



Analysis. Answers. Action.

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Timeliness 2.0 Workgroup

August 28, 2015

Membership

Cathy Wicklund, co-chair	Kellie Kelm, co-chair
Susan Tanksley, Texas PH Lab, APHL	Beth Tarini, pediatrician, researcher
Stephen McDonough, pediatrician	*Rebecca Goodwin, NLM
*Klaas Wierenga, pediatrician, geneticist	Ed McCabe, March of Dimes
*Laura Malone – Vice President, Nursing and Clinical Services, Iowa	Emily Drake, Association of Women's Health, Obstetrics and Neonatal Nurses (AWHONN)
Amy Gaviligio, Follow up, Minnesota	Erica Wright, Follow up, Colorado
Bob Ostrander – family physician, ACMG	Stan Berberich, Iowa NBS Lab
George Dizikes, Illinois NBS lab	*Erin Dupree, Joint Commission
Bill Morris, parent	Cate Walsh Vockley, genetic counselor
*Joseph Bocchini, pediatrician, SACHDNC Chair	*Dieter Matern, Mayo
*Neil MacVicar, parent, MHA Service Corp.	APHL



* Invited but could not attend

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SACHDNC RECOMMENDATIONS FOR TIMELY NBS

- A. To achieve the goals of timely diagnosis and treatment of screened conditions and to avoid associated disability, morbidity and mortality, the following time frames should be achieved by NBS programs for the initial newborn screening specimen:
 - 1. Presumptive positive results for time-critical conditions should be communicated immediately to the newborn's healthcare provider but no later than five days of life.
 - 2. Presumptive positive results for all other conditions should be communicated to the newborn's healthcare provider as soon as possible but no later than seven days of life.
 - 3. All NBS tests should be completed within seven days of life with results reported to the healthcare provider as soon as possible.

- B. In order to achieve the above goals:
 - 1. Initial NBS specimens should be collected in the appropriate time frame for the newborn's condition but no later than 48 hours after birth, and
 - 2. NBS specimens should be received at the laboratory as soon as possible; ideally within 24 hours of collection.

CHARGE

- Optimize successful strategies to address NBS specimen collection and transport:
 - Engage key stakeholders in these processes
- Collect and disseminate timeliness specific practices from state NBS programs, including programs that have implemented efficiencies in collection, transport, screening and follow-up. This may include:
 - Updates from states at NBSTRN Regional Collaborative meetings
 - Updates from states participating in the NewSTEPs Collaborative Improvement and Innovation Network (CoIN) for Timeliness in newborn screening; NewSTEPs 360.
 - Updates from other timeliness efforts
- Investigate strategies for improved standardization of communication of NBS results to providers and families



DISCUSSION

- Received reports of ongoing/new activities
 - CoIIN
 - NewSTEPs 360
 - Modeling & cost-analysis of NBS timeliness
 - MoD NBS Quality Improvement Workgroup



DISCUSSION

- Brainstorming on projects for the Workgroup
 - improved standardization of communication of NBS results to providers and families
 - Collect data first
 - Figure out areas where our workgroup could contribute



DISCUSSION

- Specimen collection
 - High unsat rate, hospital process issues
 - Collect data first
 - Figure out areas where our group could contribute
 - Prospective partners: Joint Commission, Midwives, Head of Hospital labs (SOPs), Hospital Association



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