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Health and Welfare

Environmental scan and assessment of the feasibility of developing a national neonatal hearing screening data collection

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Canberra

Catalogue number PER 125

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About this report

From June 2022 to February 2023, the Australian Institute of Health and Welfare (AIHW) was contracted by the Commonwealth Department of Health and Aged Care (Health) to undertake an assessment of the feasibility of building a national data collection regarding neonatal hearing screening in Australia.

In February 2023, the AIHW submitted this report to Health to provide advice on current neonatal hearing screening collections and/or practices across states and territories, and the environment for establishing a national data collection, including determining the scope of a national collection; analysis of currently available national data; and recommended next steps.

This project was overseen by Jacqueline Rek and Bernice Cropper from the Maternal and Perinatal Health Unit at the AIHW.

The Contract Liaison Officer for Health was Michael Crowther, Director, Hearing Policy and Compliance.

The AIHW gratefully acknowledges the following representatives from the state and territory neonatal hearing screening programs who provided valuable input regarding the programs, practices, and data availability in their jurisdiction:

- Sarah Morton and Stephanie Blows (New South Wales)
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- Amarjit Anand, Rebecca Matthews and Sarah Yuen (Northern Territory).

Executive summary

All Australian states and territories have universal neonatal hearing screening programs. However, there is no standardised national data collection to support the measuring of screening delivery and outcomes from these programs.

The aim of this report is to describe current neonatal hearing screening data collections and/or practices across states and territories, and the environment for establishing a national data collection.

A national data collection is an agreed set of specifications to collect data for a particular purpose. An Australian national data collection for neonatal hearing screening would improve the availability and quality of data, allowing for consistent measurement, reporting, and benchmarking for programs and outcomes nationally and internationally.

To build a successful national data collection, consistency and standardisation in data collection methods and agreed definitions are required. While there are challenges arising from differences in program practices and data collection across the states and territories, there is an opportunity to develop a national neonatal hearing screening data collection that would, initially, collate data on demographics and hearing screening for all liveborn babies, and could be built upon further to include data items on diagnostic audiological assessment, identifiers (to aid data linkage), early intervention, and risk factors. Stakeholders, including representatives from all states and territories, should be engaged to develop and work towards consistent national data standards.

The AIHW is well positioned to govern a national data collection on neonatal hearing screening and welcomes the opportunity to play a key role in developing, collating, validating, analysing, and reporting neonatal hearing screening data as part of a national data collection.

Key recommendations

1. The development of an Australian national data collection for neonatal hearing screening is feasible and should be developed as it would enable improved availability and quality of data, resulting in:
 - regular and consistent reporting, both within jurisdictions and nationally
 - the ability to measure key performance indicators
 - the provision of benchmarks for service improvement
 - the ability for comparison across services, nationally and internationally.
2. All states and territories should be engaged to develop and work towards consistent national data standards.
3. The AIHW should oversee the development and governance of a national data collection on neonatal hearing, including the establishment of an advisory committee with expert stakeholders to provide advice on neonatal hearing screening data and statistics and other work in this area.
4. A National Best Endeavours Data Set (NBEDS) for neonatal hearing screening should be formed, and capture, as a minimum, unit-record data on demographics and

hearing screening for all liveborn babies in Australia; and could be built upon further to include data on diagnostic audiological assessment.

5. Data development work is required to form a national neonatal hearing screening data collection, including:
 - engagement of stakeholders
 - agreement on the scope of the data collection
 - identification of data items for development
 - development of data items
 - authoritative endorsement
 - implementation of data collection
 - ongoing monitoring and review.
6. Further consultation and development work should be done to assess the capacity to collate information on risk factors and early intervention in a national data collection on neonatal hearing screening. Work is required to ascertain the most appropriate source(s) of data on early intervention.
7. Data should be reported on annually as a minimum, in consultation with stakeholders to determine the appropriate methodology and data used for reporting. The capacity for allowing state and territories to access their own data for reporting within their jurisdiction should also be considered.
8. The inclusion of identifying data and/or a data linkage key is important and should be considered to enable future linkage with socio-demographic, medical, educational and employment administrative datasets.
9. The current national performance indicators for neonatal hearing in Australia should be reviewed so they align with a revised national framework and remain relevant and valid.

Recommended next steps

Short-term *estimated timeframe 2 years*

- Engage stakeholders and establish **advisory committee**
- Develop a Neonatal Hearing Screening NBEDS that includes **demographic** and **screening data**
- Review **national performance indicators** to ensure relevancy and alignment with the revised national framework

Medium-term *estimated timeframe 2–4 years*

- Develop Neonatal Hearing Screening NBEDS further to include **audiological assessment data**
- Develop Neonatal Hearing Screening NBEDS further to include **identifiers** to enable data linkage
- Develop a secure **electronic data collection tool** to enable streamlined data collection, validation and reporting

Longer-term *estimated timeframe 5+ years*

- Develop Neonatal Hearing Screening NBEDS further to include **early intervention** and **risk factors data**
- **Ongoing review** of the NBEDS to ensure consistency and relevancy
- Progression from an NBEDS to a **National Minimum Data Set (NMDS)**
- Establish **enduring linkage** to other key data sets

1 Introduction

Each year close to 300,000 babies are born in Australia (AIHW 2022a) and permanent hearing loss is believed to affect at least 1 to 2 babies per 1,000 births (Vos et al 2019), potentially 300–600 babies per year. Universal neonatal hearing screening aims to identify those born with moderate to profound permanent childhood hearing impairment (PCHI) and provide them and their families with access to an appropriate intervention to minimise the impact of their hearing impairment and improve outcomes.

All Australian states and territories have universal neonatal hearing screening programs, and it is intended, nationally, that more than 97% of newborn babies will be screened for hearing impairment (Department of Health 2013). However, there is currently no standardised data collection to support measuring the coverage of screening delivery and outcomes of these programs nationally.

1.1 A national framework

In 2013, the *National Framework for Neonatal Hearing Screening in Australia* was developed in consultation with jurisdictions to underpin a national approach to neonatal hearing screening in Australia (Department of Health 2013).

The framework has 6 components, including a national approach to data collection, management, and data sharing. The framework outlines the importance of the development of a national data set that would:

- enable the monitoring and evaluation of neonatal hearing screening programs
- enable monitoring of engagement with early intervention services
- underpin the development of a nationally consistent quality and standards framework
- permit national and international benchmarking and collaboration
- enable research into risk factors and health conditions associated with PCHI.

1.2 National performance indicators

In addition to the *National Framework*, in 2013, the AIHW published the *National performance indicators for neonatal hearing screening in Australia*, an indicator framework for national evaluation and monitoring of neonatal hearing screening (AIHW 2013). The indicator set (**Table 1**) was designed to provide a measure of how well universal neonatal hearing screening is achieving its aims and objectives and to enable strengthening of screening practices and administrative processes to further improve programs and outcomes for Australian infants.

While some jurisdictions have their own, usually internal, reporting mechanisms against the indicators, there is currently no national indicator reporting as national data have not been collected and collated.

Table 1: National performance indicators for neonatal hearing screening in Australia

Performance indicators	Aim
Indicator 1 Participation 1.1 Participation in screening	To maximise the number of eligible infants screened for permanent childhood hearing impairment
Indicator 2 Screening 2.1 Positivity rate of the screening test 2.2 Positive predictive value of the screening test	To maximise the identification of infants with potential hearing impairment while minimising parental anxiety and cost
Indicator 3 Audiological assessment and diagnosis 3.1 Audiological assessment 3.2 Detection of permanent childhood hearing impairment	To accurately identify infants born with permanent childhood hearing impairment
Indicator 4 Early intervention and management 4.1 Attend early intervention service 4.2 Infants fitted with an assistive hearing device	To maximise engagement of infants identified as requiring a service with early intervention services

Source: AIHW 2013.

1.3 The lack of national data

Despite the *National Framework* and *National Performance Indicators* stating the importance of a national data collection for neonatal hearing screening, there is currently no data being collected or reported at a national level in Australia.

In 2017, the Australian Parliament tabled a report, *Still waiting to be heard...*, following its Inquiry into the Hearing Health and Wellbeing of Australia. In its concluding comments, the report highlighted the lack of national data, stating that:

“The Committee received evidence that, although universal newborn hearing screening is considered extremely successful in Australia, there is no data collection or monitoring of program outcomes at the national level. As such, we cannot be certain that all children are being captured by the screening programs and that no child is being lost to follow up. The Committee considers that national data collection and monitoring of newborn screening programs should be implemented to ensure children are not falling through the gaps.” (House of Representatives Standing Committee on Health, Aged Care and Sport 2017).

In June 2022, the AIHW released a report, *Ear and hearing health of Aboriginal and Torres Strait Islander people 2021*, which also identified the lack of national data on neonatal hearing screening as an important data gap (AIHW 2022). The report included analysis of aggregated neonatal hearing screening data from Victoria, Queensland, Western Australia (for births in public maternity hospitals only), South Australia and the Northern Territory. Data from New South Wales, Tasmania and the Australian Capital Territory were not available. The report noted that while states and territories collect data on their neonatal hearing screening programs, the content and scope vary and there is a clear need for a national data set that would:

- *enable consistent monitoring and evaluation of programs*
- *enable monitoring of program coverage for Indigenous Australians*
- *enable monitoring of engagement with early intervention services*

- *underpin the development of a nationally consistent quality and standards framework*
- *permit national and international benchmarking and collaboration*
- *enable research into risk factors and health conditions associated with permanent congenital hearing impairment*
- *enable research and reporting on patient pathways through screening, diagnosis and intervention, potentially linking with other data sources to understand outcomes of children with hearing loss.” (AIHW 2022b)*

A nationally consistent approach to data collection and reporting is integral for monitoring the quality, performance and outcomes of the national screening program.

1.4 Purpose and scope of this report

In June 2022, the Department of Health and Aged Care contracted the AIHW to undertake a scoping project on the feasibility of developing a national neonatal hearing screening data collection.

The findings detailed in this report provide advice on current neonatal hearing screening collections and/or practices across states and territories, and the environment for establishing a national data collection.

This was conducted through a review of neonatal hearing screening in all states and territories by:

- assessing jurisdictional data holdings including what data are collected, coverage, quality and timeliness of data including relevant policies, frameworks and procedures
- providing an assessment of jurisdictional data suitability and availability for provision to a national collection
- identifying opportunities and/or barriers including information and/or data gaps or identification of data harmonisation needs
- reviewing legislative and governance arrangements
- advising on the scope and coverage of data collection
- establishing reporting needs and frequency.

The following was *out of scope* for this initial program of work:

- Establishment of an ongoing National Neonatal Hearing Screening Data Collection.
- A review of the national performance indicators for neonatal hearing screening in Australia (AIHW 2013).

2 Scoping the feasibility of a national neonatal hearing screening data collection

2.1 What is a national data collection?

A national data collection is an agreed set of specifications to collect data for a particular purpose.

To build a successful national data collection, consistency and standardisation in data collection methods and agreed definitions are required. These standardised specifications, known as 'metadata', ensure that services and jurisdictions are collecting the same data and are using it in the same way.

The metadata endorsed for use across Australia are referred to as 'data standards'. These standards improve the quality, relevance, consistency and availability of national information. They describe the expected meaning and recommended representation of data for use within a defined context.

Consistent content and standard definitions for the collection of information means that users can then understand and compare the data, regardless of how these data are collected or stored across different organisations and jurisdictions.

Data standards also help reduce the duplication of data. They provide a common and consistent platform for organisations to work from and simplify the data development process by reusing standards that already exist. This makes the adoption and implementation of the standards easier across all jurisdictions. These standards are critical for the development and implementation of policies for improving health and welfare outcomes for all Australians. A set of metadata can include the following types of data collections:

A **National Best Endeavours Data Set** (NBEDS) is a metadata set for which there is a commitment to provide data nationally on a best endeavours basis, but is not formally mandated for national collection.

When data quality, comparability, and universal coverage are achieved, a business case is made to the advisory committee and then the National Health Data and Information Standards Committee (NHDISC), for these data items to become mandatory for collection.

A **National Minimum Data Set** (NMDS) is a metadata set which specifies a minimum set of data elements which must be collected and reported across Australia. There must be national agreement for the NMDS to collect uniform data and to supply it as part of the mandatory national collection.

Over time, an Australian national data collection for neonatal hearing screening would enable improved availability and quality of data which would result in:

- regular and consistent reporting, both within jurisdictions and nationally
- the ability to measure key performance indicators

- the provision of benchmarks for service improvement
- the ability for comparison across services, nationally and internationally.

2.2 Project methodology

To scope the feasibility of developing a national neonatal hearing screening data collection, the AIHW consulted with screening managers from each state and territory to assess their jurisdictional data holdings. Screening managers were asked to provide information about their jurisdiction's neonatal hearing screening program including:

- current reporting arrangements
- data processes
- coverage, quality, and timeliness of data
- ability to link to other data collections
- relevant policies, frameworks, and procedures
- their ability to provide data to report against the current national performance indicators on neonatal hearing screening (AIHW 2013).

As part of this consultation process, a sample of neonatal hearing screening data was requested from each state and territory to further inform the availability and consistency of data items for potential inclusion in a national data collection, and the ability of each jurisdiction to collate and supply these data to the AIHW.

Consultation focused on processes and data available at all stages of the screening pathway outlined in the *National Framework for Neonatal Hearing Screening* (Department of Health 2013), summarised here as:

- **Recruitment:** the population to be screened.
- **Screening:** identification of babies with possible PCHI.
- **Diagnosis:** diagnostic audiological assessment of PCHI.
- **Early intervention:** treatment and management of PCHI.

Findings are detailed in **Section 3** of this report.

Throughout this project, the AIHW also engaged regularly with the:

- *National Hearing Screening Managers Group:* neonatal hearing screening managers from each state and territory meet every 6 weeks. The AIHW was invited to attend these meetings to ask and answer questions regarding the scoping project.
- *Hearing Health Working Group:* overseen by the Department of Health and Aged Care this group includes relevant stakeholders from state and territory governments. The AIHW was invited to attend these meetings to provide updates on the project and answer questions from stakeholders.

3 Findings

3.1 State and territory neonatal hearing screening programs

Bilateral meetings were held with neonatal hearing screening managers from each state and territory to gain an understanding of current neonatal hearing screening data collections and/or practices in each jurisdiction. Detailed findings on the programs for each state and territory are provided in **Appendix A**.

Overall, the consultation process found that:

- All states and territories have established neonatal hearing screening programs and collect data within their program.
- Data collection methods vary, with some jurisdictions using automated, purpose-built databases while some use more manual data collection methods. Some jurisdictions are also in the process of upgrading or implementing new data collection systems.
- Data on screening is well-collected across all states and territories. This includes data on the number of babies being screened, where and when they are screened, the number of screens for each baby and the outcomes; as well as information on babies who weren't screened (for example, if their parent(s) declined or they weren't eligible for screening). Screening data are not currently available for private hospital births in the NT which impacts coverage of these data.
- Program managers were confident that screening is offered to all eligible newborns within their state or territory, including babies born in hospitals, at home and in community healthcare settings. There was acknowledgement that there may be some babies born outside these settings (such as 'freebirths' where a baby is born without formal medical or midwifery assistance) who may not be offered screening if there is no knowledge of the birth and no engagement with the healthcare system by the parents, but it is believed the number of these instances is small.
- Data on diagnostic audiological assessment is well collected but can be limited in some states and territories. Some jurisdictions offer audiological assessment within their programs which enables consistent access to data, while for others, the audiological assessment services are run independently from the screening program which means the program must rely on data provision from the services which can be inconsistent.
- Data on early intervention is very limited across most jurisdictions and may need to be sourced from outside the states and territories.
- The ability to link screening data to other data collections, such as the National Perinatal Data Collection, to ascertain further demographic, antenatal, birth, and risk factor information, may be restricted in some jurisdictions due to the use of different identifiers.
- Most current state and territory data analysis and reporting is ad hoc and/or internal so there is little to no public information available on the performance and outcomes of the screening programs.

- All states and territories expressed willingness to participate in the development of a national data collection, recognising that the availability of accurate data and reporting would be beneficial for their program, particularly in measuring performance and resourcing, and would allow for national and international benchmarking.
- Due to variation across jurisdictions in processes and data collection, further development work would need to be done to ensure national agreement and consistency in data definitions and collection methods for a national data collection.

3.2 Analysis of currently available neonatal hearing screening data from states and territories

To further inform the availability and consistency of neonatal hearing screening data across Australia, a sample of data from each state and territory neonatal hearing screening program was requested from all jurisdictions for supply to the AIHW.

3.2.1 Methodology

To assess the ability of each state and territory to collate and supply neonatal hearing screening data to a national data collection and to ascertain the availability of specific data items, jurisdictions were asked to supply de-identified data for all babies born in November 2021. Specifying a particular birth cohort allowed for consistent comparison across all jurisdictions and with births data from the National Perinatal Data Collection. Requesting one month of data was preferred as it provided an appropriate sample for analysis, without the potential burden on state and territory resources that requesting a larger sample of data (such as 12 months) may have.

The data items requested were selected to provide detail on the availability of relevant demographic and birth information, as well as data on screening, audiological assessment, and early intervention. The requested data items are listed in **Appendix B**. These data items provide a basis for assessment of data items that *could* potentially be included in a national data collection, but a national data collection would not be required to contain these specific data items, nor would it be limited to only containing these data items.

The NSW Ministry of Health were unable to provide a sample of data for analysis as part of this project as they do not currently hold person-level data. Data are aggregated by Local Health Districts prior to reporting to the Ministry of Health. NSW is currently progressing a data extension and IT infrastructure project that will enable state-wide data collection and timely data delivery. It is anticipated these data will start to be available by the end of 2023; **Table 2** provides some detail on which data items NSW have indicated will be available. There is also opportunity to work collaboratively to ensure that data items for inclusion in a national data collection are incorporated into NSW's new data collection system.

ACT Health provided a sample of data for their two public birthing hospitals, but time constraints did not permit them to fulfil this request for their one private birthing hospital. They have indicated they would be able to provide data from all hospitals to a future national data collection.

Screening data for babies born in the NT's one private birthing hospital were not available as they are screened as part of a privately-run program within the hospital that does not provide data to the NT Department of Health.

All data provided by the states and territories were analysed for coverage and each data item was analysed for the percentage of records in the data sample that the data were available for. The findings are detailed in **Table 2** and in the remainder of **Section 3**.

Table 2: Coverage and availability of neonatal hearing screening data by states and territories (babies born in November 2021)

Overview of records provided	NSW ^(a)	Vic	Qld	WA	SA	Tas	ACT ^(b)	NT ^(c)
Number of screening records provided (for babies born in November 2021) ^(d)	–	6,313	4,812	2,692 (2,086 public & 606 private)	1,596	565	532 (432 for public hospitals only + ~100 babies were screened in the private hospital however data from the private hospital were not provided)	228 (public)
Number of births in the NPDC (preliminary data for November 2021) ^(e)	7,850	6,374	4,817	2,775	Not available ^(f)	539	519	Not available ^(f)
Were babies who weren't screened or weren't eligible for screening included in data sample? (for example, declined, deceased, lost contact)	–	✓ Included 65 babies who weren't screened or weren't eligible for screening	✓ Included 103 babies who weren't screened or weren't eligible for screening	✓ Included 14 (public) and 0 (private) babies who weren't screened or weren't eligible for screening	✓ Included 8 babies who weren't screened or weren't eligible for screening	✓ Included 28 babies who weren't screened or weren't eligible for screening	✓ Included 8 (public) babies who weren't screened or weren't eligible for screening	✗ Included 0 babies who weren't screened or weren't eligible for screening, though data for these babies are available
Estimated coverage = (Number of screening records provided / Number of births in the NPDC) x 100	–	99.0%	99.9%	97.0%	Not available ^(f)	104.8% ^(g)	102.5% ^(g)	Not available ^(f)

(continued)

Table 2 (continued): Coverage and availability of neonatal hearing screening data by states and territories (babies born in November 2021)

Demographic and identifier information	NSW ^(a)	Vic	Qld	WA	SA	Tas	ACT ^(b)	NT ^(c)
Baby's name (first name and surname)	✘ Have indicated data are unavailable	✓ 100.0%	✘ 7.3%	✘ 6.5% (Public) ✓ 99.2% (Private)	✓ % undisclosed; have indicated data are available	✓ 100.0%	✘ % undisclosed; have indicated data are unavailable	✘ 0.0% (Public)
Mother's name (first name and surname)	– Unknown	✓ 99.9%	✓ 99.6%	✘ 9.0% (Public) ✓ 99.2% (Private)	✓ % undisclosed; have indicated data are available	✓ 99.5%	✓ % undisclosed; have indicated data are available	✓ 100.0% (Public)
Mother's or baby's address	– Unknown	✓ 99.9%	✓ 99.6%	✘ 3.5% (Public) ✓ 99.2% (Private)	✓ % undisclosed; have indicated data are available	✓ 99.3%	✓ % undisclosed; have indicated data are available	✓ 100.0% (Public; Paper record)
Mother's or baby's Medicare number	– Unknown	✘ 0.0%	✘ 0.0%	✘ 0.0% (Public & private)	✘ 0.0%	✓ 54.0% (Baby)	– Unknown	✘ 0.0% (Public)
Baby's date of birth	✓ Have indicated data will be available	✓ 100.0%	✓ 100.0%	✓ 100.0% (Public & private)	✓ 100.0%	✓ 100.0%	✓ 100.0% (Public)	✓ 100.0% (Public)

(continued)

Table 2 (continued): Coverage and availability of neonatal hearing screening data by states and territories (babies born in November 2021)

Demographic and identifier information	NSW ^(a)	Vic	Qld	WA	SA	Tas	ACT ^(b)	NT ^(c)
Sex of baby	✓ Have indicated data will be available	✓ 100.0%	✓ 100.0%	✓ 99.7% (Public) ✗ 2.3% (Private)	✓ 100.0%	✓ 100.0%	✓ 100.0% (Public)	✓ 100.0% (Public)
Geographic identifier of usual residence	– Unknown	✓ 99.6% (Postcode)	✓ 99.5% (Postcode)	✗ 0.0% (Public) ✓ 99.2% (Private; postcode)	✓ 99.1% (Postcode)	✓ 99.5% (Postcode)	✓ 99.0% (Public; postcode)	✓ 99.5% (Public; region)
Indigenous status of baby	✓ Have indicated data will be available	✓ 100.0% (Aboriginal and/or Torres Strait Islander combined)	✓ 99.6%	✓ 100.0% (Public) ✗ 0.0% (Private)	✓ 96.9%	✓ 79.6%	✓ 59.1% (Public)	✓ 100.0% (Public)
Culturally and linguistically diverse identifier	– Unknown	✓ 99.9% (Language of primary contact (usually mother))	✓ 78.6% (Language and/or whether an interpreter was required, though many records denoted as 'Newborn')	✗ 0.0% (Public & private)	✗ (Limited data available on interpreter requirements)	✗ 0.0%	✓ 99.0% (Public; mother's country of birth)	✗ (Limited data available on interpreter requirements; public)

(continued)

Table 2 (continued): Coverage and availability of neonatal hearing screening data by states and territories (babies born in November 2021)

Demographic and identifier information	NSW ^(a)	Vic	Qld	WA	SA	Tas	ACT ^(b)	NT ^(c)
State or territory of birth	✓ Have indicated data will be available	✗ (Collected as Vic or 'other')	✗ (Collected as Qld or 'other')	✓ 100.0% (Public & private)	✗ (Only if registered with CaFHS)	✓ 98.6%	– Unknown	✓ 100.0% (Public)
Gestational age at birth	✓ Have indicated data will be available	✓ 99.8%	✓ 99.0%	✓ 100.0% (Public) 99.2% (Private)	✓ 81.1%	✓ 75.2%	✓ (Public; Have advised will be available as part of the new Digital Health Record system)	✓ 69.7% (Public)
Screening information								
Date of screen	✓ Have indicated data will be available	✓ 100.0% (Date available for all screens)	✓ 100.0% (Date of up to 10 screens)	✓ 100.0% (Public: date of up to 3 screens; Private: date of latest screen)	✓ 100.0% (Date of up to 3 screens)	✓ 100.0% (Date of up to 3 screens)	✓ 100.0% (Public: date of up to 3 screens; Private: unknown)	✓ 100.0% (Public; date of up to 2 screens)
Screen outcome	✓ Have indicated data will be available	✓ 100.0% (Outcome available for all screens)	✓ 100.0% (Outcome of up to 10 screens)	✓ 100.0% (Public: outcome of up to 3 screens; Private: outcome of latest screen)	✓ 100.0% (Outcome of up to 3 screens)	✓ 100.0% (Outcome of up to 3 screens)	✓ 100.0% (Public: outcome of up to 3 screens; Private: unknown)	✓ 100.0% (Public; Outcome of up to 2 screens)

(continued)

Table 2 (continued): Coverage and availability of neonatal hearing screening data by states and territories (babies born in November 2021)

Audiological assessment information	NSW ^(a)	Vic	Qld	WA	SA	Tas	ACT ^(b)	NT ^(c)
Date of audiological assessment	✓ Have indicated data will be available	✓ 100.0%	✓ 100.0% (Date of up to 10 assessments)	These data are collected by the Audiology Department at the Perth Children's Hospital. The Neonatal Hearing Screening Program does not currently have the data-linkage capability to report on this information – however the information is available and can be entered manually and recorded if necessary.	✓ 100.0%	✓ 100.0%	Information held in baby's medical record, not in screening database. Information would need to be entered manually. It is anticipated this information will be captured in the new Digital Health Record system.	✓ 100.0%
Audiological assessment outcome	✓ Have indicated data will be available	✓ 100.0% (Initial & final assessments)	✓ 100.0% (Outcome of up to 10 assessments)		✓ 100.0%	✓ 100.0%		✓ 100.0%
Type and degree of hearing loss	✓ Have indicated data will be available	✓ Have indicated data are available	✓ 100.0%		✓ Have indicated data are available	✓ 100.0%		✓ 100.0%

(continued)

Table 2 (continued): Coverage and availability of neonatal hearing screening data by states and territories (babies born in November 2021)

Early intervention information	NSW ^(a)	Vic	Qld	WA	SA	Tas	ACT ^(b)	NT ^(c)
Date of first attendance at early intervention	x	x	Some limited data available on the date and status of enrolment in early intervention services	x	x	Some limited data available on the date and status of enrolment in early intervention services	x	✓ 100.0%
Assistive hearing device flag								
Date first hearing device fitted								
First assistive hearing device type								

(a) The NSW Ministry of Health were unable to provide a sample of data for analysis as part of this project as they do not currently hold person-level data. Data are aggregated by Local Health Districts prior to reporting to the Ministry of Health. NSW is currently progressing a data extension and IT infrastructure project that will enable state-wide data collection and timely data delivery. It is anticipated these data will start to be available by the end of 2023.

(b) ACT Health provided a sample of screening data for their two public birthing hospitals but were unable to provide a data sample for their one private birthing hospital as time constraints did not permit them to fulfil this request. They have indicated they would be able to provide data from all hospitals to a future national data collection.

(c) Screening data for babies born in the NT's one private birthing hospital were not available as they are screened as part of a privately-run program within the hospital that does not provide data to the NT Department of Health.

(d) Includes babies who weren't screened (for example, deceased, declined screening, lost contact).

(e) Includes livebirths and stillbirths.

(f) The preliminary number of births for November 2021 were not available from the NPDC for SA or the NT.

(g) Estimated coverage will be >100% when there were more babies reported in the screening data than the number of births reported to the NPDC. This may indicate duplicate records in the screening database or could be a result of cross-border flows (where a baby was born in one jurisdiction and then transferred and screened in another jurisdiction).

NPDC = National Perinatal Data Collection.

Sources: AIHW analysis of data supplied by states and territories for the purposes of this project. NPDC preliminary data are sourced from *Australia's mothers and babies* (AIHW 2022a).

3.2.2 Coverage

Table 2 shows the number of babies born in November 2021 in state and territory screening databases compared to the number of births recorded in the National Perinatal Data Collection (NPDC) for November 2021 (noting that the number of births for that period were not yet available for South Australia or the Northern Territory). Comparing the overall number of babies in the screening databases to the number of births in the NPDC provides an indication of the coverage of the screening data held by states and territories, compared to overall births data. It should be noted that these data are based on all babies born in the reference period regardless of their screening status so this is not representative of the screening participation rate of the state and territory programs.

Overall, the number of babies included in the screening data samples was comparable to the number of births in the NPDC (>97%) indicating strong coverage of available screening data for the birth cohort. Further investigation should be undertaken to understand the source of discrepancies in the number of babies in the state and territory screening data sets compared to the number of births in the NPDC. The estimated coverage equalled >100% where there were more babies in the screening data than the number of births (such as for Tasmania and the ACT (**Table 2**), where the number of records supplied from their screening database was higher than the number of births in the NPDC). This may indicate duplicate records in the screening database or could be a result of cross-border flows (where a baby was born in one jurisdiction and then transferred and screened in another jurisdiction). As part of a national data collection, occurrences such as these should be investigated to determine the specific cause and ensure data validity.

3.2.3 Identifiers and demographics

Availability of the following identifier and demographic data items across states and territories is shown in **Table 2**:

- **Baby's name:** The inclusion of this data item in a national collection could allow for linkage of screening records with other data collections. However, the collection of this data item is currently inconsistent nationally. Newborns are often considered a difficult cohort to collect this type of information for as they are often screened and discharged from hospital prior to their name being recorded (often being recorded instead as "baby of <mother's name>" in most screening databases).
- **Mother's name:** The inclusion of this data item in a national collection could allow for linkage of screening records with other data collections. This data item is well collected nationally, except for the data provided by WA for public hospitals.
- **Mother's or baby's address:** The inclusion of this data item in a national collection could allow for data linkage of screening records with other data collections. This data item is well collected nationally, except for the data provided by WA for public hospitals.
- **Mother's or baby's Medicare number:** The inclusion of this data item in a national collection could allow for linkage of screening records with other data collections. However, this data item is predominantly unavailable in state and territory screening databases.
- **Baby's date of birth:** The inclusion of this data item in a national collection could allow for linkage of screening records with other data collections and enables the

calculation of baby's age throughout the screening pathway. This data item is consistently collected nationally.

- **Sex of baby:** The inclusion of this data item in a national collection could allow for linkage of screening records with other data collections and would enable data analysis to be disaggregated by baby's sex. This data item is well collected nationally, except for the data provided by WA for private hospitals.
- **Geographic identifier of usual residence:** The inclusion of this data item in a national collection could allow for geographical analysis such as remoteness area of usual residence, access to services and socioeconomic status. This information is well collected nationally, except the data provided for WA public hospitals. Most jurisdictions collected postcode and the NT collected data by geographical region. A national data collection should include a geographical identifier that is used consistently across all states and territories.
- **Indigenous status of baby:** Indigenous status is a measure of whether a person identifies as being of Aboriginal and/or Torres Strait Islander origin. The inclusion of this data item in a national collection could allow for the disaggregation of analysis by Indigenous status which can provide a baseline measure of health for all Indigenous children. This information is well collected nationally, except for in the data provided by WA for private hospitals. Further development work would need to be undertaken to ensure consistency in the collection of this data item across states and territories (for example, in the way the information is ascertained and recorded).
- **Culturally and linguistically diverse identifier:** People from some culturally and linguistically diverse (CALD) backgrounds can face greater challenges when navigating the healthcare system than people who do not identify as CALD. The collection of CALD data across jurisdiction's screening databases is limited, with information collected usually around the mother's primary spoken language and/or whether an interpreter is required. These are not currently considered to be a good indicator of a person's CALD background. More beneficial data would likely be sourced using linked data (for example, country of birth data from the Census), which is often used to supplement information in data sets that do not collect this information.
- **State or territory of birth:** The inclusion of this data item in a national data set could allow for further analysis on whether babies who are born in one jurisdiction and then enter the screening pathway in another jurisdiction are accounted for. However, the collection of this data nationally is currently inconsistent.
- **Gestational age at birth:** The inclusion of this data item in a national data set could allow for the calculation of baby's corrected age (that is, a premature baby's chronological age minus the number of weeks or months early they were born) throughout the screening pathway. This data item is well collected nationally.

3.2.4 Screening

The availability of data items regarding screening across states and territories is shown in **Table 2**.

The inclusion of screening data items on the date and outcome of screening in a national data set could allow for the calculation of overall screening participation rates, baby's age and corrected age at time of screening, as well as the proportion of infants who return a positive screen for potential PCHI. These data items are well collected nationally, though

inclusion of NT data for babies born in their one private birthing hospital would be required for complete national coverage.

In a national data collection, the collation of data on the date and outcome for all screens performed (where an infant undergoes more than 1 screen) could be beneficial in providing data on the number of screens performed, informing resourcing and any variation in screening outcomes over multiple screens.

3.2.5 Audiological assessment

The national framework states that, for babies who are referred following screening, comprehensive audiological assessment must be undertaken to confirm a hearing impairment (Department of Health 2013).

The availability of data regarding diagnostic audiological assessment (for infants where this was required) across states and territories is shown in **Table 2**.

The inclusion of data items regarding diagnostic audiological assessment in a national data set could allow for the calculation of the number of infants who returned a positive screen who complete audiological assessment, the timing in which this is completed, and diagnosis outcomes, including the type and degree of hearing loss.

Overall, these data are well collected nationally. Some jurisdictions have indicated that the collation of this data would require manual linkage to the infant's screening record which may add a reporting burden for these jurisdictions. However, these data items would be beneficial to show the outcomes of hearing screening so their inclusion, as well as more efficient methods of data collection, should be considered.

3.2.6 Early intervention

Following diagnosis of PCHI, the national framework states a referral should be initiated to an early intervention program and to Australian Hearing for advice about ongoing management of the hearing loss, including amplification options (Department of Health 2013).

The availability of data items regarding early intervention (for infants where this is required), particularly regarding amplification, across states and territories is shown in **Table 2**.

The inclusion of data items regarding early intervention in a national data set could allow for the calculation of the number of infants diagnosed with PCHI who engage with early intervention services, the timing in which this is completed and outcomes. As well as amplification, early intervention can include other services such as speech pathology, sign language, and counselling.

However, data on engagement with early intervention services is poorly collected nationally, with 7 of 8 jurisdictions reporting no, or extremely limited, data. Most jurisdictions advised that these data are not usually provided back to the state and territory programs by the early intervention service providers. Further data development work would need to be undertaken to establish the most appropriate source(s) of these data (for example, sourcing data directly from the early intervention services may need to be considered).

4 Considerations and recommendations for a national data collection

4.1 Scope of a national data collection

The recommended scope for a national neonatal hearing screening data collection would include unit-record data on all babies liveborn in each Australian state and territory. Including all liveborn babies would enable reporting on how many babies were eligible for screening, how many were screened, how many declined screening and how many were not offered screening.

It is recommended that, at a minimum, a national data collection on neonatal hearing screening should collect information on:

- **Demographics:** including baby's Indigenous status, sex, date of birth, geographical area of usual residence and gestational age at birth. These data items are currently well collected across states and territories but would require some further development to ensure national uniformity.
- **Screening:** including the number of screens, dates of screening, outcomes and, where applicable, reason screening was not performed. These data items are currently well collected across states and territories but would require some further development to ensure national uniformity.

It is further recommended that the following data items also be considered for a national data collection on neonatal hearing screening:

- **Audiological assessment:** the inclusion of information on the number of diagnostic audiological assessments undertaken, dates and outcomes, including the type and degree of hearing loss, in a national data collection could provide further information on the number of infants who require audiological assessment and who are diagnosed with PCHI. These data items are currently well collected across states and territories but would require some further development to ensure national uniformity.
- **Identifiable information:** the inclusion of identifiable information such as infant's name, mother's name, address and Medicare number in a national data collection could allow for linkage to other key data collections. Linkage of a neonatal hearing screening data collection would enable the long term aims and objectives of screening to be measured, such as the improvement of social, emotional and educational outcomes for infants born with PCHI (AIHW 2013). The current collection of these data items varies across states and territories but further consideration of the value of including and collecting these items as part of a national data collection would be beneficial.
- **Early intervention:** currently state and territory data on engagement with early intervention services is poorly collected with no or limited data available from most jurisdictions. While the current national performance indicators on early intervention focus on the fitting of assistive hearing devices (AIHW 2013), consultation with state and territory stakeholders suggests broadening the scope to also include information on other services involving, for example, speech pathology, sign language, and counselling, would provide a more complete picture of early intervention services in Australia following a diagnosis of PCHI. The collection of data on these services would enable research into patient pathways and health outcomes associated with

PCHI. Further data development work would be needed to establish the most appropriate source(s) of these data, such as consultation with Hearing Australia and the National Disability Insurance Scheme to assess their data holdings in this area.

- **Risk factors:** some states and territories indicated that their screening and audiological programs also monitor infants at risk for PCHI. Risk factors can include a family history of hearing impairment, exposure to congenital infections or ototoxic medications, and syndromes associated with hearing loss, such as Down syndrome. Data items on the prevalence and monitoring of infants with these risk factors and their outcomes should also be considered for inclusion in a national data collection to enable research into risk factors and health outcomes associated with PCHI.

Figure 1 proposes a 3-phase workplan to develop a national collection that commences with the development and collection of unit-record non-identifiable demographic and screening data items. Following further consultation with stakeholders, the data collection could be built-upon to include information on audiological assessment, identifiers (which could aid data linkage), risk factors and early intervention.

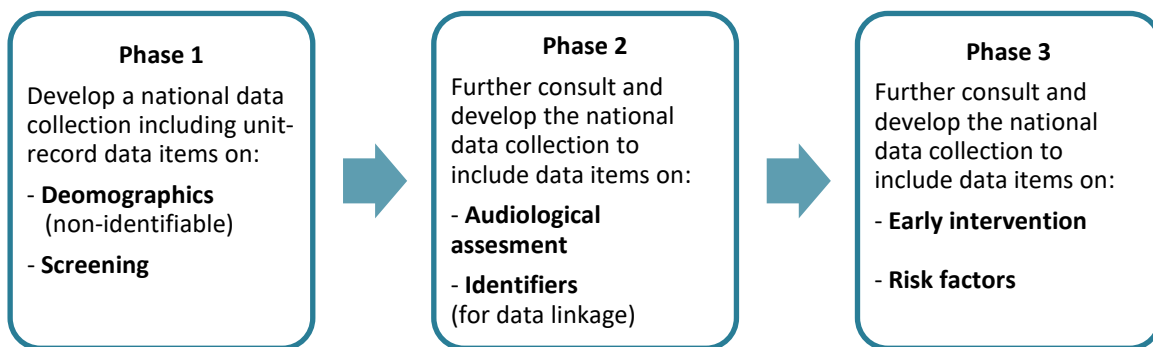


Figure 1: Recommended workplan to develop a Neonatal Hearing Screening National Data Collection

4.2 Data development

Data development is the process of building a data set for a specific purpose. Data development includes developing or adopting data standards in consultation with stakeholders to ensure uniform data collection and reporting and obtaining authoritative approval for the data set.

It is recommended that data development work be undertaken to form a National Best Endeavours Data Set (NBEDS) on neonatal hearing screening set that captures, as a minimum, information on neonatal demographic and hearing screening and can be built upon to include additional data (such as data items on audiological assessment and early intervention) in the future.

The data development process should include the following steps:

- **Engagement of stakeholders:** including relevant state and territory health authority representatives, representatives from the AIHW and the Department of Health and Aged Care, and subject-matter experts as required.

- **Agreement on the scope of the data collection:** consultation and collaboration to define and agree on what the data collection will include and exclude to ensure national uniformity.
- **Identification of data items for development:** consultation and collaboration to agree on data items to be included in a national collection.
- **Development of data items:** consultation and collaboration to develop and agree on definitions and collection methods for data items to be included in a national collection to ensure uniformity.
- **Authoritative endorsement:** the [National Health Data and Information Standards Committee \(NHDISC\)](#) provides advice to the AIHW in its work in developing and maintaining national health data and information standards. The NHDISC would oversee and endorse a National Neonatal Hearing Screening NBEDS. Approval from the AIHW Ethics Committee would also be required to establish a data collection.
- **Implementation of data collection:** national agreement to commence data collection, and around the frequency and methodology of the supply of data.
- **Ongoing monitoring and review:** monitoring and review of the data collection to ensure it is achieving its desired outcomes, including the refining of data items and specifications as necessary and the progression from a National Best Endeavours Data Set to a National Minimum Data Set when appropriate data quality and coverage are achieved.

4.3 Data governance

The AIHW is a major national agency established under the [Australian Institute of Health and Welfare Act 1987](#) (AIHW Act) as an independent statutory body to collect and produce information and statistics on Australia's health and welfare. The AIHW is well positioned to govern a national data collection on neonatal hearing screening and welcomes the opportunity to play a key role in developing, collating, validating, analysing, and reporting neonatal hearing screening data as part of a national data collection.

4.3.1 States and territories

State and territory neonatal hearing screening programs each have their own governance arrangements in place (**Appendix A**). To collate state and territory data into a national data collection, the AIHW enters into agreements with the data suppliers in each of the states and territories. Data suppliers are subject to the legislation and regulations of their respective jurisdictions, the requirements of which may differ to those of the Commonwealth. These agreements must recognise and reflect those requirements.

4.3.2 Advisory committee

To establish a national data collection on neonatal hearing screening, it is recommended an advisory committee be formed to provide expert technical advice on neonatal hearing screening data and statistics.

The advisory committee would initially be required to:

- provide advice to the AIHW for the development of data items for inclusion in a national collection
- advise the AIHW on state and territory data collection processes

- advise on the costs and timing of implementing proposed new data items for national reporting, including the capacity and preparedness of the jurisdictions and other relevant bodies/agencies to collect and provide these data
- advise on the content and structure of draft AIHW reports relating to neonatal hearing screening data
- promote the use of national standards in relevant local and national data collections.

It is recommended the group be comprised of, as a minimum, a suitable representative from each state and territory health authority/organisation and the AIHW, with observers and temporary members invited on a transitory basis as their expertise is required. The AIHW could form a group meeting these requirements or seek permission to utilise a suitable pre-existing group for this purpose.

4.3.3 The National Health Data and Information Standards Committee

Further to an advisory group, any data development associated with a National Best Endeavours Data Set (NBEDS) or National Minimum Data Set (NMDS) on neonatal hearing screening would be required to go to the National Health Data and Information Standards Committee (NHDISC) for approval. The NHDISC provides advice to the AIHW in its work in developing and maintaining national health data and information standards and is required to oversee and endorse the development of NBEDS and NMDS for national collection and reporting. The AIHW can manage the progression of work through the NHDISC. Further information on the role of the NHDISC can be found here: [National Health Data and Information Standards Committee - Australian Institute of Health and Welfare](#).

4.3.4 Ethics

The AIHW manages data with respect for its sensitivity, and with privacy and confidentiality assured through legislation, accountability practices and procedures. Therefore, the formation of a national data collection on neonatal hearing screening would require approval from the AIHW Ethics Committee. Further information on the role of the AIHW Ethics Committee can be found here: [AIHW Ethics Committee - Australian Institute of Health and Welfare](#).

4.4 Data supply models for national data collection

Two methods for the supply of data from the states and territories to a national neonatal hearing screening data collection of data are proposed for consideration:

4.4.1 Submission of an annual data file

Data would be supplied to a national collection via jurisdictions submitting a data file to the AIHW according to an agreed set of specifications. It is recommended that data are collected annually as a minimum. Data would be collected by the birth cohort for a particular calendar year. At least 3 months would be required at the end of the calendar year for babies to complete screening and for the states and territories to undertake data entry and validation. Data would then be requested from the states and territories for submission to the national collection. Data would undergo further validation by the AIHW to ensure consistency and reliability both within and across jurisdictions. Assuming data are provided in a timely way by

the states and territories, data could be analysed for national reporting within 12 months of the end of the calendar year for the birth cohort.

This data collection method would involve minimal cost for establishing a system of data supply to the AIHW, however it does require more manual data validation, processing and analysis which may result in slower reporting. This method also limits the ability to update records as babies move through the screening pathway to audiological assessment and early intervention services.

Figure 2 shows an example of the timeline using this model.

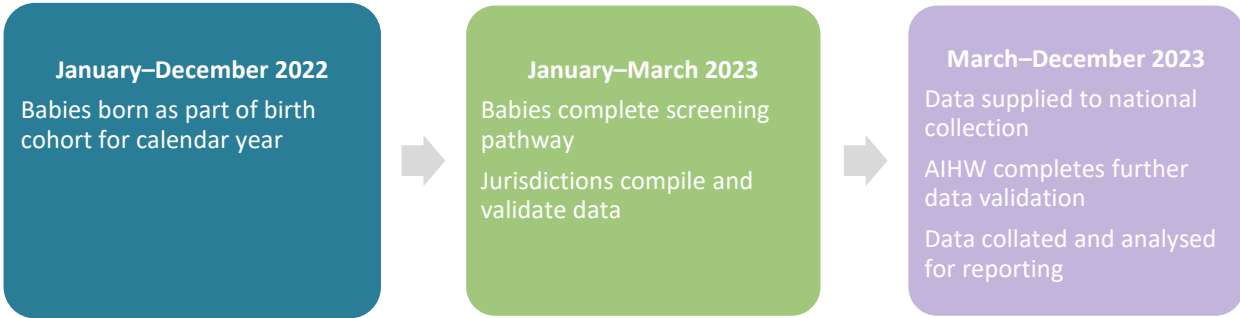


Figure 2: Timeline of annual data supply to a national neonatal hearing screening data collection via submission of a standardised data file (using the 2022 birth cohort as an example)

4.4.2 Secure electronic data collection tool

The AIHW would develop a secure web-based data collection tool that would allow registered users in each state and territory to submit data, according to an agreed set of specifications, at agreed regular intervals (for example, monthly or quarterly). Validation checks would be in-built to the data collection tool to allow for quicker data processing. Users would be able to update data as the child progresses through the screening pathway. Automated analysis and reporting methodologies could also be in-built to allow for more timely data reporting (for example, quarterly or biannually). State and territory program managers would also be able to access their own jurisdictional data for querying and reporting.

This method allows for streamlined data processing and reporting and has the advantage of being able to regularly update records as babies progress through the screening pathway. It could also allow for program managers to be able to access their own data for reporting at both the establishment/service, region and state levels. While it would improve timeliness and reporting in the long-term, this method would cost more, take longer to develop initially, and would require ongoing maintenance.

Figure 3 shows an example of the timeline using this model.



Figure 3: Timeline of annual data supply to a national neonatal hearing screening data collection via use of a secure electronic data collection tool

With many of the objectives of neonatal hearing screening needing to be met within short time frames and a growing appetite for more timely data, the AIHW considers the development of a secure electronic data collection tool as the most efficient model for national data collection. It is recommended that consultation with states and territories be ongoing to determine the most appropriate model of data supply for a national data collection.

4.5 Reporting

Reporting data on neonatal hearing screening collated as part of a national data collection would allow for measuring the performance of universal neonatal hearing screening programs and national and international benchmarking. Reporting should align with the objectives of the national framework and data should be reported against national performance indicators. It is recommended that data be reported on annually as a minimum but could be reported more frequently, for example, quarterly or biannually, if beneficial. It is recommended that consultation with stakeholders be undertaken to determine appropriate analysis methods and the data to be included in reporting.

The capacity for allowing state and territories access to their own data for reporting within their jurisdiction should also be considered. This would allow for internal reporting across establishments/services and regions within a jurisdiction. This could inform the performance of specific establishments/services and regions, resourcing requirements, and allow for benchmarking against peer services, and state and national level data.

4.6 Data Linkage

Data linkage is when information about people and events from different data collections is brought together. Linkage of national neonatal hearing screening data with other data collections would enable the long term aims and objectives of screening to be measured, such as the improvement of social, emotional, and educational outcomes for infants born with PCHI (AIHW 2013). It is recommended that the development of identifying data items and/or a data linkage key be considered as part of a national neonatal hearing screening data collection, to enable future linkage with socio-demographic, medical, educational and employment administrative datasets to assess whether neonatal hearing screening in Australia is meeting these long-term aims. Identified data usually includes information such as name, date of birth, address and Medicare number. Once appropriate data quality and coverage are achieved, the establishment of enduring linkage with other key data sets should be considered. Requirements regarding consent to enable linkage of collected data should also be considered.

Linkage to the National Perinatal Data Collection (NPDC) should be explored further as it would enable access to demographic, antenatal and birth data for all babies born in Australia which would provide an information base for all babies undergoing neonatal hearing screening and those who are not screened. Linkage to the NPDC would also enable further linkage to the National Congenital Anomalies Data Collection containing information on babies with a congenital anomaly which may inform research on babies with PCHI. Shared identifiers with the NPDC and/or a data linkage key should be considered for inclusion in a national data collection for neonatal hearing screening.

4.6 Additional considerations

At the time of preparing this report, it is understood the Department of Health and Aged Care is drafting an updated national framework for neonatal hearing screening. The release of an updated framework may further inform key definitions, the scope and aims of a national neonatal hearing screening data collection and alignment between the revised framework and a national data collection is important.

Through the consultation process, it became apparent additional work may need to be undertaken to review and refine the national neonatal hearing screening indicators previously published by the AIHW (AIHW 2013). While a review of the indicators is out of scope for this project, reviewing the indicators so they align with a revised national framework would ensure they remain relevant and valid. Authoritative endorsement of the indicator set by the National Health Data and Information Standards Committee is also recommended.

5 Recommendations and next steps

5.1 Recommendations

Based on the AIHW's consultation with all states and territories and the assessment of their neonatal hearing screening programs and data holdings, the following recommendations are made regarding the feasibility of developing a national neonatal hearing screening data collection:

1. The development of an Australian national data collection for neonatal hearing screening is feasible and should be developed as it would enable improved availability and quality of data, resulting in:
 - regular and consistent reporting, both within jurisdictions and nationally
 - the ability to measure key performance indicators
 - the provision of benchmarks for service improvement
 - the ability for comparison across services, nationally and internationally.
2. All states and territories should be engaged to develop and work towards consistent national data standards.
3. The AIHW should oversee the development and governance of a national data collection on neonatal hearing, including the establishment of an advisory committee with expert stakeholders to provide advice on neonatal hearing screening data and statistics and other work in this area.
4. A National Best Endeavours Data Set (NBEDS) for neonatal hearing screening should be formed, and capture, as a minimum, unit-record data on demographics and hearing screening for all liveborn babies in Australia; and could be built upon further to include data on diagnostic audiological assessment.
5. Data development work is required to form a national neonatal hearing screening data collection, including:
 - engagement of stakeholders
 - agreement on the scope of the data collection
 - identification of data items for development
 - development of data items
 - authoritative endorsement
 - implementation of data collection
 - ongoing monitoring and review.
6. Further consultation and development work should be done to assess the capacity to collate information on risk factors and early intervention in a national data collection on neonatal hearing screening. Work is required to ascertain the most appropriate source(s) of data on early intervention.
7. Data should be reported on annually as a minimum, in consultation with stakeholders to determine the appropriate methodology and data used for reporting. The capacity for allowing state and territories to access their own data for reporting within their jurisdiction should also be considered.

8. The inclusion of identifying data and/or a data linkage key is important and should be considered to enable future linkage with socio-demographic, medical, educational and employment administrative datasets.
9. The current national performance indicators for neonatal hearing in Australia should be reviewed so they align with a revised national framework and remain relevant and valid.

5.2 Next steps

The findings of this project show that all Australian states and territories have established universal neonatal hearing screening programs and that data on demographic and hearing screening is generally well collected across all jurisdictions. The key next step is to develop a national neonatal hearing data collection that focuses, initially, on demographic and screening information and can be built upon further to include data on diagnostic audiological assessment. Further work should also be undertaken to assess the capacity to include information on identifiers (to aid data linkage), risk factors and early intervention. Given there are challenges that arise from differences in program practices and data collection between the states and territories, all jurisdictions need to be engaged to develop and work towards consistent national data standards.

A range of short-, medium- and longer-term steps are recommended to build this work (Figure 4).

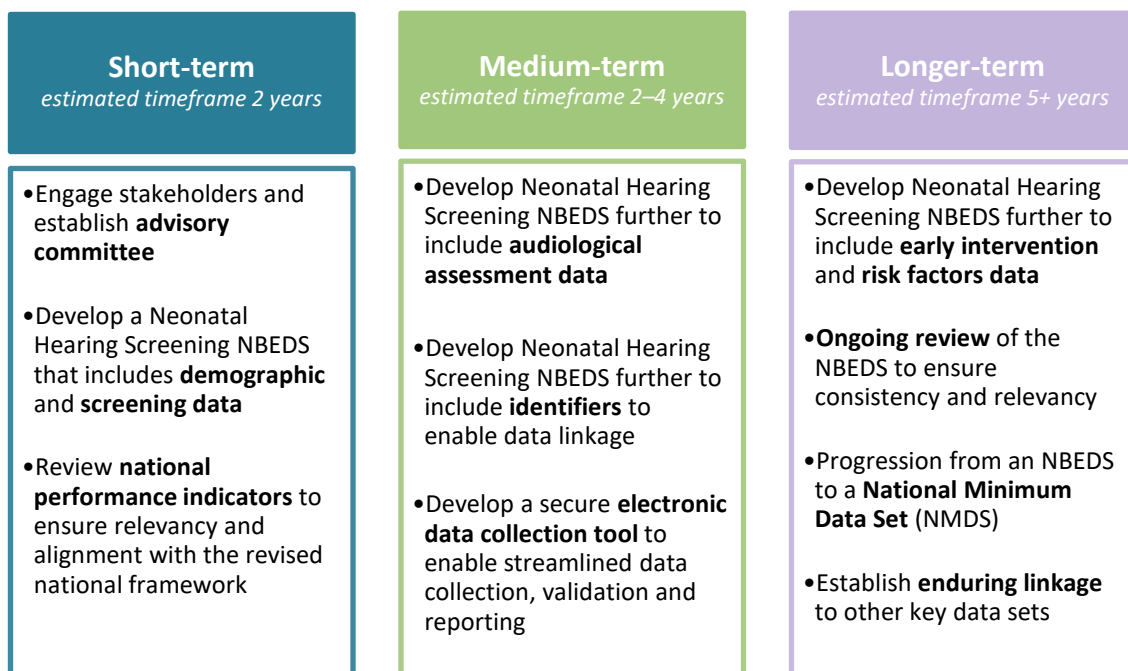


Figure 4: Recommended next steps

Progressing these short- and medium-term opportunities initially will build a nationally consistent evidence base about national neonatal hearing screening and inform the longer-term goals to establish an enduring and comprehensive data collection.

Acronyms

- ACT – Australian Capital Territory
- ACTPAS – Australian Capital Territory Patient Administration System
- AIHW – Australian Institute of Health and Welfare
- CaFHS – Child and Family Health Service
- CAHS – Child and Adolescent Health Service
- CALD – Culturally and Linguistically Diverse
- CHAMP – Childhood Hearing Australasian Medical Professionals
- DARF – Diagnostic Assessment Report Form
- eCHIMS – electronic Child Health Information Management System
- ENT – Ear, Nose and Throat
- HRN – Hospital Record Number
- LHD – Local Health District
- MoU – Memorandum of Understanding
- NBEDS – National Best Endeavours Data Set
- NHDISC – National Health Data and Information Standards Committee
- NMDS – National Minimum Data Set
- NPDC – National Perinatal Data Collection
- NSW – New South Wales
- NT – Northern Territory
- OZeSP – OZ eScreener Plus
- PCHI – Permanent Childhood Hearing Impairment
- RCH – Royal Children’s Hospital
- SA – South Australia
- SCHN – Sydney Children’s Hospital Network
- SWISH – State-wide Infant Screening – Hearing
- URN – Unit Record Number
- VIHSP – Victorian Infant Hearing Screening Program
- WA – Western Australia
- WCHN – Women’s and Children’s Health Network

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Appendix A: Findings on state and territory neonatal hearing screening programs

New South Wales

Program overview

The NSW State-wide Infant Screening - Hearing (SWISH) Program is operated by the NSW Ministry of Health. Each of the fifteen Local Health Districts (LHD) and Sydney Children's Hospitals Network (SCHN) in NSW have SWISH coordinators who are responsible for implementing and managing the screening program across all facilities in their district. For infants who require further audiological assessment, SWISH provides diagnostic audiology services at three tertiary paediatric hospitals (with SWISH reimbursing travel costs for those living more than 100km away).

Current data holdings

SWISH coordinators in each LHD compile aggregate data monthly into a standardised Excel spreadsheet and provide it to the program coordinator at the Ministry of Health. Outcome reports are also provided by the three diagnostic audiology assessment centres. Current data holdings are limited due to only aggregate data (not person-level data) being available centrally in NSW and these data being held across multiple spreadsheets.

NSW are currently progressing a data extension and IT infrastructure project which will enable the collection of all SWISH person-level data in a central database. This is anticipated to be available at the end of 2023.

Early intervention services are provided by Hearing Australia and data are not provided to NSW.

Current reporting

Aggregate data from each LHD are periodically compiled for internal reporting.

Monitoring of performance against indicators is done within the LHDs.

It is anticipated that with the introduction of a state-wide centrally located data system, the ability to analyse and extract data will be streamlined allowing for more frequent and automated monitoring and reporting.

Governance arrangements

The SWISH program is governed by the Disability, Youth and Paediatric Health section of the NSW Ministry of Health.

Relevant policies, frameworks or procedures

Guidelines for the SWISH Program were developed to encompass all protocols and procedures of the program. The guidelines were published in 2010. A scheduled review of the guidelines commenced in January 2023. The Guidelines can be viewed at: [Statewide Infant Screening - Hearing \(SWISH\) Program \(nsw.gov.au\)](https://www.nsw.gov.au/health-and-care-services/infant-screening-hearing).

Ability for linkage to other data collections

Current identifier information is specific to the LHD where the screening occurred. However, in the state-wide data extension project currently in progress in NSW, there are opportunities to include unique identifiers for babies across the state that could allow for linkage with other NSW data collections potentially leading to better monitoring of outcomes following screening.

Overall assessment

Data on neonatal hearing screening is currently collected across fifteen LHDs and SCHN in NSW, however, is limited as it is collated into aggregate data prior to reporting to the NSW Ministry of Health. These current arrangements would not allow NSW to report person-level data to a national data collection.

However, the NSW Ministry of Health is currently progressing a data extension and IT infrastructure project that will enable state-wide data collection and timely data delivery. This new mechanism will make the collation and extraction of data for reporting to a national data collection more streamlined and automated. It is anticipated these data will start to be available by the end of 2023. There is also opportunity to work collaboratively to ensure that data items for inclusion in a national data collection are incorporated into NSW's new data collection system.

Victoria

Program overview

The Victorian Infant Hearing Screening Program (VIHSP) is operated by the Royal Children's Hospital (RCH) in Melbourne who reports to the Victorian Department of Health and screens babies born across Victoria.

Infants who require further audiological assessment are referred for detailed testing by an audiological assessment service. These services are run independently from VIHSP and are usually based in hospitals or community health services or are privately run (under contract with local hospitals or community health services so there is no cost for families). Families can select which service they wish to attend, usually based on geographic location. Families are supported by the VIHSP Early Support Service from the time of referral onwards.

Infants diagnosed with hearing loss will be referred to hearing health professionals for early intervention.

Current data holdings

Screening data are captured in a purpose-built information system called OZ eScreener Plus (OZeSP). The database allocates a unique confidential identifier for each baby, and this identifier is not used in any other systems within Victoria outside of VIHSP.

The VIHSP requests data from the audiological assessment services via a Diagnostic Assessment Report Form (DARF) which is provided by VIHSP. A Memorandum of Understanding (MoU) exists between VIHSP and the diagnostic audiology services that VIHSP refers infants to. The MoU covers this provision of DARF data as well as expectations regarding staffing, services and equipment. Each time a referred baby is seen by the service, a DARF is completed and returned to VIHSP. DARF data are entered into a separate Access database and use the same unique identifier to enable linkage to the baby's screening record

in the OZeSP database. DARF data are followed up until there is a definitive diagnosis or baby is discharged from the service.

Data are also collected on the date of enrolment in early intervention (from early intervention services), date of first amplification (from Hearing Australia) and date of first cochlear implant (from the Cochlear Implant Clinic at the Royal Victorian Eye and Ear Hospital or NextSense). However, there is no formalised information exchange process for regular supply of this information to VIHSP. Therefore, data are collected on a case-by-case basis and require regular follow-up by VIHSP staff. Challenges to the data collection include variance in the amount and type of data provided by services. These data do not include the unique identifier used by VIHSP so require data to be manually linked to the baby using identifiable information such as name and date of birth.

Current reporting

The VIHSP prepares two reports monthly:

- Screening report: focuses on the proportion of eligible babies who are screened by one month corrected age. This report is supplied to the RCH Executive Director of Medicine and to the Victorian Department of Health.
- Post-screening report: for babies who are referred for further assessment following screening, this report focuses on the proportion of families contacted by the VIHSP Early Support Service within 3 days of referral and the commencement of audiological assessment by 3 months corrected age. This report is supplied to the RCH Executive Director of Medicine.

Annual aggregate data are published externally on the VIHSP website ([Victorian Infant Hearing Screening Program : News and updates \(rch.org.au\)](https://www.rch.org.au/vihsp/news)).

Governance arrangements

VIHSP and its data are governed by the senior program managers, RCH Executive and Board.

Relevant policies, frameworks or procedures

The VIHSP policy is to uphold standards set by national and international newborn hearing screening guidelines. The program has an extensive set of manuals to support program operations and management.

Ability for linkage to other data collections

Because babies are allocated an identifier that is unique within the OZeSP information system, the ability to link data to other collections would require manual linkage using other identifiable data items such as name and date of birth.

Overall assessment

Victoria has consistent state-wide electronic data collection on screening. VIHSP is also committed to collecting data on audiological assessment and early intervention where possible, though this data relies on what the services are willing to provide, so there are data gaps. Challenges may lie in the ability to link data to other data collections for further research.

Queensland

Program overview

Queensland's neonatal hearing screening program operates under Queensland Health's Healthy Hearing Program. Operationally, the program is run by local teams based in hospitals across the state and includes screening, audiological assessment and diagnosis, family support and speech pathology paediatric early intervention.

Current data holdings

Data are held in an electronic state-wide custom-built database (QChild), which contains data on screening, diagnosis, early intervention, and risk factors and aetiology of hearing loss. Data are collected each time the baby engages with the program or service areas.

The database allocates a unique identifier for each baby; however, this identifier is not used in any other systems within Queensland. The QChild system can cross-check data to avoid duplicate records.

Data are collected on hearing screening attendance and outcomes and audiological attendance and outcomes. Monitoring of the hearing screening and audiology outcomes are regularly followed-up to ensure data entry for babies who have attended.

Data on early intervention, such as speech and language therapy, are collected and are estimated to be available for approximately 75% of babies who access those early intervention services, however, there are some services who are unable to supply data due to consent policies. Data on amplification through Hearing Australia are not supplied back to the program.

Data on medical outcomes (aetiology) are entered for the subset of children who attend these services. Not all children will attend the medical clinics for a variety of reasons (for example, they may attend a private clinic).

Current reporting

The Healthy Hearing Program prepares regular internal reports against performance indicators on screening capture rates, screening rates by 30 days, referral and diagnosis rates, and screening performance of services across Queensland.

Governance arrangements

The Healthy Hearing Program is governed by Children's Health Queensland in the Queensland Government. Health Chief Executive approval is required to release data from the program.

Relevant policies, frameworks or procedures

Internal documents outline protocols and procedures of the program. Some of these can be viewed here: [For health professionals | Service Detail | Children's Health Queensland](#)

Ability for linkage to other data collections

Because babies are allocated an identifier that is unique within the QChild database, the ability to link data to other collections would require manual linkage using other identifiable data items such as name and date of birth.

Overall assessment

Queensland has consistent state-wide electronic data collection on neonatal hearing screening. They are also committed to collecting data on audiological assessment, diagnosis and early intervention where possible, though, early intervention data relies on what the services can provide and may be limited in some instances. Challenges may lie in the ability to link data to other data collections for further research because of the unique identifier used that is specific to the Healthy Hearing Program.

Western Australia

Program overview

The WA Newborn Hearing Screening Program provides hearing screening for all newborn babies at public, private, metropolitan, and regional maternity services across Western Australia. The program is funded by the WA Department of Health and coordinated by the Child and Adolescent Health Service (CAHS). Maternity hospital staff undertake screening at WA's public hospitals and CAHS currently contract a private entity, the Earbus Foundation of WA, to undertake screening in private hospitals. There are 3 private hospitals in WA that admit public patients and babies born in these hospitals are screened by internal hospital staff.

Babies who do not pass their newborn hearing screen and require audiological assessment are referred to the Audiology department located at Perth Children's Hospital (transport and accommodation can be provided for families who need to travel to attend). Babies who pass their screen but require monitoring for other risk factors associated with hearing loss can access audiological assessments at either Perth Children's Hospital, the Child Development Service (those who live in the metropolitan area) or the WA Country Health Service (those who live remotely) depending on the risk factor/s identified.

Following audiological assessment, babies who require it, will be referred to early intervention services. CAHS has recently engaged an early intervention support officer to assist families with engaging in early intervention services.

Current data holdings

CAHS receives data on all public hospital births from the Maternal and Child Health Unit in the WA Department of Health. These data are uploaded into a purpose-built database for the newborn hearing screening program. Hospitals provide raw screening data from their machines to CAHS, which are uploaded to the database. The screening data are linked to the birth record based on the baby's unique medical record number which is used in both the births and screening data. A data entry clerk validates the data, for example, checking for duplicate records, monthly.

Data for babies screened in private hospitals are received from the Earbus Foundation, however, due to current legislation, data on private hospital births are not permitted to be shared by the Maternity and Child Health Unit with CAHS, therefore the capture rate for private births cannot be derived and state-wide reporting for all births cannot be completed. CAHS is currently seeking resolution on this issue.

For the public births that occur in the 3 private hospitals that admit public patients, CAHS is responsible for the screening of those babies, however, the birth data from these hospitals are not provided to CAHS so the screening capture rate is unable to be derived. CAHS is also currently seeking resolution on this issue.

Data on audiological assessments are recorded in a separate database and work is underway to enable linkage of these records with babies in the screening database. Currently linkage would need to be done manually.

For babies referred to Hearing Australia, data are provided back to the audiological database; though there can be data gaps in the information provided.

Data from early intervention services is not currently collected. It is hoped the engagement of an early intervention support officer will assist in these data being collected.

Current reporting

CAHS generate annual dashboards for each maternity hospital showing their data against performance indicators and on the number of eligible births, screening capture rate, reasons babies were not screened, screening pass/refer rates, and the number of babies with risk factors.

CAHS also reports against national performance indicators (excluding those on early intervention and management) to WA Department of Health.

Governance arrangements

CAHS is governed by the Office of Population Health Genomics in the WA Department of Health. A governance committee for newborn hearing screening is currently being established.

Relevant policies, frameworks or procedures

The WA Department of Health has a mandatory policy for newborn hearing screening across the state: [Newborn Hearing Screening Program Policy \(health.wa.gov.au\)](https://www.health.wa.gov.au)

Ability for linkage to other data collections

Linkage to births in the perinatal data collection may be possible via use of the unique medical record identifier. Linkage to other collections not using the unique medical record identifier would require manual linkage using other identifiable data items such as name and date of birth.

Overall assessment

CAHS collects consistent data on newborn hearing screening in public hospitals and less-complete data on screening in private hospitals as supplied by the Earbus Foundation. There are some known data gaps that CAHS is currently working to rectify, including:

- CAHS not currently being able to obtain overall births data for private hospitals, meaning the overall screening capture rate cannot be derived. These data are available in the National Perinatal Data Collection held by the AIHW, however permission would be required from the WA perinatal data custodian to use these data for this purpose
- the current requirement to manually link audiological data to the screening data
- a lack of data from early intervention services.

South Australia

Program overview

South Australia's Universal Newborn Hearing Screening Program is governed by the Women's and Children's Health Network (WCHN) in SA Health. The screening program consists of up to two stages; the first hearing screen is completed in hospital by midwives, except for babies born at the Women's and Children's Hospital, where designated hearing screeners perform hearing screen. For babies who don't pass the first screen, a second screen is completed by nurses, midwives or a designated screener at the Child and Family Health Service (CaFHS) in a clinic setting or in the home across the state.

For babies who require audiological assessment, this service is provided by WCHN Children's Audiology Service, who use portable electrophysiological equipment to provide audiology assessments at locations across the state. Those who require amplification are referred to Hearing Australia.

Current data holdings

Screening results are manually recorded on a hearing screening card which is manually entered into a purpose-built SA Pathology database. The data are exported daily to the CaFHS electronic Child Health Information Management System (eCHIMS). Audiological assessment data are also held in the eCHIMS database. Data are regularly cleaned and checked for duplicates, particularly as the system relies on manual data entry. Data are downloaded from eCHIMS to Excel files and used for reporting.

For babies who are referred to early intervention services, an Excel spreadsheet is kept with referral dates and any information the services provide back to CaFHS, however these data are very limited; it is estimated to be approximately 25% complete.

Current reporting

Monthly internal reports are prepared for SA Health on screening and pass rates by local health networks.

Governance arrangements

SA's Universal Newborn Hearing Screening Program is governed by the Women's and Children's Health Network in SA Health.

Relevant policies, frameworks or procedures

Internal policy and procedure documents are based on the national framework. Some additional indicators around establishment performance have been included.

Ability for linkage to other data collections

A hospital Unit Record Number (URN) is supplied and could be used to link to other data collections that hold this information. The URN is also collected in the SA perinatal database however is not a data item collected in the National Perinatal Data Collection held by the AIHW. Use of hospital URN can be limiting, for example, if baby changes hospitals, it will likely be given a new URN for that hospital. Some smaller hospitals in SA don't generate the baby's URN until baby is discharged so this information is not provided. Linkage to other collections not using the hospital URN would require manual linkage using other identifiable data items such as name and date of birth.

Overall assessment

SA collects consistent state-wide data on newborn hearing screening. Screening data are not automatically uploaded and require manual recording and database entry, which can sometimes take 7-10 days to enter the first screening results into the database. CaFHS collect consistent data on audiological assessments, but data on early intervention are extremely limited.

Tasmania

Program overview

The Tasmanian Health Service – Allied Health Services – Statewide Audiology Service provides the Tasmanian Infant Hearing Screening Program. Screening is undertaken in every birthing hospital across Tasmania.

For babies who are referred for diagnostic audiological assessment, the program includes infant diagnostic audiology and cochlear implant service. Diagnostic audiology is performed in hospitals in Hobart, Launceston, Mersey and Burnie, through a combination of face-to-face, outreach and telehealth services.

A family support team is available to support families to the point of engagement with early intervention service. The Paediatric Hearing Loss is a multidisciplinary clinic that accepts referrals for infants and children with hearing loss to access a Paediatrician, ENT, Clinical Geneticist and family support in one clinic for medical investigations consistent with the Childhood Hearing Australasian Medical Professionals (CHAMP) guidelines.

For those requiring amplification, infants are referred to their local Paediatric Audiologist at Hearing Australia in the South, North or Northwest of Tasmania.

Current data holdings

Data for all babies born who need to be screened are captured in an electronic database which uses the same software as Victoria's information system. Tasmania is currently in the process of making upgrades.

The hospital system allocates a unique confidential identifier for each baby and this is used in the screening database. Screening data are automatically uploaded into the database daily. The database has some capacity to capture information on audiological assessments, diagnoses, some early intervention services, and cochlear implant fittings from within their audiological services. The database is frequently being checked and cleaned to remove duplicate records.

Challenges lie in extracting data from the database and a continuous software upgrade process has been ongoing since 2016, aiming to improve the functionality of the database to allow more streamlined extraction and reporting of data.

Current reporting

External reporting is provided on request to stakeholders. Internal reporting and review is routine.

Governance arrangements

The Tasmanian Infant Hearing Screening Program is governed by the Allied Health Section of the Tasmanian Department of Health.

Relevant policies, frameworks or procedures

Tasmania has an internal procedures policy.

Ability for linkage to other data collections

Babies are allocated a unique hospital identifier which is used across the Tasmanian Health Service as part of the state-wide digital medical record.

Overall assessment

Tasmania has consistent state-wide electronic data collection on screening. They also collect data on audiological assessment, early intervention and cochlear implantation occurring within their audiology services. The extraction of data is currently challenging, and Tasmania are in the process of updating software systems to increase the efficiency of data extraction and reporting. This provides an opportunity to work collaboratively to ensure that data items for inclusion in a national data collection are incorporated into Tasmania's data collection system.

Australian Capital Territory

Program overview

The ACT Newborn Hearing Screening Program is operated by Canberra Health Services and screens babies across all birthing hospitals in the ACT.

Babies who require audiological assessment are referred to an audiologist within Canberra Health Services. Babies may then be referred to an Otolaryngologist and then to Hearing Australia for early intervention services.

Current data holdings

Currently, babies born are entered into the ACT Patient Administration System (ACTPAS). A unique identifier is given to each baby which is carried across all public health services in the ACT. Babies born in private hospitals are given their own hospital identifier and birth information is provided to screeners. All screening data are entered in an Excel spreadsheet.

For babies who undergo audiological assessment, results are captured in the baby's medical record and provided back to the screening program by the audiologist within Canberra Health Services.

From November 2022, data on births, screening and audiological services across all ACT public hospitals and health services will be collected as part of an individual's Digital Health Record. This system will better capture key information and streamline the extraction and reporting of data.

No data on amplification or early intervention services are received from Hearing Australia.

Current reporting

Reporting is done internally on an ad hoc basis. It is intended the introduction of the Digital Health Record will streamline the extraction and reporting of data.

Governance arrangements

The ACT Newborn Hearing Screening Program reports to the Director of Allied Health in the Division of Women, Youth and Children, Canberra Health Services.

Relevant policies, frameworks or procedures

The ACT has an internal procedures policy. The ACT notes that a point of difference in their procedure, compared with most other states and territories, is that babies who do not pass testing in both ears will be screened 3 times before being referred to audiology (whereas other jurisdictions will usually test twice before referring).

Ability for linkage to other data collections

The new digital health record will contain a unique identifier that would allow for data linkage across all ACT public hospitals and health services. The ability to link data to other collections outside of these services would require manual linkage using other identifiable data items such as name and date of birth.

Overall assessment

The ACT currently collects data on all babies screened in the ACT and audiological assessments, however data collection is a manual process. The introduction of the digital health record system from November 2022 will better capture key information and allow for streamlined extraction and reporting of data across all ACT public hospitals and health services. Data from the ACT's single private birthing hospital are not captured in the digital health record system and so will continue to be collated manually. Data on early intervention are not currently collected in the ACT.

Northern Territory

Program overview

The NT's newborn hearing screening program is run by NT Hearing within the NT Department of Health and screens babies born in public birthing hospitals either in hospital or in community health settings across the NT.

Babies who require audiological assessment are offered specialised diagnostic as part of the screening program. Babies may then be referred to Hearing Australia for early intervention services, and, if required, referred on to a cochlear implant clinic.

The NT has one private birthing hospital which offers their own screening service. The service's screening protocol is guided by NT Hearing and babies requiring diagnostic assessment and targeted surveillance are referred to NT Hearing.

Current data holdings

When a baby is screened, a paper form is completed and filed in their hospital record. Babies are identified using a Hospital Reference Number (HRN) which is a unique identifier for all public health services in the NT. Digital data from the screening equipment are downloaded weekly and analysed monthly by NT Hearing in an Excel spreadsheet.

NT Hearing are currently in a phase of transition as a new Scanmedics database is implemented. NT Hearing are currently working on the database's functionality with the intention to streamline and improve efficiency of data analysis and reporting.

Data are captured until the end of the baby's diagnostic journey. Data on babies referred to Hearing Australia used to be provided through regular update meetings with Hearing Australia, however this arrangement has lapsed due to changes in Hearing Australia staffing.

Data for babies screened at Darwin Private Hospital are not provided to NT Hearing.

Current reporting

The NT currently prepare internal reports against indicators for the program's management. As part of their service delivery agreement under NT Health, the program also reports to the Executive Director on coverage of the program and, in the past, also reported on coverage of the program in NT Health annual report.

Governance arrangements

The program is governed by the Chief Executive of the NT Department of Health through Regional Executive Directors of the relevant regions in the NT.

Relevant policies, frameworks or procedures

The NT has an internal procedures policy.

Ability for linkage to other data collections

The baby's HRN could be used to link to other data collections that also hold this information. Linkage to other collections not using the HRN would require manual linkage using other identifiable data items such as name and date of birth.

Overall assessment

The NT currently collects screening data on all babies born in NT public birthing hospitals, audiological assessments, and diagnoses, however data extraction and reporting is a manual process. The introduction of their new Scanmedics database would allow for streamlined extraction and reporting of data across the NT. The development of this database could provide an opportunity to work collaboratively to ensure that data items for inclusion in a national data collection are incorporated into the NT's data collection system. Challenges lie in obtaining screening data from NT's one private birthing hospital who currently do not share data with the NT Department of Health.

Appendix B: Data items requested for analysis

Data items requested from states and territory to inform the ability of each state and territory to collate and supply neonatal hearing screening data to a national data collection and to further ascertain the availability of these data items. These data items provide a basis for assessment of data items that *could* potentially be included in a national data collection, but a national data collection would not be required to contain these specific data items, nor would it be limited to only containing these data items.

Table B1: Data items requested from states and territories for analysis

Data item	Description/notes
Demographic information	
Baby's name ^(a)	First and last names. Identifiable data item could be used for data linkage.
Mother's name ^(a)	First and last names. Identifiable data item could be used for data linkage.
Mother's or baby's address ^(a)	Full address of usual residence. Identifiable data item could be used for data linkage.
Mother's or baby's Medicare number ^(a)	Medicare number. Identifiable data item could be used for data linkage.
Sex of baby	<ul style="list-style-type: none"> • Male • Female • Other/indeterminate • Not stated
Geographic identifier of usual residence	The geographical region in which mother/baby usually resides, as represented by a Statistical area level 2 (SA2) code or post code.
Indigenous status of baby	Whether a person identifies as being of Aboriginal or Torres Strait Islander origin. Please include all the categories you collect, for example: <ul style="list-style-type: none"> • Aboriginal but not Torres Strait Islander origin • Torres Strait Islander but not Aboriginal origin • Both Aboriginal and Torres Strait Islander origin • Neither Aboriginal nor Torres Strait Islander origin • Not stated
Culturally and linguistically diverse (CALD) identifier	If available, please include any information you collect to identify those whose first language is one other than English, or whose family background involves migration from a non-English speaking country.
Birth information	
Date of birth	The date of birth of the baby. This item is required to derive the adjusted age.
Jurisdiction of birth	The state or territory in which the baby was delivered.
Gestational age	The gestational age that baby was born at.
Screening information (if multiple screens, please provide information for all)	
Date of screen	Date on which infant received either a positive (refer) or negative (pass) screen result.
Screen outcome	Whether an infant tested positive (refer) or negative (pass) for potential PCHI.
Audiological assessment information (if multiple assessments, please provide information for all)	

Date of audiological assessment	Date on which an infant completed audiological assessment.
Audiological assessment outcome	Outcome of audiological assessment including whether an infant was diagnosed with PCHI.
Type and degree of hearing loss	The type and degree of hearing loss.
Early intervention information	
Date of first attendance early intervention	Date on which an infant attends their first appointment at an early intervention service (or date of enrolment if that is what you collect – please specify which has been provided).
Assistive hearing device flag	Whether it was decided to fit the infant with an assistive device.
Date first assistive hearing device fitted.	Date on which an infant receives their first fitting of a hearing device.
First assistive hearing device type	Categorical data element that records the type of first assistive hearing device fitted.

(a) Identifiable data items were requested to be supplied as aggregate data to maintain a de-identified data sample.



All Australian states and territories have universal neonatal hearing screening programs, however, there is no standardised national data collection to support the measuring of screening delivery and outcomes from these programs.

This report provides advice on current neonatal hearing screening data and practices across the states and territories, and the opportunities for establishing a national data collection, including recommended next steps.

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