

Emerging Issues in Newborn Screening

Advisory Committee on Heritable Disorders in Newborns and Children

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Key Considerations

- **Timeline Trade-offs**

- Deliberate approach vs. speed

- **Capacity**

- Potential for the number of nominations to outpace Committee capacity.

- **Equity**

- Does the RUSP nomination process favor conditions whose stakeholders have more resources? Does it limit conditions whose stakeholders have fewer resources?

Questions to Start the Discussion

- Is the system biased towards conditions that have more resources?
 - Should the Committee actively monitor conditions which are good candidates for nomination?
- Should the Committee consider a process that reviews groups of conditions at once (multiplexed reviews)?
 - How would this impact states and other components of the newborn screening system?
- Does FDA approval of a treatment = treatable disorder?
 - Should there be a streamlined process to recommend a condition for the RUSP if FDA approves a drug?
- What key stakeholders are under-represented (or not represented)?