

# Subcommittee on Treatment and Follow up



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# Charge (draft)

- Recommend guidelines/standards for short and long-term follow up
- Recommend a mechanism for dissemination and education on guidelines/standards to key stakeholders
- Recommend models that would lead to adoption of guidelines/standards
- Recommend mechanism(s) for accountability to guidelines/standards



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# Develop standards for short and long-term follow up

- “State of newborn screening follow-up”
  - Inventory of activities related to the development of guidelines (e.g., PEAS, NCCLS, ACMG Txt guidelines, CA/MA MS/MS projects)
  - Inventory of state practices and impediments to follow-up (costs, lab and clinical expertise)
  - Parent/caregiver perspective
- Identify models of care that work—identify common features or key elements



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# Other Issues

- Tracking impact of implementation of ACMG report recommendations on the follow up system
- Clear definitions of follow up (e.g. how long, how often and whose responsible)
- Financing of follow up—can't adequately deal with the children identified
- Tie in with child health information system—potential link with services



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