Detecting hearing loss beyond the newborn period – no consensus, no evidence, what next?

Lauren McHugh Qld
Zeffie Poulakis Vic

On behalf of the ANHS Consensus Statement on post-natal hearing loss sub-committee

The ANHS Consensus Statement on post-natal hearing loss sub-committee

- Dr Rachael Beswick (Qld)
- Michelle Chacksfield (Tas)
- Dr Kirsty Gardner-Berry (NSW)
- Prof. Greg Leigh (NSW)
- Bianca Liersch (SA)
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- Dr Zeffie Poulakis (Vic)
- Jasmine Plimmer (NZ)
- A/Prof Valerie Sung (Vic)
- Patricia van Buynder (Vic)

Detecting hearing loss in early childhood

Congenital hearing loss – UNHS

Progressive/acquired/mild loss – second-phase (post-natal) screening

- We should offer a second-phase hearing screen to every child.
- Should we offer a second-phase hearing screen to every child?
- Should we offer a second-phase hearing screen (only) to children who are vulnerable or at higher risk of undetected hearing loss?
- Should we offer a second-phase hearing screen to children at all?

Second-phase (post natal) screening for childhood hearing loss

World Health Organization

LNP to deliver free health checks for kindy kids

21 October 2024 Share this

· Every Queensland kid to have free vision, hearing and speech development checks in their kindy year.

Key actions: “Undertake a pilot program of screening tests for school aged children, especially at-risk children, and evaluate the resulting data to determine long term value.”

Second-phase (post natal) screening for childhood hearing loss

JCIH
JOINT COMMITTEE on INFANT HEARING

RACGP

Screening for permanent hearing loss in children at school entry

External review against programme appraisal criteria for the UK National Screening Committee

Version: Final

Author: Solutions for Public Health

Date: February 2019

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"Just because we can doesn't mean we should"
Lucinda Freeman, ANHS 2025

What is screening?

Screening involves identifying people in an apparently healthy population who are at higher risk of a health problem or a condition.

UK National Screening Committee 1998
WHO 2020

Principles of screening (WHO 1968)

- the condition should be an important health problem
- there should be a recognisable latent or early symptomatic stage
- the natural history of the condition, including development from latent to declared disease, should be adequately understood
- there should be an accepted treatment for patients with recognised disease
- there should be a suitable test or examination that has a high level of accuracy

https://iris.who.int/handle/10665/37650

Principles of screening (WHO 1968)

- the test should be acceptable to the population
- there should be an agreed policy on whom to treat as patients
- facilities for diagnosis and treatment should be available
- the cost of screening (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole, and
- screening should be a continuing process and not a ‘once and for all’ project.

https://iris.who.int/handle/10665/37650

Should we screen? Questions to ask (www.healthknowledge.org.uk)

The disease	Is it an important health problem?
	Is the natural history well understood?
	Is there a long time between the presence of risk factors/sub-clinical disease to overt disease?
	Does early intervention improve clinical/public health outcome?
Screening test	Is the test valid (sensitivity and specificity)?
	Is the test simple, reliable and affordable?
	Is the test acceptable to patient and staff?
Diagnosis and treatment	Is access to diagnostic facilities available and rapid?
	Is treatment effective and accessible?
	Is it cost-effective?
	Is it sustainable?
	Does benefit outweigh the harm?

Benefit versus harm

"All screening programmes do harm; some do good as well, and, of these, some do more good than harm at reasonable cost."

Gray JA, Patnick J, Blanks RG (2008)

Screening is not (just) a test

- Providing the screening test (genomic, hearing, bloodspot) is not enough - it has to be part of a service that provides what follows after the test (Edwin Kirk, ANHS 2025)
- Screening involves appraisal of the system (KPI, principles, outcomes)

Screening programs in Australia

Yes

Prenatal screening
Bowel cancer screening
Cervical cancer screening
Breast cancer
Newborn bloodspot screening
Newborn hearing screening

No

Lung cancer
Prostate cancer
Skin cancer
Congenital CMV
Carrier screening for CHL
Second-phase (post-natal) childhood hearing screening

Alternatives to screening for health conditions

Ad hoc clinical case-finding

Case finding and opportunistic screening
Usually done as part of a clinical encounter for some other health condition

Patient initiated screening
e.g. glaucoma screening at a community event, direct-to-consumer genetic testing

Targeted screening
Based on a characteristic associated with increased risk of the condition
e.g. staff at risk of workplace noise-induced hearing loss

Surveillance
“Keeping an eye” on things

ANHS Committee:

Consensus Statement on Hearing Screening Beyond the Newborn Period

Consensus Statement development

1. Systematic Review
2. Catalogue of programs & available data

3. Seek to reach consensus with professionals, academics, parents/carers, stakeholders

Systematic Review:

Are there

- improved health or developmental outcomes associated with the introduction of population-based second-phase screening programs (i.e., beyond UNHS) and associated interventions?
- any harms of introducing such programs and associated interventions?

Systematic Review results (Ching et al, unpublished)

- inconclusive evidence on whether population-based hearing screening provides earlier identification and intervention to improve child health/developmental/ educational outcomes of children with hearing loss
- inconsistent results regarding cost-effectiveness
- some evidence of harms (LTFU, missed detection)
- no studies examining effectiveness/harms of interventions

Systematic Review conclusions (i)

"No conclusive evidence in this systematic review was identified to support the claim that implementing universal population-based hearing screening in childhood, in addition to universal newborn hearing screening, will improve outcomes via earlier identification and intervention for hearing loss."

Systematic Review conclusions (ii)

“Ultimately, childhood population-based hearing screening remains a topic that urgently requires more research in multiple directions (beyond the development and validation of screening tests) in order to fully understand and quantify the benefit or harm they could provide.”

Catalogue of programs

8 Au jurisdictions

- 3 state/territory-wide publicly-funded universal screening to all children aged 4-6 years
- 4 offering community-based programs (government, NFP, NGO and private)
- all offer targeted surveillance

ANHSC Consensus statement activities

Consensus building workshop July 2022

- Facilitated analysis of comments and responses from clinicians, academics, parents/carers, stakeholders
- Specific statements presented to attendees who indicated if the statements were
  (a) accepted
  (b) accepted subject to further discussion/editing, or
  (c) rejected

ANHSC Consensus statement activities

Conference presentation March 2023

- Revised statements (from first workshop) presented to the delegation, who indicated if statements were
  (a) accepted
  (b) accepted subject to further discussion/editing, or
  (c) rejected

Consensus statement

Broad agreement was reached for the following statements:

- Any post UNHS program should aim to detect significant hearing loss, including sensorineural or chronic conductive hearing loss, that will impact on a child's speech, language, and cognitive development
- Targeted hearing screening should be the mechanism to detect hearing loss in children who are at greater risk of having an unidentified hearing loss

Consensus statement

Broad agreement was reached for the following statements:

- Pure Tone Audiometry is the gold standard, app-based technology may help with reach
- Workforce issues across the screening pathway need to be addressed
- Availability, accessibility, affordability, and connectivity of downstream pathways needs to be addressed
- Need to capture data from end to end

Consensus statement

Agreement could not be reached on:

- Age at which screening should be undertaken
- Inclusion of tympanometry as a screening technology

Systematic review and consensus workshop results combined

- No definitive guidance on how post-natal detection of hearing loss could or should occur

In summary

- the evidence base does not unequivocally support implementation of universal screening for hearing loss in early childhood
- there are differences in current practices across jurisdictions
- no consensus on if, how and when screening in childhood should occur

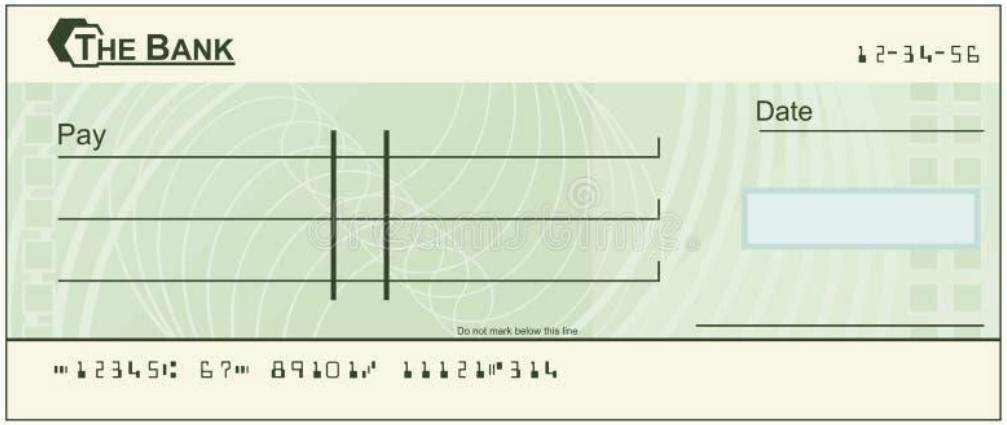
Require more research compare screening approaches on

- detection rate
- types of hearing loss detected
- core outcomes at diagnosis and follow-up
- interventions

So, where to now?

"Implement (or improve, review, evaluate) something that will identify undetected hearing loss in children"

What would the best way to approach this question in the absence of evidence, guidelines or a consensus?



Beyond Healthy Hearing for children without a HL

No universal pathway for children to access hearing diagnosis / screening after the newborn period.

No consensus, no evidence

QLD Committed $9.94 million for Community Hearing Screening

Putting Queensland Kids First

Giving our kids the opportunity of a lifetime

Responsive support for healthy development and positive life courses

Supporting individual development through the earliest possible access to support to identify and respond to the diverse needs of Queensland children.

We are investing:

- **$71.4 million** for enhanced child health development checks in the first five years of life.
- **$56.55 million** for Enhanced Child Development Services in priority locations to improve the health and wellbeing of children with developmental concerns.
- **$9.94 million** for improved children's hearing screening and diagnostic services.
- **$2.04 million** to strengthen family connections through an early intervention program for families experiencing complex challenges.
- **$3.59 million** for housing and support link services for young mothers, babies and families.

Every Queensland child and family deserves the best start and a lifetime of opportunities. This is our vision for *Putting Queensland Kids First: Giving our kids the opportunity of a lifetime*, backed by a clear objective to strengthen investment in prevention and access to the earliest possible supports.

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Surveillance
“Keeping an eye” on things

Delivering Community Hearing Screening in Queensland

Greater Brisbane

Toowoomba

Gold Coast

Wide Bay

How to develop a quality service without a framework?

Coalition for Global Hearing Health Hearing Care Pathways Working Group: Guidelines for Clinical Guidance for Readiness and Development of Evidence–Based Early Hearing Detection and Intervention Programs

Christine Yoshinaga-Itano [1 2], Gwen Carr [3], Adrian Davis [3 4 5 6], Teresa Y C Ching [7 8 9], King Chung [10], Jackie Clark [11], Samantha Harkus [12], Meei-Ling Kuan [13], Suneela Garg [14], Sheila Andreoli Balen [15], Shannon O'Leary [16]

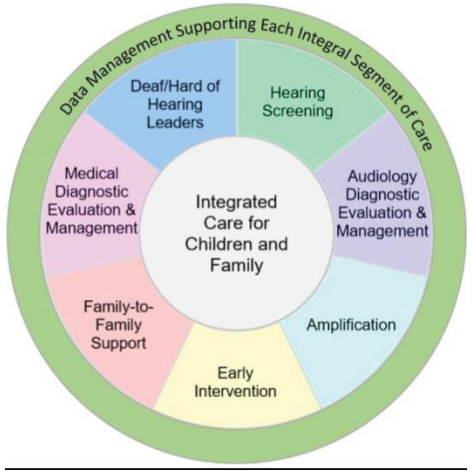
Affiliations + expand

PMID: 38783422 PMCID: PMC11325981 DOI: 10.1097/AUD.0000000000001501

Abstract

Editor's Note: The following article discusses the timely topic Clinical Guidance in the areas of Evidence-Based Early Hearing Detection and Intervention Programs. This article aims to discuss areas of services needed, guidance to countries/organizations attempting to initiate early hearing detection and intervention systems. Expert consensus and systematic/scoping reviews were combined to produce recommendations for evidence-based clinical practice. In Ear and Hearing, our long-term goal for the Point of View article is to stimulate the field's interest in and to enhance the appreciation of the author's area of expertise. Hearing is an important sense for children to develop cognitive, speech, language, and psychosocial skills. The goal of universal newborn hearing screening is to enable the detection of hearing loss in infants so that timely health and educational/therapeutic intervention can be provided as early as possible to improve outcomes. While many countries have implemented universal newborn hearing screening programs, many others are yet to start. As hearing screening is only the first step to identify children with hearing loss, many follow-up services are needed to help them thrive. However, not all of these services are universally available, even in high-income countries. The purposes of this article are (1) to discuss the areas of services needed in an integrated care system to support children with hearing loss and their families; (2) to provide guidance to countries/organizations attempting to initiate early hearing detection and intervention systems with the goal of meeting measurable benchmarks to assure quality; and (3) to help established programs expand and improve their services to support children with hearing loss to develop their full potential. Multiple databases were interrogated including PubMed, Medline (OVIDSP), Cochrane library, Google Scholar, Web of Science and One Search, ERIC, PsychInfo. Expert consensus and systematic/scoping reviews were combined to produce recommendations for evidence-based clinical practice. Eight essential areas were identified to be central to the integrated care: (1) hearing screening, (2) audiologic diagnosis and management, (3) amplification, (4) medical evaluation and management, (5) early intervention services, (6) family-to-family support, (7) D/deaf/hard of hearing leadership, and (8) data management. Checklists are provided to support the assessment of a country/organization's readiness and development in each area as well as to suggest alternative strategies for situations with limited resources. A three-tiered system (i.e., Basic, Intermediate, and Advanced) is proposed to help countries/organizations at all resource levels assess their readiness to provide the needed services and to improve their integrated care system. Future directions and policy implications are also discussed.

The elements of Integrated Care for Children and Family



Mapping out the features of Community Hearing Screening against the desired elements of integrated care – where do we live up to this and where can we improve?

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Implementation Factors & Risk Register

- Models of Care – existing services
- Screening Protocols - universality
- Workforce - codesign
- Infrastructure – equipment
- Integration into Audiology – multi model

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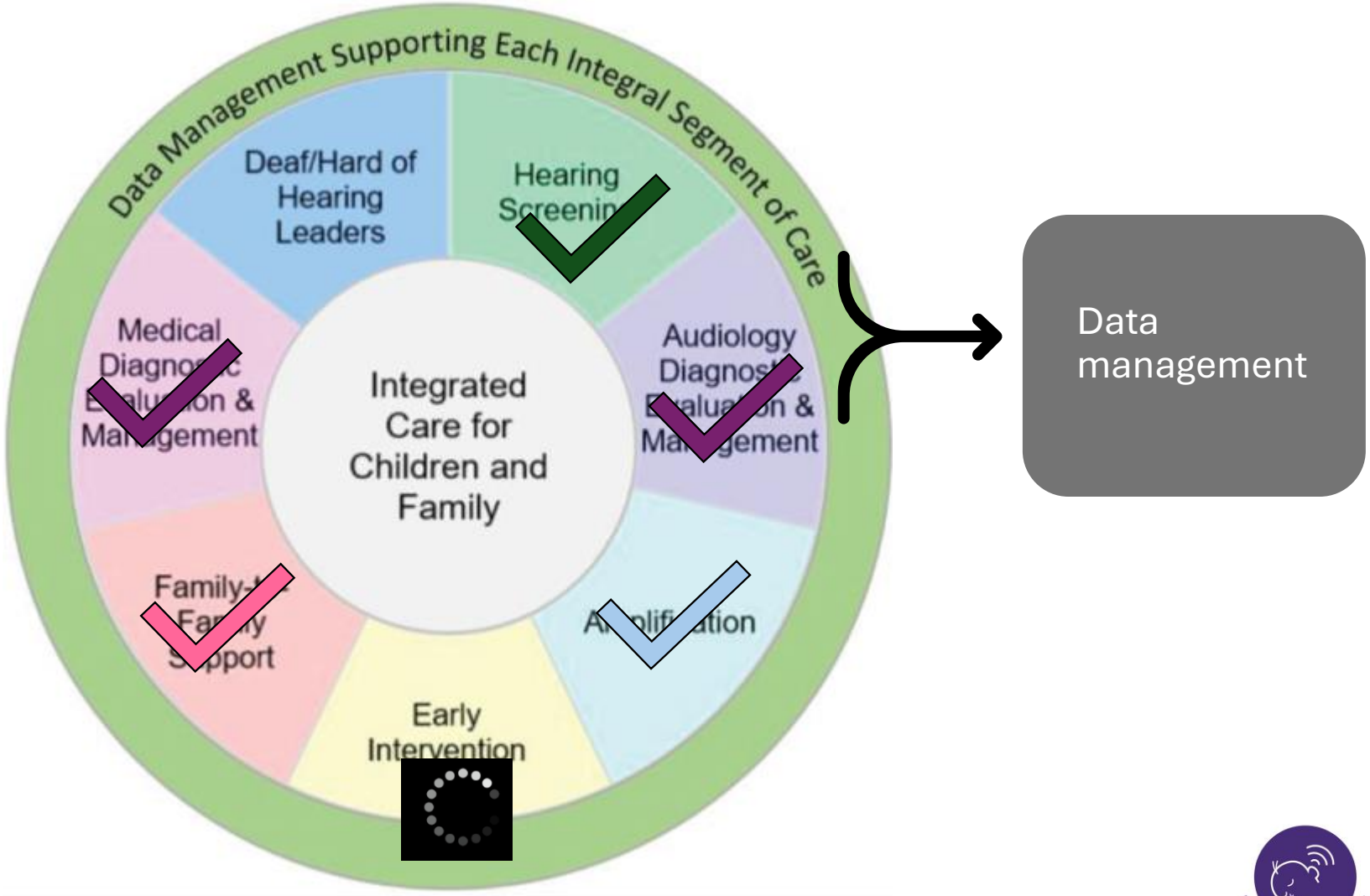
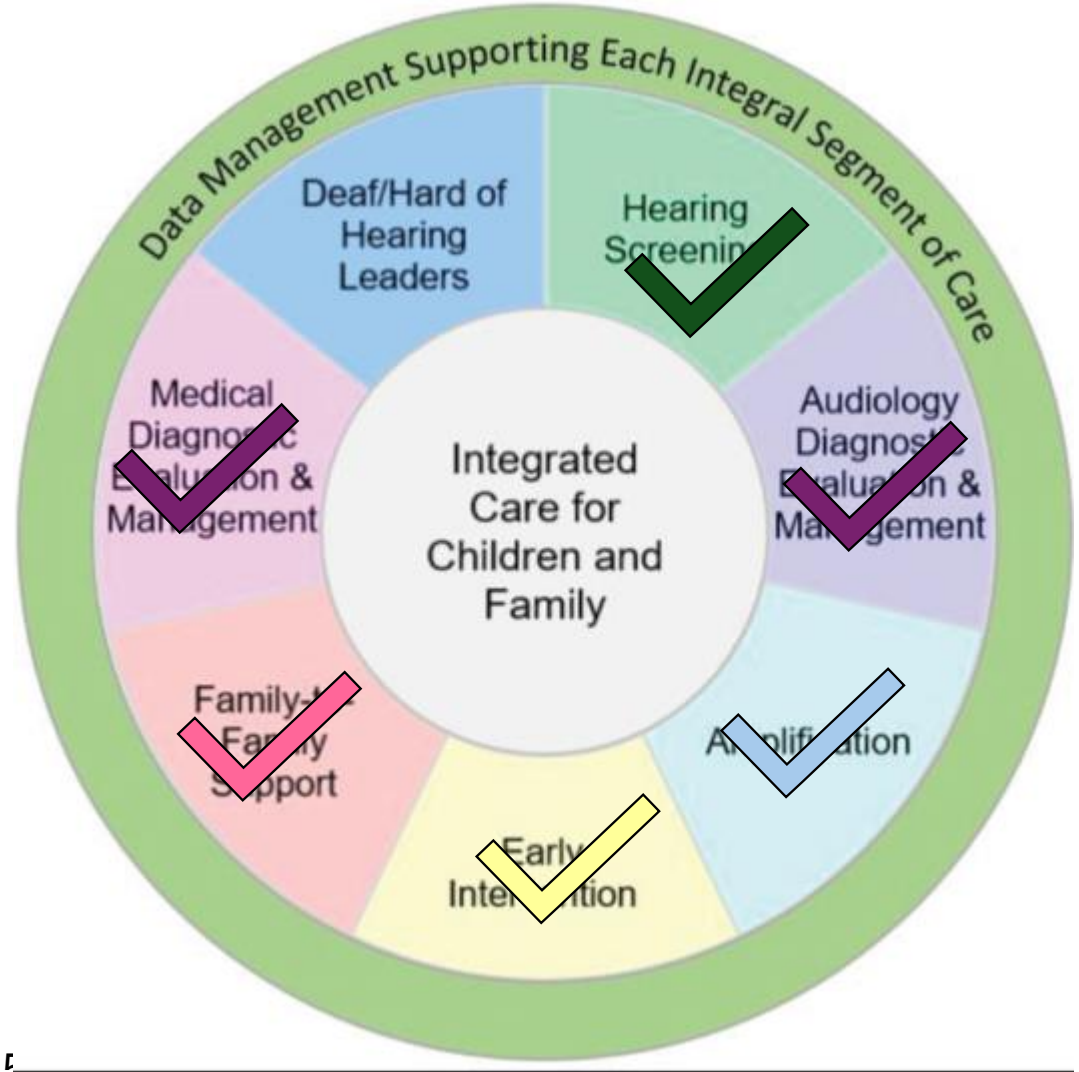
Adopting the elements of Integrated Care for Children and Family



~~Integrated~~ Care for Children and Family

KPI driven frameworks



ANHS 2025 - Detecting hearing loss beyond the newborn period

Develop KPIs

Data management

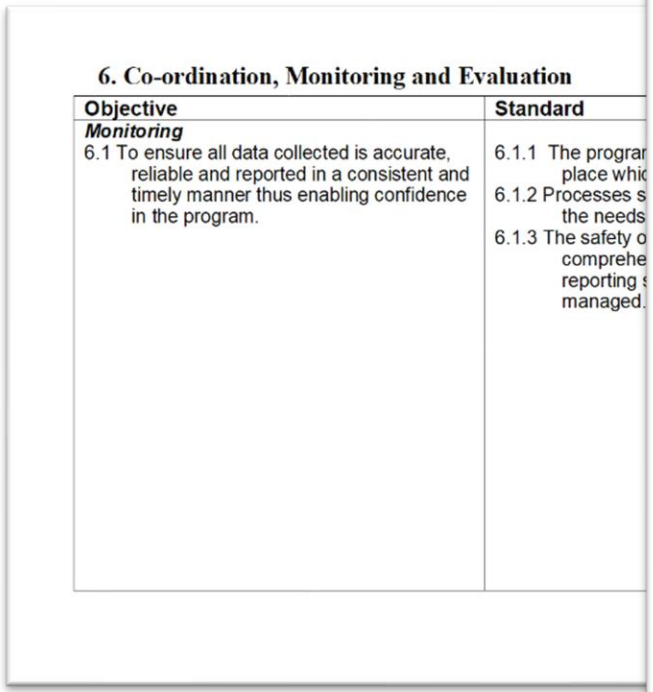
- Positivity rate - screening
- Positivity rate – diagnostic
- Outcomes – clinical
- Outcomes – quality
- Compliance / acceptance

Community Hearing Screening Measures

Children referred to Community Hearing Screening:	**9,612**
By Referral Source:	
Health Provider	2,027
Education Provider	703
Self / Parent	4,422
Other / Source Unknown	2,460
Number of children offered screening:	**9,591**
Number of children received a screening outcome:	**9,352**
By Outcome:	
Passed - Discharged (without the need to see an Audiologist)	6,798
Referred to Audiology and/or ENT	1,913
Number of children received an Audiology outcome:	**1,036**
By Outcome:	
Within Normal Limits / Functionally Normal / Adequate Hearing	596
Confirmed PCHL - Unilateral / Bilateral	67
Suspected PCHL - Unilateral / Bilateral	10
Transient Conductive HL	139
Moved out of QLD / Lost Contact / FTA'd / No outcome avail.	224

- Volume
- Compliance
- Outputs
- Treatment

Evaluation approach – Fidelity of Community Hearing Scre



6. Co-ordination, Monitoring and Evaluation

Objective	Standard
Monitoring	
6.1 To ensure all data collected is accurate, reliable and reported in a consistent and timely manner thus enabling confidence in the program.	6.1.1 The prograr place whic 6.1.2 Processes s the needs 6.1.3 The safety o comprehe reporting managed.

Benchmarks and Quality Indicators

The JCIH supports the concept of regular measurements of performance and recommends routine monitoring of these measures for inter-program comparison and continuous quality improvement. These performance benchmarks represent a consensus of expert opinion in the field of newborn hearing screening and intervention. The benchmarks are the minimal requirements that should be attained by high-quality EHDI programs. Frequent measures of quality permit prompt recognition and correction of any unstable component of the EHDI process.

Quality Measurement and Improvement
The provision of EHDI services can be improved and better coordinated when data are captured to measure performance and that information is shared among all stakeholders. Use of consensus-based standardized measures lessens reporting burden, focuses on a discrete targeted set of measures to improve services, and allows stakeholders to compare results.

To report and ensure information is accurate, complete, and transparent, all measures should have clear, unambiguous definitions for each numerator and denominator with well-defined exclusions/exceptions and data elements/value sets used for calculation. Whenever possible, nationally endorsed measures and standard data elements/coded value sets should be used. In addition, steps should be taken to measure and report individual-level geographic and demographic data.

National standard EHDI data elements/value sets are maintained and available for public use through:
- Agency for Healthcare Research and Quality (AHRQ, n.d.) U. S. Health Information Knowledge Base (USHIK)
- CDC (n.d.-c) Public Health Information Network (PHIN) Vocabulary Access and Distribution System (VADS)
- National Library of Medicine (NLM) Newborn Screening Coding and Terminology Guide (NLM, n.d.-a)
- NLM Value Set Authority Center (VSAC; NLM, n.d.-b)

EHDI has three measures endorsed by the NQF:
- Hearing screening prior to hospital discharge (NFQ1354) [NQF, n.d.-b]
- Audiological evaluation no later than 3 months of age (NFQ1360; NQF, n.d.-a)

coordinated, ongoing measurement and improvement of EHDI processes and developmental outcomes. As relevant quality measures are developed and communicated, stakeholder organizations should address what is important to achieve the best outcomes for deaf and hard-of-hearing children and their families, without creating an undue burden of data collection. Rather than promoting specific recommended benchmarks, JCIH strongly encourages the documentation of current baseline measurements and establishment of quality improvement activities for documenting continuous and measurable improvements in screening, confirmation of hearing status, and receipt of intervention services.

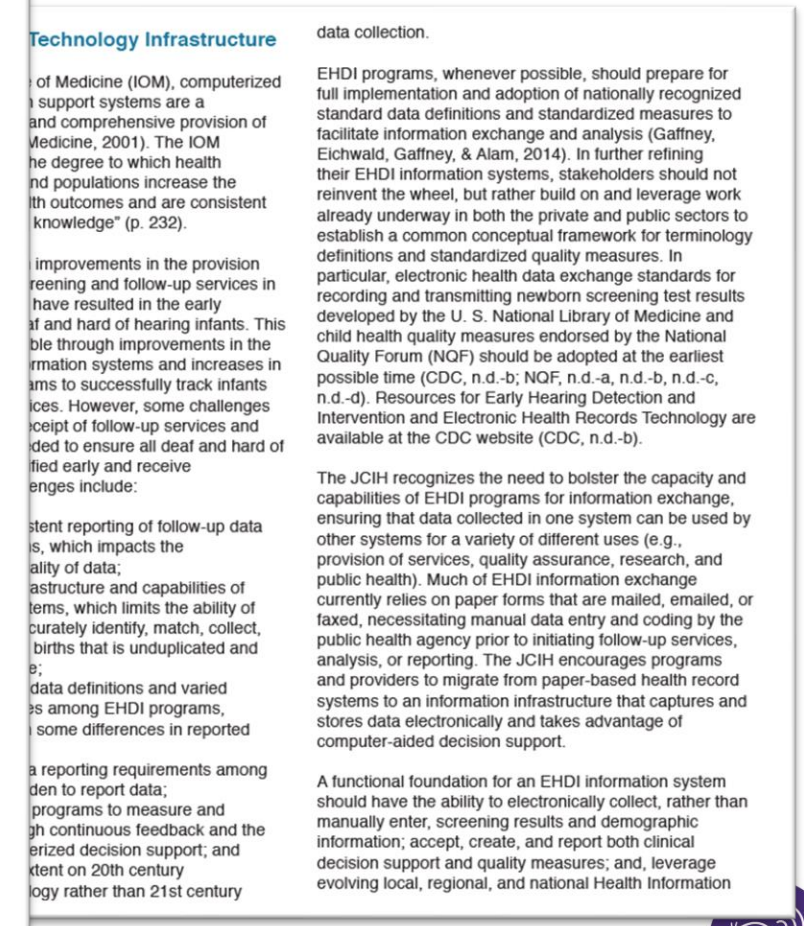
Quality Indicators for screening. Quality indicators for newborn hearing screening are:
- Percentage of all newborn infants who complete screening by one month of age;
- Percentage of all newborn infants who do not pass initial hospital-based screening and require subsequent outpatient rescreening;
- Percentage of newborn infants who do not pass initial and any/all subsequent rescreening(s) prior to comprehensive audiologic evaluation; and
- Percentage of newborn infants who do not pass initial screening and subsequently pass a re-screening.

Quality Indicators for confirmation that a child is deaf or hard of hearing. Quality indicators for confirmation of hearing status and diagnosis of hearing thresholds are:
- Percentage of infants who do not pass initial birth screening and any subsequent rescreening, and
- Percentage of infants who complete a comprehensive audiologic evaluation by three months of age.

For families who elect amplification:
- Percentage of deaf and hard of hearing infants receiving amplification devices within one month of confirmation of hearing status.

Quality Indicators for early intervention. Quality indicators for early intervention for infants confirmed as deaf or hard of hearing and qualify for Part C services include:
- Percentage of infants for whom parents have signed an IFSP no later than six months of age.

For children who are deaf or hard of hearing and have



Technology Infrastructure

of Medicine (IOM), computerized
support systems are a
and comprehensive provision of
Medicine, 2001). The IOM
he degree to which health
nd populations increase the
lth outcomes and are consistent
knowledge" (p. 232).

improvements in the provision
reening and follow-up services in
have resulted in the early
f and hard of hearing infants. This
ble through improvements in the
rmation systems and increases in
ms to successfully track infants
ices. However, some challenges
ceipt of follow-up services and
ded to ensure all deaf and hard of
fied early and receive
enges include:

stent reporting of follow-up data
s, which impacts the
ality of data;
astructure and capabilities of
tems, which limits the ability of
curately identify, match, collect,
births that is unduplicated and
e;
data definitions and varied
s among EHDI programs,
some differences in reported

a reporting requirements among
den to report data;
programs to measure and
gh continuous feedback and the
erized decision support; and
tent on 20th century
logy rather than 21st century

data collection.

EHDI programs, whenever possible, should prepare for full implementation and adoption of nationally recognized standard data definitions and standardized measures to facilitate information exchange and analysis (Gaffney, Eichwald, Gaffney, & Alam, 2014). In further refining their EHDI information systems, stakeholders should not reinvent the wheel, but rather build on and leverage work already underway in both the private and public sectors to establish a common conceptual framework for terminology definitions and standardized quality measures. In particular, electronic health data exchange standards for recording and transmitting newborn screening test results developed by the U. S. National Library of Medicine and child health quality measures endorsed by the National Quality Forum (NQF) should be adopted at the earliest possible time (CDC, n.d.-b; NQF, n.d.-a, n.d.-b, n.d.-c, n.d.-d). Resources for Early Hearing Detection and Intervention and Electronic Health Records Technology are available at the CDC website (CDC, n.d.-b).

The JCIH recognizes the need to bolster the capacity and capabilities of EHDI programs for information exchange, ensuring that data collected in one system can be used by other systems for a variety of different uses (e.g., provision of services, quality assurance, research, and public health). Much of EHDI information exchange currently relies on paper forms that are mailed, emailed, or faxed, necessitating manual data entry and coding by the public health agency prior to initiating follow-up services, analysis, or reporting. The JCIH encourages programs and providers to migrate from paper-based health record systems to an information infrastructure that captures and stores data electronically and takes advantage of computer-aided decision support.

A functional foundation for an EHDI information system should have the ability to electronically collect, rather than manually enter, screening results and demographic information; accept, create, and report both clinical decision support and quality measures; and, leverage evolving local, regional, and national Health Information

Should we screen? Questions to ask (www.healthknowledge.org.uk)

The disease	Is it an important health problem?
	Is the natural history well understood?
	Is there a long time between the presence of risk factors/sub-clinical disease to overt disease?
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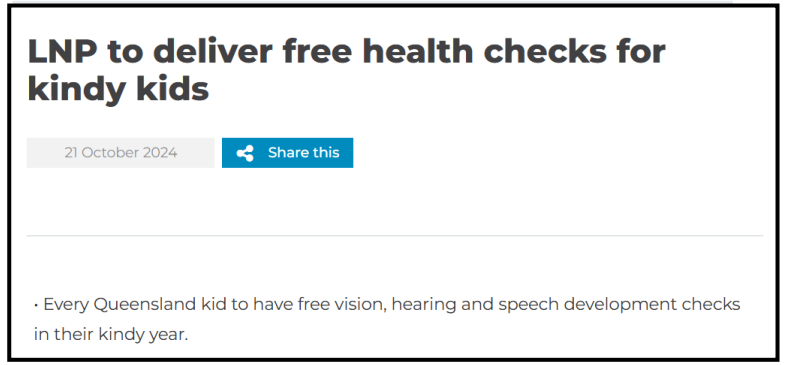
	Is the test acceptable to patient and staff?
Diagnosis and treatment	Is access to diagnostic facilities available and rapid?
	Is treatment effective and accessible?
	Is it cost-effective?
	Is it sustainable?
	Does benefit outweigh the harm?

The Integrated Care for Children and Family paradigm can be used to approach screening programmes, both targeted and universal

Existing	New	Theoretical
Newborn hearing screening	CMV	Child Health / Healthy Kids
Newborn screening	Genomic Carrier	
Vision screening		
Community Hearing Screening		

In the absence of consensus, guidelines, or empirical evidence, what do we do to detect post-natal hearing loss?

- Use relevant frameworks (not specific to HL)
- Evaluate what you are doing
- Do research and QI to address evidence gaps