Innovations in Newborn Screening Interoperability

A National Resource Center

NewSTEPs

A Program of the Association of Public Health Laboratories™

Interoperability with Vital Records and Newborn Screening Data

July 2024

Learning Objectives

At the end of this session, participants will be able to:

- Identify benefits to a closer integration between newborn screening and vital records programs
- Recognize opportunities to improve data sharing locally

Agenda

- Welcome
- Case story from Florida (Juan Vasquez)
- Case story from Utah (Jonathan Himes)
- Discussion (everyone)

Role of Vital Records Programs

- Tasked with the registration, processing and analysis of vital events in their jurisdiction including certification of births and deaths (among other life events)
- Programs are implemented locally but have integrations both with a jurisdiction as well as reporting to the National Center for Health Statistics (NCHS)
- Leadership and advocacy through the National Association for Public Health Statistics and Information Systems (NAPHSIS)
- Sharing of key vital events with newborn screening can provide tremendous benefits

Interoperability Implementation Activities
NBS/Vital Stats Data Matching

State Newborn Screening Interoperability Implementation SNBSII project

Florida Department of Health

Florida Newborn Screening (NBS) Interoperability Implementation Activities NBS/Vital Stats Data Matching

July 12, 2024

Presenters

Patricia Ryland
Project Manager, Newborn Screening Laboratory
Bureau of Public Health Laboratories (BPHL)
Florida Department of Health

Juan Vasquez
Project Coordinator, NBS Interoperability Implementation Project
Ruvos | Florida Department of Health

Presentation Outline

- Stakeholders and partners
- Assessment and planning
- High-level design and flow
- The NBS/VS Matching Application
- Results and findings
- User feedback and outcomes
- Contact information

Stakeholders and Project Partners

FDOH, NBS, FVS	Newborn Screening Modernization	TECHNICAL TEAM
Susanne Crowe, FDOH	Chad Lakin, FDOH Data Administration	BPHL Information Technology Team
Pati Ryland, FDOH	Kristin Leffel, Ruvos	Daniel Golan, Ruvos (Developer, Integration Architect)
Elliott Bailey, FDOH	Linda Min, Ruvos	
Juan Vasquez, Ruvos	Brian Ramos, FDOH/Ruvos, Integration Services	

Self and Readiness Assessment

- Staff interviews
- Focus group interviews
- Mapping of current process (As Is)
  - Workflow
  - Dataflow
- Identify existing interoperability

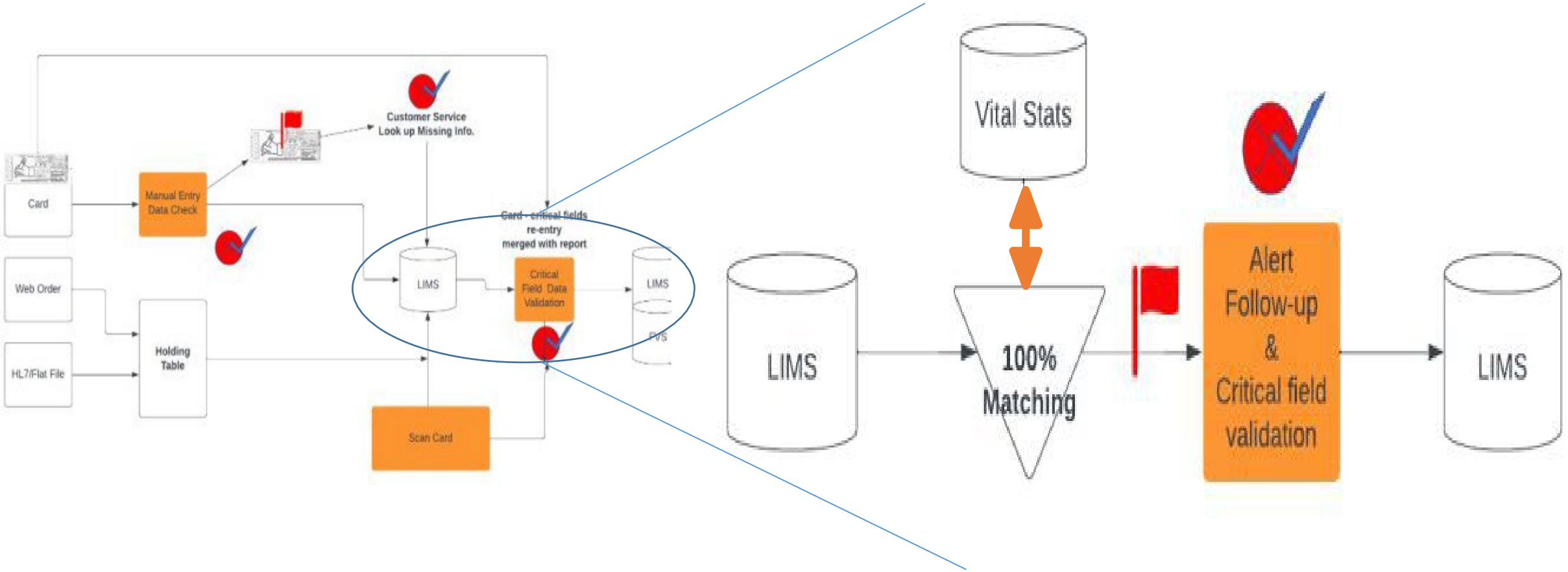
Interoperability Plan

- Identify opportunities for interoperability and/or modernization
- Workflow and data flow “to-be” recommendations
- Match program/lab goals with:
  - Leading standards
  - Modernization tools

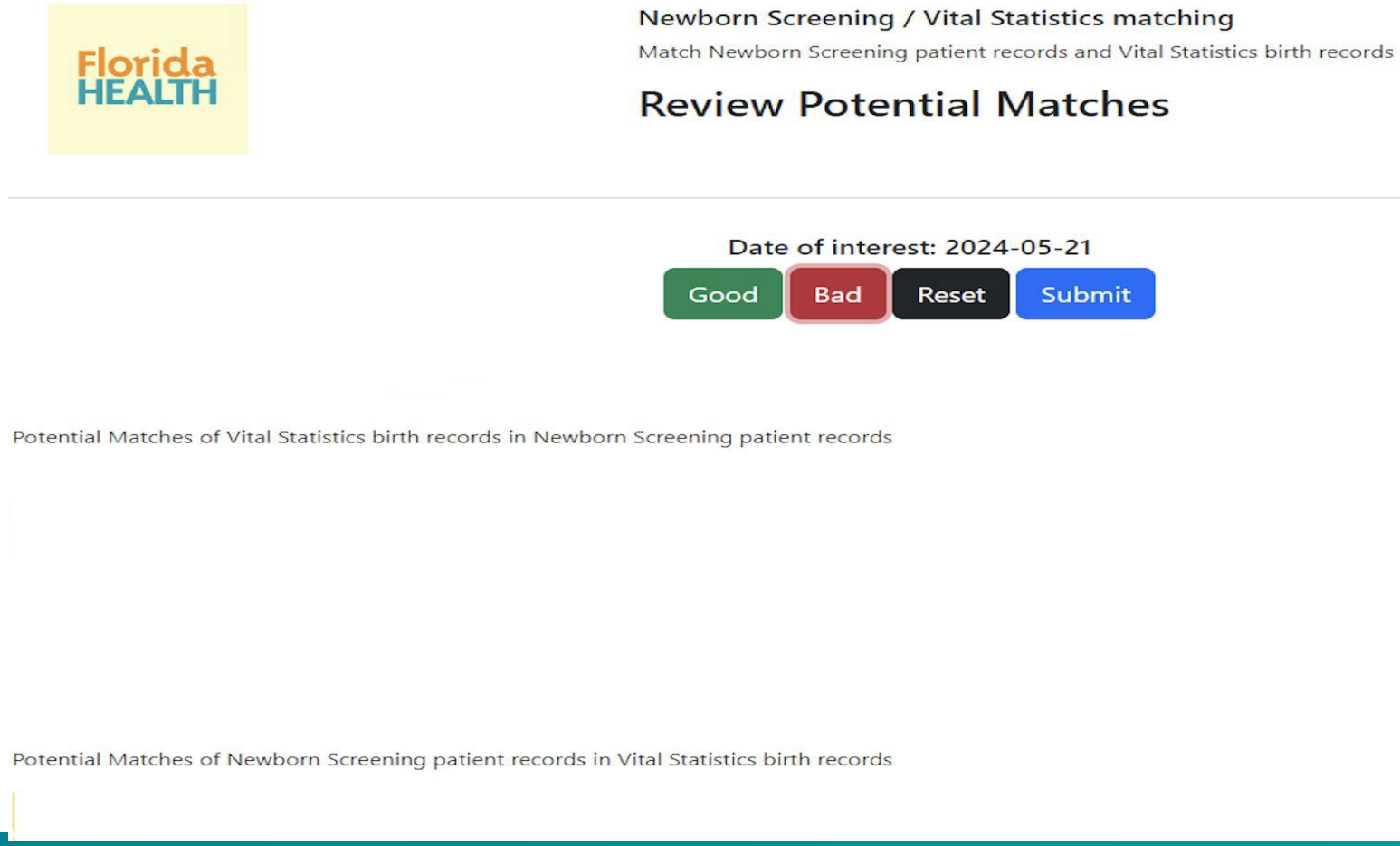
Data Quality – NBS/VS Data Matching Implementation

- Requirements
  - 100% Matching of newborn screening record with and Florida Vital Statistics (VS) birth records
  - Bi-directional matching of records
    - Birth Date and Time
    - Medical Record Number (MRN)
    - Mother's Address
    - Birth Hospital

NBS LIMS and Vitals Statistics Matching



The Matching Application



The Matching Application

Newborn Screening / Vital Statistics matching

Match Newborn Screening patient records and Vital Statistics birth records

Review Potential Matches

Date of interest: 2024-05-21

Good | Bad | Reset | Submit

	field	lifecycle	vitalstats
0	id		
1	motherFirstName		
2	motherMaidenName		
3	motherLastName		
4	motherAddressLine1		
5	motherZip		
6	birthFacility		
7	patientSex		
8	dateOfBirth		
9	timeOfBirth		
10	birthWeightGrams		
11	plurality		
12	birthOrder		
13	gestationWeeks		
14	infantLiving		
15	patientMRN		
16	patientFirstName		
17	patientLastName		

The Matching Application

Newborn Screening / Vital Statistics matching

Match Newborn Screening patient records and Vital Statistics birth records

Results

Date of interest: 2024-04-01

Core	Records	Automatic Matches	Manual Evals	Manual Matches	UnMatched
lifecycle	597	586	11	11	0
vitalstats	595	586	9	8	1

Results and Findings

Discrepancies	Findings	Actions
• DOB: VS vs. LIMS • VS record with no NBS record • Missing information in LIMS • Address • Multiple record numbers, • Multiple cards	• newborns not registered, born out of state • home births with no screening, but have a VS record • midwives - collect card info	• follow up on face sheet, vital stats look up, communicate with hospital/birthing center. • Education, outreach and training with hospitals, midwives, centers • Further research and study on causes for missing or incorrect info

User Feedback and Outcomes

- Time spent on data quality and validation
- 2 days vs 10 minutes
- Process Improvement
- 1 by 1 review vs Full matching runs
- DOB data issues identified/resolved quicker

- Improved reporting accuracy

- Improved communication between program, providers and patients in relation to deceased babies and nbs results.

NBS Modernization

- Data Quality
- Workflow and Process improvement
- Data exchange and interoperability

Contact Information

Juan Vasquez, MHA
Project Coordinator, NBS Interoperability Implementation Project
jvasquez@ruvos.com

Utah newborn screening program

SNBSII project

State Newborn Screening Interoperability Implementation

Utah Department of Health & Human Services

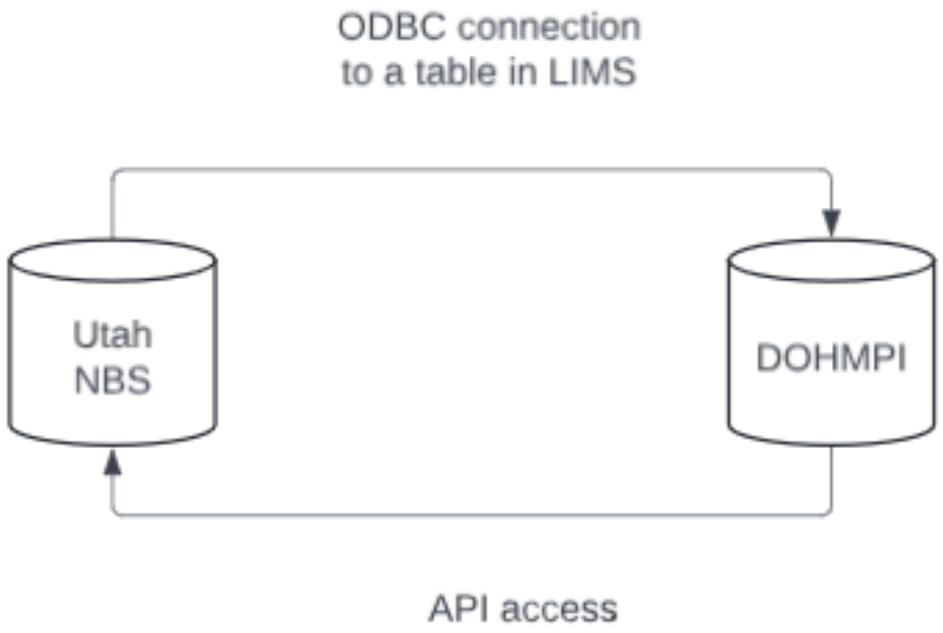
DOHMPI integration of NBS data

DOHMPI: Department of Health Master Person Index

High level overview

- Integrate newborn screening data into the department of department of health master person index (DOHMPI)
- Create an API for the newborn screening program to access the data from the DOHMPI

High level overview



What is DOHMPI

Data repository housing patient data across services within the Utah DHHS

DOHMPI sources

- Utah Birth Registry
- Newborn Hearing Screening
- Ages and Stages Questionnaire Screening
- Early Intervention Part C (Baby Watch)
- DWS - Child Care Subsidy
- DOPL - Controlled Substance Database
- Utah Death Registry
- Medicaid
- Office of Home Visiting
- DOPL - Professional Licensing
- Utah Cancer Registry
- Utah Immunization Registry
- Women Infant and Children
- Head Start
- Office of Home Visiting Penelope
- Healthcare Facilities Database

Demographic data available For NBS use

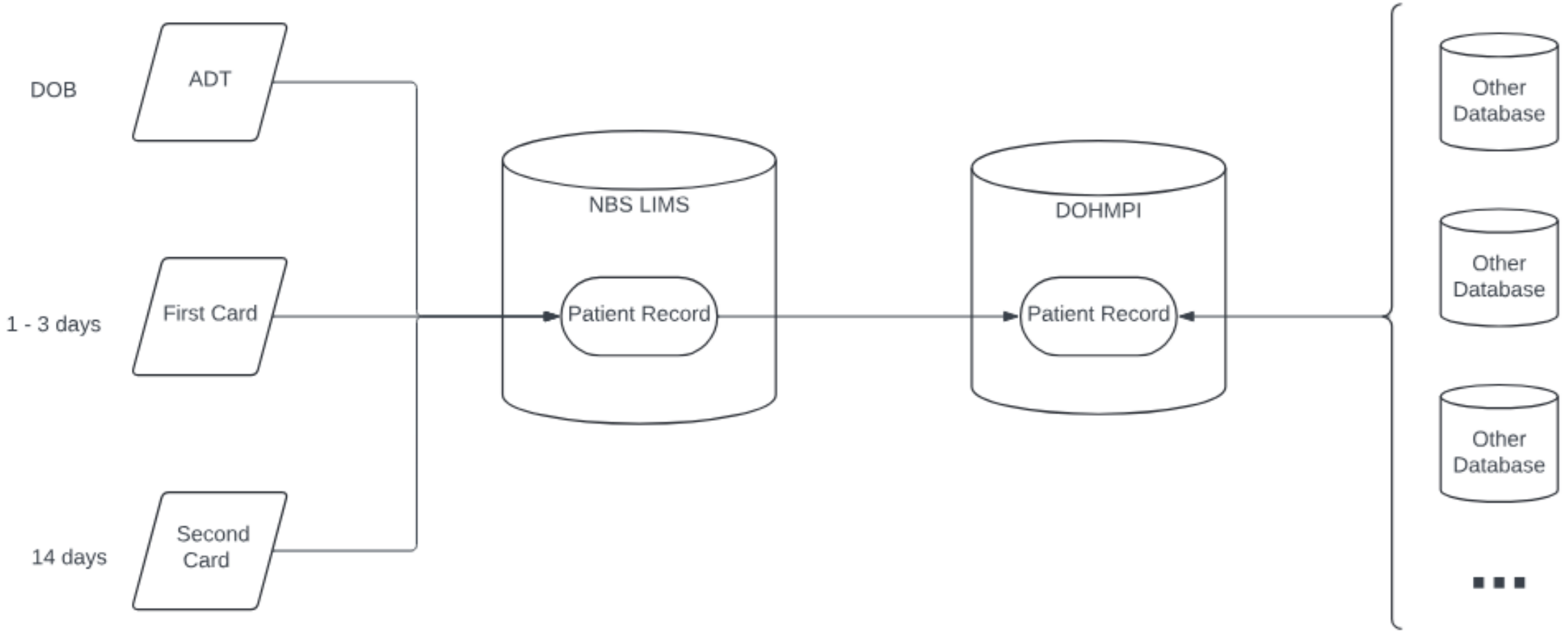
- NewbornScreeningNumber
- StateFileNumber
- MomLast
- MomFirst
- MomMiddle
- MomBirth
- MomPhoneAreaCode
- MomPhoneNumber
- ChildLast
- ChildFirst
- ChildMiddle
- BirthCCYY
- BirthMM
- BirthDD
- CityOfBirth

NBS integration benefits

- Reconcile our patient data with other organizations' data
- Identify babies that have slipped through the crack and have not had a newborn screen.

DHHS integration benefits

- Quicker access to patient data
- Updated patient information



Challenge: data reconciliation

Challenge: data reconciliation

- Coincide with ETOR project
- Card # is wrong
- Misc Card
- Baby doesn’t have a name yet
- Different parent information
- Twins
- Same/Wrong MRN #

Current Status

- **Completed**
  All data reconciliation and integration of NBS data has been built in our TEST and DEV systems. We are ready to move to PROD
- **Current task**
  Build the API for us to access the data
- **Remaining task**
  Write scripts to call the API and query and process the results

Questions

Discussion

- Questions for our presenters
- What is happening in your program?

Innovations in Newborn Screening Interoperability

A National Resource Center

NewSTEPs

A Program of the Association of Public Health Laboratories™

Thank you for joining us!

These programs are supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit HRSA.gov.