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National performance indicators for neonatal hearing screening in Australia

CANCER AND SCREENING UNIT WORKING PAPER

Australian Government
Australian Institute of Health and Welfare

Authoritative information and statistics to promote better health and wellbeing

National performance indicators to support neonatal hearing screening in Australia

Cancer and Screening Unit Working Paper

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Contents

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To inform and progress this work, an expert advisory group, the Neonatal Data Specification Subgroup, was convened with members listed in Appendix B. Their valuable contribution is gratefully acknowledged.

Abbreviations

AABR	Automated auditory brainstem response
ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
APHDPC	Australian Population Health Development Principal Committee
APHDPCSS	Australian Population Health Development Principal Committee Screening Subcommittee
CCPHPC	Community Care and Population Health Principal Committee
COAG	Council of Australian Governments
DOHA	Department of Health and Ageing
MSAC	Medical Services Advisory Committee
NDSS	Neonatal Data Specification Sub Group
NICU	Neonatal Intensive Care Unit
NHSWG	Neonatal Hearing Screening Working Group
NPDC	National Perinatal Data Collection
OAE	Otoacoustic emission
PCHI	Permanent childhood hearing impairment
SCCYH	Standing Committee on Child and Youth Health
WHO	World Health Organization

Summary

Each year in Australia approximately 551 children are born with moderate to profound permanent childhood hearing impairment (PCHI) (MSAC 2007). Universal neonatal hearing screening aims to identify those children born with moderate to profound PCHI and provide them and their families with access to an appropriate intervention in order to minimise the impact of their hearing impairment. Universal neonatal hearing screening is undertaken in each Australian state and territory.

This working paper presents a set of performance indicators for monitoring neonatal hearing screening activity in Australia at a national level. National evaluation and monitoring provides a measure of how well neonatal hearing screening is achieving its aims and objectives and will enable strengthening of screening practices and administrative processes to further improve outcomes for Australian infants.

The indicators are based on the aims, standards and objectives for neonatal hearing screening outlined in the *National Framework for Neonatal Hearing Screening* (NHSWG 2013). They were developed in consultation with experts and endorsed by the Community Care and Population Health Principal Committee.

This working paper documents both the indicator development process and the technical specifications for the indicators. This working paper also identifies potential data sources, data elements and future data development and evaluation needs.

Key findings

Seven national performance indicators are described that cover four key areas along the screening pathway. The indicators, and how each relates to the four key aims of neonatal hearing screening, are listed below.

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

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

1 Introduction

1.1 Purpose and structure

This working paper should be considered in the context of the *National Framework for Neonatal Hearing Screening*. It aims to provide the Australian neonatal hearing community with a national reference point for monitoring of neonatal hearing screening activity and outlines the development of seven performance indicators. It also provides technical specifications and lists data elements necessary to calculate and report against these indicators.

This working paper has four chapters:

- **Chapter 1** details the historical background and governance of national monitoring of neonatal hearing screening in Australia and highlights key issues that require further consideration before implementing standardised reporting for neonatal hearing screening in Australia.
- **Chapter 2** provides basic information on performance indicators and the data and metadata that are an essential part of using indicators to measure performance. The second half of the chapter describes the indicator development process and presents the national performance indicator set.
- **Chapter 3** details the national performance indicators in the order an infant progresses through the screening pathway. Each indicator is presented with accompanying explanatory information including a definition that explains what the indicator is measuring and a brief rationale for inclusion.
- **Chapter 4** presents clear and concise technical information including a numerator and denominator for calculating each indicator to ensure all those who collect, provide, analyse and use the data clearly understand its meaning.

1.2 Childhood hearing impairment in Australia

Each year in Australia approximately 551 children are born with moderate to profound permanent childhood hearing impairment (PCHI) (MSAC 2007). Early detection of PCHI, coupled with access to an appropriate intervention, minimises the impact of hearing impairment for children born with PCHI by potentially improving their communication and language skills, subsequent education and employment prospects, and psychological wellbeing (Yoshinaga-Itano 2003; Moeller 2000).

1.3 Background and governance

Evidence to recommend the screening of newborns for hearing impairment was determined by the National Health and Medical Research Council in 2002 and supported by the Medical Service Advisory Committee in 2008.

In March 2008, the Screening Subcommittee of the Australian Population Health Development Principal Committee (APHDPC) of the Australian Health Ministers Advisory Council established the Neonatal Hearing Screening Working Group (NHSWG) to provide

high level advice on how to progress issues related to universal neonatal hearing screening in Australia.

In September 2009, a Senate Inquiry into hearing health in Australia was established to report on the extent, causes and costs of all hearing impairment in Australia. The report, titled *Hear us* (The Senate Community Affairs References Committee 2010), was tabled in May 2010. The Committee supported the development of a national register for neonatal hearing screening and recommended that it be able to:

- track children through neonatal hearing screening, diagnosis and intervention
- record and report cognitive, linguistic, social and emotional development outcomes of children diagnosed at birth with a hearing loss
- be expanded in future years to track all children diagnosed with a hearing impairment later in life.

1.3.1 Data development activities for neonatal hearing screening

The NHSWG was tasked with developing a screening pathway for neonatal hearing screening; developing minimum national standards for screening and post screening services; and establishing a national quality and reporting framework to underpin a national approach to data collection. NHSWG undertook the work in two stages.

The first stage involved the development of the *National Guidelines for Neonatal Hearing Screening: Draft National Framework* (later titled the *National Framework for Neonatal Hearing Screening*, NHSWG 2013). The framework defines the screening pathway for neonatal hearing screening and outlines minimum national standards to underpin reporting for neonatal hearing screening in Australia and provide quality service delivery. At the APHDPC meeting on 9 March 2011, members endorsed the Framework pending a review of the proposed performance indicators to enable nationally consistent reporting.

The second stage involved the development of a reporting framework for consideration by the Screening Subcommittee, and to establish an agreed approach to data collection, management and sharing.

To progress this work, the Australian Institute of Health and Welfare (AIHW) conducted an analysis of available national data sources relating to neonatal hearing screening and presented a discussion paper *Data requirements to support a national approach to neonatal hearing screening* (AIHW unpublished) to the NHSWG for consideration at their March 2010 meeting. This discussion paper reviewed existing data collections relating to infants and young children in Australia, presented potential models for collecting data and monitoring neonatal hearing screening, and made a number of recommendations including the development of a nationally consistent set of data elements.

In response to these recommendations, the NHSWG convened a working subgroup, the Neonatal Data Specification Subgroup (NDSS), chaired by the AIHW to oversee and coordinate the development of a core set of performance indicators and associated technical specifications and data elements for national reporting and analysis of neonatal hearing screening in Australia. A draft of these performance indicators was presented to the Screening Subcommittee in March 2011.

Responsibility for implementation of the framework was passed from the Screening Subcommittee to the Child Health and Wellbeing Subcommittee (now Standing Committee on Child and Youth Health – SCCYH), a subcommittee of the Community Care & Population

Health Principal Committee (CCPHPC) in November 2011. The framework was revised by the SCCYH and the title was changed to the *National Framework for Neonatal Hearing Screening* (NHSWG 2013). The revised framework and the associated performance indicators presented here were endorsed by the CCPHPC in August 2013.

The national framework recognises that neonatal hearing screening has developed separately across jurisdictions with various levels of sophistication. It was developed in consultation with jurisdictions with an aim of achieving harmonisation of these efforts.

The national framework and performance indicators presented in this working paper are intended as a resource for jurisdictions to use when developing and monitoring neonatal hearing screening services.

1.4 Aims and objectives of neonatal hearing screening

The aim of neonatal hearing screening is for all infants to be screened for congenital PCHI, and, if necessary, to have access to appropriate intervention to minimise the impact of their hearing impairment. This will improve the quality of life for children with PCHI in terms of their communication and language skills, subsequent education and employment prospects, and psychological wellbeing.

The objectives of neonatal hearing screening are to:

- maximise the early detection of congenital PCHI in Australian infants through the use of an approved screening test and appropriate follow up medical and support services
- ensure that all Australian families are offered the opportunity to participate in neonatal hearing screening
- ensure equitable access to neonatal hearing screening for all Australian infants irrespective of their geographic, socioeconomic or cultural background
- ensure that assessment services provided to infants requiring follow up care and intervention as a result of screening are timely, acceptable and appropriate and are undertaken in accordance with professional standards
- ensure families with infants diagnosed with impaired hearing engage with an early intervention service following diagnosis
- maximise benefit and minimise harm to the individual
- achieve consistent standards of screening management, co-ordination, quality and safety, service delivery, monitoring, evaluation and accountability
- ensure that the national approach to neonatal hearing screening is implemented in a manner that is cost effective and will significantly increase quality of life for Australian children with PCHI.

1.5 Issues for consideration

This section details issues that may need to be considered in using these indicators. Further issues specific to each indicator are detailed in chapters 3 and 4.

1.5.1 Definitions and terminology

Fundamental to the development of national reporting for neonatal hearing screening is clarity on definitions and terms.

1.5.1.1 Undefined and non-standard terms

A glossary of standard terms is included at the end of this working paper; however, there are a number of terms such as 'eligible', 'medically unfit' and the 'corrected age' of infants that will require consensus for nationally consistent monitoring.

Some suggestions and examples are provided in the discussion for the indicators.

1.5.1.2 Describing screening outcomes

Clinicians involved in neonatal hearing screening use the terms *pass* and *refer* to classify outcomes from the screening test. To facilitate clear communication between screeners, nurses, doctors, audiologists, data managers and infant hearing screening program managers; it is recommended that when discussing the monitoring and evaluation of neonatal hearing screening the terms *pass* and *refer* are changed to:

- **negative** screening result which indicates that the screening test was negative for suspected hearing loss (*pass*)
- **positive** screening result which indicates that the screening test was positive for suspected hearing loss (*refer*).

This terminology is consistent with both the World Health Organization principles of early disease detection (Wilson 1968) and the Australian Population Health Development Principal Committee Screening Subcommittee (APHDPCSS) Population Based Screening Framework (APHDPCSS 2008) and is used in these indicators to describe outcomes of the screening test.

1.5.2 The target population

In order for indicators to successfully monitor the impact of screening, they must refer to a clearly defined target population, which is referred to as the 'eligible' population. These indicators are developed based on the following considerations.

1.5.2.1 Inclusion of infants with symptoms or a risk factor

Theoretically, screening involves the testing of an asymptomatic population (that is, individuals who have no symptoms or signs of the condition). In practice however, screening programs routinely include individuals who are symptomatic or at increased risk of suffering from an illness. This occurs not only because it is in the interest of the community to ensure those at higher risk or with symptoms receive access to medical services, but also because identification of these individuals is often difficult at population level.

An estimated 40% to 60% of children diagnosed with congenital PCHI display a known risk factor (Bailey et al. 2002). These infants form part of the target population for the indicators presented here.

1.5.2.2 Infants not eligible for screening

While the aim of neonatal hearing screening is for all infants to be screened for congenital PCHI by 4 weeks of (corrected) age, this is restricted to eligible infants. Infants who are not

eligible for screening include infants deemed to be medically unfit for screening. It is anticipated that this subgroup of infants will be very small and best monitored at the jurisdictional level. Note that the term 'medically unfit' is not defined and may differ between jurisdictions. Box 1 presents protocols used by Queensland Health for infants considered medically unfit for screening.

Box 1: Queensland Health protocols for infants considered medically unfit for screening

In rare situations, screening may not be possible or is medically inadvisable. The decision to exclude a baby from the screening program must be made by the treating clinician. Such situations include:

- when it is medically inadvisable to attach the sensors and/or ear couplers: for example, if the baby has compromised skin
- the presence of a major cranio-facial abnormality: in particular the absence of outer ear anatomy, including babies with unilateral or bilateral atresia
- for babies with only 1 normal-looking ear, do not screen the 'good' ear
- other conditions which medical staff deem require a full diagnostic assessment by audiology.

1.5.2.3 Measuring how many families decline screening

Families have the right to decline screening services. Although it is anticipated that only a small proportion of families will do so, it is important to monitor the proportion of families who decline screening. A high decline rate, especially if it is higher for some population subgroups compared to others, could warrant implementation of programs to address this issue as higher participation at each point along the screening pathway is necessary for achieving the best outcomes for infants.

It is considered that monitoring the decline rate is a program management issue and should not form part of a performance indicator set at the national level.

1.5.3 Data considerations

In order to report against these indicators, the following issues should be considered when developing data collections to support the monitoring and evaluation of neonatal hearing screening.

1.5.3.1 National v. jurisdictional data collection

These indicators were originally developed to be reported against using a national data collection; however, the indicators are also suitable to be used and reported by state and territory neonatal hearing screening programs.

1.5.3.2 Data availability

Good quality, reliable, appropriate data are central to indicator-based monitoring. To be useful, the data need to be provided from a reliable source and available on a regular basis.

1.5.3.3 The use of identified data and a data linkage key

Many of the aims and objectives of neonatal hearing screening are long term and not easily measurable, in particular the improvement of social, emotional and educational outcomes for infants born with PCHI. It is recommended that identified data and/or a data linkage key be developed to enable future linkage with a number of medical, educational and employment administrative datasets in order to assess whether neonatal hearing screening in Australia is meeting these long term aims.

Data linkage can only be done after approval from appropriate Ethics Committees in accordance with all relevant legislation and guidelines, including the Information Privacy Principles defined in the *Privacy Act 1988* and ethical principles and standards defined by the National Health and Medical Research Council Guidelines for Human Research Ethics Committees.

Statistical linkage key SLK581 is an example of such a data linkage key. SLK581 is a series of data elements that have been found to prove useful for inclusion in a data set if that data set is to be used for future linkage. The SLK581 is not considered to be 'personal information' in the same way as name and address, and cannot be reverse engineered to provide such personal information.

Analysis of the efficacy of SLK581 has shown it to be highly deterministic in linkage practices; however, its effectiveness can be maximised through the use of extra data items (such as full names, postcode, or date of death). It is recommended that these data elements are collected in any data sets used in monitoring neonatal hearing screening. Box 2 explains SLK581.

Box 2: Linking data using Statistical Linkage Key SLK581

In Australia, many community service program data collections developed over the last decade, including several for aged care programs, contain a statistical linkage key (SLK) to enable derivation of client-level data. In addition, a common SLK is now used in many collections to facilitate the statistical examination of cross-program use. SKL581 is:

3 letters of surname + 2 letters of given name (5) — Date of birth (8) — Sex (1)

SLK581 can be calculated and added as a variable to the dataset before sharing this data set. This allows the removal of identifying information and thus protects privacy while enabling linkage with other data sets.

An example of how SLK581 works:

For example, Dorothy Windsor 08/06/1921 F

SLK-581 would be INSOR08061921F

Appendix D provides a list of data elements necessary to calculate nationally consistent performance indicators. Those data elements necessary to create an appropriate linkage key are identified by a 'key' (🗝) icon.

1.5.3.4 Data standards

The data elements included in Appendix D were defined at the time of the indicator development. As data standards are continually updated, the most recent standards should be used when using these indicators.

Geographic identifier to calculate socioeconomic status and remoteness

To calculate socioeconomic status and remoteness, the NDSS recommends that a geographic identifier of usual residence is collected. Ideally this should be consistent with current geocoding standards. At the time of the indicator development, this was the Australian Standard Geographical Classification (ASGS). This was replaced by the Australian Statistical Geography Standard in 2011 (ABS 2011). The combination of locality, state and postcode should provide enough information to allocate a suitable geographic identifier; however, in the absence of technology to derive a geocode, postcode will provide an acceptable alternative.

1.5.3.5 Privacy and methodological consideration of small numbers

Some of the indicators rely on data from a small number of infants, especially where data are disaggregated by different population subgroups. Reporting categories with a small number of cases has privacy and ethical concerns as it may be possible to identify the persons whom the data represent. Additionally, data reliability is questionable when rates are based on only a small number of cases, or a small population, as may be the case with neonatal hearing screening follow-up. In both these instances it can be almost impossible to distinguish random fluctuation over time or between different population groups from real differences or trends.

Consequently, performance indicators later in the screening pathway may not have sufficient data to disaggregate by population subgroups and may need to be calculated and reported over multiple years.

1.5.4 State and territory considerations

Infants who have contact with neonatal hearing service providers outside their jurisdiction of (the mother's) residence are at increased risk of being lost to follow-up and not receiving the support and services they need. The issue of which jurisdiction should be responsible for monitoring the progress of infants through the screening pathway needs to be considered.

The NDSS recommend that for the purposes of reporting by jurisdiction, the jurisdiction responsible for monitoring an infant's progress through the screening pathway should be the jurisdiction of screen. It is noted that the jurisdictions currently liaise to ensure these infants are adequately followed up.

Performance data for each stage of the screening pathway (participation, screening, audiological assessment and diagnosis, and early intervention and management) is recommended to be presented by jurisdiction of activity. This means that for example, when calculating indicators that use screening data (Indicator 1 *Participation* and Indicator 2 *Screening*) jurisdiction of screen is used, while when calculating audiological assessment indicators, jurisdiction of audiological assessment is used.

1.5.5 Ongoing refinement and development

Indicator development is an iterative process. To ensure the indicators remain relevant and valid, they should be regularly reviewed and refined.

2 Performance indicator development

Performance indicators are regularly used to monitor diseases, conditions and health-related interventions such as screening. The principles and methodology underpinning indicator development are outlined in section 2.1.

Recently in Australia, the specification of performance indicators has become more formalised due to the need to support comparative reporting under the various agreements entailed in the *Intergovernmental agreement on federal financial relations* (COAG 2008). The formalisation takes two main forms: the 'metadata' relating to the indicator specification, and the data quality statement that accompanies the reporting of the indicator. These are discussed further in section 2.2.

2.1 Performance indicator development principles and methodology

2.1.1 Performance indicator principles

A health performance indicator can be defined as a statistic or other unit of information that reflects, directly or indirectly, for a population or an individual:

- an aspect of health
- a change in an aspect of the health status
- the performance of a health intervention, facility, service or system.

The value of a formally-endorsed performance indicator is that it consistently reports a single concept that can be interpreted in the context of changing policies and guidelines.

Performance indicators are developed against the selection criteria outlined in Box 2.1.

Box 2.1: Selection criteria for developing performance indicators

Performance indicators should meet some or all of the following criteria:

1. Be worth measuring
2. Be measurable for diverse populations
3. Be understood by people who need to act
4. Galvanise action
5. Be relevant to policy and practice
6. Reflect results of actions when measured over time
7. Be feasible to collect and report
8. Comply with national processes of data definitions.

Source: National Health Performance Committee 2001.

It is important to note that the *availability* of data is not a criterion in selecting a performance indicator; however, a potential performance indicator should be capable of being measured (that is, capable of having data collected to calculate the performance indicator value).

Importantly, a core set of performance indicators cannot be expected to meet every need for information, and performance indicators are not a substitute for research and policy analysis. Additional performance indicators may be nominated to monitor other aspects of policy, practice or guidelines, but will not be considered core. Based on previous AIHW experience in developing national performance indicators, a core set would generally comprise fewer than 10 performance indicators.

2.2 Data concepts

In order to effectively measure performance of neonatal hearing screening in Australia, it is necessary to use quality data which are defined by standards. Data elements used to compute performance indicators should have standardised definitions and collection methods across all jurisdictions so that this information may be compared and used to monitor neonatal hearing screening against its objectives.

2.2.1 Data elements

Data elements are the basic unit of identifiable and definable information. A number of data elements and standards relating to health are defined in National Minimum Data Sets and Data Set specifications and are published as the National health data dictionary (NHDD). The NHDD contains standard data definitions and data elements for use in Australian health data collections. It is a source of information about endorsed national metadata standards and provides the basis for consistent national collection and reporting. The national metadata standards are approved by the Australian government and all state and territory relevant health services departments as well as the Australian Bureau of Statistics (ABS) and the AIHW.

Under these agreements, all parties agree to ensure that the collection, compilation and interpretation of national information is appropriate and is carried out efficiently. This requires agreement on definitions, standards and rules of collection of information and on guidelines for the coordination of access, interpretation and publication of national health information.

The data elements necessary to monitor the performance indicators for neonatal hearing screening are listed in Appendix D. Where possible, existing data elements were identified in national data dictionaries; however, a number of data elements specific to neonatal hearing will need to be developed.

2.2.2 Metadata

Metadata, loosely translated as 'data about data', covers the detailed specification of a performance indicator such as numerator, denominator, relevant population, time period, target/change, measurement details, and possibly a nominated data collection. Metadata are included in the technical specifications outlined in Chapter 4.

2.2.3 Data quality statements

Despite best intentions in performance indicator development, often there are gaps between the real world, the data relating to the real world, and the concept being expressed by an indicator. Data quality statements are useful in describing and understanding the gap between the data collected and the performance indicator as specified. A quality statement shows the degree of compliance with the formal specification, and helps users interpret the results of indicator data.

2.2.4 METeOR and the National Indicator Catalogue

Part of the formalisation of performance indicator specification in the context of the *Intergovernmental agreement on federal financial relations* (COAG 2008) is the inclusion of performance indicator metadata in the AIHW metadata online register (METeOR). The development of performance indicators in METeOR improves quality, relevance, consistency and the availability of national information about the health and welfare of Australians.

To assist people to access performance indicator metadata, the National Indicator Catalogue has been established—a web-based search tool containing many of the performance indicators used in Australia. The National Indicator Catalogue can be accessed at <www.aihw.gov.au/national-catalogue-indicator/>.

Implementation of the indicators in this working paper should include the development of a data quality statement, a data set containing the data elements required for reporting and registration in METeOR and the National Indicator Catalogue.

2.3 The current indicator set

National performance indicators provide a framework by which to measure whether neonatal hearing screening in Australia is achieving its aims and objectives. This will help improve and strengthen nationally consistent screening practices and administrative processes to further improve outcomes for Australian infants.

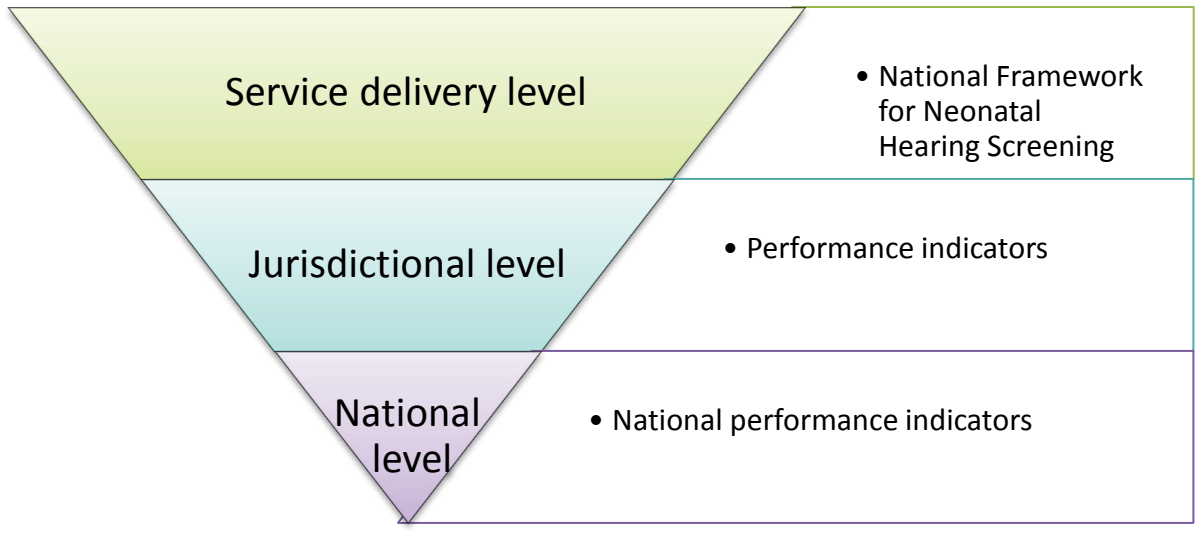

Figure 2.1: Service, jurisdictional and national level reporting and monitoring

National performance indicators should complement routine monitoring and reporting by jurisdictions and services. Figure 2.1 shows the relationship between service delivery-, jurisdictional- and national-level analysis and reporting. Monitoring at the national level is less detailed than at a service or jurisdictional level.

The process undertaken to develop the proposed national performance indicator set for neonatal hearing screening is described in the following sections.

2.1.2 Performance indicator development methodology

Indicator development is an iterative process, commencing with a review of relevant policies, strategies, statements and guidelines, and cataloguing existing performance indicators. This feeds into a 'refinement' stage, including seeking stakeholder feedback and assessing potential performance indicators against the selection criteria. This process is summarised in Figure 2.2.

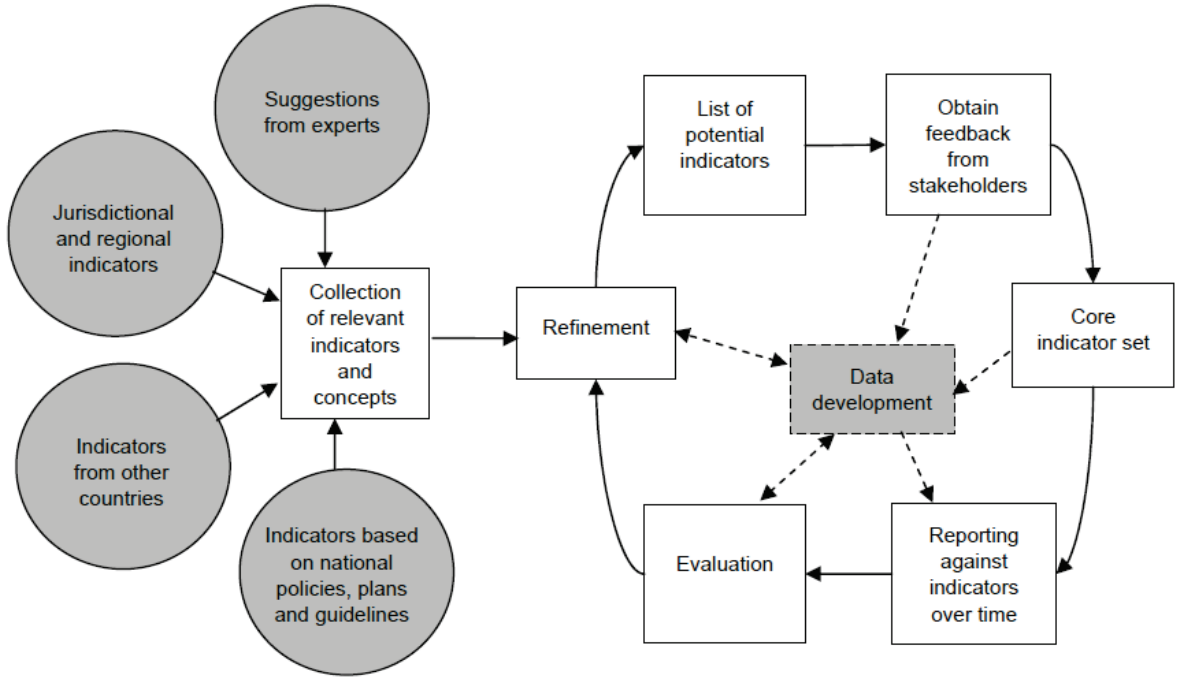

Figure 2.2: Process for indicator development

2.3.1 Objective

Under the direction of the NHSWG, the AIHW convened a Neonatal Data Specification Subgroup (NDSS) to oversee and coordinate the development of a core set of national performance indicators and data elements for reporting and analysis of neonatal hearing screening in Australia. The composition of the group was designed to take advantage of the knowledge and experience of the personnel involved in neonatal hearing screening service and delivery in Australia, and performance indicator development. The NDSS members involved in this process are listed in Appendix B.

The national performance indicators were chosen to be consistent with the aims and objectives for neonatal hearing screening outlined in the *National Framework for Neonatal Hearing Screening* (NHSWG 2013) to provide a basis for monitoring and evaluating the

effectiveness of neonatal hearing screening in Australia. The 29 objectives, 69 standards and 83 targets described in the framework were used as a starting point for the indicator development.

The NDSS also undertook a review of relevant literature and frameworks, of performance indicators for other screening programs (such as BreastScreen Australia and the National Cervical Screening Program), and of jurisdictional and international performance indicators for monitoring neonatal hearing screening to provide further information and guidance in developing the indicators.

2.3.2 Boundary, scope and approach

During the indicator development process, a number of decisions were made with regard to appropriate boundary, scope and approach of the work. These are listed below.

- The national performance indicators should:
  - support (not replace) the objectives, standards and targets described in the *National Framework for Neonatal Hearing Screening* (NHSWG 2013)
  - supplement jurisdictional and service-level reporting already routinely conducted by providing a high level measure of performance of neonatal hearing screening in Australia.
- Only quantitative objectives, standards and targets from the *Draft National Framework* (later titled the National Framework for Neonatal Hearing Screening, NHSWG 2013) were considered for potential inclusion. Quantitative objectives were considered to be more appropriately measured at the service provision or jurisdictional level.
- Consideration was given to the fewest number of indicators that would appropriately measure performance of neonatal hearing screening in Australia. Performance indicators appropriate for monitoring at a national level should be robust enough to appropriately measure performance of neonatal hearing screening against its aims and objectives, while imposing minimal reporting burden to allow services and jurisdictions to more appropriately use resources in program management. As a result, indicators were proposed that:
  - cover the key guidelines and strategy objectives of neonatal hearing screening;
  - cover these with a certain efficiency
  - provide a degree of compliance with the APHDPC *Population Based Screening Framework* and World Health Organization (WHO) principles of early disease detection (Wilson 1968)
  - enable flexibility/scalability of reporting depending on the data source.
- As the *availability* of data is not a criterion in selecting an indicator, the final list contains indicators for which data development will need to occur before they can be reported by data providers (usually the jurisdictional health services or Australian Hearing) to be analysed at a national level. It was noted that a potential performance indicator should be capable of being measured (that is, capable of having data collected to calculate the indicator).
- During performance indicator development, it was noted that COAG and the National Health Information Standards and Statistics Committee are working to strengthen and improve performance monitoring, while reducing and streamlining performance

indicators and harmonising data sets. The proposed set of national performance indicators were created with this principle in mind.

2.3.3 Performance indicator development workshop

The AIHW held a workshop for NDSS members in Canberra in July 2010. The aims and objectives of the workshop were to:

- determine what should be measured and its relevance as a national performance indicator
- consider data availability, appropriateness and reliability
- identify data elements to support proposed indicators.

Each of the objectives and targets developed by the NHSWG as part of the *Draft National Framework* (later titled the National Framework for Neonatal Hearing Screening, NHSWG 2013) were systematically assessed by the NDSS for their utility for national monitoring against the selection criteria for developing indicators (see Box 2.1) and compared to national performance indicators for screening programs (such as BreastScreen Australia and the National Cervical Screening Program) and existing neonatal hearing screening programs in Australia, the United States of America, the United Kingdom and New Zealand.

The workshop participants considered a total of 69 standards and 83 targets. A decision matrix summarising the outcomes of the assessment process is presented in Appendix C (Table C.1).

2.3.4 Deciding on the national performance indicators

Using the decision matrix listed in Appendix C, a list of potential national performance indicators, including operational definitions, technical specifications and a list of related data elements was developed by the AIHW. These potential national performance indicators were assessed by the NDSS using the National Health Performance Framework criteria for performance indicator development (Box 2.1) and developed into a short list of indicators. Feedback was sought from the NDSS via a series of teleconferences, and finally from members of the Screening Subcommittee, from which the composition of the proposed core indicator set and related operational definitions was finalised.

2.3.5 Bringing it all together

Following the process outlined above, and using the *Population based screening framework* (APHDPCSS 2008), the NDSS identified four areas from the *Draft National Framework* (later titled the National Framework for Neonatal Hearing Screening, NHSWG 2013) as appropriate to be monitored using national performance indicators. These are listed below.

- **Participation** in the program, which aims to maximise the number of infants screened for PCHI
- **Screening,** which aims to maximise the identification of infants with potential hearing impairment while minimising parental anxiety and cost
- **Audiological assessment and diagnosis,** which aims to accurately identify infants born with PCHI
- **Early intervention and management,** which aims to maximise engagement of infants identified as requiring a service with early intervention services.

Other areas identified by the NHSWG as central to the effective functioning of neonatal hearing screening programs but more appropriately monitored at a jurisdictional or service delivery level included parent support; co-ordination, monitoring and evaluation of the program; and professional education. Table 2.2 presents the final indicator list.

Table 2.1: National performance indicators for neonatal hearing screening in Australia

Performance indicators
Indicator 1 Participation
1.1 Participation in screening
Indicator 2 Screening
2.1 Positivity rate of the screening test
2.2 Positive predictive value of the screening test
Indicator 3 Audiological assessment and diagnosis
3.1 Audiological assessment
3.2 Detection of permanent childhood hearing impairment
Indicator 4 Early intervention and management
4.1 Attend early intervention service
4.2 Infants fitted with an assistive hearing device

Figure 2.3 presents a framework for monitoring neonatal hearing screening in Australia and illustrates the relationship between the Population-based screening framework (APHDPCSS, 2008), the National Framework (NHSWG 2013) and the proposed national performance indicators and targets.

Figure 2.4 describes an infant's progress through the screening pathway noting those points at which data is collected for national reporting. The proposed end of the screening pathway is contact with Australian Hearing for a hearing and communication improvement program or a jurisdictional health service for cochlear implantation, if required. Monitoring of longer term outcomes beyond the screening pathway would be facilitated by the use of identified data and the development of a data linkage key.

Together, the National Framework and indicators provide a roadmap to support consistent reporting on key indicators across States and Territories which can be followed as their screening programs develop and as resources permit.

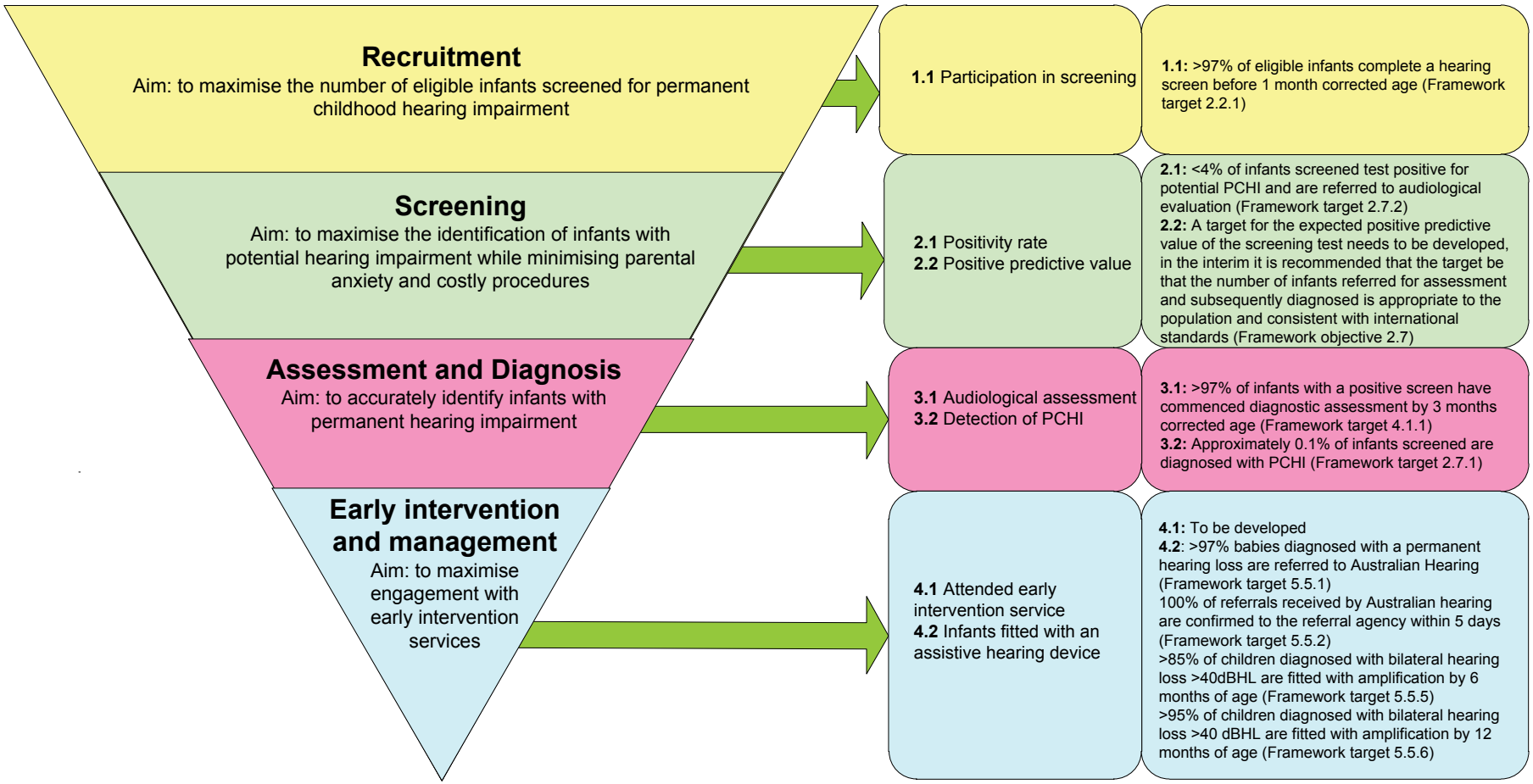

Figure 2.3: National neonatal hearing screening monitoring framework

Note: Because targets are listed as dot points in the National Framework (NHSWG 2013) the numbering of the targets does not refer to the standards in the framework but instead refers to number of the target under the relevant objective.

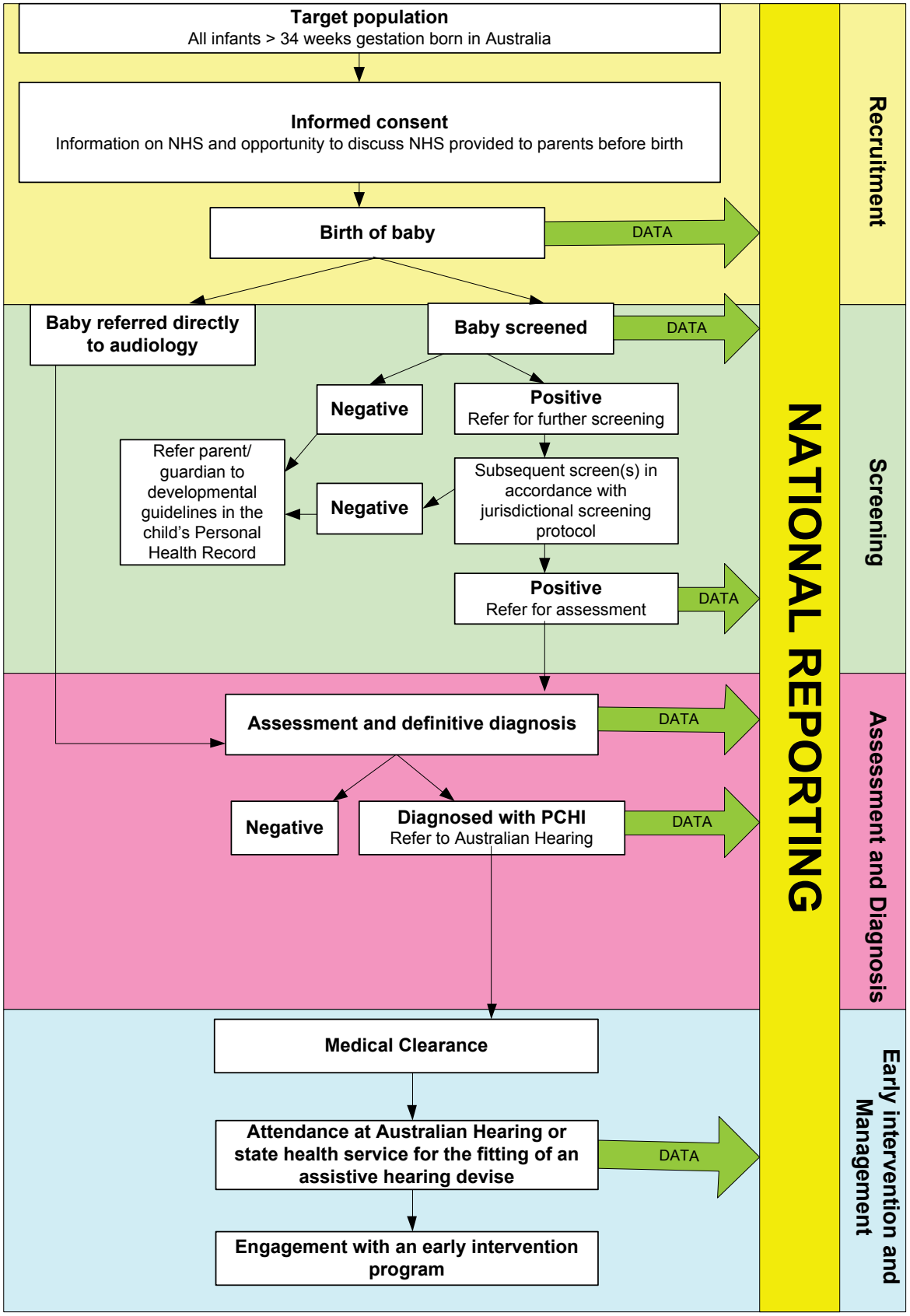

Figure 2.4: National performance indicator data collection points for neonatal hearing screening

3 National performance indicators

The indicators were chosen that measure of the aims and objectives of neonatal hearing screening as outlined in the *National Framework for Neonatal Hearing Screening* (NHSWG 2013) and are presented in the order that an infant progresses through the screening pathway.

3.1 How to use the information on indicators

Indicator

A statistic or other unit of information that reflects, directly or indirectly, for a population or an individual

- an aspect of health
- a change in an aspect of the health status
- the performance of a health intervention, facility, service or system.

Definition

The definition is a statement that explains what the indicator is measuring. Along with the Technical Specifications (outlined in chapter four) the definition is a clear, concise, unambiguous, and comprehensive statement that provides sufficient information to ensure all those who collect, provide, analyse and use the data clearly understand its meaning.

Objective

An aim of the program, usually presented with an accompanying standard which elaborates one component of the aim, and a target that quantifies an outcome.

Target

Targets quantify standards and objectives (for example, >*97% participation*). Because the targets are listed as dot points in the National Framework (NHSWG 2010 unpublished) the numbering of the targets does not refer to the standards in the framework but instead refers to the number of the target under the relevant objective.

Rationale

The rationale presents the justification for including the indictor in national reporting.

Sub-indicator names

Sub-indicators are components of an indicator.

Disaggregations

This section lists how data will be separated into sub-categories (for example, by socioeconomic status or age).

Issues for consideration

In this section any issues are detailed that require further consideration prior to implementation.

Indicator 1 Participation

Indicator 1.1 Participation in screening

Definition:

Proportion of infants born in a calendar year who complete a neonatal hearing screen through a jurisdictional neonatal hearing screening program.

National Framework Objectives:

- **1.1:** To enable early identification of all infants with a congenital hearing loss of >40dB HL, including: bilateral, unilateral, sensory or neural hearing loss (e.g. Auditory Neuropathy Spectrum Disorder) and permanent conductive hearing loss.
- **2.1:** Families are able to make an informed decision on hearing screening and diagnostic services.
- **2.2:** All eligible infants complete a hearing screen.

National Framework Target:

- >97% of eligible infants complete a hearing screen before 1 month corrected age (Framework target 2.2.1).

Rationale:

This indicator measures the proportion of the population who are screened by a jurisdictional neonatal hearing screening program. Higher participation is necessary for achieving the overall aim of improving linguistic, educational and social outcomes for infants born with PCHI. Early identification of PCHI allows early engagement with intervention services which research has shown is necessary for achieving the overall aim of improving linguistic, educational and social outcomes for infants with permanent hearing loss. Therefore, it is necessary to monitor the age at which screening is occurring so the program is being run to maximum benefit.

Because the age at which an infant completes their neonatal hearing screen is closely tied to the identified aim of improving outcomes for infants born with PCHI, the calculation associated this indicator will present data disaggregated by age.

Calculation:

This calculation measures the number of infants who complete a neonatal hearing screen through a jurisdictional screening program as a proportion of all infants born in a calendar year.

Disaggregation:

The data will be presented by the following stratifications:

- Jurisdiction
- Sex
- Remoteness
- Socioeconomic status
- Aboriginal and Torres Strait Islander status
- CALD
- Preterm birth
- Age completed screen – disaggregated as <1 month, 1–3 months, 3–6 months, >6 months corrected age.

Issues for consideration:

- Infants who do not enter the screening pathway before being discharged from hospital may be at a higher risk of not completing a hearing screen. To ensure equitable access for all infants, those who do not enter the screening pathway by receiving at least their first screen prior to discharge should be followed up to ensure they complete their hearing screen. It is noted that this is a jurisdictional issue best monitored at the jurisdictional level.
- The denominator should be the number of live births. The National Perinatal Data Collection (NPDC) provides a comprehensive validated dataset of all live births in Australia, but is only is available after a two-year delay. State/territory neonatal screening programs are able to provide a suitable and timely alternative.
- While the aim of neonatal hearing screening is for all infants to be screened for congenital PCHI by 4 weeks of (corrected) age, the National Framework (NHSWG 2013) restricts this to eligible infants. Infants who are not eligible for screening include infants deemed to be medically unfit for screening. It is anticipated that this subgroup of infants will be very small and best monitored at the jurisdictional level.

Indicator 2 Screening

Indicator 2.1 Positivity rate of the screening test

Definition:

The proportion of infants who are screened and test positive for potential permanent childhood hearing impairment.

National Framework Objective 2.7:

To ensure that the number of infants referred for assessment and subsequently diagnosed with the target condition is appropriate for the population and is consistent with international standards.

National Framework Target:

- <4% of infants who are screened test positive for potential PCHI and are referred for audiological evaluation (Framework Target 2.7.2).

Rationale:

The positivity rate of the screening test provides an indication of how well the screening test is functioning as a test of potential PCHI. Current research suggests that a positivity rate higher than 4% could mean the screening test is yielding too many false positives (NHSWG, 2010). Additionally, a positivity rate higher than 4% (along with the confirmed diagnosis rate) may be an indication of an increase in PCHI among infants in Australia which would be a public health concern.

Another indication of how well the screening test is functioning can be obtained from the positive predictive value of the screening test, which is the proportion of infants who receive a positive hearing screen who after further examination are diagnosed with PCHI. The disaggregations for this indicator will ensure that the screening test is performing equally for all population subgroups.

Calculation:

This calculation measures the number of infants who returned a positive neonatal hearing screen as a proportion of all infants screened.

Disaggregations:

The data will be presented by the following stratifications:

- Jurisdiction
- Sex
- Remoteness
- Socioeconomic status
- Aboriginal and Torres Strait Islander status
- CALD
- Preterm birth
- Age – disaggregated as <1 month, 1–3 months, 3–6 months, >6 months corrected age.

Issues for consideration:

- The two approved screening technologies, OAE and AABR, have different positivity rates (i.e. AABR should be <2%, OAE <4%).

Indicator 2.2 Positive predictive value of the screening test

Definition:

The proportion of infants who test positive on their screening test for potential PCHI and upon further assessment receive a definitive diagnosis of PCHI.

National Framework Objective 2.7:

To ensure that the number of infants referred for assessment and subsequently diagnosed with the target condition is appropriate for the population and is consistent with international standards.

National Framework Target:

- A target for the expected positive predictive value of the screening test needs to be developed, in the interim it is recommended that the target be that the number of infants referred for assessment and subsequently diagnosed is appropriate to the population and consistent with international standards (Framework objective 2.7).

Rationale:

Currently, a combination of the otoacoustic emissions (OAE) test and the automated auditory brainstem response (AABR) test are used as the screening procedure for neonates in Australia. The screening process in neonatal hearing screening, like other screening tests, is not intended to be diagnostic. Rather, screening aims to identify infants who are more likely to have hearing impairment, and therefore require further investigation from diagnostic tests.

In order to understand the characteristics of the screening test, it is useful to compare the results of screening tests performed with the 'truth'. To do this, the number of infants with a positive screening test who are subsequently diagnosed with PCHI is viewed as a proportion of the number of infants with a positive screening test. These data can also be used to compute the number of false positives the screening test is yielding. It is important to monitor how well the screening test is functioning to ensure the screening process does not cause unnecessary anxiety or distress to families; and that the program is not unnecessarily resource intensive by referring too many infants for further investigation.

Indicator 2.2 is an important indicator to be interpreted in conjunction with indicator 2.1 as it ensures that of the infants who are being referred to audiological assessment, an appropriate number of these infants are found to have the target condition.

Calculation:

The number of infants who test positive on their screening test for potential PCHI and upon further assessment are given a definitive diagnosis of PCHI as a proportion of all infants who test positive for potential PCHI.

Disaggregations:

The data will be presented by the following stratifications:

- Jurisdiction
- Sex
- Remoteness
- Socioeconomic status
- Aboriginal and Torres Strait Islander status
- CALD
- Preterm birth
- Age – disaggregated as <1 month, 1–3 months, 3–6 months, >6 months corrected age.

Issues:

- In the short term, it is recommended that the target for this indicator be that the number of infants diagnosed with PCHI is appropriate for the population and consistent with international standards. Research needs to be conducted as to the incidence of PCHI in Australia. In the long term, an appropriate target for this indicator needs to be researched and developed.
    - According to the Medical Services Advisory Committee's Universal Neonatal Hearing Screening Assessment Report (2007) the PPV of TEOAE is 1.5% and of AABR is 2.2%. Research needs to be conducted on the PPV of the screening process that is used by jurisdictional screening programs.

Indicator 3 Audiological assessment and diagnosis

Indicator 3.1 Audiological assessment

Definition:

The proportion of infants who test positive for potential PCHI that complete audiological assessment.

National Framework Objectives:

- 2.6 To ensure infants identified at risk of PCHI are referred for assessment in a timely manner.
- 4.1 To ensure that infants who meet the defined criteria for referral receive follow-up audiological and medical evaluations in a timely manner.

National Framework Target:

- >97% diagnostic audiology assessment is commenced by three months of corrected age (Framework target 4.1.1).

Rationale:

This indicator measures the proportion of infants who returned a positive neonatal hearing screen and complete diagnostic assessment. It is important to ensure that infants who are referred to audiological assessment following a positive screen receive that assessment so they can continue to receive an intervention as appropriate.

Calculation:

This calculation measures the number of screened infants who test positive for potential PCHI and complete audiological assessment as a proportion of all infants who test positive on their screening test.

Disaggregations:

The data will be presented by the following stratifications:

- Age of infant when completed audiological assessment – disaggregated as <1 month, 1–2 months, 2–4 months, 4–6 months, >6 months corrected age
- Jurisdiction.

Issues:

- The NDSS recommends the below National Framework target >*97% of infants diagnosed with a permanent hearing loss are referred to Australian hearing* (Framework target 5.5.1) be considered as a target for this indicator. Adding a time element could improve this target.

Indicator 3.2 Detection of permanent childhood hearing impairment

Definition:

The proportion of infants who are diagnosed with PCHI.

National Framework Objective 2.7:

To ensure that the number of infants referred for assessment and subsequently diagnosed with the target condition is appropriate for the population and is consistent with international standards.

National Framework Target:

- Approximately 0.1% of infants screened are diagnosed with the target condition (Framework target 2.7.1).

Rationale:

The detection of PCHI is an indicator of program performance. Variation in this indicator over time could indicate an increase in the incidence of PCHI or that the screening and diagnostic instruments are not functioning properly.

When expressed as a proportion of the number of infants who test positive for potential PCHI, these data form Indicator 2.2 *positive predictive value of the screening test*.

Annual monitoring of these data with various stratifications (such as age or location) may reveal findings of concern that need to be addressed by the program, or positive trends that let the program know it is performing well.

This indicator will also monitor the age that PCHI is diagnosed.

Calculation:

This calculation measures the number of screened infants who are diagnosed with PCHI as a proportion of all infants screened.

Disaggregations:

The data will be presented by the following stratifications:

- Age at diagnosis – disaggregated as <2 months, 2–4 months, 4–6 months, >6 months corrected age
- Jurisdiction
- Degree, configuration and type of hearing loss.

Issues:

- The disaggregation of age at diagnosis (presently <2 months, 2–4 months, 4–6 months, >6 months corrected age) needs to be agreed upon.
- A further issue that requires consideration is whether infants are diagnosed with either congenital permanent childhood hearing impairment or no congenital childhood hearing impairment or whether there are other possible diagnoses.
- Hearing status for any individual person is not static. For the purposes of newborn hearing screen, this indicator's definition could be hearing status based on a completed newborn audiological assessment, with a maximum age at assessment of 6 months.

Indicator 4 Early intervention and management

Indicator 4.1 Attend early intervention service

Definition:

The proportion of infants diagnosed with PCHI who attend an early intervention service.

National Framework Objective: *to be created*

To ensure that families and infants engage with an early intervention service.

National Framework Target:

- A suitable target needs to be created.

Rationale:

It is important that infants who are diagnosed with PCHI attend early intervention services. This is necessary to achieve the program's overall aim of improving linguistic, educational and social outcomes for infants with congenital hearing loss which is of clear benefit to the infant, family and the community.

It is important to capture these data to monitor the reasons infants are not progressing through the screening pathway as the National Framework (NHSWG 2013) posits that all eligible infants should proceed as far through the screening pathway as their hearing status warrants so that all Australian infants can benefit from the best possible linguistic, educational and social outcomes. Legitimate reasons that infants may not progress through the screening pathway include the family not consenting, or the infant having other medical problems that prevent attendance.

Indicator 4.1 compares the number of infants diagnosed with PCHI who attend an early intervention service as a proportion of the number of infants diagnosed with PCHI whose parents are referred to early intervention. This is because infants who are captured in Indicator 4.1 should be referred through the program.

Calculation:

This calculation measures the number of infants diagnosed with PCHI and attend early intervention services as a proportion of the number of infants diagnosed with PCHI.

Disaggregations

The data will be presented by the following stratifications:

- Jurisdiction
- Age at attendance at early intervention services – disaggregated as <2 months, 2–4 months, 4–6 months, >6 months corrected age
- Time (weeks) elapsed between date of completing diagnostic services and attending early intervention services – disaggregated as <6 weeks, 6–9 weeks, 9–12 weeks, >12 weeks.

Issues:

- A suitable objective and target need to be created. A possible objective could be *To ensure that families and infants engage with an early intervention service.*

Indicator 4.2 Infants fitted with an assistive hearing device

Definition:

The proportion of infants diagnosed with PCHI who are fitted with an assistive hearing device.

National Framework Objective:

Infants who have a permanent, moderate or greater bilateral sensorineural hearing loss are provided with amplification/implants in an appropriate time frame for optimal speech and language development.

National Framework Target:

- >97% babies diagnosed with a permanent hearing loss are referred to Australian Hearing (Framework target 5.5.1).
- 100% of referrals received by Australian hearing are confirmed to the referral agency within 5 days (Framework target 5.5.2).
- >85% of children diagnosed with bilateral hearing loss >40 dBHL are fitted with amplification by 6 months of age (Framework target 5.5.5).
- >95% of children diagnosed with bilateral hearing loss >40 dBHL are fitted with amplification by 12 months of age (Framework target 5.5.6).

Rationale:

It is appropriate to monitor factors around hearing aid fitting and cochlear implants. Monitoring these data will assist in service provision and understanding of the types of devices commonly used. It is important to note that audiological management of a hearing impaired child may not always involve a device fitting.

Calculation:

This calculation measures the number of infants who are fitted with an assistive hearing device as a proportion of all infants diagnosed with PCHI.

Disaggregations:

The data will be presented by the following stratifications:

- Jurisdiction
- Age at fitting of first assistive hearing device – disaggregated as <2 months, 2–4 months, 4–6 months, >6 months corrected age
- Type of first assistive hearing device – hearing aid, cochlear implant, other.

Issues:

- Australian Hearing can report on hearing aids. Jurisdictional health departments should report on cochlear implant fitting.
- The following Framework targets could be considered after initial implementation:
  - **5.3.1** Age of initiation of formal early intervention is recorded centrally in the program for all children diagnosed with permanent hearing impairment.
  - **5.3.2** >97% of babies with permanent hearing impairment are engaged in formal early intervention by four months of corrected age.
  - **5.5.3** >97% of families attend appointment within three weeks of the referral.

4 Technical specifications

Chapter 4 presents clear and concise technical information for each indicator to ensure all those who collect, provide, analyse and use the data clearly understand its meaning.

4.1 How to use the information on technical specifications

Formula

This section provides the conceptual formula that is needed to compute the indicator.

Numerator and denominator definitions

This section elaborates on the formula providing the information necessary to compute the formula such as specifying the boundary of data included for example for one calendar year.

Numerator and denominator data collection

The data collection is the name of the data collection from which the data elements were derived.

Numerator and denominator data source

The data source refers to the source of the data for the indicator; for some indicators the numerator and denominator data source will be different.

Data elements

The basic unit of identifiable and definable information:

- *Selection data elements* refer to data elements necessary to compute the indicator.
- *Disaggregation data elements* refer to data elements necessary to disaggregate the indicator, for example by socioeconomic status or jurisdiction of birth.

Numerator and denominator specifications

This section may include information on how to calculate components of an indicator, such as corrected age; and what values of a data element to include to calculate an indicator, for example to only include infants with a diagnosis of PCHI when using the data element *Audiological assessment outcome*.

Multiplication factor

The multiplication factor is a number that the formula is multiplied by for ease of interpretation, for example a multiplication factor of 100 turns the participation indicator into a rate of per 100 infants otherwise known as a per cent.

Unit

The unit refers to the unit of measurement used in that indicator, for example infants or screening tests.

Indicator 1 Participation

Indicator 1.1 Participation in screening

Formula

$$\frac{\text{Number of infants born in a calendar year who complete a hearing screen}}{\text{Number of infants born in a calendar year}} * mf$$

Numerator

Numerator definition:	Number of infants born in a calendar year who complete a hearing screen.
Numerator data collection:	Jurisdictional neonatal hearing screening program register data collection.
Numerator data source:	Jurisdictional neonatal hearing screening programs.
Numerator data elements:	*Selection data elements:* Date of birth Date screen completed *Disaggregation data elements:* Jurisdiction Sex Geographic identifier of usual residence Corrected age Indigenous identifier CALD identifier
Numerator specifications:	• While the aim of neonatal hearing screening is for all infants to be screened for congenital PCHI by 4 weeks of (corrected) age, the *National Framework for Neonatal Hearing Screening* (NHSWG 2013) restricts this to eligible infants. Infants who are not eligible for screening include infants deemed to be medically unfit for screening. It is anticipated that this subgroup of infants will be very small and best monitored at the jurisdictional level. • Count is of all infants born in the designated calendar year where *date screen completed* is *NOT NULL.* • Corrected age is calculated as *chronological age at screen* less *gestational age.* • *Chronological age at screen* is calculated by subtracting *date of birth* from *date screen completed*. • *Geographic identifier of usual residence* is used to calculate remoteness and socioeconomic status, Statistical Local Area (or equivalent) is preferred; however postcode is an acceptable alternative. • CALD should be identified through standard questions as per 2006 census. Country of birth of mother (as collected in the NPDC) could be used as a proxy, but only partially represents an infant's cultural heritage. • Identification of an infant as Aboriginal and Torres Strait Islander is based on identification to the jurisdictional register or Australian Hearing by the infant's family. Aboriginal and Torres Strait Islander status of mother (as collected in the NPDC) could be used as a proxy, but only partially represents an infant's Indigenous heritage.

Denominator

Denominator definition:	The number of infants born in a calendar year.
Denominator data collection:	Jurisdictional neonatal hearing screening program register data collection. NB: This can be validated after a 2-year period by National Perinatal Data Collection.
Denominator data source:	Jurisdictional neonatal hearing screening programs. National Perinatal Epidemiology and Statistics Unit, AIHW.
Denominator data elements:	*Selection data elements:* Date of birth *Disaggregation data elements:* Jurisdiction
Denominator specifications:	• While the aim of neonatal hearing screening is for all infants to be screened for congenital PCHI by 4 weeks of (corrected) age, the *National Framework for Neonatal Hearing Screening* (NHSWG 2013) restricts this to eligible infants. Infants who are not eligible for screening include infants deemed to be medically unfit for screening. It is anticipated that this subgroup of infants will be very small and best monitored at the jurisdictional level.

Multiplication factor

Multiplication factor (mf):	100
Unit:	Infants

Indicator 2 Screening

Indicator 2.1 Positivity rate of screening test

Formula

$$\frac{\text{Number of infants who returned a positive neonatal hearing screen}}{\text{Number of infants who completed a neonatal hearing screen}} * mf$$

Numerator

Numerator definition:	Number of infants born in a calendar year who returned a positive neonatal hearing screen.
Numerator data collection:	Jurisdictional neonatal hearing screening program registers.
Numerator source:	Jurisdictional neonatal hearing screening programs.
Numerator data elements:	*Selection data elements:* Date of birth Date screen completed Screen outcome *Disaggregation data elements:* Jurisdiction Sex Geographic identifier of usual residence Indigenous identifier CALD identifier
Numerator specifications:	• Count is of all infants born in the designated calendar year where *screen outcome* is *positive.* • *Geographic identifier of usual residence* is used to calculate remoteness and socioeconomic status, Statistical Local Area (or equivalent) is preferred; however postcode is an acceptable alternative. • Identification of an infant as Aboriginal and Torres Strait Islander is based on identification by the infant's family to the jurisdictional register or Australian Hearing. Aboriginal and Torres Strait Islander status of mother (as collected in the NPDC) could be used as a proxy, but only partially represents an infant's Indigenous heritage. • CALD should be identified through standard questions as per 2006 census. Country of birth of mother (as collected in the NPDC) could be used as a proxy, but only partially represents an infant's cultural heritage. • Measured once in a calendar year at a national level – may be measured more frequently at a jurisdictional or service level.

Denominator

Denominator definition:	Number of infants born in a calendar year who completed a neonatal hearing screen.
Denominator data collection:	Jurisdictional neonatal hearing screening program register data collection.

Denominator data source:	Jurisdictional neonatal hearing screening programs.
Denominator data elements:	*Selection data elements:* Date of birth Date screen completed *Disaggregation data elements:* Jurisdiction of birth Sex Geographic identifier of usual residence Indigenous identifier CALD identifier
Denominator specifications:	• Count is of all infants born in the designated calendar year with *date screen completed* NOT NULL. • *Geographic identifier of usual residence* is used to calculate remoteness and socioeconomic status, Statistical Local Area (or equivalent) is preferred; however postcode is an acceptable alternative. • Identification of an infant as Aboriginal and Torres Strait Islander is based on identification to the jurisdictional register or Australian Hearing by the infant's family. Aboriginal and Torres Strait Islander status of mother (as collected in the NPDC) could be used as a proxy, but only partially represents an infant's Indigenous heritage. • CALD should be identified through standard questions as per 2006 census. Country of birth of mother (as collected in the NPDC) could be used as a proxy, but only partially represents an infant's cultural heritage. • Measured once in a calendar year at a national level – may be measured more frequently at a jurisdictional or service level.

Multiplication factor

Multiplication factor (mf):	100
Unit:	None

Indicator 2.2 Positive predictive value of the screening test

Formula

$$\frac{\text{Number of infants who returned a positive neonatal hearing screen and subsequently diagnosed with PCHI}}{\text{Number of infants who returned a positive neonatal hearing screen}} * mf$$

Numerator

Numerator definition:	Number of infants born in a calendar year who returned a positive neonatal hearing screen and were subsequently diagnosed with PCHI.
Numerator data collection:	To be determined.
Numerator data source:	To be determined.
Numerator data elements:	*Selection data elements:* Date of birth Date screen completed Screen outcome Audiological assessment outcome *Disaggregation data elements:* Jurisdiction Sex Geographic identifier of usual residence Indigenous identifier CALD identifier
Numerator specifications:	• Count is of all infants born in the designated calendar year where *screen outcome* is *positive* and *audiological assessment outcome* is *positive.* • *Geographic identifier of usual residence* is used to calculate remoteness and socioeconomic status, Statistical Local Area (or equivalent) is preferred; however postcode is an acceptable alternative. • Identification of an infant as Aboriginal and Torres Strait Islander is based on identification to the jurisdictional register or Australian Hearing by the infant's family. Aboriginal and Torres Strait Islander status of mother (as collected in the NPDC) could be used as a proxy, but only partially represents an infant's Indigenous heritage. • CALD should be identified through standard questions as per 2006 census. Country of birth of mother (as collected in the NPDC) could be used as a proxy, but only partially represents an infant's cultural heritage. • Measured once in a calendar year at a national level – may be measured more frequently at a jurisdictional level.

Denominator

Denominator definition:	Number of infants born in a calendar year who returned a positive neonatal hearing screen.
Denominator data collection:	Jurisdictional neonatal hearing screening program register data collection.
Denominator data source:	Jurisdictional neonatal hearing screening programs.
Denominator data elements:	*Selection data elements:* Date of birth Date screen completed Screen outcome *Disaggregation data elements:* Jurisdiction Sex Geographic identifier of usual residence Indigenous identifier CALD identifier
Denominator specifications	• Count is of all infants born in the designated calendar year where *screen outcome* is *positive*. • *Geographic identifier of usual residence* is used to calculate remoteness and socioeconomic status, Statistical Local Area (or equivalent) is preferred; however postcode is an acceptable alternative. • Identification of an infant as Aboriginal and Torres Strait Islander is based on identification to the jurisdictional register or Australian Hearing by the infant's family. Aboriginal and Torres Strait Islander status of mother (as collected in the NPDC) could be used as a proxy, but only partially represents an infant's Indigenous heritage. • CALD should be identified through standard questions as per 2006 census. Country of birth of mother (as collected in the NPDC) could be used as a proxy, but only partially represents an infant's cultural heritage. • Measured once in a calendar year at a national level – may be measured more frequently at a jurisdictional level.

Multiplication factor

Multiplication factor (mf):	100
Unit:	Infants

Indicator 3 Audiological assessment and diagnosis

Indicator 3.1 Audiological assessment

Formula

$$\frac{\text{Number of infants who returned a positive neonatal hearing screen who complete audiological assessment}}{\text{Number of infants who returned a positive neonatal hearing screen}} * mf$$

Numerator

Numerator definition:	Number of infants born in a calendar year who returned a positive screen who complete audiological assessment.
Numerator data collection:	To be determined.
Numerator data source:	To be determined.
Numerator data elements:	*Selection data elements:* Date of birth Date screen completed Screen outcome Date audiological assessment completed *Disaggregation data elements* Jurisdiction Gestational age
Numerator specifications:	• Count is of all infants born in the designated calendar year with *date screen completed* NOT NULL and *screen outcome* is *positive* AND *date audiological assessment completed* is NOT NULL. • *Chronological age at completion of audiological assessment* is calculated by subtracting *date of birth* from *date audiological assessment completed.* • Corrected age is calculated as *chronological age at audiological assessment* less *gestational age.* • Time (days) elapsed from completion of screening test to completion of audiological assessment is calculated as the difference (in days) between *date screen completed* and *date audiological assessment completed* – disaggregated as <6 days, 6–10 days, 10–15 days, >15 days.

Denominator

Denominator definition:	Number of infants born in a calendar year who returned a positive neonatal hearing screen.
Denominator data collection:	Jurisdictional neonatal hearing screening program registers.
Denominator data source:	Jurisdictional neonatal hearing screening programs.

Denominator data elements:	*Selection data elements:* Date of birth Date screen completed Screen outcome *Disaggregation data elements:* Jurisdiction
Denominator specifications	• Count is of all infants born in the designated calendar year with *date screen completed* NOT NULL and *screen outcome* is *positive*.

Multiplication factor

Multiplication factor (mf):	1,000
Unit:	Infants

Indicator 3.2 Detection of PCHI

Formula

$$\frac{\text{Number of infants screened through the program who are diagnosed with PCHI}}{\text{Number of infants who complete a neonatal hearing screen}} * mf$$

Numerator

Numerator definition:	Number of infants born in a calendar year screened through the program who are diagnosed with PCHI.
Numerator data collection:	To be determined.
Numerator data source:	To be determined.
Numerator data elements:	*Selection data elements:* Date of birth Date screen completed Audiological assessment outcome *Disaggregation data elements:* Jurisdiction Type and degree of hearing loss
Numerator specifications:	• Count is of all infants born in the designated calendar year where *date screen completed* NOT NULL and *audiological assessment outcome* is *positive.*

Denominator

Denominator definition:	Number of infants born in a calendar year who complete a neonatal hearing screen.
Denominator data collection:	Jurisdictional neonatal hearing screening program registers.
Denominator data source:	Jurisdictional neonatal hearing screening programs.
Denominator data elements:	*Selection data elements:* Date of birth Date screen completed *Disaggregation data elements:* Jurisdiction
Denominator specifications:	• Count is of all infants born in the designated calendar year with *date screen completed* NOT NULL.

Multiplication factor

Multiplication factor (mf)	1,000
Unit	Infants

Indicator 4 Early intervention and management

Indicator 4.1 Attend early intervention service

Formula

$$\frac{\text{Number of infants diagnosed with PCHI who attend early intervention services}}{\text{Number of infants who are diagnosed with PCHI}} * mf$$

Numerator

Numerator definition:	Number of infants born in a calendar year diagnosed with PCHI who attend early intervention services.
Numerator data collection:	To be determined.
Numerator data source:	To be determined.
Numerator data elements:	*Selection data elements:* Date of birth Date audiological assessment completed Outcome of audiological assessment Date of first attendance early intervention service *Disaggregation data elements:* Jurisdiction
Numerator specifications:	• Count is of all infants born in the designated calendar year where *audiological assessment outcome* is *positive* and *date first attended Early Intervention Service* is *NOT NULL*. • Time (days) elapsed from completion of screening test to commencement of audiological assessment calculated as the difference in days between *Date audiological assessment completed* and *Date of first attendance early intervention* – disaggregated as <6 days, 6–10 days, 10–14 days, >14 days.

Denominator

Denominator definition:	Number of infants born in a calendar year who are diagnosed with PCHI.
Denominator data collection:	To be determined.
Denominator data source:	To be determined.
Denominator data elements:	*Selection data element:* Date of birth Outcome of audiological assessment *Disaggregation data elements:* Jurisdiction
Denominator Specifications:	• Count is of all infants born in the designated calendar year where *audiological assessment outcome* is *positive.*

Multiplication factor

Multiplication factor (mf):	1,000
Unit:	Infants

Indicator 4.2 Infants fitted with an assistive hearing device

Formula

$$\frac{\text{Number of infants diagnosed with PCHI who are fitted with an assistive hearing device}}{\text{Number of infants who are diagnosed with PCHI}} * \textbf{mf}$$

Numerator

Numerator definition:	Number of infants born in a calendar year who are diagnosed with PCHI and are fitted with an assistive hearing device.
Numerator data collection:	To be determined.
Numerator data source:	Australian Hearing.
Numerator data elements:	• To be created in collaboration with jurisdictional health department and Australian Hearing
Numerator specifications:	• To be created in collaboration with jurisdictional health department and Australian Hearing

Denominator

Denominator definition:	Number of infants born in a calendar year who are diagnosed with PCHI.
Denominator data collection:	To be determined.
Denominator data source:	To be determined.
Denominator data elements:	*Selection data elements:* Date of birth Audiological assessment outcome *Disaggregation data elements:* Jurisdiction Date screen completed First assistive hearing device type
Denominator specifications	• Count is of all infants born in the designated calendar year where *audiological assessment outcome* is *positive.*

Multiplication factor

Multiplication factor (mf)	1,000
Unit	Infants

Appendix A Neonatal Hearing Screening Working Group membership

Table A.1: NHSWG membership

NHSWG member	Organisation
Ms Melinda Bromley (Chair)	DOHA, Assistant Secretary Population Health Programs Branch
Mr Alan Keith (Secretariat)	DOHA, Population Health Programs Branch
Ms Karen Granton (Secretariat)	DOHA, Population Health Programs Branch
Ms Renee Garuccio	Northern Territory Department of Health and Families,Northern Territory Hearing Services
Professor Greg Leigh	Royal Institute for Deaf and Blind Children / Australasian Newborn Hearing Screening Committee
Ms Elizabeth Low	DOHA, Office of Hearing Services
Ms Jan MacLean	West Australian Newborn Hearing Screening Program / Australasian Newborn Hearing Screening Committee
Ms Tina Carter	Consumer representative, Australia and New Zealand Parents of Deaf Children
Ms Christine Sturrock	AIHW, Cancer and Screening Unit
Professor Melissa Wake	Centre for Community and Child Health / Australasian Newborn Hearing Screening Committee
Ms Alison King	Australian Hearing, Principal Audiologist Paediatric Services
Ms Jane McEntee	Ministry of Health New Zealand, Antenatal and Newborn Screening Health and Disability
Dr Elisabeth Murphy	NSW Department of Health / Child Health and Wellbeing Subcommittee

Appendix B Neonatal Data Specification Subgroup membership

Table B.1: NDSS membership

NDSS member	Organisation
Christine Sturrock (Chair)	AIHW, Cancer and Screening Unit
Melissa Goodwin	AIHW, Cancer and Screening Unit
Theresa Negrello	AIHW, Cancer and Screening Unit
Alan Keith	DOHA, Population Health Programs Branch
Alison King	Australian Hearing, Principal Audiologist Paediatric Services
Michelle Forte	South Australian Department of Health, Newborn and Children's Hearing Services
Paula Laws	AIHW, National Perinatal Statistics Unit (Collaborating Unit)
Elizabeth Sullivan	AIHW, National Perinatal Statistics Unit (Collaborating Unit)
Lisa Hilder	AIHW, National Perinatal Statistics Unit (Collaborating Unit)
Shirley Glennon	Queensland Health, Healthy Hearing Program
Sue Stratton	NSW Health, Hearing Health Network Co-ordinator
Carol McWeeney	New South Wales State wide Infant Screening Hearing Program
Zeffie Poulakis	The Royal Children's Hospital, Melbourne, Victorian Infant Hearing Screening Program

Appendix C National Framework targets and indicator decision matrix

Each of the 29 objectives, 69 standards and 83 targets of the *Draft National Framework* (later titled the National Framework for Neonatal Hearing Screening, NHSWG 2013) were systematically audited to assess their appropriateness for national reporting. Consideration was given to the fewest number of indicators which would appropriately measure performance of neonatal hearing screening in Australia. The aim was to create a set of indicators that were robust enough to measure performance of neonatal hearing screening at the national level, while providing minimal reporting burden to allow jurisdictions to better use resources in program management. Monitoring national performance indicators has to be less detailed than at a jurisdictional or service level and Table C.1 reflects this principle. The objectives, standards, and targets of the *Draft National framework* provide an appropriate model for quality service provision.

Table C.1: Neonatal hearing screening: target performance indicator decision matrix.

Note: that sections 3 *Parental Support*, 6 *Coordination, Monitoring and Evaluation*, and 7 *Professional Education* are not included as they refer to qualitative standards not appropriate for national reporting.

Draft national framework objective	Draft national framework targets	Suitable for measuring performance at a national level?	Rationale	National performance indicator
1 Recruitment				
1.1 To enable early identification of all babies with a congenital hearing loss of >40dB HL, including: bilateral, unilateral, sensory or neural hearing loss (e.g. Auditory Neuropathy Spectrum Disorder) and permanent conductive hearing loss.	100% of eligible babies are offered hearing screening.	No	Although recognised as an important target that should be monitored, this can be provided at a jurisdictional level.	-
	>97% of eligible babies complete a hearing screen.	No	Although recognised as important target that should be monitored nationally, this target is covered under the first target in 2.2.	-
	100% babies not screened prior to hospital discharge are followed up within one month.	No	Although recognised as an important target that should be monitored, this can be provided at a jurisdictional level. For the purposes of national reporting, these data are sufficiently captured by indicator 1.1.	-

Draft national framework objective	Draft national framework targets	Suitable for measuring performance at a national level?	Rationale	National performance indicator
1.2 To ensure that all parents are aware of newborn hearing screening and its benefits and risks.	Written information that describes the screening process and the reason for screening is provided to parents.	No	Qualitative target that can be demonstrated and monitored by the jurisdictional programs.	-
2 Screening				
2.1 Parents are able to make an informed decision on hearing screening and diagnostic services.	Written parental consent is obtained to perform a screen.	No	Qualitative target that can be demonstrated and monitored by the jurisdictions programs.	-
	<1% of parents decline screening.	No	Although recognised as an important target that should be monitored, this can be provided at a jurisdictional level. These national performance indicators were created on the assumption that decline of service is a jurisdictional issue.	-
	A decline form is signed by all parents who choose to decline a screen.	No	Qualitative target that can be demonstrated and monitored by the jurisdictional programs.	-
	A decline to participate in screening is recorded appropriately in the infant's medical file.	No	Qualitative target that can be demonstrated and monitored by the jurisdictional programs.	
	Written consent is obtained to collect data for those babies with a refer (positive) result on the screen.	No	Not necessary to be monitored at a national level but a national data collection may only receive information on those infants for whom consent is obtained.	-
2.2 All eligible newborns complete a hearing screen.	>97% eligible babies complete a hearing screen before one month corrected age.	Yes	Recognised as an important target that should be monitored nationally.	1.1
	All babies with a 'refer' (positive) result are referred for audiological assessment.	No	Although recognised as an important target that should be monitored nationally, this target is included in objective 4.1 and will be monitored using the target >97% of infants with a positive screen commenced audiological assessment by three months corrected age.	-

Draft national framework objective	Draft national framework targets	Suitable for measuring performance at a national level?	Rationale	National performance indicator
2.3 All babies in Neonatal Intensive Care Units (NICU) and Special Care Units are screened with technology capable of identifying Auditory Neuropathy Spectrum Disorder.	All babies admitted to NICU are screened according to NICU protocols.	No	This is a standard of care and not appropriate for inclusion in national reporting against performance.	-
2.4 Results of screening processes are communicated to families accurately, effectively and considerately.	All results are provided verbally and in written form. Outcomes are recorded.	No	Qualitative target that can be demonstrated and monitored by the jurisdictional programs.	-
2.5 Informed consent processes are followed for referral to diagnostic audiology.	>99% parents of babies with a refer result consent to diagnostic assessment.	No	Recognised as an important target that should be monitored nationally.	-
2.6 To ensure newborns are referred in a timely manner.	>97% babies with a refer (positive) result are referred, monitored and followed up through to diagnostic services.	No	Although recognised as important target that should be monitored nationally, this TPI is a summary of the screening process and is covered in multiple subsequent indicators.	-
	>97% of referrals to diagnostic assessment are made in less than 5 days.	No	Although recognised as an important target, this is covered in target 4.1.1.	-
2.7 To ensure that the number of infants referred for assessment and subsequently diagnosed with the target condition is appropriate for that population and is consistent with international standards.	Approximately 0.1% of babies screened will be diagnosed with the target condition.	Yes	Recognised as an important target that should be monitored nationally.	3.2
	<4% of infants who are screened test positive for potential PCHI and are referred for audiological evaluation.	Yes	Recognised as an important target that should be monitored nationally.	2.1
2.8 To provide parents with information explaining that changes can occur in their child's hearing over time.	All parents of babies screened are provided with a check list of developmental milestones for hearing and signs of hearing loss.	No	Qualitative target that can be demonstrated and monitored by the jurisdictional programs.	-
	Parents with children at higher risk are provided with clear written information of their risk factors.	No	Qualitative target that can be demonstrated and monitored by the jurisdictional programs.	-

Draft national framework objective	Draft national framework targets	Suitable for measuring performance at a national level?	Rationale	National performance indicator
4 Diagnosis				
4.1 To ensure that infants who meet the defined criteria for referral receive follow-up audiological and medical evaluations in a timely manner.	>97% of infants with a positive screen have commenced diagnostic assessment by three months corrected age.	Yes	Recognised as an important target that should be monitored nationally.	3.1
	>97% of families are referred to Australian Hearing within three days of confirmed hearing loss.	No	Qualitative target that can be demonstrated and monitored by the jurisdictional programs.	-
4.2 To define the degree, configuration and type of hearing loss in each ear for fitting of hearing devices.	All children referred are tested with a full range of diagnostic electrophysiological tests in accordance with agreed national standards.	No	Qualitative target that can be demonstrated by audiologists and monitored by the jurisdictional programs.	-
	Diagnostic electrophysiological tests and behavioural test outcomes are clearly and accurately documented.	No	Qualitative target that can be demonstrated by audiologists and monitored by the jurisdictional programs.	-
	Results are included with referrals to Australian Hearing.	No	Qualitative target that can be demonstrated by audiologists and monitored by the jurisdictional programs.	-
	Families are provided with an explanation of the results on completion of the diagnostic assessment.	No	Qualitative target that can be demonstrated by audiologists and monitored by the jurisdictional programs.	-
	Families are provided with a written copy of the results within five working days.	No	Qualitative target that can be demonstrated by audiologists and monitored by the jurisdictional programs.	-
4.3 To ensure babies obtain otologic, ophthalmic and developmental assessment and the opportunity for aetiological investigation including genetic advice/counselling.	An appointment with an otolaryngologist /paediatrician with expertise in paediatric hearing loss should be made within two weeks of confirmation of hearing loss.	No	Standard of care that is not appropriate for national reporting.	-
	Following confirmation of hearing loss, all babies are referred for otological and other appropriate medical evaluation so that a medical management plan including other interventions, can be developed by three months of age in collaboration with the family.	No	This is a standard of care and not a target for a national performance indicator.	-

Draft national framework objective	Draft national framework targets	Suitable for measuring performance at a national level?	Rationale	National performance indicator
	All families are provided with a written explanation of the implications of the outcomes of aetiological investigation.	No	Qualitative target that can be demonstrated and monitored by the jurisdictional programs.	-
	There is evidence of processes for reviewing and correlating clinical, neurological, audiology (etc) findings for hearing loss that has been detected as a result of screening.	No	Qualitative target that can be demonstrated and monitored by the jurisdictional programs.	-
	>97% of babies are seen within targeted timeframes.	No	This target is a summary of other targets.	-
5 Early intervention and management				
5.1 Early intervention, support and advocacy services are family centred.	>97% of families are provided with a range of options regarding amplification technology, communication and intervention within six weeks of diagnosis.	No	Although important, it is suggested that this standard is best monitored at a jurisdictional level.	-
	Families (particularly in rural and remote areas) are provided with information on eligibility and access to travel assistance particularly for rural and remote areas.	No	Qualitative target that can be demonstrated and monitored by Australian Hearing.	-
	Services provide evidence of a mechanism to engage parents in the development of service delivery standards and protocols.	No	Qualitative target that can be demonstrated and monitored by Australian Hearing.	-
5.2 All families remain engaged with an early intervention service provider.	Services demonstrate that protocols have been put in place to provide a smooth transition process between other hearing impairment services.	No	Qualitative target that can be demonstrated and monitored Australian Hearing.	-
	Early intervention providers report on continuing enrolment or disengagement quarterly.	No	Qualitative target that can be demonstrated and monitored by Australian Hearing.	-
	Families that disengage with an early intervention service provider are offered support through central family advocacy/support services to engage with alternative providers within two months.	No	Qualitative target that can be demonstrated and monitored by Australian Hearing.	-

Draft national framework objective	Draft national framework targets	Suitable for measuring performance at a national level?	Rationale	National performance indicator
	Service providers assist in the development of a transition plan six months prior to enrolment in an educational system.	No	Qualitative target that can be demonstrated and monitored by Australian Hearing.	-
5.3 All families are informed about the range and nature of early intervention service options in order to facilitate timely engagement with early intervention.	Age of initiation of formal early intervention is recorded centrally in the program for all children diagnosed with permanent hearing impairment.	Consider	To be considered after initial implementation of the indicators.	Would refer to 4.2
	>97% of babies with permanent hearing impairment are engaged in formal early intervention by four months of corrected age.	Consider	To be considered after initial implementation of the indicators.	Would refer to 4.2
	Families who do not attend audiology or early intervention services are notified to the family's GP and/or Maternity and Child Health Nurse for follow-up within four weeks.	No	Qualitative target that can be demonstrated and monitored by Australian Hearing.	-
5.4 All early intervention programs assess language skills, cognitive skills, auditory skills, speech, vocabulary, and social-emotional development of all children with hearing impairment.	Services demonstrate that all professional staff members have the skills/qualifications that are necessary for providing families with the highest quality of service specific to children with hearing impairment.	No	Qualitative target that can be demonstrated and monitored by Australian Hearing.	-
	Services have a comprehensive orientation and training program for staff involved in the delivery of services to children and their families.	No	Qualitative target that can be demonstrated and monitored by Australian Hearing.	-
	>97% of babies with confirmed hearing impairment receive a full developmental assessment with standardised assessment protocols (not criterion reference checklists) for language, speech, and nonverbal cognitive development by 12 months of age.	No	Beyond the scope of a national neonatal hearing screening program but could be monitored at a jurisdictional level.	-
	>97% of babies with confirmed hearing impairment in early intervention programs receive a language, cognitive skills, auditory skills, speech, vocabulary, and social-emotional assessment at six-month intervals during the first three years of life.	No	Beyond the scope of a national neonatal hearing screening program but could be monitored at a jurisdictional level.	-

Draft national framework objective	Draft national framework targets	Suitable for measuring performance at a national level?	Rationale	National performance indicator
5.5 Babies who have a permanent, moderate or greater bilateral sensorineural hearing loss are provided with amplification/implants in an appropriate time frame for optimal speech and language development.	>97% babies diagnosed with a permanent hearing loss are referred to Australian Hearing.	Yes	Recognised as an important target that should be monitored nationally.	3.1
	100% of referrals received by Australian Hearing are confirmed to the referral agency within 5 days.	Consider	To be considered after initial implementation of the indicators.	Would refer to 4.1
	>97% of families attend appointment within three weeks of the referral.	No	Recognised as important but a jurisdictional matter.	-
	Australian Hearing confirms attendance at initial appointment of all referred newborns.	No	Qualitative target that can be demonstrated and monitored by Australian Hearing and is therefore not necessary reporting at a national level.	4.2
	>85% of children diagnosed with bilateral hearing loss >40 dBHL are fitted with amplification by six months of age.	Yes	Recognised as an important target that should be monitored nationally.	4.2
	>95% of children diagnosed with a bilateral hearing loss >40 dBHL are fitted with amplification by 12 months of age.	Yes	Recognised as an important target that should be monitored nationally.	4.2
	>97% of children with 3FAHL of ≥90 dBHL at the initial diagnostic audiology appointment are offered referral for cochlear implant candidacy.	No	Recognised as important but a jurisdictional matter.	-
	Other children are offered a cochlear implant referral when appropriate to the family's program.[a]	No	Qualitative target that can be demonstrated and monitored by Australian Hearing.	-

(a) Other reasons for referral include: parents' wish to obtain information about cochlear implantation, child's functional auditory performance is measured to fall > 2 standard deviations below average for the child's age; aetiology of the hearing loss is one where research suggests that the child may benefit from a cochlear implant.

Appendix D Data elements required to calculate performance indicators

METeOR and metadata

METeOR stands for Metadata Online Repository and is Australia's repository for national metadata standards for the health, community services and housing assistance sectors developed by the Australian Institute of Health and Welfare.

Metadata is often called 'data about data'. More precisely, it is the underlying definition or structured description of the content, quality, condition or other characteristics of data. Metadata that have been endorsed for use across Australia are referred to as data standards.

Below is a table that contains proposed data elements, their definitions and provides metadata information already held in METeOR if it exists. Where a data element needs to be developed, this is indicated in the table.

Items with a 🗝 denote a data element that can be used as a statistical linkage key. These items can be calculated and added as a variable to the dataset before sharing this data set. This allows the removal of identifying information and thus protects privacy while enabling linkage with other data sets.

Table D.1: Proposed data elements, definitions and metadata information held in METeOR for a national neonatal hearing screening data set

	Data element	Definition	Metadata item title	Metadata item type	METeOR identifier
Person information					
	Infant's person ID	Person identifier unique within an establishment or agency and jurisdiction. This is allocated at first contact with the service. An ID that is not duplicated in different jurisdictions is advisable for ease of national reporting.	To be developed	Data element	. .
🗝	Infant's given name	The person's identifying name within the family group or by which the person is socially identified, as represented by text.	Person (name)—given name, text [X(40)]	Data element	287035
🗝	Infant's family name	That part of a name a person usually has in common with some other members of his/her family, as distinguished from his/her given names, as represented by text.	Person (name)—family name, text X[X(39)]	Data element	286953
🗝	Sex	The biological distinction between male and female, as represented by a code.	Person—sex, code N	Data element	287316

	Data element	Definition	Metadata item title	Metadata item type	METeOR identifier
Demographic information					
🗝	Geographic identifier of usual residence	Geographical location of usual residence of the person, as represented by a code. *Note*: Geographical location is reported using Statistical Local Area (SLA) to enable accurate aggregation of information to larger areas within the Australian Standard Geographical Classification (ASGC) (such as Statistical Subdivisions and Statistical Divisions) as well as detailed analysis at the SLA level.	Person—area of usual residence, geographical location code (ASGC 2009) NNNNN	Data element	386783
	Indigenous status	Whether a person identifies as being of Aboriginal or Torres Strait Islander origin, as represented by a code. This is in accord with the first two of three components of the Commonwealth definition.	Person—Indigenous status, code N	Data element	291036
	Culturally and linguistically diverse (CALD) identifier	Includes those whose first language is one other than English, or whose family background involves migration from a non-English speaking country – as defined in 2006 census.	To be developed	Data element	
Birth information					
🗝	Date of birth	The date of birth of the person.	Person—date of birth, DDMMYYYY	Data element	287007
	Jurisdiction of birth	The state or territory in which the baby was delivered, as represented by a code.	Birth event—state/territory of birth, code N	Data element	270151
	Gestational age	The age of a product of conception in completed weeks.	Product of conception—gestational age, completed weeks N[N]	Data element	298105
Screening information					
	Infant's jurisdictional ID	Person identifier unique within a jurisdictional screening program. This is allocated with the first contact with the service.	To be developed	Data element	. .
	Date screen completed	Date on which infant received either a positive – and was therefore referred to audiological assessment – or negative screen result.	To be developed	Data element	. .
	Screen outcome	Dichotomous data element indicating whether an infant tested positive or negative for potential PCHI.	To be developed	Data element	. .
Audiological assessment information					
	Date audiological assessment completed	Date on which an infant completed audiological assessment.	To be developed	Data element	. .
	Audiological assessment outcome	Outcome of audiological assessment including whether an infant was diagnosed with PCHI.	To be developed	Data element	. .

	Data element	Definition	Metadata item title	Metadata item type	METeOR identifier
	Type and degree of hearing loss	A categorical data element that identifies the type and degree of hearing loss.	To be developed	Data element	. .
Early intervention information					
	Date of first attendance early intervention	Date on which an infant attends their first appointment at an early intervention service.	To be developed	Data element	. .
	Assistive hearing device flag	Dichotomous data element that records whether it was decided to fit the infant with an assistive hearing device .	To be developed	Data element	. .
	Date first assistive hearing device fitted	Date on which an infant receives their first fitting of a hearing device.	To be developed	Data element	. .
	First assistive hearing device type	Categorical data element that records the type of first assistive hearing device fitted.	To be developed	Data element	. .

Note: 🗝 denotes statistical linkage key data item.

Glossary

This section provides a general description of the terms used in this working paper. The terms have been defined in the context of this paper; some terms may have other meanings in other contexts.

Aboriginal and Torres Strait Islander: a person of Aboriginal and/or Torres Strait Islander descent who identifies as an Aboriginal and/or Torres Strait Islander.

Asymptomatic: without symptoms.

Auditory Brainstem Response Test (ABR): the ABR is an electrophysiological test that measures electrical activity generated in various parts of the nerve pathway from the ear to the brain when a sound is presented. Electrodes (small metal disks) are attached to the child's head and sounds are presented to the child's ears through ear plugs or earphones.

Audiologist: an audiologist is a university-trained professional who is specially qualified to measure hearing, diagnose the degree, configuration and type of hearing loss, advise on the non-medical management of hearing disorders, and supply and fit hearing aids and other hearing devices to suit.

Audiology: a field of research and clinical practice devoted to the study of hearing disorders, assessment of hearing, hearing conservation, and aural rehabilitation.

Automated Auditory Brainstem Response (AABR): a non-invasive screening ABR test that is used to identify whether a child is at risk for having a hearing loss.

Baby referred directly to audiology: babies referred directly to audiological assessment because of identified risk factors.

Bilateral hearing loss: a hearing impairment in both ears.

Chronological age: is number of days since birth.

Cochlear implant: unlike hearing aids, which simply amplify sound, a cochlear implant is a surgically implanted device that bypasses the part of the ear that is not working and electrically stimulates the hearing nerve directly.

Corrected age: the age an infant would be had they been born on their due date. Corrected age takes into account the time between premature birth and the actual due date of a full term pregnancy. Calculating corrected age provides a truer reflection of what an infant's developmental progress should be. Corrected age is calculated as chronological age less gestational age.

Decibel (dB): the unit of measurement for the loudness of a sound. The higher the decibel level, the louder the sound.

Diagnostic Audiology Assessment: an assessment that occurs after a child has received a 'refer' result in a second hearing screen. The assessment is performed by an audiologist, and includes diagnostic hearing tests to assess the type and degree of hearing impairment.

Early intervention programs: programs which aim to provide hearing impaired children in the first six months of life with immediate intervention. Children who undergo early intervention have significantly better outcomes than later-identified children in both speech and social-emotional development.

False positive: a test result that incorrectly indicates a person may have the condition being tested.

Gestational age: the duration of pregnancy in completed weeks calculated from the date of the first day of a woman's last menstrual period and her baby's date of birth, or via ultrasound, or derived from clinical assessment during pregnancy or from examination of the baby after birth. Gestational age is used to identify preterm births.

Hearing aid: an electronic device that amplifies sound and conducts it to the ear.

Hearing and communication improvement program: a habilitation or rehabilitation program that aims to ensure, over time, that the negative effects of the child's hearing loss are minimised. A program would include assessment of the child's hearing status, establishment of communication goals with the family, implementation of strategies to address the goals and evaluation of outcomes. The strategies usually, but not always, include the fitting of a hearing aid or other assistive device.

Hearing Screening: hearing screening aims to identify children who are at risk for a hearing loss, so that they can be referred for further detailed assessment. A screening test result can be a pass (hearing is at levels required for normal speech and language development at the time of screen) or refer (at risk for hearing loss and requiring further assessment). Infants in Australia have their hearing screened with either AABR or OAE tests.

Incidence: the number of new cases (for example, of an illness for event) occurring during a given period.

Indigenous Australian: a person of Aboriginal and/or Torres Strait Islander descent who identifies as Aboriginal and/or Torres Strait Islander.

Infant: the term *infant* is used to describe neonates, infants and children as they progress through the screening pathway.

Jurisdiction of birth: the state or territory in which the baby was delivered.

Jurisdiction of (the mother's) residence at birth: geographical location of usual residence of the mother at the time she gave birth.

Negative screen result: indicates that the screening test was negative for suspected hearing loss.

Otoacoustic Emissions (OAE) Test: the OAE test measures the response of the outer hair cells in the inner ear (cochlea) to sound. A small probe is placed in the ear canal. A series of clicks or tones is presented to the child's ear and a small microphone records echoes (emissions) that come from the cochlear.

Positive predictive value of the screening test: the proportion of infants who test positive on their screening test for potential PCHI and upon further assessment receive a definitive diagnosis of PCHI.

Positive screen: indicates that the screening test was positive for suspected hearing loss.

Positivity rate: the proportion of infants who are screened and test positive for potential PCHI.

Preterm birth: an infant born where gestational age < 37 weeks.

Program population: all live births in Australia

Risk factor: an attribute or exposure that is associated with an increased probability of a specified outcome, such as occurrence of a disease. Risk factors are not necessarily the causes of disease.

Screening: the performance of tests on apparently well people in order to detect a medical condition at an earlier stage than would otherwise be the case. Because a screening test is not intended to be diagnostic, a person with a positive or suspicious result must be referred for diagnosis and treatment.

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List of figures

Around half the children born with hearing impairment have no identified risk factor for the condition. It is widely acknowledged that delays in the identification and treatment of permanent childhood hearing impairment may profoundly affect quality of life in terms of language acquisition, social and emotional development, and education and employment prospects. All states and territories in Australia have universal neonatal hearing screening.

This working paper presents a set of performance indicators for monitoring neonatal hearing screening activity in Australia at a national level. National evaluation and monitoring provides a measure of how well neonatal hearing screening is achieving its aims and objectives and will enable strengthening of screening practices and administrative processes to further improve outcomes for Australian infants.