Advisory Committee on Heritable Disorders in Newborns and Children

Assessing the Public Health System Impact (PHSI) of Adding Conditions to the RUSP
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Background

- Per the Newborn Screening Saves Lives Act, an assessment of the impact of public health was integrated into the evidence-based review of conditions nominated for addition to the RUSP.

- Purpose: to evaluate states’ ability to implement the screening of a new condition and cost implications of implementing population based screening.
Background

To inform the Committee about the implementation issues facing NBS programs, information regarding implementation is requested from each State based on the following key factors:

- NBS Program Organization and Authorization
- Screening Methods
- Short-Term Follow-up
- Long-Term Follow-Up
- Anticipated resources and costs
- Projected timeline for adoption
The evaluation allows the Committee to:

- Identify the resources needed, impacts, and costs, including opportunity costs, that can affect a State’s ability to implement screening
- Estimate how long it will take for state NBS programs to add a particular condition to their screening panel
Background

- Public Health Impact Assessments conducted for:
  - Pompe
  - MPS1
  - X-ALD
  - SMA
Survey tools

- Initial Survey – administered to all state and territory newborn screening programs

- Follow Up Survey – administered to a few states and territories to supplement information gathered through the Initial Survey

Survey tools require approval by OMB; Current approval expires this year; A continuation application will be submitted to OMB in 2018.
Workgroup Assignments

- Review surveys this afternoon and present feedback to the full Committee tomorrow

Guidance for the Review Process:
  - Identify potential high level revisions for the next iteration of the surveys:
    - Are there gaps in information collected which could be addressed via the surveys?
    - Recommendations for adding or removing questions from the surveys?

- Tomorrow the Committee will discuss revisions needed