Members

New Members
- Yvonne Kellar-Guenther
- Sarah Viall
- Mary Klein
- Barbara Ferreira
- Cynthia Powell
- Beth Tarini
- Cathy Wicklund
- Joseph Bocchini

- Amy Gaviglio
- Aaron Goldenberg
- Joyce Graff
- Stacy Hines-Dowell
- Siobhan Dolan
- Keri LeBlanc
- Jeremy Penn
- Adam Kanis
- Natasha Bonhomme
- Cate Walsh Vockley
- Britton Rink
Workgroup Charge

Review existing educational and training resources, identify gaps and make recommendations regarding the following five groups: health professionals, parents, screening program staff, hospital/birthing facility staff, and the public.
Create a Newborn Screening Educational Planning Guide that can be used by newborn screening programs to develop and improve NBS educational resources

Provide all NBS stakeholders a list of relevant content areas to consider for inclusion in their educational materials.
Next Steps

- Create legend/definition of content areas
- Validation before dissemination and publication
  - Explore validation methods used with similar tools
    - Literature review
    - Experts in the education field
- Dissemination
  - Complete list of groups
  - Prioritize groups
Abnormal NBS Result Communication Guide

- Create a Communication Guide that can be used by clinicians and providers to help frame the initial notification and discussion of out-of-range results with parents about the newborn screening result.

- Address the reported dissatisfaction by parents regarding the initial notification discussion
The goal of this document is to enable the clinician to fulfill the following important objectives in disclosing newborn screening results:

- Discussing the result and relevant medical information
- Gathering information from the family regarding understanding
- Providing support to the family
- Collaborating with the family in developing a follow-up plan
Next Steps

- Improve design and formatting
- Measure Utility
  - Pilot study on the use of the Communication guide; possible existing opportunities through collaborators
  - Baby’s First Test has some language already we might be able to use
- Broaden expertise in Workgroup
- Dissemination
  - Continue to work on building a comprehensive list
  - Prioritize organizations to contact
Other Discussion/Projects

- Communication Guide for normal results
- How can our workgroup help support the issue of basic concepts of screening and risk assessment?
  - Members of the workgroup have some relevant projects they are currently working on: workgroup will provide feedback
Questions?
Feedback on Public Health System Assessment Surveys

- Clarify purpose: Assessment of NBS program readiness/feasibility only, not the public health system
- Question 1: Make it clear that this question is asking if a state is already screening for a condition
- Question 5: Consider changing categories
  - Should we define how challenging it is with how many years it may take?
  - Not known should be an option
  - Is there funding for...Yes/No as options
- Do all health departments reach out to providers/specialists to answer the questions regarding support for specialists and treatment?
Feedback Continued

- **Question 6b:** how useful are all of the categories?
  - Need five choices?
  - How are they analyzed?  Collapsed?

- **Question 7:** How long from start up to implementation?
  - How accurate/valid are the answers?
  - Need more choices and/or just ask specific numbers?
  - What are things that may inhibit you from reaching that goal?
Feedback Continued: General Thoughts

- Expand questions to include issues of equity and disparities?
- Address sustainability
- Initial survey is hypothetical: Follow up survey may be more important
- Transparency: how much will this be weighted in the decision matrix?
Follow-Up Survey

- Question 5: Specify various phases of implementation
- Question 6: Add specific probes
- Methodology Questions
  - Beyond the scope of this survey?
  - Other ways to assess this/bigger issue that needs separate attention?
- Assess downstream impact
- Other stakeholders to interview? Specialists/those providing care, other people at public health department?