

Education and Training Workgroup



Catherine Wicklund, Chair
Beth Tarini, Chair

ACHDNC MEETING
MAY 9, 2018

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.

NBS Education Planning Guide



- **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**

What is tool designed to do?



- 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

Education and Training Workgroup



Questions?

Education and Training Workgroup PHSI Feedback



BETH TARINI AND CATHERINE WICKLUND
MAY 10, 2018

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?**