Review of Best Practices in Documenting Newborn Screening Refusals for States

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<th>Reason</th>
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<td>No State Form</td>
<td>Optional State Form</td>
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<td>6</td>
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<td>12%</td>
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<td>Refusal for religious reason</td>
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<tr>
<td><strong>Total:</strong></td>
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<tr>
<td></td>
<td>39%</td>
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Purpose of Project

• Documentation of refusals is considered good practice for state programs and supports the goals of newborn screening programs

• Wide variation in what states do to document refusals

• Little information available on how to effectively document refusals
Methods

• Survey of state newborn screening coordinators
  – 82% response rate
  – $5 gift card offered
• Collected newborn screening refusal forms
  – 93% of optional or required forms gathered
• In-depth interviews with five states
  – $10 gift card offered
• Focus group with parent advocates on refusal forms
Results

• Highlighted the value of documenting refusals at the program level

All newborn screening programs should require program-level documentation of newborn screening refusals

(States without a provision for refusals should document refusals so information is available for appropriate follow-up)
Basic model for documenting refusals

Challenges:
• Cost / benefit ratio seems high
• Emphasis on counting and protection from liability
• Can be easy to see why some programs wouldn’t want to bother with this
Enhanced Model for Documenting Newborn Screening

Birth Provider → Educate 

Parents

Screen → Record, Liability, Counts 

Refuse → 

NBS Program

Well-child Provider → Future parents & providers, Policymakers 

Feedback & Educate

Follow-up & Offer screening → Education campaign
The most important purpose for documenting newborn screening refusals is to facilitate communication between the many stakeholders while record-keeping, liability protection, and counting serve a secondary role.
Gathering accurate data regarding newborn screening refusals allows newborn screening programs to follow-up with parents, hospitals, birth providers, and well-child providers, and reduces the number of babies who are not screened.
What to Include on the Form

• Contact information for:
  – Parents
  – Birth center / hospital
  – Birth provider
  – Well-baby provider

• Make the form available in multiple languages

• Ask for the reason for refusal

• Educate about screening – might be the only NBS document a parent sees
  – Summary of conditions screened
What to Include on the Form

- Include website and phone number for additional information about screening
- Clear instructions on the form
- Separate refusal for screening with refusal for storage / research of bloodspot cards
- Have separate options for metabolic / genetic, CCHD, hearing
- Use a paper form (or require a portion be printed and given to the parents)
- Do not rely on bloodspot card (insufficient space for all of the information needed and parents do not usually see the bloodspot card)
Linking Records

- Link laboratory records, birth certificate records, and refusals to ensure all babies are accounted for
- Some smaller states did this by hand
- Integrated electronic data systems would be best
- Want to avoid “misses”
Next Steps

• Find out what your state’s NBS program does to document refusals (and your state’s policy on refusals!)
• Update your state’s refusal documentation form
• You can request specific feedback from the authors: jeremy.penn@ndsu.edu
• Communicate the change with key stakeholders
• Support additional research on educating providers, follow-up with patients, reasons parents refuse, and using information on refusal to inform policy decisions

Note: statements in this presentation are those of the authors and not necessarily those of NDSU or HRSA