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

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ACHDNC Meeting

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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