



Recap of Key Issues Identified for Future Consideration

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Key Issues Identified as Needs Discussion, Research or Policy/System-Wide Change

- **Establish a Plan to Conduct Regular Review of Conditions on the RUSP**
 - Decisions needed to define the process including:
 - Frequency
 - Process for prioritizing
 - Nominating or selection
 - Considerations and criteria
 - Goals and outcomes



Key Issues Identified as Needs Discussion, Research or Policy/System-Wide Change

- **Assess Long-term Follow-Up of Newborn Screening**
 - Impact of NBS
 - Treatment and clinical outcomes, short and longer term
 - Costs of implementation, treatment
 - Impact on health care system and providers
 - Equity and access long term

Key Issues Identified as Needs Discussion, Research or Policy/System-Wide Change

- **Establish a Priority List of Research and Development Issues (ongoing)**
- **Revisiting the Decision Matrix**
 - B-ratings (moderate certainty of evidence): further discussion needed to develop guidance
- **Determine Values of Stakeholders and Include in Decision-Making**
 - Preferences for NBS, esp. patients/families, public
 - Values and preferences/attitudes re: Critical Outcomes

