Readability and quality of online information regarding the hearing disorder “Auditory Processing Disorder” in English

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Abstract

Purpose: This study investigated the readability and quality of online information available for the hearing disorder called "Auditory Processing Disorder" (APD) written in the English language.

Method: The search terms "auditory processing disorder" and "APD" were used in 21 English speaking country specific Google domains. The first ten relevant webpages were captured. After removing duplicates, a total of 210 webpages were assessed and further subsampled ensuring the geographic distributions were even and giving a total sample size of 108. The country of origin, type of organisation (commercial and other), and HONcode certification were recorded for each webpage. Readability was assessed using the FOG, SMOG, and F-K readability formulas. Quality was assessed using the DISCERN and PEMAT tools. The language was assessed using a newly developed Plain English Language Checklist Tool.

Results: Online APD information in English was found to have high readability levels and none of the webpages met the recommended sixth RGL. The Quality assessed by the DISCERN tool was variable with almost half the materials scoring the minimum score. The PEMAT results showed better understandability scores and worse actionability scores. There was an even distribution of webpages based on region and type of organisation. There were no significant differences in readability, or the quality of webpages based on their region, but the type of organisation had a significant effect. The non-commercial webpages (government and academic sources) had worse readability and quality scores compared to commercial webpages.

Conclusions: The effectiveness of online information to increase health literacy is largely determined by the readability and the quality of current online materials. Given the highly contentious origin of the hearing disorder APD, accessible resources are an

important aspect of improving the awareness and understanding of the disorder. The current online materials have been found to have limited usefulness in increasing the health literacy due to high levels of readability and the large variation in the material's quality. There is a need to development new materials that embrace Plain Language initiatives to produce more easily understood materials of high quality.

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Table of Contents

Abbreviations

ADHD	Attention deficit hyperactivity disorder
ANOVA	Analysis of variance
APD	Auditory processing disorder
ASHA	American Speech Language and Hearing Association
AV	Audio-visual
BSA	British Society of Audiology
CAP	Central auditory processing
cAPD or CAPD	Central auditory processing disorder
ccTLD	Country coded top-level domain
CI	Cochlear implant
CIA	Central Intelligence Agency
ENT	Ear nose and throat
GP	General practitioner
F-K	Flesch Kincaid reading ease
FM	Frequency modulation
FOG	Gunning Fox index
HON Code	Health on the Net Code
ICC	Intra class coefficient
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
N/A	Not applicable
NZ	New Zealand
OME	Otitis media with effusion
ORL	Otolaryngology
PEMAT	Patient education materials assessment tool
RE	Reading ease
RGL	Reading grade level

RMHA	Remote microphone hearing aid
SAM	Suitability Assessment of Materials
SMOG	Simple measure of Gobbledygook
UK	United Kingdom
URL	Unique resource locator
USA	United States of America

List of Figures

List of Tables

Introduction

1.1. Auditory Processing Disorder

Auditory processing disorder (APD) is described as difficulty in listening or processing of speech that often coexists with difficulties in language and attentional modalities (Iliadou, Sirimanna, & Bamiou, 2016; Wilson, 2018, 2019). APD is known to occur even when standard audiometric thresholds are within normal limits (American Speech-Language-Hearing Association, 2005a). Despite being included in the tenth edition of the World Health Organisation (WHO) International Classification of Diseases (ICD 10) (Iliadou et al., 2016; World Health Organization, 2010), there is still considerable controversy as to the neurobiological basis of these deficits and difficulties (Moore, 2015) and this significantly contributes to there being no globally accepted definition for APD (Wilson, 2018, 2019). APD is a hearing disorder characterised by low levels of awareness/knowledge by medical and educational professionals charged with the diagnosis and management of the disorder (Baldry & Hind, 2008; Esplin & Wright, 2014; A. Ryan & Logue-Kennedy, 2013).

1.1.1. APD diagnostic definition

Various audiological professional organisations/bodies around the world have attempted to define the disorder. The WHO International Classification of Functioning, Disability and Health (ICF) model (World Health Organisation, 2001) confirms that APD can place limitations on a person's quality of life by limiting participation in listening and discussion activities as well as in more complex situations such as the development of interpersonal interactions and learning at school (Canadian

Interorganizational Steering Group for Speech Language Pathology and Audiology, 2012; Rosen, Cohen, & Vanniasegaram, 2010).

While there is no globally accepted definition, there are some consistent themes than are evident through the various definitions postulated by professional audiology organisations. APD is best described as a disorder (or at least deficits) in the bottom-up processing of speech or sound by the primary auditory nervous system that is not due to language or cognitive deficits (American Speech-Language-Hearing Association, 2005a, 2005b; British Society of Audiology, 2018; Canadian Interorganizational Steering Group for Speech Language Pathology and Audiology, 2012; de Wit et al., 2016; Iliadou et al., 2017; W. Keith, Purdy, Baily, & Kay, 2019; Moore, 2006; Wilson, 2018). The Canadian Interorganizational Steering Group for Speech Language Pathology and Audiology provide a useful view of APD contextualised against the WHO International Classification of Functioning, Disability and Health (ICF) model disability. They, like most other professional bodies, agree that APD is describes hearing disorders resulting from atypical processing of auditory information at the level of the brain. They characterise the symptoms of APD as “persistent limitations” in auditory processes that may impact participation in everyday life which is line with the WHO ICF model of Health and Disability (Canadian Interorganizational Steering Group for Speech Language Pathology and Audiology, 2012; World Health Organisation, 2001)

The British Society of Audiology (BSA) have suggested that it is helpful to view APD as three distinct chronological/developmental subgroups (British Society of Audiology, 2018). The first subgroup, developmental APD, describes a condition where listening/processing difficulties occur despite normal hearing thresholds and is diagnosed at/in childhood but is probably present since birth. This is the category that is most used to describe difficulties observed in school aged children and is also the category of most academic contention. The second, secondary APD, describes listening difficulties associated with genetic causes or peripheral hearing impairment and the third category, acquired APD, is usually related to traumatic neurological events such as stroke, physical trauma, or infection.

There are, however, significant concerns with the view that APD is solely a bottom-up process affecting auditory processing required for listening, learning and language acquisition. One of the most controversial and vigorously debated issues in the APD literature is to what degree does top down processing (attention, working memory and cognition) have on perceived auditory processing ability (Cacace & McFarland, 1998; Dilion, Cameron, Glyde, Wilson, & Tomlin, 2012; Iliadou et al., 2017; Iliadou et al., 2016; W. Keith, Keith, & Purdy, 2018; Moore, 2006, 2015, 2018; Sharma, Purdy, & Kelly, 2009; Stravrinos, Iliadou, Edwards, Sirimanna, & Bamiou, 2018; Wilson, 2018).

The alternative view is that the term APD is better used as an umbrella term to describe listening difficulties caused by a number of speech, language and attentional deficits (Moore, 2018). There is wide consensus that an overlap in behavioural symptoms exists between specific speech and language disorders, attentional deficits (i.e. ADHD) and APD symptoms (Gyldenkærne, Dillon, Sharma, & Purdy, 2014; W. Keith et al., 2018; Sharma, Purdy, & Humburg, 2019; Sharma et al., 2009). It is very difficult however, to separate these higher processes from simple auditory responses especially when the diagnostic tests and stimulus become more complex (Moore, 2018). Neural processing of auditory signals has been shown to involve many brain locations and interconnected processes. A more recent and holistic view from Wilson (2018) suggests that the concept of APD might be better discussed by considering it as a spectrum disorder which includes both bottom-up and top-down cognitive processes (particularly attention). By viewing APD as a spectrum disorder, Wilson (2018) assert that there would be no need to establish if APD is a result of exclusively bottom down or top down processes as both would be covered by a spectrum disorder definition.

1.1.2. Symptoms of Auditory Processing Disorder

Neural processing of auditory signals involves many neural loci and interconnected processes. Moore (2018) suggests that responding to even a simple auditory stimulus requires neural processing to occur in the peripheral hearing system, the brainstem, the midbrain, the thalamus, auditory cortex including the many interconnected multimodal parts and finally at the motor action centres and demonstrates that higher level processing is required for even simple auditory tasks. Because of the complex neural networks needed to process auditory stimuli, symptoms of APD are known to vary with time, situation and by patient. A comprehensive list of difficulties and limitations of participation can usefully be obtained by looking at the position statements from the various global professional organisations (American Speech-Language-Hearing Association, 2005a, 2005b; British Society of Audiology, 2018; Canadian Interorganizational Steering Group for Speech Language Pathology and Audiology, 2012; Esplin & Wright, 2014; Iliadou et al., 2017; Iliadou et al., 2016; W. Keith et al., 2019; Rosen et al., 2010) and include:

i. difficulty understanding speech especially in noise or with degraded speech sounds
ii. frequent repetition and/or rephrasing of information

iii. slow processing and poor auditory memory including difficulty following multiple or lengthy oral instructions

iv. mishearing/inconsistent/ inappropriate responses to spoken requests

v. difficulty or inability to interpret prosody cues

vi. difficulty maintaining attention resulting in listening fatigue or being easily distracted

vii. hyperacusis (sensitivity to loud sounds)

viii. difficulty localising sounds.

1.1.3. Risk Factors

Iliadou et al. (2017) suggest that there are four risk domains for developing APD. They list (i) ear related, (ii) brain related or genetic neurological syndromes, (iii) development related attentional deficits and (iv) age-related risk factors as the most significant risks for developing APD.

At the ear level, a major contributor for APD development is recurrent otitis media with effusion (OME) which causes fluctuating conductive hearing losses due to fluid filling the middle ear space. OME is highly prevalent in preschool children and is known to occur at a time of intense language development. Observations have shown that while ventilation tubes/grommet surgery resolves the OME, listening difficulties (both monaural and binaural) often persist well beyond the return of normal hearing thresholds (Hartley & Moore, 2005). It has been shown by Dawes, Bishop, Sirimanna, and Bamiou (2008) that the fluid in the middle ear space slows and attenuates the transduction of sound through the middle ear and may impact binaural hearing development which are key processes needed for separating sound sources and understanding speech in noise (Hogan & Moore, 2003). Neural plasticity is high in preschool age children and it is likely that significant deprivation of auditory signals will result in changes in neural network mapping. Observations in special populations with high chronic OME rates have also shown increased levels of APD indicating that auditory deprivation and changes in temporal signal processing can be risk factors for APD (Mealings et al., 2020; Moore, 2015; Purdy et al., 2012).

At the brain level, an APD diagnosis is most likely to follow a head trauma, genetic syndrome or stroke (Bamiou et al., 2006; Humes, Christopherson, & Cokely, 1992; Koohi, Vickers, Chandrashekar, et al., 2017; Koohi, Vickers, Lakshmanan, et al., 2017). Traumatic brain injuries include high impact injuries such as those suffered in vehicle accidents or falls and to exposure to extremely loud sounds such as blast traumas. It can also cover medical events such as strokes, ototoxic events and brain tumours. A very high proportion of stroke victims suffer some sort of hearing loss and many show signs of APD. Koohi, Vickers, Lakshmanan, et al. (2017) age matched a population of stroke victims against a control population and compared the prevalence of APD against the stroke and control groups. They found that 56% of stroke patients greater than 61 years had both peripheral and APD hearing difficulties compared to 6% of the age matched control group who had not had a stroke. The younger stroke cohort (<61 years) had CAPD rates of 40% compared to 4% in the young non-stroke cohort.

The auditory effects of strokes can be seen acutely before, during or after the event (Koohi, Vickers, Chandrashekar, et al., 2017; Koohi, Vickers, Lakshmanan, et al., 2017). Stroke sufferers describe difficulties in understanding speech in noise (Bamiou et al., 2006; Hoover, Souza, & Gallun, 2017; Koohi, Vickers, Lakshmanan, et al., 2017) and issues with temporal resolution and sequencing (Bamiou et al., 2006). Military service personal are increasingly exposed to extremely loud bomb and mine explosions often resulting in traumatic brain injuries, hearing loss, vestibular issues and APD symptoms (Myers, Wilmington, Gallun, Henry, & Fausti, 2009). Common post concussive symptoms, even from mild concussions, include central auditory complaints which may or may not be accompanied by a shift in auditory thresholds (Gallun et al., 2012; Hoover et al., 2017). Testing has shown that blast victims perform significantly worse than normative populations in many of the APD test battery but specifically with speech in noise tests, gaps in noise testing, masking level differences and staggered spondaic words test (Gallun et al., 2012).

In regards to developmental attentional deficits, Dawes et al. (2008) suggest that inherited factors and/or pre/perinatal complications may influence the neurodevelopmental aspects of auditory processing while auditory deprivation is suggested as a cause of maturational delays. It is very difficult to separate higher processes from simple auditory responses especially when the diagnostic tests and stimulus become more complex (Moore, 2018). Moore (2018) questions how one can separate out just auditory function from this complex interaction and suggests that any delay in maturation of any one part of this complex system would be enough to result in APD like symptoms.

There is a clear relationship between aging and the development of APD symptoms (Golding, 2007; Humes et al., 1992). Golding (2007) found that for adults older than 55 years, there were observable declines in the ability to process sounds that ranged from severe to mild. The declines in sound processing often occurred in the absence of changes in audiometric thresholds/peripheral hearing loss. They also showed that there was a clear relationship between increasing severity of abnormal sound processing and cognitive decline. Speech understanding significantly declines with aging, particularly in noisy environments and behavioural studies have suggested that deficient auditory temporal processing is a key factor in explaining age-related difficulties with understanding speech in noise (Presacco, Simon, & Anderson, 2019). Presacco et al. (2019) suggest that peripheral hearing loss may lead to reorganization of cortical activity and changes in cortical resource allocation, so that additional brain resources (that would otherwise be allocated for other sensory or cognitive functions) would need to be harnessed to assist with auditory tasks. In another review on central presbycusis, Humes et al. (2012) suggested that cognitive functioning such as short term memory, attention, inhibition, and arousal all contribute to speech understanding in noise and therefore may also contribute to central auditory processing abilities.

1.1.4. Diagnostics

Once a full audiological, family, medical and developmental history has been taken for evaluation, it is common for both standard audiometric threshold testing and a specific APD test battery to be undertaken. It is also common for cognitive and language assessments to be undertaken at the same time to determine if the auditory deficits are associated with top down deficits (W. Keith et al., 2019). The widely applied “fail measure” for many of these tests batteries is performance below 2 standard deviations below the mean for at least one ear on at least 2 different behavioural tests (American Speech-Language-Hearing Association, 2005a). Consideration must also be given to the degree of real-life listening difficulties described by the participant as currently there is a lack of knowledge as to what level of “failure” in a given test correlates to what level of real life difficulty (Dilion et al., 2012). There have been several APD/Listening Difficulty questionnaires designed to assist clinician gather detailed histories without introducing bias and allowing a full history to be taken

(Atcherson, Richburg, Zraick, & George, 2013; O'Hara & Mealings, 2018; Smith, 2008).

1.1.4.1. Test Battery design

One of the major downfalls of APD diagnosis is the lack of a gold standard diagnostic test (Dilion et al., 2012; Moore, 2018). Currently, test battery design is decided by each clinician, there is no set number of tests to be included nor is there any requirement to include a particular type of test (Dilion et al., 2012). Ferguson, Hall, Riley, and Moore (2011) report that in a survey of APD assessment providers in the United Kingdom (UK) and the United States of America (USA) that at least 36 diagnostic tests were being used in the UK and 35 tests in the USA. It is well recognised that many of the test batteries are lengthy and can often lead to participant fatigue. Gyldenkærne et al. (2014) note that most APD tests require multiple tests each requiring listening and sustained attention for 10-15 minutes per test. Dilion et al. (2012) strongly exerts that for this reason clinicians must be careful about the choice and number of tests used to minimise fatigue and increase clinical efficiency. They caution that even if a participant fails at least 2 tests then the APD diagnosis should not be given without probing for other reasons as to why a child might have failed. APD test batteries often include several tests which test different parts of the auditory perception pathways and may include any of the following test types

- Auditory discrimination tests
- Dichotic listening – binaural separation
- Dichotic listening – binaural integration
- Distorted Speech

- Speech in Noise tests
- Lateralisation/Localisation
- Spatialised segregation – LiSN -S
- Pattern perception – frequency pattern test
- Memory tests – forward and backward digit span test

1.1.5. Prevalence

Global prevalence data is reasonably consistent despite the application and use of different tests and test batteries, suggesting that in children the rates of APD range from 2 -10% (Bamiou, Musiek, & Luxon, 2001; Esplin & Wright, 2014; Hind et al., 2011; Iliadou et al., 2017; Nagao et al., 2016; Skarzynski et al., 2015). Auditory processing disorder (APD) is frequently first diagnosed in school-age children (Reynolds, Kuhaneck, & Pfeiffer, 2016) often when the demands of the predominantly aural route of instruction at school identifies a child's difficulty listening in noise (Ferguson, Hall, Riley, & Moore, 2011).

APD prevalence is increased within certain "at risk populations" including those with high OME prevalence. APD was measured at 34% in children of Pacific Island families in Auckland with known high incidence of OME (Purdy et al., 2012). This is consistent with the findings of Mealings et al. (2020) who found the rates of OME and APD like symptoms higher in the socially disadvantaged Torres Island Aboriginal populations.

In adults, the rates of APD increase with age due to the physical deterioration of the peripheral hearing system (presbycusis) resulting in degraded auditory information reaching the central auditory processing mechanisms but also due to declines in cognitive processes (Humes et al., 1992; Humes et al., 2012). APD rates have been found to be as high as 75% in adults older than 79 years of age (Jerger, Jerger, Oliver, & Pirozzolo, 1989) ranging down to rates of 22.6% in a group of an unselected aging adults participating in the Framington Cohort study (Cooper & Gates, 1991).

1.1.6. Rehabilitation/accommodations

1.1.6.1. Children

The New Zealand APD guidelines (W. Keith et al., 2019) strongly encourage treatment for children whose auditory processing skills are significantly less developed/worse compared to age related norms. They state that because APD is associated with a dysfunction or deficit in neural processing, that the high levels of neuroplasticity present in young children, will enable the brain to adapt and auditory processing skills may improve. Iliadou et al. (2017) suggest that accommodations and rehabilitation interventions for APD should be individualised to the patient as much as possible but should involve environmental modifications such as improved room acoustics for increased SNR, the use of FM/ RMHA systems and auditory training where possible. They also suggest that best results will occur when a multidisciplinary team are involved (medical and education professionals) and that involvement of education providers is of the utmost importance for children still involved in education.

The New Zealand APD Guidelines (W. Keith et al., 2019) indicate that the first priority of APD treatment is to address the audition issues first by providing auditory training and fitting of digital remote microphone hearing aids (RMHA) where indicated. Additional supportive top down therapy (phonological awareness training and other language therapy) should be initiated once the issues of audibility have been addressed.

The use of RMHA is a well proven treatment approach for treating APD by increasing audibility through increases in signal to noise ratios (Johnston, John, Kreisman, Hall, & Crandell, 2009; Reynolds et al., 2016). A modern RMHA system comprises of three parts. The first is a microphone that captures the signal of interest (often worn by a teacher/presenter at a conference/meeting etc), secondly a transmitter that sends the signal to a final receiver often coupled to a hearing aid (Wolfe et al., 2015). The hearing aids used in these cases are often a "low/no gain" hearing aid meaning that no frequency specific gain adjustments are made to the incoming sound source. Remote microphone systems can result in improvements in signal to noise ratios of 20 dB, even at high classroom noise levels (Hanschmann, Wiehe, Müller-Mazzotta, & Berger, 2010; Johnston et al., 2009; Kuk, Jackson, Keenan, & Lau, 2008; Wolfe et al., 2015). These systems are particularly valuable for children as most instruction and learning at school occurs via the aural route, and such RMHA systems remove the fatigue associated with the strain of constant auditory attention in background noise (Reynolds et al., 2016).

1.1.6.2. Adults

The diagnosis of APD in adults is often made in parallel to the diagnosis of serious brain injuries, advancing cognitive decline and more generalised age-related auditory decline. These other diagnoses complicate the treatment of APD. At present rehabilitation strategies for adults with APD are limited and many of the rehabilitation strategies identified for children are not appropriate for this population. Current practice is essentially restricted to the use of remote microphone systems alongside other medical interventions for co-morbid conditions. Personal low gain hearing aids paired with remote microphones which increase the speech signal to noise have been trialled successfully with stroke patients (Koohi, Vickers, Chandrashekar, et al., 2017). In patients experiencing traumatic brain injuries, time is required to heal the brain injury and many patients find that they are not able undertake taxing auditory training while this happens. When cognitive decline features in the diagnosis, auditory training will likely be difficult or not even considered.

1.1.7. Summary of APD knowledge

The APD academic space is constantly evolving with significant advances having been made toward understanding the neurobiological basis of the disorder over the last few decades. The lack of academic and clinical consensus however often results in fragmented and contradictory information being populated in the clinical and academic spaces as well as in popular and online media formats.

The APD situation in New Zealand is even more confused as two separate government departments are responsible for the diagnosis (Ministry of Health Manatū Hauora) and treatment (Ministry of Education Te Tāhuhu O Te Mātauranga) of APD in a system that has significant operational and strategy differences (W. Keith et al., 2019). The Sapre report "Auditory Processing Disorder: New Zealand Review" prepared jointly for the New Zealand Ministry of Education Te Tāhuhu O Te Mātauranga and Ministry of Health Manatū Hauora (Esplin & Wright, 2014) strongly advocates for parents, teachers and support workers to have easy access to high quality information and resources on APD. However, this report and others from similar healthcare systems in Europe and South Africa (Baldry & Hind, 2008; Fouché-Copley, Govender, & Khan, 2016; A. Ryan & Logue-Kennedy, 2013) identify that there is a widespread and significant knowledge gap regarding APD in the general community and more concerningly among many health and education professionals. In relation to the involvement of the family in patient centred care, this significant information gap may adversely affect the patient’s ability to make informed medical decisions.

1.2. Health Literacy and Patient Centred Care

1.2.1. Health literacy

Health literacy is a term used to describe the personal qualities and social resources needed for a patient to find, understand and then use health information for making health decisions (Beauchamp et al., 2015; Nutbeam, 2000). It includes skills such as the ability to communicate with health care professionals, consider the options and then enact their decisions (Beauchamp et al., 2015). Health literacy is known to be affected by cognitive ability, processing speed, and working memory (Bostock & Steptoe, 2012). Nutbeam (2000) suggests that health literacy needs to be viewed as much more than reading and writing ability and that health literacy is gained through three cognitively defined steps progressing from basic/ functional literacy onto communicative/interactive literacy and finally reaching critical levels of literacy. The most basic level of health literacy is functional literacy which describes those patients who have adequate reading and writing skills to participate in everyday life. Moving up to communicative/ interactive literacy requires a more sophisticated level of skills especially social skills that enable the patient to analyse information from different forms of communication sources (i.e. spoken and written) and apply this information to their own situation which may be slightly different from that described in the education materials. Critical literacy, the most advanced level of health literacy, requires that the patient not only critically analyse information but to use it to gain a level of control over their situation. The increasing levels of health literacy reflect greater levels of autonomy and personal empowerment. Higher levels of health literacy require increased levels of cognitive ability as well as the personal and social skills required for self-efficacy.

Low health literacy is consistently predicted by increasing age, low socioeconomic status, fewer educational qualifications, multiple chronic conditions and being from an ethnic minority group (Beauchamp et al., 2015; Bostock & Steptoe, 2012).

Low health literacy is consistently seen even in developed counties (Beauchamp et al., 2015). The Canadian Public Health Association reported for people aged 16-65 that less than half of the population (45%) had sufficient health literacy skills that would allow them to successfully complete tasks associated with daily health-care duties. When the over 65 years old subpopulation is included the rates this decreases to less than 40% (Rootman & Gordon-El-Bihbety, 2008). Protheroe et al. (2017) similarly report rates of low health literacy in excess of 52% for a town of low socioeconomic status in the UK. The factors they found associated with low health literacy are consistent with international trends and include older age, less formal educational, lower socioeconomic status, poor health and lack of access to the Internet. Bostock and Steptoe (2012) report that over a third of older adults in the UK have low health literacy. In 2006 the health literacy of Australian adults was surveyed in the Adult Literacy and Life Skills Survey (Australian Bureau of Statistics, 2008). This survey included questions assessing content, numeracy, and problem-solving skills. The survey found that 60% of Australians lack basic health literacy, described as the “minimum required for individuals to meet the complex demands of everyday life and work in the emerging knowledge-based economy”

In line with the broader definition of health literacy described by Nutbeam (2000), Bo, Friis, Osbourne, and Maindal (2014) investigated both the ability to understand health information and the patients ability to interact with healthcare professionals in Denmark. The study revealed that up to 20% of the adult population have difficulty understanding healthcare literature well enough that they would know what to do next. This was especially true of people from lower socioeconomic groups, those of non-Danish ethnicity and older people.

When health literacy rates were assessed in New Zealand (Ministry of Health Manatū Hauora, 2010), it was found that over half of the adult population had low health literacy skills. The level of health literacy measured would not allow the majority of adult New Zealanders to participate satisfactorily in most expected health care interactions. When the data was examined further, lower rates of health literacy were measured for Māori vs non-Māori and health literacy was lowest for Māori living in rural areas. The lowest health literacy by age occurred in Māori of ages 16-24 and from 50-65 years. Consistent with other overseas examples, obtaining tertiary education was related to high levels of health literacy.

1.2.2. Effects of low health literacy

Health literacy is increasingly viewed as not only a critical personal skill but also as a key public health priority to reduce the health burden of chronic diseases management (Nutbeam, 2000). When dealing with long term illnesses including hearing impairment, outcomes are more successful if a shared decision-making model is used (Ishikawa & Yano, 2011; Joosten et al., 2008). They found that greater patient satisfaction, adherence to treatment protocols and higher levels of wellbeing are often seen when the patient can participate in their own treatment plan. A key premise of shared decision-making model however is that the patient has sufficient health literacy including access to the internet, key information seeking behaviours to assess and process information given to them as part of this process (Gutierrez, Kindratt, Pagels, Foster, & Gimpel, 2014). The biggest risk to a patient's health occurs when a mismatch occurs between a patient's health literacy and the demands placed on that patient by the health care system (Rowlands et al., 2013).

The Korero Marama report from New Zealand (Ministry of Health Manatū Hauora, 2010) states that people of low health literacy are (i) less likely to use prevention services (i.e. screenings) (ii) have less knowledge of their illness, treatment and medicines (iii) are less likely to manage their chronic condition (iv) are more likely to be hospitalised by their chronic condition (v) are more likely to use emergency services and (vi) are more vulnerable to workplace injury because they do not understand safety precaution message. All of these outcomes are consistent with international reports and carry heavy economic and social costs (Agarwal, Shah, Stone, Ricks, & Friedlander, 2015; Eichler, Wieser, & Brügger, 2009; Haun et al., 2015; Stielke, Dyakova, Ashton, & van Dam, 2019).

When a patient has a long-term condition, the amount of contact the patient has with medical professionals and service providers increases. Additionally, the aging process may compromise cognitive ability ironically at a time they need increased access to medical information and the ability to process this information (Kobayashi, Wardle, & von Wagner, 2015). In a study of older adults in the UK, it was found that a third of older adults had difficulties understanding basic levels of written health information (Bostock & Steptoe, 2012) and that low health literacy was correlated to higher mortality, less knowledge of chronic disease processes, lower mental and physical health, limited use of preventive services leading to higher rates of hospital admissions.

At a more personal level, when patients do not understand the health care material presented to them, feelings of shame and embarrassment may impose a psychological barrier to asking for future help (Parikh, Parker, Nurss, Baker, & Williams, 1996). Parikh et al. (1996) found patients with low health literacy were not willing to admit to feelings of shame in front of medical staff and this caused them to delay or miss future appointments entirely. They were also less likely to bring a support person with them to appointments in case they revealed their low literacy level nor were they willing to ask for clarification or for material in a more accessible form.

Many governments and not for profit organisations have recognised the limitations that low health literacy can place on individuals as well as society as a whole (Eichler et al., 2009). Very clearly, when a text is too difficult to read/ understand then it has no health literacy worth regardless of the importance of the information it contains. The ability and responsibility to write clearly and plainly has long been suggested and is one of the simplest and most cost effective ways to increase health literacy (Grene, Cleary, & Marcus-Quinn, 2017). The application of plain language to scientific and technical texts including medical information is one of the key drivers of the Plain Language movement.

1.3. Plain language initiatives

Plain language refers to presenting information in a way that can be understood easily by the majority of the target population and is viewed as a key strategic approach to combatting low health literacy (Grene et al., 2017; Stableford & Mettger, 2007).

Plain language initiatives are described as being the combination of a communicator's ethical responsibility to make understandability a priority and the application of communication skills to best meet the interests of the intended audience (Grene et al., 2017). Plain language initiatives were first described in the 1970's (Matveeva, Moosally, & Willerton, 2017) but have gained renewed significance recently due to the signing of the Plain Writing Act in 2010 and the Executive Order 13563 in 2011 which mandates that all US Government Departments are to use plain language in any/all communications. Plain language initiatives are being applied globally by most government and non-government organisations interested in improving access to health care. The WHO have a guiding principle that all health-related materials should be empowering and use clear and plain language (The World Health Organisation, 2019). ASHA have an organisational vision statement of "making effective communication, a human right, accessible and achievable for all" which is a clear statement of commitment to the use of plain language initiatives towards improving health literacy (American Speech-Language-Hearing Association, 2019). ASHA state that the use of plain language should not be limited to written materials but must be carried forward to all communications with patients and their families (American Speech-Language-Hearing Association, 2019). Many organisations now provide clear guidelines on their website regarding best practice guidelines for plain language usage (American Speech-Language-Hearing Association, 2019; Centers for Disease Control and Prevention, 2019; National Institute of Health, 2019; The World Health Organisation, 2019).

The use of plain language means the use of effective and clear communication strategies that engage and are fit for purpose for the intended audience. It does not mean the importance or emphasis of the content will be reduced (National Institute of Health, 2019). The principles of plain language suggest a careful consideration of the intended audience, using an active voice, organising materials in a logical way and using technical approaches such as bulleted lists, shorter sentences and paragraphs and the use of common everyday words (Matveeva et al., 2017). The US government health communication professionals agree that the following 6 items (Grene et al., 2017) need consideration when preparing plain language items:

a. Write for the audience’s level of understanding with the subject matter
b. Write for the literacy level of the target population
c. Present information in a logical order
d. Use simple sentence structure
e. Define unfamiliar concepts
f. Use correct grammar and sentence structure

A meta study of the application of plain language approaches in improving health literacy by Grene et al. (2017) showed that where plain language was used in medical interventions the patients understanding of the material increased. However, education of medical professionals in how to best use and apply plain language in their interactions with patients was strongly suggested. Otal et al. (2012) found that when plain language was used to prepare an information sheet for parents about how to deal with a fever, that the plain language materials were well received and understandable irrespective of the parent’s health literacy. In the area of otolaryngology, when best practice guidelines have been clinically reviewed, plain language summaries have also been prepared. These are intended to be a useful overview of the pathology or surgery and to aid patient centred care discussions around expectations, planning care, and improving surgical outcomes (Krouse, Magit, O’Connor, Schwarz, & Walsh, 2017). These are currently available for otitis media with effusion (O’Connor et al., 2016), Benign paroxysmal positional vertigo (Bhattacharyya, Hollingsworth, Mahoney, &

O'Connor, 2017), tonsillectomy (Finestone et al., 2019), sudden hearing loss (Chandrasekhar, Hollingsworth, Monjur, & Satterfield, 2019), cerumen management (Krouse et al., 2017) and will expand to include more pathologies/surgical procedures as more best practice guidelines are reviewed. A plain language summary is currently not available for APD.

1.4. Health Information

Access to good, reliable information is the cornerstone of health literacy (Charnock, Sheppers, Needham, & Gann, 1999; Kickbusch, Maag, & Wait, 2006). To achieve a full health literate society, health literacy must be understood and prioritised by health professionals, politicians and policy-makers (Batterham, Hawkins, Collins, Buchbinder, & Osbourne, 2016; Kickbusch et al., 2006). Traditional healthcare models which have patients access health information predominantly from their regular medical practitioner are undergoing radical change driven by readily available health information on the internet (Lee, Hoti, Hughes, & Emmerton, 2017). The traditional doctor/patient relationship is increasingly evolving from a static one-way information exchange to a flexible shared care model where the patient is actively encouraged to participate in all the decisions about treatment. Traditionally the patient/doctor relationship has been hierarchical and uneven in nature with information predominantly being provided by the health practitioner (Pagedar, Scularick, Lee, & Karnell, 2018) however Leroy, Helmreich, Cowie, Miller, and Zheng (2008) suggest consistent with patient centred practices that patient sourced health information (mainly online) should be considered a prologue and epilogue to interactions with medical personnel.

McCarthy et al. (2012) found individuals had great difficulty recalling the medical instructions provided to them during a consultation, and patients with low literacy skills faired significantly worse. Patients with adequate health literacy skills had recall as low as 31%, indicating that the recall ability of spoken communication was a very challenging task. This is consistent with the study by Pianosi et al. (2016) who also found that parents remembered only about half the benefits of surgery and only one-third the risks mentioned during the consultation. Clinicians need to be aware that when parents have low recall, they were likely to be seeking additional information from other sources and this is increasingly being provided via online information. Pletneva, Cruchet, Simonet, Kajiwara, and Boyer (2011) report that when citizens needed to clarify any sort of medical information, that in 79% of cases, a web search was their starting point.

1.4.1. Global internet usage and health care

Global access to the internet has increased dramatically over the recent years and has become a normal part of everyday life for many people (Atcherson et al., 2014; C. Ryan, 2017). Currently, almost 57% of the world's population is using the internet, equating to 4383 million people (Internet World Stats, 2019). In 1997, 41% of internet users had sought medical/health information online and this had risen to 79% by 2004 (Rice, 2006). In 2016, C. Ryan (2017) reported that 89% of American households had access to the internet either through a smartphone or desktop/laptop or tablet. C. Ryan (2017) notes that increased internet access has impacted many areas of everyday life including the ability to pay bills and do shopping online, to socially connect with people, and that the internet has become a route to pursuing formal education, allowing work from home options and to collaborate with people regardless of geographic or physical boundaries. However caution is needed as it can never be assumed that access to a computer directly translates to the motivation and ability to use it (Bodie & Dutta, 2008; Pagedar et al., 2018).

Whilst it is very clear that internet access has increased, the pattern of access is far from even (Rice, 2006). Some demographic groups appear to have higher degrees of access to the internet compared to other demographic groups (C. Ryan, 2017). "The Digital Divide" historically describes inequalities of internet access between populations of higher education/socioeconomic status (internet usually provided within homes compared) to lower educated/lower socioeconomic populations (internet access usually via public access devices) (Bidmon & Terlutter, 2015; Bodie & Dutta, 2008). The Digital Divide still exists but as internet penetrance and access increases, the Divide is more often reflecting a difference in usage rather than traditional access (Bodie & Dutta, 2008; van Deursen & van Dijk, 2014). van Deursen and van Dijk (2014) suggest that people of higher socioeconomic predominately use the internet for reading newspapers, planning travel and searching for information while the lower socioeconomic demographics are more inclined to use the internet to engage in leisure/entertainment activities (streaming or downloading music, playing games or interacting on social media) (van Deursen & van Dijk, 2014).

According to the main themes from the PEW Internet and American Life Project (Rice, 2006) the main reason people access online health information is (i) someone the person knows has been diagnosed with a medical condition (81%), (ii) they have been diagnosed with a new medical condition themselves (58%), (iii) they have been prescribed a new medication/prescription (56%), (iv) they are dealing with an ongoing medical condition (47%), (v) they have answered questions form a recent doctors visit

(47%), (vi) they are deciding to change their diet or exercise regime (46%), (vii) or they are a caregiver to someone else (38%) (Rice, 2006).

Kontos, Blake, Chou, and Prestin (2014) investigated how Americans use eHealth websites to augment their medical care and found that 18.59% of people had used the internet to email providers, buy medicines and track health information. They found an increased number had used it for searching for a healthcare provider (38.42%) but most of the healthcare related internet usages was related to finding information about a specific problem for themselves (79.04%) or for someone else (57.04%). They found that having a college degree was a high predictor of accessing healthcare online and that younger adults (18-34 years old) were 3.5 times as likely to access health information online compared to older adults (65 years plus). Women were also more likely than men to access online healthcare for themselves or for others (i.e. a family member). It was also found that those people with lower income (less than $US20,000) and low education were more likely to rely on social networking sites such as Facebook for medical information compared to higher income earners and those with college degrees. Almost half of parents whose children have ear nose and throat (ENT) concerns seek online health information about their children's medical concerns and about half of these parents make medical decisions based on what they read online (Rees, Ford, & Sheard, 2002; Wozney et al., 2017).

1.4.2. Benefits and risks of online health information

Simpson, Le, and Malicka (2018) and (Saxena et al., 2015) suggest that as well as providing information, that the online health information encourages social supports through targeted online forums and chat groups. Such groups can act as virtual support groups connecting people with similar experiences with no limits on physical locations and removing any participatory limitations that often come with “in real life” social situations. Rice (2006) also notes that the internet health information sites can remove obstacles found in traditional medical models including providing anonymous access, tailored information and social support.

Despite the many benefits to accessing online health information, many people are overwhelmed with the sheer volume, the high complexity of the information and the hugely varying quality of health information available online (Lee et al., 2017; Simpson et al., 2018). In a study of older adults in the UK, it was found that a third of older adults had difficulties understanding even the most basic level of written health information (Bostock & Steptoe, 2012) and that low health literacy was correlated to higher mortality, less knowledge of chronic health processes, lower mental and physical health, limited use of preventive services, higher rates of hospital admissions. Lee et al. (2017) found that patients with lower health literacy i.e. those indicating that they needed help navigating health information on the internet, indicated that they really wanted health professionals to help guide them to suitable health information in the internet. Similar results were found by Birru et al. (2004) who observed that adults with low literacy did not use optimal searching terms (often unspecific) or techniques (unwilling to click on information links) when searching for health information and often the information they did find was written in language above their comprehension level. They were also unable to interpret health information when it was presented i.e., they were unable to describe the information in their own words after reading it.

1.5. Assessing the quality of online health information

While internet usage has infiltrated nearly every aspect of modern life, (Beaunoyer, Arsenault, Lomanowska, & Guitton, 2017) caution that online health related information especially needs to be carefully curated to ensure that it is accurate, appropriate and understandable (Diviani, van den Putte, Giani, & van Weert, 2015). Without these considerations, the usefulness of the information to patients is limited and possibly dangerous. Most people accessing online health information prioritise accessibility (Simpson et al., 2018). When patients encounter health materials that are above their health literacy level, they can often shift to sources which are within their understanding but are without health professional endorsement. Sources such as Wikipedia are among those websites that persons of low health literacy might turn to for options around medical care or treatment options (Beaunoyer et al., 2017). Therefore, producing accurate and accessible information is a key requirement.

Assessing online health information is not a simple task due to the multiple elements that need assessing. Beaunoyer et al. (2017) suggest that validity and reliability of information, the semantic complexity the way the content is organised and presented, the emotional tone of the material and the use of multimedia all need to be considered when assessing online health material. (Wang, Miller, Schmitt, & Wen, 2013) suggest that the greatest aspects that affect text understanding are content, style and presentation, format and organisation. Currently no one tool that can assess all of these areas (Beaunoyer et al., 2017). Multiple tools can be used ranging from traditional readability assessments, use of specifically designed health literacy tools or through to the adaption of medical questionnaires and specific health literacy tools.

1.5.1. Readability

Readability is refers to how difficult a text is to understand (Ley & Florio, 1996) and is one of the many tools used to assess written text. Other methods used to analyse written text include analysis of vocabulary, the Cloze procedure (comprehension test) and pretesting of materials with ad-hoc comprehension tests (Ley & Florio, 1996; Wang et al., 2013). Readability formulas have historically been used in education, the military, by publishers and are increasingly being used to guide the development of patient-oriented health literature. They are especially attractive given their integration into many word processing programmes (Ley & Florio, 1996).

Readability formulas have common developmental characteristics namely that they use multiple regressions to predict the difficulty of understanding a text based upon measuring some common linguistic component of the text (Ley & Florio, 1996). Commonly measured linguistic components include (i) average word length in syllables, (ii) average sentence length in words, (iii) proportion of common words used, (iv) proportion of words with three or more syllables in them and (v) the proportion of words used that are monosyllabic (Ley & Florio, 1996).

By 1980 there were over 200 readability formulas in use (DuBay, 2004). However, the six most commonly used readability formulas used to assess medical information are the Flesch Kincaid Grade Level, The Flesch Reading ease, the Simple Measure of Gobbledygook, the Fry Readability Graph, the Gunning Fog Index and the New Dale-Chall (Beaunoyer et al., 2017).

1.5.1.1. Simple Measure of Gobbledegook (SMOG)

The SMOG test was developed by G. Harry McLaughlin in 1969 and uses sentence length as the main determinant.

Reading grade level (RGL) = 3+ $\sqrt{lw_{30}}$

Where: $\sqrt{lw_{30}}$ = the square root of the number of words of three or more syllables per 30 sentences (10 from the beginning of the text, 10 from the middle and 10 from the end of the text)

1.5.1.2. Flesch – Kincaid Formula

Reading grade level (RGL) = 0.39sl + 11.8spw – 15.59

Where: Sl = average number of words per sentence

Spw = average number of syllables per word

1.5.1.3. Gunning FOG Index

Grade Level = 0.4 (average sentence length + hard words)

Where: Hard words = number of words of more than two syllables

Material written for the general public must be written in such a way that the members least able to read and comprehend the material still gain benefit from it. The more critical the information is for health and safety purposes, the greater the need for readability and understanding becomes (DuBay, 2004). The widely accepted reading comprehension level that allows most of the general public to access and then process a text is a reading grade level of 6 years (Stossel, Segar, Gliatto, Fallar, & Karani, 2012). This means that a person who has received 6 years of formal reading instruction should be able to read, understand and use the information contained in the text. When a person encounters written material at a level greater than they can understand they usually stop reading it (DuBay, 2004), or for questionnaires they may not complete all questions, provide partial answers or complete the questionnaire with information inconsistent with their actual health status (Atcherson et al., 2013).

While there is no widespread agreement on which readability formula is the best choice for analysing online medical information (Masoni & Guelfi, 2017), the SMOG grade level equivalency process does assumes 100% comprehension of the material for that grade level, has greater consistency across different reading passages, simplicity and more recently updated validation . Friedman and Hoffman-Goetz (2006) note that using two or more readability formulas is advantageous and can increase the reliability of the readability scores as readability scores are known to vary widely when different formulas are used (Wang et al., 2013).

The subtleties in readability formulas mean that often a range of readability values/reading grade levels can be obtained for the same text and must be interpreted with caution (Wang et al., 2013). In cases where multiple readability tools are used to assess the same text, a conservative approach of using the highest reading grade level should be applied. The SMOG formula expects a 100% comprehension rate and is suggested to be a better readability formula for health care literature where the comprehension of the material is pertinent. The Flesch Reading Ease and Flesch Kincaid formulas have lower comprehension expectations of 75% compared to the 90% criterion for the SMOG formula. There is a significant risk that the readability of health literature will be overstated due to limited comprehension (Beaunoyer et al., 2017; Wang et al., 2013)

A large review was carried out by (Laplante-Lévesque, Brannstrom, Andersson, & Lunner, 2012) to review the readability of online audiology materials. In this study, 66 webpages were analysed, and the readability assessed using the Flesch Reading ease method, the SMOG and Flesch Kincaid Reading Grade Level Formula. The RGL that were obtained for the Flesch Kincaid was an average of 11.10 with a range of 7.3-17.16 and an average of 12.36 for the SMOG with a range of 8.48 to 17.775. In all cases the readability indicated that the material was written above the level needed for widespread public understanding and showed that a person would need on average 11-12 years of education to understand these materials. These high readability scores are replicated in studies of online tinnitus material (McKearney, MacKinnon, Smith, & Baker, 2018), glue ear websites (Ritchie, Tornari, Patel, & Lakhani, 2016), aural atresia (Alamoudi & Hong, 2015) and more generalised audiology webpages (Laplante-Lévesque & Sundewall Thorén, 2015). To date there has been no attempt to assess the readability of online APD material. Clearly, more work is needed to assess and produce readable online material in the topics of audiology, including APD, that will be useful for patients wanting to improve their knowledge and part take in shared decision making.

1.5.2. PEMAT

The Patient Education Material Assessment Tool (PEMAT) was recently developed to allow assessment of health educational materials by untrained lay persons as well as by health professionals in both written and audio-visual formats (Shoemaker, Wolf, & Brach, 2014). Currently, the PEMAT Tool is the only quality assessment tool that can assess audio visual material (Vishnevetsky, Burrow Walters, & See Tan, 2018). The PEMAT tool has two parts – the first considers the understandability of the education material while the second part and probably the most valuable part considers the actionability i.e. the ability of the person reading the material to decide what happens next and what is needed to action this (Shoemaker et al., 2014). The Understandability section has 19 questions and considers content, word choice and style, use of numbers, organisation of information and layout and design and the use of visual aids. Each category is scored either a 1 for agree or a 0 for disagree. The actionability section has a further 5 questions, also rated 1 for agree or 0 for disagree, that relate to whether the material provides clear outcomes and a clear pathway for these to be acted upon. The tool has been tested extensively tested and has good interrater reliability (Vishnevetsky et al., 2018). To date PEMAT has only been used to evaluate a small number of audiological patient materials, probably mostly related to its very recent development. However, it shows clear application to APD as it can be applied to AV materials which are commonly used in commercial websites such as those from commercial APD treatment providers.

1.5.3. DISCERN

The DISCERN tool was the first quality assessment tool developed that could be employed by producers of health promotion materials (i.e. medical professionals) and the end user i.e. the patient (Charnock et al., 1999). When considering the quality of written health information it is important to consider and disclosures and qualifications of the author(s), all sponsorship and funding sources, statements about confidentiality and privacy concerns given by the authors, that it contains current and clear unbiased information and that all treatment options and their risks/ benefits are considered (Shedlosky-Shoemaker, Sturm, Saleem, & Kelly, 2009). The DISCERN tool consists of 15 key quality criteria, and an overall quality rating (Charnock et al., 1999). Each of the quality criteria are assessed on a 5 point. The first part of the DISCERN Tool concentrates on issues of reliability. There are 8 questions that examine the sources of information used to compile the health resources, whether is it biased in its presentation and whether areas of uncertainty are identified. The second part of the Tool consists of 7 questions focussed on the quality of information around treatment options. These questions assess whether both the benefits and risks are presented, whether the "watchful waiting"/no treatment option is adequately addressed and what impact these treatment options may have on quality of life and the ability to use it for decision making. The final section asks for a final quality assessment made after considering both the first and second sections. This quality rating is provided on the scale from serious or extensive shortcomings (score of 1), potentially important but not serious shortcomings (score of 3) to minimal shortcomings (score of 5) (Charnock et al., 1999).

The DISCERN tool has been used to assess a number of audiological materials including general otolaryngology topics (Danino, Muzaffar, Mitchell-Innes, Howard, & Coulson, 2016; Pusz & Brietzke, 2012), ear nose and throat surgery (Goslin & Elhassan, 2013), glue ear (otitis media with effusion) (Ritchie et al., 2016), tonsillectomy and sleep apnoea (Chi, Jabbour, & Aaronson, 2017) and tinnitus (Fackrell, Hoare, Smith, McCormack, & Hall, 2012; McKearney et al., 2018). In most of these studies, the average quality of audiological information on the internet based on the DISCERN tool is rated poor to fair. To date, the DISCERN tool has not been used to assess online APD materials.

1.5.4. HON code

The Health on the Net (HON) Certification programme is a voluntary certification programme created as a means to vet/certify the correctness and quality of health information online and to create a searchable database that facilitates easy access to these materials (Team HoN, 2019). Websites having HON certification have greater reliability and credibility compared to non-certified sites (Manchaiah et al., 2019). Certification is granted and displayed on a website once all medical material on the website is verified (Shedlosky-Shoemaker et al., 2009) and assessed by a qualified medical specialist. The full list of HON certified websites can be found at http://www.hon.ch and a downloadable tool bar can be added to web browser. (Shedlosky-Shoemaker et al., 2009) caution that ongoing compliance with the HON Code is not always enforced after accreditation is gained.

1.6. Study Rationale

The hearing disorder, APD, is unknown by many members of the medical and general populations (Baldry & Hind, 2008; Esplin & Wright, 2014; A. Ryan & Logue-Kennedy, 2013). When a diagnosis of APD is made, it is possible that the patient and/or their support person(s) may have never heard of the disorder. They may seek additional information to assist in their understanding and further medical decision making. Given the large role that the internet plays in most people lives, online information sources may well be their first port of call. Increasingly many people are turning to online information sources to seek out health related information however, the quality of online information for rare, new or niche disorders is often low (Badiu et al., 2017; Pauer et al., 2017).

Previous studies have shown that the readability of all most all online health information including audiology information exceeds the recommended sixth RGL and that the quality of online health information is variable (Daraz et al., 2018) and most do not score highly enough to have a positive effect on health literacy. Given the niche and largely unknown nature of the APD diagnosis, it is important that all information available online be of sufficient quality and understandability to aid people in improving their knowledge and being able to use the information to aid medical decisions. To date, the readability or quality of online APD information has not been reported.

1.6.1. Research Aims and Hypotheses

The aim of this study was to report on the readability and quality of online information regarding the hearing disorder Auditory processing disorder available in English. The study aimed to investigate the following research questions:

1. Is there an even distribution of APD related online written material from different regions?

2. Is there an even distribution of APD related online written material from different types of organisations?

3. Is there an even distribution of APD related online written material from webpages with and without HON certification?

4. Are there significant differences in the readability of APD related online written material from different regions?

5. Are there significant differences in the readability of APD related online written material from different types of organisations?

6. Are there significant differences in the readability of APD related online written material from webpages with and without HON certification?

7. Are there significant differences in the quality of APD related online written material from different regions using the DISCERN tool?

8. Are there significant differences in the quality of APD related online written material from different regions using the PEMAT tool?

9. Are there significant differences in the quality of APD related online written material from different regions using the Plain Language tool?

10. Are there significant differences in the quality of APD related online written material from different types of organisations using the DISCERN tool?

11. Are there significant differences in the quality of APD related online written material from different types of organisations using the PEMAT tool?

12. Are there significant differences in the quality of APD related online written material from different types of organisations using the Plain Language tool?

13. Are there significant differences in the quality of APD related online written material from webpages with and without HON certification?

Based on these research questions 15 null hypotheses exist:

1. There is an even distribution of webpages based on region.

2. There is an even distribution of webpages based on type of organisation.

3. There is an even distribution of webpages based on HON certification.

4. There is no significant difference in mean RGL of webpages based on region.

5. There is no significant difference in mean RGL of webpages based on type of organisation.

6. There is no significant difference in mean RGL of webpages based on HON certification.

7. There is no significant difference in DISCERN scores of webpages based on region.

8. There is no significant difference in DISCERN scores of webpages based on type of organisation.

9. There is no significant difference in DISCERN scores of webpages based on HON certification.

10. There is no significant difference in PEMAT scores of webpages based on region.

11. There is no significant difference in PEMAT scores of webpages based on type of organisation.

12. There is no significant difference in PEMAT scores of webpages based on HON certification

13. There is no significant difference in Plain language scores of webpages based on region.

14. There is no significant difference in Plain language scores of webpages based on type of organisation.

15. There is no significant difference in Plain language scores of webpages based on HON certification.

Method

2.1. Overview

The aims of this study were to investigate the readability and quality of online information regarding APD which is written in the English language. The methodology used in this study is consistent with that previously described by Manchaiah et al. (2019). The APD webpages were collected using search terms returned from a survey that asked people to list search terms related to APD information. Once collected, the webpage collection was subsampled and reduced by approximately 50% for further analysis. Firstly, readability was assessed using an automated readability tool which included the FOG, SMOG, and F-K formulas. Secondly, the quality of the retrieved material was assessed using the Plain English Language Checklist, The Patient Education Material Assessment Tool (PEMAT tool) and the DISCERN tool. Quality of the materials was additionally assessed by determining the presence of HONcode certification. A Low Risk Ethics approval was required for this study (recruitment of survey participants) and was granted before the data collection began (University of Canterbury HEC 2019/07/LR granted 1 April 2019).

2.2. Identification of Search Terms

The search terms for this study were determined by asking two independent groups of participants what search terms they would use to access online APD information. The first group of participants were from an online community who were not expected to have prior knowledge about APD. This population was recruited when they replied to a request on the authors Facebook page asking for volunteers to complete a short survey. This population were referred to as the naïve population. The second population were assumed to have prior knowledge of APD. These adults were recruited from an online community that either had children diagnosed with APD or were adults professionally supporting children with APD. The online community used for recruitment of this population was the closed Facebook Group “Auditory Processing Disorder Australia/New Zealand”. This population was referred to as the non- naïve population. The survey question was consistent for both populations and asked: “If you had a child diagnosed with a hearing disorder called Auditory Processing Disorder, what words would you search in Google? Feel free to mention as few or as many as you can think of”. The survey participants were required to be fluent, adult speakers of English.

The most-mentioned search terms related to APD from each population were selected for further analysis using Google trends (www.google.com/trends). Google trends is a free public analysis tool that assesses the popularity of search queries in Google Search across various regions and languages. It was used to select the search terms to carry forward for the website collection. The following settings were selected for the analysis: *worldwide* in the *past 12 months* within *all categories* using *web search*. Based on this, two search terms “auditory processing disorder” and “APD” were selected for further use.

2.3. Search Locations

Search locations were based on countries with Google domains, English as an official language, and more than 2 million internet users. Firstly, countries with Google domains were retrieved from the list of regions selectable in the Advanced Search section of Google Settings. Secondly, countries with English as an official language were selected using information from the CIA World Factbook (Central Intelligence Agency, 2007). This resulted in 66 countries. The total internet users from these countries was 1,420,288,344. To narrow the search, countries with less than two million internet users were eliminated using information from Internet World Stats (2019). This resulted in 21 countries and 1,377,149,400 internet users and encompassed 97% of English-speaking internet users. The internet penetrance rates of these countries were retrieved from World Stats (2019) (Table 1). The regions that each country belonged to was derived using World Health Organisation regional offices (World Health Organisation, 2018).

Table 1. Countries included in the internet search with English as an official language and/or used for commerce and at least two million internet users.

Country	Region	Internet Penetration Rate	Population of Internet Users
Kenya	Africa	83.0%	43,329,434
Liberia	Africa	80.90%	4,028,418
South Africa	Africa	53.7%	31,185,634
Sudan	Africa	27.80%	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. Inclusion and Exclusion Criteria

The inclusion criteria for the webpages were: (1) written in English, (2) provided relevant information about APD and (3) available to the public. Webpages were excluded if they: (1) were Google identified advertisements or had a paywall (were not open access), (2) were a directory listing, and (3) were less than 100 words long. The exclusion criteria associated with length of the webpage were set based on the minimum requirements of 100 words for the readability tools. Videos were only included for analysis with the PEMAT tool.

2.5. Search Procedure

To perform the Google search, the ccTLD of each country was selected through Google advanced settings. The search was completed on the 4th June 2019 using a Microsoft Edge browser which had not been used to search for APD materials before. The two search terms were entered the 21 ccTLDs one at a time. The first ten search listings were accessed and measured against the inclusion and exclusion criteria. This is based on research that demonstrates that individuals only access the first page of Google results, that defaults to ten listings, when searching for information online. Only the webpages that met the criteria were selected for analysis. Once the search was completed, all duplicate webpages were removed. This gave a final list of 210 unique webpages.

An Excel file was created to record the Uniform Resource Locator (URL), the country of origin, type of organisation, and HONcode certification of the captured webpages. Country of origin was determined by the country used in the Google search. Webpages that targeted a global audience (e.g. Wikipedia) or provided information in multiple languages were coded as World. The website type of organisation referred to whether the organisation was non-profit, commercial, academic or government. This was determined either by the URL, information provided in the *About Us* (or similar) section of each webpage or the intent of the web content. The webpage was coded as commercial if it was supported by advertisers or if it was the webpage of a company offering commercial services i.e. diagnostic audiological services or educational training. It was coded as government if it was produced by a governmental agency. It was coded academic if it contained a peer reviewed paper, academic discussion paper or a thesis. It was coded as non-profit if it was verified as being non-profit on the *About Us* (or similar) section of the webpage or further search information on the Internet.

2.6. Subsampling for analysis

A power analysis was undertaken to determine the minimum sample size needed to ensure even sampling of each geographic location as well as ensuring normal distribution. The minimum sample size determined was 18 webpages per geographic region. Therefore, 18 webpages were randomly selected from each geographic region for further analysis. Randomisation was used to ensure each country domain in that region had an equal chance of representation. The final size of the subsample that was used for all further analyses was 90 unique webpages across 6 different geographic locations.

2.7. Readability Analysis

A free online English readability tool was used to estimate readability (www.online-utility.org/english/readability_test_and_improve.jsp) using the FOG, SMOG, and F-K formulas. This was done by copying the content of each webpage into the readability tool. If the copied text included text in bullet points or as numbered points, a full stop was placed at the end of each bullet point to ensure the readability tool did not misinterpret the bullet points as one long string of text. If the website contained very large reports or a thesis (> 10 pages) only the executive summary or abstract was copied. Lists of references were excluded from the readability assessment. The calculated readability scores were entered an excel spreadsheet and the average RGL was calculated (the mean of the FOG, SMOG and F-K readability values).

2.8. Quality assessment

2.8.1 Calibration of quality score ratings

Calibration of quality ratings was carried out for all quality matrices (Plain English Language Checklist, PEMAT and DISCERN) by seven individual raters. Initial calibration included rating 3 practice internet-based hearing health articles. A discussion of the criteria for each tool was then discussed alongside the intra-class coefficient (ICC) results. The ICC kappa value represents *the proportion of agreement corrected for chance* (Fleiss & Cohen, 1973) and values greater than 0.75 suggest excellent agreement between raters beyond chance, and values between .40 and .75 suggest fair agreement beyond chance (Fleiss, 1981). The remaining webpages were then independently assessed by the researcher.

2.8.2 HONcode Certification

HONcode certification was used as a measure of quality. The captured webpages were entered into the search function on the HONcode webpage and if an exact match was found was coded as present or absent if no results or no exact matches were found (https://www.hon.ch/HONcode/Search/search.html). The presence or absence of

HONcode certification for each captured webpage was recorded (present or absent) in the overall Excel worksheet.

2.8.3 PEMAT

The PEMAT tool is a tool specifically designed for both clinicians and patients to use to rate education materials available in the healthcare setting. The tool has 2 sections (actionability and understandability) which were assessed individually and pooled to produce a single overall score. The Understandability section (16 questions) rated material based on content, word choice and style, use of numbers, organisation, layout and design, and visual aids. The actionability section (6 questions) rated the material on what actions were given for a reader to follow and what tools were provided to enable this. Where a "not applicable" score was recorded, the question was excluded from the total score and the final percentage score was adjusted. The final scores for each section and a pooled score were recorded in the global analysis spreadsheet.

2.8.4 Plain English Language Checklist

The Plain English Language Checklist was a novel tool developed specifically for this study and consisted of 20 criteria known to be important for ease of information transfer including reader focus, organisation, writing style and design and style. These factors were rated as either meeting the standard required (recorded as "yes"), not at standard (recorded as "no") or not applicable (i.e. print materials were not assessed on factors associated with audio visual criteria). Where a "not applicable" score was recorded, the question was excluded from the total score and the final percentage score was adjusted. The final scores were recorded in the global analysis spreadsheet.

2.8.5 DISCERN

The DISCERN tool is a well validated tool that focuses on assessing the quality of patient education materials centred on treatment options in healthcare. The tool consists of 15 criteria that rate patient education materials based on sources of evidence used to prepare the material, evidence of bias, the treatment choices available and the risks and benefits of these treatment choices. The DISCERN tool is available at the following webpage: http://www.discern.org.uk/discern_instrument.php. Based on the answers to all the above questions, the tool gives asks the rater to give an overall rating "Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices". The final DISCERN scores were recorded for all the websites analysed (except videos) and entered the global analysis spreadsheet.

2.9. Data Analysis

There were four dependent variables in this study. They were average RGL and the material quality scores (DISCERN, Plain English Language Checklist and PEMAT). The three independent variables were country of origin (6 geographic locations), HONcode Certification (2 levels) and type of organisation (5 types). Statistical analysis of data was performed using IBM SPSS Version 24 software (IBM Corp, 2016). The assumptions of normality were tested, and the data were analysed using parametric methods or non-parametric analyses depending on whether these assumptions were violated. The descriptive statistics included intraclass correlation coefficient (ICC) and Chi-square test and hypothesis testing used univariate analysis and the Kruskal Wallis H test. An alpha level of 0.05 was used to determine significance for all statistical analyses.

Results

3.1. Results overview

The purpose of this study was to assess the readability and quality of online information available for the hearing disorder APD that is presented in the English language. This online information is representative of the information that may be sought by parents, teachers and other support workers after a person is diagnosed with APD. The study also aimed to investigate the relationship between readability and quality scores with the webpage's country of origin, the type of organisation producing the webpage and the presence of a HONcode certification.

3.2. Survey Data

The surveys were conducted with two sample populations (Naïve and non-naïve populations) each answering the same question. Surveys completed by the naïve population (i.e. having no prior knowledge of APD) were predominantly done by women aged 30 - 50 years of NZ/European ethnicity with most of them having at least a bachelor's level educational attainment. The survey respondents for the non-naïve populations was similar to that of the naïve population. The top 10 most common search terms provided by both groups are shown in Table 2.

Table 2. The top 10 search terms provided in the survey by the participants of the naïve and non-naïve populations.

Percentage of time a key word was suggested by the Naïve population (n = 51)		**Percentage of time a key word was suggested by the Non-naïve population (n = 11)**	
Auditory processing disorder	35%	APD	55%
APD	25%	cAPD	36%
Hearing loss in children	25%	Auditory processing disorder	27%
Treatment for APD	12%	Auditory processing	18%
Auditory processing	10%	APD NZ	18%
Auditory processing disorder children	10%	Central auditory processing disorder	9%
Auditory processing disorder treatment	8%	What is APD	9%
Auditory processing disorder symptoms	6%	What can we do at home to help	9%
Hearing	6%	What help at school is he entitled to?	9%
Hearing disorders	6%	What are the signs of auditory processing disorder?	9%

A Google Trends search showed that only the terms APD and Auditory Processing Disorder had significant search histories. The addition of search terms "cAPD or central auditory processing" did not change the Google Trends analysis. The addition of other broader search terms provided by the survey respondents did not improve the number of URLS being returned. The decision was made to proceed from this point onwards with only the search terms of APD and Auditory Processing Disorder. Since these two terms were highly ranked search terms for both the naïve and non-naïve populations, it was concluded that prior exposure to APD did not produce a difference in the search terms provided. No distinctions were made from this point forward between the two survey groups.

Using the search terms "auditory processing disorder and APD", 210 webpages were captured in the initial web search and 90 of these webpages were subsampled for further analysis. Over the course of the analysis, 8 webpages were further excluded from the analysis. The reasons for this included webpage content changing and not including APD information, (*n* = 1, 12.5%), webpages being removed (i.e. page no longer found) (*n* = 3, 37.5%), the content whilst including the search terms APD were found not to be specific enough to the topic (*n* = 2, 25%) and a repeat of a webpage but located at a unique URL (*n* = 1, 12.5%).

3.3. Descriptive Statistics

3.3.1. Region and Type of organisation.

Excluding the 8 webpages that were excluded during the analysis, 82 webpages were subject to the readability and quality assessments. Africa, Europe and the Western Pacific regions had 15 webpages each included in the final analysis and Asia and the Americas regions had 16 webpages each included. The type of organisation that produced the webpage was recorded. Most were commercial companies offering diagnostic testing and remedial therapy for APD. Commercial educational and educational psychology-based providers had the highest number of webpages (n = 25, 30.5%). The second greatest webpage type was academic papers (n = 15, 18.3%) followed by commercial webpages from ENTs/Audiologists (n = 14, 17.1%), media reports (n = 13, 15.9%) and the least were provided by Not for Profit organisations/ Government agencies (n= 12, 14.6%). Given the uneven sample number in each of the type of organisation category, the categories were collapsed into 2 categories for further analysis. All commercial webpages run by either ENTs, audiologists or education, speech language and psychology professionals (n = 39) were grouped together and called “commercial” and the government/not for profit, academic and media categories were grouped together and called “Other” (n = 42).

3.3.2. HONcode certification

Only 4 out of the 82 webpages (4.9%) had HONcode certification. The webpages that did contain the certification were 2 academic papers, one commercial webpage from an ENT/Audiology provider in Ireland and a child health webpage from America. Due to the small number of sites having the HONcode Certification, the null hypotheses related to the HONcode certification were removed.

3.3.3. Readability

Readability was assessed using a free online tool that simultaneously calculates the readability scores for the FOG, SMOG and F-K formulas (Figure 1). The RGL calculated by the FOG formula ranged from 7.81 to 25.72 (M = 14.51, SD = 3.16). Using the SMOG formula, the RGL values ranged from 8.80 to 22.51 (M = 14.08, SD = 2.37) and finally using the F-K formula the RGLs ranged from 6.31 to 22.98 (M = 12.52, SD = 2.91). The mean RGL calculated from all three formulas had RGLs that ranged from 7.64 to 23.74 (M = 13.71, SD = 2.81). To determine if the mean RGL (M = 13.71, SD = 2.81) was higher than the recommended reading grade level of 6, a one sample t-test was performed. The mean RGL was significantly higher than the ideal RGL of 6 by a mean RGL of 7.71, 95% CI [7.10 to 8.34], $t(80) = 24.87$, $p < .001$.

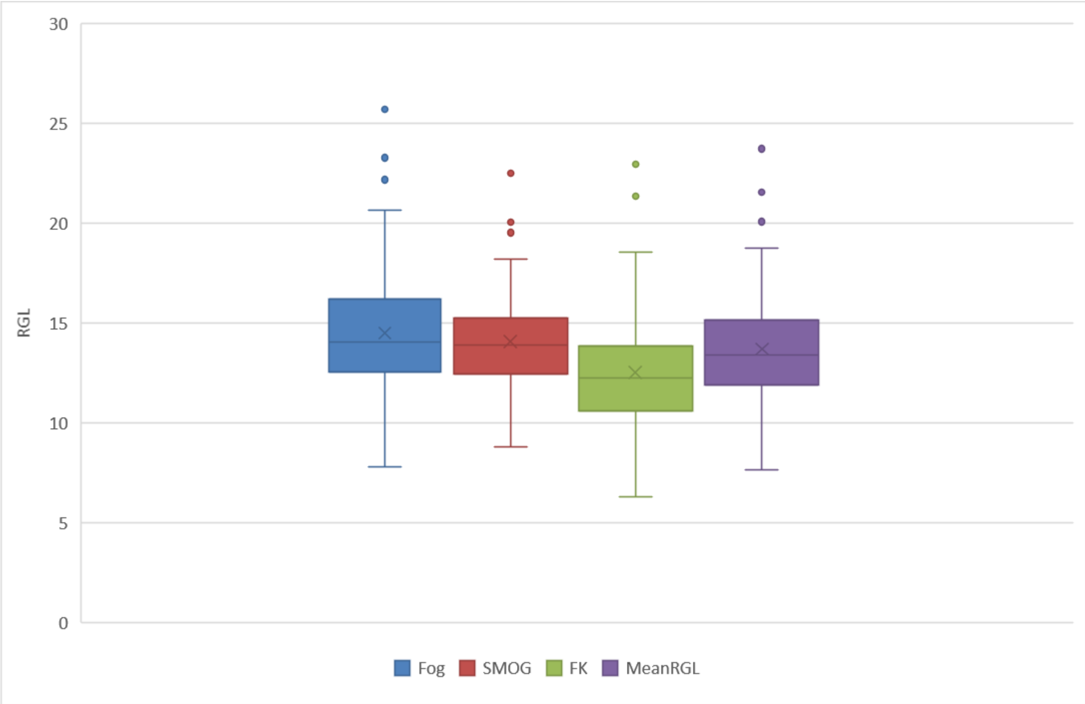

Figure 1. Reading Grade Level (RGL) for Gunning Fox Index (FOG), Simple measure of gobbledygook (SMOG) and Flesch-Kincaid (F-K) readability formulas. Mean RGL is the mean of the FOG, SMOG and F-K RGL. The horizontal line within the boxes represents the median, the upper and lower boundaries of the boxes are the 75th and 25th centiles and the whiskers represent the highest and lowest values excluding any outliers. The dots outside of the box and whiskers represent non-significant outliers.

3.3.4. Quality Measures

3.2.1 DISCERN

The DISCERN final rating (Question 16) was recorded for all webpages excluding videos (n = 77). The final scores showed great variability (Figure 2) and ranged from 5 to 1 (M = 2.17, SD = 1.31). 35 of the included webpages (45.5%) had a DISCERN rating of 1, which significantly skews the distribution. Inter rater agreement (ICC) analysis for the DISCERN final scores was high across 7 different independent scorers with an ICC value of .872. According to Fleiss and Cohen (1973) kappa values greater than 0.75 indicate “excellent agreement beyond chance.”

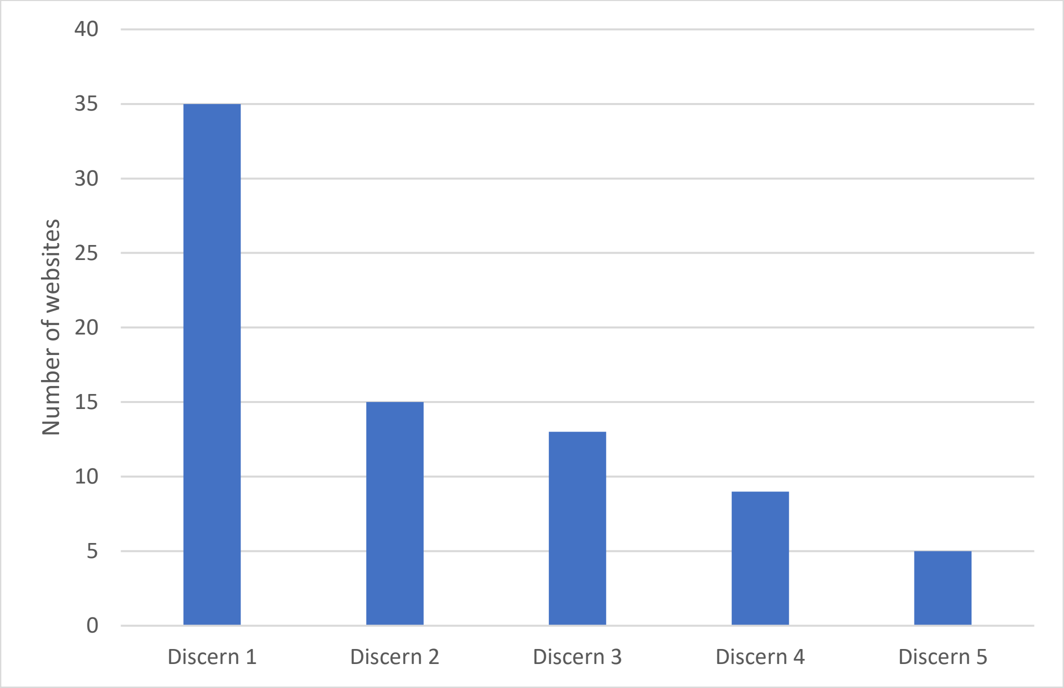

Figure 2. Final DISCERN ratings (question 16 only) for APD webpages in English language.

3.2.2 Plain English Language Checklist

The total scores (Figure 3) for the Plain English Language Checklist ranged from 100 to 47% (*M* = 80, *SD = 14.6*). Inter rater agreement (ICC) analysis for the Plain English Language Checklist final scores was high across 7 different independent scorers with an ICC value of .92 and indicate "excellent agreement beyond chance" (Fleiss & Cohen, 1973). There were occasions where some of the webpages did not contain examples of the factor being examined (*Table 3*). The scores for these questions were denoted as "Not Applicable" and were excluded from the final score with the percentage score taking this into account. The percentages of present items are presented in Table 3 below.

Table 3. Individual question scores for each question in the Plain English Language Checklist analysis. The table shows the percentage (%) of items that were present at a suitable standard (yes), absent or not at standard (no) or where an item was not expected to be present (N/A).

Reader Focus	**Yes**	**No**	**N/A**
Do the headings contain the topic of interest?	96.15	3.85	0
Does the introduction inform the reader about what they will read?	94.87	5.13	0
Is the content relevant?	98.72	1.28	0
Organisation			
Does the material begin with the most important message?	94.87	5.13	0
Is the content arranged in a sensible order?	98.72	1.28	0
Are different topics grouped appropriately?	64.10	35.90	0
Writing			
Are personal pronouns used throughout?	11.54	88.46	0
Is an active voice used throughout?	69.23	30.77	0
Are lay terms predominately used throughout?	55.13	44.87	0
If technical terms are used, are they explained?	48.72	51.28	0
Are simple sentences used throughout?	62.82	37.18	0
Is correct grammar used throughout?	97.44	2.56	0
Is correct punctuation used throughout?	97.44	2.56	0
Are unnecessary words eliminated?	60.26	39.74	0
Design & Formatting			
Is the appearance of the material consistent throughout?	98.72	1.28	0
Does the material look easy to read?	71.79	28.21	0
Are the fonts clean and easy to read?	98.72	1.28	0
Is the text size large enough for easy reading?	98.72	1.28	0
Are italics, underlining, capitalisation, and bold used sparingly?	96.15	3.85	0
Are images clear, uncluttered and related to the content?	40.51	6.33	53.16

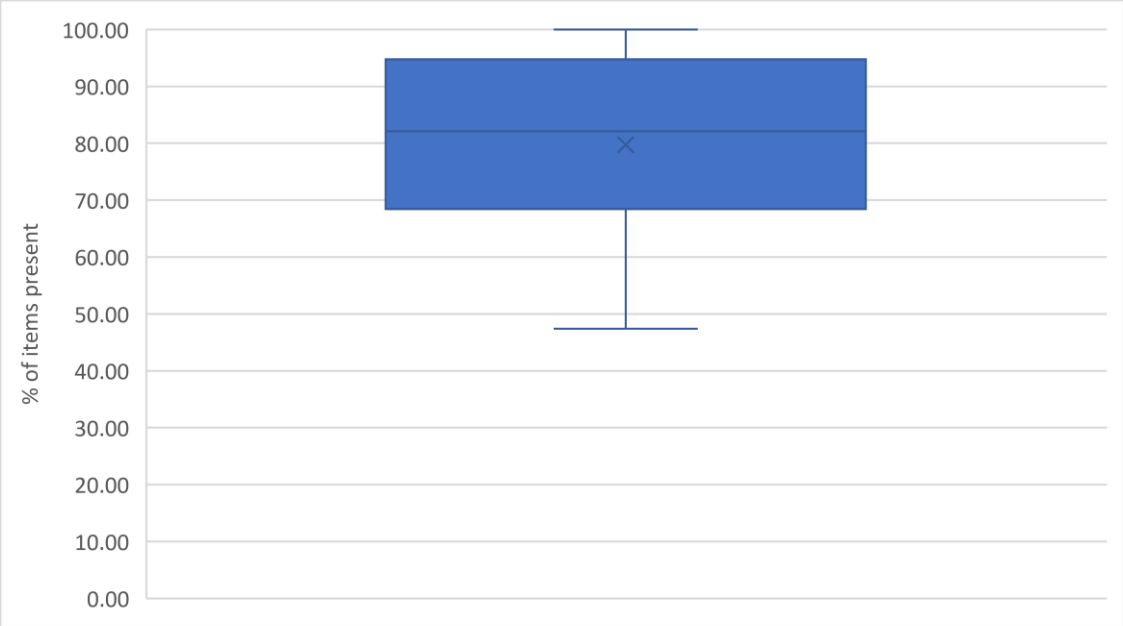

Figure 3. Final scores for the Plain English Language Checklist. The horizontal line within the boxes represents the median, the cross within the box the mean, the upper and lower boundaries of the boxes are the 75th and 25th centiles and the whiskers represent the highest and lowest values excluding any outliers.

3.2.3 PEMAT

The total scores (Figure 3) for the PEMAT assessment ranged from 88.89 to 21.05% (*M* = 60.82, *SD* = 16.41). Inter rater agreement (ICC) analysis for the PEMAT assessment was done for each of the sections (Understandability and Actionability) and the scores for each section were high across the 7 different independent scorers with an ICC value of .887 for the Understandability section and .805 for the Actionability section indicating "excellent agreement beyond chance" (Fleiss & Cohen, 1973). There were occasions where some of the webpages did not contain examples of the items being described in each question. The scores for these questions were denoted as "Not Applicable" and they were excluded from the final score with the percentage score taking this into account. The frequencies and percentages of present items is presented in Table 4 below. A final PEMAT score was calculated by adding both the

Understandability and actionability scores together to give a combined percentage. This final score was used in all further analyses.

Table 4: Individual question scores for each question in the PEMAT analysis. The table shows the percentage (%) of items that were present at a suitable standard (yes), absent or not at standard (no) or where an item was not expected to be present (N/A).

Item	**Yes (%)**	**No (%)**	**N/A (%)**
Understandability			
Content			
The material makes its purpose completely evident	90.12	9.88	0.00
Word Choice and Style			
The material only includes purposeful information	100.00	0.00	0.00
The material uses common, everyday language	56.09	43.90	0.00
Medical terms are used sparingly	58.03	41.98	0.00
The material uses the active voice	73.17	26.83	0.00
Use of numbers			
Numbers are clear and easy to understand	54.88	15.85	29.27
Calculations are not expected of the user	98.78	0.00	1.22
Organisation			
The material breaks information into short sections	90.12	9.88	0.00
The material's sections have informative headers	59.76	29.27	10.98
The material presents information in a logical sequence	96.34	3.66	0.00
The material provides a summary	34.15	62.15	3.66
Layout and Design			
The material uses visual cues to draw attention to key points	43.90	56.10	0.00
Text on screen is easy to read	80.49	19.51	0.00
The material allows the user to hear the words clearly	9.76	1.22	89.02
Use of Visual Aids			
The material uses visual aids when appropriate	24.39	74.39	1.22
Visual aids reinforce rather than distract from the content	20.73	0.00	79.27
Visual aids have clear titles or captions	13.42	6.10	80.49
Illustrations and photographs are clear and uncluttered	17.07	2.44	80.49
Simple tables are used	6.10	3.66	90.24
Actionability	**Yes (%)**	**No (%)**	**N/A (%)**
At least one action is clearly identified	39.02	60.98	0.00
The user is directly addressed when describing actions	19.51	79.27	1.22
The action is broken down into manageable, explicit steps	23.17	73.17	3.66
A tangible tool is provided to help the user take action	14.63	71.95	13.42
Charts, graphs, tables, or diagrams are used to describe how to take action	1.24	11.11	87.65
Visual aids are used to make it easier to act	3.66	7.31	89.02

3.4. Hypothesis testing

3.4.1. Normality

Normality testing was conducted for the mean RGL, Plain Language, PEMAT and DISCERN variables. PEMAT was found to be normally distributed but RGL had significant skewness and kurtosis, Plain English Language Checklist had significant kurtosis and the DISCERN variable had significant skewness. Even though the Plain language and mean RGL variables violated the assumption of normal distribution, Central Limit Theorem tells us that normal distribution can be assumed given the large samples sizes (n = 81). There were no significant outliers in the dataset. The data for these analyses were therefore determined to meet the assumptions of normality and that parametric testing was appropriate. The distribution of the DISCERN variable however was very heavily influenced by the large number of webpages that recorded a DISCERN score of 1. Almost half of the frequency counts were in this category. It was decided that non-parametric analysis would provide a better analysis.

3.4.2. Distribution based on Region and Type of Organisation

A chi-square test of goodness-of-fit was performed to determine whether there was an even distribution in the type of webpages (commercial provider or other) found using the search criteria. There was an even distribution of webpages from each location (Africa, Europe, Americas, Asia, W Pacific) X^2 (4, N = 82) = .317, p = .993. A chi-square goodness of fit test also showed that there was an even distribution of webpages based on the type of organisation X^2 (4, N = 82) = .049, p = .912. To determine if the variables location and type of organisation were independent, a chi-square test of independence was done. Location and organisation type were found to be independent with a one-sided Pearson Chi square test X^2 (4, N = 82) = .7.752, p = .052.

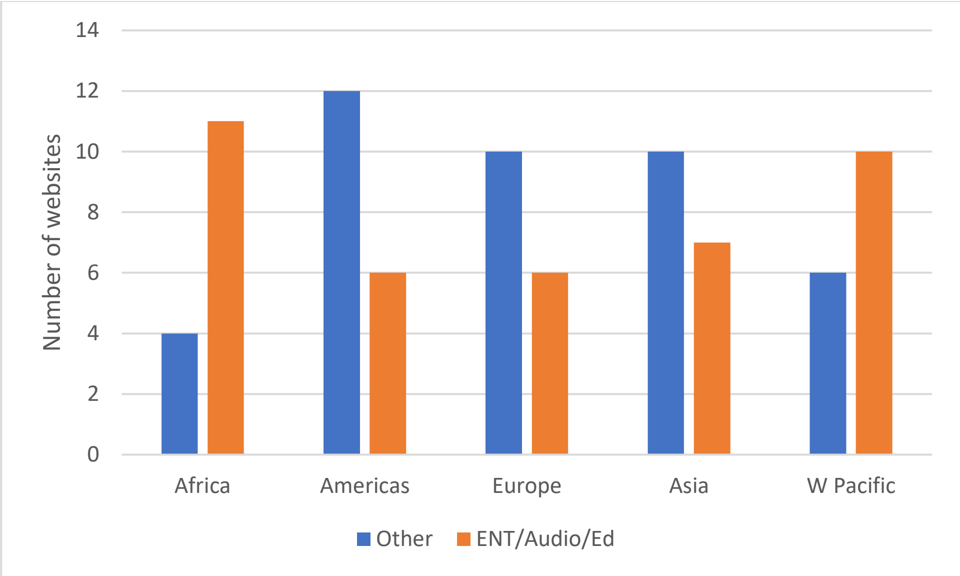

Figure 4. Number of Ear Nose and Throat /audiology/education webpages that were sampled from each region. The "other" category consisted of webpages described as academic, government/not for profit and media.

Hypothesis testing:

- The null hypothesis that there is an even distribution of webpages from each location is supported.
- The null hypothesis that there is an even distribution of webpages from each organisation type is supported.
- The null hypothesis that location and type of organisation are independent is supported.

3.4.3. Readability based on region and type of organisation

To determine if there were any significant difference in the mean RGL based on locality and type of organisation a 2 Factor ANOVA was performed. The ANOVA tested the main effects of location (5 levels) and type of organisation (2 levels). Levene's test of homogeneity indicated unequal variances ($F(1,79) = 15.73$, $p = .000$) and violated the assumptions of the ANOVA. A univariate analysis for each main effect was then undertaken with a Games-Howell correction for uneven variance. The univariate ANOVA results showed that online materials produced by commercial webpages had a significantly lower reading grade level than materials produced by all other types of organisations, $F(1,79) = 8.36$, $p = .005$, $\eta_p^2 = 0.096$. There was no significant difference in mean RGL, $F(4,76) = .597$, $p = .666$, $\eta_p^2 = 0.03$ between the locations of Africa, Americas, Europe, Asia and Western Pacific. Post hoc pair wise comparisons were not necessary for the significant main effect of organisation type due to only having 2 levels.

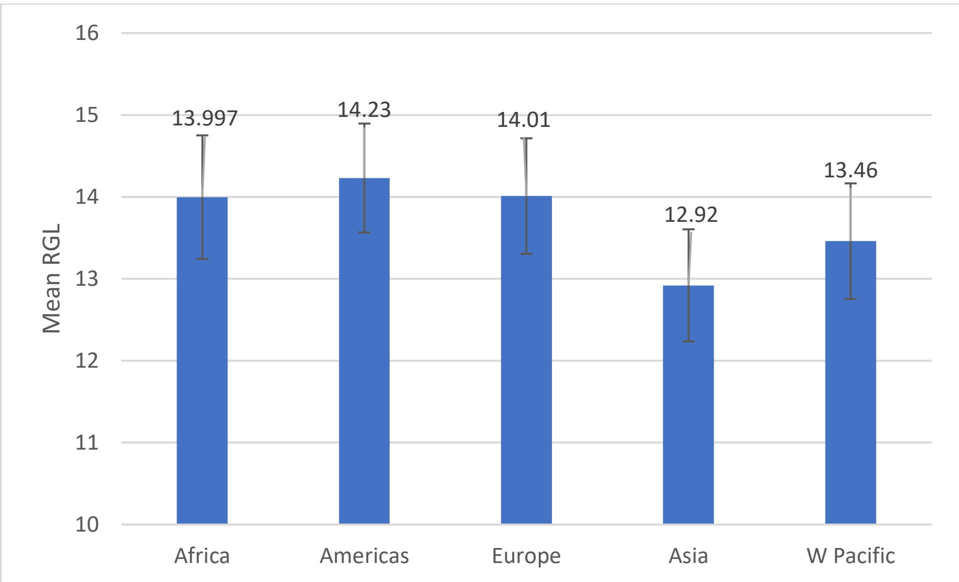

Figure 5. Mean reading grade level (RGL) levels grouped by location. Error bars are standard error of the mean.

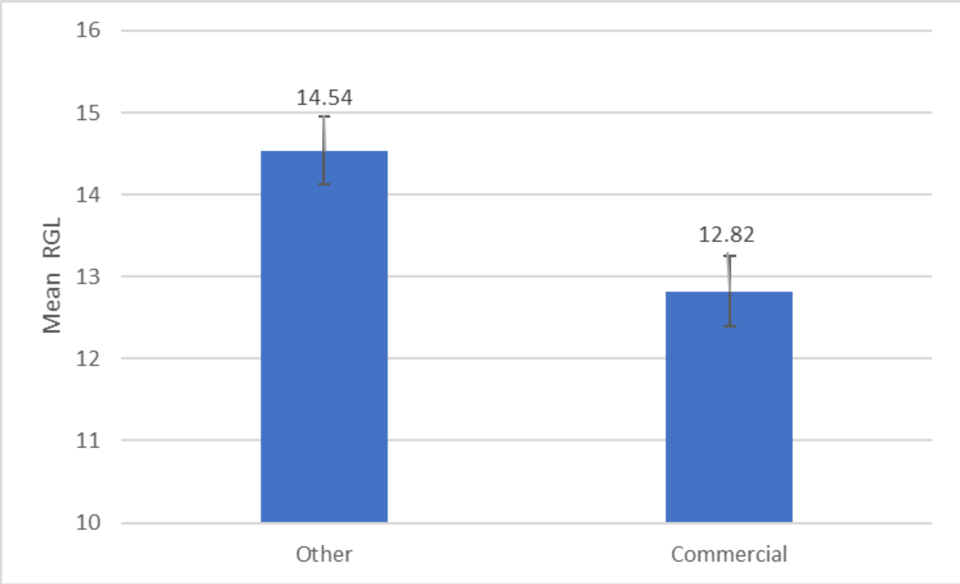

Figure 6. Mean reading grade level (RGL) levels grouped by organisation type. Error bars are standard error of the mean.

Hypothesis tests:

- The hypothesis that there is no significant difference in mean RGL across organisation type is not supported.
- The hypothesis that there is no significant difference in mean RGL across locations is supported.

3.4.4. Quality based on region and type of organisation

3.4.4.1. PEMAT

To determine if there were any significant difference in PEMAT scores between webpages based on locality and type of organisation a 2 Factor ANOVA was performed. The ANOVA tested the main effects of location (5 levels) and type of organisation (2 levels). Levene's test indicated equal variances ($F(1,72) = 1.77$, p = .089) and supported the assumptions of the ANOVA. The 2 Factor ANOVA results showed that online materials produced by commercial providers had significantly higher PEMAT scores than those being produced by all others $F(1,72) = 6.10$, $p = .016$, $\eta_p^2 = 0.041$. There was no significant difference in PEMAT scores, $F(4,72) = 1.14$, $p = .346$, $\eta_p^2 = 0.030$, between Africa, Americas, Europe, Asia or the Western Pacific. No significant interactions between location and type of organisation $F(4,72) = 1.047$, $p=.389$, $\eta_p^2 = 0.055$ were observed. Post Hoc pair wise comparisons were not necessary for the significant main effect due to only having 2 levels.

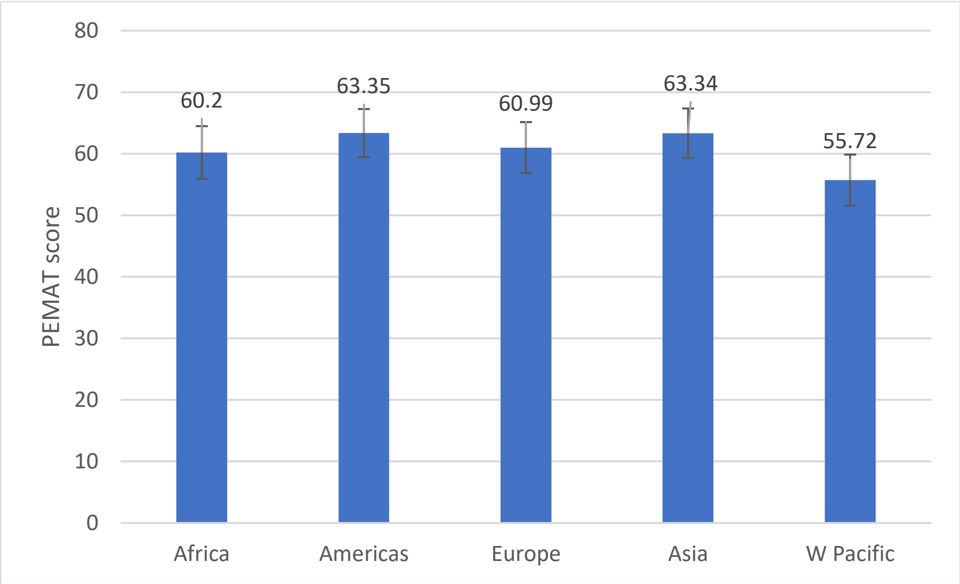

Figure 7. Patient Education Material Assessment Test (PEMAT) scores by location. Error bars represent standard error of the mean.

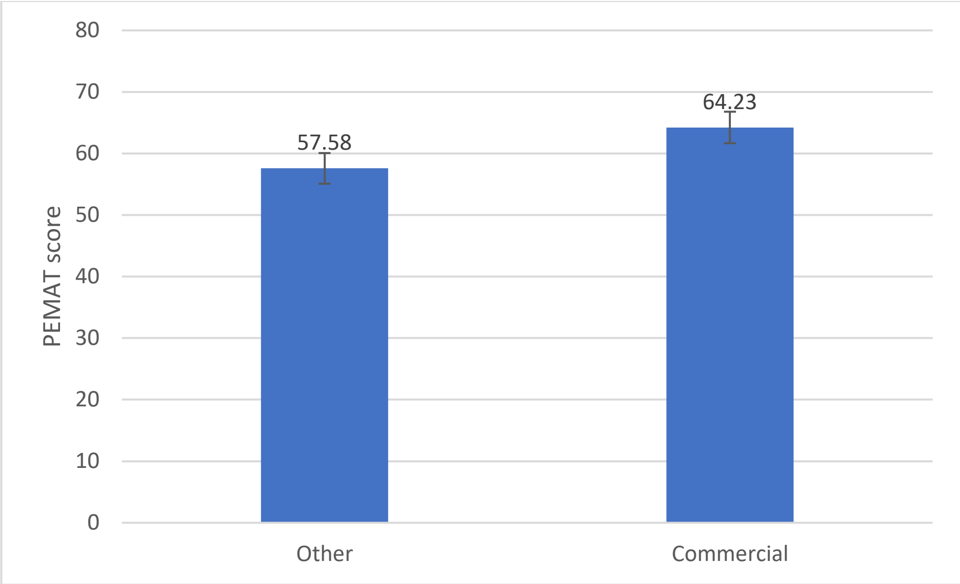

Figure 8. Patient Education Material Assessment Test (PEMAT) scores by organisation type. Error bars represent standard error of the mean.

Hypothesis tests:

- The hypothesis that there is no significant difference in PEMAT scores across organisation type is not supported.
- The hypothesis that there is no significant difference in PEMAT scores across locations is supported.

3.4.4.2. Plain English Language Checklist

To determine if there were any significant difference in the Plain English Language Checklist scores based on locality and type of organisation a 2 Factor ANOVA was performed. The ANOVA tested the main effects of location (5 levels) and type of organisation (2 levels). Levene's test indicated unequal variances ($F(1,71) = 2.24$, $p = .030$) and violated the assumptions of the ANOVA. A univariate analysis for each main effect was then undertaken with a Games-Howell correction applied for any post hoc comparisons. The univariate ANOVA results showed that online materials produced by commercial providers had a significantly higher Plain English language Checklist score than materials produced by all other types of organisations $F(1,74) = 9.24$, $p = .003$, $\eta_p^2 = 0.111$. There was no significant difference in the Plain English Language Checklist scores, $F(4,71) = .248$, $p = .910$, $\eta_p^2 = 0.041$ between the locations of Africa, Americas, Europe, Asia or the Western Pacific. Post hoc pair wise comparisons were not necessary for the significant main effect due to only having 2 levels.

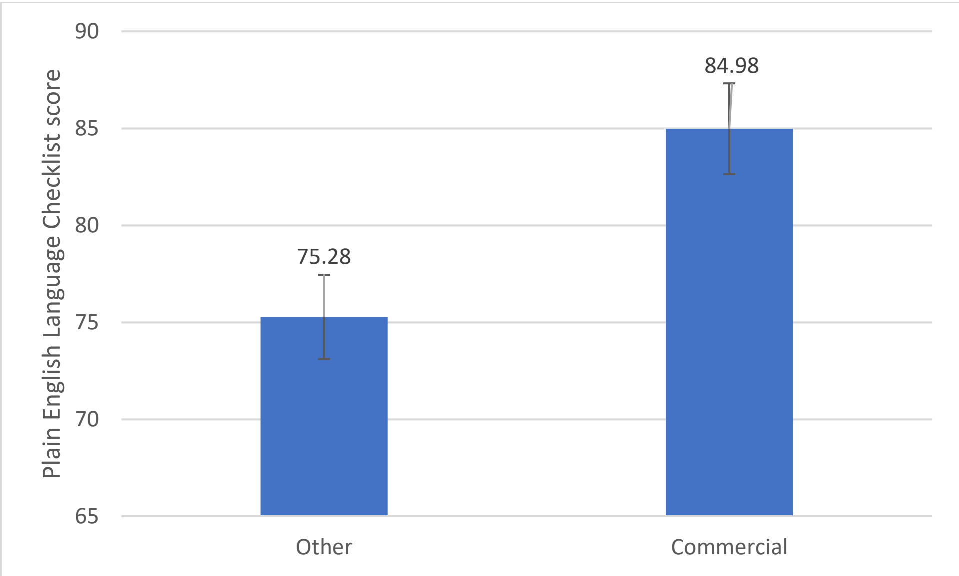

Figure 9. Plain English Language Checklist scores by type of organisation. Error bars represent standard error of the mean.

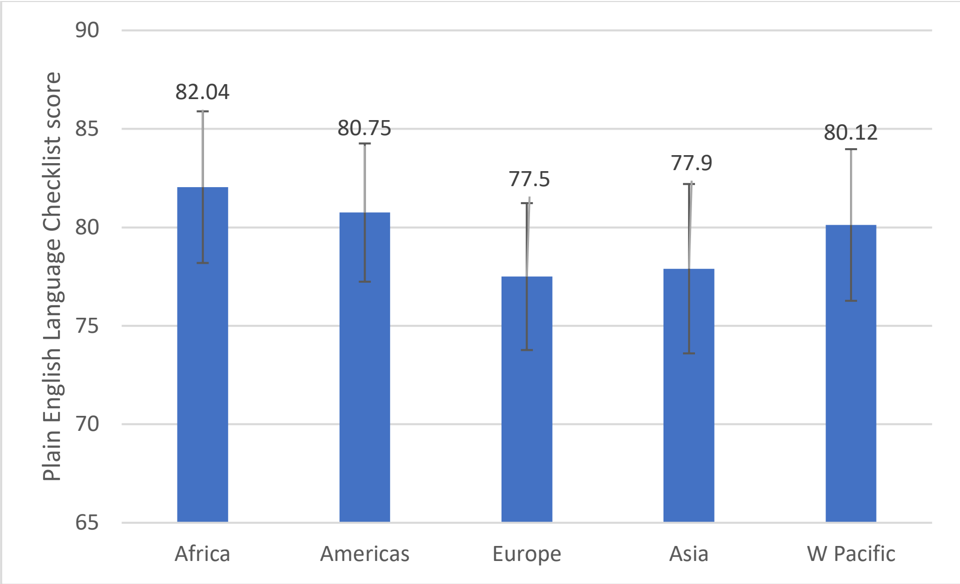

Figure 10. Plain English Language Checklist scores by location of the webpage. Error bars represent standard error of the mean.

Hypothesis tests:

- The hypothesis that there is no significant difference in Plain English Language Checklist scores across organisation type is not supported.
- The hypothesis that there is no significant difference in Plain English Language Checklist scores across locations is supported.

3.4.4.3. DISCERN Scores

To determine if there were any significant difference in the DISCERN scores based on locality and type of organisation a Kruskal-Wallis H test was performed. The non-parametric ranked ANOVA tested the main effects of location (5 levels) and type of organisation (2 levels) on the DISCERN scores. The Kruskal-Wallis H test showed that there was no statistically significant difference in DISCERN scores based on organisation type $\chi2(1) = 0.393$, $p = .537$, with a mean rank DISCERN score of 36.87 for commercial providers and 39.89 for all Others. The Kruskal-Wallis H test showed that there was a statistically significant difference in DISCERN scores based on the webpage country of origin, $\chi2(4) = 9.596$, $p = .048$, with a mean rank DISCERN score of 33.33 for Africa, 50.47 for Americas, 40.72 for Europe, 30.50 for Asia and 33.33 for Western pacific. However, post hoc pairwise analysis with the conservative Bonferroni correction indicated that none of the pairwise comparisons were significantly different.

Hypothesis tests:

- The hypothesis that there is no significant difference in DISCERN scores across organisation type is supported.
- The hypothesis that there is no significant difference in DISCERN scores across locations is not supported.
- Post hoc pair wise analysis with the conservative Bonferroni correction however showed none of the pairwise comparisons were significant.

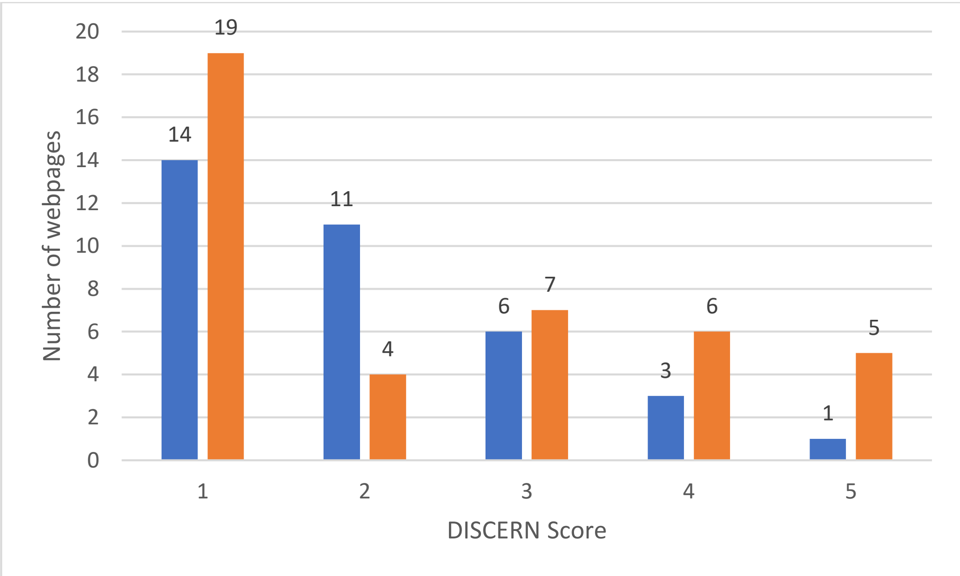

Figure 11: Number of webpages for each DISCERN score based on the type of organisation producing the webpage. The blue bars represent the commercial webpages and the red bars represent all other types of webpages.

Table 5: The frequency of DISCERN scores based on the country of origin of the webpage.

	Location						
		Africa	Americas	Europe	Asia	W Pacific	Total
DISCERN	1	7	5	7	7	7	33
	2	5	2	1	2	5	15
	3	2	2	4	3	2	13
	4	1	4	3	0	1	9
	5	0	5	1	0	0	6
Total		15	18	16	12	15	76

3.5 Summary of results

All hypotheses relating to HONCode certification were removed as the small number of webpages with HONCode certification meant the distribution was uneven. Parametric statistical analysis (with Games-Howell corrections for non-equal variance where necessary) were used for the variables mean RGL, PEMAT and Plain English Language Checklist. Based on these parametric analyses, it was found that all the null hypotheses for the mean RGL, PEMAT and Plain English Language variables were supported except those that investigated the role of organisation type. Organisation type was found to be a significant factor for the variables of mean RGL, PEMAT and Plain English language Checklists. Non-parametric testing of the DISCERN variable showed that the location of the webpage had a significant effect on the DISCERN scores.

Discussion

4.1. Overview

The webpages collected during this study provide a snapshot of the type and quality of information that is readily available online regarding APD. The methodology used replicates an online search that people might do if they needed to find online health information (Manchaiah et al., 2019). The methodology uses simple search terms and uses the Google search engine, which is the most commonly used search engine with 81.5% of the market share (Reliablesoft, 2019), to find suitable webpages.

4.2. Key word survey results

Experience with a topic is one of the elements that can contribute to improved health literacy and it was suspected that prior exposure to the topic of APD might influence the search terms chosen. McKearney et al. (2018) found that the search terms used in their study of the quality of tinnitus online information did have an effect on the quality scores with lower DISCERN scores occurring when simpler language was used in the search terms. For this reason, both naïve and non-naïve populations were surveyed in the initial search term gathering phase.

The demographics of the survey participants are representative of the global population that regularly access health info online (van Deursen & van Dijk, 2014). There were differences in search terms collected between the naïve and non-naïve populations, however the Google Trends analysis showed that only the search terms “APD” and “auditory processing disorder” were significant. This is likely reflective of a small search history worldwide for this hearing disorder and that the search topic is relatively niche. When the search terms were used in the final webpage capture, it was often found that the term “APD” represented “ambulatory peritoneal dialysis” rather than “auditory processing disorder”. It is possible that this may have skewed the Google Trends analysis towards a higher result for the search term “APD” than would have been seen if APD only represented the acronym for “auditory processing disorder” not the result for the combined acronyms of “auditory processing disorder and ambulatory peritoneal dialysis”. This may have led to a different set of search terms being used and a very different set of webpages being collected. It is difficult to extrapolate from this study whether the population from which the search terms are drawn has a significant effect due to the relatively niche nature of APD. For other more well-known or more widely searched hearing disorders, the search terms given by naïve/non naïve populations could very well be different in line with studies such as McKearney et al. (2018).

4.3. Readability

The readability formulas selected for analysis in this study are all well cited, validated and are included in the top readability formulas used to assess online information (Wang et al., 2013). Reading grade levels assessed for the webpages using the FOG formula ranged from 7.81 to 25.72, between 8.80 to 22.51 using the SMOG formula between 6.31 to 22.98 for the F-K formula. The RGL calculated as a mean of all three formulas had RGL’s that ranged from 7.64 to 23.74 indicating the reading level ranged from materials that could be understood by US middle schoolers right through to materials only understandable if you had a college degree. The readability levels are significantly higher than the recommended reading grade level 6 which allows 75% of adults to understand the materials (Doak, Doak, & Root, 1996). Only one webpage in the study had a reading grade level of less than 7. This was statistically determined to be an outlier which is concerning given it is still well above the recommended grade level. It is clear from these results that the materials contained in the APD webpages are not written at a level where the majority of adults could understand the material (Doak et al., 1996). This has serious medical and ethical implications as it has been shown that mistakes in treatment are more likely as is noncompliance with the treatment protocols when patient materials are not understood (Doak et al., 1996). This result however is not unexpected (Daraz et al., 2018). Reading grade levels above that of the Grade 6 recommendations are consistent across audiology studies (Alamoudi & Hong, 2015; Greywoode, Bluman, Spiegel, & Boon, 2009; Laplante-Lévesque & Sundewall Thorén, 2015; Manchaiah et al., 2019; Rees et al., 2002; Wong & Levi, 2017) and other health disciplines (as reviewed by Daraz et al. (2018)). They have remained high despite increased research and attention in this field for almost 40 years (Sharp, Hall, Eleftherion, Simpson, & Neuhauser, 2019; Stableford & Mettger, 2007). Laplante-Lévesque and Sundewall Thorén (2015) assert that we know the readability levels of online hearing information are too high and that valid and sustainable initiatives to address this must be prioritized. Unless professionals dedicate specific attention and effort towards rectifying this situation, the variability in achievement/quality assessment and gaps in availability of information will not change dramatically (Berland et al., 2001).

4.4. Quality measures

4.4.1. PEMAT

PEMAT scores for understandability were higher than those for actionability across all organisation types and countries. Scores for actionability were uniformly low, indicating that most websites do not provide explicit instruction on what the reader might do after reading the webpage content. In the understandability section, the subsection of “word choice” and “style” indicated that webpage designers are careful to only include pertinent information and that they use an active voice in the text. However, when looking at whether everyday language is used and limiting the use of medical jargon, just over 40% of the webpages were scored as a fail. Adoption of plain language initiatives would help to simplify the language and sentence structure so that it was more accessible. The “use of numbers” sub section achieved high scores. When numbers were used in the webpages, only 16% of the webpages used numbers in a way which was not understandable and only 2% of the webpages expected users to perform any calculations. In the “physical organisation” subsection, the webpages were well organised with 90% of the webpages breaking the content down into manageable chunks and 96% of the webpages presented the content in a logical way. However, 62% of the webpages failed to provide an adequate summary and many webpages (29%) failed to make good use of headings. The use of visual aids to enhance the text was an area which performed poorly across the PEMAT analysis. Only 24% of the webpages used visual aids to enhance the users experience and only 44% used visual cue to highlight significant areas of content. Meaningful gains could be made in this area. The results indicate that if simple changes to webpages such as simplifying the language, adding better summaries to the content and using visual aids to compliment the text then higher understandability scores could be easily achieved.

The use of visual aids for better health communications has been reviewed and strongly indicate that visuals are a powerful tool in increasing recall and understanding risks of surgeries (Edwards, Elwyn, & Mulley, 2002; Garcia-Retamero & Galesic, 2010; Garcia-Retamero & Hoffrage, 2013). Visual aids are extremely useful when presenting numeric data to diverse groups of people as they remove the barrier that low numeracy and graph literacy often place (Garcia-Retamero & Hoffrage, 2013). Hallgreen et al. (2016) reviewed the types of visual aids that can be useful in medical materials and found that the greatest influencer in visual aid choice was the level of detail that needs to be communicated. They also state that similar design choices can be applied to interactive/dynamic visual representations. This is hugely important given the increasing influence YouTube and other interactive web resources are having in the health literacy space. Hallgreen et al. (2016) are excited by the increased use of interactive/dynamic visuals in health education materials as they engage the audience to a higher degree, and this will likely increase attention to and perception of the materials.

In the actionability section less than 40% of webpages identified one action that a reader could take after reading the content and 79% of webpages failed to address the reader directly when doing this. Less than 25% of the webpages provide a detailed description of what steps to take and less than 15% provide any tools or visual aids to help when multistep instructions are given. The actionability section of the PEMAT tool is a significant area of deficit for these webpages and contributed to low PEMAT scores.

The PEMAT tool is a reasonably new tool for assessing patient material quality and currently there are few PEMAT assessments of ontological relevance. Combining the understandability and actionability scores was done in this study to facilitate analysis however it makes it harder to compare to literature. Arsenault, Blouin, and Guitton (2016) used the PEMAT tool to investigate the quality of web resources available for the surgical procedure of tonsillectomy. They also found that most webpages scored poorly for actionability. The medical association websites had better understandability scores and actionability scores compared to the health portals scores.

Wong, Gilad, Cohen, Kirke, and Jalisi (2017) found that understandability of patient materials for laryngectomy were similar for understandability and actionability scores however considerable variation (up to 60%) still existed.

PEMAT assessments of patient education materials from other medical specialities are also consistent in showing that the actionability sections of the tool are especially poorly performing. Kang and Lee (2019) found that understandability scores were much higher than actionability scores for diabetes patient education materials. They found that 41% of the audio-visual materials examined provided no evidence of any actionability criteria and had actionability scores of 0%. The quality of existing print patient education materials provided by urology specialists also show considerable variation in the actionability scores (Maciolek, Jarrard, Abel, & Best, 2017). The authors found that failure to include visuals and tools resulted in low PEMAT scores. Gazarian et al. (2019) used the PEMAT tool to evaluate 20 patient education materials used in geriatric advanced care planning. The resources scored very highly in the PEMAT assessment with mean understandability scores of 86% for understandability and 90% for actionability. However, the range within this data was large; understandability had a range of 58-100% and actionability ranged from 40-100%.

A significant downside to the PEMAT tool is the lack of a validated score/matric to indicate acceptable understandability and actionability scores (Kang & Lee, 2019; Maciolek et al., 2017). Currently all that is available is the general notion that higher PEMAT scores indicate better understandability or actionability. This is most likely a reflection of the newness of the tool. When greater numbers of studies are available for collation, then appropriate validations will be possible and setting of acceptable understandability and actionability scores will likely result.

4.4.2. DISCERN

The DISCERN scores for the APD webpages were very heavily skewed with 45% of the webpages scoring a DISCERN score of 1. This is reflective of the webpages not containing any information about treatment options. The average DISCERN score was 2.17 with only 4 webpages scoring a DISCERN score of 5. Alamoudi and Hong (2015) found an overall DISCERN score of 3.0 for aural atresia webpages and 3.6 for microtia webpages. Manchaiah et al. (2019) found a rate of 2.39 for tinnitus information. Pusz and Brietzke (2012) analysed a number of ORL relevant conditions on Google and found the DISCERN scores to be poor to moderate at best. The highest rated webpages were about sleep apnoea with a DISCERN score of 3.48 and the lowest average DISCERN score was 2.49 for hoarseness. They found the chronic ORL conditions are dominated by commercial sites and are inherently biased in the information presented. Fackrell et al. (2012) measured the overall DISCERN score for tinnitus and found that the highest score was 3.5 out of 5. The shortcomings in these medical webpages were mainly identified in the areas of quality of treatment choices rather than the reliability of information provided. Even in medically trusted sources no one resource effectively covered all the questions in the DISCERN tool.

Diagnosis and identification of treatment providers were the predominant themes of the APD webpages sampled in this study. Treatment options were often not discussed, and this translated to 45% of the webpages scoring the lowest possible overall DISCERN score. The high number of webpages that obtained a DISCERN score of 1 resulted in a positively skewed distribution that violated the assumptions of parametric analysis. A non-parametric model analysis was required but resulted in many tied ranks. The nonparametric approach also resulted in a loss of statistical power. When analysing the effect of location on DISCERN scores, the Kruskal Wallis H test showed a significant effect however when the conservative Bonferroni correction was made for pairwise comparisons, no differences were seen. Manchaiah et al. (2019) found a similar positive skew in the DISCERN scores for online tinnitus information. To allow analysis of this data they log transformed the data to allow parametric analysis. Laplante-Lévesque et al. (2012) found the DISCERN scores were also positively skewed and that a transformation was needed to allow parametric analysis. The DISCERN scores in Laplante-Lévesque et al. (2012) ranged from 1.13 to 3.93 and are similar to those recorded in the current study. A transformation of this studies data in a manner described by Laplante-Lévesque et al. (2012) and Manchaiah et al. (2019) would be a useful further analysis as it would allow parametric analysis to be completed. The use of parametric analysis tools may give the analysis the additional statistical power to reveal any significant treatment effects.

In this study, the DISCERN score was only measured from the overall score (Question 16). The drawback of only using the overall score in the DISCERN tool is that the final overall score is solely treatment centred and does not reflect any of the critical analysis around bias/quality of evidence that earlier questions ask (Questions 1-8). Using the overall score (Question 16 only) gives a different assessment of quality compared to score derived from using the full DISCERN tool. If the speed of assessment is an important criterion for the selection of analysis tools, then there is clearly an advantage of using the DISCERN overall score. However, it could be argued that the DISCERN tool could be further improved if an additional overall score/question was added that would solely reflect a summary of the critical assessment of bias and quality of evidence collected in Questions 1-9. This additional representative score would further compliment the representative score already made for treatment options.

4.4.3. HONcode Certification

HONcode certification was rarely used in the webpages curated for this study. Only 4% of the final webpages had certification and is consistent with the certification rate obtained for atresia websites (Alamoudi & Hong, 2015; Laplante-Lévesque et al., 2012). This low certification rate made it impossible to include in further analysis.

4.4.4. Plain English Language Checklist

The “reader focus” section achieved very high scores. The three questions in this section show that the content is relevant (99%), the introductions inform the reader to what they will find in the webpage (95%) and that the title of the page is reflective of the content (96%). The “writing” subsection was the most variable of all the subsections. The webpages had very few punctuation and grammar issues (97%) which would have contributed to the ease of reading. However, the use of simple language was more variable with only 55% of the webpages using lay terms, 40% of webpages contained unnecessary words and technical terms were often not explained (51%). The text in the webpages rarely used personal pronouns (12%) preferring the third person. The organisation subsection was well done with the most important message being presented first (95%) and the rest of the information then following in a sensible order (99%). There were concerns around the grouping of topics where 36% of webpages had materials that were grouped in such a way that the assessor felt was not appropriate. In respect to the physical layout of the webpages, all most all had fonts that were large enough and easy to read, and the material had a consistent visual appearance throughout the webpage. Over half the time visuals that would complement the text were not included in the webpages (53%). This result is consistent with that of the PEMAT analysis which also highlighted the lack of appropriate visuals.

4.5. The effect of region and type of organisation

The type of organisation that produced the webpage was found to be significant, with the RGL of the sites described as being produced by “other” having a higher RGL compared to the commercial webpages. This is the result of the category including academic papers which are expected to have a higher RGL. The region that a webpage came from did not significantly affect the readability or any of the quality scores (DISCERN, PEMAT and Plain Language). The organisation type that produced the webpages did have a significant effect on the PEMAT and Plain language scores, with commercial sites having better scores than all others. Caution is needed when interpreting this result. This is perhaps a better reflection of the “other types” performing worse than the commercial organisations due a skewing of the “other category” by the academic papers which had worse scores across all assessments (data not presented). Laplante-Lévesque et al. (2012) found for online information about “hearing loss” that websites from non-profit organisations had higher DISCERN scores than those of a commercial or government origin. Manchaiah et al. (2019) found no differences in discern scores for online tinnitus information based on organisation type webpage. Ritchie et al. (2016) found that webpages of commercial origin had better readability and had higher DISCERN scores.

4.6. Web design

Access to reliable medical information is perceived as important by 96% of English speaking citizens with 74% of them agreeing that learning about health on webpages should feature interactivity (Pletneva et al., 2011). Online interactions between patients and clinicians is widely expected to increase and in doing so are likely to streamline communication, increase provider efficiency, facilitate patient self-management and advocacy, and ultimately result in greater patient satisfaction (Schickedanz et al., 2013). However, when it comes to engaging with online materials most people spend between 10 sec and 2 minutes reading a webpage and if it is too hard then they give up more quickly (Simpson et al., 2018). Clearly, effective web design has a huge role to play in initially capturing people's attention and then using interactive design to keep them connected with health information materials in a way that can deliver meaningful improvements to their health literacy.

Kreps and Neuhauser (2010) have suggest four strategies to make health webpages more effective in delivering increases in health literacy. They suggest that (i) webpages must support interactive communication, (ii) work across different technology platforms (PC, Tablet, phones and on different operating systems) (iii) be relevant to diverse populations of users and (iv) engage the interests of users. Health associated literature must follow these guidelines to stay current and meet the needs of as many consumers as possible. With so many ways to access online health information, it is becoming even more important to support digital literacy.

While online information has traditionally been viewed alongside hardcopy/written materials, most online resources are unlikely to ever be used as a hard copy and ever only as a digital resource. Online health information has some similarities to audio visual material as most often it is viewed over a device and increasingly on the smaller screens of smart phones rather than traditional computer or tablet screens. Increasingly, online health information is stretching into the more visual domains with video, multimedia and AV materials becoming popular (Penfold, 2013). Social media (Facebook, YouTube, Instagram, Twitter etc) has the benefits of being interactive, immediate, and inclusive of more formats than just the written word (Osborne, 2017). Clear benefits of social media over hard copy patient education materials include being able to engage quickly and for users to communicate back-and-forth from anywhere in the world (Roberts, Callahan, & O'Leary, 2017). A study of cochlear implant (CI) users found that the CI community uses social media for a wide range of supports including advocacy, rehabilitation information, research endeavours, and sharing of personal experiences (Saxena et al., 2015). YouTube is seen as a cheap and easily accessible way to communicate with patients. A study by Penfold (2013) showed that after watching a YouTube clip patients often feel more at ease when speaking with a GP or nurse and can allow the consultation to get to the heart of the patient's health issue quickly. However, healthcare providers and government agencies alike have expressed similar concern about health care information on YouTube as they have about other forms of online health materials (Madathil, Rivera-Rodriguez, Greenstein, & Gramopadhye, 2015) namely, the veracity and quality of the information available on this platform. The authors note in their study they found that YouTube had high levels of anecdotal information and more concerningly that there was still minimal guidelines and interventions regulating the content of the material uploaded on the site. As with hardcopy patient education materials, increases in health literacy will be greatest when the interactive and real time aspects of social media platforms are integrated with key content controls and quality guidelines such as the use of plain language techniques (Saxena et al., 2015). It is in these situations where the benefits of the PEMAT analysis tool become clear as it is one of a very small number of quality analysis tools that can be used to analyse audio visual materials.

4.6.1. Consistent messages throughout all analysis tools

Materials that are interactive, personally engaging, with the ability to be delivered to mass audiences can really make a difference in enhancing the quality of health care and health promotion efforts (Kreps & Neuhauser, 2010). Several consistent themes emerged from the current research on online APD information namely the use of inaccessible language and the lack of visuals and tools used in the materials. The readability analysis showed that the language used was too advanced to allow most adults to understand the material and make appropriate health decisions from. This is consistent with the plain language analysis and the PEMAT analysis which also showed that the materials used long/complex sentences, materials often had complex vocabularies and that medical jargon was often used without explanation. This all contributes to less readable material. Reducing the burden on consumers bought about by high readability scores does not necessarily mean that the quality of the content needs to be compromised if done well (Laplante-Lévesque et al., 2012).

The PEMAT, DISCERN and plan language assessments all show that the materials do not use enough (or any at all) visuals/diagrams to improve the reader experience. Sites that score well in DISCERN make good use of visuals/diagrams and audio-visuals to engage and inform the reader (Ritchie et al., 2016). Simpson et al. (2018) also found a statistically significant positive relationship between DISCERN scores and the number of figures in the article. A statistically significant relationship was also found between readability and the number of figures used – the readability increased as the number of figures increased. The use of appropriate and interesting language, graphics, video and audio clips can enhance the understandability and impact of eHealth messages (Kreps & Neuhauser, 2010). The need for increased use of visual aids is one very clear outcome of this study. If we want to produce online APD materials that engage readers and improve interaction, then better, clearer and information rich diagrams and images need to be included in the materials.

4.7. Clinical implications

Higher demands on clinical time and financial imperatives have resulted in reduced time for patient appointments in many clinical settings. This has meant patients often leave the clinic not understanding what has been discussed or have understood the material presented to them during the appointment (Aaronson, Joshua, & Boss, 2018; Arsenault et al., 2016). The role of online information in filling these gaps in information and understanding is rapidly increasing (Rice, 2006). Significant gains can be made around patient's levels of health literacy if efforts are made by practitioners at all levels of the healthcare model. Increases in health literacy, unlike socio-demographic characteristics which are fixed or difficult to alter, can provide clinically relevant pathways to delivering more effective, patient centred, and efficient healthcare (Carlson, Barnes, & McCreanor, 2019; Panagioti et al., 2018).

4.7.1. Physician provided materials

Providing supplementary educational materials such as handouts or pamphlets is one way that clinicians can reinforce the key points of any conversation had with patients and their families. Provision of supplementary materials may lead to improved understanding and recall. Printed materials are simple and inexpensive tools that can easily be applied in the clinical setting (Papsin, Haworth, Chorney, Bezuhly, & Hong, 2014). The expectation that clinicians will either give patients appropriate take home information or guide them to specifically curated websites is increasing. Pletneva et al. (2011) report that 72% of professionals think it would be helpful for them to guide patients to trustworthy online information and that 80% of citizens think that healthcare providers should suggest trustworthy sources of online health information.

Clinical input with selecting and reading online information is seen as desirable as many patients lack the skills to successfully read, understand and critically appraise medical information (Pletneva et al., 2011). However, the concern is that the internet is constantly changing and is an extremely dynamic environment (Laplante-Lévesque et al., 2012). For example, during the active data collection phase (4 months) of this study, nearly 10% of the selected webpages had changed or moved. In this constantly evolving space one must question the size of the job for a clinician to be constantly curating a list of appropriate webpages (Bernstama, Sheltona, Waljia, & Meric-Bernstamb, 2005). General practice doctors prefer to guide patients to specific healthcare websites rather than general search engines as sources of health care information however, even these medically based resources failed to provide comprehensive information on both assessment and management of tinnitus (Fackrell et al., 2012). To get a full picture at least 2 sources of information needed to be consulted increasing the clinician's workload. The clinical load for curating an approved list of online resources increases with every additional source added. A more time efficient option may be to embrace plain language efforts and produce specific patient materials that are both readable and can provide comprehensive information regarding treatment options. Such materials may be used during the clinical appointment and then be taken away for further reading.

Arsenault et al. (2016) very wisely state that low "quality scores" do not necessarily mean the information is of poor quality/erroneous but rather the way information is presented to the reader is not optimized for the specific audience intended. Quality scores also do not distinguish between good, bad or outdated treatment options. Pusz and Brietzke (2012) caution that while quality measures and tools such as DISCERN provide a framework for assessing webpages, such tools do not measure the accuracy of the information. It is perfectly plausible to have high quality scoring webpages that still contains significant inaccuracies (Bernstama et al., 2005).

4.7.2. Using webpages to improve health literacy

From an evidence-based perspective, it would be difficult for patients to use webpages such as those collected for this study to make an informed decision around APD treatment. The websites were primarily focussed on APD diagnosis and lacked significant information regarding treatment options. However, this is hardly unexpected when so many of the webpages were produced by commercial groups. Specific treatment details and objective assessment of the likelihood of treatment success are the intellectual property and provide the commercial advantage for each provider. It is unlikely given how commercially sensitive this information is that much would be shared on an online platform. While not unsurprising from a commercial perspective, it does make it difficult to objectively evaluate the treatment options available and what the likely success rates would be. This is clearly reflected in poor scores for the DISCERN tool and in the PEMAT actionability score. Pusz and Brietzke (2012) found that webpages for more chronic otolaryngologic concerns were more likely to contain advertisements for products which were often misrepresented as non-commercial information. Similarly Manchaiah et al. (2019) found that tinnitus online information was heavily dominated by commercial webpages which gave the reader enough information to sell a product but did not necessarily give sufficiently accurate or unbiased information. These webpages share many of the characteristics of the APD webpages particularly as many websites shared personal experiences and success stories which do not always equate to accurate or impartial quality information.

4.7.3. Application to APD scope of practice in New Zealand

In New Zealand, APD assessment falls under the professional scope of practice for audiologists. Input will often be sought from speech language therapy and psychology professionals to rule out language and cognitive impairments but a diagnosis of APD can only be given by an audiologist (W. Keith et al., 2019). Treatment for APD in New Zealand is usually provided by the small number of specifically trained audiologists with inputs where required from other specialists. APD assessments in New Zealand can be done privately through a small number of providers, by audiologists working at some District Health Boards or through the two universities providing audiology training (Esplin & Wright, 2014). The providers of APD diagnosis and treatment captured by the webpages in this study are from a broad range of professionals and represent a different scope of professional practice operating globally. In this study all professional/commercial providers of APD diagnosis or treatment were considered as one group, but when the type of organisation was further broken down, 31% of the total webpages were from education/speech language /psychology based providers and 17% were from ENT and audiologists (data not presented). From the New Zealand perspective, if parents/caregivers looking for APD services use these webpages as a guide when searching for professional services, they may approach professionals for whom APD diagnosis or treatment is out of their professional scope of practice. Future work could include repeating this search but limited to New Zealand and Australian webpages where APD diagnosis and treatment falls exclusively within the scope of practice for audiologists. This new research would be useful to show how the "type of organisation" of the webpages reflected the narrowed scope of professional practice and what role that other supporting professionals played in increasing health literacy in this area.

4.8. Limitations and Future research

There are some areas within this study that must be considered with caution. The study design used the country coded top-level domains as one way to capture country specific materials. This is consistent with other studies but increasingly and especially with videos and other audio-visual materials, the country of origin is often unknown. In this study, the country coded top-level domain was used as the primary degerminator of country. In these instances, the role that country plays in the quality metrics can get confused and the role of country in further studies could be reduced owing to the descriptor not being specific enough.

The readability work provides an estimation of how difficult a text is to read, and comprehension is implied. The readability formulas are a mathematical construct and do not consider the readers understanding of the text. Caution must be used as readability is not a surrogate for comprehension (Atcherson et al., 2013). The choice of the passages to analyse is important as the often easier to understand material is presented in the introduction and the more difficult passages are found in the middle and later parts of the text. (Wang et al., 2013)showed that up to a 3 reading grade level difference could be recorded based solely on where passages of text were chosen. The conservative approach of analysing the entire passage mitigates the impact of passage selection but misses the point that different parts of the passage may have very different RGL and that critical information may be missed if the RGL of those passages is too high.

The readability formulas also omit the role that motivation, familiarity with the content and readers experience have in improving reading comprehension of difficult or new materials. The application of readability formulas while being a simple and automated process to estimate how difficult a text is, should be viewed more as a gross estimate and will vary considerably from person to person depending on the person specific skills of motivation and experience.

A particular concern when using readability formulas for medical material is that often several smaller/simpler words when added together can result in a much harder to understand concept than when each individual word is considered. Beaunoyer et al. (2017) give the example of blood, white, cell and count. Each word by itself has a readability less than sixth grade reading level but when taken together “white blood cell count” is a very specific medical term and has an associated meaning probably in excess of a sixth-grade level. The algorithms used in the readability formulas can sometimes oversimplify the text and significantly over or underestimate the actual reading grade level.

The Plain Language tool that was used is this study was compiled specifically for this project. The author’s used a common set of questions that commonly occur in other already published tools to compile the tool. This new tool was first employed in this study and has not undergone external validation and how this tool performs against other plain language tools is unknown. However, the tool has undergone some internal validation checks. The ICC kappa value (Fleiss & Cohen, 1973) from 7 internal reviewers all came back with an excellent score indicating that the scores given by the reviewers were occurring more often than chance. This does give some confidence in the validity of the scores. Yet, it has not been established what a baseline for a "good/satisfactory" score is. At present all that can be stated is that the better the score the better the text does in covering more items in the Plain Language checklist. More work using this tool should focus on validating the tool against already published tools and determining some qualitative descriptors for good, fair and excellent results.

The PEMAT tool does not consider the materials purpose, target audience or completeness of relevant information (Mastroianni et al., 2019) nor does it provide a validated score/metric to indicate what are acceptable understandability and actionability scores (Kang & Lee, 2019; Maciolek et al., 2017). Currently all that is available is the general notion that higher PEMAT scores indicate better understandability or actionability with a score of 70 being acceptable (Vishnevetsky et al., 2018). This is most likely a reflection of the newness of the tool. When greater numbers of studies are available for collation, then appropriate validations will be possible and setting of acceptable understandability and actionability scores will result.

The DISCERN tool is a highly validated and well used tool applied to many different health disciplines. The tool has a specific focus on the quality of information aimed at treatment options. It is the very specific focus of the tool which limits its usefulness in studies such as this. In this study it was very apparent that the focus of most of the online information was about pathology description and then the route to diagnosis. Treatment options were very rarely described as they fall into the commercial advantage each company has and safeguards. This alerts us to the problem of blind application of quality tools regardless of the focus of the online content. The DISCERN tool performs poorly and adds very little to the assessment when the focus of the materials is not treatment. In hindsight the application of this tool was not a good choice for this data set and resulted in a very skewed distribution. The skewed distribution was analysed using non-parametric tools and lead to a significant loss of power. A better choice of quality assessment tool was perhaps the SAM tool (Doak et al., 1996) which does not have such a strong treatment focus but does cover the bias assessment the DISCERN tool uses in the first part of the tool.

The DISCERN tool also has problems in that it provides a qualitative scale for the questions The integer scale has 5 categories of which 2 are unnamed leading to subjective choice as to what they represent. Shedlosky-Shoemaker et al. (2009) point out that there are no clear guidelines or explanations for what a 2,3, or 4 represent on the DISCERN scale. There is also the possibility of researchers ascribing the scales values as ordinal or scale variable. The variables used are not defined by the authors so there is a need to make subjective judgements around the variables.

4.9. Conclusions

One of the greatest barriers faced by patients diagnosed with a new, rare or largely unknown medical disorder is that information is often scarce and of poor quality (Badiu et al., 2017; Pauer et al., 2017). The lack of appropriate patient education materials can significantly impact a patient’s ability to be informed and reduce their ability to take an active role in their medical journey. This certainly appears true for the niche otological disorder of APD. Many patients, parents, teachers and support workers are likely to be accessing medical information regarding APD from online resources. Concerns have been expressed that critical evaluation of online medical information is required to ensure that it is of sufficient quality and is presented in a way that is accessible to the people who most need it.

The results of this study show that readability and quality of the online APD information does not meet international best practice guidelines for readability or quality. As it stands, the available online APD materials are not fit for the purpose of facilitating improvements in APD health literacy While this result is not a surprise, it is concerning given the information in the public domain is limited. Future efforts must be directed to producing more accessible and quality patient education materials for use with APD patients.

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