

Inquiry into the Hearing Health and Wellbeing of Australia
Submission from Experts at Macquarie University

Terms of Reference 1

The current causes and costs of hearing loss, and ear or balance disorder to the Australian health care system should existing arrangements remain in place

What is the cost of not prioritising deafness and hearing problems?

A 2006 report—‘Listen Hear’ by Access Economics¹—put the cost of hearing loss to Australia at around \$12B, in terms of lost productivity and health costs (spanning direct costs of therapeutic interventions to associated health issues such as depression). This economic impact is comparable to that of similar European economies; a recent report by the UK’s Ear Foundation² estimates the cost to be €22B each for Britain and France, and €30B for Germany. The financial imperative is clear; hearing loss costs the nation a significant proportion of its wealth and human capital.

Compelling evidence indicates that the cost of not providing hearing technologies far exceeds the cost of doing so³, yet current awareness and provision of hearing technologies, especially for the adult population, is poor. This is despite significant advances in the design, capabilities and aesthetics of hearing-aids, and the development of new assistive listening devices that could transform people’s communication abilities, extend their working lives and ensure their independence well into old age.

The economic impact of hearing loss must also be considered with respect to its impact on other health problems. Given that age is the largest predictor of hearing impairment⁴, deafness is likely the common co-morbidity with six of Australia’s current National Health Priority areas (Cancer, Cardiovascular Health, Diabetes⁵, Arthritis & Musculoskeletal Conditions, Obesity, and Dementia) and explicitly associated as a risk factor for two of them (Dementia⁶ and Mental Health⁷). The link, now well established, between hearing loss and cognitive decline into dementia⁸ (with risk factors increased by 2, 3 and 5 times for mild, moderate and severe hearing impairment) has clear financial and societal impact behind the immediate cost of hearing loss itself.

Hearing loss is a chronic health condition

Hearing loss is progressive, cumulative and irreversible, and for these reasons is classified as a chronic health condition by the World Health Organization⁹ and by the Federal Government's Department of Health¹⁰. It therefore requires a life-course perspective in terms of its management and the provision of care. Whilst hearing technologies provide invaluable assistance in enhancing communication abilities, they do not restore normal hearing function. Hearing aids, the most common intervention for permanent hearing loss, amplify sounds to make them louder, but they do not render sounds more easily distinguishable. 'I can hear you, but I can't understand you' is a common response from many hearing-aid users. Hearing aids are useful in relatively quiet environments, but even moderate levels of background noise in social settings are not only one reason for dissatisfaction and discontinued use, but also why they may not be sought in the first place^{11 12}. The uptake of hearing technologies is often significantly delayed; hearing-aid users wait on average 10 years between perceived need for a solution to their hearing problems and actually seeking help¹³, during which time sensory deprivation might have reduced the hearing brain's capacity to maximise the benefits of assistive devices. Because of this impact on brain function, adult hearing-aid users, require, but rarely receive, the type of rehabilitation program considered routine for other therapeutic interventions (e.g. artificial hip- and knee-joints). Timely intervention through a recognized healthcare pathway, coupled with an effective program of rehabilitation, would increase the uptake, use and efficacy of hearing aids, reducing the burden of disease for individuals and their families, and ensuring they remain active members of society for longer.

Cochlear implants ('bionic ears') are a transformative technology. Their success can be gauged against the rudimentary devices developed for vision loss or spinal injury, which remain experimental. Nevertheless, a child born profoundly deaf today and implanted by the age of 6 months, will likely require up to a 100-year program of hearing healthcare, including training/habilitation, technology upgrades, specialist assessments, and potentially several re-implantation surgeries, as well as non-standard contingencies for unrelated health problems (e.g. cochlear implants are incompatible with procedures such as MRI—magnetic resonance imaging—scans).

Chronic middle-ear disease is a common cause of conductive hearing loss^{14 15}, often overlooked in the context of the more extreme 'sensorineural loss' arising from diseases of, or damage to, the inner ear. Nevertheless, it is highly prevalent in Australian children, particularly in Australian Aboriginals and Torres Strait Islanders, and elicits similar communication problems, being linked to poor language development and reading abilities, with consequences extending over the life-course. The deep entanglement of hearing with the acquisition of language, and indeed general education, wellbeing, connectedness and psycho-social development, highlights that, even following medical intervention, the impact of hearing impairment from conductive hearing loss is evident across the life-course for individuals, their families and society.

Terms of Reference 4

Current access, support and cost of hearing health care for vulnerable populations, including: culturally and linguistically diverse people, the elderly, Aboriginal and Torres Strait Islanders and people living in rural and regional areas

Perhaps the most egregious area of unmet need concerns the poor hearing health of Australian Aboriginals and Torres Strait Islanders¹⁶ – with a rate of middle-ear disease the World Health Organization categorizes as 'a massive public health problem'. Poor hearing-health in Indigenous Australians is not especially unique amongst aboriginal populations globally, but it is particularly stark in the context of hearing outcomes for non-indigenous Australians, particularly infants and young children. The impact of hearing loss on Indigenous Australians is not simply related to reduced socio-economic circumstances (though this is a known risk factor) but is also due to a specific genetic disposition in Aboriginal people for chronic middle-ear disease, especially during childhood. Potentially less severe than sensorineural hearing loss (hearing loss due to damage to the inner ear), at least if diagnosed and treated early, conductive hearing loss nevertheless has similar impacts on communication abilities, language development and educational attainment and can easily progress to more permanent hearing loss if left untreated. The current Royal Commission into the Protection and Detention of Children in the Northern Territory has highlighted the role hearing loss plays in generating negative attitudes, including how, in the context of hearing problems, alternative communication strategies (e.g. gesturing) can be

mistaken as signs of aggression. Such findings are not new. Indeed, the link between high rates of incarceration in Aboriginal people and hearing loss is well established – with one study showing 94% of inmates in a Darwin prison had moderate-to-severe hearing impairment.¹⁷

For Indigenous Australians, the issue of undiagnosed and untreated hearing problems remains a barrier to equitable access to, and utilization of, education, employment and life chances. In the context of a wider program of increasing the nation's hearing health and wellbeing, a concerted effort must be made to generate equality of outcomes for Indigenous and non-indigenous Australians.

Terms of Reference 7

Best practice and proposed innovative models of hearing health care to improve access, quality and affordability

What does Australia do well?

Australia is the standout country globally for hearing healthcare in the paediatric population and this high level of performance must be maintained. Starting with the new-born hearing screening program, a hearing test within a few days of birth undertaken for all children born in private and public hospitals in Australia (and administered at State level), Australia's care pathway for infants diagnosed with hearing loss in the maternity ward garners almost universal acclaim. Although hearing screening is widely implemented across many high- and medium-income nations, Australia's capacity for early intervention and sustained follow-up to ameliorate the effects of hearing loss in infancy is outstanding, both in terms of attrition (i.e. loss to follow up; <1%; c.f. ~40% in the USA¹⁸) and in terms of easily accessible and identifiable pathways to secure hearing technology and assistive devices for children (e.g. through Australian Hearing Services, AHS, or providers of cochlear implant technologies and education services such as the Royal Institute for Deaf and Blind Children, RIDBC).

Given the unarguable benefits of early detection, intervention and habilitation for life chances in children born deaf and hard-of-hearing¹⁹, it is critical that emerging and future models of funding for hearing healthcare in this paediatric population provide the same 'gold-standard' service. The National Disability Insurance Scheme (NDIS) must be applied

with the view to maintaining Australia's excellent standard of care in this regard. With a move towards greater competition in the market for hearing services in Australia, lessons must be learned from other jurisdictions that have followed this route. In the UK, for example, audiological services were the first to be opened up to the 'Any Qualified Provider (AQP)' program, by which private providers could compete for the tariff for hearing services formerly provided by the National Health Service (NHS). 'Despite 'Boots hearingcare'—one of the two dominant providers of audiological services under the AQP scheme—having exceptional 'high-street' presence ('Boots the Chemist' is a national brand) and being 51% owned by Sonova—the parent company of the hearing-aid manufacturer 'Phonak' and 'Advanced Bionics' (the second largest cochlear-implant company)—they withdrew from the AQP contract in April 2016²⁰, unable to sustain a business model that included the significant number of complex cases normally referred to specialized NHS clinics and hospitals.

Care must be taken as the tariff for hearing services is transferred to the NDIS that services supporting the often-complex needs of vulnerable children and their families are maintained to the current high standards.

What should Australia prioritise in hearing healthcare?

1) Make hearing loss a public-health issue

Australia should undertake a strong commitment to make hearing loss a major public-health issue. This might include a campaign to prevent or minimize the cumulative damaging effects of social noise exposure, along the lines of the SunSmart ('slip-slop-slap') campaign for sun exposure that succeeded in altering behaviour in early life to reduce the incidence of skin cancer²¹. A blend of public information, self-monitoring and changes to legislation (unregulated exposure to noise in social settings, especially in the absence of informed consent) should be undertaken. A key goal should be to educate the public concerning the link between healthy hearing and healthy cognition, especially in later life.

An important part of this strategy should be a campaign to 'normalize' devices that protect, monitor and enhance hearing. With in-ear devices increasingly common across wide range of users (including 'wearables' for health monitoring, for example), the possibility of de-

stigmatizing technologies that protect, enhance/augment (and even replace) normal hearing function is imminent. Australia should capitalize on this trend by providing the same level of tax incentive for assistive listening devices for work environments as is provided for other communication devices such as phones and laptop computers.

We should also prioritize effective communication in the design, implementation and maintenance of public and private spaces. Currently, no Australian Standards exist for the acoustical design of classrooms²², unlike in the UK, USA and Canada – to name a few comparable societies. Such Standards must be developed and enforced -- poor classroom acoustics is a critical factor for effective listening and learning. The current move to open-class designs, for example, is highly detrimental to speech understanding, even for normal-hearing listeners, and will be likely to have negative impacts on educational attainment. Children with hearing problems, or with English as a second or additional language are particularly disadvantaged by poor class-room acoustics and a lack of consideration to sound design.

We also need to educate health professionals as to the impact of hearing loss. Despite its negative impact on health and wellbeing, and its strong association with ageing, many healthcare professionals outside the specialities of audiology, speech pathology and ENT medicine, remain unaware of the detrimental effects of hearing loss on communication abilities *per se*, and on the wider health and wellbeing of patients (e.g. increased risk of mental health issues, reduced cognitive capacity, increased risk of dementia). A persistent view remains that hearing loss should be accepted as a consequence of ‘getting old’, a view that would not be countenanced in the management of other chronic conditions such as diabetes and cardiovascular disease.

2) Ensure regular hearing health is included in health screening

Hearing-health checks should be established as standard practice in front-line health- and social-care delivery, from general practitioners to nurses, gerontologists and care workers, and healthcare professionals should be incentivized to monitor hearing health on a regular basis. With increasing availability of ‘app-based’ hearing-health checkers (e.g. ‘mimi’²³), it is possible to determine an individual’s ‘hearing age’ (standardized to audiometric norms) with an acceptable level of accuracy. Establishing a rapid and easily delivered hearing check into

general health screens would initiate formal diagnosis, helping reduce the current decade-long gap between individuals acknowledging they have a hearing problem and them seeking help from a professional.

Australia should prioritize hearing health in late- and end-of-life care. Effective communication in residential care facilities, or within the home (where carers themselves might have a hearing problem), can be the key to ensuring social engagement is maintained and that communication of other basic needs are met by carers. Many older Australians living in care homes, and with untreated or poorly managed hearing problems, are being robbed of a critical element of their social and cultural interactions at a point in life where many such opportunities have already been curtailed by frailty or illness. In many instances, it is likely that family members are the *de facto* care givers for hearing health (e.g. changing batteries or amplification settings) even though they are likely not skilled to provide this function (this would not be countenanced for other interventions such as medication). All workers in social-care settings should be trained to monitor and assess the function of hearing aids and assistive listening devices for residents. We need to mandate minimum standards of hearing care in residential care homes, including basic ear care, regular checking of devices, and monitoring of basic hearing function. Given that regular use of functional hearing aids is a critical factor in their efficacy, prioritising hearing-health care in residential care homes has the potential to generate a range of inter-personal and social benefits for residents and carers alike.

3) Increase access to, and choice of, hearing technologies and assistive devices

The cost of a hearing aid ranges from under one hundred dollars to many thousands of dollars, and it is unclear to most people seeking a technological solution to their hearing problems what the potential benefits (and limitations) of each of these devices might be. Hearing aids are strongly marketed in terms of life-style choice in a way that, say, artificial hips and knees are not. Despite this apparent consumer-focused perspective, access to technologies remains poor, patients/customers are confused about the relative benefits of different devices, non-specialist healthcare workers are poorly informed with respect to the broad range of possible therapy options that are available to patients, and rehabilitation pathways (other than for cochlear implantation) are virtually non-existent for the adult population.

Beyond or in addition to, hearing aids, a range of assistive devices exist to aid communication. Historically, hearing impairment created potentially insurmountable communication barriers in a range of scenarios where the benefits of traditional hearing aids were limited. Most notably, hearing-aid use does not ameliorate the difficulties caused by background noise or the degradation of an acoustic signal over distance. The use of remote microphones, where a communication partner wears a microphone that can send a direct, wireless signal to a device worn by the hearing-impaired individual, has long been known to be an effective strategy in combating the effects of noise and distance in complicated listening environments. Adults with hearing impairment generally have to fund these devices through their own means, one potential reason why uptake remains relatively low, despite empirical and anecdotal evidence showing their effectiveness in increasing access to sound.

Modern developments, like Bluetooth and near-field induction technology, have also opened up a range of connectivity options for hearing aid users. Users of hearing aids, for example, can stream phone calls, or other audio, from Bluetooth-enabled mobile devices directly to their hearing aids. The advantage of this approach compared to a regular Bluetooth headset is that the signal received by the hearing impaired person can be adjusted on the hearing aid to optimally compensate for their loss of hearing. A comprehensive model of intervention for hearing-impaired individuals should include these wireless devices as part of the range of technologies that can reduce the negative impacts of hearing loss.

For individuals with greater hearing impairment, an urgent need exists to increase access to cochlear implantation. Cochlear implants—developed over 40 years ago—remain the only viable therapy for those with severe to profound hearing loss. With improved surgical techniques and design of implant electrodes, candidacy is increasing to include those with less severe forms of hearing loss. A strong correlation exists between age-of-implantation/duration of deafness and outcomes with cochlear implants; the shorter the wait, the greater the benefit and improvement over time²⁴, and therefore less reliance on costly re/habilitation services. Despite Australia's leading role in the development of this technology, however, and the acknowledged smooth pathway to implantation for children diagnosed through new-born screening, adult access to cochlear implants is woefully poor;

fewer than 5% of adults in the developed world who would benefit from cochlear implants actually receive one (this includes Australia), the waiting time for implantation without access to private health insurance is between 6 months and 5 years, and many health professionals remain ignorant as to the benefits implantation would bring to older adults, seeing them (mistakenly) as suitable only for the paediatric population, or even as an experimental technology. Resistance to what is seen (by potential patients or health professionals) as a strongly branded product may also generate negative connotations, especially for those individuals with progressively more severe hearing loss and for whom increasingly more powerful (and expensive) hearing aids are providing less and less benefit. Current access to cochlear implants is failing to meet the backlog of need, never mind the likely increase in need that will come from an ageing population and the expansion of candidacy criteria. Cochlear implantation must become the standard-of-care for adults with severe to profound hearing loss, all adults who need bilateral implants (i.e. one in each ear) should receive them, and the time between diagnosis and surgery must be reduced substantially.

4) Develop a clear and concise care pathway for adults with hearing loss

In addition to the almost total absence of regular hearing checks during adult life, no clear pathway for hearing healthcare exists. The existing model of hearing healthcare is strongly focussed on the provision of hearing aids. The Government Hearing Healthcare program for older adults – the Office of Hearing Services – reinforces this by paying (and therefore rewarding the practitioner or their organisation) for the numbers of hearing aids fitted, rather than the outcome of services delivered. This strongly directs any service towards providing a hearing aid for each patient rather than accessing a range of options that might benefit patients in different ways (e.g. through the provision of communication training). A more informed and connected model of care would provide clearer (and unbiased) information to individuals about which intervention choices are available (including combining audiological intervention with psychological interventions to address the negative social and psychological consequences of hearing loss), and inform patients about the likely success of each intervention (thereby enabling informed consent to treatment). It would also be embedded within other pathways of care so that hearing healthcare would intersect with areas that treat medical conditions with drugs known to cause hearing loss

(e.g. certain cancer drugs, and antibiotics commonly administered to those with cystic fibrosis).

5) Invest in research into new technologies and therapies

Capitalizing on the National Innovation and Science Agenda, 'NISA', Australia should invest in research into emerging technologies—and the means of delivering those technologies—that protect and improve hearing function and communication, including novel forms of assistive hearing devices. Globally, a range of 'disruptions' to hearing devices is underway, with new 'apps' being developed for hearing screening beyond the hearing-aid industry, the development of general health (e.g. heart rate, balance) monitors embedded in ear-buds ('the ear is the new wrist') that provide the opportunity to augment hearing, as well as more explicit research programs aimed at improving speech-in-noise performance of existing hearing devices employing concepts such as 'deep neural networks'. Given Australia's historic engagement in hearing technologies, especially through Cochlear and the National Acoustic Laboratories (NAL), and the opportunity afforded by NISA to recast the economy in terms of innovation, a dedicated program of research into new technologies, therapies and modes of healthcare delivery in hearing and communication should be established. A key aspect of this might be to establish a national database of hearing health and patient engagement with hearing devices/services, from which information key to scientists, technologists, health professionals, and, potentially, corporate partners might be utilized in the development of new technologies and interventions, as well as assessing better the outcomes of current ones. As part of this, Australia should also invest in research around developing a formal hearing healthcare pathway that considers all elements in the care pathway, including the plethora of private and public providers of hearing services and technologies. Australia's healthcare and research eco-system, with strong public engagement on public health issues, provide opportunities for Australia to take global leadership in the development of the next generation of hearing healthcare research and implementation. Such a program could also form the framework around which hearing services funded through the NDIS are costed, agreed and delivered.

Other significant areas of research growth come through pioneering radical new technologies in hearing healthcare, utilizing genetics, pharmacology and biological therapies. Establishing a global-leading coherent program of clinical trials to deliver new, or

augment current, therapeutic interventions is within Australia's grasp and would be truly revolutionary. Many of the elements required to make a success of this venture already exist in Australia, including public and corporate research leaders such as Macquarie University's Hearing Hub, The Bionics Institute in Melbourne, Cochlear and the NAL, and world-leading translational neuroscience programs such as those at UNSW, for example. Investing in a dedicated national program of fundamental research geared towards the delivery of a clinical-trial pipeline, and with strong public and practitioner engagement (such as occurs for various types of cancer), would position Australia as the undisputed global leader in understanding, combatting and ultimately defeating the silent scourge of hearing loss.

6) Transform hearing healthcare for indigenous Australians

The current poor hearing health of Aboriginal and Torres Strait Islanders, especially children and young people, exists in the context of the known effects of poor hearing and communication skills on the wider population during the early years on educational attainment, future employment and life-chances. Although, as for non-indigenous Australians, adult hearing-health remains relatively poor, Australia is the global leader in hearing services and outcomes for children, especially those with sensorineural hearing loss, and it must ensure that young indigenous Australians who largely, although not exclusively, suffer the effects of chronic conductive hearing loss, receive the same high-quality services and achieve similar outcomes. Given the often broad range of health and social services engaged with Aboriginal children and their families, knowledge and expertise in hearing health, and timely and repeated engagement with hearing services must form part of the repertoire of all organisations and individuals working to serve Aboriginal people. Scandals such as that recently exposed in the Northern Territory might have been ameliorated or avoided altogether if the consequences for communication abilities, as well as the physical, cognitive and psycho-social impacts, of hearing loss resulting from a genetic disposition to chronic middle-ear disease were better understood, including by those working in the criminal justice system. A national campaign aimed at ensuring Aboriginal people, especially children, are afforded the same opportunity for hearing health as non-indigenous people would benefit from the type of engagement currently under development in other healthcare systems (e.g. the UK's NHS), in which public and patient groups are included in

the process of deciding research priorities, and where the healthcare spend might be most effectively targeted. A program of engagement with Aboriginal people regarding hearing health would stimulation effective communication in a number of senses.

Terms of Reference 8

Developments in research into hearing loss, including: prevention, causes, treatment regimes, and potential new technologies;

Historically, Australia has performed well by international standards in terms of the quality and breadth of research into hearing and deafness, and in the level of resourcing provided for that research—though this is relative to hearing research in other countries, rather than with respect to other, often less-common, health disorders. Globally, and Australia is not exceptional in this regard, hearing research is underfunded relative to the number of individuals affected, and the cost to the economy of untreated hearing loss. The more fragmented nature of healthcare delivery in Australia makes a direct comparison difficult, but the Australia experience likely follows that of the UK, in which the estimated spend on hearing research *per* individual affected is just 10% of that spend on vision research, 5% of the spend on diabetes, and only 2% of the spend on cardiovascular disease²⁵. The relatively poor funding for research into hearing health—to which the lack of status as a National Health Priority contributes—likely impact on a range of factors including poor public awareness of deafness and hearing problems, poor access to appropriate technologies, and the lack of a co-ordinated (across health specialities) care pathway for adults with hearing loss.

Australia is also recognized internationally in terms of its research into new technologies and therapeutic interventions for hearing loss, exemplified by the iconic company Cochlear, as well as the global reach of research aimed at improving hearing-aid technologies and hearing outcomes through the NAL. As the global leader in implantable solutions for severe-to-profound hearing loss, Cochlear is rightly considered as pivotal to Australia's relatively healthy research ecosystem for hearing sciences. However, this leadership is qualified by the fact that less than 5% of adult need for cochlear implants is met globally in the developed world, including in Australia²⁶. This lack of market/clinical penetration appears

incongruous, but arises through a combination of lack of awareness of potential solutions for hearing loss, including by healthcare professionals²⁷, limited funding for implants through public funding (with waiting times for adults seeking implantation in Australia ranging from 6 months to 5 years²⁸) and the current delivery model of adult hearing healthcare, with its reliance on often disjointed specialist services along the patient journey.

Australia's leadership in hearing sciences, and in design and delivery of hearing technologies, must be matched by the development of new pathways to implementation for hearing healthcare.

Terms of Reference 9

Whether hearing health and wellbeing should be considered as the next National Health Priority for Australia

Hearing loss is a global public-health problem. As such, a strong imperative exists to make Hearing Loss the next National Health Priority for Australia. A recent report by 'The Lancet'¹⁴ confirms hearing loss to be the second-most common impairment (after anaemia) contributing to the Global Burden of Disease, and Australia is no exception to this. Consistent with other developed countries, deafness is the most common sensory disability, affecting 1 in 6 Australians at any one time, and the majority of individuals over their life course—a third of Australians over the age of 65 have significant hearing loss, and this progresses in severity and frequency with age (>80% of 85 year olds have significant hearing loss). Hearing loss hampers individuals' ability to communicate, renders them at risk of social isolation and depression, and increases their risk of other physical and cognitive health problems, including dementia⁸. Hearing loss also increases the risk of mortality²⁹. The life-time probability of acquiring significant hearing loss that requires therapeutic intervention is therefore considerably higher than other conditions that have been afforded the status of National Health Priority, where risk of acquiring the disease (beyond those born with the condition) is lower; e.g. 3.4M Australians have hearing loss compared with 1M Australians who suffer or are at risk from diabetes³⁰.

The benefits of establishing Hearing Loss as the next National Health Priority extend far beyond the domain of hearing. The links between permanent hearing impairment and

quality of life are well established. Our growing understanding of the connections between hearing loss and mental health, cognitive well-being and community participation, make this an ideal time for Australia to build on our strengths in the diagnosis and treatment of hearing loss in infants and develop a similar strategy for prevention, identification, management and rehabilitation for all Australians affected by hearing loss. Long known as the hidden handicap, the deep and real impact of hearing loss is too often only acknowledged by professionals in the field, and the individuals affected and their families. The real cost of inaction, while measurable and significant in an economic sense, is immeasurable in terms of the emotional and societal impact on the millions of Australians who experience hearing loss in their life time. A concerted effort to improve our national outcomes must involve a frank assessment of our current strengths and weaknesses, consultation with Australians with hearing loss, as well as professionals and academics in the field, and the development of articulated, life-long services with a focus on reducing preventable hearing loss and offering evidence-based rehabilitation. This approach gives us our best chance of engaging with the hundreds of thousands of Australians who have not yet sought or found assistance in managing their hearing and communication difficulties.

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