

Follow-Up and Treatment Subcommittee

Proposed Priorities and Projects

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Proposed Priorities

- **SCREENING PROGRAM IMPLEMENTATION**
 - Learning from the past to inform future (recurring theme)
- **CLOSING GAPS IN SYSTEMS OF CARE**
 - Focus on understanding process
- **REAL WORLD IMPACTS AND OUTCOMES**
 - Focus on outcomes

“Tabled”

- Name change?
 - Not now, possible to revisit, reasons to add “quality” in title but reasons to keep “follow up and treatment”
- Beyond NBS
 - Focus remains on some critical NBS questions, possible to revisit

Overview

- Lessons from the past to inform the future
- Framing questions of interest and identifying sources of data (and gaps)
 - Coordination across existing projects and programs
- Projects of intrinsic value selected and designed to be help/model for other conditions
- Focus on issues with opportunity to add value to ongoing and newly developing programs
- Next steps – after input from full Committee, workgroups are poised to start fleshing out projects

Screening Program Implementation – Possible Case Studies/Projects

Short and LTFU and treatment - what are/should be the metrics? * what are the costs? what is the impact on families? * Explore current and possible models.

- Ongoing evaluation of critical congenital heart disease (CCHG) implementation
- **Hearing screening follow-up**
- Connecting point-of-care testing with DBS screening (perhaps using HIT)

* examples – impact of FP, specific metrics focused on process and on outcomes, e.g. developmental outcomes in CCHD)

Closing Gaps in Systems of Care - Possible Case Studies/Projects

- **Roles and responsibilities in LTFU**
 - As part of case studies, include focus on learning what are the current (and variable) roles and responsibilities in LTFU for children with hearing impairment and sickle cell (disease or carrier).
 - Consider a focused case study of NBS results in the EMR and the EMR as a source of LTFU data
- **Challenges and opportunities in the changing health care environment**
 - Request presentation (after SCOTUS decision) on impact of changes in care systems on children with heritable disorders

Real World Impacts and Outcomes - Possible Case Studies/Projects

- Explore the extent to which we can document improved clinical outcomes; whether we are realizing the potential of NBS.
 - Sickle cell as a “test case”: gaps between technology and disease mgt.; variability in SC trait notification and FU conditions; long history, rich data sources; multiple issues that are important for other conditions
 - Coordinate with ongoing work including HHS initiative
 - Focus on developing key questions and on understanding data sources to identify gaps
- Consider options for overarching approaches and/or other case studies or comparisons that might provide guidance to FU for those in the panel or for those to come in the future