Newborn Screening and Health Information Technology

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Overview

- Newborn Screening at the Crossroads
- Roles/Phases of HIT in NBS
  - Newborn Screening is a Process not a One Time Event
- Different pathways for laboratory and bedside testing
- Who is responsible for recording the data and sending follow-up to public health?
- What is recorded in the EHR determines whether electronic chart audit is possible
- Using HIT for Care Coordination and Medical Home
- Linking newborn screening to electronic birth certificates and immunization registries
- Rethinking HIT and NBS: Using NBS as a model of best practices
Newborn Screening at the Crossroads

- Newborn screening takes place at the crossroads:
  - Hospitals – Ambulatory Care – Public Health
  - Primary Care – Specialists – Population Health
  - Laboratory Testing – Bedside Testing

- Health Information Technology can be an important tool for improving newborn screening – making information available when and where it is needed

- Because all infants are screened and the data is limited, NBS can be a test case for the value of HIT and multiple settings create a need for mandatory interoperability

- NBS is evolving rapidly and HIT can help track what was done and monitor the benefits
Newborn Screening is a Process not a One time Event

- When newborns screening was introduced with the Guthrie test for PKU 50 years ago, it was a simple one time lab test that was done and if no treatment was required, it was forgotten.
- The usual approach to newborn screening follow-up has been “No news is good news” – the health department will find you if there is a problem.
- Today we test for over 30 conditions and checking results is essential.
- First step is to make sure all infants are screened.
- Some infants, such as premature infants or those transfused or on soy feeding need a second screen.
- Then comes diagnostic testing for out of range results to rule out false positives.
- True positives with confirmed diagnoses are entered in registries to track therapy, services, and long term follow-up.
- Some newborn screening identifies carrier states or future risks.
- Some NBS now uses second tier genomic testing to validate the results.
Some NBS takes place in the Lab and some at the Bedside

- Most newborn screening is done in a laboratory on dried blood spots
- While we have a national recommended panel, states still vary in what they do and the methods they use
- New tests for SCID and Lysosomal Storage Diseases are being evaluated in some states
- Newborn Hearing Screening or EHDI was the first non-lab based newborn screening
- Pulse Oximetry for Critical Cyanotic Congenital Heart Disease, and universal bilirubin screening may become part of NBS
- The HIT needs of NBS change when it is no longer a lab test, but instead part of the standard of care
- Instead of a laboratory report, some NBS tests will need to become part of hospital newborn discharge summaries
One of the greatest challenges of using HIT in newborn screening is deciding who is responsible for recording data and tracking follow-up.

Is newborn screening the on-going responsibility of the birth hospital, the primary care pediatrician, or the health department?

Where should you go to find the results? The hospital, the lab, the health department, or the patient? Whose EHR has the data?

Who should be informed that follow-up is complete and if a diagnosis was confirmed?

Is it a PUSH or a PULL activity? Do you ask for results when you need them, or should they be sent in advance?

Knowing the post-discharge primary care provider and practice as well as the correct patient name and identifiers is not easy.
Automated Quality Measurement Depends on What Data is in the EHR

- Quality measurement, reporting, and improvement is now becoming an essential part of meaningful use of EHR
- Many of today’s validated quality measures (such as HEDIS) were developed in an era of manual chart audits that are becoming too expensive for widespread use
- The ability to conduct automated electronic audits based on EHR depends on how data is recorded in the EHR
- For newborn screening, a uniform laboratory report message has been proposed by HRSA and NLM
- Automated audits for NBS will depend on filing the NBS lab results in the chart and capturing the results of hospital-based bedside testing
- Lab reports must contain not only the results but also notation of any required actions
Sources of Guidance on How Newborn Screening Should Appear in an EHR

- **Serving the Family From Birth to the Medical Home – Newborn Screening: A Blueprint for the Future – A Call for a National Agenda on State Newborn Screening Programs – Pediatrics 106(2):389-427 2 August 2000**
  - Ten roles and responsibilities of the Medical Home Health Care Professional
  - Identifies the need for office protocols to retrieve results
  - Establishes role to follow positive screening results to diagnosis
  - Calls for integration and communication with specialists and community resources
  - Calls for maintaining a central record and database of all pertinent medical information and sharing it with families subject to confidentiality protection

- **Newborn Screening Expands: Recommendations for Pediatricians and Medical Homes – Implications for the System – Pediatrics 121(1):192-216 January 2008**
  - Flowcharts refine and guide the role of the primary care provider
  - Recommendations on preparing the practice
  - Insights into finding patients who were not screened
  - Insights into addressing parental refusal with educational materials
Understanding the HRSA/NLM NBS HL7 Laboratory Result Message

- Newborn screening results can be sent to hospitals and physician offices using standard HL7 laboratory result messages used for all general laboratory test results.
- All certified EHR under ARRA Meaningful Use can accept and store these standard messages.
- At present, very few states are able to send these messages, but that is expected to change soon and only a few vendors provide software to NBS labs and programs.
- NLM and HRSA have worked together with state labs and programs to develop the necessary codes and information structure to send newborn screening information.
- The message summarizes normal results, identifies what requires action, and documents what was tested and methods used.
- Quantitative results, such as TSH and T4, can be included when useful or made available only to specialists or only for abnormal results.
When we talk about HIT support for newborn screening, we should also talk about HIT support for children with conditions identified through newborn screening.

Children with complex genetic conditions require care coordination through a medical home.

A patient summary or continuity of care record shares data between all providers.

Team practice in a medical would have one member of the office staff check all NBS results before the visit and track those who need repeat screening or diagnostic testing.

Practice registries help manage patients with chronic conditions.

A medical home is family centered and compassionate providing continuous, comprehensive, and accessible care.
Linking Newborn Screening to Immunization Registries

- An exciting new development in newborn screening are projects that link newborn screening results to the immunization registry for one stop health information exchange.
- Two-way data exchange moves results into practice records and tracks that the screening process is complete.
- As with immunizations, getting newborn screening results on an infant born in another state can be a challenge.
- Agreements between states to share data are beginning to happen mainly between bordering states like CO-WY, NY-NJ.
- Some day we will have a Nationwide Health Information Infrastructure where the physician will connect to their own state system and all NBS programs will share data with patient permission.
Understanding the Difference Between Interoperability and Information Access

- The challenges of HIT in newborn screening are similar to those in Immunizations
- When you see a new patient you need to get the information from previous providers
- You do not want to interrupt the visit to go to a web browser to get the data, but you will if not having it will delay care
- Using the web is easier and faster than using the phone
- You cannot always trust what a patient tells you unless you have the records
- You need to enter the data into your medical record (EHR) and you do not want to retype the data
- The best systems will have the data ready before the visit
- Scanned paper reports must be read by people, electronic reports work with clinical decision support and can create reminders
Linking NBS to Electronic Birth Certificates and Integrated Child Health Data Systems

- Electronic birth certificates are an important tool for assuring that all newborns are screened by matching the birth certificates with lab reports and hearing screening.
- In many states, hospitals enter data directly into the electronic birth certificate instead of sending in forms.
- Data on the birth certificate can contain accurate demographics and in some states includes the hearing screening results and risk factors.
- The serial number and barcode on the NBS filter paper card can be added to the birth certificate to link the lab results to the birth certificate instead of relying on names.
The relevance of newborn screening extends beyond the first month of life. Getting good prenatal family history can guide screening and knowing the results of previous NBS in relatives is an important question for pre-natal care. Some hemoglobinopathies cannot be evaluated until the infant is older. Some genetic screening may be appropriate after the newborn period – NBS focuses on the impact of immediate intervention such as PKU and hypothyroidism. As the NCAA interest in Sickle Cell Trait has shown, the results of NBS may be important later in life to avoid repeat testing. Some conditions found at NBS, such as G6PD or some LSD, may have a later onset or significance.
Rethinking HIT: The PCAST Report and CHIP-RA Model EHR Format for Children

- The President’s Council of Advisors on Science and Technology (PCAST) report, “Realizing the Full Potential of Health Information Technology to Improve Healthcare for Americans: The Path Forward,” December 2010, describes the tremendous potential benefits of HIT and the slow rate of adoption and use.
- It suggests new strategies for a universal health information exchange language.
- CHIP-RA call for a model EHR that will show that children are getting the care they require.
- Newborn screening may be an ideal test case for new approaches to information sharing because it is simple and universal connecting hospitals, practices, and public health.
- Meaningful Use of EHR is not just a Medicaid incentive program that half of the pediatricians will not qualify to use, it is a mantra that call for change in how we use HIT to improve care and not just document it.
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QUESTIONS & DISCUSSION?