Assessment of Online Information on Auditory Neuropathy Spectrum Disorder

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Abstract

***Purpose*:** This study assessed the readability, use of plain language, understandability, actionability, and quality of online information on ANSD.

***Method*:** Six relevant search terms were input into 21 country specific Google domains. The first 10 webpage results for each search term were included. Duplicate webpages were removed. A total of 66 webpages were included for assessment. For each webpage, locality of hosting organisation, type of hosting organisation, and HONcode certification were recorded. Readability was analysed using three readability formulas: (1) FOG, (2) SMOG, and (3) F-K. Use of plain language was assessed using an adapted PLC, understandability and actionability were assessed using the PEMAT, and quality was assessed by the DISCERN tool. Quality was also indicated by presence or absence of HONcode certification.

Results: Online information on ANSD was found to be written significantly above the recommended 6th RGL. Poor to moderate use of plain language, understandability and actionability, and quality of treatment information was found. No significant difference in RGL, use of plain language, PEMAT scores, or DISCERN scores was found based on location and type of organisation.

Conclusion: Online information on ANSD does not support low health literacy, parental understanding, self-efficacy, or participation in shared decision making. Health professionals should ensure that parents have access to suitable resources on ANSD. Development of easy-to-read, understandable, actionable, and quality information on ANSD is needed.

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List of Abbreviations

ABR	Auditory brainstem response
ANOVA	Analysis of variance
ANSD	Auditory neuropathy spectrum disorder
CI	Cochlear implant
CM	Cochlear microphonic
F-K	Flesch-Kincaid Grade Level
FOG	Gunning Fog Index
FRE	Flesch Reading Ease
HON	Health on the Net
ICC	Intraclass correlation coefficient
OAE	Oto-acoustic emission
PEMAT	Patient Education Materials Assessment Tool
PLAIN	Plain Language Action and Information Network
PLC	Plain Language Checklist
RGL	Reading grade level
SD	Standard deviation
SES	Socio-economic status
URL	Uniform Resource Locator
VRA	Visual reinforcement audiometry
WHO	World Health Organisation

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1. Introduction

1.1. Hearing Loss in Children

Approximately 466 million people (over 5% of the world population) have a significant hearing loss worldwide. This includes about 34 million children (World Health Organisation (WHO), 2019). Approximately 180 to 210 children are diagnosed with a permanent hearing loss in New Zealand each year (Digby, Purdy, & Kelly, 2018). Hearing loss in children can be due to genetic or non-genetic causes (Roizen, 2003). There are approximately 100 genes implicated in non-syndromic hearing loss (Bolz, 2016) and hearing loss has been identified as being part of more than 400 syndromes (Bolz, 2016). Non-genetic causes include meningitis, mumps, congenital infections, ototoxic medications, head trauma, middle ear effusion, and other infections (Roizen, 2003).

1.2. Auditory Neuropathy Spectrum Disorder

Among those children diagnosed with hearing loss each year, approximately 10% are likely to have auditory neuropathy spectrum disorder (ANSD) (Berlin et al., 2010). ANSD is a hearing disorder characterised by poor speech recognition (Moser & Starr, 2016) and poor temporal processing abilities (Berlin et al., 2010; Moser & Starr, 2016). ANSD involves intact outer hair cell function in the cochlea but disordered inner hair cell function and/or auditory nerve function (Zeng, Kong, Michalewski, & Starr, 2005). Pure-tone hearing thresholds can vary from normal to profoundly impaired (Moser & Starr, 2016) and speech recognition abilities are often poorer than what is usually predicted by behavioural hearing thresholds (Moser & Starr, 2016).

1.2.1. Pathophysiology

A study by Star, Sininger, and Pratt (2000), including 67 patients with ANSD, investigated the causes of ANSD. They found that 42% of patients had ANSD associated with hereditary

neurological disorders while 10% had ANSD associated with infectious, immunological, metabolic, or toxic causes (Starr, Sininger, & Pratt, 2000). The cause was unknown in 48% of patients (Starr et al., 2000). ANSD is largely caused by genetic factors (Manchaiah, Zhao, Danesh, & Duprey, 2011). Genetic ANSD may be non-syndromic, syndromic, or mitochondrial, with different genetic mutations resulting in varied pathological disruption of the auditory system (Manchaiah et al., 2011).

The term ANSD is used because the site of lesion or degree of dysfunction in the auditory system can vary (Moser & Starr, 2016). Differing clinical presentation and patient outcomes are likely due to these pathophysiological variations (Gardner-Berry, Hou, & Ching, 2017). ANSD site of lesion can include missing or disordered inner hair cells (IHCs), disordered synapses between IHCs and type 1 afferent neurons, and disordered propagation of neural signals along the auditory nerve (Moser & Starr, 2016).

1.2.2. Diagnosis

ANSD is diagnosed using several electrophysiological tests. The key features of ANSD include functioning cochlear outer hair cells (OHCs) indicated by the presence of otoacoustic emissions (OAEs) and presence of a cochlear microphonic (CM), determined through auditory brainstem response (ABR) testing, combined with absent or abnormal ABR waveforms (Gardner-Berry et al., 2017; Rance & Starr, 2015). However, OAEs may be absent in children with ANSD in approximately 50% of cases (Rance et al., 1999). Additionally, tympanometry should be used to exclude the presence of middle-ear pathology which may reduce OAEs or the CM due to a conductive component (Berlin, Hood, Morlet, Rose, & Brashears, 2003; Gardner-Berry et al., 2017). Acoustic reflexes are often absent or elevated due to disordered propagation of auditory information along the auditory nerve (Berlin et al., 2003).

The absent or abnormal brainstem activity characteristic of ANSD means that ABR cannot be used to predict hearing thresholds. Therefore, behavioural measures of hearing, visual reinforcement audiometry (VRA) or play audiometry, must be used. This can result in a delay in obtaining behavioural thresholds because it is usually not possible to conduct VRA with an infant until they are approximately 6 months mental age or 8 months developmental age (Moore, Thompson, & Folsom, 1992). ANSD can also develop later in childhood (Gardner-Berry et al., 2017). In this case, speech discrimination testing can be used to support a diagnosis (Moser & Starr, 2016). If a child's speech discrimination ability is poorer than what is predicted by their behavioural hearing thresholds, possibility of ANSD may be investigated (Gardner-Berry et al., 2017; Moser & Starr, 2016).

1.2.3. Treatment

The difficulty obtaining accurate hearing thresholds for patients with ANSD using electrophysiologic techniques means there can be a delay in amplification until behavioural threshold testing is possible (Teagle et al., 2010). Due to the variable nature of ANSD, amplification using hearing aids has previously been disregarded as a beneficial treatment approach (Berlin, Hood, Hurley, & Wen, 1996). This was challenged by Rance et al. (2002) who found that there was a significant improvement in speech perception in a considerable proportion of children with ANSD with hearing aid use (Rance, Cone-Wesson, Wunderlich, & Dowell, 2002). However, it is difficult to predict whether children with ANSD will benefit from hearing aid use (Uus, Young, & Day, 2015).

Children with ANSD may benefit from cochlear implants (CIs) (Breneman, Gifford, & DeJong, 2012; Teagle et al., 2010). CIs are usually considered after a three to six month trial of hearing aids where there is no benefit (Teagle et al., 2010). Long-term benefits for implanted children with ANSD are similar to those of implanted children with a non-ANSD sensorineural hearing loss with improved speech perception abilities (Breneman et al., 2012).

There is a better prognosis for CI outcomes in children with intact auditory nerve function (Breneman et al., 2012; Teagle et al., 2010).

1.2.4. Parental Experience of ANSD Diagnosis

A diagnosis of ANSD is often given while the family and child are dealing with several other health problems and decisions. Therefore, for most parents, ANSD is not a priority at the time of diagnosis (Uus, Young, & Day, 2012). ANSD becomes more of a priority when other health difficulties resolve and when ANSD symptoms manifest more obviously as the child matures (Uus et al., 2012). Uus et al. (2012) found that the majority of parents in their study felt that, long-term, ANSD was the worst of their health concerns. Parents also reported feeling guilty and sad that they had ignored the potential consequences and seriousness of ANSD because their child's other diagnoses felt more concerning in the short-term (Uus et al., 2012).

Parents of children diagnosed with ANSD report having a poorer understanding of the diagnosis compared to parents of children with a non-ANSD sensorineural hearing loss (Stroebel & Swanepoel, 2014). Generally, parents feel overwhelmed and confused following a diagnosis of ANSD (Uus et al., 2012) and often turn to the internet for assistance and advice (Porter & Edirippulige, 2007; Uus et al., 2012). The difficulty parents face understanding a diagnosis and the potential consequences of ANSD highlights the need for audiologists to support families and provide them with suitable information and resources.

1.3. Sources of Health Information

There are several sources from which individuals can obtain health information (Dutta-Bergman, 2004). An individual's doctor or primary health care provider plays a critical role in providing health information and support (Fox & Duggan, 2013). Health information can also be obtained through printed written materials such as flyers, booklets, brochures,

newspapers, and magazines (Dutta-Bergman, 2004). Health professionals often use printed written health information to support verbal information given to patients (Shieh & Hosei, 2008). Written health information can also be accessed online (Schiavo, 2008).

Health information may be sought out through interpersonal networks, or friends and family (Dutta-Bergman, 2004). Fox and Duggan (2013) reported that 39% of adults sought health information on behalf of someone else, while Elkin (2008) found that 29% of adults talked to friends, family, or co-workers to gain health information. This indicates that individuals seek health information and exchange it with others. Health information seeking and exchange may occur online, including through social media (Elkin, 2008; Fox & Duggan, 2013). Fox and Duggan (2013) reported that 26% of internet users had watched or read information on someone else's health experience. They also found that 16% reported seeking out others who had similar health concerns online.

Another health information channel, which is gaining popularity, is audio-visual information (Ahmed, Alike, & Keselman, 2015). Audio-visual information is often accessed online has been found to improve the recall of health information in both younger and older adults, compared to web-based written information (Bol, van Weert, de Haes, Loos, & Smets, 2015). In particular, audio-visual information in a conversational style increases information recall compared to audio-visual information in a formal style and written information in a conversational style (Bol et al., 2015). Similarly, Björklund, Marsk, Levin, and Öhman, (2011) found that using a video to supplement verbal and written information increased knowledge and informed choice on Down Syndrome screening compared to verbal and written information alone. Therefore, audio-visual health information can successfully supplement both verbal and written health information. Additionally, promoting understanding and accurate information recall through the use of audio-visual materials may improve the accuracy of health information exchange through interpersonal networks.

1.3.1. Supporting Verbal Health Information

Memory for health information is often poor and inaccurate (Kessels, 2003). Medical information and advice given by healthcare professionals, including audiologists, should be supported by written information to improve knowledge and understanding (Kessels, 2003; Little, Griffin, Kelly, Dickson, & Sadler, 1998; Morris & Halperin, 1979). Audio-visual information can also be used to improve recall and understanding of health information (Björklund et al., 2011; Bol et al., 2015) and supplement both verbal and written health information. The use of the internet as a source of supplementary written health information is steadily rising (Lin, Zhang, Song, & Omori, 2016) and audio-visual health information is gaining popularity (Ahmed et al., 2015). Health professionals can recommend suitable online information or patients and their families can access information in relation to a specific question or issue. Therefore, it is important to know whether online health information, particularly information on ANSD, promotes understanding.

1.4. Online Health Information

1.4.1. Rise and Use of Online Health Information

The growth of the internet has allowed individuals to readily search and access online health and medical information (Schiavo, 2008). There has been a steady rise in the number of people who use the internet to learn about prevention of disease, healthcare, rehabilitation, and other health information (Lin et al., 2016). The majority of searches for online health information are made to clarify medical information (Pletneva, Cruchet, Simonet, Kajiwara, & Boyer, 2011). Those who search for health information online generally look for specific answers to questions (Fox & Rainie, 2002).

The internet is used to access health information worldwide. Fox and Duggan (2013) reported that 59% of American adults sought health information online from 2012-2013. In

most cases, the internet was used to help themselves or their loved ones increase understanding of a health condition. Likewise, Kontos, Blake, Chou, and Prestin (2014) found that nearly 80% of American adults who used the internet had searched online for health information for themselves and 57.04% had searched for online health information for someone else. Similar results were outlined in the 2001 Pew Internet Health Report (Fox & Rainie, 2002). Powell, Inglis, Ronnie, and Large (2011) reported data from a 2007 survey involving seven European countries. They found that 33.9% of citizens used online health information to decide if they should consult a health professional, 25.6% accessed online health information prior to an appointment, and 29.2% accessed online health information following an appointment. Additionally, Honey, Roy, Bycroft, Boyd, and Raphael (2014) investigated rates of online health information use among New Zealanders. They found that two thirds of participants had accessed online health information. High rates of online health information use were attributed to ease and speed of access. Half of internet users reported using the internet to access health information for themselves, while 26.8% reported seeking health information for someone else. The majority of participants (76.1%) found online health information useful or very useful.

Kontos et al. (2014) investigated engagement in online health activities, including searching for online health information, based on sociodemographic factors including ethnicity, socio-economic status (SES), age, and sex. They used data from the National Cancer Institute's 2012 Health Information National Trends Survey consisting of 3959 participants. Their findings indicated no difference in engagement in online health activities by ethnicity. However, they did find that lower SES, older age, and being male was associated with lower likelihood of using the internet to find health information (Kontos et al., 2014). Similarly, Fox and Rainie (2002) reported that women were more likely to use the internet to search for health information with no difference in use between ethnicity.

Individuals with more internet experience and those with a chronic health condition have been found to be more likely to search for health information (Bundorf, Wagner, Singer, & Baker, 2006; Fox & Rainie, 2002).

Parents also seek child health information on the internet (Khoo, Bolt, Babl, Jury, & Goldman, 2008; Uus et al., 2012). Knapp, Madden, Wang, Sloyer, and Shenkman (2011) found that 82% of parents in their study of 2371 participants were internet users and that 71% were able to access the internet from their home. Parents of children with special healthcare needs were more likely to seek out health information online in comparison to parents of children without these needs (Knapp, Madden, Wang, Sloyer, & Shenkman, 2011). It can be difficult for parents to find online health information that is relevant to their child due to a number of factors including growth, changing physiology, and development. Information aimed at adults often does not take these factors into consideration (Wainstein, Sterling-Levis, Baker, Taitz, & Brydon, 2006). However, many parents find the extra information they find online beneficial (Semere et al., 2003; Tuffrey & Finlay, 2002; Wainstein et al., 2006), with 94% of parents using the internet to seek further information on their child's condition finding it useful (Sim et al., 2007).

1.4.2. Benefits and Risks of Online Health Information

The abundance of online health information and ease of access means that a diverse range of individuals are able to readily search for information (Kreps & Neuhauser, 2010). Using the internet to access health information is convenient because people are able to search for information at any time of the day (Fox & Rainie, 2000). Individuals also feel that they have access to more health information online in comparison to other sources and like the anonymity (Fox & Rainie, 2000).

However, there is large variation in the credibility of health information online (Eysenbach, Powell, Kuss, & Sa, 2002). Publishers can post almost anything without having the accuracy approved (Morahan-Martin & Anderson, 2000). Therefore, inaccurate and potentially dangerous information may be accessed by online health users. Impicciatore, Pandolfini, Casella, and Bonati (1997) investigated the reliability of online information on child fever management. They found that some webpages provided potentially dangerous medical advice and only 9.8% of assessed webpages provided recommendations adhering to official guidelines. Similarly, Ioannidis, Stuart, Brownlee, and Strite (2017) reported when internet users search for answers to medical questions, about half of the websites which appear contain inaccurate information.

About half of online health seekers feel that the health information they are accessing online is mostly credible while the other half believe they can rely on only some of the health information available online (Fox & Rainie, 2000). Honey et al. (2014) found that 45% of New Zealanders who accessed online health information perceived online health information as ‘quite’ or ‘very’ trustworthy. The belief by many internet users that most online health information is credible or trustworthy combined with the inaccuracy of some information could be harmful.

1.4.3. Quality of Online Health Information

Quality of online health information is important to internet users and is the most significant barrier users face when seeking health information online (Pletneva et al., 2011). Most information published online is not moderated by health professionals, therefore some online health information is inaccurate and incomplete (Eysenbach et al., 2002). There appears to be more variation in the overall quality of online health information compared to printed material (Fitzmaurice & Adams, 2000). However, no significant difference on content,

writing style, readability, and design for online health information compared with printed patient education material has been found (Fitzmaurice & Adams, 2000).

1.4.3.1. HONcode Certification

With the increase in use of online health information (Lin et al., 2016), the variable quality of online health information (Eysenbach et al., 2002), and the previous lack of an online publication policy to ensure the quality of online health information, Health On the Net (HON) Foundation created a code of conduct (HONcode) (Boyer, Selby, Scherrer, & Appel, 1998). The HONcode proposes guidelines to content providers and aims to raise the quality of health information available online (Boyer et al., 1998). The HONcode also aims to identify websites which provide reliable and credible information (Boyer et al., 1998). If a webpage or website upholds the HONcode, the HON Foundation logo will be displayed on their webpage. There are more than 8000 websites in 102 countries which are HONcode certified (Health on the Net Foundation, 2013). However, this is a small proportion of the health information available online. Laplante-Lévesque, Brännström, Andersson, and Lunner (2012) found that only 14% of websites containing hearing-related information had HONcode certification.

The HONcode ensures webpages uphold the following principles: (1) authoritative: the qualifications of the authors are indicated, (2) complementarity: information should supplement information given by the clinician, not replace it, (3) privacy: the website should respect the privacy and confidentiality of personal information submitted by the user, (4) attribution: sources of published information are cited and medical or health webpages are dated, (5) justifiability: performance or benefit claims must be supported by appropriate evidence, (6) transparency: information is presented as clearly as possible and accurate contact details are given, (7) financial disclosure: funding sources are identified, and (8)

advertising policy: advertisements will be distinguished and it will be clear if advertising is a source of funding.

1.5. Health Literacy

1.5.1. Definition

In order to effectively use healthcare education materials an individual needs to possess health literacy skills. Health literacy requires the application of a complex cluster of literacy skills to the healthcare context (Glassman, 2013; Mackie, 2012). Health literacy is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services in order to make informed and appropriate health decisions" (p. 1; New Zealand Ministry of Health/Manatū Hauora, 2010). As an individual and their family navigate the healthcare system, there are a number of health literacy demands placed upon them. These demands include reading medical letters, reading written material that a healthcare professional may have given them, and asking questions if they do not understand something (Ministry of Health/Manatū Hauora, 2015).

Nutbeam (2000) proposed that health literacy involves 3 different types of literacy skills: (1) functional literacy: basic reading and writing skills required to function effectively day to day, (2) communicative literacy: advanced cognitive and literacy skills which facilitate active participation in situations and allow individuals to gain understanding and meaning from different communication methods and apply this to their changing circumstances, and (3) critical literacy: advanced cognitive and social skills used to critically analyse and use information to gain control over life situations (Nutbeam, 2000). Individuals who do not possess these essential literacy skills have low health literacy.

1.5.2. Low Health Literacy

Low health literacy is associated with poorer health outcomes including increased hospitalisations and emergency care, decreased ability to take medications correctly, and poor ability to interpret medical instruction and health messages (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004). Generally, patients with low health literacy are 1.5 to 3 times more likely to experience a poor health outcome when compared to people who are able to read at higher levels (DeWalt et al., 2004). Low health literacy also predicts poorer use of healthcare services overall (Berkman et al., 2011)

Low health literacy is associated with poorer comprehension and health-related knowledge (DeWalt et al., 2004). Additionally, it predicts poorer ability to evaluate the quality of online health information and whether or not it should be trusted (Diviani, van den Putte, Giani, & van Weert, 2015; Song, Zhao, Song, & Zhu, 2019). Low health literacy is also associated with lower desire to participate in health decision making (DeWalt, Boone, & Pignone, 2007). Health literacy skills are not always related to years of education or general reading skills (Glassman, 2013). The literacy skills required in a healthcare environment may be more demanding than those required in every-day contexts such as at home or work (Glassman, 2013). Therefore, healthcare providers should not assume an individual's health literacy skill level.

1.5.3. Prevalence

In a systematic review by Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, and Rudd (2005), about half of participants had low or marginal health literacy, with one in four having low health literacy. Level of health literacy is consistently associated with education level, ethnicity, and age (Paasche-Orlow et al., 2005). Studies which included participants with higher high-school graduation rates found lower prevalence of low health literacy.

Additionally, ethnic minority populations were found to have higher rates of low health literacy. Studies including participants with an average age of over 50 years found higher rates of low health literacy compared with studies including participants of a younger age (Paasche-Orlow et al., 2005). Low health literacy can also be associated with low income, lower self-assessed social status, and poorer health status (WHO, 2017). English as the first language and being female predicts better health literacy (Adams et al., 2009; Otal et al., 2012).

The New Zealand wide survey, 'Adult Literacy and Life Skills Survey' (Ministry of Health/Manatū Hauora, 2010), which measured literacy skill levels of the population, found that New Zealanders, on average, have limited health literacy with poor ability to obtain, process, and understand health information and services. Therefore, the ability of New Zealanders to make appropriate and informed health choices may be reduced. The survey also indicated that Māori have much poorer health literacy skills in comparison to non-Māori. This was the case regardless of level of education, age, gender, household income, and geographical region. This lower health literacy is likely to negatively impact Māori health outcomes (Ministry of Health/Manatū Hauora, 2010).

Low health literacy is common worldwide. Across Europe, rates of inadequate and problematic health literacy range from approximately 30% to 60% (WHO, 2017). Approximately one third of older adults in England have low health literacy, with difficulties understanding basic written health information (Bostock & Steptoe, 2012). Similarly, a study by Adams et al. (2009), including 2824 Australians, found that approximately half had low or inadequate health literacy. Results from the 2003 National Assessment of Adult Literacy indicated that one third of American adults also have basic or below basic literacy, indicating inadequate literacy for the healthcare setting (Cutilli & Bennett, 2009).

1.5.4. Parental Health Literacy

Lower online health literacy is more prevalent in parents who are of older age, have a lower education level, and are non-English speaking (Knapp et al., 2011). Kumar et al. (2010) found that many parents are not able to understand common health information or follow healthcare instructions for their infants (Kumar et al., 2010). In a systematic review of 215 articles by Sanders, Federico, Klass, Abrams, and Dreyer (2009), it was found that low health literacy in caregivers is common and poor preventative care and child health outcomes are more likely with low caregiver health literacy. Also, children with chronic illness being cared for by individuals with low health literacy were twice as likely to use health services than those with higher health literacy levels (Sanders et al., 2009).

1.5.5. Improving Health Literacy

The prevalence of low health literacy worldwide and the poor health outcomes associated with low health literacy indicate the importance of supporting and improving health literacy. Improving health literacy relies not only on the individual but various professionals involved in the healthcare journey (Brach et al., 2012). To promote health literacy, healthcare organisations should: (1) have health literacy as a key goal and consider it in all aspects of planning, evaluation, patient safety, and improvement, (2) prepare staff to be health literate, (3) consider the needs of the population in the creation and evaluation of health services and information, (4) strive to meet the needs of those with varied health literacy skills, (5) confirm patient understanding in all situations, (6) consider health literacy particularly in high-risk situations, (7) clear communication of available health services and what they will cost, (8) provide health information and services which are easy to access, and (9) create health information materials which are understandable and easy to act upon (Brach et al., 2012).

Suitable supplementary health information plays a key role in supporting health literacy. Health information should match the health literacy levels of the intended audience to promote comprehension and informed decision making. Health information, including written and audio-visual materials, which supports low health literacy is understandable, employs plain language principles, and communicates specific actions which should be taken (Brach et al., 2012; Campbell, Goldman, Boccia, & Skinner, 2004). Health information should also be written at the lowest level of reading difficulty possible (Weiss & Coyne, 1997). Health information that supports the health literacy of readers is important in the field of audiology, similar to other health fields, because of the difficulty patients have understanding both verbal information and patient education materials (Nair & Cienkowski, 2010). This is also important for parents or caregivers of children with ANSD because of the poorer child health outcomes associated with low caregiver health literacy levels (Sanders et al., 2009).

1.5.6. Self-Efficacy, Shared Decision Making, and Patient-Centred Care

Health literacy, particularly critical and communicative health literacy, is associated with greater patient self-efficacy (Inoue, Takahashi, & Kai, 2013; Osborn, Cavanaugh, Wallston, & Rothman, 2010) and understanding of healthcare information (Inoue et al., 2013). Difficult-to-read health information which is unsuitable for an individual's health literacy level can contribute to low self-efficacy (McMullan, Kelly-Campbell, & Wise, 2017). Improving the readability, content, language, layout, and organisation of health material can increase sense of self-efficacy (Donald & Kelly-Campbell, 2016). Self-efficacy is defined as an individual's confidence in their performance on a goal-directed task or behaviour (Bandura, 1990). According to Bandura (1982), self-efficacy is the result of a complex process of self-persuasion arising from cognitive processing of a range of different sources of efficacy information, including socially and physiologically. Self-efficacy is central to an

individual's exercise of personal agency (Bandura, 1990). Self-efficacy has been found to be significantly associated with improved self-management behaviours across race/ethnicity (Sarkar, Fisher, & Schillinger, 2006). Higher self-efficacy may also promote more active involvement in shared-decision making (Arora, Ayanian, & Guadagnoli, 2005).

Shared decision making is the process by which clinicians and patients make decisions through sharing the best available evidence. This process also involves the patient being supported to develop informed preferences (Elwyn et al., 2010). The goal of shared decision making is self-determination. However, patients are supported by the clinician on the road to self-determination where possible (Elwyn et al., 2012). Laplante-Lévesque, Hickson, and Worrall (2010a) found that patient involvement in decision making relied on several factors: (1) trust with the audiologist, (2) being provided different options, and (3) being informed and educated. Parents view shared decision making positively, as a partnership with between equals (Fiks, Hughes, Gafen, Guevara, & Barg, 2011). The clinician provides expert information and opinion while the family provides an in-depth knowledge of the child (Fiks et al., 2011). Parents with low health literacy have reported preferring less participation in decision making and would rather rely on the clinician to make decisions for them (Yin et al., 2012). Therefore, supporting health literacy by providing readable, reliable, and understandable written materials to enhance patient understanding is important for patient and parental participation in shared decision making (Mackie, 2012).

Shared decision making is an integral part of patient-centred care (Grenness, Hickson, Laplante-Lévesque, & Davidson, 2014; Laplante-Lévesque, Hickson, & Worrall, 2010a, 2010b). Patient-centred care entails quality health care in which each patient is seen as an individual with unique experiences and needs. In order to meet their needs, each patient should be informed and involved in health decisions, particularly if the individual suffers from a chronic condition (Grenness et al., 2014). Overall, patient-centred care is associated

with positive outcomes including patient health status, patient adherence to treatment, and patient and practitioner satisfaction (Grenness et al., 2014).

Supporting the health literacy of patients through effective patient education materials is important. Providing suitable resources can improve sense of self-efficacy (Donald & Kelly-Campbell, 2016), promote a more active role in shared decision making (Arora et al., 2005; Mackie, 2012), and improve implementation of the patient-centred care approach (Grenness et al., 2014; Laplante-Lévesque et al., 2010a, 2010b). This has the potential to improve self-management behaviours (Sarkar et al., 2006), patient and parental satisfaction (Fiks et al., 2011; Grenness et al., 2014), health outcomes, and adherence to treatment (Grenness et al., 2014). To be effective, patient education materials need to be understandable, actionable, reliable, and have suitable readability.

1.6. Readability

1.6.1. Definition

Readability indicates how easy it is for a person to read and understand a given material (Freda, 2005; Ley & Florio, 1996). Readability, and the level of reading ability, is often indicated by a reading grade level (RGL) which is given as the number of years of U.S. education required to understand the material (Ley & Florio, 1996). To support low health literacy and promote readability and understandability of health information, an RGL at or below the 5th or 6th RGL is recommended by the American Medical Association (Weiss, 2003).

1.6.2. Readability Formulas

Readability of materials can be analysed using formulas which offer an objective and quantifiable estimate of the reading difficulty (Gemoets, Rosemblat, Tse, & Logan, 2004). Readability formulas use equations to predict the level of reading ability that would allow the

reader to understand a particular piece of text (Ley & Florio, 1996). The formulas often analyse one or more of the following aspects of the text: (1) average word length in syllables, (2) average sentence length in words, (3) proportion of common words, (4) proportion of words with three or more syllables, and (5) proportion of monosyllabic words (Ley & Florio, 1996). Readability formulas are validated using a criterion variable which is often a set of text passages with a specified RGL (Ley & Florio, 1996).

Readability formulas are commonly used on health information (Ley & Florio, 1996). Common readability formula used on health information include the Gunning Fog Index (FOG), Simple Measure of Gobbledygook (SMOG), Flesch Reading ease (FRE), Flesch-Kincaid Grade Level (F-K), Fry, and Dale-Chall Formula (Ley & Florio, 1996). Ley & Florio (1996) recommend that several readability formulas be used to give an average RGL because this is more reliable than an RGL estimate given by a single formula. Therefore, three readability formulas will be used to analyse webpages on ANSD in the present study: (1) FOG, (2) SMOG, and (3) F-K.

1.6.2.1. Gunning Fog Index

Gunning (1952) developed the FOG which calculates reading grade level using two variables; (1) average sentence length and (2) number of words with more than two syllables per 100 words (DuBay, 2004). The FOG formula was developed based on a 90% comprehension score with McCall-Crabbs reading tests (DuBay, 2004). FOG RGL is calculated using the following formula (DuBay, 2004):

$$\text{Grade} = 0.4 + (average\ sentence\ length + complex\ words)$$

1.6.2.2. Simple Measure of Gobbledygook

The SMOG formula calculates reading difficulty based on the number of polysyllabic words per 30 sentences (Mc Laughlin, 1969). To convert this number into a meaningful value,

McCall-Crabbs reading tests are used (Mc Laughlin, 1969). The SMOG is based on a 100% comprehension score (Wang, Miller, Schmitt, & Wen, 2013). The SMOG readability formula is best suited for the health care context because of the consistency of results, more recent validation, and the 100% comprehension estimate which supports understanding of healthcare information (Wang et al., 2013). The SMOG formula uses the following equation to estimate RGL (Mc Laughlin, 1969):

$$\text{Grade} = 3 + \sqrt{(polysyllabic\ word\ count) \times (30 \div number\ of\ sentences)}$$

1.6.2.3. Flesch-Kincaid Grade Level

The F-K readability formula was adapted from the FRE formula (Kincaid, Fishburne Jr, Rogers, & Chissom, 1975). The F-K RGL criteria is based on a criterion score of 35% on a cloze test which is the equivalent of 75% comprehension on McCall-Crabbs reading tests (Kincaid et al., 1975). The F-K estimates a lower RGL compared to the FRE formula, FOG, and SMOG (Wang et al., 2013). The F-K formula calculates RGL using the following formula (Kincaid et al., 1975):

$$\text{Grade} = (0.39 \times average\ no.of\ words\ per\ sentence) + (11.8 \times average\ no.of\ syllables\ per\ word) - 15.59$$

1.6.3. Readability of Hearing-Related Health Information

Swartz (2010) determined the mean RGL of eight patient information leaflets available for children with otitis media. They found that only four of the materials had a mean RGL of 8 or less, with none below the 5th RGL. Caposecco, Hickson, and Meyer (2014) assessed the readability of 36 hearing aid user guides for a range of technologies and styles and found that they were written at the 9th to10th RGL, on average. The majority of assessed hearing aid user guides had a mean RGL of 9 or higher (Caposecco et al., 2014).

Laplante-Lévesque, Brännström, Andersson, and Lunner (2012) evaluated the quality and readability of online information in English for adults with hearing loss and their significant others. They entered 2 search terms: (1) hearing loss and (2) hearing aids into several country-specific versions of Google. They assessed readability using three different readability formulas: (1) FRE, (2) F-K, and (3) SMOG. Across readability tools, online hearing-related information was above the recommended RGL. In general, 11 to 12 years of education would be required to read and understand the information (Laplante-Lévesque, Brännström, Andersson, & Lunner, 2012). Similarly, Laplante-Lévesque and Thorén (2015) conducted a systematic literature review on the readability of online hearing-related information which individuals with hearing impairment and their significant others are able to access. Their findings showed that, on average, people needed 9 to 14 years of education to read and understand the online hearing-related information.

Joury et al. (2018) assessed 35 websites on otitis media which parents or patients may have accessed when searching for information on otitis media. They concluded that there are easy-to-read webpages on otitis media, however, found that websites, on average, were written at the 9th/10th RGL. Similarly, Manchaiah et al. (2019) found online information on tinnitus was, on average, written at a level which requires 10 to 12 years of education to read and understand. Almost all of assessed online tinnitus information exceeded the recommended 6th RGL (Manchaiah et al., 2019). While the readability of online hearing-related information has been investigated, readability of online information on ANSD has not previously been assessed.

1.7. Content Assessment of Health Information

In addition to being readable, health information which is understandable, actionable, and employs plain language principles is important in supporting low health literacy (Brach et al., 2012; Campbell, Goldman, Boccia, & Skinner, 2004), sense of self-efficacy (Donald &

Kelly-Campbell, 2016), and participation in shared decision making (Arora, Ayanian, & Guadagnoli, 2005). Therefore, the content of materials should be assessed using additional tools. There are several tools which are designed to indicate how reliable and easy a piece of text is to read and understand. These tools assess a number of elements including quality of information, use of instructions, visual aids, organisation, grammar, punctuation, use of text, and use of easy-to-understand language.

1.7.1. Plain Language Checklist

Using plain language when creating resources can help to support low health literacy. Plain language is a group of text characteristics which promote reading ease (Stableford & Mettger, 2007). Use of plain language is being promoted for communication with the public by health policy creators (Stableford & Mettger, 2007). WHO (2019) states that effective and understandable resources are essential to promote public understanding of health information. Plain language is a critical element of understandable health information (WHO, 2019).

Plain language consists of several key elements including: (1) arranging the content so the most important message comes first, (2) breaking information down into chunks, (3) use of simple language, (4) defining technical terms, (5) using an active voice, (6) short sentences, and (7) easy-to-read typography with plenty of white space (Kimble, 2002). One way to employ the use of plain language when creating health content is to use a plain language checklist (PLC). PLCs summarise the guidelines of the Plain Writing Act 2010. PLCs can also be used to assess whether or not an existing material uses plain language.

A systematic review by Grene, Cleary, and Marcus-Quinn (2017), which included 13 articles in which plain-language guidelines had been applied to health-information resources across several health contexts, found the use of plain language improved patient understanding of information. Additionally, in a study conducted by Otal et al. (2012), which

included 79 parents and aimed to assess parental satisfaction with plain language use in a patient education material on fever in a surgery outpatient clinic, parents expressed satisfaction with the plain language material regardless of health literacy level. The assessed materials were also described as easy to understand (Otal et al., 2012). A search of the literature revealed no previous assessment of the use of plain language in hearing-related health information or information on ANSD.

1.7.2. PEMAT

The Patient Education Materials Assessment Tool (PEMAT) has been developed to assess how understandable and actionable a piece of information is (Shoemaker, Wolf, & Brach, 2014). Materials are defined as understandable when "consumers of diverse backgrounds and varying levels of health literacy can process and explain key messages" (Shoemaker et al., 2014; pp.396). The PEMAT tool assesses content, word choice and style, use of numbers, organisation, layout and design, and use of visual aids to determine understandability. Materials are defined as actionable when "consumers of diverse backgrounds and varying levels of health literacy can identify what they can do based on the information presented" (Shoemaker et al., 2014; pp. 396). The PEMAT is the only tool which can objectively measure audio-visual (A/V) materials and has been found to have moderate to excellent inter-rater reliability overall (Vishnevetsky, Walters, & Tan, 2018). The PEMAT uses a scoring system of 0 to 100. PEMAT scores above 70% indicate more understandable and actionable materials (Wong, Gilad, Cohen, Kirke, & Jalisi, 2017).

The PEMAT has not been applied to the field of audiology, or health information on ANSD. However, it has been used to assess health information in related fields, for example, heart failure (Cajita, Rodney, Xu, Hladek, & Han, 2017), laryngectomy (Wong et al., 2017), and vocal cord paralysis (Balakrishnan, Chandy, Hseih, Bui, & Verma, 2016). The PEMAT will be used to assess the understandability and actionability of online information on ANSD

in the present study due to the importance of understandable and actionable health information in effective communication and supporting health literacy (Brach et al., 2012; WHO, 2019).

1.7.3. DISCERN

The DISCERN tool assesses the quality and reliability of materials and whether treatment recommendations are evidence-based (Charnock, Shepperd, Needham, & Gann, 1999). It is a standardised tool which can be used by health professionals, patients, and content producers (Charnock, Shepperd, Needham, & Gann, 1999). The DISCERN tool uses three sections to assess material (Charnock, 1999). Section one addresses the reliability of the material. It includes eight questions such as "are the aims clear?" and "Is it clear what sources of information were used to compile the publication (other than the author or producer)?" Section two aims to assess the quality of the information on treatment choices. Section two consists of seven questions including "Does it describe how each treatment works?" and "Does it describe how the treatment choices affect overall quality of life?" Section three addresses the overall rating of the material through one question; "Based in the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices." Each question is rated from one to five, with one being "No" or "Low" and five being "Yes" or "High."

1.7.3.1. Evaluation of Hearing-Related Health Information using the DISCERN

While the DISCERN tool has not been used to assess health information on ANSD, it has been applied to other areas of audiology. For example, a study by Ritchie, Tornari, Patel, and Lakhani (2016) investigated the readability and quality of online health information related to glue ear. The study included 27 relevant webpages. They found that there was significant variation in the quality of information on glue ear available online. Only 40% of webpages scored above four on the DISCERN, indicating that the majority of information is unlikely to

be of good quality or aid patients in treatment decision-making (Ritchie et al., 2016). Similarly, Joury et al. (2018) found highly variable quality across websites on otitis media, with material being, on average, of low to medium quality.

Online information on tinnitus was also found to have highly variable quality with a mean DISCERN score of 2.39 across assessed webpages, indicating low overall quality. No significant influence of type of organisation on DISCERN scores was found (Manchaiah et al., 2019). Similarly, a study by Laplante-Lévesque et al. (2012) which assessed online information on hearing-impairment for adults and their significant others found a mean DISCERN score of 2.04. Scores ranged from 1.13 to 3.93. However, it was found that websites originating from non-profit organisations (2.64) had a higher mean DISCERN score than those from commercial (1.88) or government organisations (1.90).

1.8. Study Rationale

Previous research indicates poor and highly variable readability and quality of online hearing-related health information (Laplante-Lévesque, Brännström, Andersson, & Lunner, 2012; Laplante-Lévesque & Thorén, 2015). The increasing use of the internet to seek health-related information (Amante, Hogan, Pagoto, English, & Lapane, 2015) combined with the difficulty parents have understanding a diagnosis of ANSD (Stroebel & Swanepoel, 2014) indicate that it is important to determine the readability, use of plain language, understandability, actionability, and quality of online information on ANSD. A systematic literature search revealed no existing literature investigating the readability, use of plain language, understandability, actionability, and quality of online information on ANSD. The results from this study could be used by healthcare professionals to guide recommendations on which resources parents of children with ANSD should access. Additionally, this information will be used to make recommendations for web-developers.

1.9. Research Aims and Hypotheses

The aim of this study was to examine the readability, use of plain language, understandability, actionability, and quality of online information on ANSD.

This study aimed to answer the following research questions:

1. Are there significant differences in the distribution of webpages on ANSD based on: (1) locality of hosting organisation, (2) type of hosting organisation, and (3) HONCode certification?
2. Are there significant differences in the readability of webpages on ANSD based on: (1) locality of hosting organisation, (2) type of hosting organisation, and (3) HONCode certification?
3. Is there a significant difference between the mean RGL of webpages on ANSD and the recommended 6th RGL?
4. Are there significant differences in the use of plain language for webpages on ANSD based on: (1) locality of hosting organisation, (2) type of hosting organisation, and (3) HONCode certification?
5. Are there significant differences in understandability and actionability of webpages on ANSD based on: (1) locality of hosting organisation, (2) type of hosting organisation, and (3) HONCode certification?
6. Are there significant differences in the quality of webpages on ANSD based on: (1) locality of hosting organisation, (2) type of hosting organisation, and (3) HONCode certification?

Based on these research questions, there are several null hypotheses:

1. There are no significant differences in the distribution of webpages on ANSD based on: (1) locality of hosting organisation, (2) type of hosting organisation, and (3) HONCode certification.

2. There are no significant differences in the readability of webpages on ANSD based on: (1) locality of hosting organisation, (2) type of hosting organisation, and (3) HONCode certification.
3. There is no significant difference between the mean RGL of webpages on ANSD and the recommended 6th RGL.
4. There are no significant differences in the use of plain language for webpages on ANSD based on: (1) locality of hosting organisation, (2) type of hosting organisation, and (3) HONCode certification.
5. There are no significant differences in understandability and actionability of webpages on ANSD based on: (1) locality of hosting organisation, (2) type of hosting organisation, and (3) HONCode certification.
6. There are no significant differences in the quality of webpages on ANSD based on: (1) locality of hosting organisation, (2) type of hosting organisation, and (3) HONCode certification.

2. Methods

2.1. Overview

This study examined the readability, plain language, understandability and actionability, and quality of online information on ANSD. First, relevant search terms were identified and input into several Google domains. The relevant webpages were analysed using various tools. RGL was determined through the use of three readability formulas: (1) F-K, (2) FOG, and (3) SMOG. Use of plain language was assessed using a checklist adapted from two existing PLCs: (1) Quick Checklist for Plain Language (Center for Health Literacy, 2012) and (2) Checklist for Plain Language on the Web (Plain Language Action and Information Network (PLAIN), 2019). Understandability and actionability was assessed using the PEMAT. Quality of treatment information was assessed using the DISCERN tool. HONcode certification was also used to indicate webpage quality.

2.2. Participants

In order to identify relevant search terms, participants were recruited through social media (Facebook) and email. Participants needed to be over 18 years old and fluent speakers of English. Prior knowledge of hearing or hearing healthcare was not required. Participants were asked to fill out an online survey which took approximately 10 minutes. Ethics approval was granted by the Human Ethics Committee (see appendix 1).

2.3. Search Term Identification

The recruited participants were asked to follow a link to an anonymous survey created using Qualtrics. Participants were required to input demographic information into the survey: (1) age, (2) gender, (3) ethnicity, and (4) highest level of education achieved (for example, ‘High School’ or ‘Bachelor’s Degree’). Initially, a pilot survey was distributed which asked; “If you had a child who didn’t pass their newborn hearing screening and was given a diagnosis

of auditory neuropathy spectrum disorder, which search terms would you put into Google?" This survey question resulted in the identification of Google search terms which were irrelevant to the topic of interest. As a result, the survey question was edited to be more easily interpreted. The survey was redistributed with the following question; "If you had a child who was diagnosed with a type of hearing loss called auditory neuropathy spectrum disorder at birth, what words or phrases would you put into Google to find out more? Please write a word or phrase in the boxes below." Participants were required to list one to eight search terms.

Recruitment continued until search term saturation was reached. The most common identified search terms related to ANSD were further analysed using Google Trends (google.com/trends). Google Trends indicates the search frequency for a particular search term based on geographical region. It also identifies popular related search terms.

2.4. Internet Search

2.4.1. Google Domain Inclusion

For the internet search, Google domains were selected based on whether the countries used English as an official language and/or used English for commerce. To do this, all countries with a Google domain were recorded from list of regions available in the 'Advanced Search' settings in Google. Next, countries which used English as an official language were determined using data from the CIA World Factbook (Central Intelligence Agency, 2007). There were 66 English speaking countries, with a total of 1,420,288,344 internet users. To reduce the number of domains, countries with less than 2 million internet users were excluded (Internet World Stats, 2019). This resulted in 21 countries. The following details were recorded for each country: (1) region, (2) internet penetration rate, (3) total number of internet users.

Table 1. Countries with more than 2 million internet users in which English is an official language and/or is used for commerce.

Country	**Region**	**Internet Penetration Rate**	**Population of Internet Users**
Kenya	Africa	83.0%	43,329,434
Liberia	Africa	80.9%	4,028,418
South Africa	Africa	53.7%	31,185,634
Sudan	Africa	27.8%	11,816,570
Tanzania	Africa	37.8%	23,000,000
Uganda	Africa	41.6%	19,000,000
Zimbabwe	Africa	39.3%	6,796,314
Cameroon	Africa	24.2%	6,128,422
United States	Americas	89.2%	292,892,868
Canada	Americas	92.7%	34,558,385
Puerto Rico	Americas	83.3%	3,047,311
United Kingdom	Europe	94.2%	63,061,419
Ireland	Europe	91.9%	4,453,436
India	South-East Asia	40.9%	560,000,000
Indonesia	South-East Asia	53.2%	143,260,000
Philippines	South-East Asia	62.0%	67,000,000
Malaysia	South-East Asia	80.1%	26,009,000
Australia	Western Pacific	87.8%	21,743,803
Hong Kong	Western Pacific	89.4%	6,698,252
Singapore	Western Pacific	84.5%	4,955,614
New Zealand	Western Pacific	88.1%	4,184,520
Total in study			**1,377,149,400**
Percentage in study			**97%**

2.4.2. Webpage Inclusion and Exclusion Criteria

For each Google domain, the first 10 webpages which appeared in the search were included. Webpages were included if they: (1) were written in English, (2) provided relevant information about ANSD, and (3) were available to the general public. Webpages were excluded if they: (1) contained paid advertisements or were not open access because of a paywall, (2) were a directory listing, or (3) were less than 100 words in length. These

exclusion criteria were required to ensure all webpages could be analysed using readability formulas and content assessment tools.

2.4.3. Procedure

In Google settings, the Google domain for each country was selected. The search terms were input into each Google domain individually. The first 10 webpages from each Google domain which met the inclusion and exclusion criteria were included for further assessment. The first 10 webpages were selected based on previous research which showed that internet users primarily access the first page of a Google search, which includes 10 webpages, when searching online (Eysenbach & Köhler, 2002). Upon completion of the search, duplicate webpages were removed before further assessment. Only relevant webpages on the included websites underwent readability analysis and content assessment. If relevant, internal links to other webpages were included. External links were not included. The search was conducted on 17th June 2019 using a Chrome browser on a Hewlett-Packard laptop with a Windows 10 Home operating system. An incognito Chrome tab was used to ensure that previous hearing-related search history did not bias the search results.

The following details were recorded in a Microsoft Excel spreadsheet for each webpage: (1) the Uniform Resource Locator (URL), (2) locality of hosting organisation, (3) type of hosting organisation, and (4) HONcode certification. Type of organisation specifies whether the organisation was 'commercial' or 'other' (government, non-profit, or personal/blog). The type of organisation was determined through the URL or the 'About Us' page on the website. Commercial webpages were classified as including advertisements. Government webpages were classified as being created by a government agency. Non-profit webpages were classified as those which were verified as non-profit on the 'About Us' page on the website or through further investigation online. Country of origin was also indicated by the URL or information on the 'About Us' webpage. If a country of origin could not be determined, a further internet

search was made to gather information. Webpages which were multi-lingual or aimed at a global audience were classified as world.

2.5. Health on the Net (HON) Certification

HONcode certification was used to indicate the quality of information on each webpage. HONcode certification was determined by pasting the URL of each included webpage into the HONsearch page (https://www.hon.ch/HONsearch/Patients/hunt.html). Only HONcode certified websites appeared in the search. HONcode certification was recorded as 'present' or 'absent' in a Microsoft Excel spreadsheet.

2.6. Readability Analysis

Each included webpage was analysed using three readability formulas: (1) FOG, (2) SMOG, and (3) F-K. This was done by copying the content of each webpage into a free online English readability tool (https://www.online-utility.org/english/readability_test_and_improve.jsp). The three calculated RGLs for each webpage were recorded in a Microsoft Excel spreadsheet. Mean RGL was calculated for each webpage.

2.7. Plain Language Analysis

The content of each webpage was assessed using the PLC which was developed by the University of Canterbury (UoC) Readability Thesis Group (adapted from: Quick Checklist for Plain Language (Center for Health Literacy, 2012) and Checklist for Plain Language on the Web (PLAIN, 2019)). The scores were input into a Microsoft Excel spreadsheet.

2.8. PEMAT

The understandability and actionability of each webpage was assessed using the PEMAT. The PEMAT was revised by the UoC Readability Thesis Group in order to maximise inter-rater reliability. The PEMAT consists of several items under two categories: (1)

understandability and (2) actionability.' Each applicable item was scored using 0 or 1 to indicate the absence or presence of each PEMAT item.

2.9. DISCERN

The quality of treatment information was assessed using the DISCERN tool. The DISCERN tool includes three sections consisting of several criteria: Section 1: is the publication reliable? Section 2: how good is the quality of information on treatment choices? and Section 3: overall rating of the publication. Each item was rated using a scale of 1 to 5. A score of 1= No, 2-4= Partially, and 5= Yes. Section 3 asked the rater to give an overall rating based on the ratings given in sections 1 and 2. The overall rating for each webpage was input into a Microsoft Excel Spreadsheet.

2.10. Inter-rater Reliability

Several steps were taken in order to establish and assess inter-rater reliability. Firstly, three practice articles were rated by the lab group using the PLC and PEMAT. The intraclass correlation (ICC) kappa values were used to indicate which measures needed improvement of inter-rater agreement. Secondly, webpages were selected for the reliability check consisting of 20% of webpages from each region. A random number generator was used to select webpages. Webpages were distributed among the research team as evenly as possible for the reliability check, with each researcher analysing 18 to 19 webpages. The reliability check was carried out in two rounds. In the first round, each researcher rated four of their own webpages and four from other researchers in the research group using the PLC, PEMAT, and DISCERN tool. Once reliability was established, the second round of reliability checks were carried out. In the second round, the remaining webpages assigned to each researcher were rated.

2.11. Statistical Analysis

The dependent variables in this study were the mean RGL, use of plain language, PEMAT score, and DISCERN score. The independent variables were location, type of organisation, and HONcode certification. For data analysis, locality of hosting organisation was grouped into four overall regions: (1) Americas, (2) Europe, (3) Western Pacific, and (4) World. Type of organisation was grouped into two overall groups: (1) commercial, and (2) other.

The data was analysed using IBM SPSS Statistics 25. Assumptions of normality were tested to ensure parametric testing was able to be carried out on the data. As a result, two statistically significant outliers were trimmed from the dataset and research questions associated with HONcode certification were removed. To answer the research questions, several statistical analyses were carried out: (1) intraclass correlation coefficient (ICC), (2) chi-square test, (3) analysis of variance (ANOVA), and (4) single-sample t-test. ICC was used to examine inter-rater reliability for PLC, PEMAT, and DISCERN ratings. A Chi Square goodness of fit was conducted to determine any significant differences in the distribution of webpages based on location and type of organisation. A chi-square test of independence determined whether the distribution of location and type of organisation were independent from each other. A series of univariate ANOVAs examined if there were any significant differences between (1) mean RGL, (2) use of plain language, (3) PEMAT scores, and (4) DISCERN scores based on location and type of organisation. A single-sample t-test was used to determine if there was a significant difference between mean RGL and the recommended 6^{th} RGL.

3. Results

3.1. Overview

This study aimed to assess the content of online information on ANSD in the English language using several tools: (1) PLC, (2) PEMAT, and (3) DISCERN. A mean RGL was obtained for each webpage. This study also aimed to compare the readability, use of plain language, understandability and actionability, and quality of information and treatment recommendations based on locality of hosting organisation, type of organisation, and presence or absence of HONcode certification.

3.2. Survey Outcomes

A total of 10 participants took the search term survey before saturation was reached. Search terms which were not relevant to the topic of interest or were too broad were eliminated. The remaining search terms were grouped by similarity. These groups of search terms were then compared in Google Trends. Search terms were listed in descending order of popularity within each of the groupings. The groups were ordered by relevance to the topic of interest. This gave three groups of search terms: Group 1: auditory neuropathy spectrum disorder, auditory disorder, auditory neuropathy, Group 2: hearing loss in children, infant hearing loss, and Group 3: hearing loss. The search terms were input into each Google domain in order of group and popularity within each group.

3.3. Inter-Rater Reliability

The first round of reliability checks showed fair to excellent agreement across ratings for the PLC, PEMAT, and DISCERN. The second round of reliability checks yielded average ICC values which indicated excellent agreement beyond chance for the following measures: (1) PEMAT understandability (ICC kappa = .905), (2) PEMAT actionability (ICC kappa = .887),

and (3) PLC (ICC kappa = .901) (Fleiss, 1981). The average ICC measure for DISCERN (ICC kappa = .682) indicated good agreement beyond chance (Fleiss,1981).

3.4. Location and Type of Organisation

For each webpage, the location and type of hosting organisation was recorded. To ensure relatively equal sample sizes from each region, webpages were grouped into four regions: (1) The Americas (n = 16, 25%), Europe (n = 15, 23.4%), Western Pacific (n = 15, 23.4%), and World (n = 18, 28.1%). World included webpages originating from Africa, South East Asia, and any webpages which were aimed at a global audience or contained multiple languages. Similarly, webpages were grouped into two different types of hosting organisations: (1) commercial (n = 38, 59.4%) and (2) other (n = 26, 40.6%). 'Other' included webpages with hosting organisations which were non-profit, government, and personal/blogs. These data are shown in Figure 1.

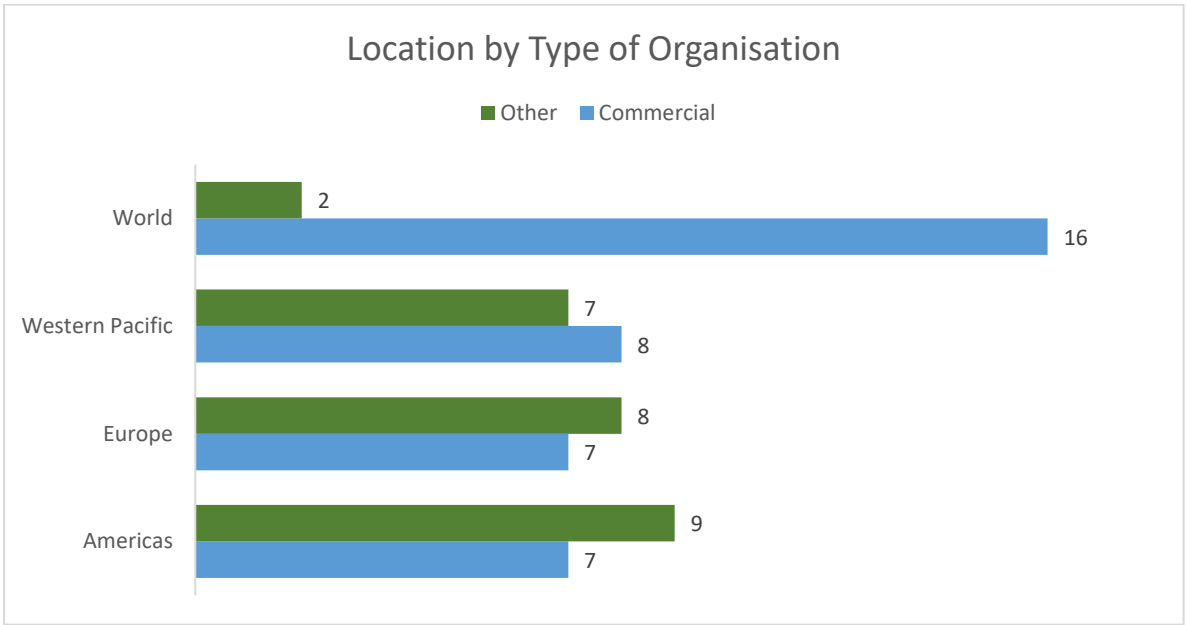

Figure 1. Number of webpages from each location and type of organisation.

3.5. Distribution Based on Location and Type of Organisation

This study aimed to answer the following research questions:

1. Are there significant differences in the distribution of webpages on ANSD based on locality of hosting organisation?
2. Are there significant differences in the distribution of webpages on ANSD based on type of hosting organisation?

To determine whether the distribution of webpages on ANSD was significantly different based on location and type of organisation, a chi-square goodness of fit test was performed. There was no significant difference in the distribution of webpages on ANSD based on location, $\chi 2$ (3, N = 64) = .375, p = .966. Similarly, no significant difference in the distribution of webpages on ANSD based on type of organisation was found, $\chi 2$ (1, N = 64) = 2.250, p = .169. Therefore, the null hypothesis that there would be no significant difference in the distribution of webpages based on location or type of organisation was supported. A chi-square test of independence was also conducted to determine if there was an independent relationship between location and type of organisation. A significant relationship between location and type of organisation was found $\chi 2$ (3, N = 64) = 9.351, p = .025.

3.6. HON Certification

Only one webpage (0.64%) of the total 64 webpages was recorded as having HONcode certification. This webpage was government run by the Ministry of Health, Malaysia. This lack of variance resulted in the removal of all null hypotheses associated with HONcode certification.

3.7. Testing Statistical Assumptions

Initial descriptive statistics revealed several statistically significant outliers for the PEMAT actionability subscale. To reduce the number of outliers, PEMAT subscales were combined to give a total PEMAT score. The remaining two outliers were then trimmed from the dataset to allow parametric statistical tests to be carried out. A total of 64 webpages remained.

3.8. Readability

Several RGLs were calculated: (1) FOG (*M* =14.91, *SD* =3), (2) SMOG (*M* =13.89, *SD* =2.19), and (3) F-K (*M* =12.78, *SD* =2.82). An overall mean RGL was calculated from FOG, SMOG, and F-K data. Overall mean RGL ranged from 7.96 to 21.45 (*M* =13.86, *SD* = 2.66).

3.8.1. Mean RGL and Recommended RGL

A single-sample t-test was conducted to determine whether there was a significant difference between the mean RGL of webpages on ANSD and the recommended 6th RGL. The mean RGL for webpages on ANSD was significantly higher than the recommended 6th RGL, $t(64) = 23.68$, $p < .001$. This result did not support the null hypothesis that there would be no significant difference between the mean RGL for webpages on ANSD and the recommended 6th RGL.

3.8.2. Readability Based on Location and Type of Organisation

This study aimed to answer the following research questions:

1. Is there a significant difference in readability of webpages on ANSD based on locality of hosting organisation?
2. Is there a significant difference in readability of webpages on ANSD based on type of hosting organisation?

The influence of location and type of organisation on readability was assessed using a two-way ANOVA. Type of organisation consisted of two levels: (1) commercial and (2) other. Location consisted of four levels: (1) Americas, (2) Europe, (3) W Pacific, and (3) World. There was no significant interaction between location and type of organisation, $F(3, 56) = .575$, $p = .634$, $\eta_p^2 = .030$. There were no significant main effects for location ($F(3,56) = .140$, $p=.936$, $\eta_p^2 = .074$) or type of organisation ($F(1,56) = .000$, $p = .994$, $\eta_p^2 = .050$). Therefore, the following null hypotheses were supported: there are no significant differences

in readability of webpages on ANSD based on (1) location or (2) type of organisation. These data are shown in Figure 2.

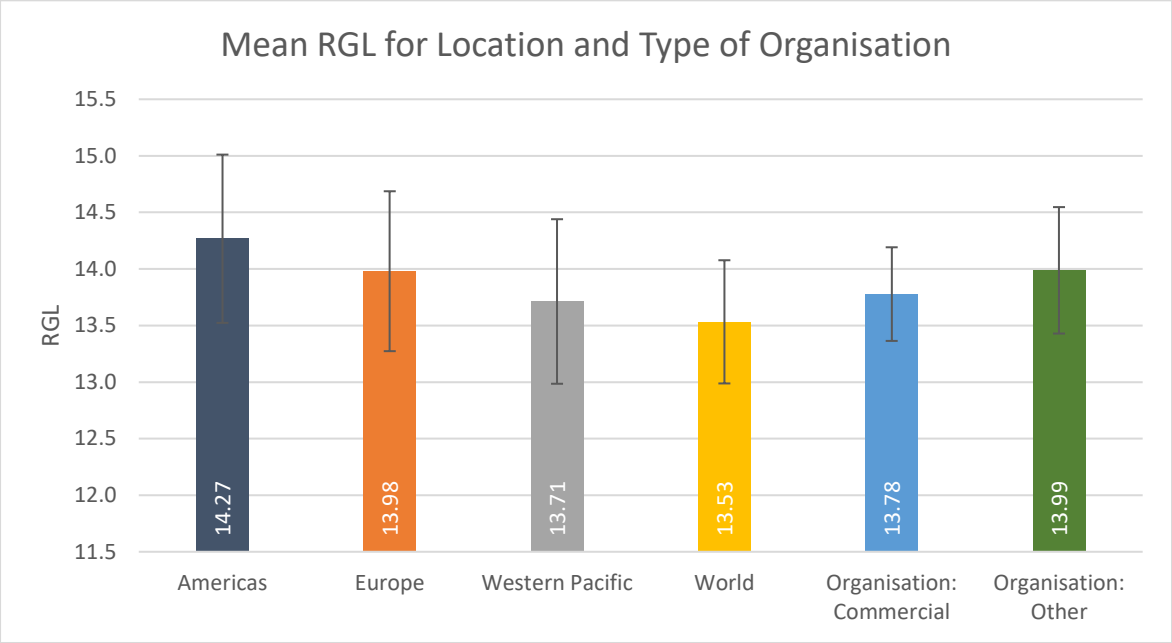

Figure 2. Mean reading grade level (RGL) based on location and type of organisation. Error bars represent one standard error.

3.9. Plain Language

Use of plain language scores ranged from 7 to 20 (M = 12.32, SD = 2.52). The maximum possible score for plain language was 20, with higher numbers indicating better use of plain language. Plain language scores for each PLC item are shown in Table 2. 'Yes (%)' refers to the percentage of webpages which contained each PLC item.

Table 2. Summary of webpages which met each plain language criterion. N indicates the number of webpages for which each Plain Language Checklist item was applicable.

Plain Language Checklist		
	N	Yes (%)
Reader Focus		
Does one or more of the headings contain the topic of interest?	64	90.63%
Does the introduction (first paragraph) inform the reader what they are about to read?	64	68.75%
Is the content relevant to the topic of interest?	64	95.31%
Organisation		
Does the material begin with the most important message of that webpage/video?	64	48.44%
Is the content arranged in a sensible order?	64	90.63%
Are different topics grouped under separate headings or subheadings?	64	51.56%
Writing		
Are personal pronouns such as "you" and "we" used throughout?	64	10.94%
Is an active voice used throughout?	64	51.56%
Are lay terms predominately used throughout?	64	21.88%
If technical terms are used, are they explained?	64	18.75%
Are simple sentences used throughout (i.e. no more than one new idea per sentence)?	64	10.94%
Is correct grammar and used throughout?	64	89.06%
Is correct punctuation used throughout?	64	87.50%
Are unnecessary words eliminated (e.g. technical jargon or adverbs)?	64	31.25%
Design & Formatting		
Is the appearance of the material consistent throughout (i.e. consistent use of fonts, italics, bold print, colour, and bullet points)?	64	98.44%
Does the material look easy to read, with an uncluttered layout, plenty of white space, and dark text on a light background or light text on a dark background?	64	76.56%
Are the fonts clean in their design and easy to read (not fancy or unusual, e.g. Arial)?	64	100%
Is the text size large enough for easy reading and does each line have about 10-15 words?	64	75%
Are italics, underlining, capitalisation, and bold print used sparingly?	64	96.88%
Are images clear and uncluttered and related to the content?	25	68.00%

3.9.1. Plain Language Based on Location and Type of Organisation

This study aimed to answer the following research questions:

1. Is there a significant difference in the use of plain language for webpages on ANSD based on locality of hosting organisation?
2. Is there a significant difference in the use of plain language for webpages on ANSD based on type of hosting organisation?

A two-way ANOVA was conducted to determine the effects of locality of hosting organisation and type of hosting organisation on use of plain language for webpages on ANSD. There was no significant interaction between location and type of organisation, $F(3, 56) = .270$, $p = .847$, $\eta_p^2 = .014$. There were no significant main effects for location ($F(3,56) = .370$, $p = .775$, $\eta_p^2 = .019$) or type of organisation ($F(1,56) = 1.620$, $p = .210$, $\eta_p^2 = .028$). Therefore, the following null hypotheses were supported: there are no significant differences in the use of plain language for webpages on ANSD based on (1) location or (2) type of organisation. Mean PLC scores based on location and type of organisation are displayed in Figure 3.

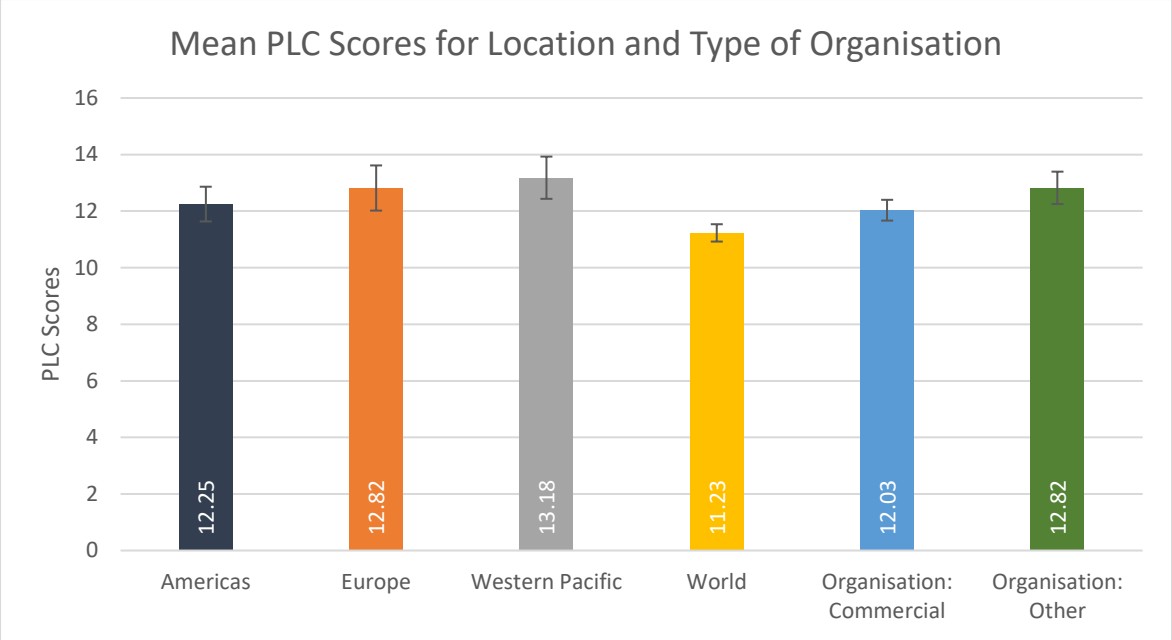

Figure 3. Mean plain language checklist (PLC) scores based on location and type of organisation. Plain language scores could range from 0 to 20. Error bars represent one standard error.

3.10. PEMAT

The PEMAT was scored using two separate subscales: (1) understandability and (2) actionability. These subscales were combined to give an overall PEMAT score. PEMAT scores ranged from 16.7% to 76.19% (M= 40.43%, SD= 13.82%). Scores for each PEMAT item are shown in Table 3.

Table 3. Percentage of webpages which scored "yes" for each Patient Education Materials Assessment Tool (PEMAT) item. P (print) indicates items which were applicable to printable materials. A/V (audio-visual) indicates items which were applicable to materials with audio-visual content. N indicates the number of webpages for which each item of the PEMAT was applicable.

Understandability		
	N	Yes (%)
Topic: Content		
1. Purpose evident (P and A/V)	64	83.21%
Topic: Word Choice and Style		
2. Information or content does not distract from purpose (P)	64	78.13%
3. Common, everyday language (P and A/V)	64	23.44%
4. Medical terms used only to familiarise and are defined (P and A/V)	64	15.63%
5. Active Voice (P and A/V)	64	54.69%
Topic: Use of Numbers		
6. Numbers clear and easy to understand (P)	52	63.46%
7. No calculations (P)	64	98.44%
Topic: Organisation		
8. "Chunked" information (P and A/V)	64	84.38%
9. Informative headers (P and A/V)	64	46.88%
10. Logical sequence (P and A/V)	64	92.19%
11. Summary (P and A/V)	64	37.50%
Topic: Layout & Design		
12. Visual cues to highlight key points (P and A/V)	64	6.25%
13. Clear on-screen text (A/V)	0	0%
14. Clear words (A/V)	1	100%
Topic: Use of visual aids		
15. Visual aids whenever possible to make content more easily understood (P)	64	7.81%
16. Visual aids reinforce content (P)	34	58.82%
17. Visual aids have clear titles or captions (P)	35	45.71%
18. Visual aids are clear and uncluttered (P and A/V)	27	62.96%
19. Simple tables with short and clear headings (P and A/V)	17	47.06%
Actionability		
1. At least one action the user can take (P and A/V)	64	17.19%
2. Addresses user directly when describing actions (P and A/V)	64	12.50%
3. Breaks down actions into manageable, explicit steps (P and A/V)	64	3.13%
4. Provides a tangible tool (P)	64	0%
5. Explains how to use charts, graphs, tables, or diagrams to take actions (P and A/V)	0	0%
6. Visual aids make it easier to act on the instructions (P)	64	0%

3.10.1. PEMAT Scores Based on Location and Type of Organisation

This study aimed to answer the following research questions:

1. Is there a significant difference in understandability and actionability of webpages on ANSD based on locality of hosting organisation?
2. Is there a significant difference in understandability and actionability of webpages on ANSD based on type of hosting organisation?

A two-way ANOVA was conducted to determine the effects of locality of hosting organisation and type of hosting organisation on understandability and actionability of webpages on ANSD. There was no significant interaction between location and type of organisation, $F(3, 56) = .866$, $p = .464$, $\eta_p^2 = .044$. There were no significant main effects for location ($F(3,56)= 1.930$, $p=.135$, $\eta_p^2 = .094$) or type of organisation ($F(1,56)= 3.000$, $p=.089$, $\eta_p^2 = .051$). Therefore, the following null hypotheses were supported: there are no significant differences in understandability and actionability of webpages on ANSD based on (1) location or (2) type of organisation. These data are shown in Figure 4.

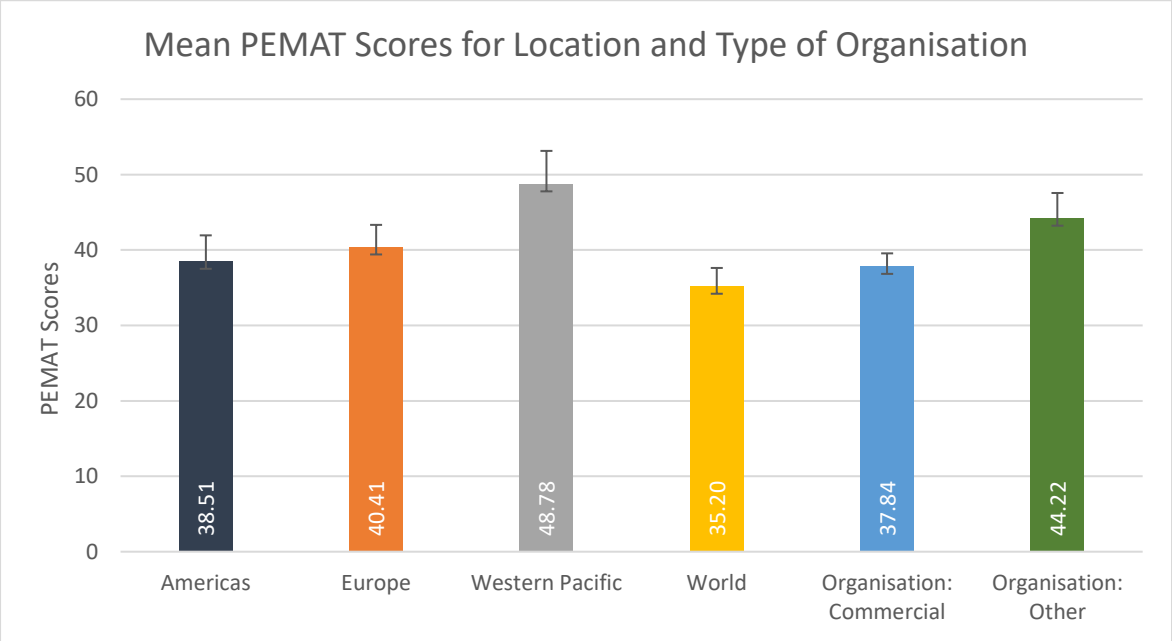

Figure 4. Mean Patient Education Material Assessment Tool (PEMAT) scores based on location and type of organisation. PEMAT scores could range from 0 to 100. Error bars represent one standard error.

3.11. DISCERN

The minimum DISCERN score was 1 while the maximum score was 4 (*M* = 2.37, *SD*= .68). The mean score (*M* = 2.37) is consistent with a low score (1-2) with treatment choices having serious or extensive shortcomings (Charnock, 1997). The means and SD for each DISCERN item are shown in Table 4.

Table 4. Mean and standard deviation (SD) for each DISCERN item.

DISCERN Item	**Mean (SD)**
1. Are the aims clear?	3.00 (0.91)
2. Does it achieve its aims?	3.05 (0.93)
3. Is it relevant?	2.56 (0.92)
4. Is it clear what sources of information were used to compile the publication?	3.06 (1.57)
5. Is it clear when the information used or reported in the publication was produced?	3.05 (1.53)
6. Is it balanced and unbiased?	2.89 (1.03)
7. Does it provide details of additional support and information?	2.58 (1.08)
8. Does it refer to areas of uncertainty?	2.78 (0.90)
9. Does it describe how each treatment works?	1.52 (0.92)
10. Does it describe the benefits of each treatment?	2.52 (0.84)
11. Does it describe the risks of each treatment?	2.17 (0.94)
12. Does it describe what would happen if no treatment is used?	1.31 (0.65)
13. Does it describe how the treatment choices affect overall quality of life?	1.52 (0.90)
14. Is it clear that there may be more than one possible treatment choice?	2.93 (0.81)
15. Does it provide support for shared decision making?	1.10 (0.41)
16. Overall rating	2.37 (0.68)

3.11.1. DISCERN Scores Based on Location and Type of Organisation

This study aimed to answer the following research questions:

1. Is there a significant difference in DISCERN ratings of webpages on ANSD based on locality of hosting organisation?
2. Is there a significant difference in DISCERN ratings of webpages on ANSD based on type of hosting organisation?

A two-way ANOVA was conducted to determine the effects of locality of hosting organisation and type of hosting organisation on DISCERN scores for webpages on ANSD. There was no significant interaction between location and type of organisation, $F(3, 56) = 1.241$, $p = .303$, $\eta_p^2 = .062$. There were no significant main effects for location ($F(3,56)= 1.457$, $p=.236$, $\eta_p^2 = .072$) or type of organisation ($F(1,56)= .726$, $p=.398$, $\eta_p^2 = .013$). Therefore, the following null hypotheses were supported: there are no significant differences in DISCERN scores for webpages on ANSD based on (1) location or (2) type of organisation. These data are shown in Figure 5.

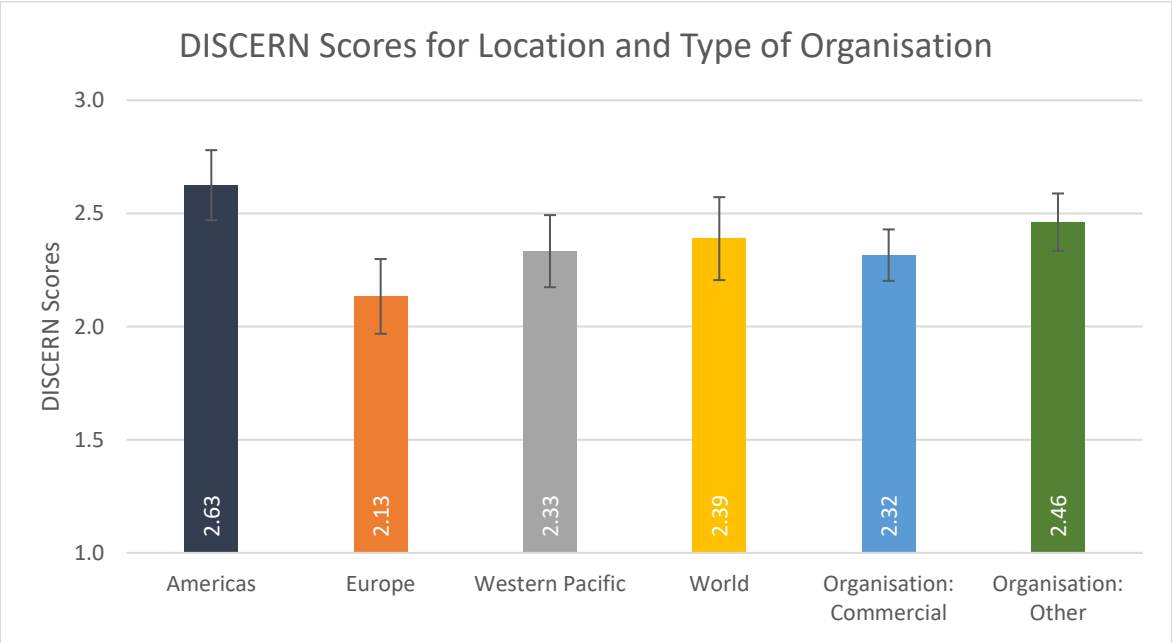

Figure 5. Mean DISCERN scores (for item 16) based on location and type of organisation. DISCERN scores could range from 0 to 5. Error bars represent one standard error.

4. Discussion

4.1. Overview

This study analysed the readability, use of plain language, understandability and actionability, and quality of 64 English-language webpages related to ANSD. This was done using several tools: (1) PLC, (2) PEMAT, and (3) DISCERN. Several readability formulas were used to determine RGL. The influence of location and type of organisation for each measure was investigated. The mean RGL of webpages on ANSD was found to be significantly higher than the recommended 6th RGL. Poor to moderate use of plain language, understandability and actionability, and quality of treatment information for webpages on ANSD was found. No significant difference in RGL, plain language use, PEMAT scores, or DISCERN scores was found based on locality of hosting organisation and type of hosting organisation. This chapter will discuss the results of this study in relation to the literature. Clinical implications and future research directions will also be discussed.

4.2. Readability of Online Information on ANSD

This study found that the RGL of webpages on ANSD in the English language were high, with no webpages having content at or below the recommended 6th RGL. In general, online information on ANSD was written at the 13th to 14th RGL. An RGL at or above the 9th RGL is considered unsuitable (Doak, Doak, & Root, 1996). The results of this study support the general finding that online audiological material tends to have a high RGL. For example, Laplante-Lévesque, Brännström, Andersson, and Lunner (2012) found that the mean RGL was above the recommended 6th RGL for online hearing-related information, with 11 to 12 years of education required to read and understand the information. Similarly, a systematic review by Laplante-Lévesque and Thorén (2015) reported high mean RGLs across online hearing-related information, with 9 to 14 years of education required to read and understand the information. High RGLs have also been found across other hearing-related information.

Online and printed information on otitis media was found to be written at the 8th to 10th RGL (Joury et al., 2018; Swartz, 2010). Online information on tinnitus exceeded the recommended 6th RGL, with 10 to 12 years of education required to read and understand the material (Manchaiah et al., 2019).

The high RGL of online materials on ANSD indicates health information on ANSD needs to be improved in order to support the health literacy of readers. Therefore, it does not promote understanding or retention of health information (Shieh & Hosei, 2008; Weiss, 2003). Low health literacy is prevalent in New Zealand and around the world (Ministry of Health/Manatū Hauora, 2010; WHO, 2017). New Zealanders, on average, have limited health literacy with poor ability to process and understand health information (Ministry of Health/Manatū Hauora, 2010). Low health literacy is also prevalent among parents and caregivers (Kumar et al., 2010; Sanders et al., 2009). Low health literacy in caregivers is associated with less health knowledge, poor preventative care behaviours, and poorer child health outcomes (DeWalt & Hink, 2009; Sanders et al., 2009). Therefore, readable and understandable resources are important for parents and caregivers. In particular, materials on ANSD which support the health literacy of readers are important because of the reported increased difficulty understanding a complex ANSD diagnosis (Stroebel & Swanepoel, 2014; Uus et al., 2012).

4.3. Content Assessment of Online Information on ANSD

4.3.1. Plain Language

There was moderate use of plain language across online information on ANSD, with a mean score of 12.32 and scores ranging from 7 to 20. No significant difference for use of plain language based on location and type of organisation was found. There were several items on the PLC which 90% or more of the assessed material included: (1) one or more of the headings contained the topic of interest (90.63%), (2) the content was relevant to the topic

(95.31%), (3) the content was arranged in a sensible order (90.63%), (4) consistent appearance of the material throughout, (5) easy-to-read font design (100%), and (6) sparing use of italics, underlining, capitalisation, and bold print (96.88%). Items which 30% or fewer of the assessed materials included were: (1) use of personal pronouns (10.9%), (2) predominant use of lay terms (21.88%), (3) explanation of technical terms (18.75%), and (4) use of simple sentences (10.94%). The PLC has not been used in any previously published study, therefore, the results of the present study cannot be compared to the literature.

Overall, online information on ANSD scored well on reader focus, design, and formatting, moderately on text organisation, and poorly on most writing aspects. Therefore, while some aspects of plain language have been executed relatively well, more plain language principles need to be implemented when creating online information on ANSD. Use of plain language will help to support low health literacy as well as promote reading ease and understanding. In particular, writing style needs to be improved and technical language needs to be simplified. Improvement and simplification could be achieved by making several changes, including: (1) addressing the user directly throughout the material, using language such as 'you' or 'your child,' (2) using simple sentences which consist of only one idea, (3) using lay terms wherever possible, such as 'nerve that connects the inner ear to the brain' instead of 'auditory nerve,' and (4) defining technical terms if they are used.

4.3.2. PEMAT

The PEMAT showed high variability for understandability and actionability across online information on ANSD, with scores ranging from 16.7% to 76.19%. On average, online information scored poorly to moderately on the PEMAT (40.43%). No significant difference for PEMAT scores based on location and type of organisation was found. For the understandability subscale, there were several items which the majority of materials included: (1) the purpose was evident (83.21%), (2) the reader was not required to perform calculations

(98.44%), (3) information was chunked (84.38%), and (4) information was presented in a logical sequence (92.19%). There were also several items that few materials included: (1) medical terms were defined and only used to familiarise audience (15.63%), (2) use of visual cues to highlight key points (6.25%), and (3) use of visual aids whenever possible to make content more easily understood (7.81%). For the actionability subscale, the majority of assessed materials did not include any of the applicable items: (1) at least one action identified (17.19%), (2) user addressed directly when describing actions (12.50%), (3) actions broken down into manageable, explicit steps (3.13%), and (4) visual aids made it easier to act on instructions (0%).

These findings support the results of several previous studies on health information. For example, Cajita et al. (2017) found moderate mean understandability scores (53.3% $\pm$ 16.2%) and poor mean actionability scores (34.7% $\pm$ 28.7%) for online information on heart failure. Similar to the present study, they found that the materials scored highest on the following items: (1) clear purpose, (2) no calculations required, and (3) logical order of information. They also found that the assessed materials scored most poorly on the use of visual aids. However, most of the websites stated at least one action the reader could take while the present study found few websites provided a call to action. Balakrishnan et al. (2016) also found that 95% of online health information on vocal cord paralysis presented information in a logical order while only 21% of articles used visual aids to improve understanding. They found that none of the assessed vocal cord paralysis materials provided a summary, while 37.5% of webpages assessed in the present study did. Wong et al. (2017) also found that the understandability and actionability of online laryngectomy-related health information was not easy to understand or act upon.

Overall, similar to patient health information in other health fields, online information on ANSD is not easily understood or acted upon. In particular, use of technical language needs

to be decreased, use of visual cues to highlight key points needs to be improved, and use of visual aids where impossible to aid understanding of content needs to be increased. Information which is understandable and actionable is a key element of effective health communication (WHO, 2019). Readers need to be able to understand and act on the content in order to adopt positive health behaviours which will impact themselves and their family.

4.3.3. DISCERN

The mean DISCERN score for the assessed online information on ANSD was 2.37 with scores ranging from 1 to 4. According to Charnock (1997), this is a poor to fair score. A material which is rated as a 2 or below (poor), indicates serious shortcomings and suggests that the material is unlikely to benefit the reader or provide appropriate treatment information (Charnock, 1997). A score of 3 (fair) indicates the material provides useful treatment information, however, has some limitations and would need to be supplemented with additional information and support (Charnock, 1997). No significant difference for DISCERN scores based on location and type of organisation was found.

The results of the present study are similar to the findings of several previous studies. Laplante-Lévesque, Brännström, Andersson, Lunner, et al. (2012) investigated the quality of online materials aimed at adults with hearing-impairment and their significant others. They found a mean DISCERN score of 2.04, with scores ranging from 1.13 to 3.93. Unlike the present study, they found there was a significant difference between mean DISCERN scores across type of organisation. They found that websites from non-profit organisations (2.64) were of higher quality than those from government (1.90) or commercial (1.88) organisations. However, similar to webpages on ANSD, websites on hearing-impairment aimed at adults and their significant others were of poor quality overall. Poor to fair quality online information was also found on otitis media and tinnitus (Joury et al., 2018; Manchaiah et al., 2019). Similar to the present study, Manchaiah et al. (2019) found no significant

difference in DISCERN scores for online information on tinnitus across location and type of organisation.

Mean DISCERN scores were the highest for the following four items: (1) clear sources (3.06), (2) achieves its aims (3.05), (3) clear when the information used was produced (3.05), and (4) clear aims (3.00). Mean DISCERN scores were the lowest for the following four items: (1) provides support for shared decision making (1.10), (2) describes the consequences of no treatment (1.31), (3) describes how each treatment works (1.52), and (4) describes how treatment choices affect quality of life. Overall, online information on ANSD does not provide adequate treatment information. In particular, it does not provide sufficient information on the effects of no treatment or effects of treatment on quality of life and does not facilitate shared decision making.

4.4. Clinical Implications

Healthcare information provided by healthcare providers is often forgotten or not accurately remembered (Kessels, 2003). Therefore, verbal information and advice should be supplemented with written information to improve understanding (Kessels, 2003; Little et al., 1998; Morris & Halperin, 1979). This is particularly important for parents and caregivers of children with ANSD due to the difficulty understanding a diagnosis (Stroebel & Swanepoel, 2014). Individuals may turn to the internet to find supporting written information (Lin et al., 2016).

Overall, online information on ANSD does not promote understanding. Online information on ANSD has poor readability, poor quality treatment information, moderate use of plain language, and variable understandability and actionability. Therefore, healthcare specialists should caution parents and caregivers of children with ANSD about the use of online information and emphasise the healthcare provider as the primary source. Healthcare

specialists should aim to provide supplementary information on ANSD which promotes understanding and supports the health literacy of the reader. This could be ensured by assessing a specific material using the tools implemented in the present study. Alternatively, they could create their own health resources. See appendix 2 for a list of webpages assessed in the present study.

The findings of the present study also highlight areas which need special consideration when producing online health information on ANSD. Areas which need particular improvement are: (1) information written at a suitable RGL, (2) simplified language and sentence structure, (3) use of personal pronouns, (4) use of visual cues and aids, (5) actionability, and (6) comprehensive treatment information.

4.5. Study Limitations

4.5.1. Readability Formulas

Readability formulas are easy and inexpensive to use. However, there are several limitations (Redish, 1981). The readability formulas used in the present study calculate an RGL based on word and sentence length and assume that sentences are grammatically correct, well-formed, and understandable. Therefore, readability formulas are unable to analyse other aspects of a text which are important for reading-ease and understandability (Redish, 1981). For example, they cannot assess organisation, font characteristics, use of white space, whether the purpose is clear (Redish, 1981), or relevance to the topic of interest (Sticht & Zapf, 1976). The use of the PLC and PEMAT in the present study has allowed assessment of several elements which readability formulas miss. While readability formulas do provide an objective and convenient way to indicate how easily a text can be read (DuBay, 2004), RGLs cannot predict understandability, reliability, or whether a text effectively communicates its intended message. Therefore, RGLs need to be considered alongside other measures.

4.5.2. Plain Language Checklist

The PLC used did not have established reliability and validity. Therefore, the degree to which the PLC measures plain language use is replicable and the accuracy of the PLC in assessing use of plain language cannot be determined. In addition, there is no established criteria to interpret the qualitative score of the PLC. A PLC score closer to 20 indicates that a material appears to use more plain language principles. However, it is not possible to accurately discuss what exactly a PLC score indicates in terms of plain language use. The results of the PLC should be interpreted with caution.

4.5.3. PEMAT

In order to meet the assumptions of parametric testing, the PEMAT subscales (understandability and actionability) were combined due to several statistical outliers present for the actionability subscale. This allowed assessment of the influence of location and type of organisation on the combined PEMAT score. However, the mean, standard deviation, and range indicate combined understandability and actionability. Several previous studies have analysed the two subscales separately (Balakrishnan et al., 2016; Cajita et al., 2017; Wong et al., 2017) which makes it difficult to compare the PEMAT findings of the present study to previous literature. Although, the means for individual items of the PEMAT, unique to understandability and actionability, can still be discussed.

4.5.4. DISCERN

The DISCERN tool measures some important aspects of quality, but not all. For example, the DISCERN tool does not measure how accurate information is or how trustworthy the sources used in a material are (Charnock, 1997). Charnock (1997; pp.7) states that the DISCERN tool assesses "the most common causes of inaccurate or unreliable information," rather than accuracy of the information itself. Additionally, the DISCERN was scored using integers in the present study, unlike the scoring used by (Laplante-Lévesque, Brännström,

Andersson, & Lunner, 2012) who assessed online hearing-related information. Scoring using decimals may have resulted in more precise scoring for each DISCERN item.

4.5.5. Search Procedure

The search procedure used in the current study is unlikely to represent search behaviours exhibited by actual health consumers. Generally, consumers do not systematically search the web for health information by accessing the first 10 search results given by each search term in a single search engine, as was done in the present study (Eysenbach & Köhler, 2002). Additionally, the search terms used were not given by parents seeking health information on ANSD, therefore, there may have been search term bias. Only one search engine was used (Google) and only webpages in the English language were assessed. Therefore, the full range of online information on ANSD may not have been analysed.

4.6. Future Research Directions

The present study has provided valuable insights into information on ANSD which is available online. However, there are several useful future research directions which could further assess patient education materials currently available on ANSD. For example, printed material on ANSD and information which is written in other languages could be assessed. In future research, search terms could be gathered from parents of children with ANSD who are actual ANSD health-information seekers to more accurately represent search behaviours. More focus could also be placed on how to improve online information on ANSD. This could be done by revising material on ANSD based on best-practice guidelines for formatting and content. The potential benefit of this could then be assessed through user questionnaires. This revised material can then be distributed to hearing-healthcare specialists and the public.

4.7. Conclusion

The rise in use of online health information (Lin et al., 2016), the difficulty parents have understanding an ANSD diagnosis (Stroebel & Swanepoel, 2014), and the poorer child health outcomes associated with low caregiver health literacy (Sanders et al., 2009) highlight the importance of suitable ANSD materials which support patient and parental health literacy and understanding. Health information that does not support low health literacy reduces self-efficacy (McMullan et al., 2017) and, therefore, may reduce positive health behaviours. Low health literacy can also reduce participation in shared decision making (Yin et al., 2012), which is an integral part of patient-centred care and can increase positive health outcomes (Grenness et al., 2014). Overall, online information on ANSD does not support low health literacy or promote understanding. Health professionals should ensure parents of children with ANSD have access to approved and effective resources. Development of readable, understandable and actionable, and quality information on ANSD is needed.

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Appendix 1: Human Ethics Committee Approval Letter

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

HUMAN ETHICS COMMITTEE

Secretary, Rebecca Robinson
Telephone: +64 03 369 4588, Extn 94588
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2019/07/LR

1 April 2019

Ana Blagojevic, Aynsley Hickson, Carol Hewitt, Katie Murphy, and Sarah Folkerts
Psychology, Speech and Hearing
UNIVERSITY OF CANTERBURY

Dear Ana, Aynsley, Carol, Katie, and Sarah

Thank you for submitting your low risk application to the Human Ethics Committee for the research proposal titled "Quality of Hearing-Related Internet Information".

I am pleased to advise that this application has been reviewed and approved.

With best wishes for your project.

Yours sincerely

Dr Dean Sutherland
Chair, Human Ethics Committee

Appendix 2: List of Assessed Webpages on ANSD

List of assessed webpage URLs with mean reading grade level (RGL) and Patient Education Materials Assessment Tool (PEMAT), Plain Language Checklist (PLC), and DISCERN scores. Webpage URLs are organised by locality of hosting organisation. Shaded webpage data indicates a trimmed, statistically significant outlier.

Organisation	**URL**	**Location**	**Mean RGL**	**PEMAT**	**PLC**	**DISCERN**
Provincial Health Services Authority	http://www.phsa.ca/bc-early-hearing/Documents/ANSD%20Information%20for%20BC%20Families.pdf	Americas	7.96	76.19	19	4
Ontario Ministry of Children and Youth Services	http://www.mountsinai.on.ca/care/infant-hearing-program/staff-support-1/Rancearticle.pdf/at_download/file	Americas	12.66	35.00	9	3
Ontario Ministry of Children and Youth Services	https://www.mountsinai.on.ca/care/infant-hearing-program/documents/protocol-for-auditory-brainstem-response-2013-based-audiological-assessement-abra	Americas	14.15	40.91	12	2
National Institute on Deafness and Other Communication Disorders	https://www.nidcd.nih.gov/health/auditory-neuropathy	Americas	14.05	52.94	17	3
McGill University	http://103.94.125.242/20.ebook/03.Keperawatan/01.Ebook/buku%20aminoff's%20electrodiagnosis%20in%20clinical%20neurology/capt%2025.pdf	Americas	16.66	22.22	9	2
Canadian Society for Clinical Investigation	https://cimonline.ca/index.php/cim/article/download/13720/10598/	Americas	12.10	28.57	14	3
WebMD	https://emedicine.medscape.com/article/836769-overview	Americas	15.10	42.86	15	3

Wikimedia Foundation	https://en.m.wikipedia.org/wiki/Auditory_neuropathy	Americas	16.45	28.57	13	2
Wikimedia Foundation	https://en.wikipedia.org/wiki/Auditory_neuropathy_spectrum_disorder	Americas	21.45	33.33	12	2
American Medical Association	https://jamanetwork.com/journals/jamaotolaryngology/fullarticle/483038	Americas	15.73	23.81	12	3
Wolters Kluwer	https://journals.lww.com/thehearingjournal/fulltext/2014/06000/Making_Sense_of_Auditory_Neuropathy_Spectrum.1.aspx	Americas	12.85	38.10	12	3
Speech-Language and Audiology Canada	https://www.cjslpa.ca/download.php?file=2016_CJSLPA_Vol_40/No_01/CJSLPA_Vol_40_No_1_2016_Barreira-Nielsen_et_al_67-79.pdf	Americas	13.21	52.38	15	3
Chicago Dizziness and Hearing	https://www.dizziness-and-balance.com/disorders/hearing/aud_neuropathy.html	Americas	12.46	42.86	9	3
American Association for the Advancement of Science (AAAS)	https://www.eurekalert.org/pub_releases/2017-01/bsp-rbp010317.php	Americas	16.85	27.78	11	2
IGI Global	https://www.igi-global.com/chapter/late-onset-auditory-neuropathy-spectrum-disorder/206425	Americas	14.97	27.78	9	2
Peel Audiology and Hearing Aid Services	https://www.peelaudiology.com/auditory-neuropathy-spectrum-disorder-ansd/	Americas	11.62	42.86	16	2

Cued Speech Association UK (CSAUK)	http://www.cuedspeech.co.uk/uploads/documents/2016%20Info%20Sheets/2016%20-%20ANAD.pdf	Europe	12.65	31.82	7	2
University of Edinburgh	http://www.ssc.education.ed.ac.uk/courses/deaf/dnov09i.html	Europe	11.78	28.57	12	2
British Association of Teachers of the Deaf	https://www.batod.org.uk/wp-content/uploads/2018/03/ANSD-ppt-NDCS.ppt	Europe	11.45	36.36	12	2
National Deaf Children's Society	https://www.ndcs.org.uk/information-and-support/childhood-deafness/causes-of-deafness/auditory-neuropathy-spectrum-disorder-ansd/	Europe	17.86	42.86	15	1
University of Bristol	http://www.bristol.ac.uk/social-community-medicine/people/35381/pub/9823470	Europe	14.07	44.44	13	2
National Deaf Children's Society	http://www.wales.nhs.uk/sitesplus/980/opendoc/242644	Europe	10.61	71.43	20	2
Oxford University Press	https://academic.oup.com/brain/article/138/11/3141/332377	Europe	17.32	40.91	12	3
The Open University	https://core.ac.uk/reader/82706143	Europe	12.57	42.86	12	3
Sound Advice	https://sound-advice.ie/parent-question-auditory-neuropathy-an/	Europe	12.21	52.94	16	2
Action on Hearing Loss	https://www.actiononhearingloss.org.uk/finding-cures/our-biomedical-research/research-projects/developing-a-diagnostic-test-for-auditory-neuropathy/	Europe	17.50	33.33	14	2
Pinpoint Scotland Ltd	https://www.entandaudiologynews.com/reviews/journal-reviews/post/auditory-neuropathy-spectrum-disorder	Europe	18.76	35.29	10	1

Hidden Hearing	https://www.hiddenhearing.co.uk/hearing-information/hearing-glossary/auditory-neuropathy	Europe	10.76	47.06	12	2
British Society of Audiology	https://www.thebsa.org.uk/wp-content/uploads/2019/01/FINAL-JAN2019_Recommended-Procedure-Assessment-and-Management-of-ANSD-in-Young-Infants-GL22-01-19.pdf	Europe	12.58	38.10	13	3
Tel Aviv University	www.kbalab.com/wp-content/uploads/2012/05/Avraham_K_EMBO-J_2016.pdf	Europe	15.17	36.36	10	2
Tel Aviv University	www.kbalab.com/wp-content/uploads/2012/05/Brownstein_et_al_2013-.pdf	Europe	14.39	23.81	9	3
Hearing Cooperative Research Centre	https://hearnet.org.au/hearing-problems/auditory-neuropathy	Western Pacific	12.55	47.83	15	2
University of Melbourne	https://minerva-access.unimelb.edu.au/bitstream/handle/11343/27535/119517_vol11_1221.pdf?sequence=1&isAllowed=y	Western Pacific	10.29	23.53	10	2
Aussie Deaf Kids	https://www.aussiedeafkids.org.au/ansd	Western Pacific	12.53	52.38	16	3
Stuff NZ	https://www.stuff.co.nz/dominion-post/news/72019269/	Western Pacific	11.87	52.38	12	1
University of Hong Kong	http://hub.hku.hk/handle/10722/82546	Western Pacific	15.25	44.44	13	2
Annals, Academy of Medicine, Singapore	http://www.annals.edu.sg/pdf/37VolNo12SupplDec2008/V37N12(Suppl)p60.pdf	Western Pacific	16.35	44.44	12	3
Department of Education and	http://www.education.vic.gov.au/Documents/childhood/parents/needs/hearinglossmean.docx	Western Pacific	11.05	76.19	18	3

Early Childhood Development						
Ministry of Health, Malaysia	http://www.myhealth.gov.my/en/auditory-neuropathy-in-children/	Western Pacific	13.07	61.11	13	3
National Acoustic Laboratories	https://dspace.nal.gov.au/xmlui/bitstream/handle/123456789/668/Chapter%2032_ANSD.pdf?sequence=1&isAllowed=y	Western Pacific	15.86	33.33	12	3
Maquarie University	https://researchers.mq.edu.au/en/publications/identification-of-different-subtypes-of-auditory-neuropathy-using	Western Pacific	19.86	33.33	10	2
Maquarie University	https://researchers.mq.edu.au/en/publications/impact-of-the-presence-of-auditory-neuropathy-spectrum-disorder-a	Western Pacific	13.03	44.44	10	2
Aussie Deaf Kids	https://www.aussiedeafkids.org.au/ansd-webinar-for-parents	Western Pacific	10.32	94.12	18	N/A
Aussie Deaf Kids	https://www.aussiedeafkids.org.au/olivers-story.html	Western Pacific	9.65	76.19	14	3
Cicada Australia	https://www.cicada.org.au/index.php/hidden/faq-medical/229-what-is-auditory-neuropathy-and-is-it-easy-to-diagnose	Western Pacific	13.58	23.53	12	2
Colin R.S Brown Ear Surgery	https://www.ear.co.nz/childhood-deafness	Western Pacific	12.98	71.43	19	2
Elsevier/Science Direct	https://www.sciencedirect.com/science/article/abs/pii/S0030666515000870?via%3Dihub	Western Pacific	17.76	47.06	12	2
Wolters Kluwer	http://www.ejo.eg.net/article.asp?issn=1012-5574;year=2017;volume=33;issue=1;spage=67;epage=77;aulast=Hassan	World	13.58	22.22	9	3
FairGaze	https://fairgaze.com/FGNews/ansd-a-form-of-hearing-loss_1015.html	World	9.95	33.33	12	1

MoreFocus	http://morefocus.com/health/auditory-system-hearing-disorders-auditory-neuropathy/	World	13.03	61.11	16	2
Phonak pro/University of Manchester	https://www.phonakpro.com/content/dam/phonakpro/gc_hq/en/events/2011/fourth_pediatric_conference/15_Kai_Uus_Istanbul_2011.pdf	World	8.39	33.33	11	3
Elsevier	https://www.sciencedirect.com/topics/medicine-and-dentistry/auditory-neuropathy	World	14.20	16.67	10	2
Exclusive van der Sandt Audiology	http://exclusiveaudio.co.za/sensori_neural_hearing_loss.html	World	14.18	33.33	9	1
Dr Louis Hofmeyr	https://lmhofmeyr.co.za/conditions/hearing/auditory-neuropathy/	World	12.20	38.89	12	2
University of Cape Town	https://vula.uct.ac.za/access/content/group/27b5cb1b-1b65-4280-9437-a9898ddd4c40/Classification%20of%20hearing%20loss.pdf	World	17.82	29.41	10	1
Indian Speech and Hearing Association	http://ishaindia.org.in/jisha_Vol26_1_articles_final/audiological_characteristics_and_duration.pdf	World	12.15	38.10	12	3
Brazilian Association of Otorhinolaryngology-Head and Neck Surgery	http://www.bjorl.org/en-prevalence-auditory-neuropathy-spectrum-disorder-articulo-S1808869415301920	World	12.65	28.57	11	3
The International Organization of Scientific Research (IOSR),	http://www.iosrjournals.org/iosr-jdms/papers/Vol15-Issue%209/Version-6/S150906130134.pdf	World	14.00	38.10	10	3

Brazilian Association of Otorhinolaryngology-Head and Neck Surgery	http://www.rborl.org/en-performance-hearing-skills-in-children-articulo-S1808869414001281	World	14.52	42.86	13	3
Google Books	https://books.google.com.pr/books?id=HBqNRXtI2zAC&printsec=frontcover&rview=1#v=onepage&q&f=false	World	16.90	27.27	12	3
F1000 Prime	https://f1000.com/prime/ext/726115033?referrer=GOOGLE	World	13.67	27.78	10	2
Frontiers in Neuroscience	https://www.frontiersin.org/articles/10.3389/fnins.2017.00416/full	World	14.78	36.36	12	3
Nature Research/Springer Nature	https://www.nature.com/articles/s41598-017-16676-9	World	16.79	31.82	10	3
Search Video/Provincial Health Services Authority (PHSA)	https://www.searchvideo.me/video/ZZFERUP15wE/provincial-health-services-authority-phsa.html	World	12.22	92.86	19	N/A
Yumpu.com/University of North Carolina	https://www.yumpu.com/en/document/read/36574413/understanding-auditory-neuropathy-diagnosis-and-management	World	12.14	50.00	12	3
Yumpu.com/Paediatric Audiology Consulting	https://www.yumpu.com/en/document/read/47286978/auditory-neuropathy-spectrum-disorder-janemadellcom	World	12.62	44.44	13	2