Australian Government
Australian Institute of Health and Welfare

Next steps in developing a national newborn hearing screening data set

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About

Between June 2023 and September 2024, the Australian Institute of Health and Welfare (AIHW) was contracted by the Australian Government Department of Health, Disability and Ageing (formerly the Department of Health and Aged Care) to progress development of nationally comparable data items that could support a future national data collection for newborn hearing screening. This report summarises the work of this project and outlines the recommended next steps to develop a national data collection.

The AIHW gratefully acknowledges the members of the newborn hearing screening data development committee, who provided valuable input regarding newborn hearing screening programs, practices, and data availability in their jurisdiction.

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Findings from this report:

- All jurisdictions have universal newborn hearing screening programs and collect screening data
- The national newborn hearing screening data development committee agreed to 21 data items for a national collection
- The AIHW recommends a range of short, medium and longer-term steps to build on this work
- A future national collection could potentially include assessment outcomes, identifiers, risk factors and interventions

Summary

Permanent hearing loss affects approximately 1 to 2 babies per 1,000 births (Vos et al 2019). Universal newborn hearing screening aims to identify those born with permanent congenital hearing impairment. All Australian states and territories have universal newborn hearing screening programs, however, there is no standardised national data collection to support the measurement of screening delivery.

In February 2023, the AIHW submitted a feasibility report to the Department of Health, Disability and Ageing which provided advice on current newborn hearing screening collections and practices across states and territories, and made recommendations 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 newborn hearing screening would improve the availability and quality of data, allowing for consistent measurement, reporting, and benchmarking for programs and outcomes nationally and internationally.

In June 2023, the Department of Health, Disability and Ageing further funded the AIHW to develop a national data collection for newborn hearing screening. The key outcomes of this project include:

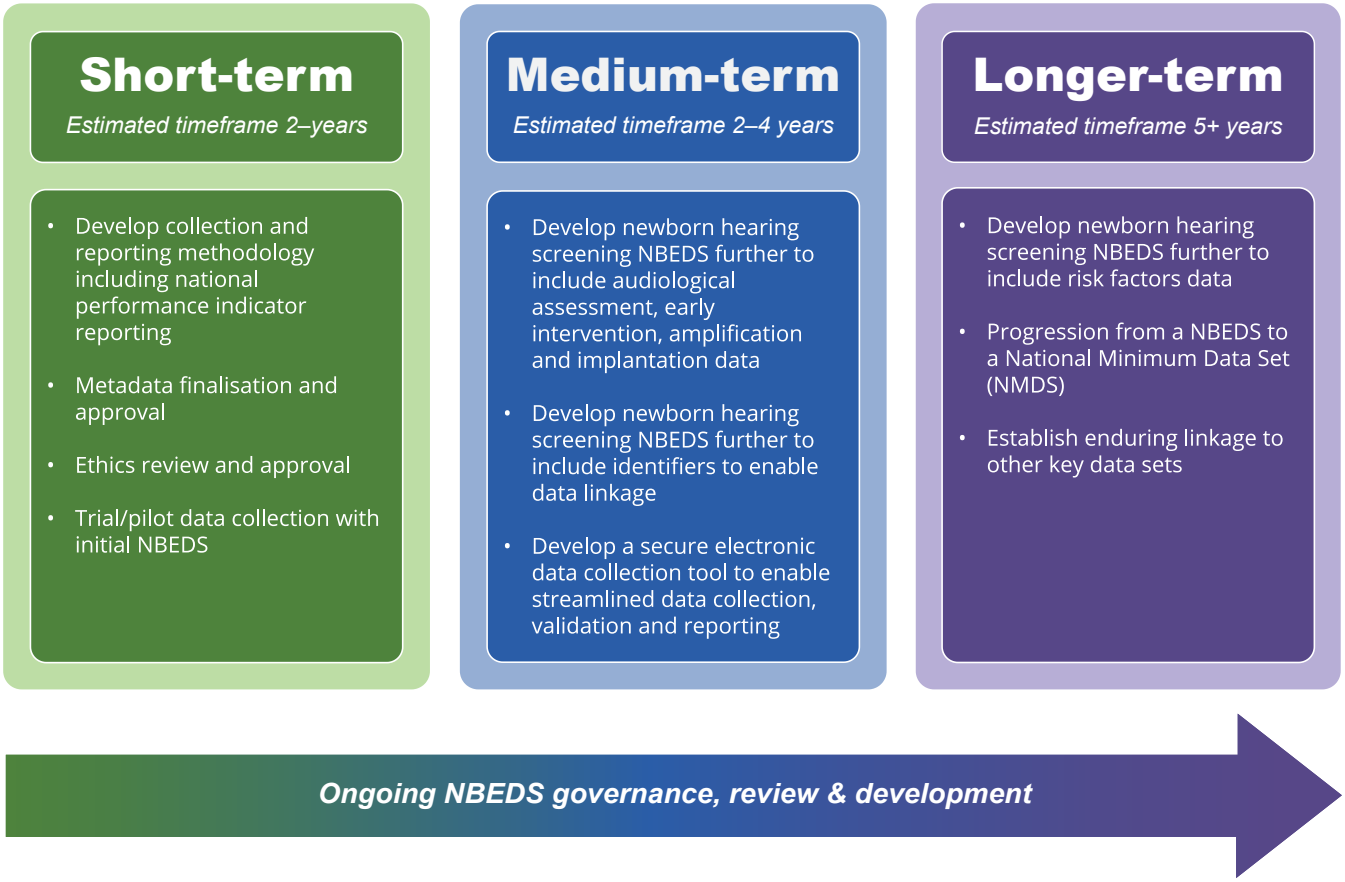
- Establishment of an advisory committee, the National Neonatal Hearing Screening Data Development Committee (the data development committee), to advise the AIHW on the development of the data collection. Chaired by the AIHW, the committee includes representation from all state and territory departments responsible for newborn hearing screening to ensure national agreement and consistency.
- The data development committee agreement that the scope of the data collection would include unit-record data on all liveborn babies in each Australian state and territory.
- Development of data standards and specifications for 21 data items to capture key demographic information, as well as data on the screening, outcomes, referrals, and reasons a newborn was not screened. These data items have been agreed to by the data development committee.
- Outlining the feasibility of reporting against the newborn hearing screening national performance indicators under the *National Framework for Newborn Hearing Screening*, published by the Department of Health, Disability and Ageing. This replaced the former *National Framework for Neonatal Hearing Screening*, published in 2013.

Initially, this work has focused solely on the newborn screening component of hearing programs, as this is where data is readily available across all jurisdictions. Future work could ensure the development of data along the screening pathway, such as audiological assessment and early intervention services.

Further medium- to long-term development could include expansion and further improvement of the collection to include data on audiological assessment, amplification, implantation, early intervention and risk factors. These next steps would enable a more holistic national understanding of the hearing screening pathway, and the ability to report against all proposed National Framework indicators.

A summary of recommended next steps, from short- to long-term development, is provided in Figure 1 below.

Figure 1: Summary of recommended next steps



Note: 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, for these data items to become mandatory for collection. See Glossary for full definitions.

References

Department of Health, Disability and Ageing (2025) National Framework for Newborn Hearing Screening, Department of Health, Disability and Ageing, Australian Government, accessed 4 August 2025.

Vos, B., Noll, D., Pigeon, M. et al. 2019. Risk factors for hearing loss in children: a systematic literature review and meta-analysis protocol. Systematic Reviews 8, Article number 172, accessed 3 September 2024.

Background

Each year around 300,000 babies are born in Australia (AIHW 2024) and permanent hearing loss is believed to affect at least 1 to 2 babies per 1,000 births (Morton & Nance 2006; Vos et al 2019), potentially 300 to 600 babies per year. Universal newborn hearing screening aims to identify those born with permanent congenital hearing impairment and provide them and their families with access to appropriate interventions to minimise the impact of their hearing impairment and improve outcomes.

All Australian states and territories have universal newborn 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 project was to start to fill this significant gap by developing a national collection on newborn hearing screening. The current project focused on the newborn screening program within the hearing pathway. Future work could ensure the development of data on audiology assessment, amplification, implantation and early intervention services.

References

Australian Institute of Health and Welfare (2024) Australia's Mothers and Babies, catalogue number PER 101, AIHW, Australian Government, accessed 3 September 2024.

Morton CC and Nance WE (2006) Newborn Hearing Screening – A Silent Revolution, The New England Journal of Medicine, 354:2151-2164, doi: 10.1056/NEJMra050700.

Vos, B., Noll, D., Pigeon, M. et al. 2019. Risk factors for hearing loss in children: a systematic literature review and meta-analysis protocol. Systematic Reviews 8, Article number 172, accessed 3 September 2024.

Scoping and feasibility project

From June 2022 to February 2023, the AIHW was contracted by the Department of Health, Disability and Ageing to undertake an assessment of the feasibility of building a national data collection regarding newborn hearing screening in Australia.

In February 2023, the AIHW submitted a report, *Environmental scan and assessment of the feasibility of developing a national neonatal hearing screening data collection*, to the Department of Health, Disability and Ageing to provide advice on current newborn hearing screening collections and practices across states and territories, and the environment for establishing a national data collection. This report, published by the AIHW in November 2023, concluded that the development of an Australian national data collection for newborn hearing screening is feasible and would enable improved availability and data quality (AIHW 2023). This collection could allow for regular and consistent reporting, the ability to measure key performance indicators, the provision of benchmarks for service improvement and the ability to make comparisons across services, nationally and internationally. The report outlined:

- the proposed scope of a national collection: unit-record data on all babies live born in each Australian state and territory
- analysis of available national data
- recommended next steps and timeframes.

Short-term (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 National Framework

Medium-term (2–4 years)

Develop Neonatal Hearing Screening NBEDS further to include:

- audiological assessment data
- identifiers to enable data linkage

Develop a secure electronic data collection tool to enable streamlined data collection, validation and reporting

Longer-term (5+ years)

Develop Neonatal Hearing Screening NBEDS further to include early intervention and risk factors data

Ongoing review of NBEDS to ensure consistency and relevancy

Progression from a NBEDS to a NMDS*

Establish enduring linkage to other key data sets

* 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. 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. See Glossary for full definitions.

Note: These timeframes are estimates.

References

Australian Institute of Health and Welfare (2023) Environmental scan and assessment of the feasibility of developing a national neonatal hearing screening data collection, catalogue number PER 125, AIHW, Australian Government, accessed 4 July 2024.

Development of a national data collection

In this section

Introduction

Following the scoping and feasibility project, the Department of Health, Disability and Ageing further funded the AIHW, through an Official Order, to progress the development of a data collection, in the form of a National Best Endeavours Data Set (NBEDS) for newborn hearing screening. A summary of the status of all activities in this project are outlined in Table 1 and further detail on each of these activities are provided below.

Table 1: Status of agreed activities in the Official Order

Activities	Status	Notes
1a. Establishment of an advisory committee to: • Advise the AIHW on the scope of and development of data items for inclusion in a national collection. • Advise the AIHW on newborn hearing screening data collection processes within their state/territory's jurisdiction. • 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 revision of national performance indicators. • Advise on the content and structure of draft AIHW reports relating to newborn hearing screening data. • Promote the use of national standards in relevant local and national data collections.	Complete	The National Neonatal Hearing Screening Data Development Committee, chaired by the AIHW, was established in October 2023. All state and territory departments responsible for newborn hearing screening are represented on the data development committee to ensure national agreement and consistency. The committee met formally three times and collaborated on 2 out-of-session consultation papers.
1b. Agreement on the scope of the data collection: In consultation with the advisory committee, AIHW will define and gain agreement on what the NBEDS will include and exclude. • Identification of data items for development: through consultation and collaboration with the advisory committee, AIHW will gain agreement on data items to be included in the NBEDS. • Draft standards for data items: consultation and collaboration through the advisory committee to draft standards for data items to be included in the NBEDS.	Complete	The scope of the data collection, with inclusion and exclusion criteria has been agreed by the data development committee. 21 data items have been agreed for inclusion in the initial NBEDS by the data development committee. Data standards have been developed to accompany the data items.
1c. Agreement of definitions and collection methods for data items to be included in a national collection, by the advisory committee.	Partially complete	The data development committee reached agreement on definitions of data items in August 2024. Specifics on collection methods are yet to be discussed, pending the next phase of development of the data collection.

1d. Revision of the national performance indicators: to align with the revised National Framework	In progress, in collaboration with the Department of Health, Disability and Ageing	Development of the NBEDS has sought to align with the proposed reporting under the *National Framework for Newborn Hearing Screening*. This report outlines feasibility of reporting against the newborn hearing screening indicators (1–4). Further development and feasibility assessment are required for indicators related to audiology, amplification and implantation services and early intervention.
1e. Preparation for Authoritative endorsement of the NBEDS by the National Health Data and Information Standards Committee (NHDISC).	In progress	The data specifications have been agreed to by the data development committee. They will require formal approval from National Health Data and Information Standards Committee and input into the AIHW'S metadata register METEOR.

Note: Activities 1a and 1b were agreed actions under the Official Order. Activities 1c, 1d and 1e were not bound as deliverables.

Establishment of an advisory committee

In October 2023, the National Newborn Hearing Screening Data Development Committee (the data development committee) was established. This committee is chaired by the AIHW and includes representatives from each state and territory department responsible for newborn hearing screening to ensure national agreement and consistency. A summary of each meeting and outcomes is outlined in Table 2.

Table 2: National Newborn Hearing Screening Data Development Committee meeting outcomes

Meeting date	Key outcomes
18 October 2023	Terms of reference were endorsed. Feedback on proposed NBEDS scope and data items were obtained.
28 March 2024*	Committee provided out-of-session comment on the proposed data specifications for the NBEDS.
5 June 2024	Refined scope of the NBEDS, detailed data specifications and definitions were discussed.
3 July 2024*	Committee provided out-of-session feedback on the revised data specifications for the NBEDS.
21 August 2024	Final scope, detailed data specifications and definitions were agreed for inclusion in the NBEDS.

* Note: These outcomes were progressed out-of-session.

Developing a national data collection

A national data collection is an agreed set of specifications to collect data for a particular purpose. A successful national data collection requires consistency and standardisation in data collection methods and agreed definitions.

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. There are different types of data sets that are each defined based upon the degree to which data provision is mandated (see Box 1).

Box 1: Types of data sets

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**, 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.

For more information see Data set specifications, AIHW 2024

The previous scoping report (AIHW 2023) recommended that data development work be undertaken to form a National Best Endeavours Data Set (NBEDS) on newborn hearing screening set that captures, as a minimum, information on newborn demographic and hearing screening and can be built upon to include additional data (such as audiological assessment and early intervention) in the future. The work to develop the NBEDS commenced with defining an agreed scope for the collection.

Scope of the NBEDS

The previous scoping report (AIHW 2023) recommended the scope for a national newborn hearing screening data collection would include unit-record data on all liveborn babies 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 would also allow for comparison to the number of babies born in Australia each year, as collected in the National Perinatal Data Collection (NPDC).

It was also recommended that, at a minimum, the initial national data collection should include information on:

- **Demographics**: including baby's Indigenous status, sex, date of birth, geographical area of usual residence and gestational age at birth
- **Screening**: including the number of screens, dates of screening, outcomes and, where applicable, reason screening was not performed.

During the current project phase, the scope was further refined and agreed to by the data development committee. It was agreed the scope of the data set would include:

- Unit record data on all liveborn babies – **babies of at least 20 weeks' gestation or 400 grams in birth weight in Australia**, in hospitals, birth centres and the community. The Australian national health data dictionary defines a 'live birth' as *the complete expulsion or extraction from its mother of a baby, of any gestation, that shows signs of life.*
- Stillbirths are excluded from this collection.

Data for the newborn hearing screening NBEDS would initially be provided to the AIHW by each state and territory department responsible for newborn hearing screening on a best endeavours (voluntary) basis, to form the national dataset.

Eligibility for newborn screening

All efforts are made to maximise participation in newborn hearing screening in Australia, taking into consideration baby's medical suitability and parental consent to undertake screening activities.

Babies considered eligible or ineligible for screening could be distinguished using the proposed NBEDS. For national reporting, 'eligible babies' could be defined using the National Framework criteria or a jurisdictional-based approach could be adopted, where babies are deemed eligible according to each state and territory program protocols. Eligibility criteria according to the National Framework and jurisdictional programs are outlined below.

National eligibility criteria for newborn hearing screening programs

The *National Framework for Newborn Hearing Screening* (Department of Health, Disability and Ageing, 2025) outlines a proposed national scope of newborn hearing screening:

Eligibility: All babies of at least 34 weeks' gestation and up to 6 months of age are eligible for newborn hearing screening, except for those that are unsuitable for screening.

Exclusions/Unsuitable for Screening: Some babies may be deemed unsuitable for screening and therefore excluded from newborn hearing screening. These include babies that:

- have microtia or atresia (infants with congenital aural atresia in one or both ears or with visible pinna/ear canal deformity such as stenosis or severe malformation are instead referred immediately for diagnostic audiologic evaluation)
- are medically unwell
- are stillborn or have died.

The National Framework states that reason(s) why infants are excluded from newborn hearing screening will be recorded in accordance with jurisdiction procedures.

State and territory newborn hearing screening programs' eligibility criteria

Future national reporting would need to consider jurisdictional differences in the scope of newborn hearing screening programs, which can differ from the nationally proposed scope under the National Framework. The NBEDS items will enable differentiation of eligible/ineligible babies and can account for jurisdictional differences. Jurisdictional differences in eligibility criteria are summarised in Table 3.

Table 3: State and territory differences in the scope of newborn hearing screening programs

State or territory newborn hearing screening program	Inclusion criteria	Exclusion criteria	Unsuitable for screening

NSW	Statewide Infant Screening - Hearing (SWISH) Program: • Well baby (medically stable) over 34 weeks gestation. • Four hours old to one month (corrected age). Note: The NSW Health SWISH Program aims to complete newborn hearing screening to eligible babies by one month of age, identify babies born with congenital permanent childhood hearing impairment by 3 months of age and facilitate access to appropriate amplification and early intervention by 6 months of age. Screening can be completed up to 6 months of age.	Stillborn. Neonatal death prior to newborn hearing screening. Note that the NSW Policy Directive is still being reviewed and there may be additional exclusion criteria. Screening should not be performed on babies less than gestational age of 34 weeks.	Babies with confirmed bacterial meningitis. Babies with microtia or atresia. Babies who remain medically unfit to screen at 3 months of age (corrected age).
Vic	Babies greater than 34 weeks and less than 6 months. At least 4–6 hours old. After treatments (vents, ototoxic meds) have ceased and ready for discharge. Babies with known neurological conditions or compromised skin– discussed on case-by-case basis to decide direct refer or screen and refer.	Non live births.	Babies with Microtia/atresia are directly referred. Babies with a pacemaker or programable implant need to be directly referred.
Qld	Live births, older than 34 weeks gestational age (ideally <1 month corrected age), are eligible to participate in the Healthy Hearing screening program. Include deceased as eligible.	–	Note that hearing screening is not performed on the following and these bypass screening with direct refer to audiology: • Medically unwell • Microtia / atresia.
WA*	Greater than 34 weeks gestational age and less than six months. Above 1500 grams. After treatments (vents, ototoxic meds) have ceased and ready for discharge. Medically stable. Asleep or in a quiet settled state. Have normal outer-ear anatomy in at least one ear and no major craniofacial anomalies that could impact on the screen (babies with microtia or atresia are included in newborn hearing screening).	It is medically inadvisable to attach the sensors and/or ear couplers, such as to compromised skin. Major craniofacial anomaly exists. Other conditions exist, which are deemed unsuitable for screening by medical staff and require a full diagnostic assessment by Audiology.	Occasional cases when the baby is receiving palliative care and the family and medical team have advised against screening.
SA	Includes babies >34 weeks gestation.	Babies <34 weeks.	Babies with microtia or atresia.
TAS	• Babies at >32 weeks' gestation. • Babies at least 4 hours old.	Babies <32 weeks.	Babies with microtia or atresia.
ACT	Babies >34 weeks gestation.	–	Babies deemed medically unfit (usually due to a neurological issue or severe skin condition).
NT	Babies ≥35 weeks' gestation. Screening may be delayed post 35 weeks for any number of medical reasons, but we would aim to screen all babies who meet that milestone.	Occasional cases where babies are not screened because it is clear the baby is only receiving short term palliative care – often these babies have neurological conditions, sometimes not.	Babies with severe neurological conditions. Babies with ear canal atresia or pinna.

* Note: Maternity hospital staff undertake screening at WA's public hospitals and the program coordinator, Child and Adolescent Health Service on behalf of the WA Department of Health, currently contract a private entity, the Earbus Foundation of WA, to undertake screening in private hospitals.

Data items for development

The scoping report (AIHW 2023) recommended there was sufficient interest and data availability to develop a national data collection that should initially focus on capturing demographic and screening information and could be built upon in future to include data on audiological assessment, risk factors, and early intervention.

As a result,16 demographic and screening data items were originally proposed for development to form the NBEDS at the first meeting of the data development committee in October 2023. These items were further developed, refined and discussed with the data development committee between March and August 2024. Some items were removed due to feasibility issues and others were added to establish a more complete collection.

The status of the items is outlined in Table 4.

Table 4: Development status of proposed data items

Data item	Data item topic	Rationale for inclusion	Status
State or territory identifier (baby) Person – person identifier, XXXXXX[X(14)]	Demographic	Identifier for each baby that is unique within a state/territory screening program. Allows for checking that records are unique and enables the AIHW to query records back to the state/territory. Where possible, having the same identifier as provided to the National Perinatal Data Collection would allow for future linkage (noting the correct ethics and consent requirements would need to be fulfilled prior to linkage being undertaken).	Retained for inclusion in the NBEDS.
State or territory of birth (baby) Birth event – state/territory of birth, code N (aihw.gov.au)	Demographic	Provides demographic information.	Retained for inclusion in the NBEDS.
Sex (baby) Person – sex, code X (aihw.gov.au)	Demographic	Provides demographic information.	Retained for inclusion in the NBEDS.
Date of birth (baby) Person – date of birth, DDMMYYYY (aihw.gov.au)	Demographic	Allows for calculation of chronological age.	Retained for inclusion in the NBEDS.
Gestational age (baby) Product of conception – gestational age, total completed weeks N[N] (aihw.gov.au)	Demographic	Allows for the calculation of corrected age (that is, a premature baby's chronological age minus the number of weeks or months early they were born).	Retained for inclusion in the NBEDS.
Indigenous status (baby) Person – Indigenous status, code N (aihw.gov.au)	Demographic	This item, when used in conjunction with the mother's Indigenous status, is a baseline measure of health for Indigenous children.	Retained for inclusion in the NBEDS.
Indigenous status (mother)	Demographic	Indigenous status of mothers is a key data resource for assessing antenatal care in pregnancy and other interventions before or during pregnancy, aimed at improving the health of mothers and babies.	Removed: this item is not commonly collected as part of newborn hearing screening data. Capture of baby's Indigenous status was considered to have primary importance for this collection.
Statistical Area Level 2 (SA2) of usual residence (mother) Person – area of usual residence, statistical area level 2 (SA2) code (ASGS Edition 3) N(9) (aihw.gov.au)	Demographic	Used for geographical analysis (for example remoteness, socioeconomic status). SA2 is the preferred data element to be used for geographical analysis (postcode should only be used when SA2 is not available). SA2 can be geocoded within state/territory health departments using the client's address.	Retained for inclusion in the NBEDS.
Postcode of usual residence (mother) Address – Australian postcode, code (Postcode datafile) NNNN (aihw.gov.au)	Demographic	May be used for geographical analysis (for example remoteness, socioeconomic status), however SA2 is preferred.	Retained for inclusion in the NBEDS.

State or territory of screen Australian state/territory code N	Hearing screening	State/territory where screen was performed as this may occasionally differ from state/territory of birth.	Retained and developed during the current project phase.
Date of screen (date of screen 1, screen 2 & screen 3)	Hearing screening	Allows for calculation of age at screening. Collecting 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.	Revised; further developed during the current project phase. Revisions included: • three separate items were included for the first three completed screens. • 'completed screen' was defined. • DDMMYYYY format was agreed.
Screen outcome (Screen outcome 1, Screen outcome 2 & Screen outcome 3)	Hearing screening	Collecting 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.	Revised; further developed during the current project phase. Revisions included: • three separate items were included for the first three completed screens. • 'completed screen' was defined. • revised from being a dichotomous data element indicating whether an infant tested positive (refer) or negative (pass) to include pass, unilateral refer, bilateral refer, not screened and not stated.
Overall outcome of screening	Hearing screening	Provides a determination of the overall outcome of the screening process according to the following categories: 1. Complete, discharged from screening 2. Complete, referred for targeted follow-up 3. Complete, referred for audiological assessment 4. Bypass, non-screening pathway 5. Screening in process 6. Incomplete 9. Not stated/inadequately described Enables the calculation of the proportion of eligible babies that have completed screening by 30 days of age (corrected).	New item added in the current project phase.
Date of hearing screening completion	Hearing screening	Screening completion date enables the calculation of the proportion of eligible babies that have completed screening by 30 days of age (corrected).	New item added in the current project phase. Agreed to be collected in DDMMYYYY format.
Reason not screened	Hearing screening	Provides an overview of why some babies are unable to be screened: 1. Declined 2. Missed screening 3. Moved interstate 4. Medical exclusion 5. Hearing screen bypass 6. Baby deceased 7. Ineligible 8. Other 9. Not stated/ inadequately described	Revised and further developed during the current project phase. Revisions included: • categorisation of reasons into 8 discrete categories that reflected current practice. • noted the item should pertain to the primary/main reason not screened.

Referral outcome	Hearing screening	This item captures the referral from the jurisdictional newborn hearing screening program within the following categories: 1. Referral following positive screen 2. Referral following negative screen 3. Referral without screening 4. No referral required 5. No referral provided 9. Not stated/inadequately described	New item added in the current project phase. Will aid in the calculation of the National Framework indicator: *Proportion of babies that require referral to audiological assessment are referred within 3 business days of screening*.
Date of referral	Hearing screening	This item captures the date in which the newborn has been referred from the jurisdictional hearing screening program.	New item added in the current project phase. Will aid in the calculation of the National Framework indicator: *Proportion of babies that require referral to audiological assessment are referred within 3 business days of screening*.
Referral type	Hearing screening	This item captures the type of service the referral was made (from the jurisdictional hearing screening program) within the following categories: 1. Audiologist: audiological assessment 2. Audiologist: targeted follow-up 7. Other 9. Not stated/inadequately described	New item added in the current project phase. Will provide context to the National Framework indicator: *Proportion of babies that require referral to audiological assessment are referred within 3 business days of screening*.

Data items for future development

In October 2023, the data development committee agreed that data items on diagnostic audiological assessment were not feasible for current reporting due to inconsistencies in data availability. However, it was noted that these items could be reassessed at a later stage of data development.

Depending on data quality, data from audiological assessment services could enable reporting on the number of babies who receive an audiological diagnosis, by screening outcome, diagnosis type(s) and age. Time between hearing screening completion to audiology assessment commence/complete date could also be explored. Further detail on these potential items is outlined in Table 5.

Table 5: Data items for potential future development

Data item	Status
Date of diagnostic audiological assessment	Not included, requires further development.
Diagnostic audiological assessment outcome	Not included, requires further development.
Date of audiological diagnosis completion	Not included, requires further development.
Type and degree of hearing loss	Not included, requires further development.

Note: 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.

Data items for future (medium to long term) development

Data items on more detailed demographics, amplification, implantation, early intervention, risk factors (and potential linkage identifiers) should also be considered for future development.

Depending on data quality, data from these items would enable a more complete picture of the patient characteristics, journey and outcomes along the hearing pathway. Given the data quality and availability of these items are largely unknown (or held outside existing established newborn hearing screening collections), these data items would require a longer lead time to develop and include in a national collection. Further detail on these potential items is outlined in Table 6.

Table 6: Items for potential medium to long term development

Data item	Rationale	Status

Name (baby)	May be considered for future development to enable linkage with other data collections. 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). Use of client identifiers such as the Statistical Linkage Key ‘SLK-581’ which includes 3 letters of family name, 2 letters of given name, date of birth and sex) may be considered if robust client demographics can be collected.	Not included, requires further development.
Name (mother)	May be considered for future development to enable linkage with other data collections.	Not included, requires further development.
Address (mother/baby)	May be considered for future development to enable linkage with other data collections.	Not included, requires further development.
Medicare number (mother/baby)	May be considered for future development to enable linkage with other data collections. This data item is predominantly unavailable in state and territory screening databases.	Not included, requires further development.
Culturally and linguistically diverse (CALD) identifier (mother)	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 in future (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.	Not included, requires further development.
Risk factors	May be considered for future development. 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 permanent congenital hearing impairment.	Not included, requires further development.
Early intervention Could include: • Date of first attendance at early intervention • Active/approved NDIS client status	May be considered for future development. 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). Data sources may include NDIS.	Not included, requires further development.
Amplification services data • Assistive hearing device flag • Date first hearing device fitted • First assistive hearing device type	Data could potentially be sourced from Hearing Australia.	Not included, requires further development.
Implantation services • Implantable hearing device flag • Date first implantable hearing device fitted • First implantable assistive hearing device type	Cochlear implants, bone conduction implants (surgical and non-surgical) and middle ear implants are some examples of implantable hearing devices. Hearing Australia do provide bone conduction devices to eligible people and may hold relevant data. Hearing Australia do not perform cochlear implant evaluation or surgery but do provide support and have a close relationship with cochlear implant clinics. The relevant data holdings for cochlear implants would require further exploration.	Not included, requires further development.

Agreed newborn hearing screening data items

A summary of the 21 agreed newborn hearing screening data items for the NBEDS are provided in Table 7. All items relate to the newborn hearing screening component of the pathway and have been agreed in-principle by the data development committee at their August 2024 meeting. Where current standardised metadata exist, a link to the standard in METEOR is provided.

Table 7: Data items agreed to form the newborn hearing screening NBEDS

Data item name	Data item topic	Data item information
1. Person identifier (baby)	Demographic	**Definition:** Identifier for each baby that is unique within a state/territory screening program. **Permissible values:** 2–20 characters long. This can be a combination of alphanumeric characters and dashes (-). **METEOR identifier**: 290046 **Guide for use:** • Individual agencies, establishments or collection authorities may use their own alphabetic, numeric or alphanumeric coding systems. • Field cannot be blank. • Identifier for each baby that is unique within a state/territory screening program. • Each ID is used by only one baby and each baby has only one ID.
2. State or territory of birth (baby)	Demographic	**Definition:** The state or territory in which a baby was delivered, as represented by a code. **Permissible values:** 1. New South Wales 2. Victoria 3. Queensland 4, South Australia 5. Western Australia 6. Tasmania 7. Northern Territory 8. Australian Capital Territory 9. Other 99. Not stated/inadequately described **METEOR identifier**: 718242 **Guide for use:** • The order presented here is the standard for the Australian Bureau of Statistics (ABS). Other organisations (including the Australian Institute of Health and Welfare) publish data in state order based on population (that is, Western Australia before South Australia and Australian Capital Territory before Northern Territory). • Only date of birth for the baby is collected. • In this collection 'other territories' is replaced with 'other'. • 'Other' refers to babies who are born outside of the state or territory of their current newborn hearing screening, but the specific jurisdiction of birth is unknown. • Where a baby was born outside Australia, this may also be captured in the 'Other' category.

3. Date of birth (baby)	Demographic	**Definition:** The date of birth of the person, expressed as DDMMYYYY. **Permissible values:** DDMMYYYY **METEOR identifier:** 287007 **Guide for use:** • If date of birth is not known or cannot be obtained, provision should be made to collect or estimate age. Collected or estimated age would usually be in years for adults, and to the nearest three months (or less) for children aged less than two years. Additionally, an estimated date flag or a date accuracy indicator should be reported in conjunction with all estimated dates of birth. • For data collections concerned with children's services, it is suggested that the estimated date of birth of children aged under 2 years should be reported to the nearest 3-month period, that is, 0101, 0104, 0107, 0110 of the estimated year of birth. For example, a child who is thought to be aged 18 months in October of one year would have his/her estimated date of birth reported as 0104 of the previous year. Again, an estimated date flag or date accuracy indicator should be reported in conjunction with all estimated dates of birth. • Only date of birth for the baby is collected. • Allows for the calculation of chronological age. • No estimated date flag is included as this is considered a robust item within newborn hearing screening. If the date is not unknown and cannot be estimated, it can be recorded as 99999999.

4. Gestational age at birth (baby)	Demographic	**Definition:** The gestational age of a baby in completed weeks.
		
		Permissible values:
		
		• Total completed weeks
		• Supplementary value: 99 Not stated/unknown.
		
		METEOR identifier: 695332
		
		Guide for use:
		
		• Gestational age is the best clinical estimate of the duration of pregnancy at a specific point in time, based on the first day of the last menstrual period (LMP), ultrasound or physical examination of the baby.
		• Gestational age is conventionally expressed in completed weeks. When gestational age is calculated using the first day of the LMP, the first day is counted as day zero and not day one. Therefore, a 25 week, 5 day fetus is considered a 25 week fetus (25+0, 25+1, 25+2, 25+3, 25+4, 25+5, 25+6).
		• When ultrasound is used to date a pregnancy, the earliest ultrasound examination should be used and should preferably be between 6 and 10 weeks gestation. Scans performed beyond 24 weeks gestation are unlikely to be reliable in estimating gestational age and should not be used for this purpose.
		• The World Health Organization identifies the following categories for duration of gestation:
		  ◦ pre-term: less than 37 completed weeks (less than 259 days) of gestation
		  ◦ term: from 37 completed weeks to less than 42 completed weeks (259 to 293 days) of gestation
		  ◦ post-term: 42 completed weeks or more (294 days or more) of gestation
		• Gestational age allows for the calculation of corrected age (that is, a premature baby’s chronological age minus the number of weeks or months early they were born).
		• Gestational age relates to the baby.

5. Sex (baby)	Demographic	**Definition:** The sex of a person, as represented by a code. **Permissible values:** 1. Male 2. Female 3. Another term 9. Not stated/inadequately described **METEOR identifier**: 741686 **Guide for use:** • This Value Domain is based on the Australian Bureau of Statistics Standard for sex, gender, variations of sex characteristics and sexual orientation variables (ABS 2021). The values are defined as follows: CODE 1 – Male Persons whose sex at birth or infancy was recorded as male, or who reported their sex as male at the time of collection. CODE 2 – Female Persons whose sex at birth or infancy was recorded as female, or who reported their sex as female at the time of collection. CODE 3 – Another term Persons whose sex at birth or infancy was recorded as another term (not male or female), or who reported their sex as another term (not male or female) at the time of collection. The value meaning of "Another term" has been assigned to Code 3 for this value domain, which replaces "Other" and "Intersex or indeterminate" in previous versions of this element. The third option recognises that across Australian jurisdictions and elsewhere there are a range of terms used. CODE 9 – Not stated/inadequately described This supplementary value is used to code inadequately described responses and non-responses for sex. It is not to be used on primary collection forms. It is primarily for use in administrative collections when transferring data from data sets where the item has not been collected. • A person's sex is based upon their sex characteristics, such as their chromosomes, hormones and reproductive organs. While typically based upon the sex characteristics observed and recorded at birth or in infancy, a person's reported sex can change over the course of their lifetime and may differ from their sex recorded at birth. • Sex is only collected for the baby.

6. Indigenous status (baby)	Demographic	**Definition:** Whether a person identifies as being of Aboriginal or Torres Strait Islander origin, as represented by a code.
		
		Permissible values:
		
		1. Aboriginal but not Torres Strait Islander Origin
		
		2. Torres Strait Islander but not Aboriginal origin
		
		3. Both Aboriginal and Torres Strait Islander origin
		
		4. Neither Aboriginal nor Torres Strait Islander origin
		
		Supplementary values:
		
		9. Not stated/inadequately described
		
		METEOR identifier: 602543
		
		Guide for use:
		
		• This metadata item is based on the Australian Bureau of Statistics (ABS) standard for Indigenous status (ABS 2014).
		• The classification for Indigenous status has a hierarchical structure comprising two levels. There are four categories at the detailed level of the classification which are grouped into two categories at the broad level. There is one supplementary category for 'Not stated/inadequately described' responses. The classification is as follows:
		• Indigenous Australians:
		  ◦ Aboriginal but not Torres Strait Islander origin.
		  ◦ Torres Strait Islander but not Aboriginal origin.
		  ◦ Both Aboriginal and Torres Strait Islander origin.
		• Non-Indigenous Australians:
		  ◦ Neither Aboriginal nor Torres Strait Islander origin.
		• Not stated/inadequately described: This category is not to be available as a valid answer to the questions but is intended for use:
		  ◦ Primarily when importing data from other data collections that do not contain mappable data.
		  ◦ Where the answer cannot be determined without clarification from the respondent (for example, 'No' and 'Yes, Aboriginal' are both selected).
		  ◦ Where an answer was declined.
		  ◦ Where the question was not able to be asked because the client was unable to communicate or a person who knows the client was not available.
		• This item refers to the Indigenous status of the baby – whether either the mother or the father, or both parents, identified as being of Aboriginal or Torres Strait Islander origin, as represented by a code.
		• For Indigenous status of the baby, it is recommended that parents are asked if the baby's mother or father are of Aboriginal or Torres Strait Islander origin, (or both).
		• Indigenous status of the mother is not collected.

7. Statistical Area Level 2 (SA2) of usual residence (mother)	Demographic	**Definition:** The geographical region in which a person or group of people usually reside, as represented by a statistical area level 2 (SA2) code. **Permissible values:** Components of SA2: State, SA4, SA3, SA2. **METEOR identifier:** 747315 **Guide for use:** • An SA2 is identifiable by a 9-digit fully hierarchical code. The SA2 identifier is a 4-digit code, assigned in alphabetical order within a Statistical area level 3 (SA3). An SA2 code is only unique within a state/territory if it is preceded by the state/territory identifier. • The SA2 should be collected based on the usual residence of the mother of the baby. • This item is used for geographical analyses (for example remoteness, socioeconomic status). • SA2 is the preferred data element to be used for geographical analysis (postcode should only be used when SA2 is not available). SA2 can be geocoded within state/territory health departments using the client's address.

8. Postcode of usual residence (mother)	Demographic	**Definition:** The Australian numeric descriptor for a postal delivery area for an address.
		
		Permissible values:
		
		• A full list of Australian postcodes can be found at Australia Post
		• Supplementary values:
		  ◦ 0097 Not applicable
		  ◦ 0098 Unknown
		  ◦ 0099 Not stated/ inadequately described
		  ◦ Code 0097 Not applicable: This code should be used in circumstances where it is not applicable to record an Australian postcode, for example, when there is no fixed address, or when an international (non-Australian) postcode is supplied.
		• This item refers to the postcode of the usual residence of the mother of the baby.
		• This data element may be used in the analysis of data on a geographical basis (for example remoteness, socioeconomic status) which involves coding data containing an address with a postcode to the Australian Bureau of Statistics (ABS) Australian Statistical Geography Standard (ASGS) areas.
		• A more accurate way to convert address data to ASGS geography is to use the locality to SA2 coding index, available from ABS, where the locality, postcode and state, (which are all part of an address), used in conjunction can effectively code data to the SA2 level and above in the ASGS.
		• While postcode may be used for geographical analysis, SA2 is preferred for this collection.
		
		METEOR identifier: 611398
		
		Guide for use:
		
		• Code 0097 Not applicable: This code should be used in circumstances where it is not applicable to record an Australian postcode, for example, when there is no fixed address, or when an international (non-Australian) postcode is supplied.
		• This item refers to the postcode of the usual residence of the mother of the baby.
		• This data element may be used in the analysis of data on a geographical basis (for example remoteness, socioeconomic status) which involves coding data containing an address with a postcode to the Australian Bureau of Statistics (ABS) Australian Statistical Geography Standard (ASGS) areas.
		• A more accurate way to convert address data to ASGS geography is to use the locality to SA2 coding index, available from ABS, where the locality, postcode and state, (which are all part of an address), used in conjunction can effectively code data to the SA2 level and above in the ASGS.
		• While postcode may be used for geographical analysis, SA2 is preferred for this collection.

9. State or territory of screen	Hearing screening	**Definition:** State or territory where the current hearing screen was performed, as represented by a code. **Permissible values:** 1. New South Wales 2. Victoria 3. Queensland 4.South Australia 5. Western Australia 6. Tasmania 7. Northern Territory 8. Australian Capital Territory 9. Not stated/inadequately described **METEOR identifier:** 718228 **Guide for use**: State of screen relates to the baby. • This item may differ from state or territory of birth. • Does not include other territories.
10. Date of first completed screen	Hearing screening	**Definition:** The date in which the newborn has been screened for possible hearing loss for the first time, expressed as DDMMYYYY. **Permissible values:** DDMMYYYY **METEOR identifier:** 270566 **Guide for use**: Date of screen relates to the baby. • No estimated date flag is included as this is considered a robust item within newborn hearing screening. • If the date is not unknown and cannot be estimated, it can be recorded as 99999999.

11. Outcome of first completed screen	Hearing screening	**Definition:** Whether a baby tested positive (refer) either unilaterally or bilaterally or negative (pass) for possible hearing loss on the first screen, as represented by a code. **Permissible values:** 1. Pass (negative) 2. Unilateral refer (positive) 3. Bilateral refer (positive) 4. Not Screened 9. Not stated/inadequately described **METEOR identifier**: to be developed **Guide for use:** Outcome of completed screens relate to the baby. • The outcome of screen 1 can be used to determine the overall pass or refer status of the baby's screen (if this is the baby's first and final completed screen). • In conjunction with other items (discharge date) allows for reporting on proportion of babies that have pass results on first screen who are discharged.
12. Date of second completed screen	Hearing screening	**Definition:** The date in which the newborn has been screened for possible hearing loss for a second time, expressed as DDMMYYYY. **Permissible values**: DDMMYYYY **METEOR identifier:** 270566 **Guide for use:** • Date of screen relates to the baby. • No estimated date flag is included as this is considered a robust item within newborn hearing screening. • If the date is not unknown and cannot be estimated, it can be recorded as 99999999.
13. Outcome of second completed screen	Hearing screening	**Definition:** Whether a baby tested positive (refer) either unilaterally or bilaterally or negative (pass) for possible hearing loss on the second screen, as represented by a code. **Permissible values:** 1. Pass (negative) 2. Unilateral refer (positive) 3. Bilateral refer (positive) 4. Not Screened 9. Not stated/inadequately described **METEOR identifier:** to be developed **Guide for use:** • Outcome of completed screens relate to the baby. • The outcome of screen 2 can be used to determine the overall pass or refer status of the baby's screen (if it relates to the second and final completed screen).
14. Date of third completed screen	Hearing screening	**Definition:** The date in which the newborn has been screened for possible hearing loss for the third time, expressed as DDMMYYYY. **Permissible values:** DDMMYYYY **METEOR identifier:** 270566 **Guide for use:** • Date of completed screens related to the baby. • Three screens are not applicable in all jurisdictions. • Date of screen relates to the baby. • No estimated date flag is included as this is considered a robust item within newborn hearing screening. • If the date is not unknown and cannot be estimated, it can be recorded as 99999999.

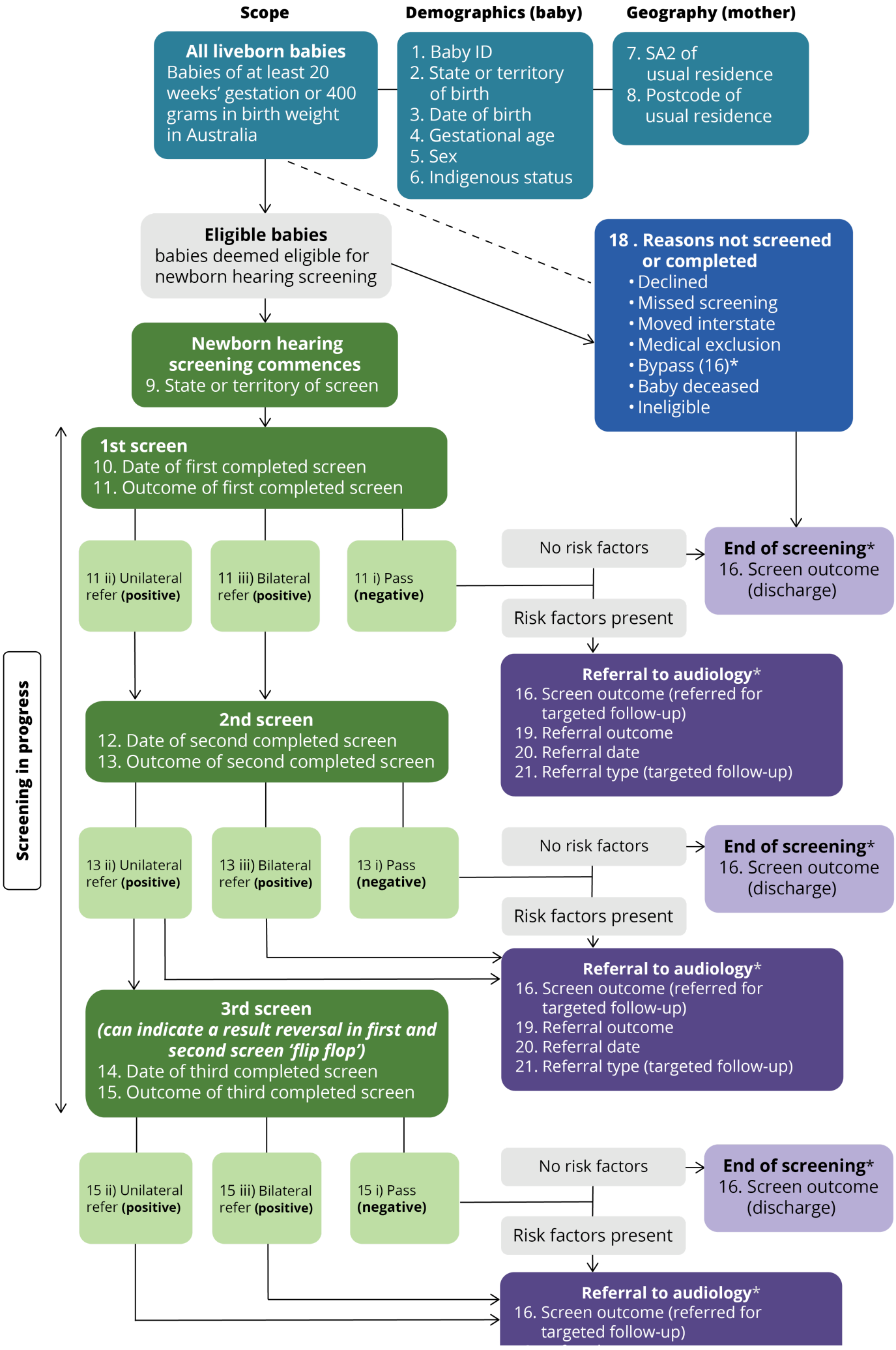
15. Outcome of third completed screen	Hearing screening	**Definition:** Whether a baby tested positive (refer) or negative (pass) for possible hearing loss on the third screen, as represented by a code. **Permissible values:** 1. Pass (negative) 2. Unilateral refer (positive) 3. Bilateral refer (positive) 4. Not Screened 9. Not stated/inadequately described **METEOR identifier:** to be developed. **Guide for use:** • Outcome of completed screens relate to the baby. • The outcome of screen 3 can be used to determine the overall pass or refer status of the baby's screen. • Some jurisdictions perform a 3rd screen where babies obtain result reversals (flip flop) in the first 2 screens. However, third screens can also be performed for other reasons.
16. Overall outcome of screening	Hearing screening	**Definition:** The outcome of the newborn hearing screening process, as represented by a code. **Permissible values:** 1. Complete, discharged from screening 2. Complete, referred for targeted follow-up 3. Complete, referred for audiological assessment 4. Bypass, non-screening pathway 5. Screening in process 6. Incomplete 9. Not stated/inadequately described **METEOR identifier:** to be developed. **Guide for use:** • Screen outcome relates to the baby. • Screen outcome enables the calculation of the proportion of eligible babies that have completed screening by 30 days of age (corrected).
17. Date of hearing screening completion	Hearing screening	**Definition:** The date in which the baby has completed hearing screening expressed as DDMMYYYY. **Permissible values:** DDMMYYYY **METEOR identifier:** 270566 **Guide for use:** Screening completion date relates to the baby. • Screening completion date enables the calculation of the proportion of eligible babies that have completed screening by 30 days of age (corrected). • Date of hearing screening completion relates to the baby. • No estimated date flag is included as this is considered a robust item within newborn hearing screening. • When an estimate is required, all known fields should be entered (for example if year and month are known use 01/MM/YYYY; if the exact date is unknown but the calendar year to which it relates can be determined, use 01/07/YYYY). • If the date is not known and can't be estimated, please record 99999999.

18. Primary reason not screened or completed	Hearing screening	**Definition:** The primary reason why a baby was not screened or where screening was incomplete, as represented by a code. **Permissible values:** 1. Declined 2. Missed screening 3. Moved interstate 4. Medical exclusion 5. Hearing screen bypass 6. Baby deceased 7. Ineligible 8. Other 9. Not stated/ inadequately described **METEOR identifier:** to be developed. **Guide for use**: Reasons not screened relate to the baby. If multiple reasons are known, only the main reason to be recorded.
19. Referral outcome	Hearing screening	**Definition:** The outcome of the referral from the jurisdictional hearing screening program, as represented by a code. **Permissible values:** 1. Referral following positive screen 2. Referral following negative screen 3. Referral without screening 4. No referral required 5. No referral provided 9. Not stated/inadequately described **METEOR identifier:** to be developed. **Guide for use:** Referral outcome relates to the baby.
20. Date of referral	Hearing screening	**Definition:** The date in which the newborn has been referred from the jurisdictional hearing screening program, expressed as DDMMYYYY. **Permissible values:** DDMMYYYY **METEOR identifier:** 270566 **Guide for use:** • Referral date of screen relates to the baby. • No estimated date flag is included as this is considered a robust item within newborn hearing screening. • When an estimate is required, all known fields should be entered (for example, if year and month are known use 01/MM/YYYY; if the exact date is unknown but the calendar year to which it relates can be determined, use 01/07/YYYY). • If the date is not unknown and cannot be estimated, it can be recorded as 99999999.
21. Referral type	Hearing screening	**Definition:** The type of service the referral was made (from the jurisdictional hearing screening program). **Permissible values:** 1. Audiologist: audiological assessment 2. Audiologist: targeted follow-up 7. Other 9. Not stated/inadequately described **METEOR identifier:** to be developed. **Guide for use:** • Referral type relates to the baby.

Note: Queensland, South Australia, Tasmania, Western Australia's public program and the Northern Territory perform a third screen where babies obtain 'flip-flop' results in the first 2 screens. Third screens can also be performed for other reasons.

Figure 2 below demonstrates how the agreed data items fit within the newborn hearing screening pathway.

Figure 2: NBEDS DATA items within the newborn hearing screening pathway


Scope
Demographics (baby)
Geography (mother)
All liveborn babies
Babies of at least 20 weeks' gestation or 400 grams in birth weight in Australia
1. Baby ID
2. State or territory of birth
3. Date of birth
4. Gestational age
5. Sex
6. Indigenous status
7. SA2 of usual residence
8. Postcode of usual residence
Eligible babies
babies deemed eligible for newborn hearing screening
18 . Reasons not screened or completed
• Declined
• Missed screening
• Moved interstate
• Medical exclusion
• Bypass (16)*
• Baby deceased
• Ineligible
Newborn hearing screening commences
9. State or territory of screen
Screening in progress
1st screen
10. Date of first completed screen
11. Outcome of first completed screen
11 ii) Unilateral refer (positive)
11 iii) Bilateral refer (positive)
11 i) Pass (negative)
No risk factors
End of screening*
16. Screen outcome (discharge)
Risk factors present
Referral to audiology*
16. Screen outcome (referred for targeted follow-up)
19. Referral outcome
20. Referral date
21. Referral type (targeted follow-up)
2nd screen
12. Date of second completed screen
13. Outcome of second completed screen
13 ii) Unilateral refer (positive)
13 iii) Bilateral refer (positive)
13 i) Pass (negative)
No risk factors
End of screening*
16. Screen outcome (discharge)
Risk factors present
Referral to audiology*
16. Screen outcome (referred for targeted follow-up)
19. Referral outcome
20. Referral date
21. Referral type (targeted follow-up)
3rd screen
(can indicate a result reversal in first and second screen 'flip flop')
14. Date of third completed screen
15. Outcome of third completed screen
15 ii) Unilateral refer (positive)
15 iii) Bilateral refer (positive)
15 i) Pass (negative)
No risk factors
End of screening*
16. Screen outcome (discharge)
Risk factors present
Referral to audiology*
16. Screen outcome (referred for targeted follow-up)

* Note: Screen completion date (17) can be derived at this point.

19. Referral outcome
20. Referral date
21. Referral type (targeted follow-up)

Extended description for Figure 2: NBEDS DATA items within the newborn hearing screening pathway

A diagram that provides an overview of newborn babies' hearing screening pathways, including:

- the process through which eligible newborn babies can progress through a maximum of three hearing screens
- the reasons for which babies are not screened or able to have screening completed

The diagram outlines how each of the proposed data items fit within the newborn hearing screening process.

This includes a summary of the scope of the collection and the demographic and geographic information collected.

Definitions of data items

To accompany the data specifications, a comprehensive glossary was also developed (see Glossary). Glossary items were developed to align with existing data standards, where these existed. New newborn hearing-specific definitions were developed collaboratively with the data development committee to ensure they aligned with current jurisdictional policy and practice.

Collection methodology

Although the specific collection methodology is yet to be finalised, it was agreed that jurisdictions would provide unit-record level data to the AIHW on a best endeavours (voluntary) basis for national collection and reporting.

The AIHW recommends that the frequency of the collection be annual, at minimum. Further feasibility assessment and discussion with the data development committee would be required to determine collection frequency and the specific methodology for data provision.

References

Australian Institute of Health and Welfare (2023) Environmental scan and assessment of the feasibility of developing a national neonatal hearing screening data collection, catalogue number PER 125, AIHW, Australian Government, accessed 4 July 2024.

Department of Health, Disability and Ageing (2025) National Framework for Newborn Hearing Screening, Department of Health, Disability and Ageing, Australian Government, accessed 4 August 2025.

National Framework indicator reporting

According to the *National Framework for Newborn Hearing Screening* (Department of Health, Disability and Ageing, 2025), 10 national performance indicators have been outlined which cover five key areas of the screening pathway (Table 8).

Further development of assessment and intervention data would be required to enable national reporting against national performance indicators 5–10.

Table 8: National performance indicators

Number	National performance indicator	Service area
1	Proportion of eligible babies that complete newborn hearing screening.	Screening
2	Proportion of eligible babies that have completed screening by 30 days of age.	Screening
3	Proportion of babies receiving a refer (positive) result following screening.	Screening
4	Proportion of babies that require referral to audiological assessment are referred within 3 business days of screening.	Screening
5	Proportion of referred babies that have audiological diagnosis completed by 3 months of age.	Audiology
6	Proportion of screened babies that receive a diagnosis of permanent bilateral moderate to profound hearing loss.	Audiology
7	Proportion of babies referred to Hearing Australia offered an appointment within 2 weeks of referral.	Amplification
8	Proportion of babies with bilateral permanent moderate to profound hearing loss recommended for hearing aid that have their hearing aid fitted by 6 months of age.	Amplification
9	Proportion of babies that meet criteria for cochlear implantation that receive the implant by 12 months of age.	Implantation
10	Proportion of eligible babies that have access to NDIS support by 6 months of age.	Early Intervention

Note: Indicators are reported in the National Framework, published July 2025.

The 21 agreed hearing screening data items as part of the NBEDS would allow reporting on the National Framework indicators relating to screening pathway (national performance indicators 1–4). Tables 9, 10, 11 and 12 further delineate the technical specifications to enable the calculation of the reportable indicators.

Table 9: Technical indicator specifications for national performance indicator 1

Indicator	National performance indicator 1
Indicator description	Proportion of eligible babies that complete newborn hearing screening
Formula	[Number of eligible babies born in a reference period who complete a newborn hearing screen/Number of eligible babies born in a reference period] *100
Definition	Proportion of eligible babies born in a reference period who complete a newborn hearing screen through a jurisdictional newborn hearing screening program.
Numerator	Number of eligible babies born in a reference period who complete a hearing screen. Relevant NBEDS items: • Date of screening completion (not null). • Overall outcome of screening (values 1– 4: 1. Complete, discharged from screening; 2. Complete, referred for targeted follow-up; 3. Complete, referred for audiological assessment; 4. Bypass, non-screening pathway). • Of these, babies ineligible for newborn hearing screening will be excluded.
Denominator	Number of eligible babies born in a reference period. Relevant NBEDS items: • Total number of unique baby IDs with a valid date of birth. Note: Comparison to the number of babies collected in the National Perinatal Data Collection may be undertaken. • Of these, babies ineligible for newborn hearing screening will be excluded.
Calculation	The number of eligible babies who complete a newborn hearing screen through a jurisdictional screening program as a proportion of all eligible babies born in a reference period.
National Framework objectives	1.1.1. All babies of at least 34 weeks' gestation and up to 6 months of age are eligible for newborn hearing screening, except for babies that are unsuitable for screening. 1.1.2. Newborn hearing screening should be offered to all eligible babies. Babies over 6 months are out of scope for newborn hearing screening due to equipment limitations.

Rationale	This indicator measures the proportion eligible babies who complete a newborn hearing screening program. Newborn hearing screening should be offered to all eligible babies. Eligible babies are all babies of at least 34 weeks gestation and up to 6 months of age, excluding babies that are unsuitable for screening (for example those with microtia or atresia, are medically unwell, are stillborn or have died). For some babies, a referral for medical bypass is more appropriate than screening. All efforts are made to maximise participation in newborn hearing screening in Australia, taking into consideration medical suitability and parental consent to undertake screening. Universal newborn hearing screening is important for population health as it lowers the age of diagnosis of permanent hearing loss.
Disaggregation	Depending on data quality and availability, the data could be disaggregated by: • State or territory of birth • State or territory of screen • Age (chronological and corrected) at completed screen • Gestational age • Corrected age • Sex • Indigenous status • Remoteness and SEIFA (usual residence of the mother) • Number of completed screens • Screen outcome • Reason not screened
Issues for consideration	• The denominator should be the number of live births. The National Perinatal Data Collection provides a comprehensive validated dataset of all live births in Australia. The National Perinatal Data Collection data is often available 18 months after the collection period (with preliminary data from most states available within 12 months). Most jurisdictional newborn screening programs can provide a suitable and timely alternative which would likely be used for reporting. • This indicator restricts the inclusion criteria to eligible babies. Differences in jurisdictional programs' eligibility criteria need to be considered alongside any indicator reporting. Eligibility status may be determined by the nationally proposed scope. In this case, the AIHW will be able to filter eligible records based on babies age and 'reasons not screened'. If, however, jurisdiction-specific eligibility is used, states and territories would need to provide a flag or code to highlight eligible babies according to their criteria. • The National Framework notes that the reason why babies are excluded from newborn hearing screening should be recorded in accordance with jurisdiction procedures. Therefore, consideration and reporting of the subgroup of babies who are not screened will be useful adjunct reporting. • Babies who bypass screening and are referred directly to audiology are often still included as having completed screening as a clinical determination and valid referrals are made in these cases. These cases can be captured using the agreed items. • The reference period is yet to be determined. This could be a calendar or financial year period depending on administrative and collection processes.

Table 10: Technical indicator specifications for national performance indicator 2

Indicator	National performance indicator 2
Indicator description	Proportion of eligible babies that have completed screening by 30 days of age (corrected)
Formula	[Number of eligible babies born in a reference period who complete a hearing screen within 30 days/Number of eligible babies born in a reference period] *100
Definition	Proportion of eligible babies born in a reference period who complete a newborn hearing screen through a jurisdictional newborn hearing screening program by 30 days of age (corrected).
Numerator	Number of eligible babies born in a reference period who complete a hearing screen within 30 days. Relevant NBEDS items: • Date of screening completion (not null and within 30 days of age or corrected age). • Overall outcome of screening (values 1– 4: 1. Complete, discharged from screening; 2. Complete, referred for targeted follow-up; 3. Complete, referred for audiological assessment; 4. Bypass, non-screening pathway). • Baby's date of birth. • Gestational age (to calculate corrected age). • Corrected age (derived): to be used where babies are born prior to 37 weeks' gestation. Babies ineligible for newborn hearing screening will be excluded.
Denominator	Number of eligible babies born in a reference period. Babies ineligible for newborn hearing screening will be excluded. Relevant NBEDS item: Total number of unique baby IDs with a valid date of birth. Comparison to the number of babies collected in the National Perinatal Data Collection may be undertaken.

Calculation	The number of eligible babies who complete a newborn hearing screen through a jurisdictional screening program within 30 days of (corrected) age as a proportion of all eligible babies born in a reference period.
National Framework objectives	1.3.1. Where possible, eligible babies should have completed screening by 30 days of age (corrected). 1.3.2. Reasons for screening being completed after 30 days (corrected age) should be recorded consistent with jurisdiction protocols.
Rationale	This indicator reflects the internationally recognised '1-3-6 benchmark' for newborn hearing screening which aims for screening to be completed by one month (30 days); audiologic diagnosis by 3 months, and enrolment in early intervention by 6 months (Joint Committee on Infant Screening 2007). However, the 2019 Joint Committee on Infant Heating (JCIH 2019) position statement recommends that jurisdictions already meeting the '1-3-6' benchmark should be striving for a more ambitious '1-2-3 benchmark'. Evidence indicates that early detection and management of hearing loss leads to improved speech, language and educational outcomes (Ching 2015).
Disaggregation	Depending on data quality and availability, the data could be disaggregated by: • State or territory of birth • State or territory of screen • Age (chronological and corrected) at completed screen • Sex • Indigenous status • Remoteness, SEIFA (usual residence of the mother) • Number of completed screens • Screen outcome • Reason not screened
Issues for consideration	• This indicator is a subset of indicator 1. It could therefore be reported as a disaggregation of Indicator 1 instead of a standalone indicator. • The denominator should be the number of live births. The National Perinatal Data Collection provides a comprehensive validated dataset of all live births in Australia. The National Perinatal Data Collection data is often available 18 months after the collection period (with preliminary data from most states available within 12 months). Most jurisdictional newborn screening programs can provide a suitable and timely alternative which would likely be used for reporting. • This indicator restricts the inclusion criteria to eligible babies. Differences in jurisdictional programs' eligibility criteria need to be considered alongside any indicator reporting. Eligibility status may be determined by the nationally proposed scope. In this case, the AIHW will be able to filter eligible records based on babies age and 'reasons not screened'. If however, jurisdiction-specific eligibility is used, states and territories would need to provide a flag or code to highlight eligible babies according to their criteria. • The National Framework notes that the reason/s why babies are excluded from newborn hearing screening should be recorded as applicable in accordance with jurisdiction procedures. Therefore, consideration and reporting of the subgroup of babies who are not screened will be useful adjunct reporting. • Babies who bypass screening and are referred directly to audiology are often still included as having completed screening as a clinical determination and valid referrals are made in these cases. These cases can be captured using the agreed items. • The reference period is yet to be determined. This could be a calendar or financial year depending on administrative and collection processes. • 30 days is used as an 'average month' and is consistent with measures used across other nationally reported indicators. • Calculation of corrected age: Corrections are applied for babies who are born <37 weeks gestation. For example, a baby born at 36 + 0 weeks has 7 days (1 week) + 30 days to complete hearing screening to meet the target for National Performance Indicator 2. 37 weeks is based on the WHO definition that identifies 37 weeks as the earliest point of a term birth (see product of conception). The AIHW notes that perinatal literature (such as Tita et al. 2018, Bentley et al 2018) suggests that a birth between 37-38 weeks is considered 'early term' with poorer outcomes than those born between 39-41 weeks. As the clinical understanding on pre-term outcomes evolves, amendments to the calculation of corrected age could be considered.

Table 11: Technical indicator specifications for national performance indicator 3

Indicator	National performance indicator 3
Indicator description	Proportion of babies receiving a refer (positive) result following screening
Formula	[Number of eligible babies born in a reference period who receive a refer (positive) result following screening/Number of babies screened in a reference period] *100
Definition	Proportion of eligible babies that have received a refer (positive) result following newborn hearing screening.

Numerator	Number of babies born in a reference period who returned a refer (positive) newborn hearing screen. Relevant NBEDS items: • Total number of unique baby IDs with a valid date of birth • Outcome of the final completed screen (unilateral refer or bilateral refer) • Date of hearing screening completion (not null) Babies ineligible for newborn hearing screening will be excluded.
Denominator	Number of babies born in a reference period who completed a newborn hearing screen (excluding screening bypass babies). Relevant NBEDS items: • Total number of unique baby IDs with a valid date of birth • Date of screening completion (not null) • Overall outcome of screening (values 1-3): 1. Complete, discharged from screening 2. Complete, referred for targeted follow-up 3. Complete, referred for audiological assessment
Calculation	The number of babies who returned a refer (positive) newborn screening hearing result as a proportion of all babies screened.
National Framework objectives	2.2.5 Screening programs will monitor screening results and investigate if positivity rates are substantially higher (or lower) than 2% of total screens conducted.
Rationale	The positivity or referral rate of the screening test is an important indication of how well the screening test is performing. A positivity rate of less than 2% is expected using AABR technology; a higher rate could indicate that the screening test is yielding too many false positive results or indicate an increase in the prevalence of hearing loss worthy of further investigation. A notably low positivity rate could indicate testing is yielding too many false negative results. The positivity rate of the screening test provides an indication of how well the screening test is functioning as a test of potential congenital permanent bilateral, unilateral sensory, or permanent conductive hearing (or mild hearing loss).
Disaggregation	Depending on data quality and availability, the data could be disaggregated by: • State or territory of birth • State or territory of screen • Age (chronological and corrected) at completed screen • Sex • Indigenous status • Remoteness, SEIFA (usual residence of the mother) • Number of completed screens • Screen outcome • Refer status (unilateral or bilateral)
Issues for consideration	• This indicator restricts the inclusion criteria to eligible babies. Differences in jurisdictional programs' eligibility criteria need to be considered alongside any indicator reporting. Eligibility status may be determined by the nationally proposed scope. In this case, the AIHW will be able to filter eligible records based on babies age and 'reasons not screened'. If however, jurisdiction-specific eligibility is used, states and territories would need to provide a flag or code to highlight eligible babies according to their criteria. • The reference period is yet to be determined. This could be a calendar or financial year period depending on administrative and collection processes. • Babies can be screened on multiple occasions. The NBEDS captures outcomes from 3 completed screens. The outcome of the last completed screen can be used to determine the overall pass or refer status of the baby's screen. There is also a separate item that captures the overall outcome of the screening process. • The NBEDS will be able to distinguish unilateral refer results from bilateral refer results. • The proportion of babies who receive a refer (positive) result may include those who obtain false positive results. Research has indicated that false positives using AABR equipment can be around 2% (Mehl & Thomson 1998). • The disaggregation for this indicator will ensure that the screening test is performing equally across some population subgroups. Investigation of other subpopulations based on CALD and socioeconomic status would require further development. • An understanding of how many babies bypass the screening pathway and obtain direct referral to audiology are considered helpful adjunct reporting. Bypass babies are excluded from the calculation as this indicator seeks to determine positive results following a screen. • In the future, another indicator of how well the screening test is functioning could be obtained from the positive predictive value of the screening test, which is the proportion of babies who receive a refer (positive) hearing screen who, following further assessment, are diagnosed with is congenital permanent bilateral, unilateral sensory, or permanent conductive hearing loss including neural hearing loss of >40 decibels (or mild hearing loss).

Table 12: Technical indicator specifications for national performance indicator 4

Indicator	National performance indicator 4

Indicator description	Proportion of babies that require referral to audiological assessment are referred within 3 business days of screening
Formula	[Number of eligible babies born in a reference period who were referred to audiological assessment within 3 business days of screening completion/Number of eligible babies born in a reference period who required a referral to audiological assessment] *100
Definition	Proportion of eligible babies that received a referral to audiological assessment within 3 business days of screening completion.

Numerator	Number of babies born in a reference period who were referred within 3 business days of screening completion.
	
	Relevant NBEDS items:
	
	• Total number of unique baby IDs with a valid date of birth.
	• Date of screening completion (not null).
	• Screen outcome (values 2–3):
	  ◦ value 2: complete referred for targeted follow-up.
	  ◦ value 3: complete, referred for audiological assessment.
	• Referral outcome (values 1–3: 1 referral following positive screen, 2 referral following negative screen, 3. referral without screening).
	• Referral date (not null, <3 business days from date of screening completion).

Denominator	Number of babies born in a reference period who required a referral to audiological assessment Relevant NBEDS items: • Total number of unique baby IDs with a valid date of birth. • Date of screening completion (not null). • Screen outcome (values 2–3: 2. complete referred for targeted follow-up, 3. complete, referred for audiological assessment). • Referral outcome (values 1–3: 1 referral following positive screen, 2 referral following negative screen, 3 referral without screening).
Calculation	This calculation measures the number of babies who were referred for audiological assessment within 3 business days of screening completion, as a proportion of all babies who required a referral.
National Framework objectives	2.4.3. Referrals to audiological assessment should be made within 3 business days of completing screening.
Rationale	All state and territory screening programs aim to identify babies who are likely to be born with hearing loss or require further evaluation. Referral to hearing services for audiological assessment are made as soon as possible. To meet the Internationally recognised best-practice of audiologic diagnosis by 3 months of age (Joint Committee on Infant Screening 2007), prompt referral following screening is paramount. Evidence indicates that early detection and management of hearing loss leads to improved speech, language and educational outcomes.
Disaggregation	Depending on data quality and availability, the data could be disaggregated by: • State or territory of birth • State or territory of screen • Age (chronological and corrected) at completed screen • Sex • Indigenous status • Remoteness, SEIFA (usual residence of the mother) • Number of completed screens • Screen outcome • Referral outcome • Referral type (audiological assessment, audiologist, targeted follow-up or ‘other’)

Issues for consideration	• The reference period is yet to be determined. This could be a calendar or financial year period depending on administrative and collection processes. • Jurisdictional practice regarding referrals needs to be considered. Babies can be referred to audiological assessment for different reasons and the reason for referral must be factored into reporting. For example, there may be triage process and differing priorities between a referral following a positive screen result versus a referral for risk factors. • This indicator does not delineate wait times to attend and complete audiological assessment. • The program logic for determining a 3-business-day window for referral is unknown. While prompt referral is required, it is unclear whether 3 business days provides the best indicator of promptness. • The calculation of three business days also requires further development. At present, the data only allows for simple date-to-date analysis and would not account for the time of day in which screening or referral was undertaken. • Analysis of non-referrals could be undertaken. That is, babies who completed screening (and were noted to have been referred) but for whom no referral was provided (or required). • An understanding of what proportion of babies bypass the screening pathway and obtain direct referral to audiology are considered helpful adjunct reporting. 'Bypass babies' are included in this indicator as they are considered babies that require referral.

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Recommendations and next steps

Recommendations

Based on the AIHW's consultation with the National Newborn Hearing Screening Data Development Committee, the following recommendations are made regarding the continued development of a national newborn hearing screening NBEDS:

Recommendation 1

All state and territory newborn hearing screening programs should continue to be engaged through the data development committee to maintain and develop consistent data standards in the newborn hearing screening National Best Endeavours Data Set (NBEDS). This will ensure:

- 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.

Recommendation 2

Further work be undertaken to progress the NBEDS to an implementation phase, including:

- development of specific collection and reporting methodology
- finalisation of data provision and reporting frequency
- authoritative review and endorsement of metadata
- AIHW ethics approval of the new collection
- implementation of a trial or pilot data collection
- ongoing monitoring and review
- exploration of the capacity for reporting data back to services.

Recommendation 3

Further data development work be undertaken to expand the national newborn hearing screening NBEDS, including:

- identification and development of new data items to capture data from other parts of the screening pathway.
- consultation to assess the capacity to collate information on audiological assessment, risk factors, early intervention, amplification and implantation services in the NBEDS. The most appropriate data sources for these hearing screening pathway components need to be explored.
- the inclusion of identifying data and/or a data linkage key to enable future linkage with socio-demographic, medical, educational and employment administrative datasets.

Recommendation 4

The continued development and governance of the newborn hearing screening NBEDS, through engagement with the following key stakeholders:

- state and territory newborn hearing screening programs via the data development committee, to ensure national agreement and consistency on data standards and reporting
- other hearing specialists and organisations (including audiologists, Hearing Australia and the National Disability Insurance Agency) to better understand data from these aspects of the hearing pathway
- the AIHW metadata team to ensure data specifications meet national standards
- the AIHW Ethics Committee to ensure the data collection are ethically acceptable and that data about people is handled with respect and in best practice.

Next steps

All jurisdictions support the development of a newborn hearing screening NBEDS and have provided agreement on the data items for inclusion. The key next step is to progress the national newborn hearing screening NBEDS to an implementation phase, to facilitate data collection and reporting.

The initial focus of the collection is 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, early intervention, amplification and implantation services.

Given there are challenges that arise from differences in program practices and data collection between the states and territories, all jurisdictions need to continue to be engaged to develop and work towards consistent national data standards. The National Framework may also provide a strong impetus for jurisdictional collaboration, and national consistency towards common goals.

A range of short, medium and longer-term steps are recommended to build on this work.

Short-term development (2 years)

The AIHW recommends the next steps be undertaken to ensure the timely continued development of the NBEDS during 2025–26.

Step 1: Development of collection and reporting methodology

The following collection methodologies need to be further discussed and agreed by the data development committee:

- Frequency of data collection
- Means of data provision from jurisdictional systems to the AIHW
- Data validation processes

- Frequency of reporting
- Required reporting products (such as published reports and resources, data tables and other products, such as data return to source)

Processes for reporting on the national performance indicators under the National Framework will also need to be established.

Step 2: Metadata finalisation and authoritative endorsement

- Technical review of metadata items: The approved data specifications require review by the team of metadata experts at the AIHW. This will ensure the specifications meet national standards and are correctly formatted for input on AIHW's metadata online registry (METEOR).
- National Health Data and Information Standards Committee approval: Following input into METEOR, the specifications will require formal approval from the National Health Data and Information Standards Committee. This committee provides advice to the AIHW for its work in developing and maintaining national health data and information standards and related national health information infrastructure, in the context of the National Health Information Agreement. Membership of the committee comprises all signatories to the National Health Information Agreement, including the Department of Health, Disability and Ageing. It is anticipated that the Newborn Hearing Screening NBEDS could be put to the National Health Data and Information Standards Committee for endorsement in the next project phase.

Step 3: Ethics approval

All new projects and data collections require an ethics application to be reviewed and approved by the AIHW Ethics Committee prior to the collection of data.

The AIHW Ethics Committee is established under section 16(1) of the *Australian Institute of Health and Welfare Act 1987* and the *Australian Institute of Health and Welfare (Ethics Committee) Regulations 2018*. Its main responsibilities are to:

- advise on the ethical acceptability or otherwise of current or proposed health and welfare-related activities of the AIHW, or of bodies with which we collaborate or interact
- advise on the ethical acceptability of the AIHW activities involving information which can identify a person ('identifiable data')
- ensure data about people is handled with respect and in line with best practice

It is anticipated that an application to the AIHW Ethics Committee could be undertaken during the next project phase.

Step 4: Trial data/pilot collection

A pilot national data collection could potentially commence during 2025–26, pending relevant approvals and funding. Data would be provided to the AIHW by each state and territory department responsible for newborn hearing screening. A pilot test could be used to evaluate:

- the quality and consistency of the data received
- the ability of the NBEDS to meet national reporting requirements
- data provision challenges
- data validation issues
- modifications to data items that may be required

Ongoing review and development

The data development committee has provided in-principal approval for the 21 newborn hearing screening items. While these items have been agreed as a strong foundation for the data collection, further development of the data items may be required as the collection evolves and matures. Iterative improvements and annual reviews of data items are standard practice to ensure that items continue to be meaningful and fit-for purpose.

Development of a precise Data quality statement (outlining timeliness, accessibility, interpretability, relevance, accuracy and coherence) would also be required to accompany the NBEDS.

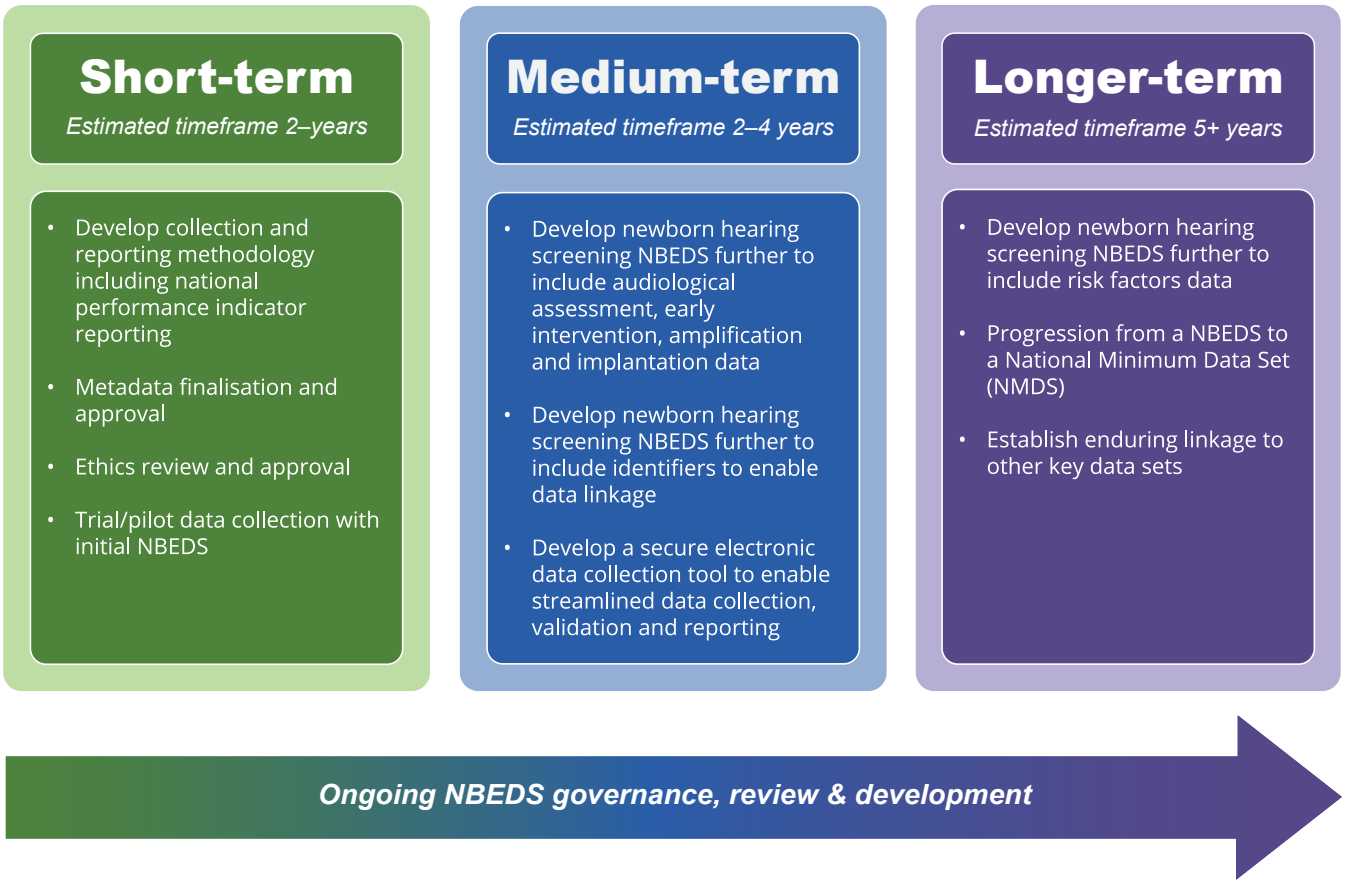
Medium to longer-term development (2–5 years+)

The agreed NBEDS data items are focused on the newborn hearing screening component of the pathway. Further development work is required develop the following data pertaining to other areas pathway including:

- **audiological assessment**: development of data on audiology assessment services could be undertaken by further exploring which jurisdictions hold audiology data within their newborn hearing screening programs and developing methods to overcome any data barriers. Engaging other relevant audiology stakeholders could also be progressed.
- **early intervention** (for example National Disability Insurance Scheme): Some relevant data on early intervention National Disability Insurance Scheme programs are likely captured by the National Disability Insurance Agency (such as status of the access request, date of access request decision, whether the participant is active and/or eligible, start date of paid support, whether the child has initial supports through the early childhood approach).
- **amplification services** (such as Hearing Aids): Amplification data could potentially be sourced from Hearing Australia. Initial scoping and steps towards appropriate national data provision and collection could also be explored.
- **implantation services** (such as Cochlear implants, bone conduction devices): Hearing Australia do not perform Cochlear implant evaluation or surgery but do provide support and have close relationships with cochlear implant clinics. The relevant data holdings for Cochlear implants would require further exploration. Hearing Australia do provide bone conduction devices to eligible people and may hold relevant data.
- **risk factors:** these could 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 babies 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 permanent congenital hearing impairment.
- **identifiers** to enable future data linkage: This could include linkage between screening, assessment and intervention datasets to better understand the context and pathway of participants. The AIHW are international leaders in data linkage with a strong record and accreditation as a data service provider (ADSP).
- **secure electronic data collection** tool to enable streamlined data collection, validation, and reporting could also be developed.

A summary of all potential development activities from short- to long-term are summarised in Figure 3 below.

Figure 3: Summary of recommended next steps



Note: 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, for these data items to become mandatory for collection. See Glossary for full definitions.

Technical notes

Table 13: Abbreviations

Term	Meaning
AIHW	Australian Institute of Health and Welfare
NBEDS	National Best Endeavours Data Set
NMDS	National Minimum Data Set
NPDC	National Perinatal Data Collection

Glossary

Glossary items with existing metadata include a link to the item on METEOR.

Attempted screen: hearing screens which are interrupted or stopped for clinical or equipment reasons and do not lead to a pass or refer result are not included.

Audiology: A field of research and clinical practice devoted to the study of hearing disorders, assessment of hearing, hearing conservation and aural rehabilitation. [METEOR identifier 562492]

Audiology assessment: An audiology assessment provides information about the status of middle ear function, diagnosis of hearing loss, and recommendations for clinical care and rehabilitation, such as communication strategies, classroom amplification, hearing aids, speech therapy and educational support. An audiological assessment can also monitor changes in hearing associated with medical and surgical management of middle ear conditions. [METEOR identifier 529778]

Corrected age: The number of weeks since birth minus the number of weeks born pre-term (see Duration of conception). Corrected age is used for pre-term births to consider the developmental progress of the baby.

Duration of conception: The World Health Organization identifies the following categories for duration of gestation:

- pre-term: less than 37 completed weeks (less than 259 days) of gestation
- term: from 37 completed weeks to less than 42 completed weeks (259 to 293 days) of gestation
- post-term: 42 completed weeks or more (294 days or more) of gestation

[See related 'product of conception' METEOR identifier 695332]

Flip-flop screen result: A screening result where a unilateral refer (positive) result switches ear on the second screen. Such results can be due to screener error or have a clinical basis.

Gestational age: The gestational age of a product of conception in completed weeks. Gestational age is the best clinical estimate of the duration of pregnancy at a specific point in time, based on the first day of the last menstrual period (LMP), ultrasound or physical examination of the baby. [METEOR identifier 695332]

Hearing Screen: a single stage in the hearing screening procedure, used to detect possible hearing loss. A screen must produce a test result outcome which can be a pass (negative) or refer (positive). Screening is typically conducted in hospital settings but can also be conducted through outpatient and outreach services. *Attempted screens* which do not lead to a pass or refer result are not included.

Hearing screen complete, discharged from screening: the planned exit of a baby from the screening pathway after a finding of functionally normal hearing at screening. The parent/guardian has received the pass result. Not to be confused with discharge from any other clinical care (such as a hospital).

Hearing screen outcome: the overall outcome of the hearing screening process, which includes the following categories:

- **Hearing screen complete, referred for targeted follow-up:** the follow-up of babies, otherwise discharged from the screening program (following a bilateral pass result), for diagnostic audiological assessment due to the presence of known risk factors for hearing loss.
- **Hearing screen complete, referral made for audiological assessment:** where a baby has undergone a hearing screen, the parent/guardian has received a refer result and referral for audiological assessment has been made.
- **Hearing screen bypass, non-screening pathway:** where a baby cannot be screened for clinical reasons and a direct referral to Audiology is made instead. Some reasons for direct referral include: Atresia (absence of an ear canal), Microtia (incomplete or underdeveloped ear), Bacterial or Viral Meningitis (confirmed or suspected), Cleft Lip/Palate, Down Syndrome, craniofacial abnormalities, babies who spend time in intensive care.
- **Hearing screen in process:** This category is to be used for babies when a screening outcome has not been made by the end of the reference period.

Hearing screen, incomplete: when a baby has not undergone any stage of hearing screening or has not completed a follow-up screen following a refer result on a previous screen (see also *Primary reason not screened*). This may also include cases where the parent/guardian has not consented to screening (see *Informed consent*) or been informed of the screening result. This excludes cases that are directly referred to audiology for clinical reasons (see *hearing screen bypass, non-screening pathway*).

Indigenous status: An indicator of identification as an Aboriginal and/or Torres Strait Islander. [METEOR identifier 602543]

- **Indigenous Australians (also known as First Nations Australians):**
  - Aboriginal but not Torres Strait Islander origin.
  - Torres Strait Islander but not Aboriginal origin.
  - Both Aboriginal and Torres Strait Islander origin.
- **Non-Indigenous Australians:**
  - Neither Aboriginal nor Torres Strait Islander origin.
- **Not stated/inadequately described:** This category is not to be available as a valid answer to the questions but is intended for use:
  - Primarily when importing data from other data collections that do not contain mappable data
  - Where the answer cannot be determined without clarification from the respondent (for example, 'No' and 'Yes, Aboriginal' are both selected)
  - Where an answer was declined
  - Where the question was not able to be asked because the client was unable to communicate or a person who knows the client was not available

Informed consent: Voluntary consent given by a legal guardian for a baby to participate in the screening program after being informed of the purpose, methods, procedures, potential benefits and potential harms. The essential criteria of informed consent are that the legal guardian has both knowledge and comprehension, that consent if freely given without duress or undue influence, and that the right of withdrawal at any time is clearly communicated.

Live birth: defined by the World Health Organization to be the complete expulsion or extraction from the mother of a baby, irrespective of the duration of the pregnancy, which, after such separation, breathes or shows any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of the voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached. Each product of such a birth is considered live born. [METEOR identifier 733187]

National Best Endeavours Data Set (NBEDS): 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, for these data items to become mandatory for collection. [METEOR identifier 344846]

National Minimum Data Set (NMDS): 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. [METEOR identifier 344846]

Neonate: a live birth who is less than 28 days old. The neonatal period is exactly four weeks or 28 completed days, commencing on the date of birth (day 0) and ending on the completion of day 27. [see METEOR identifier 327284]

Pass (negative) screen result: A result indicating that increased risk of hearing loss was not detected by hearing screening. Babies receiving a pass (negative) screen result are generally discharged from the screening program if no risk factors are present.

Postcode: The Australian numeric descriptor for a postal delivery area for an address. [METEOR identifier 611398]

Primary reason not screened: the main contraindication or reason why screening of a newborn was not performed or completed, as indicated by the Screener. If there were multiple reasons, only the most relevant or obvious reason is to be recorded. Primary reasons for not screening are:

- **Declined:** neonates parents/guardian opted out or declined to consent to screening. A decline form is signed by all parents/guardians who decline a screen.
- **Missed screening or invitation:** Where babies are:
  - Not captured or invited for screening, such as when they did not appear on the list of deliveries and contact with families is lost.
  - Screened once but not subsequently rescreened when required; or where screening results are not documented.
  - Where babies did not attend a scheduled appointment.
- **Moved interstate:** where a newborn moves interstate after birth but prior to screening in the jurisdiction of birth.
- **Medical exclusion:** newborns deemed medically unfit or unstable for screening by a treating clinician. This can include the baby being unwell, being treated for hyperbilirubinemia/jaundice, requiring continuous cardio-respiratory or oximetry monitoring, taking medication that affect brain/ears, on a ventilator, in an incubator.
  This category may also include babies with microtia or atresia or those with genetic conditions known to be associated with hearing loss (for example, Usher Syndrome, Pendred Syndrome).
- **Hearing screening bypass, non-screening pathway:** when a baby cannot be screened for clinical reasons and a direct referral to Audiology is made instead.
- **Baby deceased:** neonatal death prevented the screen being performed or completed.
- **Ineligible:** when babies do not meet age criteria when screening is able to be undertaken.
- **Other:** other reasons screening was not completed (not captured by other response categories)
- **Not stated/inadequately described:** the primary reason why screening was not performed or completed is unknown.

Referral: a referral made from the jurisdictional hearing screening program following a refer (positive) result (either unilaterally or bilaterally) or referral directly to audiology due to known risk factors for hearing loss and/or factors that make them unsuitable for screening.

Referral outcome: The outcome of the referral from the jurisdictional hearing screening program. These include:

- **Referral following positive screen**: a referral has been made from the jurisdictional hearing screening program following a refer (positive) result (either unilaterally or bilaterally).
- **Referral following negative screen**: a referral has been made from the jurisdictional hearing screening program following a bilateral pass result for diagnostic audiological assessment due to the presence of known risk factors for hearing loss.
- **Referral without screening**: referral direct to audiological assessment due to known risk factors for hearing loss and/or factors that make them unsuitable for screening.
- **No referral required**: where no referral was needed following completed screening.
- **No referral provided**: where no referral had been provided. This could include cases where the referral was in progress but not completed or where a parent/guardian was unable to be contacted.

Refer (positive) screen result: A result indicating that possible hearing loss was detected by hearing screening. Babies receiving a refer (positive) screening result are generally referred to audiological assessment. These are separated into two specific results:

- **Unilateral refer (positive) screen result:** A result indicating that possible hearing loss was detected in one ear by hearing screening. Babies receiving a unilateral refer (positive) screening result are generally re-screened and/or referred to audiological assessment.
- **Bilateral refer (positive) screen result:** A result indicating that possible hearing loss was detected in both ears by hearing screening. Babies receiving a bilateral refer (positive) screening result are generally rescreened or referred to audiological assessment.

Referral type: the type of service that a baby was referred to from a jurisdictional hearing screening program. These include:

- **Audiologist, audiological assessment:** audiological assessment that occurs after a baby has received a refer (positive) result at screening. The assessment, performed by an audiologist, includes hearing tests to assess and diagnose the type and degree of hearing loss.

- **Audiologist, targeted follow-up:** the follow-up of babies, otherwise discharged from the screening program (following a bilateral pass result), for diagnostic audiological assessment due to the presence of known risk factors for hearing loss.
- **Other:** any other referrals made that do not include the above types.

Rescreen: A second screening for babies who do not pass the initial screen. The rescreen generally occurs after 24 hours but within two weeks of the initial screen.

Screener: persons trained to use hearing screening equipment and perform newborn hearing screening.

Statistical Area Level 2 (SA2) of usual residence (mother): The geographical region in which the mother of the baby usually resides, as represented by a statistical area level 2 (SA2) code. SA2s are a code set representing a medium-sized general purpose area aggregated from whole Statistical Area Level 1s (SA1s). An SA2 is identifiable by a 9-digit fully hierarchical code. [METEOR identifier 747275]

Stillbirth: A fetal death prior to the complete expulsion or extraction from its mother of a product of conception of 20 or more completed weeks of gestation or of 400 grams or more birthweight. The death is indicated by the fact that after such separation the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles. [METEOR identifier 733271]

Usual (residence): The place where the person has or intends to live for 6 months or more, or the place that the person regards as their main residence, or where the person has no other residence, the place they currently reside.

Notes

Amendments

3 September 2025: References to the unpublished and/or draft National Framework throughout the report have been updated to refer to the *National Framework for Newborn Hearing Screening*, published by the Department of Health, Disability and Ageing in July 2025.

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