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

Background

- **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 <u>high level </u>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**