


# The Researchers.



A special One in Six  
edition highlighting  
publicly funded research  
in Australia.

NHMRC projects.

Interesting research  
overseas.

Before we begin this special newsletter on research,

## A crisis at Adelaide Children's Hospital.

From an article by [Claire Campbell](#) for [ABC News](#):

Adelaide's Women's and Children's Hospital has apologised for wrongly programming the cochlear implants of 30 children in its program, causing what are expected to be lifelong development problems.

Audiologist Nicole Eglinton alerted the hospital and health regulators last April after seeing the same problem in nine of her patients.

"The first child that came through, we thought that might be an anomaly," she said. "This is not something we see often and we were alarmed and really in disbelief.

"Our initial testing has shown that they didn't have the important access to all of the sounds that they needed to learn to listen or speak.

"Critical periods are between zero and three years to learn and develop spoken language. Many of these children have missed this opportunity."

She said she had to "battle" to get the hospital to investigate her and the affected families' concerns.

### Tracking your child's progress.

It is crucial that an investigation quickly identifies the cause of the problem at Adelaide's Women's and Children's Hospital, but for the moment the attention of families will be closer to home - they will be tracking the progress of their child.

The Parents will also need a great deal more support.

We asked The Shepherd Centre - a not-for-profit providing specialised programs for

children with hearing loss - to prepare a brief resource to share that outlines a child's developmental milestones and when to raise concerns about a child's progress. Our thanks to Joanna McAdam for this information sheet. Ms McAdam is Principal Listening and Spoken Language/ Principal Learning and Development for The Shepherd Centre.

Download [Tracking progress for your child](#).

### Audiology is a self-regulated healthcare service.

In a statement on 24 March 2023, Independent Audiologists Australia (IAA) said:

We welcome the announcement that an independent and external review will be conducted by the South Australian government.

IAA supports the call for an extensive and independent review of the Hospital's cochlear implant mapping program, in addition to the diagnostic audiology program. The importance of reviewing both areas relates to the overlap of knowledge and skills required to work in both areas of audiology.

IAA has been advocating for many years to have the audiology industry regulated as a healthcare profession that requires mandatory registration under the Australian Health Practitioner Regulation Agency (AHPRA). Change is needed. We are calling on State, Territory and Federal governments to recognise that insufficient safeguards against harm are given to vulnerable Australians living with hearing loss, due to an ineffectively self-regulated industry.

IAA applauds and supports Ms Eglinton for championing the children and their families who have been greatly impacted by these events.

IAA strongly believes that families need choice and control when managing the hearing care of their children, to ensure quality of care and opportunity for second opinions where needed.

Registration of Audiologists under AHPRA is an important part of this picture.



## Australia's high levels of untreated hearing loss.

**The first results of a major study into hearing loss in Australia are in – and if you are over 50, you should probably book a test.**

Nearly half the people screened in the first rounds of the Australian Eye and Ear Health Survey who said they did not have a hearing problem had some level of hearing loss when they were tested by audiologists.

The Australian Eye and Ear Health Survey will visit 30 sites across the country to screen hearing and vision in 1750 Indigenous Australians over the age of 40, and 3250 non-Indigenous Australians over 50.

Inaugural Cochlear Chair in Hearing and Health at Macquarie University Hearing, Professor Bamini Gopinath (pictured), is leading the ear health component of the survey.

While about 400 of a planned 5,000 people have been screened to date, she says the early results suggest there is cause for concern.

“We found 97 per cent of the Indigenous people and 91 per cent of the non-Indigenous people we screened had some level of suspected hearing loss,” she says.

“All the participants are asked if they think they have any problems with their hearing. Forty-six per cent of the people who answered no to that question did in fact have some hearing loss.

**“Many people don’t want to admit they have hearing loss, as there is still a high level of stigma attached to it.”**

“Another concerning factor is that more than a third of people with suspected hearing loss had never spoken to a healthcare professional about their hearing – and that included the people who knew they had an issue as well as those who were unaware.”

“We still have many more people to screen, but this data indicates there could be a high percentage of people with undetected hearing loss in Australia, and many are not getting the support they need even when they know they are having problems with their hearing.”

### **Why are people not having treatment?**

While Australians have become used to having regular eye tests, fewer have routine hearing tests – and this is a cause for concern, given that midlife hearing loss is the single biggest modifiable risk factor for dementia diagnosis in later life.

Gopinath says there are many factors at play in why people either choose not to be tested or do not have treatment if they do become aware of a problem.

“Many people don’t want to admit they have hearing loss, as there is still a high level of stigma attached to it. It is often associated with ageing, and for this reason it can be hard for people to admit to themselves that their hearing is deteriorating, let alone acknowledge it publicly by wearing a hearing aid,” she said.

“Some people think it’s a natural part of the aging process, so they accept their hearing is

getting worse and assume there is nothing they can do about it.”

In some cases, she says a person may be tested but not get a hearing aid because of the cost; in others, they may have a number of health conditions, which pushes hearing down the list of priorities.

## Risk factors and warning signs

In many cases, hearing loss is gradual, and changes can be difficult to detect, especially at the beginning.

Often, the first ones to notice hearing loss are the person’s companions rather than the person themselves, but there are signs to look out for.

Some common signs include thinking things sound muffled, feeling people are talking too fast, struggling to understand or follow conversation, especially in noisy environments, having to ask people to repeat themselves, having trouble hearing when talking on the phone, and having to turn the TV up very loud.

You may also notice that you are watching others’ lips or gestures for hints to what they are saying, and focusing on conversation may be tiring or stressful, even to the point that you begin to avoid socialising.

Tinnitus (a ringing sound in the ears) and vertigo (the sensation that the room is moving around you) can also be indications of hearing loss.

Regular hearing tests are particularly important for these groups:

- **Anyone aged 50 and older**  
Even if you don’t think you have any hearing loss now, it is useful to have a baseline test on file to measure against any future changes.
- **Anyone who spends a lot of time in noisy environments**  
People who work in industries such as mining, manufacturing, transport, storage, and music are at particular risk, but some leisure activities, such as listening to loud music for long periods, can also be

dangerous. Hearing loss caused by noise is cumulative, so it is important to protect your hearing by wearing earmuffs or ear plugs around noisy equipment and power tools, and limit time spent listening to music at high volumes.

- **Anyone who is prone to ear infections**

Ear infections can damage the ear if left untreated, so make sure you seek medical advice.



[The Australian Eye and Ear Health Survey](#) is being led by the Westmead Institute for Medical Research and the University of Sydney, with partners the Macquarie University, University of New South Wales, the George Institute for Global Health, and the Brien Holden Foundation.

It is funded by the Australian Government Department of Health and Macquarie University.

The Australian Eye Health Survey was last held in 2015-16, and this is the first time that hearing has been included.

The findings will contribute to Australia’s commitment to United Nations and World Health organisation resolutions to eradicate avoidable blindness, as well as fulfilling several key priorities and actions outlined in Australian Government’s Roadmap for Hearing Health.

From [The Lighthouse](#)

# Working with culturally and ethnically diverse communities to address hearing loss.



**Untreated hearing loss can have a terrible effect on a person's education, communication, productivity, social engagement, physical and mental wellbeing.**

People from culturally and ethnically diverse (CALD) communities are more likely to experience hearing loss and less likely to access hearing services.

In the UK, hearing loss is 5 times more common among people in CALD communities. Although they were more likely to have hearing loss, use of hearing services and hearing aids was 50% lower, compared to those with white British background. Similar inequalities exist in Australia; one national survey reported hearing loss being twice as common among children in CALD communities.

Australia is one of the most culturally diverse countries in the world, with 30% of people born overseas. 20% of people speak a language other than English at home. Hearing health inequality related to CALD background is therefore a major challenge. Inequalities in hearing health undermine health and wellbeing, work opportunities and sustainable and cohesive communities. A key priority for governments is reducing health inequalities.

University of Queensland (UQ) researchers previously found that congenital hearing loss is up to three times higher among children born in regions such as Africa and the Middle East

compared to those born in Australia. Speaking with families, UQ researchers also found access to hearing services for children from CALD families is challenging for many reasons including language barriers, working with interpreters, stigma and shame towards hearing loss, cultural barriers and attitudes towards the role of caregivers in early intervention services, and cross-cultural miscommunication, including difficulties accessing information.

Effective interventions for hearing loss among children and adults are available via the Australian Government Hearing Services Program. A 2021 review of the Program recommended that the Government should identify and analyse shortfalls in engagement with CALD communities.



Professor Piers Dawes from University of Queensland's Centre for Hearing Research ([CHEAR](#)) and colleagues received funding from the National Health and Medical Research

Council for a project to address the recommendations of the Hearing Services Program review. The UQ-led team includes researchers and clinicians from Hearing Australia, Macquarie University's translation & interpreting and audiology programs, health services and inequalities experts from UNSW and world leaders in health behaviour from the University of Manchester in the UK.

Professor Dawes and colleagues are working with people from CALD communities and with community organisations to understand the challenges and develop solutions to improve access to the hearing services program for people from CALD communities in Australia.

This new project, based at CHEAR, will inform the development and delivery of accessible, equitable and culturally safe hearing services and provide an evidence base for strategies to encourage and promote behaviours that preserve and protect hearing health in Australian CALD communities across all stages of life.

"We are working to develop effective, equitable and sustainable solutions so that everyone can achieve their goals in life without being limited by hearing loss," said Professor Dawes.

<https://shrs.uq.edu.au/research/research-centres-and-units/centre-hearing-research>

## Premies exposed to a different sound landscape.

Along with the other challenges that come with being born early, premature infants are exposed to a completely different sound landscape than fetuses that remain in the womb for the full course of pregnancy.

A new study is the first to compare the sound exposures of fetuses in the last 16 weeks of pregnancy with their age-matched premature peers. The analysis reveals profound differences in their exposures to noise, language, the biological sounds of the mother, other voices nearby, music and other outside sounds.

"The intrauterine environment is unique, with constant, primarily low-frequency sounds of the mother's cardiovascular and digestive systems and her voice", said University of Illinois Urbana-Champaign speech and hearing science professor Brian Monson.



In contrast, premature babies in hospital neonatal intensive care units are often exposed to a variety of unnatural electronic and mechanical sounds, including the beeps of alarms. They are exposed to language, but only when nurses or parents are speaking nearby.

Deprived of the sounds normally heard in the womb, very preterm infants also spend long periods in silence, a condition that never occurs in utero. Instead of hearing language there were the sounds of the neonatal intensive care unit - mechanical noise and alarms from equipment."

For these premature infants, the sound exposures were evenly distributed throughout a 24-hour period, but fetuses in the womb experience a much more pronounced day/night cycle of sounds. Remedying this difference may allow the preterm infants to establish a healthy circadian rhythm.

"This is a time of life when the auditory nervous system is anticipating healthy sound exposures in order to mature properly. These differences could be having negative effects on these tiny infants and their developing brains."



# Deaf and Hard of Hearing mob and the NDIS.

## **Hey! Hear me out. Voices of Deaf and Hard of Hearing Mob on the National Disability Insurance Scheme in the Northern Territory.**

A new report aims to understand what helps, and what makes it hard for First Nations people who are Deaf or Hard of Hearing, to use their National Disability Insurance plans in a way that meets their needs and aspirations.

Using participants' own language and modes of communication, Jody Barney, a Deaf Birri-Gubba and Urangan woman yarned with First Nations NDIS participants living in rural and remote communities in the Northern Territory.

All participants identified the need for a cultural, local language and/or sign interpreter to support NDIS planning and use. Many experienced challenging life circumstances such as family separation, insecure housing and interaction with the justice system.

### **What helped people use their plans.**

Participants were more enabled to engage in the planning process and use their plan to achieve their outcomes when they were provided with enough relevant cultural and communication supports. They benefitted when skilled NDIS staff and service providers supported individual communication needs, and used culturally safe 'proper way' behaviours to engage with families, cultural guardians and advocates.

### **What made it hard for people to use their plans.**

The persistent discrimination and disadvantage associated with colonisation, and ongoing challenges in access to culturally safe services and support, impact the ability for Deaf or Hard of Hearing mob in the NT to engage with and benefit from the NDIS.

Key challenges included:

- intergenerational trauma.
- complex life circumstances where disadvantage and discrimination in one part of life led to challenges in other areas of life like health or interactions with the criminal justice system.
- challenges across and within 'white fella' systems impacting Deaf mob ability to live better lives, connected to Country, family, culture and community.
- insufficient cultural and communication supports to understand the NDIS and to advocate for plans.
- a mistrust of 'white fella' systems, compounded by limited NDIS recognition and understanding of Deaf mob circumstances and needs.
- limited timely access to culturally safe supports to respond to the challenges of early childhood onset of hearing loss.

- limited availability of culturally safe and communication responsive services and supports, particularly on Country.
- having to move off Country, away from family and culturally aligned supports, was commonly extremely distressing.
- when services e.g., Specialist Disability Accommodation and/or Supported Independent Living, were culturally unsafe and communication unresponsive, misunderstanding placed participants at risk of harmful practices, re-traumatising them and their families.

**Challenges experienced by First Nations people who are Hard of Hearing are often different to the challenges experienced by people who are Deaf.**

Despite the high prevalence of hearing loss across many communities, people are often unaware that they experience hearing loss.

For those that are Deaf and communicate using sign, people they engage with generally understand they communicate differently. When people are Hard of Hearing, other people often don't know that they have to do something different to communicate with them.

Increasing awareness that so many mob are Hard of Hearing is the first step for improving outcomes for this group. It is then important for families, communities and service providers to learn what they can do to improve communication with people with hearing loss.

**Actions.**

Enhance awareness and understanding of experiences of First Nations people who are Deaf or Hard of Hearing.

Enable 'proper way engagement' between the NDIS, individuals, families, communities and services and supports.

Recognise the importance of connection to Country, family, community and culture for First Nations people who are Deaf or Hard of Hearing.

Recognise the diversity of local sign languages and ways of communicating, resource the provision of sufficient cultural and communication training and supports within participants engagement with NDIS.

Promote First Nations led, localised solutions, services and supports. Where they are not yet available, improve access to culturally safe, hearing loss communication responsive and trauma informed services and supports.

Ensure shared responsibility to improve the way the NDIS interfaces with other systems.

Ensure that the needs of First Nations individuals who are Deaf or Hard of Hearing or are at risk of hearing loss are better considered within all strategies to close the gap in inequalities.

**HEY HEAR ME OUT!**  
**Voices of Deaf & Hard of Hearing Mob on the NDIS in the NT**



**Contact the authors**

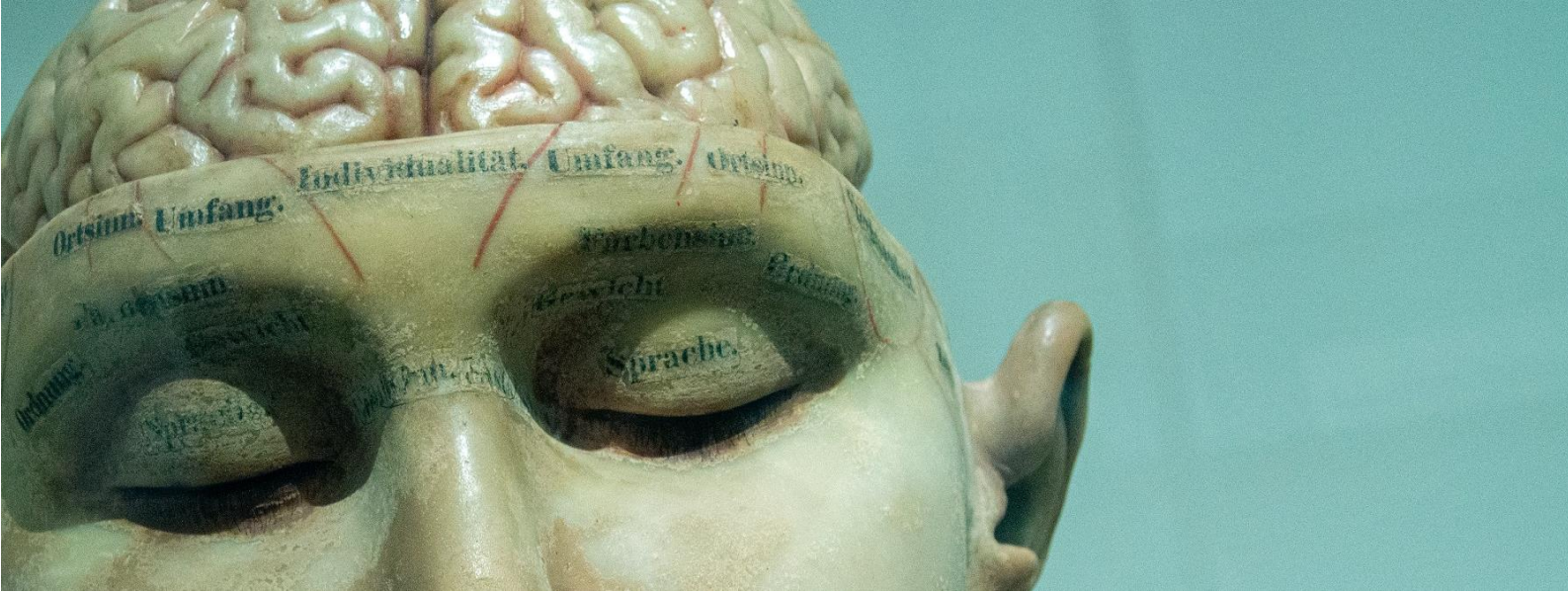
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**Download [Hey! Hear me out - Voices of Deaf and Hard of Hearing Mob on the NDIS in the NT.](#)**





## Why some cochlear implant users improve faster than others.

**Kickstarting the brain's natural ability to adjust to new circumstances, or neuroplasticity, improves how effectively a cochlear implant can restore hearing loss.**

Researchers say this may help explain the extreme variation in hearing improvements experienced by implant recipients.

Cochlear implants send electrical signals that represent sounds directly to the brain. It can take time to understand the meaning of the signals. Some cochlear implant users understand speech hours after receiving a device but others required months or years to do so.

A new investigation evaluated whether stimulating the locus coeruleus, a major site of neuroplasticity deep in the brainstem, improved how quickly they learned to use their devices.

"Our findings suggest that differences in neuroplasticity may help explain why some cochlear implant users improve faster than others," says neuroscientist Erin Glennon at New York University.

"We need to determine what noninvasive mechanisms can trigger the brain region."

From [Science Daily](#)

## Genetics of tinnitus.

Researchers have identified a number of interesting genes that may be linked to tinnitus.

The study by at King's College and University College London used the records of over 170,000 participants in UK Biobank to identify a gene they link to the risk of developing tinnitus.

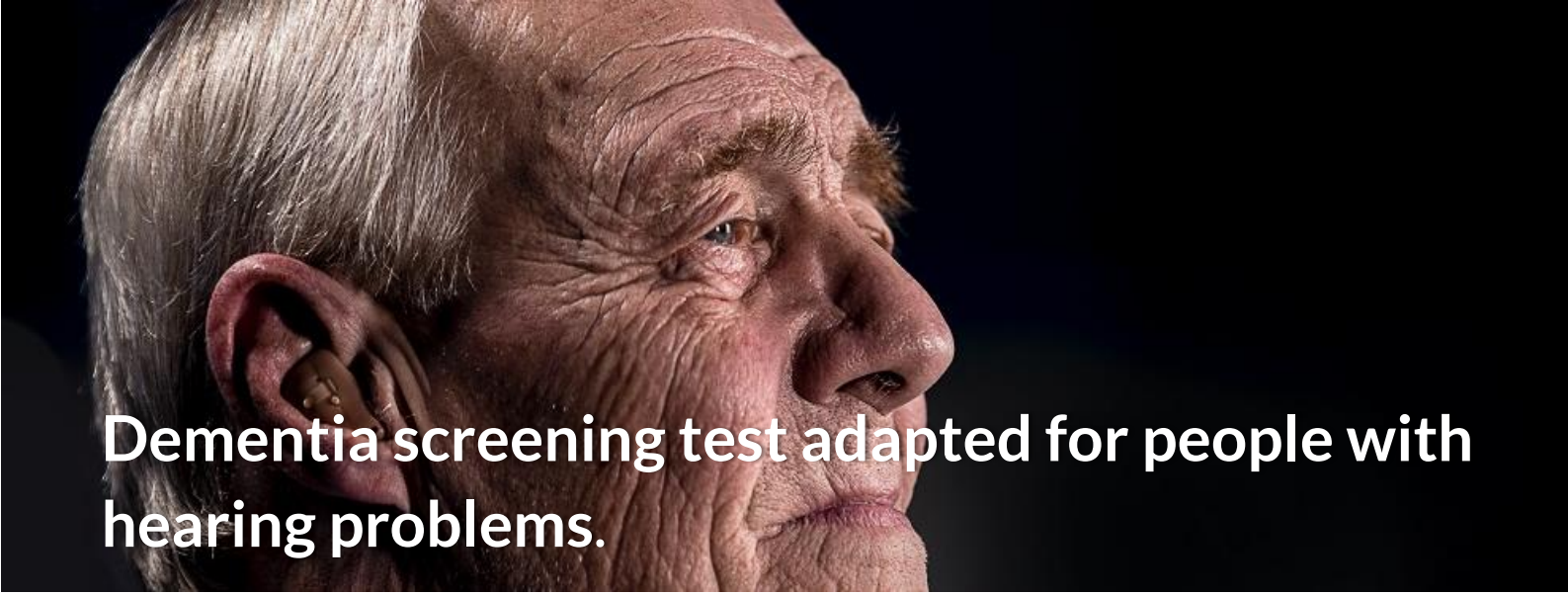
Importantly, the gene was not linked to hearing loss, but seems to have an independent link to tinnitus.

Future research on this gene might help to identify mechanisms of tinnitus or develop new treatments.

Understanding the genetic factors underpinning tinnitus is one of the approaches that can be used to identifying the biological pathways of importance, and from this to develop targeted therapies.

"This project's findings were very interesting and indicate that there are possible genetic risk factors for developing tinnitus," said Deanne Thomas, Chief Executive of Tinnitus UK.

"The study shows the potential benefits that a dedicated Tinnitus Biobank could bring, allowing us to understand the condition much better and answer many other questions that, thanks to chronic underinvestment, so far remain unanswered."



## Dementia screening test adapted for people with hearing problems.

**University of Queensland researchers have adapted an internationally used test which screens patients for dementia and Alzheimer's disease, to make it suitable for people with hearing loss.**

Professor Piers Dawes from UQ's School of Health and Rehabilitation Sciences said The Montreal Cognitive Assessment (MoCA) is the most widely used cognitive screening test in the world, but it's not suitable for people with hearing problems because it uses verbal questions.

"The MoCA has been in use for around 18 years and is largely used by health professionals as a tool to assess short term memory, executive functions, attention, language, and orientating time and place. However, as the test is administered verbally there is the possibility of people being misdiagnosed with conditions such as dementia, when in fact they may have hearing problems," Professor Dawes said.

"Due to the design of the test, examiners are unable to repeat questions so people with hearing problems may end up with an over estimation of their cognitive impairment because they misheard or didn't hear a question.

"Working with an international team we developed The MoCA-H, a version which utilises written stimuli instead of spoken word. Results showed the MoCA-H is a sensitive and reliable means of identifying dementia among adults with a hearing impairment."

Professor Piers Dawes said the MoCA-H is currently being translated into other languages and will be used around the world.

"There have been previous attempts to make the test suitable for people with hearing problems, but this is the first time it's been rigorously developed and evaluated," Professor Dawes said.

"More than 75% of people aged over 75 have a hearing impairment, which is why it's so important to have this alternate means of testing.

"The MoCA-H ensures they have an opportunity to be accurately screened for cognitive impairments like dementia and Alzheimer's, so they can take appropriate measures to manage their quality of life."

The research is published in the *Journal of the American Geriatrics Society*.

From [Medical Express](#).

## Research trends and hotspot analysis of age-related hearing loss.

Up-to-date information about the trends of age-related hearing loss and how this varies between countries is essential to plan for an adequate health-system response.

This study conducted an analysis of publications from 2002-2021. From [Frontiers in Psychology](#).

# Google to work with Australian researchers on new hearing AI.

Google has announced a partnership in Australia to explore new possibilities and AI solutions for hearing healthcare.

The collaboration, part of Google's Digital Future Initiative, involves five organisations across healthcare service delivery, research and technology sectors including Cochlear, Macquarie University Hearing, National Acoustic Laboratories (NAL), NextSense and The Shepherd Centre.



“Together, we’ll be focused on new applications of AI and machine learning to develop listening and communications technologies, overcome its current challenges, and pave the way for more customised hearing healthcare,” said [Grace Chung](#), Head of Google Research Australia.

“Our first project seeks to personalise hearing models to better address individual listening needs to enhance hearing aids and other listening devices.”

This technology could be particularly beneficial for people using listening devices in complex listening environments such as busy restaurants, group brainstorming or live orchestral performances.

The overlapping sounds in these settings can make it strenuous or overwhelming for people using devices to process and decipher various types of sound.

The project will explore new applications of AI to better identify, categorise and segregate sound sources. Ultimately, this might make it easier for people using assistive listening devices to follow a conversation or activity as the technology could help to prioritise sounds, such as a person speaking and filter out others, such as background noise.


“The collaboration is intended to invest in the extraordinary talent of Australians, and help continue Australia’s proud track record of hearing technology innovation.

“To help lead this effort on ground, we are delighted to welcome Simon Carlile, a distinguished world leader in this field, as he returns to join Google Research Australia,” Grace Chung said.



In the photograph, Professor Greg Leigh AO (NextSense), Dr Simon Carlile (Google Research), Prof David McAlpine (Macquarie University), Dr Zachary Smith (Cochlear), Prof Catherine McMahon (Macquarie University), Dr Aleisha Davis (Shepherd Centre), Dr Malcolm Slaney (Google Research), Sam Sepah (Google Research), Dr Brent Edwards (National Acoustic Laboratories).

From [Google Australia](#).



# HearChoice increases informed choice, accessibility and uptake of hearing healthcare.

**Millions of Australians with hearing loss do not get the help they need to improve their hearing difficulties and quality of life.**

**Hearing aids are effective, but uptake is poor, and only one in three people who would benefit from hearing aids has them.**

When they notice their hearing difficulties, people wait on average nine years before seeking help, and 60% of those eligible for assistance from the Government's Hearing Services Program do not engage with it.

None of this is new. But what can be done to improve the poor uptake of hearing healthcare?

Associate Professor Mel Ferguson from WA's Curtin University and her team were recently awarded a National Medical & Research Council grant to address this important question.

"There are many barriers to accessing and taking up hearing healthcare" said A/Prof Ferguson, "such as poor understanding of the impact of hearing loss, inappropriate expectations about hearing aids, and a lack of information or misinformation about hearing loss, hearing aids and rehabilitation options.

"A large proportion of people do not believe hearing aids provide benefits, and there is little information offered about the different options available (e.g. range and function), and even less for other technological and non-technological options."

This research will develop and evaluate an online decision support intervention called *HearChoice* that aims to empower adults with hearing loss by improving motivation, readiness, help-seeking and decision-making to improve access and uptake of hearing healthcare. It will enable the Government's Hearing Services Program to provide decision aid tools co-designed with consumers that illustrate healthcare pathways and choice of options, including educational support.



Associate Professor Mel Ferguson.

"I am so fortunate to work with an excellent team of internationally-recognised researchers, advocacy groups and adults with hearing loss, professional audiology bodies, and experts in cutting edge technologies.

"Building on theories of behaviour change and implementation science, I am confident our research findings will translate into clinical practice and policy, and make a real difference to the lives of many adults with hearing loss."



# World-first bedside genetic test to prevent babies going deaf.

**A world-first genetic test that could save the hearing of babies has been developed and successfully piloted.**

Taking just 25 minutes, the bedside machine identifies whether a critically ill baby admitted to intensive care has a gene that could result in permanent hearing loss if they are treated with a common emergency antibiotic.

The new swab test technique developed in England by the Government National Health Service would replace a test that traditionally took several days and could save the hearing of 180 babies in England alone every year.

People admitted to intensive care are usually given an antibiotic called Gentamicin within 60 minutes. While Gentamicin is used to safely treat about 100,000 babies every year in England, one in 500 babies carry the gene that can make it cause permanent hearing loss.

The new test means that babies found to have the genetic variant can be given an alternative antibiotic within the 'golden hour.'

It is expected the test could save the NHS £5 million every year by reducing the need for other interventions, such as cochlear implants.

First-year nursing student Mary, from Preston, is mother to 18-month-old Khobi, who was born and treated at Saint Mary's Hospital, part of Manchester University NHS Foundation Trust.

Mary said: "Khobi was born with her bowel outside her tummy, which put her at risk of infection – she needed antibiotics quickly but

was given this new genetic test which showed she was susceptible to hearing loss from gentamicin.

"She was given an alternative antibiotic which didn't affect her hearing, and it worked well. She's doing fine and is such a happy, sociable baby. This test is great, and I think all babies should have it".

Professor Bill Newman, a consultant in genomic medicine at Manchester University NHS Foundation Trust and Professor of Translational Genomic Medicine at the University of Manchester, led the Pharmacogenetics to Avoid Loss of Hearing (PALoH) study.

"I am absolutely thrilled with the success of the study, and that this testing is now going to be used in three of our Trust's Neonatal Intensive Care Units – it's actually going to make a real difference, so babies are not going to lose their hearing for a preventable reason.

"The trial demonstrated that you can deploy rapid genetic testing in a clinical setting, and that the tests can be carried out within the 'golden hour' when severely unwell babies should be treated with antibiotics."

Professor Dame Sue Hill, Chief Scientific Officer for England and Senior Responsible Officer for Genomics in the NHS, said "Genomic medicine is transforming healthcare, and this is a powerful example of how genetic testing can now be done extremely quickly and become a vital part of triage – not only in intensive care but across our services.

# This PhD candidate is an enthusiastic advocate for inclusion.



**Paulina Lewandowska was 3 years old in Poland when her parents became concerned about her not reacting to voices and sounds.**

They took Paulina for a hearing test, where she was diagnosed with hearing loss in both ears, most likely caused by the meningitis she suffered as a newborn. Paulina fondly remembers her first visits to a hearing specialist, describing them as a fun and pleasant experience. “The doctor played games with me while conducting the tests. I still have my first hearing aid somewhere in my room”.

Paulina’s parents spent hours every day helping her with rehabilitation and language development. “My mother even tried to teach me English, though she doesn’t speak it herself,” Paulina says with awe.

“We got a Polish–English dictionary, and she would learn the words first and then teach me how to pronounce them”.

That was 20 years ago, when schools were less able to help students with hearing loss.

Now a PhD candidate at the John Paul II Catholic

University of Lublin, Paulina researches inclusive education for hard of hearing students, defining success in school broadly to include academic performance as well as social and psychological wellbeing.

Besides this, she is the Secretary of the International Federation of Hard of Hearing and Vice-President of the Polish Association of Hard of Hearing People and Cochlear Implant Users.

## **Awareness and education**

Describing the services available in Poland, she notes multiple remarkable initiatives. For example, citizens can receive a life-changing cochlear implant surgery free of charge. Of course, there’s always room for improvement in terms of waiting times or availability of financial support.

How would Paulina like for policy change to take place in her country? “I think we should start from the beginning,” she answers after careful consideration. “Do research, gather data about people with hearing loss. It’s important to talk to them when considering policy change, because no one knows more about the needs of d/Deaf and hard of hearing people than themselves. Of course, there’s not enough money to cover all the needs, but I believe the resources that are available can be spent wisely. And I would put more emphasis on awareness and education, because there are still gaps in knowledge about the consequences of hearing problems, as well as many misunderstandings”.

Paulina is an enthusiastic advocate for inclusion. “Hearing or non-hearing criteria shouldn’t define us as human beings. Yes, we are hard of hearing or d/Deaf, but, more importantly, we are citizens, relatives, workers, students and so much more,” she explains.

“True inclusion becomes possible when the environment adapts in such a way that people with disabilities don’t feel like something is limiting them.

“This is why it’s important to challenge public perceptions and attitudes”.



## Navigating the journey to cochlear implantation.

**Cochlear implants are well used by children with significant levels of hearing loss, but only 1 in 10 adults in Australia who could benefit from a cochlear implant actually get one.**

The pathway to cochlear implantation, or even assessment for candidacy, can be very complex. Many people who could benefit from a cochlear implant have very limited awareness and understanding about the potential benefits.

Over the past year, Dr Cathy Sucher (pictured) and her team at the Ear Science Institute Australia in Perth have been working in collaboration with industry partners to improve the rate of use of cochlear implants among Australian adults. Their research has shown that despite many potential candidates having annual hearing aid checkups, cochlear implants are often not discussed in these appointments. The reasons for this oversight can include limited appointment time, and limited assessment of speech understanding making it difficult for clinicians to know the functional implications of the hearing loss specific to the individual. Clinicians sometimes fear that discussing cochlear implants might cause their client distress, or harm the client-clinician relationship.

Often, clinicians, hearing aid users and their loved ones focus on the ability of a new hearing aid to resolve hearing issues. Uncertainty about what could be achieved with cochlear implants can be cause for hesitancy. And reliable information about cochlear implant outcomes can be difficult to find or perceived as untrustworthy.

There are often concerns about the health status or age of the potential candidate, and also their ability to afford a cochlear implant. Even if the clinician and client can navigate past all these barriers, the referral procedures can be complicated and confusing.

Based on a series of appointment observations and focus groups, Cathy Sucher's team identified two potential tools to help support and empower clinicians and candidates as they navigate the cochlear implant journey. One is a basic paper-based tool, modified from one recently developed in the USA. This tool asks individuals to identify their level of hearing loss based on verbal descriptors, and then provides a range of hearing management options applicable to that level of hearing loss. The research team is currently piloting this tool in hearing aid clinics. It is anticipated that the tool could be modified for use online, or by hearing aid clinics, GPs and other allied health providers.

The second tool is a comprehensive, interactive website that provides generic, consistent and reliable information about cochlear implants; and tools to identify, support and refer cochlear implant candidates for assessment, facilitating the pathway to cochlear implantation. A prototype tool has been developed and is currently being tested. The team will be looking for funding opportunities to further develop, release and maintain an online version of the tool in 2024.

If you are interested in this work, further details, and contact information can be found at <https://www.earscience.org.au/research/brain-hearing/>



## Seeking community input on research priorities

Do you know of a knowledge gap on a health issue, and/or of a topic for which research is underfunded?

The National Health and Medical Research Council's (NHMRC) [Community Research Priorities Portal](#) allows citizens, community representatives and health organisations to propose health and medical research topics for consideration for the [Targeted Calls for Research](#) (TCR) scheme.

Submissions are reviewed to assess whether a TCR would stimulate research that would benefit the health of Australians.

NHMRC is the key driver of health and medical research in Australia. It advises the Australian Government and facilitates networking in the research community.

NHMRC aims to fund health and medical research that reflects consumer and community priorities and responds to unmet or emerging health needs.

The current cycle closes on 30 June 2023.

More information on the portal and how to make a submission can be found on the [Community Research Priorities Portal](#) webpage.

## Disability research

### [Australia's disability strategy 2021–2031 outcomes framework: first annual report](#)

This first annual report for Australia's Disability Strategy Outcomes Framework provides an overview of all measures being tracked since the current Strategy began in 2021.

### [Economic cost of violence, abuse, neglect and exploitation of people with disability](#)

The Disability Royal Commission contracted the Centre for International Economics to cost violence, abuse, neglect and exploitation of people with disability in Australia. This report has the findings.

### [Improving employment outcomes for young people with disability](#)

Pathways to Employment was a small, proof-of-concept trial by Brotherhood of St Laurence to test the efficacy of mainstream employment pathway support for young people in the National Disability Insurance Scheme.

### [NDIA research and evaluation strategy 2022–2027](#)

This strategy sets out a pathway to build and mobilise evidence to enhance the National Disability Insurance Agency and shape innovative services and supports that optimise the lives of participants.





# Aboriginal and Torres Strait Islander Research Leadership Group.

## **Researchers at National Acoustic Laboratories are working on a range of projects relating to hearing loss in Australian children, including Aboriginal and Torres Strait Islander children.**

Here we will summarise two of those projects that were recently completed.

### **Project 1: Development of national recommendations for routine Ear Health and Hearing Checks for young Aboriginal and Torres Strait Islander children in primary healthcare settings.**

Otitis media (OM) in young Aboriginal children is prevalent, early, persistent, and often asymptomatic. Early detection and support is critical to preventing damaging impacts on listening and communication skills development, learning, quality of life, and wellbeing. Primary health checks are key to OM detection: parents and carers watch for problems, but OM is hard to notice. Across Australian health systems, there are huge variations in the timing and components of checks, and checks are not often undertaken routinely nor proactively.

The goal of this interdisciplinary 18 month-project was to develop national recommendations for routine Ear Health and Hearing Checks for Aboriginal and Torres Strait Islander children aged under 6 years, in primary health settings. We aimed to do this by reviewing relevant published evidence, and consulting key Aboriginal and Torres Strait

Islander and non-Indigenous sector experts. The final set of recommendations relate to the goals, components, and timing of the checks.

In summary, Ear Health and Hearing Checks are recommended for Aboriginal and Torres Strait Islander children aged under 6 years at least 6-monthly until age 4 years, then one check at 5 years. More frequent checks are recommended in certain circumstances. Checks should always include asking parents/carers about concerns, signs/symptoms, checking listening & communication skills, and assessing middle ear appearance & mobility. Where health services have equipment, training and capacity, checks may include otoacoustic emissions and capture of ear drum images. These recommendations have been shared with the contributing experts, the Department of Health and Aged Care, and the National Aboriginal Community Controlled Health Organisation. A publication on the recommendations is under review. This research project was funded by the Australian Government through the Department of Health and Aged Care.

### **Project 2: Aboriginal caregivers' perspectives on supporting young children's hearing health and language development.**

The hearing loss often associated with persistent otitis media (OM) can have enormous negative impacts on Aboriginal and Torres Strait Islander children and families, but these are not well documented in published literature.

This study aimed to explore the perspectives of caregivers of young Aboriginal and Torres Strait

Islander children with hearing problems on how they support their children's hearing health and language development and on audiology and speech pathology services. With oversight from a local Aboriginal Research Leadership Team, this study privileged the voices and experiences of caregivers, who shared stories of advocating for and supporting their children's ear health, hearing, and language development.

Two main themes were identified across the interviews: 1. Caregivers are—and have to be—proactive; 2. Ear and hearing health pathways for treatment and support are complex and difficult to access and navigate. Caregivers had suggestions to improve support pathways including providing caregivers with more information about OM and related hearing loss, and support service pathways; having regular ear health and hearing checks; and ensuring that hearing screening links to health records. The insights and suggestions from caregivers can help improve support pathways and services, to ensure family-centred, culturally responsive service provision and clinical care. This project was funded by Deafness Foundation.

One of the aims of NAL's Aboriginal and Torres Strait Islander research portfolio is to prevent the long-term negative impacts of OM-related hearing loss. The team at NAL will continue to work with Aboriginal and Torres Strait Islander caregivers, communities, and stakeholders to co-develop solutions for identified priorities, under the guidance of NAL's recently established national Aboriginal and Torres Strait Islander Research Leadership Group.



## **Hearing health research activities are undertaken by the National Acoustic Laboratories (NAL) using Commonwealth Government funding.**

NAL's research projects focus on ways to reduce the impact of hearing loss and the incidence and consequence of avoidable hearing loss. Each year, the Department of Health and Aged Care and the NAL agree on the research activities for the year ahead. The research falls under one or more fields:

- Adult hearing loss
- Paediatric hearing loss
- Technology
- Hearing and human behaviour
- Clinical trials
- Informing and improving Hearing Services Program outcomes.

Research to improve outcomes for particular population groups include:

- improving hearing health outcomes for First Nations people
- improving awareness of and access to hearing health services for:
  - people living in regional and remote communities
  - people living with disability
  - people from culturally and linguistically diverse backgrounds.

NAL publishes a summary of research activities on its [Our research – All projects](#) webpage. It promotes its activities in peer-review journals and promotes its work at conferences, on social media and media releases.

Providing this information publicly enables the use of its research findings by a broad range of stakeholders. It increases public awareness of investments into improving the hearing health of Australians and supports sector engagement in identifying future research priorities.



# To create an Australian child hearing health outcomes registry.

**A team of researchers led by A/Professor Valerie Sung at the Royal Children's Hospital and Murdoch Children's Research Institute in Melbourne was awarded a grant from the National Health and Medical Research Council to prepare for the creation of a national register of Deaf and Hard of Hearing children.**

More than 30 organisations are engaged in the project over the next three years.

Australia has well-developed services for Deaf and Hard of Hearing children. All states now have Universal Newborn Hearing Screening and referral pathways for babies on to diagnostic audiology. However, there is no unified way for services to document how these children are faring around the country.

We know that many Deaf and Hard of Hearing children do not reach their full developmental, learning and health potentials, in part due to inequities in service access. A national data system, linking hearing and related services to measured outcomes, could address these inequities by identifying children who need additional services, and identifying areas for improvement in practices and processes.

## **What outcomes matter to families of Deaf and Hard of Hearing children?**

The most common question Dr Valerie encounters from parents when she sees newly

diagnosed babies in her clinics is "What will the future look like for my child?"

Without outcomes data, the question is difficult to answer. We all want our children to reach their full potential, but what does that mean for families of Deaf and Hard of Hearing children? Part of this work will involve talking to communities around the country, including Auslan users, Aboriginal and Torres Strait Islander families, and Culturally and Linguistically Diverse families, to find out what outcomes are important to children and their families.



Professor Valerie Sung.

Maintaining registries can be expensive and time-consuming. But by linking information that is already collected by various organisations, it is possible to keep costs and

effort to a minimum. The project team will find out what information is already collected by different organisations around Australia, and whether it can be linked up.

We hope the Australian National Child Hearing Health Outcomes Registry, aka ANCHOR will provide a national evidence base to inform future hearing policies and optimise service delivery models and supports. We also hope ANCHOR will provide a pathway to national reporting for developmental, educational, health and wellbeing outcomes, and be a national platform to facilitate population-based research for DHH children. The registry will specifically include Aboriginal and Torres Strait Islander children whose hearing loss is dominated by early middle ear infections, enabling tracking of identification, treatment, and outcomes.

### What kind of questions could be answered?

A national registry could answer many important questions that we don't yet have answers to, such as: Do children born with mild hearing loss benefit from hearing aids or early intervention? Should we do hearing screening later in childhood? How can we achieve equity in outcomes, especially in Aboriginal and Torres Strait Islander communities, and culturally and linguistically diverse communities? Why do some DHH children do very well, while others struggle?

Please get in touch with us if you would like to be part of the conversation while we work with families and stakeholders to develop a child hearing Core Outcomes Set relevant to Australia. We look forward to providing updates on the progress of ANCHOR over the next three years. Look out for our progress in future editions of One in Six!

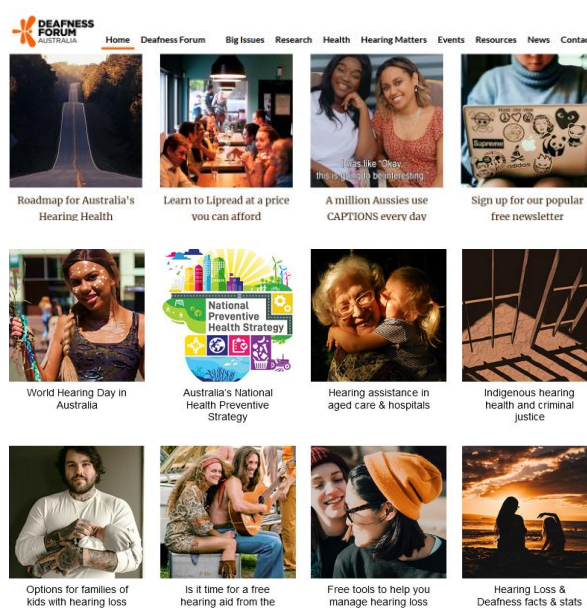
For more information visit [ANCHOR](#): Australian National Child Hearing Health Outcomes Registry - Murdoch Children's Research Institute, or contact Ms Libby Smith and Associate Professor Valerie Sung on [anchor@mcri.edu.au](mailto:anchor@mcri.edu.au).



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