Standardization in Newborn Screening Communication:

Resources for Responding to a Shifting Landscape

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Genetic Alliance
Who We Are
Baby’s First Test brings together the latest information and resources to help guide parents, families, loved ones, and their health professionals throughout the newborn screening process.
What Can You Do?
Newborn Screening: More Than a PKU Screen
Newborn Screening: More Than a PKU Screen

Newborn screening (NBS) began in the 1960s with a screen for Phenylketonuria (PKU), but over the years, NBS has expanded to screen babies for many conditions. Despite this growth, many healthcare professionals still use the term "PKU test." With more conditions added to newborn screening panels, this term is no longer accurate and is confusing for parents and clinicians.

REMEMBER:
State and national health programs have accepted and widely use the term NEWBORN SCREEN to refer to the collective group of conditions screened for at birth. References to the 'PKU test' should be updated to NEWBORN SCREEN - including any language found in textbooks, reporting systems, or in daily use.

A STATE NBS STORY:
WHY YOUR WORDS MATTER

A family received an urgent call informing them that their child needed follow-up for an abnormal newborn screen. Arriving at the lab, a staffer came up to them and said "You must be the people here for the PKU test." Returning home, this family spent all weekend researching PKU. Arriving at the metabolic clinic, they were surprised to find their newborn was not suspected of having PKU at all. Instead, their child was actually at risk for an entirely different condition.

Clinic staff had to spend a lot of time helping the family "unlearn" all the information they had gathered, a time-consuming task which could have been avoided had the correct terminology for newborn screening been used from the beginning. Iowa NBS staff have been discussing this issue for several years now in their presentations to perinatal staff. After presentations, staff will often say, "We didn't know we weren't supposed to say PKU test".

What can we learn from this story?
1. The term 'newborn screen' should be used in place of PKU test.
2. Using the incorrect terminology for newborn screening is an important issue in clinical practice.
3. Using the term PKU test has tangible consequences.
4. Using inaccurate terminology may lead to incorrect follow-up testing.

WHY IS THIS IMPORTANT TO REMEMBER?
Being a new parent of a child with an abnormal newborn screen can be overwhelming. It is important to provide consistent, accurate information to families about the newborn screening process to minimize anxiety, confusion and misinformation.

If you have further questions about newborn screening or the conditions found in your state, please visit BabysFirstTest.org
Michigan Beta Testing Results

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>23%</td>
<td>Called newborn screening “the PKU Test” before reading the document</td>
</tr>
<tr>
<td>96%</td>
<td>Recognized the importance of shifting language to newborn screening</td>
</tr>
<tr>
<td>73%</td>
<td>Thought the document would be useful for their hospital</td>
</tr>
</tbody>
</table>
Precontemplation
Unaware of issue with the term "the PKU test"

Contemplation
Understands the consequences of using the term "the PKU test"

Preparation
Talking to a supervisor about changing the term "the PKU test"

Action
Beginning to incorporate the term "newborn screening" instead of "the PKU test"

Maintenance
Permanently shifting to the term "newborn screening"

https://www.prochange.com/transtheoretical-model-of-behavior-change
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Strategies for Implementation

- Disseminate the document to healthcare professionals
- Use posters in break rooms
- Present in trainings
- Partner with provider education programs at universities

*Baby’s First Test can provide support!*
Recommendations for Plain Language Newborn Screening Results
Plain Language Recommendations for Reporting Newborn Screening Results

By law, lab results must be reported to anyone testing and the individuals they legally represent. People undergoing laboratory testing are encouraged to review their reports, including newborn screening results. With this in mind, newborn screening lab reports must be understandable to parents and families. While some aspects of these reports may be difficult to change due to regulatory requirements, when an opportunity comes to make edits, these recommendations serve as a guidance document to create clear reports.

1. SUMMARIZE THE RESULTS

Screening results should be concisely and simply summarized:
- As more diseases are added to screening panels, reports become more complex—summaries are useful to highlight key information.
  - List key information and immediate action items
  - Include appropriate contact information for follow-up questions
  - Be clear when further follow-up is necessary

See below for examples of summary text:
- This screen showed high risk for [CONDITION NAME]. Please take this child for immediate further testing. This screen showed a low risk for all other conditions.
- This screen was low risk for ALL CONDITIONS. No further action is needed at this time. Should this child develop any health concerns, a healthcare provider may suggest diagnostic testing.

2. LANGUAGE RECOMMENDATIONS

Clearly and concisely state the meaning of results:
- Writing should be at or below an 8th grade reading level.
- Use the Federal Plain Language Guidelines to learn to write in plain language: [https://www.plainlanguage.gov/guidelines/](https://www.plainlanguage.gov/guidelines/)
- Alternatively, use plain language software such as:
  - Visible Thread Readability
  - Readable.io

Include a noticeable disclaimer stating that false negatives can happen in newborn screening. Example: “In very rare cases, a child with a condition on the newborn screening panel may not be identified by the screen.”

3. RISK TERMINOLOGY IS RECOMMENDED

Move towards risk terminology:
- Include specific language about high risk conditions or if all results are low risk.
  - Use high risk, indeterminate risk (borderline), and low risk.
  - The terms “positive” and “negative” can be confusing and imply diagnostic testing. These terms should only be used if the results are considered diagnostic - further follow-up is necessary for any result not considered normal.

Terminology should always be clearly explained.

4. DESIGN RECOMMENDATIONS

Abnormal results should stand out from other results:
- Highlight, change the font color, CAPITALIZE, underline or bold important points

Place summaries and action steps before any other results so the eye goes there first. Some parents won’t read the whole report.

If there is a trailer/footnote at the bottom of the results page, make sure any important information stands out.

If analytes are listed, use a table and clearly state the risk profile of each condition in a column next to the analyte.

<table>
<thead>
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<th>Analyte</th>
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<tbody>
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<td>High Risk of Condition</td>
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<tr>
<td>Cystic Fibrosis</td>
<td>Immuno-reactive Trypsinogen</td>
<td>Low Risk of Condition</td>
</tr>
<tr>
<td>Hyperthyroidism</td>
<td>Thyroid Stimulating Hormone</td>
<td>Indeterminate Risk (Rescreen)</td>
</tr>
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References


| Summarize the Results | • Concisely and simply summarize results  
• Highlight key information |
|-----------------------|------------------------------------------------------------------|
| Language Recommendations | • Use plain language  
• Include a disclaimer about false negatives |
| Risk Terminology | • Avoid implying that results are diagnostic  
• Stress follow-up |
| Design | • Place important points at the beginning  
• Use charts and visuals |
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Strategies for Implementation

- Address during regulations changes
- Address during process updates
- Make text edits where possible

Baby’s First Test can provide support!
SAN FRANCISCO -- You probably know where your Social Security card, birth certificate and other sensitive information is being stored, but what about your genetic material? If you or your child was born in California after 1983, your DNA is likely being stored by the
SC lawmakers considering testing newborns for more disorders

Posted March 27

By CHRISTINA L. MYERS, Associated Press

COLUMBIA, S.C. — South Carolina lawmakers are considering legislation that would require neonatal testing for certain genetic disorders and diseases in addition to the existing newborn screenings.
Newborn Screening Education Best Practice Framework
GUIDING QUESTIONS

What is the overall goal of the education?  
What is the issue that needs to be addressed?  
Are the plans people and purpose driven?  
What type of information dissemination will meet the goal?

Why does the issue need to be addressed?  
What is the cause of the issue?  
What is the motivation to address the issue now?  
How high is the priority?

Who is the target audience?  
What is the geographical target area?  
What special considerations are necessary for the target population?

When does the intended change need to take place?  
Is there an urgent need to address the issue? Provider needs, family needs etc.

What modalities and distribution strategies are planned?  
What resources are available for developing new materials or modifying existing materials?  
What other barriers exist in developing/implementing?  
What is the best modality for the target population?

Is the need, desired outcome, or audience unprecedented?  
Are there existing education materials available to meet this need?
How Can We Help?
Available Support and Resources

*Baby’s First Test Offers Assistance and Partnership*

- Design and Tailor Education Materials
- Build Strategic Education and Training Plans
- Engage Communities and Professionals
- Support Implementation of NBS Education Best Practices Framework
## Thank You!

### State Workgroup

<table>
<thead>
<tr>
<th>NAME</th>
<th>STATE</th>
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<tbody>
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<td>Amy Gaviglio</td>
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<td>Joyal Meyer</td>
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### Best Practices Workgroup

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<thead>
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<tbody>
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<td>The College of Education, University of Iowa</td>
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<td>Carol Johnson</td>
<td>University of Iowa</td>
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<td>Beth Vogel</td>
<td>New York State Department of Health</td>
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<td>Siobhan Dolan</td>
<td>Albert Einstein College of Medicine</td>
</tr>
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### Michigan Beta Testing Team

Kristen Thompson and Mary Kleyn

### The Baby’s First Test Team

Natasha Bonhomme and Jackie Seisman
Questions?

Learn More:
BabysFirstTest.org
Spanish.BabysFirstTest.org

Visit Booth #104 to Check Out More Resources