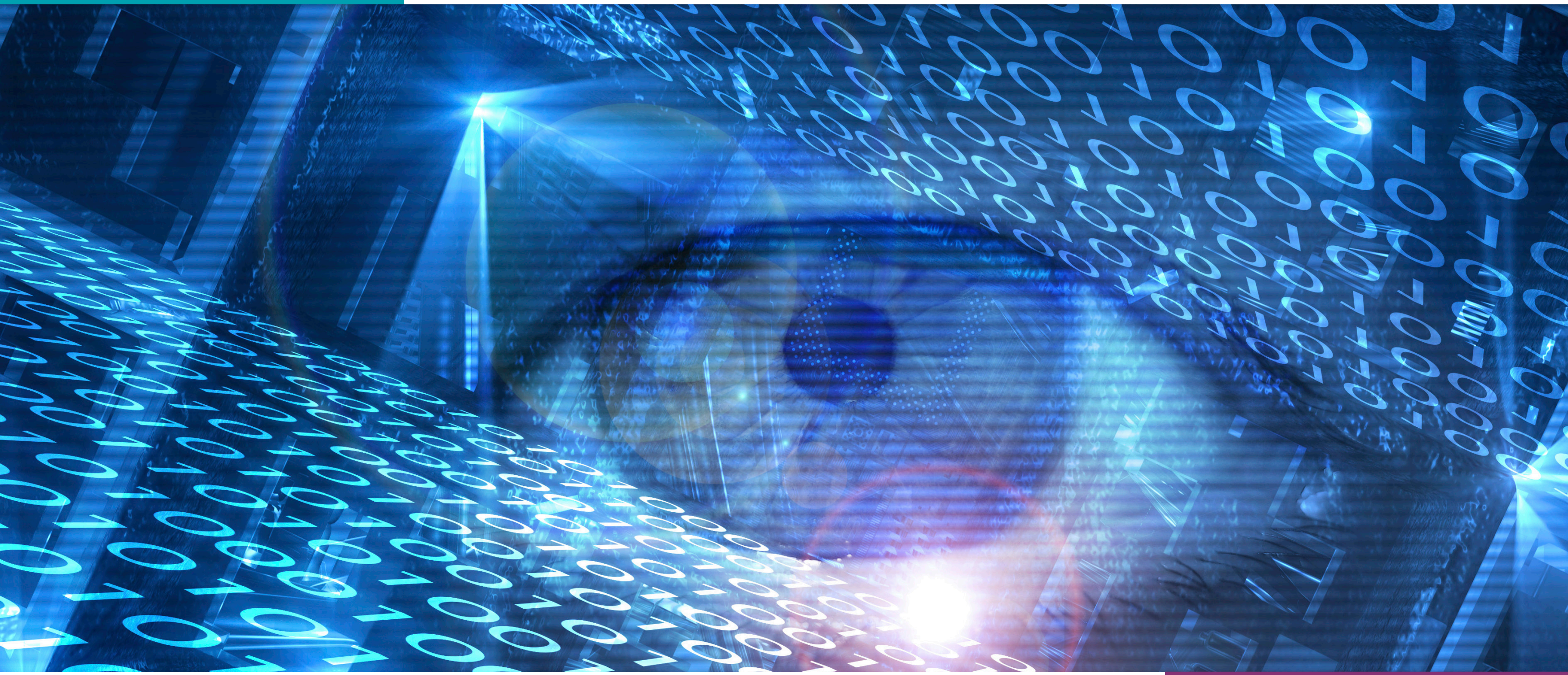
Newborn Screening Health Information Technology Interviews Summary Report 2016-2017



MAY 2020

APHL ASSOCIATION OF PUBLIC HEALTH LABORATORIES®

NewSTEPs
A Program of The Association of Public Health Laboratories®

ACKNOWLEDGMENTS

The Association of Public Health Laboratories (APHL) gratefully acknowledges the contributions of the 25 newborn screening programs and public health laboratories, Newborn Screening Health Information Technology Workgroup members and staff that participated in health information technology interviews conducted.

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EXECUTIVE SUMMARY

Health information technology (HIT) involves the management and secure exchange of health data across computer systems. Widespread use of HIT will improve the quality of health care by preventing errors, reducing paperwork and increasing efficiency.[1] To enhance the use of HIT within newborn screening (NBS), the Health Resources and Services Administration (HRSA) and the US Centers for Disease Control and Prevention (CDC) have provided financial support to the Association of Public Health Laboratories' (APHL) NBS HIT Workgroup and activities via Cooperative Agreements #U22MC24078 and #5NU60OE000103 respectively.

Initial activities of the APHL NBS HIT Workgroup included describing the landscape of HIT utilization within public health laboratories and more specifically within NBS programs. In 2016 and 2017, Workgroup members and staff conducted telephone interviews with public health laboratories and NBS programs within each laboratory to determine HIT capabilities nationwide.

This report provides a comprehensive overview of the Workgroup, interviews conducted, data generated from interviews and next steps in terms of workgroup technical assistance (TA) efforts. As national NBS programs continue to pursue electronic data exchange, the need to collaborate and learn from existing capabilities and each other's experiences remains clear.

Since the development of this report, the HIT Workgroup has completed a number of accomplishments including, but not limited to, creation of informatician job descriptions, updating and revising Laboratory Order Interface (LOI) and Laboratory Results Interface (LRI) implementation guides, input into a Common Data Model, presentations at national meetings on the Workgroup's behalf and formation of four HIT User Groups where participants can candidly discuss NBS activities as they relate to Information Management Systems. In January 2020, the Workgroup transitioned into a Subcommittee given increasing discussion at the Federal level and increasing awareness of interoperability in the NBS community. This transition has increased visibility and appropriately addresses the work being done by Subcommittee members.

BACKGROUND

The APHL Newborn Screening (NBS) Health Information Technology (HIT) Workgroup (the “Workgroup”) is charged with supporting the development and implementation of HIT-related solutions for NBS programs and their associated stakeholders.* It meets the priorities of the Newborn Screening and Genetics in Public Health (NBSGPH) Committee by reviewing and providing guidance into the implementation of NBS-related HIT standards. Workgroup activities include the following key goals and objectives:

1. Assess current status of HIT among NBS programs
2. Identify and address gaps and barriers to NBS HIT implementation
3. Develop and support quality improvement initiatives in NBS HIT
4. Identify and share information regarding HIT issues with the NBS community in collaboration with APHL’s Informatics Committee
5. Build trust, strengthen relationships and advocate among local, state, regional and national NBS stakeholders, private partners and Newborn Screening Technical assistance and Evaluation Program (NewSTEPs).

Members of the Workgroup are comprised of representatives from NBS programs, state departments of health and from federal partners, information management vendors and organizational liaisons on an as-needed basis.

OBJECTIVE

To ascertain HIT capabilities and specifically identify how NBS programs within each state public health laboratory leverage existing informatics capabilities, the Workgroup decided to conduct in-depth interviews. The objectives of the interviews were to:

1. Better understand the variety of ways that laboratories perform dataexchange
2. Identify developing needs of each laboratory
3. Gather various approaches and best practices for addressing common barriers

Improving HIT capabilities will ensure that data exchanged is timely, efficient, accurate, complete and, ultimately, improve patient outcomes.

METHODS

During 2016 and 2017, Workgroup members and staff conducted telephone interviews with staff of public health laboratories. Telephone interviews permitted further explanation of questions and explanation of nuances regarding data exchange, as well as an opportunity to ask follow-up questions to ensure a complete understanding of the laboratories’ HIT capabilities. The Workgroup developed these questions to understand data exchange capabilities at the public health laboratory, and then how NBS could leverage these capabilities. Workgroup members initially requested participation from NBS program and information technology (IT) staff via NBS Listserv® messages and targeted outreach. Invitations were extended to section supervisors and laboratory information management system (LIMS) administrators. Programs—which this report refers to as public health laboratories including NBS programs—interested in participating were randomly matched with a Workgroup member as well as an APHL or NewSTEPs staff member depending on staff availability. Telephone interviews were scheduled for one-hour time intervals. The HIT interviews were separated into two sections: a comprehensive laboratory assessment and NBS-specific components.

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* Since the time of publication, the new Subcommittee has been broadened in its scope and membership. However, the Subcommittee’s leadership remains the same and is building off of initial activities.

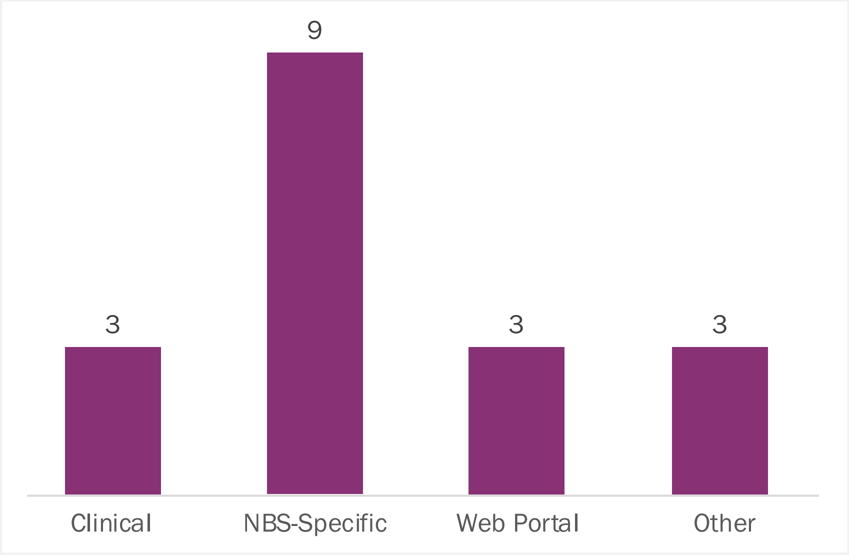
RESULTS

In total, 25 programs responded to Listserv® messages and targeted outreach, and thus were interviewed. Programs represented a cross-section of states, with varying births, laboratory types and number of required screens. The programs interviewed encompassed 50% of babies born in 2017 in the US; 28% (n=7) were two screen states; and, 16% (n=4) of programs interviewed did not perform NBS at the state public health laboratory (either contracted out to private laboratories or regional public health laboratories). In accordance with APHL's data access and sharing policy, findings presented in this report are in aggregate form without individual identifiers.

Question One: Experience with Data Exchange

Results from interview responses indicated that most of the public health laboratories interviewd have experience with various types of data exchange. Of the 25 programs interviewed, 48% (n=12) reported experience with hospital level data exchange. Of these 12 programs with hospital level data exchange, 25% (n=3) mentioned clinical data exchange (such as Aetna healthcare, Planned Parenthood), 75% (n=9) mentioned NBS specific data exchange (hearing, Critical Congenital Heart Disease (CCHD) and demographic data), 25% (n=3) mentioned data exchange through web portals or central hubs and 25% (n=3) mentioned other data exchange apart from hospitals. The "other" category included receiving data from hospitals that was non-NBS related, exchanging environmental data and receiving electronic files from the Department of Health Vital Records (**Figure 1**).

Figure 1: Experience with Data Exchange between Hospitals and Public Health Laboratories (n=12)*



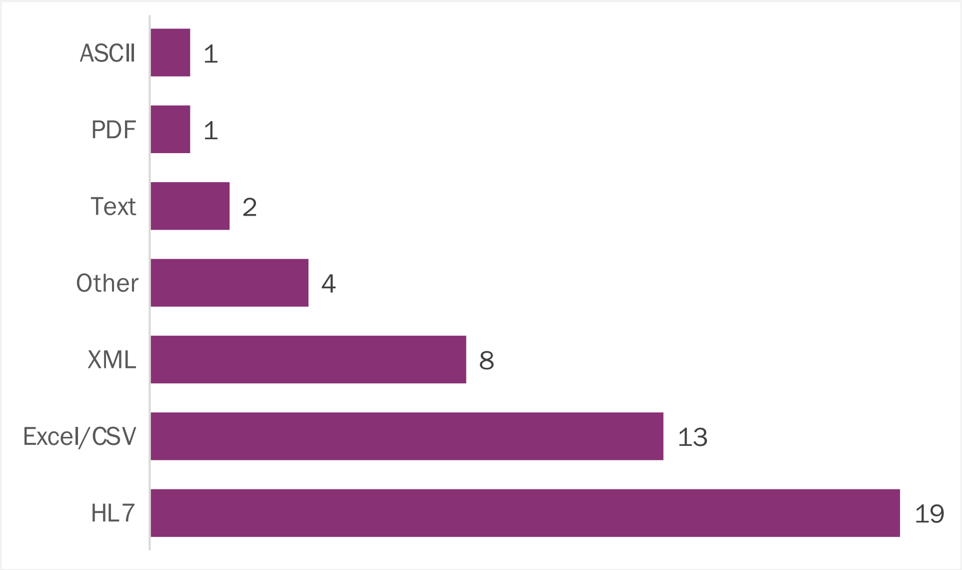
*Programs were permitted to give multiple responses

Of the 25 programs interviewed, 80% (n=20) reported electronic data exchange with state and national repositories. Examples included exchange with Vital Statistics, NewSTEPs, Region 4 Stork (R4S)/ Collaborative Laboratory Integrated Reports (CLIR), local health departments, Newborn Screening Translational Research Network (NBSTRN), Immunization Information Systems and with Electronic Laboratory Reporting. Eighty-four percent (n=21) reported data exchange with the US Environmental Protection Agency (EPA) (Safe Drinking Water Information System, Air Quality System), US Food and Drug Administration (FDA) (Electronic Laboratory Exchange Network) and CDC (Public Health Laboratory Interoperability Project (PHLIP), Rabies Surveillance Network, Laboratory Response Network, Laboratory Information Management Systems integration).

However, while most programs reported some level of data exchange, the volume of data being exchanged was unclear. Fifty-two percent (n=13) answered this question, however answers were difficult to analyze as some programs stratified data exchange by day, some by week and some by month. Furthermore, some programs stratified volume of data exchanged by whom they send data to. For example, a program might have received 50 electronic order messages per day from submitters to NBS laboratories, sent 200 messages per day to Planned Parenthood and sent 20 per week via PHLIP for influenza reporting.

Automation of data exchanged also varied. Of the 16 programs that responded, 56% (n=9) reported that data exchanged was fully automated, meaning there was no need for any staff intervention. Thirty-one percent (n=5) reported data exchanged was partially automated, and 13% (n=2) reported that data was exchanged in a manual fashion.

Figure 2: Formats Used to Send or Receive Electronic Data (n=20)*



*Programs were permitted to give multiple responses

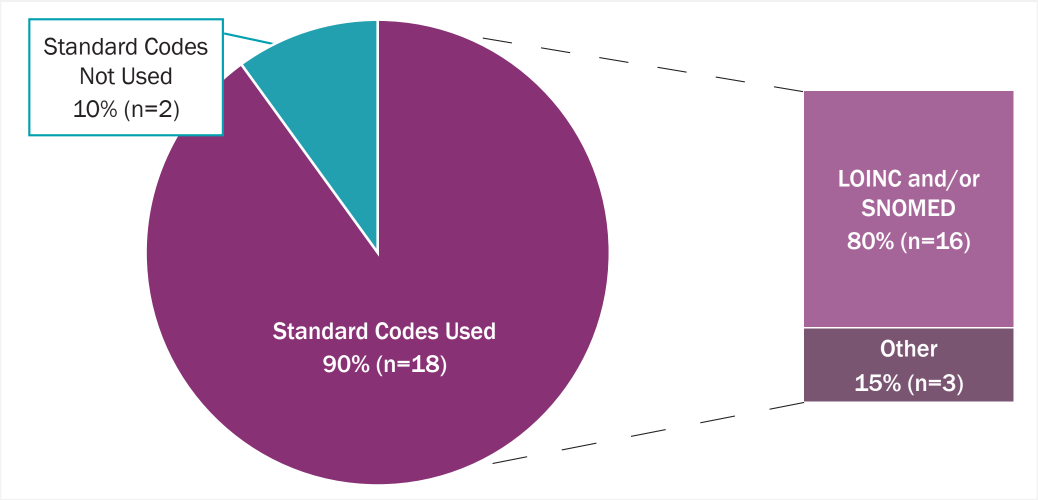
Twenty programs also indicated that they receive and send this information in a multitude of formats including Health Level 7 (HL7), Extensible Markup Language (XML), Text, Excel/ Comma Separated Value (CSV), Portable Document Format (PDF), American Standard Code for Information Interchange (ASCII) or Other. The "other" answers were not formats but rather specific vendors (e.g., Electronic Test Ordering and Results system (ETOR) or Secure File Transfer Protocol (SFTP)) (**Figure 2**).

Question Two: Data Exchange Infrastructures and Capabilities

Most public health programs have data exchange infrastructures and capabilities in place. Twenty-one programs indicated that they use tools like integration engines, which transform message formats and connect different systems, to send and receive data.[2] Of those 21 programs, 90% (n=19) mentioned Rhapsody and/or Mirth specifically. One program indicated that their LIMS software directly sends data in addition to Rhapsody, one program mentioned Cloverleaf specifically, and one program referenced scheduled Structured Query Language (SQL) jobs and an HL7 interface engine.

Of the 20 programs that responded to use of standard codes, 90% (n=18) do indeed use standard codes, while 10% (n=2) do not. Eighty percent (n=16) mentioned Logical Observation Identifiers, Names and Codes (LOINC) and/or Systemized Nomenclature of Medicine-Clinical Terms (SNOMED) specifically, and 15% (n=3) also mentioned use of Unified Code for Units of Measure (UCUM), Current Procedural Terminology (CPT) codes and internal codes represented in the "other" category (**Figure 3**).

Figure 3: Types of Standard Codes Used to Exchange Data (n=20)



Programs use mapping to establish the relationship between data elements using different systems.[2] Of the 25 programs interviewed, 89% (n=19) map to codes via LIMS or map using both LIMS and an integration engine. When asked if programs can code information based on each partner, 32% (n=8) said they use one vocabulary for everyone, 32% (n=8) said they can use vocabulary specific to partners and 36% (n=9) did not know or did not have the information at that time.

Twenty programs noted use of three main transport methods to deliver information: Virtual Private Network (VPN) (n=8), Public Health Information Network Messaging System (PHINMS) (n=9) and SFTP (n=12). These transport methods act as tunnels to help transfer data, which can be scheduled or on demand as results are released. Of the 20 programs that responded, 60% (n=12) said scheduled, 10% (n=2) said on demand and 30% (n=6) said both, again demonstrating variability among programs.

Question Three: Ways for Clients to Access Data

Public health programs have various ways for clients to access data. Of the 23 programs that responded, 78% (n=18) said their program has a web portal, 13% (n=3) said they are working on a web portal but do not have one at the time, and 9% (n=2) do not have a web portal. Of the 18 programs that do have a web portal, 89% (n=16) said clients and partners can download result reports directly. When asked if results were available in the portal in real-time, 56% (n=10) of the 18 respondents said yes, meaning they are available immediately after the results are released. Forty-four percent (n=8) said results are not in real-time, but are either scheduled, uploaded in batches, generated overnight and viewable the next day, or uploaded several times a day from the LIMS to the web portal.

When asked if clients can order tests from the portal and print labels to send their samples, the answers were more varied. Of the 19 programs that responded, 42% (n=8) said yes, however answers given were stratified by department or entity as shown in the table below, and 58% (n=11) said they cannot order tests from the portal or print labels (**Table 2**).

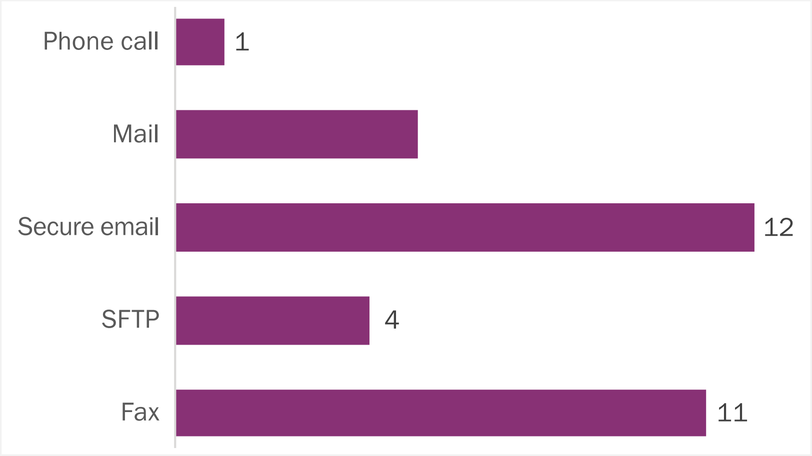
Table 2: Ability to Order Tests and Print Labels from Portal

Respondent Number	Can Order Tests from Portal	Can Print Labels to Send Samples
1	Yes for NBS	Yes for NBS
2	Yes	Yes
3	Yes	For non-NBS only
4	Yes for clinical laboratory	Yes for clinical laboratory
5	Yes for clinical laboratory	Yes for clinical laboratory
6	For NBS only	For NBS only
7	No	Yes
8	No	Yes

Seven programs responded with other reports accessed from the portal, including various types of quality assurance reports (n=6), hospital report cards for NBS (n=2) and sample receipt reports (n=1).[1]

Of the 20 programs that responded, 60% (n=12) indicated that clients can request auto-fax of results, while 40% (n=8) said they could not. Other ways for clients to access data besides paper and web portal included SFTP, secure e-mail, fax or auto-fax, phone calls and “snail mail” (**Figure 4**).

Figure 4: Other Ways to Access Data (n=20)



Question Four: Routine Challenges

Twenty-four programs responded to this question, establishing it as the most response-generating interview question. Responses were classified into four main categories:

$ Cost (n=6)

Staffing (n=22)

Complexity (n=21)

Hospital Buy-in (n=7)

Twenty-two programs noted staffing as a routine challenge, which encompassed maintaining staff, lack of staffing or turnover. Some noted lack of dedicated IT staff in particular, or hiring knowledgeable staff with specific skillsets and necessary expertise for HIT activities. One program also noted a hiring freeze that hindered data entry and sufficient staffing.

Twenty-one programs noted that electronic data exchange is multifaceted with varying degrees of complexity, and involves much consideration. Complexity issues included, but are not limited to, having different requirements from different hospitals, issues with streamlining all electronic data exchange projects, lacking documentation from LIMS and requiring changes in workflow. This was summarized by one interviewee,

> *"Trying to accommodate the fact that there are limitations that hospitals have, different resources that they have, different information systems and different version of information systems, different additional add-ons to their information system that some do and some don't have; trying to accommodate that to improve our information transfer has unintended consequences that make it difficult to try to standardize things. Every time that we accommodate, we just have added one more degree of complexity into our information processes."*

Hospital buy-in (n=7), including lack of incentives for hospitals to participate or prioritize electronic data exchange and general difficulties with bringing on new facilities, was another pain point among interviewees. It was unclear how to incentivize hospitals to bring on HL7 without pay or financial incentive. One program said,

> *"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."*

Other routine challenges (**Figure 5**), included data error or data integrity (bad or missing data, inconsistency of data), lack of infrastructure and capabilities, lack of training, lack of resources, streamlining all electronic data exchange projects, competing priorities, getting LIMS to do what is wanted, leadership support and time. The bigger and bolder words shown below indicate that multiple programs responded and identified with those challenges. Programs responded with more than one answer.

Figure 5: Routine Challenges

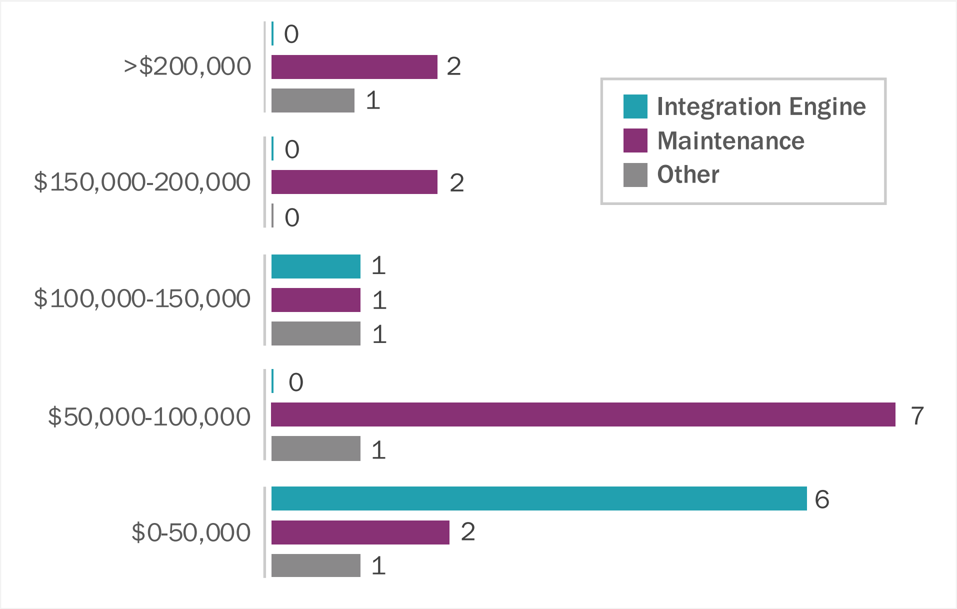
Question Five: Cost of Data Exchange

Out of the 15 programs that responded to this question, 20% (n=3) had less than one full time equivalent (FTE), 33% (n=5) had one FTE, 20% (n=3) had two FTEs, 13% (n=2) had three FTEs, and 13% (n=2) had four or greater FTEs. It should be noted that one program which noted having two FTEs was specifically for integration engine responsibilities, but additional staff, such as IT personnel, were still necessary.

Seven programs knew or had access to the integration engine cost. Out of these programs, 86% (n=6) said that the integration engine cost between $0-50,000. 50% (n=3) of these six programs said that the integration engine was free as it was paid for by the department or “piggy backed” on another department’s license. The highest recorded cost was $100,000 per year only for integration engine costs (**Figure 6**).

Cost for maintenance of data exchange for the entire public health laboratory, again, varied. Out of the 14 programs that responded, 14% (n=2) said cost ranged from $0-50,000 per year, 50% (n=7) said cost ranged from $50,000=100,000 per year, 7% (n=1) said cost ranged from $100,000-150,000 per year, 14% (n=2) said cost ranged from $150-200,000 per year, and 14% (n=2) said cost was greater than or equal to $200,000 per year. Five programs also responded with other significant costs that included IT ($250-300,000), health integration engines or HIEs ($12,000), purchasing licenses for hospitals, training costs and bringing on hospitals with HL7. One program said it cost $80,000 to bring one hospital online with HL7 (**Figure 6**).

Figure 6: Cost of Data Exchange in Public Health Laboratories



Question Six: Electronic NBS Results Sent

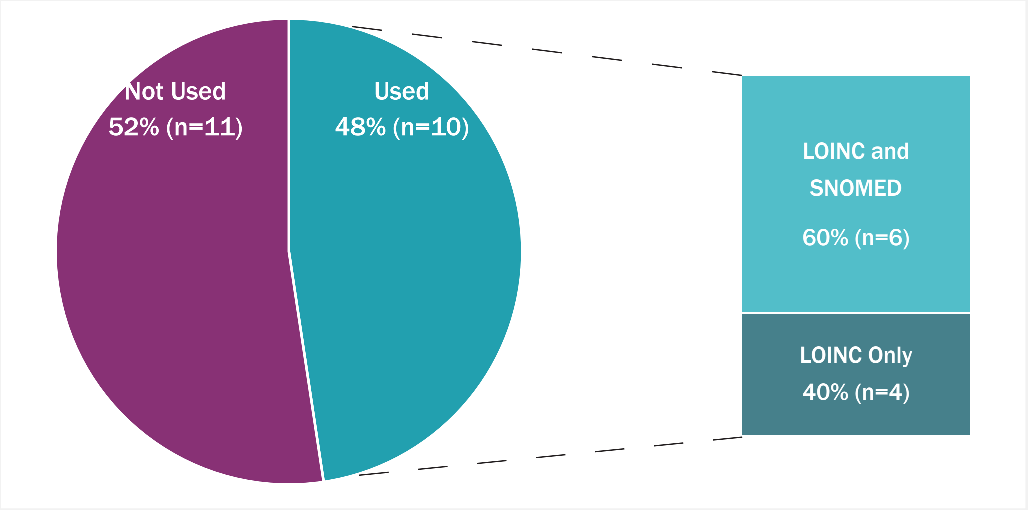
The remaining questions were asked specifically about the NBS program. When asked if programs sent HL7 electronic results to hospitals, 32% (n=8) said yes, 32% (n= 8) said no and 36% (n= 9) said they are working on it, meaning they are waiting for their LIMS or they are pilot testing. Of the 13 programs that specified which HL7 version they use to send electronic results, 62% (n= 8) said version 2.5.1. It should be noted that one additional program said the version of HL7 used depended on the client.**

Of the 21 programs that responded regarding use of standard codes, 48% (n= 10) said they use standard codes, and 52% (n= 11) did not (**Figure 7**). Of those programs that said yes, four mentioned LOINC only and six mentioned LOINC and SNOMED.

** This was the most recent version of HL7 at the time of the interviews, but not at the time of publication.

Out of the ten programs that responded, the number of hospitals receiving electronic results from NBS programs varied from one hospital to 68 hospitals (mean=9). It should be noted that one program said one hospital was in the pilot phase of receiving electronic results, and one program said they send messages to the Health Information Exchange (HIE), and that several of the hospitals in their state have access. Of the 23 programs that responded regarding the percentage of samples resulted electronically, 70% (n= 16) said zero percent of sample screening results were sent electronically, with other responses varying from 10 to 100%. The average percent of sample screening results sent electronically was 15%.

Figure 7: Standard Codes Used by NBS Programs (n=21)



Question Seven: Electronic NBS Orders Received

Of the 23 programs that responded to this question, 35% (n= 8) received electronic orders from hospitals, birthing facilities and/ or submitters. Of the seven programs that responded in regard to HL7 version used, 57% (n= 4) use HL7 version 2.5.1, which is consistent with the version used to send HL7 results noted in the section above.

Of the seven programs that responded regarding data elements received electronically and data elements missing, 71% (n= 5) said that no electronic data elements were missing. The following missing data fields were noted from other respondents: specimen collector's initials, transfusion status, whether the newborn is in the Neonatal Intensive Care Unit or not, mother's name and date of birth, meconium ileus or other bowel obstruction status, parenteral nutrition status, antibiotic status and mother's phone number.

Only five programs mentioned they get notified for orders via electronic ordering from their hospitals or via demographic data pre-population. Furthermore, 17 of 19 respondents (89%) said they cannot send back results if there was no order.

Seven programs responded in regard to the number of hospitals sending electronic orders. Responses varied from one hospital to 50 hospitals (mean=15). Out of the eight programs that responded to percentage of samples coming through electronic orders, the average was approximately 41%.

Question Eight: NBS Program Data Exchange with Other Programs

Seven NBS programs mentioned that they send data to Vital Records. Formats used to do this included HL7, CSV and one mentioned interfacing with Vital Records directly. Two NBS programs mentioned sending data to their Birth Defects Registry via CSV files. Other entities that exchanged data with NBS included NewSTEPs, R4S, clinical consultants, Title V, follow-up and an "immunization portal for expired babies." Data was sent to these programs in a variety of formats including secure email, Excel and CSV.

Nine programs used HIEs, which are central data storage hubs for a state's data that health care professionals and patients use to securely exchange and share medical information.[3] Of those programs, four said the HIE was a pass-through, meaning a conduit or pipeline for medical data to be exchanged; one said the HIE was a repository, which is a means for data storage; two said their HIE was both pass-through and repository and two did not know the answer or have the information at the time. One program that used an HIE as a repository noted that the repository had its own HL7 message format.

DISCUSSION

Experience with Data Exchange

Programs that screen for more babies may perhaps have additional or a greater need for more robust electronic data exchange, and reduction of manual data entry. Two screen states have unique HIT challenges in terms of results reporting and linking specimens. Those programs that contract out NBS may also have unique challenges in terms of exchanging data between different systems and entities.

Results from interview responses indicated that most of the public health laboratories interviewed have experiences with various types of data exchange, whether that be with hospital level data exchange, with state and national repositories, or with EPA, FDA and CDC. APHL Informatics has additional resources and tools available in regard to ways that public health laboratories are implementing data exchange. However, the volume of data exchanged was unclear. Only 13 programs were able to answer this question, and answers given were difficult to summarize as some programs stratified data exchanged by day, some by week and some by month. Furthermore, some programs stratified data exchanged by to whom they send data. This emphasized the variability in operations between public health laboratories.

There were also a variety of formats used to send or receive electronic health data. When discussing data exchange, it is common to refer to HL7, a widely used messaging standard to exchange electronic health data. However, other formats such as XML, Text, CSV, PDF and ASCII were all mentioned in interviews. One program answered SFTP, which is a method used to deliver information rather than a format, demonstrating that programs may have conflated terms between questions, or may not have fully understood HIT terminology.

Data Exchange Infrastructure and Capabilities

Most of the public health programs interviewed have data exchange infrastructures and capabilities in place, including use of integration engines and standard codes, which are baseline terminology used by healthcare professionals in order to avoid error when handling patient data. These universal code systems are used to report disease results to public health laboratories.[4,5] Most programs mapped to codes via LIMS or both LIMS and an integration engine, however there was variability regarding if programs were able to code information based on each partner, and whether data was delivered in a scheduled or on demand manner.

Ways for Clients to Access Data

Public health programs have various ways for clients to access data. Most programs used a web portal, and of those that used a portal, most said clients and partners can download result reports directly and in real-time. However, when asked if clients can order tests from the portal and print labels to send their samples, the answers were more varied and thus difficult to analyze. Often, answers were stratified by department (i.e. only for NBS, for non-NBS only, only for clinical laboratories). Other ways to access data included fax, SFTP, secure e-mail, mail and phone call.

Routine Challenges

Routine challenges was the most response-generating interview question, indicating that electronic data exchange is not an easy feat. The top barriers included cost, staffing, complexity and hospital buy-in. Other routine challenges included data error or data integrity, lack of infrastructure and capabilities, lack of training, lack of resources, streamlining all electronic data exchange projects, competing priorities, getting LIMS to do what is wanted, leadership support and time.

Qualitative and contextual data gathered from interviews indicated that while electronic data exchange is often posed as a cost-saving measure, long-term maintenance and added complexities, such as restructuring workflow(s), cannot be underestimated. One program said,

> *"It's really not a cost saving. It's a shifting of burden. Yes, you're not sending any paper out, but then your cost of staff is going to go up because somebody needs to write those messages, make sure those messages go out every day... We sell these types of activities as the cost that it saves and reduces cost and so forth, but it's usually downstream where these costs are saved. Those people who are actually at the front lines, the ones that are implementing, it ends up being more difficult and actually can add to the complexity of their work, not reducing it. I think that's one of the lessons that I've had to come to understand, is that I need to communicate this type of work with its importance and benefits and so forth, but also by providing the reality that it may in fact make our lives a little bit more complex than it was before."*

Cost of Data Exchange

There were significantly fewer responses to questions regarding data exchange cost, suggesting that the programs interviewed did not know or did not have access to this information. Staffing costs, integration engine costs and cost for maintenance of data exchange all varied. However, the long-term maintenance and downstream costs of data exchange seem to bear the heaviest expenses.

Electronic NBS Results Sent and Orders Received

Out of the 44 programs that submitted data in the NewSTEPs data repository in regard to HL7 order messages, as of April 2020, 32% (n=14) of NBS programs submit HL7 orders by at least one submitter. Furthermore, out of the 44 programs that submitted data in the NewSTEPs data repository in regard to HL7 result messages, as of April 2020, 34% (n=15) of NBS programs accept HL7 result messages by at least one submitter. The use of HL7 order message acceptance and result reporting by at least one submitter in NBS programs has increased since the time of the interviews.[***]

NBS Program Data Exchange with Other Programs

Newborn screening programs exchange data with a variety of entities, including Birth Defects Registries, NewSTEPs, clinical consultants, R4S and Title V. Data is sent to these entities in a variety of formats, including secure email and CSV, which is consistent with question one responses. Nine programs use HIEs as either a pass through or repository for states to securely share medical information.

LIMITATIONS

While interviews conducted generated important data that are currently guiding national HIT efforts, they were not without limitations. It proved difficult getting the correct people to answer these questions. Workgroup members and staff recruited NBS program staff, IT staff, section supervisors and LIMS administrators at the state public health laboratory to participate, however due to scheduling conflicts and timing, interview participation differed by program. Not all of the 25 programs that participated in interviews answered every question, and, since there were no individual identifiers in interview responses, it was difficult to match sub-questions. For example, the programs that send HL7 electronic results to hospitals may or may not overlap with the programs using standard codes.

[***] It should be noted that the programs submitting data for HL7 order messages may not be the same programs submitting data for HL7 result messages. NewSTEPs' electronic messaging data visualizations can be found on the NewSTEPs website.

CONCLUSION

Conclusions and key findings can be drawn from qualitative and contextual data provided in tandem with interview question responses. First, it is clear that not everyone understands HIT terminology. Several programs asked clarifying questions such as, “what do you mean by integration engine?” that signified a lack of understanding. Furthermore, at times programs conflated terms or used them interchangeably. For example, “SFTP” was given as an answer for a format used to send and receive data, when in actuality it is a method used to deliver information. This suggests that there is a need for national HIT- centered education.

Interview responses also made it clear that NBS programs operate independently from state to state. Programs have different data exchange phases and have different experience, infrastructure, capabilities and readiness regarding electronic data exchange. Some programs have zero staffing for data exchange responsibilities and do not send or receive electronic results or orders, while others have seven FTEs and have 100 percent of sample results sent out electronically. What is similar between programs are challenges faced with regard to electronic data exchange, the most coming being cost, hospital buy-in, complexity and staffing. There is an opportunity here for collaboration and learning between programs in different stages of data exchange.

It is clear that every program is working toward full data exchange capability. While NBS is perhaps behind, there is an opportunity to leverage existing informatics capabilities. This is summarized by one interviewee,

> *“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.”*

By gaining a better understanding of the variety of ways laboratorians perform data exchange, and the developing HIT needs of each laboratory, APHL and the Workgroup have gathered various approaches and best practices for addressing common barriers. In January 2018, the Workgroup established four vendor-specific user groups that serve as structured and moderated forums where participants can discuss NBS activities as they relate to information management systems. User groups share experiences specific to areas of interest and identify challenges and solutions; develop comprehensive summaries of solutions and lessons learned to support NBS programs in their activities; and collaborate with vendors as needed to address challenges identified that have no readily available solutions. The four user groups are OZ Systems, PerkinElmer, Natus/Neometrics and Interoperability. The establishment of these user groups and engagement of information management vendors have informed the objective of gathering various approaches and best practices for addressing common barriers.

The Workgroup is also continuously collaborating with the APHL Informatics Committee, which is establishing an HIT curriculum to address previously mentioned educational gaps. Several other tangible resources developed include an HL7 implementation guide for test ordering and results reporting, an informatician job description and work on a common data model.[6] As stated in the Executive Summary (link) The Workgroup transitioned into a Subcommittee in January 2020, given increasing discussion at the Federal level and increasing awareness of interoperability in the NBS community. This transition has increased visibility and appropriately addresses the work being done by Subcommittee members.

Furthermore, the HIT Workgroup is collaborating with the newly formed Newborn Screening Workforce Taskforce to address top barriers around staffing and lack of training. Since the time of the interviews NewSTEPs has initiated creating Extract Transform and Load (ETL) processes for programs that have a LIMS incapable of automating data extraction for submission to the NewSTEPs data repository. Through utilization of Structured Query Language (SQL), which can be applied directly to an existing interface for the LIMS, and writing queries and applications using R, which is free and open-source, NewSTEPs can assist programs pull their own data and provide resources otherwise unavailable to them. Continuous collection and monitoring of NewSTEPs’ HIT related data allows for analysis of and potential answers to HIT related problems. All of the aforementioned approaches, including the elevation of the Workgroup to a Subcommittee, work toward addressing common barriers and better identifying each laboratory’s needs in terms of electronic data exchange.

Full electronic data exchange is the inevitable future. Improving these capabilities will ensure that data exchanged is timely, efficient, accurate, complete, and ultimately, will improve patient outcomes. Thus, while it poses challenges including an underlying paradigm shift in laboratory workflow, NBS programs must work together to utilize internal and external experiences and capabilities.

ACRONYMS

APHL	Association of Public Health Laboratories
ASCII	American Standard Code for Information Interchange
CCHD	Critical Congenital Heart Disease
CDC	Centers for Disease Control and Prevention
CLIR	Collaborative Laboratory Integrated Reports
CPT	Current Procedural Terminology
CSV	Comma Separated Value
EPA	Environmental Protection Agency
ETOR	Electronic Test Ordering and Reports system
FDA	Food and Drug Administration
FTE	Full Time Employee
HIE	Health Integration Engine
HIT	Health Information Technology
HL7	Health Level 7
IT	Information Technology
LIMS	Laboratory Information Management System
LOINC	Logical Observation Identifiers, Names and Codes
NBS	Newborn Screening
NBSGPH	Newborn Screening and Genetics in Public Health
NBSTRN	Newborn Screening Translational Research Network
NewSTEPs	Newborn Screening Technical Assistance and Evaluation Program
PDF	Portable Document Format
PHINMS	Public Health Information Network Messaging System
PHLIP	Public Health Laboratory Interoperability Project
R4S	Region 4 Stork
SFTP	Secure File Transfer Protocol
SNOMED	Systematized Nomenclature of Medicine-Clinical Terms
TA	Technical Assistance
UCUM	Unified Code for Units of Measure
VPN	Virtual Private Network
XML	Extensible Markup Language

APPENDIX: NBS HIT INTERVIEW QUESTIONS WITH SAMPLE RESPONSES

General Questions

1. What experience does your NBS/State laboratory have in data exchanges with the following:

    a. Hospitals?
    - Clinical results to hospitals
    - Newborn Screening

    b. Other state/national repositories?
    - Notifiable conditions(ELR messaging)
    - Vital statistics
    - NBSTRN
    - APHL NewSTEPs
    - SDWIS Prime
    - Region 4 (Stork)
    - Immunizations

    c. EPA/FDA/CDC?
    PHLIP (CDC), LIMSi (CDC), ELXnet (FDA), SDWIS (EPA), Air Quality (EPA)

    d. Volume of data being exchanged?
    Once a month, 200 messages/day

    e. Is it automated?
    - Fully - does not need any staff intervention
    - Partially - requires staff to upload results
    - Manual - requires staff to type in the result

    f. What are some of the formats that you use to receive/send this information?
    HL7, XML, Text, Excel, CSV (Comma delimited)

2. What are your data exchange infrastructures and capabilities

    a. Do you use any kind of tool like an integration engine to send/receive the information?
    Rhapsody, BizTalk, Mirth, Middleware, LIMS software directly sends data

    b. Do you use standard codes?
    LOINC, SNOMED, CAS, UCUM

    c. Where do you map to codes?
    LIMS, Integration engine, Both, Neither

    d. Can you code your information based on each partner?
    - Yes - can use vocabulary specific to my partner
    - No - one vocabulary for everyone

    What transport methods do you use to deliver information?
    PHINMS, VPN, SFTP

    e. Are the transfers scheduled or is it on demand?
    Scheduled, On demand as results are released

3. Other ways for clients to access your data

    a. Does you lab have a web portal?
    Yes/No

    b. Can clients/partners download result reports from the portal?
    Yes/No

    c. Are the results posted in real-time?
    - Yes - they are available immediately after the results are released
    - No - they are uploaded several times a day from the LIMS to the portal

    d. Can clients order tests from portal?
    Yes/No

    e. Can they print labels to send their samples?
    Yes/No

    f. Can they access other reports from the portal?
    Yes/No

    What type of reports?
    QA Reports, Hospital Report Cards, Sample Receipt Reports, etc.

    g. Can clients request auto-fax of results?
    Yes/No

    h. Are there other ways, beside paper, that you send/receive information?
    Fax, Email, Secure E-mail, SFTP, Carrier Pigeon

4. What are some of your routine challenges?
    - Differences between blood spot cards data and electronic messaged data
    - Cannot maintain staff
    - Lack of incentive for hospitals to participate
    - Infrastructure and capabilities

5. How much does data exchange cost you per year?
    - Staffing - $250,000 (3 staff)
    - Integration Engine - $10,000 - $30,000
    - LIMS Maintenance for data exchange - $50,000 - $100,000

Questions Specific to NBS

6. Do you send HL7 electronic results to hospitals?

   Yes/No

   a. What HL7 version do you use to send the data?
      2.5.1, 2.5.1.1, 2.4, 2.3.1, 2.6
   b. Are you using standard codes?
      LOINC, SNOMED, CAS, UCUM
   c. To how many hospitals are you sending messages?
      Five hospital systems, covering 40 hospitals
   d. What is the % of samples that are resulted electronically?
      0-100%

7. Do you receive electronic orders from hospitals?

   Yes/No

   a. What HL7 version?
      2.5.1, 2.5.1.1, 2.4, 2.3.1, 2.6
   b. Do you get most of your data elements electronically?
      Yes/No

      What is missing?
      Date and time of collection, race, feeding type, transfusion status, NICU, time of birth, etc.
   c. When you receive a DBS, how do you know if something was electronically ordered?
      Sticker on data entry form, manifest, hospital order #

      Does it ever fail?
      Yes – example given
   d. Can you send back the results if there was no order?
      Some hospitals accept results without an order, others require an order number.
   e. How many hospitals?
      1-100
   f. What % of your samples come through electronic orders?
      0-100%

8. What other programs do you send data to?

   a. Vital records? What format?
      Yes - CSV, Text, etc.
   b. Birth Defect? What Format?
      Yes – CSV, Text, etc.
   c. Others? What format?
      Immunizations, Baby's 1st Test, Well Check
   d. Do you use HIE to deliver results to the hospitals/partners

      I. Is the HIE pass-through?
         Yes/No
      II. Is it a repository?
         Yes/No
      III. Does the repository have its own message format?
         Yes/No, HL7 version 2.5.1, 2.5.1.1, 2.4, 2.3.1, 2.6
      IV. Does repository re-map data over time?
         Yes/No

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Association of Public Health Laboratories

The Association of Public Health Laboratories (APHL) works to strengthen laboratory systems serving the public's health in the US and globally. APHL's member laboratories protect the public's health by monitoring and detecting infectious and foodborne diseases, environmental contaminants, terrorist agents, genetic disorders in newborns and other diverse health threats.

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