

Follow-up and Treatment Workgroup Report:

The Role of Quality Measures to Promote Long-Term Follow-up of Children Identified by Newborn Screening Programs

ACHDNC Meeting, February 8, 2018

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The Report

- Drafted in response to the February 2016 Charge to the Workgroup:
 - Promoting the role of clinical quality measures to promote long-term follow-up
- Aim:
 - Focus on the use of quality measures to assess and help drive long-term follow-up in NBS
 - Describe quality measures
 - Provide case studies as examples of what is currently being done in the field of NBS and related fields
 - Identify gaps and possible next steps
- Dissemination Plan:
 - If there is consensus from the Committee, post the report on the Committee's website
 - Encourage NewSTEPs, NBSTRN, NCC, Genetic Alliance, etc. to highlight report
 - Pursue publication of the executive summary
 - Encourage colleagues in specialty areas of medicine and public health that intersect with newborn screening to build on the information provided in the report to develop manuscripts relevant to their specialty (e.g. pediatric neurologists)

Possible Next Steps Identified in the Report

- Engage a broad range of stakeholders (e.g. Federal, State, Provider, and Consumer groups, Professional Organizations) to:
 - participate in LTFU of NBS.
 - leverage research networks that collect data from patients and families to participate in quality measure development and quality improvement activities targeted to LTFU of NBS.
- Identify a core set of long term follow-up quality measures and associated data resources for conditions identified by newborn screening.
- Encourage the use of large data collection activities such as the National Survey of Children's Health (NSCH) and quality improvement activities such as Medicaid quality reporting and HEDIS to provide data on LTFU of NBS.
- Assist the use of new Health Information Technology (HIT) standards for implementing and sharing quality measures as a strategy for integrating quality measures into routine care and using Clinical Decision Support (CDS) in the EHR to capture data and guide care.

Questions?

Committee Discussion