2019 APHL Newborn Screening and Genetic Testing Symposium
Strong Foundations Lead to New Heights
APHL Health Information Technology (HIT) Activities: An Overview

Sari Edelman, MPH

This work was supported under Cooperative Agreement #5NU60OE000103 between the Association of Public Health Laboratories and CDC, and under Cooperative Agreement #U22MC24078 between the Association of Public Health Laboratories and HRSA. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of CDC and HRSA.
NBS HIT Workgroup

• Charge: Support the development and implementation of HIT – related solutions for newborn screening (NBS) programs and their associated stakeholders

• Key goals and objectives:
  – Assess current status of HIT among NBS programs
  – Identify and address gaps and barriers to NBS HIT implementation
  – Develop and support quality improvement initiatives in NBS HIT
  – Identify and share information regarding HIT issues with NBS community
  – Build trust, strengthen relationships and advocate among local, state, regional and national NBS stakeholders, private partners and NewSTEPs
HIT Interviews

• Purpose
  – Better understand the variety of ways that laboratories exchange data
  – Identify developing needs of each laboratory
  – Gather various approaches and best practices for addressing common barriers

• Separated into two sections focused on 1) comprehensive laboratory assessment and 2) NBS specific components

• Requested participation from NBS program and IT staff

• Ultimately interviewed 25 NBS programs

• *In accordance with APHL’s data access and sharing policy, findings are in aggregate form without individual identifiers
Question 1: What experience does your NBS/ State laboratory have in data exchange?

• Most programs have experience with data exchange
  – 48% have experience with hospital level data exchange
  – 80% have experience with other state/ national repositories
  – 84% have experience with EPA/ FDA/ CDC

• Variability in responses
  – Volume of data exchange
  – Automation of data exchange
  – Formats of data exchanged
Question 2: What are your data exchange infrastructure and capabilities?

- Most programs have data exchange infrastructure and capabilities in place
  - 84% use integration engines (Rhapsody and Mirth)
  - 72% use standard codes (LOINC and SNOMED)
- Transport methods used: VPN\(^1\), PHINMS\(^2\), SFTP\(^3\)

---

\(^1\) Virtual Private Network
\(^2\) Public Health Information Network Messaging System
\(^3\) Secure File Transfer Protocol
Question 3: What are other ways for clients to access data?

- Most programs use a web portal (78%)
  - Clients/partners can download result reports from the portal (PDF)
  - 55% results posted in real-time
- Other ways, besides paper used to send/receive information:

- Auto-fax/fax: 35%
- SFTP: 15%
- Secure e-mail: 35%
- Mail: 12%
- Phone call: 3%
Question 4: What are your routine challenges?

- Cost
- Hospital buy-in
- Complexity
- Staffing
Hospital buy-in

“I’m looking at it kind of from the 30,000 foot view that it seems to me that getting hospitals motivated to prioritize this, they have a whole lot of different IT demands and this one doesn’t seem to be high-priority unless you hold money in front of them, and even then, just trying to get a number of hospitals when the money isn’t enough to cover their expenses, would probably not be worth their trouble... if they’re not a big enough entity, they’re not going to prioritize this.”
Question 5: How much does data exchange cost you per year?

Cost of Data Exchange

- Variability in cost of data exchange
- Costs include integration engines, maintenance and “other”:
Question 6: Do you send electronic results to hospitals? (NBS)

• Even split between yes, no, “not yet”
• 47% use standard codes (LOINC, SNOMED)
• Number of hospitals being sent electronic results varies (~18)
• Percent of samples resulted electronically varies (~16%)
Question 7: Do you receive electronic orders from hospitals? (NBS)

- Most programs don’t receive electronic orders (40%) – What is missing: collector’s initials, transfusion status, NICU, mother’s name and DOB, parental nutrition status, antibiotic status, mother’s phone number
- Number of hospitals sending electronic orders varies (~15)
- Percent of samples coming through electronic orders varies (~40%)
- 68% cannot send back results without an order
NewSTEPs HIT Data

HL7 Orders Messaging Status Map

HL7 Results Messaging Status Map
Question 8: What other programs do you send data to? (NBS)

- 28% exchange with Vital Records (HL7, CSV, interface)
- 32% exchange with Birth Defects Registry (CSV)
- Others:
  - Community health record, NewSTEPs, R4S/ CLIR, clinical consultants, MCH program, Title V, follow-up (secure email, CSV, paper reports)
- 36% use HIE to deliver results to hospitals/ partners
Lessons Learned and Limitations

• Not everyone understands HIT terminology
  – “What do you mean by integration engine?”
• One NBS program is one NBS program
• Everyone is doing something with electronic data exchange. NBS is behind, but can leverage/ “piggyback” existing informatics capabilities
  – “I think one of our biggest challenges... I don’t feel like we’re part of an organized effort... Many of the labs are using the same software. Let’s leverage that and get people to work together.”
Current Activities

• User groups
• Continuous collaboration with the HIT NBS workgroup and APHL Informatics committee
• HL7 implementation guide for test ordering and results reporting
• Informatician job description
• Common data model
Thank you:

• NBS HIT Workgroup
• Interview participants
  • Federal partners
• APHL Informatics Committee

For any further questions, please reach out to:

Sari Edelman, MPH
Sr. Specialist, NewSTEPs, Newborn Screening and Genetics
Sari.Edelman@aphl.org
240.485.3839