

# Report from the Data Collection for Newborn Screening Meeting: A National Approach.

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# Agenda Set by HRSA, APHL, NLM, others & Genetic Alliance

- Special Meeting of Association of Public Health Laboratories
- May 6, 2010
- Orlando, FL
- Afternoon of the final day
- ~130 people present, mostly APHL members= state NBS programs, regional collaboratives

# GOALS

- Begin a year long process of collecting information for HRSA on the needs of a data system for the nation
- Listen and Understand:
  - various states model data system projects
  - needs of the state programs
  - Needs of other stakeholders
  - easy solutions and the difficult interfaces between HIT, HIE and other efforts
- Describe to the APHL members some of the external activity in data collection, storage, use
- Report back to ACHDNC



# Concerns (1 of 4)

- Are the indicators collected today by NNSIS suitable for the emergence of HIT?
- No consensus on definitions of disease or out of range, preference by some states to default to “as defined by (local) specialist”
- If there are common definitions, concerns about who makes the decision to set standards.

## Concerns (2 of 4)

- Shouldn't the coding and terminology guide be mandatory/voluntary?
- Will standards drive program activity for the “sake of standards”?
- How will the States be compared if data collected?
- NBS system is split amongst HRSA and CDC with little coordination

## Concerns (3 of 4)

- Not only does each State decide what it wants to measure and how, but sometimes one individual in the state decides.
- *“We are moving in one direction putting money into special reports and HL7, but will have to start all over again when national policy changes again?”*

# Concerns (4 of 4)

- Will state NBS programs be required to report to many... multiple times? Which agencies, organizations, systems?
- State NBS programs can't expand the NBS program workload beyond capacity.
- Don't make this a 'shame on you' data collection system.



# Concerns about the Survey

- Concern about low response rate
- Not able to discern true state snapshot due to only 18 identifiable states
- Fitting responses into survey is like trying to fit round pegs into square holes. For example, some programs have the lab and follow-up in same program.

# Recommendations (1 of 3)

- Useful reports organized by state, diseases, screens, so that comparisons can be made
- Simply push state program data to a collection center without onerous manual labor
- Compare what states are already tracking for their own needs with the data tracked by NNSIS.

# Recommendations (2 of 3)

- Ask other stakeholders besides state programs, how are they using the data.
- Understand importance of standardization. Need forum to discuss amongst the state program, ie. Units of measurement, seasonal variations.
- Give state NBS programs guidances and definitions
- Gather all available data now, to elucidate cut offs, definitions, standards, problems – better to come from the real data and not from ideals

# Recommendations (3 of 3)

- Encourage vendors to work with one another and states to create customizable programs, with interoperability and standards basis
- AARA HITECH funding for infectious diseases- interoperability interaction with Health Information Exchanges, need similar AARA funding for NBS
- Learn from the infectious disease world systems overall

# Meta Comments

- Familiar stresses of state programs serving state needs and national health agenda
- Tsunami of HIT infrastructure changes and needs not yet felt at state level
- Resources need to be carefully evaluated and capitalized upon
- Care coordination most critical to states, and complex across systems
- Families (babies) need the best

# ACHDNC Might Consider

- Positioning NBS system as prime example of HIT system for nation
- Recommending mandatory use of coding and terminology guide
- Examining inefficiencies in disparate national system
- Highlighting exemplary programs in disparate national system and propagating them
- Enabling interstate cooperation/collaboration, instead of competition

# ACHDNC Might Consider

- Stronger and clearer national mandates
- Incentivizing vendors' and states' systems to create technologies that enable HIE that is platform agnostic but interoperable
- Establishing more of the elements needed for standardization: definitions, cut offs...
- Utilizing the capability of the current systems to automatically deliver data now