

Newborn Screening Education and Training Tools: a Communication Guide and an Educational Planning Guide

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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

Goal/Purpose of Project

- Create a Newborn Screening Educational Planning Guide that can be used by newborn screening programs to develop and improve NBS educational resources

Highlights of Tool

- Grid:
 - lists various NBS content areas in columns
 - Lists stakeholders in rows
- Can be used like an index
- Specific to each stakeholder

What is tool designed to do?

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

How was tool created?

- Blood, sweat, and tears
- Through several innumerable revisions by a small workgroup of E&T members and full committee members
- Reviewed by stakeholder groups; differences resolved by project group leadership
- Reviewed by ACHDNC committee members

Intended Users

- Any and all relevant stakeholders – examples...
 - Public
 - Families
 - Programmatic
 - Legislative
 - Providers

Dissemination Plan

- House on the Committee's website and the Clearinghouse (and others) will link to it
- Publishable manuscript / white paper
- APHL Webinar NewSTEPS listserv
- Professional societies and other organizations

Abnormal NBS Result Communication Guide

Goal/Purpose of Project

- 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

Highlights of Tool

- Fills a gap not previously addressed (the *how* to communicate; not the *what* to communicate)
 - Builds upon family focus group work already conducted by Baby's First Test and Dr. Carol Greene
- Utilizes known and studied protocol for providing high-anxiety news
- Utilizes mnemonic of SCREEN for enhanced memory of steps
- Fits on one page!!

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

How was tool created?

- Blood, sweat, and tears
- Through several innumerable revisions by a small workgroup of E&T members and full committee members
- The Communication Guide was modeled after the SPIKES protocol for delivering unfavorable information (Baile, et al., 2000)
 - This protocol has generally been utilized in the oncology realm
- Additionally, genetic counseling core skills and tenants were utilized

Intended Users

- Primary Care Providers and/or Specialists who provide initial notification of out-of-range newborn screening results to families
- State NBS Programs for dissemination to their providers and/or if programs need to directly notify families

Dissemination Plan

- Incorporate into Midwest Regional Genetics Collaborative work on creation of AAP MOC 4 for communicating NBS results to families
- Other Organizations (*cue alphabet soup*):
 - ACMG – Linked to ACT Sheets
 - AAFP
 - AAP
 - ANA
 - ASHG
 - Baby's First Test
 - Disorder-specific advocacy organizations
 - ISONG
 - NBS Programs
 - NSGC
 - NCHPEG