



SAVING LIVES WITH A SIMPLE BLOOD SPOT



INTEROPERABILITY FOR NEWBORN
SCREENING PROGRAMS

Presented to the Advisory Committee on Heritable Disorders in Newborns and Children

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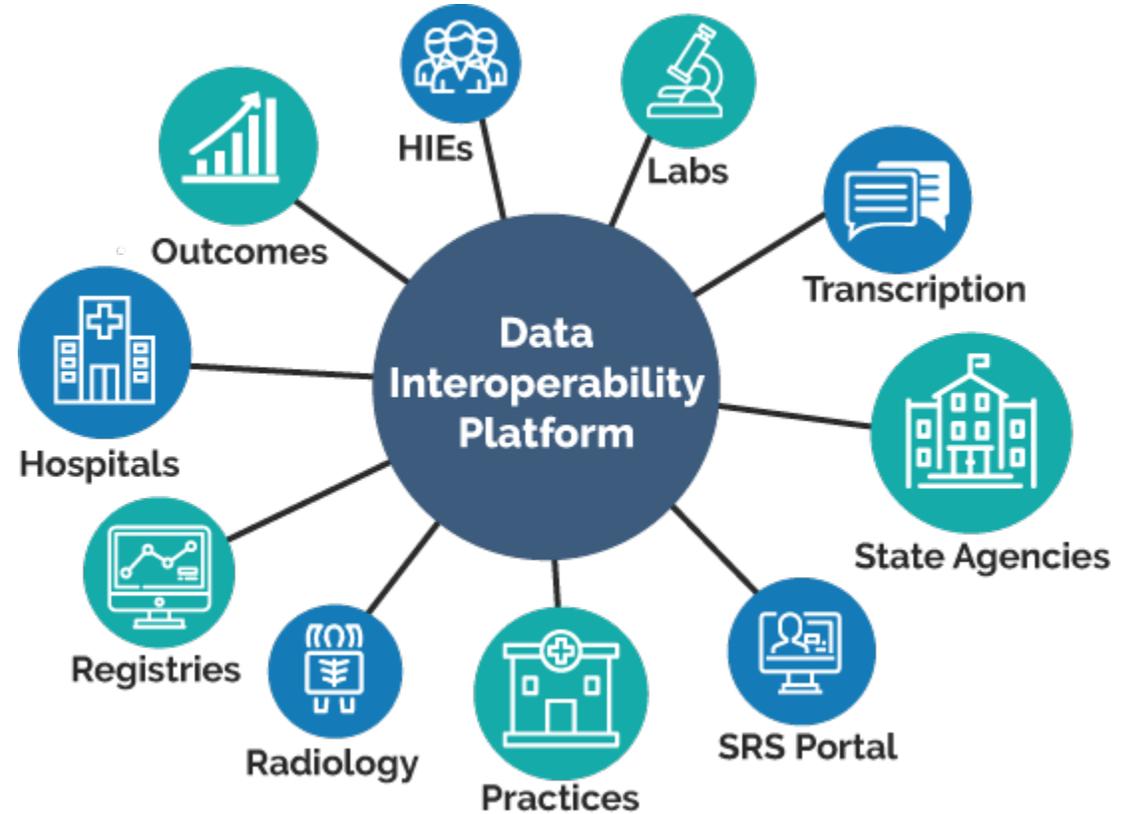
Why are we here?

- What is interoperability?
- Why is interoperability important for Newborn Screening?
- What is the current state of interoperability?
- What is the future state of interoperability for Newborn Screening?
- What are the barriers to interoperability?

What is interoperability?

Interoperability:

The exchange of data between computer systems or software that leads to **the use** of the information that is exchanged

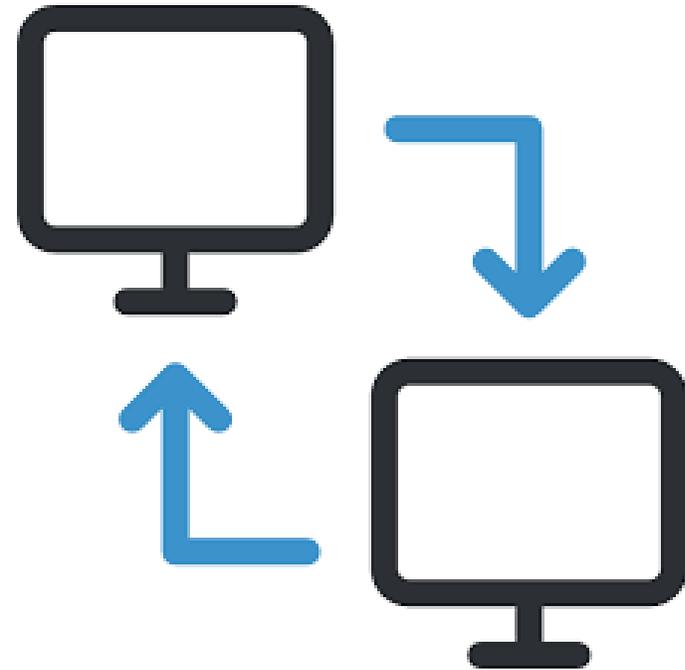


What is interfacing?

Interfacing:

the act of two or more electronic devices interacting or communicating to exchange information

When my phone sends your phone a text message our phones are interfacing

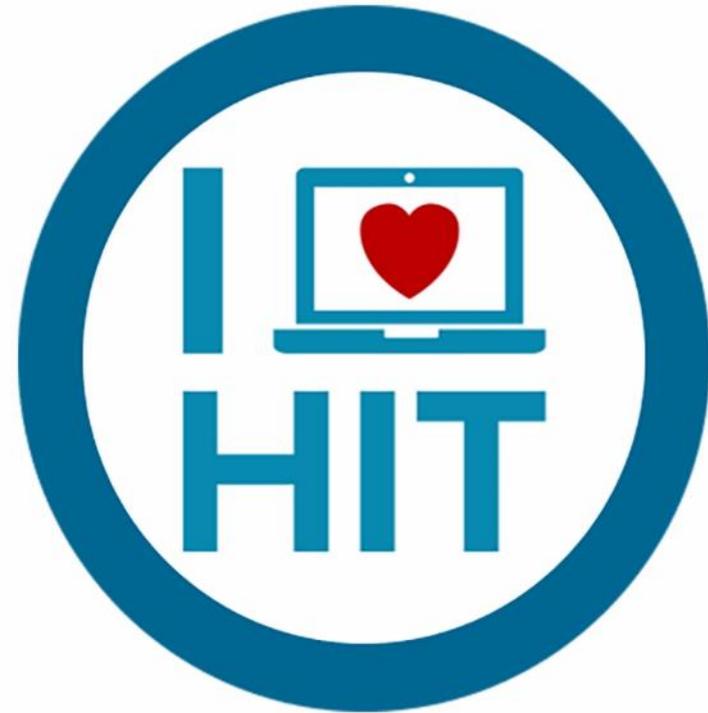


Interoperability vs Interfacing vs Integration?

Interoperability encompasses the entire exchange process, which includes interfacing, and the use of the information exchanged.

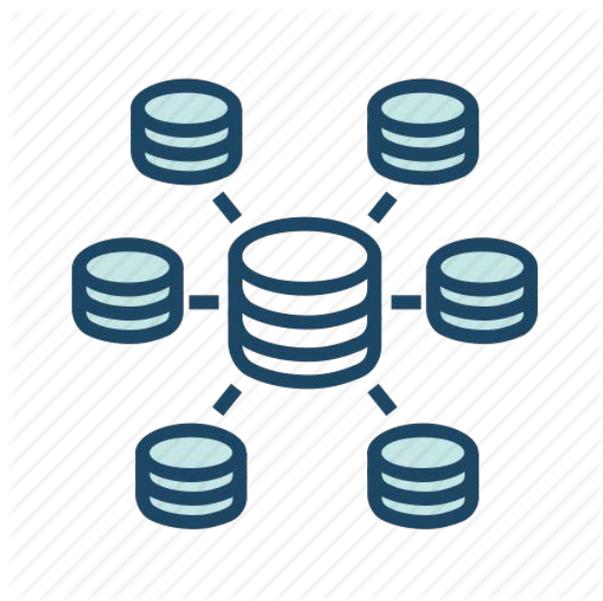
Interfacing is the act of exchanging.

Data Integration involves combining data residing in different sources and providing users with a unified view.



Components of Interoperability

In order for databases to be interoperable, they need a connection, a data route and a common language



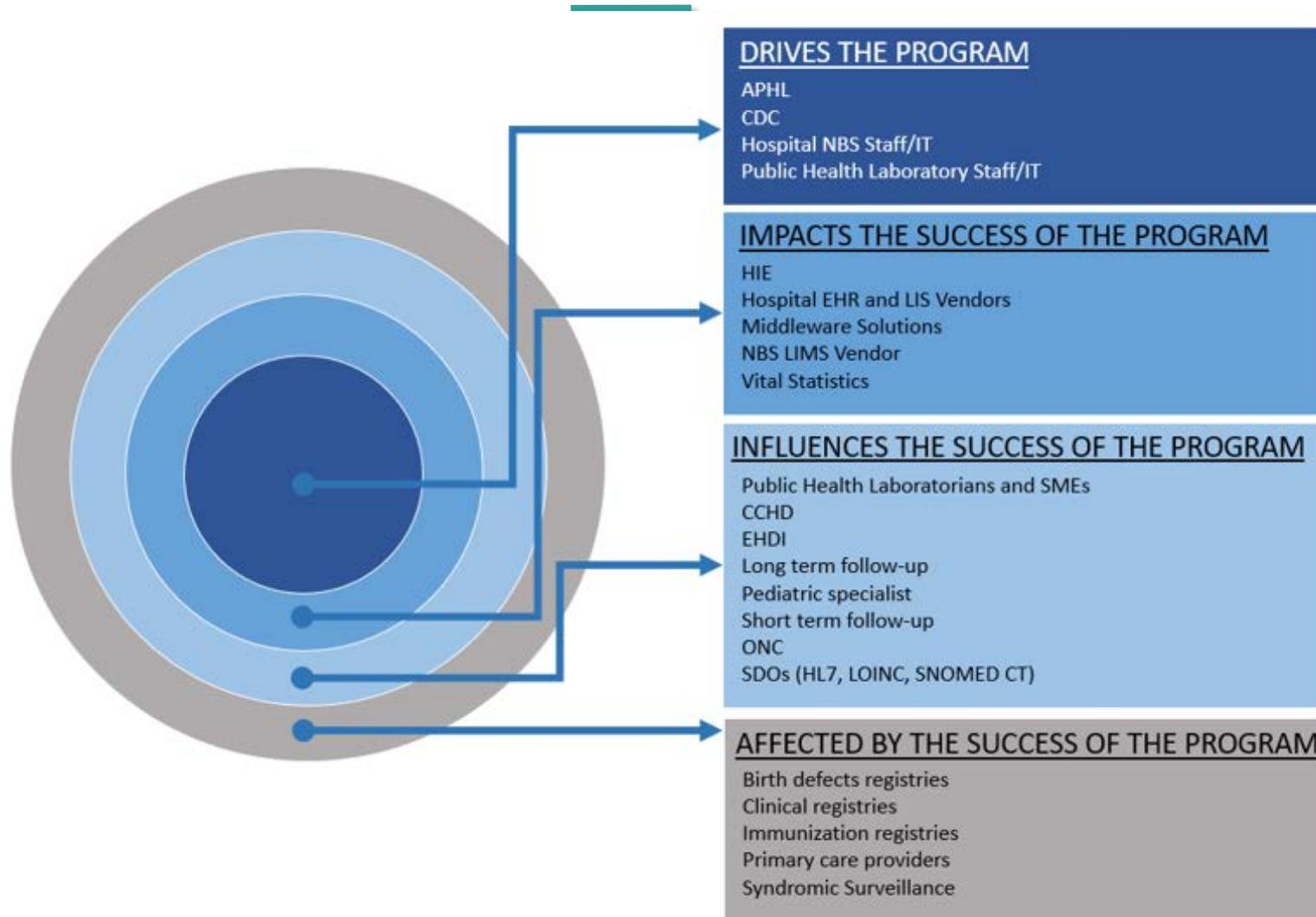
Interoperability Basics in Newborn Screening

Interoperability is done every day in Newborn screening when the laboratory information management system (LIMS) used in the laboratory interfaces with the case management system (CMS) used by newborn screening follow-up

But that is not where interoperability for NBS ends.....



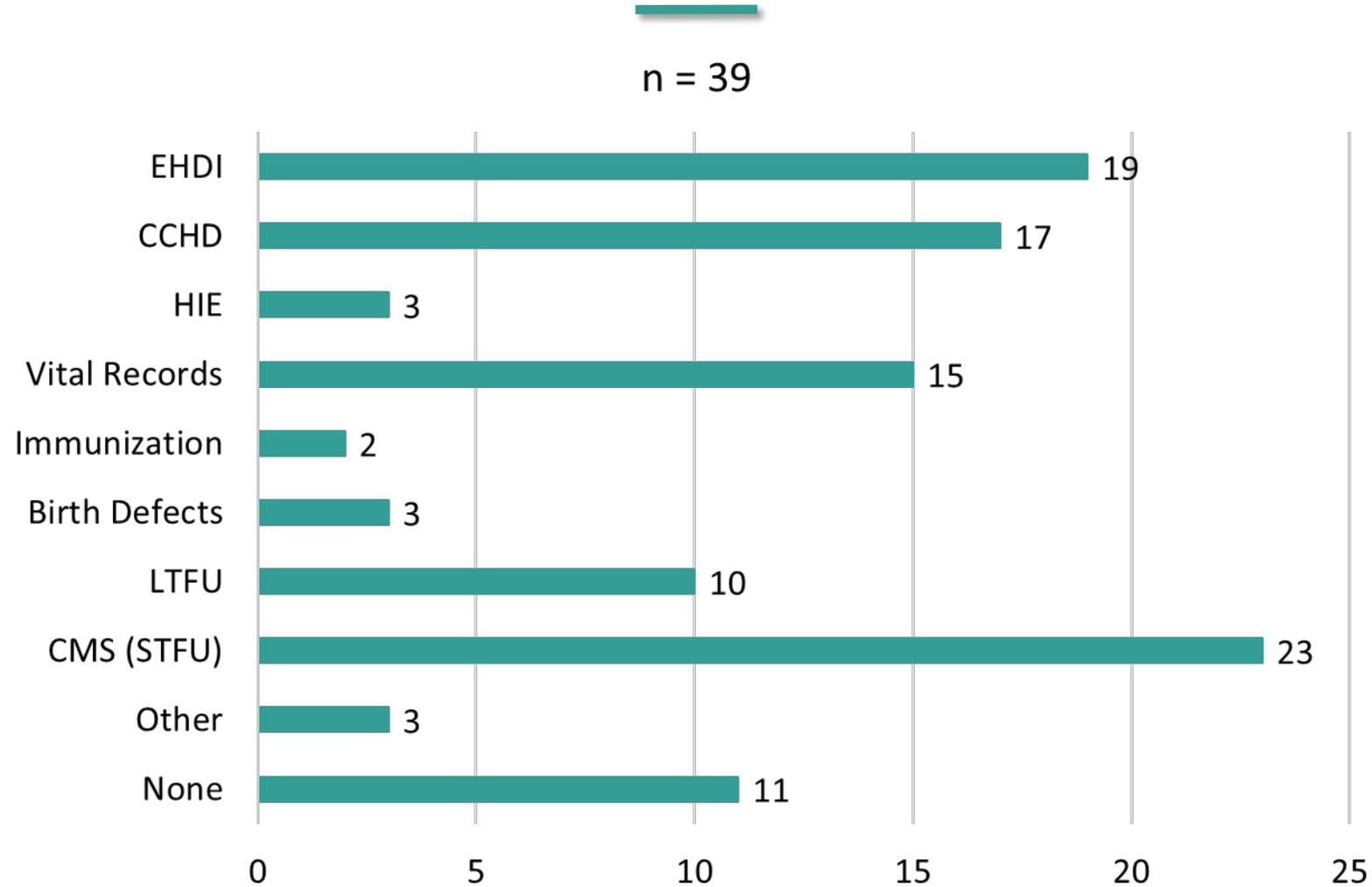
Newborn Screening Stakeholders



Areas of Interoperability

- Specimen tracking
- Electronic ordering and reporting(ETOR)
- Hearing Screening
- CCHD Screening
- Vital Records
- Birth Defects Registry
- Long-term follow-up (LTFU)
- Pediatric Specialists
- Data repositories
- Immunization Registry

How many NBS programs have the following data integrated with their LIMS?



Data Integration with Vital Records

Linking with vital records and birth records is a critical function of NBS to ensure every baby born is screened

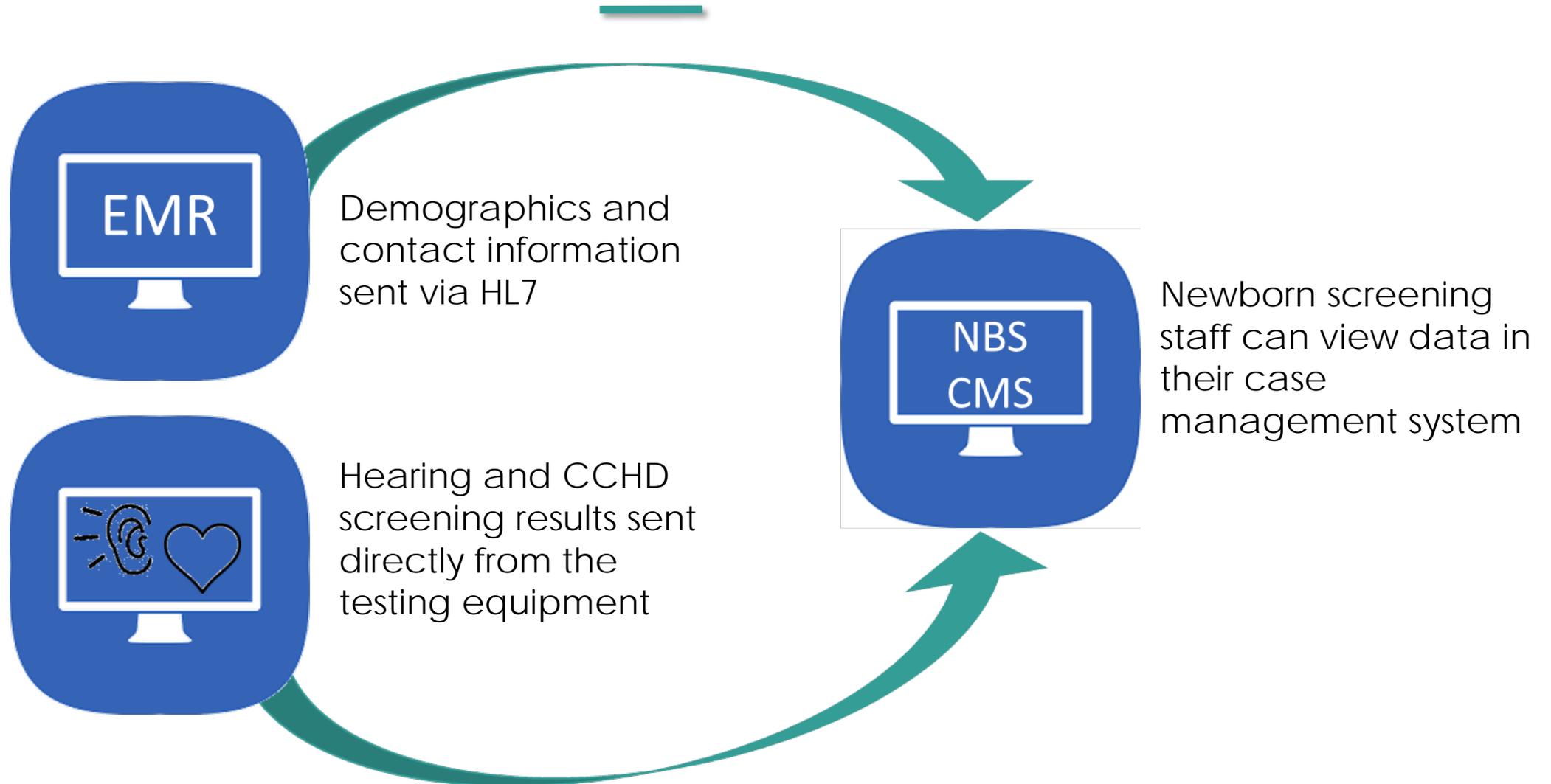
- Identifies infants that may not have received screening
- Provides a more accurate denominator for program statistics

Most states integrate with Vital Records but very few are able to fully interface

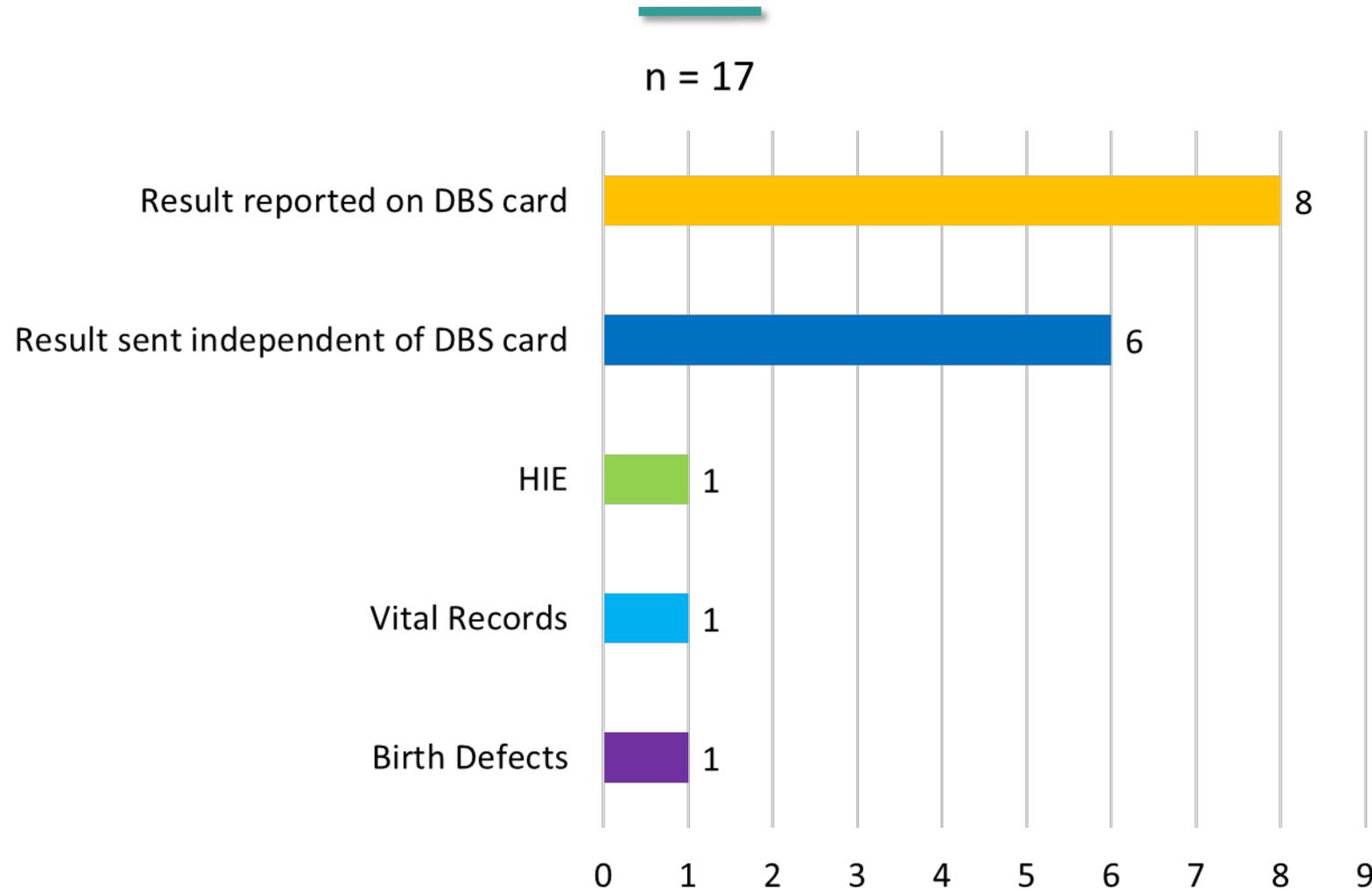
- Interfacing is more reliable and accurate than exports or paper monitoring
- Minnesota has an interfaced data system with vital records, allowing for automated flow of information into the newborn screening database.



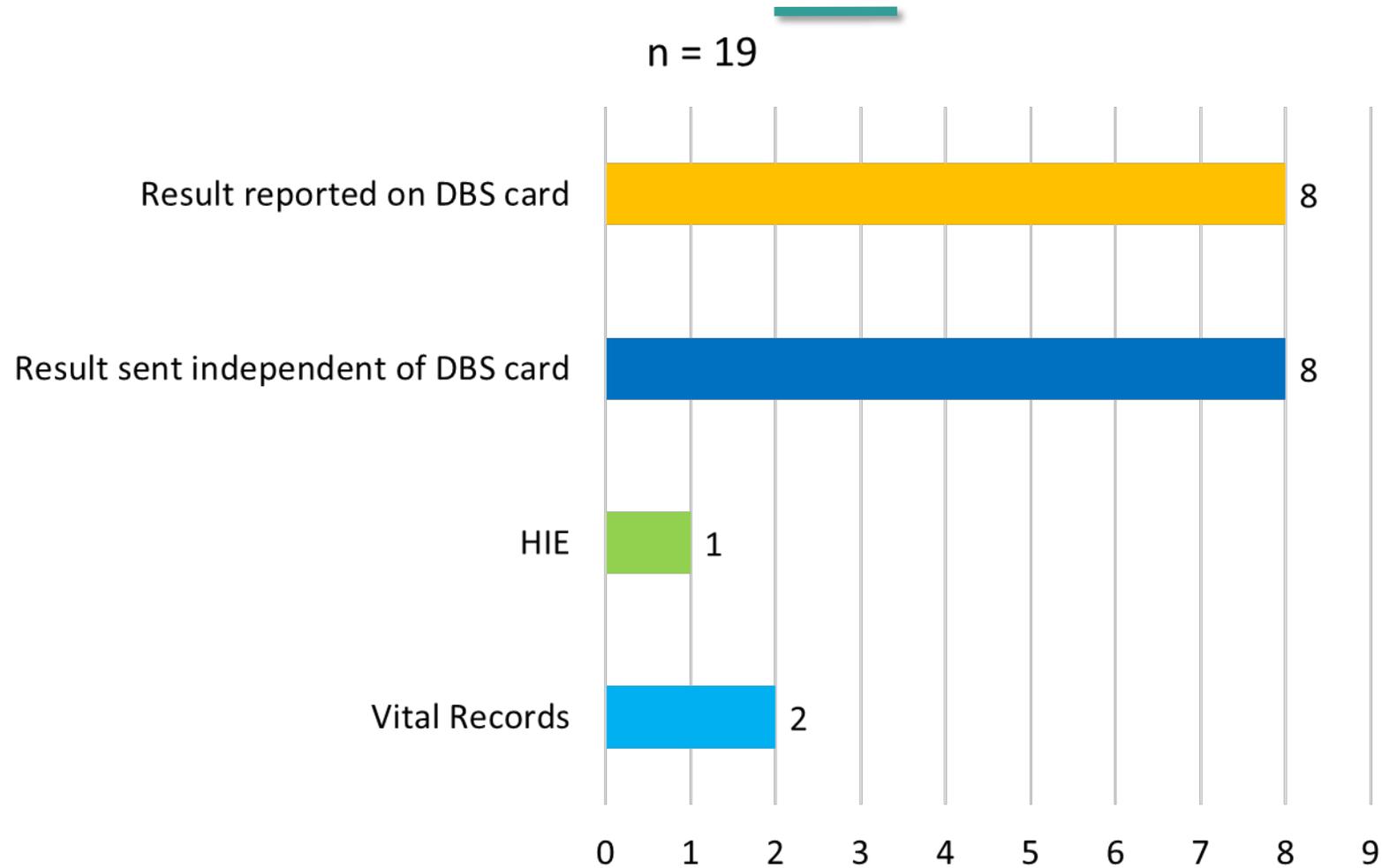
Point of Care Screening Interoperability



How are NBS Programs integrating CCHD data?



How are NBS Programs integrating EHDI data?

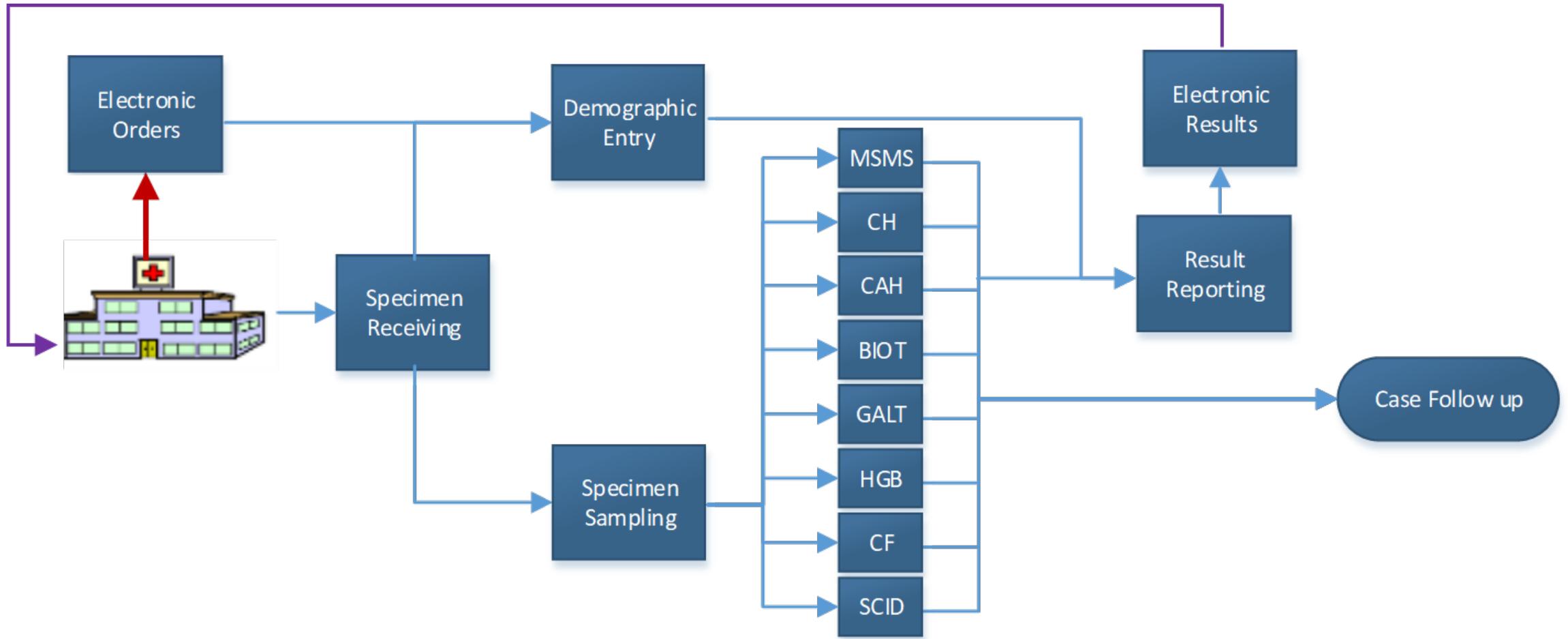


Data integration with Birth Defects Registry

- Identify CCHD cases missed by pulse ox screening
 - False negative feedback loop
 - Targeted education
 - Better understanding of CCHD in population
- Quicker outcome collection after failed pulse ox screen
- NBS reporting to Birth Defects will help them identify unreported CCHD cases



Electronic Test Ordering and Reporting (ETOR)



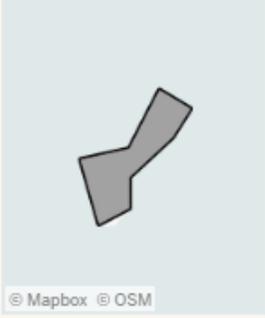
HL7 Orders Messaging Status Map



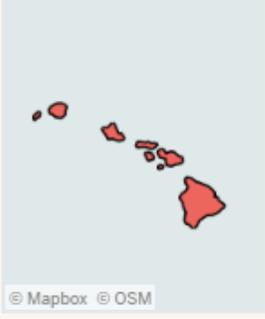
Alaska



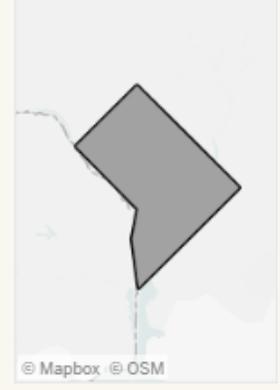
Guam



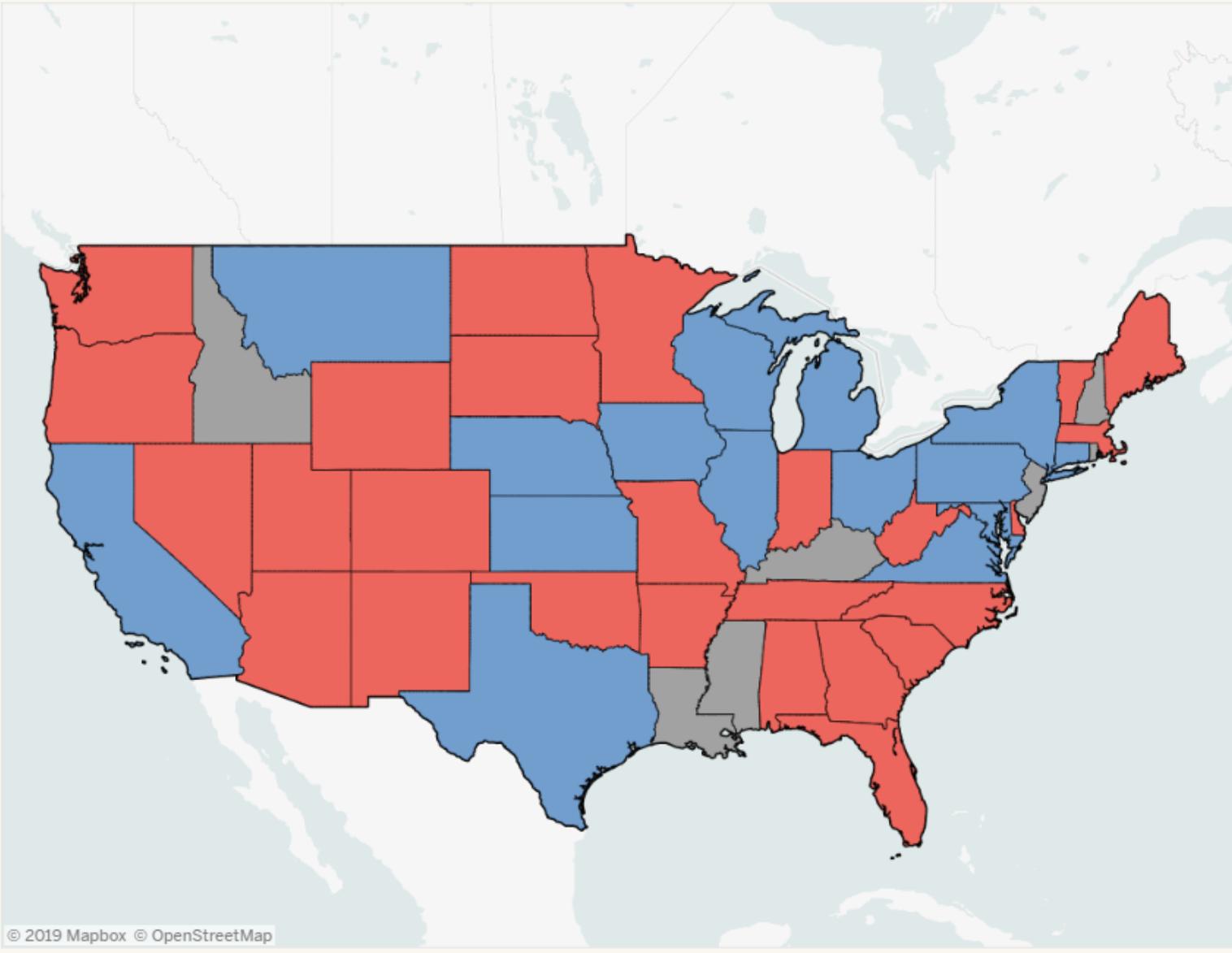
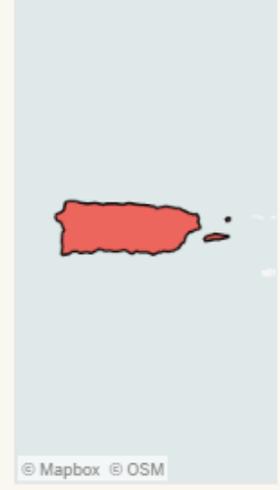
Hawaii



D.C.



Puerto Rico



- HL7 Orders Accepted
- HL7 Orders Not Accepted
- Data Not Provided

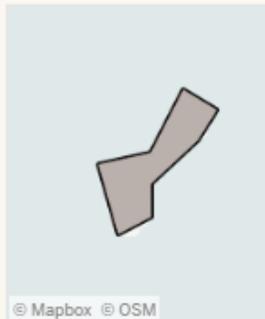
HL7 Results Messaging Status Map



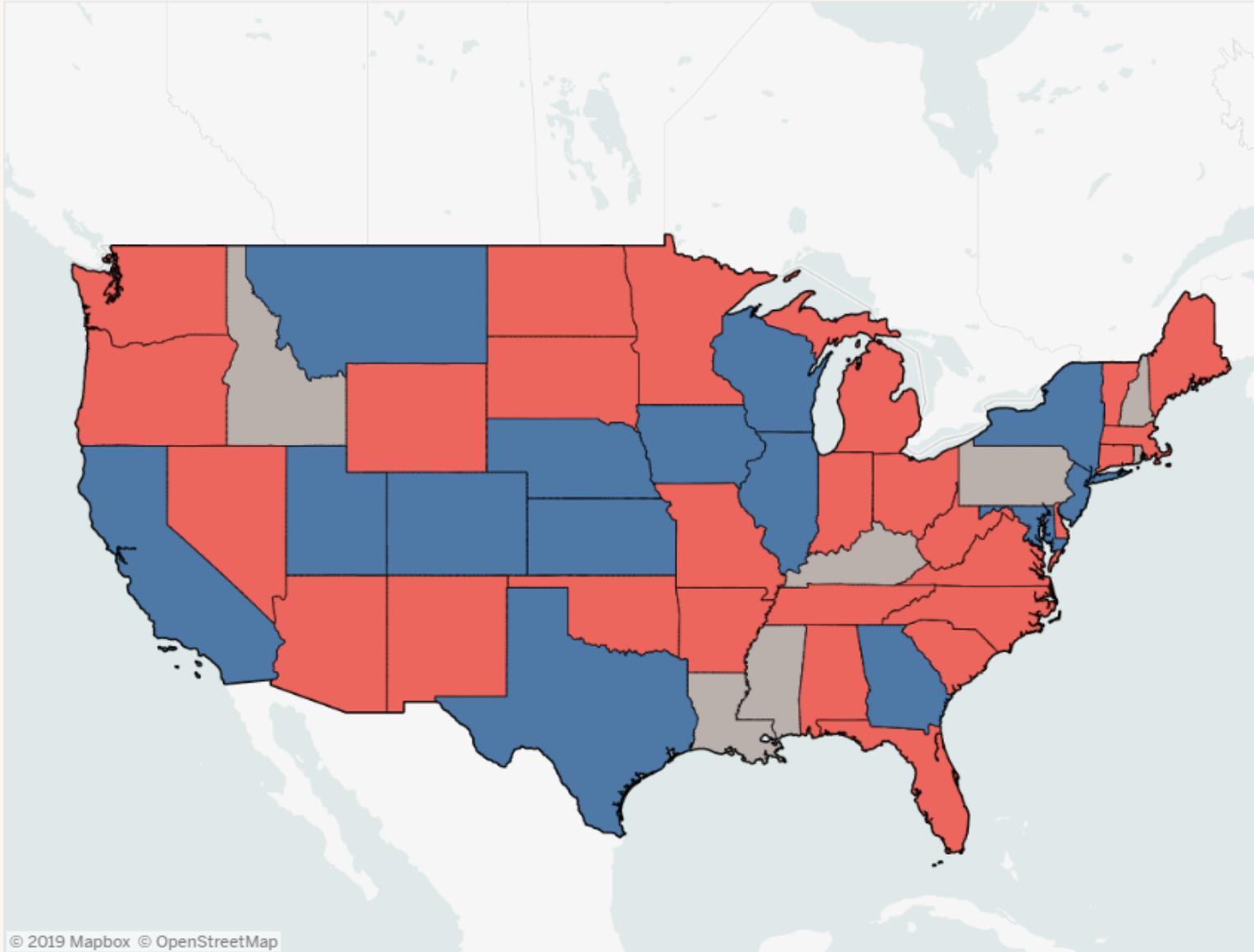
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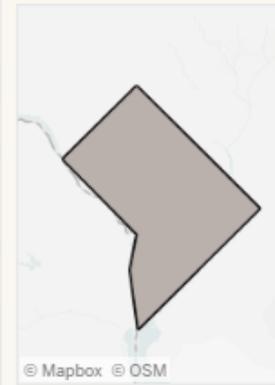
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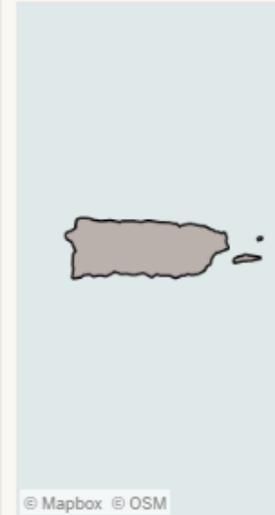
Hawaii



D.C.



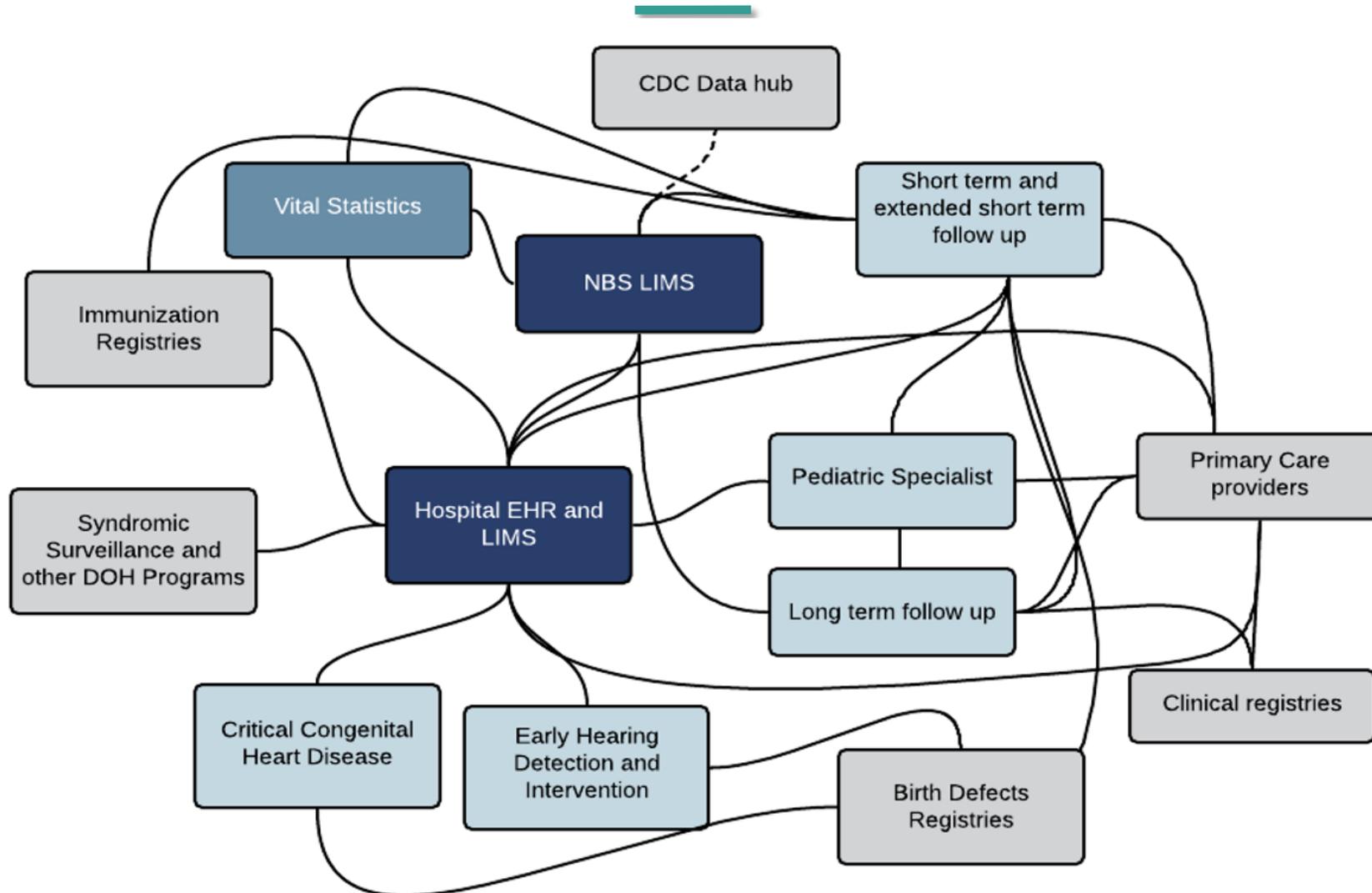
Puerto Rico



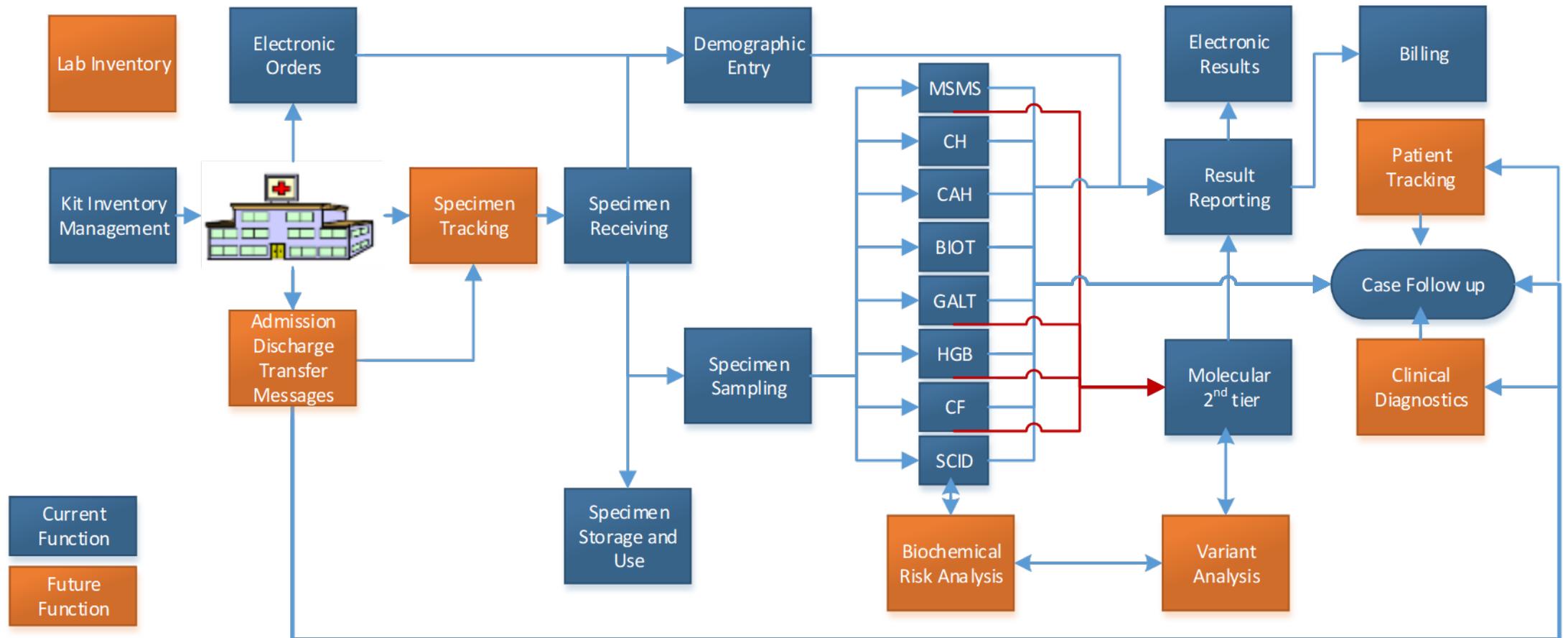
Legend:

- HL7 Result Messages Sent
- HL7 Result Messages Not Sent
- Data Not Provided

The NBS Spider Web



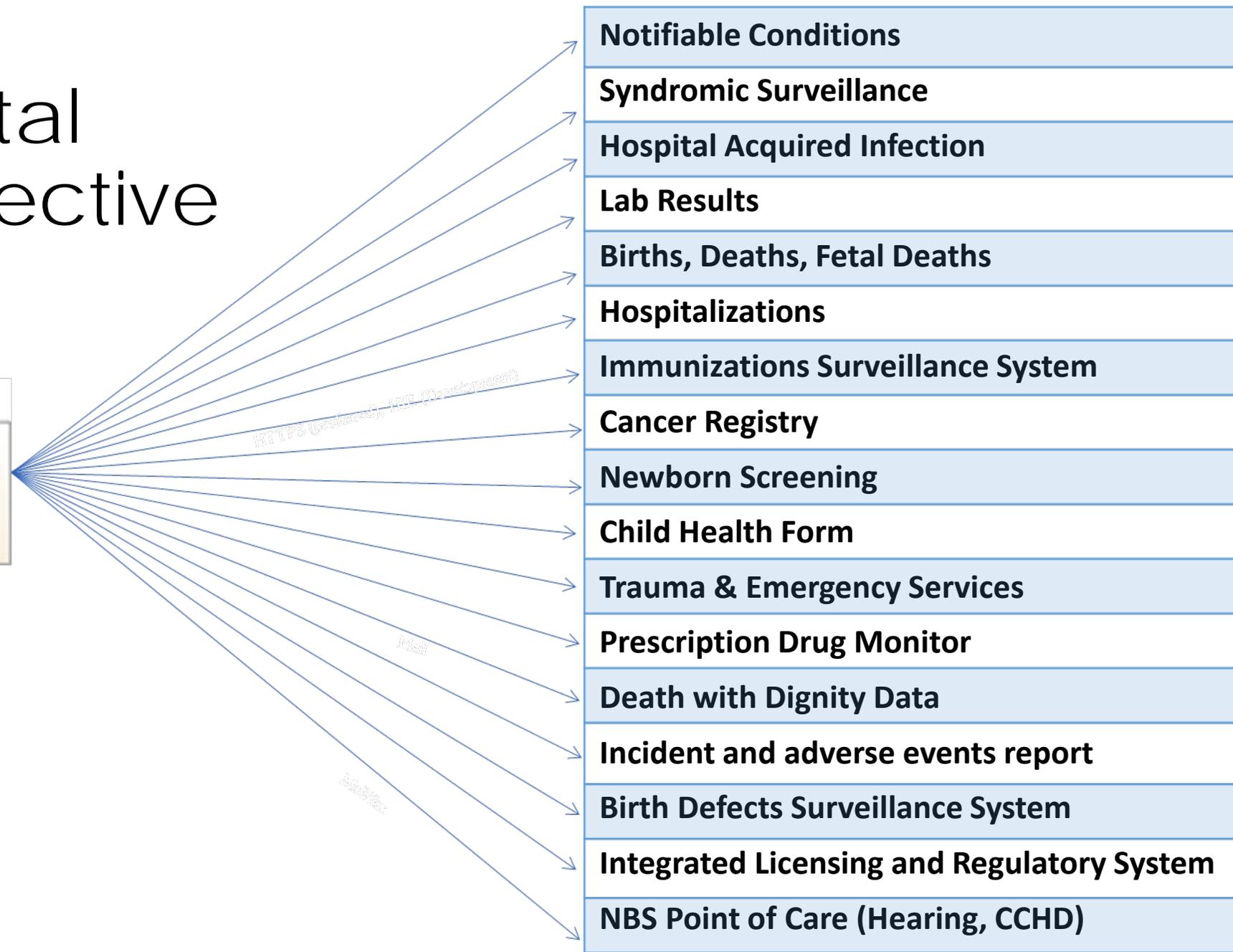
Newborn Screening Lab Xanadu



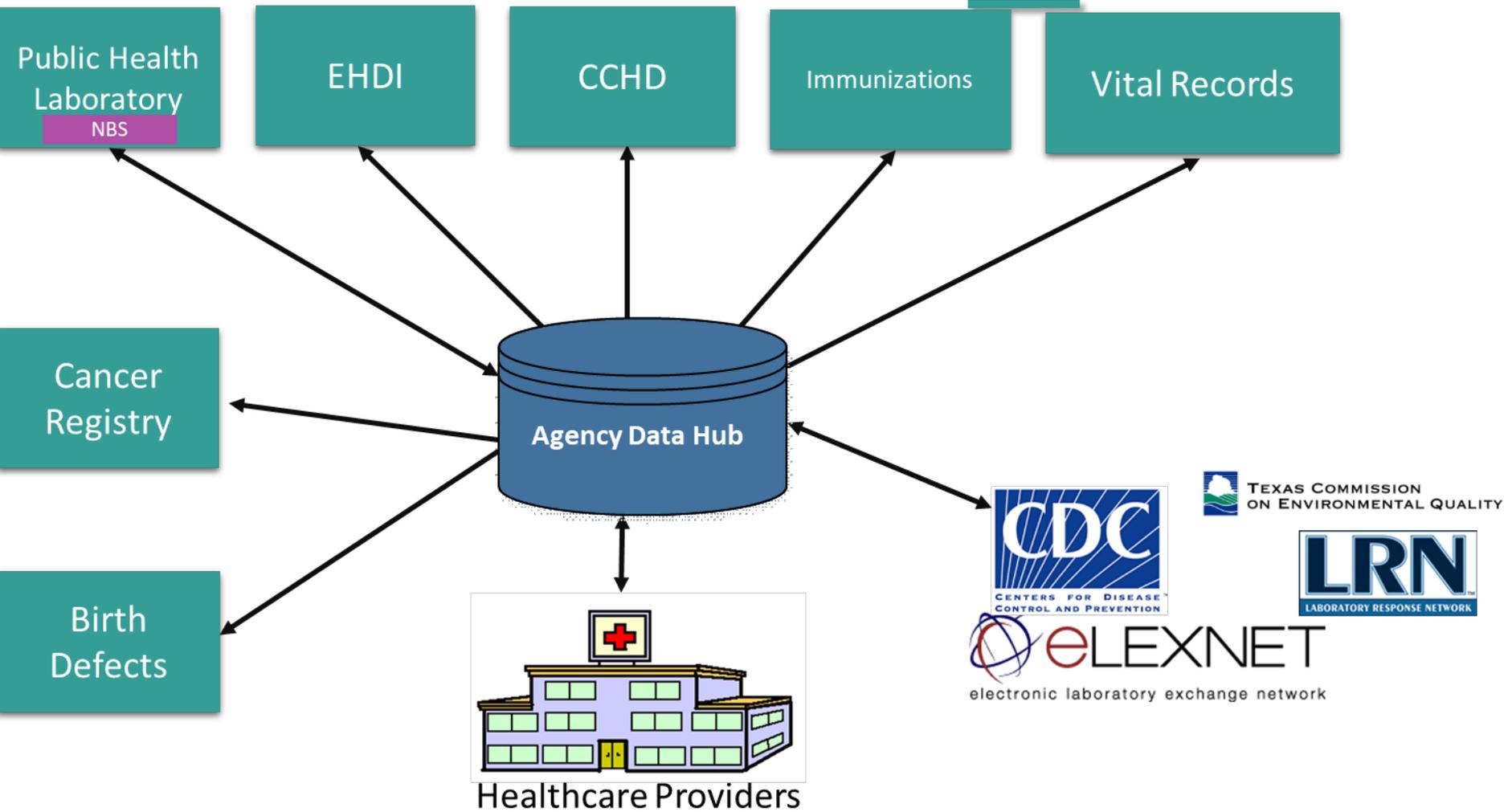
What's in Xanadu?

- Birth notifications
- Specimen tracking
- Real-time quality monitoring
- Real-time patient follow up info
 - Current provider
 - Diagnosis
 - Treatments
 - Diagnostic testing status / results
 - Long-term follow-up measures
- Reduced data entry
- Simplified order messaging

Hospital Perspective

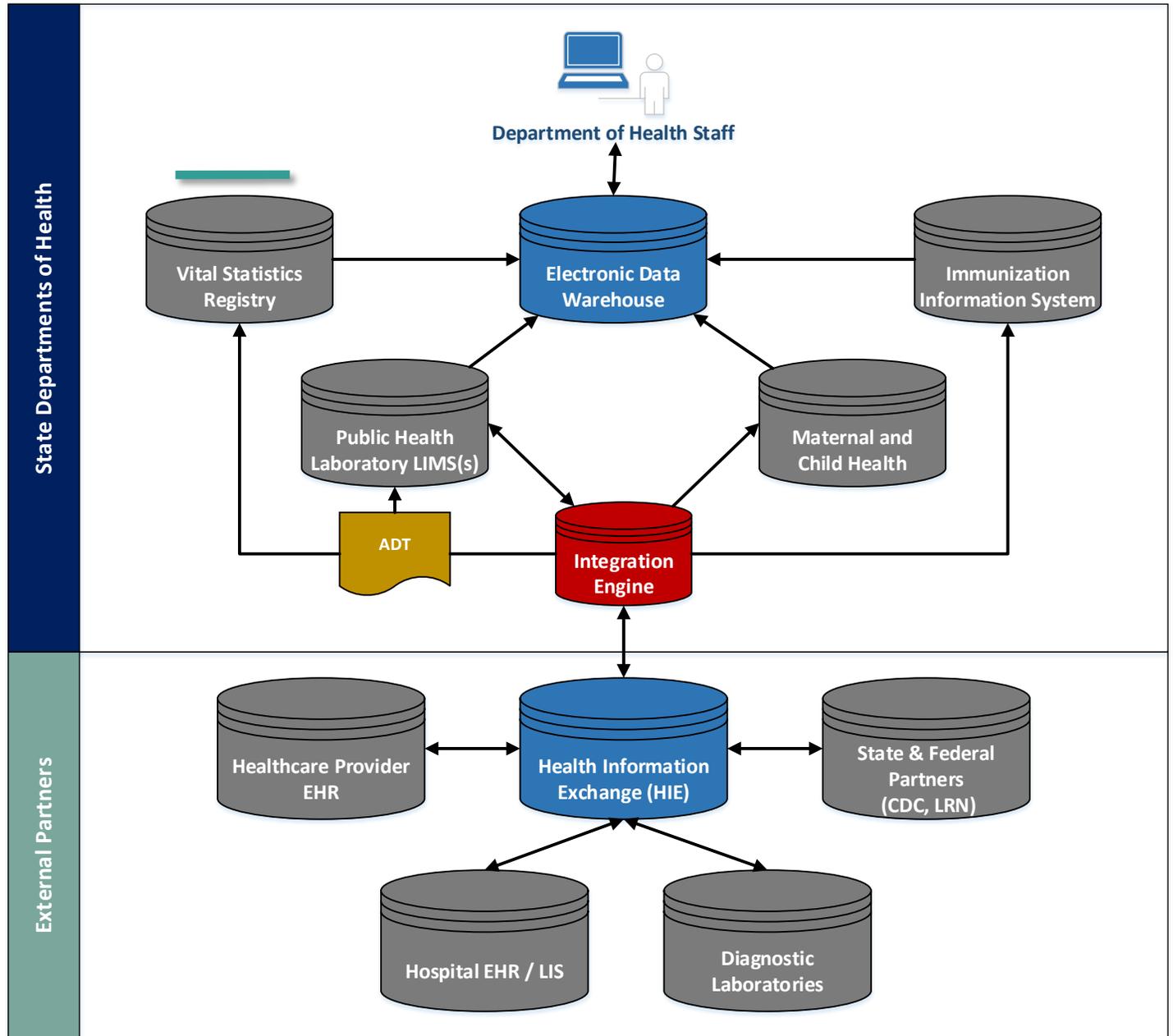


Agency Xanadu



Slide courtesy of Brendan Reilly
Texas State Health Services NBS

Public Health Xanadu



Recap of Interoperability Benefits

- Identification of False Negatives
- Identify babies that may have missed screening
- Improved data quality
 - Timeliness
 - Completeness and accuracy
 - Integrity of the data
- Improved data security by reducing faxing/emailing/mailing of PHI
- Defined case definitions, updating disease status or change in diagnosis
- Increased efficiency for NBS staff, hospital/submitter staff and other public health staff

Barriers to Interoperability

- Agency policy
- Agency-wide informatics infrastructure
- Program prioritization (opportunity cost)
- Having the right partners at the table
- Privacy issues
- Funding sources
- Lack of trained professionals in Public Health Informatics

Data standards are like toothbrushes. Everyone agrees they are a good thing but everyone wants to use their own

Why are we telling you this?

- Expanded interoperability allows NBS to:
 - Gain efficiency
 - Redirect FTEs
 - Increase testing accuracy
 - Improve patient outcomes
- How can we advance these efforts:
 - Encouraging agencies to develop interoperability priorities
 - Developing a lab level interoperability plan
 - Pursuing interoperability funding opportunities
 - Expanding informatics workforce/training programs
- **How else could ACHDNC help?**

Thank You!!

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Questions?

