

# **ASSESSMENT AND REVISION OF A PAEDIATRIC DIAGNOSTIC AUDIOLOGY REPORT**

---

Ashleigh J. Donald

A thesis submitted in partial fulfilment of the  
requirements for the Degree of  
**Master of Audiology**  
in the Department of Communication Disorders  
at the University of Canterbury  
2015

## ACKNOWLEDGEMENTS

---

This thesis would not have been possible without the help and support of many people. I would like to express my gratitude to my supervisor, Dr Rebecca Kelly-Campbell, who enabled me to carry out a project that I am truly passionate about. Thank you for being an academic genius and one of the most generous people I have met. Your continuous support, insightful advice, exceptional efficiency and constant accessibility helped smooth the speed bumps of my thesis journey.

I would also like to thank Fiona Yip and Virginia Good for helping me ensure the reports I created were clinically accurate. A special thank you to Catherine Coppell, who, over late night hot chocolate and endless emails, offered astute guidance during report revision. I valued and appreciated the advice from you all.

I am very appreciative of the generous scholarships granted to me by the Department of Communication Disorders and the University of Canterbury, both of which gave me a little more financial freedom.

Thank you also to all of the parents who took the time to participate in this study amidst their own hectic schedules. I hope the honest and detailed feedback you provided will serve to improve the experience of parents within New Zealand audiology.

To my classmates; thanks for your friendship, support and entertainment over the last two years. I know you will all make great audiologists and I can't wait to work alongside you in the big, wide world.

For the endless supply of coffee dates, dessert nights, gossip sessions, and laughter for the soul; I would like to thank my friends. You continuously reminded me that there is more to life than theses, and I feel so lucky to have each of you in my life.

To my family, albeit your surname Donald, Mayes, Loader or Field; thanks for supporting me through the successes and through the challenges. I would like to make special mention of my mum, who may be the most inspirational person on this planet. From day one she taught me "there is no such word as can't", and followed me with such love, faith and pride that I realised the truth behind these words. Mum, I dedicate this thesis to you.

And last, but not least, to Nick. Thanks for supplying me with caffeine, making me laugh with your "dad" jokes, squishing me with bear hugs, acting as my personal laundromat, tolerating my tantrums, and offering unwavering support, encouragement and love; despite recurrent episodes of "thesis brain". I do believe *you* are the gift that never stops giving.

*“The need and right to communicate is the most fundamental of human rights.  
To deny it is to harm the human spirit; to foster communication is to reveal all  
the possibilities of life”*

(Siegal, 2000)

## ABSTRACT

---

Optimising outcomes for children with hearing impairment (HI) requires a family centred approach that prioritises parent involvement. Families must be provided with information to encourage participation; and meet their need for emotional support and knowledge.

Diagnostic audiology reports can help provide this information, but their delivery alone is insufficient. If these reports are not readable and comprehensible they cannot meet national and international legal standards, nor can they support the health literacy of parents. The majority of New Zealand adults have insufficient health literacy skills, a concerning fact given the strong association between poor health literacy and negative health outcomes. The aim of this study was to evaluate a paediatric diagnostic audiology report, revise it and verify the revision.

A mock audiology report was evaluated via a readability analysis and semi-structured interviews with parent participants. Results confirmed that the report was difficult to read and understand. Next, the report was revised using best practice guidelines and parental recommendations. Verification of the revision process with 32 participants revealed that parents who read the revised report had significantly greater comprehension, self-efficacy and perception ratings than parents who read the unrevised report. Additionally, the report's readability was markedly improved.

These results may have critical implications for parents and their children with HI.

Incomprehensible audiology reports fail to support parental health literacy, promote understanding, encourage participation or offer emotional support. Because knowledge is power for these families, it is hoped that the findings of this study will be recognised and implemented into clinical practice.

## TABLE OF CONTENTS

---

<b>ACKNOWLEDGEMENTS .....</b>	<b>II</b>
<b>ABSTRACT .....</b>	<b>IV</b>
<b>TABLE OF CONTENTS .....</b>	<b>V</b>
<b>LIST OF TABLES .....</b>	<b>X</b>
<b>LIST OF FIGURES .....</b>	<b>XI</b>
<b>LIST OF ABBREVIATIONS .....</b>	<b>XII</b>
<b>DEFINITIONS .....</b>	<b>XIII</b>
<b>CHAPTER 1 .....</b>	<b>1</b>
<b>1.1 Overview .....</b>	<b>1</b>
<b>1.2 Hearing Impairment .....</b>	<b>3</b>
1.2.1 Overview .....	3
1.2.2 Prevalence .....	5
1.2.3 Impact of child HI .....	8
1.2.4 Effect of intervention on the impact of HI .....	14
1.2.5 Outcomes of intervention and factors that influence outcomes .....	18
<b>1.3 Health Literacy .....</b>	<b>22</b>
<b>1.4 Readability .....</b>	<b>27</b>
1.4.1 Purpose and use of readability formulas .....	27
1.4.2 Comprehension .....	31
<b>1.5 Patient education .....</b>	<b>34</b>
1.5.1 General overview .....	34
1.5.2 Written patient materials in New Zealand audiology .....	38
1.5.3 Revising patient education materials .....	41
1.5.4 Outcomes of document revision .....	44
<b>1.7 Aims and Hypotheses .....</b>	<b>48</b>
<b>CHAPTER TWO <i>METHODS STAGE ONE: EVALUATION</i> .....</b>	<b>51</b>
<b>2.1 Overview .....</b>	<b>51</b>
<b>2.2 Mock paediatric diagnostic audiology report .....</b>	<b>52</b>
2.2.1 Readability analysis of mock report .....	53

<b>2.3 Participants.....</b>	<b>54</b>
2.3.1 Recruitment .....	54
2.3.2 Inclusion and exclusion criteria.....	55
<b>2.4 Procedures .....</b>	<b>56</b>
<b>2.5 Measures .....</b>	<b>58</b>
2.5.1 Demographic questionnaire.....	58
2.5.2 Interview schedule.....	58
<b>2.6 Data Analyses .....</b>	<b>60</b>
2.6.1 Thematic analysis .....	60
2.6.2 Research rigor .....	61
<b>CHAPTER THREE <i>RESULTS STAGE ONE: EVALUATION</i> .....</b>	<b>62</b>
<b>3.1 Overview .....</b>	<b>62</b>
<b>3.2 Readability assessment .....</b>	<b>62</b>
<b>3.2 Participant characteristics .....</b>	<b>63</b>
<b>3.3 Thematic analysis of interview data.....</b>	<b>64</b>
3.3.1 General themes .....	65
3.3.2 Specific themes .....	71
<b>CHAPTER FOUR <i>STAGE TWO: REVISION</i> .....</b>	<b>76</b>
<b>4.1 Overview .....</b>	<b>76</b>
<b>4.2 Use of best practice guidelines .....</b>	<b>76</b>
<b>4.3 Use of parental recommendations .....</b>	<b>77</b>
<b>4.4 Veracity check .....</b>	<b>80</b>
<b>CHAPTER FIVE <i>METHODS STAGE THREE: VERIFICATION</i> .....</b>	<b>83</b>
<b>5.1 Overview .....</b>	<b>83</b>
<b>5.2 <i>A Priori</i> Analysis.....</b>	<b>83</b>
<b>5.3 Participants.....</b>	<b>84</b>
5.3.1 Recruitment .....	84
5.3.2 Inclusion and exclusion criteria.....	85
<b>5.4 Procedures .....</b>	<b>85</b>
<b>5.5 Measures .....</b>	<b>88</b>
5.5.1 Unrevised diagnostic report .....	88

5.5.2 Revised diagnostic report .....	88
5.5.3 Demographic questionnaire.....	88
5.5.4 Cloze procedure.....	89
5.5.5 Subjective questionnaire .....	89
5.5.5.1 Overview .....	89
5.5.5.2 Item development .....	90
5.5.5.3 Scoring.....	91
5.5.5.4 Pilot testing .....	92
5.5.6 Readability .....	92
<b>5.6 Statistical Analysis .....</b>	<b>93</b>
<b>CHAPTER SIX RESULTS STAGE THREE: VERIFICATION .....</b>	<b>94</b>
<b>6.1 Overview .....</b>	<b>94</b>
<b>6.2 Readability results .....</b>	<b>94</b>
<b>6.3 Sample characteristics .....</b>	<b>96</b>
<b>6.4 MANOVA .....</b>	<b>98</b>
6.4.1 Examining MANOVA assumptions.....	98
6.4.2 MANOVA results .....	98
<b>6.5 Correlations .....</b>	<b>100</b>
<b>6.6 ANCOVA .....</b>	<b>103</b>
<b>6.6. Correlation between Cloze scores and comprehension scores.....</b>	<b>103</b>
<b>6.6 Summary.....</b>	<b>104</b>
<b>CHAPTER SEVEN: DISCUSSION .....</b>	<b>106</b>
<b>7.1 Introduction.....</b>	<b>106</b>
<b>7.2 Evaluation stage: Hypotheses, relation to the literature and clinical significance ..</b>	<b>106</b>
7.2.1 Readability .....	106
7.2.2 Parental interviews .....	108
<b>7.3 Revision stage: Hypotheses, relation to the literature and clinical significance .....</b>	<b>111</b>
<b>7.4 Verification stage: Hypotheses, relation to the literature and clinical significance.</b>	<b>115</b>
7.4.1 Readability .....	115
7.4.2 Comprehension.....	117
7.4.3 Self-efficacy .....	121
7.4.4 Perceptions .....	123
<b>7.5 Limitations and directions for future research .....</b>	<b>125</b>

7.6 Clinical applications.....	131
7.7 Conclusion .....	134
<b>REFERENCE LIST .....</b>	<b>136</b>
<b>APPENDIX A: <i>RECOMMENDED STRATEGIES FOR IMPROVING WRITTEN PATIENT EDUCATION MATERIALS</i>.....</b>	<b>151</b>
<b>APPENDIX B: <i>EVALUATION STAGE</i> .....</b>	<b>153</b>
<b>B.1 Ethical approval letter, University of Canterbury Human Ethics Committee .....</b>	<b>153</b>
<b>B.2 Study advertisement.....</b>	<b>154</b>
<b>B.3 Information sheet .....</b>	<b>155</b>
<b>B.4 Consent form .....</b>	<b>157</b>
<b>B.5 Demographic questionnaire .....</b>	<b>158</b>
<b>B.6 Original mock paediatric audiology diagnostic report.....</b>	<b>160</b>
<b>B.7 Semi-structured interview schedule .....</b>	<b>162</b>
<b>APPENDIX C: <i>IMPLEMENTED REVISION TECHNIQUES FROM APPENDIX A AND COMPARISON BETWEEN THE TWO REPORTS</i>...</b>	<b>164</b>
<b>APPENDIX D: <i>COPY OF THE REVISED REPORT, ANNOTATED TO HIGHLIGHT MODIFICATIONS MADE</i> .....</b>	<b>167</b>
<b>APPENDIX E: <i>COPY OF UNREVISED REPORT, ANNOTATED TO HIGHLIGHT ISSUES</i>.....</b>	<b>179</b>
<b>APPENDIX F: <i>VERIFICATION STAGE</i> .....</b>	<b>183</b>
<b>F.1 Ethical approval letter, University of Canterbury Human Ethics Committee.....</b>	<b>183</b>
<b>F.2 Study advertisement.....</b>	<b>184</b>
<b>F.3 Information sheet.....</b>	<b>185</b>
<b>F.4 Consent form.....</b>	<b>187</b>
<b>F.5 Demographic questionnaire.....</b>	<b>188</b>
<b>F.6 Cloze procedure for unrevised report .....</b>	<b>190</b>
<b>F.7 Cloze procedure for revised report.....</b>	<b>192</b>



<b>F.8 Verification questionnaire .....</b>	<b>194</b>
<b>F.9 Debriefing sheet .....</b>	<b>199</b>
<b>APPENDIX G: <i>FURTHER ANALYSES OF PARTICIPANT RESPONSES TO THE QUESTIONNAIRE</i> .....</b>	<b>200</b>
<b>G.1 Comparison of the revised and unrevised report groups on comprehension questions.....</b>	<b>200</b>
<b>G.2 Comparison of the revised and unrevised report groups on self-efficacy questions .....</b>	<b>201</b>
<b>G.3 Comparison of the revised and unrevised report groups on the perception questions .....</b>	<b>202</b>
<b>G.4 Additional comments made by participants in the questionnaire.....</b>	<b>203</b>

## LIST OF TABLES

---

<b>Table 1.</b> Common impact of varying degrees of HI on receptive and expressive language skills and activities and participation. HI= Hearing Impairment, AL= Activity limitation, PR= participation restriction (Olusanya & Newton, 2007).....	13
<b>Table 2.</b> Participant inclusion and exclusion criteria, Stage 1: Evaluation .....	55
<b>Table 3.</b> Textual feature analysis of difficult words and sentences.....	63
<b>Table 4.</b> Results of thematic analysis: General themes, sub-themes and illustrative quotes.....	65
<b>Table 5.</b> Revision techniques suggested by parents that were feasible to implement .....	78
<b>Table 6.</b> Participant inclusion and exclusion criteria, Stage three: Verification .....	85
<b>Table 7.</b> Readability estimates for the revised and unrevised reports. ....	95
<b>Table 8.</b> Comparison of the text-based features of the two report versions .....	96
<b>Table 9.</b> Demographic variables for participants assigned to read the unrevised or revised report. ....	97
<b>Table 10.</b> Summary table for the results of each univariate ANOVA conducted. ....	99
<b>Table 11.</b> Analysis of Co-Variance for Years of Education by cloze score, comprehension, self-efficacy, perceptions and report allocation .....	103

## LIST OF FIGURES

---

<b>Figure 1.</b> World Health Organization model of disability showing the interaction between the different components of the ICF model (World Health Organization, 2002, p. 9) .....	10
<b>Figure 2.</b> Mean reading grade level of the revised report compared to the unrevised report and international readability recommendations. Mean calculated by averaging the Flesch-Kincaid (F-K), Fry and Simple Measure of Gobbledygook (SMOG) scores. ....	95
<b>Figure 3.</b> Mean cloze, comprehension, self-efficacy and perception scores for groups assigned the revised report and the unrevised report (error bars display standard deviations). ....	100
<b>Figure 4.</b> Years of education plotted against cloze scores (%) for all participants (p= .009) .....	101
<b>Figure 5.</b> Years of education plotted against comprehension scores (%) for all participants (p= .062) .....	101
<b>Figure 6.</b> Years of education plotted against self-efficacy scores (%) for all participants (p= .022). ....	102
<b>Figure 7.</b> Years of education plotted against perception scores (%) for all participants (p=.009).....	102
<b>Figure 8.</b> Cloze scores (%) plotted against comprehension scores (%) for all participants (P<.001) .....	104

## LIST OF ABBREVIATIONS

---

ABR	Auditory Brainstem Response
ALL	Adult Literacy and Life skills
ASHA	American Speech-Language-Hearing Association
CAMHS	Child And Adolescent Mental Health Services
dB eHL	Decibel estimated Hearing Level
dB HL	Decibel Hearing Level
DND	Deafness Notification Database
DPOAE	Distortion Product Otoacoustic Emission
EHDI	Early Hearing Detection and Intervention
EQIP	Ensuring Quality Information for Patients
ESL	English as a Second Language
F-K	Flesch-Kincaid
FRE	Flesch Reading Ease
GP	General Practitioner
HI	Hearing Impairment
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health for Children and Youth
kHz	Kilohertz
NHS	Newborn Hearing Screening
NSU	National Screening Unit
OECD	Organisation for Economic Co-operation and Development
PHLAT	Parental Health Literacy Activities Test
RGL	Reading Grade Level
SAM	Suitability Assessment of Materials
SMOG	Simple Measure Of Gobbledygook
UNHSAG	Universal Newborn Hearing Screening Advisory Group
UNHSEIP	Universal Newborn Hearing Screening Early Intervention Programme
WHO	World Health Organization
YLD	Years Lost to Disability

## **DEFINITIONS**

---

For the purposes of this thesis and for ease of reading, the term “parent” will be used hereafter to refer to the guardian responsible for the care of a child with hearing impairment.

Further, the term hearing impairment will be used instead of hearing loss throughout this thesis. Hearing impairment is consistent with the World Health Organization’s International Classification of Functioning, Disability and Health (WHO ICF), which acknowledges that a limitation in auditory sensitivity will have unique, multi-faceted consequences for an individual.

## CHAPTER 1

---

### 1.1 Overview

Hearing impairment (HI) is an invisible disability that contributes significantly to national and international disease burden (Digby et al., 2004). In fact, HI is the most common congenital anomaly, affecting an estimated three New Zealand babies in every 1,000 live births (National Screening Unit, 2009). Any impairment in auditory functioning can have far-reaching and profound effects on child development; affecting their ability to acquire verbal speech and language skills, function socially, achieve academically and experience unlimited vocational choice (Schrijver, 2004). The negative repercussions of child HI can also extend to the child's family, creating emotional stress as parents try to cope with the logistics and implications of their child's HI (Kurtzer-White & Luterman, 2003).

Timely diagnosis and intervention can help mitigate these negative ramifications, allowing children with HI to enjoy equal opportunities with their normal hearing peers (Harlor & Bower, 2009). Consequently, Universal Newborn Hearing Screening Early Intervention Programmes (UNHSEIPs) have become the standard of care internationally, and have resulted in substantial reductions in the average age of HI diagnosis (Yoshinaga-Itano, Coulter, & Thomson, 2000). However, the success of intervention depends on a number of factors beyond simply meeting targets on a timeline. The individual characteristics of the child and their HI, the health system in place and the involvement of the family and whānau are recognised to all play a significant role (Digby et al., 2004). Evidence suggests that parental coping, self-efficacy and knowledge also moderate the outcomes of children with HI. Consequently, UNHSEIPs typically acknowledge and prioritise family-centred approaches (ASHA, 2008).

Providing parents with adequate and appropriate information is a fundamental component of this process. Because parents may struggle to accurately retain information immediately after diagnosis, it is recommended that written materials should be offered to consolidate verbal counselling (Driscoll, 2011; Russ et al., 2004). Within New Zealand audiology, such written documents include a brochure or book introducing HI, in addition to a written report outlining the results of the diagnostic appointment.

Although these documents are provided with the purpose of benefiting parents, they can only achieve this if they are written in a manner that supports parental health literacy. Increasing attention is being directed to this notion, as evidence suggests that the majority of New Zealand adults have insufficient skills to cope with the daily health literacy demands they face (Ministry of Health, 2010). Given the strong relationship between health literacy and health status, improving health literacy is considered an international priority. Redesigning health information materials so they better match the skills of health consumers is one commonly recommended strategy for building health literacy (Kickbusch, 2001).

Comparing the readability of written health materials to international recommendations is an efficient way to evaluate the appropriateness of a document. The general consensus is that patient education materials should be written at the US sixth reading grade level, or below (Doak, Doak, & Root, 1996). However, a multitude of studies have revealed significant discrepancies between the recommended level and the level at which written materials are actually written (for a review see Institute of Medicine, 2004). Anecdotal evidence suggests that a similar discrepancy exists for the audiology diagnostic reports written to parents of children with HI.

Currently, no studies have investigated this issue, yet research into the development of effective and meaningful resources for parents of children with HI is critically important.

Readable and comprehensible paediatric diagnostic audiology reports could serve to enhance parental understanding, promote self-efficacy and offer emotional reassurance; whilst simultaneously supporting the health literacy skills of New Zealand parents. Combined, these advantages could indirectly help protect the health status of children with HI. This thesis thus aims to evaluate the readability and comprehensibility of a mock paediatric diagnostic audiology report, with the goal of revising the report, before verifying the effectiveness of revision.

## **1.2 Hearing Impairment**

### **1.2.1 Overview**

In order to discuss HI in children, it is necessary to begin by outlining how the human auditory system normally functions. The human ear consists of three sections: the outer ear, comprised of the visible portion of the ear and the ear canal; the middle ear with the tympanic membrane, the three ossicular bones and the eustachian tube; and the inner ear, where the two sensory organs of hearing (the cochlea) and balance (the vestibular system) reside. The primary function of the outer ear is to collect and transmit sound waves down the ear canal to the tympanic membrane, causing it to vibrate. The role of the middle ear is to conduct these vibrations to the fluid-filled space of the inner ear, whilst compensating for the loss of sound energy which occurs during the transition between medium types (Duthey, 2013). Finally, movement of fluids within the cochlea generate changes in microscopic hair cells which function to transform mechanical energy into electrical signals. The auditory nerve carries these signals to the brain, where they are interpreted as sound (Bess & Humes, 2008). Abnormal structure or function at any point along this auditory pathway can result in a HI, defined as the partial or complete loss of sound sensitivity (Martin & Clark, 2012).



Depending on the location of the problem within the auditory pathway, HI is classified as one of three types: conductive, sensorineural or mixed. Conductive HI occurs secondary to problems in the outer ear or the middle ear, and prevents the effective conduction of sound to the inner ear. Common causes of conductive HI include impacted cerumen, abnormalities in the ossicular chain, and otitis media (Martin & Clark, 2012). Conductive HI is often treatable with medical or surgical management and so is often considered temporary in nature (Stach & Ramachandran, 2008). In contrast, sensorineural HI arises from abnormalities in the inner ear or the auditory nerve and causes defective transduction of sound vibrations to electrical signals (Martin & Clark, 2012). Sensorineural HI is generally not correctable by medical or surgical treatment, and is subsequently referred to as permanent in nature (Stach, & Ramachandran, 2008). The presence of problems in both the conduction of sound to the inner ear and the transmission of sound to the brain results in a mixed type of HI.

HI may be further classified by its time of onset and causality. Time of onset is established as either congenital, where the HI was present and detectable at or very soon after birth; or acquired, where the HI was detected postnatally (Bess & Humes, 2008). A congenital HI is often referred to as a prelingual HI as they occur before the child has had an opportunity to develop speech and language. In contrast, many cases of acquired HI are postlingual, in that the child has already developed spoken speech and language skills prior to the onset of the HI (Finsterer & Fellingner, 2005).

Regarding causality, approximately 50% of cases of congenital HI are attributable to genetic changes, 25% to environmental causes, while the aetiology is unknown in the remaining 25% of cases (Schrijver, 2004). In contrast, acquired HI tend to be sequela to environmental causes such as including meningitis, head injuries or exposure to ototoxic medications (Harolor & Bower, 2009). However, some cases of acquired HI in children are

attributable to genetic origins, with the phenotype one of late onset (Smith, Bale, & White, 2005).

Following a hearing assessment, audiologists use descriptors of severity and configuration to characterize the HI. The severity, or degree of the HI is quantified by assigning qualitative labels that correspond to the decibel (dB) level associated with the individual's hearing thresholds. There are various severity classification systems in use, all of which describe the HI on a continuum from normal to profound. Within New Zealand, the New Zealand Audiological Society (NZAS) guidelines recommend the use of Clark's 1981 classification. This system grades HI as being slight (16-25 dB HL), mild (26-40 dB HL), moderate (41-55 dB HL), moderately-severe (56-70 dB HL), severe (71-90 dB HL) or profound ( $\geq 91$  dB HL); using a pure-tone average (PTA) of the thresholds at frequencies 0.5 kHz, 1 kHz, 2 kHz and 4 kHz. Because it is common for the degree of HI to vary at different frequencies, the configuration (or shape) of the hearing loss is used to describe how frequency-specific thresholds are positioned with respect to each other (Digby et al., 2004). For example, the term flat is used to describe a HI where there is little variation in the thresholds across frequency, whereas a HI that increases from the low to high frequencies is described as sloping.

### **1.2.2 Prevalence**

It is estimated that 5.3% of the world's population are affected by a disabling HI, equivalent to 360.8 million people (World Health Organization, 2012). Indeed, HI is the most common disabling condition to affect all ages globally (Duthey, 2013). Accurate estimates of the prevalence of HI in the New Zealand population have yet to be achieved, but data collected from four census surveys predicts the prevalence of HI in non-institutionalised New Zealand adults to be between 5.7-9.8% (Greville, 2005; Statistics New Zealand Tauranga

Aotearoa, 2014). Unfortunately, the validity of these census estimates is equivocal as they are based on self-reported data, likely involving sampling error issues and affected by the interpretation of ambiguously worded questions (Greville, 2005).

Although the highest prevalence of HI exists among older adults, children account for approximately 9% of individuals with HI around the world (Duthey, 2013). The cumulative prevalence of HI in children increases with age, with 50-90% of children diagnosed with permanent childhood HI by the age of 9 years (Ching, Oong, & Wanrooy, 2006; Digby, Purdy, & Kelly, 2014; Fortnum, Summerfield, Marshall, Davis, & Bamford, 2001). Unfortunately, accurate report of the prevalence of paediatric congenital HI worldwide is challenging due to a lack of standardised methodologies between nations. Despite this, an increasing number of studies are converging at prevalence estimates of 1-3 per one thousand children for permanent childhood HI of a moderate or greater degree in high income countries (Ching et al., 2006; Davis & Davis, 2011; Fortnum & Davis, 1997).

Currently, there are no prevalence data available for permanent HI among New Zealand children (Digby et al., 2014). The best prevalence estimates presently available are obtained from information in the national Deafness Notification Database (DND). The DND has been in use since 1982, developed with the aim of collecting data on the number of new cases of HI among children and young people in New Zealand within a given calendar year. The criteria for inclusion in the database are currently: 'Children and young people 18 years or younger, born in New Zealand or overseas, with (1) a permanent hearing loss in one or both ears and (2) an average loss of 26 dB HL or greater over four audiometric frequencies (0.5, 1.0, 2.0 and 4.0 kHz)' (Digby et al., 2014, p. 6).

In the most recent report for the year 2013, the total number of diagnoses reported to the DND was 200, consistent with the 185-191 notifications reported between 2010 and 2012

(Digby, Purdy, & Kelly, 2011, 2012, 2013; Digby et al., 2014). These notifications are estimated to represent 50-80% of all cases of child HI in New Zealand in a given year, as international data predicts 245 new cases of child HI in New Zealand each year (based on a population estimate of 1.167 million children) (Digby et al., 2014). Of the 172 notifications pertaining to children born in New Zealand, 53 were identified from the New Zealand UNHSEIP (Digby et al., 2014). While this percentage initially suggests poor sensitivity of the UNHSEIP, it must be noted that the UNHSEIP was gradually implemented between 2007 and 2010 in New Zealand, and as a consequence, nearly half of the children identified in 2013 were born when newborn hearing screening was not in place years (Digby et al., 2014). Further, the DND reports cases of child HI diagnosed in children aged up to 19 years, and thus some of the cases will represent late-onset or acquired HI which would not have been present at birth anyway (Digby et al., 2014).

The proportion of diagnoses resulting from newborn hearing screening referrals are accordingly expected to increase over the coming years; and may eventually approach the National Screening Unit's (NSU) estimate that 135-170 babies are born with mild to profound congenital HI in New Zealand each year. This is equivalent to an incidence of 3 per one thousand births, which is at the upper range of international estimates (NSU, 2009). However, the NSU's prediction includes cases of mild HI, whereas studies in other countries have considered only cases of HI with a moderate or greater severity (Ching et al., 2006; Fortnum & Davis, 1997).

It is also noteworthy that Māori children account for a disproportionate number of HI diagnoses within New Zealand. In 2013, 38% and 39% of notifications to the DND were for children of Māori and NZ European ethnicity, respectively (Greville, 2005). Given that Māori make up only 14.9% of the total population in New Zealand (Statistics New Zealand Tatauranga Aotearoa, 2014), such evidence of the 'ethnic effect' is concerning. Furthermore,

it is thought that these statistics may actually underestimate the number of Māori children affected by HI, due to Māori children having reduced access to the healthcare system and their higher chance of experiencing mild degrees of HI which often remain undiagnosed (Digby et al., 2014).

While the data obtained in the DND provides good information about the demographics of childhood HI in New Zealand, it cannot be ascertained that the reported cases are a complete reflection of all diagnoses of child HI made in New Zealand. This is because the database relies on voluntary reporting of cases by audiologists. Indeed, evidence from a widely distributed survey of audiologists in 2014 support this, with audiologists admitting that 26 cases of identified childhood HI were not registered during 2013. Therefore, it is important to take heed of the authors' warning that inferences from the DND data should be made with caution (Digby et al., 2014).

### **1.2.3 Impact of child HI**

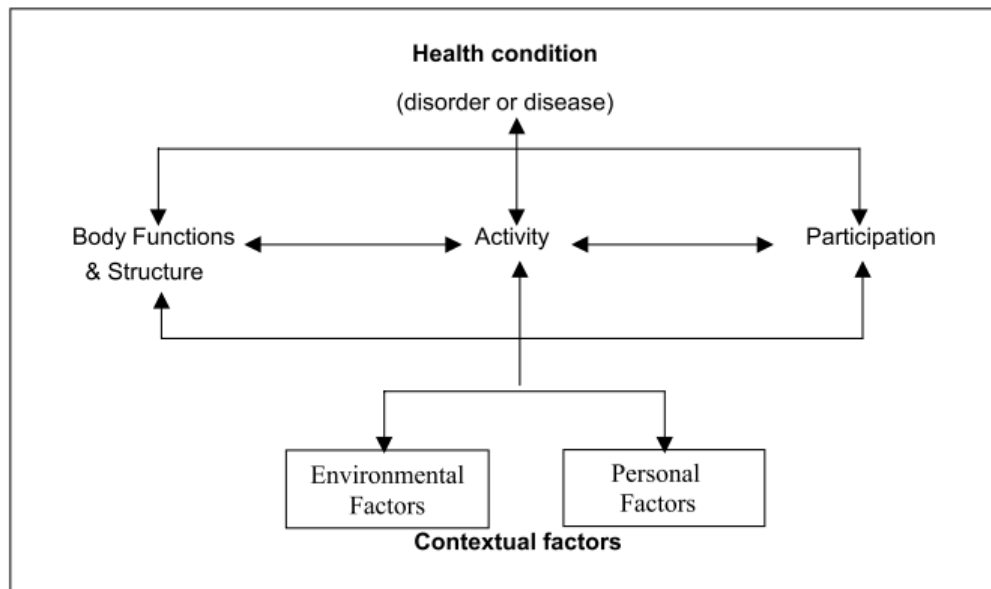
The consequences of HI are significant and extensive for all individuals, as evidenced by the World Health Organization (WHO) classifying adult-onset HI as the third leading cause of years lost to disability (YLD) (Stevens et al., 2013). Unfortunately, the WHO does not consider childhood-onset HI when evaluating causes of YLD as they claim that most cases of childhood HI are attributable to congenital causes, infectious diseases or injury, and thus are accounted for under these health conditions (Olusanya & Newton, 2007). However, authors argue that if accurately appraised, the burden of disease for childhood HI would substantially exceed that of adult-onset HI, given that (1) children's normal development is incredibly vulnerable to assaults on their perceptual sensory system; and (2) they experience the adversities of their HI for a longer proportion of their lives (Olusanya & Newton, 2007).

The consequences of child HI have been demonstrated for cases of even mild severity, affecting acquisition of speech and language, future educational and vocational prospects in addition to cognitive and psychosocial development (Convery et al., 2013; Digby et al., 2004; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). Child HI also indirectly affects other individuals, often creating a change in dynamics which can cause tension or dysfunction in the family and whānau of the child (Northern & Downs, 2014). Furthermore, significant societal and economic adversities are generated for a nation as a result of child HI. Specifically, it is estimated that over US\$1,000,000 will be spent on an individual with congenital severe to profound HI over their lifetime (Mohr et al., 2000).

The impact of HI on child development may be best understood within the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) model developed by the WHO in 2007. The ICF-CY is included within the family of international classifications produced by the WHO, all of which aim to provide a “common language and framework for the description of health and health-related states” (World Health Organization, 2002, p. 2). Under the ICF model, the health condition and contextual factors of an individual are conceptualised to understand how human functioning is affected at three levels: body structure and function (the level of the body or body parts), activities (the level of the person) and participation (the level of a person within an environment). Together, these three levels contribute to the first part of the ICF model known as functioning and disability. Within this, a disability is defined as dysfunction at any of the three levels, resulting in an impairment, activity limitation or participation restriction; antonyms to the functioning terms described above (World Health Organization, 2002)

The ICF model also takes the perspective that an individual does not exist in isolation, but instead is affected by a variety of both personal and environmental factors. Together, these contribute to the second part of the ICF model regarded as contextual features. Personal

factors pertain to those internal to the person such as gender, age, social background, coping style and previous experience; whereas environmental factors are external and relate to the physical, social and attitudinal influences of the world in which people live (World Health Organization, 2002). Figure 1 displays the interaction of these components.



**Figure 1.** World Health Organization model of disability showing the interaction between the different components of the ICF model (World Health Organization, 2002, p. 9)

In recent years, professionals within the communication disorders field have begun to employ the ICF model to help conceptualise their client’s health problem and the impact it has on their life (Cruice, 2008; Eadie, 2003; McLeod & McCormack., 2007; McLeod & Threats, 2008). For example, a child with HI may have a bilateral, moderate to severe sensorineural HI in their auditory sensory system (body function and structure) which, if untreated, can have substantial and irreversible effects on their linguistic and communicative competence (activity limitation). In turn, this may restrict children from achieving academic success, developing normal psychosocial skills and enjoying unlimited vocational opportunities (participation restrictions).

These limitations and restrictions are thought to arise because a large proportion of child development depends on normal verbal language acquisition. Essentially, the prerequisite to developing verbal language skills is the reception of meaningful auditory stimuli within a precise time period in a child's life (often referred to as the critical period, or more broadly, the sensitive period). In order to receive this stimulation, children must possess an intact and functioning hearing mechanism (Paul & Whitelaw, 2011). If this is impaired for all, or part of the child's sensitive period, they are at increased risk for irreversible damage to their speech and language. Multiple studies have highlighted this association, showing that children with HI often speak with fewer and shorter utterances, have reduced articulation skills and poorer speech recognition scores (Digby et al., 2004; Tharpe & Bess, 1991).

The ability to hear is also fundamental to child development in areas beyond acquiring normal verbal speech and language. Particularly in young children, reduced listening abilities may limit opportunities for incidental learning, resulting in children with HI having a reduced knowledge base when compared to their normal hearing peers (Flexer, 1999). Further, because the development of verbal language precedes the acquisition of literacy skills, children with HI often lag behind their normally hearing peers in measures of reading level, with the average student with HI able to read at only the fifth grade level when they graduate from high school (Yoshinaga-Itano, Sedey, Coulter & Mehl, 1999). Combined, these impairments likely contribute to the significant disparities observed in the educational achievement rates of New Zealanders with HI and New Zealanders with normal hearing (Greville, 2005).

Furthermore, because normal social interaction emphasises effective communication, children with HI are often placed at significant social disadvantage, which in turn may produce high levels of stress, low motivation and feelings of frustration and isolation (Stinson, Whitmire, & Kluwin, 1996). These emotions have been associated with personal-



social maladjustments, causing children with HI to be more likely to develop mental health issues, drop out of school and become involved in juvenile delinquency or gangs (Digby et al., 2004). A combination of these described limitations and restrictions probably also contributes to the higher unemployment rates and lower vocational choice observed among people with HI (Digby et al., 2004). For example, a study of 288 people with HI within the city of Copenhagen found a significantly higher self-reported unemployment rate among persons with congenital or early acquired HI compared to an age-matched normally hearing group (Parving & Christensen, 1993).

Such negative consequences of child HI occur for all degrees of HI, indicating that the audiogram is not a valid predictor of HI disability (Tharpe & Bess, 1991). Despite this, there is evidence to suggest that the extent of the activity limitations and participation restrictions which result from a HI do increase with the severity of the impairment, as depicted in Table 1 below (Stevens et al., 2013).

**Table 1.** Common impact of varying degrees of HI on receptive and expressive language skills and activities and participation. HI= Hearing Impairment, AL= Activity limitation, PR= participation restriction (Olusanya & Newton, 200, p. 1314).

<i>Degree of HI</i>	<i>Receptive language</i>	<i>Expressive language</i>	<i>AL/ PR</i>
Normal hearing (0-15 dB HL)	Detects all speech signals	Normal range	None
Slight HI (16-25 dB HL)	Misses up to 10% of speech sounds (e.g. unvoiced consonants) especially in difficult situations	Mild dysfunction in language learning	Inappropriate response to sound Learning difficulties Poor social interaction
Mild HI (26-40 dB HL)	Misses 25-40% of speech especially in difficult situations	Mild language retardation and speech problems	Inattention Learning difficulties Behaviour problems
Moderate HI (41-55 dB HL)	Misses 50-75% of speech	Moderate language retardation and poor speech intelligibility	Learning dysfunction Significant social problems
Moderately-severe HI (56-70 dB HL)	Misses 75-100% of speech	Severe language retardation and speech problems	Severe learning dysfunction Stigmatisation and possible social isolation
Severe HI (71-90 dB HL)	Misses up to 100% of conversational speech	Severe speech problems and language retardation	Severe learning dysfunction Stigmatisation and possible social isolation
Profound HI ( $\geq 91$ dB HL)	Misses all loud speech sounds except vibrations	Visual cues essential for communication	Complete social isolation

As mentioned earlier, the level of disability experienced by a child is mediated by other environmental factors including the support provided by the family (Sass-Lehrer, 2004). This interaction is considered to be reciprocal in that child HI also impacts on the family, causing them to experience their own activity limitations and participation restrictions. The WHO refers to this phenomenon as third party disability and defines it as “disability and functioning of family members due to the health condition of significant others” (World Health Organization, 2001, p. 251). Previous research has revealed that the

level of an adult's HI is linked with poorer mental, social and physical well-being in their significant other (Wallhagen, Strawbridge, Shema, & Kaplan, 2004; Scarinci, Worrall & Hickson, 2012). It is intuitive that child HI also creates third party disability for parents. Indeed, research has identified that child HI can cause significant psychological stress in parents and affect various family decisions related to areas such as vocation, finances and living arrangements (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008; Gilbey, 2010; Hintermair, 2006; Moores, Jatho, & Dunn, 2001).

Overall, it is pivotal to consider that child HI has pervasive and multifaceted consequences on for the individual child, which oft extend to affect surrounding family and whānau. The design of intervention plans should therefore involve evaluating each child's unique framework of contextual factors and should be guided under a family-centred approach to minimise third party disability (Ching et al., 2006; Sass-Lehrer, 2004; Shulman et al., 2010).

#### **1.2.4 Effect of intervention on the impact of HI**

One of the most effective strategies for minimising or preventing auditory sensory deprivation is the implementation of early detection and intervention (Paul & Whitelaw, 2011). Past research has consistently highlighted the association between early intervention, improved speech intelligibility and enhanced academic, educational and emotional success in children with HI (Markides, 1986). This implied need for timely intervention resulted in the WHO recommending the development of international neonatal hearing screening programmes in 2000, which have rapidly become the standard of care throughout the majority of developed countries (Digby et al., 2004).

Prior to the implementation of a Universal Newborn Hearing Screening Early Intervention Programme (UNHSEIP) in New Zealand, the average age of identification for

children with a moderate or greater HI was around three to four years, and was higher for Māori and Pacific children (NSU, 2009). This age reflects the limitations of the previous high-risk screening approach. Under this system, hearing screening was selective, where only those babies presenting at birth with one or more risk factors for HI were screened (Digby et al., 2004). Unfortunately, this programme was ineffective at identifying cases of child HI, as only a small proportion of infants actually present with risk factors at birth, and statistics suggest that even those infants with risk factors were not always screened (Digby et al., 2004; Flynn, Austin, Flynn, Ford, & Buckland, 2004).

In comparison to overseas reports, it was evident that New Zealand's average age of identification was late, substantially exceeding the international recommendation of 3 months (Digby et al., 2004). Given the strong evidence for superior outcomes and the recent availability of reliable, efficient and cost-effective screening technologies, the Universal Newborn Hearing Screening Advisory Group (UNHSAG) strongly endorsed the introduction of a UNHSEIP in New Zealand in 2004 (Digby et al., 2004). The programme was designed to follow the 1-3-6 best practice timeline; with the goal that all babies should be screened by 1 month of age, have completed full audiological assessment by 3 months of age and interventions should be initiated by 6 months of age. While newborn screening is effective at identifying HI at birth, it is only the first step in the provision of appropriate diagnosis and intervention. Other necessary elements include ongoing monitoring to detect cases of late onset or acquired HI, thorough diagnostic evaluation, and the implementation of rehabilitation; all of which should be guided by a family-centred approach (Kurtzer-White & Luterman, 2003).

Accordingly, the monitoring of hearing status is ongoing until school age in New Zealand, via the targeted follow-up programme and the Well Child Tamariki Ora Schedule.

Targeted follow-up requires a second audiology assessment around 18 months of age for those babies who present with normal hearing at birth but have one or more risk factors for HI. It is employed to monitor potential cases of progressive or late-onset HI (Ministry of Health, 2013a). Moreover, inclusion of hearing assessments in the Well Child service Tamariki Ora Schedule is believed to offer a vigilant method for detecting cases of acquired HI (Ministry of Health, 2013b). The schedule consists of 12 core contacts with health professionals from birth to 5 years of age, including the B4 School Check which includes a hearing test performed by a vision and hearing technician (Ministry of Health, 2013b).

If a child refers on their screen or concerns are raised about their hearing ability through the monitoring schemes, the next step involves a full diagnostic assessment conducted by an audiologist. The precise nature of the assessment will vary depending on the age of the child, but may employ subjective (behavioural) tests, objective (physiological) tests or a combination of the two. Physiological tests such as tympanometry and distortion product otoacoustic emissions (DPOAEs) are objective as they assess functional aspects of the auditory system and do not depend on a response from the child. These two tests are mandatory for all child diagnostic assessments, with tympanometry assessing middle ear function, whereas DPOAEs assess the integrity of the cochlea (Martin & Clark, 2012).

While these two tests may indicate an abnormality in the auditory pathway, they cannot provide a precise indication of the degree to which the system is functional or dysfunctional (Bess & Humes, 2008). To obtain a complete picture, more complex testing procedures must be employed which allow hearing ability to be assessed across different frequencies, intensities and via the two sound conduction pathways. For babies under 6 months of age, or those experiencing severe developmental disabilities, the Auditory Brainstem Response (ABR) is the test of choice (Madell & Flexer, 2008). Once children

reach approximately 6 months of age, their hearing should first be assessed through subjective tests, however. These rely on the child providing a voluntary, but measurable behavioural response to sound (ASHA, 2004). From 6 months to approximately 2.5 years, visual reinforcement audiometry (VRA) is recommended, while play audiometry is generally employed once children reach approximately 2.5 years of age (Madell, 2008).

Following the diagnosis of a HI in New Zealand, the family and whānau are referred to a selection of other health professionals (referred to as the multi-disciplinary team) whose role is to develop an intervention action plan for the child. In addition to the audiologist, this team always includes an otolaryngologist and an adviser on deaf children (AoDC). The role of the otolaryngologist is to assess possible causes of the HI, and investigate if the HI can be medically managed (Digby et al., 2004). The AoDC acts to provide the family and whānau with information and support, while also liaising with other members of the multi-disciplinary team (Digby et al., 2004). Other professionals including an ophthalmologist, paediatrician, geneticist and speech language therapist may also be involved, depending on the age of the child and the co-existence of other developmental disabilities (Madell & Flexer, 2008).

Intervention for children with HI in New Zealand typically employs a medical framework, where speech and language therapy is combined with technology such as hearing aids or cochlear implants (Smiler, 2006). A sociolinguistic framework for intervention also exists, involving the use of New Zealand Sign Language and contact with the Deaf community to help children develop their social identity (Smiler, 2006). If parents decide that spoken language is how they want their child to communicate, then it is essential that the multi-disciplinary team works to try and provide the child with access to the sounds of speech. The recommended intervention(s) will vary depending on each individual case. For

some children, medical procedures may reduce or eliminate the hearing loss, as often observed with grommet insertion or reconstruction of the middle ear bones (Smith et al., 2005). However, the majority of children with HI experience impairment which is not directly remediable, and instead requires auditory intervention through technological devices. Typical auditory options may include hearing aids, assistive listening devices or more invasive hearing devices such as cochlear implants or bone anchored hearing aids, which require implantation via surgical procedures (Smith et al., 2005).

For some children, the optimal intervention strategy is not clear, and requires complex shared decision-making. Two underlying principles of the UNSHEIP should guide these decisions: (1) Provision of support from the multi-disciplinary team, and (2) Prioritisation of a family-centred approach and (Crowe, Fordham, Mcleod, & Ching, 2014). Essentially, the goal of the multi-disciplinary team is to provide the family with accurate information about all of the available options so they can make well-informed and timely decisions (Harlor & Bower, 2009). Including family members in the process is critical as partnerships with parents are linked with improved outcomes for children with HI (Sass-Lehrer, 2004).

### **1.2.5 Outcomes of intervention and factors that influence outcomes**

Successful outcomes have been observed for all of the different intervention strategies described above, provided they are executed in a timely fashion (Markides, 1986; Yoshinaga-Itano, 1998; Waltzman & Roland, 2005). Research suggests that the implementation of UNHSEIPs throughout the world are helping lower the age of identification and intervention of children with HI, and that these reductions are subsequently enabling the anticipated improvements in language development (Ching et al., 2006; Harrison, Roush, & Wallace, 2003; Yoshinaga-Itano 1998). Achieving these optimal outcomes for children with HI is more complex than simply meeting targets on the recommended intervention timeline,

however. The choice of intervention and the effectiveness of the approach are affected by a number of other variables specific to the child, the intervention programme and the family (Digby et al., 2004; Harlor & Bower, 2009).

As suggested by the WHO model, family involvement is a particularly important factor in predicting the health outcomes of children with HI. This was confirmed in a seminal study by Moeller (2000) who investigated the relationship between the age of enrolment in intervention and the resulting language outcomes at five years of age in a cohort of children with HI. Using a multi regression analysis, the author assessed what factors accounted for the most variance in language performance between children. Interestingly, the level of parental involvement accounted for significantly more variance than any of the other factors investigated, including the age of enrolment in intervention. This gives further impetus to the theory that the active involvement of parents should be prioritised during design of UNHSEIPs (Moeller, 2000).

However, the participation of families in their child's intervention is not straightforward and is itself affected by various demographic and psychological variables (Harlor; & Bower, 2009; Luterman & Kurtzer-White, 1999). More specifically, it is well understood that the period following HI diagnosis is a challenging and stressful time for the family and whānau (Kurtzer-White & Luterman, 2003). Shock, depression, sorrow, confusion, anger, denial, guilt, inadequacy, isolation and vulnerability are all common emotions reported by parents following diagnosis (Kurtzer-White & Luterman, 2003; Martin, 1987; Russ et al., 2004). Research has shown that the manner by which families manage to cope with this emotional stress is associated with successful family adjustment, and subsequently, positive child outcomes in areas of competence, achievement and adjustment (Feher-Prout, 1996; Kurtzer-White & Luterman, 2003). Conversely, parents who experience difficulty adjusting



to their child's HI may struggle to connect and communicate with their child, predisposing them to reduced social skills and educational achievement (Driscoll, 2011).

Whilst trying to cope emotionally with the reality of their child's HI, parents are simultaneously expected to make life-altering intervention decisions. These choices require careful consideration of a number of issues, and the confidence parents feel in making these decisions is reflected by a construct known as self-efficacy. Self-efficacy is defined as an individual's confidence in their ability to successfully undertake behaviours to achieve specific goals, including improved health (Hwang, Hawkins, & Pingree, 2008; Marks, Allegrante, & Lorig, 2005). Classically, Bandura (1989) identified four major information sources which can moderate self-efficacy, including: prior experience (enactive attainment), observation of others engaging in particular tasks (vicarious experience), the encouragement or discouragement received from others (verbal persuasion), and the physical and emotional reactions an individual experiences prior to attempting to achieve a goal (physiological factors).

Unfortunately, these factors may be reduced or absent in parents of children with HI. First, 90% of children with HI are born to hearing families, where parents typically have little prior knowledge or past experiences (enactive attainment and vicarious experiences) to draw on (Kurtzer-White & Luterman, 2003). Second, parents are often exposed to a multitude of opinions from members of the multi-disciplinary team and other family or friends regarding intervention options for the child (Sass-Lehrer, 2004). This verbal persuasion is often conflicting and may serve to confuse parents, rather than empower them. Third, as described above, parents typically experience strong emotions (physiological factors) following diagnosis of their child's HI, oft intensified due to the unpredictability of many modern HI diagnoses. This is observed with the implementation of UNHSEIPs which have caused movement away from parent-initiated diagnoses to institution-initiated diagnoses (Kurtzer-

White & Luterman, 2003). Consequently, parents must now accept the diagnosis, without the benefit of time or observation to develop their own suspicions or concerns. A combination of these factors is likely to contribute to reports that parents often feel overwhelmed, lost, or inadequate at evaluating the best option from the myriad of interventions posited (Crowe et al., 2014; Feher-Prout, 1996; Larsen, Munoz, DesGeorges, Nelson, & Kennedy, 2012).

It is logical that high parental self-efficacy should encourage positive child outcomes, and such associations are confirmed by the literature (Desjardin, 2003; Grus et al., 2001; Jones & Prinz, 2005). In regards to parents of children with HI, parents who feel overwhelmed or lack understanding are less likely to proceed with intervention/amplification within the critical 6 month time period; and are also less likely to actively participate in their child's language development and adhere to recommended intervention strategies (Desjardin, 2003; Khoza-shangase, Barratt, & Jonosky, 2010).

Given these points, an approach to intervention that values involving and informing the family appears to be as important for facilitating positive child outcomes as the timeliness by which intervention is initiated. Consequently, many UNHSEIPs prioritise family-professional relationships that emphasize the parent's role as collaborator and decision maker and provide families with the necessary information and skills to promote self-efficacy (Crowe et al., 2014; Sass-Lehrer, 2004). If properly implemented, these programmes may serve to reassure and support parents; encourage their participation in intervention decisions and child development; and foster a sense of trust between professionals and the family, thereby facilitating effective future management of the child's HI (ASHA, 2008; Fitzpatrick et al., 2008; Khoza-Shangase et al., 2010; Russ et al., 2004; Waterston & San Lazaro, 1994).

### **1.3 Health Literacy**

Involving and informing patients and their significant others is a critical concept of health literacy. Health literacy is a relatively new and burgeoning notion, which only emerged in the last few decades of the 20<sup>th</sup> century (Speros, 2005). Multiple definitions are available for health literacy, most of which fit into one of two categories: those that view health literacy as an individual skill set, or those that believe health literacy is a dynamic process determined by both the skills of an individual and the demands imposed by the healthcare system (Egbert & Nanna, 2010; Shoemaker, Wolf, & Brach, 2014; Workbase, 2013). The WHO employs a definition of the former style, defining health literacy as the constellation of skills required by individuals to “gain access to, understand, and use information in ways which promote and maintain good health” (World Health Organization, 1998, p. 10). In contrast, organisations such as the Institute of Medicine employ more multifaceted definitions where health literacy is considered a shared responsibility between individuals and health institutions that “emerges when the expectations, preferences and skills of individuals seeking health information and services meet the expectations, preferences and skills of those providing the information and services” (Institute of Medicine, 2004, p2).

In New Zealand, the Ministry of Health has adopted “the degree to which individuals have the capacity to obtain, process and understand basic health information and services in order to make informed and appropriate health decisions” as their definition of health literacy (Ministry of Health, 2010, p. 1). The Ministry of Health also emphasises the point that health literacy extends beyond basic literacy skills, involving not only an individual’s ability to read and comprehend health information; but also their ability to search, access and use health information to make informed choices and take ownership of their health outcomes (Berkman et al., 2011; Friedman, Corwin, Dominick, & Rose, 2009). The health literacy of an individual is thus dynamic, varying with context due to internal factors (which determine the

knowledge and skills an individual brings to the situation) and external factors (which determine the complexity of the demands created by the situation) (McGee, 2010; Workbase, 2013). Internal factors include an individual's experience and knowledge with the health topic and health system, their literacy skills, their available time and resources, the stress they are experiencing and their confidence, attitudes, beliefs and values (Ministry of Health, 2010). On the other hand, external factors include the design and delivery of healthcare services, the organisational and funding procedures in place, the complexity of the health issue, the communication skills of health professionals, and the use of complex documents (Ministry of Health, 2012).

Recently, health literacy has begun to be prioritised as a pivotal issue, with the WHO promoting it as a key goal of Health 2020, the European policy for health and well-being adopted by 53 member states in 2012 (Kickbusch, Pelikan, Apfel, & Tsouros, 2013). This emphasis has developed because the WHO claims we are in a global health literacy crisis; caused by the fact that although the health literacy demands imposed on patients are greater than ever before, patients are not equipped with the necessary skills to navigate these demands (World Health Organization, 2013).

Further, research indicates that health literacy is a stronger predictor of health status than age, ethnicity, socioeconomic status, or educational level (Institute of Medicine, 2004; Speros, 2005). Indeed, studies have identified associations between low levels of health literacy and poorer understanding of health information, poorer health behaviours and worse health outcomes (Berkman et al., 2011; Kumar et al., 2010). Specifically, individuals with low levels of health literacy are less likely to take preventive measures, accurately interpret labels and health documents, seek help from or communicate with health professionals, and demonstrate understanding of their illness, treatment, and medicines (Dewalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Ministry of Health, 2010). Consequently, these individuals

are more likely to have greater use of emergency care, higher hospitalisation rates, poorer health status and difficulties managing their long-term/chronic condition (Doak et al., 1996; Kickbusch, 2001; Ministry of Health, 2010; Safeer & Keenan, 2005). Limited health literacy also has substantial societal impacts, accounting for an estimated \$106 to \$238 billion dollars in additional annual health care costs in the US (Yin et al., 2013).

Although research into health literacy has tended to focus on adult health outcomes, there are also important implications for child well-being, as the health literacy of an individual can also moderate the health outcomes of others they care for (Yin et al., 2007). Low caregiver health literacy also has negative impacts, predisposing families to worse health behaviours and worse child health outcomes, often as a consequence of reduced adherence to treatment recommendations (Sanders, 2010). This theory was confirmed in a study by Ross, Frier & Kelnar, (2001), where a positive and significant correlation between increased parental literacy and improved glycaemic control in diabetic children was demonstrated. Similarly, Kumar et al. (2010) found that parents with lower health literacy levels frequently struggled to understand and interpret basic child health tasks on the Parental Health Literacy Activities Test (PHLAT) (Kumar et al., 2010).

The poor health outcomes associated with low health literacy are particularly concerning given the prevalence of insufficient health literacy skills within communities. While estimating the health literacy abilities of a population is challenging, reasonable approximations have been achieved from the results of the Adult Literacy and Life Skills (ALL) Survey. This survey was developed by Statistics Canada and the Organisation for Economic Co-operation and Development (OECD), and was conducted in 12 countries between 2003 and 2008 (Ministry of Health, 2010). The survey consisted of 191 health-related questions designed to assess numeracy, prose literacy, document literacy, and problem-solving skills pertaining to the healthcare system (Australian Bureau of Statistics,

2006). An individual's score was categorised into one of five skills levels, with level 1 representing the lowest literacy level, level 5 the highest, and level 3 the minimum level "required for individuals to meet the complex demands of everyday life and work in the emerging knowledge-based economy" (Ministry of Health, 2012, p. 4). Thus, individuals with scores at level 1 or 2 were considered to have insufficient skills to cope with the everyday demands of the healthcare system (Ministry of Health, 2012).

The literacy skills of 7000 New Zealanders aged between 16-65 years were assessed as part of the second round of data collection during 2006. The results were consistent with other OECD countries in demonstrating that the majority of adult New Zealanders (56.2%) have insufficient health literacy skills (Kickbusch, Pelican, Apfel & Tsouros, 2013; Ministry of Health, 2010). Furthermore, the results of the survey support the suggestion that health literacy may contribute to ethnic disparities, as Māori adults had significantly lower health literacy levels than non-Māori (Rudd, Moeykens, & Colton, 1999). The data are also consistent with the theory that health literacy follows a social gradient, as positive correlations between an individual's health literacy score and their income, and level of education were found (Institute of Medicine, 2004). These findings support international research in suggesting that health literacy may exacerbate existing inequalities within a society (Kickbusch et al., 2013).

However, despite these demographic trends, low health literacy can affect all types of people, including parents (World Health Organization, 2013). For instance, over 28% of US parents surveyed were found to have below basic/basic health literacy skills, and only 1 in 7 parents had proficient health literacy skills (Yin et al., 2009). Furthermore, although years of education is often employed as a way of identifying individuals at risk for low health literacy, the correlation between years of education and literacy level is imperfect, and often overestimates reading ability (Berkman et al., 2011). Individuals educated to high levels with

extensive literacy skills can still experience difficulties interpreting and understanding technical health information in a foreign context (Joubert & Githinji, 2014). As an example, an individual with postgraduate education may feel just as perplexed when confronted with terms such as “otoacoustic emissions” and “tympanometry” in the field of audiology as an individual with a high school level of education.

The fact that low literacy is an invisible problem which cannot be accurately predicted from appearance or educational level is compounded by the feelings of shame, embarrassment or inadequacy which often surround reading difficulties (Parikh, Parker, Nurss, Baker, & Williams, 1996). The fear of discrimination or stigmatisation can cause patients to conceal their poor literacy skills and deter them from seeking medical care or requesting explanations from health professionals (Kickbusch, 2001). Past research confirms this, revealing that although 46% of patients admitted that they did not understand the contents of the letter outlining their endoscopy results, only 55% of these patients planned on seeking additional information from a health professional (Karnieli-Miller, Adler, Merdler, Rosenfeld, & Eidelman, 2009).

Given the association between health literacy and health outcomes, and the high prevalence of insufficient health literacy skills in societies, it is clear that improving health literacy is an international necessity. Enhancing health literacy is a reciprocal responsibility, in that health systems must recognise they also play a significant role in determining the health literacy skills of their patients. Healthcare professionals should work to both build the skill set of individuals, while simultaneously reducing the literacy demands imposed by the healthcare system (Nutbeam, 2006). Incorporating health literacy skills into educational programmes for children and adults may serve to improve skills, while providing readable and meaningful health information that matches the skills of readers can help reduce literacy demands (Institute of Medicine, 2004).

## **1.4 Readability**

### **1.4.1 Purpose and use of readability formulas**

An important component of health literacy is the readability of written health information provided to patients. Readability refers to the “ease with which a person can read and understand written materials” (Freda, 2005, p. 152). The provision of readable information is prioritized as a health goal for a number of reasons. First, regardless of reading ability, all patients prefer basic and easy-to-read materials (Davis et al., 1996). Second, creating text materials is time-consuming, expensive, and essentially pointless if patients are unable to comprehend them. Not only do unreadable materials fail to fulfil their purpose, they “may be misleading or even harmful” for readers (Kahn & Pannbacker, 2000, p.4). Third, improving the match between the readability of materials and the literacy skills of health consumers is one known strategy for improving an individual’s health literacy (Friedman, 2006). As aptly explained by Kickbusch & Maag, “One cannot be health literate if the path is incomprehensible” (Kickbusch & Maag, 2008, p. 206).

One method of estimating how easily individuals are likely to be able to understand written materials involves using “readability formulas”, which measure the readability of a given document. Readability formulas are simple algorithms which analyse characteristics of the words or sentences used in a written passage, and in doing so offer health care providers an objective, quantitative and cost-effective estimate of the reading difficulty of the difficulty of health materials (Gemoets, Rosemblat, Tse, & Logan, 2004; Ley & Florio, 1996). For many of the formulas currently available, the estimate of readability is represented as a reading grade level (RGL), which can be interpreted as the number of years of US education required to understand that text (Ley & Florio, 1996).



To be able to apply the results of readability analyses, criteria for acceptable and unacceptable RGLs must be established (Bennett; Kann & Pannbacker, 2000). Various recommendations exist for the RGL at which patient education materials should be written to facilitate optimal comprehension, with most ranging between the fourth to eighth RGL (Bennett, Drane, & Gilchrist, 2012; Joubert & Githinji, 2014). The general consensus is that documents should be written at the sixth RGL or below, and should communicate information in a manner which is clear and concise and avoids technical terminology (Doak et al., 1996; Friedman & Hoffman-Goetz, 2006; National Institute of Health, 2013; Safeer & Keenan, 2005; Yin et al., 2007).

Currently, more than 200 different formulas have been published, differing in terms of the number, weight and types of variables used in the equation. The types of variables assessed are commonly categorised into syntactic or semantic factors. Syntactic factors relate to the structure or length of sentences (e.g. sentence length and active voice), whereas semantic factors relate to the words used (e.g. word length, word familiarity or word complexity) (Stephens, 2000). Typically, formulas are based on one syntactic and one semantic factor (Pothier, Day, Harris, & Pothier, 2008; Rush, 1985).

The formulas most frequently elected to evaluate health education materials include the Flesch Reading Ease Scale (FRE), Flesch-Kincaid Readability formula (F-K), Simple Measure Of Gobbledygook (SMOG) and the Fry (D'Alessandro, Kingsley, Johnson-West, 2001). These formulas are well validated and have been found to correlate strongly with one another. For example, the SMOG correlates strongly with the FRE ( $r = .95$  to  $.96$ ), F-K ( $r = .93$ ), and the Fry Readability Graph ( $r = .93$  to  $.96$ ) (Friedman & Hoffman-Goetz, 2006).

The FRE formula differs to most other readability formulas as it produces a readability score ranging from 100 (very easy to read) to 0 (very difficult to read) rather than

a RGL (Flesch, 1948). It tests at least three 100-word passages from the text, analysing the average words per sentence and the average syllables per word. The FRE is valid for measuring the readability of texts written between the fifth-grade and college-graduate level (Meade & Smith, 1991)

The F-K formula is an adapted version of the FRE, where the readability score is converted into an equivalent US RGL between Grade 5 and college level (Friedman & Hoffman-Goetz, 2006). Together, the FRE and the F-K are two of the most well validated and widely used formulas in the literature, partly because they are readily available in most computer word processing programs. However, because they require that individuals reading at the calculated level need only comprehend 75% of the text, they are often criticised as underestimating the readability of a passage (D'Alessandro, Kingsley, Johnson-West, 2001).

In contrast, the SMOG (developed by McLaughlin in 1969) classifies RGLs based on 100% comprehension, and is thus preferred by many health researchers who justify that even small miscomprehensions in health-care settings can have significant implications for patient well-being (D'Alessandro, Kingsley, & Johnson-West, 2001; Shoemaker et al., 2014; Wang, Miller, Schmitt, & Wen, 2013). The SMOG is considered valid between the 3<sup>rd</sup> and 19<sup>th</sup> RGL, and calculation involves counting the total number of multisyllabic words (containing 3 or more syllables) from 10 consecutive sentences selected from the beginning, middle and end of a text. This final polysyllabic word count is then applied to a conversion table to determine the corresponding RGL of the text (Kann & Pannbacker, 2000).

The final formula relevant to this thesis is that of the Fry formula, developed in 1968 (Fry, 1968). This formula is considered valid between the 1st and 17th RGLs and is calculated by randomly selecting three 100-word passages from the document of interest. The number of sentences and the number of syllables in each 100-word excerpt are then counted,

before being averaged over the three excerpts. The intersection between the average number of syllables per 100 words and the average number of sentences per 100 words on a Fry graph reveals the readability estimate. The Fry is widely used in conjunction with the SMOG to assess the readability of patient education materials, as these two formulas have been found to produce lower intrapamphlet variability (i.e. estimates taken from multiple sections within a pamphlet correlate highly when using these formulas) (Klingbeil, Speece, & Schubiner, 1995).

Although readability formulas correlate highly with one another, their methodological differences in calculation and validation often create different RGL estimates for a given document (Klingbeil, Speece, & Schubiner, 1995; Ley & Florio, 1996). For example, because the SMOG assumes that the RGL assigned to a text should enable readers at that level to achieve 100% comprehension, the produced RGL estimates are often 1-2 grades higher than estimates predicted by other readability formulas, which are validated against lower comprehension levels (Klingbeil, Speece & Schubiner, 1995). Consequently, the literature recommends using multiple formulas to produce the most accurate and valid estimate of readability (Kahn & Pannbacker, 2000; Pothier et al., 2008; Sakai, 2013).

Readability formulas are often further criticised as they cannot guarantee the accuracy, or predict the usefulness or appropriateness of a particular publication (Friedman & Hoffman-Goetz, 2006). For instance, because formulas only assess surface-level features of a text, monosyllabic terms are classified as easy to read, and polysyllabic terms as difficult, regardless if they are clearly defined or are familiar to the reader (D'Alessandro et al., 2001). Therefore, it is understandable that readability results do not always equate to reader comprehension, which is considered a vastly interactive process affected by a multitude of factors relating to both the text (such as content, format and organisation) and the reader

(including motivation, personal experience or prior knowledge) (Friedman & Hoffman-Goetz, 2006; Gemoets, Rosemblat, Tse, & Logan, 2004; Wang et al., 2013). These factors are simply too complex for readability formulas to measure accurately, and so researchers caution that readability estimates should be used as a tentative estimate of reader comprehension only (Atcherson, Richburg, Zraick, & George, 2013; Rush, 1985).

### **1.4.2 Comprehension**

Because it is such an interactive construct, reader comprehension is a challenging dimension to assess, but may be approximated through various measures including the cloze procedure (Taylor, 1953). The cloze requires individuals to read a passage from which words have been deleted at periodic intervals. Intended readers must then fill in each space with the word they think belongs in the blank, using pragmatic, syntactic and semantic clues available in the remaining text (Gemoets et al., 2004). The entire procedure is founded on the theory that readers at the appropriate level of the text should be able to provide closure to the extract as they construct meaning by correctly filling in the blanks (Stephens, 2000). The ability of individuals to obtain closure is thought to be a reliable and valid indicator of reader comprehension of the passage, and thus the cloze procedure has been widely used to evaluate reader comprehension in a variety of settings, including healthcare (Friedman & Hoffman-Goetz, 2006; Miller, DeWitt, McCleary, & O'Keefe, 2009).

One of the advantages of the cloze procedure test is that a version can be easily developed for any document, simply requiring an extract of at least 250 words from the text of interest (Miller et al., 2009). The first and last sentences of the extract remain intact, with words deleted at regular intervals from the second sentence. Doak et al. (1996) recommends five words as the ideal deletion interval, because it provides more interpretable results and a better estimate of text difficulty than intervals where words are deleted more, or less,

frequently (Taylor, 1953). An individual's score on the cloze procedure is calculated by dividing the number of correct guesses by the total number of blanks, with this percentage of correctly replaced words thought to reflect reader comprehension of the passage (Miller et al., 2009).

A variety of methods may be used to score the reader's replacements, including acceptable-answer or exact-answer. The acceptable-answer method scores all contextually-appropriate synonyms as correct, whereas the latter method considers only those replacements identical to the deleted word as correct (Brown, 1980). Although there is evidence to suggest that acceptable-answer may be more appropriate in English as a Second Language (ESL) contexts, there is little difference in the two methods when discriminating the difficulty level of two passages written in the reader's native language (Taylor, 1953). However, correlations between an individual's cloze score and their score on other comprehension assessments are highest when the exact-answer method is used (Bormuth, 1968), and thus this is generally preferred by the literature (Miller et al., 2009).

The resulting percentage is interpreted by comparing it to various threshold criteria indicating different levels of comprehension. Specifically, scores greater than 56% are considered to indicate adequate comprehension, scores between 44-56% suggest marginal reader comprehension, whereas scores less than 44% suggest that comprehension problems exist, with the individual described as having inadequate comprehension of the text (Friedman, Corwin, Dominick, & Rose, 2009). The cloze test scores may also be used to estimate likely reader performance on a conventional multiple-choice comprehension test. For example, a score of 44% on the cloze procedure is comparable to a 75% comprehension score, whereas a cloze score of 57% is considered comparable to a comprehension score of 90% (Rush, 1985). Finally, Doak et al. (1996) recommends qualitatively analysing the cloze

results as common incorrect replacements may suggest more appropriate words for use in the original text.

The cloze procedure has been shown to produce significant and inverse correlations with readability formulas ( $r = -0.581$ ), suggesting that as the RGL of a document increases, the comprehension of readers declines (Gemoets et al., 2004). The exception to this is the Bormuth Cloze Mean Test, a readability formula often incorporated into readability software packages. This formula predicts the average cloze score that would be obtained if the text under evaluation was given as a cloze procedure to a group of students. Consequently, estimates produced by the Bormuth Cloze Mean Test should correlate positively with reader comprehension of a given text.

Limitations of the cloze procedure include the fact that the accuracy of the cloze in testing reader comprehension of texts not written in their native language is equivocal. Although there is some evidence to suggest that native and non-native English speakers perform similarly on the cloze procedure (Alderson, 1980); this is not a consistent finding, and seems to be dependent on an individual's experience with the English language and the marking method used (Oller, 1972). Additionally, the results of the cloze test only indicate whether a text is too difficult for readers to comprehend, not why the text is too difficult. To overcome this, authors recommend employing other measures of comprehension and also involving target audience members in a process known as learner verification (Doak et al., 1996; Sakai, 2013; Shieh & Hosei, 2008).

## **1.5 Patient education**

### **1.5.1 General overview**

Patient education materials are an effective and common method of openly communicating health information to patients and educating them about their health status (Freda, 2005). Patients are provided with an assortment of written materials in modern day healthcare, including brochures, handouts, instruction guides, letters and reports. Not only do such materials provide a point of reference for patients once they leave the healthcare setting, they also offer additional information to help clarify and broaden the client's knowledge, thereby assisting them in making informed health decisions (Klingbeil et al., 1995). Written materials are also a valuable strategy for supplementing or reinforcing information communicated verbally (Hoffmann & Worrall, 2004; Shieh & Hosei, 2008). This is particularly important given that research has consistently shown that patients tend to recall only 50% of the information they are told during their appointment; and a further 50% of that which is retained is remembered incorrectly (Anderson, Dodman, Kopelman, & Fleming, 1979; Kessels, 2003; Shapiro, Boggs, Melamed, & Graham-Pole, 1992).

Regardless of their purpose, it is imperative that written materials are produced at a level that may be understood by people with a range of reading abilities. If written at appropriate levels, research suggests that written materials can improve patient knowledge, satisfaction, self-management and adherence to treatment (Hoffmann & Worrall, 2004). However, if these materials are not noticed, read and understood by patients they are of little use, and may prompt patients to consult other sources of information, such as the Internet (Hoffmann & Worrall, 2004; Laplante-Lévesque, Brännström, Andersson, & Lunner, 2012). Searching the Internet for health information is incredibly common, and even more so for researching stigmatizing conditions such as HI (Fitzpatrick et al., 2008). Unfortunately, it is

impossible to guarantee the accuracy and quality of Internet sources, and thus patients may be misinformed. Indeed, Laplante-Lévesque and colleagues (2012) found that the 66 websites uncovered by a search of “hearing loss” and “hearing aids” required an average RGL of 11 to 12 years to understand. Further, on average, the websites met defined quality criteria “to some extent” only (Laplante-Lévesque, Brännström, Andersson, & Lunner, 2012).

Materials that are incomprehensible by the target audience can also compound the difficulties experienced by individuals with low health literacy levels, increasing their risk to the negative health consequences discussed in section 1.3 above (Wilson & Park, 2008). Because improving the health literacy skills of individuals themselves is difficult, Rudd (1999) recommends that providers should reduce health literacy demands by ensuring information is communicated in a manner which is understandable from a patient’s perspective. Unfortunately, it would appear that this recommendation is continuing to be overlooked. Despite the fact that the average adult reader reads at the eighth grade level, health care materials continue to be written at reading levels equalling or exceeding the 10th grade (Levandowski et al., 2006).

Studies assessing the readability of written healthcare materials abound, and have been conducted across a range of health disciplines and document types. Consistently, results have suggested that these materials are written above the average adult’s reading ability, and more importantly, that they surpass the recommended reading level target of sixth grade or below (Atcherson, Zraick, & Brasseux, 2011; Bennett et al., 2012; Hoffmann & McKenna, 2006; Kelly & Kahn, 1991; Kelly, 1996; Klingbeil et al., 1995; Pothier et al., 2008; Shieh & Hosei, 2008; Smith et al., 2014; Yin et al., 2013; Zeng-Treitler et al., 2007).

Health education materials are also targeted towards the parents of paediatric patients. To be able to provide adequate care for their children, it is essential that parents can



understand the documents they are provided (Davis et al., 1994). However, research has identified similar discrepancies between the levels at which materials are written and the reading skills of the average parent (Arnold et al., 2006; Atcherson et al., 2013; Davis et al., 1994; Freda, 2005; Kahn & Pannbacker, 2000; Swartz, 2010). For example, a study performed by Levandowski et al. (2006) found that over half of the adults in the city of Syracuse read at or below the eighth RGL, while a quarter read at or below the fifth-grade level. Yet, when the authors analysed 28 health education brochures distributed to pregnant women in this city, 100% of the documents were written at the sixth RGL or higher. In a related area, Arnold and colleagues (2006) found that the mean FRE score of parent educational brochures about newborn screening of genetic disorders was 53.26, equivalent to the 10<sup>th</sup>-12<sup>th</sup> RGL. Furthermore, 92% of the brochures had FRE scores below 70, meaning that only 8% of the brochures were written below the eighth RGL of the average US adult (Arnold et al., 2006). Additional research published on the readability of paediatric patient education materials has demonstrated that these materials are consistently written above the eighth RGL when measured by the SMOG formula, regardless of the publisher or the purpose of the material (Freda, 2005; Kahn & Pannbacker, 2000; Klingbeil, Speece, & Schubiner, 1995; Freda, 2005; Yin et al., 2013).

Although the literature on the readability and comprehensibility of written patient education materials has substantially expanded in the past 20 years, research within the audiology domain is relatively new, and studies are limited (Atcherson et al., 2013). However, the results from research which has been conducted further highlight that patient education materials are difficult to read. For example, a seminal study performed by Kelly & Kahn (1991) found that over half of the speech and hearing documents provided to patients required a high school age reading level to comprehend. As a follow-up to this study, Kelly

(1996) identified that 58% of the 109 instructional and informational HA brochures required a college-age reading level to understand.

More recent research has identified that the readability of HA brochures has improved only marginally during the past two decades (Caposecco, Hickson, & Meyer, 2014). Indeed, the average RGL of 36 HA user guides was found to be 9.6 (calculated using the F-K, Fry and Fog readability formulas), which continues to exceed recommended levels (Caposecco et al., 2014). These authors also investigated the suitability of these materials, with analyses showing that none of the HA user guides achieved a 'superior' suitability rating, and 69% of the user guides were assigned a 'not suitable rating'. A consistent area of concern in the user guides was their insufficiency at providing motivation and self-efficacy, due to the complexity of the information. The authors thus concluded that difficulty comprehending brochures may be a contributing factor to reduced HA uptake and successful HA use.

Research regarding the readability of materials provided to parents within the audiology domain has also recently begun to emerge. In two separate studies, Swartz (2010) and Atcherson et al. (2013) found that of eight hand-outs on otitis media, and eight questionnaires screening for (central) auditory processing disorders; none had reading levels below grade 5. Furthermore, Joubert & Githinji (2013) assessed the readability of pamphlets provided to parents as part of the Early Hearing Detection and Intervention (EHDI) programmes in South Africa. Evaluation of the readability and quality of 21 pamphlets from 26 hospitals was conducted using the SMOG and Ensuring Quality Information for Patients (EQIP) questionnaire. The results of this analysis revealed that 95% of the brochures provided to parents of children with HI surpassed the South African readability recommendation of fourth grade, and none of the pamphlets were considered to be "high" quality. Given parents' need for emotional support and comprehensible information following diagnosis of their child's HI, this research is particularly concerning.

### **1.5.2 Written patient materials in New Zealand audiology**

Within New Zealand, the ethical reasons behind providing written education materials to patients, or parents of paediatric patients, are further emphasised by legal requirements. Under Right 6 of the 1996 New Zealand Health and Disability Commissioner Code of Health and Disability Services Consumers' Rights, parents have the “Right to be Fully Informed” (p. 4) about any health conditions affecting their child. Further, under Right 5 of this act, parents are entitled to “Effective Communication” in a “form, language and manner that enables the consumer to understand the information provided” (p.4).

Consequently, standard 20 of the UNHSEIP National Policy and Quality Standards states: “The results of audiology assessment, and information about next steps, will be communicated to the parents/guardians immediately, in a sensitive and culturally appropriate manner” (Ministry of Health, 2013, p. 29). Specifically, this requires the audiologist to provide parents with: a verbal explanation of the results, opportunities to ask questions, written resources such as the Family Book or the Getting Started Guide to Hearing Aids, an explanation of the roles of the multidisciplinary team, and finally, a “written report of the audiologist assessment and subsequent referrals to the parents/guardians and GP (and AODC, ENT, paediatrician, and Well Child provider as required) within two weeks of the assessment” (Ministry of Health, 2013, p. 42).

As implied above, verbal discussion of the assessment results with parents is an essential part of the UNHSEIP. It is also a step valued by many audiologists as the importance of providing informational and personal adjustment counselling following a HI diagnosis is often emphasised during training (ASHA, 2008). Although it is easy to assume that the verbal information provided is clear and unequivocal to parents, previous research suggests this is not always the case. Indeed, many parents report feeling dissatisfied with

communication at the time of diagnosis due to the audiologists' persistent use of jargon, rapid delivery of information and assumptions that parents had knowledge they did not (Gilbey, 2010; Russ et al., 2004; Tattersall & Young, 2006). This results in parents often leaving confused about the specific nature and implications of their child's HI (Martin, George, O'Neal, & Daly, 1987).

These findings point to the need for providing comprehensible written information to help supplement, reinforce and remind parents of the verbal information and results provided at the time of diagnosis (Joubert & Githinji, 2014). This need is further emphasised because the emotional distress experienced by parents during this period also reduces their reception and comprehension of verbal information (Pretto & Harrison, 2011). Diagnostic reports are one example of a written resource commonly provided to parents involved with audiology services. As mentioned in standard 20, these reports are sent to the parents and members of the multi-disciplinary team and act as a common way for the test results to be relayed to those involved in the care of the child with HI (Johnson & Seaton, 2012).

Providing patients with their health information and results is also common within other health disciplines. The provision of this information ensures open communication between the health professional and the patient or parent, whilst also facilitating understanding of the condition and encouraging participation in informed and shared decision-making (Davey, Austoker, & Jansen, 1998; Karnieli-Miller et al., 2009). Patients are known to prefer receiving written notification of their test results as it helps them feel reassured, better informed and more in control (Jelley & Walker, 2003). However, because reports or letters are typically designed for other professionals, they often contain considerable medical jargon, vague wording and ambiguous messages which can hamper patient comprehension (Karnieli-Miller et al., 2009).

The majority of studies examining this issue have been conducted within the United Kingdom, where it is clinical protocol for all letters written by health professionals to be copied to the patient, or where appropriate, the parent or legal guardian (Bhandari, 2010). In theory, all letters should abide by the guidelines released by the Department of Health in 2003, which stress the importance of using plain language. However, studies have identified that the language used in these letters is frequently incomprehensible. For instance, an ‘audit’ conducted by Bhandari (2010) into the letters sent by doctors and nurses to mental health patients revealed that the average RGL of the letters measured by SMOG was 17.2. Furthermore, not a single letter had a RGL below 14 years. Follow-up work conducted by O’Mahony & Kalk (2011) found that none of the letters sent to mental health patients over a 3 month period had scores above 80 on the FRE test, indicating that none of the letters were ‘easy’ or ‘very easy’ to read (O’Mahony & Kalk, 2011).

Combined, these studies suggest that that the majority of patients receiving copies of clinical letters are unlikely to understand all of the contents of the document, which reduces the inherent benefits of sending clinical letters to patients. This is supported by subjective comments made by patients after they received letters advising them of their endoscopy results. During a telephone interview, over 50% of patients reported that they did not understand the content of the letter, with patients making quotes such as “I didn’t understand a word... it was about me, but not to me” and “[it] looked like ancient Chinese to me” (Karnieli-Miller et al., 2009, p. 345).

Anecdotal reports indicate that New Zealand parents often express analogous concerns after receiving diagnostic paediatric audiology reports. Currently, no research has addressed this issue, yet providing readable reports is a necessity that should be prioritised for several reasons. First, readable education materials may prevent parents turning to equivocal

information on the Internet, although also reinforcing verbal information communicated. This is particularly important given the emotional distress experienced by most parents following diagnosis, which limits their retention of verbal information at this time. Second, New Zealand parents are legally entitled to receive informative and readable materials. Parents of children with HI may need these even more because they tend to be poorly equipped with prior knowledge about HI on which to develop their understanding. Finally, there is evidence to suggest that providing readable materials may reduce the negative effects of HI on child development, by supporting the emotional adjustment, self-efficacy and health literacy skills of parents. Essentially, for parents of children with HI, knowledge is power.

### **1.5.3 Revising patient education materials**

While there is a growing body of evidence documenting the mismatch between patient reading abilities and the readability of written materials, less research has focused on revising inadequate documents. This is not for want of recommendations on how to write materials in a clear and simple manner, as the literature is rich with such advisory guidelines (Centers for Disease Control and Prevention, 2009; Lane, Blanco, Ford, & Smith Mirenda, 2005; McGee, 2010; Plain Language Action and Information Network (PLAIN), 2011). One of the classic sources of guidance in this area is the publication entitled “Teaching Patients with Low Literacy Skills” written by Doak, Doak & Root in 1996. Within this book, the authors explain that the process of producing simplified patient education materials involves three key stages: 1) Planning 2) Writing and production and 3) Testing.

During the planning stage, Doak and colleagues (1996) recommend that authors should focus on understanding the characteristics of the target audience and what they need and expect from the health document. This process will enable authors to define the intended purpose and key objectives of the document, which can be further narrowed so that only the

minimum amount of information “needed to change behaviour or perform the procedure” is included (Doak et al., 1996, p. 78).

The second phase, writing and production, involves the application of a range of best practice techniques to decide “what to say and how to say it” (McGee, 2010). In recent years there has been a significant increase in the number of prescriptive guides and checklists outlining evidence-based techniques for writing readable texts (e.g. Centers for Disease Control and Prevention, 2009; Doak et al., 1996; Houts, Doak, Doak, & Loscalzo, 2006). This expansion is probably attributable to health literacy concerns, further augmented by plain language legislation which has been promulgated in various countries including the United States of America, Sweden and South Africa (Plain English Power, 2010). There are an expansive number of techniques recommended for writing easy-to-read documents. To avoid superfluous information and to facilitate easy reading of this document, Appendix A presents a summary of the most consistently recommended strategies within the literature. Each strategy is organised under one of the five key elements of language, content, layout/typography, organisation or graphics, recommended by Caposecco et al. (2011) as the critical areas to consider when developing instructional materials for use in audiology.

The third and final phase of writing readable documents is the “testing”, or verification stage. A number of methods may be used to assess the appropriateness and suitability of revised documents. Readability formulas are useful as a preliminary measure to efficiently and objectively estimate whether the reading ease of a document has been improved (Doak et al., 1996; Kahn & Pannbacker, 2000). However, as described in section 1.4, readability formulas do not account for all of the factors which affect reader comprehension, such as the content, organisation and design of the materials; as well as reader motivation (McGee, 2010). For example, while reducing the number of syllables per word and the number of words per sentence may lower the FRE score, these modifications

may also give rise to a choppy, disconnected text that is subjectively harder for patients to read if they are not carefully implemented. To alleviate these limitations, the literature strongly recommends that other methods such as professional peer veracity checks, objective comprehension measures, and the subjective opinions of readers should be used to validate document revision (Doak et al., 1996; Hoffmann & Worrall, 2004; PLAIN, 2011).

Review of the document by professionals is a fundamental part of any testing phase to ensure that the accuracy and veracity of the document has been maintained following revision (D'Alessandro et al., 2001). However, the knowledge and experience that health professionals possess makes it impossible for them to view a document in the same way as the target audience. As such, actual readers should also be asked to evaluate the document, a process often referred to as field testing or learner verification (Kahn & Pannbacker, 2000; PLAIN, 2011).

Learner verification is considered the ultimate way to test a revised text, and may occur via paraphrase, usability, or controlled comparison testing (McGee, 2010; PLAIN, 2011). The first two methods involve interviewing readers of the document, and asking them to interpret the meaning of the document, or to find specific information (PLAIN, 2011). In contrast, controlled comparative studies involve collecting quantitative data from two groups of participants to demonstrate improvement of a selected document. Typically, one group of participants is asked to read the original version, while an equal number of participants read the revised version; before the two versions are compared along pre-determined outcome measures. Doak et al. (1996) suggests comprehension and self-efficacy as two useful constructs to verify during this process. Reader comprehension is an important variable to measure as it assesses reader knowledge and understanding of the health condition; whereas reader self-efficacy can affect patient motivation to use written materials, adhere to recommendations and also manage their health condition (Doak et al., 1996). Further, asking



readers to rate how acceptable, readable and helpful they find the document is another popular outcome measure used to verify a document (Davis et al., 1996; Hoffmann & Worrall, 2004; Sakai, 2013).

#### **1.5.4 Outcomes of document revision**

A number of studies have applied versions of these three key stages to show that the literacy demands of health materials can be reduced by carefully considering the readability and design of such materials (Hoffmann & Worrall, 2004). A seminal study in this area was that conducted by Davis and colleagues in 1996. These authors aimed to simplify a polio vaccine information pamphlet written for parents of paediatric patients. The revised version was much shorter, contained graphics and was written at the sixth RGL, four levels below the original document. Overall, the simplified pamphlet required significantly less reading time, resulted in significantly higher comprehension for parents reading above the third grade level, and generated significantly higher approval ratings. Furthermore, the study found that all readers, even those with advanced reading skills, preferred the simplified pamphlet (Davis et al., 1996).

Further evidence for the merits of applying best practice recommendations has been identified in more recent research. For example, Pothier et al. (2008) revised twenty leaflets from a speech and language therapy department according to best practice recommendations. The revised leaflets were both shorter in length (in terms of words, sentences and paragraphs) and less complex (as measured by words per sentence, characters per word and number of passive sentences). Furthermore, the mean FRE score significantly improved from 59.5 on the original leaflets to 72.3 on the revised leaflets, while the mean F-K RGL was reduced from 7.7 to 5.4 in the revised leaflets (Pothier et al., 2008).

The positive effects of text revision are also apparent when comprehension and reader preferences are used as outcome measures. For instance, Sakai (2013) found that revising Japanese texts on chronic suppurative otitis media along the features of syntax, vocabulary and structure resulted in a significant improvement in the comprehension of student readers, as measured by both the cloze procedure and true/false questions (Sakai, 2013). Further, students rated the revised texts as significantly easier to read and understand when compared to the original text. Although these texts were written in Japanese, it seems probable that revising English documents along multiple text features would also produce advantages for reader comprehension. Additionally, Karniele-Miller et al. (2009) demonstrated that attaching a cover letter which clarified the endoscopy histopathology report sent to patient's significantly reduced patient confusion and improved comprehension. This suggests that even short explanations about medical results can have notable positive impacts on patient understanding.

The principles of writing readable materials have also been applied within the audiology domain, as illustrated through research into producing effective instructions for a self-fitting HA (Caposecco, Hickson, & Meyer, 2011). Design of these instructions followed best-practice principles, producing an instructional guide with an average RGL of 3.5. Two later studies used learner verification to evaluate the effectiveness of the instructions, and revealed that nearly 99% of Australian participants, 95% of the South African participants and 60% of the Chinese participants were able to assemble the HA by following the instructions (Convery et al., 2011, 2013). The authors highlight the fact that despite markedly lower levels of health literacy, cognitive function and formal education, South African participants had a success rate which was comparable to the Australian participants. This reinforces the concept that health literacy levels should not impede individuals

comprehending health information, provided the information is written in accordance with best practice guidelines and in the patient's native language (Convery et al., 2013).

## **1.6 Study Rationale**

This study sought to provide necessary information about the readability and comprehensibility of a typical paediatric diagnostic audiology report provided to parents of children with HI in New Zealand. Such research is necessary to fill the knowledge gap in this area for several reasons. First, it is known that high levels of parental understanding, knowledge, emotional coping and self-efficacy may help mitigate or eliminate the negative outcomes associated with child HI. One strategy for achieving these positive outcomes involves providing parents with written materials, including diagnostic reports. If written accurately and in an easy-to-read manner, these materials can help support parents emotionally, empower them to make well-informed and timely intervention decisions, and encourage them to be active participators in their child's rehabilitation and development.

Second, the majority of New Zealand adults have insufficient health literacy skills, and thus parents may struggle to understand their child's complex diagnostic audiology reports. Furthermore, because an individual's health literacy is dynamic, even those parents with high health literacy abilities may struggle to comprehend information about HI as the personal factors that promote health literacy (including familiarity or experience with the topic, low stress, and time), often do not apply. This issue is particularly important given the well-documented correlation between low parental health literacy and worse child health outcomes. Therefore, it is essential that all parents are provided with materials that are easy to read and understand.

Third, the literature contains expansive information regarding the production of readable and comprehensible materials, and further, documents encouraging findings upon implementing such best practice guidelines. Thus, there is evidence to suggest that revising audiology reports is possible and that revision could prevent these reports from compounding the adverse effects of HI on child development.

Lastly, this study aimed to add to the body of literature on health literacy in New Zealand, and in the field of audiology. While there is some research into the readability of documents provided to parents of children with HI overseas, no studies have investigated the quality or readability of diagnostic reports. There is certainly no such research within New Zealand, where studies assessing readability or health literacy in general are rare.

The ultimate aim of this study was to improve the match between parent's health literacy skills and the demands of the health system, which may produce associated improvements in the health outcomes of New Zealand children with HI.

### **1.7 Aims and Hypotheses**

This thesis aimed to evaluate the readability and comprehensibility of a mock paediatric diagnostic audiology report; and if indicated, improve this report following best practice principles and parents' recommendations. Thus, the purpose of this study is consistent with ASHA's vision to make "effective communication a human right, accessible and achievable for all". Ultimately, this study sought to answer the following research questions:

- (1) Is the readability of a mock paediatric diagnostic audiology report consistent with international readability recommendations?
- (2) What are the opinions of naïve parents about this mock paediatric diagnostic audiology report?
- (3) Can the mock report be revised according to best practice principles and parent recommendations to maintain veracity?
- (4) Are there significant differences between the unrevised and revised report as measured by:

- (a) Readability estimates
- (b) Comprehension of participants
- (c) Self-efficacy of participants
- (d) Participant opinion

Formal research within the audiology domain and anecdotal reports suggest that it is unlikely that the mock paediatric diagnostic audiology report will comply with recommended reading levels. Further, research indicates that patient opinions tend to be consistent with readability estimates, and thus it was expected that interviews with parents would reveal their difficulties comprehending the report (Davis et al., 1996). If analysis did reveal these results then it would be imperative to develop an improved, effective, and readable report for the reasons outlined above. Previous research across multiple health domains and document types has demonstrated that abiding by plain language guidelines and stakeholder suggestions can improve written documents along measures of readability, comprehension and approval ratings (Convery et al., 2013; Davis et al., 1996; Karnieli-Miller et al., 2009; Pothier et al., 2008). Logically, it is also expected that these changes can enhance self-efficacy.

Based on the literature available, the following hypotheses were proposed:

- (1) That the readability of the mock paediatric diagnostic audiology report will exceed international readability recommendations.
- (2) That the subjective opinions of parents will indicate that they struggled to comprehend the report.
- (3) The report will be revised according to best practice guidelines and parent recommendations, yet maintain veracity.

(4) That the revised version of the report will offer significant improvements when compared to the unrevised report along measures of:

(a) Readability

(b) Comprehension

(c) Self-efficacy

(d) Participant opinions

## CHAPTER TWO

### *METHODS STAGE ONE: EVALUATION*

---

#### **2.1 Overview**

The purpose of this thesis was to investigate the readability and comprehensibility of a mock paediatric diagnostic audiology report; and if indicated, improve this report using a combination of best practice principles and parental suggestions. To achieve this aim, the methodology was divided into three stages: (1) evaluation, (2) revision and (3) verification.

In stage one of the study, the readability and comprehensibility of the mock report was evaluated by interviewing five naïve parents (those without any prior experience with audiology services or HI) to gauge their comprehension and perceptions of the report. Simultaneously, the report was analysed by multiple readability formulas, with the results then compared to international readability recommendations. In stage two of the study, best practice guidelines were implemented alongside parental suggestions to revise the report. Finally, in stage three, the revision process was verified by comparing the revised and unrevised reports along outcomes of readability, comprehension, self-efficacy and opinions. Comparison of the latter three variables involved a randomised experimental design where 32 naïve parent participants were randomly assigned to read either (1) the unrevised report or (2) the revised report, before completing a cloze test and a subjective questionnaire. The two reports were compared along the four outcome measures, using a Multivariate Analysis of Variance (MANOVA).

The following chapters discuss the methodology behind each stage of the study individually; including the participants recruited, procedures used, measures employed and statistical analysis applied. To provide a sense of logical flow to the thesis, the methods and results of each stage are presented consecutively.



This study received ethical approval from the University of Canterbury Human Ethics Committee, New Zealand on the 30<sup>th</sup> of April 2014 (Appendix B.1). All procedures conducted in this study were in accordance with the Committee's approval. All participants signed informed consent forms prior to their involvement in this study.

## **2.2 Mock paediatric diagnostic audiology report**

The mock diagnostic report was modified from a basic report template provided by the Audiology Department at Christchurch Hospital. A hypothetical child with HI was designed to reflect the average child with a HI in New Zealand, based on data from the 2013 deafness notification report (Digby et al., 2014). First, the child was male, as 57% of the notified cases in New Zealand during 2013 were male, consistent with international gender ratios (Digby et al., 2014). Second, the child exhibited a bilateral HI, as HI affecting both ears is more common than unilateral HI in New Zealand (65% of cases, compared to 35%) (Digby et al., 2014). Third, the child was identified from newborn hearing screening, as data from 2013 suggests that the largest proportion of diagnoses resulted from newborn hearing screening (Digby et al., 2014). Further, because 77% of the cases identified through newborn hearing screening in 2013 were diagnosed by the recommended age of 3 months, it was considered realistic for this child to also receive a diagnosis within 3 months of his birth date (Digby et al., 2014).

The degree, configuration and type of HI also reflected the data from the 2013 New Zealand deafness notification database: (1) mild and moderate are the two most common degrees of HI in New Zealand (using the average of the pure-tone thresholds at 0.5 kHz, 1.0 kHz, 2.0 kHz and 4.0 kHz), (2) sensorineural HI is the most common type of HI, (3) HI often displays a sloping configuration (Digby et al., 2013). Finally, the child was developed to have no clear risk factors for developing HI, consistent with the majority of babies with HI in New

Zealand (Digby et al., 2014). Moreover, it was important to conceptualise a child likely to be born to unconcerned and unsuspecting parents; similar to the “naïve” parent participants recruited in this study. Two clinical supervisors employed at the Hearing Clinic at the University of Canterbury evaluated the veracity of the final draft of the report. Both agreed that the report was technically accurate and an appropriate representation of a typical diagnostic report in New Zealand.

### **2.2.1 Readability analysis of mock report**

A readability analysis of the mock report was performed using the Readability Studio (Windows) 2012.1 software (Oleander, 2014). To determine the document structure, the composition of the document was selected as “narrative text”, and the layout as “centred/left-aligned”. “Technical report” was selected as the document type.

Although it is recommended that multiple measures of readability should be used to increase the accuracy and validity of results, it is also recognised that there are constraints on the maximum number of formulas that can be used and still yield valuable information (Kahn & Pannbacker, 2000; Pothier, 2008). Considering this, only a sample of the available formulas were utilised in this study, including the FRE, F-K, Fry and SMOG. This selection was based on the fact that these four formulas are the most commonly used within the healthcare literature, and have been shown to correlate highly with one another (Klingbeil et al., 1995; Ley & Florio, 1996; Wang et al., 2013).

The results from the F-K, Fry and SMOG formulas were presented as the US grade level of education (and corresponding reader age) required to read and understand the document. In contrast, the FRE formula results were presented as scores ranging from 0-100, with higher scores indicating greater readability. The results from the readability formula

were then compared to the internationally recommended reading level, and precise text characteristics of the document were also investigated.

## **2.3 Participants**

### **2.3.1 Recruitment**

To establish the opinions of naïve parents on the diagnostic audiology report, participants were recruited and interviewed until the data set achieved saturation. This was defined as the point at which the addition of data from two consecutive interviews did not result in the creation of new themes. At this point, the dataset was considered complete, and the interview process was terminated. In the present study, the interviewing of five participants resulted in saturation. Participants were recruited over a six week period via a combination of purposive and convenience sampling techniques. This process employed posting advertisements to target participants of interest (Appendix B.2). Advertisements were posted at five locations around Christchurch and briefly detailed the aim of the study while also listing the eligibility criteria for participation. Six individuals responded to the advertisement and were provided with additional information about the study's requirements. All candidates were screened to ensure they were suitable to participate in the study, as per the eligibility criteria detailed in table 2. Of the initial six candidates, five met the eligibility criteria to participate and thus were involved in stage one of the study. One candidate did not meet the criterion of having a child within the 0-5 year age bracket and thus did not participate in the study.

### 2.3.2 Inclusion and exclusion criteria

**Table 2.** *Participant inclusion and exclusion criteria, Stage 1: Evaluation*

<b>Inclusion criteria</b>	<b>Exclusion criterion</b>
Parent of at least one child aged between 0-5 years	Prior experience with hearing loss or audiology/ENT services, either personally, or via a family member
Aged over 18 years	
Willing and able to read a 388-word report and participate in a structured interview	

During the conceptualisation of this study, it was decided to avoid interviewing actual parents of children with HI about the diagnostic audiology report they received. This is because these interviews would need to be conducted shortly after parents first received the report to ensure that the influence of future experiences and knowledge on parents' recall would be minimised (Hassan, 2005).

However, because this was an exploratory study, it did not seem necessary or appropriate to infringe on parents shortly after their child's diagnosis given the emotional stress families typically experience during this period. Consequently, a prospective study design was used, where the selection criteria for participation was developed with the goal of obtaining a group of participants reflective of the average parent of a New Zealand child with HI.

The exclusion criterion attempted to ensure that all candidates with previous experience with HI, audiology or otolaryngology services were excluded, regardless if this experience was personal or through a family member. The rationale behind this is that the majority of children with HI are born to parents with normal hearing, who, prior to their child's diagnosis, have had little experience with HI or audiology (Feher-Prout, 1996). Thus, ensuring the recruited parents were also "inexperienced", or "naïve" offered a closer

approximation to the thoughts and feelings parents are likely to experience when they first receive an audiology report.

Regarding the first inclusion criteria, parents were to be included in this study only if they had at least one child aged 0-5 years. This age bracket is thought to reflect the age at which most children are diagnosed with a HI in New Zealand, without any prior parental concerns (Digby, Purdy & Kelly, 2013). The second inclusion criterion was necessary to define the lower age limit of parents in this study. Statistics New Zealand Tauranga Aotearoa, (2012) indicates that the median age of the average mother in New Zealand in 2011 was 30 years of age; while in 2011, the age of the average father was 32 years. Furthermore, only 6.9% of births in 2011 occurred in women aged 19 years or below. The third and final inclusion criterion attempted to ensure that all participants were capable of completing all tasks required of them, including reading the report, answering the questionnaire and participating in a structured interview.

## **2.4 Procedures**

As is frequently the case in qualitative research, the sample size was unknown *a priori* and was instead informed by saturation. Consequently, all interested candidates beyond the second individual were warned that they might not be required to participate in the study. The next participant was contacted only if analysis of the preceding interview revealed new themes. No participants withdrew from the study during this delay.

Once each participant was confirmed, they were instructed that they would receive an information packet in the mail containing five items: (1) an information sheet (Appendix B.3) (2) a consent form (Appendix B.4) (3) a demographic questionnaire (Appendix B.5) (4) the mock diagnostic audiology report (Appendix B.6) and (5) a postage paid return envelope. Participants were instructed to read the information sheet, sign the consent form, and

complete the demographic questionnaire. Finally, participants were asked to read the 388-word report in their own time, and as if it was written for their child.

After participants received the information packet they were requested to contact the researcher so that an interview could be scheduled within three days. All participants were reminded that they could partake in the interview either at a room within the Communication Disorders Department at the University of Canterbury, or over the telephone. The choice of interview type was included to offer flexibility for parents and assist in recruitment. As there is evidence to suggest that both in-person and phone interviews can elicit valid and detailed data, there was little concern about a difference in quality between the two interview types (Karnieli-Miller et al., 2009). Of the five participants interviewed, two decided to participate in the interview in person, with three electing to have a phone interview.

Each interview was conducted by a single interviewer in a quiet and private location and was recorded using an Olympus DS-5000 recording device. All interviews began by providing the participants with a brief outline of what could be expected in the interview, and asking if they had any questions. The interview then proceeded by following the devised semi-structured schedule in Appendix B.7. At the completion of the interview, participants were “debriefed” in an attempt to minimise any embarrassment they may have experienced had they struggled to read or understand the report. This debrief explained to participants that the report was written above recommended levels and at a difficulty which the high RGL which is likely to be challenging for the majority of New Zealand adults are likely to find challenging to comprehend.

At the conclusion of the in-person interviews, the completed consent forms and demographic questionnaires were collected; whereas participants interviewed over the phone were advised to send their forms back in the provided return envelope. Upon receiving these

forms, each participant was mailed a \$20 voucher to reimburse them for their time and participation in the study.

Following completion of the interview, participants' responses were transcribed verbatim into a word processing document, before being qualitatively analysed for common themes by two independent researchers. Further details of this process are found under section 2.6.1.

## **2.5 Measures**

### **2.5.1 Demographic questionnaire**

The demographic questionnaire was developed to provide basic information about the participants in this study. The questionnaire employed 10 items, which assessed variables including sex, age, ethnicity, marital status, level of education, and vocation; as well as the number of children under the parent's care, their age(s) and their relationship(s) to the participant.

### **2.5.2 Interview schedule**

Each individual semi-structured interview was conducted with the intention of establishing the parents' opinions of the mock diagnostic report. Semi-structured interviews are commonly used within audiology, and are considered advantageous as they create broad interview topics which can encapsulate the uniqueness of each participant's experience (Knudsen et al., 2012).

All interviews were conducted by the same researcher and were audio-recorded, lasting between 9 and 21 minutes in duration. The interview schedule consisted of between 13 to 17 questions, with the total number of questions asked dependent on the participant's response to previous questions. The majority of the questions were open-set, in that they

allowed participants to offer their personal opinions on reading the report, without restricting them to categorised answers. However, a few questions utilised a closed-set answer format, in an attempt to understand which strategies participants preferred for improving the report.

The main part of the interview focused on uncovering whether participants found the report to be readable, understandable and useful. Four questions were also used to verify parent comprehension of the report. These questions were designed to indicate if the degree to which parents thought they understood the report was actually related to their ability to accurately interpret the report. Because this part of the study was focused on assessing the perceptions of parents in a qualitative manner, a more precise comprehension measure was not considered necessary. If participants indicated that they had difficulty easily understanding the report, they were asked towards the end of the interview to comment on how they felt the report could be improved. Depending on their answers to these questions, some participants were also probed with additional questions to the specific changes they felt would optimally improve the report.

As this was a newly developed interview schedule, it was piloted on three non-participating parents prior to study commencement. This helped ensure that participants would find the question order logical and would not interpret the questions as implying they should have struggled to read the report. Subsequently, a few adjustments were made to the schedule, including: adding “planned prompts” to some of the questions, placing the comprehension questions earlier in the schedule, adding an additional question about the next step following diagnosis and finally, ensuring that participants were only asked about improving the report if they indicated that it was currently unsatisfactory.



## **2.6 Data Analyses**

### **2.6.1 Thematic analysis**

The analysis of the qualitative data occurred simultaneously with data collection in this study and employed a thematic content analysis approach. To begin this process, each interview was transcribed verbatim into a Microsoft Word document within 48 hours of taking place. The supervising researcher reviewed 40% of the transcriptions. No significant deviations were found during this review process.

Next, each transcript was read in full to capture an impression of the text as a whole, and to provide a foundation for the thematic analysis. Within this method, the data from each interview was organised into a series of meaning units, each of which identified a particular point of interest. Once identified, the meaning units were compared across interviews to identify commonalities which clustered the units into “sub-themes”. This process of data categorisation and comparison occurred continuously until the interview dataset reached saturation. Following the clustering of units for the final interview, the researcher compared all of the sub-themes to one another to enable the abstraction of superordinate, broader-encompassing, “themes”. This process developed a thematic hierarchy; where the sub-themes at the lower level highlight definitive consistencies between participants, while at the higher level, the general themes describe more overarching consistencies between participants.

The resulting themes were then divided into general and specific categories, depending on the nature of the theme. More precisely, themes describing issues participants had with the report as a whole were classified as general, and typically arose from the first 13 questions. In contrast, themes identified from the remaining questions in the interview schedule tended to relate to particular suggestions for improving the report, and were thus classified as “specific” in nature. Because the specific themes were inherently precise, they did not tend to involve sub-themes.

### **2.6.2 Research rigor**

Establishing research rigor and credibility of the thematic analysis process was an important consideration, and was obtained using three methods. The first step involved ensuring participants felt comfortable disclosing their true perceptions of the report in a non-judgemental environment. This was achieved by reminding participants that their identities would remain confidential and placing them in private and comfortable settings where they felt confident expressing their opinions. Further, those participants who indicated significant difficulty reading the report were reassured that the majority of New Zealand adults would also experience difficulties reading and interpreting this report. Second, the abstraction process was validated using researcher triangulation. This process involved the primary researcher and the supervising researcher independently evaluating the transcripts to develop their own meaning units and thematic hierarchy. Through a collaborative process, the two analyses were reviewed and a consensus was reached on a hierarchy that optimally reflected the themes inherent in the data. Finally, a summary of the thematic analysis results were sent to each participant during the process of member checking. Each participant was asked to comment on whether they felt the findings accurately represented their perspective of the mock report. Four of the participants responded to this contact, and all agreed that the analysis was an accurate summary of their perceptions of the report. The precise themes identified from the interview process are outlined in the following chapter.

## CHAPTER THREE

### *RESULTS STAGE ONE: EVALUATION*

---

#### **3.1 Overview**

This chapter presents the results collected from the evaluation stage of this study. Specifically, the findings from the readability assessment and the parental interviews are documented, and evaluated in relation to the first two hypotheses of the thesis.

#### **3.2 Readability assessment**

Hypothesis 1: The readability of the hypothetical paediatric diagnostic report will exceed international readability recommendations.

The results of the readability assessment were consistent with the first hypothesis, indicating that the mock report is written at a reading level that exceeds the internationally recommended sixth RGL. The reading ease score produced by the FRE formula was 35, suggesting that the report was written at a “difficult” reading level. Converting this to grade level via the F-K formula revealed that the RGL of the report was nearly at the fifteenth grade level (14.8). The RGLs assigned by the SMOG and Fry formulas were even higher, estimating a required RGL of 16 and 17+ years, respectively.

The readability analysis also assessed various textual features of the report related to sentences, words, grammar and difficult words. For example, the average sentence length of the report was 20.6 words, with the longest sentence consisting of 33 words. The average number of syllables per word was 1.8, and grammar analysis revealed 18 wordy items and 6 examples of passive voice. “Difficult words” were categorised according to four different criteria, defined in table 3. Table 3 also reveals the frequency and proportion of each class of “difficult words”, alongside the frequency and proportion of difficult sentences.

**Table 3.** *Textual feature analysis of difficult words and sentences*

<b>Feature</b>	<b>Frequency</b>	<b>Proportion</b>
Difficult words		
1. <i>Complex</i> (Words with 3+ syllables)	76	21.7% of all words
2. <i>Hard</i> (Words with 3+ syllables including fully syllabised numerals)	86	24.6% of all words
3. <i>Long</i> (words consisting of 6+ characters)	151	41.3% of all words
4. <i>Unfamiliar</i> (words not appearing on the Dale-Chall familiar word list)	130	36.1% of all words
Difficult sentences		
1. Greater than 22 words in length	8	47.1% of all sentences

To provide some context to these results, it is worth considering how they affect the readability level calculated by a given formula. For example, using the F-K formula, the average sentence length of this report would need to be reduced to less than one word in length (if the average number of syllables per word remained at 1.8), to achieve the recommended sixth RGL. Similarly, achieving recommended readability using the average sentence length of 20.6 words would require the average syllables per word to be lowered to 1.2 syllables. Clearly, neither of these changes is particularly realistic, and thus it is evident that improving the readability of a document requires modification along a number of different text features.

### **3.2 Participant characteristics**

Five participants were interviewed during the evaluation phase of the study. The characteristics of each participant are described in detail below:

*Participant one:* Participant one was a 32-year-old male of Chinese ethnicity. At the time of interview, he was married and the father of one 17-month-old child. He had completed 11 years of tertiary education, culminating in a PhD qualification and was employed as an Engineer.

*Participant two:* Participant two was a 22-year-old female of New Zealand European ethnicity. At the time of interview she was in a committed relationship and the mother of one 15-month-old child. She had completed 1 year of tertiary education, and her occupation was a full-time mother.

*Participant three:* Participant three was a 35-year-old female of New Zealand European ethnicity. She was the married mother of two children, aged 6 ½ and 3 years. She had completed three years of tertiary study, resulting in a Bachelor of Commerce. At the time of interview was working as an intelligence analyst.

*Participant four:* Participant four was a 30-year-old female of New Zealand European ethnicity. She was in a committed relationship and the mother of one child aged 15 months. She cited ‘school certificate’ as her highest qualification and at the time of interview, was employed as a clerk.

*Participant five:* Participant five was a 25-year-old male of New Zealand European ethnicity. At the time of interview, he was in a committed relationship and the father of two children, aged 2 and 4 years. His highest qualification was a Level 4 certificate in Building and Carpentry, and he was working as a carpenter.

### **3.3 Thematic analysis of interview data**

Hypothesis 2: The subjective opinions of parents will indicate that they struggled to comprehend the report.

Inspection of the interview data obtained from the five parent participants supports hypothesis 2, with all parents indicating that they struggled to read and comprehend the report, on various levels. In total, seven general themes and nine specific themes emerged from the interviews with participants.

### 3.3.1 General themes

The seven general themes identified were: difficulty and confusion when reading the report, issues with the language used, inaccurate comprehension of information, the limited use and value of the report, the need for professional assistance, the length of the report, and the failure of the report to meet expectations. Sub-themes were also identified for six of the general themes. Table 4 documents the sub-themes that contributed to each theme and the number of participants who mentioned the theme, alongside an illustrative quote. Within these quotations, ellipses (...) indicate omissions from the full transcript, and clarifying words are provided in [square brackets]. At the end of each quotation, the names of participants are replaced with P‘X’, where X indicates the order in which the participant was interviewed.

**Table 4.** Results of thematic analysis: General themes, sub-themes and illustrative quotes

Theme	Illustrative parental quote	# mentioning sub-theme
<b>The report is confusing and difficult to read</b>		
Results section is difficult to interpret	<i>I felt completely lost when it began to talk about all the actual results (P3)</i>	5
Not intuitive to understand	<i>The report did not make sense by itself (P1)</i>	5
Need to re-read the report	<i>I did re-read it a few times and every time I started to read it slower (P3)</i>	3
<b>Language</b>		
Audiology-specific terminology	<i>...all the jargon stuff in the middle (P5)</i>	5
Use of units and numbers	<i>All the numbers and words and things I couldn't quite figure out (P2)</i>	4
Successive use of jargon	<i>When you get three or more words you don't understand in a sentence, well, it's just sort of like what's the point in trying to understand (P3)</i>	2
Loss of meaning	<i>I felt that the actual meaning began to be lost in all the "500 Hz's" (P3)</i>	2

**Inaccurate comprehension of information**

Presence of a hearing loss	<i>And so when they were saying normal I was thinking it was all fine, until the very end when I thought maybe it's not normal? (P2)</i>	3
Type of hearing loss	<i>It was... just when calling but he was still able to hear loud bangs? (P4)</i>	5
Meaning of ABR	<i>Wouldn't have a clue." (P2)</i>	5
Type of tympanogram and its meaning	<i>The type of what? I don't know what that is. (P3)</i>	5
Next step	<i>Well I don't really know, I mean maybe we would find out at this follow up (P1)</i>	2

**Use/ value**

Ensures parents are well informed	<i>I would want to know the results of any tests that my daughter or son had had (P4)</i>	2
Provides permanent record	<i>... you have a copy of the report to take with you (P3)</i>	1
Little value or utility by itself	<i>Not really useful... you'd probably just Google it wouldn't you? (P5)</i>	4

**Need for professional assistance**

Information required at the time of the appointment	<i>[I'd] ask a million questions at the time of the appointment. (P3)</i>	1
Information required upon receiving the report	<i>My conclusion would be that I would need to call up somebody to find out what is going on (P2)</i>	2

**Length of the report**

Acceptable	<i>I think the length is fine (P1)</i>	2
Not beneficial for length	<i>It's just that you're not getting much information for that length (P1)</i>	3
Inconsistent	<i>The summary was quite short compared to the test results. (P4)</i>	1

**Meeting expectations**

	<i>I thought that with my background knowledge I would be kind of ok (understanding the report) (P1)</i>	3
--	--	---

---

### ***General theme 1: The report is confusing and difficult to read***

All participants contributed meaning units to this theme. The overwhelming comment made during all five interviews was that the report was very challenging to read and interpret. These perceptions are summarised by the remark: *I could hardly even read it to tell you the truth* (P5). When participants discussed the source of confusion in the report, the results section was commonly emphasised, also described as the ‘middle paragraph’ by some participants. Parents consistently described that this area of the report was particularly difficult to understand and interpret, a concept shown in this quote: *the test results though I couldn't understand at all. The summary- the summary was fine, but definitely the results part was tough* (P3).

Participants also highlighted that the report was not intuitive to understand, and would require additional information or explanation to be useful: *I mean if this was the very first thing you had seen, I don't think you would have any idea what they were talking about* (P3). Finally, three participants indicated that they re-read the report at least once, in an attempt to better understand the information provided. However, these participants all agreed that this second reading was essentially futile: .... *It didn't really help* (P5).

### ***General theme 2: Language***

When asked to consider why the report was difficult to read and understand, all five participants cited the technical and specific language of the report. All five participants attributed their difficulties understanding the overall content of the report to the unfamiliar terminology used. As indicated by one participant, this language was: *Just like gobbledygook* (P4). Indeed, participants held the perception that only audiologists would be able to understand the jargon included in the report: *I think you'd have to be in the profession to understand it [the language]* (P2). Another salient feature of the interviews was the



expression of difficulty interpreting numbers and units used in the report. Participant 1 was surprised that his background in engineering did not help him decipher units: *I know dB, but I have never seen dBeHL before. What even is that?* (P1). Moreover, participant 2 was frustrated by the vague reference to different hearing levels: *It was saying things about normal, in the normal range, but I have no idea what ranges are supposed to be* (P2).

Two participants explained that the difficulty of the report was inflated because of the consecutive use of unfamiliar terms. Participant 1 explained that experienced readers may be able to deduce meaning when they encounter a single difficult word, but the presentation of several difficult words sequentially impairs this reasoning: *When you get three or more words you don't understand in a sentence, well, it's just sort of like what's the point in trying to understand really* (P1). Finally, two participants indicated difficulty understanding the overall message of the report as they felt it was obscured in the technical information reported: *every time I [re-read it I] started to read it slower... I felt that the actual meaning began to be lost in all the "500 Hz's" etc.* (P3).

### ***General theme 3: Inaccurate comprehension of information***

As implied by the general comments made by participants about the difficulty of the report, all parents struggled to answer the five comprehension questions included in the interview. Specifically, only two of the five participants were confident in stating that the child did have a hearing loss. The remaining three participants were much less certain, and the use of the word 'normal' appeared to particularly confuse participants. For example, participants 1 and 2 expressed analogous concerns: *At some points it seems his hearing is okay, but then at others I think, is this actually bad news?* (P1). *And so when they were saying normal I was thinking it was all fine, until the very end when I thought maybe it's not normal?* (P2).

When asked what type of hearing loss the child had, none of the participants recalled the sensorineural nature of the hearing loss. It was clear that participants were uncertain what was meant by 'type' and what the corresponding answer should be: *Not sure... the word did not stick in my head. Maybe type 1/A/2 or something?* (P1).

Similar to the results above, none of the participants could completely recall what the acronym ABR stood for, with only one participant attempting a guess: *Brainstem something-rather?* (P3). Further, all participants were confused by the question asking what type of tympanogram the child had, with three participants reporting that they: *.. don't know..*(P1, P3, P4).

Three of the participants understood that the child needed to return for further testing when questioned about the likely next step for this child. However, parents did not appear to have considered the possibility of further treatment or rehabilitation beyond this assessment. One participant offered a possible rehabilitation option; but this suggestion only highlighted the participant's misunderstanding of the permanent nature of the hearing loss: *Obviously going to see a specialist and I don't know, I don't know much about it, maybe grommets?* (P4).

#### ***General theme 4: Use/ value of report***

Participants held both positive and negative perceptions regarding the use or value of the report. Participants explained that the report could be useful either for informing parents, or to have as a permanent record for the future. For example, participant 4 emphasised the importance of knowing the results of the appointment so she would be able to optimally support her child: *... there is obviously a problem and I would want to get it sorted and I would want to know the results of my tests that my daughter or son had had* (P4). Likewise, participant 3 justified the utility of the report, explaining that a copy of the report would be

useful for parents if they had appointments with other professionals in the future: *I guess then if they get referred on to other practitioners then you have a copy of the report to take with you and show them* (P3).

Nevertheless, four parents felt that the report would be of minimal benefit unless additional information was provided. For example, one participant explained: *It would be valuable to have, but not in the sense that I could just use it to look up as a reference quickly* (P1). Indeed, two participants suggested that they would need to be able to do their own research to better interpret the report: *But you'd probably just Google it wouldn't you?* (P5).

#### ***General theme 5: Need for professional assistance***

Three participants contributed meaning units to this theme, commenting that the audiologist should provide additional information to help the parents understand the report, either at the time of the appointment, or upon receiving the report. Participant 3 emphasised the importance of having the procedures and results well explained at the time of the diagnostic appointment: *Yeah, they need to be explaining everything that is going on so that when the parents do get the report, they have a hope of understanding what it means. They'll be able to match it up to what they experienced at the time* (P3). Further, two participants felt that if the report had been sent to them in real life they would have wanted to speak to an audiologist immediately to help them understand the contents. Participant 4 expressed concern about receiving such a report in the mail without any contact information for professionals. This seemed to generate a sense of panic and urgency within her, which she articulated as “freaking out” as she questioned: *Am I meant to be understanding this? What does it all mean?* (P4). This sense of consternation was shared by participant 2: *I think I probably would have just called the professionals straight away to find out what is actually going on!* (P2).

### ***General theme 6: Length of the report***

Participants reported mixed reactions while considering the length of the report. Although two participants thought the report was not particularly onerous to read, others highlighted that the report did not offer sufficient information given its length: *It's just that you're not getting much information for that length* (P1). Participant 4 indicated similar dissatisfaction due to the inconsistency of the length of sections within the report: *I thought the summary was quite short compared to the test results* (P4).

### ***General theme 7: Meeting expectations***

Three participants described that the report did not meet their expectations in some way, thereby contributing meaning units to this theme. Participants implied that the report did not offer them the benefit they had expected. For example, one participant described what she thought an audiology diagnostic report should contain, but which she felt this report failed to offer: *I would have hoped to have a report that's understandable and actually explains what they think and what the next step is and things like that* (P2). For participant 1, the difficulty of the report was particularly surprising, and generated a sense of failure as he struggled to read it: *I'm an ... engineer, I thought that I would do pretty well reading it. But actually I felt like I had failed an exam. Normally, I like to do things well* (P1).

### **3.3.2 Specific themes**

Towards the end of the interview, participants were asked a series of questions designed to elicit how they felt the report could be improved to be more readable and understandable. First, participants volunteered their own recommendations, which were further explored with prompts from the interviewer, and are presented as specific themes 1 through 4 below. Next, the structured interview assessed parents' perceived level of benefit

for a variety of possible revision strategies, the results from which are presented as specific themes 5 through 9 below.

***Specific theme 1: Improvement of the language used***

Improving the language of the report was the most common improvement strategy spontaneously expressed by participants. All participants contributed meaning units to this theme and explained that the level of language was too difficult to easily understand. Suggestions for ameliorating this included following a “keep it basic” (P5) approach which uses “plain English” (P1), “everyday language” (P2), and “common words” (P3). Participants considered improving the language to be important not only for increasing their own understanding, but also to ensure that other, potentially less skilled readers would be able to interpret the findings: *Someone who struggles to read and write may also have to read the report. And it’s just as important that those people are able to understand the report too.* (P3). Participant 3 made the suggestion that the report would be more understandable if it used similar terminology to that used during the actual appointment. She felt that this reiteration may further enhance parent’s comprehension of the test procedures and results: *So if they actually refer to it at the time as the ‘beep test’ or a more common name, could they refer to it in the report by that name? Rather than some phandangle word? To help reinforce to the parents ‘oh yes, that was that test they did, and then they found that, rather than calling it one thing at the time, and then another in the report?’* (P3).

***Specific theme 2: Reorganisation of report order***

Participants also suggested revising the order of the report as an improvement strategy. Three participants contributed meaning units to this specific theme, and identified the need to understand the overall outcome earlier in the report: *As soon as I read the summary, I thought ‘wow that should have come first’* (P4). These participants consequently

recommended that a concise summary of the results should occur near the beginning of the report. Related to this idea, participant one suggested that parents could then choose whether to continue reading the more comprehensive and complicated results section, depending on their own reading abilities: *The first paragraph could give a summary of the most important information. And then you could explain like all the results and the units below. Then it could be up to the parent to decide if they wanted to read this extra information (P1).*

### ***Specific theme 3: Need for information about prognosis***

All of the participants indicated that they were uncertain about what the future may hold for the hypothetical child. Two participants found this to be concerning and emphasised the importance of including extra information about the implications of the results for the child: *I think maybe there needed to be some more information about what these results actually meant for the child (P1).*

### ***Specific theme 4: Need for the original version of the report***

Despite the fact that participants were dissatisfied with the current report, three parents favoured the idea of continuing to provide it to parents. Parents expressed that it is important to provide the precise information for those who may want it: *It is good to have all the proper information for parents (P1).* Participants also explained that it might be useful for parents to have a copy of the report to be able to show to other health professionals: *I guess then if they get referred on to other practitioners then you have a copy of the report to take with you and show them. Because you know, things do get lost (P3).*

### ***Specific theme 5: Employing a glossary***

All participants contributed meaning units to this theme. Of all the improvements suggested during the interview, employing a glossary was the most consistently endorsed by participants. All of the participants felt that a glossary would be a good idea, and three of the

participants spontaneously suggested using a glossary, prior to being directly asked: *Maybe like a key for what some of those technical terms mean?* (P4). Participant 1 made the recommendation that two versions of the report could be given to parents: one that is easy to read and understand, and the other that is simply a copy of the original report sent to members of the multidisciplinary team. He suggested that attaching a glossary to the original report would help ensure parents are not overwhelmed: *Maybe it is good to have all the proper information for parents. But it should still be understandable. So that is where a glossary could help* (P1).

### ***Specific theme 6: Website references***

Participants were also asked to consider the value of providing parents with links to websites where they can find additional information on child HI. Four of the five participants felt this would be a useful addition for those parents wanting to enhance their knowledge of their child's HI: *Also references to websites [is a really good idea]* (P2). Participant 1 also suggested that it would be beneficial if the references were hierarchical in nature, such that parents who want simple information, as well as those who desire more advanced education are all supported: *Maybe like good websites but also journal articles too for those who want them* (P1). However, participant 3 emphasised the importance of ensuring these hyperlinks are not used in place of the verbal and written information and advice provided by the audiologist: *... everything should still be provided in the report* (P4).

### ***Specific theme 7: Use of graphics***

Parents were also asked for their opinion on the use of graphics. Three participants contributed meaning units to this theme, suggesting that a diagram could be useful in explaining how the different test results related to each other: *Yeah maybe a picture showing the different parts of the ear?* (P3). Participant 2 also described that a visual displaying

normative data could be beneficial to help parents understand the degree of their child's HI: *The other thing I thought about was like a table, for the normal ranges of everything. Like how the child's results compare to others... maybe it could put the results of this child in perspective a bit?* (P2).

#### ***Specific theme 8: Frequently asked question section***

Three of the participants were asked whether they thought a frequently asked question (FAQ) section would be helpful. All of the participants queried favoured such an idea, agreeing that it would be “helpful” (P2, P4). However, two participants concurred that the combination of a glossary and website references would be more valuable: *I think the glossary and websites would work pretty well* (P5).

#### ***Specific theme 9: Other suggestions***

Finally, participants were asked if they had any other ideas of how the report could be improved to be more understandable for parents to read in the future. In answering this question, participants 3 and 4 reiterated the importance of revising the ‘middle’ or ‘results’ section. Participants 2 and 4 also mentioned that it could be beneficial to provide contact details for support groups: [I] *Probably [would have liked information for] support groups* (P2).



## CHAPTER FOUR

### *STAGE TWO: REVISION*

---

#### **4.1 Overview**

This chapter outlines the process that was undertaken to revise the mock paediatric diagnostic audiology report. The results of the readability assessment and parental interview presented in the previous chapter indicated that this revision process was warranted. The overall goal of the revision process was to produce a more easily readable and comprehensible report for parents of children with HI, whilst maintaining the veracity of information provided. The production of such a document involved applying a combination of best practice plain language guidelines alongside the parental recommendations offered during the evaluation stage.

#### **4.2 Use of best practice guidelines**

As outlined in section 1.3.2 there are a vast number of resources available to guide writers in producing plain language documents. The ultimate goal of these guidelines is to help authors write documents that the target audience is able to read, understand and act on with confidence. Specific techniques for revising documents can generally be categorised into elements of content, language, layout/typography, organisation and graphics (as outlined in Appendix A). As many of these suggestions were incorporated into the revised report as were feasibly possible. An overview of the suggestions implemented, and a comparison of the original and revised version of the report for each suggestion is offered in Appendix C.

The revised version implemented various changes in relation to the language, content, organisation, layout/typography and graphics used in the report. In regards to the language element, the report was modified to reduce the sentence length, number of polysyllabic words, and the number of passive sentences, which, when combined, contributed to reducing

the RGL of the document. Further, the amount of jargon and technical language was minimised via the substitution of more commonly understood words. Within the content element, the revision process ensured that the report provided only the essential information that parents need to know, while also relaying results in a more personalised manner, where only those examples relevant to the hypothetical child's hearing loss were included. In addition, parents were provided with two options for where they could obtain more information: via either directly contacting the hospital, or investigating the website links included in the report. Changes to the organisation of the report involved prioritising the presentation of information and including a glossary. Both strategies aimed to assist parents in their interpretation and understanding of the report. Minimal modifications were made to the layout/typography of the document, as it was necessary to maintain the formality of a report. However, the revised report did use additional bolding of text, while also implementing the use of colour. Finally, the revised report included three graphics, all of which were used to deepen parental understanding by illustrating concepts within the text. The simplicity, positioning and explanatory markers used were all considered for these graphics.

### **4.3 Use of parental recommendations**

The revision process also attempted to address as many of the concerns expressed by parents as possible. Specifically, based on the feedback obtained from parents, attempts were made to simplify the language in the report, reorganise the order, improve explanations of the test procedures and results, include a glossary, provide website references and incorporate graphics. Table 5 provides an overview of the concerns identified from the interview data, as well as the recommendations suggested by parents to resolve these issues. This table also offers a quotation demonstrating the need for modification, before explaining how each suggestion was implemented.

**Table 5.** *Revision techniques suggested by parents that were feasible to implement*

<b>Theme and suggestions</b>	<b>Quote</b>	<b>Implementation of suggestions</b>
<i>1. Improving the language used</i>		
i. Avoid jargon	<i>There was a lot of jargon and it was very difficult to understand (P2)</i>	Made numerous word substitutions, replacing complex or medical terminology with more common words. For example, replacing “intensity” with “volume”, “frequency” with “pitch” and so on.
ii. Replace confusing units	<i>I have never seen dBeHL before. What even is that? (P1)</i>	Replaced terms such as ‘500 Hz’ and ‘moderately-severe elevated levels (70dBeHL)’ with more descriptive and familiar phrases like ‘low pitch, bass-like tones’ and ‘same loudness as a vacuum cleaner or people talking in a restaurant’
iii. Use language in the report which is consistent with that used during the diagnostic assessment	<i>But I still think it is important to match the language in the report to the language you used in the testing process (P3)</i>	Report attempted to use terms often employed by audiologists in practice. For example, “Mountain” to describe a type A tympanogram, “Box behind the ear” for a bone conductor.
<i>2. Reorganisation of report order</i>		
i. Inclusion of a summary earlier in the report	<i>As soon as I read the summary, I thought ‘wow that should have come first’ (P4)</i>	Placed a summary of Jack’s overall HI near the beginning of the report, within the ‘What did we find?’ section.
<i>3. Information about prognosis</i>		
i. Provide parents with some information about the expected outcomes	<i>I think maybe there needed to be some more information about what these results actually meant for the child (P1)</i>	The revised report included a ‘what do we do now?’ section mentioning the likely intervention, how this process will begin and the support networks available.
<i>4. Provision of unrevised report</i>		
i. Need for unrevised version of the report to be included	<i>It is good to have all the proper information for parents. (P1)</i>	Attached a copy of the unrevised report to the revised version.
<i>5. Inclusion of a glossary</i>		

i. Definition of unfamiliar terminology used in the unrevised report	<i>Maybe like a key for what some of those technical terms mean?</i> (P4)	Glossary positioned at the back of the unrevised report, in alphabetical order. The glossary defines and explains words in the unrevised report likely to be unfamiliar or confusing for parents.
<i>6. Website references</i>		
i. Include accurate links to websites for more information	<i>Also references to websites [Is a really good idea]</i> (P2)	Provided references to three different websites, and an explanation of the information available at each link.
ii. Hierarchy of sources	<i>Maybe like good websites but also journal articles too for those who want them</i> (P1)	The third website cites various scientific sources, which would be useful for those parents interested in discovering more detailed articles about child HI.
<i>7. Inclusion of graphics</i>		
i. Use of graphics to help explain test purpose	<i>Yeah maybe a picture showing the different parts of the ear?</i> (P3)	Included a figure labelling common anatomical landmarks of the ear and dividing the ear into the outer, middle and inner ear using different colours. The test result headings were correspondingly coloured to match the division of the ear that the test predominately assessed.
ii. Use of graphics to compare the hypothetical child's hearing to other hearing abilities	<i>...like a table, for the normal ranges of everything. Like how the child's results compare to others.</i> (P2)	Provided a graphic denoting the different degrees of HI and common sounds at different intensities and frequencies. These examples aimed to help parents understand the terms frequency and intensity, while also illustrating the difference in sound intensity accompanying different degrees of HI.
<i>8. Frequently asked question section</i>		
i. Inclusion of a section where common questions are answered	[A FAQ section would be] 'helpful' - (P2, P4)	Did not include a FAQ section per se as participants indicated that they felt a combination of a glossary and website references would be more valuable. However, question headings were used to help direct parents to relevant sections.
<i>9. Improvement of the results section</i>		
i. Explanation of what each test is assessing	<i>...Even just explaining what the tests actually are</i> (P2)	Provided a brief explanation in common language of what each test assesses and what it involves. This was supported with additional explanation in the glossary. In addition, the colour coding described above indicated which part of the ear each test was assessing, with the test

ii. Need to understand the results section	... <i>the test results though I couldn't understand at all</i> (P4)	results summary also following this colour theme. Described the results in common language, and explained what these results could tell us about Jack's hearing ability
iii. Need to comprehend the significance of the results.	<i>I'm not sure about a complete hearing loss. Maybe like mild or minor problems</i> (P1) <i>And so when they were saying normal I was thinking it was all fine, until the very end when I thought maybe it's not normal</i> (P2)	The final diagnosis of a permanent HI is repeated three times within the report. In addition, examples included in the results section like: "This is about the same loudness as a vacuum cleaner or people talking in a restaurant" provide a reference point for parents to understand their child's hearing in comparison to their own.

#### 4.4 Veracity check

Hypothesis 3: The report will be revised according to best practice guidelines and parent recommendations, yet maintain veracity.

To evaluate hypothesis 3, two different professionals, both of whom have extensive paediatric clinical experience in New Zealand, independently assessed the revised report. Each clinician read the report with the purpose of ensuring the revision process had not compromised the accuracy of the content. Both audiologists supported hypothesis 3, indicating that the revised report maintained the veracity of the original report. However, each professional had a few suggestions on how the report's accuracy could be enhanced.

Specifically, the first audiologist commented that the term "echoes" was not an accurate descriptor of otoacoustic emissions (OAEs). In addition, the clinician recommended introducing the permanent nature of the hearing loss within the opening paragraph to eliminate any parental uncertainty. She also suggested numbering the results from each specific test, and including a brief summary of all of the results at the end of the "What did we find?" section. Finally, she recommended including other tympanogram types in the glossary so that parents can compare their child's result to others. This would also have the

benefit of enabling the glossary to serve as a document that can be easily attached to every child's report.

The second audiologist noted three issues with the report, all of which affected both the original and the revised versions. First, the audiologist explained that eliciting an acoustic reflex to broadband stimuli at the normal 80 dB HL screening level is unlikely given the hypothetical HI. Second, she mentioned that it is not technically accurate to say the client has normal hearing at 500 Hz, as reliable ABR traces down to "normal" intensity levels of 15 dB HL or 20 dB HL are generally not obtainable. Thus, she recommended that the phrase 'normal to near-normal hearing' should be adopted when describing the 500Hz threshold. Third, she remarked that if additional ABR testing needed to be completed on an infant, a report would not typically be written until after that second appointment. Therefore, the clinician suggested that both the original and revised versions of the report should be written as if two appointments had already occurred, allowing a complete diagnosis to be made.

Implementing these suggestions required modification of both versions of the report. First, ipsilateral acoustic reflexes were changed to be absent at the 80 dB HL screening level in both reports. Next, the phrase 'normal to near-normal hearing' explained the results of the ABR test at 500 Hz. Finally, the report communicated the results from two appointments. To reflect realistic testing of an infant, the report explained that only half of the ABR test was conducted during the first appointment before the child 'woke up'. The results obtained in each appointment reflected the testing protocols outlined in the UNHSEIP National Policy and Quality Standards Appendix F (Ministry of Health, 2013). To maintain consistency with the new results format, the 'summary and recommendations' section of the original report was also altered to explain the onward referrals made as a consequence of the HI diagnosis.

The second audiologist also recommended using the correct audiology terms for each test. She explained that as parents will encounter these terms for the rest of their child's life,

it is necessary to begin introducing and explaining some of this language. In addition, she suggested that an explanation of bone conduction results was unnecessary given the sensorineural nature of the HI. However, she felt that retaining an explanation of the different sound conduction pathways in the glossary would be helpful, again allowing the glossary to be a universal attachment to all reports.

The final version of the revised report includes the recommendations offered by best practice guidelines, parental interview data and professional correspondence. Because some of the recommendations suggested by audiologist two affected both the original and revised versions of the report, the updated version of the original report will be referred to as the “unrevised” report herein. A copy of the revised report is provided in Appendix D, with annotations used to highlight the changes made. A copy of the unrevised report is also included in Appendix E for purposes of comparison.

## CHAPTER FIVE

### *METHODS STAGE THREE: VERIFICATION*

---

#### **5.1 Overview**

This chapter outlines the methodology behind the experimental verification stage of this study, where participants were randomly assigned to read either the unrevised or revised report before their comprehension, self-efficacy and perceptions were measured via a cloze procedure and a novel questionnaire. The two reports were also subjected to a readability assessment which compared the two versions to each other and to international recommendations. This chapter will discuss the specifics of these processes including participant recruitment, implementation, measurement and analysis.

This stage of the study received ethical approval from the University of Canterbury Human Ethics Committee, New Zealand on the 18<sup>th</sup> of August 2014 (Appendix F.1). All procedures conducted in this study were in accordance with the Committee's approval. All participants signed informed consent forms prior to their involvement in this study.

#### **5.2 *A Priori* Analysis**

Prior to the recruitment of participants, an *a priori* analysis was conducted to determine the required participant sample size. Due to the lack of previous research in this area, a relatively conservative effect size of  $d = 1.0$  was used to constitute a 'clinically significant' effect size. Statistical power was specified at the recommended 0.8 and the level of significance at 0.05. The results of this analysis revealed that a minimum of 11 participants would be required in each group to detect this effect size.



## **5.3 Participants**

### **5.3.1 Recruitment**

Participants were recruited via a number of approaches. Because correspondence with participants did not require any face-to-face contact during this stage of the study, participants were able to be recruited over a wider geographical area. First, purposive convenience sampling was used in a similar fashion as in stage one of the study. This involved posting advertisements (see Appendix F.2) at three different locations in Christchurch City, two locations in North Canterbury and one location in Dunedin. Second, snowball sampling was applied, whereby one participant lead to the next by asking each participant to recommend other family members or friends suitable for participation. Finally, word of mouth recruitment through the avenues of family, friends, co-workers and social media also contributed to the selection of participants.

A total of 34 candidates responded to these recruitment methods. All enquiries were answered with additional information about the study, as well as five questions designed to assess the eligibility of candidates to participate. All interested candidates met the required criteria (table 6) to be included in this study. However, two participants failed to respond to contact attempts after they initially registered interest in participating, and thus 32 participants comprised the final sample size. Upon inclusion in the study, each participant was randomly assigned to read either (1) the unrevised report or (2) the revised report.

### 5.3.2 Inclusion and exclusion criteria

**Table 6.** *Participant inclusion and exclusion criteria, Stage three: Verification*

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Parent of at least one child aged between 0-5 years	Prior experience with HI or audiology/ENT services, either personally, or via a family member
Aged over 18 years	Non-native English language speaker
Willing and able to read a hypothetical diagnostic report and complete a questionnaire	

With the exception of the second exclusion criterion, the same inclusion and exclusion criteria used during the evaluation stage of the study were also applied for the verification stage. This was rationalised because validating the revision process involved evaluating the comprehension, self-efficacy and perceptions of parents after they read the report. Thus, to produce externally applicable results, it was necessary to recruit a group of participants similar to parents likely to encounter audiology reports in reality. Consequently, the justifications behind the exclusion and inclusion criteria described in stage one of the study remained valid for stage three.

The additional exclusion criterion included for the verification stage was developed to restrict participation from candidates who are not native speakers of the English language. This criterion is often employed within the health literacy literature in an attempt to minimise the confounding effect of language skills on comprehension (Miller et al., 2009; Parker, Baker, Williams, & Nurss, 1995).

### 5.4 Procedures

To assess the hypotheses relating to the revised report improving parent comprehension, self-efficacy and positive perceptions, a randomised experimental design was employed where participants were assigned to read either the unrevised or revised version of

the report. In contrast to a repeated measures study design, this design had the advantage of minimising possible practice effects which may have affected the validity of the comprehension or perceptions measurements.

All interested candidates who responded to recruitment strategies were screened to ensure they met the specified study selection criteria. Once eligibility was confirmed, candidates began the study in one of two formats, depending on their method of recruitment.

The seven participants who responded to advertisements placed at preschools were randomly assigned an opaque, sealed envelope from the preschool manager. Each envelope was numbered, thereby assigning each participant an identification number. The envelope contained four items: (1) an information sheet (Appendix F.3) (2) a consent form (Appendix F.4) (3) a demographic questionnaire (Appendix F.5) and (4) a cloze procedure designed for either the unrevised or the revised report (Appendix F.6 and Appendix F.7, respectively). Because the envelopes were sealed, randomly ordered, and contained no revealing information, all managers and participants were blinded to which report version was assigned. Participants were asked to read the information sheet and to sign the consent form if they agreed to participate in the study. Each consent form also provided participants an opportunity to indicate if they would like to receive a copy of the version of the report that they were not assigned at the completion of the study. Next, participants were asked to complete the demographic questionnaire, and then attempt the cloze test by filling in each blank with the word they considered to be the best fit. Participants then returned their completed cloze test, their consent form and their demographic questionnaire to the preschool where the study was initiated.

At this point, the preschool manager provided each participant a second envelope with the same number as the first envelope. This system ensured that the correct version of the

report was given to each participant, in addition to a verification questionnaire (Appendix F.8) and a voucher retrieval form. Participants were asked to read the report as if it was written for their own child and then wait 24 hours before completing the questionnaire. Although this request relied on participant honesty, it was employed to try and create a more accurate perspective of parental comprehension, minimising the simple recital of recently read information. After completing the questionnaire, participants returned this and their voucher retrieval form in the provided postage-paid addressed return envelope.

For the other 25 participants, random assignment to read either the unrevised or revised report was achieved by flipping a coin. A ‘heads’ outcome assigned the participant to read the unrevised report, whereas a ‘tails’ result assigned the participant to read the revised report, abiding by the caveat that equal numbers were required in each group. Following group allocation, participants were emailed an information sheet and their allocated version of the cloze procedure. Participants were instructed to complete the cloze test by typing in the word they thought would most appropriately fill each blank, before returning their completed test via email. Email was used to improve the efficiency of data collection for these participants.

Within 48 hours of receiving their returned cloze test, an information packet was mailed to each participant. Five items were included in each packet: (1) another copy of the study’s information sheet, (2) a consent form, (3) a demographic questionnaire, (4) the participant’s allocated version of the report, (5) the verification questionnaire, (6) a voucher retrieval form, and (7) a postage-paid addressed return envelope. Participants were instructed to read the information sheet, and sign the consent form if they felt the study requirements were acceptable. Participants then read the report and completed the two questionnaires in the same manner as the preschool participants above. Finally, participants were instructed to

return their consent form, two questionnaires and the completed voucher retrieval form in the provided postage-paid addressed return envelope.

Once the complete dataset was received for each participant, they were remunerated for their time and participation through a \$10 voucher. The voucher was sent to the participant alongside the other version of the report if the participant requested this on their consent form. A personalised debriefing sheet (Appendix F.9) was also sent to each parent, which served to explain which report the participant was assigned to read, as well as the years of education required to read that version.

## **5.5 Measures**

### **5.5.1 Unrevised diagnostic report**

As outlined in section 4.3, the original report used during stage one of the study was modified slightly for stage three, following the external feedback received from clinical professionals. Specifically, several semantic and organisational changes were made, meaning that additional results and recommendations were included. The final version of this “unrevised” report is found annotated in Appendix E.

### **5.5.2 Revised diagnostic report**

The results from stage one of this study were combined with best practice guidelines and clinical recommendations in an attempt to improve the readability and ease of comprehension of the unrevised report. More precise details on this adaptation process were provided in chapter four.

### **5.5.3 Demographic questionnaire**

The demographic questionnaire employed in stage two of the study was identical to that designed for stage one of the study (refer to section 2.5.1 for details).

#### **5.5.4 Cloze procedure**

The first measure used to compare the unrevised and revised reports was the cloze procedure test. As described in the first chapter, this test is thought to be a valid and reliable measure of reader comprehension, with the advantage that it is applicable to any document and is easy to score (Friedman et al., 2009). A cloze test was developed for both the unrevised and revised reports following the procedure outlined below.

Consistent with Doak et al., 1996's recommendations, an extract of approximately 300-350 words was taken from the report. Specifically, the unrevised extract length was equal to 305 words, whereas the extract from the revised report was equal to 325 words. The first and last sentences of both passages remained intact, with every fifth word deleted between these sentences and replaced with an underlined blank space of uniform length. Applying this procedure to the unrevised report resulted in 50 cloze units, whereas 52 units were formed for the revised document. This number is consistent with the recommendation that the generated "cloze test should have about 50 blanks to fill in" (Doak et al., 1996, p. 35). A copy of the cloze test produced for each version is provided in Appendix F.6 and F.7, respectively.

Scoring the cloze tests used an exact-match method, where the proportion of correct insertions made by the participant was calculated, and then multiplied by 100. The resulting percentage was then compared between the two groups, and in relation to traditional comprehension tests.

#### **5.5.5 Subjective questionnaire**

##### ***5.5.5.1 Overview***

As explained in section 1.3, an important step in the revision of health documents is the process of learner verification, where feedback from the target audience is sought to

verify the suitability of the document. Although it would have been preferable for this process to involve interviews with audience members (Doak et al., 1996), conducting interviews was not feasible during this stage of the study due to time and resource constraints. Additionally, because the research questions for this stage of the study focus on comparing the two versions of the report, it was desirable to collect quantitative data.

Thus, a questionnaire was used in this study to satisfy these requirements and compare the two versions along measures of comprehension, self-efficacy and parental perception. The questionnaire served an important role in (1) reinforcing the results of the cloze test through an additional comprehension measure, (2) assessing self-efficacy which is known to be associated with health outcomes, and (3) understanding whether the report actually satisfied the needs of parents. As a literature review failed to yield any current questionnaires that address these three constructs, a new questionnaire was conceptualised.

#### ***5.5.5.2 Item development***

The developed questionnaire consisted of 3 sub-scales: comprehension, self-efficacy and perception. The items included in each subscale were generated from a combination of literature review, expert opinion, and the interview data from part one of the study.

Six multiple-choice questions were included to evaluate reader comprehension. These were based on questions used during an ‘introduction to hearing loss’ lecture given to adult learners. Each question aimed to assess parental understanding of critical information in the report, including test purpose, the meaning of test results, the type of hearing loss and future recommendations. Each multiple-choice question used a 4-choice answer format, and only one of these answers was correct for each question.

Self-efficacy was measured by asking participants to note their level of confidence in understanding the terms, test procedures, test results and recommendations included in the

report. It was ensured that the items were task specific rather than addressing global beliefs, as this is thought to provide a better estimate of an individual's self-efficacy (Desjardin, 2003). Participants were asked to mark their confidence on a 10-point scale, where 0 indicated participants felt 'not confident at all' and 10 signified that the participant felt 'very confident'.

Participant perceptions of the report were gauged through eight questions, which were developed by revisiting the themes present in the interview data from stage one of the study. For example, the commonly reported issue of difficult language was evaluated by the statement 'I thought the report used too much jargon', whereas the need for revision of the order of the report was assessed through the item 'The order of information in the report was helpful'. Both positively and negatively worded items were included in this subscale, in an attempt to minimise acquiescence response bias, that is, the tendency for participants to agree with statements irrespective of their content (Rattray & Jones, 2007). Participants indicated their opinions of the report using a fixed choice, 5-point scale of agreement, where 1 indicated 'not at all', 3 indicated 'moderately' and 5 'very much'.

#### ***5.5.5.3 Scoring***

All responses to the questionnaire were scored by hand and subsequently entered into a Microsoft Office Excel spreadsheet. Every correct answer to one of the comprehension multiple-choice questions was awarded a '1', whereas incorrect answers were awarded '0'. The scores for each question were then tallied to provide the total comprehension score, where the minimum possible score was 0 and the maximum possible score was 6. The total self-efficacy score was calculated by adding the ratings given for each self-efficacy item. Possible scores on this sub-scale ranged from 0 to 40, with higher scores indicating greater self-efficacy. To score the opinion sub-scale of the questionnaire, the number circled by participants for the positively worded items were added. For negatively worded items, the



number circled was first reverse-scored and then combined to the score from the items above. The total opinion score range from 8 to 40, where higher scores indicate a more positive opinion of the report.

#### ***5.5.5.4 Pilot testing***

Assessment of both the content and face validity of this questionnaire occurred prior to the questionnaire being used in this study. First, to evaluate content validity, an audiologist with extensive research experience was asked to comment whether she felt the items accurately represented what the questionnaire was designed to measure. The face validity was assessed by asking three target audience members to read the questionnaire. Each individual was then asked about their view of the comprehensiveness, order and the clarity of the questionnaire.

Following these assessments, only minor amendments were made to the questionnaire. No items were removed, but four items were added; including three fixed-response questions and one open-ended question. The open-ended question simply asked participants if they had any comments about the readability and comprehensibility of the report. This provided participants an opportunity to expand on their answers and express additional perceptions about the report.

#### **5.5.6 Readability**

Both the unrevised report and the revised report were subjected to the same readability analysis as was described in section 2.4. Specifically, the analysis was again performed using the Readability Studio (Windows) 2012.1 software (Oleander, 2014), with the same textual features selected. The four formulas utilised in stage one of the study (the F-K, FRE, SMOG and Fry) were again used, and the Bormuth Cloze mean was also added. This test was included for interest as a comparison between the predicted cloze score and the cloze

score actually obtained by participants for each version of the report. It should be noted that the unrevised report and the glossary were excluded from the readability analysis of the revised report as both were considered only supplementary to the revised report.

## **5.6 Statistical Analysis**

The statistical analyses performed during this study used the Statistical Package for the Social Sciences (SPSS version 19). The statistical tests were chosen based on the characteristics of the data, but the significance level was always set at  $\alpha = 0.05$ , and a clinically significant effect size was considered to be  $d = 1.0$ .

First, the readability estimates and the textual features of each report were compared. Second, a combination of descriptive statistics, chi-squared tests and Analysis of Variance (ANOVAs) were used to describe the participants in the study and test for any significant differences in the demographic characteristics of the two report groups. Next, a multivariate Analysis of Variance was conducted to determine whether a linear combination of cloze score, comprehension score, self-efficacy score and perception rating was significantly affected by the assigned version of the report each group was assigned. Follow-up univariate ANOVAs using a Bonferroni correction were then conducted to investigate the effect of report allocation on each respective outcome variable. Correlation analyses were also used to investigate whether cloze scores, comprehension scores, self-efficacy scores or perception ratings were significantly related to education level. Subsequently, an Analysis of Covariance (ANCOVA) was used to determine the effect of report allocation on the assessed outcome variables while education level was controlled for as a covariate.

## CHAPTER SIX

### *RESULTS STAGE THREE: VERIFICATION*

---

#### **6.1 Overview**

This chapter presents the results of the data collected in stage three of the study: verification. To begin, the results of the readability assessment are presented and compared between the unrevised and revised versions of the report. Next, the results of the experimental verification process are described. In total, 32 participants were recruited for this part of the study, with half of these individuals randomly assigned to read the unrevised report, while the remaining half were assigned the revised report. The two groups did not significantly differ on the compared demographic variables, but did significantly differ on the two comprehension measures, in addition to their self-efficacy scores and perception ratings. These differences remained statistically significant with large observed effect sizes even when level of education was controlled for.

#### **6.2 Readability results**

Hypothesis 4a: The revised report will offer substantial improvements when compared to the unrevised report along the measure of readability.

The readability data supports hypothesis 4a, with the readability of the revised report substantially greater than that of the unrevised report across all five readability estimates (see table 7). More specifically, the revised report reduced the RGL required to read the report by 8.3 years, 7.4 years and at least 10 years when assessed by the F-K, SMOG and Fry formulas, respectively. The less precise estimate from the Fry formula arose because the assessed metrics of the unrevised report exceed the maximum RGL the Fry is designed to assess (17<sup>th</sup> grade). A substantial improvement in the FRE score is also apparent in table 7, where the reading ease of the revised report is over twice that of the unrevised report. Furthermore, the

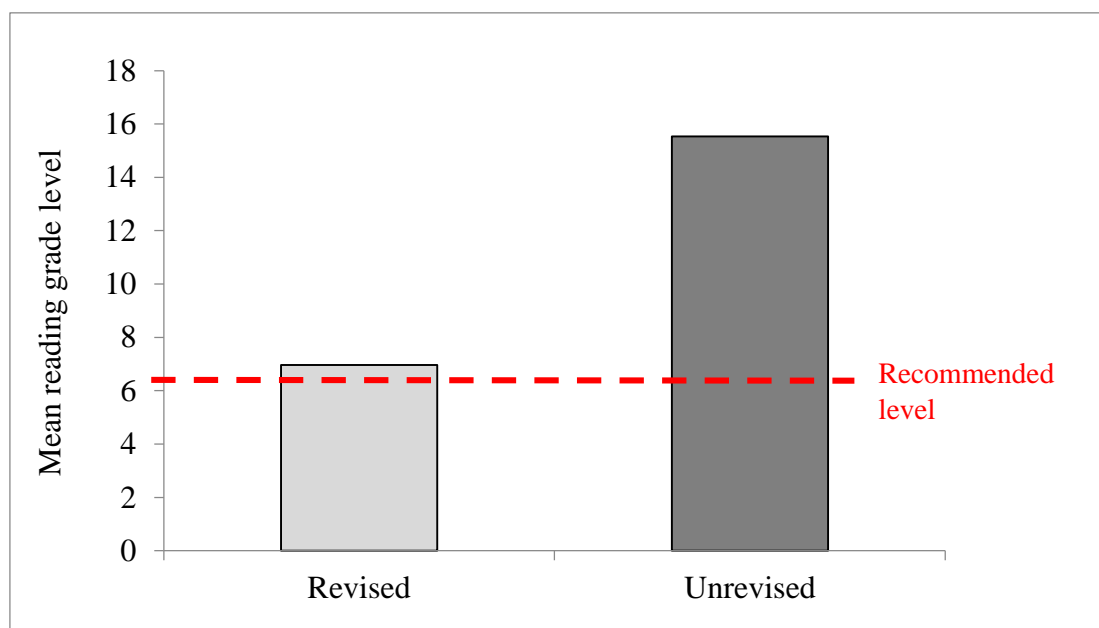
revised report predicts an improvement in cloze score of 18% when compared to the unrevised version, suggesting that the revised report should provide readers with at least marginal comprehension (equivalent to 75% on a comprehension test), whereas the unrevised report is likely to result in “inadequate” reader comprehension.

**Table 7.** Readability estimates for the revised and unrevised reports.

Readability test	Unrevised Report	Revised Report
F-K	14.1	5.8
SMOG	15.5	8.1
Fry	17+	7
FRE	34	78
Bormuth Cloze Mean	26	44

*Note.* F-K= Flesch-Kincaid; SMOG= Simple Measure of Gobbledygook; FRE= Flesch Reading Ease. Estimates are presented as reading grade level for the F-K, Fry and SMOG formulas; and as scores from 0-100 for the FRE formula and the Bormuth Cloze Mean.

As displayed in figure 2, the average RGL of the revised report (calculated by averaging the scores from the F-K, Fry and SMOG formulas) approximates the internationally recommended sixth RGL for written health materials (6.97 RGL), whereas the unrevised report substantially exceeds this recommendation (15.5 RGL)



**Figure 2.** Mean reading grade level of the revised report compared to the unrevised report and international readability recommendations. Mean calculated by averaging the Flesch-Kincaid (F-K), Fry and Simple Measure of Gobbledygook (SMOG) scores.

As reported in chapter 3, the readability software also conducts a series of analyses on the textual features of the document being assessed. Despite the revised report including a greater number of words (1300) than the unrevised report (566), it offers improvements in all other metrics known to be associated with the readability of the text. Table 8 displays these features and compares their occurrence between the two report versions.

**Table 8.** *Comparison of the text-based features of the two report versions*

<b>Readability feature</b>	<b>Unrevised Report</b>	<b>Revised Report</b>
Word characteristics		
1. Average number of syllables per word	1.8	1.4
2. Percentage of complex words ( <i>words of 3+ syllables</i> )	22.1%	5.8%
3. Percentage of hard words ( <i>words of 3+ syllables including fully syllabized numerals</i> )	24.2%	6.7%
4. Percentage of long words ( <i>words of 6+ characters</i> )	43.1%	26.5%
5. Percentage of unfamiliar words ( <i>words which do not appear on the Dale-Chall familiar word list</i> )	34.3%	12.5%
Sentence characteristics		
1. Average sentence length ( <i>number of words</i> )	19.5	11.5
2. Percentage of difficult sentences ( <i>greater than 22 words in length</i> )	37.9%	2.7%
3. Percentage of sentences involving passive voice	24.1%	0.885%

### 6.3 Sample characteristics

In total, 34 people responded to recruitment efforts, all of whom met the eligibility criteria. Two participants failed to return their assigned cloze procedure after initial contact and did not respond to follow up attempts. Thus, complete datasets were collected from 32 participants, 16 of whom were assigned to read the unrevised report and 16 the revised report. Because report allocation was based on random assignment, it was expected that there would be no significant differences between the two groups along the measured demographic variables (gender, ethnicity, education level, relationship status, age and number of children). To assess this assumption, a combination of chi-square tests and analysis of variance

(ANOVAs) were employed. Gender, ethnicity, education level and relationship status were compared using chi-square tests. The outcome variables for education level were categorised into High School (HS), university undergraduate (UG) or university postgraduate (PG), while the outcome variables for relationship status was dichotomised into “Yes” or “No”. Further, because participants only reported two ethnicities (New Zealand European (NZE) and other), this variable was dichotomised. Such categorisation helped create a sampling distribution sufficiently large to approximate a chi-square distribution. The number of children and parental age remained as continuous measurements and were therefore assessed using ANOVA.

Analyses revealed no significant differences between the groups in terms of gender, ethnicity, qualification, relationship status, number of children or age. The demographic characteristics of each group and the results of the statistical analyses are displayed in table 9 below.

**Table 9.** *Demographic variables for participants assigned to read the unrevised or revised report.*

<b>Variable</b>	<b>Unrevised Report</b>		<b>Revised report</b>		<b><math>\chi^2</math> or F</b>	<b>df</b>	<b>p</b>																																																				
<i>Gender</i>	M	5	M	6	0.14	1	.71																																																				
	F	11	F	10				<i>Ethnicity</i>	NZE	14	NZE	15	0.34	1	.54	Other	2	Other	1	<i>Qualification</i>	HS	12	HS	14	6.15	2	.058	UG	3	UG	8	PG	1	PG	1	<i>Relationship status</i>	Yes	13	Yes	12	0.18	1	.67	No	3	No	4	<i>Number of children</i>	M= 1.63 SD=.81		M=1.56 SD=.73		0.05	1, 31	.82	<i>Age</i>	M=33.44 SD=5.74		M=33.87 SD=6.53
<i>Ethnicity</i>	NZE	14	NZE	15	0.34	1	.54																																																				
	Other	2	Other	1				<i>Qualification</i>	HS	12	HS	14	6.15	2	.058	UG	3	UG	8		PG	1	PG	1				<i>Relationship status</i>	Yes	13	Yes	12	0.18	1	.67	No	3	No	4	<i>Number of children</i>	M= 1.63 SD=.81		M=1.56 SD=.73		0.05	1, 31	.82	<i>Age</i>	M=33.44 SD=5.74		M=33.87 SD=6.53		0.02	1, 31	.89				
<i>Qualification</i>	HS	12	HS	14	6.15	2	.058																																																				
	UG	3	UG	8																																																							
	PG	1	PG	1																																																							
<i>Relationship status</i>	Yes	13	Yes	12	0.18	1	.67																																																				
	No	3	No	4																																																							
<i>Number of children</i>	M= 1.63 SD=.81		M=1.56 SD=.73		0.05	1, 31	.82																																																				
<i>Age</i>	M=33.44 SD=5.74		M=33.87 SD=6.53		0.02	1, 31	.89																																																				

Note: M=Male; F= Female; NZE= New Zealand European; HS= High School; UG= Undergraduate degree; PG= Postgraduate degree

## 6.4 MANOVA

Hypothesis 4b, c, d: The revised report will offer significant improvements when compared to the unrevised report along measures of comprehension, self-efficacy and parental perceptions.

### 6.4.1 Examining MANOVA assumptions

To assess hypothesis 4, a Multivariate Analysis of variance (MANOVA) was conducted. Consideration was given to the assumptions of independence of observation, normality, and homogeneity of covariance matrices prior to this analysis. No significant skewness or kurtosis was detected within the dataset for any measured variable, thereby indicating that the assumption of normality was met. Further, results of Box's test indicated that the homogeneity of covariate matrices assumption was met (Box's  $M = 16.87$ ,  $p = .154$ ). Finally, no significant outliers were identified following inspection of the data box plots for the unrevised and revised report groups. Inspection of these results determined that the data did not contain bias, thus allowing parametric testing to occur.

### 6.4.2 MANOVA results

The MANOVA analysis revealed a significant multivariate effect of report allocation on the assessed outcome variables (Wilks  $\Lambda = .007$ ,  $F(4, 27) = 1017.47$ ,  $p < .001$ ). The power to detect this relation was estimated post-hoc to be  $1 - \beta > .999$ , while the effect size was estimated to be  $\eta_p^2 = 0.993$ , indicating that 99.3% of the variance in scores was accounted for by report allocation. Such a large effect size suggests that the four outcome variables assessed were successful at encapsulating the majority of the variance between the two groups.

Subsequent Bonferroni adjusted ( $p = .05 / 4 = .0125$ ) univariate ANOVAs were performed on each of the outcome variables. As illustrated in table 10, these follow-up

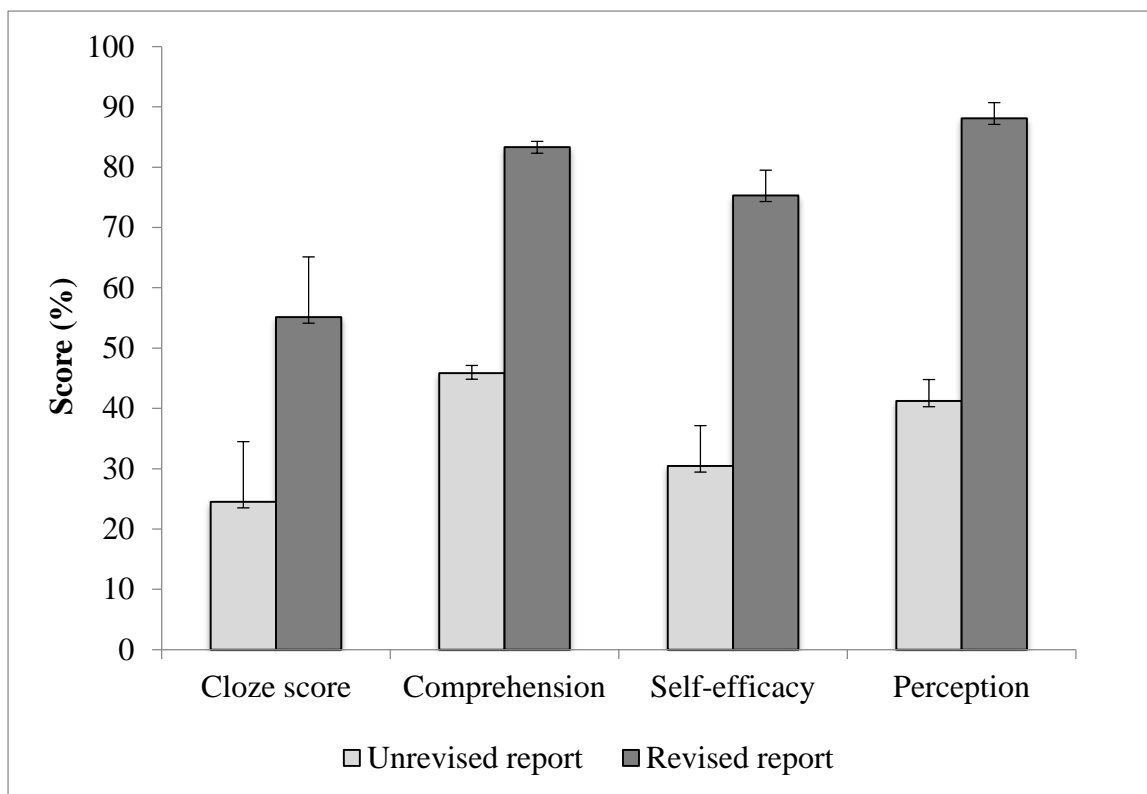
ANOVAs revealed statistically significant effects of report allocation on cloze score, comprehension, self-efficacy and perception. The observed effect sizes ranged from 2.03 to 6.13, and thus all exceeded the *a priori* defined clinically meaningful effect size. Further analyses of participant responses to the questionnaire are provided in Appendix G.

**Table 10.** Summary table for the results of each univariate ANOVA conducted.

Variable	F	Hypothesis df	Error df	p	$\eta^2$	d	1- $\beta$
Cloze score	288.67	1	30	< .001	.91	6.00	> .999
Comprehension	32.84	1	30	< .001	.52	2.03	> .999
Self-efficacy	89.05	1	30	< .001	.75	3.34	> .999
Perception	300.27	1	30	< .001	.91	6.13	> .999

These results clearly support hypothesis 4. Compared with the group of participants assigned the unrevised report, the revised report group had significantly higher comprehension scores when assessed by both the cloze test and multiple-choice questions. Furthermore, the revised report group had significantly higher self-efficacy scores and significantly more positive perception ratings (Figure 3).

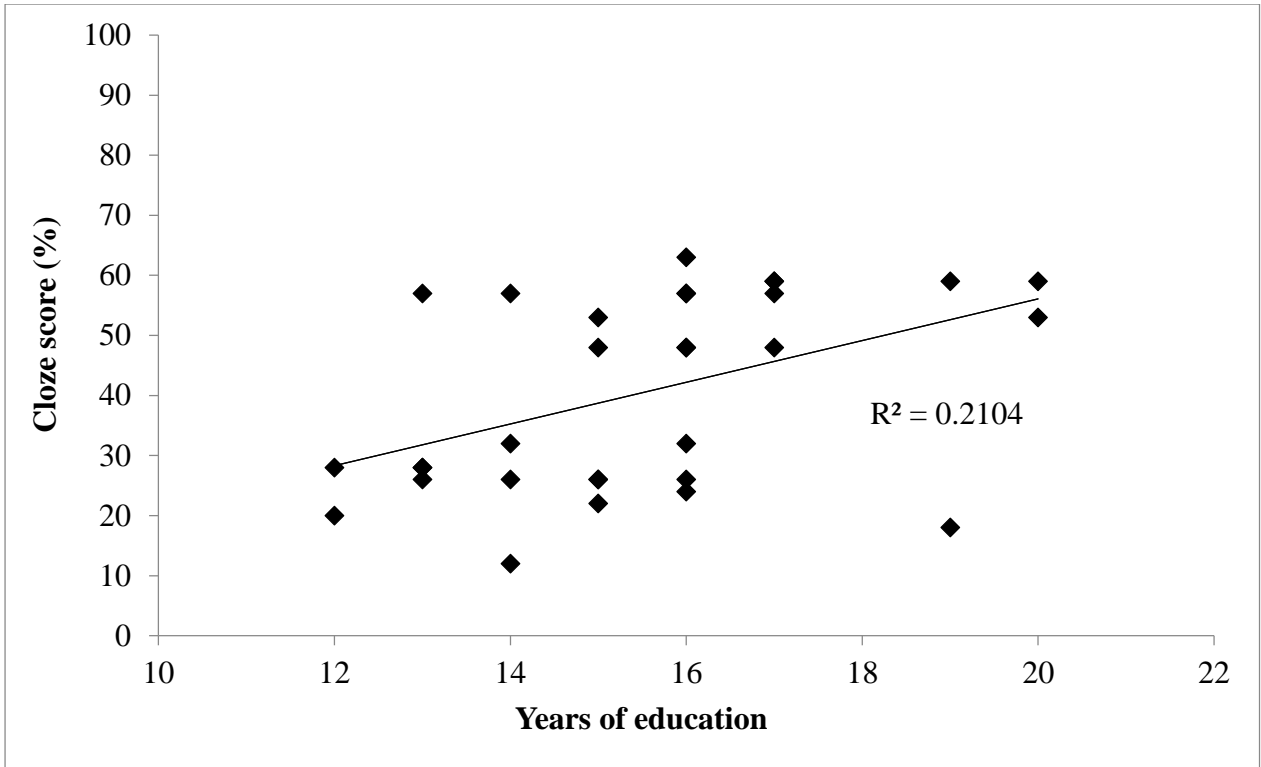




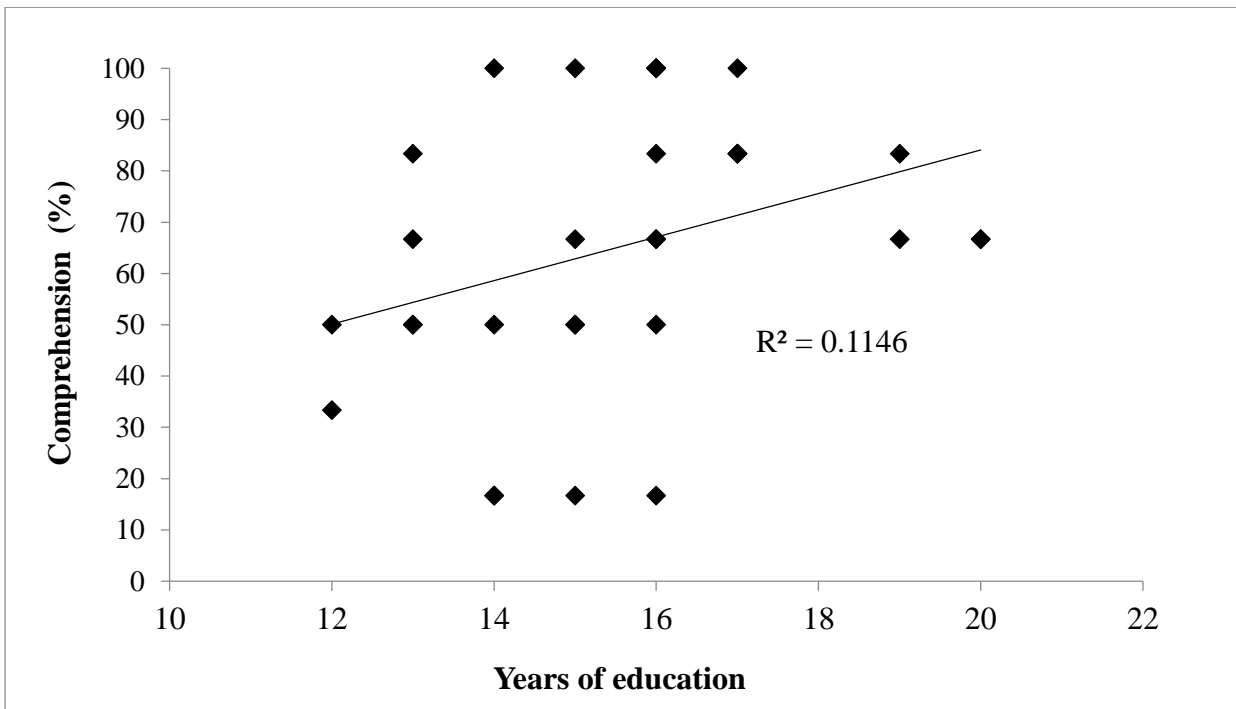
**Figure 3.** Mean cloze, comprehension, self-efficacy and perception scores for groups assigned the revised report and the unrevised report (error bars display standard deviations).

## 6.5 Correlations

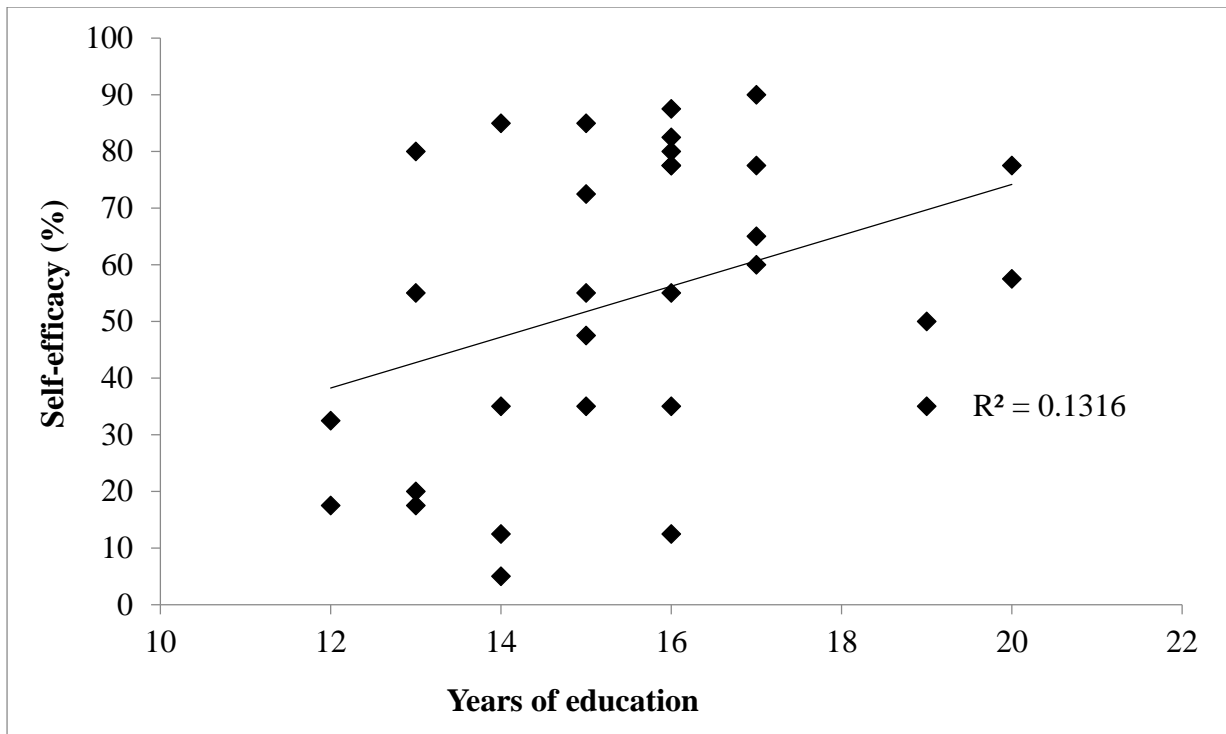
Because the results of the chi square test comparing the education level of the two groups approached significance, a series of correlations were conducted to evaluate whether there was a significant relationship between years of education, and the outcome variables of cloze score, comprehension, self-efficacy, and perception. The results of these Pearson product-moment correlations revealed that there was no significant correlation between years of education and comprehension scores on the multiple choice test ( $r = .330$ ,  $p = .062$ ). Conversely, years of education and cloze scores were found to be significantly and positively correlated ( $r = .460$ ,  $p = .009$ ), as were years of education and self-efficacy scores ( $r = .411$ ,  $p = .022$ ), and years of education and perception ratings ( $r = .460$ ,  $p = .009$ ). Figures 4-7 show the relationship between years of education and each of these respective outcomes measures.



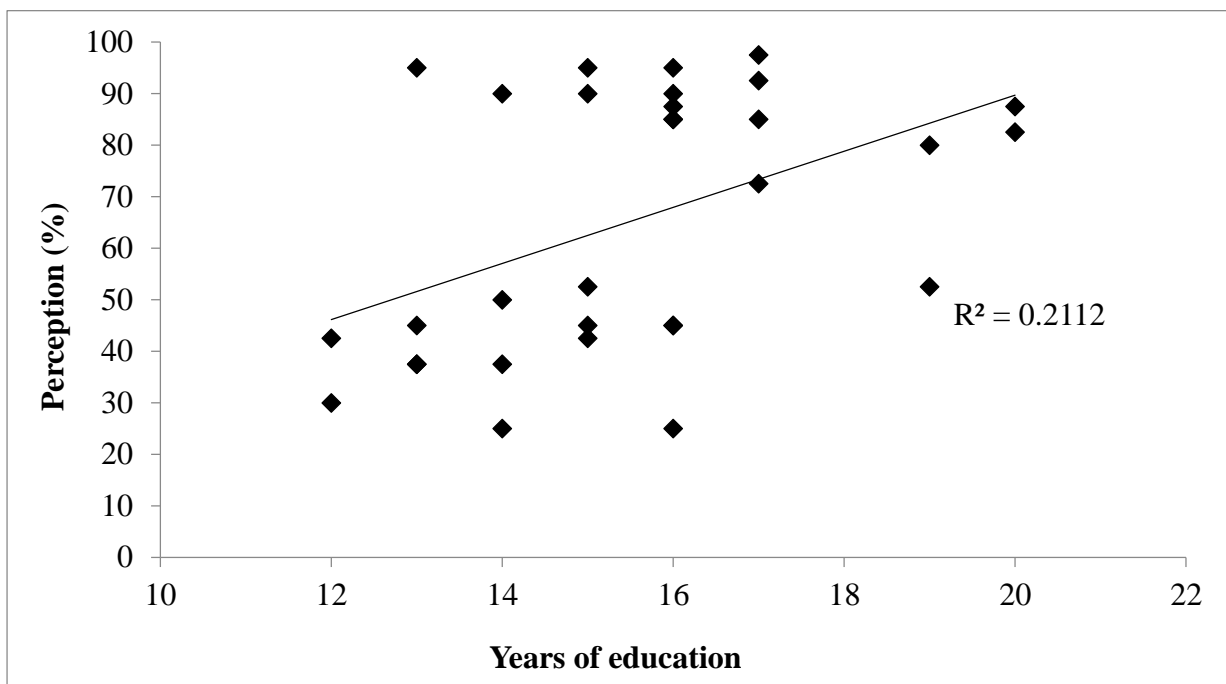
**Figure 4.** Years of education plotted against cloze scores (%) for all participants ( $p = .009$ )



**Figure 5.** Years of education plotted against comprehension scores (%) for all participants ( $p = .062$ )



**Figure 6.** Years of education plotted against self-efficacy scores (%) for all participants ( $p=.022$ )



**Figure 7.** Years of education plotted against perception scores (%) for all participants ( $p=.009$ )

## 6.6 ANCOVA

As a consequence of the significant correlations identified between education level and the outcome variables of cloze score, self-efficacy and perception; a one-way analysis of covariance (ANCOVA) was conducted, where years of education was used as a covariate.

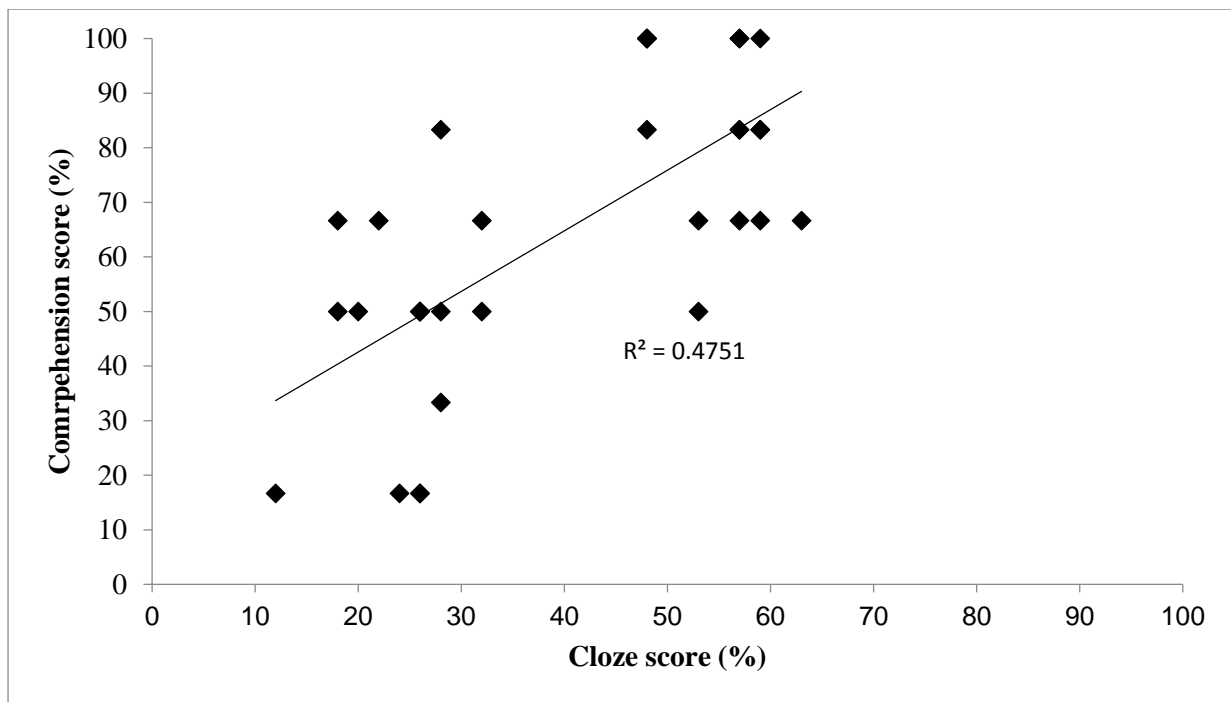
Table 11 presents the results of these analyses for each dependent variable (cloze score, comprehension, self-efficacy and perception ratings). These results indicate that, even after controlling for years of education, significant differences between the groups remain for cloze, comprehension, self-efficacy and perception scores. Additionally, a significant effect of report allocation on each outcome variable continued to be observed, with  $\eta_p^2$  ranging between .456 and .866.

**Table 11.** Analysis of Co-Variance for Years of Education by cloze score, comprehension, self-efficacy, perceptions and report allocation

Variable	F	Hypothesis df	Error df	p	$\eta_p^2$	1- $\beta$
Cloze score	206.51	1	28	< .001	.881	>.999
Comprehension	23.51	1	28	< .001	.456	.998
Self-efficacy	61.74	1	28	< .001	.688	>.999
Perception	217.17	1	28	< .001	.886	>.999

### 6.6. Correlation between Cloze scores and comprehension scores

Finally, it was of interest to determine if there was a significant correlation between the scores obtained on the cloze procedure and those obtained on the comprehension questions in the questionnaire. The result of a Pearson product-moment correlation revealed that these two variables were significantly and positively correlated ( $r = .689$ ,  $p < .001$ ), sharing nearly half of their variance. Figure 8 displays this association. In part, this analysis served to validate the multiple choice comprehension questions developed for the novel questionnaire used in this study.



**Figure 8.** Cloze scores (%) plotted against comprehension scores (%) for all participants ( $p < .001$ )

## 6.6 Summary

The main results of the three stages of this study can be summarised as follows:

- (1) The readability of the mock paediatric diagnostic audiology report exceeded international recommendations by an average eight RGLs.
- (2) Parent participants verified this poor readability by indicating that the report was confusing to read, contained excessive amounts of jargon, was of little use or value, failed to meet their expectations and required additional information to be understood. Further, participants demonstrated poor comprehension of the information contained in the report.
- (3) The report was able to be revised in accordance with best practice guidelines and parental recommendations without compromising the veracity of the information. Noteworthy strategies included improving the language used; reducing the content; reorganising the report order; using bold, colour and headings to clarify results;

providing information about prognosis; and including a copy of the original report, a glossary, three website references and a selection of graphics.

- (4) When compared to the unrevised version, the revised report produced: (a) a substantially lower average RGL which approximated international readability recommendations; (b) significant improvements in parent comprehension as measured by the cloze procedure and the multiple-choice questions; (c) significant improvements in the reported self-efficacy of parent participants; (d) significant improvements in parents' perceptions of the report.

## CHAPTER SEVEN: *DISCUSSION*

---

### **7.1 Introduction**

The purpose of this thesis was to evaluate the readability and comprehensibility of a mock paediatric diagnostic audiology report; and subsequently revise the report to improve its readability; in addition to the comprehension, self-efficacy and perceptions of parent participants. The results of the readability analysis and parental interviews during the evaluation stage of the study confirmed that the mock report was difficult to read and comprehend. Clinical professionals ascertained that the report could be revised using best practice guidelines and parental recommendations without compromising the veracity of the report. Finally, the verification stage indicated that the revised report approximated readability recommendations; and resulted in significantly greater parental comprehension, self-efficacy scores and perception ratings. These findings justify the need for improving paediatric diagnostic audiology reports in New Zealand. The advantages offered by the revised report may have important clinical implication for parents and their children with HI. This chapter will discuss these findings in relation to the literature, outline the clinical applications and limitations of the study, and describe future areas of research.

### **7.2 Evaluation stage: Hypotheses, relation to the literature and clinical significance**

#### **7.2.1 Readability**

The first hypothesis of this study predicted that the readability of the mock report would exceed the international recommendation that patient education materials should be written at or below the sixth RGL. As expected, the results of the readability analysis supported this hypothesis, revealing that the RGL of the report ranged between 14.8 and 17+

when measured by the F-K, SMOG and Fry formulas. Further, the FRE score of the original report was 35, indicative of a document that is “difficult” to read. These results are consistent with studies from a number of other health domains which have also identified a clear mismatch between the recommended RGL at which patient materials should be written, and the RGL level at which they are actually written (e.g. Arnold et al., 2006; Atcherson et al., 2011; Bennett et al., 2012; Caposecco et al., 2014; Hoffmann & McKenna, 2006; Kelly, 1996; Pothier et al., 2008; Yin et al., 2013; Zeng-Treitler et al., 2007).

It is interesting to note that the readability estimates uncovered in this study exceed those of other audiology resources previously evaluated (Atcherson et al., 2013; Joubert & Githinji, 2014; Swartz, 2010). More specifically, although 52% of pamphlets about hearing and hearing loss provided to parents in South Africa exceeded the sixth RGL, few exceeded the eighth RGL (Joubert and colleagues, 2013). This difference is probably attributable to the fact that the pamphlets in the Joubert study were developed with the parents in mind; whereas audiology reports are often written to communicate results to other health professionals and are simply copied to parents.

Support for this theory is found in a previous study conducted by Bennett and colleagues (2012). These authors found that the average readability of letters sent by health professionals to child and adolescent mental health service (CAMHS) patients in the United Kingdom was 12.78 when measured by the SMOG formula (Bennett et al., 2012). Interestingly, however, when the CAMHS letters were further analysed by addressee, the authors found that letters written to health professionals and copied to adolescent patients had an average RGL of 14.61, significantly higher than the mean RGL of letters addressed directly to patients (11.71) (Bennett et al., 2012). These readability results better approximate those found in this study, and suggest that considering the addressee when writing letters can significantly impact readability.



According to Doak et al. (1996), the readability of a document can be used as an efficient screening tool to predict patient comprehension and indicate when text revision is necessary. Specifically, these authors recommend that if the readability of a document exceeds the 9<sup>th</sup> RGL, revision should be undertaken; irrespective of how suitable the document is in other areas. The impetus for revising patient education materials has recently been emphasised as a strategy for lessening the global health literacy crisis. Essentially, improving the readability of written materials can serve to improve the match between the skills of readers and the demands imposed by the healthcare system. Such interventions are necessary because of the strong association between poor health literacy skills and negative health outcomes. With an average RGL of 15.9, the need to revise this audiology report was evident, and was subsequently initiated.

### **7.2.2 Parental interviews**

Although the results of the readability analysis alone confirmed the need to revise the report, the literature also recommends that target audience members should be consulted when evaluating health documents (Doak et al., 1996; Hoffman & Worrall, 2004). Accordingly, the second component of the evaluation stage tested the hypothesis that the subjective opinions of parent participants during semi-structured interviews would indicate that they struggled to comprehend the report.

Overall, the results from the qualitative thematic analysis supported this hypothesis, with all participants mentioning that they felt the report was confusing or difficult to read. This finding verified the poor readability of the report, and also supported previous qualitative research which have highlighted the complexity of other material types including pamphlets and instruction guides (Arnold et al., 2006; Caposecco et al., 2014; Sakai, 2013). Although studies assessing the comprehensibility of clinical letters are less common,

generally research has uncovered trends that align with the results of the current study. For instance, 46% of patients admitted they had difficulty understanding the contents of a letter outlining their endoscopy biopsy results during a phone interview (Karnieli-Miller et al., 2009). It is interesting that a lower proportion of patients reported difficulties reading their endoscopy results compared to the unanimous difficulties experienced by parents in this study. A possible explanation for this is that all patients in the Karnieli-Miller et al. (2009) study received clinically non-significant results. This may have caused patients to feel less motivated to comprehend the intricacies of their results, as compared to participants in this study who received a potentially distressing diagnosis.

Further analysis of the interview data found that the majority of participants attributed their difficulty understanding the report to the continuous use of audiology-specific terms, numbers and units. The use of jargon appears to be a common issue in audiology patient education materials, and has been shown to affect the quality of a wide range of material types (Atcherson et al., 2013; Joubert & Githinji, 2014; Kelly, 1996). For instant, recent work by Caposecco et al. (2014) found that 94% of hearing aid brochures failed to achieve a superior rating for vocabulary on the objective Suitability Assessment of Materials (SAM) scale because of their excessive use of undefined specific terminology (Caposecco et al. 2014).

The unfamiliarity and technicality of the language used in the mock audiology report also led some participants to feeling angry, anxious or disrespected. Such negative emotions have been reported by patients elsewhere following reception of complex written information, and can affect patient appreciation of the health system (Karnieli-Miller et al., 2009). Moreover, the complex language of the report had an adverse effect on parent understanding, demonstrated by the poor performance of participants on the comprehension questions. Specifically, only two parents could confidently confirm that the hypothetical child

had a HI; and only one participant acknowledged that some form of treatment or rehabilitation was likely to be necessary. These results are in agreement with the literature which has documented that written health materials often fall short of clearly explaining future health management recommendations (Joubert & Githinji, 2014; Karnieli-Miller et al., 2009). Such poor parental comprehension has concerning clinical implications, as parents may fail to understand that their child has a permanent HI requiring long-term remediation. Resulting misunderstandings could then impede the development of trusting relationships between the audiologist and the family, a factor known to be critical to effective management of child HI (DesGeorges, 2003).

Not only did participants struggle to comprehend the report, they also commonly expressed that the report would be of little use or value to them unless additional information was provided. This was a unique discovery of this study, as a previous investigation conducted by Cowper & Lenton (1996) identified that 100% of parent respondents were pleased to receive letters from a paediatrician following consultation. This trend has also been identified by other studies which have shown that patients value receiving clinical results and letters because they help maintain open communication, reduce anxiety and enable a sense of control (Baldwin, Quintela, Duclos, Staton, & Pace, 2005; Jelley & Walker, 2003; Waterston & San Lazaro, 1994). It would appear that the complexity of the diagnostic report revoked these benefits in this study.

However, it is important to note that it is protocol within the New Zealand UNHSEIP to provide parents with other information beyond the diagnostic report, including verbal counselling. Hence, parents who receive audiology diagnostic reports in reality may actually experience less anxiety and greater comprehension than the participants in this study. Nevertheless, recall that parents' retention and comprehension of oral information is often compromised due to the shock and anxiety experienced following diagnosis (Cowper &

lenton, 1996; Kurtzer-White & Luterman, 2003; Russ et al., 2004). There is also research to suggest that the quality of verbal counselling from audiologists varies, and is frequently perceived to be complex, overwhelming and filled with jargon (Russ et al., 2004; Spork, 2006). Thus, although some parent participants thought that verbal information would enhance their understanding of the report, there is evidence to suggest that in actuality, the benefits of verbal counselling may be limited. This emphasises the importance of supplementing and reinforcing verbal explanation with written materials, providing they use “simpler language, diagrams, and clearer explanations of the implications of hearing loss for language development” (Russ et al., 2004, p. 358).

Combined, the results from the evaluation stage of this study indicate that a mock paediatric diagnostic audiology report failed to satisfy international readability recommendations or the needs of parents. Consequently, there was a clear rationale for revising this report. The ultimate aim of revision was to produce a document capable of reassuring, supporting and educating parents. To facilitate this revision, participants were asked a number of questions about the modifications they thought would optimally improve the report. This process yielded valuable and consistent findings, with parents suggesting simplification of the language, reorganisation of the order, provision of prognosis information, inclusion of the original report, and finally, addition of a glossary, website references and graphics as techniques that would benefit their understanding of the report.

### **7.3 Revision stage: Hypotheses, relation to the literature and clinical significance**

Within the health literacy and readability literature, interest largely focuses on either identifying patient education materials that are failing to meet readability targets, or understanding the best strategies for improving these documents. Unfortunately, less research

is directed towards applying these strategies, and verifying the outcomes. However, active changes are necessary to reduce the health literacy crisis and consequently, revising the paediatric diagnostic audiology report was a priority of this study.

To facilitate optimal revision, best practice guidelines were combined with the specific recommendations made by parents during the evaluation stage. Interestingly, these two sources of advice aligned remarkably well, with parents making a number of suggestions also recommended by the literature regarding improving the language, content, organisation, layout and graphics of the report. For instance, participants in this study noted the importance of using “plain language”, a concept consistently highlighted in published studies and advisory guidelines (Caposecco et al., 2011; D’Alessandro et al., 2001; Hoffmann & Worrall, 2004; Joubert & Githinji, 2014).

A critical element when adopting a “plain language” writing style involves the use of simple vocabulary. Consequently, a number of technical terms in the unrevised report were replaced with more commonly recognised synonyms. Nonetheless, some audiology-specific terms were still included as Doak et al. (1996) suggests that it can be necessary to retain examples of technical language in health materials designed to educate the target audience. As the parents of the hypothetical child in this report will be exposed to audiology terms for the foreseeable future, it was considered appropriate to begin to introduce some audiology terminology and concepts.

Including some specific terminology was also justified as the terms were clearly explained both within the text and in the glossary. The decision to include the glossary was itself a somewhat controversial decision. While participants unanimously supported a glossary, the literature is divided on the benefit of glossaries. Some authors argue that cross-referencing is confusing for patients; and that glossaries should be unnecessary if clear

definitions and explanations are provided (Center for Medicare Education, 2000; Doak et al., 1996; PLAIN, 2011). Conversely, many studies recommend including a glossary as a useful way of explaining complex terms and building the vocabulary of the reader (D'Alessandro et al., 2001; Hoffmann & Worrall, 2004; Jelley & Walker, 2003). With this advice in mind, a glossary was not attached to the revised version of the report as the extensive use of definitions, explanations and examples in this version did not necessitate further explanation. However, a glossary was added to the unrevised version of the report to assist those parents who attempted to read this version of the report.

The decision to include a copy of the original report written to health professionals was the one suggestion made by parents that did not align with recommendations in the literature. Previously, researchers have advised that clinical letters to professionals should not be copied to patients without first being simplified (Cowper & Lenton, 1996; Waterston & San Lazaro, 1994). However, a proportion of parents in this study strongly felt that having a copy of the unrevised audiology report for their records would be beneficial. Because this study emphasised the views of parents during revision, this suggestion was implemented. It would be interesting to investigate in future studies whether parents would still feel this way had they never seen the unrevised report. It is possible that the revised report may be able to meet the needs of parents alone, and including the revised report may offer little benefit.

The content of the report was also addressed due to participants' comments that they felt overwhelmed and struggled to understand the overall message of the report. These expressions are consistent with the findings of Davis et al. (2006) who showed that 81% of brochures about newborn screening needed improvement so that parents could easily discern the essential information and action messages. To overcome these issues in the current study, the revised report was written so that all information included was essential, practical, and limited to that which is "need to know" rather than that which is "nice to know" (Arnold et

al., 2006). The content of the report was also personalised so that it contained only results, explanations and examples relevant to the hypothetical child. Various studies have documented that readers prefer information that is relevant to their specific needs, and that tailoring can result in improved patient recall and positive behavioural modification (Brug, Steenhuis, van Assema, & de Vries, 1996; Jones et al., 1999; Tang & Newcomb, 1998). The fact that audiology diagnostic reports can be personalised is therefore a significant advantage of these materials over other, generic, resources provided to parents of children with HI. The final modification to the report's content involved including three website links. These were provided as participants emphasised the importance of having additional support mechanisms to help them understand the content of the report. Further, Crowe et al. (2014) previously identified that parents of children with HI often prefer to do their own independent research.

A few minor changes to the layout of the report were also implemented to offer clarity and encourage reader engagement with the text. These changes included: using colour to aid understanding of complex concepts, bolding critical points and the inclusion of three figures to help explain the nature of each test and the meanings of the results. It was hoped that the figures would improve parent recall and comprehension of the information in the report, as evidence suggests the brain has improved access pathways and storage capacity for visuals over words alone (Doak et al., 1996; Houts, Doak, Doak & Loscalzo, 2006).

As mentioned above, the ultimate aim of the revision stage was to implement this combination of recommendations without compromising the veracity of the report. Consultation with two clinical professionals confirmed that the revised report still relayed all necessary information to parents. Even so, the second clinician did suggest a few syntactic and structural changes to the format of the report to ensure it was consistent with audiology procedures in New Zealand. These modifications affected both the unrevised and revised versions of the report, and thus the original report assessed during the evaluation stage

differed slightly to the edition considered during the final verification stage. Nevertheless, this was not a point of concern as the readability, and the content and semantics of the results section were remarkably similar between the two editions of the report.

## **7.4 Verification stage: Hypotheses, relation to the literature and clinical significance**

In accordance with Doak et al.'s (1996) recommended process for simplifying patient education materials, the evaluation and revision of the original report was followed by a verification stage. In this stage, the effectiveness of the revision process was evaluated through both a readability analysis and "learner verification" involving participants. This was a unique and valuable aspect to this study, because, as noted by Caposecco et al. (2014), studies that revise materials often fail to measure the impact of revision on patient comprehension and self-efficacy.

Hypothesis 4 was therefore developed for the verification stage; anticipating that the revised report would offer significant improvements along measures of (a) readability, (b) comprehension, (c) self-efficacy and (d) participant perceptions when compared to the unrevised report.

### **7.4.1 Readability**

As expected, the various strategies implemented during the revision stage of this study worked collectively to improve the readability of the revised report. Indeed, the readability of the mock diagnostic audiology report was improved by over eight RGLs and was within internationally acceptable readability levels when measured by the F-K formula.



This finding is in line with the literature which has also documented improvements in readability following text revision. For example, Davis et al. (1996) found that the RGL of a polio vaccine information pamphlet was halved to the fourth RGL when it was revised to conform to published guidelines and the needs of parents. Similarly, Pothier et al. (2008) documented an improvement in readability estimates when speech language therapy leaflets were revised according to the NHS Toolkit for Producing Patient Information. This had the result of improving the average reading ease of these leaflets from a “standard” reading difficulty to a “fairly easy” difficulty. This is similar to the improvement found in this study, where the initial “difficult” reading ease of the unrevised report was also improved to be “fairly easy”. These results suggest that following best practice guidelines can improve readability, regardless of the starting complexity of a document. This finding should serve as motivation for New Zealand health professionals to attempt revision of any document that exceeds readability standards.

The value of enhancing the report’s readability should not be underestimated, as it could help support the health literacy of parents of children with HI. The need for readable information is particularly great in New Zealand given that less than 30% of the adult population are estimated to have adequate or strong health literacy skills (Ministry of Health, 2010). Further, because an individual’s health literacy is dynamic, it is possible that the health literacy skills among parents of children with HI may be lower still. This is because the personal factors that can bolster health literacy, (including familiarity with the topic, available time, low stress and high confidence) are often absent or reduced in this cohort of parents following diagnosis of child HI. As poor parental health literacy is strongly associated with negative child health outcomes, the substantial improvement in the readability of the revised report may also indirectly protect the vulnerable health status of children with HI.

### 7.4.2 Comprehension

Although analytical readability results offer a rapid estimate of the success of document revision, in isolation they cannot predict the comprehensibility or appropriateness of a document (Atcherson et al., 2011; Kahn & Pannbacker, 2000). As even readable texts do not guarantee patient action, authors recommend using a combination of methods to evaluate the effectiveness of document revision. Consequently, this study employed “learner verification” via a randomised experimental design to assess factors other than readability that can affect the appropriateness of a document, including comprehension, self-efficacy and reader perceptions. Examining these constructs extends the uniqueness of this study, as readability critics suggest that many studies fail to supplement readability estimates with another construct (Homer & Surratt, 2000). In this study, the comprehension estimate was strengthened by utilizing two measures: (1) cloze test procedure and (2) multiple choice questions.

The statistical analyses supported hypothesis 4b, revealing a significant effect of report allocation on both measures of comprehension. In regards to the cloze procedure comprehension estimate, the mean cloze score from participants assigned the unrevised report indicated that this text is unlikely to be understandable or suitable for readers, and will most likely result in “inadequate” comprehension (Doak et al., 1996; Friedman & Hoffman-Goetz, 2006). In contrast, participants assigned the revised report had a cloze score of 55%, which approached the 56% threshold score indicative of a text that is both easy to understand and adequately comprehended (Doak et al., 1996; Friedman & Hoffman-Goetz, 2006).

Overall, the effect of report assignment on cloze procedure performance accounted for over 90% of the variance between the two groups ( $\eta_p^2 = .906$ ), and was large in size in accordance with Cohen’s (2003) conventions ( $d = 6.00$ ). Recall that in this study, a clinically

significant effect size was defined as  $d = 1.0$ . Thus, the revised report improved performance on the cloze procedure by both a statistically and clinically significant degree. Additionally, controlling for education level as a potentially extraneous variable had little impact on the statistical significance of these findings, and large effect sizes were maintained (Cohen, Cohen, West, & Aiken, 2003).

It is encouraging to note that these convincing results were obtained using an exact-answer method, which uses a more stringent marking criteria than the alternative acceptable-answer method. It was observed that participants who completed the revised report cloze procedure frequently made synonymous word replacements which maintained the semantic and syntactic nature of the sentence (for example, “hearing slopes” instead of “hearing drops”). In contrast, participants completing the unrevised report cloze procedure had a tendency to make contextually inappropriate guesses. Thus, it is likely that an even larger effect of report allocation on cloze performance would have been observed had the acceptable-answer method been used.

Comparison of the mean group cloze scores to the predicted cloze scores from the Bormuth cloze mean readability formula revealed reasonably close relations. Although parent participants performed better than predicted on the revised report cloze procedure (mean group percentage of 55% as compared to the predicted 44%), the comprehension of parents assigned the unrevised report approximated the predicted value closely (mean group percentage of 24.5%, compared to the predicted score of 26%). The fact that participants exceeded expectations on the revised cloze test may be because reader comprehension is affected by a number of factors which readability formulas cannot assess (Atcherson et al., 2013). Thus, it is possible that the comprehension of parents reading the revised report may have been enhanced by features of the report which were not evaluated by the Bormuth cloze mean such as layout or organisation.

Although the cloze procedure is a useful, objective measure that is widely used in the literature, it cannot inform health providers of the exact concepts readers are struggling to understand. Consequently, six multiple choice questions were also employed to evaluate participant comprehension in this study. Similar to the findings from the cloze test, the group assigned the revised report had significantly higher comprehension scores than the participants assigned the unrevised report. For instance, while 94% of parents who read the revised report were able to correctly answer the question pertaining to the nature of the child's hearing loss, only 18.75% of parents assigned the unrevised report correctly answered this question. Given such large discrepancies in understanding between the two groups, it is unsurprising that large and clinically significant effect sizes were also identified for this analysis ( $\eta_p^2 = .52$  and  $d = 2.03$ ). Further, the effect of report allocation on multiple choice comprehension continued to remain statistically and clinically significant even when education level was controlled for.

Investigating the relationship between these two comprehension measures revealed a positive, statistically significant association. This result suggests that the two measures approximate a similar construct. As the cloze procedure is considered a reliable estimate of reader comprehension, we can assume that the multiple choice questions were also assessing reader comprehension. This result has the benefit of increasing the validity of the novel questionnaire developed in this study.

Combined, these findings indicate that revising the mock audiology report according to best practice guidelines and recommendations from the intended audience offered statistically and clinically significant improvements in reader comprehension. Similar effects of text revision on reader comprehension have been noted previously (Davis et al., 1996; Sakai, 2013). The work by Davis et al. (1996) is considered a seminal study in the health literacy and readability domain. These authors noted an improvement in the comprehension

of parents after they read a simplified version of a polio vaccine information pamphlet compared to their comprehension after reading the original pamphlet. Although this 15% improvement was significant, it is much lower than the 36.5% improvement noted between the revised and unrevised reports in the current study. The differences between these two studies could be attributed to differences in study design or the readability of the compared materials. While the current study used a controlled comparison design where parents were randomly assigned to read only one report, parents in the Davis et al. (1996) study read both versions of the pamphlet. Consequently, practice effects may have reduced the magnitude of the observed difference in comprehension. Further, the F-K readability improved to a lesser extent in the Davis study, decreasing by four RGLs as compared to the eight RGL reduction seen in the current study. Therefore, it is expected that a smaller degree of improvement in comprehension should accompany this lesser improvement in readability.

The finding that the significance of report allocation on both comprehension measures was maintained when education level was controlled for was another important finding of this study. Although, education level is not always an accurate predictor of health literacy, these results suggest that the revised report may be able to enhance parent comprehension across a range of health literacy levels. Similar results have been uncovered by previous work centred in the audiology domain which has demonstrated that older adults are capable of accurately assembling a self-fitting hearing aid when they follow instructions which meet readability recommendations and follow best practice design principles (Caposecco et al., 2011; Convery et al., 2011, 2013). These authors found that over 95% of adults from both developed and developing countries were able to follow these instructions accurately, irrespective of their different health literacy levels. These results suggest that writing materials in an easy-to-read format can facilitate reader comprehension and appropriate actions, regardless of the reader's health literacy skills.

This is an important concept because low health literacy is an invisible problem that affects all types of individuals and cannot be accurately judged by appearance, education level or socioeconomic status (Joubert & Githinji, 2014; Kahn & Pannbacker, 2000). Further, recall that a person may have excellent literacy skills when placed in familiar contexts, yet become functionally illiterate when asked to read and understand written materials in unfamiliar contexts (Joubert & Githinji, 2013). The fact that parents with postgraduate levels of education also experienced difficulty comprehending the unrevised report ascertains the truth behind this phenomenon. Additionally, because low levels of literacy are often associated with shame and embarrassment, individuals may often avoid asking for explanations of confusing results (Jackson, 2006; Parikh et al., 1996). Thus, rather than trying to identify parents with insufficient health literacy skills, the most effective method is to ensure that all parents are provided with audiology reports that are easy to comprehend.

Unfortunately, the results from this study imply that the reports currently written in audiology are not easy for parents to comprehend. If parents struggle to comprehend the reports they are provided there may be significant negative implications: parents may ignore the information entirely, they may require additional appointments to understand results and implications, they may miss follow-up appointments, or they may use audiology services in an erratic or inefficient manner, compromising the positive effects of the New Zealand UNHSEIP.

### **7.4.3 Self-efficacy**

In this study, a significant effect of report version on self-efficacy score was identified, supporting hypothesis 4(c). Specifically, the group of parent participants allocated the revised report had significantly greater self-efficacy scores than those allocated the unrevised report. This finding was associated with large, clinically meaningful effect sizes

( $\eta_p^2 = .75$ ,  $d = 3.34$ ). Further, as observed for the two comprehension outcome measures, the effect of report allocation on self-efficacy remained significant even when participant education level was controlled for.

Although it is recommended that reader self-efficacy should be assessed as an outcome measure to verify text revision (Doak et al., 1996), the healthcare literature currently holds no examples of studies that have assessed this construct. Consequently, there is little directly comparable research to support or refute the findings herein. However, a recent study by Caposecco and colleagues (2014) identified that out of 36 hearing aid user guides, none achieved a superior rating for the “motivation and self-efficacy” factor according to the SAM instrument. The authors attributed these poor ratings to the complexity of the information, and concluded that revising the guides in accordance with best practice principles could help enhance reader motivation and self-efficacy.

Similarly, qualitative work by Karnieli-Miller et al. (2009) found that complex written biopsy reports were disempowering for patients, often creating feelings of inadequacy as patients struggled to comprehend their results (Karnieli-Miller et al., 2009). On the other hand, research has shown that when parents receive appropriate communication and advice from professionals, they feel empowered to provide adequate care for their children with HI (Russ et al., 2004). Combined, these findings suggest that producing simplified written materials should actively improve parent self-efficacy. The results uncovered by this study validate this conclusion, and suggest that revised audiology reports could enhance parent’s sense of confidence that they understood the contents of the report.

The observed difference between the groups on the self-efficacy portion of the questionnaire may have important clinical significance. Specifically, supporting self-efficacy is particularly important for parents of children with HI. This is because the factors known to

promote self-efficacy, (including enactive attainment, vicarious experience, verbal persuasion and minimal physiological stress), are often reduced or absent in this cohort. Further, research indicates that promoting self-efficacy may facilitate timely intervention for children with HI and increase the active involvement of parents; factors which are both associated with improved outcomes in children with HI (Desjardin, 2006; Driscoll, 2011; Khoza-shangase et al., 2010). Thus, the positive impact on self-efficacy produced by the revised report may have implications for improving the participation of parents under the “family-centred approach” of the New Zealand UNHSEIP (Ministry of Health, 2013a, p. 14).

#### **7.4.4 Perceptions**

As the final component of hypothesis four, it was predicted that the group of participants who read the revised report would perceive this version more positively than participants assigned the unrevised report. This prediction was supported by analysing the results of the questionnaire, with the perception ratings of the revised report found to significantly exceed those obtained for the unrevised report. Again, large effect sizes were measured for this difference ( $\eta_p^2 = .91$ ,  $d = 6.13$ ) and notably exceeded the criterion for a clinically significant effect size. Further, this effect remained both statistically and clinically significant when education level was controlled for. These findings suggest that revising audiology reports is likely to create meaningful, positive improvements in the way parents view reports, irrespective of parent education level.

The feedback offered by participants further validated this conclusion, as analogous comments were made by parents, regardless of their education level (Appendix G.4). For example, two participants remarked positively about the revised report, noting that it “was surprisingly easy to read” (P10) and “did a good job of putting medical terminology and testing into layman’s terms” (P28); despite the fact that participant 28 had completed an



additional 7 years of education than participant 10. These findings are in agreement with the literature which has previously identified that readers of all abilities prefer materials which are easy to read and comprehend (Davis et al., 1996).

Earlier research has documented similar improvements in reader perceptions of a text following revision. For instance, parent participants in the Davis et al. (1996) indicated that they would be more likely to read, understand, and follow the recommendations of the revised version of a polio vaccine pamphlet as opposed to the original version. Similarly, participants whose biopsy results included an attached explanatory cover letter reported significantly lower confusion, fewer negative emotions and higher understanding when compared to those patients who received a clinical biopsy letter alone Karnieli-Miller et al. (2009).

Swartz (2010) uncovered discrepant results to the above studies, finding that the readability of three different hand-outs written on otitis media had no significant bearing on parental satisfaction. One possible explanation for this conflicting finding may be due to the fact that parental satisfaction was measured using a 100 mm visual analogue scale (VAS) from the single question “How useful would this handout be to the caregiver of a child with an earache?” It is possible that this single question failed to accurately capture the percept of satisfaction. Further, the use of a VAS may have limited the validity of the results as research indicates that patients, particularly those with low literacy, find these scales harder to interpret and accurately complete than Likert-type response formats (Guyatt, Townsend, Berman, & Keller, 1987). Finally, it is important to consider that in the Swartz (2010) study none of the handouts assessed were below the recommended sixth RGL, so it is plausible that participants were unsatisfied with all three documents due to their complexity.

Overall, the results of this study suggest that an audiology report revised in accordance with best practice recommendations could significantly improve the way parents currently perceive these reports. The clinical significance of this finding is in two parts. First, the revised report seemed to better meet parents' need for information. This may mean that parents feel less compelled to search other sources for information, where the quality of information could be less reputable (Crowe et al., 2014; Laplante-Lévesque et al. 2012). Second, the fact that the revised report resulted in parents feeling less frustrated (appendix G.3), suggests that revising current audiology reports could provide parents with better emotional support. Offering support and reassurance to families is a critical responsibility of audiologists during diagnosis, and may be even more important nowadays with the shift to institution-initiated diagnoses. Ultimately, audiologists must provide information to help increase the family's emotional strength and knowledge base. Provided this information is communicated appropriately, it can serve to develop trusting, reciprocal relationships between families and professionals.

## **7.5 Limitations and directions for future research**

Despite the encouraging results of this study, there are several limitations which warrant discussion. First, it is important to recognise that the conclusions of this study are established on only one example of an audiology diagnostic report. While there is no reason to suspect that the format or language of this report was unusual or unique compared to those written elsewhere in New Zealand, variability in the readability between reports is to be expected. Reports are based on the unique medical history and hearing status of an individual child; and furthermore, are written by different audiologists who will have unique personal styles. In an attempt to minimise this limitation, the report was written to reflect the average New Zealand child diagnosed with a HI to make the results as applicable as possible.

Additionally, a brief readability analysis on five randomly selected reports written for paediatric patients at the University of Canterbury's Speech and Hearing clinic found that all had RGLs ranging between 13.4 and 15.9 as measured by the F-K formula; supporting the assumption that the RGL of the unrevised report was not unusually high. Nonetheless, replication of this study with an expanded sample of reports from different authors and different district health boards in New Zealand would be beneficial.

Furthermore, the report in this study outlined a HI diagnosis made for a child referred by newborn hearing screening. Future research should assess reports describing HI diagnoses made for older children via different test procedures, as well as reports informing parents that their child has normal hearing. Although research suggests that parents of children identified with HI at later ages may not require the same degree of emotional support as parents of children diagnosed as newborns (Kurtzer-White & Luterman, 2003), maximising the knowledge and health literacy skills of all parents should still be a priority. Moreover, research has noted the importance of ensuring that notifications of normal or non-serious results are also readable and comprehensible (Karnieli-Miller et al., 2009). Outlining normal results in a readable fashion may serve to minimise parent anxiety, encourage adherence to future recommendations, and also develop and maintain patient respect of the audiology and UNHSEIP system. Within New Zealand, this may be particularly important for parents of children found to have normal hearing at birth, but who have risk factors for developing HI later in life. As part of the "targeted follow-up" component to UNHSEIP, these children are required to return for an additional hearing assessment at approximately 18 months of age to monitor if there has been a change in their hearing status. Accordingly, the reports written to parents of these children must explicitly outline the need for this future follow-up assessment, without causing undue stress.

An additional limitation of this study was that the results of the evaluation stage were based on five interviews with voluntary participants from the Canterbury region of New Zealand. Although this small sample size was all that was needed to meet the “saturation” requirements of the study’s methodology, it may reduce the accuracy of generalisations made from the results. Indeed, because parents are an incredibly heterogeneous group of people, it is unlikely that the opinions uncovered herein encompass those of all parents within New Zealand. Further, it was difficult to obtain an accurate cultural representation in such a small sample, and consequently, the views of ethnic minority groups may not have been captured. It would be of interest to conduct a follow-up study involving parents from a range of ethnic groups.

When considering participants, it should be noted that this exploratory study recruited parents without any prior experience with HI or audiology services. This was done in an attempt to better approximate the perceptions of parents of children with HI in real life, the majority of whom have normal hearing themselves and little previous experience to draw on. Further, recruiting naïve parents reduced the possible effects of response and recall bias which have been found to affect the results of previous qualitative studies investigating parent’s experiences of HI diagnosis (Russ et al., 2004; Young & Tattersall, 2005). The disadvantage of this approach was that this study could not consider additional, realistic impacts on parent understanding. For instance, UNHSEIP protocols state that parents must be provided information via multiple communication modalities following a HI diagnosis. Although the comprehension of participants in this study probably would have been enhanced if they were also provided these additional resources, it is uncertain whether this benefit would hold for parents in real life. This is because these parents typically experience strong emotions that may impair their comprehension, regardless of the type or amount of

information. Future studies should therefore focus on identifying the factors that affect parent comprehension in reality. This would help offer practical value to the findings herein.

Another limitation arising from participant recruitment in the verification stage is that participants were excluded if they were not native speakers of the English language. This restriction attempted to minimise the alleged confounding effects of language on cloze procedure performance (Miller et al., 2009; Parker et al., 1995). However, this criterion also precluded the report from being assessed by a diverse array of ethnicities, which may have better represented the multi-cultural nature of modern New Zealand society. With the proportion of ethnic minority groups contributing to the New Zealand population continuing to grow (Statistics New Zealand Tatauranga Aotearoa, 2014), future research should use New Zealanders whose native language is not English to compare the revised and unrevised reports during a process of “learner verification”. Given that New Zealanders with established English skills struggled to read these reports, individuals with less developed English skills are likely to experience additional challenges when reading these reports. This is an issue that could have important clinical implications in regards to meeting New Zealand’s aim to ensure equality across all ethnic communities (Singham, 2006).

Similarly, males were underrepresented in the participant sample. Although this is reflective of the maternal dominance in the management of family health and childcare (Ranji & Salganicoff, 2014; Statistics New Zealand Tatauranga Aotearoa, 2013), it may have affected the accuracy of the comprehension, self-efficacy and perception results. For example, females have been previously found to have higher health literacy levels than males. Consequently, the comprehension results of this study may have been slightly elevated than if a more equal gender distribution been achieved (Australian Bureau of Statistics, 2008; Ministry of Health, 2010).

Further limitations stemmed from the exploratory nature of this study, which required innovative methodology that is not yet perfect. For example, during the readability analysis of the revised report, the attached unrevised report and glossary were excluded, as they were considered supplementary to the revised report only. However, parents read the entire report before completing the questionnaire, and this may have affected their self-efficacy scores and perception ratings. As mentioned above, future research is warranted to understand whether attaching the unrevised report and glossary is actually beneficial for parents. Additionally, this study developed a novel verification questionnaire to assess three outcome measures. Largely, this questionnaire was considered a strength of this study as it is believed this is the first research that has evaluated the comprehension, self-efficacy and perception of readers during “learner verification”. Assessing these attributes allowed for a comprehensive comparison of the two report versions, assessing factors beyond those measured by readability formulas and the cloze procedure (Smith et al., 2014).

However, due to time and resource constraints, this questionnaire was not thoroughly validated. Although the significant correlation between the results of the comprehension questions and the cloze procedure results indicated that the comprehension scale of the questionnaire has reasonable construct validity, the validity of the self-efficacy and perception scales remain somewhat uncertain. This lack of validation may have accentuated the inherent limitations of questionnaire-based research. Specifically, the validity of questionnaires is known to be affected by the degree to which questions actually measure the construct under investigation, the participant’s interpretation of the questions, and the effect of social desirability on the honesty of their answers (Staples, 1991).

The honesty of participants may have therefore further threatened the validity of the comprehension scale of the questionnaire. Participants were asked to wait at least 24 hours between reading the report and attempting the comprehension questions, and were instructed

to abstain from referring to the report when answering the questions. Although the significant difference in comprehension between the two reports suggests that these instructions were followed, this study did not collect information about the length of time between reading the report and completing the questionnaire. Because it is probable that participants waited variable lengths of time, future studies could benefit from assessing the relation between comprehension performance and length of time after reading the report. It would also be interesting to investigate if the short-term improvements in comprehension offered by the revised report are sustained in the weeks that follow.

The unvalidated nature of the questionnaire also restricted the degree to which the results from this study could be compared to others in the field. Future research focusing on assessing the suitability, or user-friendliness of the revised report through a validated rating scale would offer useful, and comparable, clinical information. There are a number of tools fit for this purpose in the healthcare domain. All of these share similarities regarding the type of features they assess; yet are distinguishable by their purpose, the extent and nature of psychometric testing and their resulting reliability and validity ratings (Clayton, 2009). The Suitability Assessment of Materials (SAM) (Doak et al., 1996) is probably the most appropriate scale to assess this report, as it is the most widely recognised and used of these tools. Furthermore, it can be modified to exclude irrelevant sections from the evaluation, provided the total possible score is reduced accordingly.

Finally, because the results of this study were based on New Zealand child HI statistics, UNHSEIP protocols and basic report templates, it is uncertain how applicable the results are to other nations. However, the low readability and poor comprehensibility of the report uncovered in this study are likely to be symptomatic of the quality of audiology reports or letters in other countries. Overall, the encouraging outcomes of this revision process,

combined with the importance of meeting the needs of parents of children with HI should serve as a major impetus for conducting similar research internationally.

## **7.6 Clinical applications**

This study is the first to explore the readability and comprehensibility of reports written to parents of children with HI. The results of this study clearly demonstrate that the types of reports currently written in New Zealand audiology are likely to be difficult for parents to read and comprehend. Further, this study has proven that revising a mock paediatric diagnostic audiology report in accordance with best practice guidelines and parental recommendations can produce significant improvements in parental comprehension, self-efficacy and perceptions.

These findings may have valuable clinical applications for the UNHSEIP in New Zealand. With the benefit of such early intervention programmes now well established internationally, attention must shift to developing procedures and processes to optimise the advantages of early diagnosis and intervention for children with HI. Part of this involves acknowledging the ICF-CY's theory that the amount of disability experienced by children with HI is moderated by a multitude of factors beyond the timing of service initiation. The degree of parental support and involvement has been suggested as the most critical of these factors and consequently a "family-centred approach" directs the New Zealand UNHSEIP (Ministry of Health, 2013a, p. 14). A critical component of this approach involves providing parents with appropriate written education materials to facilitate their active participation in their child's health management. Unfortunately, the findings from this study suggest that the diagnostic audiology reports currently provided to parents offer little in terms of enhancing parental understanding, offering emotional support or equipping parents to participate in



shared decision making and their child's development. Furthermore, these reports do not abide by the legal right of parent's to "effective communication", nor do they meet the needs of the family and whānau as required by the New Zealand UNHSEIP (Ministry of Health, 2013). Providing parents with materials they do not find valuable or useful is not an efficient use of clinical resources, and could impact on the cost-effectiveness of the New Zealand UNHSEIP.

For the above reasons, it is hoped the findings of this study will be recognised and implemented into clinical practice. Although achieving this will require modification of the current procedures in New Zealand audiology, the potential benefits for parents and for their children with HI should offset the challenges of implementing these changes. It should also be emphasised that a considerable portion of the revised report developed by this study can be retained for every child (including the description of test procedures, the figures, the website references and the glossary). Thus, the audiologist need only personalise the specific test results and recommendations for each child, a process that should be both efficient and straightforward. Recent research has advocated the benefits of computer-based database systems as a method for generating health materials that are tailored to the needs of the reader (Caposecco et al., 2014; Hoffman & McKenna, 2006). Such systems warrant further investigation as they could prove beneficial for creating personalised and comprehensible paediatric audiology reports without compromising efficiency.

Despite the applicable nature of the revised report, the report-writing process may be more time consuming for audiologists if they continue to write a second, standard report to multi-disciplinary team members. However, there is reason to suggest that professionals may also prefer simplified and concise reports (Cowper & Lenton, 1996). Indeed a study by these authors found that 83.6% of GPs indicated that letters written for parents were as helpful, if not more so, than the clinical letters they normally receive. While this study had low GP

response rates, the results warrant further research as they suggest that providing both a parental and professional version of the report is unlikely to become an intensive process.

There is also little reason for concern regarding the length and colour print of this report. Although printing these reports may be more taxing on hospital resources over prolonged periods, the possibility of emailing these reports to parents in the future also has value. Indeed, as technology is becoming an increasingly large part of service delivery across a variety of domains, authors recognise that it is only a matter of time before email becomes widely integrated into healthcare settings (Sittig, King & Hazelhurst, 2001). During a Cochrane systematic review conducted by Atherton and colleagues in 2012, a number of studies identified no significant differences in patient or health professional satisfaction when email and standard methods of communication were compared, suggesting that email is acceptable to patients and health professionals alike. However, it should be noted that the majority of studies investigated in this review were considered to be low quality, and thus the authors avoided decisive conclusions about the use of email communication between patients and professionals (Atherton, Sawmynaden, Sheikh, Majeed, & Car, 2012). Although additional research is clearly needed in this area, it is probable that emailing report could have positive implications for parents, including the more timely delivery of materials. This could be particularly helpful for this cohort as it would ensure parents are provided with information during the period in which they need it, thereby preventing their use of less reputable sources such as the Internet.

It is clear that further investigation is needed into the best strategy for improving paediatric audiology reports in New Zealand. The strong results of this study suggest that in the meantime, revised reports could still be provided, albeit on a smaller scale. For instance, District Health Boards could benefit from developing a revised report template to offer parents in cases where additional support and resources are warranted. As pertinently put by

one clinician, revised report templates could serve as a “valuable tool in an audiologist’s toolbox of resources for parents [of children with HI]”.

Finally, a cautionary note is required here: this study does not suggest that we should use written reports in lieu of the verbal counselling and other written materials currently provided to parents. Rather, audiologists should view paediatric diagnostic reports as a necessary adjunct to these other sources of information. To optimally facilitate a trusting relationship between the family and whanau and professionals, it is important that every resource given to parents helps promote their understanding and knowledge, thereby facilitating effective future management of the child’s HI. Ultimately, the results of this study imply that the benefits of providing parents with revised report should significantly offset the initial costs of implementing these changes.

## **7.7 Conclusion**

This study aimed to investigate the readability and comprehensibility of a mock report reflective of a typical paediatric diagnostic audiology report written in New Zealand. The results of this study suggest that the diagnostic reports currently provided in audiology are likely to be difficult for the majority of New Zealand parents to read and comprehend. Consequently, reports may be failing to meet both international readability recommendations and parents’ rights to effective communication.

Encouragingly, however, applying a combination of best practice recommendations and parental suggestions improved the readability of the report, in addition to parental comprehension, self-efficacy scores and perception ratings. These positive effects were both statistically and clinically significant. From a clinical perspective, revising audiology reports could have important implications for supporting the health literacy of New Zealand parents, improving their understanding of their child’s HI, empowering their participation in shared

decision making and providing emotional support. Combined, these factors may indirectly help protect the vulnerable health status of children with HI.

It is hoped that the positive results from this study will not only contribute to the audiology and health literacy literature, but will also be recognised and implemented into clinical practice. Ultimately, because knowledge is power for parents of children with HI, the simple revision of diagnostic reports could have positive implications for parents and their children alike.

## REFERENCE LIST

---

- ASHA. (2004). *Guidelines for the Audiologic Assessment of children from birth to 5 years of age*. Retrieved from [www.asha.org/policy](http://www.asha.org/policy)
- ASHA. (2008). Guidelines for Audiologists Providing Informational and Adjustment Counseling to Families of Infants and Young Children With Hearing Loss Birth to 5 Years of Age. Retrieved from: <http://www.asha.org/policy/GL2008-00289.htm>
- Alderson, J. C. (1980). Native and non-native speaker performance on cloze tests. *Language Learning*, 30, 59–76.
- Anderson, J., Dodman, S., Kopelman, M., & Fleming, A. (1979). Patient information recall in a rheumatology clinic. *Rheumatology and Medical Rehabilitation*, 18, 245–55.
- Arnold, C. L., Davis, T. C., Frempong, J. O., Humiston, S. G., Kennen, E. M., Lloyd-puryear, M., & Bocchini, A. (2006). Assessment of Newborn Screening Parent Education Materials. *Pediatrics*, 117(5), S320–S325. doi:10.1542/peds.2005-2633L
- ASHA. (2008). Guidelines for Audiologists Providing Informational and Adjustment Counseling to Families of Infants and Young Children With Hearing Loss Birth to 5 Years of Age. Retrieved June 19, 2014, from <http://www.asha.org/policy/GL2008-00289.htm> -
- Atcherson, S. R., Richburg, C. M., Zraick, R. I., & George, C. M. (2013). Readability of Questionnaires Assessing Listening Difficulties Associated With (Central) Auditory Processing Disorders. *Language, Speech and Hearing Services in Schools*, 44, 48–60. doi:10.1044/0161-1461(2012/11-0055)Stelmachowicz
- Atcherson, S. R., Zraick, R. I., & Brasseur, R. E. (2011). Readability of patient-reported outcome questionnaires for use with persons with tinnitus. *Ear and Hearing*, 32(5), 671–3. doi:10.1097/AUD.0b013e3182134654
- Atherton, H., Sawmynaden, P., Sheikh, A., Majeed, A., & Car, J. (2012). Email for clinical communication between patients / caregivers and healthcare professionals. *Cochrane Database of Systematic Reviews*, (11).
- Australian Bureau of Statistics. (2008). Adult Literacy and Life Skills Survey, Summary Results. Retrieved from [www.abs.gov.au](http://www.abs.gov.au)
- Baldwin, D. M., Quintela, J., Duclos, C., Staton, E. W., & Pace, W. D. (2005). Patient preferences for notification of normal laboratory test results: a report from the ASIPS Collaborative. *BMC Family Practice*, 6(1), 11. doi:10.1186/1471-2296-6-11
- Bennett, D. M., Drane, E., & Gilchrist, A. (2012). Readability of CAMHS clinical letters. *Child and Adolescent Mental Health*, 17(3), 161–165. doi:10.1111/j.1475-3588.2011.00624.x

- Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., ... Viswanathan, M. (2011). Health literacy interventions and outcomes: an updated systematic review. *Evidence Report/technology Assessment*, (199), 1–941. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/23126607>
- Bess, F. H., & Humes, L. E. (2008). *Audiology the fundamentals* (4th ed.). Pennsylvania, PA: Lippincott Williams & Wilkins.
- Bhandari, N. (2010). Readability - writing letters to patients in plain English. *The Psychiatrist Online*, 34(10), 454–454. doi:10.1192/pb.34.10.454
- Bormuth, J. R. (1968). Cloze readability procedure. *Elementary English*, 45(4), 429–436.
- Brown, J. D. (1980). Relative merits of four methods for scoring cloze test. *The Modern Language Journal*, 64(3), 311–317.
- Brug, J., Steenhuis, I., van Assema, P., & de Vries, H. (1996). The Impact of a Computer-Tailored Nutrition Intervention. *Preventive Medicine*, 25, 236–242.
- Caposecco, A., Hickson, L., & Meyer, C. (2011). Assembly and insertion of a self-fitting hearing aid: design of effective instruction materials. *Trends in Amplification*, 15(4), 184–95. doi:10.1177/1084713811430837
- Caposecco, A., Hickson, L., & Meyer, C. (2014). Hearing aid user guides: suitability for older adults. *International Journal of Audiology*, 53, S43–51. doi:10.3109/14992027.2013.832417
- Center for Medicare Education. (2000). Writing easy-to-read materials. *Issue Brief (Center for Medicare Education)*, 1(2), 1–6. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/11813742>
- Centers for Disease Control and Prevention. (2009). Simply put: A guide to creating easy-to-understand materials. Retrieved March 22, 2014, from [http://www.cdc.gov/healthliteracy/pdf/Simply\\_Put.pdf](http://www.cdc.gov/healthliteracy/pdf/Simply_Put.pdf)
- Ching, T. Y., Oong, R., & Wanrooy, E. Van. (2006). The ages of intervention in Regions with and without universal newborn hearing screening and prevalence of childhood hearing impairment in Australia. *Australian and New Zealand Journal of Audiology*, 28(2), 137–150. doi:10.1375/audi.28.2.137
- Clayton, L. H. (2009). TEMPtEd: development and psychometric properties of a tool to evaluate material used in patient education. *Journal of Advanced Nursing*, 65(10), 2229–38. doi:10.1111/j.1365-2648.2009.05049.x
- Cohen, J., Cohen, P., West, S., & Aiken, L. (2003). *Applied multiple regression/correlation analysis for the behavioral sciences* (3rd ed.). New York: Routledge.
- Convery, E., Keidser, G., Caposecco, A., Swanepoel, D. W., Wong, L. L. N., & Shen, E. (2013). Hearing-aid assembly management among adults from culturally and

- linguistically diverse backgrounds: toward the feasibility of self-fitting hearing aids. *International Journal of Audiology*, 52(6), 385–93. doi:10.3109/14992027.2013.773407
- Convery, E., Keidser, G., Hartley, L., Caposecco, A., Hickson, L., & Meyer, C. (2011). Management of hearing aid assembly by urban-dwelling hearing-impaired adults in a developed country: implications for a self-fitting hearing aid. *Trends in Amplification*, 15(4), 196–208. doi:10.1177/1084713811431694
- Cowper, D. M., & Lenton, S. W. (1996). Letter writing to parents following paediatric outpatient consultation: a survey of parent and GP views. *Child: Care, Health and Development*, 22(5), 303–310. doi:10.1111/j.1365-2214.1996.tb00432.x
- Crowe, K., Fordham, L., Mcleod, S., & Ching, T. Y. C. (2014). “Part of Our World”: Influences on caregiver decisions about communication choices for children with hearing loss. *Deafness & Education International*, 16(2), 61–85. doi:10.1179/1557069X13Y.0000000026
- Cruice, M. (2008). The contribution and impact of the International Classification of Functioning, Disability and Health on quality of life in communication disorders. *International Journal of Speech-Language Pathology*, 10(1-2), 38–49. doi:10.1080/17549500701790520
- D’Alessandro, D. M., Kingsley, P., & Johnson-West, J. (2001). The readability of pediatric patient education materials on the World Wide Web. *Archives of Pediatrics & Adolescent Medicine*, 155(7), 807–12. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/11434848>
- Davey, C., Austoker, J., & Jansen, C. (1998). Improving written information for women about cervical screening: evidence-based criteria for the content of letters and leaflets. *Health Education Journal*, 57(3), 263–281. doi:10.1177/001789699805700309
- Davis, A., & Davis, K. A. (2011). Descriptive epidemiology of childhood hearing impairment. In R. Tharpe & Seewald A. M. (Eds.), *Comprehensive Handbook of Pediatric Audiology* (pp. 85–112). Oxfordshire: Plural Publishing, Inc.
- Davis, T. C., Bocchini, J. A., Fredrickson, D., Arnold, C., Mayeaux, E. J., Murphy, P. W., ... Paterson, M. (1996). Parent comprehension of polio vaccine information pamphlets. *Pediatrics*, 97(6), 804–810. Retrieved from <http://pediatrics.aappublications.org/content/97/6/804.short>
- Davis, T. C., Mayeaux, E. J., Fredrickson, D., Bocchini, J. A., Jackson, R. H., & Murphy, P. W. (1994). Reading ability of parents compared with reading level of pediatric patient education materials. *Pediatrics*, 93(3), 460–468. Retrieved from <http://pediatrics.aappublications.org/content/93/3/460.short>
- Department of Health. (2003). *Copying Letters to Patients: Good Practice Guidelines*. Retrieved from [http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4007561](http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4007561)

- DesGeorges, J. (2003). Family perceptions of early hearing, detection, and intervention systems: listening to and learning from families. *Mental Retardation and Developmental Disabilities Research Reviews*, 9(2), 89–93. doi:10.1002/mrdd.10064
- Desjardin, J. L. (2003). Assessing parental perceptions of self-efficacy and involvement in families of young children with hearing loss. *The Volta Review*, 103(4), 391–209. Retrieved from <http://listeningandspokenlanguage.org/TheVoltaReview/>
- Desjardin, J. L. (2006). Family Empowerment : Supporting Language Development in Young Children Who Are Deaf or Hard of Hearing. Retrieved from <http://listeningandspokenlanguage.org/TheVoltaReview/>
- Dewalt, D. A., Berkman, N. D., Sheridan, S., Lohr, K. N., & Pignone, M. P. (2004). Literacy and Health Outcomes. *Journal of General Internal Medicine*, 19(12), 1228–1239. doi:10.1111/j.1525-1497.2004.40153.x
- Digby, J. E., Purdy, S. C., & Kelly, A. S. (2011). *Hearing loss in New Zealand children: 2010*. Retrieved from <http://www.audiology.org.nz/deafness-notification-database.aspx>
- Digby, J. E., Purdy, S. C., & Kelly, A. S. (2012). *Hearing loss in New Zealand children: 2011*. Retrieved from <http://www.audiology.org.nz/deafness-notification-database.aspx>
- Digby, J. E., Purdy, S. C., & Kelly, A. S. (2013). *Deafness Notification Report (2012) Hearing loss (not remediable by grommets) in New Zealanders under the age of 19*. Retrieved from <http://www.audiology.org.nz/deafness-notification-database.aspx>
- Digby, J. E., Purdy, S. C., & Kelly, A. S. (2014). *Deafness Notification Report (2013) Hearing loss (not remediable by grommets) in New Zealanders under the age of 19*. Retrieved from <http://www.audiology.org.nz/deafness-notification-database.aspx>
- Digby, J., Thorne, P., Webster, D., Keith, W., Wilson, O., & Cooper, M. (2004). *Improving outcomes for children with permanent congenital hearing impairment: the case for a national newborn hearing screening and early intervention programme*. Auckland: Project HIEDI.
- Doak, C., Doak, L., & Root, J. (1996). *Teaching patients with low literacy skills* (2nd ed.). Philadelphia: J.B. Lippincott Company.
- Driscoll, C. (2011). Counselling of families and children with hearing loss. In J. P. Dupont (Ed.), *Hearing loss classification, causes and treatment* (pp. 213–233). New York: Nova Science Publishers, Inc.
- Duthey, B. (2013). *Priority Medicines for Europe and the World “A Public Health Approach to Innovation”*. *Background Paper 6 . 21 Hearing Loss*. Retrieved from [http://www.who.int/medicines/areas/priority\\_medicines/en/](http://www.who.int/medicines/areas/priority_medicines/en/)
- Eadie, T. (2003). The ICF: A proposed framework for comprehensive rehabilitation of individuals who use alaryngeal speech. *American Journal of Speech–Language Pathology*, 12, 189–197.



- Egbert, N., & Nanna, K. M. (2010). Health Literacy : Challenges and Strategies. *The Online Journal of Issues in Nursing*, 14(3), 1–12. Retrieved from [www.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN](http://www.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN)
- Feher-Prout, T. (1996). Stress and coping in families with deaf children. *Journal of Deaf Studies and Deaf Education*, 1(3), 155–65. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/15579820>
- Finsterer, J., & Fellingner, J. (2005). Nuclear and mitochondrial genes mutated in nonsyndromic impaired hearing. *International Journal of Pediatric Otorhinolaryngology*, 69(5), 621–47. doi:10.1016/j.ijporl.2004.12.002
- Fitzpatrick, E., Angus, D., Durieux-Smith, A., Graham, I. D., & Coyle, D. (2008). Parents' needs following identification of childhood hearing loss. *American Journal of Audiology*, 17(1), 38–49. doi:10.1044/1059-0889(2008/005)
- Flesch, R. (1948). A new readability yardstick. *Journal of Applied Psychology*, 32(3), 221–233. Retrieved from <http://psycnet.apa.org/journals/apl/32/3/221/>
- Flexer, C. M. (1999). *Facilitating Hearing and Listening in Young Children*. San Diego, USA: Singular Publishing Group.
- Flynn, M., Austin, N., Flynn, T. S., Ford, R., & Buckland, L. (2004). Universal newborn hearing screening introduced to NICU infants in Canterbury Province, New Zealand. *The New Zealand Medical Journal*, 117(1206), 1–10.
- Fortnum, H., & Davis, A. (1997). Epidemiology of permanent childhood hearing impairment in Trent Region, 1985-1993. *British Journal of Audiology*, 31(6), 409–46. doi:10.3109/03005364000000037
- Fortnum, H. M., Summerfield, A. Q., Marshall, D. H., Davis, A. C., & Bamford, J. M. (2001). Prevalence of permanent childhood hearing impairment in the United Kingdom and implications for universal neonatal hearing screening: questionnaire based ascertainment study. *BMJ (Clinical Research Ed.)*, 323(7312), 536–40. Retrieved from <http://www.bmj.com/content/323/7312/536.abstract>
- Freda, M. C. (2005). The readability of American Academy of Pediatrics patient education brochures. *Journal of Pediatric Health Care : Official Publication of National Association of Pediatric Nurse Associates & Practitioners*, 19(3), 151–6. doi:10.1016/j.pedhc.2005.01.013
- Friedman, D. B., Corwin, S. J., Dominick, G. M., & Rose, I. D. (2009). African American men's understanding and perceptions about prostate cancer: why multiple dimensions of health literacy are important in cancer communication. *Journal of Community Health*, 34(5), 449–60. doi:10.1007/s10900-009-9167-3
- Friedman, D., & Hoffman-Goetz, L. (2006). A systematic review of readability and comprehension instruments used for print and web-based cancer information. *Health Education & Behavior : The Official Publication of the Society for Public Health Education*, 33(3), 352–73. doi:10.1177/1090198105277329

- Fry, E. (1968). A readability formula that saves time. *Journal of Reading*, 11(513-516), 575–578.
- Gemoets, D., Roseblat, G., Tse, T., & Logan, R. (2004). Assessing readability of consumer health information : An exploratory study. *Medinfo*, 11(Pt 2), 869–873. Retrieved from <http://www.unboundmedicine.com/medline/journal/Medinfo>
- Gilbey, P. (2010). Qualitative analysis of parents' experience with receiving the news of the detection of their child's hearing loss. *International Journal of Pediatric Otorhinolaryngology*, 74(3), 265–70. doi:10.1016/j.ijporl.2009.11.017
- Greville, A. (2005). *Hearing impaired and deaf people in New Zealand : an update on population numbers and characteristics*. Retrieved from <http://www.oticon.org.nz/pdf/HearingimpaireddeafpeopleNZMar05a.pdf>
- Grus, C. L., Lopez-Hernandez, C., Delamater, A., Appelgate, B., Brito, A., Wurm, G., & Wanner, A. (2001). Parental self-efficacy and morbidity in pediatric asthma. *The Journal of Asthma : Official Journal of the Association for the Care of Asthma*, 38(1), 99–106. Retrieved from <http://informahealthcare.com/doi/abs/10.1081/JAS-100000027>
- Guyatt, G., Townsend, M., Berman, L., & Keller, J. (1987). A comparison of Likert and visual analogue scales for measuring change in function. *Journal of Chronic Disease*, 40, 1129–1133. Retrieved from <http://www.sciencedirect.com/science/article/pii/0021968187900804>
- Harlor, A. D., & Bower, C. (2009). Hearing assessment in infants and children: recommendations beyond neonatal screening. *Pediatrics*, 124(4), 1252–63. doi:10.1542/peds.2009-1997
- Harrison, M., Roush, J., & Wallace, J. (2003). Trends in age of identification and intervention in infants with hearing loss. *Ear and Hearing*, 24(1), 89–95. doi:10.1097/01.AUD.0000051749.40991.1F
- Hassan, E. (2005). Recall bias can be a threat to retrospective and prospective research designs. *The Internet Journal of Epidemiology*, 3(2).
- Hintermair, M. (2006). Parental resources, parental stress, and socioemotional development of deaf and hard of hearing children. *Journal of Deaf Studies and Deaf Education*, 11(4), 493–513. doi:10.1093/deafed/enl005
- Hoffmann, T., & McKenna, K. (2006). Analysis of stroke patients' and carers' reading ability and the content and design of written materials: recommendations for improving written stroke information. *Patient Education and Counseling*, 60(3), 286–93. doi:10.1016/j.pec.2005.06.020
- Hoffmann, T., & Worrall, L. (2004). Designing effective written health education materials: considerations for health professionals. *Disability and Rehabilitation*, 26(19), 1166–73. doi:10.1080/09638280410001724816

- Homer, S. D., & Surratt, D. (2000). Improving Readability of Patient education materials. *Journal of Community Health Nursing, 17*(1), 15–23. doi:10.1207/S15327655JCHN1701\_02
- Houts, P. S., Doak, C. C., Doak, L. G., & Loscalzo, M. J. (2006). The role of pictures in improving health communication: a review of research on attention, comprehension, recall, and adherence. *Patient Education and Counseling, 61*(2), 173–90. doi:10.1016/j.pec.2005.05.004
- Lee, S. Y., Hwang, H., Hawkins, R., & Pingree, S. (2008). Interplay of negative emotion and health self-efficacy on the use of health information and its outcomes. *Communication Research, 35*(3), 358–381. doi:10.1177/0093650208315962
- Institute of Medicine. (2004). *Health Literacy: A Prescription to End Confusion*. Washington, DC: National Academies Press.
- Jackson, R. (2006). Parental health literacy and children's dental health: Implications for the future. *Pediatric Dentistry, 28*(1), 72–75. Retrieved from <http://www.ingentaconnect.com/content/aapd/pd;jsessionid=9a25knjh8sgtt.alice>
- Jelley, D., & Walker, C. (2003). Copying clinical letters : access issues for specific patient groups. *Quality in Primary Care, 11*, 215–220. Retrieved from [http://www.researchgate.net/journal/1479-1072\\_Quality\\_in\\_primary\\_care](http://www.researchgate.net/journal/1479-1072_Quality_in_primary_care)
- Johnson, C. D., & Seaton, J. (2011). *Educational Audiology Handbook* (2nd ed.). NY: Delmar Cengage Learning.
- Jones, R., Pearson, J., Mcgregor, S., Cawsey, A. J., Barrett, A., Craig, N., ... McEwen, J. (1999). Randomised trial of personalised computer based information for cancer patients. *British Medical Journal, 319*, 1241–1247. Retrieved from <http://www.bmj.com/content/319/7219/1241?variant=full-text>
- Jones, T. L., & Prinz, R. J. (2005). Potential roles of parental self-efficacy in parent and child adjustment: a review. *Clinical Psychology Review, 25*(3), 341–63. doi:10.1016/j.cpr.2004.12.004
- Joubert, K., & Githinji, E. (2014). Quality and readability of information pamphlets on hearing and paediatric hearing loss in the Gauteng Province, South Africa. *International Journal of Pediatric Otorhinolaryngology, 78*(2), 10–14. doi:10.1016/j.ijporl.2013.12.018
- Kahn, A., & Pannbacker, M. (2000). Readability of educational materials for clients with cleft lip / palate and their families. *American Journal of Speech-Language Pathology, 9*, 3–9. doi:10.1044/1058-0360.0901.03
- Karnieli-Miller, O., Adler, A., Merdler, L., Rosenfeld, L., & Eidelman, S. (2009). Written notification of test results: meanings, comprehension and implication on patients' health behavior. *Patient Education and Counseling, 76*(3), 341–7. doi:10.1016/j.pec.2009.07.021

- Kelly, L. J. (1996). The readability of hearing aid brochures. *Journal of the Academy of Rehabilitative Audiology*, 29, 41–47. Retrieved from <http://www.audrehab.org/jara.htm>
- Kelly, L. J., & Kahn, A. (1991). Illiteracy and hearing loss management: the readability of clinic forms. *Journal of the Academy of Rehabilitative Audiology*, 24, 35–42.
- Kessels, R. P. C. (2003). Patients' memory for medical information. *Journal of the Royal Society of Medicine*, 96(5), 219–22. Retrieved from <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=539473&tool=pmcentrez&endertype=abstract>
- Khoza-Shangase, K., Barratt, J., & Jonosky, J. (2010). Protocols for early audiology intervention services : Views from early intervention practitioners in a developing country. *SA Journal of Child Health*, 4(4), 100–105. Retrieved from <http://www.ajol.info/index.php/sajchh/article/view/69993>
- Kickbusch, I., & Maag, D. (2008). Health literacy. In K. Heggenhougen & S. Quah (Eds.), *International encyclopedia of public health* (Vol 3., pp. 204–211). Retrieved from <http://www.ilonakickbusch.com/kickbusch-wAssets/docs/kickbusch-maag.pdf>
- Kickbusch, I., Pelikan, J. M., Apfel, F., & Tsouros, A. D. (2013). *Health literacy The solid facts*. Retrieved from [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0008/190655/e96854.pdf?ua=1](http://www.euro.who.int/__data/assets/pdf_file/0008/190655/e96854.pdf?ua=1)
- Kickbusch, I. S. (2001). Health literacy : addressing the health and education divide. *Health Promotion International*, 16(3). doi:10.1093/heapro/16.3.289
- Klingbeil, C., Speece, M. W., & Schubiner, H. (1995). Readability of pediatric patient education materials: Current perspectives on an old problem. *Clinical Pediatrics*, 34(2), 96–102. doi:10.1177/000992289503400206
- Knudsen, L. V, Laplante-Lévesque, A., Jones, L., Preminger, J. E., Nielsen, C., Lunner, T., ... Kramer, S. E. (2012). Conducting qualitative research in audiology: a tutorial. *International Journal of Audiology*, 51(2), 83–92. doi:10.3109/14992027.2011.606283
- Kumar, D., Sanders, L., Perrin, E. M., Lokker, N., Patterson, B., Gunn, V., ... Rothman, R. L. (2010). Parental understanding of infant health information: health literacy, numeracy, and the Parental Health Literacy Activities Test (PHLAT). *Academic Pediatrics*, 10(5), 309–16. doi:10.1016/j.acap.2010.06.007
- Kurtzer-White, E., & Luterman, D. (2003). Families and children with hearing loss: grief and coping. *Mental Retardation and Developmental Disabilities Research Reviews*, 9(4), 232–5. doi:10.1002/mrdd.10085
- Lane, P., Blanco, M., Ford, L., & Smith Mirenda, H. (2005). *The Health Literacy Style Manual*. Columbia, SC: Covering Kids & Families National Program Office. Retrieved from <http://libguides.rutgers.edu/content.php?pid=479328&sid=3926944>
- Laplante-Lévesque, A., Brännström, K. J., Andersson, G., & Lunner, T. (2012). Quality and readability of English-language internet information for adults with hearing impairment

- and their significant others. *International Journal of Audiology*, 51(8), 618–26.  
doi:10.3109/14992027.2012.684406
- Larsen, R., Munoz, K., DesGeorges, J., Nelson, L., & Kennedy, S. (2012). Early hearing detection and intervention: Parent experiences with the diagnostic hearing assessment. *American Journal of Audiology*, 21, 91–99. doi:10.1044/1059-0889(2012/11-0016)b
- Levandowski, B. A., Sharma, P., Lane, S. D., Webster, N., Nestor, A. M., Cibula, D. A., & Huntington, S. (2006). Parental literacy and infant health: an evidence-based healthy start intervention. *Health Promotion Practice*, 7(1), 95–102.  
doi:10.1177/1524839904266517
- Ley, P., & Florio, T. (1996). The use of readability formulas in health care. *Psychology, Health & Medicine*, 1(1), 7–28. doi:10.1080/13548509608400003
- Luterman, D., & Kurtzer-White, E. (1999). Identifying hearing loss: parents' needs. *American Journal of Audiology*, 8(1), 13–8. doi:10.1044/1059-0889(1999/006)
- Madell, J. R., & Flexer, C. (2008). Hearing test protocols for children. In J. R. Madell & C. Flexer (Eds.), *Pediatric Audiology Diagnosis, Technology, and Management* (pp. 45–53). NY: Thieme Medical Publishers.
- Markides, A. (1986). Age at fitting of hearing aids and speech intelligibility. *British Journal of Audiology*, 20, 165–167.
- Marks, R., Allegrante, J. P., & Lorig, K. (2005). A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing chronic disability: implications for health education practice (part II). *Health Promotion Practice*, 6(2), 148–56.  
doi:10.1177/1524839904266792
- Martin, F. N., & Clark, J. G. (2012). *Introduction to audiology*. New Jersey: Pearson Education Inc.
- Martin, F. N., George, K. A., O'Neal, J., & Daly, J. A. (1987). Audiologists' and parents' attitudes regarding counseling of families of hearing-impaired children. *ASHA*, 27, 27–33.
- McGee, J. (2010). *Toolkit for making written material clear and effective*. U.S Department of Health and Human Services, Center for Medicare and Medicaid Services. Retrieved from <http://www.cms.gov/Outreach-and-Education/Outreach/WrittenMaterialsToolkit/index.html>
- McLeod, S., & McCormack, J. (2007). Application of the ICF and ICF-Children and Youth in children with speech impairment. *Seminars in Speech and Language*, 28(4), 254–264. Retrieved from <https://www-thieme-connect-de.ezproxy.canterbury.ac.nz/products/ejournals/pdf/10.1055/s-2007-986522.pdf>
- McLeod, S., & Threats, T. T. (2008). The ICF-CY and children with communication disabilities. *International Journal of Speech-Language Pathology*, 10(1-2), 92–109.  
doi:10.1080/17549500701834690

- Meade, C. D., & Smith, C. F. (1991). Readability formulas: Cautions and criteria. *Patient Education and Counseling Journal*, 17, 153–158.
- Miller, M. J., DeWitt, J. E., McCleary, E. M., & O’Keefe, K. J. (2009). Application of the cloze procedure to evaluate comprehension and demonstrate rewriting of pharmacy educational materials. *The Annals of Pharmacotherapy*, 43(4), 650–7. doi:10.1345/aph.1L642
- Ministry of Health. (2010). *Kōrero Mārama: Health Literacy and Māori Results from the 2006 Adult Literacy and Life Skills Survey*. Retrieved from <http://www.health.govt.nz/system/files/documents/publications/korero-marama.pdf>
- Ministry of Health. (2012). *Rauemi Atawhai a guide to developing health education resources in New Zealand*. Retrieved from <http://www.health.govt.nz/system/files/documents/publications/rauemiatawhai4web.pdf>
- Ministry of Health. (2013a). *Universal Newborn Hearing Screening and Early Intervention Programme National Policy and Quality Standards Appendix F : Diagnostic and amplification protocols*. Retrieved from <https://www.nsu.govt.nz/files/UNHSEIP-appendix-F-jun13.pdf>
- Ministry of Health. (2013b). *Well Child / Tamariki Ora Programme Practitioner Handbook: Supporting families and whānau to promote their child’s health and development- Revised 2014*. Retrieved from [http://www.health.govt.nz/system/files/documents/publications/well-child-tamariki-ora-programme-practitioner-handbook-v2-apr14\\_1.pdf](http://www.health.govt.nz/system/files/documents/publications/well-child-tamariki-ora-programme-practitioner-handbook-v2-apr14_1.pdf)
- Moeller, M. P. (2000). Early intervention and language development in children who are deaf and hard of hearing. *Pediatrics*, 106(3), e43–e43. doi:10.1542/peds.106.3.e43
- Mohr, P. E., Feldman, J. J., Dunbar, J. L., McConkey-Robbins, A., Niparko, J. K., Rittenhouse, R. K., & Skinner, M. W. (2000). The societal costs of severe to profound hearing loss in the United States. *International Journal of Technology Assessment in Health Care*, 16(4), 1120–1135.
- Moores, D. F., Jatho, J., & Dunn, C. (2001). Families with deaf members : American annals of the deaf, 1996 to 2000. *American Annals of the Deaf*, 146(3), 245–250. Retrieved from [http://muse.jhu.edu/journals/american\\_annals\\_of\\_the\\_deaf/](http://muse.jhu.edu/journals/american_annals_of_the_deaf/)
- National Institutes of Health. (2013). How to write easy-to-read health materials. Retrieved June 26, 2014, from <http://www.nlm.nih.gov/medlineplus/etr.html>
- National Screening Unit. (2009). *Universal newborn hearing screening and early intervention programme (UNHSEIP): Monitoring framework*. Retrieved from [http://www.nsu.govt.nz/files/UNHSEIP\\_Monitoring\\_Framework\\_pdf.pdf](http://www.nsu.govt.nz/files/UNHSEIP_Monitoring_Framework_pdf.pdf)
- Northern, J. L., & Downs, M. P. (2014). *Hearing in Children* (Sixth ed.). Philadelphia, PA: Williams & Wilkins.

- Nutbeam, D. O. N. (2006). Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International, 15*(3), 259–268. doi:10.1093/heapro/15.3.259
- O'Mahony, E. A., & Kalk, N. J. (2011). More can be done to improve readability of patient letters. *The Psychiatrist, 35*(1), 30–30. doi:10.1192/pb.35.1.30
- Oleander. (2014). Readability Studio. [Computer software]. Oleander Software.
- Oller, J. (1972). Scoring methods and difficulty levels for cloze tests of proficiency in English as a second language. *Modern Language Journal, 56*, 151–158.
- Olusanya, B. O., & Newton, V. E. (2007). Global burden of childhood hearing impairment and disease control priorities for developing countries. *Lancet, 369*(9569), 1314–7. doi:10.1016/S0140-6736(07)60602-3
- Parikh, N. S., Parker, R. M., Nurss, J. R., Baker, D. W., & Williams, M. V. (1996). Shame and health literacy: the unspoken connection. *Patient Education and Counseling, 27*(1), 33–9. Retrieved from <http://www.jgim.org/>
- Parker, R. M., Baker, D. W., Williams, M. V., & Nurss, J. R. (1995). The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine, 10*, 537–541.
- Parving, A., & Christensen, B. (1993). Training and employment in hearing-impaired subjects at 20-35 years of age. *Scandinavian Audiology, 22*(2), 133–9.
- Paul, P. V., & Whitelaw, G. M. (2011). *Hearing and Deafness an introduction for health and education professionals*. Massachusetts, MA: Jones and Bartlett Publishers, LLC.
- PLAIN. (2011). Federal Plain Language Guidelines. Retrieved from <http://www.plainlanguage.gov/howto/guidelines/FederalPLGuidelines/index.cfm>
- Plain English Power. (2010). It's the law: legal aspects of plain English in New Zealand. Retrieved September 06, 2014, from <http://www.plainenglish.org.nz/law.php>
- Pothier, L., Day, R., Harris, C., & Pothier, D. D. (2008). Readability statistics of patient information leaflets in a Speech and Language Therapy Department. *International Journal of Language & Communication Disorders, 43*(6), 712–722. doi:10.1080/13682820701726647
- Pretto, A., & Harrison, M. (2011). Family-centred approaches. In R. Seewald & A. M. Tharpe (Eds.), *Comprehensive Handbook of Pediatric Audiology*. San Diego, CA: Plural Publishing, Inc.
- Ranji, U., & Salganicoff, A. (2014). *Balancing on Shaky Ground: Women, Work, and Family Health*. Kasier Family Foundation. Retrieved from <http://kff.org/womens-health-policy/issue-brief/data-note-balancing-on-shaky-ground-women-work-and-family-health/>

- Rattray, J., & Jones, M. C. (2007). Essential elements of questionnaire design and development. *Journal of Clinical Nursing*, *16*, 234–243.
- Rudd, R. E., Moeykens, B. A., & Colton, T. C. (1999). Health and Literacy : A Review of Medical and Public Health Literature. *Office of Educational Research and Improvement*, *1*, 1-41.
- Rush, T. R. (1985). Assessing readability: Formulas and alternatives. *The Reading Teacher*, *39*(3), 274–283.
- Russ, S. A., Kuo, A. A., Poulakis, Z., Barker, M., Ricakrds, F., Saunders, K., ... Oberklaid, F. (2004). Qualitative analysis of parents' experience with early detection of hearing loss. *Archives of Disease in Childhood*, *89*(4), 353–358. doi:10.1136/adc.2002.024125
- Safeer, R. S., & Keenan, J. (2005). Health literacy: the gap between physicians and patients. *American Family Physician*, *72*(3), 463–8. Retrieved from <http://www.aafp.org/journals/afp>.
- Sakai, Y. (2013). The role of readability in effective health communication: an experiment using a Japanese health information text on chronic suppurative otitis media. *Health Information and Libraries Journal*, *30*(3), 220–31. doi:10.1111/hir.12022
- Sanders, L. M. (2010). Health literacy and the health reform: Where do children fit in?, 101–114. Retrieved from <http://www.healthliteracy.org.nz/resource/>
- Sass-Lehrer, M. (2004). Early detection of hearing loss: Maintaining a family-centered perspective. *Seminars in Hearing*, *25*(4).
- Scarinci, N., Worrall, L., & Hickson, L. (2012). Factors associaed with third-party disability in spouses of older people with hearing impairment. *Ear and Hearing*, *33*(6), 698–708. doi:10.1097/AUD.0b013e31825aab39
- Schrijver, I. (2004). Hereditary non-syndromic sensorineural hearing loss. *Journal of Molecular Diagnostics*, *6*(4), 275–284.
- Shapiro, D. E., Boggs, S. R., Melamed, B. G., & Graham-Pole, J. (1992). The effect of varied physician affect on recall, anxiety, and perceptions in women at risk for breast cancer: an analogue study. *Health Psychology : Official Journal of the Division of Health Psychology, American Psychological Association*, *11*(1), 61–6. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/1559536>
- Shieh, C., & Hosei, B. (2008). Printed health information materials: evaluation of readability and suitability. *Journal of Community Health Nursing*, *25*(2), 73–90. doi:10.1080/07370010802017083
- Shoemaker, S. J., Wolf, M. S., & Brach, C. (2014). Development of the Patient Education Materials Assessment Tool (PEMAT): A new measure of understandability and actionability for print and audiovisual patient information. *Patient Education and Counseling*, *96*(3), 395–403. doi:10.1016/j.pec.2014.05.027



- Shulman, S., Besculides, M., Saltzman, A., Ireys, H., White, K. R., & Forsman, I. (2010). Evaluation of the universal newborn hearing screening and intervention program. *Pediatrics*, *126*(S19), S19–27. doi:10.1542/peds.2010-0354F
- Singham, M. (2006). Multiculturalism in New Zealand – the need for a new paradigm. *Aotearoa Ethnic Network Journal*, *1*(1), 33–37. Retrieved from <http://www.aen.org.nz/journal/>
- Smiler, K. (2006). *Refocusing successful interventions for Maori deaf and hearing impaired children*. Retrieved from [http://www.hrc.govt.nz/sites/default/files/HRC80 \(Smiler\).pdf](http://www.hrc.govt.nz/sites/default/files/HRC80%20(Smiler).pdf)
- Smith, F., Carlsson, E., Kokkinakis, D., Forsberg, M., Kodeda, K., Sawatzky, R., ... Öhlén, J. (2014). Readability, suitability and comprehensibility in patient education materials for Swedish patients with colorectal cancer undergoing elective surgery: a mixed method design. *Patient Education and Counseling*, *94*(2), 202–9. doi:10.1016/j.pec.2013.10.009
- Smith, R. J. H., Bale, J. F., & White, K. R. (2005). Sensorineural hearing loss in children. *Lancet*, *365*(9462), 879–90. doi:10.1016/S0140-6736(05)71047-3
- Speros, C. (2005). Health literacy: concept analysis. *Journal of Advanced Nursing*, *50*(6), 633–40. doi:10.1111/j.1365-2648.2005.03448.x
- Spork, H. (2006). *Face to Face: the experiences, decisions, issues, and needs of parents who have a child who is deaf or has a hearing loss*. Retrieved from [http://www.health.qld.gov.au/healthyhearing/docs/hearing\\_report.pdf](http://www.health.qld.gov.au/healthyhearing/docs/hearing_report.pdf)
- Stach, B. A., & Ramachandran, V. S. (2008). Hearing disorders in children. In J. R. Madell & C. Flexer (Eds.), *Pediatric Audiology diagnosis, technology, and management* (pp. 3–12). New York: Thieme Medical Publishers.
- Staples, D. (1991). Questionnaires. *Clinical Rehabilitation*, *5*(4), 259–264.
- Statistics New Zealand Tatauranga Aotearoa. (2012). *Births and Deaths: Year ended March 2011*. Retrieved from <http://www.stats.govt.nz/>
- Statistics New Zealand Tatauranga Aotearoa. (2013). *Caring for children: Findings from the 2009/10 Time Use Survey*. Retrieved from [www.stats.govt.nz](http://www.stats.govt.nz)
- Statistics New Zealand Tatauranga Aotearoa. (2014). *2013 Census QuickStats about culture and identity*. Retrieved from [www.stats.govt.nz](http://www.stats.govt.nz)
- Stephens, C. (2000). All about readability. Retrieved from <http://plainlanguage.com/newreadability.html>
- Stevens, G., Flaxman, S., Brunskill, E., Mascarenhas, M., Mathers, C. D., & Finucane, M. (2013). Global and regional hearing impairment prevalence: an analysis of 42 studies in 29 countries. *European Journal of Public Health*, *23*(1), 146–52. doi:10.1093/eurpub/ckr176

- Stinson, M. S., Whitmire, K., & Kluwin, T. N. (1996). Self-Perceptions of Social Relationships in Hearing-Impaired Adolescents. *Journal of Educational Psychology*, 88(1), 132–143. Retrieved from <http://www.apa.org/pubs/journals/edu/>
- Swartz, E. N. (2010). The readability of pediatric patient information materials : Are families satisfied with our handouts and brochures. *Paediatrics and Child Health*, 15(8), 509–513. Retrieved from <http://www.paediatricsandchildhealthjournal.co.uk/>
- Tang, P. C., & Newcomb, C. (1998). Informing Patients: A guide for providing patient health information. *Journal of the American Medical Informatics Association*, 5(6), 563–570.
- Tattersall, H., & Young, A. (2006). Deaf children identified through newborn hearing screening: parents' experiences of the diagnostic process. *Child: Care, Health and Development*, 32(1), 33–45. doi:10.1111/j.1365-2214.2006.00596.x
- Taylor, W. L. (1953). Cloze procedure: A new tool for measuring readability. *Journalism Quarterly*, 30, 415–433.
- Tharpe, A. M., & Bess, F. H. (1991). Identification and management of children with minimal hearing loss. *International Journal of Pediatric Otorhinolaryngology*, 21(1), 41–50. doi:10.1016/0165-5876(91)90058-J
- Wallhagen, M. I., Strawbridge, W. J., Shema, S. J., & Kaplan, G. a. (2004). Impact of self-assessed hearing loss on a spouse: a longitudinal analysis of couples. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 59(3), S190–6. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/15118025>
- Waltzman, S. B., & Roland, J. T. (2005). Cochlear implantation in children younger than 12 months. *Pediatrics*, 116(4), e487–93. doi:10.1542/peds.2005-0282
- Wang, L.-W., Miller, M. J., Schmitt, M. R., & Wen, F. K. (2013). Assessing readability formula differences with written health information materials: application, results, and recommendations. *Research in Social & Administrative Pharmacy : RSAP*, 9(5), 503–16. doi:10.1016/j.sapharm.2012.05.009
- Waterston, T., & San Lazaro, C. (1994). Sending parents outpatient letters about their children: parents' and general practitioners' views. *Quality in Health Care : QHC*, 3(3), 142–6. Retrieved from <http://qualitysafety.bmj.com/content/3/3/142.short>
- Wilson, E. a H., & Park, D. C. (2008). A case for clarity in the writing of health statements. *Patient Education and Counseling*, 72(2), 330–5. doi:10.1016/j.pec.2008.02.008
- Workbase. (2013). *Literature review of health literacy education , training tools and resources for health providers*. Retrieved from <http://www.healthliteracy.org.nz/resource/literature-review-of-health-literacy-education-training-tools-and-resources-for-health-providers-nz/>
- World Health Organization. (1998). *Health Promotion Glossary*. Geneva. Retrieved from <http://www.who.int/healthpromotion/>

- World Health Organization. (2001). *International Classification of Functioning, Disability and Health, ICF*. Geneva: World Health Organization.
- World Health Organization. (2002). *Towards a Common Language for Functioning, Disability and Health ICF*. Retrieved from <http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf>
- World Health Organization. (2012). *WHO global estimates on prevalence of hearing loss*. Retrieved from <http://www.who.int/pbd/en/>
- Yin, H. S., Forbis, S. G., & Dreyer, B. P. (2007). Health literacy and pediatric health. *Current Problems in Pediatric and Adolescent Health Care*, 37(7), 258–86. doi:10.1016/j.cppeds.2007.04.002
- Yin, H. S., Gupta, R. S., Tomopoulos, S., Wolf, M. S., Mendelsohn, A. L., Antler, L., ... Dreyer, B. P. (2013). Readability, suitability, and characteristics of asthma action plans: examination of factors that may impair understanding. *Pediatrics*, 131(1), e116–26. doi:10.1542/peds.2012-0612
- Yin, H. S., Johnson, M., Mendelsohn, A. L., Abrams, M. A., Sanders, L. M., & Dreyer, B. P. (2009). The health literacy of parents in the United States: a nationally representative study. *Pediatrics*, 124 Suppl , S289–98. doi:10.1542/peds.2009-1162E
- Yoshinaga-Itano, C., Coulter, D., & Thomson, V. (2000). The Colorado newborn hearing screening project: Effects on speech and language development for children with hearing loss. *Journal of Perinatology: Official Journal of the California Perinatal Association*, 20(8(Pt2)), S132–137.
- Yoshinaga-Itano, C., Sedey, A. L., Coulter, D. K., & Mehl, A. L. (1998). Language of early- and later-identified children with hearing loss. *Pediatrics*, 5, 1161–1171.
- Young, A., & Tattersall, H. (2005). Parents' of deaf children evaluative accounts of the process and practice of universal newborn hearing screening. *Journal of Deaf Studies and Deaf Education*, 10(2), 134–45. doi:10.1093/deafed/eni014
- Zeng, F., Kong, Y., Michalewski, H. J., & Starr, A. (2005). Perceptual Consequences of Disrupted Auditory Nerve Activity. *Journal of Neurophysiology*, 96(3), 3050–3063. doi:10.1152/jn.00985.2004.
- Zeng-Treitler, Q., Kim, H., Goryachev, S., Keselman, A., Slaughter, L., & Arnott Smith, C. (2007). Text characteristics of clinical reports and their implications for the readability of personal health records. *Studies in Health Technology and Informatics*, 129(Pt 2)(pp. 1117–1121).

## APPENDIX A:

### *RECOMMENDED STRATEGIES FOR IMPROVING WRITTEN PATIENT EDUCATION MATERIALS*

---

<b>Element</b>	<b>Factor to improve readability</b>
<i>Language</i>	<p>Ensure readability of the document is at or below sixth grade reading level (Caposecco et al., 2011).</p> <p>Link new information to patient's prior knowledge to help introduce foreign concepts and terms (Lane et al., 2005).</p> <p>Write text in active rather than passive voice (D'Alessandro et al., 2001; Sakai, 2013).</p> <p>Avoid using negatively worded statements (Wilson &amp; Park, 2008).</p> <p>Use short paragraphs (&lt;4-5 lines) (Arnold et al., 2006) which cover only one idea per paragraph (PLAIN, 2011) .</p> <p>Write sentences which are short (8-10 words) and which use a simple structure (Caposecco et al., 2011; D'Alessandro et al., 2001; Joubert &amp; Githinji, 2013; Maximus, 2005).</p> <p>Use simple vocabulary with common, short words (1-2 syllables) (Osborne, 2013).</p> <p>Avoid using jargon, technical language, abbreviations and unnecessary acronyms (Caposecco et al., 2011; D'Alessandro et al., 2001; Hoffmann &amp; Worrall, 2004; Joubert &amp; Githinji, 2014).</p> <p>When it is necessary to use medical or unfamiliar terms, define and explain them clearly. Supplement with examples where possible to help clarify complex or unfamiliar concepts and terminology, and help the readers engage with the text (D'Alessandro et al., 2001; PLAIN, 2011; Sakai, 2013).</p> <p>Use terms and phrases consistently (PLAIN, 2011).</p> <p>Include a glossary to help readers understand unfamiliar terminology or concepts, positioned at the end of the document in alphabetical order (D'Alessandro et al., 2001 &amp; Jelley &amp; Walker, 2003, PLAIN, 2011).</p>
<i>Content</i>	<p>Ensure the information being reported is current and accurate (Hoffmann &amp; Worrall, 2004; McGee, 2010).</p> <p>Avoid providing unnecessary or overwhelming information to ensure the overall message is clear (Arnold et al., 2006).</p> <p>Use personal pronouns and personalise some of the information so the individual can understand how the information relates to them (Arnold et al., 2006; Caposecco et al., 2011; Centers for Disease Control and Prevention, 2009).</p>

---

Include other sources of information that parents may refer to, such as links to explanatory websites or scientific information (Jelley & Walker, 2003; Joubert & Githinji, 2014).

Provide details of who patients can contact to help explain the document (Lane et al., 2005).

Ensure information is non-judgmental and culturally appropriate (Hoffman & Worrall, 2004).

---

<i>Organisation</i>	<p>Present the most important information first, and include more specific details later (Caposecco et al., 2011).</p> <p>Organise information so it quickly and easily answer the concerns of patients (PLAIN, 2011).</p> <p>Use headings and subheadings (including “question headings”) to segregate and highlight information (Caposecco et al., 2011; Jelley &amp; Walker, 2003; PLAIN, 2011).</p> <p>Use summary paragraphs at the end of each section and/or end of the document to reinforce key information (Caposecco et al., 2011; Lane et al., 2005).</p> <p>Use numbers or bullet points to provide order to the document (Hoffmann &amp; Worrall, 2004; Lane et al., 2005).</p>
<i>Layout/ typography</i>	<p>Select simple and familiar fonts and do not use more than two types per document. Use serif font for text and san serif for headings (McGee, 2010).</p> <p>Use size 11-13 font (Lane et al., 2005).</p> <p>Use left text alignment to minimise reader confusion (Lane et al., 2005; McGee, 2010).</p> <p>Use bold to emphasise words and phrases, but limit the use of italics, underlining and capital letters (Caposecco et al., 2011; Lane et al., 2005).</p> <p>Limit the amount of text and graphics on the page to provide at least 10-35% of white space (Arnold et al., 2006)</p> <p>Use colour to highlight, draw attention to, clarify or differentiate key concepts (Doak et al., 1996).</p>
<i>Graphics</i>	<p>Include graphics to aid reader understanding, but ensure that they are:</p> <ol style="list-style-type: none"><li>i. Simple, realistic and avoid unnecessary details (Arnold et al., 2006; Centers for Disease Control and Prevention, 2009);</li><li>ii. Culturally relevant and sensitive (Centers for Disease Control and Prevention, 2009);</li><li>iii. Positioned near relevant text (Joubert &amp; Githinji, 2014);</li><li>iv. Clearly labelled with captions and explanatory arrows (Caposecco et al., 2011; Osborne 2013).</li></ol>

---

## APPENDIX B: *EVALUATION STAGE*

---

### B.1 Ethical approval letter, University of Canterbury Human Ethics Committee



HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen  
Email: [human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)

Ref: HEC 2014/16

30 April 2014

Ashleigh Donald  
Department of Communication Disorders  
UNIVERSITY OF CANTERBURY

Dear Ashleigh

The Human Ethics Committee advises that your research proposal "Readability and comprehensibility of audiological reports provided to New Zealand caregivers of hearing impaired children" has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 29 April 2014.

Best wishes for your project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'L. MacDonald'.

Lindsey MacDonald  
*Chair*  
*University of Canterbury Human Ethics Committee*

## B.2 Study advertisement



## ARE YOU A CAREGIVER OF A CHILD AGED 0-5 YEARS?

### WE NEED YOUR HELP!

Approximately 245 children are diagnosed with a hearing loss in New Zealand every year. It is normal to provide caregivers of these children with written reports from an audiologist explaining the child's hearing loss. We are interested in the opinions of caregivers like yourself about how understandable and easy to read these reports are. We hope that information from this study will help us ensure that reports are providing parents with the clear and easy to understand information that they need.

To take part in this research or for more information, please contact:

Ashleigh Donald /  
Dr Rebecca Kelly-Campbell  
(03) 364-2987 ext. 8327  
OR  
aj1d8c@ucdive.ac.nz

Ashleigh Donald /  
Dr Rebecca Kelly-Campbell  
(03) 364-2987 ext. 8327  
OR  
aj1d8c@ucdive.ac.nz

Ashleigh Donald /  
Dr Rebecca Kelly-Campbell  
(03) 364-2987 ext. 8327  
OR  
aj1d8c@ucdive.ac.nz

Ashleigh Donald /  
Dr Rebecca Kelly-Campbell  
(03) 364-2987 ext. 8327  
OR  
aj1d8c@ucdive.ac.nz

### Who do we need?

Caregivers aged 18 years or older who:

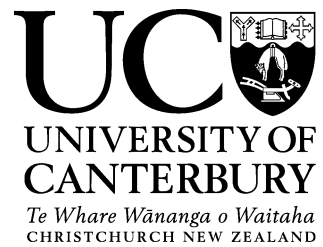
- ✓ Have at least one child between 0-5 years.
- ✓ Are of any gender, marital, employment and educational status
- ✓ Have no experience with hearing impairment

### What do you need to do?

- ✓ Read a typical 400-word report that is sent to parents
- ✓ Participate in a short interview asking your opinions about the report. The interview will be arranged for a time that suits you either over the telephone or at Canterbury University (you are welcome to bring your child(ren) with you)
- ✓ You will receive a Petrol or supermarket voucher for your participation and time.

### B.3 Information sheet

University of Canterbury  
Department of Communication Disorders  
Private Bag 4800  
Christchurch 8140  
New Zealand



#### STUDY INFORMATION

You are invited to participate as a participant in the research project entitled **“Readability and Comprehensibility of Audiological Reports provided to New Zealand Caregivers of Hearing Impaired Children.”**

The aim of this Masters project is to investigate the readability and comprehensibility of audiology reports written to caregivers of newly diagnosed hearing impaired children are. Previous research suggests that written materials provided to parents within the healthcare domain are often at a level that is difficult for the average adult to understand. Furthermore, the readability of such written materials is a known contributor to an individual’s health literacy; in that complex texts may reduce health literacy. Because low health literacy is associated with poorer health outcomes, it is imperative that the reports we write are clear and easy to understand for caregivers. No research has been done on the readability of audiology reports, and New Zealand research in the health literacy domain is also lacking. It is hoped that information from this research may be used to improve audiology reports in New Zealand.

Your involvement in this project will include: (1) filling in a questionnaire about yourself that you will receive in the mail, (2) reading a mock diagnostic audiology report that you will also receive in the mail, and (3) participating in a recorded structured interview regarding your opinions and comprehension of the report. You will have the choice of participating in the interview either over the telephone or at the University of Canterbury. If you wish to participate in the interview at the University, you are welcome to bring your child(ren) along with you. You will also be provided with a petrol voucher, regardless of how you prefer the interview to be conducted.

You will have the opportunity to review the transcript from your interview at any time. You have the right to withdraw from the project at any time, including withdrawal of any information you have provided. Your involvement (or withdrawal) in this project will not affect how you or your children are treated within the audiology field of health.



You will be asked to read the audiology diagnostic report as if it was written for your own child, and will be then asked about your feelings and opinions about the report. The risk of participating in this study includes the possibility of feeling distressed as you read the report and participate in the interview. A list of available support services is provided at the end of this document.

The results of the project may be published, but you may be assured of the complete confidentiality of data gathered in this investigation. To ensure confidentiality, your name will not be used on your information sheet or during the structured interview. In both situations you will be given a participant number and referred to only by this. In addition, the consent form will be kept in a locked cabinet in a locked room in the Department of Communication Disorders on the University of Canterbury campus in Christchurch, New Zealand. The audio recording of the interview and any other electronic data will be kept on password-protected computers that are stored in a locked room in the Department of Communication Disorders on the University of Canterbury campus in Christchurch, New Zealand.

This project is being carried out by Ashleigh Donald, a Master of Audiology student at the University of Canterbury and is being supervised by Dr Rebecca Kelly-Campbell. Either Ashleigh or Rebecca will be pleased to discuss any concerns or questions you may have about participating in the project and may be reached on 64 (3) 364-2987 ext. 8327.

The project and been reviewed **and approved** by the University of Canterbury Human Ethics Committee. The Human Ethics Committee can be contacted at University of Canterbury, Okeover House, Christchurch and on 03-364-2987.

Available support services:

LifeLine

09 5222999 (within Auckland)

0800 543 345 (outside Auckland)

<http://www.lifeline.org.nz/>

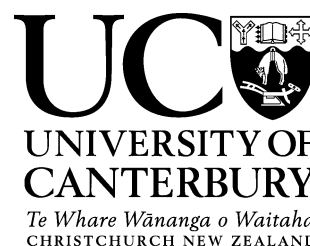
New Zealand Association of Counsellors

[http://nzac.org.nz/nzac\\_counsellor\\_search.cfm](http://nzac.org.nz/nzac_counsellor_search.cfm)

07 834 0220 (National Office)

## B.4 Consent form

University of Canterbury  
Department of Communication Disorders  
Private Bag 4800  
Christchurch 8140  
New Zealand



Researchers: Rebecca Kelly-Campbell, Ashleigh Donald

Contact address: University of Canterbury  
Department of Communication Disorders  
Private Bag 4800  
Christchurch 8140  
New Zealand

Date:

Consent Form

### **“Readability and Comprehensibility of Audiological Reports provided to New Zealand Caregivers of Hearing Impaired Children.”**

I have read and understood the description of the above-named Master’s project. On this basis, I agree to participate as a subject in the project, and I consent to publication of the results of the project with the understanding that anonymity will be preserved.

I understand also that I may at any time withdraw from the project, including withdrawal of any information I have provided.

I note that the project has been reviewed **and approved** by the University of Canterbury Human Ethics Committee.

Name: (please print): \_\_\_\_\_

Would you like to receive a summary of the results of the project? *(Please tick):*

\_\_\_\_\_ Yes    \_\_\_\_\_ No

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## B.5 Demographic questionnaire

University of Canterbury  
Department of Communication Disorders  
Private Bag 4800  
Christchurch 8140  
New Zealand



### QUESTIONNAIRE

ID number: \_\_\_\_\_  
(For the researcher to complete)

*Please answer the following questions*

1. Gender:

Male       Female

2. Years of age:

\_\_\_\_\_

3. What is your current marital status:

Single (never married)       Widowed  
 Married       Divorced  
 In a committed relationship       Separated

4. Which ethnic group do you belong to?

New Zealand European       Maori  
 Samoan       Cook Island Maori  
 Tongan       Niuean  
 Chinese       Indian  
 Other such as Dutch, Japanese or Tokelauan. Please state: \_\_\_\_\_

5. How many children do you have under your care?

---

6. What is the age of each child?

---

7. What is your relationship to each child?

---

8. How many years of education have you completed?

---

9. What is your highest qualification? (*E.g. NCEA/school certificate, degree/diploma, trade certificate etc.*)

---

10. What is your occupation?

---

## B.6 Original mock paediatric audiology diagnostic report

04/03/2014

Jane Eyre  
Newborn Hearing Screening  
Level 5  
CHRISTCHURCH WOMENS' HOSPITAL

Dear Jane,

<b>Re</b>	<b>Oliver TWIST</b>	<b>DOB</b>	<b>8/01/2014</b>
	<b>567 Titanic Road</b>	<b>Gender</b>	<b>Male</b>
	<b>New Brighton</b>	<b>NHI Number</b>	<b>ABC1234</b>

Thank you for referring Oliver who was seen for audiological assessment on 4 March 2014 following a bilateral refer result from his newborn hearing screen. Today, his mother Julie reported that she has some concerns about Oliver's hearing as he will not always turn to voices; although he does startle to loud sounds like slamming doors. I understand that Julie experienced a normal pregnancy and birth that were free of any complications. No ear infections or colds were reported and a family history of hearing loss was denied.

### Test Results

Otoscopy revealed a visible light reflex in both ears and clear ear canals.

Immittance audiometry performed with a 1 kHz probe tone yielded type A tympanograms in both ears, indicative of normal middle ear pressure and compliance. Ipsilateral acoustic reflexes to broadband stimuli were elicited at elevated levels of 90 dB in both ears.

Auditory Brainstem Response (ABR) audiometry was performed during natural sleep via insert earphones. Reliable responses to 500 Hz tone burst stimuli were identified down to passing levels (35 dBeHL) in both ears. Repeatable responses were found at moderately elevated levels (50 dBeHL) for 2 kHz tone-pip stimuli in both ears; and moderate-severely elevated levels (60 dBeHL) for 4 kHz stimuli bilaterally. Follow up testing via unmasked bone conduction produced repeatable responses at passable stimulus levels (30 dBeHL) at 500Hz; and repeatable responses at moderately elevated levels (50 dBeHL) at 2 kHz in both ears.

Objective measures of cochlear sensory hair cell function via Distortion Product Otoacoustic Emissions (DPOAEs) yielded a present response at 1.5 kHz and absent emissions between 2-8 kHz in the right ear. Testing in the left ear revealed absent emissions from 1.5-8 kHz. These results were considered to be consistent with the sensorineural hearing loss suggested by the acoustic reflex and ABR findings.

**Summary and recommendations:**

Overall, today's results are consistent with normal to near-normal hearing in the low frequencies, sloping to a moderate-severe sensorineural hearing loss in both ears. In light of these results we have arranged to see Oliver on the 12/03/2014 to complete testing and further discuss management options with his parents.

Kind regards,

Ashleigh Donald  
Master of Audiology Student

## B.7 Semi-structured interview schedule

How long did the report take you to read?

1. What were your initial thoughts about the report?
2. Did you feel you easily understood the content of the report?  
*If the participant does not answer these in their reply to question 3, I will use the following prompts:*
  - Did you feel you understood the language/terminology used in the report?
  - Did you feel you understood the overall message of the report?
3. What conclusions were you able to make from the report?  
*If the parent describes that the child has a hearing loss in their answer to question 4, I will proceed to question 6. If the parent does not mention the child having a hearing loss in their answer to question 4, I will continue with question 5:*
4. Does the child have a hearing loss?  
*If yes, proceed to question 6; if no, proceed to question 7.*
5. What type of hearing loss?
6. What does ABR mean?
7. What type of tympanogram did this child have?
  - a.) And what does that indicate?
8. What did you do after you had read the report?  
*If the participant does not answer these in their reply to question 4, I will use the following prompts:*
  - Did you talk to your partner?
  - Consult family members or friends?
  - Do any research on the internet?
  - Re-read the report?
9. Did you think the length of the report was acceptable?
10. As a parent, did you find the report valuable?
11. Was there any other information you would have liked to know as a parent?
  - a.) If so, what?

12. Do you think it is useful for parents to receive reports like these?

a.) Why is that?

*If the participant answered question 3 earlier suggesting that they did not easily understand the report, I will continue by asking question 14. If the participant indicated that they easily understood the content of the report, I will proceed to question 17.*

13. How do you think the report could be made more understandable?

*Depending on the answer the participant provides to question 13, I may then choose to ask some or all of the following questions to elicit more detail:*

14. Do you think the report would be improved by:

a.) Using more simplified language?

b.) Using a glossary?

c.) Placing the layperson's definition in brackets after the medical term?

d.) Providing references to good websites?

e.) Using graphics?

f.) Providing a frequently asked question and answer section?

*If the participant answered yes to two or more of the above questions I will then ask:*

15. Of these suggested improvements, what two do you personally think would help increase your understanding of the report the most?

16. Is there anything else you would like to add that you feel could help improve reports like these?



**APPENDIX C:**

***IMPLEMENTED REVISION TECHNIQUES FROM APPENDIX A AND COMPARISON BETWEEN THE TWO REPORTS***

<b>Element</b>	<b>Factor to improve readability</b>	<b>Comparison of revised and unrevised reports</b>
<i>Language</i>	Ensure readability of the document is at or below sixth RGL	The readability of the revised report is substantially improved to be below the sixth RGL as measured by the F-K formula.
	Link new information to patient’s prior knowledge to help introduce foreign concepts and terms	Although the unrevised report did not link information to the prior knowledge of parents, the revised report includes references to common sounds. Such references were employed to help parents understand the frequency and intensity dimensions.
	Write text in active rather than passive voice	The majority of passive sentences in the unrevised report are converted to active voice in the revised report.
	Use short paragraphs (<4-5 lines) which cover only one idea per paragraph	Paragraph length is inconsistent in the unrevised report, with some paragraphs covering multiple ideas. In contrast, paragraphs in the revised report are modified to present only one result or concept whenever possible.
	Write sentences which are short (8-10 words) and which use a simple structure	The readability software produced a warning stating that “a large percentage of sentences are overly long” for the unrevised report. Sentence length and complexity was notably reduced in the revised report by ensuring that only one idea was presented per sentence and limiting the number of words per sentence.
	Use simple vocabulary with common, short words (1-2 syllables)	A large proportion of the words used in the unrevised report exceeded two syllables in length. These polysyllabic words were replaced with shorter synonyms during revision.
	Avoid using jargon, technical language, abbreviations and unnecessary acronyms.	Jargon and technical language is used frequently in the unrevised report, but most unfamiliar terms are replaced or clearly defined in the revised version.
	When it is necessary to use medical or unfamiliar terms, define and explain them clearly. Supplement with examples where possible.	No definitions, explanations or examples are offered to help parents understand unfamiliar terms in the unrevised report. In the revised version, each test procedure is well explained to help parents link their knowledge from the appointment to that provided in the report.

	Include a glossary to help readers understand unfamiliar terminology or concepts.	The revised report includes a glossary with definitions listed in alphabetical order at the end of the report to further assist parent's understanding of unfamiliar terms.
<i>Content</i>	Avoid providing unnecessary or overwhelming information to ensure the overall message is clear.	Parents consistently indicated that they found the amount of information in the unrevised report to be overwhelming, and felt that the overall message was "lost" (P3). The revision process thus focused on providing only information that was "need to know", and reiterated the overall message of a permanent hearing loss.
	Use personal pronouns and personalise some of the information so the individual can understand how the information relates to them.	Although the unrevised report included personal pronouns, it was not personalised and was written in a distant manner. In contrast, the revised version provides information unique to the child's HI, including examples of common sounds equivalent to the child's degree of HI.
	Include other sources of information that parents can refer to. Suggestions include links to explanatory websites, or scientific information.	The unrevised report did not offer any other sources of information, whereas the revised report includes links to 3 different websites, with each website offering slightly different information.
<i>Organisation</i>	Present the most important information first, and include more specific details later.	In the revised report, information is presented in order of importance as opposed to the sequential order used in the unrevised report (which reflects the order of the actual appointment). Consequently, the overall HI diagnosis is mentioned early in the report.
	Organise information so that it quickly and easily answers the concerns of patients.	In contrast to the unrevised report, five "question headings" are used to organise the report so that parents can find useful information efficiently.
	Use headings and subheadings (including "question headings") to segregate and highlight information.	The revised report utilises sub-headings within the test results section to help distinguish each of the different test results.
	Use summary paragraphs at the end of each section and/or end of the document to reinforce key information (Caposecco et al., 2011; Lane et al., 2005)(Caposecco et al., 2011; Lane et al., 2005)(Caposecco et al., 2011; Lane et al., 2005)(Caposecco et al., 2011; Lane et al., 2005)	Although the unrevised report used a summary paragraph at the end of the document, the revised report includes three summaries: at the start of the report, at the end of the results section and also at the end of the document.

	2005)(Caposecco et al., 2011; Lane et al., 2005)	
	Use numbers or bullet points throughout the document	In the unrevised report, the only numbering used was page numbers. In the revised report, the results of each test were numbered and lettering was used in the ABR section. This helped distinguish the different test results to facilitate parent understanding.
<i>Layout/ typography</i>	Use bold to emphasise words and phrases, but limit the use of italics, underlining and capital letters	In addition to bolding the headings as in the unrevised report, the revised version also bolds the words “cochlear” and ‘permanent’ to highlight the fact that the hearing loss is not transient.
	Use colour to highlight, draw attention to, clarify or differentiate key concepts	While the unrevised report was not presented in colour, colour is used in the revised report to distinguish what portion of the ear each test is assessing, the different hearing levels on the audiogram and also the different sound pathways in the glossary figure.
<i>Graphics</i>	Include graphics to aid the reader’s understanding, but ensure that they are: (1) Simple, realistic and avoid unnecessary details (2) Culturally relevant and sensitive (3) Positioned near relevant text (4) Clearly labelled with captions and explanatory arrows	In contrast to the unrevised report, graphics were developed and included in the revised report. All of these were considered easy to understand, meaningful and relevant to the information provided in the text; and included explanatory captions and prompts to identify key components of the image.

**APPENDIX D:**

***COPY OF THE REVISED REPORT, ANNOTATED TO HIGHLIGHT MODIFICATIONS MADE***

---

13/03/2014

Julie Twist  
567 Titanic Road  
New Brighton  
Christchurch

Dear Julie,

<b>Re</b>	<b>Jack Bean</b>	<b>DOB</b>	<b>08/01/2014</b>
	<b>567 Titanic Road</b>	<b>Gender</b>	<b>Male</b>
	<b>New Brighton</b>	<b>NHI Number</b>	<b>ABC1234</b>

Thank you for bringing Jack in to have his hearing tested on 4 March and 13 March 2014. Jack came to us because he did not pass his newborn hearing screen.

The following report gives the results from both of these appointments. We have tried to write these in a way that is easy to understand. You will also find a copy of the medical report sent to other experts involved in Jack’s care. We have added a glossary to this report to help you understand the terms used.

Outlining what parents can expect from the report.

Included a summary earlier in the report.

**What did we find?**

Use of question headings throughout the report to help parents find the information they want to know.

Our results show us that Jack has “near normal hearing sloping to a moderately-severe hearing loss” in both ears. This means that Jack has normal or near normal hearing for [low, bass-like sounds] in both ears. For [higher, treble-like sounds], Jack’s hearing drops to a moderately-severe hearing loss in both ears. Our results point to this being a [lasting, or permanent], hearing loss.

Explanation of the configuration of the child’s hearing loss by explaining frequency in common language.

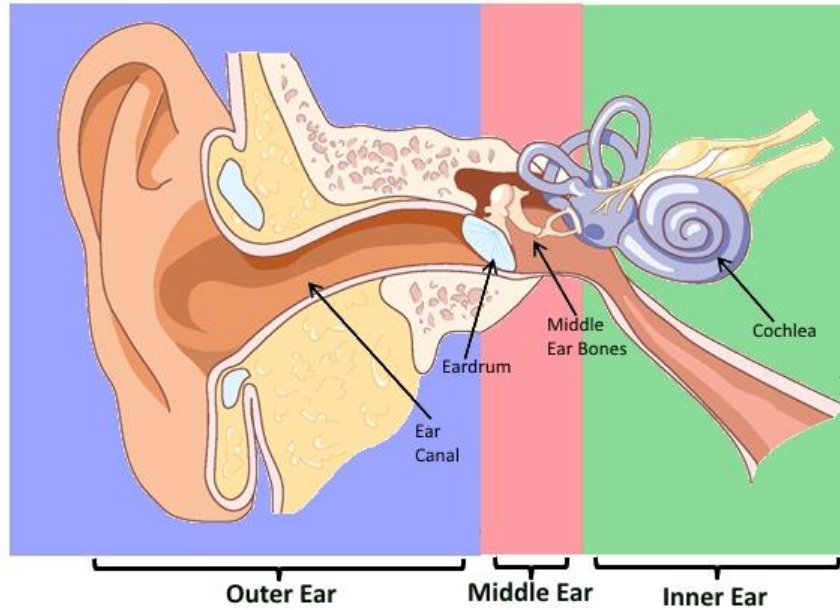
Explained that the hearing loss is permanent using common words instead of the term sensorineural

Please see the hearing chart on page 5 to help you understand how we describe hearing loss.

**Can you tell me the results of each test?**

We have given the results of each test in the order we did them at the first appointment. We have also colour coded each test to match the picture below. This helps show what part of the ear each test was looking at.

Explanation of how the results will be ordered; linking of appointment to report.



Inclusion of a figure to label the different parts of the ear and use of colour to distinguish the outer, middle and inner ear. Figure is clearly labelled and surrounded by relevant text.

Headings are coloured to match the figure above to show what part of the ear each test is assessing.

### 1. Otoscopy

First, we looked inside Jack’s ears. Both of his eardrums looked normal and healthy. We found that this was the same at both appointments.

### 2. Tympanometry

[Next, we checked how Jack’s eardrums were working. To do this, we placed a rubber tip inside his ear and sent a small puff of air down the canal. This made Jack’s eardrum move back and forth.] Our machine measured this movement and drew a shape like a [“mountain”]. [We call this a type “A”. This told us that both of Jack’s eardrums were moving normally on both days we tested them.]

Use of language common to the appointment to help parents connect their experience during the appointment to the information contained in the report.

Example of test procedure explanation.

### 3. Acoustic reflex testing

With the rubber tip in place, we also tested a reflex in Jack’s ears. The reflex causes two tiny muscles to tense in response to sounds. During this test, we play different [beeps] to see if they trigger the reflex. This can give us helpful information about Jack’s hearing.

At the first appointment, we played beeps at a “screening” [volume]. This volume should [trigger a reflex] if the hearing is normal. In Jack’s case, we found that this volume was not [loud] enough to trigger the reflex in either ear. This result agrees with Jack having a hearing loss. We did not do this test at the second appointment.

Clear explanation of what this result actually means.

Use of common language to explain a challenging concept.

While Jack was asleep, we tested his hearing in two ways:

#### 4. Distortion Product Otoacoustic Emissions (DPOAEs) test.

This test measures how well a part of Jack’s inner ear works. To test this, we [play different beeps] into Jack’s ear. If everything is working normally, we can [measure soft sounds back from his inner ear]. It is important that children are very [still and quiet] when we do this test.

Reinforcement of information parents are likely to have been told during the appointment.

On the 4/3/14, we did not measure any sounds back from Jack’s inner ear when we played the beeps. This result suggests that at least some of Jack’s inner ear is not working normally.

#### 5. Auditory Brainstem Response (ABR) test

Use of phrase audiologist likely to have used during appointment.

The ABR is our [most reliable way of testing hearing in infants]. To start, we put some sticky pads on Jack’s head. We then played Jack some sounds through both earphones and a small [box behind his ear]. The sticky pads helped us detect whether Jack heard each sound. We found that:

Explanation of the meaning behind the term “near-normal”.

Use of a lettering system to help differentiate the ABR results.

a) Jack could hear low pitch, bass-like tones (500 Hz) at a normal or near-normal loudness in both ears. [Unfortunately, we cannot say for sure that Jack’s hearing is normal at this pitch. This is because the ABR cannot measure hearing at these very quiet levels. At worst, Jack may have a mild hearing loss at this pitch. As Jack gets older, we will be able to do other tests to give us a better idea of his hearing at this pitch.]

Inclusion of both the actual frequencies tested and a common language explanation.

b) We needed to increase the loudness to a “moderate” level for Jack to hear middle pitch sounds (1000 Hz and 2000 Hz) in both ears. [This is about the same loudness as a dishwasher, or people talking in a quiet room.]

Inclusion of personalised common sound examples to offer some context to these value judgement descriptors of the HI.

c) We needed to turn the volume up to a “moderately-severe” loudness for Jack to hear high pitch sounds (4000 Hz) in both ears. [This is about the same loudness as a vacuum cleaner or people talking in a restaurant.]

d) Jack’s hearing was similar when we played sounds through the box and the earphones. This means he has a [sensorineural] hearing loss. This is a [permanent] type of hearing loss.

Use of both technical audiology term and common language. Bolding to reinforce permanent nature of HI.

In summary:

1. Both of Jack’s ears looked normal and healthy.
2. Jack’s eardrums were moving normally in both ears.
3. Jack had muscle reflexes in both ears. However, we needed to make the volume louder to trigger them.
4. Jack’s inner ear did not produce its own sounds to all of the beeps played.
5. For Jack to hear middle- and high-pitched sounds we needed to increase the volume.

Colour-coded and numbered summary of each of the test

## The Audiogram- what does it show?

On page 7 you will find Jack's audiogram. This shows the softest level Jack could hear at different pitches.

- Each circle shows how well Jack heard when we played sounds to his right ear through earphones.
- Each cross shows how well Jack heard when we played sounds to his left ear through earphones.
- The triangles show how Jack heard when we played sound through the box behind his ear.

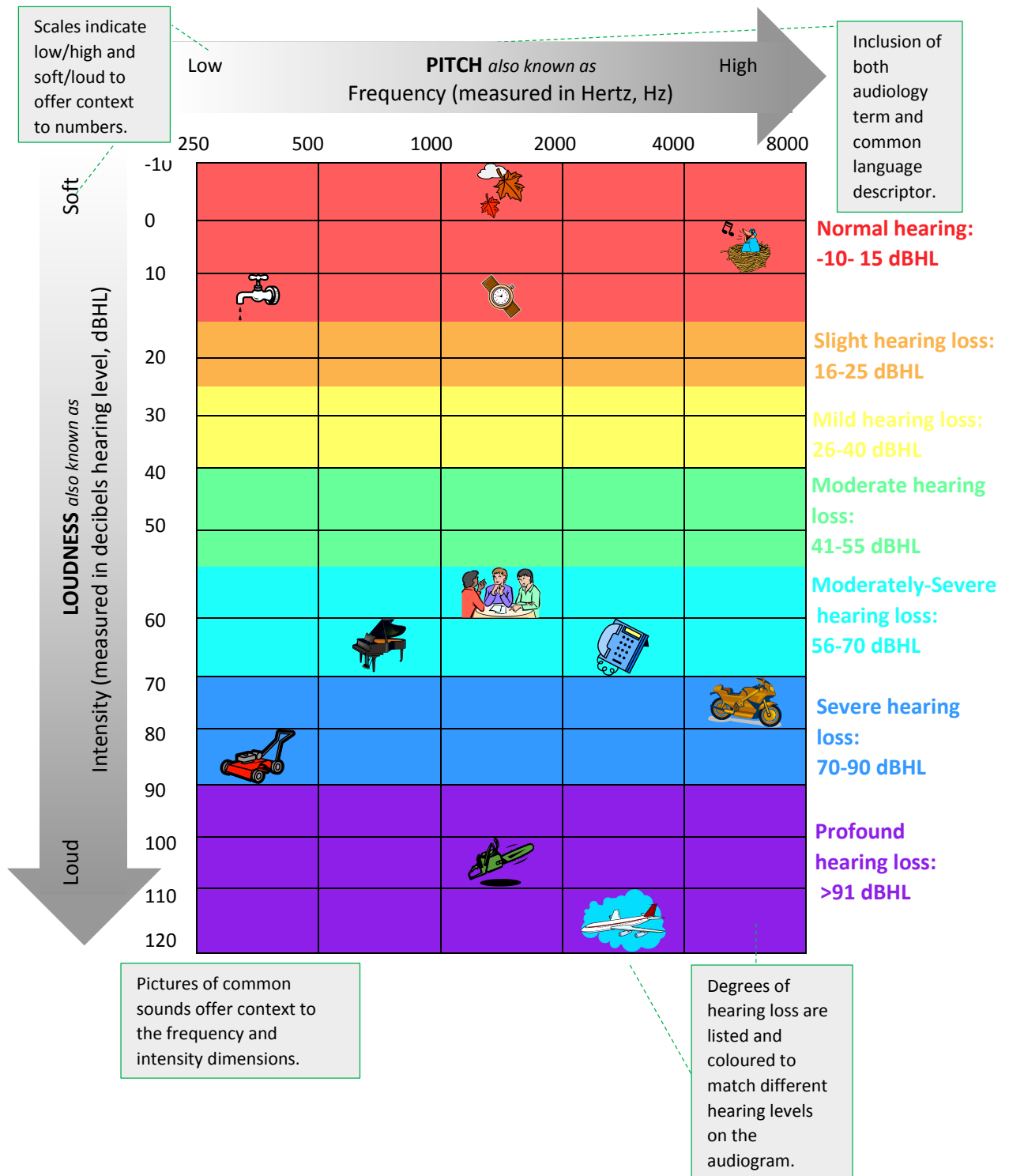
Explanation of the symbols used on the audiogram.

Explanation of frequency and intensity axes on audiogram using common language.

The numbers along the side of the graph show how loud the sound is. Loudness is measured in decibels. Very quiet sounds are at the top of the graph, and very loud sounds are at the bottom. The numbers along the top of the graph show the pitch of the sound. Pitch increases from the bass-like sounds on the left side of the graph to the treble sounds on the right side.

The picture below shows this information. Different levels of hearing loss are also shown on the right hand side of the graph. We have included some common sounds that are at a similar loudness level. [For example, a person with a severe hearing loss may not hear the phone ring.]

Example of how individuals with different degrees of HI may not be able to hear particular sounds.





## What do we do now?

Another summary reiterates the main finding.

As you have read, [Jack has a moderate to moderately severe hearing loss in the middle to high pitches. This is a lasting hearing loss.] [Because of this, Jack may not develop normal speech and language without the help of a device like hearing aids.]

Brief mention of what this result may mean for Jack.

Therefore, we have referred Jack to the Children's Hearing Aid Services. They will contact you to arrange a time to talk about the best way we can help Jack to hear. An Adviser of Deaf Children will also be in touch with you. All of these people are here to support Jack and your family in any way we can.

## Where can I go for more information?

Outlines the next step in plain language.

You can call the hospital if you want to talk about any of these results further. You can also have a look at some of these helpful websites:

Web addresses and brief overview of three sites where parents can go for further information

1. <http://www.audiologyonline.com/articles/what-parents-should-know-about-1163>  
This link helps answer some common questions that parents have after finding out their child has a hearing loss.
2. <https://www.entnet.org/content/childrens-hearing-loss>  
This link explains the different health professionals you may work with.
3. <http://www.asha.org/aud/Facts-about-Pediatric-Hearing-Loss/>  
This link gives good facts about hearing loss in children. The website supports the facts with research results.

You will be given plenty of extra information and resources during your next few appointments.

Reassurance that additional information will follow.

Kind regards,

Ashleigh Donald  
Master of Audiology Student

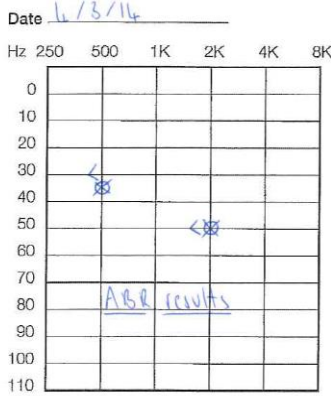
Jack Bean  
D.O.B: 8/1/14

Inclusion of Jack's personal audiogram for parents to refer to. Interpretation should be aided using the audiogram figure included on page 5.

- O Air X
- Air Masked #
- < Bone >
- ◁ Bone Masked ▷
- S Freefield S
- ↓ No Response ↓

Christchurch Hospital

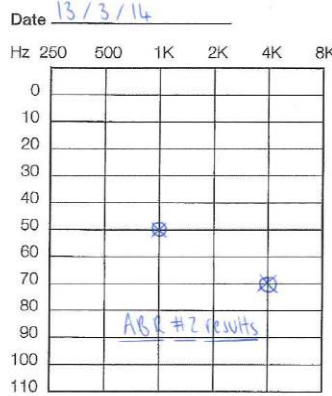
**Audiology**



Impedance Audiometry

RIGHT	Tymp	LEFT
<u>A</u>	<u>-10</u>	<u>A</u>
	MEP	<u>-5</u>
	Compl.	
	Volume	
<input type="checkbox"/> Contra. (Sound Ear)		<input type="checkbox"/> GP Pread
<input checked="" type="checkbox"/> Ipsilateral		<input checked="" type="checkbox"/> P.T.A. Imp

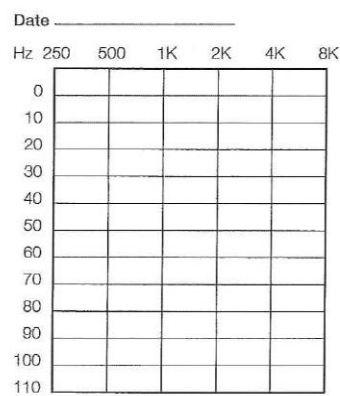
Audiologist A.O



Impedance Audiometry

RIGHT	Tymp	LEFT
<u>A</u>	<u>5</u>	<u>A</u>
	MEP	<u>-10</u>
	Compl.	
	Volume	
<input type="checkbox"/> Contra. (Sound Ear)		<input type="checkbox"/> GP Pread
<input checked="" type="checkbox"/> Ipsilateral		<input type="checkbox"/> P.T.A. Imp

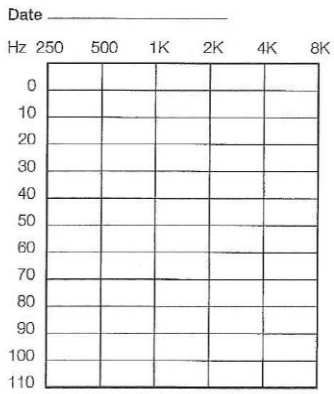
Audiologist A.O



Impedance Audiometry

RIGHT	Tymp	LEFT
	MEP	
	Compl.	
	Volume	
<input type="checkbox"/> Contra. (Sound Ear)		<input type="checkbox"/> GP Pread
<input type="checkbox"/> Ipsilateral		<input type="checkbox"/> P.T.A. Imp

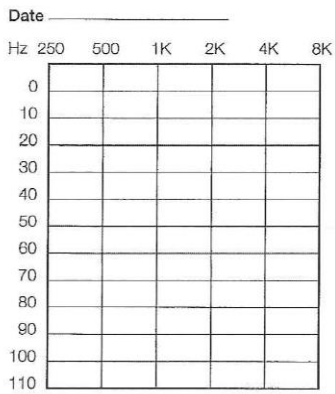
Audiologist \_\_\_\_\_



Impedance Audiometry

RIGHT	Tymp	LEFT
	MEP	
	Compl.	
	Volume	
<input type="checkbox"/> Contra. (Sound Ear)		<input type="checkbox"/> GP Pread
<input type="checkbox"/> Ipsilateral		<input type="checkbox"/> P.T.A. Imp

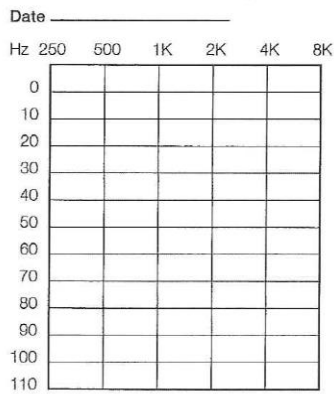
Audiologist \_\_\_\_\_



Impedance Audiometry

RIGHT	Tymp	LEFT
	MEP	
	Compl.	
	Volume	
<input type="checkbox"/> Contra. (Sound Ear)		<input type="checkbox"/> GP Pread
<input type="checkbox"/> Ipsilateral		<input type="checkbox"/> P.T.A. Imp

Audiologist \_\_\_\_\_



Impedance Audiometry

RIGHT	Tymp	LEFT
	MEP	
	Compl.	
	Volume	
<input type="checkbox"/> Contra. (Sound Ear)		<input type="checkbox"/> GP Pread
<input type="checkbox"/> Ipsilateral		<input type="checkbox"/> P.T.A. Imp

Audiologist \_\_\_\_\_

13/03/2014

Inclusion of unrevised report for parent's records or to further supplement their understanding.

Jane Eyre  
Newborn Hearing Screening  
Level 5  
CHRISTCHURCH WOMENS' HOSPITAL

Dear Jane,

<b>Re</b>	<b>Jack Bean</b>	<b>DOB</b>	<b>08/01/2014</b>
	<b>567 Titanic Road</b>	<b>Gender</b>	<b>Male</b>
	<b>New Brighton</b>	<b>NHI Number</b>	<b>ABC1234</b>

Thank you for referring Jack who was seen for a diagnostic audiological assessment on 4 March 2014 and 13 March 2014 following a bilateral refer result from his newborn hearing screen. Jack attended both appointments with his mother, Julianne. She reported that she does have some concerns about Jack's hearing as he will not always turn to voices; although he does startle to loud sounds like slamming doors. I understand that Julianne experienced a normal pregnancy and birth that were free of any complications. No ear infections or colds were reported and a family history of hearing loss was denied.

### **Test Results**

**04/03/14**

Otosopic examination revealed a visible light reflex and clear ear canals in both ears.

Immittance audiometry performed with a 1 kHz probe tone yielded type A tympanograms in both ears, indicative of normal middle ear pressure and compliance. Ipsilateral acoustic reflexes to broadband stimuli were absent at normal screening levels (80 dBHL) bilaterally.

Auditory Brainstem Response (ABR) audiometry was performed during natural sleep via insert earphones. Reliable responses to 500 Hz tone burst stimuli were identified down to passing levels (35 dBeHL) in both ears. Repeatable responses were found at moderately elevated levels (50 dBeHL) for 2 kHz tone-pip stimuli in both ears. Follow up testing via unmasked bone conduction produced repeatable responses at passable stimulus levels (30 dBeHL) at 500Hz; and repeatable responses at moderately elevated levels (50 dBeHL) at 2 kHz bilaterally.

Objective measures of cochlear sensory hair cell function via *Distortion Product Otoacoustic Emissions* (DPOAEs) yielded absent emissions between 1.5-8 kHz in both ears. These results were considered to be consistent with the sensorineural hearing loss suggested by the acoustic reflex and ABR findings.

Unfortunately, Jack woke up before we could complete assessment at all necessary frequencies. It was therefore recommended that he return in one week's time for further testing.

**13/03/14**

Otoscopy revealed a visible light reflex in both ears and clear ear canals.

Immittance audiometry performed with a 1 kHz probe tone yielded type A tympanograms in both ears, indicative of normal middle ear pressure and compliance.

Auditory Brainstem Response (ABR) audiometry was performed during natural sleep via insert earphones. Repeatable responses were found at moderately elevated levels (50 dBeHL) for 1 kHz tone-pip stimuli in both ears; and moderately-severe elevated levels (70 dBeHL) for 4 kHz stimuli bilaterally.

**Summary and recommendations:**

Overall, the results of these two assessments are consistent with normal to essentially normal hearing in the low frequencies, sloping to a moderately-severe sensorineural hearing loss in both ears. As discussed with Julianne, I have made an onward referral to Triton Paediatric Hearing Aid Services to discuss amplification and rehabilitation options. A referral has also been made to the Ear, Nose and Throat Department at Christchurch Public Hospital (CPH) for their opinion and assessment of Jack's hearing loss. Jack has also been referred to the Paediatric and Ophthalmology departments at CPH for evaluation. Finally, I have referred Jack to the Advisers on Deaf Children to evaluate and discuss his hearing needs at home and in future educational settings

I would be grateful if you could accept this referral for Jack and his family. We look forward to meeting Jack and his family on the 21 March 2014 to discuss the management of his hearing loss and welcome your presence at this appointment.

Should you have any questions or concerns regarding today's results and/or Jack's hearing, please do not hesitate to contact me.

Kind regards,

Ashleigh Donald  
Master of Audiology Student

Inclusion of a glossary which defines and explains the unfamiliar terminology used in the unrevised report above.

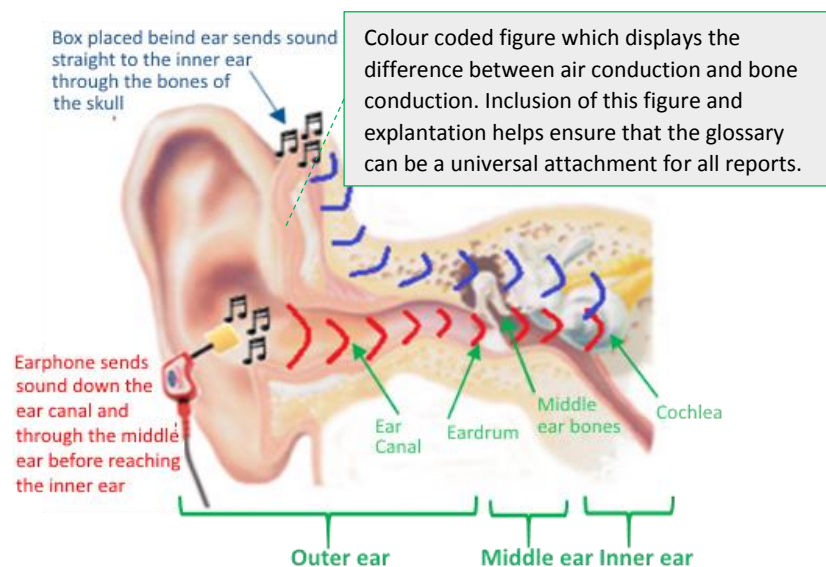
## Glossary

**Acoustic reflex-** This reflex causes two muscles in the middle ear to tense in response to sounds. In infants, we try to trigger this reflex by playing a sound at a standard volume. If the reflex is triggered at this volume we say it is present. If there is no reflex to this volume of sound we say it is absent. The presence or absence of a reflex can give us important information about a child's hearing.

**Auditory brainstem response (ABR)-** This test measures your child's hearing while they are sleeping or sedated. We normally play sounds both through earphones, and also through a small box placed behind the ear. Your child will also have small sticky pads (electrodes) placed on their forehead and behind their ears. These allow us to measure the activity from their ear to their brain in response to sound. We use this activity to work out the softest volume of sound your child can hear in each ear across a range of pitches.

**Bilateral-** Relating to both ears.

**Bone conduction-** This is where sound travels to the inner ear through the bones of the skull. We test hearing in this way by placing a small box on the bone behind the ear. This vibrates the bone, allowing sound to be heard. Bone conduction lets us test the hearing of the inner ear alone. Bone conduction is different to air conduction. During air conduction, sound travels down the ear canal to the eardrum, through the middle ear and then reaches the inner ear. Air conduction is tested through earphones. The picture below shows these two pathways of hearing. Air conduction is in blue and bone conduction is in red.



Pathways of air conducted and bone conducted sound.

*Cochlear sensory hair cell*- The cochlea is the inner organ of hearing. It is the snail-shaped object in the picture above. Inside the cochlea are thousands of tiny hair cells. The job of these hair cells is to change sound into nerve signals to be sent to the brain. Because these hair cells are so delicate, they can be easily damaged. Damaged hair cells can result in a hearing loss.

*Conductive hearing loss*- This type of hearing loss is seen when the hearing by bone conduction is better than the hearing by air conduction. It is caused by a problem in the outer or middle ear, while the inner ear is normal. This type of hearing loss will often go away by itself if it is caused by your child's cold. In other children the hearing can be improved by surgery (such as putting in grommets). Sometimes this type of hearing loss can also be permanent.

*dBeHL*- We measure hearing in this unit. It is known as "decibels estimated hearing level". Decibels are the unit we measure the loudness of sound in. "Hearing Level" is the decibel scale that we measure hearing loss in. It lets us compare the hearing of one person to the hearing of an average normal-hearing person. "Estimated" means that the ABR test results have been changed slightly to be the best estimate of your child's actual hearing.

*Distortion product otoacoustic emissions*- Healthy hair cells within the cochlea respond to sound by producing soft sounds of their own. These soft sounds are known as otoacoustic emissions. We can measure them by playing beeps through a small tip placed in the ear. This lets us see if the hair cells are working. "Distortion product" refers to the type of sound we are measuring.

*Frequency/ frequencies*- This is the pitch of a sound. It is measured as the number of sound wave vibrations per second. The unit for this measurement is the Hertz (Hz). When sound waves vibrate quickly, high frequency sounds like bird chirping or a siren are heard. When sound waves vibrate slowly, low frequency sounds like thunder, drums or a motorbike are heard. Humans can hear a range of frequencies from about 20 Hz to 20,000 Hz. We normally test hearing between 250 Hz to 8000 Hz because most of the sounds of speech are in this range.

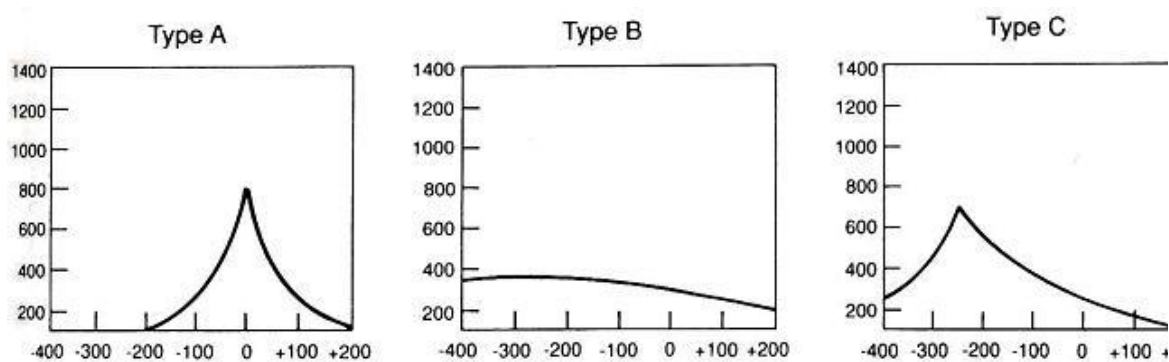
*Immittance audiometry*- Immittance audiometry is another name for tympanometry. Tympanometry is a test done to check that your child's eardrum and middle ear are working normally. A small puff of air is sent into the ear canal, causing the eardrum to move back and forward. Our machine measures this movement and draws a shape. Different types of shapes can tell us different things about your child's eardrum and middle ear. The pictures below show these shapes.

Including different tympanogram types in the glossary further ensures the glossary can function as a universal document. In addition, it can act as a reference for parents if their child's tympanometry results change in the future.

*Type A-* Your audiologist may have referred to this as a “mountain” or a peaked shape. This means that the eardrum is at a normal position and is moving well.

*Type B-* Your audiologist may have referred to this type as a “river” or a flat line. Sometimes this means that there is a problem in the middle ear which is stopping the eardrum from moving normally. This is often seen when there is fluid behind the eardrum, like in “glue ear”. In other children it can mean that there is a hole in the eardrum.

*Type C-* This shape still has a “Mountain” peak, but it is moved to the left a bit. This means that the eardrum is being “sucked back” towards the middle ear. This shape means that the tube which connects the back of the throat to the nose (the Eustachian tube) is not working normally. This is often the case when your child has a cold, or is getting over one.



*Light reflex-* This is a sign of a healthy eardrum.

*Otoscopy-* This is a visual check of the outer ear and eardrum.

*Sensorineural hearing loss-* This type of hearing loss is seen when the hearing by bone conduction is the same as the hearing by air conduction. A problem in the cochlea or hearing nerve causes the hearing loss. This type of loss is permanent.

*Tympanogram-* see immittance audiometry



APPENDIX E:

COPY OF UNREVISED REPORT, ANNOTATED TO HIGHLIGHT ISSUES

13/03/2014

Jane Eyre  
Newborn Hearing Screening  
Level 5

CHRISTCHURCH WOMENS' HOSPITAL

Dear Jane,

<b>Re</b>	<b>Jack Bean</b>	<b>DOB</b>
<b>08/01/2014</b>	<b>567 Titanic Road</b>	<b>Gender</b>
<b>Male</b>	<b>New Brighton</b>	<b>NHI Number</b>
<b>ABC1234</b>		

All words underlined in red have been identified by spellcheck as a misspelled word because they are too rare to be included in the Microsoft Word dictionary.

All sentences in green exceed 25 words in length.

Thank you for referring Jack who was seen for a diagnostic audiological assessment on 4 March 2014 and 13 March 2014 following a bilateral refer result from his newborn hearing screen. Jack attended both appointments with his mother, Julianne. She reported that she does have some concerns about Jack's hearing as he will not always turn to voices; although he does startle to loud sounds like slamming doors. I understand that Julianne experienced a normal pregnancy and birth that were free of any complications. No ear infections or colds were reported and a family history of hearing loss was denied.

Phrases highlighted in blue indicate passive sentence structure.

**Test Results**

**04/03/14**

[Otoscopic] [examination] [revealed] a [visible] light [reflex] and clear ear [canals] [bilaterally].

The following [bracketed terms] are examples of Dale-Chall "unfamiliar words"

Immittance audiometry performed with a 1 kHz probe tone yielded type A tympanograms in both ears, indicative of normal middle ear pressure and compliance. Ipsilateral acoustic reflexes to broadband stimuli were absent at [normal screening levels] (80 dB HL) bilaterally.

Examples of a concept phrase which describe an abstract concept.

Auditory Brainstem Response (ABR) audiometry was performed during natural sleep via insert earphones. Reliable responses to 500 Hz tone



Example of a value judgement word.

burst stimuli were identified down to [passing levels] (35 dB eHL) in both ears. Repeatable responses were found at [moderately] elevated levels (50 dB eHL) for 2 kHz tone-pip stimuli in both ears. Follow up testing via unmasked bone conduction produced repeatable responses at passable stimulus levels (30 dB eHL) at 500Hz; and repeatable responses at moderately elevated levels (50 dB eHL) at 2 kHz bilaterally.

Objective measures of cochlear sensory hair cell function via *Distortion Product Otoacoustic Emissions* (DPOAEs) yielded absent emissions between 1.5-8 kHz in both ears. These results were considered to be consistent with the sensorineural hearing loss suggested by the acoustic reflex and ABR findings.

Unfortunately, Jack woke up before we could complete assessment at all necessary frequencies. It was therefore recommended that he return in one week's time for further testing.

**13/03/14**

Otoscopy revealed a visible light reflex in both ears and clear ear canals.

Immittance audiometry performed with a 1 kHz probe tone yielded type A tympanograms in both ears, indicative of normal middle ear pressure and compliance.

Auditory Brainstem Response (ABR) audiometry was performed during natural sleep via insert earphones. Repeatable responses were found at moderately elevated levels (50 dBeHL) for 1 kHz tone-pip stimuli in both ears; and moderately-severe elevated levels (70 dBeHL) for 4 kHz stimuli bilaterally.

This sentence is the only summary provided in the report. However, at 29 words, it is also

#### **Summary and recommendations:**

Overall, the results of these two assessments are consistent with normal to essentially normal hearing in the low frequencies, sloping to a moderately-severe sensorineural hearing loss in both ears. As discussed with Julianne, I have made an onward referral to Triton Paediatric Hearing Aid Services to discuss amplification and rehabilitation options. A referral has also been made to the Ear, Nose and Throat Department at Christchurch Public Hospital (CPH) for their opinion and assessment of Jack's hearing loss. Jack has also been referred to the Paediatric and Ophthalmology departments at CPH for evaluation. Finally, I have referred Jack to the Advisers on Deaf Children to evaluate and discuss his hearing needs at home and in future educational settings.

I would be grateful if you could accept this referral for Jack and his family. We look forward to meeting Jack and his family on the 21 March 2014 to discuss the management of his hearing loss and welcome your presence at this appointment.

Should you have any questions or concerns regarding today's results and/or Jack's hearing, please do not hesitate to contact me.

Kind regards,

Ashleigh Donald  
Master of Audiology Student

Jack Bean  
D.O.B: 8/1/14

R O L  
O Air X  
● Air Masked #  
< Bone >  
< Bone Masked >  
S Freefield S  
↓ No Response ↓

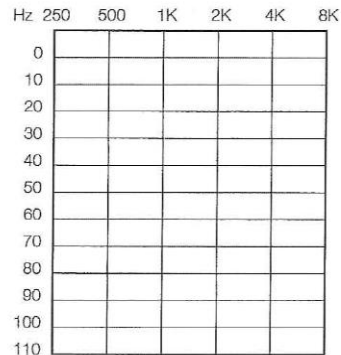
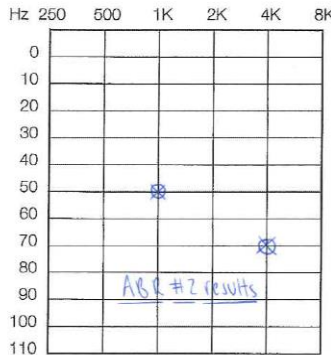
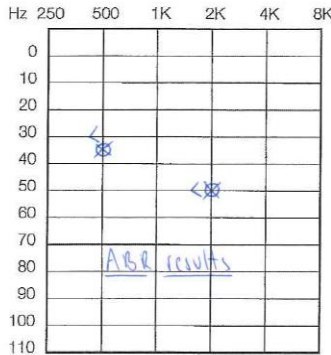
Christchurch Hospital

**Audiology**

Date 6/3/14

Date 13/3/14

Date \_\_\_\_\_



Impedance Audiometry

RIGHT		LEFT	
<u>A</u>	Tymp	<u>A</u>	
<u>-10</u>	MEP	<u>-5</u>	
	Compl.		
	Volume		
<input type="checkbox"/>	Contra. (Sound Ear)	<input type="checkbox"/>	GP Pread
<input checked="" type="checkbox"/>	Ipsilateral	<input checked="" type="checkbox"/>	
Audiologist <u>A.O</u>		P.T.A. Imp	

Impedance Audiometry

RIGHT		LEFT	
<u>A</u>	Tymp	<u>A</u>	
<u>5</u>	MEP	<u>-10</u>	
	Compl.		
	Volume		
<input type="checkbox"/>	Contra. (Sound Ear)	<input type="checkbox"/>	GP Pread
<input checked="" type="checkbox"/>	Ipsilateral	<input type="checkbox"/>	
Audiologist <u>A.O</u>		P.T.A. Imp	

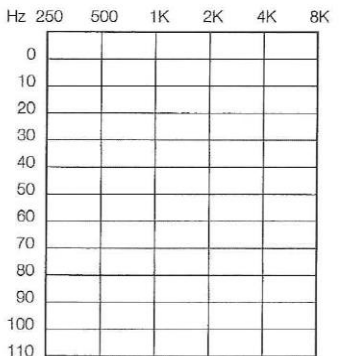
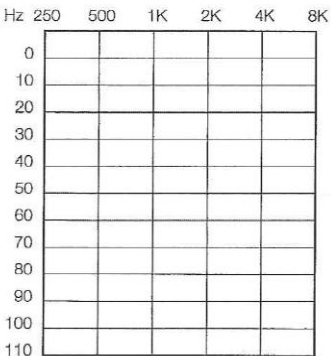
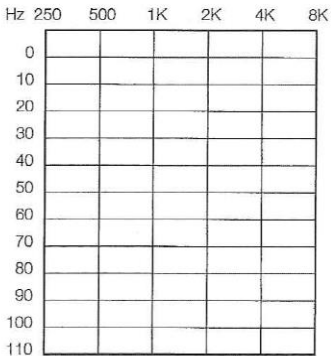
Impedance Audiometry

RIGHT		LEFT	
	Tymp		
	MEP		
	Compl.		
	Volume		
<input type="checkbox"/>	Contra. (Sound Ear)	<input type="checkbox"/>	GP Pread
<input type="checkbox"/>	Ipsilateral	<input type="checkbox"/>	
Audiologist _____		P.T.A. Imp	

Date \_\_\_\_\_

Date \_\_\_\_\_

Date \_\_\_\_\_



Impedance Audiometry

RIGHT		LEFT	
	Tymp		
	MEP		
	Compl.		
	Volume		
<input type="checkbox"/>	Contra. (Sound Ear)	<input type="checkbox"/>	GP Pread
<input type="checkbox"/>	Ipsilateral	<input type="checkbox"/>	
Audiologist _____		P.T.A. Imp	

Impedance Audiometry

RIGHT		LEFT	
	Tymp		
	MEP		
	Compl.		
	Volume		
<input type="checkbox"/>	Contra. (Sound Ear)	<input type="checkbox"/>	GP Pread
<input type="checkbox"/>	Ipsilateral	<input type="checkbox"/>	
Audiologist _____		P.T.A. Imp	

Impedance Audiometry

RIGHT		LEFT	
	Tymp		
	MEP		
	Compl.		
	Volume		
<input type="checkbox"/>	Contra. (Sound Ear)	<input type="checkbox"/>	GP Pread
<input type="checkbox"/>	Ipsilateral	<input type="checkbox"/>	
Audiologist _____		P.T.A. Imp	

APPENDIX F: VERIFICATION STAGE

---

F.1 Ethical approval letter, University of Canterbury Human Ethics Committee



HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen  
Email: [human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)

Ref: HEC 2014/83

18 August 2014

Ashleigh Donald  
Department of Communication Disorders  
UNIVERSITY OF CANTERBURY

Dear Ashleigh

The Human Ethics Committee advises that your research proposal "Readability and comprehensibility of reports provided to New Zealand caregivers of hearing impaired children in audiology" has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 18 August 2014.

Best wishes for your project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'L. MacDonald'.

Lindsey MacDonald  
*Chair*  
*University of Canterbury Human Ethics Committee*

## F.2 Study advertisement



# ARE YOU THE CAREGIVER OF A CHILD AGED 0-5 YEARS? WE NEED YOUR HELP!

Approximately 245 children are diagnosed with a hearing loss in New Zealand every year. It is normal to provide the caregivers of these children with written reports explaining their child's hearing loss. However, there is reason to believe that these reports are difficult for caregivers to read and understand. We are currently trying to improve these reports to help caregivers better understand hearing loss. However, we need your feedback on these reports so we know the best way to improve them.

**You will receive your choice of a \$10 supermarket or fuel voucher to thank you for your participation in the study!**

### Who do we need?

Caregivers aged 18 years or older who:

- ✓ Have at least one child aged between 0-5 years.
- ✓ Speak English as their first language
- ✓ Have no previous experience with hearing loss

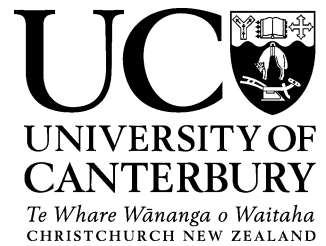
What do you need to do?

- ✓ Complete a brief measure of reading comprehension
- ✓ Read a hypothetical report written for a hearing impaired child. You will be randomly assigned to read either the original or the revised report
- ✓ Complete a questionnaire asking your opinion about the report, including how well you understood it

To take part in this research or for more information, please contact:  
Ashleigh Donald or Rebecca Kelly-Campbell  
(03) 364-2987 ext. 8327  
OR  
ajd182@uclive.ac.nz

### F.3 Information sheet

University of Canterbury  
Department of Communication Disorders  
Private Bag 4800  
Christchurch 8140  
New Zealand



#### STUDY INFORMATION

You are invited to take part as a participant in the research project entitled **“Readability and Comprehensibility of Audiological Reports provided to New Zealand Caregivers of Hearing Impaired Children.”**

The aim of this Masters project is in two parts. First, we aim to understand how readable and understandable the reports written to caregivers of hearing impaired children are. Next, we hope to try and improve these reports so that caregivers find them easier to read and understand.

This research is important because health information that is not easy to read may lower a caregiver’s ability to make informed and appropriate health decisions. In turn, this increases the risk of poor health outcomes for their children. Furthermore, the diagnosis of a hearing loss in a child can be a stressful and emotional time for caregivers. Therefore, it is essential that the written information we are providing caregivers is clear, understandable and helpful.

This project is unique because there is no previous research on the readability of reports used in audiology. Research into health literacy within New Zealand is also lacking. It is hoped that information from this research may be able to improve the reports that are currently used within New Zealand audiology.

Your participation in this project will firstly involve being assigned to read either 1) the original audiology report or 2) the revised audiology report. Which report you read will be randomly chosen by the flip of a coin. The purpose of this random assignment is to help us measure whether the revised report is actually more readable and understandable than the original report. You will not know what group you are in until the end of the study. At this point, you will be given an opportunity to read the report you were not assigned to read if you wish.

After you have been assigned to read either report your involvement in the study will include: (1) completing a questionnaire about yourself, (2) completing a fill-in-the-blanks comprehension test, (3) reading your assigned report and (4) completing a questionnaire about your opinion and understanding of the report. All of these documents will be sent to you in the mail in two packets. First, you will receive items

(1) and (2). After you have completed and returned these to the researcher, items (3) and (4) will be sent to you. At the end of the study you will be thanked for your time and participation by being provided with your choice of a \$10 supermarket or fuel voucher.

You have the right to withdraw from the project until the 16 November, 2014, including withdrawal of any information you have provided. Your involvement (or withdrawal) in this project will not affect how you or your children are treated within the audiology field of health.

You will be asked to read your assigned report as if it was written for your own child, and will be then asked about your feelings and opinions about the report. The risk of participating in this study includes the possibility of feeling distressed as you read the report and participate in the interview. A list of available support services is provided at the end of this document.

The results of the project may be published, but you may be assured of the complete confidentiality of data gathered in this investigation. To ensure confidentiality, your name will not be used on your information sheet, comprehension measure or either of the questionnaires. You will be given a participant number and will be referred to only by this for all four of these documents. In addition, your completed consent form will be kept in a locked cabinet in a locked room in the Department of Communication Disorders on the University of Canterbury campus in Christchurch, New Zealand.

This project is being carried out by Ashleigh Donald, a Master of Audiology student at the University of Canterbury and is being supervised by Dr Rebecca Kelly-Campbell. Either Ashleigh or Rebecca will be pleased to discuss any concerns or questions you may have about participating in the project and may be reached on 64 (3) 364-2987 ext. 8327.

The project and been reviewed **and approved** by the University of Canterbury Human Ethics Committee. The Human Ethics Committee can be contacted at University of Canterbury, Okeover House, Christchurch and on 03-364-2987.

Available support services:

*LifeLine*

09 5222999 (within Auckland)

0800 543 345 (outside Auckland)

<http://www.lifeline.org.nz/>

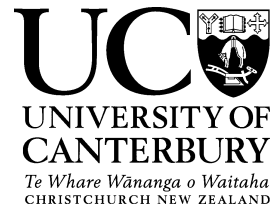
*New Zealand Association of Counsellors*

[http://nzac.org.nz/nzac\\_counsellor\\_search.cfm](http://nzac.org.nz/nzac_counsellor_search.cfm)

07 834 0220 (National Office)

## F.4 Consent form

University of Canterbury  
Department of Communication Disorders  
Private Bag 4800  
Christchurch 8140  
New Zealand



Researchers: Rebecca Kelly-Campbell, Ashleigh Donald

Contact address: University of Canterbury  
Department of Communication Disorders  
Private Bag 4800  
Christchurch 8140  
New Zealand

Date:

### **“Readability and Comprehensibility of Audiological Reports provided to New Zealand Caregivers of Hearing Impaired Children.”**

I have read and understood the description of the above-named Master’s project. On this basis, I agree to participate as a subject in the project, and I consent to publication of the results of the project with the understanding that anonymity will be preserved.

I understand also that I may withdraw from the project until the 16 November 2014, including withdrawal of any information I have provided.

I note that the project has been reviewed **and approved** by the University of Canterbury Human Ethics Committee.

Name: (please print): \_\_\_\_\_

Would you like to receive a summary of the results of the project? *(Please tick):*

\_\_\_\_\_ Yes    \_\_\_\_\_ No

Would you like to receive a copy of the other report to read? *(Please tick):*

\_\_\_\_\_ Yes    \_\_\_\_\_ No

Signature: \_\_\_\_\_

Date: \_\_\_\_\_



## F.5 Demographic questionnaire

University of Canterbury  
Department of Communication Disorders  
Private Bag 4800  
Christchurch 8140  
New Zealand



QUESTIONNAIRE  
*complete*)

ID number: \_\_\_\_\_  
(For the researcher to

*Please answer the following questions*

1. Gender:

Male       Female

2. Years of age:

\_\_\_\_\_

3. What is your current marital status?

Single (never married)       Widowed  
 Married       Divorced  
 In a committed relationship       Separated

4. Which ethnic group do you belong to?

New Zealand European       Maori  
 Samoan       Cook Island Maori  
 Tongan       Niuean  
 Chinese       Indian  
 Other such as Dutch, Japanese or Tokelauan. Please state: \_\_\_\_\_

5. How many children do you have under your care?

---

6. What is the age of each child?

---

7. What is your relationship to each child?

---

8. How many years of education have you completed?

---

9. What is your highest qualification? (*E.g. NCEA/school certificate, degree/diploma, trade certificate etc.*)

---

10. What is your occupation?

## F.6 Cloze procedure for unrevised report

Instructions: We have taken passages from the report and created a test for you. Please read the passages below and try to fill in the blanks. **It is important that you do not try to “look up” the correct answer.** If you are not sure what to write, please just take a guess. The size of the blank gives you a clue about how long the missing word is. Please do not feel upset if you do not know the correct answer or if you answer incorrectly. You'll get to see the answers to the blanks when you receive the report.

Passage from report:

Thank you for referring Jack who was seen for a diagnostic audiological assessment on 4 March 2014 and 13 March 2014 following a bilateral refer result from his newborn hearing screen. Jack attended both appointments with his mother, Julianne. She reported that she \_\_\_\_\_ have some concerns about \_\_\_\_\_ hearing as he will \_\_\_\_\_ always turn to voices; \_\_\_\_\_ he does startle to \_\_\_\_\_ sounds like slamming doors. \_\_\_\_\_ Understand that Julianne experienced \_\_\_\_\_ normal pregnancy and birth \_\_\_\_\_ were free of any \_\_\_\_\_. No ear infections or \_\_\_\_\_ were reported and a \_\_\_\_\_ history of hearing loss \_\_\_\_\_ denied.

### Test Results

**04/03/14**

\_\_\_\_\_ Examination revealed a visible \_\_\_\_\_ reflex and clear ear \_\_\_\_\_ in both ears.

Immittance \_\_\_\_\_ performed with a 1 \_\_\_\_\_ probe tone yielded type \_\_\_\_\_ tympanograms in both ears, \_\_\_\_\_ of normal middle ear \_\_\_\_\_ and compliance. Ipsilateral acoustic \_\_\_\_\_ to broadband stimuli were \_\_\_\_\_ at normal screening levels ( \_\_\_\_\_ dB HL) bilaterally.

Auditory Brainstem \_\_\_\_\_ (ABR) audiometry was performed \_\_\_\_\_ natural sleep via insert \_\_\_\_\_. Reliable responses to 500 \_\_\_\_\_ tone burst stimuli were \_\_\_\_\_ down to passing levels

(\_\_\_\_\_ dBeHL) in both ears. \_\_\_\_\_ Responses were found at \_\_\_\_\_ elevated levels (50 dBeHL) \_\_\_\_\_ 2 kHz tone-pip stimuli \_\_\_\_\_ both ears. Follow up \_\_\_\_\_ via unmasked bone conduction \_\_\_\_\_ repeatable responses at passable \_\_\_\_\_ levels (30 dBeHL) at \_\_\_\_\_ Hz; and repeatable responses at \_\_\_\_\_ elevated levels (50 dBeHL) \_\_\_\_\_ 2 kHz bilaterally.

Objective \_\_\_\_\_ of cochlear sensory hair \_\_\_\_\_ function via *Distortion Product \_\_\_\_\_ Emissions* (DPOAEs) yielded absent \_\_\_\_\_ between 1.5-8 kHz in \_\_\_\_\_ ears. These results were \_\_\_\_\_ to be consistent with \_\_\_\_\_ sensorineural hearing loss suggested \_\_\_\_\_ the acoustic reflex and \_\_\_\_\_ findings.

Unfortunately, Jack woke \_\_\_\_\_ before we could complete \_\_\_\_\_ at all necessary frequencies. It was therefore recommended that he return in one week's time for further testing.

## F.7 Cloze procedure for revised report

Instructions: We have taken passages from the report and created a test for you. Please read the passages below and try to fill in the blanks. **It is important that you do not try to “look up” the correct answer.** If you are not sure what to write, please just take a guess. The size of the blank gives you a clue about how long the missing word is. Please do not feel upset if you do not know the correct answer or if you answer incorrectly. You'll get to see the answers to the blanks when you receive the report.

Passage from report:

Thank you for bringing Jack in to have his hearing tested on 4 March and 13 March 2014. Jack came to us because he did not pass his newborn hearing screen.

The following report gives the results from both of these appointments. We have tried to \_\_\_\_\_ these in a way \_\_\_\_\_ is easy to understand. You will also find \_\_\_\_\_ copy of the medical \_\_\_\_\_ sent to other experts \_\_\_\_\_ in Jack's care. We \_\_\_\_\_ added a glossary to \_\_\_\_\_ report to help you \_\_\_\_\_ the terms used.

### **What \_\_\_\_\_ we find?**

Our results \_\_\_\_\_ us that Jack has “\_\_\_\_\_ normal hearing sloping to \_\_\_\_\_ moderately-severe hearing loss” in \_\_\_\_\_ ears. This means that \_\_\_\_\_ has normal or near \_\_\_\_\_ hearing for low, bass-like \_\_\_\_\_ in both ears. For \_\_\_\_\_, treble-like sounds, Jack's hearing \_\_\_\_\_ to a moderately-severe hearing \_\_\_\_\_ in both ears. Our \_\_\_\_\_ point to this being \_\_\_\_\_ lasting, or permanent, hearing \_\_\_\_\_.

Please see the hearing \_\_\_\_\_ on page 3 to \_\_\_\_\_ you understand how we \_\_\_\_\_ hearing loss.

### **Can you \_\_\_\_\_ me the results of \_\_\_\_\_ test?**

We have given \_\_\_\_\_ results of each test \_\_\_\_\_ the order we did \_\_\_\_\_ at the first appointment. \_\_\_\_\_ Have also colour coded \_\_\_\_\_ test to match the \_\_\_\_\_ below. This helps show \_\_\_\_\_ part of the ear \_\_\_\_\_ test was looking at.

## \_\_\_\_ **Otoscopy**

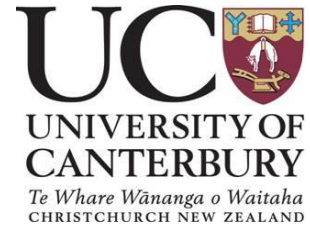
First, we looked \_\_\_\_\_ Jack's ears. Both of \_\_\_\_\_ eardrums looked normal and \_\_\_\_\_. We found that this same at both \_\_\_\_\_.

## **2. Tympanometry**

Next, we \_\_\_\_\_ how Jack's eardrums were \_\_\_\_\_. To do this, we \_\_\_\_\_ a rubber tip inside \_\_\_\_\_ ear and sent a \_\_\_\_\_ puff of air down \_\_\_\_\_ canal. This made Jack's \_\_\_\_\_ move back and forth. \_\_\_\_\_ machine measured this movement \_\_\_\_\_ drew a shape like \_\_\_\_\_ "mountain". We call this \_\_\_\_\_ type "A".

## F.8 Verification questionnaire

University of Canterbury  
Department of Communication Disorders  
Private Bag 4800  
Christchurch 8140 New Zealand



ID: \_\_\_\_\_

Date: \_\_\_\_\_

*Part 1. In this section, you will be asked questions about how well you understood what was in the report. Please read each question and choose the answer you think is correct.*

### 1. What does the term “otoscopy” mean?

- a. A visual check of the ear canal.
- b. An objective measurement of the ear drum.
- c. A measure of hearing.
- d. A measurement of the light reflex.

### 2. In tympanometry, what does a “type A” mean?

- a. There are no problems in the outer ear.
- b. There are no problems in the middle ear.
- c. There are no problems in the inner ear.
- d. The hearing is within normal limits.

### 3. What is the use of the ABR?

- a. It is a way of testing the hearing of an infant
- b. It is a way of measuring how well the outer hair cells are working
- c. It is a way of seeing how the eardrums are working
- d. it is a way of observing an infant while they are asleep

### 4. Which of the following statements is TRUE about this child’s hearing?

- a. He has normal hearing at passable levels.
- b. He has a cochlear hearing loss.
- c. He has a brainstem hearing loss.
- d. He has a bone conduction hearing loss.

**5. Which of the following statements is TRUE about this child's hearing?**

- a. Jack has better hearing in the high frequencies
- b. Jack has better hearing in the mid frequencies
- c. Jack has better hearing in the low frequencies
- d. Jack's hearing is the same at all frequencies

**6. What are the recommendations for this child?**

- a. He should receive hearing aids.
- b. He should visit a GP.
- c. He should return for further testing.
- d. He should have grommets placed in his ears.

*Part 2. In this section, you will be asked questions about how confident you feel about your understanding of the report. Please read each question and choose the answer you think best describes your level of confidence.*

**1. After reading the report, how confident are you that you understand the terms in the report?**

0	1	2	3	4	5	6	7	8	9	10
Not confident at all			Moderately confident				Very confident			



**2. After reading the report, how confident are you that you understood the test procedures?**

0	1	2	3	4	5	6	7	8	9	10
Not confident at all			Moderately confident				Very confident			

**3. After reading the report, how confident are you that you understood the test results?**

0	1	2	3	4	5	6	7	8	9	10
Not confident at all			Moderately confident				Very confident			

**4. After reading the report, how confident are you that you understood the recommendations?**

0	1	2	3	4	5	6	7	8	9	10
Not confident at all			Moderately confident				Very confident			

*Part 3. In this section, you will be asked questions about your opinion of the report. Please read each question and choose the answer you think best describes your opinion.*

**1. The report was what I expected it to be.**

1	2	3	4	5
Not at all		Moderately		Very much

**2. I found the report confusing.**

1	2	3	4	5
Not at all		Moderately		Very much

**3. The report was beneficial to me.**

1	2	3	4	5
Not at all		Moderately		Very much

**4. I felt frustrated reading the report.**

1	2	3	4	5
Not at all		Moderately		Very much

**5. The order of information in the report was helpful.**

1	2	3	4	5
Not at all		Moderately		Very much

**6. I thought the report was of a good length.**

1	2	3	4	5
Not at all		Moderately		Very much

**7. I thought the report was hard to read without some help.**

1	2	3	4	5
Not at all		Moderately		Very much

**8. I thought the report used too much "jargon."**

1	2	3	4	5
Not at all		Moderately		Very much

**Do you have any comments about how easy to read and understand you found this report?**

---

---

---

---



## F.9 Debriefing sheet

University of Canterbury  
Department of Communication Disorders  
Private Bag 4800  
Christchurch 8140  
New Zealand



### DEBRIEF INFORMATION

**“Readability and comprehensibility of audiological reports provided to New Zealand caregivers of hearing impaired children.”**

Dear [X],

Thank you for taking the time to participate in this study. The information you provided us was invaluable.

This study aimed to investigate whether it is possible to improve audiology reports written to caregivers of hearing impaired children so they are easier to read and understand. You were randomly assigned to read the [unrevised/ revised] audiology report.

*[For revised report]:*

This report was written at a level that requires just under 6 years of education to understand. The original report was also included in your package as the one with the attached glossary. This original report required nearly 15 years of education to understand, and is not normally sent with a glossary. We hope that you found the revised version of the report to be understandable and easy to read.

OR

*[For original report]:*

This report was written at a level that requires nearly 15 years of education to be able to understand. This makes it a very challenging piece of information to read. We expect that most caregivers would experience difficulty understanding the specific and complex content contained in this report. We hope that we have succeeded in improving this report to be more understandable and readable for caregivers like yourself. [As requested, we have enclosed a copy of the revised report for you to read.]

Please contact Rebecca Kelly Campbell or Ashleigh Donald via 64 (3) 364-2987 ext. 8327. if you have any questions regarding this study.

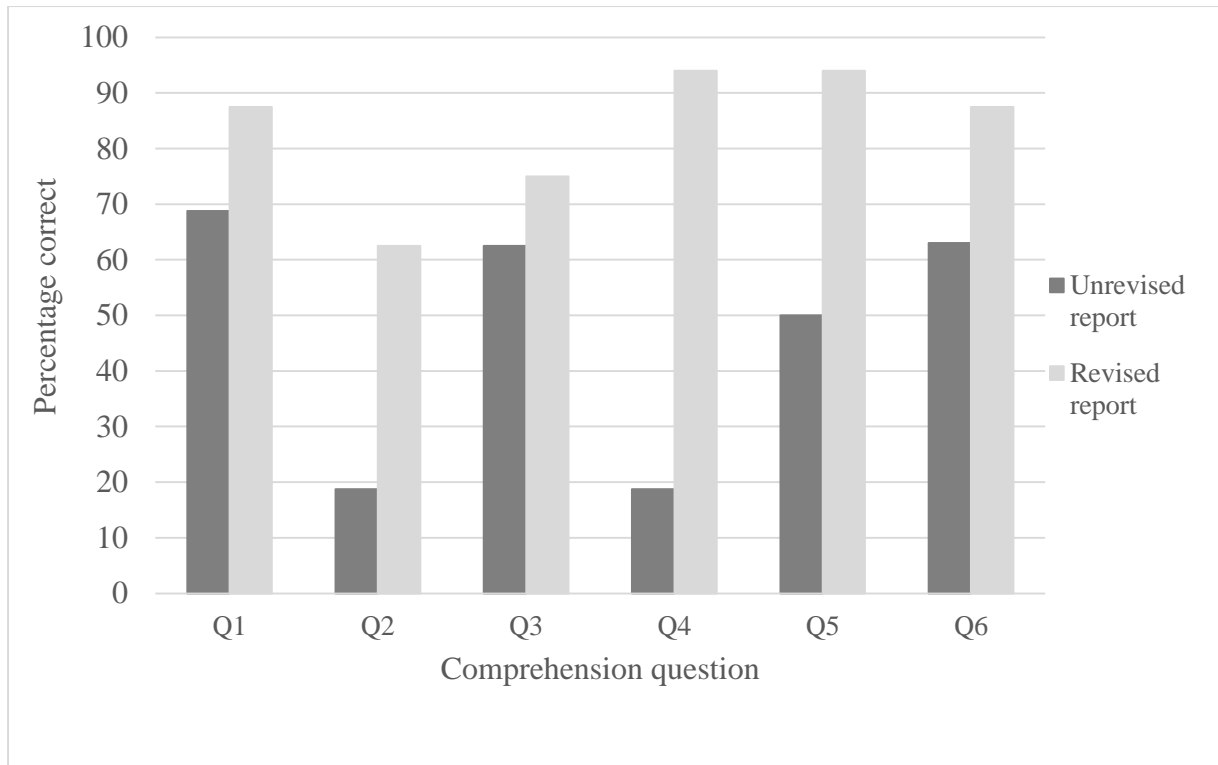
Thank you again for your participation.

**APPENDIX G:**

***FURTHER ANALYSES OF PARTICIPANT RESPONSES TO THE QUESTIONNAIRE***

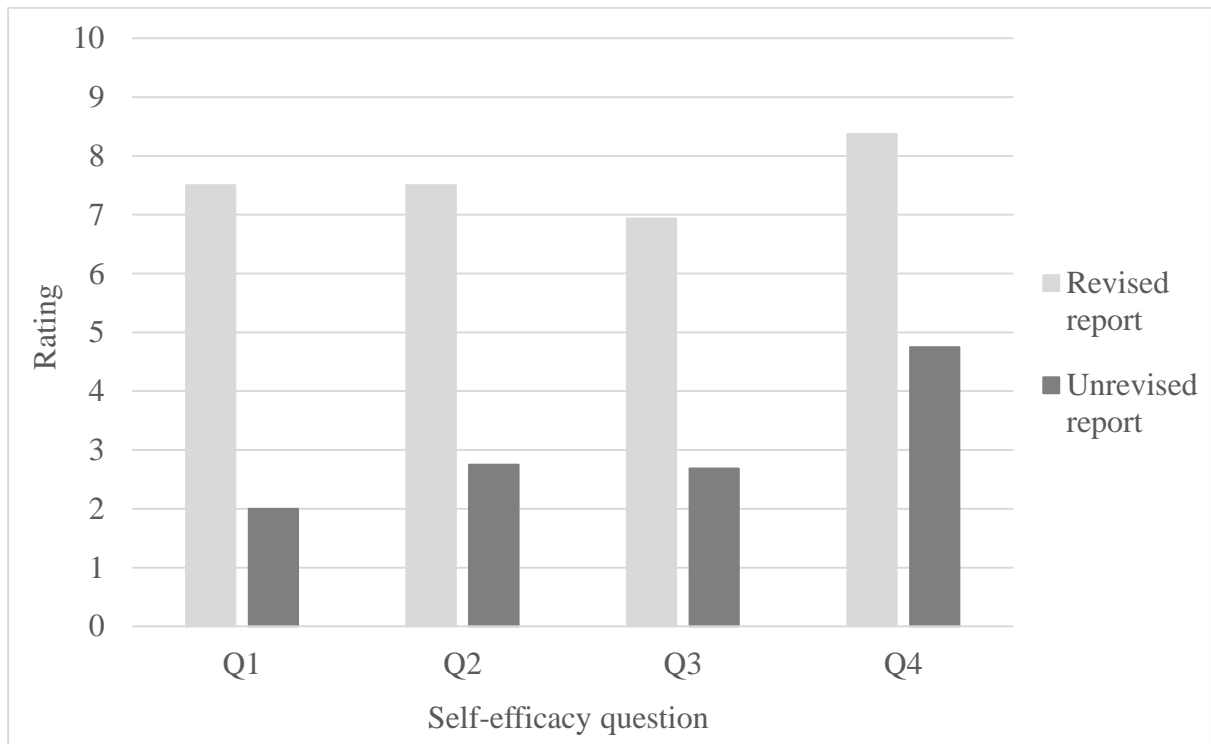
---

**G.1 Comparison of the revised and unrevised report groups on comprehension questions**



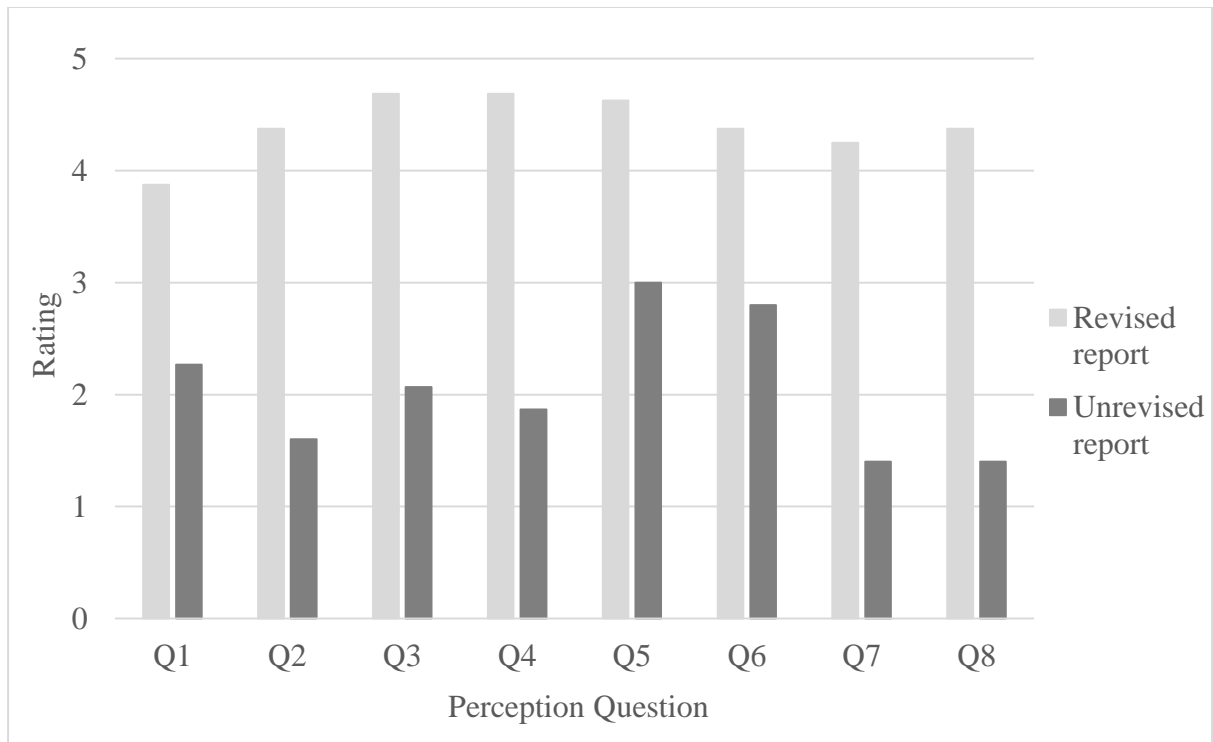
## G.2 Comparison of the revised and unrevised report groups on self-efficacy questions

Note that a higher rating indicates greater self-efficacy for each question.



### G.3 Comparison of the revised and unrevised report groups on the perception questions

Note that a higher rating indicates stronger positive perception for each question.



#### G.4 Additional comments made by participants in the questionnaire

---

#### Unrevised Report

---

<i>Participant</i>	<i>Years of education</i>	<i>Comment</i>
5	12	This was very confusing to read for the average parent with little medical knowledge and I would be concerned if I received this about my child as it is very hard to understand.
8		This report was difficult to understand due to the amount of "technical" wording.
10	13	Most of the report seemed to be in a different language. The recommendation was understandable but not the reason for it. I would have needed to contact someone to help me understand what was Jack's problem.
12	13	The report has too many terms that only a professional would understand e.g. DPOAE ABR etc. As a parent, if my child had a problem with hearing I would want it put in a simple way to understand so I could get a better idea of what to do to fix it.
14	13	Yes, too much jargon. I found the testing part especially confusing.
16	14	Too short, not enough "real" information.
22	14	As mentioned above very frustrating. If I had a more vested interest in this child I would have tried to research the terms online to get a better understanding which could lead me to misleading info.
24	15	Felt that a list of definitions for certain words, particularly "jargon" or "industry" words would have gone a long way in producing some context or understanding (further) to the report. I understand that there may be no way to simplify the actual explanation, but it could help to give some idea to the reader particularly if it is going to be discussed further in terms of why different or specific treatments are being stressed

---



---

## Revised Report

---

<i>Participant</i>	<i>Years of education</i>	<i>Comment</i>
1	17	This report was as I expected. It does contain jargon and medical terms but that is expected. The glossary is helpful as are the coloured headings and matching statements in the summary. It was relatively easy to understand. As a parent I would be happy with this, but would also expect a detailed breakdown by a doctor to explain it.
3	19	I found I skipped most of the glossary section as it was confusing. It was hard to understand most of the report but I managed to understand what they wanted to do now. I figured the most important part knew what to do about the problem. The rest of it I figured it didn't matter if I understood it or not as long as I could understand the solutions.
6	16	As a parent you desperately want to understand a report when you receive it. It is very frustrating when you don't understand what is in it (as with this report). I felt the recommendations were much easier to understand.
7	17	The use of colour was effective when referring to the charts. It was longer in length than expected but easy to read with the attached glossary.
9	13	The report was surprisingly easy to read especially giving day to day examples, e.g. dishwasher on what loudness the tests were.
13	14	I liked the pictures. They helped explain the concepts and results.
15	16	Good idea to have a glossary.
23	16	The report sent to the parent was reasonably easy to understand, although the copy of the medical report confused things, and had to re-read the "parent" report.
26	20	I thought the report did a good job of putting medical terminology and testing into layman's terms. The only confusion I had was that the audiogram showed loudness of 30-40 dB for 500 Hz sound which indicated mild hearing loss at that frequency per to picture on page 4.
27	20	I needed to re-read some parts as I was reading to ensure I understood. The colour-coding and diagrams are helpful.

---

