



# Deliberative Community Engagement – Recommendations for Communication

KIMBERLY NOBLE PIPER

EXECUTIVE OFFICER, CENTER FOR CONGENITAL AND INHERITED DISORDERS

IOWA DEPARTMENT OF PUBLIC HEALTH

PRESENTED TO THE ADVISORY COMMITTEE ON HERITABLE DISORDERS IN NEWBORNS AND CHILDREN

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# Background



- ▶ RUSP - Adding new genetic and inherited conditions with late onset types, potentially higher false positive rates, and treatments with high cost and potentially devastating side effects poses challenges that the Iowa Newborn Screening Program (INSP) needed to address as it provides mandatory newborn screening for Iowa's newborns.
- ▶ Advocates, providers, commercial interests, and families affected by these conditions have a prominent voice, and are vocal and passionate about what their recommendations are for screening for these conditions.
- ▶ INSP leadership wanted to hear from Iowans that weren't directly affected by these conditions, in order to obtain objective, deliberated recommendations for Iowa's NBS processes that best reflect the values of Iowans.

Hence the Iowa Deliberative Community Engagement  
for Newborn Screening Project

# What is Deliberative Community Engagement?



**DEFINITION:** Deliberative (community) engagement is a distinctive approach to involving people in decision-making. It is different from other forms of engagement in that it is about giving participants time to consider and discuss an issue in depth before they come to a considered view.\*

**PURPOSE:** **Deliberative** processes can improve the quality of decision making and engage the broad **community** in the policy development process. They can be used to resolve divisive issues and generate discussion about big picture policy issues. †

“Possibly the closest that everyday people can get to actually influencing policy. Powerful because policy makers receive educated recommendations from their own constituents.”

- Dr. Michele Gornick, DCE Facilitator

\*Involve UK. Accessed 10-23-18 at <https://www.involve.org.uk/resources/publications/practical-guidance/deliberative-public-engagement-nine-principles>

† Gregory J. et al. Using deliberative techniques to engage the community in policy development. *Aust New Zealand Health Policy*. 2008; 5: 16. Accessed 10-23-18 at [www.ncbi.nlm.nih.gov/pmc/articles/PMC2500036/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2500036/)

# Deliberative Community Engagement

- ▶ Recruited a sample of 30 Iowans from across the state.
- ▶ Asked the deliberants to consider three deliberative questions -
  - ▶ **Questions to consider:**
    1. What are important factors to consider when planning for future additions or changes to Iowa's Newborn Screening Panel?
    2. How should Iowa Department of Public Health change communication to families?
    3. How can IDPH continue engaging the public to provide ongoing feedback for the Newborn Screening Program?

# What did we hear?

Question 2: How should Iowa Department of Public Health change communication to families?

- ▶ Several recommendations about the timing of education to families (PRENATAL), medium, approaches, and content
- ▶ Suggestions for provider education & information, such as who should communicate abnormal results, how to communicate results, reporting all results (not just abnormal)
- ▶ Content of communications – early vs. late onset; false positives; opt out; availability and effectiveness of treatments; costs

*“Also include in prenatal information; like how they give that packet of information to the new mothers, but then the new mothers are probably stressing about their newborns and don't have time to read that packet, so I think that should be stressed and have that information be provided while I'm pregnant.”*

*“I think it should be done a couple of times even if it gets closer to delivery and then ask if they have any questions because people are not educated enough at their level.”*

# Who, what, where, when and how - NBS education

- ▶ Who – NBS staff, prenatal educators, prenatal care providers, local MCH programs, WIC programs, hospital staff
- ▶ What – early vs. late onset types; false positives; opt out; availability and effectiveness of treatments; costs; NBS not intended to screen for late onset
- ▶ Where – public setting (PSAs, flyers, presentations to civic organizations, high schools); prenatal care provider clinics; childbirth education classes; hospitals; outpatient lab while getting GTT screening
- ▶ When – PRENATALLY, more than once and document information delivered
- ▶ How – brochures, online (interactive with the ability to get questions answered), videos. No more apps.

# Who, what, where, when, and how

## - Reporting Results

- ▶ Who should communicate abnormal results? - PCP, but with specialist or someone knowledgeable about the condition as back-up (don't want to be passed around to speak with different providers). Someone with good communication skills and empathy.
- ▶ What should be communicated? - What does abnormal result mean; risk for late onset; treatment started while waiting confirmatory testing; resources available to help family navigate the system. or learn factual information about the condition. Normal results reported, or families told that "no news is good news;" Where should the communication take place? - By phone, or in person if need to collect another specimen or do other testing. Provide hard copies of information when possible.
- ▶ When should results be reported? - As soon as possible, emergently if time-critical condition
- ▶ How should results be reported? - with support person present; with compassion and empathy; don't pass them around; provide hard copies of information; use standardized communication guide or checklist (similar to Minnesota's SCREEN tool) and give copy to parent

# Thank You!

*Kimberly Noble Piper, RN, BS, CPH, CPHG*

*Executive Officer, Center for Congenital and Inherited Disorders*

*Iowa Department of Public Health*

*kimberly.piper@dph.iowa.gov*

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