

Follow Up and Treatment Workgroup Update

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2019 Follow-up and Treatment Workgroup

ACHDNC MEMBERS

- Jeffrey P. Brosco, MD, PhD (FUTR Chairperson)
- Susan A. Berry, MD
- Kyle B. Brothers, MD, PhD
- Kamila B. Mistry, PhD, MPH
- Annamarie Saarinen

ORGANIZATION REPRESENTATIVES

- Christopher A. Kus, MD, MPH (FUTR Co-Chair)
Association of State & Territorial Health Officials
- Robert J. Ostrander, MD
American Academy of Family Practice Physicians
- Jed L. Miller, MD, MPH
Association of Maternal and Child Health Programs

WORKGROUP MEMBERS

- Sabra A. Anckner, RN, BSN
- Tracey Bishop
- Amy Brower, PhD
- Luca Brunelli, MD, PhD
- Christine S. Brown, MS
- Debra Freedenberg, MD, PhD
- Lawrence Merritt, II, MD
- Dawn S. Peck, M.S., CGC
- Margie A. Ream, MD, PhD
- Elna Saah, MD
- Joseph H. Schneider, MD, MBA, FAAP
- Marci Sontag, PhD
- Janet Thomas, MD

Newborn Screening Translational Research Network (NBSTRN)

Amy Brower, PhD

- Longitudinal Pediatric Data Resource (LPDR)
 - This tool enables clinicians, researchers, parents and patients to enter health information in a secure centralized system.

Goal was to create a minimum set of questions and answers from the LPDR for use by State Newborn Screening Programs

- > 2500 Questions to 4 Questions

Newborn Screening Technical assistance and Evaluation Program (NewSTEPS) Long-Term Follow-up

Marci Sontag, PhD

Minimum Question Set for Public Health – developed in partnership with NBSTRN

- Diagnosis
- Date of appropriate first intervention
- Are they alive?
- Within the last 12 months did the child receive care and treatment specific to the diagnosis? Type of care provider?

Minimum Data Set

Question:

Would the Committee approve of the FUTR Workgroup thinking about a proposal that would encourage states to utilize a minimum data set for program evaluation?

Consent and Confidentiality

- Discussion of risk of potential harm of identifying individuals
- In smaller states, it is a significant concern
- Communities vary in their willingness to consent to share their information
- Labs can be a barrier to consent
- It is important for families to know that part of consent is the ability to reconsider consent throughout the study period

Next Workgroup Call

- Minimum data set discussion
- Discuss workgroup input on key aspects of Kemper presentation (case definition, outcomes, treatment, gray literature)