

Using Data Systems to Identify Deaf or Hard-of-Hearing in Newborns: Findings from a Scoping Review

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Disclosures

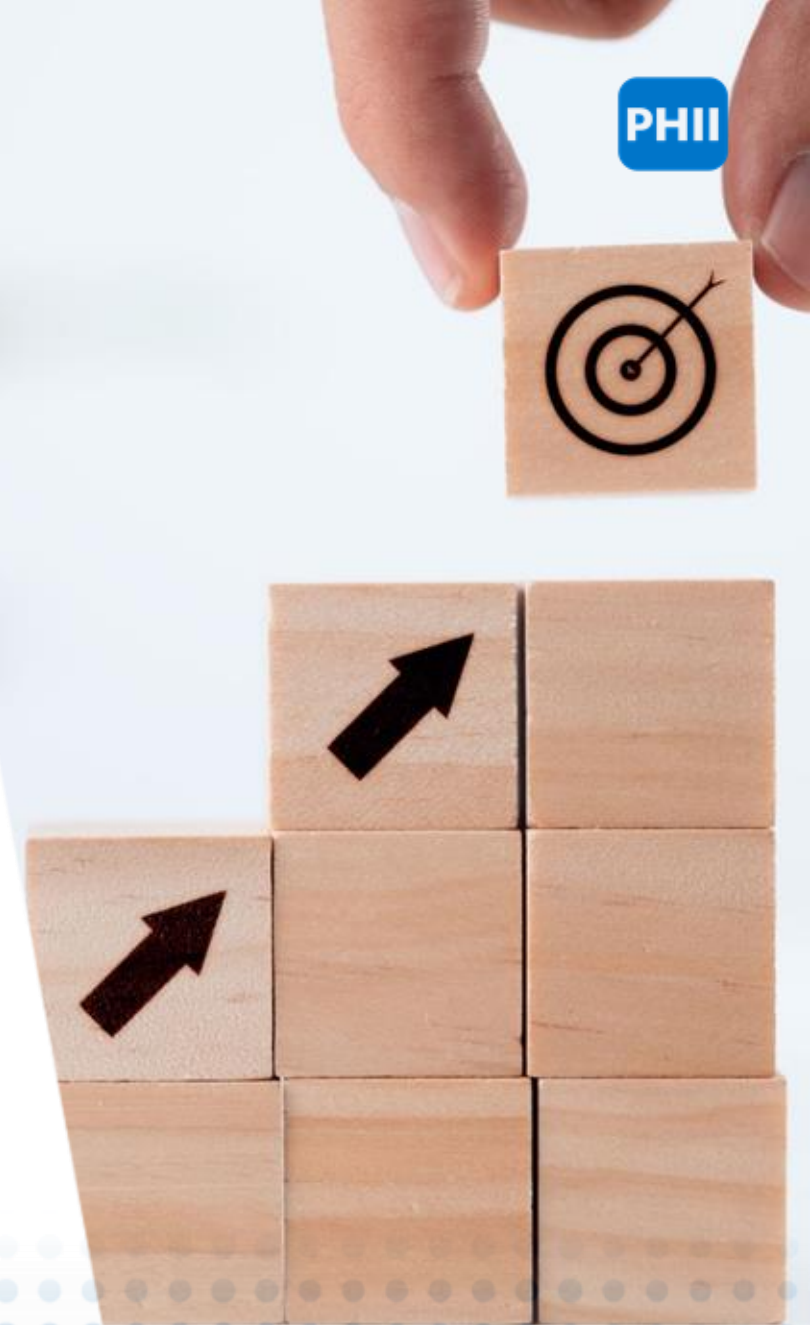
- The authors of this presentation are employed by an institution that receives funding from the Centers for Disease Control and Prevention (CDC).

Funding statement

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Session objectives

- The participant will be able to:
 - learn how public health agencies are incorporating early hearing data into integrated data capture systems.
 - understand which newborn screening services are using integrated data capture systems.
 - identify ways administrative databases, like Medicaid, can be used to assess hearing loss diagnosis in individuals aged 0-1 year.





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Background

PHII and project overview



The Task Force for Global Health overview



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What is public health informatics?



The **science** of how to use data, information, and **knowledge** to **improve** human health and the delivery of **healthcare services**.

*It's more about **people** and **systems** than **technology**.*

Project team

- Lura Daussat, Director of Practice Support
- Sarah Shaw, Senior Informatics Analyst
- Mondie Tharp, Project Manager



Background and significance

- In the United States, 1 in 500 babies are born deaf or hard of hearing (DHH) annually.
- **Critical Window:** Early identification and intervention within the first 6 months of life are essential for optimal speech, language, and social-emotional development.



The role of EHDI

- **The 1-3-6 Benchmarks:** Recommended national goals include screening by 1 month, diagnosis by 3 months and early intervention by 6 months.
- The outcomes for 1 in 4 newborns who do not pass their initial newborn hearing screening are unknown either due to lost to follow-up or documentation.





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Project scope



Project scope

- Perform a scoping review to assess data systems used to capture hearing loss for infants and to explore how integrated data capture systems and administrative databases may be leveraged to track hearing data and identify newborns who are DHH
- Develop a journal manuscript to report on gaps in the literature, promising practices, and recommendations for EHDI programs

Scoping review questions

- Which newborn screening services are using integrated data capture systems?
 - How are early hearing data included in these systems?
- How could administrative databases be used for assessing the diagnosis of hearing loss in individuals from birth to 6 months or 1 year of age?



Definitions

- An **integrated data capture system**, in this context, is defined as child health information systems that manage child health records and newborn screening services, such as EHDI, newborn bloodspot screening, critical congenital heart disease screening, and immunizations.
- **Administrative databases**, in this context, are defined as any systems that capture data on infants who are DHH, including electronic health records (EHRs), Medicaid, or all-payer claims databases.

Definitions

- **Early hearing data** is defined as any data used by EHDI programs, including but not limited to newborn hearing screening results, pediatric diagnostic results, and intervention outcomes. Hearing devices and amplification assistance should also be included. The term “early” in this context refers to the benchmarks tracked within the first 6 months of life (CDC, 2023). Timeliness for diagnosis will be considered at 3 months.



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Methods

Search strategy and selection of
sources

Search strategy

- Two reviewers with one tiebreaker
- Consultation with university librarian
- Different search approaches using same key word list
- Individual title and abstract review
- Collaborative review with consensus on all but one report

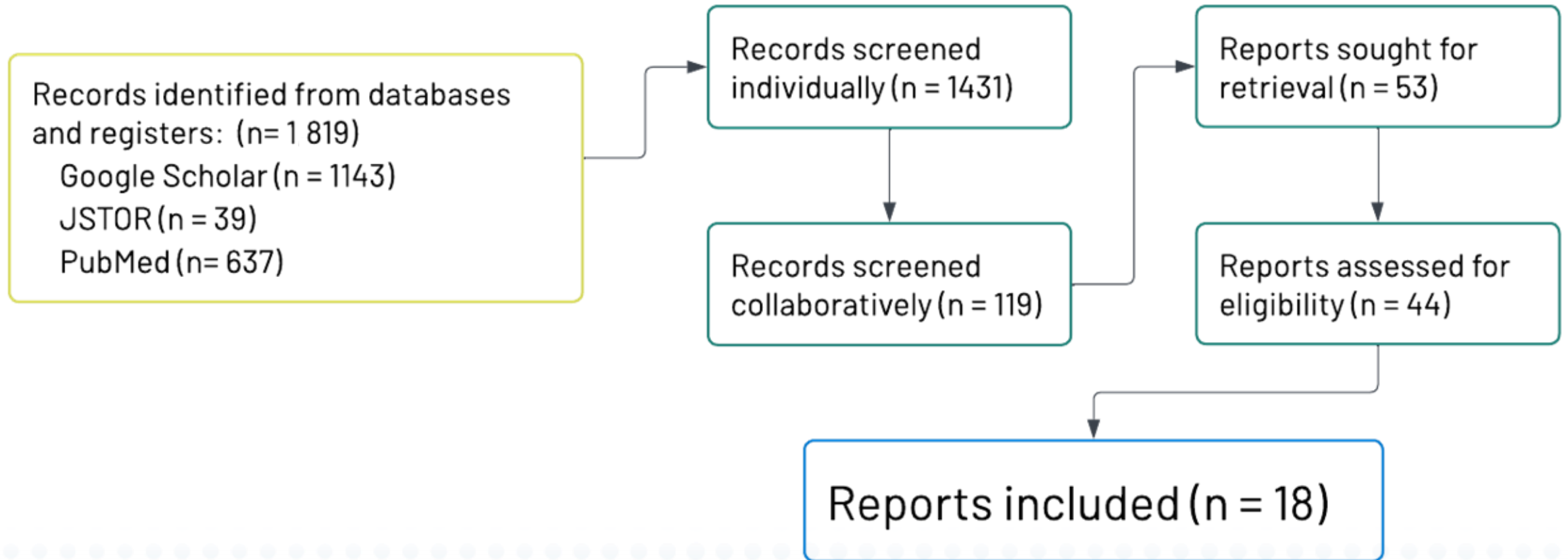
Inclusion and exclusion criteria

- **Context:** Materials in English prioritizing materials focused on findings, services, and systems within the United States, Tribal health systems, and territories.
- **Types of evidence sources:** Published peer-reviewed literature and unpublished materials, such as vendor promotional materials, EHDI websites, “grey” materials, and “white” papers.

Inclusion and exclusion criteria

- **Date range:** 2010 to present
- **Types of participants:** Individuals from birth to 6 months of age
- **Concept:** Explore integrated data systems with emphasis on the ability to capture hearing screening and diagnostic data

Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols (PRISMA-P) guidelines (Tricco et al, 2018)



Report spotlight

1. Tran, T. et al. (2016). ***Using Medicaid Data to Improve Newborn Hearing Screening Follow-Up Reporting: Results from a Pilot Study.***
2. Heins, S. et al. (2022). ***Linking Medicaid Claims, Birth Certificates, and Other Sources to Advance Maternal and Infant Health Final Report.***



Unpublished material search

Known Information Source*	Rationale
59 public health agencies EHDl program websites	Public health agency EHDl program websites contain details related to their data capture systems.
Actionable Intelligence for Social Policy from the University of Pennsylvania (AISP)	AISP's website includes a map and list of integrated data systems across public health.
National Center for Hearing Assessment and Management (NCHAM)	NCHAM houses the public health agency profiles for EHDl programs.
Newborn Screening Technical assistance and Evaluation Program (NewSTEPs)	NewSTEPs houses the public health agency profiles for newborn dried bloodspot screening programs with fields related to data integration.

* The EHDl conference website was identified as a missing information source.



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Results

Findings and recommendations



Results of scoping review question 1:

Which newborn screening services are using integrated data capture systems? How are early hearing data included in these systems?

Findings for integrated data capture systems

52 of the 59 public health agencies showed evidence of newborn screening services with integrated data capture systems as defined by the scoping review

49 of the 59 public health agencies incorporate early hearing data in an integrated system

Findings for integrated data capture systems

What types of integrated data capture systems are being used for early hearing data?*

- Combined systems = **7**
- Linked systems = **22**
- Combined and linked systems = **20**

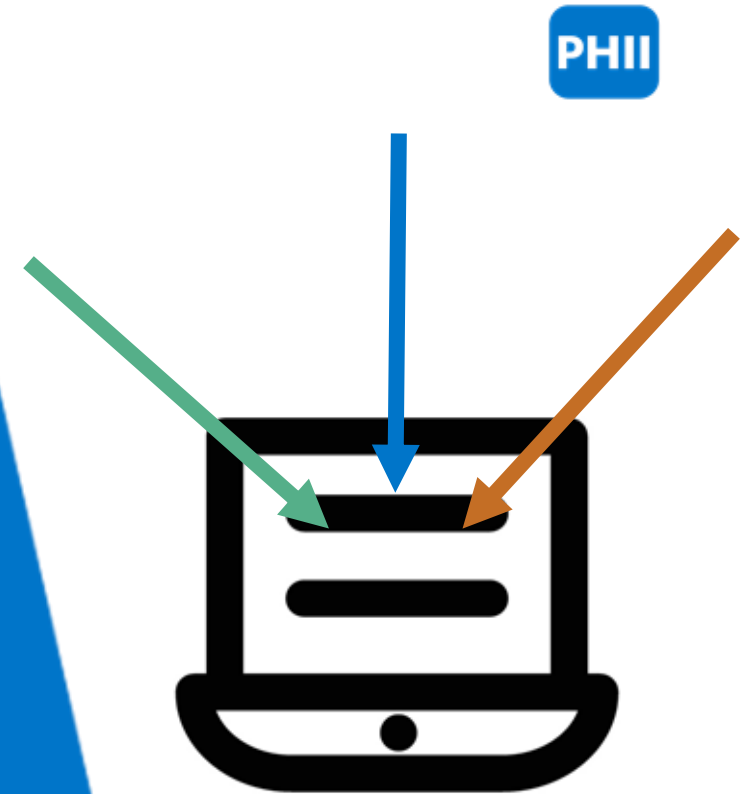
** The term “integrated data capture systems” is used to describe longitudinal databases for research and policy development. This system type did not align with the scoping review.*

Combined system

Description: Single system with data for multiple programs managed by access rights

Example: Indiana (IN)

- Home grown EHDI Alert Response System (EARS) is part of a larger system called the Indiana Department of Health's Gateway.
- Per NewSTEPs, Gateway houses data for newborn dried bloodspot, EHDI, CCHD, vital records, and birth defects.



Linked system

Description: EHDI-centric system that is connected to other data systems

Example: Louisiana (LA)

- LA EHDI's web-based data system uses HiTrack[®]
- Automated import from vital records within 24 hours of birth certificate registration and connected to Medicaid claims data (see *referenced report*).

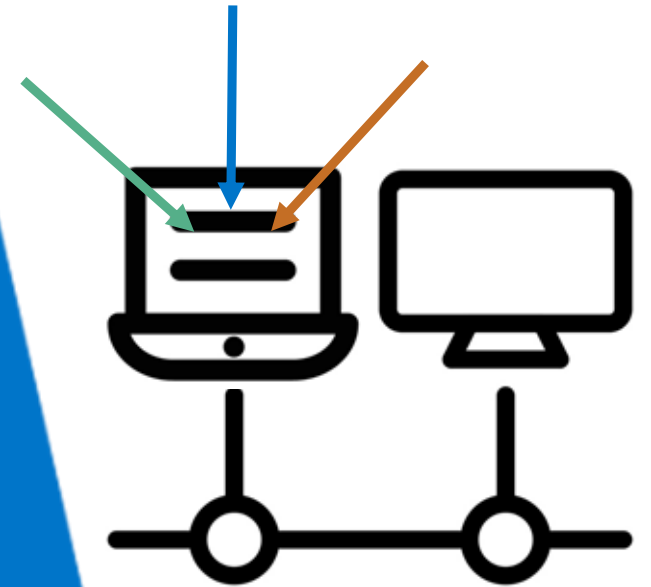


Combined & linked system

Description: Single system with data for multiple programs that is connected to other data systems

Example: Maryland (MD)

- MD EHDI's web-based data system, OZ eScreenerPlus (eSP)[®] houses data for hearing detection and intervention, birth defects, and CCHD.
- MD OZ eSP[®] links to both Medicaid claims and the state health information exchange.



Results of scoping review question 2:

How could administrative databases be used for assessing the diagnosis of hearing loss in individuals from birth to 6 months or 1 year of age?

Types of administrative databases

- **Public:**

- Medicaid
- All-payer inpatient care database
- National (Nationwide) Inpatient Sample (NIS)
- Kids' inpatient database

- **Private:**

- Health system medical claims billing data
- Agency for Healthcare Research and Quality's Healthcare Cost and Utilization Project (HCUP)

How can administrative data be used to assess hearing loss?

Evidence that administrative databases can be used

- to improve newborn hearing screening follow-up (Tran et al., 2016)
- to identify newborns who are DHH using ICD-10 codes (Ben Debba et al., 2024)(Campione et al., 2022)
- to identify patterns in developmental screening and diagnosis rates or explore patterns between factors that correlate with DHH diagnosis (Rouse et al., 2021)

How can administrative data be used to assess hearing loss?

Weaknesses of administrative databases

- Primary function is billing, not research or public health (Hashimoto et al., 2014).
- Coding errors and variations in coding practices may be seen (Jeong et al., 2024).
- Diagnosis of newborns who are DHH may be recorded, but the type of hearing loss may not be included (Jeong et al., 2024).

Project limitations

- Lack of project sponsor input
- Access to publicly available data only
- Limited stakeholder feedback
- Missing information source



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Closing thoughts

Recommendations, opportunities &
next steps

Recommendations

- **Terminology gaps:** Consider the use of a different term from "integrated data capture system" to avoid confusion with research-focused longitudinal databases.
- **Profile updates:** Regular updates to publicly available state profiles provide a place for EHDl programs to showcase their advancements without the need for a rigorous publication process.



Opportunities

- **Case identification:** Administrative data allows the use of ICD-10 codes (such as H90X for hearing loss) to identify a list of potential newborns who are DHH currently missing from EHDI records.
- **Provider details:** Linking with Medicaid data to identify new audiology providers who are not reporting and to see rates of diagnostic testing to prioritize communications.

Next steps for EHDI programs

- Review PHII's "Data systems to identify deaf or hard of hearing in newborns: a scoping review" white paper



Data systems to identify deaf or hard of hearing in newborns: a scoping review

White paper

December 2025

Authors

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Disclosures

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Funding statement

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Next steps for EHDI programs

- ❑ Participate in Council for State and Territorial Epidemiologists (CSTE) Community of Practice



Questions?





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Thank you!

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