



#nbsgts

# 2019 APHL Newborn Screening and Genetic Testing Symposium

Strong Foundations Lead to New Heights



# APHL Health Information Technology (HIT) Activities: An Overview

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# 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<sup>1</sup>, PHINMS<sup>2</sup>, SFTP<sup>3</sup>

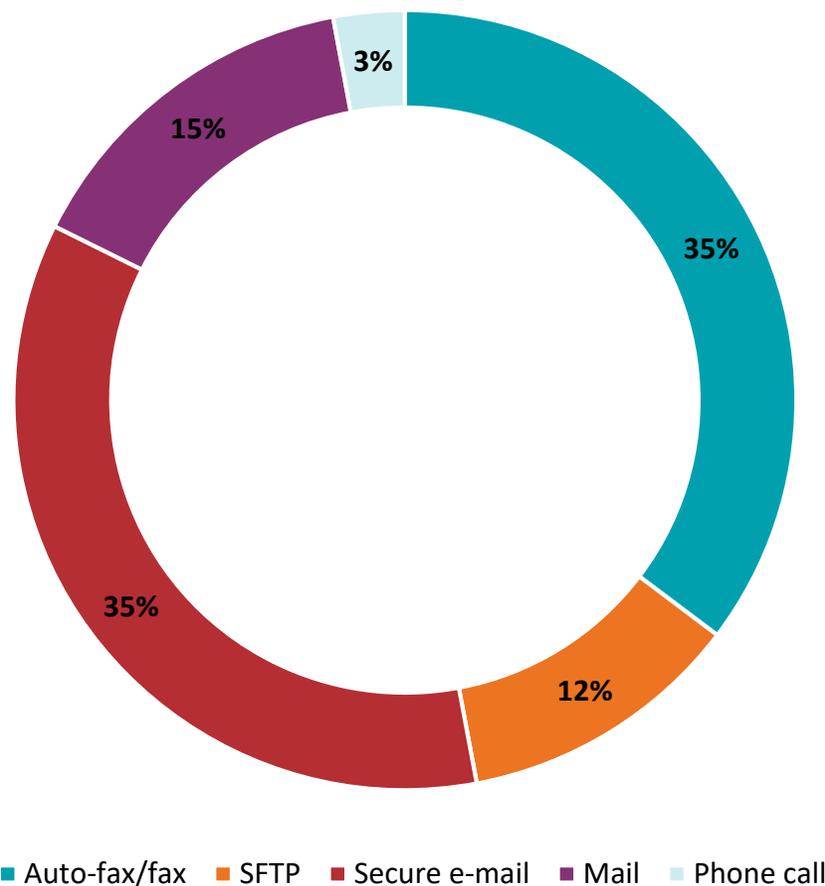
<sup>1</sup> Virtual Private Network

<sup>2</sup> Public Health Information Network Messaging System

<sup>3</sup> 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:

## Question 4: What are your routine challenges?



Cost



Hospital buy-in



Complexity



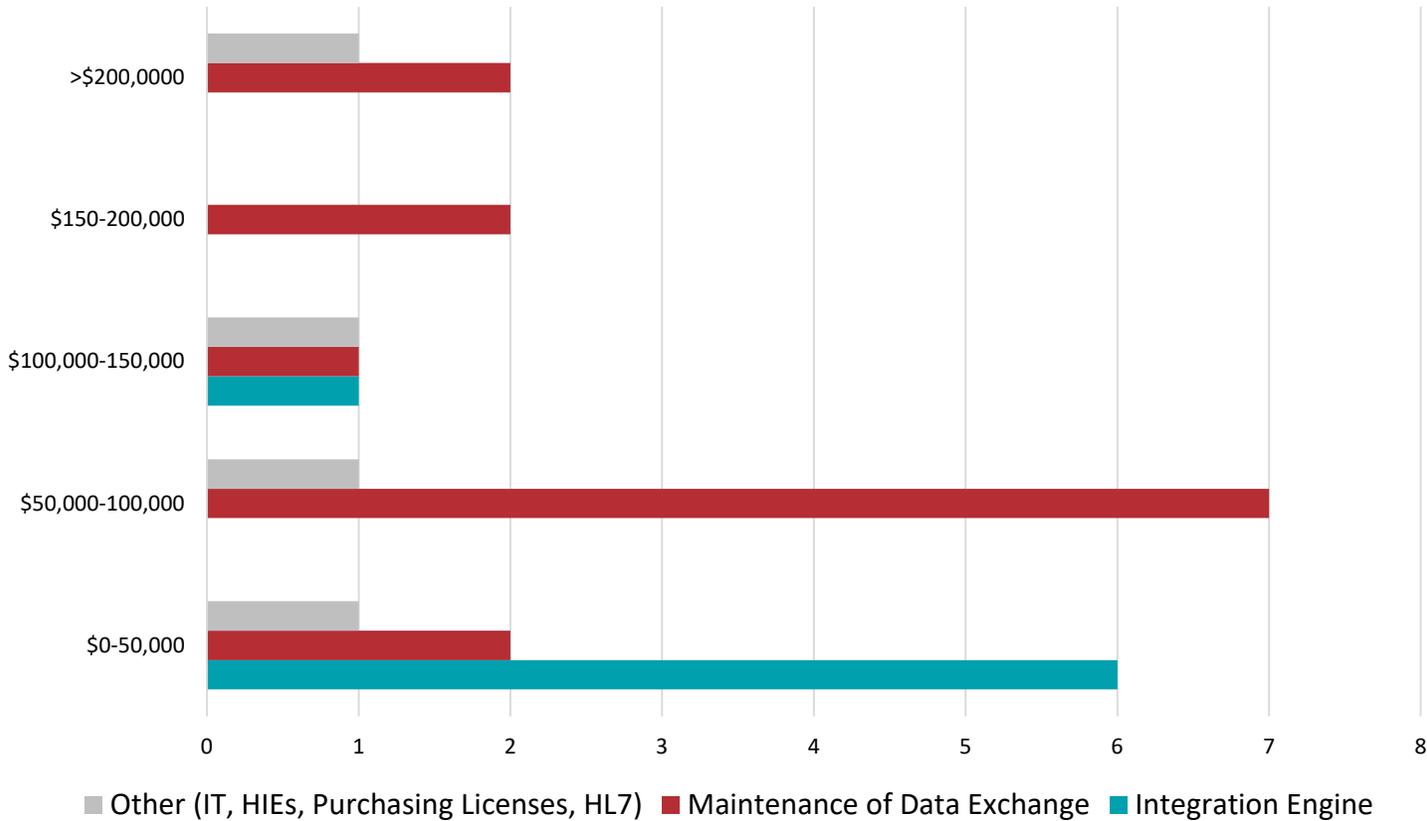
Staffing

## 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)

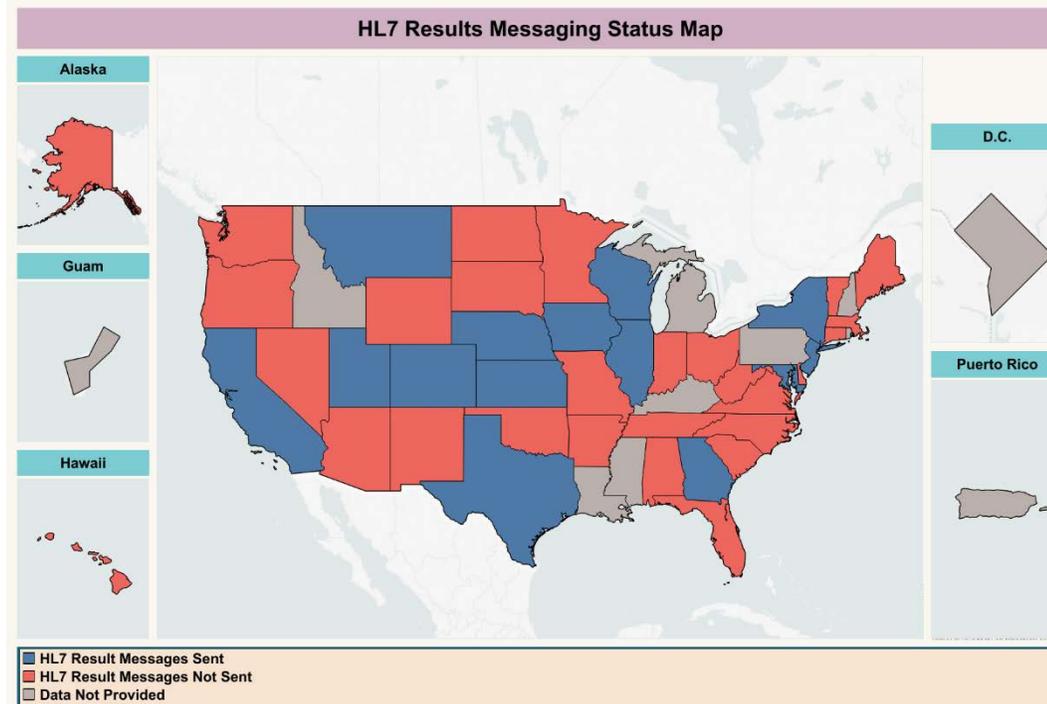
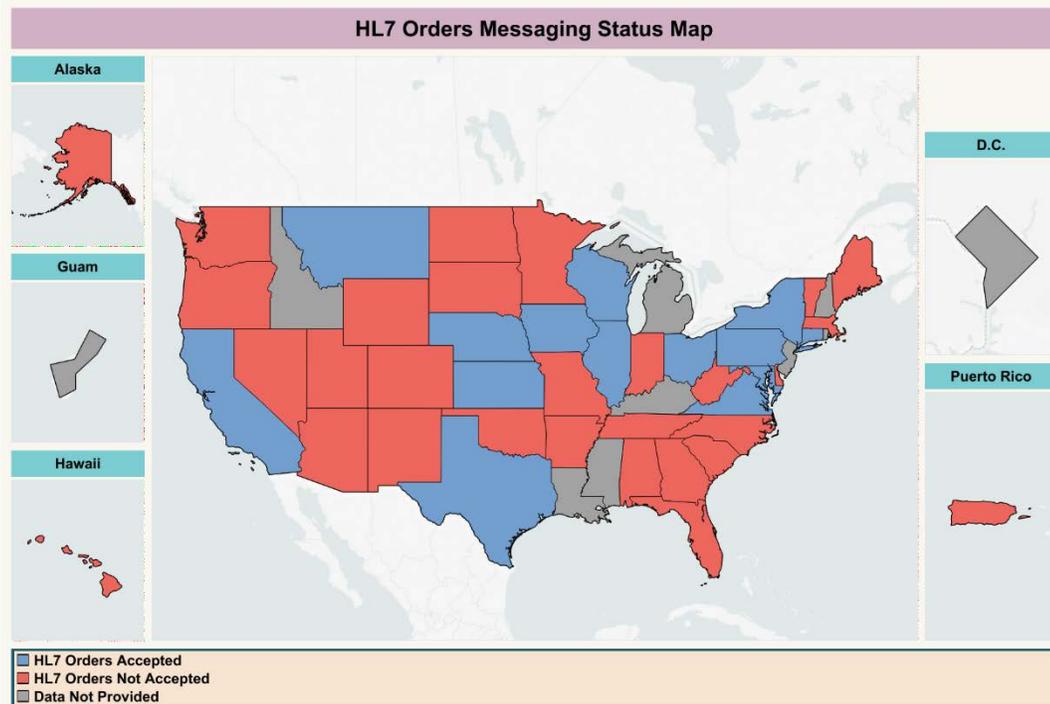
- Even split between yes, no, “not yet”
- 47% use standard codes (LOINC, SNOMED)
- Number of hospitals being sent electronic results varies (~18)
- Percent of samples resulted electronically varies (~16%)



## 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





## 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:

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