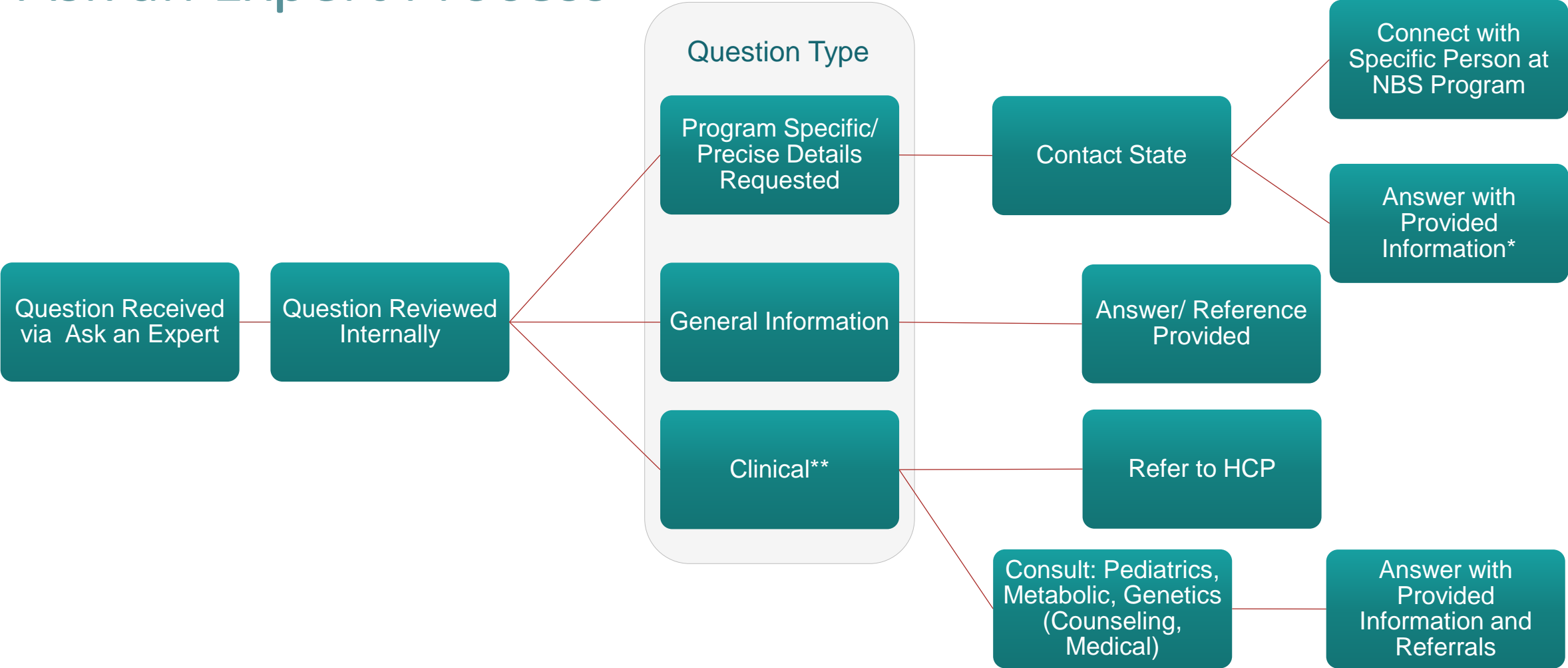
- NBS conditions are changing
- NBS technology is changing
- Parents becoming more active in all aspects of their newborn healthcare
- Increased numbers of stakeholders



Ask an Expert

- Created in September 2016 for expecting and new parents to ask questions about newborn screening Accessible throughout BabysFirstTest.org
- Who are the experts?: Baby's First Test Staff, State NBS Officials, Geneticists, Pediatricians, Genetic Counseling, etc. (Goal: connecting to the right knowledge)
- Process reviewed by HIPAA expert
- By July 2017, a total of 177 questions received

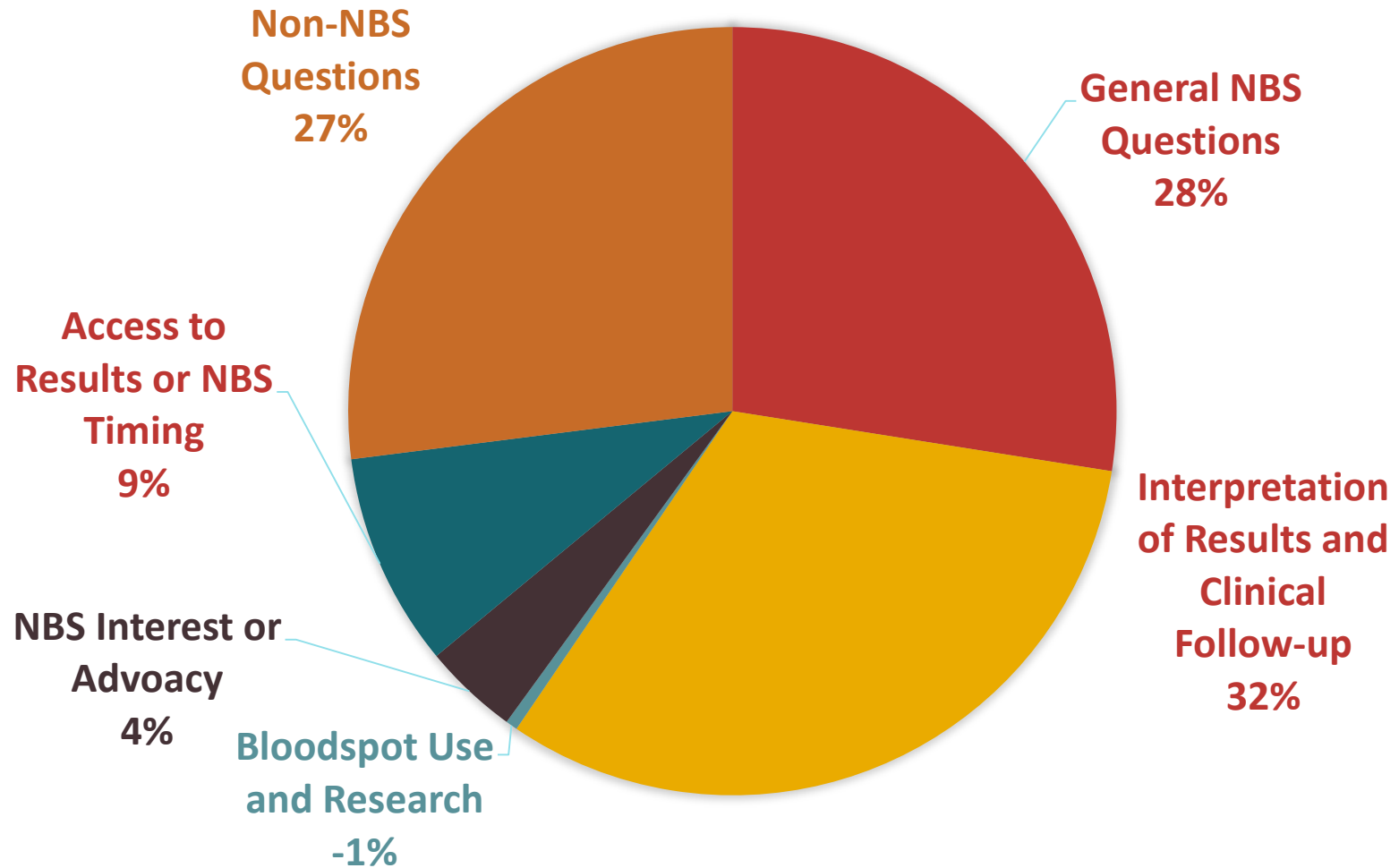
Ask an Expert Process



*When available, link to state specific information is included

**Email includes reference to speaking with a health professional and ask if they need guidance in obtaining one (i.e. genetic counselor)

Ask the Expert Questions



General NBS Questions

Timing or Screening Procedures

- *Can venous blood drawn via 23 or 25 gauge butterfly IV needle with tubing into a syringe be used to drop onto filter paper for quality NBS?*
- *Is there a minimum number of feeds required before a newborn screen should be done?*
- *Until what age can the second newborn screen be completed if missed at 2 wks of life?*

Number and Types of Conditions

- *How many core conditions are there? One resource said 32 but your site says 34, please clarify.*
- *Hi, What conditions does your new born screening service test for? What is the sample type? Can you not test the baby's saliva instead?*
- *I'm curious to know whether New York's Newborn Screening includes screening for Down's syndrome. Thanks.*

General NBS Questions

New Technology and Adding Conditions

- *Why is Krabbe disease not on the newborn screening list here in North Carolina? Is there anything being done to add this devastating disease?*
- *Is Whole Genome Sequencing included in Michigan's newborn screening?*
- *What date did Minnesota begin to screen newborns for cystic fibrosis?*

Other

- *Can I ask for test that isn't offered in my state?*
- *Do you know of any specific religions that refuse PKU/neonatal screenings?*

NBS Results and Follow Up

Interpretation of Results

- *My daughter screening came back abnormal for Galactosemia. It has the number 29.3 out beside the GALT enzyme marker. What does the #mean?*
- *I am a pediatrician & I have newborn screen results with numbers, but I'm not sure if they are in range. Where can I find the normal values?*
- *The result of my baby newborn screening in her test is "within normal limits " what does it mean? Is my baby's result is okay??*

Clinical Follow Up/Treatment

- *For congenital hypothyroidism how long is the treatment process? is it a life time treatment?*
- *What are the foods for babies with g6pd?*

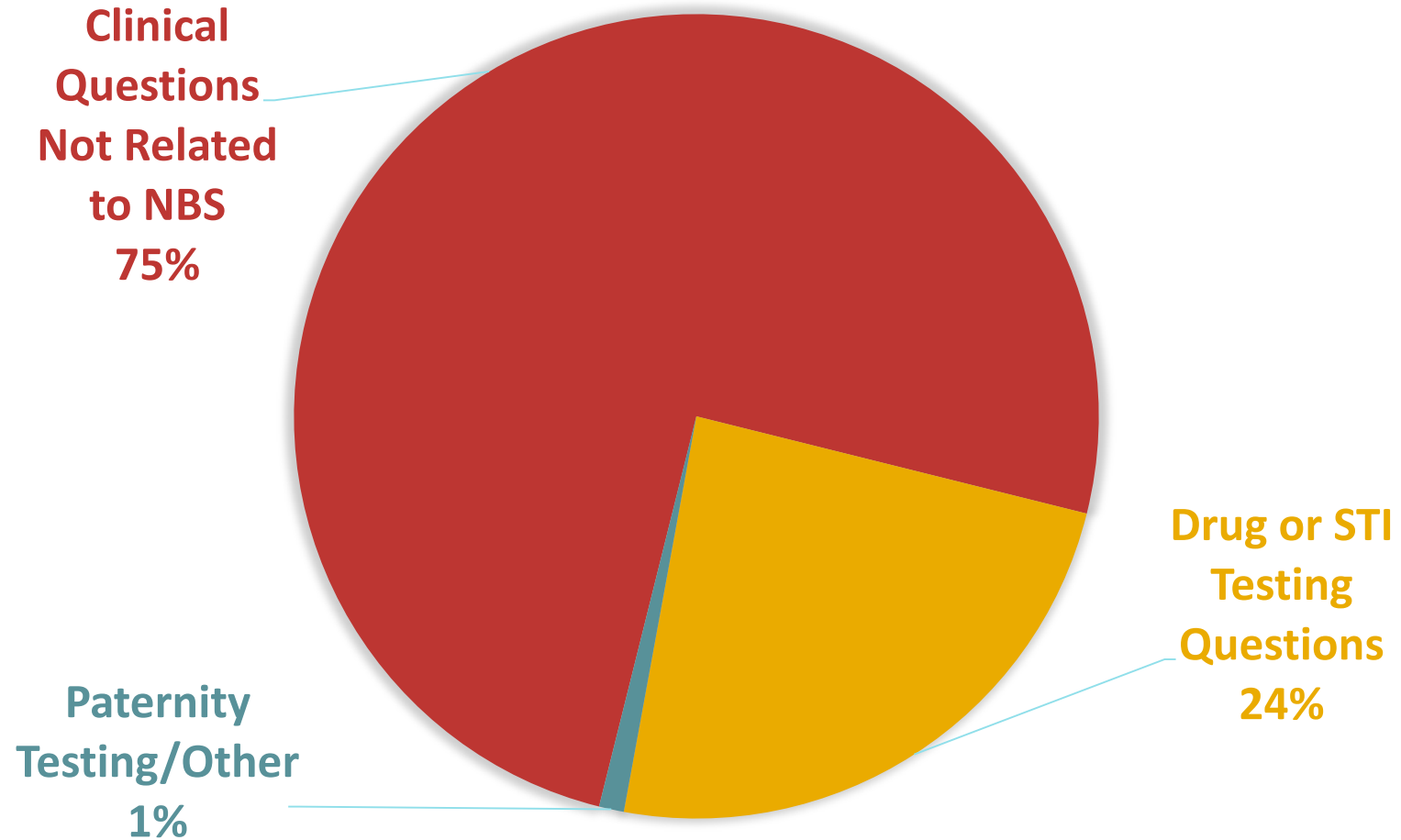
Questions on Access to Results

- *If baby has abnormal results is the birth hospital notified along with the doctor. Are the parents contacted directly ?*
- *How long does it take to get results of a newborns retest will we find out the same day or have to wait days for it? I'm a very concerned-Nana*
- *I was born at Morristown Memorial Hospital in 1998 how can I receive documentation I tested negative for sickle cell ? I need it for NCAA*

Interest in NBS/Advocacy/Bloodspot Retention

- *What happens with “residual dried blood spot” in the state of Connecticut?*
- *My daughter's newborn screening came back normal but she actually has a genetic disorder. What can I do to prevent this for future children?*
- *I am wanting to know how to have a disease added to the newborn screening in KS. SMA had the first ever treatment approved in December.*
- *Is there anything we do not know about newborn screening? I'm giving a presentation in 15 minutes and need to know what is unknown about it.*

Non NBS Questions



The Newborn Screening Public Square



The Newborn Screening Public Square is an online space dedicated to ongoing conversations about newborn screening. It's a commitment to **new ideas, knowledge sharing, and bringing together a range of communities** and experiences within newborn screening to **improve education and awareness.**





December 30, 2016

Anthony Steyermark

I agree with Kimberly Noble Piper about the importance of transparency and public trust in newborn screening. A specific extension of that is at the Population Level under Carrier, where some populations / communities may have a mistrust of government health programs, which makes it critical how the message of carrier status is delivered so that it is not misconstrued.

Also, it may be worth clarifying the "NBS State" stakeholder role. There is "Impact on state services (e.g. Medicaid, public school system)?", but this may not adequately capture the resources and services that an individual needs to reach their best possible outcome. This gets to the difference between available and accessible. While the availability of healthcare services (treatment, clinicians) is considered when exploring new conditions, the accessibility of services (local/state/federal) is rarely considered, and may lead to inequities at the individual and population levels.



September 12, 2016

Amy Gaviglio

Hi Jenna, Thank you so much for sharing your story. Certainly, TX is not alone in trying to figure out how to add ALD and the other two conditions recently added (Pompe and MPS1) to their newborn screening panels. Many states are in the same boat (I'm sure that is not very comforting to you, however!). I am really happy to see that you are looking at how to increase funding for TX as this is often a part of adding a disorder that is overlooked. Adding a test takes a lot of money and time and it extends way past just purchasing the testing equipment and hiring staff and goes into making sure a follow-up system is in place so the experience for families is as smooth as possible. No state wants to add a condition before it is ready and before the system is in place to support screening and the family throughout the process. I encourage you to work with the TX program to learn what they need to add the disorder, so you can work together to make it happen in the best way possible!

What is Engagement?

Meaningful Engagement:

An active process characterized by shared vision, responsibility, and stewardship, where all stakeholders are equally respected and their contributions are essential to its success.

*Based off of PCORnet (Patient- Centered Research Network) Definitions www.pcornet.org/



Questions?

Visit Booth #306



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