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

White paper

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Authors
Lura Daussat
Sarah Shaw
Mondie Tharp

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Contact information
ldaussat@taskforce.org

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Acronymns

AISP	Actionable Intelligence for Social Policy at the University of Pennsylvania
CCHD	Critical congenital heart defects
CDC	Centers for Disease Control and Prevention
DBS	Dried bloodspot screening
DHH	Deaf or hard of hearing
EHDI	Early Hearing Detection and Intervention
HHS	Health and Human Services
HRSA	Health Resources and Services Administration
ICD	International Classification of Diseases
IDS	Integrated data system
LTD	Lost to documentation
LTFU	Lost to follow-up
NBS	Newborn screening programs
NCHAM	National Center for Hearing Assessment and Management
NewSTEPS	Newborn Screening Technical assistance and Evaluation Program
ONSTR	Ontology for Newborn Screening Follow-up and Translational Research
PRIMSA-P	Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocols

Executive summary

Early identification and intervention for infants who are deaf or hard of hearing (DHH) is critical for optimal developmental outcomes. Despite established benchmarks, infants who fail initial hearing screenings are often lost to follow-up (LTFU) or documentation (LTD). Combining data sources offers opportunities to increase the amount of data available to Early Hearing Detection and Intervention (EHDI) programs and improve tracking and follow-up for these infants. The extent to which EHDI programs are leveraging combined data sources remains unclear. This scoping review aims to identify gaps, promising practices, and propose recommendations for integrating new data sources for the timely identification of infants who are DHH.

The scoping review aimed to answer the following question using the Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocols (PRISMA-P) guidelines: 1a. Which newborn screening services utilize integrated data capture systems? 1b. How are early hearing data included in these systems? 2. How could administrative databases be used to assess hearing loss diagnosis in individuals from birth to 1 year of age? Eligibility criteria for the scoping review included English-language literature originating in the United States (US) or its territories from 2010 onwards, focusing on infants up to 12 months. Published and unpublished materials were sourced from electronic databases and a list of known information sources.

The review found evidence that 49 public health agencies incorporate early hearing data into integrated data capture systems, although the term "integrated" is being used in a variety of ways. The review identified existing connections between public health and administrative databases, including evidence of Medicaid data being used to identify cases of DHH in infants. However, verification is needed due to potential coding errors. Evidence shows that, even in a time of change and limited resources, EHDI programs have substantial potential to enhance the timely identification of newborns who are DHH by strategically using integrated data systems and administrative databases.

Definitions

For the purpose of the scoping review, the reviewers used the following definitions to guide their work:

- An **integrated data capture system** is defined as a child health information system that manages child health records and newborn screening services (e.g., EHDI, newborn bloodspot screening, critical congenital heart disease screening, or immunizations). Demographic data should not be de-identified to ensure records across different systems are complete and families can be contacted. These are often vendor-based systems or state-hosted systems.

- **Administrative databases** are defined as any systems that capture data on infants who are DHH, including electronic health records (EHRs), Medicaid, or all-payer claims databases.
- **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.

Background

In the United States (US), 1 in 500 babies are born deaf or hard of hearing (DHH) each year (CDC, 2024a). The Early Hearing Detection and Intervention (EHDI) program, administered by the Department of Health and Human Services (HHS), aims to ensure timely screening, diagnosis, and intervention for infants who are DHH (US GAO, 2025). Early identification and management of infants who are DHH is critical to children's developmental progress and outcomes. The failure to detect hearing impairment early can significantly impede the acquisition of speech, language, and social competencies, impacting academic achievements and social and emotional outcomes (Joint Committee on Infant Hearing, 2019). The sooner infants who are DHH are linked to early intervention services, the greater their chances of improving communication and social skills and reaching their full potential (CDC, 2024b).

Recognizing that the first 6 months of life are foundational for speech and language development, two HHS programs at the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA), established recommended EHDI benchmarks for public health agencies: screening by 1 month, diagnosis by 3 months, and early intervention by 6 months (NIDOCD, 2024). EHDI programs use data systems to track the 1-3-6 benchmarks and ensure infants receive timely care. In fiscal year 2024, there were 59 public health agencies funded by HHS to support EHDI program activities, including 50 states, 5 territories, 3 freely associated states, and the District of Columbia. Table 1 outlines the list of public health agencies funded for EHDI program activities by CDC or HRSA in fiscal year 2024. (HRSA,2024),(CDC, 2024c).

Table 1. List of public health agencies funded for EHDI program activities by the CDC or HRSA in fiscal year 2024

States	
All 50 US states	
Territories	**Freely Associated States**
American Samoa	Federated States of Micronesia
Commonwealth of the Northern Mariana Islands	Republic of Palau
Guam	Republic of the Marshall Islands
Puerto Rico	**Other**
US Virgin Islands	District of Columbia

In 2022, only 39.9% of infants who did not pass their hearing screening were diagnosed by 3 months of age (CDC, 2024d). Although the COVID-19 pandemic may have affected the timeliness of diagnosis in 2022, low diagnosis rates were present prior to the pandemic. In 2019, 49.0% of infants who did not pass their hearing screening were diagnosed by 3 months of age. One in four newborns who do not pass their initial newborn hearing screening are either lost to follow-up (LTF) and not receiving services, or lost to documentation (LTD), where EHDI programs cannot confirm those services have been completed (CDC, 2023).

Connecting data sources enables more comprehensive tracking and follow-up in the form of identifying missing contact information or electronically transmitting timely test results. While the value of integration and connected data sources has long been recognized (Downing et al., 2010), it is unclear how EHDI programs are leveraging these innovative efforts to expand the knowledge of outcomes across infant hearing screening and diagnosis. This paper presents scoping review results to identify gaps in EHDI data capture systems and to better understand strategies to improve the timely identification of infants and children who are DHH.

Objectives

Research questions were developed to guide the scoping review and report on gaps in the literature, promising practices, and recommendations for state EHDI programs. The questions were refined and a scoping review was conducted to answer the following questions systematically:

1. a. Which newborn screening services are using integrated data capture systems?

   b. How are early hearing data included in these systems?

2. How could administrative databases be used to assess hearing loss diagnosis in infants from birth to 1 year of age?

Methods

A scoping review protocol was drafted using the Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocols (PRISMA-P) (Tricco et al.,2018). There were three iterations of the protocol before it was finalized. There is no existing protocol for this topic, and the final protocol was not registered. This protocol was used to conduct the scoping review.

Eligibility criteria

The research team established specific eligibility criteria for both published peer-reviewed literature and unpublished materials, such as vendor promotional materials, "grey" materials, and "white" papers. The initial review included sources published from 2000 onward, aligning with the inception of the EHDI program in the US. Following a preliminary analysis, the review protocol was revised to include literature published from 2010 onward, reflecting the significant developments in EHR systems during that period. Only sources published in English and conducted within the US were considered; studies focused on populations outside the US were excluded. Included publications were required to be in print and not retracted. The review initially targeted infants from birth to 6 months of age; however, this range was later expanded to include infants up to 12 months of age, increasing the scope of the papers.

Information sources

The scoping review used a range of information sources, including electronic databases and registries such as PubMed, Google Scholar, and JSTOR, to identify relevant publications. Systematic searches of these databases were conducted between April 22 and June 2, 2025. In addition to peer-reviewed literature, targeted searches were performed across known information sources to identify unpublished

materials pertaining to EHDI data systems, commercial vendor resources for integrated data capture systems, and organizations recognized for their expertise in integrated data systems and data governance. Table 2 presents the organizations and websites used as information sources, along with the rationale for their inclusion.

Table 2. Organizations identified as known information sources for the scoping review on data systems to identify DHH in May 2025

Known information source	Website	Rationale
59 public health agencies' EHDI program websites	Variable	Public health agency EHDI program websites contain details related to their data capture systems.
Actionable Intelligence for Social Policy (AISP) at the University of Pennsylvania	https://aisp.upenn.edu/integrated-data-systems-map/	AISP's website includes a map and list of integrated data systems across public health.
National Center for Hearing Assessment and Management (NCHAM)	https://www.infanthearing.org/states/index.html	NCHAM houses the public health agency profiles for EHDI programs.
Newborn Screening Technical assistance and Evaluation Program (NewSTEPs)	https://www.newsteps.org/data-center/state-profiles?q=data-resources/state-profiles	NewSTEPS hosts the public health agency profiles for newborn dried bloodspot screening programs with fields related to data integration.

The EHDI program websites for the 59 funded public health agencies were considered a known information source (Table 1). To further look for integrated systems that captured hearing data, the team identified organizations that gather information on the status of systems being used for early hearing data capture. These organizations include Actionable Intelligence for Social Policy at the University of Pennsylvania (AISP), National Center for Hearing Assessment and Management (NCHAM), and Newborn Screening Technical assistance and Evaluation Program (NewSTEPs).

The team selected Zotero, an online tool, paired with Microsoft Excel to support citation management and Google Drive to store sources.

Search strategy

PHII identified two reviewers to perform the search strategy, with a third reviewer identified as the tiebreaker when there was a discrepancy in the sources selection. The reviewers worked collaboratively to iteratively adjust the key terms based on initial findings. The reviewers agreed on the following keywords alone or in combination for the search:

- newborn, infant
- early, birth to 6 months
- integrated, data capture, systems; administrative database; electronic health records; Medicaid; "ICD-10"
- capture; collect; track
- hearing screening; hearing results; hearing loss; hearing loss diagnosis; auditory brainstem response; tympanometry; otoacoustic emissions
- early hearing detection and intervention; EHDI-IS

The boolean operator "AND" was used to combine the keywords and narrow the search results. The two reviewers acted independently and developed individual search strategies based on the approved eligibility criteria and agreed upon key terms.

Reviewer 1 searched PubMed using different combinations of keywords along with search limitations on date range (2000 to present) and language (equal to English). Table 3 describes the keywords and combinations used in PubMed. PubMed did not find any sources with the keywords "integrated data capture system." Reviewer 1 then searched Google Scholar for the keywords and combinations of EHDI and database, and Administrative data and EHDI.

Table 3. Keywords and combinations used by Reviewer 1 to identify peer-reviewed sources in PubMed in May 2025 for the scoping review on data systems to identify DHH

EHDI and "administrative data"	"Hearing screening" and "administrative data"	Infant and early and "administrative database"
EHDI and database	"Hearing screening" and database	"Newborn hearing screening" and database
EHDI and "electronic health records"	"Hearing screening" and "electronic health records"	Newborn and early and "administrative database"

EHDI and Medicaid	"Hearing screening" and Medicaid	Newborn or infant and "administrative database"
EHDI and systems	"Hearing screening" and Medicaid or Medicare	Newborn and "hearing screening" and "data system"
Newborn and "integrated data capture" and hearing	"Hearing screening" and Medicare	Newborn administrative screening

Reviewer 2 created a comprehensive search string and entered the string into Google Scholar, JSTOR, and PubMed with search limitations on date range (2000 to present) and language (equal to English). The search string was as follows: (newborn OR infant OR neonatal) AND (hearing loss OR "hearing loss diagnosis" OR "hearing screening" OR "auditory brainstem response" OR tympanometry OR "otoacoustic emissions" OR EHDI) AND ("integrated data" "systems" OR "integrated data systems" OR "data systems" OR "administrative database" OR "electronic health records" OR Medicaid OR "ICD-10"). The search string yielded no results in JSTOR. Reviewer 2 performed limited targeted searches in JSTOR, including:

- "administrative database" infant hearing diagnosis
- ((((newborn) AND (hearing)) AND (diagnosis)) AND (EHR)).

Search of known information sources

Reviewer 2 searched content from the known information sources to find evidence in response to research questions 1a and 1b. To identify the websites from the 59 public health agencies, Reviewer 2 searched the following keywords in Google: "EHDI" AND "system" AND "<insert the name of the public health agency>". Reviewer 2 conducted searches across the websites using key terms outlined in the search strategy. Reviewer 2 searched the AISP "integrated data systems map" to assess the incorporation of newborn screening services and the use of early hearing data in the listed integrated data systems. Reviewer 2 reviewed the NCHAM state profiles and subsequent links, when available, for the most recent CDC and HRSA grant applications for the 59 public health agencies. Reviewer 2 searched the NewSTEPS website, which hosts state profiles that outline the practices for newborn dried bloodspot screening programs. Updated in April 2025, the state profiles list specific details related to health information technology that directly relate to the research questions 1a and 1b. Evidence of integrated data capture systems from across the known information sources were logged in Microsoft Excel.

Selection of sources of evidence

The scoping review's objective was to systematically map the available resources and evidence to answer questions on integrated hearing screening data and how administrative data is used to capture DHH. The original protocol included four phases of the screening process: 1) title and abstract review, 2) full text review, 3) reference article review, and 4) author consultations. Due to timeline constraints and the volume of sources yielded from the search strategy, the reviewers did not perform reference article reviews or author consultations.

Data charting process

Each reviewer independently performed a title and abstract review on the sources. The same source found in multiple databases was marked as duplicate, and the link to the PubMed source was retained. The reviewers standardized the selection process by using the same categories for ruling out irrelevant results and added additional categories for each review phase as appropriate. Table 4 outlines the categories used by the reviewers during the selection process.

Table 4. Values used to categorize and subcategorize the sources in different phases of the scoping review on data systems to identify DHH

Values from individual review of title and abstract	Values from collaborative review of abstract	Values from full text review
Duplicate	Duplicate	Duplicate
Further review needed	Further review needed	Admin data – review of the use of claims more generally
Passed to abstract phase	Passed to full text review phase	Admin data – specific studies of using large admin databases
Ruled out – not in the date range	Ruled out – not in the adjusted date range	Directly applies and requires a detailed full review
Ruled out – not in the US	Ruled out – not in the US	General EHDI resources for full text review

Ruled out – not related to newborns	Ruled out – not related to newborns	Integrated system – proof of EHDI integration
Ruled out – not related to use of systems	Ruled out – not related to use of systems	Integrated system – proof of general integration
Ruled out – title has no relevance to the topic	Ruled out – not related to use of systems for tracking and monitoring hearing-related outcomes	Integrated system – proof of non-integrated system
Not retrievable		Ruled out after full text review – not in the adjusted date range
Withdrawn		Ruled out after full text review – not related to newborns
		Ruled out after full text review – not retrievable
		Ruled out after full text review – no evidence of integration or use of admin databases

The categories aligned with the eligibility criteria. Results that moved to the next phase of the selection process were marked "Passed" or "Further Review Needed" based on their alignment with the eligibility criteria.

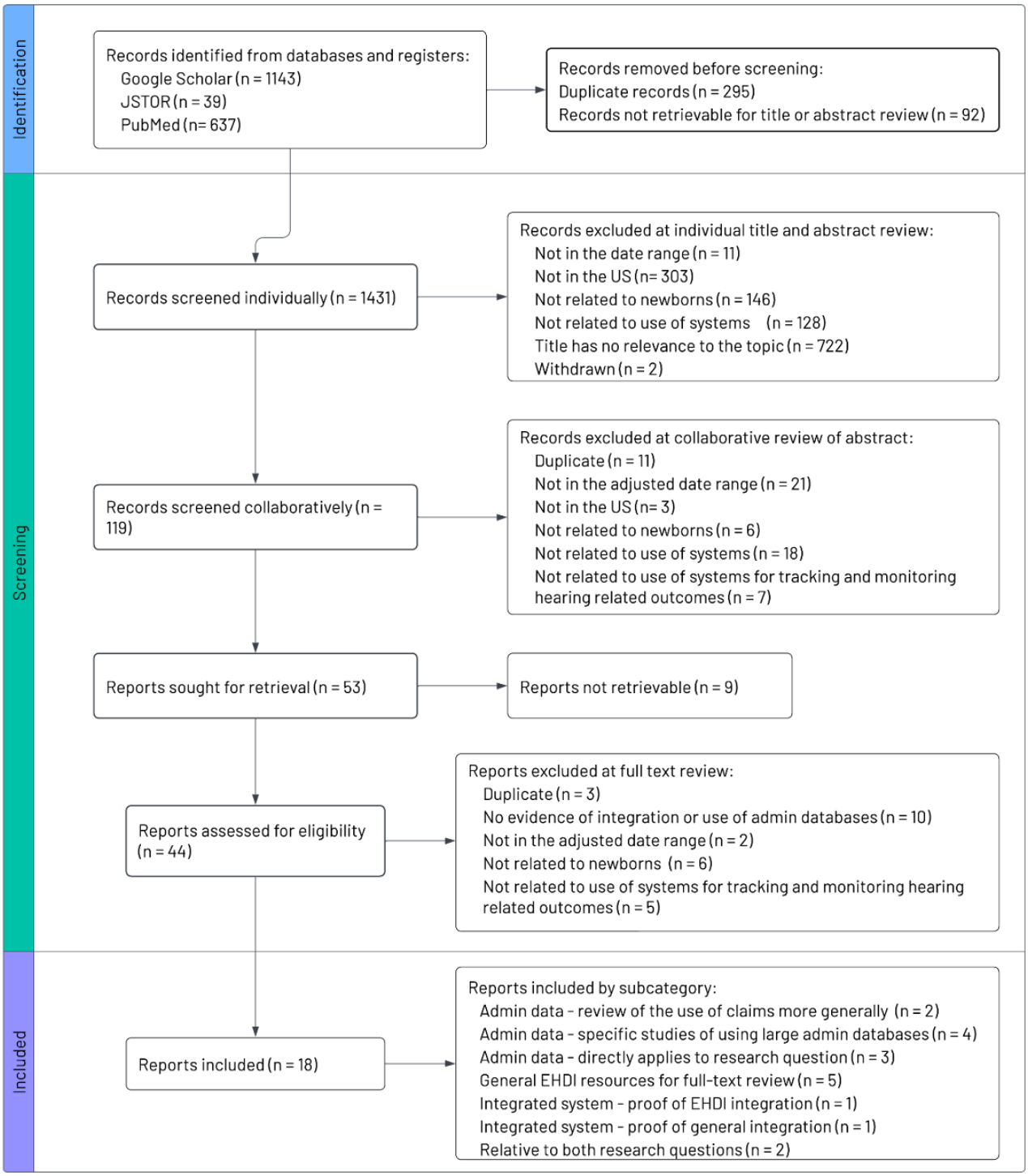
Once each reviewer completed the title and abstract review, a comprehensive list of all sources that moved to full text review was compiled. Duplicates within the list were reduced to one entry and marked for full text review. Each reviewer then performed the collaborative abstract review phase on the selected sources from the other reviewer. Once each reviewer had completed their review of the abstracts, the comparisons were made between them. The title and abstract review used the inclusion date range of 2000 to present. To reduce the number of selections and in recognition of the advancements in technology between 2000 and 2010, the selection process increased the date range from 2010 to the present. The reviewers could not agree on how to proceed for one article, and the tiebreaker reviewer was brought in to make the final decision, and determined that the result would move on to the full text review. When the team downloaded the full text of an article, nine publications were marked unretrievable in the following circumstances: the website no longer existed, the report

required direct payment, the report required a membership, or the report was retracted. These articles were not included in the final results.

Synthesis of results

For this scoping review, 44 reports were included in the full text review. From those reports identified, two reports did not meet the adjusted date range, three reports were found to be duplicates, six reports were removed because the patient population was out of the age range, and 15 additional reports were removed from the list because they did not show evidence of use of systems for early hearing data, integration or administrative data. The reviewers identified 18 reports that passed all eligibility criteria and were reviewed as part of the analysis. The team added additional categories for full text review to group the sources by research question and assist with the synthesis and selection process. Figure 1 outlines details of the search and data charting process using the PRISMA-P flowchart.

Figure 1. Data charting process using the PRISMA-P flowchart



Synthesis of known information sources

The synthesis of the unpublished information sources involved logging evidence to support research question 1a and 1b in Microsoft Excel. Reviewer 2 logged the EHDI websites identified for each funded agency and any evidence of integrated data systems. After a thorough review, the systems identified on the AISP website were deemed out of scope for this scoping review. Reviewer 2 logged the responses to the following key questions in the NewSTEPS state profiles as evidence of integrated data capture systems in newborn screening programs (NBS): "What databases are integrated with NBS Information Systems?" and "How are hearing results integrated with DBS results?"

The NCHAM website search identified copies of EHDI program grant applications to CDC and HRSA. Reviewer 2 added each grant application found on NCHAM's website into Google Gemini to assist in the synthesis of the content. The prompt, "Please review this attached narrative and search for evidence of data integration between systems," was used to assess evidence of integrated data capture systems. The output was a bulleted list describing the types of integrations outlined in the grant applications. The use of artificial intelligence (AI) was solely for initial sorting and prioritization. Evidence of integration was verified and cited by Reviewer 2. When Google Gemini flagged the possibility of integration, Reviewer 2 verified and documented the page number and specific narrative text within the grant application that aligned with the findings. Reviewer 2 did not encounter any inaccuracies in the findings from the Google Gemini review process.

In addition to the known information sources for researching the use of early hearing data in integrated data capture systems, the scoping review identified a published report, "Linking Medicaid Claims, Birth Certificates, and Other Sources to Advance Maternal and Infant Health" (Heins et al., 2022) that summarized findings on the use of Medicaid claims data by public health agencies and provided a comprehensive list of linkages between Medicaid and specific public health programs, including newborn hearing screening. The report compiled findings from a literature review, an inventory of state efforts using Title V grant applications, and a series of focus group interviews with subject matter experts.

Results of scoping review

The team identified five reports relevant to the scoping review by providing background information on EHDI programs and the foundational work done to improve data collection and follow-up efforts. Table 5 outlines the reports classified as general EHDI resources.

Table 5. Reports related to general EHDI resources

Publication year	Title	Journal/book	Authors	Data extracted
2010	Enhancing the quality and efficiency of newborn screening programs through the use of health information technology	Seminars in Perinatology	Downing, G.J., Zuckerman, A.E., Coon, C., & Lloyd-Puryear, M.A.	Makes a case for integrated systems.
2011	Achieving optimal outcomes from EHDI	The ASHA Leader Archive	Yoshinaga-Itano, C.	Provides recommendations including comprehensive data systems.
2013	ONSTR: The Ontology for Newborn Screening Follow-up and Translational Research	International Conference on Biomedical Ontology	Snezana, N., Prabhu, S., Sivaram, A., Akshaye, D., Rajshekhar. S., Sham. N., Kunal. M., & Rani, H. S.	Defines newborn screening systems as critical congenital heart defects (CCHD), hearing, and bloodspot.
2016	Progress in Standardization of Reporting and Analysis of Data from Early Hearing Detection and Intervention (EHDI) Programs	Journal of Early Hearing Detection and Intervention	Alam, S., Satterfield, A., Mason, C. A., & Deng, X.	Discusses the use of standards to capture early hearing data from healthcare systems.
2018	Measuring Early Hearing Detection and Intervention (EHDI) Quality across the Continuum of Care	The Journal of Electronic Health Data and Methods	Deng, X., Finitzo, T., & Aryal, S.	Discusses creation of Clinical Quality Measures and their potential use in monitoring effectiveness of EHDI programs using EHR data.

Table 6 outlines the reports that were classified as relevant to research question 1a. Which newborn screening services are using integrated data capture systems? and 1b. How are early hearing data included in these systems?

Table 6. Results of individual sources of evidence related to research question 1a and 1b of the scoping review on data systems to identify DHH

Publication year	Title	Journal/book	Authors	Data extracted
2022	Linking Medicaid Claims, Birth Certificates, and Other Sources to Advance Maternal and Infant Health	Office of the Assistant Secretary for Planning and Evaluation	Heins, S., Predmore, Z., Hoch, E., & Baxi, S.	Newborn screening linkages for 39 jurisdictions and Medicaid data reported. Evidence of linked data systems using early hearing data.
2017	Establishing a Standard Data Model For Large-Scale IDS Use	Actionable Intelligence for Social Policy	Wulczyn, F., Clinch, R., Coulton, C., Keller, S., Moore, J., Muschkin, C., Nicklin, A., LeBoeuf, W., & Barghaus, K.	Clearly outlines how public health is using the term integrated data system in conjunction with longitudinal databases used for policy and research. The list of data sources does not include early hearing data and therefore does not align with the definition in the scoping review.
2016	Using Medicaid Data to Improve Newborn Hearing Screening Follow-Up Reporting: Results from a Pilot Study	Journal of Healthcare Communications	Tran, T., Wang, H., Smith, MJ., Soto, P., Ibieta, T., Peat, M., & Berry, S.	Medicaid data can be linked with EHDI data to enhance follow-up reporting and improve communication with providers. Evidence of a linked system using early hearing data in Louisiana.
2014	Linking Maine Department of Education and Maine Department of Health and Human Services Early Childhood Data	Maine Education Policy Research Institute	Mason, C., Tu, S., & Song, Q.	Evidence of the value of linkages to early hearing data and the benefits of tracking outcomes. Evidence of a linked system in Maine.

Table 7 outlines the sources that were classified as relevant to research question 2: How could administrative databases be used to assess hearing loss diagnosis in individuals from birth to 6 months of age or up to 1 year of age?

Table 7. Results of individual sources of evidence for research question 2 of the scoping review on data systems to identify DHH

Publication year	Title	Journal/book	Authors	Data extracted
2014	Administrative database studies: goldmine or goose chase?	Evidence-Based Spine Care Journal	Hashimoto, R.E., Brodt, E.D., Skelly, A.C., & Dettori, J.R.	Strengths and limitations of administrative data.
2016	Using Medicaid Data to Improve Newborn Hearing Screening Follow-Up Reporting: Results from a Pilot Study	Journal of Healthcare Communications	Tran, T., Wang, H., Smith, MJ., Soto, P., Ibieta, T., Peat, M., & Berry, S.	Medicaid data can be linked with EHDI data to enhance follow-up reporting and improve communication with providers.
2017	Nonadherence to Guideline Recommendations for Tympanostomy Tube Insertion in Children Based on Mega-database Claims Analysis	Journal of Otolaryngology Head and Neck Surgery	Sajisevi M., Schulz K., Cyr D.D., Wojdyla D., Rosenfeld R.M., Tucci D., & Witsell D.L.	Hearing test and hearing loss codes are recorded in claims data, although there is often variability in how physicians code. Defined a "mega-database."
2019	Pediatric population health analysis of southern and central Illinois region: A cross-sectional retrospective study using association rule mining and multiple logistic regression	Computer Methods and Programs in Biomedicine	Buxton, E. K., Vohra, S., Guo, Y., Fogleman, A., & Patel, R.	Health systems often have administrative data that can be used to assess population-level problems or risk factors. However, they do not contain patient identifiable information, so administrative data from medical billing may not be useful for follow-up.

2020	Neonatal Abstinence Syndrome (NAS) and Infant Hearing Assessment: A Kids' Inpatient Database Review	Journal of Early Hearing Detection and Intervention	Creel, L., Van Horn, A., Hines, A., & Bush, M. L.	Databases like the Kids' Inpatient Database (KID) can be used to review diagnostic and procedure codes. This article includes the International Classification of Diseases (ICD)-10 codes used to identify a failed newborn hearing screening and diagnosed hearing loss. This article also discusses how risk factors can be reviewed from aggregated data.
2021	Developmental impacts of the COVID-19 pandemic on young children: a conceptual model for research with integrated administrative data systems	International Journal of Population Data Science	Rouse, H. L., Shearer, R. J. B., Idzikowski, S. S., Nelson, A. H., Needle, M., Katz, M. F., Bailey, J., Lane, J. T., Berkowitz, E., Zanti, S., Pena, A., & Reeves, M.	Use of administrative databases to identify patterns in developmental screening and diagnosis rates or to track the provision of early intervention services for children.
2022	Linking Medicaid Claims, Birth Certificates, and Other Sources to Advance Maternal and Infant Health	Office of the Assistant Secretary for Planning and Evaluation	Heins, S., Predmore, Z., Hoch, E., & Baxi, S.	Newborn screening linkages for 39 jurisdictions and Medicaid data reported.
2022	Missing diagnoses of congenital cytomegalovirus infection in electronic health records for infants with laboratory-confirmed infection	Current Medical Research and Opinion	Campione, A., Lanzieri, T.M., Ricotta, E., Grosse, S.D., Kadri, S.S., Nussenblatt, V., & Prevots, D.R.	Cytomegalovirus (CMV) is a risk factor for hearing loss and the codes for CMV can be queried in administrative data.
2024	Documented Newborn Hearing Screenings in	Journal of Early Hearing	Anthony, T., Barrett, B, Brown, A, & Ryan, J.	Claims data on newborn hearing screening is not regularly

	Florida Administrative Hospital Data: State Policy Compliance by Hospital Types	Detection and Intervention		documented. Policy should encourage documentation of hearing screening data in hospital administrative data. The low rate of data recording is not reflective of the care the hospital provides.
2024	Clinical and economic burden of otitis media in children under 5 years of age in the United States: A retrospective study	Human Vaccines & Immunothera-peutics	Ben Debba, L., Derreumaux, D., Lonnet, G., Taddei, L., & Scherbakov, M.	Confirmed codes that could be used include: ICD-10 codes (H90X and all the subcategories are used for conductive and sensorineural hearing loss).
2025	Associations between retinopathy of prematurity and the risks of hearing loss: A propensity matched analysis	International Journal of Pediatric Otorhinolaryn-gology	Jeong, H., Cleveland, C., & Otteson, T.	Administrative data weaknesses include hearing loss diagnosis, but not the type. In addition, administrative data may include coding errors or variations in coding practices and differences in diagnostic codes and billing codes for hearing loss evaluation.

Summary of evidence for research question 1 a. Which newborn screening services are using integrated data capture systems? 1b. How are early hearing data included in these systems?

Multiple newborn screening services are using integrated data capture systems. Before addressing the research questions, it is necessary to address the use of the term "integrated data capture system" across public health. When comparing the sources of evidence and the findings from known information sources, the research team identified five different uses for the term "integrated data capture systems." Table 89 outlines the five ways the term integrated data capture system is used across public health and their alignment with the scoping review definition.

Table 8. The 5 types of integrated data capture systems

Description	Model in EHDI context	Alignment with scoping review definition	Abbreviated name
A location for gathering data from multiple systems across agencies is used for research, policy making, and public-facing dashboards	Compiled data from multiple systems across agencies	Does not align	Longitudinal databases
A single system with line-level data on individuals that includes details for multiple conditions	Single system with user-based access to details on multiple public health programs	Aligns	Combined system
A single system that leverages data linkages to other systems to improve data completeness and continuity of care	EHDI-centric system with data linkages to other systems	Aligns	Linked system
A combined system that leverages data linkages to other systems	Single system with user-based access to details on multiple public health programs, as well as linkages to other systems	Aligns	Combined and linked system
A single system that includes all aspects of the hearing detection and intervention process from screening to diagnosis to intervention	EHDI-centric system does not link to other systems	Does not align	EHDI-centric system

Longitudinal databases

The AISP publication "Establishing a Standard Data Model For Large-Scale IDS Use" outlines integrated data systems (IDS) as primarily longitudinal databases that gather data from multiple systems across government agencies for research, policy making, and public-facing dashboards (Wulczyn et al., 2017). Longitudinal data systems compile data from various other sources, potentially including the systems used to store early hearing data. An example of a longitudinal database is the Oregon Child Integrated Dataset, which captures data on children from birth to high school to inform policy (OHSU,2020). The system includes data from different state agencies, including the public health agency. Early hearing

data are not originally stored within longitudinal data systems in public health agencies. This definition of integrated data systems does not align with the definition used in the context of this scoping review.

Combined systems

There is evidence of public health agencies using a single system with demographics alongside detailed data for multiple public health programs. Based on specific access rights, the user may be able to see details on early hearing data alongside vital records, dried bloodspot or critical congenital heart defects (CCHD) results in the same system. An example of a single system integration of demographics and user-based access can be found with Indiana's tracking system that houses data for newborn dried bloodspot, EHDI, CCHD, vital records, and birth defects (NewSTEPs, 2025). Multiple states house their early hearing data within their vital records systems, such as Arkansas (Arkansas Infant Hearing Program, 2024) and Missouri (Missouri Department of Health and Senior Services, 2019). For the purpose of this scoping review, a single system with line-level data on individuals that includes details for multiple conditions is designated as a combined system.

Linked systems

Another way integration occurs is through a program-centric system specifically designed to capture and track early hearing data that links to other systems to improve data completeness and continuity of care. Louisiana has a linked system, where the EHDI system is connected with vital records through an automated import within 24 hours of birth certificate registration (Louisiana Early Hearing Detection and Intervention, 2019). In addition, Louisiana has linkages between newborn hearing screening programs and Medicaid claims data as outlined in the referenced Medicaid report. Further details on the results of a pilot study conducted by Louisiana EHDI to identify newborns who are DHH using Medicaid claims data are in the discussion section on the second research question (Tran et al., 2016). For the purpose of this scoping review, a single system that leverages data linkages to other systems to improve data completeness and continuity of care is designated as a linked system.

Combined and linked systems

Evidence indicates that public health agencies are using a single system with data for multiple conditions and additional data linkages to other internal or external systems, such as birth certificates or health information exchanges. For the purpose of this scoping review, a single system with multiple conditions that is linked to other systems is called a combined and linked system. An example of this is Maryland's combined system that houses data for hearing detection and intervention, birth defects, and CCHD (Green, T., 2017). The referenced Medicaid report identified Maryland as linking Medicaid claims to

their newborn hearing screening program. The search of Maryland EHDI websites identified a linkage to the state health information exchange (CRISP, 2023).

EHDI-centric systems

The research showed a final way the term "integrated" is being used within EHDI programs. A system is referred to as integrated when it includes all aspects of the hearing detection and intervention process, from screening to diagnosis to intervention. This definition does not align with the definition used in context with this scoping review.

The team determined that a public health agency showed evidence of an integrated data capture system if any of the information sources noted integration or linkages with any newborn screening service that were in alignment with the scoping review. The team further quantified the number of public health agencies that incorporated early hearing data by noting which information sources specifically identified an integration or linkage to early hearing data. The results for linkages to early hearing data were further stratified by the type of systems defined for the purpose of this scoping review as combined, linked, and combined and linked to provide more context on how integration is occurring. Table 9 provides the number of public health agencies that showed evidence of integration as defined by research questions 1a and 1b.

Table 9. Summary of evidence of integrated data systems in public health agencies

How many public health agencies are using integrated data capture systems as defined by the study?	
Evidence	52
No evidence	7
How many public health agencies incorporate early hearing data in an integrated system?	
Evidence	49
No evidence	10
What types of integrated data capture systems are being used in the 49 agencies who showed evidence of incorporating early hearing data?	
Combined systems	7

How many public health agencies are using integrated data capture systems as defined by the study?	
Linked systems	22
Combined and linked systems	20

Summary of evidence for research question 2: How could administrative databases be used to assess hearing loss diagnosis in individuals from birth up to 1 year of age?

Administrative databases gather data on large patient populations and have been used for clinical research and health services, providing data on healthcare visits, diagnoses, procedure volumes, and length of hospital stays. (Hashimoto et al., 2014). The literature review suggested that administrative databases can be used for the identification of newborns who are DHH. Findings suggest that integrated administrative databases could be used to identify patterns in developmental screening and diagnosis rates or explore patterns between factors that correlate with DHH diagnosis (e.g., premature birth and maternal health conditions) and the health diagnoses (Rouse et al., 2021). The same study showed potential for administrative databases to track the provision of early intervention services for children.

What do administrative databases capture?

Administrative databases can record whether a newborn hearing screening was conducted, tracking the initial identification of individuals needing follow-up. However, some studies show that newborn hearing screening is not always documented in administrative data (Anthony et al., 2024). Medicaid can provide data on population coverage and allows linkage to other data sets (Hashimoto et al., 2014). Multiple studies searched administrative databases using ICD-10 codes to identify patients who were DHH in search of correlations to conditions causing hearing loss such as otitis media (Ben Debba et al., 2024) or cytomegalovirus (CMV) (Campione et al., 2022). A study from Louisiana successfully used Medicaid data to improve newborn hearing screening follow-up by identifying providers who had high rates of LTF or LTD (Tran et al., 2016). The study resulted in improved communication between the Louisiana EHDI program and providers and found that data linkages with Medicaid data could improve the timeliness of providers' reporting follow-up data.

Where does administrative data come from?

Administrative data can come from a variety of publicly available sources or private claims databases. Publicly available databases include Medicaid or an all-payer inpatient care database. The National (Nationwide) Inpatient Sample (NIS) is a sample of data and not all-inclusive, as it only takes 20% of patients admitted to community hospitals. (Hashimoto et al., 2014). Another available database is the Kids' Inpatient Database (KID), a part of the Healthcare Cost and Utilization Project developed through a partnership supported by the Agency for Healthcare Research and Quality. There are also commercial databases to analyze claims data (Sajisevi et al., 2017). Some health systems also have medical billing claims data that can be used to identify the diagnosis of DHH at the population level, but often do not include identifiable data (Buxton et. al, 2019). Administrative data from billing claims databases may not be helpful to EHDI programs trying to reduce LTF or LTD as they cannot track down patients with information from these systems because the records are de-identified.

Another study indicated that results from newborn hearing screening and DHH diagnosis can be identified in a database developed by the Agency for Healthcare Research and Quality's Healthcare Cost and Utilization Project (Creel et al, 2020). This database captures information on newborn hearing screening results and the diagnosis of DHH during the inpatient birth admission.

Weaknesses of administrative data

Administrative data also has some weaknesses. Administrative databases may contain coding errors and variations in coding practices (Jeong et al., 2024). The same study noted that diagnosis of DHH may be recorded in an administrative database, but the type of hearing loss may not be included. When trying to identify what types of hearing loss are occurring in the population, administrative databases may not provide a comprehensive view. Administrative data is gathered primarily for billing purposes and alternative uses for research or public health may encounter inaccuracies (Hashimoto et al., 2014). Newborn hearing screening systems may have access to administrative data, specifically Medicaid data. However, it is unclear how the programs are leveraging the connections to administrative data to support the identification of DHH populations (Heins et al., 2022).

Limitations

Limitations of the review included not having access to primary sources. The reviewers did not have an opportunity to validate the findings with known information sources, such as the EHDI program coordinators at the public health agencies. In addition, the CDC EHDI team was eliminated from the federal workforce during this project. This meant that the team's inquiries could not be answered by the

subject matter experts who developed the questions. The team did share initial findings on calls with EHDI program staff, where limited commentary and feedback was provided; however, not being able to validate findings was a significant limitation.

All findings from the scoping review were based on publicly available data. Evidence of integrated systems was found in sources dating back to 2014. The team acknowledges the limitation that systems may have been updated since these publication dates. There is a clear gap between what is published and what is currently in place for many public health agencies. In anticipation of this gap, the project's original scope included a stakeholder input component, with focus groups and key informant interviews, to validate findings. Due to time constraints and CDC EHDI program changes, the project's stakeholder input section was limited to two webinar presentations. The second presentation was at the end of the project and did not allow time to incorporate feedback into the draft manuscript.

Conclusion

The wealth of data housed in public health and healthcare systems can be connected to improve population health. The use of integrated data can improve early hearing detection and trend monitoring by providing more timely information for follow-up and connection to services. Follow-up efforts to identify newborns who are DHH can benefit from connecting to existing data sources, either by storing early hearing data within the same system or accessing other sources through data linkages.

Integrated data capture systems

Evidence suggests that the majority of EHDI programs in public health agencies use an integrated data capture system as defined by this scoping review. This review also found that there is a need to standardize terminology related to "integrated data capture systems" across public health programs, as this work identified five different uses of the phrase. When public health is advocating for additional resources or the sharing of data to create an integrated system, the variation in terminology may confuse leadership and EHDI program staff. Because the term "integrated data capture system" is tied to longitudinal systems and their supporting infrastructure, there is a need to identify a new name for the systems EHDI programs are seeking to build.

Administrative data

The widespread linkage of Medicaid claims with newborn hearing screening data demonstrates the potential to use administrative data to follow up on screening results and identify related diagnostic evaluations and services. This would allow for the assessment of diagnoses for newborns who are DHH

within these datasets. There is potential in using administrative databases to identify cases of DHH using ICD-10 codes, with the understanding that the findings need to be verified due to coding errors and variations in coding practices. In a time of change and limited resources, administrative databases can be a tool to improve follow-up efforts and potentially reduce LTF and LTD rates. Consideration of how to leverage administrative data to identify newborns who are DHH should be pursued using the identified sources in Table 8 as a starting point.

Appendix A

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