Follow-up and Treatment Workgroup Progress Report

ACHDNC Meeting, May 12, 2017
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Two Sub-workgroups

• Medical Foods for Inborn Errors of Metabolism
  • Report affirmed by ACHDNC
  • Publication planned

• Quality Measures for Long-term Follow-up
  • Quick history of ACHDNC activity
  • Progress report – Alan Zuckerman
Long-term follow-up after diagnosis resulting from newborn screening: Statement of the US Secretary of Health and Human Services’ Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children

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ACHDNC – Genetics in Medicine (2008)

- Central components
  - Care coordination
  - Evidence-based treatment
  - Quality improvement

- Features
  - Quality chronic disease management
  - Condition-specific treatment
  - Care throughout lifespan
What questions should newborn screening long-term follow-up be able to answer? A statement of the US Secretary for Health and Human Services’ Advisory Committee on Heritable Disorders in Newborns and Children

Cynthia F. Hinton, PhD, MPH, Lisa Feuchtbaum, DrPH, MPH, Christopher A. Kus, MD, MPH, Alex R. Kemper, MD, MPH, Susan A. Berry, MD, Jill Levy-Fisch, BA, Julie Luedtke, BS, Celia Kaye, MD, PhD, and Coleen A. Boyle, PhD, MS

• Central components
  • Care coordination
  • Evidence-based treatment
  • Quality improvement

• Perspectives
  • State and nation
  • Primary/specialty providers
  • Families
A framework for assessing outcomes from newborn screening: on the road to measuring its promise

Cynthia F. Hinton a,*, Charles J. Homer b, Alexis A. Thompson c, Andrea Williams d, Kathryn L. Hassell e, Lisa Feuchtbaum f, Susan A. Berry g, Anne Marie Comeau h, Bradford L. Therrell i, Amy Brower j, Katharine B. Harris k, Christine Brown l, Jana Monaco m, Robert J. Ostrander n, Alan E. Zuckerman o, Celia Kaye p, Denise Dougherty q, Carol Greene r, Nancy S. Green s, the Follow-up and Treatment Sub-committee of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC):
Framework for Assessing Outcomes from NBS

Hinton et al, 2016
The Workgroup identified potential ways to address this priority

- Draft a background document to describe what is known about quality measures and newborn screening, and identify areas of need and possible opportunities to use clinical quality measures in long-term follow-up.

- Develop case studies that provide examples of how quality measures are used in newborn screening – describe success or barriers.

- Describe other key findings (e.g. use of quality measures vs performance measures, and different approaches for disease-specific measures vs public health services vs patient/child specific measures).

- Summarize key findings
The Role of Clinical Quality Measures to Promote Long-Term Follow-up Progress Report

May 12, 2017

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We are Making Progress in Addressing the Charge to the Workgroup

• Review the state of the art of clinical quality measures
  • Quality measures are gaining increased attention for value based reimbursement and Maintenance of Certification.
  • New standards are facilitating their use.
  • They are a first step in quality improvement and a pathway to new knowledge acquisition.

• Assess the use of clinical quality measures for newborn screening
  • Use has been limited with rare conditions, but the importance of quality measures has been demonstrated for cystic fibrosis, sickle cell disease, and other conditions.
  • Substantial gaps and barriers must be overcome

• Assemble case studies illustrating the use of clinical quality measures
  • We have collected several examples that illustrate the value of quality measures for newborn screening and challenges faced.
  • This meeting we heard from the AHRQ Pediatric Quality Measures Program and a University of Maryland study of Primary Care and Long Term Follow-up of Newborn Screening.
Can Quality Measures be Used for Long-Term Follow-up of NBS?

• This current project is a continuation of 10 years of prior work by the Long Term Follow-up and Treatment subcommittee of the ACHDNC.
  • The Hinton papers on Key Questions for LTFU of NBS and A Framework for Long Term Follow-up are a good fit with the current approaches to quality measures.
  • The 2008 Kemper definition of Long Term Follow-up remains valid and can drive quality measures.

• We can learn lessons from conditions not covered by newborn screening such as Asthma and ADHD that illustrate the role quality measures can play in long term follow-up.

• Quality measures limit the ask for data and seek to answer specific questions.
• Long term follow-up is about more than collecting data, it is about providing and changing care.
• It is important to find measures that matter and have reliable data.
What are the Gaps and Barriers in Applying Quality Measures to Newborn Screening?

• Are there Gaps in Evidence?
  • This has been a concern because many conditions have sub-types and the best treatment is not always clear for some conditions.
  • There are many generic consensus measures that can apply to all conditions.
  • Cystic Fibrosis demonstrated that measures are a pathway to evidence.

• Are there Gaps in Developing Measures?
  • Developing measures is a challenge for rare disorders with late onset.
  • The NQF certification process is difficult for newborn screening.
  • Validating measures is costly.
  • The lack of pediatric quality measures led to the CMS/AHRQ PQMP mandated by CHIP-RA

• Are there Gaps in Adopting and Using Measures?
  • The cost of data collection, and small numbers of patients in a single practice are challenges – we must integrate quality measures into routine care.
  • Measures for Sickle Cell disease are now available and expected to increase in use.
  • Some models used by health departments are hard to replicate elsewhere.
There is a Need to Move Beyond Disease Specific Measures

• Traditional approaches to quality measurement may fall short for newborn screening.

• We need to include Public Health or Newborn Screening System measures to track that services are available, that individuals are not lost to follow-up, and transition into adult care.

• We need child-specific measures that focus on access to medical homes, available treatment, child well-being, and family satisfaction with the care process.

• Data sources may need to move beyond healthcare providers.
Available Resources Could Accelerate the Use of Quality Measures for Newborn Screening

• Quality measures are hard to do, new tools can make it easier in the future.

• ONC, CMS, and AHRQ have an Electronic Clinical Quality Improvement Resource Center.
  • http:ECQI.HealthIt.gov
  • Access to Health IT standards for quality measure definition and reporting
  • Access to available quality measures and incentive programs

• NewSTEPs case definitions and care reporting databases can help define the denominator for NBS quality measures.

• NBSTRN has an LPDR database with definitions of data fields and including core and public health variables.
Sub-workgroup is at a cross-roads

• Sub-workgroup has completed its task from spring 2016
  • Background document on quality measures and NBS (areas of need and opportunity)
  • Case studies that provide examples of how quality measures
  • Other findings: disease-specific measures vs public health services vs patient/child specific measures

• Recommendation
  • Finalize the report on clinical quality measures for August 2017 meeting
  • Over next few months, work on specific suggestions for next steps for the sub-workgroup to present as possibilities to the ACHDNC