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Developing a national newborn hearing screening data set

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AIHW
Stronger evidence,
better decisions,
improved health and welfare

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Who is the AIHW and what is our role?

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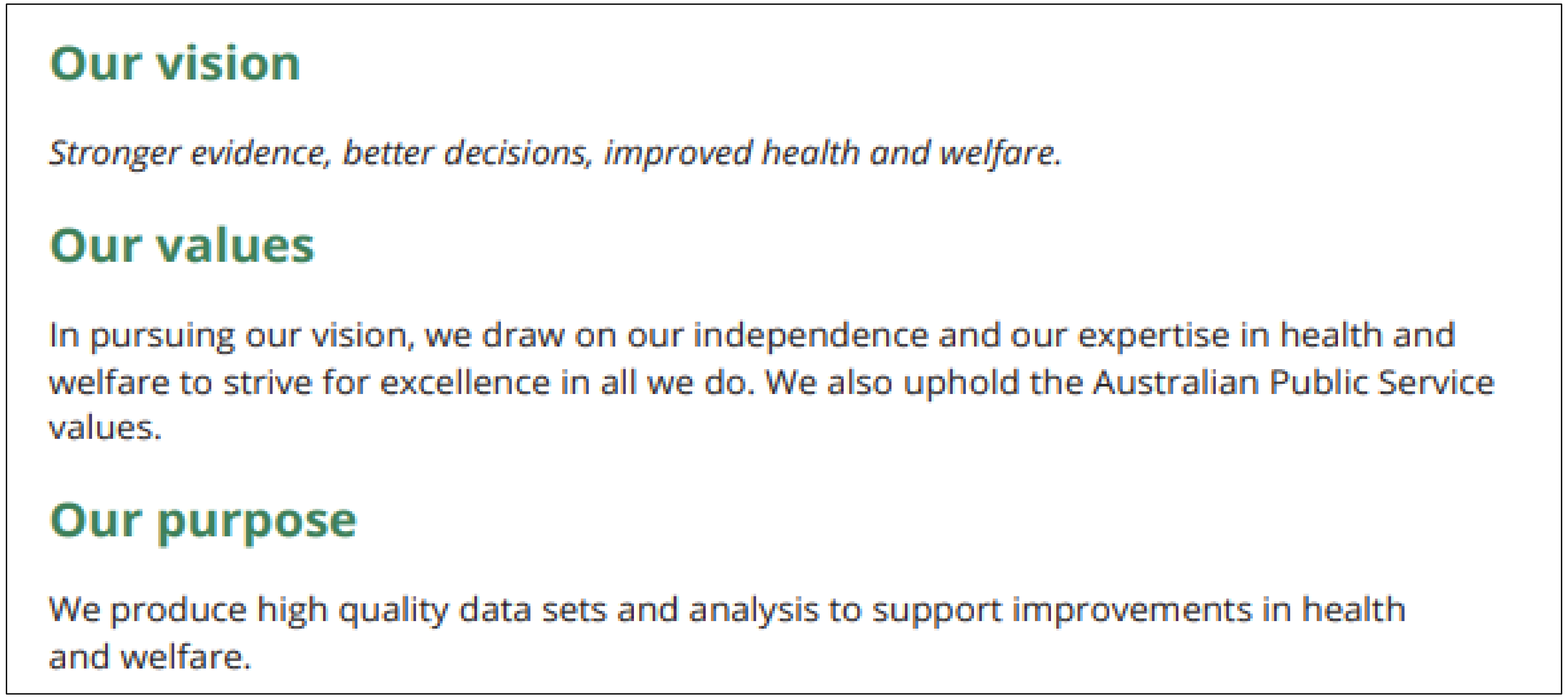
- Independent national agency
- Custodians of accessible and sustainable government data, in line with strict privacy and confidentiality requirements
- Source of reliable, quality data on Australians' health, welfare, and service use
- In-depth health and welfare knowledge and insight



Our vision

Stronger evidence, better decisions, improved health and welfare.

Our values

In pursuing our vision, we draw on our independence and our expertise in health and welfare to strive for excellence in all we do. We also uphold the Australian Public Service values.

Our purpose

We produce high quality data sets and analysis to support improvements in health and welfare.

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What is the AIHW’s role in the health of mothers and babies?

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Overview

A newborn baby's health can be a key determinant of their health and wellbeing throughout life. Factors such as physical health, social wellbeing and exposure to harmful behaviours can influence health outcomes for both mothers and babies.

Featured summary

Health of mothers and babies >

Birth rate in 2022 has returned to the 2020 level (both **56 per 1,000** women), after a spike in 2021 (**61 per 1,000**...

14 maternal deaths occurred in 2022, or 4.8 per 100,000 women giving birth >

15% of maternity models of care in Australia have midwifery continuity of carer for the whole maternity period >

1 in every 32 babies were born with a congenital anomaly in 2017 >

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Newborn hearing health of Aboriginal and Torres Strait Islander people

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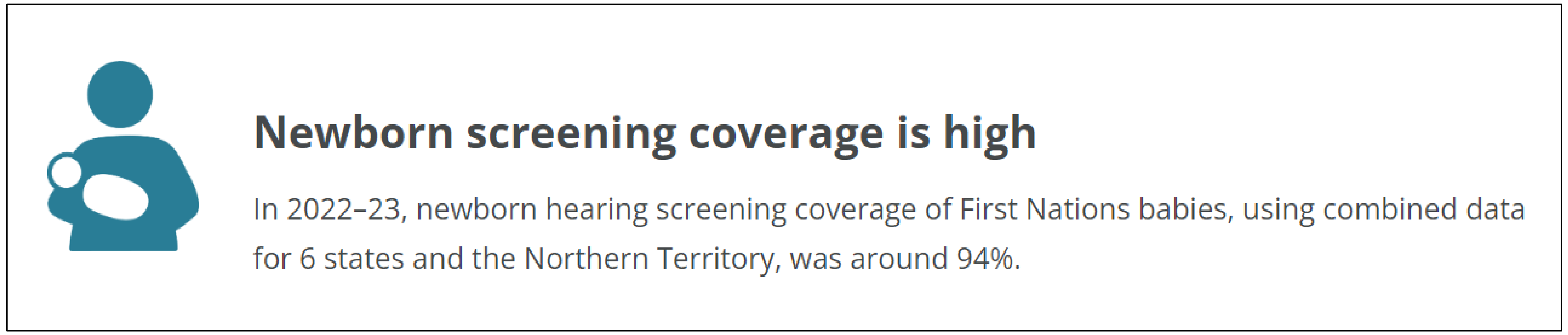

Newborn screening coverage is high

In 2022–23, newborn hearing screening coverage of First Nations babies, using combined data for 6 states and the Northern Territory, was around 94%.

- In states/territories with available data, **the proportion of First Nations babies screened are slightly lower** than the proportion of non-Indigenous babies screened, **except in NT** where proportions are similar.

- Most newborn hearing screening **occurs within one month** of birth.

- The proportions of First Nations babies who had a newborn hearing test within one month of birth were slightly lower than non-Indigenous babies.

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Why is national data important?

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It is hoped that an initial national data set could inform:

- **How many** babies are being screened across Australia?
- What are the **characteristics** of these babies?
- What are the **screening outcomes** of all babies screened?
- **How long** does the screening process take?
- Which babies are **not screened** (and why?)
- What **referrals** being made following screening?
- Understanding **patient pathways**, including waiting times from initial screening to treatment and outcomes

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What is the AIHW's role in newborn hearing screening data?

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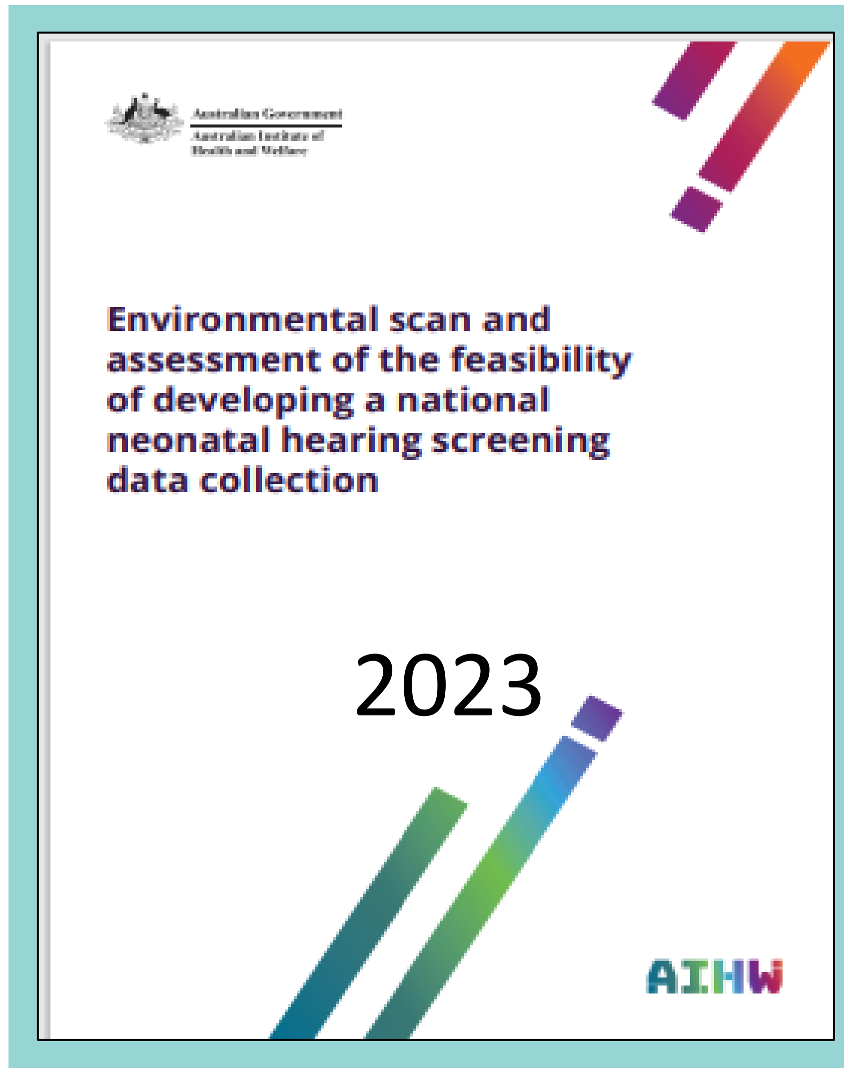
Australian Government
Australian Institute of Health and Welfare

National performance indicators for neonatal hearing screening in Australia

2013

CANCER AND SCREENING UNIT WORKING PAPER



Australian Government
Australian Institute of Health and Welfare

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

2023

AIHW

Australian Government
Australian Institute of Health and Welfare

AIHW

Development of a newborn hearing screening national best endeavours data set

September 2024
(unpublished)

2024

Revision of National Framework for Newborn Hearing Screening

Seeking endorsement 2025

Developed proposed NPIs

Assessing the feasibility of national data

First steps in developing national data

Capability to report against NPIs

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Development work to improve the evidence base

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Phase 1: Scoping and feasibility

Following consultation with states and territories this project outlined the **potential scope** of a national collection:

1. Include unit record **(person-level) data** on all babies liveborn in each Australian state and territory.

2. Should collect information on:

- **Demographics**

- **Screening:** including the number of screens, dates of screening, outcomes and, where applicable, reason screening was not performed.

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Phase 1: Scoping and feasibility

Analysis of state and territory data that was already being collected:

- ✓ High **coverage** rates (>97%)
- ✓ Collected information on babies who were **not screened or were ineligible** for screening
- ✓ Captured key **demographic** variables
- ✓ Included key **screening information**

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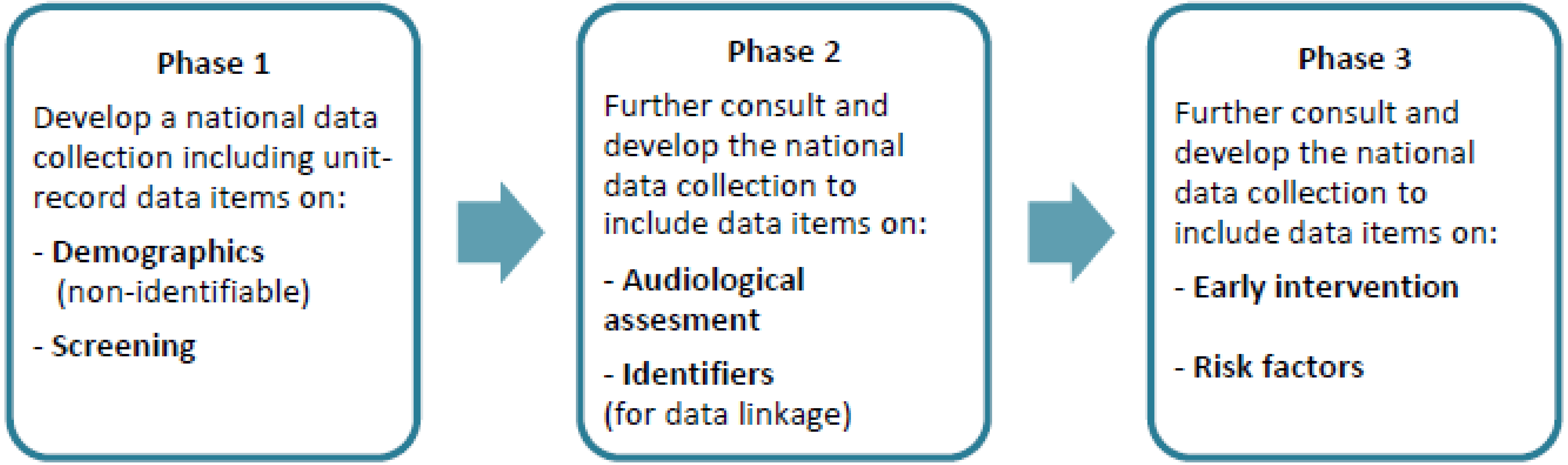
Phase 1: Scoping and feasibility recommended next steps



Phase 1

Develop a national data collection including unit-record data items on:

- **Demographics** (non-identifiable)
- **Screening**

Phase 2

Further consult and develop the national data collection to include data items on:

- **Audiological assesment**
- **Identifiers** (for data linkage)

Phase 3

Further consult and develop the national data collection to include data items on:

- **Early intervention**
- **Risk factors**

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Phase 2: Data set development

- ✓ Establishing an **advisory committee**
- ✓ Agreement on the **scope** of the collection
- ✓ Agreeing on an initial set of **data items**
- ✓ Proposals for **future development**

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Phase 2: Data set development -Proposed initial set of data items:

- Person identifier (baby)
- State or territory of birth
- Sex (baby)
- Date of birth (baby)
- Gestational age at birth (baby)
- Indigenous status (baby)
- Statistical Area Level 2 (SA2) of usual residence (mother)
- Postcode of usual residence (mother)

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Phase 2: Data set development

Proposed initial set of data items:

- State or territory of screen
- Date of screen (screen 1, screen 2 & screen 3 where applicable)
- Screen outcome (screen 1, screen 2 & screen 3 where applicable):
  - Pass (negative)
  - Unilateral refer (positive)
  - Bilateral refer (positive)
  - Not screened

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Phase 2: Data set development - Proposed initial set of data items:

- Overall outcome of screening
  - Complete, discharged from screening
  - Complete, referred for targeted follow-up
  - Complete, referred for audiological assessment
  - Bypass, non-screening pathway
  - Screening in process
  - Incomplete
  - Not stated/inadequately described
- Date of hearing screening completion

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Phase 2: Data set development - Proposed initial set of data items:

- Primary reason not screened or completed:
    - Declined
    - Missed screening
    - Moved interstate
    - Medical exclusion
    - Hearing screen bypass
    - Baby deceased
    - Ineligible
    - Other

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Phase 2: Data set development - Proposed initial set of data items:

- **Referral outcome:**
  - Referral following positive screen
  - Referral following negative screen
  - Referral without screening
  - No referral required
  - No referral provided

- **Date of referral**

- **Referral type:**
  - Audiologist: audiological assessment
  - Audiologist: targeted follow-up
  - Other

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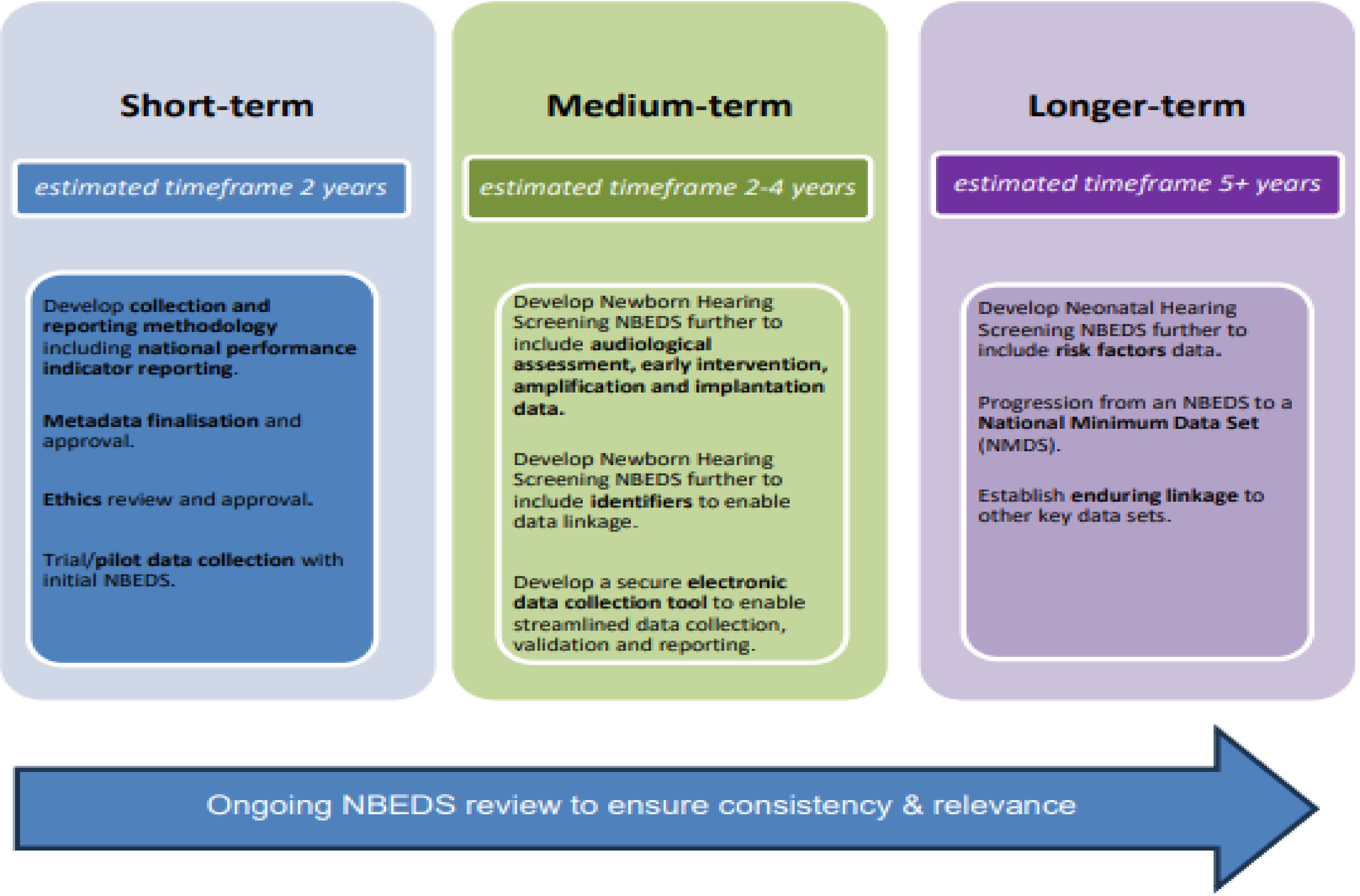
Phase 2: Next steps



Short-term

estimated timeframe 2 years

Develop **collection and reporting methodology** including **national performance indicator reporting**.

Metadata finalisation and approval.

Ethics review and approval.

Trial/**pilot data collection** with initial NBEDS.

Medium-term

estimated timeframe 2-4 years

Develop Newborn Hearing Screening NBEDS further to include **audiological assessment, early intervention, amplification and implantation data.**

Develop Newborn Hearing Screening NBEDS further to include **identifiers** to enable data linkage.

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

Longer-term

estimated timeframe 5+ years

Develop Neonatal Hearing Screening NBEDS further to include **risk factors** data.

Progression from an NBEDS to a **National Minimum Data Set** (NMDS).

Establish **enduring linkage** to other key data sets.

Ongoing NBEDS review to ensure consistency & relevance

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Further information

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For further information on national data development in the newborn hearing screening, please feel welcome to reach out to our team: newborn.hearing@aihw.gov.au

Mothers & babies

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