

**The development of a self-report outcome measure to assess
social participation restrictions in adults with hearing loss**

Eithne Heffernan, BA (Hons) MSc

Thesis submitted to the University of Nottingham
for the degree of Doctor of Philosophy

October 2016

DEDICATION

I would like to dedicate this thesis to my parents and my sister. This thesis would not have been possible without their support.

ABSTRACT

Hearing loss is a widespread condition that can substantially affect not only auditory functioning but also social functioning. Therefore, it is essential to demonstrate that auditory rehabilitation can improve social participation in individuals with hearing loss. However, currently, there is a lack of agreed-upon, gold-standard, hearing-specific outcome measures. Consequently, the primary aim of this research was to develop a high quality measure of hearing-related social participation restrictions for use in research and practice.

To achieve this aim, four consecutive studies were carried out using best practice questionnaire design techniques. Study 1 generated content for the Social Participation Restrictions Questionnaire (SPaRQ) through semi-structured interviews with 25 adults with hearing loss and nine hearing healthcare professionals. Study 2 evaluated the content of the measure through a subject matter expert panel with 20 hearing healthcare professionals and cognitive interviews with 14 adults with hearing loss. Study 3 assessed the psychometric properties of the SPaRQ by applying Rasch analysis to data collected from 279 adults with hearing loss. Finally, Study 4 further assessed the psychometric properties of the SPaRQ by applying traditional psychometric analysis to data collected from a further 102 adults with hearing loss.

This research led to the development of a 19-item questionnaire that measured two key elements: social behaviours (e.g. difficulties with social interactions) and social perceptions (e.g. feelings of isolation). There was

strong evidence to support the measurement properties of SPaRQ, including construct validity, person separation reliability, and internal consistency. Furthermore, the response scale was statistically justified and respondent burden was minimal. Future research should examine additional measurement properties, such as responsiveness and cross-cultural validity. Also, the best practice techniques used in this research should be applied to other new and existing hearing-specific questionnaires to ensure that they meet the requisite standards for use in clinical trials and clinical practice.

ACKNOWLEDGEMENTS

I would like to sincerely thank the following people for their support and guidance:

My supervision team: Mel Ferguson, Neil Coulson, Johanna Barry,
David Maidment, and Helen Henshaw

All of the students and staff in the
Nottingham Hearing Biomedical Research Unit

The participants, the members of the Patient and Public Involvement Panel,
the staff of the Nottingham Audiology Service, and the staff of the Queen
Elizabeth Hospital Audiology Centre who contributed to this research

Mike Horton of the Psychometric Laboratory for Health Sciences in the
University of Leeds

I would also like to thank the organisations who have funded this research:
the National Institute for Health Research and the University of Nottingham.

Finally, I would like to thank my family and friends in Ireland,
the United Kingdom, and beyond.

DECLARATION

I certify that this is my own work, except where indicated by referencing. No part of this thesis has been submitted elsewhere for any other degree or qualification.

Eithne Heffernan

Date

PEER REVIEWED PUBLICATIONS

Publications arising from this thesis

Heffernan, E., Coulson, N.S., Henshaw, H., Barry, J.G. and Ferguson, M.A. (2016). Understanding the psychosocial experiences of adults with mild-moderate hearing loss: An application of leventhal's self-regulatory model. *International Journal of Audiology*, 55(S3), pp.S3-S12.

Other publications

Coulson, N.S., Ferguson, M.A., Henshaw, H. and Heffernan, E. (2016). Applying theories of health behaviour and change to hearing health research: Time for a new approach. *International Journal of Audiology*, 55(S3), pp.S99-S104.

Ferguson, M.A., Coulson, N.S., Henshaw, H. and Heffernan, E. (2016). Editorial: Application of health behaviour theory to hearing healthcare research: The state of play and beyond. *International Journal of Audiology*, 55(S3), pp.S1-S2.

CONFERENCE PRESENTATIONS

Selected oral presentations

Heffernan, E., Barry, J.G., Coulson, N.S., Henshaw, H., Maidment, D. and Ferguson, M.A. (2016). The evaluation of a new outcome measure to assess social participation in adults with mild-moderate hearing loss. *World Congress of Audiology*, Vancouver, Canada.

Heffernan, E., Barry, J.G., Coulson, N.S., Henshaw, H. and Ferguson, M.A. (2016). Utilising health psychology theory to conceptualise the psychosocial experiences of adults with mild-moderate hearing loss: A qualitative study. *World Congress of Audiology*, Vancouver, Canada.

Heffernan, E., Barry, J.G., Coulson, N.S., Henshaw, H., Maidment, D. and Ferguson, M.A. (2016). The evaluation of a new outcome measure to assess social participation in adults with mild-moderate hearing loss. *Hearing Across the Lifespan (HEAL) Conference*, Como, Italy.

Heffernan, E., Coulson, N.S., Henshaw, H. and Ferguson, M.A. (2014). The psychosocial experiences of individuals with hearing loss. *British Society of Audiology Annual Conference*, Keele, UK.

Selected poster presentations

Heffernan, E., Maidment, D., Barry, J.G., Coulson, N.S. and Ferguson, M.A. (2016). The development of a new outcome measure to assess social participation in adults with mild-moderate hearing loss. *International Hearing Aid Conference (IHCON)*, Lake Tahoe, California, USA.

Heffernan, E., Coulson, N.S., Henshaw, H., Barry, J.G. and Ferguson, M.A. (2015). The development of a new aural rehabilitation outcome measure: Utilising the expertise of individuals with hearing loss and hearing healthcare professionals. *British Academy of Audiology Annual Conference*, Harrogate, UK.

Heffernan, E., Coulson, N.S., Henshaw, H., Barry, J.G. and Ferguson, M.A. (2014). The development of a measure of participation in adults with hearing loss: A qualitative study of professional and patient views. *Core Outcome Measures in Effectiveness Trials (COMET) Initiative Conference*, Rome, Italy.

ABBREVIATIONS

AHL	Adult with Hearing Loss
AOHL	Action on Hearing Loss
ASHA	American-Speech-Language-Hearing Association
BRU	Biomedical Research Unit
BSA	British Society of Audiology
CAT	Computerised Adaptive Testing
CFA	Confirmatory Factor Analysis
COM-B	Capability, Motivation, Opportunity - Behaviour Model
COSMIN	COnsensus-based Standards for the selection of health Measurement Instruments
CTT	Classical Test Theory
CVI	Content Validity Index
dB HL	decibels Hearing Level
DIF	Differential Item Functioning
EFA	Exploratory Factor Analysis
EMA	Ecological Momentary Assessment
GBI	Glasgow Benefit Inventory
GHABP	Glasgow Hearing Aid Benefit Profile
HHIE	Hearing Handicap Inventory for the Elderly
HHP	Hearing Healthcare Professional
ICC	Intra-class Correlation Coefficient
ICF	International Classification of Functioning, Disability, and Health
kHz	Kilohertz
KMO	Kaiser Meyer Olkin

LTTs	Latent Trait Theories
NHS	National Health Service
PCA	Principal Component Analysis
PHQ-4	Patient Health Questionnaire-4
PIC	Participant Identification Centre
PPI	Patient and Public Involvement
PSI	Person Separation Index
SD	Standard Deviation
SME	Subject Matter Expert
SPaRQ	Social Participation Restrictions Questionnaire
SRM	Self-regulatory model
SSQ	Speech, Spatial, and Qualities of Hearing Scale
UK	United Kingdom
USA	United States of America
WHO	World Health Organization
WHODAS 2.0	World Health Organization Disability Assessment Schedule 2.0

TABLE OF CONTENTS

DEDICATION.....	1
ABSTRACT	2
ACKNOWLEDGEMENTS	4
DECLARATION.....	5
PEER REVIEWED PUBLICATIONS	6
CONFERENCE PRESENTATIONS	7
ABBREVIATIONS	8
TABLE OF CONTENTS	10
LIST OF TABLES.....	16
LIST OF FIGURES	19
CHAPTER 1. LITERATURE REVIEW.....	21
1.1 INTRODUCTION.....	21
1.2 BACKGROUND TO HEARING LOSS.....	22
1.2.1 Degree of hearing loss.....	22
1.2.2 Types of hearing loss.....	24
1.2.3 Causes of hearing loss	25
1.3 CONSEQUENCES OF HEARING LOSS	26
1.3.1 Activity limitations and participation restrictions	26
1.3.2 Stigma and identity	29
1.3.3 Emotion.....	30
1.3.4 Mental health	31
1.3.5 Cognitive decline and dementia.....	31
1.3.6 Third party disability	32
1.4 AUDITORY REHABILITATION	33
1.5 THEORETICAL PERSPECTIVES ON HEARING LOSS.....	35
1.5.1 Transtheoretical model of behaviour change	35
1.5.2 Health belief model	37
1.5.3 Social cognitive theory and self-efficacy	38
1.5.4 Future theoretical perspectives.....	41
1.6 OUTCOME MEASUREMENT IN AUDITORY REHABILITATION	42
1.6.1 Current issues in outcome measurement	42
1.6.2 Core sets for hearing loss	46
1.6.3 Measurement of participation restrictions	49

1.7 AIMS AND OBJECTIVES.....	53
1.8 DESIGN.....	55
1.8.1 Mixed methods research.....	55
1.8.2 Stages of outcome measure development.....	55
1.9 CONCLUSION	58
CHAPTER 2. STUDY 1: A QUALITATIVE EXPLORATION OF THE PSYCHOSOCIAL EXPERIENCES OF ADULTS WITH HEARING LOSS ..	60
2.1 INTRODUCTION.....	60
2.2 AIMS AND OBJECTIVES.....	60
2.3 DESIGN.....	61
2.3.1 Qualitative research	61
2.3.2 Theoretical framework	63
2.3.3 Sample size	67
2.4 METHODS	68
2.4.1 Participants	68
2.4.2 Recruitment	69
2.4.3 Materials	73
2.4.4 Study procedure	74
2.5 DATA ANALYSIS	76
2.5.1 Thematic Analysis.....	76
2.5.2 Peer assessment	80
2.6 RESULTS.....	81
2.6.1 Theme 1: Cognitive representations of hearing loss	81
2.6.2 Theme 2: Emotional representations of hearing loss	92
2.6.3 Theme 3: Coping responses to hearing loss.....	96
2.7 DISCUSSION	104
2.7.1 Cognitive representations of hearing loss	104
2.7.2 Emotional representations of hearing loss	106
2.7.3 Coping responses to hearing loss.....	107
2.7.4 Limitations.....	109
2.7.5 Future research	111
CHAPTER 3. STUDY 2: THE DEVELOPMENT AND CONTENT EVALUATION OF THE SOCIAL PARTICIPATION RESTRICTIONS QUESTIONNAIRE	113
3.1 INTRODUCTION.....	113
3.2 CONTENT GENERATION	113

3.2.1 Conceptualisation	113
3.2.2 Item generation	117
3.2.3 Response scale design	121
3.2.4 Item ordering	125
3.3 CONTENT EVALUATION	126
3.4 AIMS AND OBJECTIVES	127
3.5 DESIGN	128
3.5.1 Subject matter expert survey	128
3.5.2 Cognitive interview	129
3.5.3 Sample size	130
3.6 METHODS	131
3.6.1 Participants	131
3.6.2 Recruitment	132
3.6.3 Materials	136
3.6.4 Study procedure	139
3.7 DATA ANALYSIS	142
3.7.1 Descriptive statistics	143
3.7.2 Thematic analysis	144
3.7.3 Taxonomy of respondent problems	144
3.8 RESULTS	147
3.8.1 Descriptive statistics results	148
3.8.2 Thematic analysis results	165
3.8.3 Taxonomy of respondent problems results	172
3.9 DISCUSSION	180
3.9.1 Construct Definition	181
3.9.2 Factor structure	182
3.9.3 Representativeness of the items	183
3.9.4 Clarity	184
3.9.5 Comprehensiveness of the questionnaire	188
3.9.6 Appropriateness of the response scale	189
3.9.7 Sensitivity of the questionnaire	193
3.9.8 Acceptability of the questionnaire	194
3.9.9 Limitations	195
3.9.10 Future research	198

CHAPTER 4. STUDY 3: RASCH ANALYSIS OF THE SOCIAL PARTICIPATION RESTRICTIONS QUESTIONNAIRE.....	200
4.1 INTRODUCTION.....	200
4.2 AIMS AND OBJECTIVES.....	200
4.3 DESIGN.....	201
4.3.1 Psychometric properties	201
4.3.2 Psychometric analysis	203
4.3.3 Sample size	215
4.3.4 Mode of delivery	216
4.4 METHODS	217
4.4.1 Participants.....	217
4.4.2 Recruitment	218
4.4.3 Materials	222
4.4.4 Study procedure	223
4.5 DATA ANALYSIS	224
4.5.1 Traditional psychometric analysis	224
4.5.2 Rasch analysis.....	227
4.6 INITIAL DATA SCREENING	236
4.6.1.1 Management of missing scores	236
4.6.1.2 Removal of Items.....	237
4.7 EXPLORATORY FACTOR ANALYSIS RESULTS.....	238
4.8 FURTHER DATA SCREENING	243
4.8.1 Choice of model derivation	243
4.8.2 Division of items.....	244
4.8.3 Removal of participants	245
4.8.4 Management of missing scores	247
4.8.5 Class intervals	248
4.9 RASCH ANALYSIS RESULTS.....	248
4.9.1 Social behaviours set.....	248
4.9.2 Social perceptions set.....	259
4.9.3 Summary of results	269
4.10 DISCUSSION.....	271
4.10.1 Factor structure.....	272
4.10.2 Item reduction	272
4.10.3 Local independence and fit to the Rasch model	274

4.10.4 Targeting.....	276
4.10.5 Person separation reliability.....	277
4.10.6 Threshold ordering.....	277
4.10.7 Limitations.....	277
4.10.8 Future research	278
CHAPTER 5. STUDY 4: TRADITIONAL PSYCHOMETRIC ANALYSIS OF THE SOCIAL PARTICIPATION RESTRICTIONS QUESTIONNAIRE	280
5.1 INTRODUCTION.....	280
5.2 AIMS AND OBJECTIVES.....	280
5.3 DESIGN.....	281
5.3.1 Traditional psychometric analysis	281
5.3.2 Psychometric properties	282
5.3.3 Sample size	286
5.3.4 Mode of delivery	287
5.4 METHODS	288
5.4.1 Participants	288
5.4.2 Recruitment	288
5.4.3 Materials	291
5.4.4 Study procedure	296
5.5 DATA ANALYSIS	297
5.5.1 Spearman's rank order correlation coefficient.....	298
5.5.2 Mann-Whitney U test	298
5.5.3 Cronbach's alpha.....	298
5.5.4 Descriptive statistics	299
5.6 RESULTS.....	299
5.6.1 Hypothesis testing results	299
5.6.2 Internal consistency results.....	306
5.6.3 Floor and ceiling effects results	308
5.7 DISCUSSION	309
5.7.1 Hypothesis testing	310
5.7.2 Internal consistency	313
5.7.3 Floor and ceiling effects	314
5.7.4 Limitations.....	317
5.7.5 Future research	320

CHAPTER 6. DISCUSSION	322
6.1 SUMMARY OF RESEARCH AND KEY FINDINGS	322
6.2 NOVEL CONTRIBUTIONS OF THE SPARQ	327
6.3 THEORETICAL IMPLICATIONS	331
6.3.1 Health psychology theory.....	331
6.3.2 Conceptualisation of participation restrictions	334
6.4 IMPLICATIONS FOR RESEARCH AND CLINICAL PRACTICE	341
6.5 FUTURE RESEARCH	344
6.5.1 Future directions for the SPaRQ.....	344
6.5.2 Future directions for outcome measurement	347
6.6 CONCLUSION	349
CHAPTER 7. APPENDICES	350
7.1 APPENDIX A. THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH (ICF) CORE SETS FOR HEARING LOSS	350
7.2 APPENDIX B. GLASGOW HEARING AID BENEFIT PROFILE	355
7.3 APPENDIX C. STUDY 1 SEMI-STRUCTURED INTERVIEW SCHEDULES	359
7.3.1 Interview schedule for the adults with hearing loss	359
7.3.2 Interview schedule for hearing healthcare professionals	360
7.4 APPENDIX D. FIRST PROTOTYPE OF THE SOCIAL PARTICIPATIONS RESTRICTIONS QUESTIONNAIRE (SPaRQ1.0) ...	361
7.5 APPENDIX E. HEARING LOSS SCREENING QUESTIONNAIRE ..	367
7.6 APPENDIX F. STUDY 2 COGNITIVE INTERVIEW SCHEDULE FOR THE ADULTS WITH HEARING LOSS	369
7.7 APPENDIX G. SECOND PROTOTYPE OF THE SOCIAL PARTICIPATIONS RESTRICTIONS QUESTIONNAIRE (SPaRQ2.0) ...	370
7.8 APPENDIX H. THIRD PROTOTYPE OF THE SOCIAL PARTICIPATIONS RESTRICTIONS QUESTIONNAIRE (SPaRQ3.0) ...	378
7.9 APPENDIX I. HEARING HANDICAP INVENTORY FOR THE ELDERLY	382
7.10 APPENDIX J. WORLD HEALTH ORGANIZATION DISABILITY ASSESSMENT SCHEDULE 2.0 SELF-ADMINISTERED SHORTENED VERSION	384
7.11 APPENDIX K. PATIENT HEALTH QUESTIONNAIRE-4 (PHQ-4) ..	385
7.12 APPENDIX L. FINALISED SOCIAL PARTICIPATIONS RESTRICTIONS QUESTIONNAIRE (SPaRQ).....	386
REFERENCES	390

LIST OF TABLES

CHAPTER 1

Table 1.1 Classification of hearing loss.....	23
Table 1.2 Key measurement properties for outcome measures.....	45
Table 1.3 Summary of research objectives and methods	59

CHAPTER 2

Table 2.1 Demographic information of the study 1 adults with hearing loss	71
Table 2.2 Demographic information of the study 1 hearing healthcare professionals.....	72

CHAPTER 3

Table 3.1 Subdomains of the SPaRQ	118
Table 3.2 Abbreviated content of the behaviour items	120
Table 3.3 Abbreviated content of the emotion and identity items.....	122
Table 3.4 Demographic information of the study 2 subject matter experts	133
Table 3.5 Demographic information of the study 2 adults with hearing loss	134
Table 3.6 Study 2 objectives, methods, and data analysis summary	147
Table 3.7 Descriptive statistics of the behaviour items representativeness ratings	152
Table 3.8 Descriptive statistics of the behaviour items clarity ratings	154
Table 3.9 Descriptive statistics of the emotion items representativeness ratings	156
Table 3.10 Descriptive statistics of the emotion items clarity ratings	157
Table 3.11 Descriptive statistics of the identity items representativeness ratings	158
Table 3.12 Descriptive statistics of the identity items clarity ratings	159
Table 3.13 Descriptive statistics of the representativeness and clarity ratings for the SPaRQ1.0 and its subscales	160
Table 3.14 Revised content of the behaviour items	190
Table 3.15 Revised content of the emotion and identity items	192

CHAPTER 4

Table 4.1 Summary of psychometric analyses performed	214
Table 4.2 Demographic information of the study 3 participants	219
Table 4.3 Eigenvalues and percentage of variance explained	239
Table 4.4 Factor correlation matrix	240
Table 4.5 Factor 1 pattern matrix and structure matrix	241
Table 4.6 Factor 2 and factor 3 pattern matrix and structure matrix.....	242
Table 4.7 Factor 2 and factor 3 item content	243
Table 4.8 Participants removed from the social behaviours item analysis .	246
Table 4.9 Participants removed from the social perceptions item analysis	247
Table 4.10 First social behaviours shortlist: Residual correlation matrix....	249
Table 4.11 First social behaviours shortlist: Individual item fit statistics.....	251
Table 4.12 Second social behaviours shortlist: Residual correlation matrix	254
Table 4.13 Second social behaviours shortlist: Individual item fit statistics	255
Table 4.14 Third social behaviours shortlist: Residual correlation matrix...	257
Table 4.15 Third social behaviours shortlist: Individual item fit statistics....	259
Table 4.16 First social perceptions shortlist: Residual correlation matrix...	260
Table 4.17 First social perceptions shortlist: Individual item fit statistics	261
Table 4.18 Rescoring of items with disordered thresholds.....	264
Table 4.19 Second social perceptions shortlist: Residual correlation matrix	267
Table 4.20 Second social perceptions shortlist: Individual item fit statistics	268
Table 4.21 Refined content of the SPaRQ	270

CHAPTER 5

Table 5.1 Demographic information of the study 4 participants	289
Table 5.2 Shapiro-Wilk tests of normality.....	297
Table 5.3 Social behaviours subscale Spearman's rank order correlation coefficients*	301
Table 5.4 Social perceptions subscale Spearman's rank order correlation coefficients*	304
Table 5.5 Mean inter-item correlations and mean item-total correlations...	307

Table 5.6 Cronbach's alpha values	308
Table 5.7 Social behaviours subscales floor and ceiling effects	309
Table 5.8 Social perceptions subscales floor and ceiling effects	310

CHAPTER 6

Table 6.1 Summary of programme of research	323
Table 6.2 Evaluation of the quality of the finalised SPaRQ.....	326
Table 6.3 ICF categories of functioning measured by the SPaRQ.....	339

LIST OF FIGURES

CHAPTER 1

Figure 1.1 ICF graphic model.....	48
-----------------------------------	----

CHAPTER 2

Figure 2.1 The self-regulatory model	65
--	----

CHAPTER 3

Figure 3.1 Expert panel construct definition assessment.....	148
Figure 3.2 Expert panel factor structure assessment.....	151
Figure 3.3 Expert panel comprehensiveness assessment.....	160
Figure 3.4 Expert panel sensitivity assessment	163
Figure 3.5 Expert panel response scale assessment.....	164

CHAPTER 4

Figure 4.1 Exploratory factor analysis scree plot	239
Figure 4.2 First social behaviour shortlist: Person-item threshold distribution (including extreme scores)	250
Figure 4.3 First social behaviour shortlist: Item characteristic curve for item 17	251
Figure 4.4 First social behaviours shortlist: Threshold map	252
Figure 4.5 First social behaviours shortlist: Category probability curve for item 26	252
Figure 4.6 First social behaviours shortlist: Differential item functioning associated with gender for item 26	253
Figure 4.7 Second social behaviours shortlist: Person-item threshold distribution (including extreme scores).....	254
Figure 4.8 Second social behaviours shortlist: Item characteristic curve for item 1	256
Figure 4.9 Second social behaviours shortlist: Item characteristic curve for item 12	256
Figure 4.10 Second social behaviours shortlist: Threshold map	257

Figure 4.11 Third social behaviours shortlist: Person-item threshold distribution (including extreme scores).....	258
Figure 4.12 Third social behaviours shortlist: Threshold map	259
Figure 4.13 First social perceptions shortlist: Person-item threshold distribution (including extreme scores).....	261
Figure 4.14 First social perceptions shortlist: Item characteristic curve for item 44	262
Figure 4.15 First social perceptions shortlist: Threshold map	262
Figure 4.16 First social perceptions shortlist: Category probability curve for item 34	263
Figure 4.17 First social perceptions shortlist: Category probability curve for item 41	263
Figure 4.18 Rescored social perceptions shortlist: Threshold map.....	264
Figure 4.19 Rescored social perceptions shortlist: Category probability curve for item 34	265
Figure 4.20 Rescored social perceptions shortlist: Category probability curve for item 41	265
Figure 4.21 Rescored social perceptions shortlist: Item characteristic curve for item 44	266
Figure 4.22 Second social perceptions shortlist: Person-item threshold distribution (including extreme scores).....	268
Figure 4.23 Second social perceptions shortlist: Threshold map	269

CHAPTER 5

Figure 5.1 Histogram of an item displaying a ceiling effect	311
Figure 5.2 Histogram of an item displaying a floor effect	312

CHAPTER 1. LITERATURE REVIEW

1.1 INTRODUCTION

Hearing loss is a widespread condition that affects an estimated 1.33 billion individuals worldwide, which means that it is one of the three most common impairments to affect people, alongside anaemia and vision loss (Vos et al., 2016). In the UK alone, 11 million adults have hearing loss, which represents approximately 17% of the population. As one of the most common causes of hearing loss is ageing, the prevalence of the condition is much greater in older adults. For example, in the UK, 41.7% of those over 50 years old and 71.1% of those over 70 years old have hearing loss (AOHL 2015). The prevalence of this condition is likely to increase in line with increases in life expectancy (Roth, Hanebuth and Probst 2011).

In addition to being pervasive, hearing loss can have substantial negative consequences (Arlinger 2003). One of the main negative consequences of the condition is that it is not only a sensory loss but also a social loss, as it can restrict participation in social activities, social relationships, and social roles (Ciorba et al., 2012; Gopinath et al., 2012a; Kramer et al., 2002).

Restricted participation has, in turn, been related to a host of negative outcomes, including depression, dementia, and mortality (Bath and Deeg 2005). It is vital to evaluate whether or not auditory rehabilitation reduces participation restrictions in individuals with hearing loss (Boothroyd 2007). However, currently there is a lack of validated, gold-standard, hearing-specific outcome measures (Akeroyd et al., 2015; Granberg et al., 2014a). Furthermore, participation has proven to be one of the most difficult healthcare outcomes to measure (Dijkers 2010).

Consequently, the primary aim of this doctoral programme of research was to develop a self-report outcome measure, or questionnaire, that can assess participation restrictions in adults with hearing loss. Participation restrictions are defined as the problems an individual experiences in involvement in life situations, particularly social situations (WHO 2001). In the future, this outcome measure could be used in research and clinical practice to evaluate whether auditory rehabilitation services and interventions reduce participation restrictions in adults with hearing loss. The questionnaire was developed across four research studies, which were conducted in accordance with best practice recommendations from the literature in order to ensure that the measure meets the required quality standards (Mokkink et al., 2012; Pesudovs et al., 2007; Turk et al., 2006). Initially, qualitative research, in which key stakeholders were consulted, was carried out so that the measure has sufficient content validity and minimal patient burden. Subsequently, quantitative research that combined traditional and modern psychometric analyses was conducted so that the measure had adequate psychometric properties, including construct validity and person separation reliability. This rigorous approach was intended to set the outcome measure apart from its predecessors and to establish it as gold-standard tool suited for use in research and practice.

1.2 BACKGROUND TO HEARING LOSS

1.2.1 Degree of hearing loss

Cases of hearing loss are typically classified as mild, moderate, severe, or profound (BSA 2011; WHO 2015). Each of these four classifications is associated with a band of average pure-tone hearing thresholds, normally

measured in decibels Hearing Level (dB HL) across a range of frequencies, as depicted in Table 1.1. In other words, these classifications are defined by the quietest sound an individual is able to hear. It is important to note that these classifications are not a direct measure of disability (BSA 2011; Cox 2003). This means that it is possible for an individual with moderate hearing loss to experience a greater degree of hearing-related difficulty in everyday life than an individual with severe hearing loss.

Table 1.1 Classification of hearing loss

Hearing loss classification	Average hearing threshold levels at 0.25, 0.5, 1, 2, & 4 kilohertz (kHz)
Mild	20-40 dB HL
Moderate	41-70 dB HL
Severe	71-95 dB HL
Profound	Greater than 95 dB HL

Mild-to-moderate hearing loss is somewhat distinct from severe-to-profound hearing loss. Prior to receiving an intervention, individuals with mild-to-moderate hearing loss often experience difficulties discriminating speech sounds, whereas individuals with severe-to-profound hearing loss often do not hear any speech sounds (AOHL 2015; Dillon 2001). Furthermore, mild-to-moderate hearing loss is by far the most common form of hearing loss. It is estimated that, of the 11 million people with hearing loss in the UK, just 910,000 have severe-to-profound hearing loss (AOHL 2015). It is also possible to distinguish the term 'hard of hearing' from the term 'Deaf'. The former normally refers to individuals with mild-to-severe hearing loss who tend to communicate through spoken language, whilst the latter normally

refers to individuals who have profound hearing loss and who tend to communicate through sign language and speech-reading (Luey, Glass and Elliott 1995; WHO 2015). Whilst individuals who are hard of hearing can become isolated from their former social contacts who have normal hearing, individuals who are Deaf often belong to the Deaf community, which has its own culture, identity, social networks, and organisations. Therefore, members of the Deaf community may have different, and possibly fewer, participation restrictions than individuals who are hard of hearing (AOHL 2015; Fellingner et al., 2007; Reagan 1995). This doctoral research, including this literature review, examines mild-to-severe hearing loss in adults, with an emphasis on mild-to-moderate hearing loss.

1.2.2 Types of hearing loss

The principal types of hearing loss are conductive hearing loss, sensorineural hearing loss, and mixed conductive and sensorineural hearing loss (ASHA 2015; Kochhar, Hildebrand and Smith 2007). Conductive hearing loss involves abnormalities in the external ear or middle ear that affect the transmission of sound to the inner ear and is caused by various conditions, including excessive wax, infections, otosclerosis, and perforated eardrums (Elberling and Worsoe 2006; Holley 2005). This form of hearing loss can often be corrected surgically or medically, such as through tympanoplasty and stapedectomy (ASHA 2015; Nadol 1993). Sensorineural hearing loss is caused by damage to the inner ear, particularly the cochlear hair cells, or to the nerve pathways from the inner ear to the brain (Elberling and Worsoe 2006; Holley 2005). The causes of sensorineural hearing loss include genetic and hereditary factors, ototoxicity, and noise exposure (Daniel 2007; Nadol

1993). In the majority of cases, sensorineural hearing loss cannot be corrected medically or surgically and is therefore permanent (ASHA 2015). Individuals with sensorineural hearing loss can engage in auditory rehabilitation to manage the difficulties caused by this condition (Boothroyd 2007).

Hearing loss can also be categorised in terms of whether there is a loss of hearing in both ears (i.e. bilateral hearing loss) or whether there is a loss of hearing in one ear and normal hearing in the other ear (i.e. unilateral hearing loss). In addition, hearing loss can be categorised in terms of whether there is the same degree and configuration of loss in both ears (i.e. symmetrical hearing loss) or whether the degree and configuration of the loss differ between the two ears (i.e. asymmetrical hearing loss) (ASHA 2015). Finally, hearing loss can be categorised in terms of its onset. Specifically, hearing loss can have a sudden onset or it can be progressive (ASHA 2015). Onset can take place at any stage of the lifespan. Congenital causes of hearing loss (e.g. birth asphyxia) can lead to the development of hearing loss at birth or shortly after birth, whereas acquired causes of hearing loss (e.g. noise exposure) can lead to the development of hearing loss at any age (WHO 2015).

1.2.3 Causes of hearing loss

Hearing loss can be the result of modifiable causes, non-modifiable causes, or a combination of the two. Specific causes include ototoxic medications, infections (e.g. rubella), immune mediated diseases (e.g. polychondritis), head injuries, tumours (e.g. acoustic neuroma), syndromes (e.g. Usher's syndrome), degenerative disorders (e.g. Meniere's disease), and genetic

anomalies (Bisht and Bist 2011; Daniel 2007; Hutchin and Cortopassi 2000; Kochhar, Hildebrand and Smith 2007; Nadol 1993; Palmer et al., 2004). In addition, noise exposure, particularly excessive or occupational noise exposure, contributes to the development of hearing loss (Kurmis and Apps 2007; Nelson et al., 2005; Palmer et al., 2004). Also, male gender and cigarette-smoking are amongst the risk factors for hearing loss (Agrawal, Platz and Niparko 2008; Cruickshanks et al., 1998). In adulthood, one of the primary causes of hearing loss is ageing (Yamasoba et al., 2013). It is thought that age-related hearing loss, or presbycusis, is the gradual result of the cumulative effects of harmful influences like noise exposure, ototoxic drugs, and genetically determined degeneration (Nadol 1993).

1.3 CONSEQUENCES OF HEARING LOSS

Hearing loss can have a considerable negative impact on numerous aspects of daily life (Arlinger 2003). The main consequences of hearing loss are considered below (Vas, Akeroyd and Hall under review).

1.3.1 Activity limitations and participation restrictions

Activity limitations are difficulties in performing tasks or actions, whilst participation restrictions are difficulties with involvement in life situations (WHO 2001). In terms of hearing loss, activity limitations can be conceived of as auditory functioning difficulties, whereas participation restrictions can be conceived of as social functioning difficulties. A variety of studies have reported that many individuals with hearing loss experience these difficulties (Dalton et al., 2003; Hickson et al., 2008; Strawbridge et al., 2000; Vas, Akeroyd and Hall under review). In terms of activity limitations, individuals with hearing loss have been reported to experience difficulties with the

following tasks: communicating in the presence of background noise; contributing to group conversations; communicating with children; communicating with unfamiliar people; hearing in restaurants, lectures, parties, and theatres; listening to the radio or television; using the telephone; detecting and localising sounds; paying attention; going places and using transportation; shopping; and housework (Albera et al., 2001; Dalton et al., 2003; Gopinath et al., 2012b; Granberg et al., 2014b; Hallberg and Carlsson 1993; Kramer, Kapteyn and Festen 1998; Stephens et al., 1990; Strawbridge et al., 2000). Such activity limitations have the potential to reduce the independence of individuals with hearing loss and make them more reliant on support services and significant others (Gopinath et al., 2012b; Schneider et al., 2010).

In terms of participation restrictions, people with hearing loss are reported to experience difficulties in the following life situations: socialising with others; establishing new contacts; family relationships and home life; romantic relationships; recreation and leisure; religious and spiritual life; volunteering and community life; and education, training, and employment (Granberg et al., 2014b; Granberg et al., 2014c; Hallberg and Carlsson 1993; Stam et al., 2013; Vas, Akeroyd and Hall under review; Woodcock and Pole 2008). The life situation of employment has received particular attention in hearing research. Studies from various countries have shown that individuals with hearing loss are more likely to have lower incomes, higher unemployment rates, and lower full-time employment rates (Dalton et al., 2003; Hogan et al., 2009; Jung and Bhattacharyya 2012; Ruben 2000; Rydberg, Gellerstedt and Danermark 2010; Stam et al., 2013). In the workplace, individuals with

hearing loss can encounter a range of barriers to both performance and safety, including a lack of organisational support and appropriate facilities (Fok et al., 2009; Jennings and Shaw 2008; Morata et al., 2005; Punch, Hyde and Power 2007; Shaw et al., 2013; Tye-Murray, Spry and Mauzé 2009). There is also evidence to suggest that employees with hearing loss take more sick-leave and have poorer psychological wellbeing than their normal hearing colleagues (Kramer, Kapteyn and Houtgast 2006; Monzani et al., 2008).

Activity limitations and participation restrictions mean that many individuals with hearing loss are at risk of becoming socially isolated. Indeed, several studies have provided evidence of a significant association between hearing loss and social isolation (Gopinath et al., 2012a; Jang et al., 2003; Kramer et al., 2002; Mulrow et al., 1990b; Strawbridge et al., 2000; Weinstein and Ventry 1982). However, some studies have not found evidence of this relationship (Clark, Bond and Sanchez 1999; Thomas et al., 1983; Yamada et al., 2012) or have found evidence only in particular subgroups (Mick, Kawachi and Lin 2014; Mick and Pichora-Fuller 2016; Mikkola et al., 2016; Pronk et al., 2011). It may be that participants with gradual-onset hearing loss, and possibly also good economic resources, have the opportunity to adjust to hearing loss (Tesch-Römer 1997; Thomas et al., 1983). Also, hearing loss may have a greater impact on certain social activities, such as meeting friends and group activities, than on other social activities, such as meeting relatives or solitary pursuits (Crews and Campbell 2004; Mikkola et al., 2015). It could also be that inconsistent findings in the literature are due to inconsistencies in the conceptualisation of participation (Mikkola et al., 2015)

or due to the use of measures of participation restrictions that have not been adequately validated (Mick, Kawachi and Lin 2014). These concerns are discussed further later in the 'Outcome measurement in auditory rehabilitation' section below.

1.3.2 Stigma and identity

Stigma refers to the possession of a trait that is devalued or shameful in a particular social context and thus threatens or diminishes one's social identity (Gagné, Jennings and Southall 2009). Social identity refers to the aspects of our self-concept, or our sense of who and what we are, that are derived from membership of certain social categories or social groups, such as belonging to a certain culture, ethnicity, religion, or sexuality (Crocker 1999; Jennings, Southall and Gagné 2013). It is thought that belonging to a valued social group is a vital aspect of psychological wellbeing, as these groups are a source of security, self-esteem, companionship, resources, learning, and purpose (Haslam et al., 2009). Stigmatisation occurs when certain attributes, such as having a disability, are viewed as an indicator that one is a member of a marginalised, low status social group (Major and O'Brien 2004).

Several studies have shown that having hearing loss or wearing hearing aids can affect the identity of individuals with hearing loss and lead them to feel stigmatised (Blood 1997; Doggett, Stein and Gans 1998; Erlen and Garstecki 2002; Espmark and Scherman 2003; Héту 1996; Southall, Gagné and Jennings 2010; Wallhagen 2010). Specifically, individuals with hearing loss can believe they are perceived as being old, disabled, unintelligent, incompetent, cognitively impaired, socially impaired, passive, unfriendly, bothersome to others, lacking in authority, or lacking in confidence (Doggett,

Stein and Gans 1998; Jonsson and Hedelin 2012; Southall, Gagné and Jennings 2010; Wallhagen 2010). These negative attitudes towards individuals with hearing loss can be held by friends, family, colleagues, the media, and even by individuals with hearing loss themselves, which is known as self-stigma (Gagné, Jennings and Southall 2009; Hetu et al., 1990; Wallhagen 2010). In some cases, the stigmatisation of hearing loss can lead people to deny or conceal the condition, to avoid seeking help and adhering to interventions, and to avoid directly informing social contacts and colleagues that they have the condition unless it is entirely necessary to do so (Erler and Garstecki 2002; Hetu et al., 1990; Jennings, Southall and Gagné 2013; Shaw et al., 2013; Southall, Gagné and Jennings 2010; Wallhagen 2010).

1.3.3 Emotion

It has been demonstrated that hearing loss can negatively affect emotional wellbeing (Eriksson-Mangold and Carlsson 1991; Gopinath et al., 2012a; Mulrow et al., 1990b; Southall, Gagné and Jennings 2010). In particular, research has shown that hearing loss is significantly associated with loneliness and that individuals with hearing loss frequently report feeling a sense of isolation due to their condition (Kramer et al., 2002; Nachtegaal et al., 2009; Pronk et al., 2011; Pronk, Deeg and Kramer 2013; Savikko et al., 2005; Sung et al., 2015; Vas, Akeroyd and Hall under review). There is also some evidence to indicate that individuals with hearing loss can experience worry, stress, frustration, and embarrassment due to their condition (Gopinath et al., 2012a; Hallberg and Carlsson 1993; Hickson et al., 2008; Nachtegaal et al., 2009; Southall, Gagné and Jennings 2010).

1.3.4 Mental health

There is evidence to suggest that hearing loss is associated with poor mental health. Specifically, several studies have found that hearing loss is linked to depressive symptoms (Abrams et al., 2006; Gopinath et al., 2009; Kramer et al., 2002; Nachtegaal et al., 2009; Saito et al., 2010). It has also been found that hearing aid use is related to reductions in these symptoms (Acar et al., 2011; Boi et al., 2012; Mener et al., 2013; Mulrow et al., 1990a). It has been proposed that the social isolation arising from hearing loss could in turn lead to depression (Acar et al., 2011; Boi et al., 2012). In addition, there is some evidence, though it is rather inconsistent, that hearing loss is associated with anxiety symptoms (Helvik, Jacobsen and Hallberg 2006b; Jones, Victor and Vetter 1984; Mehta et al., 2003; Stephens 1980; Tambs 2004). Further research is needed to clarify the nature of the association between hearing loss and mental health conditions, including the magnitude and underlying causes of this association.

1.3.5 Cognitive decline and dementia

Hearing loss has been associated with cognitive decline and dementia, though the specific mechanisms underlying this association are currently unknown (Dawes et al., 2015b; Lin et al., 2011; Pichora-Fuller et al., 2013). One proposal is that the social isolation arising from hearing loss contributes to the development of dementia by reducing auditory and intellectual stimulation (Lin et al., 2011). Another possibility is that certain regions of the brain change with ageing, resulting in both auditory and cognitive decline (Lin 2011; Pichora-Fuller et al., 2013). Nevertheless, it is clear that both conditions are prevalent in older adults and have similar symptoms, including

social isolation, conversation difficulties, and memory problems (Jorgensen, Palmer and Fischer 2014). Therefore, it has been hypothesised that hearing aid use can alleviate the symptoms of cognitive decline and dementia. While some studies support this hypothesis (Acar et al., 2011; Dawes et al., 2015b; Palmer et al., 1999), others do not (Allen et al., 2003; Dawes et al., 2015a).

1.3.6 Third party disability

Communication partners are those with whom individuals with hearing loss regularly communicate, including friends and family (Kramer 2005; Manchaiah et al., 2012). Various studies have found that communication partners, particularly spouses, can experience third party disability, which means that they can be negatively affected by hearing loss, despite not having the condition themselves (Govender et al., 2014; Manchaiah et al., 2012; Preminger 2003; Scarinci, Worrall and Hickson 2008; Scarinci, Hickson and Worrall 2011; Wallhagen et al., 2004). For instance, communication partners can find that they have fewer conversations with their spouse and also that these conversations are less enjoyable and less intimate (Echalier 2010; Scarinci, Worrall and Hickson 2008). Also, communication partners may be forced to engage in social activities alone instead of with their spouse, may engage in fewer social activities, and may obtain less enjoyment from social activities. Hearing loss can also lead to greater conflict and misunderstandings between communication partners and their spouses. These various difficulties can lead communication partners to experience negative emotions, including sadness, stress, embarrassment, and isolation (Donaldson, Worrall and Hickson 2004; Vas, Akeroyd and Hall under review; Wallhagen et al., 2004).

1.4 AUDITORY REHABILITATION

Auditory rehabilitation refers to a variety of services and interventions that aim to improve not only sensory functioning but also activity, participation, and quality of life (Boothroyd 2007). In the UK, individuals with hearing loss typically obtain auditory rehabilitation by being referred to a National Health Service (NHS) audiology clinic by their general practitioner. The majority of these clinics provide hearing healthcare free-of-charge, though some individuals with hearing loss nonetheless opt to pay for hearing healthcare from a private sector provider (Matthews 2011).

Currently, the main intervention for hearing loss is the provision of either one or two hearing aids. A hearing aid is a device that fits in the ear or behind the ear and that amplifies sound, including speech and environmental sounds, to a level that can be perceived by the wearer (Boothroyd 2007; Dillon 2001). Individuals with hearing loss can also obtain assistive listening devices, or equipment that enhances speech intelligibility (e.g. amplified telephone, induction loops) or the detection of environmental sounds (e.g. vibrating alarm clock, doorbell with flashing light) (Dillon 2001). In addition, they can undergo auditory training, (i.e. training in differentiating between individual speech sounds), and communication training (i.e. training in understanding and interpreting conversation and natural speech) (Dillon, 2001; Henshaw and Ferguson, 2013a). There has also been a growth in the availability of telehealth interventions, such as educational and counselling programmes delivered via video tutorials, mobile applications, and websites (Leighton et al., 2013; Martínez-Pérez, De La Torre-Díez and López-Coronado, 2013; Swanepoel and Hall 2010). In addition to these technological interventions,

individuals with hearing loss can use hearing strategies, such as speech-reading, asking others to speak clearly, and managing their physical environment (Dillon 2001). Finally, where appropriate, individuals with hearing loss can receive audiologic counselling to help them to understand and acknowledge their hearing loss, to engage in rehabilitation, and to explore and address the social and emotional consequences of hearing loss (Dillon 2001). In some clinics, group counselling is available (Hawkins 2005).

There is some evidence that auditory rehabilitation can achieve its aims of improving sensory functioning, activity, participation, and quality of life (Mulrow et al., 1990a; Yueh et al., 2001). However, at present, the quality of the evidence underpinning auditory rehabilitation is low (Barker et al., 2014; Henshaw and Ferguson 2013a). Furthermore, a number of factors hinder the success of auditory rehabilitation. Specifically, there is often a substantial delay between hearing loss onset and engagement in auditory rehabilitation. In the UK, it has been found that individuals with hearing loss postpone seeking help for an average of ten years and that many general practitioners fail to refer individuals with hearing loss to audiology services (Davis et al., 2007). Amongst those who do present to audiology services, intervention uptake and adherence is often poor (Laplane-Levesque, Hickson and Worrall 2010). Of particular concern is that hearing aids, the predominant intervention, are frequently under-used or not used at all (Dawes et al., 2014). This is due to a variety of factors, including hearing aids being ineffective in noisy situations, uncomfortable to wear, and difficult to insert and maintain (McCormack and Fortnum 2013). Also, there is often a lack of adequate follow-up appointments and progress reviews (Matthews 2011).

This is problematic because many patients have difficulty retaining information given to them in clinic (Kessels 2003). Much hearing research has been dedicated to understanding the factors that influence help-seeking, uptake, and adherence, including research utilising health psychology theory.

1.5 THEORETICAL PERSPECTIVES ON HEARING LOSS

The past decade has seen a rise in the application of theoretical models from the discipline of health psychology to hearing research (Coulson et al., 2016; Heffernan 2016). Health psychology models are frameworks of the social-cognitive-behavioural factors that are predicted to influence health-related behaviours, particularly health behaviour change (Leventhal et al., 2008). Health behaviour change involves commencing and maintaining healthy behaviours and/or terminating unhealthy behaviours (Manchaiah 2012). The prevailing health psychology models in hearing research are discussed henceforth.

1.5.1 Transtheoretical model of behaviour change

The transtheoretical model (Prochaska and DiClemente 1983) is perhaps the most popular health psychology model in hearing research at present. The main tenet of this framework is that there are up to seven stages of health behaviour change: **(1)** pre-contemplation, in which the individual has no desire to act, **(2)** contemplation, in which the individual intends to act, **(3)** preparation for action, **(4)** action, or overtly changing behaviour for less than six months, **(5)** maintenance, or overtly changing behaviour for more than six months, **(6)** termination, in which there is no temptation to relapse, and **(7)** relapse, in which the individual returns to their original habits (Adams and White 2005; Manchaiah et al., 2015; Velicer et al., 1998). Several studies

have utilised this model to examine health behaviour change in adults with hearing loss. For instance, two studies investigated the validity of this model, as measured by the University of Rhode Island Change Assessment questionnaire, in individuals with hearing loss who were seeking help for the first time (Laplante-Lévesque, Hickson and Worrall 2013; Manchaiah et al., 2015). They found that the model demonstrated good construct validity, though there was mixed evidence for its concurrent and predictive validity.

Although the transtheoretical model is highly popular in hearing research, it has several key theoretical limitations and the long-term effectiveness of interventions based on the model has been called into question (Adams and White 2005; West 2005). One of the most prominent criticisms of the model is that it describes 'pseudo-stages', rather than genuine stages of change (Coulson et al., 2016). For instance, pre-contemplation, contemplation, and preparation could be thought of as arbitrary stages within a larger pre-action stage, while action and maintenance are separated only by arbitrary time periods (Sutton 2001). Also, it is difficult to apply the model to complex behaviours, as an individual may be at a different stage of change for each of the actions that comprise a complex behaviour (Adams and White 2005; Brug et al., 2005). In addition, the model ignores various important influences on health-related behaviours, including operant conditioning, demographic variables, and environmental factors (Adams and White 2005; West 2005). Finally, concerns have been raised regarding the validity of measures of the model, including questionnaires and staging algorithms (Coulson et al., 2016; Sutton 2001). In light of these issues it has been suggested that the transtheoretical model be abandoned (West 2005).

1.5.2 Health belief model

This model (Rosenstock 1966) has also gained much popularity in hearing research. It proposes that health behaviours are predicted by: **(1)** perceived susceptibility to the condition, **(2)** perceived severity of the condition **(3)** perceived costs and benefits of the advised course of action, **(4)** cues or triggers for action, and **(5)** self-efficacy, or belief in one's ability to take action. The modifying influence of sociodemographic factors, such as personality and gender, are also taken into account (Champion and Skinner 2008; Saunders et al., 2013). A variety of studies have found evidence to support the application of the model to the health-related behaviours of adults with hearing loss (Meyer et al., 2014; Saunders et al., 2013; Saunders et al., 2016; Schulz et al., 2016; Van den Brink et al., 1996). For example, one study examined a range of audiological and non-audiological variables and found that success with hearing aids was significantly influenced by four health belief model constructs (i.e. perceived severity, perceived benefits, self-efficacy, and cues to action), as well as insertion gain (Hickson et al., 2014).

As with the transtheoretical model, the health belief model has several limitations. One limitation is that the model does not include emotions, such as fear, despite their substantial influence on health-related behaviours (Champion and Skinner 2008). Furthermore, there has been considerable heterogeneity in the operationalization and measurement of the model (Coulson et al., 2016; Diefenbach and Leventhal 1996). It has even been argued that the health belief model is not a true model but simply a list of factors. As such, there is a need for clarification regarding the ways in which

the different dimensions of the model relate to one another (Armitage and Conner 2000; Harrison, Mullen and Green 1992). For example, it has been proposed that perceived susceptibility only becomes a powerful predictor when perceived severity is high. It may be optimal to combine perceived susceptibility and perceived severity within a single construct: perceived threat. Furthermore, perceived benefits and perceived barriers may become weak predictors when perceived threat is low. Therefore, further research is required to establish whether the predictive power of the health belief model constructs depend on one another (Champion and Skinner 2008). However, it may be preferable to focus on alternative theoretical models, particularly in light of a review of 18 health belief model studies that found that perceived susceptibility and perceived severity were of negligible predictive value (Carpenter 2010; Coulson et al., 2016).

1.5.3 Social cognitive theory and self-efficacy

This theory (Bandura 1977; Bandura 1998), in essence, states that health behaviour change is determined by: **(1)** knowledge of health risks, **(2)** expectations of the costs and benefits of health habits, **(3)** health goals and strategies for achieving these goals, **(4)** perceived facilitators and barriers to health goals, and **(5)** self-efficacy, or one's belief in one's ability to organise and complete the courses of action necessary to manage prospective situations (Bandura 1995; Bandura 2004). Self-efficacy is at the heart of social cognitive theory, as this construct has been shown to be the most important determinant of health behaviour change (Armitage and Conner 2000). Self-efficacy is based on perceptions of: **(1)** magnitude, or the difficulty of the task, **(2)** strength, or ability to perform the task, and **(3)**

generality, or being able to generalise from one task to other tasks (Sheer 2014). Self-efficacy is derived from: **(1)** mastery experiences, or gaining the necessary cognitive and behavioural tools, **(2)** vicarious experiences, or observing similar others, **(3)** imaginal experiences, or imagining oneself or others performing effectively or ineffectively in hypothetical situations, **(4)** social persuasion, or persuading individuals that they have the necessary capability, and **(5)** physiological or emotional states, such as stress and fatigue (Bandura 1995; Maddux and Gosselin 2000; Zulkosky 2009). Self-efficacy is domain-specific or task-specific, which means that one can simultaneously have high self-efficacy for one action and low self-efficacy for another action (West and Smith 2007). This focus on specific tasks distinguishes self-efficacy from broader constructs, such as self-esteem (Meyer, Hickson and Fletcher 2014).

The application of self-efficacy to hearing loss has been advocated for over 15 years, as it is likely to be a crucial influence on hearing-related health behaviour change and auditory rehabilitation outcomes (Kricos 2000; Smith and West 2006a). Recent years have seen the development of several new questionnaires that measure self-efficacy for using hearing aids, listening to speech, and managing communication in everyday situations (Jennings, Cheesman and Laplante-Lévesque 2014; Smith et al., 2011; West and Smith 2007). Also, several studies have examined self-efficacy for specific health-related behaviours in adults with hearing loss, especially hearing aid use (Ferguson, Woolley and Munro 2016; Hickson et al., 2014; Meyer, Hickson and Fletcher 2014; Smith and West 2006b). For example, one investigation found that participants with high self-efficacy for communication were

significantly less likely to obtain hearing aids (Laplante-Lévesque, Hickson and Worrall 2012). This suggests that individuals who have developed their own coping strategies are less likely to pursue hearing aids. In this study, self-efficacy for communication was not a significant predictor of intervention outcomes.

Research from various health conditions has demonstrated that self-efficacy is one of the most important predictors of health behaviour change, particularly in terms of the self-management of chronic conditions, and that interventions incorporating self-efficacy produce better outcomes (Maddux and Gosselin 2000; Marks and Allegrante 2005; Smith and West 2006a). The construct has proven to be so successful that it has been added to other frameworks, including the transtheoretical model and the health belief model (Armitage and Conner 2000; Noar and Zimmerman 2005). Therefore, it has become ubiquitous in health psychology and is likely to continue to gain ground in hearing research and practice (Heffernan 2016; Maddux and Gosselin 2000; Smith 2014). However, self-efficacy research is associated with certain pitfalls and limitations. Specifically, a review of self-efficacy studies from various health conditions uncovered much inconsistency in how the construct was conceptualised and measured. Many studies claiming to measure self-efficacy, on closer inspection, actually measured related constructs, such as knowledge, task difficulty, and intentions. This may be because they ignored the original definition and theoretical basis of self-efficacy (Sheer 2014).

1.5.4 Future theoretical perspectives

It is clear that health psychology theory has the potential to add value to hearing research (Manchaiah 2012). However, the most frequently used health psychology frameworks in hearing research, namely the transtheoretical model and the health belief model, have considerable limitations (Coulson et al., 2016). A recent study introduced another health psychology framework to the field of hearing research, the theory of planned behaviour (Ajzen and Madden 1986), in an investigation of the intention to use hearing aids (Meister, Grugel and Meis 2014). However, this theory also has limitations, including poor predictive validity and the omission of important factors, which have prompted the proposal that the theory should be retired (Coulson et al., 2016; Sniehotta, Presseau and Araújo-Soares 2014).

It may be advisable for hearing researchers to focus on self-efficacy due to its success in numerous other fields. Another framework that does not appear to have been applied to hearing loss to date, yet has the potential to provide new insights on the condition, is the self-regulatory model (Leventhal, Meyer and Nerenz 1980). This model posits that individuals develop cognitive and emotional representations of their condition that influence their selection and maintenance of coping strategies, which in turn influence outcomes (Hagger and Orbell 2003; Hale, Treharne and Kitas 2007). This framework has been applied to numerous chronic conditions, including auditory processing disorder (Hagger and Orbell 2003; Pryce et al., 2010). It has not yet been applied to hearing loss, to the knowledge of the author. This model will be explored in greater detail in the next chapter.

1.6 OUTCOME MEASUREMENT IN AUDITORY REHABILITATION

Outcome measurement is an integral element of both research and practice. It is defined as the process of gathering information about healthcare services and interventions in order to demonstrate patient benefit, demonstrate cost effectiveness, inform the development of clinical practice guidelines, inform the allocation of healthcare resources, and ensure professional credibility (Beck 2000; Nemes 2003; Saunders, Chisolm and Abrams 2005). In the current era of evidence-based practice, it is essential to supplement patients' anecdotal reports and clinicians' expert opinions with quantitative evidence obtained using validated outcome measures (Beck 2000; Wong and Hickson 2012).

1.6.1 Current issues in outcome measurement

Outcome measures for auditory rehabilitation can be categorised as either objective or subjective (Beck 2000). Objective measures include laboratory tests of speech recognition, aided loudness judgements, insertion gain, and functional gain (Cox 2003). Subjective measures include self-report questionnaires that quantify more personal outcomes, such as patient satisfaction and quality of life, based solely on the respondent's judgement (Cox 2003; Humes 1999). Traditionally, objective measures were dominant in audiology until it became clear that subjective measures were also needed in order to capture 'real world' outcomes. In other words, measuring a construct like speech understanding in a laboratory setting is unlikely to fully capture the actual experience of that construct in everyday life. Furthermore, subjective outcome measures are needed to assess outcomes that are

important to patients but that are difficult to measure using laboratory tests, such as participation restrictions (Cox 2003).

In recognition of the importance of subjective outcome measurement, numerous hearing-specific questionnaires have been developed (Noble 2013). A systematic review of outcome measures used in adult hearing loss research studies found that 51 different questionnaires had been used in 122 adult hearing loss research articles, including both hearing-specific and generic questionnaires (Granberg et al., 2014a). Of these 51 questionnaires, only 16 had been used at least twice. The most frequently used questionnaire, the Hearing Handicap Inventory for the Elderly (Ventry and Weinstein 1982), had been used just seven times. Other reviews of outcome measures in hearing research have confirmed that a wide variety of questionnaires are used (Akeroyd et al., 2015; Barker et al., 2015). This demonstrates that, at present, there are no questionnaires in hearing loss research that are widely used and accepted as being gold-standard measures (Akeroyd et al., 2015; Granberg et al., 2014a). A lack of standardisation is also evident in clinical practice. A survey of UK adult auditory rehabilitation services found that a variety of published outcome measures are used, that 15.9% use measures that have been designed in-house, and that 12.7% do not use any outcome measures (Ferguson et al., 2016). Standardised outcome measurement is vital, as it facilitates the comparison of different research studies, the completion of meta-analyses, the prevention of outcome reporting bias, and the acquisition of high quality evidence for interventions (Barker et al., 2015; Clarke 2007).

The selection of an appropriate measure from the plethora available is a considerable challenge for researchers and clinicians (Bentler and Kramer 2000). Ideally, this choice should be based on careful examination of the measurement properties depicted in Table 1.2 (Bentler and Kramer 2000; Mokkink et al., 2010c; Oppenheim, 2000; Pesudovs et al., 2007; Reeve et al., 2013). It is vital that any outcome measure used in research or practice has adequate measurement properties so that valid conclusions can be drawn from the data collected via that measure (Reeve et al., 2013).

Consequently, various guidelines have been created to facilitate the assessment of the measurement properties of outcome measures to ensure that they meet the required standards (Bentler and Kramer 2000; Pesudovs et al., 2007; Reeve et al., 2013; Terwee et al., 2007).

In addition, the COSMIN (i.e. COnsensus-based Standards for the selection of health Measurement Instruments) checklist has been developed to guide the assessment of the methodological quality of studies that investigate the measurement properties of outcome measures (Mokkink et al., 2010c; Mokkink et al., 2012). The COSMIN checklist can be used alongside one of the aforementioned guidelines on assessing the measurement properties of outcome measures in order to select the best measure for a particular purpose. The COSMIN checklist can also be used to inform the design and reporting of an investigation of the measurement properties of an outcome measure (Mokkink et al., 2012). It would be beneficial to adopt these up-to-date approaches in hearing research, as using high quality outcome measures is a key component of carrying out high quality research and practice.

Table 1.2 Key measurement properties for outcome measures

Property	Definition
Methodology	The quality of the process and techniques used to develop and validate the measure.
Reliability	The extent to which the measure is free from measurement error.
Internal consistency	The level of inter-relatedness among the items.
Person separation reliability	The extent to which the measure can reliably detect differences between respondents.
Measurement error	The systematic and random error of a respondent's score that is not attributed to true changes in the target construct.
Test-retest reliability	The degree to which scores for respondents who have not changed are the same for repeated measurement over time.
Validity	The extent to which an instrument measures the construct it purports to measure.
Content validity	The extent to which the content of an instrument is an adequate reflection of the target construct.
Construct validity: Structural validity	The extent to which the scores of a scale are an adequate reflection of the dimensionality of the target construct.
Construct validity: Hypotheses testing	The extent to which the scores of an instrument are consistent with hypotheses based on the assumption that the instrument validly measures the target construct.
Construct validity: Cross-cultural validity	The extent to which a translated or culturally adapted scale is an adequate reflection of the original scale.
Convergent validity	The extent to which the instrument is correlated with an instrument that measures a related or similar construct.
Criterion validity	The extent to which the scores of an instrument are an adequate reflection of a gold-standard.
Concurrent validity	The extent to which the scores of an instrument are related to a criterion that is measured at the same time as the target construct.
Predictive validity	The ability of an instrument to predict a criterion that is measured at a later time than the target construct.
Responsiveness	The ability of an instrument to detect change over time in the target construct.
Interpretability	The extent to which a qualitative, clinical meaning can be assigned to an instrument's numerical scores.
Response scale	The extent to which the categories used to rate the items are statistically justified.
Unidimensionality	The extent to which all items in the measure fit with a single underlying construct.
Respondent burden	The difficulty of completing the measure in terms of length, layout, and terminology.
Investigator burden	The difficulty of learning to use the measure and interpret its results.

Unfortunately, the majority of hearing-specific questionnaires have not been validated, have been inadequately validated, or are lacking up-to-date evidence for their measurement properties (Akeroyd et al., 2015; Granberg et al., 2014a). In particular, very few hearing-specific questionnaires have been developed or validated using modern psychometric analysis techniques (Hospers et al., 2016). Most hearing-specific questionnaires that have undergone validation have used Classical Test Theory analysis; a traditional approach known to have serious limitations, as discussed in Chapter 4 (Cano and Hobart 2011). This calls the construct validity and reliability of these measures into question. Also, few hearing-specific questionnaires have been developed with patient input, which detracts from their content validity (Lasch et al., 2010; Vas, Akeroyd and Hall under review). Problems have also been identified with the responsiveness and interpretability of these questionnaires (Barker et al., 2014; Henshaw and Ferguson 2014). Therefore, the majority of currently available hearing-specific questionnaires do not meet the required standards in terms of their measurement properties. Whilst hearing researchers can opt to use validated generic questionnaires, evidence suggests that these measures lack the sensitivity required to detect changes in functioning attributable to auditory rehabilitation (Bess, 2000).

1.6.2 Core sets for hearing loss

The standardisation of outcome measurement depends not only on developing gold-standard outcome measures but also on ensuring that the 'right' outcomes are assessed. This refers to outcomes that are agreed to be important to the key stakeholders, including patients, healthcare

professionals, policy-makers, and funders (Williamson et al., 2012). These outcomes should be measured consistently across different studies to facilitate the synthesising of results, to reduce reporting bias, and to ensure that informative outcomes are not overlooked (Sinha, Smyth and Williamson 2011). Unfortunately, a lack of consensus regarding the selection and measurement of outcomes has been problematic in many healthcare fields, including audiology (Barker et al., 2015; Clarke 2007). To address this problem, core outcome sets have been introduced for numerous health conditions (Tugwell et al., 2007; Turk et al., 2003). These are an agreed collection of outcomes for a particular condition that should be reported in all clinical trials and that are also suited for use in clinical practice. Other outcomes can be reported in addition to the core set, but the core set should always be reported as a minimum requirement (Clarke 2007).

Currently, in the field of hearing loss, there is no core set specifically designed to guide the selection, measurement, and reporting of outcomes. However, core sets for hearing loss based on the International Classification of Functioning, Disability, and Health (ICF) have been developed (Granberg, Danermark and Gagné 2010; WHO 2001). The ICF is a multi-purpose, biopsychosocial framework designed to standardise the description, measurement, clinical assessment, and teaching of functioning, disability, and health for researchers, clinicians, clinical educators, and policy-makers worldwide (WHO 2001). The ICF proposes that there are three primary health-related domains: **(1)** physical impairments, which are deficits in body functions or body structures, **(2)** activity limitations, or problems executing tasks and actions, and **(3)** participation restrictions, or problems with

involvement in life situations. The positive inverse of these domains are known as body functions and structure, activity, and participation (see Figure 1.1). These domains are influenced by: **(1)** environmental factors, such as legal and social structures, and **(2)** personal factors, such as age and coping styles (Danermark et al., 2010; WHO 2001; WHO 2002).

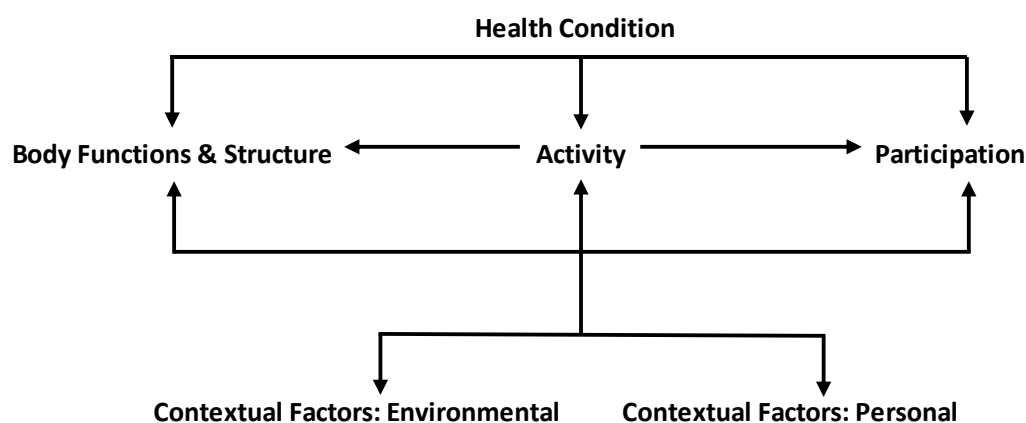


Figure 1.1 ICF graphic model

Adapted from the World Health Organization (2001) International Classification of Functioning, Disability and Health: ICF. Geneva, World Health Organization.

The ICF also consists of a comprehensive taxonomy of over 1400 categories of functioning. For example, the body functions domain contains categories such as auditory perception and attention functions (Danermark et al., 2013). This taxonomy can be distilled into a more concise list of categories that are relevant to a particular health condition (e.g. hearing loss) or to a particular healthcare context (e.g. auditory rehabilitation) through the creation of ICF Core Sets (Danermark et al., 2010). ICF Core Sets include a Comprehensive Core Set, which contains all of the categories needed to describe the difficulties arising from a particular condition, and a Brief Core Set, which contains the categories needed to facilitate a brief assessment of the

functioning of an individual with that condition. A recent international project developed ICF Core Sets for Hearing Loss through a series of research studies, including a systematic review, focus groups, a survey, a multi-centre cross-sectional study, and a consensus conference (Danermark et al., 2013). The Comprehensive Core Set contains 117 categories, while the Brief Core Set contains 27 categories (See Appendix A).

1.6.3 Measurement of participation restrictions

Participation is one of the most important healthcare outcomes (Resnik and Plow 2009; WHO 2001). This is because engagement in social relationships, social activities, and social roles is widely regarded as fundamental to leading a meaningful and rewarding life (Bowling and Dieppe 2005; Huxhold, Fiori and Windsor 2013; Pinquart and Sörensen 2000; Victor et al., 2000). For example, in a qualitative study about living with presbycusis, one participant declared: “*hearing gives you contact with people and that is life itself*” (Espmark and Scherman 2003, p.112). Participation is also argued to be crucial to good health, wellbeing, and successful ageing (Mendes de Leon 2005). Various studies have demonstrated that participation restrictions are related to a host of negative health states and outcomes, including depression, cognitive decline, dementia, reduced life satisfaction, and mortality, especially in older adults (Bennett 2002; Glass et al., 2006; Heinemann 2010; Jang et al., 2004; Wang et al., 2002; Zunzunegui et al., 2003).

Despite the importance of participation, it is widely acknowledged that it is one of the most difficult outcomes to measure (Heinemann et al., 2010;

Salter et al., 2005; Whiteneck and Dijkers 2009). One of the key barriers to the measurement of participation is that different people tend to participate in different ways, depending on their personal characteristics, preferences, and circumstances. It is difficult to capture such a highly individual and personal construct in a standardised tool (Dijkers 2010; Whiteneck and Dijkers 2009). One solution is to develop different questionnaires for different subgroups (Dijkers, Whiteneck and El-Jaroudi 2000). For example, the Hearing Handicap Inventory for Adults was created by modifying the existing Hearing Handicap Inventory for the Elderly so that greater emphasis was placed on occupational and recreational activities (Newman et al., 1990). However, using different questionnaires with different subgroups impedes standardisation and comparisons across groups and across studies. Also, individual differences within subgroups are still not taken into account, such as differences between younger adults who are employed and younger adults who are unemployed.

Another solution is to create a patient-generated outcome measure, also known as an individualised questionnaire, which permits each respondent to tailor the measure, such as by choosing which content domains or items contribute to their overall score (Patel, Veenstra and Patrick 2003). However, these questionnaires are not standardised and, as such, they are not suited to comparisons across different time periods, comparisons across individuals, and the grouping of scores (Macduff 2000; Patel, Veenstra and Patrick 2003). Therefore, whilst they may be appropriate for consultation settings, they cannot be used in clinical trials, unless they serve as an accompaniment to a standardised measure (Patel, Veenstra and Patrick

2003). Furthermore, there is evidence to suggest that respondents find personalised outcome measures cumbersome and difficult to understand (Macduff and Russell 1998; Patel, Veenstra and Patrick 2003; Tully and Cantrill 2000).

An additional barrier to the measurement of participation is that there is no standard, norm, or optimum that can be applied to the construct (Hammel et al., 2008; Heinemann et al., 2010). In other words, there is no set number of social contacts or set combination of social activities that represent full or ideal participation. Although participation is often measured through counts of social interaction frequency or social network size (Glass et al., 2006; Mick, Kawachi and Lin 2014), this does not take into account that some individuals prefer to have a relatively small number of social contacts. Indeed, it has been suggested that quality of social contacts is more important for wellbeing than quantity of social contacts (Pinquart and Sörensen 2000). In addition, it has been suggested that certain psychometric analyses are not suitable for participation measures (Whiteneck and Dijkers 2009). For example, participation is normally conceptualised as containing diverse domains or life situations that are not necessarily expected to correlate with one another, resulting in multidimensionality and low internal consistency reliability.

One of the primary barriers to the measurement of participation is the imprecise and inconsistent conceptualisation of this construct (Heinemann et al., 2010; Mendes de Leon 2005). The ICF definition of participation as involvement in life situations does not readily lend itself to measurement, as

it is so broad that it could refer to any situation between one's birth and one's death (Dijkers 2010). There is no agreement in the literature as to whether participation is made up of specific core domains, such as communication, self-care, and community life (Eyssen et al., 2011; Whiteneck 2010). For instance, reviews of participation questionnaires from other healthcare fields have found that these scales tend to measure different combinations of participation domains to each other, that important participation domains are often omitted, and that they often measure domains that could be classed as activity and physical functioning, rather than participation (Eyssen et al., 2011; Perenboom and Chorus 2003; Resnik and Plow 2009). Another considerable conceptualisation problem is that it is difficult to distinguish participation from similar terms and related constructs, including quality of life, handicap, social engagement, social networks, social integration, and social support (Bath and Deeg 2005; Mendes de Leon 2005).

Much attention has been given to the difficulties associated with differentiating activity from participation (Badley 2008; Dijkers 2010; Jette, Haley and Kooyoomjian 2003). The ICF itself is somewhat unclear in this respect, as the ICF graphic model represents activity and participation as two independent constructs, whereas the ICF taxonomy houses both constructs within a single coding structure. Furthermore, the ICF manual leaves each reader to decide, based on their individual aims, whether activity and participation should overlap and, if so, whether this should be a partial or a complete overlap (Badley 2008; Resnik and Plow 2009; WHO 2001). However, it is important to separate activity and participation so that they can be measured and applied in research and practice (Badley 2008). It has

been proposed that the primary distinction is that activity focuses on individual functioning and involves performing tasks that can be completed alone, whereas participation focuses on social functioning and involves performing social roles with or for others and engagement in society (Resnik and Plow 2009; Whiteneck and Dijkers 2009). This proposal was supported by a study that aimed to differentiate activity and participation by performing an exploratory factor analysis on the Late Life Function and Disability Instrument (Jette, Haley and Kooyoomjian 2003). Three distinct factors emerged: **(1)** mobility activity, or vigorous physical actions, such as walking a mile, **(2)** daily activities, or basic and instrumental activities necessary for daily living, such as dressing oneself, and **(3)** social participation, or complex social behaviours and social roles, such as doing voluntary work. However, many tasks that come under the category of activity take place in a social context, such as the workplace or the family home, meaning they could also be categorised as participation (Mallinson and Hammel 2010). It is clear that further research on the conceptualisation and measurement of participation is required.

1.7 AIMS AND OBJECTIVES

This literature review has demonstrated that participation restrictions are one of the most substantial difficulties facing adults with hearing loss. Therefore, it is essential that auditory rehabilitation services and interventions can be demonstrated to reduce participation restrictions. Unfortunately, at present, there is a scarcity of subjective outcome measures that have satisfactory measurement properties and that have been suitably validated for use with adults with hearing loss. Furthermore, it is widely recognised that

participation restrictions are one of the most difficult outcomes to measure. Therefore, the primary aim of this doctoral programme of research was to develop a self-report outcome measure, or questionnaire, that can assess participation restrictions in adults with hearing loss. This questionnaire was called the Social Participation Restrictions Questionnaire (SPaRQ). The intention was to design the questionnaire to have several unique features and properties that would mean that it would be an advance on existing questionnaires in the field, such as having input from both patients and clinicians in its development. This measure could go on to be used as a high quality instrument in both research and clinical practice to facilitate the standardised assessment of the impact of auditory rehabilitation on participation in adults with hearing loss. The primary objectives of this doctoral research were to:

- 1a.** Conceptualise the target construct.
- 1b.** Generate content for the measure.
- 2a.** Evaluate the content of the measure.
- 2b.** Refine the measure to improve its content.
- 3a.** Assess the psychometric properties of the measure.
- 3b.** Refine the measure to improve its psychometric properties.
- 4a.** Re-assess the psychometric properties of the measure.
- 4b.** Finalise the measure.

1.8 DESIGN

1.8.1 Mixed methods research

In accordance with best practice recommendations, questionnaire development should utilise a combination of qualitative and quantitative methods (Turk et al., 2006). Thus the research paradigm of this doctoral research was the mixed methods paradigm. Mixed methods research has become so widespread that it now stands alongside the qualitative and quantitative paradigms (Bryman 2006; Johnson and Onwuegbuzie 2004). It is a highly flexible approach that allows researchers to avail of the strengths of both qualitative and quantitative techniques and also to compensate for the weaknesses in both. The mixed methods paradigm is also known as the pragmatism paradigm, as it entails adopting the approach that best answers the research question, rather than adopting the approach that best fits with a particular research philosophy (Johnson and Onwuegbuzie 2004; Onwuegbuzie and Leech 2005).

1.8.2 Stages of outcome measure development

To maximise the quality of this research, it was conducted in accordance with published best practice recommendations for the development of subjective outcome measures. These recommendations are summarised henceforth (Brod, Tesler and Christensen 2009; Mokkink et al., 2010b; Pesudovs et al., 2007; Reeve et al., 2013; Turk et al., 2006).

Outcome measure development normally consists of multi-stage, mixed methods research with the aim of producing an instrument that possesses the measurement properties required for use in research and clinical practice. The first steps are selecting the target construct, or the construct to

be measured, and determining the purpose of the measure. The target construct in this research was hearing-related participation restrictions. The questionnaire was intended to be an outcome measure, as opposed to a diagnostic measure, and it was intended to be hearing-specific, as opposed to generic. The aim was to develop a measure that could detect changes in participation restrictions that are attributable to auditory rehabilitation services and interventions. The questionnaire was intended to be standardised, rather than individualised, so that it would be suitable for use in clinical trials and systematic reviews. The questionnaire was designed to contain multiple items, rather than a single item, as single item measures have been shown to have poor reliability, validity, and responsiveness (Hobart et al., 2007). The questionnaire was designed to be self-administered, rather than interviewer-administered, in order to reduce investigator burden. The target population must also be considered at this stage. In this research, the target population was adults with hearing loss, especially adults with mild-to-moderate hearing loss, as this is the largest hearing loss population and they are likely to be similar in terms of their language requirements and their social functioning.

The next stage of designing an outcome measure is devising a conceptual model of the target construct as it pertains to the target population. This involves defining the target construct and outlining any domains and subdomains contained within this construct. A pool of items is then prepared based on this conceptual model. The other elements of the measure, including the response scale and instructions, are also prepared at this stage. The content of the item pool should be generated by conducting a

literature review, including a review of existing questionnaires, and qualitative research with key stakeholders, including subject matter experts and patients. This rigorous approach helps to ensure that the item pool is as comprehensive as possible so that the measure has sufficient content validity. The next stage is the evaluation of the content of the measure in order to ensure that it is comprehensive, relevant, clear, and appropriate. This stage provides further support for the content validity of the measure and ensures that respondent burden is minimised. Evidence should be obtained from key stakeholders, including patients and clinicians, using qualitative or quantitative techniques. One of the most highly recommended methods for evaluating the content of a new outcome measure is cognitive interviewing, which involves interviewing potential respondents about their interpretation of the measure (Conrad, Blair and Tracy 1999; Turk et al., 2006). Another recommended technique is the recruitment of a subject matter expert panel to rate the relevance and clarity of the measure (McGartland Rubio et al., 2003). The results of this stage are used to refine the wording and format of the measure to enhance clarity and to add new items to the measure to ensure adequate coverage of the target construct.

The new outcome measure should then be field tested with a sample of the target population to facilitate psychometric analysis. This involves performing a variety of statistical tests on responses to the measure in order to assess key properties, such as construct validity, and to determine whether any alterations should be made, such as item deletion, to improve these properties. Therefore, psychometric analysis is normally an iterative process, as it should be repeated each time alterations occur until the measure has

been finalised (Hyde 2000; Mokkink et al., 2012; Turk et al., 2006). At present, the most dominant form of psychometric analysis is traditional psychometric analysis (Cano and Hobart 2011). Despite its dominance, traditional psychometric analysis and the theory on which it is based, Classical Test Theory, are widely regarded as having several serious limitations, which will be examined in Chapter 4. Fortunately, these limitations have been addressed by modern psychometric analyses that are based on latent trait theories. Consequently, modern psychometric analyses, namely Rasch analysis and Item Response Theory analysis, are considered to be the current gold-standard approaches (Cano and Hobart 2011; da Rocha et al., 2013; Turk et al., 2006; Turner et al., 2007). In this research, traditional psychometric analysis was used in conjunction with Rasch analysis, which is a widely recommended approach (Chen et al., 2013; da Rocha et al., 2013; Mokkink et al., 2012; Pusic et al., 2009).

The culmination of the development process should be finalising the measure, which means preparing the definitive version of the measure. Once the development phase has been completed, the questionnaire is ready for validation, such as investigations of cross-cultural validity.

1.9 CONCLUSION

This literature review was used as a foundation for the remainder of this doctoral programme of research. Specifically, the examination of health psychology theories and models was used to identify a theoretical framework for the outcome measure (see Chapter 2). In addition, the review of the primary consequences of hearing loss informed the design of the outcome measure, particularly the generation of item content (see Chapter 3). The

review of current issues in outcome measurement, including the issues relating to conceptualising and measuring participation, also informed the design of the outcome measure. Finally, the review of the literature on the methodology of outcome measure development guided the design of each study conducted during this programme of research (see Chapters 2-5). Four successive studies were conducted in order to produce an outcome measure with strong measurement properties. In particular, the properties of construct validity, unidimensionality, internal consistency, person separation reliability, response scale justification, and respondent burden were assessed. The methods of each study (see Table 1.3) are discussed in detail in the forthcoming chapters of this thesis.

Table 1.3 Summary of research objectives and methods

Objective	Method
<ul style="list-style-type: none"> ▪ Conceptualise the target construct ▪ Generate a first draft of the measure 	<ul style="list-style-type: none"> ▪ Semi-structured interviews with adults with hearing loss and hearing healthcare professionals ▪ Literature review
<ul style="list-style-type: none"> ▪ Evaluate the content validity of first draft the measure ▪ Generate a second draft of the measure 	<ul style="list-style-type: none"> ▪ Cognitive interviews with adults with hearing loss ▪ Subject matter expert panel with hearing healthcare professionals
<ul style="list-style-type: none"> ▪ Assess the psychometric properties of the second draft measure ▪ Generate a third draft of the measure 	<ul style="list-style-type: none"> ▪ Administration of the questionnaire to adults with hearing loss ▪ Rasch analysis of the questionnaire data
<ul style="list-style-type: none"> ▪ Re-assess the psychometric properties of the measure ▪ Finalise the measure 	<ul style="list-style-type: none"> ▪ Administration of the questionnaire and three validated measures to adults with hearing loss ▪ Traditional psychometric analysis of the questionnaire data

CHAPTER 2. STUDY 1: A QUALITATIVE EXPLORATION OF THE PSYCHOSOCIAL EXPERIENCES OF ADULTS WITH HEARING LOSS

2.1 INTRODUCTION

This chapter reports the first study of this doctoral research, which was a qualitative investigation of the psychosocial experiences of adults with hearing loss (Heffernan et al., 2016). The ultimate purpose of this study was to inform the conceptualisation of the target construct, hearing-related participation restrictions, and to generate content for the new outcome measure. The use of qualitative research in content generation helps to ensure that the questionnaire is representative of and sensitive to the lived experiences of the intended respondents. It also helps to capture the language and wording of the intended respondents, which can be embedded within the questionnaire so that it is meaningful and easily understood. To achieve this, semi-structured, individual interviews were conducted with 25 adults with hearing loss and nine hearing healthcare professionals. The self-regulatory model served as an underpinning theoretical framework in this study (Leventhal, Meyer and Nerenz 1980). The data were analysed in accordance with an established thematic analysis procedure (Braun and Clarke 2006).

2.2 AIMS AND OBJECTIVES

As stated above, the primary aim of this study was to explore the psychosocial experiences of adults with hearing loss using the self-regulatory model as a theoretical framework in order to generate content for a hearing-related participation restrictions questionnaire. The specific objectives of the study were to examine the key components of this model:

- 1) Cognitive representations of hearing loss
- 2) Emotional representations of hearing loss
- 3) Coping responses to hearing loss

The study examined a range of psychosocial experiences, rather than focusing solely on participation restrictions, in order to avoid constraining the participants' responses and to ensure that the content generated for the questionnaire was rich and comprehensive.

2.3 DESIGN

2.3.1 Qualitative research

Qualitative research is the most appropriate approach when insight is needed into individuals' experiences, beliefs, desires, values, and motivations (Ives and Damery 2014). Therefore, it was deemed to be the most appropriate approach for developing a rich understanding of the psychosocial experiences of adults with hearing loss. In hearing research, it has been argued that qualitative approaches should be used more frequently in order to uncover information that has been overlooked by the dominant quantitative approaches and to deepen our knowledge of the psychosocial experiences of adults with hearing loss, including experiences of seeking help, engaging in auditory rehabilitation, and living with hearing loss (Knudsen et al., 2012).

Furthermore, qualitative research is a crucial component of outcome measure development (Brod, Tesler and Christensen 2009; Lasch et al., 2010; Patrick et al., 2011; Rothrock, Kaiser and Cella 2011). Specifically, conducting qualitative research in the early stages of developing an outcome

measure is the primary means of ensuring that the measure has sufficient content validity (Lasch et al., 2010; Leidy and Vernon 2008). Content validity is the degree to which the measure is representative of the experiences of the intended respondents in relation to the target construct (Brod, Tesler and Christensen 2009). Without adequate content validity, a questionnaire would omit important content and include unimportant content, thus degrading the quality of the inferences that can be drawn from the questionnaire data (Haynes, Richard and Kubany 1995). Content validity can be bolstered by conducting either individual interviews or focus groups with patients and clinicians in order to elicit content for the questionnaire (Patrick et al., 2011). The themes and topics that emerge from these interviews can be used to inform the structure and content of the measure, whilst the words and expressions used by the participants can serve as the basis for items in the measure (Leidy and Vernon 2008; Pesudovs et al., 2007). This also helps to ensure that the measure has minimal respondent burden (Reeve et al., 2013).

The specific qualitative method used in this study was the semi-structured interview. This is one of the most frequently used and well-established methods in qualitative research (Brinkmann 2014). It is essentially a conversation between a researcher and one or more participants that is guided by a flexible interview schedule, which consists of open-ended questions and possible follow-up questions (Ives and Damery 2014). This fluid structure permits the development of rapport with interviewees, the exploration of unanticipated responses, the in depth discussion of complex issues, and the identification of issues that are of real importance to

interviewees (Barriball and While 1994; Britten 1995). Both individual interviews and group interviews have been recommended for use in questionnaire development, with each method having unique advantages and disadvantages (Brod, Tesler and Christensen 2009; Patrick et al., 2011). It was decided that individual interviews would be used in this study, as they are more appropriate for the exploration of sensitive and personal topics (Brinkmann 2014; Leidy and Vernon 2008). In this study, relatively sensitive and personal topics were discussed, including the experience of social isolation, depression, bereavement, and relationships with significant others. Another advantage of individual interviews is that they can uncover detailed information about each individual's experience and, unlike focus groups, they are not at risk of being dominated by the experiences of more outspoken individuals (Patrick et al., 2011).

2.3.2 Theoretical framework

In outcome measure development, it is often useful to develop a theoretical model of the target construct, which is a broad framework outlining the relationship between the target construct and other variables, such as antecedents, consequences, and modifiers (Brod, Tesler and Christensen 2009). Once the outcome measure has been finalised, this theoretical model can be tested, such as through structural equation modelling, and can guide statistical analyses that use the outcome measure, such as identifying potential confounders. The theoretical model can also inform the development of a conceptual model of the target construct. A conceptual model outlines the domains and subdomains contained within the target construct that form the basis of subscales and items in the questionnaire

(see Chapter 3). In this research, it was decided that a recognised health psychology framework that has been demonstrated to be applicable to the psychosocial experiences of patients would be used. This would circumvent the problem of introducing a new model that could potentially overlap with or be less informative than an existing, evidence-based framework.

Consequently, a variety of health psychology models and theories were reviewed (see Chapter 1), ultimately leading to the selection of the self-regulatory model (SRM).

The SRM (see Figure 2.1) was chosen for this study because it is an established framework that has been successfully applied to numerous long-term conditions, including auditory processing disorder, diabetes, psoriasis, and epilepsy (Hagger and Orbell 2003; Petrie and Weinman 1997; Pryce et al., 2010). Other models that have proven popular in hearing research, such as the transtheoretical model and the health belief model, were not deemed suitable because they focus on health behaviour change and have also been subject to serious criticisms, which means that they have fallen out of favour in health psychology (Coulson et al., 2016). In contrast, numerous studies have demonstrated that the SRM is an appropriate framework for the exploration of psychosocial experiences of individuals living with chronic conditions (Barsevick, Whitmer and Walker 2001; Heijmans 1999; Lingler et al., 2006). Furthermore, there is much evidence to support the tenets of the model, with many studies confirming that they are predictive of both health behaviours, particularly adherence, and health outcomes (Leventhal, Diefenbach and Leventhal 1992; Sharpe and Curran 2006). The SRM is an advance on other health psychology models, as it uniquely recognises the

beliefs about the condition stemming from personal knowledge and experiences, information from the media, and information from significant others. Emotional representations refer to subjective reactions to the condition, such as anxiety or fear (Hagger and Orbell 2003). Cognitive representations are normally conceptualised as having five components (Hale, Treharne and Kitas 2007; Petrie and Weinman 1997): **(1)** identity, or beliefs about the symptoms and labels associated with the condition, **(2)** causal beliefs, or beliefs about the factors that led to the condition, **(3)** timeline, or beliefs about the duration of the condition, **(4)** controllability/curability, or beliefs about the extent to which the condition can be controlled, treated, or cured and **(5)** consequences, or beliefs about the short-term and long-term effects of the condition.

According to the SRM, cognitive and emotional representations influence the selection of coping responses, which in turn influence health outcomes (Hagger and Orbell 2003). Coping responses are actions taken to solve problems posed by the condition or to regulate feelings aroused by the condition. A coping response can be multifunctional, as it can relieve both physical symptoms and emotional distress (Hale, Treharne and Kitas 2007; Leventhal et al., 1997). Once selected, individuals monitor and appraise their coping responses. These appraisals determine whether individuals amend or maintain their coping responses and also whether they amend or maintain their original cognitive and emotional representations. This process is referred to as the feedback loop (Hagger and Orbell 2003; Johnston 1997). For example, the evaluation of a coping response as unsuccessful may lead individuals to believe that their condition is uncontrollable and to choose an

alternative coping response (Leventhal et al., 1997). Both coping responses and representations can directly influence health outcomes. For example, the representation of a condition as controllable/curable has been related to improved psychological well-being and social functioning (Hagger and Orbell 2003). Therefore, the SRM is a comprehensive framework that has the potential to draw together different psychosocial elements of hearing loss within a single, unifying framework. This contrasts with previous research on the psychosocial experiences of adults with hearing loss, which has often focused on discrete aspects of these experiences, such as stigma (Wallhagen 2010) or coping (Hallberg and Carlsson 1991).

2.3.3 Sample size

Sampling in a qualitative study for the purpose of outcome measure development should continue until saturation is reached, or the point at which it is determined that no new themes and relevant information are emerging from the interviews based on an examination of field notes and transcripts (Leidy and Vernon 2008). The nature of saturation means that the sample size of a qualitative study cannot be determined in advance, though previous research does permit broad sample size estimates to be made (Kerr, Nixon and Wild 2010; Patrick et al., 2011). For example, one previous study found that saturation in qualitative research using thematic analysis can be reached with 12 participants (Guest, Bunce and Johnson 2006). Others have recommended that, for the purposes of outcome measure development, approximately 20 to 30 participants should be interviewed, though they acknowledged saturation may have been reached at an earlier

stage (Rothman et al., 2009). Therefore, in this study it was estimated that between 12 and 30 participants would be interviewed.

2.4 METHODS

This research study was approved by the East Midlands NHS Research Ethics Committee and Research and Innovation in the Nottingham University Hospitals NHS Trust.

2.4.1 Participants

Two groups of participants were recruited for this study: **(1)** adults with mild-to-moderate hearing loss and **(2)** hearing healthcare professionals, including both academics and clinicians. The purpose of capturing the perspectives of different stakeholders, known as triangulation, was to enhance the validity and credibility of the findings of this qualitative study (Lasch et al., 2010; Yardley 2008). Furthermore, it has been specifically recommended that qualitative data be collected from both patients and clinicians in order to generate comprehensive item pools for new patient-reported outcome measures (Pesudovs et al., 2007). Of the two groups, patients should be the primary source of data because the measure should capture their words and perspectives as closely as possible (Turner et al., 2007).

Consequently, 34 participants were recruited of whom 25 were adults with hearing loss (see Table 2.1) and nine were hearing healthcare professionals (see Table 2.2). The adults with hearing loss were based in the UK whilst the hearing healthcare professionals were based in both the UK and North America. The adults with hearing loss had a mean pure-tone hearing threshold of 40.84 dB HL (SD=14.52) in the better ear, averaged across 0.25-4 kHz. All of the adults with hearing loss owned hearing aids, with 22

wearing them regularly (i.e. at least several times per week). Also, they had a variety of occupations, including engineer, nurse, factory worker, teacher, musician, professor of education, shop assistant, and secretary.

2.4.2 Recruitment

2.4.2.1 Inclusion and exclusion criteria

The inclusion criteria for all of the participants were:

- 1) Willing and able to take part in a semi-structured interview.
- 2) Aged 18 years or older with no upper age limit.
- 3) Good written and spoken English. English did not have to be the participants' first language.

The adults with hearing loss had the following additional inclusion criterion:

- 1) Mild-moderate hearing loss, as defined as having a mean hearing threshold between 20-70 dB HL in the better ear averaged across 0.25-4 kHz or a unilateral hearing loss.

The exclusion criterion for all of the participants was:

- 1) Self-reported cognitive decline or dementia that would necessitate assistance in completing a questionnaire.

2.4.2.2 Adults with hearing loss recruitment

The sampling technique used was maximum variation sampling. This is a type of purposeful sampling in which diverse participants, who are likely to provide rich information about the research topic, are selected (Patton 1990). This has been recommended as the most appropriate sampling approach for qualitative studies that aim to underpin outcome measure development

(Lasch et al., 2010). Therefore, sampling continued until there was sufficient variation in relevant participant characteristics and experiences. Specifically, adults with hearing loss who differed in terms of age, gender, employment status, hearing aid use, and hearing loss onset were sought. In addition to ensuring that there was a diverse study sample, it was also ensured that recruitment did not cease until saturation had been reached.

The adults with hearing loss were recruited through the participant database of the Nottingham Hearing Biomedical Research Unit (BRU). This database contains the contact details of approximately 1400 adults who are willing to take part in hearing research, including research relating to tinnitus, hearing loss, and hyperacusis. This database was searched for individuals who were likely to meet the inclusion criteria of the study, such as individuals who were listed as owning hearing aids or as having hearing loss. Over a period of several weeks, 60 potential participants were contacted, of whom 28 initially agreed to participate in the study. Two of these potential participants ultimately decided not to take part in the study due to illness. Another potential participant decided not to take part, as he anticipated that the two hour research session would be fatiguing for him. Therefore, 25 individuals were recruited for the study, representing a response rate of 41.67%. Forty individuals were contacted via email, with 15 going on to participate in the study. Twenty were contacted via post, with ten going on to participate in the study. Both post and email were used, as it has been demonstrated that many, but not all, older adults with hearing loss use the internet (Henshaw et al., 2012).

Table 2.1 Demographic information of the study 1 adults with hearing loss

Gender	n
Men	14
Women	11
Age	Years
Mean	68.76
SD	16.45
Median	72
Range	20-91
Pure tone average	dB HL
Mean	40.84
SD	14.52
Median	36
Range	18-69
Hearing loss onset	n
Gradual	21
Sudden	2
Congenital	1
Unknown	1
Hearing loss duration	Years
Mean	11.70
SD	7.42
Median	10
Range	2-29
Hearing aid ownership	n
Yes	25
No	0
Employment status	n
Retired	18
Employed	5
Not employed	1
In education	1
GHABP scores	Mean percentage (N=25)
Hearing disability	38.13 (SD=20.67, range=6.25-81.25)
Hearing handicap	39.09 (SD=27.31, range=0-93.75)
Hearing aid use	82.32 (SD=33.30, range=0-100)
Hearing aid benefit	57.98 (SD=27.29, range=6.25-100)
Hearing aid satisfaction	56.70 (SD=20.79, range=6.25-81.25)

Table 2.2 Demographic information of the study 1 hearing healthcare professionals

Gender	n
Male	2
Female	7
Location	n
UK	6
USA	2
Canada	1
Profession	n
Audiologist	6
Hearing therapist	2
Academic	1
Current occupation	n
Audiologist	3
Hearing therapist	1
Academic	5
Professional experience	Years
Mean	19.33
SD	12.17
Median	20
Range	3-36
Areas of expertise	n
Adult rehabilitation	6
Auditory processing disorder	1
Counselling	1
Complex care	1
Tinnitus	1

2.4.2.3 Hearing healthcare professionals recruitment

Once again, the sampling technique used was maximum variation sampling. As such, sampling continued until hearing healthcare professionals who varied in terms of gender, country of employment, professional background, academic qualifications, and length of professional experience were recruited. As above, saturation was also used to determine when recruitment should cease. A list of potential participants was generated from the professional network of the author and the supervision team. This included

individuals who had relevant qualifications and experience from audiology departments and research departments in both the UK and abroad. Over several weeks, 11 individuals were contacted via email, of whom nine participated in the study, representing a response rate of 81.82%.

2.4.3 Materials

As part of a hearing assessment, the adults with hearing loss completed the following questionnaires:

2.4.3.1 Glasgow hearing aid benefit profile (GHABP)

The GHABP (see Appendix B) was developed and validated in the UK as a measure of hearing aid use, benefit, satisfaction, as well as hearing disability and hearing handicap (Gatehouse 1999; Whitmer, Howell and Akeroyd 2014). It lists four predefined situations: **(1)** listening to the television when the volume is adjusted to suit others, **(2)** conversing with one person in a quiet setting, **(3)** conversing on a busy street or shop, and **(4)** taking part in a group conversation. For each situation, respondents are asked whether or not it is applicable to them. If so, they are asked in a series follow-up questions to rate their level of hearing aid use, hearing aid benefit, hearing aid satisfaction, hearing disability and hearing handicap. Each rating is made on a scale ranging from one to five, with five representing a higher degree of the construct (e.g. higher disability, higher satisfaction).

In addition to the pre-specified situations, respondents can nominate up to four situations from their own lives. They are then asked the follow-up questions in relation to these nominated situations. In this study, the participants were asked only about the four pre-specified situations, as they would have ample opportunity to discuss situations from their own lives

during the semi-structured interview. The GHAPB was administered by the researcher to the participants, as it was designed to be an interviewer-administered measure (Gatehouse 2000). Participants who normally wear hearing aids responded to the questions based on wearing their hearing aids.

2.4.3.2 Demographics questionnaire for adults with hearing loss

This questionnaire was composed by the author (EH) and asked the adults with hearing loss to indicate their age, gender, employment status, and main occupation. It also asked about their hearing loss onset, estimated hearing loss duration, hearing aid ownership, and hearing aid use.

The following questionnaire was completed by the hearing healthcare professionals:

2.4.3.3 Demographics questionnaire for hearing healthcare professionals

This questionnaire was composed by the author (EH) and asked the hearing healthcare professionals to indicate their gender, country of employment, profession, current occupation, years of professional experience, and area of expertise.

2.4.4 Study procedure

2.4.4.1 Pilot study

Two adults with hearing loss from the BRU Public and Patient Involvement (PPI) Panel each participated in a pilot interview and pilot hearing assessment. They also provided feedback on the clarity and content of the interview schedule, as well as the interviewer's approach to communicating

with individuals with hearing loss. As they did not propose any notable changes to the interview schedule, it was decided that the pilot interview data and pilot hearing assessment data from the two adults with hearing loss would be included in the data analysis, for which written informed consent was obtained. In addition, two audiologists, who were employed by the BRU, reviewed the interview schedule for the hearing healthcare professionals and suggested minor revisions to improve its clarity and content.

2.4.4.2 Research study

Each participant was sent an invitation letter, study information sheet, and interview agenda at least 72 hours prior to their participation in the study. Each participant travelled to the BRU to take part in the study, with the exception of four hearing healthcare professionals who were interviewed via online video call, as they were not located in Nottingham. Every participant who came to the BRU was greeted by the author and shown to a quiet room, where they were given the opportunity to review the study information sheet and to ask any questions. They then provided written informed consent. The participants who were interviewed via online video call sent their completed consent forms to the researcher prior to their interview. Each participant took part in an individual, semi-structured interview that lasted approximately one hour. The author conducted all of the interviews. The interview schedules (see Appendix C, taken from Heffernan et al., 2016) were flexible but their core content remained the same across each interview.

Once the interview was completed, the participants were given the relevant demographics questionnaire, which took approximately ten minutes to complete. The participants were given several opportunities for breaks and

refreshments during their participation in the study. They were each provided with a small inconvenience allowance of ten pounds and any travel expenses they had incurred were refunded. The interviews were recorded and subsequently transcribed verbatim by professional transcribers. All of the data collected were treated confidentially and stored securely in locked filing cabinets and password protected computers in the BRU.

For the adults with hearing loss, a 30-minute hearing assessment was conducted to ensure that they had mild-to-moderate hearing loss. This normally took place prior to their interview. Otoscopy was performed prior to the measurement of pure-tone air conduction thresholds (0.25-8 kHz) for each ear and pure-tone bone conduction thresholds (0.5-2 kHz), in accordance with the British Society of Audiology recommended procedure (BSA 2011). In addition, all adults with hearing loss completed the GHABP by interview (see Table 2.1). The hearing assessments were conducted by the author with occasional support as required from an audiologist employed by the BRU.

2.5 DATA ANALYSIS

QSR International's NVivo 10 Software was used to organise the data and to support the analysis of the data. The data analysis procedure is described in detail below.

2.5.1 Thematic Analysis

The qualitative data analysis method selected for this study was thematic analysis; a widely used approach that essentially entails identifying patterns present across an entire dataset (Wilson and MacLean 2011). This form of

analysis is particularly suited to pragmatic, mixed methods research. It is a flexible approach that is not linked to a particular epistemology, which means that it can be applied to a wide variety of research topics, can be used inductively or deductively, and the depth of data interpretation and description can be adjusted to suit the research aims (Notley, Green and Marsland 2014; Wilson and MacLean 2011). Furthermore, thematic analysis is a highly practical approach, being more in-depth than some qualitative approaches, such as content analysis and framework analysis, but less time consuming than other qualitative approaches, such as grounded theory and interpretative phenomenological analysis (Wilson and MacLean 2011).

Thematic analysis was therefore deemed the most appropriate approach for a study such as this, which was guided by a theoretical framework and that had the pragmatic aim of generating content for a questionnaire that would then be subjected to psychometric analysis. It was also thought that the identification of salient patterns and themes would be ideal for the development of conceptual domains and items for the questionnaire.

In the past, thematic analysis was criticised for not having a clear, agreed-upon method or procedure (Wilson and MacLean 2011). Consequently, this study utilised a specific thematic analysis procedure set forth by Braun and Clarke (2006). They regard thematic analysis as a method of describing a dataset through the process of identifying, analysing, interpreting, and reporting themes that are present in the data. They conceptualise a theme as being a pattern of meaning or response within the data that captures important information relating to the research question. In this study, themes common to both participant groups (i.e. adults with hearing loss and hearing

healthcare professionals) were sought. The specific type of thematic analysis used in this study was theoretical, or deductive, thematic analysis. This is a top-down approach in which the themes are influenced by the researcher's theoretical and analytical interests. In this study, the theoretical framework used to guide the data analysis was the SRM (Leventhal et al., 1980). This approach contrasts with inductive thematic analysis; a bottom-up, data-driven approach in which the themes emerge only from data collected. All forms of thematic analysis should consist of several specific analytical phases (Braun and Clarke 2006):

2.5.1.1 Data familiarisation

This first phase involves becoming immersed in the data by reading and re-reading the transcripts, noting possible patterns, and cross-checking the transcripts and the audio files for accuracy.

2.5.1.2 Generating initial codes

This involves identifying the most basic units of data that are potentially interesting and meaningful and giving these units an appropriate label or code. Multiple codes can be applied to the same extract of data if that extract is particularly rich. For example, in the present study, the data excerpt below was assigned the following codes: 'Impact on Communication and Understanding', 'Impact on Social Life', 'Association of Stupidity and Hearing Loss', 'Withdrawal within Situations' and 'Emotion: Fear'.

AHL16 (woman, aged 75): *"you get to the stage where you are frightened of saying anything because you don't want to make yourself look stupid because you are half guessing at what people are talking*

about and you sort of think “Well, if I say anything, is it going to be what they are talking about?””

Researchers can code the entire dataset or they can limit their coding to particular aspects of the dataset. In this study, the entire dataset was coded, even if some data extracts did not appear to be informative in terms of the SRM and the research aims, in order to ensure that nothing of importance was overlooked (Fereday and Muir-Cochrane 2006). For example, data relating to health conditions other than hearing loss, such as stroke, were coded.

2.5.1.3 Searching for themes

This phase entails examining the long list of codes that have been generated, looking for relationships between codes, and combining certain codes together in order to form potential themes. Some frequently used codes form themes in and of themselves, some form sub-themes, and some may not appear to fit with any theme at this stage.

2.5.1.4 Reviewing themes

This involves refining the potential themes from the previous phase. Some themes remain as they are, while others are discarded, divided, or merged. It is important to evaluate whether each individual theme is coherent, meaningful, and sufficiently distinct from the other themes. It is also important to evaluate whether the themes, when put together, are representative of the dataset.

2.5.1.5 Defining and naming themes

This comprises defining the themes by stating which aspect of the data each theme captures and giving each theme a concise and meaningful name. This phase also involves further refinement of the themes by identifying whether they consist of sub-themes. In this study, the overarching themes were derived from the components of the SRM (e.g. cognitive representations), whilst sub-themes stemmed either from the model (e.g. identity) or were derived from the data (e.g. muted emotions).

2.5.1.6 Producing the report

The final phase involves reporting the analysis of the data in a manner that demonstrates that the researcher's interpretation of the data is logical, coherent, and compelling.

2.5.2 Peer assessment

During the reviewing themes phase, a peer assessment, or coding comparison, was completed. This generally involves comparing the perspectives of two or more researchers on the dataset in order to confirm that the data analysis is sensible to others and that it is not limited to the viewpoint of one researcher (Creswell and Miller 2000; Patrick et al., 2011; Yardley 2008). In this study, a second doctoral researcher, who was not otherwise involved in the study, was provided with a sample of six of the transcripts to analyse. This researcher was familiar with the SRM and theoretical thematic analysis. The transcripts were those of two hearing healthcare professionals and four adults with hearing loss. The adults with hearing loss chosen varied in terms of age, gender, and their psychosocial experiences.

The second researcher independently coded the six transcripts and considered the potential themes present in those transcripts. The author examined the coding of the second researcher to ensure that it was not markedly different from her own. Also, the two researchers met to have in depth discussion about their interpretations of the transcripts and the possible themes. They concluded that there were no substantial discrepancies between their perspectives on the data analysis. Any minor discrepancies were resolved through this discussion. The themes were further refined in the defining and naming themes phase through re-examining the data and discussions with the supervision team.

To further strengthen the rigour of the data analysis, disconfirming case analysis was performed. This means examining and reporting participants and extracts that differ from the themes identified (Creswell and Miller 2000; Yardley 2008).

2.6 RESULTS

The results are presented in terms of the primary components of the SRM. An identification code has been assigned to each adult with hearing loss (e.g. AHL1) and each hearing healthcare professional (e.g. HHP1).

2.6.1 Theme 1: Cognitive representations of hearing loss

This refers to the common sense or lay beliefs of adults with hearing loss about their condition. It was examined whether the five components of cognitive representations were relevant and meaningful for adults with hearing loss.

2.6.1.1 Identity

Identity refers to the labels and symptoms associated with a condition. The term 'symptom' is not typically used in association with hearing loss, as it is not an illness and it does not have typical symptoms, such as pain or nausea. Nonetheless, the adults with hearing loss in this study were able to identify some symptoms of hearing loss. These symptoms tended to be framed as activity limitations and participation restrictions, such as difficulties watching television, using the telephone, and conversations with communication partners. For example, AHL8 (man, aged 74) described his symptoms: *"Well, not picking up everything that is on television, having to turn the sound up...Missing half of conversations when you are talking to people"*.

In addition to identifying the symptoms of hearing loss, the participants also mentioned several labels related to the condition. These labels were largely negative, with some even suggesting that hearing loss is a stigmatising condition. One label often associated with hearing loss was being seen as 'foolish' or 'silly'. This often came as a consequence of communication difficulties. AHL24 (woman, aged 48) said: *"When...you have to ask [someone] more than twice to...speak up...they think you are stupid. They think there is something wrong with you"*. HHP5 (Hearing therapist/academic) suggested that the condition of hearing loss was perhaps unique in being associated with stupidity and that it attracts less sympathy than other conditions:

"This is perhaps the only kind of disability that carries with it this sense...of irritation. Somehow people aren't irritated about guiding a

blind person across the road in the way that they are irritated at having to repeat themselves about five times to a deaf person”.

Some found that hearing loss and hearing aids were associated with a lack of competence and authority in both work life and social life. For example, AHL21 (man, aged 60), who is a leader in his workplace, described his initial thoughts about wearing a hearing aid: *“I don't need a hearing aid. Everybody will take the mickey out of me at work...I am a responsible person. What do I need a stupid little thing like that stuck in my ear for?”* AHL16 (woman, aged 75) found that hearing loss affected her ability to organise social events: *“I have always been...ever so efficient and capable and...running things and organising things but because of my hearing, all that has gone...It has just stripped me of it”.*

Another label associated with hearing loss was being seen as ‘old’. This was not perturbing for those who saw ageing as a normal and natural process. AHL18 (man, aged 86) said: *“I wasn't particularly bothered about having a hearing aid in or you know getting on in age...it don't bother me things like that”.* However, many were unhappy about the association between hearing loss and ageing. AHL17 (woman, aged 72) said: *“I want people to see me as me; not me with a hearing aid or me with a [walking] stick...I want them to see me as I was”.*

Hearing loss was also associated with being ‘unsociable’. Some found that hearing loss has prevented them from being as sociable as they once were, such as AHL11 (man, aged 91): *“I have got an outgoing personality and it has been cramped”.* In addition, HHP5 explained that adults with hearing loss can find it challenging to be themselves in social situations: *“they can't*

really express themselves as they used to, because it is difficult to take part in a conversation...you are not really showing your personality because you are struggling so hard to hear."

Some adults with hearing loss found that they are perceived as being unfriendly or difficult. This is because communication difficulties (e.g. not replying when addressed) and communication tactics (e.g. asking people to speak more clearly) can be confused with ill-manners by those who lack awareness of hearing loss. For example, AHL20 (woman, aged 42) was perceived as aloof by colleagues who did not know that she had hearing loss:

"I actually made an effort not to talk to people...when I would be around people I would probably have my head stuck in a book...I probably came across as quite ignorant and unapproachable". She added: *"after I got my hearing aids somebody did actually say to me that they had been worried because I had been so quiet...and they thought...I was a loner".*

2.6.1.2 Causal beliefs

When asked about the causes of their hearing loss, the adults with hearing loss often cited ageing and/or noise exposure. However, few had a clear understanding of the causes of their hearing loss and some had little interest in learning more. AHL12 (man, aged 72) said: *"I have never really asked".* There was a divergence of opinion amongst the participants regarding the benefits of learning about the causes. Three hearing health care professionals suggested that patients often receive more information about hearing loss than they need from clinicians. For example, HHP9 (Academic)

said *“audiologists tend to give way too much information for what the person wants. They want to know if there’s a fix and how can they stop it getting worse. They don’t need to know all of the miniscule details”*. HHP8

(Audiologist/academic) similarly stated: *“Many [clinicians] feel that patients should be able to...rattle off their audiogram and many patients don’t particularly care”*. HHP6 (Audiologist/academic) even warned that some adults with hearing loss become fixated on uncovering the causes of their hearing loss, rather than accepting and learning to live with the condition.

On the contrary, some participants believed that a good understanding of hearing loss is beneficial. HHP2 (Hearing therapist) said that learning about hearing loss can help patients to accept and manage the condition:

“even if that piece of information wasn’t relevant...in terms of a care plan [or] in terms of fitting a hearing aid, it is still very relevant for that patient...like with anything in life, if we have a reason; if we have an explanation; if we have a foundation, we are able to then get to grips with it more”.

AHL24 said: *“reading more about it and trying to understand more about it is my way of coping with it”*. Overall, most of the professionals recommended tailoring the information given to adults based on their individual level of understanding and their level of interest.

2.6.1.3 Timeline

This refers to patients’ beliefs about whether their condition is acute or chronic. Many of the adults with hearing loss were not especially concerned about the progression of their condition. AHL18 had given it little thought: *“/*

have no idea, you know. I just go along and I suppose if it got too bad I would probably go and ask [the audiologist] if they could check my hearing or could re-adjust my hearing aids...I don't know". Many had come to accept that their hearing was likely to continue to decline and were determined to carry on regardless. AHL1 (man, aged 79) said: *"it is a gradual deterioration. So I don't have any anger, frustration or that...I passively accept that this is how it will be and just get on with doing what I can".*

A small number of the adults with hearing loss worried about further deterioration of their hearing. Although some overcame this worry with time, others continued to worry, particularly if they believed that further loss would make their condition unmanageable. AHL24 took a British Sign Language course, as she was concerned about one day being unable to communicate:

"You know I will be 68 in twenty years' time. The majority of people when they reach that age group have got some form of hearing loss...will I have lost my hearing by then or will it be just a little lower...it does bother me because I can't stop it...It is upsetting...because I think well, how will I communicate with people?"

2.6.1.4 Controllability and curability

This refers to patients' beliefs about whether or not their condition can be controlled, treated, or cured. In this study, it was found that individuals with hearing loss varied greatly in terms of whether or not they felt in control of their hearing loss. HHP5 said:

"I have probably seen people at all points on the spectrum from...people who are very much..."I have got a hearing loss but it

doesn't stop me doing anything"...to people...who are like, "I just don't know what I am going to do...my whole life has fallen apart" and...everything in between".

Most of the adults with hearing loss in this study believed that the condition is beyond their control. However, this belief did not appear to have a detrimental effect on their coping, with most regularly using hearing aids. These individuals had come to accept that they have hearing loss and that they must learn to live with the condition. AHL23 (man, aged 69) said:

"Well, it is outside of my control. There is nothing so certain as that. The only way I can control it is by putting hearing aids in and adjusting them...You have got to realise that nothing, nothing is going to replace your hearing... What you can do is find something which will enhance what you have got...And if you are not prepared to accept it then I am sorry; you have got a bit of a rotten life".

In terms of curability, some individuals with hearing loss initially hoped that hearing aids would fix their hearing loss, leading to disappointment. HHP2 said: *"the expectation is that a hearing aid fixes your hearing and I don't know whether that is the fault of explanation or...whether we, as humans...hope for it to fix things...but [it] often sets people up for a fall".* A small number of adults with hearing loss wished for a cure, perhaps through advancements in technology, though acknowledged that this was unlikely. AHL15 (woman, aged 75) said: *"I wish you could give me back my hearing...so I don't need to wear hearing aids at all, but I just have to accept*

it really...until you invent something that will help. I expect eventually there will be but it won't be [in] my lifetime".

2.6.1.5 Consequences

This refers to the perspectives of patients regarding the outcomes of their condition. A small number of participants mentioned some **positive consequences** of hearing loss, such as being able to ignore unpleasant sounds and to sleep soundly. Another positive outcome was developing a greater understanding of hearing loss and other disabilities. One participant, AHL3 (woman, aged 20) found that they experience of hearing loss was beneficial for her personal development:

"I believe it to be an annoyance but also...something that has given me an insight into...overcoming things that can be difficult and that has been quite good for me...in growing up and having to deal with things that other people my age don't have to deal with".

Another participant, AHL1, found that hearing loss benefited his relationship with his wife: *"deafness has, in a way, brought me and my wife together more...We were [already] pretty close but because of deafness, we have to talk more and closer...and we also share jokes about deafness".* However, for the majority of participants, the positive side of hearing loss was either slight or non-existent.

Hearing loss was found to have many **negative consequences**. Two of the major negative effects were stigmatisation, as discussed in the 'Identity' section and negative emotions, as discussed in the 'Emotional

representations' section. The other major negative consequences were activity limitations and participation restrictions. For example, it was reported that hearing loss impairs the detection of important sounds, such as telephones, alarms, traffic, and doorbells. This can affect one's independence and sense of personal safety. HHP1 (Audiologist) said: *"some people even don't answer the phone and they make...whoever lives at home answer the phone...They don't like going out on their own because...they don't trust themselves, especially crossing the road"*.

The majority of participants stated that hearing loss impaired their ability to communicate with others, especially in the presence of background noise, in group discussions, and on the telephone. AHL25 (woman, aged 49) said:

"if I'm out for a meal or in the pub...and there's lots of people...sometimes I can't get involved in the conversation, or I say inappropriate things because I've misheard what they've said. Or...my husband's having to reiterate all the time and sometimes at work, as well, when we're in a meeting...I struggle to hear".

Such communication difficulties can be frustrating, embarrassing, and discouraging for adults with hearing loss. AHL16 said: *"if somebody has already been discussing something and then you bring it up again, then people look at you as much to say: "Well we have just talked about that...What is the matter with you?""*. People with hearing loss can find it particularly challenging to communicate with strangers, as they tend to have unfamiliar communication styles or unfamiliar accents. Also, strangers may prove to be unaware of or unsympathetic towards hearing loss. AHL14

(woman, aged 48) explained that she had wanted to avoid strangers completely after developing sudden-onset hearing loss: *“I just wanted to be on my own and [with] people that I knew...I was frightened to meet new people because you don't know how they speak”*.

Hearing loss was found to have a negative impact on relationships with communication partners, including family relationships. It can be particularly difficult to take part in family gatherings, such as birthday parties, weddings, meals, and outings. AHL9 (woman, aged 85) said: *“I am with the family and they are talking and I feel as though I am not in the same world”*. Also, hearing loss can place a strain on romantic relationships. For example, hearing loss can lead romantic partners to have fewer joint social activities, fewer enjoyable conversations, and greater conflict. AHL3 reported experiencing tension in her relationship with her boyfriend, as he does not like repeating himself: *“He just gets annoyed at me and doesn't bother telling me what he has just said...We have lived together for just under two [years] and he still can't cope with it...And neither can I...We don't argue but it can get annoying”*. In addition, many reported that their friendships are affected by hearing loss, particularly as social gatherings often take place in noisy environments, such as pubs and restaurants. AHL5 (man, aged 81) said: *“Where I have difficulty is sitting in a gathering with friends and the conversation is flowing...I am perhaps more taciturn than I might otherwise be”*. Two participants mentioned that friendships can even come to an end if they cannot accommodate the needs of the individual with hearing loss, such as socialising in relatively quiet environments.

Hearing loss was found to impede a wide variety of social and leisure activities, including going to the theatre, cinema, concerts, talks, and sporting events. Also, many reported that hearing loss makes it difficult to enjoy watching television, especially in the company of others. AHL2 said: *"I often have to ask my husband, "What did he say? ...and he has to pause it to tell me. So it can be a little bit annoying for him and me"*. A small number of adults with hearing loss found that hearing loss affected their involvement in voluntary activities for their local community, charity, or religious organisation. AHL16 said: *"I am part of the prayer ministry team...[and] a couple of weeks ago I said: "I am really going to have to come off it."...because...I cannot hear what people want prayer for"*. She explained the significance of having to sacrifice such activities: *"it is...something else that is stripped away...it is not just your hearing that you have lost; it is a lot of other things you have lost as well"*. Some decided to adopt more solitary pastimes that do not rely on hearing. For instance, AHL11 adapted his pastimes, but felt that this area of life was not as satisfying as it once was: *"Enjoyment doesn't seem to be quite the word now...I think it is tolerable"*.

Hearing loss was reported to affect professional activities. For example, hearing loss can make it difficult to communicate and build relationships with clients and colleagues. Some worried that disclosing their hearing loss to their employers and asking for support would result in them being viewed as an inconvenience or incompetent, in being passed over for promotion, or even in being made redundant. HHP3 (Audiologist) stated that: *"it can affect...every aspect of their work, from dealing with colleagues to dealing with customers, to being able to perform in meetings, to even going out on a*

social night with your colleagues". She said that these difficulties even lead some adults with hearing loss to withdraw from work life:

"you do come across people that are actually very depressed because they have got this hearing loss and things at work are not going very well...[There] have been some people who have gone off sick because of it; have terminated their employment and said, "I can't do it anymore." Yes, that can even be with a very mild hearing loss".

In addition to difficulties at work, hearing loss was also found to create difficulties in education and training, such as struggling to follow what the teacher says, to take part in group discussions, and to fit in with fellow students.

2.6.2 Theme 2: Emotional representations of hearing loss

This refers to the emotions that individuals experience in response to hearing loss, including both their initial emotional reactions and changing emotional reactions over time.

2.6.2.1 Negative Emotions

The majority of adults with hearing loss in this study reported experiencing negative emotions due to their condition. HHP4 (Audiologist) said: *"I think there must be a lot of emotions because...you do go through the stages of grief and anger and disappointment and "Why me?"...before you can come to anything else maybe"*. One of the main negative emotions experienced was embarrassment. This included feeling embarrassed by having hearing loss, by wearing hearing aids, and by having communication difficulties, such as responding inappropriately to a misheard question or asking someone to

repeat what they have said multiple times. This can lead some to conceal their hearing loss when possible. Some found that their embarrassment diminished over time, such as AHL22 (man, aged 85): *"I felt embarrassed first of all going out with a hearing aids in...But now I don't bother if anybody sees: well blow it"*. However, some continued to feel embarrassed many years after they obtained hearing aids. AHL24 said: *"I don't think I have ever really got over it and thought: "Well people accept me the way I am"...I still feel a little bothered that people may see my hearing aids...It is almost like there is a stigma attached to it"*.

Many adults with hearing loss experienced fear and worry due to their hearing loss. Some, such as AHL2, were initially anxious about the possibility of their hearing continuing to decline: *"At first I was quite alarmed. I thought "Oh my goodness, I am going to go deaf"*. This worry dissipated for some, though not all, adults with hearing loss. Some experienced worry on a daily basis in relation to missing important sounds, such as alarms or traffic, and about missing important information, such as information from doctors or colleagues. For example, AHL15 stated that she often worried about misunderstanding conversations: *"I do worry...I go home and I think about it. I am sure they said something quite important and I didn't know what it was and, you know, that really does bother me"*.

A small number initially experienced anger at developing hearing loss, particularly if they felt that it was unfair or that they would struggle to cope. AHL1 recalled: *"It was a strange kind of feeling. It wasn't violent anger but really anger [that] it should happen to me. Why should it happen to me?"*

However, milder emotions, such as irritation and frustration, appeared to be

more common than anger. HHP2 stated that: *“It makes them fed up usually. I wouldn't say that it would send people into despair. Some it has, but not very many that I have seen”*. HHP5 warned that even mild irritation can take its toll on emotional wellbeing when it becomes a near constant presence in one's life. Indeed, many of the adults with hearing loss reported experiencing frustration regularly, due to communication difficulties and the limitations of hearing aids.

Many adults with hearing loss reported feeling isolated and lonely, as the condition makes it difficult to communicate with others and to participate in social situations. AHL4 (man, aged 68) said: *“the thing that really got me was if you are...with a group of people in a restaurant or in a bar... I was just out of it...I couldn't pick up anything...And it is really frustrating because you feel isolated then”*. This was particularly problematic for older adults who felt that their social sphere was already shrinking due to bereavement, retirement, and other health conditions. AHL9 said: *“it is just so lonely and it is so quiet and [there is] nobody to talk to”*.

2.6.2.2 Positive Emotions

There were a small number of reports of positive emotional representations of hearing loss. HHP1 explained that many patients in clinic already suspect that they have hearing loss and are relieved to have an explanation for their hearing difficulties: *“I think it is more often that you see patients who will accept it, who already know they have a loss...And they are quite glad, in a way, to know that yes it is a hearing loss”*. She also suggested that many are thankful the opportunity to receive professional help for their hearing

difficulties: *“A lot of them...are so eager and so keen to try a hearing aid...they are so grateful to have it”.*

However, only a very small number of the adults with hearing loss in this study reported experiencing positive emotions. For example, AHL3 was in some ways glad to be diagnosed with hearing loss as a teenager, as it set her apart from her peers:

“I was pretty pleased. I always loved the idea of having hearing aids...I think it is because I was a bit different from everyone...when you are 16-17, you want something special about you...I also liked the idea that there was a reason for why I was having trouble.”

However, her emotions become more negative over time: *“When I was first diagnosed, I loved the idea that it was going to get fixed and then it became less positive when I realised that hearing aids are not a fix”.*

2.6.2.3 Muted Emotions

HHP7 (Audiologist/academic) proposed that some individuals with gradual-onset hearing loss experience a relatively muted emotional reaction to the condition. For example, AHL7 (man, aged 69) was not particularly concerned when he realised that he had hearing loss: *“I don't know [that] I had many feelings about it. I mean, I well understand it is natural and ageing; things aren't functioning as they once did”.* Such muted reactions may be due to the fact that gradual-onset hearing loss provides individuals with time to realise and accept that they have hearing loss, whereas sudden-onset hearing loss can be shocking and upsetting. It was also suggested that, in comparison to other health conditions, hearing loss is not a substantial concern or a priority

for many people. HHP7 proposed that those with gradual-onset hearing loss are more likely to become emotional when they reflect on how the condition has affected their participation:

“for some people, the emotional response will start when they think about...participation in the particular situation...their emotional instincts can get triggered. Until then, they’re...fine, but when you talk about a particular situation in a particular context, then they get emotionally a bit worked up”.

2.6.3 Theme 3: Coping responses to hearing loss

This refers to perceptions of the coping strategies used by adults with hearing loss to manage the condition. The adults with hearing loss in this study displayed two main coping responses. The first, disengaged coping, involved avoiding addressing hearing loss, whilst the second, engaged coping, involved taking action in order to manage hearing loss.

2.6.3.1 Disengaged coping

There were two primary forms of disengaged coping. The first, **withdrawal from situations**, refers to avoiding being physically present in social situations. AHL20 explained: *“I was missing out on life...I was probably isolating myself from social situations...it was just too much effort to try and hear what people were saying”*. Rather than being completely withdrawn from all social situations, individuals with hearing loss tended to participate in some situations and not others, depending on whether or not they were perceived as too challenging. Specific social situations that the adults with hearing loss mentioned avoiding included parties, nightclubs, holidays, meetings, and lectures. Some found that they no longer participated in the

social activities they most valued. For example, AHL14 left her ideal job in the police force, though she had permission to stay in the role: *"I did give up my police [job] because I knew I couldn't put myself or a colleague in danger by...having this disability. So my childhood dream had to come to an end"*.

AHL9, who regarded family as *"the most important thing"*, no longer felt capable of minding her great-grandchildren: *"I feel I am too old to babysit for them because I couldn't hear what they were saying...it is depressing really"*.

The second form of disengaged coping, **withdrawal within situations**,

refers to being physically present in social situations but being passive, rather than active, in those situations. In particular, the adults with hearing loss reported 'switching-off' or sitting quietly during group conversations and large social gatherings because it was too difficult to attempt to take part.

According to HHP5, this may be the most prevalent form of withdrawal: *"they don't go or they withdraw within the situation, which is perhaps more common...they say that: "I went along but I couldn't really follow the conversation. So I was just...nodding and smiling."* AHL16 described her experience of this: *"You are there but you are not there...you begin to feel as though you are losing your identity...because you can't be yourself if you can't join in"*. She added: *"you just sit there like a fool and everything is going on around you"*.

Some adults with hearing loss said that they only attempt to participate in challenging conversations when they believe that the conversation contains particularly important or relevant information. AHL8 said: *"You...say to yourself: "Is it important that I...get involved in this conversation?"...you do sometimes adopt an isolationist attitude and say: "Well I am not going to pick*

up everything that is going on. So why bother?" Some said that they use 'bluffing', which means pretending that they are able to follow conversations, such as by guessing when to laugh or when to express agreement. Some said that they rely on communication partners to follow conversations on their behalf. For example, AHL13 (man, aged 69) said:

"It gets me down when neighbours...stop and talk...I really have to listen to what they are saying...But I am usually with the wife and she answers the questions...When we...come home...she has to repeat what they have told me...I feel awful...because I keep having to ask her: "What did they say?"...She doesn't seem to mind".

Some stated that they do not want to withdraw within situations but that they are sometimes forced to do so by other people. In particular, some reported that some people with normal hearing, who are not very patient or understanding, exclude them from conversations.

Disengaged coping was reported to have disadvantages, including causing individuals with hearing loss to respond inappropriately to questions, to miss important information, to feel isolated in social situations, and to become less socially active. It was also reported to cause conflict with communication partners who want the individual with hearing loss to address their communication difficulties. Nevertheless, this approach also has some perceived advantages. In particular, disengaged coping allows individuals to conceal their hearing loss and thus avoid the embarrassment and stigmatisation associated with the condition. HHP6 said:

“hearing loss is...invisible and so you don't have to tell people that you have a hearing loss... if you are in situations where you are likely...to expose yourself as somebody who has a hearing loss...you may decide to avoid those situations... one of the psychosocial consequences of hearing loss... specifically related to stigma...is that people tend to isolate themselves from...participating in social activities”.

Therefore, disengaged coping can be used to lessen the negative impact that hearing loss can have on emotions and identity. For example, AHL10 (man, aged 74) said: *“You seem to cover up...the least thing you want, especially when you are younger, [is] people to know you are losing your hearing...you feel a bit, not [a] second class citizen,...but you are not...one hundred percent on the mark”*. Disengaged coping also permits individuals with hearing loss to avoid the fatigue and stress associated with challenging social situations. HHP6 explained: *“[one] reason why people would avoid social gatherings...is because...it is very demanding... you know that you are just going to come back home exhausted”*.

2.6.3.2 Engaged coping

Engaged coping was both formal, such as making an audiology appointment, and informal, such as using humour, perseverance, and determination. For instance, AHL5 said:

“You either concentrate on the negative side of it and think: "My goodness...it is going to be awful." Or you say: "Well, that is how it is. Now let's get on with it"...Which sounds terribly pompous and flag

waving but...you effectively do that. There is not a lot of point in worrying”.

The majority of adults with hearing loss in this study regularly wore hearing aids and found them to be beneficial. Some were able to adjust relatively quickly to wearing hearing aids. AHL20 said: *“I started wearing it straight away and it made such a difference I didn't want to take it out...They are not just hearing aids any more. They are part of me”*. However, most needed time to get used to the idea of hearing aids, to learn how to use them, and to adjust to wearing them. AHL14 said: *“I was walking away from this hospital not knowing anything about hearing aids or...what they would do for me. I didn't want to wear these hearing aids...I didn't want people to see them, I felt embarrassed. I hated it”*. However, she now wears her hearing aids all the time: *“it...took me a long time to get used to them...now I can't live without them”*.

Although the majority of participants regularly wore hearing aids, they nevertheless reported that these devices have limitations. Some felt that hearing aids can be uncomfortable, difficult to handle, unattractive, or associated with ageing. Some mentioned that they gain little benefit from hearing aids in noisy environments, such as social gatherings, which means that their participation remains somewhat restricted. As AHL23 (man, aged 69) said: *“if you are in a crowded room, you are better off not wearing the hearing aids because you can't hear the conversation anyway...The problem is that...the hearing aid...enhances the sound around you...not just the person in front of you”*.

In addition, many of the adults with hearing loss reported successfully using communication tactics, including making people aware of their hearing loss, asking people to speak clearly, asking people to speak face-to-face, and ensuring that their environment is conducive to hearing. However, communication tactics were seen as inappropriate in certain circumstances. For example, asking for repetition can spoil group conversations, especially when a joke or story is being told. AHL6 said: *“somebody was telling a story...but you are conscious of the fact [that] if you say anything you are breaking into the story or you are breaking into the conversation. So you don't want to do that. So you keep quiet and you don't hear what they are saying”*. Some felt that communication tactics are ineffective when interacting with people who lack awareness of or sympathy towards hearing loss. In addition, some felt that using communication tactics, such as asking people to speak clearly, can result in them being perceived as demanding, annoying, or stupid. Communication tactics also require assertiveness, which does not come naturally to everyone. HHP5 said:

“you do have to make demands on people...you do have to do this thing of saying...“I need you to face me” or “Can you speak up?” or “Can you stop looking at your computer screen?”...they are quite small things but they actually take quite a lot of confidence to do”.

2.6.3.3 Personal and contextual factors

It was reported that several personal and contextual factors influence how well individuals cope with hearing loss and thus the severity of its consequences. In particular, the participants said that social support from communication partners is important in helping individuals to manage their

hearing loss. Furthermore, several of the adults with hearing loss had additional health conditions, such as depression, tinnitus, stroke, and arthritis, which added to the burden of their hearing loss. Also, many had to contend with the effects of ageing, such as impaired mobility, and life events that come with ageing, such as bereavement and retirement. AHL9 explained: *“you don't know what you put it down to; hearing loss or just because I have lost my husband and my daughter within four months and I am still getting over that...So it is as much a combination of sadness”*.

Personality is also an important factor, according to several participants. For example, some of the adults with hearing loss said that being an optimist means that they are less affected by their hearing loss. AHL7 said:

“I think, to a certain extent, personality comes in...I am a cheerful character...isn't it wonderful that [my hearing loss] can be corrected and, if it gets worse, then I can go to the hearing aids [clinic]...I don't see the point of fretting about what might happen...a certain optimism helps, as opposed to a depressive [person], who could let it prey on them”.

Some said that they have always been introverted, which means that hearing loss has not had a substantial impact on their social life. HHP5 explained: *“there is sometimes...an assumption in audiology that everybody wants to get to the stage where they can...socialise and chat to everybody and...,although that is true of many people,...some people don't much like socialising”*. However, even those who regard themselves as introverted can still be affected by hearing loss. HHP3 said: *“say we have got somebody that doesn't go out and about very much...It is going to affect things like*

somebody coming to the door, hearing the telephone ring, being able to communicate on the telephone". Also, several participants said that being confident and assertive helps with the management of hearing loss, particularly in terms of using communication tactics.

Another important factor is self-efficacy. Several adults with hearing loss described how hearing loss had diminished their belief in their ability to manage social situations and that they had to try to rebuild this belief over time. For example, AHL1 said:

"I have been asked to give a couple of seminars and I said no because I wasn't...confident; whether I would be able to listen carefully enough...to interact...So I have refused...I am hoping, though perhaps I am being [an] optimist, that I will be able to do it".

Several professionals also described how a lack of self-efficacy for managing social situations can become a crucial issue. HHP4 said:

"I saw a guy the other day...On the phone he is fine. But his wife jumps in and answers the phone first and when he is on the phone she stands next to him and she writes everything down. So she doesn't like trust him on the phone. So he has no confidence to use it".

Several professionals underlined the importance of self-efficacy for using coping strategies and interventions. HHP6 said:

"The other issue...I think is very important is everything related to self-efficacy. So it is one thing to know all of this stuff. It is another thing to think that you are...capable to use [coping strategies] and that it will

have an impact. [To] know that if you do use those strategies...it will be helpful...part of it is personality and part of it is...self-efficacy”

2.7 DISCUSSION

This study aimed to explore the psychosocial experiences of adults with hearing loss using the SRM as an underpinning theoretical framework. The results demonstrate that using the SRM can provide rich, novel insights into the psychosocial experiences of individuals with hearing loss and can enable different elements of these experiences (i.e. perceptions, emotions, and coping) to be housed together under one unifying theoretical framework. The results were used to develop the content of a new participation restrictions questionnaire, as outlined in Chapter 3. The main findings of the study are summarised and discussed below.

2.7.1 Cognitive representations of hearing loss

In terms of identity, hearing loss was found to have various negative connotations. For example, hearing loss was associated with being unintelligent, incompetent, and unfriendly. This corroborates the findings of previous studies that have found that adults with hearing loss can feel stigmatised by their condition and can perceive that it has a negative impact on their sense of identity (Espmark and Scherman 2003; Southall, Gagné and Jennings 2010; Wallhagen 2010). In terms of causal beliefs, opinions differed amongst the participants as regards the benefits of developing a detailed understanding of the nature and causes of hearing loss. Ultimately, the hearing healthcare professionals recommended tailoring the clinical information provided to patients to suit their individual preferences. Such

patient-centred approaches are now at the forefront of aural rehabilitation (Grenness et al., 2014a; Grenness et al., 2014b).

In terms of timeline, most of the adults with hearing loss were not especially concerned about the progression of their hearing loss. In addition, most believed that their hearing loss is not controllable or curable. Nevertheless, the majority of adults with hearing loss in this study regularly wore hearing aids. This contrasts with a meta-analysis of SRM studies, which showed that perceiving that a condition can be controlled or cured is positively associated with using active, problem-focused coping strategies for that condition (Hagger and Orbell 2003). As mild-to-moderate hearing loss is typically irreversible and progressive, it may be better for people with hearing loss to accept that they have a long-term condition that they must learn to manage, rather than to hope for an improvement to their hearing. Also, individuals with hearing loss may believe that, while the condition itself is uncontrollable and incurable, its consequences can be somewhat controlled through hearing aids and other coping responses. This study indicates that perceiving that hearing loss has low controllability and curability is not necessarily detrimental to engagement in aural rehabilitation.

Previous research has demonstrated that hearing loss can have positive consequences, including stronger relationships with communication partners, reduced disturbance from undesired sounds, affinity with other individuals with hearing loss and improved concentration, creativity and self-reliance (Kerr and Stephens 1997; Stephens and Kerr 2003; Yorgason, Piercy and Piercy 2007). This study confirmed that there are positive consequences of hearing loss. However, they tended to be outweighed by the negative

consequences of the condition. The most substantial negative consequences uncovered were activity limitations and participation restrictions, which confirms the findings of previous research (Dalton et al., 2003; Helvik, Jacobsen and Hallberg 2006a). In particular, hearing loss was found to have a negative impact on communication with other people, relationships with communication partners and participation in social, leisure, community and professional activities. Hearing loss also had a considerable negative impact on the participants' sense of identity and their emotional wellbeing.

2.7.2 Emotional representations of hearing loss

The adults with hearing loss had primarily negative emotional responses to hearing loss. The most common emotions experienced were frustration, embarrassment, worry and loneliness. This provides support to some previous research that has examined the link between hearing loss and loneliness (Pronk, Deeg and Kramer 2013; Weinstein and Ventry 1982). The findings of this study suggested that emotional responses can shift over time, reflecting the long-term nature of hearing loss. The importance of emotional responses to hearing loss, particularly their impact on health-related behaviours, has received relatively little attention in the literature. One exception to this is a recent investigation, which found that patients with hearing loss often express emotional concerns in audiology appointments, but that these concerns tend to be overlooked by the audiologist (Ekberg, Grenness and Hickson 2014). The authors recommended that audiologists attend to these emotional concerns to improve the therapeutic relationship and to increase the likelihood of the patient adhering to rehabilitation.

2.7.3 Coping responses to hearing loss

This study uncovered two primary coping responses: disengaged coping, or avoiding addressing hearing loss, and engaged coping, or taking action to manage hearing loss. This provides some support for another qualitative study (Hallberg and Carlsson 1991), which proposed that people with hearing loss use two main coping strategies: avoiding the social scene (e.g. pretending to understand, avoiding social situations) and controlling the social scene (e.g. making the best of social situations, asking people to repeat themselves).

In the present study, disengaged coping was found to entail both physical withdrawal from social situations, such as declining a party invitation, and psychological withdrawal from social situations, such as sitting quietly whilst others converse. This suggests that many adults with hearing loss who attend many social events could appear, on the surface, to have a high level of social functioning, yet underneath they could feel quite isolated and dissatisfied during those events. It also means that adults with hearing loss could take part in a wide range of social activities without taking part in the activities that are most important to them, such as babysitting their grandchild. Therefore, successful social participation for adults with hearing loss is not necessarily attending many social events, but rather being able to fully engage in the social situations that they value. This corresponds to the proposal that social isolation consists of both an objective component; social network size, and a subjective component; perceived loneliness (Hawthorne 2008; Weinstein 2015).

Despite the disadvantages of disengaged coping, which include increased social isolation, this strategy enables adults with hearing loss to evade the embarrassment, fatigue and stress associated with participating in social situations. Similarly, engaged coping was seen as having both advantages and disadvantages. Most of the adults with hearing loss found hearing aids to be beneficial, yet acknowledged that they also have various drawbacks. In particular, hearing aids were reported to be less effective in noisy situations, such as pubs and parties, than in quiet situations. Many of the adults with hearing loss also used communication tactics, such as asking people to speak clearly. However, these tactics were perceived as being ineffective in certain circumstances, such as when they obstruct group conversations or when communication partners are unsympathetic.

Previous research supports the finding that both disengaged coping and engaged coping have perceived benefits and limitations. One study found that individuals with hearing loss can perceive both 'adaptive' coping strategies (e.g. asking for repetition) and 'maladaptive' coping strategies (e.g. pretending to understand) to be effective, even though 'maladaptive' strategies do not facilitate communication (Gomez and Madey 2001). It may be that some adults with hearing loss feel that 'maladaptive' coping strategies enable them to avoid embarrassment and social rejection (Jaworski and Stephens 1998). Therefore, categorising coping strategies as either 'adaptive' or 'maladaptive' is arguably too simplistic, as the appropriateness of a coping strategy can depend on the specific individual and the specific situation (Andersson and Willebrand 2003). For example, individuals with hearing loss may find that communication tactics are better

suited to use with familiar communication partners than unfamiliar communication partners (Caissie et al., 1998; Tye-Murray, Purdy and Woodworth 1992).

2.7.4 Limitations

The results of this study indicate that the SRM is an appropriate framework for exploring the psychosocial experiences of adults with hearing loss.

However, this model is not without its limitations. In particular, despite the abundance of healthcare studies that describe the SRM, there have been few attempts to apply the model to the development of clinical interventions, which calls the utility of the model into question (McAndrew et al., 2008). The model has also been critiqued for placing little emphasis on the effect of personal and contextual factors (Hale, Treharne and Kitas 2007; Leventhal et al., 1997). Other frameworks, particularly the ICF, regard these factors as having an important influence on health-related behaviours and functioning. The current study examined the SRM using open-ended questions, which is argued to facilitate the exploration of personal and contextual factors (Diefenbach and Leventhal 1996). As a result of this approach, this study found that factors including social support, other health conditions, personality, and self-efficacy influence the experience and management of hearing loss.

In addition to the limitations of the SRM, the study itself had limitations.

Firstly, the participants with hearing loss were recruited from a database of individuals who are willing to take part in hearing research, many of whom are experienced hearing aid users. These individuals are likely to have accepted that they have hearing loss and are likely to be relatively socially

active. Therefore, participants from this database may not be representative of all individuals with hearing loss. In order to counteract this, hearing healthcare professionals were also interviewed, as they are likely to have encountered a broad range of patients. Also, the participants with hearing loss discussed not only their current but also their past experiences of hearing loss, including their experiences prior to engaging in auditory rehabilitation.

Another potential limitation of this study was its use of deductive, rather than inductive, thematic analysis. This approach arguably increases the risk of overlooking information that does not relate to the SRM but that could be an important aspect of psychosocial experiences of hearing loss. To limit the risk of missing important information, all of the data were coded, even those extracts that did not appear to relate to the SRM (Braun and Clarke 2006; Fereday and Muir-Cochrane 2006). Also, to ensure that the content of the participation restrictions questionnaire was comprehensive, additional sources were consulted (Turner et al., 2007), including the ICF Core Sets for Hearing Loss and existing questionnaires (Danermark et al., 2013; Granberg et al., 2014a; Seekins et al., 2012). Ultimately, the use of the SRM arguably broadened, rather than narrowed, the conceptualisation of participation restrictions. Due to this model, the conceptual model of this construct included not only the domains from the Activity and Participation categories of the ICF Core Sets for Hearing Loss; it also included the domains of emotion and identity. The questionnaire development process is described further in the next chapter.

Furthermore, it can be argued that it is difficult to achieve a truly inductive analysis, as researchers cannot entirely free themselves from the influence of their preconceptions, their epistemology, and their understanding of the relevant literature and theories (Braun and Clarke 2006; Malterud 2001). Also, according to Braun and Clarke (2006), a deductive approach is appropriate for studies that aim to answer a specific research question and to examine a particular aspect of the data in detail. In contrast, inductive thematic analysis is appropriate when the aim of the study is to devise a new research question. As the aim of the present study was not to develop a new research question but rather to generate questionnaire content, a deductive approach was deemed appropriate.

2.7.5 Future research

This study has provided an in-depth understanding of the psychosocial experiences of adults with hearing loss. The findings were used to inform the generation of content for a new subjective measure of participation restrictions in this population. Firstly, the results of the study were used to define participation restrictions and to devise a conceptual model of this construct. This definition and conceptual model formed the basis of the structure and scope of the outcome measure. Secondly, the results of the study, in particular the words and expressions of the adults with hearing loss, were used to compose the items in the questionnaire. This was so that the questionnaire would be clear and easy to understand and also so that it would be representative of and sensitive to the experiences of adults with hearing loss. As recommended, the findings of this qualitative study were cross-checked with additional sources, including a review of the literature

and other questionnaires, in order to ensure that the content of the outcome measure was comprehensive (Turner et al., 2007). The content generation process of the SPaRQ is described in detail in the forthcoming chapter.

CHAPTER 3. STUDY 2: THE DEVELOPMENT AND CONTENT EVALUATION OF THE SOCIAL PARTICIPATION RESTRICTIONS QUESTIONNAIRE

3.1 INTRODUCTION

This chapter reports the development and evaluation of the first prototype of the Social Participation Restrictions Questionnaire (SPaRQ1.0). Content for the questionnaire was generated using the findings of Study 1 and a review of the published literature. The questionnaire was then created by the author and amended based on feedback from members of the multidisciplinary supervision team. Subsequently, two research methods were used to evaluate the content of the SPaRQ1.0: **(1)** a survey of 20 subject matter experts, including researchers and clinicians, and **(2)** cognitive interviews with 14 adults with hearing loss. The aim was to examine whether the content was comprehensive, relevant, clear, and acceptable to individuals with hearing loss and to refine the questionnaire as necessary. Ultimately, this process was designed to enhance the content validity and minimise the respondent burden of the instrument. It is vital to ensure that a questionnaire possesses these measurement properties, as relevant and clear content strengthen the quality of the inferences that can be drawn from the data obtained by the questionnaire (Haynes, Richard and Kubany 1995).

3.2 CONTENT GENERATION

3.2.1 Conceptualisation

The development of an outcome measure should begin with the conceptualisation of the target construct (i.e. social participation restrictions in adults with hearing loss). Conceptualisation involves developing a clear

definition and conceptual model of the construct (Brod, Tesler and Christensen 2009; Clark and Watson 1995; Hinkin 1998). A conceptual model outlines the domains and subdomains that are contained within the construct (Brod, Tesler and Christensen 2009). Constructs are typically conceptualised using the findings of: **(1)** qualitative research with members of the target population and subject matter experts and **(2)** a literature review of previous attempts to conceptualise and measure the construct (Brod, Tesler and Christensen 2009; Haynes, Richard and Kubany 1995; Hinkin 1998; Rattray and Jones 2007).

In this research, social participation restrictions in adults with hearing loss was conceptualised based on the results of Study 1 and the literature review outlined in Chapter 1. As a result, social participation restrictions were defined as difficulties with active involvement in valued life situations. This is an extension of the ICF definition of participation restrictions: the problems an individual experiences with involvement in life situations (WHO 2002). It was decided that the term 'social participation restrictions', rather than just 'participation restrictions', would be used to distinguish this construct from activity limitations. As discussed in Chapter 1, it is difficult to clearly differentiate participation from activity but one means of doing so is to conceptualise activity as consisting of discrete, physical actions, such as dressing oneself, and to conceptualise participation as complex, social actions, such as visiting friends and family (Jette, Haley and Kooyoomjian 2003). The term 'active involvement' was chosen, as the Study 1 results demonstrated that adults with hearing loss who are physically present in social situations can appear on the surface to be involved in social situations

without being truly engaged (i.e. withdrawal within situations). The term 'valued life situations' was selected, as the Study 1 results showed that people with hearing loss are not concerned about participation in every life situation; rather they are concerned about participation in the life situations that are most important to them.

The Study 1 findings were also used to develop a conceptual model of social participation restrictions. In order to ensure that the SPaRQ1.0 was a comprehensive measure, all potentially relevant domains were included in the conceptual model. It is considered good practice to develop an initial item pool that contains a broad range of content, even if many of those items later prove to be tangential to the target construct following psychometric analysis. This is because easier to identify and remove existing irrelevant items than it is to identify and add new relevant items after a psychometric evaluation (Clark and Watson 1995; Reise, Waller and Comrey 2000). Therefore, the conceptual model contained three different domains:

- 1) Behaviour** - actions performed in a social context that can be negatively affected by hearing loss, such as taking part in group discussions, conversing on the telephone, and socialising with friends.
- 2) Emotion** - negative feelings experienced in a social context as a consequence of hearing loss, such as feeling frustrated at being excluded from conversations or feeling embarrassed by not understanding what someone has said.
- 3) Identity** - social attributes and social roles that have been negatively affected by hearing loss or that are perceived to have been negatively affected by hearing loss. For example, people with hearing loss can

believe that other people see them as being unfriendly or they can believe that they are less competent than they used to be.

Once the conceptual model was developed, a review of existing questionnaires was undertaken to confirm that the model was a comprehensive representation of social participation restrictions and to distinguish social participation restrictions from other related yet distinct constructs, which is a crucial aspect of conceptualisation (Clark and Watson 1995). Sixteen hearing-specific questionnaires, which were identified in a systematic review as being the most highly cited subjective outcome measures in hearing research, were reviewed (Granberg et al., 2014a). Also, eight generic questionnaires, which were identified in a systematic scoping review of participation measures frequently used in adult disability and rehabilitation research, were examined (Seekins et al., 2012). An examination of these questionnaires confirmed that behaviour, emotion, and identity are important domains and that they are likely to be representative of social participation restrictions.

The existing questionnaires measured several domains that were not added to the conceptual model, as they fell outside of the scope of the SPaRQ1.0 (see Chapter 1). It would be more appropriate to incorporate these domains into the broader theoretical model, the SRM. They included generic, rather than hearing-specific, domains; namely overall functioning (e.g. life satisfaction, general health) and other health issues (e.g. ambulation, pain, vision). They also included contextual factors (e.g. social support), personality factors (e.g. optimism), and third party disability.

Two domains measured by the reviewed questionnaires were difficult to classify. The first domain, coping, appears to be related to, rather than part of, social participation restrictions. For example, the SRM differentiates between coping responses and consequences, such as social participation restrictions. However, whilst some coping responses are clearly separate from social participation restrictions (e.g. hearing aid use, speech-reading use), some coping responses are arguably representative of social participation restrictions (i.e. withdrawal from situations, withdrawal within situations). Therefore, items representing these coping responses were included in the item pool. The other domain that proved difficult to classify was activity limitations. Some categories of functioning (e.g. focusing attention) could be classed as either activity or participation or both, depending on whether or not they are framed as taking place within a social context. Items that captured these categories of functioning were included in the item pool. Although these items may have proven to be unrelated to the target construct following psychometric analysis, it was important to include them at this stage for completeness.

3.2.2 Item generation

Item generation began by devising subdomains for each of the three domains in the conceptual model (See Table 3.1). The subdomains were derived from the Study 1 results and a review of existing questionnaires. The subdomains of the behaviour domain were also derived from the ICF Core Set for Hearing Loss, which contains a list of 42 activity/participation categories of functioning, such as 'Recreation and leisure' and 'Family relationships' (Danermark et al., 2013). Items were then created to assess

each subdomain (Rattray and Jones 2007). The Study 1 findings and the literature review indicated that behaviour was the most relevant domain, followed by emotion, and then identity. This was reflected in the number of subdomains and items created for each of these domains (Clark and Watson 1995).

Table 3.1 Subdomains of the SPaRQ

	Behaviour	Emotion	Identity
1	Watching	Frustrated	Foolish
2	Listening	Stressed	Impolite
3	Recreation and leisure	Embarrassed	Nuisance
4	Community life	Lonely	Unfriendly
5	Remunerative employment	Isolated	Unsociable
6	Non-remunerative employment	Worried	Incapable
7	Using transportation	Upset	Hearing impaired
8	Higher education	Sad	Disinterested
9	Vocational training	Dispassionate	
10	Using communication devices and techniques		
11	Conversing with one person		
12	Conversing with many people		
13	Discussion		
14	Communicating with - receiving - spoken messages		
15	Acquisition of goods and services		
16	Basic economic transactions		
17	Focusing attention		
18	Relating with strangers		
19	Informal social relationships		
20	Formal relationships		
21	Family relationships		
22	Intimate relationships		

It has been recommended that items are generated by consulting target respondents, experts in the field, and the published literature (Rattray and Jones 2007). In this research, items were generated by consulting the findings of Study 1 and a literature review. Where possible, the words and phrases used by the adults with hearing loss from Study 1 were re-used in the items (Tilden, Nelson and May 1990). Also, published recommendations about item generation were followed. These include recommendations to use simple words and syntax, to avoid jargon and slang, to use words and expressions that are concrete rather than abstract, to avoid ambiguous terms (e.g. probably, perhaps), to avoid double-negatives, and to refrain from creating double-barrelled items, especially items containing two verbs (Krosnick and Presser 2010; Lietz 2010; Rattray and Jones 2007). It has also been advised that items should be concise, meaning that they should contain no more than 16-20 words, with the exception of items of a sensitive nature that should not be abrupt (Boynton and Greenhalgh 2004; Lietz 2010). In total, 49 items were created for the SPaRQ1.0, (see Tables 3.2 and 3.3).

Initially, all 49 items were negatively worded (e.g. *'Because of my hearing loss, I find it difficult to have conversations on the telephone'*). However, it was felt by the supervisory team that the questionnaire would potentially be too negative and off-putting for participants if all of the items were negative. Consequently, the questionnaire was changed so that it contained a mixture of positively worded items (e.g. *'Despite my hearing loss, I can attend social gatherings'*) and negatively worded items. The other advantage of mixing positively worded items and negatively worded items is that it is thought to prevent participants from giving the same response to every question or

agreeing with every question (Rattray and Jones 2007). In order to avoid confusing participants, negatively and positively worded items were not mixed together within a subdomain (i.e. subscale). Instead the behaviour items were all positively worded and the emotion and identity items were all negatively worded.

Table 3.2 Abbreviated content of the behaviour items

Item	Abbreviated behaviour item content
1	Watch television with others
2	Watch plays, films or sporting events
3	Listen to music, radio or birdsong
4	Carry out favourite pastimes
5	Take part in voluntary activities
6	Take part in community activities
7	Use transportation
8	Follow a lecture or talk
9	Take part in a meeting
10	Take part in a group discussion
11	Converse with colleagues
12	Take part in training
13	Converse using the telephone
14	Talk with staff in shops, cafes or banks
15	Converse with a healthcare professional
16	Converse where there is background noise
17	Start a conversation with unfamiliar people
18	Attend get-togethers with friends
19	Converse with friends
20	Go out with significant other
21	Converse with significant other
22	Attend family get-togethers
23	Converse with family

It was decided that the questionnaire should be composed of closed-ended items without any open-ended items. Whilst open-ended items have the

advantage of producing rich data by allowing respondents to explain their answers in detail, these data are often difficult to analyse in a meaningful way (Rattray and Jones 2007). For example, it has been recommended that open-ended responses should be analysed by two independent researchers using a pre-determined coding framework, which is a highly time-consuming procedure (Krosnick and Presser 2010). Therefore, open-ended items have limited interpretability and create burden for clinicians and researchers. Closed-ended items have the disadvantage of being frustrating for some respondents, as their comparatively narrow range of responses may not fully reflect the views of those respondents (Boynton and Greenhalgh 2004). However, closed-ended items have the key advantage of facilitating standardisation, including the grouping of scores and the comparison of scores (Rattray and Jones 2007). Therefore, closed-ended items were used so that the measure could serve as a standardised outcome measure in clinical trials (Patel, Veenstra and Patrick 2003). Specifically, statement style items were used, as they are generally thought to be easy to understand and quick to complete (Boynton and Greenhalgh 2004).

3.2.3 Response scale design

The choice of response scale is an important one, as it can affect the reliability, validity and responsiveness of a measure (Krosnick and Presser 2010; Preston and Colman 2000; Stewart and Archbold 1993; Weng 2004). However, it is also not an easy choice, as no single response scale suits every circumstance (Cox III 1980). Instead, questionnaire developers must select the most appropriate format from the multitude of available options,

including visual analogue scales, verbal rating scales, numerical rating scales, and item-specific scales (Hjermstad et al., 2011; Saris et al., 2010).

Table 3.3 Abbreviated content of the emotion and identity items

Item	Abbreviated emotion item content
24	Frustrated when I cannot say what I want to say
25	Frustrated when I am left out of conversations
26	Embarrassed by saying the wrong thing
27	Embarrassed by ask people to repeat themselves
28	Isolated when it is difficult to take part in conversations
29	Isolated at get-togethers
30	Lonely around other people
31	Find social gatherings stressful
32	Worry about going to social gatherings
33	Worry about talking to unfamiliar people
34	Worry about missing important information
35	Lose motivation to go to get-togethers
36	Do not care about joining in conversations
37	Upset when it is difficult to take part in conversations
38	Sad when I cannot join in
Item	Abbreviated identity item content
39	Look foolish when I say the wrong thing
40	Look foolish when I cannot understand others
41	Look demanding when I ask people to repeat
42	Treated as a nuisance
43	Look rude when I do not realise that people are speaking
44	Look unfriendly when I do not join in
45	Look less sociable than I really am
46	Look like I am not interested in talking to people
47	Look less capable than I really am
48	Rather pretend that I can understand
49	Rather sit quietly whilst people talk

The first step in devising the response scale for the SPaRQ1.0 was determining how many response options there should be. Response scales

with a broad range of options are thought to be the most appropriate choice for an outcome measure, as they are likely to have greater sensitivity to change over time (Stewart and Archbold 1993). Scales with many response options (i.e. 7-10 options) tend to be preferred by respondents than scales with few options (i.e. 2-4 options) (Preston and Colman 2000). Broad scales allow respondents to provide more fine-grained responses, whereas narrow scales tend to capture little information and can frustrate respondents by preventing them from adequately expressing their attitudes (Cox III 1980; Krosnick and Presser 2010). There is also some evidence that response scales with seven to 11 response options have greater reliability and validity than response scales with just two or three options (Alwin 1997; Krosnick and Presser 2010; Preston and Colman 2000; Weng 2004). Therefore, it was decided that the response scale for the SPaRQ1.0 should have between seven and 11 response options. However it was noted that choosing between such a range of response options can make completing a questionnaire more effortful for some participants (Krosnick and Presser 2010).

The next step in devising the response scale of the SPaRQ1.0 was determining what type of scale should be used. The results of Study 1 and the literature review suggested that a self-efficacy response scale would be appropriate for use with the behaviour items, as self-efficacy is one of the most important determinants of health-related behaviours (Zulkosky 2009). Bandura (2006) designed a self-efficacy response scale that asks respondents to rate their confidence in their ability to do a specific activity on an 11-point response scale with three labelled points (0= '*Cannot do at all*',

50=*'Moderately certain can do'*, 100=*'Highly certain can do'*). This response scale has previously been used in two hearing-specific questionnaires that measure listening self-efficacy and hearing aid use self-efficacy (Smith et al., 2011; West and Smith 2007). Numerous other healthcare questionnaires have used different versions of the self-efficacy response scale (Sheer 2014). For example, the *Arthritis Self-Efficacy Scale* (Lorig et al., 1989) used a 10-point response scale with three labelled points (10=*'Very uncertain'*, 50 and 60=*'Moderately uncertain'*, 100=*'Very certain'*).

In this research, it was decided that a modified version of the self-efficacy scale (Bandura 2006) would be suitable for the behaviour items. The response options were changed from a 0-100 scale to a 0-10 scale, as it was expected that this format would be more familiar and clear to the respondents. The response option labels were also changed because their wording is inconsistent. For example, the label at point zero (i.e. *'Cannot do at all'*) does not contain the word 'certain', unlike the other labels, and it is not the opposite of the label at point 100 (i.e. *'Highly certain can do'*). The response scale was therefore changed to an 11-point scale with labelled endpoints (0=*'Certain I cannot do this'*, 10=*'Certain I can do this'*). The midpoint response option was not labelled, as it was thought that this would prompt respondents to treat the response scale as a three-point scale, rather than as a continuum. Also, offering a midpoint can encourage participants to consistently select this option throughout the questionnaire, particularly those participants with low motivation or low cognitive ability (Krosnick and Presser 2010).

As self-efficacy response scales are concerned with one's belief in one's ability to perform specific actions, they were not deemed suitable for the emotion and identity items. It was, however, decided that it would be beneficial to preserve the response scale format as much as possible throughout the questionnaire. As such, it was decided that the emotion and identity items would have an 11-point scale with labelled endpoints (0='Strongly disagree', 10='Strongly agree'). The agree/disagree format is one of the most popular response scale formats, as it is generally easy for respondents to complete (Krosnick and Presser 2010; Rattray and Jones 2007). It is applicable to most question types, which means that the response scale can remain consistent across different questions, rather than changing with each question, thus streamlining the questionnaire (Saris et al., 2010). A disadvantage of this format is that some evidence suggests that all response options should be labelled for the sake of clarity, reliability, and interpretability (Krosnick and Presser 2010; Saris et al., 2010; Weng 2004). However, it is not usually possible to devise truly meaningful labels for more than seven response options (Krosnick and Presser 2010). The response scales were further examined during the content evaluation stage.

3.2.4 Item ordering

The ordering of items in a questionnaire can affect response rates, motivation, accuracy, and fatigue (Krosnick and Presser 2010). Therefore, care was taken when arranging the items of the SPaRQ1.0. In order to gain the respondents' trust, the first items in the questionnaire were explicitly relevant to the topic of the questionnaire, as described to participants (i.e. the impact of hearing loss on everyday life). These items asked about the impact

of hearing loss on watching television, watching live events, and listening to music. Potentially sensitive items, specifically the emotion and identity items, were placed at the end of the questionnaire. Also, items about similar topics were grouped together, as this enhances the flow of the questionnaire and aids respondents' recall (Krosnick and Presser 2010). This meant that the behaviour items were grouped together, the emotion items were grouped together, and the identity items were grouped together.

3.3 CONTENT EVALUATION

Study 2 of this doctoral research was an evaluation of the content of the SPaRQ1.0 (see Appendix D). Content evaluation, also known as pre-testing or content validation, is a multi-method process in which all of the elements of a measure, including items and response scales, are evaluated against specific criteria, such as relevance and clarity (Haynes, Richard and Kubany 1995). Content evaluation ensures that valuable resources and participants' time are not wasted by administering a measure to a large sample only to discover afterwards that it has not been properly completed by the participants or that it is in some way unsuited to the sample (McGartland Rubio et al., 2003). For example, researchers can unintentionally use terms that are offensive, intimidating, or that are not appropriate for particular cultural groups (Boynton, Wood and Greenhalgh 2004). Therefore, it is important that the content of the measure is evaluated in terms of its acceptability to participants. Additionally, content evaluation can uncover whether the questionnaire omits any relevant content or includes any irrelevant content, which would degrade the quality of the clinical

inferences drawn from questionnaire data (Haynes, Richard and Kubany 1995).

Content evaluation can also identify problems with the clarity of the measure. In questionnaire research, it is often assumed that all respondents are able to understand the items, that the items are interpreted in the same manner by all respondents, and that all respondents possess and can access the information being requested by the items (Collins 2003). However, pre-testing research has shown that respondents can encounter numerous problems when completing a questionnaire, such as struggling to understand abstract expressions and technical terms or struggling to select a suitable response option (Conrad, Blair and Tracy 1999). Some respondents answer items that they do not understand out of a sense of politeness or duty, some answer items without realising that they have misunderstood them, and some answer items without making a concerted effort to retrieve or compute the required information (Collins 2003). These problems can easily go undetected, which means that, unbeknownst to the researcher, the data collected are of poor quality. It is for these reasons that content evaluation is a crucial component of questionnaire development (Mokkink et al., 2012; Reeve et al., 2013).

3.4 AIMS AND OBJECTIVES

The aim of Study 2 was to evaluate the elements of the SPaRQ1.0 in order to determine whether they required adjustment, such as clarifying existing items or introducing new items. This would enhance the content validity and minimise the respondent burden of the questionnaire. The specific objectives of the study were to evaluate the:

- 1) Construct definition
- 2) Factor structure of the questionnaire
- 3) Representativeness of the items
- 4) Clarity of the items
- 5) Comprehensiveness of the questionnaire
- 6) Appropriateness of the response scale
- 7) Sensitivity of the questionnaire
- 8) Acceptability of the questionnaire

3.5 DESIGN

The study achieved its aims and objectives by utilising two research methods, a subject matter expert survey and cognitive interviews, which are two of the most prevalent content evaluation techniques (Drennan 2003; Haynes, Richard and Kubany 1995; McGartland Rubio et al., 2003). As in Study 1, there were two groups of participants, hearing healthcare professionals and adults with hearing loss, for the purposes of triangulation (Yardley 2008).

3.5.1 Subject matter expert survey

This method entails a panel of individuals with relevant expertise evaluating the questionnaire through a series of closed-ended and open-ended questions (Grant and Davis 1997). All elements of the measure should be assessed, including the items, the response scale, and the potential factor structure (Haynes, Richard and Kubany 1995; McGartland Rubio et al., 2003). These elements are assessed in terms of specific criteria, such as clarity and comprehensiveness. The aim is to identify elements that should be refined or removed and also to identify new elements that should be

included (Haynes, Richard and Kubany 1995; McGartland Rubio et al., 2003). The subject matter experts are normally those with relevant clinical or academic qualifications and experience. Members of the target population can also be included (Grant and Davis 1997; Tilden, Nelson and May 1990). In this study, clinicians and academics were recruited for the subject matter expert survey, whilst adults with hearing loss were recruited for the cognitive interviews. This was because the terminology used in the survey (e.g. factors, representativeness, sensitivity) would not be suitable for many adults with hearing loss.

3.5.2 Cognitive interview

Cognitive interviews are individual, semi-structured interviews that aim to uncover how respondents interpret a questionnaire and, in doing so, identify potential problems with that questionnaire, such as problems comprehending certain items or the response scale (Conrad and Blair 1996; Drennan 2003). In addition to evaluating clarity, cognitive interviews can also evaluate comprehensiveness, relevance, and acceptability (Brod, Tesler and Christensen 2009; Mokkink et al., 2012). They normally take place in the pre-testing phase of a questionnaire study, with their findings being used to amend the questionnaire before the main data collection phase (Drennan 2003). It has been recommended that an element of a questionnaire should be considered a candidate for revision if two or more participants find it problematic (Brod, Tesler and Christensen 2009).

There are different types of cognitive interview, though all involve administering a questionnaire to respondents and collecting qualitative data about that questionnaire (Beatty and Willis 2007). The two primary types are

concurrent interviews, where data are gathered whilst the respondents complete the questionnaire, and retrospective interviews, where data are gathered immediately after the respondents have completed the questionnaire (Drennan 2003). Concurrent interviews often involve the think-aloud approach, in which participants verbalise their thought processes as they respond to the questionnaire, as well as observation of respondent behaviour, such as skipping questions. Both concurrent and retrospective interviews can utilise probing, such as asking the participants to paraphrase questions, to express their understanding of particular terms, to explain how they reached their responses, and to highlight aspects that they found difficult to understand (Collins 2003; Drennan 2003). The primary advantage of concurrent interviews is that participants can describe their interpretations as they arise, rather than having to rely on memory. Retrospective interviews are advantageous when the questionnaire is self-administered, as they can reveal whether respondents are able to follow the instructions and complete the questionnaire without assistance (Willis 2004). The retrospective approach was identified as the most appropriate for this study (see study procedure section).

3.5.3 Sample size

There are a variety of recommendations in the literature concerning appropriate sample sizes for cognitive interviews and subject matter expert surveys. The sample size of a subject matter expert survey usually depends on the availability of experts in the given field and the level and diversity of their expertise (Grant and Davis 1997; Haynes, Richard and Kubany 1995). For example, if it is difficult to find experts who each possess all of the

required expertise (e.g. both clinical and academic qualifications), a greater number of participants should be recruited (Davis 1992). Some research has recommended a panel of between eight and 12 experts (Polit, Beck and Owen 2007), while other research has recommended a panel of between six and 20 experts (McGartland Rubio et al., 2003). Therefore, it was anticipated that a sample size of approximately 12-20 participants would be sufficient.

Sampling for a cognitive interview study normally ceases when saturation is reached, or the point at which no new themes or problems emerge (Leidy and Vernon 2008; Rothrock, Kaiser and Cella 2011). In terms of identifying problems, it has been recommended that studies recruit between eight and 25 participants, with approximately ten participants often being an appropriate sample size (Leidy and Vernon 2008; Macefield 2009). For example, a usability testing study found that 20 participants can identify at least 95% of problems (Faulkner 2003). Therefore, it was estimated that the cognitive interviews would have a sample size between ten and 20 participants, depending on saturation.

3.6 METHODS

This research was approved by the University of Nottingham Sponsor, the North East - Tyne and Wear South Research Ethics Committee and the Research and Innovation Department at the Nottingham University Hospitals NHS Trust.

3.6.1 Participants

Twenty researchers and clinicians from the UK and abroad participated in the subject matter expert survey (see Table 3.4). Nineteen participants fully completed the survey, whilst one participant provided partial data. In

addition, 14 adults with hearing loss from the UK participated in the cognitive interviews (see Table 3.5).

3.6.2 Recruitment

3.6.2.1 Inclusion and exclusion criteria

The inclusion criteria for the subject matter experts were:

- 1) Willing and able to complete and return a survey electronically or by post.
- 2) Aged 18 years or older with no upper age limit.
- 3) Good written and spoken English. English does not have to be the participants' first language.
- 4) Able to read letters on a computer screen or on paper with or without glasses.

The inclusion criteria for the adults with hearing loss were:

- 1) Willing and able to complete paper-and-pen questionnaires.
- 2) Willing and able to take part in a semi-structured interview.
- 3) Have a hearing loss (e.g. demonstrated that they have a hearing loss on the screening questionnaire or the demographics questionnaire).
- 4) Aged 18 years or older with no upper age limit.
- 5) Good written and spoken English. English does not have to be the participants' first language.
- 6) Able to read letters on a computer screen or on paper with or without glasses.

Table 3.4 Demographic information of the study 2 subject matter experts

Gender	n
Women	17
Men	3
Country of employment	n
UK	11
The Netherlands	3
USA	3
Denmark	2
Canada	1
Profession	n
Audiologist	10
Hearing researcher	5
Hearing therapist	3
Health psychologist	1
Engineer	1
Current role	n
Hearing researcher	13
Lecturer	3
Professor	3
Audiologist	3
Head of adult audiology service	1
Hearing therapist	1
Areas of expertise	n
Adult rehabilitation	11
Outcome measurement/psychometrics	8
Bone anchored hearing aids	2
Psychosocial aspects of hearing loss	2
Tinnitus	2
Single sided deafness	1
Auditory processing disorder	1
Cochlear implants	1
Geriatrics	1
eHealth	1
Behaviour change	1
Intervention research	1
Hearing education	1
Public health	1
Epidemiology	1

Table 3.5 Demographic information of the study 2 adults with hearing loss

Gender	n
Male	7
Female	7
Age	Years
Mean	69.29
SD	9.07
Range	51-81
Median	71
Hearing loss screen	
Yes to both items	14
Yes to one item	0
No to both items	0
Hearing loss type	n
Acquired	14
Congenital	0
Hearing loss onset	n
Gradual	13
Sudden	1
Hearing loss duration	Years
Mean	14.57
SD	14.06
Range	3-51
Median	10
Hearing aid ownership	n
Yes	14
No	0
Employment status	n
Retired	10
Employed	4
Student	0
Living arrangements	n
Live with other people	11
Live alone	3

The exclusion criteria for the adults with hearing loss were:

- 1) Self-reported cognitive decline or dementia that would necessitate assistance in completing a questionnaire.
- 2) Self-reported profound hearing loss.

3.6.2.2 Subject matter expert survey recruitment procedure

A purposeful sampling strategy was used (Grant and Davis 1997; Guest, Bunce and Johnson 2006). A list of potential participants was derived from the professional network of the author and the supervisory team. The aim was to recruit clinicians and researchers who had expertise in the psychosocial impact of hearing loss or outcome measurement or both. Individuals who had relevant publications, relevant clinical qualifications, or relevant clinical experience were deemed to have met these criteria. Participants were sought from a variety of countries to ensure that the questionnaire was free of colloquial terms and thus was suited to English-speaking respondents who were not raised in the UK (Grant and Davis 1997). Recruitment continued until a sufficiently diverse and experienced sample of experts had completed the survey. In total, 29 potential participants were contacted via email. Twenty consented to participate in the study, resulting in a response rate of 68.97%. The nine remaining individuals did not provide a reason for not participating in the study.

3.6.2.3 Cognitive interview recruitment procedure

A convenience sampling strategy (Patton 1990) was used, whereby the Nottingham Hearing BRU participant database was searched for potential participants who were likely to meet the study criteria, excluding those who

had taken part in Study 1. Recruitment continued until saturation had been reached in the cognitive interviews. In total, 22 potential participants were contacted via post. Initially, 16 individuals agreed in principle to participate in the study. Two of these individuals later decided not to participate in the study; one because of work commitments and the other because of recent health problems. The remaining 14 participants consented to participate in the study, leading to a response rate of 63.64%.

3.6.3 Materials

The subject matter expert panel completed the electronic, online survey described below in order to review the SPaRQ 1.0.

3.6.3.1 Subject matter expert survey

The survey was created and the data were collected via SurveyMonkey Inc., Palo Alto, California, USA, www.surveymonkey.com. The survey was designed to gather expert opinion on the **(1)** proposed factor structure of the questionnaire **(2)**, representativeness of each item, **(3)** clarity of each item, **(4)** appropriateness of the response scales, **(5)** potential sensitivity of the questionnaire, and **(6)** comprehensiveness of the questionnaire. The design of the survey was based on published examples (Grant and Davis 1997; McGartland Rubio et al., 2003). The survey contained four sections consisting of closed-ended questions followed by open-text boxes in which respondents could provide written comments.

Section 1 contained instructions for the respondents. They were given an overview of the purpose and format of the survey, they were informed that they could take as many breaks as they wished, and they were reminded that any information provided would remain confidential. The first section

also contained five open-ended demographic questions, composed by the author, which asked about their current job role, profession, area of expertise, country of employment, and gender.

Section 2 asked respondents whether they agreed or disagreed with the proposed definition of social participation restrictions: “*The difficulties an individual experiences in active involvement in valued life situations*”. It also asked participants whether they agreed or disagreed with the proposal that the construct contained the three domains of behaviour, emotion, and identity. The response scale for these questions contained two response options: 1=‘Agree’, 2=‘Disagree’. They were also asked to suggest any additional domains via an open-text box.

Section 3 asked the participants to evaluate representativeness of each individual item, which is its relevance to hearing-related participation restrictions, on a four-point scale (1=‘Does not fulfil criterion’, 2=‘Major revisions needed’, 3=‘Minor revisions needed’, 4=‘Fulfil criterion’). They were then asked to rate the clarity of each item using this scale. The respondents were also presented with the self-efficacy response scale for the behaviour items and the agree/disagree response scale for the emotion and identity items. They were asked whether either of the response scales required alteration (1=‘No change needed’, 2=‘Change needed’).

Section 4 contained two closed-ended questions. The first question asked whether they agreed or disagreed that the questionnaire could serve as a sensitive outcome measure. The second asked whether they agreed or disagreed that the questionnaire is a comprehensive measure of social

participation restrictions in adults with hearing loss. The response scale for these questions was as follows: 1='Agree', 2='Disagree', 3='Don't know'.

The following paper-and-pen questionnaires were completed by the cognitive interview participants.

3.6.3.2 First prototype of the social participation restrictions questionnaire (SPaRQ1.0)

This is a 49 item, hearing-specific questionnaire that assesses social participation restrictions. It contains three sections: 23 behaviour items, 15 emotion items, and 11 identity items. The behaviour items are accompanied by an 11-point self-efficacy response scale with labelled endpoints (0='Certain I cannot do this', 10='Certain I can do this'). A score of ten for an item on this scale represents a high level of social participation. The emotion and identity items are accompanied by an 11-point agree/disagree response scale with labelled endpoints (0='Strongly disagree', 10='Strongly agree'). A score of ten for an item on this scale represents a high level of social participation restrictions. Respondents are also instructed to select '*Does not apply*' for any questions that are not at all relevant to them.

3.6.3.3 Hearing loss screening questionnaire

This five-item questionnaire (see Appendix E) was originally developed as part of a large scale UK study (N=1461), which investigated the effectiveness of a programme to screen for people aged 55-74 years who could benefit from wearing a hearing aid (Davis et al., 2007). Respondents are instructed to answer the questions as if they are not wearing a hearing aid. Two of the five items in the questionnaire can be used as a valid screening tool for hearing loss. These are Item 1 ('Do you have any difficulty with your

hearing?') and Item 2 ('Do you find it very difficult to follow a conversation if there is background noise, such as TV, radio, children playing?'), which are answered by selecting either 'Yes' or 'No'. It has been demonstrated that individuals who answer 'Yes' to at least one of these two items are likely to have a hearing threshold of at least 35 dB HL in the better ear averaged across 0.5-4 kHz when tested using pure tone audiometry (Davis et al., 2007). Therefore, these two items were used to screen for hearing loss amongst the participants in this study.

3.6.3.4 Demographics questionnaire

Nine closed-ended, multiple-choice, demographics questions composed by the author. These questions asked participants about their hearing loss onset, type, degree, and duration, as well as their gender, employment status, country of residence, age, and whether or not they live with other people.

3.6.4 Study procedure

The subject matter expert survey and the cognitive interviews were conducted concurrently. The procedure of each is described below.

3.6.4.1 Pilot subject matter expert survey

A pilot survey was administered to two Nottingham Hearing BRU researchers who were not otherwise involved in this study. The aim was to ensure that the survey was easy to understand and to complete. The pilot survey asked participants to rate the sensitivity of each item, as well as the representativeness and clarity of each item. The pilot participants advised against this because they found sensitivity more difficult to assess than representativeness and clarity. Also, rating each item on three separate

criteria was highly burdensome for the participants. Consequently, the survey was altered so that the participants were asked to provide a global assessment of the sensitivity of the entire questionnaire. The pilot participants also suggested some minor changes to the demographics questions to improve their clarity, which were implemented.

3.6.4.2 Subject matter expert survey procedure

Participants received a letter of invitation and study information sheet via email at least 72 hours prior to their participation in the study. They were given the opportunity to contact the author via telephone or email to ask questions about the study. Once participants informed the author that they were willing to take part, they were sent an email containing a link that allowed them to access the online survey. Completion and submission of the survey served as informed consent. The survey took approximately one hour to complete. Participants could complete it from a location of their choice and could take as many breaks as they required. They were asked to complete the survey within two weeks, in line with published guidance (Slocumb and Cole 1991). Participants who had not completed the survey within two weeks were sent a reminder about the survey via email. All participants were offered an inconvenience allowance of ten pounds for taking part in the study, with the exception of the participants who were employed by the Nottingham Hearing BRU. Only two participants accepted the offer of payment. The research data were treated confidentially and were stored securely on password protected computers or in locked filing cabinets in the BRU.

3.6.4.3 Pilot cognitive interview

The researcher conducted a pilot cognitive interview with a member of the Nottingham Hearing BRU Patient and Public Involvement (PPI) Panel who had hearing loss. The primary aim was to determine which type of cognitive interview (i.e. concurrent or retrospective) would be most appropriate for adults with hearing loss. The PPI panel member stated that the participants would feel more comfortable and be more informative in a retrospective interview. Concurrent techniques, such as thinking-aloud and observation, were considered to be too artificial and obtrusive. The PPI panel member recommended that the author inform participants that she would be working in another room whilst they completed the SPaRQ1.0 so that they did not feel observed or that they were under pressure to complete the questionnaire quickly. The author implemented these recommendations.

3.6.4.4 Cognitive interview procedure

The participants received a postal letter of invitation, study information sheet, and interview agenda at least 72 hours prior to their participation in the study. The participants contacted the author by telephone, email, or post to arrange their participation in the study. Each participant travelled to the Nottingham Hearing BRU to take part in the study. They were greeted by the author and brought to an interview room, where they were given a verbal overview of the study. They were given an opportunity to review the study information sheet and to ask questions about the study. They provided written informed consent to participate in the study by signing a consent form, which was then undersigned by the author. The participants and the author each retained a copy of the consent form. The participants then completed the hearing

screening questionnaire and demographics questionnaire, which required approximately ten minutes for completion. Subsequently, the participants completed the SPaRQ1.0 in the interview room, whilst the author waited in an adjoining room. The SPaRQ1.0 took approximately 30 minutes to complete.

The author then conducted the cognitive interview in accordance with the semi-structured interview schedule (see Appendix F). The probes used were based on published examples (Brod, Tesler and Christensen 2009). Each interview typically lasted one hour. Therefore, the entire session typically lasted two hours. Throughout, the participants were given opportunities to take breaks or to obtain refreshments. Each participant received an inconvenience allowance of ten pounds, as well as a reimbursement for any travel expenses incurred. The interviews were audio-recorded and transcribed verbatim. The research data were treated confidentially and were stored securely on password protected computers or in locked filing cabinets in the Nottingham Hearing BRU.

3.7 DATA ANALYSIS

The data analysis procedure is detailed below (see Table 3.6). The software packages used to organise and analyse the data were Microsoft Excel 2010, IBM SPSS Statistics for Windows Version 22.0, and QSR International's NVivo 10 Software. The data of the subject matter expert survey were analysed separately from the cognitive interview data. The results of the different analyses were then brought together in order to make amendments to the questionnaire.

3.7.1 Descriptive statistics

Descriptive statistics were calculated for the subject matter expert ratings (Haynes, Richard and Kubany 1995). Specifically, a mean, median, and mode were calculated for the representativeness ratings and clarity ratings of each individual item, of the scale as a whole, and of each subscale.

Frequencies were calculated for the multiple-choice questions pertaining to the construct definition, factor structure, overall comprehensiveness, overall sensitivity, and the response scales. In addition, the inter-rater reliability of the representativeness ratings and the clarity ratings was calculated (Beckstead 2009; Slocumb and Cole 1991). Specifically, a two-way random, average measures intra-class correlation coefficient (ICC) for agreement was reported, in accordance with the recommendations of Streiner and Norman (2008). Although this statistic is normally used with interval data, it is robust enough to be used with ordinal data (Streiner and Norman 2008).

Furthermore, any written comments provided in the open-text boxes of the survey were reviewed, categorised, and reported (Slocumb and Cole 1991).

Many previous studies have calculated the Content Validity Index or CVI for representativeness ratings (McGartland Rubio et al., 2003; Polit, Beck and Owen 2007). The CVI was not reported in this study because it has been subject to several serious criticisms (Beckstead 2009). For example, the CVI incorrectly specifies the statistical model of inter-rater agreement and the adjustments it makes for chance agreement are inadequate. In addition to these criticisms, the CVI was not appropriate for this study because the aim was to identify elements of the SPaRQ1.0 that required adjustment, rather

than to obtain an index of content validity for a questionnaire that is likely to substantially change during the course of Study 2 and Study 3.

3.7.2 Thematic analysis

The cognitive interview data were analysed using the deductive thematic analysis procedure outlined in Chapter 2 (Braun and Clarke 2006). Thematic analysis has frequently been used to analyse cognitive interview data (Nyman and Yardley 2009; Yardley et al., 2010). The deductive themes were derived from the published literature on the evaluation of questionnaire content, which recommends that the criteria of relevance, clarity, comprehensiveness, and acceptability be examined (Brod, Tesler and Christensen 2009; Mokkink et al., 2012). In addition, the cognitive interview data were analysed using a published taxonomy of questionnaire respondent problems (Conrad and Blair 1996). It was important to use approaches, as the taxonomy focuses on a specific set of clarity problems, whereas thematic analysis can uncover both the strengths and weaknesses of the questionnaire.

3.7.3 Taxonomy of respondent problems

This study used a taxonomy of possible problems experienced by questionnaire respondents, which was developed specifically for the analysis of cognitive interviews (Conrad and Blair 1996). This taxonomy has previously been used in various published cognitive interview studies (Andersen et al., 2010; Heesch et al., 2010; Van Uffelen et al., 2011).

3.7.3.1 Response stages

According to the taxonomy, there are three stages of responding to an item:

- 1) **Understanding** - This involves deciding what information is being requested in the question and recognising how this information should be provided. For example, if an item states '*How many times a week do you socialise with others?*', respondents must understand the meaning of the words in the question, as well as understanding that they have been given the task of counting all occurrences of a particular behaviour in a particular timeframe.
- 2) **Performance** - Performing the primary task involves producing the information needed to respond to the question through mental operations, such as retrieval, computation, and evaluation. For example, a question may require respondents to recall autobiographical events.
- 3) **Response formatting** - This involves mapping the information produced in the primary task onto the response format required by the questionnaire.

3.7.3.2 Problem types

According to the taxonomy, several types of problems can occur in each of the three response stages:

- 1) **Lexical problems** - These are problems with knowing the meanings of words and knowing how those words should be used. For example, lexical-understanding problems involve difficulty understanding the core meaning of particular words, such as scientific terminology, understanding unfamiliar idioms, and understanding unfamiliar combinations of words.
- 2) **Inclusion/exclusion problems** - These problems occur when the respondent has difficulty deciding whether particular concepts are within

the scope of the question or not. An example of an inclusion/exclusion-response formatting problem would be if the respondent provided a response that was not explicitly available on the response scale, such as writing '7.5' on a response scale that contained only whole numbers.

- 3) Logical problems** - There are various forms of logical problems, including problems with negation, complementarity, contradictions, tautologies, and presuppositions. Logical problems also occur when the respondent believes that they have been asked the same question twice, whereas the author believes that there is an important difference between the two questions. An example of a logical-performance problem would be if a respondent found it difficult to answer the question: 'How often do you experience difficulties participating in voluntary work?' as this presupposes that they engage in volunteering when this is not the case.
- 4) Computational problems** - This category is used when problems with the processing and manipulation of information are identified that do not fall into one of the other problem categories. For example, computational-understanding problems include difficulties understanding questions with complicated syntax. Computational-response formatting problems include difficulties with mental arithmetic, such as converting a count (e.g. how many times a week one socialises) into a percentage, as required by the response scale.
- 5) Temporal problems** - These are problems relating to the time period or frequencies specified in the questions. This problem type was not applicable to the SPaRQ1.0.

3.7.3.3 Peer assessment

A peer assessment was completed to ensure that the taxonomy was utilised correctly. A postdoctoral researcher, who was not otherwise involved in the study, independently applied the taxonomy to seven extracts from the cognitive interview transcripts, which the author had found particularly difficult to classify. The author met with the postdoctoral researcher to compare how they had coded the extracts using the taxonomy. It was found that there were few discrepancies between their coding. Any discrepancies were discussed and resolved.

Table 3.6 Study 2 objectives, methods, and data analysis summary

Study objective	Subject matter expert survey	Cognitive interviews
Construct definition	✓	
Factor structure of the SPaRQ	✓	
Representativeness of the items	✓	✓
Clarity of the items	✓	✓
Comprehensiveness of the SPaRQ	✓	✓
Appropriateness of the response scale	✓	✓
Sensitivity of the SPaRQ	✓	
Acceptability of the SPaRQ		✓
Data analysis	Descriptive statistics	Thematic analysis & taxonomy

3.8 RESULTS

The results of the three different analyses (i.e. descriptive statistics, thematic analysis, and taxonomy of respondent problems) are presented below. The alteration of the outcome measure based on these results is outlined in the 'Discussion' section.

3.8.1 Descriptive statistics results

The results of the analysis of the subject matter expert survey data are presented below. The subject matter experts were each assigned an anonymised identification code (e.g. SME1).

3.8.1.1 Construct definition

The majority of the experts (n=15) agreed with the proposed definition of social participation restrictions (see Figure 3.1). The written comments from the experts demonstrated that the definition required some refinement.

Firstly, it was noted that 'valued life situations' are not necessarily social in nature, with SME3 (Hearing therapist/lecturer) commenting: "*A 'valued life situation' might be something solitary such as sketching, which doesn't really have a social aspect to it. At least to me, social suggests it involves other people somehow. Perhaps add 'involving other people' to the end?*"

Therefore, clarification is required as to whether the construct deals only with social situations or broader life situations. Another expert recommended clarifying that the life situations are valued by the adult with hearing loss in question, rather than by their significant others, clinicians, or by society.

Finally, some of the experts were not sure what the term 'active involvement' meant in this context and how it differs from 'involvement'.

3.8.1.2 Factor structure

The majority of experts (n=13) agreed that social participation restrictions consist of the three primary dimensions of behaviour, emotion and identity (see Figure 3.2). However, seven experts selected '*Disagree*'. Some experts provided written comments on the potential factor structure of the

questionnaire. Two proposed that the dimension of identity is less important than the other dimensions. SME4 (Head of Adult Audiology Service) said:

“[I] don't think identity is as significant as behaviour and emotion. In my experience, people rarely report the impact of identity as defined above. Individually identified needs (i.e. as identified by the patient) mainly focus on behaviour but, with appropriate discussion, are often associated with emotional dimension”.

Another participant said that identity is important but that it should be ensured that the questionnaire measures both stigma and self-stigma.

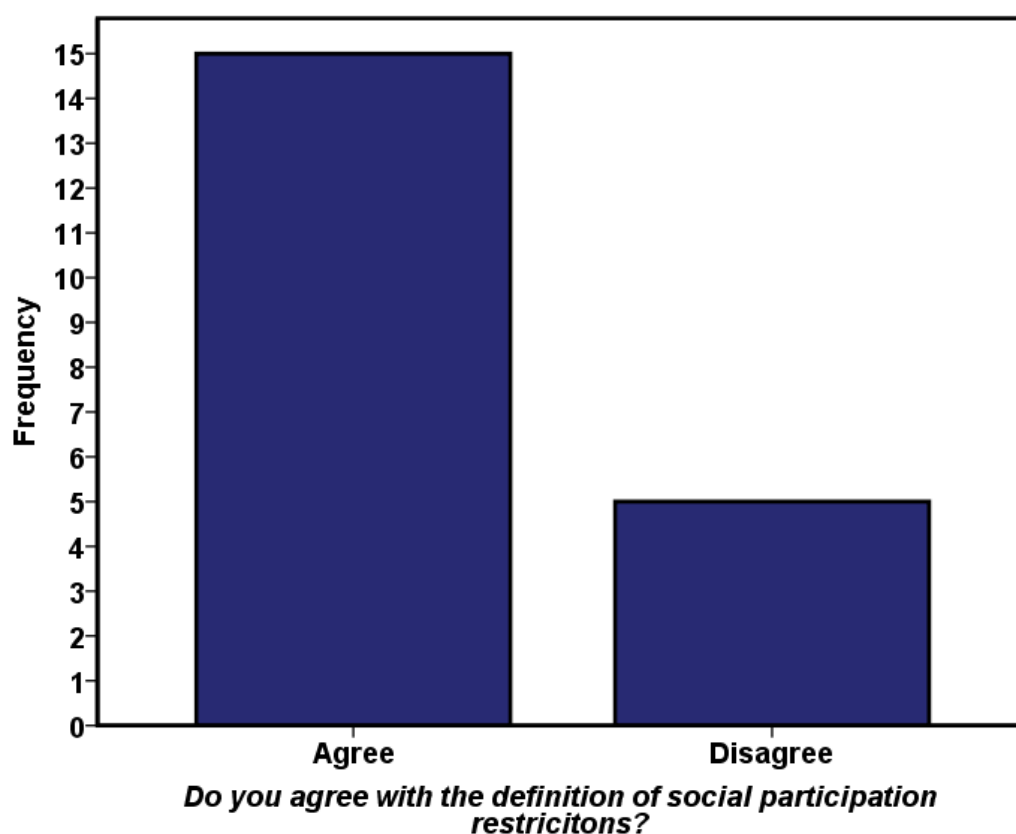


Figure 3.1 Expert panel construct definition assessment

Some stated that the behaviour dimension appeared to encompass both activity limitations and participation restrictions, as conceptualised by the ICF, and questioned whether this was appropriate. SME6 (Hearing researcher/engineer) wrote: *"[Behaviour] is very close to the ICF 'Activity Limitations' concept - difficulty in performing an action. I don't think it should be mixed into the definition. For me...Participation Restrictions are all about feelings"*.

SME12 (Hearing researcher) stated that behaviour, emotion, and identity are related to social participation restrictions but that they are unlikely to form a unidimensional construct:

"the proposed dimensions all have to do with social engagement... but I wouldn't necessarily say that they are part of the one big construct...I find...the three domains a rather big and perhaps (too) broad construct, actually not being 1 construct, but rather seems different constructs...based on face validity, that is".

The experts were asked to suggest any additional domains of social participation restrictions that should be measured by the questionnaire. Two participants suggested that personality is an important factor, particularly assertiveness and confidence. Two other participants suggested that the questionnaire could assess coping or self-management. Another proposed that the questionnaire should incorporate safety (i.e. difficulty hearing sounds that are important for personal safety). Another stated that motivation is an important factor.

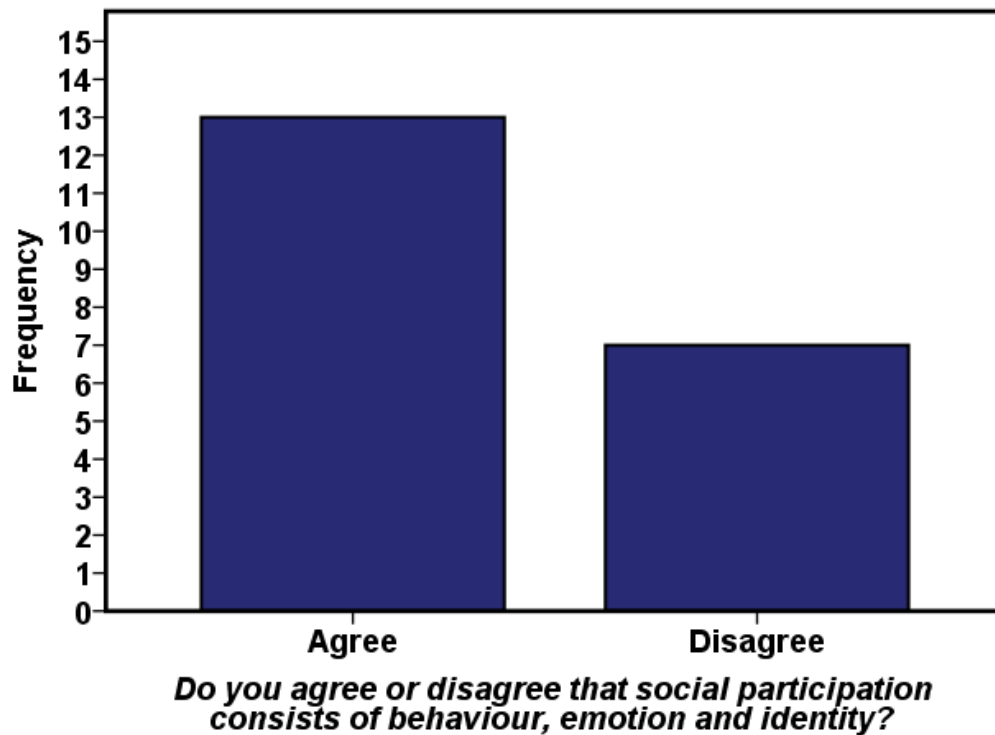


Figure 3.2 Expert panel factor structure assessment

3.8.1.3 Representativeness and clarity

The experts rated the representativeness and clarity of each item in the SPaRQ1.0 on a four-point scale (1=*Does not fulfil criterion*, 2=*Major revisions needed*, 3=*Minor revisions needed*, 4=*Fulfil criterion*).

Descriptive statistics were obtained for both the representativeness ratings and the clarity ratings of each individual item in the SPaRQ1.0.

All except one of the **behaviour items** had a median and modal representativeness rating of 4 (see Table 3.7). The mean representativeness ratings of the behaviour items ranged from 3.35 (Item 2) to 3.89 (Item 14). In addition, the majority of the behaviour items had median and modal clarity ratings of 4 (see Table 3.8). The mean clarity ratings of the behaviour items ranged from 2.9 (Item 2) to 3.79 (Item 16).

Table 3.7 Descriptive statistics of the behaviour items representativeness ratings

Item	Mean	SD	Median	Mode	Min	Max
1	3.6	0.6	4	4	2	4
2	3.35	0.75	3.5	4	2	4
3	3.5	0.76	4	4	2	4
4	3.4	0.88	4	4	1	4
5	3.5	0.76	4	4	1	4
6	3.65	0.59	4	4	2	4
7	3.7	0.47	4	4	3	4
8	3.9	0.31	4	4	3	4
9	3.75	0.55	4	4	2	4
10	3.9	0.31	4	4	3	4
11	3.55	0.76	4	4	2	4
12	3.6	0.75	4	4	1	4
13	3.84	0.37	4	4	3	4
14	3.89	0.32	4	4	3	4
15	3.79	0.42	4	4	3	4
16	3.79	0.71	4	4	1	4
17	3.68	0.67	4	4	2	4
18	3.63	0.6	4	4	2	4
19	3.79	0.42	4	4	3	4
20	3.53	0.61	4	4	2	4
21	3.68	0.58	4	4	2	4
22	3.68	0.58	4	4	2	4
23	3.84	0.37	4	4	3	4

The written comments provided by the experts on the behaviour items are summarised below. Several respondents reported that the use of the term ‘enjoy’ in Items 1-3 was somewhat confusing. For example, in relation to Item 2 (*‘Despite my hearing problem I can: Watch things that I enjoy, such as plays, films or sporting events’*), SME6 said: “*If a respondent answers 'No' to this, what does it mean? That they cannot bear to watch things they enjoy??*”

Then they don't enjoy them - so that can't be right. And if they answer 'Yes', then it means that they can watch - but can they listen?" In addition, for Item 3 (*'Despite my hearing problem I can: Listen to things that I enjoy, such as music, radio or birdsong'*), some experts commented on the fact that music, radio, and birdsong are quite distinct from one another and that it may be difficult for people with hearing loss to estimate their level of functioning across these different situations. Some experts also felt that the use of the term 'things' was ambiguous. It was also suggested that it is important to clarify whether such items refer to live events and live music or whether they refer to televised events and recorded music.

Several experts stated that Item 5, which concerned participation in voluntary activities, was potentially not relevant to many individuals with hearing loss. Also, several experts suggested that this item overlapped with Item 6, which concerned participation in community activities. Some proposed combining the two items. For Item 9, which referred to participation in meetings, several experts stated that many people with hearing loss will wish to know the size of the meeting, their role in the meeting, and the acoustic environment of the meeting. Several participants commented that this item is similar to Item 10, which referred to participation in group conversations. Some suggested merging the two items. Items 11 and 12, about conversations in the workplace and taking part in training, were seen as potentially irrelevant to many people who have hearing loss. For Item 15 (*'Despite my hearing problem I can: Discuss my health with a healthcare professional (e.g. doctor, dentist, audiologist)'*), some experts said that it should be clarified whether

this question refers to general healthcare or hearing healthcare and whether this refers to a quiet consulting room or a busy hospital environment.

Table 3.8 Descriptive statistics of the behaviour items clarity ratings

Item	Mean	SD	Median	Mode	Min	Max
1	3.45	0.6	3.5	4	2	4
2	2.9	0.72	3	3	2	4
3	3.15	0.67	3	3	2	4
4	3.4	0.68	3.5	4	2	4
5	3.35	0.81	3.5	4	1	4
6	3.45	0.69	4	4	2	4
7	3.5	0.51	3.5	3	3	4
8	3.7	0.57	4	4	2	4
9	3.55	0.6	4	4	2	4
10	3.65	0.49	4	4	3	4
11	3.6	0.6	4	4	2	4
12	3.6	0.5	4	4	3	4
13	3.58	0.69	4	4	2	4
14	3.68	0.48	4	4	3	4
15	3.68	0.58	4	4	2	4
16	3.79	0.42	4	4	3	4
17	3.68	0.67	4	4	2	4
18	3.42	0.77	4	4	2	4
19	3.58	0.51	4	4	3	4
20	3.32	0.67	3	3	2	4
21	3.53	0.61	4	4	2	4
22	3.53	0.61	4	4	2	4
23	3.58	0.61	4	4	2	4

It was also recommended that some changes were made to Item 20 (*‘Despite my hearing problem I can: Go out with a significant other (e.g. spouse, partner) to places such as restaurants, theatres or parties’*). The experts commented on the fact that theatres are a quiet environment whereas parties are noisy, which may cause confusion. They also said that

many individuals with hearing loss do not have a spouse or partner. SME12 (Hearing researcher) suggested that it would be better to refer to “*someone that is close to you*” than to a ‘significant other’. Finally, across many of the behaviour items, some of the experts thought that it would be important to give more detail on the context of the items, such as whether they referred to noisy or quiet settings and whether they referred to large or small social gatherings.

All of the **emotion items** had median and modal representativeness ratings of 4 (see Table 3.9). The mean representativeness ratings of the emotion items ranged from 3.53 (Item 24) to 4 (Item 26 and Item 27). In addition, all of the emotion items had median and modal clarity ratings of 4 (see Table 3.10). The mean clarity ratings of the emotion items ranged from 3.58 (Item 38) to 4 (Item 25).

The written comments provided by the respondents about the emotion items are summarised below. Several suggested changing the wording of Item 24 (*‘Because of my hearing problem: I feel frustrated when I cannot say what I want to say in conversation’*) to improve its clarity. In particular, it was suggested clarifying whether this item refers to not being able to follow the conversation or not being able to contribute to the conversation. Some of the experts felt that the items about feeling isolated, lonely and left out were very similar to each other. In contrast, SME12 wrote: “*Feeling isolated...and feeling lonely are two different things. Not sure if you can combine them in one scale. Further: there is always a negative loading on the word lonely. I would personally not choose items that use this word*”. However, SME16

stated that Item 31 (*'Because of my hearing problem: I feel lonely, even when I am around other people'*) is an important question.

Table 3.9 Descriptive statistics of the emotion items representativeness ratings

Item	Mean	SD	Median	Mode	Min	Max
24	3.53	0.77	4	4	2	4
25	3.95	0.23	4	4	3	4
26	4	0	4	4	4	4
27	4	0	4	4	4	4
28	3.95	0.23	4	4	3	4
29	3.84	0.5	4	4	2	4
30	3.63	0.83	4	4	1	4
31	3.84	0.5	4	4	2	4
32	3.84	0.5	4	4	2	4
33	3.95	0.23	4	4	3	4
34	3.84	0.37	4	4	3	4
35	3.84	0.37	4	4	3	4
36	3.68	0.58	4	4	2	4
37	3.89	0.32	4	4	3	4
38	3.79	0.54	4	4	2	4

Some of the experts stated that Item 36 (*'Because of my hearing problem: I stop caring about joining in conversations when it is difficult to hear what is being said'*) is complex and therefore difficult to interpret. For example, SME3 wrote: *"Not quite sure what you're asking here. I might feel that I just can't be bothered, but still care about the fact that I'm missing out"*. Another suggested that this question assesses coping rather than emotion. The experts also stated that it is important to emphasise that these questions are asking about hearing loss and not general functioning.

Table 3.10 Descriptive statistics of the emotion items clarity ratings

Item	Mean	SD	Median	Mode	Min	Max
24	3.63	0.6	4	4	2	4
25	4	0	4	4	4	4
26	3.84	0.37	4	4	3	4
27	3.95	0.23	4	4	3	4
28	3.95	0.23	4	4	3	4
29	3.84	0.37	4	4	3	4
30	3.95	0.23	4	4	3	4
31	3.79	0.54	4	4	2	4
32	3.95	0.23	4	4	3	4
33	3.95	0.23	4	4	3	4
34	3.74	0.56	4	4	2	4
35	3.79	0.42	4	4	3	4
36	3.63	0.68	4	4	2	4
37	3.79	0.42	4	4	3	4
38	3.58	0.69	4	4	2	4

All of the **identity items** had median and modal representativeness ratings of 4 (see Table 3.11). The mean representativeness ratings for the identity items ranged from 3.68 (Item 49) to 3.95 (Item 47). In addition, all of the identity items had median and modal clarity ratings of 4 (see Table 3.12). The mean clarity ratings of the identity items ranged from 3.58 (Item 41) to 3.84 (Item 48).

The written comments of the subject matter experts regarding the identity items are summarised below. For Item 41 (*‘Because of my hearing problem: I think that I look demanding when I ask people to repeat what they have said or to speak more clearly’*), SME6 suggested the following amendment to the wording: “Some respondents may feel that being demanding of others is just fine. Maybe ‘.. look too demanding ...’”. Two of the experts felt that this

was a very relevant question, with SME20 (Hearing researcher /audiologist) saying: *“This is a really good question. This especially targets the older man”*. For Item 42 (*‘People treat me as if I am a nuisance because of my hearing problem’*), several experts suggested changing the wording so that it is more similar to the other identity items and to ensure that it assesses the perceptions of the individuals with hearing loss. For example, SME6 wrote: *“Why the change of question form? I think that ‘I think that people see me as a nuisance ...’ would be better, as it stays in the domain of own feelings rather than the actions of others”*.

Table 3.11 Descriptive statistics of the identity items representativeness ratings

Item	Mean	SD	Median	Mode	Min	Max
39	3.74	0.45	4	4	3	4
40	3.79	0.42	4	4	3	4
41	3.74	0.45	4	4	3	4
42	3.74	0.56	4	4	2	4
43	3.89	0.32	4	4	3	4
44	3.89	0.32	4	4	3	4
45	3.84	0.37	4	4	3	4
46	3.95	0.23	4	4	3	4
47	3.95	0.23	4	4	3	4
48	3.74	0.65	4	4	2	4
49	3.68	0.67	4	4	2	4

Some of the experts particularly liked Item 45 (*‘I think that having a hearing problem makes me look less sociable than I really am’*). Some suggested that Item 48 (*‘I would rather pretend that I can understand what people are saying than let them know that I have a hearing problem’*) and Item 49 (*‘I would rather sit quietly whilst people are talking than interrupt to ask them to*

repeat what they have said') assess coping, or even behaviour, rather than identity. Some also felt that the wording of these items was too complex. It was also suggested that the responses of individuals with hearing loss to these items depended on which 'people' were being referred to in the items.

Table 3.12 Descriptive statistics of the identity items clarity ratings

Item	Mean	SD	Median	Mode	Min	Max
39	3.74	0.45	4	4	3	4
40	3.68	0.48	4	4	3	4
41	3.58	0.51	4	4	3	4
42	3.79	0.42	4	4	3	4
43	3.84	0.37	4	4	3	4
44	3.84	0.37	4	4	3	4
45	3.74	0.45	4	4	3	4
46	3.79	0.42	4	4	3	4
47	3.74	0.45	4	4	3	4
48	3.84	0.5	4	4	2	4
49	3.74	0.56	4	4	2	4

The representativeness and clarity ratings of each individual item were compiled in order to obtain overall representativeness descriptive statistics and overall clarity descriptive statistics for the SPaRQ1.0 and each of its subscales (see Table 3.13). The SPaRQ1.0 and its subscales each had a median and mode of 4 for representativeness and a median and mode of 4 for clarity. Also, the SPaRQ1.0 and its subscales each had a mean representativeness rating and a mean clarity rating of no less than 3.5. Overall, there was moderate inter-rater reliability for the representativeness ratings (ICC=0.477, 95% CI=0.264-0.659, $F(48)=2.08$, $p=.000$) and strong inter-rater reliability for the clarity ratings (ICC=0.686, 95% CI=0.548-0.798, $F(48)=3.46$, $p=.000$) (Landis and Koch 1977; Rosner 2005).

Table 3.13 Descriptive statistics of the representativeness and clarity ratings for the SPaRQ1.0 and its subscales

Representativeness						
Scale	Mean	SD	Median	Mode	Min	Max
SPaRQ1.0	3.75	0.54	4	4	1	4
Behaviour	3.67	0.6	4	4	1	4
Emotion	3.84	0.47	4	4	1	4
Identity	3.81	0.45	4	4	2	4
Clarity						
Scale	Mean	SD	Median	Mode	Min	Max
SPARQ1.0	3.66	0.56	4	4	1	4
Behaviour	3.51	0.63	4	4	1	4
Emotion	3.82	0.44	4	4	2	4
Identity	3.76	0.45	4	4	2	4

3.8.1.4 Comprehensiveness

The majority of participants (n=13) selected ‘Agree’ in response the question: *‘Do you agree or disagree that this questionnaire is a comprehensive measure of social participation restrictions in adults with hearing loss?’* Five participants selected ‘*Don’t know*’ and one participant selected ‘*Disagree*’. There was one missing response (see Figure 3.3).

Some of the participants also provided qualitative feedback on the comprehensiveness of the SPaRQ1.0. Some provided positive feedback, such as SME15 (Hearing researcher /audiologist): *“there are some really important questions in here, which I doubt ever get asked in the...time constraints of clinic”*. SME17 (Hearing researcher/audiologist) said: *“I think tapping into identity is a brave and good idea. I wonder [how] much of this would be expected to improve as a result of our current interventions”*.

Several participants made suggestions as to how the comprehensiveness of the questionnaire could be improved. Some suggested that the SPaRQ1.0 should include some open-ended questions that would allow the respondents to somewhat personalise the questionnaire and make it more relevant to their individual experiences. One suggested that the content of the questionnaire should be compared to the participation component of the ICF Core Set for Hearing Loss to confirm that all of the relevant content has been captured. SME6 suggested that some additional content could be included in the SPaRQ1.0: *“There is no reference to intimate communication with a love partner. Could be good with something about...[managing] an unfamiliar social situation. Something about cross-generational communication...too?”*

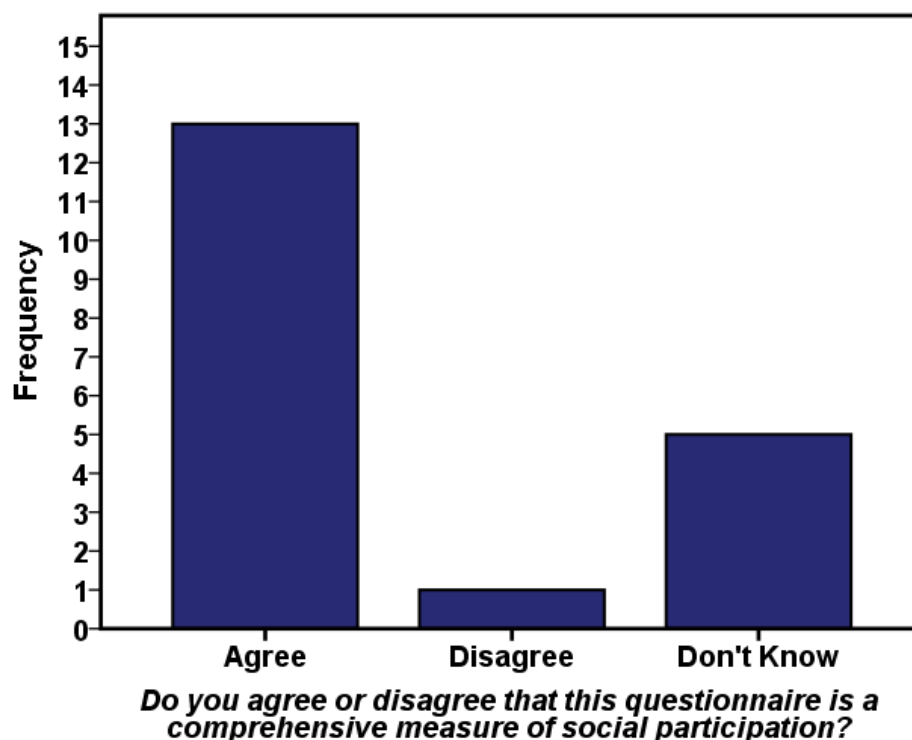


Figure 3.3 Expert panel comprehensiveness assessment

3.8.1.5 Sensitivity

The majority of participants (n=9) selected '*Don't know*' in response to the question: '*Do you agree or disagree that this questionnaire could serve as a sensitive outcome measure?*' Seven participants selected '*Agree*' and three participants selected '*Disagree*'. There was one missing response (see Figure 3.4).

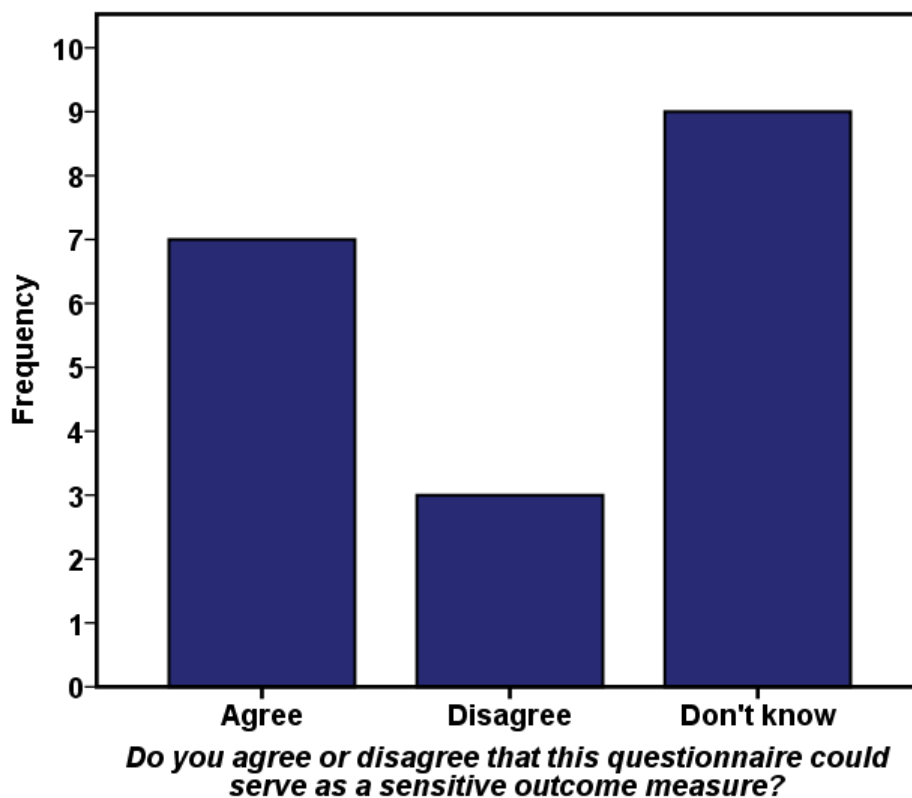


Figure 3.4 Expert panel sensitivity assessment

Some participants commented on the sensitivity of the SPaRQ1.0. As stated above, many found it difficult to predict whether or not the questionnaire could be a responsive outcome measure. SME3 (Lecturer/Hearing therapist) wrote: "*[Its] a little hard to know. I'm aware some questionnaires are designed to be sensitive to change but turn out not to be! However I do think it asks about some of the things we would like to see change as a result of*

intervention". Some made suggestions as to how the sensitivity of the measure could be enhanced. SME1 (Professor/Audiologist) advised that the instructions accompanying the questionnaire should direct respondents to *"rate the change specifically related to the intervention"*. SME2 (Hearing therapist) recommended establishing which coping strategies the respondents use at baseline: *"I'm not sure that it would be sensitive enough without asking what someone already does to combat the issues...they may not have aids but already have strategies in place or equipment they use"*. Two participants recommended ensuring that the questionnaire and its items are sufficiently hearing-specific, rather than generic.

Finally, two participants warned that social participation restrictions, as conceptualised in this research, is a particularly difficult construct to measure over time as it changes slowly and some aspects may change little if at all. SME5 (Health psychologist/hearing researcher) said: *"May be sensitive...I am guessing that these kind of life changes will probably take place over a fairly long time period which would add logistical problems to [follow-up] assessment"*. SME18 (Hearing researcher) suspected that some aspects of the questionnaire may be more sensitive than others: *"I think there are some questions that will clearly change over time and others that might confound your results, such as the identity ones, depending on the interventions"*.

3.8.1.6 Response scale appropriateness

In response to the question: *'Do you think that the behaviour items response scale needs to be changed?'* 11 participants selected *'No change needed'*, while seven participants selected *'Change needed'* (see Figure 3.5). There were two missing responses. In response to the question: *'Do you think that*

the emotion and identity items response scale needs to be changed?' 16 participants selected '*No change needed*', while two participants selected '*Change needed*'. There were two missing responses.

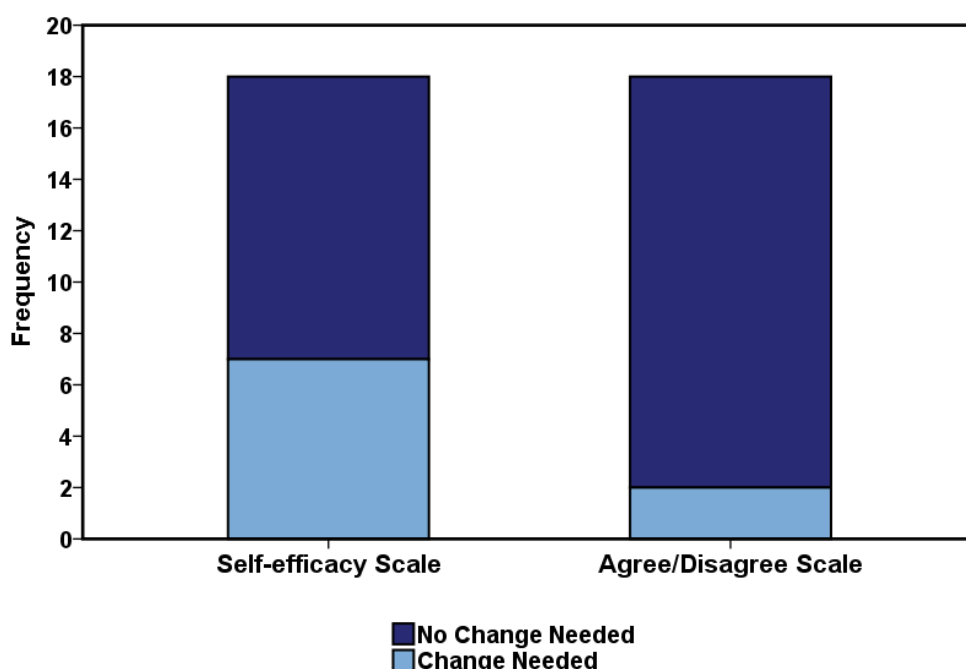


Figure 3.5 Expert panel response scale assessment

Some experts provided additional feedback on the response scales. One participant felt that the 11-point response scale contained too many response options. Two participants felt that the meaning of the response options in the middle of the response scale were ambiguous and that perhaps the middle response option should be labelled. Some noted that social participation restrictions, such as not attending an event with one's spouse, can have complex causes, not all of which are related to hearing loss. This complexity may be difficult to express using the response scale. For example SME3 noted that respondents' may find it difficult to choose one number that represents their functioning across a range of circumstances:

“either some questions need rewording or there needs to be some kind of 'depends on the situation' option. I can see sometimes responders can only take a kind of average ('on average when I'm at a family get together it's OK although if [a certain] aunt...is there it's a nightmare...') you can't account for every eventuality. But I'd think choosing one number that applies to BOTH sport and theatre, say, might be very difficult”.

3.8.2 Thematic analysis results

The results of the deductive thematic analysis performed on the cognitive interview data are presented below. Each participant was assigned an anonymised identification code (e.g. COG1).

3.8.2.1 Theme 1: Relevance

The majority of the **behaviour items** were seen as being relevant to the experiences of the participants. Behaviour items that were identified by a small number of participants as being irrelevant to them were the items about conversing with people in the workplace, training activities, voluntary activities, community activities, and significant others.

Some participants saw the **emotion items** as being highly relevant to them.

COG5 (woman, aged 51) said: *“Well I like all of it, but...I found this [emotion section] was quite...pertinent...and I've scored quite highly on all of these”.*

COG8 (woman, aged 62) said of the emotion items: *“they were very thought provoking...I thought they were very relevant”.* Contrastingly, some

participants stated that the emotion items were less relevant to them than the behaviour items, as they are rarely emotionally affected by their hearing loss.

For instance, COG10 (man, aged 80) said that, while he does sometimes struggle to take part in conversations, this does not affect him emotionally:

“I found it difficult to evaluate myself [in the emotion section]...I don’t mind being left out of a conversation...I don’t feel frustrated...It doesn’t bother me if I just write off that particular event and sit through it and then move onto the next one...this comes back to your personality, doesn’t it?...And I don’t think I feel insecure...I do think about avoiding those situations simply because I know I don’t hear...But I don’t feel stressed about that. I don’t feel upset about it...It’s just one of those things you have to live with”.

Some of the other participants also said their hearing loss did not have an emotional impact on them due to their personality. For example, COG14 (man, aged 69) said: *“I don’t feel embarrassed about it at all because I think...most people make mistakes...I’ve got thick skin...But people [who are]...sensitive...would tend to be a bit embarrassed if they said the wrong...thing in...conversation”.* A small number of participants felt that the items about feeling sad, upset and lonely were especially less relevant than the other items as they perceived these to be quite strong emotions.

Some of the participants found the **identity items** to be relevant to their experiences. For instance, COG8 (woman, aged 62) said:

“again they...made me think...and I think they’re very relevant because...that’s a different level of your hearing loss, isn’t it? A different effect that it has is about...how people perceive you...and yes...you do get treated as though you’re not quite on the planet...at

times...Especially with people who don't know that you have a hearing loss...so I think that's very relevant part of the questionnaire".

However, several participants did not find the identity items to be relevant to their experiences. For example, COG4 (man, aged 77) said:

"I don't bother about what people think about me, to be quite honest. I'm big enough and daft enough to ignore that anyway...I can always have a laugh. I mean...particularly with blokes...there's no kind of gentle [jokes]. They're always, you know: "Don't talk to him. He's as deaf as a post"...I've never felt conscious of the fact".

Several participants also reported that using their sense of humour was an effective way of dealing with identity issues and therefore these items were irrelevant to them. In addition, some of the older participants reported that they have reached a stage of life where they feel comfortable about letting people know that they have a hearing loss or asking people to repeat what they have said. Also, some participants reported that it is not in their personality to be concerned about how others perceive them, as they are not insecure or self-conscious.

3.8.2.2 Theme 2: Clarity

The participants found that the majority of items were easy to understand. In particular, the items did not have any terminology or expressions that the participants could not understand. There were just a small number of items that were identified as requiring adjustments for clarity. This meant that the majority of the items were interpreted in the way that the author had intended them to be interpreted. One exception to this was COG6 (man, aged 75),

who found the SPaRQ1.0 as a whole difficult to understand: *“it baffled me it a bit, 'cause I were never bright...you must have picked on the wrong patient today...I'm, what with spelling and [anything] like that, terrible...and that has been embarrassing through life, 'cause it held me back”*. Despite finding it difficult to read the questionnaire, he still completed it without assistance.

Although the individual items were largely clear, there was a serious problem with the clarity of the SPaRQ1.0, stemming from the change from positively-worded items with a self-efficacy response scale to negatively-worded items with an agree/disagree response scale. This will be discussed in ‘Computational problems’ section below.

3.8.2.3 Theme 3: Comprehensiveness

The questionnaire was largely regarded as being comprehensive in that it assessed all of the main hearing-related difficulties experienced by the participants. These included difficulties with conversing in background noise, taking part in group conversations, using the telephone, hearing the television, hearing at the theatre, socialising with friends, communicating with family members, and asking others to repeat what they have said. For example, COG4 said: *“I think basically you’ve got it all. I don’t think you need to change anything...I really don’t...I was quite surprised how comprehensive it is”*.

Nevertheless, the interviews uncovered some aspects of participation restrictions that were missing from the questionnaire. For example, COG3 (woman, aged 62) suggested that the questionnaire could ask respondents about becoming less outgoing and less independent:

“When I’ve got hearing, I was like...in the pubs and dancing on the tables...and then...as soon as your hearing starts to go down, you retreat more and more...[in 1991] I went to Australia on my own for three months...I couldn’t do that now...Because...I would miss everything and miss somebody at the side of me saying somebody’s talking to you...You are more dependent on people”.

Another concern not covered by the questionnaire was difficulty hearing important sounds, such as alarms, telephones, traffic, and other people approaching, which relates to the issue of being more reliant on other people. For COG13 (man, aged 67), not being able to hear important sounds caused an additional difficulty, which was conflict with his spouse:

*“I can use my headphones and that makes life a lot better.
...But...bombs can go off around you and you don’t notice...And that causes aggro for the spouse...because she has to hit me on the head with a rolling pin to get a response from me. So I tend not to use the headphones, simply because I want to be able to at least hear some sort of grunt that my attention is needed elsewhere”.*

The potential for hearing loss to cause conflict with others, particularly family members, was not directly assessed in the SPaRQ1.0. Moreover, the questionnaire did not directly ask about encountering people who are impatient and unsympathetic towards people with hearing loss. In addition, several participants highlighted the fact that the questionnaire did not ask about listening effort and fatigue. COG8 explained:

“you could get some interesting answers...if you said something about...”Are you more likely to do this at the beginning of the day or at the end when you’re tired?”...I’ll go out for a meal with a group of friends and it’ll be all hunky dory for the first half an hour...then, as the night goes on, I sit further and further back in my chair”.

Although the SPaRQ1.0 is generally comprehensive, it is missing some content that is relevant to some people with hearing loss.

3.8.2.4 Theme 4: Acceptability

The participants reported that, overall, the questionnaire had appropriate content, was appropriately worded, and was not too invasive or offensive. For example, COG4 said: *“I mean there’s nothing personal about it, is there?...it’s actually very good...It’s not intrusive...or anything like that. It don’t tell you anything that...you don’t want to answer”*. Similarly, COG14 stated: *“there was no questions there that...was too sensitive or anything like that...all the questions were meaningful, in the fact that it’s all do with your social life; your living, how you connect with people”*.

Two emotion items were identified as being potentially off-putting: ‘Because of my hearing problem: I feel upset when it is difficult for me to take part in conversations’ and ‘Because of my hearing problem: I feel sad when I cannot join in when people around me are having a good time’. COG1 (woman, aged 57) found their wording to be too extreme:

“the word 'sad' or 'upset'...I don't have those kind of things in my personality...it doesn't make me upset...or sad...they are quite strong

words, aren't they?...Like I'm going to burst into tears if can't take part in a conversation...I'm not that kind of person".

However, she added that she did not feel uncomfortable when answering any of the questions in the questionnaire.

Two identity items were also flagged as being potentially off-putting: *'People treat me as if I am a nuisance because of my hearing problem'* and *'Because of my hearing problem: I think that I look rude when I do not realise that other people are speaking to me'*. COG11 (woman, aged 73) disliked the wording of these items, particularly the word 'nuisance': *"I don't really like that...how that's phrased...And 'I think that I look rude'...that's very much an insecurity issue, isn't it?"*

In addition, one participant, COG8, reported that the process of completing the questionnaire provoked unexpected thoughts and emotions as she reflected on the impact of her hearing loss. She explained that, although this time of reflection made her feel sad, it was not necessarily a bad experience:

"it was very thought provoking 'cause it actually makes you think about how you feel about not hearing, which is something...I think most people try and avoid...it actually made me quite sad filling it in...because it actually sort of brings home just how much you miss out on things, how much you...disregard that most of the time but actually it's quite good because it's made me actually think about things a bit".

She added: *"it made me reflect but...I didn't feel like I've been sort of ripped asunder"*. She suggested that the questionnaire should address this in some

way, possibly in the instructions. COG8 also felt that the term 'hearing problem', which was used throughout the questionnaire was too negative and preferred the term 'hearing loss'. The other participants said that they were satisfied with the term 'hearing problem'.

3.8.3 Taxonomy of respondent problems results

A summary of the application of the taxonomy to the cognitive interview data is presented below.

3.8.3.1 Lexical problems

Few lexical problems were identified, as the respondents largely understood the meaning of the words and expressions used in the items. The main lexical problems were **lexical-response formatting** problems. For example, COG12 (man, aged 64) reported that he was unsure of the meaning of the response options in the middle of the self-efficacy response scale. He made the assumption that these middle response options represented being uncertain about the answer to the question. This is problematic, as it was intended that the middle of the response scale would represent having a moderate level of participation restrictions. COG12 said:

“Well, if you put a thing in the middle, you can't be certain about it, can you?...does one in the middle mean you're uncertain about it or does it mean I'm certain that I'm in the middle?...Well in the middle would be, I'm not really sure, actually...[perhaps the middle means] that's a question that I've not thought about a huge amount...or it hasn't occurred to me”.

3.8.3.2 Inclusion/exclusion problems

There were several inclusion/exclusion problems. An **inclusion/exclusion-understanding** problem arose with the item '*Despite my hearing problem, I can: Take part in a meeting*'. COG12 felt that most respondents would assume that this item refers only to workplace meetings, whereas it was intended that this item could refer to meetings in any area of life, such as social club meetings.

COG12 also highlighted an **inclusion/exclusion-performance** problem when he reported that he had based his responses on both his hearing loss and what he termed his emotional problems, which he said included a lack of self-esteem. Although he initially understood that he should focus on his hearing loss, he lost this focus during the process of completing the questionnaire. He said: "*You do bring in other aspects...But the hearing loss is part of it...I do avoid situations now...but it's not necessarily just hearing loss...[Even though the questionnaire] does say "Because of my hearing problem" in bold letters*". He added that, when he concentrates, he can separate the influence of his hearing loss from the influence of his emotional problems. However, he said that he sometimes finds it easier to attribute difficulties to his hearing loss than to his emotional problems: "*hearing loss is part of it and I, I can disentangle it but I would also say that hearing loss is...sometimes a bit of an easy...place to retreat to*". It may be difficult to ensure that respondents focus on their hearing loss, as they may not be conscious of the fact that they are drawing upon other experiences. COG12 said: "*I suppose all you could do...would be if you put [an instruction that says]...'Please disregard any other influence' or something like that*".

However, another participant, COG2, warned that adding such statements would make the questionnaire too long. This inclusion/exclusion performance problem was limited to COG12, as the other participants reported that they were able to answer based solely on the impact of their hearing loss, including participants who have other health conditions. For example, COG8 said: *"I found it easy to...just to stay focused on...my hearing"*.

Another **inclusion/exclusion-performance** problem was observed when several participants reported that it took some time to answer the questions because they could not decide which types of situations the questions encompassed in the absence of more detailed contextual information. For example, COG3 found that she needed time to deliberate over the question *'Despite my hearing problem, I can: Take part in a meeting'*, as her answer depended on whether it was a meeting where she felt comfortable, such as a meeting with a small number of people, or a meeting where she felt uncomfortable, such as a highly formal meeting. She also felt that it would be easier to answer the questionnaire if it were clarified whether the situations described in the questions were noisy or quiet. She proposed dividing the questions into different sections accordingly: *"The only thing...you need to put in is...perhaps put one section...where you are in a pub, or something like that...and another section [where you are] at home"*.

A small number of the other participants also felt that it would be helpful to have more detailed information on which situations are captured by the items, such whether they are noisy or quiet situations and whether they are large or small social gatherings. The item *'Despite my hearing problem, I can: Go out with a significant other (e.g. spouse, partner) to places such as*

restaurants, theatres or parties' was particularly difficult to answer in this respect, as some participants could not decide whether they should base their answer on the theatre or on restaurants and parties. COG10 said: *"it might be worth splitting up parties and restaurants, which are noisy, from theatre...But otherwise it was all straight forward"*. This was problematic, as it was intended that participants would answer based on their typical experience in each situation, across both noisy and quiet settings and across both large and small groups. For example, if a participant struggles on some but not all outings with their significant other, they should select a response option towards the middle of the response scale.

3.8.3.3 Logical problems

Several **logical-performance** problems were uncovered. One such problem was that some of the participants felt that there was repetition amongst the items. This is problematic because each item should assess a different aspect of participation restrictions and it was anticipated that respondents would be able to perceive the differences between the questions, even when those differences were subtle. COG3 found the emotion items particularly repetitive:

"A lot of these though, are, like repeating themselves...it's like 'I feel like isolated when I take part'...and then 'I feel isolated at get-togethers'...You could like combine that...with one question...I mean 'I feel isolated' and 'I'm feeling lonely' are...very similar....That one as well...'I worry about social gatherings' and 'I worry about talking to unfamiliar people'. They would be like the same...because...if you

went to a wedding...although your friends are there, there is other, other people there”.

In contrast, COG8 believed that it was important to ask about both isolation and loneliness, as they are distinct:

“I think it’s a really important thing to pull out because...there’s a difference between isolation and loneliness, and I think being isolated is almost like on an island watching, whereas lonely is a very personal, almost sadness or...aloneness...And I...have actually answered them differently”.

There was some perceived repetition in the behaviour items, but to a lesser extent than the emotion items. For example, COG5 stated that the item: *‘Despite my hearing problem, I can: Watch things that I enjoy, such as plays, films or sporting events’* could be interpreted as referring to televised events, rather than live events as intended. This meant that this item could be interpreted as a repeat of another item: *‘Despite my hearing problem, I can: Watch and enjoy television with other people’*. As COG5 highlighted, it is important that the questionnaire makes a clear distinction between watching live events and watching televised events, as one can adjust the volume on a television set but one cannot exert such control at a live event.

Another **logical-performance** problem was uncovered for the item: *‘Despite my hearing problem, I can: Carry out my favourite pastimes and hobbies’*. COG12 believed that listing both ‘pastime’ and ‘hobby’ was unnecessary because they are very similar. Furthermore, he felt that some participants would focus on the fact that they do not have hobbies, or specific pursuits

such as golf, and would ignore the fact that they do have pastimes, or general activities that they enjoy, such as going for walks. He said:

"I would take out 'hobbies'...I'd just put 'pastimes' because they're pretty much the same thing...and people are going to think: "Oh shit, I haven't got any hobbies. What am I going to put now?"...I should get away from the idea of having a hobby...[It] adds a...layer of complexity that it doesn't need".

Another logical-performance problem was found for Item 43: *'Because of my hearing problem: I think that I look rude when I do not realise that other people are speaking to me'*. COG14 said that such questions are difficult to answer because individuals with hearing loss do not realise when they have accidentally ignored other people unless they are made aware of it by someone else.

A **logical-response formatting** problem was discovered in the self-efficacy response scale. COG13 found that the combination of the item stem (*'Despite my hearing problem, I can:'*) and the response scale label at point zero (*'Certain I cannot do this'*) was not logical, which made it difficult to immediately respond to the items. He stated: *"it seems a little odd: 'Despite my hearing problem, I can:', 'Certain I cannot'. It just seems - grammatically, you either need that bit taken out or change the wording"*. Although he was ultimately able to select an appropriate response option, he felt this was not an easy task: *"I...sorted it out... [but] some, you know, frail old person who is...not totally with it probably wouldn't understand it"*. COG1 felt that the use of the word 'Certain' in the response scale was unnecessary and confusing: *"I find the wording a bit...Why?... 'Certain'. Why? ...personally...I'd put 'I*

cannot do this'...I like...simplicity...I think it has to be simplicity because then it's easier to do for...everybody...and then it's not time consuming for anyone".

3.8.3.4 Computational problems

A **computational-understanding** problem was identified by COG8, who reported struggling to interpret the item: *'Because of my hearing loss: I stop caring about joining in conversations when it is difficult to hear what is being said'*, although she understood the meaning of the words used in the item. It is likely that the phrasing of this item is too complex and does not capture the intended meaning of the item. COG8 explained:

"it was weird because it's about...whether I cared about it, not whether I stopped wanting to join in conversations,...which are two different feelings...If it said: 'I find it difficult to join in conversations when it's difficult to hear what's being said', it would have been 'Strongly agree', whereas I stopped caring...I'm never gonna stop caring about...joining in conversations".

This item was intended to refer to being demotivated or discouraged from contributing to a conversation in difficult listening conditions. However, it appears that this item could instead be interpreted as referring to not caring about talking to other people or not being upset by communication difficulties.

A substantial **computational-response formatting** problem was uncovered. The majority of the participants struggled to switch from using the self-efficacy response scale with the positively-worded behaviour items to using

the agree/disagree response scale with the negatively-worded emotion and identity items. Some participants did not observe that the response scale had changed and assumed that the self-efficacy scale was present throughout the questionnaire. Some participants observed that the response scale had changed but did not know how to adjust their responses accordingly. COG8 said: *“there was one bit where the, the marking changed from one to the other and that made me...stop and think...and I couldn’t really understand why it had...swapped over”*. COG2 said: *“When you swapped [the response scale] over...it nearly tripped me up...I think it probably did trip me up...the only thing I thought was, couldn’t you keep it the same way round, all the way through the questionnaire?”*

Switching from using the self-efficacy response scale, where ten represented low social participation restrictions, to using the agree/disagree response scale, where ten represented high social participation restrictions, was too difficult and complex a task for most participants. Many appeared to incorrectly assume that ten on either response scale represented low social participation restrictions. This meant that, for the emotion and identity items, they often selected a response option that did not accurately represent their level of social participation difficulty. COG1 explained: *“I had to...look at it thinking “Which way am I going from and to...is it the same?” ...This is what happened here 'cause [for Item 41]...I've put ‘Agree’ and I think I don't, actually”*. Although the participants understood the wording of the emotion and identity items and the wording of the response scale options, they still did not understand how to map their answers onto the response scale.

Another **computational-response formatting** problem was uncovered, though it was potentially less substantial than the one described above. A small number of participants felt that it would be easier to answer the questionnaire if the response scale had fewer response options, such as five response options. COG11 said: *“for me, it’s not necessary to have ten. One to five would do...because [having many options] makes it more difficult to know which one to put in...I haven’t done this kind of...questionnaire before, as other people may not have done”*. Similarly, COG12 said *“Too many options. It’s like having a big menu; you can’t make a decision”*. Although these participants felt that they would have been more comfortable with fewer response options, they were still able to use the 11-point response scale. Also, several other participants stated that they did not have any difficulties using the 11-point response scale. Furthermore, the responses provided by the participants to the questionnaire demonstrated that they tended to use a range of response options, rather than selecting options only at the extreme ends of the scale or only in the middle of the scale.

3.9 DISCUSSION

This research defined social participation restrictions as active involvement in valued life situations and conceptualised it as containing the three domains of behaviour, emotion, and identity, as well as an assortment of subdomains. The SPaRQ1.0 was developed to measure this construct. Study 2 aimed to evaluate the content of the SPaRQ1.0 in order to determine whether any of the existing elements of the questionnaire should be adjusted and to determine whether any new elements should be introduced. The ultimate goal of this study was to ensure that the questionnaire was adequate in

terms of content validity and respondent burden, which means that it produces informative data for researchers and clinicians and is easy to complete for participants. The results of the study in terms of each objective are discussed in this section, as well as how these results were used to produce the second prototype of the Social Participation Restrictions Questionnaire or the SPaRQ2.0 (see Appendix G).

3.9.1 Construct Definition

Social participation restrictions were initially defined as the difficulties an individual experiences with active involvement in valued life situations. This definition was assessed by the subject matter expert survey. The majority of experts agreed with this definition, though some recommended that alterations be made. Consequently, social participation restrictions were defined as the difficulties an individual experiences with authentic involvement in social situations that are valued by that individual. This clarifies that the situations mentioned in the definition are social in nature, which helps to distinguish the target construct from the related constructs, such as activity limitations. In this context, the term 'social situations' is an improvement on the term 'life situations', as the latter is very broad and therefore not conducive to measurement (Dijkers 2010). Finally, the term 'active' was replaced by the term 'authentic' to eliminate any potential confusion. For example, the word 'active' could bring to mind physical activities or activity limitations, as opposed to genuine or meaningful engagement in social situations.

3.9.2 Factor structure

The potential factor structure of the SPaRQ1.0 was assessed by the subject matter expert survey. Opinions were mixed as to whether the construct of social participation restrictions contains the three factors of behaviour, emotion and identity. Some proposed that identity was less relevant to social participation restrictions than the other factors. This supports the decision to include fewer identity items in the SPaRQ1.0 than behaviour and emotion items. One of the experts stated that the three domains may be too distinct from one another to form a unidimensional questionnaire. It was decided that the three factors would be retained in the SPaRQ2.0 to ensure that it is a fully comprehensive measure. The factor structure of the questionnaire will be formally tested in Study 3 through psychometric analyses, including Rasch analysis.

Some experts stated that the questionnaire appeared to contain items that assess activity, rather than participation. As discussed in Chapter 1, it is difficult to distinguish between these two constructs. For example, the ICF Core Set for Hearing Loss does not specify which categories of functioning belong to activity and which belong to participation. It was decided that all of these items should be carried forward to the SPaRQ2.0. This measure will be subjected to Rasch analysis in Study 3 in order to identify items that do not measure social participation restrictions, at which point they will be removed from the questionnaire.

Some subject matter experts proposed additional dimensions that could be relevant to social participation restrictions, including personality factors, coping and motivation. However, as discussed in the 'Conceptualisation'

section of this chapter, these dimensions do not fall within the scope of this questionnaire. For example, personality factors are not suitable for an outcome measure, as they are not normally altered by an intervention. It was decided that coping and motivation may be related to social participation restrictions but they are not part of this construct. Therefore, the factor structure of the SPaRQ1.0 was retained in the SPaRQ2.0 so that it could be subjected to stringent psychometric analyses.

3.9.3 Representativeness of the items

This refers to how well the items represent the target construct: social participation restrictions. In other words, this refers to how relevant the items are to the target construct. This was assessed by both the subject matter expert survey and the cognitive interviews. The survey results showed that each item had a high numerical representativeness rating, including the identity items. The cognitive interview thematic analysis results suggested that the majority of the behaviour items were regarded by the interviewees as being relevant to their experiences. The emotion and identity items were regarded as having high relevance by some interviewees and low relevance by others.

All of the cognitive interview data and all of the written comments of the subject matter experts regarding representativeness were reviewed and adjustments were made to the items accordingly. For example, the two items concerning participating in community activities and participating in voluntary activities were merged together to form one item: *'Because of my hearing loss, I find it difficult to: Take part in activities or events with community, voluntary or religious organisations'*. The original two items were regarded as

having overlapping content and as potentially being irrelevant to many participants. Combining these items reduced the number of potentially irrelevant items in the questionnaire whilst retaining their content, which was an important component of the ICF Core Set for Hearing Loss. The reference to religious activities was added to this item as this was also an important component of the core set and, according to some participants, overlapped with community and voluntary activities.

The vast majority of the items did not require any adjustments in terms of representativeness. This likely reflects the benefits of developing questionnaire items through qualitative research with the relevant stakeholders in conjunction with a literature review (Brod, Tesler and Christensen 2009). As stated previously, it was decided that items relating to all three factors should be retained in the SPaRQ2.0 to ensure that it is comprehensive. The psychometric analyses carried out in Study 3 would determine whether particular items or factors should be removed from the questionnaire due to a lack of relevance.

3.9.4 Clarity

This refers to the extent to which the elements of the questionnaire are easy for adults with hearing loss to understand and are interpreted as the researcher intended. This was assessed by both the subject matter expert survey and the cognitive interviews. The survey results demonstrated that the majority of items in the SPaRQ1.0 had high numerical clarity ratings. However, the written comments provided by the experts indicated that several of the items required clarification, particularly some of the behaviour items. Alterations were made to the items accordingly. For example, the

word 'enjoy' was removed from the items concerning watching and listening (e.g. '*Despite my hearing problem I can: Listen to things that I enjoy, such as music, radio or birdsong*'), as several experts regarded this phrasing as being confusing. Another example comes with the item: '*Despite my hearing problem I can: Discuss my health with a healthcare professional (e.g. doctor, dentist, audiologist)*'. The example of 'doctor' was changed to 'hospital doctor' so that respondents would not think only about quiet consultation rooms. Also the example of 'audiologist' was removed so that respondents would understand that the question was about general healthcare, rather than just hearing healthcare.

The cognitive interview thematic analysis results indicated that the majority of items were easy to understand and were interpreted as the researcher had intended. However, the application of the taxonomy of respondent problems to the cognitive interview data led to the identification of several problems with the clarity of the questionnaire. Most of these problems took place in the performance and response formatting stages, as opposed to the initial understanding phase. Few of these problems were lexical, which meant that interviewees largely understood the core meanings of the words and phrases used in the SPaRQ1.0.

Several inclusion/exclusion problems were uncovered. For example, one interviewee provided answers based both on his hearing loss and his emotional wellbeing problems, potentially due to a lapse in focus during the course of completing the questionnaire. As this problem was not replicated amongst the other interviewees, including those who had several health conditions, it was not considered to be a substantial problem (Brod, Tesler

and Christensen 2009). If necessary, this problem could be addressed by adding more instructions to the questionnaire to remind respondents to answer solely based on their hearing loss. Alternatively, the phrase '*Because of my hearing loss...*' could be placed before every item in the questionnaire. However, this approach has the considerable disadvantage of creating participant burden by adding to the amount of text that they must read. Ultimately, by the end of this doctoral research, the final version of the SPaRQ is likely to have considerably fewer items, which should make it easier for respondents to maintain their focus on their hearing loss.

The main inclusion/exclusion problem was that some interviewees required additional contextual information before they could determine which situations were included in a given item. In particular, some interviewees wanted clarification as to whether or not the situations described in the items were noisy or quiet. It was intended that respondents would answer based on their typical experience of participation in each situation described by the items, such as their general experience across both noisy and quiet settings.

It is difficult to rectify this problem without making the questionnaire complex and burdensome for respondents. One approach would be to create two sets of items, with one set describing difficult listening situations with background noise, and one set describing quiet listening situations. However, this has the drawback of considerably adding to the length of the questionnaire.

Alternatively, the questionnaire could be altered so that the items clearly ask about listening in noise and clearly do not ask about listening in quiet, as the latter are likely to be the most informative items. However, if the items become too specific, it could lead to the exclusion of some respondents who

have never been in the particular situation described. Also, focusing on ability to hear in challenging environments could mean that the questionnaire measured activity or even physical functioning, rather than participation. It is also worth noting that, although some of the participants encountered this inclusion/exclusion problem, some did not. It was decided that the disadvantages of altering the questionnaire to resolve this problem were greater than the advantages.

Several logical problems were identified in the performance stage of the response process. Many of these problems related to the perceived repetition amongst or within the items. These problems were resolved where possible in the SPaRQ2.0. For example, the item pertaining to watching plays, films or sporting events was differentiated from the item pertaining to watching television by clarifying that the former referred to live events, as opposed to televised events. However, the perceived repetition amongst the emotion items was not resolved. This repetition was reported by some but not all of the interviewees. In Study 3, Rasch analysis performed on data from a large sample of adults with hearing loss will identify items that are redundant so that they can be removed from the questionnaire.

Some computational problems were uncovered and rectified where appropriate. For example, one item (*'Because of my hearing loss: I stop caring about joining in conversations when it is difficult to hear what is being said'*) was regarded as being too complex and ambiguous. It was reworded to make its meaning clearer (*'Because of my hearing loss: I feel unenthusiastic about joining in conversations when it is difficult to hear what is being said'*). The major computation problems related to the response

scales rather than to the items, as discussed in the section: ‘Appropriateness of the response scale’.

3.9.5 Comprehensiveness of the questionnaire

This refers to the degree to which the questionnaire captures all content of potential relevance to social participation restrictions. This was assessed by both the subject matter expert survey and the cognitive interviews. The results of both methods indicated that the SPaRQ1.0 was largely comprehensive. Both the subject matter experts and the cognitive interviewees made suggestions regarding item content that could be added to the questionnaire. Consequently, a small number of new items were created for the SPaRQ2.0.

One expert recommended re-examining the ICF Core Set for Hearing Loss to ensure that all of the relevant content had been captured. This led to the introduction of two new items to assess a category of functioning (‘Handling stress and other psychological demands’) from the Brief Core Set for Hearing Loss (Danermark et al., 2013). This category refers to carrying out highly demanding and stressful tasks and managing significant responsibilities. This category had been overlooked in the SPaRQ1.0, as it was not identified in Study 1 as an important aspect of social participation restrictions. The new items created to assess this category were: *‘Because of my hearing loss, I find it difficult to: Manage stressful and challenging situations’* and *‘Because of my hearing loss, I find it difficult to: Manage my responsibilities in home life, social life or work life’*.

Other items were added to the SPaRQ2.0 based on the recommendations of the cognitive interviewees. For example, the item: *‘Because of my hearing*

loss, I find it difficult to: Persevere with lengthy conversations', was added, as some of the participants mentioned that the issue of listening effort and concentration was not captured by the SPaRQ1.0. Similarly, content concerning getting along well with others, encountering people who are impatient or unaware of hearing loss, being less independent, being less outgoing and hearing important sounds were added to the SPaRQ2.0. The modified content of the SPaRQ is summarised in Table 3.14 and Table 3.15.

3.9.6 Appropriateness of the response scale

This refers to the clarity of the response scales for adults with hearing loss and their suitability for a social participation restrictions outcome measure. This was assessed by both the subject matter expert survey and the cognitive interviews. The survey results showed that the majority of subject matter experts were satisfied with the agree/disagree response scale accompanying the emotion and identity items. However, there were mixed opinions regarding the self-efficacy scale accompanying the behaviour items. The cognitive interviews indicated that the labels on the self-efficacy response scale were difficult to understand for some participants.

Some of the participants in the subject matter expert survey and the cognitive interviews felt that there were too many response options. However, a larger number of response options have been linked to greater reliability, validity and sensitivity, which are essential psychometric properties for any outcome measure (Krosnick and Presser 2010; Preston and Colman 2000; Stewart and Archbold 1993; Weng 2004). An 11-point format has been successfully used in other outcome measures, such as the Tinnitus Functional Index (Fackrell et al., 2016). Also, all of the adults with hearing

loss who took part in the cognitive interviews were able to use the 11-point response scale and most used a wide range of response options, even those who would have preferred a response scale with a smaller range. Therefore, the 11-point format was retained in the SPaRQ2.0.

Table 3.14 Revised content of the behaviour items

Item	Abbreviated behaviour item content
1	Converse in background noise
2	Converse on telephone
3	Watch television with other people
4	Watch live events and shows
5	Listen to radio or recorded music
6	Carry out favourite pastimes
7	Take part in community, voluntary or religious activities
8	Follow talk or lecture
9	Use public transportation
10	Discuss health with healthcare professional
11	Manage stressful and challenging situations
12	Take part in a group discussion or meeting
13	Converse with unfamiliar people
14	Persevere with lengthy conversations
15	Converse with co-workers
16	Talk with staff in shops, cafes or banks
17	Manage home, work or social responsibilities
18	Take part in education and training
19	Attend get-togethers with friends
20	Go out with significant other
21	Attend family get-togethers
22	Attend large social gatherings
23	Take part in conversations with friends
24	Converse with significant other
25	Converse at family get-togethers
26	Get along with people who are close to me

The most significant problem with the response scales was discovered in the cognitive interviews, where it was observed that most of the adults with hearing loss found it difficult to switch from using the self-efficacy scale with positively-worded behaviour items to using the agree/disagree scale with negatively-worded emotion and identity items. Some interviewees did not notice that the response scale had changed, whilst some did notice that the response scale had changed but did not know how to amend their answers accordingly. In both cases, this led to inaccurate responding.

It was clear that it would be necessary to use a single response scale throughout the SPaRQ2.0 so that respondents could understand the questionnaire and provide valid answers. It was not possible to use the self-efficacy response scale throughout the questionnaire, as this scale is only applicable to the behaviour items. As a result, it was decided that the best solution would be to use the agree/disagree response scale throughout the SPaRQ2.0. This scale can be applied to all of the items and was clearer to the participants than the self-efficacy scale. Using solely this response scale involved altering the behaviour items so that they were negatively worded, rather than positively worded. For example, the item: '*Despite my hearing problem, I can: Take part in conversations with people on the telephone*' was changed to: '*Because of my hearing loss, I find it difficult to: Take part in conversations with people on the telephone*'. The disadvantage of this approach is that the questionnaire is quite negative for respondents. However, this approach is vital so that participants understand how to complete the questionnaire. It has also been argued that agree/disagree scales have the drawback of precipitating acquiescent responding, which is

when respondents agree with the statements in the questionnaire regardless of their content (Saris et al., 2010). The cognitive interviews demonstrated that the participants did not display an acquiescence bias when answering the questionnaire.

Table 3.15 Revised content of the emotion and identity items

Item	Abbreviated emotion item content
27	Frustrated when it is difficult to follow conversations
28	Find social gatherings stressful
29	Worry about missing important sounds and information
30	Isolated during group conversations
31	Embarrassed about asking people to repeat
32	Frustrated when left out of conversations
33	Unenthusiastic about socialising with friends and family
34	Lonely, even when around others
35	Embarrassed when I say the wrong thing
36	Isolated at get-togethers
37	Worry about going to social gatherings
38	Unenthusiastic about joining in conversations
39	Upset when it is difficult to take part
40	Sad when I cannot join in
41	Worry about talking to unfamiliar people
42	Irritated when people are not patient or understanding
Item	Abbreviated identity item content
43	Seem unfriendly when I do not join in conversations
44	Look less sociable than I really am
45	Rather pretend to understand what people are saying
46	Look demanding when I ask people to repeat
47	Look less capable than I really am
48	Rather sit quietly whilst people are talking than interrupt
49	Look foolish when I cannot understand people
50	Less independent than I used to be
51	Look foolish when I say the wrong thing
52	Less outgoing than I used to be
53	People see me as a nuisance

The discovery of this problem has implications for other questionnaires that use more than one response scale and for research studies that ask respondents to complete several questionnaires in a row, including many convergent validity studies. Without cognitive interviewing, it is difficult to be certain that respondents have understood how to answer different questionnaires using different response scales. As Study 2 has demonstrated, respondents can select responses that appear to be legitimate without having actually understood the response scale. This finding also contradicts the notion that having a mixture of positively worded items and negatively worded items prevents participants from mindlessly answering the questionnaire. The use of visual clues, such as showing different response scales in different colours, could be investigated.

3.9.7 Sensitivity of the questionnaire

This refers to responsiveness, or the ability of the questionnaire to detect changes in social participation restrictions following an intervention for hearing loss. This was assessed by the subject matter expert survey. The results show that many of the experts found it difficult to estimate whether or not the SPaRQ1.0 had the potential to be a sensitive outcome measure. This has implications for the questionnaire design literature, as currently there is little guidance available on how to compose sensitive questions and how best to assess their potential sensitivity at the content evaluation stage. This means that the sensitivity of the questionnaire cannot be assessed until after the questionnaire has been developed and psychometrically tested. At this stage, it is difficult to amend the items to improve their sensitivity or to introduce new sensitive items.

The experts provided several important written comments about the sensitivity of the questionnaire. One expert warned that the identity items may be less sensitive to change than the other items, which further supports the decision to make this the smallest subscale in the questionnaire. Some of the experts made recommendations about how to enhance the sensitivity of the questionnaire when it is used as an outcome measure in research or clinical practice. For example, one warned that changes to social participation restrictions are likely to take a long time to occur, which means that the timing of the follow-up assessments must be chosen carefully. Another expert recommended that information about the coping strategies and devices used by participants should be collected at baseline. These recommendations are not applicable to the SPaRQ2.0, as it will not be used to measure outcomes as part of Study 3. However, these recommendations will be applicable to the finalised version of the SPaRQ produced by the end of this PhD research.

3.9.8 Acceptability of the questionnaire

The cognitive interviews were used to assess whether the questionnaire was acceptable to adults with hearing loss. The majority of the interviewees felt that the questionnaire was not intrusive or offensive. However, one participant found that completing the questionnaire evoked an emotional response and made her contemplate the true impact of her hearing loss, though this was not necessarily an aversive experience for her. She suggested warning future participants that they could have a similar experience when completing the questionnaire. This suggestion was considered but it was ultimately decided that this instruction would itself be

off-putting or intimidating for many participants. Also, there is the possibility that, if the instructions of the questionnaire become too lengthy, many participants will be discouraged from reading them, particularly when they are also required to read invitation letters and information sheets for the study. It was decided that the information sheet provided to participants before they complete the questionnaire would contain all of the necessary information.

A few of the emotion and identity items were flagged by a small number of participants as potentially being off-putting. These participants found it difficult to relate to these items as they have not found that hearing loss affects their emotion or identity. One of these items (*'Because of my hearing problem: I think that I look rude when I do not realise that other people are speaking to me'*) was removed from the questionnaire as, not only was it perceived as off-putting, but it also displayed a logical-performance problem. Specifically, it may be difficult for people with hearing loss to answer this item, as they are unlikely to be aware of instances where they have accidentally ignored other people. The other items, which pertained to feeling sad and upset, as well as to being seen as a nuisance, were retained in the SPaRQ2.0 because their content was too relevant to omit and because they were not perceived as being off-putting by most of the participants.

3.9.9 Limitations

This study had several limitations. Firstly, convenience sampling was used to recruit adults with hearing loss for the cognitive interviews, due the limited timeframe and resources of the study. Convenience sampling is one of the least rigorous sampling methods available to qualitative researchers (Patton

1990). Its use meant that the sample was missing some relevant characteristics, such as non-ownership of hearing aids. Additionally, the ages of the participants ranged from 51 to 81 years, which means that the views of younger age groups were not captured. Another limitation is that information about the educational attainment of the cognitive interviewees was not collected as part of the demographics questionnaire, though this factor is likely to have influenced their understanding of the questionnaire. Informal discussions with the participants revealed that they had a range of occupations and education levels. These discussions also showed that some had previous experience of research, including questionnaires, whilst others did not.

In addition, the participants were aware that the author was involved in developing the questionnaire. Although they were encouraged to identify problems with the questionnaire, it is possible that some participants felt uncomfortable doing so in an effort to please the author. Another limitation is that the peer assessment was somewhat limited. Ideally, the cognitive interview data should have been fully analysed by at least two researchers who have both received formal training in this form of analysis. The agreement between the codes of the different researchers should then have been thoroughly assessed (Conrad and Blair 1996). Unfortunately, such a rigorous analysis was not feasible in this study, as there was only one researcher available to carry out the data analysis.

Furthermore, the questionnaire underwent one round of content evaluation, which contrasts with the proposal that content evaluation should be an iterative process in which the questionnaire is re-evaluated each time it has

been substantially altered (Grant and Davis 1997; Polit, Beck and Owen 2007). The restricted timeframe of this research did not permit another round of content evaluation prior to Study 3, which was a psychometric evaluation of the questionnaire. Nevertheless, it was decided that it was important to confirm that the changes to the questionnaire, particularly the altered response scale, had been effective in making the questionnaire clearer and easier to complete. Consequently, a PPI exercise was carried out in which the SPaRQ2.0 was completed by four adults with hearing loss who had not taken part in Study 2. One individual was a member of the BRU PPI panel. The others were members of the author's personal network. This exercise confirmed that the alterations to the questionnaire were successful, as these individuals were able to understand the entire questionnaire and provide accurate responses.

A final limitation pertains to content evaluation studies in general, which is that they frequently uncover more potential problems than it is possible to resolve. For example, in this study, several participants suggested additions to the instructions of the questionnaire. However, if all of these suggestions were implemented, the instructions would be so lengthy as to be burdensome and potentially off-putting for participants. It has previously been asserted that content evaluation does not lead to the design of the 'perfect' questionnaire format, if such a thing exists. Instead content evaluation facilitates informed decisions about questionnaire design by uncovering the relevant 'trade-offs', or the advantages and disadvantages of different formats questionnaire (Beatty and Willis 2007). A past cognitive interview study, which evaluated a physical activity questionnaire, stated that not all of

the problems identified qualified for a revision, as every revision is associated with both benefits and drawbacks (Andersen et al., 2010). For example, a question about the physical activity of gardening was not altered in order to distinguish between gardening in summer and gardening in winter, as this would have made the question too complex for the participants.

3.9.10 Future research

This study demonstrates the value of assessing the content validity and respondent burden of a new measure and of rigorously pre-testing that measure prior to administration in a large sample. This approach should be applied to other hearing-specific questionnaires, both new and existing, to ensure that they are interpreted as intended and thus obtain accurate and informative responses.

The results of this study were used to produce the SPaRQ2.0: a 53-item measure with a single 11-point response scale ranging from 0=‘*Completely disagree*’ to 10=‘*Completely agree*’. The next stage of this research was a quantitative investigation of the psychometric properties of this questionnaire. Rasch analysis was used to formally assess the factor structure of the SPaRQ2.0 in order to determine whether its three elements (i.e. behaviour, emotion, and identity) form a unidimensional measure of social participation restrictions. Rasch analysis was also used to identify items that fail to tap into social participation restrictions and redundant items that overlap with one another so that any such items could be removed from the questionnaire. Furthermore, Rasch analysis was used to statistically assess the appropriateness of the response scale. As such, this study concludes the

qualitative component of this doctoral research, which has provided a theoretical and conceptual foundation for the measure and a basis for the subsequent quantitative assessment of the measure.

CHAPTER 4. STUDY 3: RASCH ANALYSIS OF THE SOCIAL PARTICIPATION RESTRICTIONS QUESTIONNAIRE

4.1 INTRODUCTION

This chapter reports the third study of this doctoral research, which was a quantitative evaluation of the psychometric properties of the second prototype of the Social Participation Restrictions Questionnaire (SPaRQ2.0). It is vital to rigorously assess the psychometric properties of a new outcome measure to confirm that it is suitable for its intended purpose in its intended population (Pesudovs et al., 2007). In this case, the aim was to ensure that the SPaRQ2.0 had the requisite psychometric properties to serve as a high quality outcome measure for use in clinical trials and clinical practice with adults who have hearing loss. Consequently, a form of modern psychometric analysis, known as Rasch analysis, was performed on questionnaire data obtained from 279 adults with hearing loss. The results of the analysis were used to refine the questionnaire, such as by removing items and creating subscales, until its psychometric properties met the standards required of a high quality measure.

4.2 AIMS AND OBJECTIVES

The primary aims of this study were to **(1)** examine the psychometric properties of the SPaRQ2.0 and **(2)** to refine the questionnaire, as required, in order to improve its psychometric properties. In this study, refinement of refers to deleting items with poor psychometric properties, adjusting the response scale by collapsing response categories, and reorganising the items into subscales. The specific study objectives were to:

- 1) Explore the factor structure of the questionnaire
- 2) Identify items with poor psychometric properties and remove them from the questionnaire
- 3) Test the local independence and fit to the Rasch model of the questionnaire
- 4) Examine the targeting of the questionnaire
- 5) Assess the person separation reliability of the questionnaire
- 6) Examine the threshold ordering of the response scale

4.3 DESIGN

4.3.1 Psychometric properties

As the above objectives suggest, psychometric analysis involves examining several different properties associated with the individual items, the response scale, the subscales, and the scale as a whole. The ultimate goal of this analysis was to adjust the questionnaire, where necessary, to improve its quality and to confirm that it fulfils the necessary criteria to be used in clinical trials and clinical practice. For example, it was crucial to explore the factor structure, or dimensionality, of the questionnaire, as this provides important information about its structural validity. Structural validity refers to the extent to which the scores on a questionnaire are a sufficient representation of the dimensionality of the target construct (Mokkink et al., 2010c). In other words, examining the factor structure helps to uncover the domains that are measured by the questionnaire, helps to refine the conceptual model of the target construct, and informs the development of subscales (De Vet et al., 2011; Raykov and Marcoulides 2011). Another essential process, item reduction, was carried out in order to retain only the best quality items, which

maximises validity, reliability, and responsiveness and also minimises respondent burden. It is recommended that items are removed on the grounds of poor fit, which indicates that they do not measure the target construct, response dependency, which means that they are redundant, and due to attracting large amounts of missing data, which suggests that they are likely to be irrelevant or ambiguous (De Vet et al., 2011; Pesudovs et al., 2007).

It was also vital to evaluate the local independence of the questionnaire. This chiefly involves testing the unidimensionality of the scale or its subscales, which means testing whether the items measure a single, latent construct (i.e. social participation restrictions). Unidimensionality is a prerequisite for summing the items in order to calculate a total score. It means that the scale or subscale is a meaningful measure of a construct, rather than a list somewhat miscellaneous questions (Pesudovs et al., 2007). It was also important to demonstrate fit to the Rasch model, as this shows that the questionnaire satisfies the core requirements of measurement. This will be discussed in detail in the 'Rasch analysis' section below.

Targeting was assessed as this is another important psychometric property for any outcome measure. A well-targeted questionnaire is one in which the level of disability present in the sample is closely matched to the level of disability measured by the questionnaire (Lundgren Nilsson and Tennant 2011; Pallant and Tennant 2007). Ensuring that a scale is well-targeted maximises its efficiency and meaningfulness and minimises respondent burden (Pesudovs et al., 2007). Additionally, the person separation reliability of the measure was assessed. This is a measure of the ability of the

questionnaire to detect differences between individuals in the study sample and also indicates whether the questionnaire can be used at the individual level, as well as the group level (Hobart and Cano 2009; Pesudovs et al., 2007). Finally, in addition to assessing the items and the measure as a whole, it is vital to assess the response scale. In particular, the optimum number of response categories must be established, as it may be that there are redundant categories that can be eliminated from the response scale for certain items (Pesudovs et al., 2007).

4.3.2 Psychometric analysis

This was a quantitative study in which psychometric analysis was performed on questionnaire data collected from adults with hearing loss. As mentioned in Chapter 1, in the questionnaire development field, there are currently two major theoretical approaches to psychometric analysis, which have key philosophical differences from one another: Classical Test Theory (CTT) and latent trait theories (LTTs) (Cano and Hobart 2011).

4.3.2.1 Classical test theory

At present, psychometric analysis based on CTT, known as traditional psychometric analysis, is dominant in the questionnaire development field. Traditional psychometric analysis involves accumulating evidence for the robustness of a measure from a series of statistical analyses, including factor analysis as a measure of structural validity and correlation with a gold-standard instrument as a measure of criterion validity (Cano and Hobart 2011; Hobart and Cano 2009; Pesudovs et al., 2007). Despite the widespread use of traditional psychometric analysis, modern psychometric analyses based on LTTs are now considered to be the gold-standard

approaches. The primary reason for this is that traditional psychometric analysis has several important limitations that have been addressed by modern psychometric analyses (Cano and Hobart 2011; da Rocha et al., 2013; Turk et al., 2006).

One major limitation of traditional psychometric analysis is that the underlying measurement theory, CTT, is fundamentally flawed (Hobart and Cano 2009). A measurement theory is a theory of how the values produced by a rating scale relate to measurements of the target construct (Hobart et al., 2007). Essentially, CTT posits that individuals' observed scores (i.e. their actual questionnaire scores) are the sum of their true scores (i.e. their theoretically expected score) and error scores (i.e. the random, unsystematic deviation of observed scores from true scores). It assumes that measurement errors are randomly distributed and are not associated with the true score. It also assumes that a respondent's score is a linear combination of responses to a set of items that have been sampled from a universe of items that measure a common construct. While CTT can be a useful model, it is undermined by the fact that error scores and true scores cannot be determined because they are theoretical, unobservable variables. This means that it is not possible to adequately test and falsify CTT (Hobart and Cano 2009; Hobart et al., 2007; Raykov and Marcoulides 2011; Turk et al., 2006). It has been argued that, as CTT cannot be adequately tested, only weak inferences can be drawn from this theory and that it is relatively easy to produce and interpret data in such a way that will satisfy this theory (Hobart et al., 2007).

Another substantial limitation is that traditional psychometric analysis leads to the development of questionnaires that produce ordinal, rather than interval, data. This has implications for the analysis and interpretation of clinical trials data, as difference scores and change scores are most meaningful and accurate when they are calculated using interval data. Furthermore, ordinal data are only appropriate for group-level measurement and not individual-level measurement, due to the wide confidence intervals around an individual ordinal score. Therefore, if questionnaires are to be used as outcome measures in high quality clinical trials, they should produce interval data where possible (Cano and Hobart 2011; Hobart and Cano 2009; Hobart et al., 2007; Prieto, Alonso and Lamarca 2003).

Another limitation of traditional psychometric analysis is that the performance of a questionnaire is dependent on the sample in which that questionnaire is assessed, whereas it is preferable that questionnaires are stable across samples (Cano and Hobart 2011; Turk et al., 2006). Therefore, the properties of a questionnaire, such as reliability and validity, and item statistics, such as item difficulty and item discrimination, are sample dependent. Furthermore, an individual's score on a questionnaire is dependent on the sample in which that individual was measured, which means that an individual with a moderate level of disability will appear to be high-functioning if measured within a sample of individuals who have a severe level of disability. This does not reflect the fact that an individual's level of disability should be a fixed value (Hobart and Cano 2009). In contrast, Rasch analysis, which is a form of modern psychometric analysis, includes several sample independent statistics, such as estimates of item difficulty (i.e. the level of the target

construct captured by the items) (Bonsaksen et al., 2013). Nevertheless, some Rasch analysis statistics are sample dependent, such as the person separation index, which is a measure of internal consistency (Hobart and Cano, 2009).

In addition, traditional psychometric analysis has been criticised for providing little more than weak or circumstantial evidence for construct validity (Hobart and Cano 2008). For example, although assessments of structural validity and internal consistency, such as factor analysis and Cronbach's alpha, demonstrate the degree to which the items in a questionnaire are statistically inter-related, they do not demonstrate that the questionnaire measures a single, unidimensional construct. Also, the assessment of construct validity through testing hypotheses about correlations with related and unrelated measures is argued to be a somewhat circular approach (Hobart and Cano 2008). The absence of a correlation between the questionnaire and a dissimilar measure provides information on what the questionnaire does not measure, rather than what it does measure. The presence of a correlation between the questionnaire and a similar measure informs us that the two measures are related, but again does not provide information on what the questionnaire measures (Hobart et al., 2007). Furthermore, the use of internal consistency statistics in item reduction is problematic, as it can lead to redundant items remaining in the questionnaire. Similarly, the use of factor analysis in item reduction and subscale development has been called into question, as there is no consensus on how best to determine the number of factors to be extracted, with over-extraction and under-extraction being common problems (Prieto, Alonso and Lamarca 2003; Wright 1996).

4.3.2.2 Latent trait theories

The shortcomings of traditional psychometric analysis can be addressed by utilising modern psychometric analyses based on LTTs. Like CTT, LTTs are measurement theories that are presented as mathematical models from which statistical methods are derived to analyse questionnaire data and to assess the psychometric properties of that questionnaire. However, LTTs are considered to be superior to CTT because they can be tested and falsified (da Rocha et al., 2013; Hobart et al., 2007). In essence, LTTs assume that the response to an item is a result of the interaction between the level of disability of the respondent and the characteristics of the item, such as the level of disability captured by that item. Psychometric analyses based on LTTs assess the difference between theoretical scores and observed scores for each item. This focus on the performance of each individual item contrasts with traditional psychometric analysis, which focuses on the total test score (Belvedere and de Morton 2010; Cano and Hobart 2011; da Rocha et al., 2013). The use of analyses based on LTTs is growing in popularity because these approaches offer numerous advantages. Specifically, these analyses mean that several item statistics and several measurement properties are sample independent, transformation of questionnaire data to interval scaling is possible, the unidimensionality of the measure can be determined, the performance of each response option on the response scale can be assessed, item bias resulting from individuals with the same level of difficulty obtaining different scores due to demographic factors can be assessed, Computer Adaptive Testing is facilitated (see Chapter 6), and the linking of scores from different questionnaires that

measure the same construct is facilitated (Belvedere and de Morton 2010; da Rocha et al., 2013; Turk et al., 2006).

There are two main types of analysis based on LTTs: Item Response Theory (IRT) analysis and Rasch analysis. Both considered to be gold-standard, modern psychometric approaches that are crucial to outcome measure development (Cano and Hobart 2011; da Rocha et al., 2013; Mokkink et al., 2012; Pesudovs et al., 2007; Tennant and Conaghan 2007; Turk et al., 2006; Turner et al., 2007). Although these analyses are largely similar, there is a subtle difference between the two (Cano and Hobart 2011). In IRT analysis, the aim is to identify the statistical model that best explains the data. If the observed data do not fit the chosen IRT model, another model is sought. In Rasch analysis, the aim is to examine the extent to which the observed data fit with the Rasch model; a model which specifies the core requirements of measurement. If the observed data do not fit the model, the data are examined to determine the cause of the misfit and data are chosen that satisfy the model requirements and thus the requirements of measurement (Cano and Hobart 2011). IRT analysis uses a range of item response models that differ in the number of parameters used. In contrast, Rasch analysis uses just one model, the Rasch model, which has one parameter: the level of disability expressed by an item. In summary, IRT analysis prioritises observed data, whereas Rasch analysis prioritises the mathematical measurement model (da Rocha et al., 2013; Hobart et al., 2007).

It can be difficult to choose between Rasch analysis and IRT analysis, as both are highly recommended approaches that offer many of the same advantages. An important consideration is the impact of this choice on the

validity of the outcome measure under development. Proponents of IRT view the use of one measurement model in Rasch analysis as restrictive and the selection of data to fit that model as a potential threat to content validity. Contrastingly, proponents of Rasch analysis view the modelling of data in IRT as too accepting of poor quality data that may not meet the core requirements of measurement and that are a threat to construct validity (Cano and Hobart 2011). Additionally, Rasch analysis is proposed to be the only approach that can adequately test whether a measure meets the core measurement requirements of invariance and unidimensionality (da Rocha et al., 2013; Hobart et al., 2007). Ultimately, it was decided that Rasch analysis was preferable to IRT analysis, as it is arguably the more conservative, stringent approach. The research was designed so that potential threats to content validity associated with Rasch analysis would be circumvented by conducting the qualitative research described in previous chapters.

4.3.2.3 Rasch analysis

Rasch analysis is the formal testing of an outcome measure against the Rasch model (Tennant and Conaghan 2007). The Rasch model is a LTT, which means that it is a measurement theory that is presented in the form of a mathematical model from which statistical methods for the testing of reliability and validity of a scale and the legitimacy of summing the items in the scale are derived (Hobart and Cano 2009; Hobart et al., 2007; van der Velde et al., 2009). The Rasch model is unique in that it is built on theory relating to core measurement requirements (i.e. unidimensionality, invariance, and interval-level estimates) and is constructed prior to data collection. Therefore, Rasch analysis involves testing whether the data

obtained from an outcome measure fit the model (i.e. whether the data are unidimensional, invariant, and interval level), as opposed to testing whether the model fits the data. This determines whether the outcome measure can be said to generate values that can be classed as measurements (Hagquist 2001).

To be specific, Rasch analysis entails assessing a questionnaire to ascertain whether or not the pattern of responses aligns with the model predictions, which are a probabilistic form of Guttman scaling (Guttman 1950; Lundgren Nilsson and Tennant 2011). This means that, for the same degree of person disability, the probability of affirming a severe disability item must be higher than the probability of affirming a mild disability item (Andrich 1985; Hagquist, Bruce and Gustavsson 2009). A person with severe disability should endorse all items endorsed by a person with a milder level of disability, as well as some additional severe disability items. This probabilistic Guttman pattern allows for random variation, which means that two persons with the same score do not have to have exactly the same response pattern (Hagquist, Bruce and Gustavsson 2009). The Rasch model predicts that the probability of a certain response is determined by the difference between the person's location on the disability continuum and the item's location on the disability continuum. Rasch analysis assesses the degree to which observed responses, or participants' scores, differ from predicted responses, or the scores that were expected by model in order to fulfil the requirements of measurement. Where the differences between observed and predicted responses are within an acceptable range, it is concluded that the data fit the Rasch model (Hagquist, Bruce and Gustavsson 2009; Hobart et al., 2007;

Tesio 2003). This is taken to mean that the data fulfil the core requirements of measurement:

1) Unidimensionality - A unidimensional scale is one that taps into a single underlying construct, as opposed to a multidimensional scale that assesses several underlying constructs. Unidimensionality is a requirement of construct validity and is a necessity if a total score is to be obtained from the responses to the outcome measure. Rasch analysis facilitates the rigorous assessment of the unidimensionality of a scale (Yorke, Horton and Jones 2012). Several different approaches to the assessment of unidimensionality can be found in the Rasch analysis literature. In this study, exploratory factor analysis (EFA) was initially carried out to inform the subsequent assessment of unidimensionality in Rasch analysis (Bjorner, Kosinski and Ware Jr 2003; Tennant and Pallant 2006). For example, EFA can indicate whether multidimensionality is likely to be an issue and whether there are items that are likely to affect unidimensionality, which is important information for the iterative removal of items in Rasch analysis (Smith 1996; Tennant and Pallant 2006). Following EFA, unidimensionality was formally tested through a recognised post-hoc procedure in Rasch analysis, which is described in greater detail in the 'Data Analysis' section (Smith 2002; Tennant and Pallant 2006; Yorke, Horton and Jones 2012). This procedure was selected because it has been found a robust means of assessing unidimensionality and thus has been recommended above alternative approaches, such as examining fit to the Rasch model alone or the

Wright Unidimensionality Index (Tennant and Pallant 2006; Wright 1994; Wright and Linacre 1989).

2) Invariance - This criterion requires that the questionnaire functions in the same manner for all individuals and for all groups of individuals. For example, invariance means that male and female respondents who have the same level of disability should not display different response patterns on the individual items. Invariance also means that item and person parameters should be estimated independently of one another, such that the item parameters are the same, regardless of the person distribution, and the person parameters do not depend on which items contributed to that estimation (Hagquist, Bruce and Gustavsson 2009; Yorke, Horton and Jones 2012). In other words, the relative location of any two respondents on the disability continuum does not depend on the items used to make that comparison and also that the relative location of any two items on the disability continuum does not depend on the respondents used to make that comparison (Hobart and Cano 2009).

One of the distinctive aspects of Rasch analysis is that it facilitates the independent estimation of person and item parameters. Specifically, when the data fit the Rasch model, the sums of the raw scores across items are sufficient statistics for the person parameters and the sums of the raw scores across persons are sufficient statistics for the item parameters. The total raw scores are then used to calculate new scores on an interval scale that is common to both persons and items (Hagquist 2001). The unit of measurement of this new scale is the logit, or the log odds of a participant with a particular level of disability, as measured by

their responses to all of the items together, having a 50% chance of affirming that item (Pallant and Tennant 2007; Yorke, Horton and Jones 2012). Rasch analysis includes statistical analyses that indicate whether or not the property of invariance has been compromised. This is crucial, as overlooking invariance can lead to misinterpretation of the responses gained from composite outcome measures (Hagquist 2001; Pallant and Tennant 2007).

3) Interval-level measurement - This is a requirement if parametric statistics and minimal change scores are to be computed from the responses to the outcome measure. Rasch analysis permits the transformation of ordinal scores into interval measures, provided that the expectations of the Rasch model are met by the scale data (van der Velde et al., 2009; Yorke, Horton and Jones 2012). This means that responses to different items that each represent different disability levels can be summated (Hagquist, Bruce and Gustavsson 2009). As a result, Rasch analysis facilitates both group-level comparisons and individual-level comparisons (Cano and Hobart 2011).

4.3.2.4 Rasch analysis and traditional psychometric analysis combined

In addition to Rasch analysis, traditional psychometric analysis was also used in this research (see Table 4.1). The strengths of Rasch analysis meant that it was the primary psychometric analysis in this study. In particular, Rasch analysis was used to shape the questionnaire, through identifying items that should be removed from the questionnaire, determining whether the response scale required adjustment, and determining whether there was one overall scale or separate subscales. It was also used to assess

important measurement properties, including structural validity and person separation reliability (Pesudovs et al., 2007). Traditional psychometric analysis, in particular an exploratory factor analysis, was used in this study to inform the Rasch analysis by providing preliminary information on the potential factor structure of the questionnaire (Bjorner, Kosinski and Ware Jr 2003; Tennant and Pallant 2006). Traditional psychometric analysis was also used in the subsequent study, Study 4, to further assess the psychometric properties of the questionnaire, including convergent validity and internal consistency (see Chapter 5).

Table 4.1 Summary of psychometric analyses performed

Study	Objective	Rasch analysis	Traditional psychometric analysis
Study 3	Factor structure		✓
	Local independence	✓	
	Targeting	✓	
	Person separation reliability	✓	
	Threshold ordering	✓	
	Item reduction	✓	
Study 4	Hypothesis testing validity		✓
	Internal consistency		✓
	Floor and ceiling effects		✓

The use of traditional psychometric analysis to support Rasch analysis is a highly recommended approach, with many validated questionnaires having been developed in this way (Chachamovich et al., 2008; Chen et al., 2013; Ford et al., 2001; Hawley et al., 1999; Pusic et al., 2009; Whiteneck et al., 2011). Although traditional psychometric analysis has limitations, it remains

the dominant approach to questionnaire development (Hobart and Cano 2009). As discussed in Chapter 1, traditional psychometric analysis is a crucial component of the COSMIN checklist and other outcome measure quality criteria checklists (Mokkink et al., 2012; Terwee et al., 2007; Uijen et al., 2012). This is because traditional psychometric analysis is the only recognised means of assessing certain important psychometric properties, such as hypothesis testing validity and test-retest reliability. Therefore, traditional psychometric analysis can provide information that is not provided by Rasch analysis, such as information about the relationship between the questionnaire under development and existing, validated questionnaires. Additionally, traditional psychometric analysis, with its focus on the validity of the summed scale score, is a useful complement to Rasch analysis, which focuses on the performance of items within a scale (Chachamovich et al., 2008; da Rocha et al., 2013).

4.3.3 Sample size

To obtain robust outputs from Rasch analysis, a sample of at least 250 cases is needed (Chen et al., 2013). A smaller sample size may suffice if the questionnaire under investigation is well-targeted. The targeting of a questionnaire can be assessed as part of Rasch analysis. If the sample size is relatively small, the questionnaire should undergo additional evaluation, such as traditional psychometric analysis (Chen et al., 2013). In this study, traditional psychometric analysis in the form of Exploratory Factor Analysis (EFA) was carried out. It has been suggested that EFA requires at least five participants per item (Hyde 2000) with a minimum of at least 100 participants (Reise, Waller and Comrey 2000; Terwee et al., 2007). According to this

suggestion, 265 cases would be required to conduct EFA on the SPaRQ2.0. However, the appropriateness of EFA sample size depends on several variables that are particular to the study at hand (Guadagnoli and Velicer 1988; Hogarty et al., 2005; Reise, Waller and Comrey 2000). For example, sample sizes of between 50 and 150 cases can be sufficient when the dataset has several high factor loading scores, when the communalities of the items are consistently high, and when there are a moderate number of factors containing at least three items each (de Winter, Dodou and Wieringa 2009; Guadagnoli and Velicer 1988; MacCallum et al., 1999). Taking all of this into consideration, as well as the practicalities of recruiting participants, it was determined that a minimum sample size of 250 cases would be suitable for this study.

4.3.4 Mode of delivery

It has been proposed that different questionnaire formats can produce different outcomes, which will emerge as different participant characteristics, different responses, different completion times, and different psychometric properties. However, many studies have concluded that observations collected using the paper-and-pen version of a questionnaire are equivalent to those collected from the electronic version of that questionnaire (Bishop et al., 2010; Cook et al., 2004; Gwaltney, Shields and Shiffman 2008; Kleinman et al., 2001). In contrast, some studies have found small but potentially important differences between observations collected by means of paper-and-pen administration and those collected by means of electronic administration. For example, one study found that responses to an attitude survey were more positive online than on paper (Carini et al., 2003), whilst

another study showed that the factor structure of an online psychopathology screening questionnaire differed from its paper-and-pen counterpart (Vallejo et al., 2007).

Consequently, it was decided that the questionnaires used in this study should be administered to all participants using a single mode of delivery. It was likely that many of the participants in this study would be older adults who are less likely to have access to computers and to the internet than younger adults (Henshaw et al., 2012). For example, many members of the BRU participant database do not have an email address. Also, it was likely that many participants would be recruited via audiology clinics. For these reasons, the questionnaires were delivered to all participants in this study using a paper-and-pen format.

4.4 METHODS

This research was sponsored by the University of Nottingham. It was approved by the North East-Tyne and Wear South Research Ethics Committee, the Research and Innovation Department at the Nottingham University Hospitals NHS Trust, and the Research and Development Governance Office at the University Hospitals Birmingham NHS Trust.

4.4.1 Participants

There were 279 participants in total (see Table 4.2). In order to screen for hearing loss, the participants were asked to complete the two hearing loss screening items and the demographics questionnaire that were previously used in Study 2. The majority (N=275, 98.6%) answered 'Yes' to at least one of the two screening items, which indicates that they were likely to have a hearing threshold of at least 35 dB HL when tested using pure tone

audiometry (Davis et al., 2007). Four participants answered 'No' to both screening questions. However, their responses to the demographics questionnaire demonstrated that they did have hearing loss. Specifically, three of these individuals reported having mild, acquired hearing loss and not wearing hearing aids. The fourth individual reported having severe, sudden onset hearing loss and wearing hearing aids every day. Therefore, these individuals were included in the data analysis.

4.4.2 Recruitment

4.4.2.1 Eligibility Criteria

The inclusion criteria for the study required each participant to:

- 1) Be willing and able to complete and return questionnaires by post.
- 2) Be aged 18 years or older.
- 3) Have self-reported hearing loss.
- 4) Have good written and spoken English. English does not have to be the participant's first language.
- 5) Be able to read letters on a computer screen or on paper with or without glasses.

The exclusion criteria for the participants were:

- 1) Self-reported cognitive decline or dementia that would necessitate assistance in completing a questionnaire.
- 2) Self-reported profound hearing loss.

Table 4.2 Demographic information of the study 3 participants

Gender	n	%
Male	156	55.91
Female	123	44.09
Age	Years	
Mean	65.67	
SD	12.73	
Range	24-89	
Median	67	
Age group	n	%
18-59 years	80	28.67
60-69 years	84	30.11
70-79 years	82	29.39
80-89 years	33	11.83
Hearing loss type	n	%
Acquired	262	93.91
Congenital	16	5.73
Missing response	1	0.36
Hearing loss onset	n	%
Gradual	213	76.34
Sudden	34	12.19
Other	32	11.47
Hearing loss duration	Years	
Mean	15.4	
SD	15.29	
Range	2 months-77 years	
Median	10	
Hearing aid use	n	%
Everyday	176	63.08
Sometimes	40	14.34
Never	63	22.58
Employment status	n	%
Retired	184	65.95
Employed	82	29.39
Not employed	10	3.58
Student	3	1.08
Region of residence	n	%
England	272	97.49
Scotland	4	1.43
Wales	1	0.36
Northern Ireland	2	0.72
Living arrangements	n	%
Live with other people	217	77.78
Live alone	62	22.22

4.4.2.2 Recruitment Procedure

Recruitment for the study took place over a 15 week period and ceased when an adequate sample size had been reached. The goal was to obtain a representative sample of the SPaRQ target respondents: adults with hearing loss. Therefore, the participants were recruited from three different sources. Participants were primarily recruited through the Nottingham Hearing BRU participant database. The database was searched for potential participants who were not currently participating in any other BRU research studies and who were likely to have a hearing loss, such as individuals who were listed as owning hearing aids. They were contacted in groups of approximately 50 or 100 individuals across an eight week period in order to avoid recruiting more participants than required. In total, 377 potential participants from the database were contacted about the study.

In addition, two UK audiology clinics, the Nottingham Audiology Service and the Queen Elizabeth Hospital Audiology Centre in Birmingham, acted as participant identification centres (PICs) in this study. Several audiologists at each site were responsible for identifying patients who were potential participants for this study and providing them with brief information about the study and a research pack for completion at home. Identification could take place during clinic appointments at any stage of the care pathway (e.g. direct referral, hearing aid fitting, follow-up appointments). The Nottingham clinic received approximately 200 research packs to distribute, whilst the Birmingham clinic received approximately 100 research packs. Identification was ongoing in Nottingham for approximately 11 weeks and in Birmingham for approximately seven weeks.

Finally, participants were recruited through an online advertisement that was posted on the Deafness and Hearing Loss Forum of the website of Action on Hearing Loss; a UK hearing loss charity with hundreds of online forum members. A paper copy of this advertisement was posted in the Ear, Nose, and Throat Department of Queen's Medical Centre in Nottingham. Thirty-seven individuals responded to these advertisements and were each posted a research pack.

4.4.2.3 Non-participation

Reasons for non-participation were also available for some potential participants. Ten individuals reported that they did not have hearing loss and/or they were only interested in tinnitus research. Two individuals did not have time to take part at present. One reported that their English language ability was not sufficient, one had been diagnosed with dementia, and one was now deceased.

4.4.2.4 Recruitment Response

The questionnaire booklet was completed and returned by 295 individuals. The majority were recruited via the BRU participant database (N=227, 76.95%). This represents a response rate of 60.21% for the database. The PICs recruited 40 individuals (13.56%) in total, with the Nottingham PIC recruiting 30 individuals (10.17%) and the Birmingham PIC recruiting 10 individuals (3.39%). Twenty-eight individuals (9.49%) were recruited through advertisements, primarily via the Action on Hearing Loss website.

Ultimately, 16 participants were excluded from the data analysis. Some reported that they did not have hearing loss (N=6) or that they had a

profound hearing loss (N=3). Some provided a majority (>50%) of 'Does not apply to me' or blank responses to the SPaRQ2.0 (N=7).

4.4.3 Materials

The participants were provided with the following questionnaires to complete in order to obtain data for the assessment of the psychometric properties of the SPaRQ2.0. The goal was to determine whether alterations, such as item removal, were required to improve these properties.

4.4.3.1 Second prototype of the social participation restrictions questionnaire (SPaRQ2.0)

The SPaRQ2.0 (see Appendix G) contained 53 items divided into three sections: 26 behaviour items, 16 emotion items, and 11 identity items. The measure had an 11-point, agree/disagree response scale, ranging from 'Completely Disagree' at point zero to 'Completely Agree' at point ten. Respondents were informed that they could select a 'Does not apply to me' option for any question that is not at all relevant to them. The inclusion of this option ensured that respondents were not forced to provide answers to items that do not apply to them and it highlights items that are not relevant to a large number of participants. The questionnaire also instructs respondents who normally wear a hearing aid to answer as if they are wearing the hearing aid. This approach was chosen because it is likely to be difficult for participants who have worn hearing aids for many years to provide answers based on not wearing hearing aids and doing so would diminish the validity of their responses.

At the end of the questionnaire, an additional item asks: "Approximately how often do you wear a hearing aid? Please tick one box", which is followed by

three response options: '*Everyday*', '*Sometimes*' and '*Never*'. This item collects important contextual information, as hearing aid use could influence participants' responses to the questionnaire.

4.4.3.2 Hearing loss screening questionnaire

It was beyond the scope of this research, both in terms of the resources and the timeframe of the study, to perform audiometry on the participants or to obtain their existing audiograms from their local audiology clinic. Two items from the hearing loss screening questionnaire, described in Chapter 3, provided a cost-effective, efficient, and accessible alternative for assessing hearing ability (Davis et al., 2007).

4.4.3.3 Demographics questionnaire

The participants completed a brief demographics questionnaire that had been composed by the author (see Chapter 3).

4.4.4 Study procedure

The participants took part in this study from home or a location of their choice. They each received a research pack in the post from the author or in person from their audiologist at their clinic appointment. The pack contained an invitation letter, a study information sheet, a questionnaire booklet, and a pre-paid return envelope. Participation involved completing the questionnaire booklet at their own pace, taking as many breaks as needed. Completion and return of the booklet served as implicit consent to participate in the study. The author was available to answer queries via email or telephone during the course of the study. For instance, some participants were unsure whether they should still complete the questionnaires as, although they had hearing loss, they regarded it as quite mild or not particularly bothersome.

Other participants wanted to know more information about the purpose of the study and its potential outputs. It was estimated, based on information provided by a small number of participants, that participation in the study lasted a maximum of two hours. The participants were given the opportunity to be entered into a prize draw for a chance to win one of six gift vouchers (1x£100, 5x£50) and to receive a summary of the results of the study. All of the obtained documentation and data were treated confidentially and stored securely in either locked filing cabinets or on password-protected computers in the Nottingham Hearing BRU.

4.5 DATA ANALYSIS

The data were organised using Microsoft Excel 2010 and analysed using IBM SPSS Statistics for Windows Version 22.0 and the Rasch Unidimensional Measurement Models software program, known as RUMM2030 (Andrich et al., 2010). The statistical analyses performed are described in detail below. This detail is designed to guide the reader through the forthcoming results sections.

4.5.1 Traditional psychometric analysis

4.5.1.1 Exploratory factor analysis

Exploratory factor analysis (EFA) was used to provide information about the potential factor structure of the SPaRQ2.0 and to inform the Rasch analysis that was subsequently performed. EFA is a multivariate statistic that uses the matrix of correlations or co-variances amongst the items to identify a more general group of latent dimensions, or factors, which explain the item co-variances. Specifically, a cluster of strong correlations between a subset of items suggest that those items are measuring the same underlying

dimension (De Vet et al., 2011; Field 2009; Floyd and Widaman 1995; Raykov and Marcoulides 2011). EFA was determined to be more appropriate for this research than alternative statistics. Specifically, EFA was used rather than confirmatory factor analysis (CFA) because EFA is suited to questionnaire development, when it is difficult to make accurate predictions about the factor structure of the measure, whereas CFA is suited to questionnaire validation, when existing information on the factor structure of the measure is available (De Vet et al., 2011). EFA was used rather than Principal Component Analysis (PCA) because PCA is a data reduction method, rather than a true factor analysis method, and therefore it is not appropriate for questionnaire development (Costello and Osborne 2009; Reise, Waller and Comrey 2000).

EFA was performed in accordance with best practice recommendations in the literature, as summarised below (Costello and Osborne 2009; Fabrigar et al., 1999; Field 2009; Floyd and Widaman 1995; Raykov and Marcoulides 2011; Reise, Waller and Comrey 2000; Tabachnick and Fidell 2001; Williams, Brown and Onsman 2012). Firstly, pairwise deletion was selected to ensure that the sample size was adequate and that important information was not lost. This meant that participants with missing scores were included in analyses relating to the items that they had answered and excluded from analyses relating to the items they had not answered. Secondly, the principal axis factors extraction method was used, as the SPaRQ2.0 data were not normally distributed ($W=0.962$, $DF=279$, $p<.001$). Thirdly, the oblique rotation method, which allows factors to correlate, was used to aid the interpretation

of the factor structure. Oblique rotation was chosen because the In SPaRQ2.0 was predicted to comprise correlated factors.

Next, the number of factors to be extracted was determined. The procedure used in this study was to examine the scree plot, which contains the number of dimensions on the x-axis and the corresponding eigenvalues on the y-axis. Eigenvalues are the percentage of variance accounted for by a factor. The number of factors to be extracted is the number of eigenvalues located before the so called 'elbow-point' of the plot, or the point at which there is a considerable decrease in the magnitude of the eigenvalues. The results of this approach were cross-checked with the results of another approach: extracting the smallest number of factors with the highest eigenvalues that cumulatively explain at least 70% of the variance. The decisions surrounding factor extraction were also informed by the conceptual framework devised in the previous chapter.

Subsequently, several statistics were inspected to ensure that the SPaRQ2.0 data were suited to EFA. The Kaiser Meyer Olkin (KMO) measure of sampling adequacy was examined to ensure that the sample size was appropriate for EFA. The KMO value should be, as a minimum, 0.5 and, ideally, 0.8 or above. Sampling adequacy was further confirmed by ensuring that all of the diagonal values in the anti-image correlation matrix were greater than 0.5. In addition, the communality of each item was inspected, as consistently low communalities require a high sample size. Also, the Bartlett test of Sphericity was carried out to ensure that the data were suitable for

EFA. A significant test is desirable, as this shows that the correlation matrix is not an identity matrix.

Finally, the pattern matrix and the structure matrix were examined in conjunction with one another as a means of exploring the potential factor structure of the SPaRQ2.0. The pattern matrix displayed the factor loadings for each item. Ideally, each item should have a factor loading of at least 0.3 for a single factor. The items should be free of cross-loading, which occurs when items have factor loadings of at least 0.3 for more than one factor. In order to be considered stable, each factor should have a minimum of five items that each have a factor loading of at least 0.5. The structure matrix showed the relationship between each item and each factor. Ideally, each item should be strongly related to one factor and weakly related to the other factors. In addition, the percentage of the variance explained and the eigenvalue for each factor were examined.

4.5.2 Rasch analysis

Rasch analysis was conducted in accordance with the best practice recommendations from the literature (Hagquist 2001; Hobart and Cano 2009; Pallant and Tennant 2007; Smith 2002; Tennant and Pallant 2006; Tennant and Conaghan 2007; van der Velde et al., 2009; Yorke, Horton and Jones 2012). These recommendations are summarised below.

4.5.2.1 Test of fit to the Rasch model

A fundamental component of Rasch analysis is testing the fit of the data to the Rasch model. The Rasch model uses the total score for persons (i.e. the sum of the scores of the items each participant answers) and the total score

for items (i.e. the sum of the scores of the participants who responded to each item) to obtain estimates of person difficulty (e.g. the level of social participation restrictions present in the sample) and item difficulty (e.g. the level of social participation restrictions captured by the items). These estimates are then used to obtain the predicted responses that should have occurred for the items and persons to satisfy the Rasch model. The predicted responses derived from the Rasch model are then compared to the observed responses from the participants. Observed responses are the actual answers provided by the participants. Rasch analysis uses multiple indicators to assess fit to the Rasch model, or the degree of difference between the predicted and observed responses. In any Rasch analysis, some level of misfit is to be expected. What must be determined is how much misfit is present and how problematic it is. The indicators of fit used in this study were those provided by RUMM2030: the fit residual, the chi-squared value, and the item characteristic curve.

A **fit residual** is calculated for each individual item and summarises the interaction between the item and all persons who respond to that item. In other words, an item fit residual is a summary of the differences between observed scores and predicted scores for every response to that item. The differences between observed and predicted scores are squared, summed and transformed to obtain a summary score: the fit residual. Fit residuals are standardised, which means that they are expected to have a normal distribution with a mean of zero and a standard deviation of one. Therefore, in order for the data to fit with the Rasch model, the mean fit residual for all of the items together should be close to zero, with a standard deviation

approaching one. The fit residuals of individual items should fall within the range of -2.5 and 2.5. Over-discriminating items have negative fit residuals, whereas under-discriminating items have positive fit residuals. Over-discrimination is observed when participants with little difficulty score too low and participants with a severe difficulty score too high. Under-discrimination is observed when participants with little difficulty score too high and participants with severe difficulty score too low. In this study, fit residuals for individual items were used as one indicator of whether or not that item should be removed from the SPARQ2.0. The overall item fit residual was used as one indicator of whether or not the questionnaire data fit the Rasch model.

The **chi-squared value** is another indicator of goodness of fit. In Rasch analysis, the sample is divided into several groups, known as class intervals, based on their level of difficulty (i.e. the participants' level of social participation restrictions). The chi-square statistic compares the differences between observed scores and predicted scores for each class interval across the construct being measured (i.e. social participation restrictions). For an individual item, the chi-square values for each class interval are summed to give an overall chi-square value for that item. A chi-square value that is statistically significant, following the application of the Bonferroni correction, indicates that there is a large difference between observed and predicted scores for that item and thus that it has poor fit. An overall chi-square value is also calculated. A significant overall chi-square test indicates that the property of invariance has been compromised, as there is variation in the hierarchical ordering of items across the latent trait. In this study, the chi-

square values for individual items were used as one indicator of whether or not that item should be removed from the SPARQ2.0. The overall chi-square test was used as one indicator of whether or not the questionnaire data fit the Rasch model.

Item characteristic curves are graphical fit indicators. They were used in this study to assist with the interpretation of the fit residuals and chi-squared values in order to determine whether or not particular items should be removed from the SPARQ2.0. A graph is produced for each item, which plots the predicted response to an item on the y-axis against the person location on the difficulty continuum (i.e. level of social participation restrictions) on the x-axis. In RUMM2030, black dots on the graph represent the intersection between the mean item score for each class interval and the mean person location on the difficulty continuum for each class interval. Close alignment between these dots and the item characteristic curve indicate good fit between the observed and predicted data. The item characteristic curve can highlight whether an item is over-discriminating (i.e. steeper line than expected) or under-discriminating (i.e. flatter line than expected).

4.5.2.2 Test of local independence

Local independence is one of the primary assumptions of the Rasch model. Local independence means that once the Rasch factor (i.e. the main scale) has been extracted from the data, there should be no remaining patterns or meaningful clusters in the residuals. Therefore, after controlling for the underlying dimension, the response to one item should not be dependent on the responses to the other items. The residuals are the standardised differences between observed scores and predicted scores for every

person's response to every item. The assumption of local independence is violated when response dependency and multidimensionality are detected.

Response dependency occurs when the response to one item is dependent on the response to another item in the same questionnaire. For example, the answer to an item about socialising several times a week is dependent on the answer to an item about socialising once a week. Response dependency is undesirable as it artificially inflates internal consistency reliability and it affects parameter estimation in Rasch analysis. Also, if a total score is to be obtained by adding the item scores together, response dependency means that the concept measured by the redundant items is given a greater weight than it deserves in the total score. Response dependency is typically assessed by examining the residual correlation matrix in order to ensure that the residuals are not strongly correlated with one another. In particular, residual correlations equal to or greater than 0.2 should be examined. In this study, the residual correlation matrix was examined to identify items or clusters of items that displayed response dependency. These items were removed from the questionnaire. If dependent items are retained in the questionnaire, it is necessary to create a testlet or super-item by summarising the scores of the dependent items.

Another crucial component of local independence is **unidimensionality**. The Rasch model assumes that the items in the measure, when summed together, form a unidimensional scale, rather than a multidimensional scale. This means that the scale measures a single underlying construct, rather than several underlying constructs. In this study, unidimensionality was assessed by using a test that has been incorporated into the RUMM2030

software program. This test involves by performing a PCA of the residuals. There should be no relationships between the residuals, aside from random relationships, once the Rasch factor has been extracted. The presence of a meaningful, rather than random, pattern in the residuals suggests that the assumption of unidimensionality has been violated. This can be robustly tested by creating two sets of items, with one set containing items that have the highest positive PCA loadings on the first residual factor and another set containing items that have the highest negative PCA loadings on the first residual factor. These two item sets are used to form separate person estimates. Subsequently, a series of t-tests are used to determine whether there is a significant difference in the estimates for each person (i.e. a significant difference in the social participation restriction levels). The percentage of tests that fall outside of the range -1.96 to 1.96 should be no greater than 5%. A Binomial Proportions Confidence Interval is calculated for this percentage. If the lower confidence interval overlaps 5%, the test is non-significant and the unidimensionality of the questionnaire is confirmed. In this study, this test was performed to ascertain whether or not the SPARQ2.0 formed a unidimensional measure.

4.5.2.3 Assessment of differential item functioning

Differential Item Functioning (DIF) is a form of item bias that is detected when different participant groups who, despite having the same degree of overall difficulty, display different response patterns to an item. For example, gender DIF occurs when men and women have different scores on an item measuring an aspect of social participation restrictions, despite having the same overall level of social participation restrictions. Uniform DIF is present

when there is a significant main effect for the relevant characteristic (e.g. gender), which means that the differences between the relevant groups (e.g. men and women) are consistent across different class intervals. Non-uniform DIF is present when there is a significant interaction effect, which means that the differences between the relevant groups vary across the different class intervals. Not only is DIF indicative of item bias, the presence of DIF can affect the fit to the Rasch model. In Rasch analysis, DIF is assessed graphically and statistically. An analysis of variance is conducted for each item, comparing scores across each level of the relevant characteristic and across levels of the underlying construct (i.e. across class intervals). In this study, gender DIF and age group DIF were assessed. Items that displayed such DIF were candidates for removal from the SPARQ2.0.

4.5.2.4 Assessment of threshold ordering

Rasch analysis was used to assess the threshold ordering of the 11-point response scale in the SPARQ2.0. In this questionnaire, an increase in the response options from zero to ten should represent an increase in the underlying dimension: social participation restrictions. Therefore, participants with a high level of this underlying dimension should endorse high scoring response options. If the participants do not select response options in a manner consistent with the level of the underlying dimension being measured, the thresholds are said to be disordered. A threshold refers to the transition point between two response options where either response option is equally probable. Hence, each item in the SPARQ2.0 has 11 response options and ten thresholds. An example of disordered thresholds on this would be if the transition between response options one and two represented

a higher level of social participation restrictions than the transition between response options three and four.

Rasch analysis was used to identify items with disordered thresholds.

Specifically, category probability curves for each item highlighted whether or not each response option systematically, in turn showed the highest probability of being endorsed. Disordered thresholds can affect fit to the Rasch model and indicate that the response scale may be confusing or difficult to use. One means of restoring order is to collapse response categories. For example, an 11 point response scale could be transformed into an eight point response scale in order to resolve disordered thresholds.

4.5.2.5 Assessment of targeting

Rasch analysis was used to assess the targeting of the SPARQ2.0. This refers to the match between the range of difficulty measured by the scale and the range of difficulty present in the sample. A high level of match indicates a high level of measurement precision in the scale. Therefore, for a scale to be well-targeted, the mean location of the items, which is always zero, should be close (e.g. 0.5 logits) to the mean locations of the persons. A positive mean person location value indicates that the sample has a higher level of difficulty than the average of the scale, whilst a negative mean person location value indicates that the sample has a lower level of difficulty than the average of the scale. In this study, targeting was examined using the mean person location, as well as the person-item threshold distribution graph produced by RUMM2030. This graph compares the distribution of the items to the distribution of the persons.

4.5.2.6 Assessment of person separation reliability

The Person Separation Index (PSI) produced by RUMM2030 is a reliability index that quantifies the extent to which the scale detects differences between individuals in the study sample. In other words, it measures the ability of the scale to reliably separate respondents in the sample. It can be considered as the Rasch analysis equivalent of Cronbach's alpha, as it is calculated in the same manner as Cronbach's alpha but replaces participants' raw scores with logit scale estimates derived from Rasch analysis. The PSI is calculated as the variation among person locations relative to the error estimate for each individual. It is therefore sample-dependent, rather than a property of the scale itself. It ranges from zero to one and a minimum value of 0.7 is required for group use and 0.85 for individual use. It is thought that a value of 0.8 means that the questionnaire can distinguish between three distinct strata of person disability, whilst a value of 0.9 means that the questionnaire can distinguish between four distinct strata of person disability.

4.5.2.7 Assessment of person fit

An important aspect of Rasch analysis is assessing person fit, or examining whether there are any participants who have unusual responses that deviate from the predictions of the Rasch model. This is achieved by examining the person fit residual, which is a value that summarises the residuals from each individual's answers to each item in the scale. High, positive fit residuals are particularly indicative of individuals with response patterns that do not align with the predictions of the Rasch model. Unusual responses can occur for various reasons, such as an unmeasured comorbidity (e.g. cognitive

deficits). It may be necessary to exclude such participants, as they can detrimentally affect item fit.

4.6 INITIAL DATA SCREENING

This section describes the data screening carried out prior to EFA.

4.6.1.1 Management of missing scores

Participants with missing scores were contacted and asked to complete any questions that they had left unanswered. Following this process, 11 participants (3.94%) still had missing scores for the SPARQ2.0. Of the 53 items in the measure, 43 items each had between one and four missing scores. One method of handling a missing score is to replace it with the mean score of the relevant participant, which is calculated from the items that the participant did complete. However, this approach relies on the assumption that a participant's average score on the answered items represents how they would have responded to the unanswered item and that the answered items assesses the same level of difficulty as the unanswered item. Therefore, it is preferable to only use scores from items that have been answered (Hobart and Cano 2009). As such, missing scores were not replaced with another value.

In addition to missing data, 175 participants (62.72%) selected the '*Does not apply to me*' option for at least one item. Of the 53 items in the SPARQ2.0, 48 had 1-15 '*Does not apply to me*' responses. An additional three items had 47-118 '*Does not apply to me*' responses. '*Does not apply to me*' responses were treated in the same manner as missing scores, such that they were not replaced with another value.

4.6.1.2 Removal of Items

It is recommended that items with more than 15% missing scores should be considered for deletion, as missing scores are indicative of serious flaws, including irrelevance, ambiguity, and intrusiveness (De Vet et al., 2011). A substantial number of participants (N=120, 43.01%) selected '*Does not apply to me*' or did not respond to Item 15 ('*Because of my hearing loss, I find it difficult to: Take part in conversations with people in my workplace, such as co-workers, managers or clients*'). Similarly, a large number of participants (N=70, 25.09%) chose '*Does not apply to me*' or did not answer Item 18 ('*Because of my hearing loss, I find it difficult to: Take part in educational activities or training activities*'). Clearly, these items are not relevant to many individuals with hearing loss and are likely to attract a high number of non-responses or invalid responses in future administrations of the questionnaire. Therefore, these items were removed from the questionnaire, prior to any further statistical analyses. The salient content of these questions (i.e. participation in professional and educational activities) was not lost from the questionnaire, as it was captured by Item 8, Item 12, and Item 17.

Item 7 ('*Because of my hearing loss, I find it difficult to: Take part in activities or events with community, voluntary or religious organisations*') also attracted a large number of '*Does not apply to me*' answers and missing scores (N=49, 17.56%). However, this item was potentially more relevant than Items 15 and Item 18 and it contained unique content that was not captured by the remaining items. Therefore, this item was retained until Rasch analysis could be used to determine whether it should be removed from the questionnaire.

4.7 EXPLORATORY FACTOR ANALYSIS RESULTS

Several statistics demonstrated that it was appropriate to conduct EFA on the SPARQ2.0 data. Specifically, the Bartlett's Test of Sphericity was significant ($\chi^2(1275)=14481.65$, $p<.001$), leading to the rejection of the null hypothesis that the original correlation matrix is an identity matrix. In support of the adequacy of the sampling, the KMO value was 0.967, the diagonal values of the anti-image correlation matrix were all greater than 0.5, and the communalities were all above 0.6. Also, the inter-item correlations fell within the range of 0.3 and 0.89.

An examination of the percentage of variance explained by each factor (see Table 4.3) and the scree plot (see Figure 4.1) showed that the first factor was by far the most substantial, as it explained 62.15% of the variance (eigenvalue=31.89). Cumulatively, the first three factors explained 72.03% of the variance, which is above the 70% threshold selected for factor extraction in this study (see 'Data analysis' section). However, the scree plot indicated that the fourth factor was a potential candidate for extraction, though it only explained 2.34% of the variance (eigenvalue=1.39). Therefore, the EFA was repeated with the specification that four factors should be extracted.

The variance explained by the four factor solution was 73.89%, with Factor 1 alone explaining 62.02% of the variance. The first three factors appeared to be stable, as they each contained a minimum of five items that had a loading of at least 0.5 for that factor and that did not cross-load with any other factor. However, the fourth factor contained only three items with factor loadings of at least 0.5 and those items cross-loaded onto Factor 2. This demonstrated

that Factor 4 was not a stable factor. Therefore, the EFA was repeated with the specification that three factors should be extracted.

Table 4.3 Eigenvalues and percentage of variance explained

EFA	Factor	Eigenvalue	% of Variance	Cumulative %
Initial EFA	1	31.89	62.15	62.15
	2	3.1	5.68	67.82
	3	2.34	4.21	72.03
	4	1.39	2.34	74.37
EFA with 4 factors	1	31.89	62.02	62.02
	2	3.10	5.55	67.58
	3	2.34	4.09	71.66
	4	1.30	2.22	73.89
EFA with 3 factors	1	31.89	61.98	61.98
	2	3.10	5.51	67.49
	3	2.34	4.04	71.53

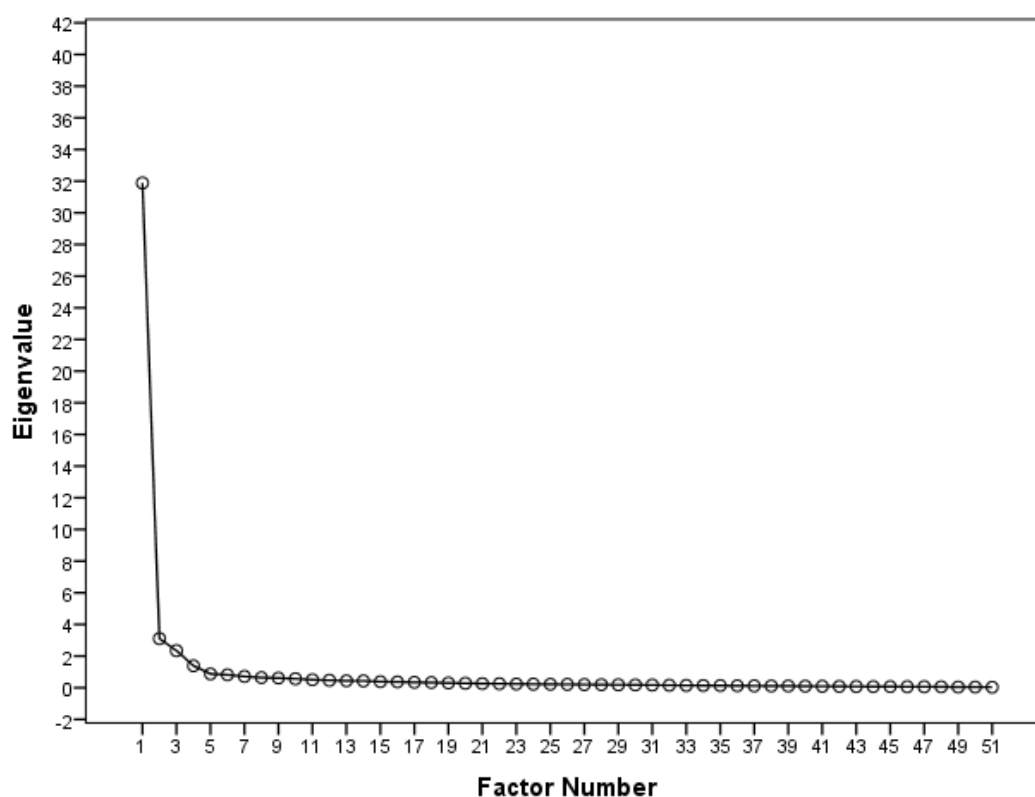


Figure 4.1 Exploratory factor analysis scree plot

The variance explained by the three factor solution was 71.53%, with Factor 1 alone explaining 61.98% of the variance. The factors had strong correlations with one another (see Table 4.4). In total, 14 items cross-loaded onto two factors. These items are shown in red font in Tables 4.5 and 4.6.

Table 4.4 Factor correlation matrix

Factor	1	2	3
1	1	0.706	0.728
2	0.706	1	0.694
3	0.728	0.694	1

Twenty-seven items loaded onto Factor 1, all of which were originally emotion and identity items (see Tables 4.5 and 4.6). Seventeen of these items loaded onto Factor 1 alone, with loadings ranging from 0.62 to 0.951, which confirms the stability of this factor. This factor was named the social perceptions factor.

Twenty items loaded onto Factor 2 (see Tables 4.5 and 4.6). Eleven of these items loaded onto Factor 2 alone, with loadings ranging from 0.522 to 0.975, which confirms the stability of this factor. These 11 items were all originally behaviour items.

Eighteen items loaded onto Factor 3 (see Tables 4.5 and 4.6). Nine of these items loaded onto Factor 3 alone, with loadings ranging from 0.582 to 0.855, which confirms the stability of this factor. These nine items were all originally behaviour items.

Table 4.5 Factor 1 pattern matrix and structure matrix

Item	Pattern matrix factors			Structure matrix factors		
	1	2	3	1	2	3
49	0.951	-0.025	-0.102	0.859	0.576	0.573
51	0.888	-0.058	0.051	0.884	0.605	0.657
39	0.854	-0.081	0.117	0.882	0.603	0.682
45	0.85	0.003	-0.186	0.716	0.474	0.435
40	0.847	0.1	-0.073	0.864	0.648	0.613
48	0.831	-0.046	0.006	0.803	0.545	0.579
38	0.823	-0.23	0.275	0.861	0.543	0.715
44	0.811	-0.012	0.046	0.835	0.592	0.627
47	0.8	0.074	-0.047	0.819	0.607	0.587
35	0.787	-0.11	0.19	0.847	0.578	0.686
43	0.76	-0.004	0.13	0.853	0.624	0.681
46	0.739	0.138	-0.081	0.777	0.603	0.552
32	0.701	-0.101	0.326	0.867	0.62	0.766
31	0.701	-0.048	0.179	0.798	0.572	0.657
37	0.688	0.252	-0.005	0.863	0.735	0.671
53	0.633	0.295	-0.13	0.747	0.652	0.536
42	0.621	-0.088	0.295	0.773	0.555	0.685
52	0.62	0.275	-0.046	0.781	0.681	0.597
34	0.611	0.448	-0.167	0.807	0.765	0.59
41	0.598	0.367	-0.026	0.839	0.772	0.664
30	0.596	0.008	0.384	0.881	0.695	0.823
33	0.586	0.437	-0.108	0.817	0.776	0.622
36	0.564	0.501	-0.091	0.852	0.837	0.668
28	0.547	0.096	0.337	0.86	0.716	0.802

An examination of the item content of Factor 2 and Factor 3 (see Table 4.7) indicates that Factor 3 concerns specific tasks, especially tasks relating to listening in challenging environments, while Factor 2 concerns broader social interactions and roles. It may be that Factor 3 measures activity limitations, whilst Factor 2 measures participation restrictions.

Table 4.6 Factor 2 and factor 3 pattern matrix and structure matrix

Item	Pattern matrix factors			Structure matrix factors		
	1	2	3	1	2	3
20	-0.033	0.975	-0.09	0.591	0.89	0.563
26	0.03	0.928	-0.152	0.575	0.844	0.514
17	-0.004	0.852	0.009	0.604	0.855	0.597
24	-0.029	0.849	0.042	0.602	0.858	0.61
21	0.131	0.844	-0.085	0.666	0.878	0.597
10	-0.211	0.766	0.235	0.501	0.78	0.613
9	-0.156	0.721	0.222	0.515	0.765	0.609
19	0.053	0.641	0.252	0.689	0.854	0.736
11	0.122	0.561	0.21	0.672	0.793	0.689
6	-0.022	0.55	0.323	0.602	0.759	0.689
25	0.169	0.541	0.2	0.697	0.8	0.699
22	0.267	0.522	0.094	0.704	0.776	0.651
7	-0.086	0.52	0.499	0.644	0.805	0.797
50	0.307	0.465	-0.011	0.628	0.674	0.535
23	0.264	0.361	0.317	0.749	0.767	0.759
8	-0.054	0.113	0.855	0.649	0.669	0.895
2	-0.11	0.066	0.835	0.544	0.568	0.801
3	-0.058	0.068	0.835	0.597	0.606	0.839
1	0.182	-0.248	0.82	0.604	0.45	0.78
4	-0.031	0.103	0.799	0.624	0.636	0.849
12	0.124	0.093	0.732	0.723	0.689	0.887
5	-0.131	0.232	0.721	0.558	0.64	0.787
13	0.089	0.172	0.693	0.715	0.715	0.877
27	0.422	-0.229	0.66	0.74	0.527	0.808
16	0.071	0.289	0.582	0.699	0.743	0.834
14	0.037	0.369	0.537	0.689	0.768	0.821
29	0.471	0.007	0.474	0.821	0.669	0.822

The pattern matrix results were largely supported by the structure matrix results, as items that strongly loaded onto one factor in the pattern matrix also had a strong relationship with that factor in the structure matrix.

However, the structure matrix showed that many items had moderate to

strong relationships with several factors, rather than being strongly related to one factor and weakly related to the remaining factors.

Table 4.7 Factor 2 and factor 3 item content

Item	Factor 2 abbreviated content
9	Use public transportation
10	Discuss health with healthcare professional
11	Manage stressful and challenging situations
17	Manage home, work or social responsibilities
19	Attend get-togethers with friends
20	Go out with significant other
21	Attend family get-togethers
22	Attend large social gatherings
24	Conversations with significant other
25	Conversations at family get-togethers
26	Get along with people who are close to me
Item	Factor 3 abbreviated content
1	Take part in conversations in background noise
2	Conversation on telephone
3	Watch television with other people
4	Watch live events and shows
5	Listen to radio or recorded music
8	Follow talk or lecture
12	Take part in a group discussion or meeting
13	Conversations with unfamiliar people
16	Talk with staff in shops, cafes or banks

4.8 FURTHER DATA SCREENING

This section describes the data screening carried out to facilitate Rasch analysis.

4.8.1 Choice of model derivation

There are two mathematical derivations of the Rasch model for polytomous data: the Rating Scale Model (Andrich, 1978) and the Partial Credit Model

(Masters, 1982). The Rating Scale Model assumes that there is a common rating scale structure across all items, whereas the Partial Credit Model assumes that each item has an individual rating scale structure. In other words, the former assumes that the distances between response options vary within an item but not across items, whilst the latter assumes that the distances between response options vary within and across items. In this study, a statistically significant log-likelihood ratio test demonstrated that the assumptions of the Rating Scale Model did not hold, leading to the use of the Partial Credit Model (Lundgren Nilsson and Alan Tennant, 2011).

4.8.2 Division of items

The EFA results indicated that the SPaRQ2.0 is multidimensional, rather than unidimensional. Initially, Rasch analysis was performed on the full set of 51 items in order to confirm this result. It was demonstrated that the full SPaRQ2.0 failed the test of unidimensionality by a considerable margin (percentage of significant t-tests=16.97%). The questionnaire also had poor fit to the Rasch model, as demonstrated by a significant overall chi-square test ($\chi^2=446.85$, $DF=153$, $p<.001$) and the overall item fit residual ($M=0.45$, $SD=2.53$). Even after the iterative removal of 17 items, the questionnaire still failed the test of unidimensionality by a substantial margin (percentage of significant t-tests=18.05%) and continued to have poor fit to the Rasch model, which was evidenced by the significant overall chi-square test ($\chi^2=163.92$, $DF=102$, $p<.001$) and the overall item fit residual ($M=0.32$, $SD=1.92$). This confirmed that the questionnaire as a whole is multidimensional rather than unidimensional.

It was decided that the questionnaire should be divided into two item sets and that Rasch analysis should be conducted separately on each set. The first set, the social behaviours set, contained all of the remaining 24 behaviour items (Item 1-Item 26). The second set, the social perceptions set, contained the 27 emotion and identity items (Item 27-Item 53). The aim was to investigate whether a unidimensional subscale could be derived from the social behaviours set and whether a second unidimensional subscale could be obtained from the social perceptions set. This would produce a questionnaire comprised of two related but distinct subscales. The emotion and identity items were grouped together because the EFA showed that these items loaded together onto a single factor. The behaviour items were grouped together in one set, despite the EFA indicating that they loaded onto two factors. This decision was based on the results of the earlier qualitative studies and the literature review (see Chapter 3), which led to the conceptualisation of behaviour as a single domain or factor. It was decided that Rasch analysis would be used to remove any behaviour items that did not fit within this domain, such as items that assessed activity limitations (e.g. listening difficulties), rather than participation restrictions (e.g. social withdrawal).

4.8.3 Removal of participants

It has previously been shown that a few participants who display an abnormal response pattern can have a detrimental impact on Rasch analysis results, particularly item fit (Tennant and Conaghan 2007). Therefore, the person fit statistics were examined to identify whether any participants should be removed from the data analysis based on having a high positive fit

residual (≥ 3), which is indicative of an aberrant response pattern. This led to the removal of nine participants from the social behaviours analysis, with 270 participants remaining (see Table 4.8).

Table 4.8 Participants removed from the social behaviours item analysis

Index	Location	Fit residual	Gender	Age group (years)	Hearing aid use
1	0.62	5.01	Male	70-79	Every day
2	1.28	4.78	Female	60-69	Every day
3	0.32	4.77	Female	60-69	Sometimes
4	0.86	4.58	Male	70-79	Sometimes
5	0.3	4.54	Male	80-89	Every day
6	1.13	3.66	Female	80-89	Every day
7	0.37	3.34	Female	60-69	Every day
8	0.39	3.22	Male	70-79	Sometimes
9	0.12	3.12	Female	70-79	Every day

Similarly, 11 participants were removed from the social perceptions analysis, with 268 participants remaining (see Table 4.9). The Rasch analysis was then repeated on the data from all 279 participants, including those with unusual response patterns, to examine whether or not there were any substantial discrepancies between the findings of the analysis excluding these individuals and the findings of the analysis including these individuals. Little impact of influential outliers was observed.

In addition, Rasch analysis normally automatically excludes respondents who are situated at the extreme ends of the scale (i.e. respondents who display floor or ceiling effects) from the calculation of item statistics. These individuals obtain the same score on all items and therefore do not contribute to the examination of relative item difficulty. In the social behaviours analysis,

the RUMM2030 software automatically removed six participants with extreme scores from the estimation of item statistics, resulting in 263 remaining participants. In the social perceptions analysis, the RUMM2030 software automatically removed ten participants with extreme scores from the estimation of item statistics, resulting in 258 remaining participants. These sample sizes remained in line with the published recommendations (Chen et al., 2013).

Table 4.9 Participants removed from the social perceptions item analysis

Index	Location	Fit residual	Gender	Age group (years)	Hearing aid use
1	-0.21	4.28	Male	80-89	Every day
2	-0.76	4.14	Male	18-59	Every day
3	1.24	3.87	Female	80-89	Every day
4	0.23	3.84	Female	70-79	Never
5	0.07	3.66	Male	80-89	Sometimes
6	-0.15	3.5	Female	70-79	Every day
7	1.85	3.46	Male	70-79	Every day
8	0.87	3.27	Female	60-69	Sometimes
9	-0.11	3.22	Male	80-89	Every day
10	0.4	3.15	Male	60-69	Sometimes
11	0.23	3.08	Female	60-69	Every day

4.8.4 Management of missing scores

One of the strengths of Rasch analysis is that it has a means of handling missing data. The Rasch algorithm compares each observed score to a predicted score, based on the overall scaling model, and uses predicted score information when accounting for missing data (Prieto, Alonso and Lamarca 2003).

4.8.5 Class intervals

In Rasch analysis, the participants are automatically split into class intervals. Class intervals are obtained by ordering all of the participants according to their level of disability based on their responses to all of the items and then dividing them into several groups of roughly equal size. Several fit statistics are calculated at the class interval level (Tennant and Conaghan 2007; Yorke, Horton and Jones, 2011). For both the social behaviours set and the social perceptions set, there were four class intervals each containing approximately 60 participants.

4.9 RASCH ANALYSIS RESULTS

The results of the Rasch analysis performed on the social behaviours and social perceptions sets are reported below. This analysis involved iteratively deleting and, in some cases, re-introducing items until each set displayed the required psychometric properties, particularly good fit with the Rasch model and local independence. The primary aim was to develop two psychometrically sound subscales for the SPaRQ2.0.

4.9.1 Social behaviours set

4.9.1.1 Item reduction

Items that displayed poor fit or response dependency or both were removed from the set. Items were removed one at a time from the set, as item statistics alter each time an item is removed and therefore must be continually reviewed. The test of unidimensionality was performed repeatedly as items were removed from the set. The item reduction process ceased when a shortlist of items that displayed good fit and local independence was produced. In total, 16 items were removed from the set. For example, Item 4

(*'Because of my hearing loss, I find it difficult to: Watch live events and shows, such as plays, films, concerts or sports matches'*) was removed due to poor fit (item fit residual=2.91, $\chi^2=1.94$, DF=3, $p=0.585$), while Item 25 (*'Because of my hearing loss, I find it difficult to: Take part in conversations at family get-togethers'*) was removed due to response dependency, as it had positive residual correlations with four other items, ranging from 0.183 to 0.572. This iterative process resulted in an initial shortlist of ten items: Items 6, 8, 11, 12, 14, 16, 17, 19, 23, and 26.

4.9.1.2 First social behaviours shortlist

The shortlist passed the test of unidimensionality upon examination of the Binomial Proportions Confidence Interval (percentage of significant t-tests=5.08%). The residual correlations of the items were 0.2 or less (see Table 4.10), indicating that the shortlist was relatively unaffected by response dependency.

Table 4.10 First social behaviours shortlist: Residual correlation matrix

Item	6	8	11	12	14	16	17	19	23
8	-0.1								
11	-0.1	-0.2							
12	-0.3	0.1	-0.1						
14	-0.2	0.1	0.0	0.2					
16	-0.1	-0.1	-0.2	0.0	0.0				
17	0.0	-0.3	0.1	-0.3	0.0	-0.1			
19	-0.1	-0.2	-0.2	-0.1	-0.3	-0.1	-0.1		
23	-0.3	-0.2	-0.2	0.1	-0.2	-0.1	-0.3	0.1	
26	0.0	-0.2	-0.2	-0.3	-0.3	-0.2	0.1	0.0	0.0

Taken together, these results indicate that the shortlist was locally independent. In addition, the shortlist had acceptable fit to the Rasch model,

as shown by the overall item fit residual ($M=-0.00$, $SD=1.41$) and the overall chi-square test ($\chi^2=41.05$, $DF=30$, $p=.086$). Also, the overall person fit residual ($M=-0.39$, $SD=1.27$) was acceptable.

The shortlist had high person separation reliability, both including extreme scores ($PSI=0.919$) and excluding extreme scores ($PSI=0.932$). An examination of the person-item threshold distribution indicated that the shortlist was relatively well-targeted (see Figure 4.2), with the mean person location being -0.31 ($SD=1.28$). However, there were some individuals at the extreme ends of the scale who were not captured by the items.

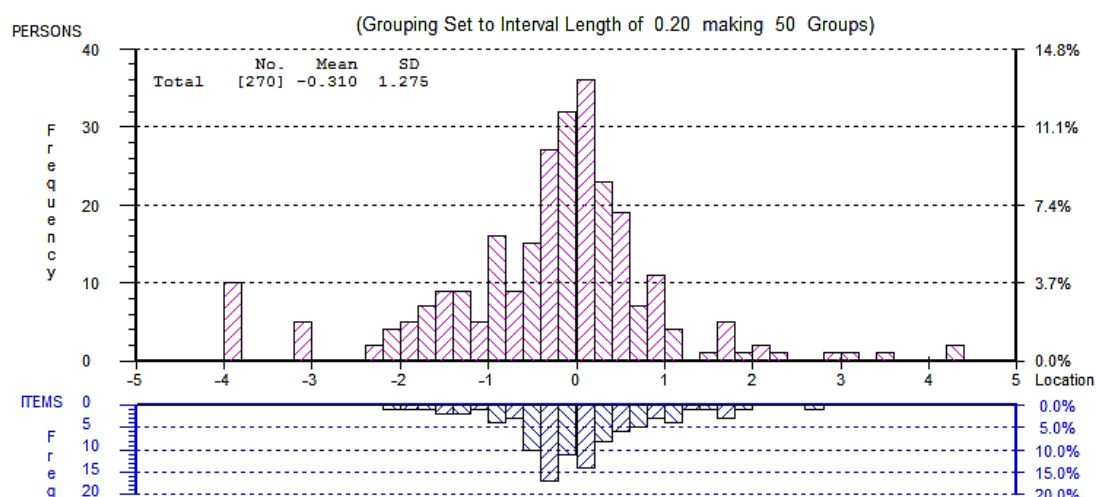


Figure 4.2 First social behaviour shortlist: Person-item threshold distribution (including extreme scores)

The individual items displayed good fit, with each one having a fit residual between the acceptable range of -2.5 and 2.5 (see Table 4.11). An example of one of these items, Item 17 (*'Because of my hearing loss, I find it difficult to: Manage my responsibilities in home life, social life or work life'*), is displayed in Figure 4.3 below.

Table 4.11 First social behaviours shortlist: Individual item fit statistics

Item	Location	Fit residual	DF	Chi-Sq	DF	Prob
6	0.34	2.12	216.84	2.87	3	0.412
8	-0.56	1.80	213.31	1.19	3	0.756
11	0.18	0.46	222.13	4.19	3	0.242
12	-0.55	-2.15	217.72	5.93	3	0.115
14	-0.18	-1.35	224.77	5.89	3	0.117
16	-0.24	0.14	223.89	1.61	3	0.658
17	0.44	-1.42	219.48	8.08	3	0.044
19	0.17	-0.73	220.36	3.17	3	0.367
23	-0.25	0.22	221.25	0.89	3	0.829
26	0.65	0.89	221.25	7.25	3	0.064

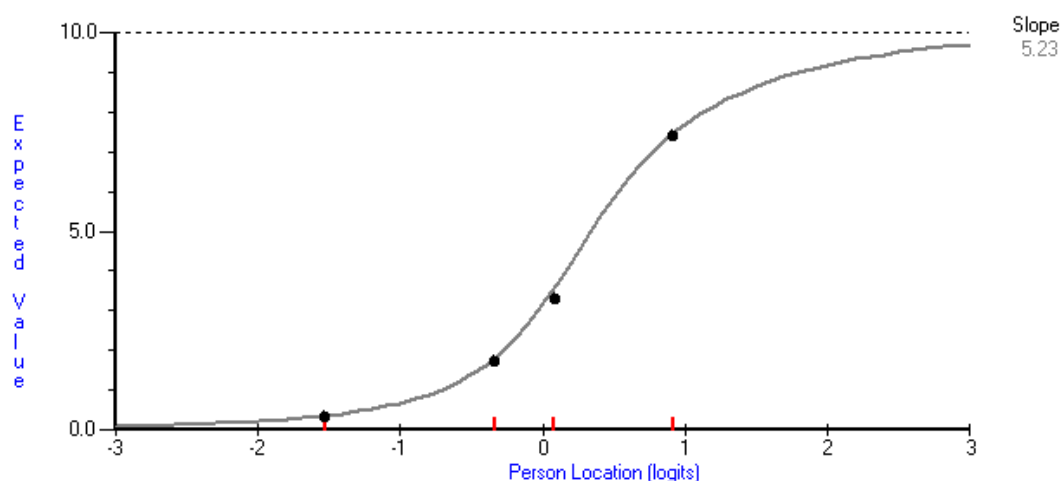


Figure 4.3 First social behaviour shortlist: Item characteristic curve for item 17

In terms of the response scale, an examination of the threshold map (see Figure 4.4) showed that all of the thresholds, with the exception of Item 26 (*‘Because of my hearing loss, I find it difficult to: Get along with people who are close to me (e.g. spouse, partner, close friend)’*), were ordered as expected. The disordered thresholds of Item 26 are displayed in Figure 4.5.

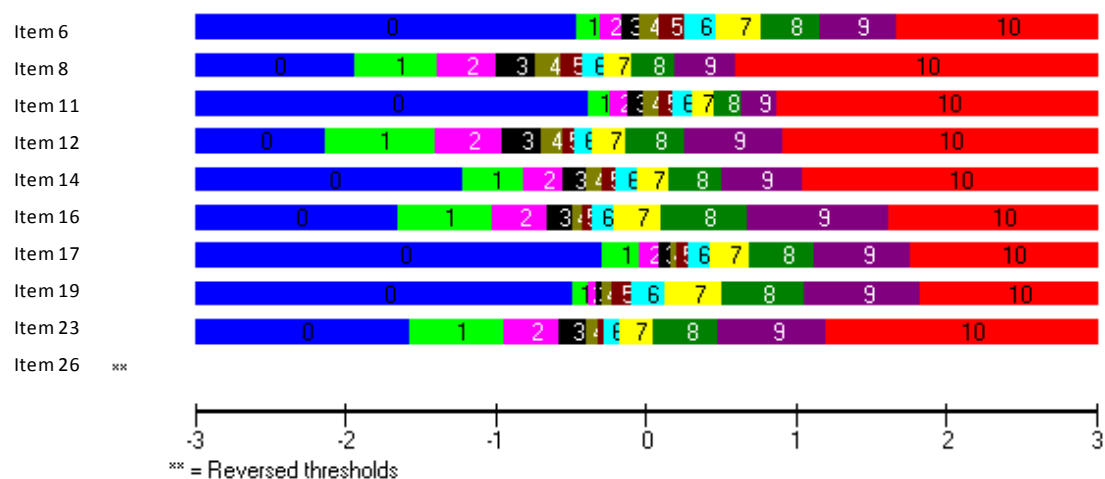


Figure 4.4 First social behaviours shortlist: Threshold map

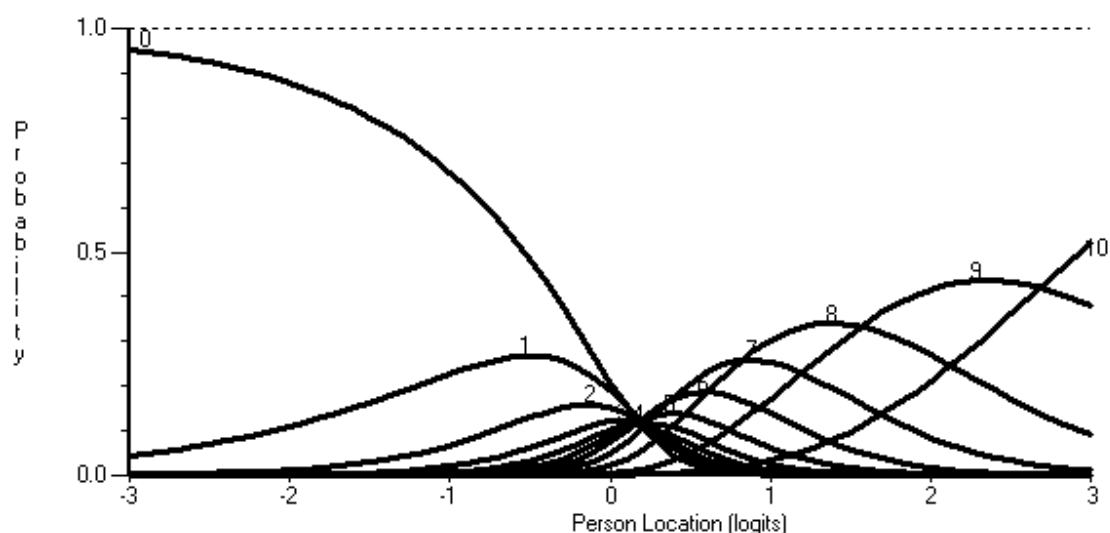


Figure 4.5 First social behaviours shortlist: Category probability curve for item 26

Item 26 was also the only item to display DIF. The DIF was associated with gender ($F=17.2$, $DF=1$, $p<.001$) and it was uniform, which meant that male participants obtained higher scores than female participants across the different class intervals (see Figure 4.6). Therefore, Item 26 was removed from the shortlist.

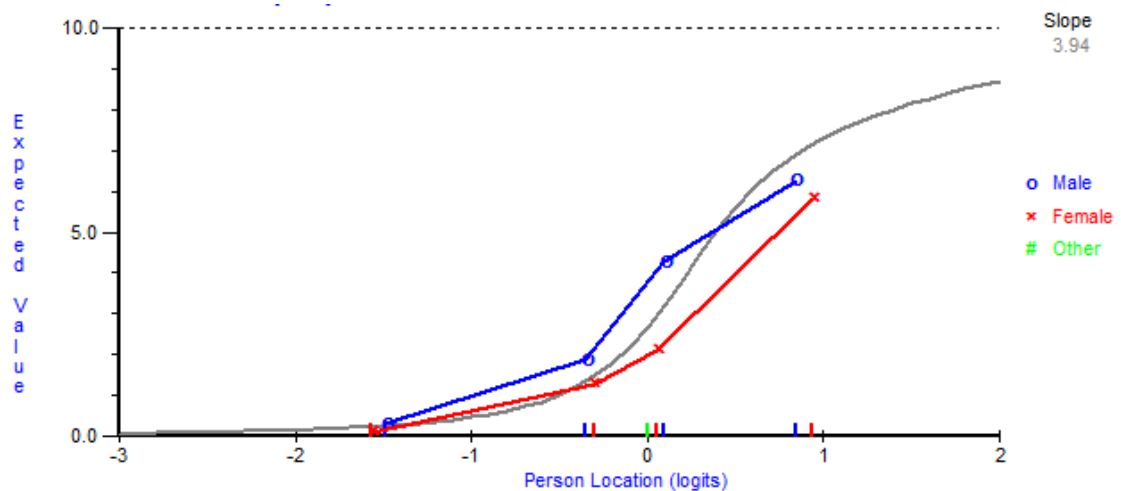


Figure 4.6 First social behaviours shortlist: Differential item functioning associated with gender for item 26

4.9.1.3 Second social behaviours shortlist

Following the removal of Item 26, previously eliminated items were reintroduced one-by-one to determine whether or not they could be added to the shortlist without compromising its psychometric properties. It was found that Item 1 (*'Because of my hearing loss, I find it difficult to: Take part in conversations in places where there is background noise, such as pubs, restaurants or parties'*) could be added to the shortlist without compromising its unidimensionality, as the shortlist passed the test of unidimensionality once the Binomial Proportions Confidence Interval was reviewed (percentage of significant t-tests=6.87%). An examination of the residual correlation matrix (see Table 4.12) showed that the residual correlations of the items were no greater than 0.2, which suggested that response dependency was not an issue in this shortlist. The person separation reliability of the shortlist was strong, both including extreme scores (PSI=0.929) and excluding extreme scores (PSI=0.937). The overall person fit residual (M=-0.33, SD=1.2) was within an acceptable range.

Table 4.12 Second social behaviours shortlist: Residual correlation matrix

Item	1	6	8	11	12	14	16	17	19
6	-0.2								
8	0.0	-0.1							
11	-0.3	-0.1	-0.2						
12	0.1	-0.3	0.0	-0.1					
14	-0.2	-0.2	0.1	0.0	0.1				
16	0.0	-0.1	-0.1	-0.2	0.0	0.0			
17	-0.4	0.1	-0.2	0.2	-0.3	0.0	-0.1		
19	-0.1	-0.1	-0.2	-0.2	-0.1	-0.3	-0.1	0.0	
23	0.0	-0.2	-0.2	-0.2	0.1	-0.2	-0.1	-0.2	0.2

The shortlist was relatively well-targeted (see Figure 4.7), with the mean person location being -0.08 (SD=1.22). Item 1 was the only item to capture participants at the extreme low end of the scale, which represents individuals with mild difficulty. However, the removal of Item 26 meant that an even fewer individuals at the extreme high end of the scale were captured by the items.

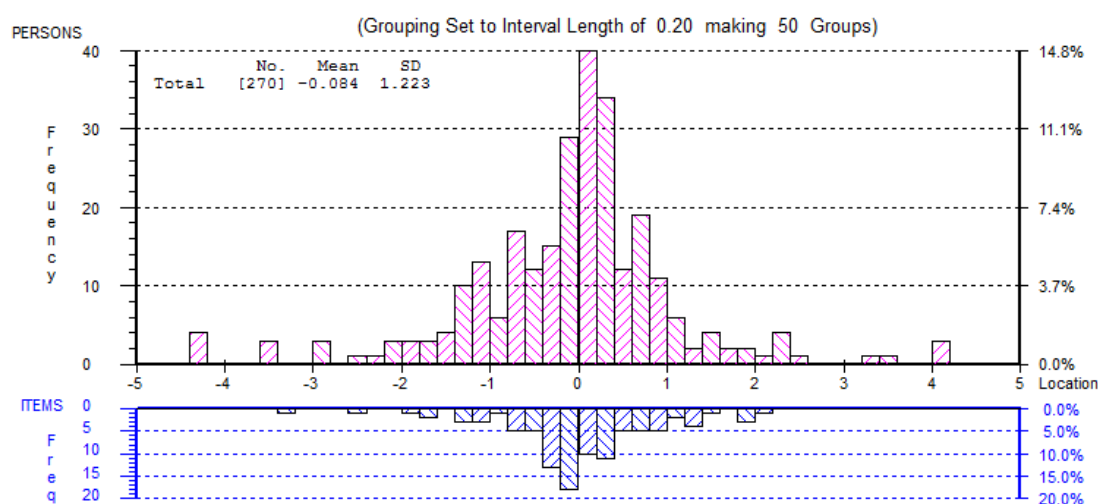


Figure 4.7 Second social behaviours shortlist: Person-item threshold distribution (including extreme scores)

The reintroduction of Item 1 had an adverse impact on fit to the Rasch model, as measured by the overall item fit residual ($M=-0.09$, $SD=1.71$) and the overall chi-squared test ($\chi^2=57.25$, $DF=30$, $p<.01$). This is likely due to the fact that this item was originally removed due to poor fit and, following its reintroduction, it continued to display poor fit, as demonstrated by its item fit residual (3.21) and its significant chi-squared test (see Table 4.13). The item characteristic curve for Item 1 suggested that it is somewhat under-discriminating (see Figure 4.8). This suggests that participants with little difficulty scored too high and participants with severe difficulty score too low on this item.

Table 4.13 Second social behaviours shortlist: Individual item fit statistics

Item	Location	Fit residual	DF	Chi-Sq	DF	Prob
1	-1.17	3.21	231.11	14.81	3	0.002
6	0.53	1.48	221.41	4.784	3	0.188
8	-0.35	0.74	217.88	0.783	3	0.854
11	0.36	0.26	226.7	1.871	3	0.600
12	-0.33	-2.97	222.29	9.158	3	0.027
14	0.02	-1.9	229.35	8.399	3	0.038
16	-0.03	-0.62	228.46	5.263	3	0.153
17	0.63	-0.56	224.05	4.476	3	0.214
19	0.37	-0.38	224.94	1.622	3	0.654
23	-0.04	-0.16	225.82	6.081	3	0.108

The properties of the individual items on the shortlist were re-examined. Item 12 (*'Because of my hearing loss, I find it difficult to: Take part in a group discussion or a group meeting'*) displayed some misfit, as evidenced by its item fit residual (-2.97). However, its chi-squared test was not significant, following the application of a Bonferroni adjustment. The item characteristic curve for this item (Figure 4.9) indicated that it had relatively good fit, despite

its negative fit residual indicating that it is somewhat over-discriminating. All of the items had ordered thresholds (see Figure 4.10). The items did not display DIF related to gender or age. Therefore, aside from Item 1, the items had adequate psychometric properties.

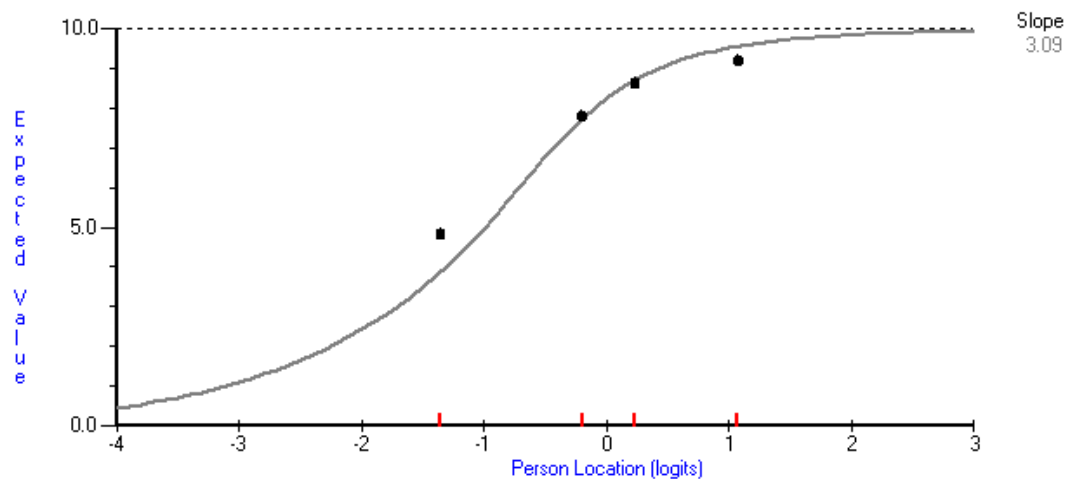


Figure 4.8 Second social behaviours shortlist: Item characteristic curve for item 1

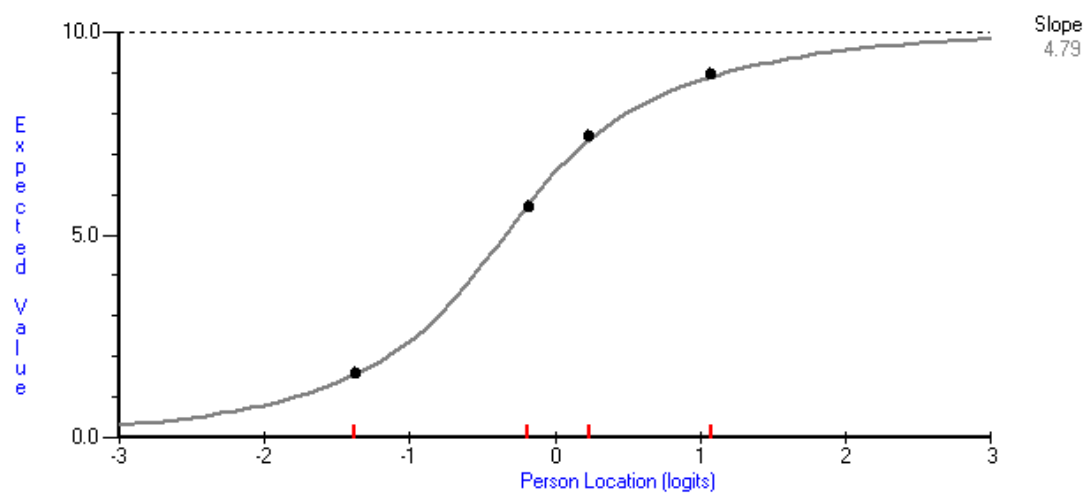


Figure 4.9 Second social behaviours shortlist: Item characteristic curve for item 12

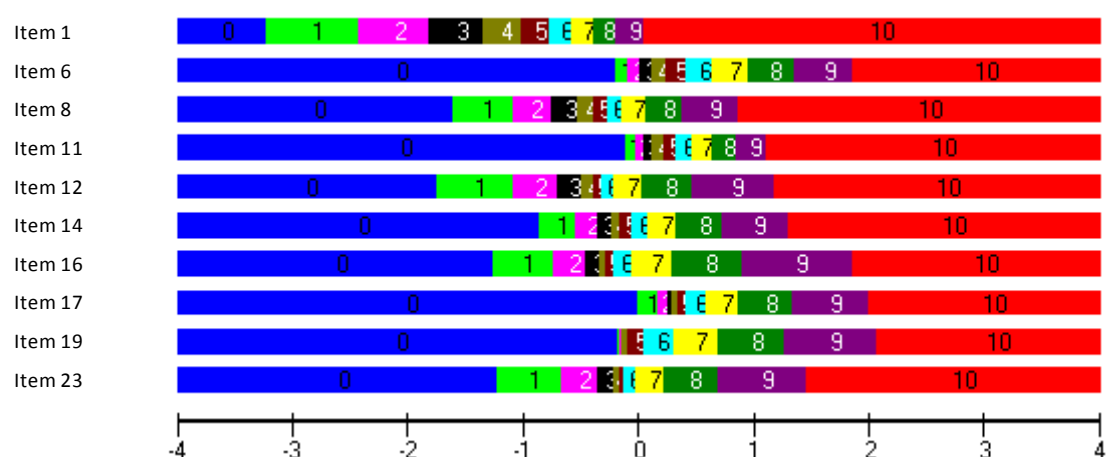


Figure 4.10 Second social behaviours shortlist: Threshold map

4.9.1.4 Third social behaviours shortlist

As Item 1 had a detrimental impact on fit to the Rasch model, the impact of removing this item from the shortlist was examined. This nine item shortlist passed the test of unidimensionality (percentage of significant t-tests=4.33%). An examination of the residual correlation matrix (see Table 4.14) showed that the items had residual correlations of no more than 0.2, which suggested that response dependency was not problematic in this shortlist.

Table 4.14 Third social behaviours shortlist: Residual correlation matrix

Item	6	8	11	12	14	16	17	19
8	-0.1							
11	-0.1	-0.2						
12	-0.3	0.0	-0.1					
14	-0.2	0.0	-0.1	0.1				
16	-0.1	-0.1	-0.2	0.0	-0.1			
17	0.0	-0.3	0.1	-0.3	0.0	-0.1		
19	-0.1	-0.2	-0.2	-0.1	-0.3	-0.2	-0.1	
23	-0.2	-0.2	-0.2	0.1	-0.2	-0.1	-0.2	0.2

The fit to the Rasch model was improved by the removal of Item 1, as evidenced by the overall fit residual (M=0.01, SD=1.54) and the overall chi-squared test ($\chi^2=36.78$, DF=27, $p=.099$). The overall person fit (M=-0.4, SD=1.25) was acceptable. The person separation reliability of the scale was high, both including extreme scores (PSI=0.914) and excluding extreme scores (PSI=0.927). The scale was relatively well-targeted (see Figure 4.11), with the mean person location being -0.23 (SD=1.28).

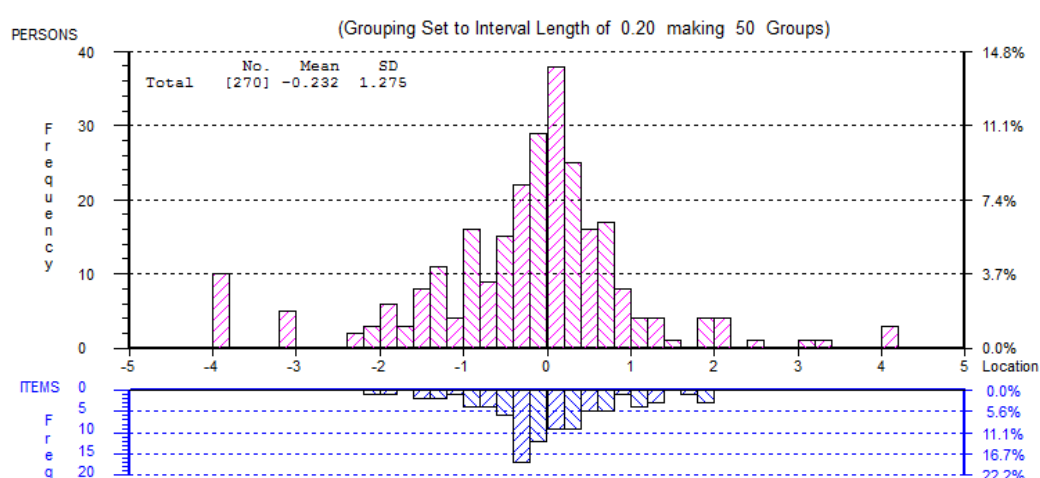


Figure 4.11 Third social behaviours shortlist: Person-item threshold distribution (including extreme scores)

Individually, the items displayed good fit to the Rasch model, as evidenced by their fit residuals being within the required range and their chi-square values being non-significant following the application of a Bonferroni correction (see Table 4.15). All of the items had ordered thresholds (see Figure 4.12). The items did not display any DIF related to gender or age.

Table 4.15 Third social behaviours shortlist: Individual item fit statistics

Item	Location	Fit residual	DF	Chi-Sq	DF	Prob
6	0.42	2.38	213.1	5.68	3	0.129
8	-0.5	1.74	209.7	1.23	3	0.745
11	0.25	0.42	218.4	1.94	3	0.586
12	-0.48	-2.47	214	6.68	3	0.083
14	-0.11	-1.7	221	6.50	3	0.09
16	-0.17	0.08	220.1	3.46	3	0.327
17	0.52	-0.8	215.7	4.93	3	0.177
19	0.24	-0.17	216.6	1.68	3	0.642
23	-0.18	0.62	217.5	4.69	3	0.196

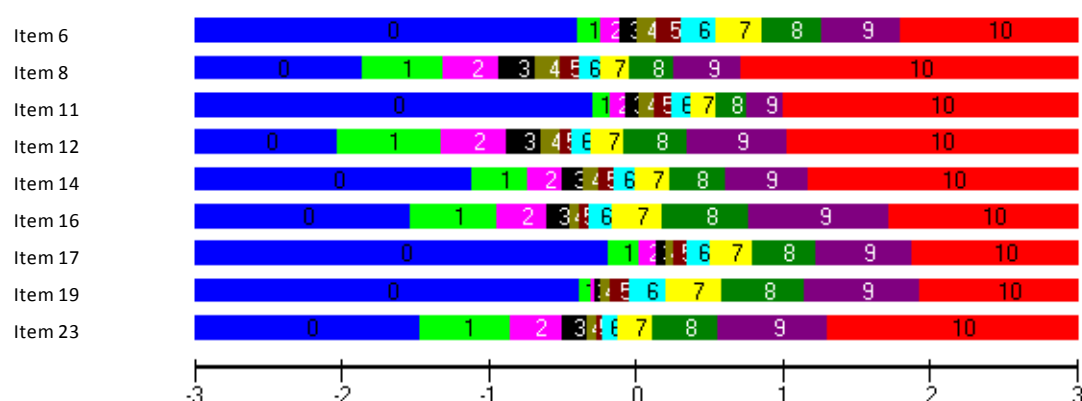


Figure 4.12 Third social behaviours shortlist: Threshold map

4.9.2 Social perceptions set

4.9.2.1 Item reduction

This set underwent the same item reduction process as the social behaviours set. This resulted in a shortlist of 11 items: Items 28, 29, 30, 32, 34, 36, 38, 39, 41, 44 and 51. Two were identity items (Item 41, Item 51), whilst the remainder were emotion items.

4.9.2.2 First social perceptions shortlist

The shortlist passed the test of unidimensionality, once the Binomial Proportions Confidence Interval had been inspected (percentage of significant t-tests=6.5%). There was little response dependency amongst the items, as demonstrated by the residual correlation matrix (see Table 4.16), where none of the correlations exceeded 0.2. The shortlist displayed good fit to the Rasch model, as demonstrated by the overall item fit residual (M=0.41, SD=1.21) and the overall chi-squared test ($\chi^2=40.05$, DF=33, $p=.186$). The person fit residual (M=-0.26, SD=1.23) was acceptable. The person separation reliability of the scale was strong, both including extreme scores (PSI=0.921) and excluding extreme scores (PSI=0.938). The targeting of the scale was relatively good (see Figure 4.13), with the mean person location being -0.09 (SD=1.52). However, there were some individuals at the extreme ends of the scale who were not captured by the items.

Table 4.16 First social perceptions shortlist: Residual correlation matrix

Item	28	29	30	32	34	36	38	39	41	44
29	0.0									
30	0.2	0.1								
32	-0.1	0.0	0.1							
34	-0.1	-0.3	-0.2	-0.2						
36	0.0	-0.1	0.0	-0.1	0.1					
38	-0.1	-0.1	0.0	-0.1	-0.2	-0.2				
39	-0.2	-0.1	-0.2	0.1	-0.2	-0.3	0.2			
41	0.0	-0.1	-0.2	-0.3	0.1	0.0	-0.2	-0.1		
44	-0.2	-0.2	-0.1	-0.1	-0.1	-0.2	-0.1	0.0	-0.1	
51	-0.2	-0.1	-0.3	-0.1	-0.2	-0.2	-0.1	0.0	0.0	0.0

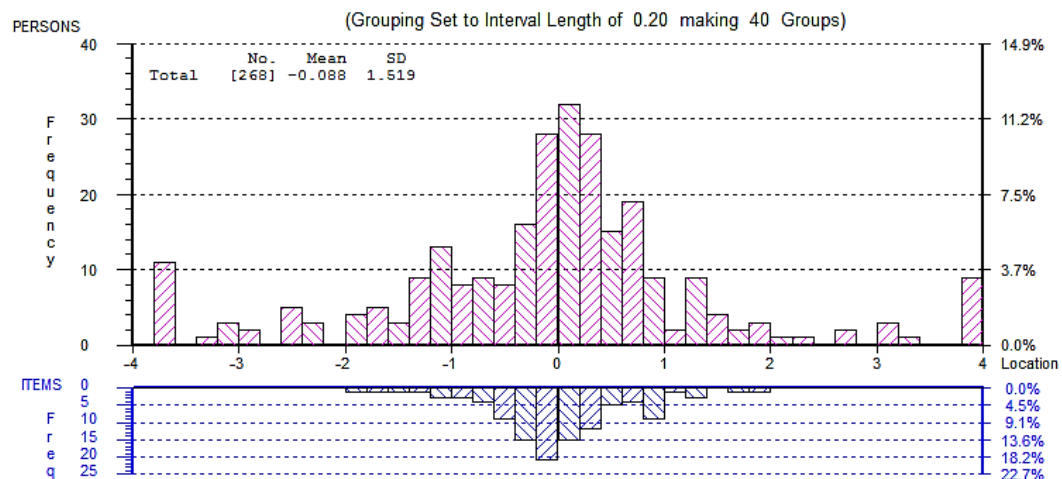


Figure 4.13 First social perceptions shortlist: Person-item threshold distribution (including extreme scores)

Individually, the items displayed good fit (see Table 4.17). Item 44 ('*Because of my hearing loss: I think that I look less sociable than I really am*') had an item fit residual outside of the required range, though its chi-square value was not statistically significant. The item characteristic curve for Item 44 indicated that it had relatively good fit (see Figure 4.14), though it was somewhat under-discriminating.

Table 4.17 First social perceptions shortlist: Individual item fit statistics

Item	Location	Fit residual	DF	Chi-Sq	DF	Prob
28	-0.08	0.04	217.5	4.27	3	0.234
29	-0.49	0.98	219.3	6.89	3	0.076
30	-0.27	-2.17	216.6	9.45	3	0.024
32	-0.24	0.79	206.8	0.34	3	0.952
34	0.51	0.58	212.1	3.4	3	0.334
36	0.43	-0.34	213.9	5.62	3	0.132
38	-0.36	0.83	218.4	0.64	3	0.887
39	-0.03	-0.05	218.4	2.46	3	0.483
41	0.35	0.22	219.3	2.31	3	0.51
44	0.07	2.88	211.2	3.75	3	0.289
51	0.1	0.79	216.6	0.94	3	0.817

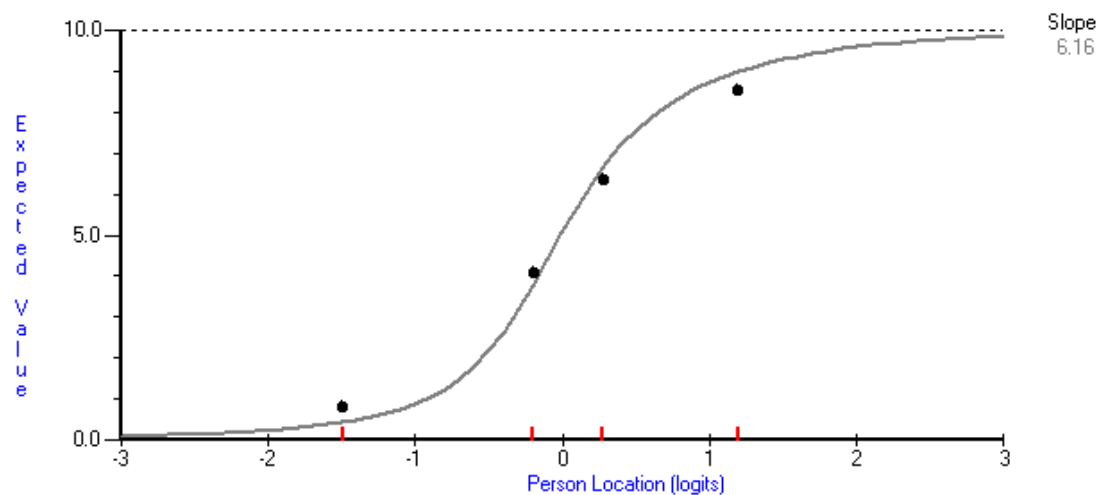


Figure 4.14 First social perceptions shortlist: Item characteristic curve for item 44

The majority of the items had ordered thresholds (see Figure 4.15) with the exception of Item 34 (*'Because of my hearing loss: I feel lonely, even when I am around other people'*) and Item 41 (*'Because of my hearing loss: I worry about talking to unfamiliar people'*), which were disordered (see Figures 4.16 and 4.17). None of the items displayed DIF associated with gender or age.

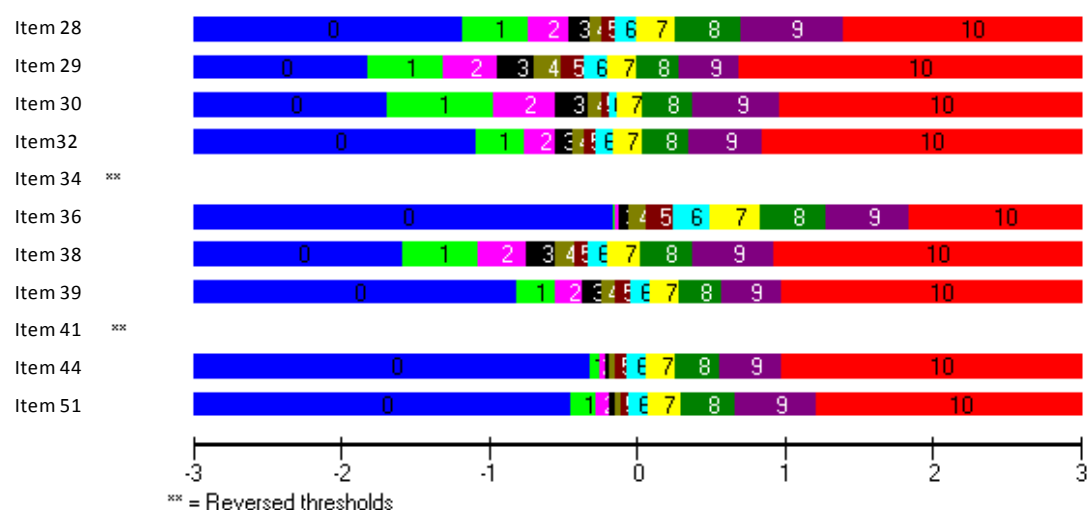


Figure 4.15 First social perceptions shortlist: Threshold map

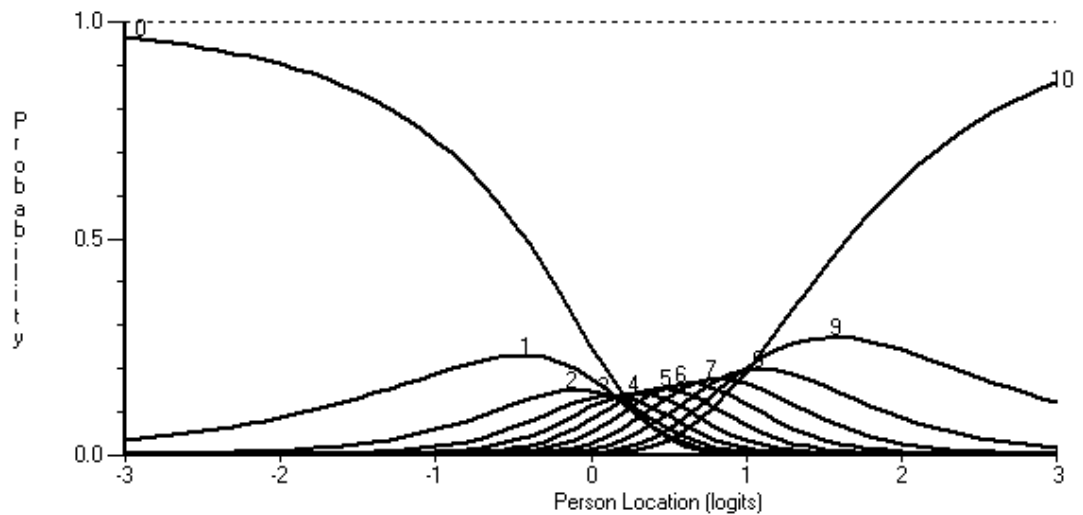


Figure 4.16 First social perceptions shortlist: Category probability curve for item 34

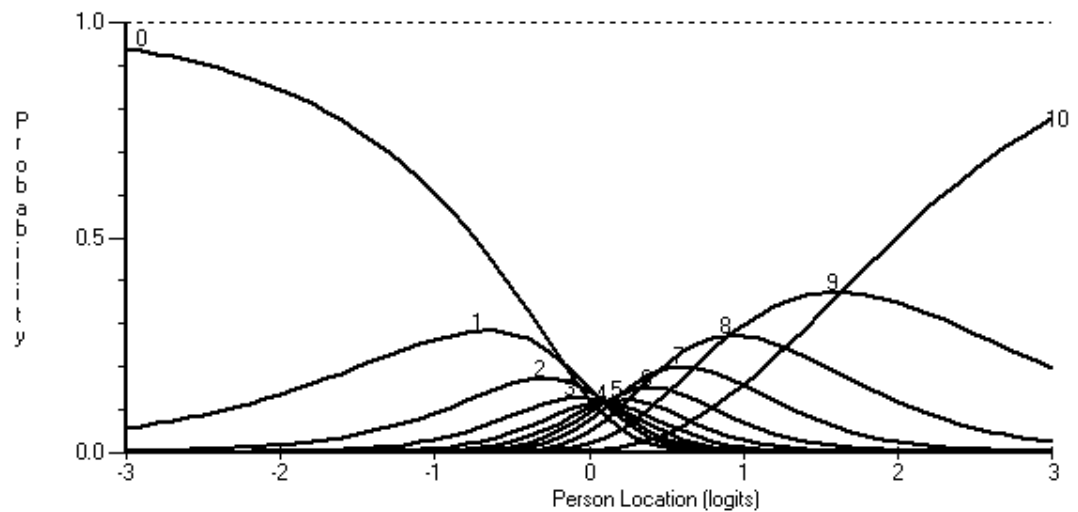


Figure 4.17 First social perceptions shortlist: Category probability curve for item 41

4.9.2.3 Re-scored social perceptions shortlist

To address the problem of disordered thresholds for Item 34 and Item 41, it was examined whether individual thresholds could be collapsed. This was an iterative process, which was complete at the point when sufficiently well-ordered thresholds were achieved for both items. It was found that collapsing

individual thresholds so that the items had seven, rather than 11, response options was effective (see Table 4.18).

Table 4.18 Rescoring of items with disordered thresholds

Response option	Previous score	Item 34 new score	Item 41 new score
0	0	0	0
1	1	1	1
2	2	1	1
3	3	1	2
4	4	2	2
5	5	2	3
6	6	3	3
7	7	3	4
8	8	4	4
9	9	5	5
10	10	6	6

Overall these items were sufficiently informative to retain in the questionnaire but the scales appended to them required an adjusted scoring algorithm to be reliable (see Figure 4.18, Figure 4.19, and Figure 4.20).

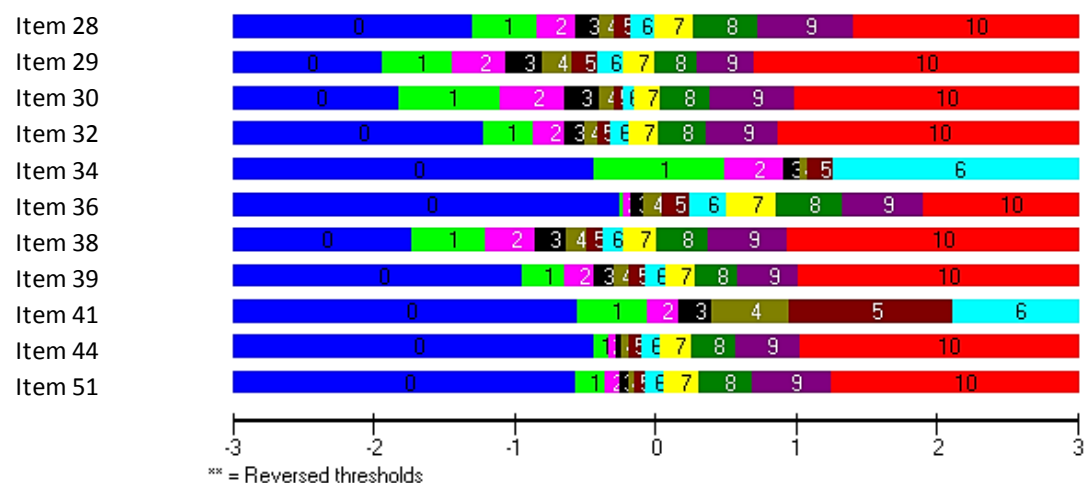


Figure 4.18 Rescored social perceptions shortlist: Threshold map

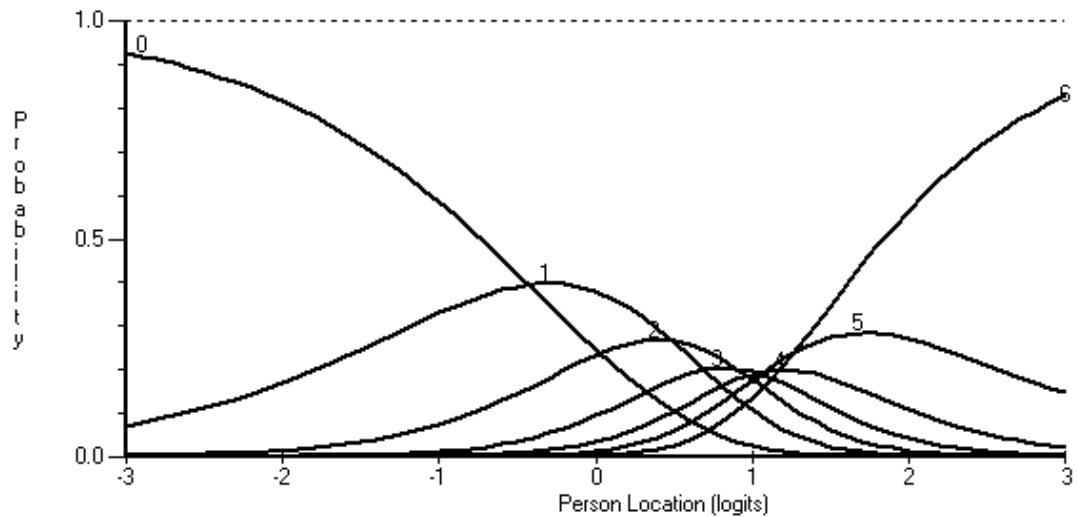


Figure 4.19 Rescored social perceptions shortlist: Category probability curve for item 34

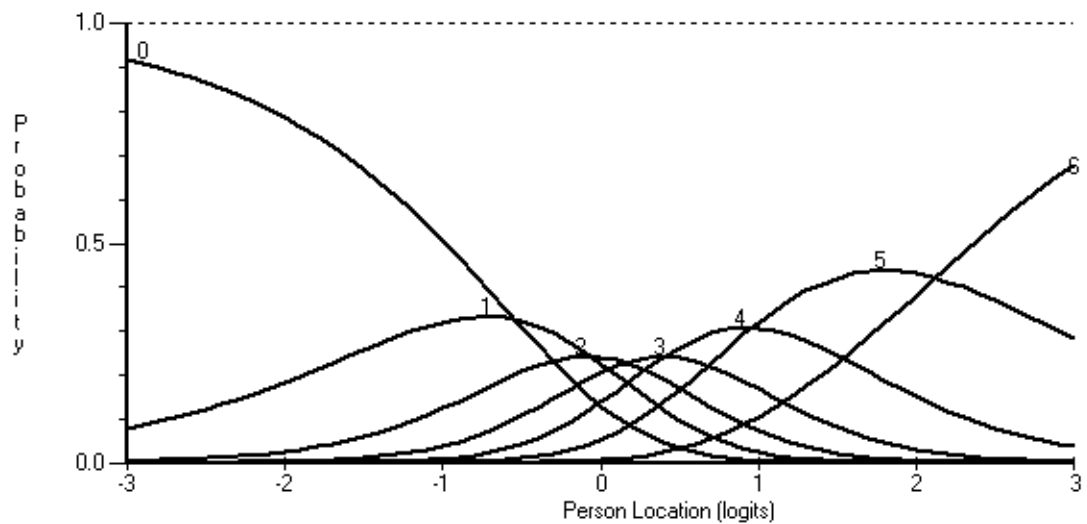


Figure 4.20 Rescored social perceptions shortlist: Category probability curve for item 41

Following rescoring, the shortlist passed the test of unidimensionality once the Binomial Proportions Confidence Interval had been examined (percentage of significant t-tests=7.76%). However, the overall fit to the Rasch model was affected. Although the overall item fit residual was within

an acceptable range ($M=0.5$, $SD=1.47$), the overall chi-square test was significant ($\chi^2=61.38$, $DF=33$, $p<.01$).

The poor overall fit to the Rasch model may be because Item 44 continued to display poor fit at the individual item level, as evidenced by its high, positive item fit residual (3.36). However, the chi-square test for this item was not significant following the application of a Bonferroni adjustment ($\chi^2=12.44$, $DF=3$, $p=0.006$). The item characteristic curve for this item (see Figure 4.21) showed that it is somewhat under-discriminating.

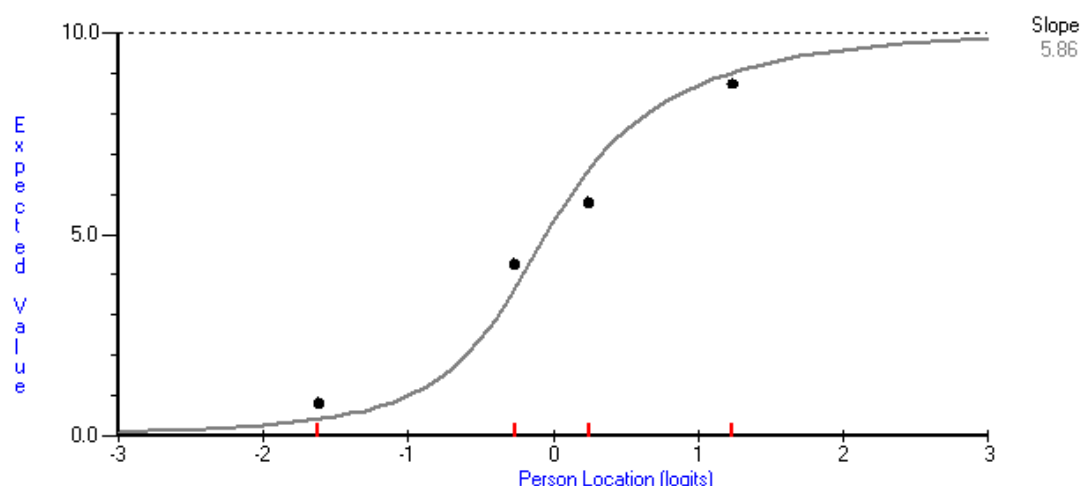


Figure 4.21 Rescored social perceptions shortlist: Item characteristic curve for item 44

4.9.2.4 Second social perceptions shortlist

The impact of removing Item 44 (*'Because of my hearing loss: I think that I look less sociable than I really am'*) from the shortlist was examined. It was found that the ten item shortlist passed the test of unidimensionality, once the Binomial Proportions Confidence Interval had been inspected (percentage of significant t-tests=6.94%). Item 34 and Item 41 had a residual

correlation of 0.229, which is suggestive of some response dependency between them. None of the remaining items exhibited response dependency, as demonstrated by the residual correlation matrix (see Table 4.19), where none of the correlations exceeded 0.2.

Table 4.19 Second social perceptions shortlist: Residual correlation matrix

Item	28	29	30	32	34	36	38	39	41
29	0.0								
30	0.2	0.1							
32	-0.2	-0.1	0.0						
34	-0.1	-0.2	-0.1	-0.2					
36	0.0	-0.2	0.0	-0.2	0.2				
38	-0.2	-0.2	-0.1	-0.1	-0.2	-0.2			
39	-0.2	-0.2	-0.3	0.1	-0.1	-0.3	0.1		
41	0.0	-0.1	-0.1	-0.2	0.2	0.1	-0.2	-0.1	
51	-0.3	-0.1	-0.3	-0.1	-0.1	-0.2	-0.1	0.0	0.0

The shortlist displayed good fit to the Rasch model, as demonstrated by the overall item fit residual ($M=0.45$, $SD=1.17$) and the overall chi-square test ($\chi^2=46.25$, $DF=30$, $p=.029$). The person fit residual ($M=-0.28$, $SD=1.23$) was acceptable. The person separation reliability of the scale was high, both including extreme scores ($PSI=0.925$) and excluding extreme scores ($PSI=0.94$).

The scale was relatively well-targeted (see Figure 4.22), with the mean person location being -0.12 ($SD=1.64$). However, there were some individuals at the extreme ends of the scale who were not captured by the items. Individually, all ten items displayed good fit, with each one having a fit residual within an acceptable range and a non-significant chi-square value, following the application of a Bonferroni correction (see Table 4.20). All of the items had ordered thresholds, following the rescoring of Item 34 and Item 41

(see Figure 4.23). None of the items displayed DIF associated with age or gender.

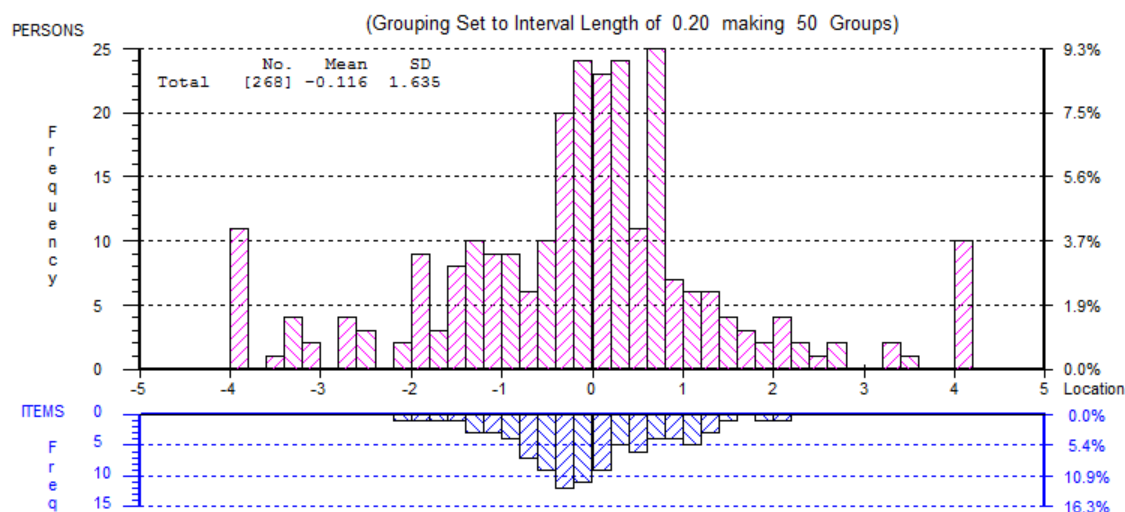


Figure 4.22 Second social perceptions shortlist: Person-item threshold distribution (including extreme scores)

Table 4.20 Second social perceptions shortlist: Individual item fit statistics

Item	Location	Fit residual	DF	Chi-Sq	DF	Prob
28	-0.12	0.63	214.4	3.03	3	0.387
29	-0.57	1.19	216.2	7.61	3	0.055
30	-0.33	-1.82	213.5	8.27	3	0.041
32	-0.30	1.26	203.8	0.17	3	0.983
34	0.76	0.15	209.1	8.35	3	0.039
36	0.44	0.29	210.9	6.58	3	0.087
38	-0.43	1.38	215.3	0.51	3	0.916
39	-0.06	0.77	215.3	2.35	3	0.503
41	0.53	-1.23	216.2	6.12	3	0.106
51	0.08	1.89	213.5	3.27	3	0.352

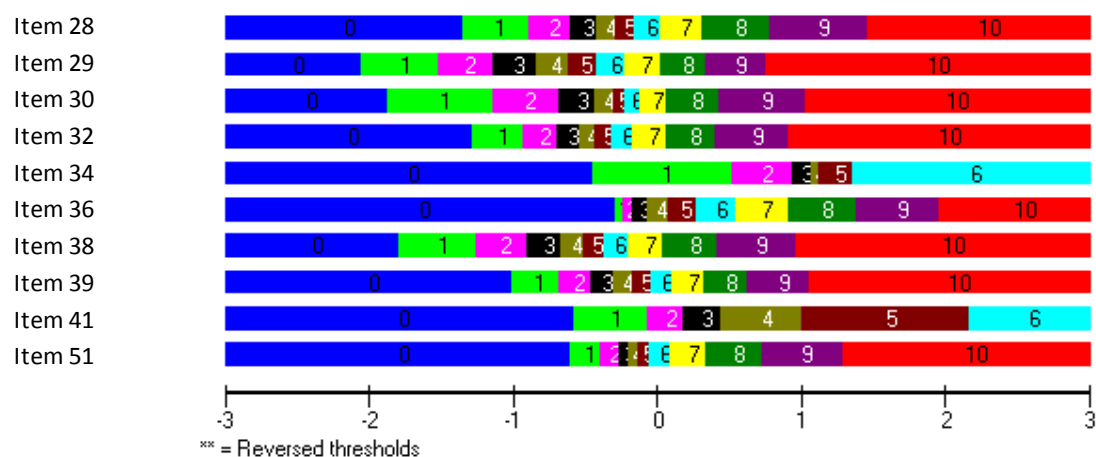


Figure 4.23 Second social perceptions shortlist: Threshold map

4.9.3 Summary of results

Rasch analysis facilitated the refinement of the SPaRQ so that it contains two subscales: a 9-item social behaviours subscale and a 10-item social perceptions subscale (see Table 4.21).

The Rasch analysis results demonstrated that each subscale has good psychometric properties. Firstly, each subscale displayed good fit to the Rasch model, which means that the data obtained from the subscales are invariant and that they are suitable for transformation into interval-level estimates, which are core requirements of measurement. In terms of local independence, each subscale was shown to be unidimensional, which means that each subscale measures a single factor. This is an important part of structural validity and justifies the calculation of a total score for each subscale. In addition, there was low response dependency amongst the items in each subscale, suggesting that item redundancy is not a concern. The results also showed that each subscale had high person separation reliability, meaning that they can reliably separate respondents in the sample

at both the individual level and group level. Furthermore, each subscale was well-targeted, meaning that they largely capture the range of participation restrictions present in the sample.

Table 4.21 Refined content of the SPaRQ

Item	Social behaviours abbreviated content
1	Take part in conversations in background noise
6	Carry out favourite pastimes
8	Follow talk or lecture
11	Manage stressful and challenging situations
12	Take part in a group discussion or meeting
14	Persevere with lengthy conversations
16	Talk with staff in shops, cafes or banks
17	Manage home, work or social responsibilities
19	Attend get-togethers with friends
23	Take part in conversations with friends
Item	Social perceptions abbreviated content
28	Find social gatherings stressful
29	Worry about missing important sounds
30	Isolated during group conversations
32	Frustrated when left out of conversations
34	Lonely, even when around others
36	Isolated at get-togethers
38	Unenthusiastic about joining in conversations
39	Upset when it is difficult to take part
41	Worry about talking to unfamiliar people
44	Look less sociable than I really am
51	Look foolish when I say the wrong thing

The individual items were found to be free of DIF, which means that there is no evidence of gender or age bias. The items each displayed adequate fit,

which suggests that they all measure the same underlying construct. The majority of the items had ordered thresholds, which statistically justifies the use of the 11-point response scale. However, two items in the social perceptions subscale had disordered thresholds and were found to be better suited to a seven point response scale. Therefore, these items require an adjusted scoring algorithm to be statistically justified.

Finally, Rasch analysis demonstrated that a tenth item, Item 1, could be added to the social behaviours subscale without compromising the majority of its psychometric properties. However, the inclusion of this item negatively affected overall fit to the Rasch model and the item itself displayed poor fit. Similarly, an eleventh item, Item 44, could be added to the social perceptions subscale without having a negative impact on the majority of its psychometric properties. However, this item had somewhat of a negative effect on the overall fit to the Rasch model and the item itself was somewhat ill-fitting. Further consideration will be given to these items in the forthcoming 'Discussion' section.

4.10 DISCUSSION

This study aimed to assess the psychometric properties of the SPaRQ2.0 and to refine the questionnaire, as required. The ultimate goal was to ensure that the measure could serve as a high quality instrument in clinical trials and clinical practice. This led to the development of the SPaRQ3.0, which contained two subscales with strong psychometric properties (see Appendix H). The results in terms of the specific study objectives are summarised and discussed below.

4.10.1 Factor structure

The first objective of the study was to explore the factor structure of the SPARQ2.0. The EFA results demonstrated that the questionnaire consisted of three main factors. The first and most substantial of these was the social perceptions factor, so called as it comprised the emotion and identity items. The second and third factors each contained behaviour items. It appeared that one factor focused on specific tasks, particularly listening in challenging environments, and one focused on broader social relationships and roles. It may be that one factor measured activity or auditory functioning and the other factor measured participation or social functioning. The dimensionality of the questionnaire was further assessed through Rasch analysis.

4.10.2 Item reduction

The second objective of the study was to identify items with poor psychometric properties and to remove those items from the questionnaire. The aim of item reduction is to ensure that only high quality items remain so that the questionnaire is as precise and efficient as possible. Firstly, Item 15 and Item 18 were removed, as they attracted more than 15% of '*Does not apply to me*' or missing responses. This demonstrates that there is a problem with these items, such as irrelevance, intrusiveness, or ambiguity (De Vet, Terwee et al. 2011). It is likely that these items, which pertained to participation in education and work, were not relevant to the large number of participants who were older adults and who were not in employment or education. This is to be expected in a representative sample of the hearing loss population, as it is an age-related condition. The content of these items was somewhat captured by three remaining items: Item 8, Item 12, and Item

17. These three items may have attracted a greater number of responses because they can be related to either professional or non-professional activities as required.

Rasch analysis was used to identify items that should be deleted from the SPaRQ2.0 primarily on the basis poor fit and response dependency. This led to the deletion of a further 30 items from the questionnaire. This included behaviour items concerning family life (Item 21, Item 25) and relationships with significant others (Item 20, Item 24, Item 26), despite the fact that Study 1 and Study 2 indicated that these are important elements of social participation. However, most of these items displayed response dependency, such that they strongly over-lapped with items concerning friendship (Item 19, Item 23). Therefore, it was necessary to remove these redundant items to avoid increasing respondent burden, artificially inflating internal consistency, over-weighting this content in the total score, and violating the assumption of local independence.

Several behaviour items concerning specific tasks and actions were removed due to poor fit, including items pertaining to conversing on the telephone, watching television, watching live events, listening to music and radio, and using public transportation. Study 1 and Study 2, as well as a review of existing hearing-specific questionnaires, suggested that conversing on the telephone (Item 2) and watching television (Item 3) are highly relevant. However, it was necessary to remove these items as the results indicated that they measure a different construct from the remaining items. It is likely that these items measure activity, rather than social participation.

The majority of the identity items were removed from the scale. This is somewhat supported by the results of Study 2, where it was suggested that there should be fewer identity items than emotion items and behaviour items in the questionnaire. It was thought that identity is not a concern for a large number of individuals with hearing loss. The results of this study suggest that most of the identity items measure a different construct to the items remaining in the questionnaire. For example, it appears that capability (Item 47) and independence (Item 50) do not fit within the construct of social participation. Item 45, which asks about pretending to understand others, and Item 48, which asks about sitting quietly whilst others talk, may be better suited to a coping strategy questionnaire. It is also possible that these items, were flagged for removal, alongside Item 46, as they are lengthier than the other items. Furthermore, the emotion items that concerned feeling embarrassed were removed from the questionnaire. It is possible that stigma and identity are a separate construct to social participation, though the two constructs may be related.

4.10.3 Local independence and fit to the Rasch model

The third objective of the study was to investigate local independence and fit to the Rasch model. In terms of local independence, the initial Rasch analysis results confirmed that the questionnaire as a whole was multidimensional, rather than unidimensional. This led to the division of the questionnaire into two item sets from which two unidimensional subscales were derived. Both the social behaviours subscale and the social perceptions subscale had low response dependency, which further supports their local independence (Hobart and Cano 2009; Lundgren Nilsson and Tennant

2011). In addition, each subscale displayed good fit to the Rasch model, which shows that they fulfil the criterion of invariance and that the ordinal scores of the questionnaire could be transformed into interval scores.

The social behaviours and social perceptions subscales are independent of one another. This means that they each have a total score but that there is no overall total score for the questionnaire. It is common for questionnaires to measure more than one dimension. For example, many mental health questionnaires measure more than one condition, such as the PHQ-4 and the Hospital Anxiety and Depression Questionnaire (Zigmond and Snaith 1983). Also many hearing-specific questionnaires measure more than one dimension, such as the Hearing Disability and Handicap Scale (Helvik et al., 2007) and the Glasgow Hearing Aid Benefit Profile (Gatehouse 1999). Unlike the SPaRQ, these hearing-specific questionnaires were developed using traditional psychometric analysis, rather than Rasch analysis. Therefore, it is presently unclear as to whether it is justifiable to calculate an overall total score for each of these questionnaires.

The social behaviours subscale consists of nine items that together form a subscale with strong psychometric properties. A tenth item (Item 1) can be added to this subscale without compromising most of these properties, including unidimensionality. However, this item had poor fit at the individual item level and it negatively affected overall fit to the Rasch model for the subscale. This item, which asks about conversing in the presence of background noise, may have displayed poor fit because it is better suited to a measure of activity than social participation. The poor fit of this item may also have been influenced by the fact that it is lengthier than the other

remaining items. This item should be subjected to further testing in order to determine whether or not it should be retained in the social behaviours subscale.

The social perceptions subscale consists of 10 items that together possess strong psychometric properties. An eleventh item (Item 44) can be added to this subscale without affecting most of these properties, including unidimensionality. This item has poor fit at the individual item level, which likely negatively affected the overall fit of the subscale to the Rasch model. These results suggest that this item does not assess the same latent trait as the other items and thus should be removed. However, the removal of this item would mean that only one identity item remained in the questionnaire, which could detract from its content validity, particularly its comprehensiveness. Therefore, it would be beneficial to subject this item to additional testing to determine whether or not it should be included in this subscale.

4.10.4 Targeting

The subscales were targeted at a slightly higher level of social participation restrictions than the level present in the sample, though overall both subscales were well-targeted. This means that the range of social participation restrictions captured by the items and the range of social participation restrictions present in the sample were relatively well-matched. However, there were some participants at the extreme low of the scale (i.e. little-to-no difficulty with social participation) and at the extreme high end of the scale (i.e. extreme difficulty with social participation) who were not captured by the items. One means of resolving this issue would be to

introduce new items that are designed to capture a more extreme level of social participation restrictions.

4.10.5 Person separation reliability

The social behaviour items subscale, both including and excluding Item 1, and the social perceptions subscale, both including and excluding Item 44, had high person separation reliability, as measured by the PSI. The PSI values were above 0.85, which indicates that the subscales can be used at both the individual level and the group level.

4.10.6 Threshold ordering

In the social behaviours subscale, the response scale thresholds were ordered for every item. Therefore, the 11-point response scale is appropriate for this subscale. In the social perceptions subscale, the thresholds were ordered for the majority of the items. However, Item 34 and Item 41 had disordered thresholds. This disorder was resolved by collapsing several response options together so that these two items had six thresholds, rather than ten. This suggests that the SPaRQ2.0 should retain the 11-point response scale but that an adjusted scoring system should be devised for Item 34 and Item 41 in a manner similar to the WHODAS 2.0 complex scoring system.

4.10.7 Limitations

One limitation of this study is that the restricted resources of the study prevented the collection of audiometric data, which meant that the exact degree of hearing loss of each participant was unknown. Another shortcoming of the study was that, of the participants included in the data

analysis, just 13.98% were recruited via audiology clinics, in comparison to 76.34% recruited via the Nottingham Hearing BRU participant database. It is likely that the database participants differed from the clinic participants in several ways that could have influenced their questionnaire responses. For example, the database contains a large number of experienced hearing aid users and a large number of individuals who are experienced in taking part in research, including completing questionnaires. Although several steps were taken to enhance recruitment via the audiology clinics, including maintaining regular communication with the audiologists involved, it remained difficult to recruit a sufficient number of clinic participants within the study timeframe.

4.10.8 Future research

This research has demonstrated the value of using Rasch analysis to develop a new measure. This stringent approach facilitates the assessment of a variety of important properties that are not typically assessed as part of traditional psychometric analysis, such as local independence, differential item functioning, and threshold ordering. In other words, Rasch analysis ensures that a questionnaire measures a single construct and thus can produce a legitimate and meaningful total score, that it does not contain redundant items that detract from the precision and efficiency of the measure, and that it does not require an adjusted scoring system due to item bias or disordered thresholds in the response scale. Therefore, it is recommended that other new hearing-specific questionnaires are developed using Rasch analysis and that existing hearing-specific questionnaires are re-validated using this approach. This is the best way to demonstrate that

they meet the standards that are now required of outcome measures in high quality clinical trials.

This study has provided strong support for the psychometric properties of the SPaRQ in the form of two independent subscales. However, in the course of this study, the questionnaire has changed substantially, primarily due to the removal of over 30 items. It has been recommended that questionnaires are reassessed following refinement, as changes to their structure and content can change their psychometric properties (Hyde 2000). In addition, several important psychometric properties of the SPaRQ were not investigated, including hypothesis testing validity and internal consistency, which meant that additional psychometric analysis was required (Terwee et al., 2007). Also, further information on the properties of Item 1 and Item 44 should be gathered so that a decision can be made regarding the inclusion or exclusion of these items in the final version of the SPaRQ. These points were addressed in Study 4, which was the final study of this doctoral research.

CHAPTER 5. STUDY 4: TRADITIONAL PSYCHOMETRIC ANALYSIS OF THE SOCIAL PARTICIPATION RESTRICTIONS QUESTIONNAIRE

5.1 INTRODUCTION

The previous chapter reported the development of the third prototype of the Social Participation Restrictions Questionnaire (SPaRQ3.0) using Rasch analysis. This chapter reports the final study of this doctoral research, which aimed to further assess the psychometric properties of this questionnaire using traditional psychometric analysis. Emphasis was placed on psychometric properties that had not previously been assessed, including hypothesis testing validity and internal consistency. These properties are currently regarded as essential quality criteria for outcome measures (Terwee et al., 2007). To achieve this aim, two different samples of data were collected: **(1)** paper-and-pen questionnaire data collected from the 279 participants in Study 3 and **(2)** online, electronic questionnaire data collected from 102 participants in Study 4. The results were used to determine whether the SPaRQ3.0 is fit for its intended purpose as a high-quality outcome measure of social participation restrictions in adults with hearing loss.

5.2 AIMS AND OBJECTIVES

The Rasch analysis at the centre of Study 3 demonstrated that the SPaRQ3.0 possesses strong psychometric properties, including local independence, targeting, and person separation reliability. The primary aim of this study was to assess additional psychometric properties of the SPaRQ3.0. This would provide important information about the quality of the questionnaire as a whole and would also provide further information about

the two items identified by Rasch analysis in Chapter 4 as potential candidates for removal. The specific study objectives were to:

- 1) Assess the hypothesis testing validity of the questionnaire
- 2) Assess the internal consistency of the questionnaire
- 3) Assess the floor and ceiling effects of the items in the questionnaire

Although these properties are intrinsically linked to traditional psychometric analysis, which has various limitations in comparison to modern psychometric analysis, they are nevertheless still widely regarded as important indicators of the quality of an outcome measure (Pesudovs et al., 2007; Terwee et al., 2007; Uijen et al., 2012).

5.3 DESIGN

5.3.1 Traditional psychometric analysis

This was a quantitative study in which traditional psychometric analysis was performed on questionnaire data collected from adults with hearing loss. As discussed in Chapter 4, it was decided that, despite its limitations, it was necessary and important to use traditional psychometric analysis to evaluate the SPaRQ3.0. In short, traditional psychometric analysis was used because remains the dominant form of psychometric analysis in the field of questionnaire design, it is an important component of many best practice guidelines on the evaluation of outcome measure quality, it has frequently been successfully used to supplement Rasch analysis, and it provides novel information about the properties of a measure, such information about its relationships with other measures (Ford et al., 2001; Hobart and Cano 2009; Jones et al., 2009; Pusic et al., 2009; Terwee et al., 2007; Uijen et al., 2012).

5.3.2 Psychometric properties

Traditional psychometric analysis can be used to evaluate a variety of psychometric properties. Those relevant to this research are presented below.

5.3.2.1 Criterion validity

Criterion validity is the extent to which scores on the scale under investigation agree with scores on a relevant gold-standard measure (De Vet et al., 2011; Mokkink et al., 2010c). In essence, criterion validity is evidence that the questionnaire under development measures the underlying construct that it purports to measure. Assessment of this form of validity relies on the prior existence of an acknowledged gold-standard measure. However, frequently there is a scarcity of gold-standard, self-report outcome measures against which new measures can be adequately assessed (De Vet et al., 2011). This was the case in this study, as there are no agreed-upon, gold-standard, hearing-specific outcome measures (Akeroyd et al., 2015; Granberg et al., 2014a). In fact, the lack of such a measure was the rationale for this doctoral research. Where a suitable gold-standard instrument is unavailable, it is recommended that evidence of construct validity should be provided instead (De Vet et al., 2011).

5.3.2.2 Construct validity

As with criterion validity, construct validity is evidence that a questionnaire measures the latent construct it has been designed to measure. One of the key elements of construct validity is structural validity, or the extent to which the measure adequately represents the underlying dimensionality of the target construct (Mokkink et al., 2010c). Study 3 used factor analysis and

Rasch analysis to assess the structural validity of the SPaRQ3.0. The other key element of construct validity is hypothesis testing validity, or the extent to which scores on the questionnaire are consistent with hypotheses that are based on the assumption that the questionnaire validly measures the target construct (De Vet et al., 2011; Scholtes, Terwee and Poolman 2011). These include hypotheses about convergent and discriminant validity (i.e. relationships between scores on the questionnaire and scores on validated instruments) and hypotheses about discriminative validity (i.e. the ability of the questionnaire to distinguish between patient subgroups) (De Vet et al., 2011; Mokkink et al., 2010c). Approximately 75% of the hypotheses should be confirmed in order to provide evidence to support construct validity (Terwee et al., 2007; Uijen et al., 2012).

Initial hypotheses concerning convergent validity and discriminative validity were formed as part of the design of Study 3. The initial convergent validity hypothesis stated that SPaRQ scores are positively and strongly correlated with scores on hearing-specific, psychosocial questionnaires and are positively and moderately correlated with scores on generic, psychosocial questionnaires. This hypothesis was based on previous research that has shown that condition-specific measures have stronger relationships with other condition-specific measures than with generic measures (Evers et al., 2008; Fackrell et al., 2016; Robinson et al., 2002). Following a literature search, three questionnaires were selected for the purpose of testing this hypothesis. The first was the Hearing Handicap Inventory for the Elderly (HHIE), which is a hearing-specific questionnaire designed to measure the emotional and situational impact of hearing loss (Ventry and Weinstein

1982). The second was the shortened WHO Disability Assessment Schedule 2.0 (WHODAS2.0), which is a generic questionnaire designed using the ICF to measure the impact of any health condition on activity and participation (Üstün et al., 2010b). The third was the Patient Health Questionnaire-4 (PHQ-4), a tool designed to screen for anxiety and depression in the general population (Kroenke et al., 2009). These questionnaires were selected, not only because their content enabled the convergent validity hypothesis to be tested, but also because they each have good reliability and validity. Furthermore, these measures are all relatively brief, which helped to minimise respondent burden. These measures are described in greater detail in the forthcoming 'Materials' section.

The initial discriminative validity stated that participants who have PHQ-4 scores that indicate that they have anxiety or depression were predicted to obtain significantly higher SPaRQ scores than the remaining participants. This hypothesis was based on previous research that demonstrated that there is an association between hearing loss and poor psychological wellbeing (Kramer et al., 2002; Nachtegaal et al., 2009; Strawbridge et al., 2000) and an association between social participation restrictions and poor psychological wellbeing in older adults (Cornwell and Waite 2009; Glass et al., 2006; Palinkas, Wingard and Barrett-Connor 1990). These initial, broad hypotheses were reviewed and more specific hypotheses formulated after the structural validity of the SPaRQ2.0 had been assessed and the SPaRQ3.0 had been developed (De Vet et al., 2011). The specific hypotheses are outlined in the forthcoming 'Hypothesis testing results' section.

5.3.2.3 Internal consistency

This refers to the level of inter-relatedness amongst the items or the degree to which the items assess the same construct (De Vet et al., 2011; Mokkink et al., 2010c). Internal consistency is argued to be an important property for any scale or subscale that purports to measure a single construct. Therefore, once unidimensional scales or subscales have been developed, it is recommended that their internal consistency be assessed by calculating Cronbach's alpha, as well as inter-item correlations and item-total correlations (De Vet et al., 2011; Terwee et al., 2007).

5.3.2.4 Floor and ceiling effects

In contrast to construct validity and internal consistency, floor and ceiling effects are undesirable properties. It has been proposed that a floor effect occurs when more than 15% of participants obtain the lowest score on an item, whilst a ceiling effect occurs when more than 15% of participants obtain the highest score on an item (McHorney and Tarlov 1995; Terwee et al., 2007). In terms of the SPaRQ3.0, a floor effect would indicate that very few individuals with hearing loss experience the particular social participation restriction expressed in that item. A ceiling effect would indicate that very many individuals with hearing loss experience the particular social participation restriction expressed in that item. The presence of items with floor and ceiling effects can have a detrimental impact on other psychometric properties. In particular, they can have a detrimental impact on the responsiveness of an outcome measure, as these items are unlikely to detect changes in participants' functioning over time. They may also have an adverse impact on person separation reliability, as it becomes difficult to

distinguish between different individuals if all are located at the floor or at the ceiling (Terwee et al., 2007). Also, including such potentially uninformative items can add to respondent burden (Pesudovs et al., 2007).

5.3.3 Sample size

Two samples of data were collected for this study. The first sample of data came from Study 3, where 279 adults with hearing loss completed the 53-item SPaRQ2.0. The responses of these participants to the 21 items that were retained in the SPaRQ3.0 were extracted and re-analysed for the purposes of this study. In addition, a second sample of data was collected by administering the 21-item SPaRQ3.0 to a new group of participants in this fourth study. A second sample was collected because completing these 21 items as part of the lengthy SPaRQ2.0 could produce different responses to completing these 21 items as part of the relatively short SPaRQ3.0. For example, the Study 3 participants who completed the 21 items as part of the SPaRQ2.0 could have experienced greater fatigue than the Study 4 participants or they could have been influenced by their responses to the other 32 items in the SPaRQ2.0. Therefore, the second sample of data ensured that the psychometric properties of the SPaRQ3.0 were accurately assessed. This is in accordance with best practice recommendations that state that questionnaires should be reassessed following refinement, as changes to their format and content can change their psychometric properties (Hyde 2000).

The Study 3 sample size was based on the primary analysis, Rasch analysis, which has a recommended sample size of at least 250 cases (Chen et al., 2013). The Study 4 sample size was based on the traditional psychometric

analysis literature. It has been demonstrated that a minimum sample size of 80 cases produces robust convergent validity correlation coefficient estimates (Hobart et al., 2012). The same study found that a minimum sample size of 20 cases was enough to produce stable Cronbach's alpha estimates, though others have recommended that approximately 100 cases is more appropriate for this statistic (Hyde 2000; Iacobucci and Duhachek 2003). Therefore, a sample size of 100 individuals was sought.

5.3.4 Mode of delivery

The Study 3 questionnaire delivery mode was a paper-and-pen format, whilst the Study 4 questionnaire delivery mode was an online, electronic format via Bristol Online Surveys, University of Bristol, UK, www.onlinesurveys.ac.uk/. Ideally, Study 4 would have adopted the same mode as Study 3 so that any differences in the results could not be attributed to differences in the two formats. However, the paper-and-pen format was not feasible within the short timescale of Study 4, as it is time-consuming and labour intensive to print, package, and post a large number of questionnaires. Therefore, an online questionnaire, which could be disseminated to a large group of potential participants via a single email, was judged to be the most suitable approach. Whilst some studies suggest that the responses and psychometric properties of online questionnaires differ from their paper-and-pen counterparts (Carini et al., 2003; Thorén, Andersson and Lunner 2012; Vallejo et al., 2007), many other studies have concluded that a paper-and-pen questionnaire is equivalent to its electronic counterpart, particularly if the appearance of the questionnaire remains very similar across the different delivery modes (Bishop et al., 2010; Cook et al., 2004; Gwaltney, Shields

and Shiffman 2008; Kleinman et al., 2001). Therefore, it was ensured that the appearance of the Study 4 online questionnaires was as similar as possible to the Study 3 paper-and-pen questionnaires. Furthermore, the advantage of the online, electronic format is that the questionnaires can be designed so that participants must answer every question, which eliminates missing data.

5.4 METHODS

This research was sponsored by the University of Nottingham. It was approved by the North East - Tyne and Wear South Research Ethics Committee, the Research and Innovation Department at the Nottingham University Hospitals NHS Trust, and the Research and Development Governance Office at the University Hospitals Birmingham NHS Trust. The Study 4 methods are detailed below (see Chapter 4 for the Study 3 methods).

5.4.1 Participants

There were two groups of participants: 279 participants from Study 3 (see Chapter 4) and 102 participants from Study 4 (see Table 5.1). The Study 4 demographic data are similar to the Study 3 demographic data, despite the different modes of delivery used. However, the proportion of participants aged 70 years and above in Study 4 was lower than in Study 3.

5.4.2 Recruitment

5.4.2.1 Eligibility criteria

Please see Chapter 4 for the inclusion criteria and exclusion criteria of this study.

Table 5.1 Demographic information of the study 4 participants

Gender	n	%
Male	54	52.94
Female	48	47.06
Age	Years	
Mean	60.92	
SD	10.53	
Range	25-90	
Median	62	
Age group	n	%
18-59 years	42	41.18
60-69 years	46	45.10
70-79 years	19	18.63
80-89 years	2	1.96
Hearing loss screen	n	%
Yes to both items	98	96.08
Yes to one item	4	3.92
No to both items	0	0.00
Hearing loss type	n	%
Acquired	99	97.06
Congenital	3	2.94
Hearing loss onset	n	%
Gradual	71	69.61
Sudden	24	23.53
Other	7	6.86
Hearing loss duration	Years	
Mean	14.28	
SD	14.1	
Range	1-68	
Median	10	
Hearing aid use	n	%
Everyday	63	61.76
Sometimes	25	24.51
Never	14	13.73
Country of residence	n	%
UK (England)	100	98.04
Republic of Ireland	1	0.98
Other	1	0.98
Living arrangements	n	%
Live with other people	86	84.31
Live alone	16	15.69

5.4.2.2 Recruitment procedure

The Study 4 participants were recruited through the Nottingham Hearing BRU participant database over a period of three weeks. The database was searched for potential participants who had not participated in Study 2 or Study 3, were not participating in any other Nottingham Hearing BRU research studies, and who were likely to have a hearing loss. A total of 184 potential participants were invited to participate in Study 4 via email.

Recruitment ceased when a sufficient number of participants (i.e. at least 100) had completed the questionnaires. Participants were not recruited through audiology clinics or notices for Study 4, as Study 3 had demonstrated that this would not be an efficient approach given the short timescale of Study 4.

5.4.2.3 Non-participation

Two potential participants contacted the author to explain why they decided not to participate in the study. One reported that they had hyperacusis, rather than hearing loss. One said that they did not wish to take part due to a recent bereavement in the family.

5.4.2.4 Recruitment response

The Study 4 online questionnaires were completed by 109 individuals, representing a response rate of 59.24%. A review of the questionnaire data and additional comments provided by the respondents led to the exclusion of seven individuals from the data analysis, as they did not meet the eligibility criteria of the study. Five were excluded because they indicated that they had profound hearing loss. One indicated that they had tinnitus and hyperacusis, rather than hearing loss. Another stated that they had auditory

processing disorder and normal hearing. Therefore, 102 participants remained in the study, representing a response rate of 55.43%.

5.4.3 Materials

The participants were provided with a series of questionnaires to complete in order to obtain data for the assessment of the psychometric properties of the SPaRQ3.0 (see Appendix H).

5.4.3.1 Third prototype of the social participation restrictions questionnaire (SPaRQ3.0)

This 21-item questionnaire contains two unidimensional subscales, each of which measures a different domain of social participation restrictions. The first 10-item subscale is called 'social behaviours', whilst the second 11-item subscale is called 'social perceptions'. The measure has an 11-point response scale, ranging from '*Completely Disagree*' at point zero to '*Completely Agree*' at point 10. The remaining points on the response scale are unlabelled. Two of the social perceptions items (Item 34 and Item 41) have an adjusted scoring algorithm, as Rasch analysis showed that they are better suited to a seven point response scale. The '*Does not apply to me*' option, present in the SPaRQ2.0, was removed from the SPaRQ3.0. This was because the purpose of this option, which was to identify items that are irrelevant to a large number of adults with hearing loss, had been achieved in Study 3. This questionnaire instructs respondents who normally wear a hearing aid to answer as if they are wearing the hearing aid. At the end of the questionnaire, an additional item asks: "*Approximately how often do you wear a hearing aid?*" which is followed by three response options: '*Everyday*', '*Sometimes*' and '*Never*'. This item was designed to capture important

contextual information, as the frequency of hearing aid use could have an influence on participants' responses to the questionnaire.

5.4.3.2 Hearing handicap inventory for the elderly (HHIE)

The HHIE (see Appendix I) was provided to participants so that the convergent validity of the SPaRQ3.0 could be assessed. It is a 25-item questionnaire consisting of a 12-item subscale assessing the social/situational impact of hearing loss and a 13-item subscale assessing the emotional impact of hearing loss (Ventry and Weinstein 1982). The questionnaire has a three-point response scale. The response options are scored as follows: 'Yes'=4, 'Sometimes'=2, and 'No'=0. In contrast to the SPaRQ3.0, all respondents are instructed to answer as if they are not wearing a hearing aid. Respondents are also told: "*Do not skip a question if you avoid a situation because of your hearing problem*" (Ventry and Weinstein 1982, pp.134).

The HHIE was selected as it is one of the most widely used questionnaires in hearing research (Granberg et al., 2014a). Also, although it is not a gold-standard questionnaire, in terms of the quality of its development and validation studies (Mokkink et al., 2011) and the quality of its psychometric properties (Pesudovs et al., 2007; Terwee et al., 2007), there is some evidence to support its reliability and validity. The original development study (N=100) found that the HHIE had high internal consistency for the scale as a whole, as well as for each subscale (Ventry and Weinstein 1982). Another study (N=27) demonstrated that the HHIE had good test-retest reliability for the questionnaire as a whole and for both subscales (Weinstein, Spitzer and Ventry 1986). In terms of validity, an additional study (N=100) established

that scores on the HHIE were significantly correlated with pure-tone audiometry, spondee threshold, and speech recognition (Weinstein and Ventry 1983). There is also some evidence that the HHIE can serve as an outcome measure. For example, it was found to be responsive to change between baseline and four months post-hearing aid fitting in a sample of 95 adults with hearing loss (Mulrow, Tuley and Aguilar 1990).

5.4.3.3 World health organization disability assessment schedule 2.0 (WHODAS 2.0) self-administered shortened version

The shortened WHODAS 2.0 (see Appendix J) was provided to participants so that the convergent validity of the SPaRQ3.0 could be assessed. It is a 12-item questionnaire designed to measure functioning in six major life domains from the 'Activity and Participation' dimension of the ICF (Üstün et al., 2010a; Üstün et al., 2010b). These domains are understanding and communication, mobility, self-care, getting along with others, life activities, and societal participation. The questionnaire can be applied to any health condition and can be used for both outcome measurement and population surveys. Respondents rate how much difficulty they have experienced in the past 30 days in 12 different areas of functioning (e.g. '*Getting dressed*' and '*Maintaining a friendship*'). Ratings are provided using a five-point response scale. The WHODAS 2.0 can be scored using a simple scoring method, suitable for analysing a specific sample, or a complex scoring method, suitable for comparative analyses of different populations. The simple scoring method means that, for every item, the response options are scored as follows: '*None*'=1, '*Mild*'=2, '*Moderate*'=3, '*Severe*'=4, and '*Extreme or Cannot Do*'=5. The complex scoring method involves differentially weighting

the response options and the items, based on the findings of an IRT analysis.

The WHODAS 2.0 was selected for this research as there is strong evidence to support its reliability, validity, and responsiveness. It was first developed through a series of studies (N=65,000) conducted in 19 countries with both the general population and specific patient populations (Üstün et al., 2010b). The measure was found to have high internal consistency, high test-retest reliability, a stable factor structure, good concurrent validity, and good responsiveness (Kim et al., 2015; Üstün et al., 2010b). IRT analysis provided further evidence that the measure has good psychometric properties (Luciano et al., 2010; Üstün et al., 2010b). Specifically, there is evidence to show that the measure is unidimensional, that the items and the response scale can discriminate between different levels of disability, and that the items are free of gender bias.

5.4.3.4 Patient health questionnaire-4 (PHQ-4)

The PHQ-4 (see Appendix K) was provided to participants so that the convergent validity and discriminative validity of the SPaRQ3.0 could be assessed. This four item measure was originally designed to screen for anxiety and depression (Kroenke et al., 2009). It consists of a depression subscale and an anxiety subscale, each containing two items. Respondents are asked to consider how often they have been affected by certain problems (e.g. *'Feeling down, depressed, or hopeless'*) in the last two weeks using a four point scale. The scoring system is as follows: *'Not at All'*=0, *'Several Days'*=1, *'More than Half the Days'*=2, and *'Nearly Every Day'*=3. A score of at least three on the depression subscale identifies potential depressive

disorder cases, whilst a score of at least three on the anxiety subscale identifies potential anxiety disorder cases. The total score for the measure represents a general measure of symptom burden and disability.

The PHQ-4 was selected for this research as it has been shown to have strong reliability and validity. It was originally developed in a large scale study of 2149 primary care patients in the United States (Kroenke et al., 2009). It was derived from the Generalized Anxiety Disorder-7 questionnaire (Spitzer et al., 2006) and the Patient Health Questionnaire-9 (Kroenke and Spitzer 2002). This study produced evidence to support construct validity of the scale, including a stable factor structure and significant correlations with other measures of disability and mental health. Two subsequent large scale studies from Germany provided support for the factor structure of the questionnaire, demonstrated that it was significantly correlated with other measures of depression, anxiety, self-esteem, life satisfaction, and resilience, found that it had good internal consistency, and provided evidence that it can detect clinically significant levels of depression and anxiety (Kerper et al., 2014; Löwe et al., 2010).

5.4.3.5 Hearing loss screening questionnaire

As described in previous chapters, two items from this questionnaire by Davis et al. (2007) were used to screen for hearing loss amongst the participants.

5.4.3.6 Demographics questionnaire

As described in previous chapters, the participants were given a series of questions composed by the author, in order to obtain relevant demographic information. In Study 4, the question concerning the participants'

employment status was erroneously omitted from the demographics questionnaire.

5.4.4 Study procedure

The Study 4 participants took part in the study from home or a location of their choice. They each received an invitation email from the author, to which a study information sheet was attached. Participation involved clicking on a link provided in the email and completing the online, electronic questionnaires at their own pace, taking as many breaks as needed. Completion of the questionnaires served as implicit consent to participate in the study. The participants could opt to receive a summary of the results of the study and to be entered into the same prize draw as the Study 3 participants, in which they had a chance to win one of six gift vouchers (1x£100, 5x£50). It was estimated, based on information provided by a small number of participants, that participation in the study lasted a maximum of one hour and 30 minutes. The author was available by telephone or email during the course of the study to answer any participant queries. For example, one participant contacted the author about difficulties they had accessing the survey, whilst another had a query about whether they should answer the questionnaires based on wearing their hearing aids or not. All of the data obtained were treated confidentially and stored securely in either locked filing cabinets or on password-protected computers in the Nottingham Hearing BRU. Any participant who obtained a score of three or more on either PHQ-4 subscale was emailed or posted a leaflet that listed the contact details of various healthcare support services and charities.

5.5 DATA ANALYSIS

The Study 3 data and Study 4 data were analysed separately due to the different modes of delivery (paper-and-pen versus electronic) and the differences in the primary questionnaire (i.e. 53-item SPaRQ2.0 versus 21-item SPaRQ3.0). The social behaviours subscale and the social perceptions subscale of the SPaRQ3.0 were analysed separately, as each is an independent, unidimensional subscale.

Two versions of the social behaviours subscale and two versions of the social perceptions subscale were assessed. Specifically, the 10 items in the social behaviours subscale were analysed before Item 1 was deleted and the remaining nine items were re-analysed. Similarly, the 11 items in the social perceptions subscale were analysed before Item 44 was deleted and the remaining 10 items were re-analysed. The purpose of this was to ascertain whether or not it was beneficial to include these items in the SPaRQ.

Several statistical analyses were performed in order to assess the psychometric properties of the SPaRQ3.0, as described below. The data of the SPaRQ subscales, with the exception of the 9-item social behaviours subscale Study 4 data, were not normally distributed (see Table 5.2).

Therefore non-parametric statistics were calculated.

Table 5.2 Shapiro-Wilk tests of normality

SPaRQ subscale	Study 3			Study 4		
	W	df	p	W	df	p
10-item social behaviours	0.963	278	0.000	0.972	104	0.031
9-item social behaviours	0.959	278	0.000	0.977	104	0.071
11-item social perceptions	0.937	278	0.000	0.968	104	0.015
10-item social perceptions	0.937	278	0.000	0.967	104	0.012

5.5.1 Spearman's rank order correlation coefficient

This correlation coefficient (r_s) is a non-parametric rank statistic that measures the strength of the association between two variables. It was selected for this study as it is used when the data are ordinal and when the distribution of the data would impede the interpretation of the parametric equivalent (Hauke and Kossowski 2011). In this study, this statistic assessed the convergent validity of the SPaRQ3.0 by measuring the strength of its association with the HHIE, the WHODAS 2.0, and PHQ-4. A rule of thumb states that coefficients of ± 0.6 and above represent a strong correlation, coefficients of ± 0.3 to ± 0.6 represent a moderate correlation, and coefficients of less than ± 0.3 represent a weak correlation (Fackrell et al., 2016).

5.5.2 Mann-Whitney U test

This is a non-parametric test used to compare two independent samples of scores and is the equivalent of the parametric independent t-test. It was selected for this study as it is used when the data are not normally distributed, the data are ordinal, and the subgroup sizes are uneven. This statistic was used to assess discriminative validity by testing whether participants with high scores on the PHQ-4 obtained different scores on the SPaRQ3.0 than participants with low PHQ-4 scores.

5.5.3 Cronbach's alpha

This statistic was used as the primary index of the internal consistency of the SPaRQ3.0. It is calculated as the mean of all of the possible split-half coefficients, with an adjustment for the number of items in the questionnaire. A split-half coefficient is obtained by dividing the items of the measure into two sets and correlating the scores of the two sets. Cronbach's alpha (α)

should fall within the range of 0.7 and 0.95 for a unidimensional scale or subscale (De Vet et al., 2011; Raykov and Marcoulides 2011). The mean inter-item correlation, or the average of all of the correlations between each pair of items, and the mean item-total correlation, or the average of all of the correlations between each item and the total score, were also calculated as further indicators of internal consistency.

5.5.4 Descriptive statistics

Descriptive statistics were used to investigate the floor and ceiling effects in the SPaRQ3.0. Specifically, the percentage of participants who selected the highest response option (i.e. 10) and the lowest response option (i.e. 0) on the response scale for each item was calculated (McHorney and Tarlov 1995; Terwee et al., 2007). Histograms of the distribution of responses to each item were also examined.

5.6 RESULTS

5.6.1 Hypothesis testing results

Following the assessment of the structural validity of the SPaRQ3.0 through factor analysis and Rasch analysis in Study 3, specific hypotheses were formulated and subsequently tested in order to establish its convergent validity and discriminative validity.

5.6.1.1 Data screening

The analysis was performed on the mean scores of **(1)** the subscales of the SPaRQ3.0, **(2)** the HHIE and its subscales, **(3)** the shortened WHODAS 2.0, and **(4)** the PHQ-4 and its subscales. Three participants were excluded from the Study 3 dataset, as they had a majority (i.e. $\geq 50\%$) of 'Does not apply to

me' or missing scores for the SPaRQ3.0 items. Therefore, the data of 276 participants were included in the Study 3 analysis. There were no missing data in the Study 4 dataset and so all 102 participants were included in the analysis. Item 34 and Item 41 in the social perceptions subscale were rescored, as Rasch analysis demonstrated that these items are better suited to a seven point response scale than an 11-point response scale. It was confirmed through repeating the analysis that the results would not have changed if the 11-point response scale had been applied to all of the items.

5.6.1.2 Social behaviours subscales

The results showed that, as required, more than 75% of the hypotheses were confirmed for the social behaviours subscales (Terwee et al., 2007).

Prediction 1: It was predicted that there would be strong, positive correlations ($r_s \geq 0.6$) between the social behaviours subscales and the HHIE (i.e. overall scale and each subscale), as both questionnaires are hearing-specific and have some similar content. This prediction was confirmed by the Study 3 and Study 4 results (see Table 5.3).

Prediction 2: It was predicted that there would be moderate, positive correlations ($r_s = 0.3$ to 0.6) between the social behaviours subscales and the shortened WHODAS 2.0. This was based on the fact that both questionnaires have similar content, as the WHODAS measures activity and participation, as conceptualised by the ICF, yet is generic, rather than hearing-specific. The Study 3 and Study 4 results confirmed this prediction.

Prediction 3: It was predicted that there would be moderate, positive correlations ($r_s = 0.3$ to 0.6) between the social behaviours subscales and the

PHQ-4 (i.e. overall scale and each subscale). This was based on the fact that, although the two questionnaires measure different constructs, previous research has provided evidence of an association between hearing loss and poor psychological wellbeing, as well as between social participation restrictions and poor psychological wellbeing. The Study 3 and Study 4 results confirmed this prediction, with the exception of the correlations with the anxiety subscale in the Study 3 dataset, which fell just below the 0.3 threshold.

Table 5.3 Social behaviours subscale Spearman's rank order correlation coefficients*

Questionnaire	Study 3 data		Study 4 data	
	10 items	9 items	10 items	9 items
HHIE				
- Overall scale	0.706	0.705	0.691	0.692
- Situational subscale	0.688	0.685	0.655	0.656
- Emotional subscale	0.675	0.676	0.661	0.664
12 Item WHODAS 2.0				
- Scale: Simple scoring	0.427	0.435	0.521	0.511
- Scale: Complex scoring	0.410	0.418	0.502	0.492
PHQ-4				
- Overall scale	0.318	0.325	0.436	0.430
- Anxiety subscale	0.275	0.280	0.395	0.388
- Depression subscale	0.333	0.343	0.417	0.412

***All correlations were statistically significant ($p < .01$)**

Prediction 4: It was predicted that the participants who obtained a score of three or more on the PHQ-4 anxiety subscale would have significantly higher scores on the social behaviours subscales than participants who obtained a score of less than three. This prediction was confirmed by the Study 3 results for the 10 item social behaviours subscale, with the participants who had an

anxiety score of at least three obtaining a significantly higher mean rank ($N=39$, mean rank=182) than participants who had an anxiety score of less than three ($N=237$, mean rank=131.34): $U(278)=2925$, $Z=-3.67$, $p=0.000$.

This prediction was also confirmed for the 9 item social behaviours subscale, with the participants who had anxiety score of at least three obtaining a significantly higher mean rank ($N=39$, mean rank=182.67) than participants with an anxiety score of less than three ($N=237$, mean rank=131.23): $U(278)=2899$, $Z=-3.73$, $p=0.000$.

This prediction was also confirmed by the Study 4 results for the 10 item social behaviours subscale, with the participants who scored at least three obtaining a significantly higher mean rank ($N=25$, mean rank=66.5) than participants who scored less than three ($N=77$, mean rank=46.63):

$U(104)=1337.5$, $Z=2.92$, $p=0.004$. This prediction was also confirmed for the 9 item social behaviours subscale, with the participants who scored at least three obtaining a significantly higher mean rank ($N=25$, mean rank=66.16) than participants who scored less than three ($N=77$, mean rank=46.74):

$U(104)=1329$, $Z=2.85$, $p=0.004$. The Study 4 results remain significant even if a correction is applied for carrying out multiple tests of statistical significance by dividing the alpha level (i.e. 0.05) by the total number of tests (i.e. 8) carried out for Prediction 4 and Prediction 5 leading to a new alpha level (i.e. 0.00625).

Prediction 5: It was predicted that the participants who obtained a score of three or more on the PHQ-4 depression subscale would have higher scores on the social behaviours subscales than participants who obtained a score of less than three. This prediction was confirmed by the Study 3 results for the

10 item social behaviours subscale, with the participants who had a depression score of at least three obtaining a significantly higher mean rank ($N=28$, mean rank=196.05) than participants who had an anxiety score of less than three ($N=248$, mean rank=132): $U(278)=1860.5$, $Z=-4.03$, $p=0.000$. This prediction was also confirmed for the 9 item social behaviours subscale, with the participants who had a depression score of at least three obtaining a significantly higher mean rank ($N=28$, mean rank=196.05) than participants with a depression score of less than three ($N=248$, mean rank=131.97): $U(278)=1852$, $Z=-4.05$, $p=0.000$.

This prediction was also confirmed by the Study 4 results for the 10 item social behaviours subscale, with the participants who scored at least three obtaining a significantly higher mean rank ($N=25$, mean rank=72.72) than participants who scored less than three ($N=77$, mean rank=44.61): $U(104)=1493$, $Z=4.13$, $p=0.000$. This prediction was also confirmed for the 9 item social behaviours subscale, with the participants who scored at least three obtaining a significantly higher mean rank ($N=25$, mean rank=72.66) than participants who scored less than three ($N=77$, mean rank=44.63): $U(104)=1491.5$, $Z=4.12$, $p=0.000$.

5.6.1.3 Social perceptions subscales

The results showed that all five hypotheses were confirmed for the social perceptions subscales, which exceeds the required 75% threshold (Terwee et al., 2007).

Prediction 1: It was predicted that there would be strong, positive correlations ($r_s \geq 0.6$) between the social perceptions subscales and the HHIE (i.e. overall scale and each subscale), as the questionnaires are both

hearing-specific and have some similar content. This prediction was confirmed by both the Study 3 and Study 4 results (see Table 5.4).

Table 5.4 Social perceptions subscale Spearman's rank order correlation coefficients*

Questionnaire	Study 3 data		Study 4 data	
	11 items	10 items	11 items	10 items
HHIE				
- Overall scale	0.794	0.795	0.798	0.793
- Situational subscale	0.751	0.753	0.719	0.712
- Emotional subscale	0.782	0.782	0.793	0.788
12 Item WHODAS 2.0				
- Scale: Simple scoring	0.428	0.429	0.443	0.454
- Scale: Complex scoring	0.411	0.411	0.429	0.442
PHQ-4				
- Overall scale	0.398	0.398	0.478	0.474
- Anxiety subscale	0.354	0.351	0.466	0.464
- Depression subscale	0.401	0.402	0.419	0.410

* All correlations were statistically significant ($p < .01$)

Prediction 2: It was predicted that there would be moderate, positive correlations ($r_s = 0.3$ to 0.6) between the social perceptions subscales and the shortened WHODAS 2.0. This was based on the fact that, whilst the WHODAS 2.0 also measures participation, it is generic, rather than hearing-specific, and it emphasises behaviour, rather than emotion. This prediction was confirmed.

Prediction 3: It was predicted that there would be moderate, positive correlations ($r_s = 0.3$ to 0.6) between the social perceptions subscales and the PHQ-4 (i.e. overall scale and each subscale). This is because, although the two questionnaires measure different constructs, previous research has provided evidence of an association between hearing loss and poor

psychological wellbeing, as well as between social participation restrictions and poor psychological wellbeing. This prediction was confirmed.

Prediction 4: It was predicted that the participants who obtained a score of three or more on the PHQ-4 anxiety subscale would have higher scores on the social perceptions subscales than participants who obtained a score of less than three. The Study 3 results confirmed this prediction, with the participants who had an anxiety score of at least three obtaining a significantly higher mean rank ($N=39$, mean rank=186.54) on the 11-item social perceptions subscale than participants who had an anxiety score of less than three ($N=237$, mean rank=130.59): $U(278)=2748$, $Z=-4.06$, $p=0.000$. Also, participants who had an anxiety score of at least three obtained a significantly higher mean rank ($N=39$, mean rank=187.12) on the 10-item social perceptions subscale than participants who had an anxiety score of less than three ($N=237$, mean rank=130.5): $U(278)=2725.5$, $Z=-4.11$, $p=0.000$.

This prediction was also confirmed by the Study 4 results, with the participants who scored at least three obtaining a significantly higher mean rank ($N=25$, mean rank=69.52) on the 11-item social perceptions subscale than participants who scored less than three ($N=77$, mean rank=45.65): $U(104)=1413$, $Z=3.51$, $p=0.000$. Also, participants who had scored at least three obtained a significantly higher mean rank ($N=25$, mean rank=69.12) on the 10-item social perceptions subscale than participants who scored less than three ($N=77$, mean rank=45.78): $U(104)=1403$, $Z=3.43$, $p=0.000$.

Prediction 5: It was predicted that the participants who obtained a score of three or more on the PHQ-4 depression subscale would have higher scores

on the social perceptions subscales than participants who obtained a score of less than three. This prediction was confirmed by the Study 3 results, with the participants who had a depression score of at least three obtaining a significantly higher mean rank ($N=28$, mean rank=202.32) on the 11-item social perceptions subscale than participants who had a depression score of less than three ($N=248$, mean rank=131.29): $U(278)=1685$, $Z=-4.46$, $p=0.000$. Also, participants who had a depression score of at least three obtained a significantly higher mean rank ($N=28$, mean rank=202.63) on the 10-item social perceptions subscale than participants who had a depression score of less than three ($N=248$, mean rank=131.26): $U(278)=1676.5$, $Z=-4.49$, $p=0.000$.

This prediction was also confirmed by the Study 4 results, with the participants who scored at least three obtaining a significantly higher mean rank ($N=25$, mean rank=71.62) on the 11-item social perceptions subscale than participants who scored less than three ($N=77$, mean rank=44.97): $U(104)=1465.5$, $Z=3.91$, $p=0.000$. Also, participants who scored at least three obtained a significantly higher mean rank ($N=25$, mean rank=71.04) on the 10-item social perceptions subscale than participants who scored less than three ($N=77$, mean rank=45.16): $U(104)=1451$, $Z=3.8$, $p=0.000$.

5.6.2 Internal consistency results

5.6.2.1 Data screening

List-wise deletion was used for this analysis, which meant that any participants with at least one missing score were entirely excluded from the analysis. Once again, Item 34 and Item 41 were rescored, in accordance

with the Rasch analysis results in Chapter 4. It was confirmed through repeating the analysis that the results would not have changed if the original scoring system had been applied to all of the items.

5.6.2.2 Inter-item and item-total correlations

The mean inter-item correlation and mean item-total correlation for the SPaRQ3.0 subscales indicated that they had good internal consistency (see Table 5.5).

Table 5.5 Mean inter-item correlations and mean item-total correlations

Study 3 data	N	Mean inter-item correlation	Mean item-total correlation
10-item social behaviours subscale	242	0.681	0.806
9-item social behaviours subscale	242	0.707	0.827
11-item social perceptions subscale	247	0.743	0.847
10-item social perceptions subscale	251	0.751	0.851
Study 4 data	N	Mean inter-item correlation	Mean item-total correlation
10-item social behaviours subscale	102	0.629	0.768
9-item social behaviours subscale	102	0.639	0.772
11-item social perceptions subscale	102	0.643	0.780
10-item social perceptions subscale	102	0.655	0.786

5.6.2.3 Cronbach's alpha

The Cronbach's alpha values (see Table 5.6) of the SPaRQ3.0 subscales were all above the required threshold of 0.7 (De Vet et al., 2011; Raykov and Marcoulides 2011).

Table 5.6 Cronbach's alpha values

Study 3 data	N	α
10-item social behaviours subscale	242	0.956
9-item social behaviours subscale	242	0.956
11-item social perceptions subscale	247	0.970
10-item social perceptions subscale	251	0.968
HHIE	261	0.956
HHIE situational subscale	264	0.898
HHIE emotional subscale	275	0.935
12-Item WHODAS 2.0 (simple scoring)	266	0.902
12-Item WHODAS 2.0 (complex scoring)	266	0.883
PHQ-4	277	0.886
PHQ-4 anxiety subscale	278	0.882
PHQ-4 depression subscale	278	0.836
Study 4 data	N	α
10-item social behaviours subscale	102	0.944
9-item social behaviours subscale	102	0.941
11-item social perceptions subscale	102	0.952
10-item social perceptions subscale	102	0.950
HHIE	102	0.931
HHIE situational subscale	102	0.857
HHIE emotional subscale	102	0.897
12-Item WHODAS 2.0 (simple scoring)	102	0.929
12-Item WHODAS 2.0 (complex scoring)	102	0.902
PHQ-4	102	0.923
PHQ-4 anxiety subscale	102	0.872
PHQ-4 depression subscale	102	0.901

5.6.3 Floor and ceiling effects results

Table 5.7 and Table 5.8 show the percentage of participants who were located at the floor (i.e. the response option of '0') and ceiling (i.e. the response option of '10') of each item in the social behaviours subscale and the social perceptions subscale. Floor effects ($n \geq 15\%$ at floor) and ceiling effects ($n \geq 15\%$ at ceiling) are depicted in bold font in these tables (Terwee

et al., 2007). Figure 5.1 and Figure 5.2 provide examples of an item with a ceiling effect and an item with a floor effect respectively.

Table 5.7 Social behaviours subscales floor and ceiling effects

Study 3 data	n at floor (%)	n at ceiling (%)
Item 1	1.8	32.3
Item 6	23.3	5
Item 8	7.2	16.1
Item 11	24.7	8.2
Item 12	7.5	14.7
Item 14	14.3	11.1
Item 16	11.8	8.6
Item 17	30.5	5.4
Item 19	22.6	5.4
Item 23	11.8	10.8
Study 4 data	n at floor (%)	n at ceiling (%)
Item 1	3.9	46.1
Item 6	8.8	7.8
Item 8	2	19.6
Item 11	5.9	6.9
Item 12	2.9	20.6
Item 14	7.8	14.7
Item 16	3.9	16.7
Item 17	17.6	4.9
Item 19	13.7	10.8
Item 23	5.9	14.7

5.7 DISCUSSION

This study aimed to assess the psychometric properties of the SPaRQ3.0.

Evidence was obtained to support the hypothesis testing validity and the internal consistency of the social behaviours and the social perceptions subscales. Below, the results are discussed in greater detail in terms of the specific objectives of this study.

Table 5.8 Social perceptions subscales floor and ceiling effects

Study 3 data	n at floor (%)	n at ceiling (%)
Item 28	16.5	14.7
Item 29	10	21.5
Item 30	12.9	18.6
Item 32	14.3	18.3
Item 34	33.7	10
Item 36	25.1	10
Item 38	11.8	19.7
Item 39	19.4	15.4
Item 41	27.2	11.8
Item 44	21.1	15.4
Item 51	21.1	15.1
Study 4 data	n at floor (%)	n at ceiling (%)
Item 28	7.8	14.7
Item 29	2	32.4
Item 30	4.9	21.6
Item 32	7.8	20.6
Item 34	22.5	8.8
Item 36	16.7	9.8
Item 38	2	28.4
Item 39	8.8	12.7
Item 41	12.7	11.8
Item 44	10.8	18.6
Item 51	9.8	17.6

5.7.1 Hypothesis testing

5.7.1.1 Convergent validity

This form of validity was assessed by testing hypotheses about the relationships between the SPaRQ3.0 subscales and three existing questionnaires. As predicted, the social behaviours subscales and the social perceptions subscales each had strong, positive correlations with the hearing-specific, psychosocial questionnaire (i.e. the HHIE) and moderate,

positive correlations with the generic activity and participation questionnaire (i.e. shortened WHODAS 2.0) and the mental health screening tool (i.e. the PHQ-4). This finding provides support for the convergent validity of each subscale in the SPaRQ3.0.

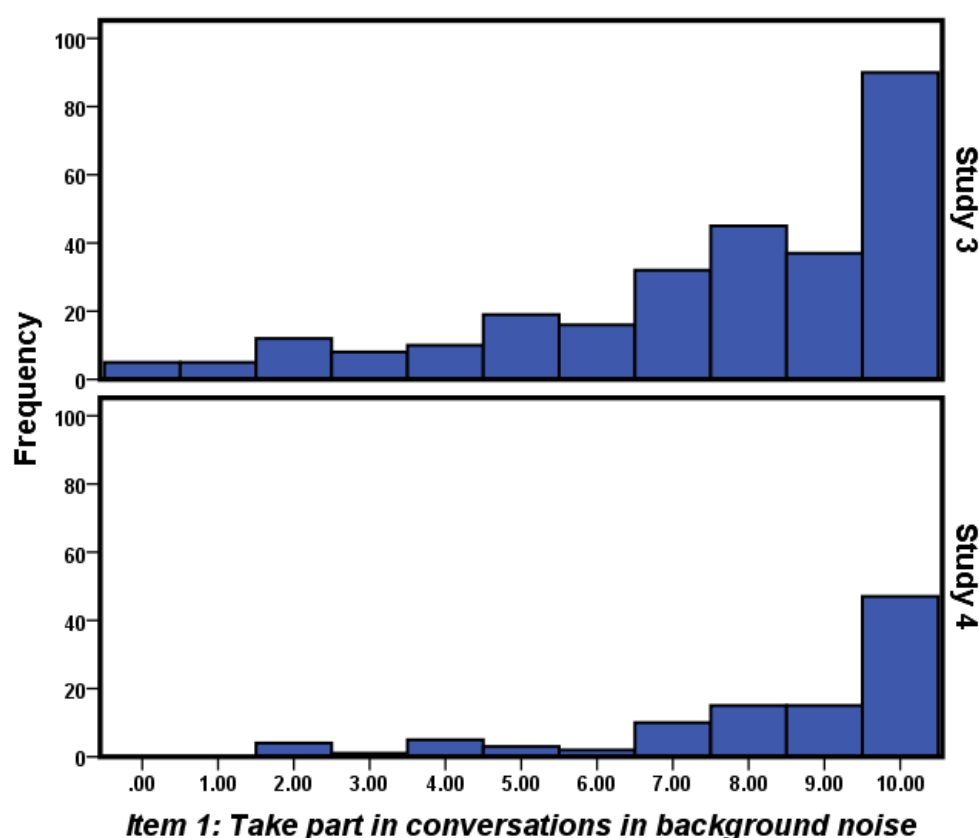


Figure 5.1 Histogram of an item displaying a ceiling effect

5.7.1.2 Discriminative validity

The study also produced support for the discriminative validity of the SPaRQ3.0, or its ability to distinguish between different participant subgroups. As predicted, participants who scored at least three on the PHQ-4 anxiety subscale, which is indicative of having anxiety, had significantly higher SPaRQ3.0 scores than the remaining participants. This result was

replicated for the PHQ-4 depression subscale. Taken together, the results of the convergent validity analysis and discriminative validity analysis, in which more than 75% of the hypotheses were confirmed, provide support for the construct validity of the questionnaire (Terwee et al., 2007). Additional support for construct validity came from the investigation of the structural validity of the questionnaire in Study 3, particularly the Rasch analysis results. This means that the SPaRQ3.0 is a valid measure of the target construct: hearing-related social participation restrictions.

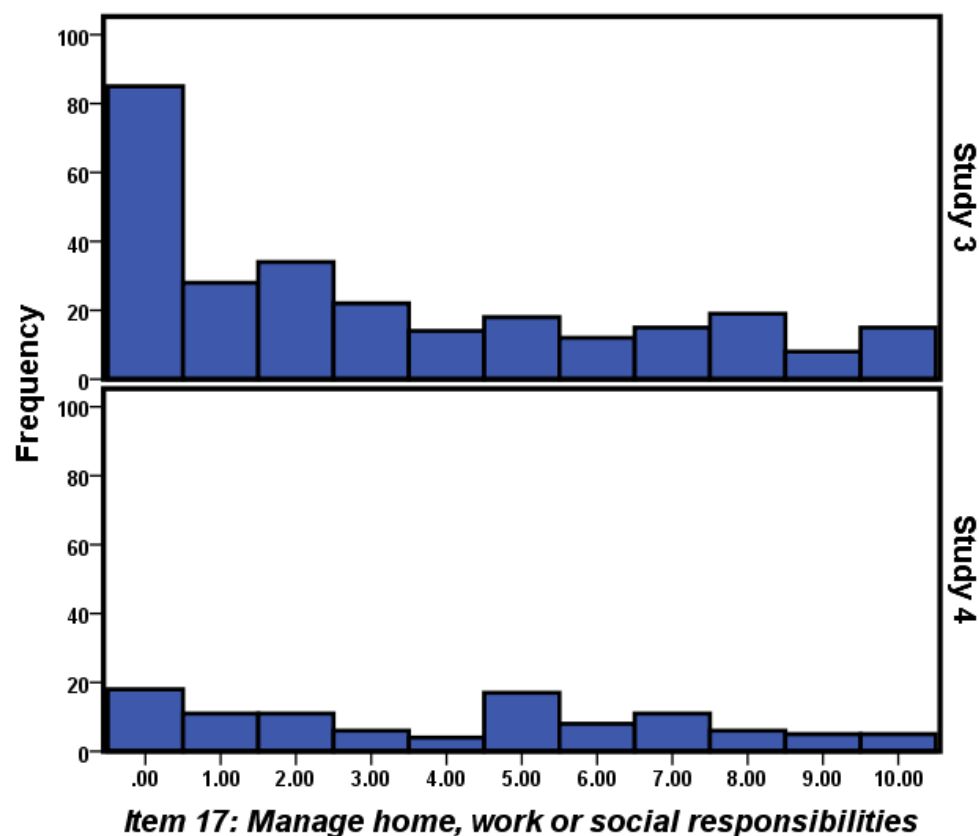


Figure 5.2 Histogram of an item displaying a floor effect

A limitation of the discriminative validity analysis was that the subgroups who had high depression and anxiety scores on the PHQ-4 had small sample

sizes ranging from 25 to 39 cases. The COSMIN checklist, which is used to assess the methodological quality of questionnaire validation studies, rates discriminative validity samples sizes of less than 30 cases as 'poor', 30-49 cases as 'fair', 50-99 cases as 'good', and 100 or more as 'excellent' (Mokkink et al., 2011). Also, subgroups were unequal in size. Therefore, the methodological quality of the discriminative validity analysis was less than ideal. Future research should further examine the discriminative validity of the SPaRQ3.0, including an examination of different types of participant subgroups with larger sample sizes.

5.7.2 Internal consistency

The social behaviours subscales and the social perceptions subscales were found to have high Cronbach's alpha values, with each value exceeding the required threshold of 0.7 (De Vet et al., 2011; Terwee et al., 2007). This demonstrates that the SPaRQ3.0 has high internal consistency. This conclusion is supported by the Rasch analysis results, chiefly the test of unidimensionality results, from the previous chapter. However, some of the Cronbach's alpha values for the SPaRQ3.0 subscales exceeded 0.95, which can indicate that the questionnaire contains redundant items (Pesudovs et al., 2007; Streiner 2003; Terwee et al., 2007). Redundant items are items that are correlated so strongly with other items in the same questionnaire that they add little value to that questionnaire. In addition, the inclusion of redundant items means that their content has a disproportionate weight in the total score, that respondent burden is increased, and that internal consistency is artificially inflated. However, the Rasch analysis results in Study 3 demonstrated that the SPaRQ3.0 subscales have relatively low

levels of response dependency, suggesting that the high Cronbach's alpha values are not attributable to the presence of redundant items. Cronbach's alpha can also be artificially inflated by having a relatively large number of items in a measure (Streiner 2003). For example, it has been found that any scale of 20 items would have a high Cronbach's alpha (Cortina 1993). This may not have been the case for the SPaRQ3.0, as the subscales had a maximum of 11 items. It is more likely that the large number of response options in the response scale contributed to the high Cronbach's alpha values (Weng 2004).

As the above passage suggests, the Cronbach's alpha statistic has several limitations that mean it must be interpreted with caution. For instance, as with many traditional psychometric analysis statistics, it is not a property of the questionnaire itself but is a characteristic of the questionnaire scores, which means that its value changes from one sample to another (Streiner 2003). Consequently, the internal consistency of the SPaRQ3.0 must be re-examined in future administrations of this questionnaire. These limitations mean that Cronbach's alpha is often reported as a matter of tradition, rather than because it is an informative statistic (Pesudovs et al., 2007). Nevertheless, it remains a requirement of many quality criteria checklists (Pesudovs et al., 2007; Terwee et al., 2007), though this may change following the advent of modern psychometric analysis.

5.7.3 Floor and ceiling effects

The results showed that several SPaRQ3.0 items displayed floor effects or ceiling effects. In the social behaviours subscale, a total of four items displayed floor effects. In other words, more than 15% of the respondents

selected 'zero' as their answer for these items. These items concerned having difficulty with carrying out pastimes, managing stressful situations, managing responsibilities, and attending get-togethers with friends. This result suggests that few individuals with hearing loss experience difficulty with these activities. In the social perceptions subscale, a total of seven items displayed floor effects. However, three of these items displayed not only floor effects but also ceiling effects. In addition, Item 28, which concerned finding social gatherings stressful, had a relatively small floor effect, as only 16.5% of respondents selected 'zero' for this item. The remaining items with floor effects concerned feeling lonely around others, isolated at get-togethers, or worried about talking to unfamiliar people. This suggests that few adults with hearing loss have these emotional experiences. Items with floor effects can have a negative impact on the responsiveness of a questionnaire, as many participants are unlikely to show change over time on these items because they are not experiencing the difficulties captured by the items.

In the social behaviours subscale, four items in total displayed ceiling effects. In other words, more than 15% of the respondents selected 'ten' as their answer for these items. Item 1, which concerned conversing in the presence of background noise, had a substantial ceiling effect. Rasch analysis previously identified this item as being a candidate for removal from the questionnaire. In contrast, Item 16, which concerned communicating with staff in shops, cafes or banks, had a relatively small ceiling effect, with only 16.7% of respondents selecting 'ten' as their answer for this item. The other two items concerned having difficulty with following a talk or lecture and

difficulty taking part in a group discussion or meeting. This suggests that many individuals with hearing loss experience difficulty with these activities. In the social perceptions subscale, seven items in total had ceiling effects. Three of these items had marginal ceiling effects and also had floor effects. The remaining four items concerned feeling worried about missing important sounds, isolated during group conversations, frustrated when left out of conversations and unenthusiastic about joining in conversations when it is difficult to hear. This suggests that many individuals with hearing loss have these emotional experiences.

Ceiling effects are potentially less problematic than floor effects in terms of their impact on the responsiveness of the questionnaire, as it may be possible for the respondents to show change over time on these items. For example, participants may display an improvement on these items if they receive a new intervention for hearing loss or if their self-management of their hearing loss changes. The majority of participants in this study had already received an intervention for hearing loss in the form of hearing aids. The presence of ceiling effects on several items indicates that certain social situations, especially conversations in background noise, remain difficult despite the fitting of hearing aids. Ideally, the SPaRQ3.0 questionnaire should be validated in a clinical trial with a patient population to see if these effects remain. Such a population may display fewer floor effects than the sample in this research, who were largely experienced hearing aid users. It is possible that these items would capture change over time if administered to participants before and after the fitting of hearing aids or another intervention or combination of interventions.

Furthermore, this study used stringent criteria for floor and ceiling effects, which was based on 15% of respondents selecting the lowest response option or the highest response option respectively (McHorney and Tarlov 1995; Terwee et al., 2007). It has been acknowledged that this 15% cut-off point is arbitrary and thus may be a questionable means of evaluating the quality of a questionnaire, particularly because floor and ceiling effects can change depending on the sample being measured (Bot et al., 2003). Others regard a cut-off point of 50% of respondents selecting the lowest response option or the highest response option as appropriate indicators of floor and ceiling effects (Pesudovs et al., 2007). Using these criteria, none of the SPaRQ3.0 items display floor or ceiling effects. This aligns with the Rasch analysis results, which showed that the each subscale was well-targeted.

5.7.4 Limitations

One limitation of this research, which was outlined in the previous chapter, is that the restricted resources of this study meant that pure tone audiometry could not be performed on the participants. Instead, a validated hearing loss screening questionnaire (Davis et al., 2007) was used. Consequently, it was not possible to obtain the exact degree of hearing loss of each participant or relate it to their SPaRQ3.0 scores. Another limitation of this research, also discussed in previous chapters, is that the majority of the participants were recruited through the BRU participant database, which means that they may not be representative of all adults with hearing loss. Efforts were made in Study 3 to recruit participants through audiology clinics but this approach was discontinued in Study 4, as it proved to be inefficient.

Furthermore, in Study 4, the nine item social behaviours subscale was examined by deleting the Item 1 responses from the 10-item social behaviours subscale dataset during the data analysis. Similarly, the 10-item social perceptions subscale was examined by deleting the Item 44 responses from the 11-item social perceptions subscale dataset during the data analysis. However, the optimum approach would have been to analyse the nine item social behaviours subscale and the 10-item social perceptions subscale by obtaining another sample of data by recruiting an additional 100 participants to complete these shortened subscales. This is because even relatively small changes, such as removing one or two items, could have an impact on the psychometric properties of the questionnaire (Hyde 2000). Unfortunately, the ideal approach could not be adopted in Study 4, as the BRU participant database had been exhausted and the other recruitment streams had proven to be inefficient in Study 3.

Another limitation of this research is that the SPaRQ and the validated questionnaires used for assessing hypothesis testing validity were administered to participants on one single occasion. This is a shortcoming because, ideally, participants should receive the questionnaire undergoing development prior to receiving the validated questionnaires so that responses to the former do not influence responses to the latter (De Vet et al., 2011). Unfortunately, it was not possible to administer the questionnaires on separate occasions due to the limited resources and time constraints of this research. It is actually common practice in investigations of convergent and discriminant validity to administer all of the relevant questionnaires to participants on one occasion. This includes investigations of the convergent

and discriminant validity of the Tinnitus Functional Index (Fackrell et al., 2016), the World Health Organization Disability Assessment Schedule II (Chisolm et al., 2005), and the ICF Measure of Participation and Activities Screening Questionnaire (Post et al., 2008).

A final limitation stems from the fact that it is preferable for convergent validity and discriminative validity hypotheses to be formulated after structural validity has been assessed and before data has been collected for hypothesis testing (De Vet et al., 2011; Mokkink et al., 2012). In Study 3, the data for the assessment of structural validity and the data for hypothesis testing were collected at the same time. In other words, participants were provided with the SPaRQ2.0 and the validated questionnaires in one postal, paper-and-pen questionnaire booklet. The decision to post all of the questionnaires in one booklet, rather than to post two sets of questionnaires in two successive booklets, was based on the aforementioned limited resources and time constraints of the research. It was also thought that requiring participants to complete and return two separate booklets would be confusing and burdensome, leading to a loss of data. Therefore, it was only possible to formulate broad, initial hypotheses prior to the collection of data for hypothesis testing. Specific hypotheses could not be formulated until after all of the data had been collected, structural validity had been assessed, and the SPaRQ had been refined. They were, of course, formulated before the data from the validated questionnaires were analysed. Ultimately, the specific hypotheses were essentially the same as the initial, broad hypotheses.

5.7.5 Future research

This study was the final step of a mixed methods, multi-stage doctoral programme of research that aimed to develop a new hearing-specific participation restrictions outcome measure. The study provided support for the psychometric properties of the questionnaire. In particular, evidence was obtained to support the hypothesis testing validity and internal consistency of each subscale, though several items did display floor and ceiling effects. These results, alongside the findings of the previous research studies, show that this measure has strong measurement properties.

In addition, the results of this study were used to finalise the outcome measure and thus bring its development phase to an end. Specifically, it was concluded that the questionnaire should contain a nine item social behaviours subscale and a 10-item social perceptions subscale (see Appendix L). As such, the SPaRQ measures two distinct but important aspects of social participation restrictions. It was determined that two additional items, Item 1 and Item 44, should be excluded from the questionnaire. This was because their inclusion did not improve the psychometric properties of the measure, according to the traditional psychometric analysis results of this study. For example, the internal consistency of each subscale remained high, whether or not these items were included. Also, Item 1 displayed a large ceiling effect, indicating that it was not an informative question. Furthermore, the Rasch analysis in the previous study demonstrated that each item displayed poor fit and they contributed to poor overall fit to the Rasch model. Consequently, it was

decided that these items should not feature in the finalised SPaRQ, particularly given that Rasch analysis is widely considered to be superior to traditional psychometric analysis in terms of identifying items for removal.

As with all outcome measures, the conclusion of the development phase does not mean that research relating to the questionnaire should come to an end. Ideally, a validation phase should commence in which new measurement properties are assessed in new populations. This reflects the fact that questionnaire development and validation are iterative processes that never truly reach an end. For instance, the conceptualisation of the target construct, related hypotheses, and the measure itself should be continually refined as more research is carried out and more data becomes available (Smith 2005). In addition, there is always scope to examine cross-cultural applications and translations of existing outcome measures (Terwee et al., 2007). Furthermore, the quality criteria for outcome measures is continually evolving, particularly as more modern psychometric analyses emerge (Pesudovs et al., 2007; Smith 2005). The strong measurement properties of the SPaRQ demonstrate that this questionnaire has the potential to become a gold-standard measure in clinical trials and clinical practice. As such, it is a worthy candidate for further validation, particularly in the absence of an existing gold-standard, hearing-specific outcome measure. In particular, the SPaRQ could be investigated as part of a longitudinal study in a clinical population so that additional measurement properties, such as responsiveness, can be assessed. These ideas will be explored in greater depth in the forthcoming discussion chapter, which will bring this doctoral thesis to a close.

CHAPTER 6. DISCUSSION

6.1 SUMMARY OF RESEARCH AND KEY FINDINGS

Restricted social participation is one of the most substantial consequences of hearing loss (Gopinath et al., 2012a; Kramer et al., 2002). Therefore, it is crucial for researchers and practitioners to demonstrate that auditory rehabilitation services and interventions can help adults with hearing loss to overcome these restrictions (Boothroyd 2007). However, it has been recognised that, at present, there is a lack of high quality evidence to support auditory rehabilitation (Barker et al., 2014; Henshaw and Ferguson 2013a).

One reason for this is that, currently, there are no agreed-upon gold-standard, hearing-specific outcome measures (Akeroyd et al., 2015; Granberg et al., 2014a). Consequently, the primary aim of this doctoral programme of research was to develop a questionnaire that could serve as a gold-standard outcome measure of participation restrictions in adults with hearing loss. This aim was achieved by conducting four consecutive studies (see Table 6.1) using techniques that have been featured in current best practice guidelines but that remain novel in the field of hearing research (Mokkink et al., 2012; Pesudovs et al., 2007; Turk et al., 2006).

Study 1 was a qualitative exploration of the psychosocial experiences of adults with hearing loss using the self-regulatory model or SRM (Leventhal, Meyer and Nerenz 1980) as a theoretical framework. The findings of Study 1 were coupled with the findings of a literature review in order to devise an initial conceptual model of the target construct: hearing-related participation restrictions. This model contained three domains that proposed to be pertinent to the target construct and that are negatively affected by hearing

loss: behaviour, emotion, and identity. A pool of 49 items was then generated to measure these key domains. The behaviour items were paired with a self-efficacy response scale, whilst the emotion and identity items were paired with an agree/disagree response scale, thus creating the first prototype of the Social Participation Restrictions Questionnaire (i.e. SPaRQ1.0).

Table 6.1 Summary of programme of research

Aim	Methods	Participants	Analysis
Study 1: Explore psychosocial experiences of adults with hearing loss	Semi-structured interviews	25 adults with hearing loss & 9 hearing healthcare professionals	Deductive thematic analysis
Study 2: Evaluate the content of the first 49-item SPaRQ prototype	Cognitive interviews & subject matter expert survey	14 adults with hearing loss & 20 hearing healthcare professionals	Deductive thematic analysis, taxonomy of respondent problems, & descriptive statistics
Study 3: Assess the psychometric properties of the second 53-item SPaRQ prototype	Postal administration of the measure	279 adults with hearing loss	Rasch analysis
Study 4: Assess the psychometric properties of the third 21-item SPaRQ prototype	Online administration of the measure	102 adults with hearing loss	Traditional psychometric analysis

Study 2 evaluated the content validity of this measure, with the results showing that the majority of items had good representativeness and clarity.

In addition, the questionnaire as a whole had good acceptability, as it was not intrusive or offensive, and good comprehensiveness, as it included most of the difficulties experienced by individuals with hearing loss in daily life. However, many adults with hearing loss found it difficult to switch from using the self-efficacy response scale that accompanied the behaviour items to using the agree/disagree response scale that accompanied the emotion and identity items, leading to inaccurate responding. Therefore, it was necessary to remove the self-efficacy scale, leaving the agree/disagree scale as the only response scale in the questionnaire. In addition, several items were revised and a small number of new items were introduced in order to enhance the clarity and comprehensiveness of the measure. These refinements helped to ensure that the questionnaire had acceptable content validity and minimal respondent burden.

The principal aims of Study 3 were to assess the psychometric properties of the second prototype of the questionnaire, the 53-item SPaRQ2.0, and to refine the measure using Rasch analysis. An analysis of the structural validity of the questionnaire demonstrated that it was multidimensional, rather than unidimensional. Subsequently, two unidimensional subscales were created: the social behaviours subscale, which was derived from the behaviour items, and the social perceptions subscale, which was derived from the emotion and identity items. Over 30 items with poor psychometric properties, including poor fit and response dependency, were removed. Two of the social perceptions items were found to require an adjusted scoring system. Each subscale had strong psychometric properties, including good fit to the Rasch model, local independence, good targeting, good person

separation, and an absence of differential item functioning (DIF), or item bias. Two additional items could be added to the measure without compromising its psychometric properties, with the exception of fit to the Rasch model.

The final study aimed to further evaluate the psychometric properties of the third prototype of the questionnaire: the 21-item SPaRQ3.0. The results showed the questionnaire had good hypothesis testing validity, including both convergent validity and discriminative validity. These results, coupled with the structural validity results from the previous study, support the construct validity of the questionnaire. However, several items displayed floor and ceiling effects, which could negatively affect the responsiveness of the measure. It was decided that all but one of these items should be retained in the questionnaire as they have the potential to be informative and because Rasch analysis showed that the questionnaire was well-targeted. Finally, the questionnaire was found to have high internal consistency. It was determined that the two additional items should be excluded from the measure because they did not improve its psychometric properties and they negatively affected overall fit to the Rasch model. Therefore, the finalised SPaRQ is a 19-item measure containing a 9-item social behaviours subscale and a 10-item social perceptions subscale. As they measure related but distinct aspects of participation restrictions, it is recommended that each subscale has its own total score, as opposed to there being a single total score for the entire questionnaire. The psychometric properties of the measure are summarised in Table 6.2 in accordance with a published quality assessment tool for health status questionnaires (Pesudovs et al., 2007).

Table 6.2 Evaluation of the quality of the finalised SPaRQ

Property	Grade	Evidence
Pre-study hypothesis	✓✓	Clear description of the aim of the measure & the intended population.
Intended population	✓✓	Measure studied in the intended population & the sample size was adequate.
Actual content area	✓	Members of the target population & subject matter experts considered the items to be relevant. Unclear whether they consider the finalised measure to be complete.
Item identification	✓✓	Comprehensive consultation of adults with hearing loss, subject matter experts, & a literature review.
Item selection	✓	Measure developed and tested with Rasch analysis, statistical justification provided for removing items, & the amount of missing data considered. However, the measure contains items with floor and ceiling effects.
Unidimensionality	✓✓	Each subscale displayed good fit to the Rasch model, passed the test of unidimensionality (Tennant and Pallant 2006), & had Cronbach's alphas >0.7. Although the subscales had Cronbach's alphas >0.9, which can be indicative of redundancy, Rasch analysis showed that the items had low response dependency (Hobart and Cano 2009)
Response scale	✓	Response scale evaluated using Rasch analysis. All items had ordered thresholds, with the exception of two items, which will have adjusted scores. However, some items displayed floor and/or ceiling effects (Terwee et al., 2007).
Convergent validity	✓	Tested against appropriate measures. Majority of correlations between 0.3 and 0.9.
Hypotheses testing	✓✓	Specific hypotheses formulated & at least 75% were confirmed (Terwee et al., 2007)
Person and item separation reliability	✓✓	PSI of each subscale was greater than 0.8. Each subscale was well-targeted, with the items assessing a range of disability. Items had low response dependency, as shown by their residual correlations being no more than 0.2 (Hobart and Cano 2009).

Key: ✓✓ Positive rating, ✓ minimal acceptable rating, X negative rating

6.2 NOVEL CONTRIBUTIONS OF THE SPARQ

It is essential to demonstrate the advantages that a new scale offers (e.g. decreased respondent burden or increased construct validity) over existing instruments (Turk et al., 2006). Therefore, the unique facets that set the SPaRQ apart from other questionnaires in the field are outlined below.

Firstly, the content of the SPaRQ was developed using input from adults with hearing loss, as well as researchers and clinicians. In contrast, few existing hearing-specific questionnaires have been developed with input from patients (Vas, Akeroyd and Hall under review). This is a serious limitation, as a crucial component of designing a subjective outcome measure is conducting qualitative research with patients so that their perspectives, language, and terminology can be incorporated into the questionnaire. This ensures that the measure has sufficient content validity and minimal respondent burden (Brod, Tesler and Christensen 2009; Lasch et al., 2010; Turk et al., 2006). In particular, it has been recommended that individual interviews or focus groups are conducted to generate content for the measure before cognitive interviews are carried out to review this content (Brod, Tesler and Christensen 2009). It is rare in hearing research that such in depth qualitative research is carried out for the purposes of outcome measure design. As a result, many existing hearing-specific questionnaires could be difficult for individuals with hearing loss to understand and could omit important content, which would reduce the quality of the data collected by those questionnaires. For instance, a recent study found that many hearing-related burdens identified in a qualitative study were under-represented by frequently used hearing-specific questionnaires, including the

GHABP, the Speech, Spatial, and Qualities of Hearing Scale or SSQ, and the Glasgow Benefit Inventory or GBI (Lucas, Katiri and Kitterick under review). A number of these under-represented burdens (e.g. loneliness, effort, stress about social situations, and reduced awareness of hazards) were, however, represented in the SPaRQ, supporting the value of the approaches taken.

A second unique facet of the SPaRQ is that it has a strong theoretical and conceptual foundation. It is recommended that one of the first steps in developing an outcome measure should be to establish the underpinning theoretical model and conceptual model for the target construct (Brod, Tesler and Christensen 2009; Patrick et al., 2011). In Study 1, the SRM (Leventhal, Meyer and Nerenz 1980) served as the theoretical framework underpinning the exploration of the psychosocial experiences of adults with hearing loss. The results of this study, along with a review of the literature, the ICF Core Sets for Hearing Loss (Danermark et al., 2013), and existing questionnaires (Granberg et al., 2014a; Seekins et al., 2012), provided the basis of the initial conceptual framework of the target construct. This conceptual framework was reviewed in Study 2 and refined in Study 3. This research represents one of the first applications of the SRM, an established health psychology model, in hearing research. It also represents one of the first applications of the recently developed ICF Core Sets for Hearing Loss.

A third unique facet of the SPaRQ is that it underwent a rigorous psychometric evaluation using both traditional and modern psychometric analyses. The majority of hearing-specific questionnaires that have undergone psychometric evaluation have used the traditional approach

based on Classical Test Theory. Modern approaches based on Latent Trait Theories, namely IRT analysis and Rasch analysis, have very rarely been used in the field (Hospers et al., 2016). To date, IRT analysis appears to have been applied to just three questionnaires designed for adults with hearing loss: the Communication Profile for the Hearing Impaired, the Hearing Attitudes in Rehabilitation Questionnaire, and the Amsterdam Inventory for Auditory Disability and Handicap (Chenault et al., 2013; Demorest, Wark and Erdman 2011; Hospers et al., 2016; Mokkink et al., 2010a). IRT analysis was primarily used to re-assess and redevelop these questionnaires, as they were originally developed using traditional psychometric analysis (Demorest and Erdman 1987; Hallam and Brooks 1996; Kramer et al., 1995). The SPaRQ is one of the first, if not the first, hearing-specific questionnaires to have been developed using modern psychometric analysis. This represents an important advance in the field, as Rasch analysis and IRT analysis are gold-standard approaches that offer numerous advantages over traditional psychometric analysis alone (Cano and Hobart 2011; Turk et al., 2006). Future research on the development and validation of hearing-specific outcome measures should utilise more modern approaches. For instance, the HHIE data collected as part of this research will be analysed using Rasch analysis in order to assess psychometric properties that have not previously been assessed for this measure, including unidimensionality, fit to the Rasch model, and DIF.

In this research, Rasch analysis was used to rigorously test the unidimensionality of the SPaRQ and found that the optimal structure of the questionnaire contains two unidimensional subscales, rather than one overall

unidimensional scale. As most hearing-specific questionnaires have not been subjected to Rasch analysis, they are assumed, rather than proven, to be unidimensional. This means that they may not be justified in recommending that a total score be calculated by summing their items (Terwee et al., 2007). Rasch analysis was also used to ensure that the SPaRQ items do not display age-related or gender-related biases. Again, most hearing-specific questionnaires have not examined DIF, which means that they could contain biased items that require removal or an adjusted scoring system. In addition, Rasch analysis was used to examine the threshold ordering of the response scale of the SPaRQ. This 11-point response scale is another unique facet of the questionnaire, as it was specifically designed to permit respondents to provide fine-grained responses and to enhance the responsiveness of the measure (Stewart and Archbold 1993). The response scale was demonstrated to function well for all of the items, with the exception of two social perceptions items that should have an adjusted scoring system. Once again, most hearing-specific questionnaires are assumed, rather than proven, to have response scales with ordered thresholds that do not necessitate adjusted scoring.

A final unique aspect of the SPaRQ is that it is one of the few hearing-specific questionnaires to have been developed in the UK. Other UK designed hearing-specific include the GHABP, the SSQ, and the GBI (Gatehouse 1999; Noble and Gatehouse 2004; Robinson, Gatehouse and Browning 1996). The SPaRQ could meet the need for a participation restrictions measure that is suited for use in UK clinical practice and research. One of the most commonly used measures of social functioning,

the HHIE, was developed in the USA in the 1980s and, consequently, contains content and language that does not appear suitable for a contemporary UK audience. For example, the HHIE uses the terms 'dumb' and 'handicapped', which are unlikely to be considered appropriate at present. Researchers and clinicians have been particularly encouraged to abandon the term 'handicapped' since the publication of the ICF (Field and Jette 2007). Although the SPaRQ is likely to be well-suited to a UK audience, it could be suited to other audiences as well, especially as it was developed with input from international hearing healthcare professionals. One direction for future research would be to translate the SPaRQ into other languages and cultural contexts and to assess its cross-cultural validity (Mokkink et al., 2012).

6.3 THEORETICAL IMPLICATIONS

6.3.1 Health psychology theory

6.3.1.1 Self-regulatory model

This research demonstrated that the SRM is an appropriate theoretical framework for the exploration of the psychosocial experiences of adults with hearing loss. Initially, a number of theoretical models from the discipline of health psychology were reviewed. Models that are currently dominant in hearing research, including the transtheoretical model and the health belief model, were discounted because they have considerable limitations, such as ignoring the important influence of emotion on behaviour (see Chapter 1 for further details). Also, these models are more appropriate for investigating health behaviour change than to examining the experience of living with a chronic condition. In contrast, the SRM is a comprehensive framework that

incorporates beliefs, emotions, and coping responses and considers how they change over time. Research from other health conditions has shown that the model has a variety of applications beyond the exploration of psychosocial experiences, including investigating the relationship between beliefs and coping behaviours, investigating the relationship between beliefs and outcomes, especially adherence, and the design of interventions (Hagger and Orbell 2003; Leventhal, Diefenbach and Leventhal 1992; McAndrew et al., 2008). Depending on the researcher's key questions, this work demonstrates the capacity of the SRM to provide valuable insights into the behaviours and experiences of individuals with hearing loss.

In addition, hearing research must adapt to recent advances in health psychology, as new frameworks regularly emerge from this growing field. In particular, there has been a trend towards the creation of 'supra-theories' that amalgamate the salient components of older models and theories (Barker, Atkins and de Lusignan 2016; Michie et al., 2005). This represents an effort to streamline the field, which has been criticised for the proliferation of overlapping frameworks that have not been adequately tested (Noar and Zimmerman 2005; Ogden 2003). One such supra-theory is the COM-B model, which in essence proposes that health behaviour change is determined by capability, motivation, and opportunity (Michie, van Stralen and West 2011). Though relatively new, this model has already been used to examine collaborative behavioural planning for hearing aid use by audiologists (Barker, Atkins and de Lusignan 2016) and barriers and facilitators to receiving rehabilitation in adults with hearing loss (Rolfe and Gardner 2016). It was developed as part of the larger Behaviour Change

Wheel framework, which facilitates the systematic design of health behaviour change interventions (Coulson et al., 2016; Michie, van Stralen and West 2011). Another supra-theory is the working model of adapting to chronic illness (Moss-Morris 2013). This recent framework is based on various chronic illness models, including the SRM, and examines how different factors, including personal, social, environmental, and condition-specific factors, ultimately lead to successful or unsuccessful adjustment. Although promising, this framework was not used in this doctoral research because it does not yet have empirical support, unlike the SRM.

6.3.1.2 Self-efficacy

This research also has implications for the conceptualisation and measurement of self-efficacy. Specifically, Study 2 investigated whether self-efficacy for participation could be incorporated into the SPaRQ. This construct has previously been incorporated into numerous healthcare questionnaires, including participation questionnaires and hearing-specific questionnaires (Amagai et al., 2012; Jennings, Cheesman and Laplante-Lévesque 2014; Sheer 2014). It has been demonstrated to be a strong predictor of health-related behaviours, including participation (Bandura 1977; Craig et al., 2015; Zulkosky 2009). However, the Study 2 results demonstrated that self-efficacy is a somewhat difficult construct to operationalise. Some participants felt that the wording of the self-efficacy response scale was unclear and possibly too elaborate. Also, this response scale proved to be somewhat inflexible, as it could only be used with the behaviour items, meaning that a different response scale was required for

the emotion and identity items, which was highly confusing for many participants.

As mentioned in Chapter 1, difficulties with the operationalising and measuring self-efficacy are not uncommon in healthcare research (Ferguson, Woolley and Munro 2016; Saunders et al., 2013; Sheer 2014). This comes despite the fact that self-efficacy is a well-established construct and there is published guidance available on composing a self-efficacy questionnaire (Bandura 2006). A major barrier to operationalising self-efficacy is the heterogeneous representation of the construct. For example, different self-efficacy response scales use different terms from one another, including confidence, certainty, knowledge, and intentions (Sheer 2014). This may be because the term 'self-efficacy' itself cannot be used in a questionnaire because it is an academic term that is likely to be unfamiliar to lay people and that does not have an obvious plain English equivalent. Academics themselves can struggle to grasp the concept, often confusing it with related constructs, including locus of control, self-esteem, and self-confidence (Maibach and Murphy 1995). It seems that self-efficacy is a complex construct that is difficult to represent in a way that is simultaneously conceptually accurate and easy to understand. Therefore, consensus is needed on how best to operationalise this construct in healthcare questionnaires.

6.3.2 Conceptualisation of participation restrictions

6.3.2.1 Definition of participation restrictions

This research has several implications concerning the conceptualisation of participation restrictions in adults with hearing loss. Previously, participation

restrictions have been defined as difficulties individuals experience in involvement in life situations. In this research, participation restrictions were redefined as the difficulties individuals experience with authentic involvement in social situations that are valued by that individual. The term ‘authentic involvement’ reflects the findings of Study 1, where it was found that individuals can appear to be engaged in social situations without genuinely being engaged, such as by pretending to follow a conversation. The term ‘social situations’ was used because ‘life situations’ has been criticised for being too broad to lend itself to measurement (Dijkers 2010). Also, previous research has suggested that the defining characteristic of participation restrictions is that it refers to social functioning, as opposed to physical functioning, cognitive functioning, or the performance of instrumental activities of daily living (Jette, Haley and Kooyoomjian 2003).

The definition used the term ‘valued’ because Study 1 showed that individuals with hearing loss often value certain social situations more than others. The research conducted in Study 1 and Study 2 helped to ensure that the SPaRQ measured social situations that are important to most, if not all, individuals with hearing loss. However, from the outset, the SPaRQ was designed to be a standardised instrument, rather than a patient-generated questionnaire. Therefore, it was not possible to perfectly capture the value of different social situations to different respondents as part of the questionnaire, such as by allowing respondents to only answer items that relate to the social situations that are important to them or to rank the social situations described in the items in order of importance. This added complexity would likely increase the respondent burden and investigator

burden of the measure and reduce its interpretability. Furthermore, it would mean that the questionnaire would be unsuitable for inclusion in clinical trials and meta-analyses (Macduff 2000; Patel, Veenstra and Patrick 2003).

6.3.2.2 Dimensionality of participation restrictions

This research has provided new insights regarding the composition of participation restrictions in adults with hearing loss. The ICF conceptualises participation restrictions as consisting of numerous potentially challenging categories of functioning, such as listening and family relationships (Danermark et al., 2013; WHO 2001). Others have conceptualised social isolation, an equivalent construct to participation restrictions, as consisting of an objective domain, such as a reduction in the number of social contacts, and a subjective domain, or the perceived, emotional experience of isolation (Cornwell and Waite 2009; Hawthorne 2008). Similarly, the HHIE conceptualises hearing handicap, another equivalent construct to participation restrictions, as consisting of a situational component (e.g. avoiding groups of people) and an emotional component (e.g. feeling irritable) (Ventry and Weinstein 1982).

This doctoral research confirms that the subjective component of participation restrictions should not be overlooked. Consequently, the SPaRQ contains a social behaviours subscale, which contains items that can be mapped onto the ICF activity and participation categories of functioning, and a social perceptions subscale, which contains items that tap into the subjective, emotional experience of participation restrictions. These subscales are independent of one another but are both important and informative. For instance, a respondent could have a low social behaviours

score and a high social perceptions score, indicating that, despite partaking in various social activities, they nevertheless feel isolated. Previous research has confirmed that it is crucial to measure both objective and subjective social isolation, as they are independently related to the health status of older adults (Coyle and Dugan 2012). The SPaRQ does not measure objective participation restrictions, such as counts of social contacts or counts of social activities, because this would overlook the fact that many individuals are satisfied with having a modest social life. Instead, the SPaRQ contains the social behaviours scale as an accompaniment to the subjective social perceptions scale.

This research suggests that many aspects of social identity and stigma may be related to, yet largely distinct from, the construct of participation restrictions. This is because the majority of the identity items and all of the items measuring embarrassment were removed from the SPaRQ, primarily due to displaying poor fit in the Study 3 Rasch analysis. Furthermore, the Study 2 findings indicated that identity was considered by some participants to be the least important domain in the questionnaire. Together, these results suggest that social identity is tangential, rather than central, to the construct of participation restrictions. Whilst restricted participation is generally considered to be an essential or core outcome domain, it may be that identity is a minor outcome domain because it is important to some individuals with hearing loss and unimportant to others. This is supported by a systematic review of the difficulties experienced by individuals with hearing loss that demonstrated that problems with stigma and identity are infrequent in comparison to problems with isolation, social withdrawal, and listening to

speech in noise (Vas, Akeroyd and Hall under review). It is clear that more research is needed to disentangle the wide variety of constructs, such as social identity, social support, and social integration, that are either related to or that are part of participation. To date, as Mendes de Leon (2005) argues, this issue has been a source of much confusion in healthcare research. It would also be beneficial to establish a core outcome set for hearing loss to provide guidance on essential and non-essential outcome domains to measure and how these domains relate to one another. This doctoral research could be used as the foundation of a future study that aims to develop a new questionnaire that measures the impact of hearing loss on identity, if there were need of such a measure.

6.3.2.3 Application of ICF core sets for hearing loss

To the author's knowledge, this is one of the first research studies to utilise the newly developed ICF Core Sets for Hearing Loss (Table 6.3). Five of the nine categories of functioning from the Brief Core Set were directly assessed by the 19-item SPaRQ, which are categories that are essential for a brief assessment of the functioning of an individual with hearing loss (Danermark et al., 2013). The four remaining categories from the Brief Core Set were not directly assessed by the SPaRQ for several reasons. Firstly, items assessing 'Using communication devices and techniques' were removed during Rasch analysis, which suggests that they do not fit with the other items. 'Higher education', rather than 'School education', was assessed because the questionnaire was designed for adults. Items that directly measured 'Family relationships' were removed because they were dependent on, or overlapped with, items about friendship. The item that directly assessed

‘Community life’ was removed due to poor fit. It also attracted a large number of non-responses, indicating that community life was not important to many of the respondents. These findings demonstrate that there is some, but not perfect, agreement between the content of the SPaRQ and the Brief Core Set. This is perhaps unsurprising, as the core set is arguably more suited to clinical facilitation than outcome measurement. Also, the SPaRQ employed different methods and techniques in its development than the core set. In particular, this research used Rasch analysis, which was stringent in terms of removing items that did not fit with the target construct and that undermined unidimensionality.

Table 6.3 ICF categories of functioning measured by the SPaRQ

Brief core set
Listening
Handling stress and other psychological demands
Communicating with - receiving - spoken messages
Conversation
Remunerative employment
Comprehensive core set
Discussion
Basic economic transactions
Acquisition of goods and services
Higher education
Recreation and leisure
Focusing attention
Conversing with many people
Informal social relationships
Relating with strangers

6.3.2.4 Separation of activity limitations and participation restrictions

The development of the SPaRQ has shed light on the potential distinction between the concepts of activity limitations and participation restrictions,

which has been a contentious issue since the publication of the ICF (Badley 2008). The Study 3 Rasch analysis led to the removal of a number of items from the questionnaire that did not fit with the overall construct measured by the questionnaire: participation restrictions. Many of the removed items measured ICF categories of functioning that were arguably less social (e.g. watching, listening, using transportation) than the categories of functioning measured by the retained items (e.g. informal social relationships, conversing with many people). This supports the proposal that participation restrictions relate to social functioning, or performing actions or roles with and for others, whilst activity limitations relate to individual functioning, or performing actions that can be completed alone (Jette, Haley and Kooyoomjian 2003; Resnik and Plow 2009; Whiteneck and Dijkers 2009).

An alternative interpretation is that the removed items represented basic or simple tasks, whereas the retained items represented complex or challenging tasks and roles. Indeed, it has previously been proposed that activity and participation categories of functioning should be subdivided based on their respective simplicity and complexity (Jette, Tao and Haley 2007; Nordenfelt 2003). This may prove more useful than distinguishing activity and participation on the basis that the former takes place at the individual level and the latter takes place at the societal level because many actions, such as watching television, can take place either alone in the presence of others (Mallinson and Hammel 2010). Also many individual actions, such as cooking, could also be classed as performing a social role, such as homemaker.

6.4 IMPLICATIONS FOR RESEARCH AND CLINICAL PRACTICE

It is vital that clinicians and researchers have high quality outcome measures at their disposal to provide sound evidence that auditory rehabilitation benefits patients and is cost effective, as well as to monitor and improve the quality of auditory rehabilitation (Bentler and Kramer 2000; Cox et al., 2000; Wilkerson 2000). This research has produced a new questionnaire, the SPaRQ, which fulfils an array of the required quality criteria for outcome measures. As such, this research highlights the benefits of adopting a rigorous approach to the development of outcome measures, including the use of in-depth qualitative techniques, such as cognitive interviews, and the use of modern psychometric analyses, such as Rasch analysis.

Given that the SPaRQ has strong measurement properties, it has the potential to be used in clinical trials and other research studies to measure whether auditory rehabilitation improves participation in adults with hearing loss. Unlike many other hearing-specific questionnaires that focus on hearing aids, such as the GHABP, the SPaRQ can be used to assess any hearing healthcare service or intervention. In particular, the SPaRQ could be used in trials that aim to assess the impact of relatively new interventions for hearing loss. For instance, the SPaRQ could be used in a clinical trial that aims to assess cognitive training, or the training of attention and memory in order to improve listening abilities, particularly in complex listening environments (Henshaw and Ferguson, 2013b). The SPaRQ would be a suitable outcome measure for this intervention, as it asks about participation in challenging listening environments, such as noisy environments (e.g. shops, cafes), multiple-speaker environments (e.g. meetings, gatherings of friends), and

also lengthy conversations. Similarly, the SPaRQ could be used in trials that aim to evaluate the impact of new telehealth interventions for hearing loss, such as internet-based counselling programmes. The SPaRQ is particularly suited to the evaluation of counselling because the primary aim of this intervention is to improve emotional and social wellbeing (Boothroyd 2007; Dillon 2001; Swanepoel and Hall, 2010). The SPaRQ could also be used to assess whether hearing aid accessories, such as remote microphone systems, improve social participation. These accessories are generally designed to enhance the benefit obtained from hearing aids, such as by improving speech perception and reducing background noise in social settings (Boothroyd 2004). Finally, the SPaRQ could be used to evaluate self-fitting hearing aids in comparison to traditional audiologist-fitted hearing aids. Whilst both interventions are intended to improve social participation, self-fitting hearing aids are relatively new and therefore do not yet have a strong evidence base (Maidment et al., 2016).

In addition to research, the SPaRQ could be used in clinical practice to measure the impact of hearing healthcare services and interventions on participation in adults with hearing loss. Outcome measurement in clinical practice serves several purposes, including ensuring that patients benefit from interventions at the individual and group level, monitoring and improving the services offered to patients, justifying the allocation of funding and resources, informing shared decision-making and goal-setting for patients and clinicians, and enhancing professional credibility (BSA 2016; Saunders, Chisolm and Abrams 2005; Nemes 2003; Beck 2000). It has been recommended in the UK Action Plan for Hearing Loss (NHS England, 2015)

and the British Society of Audiology practice guidance for adult auditory rehabilitation (BSA, 2016) that a number of outcome domains are measured in UK audiology clinics, including social participation. Therefore, it is important that these clinics have access to a psychometrically sound hearing-specific measure of social participation.

One of the main advantages of using the SPaRQ in research or practice is that it is self-administered and thus can be completed by individuals with hearing loss at home or in a waiting room. This means that it is less time-consuming than interviewer-administered questionnaires that are currently popular, such as the GHABP or the Client Oriented Scale of Improvement (Dillon, James and Ginis, 1997; Ferguson et al., 2016; Gatehouse 1999).

One of the main disadvantages of the SPaRQ is that it measures just one outcome domain, which means that it must be used in conjunction with other questionnaires to ensure that all of the relevant domains are captured (e.g. hearing aid use, patient satisfaction, and overall quality of life). This can be burdensome for adults with hearing loss, especially those who are elderly, and it can also be challenging for clinicians to administer, record, and interpret several different questionnaires. Consequently, some clinicians may prefer to use a single questionnaire that is purported to measure multiple domains, such as the 7-item International Outcome Inventory for Hearing Aids (Cox et al., 2000), in order to streamline the outcome measurement process. However, as has been noted elsewhere in this thesis, multidimensional questionnaires can have limitations in comparison to unidimensional questionnaires, especially in terms of the meaningfulness of their overall total scores (Yorke, Horton and Jones 2012).

6.5 FUTURE RESEARCH

6.5.1 Future directions for the SPaRQ

This doctoral programme of research has opened up several avenues for future research, in addition to those mentioned above. As discussed in Chapter 5, the first avenue should be to validate the SPaRQ in a longitudinal study with a clinical population. This would primarily entail administering the SPaRQ to patients before they receive an established intervention for hearing loss, such as hearing aids, and at several time-points after they receive this intervention. A priority for this study would be to assess responsiveness and interpretability, as these are important measurement properties for any outcome measure that is to be used in clinical trials and clinical practice (Mokkink et al., 2010c; Terwee et al., 2007). Responsiveness refers to the capacity of the SPaRQ to detect clinically important changes in social participation over time, whilst interpretability refers to the extent to which qualitative meaning can be assigned to the scores of the SPaRQ (Terwee et al., 2007).

A range of metrics can be used to evaluate responsiveness and interpretability (García de Yébenes Prous, Salvanés and Ortells 2008; Terwee et al., 2007). These include **(1)** the Smallest Detectable Change, or the smallest within-person change in a score that can be interpreted as a genuine change above and beyond measurement error, **(2)** the Minimal Important Change, or the smallest difference in a score that patients perceive as beneficial and that would lead to a change in the management of a patient, **(3)** the means and standard deviations of the scores of patients before and after receiving an intervention that is known to be efficacious, **(4)**

the means and standard deviations of patient subgroup scores based on the patients' global ratings of their change, and **(5)** the area under the receiver operating characteristics curve, which measures the capacity of a questionnaire to differentiate between patients who have and have not changed in accordance with an external criterion (Terwee et al., 2007). This would be a novel piece of research, as the evaluation of responsiveness and interpretability is a relatively new area in the field of outcome measurement (García de Yébenes Prous, Salvanés and Ortells 2008; Terwee et al., 2007) and it is thought that many hearing-specific questionnaires are lacking in terms of these particular properties (Barker et al., 2014; Henshaw and Ferguson 2014).

The validation study could also be used to further assess the construct validity of the SPaRQ. Study 3 of this research used unidimensional, rather than multidimensional, Rasch analysis to assess the structural validity of the questionnaire. This is because unidimensional models are currently dominant, whereas multidimensional models are relatively new and still developing (Belvedere and de Morton 2010). However, Study 3 demonstrated that the target construct, hearing-related participation restrictions, is not unidimensional but instead consists of a behavioural dimension and a perceptual or emotional dimension. Therefore, future research could utilise emerging multidimensional Rasch models to examine the structural validity of the SPaRQ. For instance, a recent study used multidimensional Rasch analysis to develop a measure of participation for adults with serious mental illnesses that contains three dimensions: productive activities, social participation, and recreation/leisure (Chang et al.,

2016). In addition, confirmatory factor analysis could be used to consolidate the structural validity of the SPaRQ (Mokkink et al., 2012).

Another avenue of future research is the re-evaluation of the content validity of the SPaRQ in a study similar in design to Study 2, which involved cognitive interviews with adults with hearing loss and a subject matter expert survey with clinicians and researchers. This is in line with recommendations that content validity should be re-assessed following substantive changes to a questionnaire, such as the removal of items (Grant and Davis 1997; Polit, Beck and Owen 2007). However, a balance must be struck between ensuring that the content of the 19-item SPaRQ is a comprehensive reflection of hearing-related participation restrictions and ensuring that the questionnaire has the requisite psychometric properties, including unidimensionality.

A major advantage of conducting a second content validity study would be the opportunity to ensure that the SPaRQ captures clinically meaningful and useful information and to ensure that it has minimal clinician burden.

Clinician burden refers to the ease of administering, scoring, and interpreting an outcome measure (Reeve et al., 2013). It is important that the SPaRQ is feasible for use not only in clinical trials but also in clinical practice, where hearing healthcare professionals often have limited time and resources to dedicate to outcome measurement. Therefore, this study would involve obtaining qualitative and quantitative feedback from participants who are potential users of the SPaRQ, including researchers, clinicians, and commissioners, in order to maximise its utility and feasibility. For example, the participants could be consulted on how best to manage the two social

perceptions items that require adjusted scores, such as whether they would find it useful to be provided with a spreadsheet or code that can score the SPaRQ. They could also be consulted on developing informative qualitative descriptors to accompany the numerical scores of the questionnaire that are suitable for various audiences, including patients and funding bodies. This content validity study, in conjunction with the quantitative assessment of responsiveness and interpretability, would help to ensure that the SPaRQ is a meaningful and useful measure for both clinical trials and clinical practice.

6.5.2 Future directions for outcome measurement

This research has highlighted additional avenues of future research that go beyond the further examination of the measurement properties of the SPaRQ. For example, it would be beneficial to establish a core outcome set specifically for auditory rehabilitation for adults with hearing loss (Barker et al., 2014). This would help to standardise outcome measurement across clinical trials, which would improve the quality of the evidence obtained for auditory rehabilitation (Barker et al., 2015; Clarke 2007). Whilst the existing ICF Core Sets for Hearing Loss are undoubtedly useful and informative, they were not specifically designed for outcome measurement and, consequently, they omit some potentially important outcome domains, such as identity, intervention adherence, patient satisfaction, and quality of life (Cox and Alexander 2002; Field and Jette 2007; Vas, Akeroyd and Hall under review). The development of a core outcome set for hearing loss would establish the relative importance of different outcome domains. For instance, quality of life could be a mandatory, core domain whereas stigma and identity could be an optional, secondary domain.

Another potential direction for future research would be to examine alternative ways to measure participation restrictions that offer advantages above and beyond the questionnaire format. One approach that is growing in popularity in healthcare research, including the measurement of participation restrictions, is ecological momentary assessment or EMA (Seekins, Ipsen and Arnold 2007). This refers to a variety of techniques that enable participants, over the course of a study, to provide repeated reports of symptoms, emotions, behaviours, and thoughts close in time to experiencing them and to do so from their natural environment, such as the home or workplace (Moskowitz and Young 2006; Shiffman, Stone and Hufford 2008). The data can be obtained using a range of technologies, including record forms, paper-and-pen diaries, electronic diaries, telephones, and physiological sensors. As EMA relies on repeated sampling and does not rely on recall of past events, it is thought to be more accurate than questionnaires and also more sensitive to changes in functioning over time, though it is time-consuming for participants (Moskowitz and Young 2006; Shiffman, Stone and Hufford 2008).

Another increasingly popular alternative measurement approach is computerised adaptive testing (CAT). This entails using modern psychometric analysis, such as Rasch analysis, to establish a large bank of calibrated, unidimensional items. CAT then selects items from this pool that are targeted to each respondent until a predetermined criterion (e.g. adequate measurement precision) is fulfilled (Forkmann et al., 2009). For instance, CAT can present items that are tailored to an individual based on specific characteristics, such as age or degree of disability (Jette and Haley

2005). The advantages of CAT are that it is brief and personalised, as well as having good precision and reliability (Forkmann et al., 2009). Future research could use the items developed in this doctoral research to develop an EMA or CAT method for the assessment of participation restrictions in adults with hearing loss.

6.6 CONCLUSION

This doctoral research has delivered a psychometrically sound outcome measure of participation restrictions in adults with hearing loss. As a result, this research has highlighted the importance of using modern, gold-standard techniques in the development and evaluation of self-report outcome measures. Whilst these approaches are now at the forefront in other healthcare fields, they are just beginning to gain ground in hearing research. This development should lead to improvements in the quality of new and existing hearing-specific outcome measures. This is an integral component of improving the quality of hearing research and clinical practice.

CHAPTER 7. APPENDICES

7.1 APPENDIX A. THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH (ICF) CORE SETS FOR HEARING LOSS

Body function and structure categories of the comprehensive core set:

b117 Intellectual functions
b126 Temperament and personality functions
b1300 Energy level
b1301 Motivation
b140 Attention functions
b144 Memory functions
b152 Emotional functions
b1560 Auditory perception
b1561 Visual perception
b164 Higher-level cognitive functions
b167 Mental functions of language
b210 Seeing functions
b2300 Sound detection
b2301 Sound discrimination
b2302 Localization of sound source
b2304 Speech discrimination
b235 Vestibular functions
b240 Sensations associated with hearing and vestibular function
b280 Sensation of pain
b310 Voice functions
b320 Articulation functions
b330 Fluency and rhythm of speech functions
s110 Structure of brain
s240 Structure of external ear
s250 Structure of middle ear
s260 Structure of inner ear

Participation categories of the comprehensive core set:

d110 Watching
d115 Listening
d140 Learning to read
d155 Acquiring skills
d160 Focusing attention

d175 Solving problems
d220 Undertaking multiple tasks
d240 Handling stress and other psychological demands
d310 Communicating with—receiving—spoken messages
d315 Communicating with—receiving—nonverbal messages
d330 Speaking
d3503 Conversing with one person
d3504 Conversing with many people
d355 Discussion
d360 Using communication devices and techniques
d440 Fine hand use
d470 Using transportation
d475 Driving
d620 Acquisition of goods and services
d660 Assisting others
d710 Basic interpersonal interactions
d720 Complex interpersonal interactions
d730 Relating with strangers
d740 Formal relationships
d750 Informal social relationships
d760 Family relationships
d770 Intimate relationships
d810 Informal education
d820 School education
d825 Vocational training
d830 Higher education
d840 Apprenticeship (work preparation)
d845 Acquiring, keeping and terminating a job
d850 Remunerative employment
d855 Non-remunerative employment
d860 Basic economic transactions
d870 Economic self-sufficiency
d910 Community life
d920 Recreation and leisure
d930 Religion and spirituality
d940 Human rights
d950 Political life and citizenship

Environment categories of the comprehensive core set:

e115 Products and technology for personal use in daily living

e120 Products and technology for personal indoor and outdoor mobility and transportation
e125 Products and technology for communication
e130 Products and technology for education
e135 Products and technology for employment
e140 Products and technology for culture, recreation, and sport
e145 Products and technology for the practice of religion and spirituality
e150 Design, construction, and building products and technology of buildings for public use
e155 Design, construction, and building products and technology of buildings for private use
e225 Climate
e240 Light
e2500 Sound intensity
e2501 Sound quality
e310 Immediate family
e315 Extended family
e320 Friends
e325 Acquaintances, peers, colleagues, neighbors, and community members
e330 People in positions of authority
e335 People in subordinate positions
e340 Personal care providers and personal assistants
e345 Strangers
e350 Domesticated animals
e355 Health professionals
e360 Other professionals
e410 Individual attitudes of immediate family members
e415 Individual attitudes of extended family members
e420 Individual attitudes of friends
e425 Individual attitudes of acquaintances, peers, colleagues, neighbors, and community members
e430 Individual attitudes of people in positions of authority
e440 Individual attitudes of personal care providers and personal assistants
e445 Individual attitudes of strangers
e450 Individual attitudes of health professionals
e455 Individual attitudes of health-related professionals
e460 Societal attitudes
e465 Social norms, practices, and ideologies
e515 Architecture and construction services, systems, and policies
e525 Housing services, systems, and policies
e535 Communication services, systems, and policies
e540 Transportation services, systems, and policies
e545 Civil protection services, systems, and policies

e550 Legal services, systems, and policies
e555 Associations and organizational services, systems, and policies
e560 Media services, systems, and policies
e570 Social security services, systems, and policies
e575 General social support services, systems, and policies
e580 Health services, systems, and policies
e585 Education and training services, systems, and policies
e590 Labor and employment services, systems, and policies

Body function and structure categories of the brief core set:

b126 Temperament and personality functions
b140 Attention functions
b144 Memory functions
b152 Emotional functions
b210 Seeing functions
b230 Hearing functions
b240 Sensations associated with hearing and vestibular function
Body Structure
s110 Structure of brain
s240 Structure of external ear
s250 Structure of middle ear
s260 Structure of inner ear
d115 Listening

Participation categories of the brief core set:

d240 Handling stress and other psychological demands
d310 Communicating with—receiving—spoken messages
d350 Conversation
d360 Using communication devices and techniques
d760 Family relationships
d820 School education
d850 Remunerative employment
d910 Community life

Environment categories of the brief core set:

e125 Products and technology for communication
e250 Sound
e310 Immediate family
e355 Health professionals

e410 Individual attitudes of immediate family members

e460 Societal attitudes

e580 Health services, systems, and policies

7.2 APPENDIX B. GLASGOW HEARING AID BENEFIT PROFILE

PARTICIPANT:

DATE:

ANSWERS BASED ON SITUATIONS WITH HEARING AIDS (YES/NO):

Does this situation happen in your life? 0 ___ No 1 ___ Yes		LISTENING TO THE TELEVISION WITH OTHER FAMILY OR FRIENDS WHEN THE VOLUME IS ADJUSTED TO SUIT OTHER PEOPLE			
How much difficulty do you have in this situation?	How much does any difficulty in this situation worry, annoy or upset you?	In this situation, what proportion of the time do you wear your hearing aid?	In this situation, how much does your hearing aid help you?	In this situation, <u>with your hearing aid</u> , how much difficulty do you <u>now</u> have?	For this situation, how satisfied are you with your hearing aid?
0 ___ N/A	0 ___ N/A	0 ___ N/A	0 ___ N/A	0 ___ N/A	0 ___ N/A
1 ___ No difficulty	1 ___ Not at all	1 ___ Never/Not at all	1 ___ Hearing aid no use at all	1 ___ No difficulty	1 ___ Not satisfied at all
2 ___ Only slight difficulty	2 ___ Only a little	2 ___ About ¼ of the time	2 ___ Hearing aid is some help	2 ___ Only slight difficulty	2 ___ A little satisfied
3 ___ Moderate difficulty	3 ___ A moderate amount	3 ___ About ½ of the time	3 ___ Hearing aid is quite helpful	3 ___ Moderate difficulty	3 ___ Reasonably satisfied
4 ___ Great difficulty	4 ___ Quite a lot	4 ___ About ¾ of the time	4 ___ Hearing aid is a great help	4 ___ Great difficulty	4 ___ Very satisfied
5 ___ Cannot manage at all	5 ___ Very much indeed	5 ___ All the time	5 ___ Hearing is perfect with aid	5 ___ Cannot manage at all	5 ___ Delighted with aid

<div>Does this situation happen in your life?</div> <div>HAVING A CONVERSATION WITH ONE OTHER PERSON WHEN</div> <div>0 ___ No 1 ___ Yes</div> <div>THERE IS NO BACKGROUND NOISE</div>					
How much difficulty do you have in this situation?	How much does any difficulty in this situation worry, annoy or upset you?	In this situation, what proportion of the time do you wear your hearing aid?	In this situation, how much does your hearing aid help you?	In this situation, <u>with your hearing aid</u> , how much difficulty do you <u>now</u> have?	For this situation, how satisfied are you with your hearing aid?
0 ___ N/A	0 ___ N/A	0 ___ N/A	0 ___ N/A	0 ___ N/A	0 ___ N/A
1 ___ No difficulty	1 ___ Not at all	1 ___ Never/Not at all	1 ___ Hearing aid no use at all	1 ___ No difficulty	1 ___ Not satisfied at all
2 ___ Only slight difficulty	2 ___ Only a little	2 ___ About ¼ of the time	2 ___ Hearing aid is some help	2 ___ Only slight difficulty	2 ___ A little satisfied
3 ___ Moderate difficulty	3 ___ A moderate amount	3 ___ About ½ of the time	3 ___ Hearing aid is quite helpful	3 ___ Moderate difficulty	3 ___ Reasonably satisfied
4 ___ Great difficulty	4 ___ Quite a lot	4 ___ About ¾ of the time	4 ___ Hearing aid is a great help	4 ___ Great difficulty	4 ___ Very satisfied
5 ___ Cannot manage at all	5 ___ Very much indeed	5 ___ All the time	5 ___ Hearing is perfect with aid	5 ___ Cannot manage at all	5 ___ Delighted with aid

<p>Does this situation happen in your life? CARRYING ON A CONVERSATION IN A BUSY STREET OR SHOP</p> <p>0 ___ No 1 ___ Yes</p>					
How much difficulty do you have in this situation?	How much does any difficulty in this situation worry, annoy or upset you?	In this situation, what proportion of the time do you wear your hearing aid?	In this situation, how much does your hearing aid help you?	In this situation, <u>with your hearing aid</u> , how much difficulty do you <u>now</u> have?	For this situation, how satisfied are you with your hearing aid?
0___ N/A 1___ No difficulty 2___ Only slight difficulty 3___ Moderate difficulty 4___ Great difficulty 5___ Cannot manage at all	0___ N/A 1___ Not at all 2___ Only a little 3___ A moderate amount 4___ Quite a lot 5___ Very much indeed	0___ N/A 1___ Never/Not at all 2___ About ¼ of the time 3___ About ½ of the time 4___ About ¾ of the time 5___ All the time	0___ N/A 1___ Hearing aid no use at all 2___ Hearing aid is some help 3___ Hearing aid is quite helpful 4___ Hearing aid is a great help 5___ Hearing is perfect with aid	0___ N/A 1___ No difficulty 2___ Only slight difficulty 3___ Moderate difficulty 4___ Great difficulty 5___ Cannot manage at all	0___ N/A 1___ Not satisfied at all 2___ A little satisfied 3___ Reasonably satisfied 4___ Very satisfied 5___ Delighted with aid

<p>Does this situation happen in your life? HAVING A CONVERSATION WITH SEVERAL PEOPLE IN A GROUP</p> <p>0 ___ No 1 ___ Yes</p>					
How much difficulty do you have in this situation?	How much does any difficulty in this situation worry, annoy or upset you?	In this situation, what proportion of the time do you wear your hearing aid?	In this situation, how much does your hearing aid help you?	In this situation, <u>with your hearing aid</u> , how much difficulty do you <u>now</u> have?	For this situation, how satisfied are you with your hearing aid?
0 ___ N/A	0 ___ N/A	0 ___ N/A	0 ___ N/A	0 ___ N/A	0 ___ N/A
1 ___ No difficulty	1 ___ Not at all	1 ___ Never/Not at all	1 ___ Hearing aid no use at all	1 ___ No difficulty	1 ___ Not satisfied at all
2 ___ Only slight difficulty	2 ___ Only a little	2 ___ About ¼ of the time	2 ___ Hearing aid is some help	2 ___ Only slight difficulty	2 ___ A little satisfied
3 ___ Moderate difficulty	3 ___ A moderate amount	3 ___ About ½ of the time	3 ___ Hearing aid is quite helpful	3 ___ Moderate difficulty	3 ___ Reasonably satisfied
4 ___ Great difficulty	4 ___ Quite a lot	4 ___ About ¾ of the time	4 ___ Hearing aid is a great help	4 ___ Great difficulty	4 ___ Very satisfied
5 ___ Cannot manage at all	5 ___ Very much indeed	5 ___ All the time	5 ___ Hearing is perfect with aid	5 ___ Cannot manage at all	5 ___ Delighted with aid

7.3 APPENDIX C. STUDY 1 SEMI-STRUCTURED INTERVIEW SCHEDULES

7.3.1 Interview schedule for the adults with hearing loss

Opening Question	Potential Follow-Up Questions	Self-Regulatory Model Component
Can you tell me about when you first discovered that you had hearing loss?	<ul style="list-style-type: none"> - What were your thoughts when you realised? - How did you feel when you realised? - What did you decide to do next? 	Stimuli, Initial Representations
Can you describe the main 'symptoms' of your hearing loss?	<ul style="list-style-type: none"> - How would you describe the level or severity of your hearing loss? 	Cognitive Representations: Identity
What do you think are the main 'labels' associated with hearing loss?	<ul style="list-style-type: none"> - Does hearing loss change the way people see you? How? - Does hearing loss change the way you see yourself? How? 	Cognitive Representations: Identity
What do you think caused your hearing loss?	<ul style="list-style-type: none"> - Where did you learn about the causes of your hearing loss? - How do you feel about the cause(s) of your hearing loss? - Does this affect how you cope with your hearing loss? How? 	Cognitive Representations: Causal Beliefs
Can you tell me what you think your hearing loss will be like in the coming years?	<ul style="list-style-type: none"> - Do you think it will progress or stay the same? - How do you feel about this? - Does this affect how you cope with your hearing loss? How? 	Cognitive Representations: Timeline
Can you tell me whether you feel you can control your hearing loss? Why so?	<ul style="list-style-type: none"> - Does this affect how you cope with your hearing loss? How? 	Cognitive Representations: Controllability/ Curability
Can you tell me the main ways hearing loss affects your daily life?	<ul style="list-style-type: none"> - Can you give me some examples (e.g. work, family, pastimes, education, social life)? - What is the main problem caused by your hearing loss? - Are there any positive aspects of hearing loss? 	Cognitive Representations: Consequences
Can you tell me whether hearing loss affects your mood?	<ul style="list-style-type: none"> - Have your feelings towards your hearing loss changed over time? 	Emotional Representations
Can you tell me about the things you do to cope with your hearing loss?	<ul style="list-style-type: none"> - What works well and what does not? - What are the advantages and disadvantages of these approaches? 	Coping Responses

7.3.2 Interview schedule for hearing healthcare professionals

Opening Question	Potential Follow-Up Questions	Self-Regulatory Model Component
In your experience, how do people react when it is confirmed in clinic that they have hearing loss?	- How does this reaction relate to how they manage their hearing loss?	Stimuli, Initial Representations
What do people see as being the main 'symptoms' of their hearing loss?	- How do people judge the severity of their hearing loss?	Cognitive Representations: Identity
What are the main 'labels' that people associate with hearing loss?	- Does having a hearing loss change how people perceive themselves? How? - How do they feel that other people perceive them?	Cognitive Representations: Identity
What understanding do people have about the causes of their hearing loss?	- Where do they learn about the causes of their condition? - How do they feel about these causes? - Does this affect how they cope with their hearing loss? How?	Cognitive Representations: Causal Beliefs
What are the perceptions of people with hearing loss about the progression of their condition?	- How do people feel about this? - Does this affect how they cope with their hearing loss? How?	Cognitive Representations: Timeline
Can you tell me whether people with hearing loss believe that the condition is controllable?	- Do people with hearing loss believe that the condition is curable? - Does this affect how they cope with their hearing loss? How?	Cognitive Representations: Controllability/ Curability
Can you tell me about the main ways hearing loss affects daily life?	- Can you give me some examples (e.g. work, family, pastimes, education, social life)? - What is the main problem caused by hearing loss? - Are there any positive consequences?	Cognitive Representations: Consequences
Can you tell me about the emotional impact of hearing loss?	- Does the emotional impact of hearing loss change over time? How?	Emotional Representations
Can you tell me about the main coping strategies used by people with hearing loss?	- From their perspective, what works well and what does not work well? - What do they see as the advantages and disadvantages of these coping strategies?	Coping Responses

7.4 APPENDIX D. FIRST PROTOTYPE OF THE SOCIAL PARTICIPATIONS RESTRICTIONS QUESTIONNAIRE (SPaRQ1.0)

Section 1

The questions below ask you about how certain you are that, despite your hearing problem, you can do different everyday activities. Please read each question carefully and answer by circling **one** number for each question. If you strongly believe that a question does not apply to you, then you can place a tick in the 'Does not apply' box.

Item Index	Despite my hearing problem, I can:	<div> <div>Certain I cannot do this</div> <div>Certain I can do this</div> </div>											Does not apply
1	Watch and enjoy television with other people	0	1	2	3	4	5	6	7	8	9	10	
2	Watch things that I enjoy, such as plays, films or sporting events	0	1	2	3	4	5	6	7	8	9	10	
3	Listen to things that I enjoy, such as music, radio or birdsong	0	1	2	3	4	5	6	7	8	9	10	
4	Carry out my favourite pastimes and hobbies	0	1	2	3	4	5	6	7	8	9	10	
5	Take part in activities for voluntary organisations or charity organisations	0	1	2	3	4	5	6	7	8	9	10	
6	Take part in community activities or community events	0	1	2	3	4	5	6	7	8	9	10	
7	Use transportation, such as buses, trains or aeroplanes	0	1	2	3	4	5	6	7	8	9	10	
8	Follow what is said in a lecture or in a talk	0	1	2	3	4	5	6	7	8	9	10	
9	Take part in a meeting	0	1	2	3	4	5	6	7	8	9	10	

Item Index	Despite my hearing problem, I can:	Certain I cannot do this											Certain I can do this	Does not apply
		0	1	2	3	4	5	6	7	8	9	10		
10	Take part in a group discussion	0	1	2	3	4	5	6	7	8	9	10		
11	Take part in conversations with people in my workplace, such as co-workers, managers or clients	0	1	2	3	4	5	6	7	8	9	10		
12	Take part in training courses or training events	0	1	2	3	4	5	6	7	8	9	10		
13	Take part in conversations with people on the telephone	0	1	2	3	4	5	6	7	8	9	10		
14	Talk to staff in places such as shops, cafes or banks	0	1	2	3	4	5	6	7	8	9	10		
15	Discuss my health with a healthcare professional (e.g. doctor, dentist, audiologist)	0	1	2	3	4	5	6	7	8	9	10		
16	Take part in conversations in places where there is background noise, such as pubs, restaurants or parties	0	1	2	3	4	5	6	7	8	9	10		
17	Start a conversation with unfamiliar people	0	1	2	3	4	5	6	7	8	9	10		
18	Attend get-togethers with my friends	0	1	2	3	4	5	6	7	8	9	10		
19	Take part in conversations with my friends	0	1	2	3	4	5	6	7	8	9	10		

Item Index	Despite my hearing problem, I can:	Certain I cannot do this											Certain I can do this	Does not apply
20	Go out with a significant other (e.g. spouse, partner) to places such as restaurants, theatres or parties	0	1	2	3	4	5	6	7	8	9	10		
21	Take part in conversations with a significant other (e.g. spouse, partner)	0	1	2	3	4	5	6	7	8	9	10		
22	Attend get-togethers with my family	0	1	2	3	4	5	6	7	8	9	10		
23	Take part in conversations with my family	0	1	2	3	4	5	6	7	8	9	10		

Section 2

The questions below ask you about how hearing problem affects the way you feel in everyday life. Please read each question carefully and answer by circling **one** number for each question. If you strongly believe that a question does not apply to you, then you can place a tick in the 'Does not apply' box.

Item Index	Because of my hearing problem:	Strongly Disagree											Strongly Agree	Does not apply
24	I feel frustrated when I cannot say what I want to say in conversation	0	1	2	3	4	5	6	7	8	9	10		
25	I feel frustrated when I am left out of conversations	0	1	2	3	4	5	6	7	8	9	10		
26	I feel embarrassed when I say the wrong thing in conversation	0	1	2	3	4	5	6	7	8	9	10		

Item Index	Because of my hearing problem:	Strongly Disagree Strongly Agree											Does not apply
27	I feel embarrassed when I have to ask people to repeat what they have said	0	1	2	3	4	5	6	7	8	9	10	
28	I feel isolated when it is difficult for me to take part in conversations	0	1	2	3	4	5	6	7	8	9	10	
29	I feel isolated at get-togethers with family or friends	0	1	2	3	4	5	6	7	8	9	10	
30	I feel lonely, even when I am around other people	0	1	2	3	4	5	6	7	8	9	10	
31	I find social gatherings stressful	0	1	2	3	4	5	6	7	8	9	10	
32	I worry about going to social gatherings	0	1	2	3	4	5	6	7	8	9	10	
33	I worry about talking to unfamiliar people	0	1	2	3	4	5	6	7	8	9	10	
34	I worry that I will miss important information	0	1	2	3	4	5	6	7	8	9	10	
35	I lose my motivation to go to get-togethers with family or friends because of my hearing problem	0	1	2	3	4	5	6	7	8	9	10	
36	I stop caring about joining in conversations when it is difficult to hear what is being said	0	1	2	3	4	5	6	7	8	9	10	
37	I feel upset when it is difficult for me to take part in conversations	0	1	2	3	4	5	6	7	8	9	10	
38	I feel sad when I cannot join in when people around me are having a good time	0	1	2	3	4	5	6	7	8	9	10	

Section 3

The questions below ask you about how hearing problem affects the way you look in everyday life. Please read each question carefully and answer by circling **one** number for each question. If you strongly believe that a question does not apply to you, then you can place a tick in the 'Does not apply' box.

Item Index	Because of my hearing problem:	Strongly Disagree											Strongly Agree	Does not apply
39	I think that I look foolish when I say the wrong thing in conversation	0	1	2	3	4	5	6	7	8	9	10		
40	I think that I look foolish when I cannot understand what other people are saying	0	1	2	3	4	5	6	7	8	9	10		
41	I think that I look demanding when I ask people to repeat what they have said or to speak more clearly	0	1	2	3	4	5	6	7	8	9	10		
42	People treat me as if I am a nuisance because of my hearing problem	0	1	2	3	4	5	6	7	8	9	10		
43	I think that I look rude when I do not realise that other people are speaking to me	0	1	2	3	4	5	6	7	8	9	10		
44	I think that I look unfriendly when I do not join in a conversation	0	1	2	3	4	5	6	7	8	9	10		
45	I think that having a hearing problem make me look less sociable than I really am	0	1	2	3	4	5	6	7	8	9	10		
46	I think that I look like I am not interested in talking to people because of my hearing problem	0	1	2	3	4	5	6	7	8	9	10		

Item Index	Because of my hearing problem:	Strongly Disagree											Strongly Agree	Does not apply
		0	1	2	3	4	5	6	7	8	9	10		
47	I think that having a hearing problem makes me look less capable than I really am	0	1	2	3	4	5	6	7	8	9	10		
48	I would rather pretend that I can understand what people are saying rather than let them know that I have a hearing problem	0	1	2	3	4	5	6	7	8	9	10		
49	I would rather sit quietly whilst people are talking than interrupt to ask them to repeat what they have said	0	1	2	3	4	5	6	7	8	9	10		

7.5 APPENDIX E. HEARING LOSS SCREENING QUESTIONNAIRE

Instructions: Please tick (✓) only **one** box for each question.
If you normally wear a hearing aid, please answer questions 1-4
as if you were **not** wearing a hearing aid.

1. Do you have any difficulty with your hearing? <div style="text-align: right;">No Yes</div>	Please Tick One Option: <div style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> </div>
2. Do you find it very difficult to follow a conversation if there is background noise (such as TV, radio, children playing)? <div style="text-align: right;">No Yes</div>	Please Tick One Option: <div style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> </div>
3. How well do you hear someone talking to you when that person is sitting on your <u>RIGHT SIDE</u> in a quiet room? <div style="text-align: right;"> With no difficulty With slight difficulty With moderate difficulty With great difficulty Cannot hear at all </div>	Please Tick One Option: <div style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </div>
4. How well do you hear someone talking to you when that person is sitting on your <u>LEFT SIDE</u> in a quiet room? <div style="text-align: right;"> With no difficulty With slight difficulty With moderate difficulty With great difficulty Cannot hear at all </div>	Please Tick One Option: <div style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </div>
5. Do you use a hearing aid nowadays? <div style="text-align: right;">No Yes</div>	Please Tick One Option: <div style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> </div>

Scoring: Item 1 and Item 2 of this questionnaire were used to screen for hearing loss amongst the participants who were potential adults with hearing loss in Studies

2, 3, and 4. Specifically, a participant was deemed to have passed the hearing loss screen if they answered 'Yes' to Item 1 alone (score=1), to Item 2 alone (score=1), or to both items (score=2). Items 3-5 were administered to the participants because they are part of the validated tool but they were not used to screen for hearing loss.

7.6 APPENDIX F. STUDY 2 COGNITIVE INTERVIEW SCHEDULE FOR THE ADULTS WITH HEARING LOSS

Initial Question	Potential follow-up	Component assessed
Can you tell me how you found filling out this questionnaire?	<ul style="list-style-type: none"> - Can you tell me more about that? - How did you find the length of the questionnaire? Did you find the questionnaire to be tiring to fill out? 	<ul style="list-style-type: none"> - General
Can you tell me what that question means to you?	<ul style="list-style-type: none"> - Can you put that question in your own words? - How would you phrase that question? - What did that question bring to mind? - Was this question relevant to you? 	<ul style="list-style-type: none"> - Clarity - Relevance
Can you tell me what that word/expression means to you?	<ul style="list-style-type: none"> - Can you put that expression in your own words? - How would you say it? 	<ul style="list-style-type: none"> - Clarity
Can you tell me how you chose an answer to that question?	<ul style="list-style-type: none"> - Why did you choose that answer? - What were you thinking about when you were answering that question? 	<ul style="list-style-type: none"> - Clarity
Were there any questions that you found difficult to understand?	<ul style="list-style-type: none"> - Can you tell me more about that? What made it difficult? 	<ul style="list-style-type: none"> - Clarity
Were there any questions that you felt were not relevant to you?	<ul style="list-style-type: none"> - Can you tell me more about that? - Were there any questions that were especially relevant to you? 	<ul style="list-style-type: none"> - Relevance
Were there any parts of the questionnaire that you found off-putting?	<ul style="list-style-type: none"> - Were there any questions that you didn't like? Were there any words or terms that you didn't like? - Were there any questions that you felt were too personal? - Were there any questions that you felt were offensive? 	<ul style="list-style-type: none"> - Acceptability
Is the questionnaire missing any important questions?	<ul style="list-style-type: none"> - Are all of the main ways hearing loss affects people included in the questionnaire? 	<ul style="list-style-type: none"> - Comprehensiveness
Can you tell me what you think about the instructions that come with the questionnaire?	<ul style="list-style-type: none"> - Were any of the instructions difficult to understand? - Do any of the instructions need to be changed? - Do any new instructions need to be added? 	<ul style="list-style-type: none"> - Clarity
Can you tell me how you found using the rating scale?	<ul style="list-style-type: none"> - Did you have any problems using the rating scale? - What do the options on the rating scale mean to you? - What does the middle of the rating scale mean? - How did you decide what option to choose? 	<ul style="list-style-type: none"> - Clarity - Appropriateness of the response scale
Can you tell me what you thought about the change in the rating scale?	<ul style="list-style-type: none"> - Can you tell me more about that? When did you realise it had changed? - Did that make the questionnaire more difficult for you? 	<ul style="list-style-type: none"> - Clarity - Appropriateness of the response scale
Can you tell me what think of the layout of the questionnaire?	<ul style="list-style-type: none"> - Are there any changes that need to be made to the layout? 	<ul style="list-style-type: none"> - Clarity
What do you think of the questionnaire overall?	<ul style="list-style-type: none"> - What was your overall reaction to the questionnaire? - What parts did you like and why? - What parts did you dislike and why? 	<ul style="list-style-type: none"> - Relevance - Acceptability

7.7 APPENDIX G. SECOND PROTOTYPE OF THE SOCIAL PARTICIPATIONS RESTRICTIONS QUESTIONNAIRE (SPaRQ2.0)

Instructions

This questionnaire asks whether hearing loss affects your everyday life.

If you normally wear a hearing aid, please answer as if you are wearing your hearing aid.

Please answer by circling **one** number between zero and ten for each statement.

Circling zero means that you completely disagree with the statement. Circling ten means that you completely agree with the statement.

If you make a mistake, please place a cross (X) through your first answer and then circle your second answer.

If a question is not at all relevant to you, please place a tick (✓) in the 'Does not apply to me' box.

Example Statement

Because of my hearing loss, I find it difficult to:	Completely disagreeCompletely agree										Does not apply to me	
Take part in conversations with people on the telephone	0	1	2	3	4	5	6	7	8	9	10	

Section 1

This section asks whether hearing loss makes it difficult for you to do different everyday activities.

Item Index	Because of my hearing loss, I find it difficult to:	Completely disagree	Completely agree	Does not apply to me
1	1. Take part in conversations in places where there is background noise, such as pubs, restaurants or parties	0 1 2 3 4 5 6 7 8 9 10		
2	2. Take part in conversations with people on the telephone	0 1 2 3 4 5 6 7 8 9 10		
3	3. Watch television with other people	0 1 2 3 4 5 6 7 8 9 10		
4	4. Watch live events and shows, such as plays, films, concerts or sports matches	0 1 2 3 4 5 6 7 8 9 10		
5	5. Listen to the radio or recorded music	0 1 2 3 4 5 6 7 8 9 10		
6	6. Carry out my favourite pastimes	0 1 2 3 4 5 6 7 8 9 10		
7	7. Take part in activities or events with community, voluntary or religious organisations	0 1 2 3 4 5 6 7 8 9 10		
8	8. Follow what is said in a talk or in a lecture	0 1 2 3 4 5 6 7 8 9 10		

Section 1 Continued

Item Index	Because of my hearing loss, I find it difficult to:	Completely disagree Completely agree											Does not apply to me
9	9. Use public transportation, such as buses, trains or aeroplanes	0	1	2	3	4	5	6	7	8	9	10	
10	10. Discuss my health with a healthcare professional, such as a dentist or hospital doctor	0	1	2	3	4	5	6	7	8	9	10	
11	11. Manage stressful and challenging situations	0	1	2	3	4	5	6	7	8	9	10	
12	12. Take part in a group discussion or a group meeting	0	1	2	3	4	5	6	7	8	9	10	
13	13. Take part in conversations with unfamiliar people	0	1	2	3	4	5	6	7	8	9	10	
14	14. Persevere with lengthy conversations	0	1	2	3	4	5	6	7	8	9	10	
15	15. Take part in conversations with people in my workplace, such as co-workers, managers or clients	0	1	2	3	4	5	6	7	8	9	10	
16	16. Talk with staff in places such as shops, cafes or banks	0	1	2	3	4	5	6	7	8	9	10	
17	17. Manage my responsibilities in home life, social life or work life	0	1	2	3	4	5	6	7	8	9	10	

Section 1 Continued

Item Index	Because of my hearing loss, I find it difficult to:	<div> <div>Completely disagree</div> <div>Completely agree</div> </div>											Does not apply to me
18	18. Take part in educational activities or training activities	0	1	2	3	4	5	6	7	8	9	10	
19	19. Attend get-togethers with my friends	0	1	2	3	4	5	6	7	8	9	10	
20	20. Go out with my significant other (e.g. spouse, partner, close friend)	0	1	2	3	4	5	6	7	8	9	10	
21	21. Attend family get-togethers	0	1	2	3	4	5	6	7	8	9	10	
22	22. Attend large social gatherings, such as functions or weddings	0	1	2	3	4	5	6	7	8	9	10	
23	23. Take part in conversations at get-togethers with my friends	0	1	2	3	4	5	6	7	8	9	10	
24	24. Take part in conversations with my significant other (e.g. spouse, partner, close friend)	0	1	2	3	4	5	6	7	8	9	10	
25	25. Take part in conversations at family get-togethers	0	1	2	3	4	5	6	7	8	9	10	
26	26. Get along with people who are close to me (e.g. spouse, partner, close friend)	0	1	2	3	4	5	6	7	8	9	10	

Section 2

This section asks whether hearing loss affects the way you feel in everyday life.

Item Index	Because of my hearing loss:	Completely disagree												Completely agree	Does not apply to me
27	1. I feel frustrated when it is difficult for me to follow a conversation	0	1	2	3	4	5	6	7	8	9	10			
28	2. I find social gatherings stressful	0	1	2	3	4	5	6	7	8	9	10			
29	3. I worry that I will miss important sounds or important information	0	1	2	3	4	5	6	7	8	9	10			
30	4. I feel isolated during group conversations	0	1	2	3	4	5	6	7	8	9	10			
31	5. I feel embarrassed about asking people to repeat what they have said	0	1	2	3	4	5	6	7	8	9	10			
32	6. I feel frustrated when I am left out of conversations	0	1	2	3	4	5	6	7	8	9	10			
33	7. I feel unenthusiastic about socialising with friends or family	0	1	2	3	4	5	6	7	8	9	10			
34	8. I feel lonely, even when I am around other people	0	1	2	3	4	5	6	7	8	9	10			

Section 2 Continued

Item Index	Because of my hearing loss:	<div> <div>Completely disagree</div> <div>Completely agree</div> </div>											Does not apply to me
35	9. I feel embarrassed when I say the wrong thing in conversation	0	1	2	3	4	5	6	7	8	9	10	
36	10. I feel isolated at get-togethers with family or friends	0	1	2	3	4	5	6	7	8	9	10	
37	11. I worry about going to social gatherings	0	1	2	3	4	5	6	7	8	9	10	
38	12. I feel unenthusiastic about joining in conversations when it is difficult to hear what is being said	0	1	2	3	4	5	6	7	8	9	10	
39	13. I feel upset when it is difficult for me to take part in conversations	0	1	2	3	4	5	6	7	8	9	10	
40	14. I feel sad when people around me are having a good time but I cannot join in	0	1	2	3	4	5	6	7	8	9	10	
41	15. I worry about talking to unfamiliar people	0	1	2	3	4	5	6	7	8	9	10	
42	16. I feel irritated when people are not patient or understanding when I do not hear them	0	1	2	3	4	5	6	7	8	9	10	

Section 3

This section asks whether hearing loss affects the way you are seen in everyday life.

Item Index	Because of my hearing loss:	Completely disagree	Completely agree	Does not apply to me
43	1. I think that I seem unfriendly when I do not join in conversations	0 1 2 3 4 5 6 7 8 9 10		
44	2. I think that I look less sociable than I really am	0 1 2 3 4 5 6 7 8 9 10		
45	3. I would rather pretend to understand what people are saying than let them know that I have a hearing difficulty	0 1 2 3 4 5 6 7 8 9 10		
46	4. I think that I look too demanding when I ask people to speak more clearly or to repeat what they have said	0 1 2 3 4 5 6 7 8 9 10		
47	5. I think that I look less capable than I really am	0 1 2 3 4 5 6 7 8 9 10		
48	6. I would rather sit quietly whilst people are talking than interrupt to ask them to repeat what they have said	0 1 2 3 4 5 6 7 8 9 10		
49	7. I think that I look foolish when I cannot understand what other people are saying	0 1 2 3 4 5 6 7 8 9 10		

Section 3 Continued

Item Index	Because of my hearing loss:	Completely disagree	Completely agree	Does not apply to me
50	8. I am less independent than I used to be	0 1 2 3 4 5 6 7 8 9 10		
51	9. I think that I look foolish when I say the wrong thing in conversation	0 1 2 3 4 5 6 7 8 9 10		
52	10. I am less outgoing than I used to be	0 1 2 3 4 5 6 7 8 9 10		
53	11. I think that people see me as a nuisance	0 1 2 3 4 5 6 7 8 9 10		

Section 4

Approximately how often do you wear a hearing aid? Please tick (✓) one box:

Everyday ☐

Sometimes ☐

Never ☐

7.8 APPENDIX H. THIRD PROTOTYPE OF THE SOCIAL PARTICIPATIONS RESTRICTIONS QUESTIONNAIRE (SPaRQ3.0)

Instructions

This questionnaire asks about the impact of hearing loss on your everyday life.

If you normally wear a hearing aid, please answer as if you are wearing your hearing aid.

For each question, please choose any **one** number between zero and ten to indicate the level of difficulty your hearing loss causes you.

Choosing **zero** means that you **completely disagree** with the statement in the question.

Choosing **ten** means that you **completely agree** with the statement in the question.

Section 1

Item Index	Because of my hearing loss, I find it difficult to:	Completely disagree											Completely agree
16	1. Talk with staff in places such as shops, cafes or banks	0	1	2	3	4	5	6	7	8	9	10	
12	2. Take part in a group discussion or a group meeting	0	1	2	3	4	5	6	7	8	9	10	
6	3. Carry out my favourite pastimes	0	1	2	3	4	5	6	7	8	9	10	
1	4. Take part in conversations in places where there is background noise, such as pubs, restaurants or parties	0	1	2	3	4	5	6	7	8	9	10	
11	5. Manage stressful and challenging situations	0	1	2	3	4	5	6	7	8	9	10	
14	6. Persevere with lengthy conversations	0	1	2	3	4	5	6	7	8	9	10	
19	7. Attend get-togethers with my friends	0	1	2	3	4	5	6	7	8	9	10	
17	8. Manage my responsibilities in home life, social life or work life	0	1	2	3	4	5	6	7	8	9	10	
8	9. Follow what is said in a talk or in a lecture	0	1	2	3	4	5	6	7	8	9	10	
23	10. Take part in conversations at get-togethers with my friends	0	1	2	3	4	5	6	7	8	9	10	

Section 2

Item Index	Because of my hearing loss:	Completely disagree										Completely agree
28	1. I find social gatherings stressful	0	1	2	3	4	5	6	7	8	9	10
32	2. I feel frustrated when I am left out of conversations	0	1	2	3	4	5	6	7	8	9	10
29	3. I worry that I will miss important sounds or important information	0	1	2	3	4	5	6	7	8	9	10
30	4. I feel isolated during group conversations	0	1	2	3	4	5	6	7	8	9	10
38	5. I feel unenthusiastic about joining in conversations when it is difficult to hear what is being said	0	1	2	3	4	5	6	7	8	9	10
34	6. I feel lonely, even when I am around other people	0	1	2	3	4	5	6	7	8	9	10
41	7. I worry about talking to unfamiliar people	0	1	2	3	4	5	6	7	8	9	10
36	8. I feel isolated at get-togethers with family or friends	0	1	2	3	4	5	6	7	8	9	10
39	9. I feel upset when it is difficult for me to take part in conversations	0	1	2	3	4	5	6	7	8	9	10
44	10. I think that I look less sociable than I really am	0	1	2	3	4	5	6	7	8	9	10
51	11. I think that I look foolish when I say the wrong thing in conversation	0	1	2	3	4	5	6	7	8	9	10

Section 3

Approximately how often do you wear a hearing aid? Please tick (✓) one box:

Everyday ☐

Sometimes ☐

Never ☐

7.9 APPENDIX I. HEARING HANDICAP INVENTORY FOR THE ELDERLY

Instructions: The purpose of this scale is to identify the problems your hearing loss may be causing you.

Answer YES, SOMETIMES, or NO for each question. Please tick (✓) only **one** option per question.

Do **not** skip a question if you avoid a situation because of your hearing problem.

If you use a hearing aid, please answer the way you hear **without** the aid.

Question	Yes	Sometimes	No
1. Does a hearing problem cause you to use the phone less often than you would like?			
2. Does a hearing problem cause you to feel embarrassed when meeting new people?			
3. Does a hearing problem cause you to avoid groups of people?			
4. Does a hearing problem make you irritable?			
5. Does a hearing problem cause you to feel frustrated when talking to members of your family?			
6. Does a hearing problem cause you difficulty when attending a party?			
7. Does a hearing problem cause you to feel "stupid" or "dumb"?			
8. Do you have difficulty hearing when someone speaks in a whisper?			
9. Do you feel handicapped by a hearing problem?			
10. Does a hearing problem cause you difficulty when visiting friends, relatives, or neighbours?			

Question	Yes	Sometimes	No
11. Does a hearing problem cause you to attend religious services less often than you would like?			
12. Does a hearing problem cause you to be nervous?			
13. Does a hearing problem cause you to visit friends, relatives, or neighbours less often than you would like?			
14. Does a hearing problem cause you to have arguments with family members?			
15. Does a hearing problem cause you difficulty when listening to TV or radio?			
16. Does a hearing problem cause you to go shopping less often than you would like?			
17. Does any problem or difficulty with your hearing upset you at all?			
18. Does a hearing problem cause you to want to be by yourself?			
19. Does a hearing problem cause you to talk to family members less often than you would like?			
20. Do you feel that any difficulty with your hearing limits or hampers your personal or social life?			
21. Does a hearing problem cause you difficulty when in a restaurant with relatives or friends?			
22. Does a hearing problem cause you to feel depressed?			
23. Does a hearing problem cause you to listen to TV or radio less often than you would like?			
24. Does a hearing problem cause you to feel uncomfortable when talking to friends?			
25. Does a hearing problem cause you to feel left out when you are with a group of people?			

7.10 APPENDIX J. WORLD HEALTH ORGANIZATION DISABILITY ASSESSMENT SCHEDULE 2.0 SELF-ADMINISTERED SHORTENED VERSION

Instructions: This questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Think back over the **past 30 days** and answer these questions, thinking about how much difficulty you had doing the following activities.

Please tick (✓) only **one** option per question.

In the PAST 30 DAYS, how much difficulty did you have in:	None	Mild	Moderate	Severe	Extreme or Cannot Do
1. Standing for long periods such as 30 minutes?					
2. Taking care of your household responsibilities?					
3. Learning a new task, for example, learning how to get to a new place?					
4. How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?					
5. How much have you been emotionally affected by your health problems?					
6. Concentrating on doing something for ten minutes?					
7. Walking a long distance such as a kilometre [or equivalent]?					
8. Washing your whole body?					
9. Getting dressed?					
10. Dealing with people you do not know?					
11. Maintaining a friendship?					
12. Your day-to-day work?					

7.11 APPENDIX K. PATIENT HEALTH QUESTIONNAIRE-4 (PHQ-4)

Instructions: This questionnaire asks how often you have been bothered by four wellbeing problems over the **last 2 weeks**.

Please tick (✓) only **one** option per question.

Please remember that any information you provide will be strictly confidential.

Over the LAST 2 WEEKS, how often have you been bothered by the following problems?	Not at all	Several Days	More than Half the Days	Nearly Every Day
1. Feeling nervous, anxious or on edge				
2. Not being able to stop or control worrying				
3. Little interest or pleasure in doing things				
4. Feeling down, depressed, or hopeless				

7.12 APPENDIX L. FINALISED SOCIAL PARTICIPATIONS RESTRICTIONS QUESTIONNAIRE (SPaRQ)

Instructions

This questionnaire asks about the impact of hearing loss on your everyday life.

If you normally wear a hearing aid, please answer as if you are wearing your hearing aid.

For each question, please circle any **one** number between zero and ten to indicate the level of difficulty your hearing loss causes you.

Choosing **zero** means that you **completely disagree** with the statement in the question.

Choosing **ten** means that you **completely agree** with the statement in the question.

If you make a mistake, please place a cross (X) through your first answer and then circle your second answer.

Section 1

Item Index	Because of my hearing loss, I find it difficult to:	Completely disagree										Completely agree
16	1. Talk with staff in places such as shops, cafes or banks	0	1	2	3	4	5	6	7	8	9	10
12	2. Take part in a group discussion or a group meeting	0	1	2	3	4	5	6	7	8	9	10
6	3. Carry out my favourite pastimes	0	1	2	3	4	5	6	7	8	9	10
11	5. Manage stressful and challenging situations	0	1	2	3	4	5	6	7	8	9	10
14	6. Persevere with lengthy conversations	0	1	2	3	4	5	6	7	8	9	10
19	7. Attend get-togethers with my friends	0	1	2	3	4	5	6	7	8	9	10
17	8. Manage my responsibilities in home life, social life or work life	0	1	2	3	4	5	6	7	8	9	10
8	9. Follow what is said in a talk or in a lecture	0	1	2	3	4	5	6	7	8	9	10
23	10. Take part in conversations at get-togethers with my friends	0	1	2	3	4	5	6	7	8	9	10

Section 2

Item Index	Because of my hearing loss:	<div> <div>Completely disagree</div> <div>Completely agree</div> </div>										
28	1. I find social gatherings stressful	0	1	2	3	4	5	6	7	8	9	10
32	2. I feel frustrated when I am left out of conversations	0	1	2	3	4	5	6	7	8	9	10
29	3. I worry that I will miss important sounds or important information	0	1	2	3	4	5	6	7	8	9	10
30	4. I feel isolated during group conversations	0	1	2	3	4	5	6	7	8	9	10
38	5. I feel unenthusiastic about joining in conversations when it is difficult to hear what is being said	0	1	2	3	4	5	6	7	8	9	10
34	6. I feel lonely, even when I am around other people	0	1	2	3	4	5	6	7	8	9	10
41	7. I worry about talking to unfamiliar people	0	1	2	3	4	5	6	7	8	9	10
36	8. I feel isolated at get-togethers with family or friends	0	1	2	3	4	5	6	7	8	9	10
39	9. I feel upset when it is difficult for me to take part in conversations	0	1	2	3	4	5	6	7	8	9	10
51	10. I think that I look foolish when I say the wrong thing in conversation	0	1	2	3	4	5	6	7	8	9	10

Section 3

Approximately how often do you wear a hearing aid? Please tick (✓) one box:

Everyday ☐

Sometimes ☐

Never ☐

REFERENCES

- Abrams, T.E., Barnett, M.J., Hoth, A., Schultz, S. and Kaboli, P.J. (2006). The relationship between hearing impairment and depression in older veterans. *Journal of the American Geriatrics Society*, 54(9), pp.1475-1477.
- Acar, B., Yurekli, M.F., Babademez, M.A., Karabulut, H. and Karasen, R.M. (2011). Effects of hearing aids on cognitive functions and depressive signs in elderly people. *Archives of Gerontology and Geriatrics*, 52(3), pp.250-252.
- Adams, J. and White, M. (2005). Why don't stage-based activity promotion interventions work? *Health Education Research*, 20(2), pp.237-243.
- Agrawal, Y., Platz, E.A. and Niparko, J.K. (2008). Prevalence of hearing loss and differences by demographic characteristics among us adults: Data from the national health and nutrition examination survey, 1999-2004. *Archives of Internal Medicine*, 168(14), pp.1522-1530.
- Ajzen, I. and Madden, T.J. (1986). Prediction of goal-directed behavior: Attitudes, intentions, and perceived behavioral control. *Journal of Experimental Social Psychology*, 22(5), pp.453-474.
- Akeroyd, M.A., Wright-Whyte, K., Holman, J.A. and Whitmer, W.M. (2015). A comprehensive survey of hearing questionnaires: How many are there, what do they measure, and how have they been validated? *Trials*, 16(1), pp.1.
- Albera, R., Cavalot, A., Beatrice, F., Romano, C., Bosia, S., Luccoli, L., Vergnano, P., Schindler, A. and Argentero, P. (2001). Self-reported disability and handicap in individuals with noise-induced hearing loss. *Journal of Audiological Medicine*, 10(3), pp.175-183.
- Allen, N.H., Burns, A., Newton, V., Hickson, F., Ramsden, R., Rogers, J., Butler, S., Thistlewaite, G. and Morris, J. (2003). The effects of improving hearing in dementia. *Age and Ageing*, 32(2), pp.189-193.
- Alwin, D.F. (1997). Feeling thermometers versus 7-point scales which are better? *Sociological Methods & Research*, 25(3), pp.318-340.
- Amagai, M., Suzuki, M., Shibata, F. and Tsai, J. (2012). Development of an instrument to measure self-efficacy for social participation of people with mental illness. *Archives of Psychiatric Nursing*, 26(3), pp.240-248.
- Andersen, L.G., Groenvold, M., Jørgensen, T. and Aadahl, M. (2010). Construct validity of a revised physical activity scale and testing by cognitive interviewing. *Scandinavian Journal of Public Health*, 38(7), pp.707-714.

- Andersson, G. and Willebrand, M. (2003). What is coping? A critical review of the construct and its application in audiology. *International Journal of Audiology*, 42(S1), pp.97-103.
- Andrich, D. (1985). An elaboration of guttman scaling with rasch models for measurement. *Sociological methodology*(15), pp.33-80.
- Andrich, D., Lyne, A., Sheridan, B. and Luo, G. (2010). Rumm 2030. Perth, RUMM Laboratory.
- AOHL (2015). Hearing matters. Action on hearing loss, United Kingdom.
- Arlinger, S. (2003). Negative consequences of uncorrected hearing loss: A review. *International Journal of Audiology*, 42, pp.2S17-12S20.
- Armitage, C.J. and Conner, M. (2000). Social cognition models and health behaviour: A structured review. *Psychology and Health*, 15(2), pp.173-189.
- ASHA (2015). Type, degree, and configuration of hearing loss. *American Speech-Language-Hearing Association Audiology Information Series*, pp.1-2.
- Badley, E.M. (2008). Enhancing the conceptual clarity of the activity and participation components of the international classification of functioning, disability, and health. *Social Science & Medicine*, 66(11), pp.2335-2345.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84(2), pp.191-215.
- Bandura, A. (1995). Self-efficacy in changing societies. Cambridge University Press, Cambridge.
- Bandura, A. (1998). Health promotion from the perspective of social cognitive theory. *Psychology and Health*, 13(4), pp.623-649.
- Bandura, A. (2004). Health promotion by social cognitive means. *Health Education & Behavior*, 31(2), pp.143-164.
- Bandura, A. (2006). Guide for constructing self-efficacy scales. In: Self-efficacy beliefs of adolescents: Volume 5. pp. 307–337, (Eds. Pajares, F. and Urdan, T.) Information Age Publishing, Greenwich, Connecticut.
- Barker, F., Mackenzie, E., Elliott, L., Jones, S. and de Lusignan, S. (2014). Interventions to improve hearing aid use in adult auditory rehabilitation. *Cochrane Database of Systematic Reviews*, 7(Art. No.: CD010342), pp.1-129.
- Barker, F., MacKenzie, E., Elliott, L. and de Lusignan, S. (2015). Outcome measurement in adult auditory rehabilitation: A scoping review of

measures used in randomized controlled trials. *Ear and Hearing*, 36(5), pp.567-573.

Barker, F., Atkins, L. and de Lusignan, S. (2016). Applying the com-b behaviour model and behaviour change wheel to develop an intervention to improve hearing-aid use in adult auditory rehabilitation. *International Journal of Audiology*, 55(sup3), pp.S90-S98.

Barriball, L.K. and While, A. (1994). Collecting data using a semi structured interview: A discussion paper. *Journal of Advanced Nursing*, 19(2), pp.328-335.

Barsevick, A.M., Whitmer, K. and Walker, L. (2001). In their own words: Using the common sense model to analyze patient descriptions of cancer-related fatigue. *Oncology Nursing Forum*, 28(9), pp.1363-1369.

Bath, P.A. and Deeg, D. (2005). Social engagement and health outcomes among older people: Introduction to a special section. *European Journal of Ageing*, 2(1), pp.24-30.

Beatty, P.C. and Willis, G.B. (2007). Research synthesis: The practice of cognitive interviewing. *Public Opinion Quarterly*, 71(2), pp.287-311.

Beck, L.B. (2000). The role of outcomes data in health-care resource allocation. *Ear and Hearing*, 21(4), pp.89S-96S.

Beckstead, J.W. (2009). Content validity is naught. *International Journal of Nursing Studies*, 46(9), pp.1274-1283.

Belvedere, S.L. and de Morton, N.A. (2010). Application of rasch analysis in health care is increasing and is applied for variable reasons in mobility instruments. *Journal of Clinical Epidemiology*, 63(12), pp.1287-1297.

Bennett, K.M. (2002). Low level social engagement as a precursor of mortality among people in later life. *Age and Ageing*, 31(3), pp.165-168.

Bentler, R. and Kramer, S. (2000). Guidelines for choosing a self-report outcome measure. *Ear and Hearing*, 21(4), pp.37S-49S.

Bishop, F.L., Lewis, G., Harris, S., McKay, N., Prentice, P., Thiel, H. and Lewith, G.T. (2010). A within-subjects trial to test the equivalence of online and paper outcome measures: The roland morris disability questionnaire. *BMC Musculoskeletal Disorders*, 11(1), pp.1-7.

Bisht, M. and Bist, S. (2011). Ototoxicity: The hidden menace. *Indian Journal of Otolaryngology and Head & Neck Surgery*, 63(3), pp.255-259.

Bjorner, J.B., Kosinski, M. and Ware Jr, J.E. (2003). Calibration of an item pool for assessing the burden of headaches: An application of item

- response theory to the headache impact test (hit™). *Quality of Life Research*, 12(8), pp.913-933.
- Blood, I.M. (1997). The hearing aid effect: Challenges for counseling. *Journal of Rehabilitation*, 63(4), pp.59-62.
- Bonsaksen, T., Kottorp, A., Gay, C., Fagermoen, M. S. and Lerdal, A. (2013). Rasch analysis of the General Self-Efficacy Scale in a sample of persons with morbid obesity. *Health and Quality of Life Outcomes*, 11(1), pp.202.
- Boi, R., Racca, L., Cavallero, A., Carpaneto, V., Racca, M., Dall'Acqua, F., Ricchetti, M., Santelli, A. and Odetti, P. (2012). Hearing loss and depressive symptoms in elderly patients. *Geriatrics & Gerontology International*, 12(3), pp.440-445.
- Boothroyd, A. (2007). Adult aural rehabilitation: What is it and does it work? *Trends in Amplification*, 11(2), pp.63-71.
- Boothroyd, A. (2004). Hearing aid accessories for adults: The remote FM microphone. *Ear and Hearing*, 25(1), pp.22-33.
- Bot, S., Terwee, C., Van der Windt, D., Bouter, L., Dekker, J. and De Vet, H. (2003). Psychometric evaluation of self-report questionnaires: The development of a checklist. *Second Workshop on Research Methodology Proceedings*.
- Bowling, A. and Dieppe, P. (2005). What is successful ageing and who should define it? *British Medical Journal*, 331(7531), pp.1548-1551.
- Boynton, P.M. and Greenhalgh, T. (2004). Hands-on guide to questionnaire research: Selecting, designing, and developing your questionnaire. *British Medical Journal*, 328(7451), pp.1312–1315.
- Boynton, P.M., Wood, G.W. and Greenhalgh, T. (2004). Hands-on guide to questionnaire research: Reaching beyond the white middle classes. *British Medical Journal*, 328(7453), pp.1433-1436.
- Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), pp.77-101.
- Brinkmann, S. (2014). Unstructured and semi-structured interviewing. In: *The oxford handbook of qualitative research*, pp. 277-299 (Ed. Leavy, P). Oxford University Press, Oxford.
- Britten, N. (1995). Qualitative interviews in medical research. *British Medical Journal*, 311(6999), pp.251-253.
- Brod, M., Tesler, L.E. and Christensen, T.L. (2009). Qualitative research and content validity: Developing best practices based on science and experience. *Quality of Life Research*, 18(9), pp.1263-1278.

- Brug, J., Conner, M., Harre, N., Kremers, S., McKellar, S. and Whitelaw, S. (2005). The transtheoretical model and stages of change: A critique observations by five commentators on the paper by adams, j. and white, m.(2004) why don't stage-based activity promotion interventions work? *Health education research*, 20(2), pp.244-258.
- Bryman, A. (2006). Integrating quantitative and qualitative research: How is it done? *Qualitative Research*, 6(1), pp.97-113.
- BSA (2016). Practice guidance: Common principles of rehabilitation for adults in audiology services. British Society of Audiology, Reading, UK.
- BSA (2011). Recommended procedure: Pure-tone air-conduction and bone-conduction threshold audiometry with and without masking. British Society of Audiology, Reading, UK, pp.1-32.
- Caissie, R., Dawe, A.L., Donovan, C., Brooks, H. and MacDonald, S.M. (1998). Conversational performance of adults with a hearing loss. *Journal-Academy of Rehabilitative Audiology*, 31, pp.45-68.
- Cano, S.J. and Hobart, J.C. (2011). The problem with health measurement. *Patient Preference and Adherence*, 5, pp.279-290.
- Carini, R.M., Hayek, J.C., Kuh, G.D., Kennedy, J.M. and Ouimet, J.A. (2003). College student responses to web and paper surveys: Does mode matter? *Research in Higher Education*, 44(1), pp.1-19.
- Carpenter, C.J. (2010). A meta-analysis of the effectiveness of health belief model variables in predicting behavior. *Health Communication*, 25(8), pp.661-669.
- Chachamovich, E., Fleck, M.P., Trentini, C.M., Laidlaw, K. and Power, M.J. (2008). Development and validation of the brazilian version of the attitudes to aging questionnaire (aaq): An example of merging classical psychometric theory and the rasch measurement model. *Health and Quality of Life Outcomes*, 6(5), pp.1-10.
- Champion, V.L. and Skinner, C.S. (2008). The health belief model. In: Health behavior and health education: Theory, research, and practice. (Eds. Glanz, K., Rimer, B.K. and Viswanath, K.) John Wiley & Sons, San Francisco.
- Chang, F.-H., Coster, W.J., Salzer, M.S., Brusilovskiy, E., Ni, P. and Jette, A.M. (2016). A multidimensional measure of participation for adults with serious mental illnesses. *Disability and Rehabilitation*, 38(7), pp.695-703.
- Chen, W.-H., Lenderking, W., Jin, Y., Wyrwich, K.W., Gelhorn, H. and Revicki, D.A. (2013). Is rasch model analysis applicable in small sample size pilot studies for assessing item characteristics? An

example using promis pain behavior item bank data. *Quality of Life Research*, 23(2), pp.485-493.

Chenault, M., Berger, M., Kremer, B. and Anteunis, L. (2013). Quantification of experienced hearing problems with item response theory. *American Journal of Audiology*, 22(2), pp.252-262.

Chisolm, T.H., Abrams, H.B., McArdle, R., Wilson, R.H. and Doyle, P.J. (2005). The who-das ii: Psychometric properties in the measurement of functional health status in adults with acquired hearing loss. *Trends in Amplification*, 9(3), pp.111-126.

Ciorba, A., Bianchini, C., Pelucchi, S., Pastore, A., Ciorba, A., Bianchini, C., Pelucchi, S. and Pastore, A. (2012). The impact of hearing loss on the quality of life of elderly adults. *Clinical Interventions in Aging*, 7, pp.159-163.

Clark, L.A. and Watson, D. (1995). Constructing validity: Basic issues in objective scale development. *Psychological Assessment*, 7(3), pp.309-319.

Clark, M.S., Bond, M.J. and Sanchez, L. (1999). The effect of sensory impairment on the lifestyle activities of older people. *Australasian Journal on Ageing*, 18(3), pp.124-129.

Clarke, M. (2007). Standardising outcomes for clinical trials and systematic reviews. *Trials*, 8(39), pp.1-3.

Collins, D. (2003). Pretesting survey instruments: An overview of cognitive methods. *Quality of Life Research*, 12(3), pp.229-238.

Conrad, F. and Blair, J. (1996). From impressions to data: Increasing the objectivity of cognitive interviews. Proceedings of the Section on Survey Research Methods, Annual Meetings of the American Statistical Association.

Conrad, F., Blair, J. and Tracy, E. (1999). Verbal reports are data! A theoretical approach to cognitive interviews. Proceedings of the Federal Committee on Statistical Methodology Research Conference, Citeseer.

Cook, A.J., Roberts, D.A., Henderson, M.D., Van Winkle, L.C., Chastain, D.C. and Hamill-Ruth, R.J. (2004). Electronic pain questionnaires: A randomized, crossover comparison with paper questionnaires for chronic pain assessment. *Pain*, 110(1), pp.310-317.

Cornwell, E.Y. and Waite, L.J. (2009). Social disconnectedness, perceived isolation, and health among older adults. *Journal of Health and Social Behavior*, 50(1), pp.31-48.

Cortina, J.M. (1993). What is coefficient alpha? An examination of theory and applications. *Journal of Applied Psychology*, 78(1), pp.98-104.

- Costello, A.B. and Osborne, J.W. (2009). Best practices in exploratory factor analysis: Four recommendations for getting the most from your analysis. *Practical Assessment, Research and Evaluation*, 10(7), pp.1531-7714.
- Coulson, N.S., Ferguson, M.A., Henshaw, H. and Heffernan, E. (2016). Applying theories of health behaviour and change to hearing health research: Time for a new approach. *International Journal of Audiology*, 55(S3), pp.S99-S104.
- Cox III, E.P. (1980). The optimal number of response alternatives for a scale: A review. *Journal of Marketing Research*, 17(4), pp.407-422.
- Cox, R., Hyde, M., Gatehouse, S., Noble, W., Dillon, H., Bentler, R., Stephens, D., Arlinger, S., Beck, L. and Wilkerson, D. (2000). Optimal outcome measures, research priorities, and international cooperation. *Ear and Hearing*, 21(4), pp.106S-115S.
- Cox, R.M. and Alexander, G.C. (2002). The international outcome inventory for hearing aids (ioi-ha): Psychometric properties of the english version. *International Journal of Audiology*, 41(1), pp.30-35.
- Cox, R.M. (2003). Assessment of subjective outcome of hearing aid fitting: Getting the client's point of view. *International Journal of Audiology*, 42(S1), pp.90-96.
- Coyle, C.E. and Dugan, E. (2012). Social isolation, loneliness and health among older adults. *Journal of Aging and Health*, 24(8), pp.1346-1363.
- Craig, A., Nicholson Perry, K., Guest, R., Tran, Y. and Middleton, J. (2015). Adjustment following chronic spinal cord injury: Determining factors that contribute to social participation. *British Journal of Health Psychology*, 20(4), pp.807-823.
- Creswell, J.W. and Miller, D.L. (2000). Determining validity in qualitative inquiry. *Theory Into Practice*, 39(3), pp.124-130.
- Crews, J.E. and Campbell, V.A. (2004). Vision impairment and hearing loss among community-dwelling older americans: Implications for health and functioning. *American Journal of Public Health*, 94(5), pp.823-829.
- Crocker, J. (1999). Social stigma and self-esteem: Situational construction of self-worth. *Journal of Experimental Social Psychology*, 35(1), pp.89-107.
- Cruickshanks, K.J., Klein, R., Klein, B.E., Wiley, T.L., Nondahl, D.M. and Tweed, T.S. (1998). Cigarette smoking and hearing loss: The epidemiology of hearing loss study. *Journal of the American Medical Association*, 279(21), pp.1715-1719.

- da Rocha, N.S., Chachamovich, E., de Almeida Fleck, M.P. and Tennant, A. (2013). An introduction to rasch analysis for psychiatric practice and research. *Journal of Psychiatric Research*, 47(2), pp.141-148.
- Dalton, D.S., Cruickshanks, K.J., Klein, B.E.K., Klein, R., Wiley, T.L. and Nondahl, D.M. (2003). The impact of hearing loss on quality of life in older adults. *Gerontologist*, 43(5), pp.661-668.
- Danermark, B., Cieza, A., Gimigliano, F., Granberg, S., Hickson, L., Kramer, S.E., McPherson, B., Möller, C., Russo, I. and Strömberg, J.P. (2010). International classification of functioning, disability, and health core sets for hearing loss: A discussion paper and invitation. *International Journal of Audiology*, 49(4), pp.256-262.
- Danermark, B., Granberg, S., Kramer, S.E., Selb, M. and Möller, C. (2013). The creation of a comprehensive and a brief core set for hearing loss using the international classification of functioning, disability and health. *American Journal of Audiology*, 22(2), pp.323-328.
- Daniel, E. (2007). Noise and hearing loss: A review. *Journal of School Health*, 77(5), pp.225-231.
- Davis, A., Smith, P., Ferguson, M., Stephens, D. and Gianopoulos, I. (2007). Acceptability, benefit and costs of early screening for hearing disability: A study of potential screening tests and models. *Health Technology Assessment*, 11(42), pp.1-294.
- Davis, L.L. (1992). Instrument review: Getting the most from a panel of experts. *Applied Nursing Research*, 5(4), pp.194-197.
- Dawes, P., Fortnum, H., Moore, D.R., Emsley, R., Norman, P., Cruickshanks, K., Davis, A., Edmondson-Jones, M., McCormack, A. and Lutman, M. (2014). Hearing in middle age: A population snapshot of 40-to 69-year olds in the united kingdom. *Ear and Hearing*, 35(3), pp.e44-e51.
- Dawes, P., Cruickshanks, K.J., Fischer, M.E., Klein, B.E.K., Klein, R. and Nondahl, D.M. (2015a). Hearing-aid use and long-term health outcomes: Hearing handicap, mental health, social engagement, cognitive function, physical health, and mortality. *International Journal of Audiology*, 54(11), pp.838-844.
- Dawes, P., Emsley, R., Cruickshanks, K.J., Moore, D.R., Fortnum, H., Edmondson-Jones, M., McCormack, A. and Munro, K.J. (2015b). Hearing loss and cognition: The role of hearing aids, social isolation and depression. *PLoS One*, 10(3 (e0119616)), pp.1-9.
- De Vet, H.C., Terwee, C.B., Mokkink, L.B. and Knol, D.L. (2011). Measurement in medicine: A practical guide, Cambridge University Press, Cambridge.

- de Winter, J.C.F., Dodou, D. and Wieringa, P.A. (2009). Exploratory factor analysis with small sample sizes. *Multivariate Behavioral Research*, 44(2), pp.147-181.
- Demorest, M.E. and Erdman, S.A. (1987). Development of the communication profile for the hearing impaired. *Journal of Speech and Hearing Disorders*, 52(2), pp.129-143.
- Demorest, M.E., Wark, D.J. and Erdman, S.A. (2011). Development of the screening test for hearing problems. *American Journal of Audiology*, 20(2), pp.100-110.
- Diefenbach, M.A. and Leventhal, H. (1996). The common-sense model of illness representation: Theoretical and practical considerations. *Journal of Social Distress and the Homeless*, 5(1), pp.11-38.
- Dijkers, M.P. (2010). Issues in the conceptualization and measurement of participation: An overview. *Archives of Physical Medicine and Rehabilitation*, 91(9, Supplement), pp.S5-S16.
- Dijkers, M.P.J.M., Whiteneck, G. and El-Jaroudi, R. (2000). Measures of social outcomes in disability research. *Archives of Physical Medicine and Rehabilitation*, 81, Supplement 2(0), pp.S63-S80.
- Dillon, H. (2001). Hearing aids. Sydney, Bommerang Press.
- Dillon, H., James, A. and Ginis, J. (1997). Client Oriented Scale of Improvement (COSI) and its relationship to several other measures of benefit and satisfaction provided by hearing aids. *Journal-American Academy Of Audiology*, 8, 27-43.
- Doggett, S., Stein, R.L. and Gans, D. (1998). Hearing aid effect in older females. *JOURNAL-AMERICAN ACADEMY OF AUDIOLOGY*, 9, pp.361-366.
- Donaldson, N., Worrall, L. and Hickson, L. (2004). Older people with hearing impairment: A literature review of the spouse's perspective. *The Australian and New Zealand Journal of Audiology*, 26(1), pp.30-39.
- Drennan, J. (2003). Cognitive interviewing: Verbal data in the design and pretesting of questionnaires. *Journal of Advanced Nursing*, 42(1), pp.57-63.
- Echalier, M. (2010). In it together: The impact of hearing loss on personal relationships, Royal National Institute for Deaf People, pp. 1-28.
- Ekberg, K., Grenness, C. and Hickson, L. (2014). Addressing patients' psychosocial concerns regarding hearing aids within audiology appointments for older adults. *American Journal of Audiology*, 23(3), pp.337-350.

- Elberling, C. and Worsoe, K. (2006). Fading sounds - About hearing and hearing aids. The Oticon Foundation, Denmark, pp.1-104.
- Eriksson-Mangold, M. and Carlsson, S.G. (1991). Psychological and somatic distress in relation to perceived hearing disability, hearing handicap, and hearing measurements. *Journal of Psychosomatic Research*, 35(6), pp.729-740.
- Erler, S.F. and Garstecki, D.C. (2002). Hearing loss-and hearing aid-related stigma: Perceptions of women with age-normal hearing. *American Journal of Audiology*, 11(2), pp.83-91.
- Espmark, A.-K.K. and Scherman, M.H. (2003). Hearing confirms existence and identity - experiences from persons with presbycusis. *International Journal of Audiology*, 42(2), pp.106-115.
- Evers, A.W.M., Duller, P., Van De Kerkhof, P.C.M., Van Der Valk, P.G.M., De Jong, E.M.G.J., Gerritsen, M.J.P., Otero, E., Verhoeven, E.W.M., Verhaak, C.M. and Kraaijmaat, F.W. (2008). The impact of chronic skin disease on daily life (isdli): A generic and dermatology-specific health instrument. *British Journal of Dermatology*, 158(1), pp.101-108.
- Eyssen, I.C., Steultjens, M.P., Dekker, J. and Terwee, C.B. (2011). A systematic review of instruments assessing participation: Challenges in defining participation. *Archives of Physical Medicine and Rehabilitation*, 92(6), pp.983-997.
- Fabrigar, L.R., Wegener, D.T., MacCallum, R.C. and Strahan, E.J. (1999). Evaluating the use of exploratory factor analysis in psychological research. *Psychological Methods*, 4(3), pp.272.
- Fackrell, K., Hall, D.A., Barry, J.G. and Hoare, D.J. (2016). Psychometric properties of the tinnitus functional index (tfi): Assessment in a uk research volunteer population. *Hearing Research*, 335, pp.220-235.
- Faulkner, L. (2003). Beyond the five-user assumption: Benefits of increased sample sizes in usability testing. *Behavior Research Methods, Instruments, & Computers*, 35(3), pp.379-383.
- Fellinger, J., Holzinger, D., Gerich, J. and Goldberg, D. (2007). Mental distress and quality of life in the hard of hearing. *Acta Psychiatrica Scandinavica*, 115(3), pp.243-245.
- Fereday, J. and Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5(1), pp.80-92.
- Ferguson, M., Coulson, N., Handscomb, L., Brassington, W. and Downes, B. (2016). A national survey of adult rehabilitation practice in uk audiology services. Proceedings of the British Society of Audiology Annual Conference, Coventry, UK.

- Ferguson, M.A., Woolley, A. and Munro, K.J. (2016). The impact of self-efficacy, expectations, and readiness on hearing aid outcomes. *International Journal of Audiology*, 55(S3), pp.S34-S41.
- Field, A. (2009). *Discovering statistics using spss*, Sage Publications.
- Field, M.J. and Jette, A. (2007). *The future of disability in america*, National Academies Press.
- Floyd, F.J. and Widaman, K.F. (1995). Factor analysis in the development and refinement of clinical assessment instruments. *Psychological Assessment*, 7(3), pp.286-299.
- Fok, D., Shaw, L., Jennings, M.B. and Cheesman, M. (2009). Towards a comprehensive approach for managing transitions of older workers with hearing loss. *Work: A Journal of Prevention, Assessment and Rehabilitation*, 32(4), pp.365-376.
- Ford, H.L., Gerry, E., Tennant, A., Whalley, D., Haigh, R. and Johnson, M.H. (2001). Developing a disease-specific quality of life measure for people with multiple sclerosis. *Clinical Rehabilitation*, 15(3), pp.247-258.
- Forkmann, T., Boecker, M., Norra, C., Eberle, N., Kircher, T., Schauerte, P., Mischke, K., Westhofen, M., Gauggel, S. and Wirtz, M. (2009). Development of an item bank for the assessment of depression in persons with mental illnesses and physical diseases using rasch analysis. *Rehabilitation Psychology*, 54(2), pp.186-197.
- Gagné, J.-P., Jennings, M.B. and Southall, K. (2009). Understanding the stigma associated with hearing loss in older adults. *Hearing Care for Adults*, pp.203-212.
- García de Yébenes Prous, M.J., Salvanés, F.R. and Ortells, L.C. (2008). Responsiveness of outcome measures. *Reumatología Clínica (English Edition)*, 4(6), pp.240-247.
- Gatehouse, S. (1999). Glasgow hearing aid benefit profile: Derivation and validation of a client-centered outcome measure for hearing aid services. *Journal of the American Academy of Audiology*, 10(2), pp.80-103.
- Gatehouse, S. (2000). The glasgow hearing aid benefit profile: What it measures and how to use it. *The Hearing Journal*, 53(3), pp.10-12.
- Glass, T.A., De Leon, C.F.M., Bassuk, S.S. and Berkman, L.F. (2006). Social engagement and depressive symptoms in late life longitudinal findings. *Journal of Ageing and Health*, 18(4), pp.604-628.
- Gomez, R.G. and Madey, S.F. (2001). Coping-with-hearing-loss model for older adults. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 56(4), pp.P223-P225.

- Gopinath, B., Wang, J.J., Schneider, J., Burlutsky, G., Snowdon, J., McMahon, C.M., Leeder, S.R. and Mitchell, P. (2009). Depressive symptoms in older adults with hearing impairments: The blue mountains study. *Journal of the American Geriatrics Society*, 57(7), pp.1306-1308.
- Gopinath, B., Hickson, L., Schneider, J., McMahon, C.M., Burlutsky, G., Leeder, S.R. and Mitchell, P. (2012a). Hearing-impaired adults are at increased risk of experiencing emotional distress and social engagement restrictions five years later. *Age and Ageing*, 41(5), pp.618-623.
- Gopinath, B., Schneider, J., McMahon, C.M., Teber, E., Leeder, S.R. and Mitchell, P. (2012b). Severity of age-related hearing loss is associated with impaired activities of daily living. *Age and Ageing*, 41(2), pp.195-200.
- Govender, N.G., Maistry, N., Soomar, N. and Paken, J. (2014). Hearing loss within a marriage: Perceptions of the spouse with normal hearing. *South African Family Practice*, 56(1), pp.50-56.
- Granberg, S., Danermark, B. and Gagné, J.-P. (2010). The development of icf core sets for hearing loss. *Perspectives on Audiology*, 6(1), pp.20-23.
- Granberg, S., Dahlström, J., Möller, C., Kähäri, K. and Danermark, B. (2014a). The icf core sets for hearing loss – researcher perspective. Part i: Systematic review of outcome measures identified in audiological research. *International Journal of Audiology*, 53(2), pp.65-76.
- Granberg, S., Pronk, M., Swanepoel, D.W., Kramer, S.E., Hagsten, H., Hjal Dahl, J., Möller, C. and Danermark, B. (2014b). The icf core sets for hearing loss project: Functioning and disability from the patient perspective. *International Journal of Audiology*, 53(11), pp.777-786.
- Granberg, S., Swanepoel, D.W., Englund, U., Möller, C. and Danermark, B. (2014c). The icf core sets for hearing loss project: International expert survey on functioning and disability of adults with hearing loss using the international classification of functioning, disability, and health (icf). *International Journal of Audiology*, 53(8), pp.497-506.
- Grant, J.S. and Davis, L.L. (1997). Selection and use of content experts for instrument development. *Research in Nursing & Health*, 20(3), pp.269-274.
- Grenness, C., Hickson, L., Laplante-Lévesque, A. and Davidson, B. (2014a). Patient-centred care: A review for rehabilitative audiologists. *International Journal of Audiology*, 53(1), pp. S60-S67.

- Grenness, C., Hickson, L., Laplante-Lévesque, A. and Davidson, B. (2014b). Patient-centred audiological rehabilitation: Perspectives of older adults who own hearing aids. *International Journal of Audiology*, 53(S1), pp.S68-S75.
- Guadagnoli, E. and Velicer, W.F. (1988). Relation to sample size to the stability of component patterns. *Psychological Bulletin*, 103(2), pp.265-275.
- Guest, G., Bunce, A. and Johnson, L. (2006). How many interviews are enough?: An experiment with data saturation and variability. *Field Methods*, 18(1), pp.59-82.
- Guttman, L. (1950). The basis for scalogram analysis. In: *Studies in social psychology in world war ii: Vol. 4 Measurement and prediction*, pp.60-90. (Eds. Guttman, L., Suchman, F., Lazarsfeld, P., Star, S. and Clausen, J.) Princeton University Press, Princeton.
- Gwaltney, C.J., Shields, A.L. and Shiffman, S. (2008). Equivalence of electronic and paper-and-pencil administration of patient-reported outcome measures: A meta-analytic review. *Value in Health*, 11(2), pp.322-333.
- Hagger, M.S. and Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health*, 18(2), pp.141-184.
- Hagquist, C. (2001). Evaluating composite health measures using rasch modelling: An illustrative example. *Sozial- und Präventivmedizin*, 46(6), pp.369-378.
- Hagquist, C., Bruce, M. and Gustavsson, J.P. (2009). Using the rasch model in nursing research: An introduction and illustrative example. *International Journal of Nursing Studies*, 46(3), pp.380-393.
- Hale, E., Treharne, G. and Kitas, G. (2007). The common-sense model of self-regulation of health and illness: How can we use it to understand and respond to our patients' needs? *Rheumatology*, 46(6), pp.904-906.
- Hallam, R.S. and Brooks, D.N. (1996). Development of the hearing attitudes in rehabilitation questionnaire (harq). *British Journal of Audiology*, 30(3), pp.199-213.
- Hallberg, L.R.-M. and Carlsson, S.G. (1991). A qualitative study of strategies for managing a hearing impairment. *British Journal of Audiology*, 25(3), pp.201-211.
- Hallberg, L.R.M. and Carlsson, S.G. (1993). A qualitative study of situations turning a hearing disability into a handicap. *Disability, Handicap & Society*, 8(1), pp.71-86.

- Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J. and Rodriguez, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability & Rehabilitation*, 30(19), pp.1445-1460.
- Harrison, J.A., Mullen, P.D. and Green, L.W. (1992). A meta-analysis of studies of the health belief model with adults. *Health Education Research*, 7(1), pp.107-116.
- Haslam, S.A., Jetten, J., Postmes, T. and Haslam, C. (2009). Social identity, health and well-being: An emerging agenda for applied psychology. *Applied Psychology*, 58(1), pp.1-23.
- Hauke, J. and Kossowski, T. (2011). Comparison of values of pearson's and spearman's correlation coefficients on the same sets of data. *Quaestiones Geographicae*, 30(2), pp.87-93.
- Hawkins, D. B. (2005). Effectiveness of Counseling-Based Adult Group Aural Rehabilitation Programs: A Systematic Review of the Evidence. *Journal of the American Academy of Audiology*, 16(7), pp. 485-493.
- Hawley, C.A., Taylor, R., Hellawell, D.J. and Pentland, B. (1999). Use of the functional assessment measure (fim+fam) in head injury rehabilitation: A psychometric analysis. *Journal of Neurology, Neurosurgery & Psychiatry*, 67(6), pp.749-754.
- Hawthorne, G. (2008). Perceived social isolation in a community sample: Its prevalence and correlates with aspects of peoples' lives. *Social Psychiatry and Psychiatric Epidemiology*, 43(2), pp.140-150.
- Haynes, S.N., Richard, D. and Kubany, E.S. (1995). Content validity in psychological assessment: A functional approach to concepts and methods. *Psychological assessment*, 7(3), pp.238-247.
- Heesch, K.C., Van Uffelen, J.G., Hill, R.L. and Brown, W.J. (2010). Research what do ipaq questions mean to older adults? Lessons from cognitive interviews. *International Journal of Behavioral Nutrition Physical Activity*, 7(35), pp.2-13.
- Heffernan, E. (2016). The application of health psychology theory to hearing loss research. *PsyPAG Quarterly*, 99, pp.23-26.
- Heffernan, E., Coulson, N.S., Henshaw, H., Barry, J.G. and Ferguson, M.A. (2016). Understanding the psychosocial experiences of adults with mild-moderate hearing loss: An application of leventhal's self-regulatory model. *International Journal of Audiology*, 55(S3), pp.S3-S12.
- Heijmans, M. (1999). The role of patients' illness representations in coping and functioning with addison's disease. *British Journal of Health Psychology*, 4(2), pp.137-149.

- Heinemann, A.W. (2010). Measurement of participation in rehabilitation research. *Archives of Physical Medicine and Rehabilitation*, 91(9), pp.S1-S4.
- Heinemann, A.W., Tulsy, D., Dijkers, M., Brown, M., Magasi, S., Gordon, W. and DeMark, H. (2010). Issues in participation measurement in research and clinical applications. *Archives of Physical Medicine and Rehabilitation*, 91(9), pp.S72-S76.
- Helvik, A.-S., Jacobsen, G.W. and Hallberg, L.R. (2006a). Life consequences of hearing loss in terms of activity limitation and participation restriction. *Scandinavian Journal of Disability Research*, 8(1), pp.53-66.
- Helvik, A.-S., Jacobsen, G.W. and Hallberg, L.R.M. (2006b). Effects of impaired hearing on perceived health and life situation. *Scandinavian Journal of Disability Research*, 8(4), pp.263-277.
- Helvik, A.-S., Thürmer, H., Jacobsen, G.W., Bratt, M. and Hallberg, L.R.-M. (2007). Psychometrical evaluation of the hearing disability and handicap scale. *Scandinavian Journal of Disability Research*, 9(2), pp.112-124.
- Henshaw, H., Clark, D.P., Kang, S. and Ferguson, M.A. (2012). Computer skills and internet use in adults aged 50-74 years: Influence of hearing difficulties. *Journal of Medical Internet Research*, 14(4), pp.e113.
- Henshaw, H. and Ferguson, M.A. (2013). Efficacy of individual computer-based auditory training for people with hearing loss: A systematic review of the evidence. *PLoS One*, 8(5), pp.e62836.
- Henshaw, H. and Ferguson, M. A. (2013). Working memory training for adult hearing aid users: study protocol for a double-blind randomized active controlled trial. *Trials*, 14(1), pp.417.
- Henshaw, H. and Ferguson, M.A. (2014). Assessing the benefits of auditory training to real-world listening: Identifying appropriate and sensitive outcomes. Proceedings of the International Symposium on Auditory and Audiological Research. In: Auditory plasticity - Listening with the brain. Danavox Jubilee Foundation, Ballerup, Denmark, pp.45-52.
- Hétu, R., Riverin, L., Getty, L., Lalande, N. and St-Cyr, C. (1990). The reluctance to acknowledge hearing difficulties among hearing-impaired workers. *British Journal of Audiology*, 24(4), pp.265-276.
- Hétu, R. (1996). The stigma attached to hearing impairment. *Scandinavian Audiology Supplement*, 25(S43), pp.12-24.
- Hickson, L., Allen, J., Beswick, R., Fulton, M., Wolf, D., Worrall, L. and Scarinci, N. (2008). Relationships between hearing disability, quality of life and wellbeing in older community-based australians. *Australian and New Zealand Journal of Audiology, The*, 30(2), pp.99-111.

- Hickson, L., Meyer, C., Lovelock, K., Lampert, M. and Khan, A. (2014). Factors associated with success with hearing aids in older adults. *International Journal of Audiology*, 53(S1), pp.S18-S27.
- Hinkin, T.R. (1998). A brief tutorial on the development of measures for use in survey questionnaires. *Organizational Research Methods*, 1(1), pp.104-121.
- Hjermstad, M.J., Fayers, P.M., Haugen, D.F., Caraceni, A., Hanks, G.W., Loge, J.H., Fainsinger, R., Aass, N., Kaasa, S. and Collaborative, E.P.C.R. (2011). Studies comparing numerical rating scales, verbal rating scales, and visual analogue scales for assessment of pain intensity in adults: A systematic literature review. *Journal of Pain and Symptom Management*, 41(6), pp.1073-1093.
- Hobart, J. and Cano, S. (2008). Rating scales for clinical studies in neurology—challenges and opportunities. *US Neurology*, 4(1), pp.12-18.
- Hobart, J. and Cano, S. (2009). Improving the evaluation of therapeutic interventions in multiple sclerosis: The role of new psychometric methods. *Health Technology Assessment*, 13(12), pp.1-202.
- Hobart, J.C., Cano, S.J., Zajicek, J.P. and Thompson, A.J. (2007). Rating scales as outcome measures for clinical trials in neurology: Problems, solutions, and recommendations. *The Lancet Neurology*, 6(12), pp.1094-1105.
- Hobart, J.C., Cano, S.J., Warner, T.T. and Thompson, A.J. (2012). What sample sizes for reliability and validity studies in neurology? *Journal of Neurology*, 259(12), pp.2681-2694.
- Hogan, A., O'Loughlin, K., Davis, A. and Kendig, H. (2009). Hearing loss and paid employment: Australian population survey findings. *International Journal of Audiology*, 48(3), pp.117-122.
- Hogarty, K.Y., Hines, C.V., Kromrey, J.D., Ferron, J.M. and Mumford, K.R. (2005). The quality of factor solutions in exploratory factor analysis: The influence of sample size, communality, and overdetermination. *Educational and Psychological Measurement*, 65(2), pp.202-226.
- Holley, M.C. (2005). Keynote review: The auditory system, hearing loss and potential targets for drug development. *Drug Discovery Today*, 10(19), pp.1269-1282.
- Hospers, J.M.B., Smits, N., Smits, C., Stam, M., Terwee, C.B. and Kramer, S.E. (2016). Reevaluation of the amsterdam inventory for auditory disability and handicap using item response theory. *Journal of Speech, Language, and Hearing Research*, 59(2), pp.373-383.
- Humes, L.E. (1999). Dimensions of hearing aid outcome. *Journal of the American Academy of Audiology*, 10(1), pp.26-39.

- Hutchin, T.P. and Cortopassi, G.A. (2000). Mitochondrial defects and hearing loss. *Cellular and Molecular Life Sciences*, 57(13-14), pp.1927-1937.
- Huxhold, O., Fiori, K.L. and Windsor, T.D. (2013). The dynamic interplay of social network characteristics, subjective well-being, and health: The costs and benefits of socio-emotional selectivity. *Psychology and Aging*, 28(1), pp.3-16.
- Hyde, M.L. (2000). Reasonable psychometric standards for self-report outcome measures in audiological rehabilitation. *Ear and Hearing*, 21(4), pp.24S-36S.
- Iacobucci, D. and Duhachek, A. (2003). Advancing alpha: Measuring reliability with confidence. *Journal of Consumer Psychology*, 13(4), pp.478-487.
- Ives, J. and Damery, S. (2014). Qualitative data collection. In: An introduction to health services research, pp. 99-113 (Ed. Walker, D.-M.) Sage, London.
- Jang, Y., Mortimer, J.A., Haley, W.E., Small, B.J., Chisolm, T.E.H. and Graves, A.B. (2003). The role of vision and hearing in physical, social, and emotional functioning among older adults. *Research on Aging*, 25(2), pp.172-191.
- Jang, Y., Mortimer, J.A., Haley, W.E. and Graves, A.R.B. (2004). The role of social engagement in life satisfaction: Its significance among older individuals with disease and disability. *Journal of Applied Gerontology*, 23(3), pp.266-278.
- Jaworski, A. and Stephens, D. (1998). Self-reports on silence as a face-saving strategy by people with hearing impairment. *International Journal of Applied Linguistics*, 8(1), pp.61-80.
- Jennings, M.B. and Shaw, L. (2008). Impact of hearing loss in the workplace: Raising questions about partnerships with professionals. *Work: A Journal of Prevention, Assessment and Rehabilitation*, 30(3), pp.289-295.
- Jennings, M.B., Southall, K. and Gagné, J.-P. (2013). Social identity management strategies used by workers with acquired hearing loss. *Work*, 46(2), pp.169-180.
- Jennings, M.B., Cheesman, M.F. and Laplante-Lévesque, A. (2014). Psychometric properties of the self-efficacy for situational communication management questionnaire (sesmq). *Ear and Hearing*, 35(2), pp.221-229.
- Jette, A.M., Haley, S.M. and Kooyoomjian, J.T. (2003). Are the icf activity and participation dimensions distinct? *Journal of Rehabilitation Medicine*, 35(3), pp.145-149.

- Jette, A.M. and Haley, S.M. (2005). Contemporary measurement techniques for rehabilitation outcomes assessment. *Journal of Rehabilitation Medicine*, 37(6), pp.339-345.
- Jette, A.M., Tao, W. and Haley, S.M. (2007). Blending activity and participation sub-domains of the icf. *Disability and Rehabilitation*, 29(22), pp.1742-1750.
- Johnson, R.B. and Onwuegbuzie, A.J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher*, 33(7), pp.14-26.
- Johnston, M. (1997). Representations of disability. In: Perceptions of health and illness, pp. 189-212. (Eds. Petrie, K. and Weinman, J.) Harwood Academic Publishers, Canada.
- Jones, D.A., Victor, C.R. and Vetter, N.J. (1984). Hearing difficulty and its psychological implications for the elderly. *Journal of Epidemiology and Community Health*, 38(1), pp.75-78.
- Jones, P.W., Harding, G., Berry, P., Wiklund, I., Chen, W.-H. and Kline Leidy, N. (2009). Development and first validation of the copd assessment test. *European Respiratory Journal*, 34(3), pp.648-654.
- Jonsson, I. and Hedelin, B. (2012). Striving for genuine connections: Men's experiences of living with hearing impairment. *Scandinavian Journal of Disability Research*, 14(4), pp.313-326.
- Jorgensen, L., Palmer, C. and Fischer, G. (2014). Evaluation of hearing status at the time of dementia diagnosis. *Audiology Today*(Jan/Feb), pp.38-45.
- Jung, D. and Bhattacharyya, N. (2012). Association of hearing loss with decreased employment and income among adults in the united states. *Annals of Otology, Rhinology & Laryngology*, 121(12), pp.771-775.
- Kerper, L., Spies, C., Tillinger, J., Wegscheider, K., Salz, A.-L., Weiss-Gerlach, E., Neumann, T. and Krampe, H. (2014). Screening for depression, anxiety and general psychological distress in preoperative surgical patients: A psychometric analysis of the patient health questionnaire 4 (phq-4). *Clinical Health Promotion*, 4(1), pp.5-14.
- Kerr, C., Nixon, A. and Wild, D. (2010). Assessing and demonstrating data saturation in qualitative inquiry supporting patient-reported outcomes research. *Expert Review of Pharmacoeconomics & Outcomes Research* 10(3), pp.269-281.
- Kerr, P.C. and Stephens, D. (1997). The use of an open-ended questionnaire to identify positive aspects of acquired hearing loss. *International Journal of Audiology*, 36(1), pp.19-28.

- Kessels, R.P. (2003). Patients' memory for medical information. *Journal of the Royal Society of Medicine*, 96(5), pp.219-222.
- Kim, J.-I., Long, J.D., Mills, J.A., Downing, N., Williams, J.K., Paulsen, J.S., the P.-H.D.I. and Coordinators of the Huntington Study, G. (2015). Performance of the 12-item whodas 2.0 in prodromal huntington disease. *European Journal of Human Genetics*, 23(11), pp.1584-1587.
- Kleinman, L., Leidy, N.K., Crawley, J., Bonomi, A. and Schoenfeld, P. (2001). A comparative trial of paper-and-pencil versus computer administration of the quality of life in reflux and dyspepsia (qolrad) questionnaire. *Medical Care*, 39(2), pp.181-189.
- Knudsen, L.V., Laplante-Levesque, A., Jones, L., Preminger, J.E., Nielsen, C., Lunner, T., Hickson, L., Naylor, G. and Kramer, S.E. (2012). Conducting qualitative research in audiology: A tutorial. *International Journal of Audiology*, 51(2), pp.83-92.
- Kochhar, A., Hildebrand, M.S. and Smith, R.J. (2007). Clinical aspects of hereditary hearing loss. *Genetics in Medicine*, 9(7), pp.393-408.
- Kramer, S.E. (2005). The psychosocial impact of hearing loss among elderly people. In: *The impact of genetic hearing impairment*, pp.137-164. (Eds. Stephens, D. and Jones, L.). Whurr, London.
- Kramer, S.E., Kapteyn, T.S., Festen, J.M. and Tobi, H. (1995). Factors in subjective hearing disability. *Audiology*, 34(6), pp.311-320.
- Kramer, S.E., Kapteyn, T.S. and Festen, J.M. (1998). The self-reported handicapping effect of hearing disabilities. *Audiology*, 37(5), pp.302-312.
- Kramer, S.E., Kapteyn, T.S., Kuik, D.J. and Deeg, D.J. (2002). The association of hearing impairment and chronic diseases with psychosocial health status in older age. *Journal of Ageing and Health*, 14(1), pp.122-137.
- Kramer, S.E., Kapteyn, T.S. and Houtgast, T. (2006). Occupational performance: Comparing normally-hearing and hearing-impaired employees using the amsterdam checklist for hearing and work. *International Journal of Audiology*, 45(9), pp.503-512.
- Kricos, P.B. (2000). The influence of nonaudiological variables on audiological rehabilitation outcomes. *Ear and Hearing*, 21(4), pp.7S-14S.
- Kroenke, K. and Spitzer, R.L. (2002). The phq-9: A new depression diagnostic and severity measure. *Psychiatric Annals*, 32(9), pp.1-7.

- Kroenke, K., Spitzer, R.L., Williams, J.B.W. and Löwe, B. (2009). An ultra-brief screening scale for anxiety and depression: The phq-4. *Psychosomatics*, 50(6), pp.613-621.
- Krosnick, J.A. and Presser, S. (2010). Question and questionnaire design. *Handbook of survey research*, 2, pp.263-314.
- Kurmis, A. and Apps, S. (2007). Occupationally-acquired noise-induced hearing loss: A senseless workplace hazard. *International Journal of Occupational Medicine and Environmental Health*, 20(2), pp.127-136.
- Landis, J.R. and Koch, G.G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, pp.159-174.
- Laplante-Levesque, A., Hickson, L. and Worrall, L. (2010). Rehabilitation of older adults with hearing impairment: A critical review. *Journal of Aging and Health*, 22(2), pp.143-153.
- Laplante-Lévesque, A., Hickson, L. and Worrall, L. (2012). What makes adults with hearing impairment take up hearing aids or communication programs and achieve successful outcomes? *Ear and hearing*, 33(1), pp.79-93.
- Laplante-Lévesque, A., Hickson, L. and Worrall, L. (2013). Stages of change in adults with acquired hearing impairment seeking help for the first time: Application of the transtheoretical model in audiologic rehabilitation. *Ear and Hearing*, 34(4), pp.447-457.
- Lasch, K.E., Marquis, P., Vigneux, M., Abetz, L., Arnould, B., Bayliss, M., Crawford, B. and Rosa, K. (2010). Pro development: Rigorous qualitative research as the crucial foundation. *Quality of Life Research*, 19(8), pp.1087-1096.
- Leidy, N.K. and Vernon, M. (2008). Perspectives on patient-reported outcomes. *PharmacoEconomics*, 26(5), pp.363-370.
- Leighton, P., Brandreth, M., Wharrad, H. and Ferguson, M. (2013). Evaluation of interactive video tutorials to educate first-time hearing aid users. *The European Journal of Public Health* 23(S1).
- Leventhal, H., Meyer, D. and Nerenz, D. (1980). The common sense model of illness danger. In: *Medical psychology*, pp. 7-30 (Ed. Rachman, S). Pergamon, New York.
- Leventhal, H., Diefenbach, M. and Leventhal, E.A. (1992). Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy and Research*, 16(2), pp.143-163.
- Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E.A., Patrick-Miller, L. and Robitaille, C. (1997). Illness representations: Theoretical foundations. In: *Perceptions of health and illness*, pp.19-

46. (Eds. Petrie, K.J. and Weinman, J.A). Harwood Academic Publishers, Canada.
- Leventhal, H., Weinman, J., Leventhal, E.A. and Phillips, L.A. (2008). Health psychology: The search for pathways between behavior and health. *Annual Review of Psychology*, 59(1), pp.477-505.
- Lietz, P. (2010). Research into questionnaire design. *International Journal of Market Research*, 52(2), pp.249-272.
- Lin, F.R. (2011). Hearing loss and cognition among older adults in the united states. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 66A(10), pp.1131-1136.
- Lin, F.R., Metter, E.J., O'Brien, R.J., Resnick, S.M., Zonderman, A.B. and Ferrucci, L. (2011). Hearing loss and incident dementia. *Archives of Neurology*, 68(2), pp.214-220.
- Lingler, J.H., Nightingale, M.C., Erlen, J.A., Kane, A.L., Reynolds, C.F., Schulz, R. and DeKosky, S.T. (2006). Making sense of mild cognitive impairment: A qualitative exploration of the patient's experience. *Gerontologist*, 46(6), pp.791-800.
- Lorig, K., Chastain, R.L., Ung, E., Shoor, S. and Holman, H.R. (1989). Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. *Arthritis & Rheumatism*, 32(1), pp.37-44.
- Löwe, B., Wahl, I., Rose, M., Spitzer, C., Glaesmer, H., Wingenfeld, K., Schneider, A. and Brähler, E. (2010). A 4-item measure of depression and anxiety: Validation and standardization of the patient health questionnaire-4 (phq-4) in the general population. *Journal of Affective Disorders*, 122(1), pp.86-95.
- Lucas, L., Katiri, R. and Kitterick, P.T. (under review). A model of the functional, psychological, and social burdens imposed by unilateral severe-to-profound deafness in adulthood. *Ear and Hearing*.
- Luciano, J.V., Ayuso-Mateos, J.L., Aguado, J., Fernandez, A., Serrano-Blanco, A., Roca, M. and Haro, J.M. (2010). The 12-item world health organization disability assessment schedule ii (who-das ii): A nonparametric item response analysis. *BMC Medical Research Methodology*, 10(1), pp.45.
- Luey, H.S., Glass, L. and Elliott, H. (1995). Hard-of-hearing or deaf: Issues of ears, language, culture, and identity. *Social Work*, 40(2), pp.177-182.
- Lundgren Nilsson, Å. and Tennant, A. (2011). Past and present issues in rasch analysis: The functional independence measure (fim™) revisited. *Journal of Rehabilitation Medicine*, 43(10), pp.884-891.

- MacCallum, R.C., Widaman, K.F., Zhang, S. and Hong, S. (1999). Sample size in factor analysis. *Psychological Methods*, 4(1), pp.84-99.
- Macduff, C. and Russell, E. (1998). The problem of measuring change in individual health-related quality of life by postal questionnaire: Use of the patient-generated index in a disabled population. *Quality of Life Research*, 7(8), pp.761-769.
- Macduff, C. (2000). Respondent-generated quality of life measures: Useful tools for nursing or more fool's gold? *Journal of Advanced Nursing*, 32(2), pp.375-382.
- Macefield, R. (2009). How to specify the participant group size for usability studies: A practitioner's guide. *Journal of Usability Studies*, 5(1), pp.34-45.
- Maddux, J.E. and Gosselin, J.T. (2000). Self-efficacy: The power of believing you can. Handbook of positive psychology. Snyder, C.R. and Lopez, S.J. New York, Oxford University Press: 218-238.
- Maibach, E. and Murphy, D.A. (1995). Self-efficacy in health promotion research and practice: Conceptualization and measurement. *Health Education Research*, 10(1), pp.37-50.
- Maidment, D. W., Barker, A.B., Xia, J. and Ferguson, M.A. (2016). Effectiveness of alternative listening devices to conventional hearing aids for adults with hearing loss: A systematic review protocol. *British Medical Journal Open*, 6(10), pp.e011683.
- Major, B. and O'Brien, L.T. (2004). The social psychology of stigma. *Annual Review of Psychology*, 56(1), pp.393-421.
- Mallinson, T. and Hammel, J. (2010). Measurement of participation: Intersecting person, task, and environment. *Archives of Physical Medicine and Rehabilitation*, 91(S9), pp.S29-S33.
- Malterud, K. (2001). Qualitative research: Standards, challenges, and guidelines. *The Lancet*, 358(9280), pp.483-488.
- Manchaiah, V., Rönnberg, J., Andersson, G. and Lunner, T. (2015). Stages of change profiles among adults experiencing hearing difficulties who have not taken any action: A cross-sectional study. *PLoS One*, 10(6), pp.e0129107.
- Manchaiah, V.K.C. (2012). Health behaviour change in hearing healthcare: A discussion paper. *Audiology Research*, 2(4), pp.12-16.
- Manchaiah, V.K.C., Stephens, D., Zhao, F. and Kramer, S.E. (2012). The role of communication partners in the audiological enablement/rehabilitation of a person with hearing impairment: An overview. *Audiological Medicine*, 10(1), pp.21-30.

- Marks, R. and Allegrante, J.P. (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), pp.148-156.
- Martínez-Pérez, B., De La Torre-Díez, I. and Lopez-Coronado, M. (2013). Mobile health applications for the most prevalent conditions by the World Health Organization: review and analysis. *Journal of Medical Internet Research*, 15(6), pp.e120.
- Matthews, L. (2011). Seen but not heard: People with hearing loss are not receiving the support they need. London, *Action on Hearing Loss/Royal National Institute for Deaf People*, pp.1-81.
- McAndrew, L.M., Musumeci-Szabó, T.J., Mora, P.A., Vileikyte, L., Burns, E., Halm, E.A., Leventhal, E.A. and Leventhal, H. (2008). Using the common sense model to design interventions for the prevention and management of chronic illness threats: From description to process. *British Journal of Health Psychology*, 13(2), pp.195-204.
- McCormack, A. and Fortnum, H. (2013). Why do people fitted with hearing aids not wear them? *International Journal of Audiology*, 52(5), pp.360-368.
- McGartland Rubio, D., Berg-Weger, M., Tebb, S.S., Lee, E.S. and Rauch, S. (2003). Objectifying content validity: Conducting a content validity study in social work research. *Social Work Research*, 27(2), pp.94-104.
- McHorney, C.A. and Tarlov, A.R. (1995). Individual-patient monitoring in clinical practice: Are available health status surveys adequate? *Quality of Life Research*, 4(4), pp.293-307.
- Mehta, K.M., Simonsick, E.M., Penninx, B.W.J.H., Schulz, R., Rubin, S.M., Satterfield, S. and Yaffe, K. (2003). Prevalence and correlates of anxiety symptoms in well-functioning older adults: Findings from the health aging and body composition study. *Journal of the American Geriatrics Society*, 51(4), pp.499-504.
- Meister, H., Grugel, L. and Meis, M. (2014). Intention to use hearing aids: A survey based on the theory of planned behavior. *Patient Preference and Adherence*, 8, pp.1265-1275.
- Mendes de Leon, C.F. (2005). Social engagement and successful aging. *European Journal of Ageing*, 2(1), pp.64-66.
- Mener, D.J., Betz, J., Genther, D.J., Chen, D. and Lin, F.R. (2013). Hearing loss and depression in older adults. *Journal of the American Geriatrics Society*, 61(9), pp.1627-1629.

- Meyer, C., Hickson, L. and Fletcher, A. (2014). Identifying the barriers and facilitators to optimal hearing aid self-efficacy. *International Journal of Audiology*, 53(S1), pp.S28-S37.
- Meyer, C., Hickson, L., Lovelock, K., Lampert, M. and Khan, A. (2014). An investigation of factors that influence help-seeking for hearing impairment in older adults. *International Journal of Audiology*, 53(S1), pp.3-17.
- Michie, S., Johnston, M., Abraham, C., Lawton, R., Parker, D. and Walker, A. (2005). Making psychological theory useful for implementing evidence based practice: A consensus approach. *Quality and Safety in Health Care*, 14(1), pp.26-33.
- Michie, S., van Stralen, M.M. and West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science : IS*, 6, pp.42-42.
- Mick, P., Kawachi, I. and Lin, F.R. (2014). The association between hearing loss and social isolation in older adults. *Otolaryngology - Head and Neck Surgery*, 150(3), pp.378-384.
- Mick, P. and Pichora-Fuller, M.K. (2016). Is hearing loss associated with poorer health in older adults who might benefit from hearing screening? *Ear and Hearing*, 37(3), pp.e194-e201.
- Mikkola, T.M., Portegijs, E., Rantakokko, M., Gagné, J.-P., Rantanen, T. and Viljanen, A. (2015). Association of self-reported hearing difficulty to objective and perceived participation outside the home in older community-dwelling adults. *Journal of Aging and Health*, 27(1), pp.103-122.
- Mikkola, T.M., Polku, H., Portegijs, E., Rantakokko, M., Tsai, L.-T., Rantanen, T. and Viljanen, A. (2016). Self-reported hearing is associated with time spent out-of-home and withdrawal from leisure activities in older community-dwelling adults. *Aging Clinical and Experimental Research*, 28(2), pp.297-302.
- Mokkink, L.B., Knol, D.L., van Nispen, R.M. and Kramer, S.E. (2010a). Improving the quality and applicability of the dutch scales of the communication profile for the hearing impaired using item response theory. *Journal of Speech, Language, and Hearing Research*, 53(3), pp.556-571.
- Mokkink, L.B., Terwee, C.B., Knol, D.L., Stratford, P.W., Alonso, J., Patrick, D.L., Bouter, L.M. and De Vet, H.C. (2010b). The cosmin checklist for evaluating the methodological quality of studies on measurement properties: A clarification of its content. *BMC Medical Research Methodology*, 10(1), pp.22.

- Mokkink, L.B., Terwee, C.B., Patrick, D.L., Alonso, J., Stratford, P.W., Knol, D.L., Bouter, L.M. and de Vet, H.C.W. (2010c). The cosmin study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. *Journal of clinical epidemiology*, 63(7), pp.737-745.
- Mokkink, L.B., Terwee, C.B., Patrick, D.L., Alonso, J., Stratford, P.W., Knol, D.L., Bouter, L.M. and De Vet, H.C. (2011). Cosmin checklist with 4-point scale Amsterdam, VU University Medical Center
- Mokkink, L.B., Terwee, C.B., Patrick, D.L., Alonso, J., Stratford, P.W., Knol, D.L., Bouter, L.M. and De Vet, H.C. (2012). The cosmin checklist manual. Amsterdam, VU University Medical Center
- Monzani, D., Galeazzi, G., Genovese, E., Marrara, A. and Martini, A. (2008). Psychological profile and social behaviour of working adults with mild or moderate hearing loss. *Acta Otorhinolaryngologica Italica*, 28(2), pp.61-66.
- Morata, T.C., Themann, C.L., Randolph, R.F., Verbsky, B.L., Byrne, D.C. and Reeves, E.R. (2005). Working in noise with a hearing loss: Perceptions from workers, supervisors, and hearing conservation program managers. *Ear and Hearing*, 26(6), pp.529-545.
- Moskowitz, D.S. and Young, S.N. (2006). Ecological momentary assessment: What it is and why it is a method of the future in clinical psychopharmacology. *Journal of Psychiatry & Neuroscience: JPN*, 31(1), pp.13.
- Moss-Morris, R. (2013). Adjusting to chronic illness: Time for a unified theory. *British Journal of Health Psychology*, 18(4), pp.681-686.
- Mulrow, C.D., Aguilar, C., Endicott, J.E., Tuley, M.R., Velez, R., Charlip, W.S., Rhodes, M.C., Hill, J.A. and DeNino, L.A. (1990a). Quality-of-life changes and hearing impairment: A randomized trial. *Annals of Internal Medicine*, 113(3), pp.188-194.
- Mulrow, C.D., Aguilar, C., Endicott, J.E., Velez, R., Tuley, M.R., Charlip, W.S. and Hill, J.A. (1990b). Association between hearing impairment and the quality of life of elderly individuals. *Journal of the American Geriatrics Society*, 38(1), pp.45-50.
- Mulrow, C.D., Tuley, M.R. and Aguilar, C. (1990). Discriminating and responsiveness abilities of two hearing handicap scales. *Ear and Hearing*, 11(3), pp.176-180.
- Nachtegaal, J., Smit, J.H., Smits, C., Bezemer, P.D., van Beek, J.H., Festen, J.M. and Kramer, S.E. (2009). The association between hearing status and psychosocial health before the age of 70 years: Results

- from an internet-based national survey on hearing. *Ear and Hearing*, 30(3), pp.302-312.
- Nadol, J.B. (1993). Hearing loss. *New England Journal of Medicine*, 329(15), pp.1092-1102.
- Nelson, D.I., Nelson, R.Y., Concha-Barrientos, M. and Fingerhut, M. (2005). The global burden of occupational noise-induced hearing loss. *American Journal of Industrial Medicine*, 48(6), pp.446-458.
- Nemes, J. (2003). Despite benefits of outcomes measures, advocates say they're underused. *The Hearing Journal*, 56(8), pp.19-20.
- Newman, C.W., Weinstein, B.E., Jacobson, G.P. and Hug, G.A. (1990). The hearing handicap inventory for adults: Psychometric adequacy and audiometric correlates. *Ear and Hearing*, 11(6), pp.430-433.
- NHS England, (2015). Action Plan on Hearing Loss. Department of Health, UK, pp.1-44.
- Noar, S.M. and Zimmerman, R.S. (2005). Health behavior theory and cumulative knowledge regarding health behaviors: Are we moving in the right direction? *Health Education Research*, 20(3), pp.275-290.
- Noble, W. and Gatehouse, S. (2004). Interaural asymmetry of hearing loss, speech, spatial and qualities of hearing scale (ssq) disabilities, and handicap. *International Journal of Audiology*, 43(2), pp.100-114.
- Noble, W. (2013). Self-assessment of hearing. Oxford, Plural Publishing.
- Nordenfelt, L. (2003). Action theory, disability and icf. *Disability and Rehabilitation*, 25(18), pp.1075-1079.
- Notley, C., Green, G. and Marsland, L. (2014). Qualitative analysis. In: An introduction to health services research, pp: 327-342 (Ed. Walker, D.-M). Sage, London.
- Nyman, S.R. and Yardley, L. (2009). Usability and acceptability of a website that provides tailored advice on falls prevention activities for older people. *Health Informatics Journal*, 15(1), pp.27-39.
- Ogden, J. (2003). Some problems with social cognition models: A pragmatic and conceptual analysis. *Health Psychology*, 22(4), pp.424.
- Onwuegbuzie, A.J. and Leech, N.L. (2005). On becoming a pragmatic researcher: The importance of combining quantitative and qualitative research methodologies. *International Journal of Social Research Methodology*, 8(5), pp.375-387.
- Oppenheim, A. N. (2000). Questionnaire design, interviewing and attitude measurement. Bloomsbury Publishing.

- Palinkas, L.A., Wingard, D.L. and Barrett-Connor, E. (1990). The biocultural context of social networks and depression among the elderly. *Social Science & Medicine*, 30(4), pp.441-447.
- Pallant, J.F. and Tennant, A. (2007). An introduction to the rasch measurement model: An example using the hospital anxiety and depression scale (hads). *British Journal of Clinical Psychology*, 46(1), pp.1-18.
- Palmer, C.V., Adams, S.W., Bourgeois, M., Durrant, J. and Rossi, M. (1999). Reduction in caregiver-identified problem behaviors in patients with alzheimer disease post-hearing-aid fitting. *Journal of Speech, Language, and Hearing Research*, 42(2), pp.312-328.
- Palmer, K., Griffin, M., Syddall, H. and Coggon, D. (2004). Cigarette smoking, occupational exposure to noise, and self reported hearing difficulties. *Occupational and Environmental Medicine*, 61(4), pp.340-344.
- Patel, K.K., Veenstra, D.L. and Patrick, D.L. (2003). A review of selected patient-generated outcome measures and their application in clinical trials. *Value in Health*, 6(5), pp.595-603.
- Patrick, D.L., Burke, L.B., Gwaltney, C.J., Leidy, N.K., Martin, M.L., Molsen, E. and Ring, L. (2011). Content validity—establishing and reporting the evidence in newly developed patient-reported outcomes (pro) instruments for medical product evaluation: Ispor pro good research practices task force report: Part 1—eliciting concepts for a new pro instrument. *Value in Health*, 14(8), pp.967-977.
- Patton, M.Q. (1990). Qualitative evaluation and research methods. New York, Sage Publications, Inc.
- Perenboom, R.J. and Chorus, A.M. (2003). Measuring participation according to the international classification of functioning, disability and health (icf). *Disability & Rehabilitation*, 25(11-12), pp.577-587.
- Pesudovs, K., Burr, J.M., Harley, C. and Elliott, D.B. (2007). The development, assessment, and selection of questionnaires. *Optometry & Vision Science*, 84(8), pp.663-674.
- Petrie, K.J. and Weinman, J. (1997). Perceptions of health and illness. Canada, Harwood Academic Publishers.
- Pichora-Fuller, M.K., Dupuis, K., Reed, M. and Lemke, U. (2013). Helping older people with cognitive decline communicate: Hearing aids as part of a broader rehabilitation approach. *Seminars in Hearing*, 34(4), pp.308-330.
- Pinquart, M. and Sörensen, S. (2000). Influences of socioeconomic status, social network, and competence on subjective well-being in later life: A meta-analysis. *Psychology and Aging*, 15(2), pp.187-224.

- Polit, D.F., Beck, C.T. and Owen, S.V. (2007). Is the cvi an acceptable indicator of content validity? Appraisal and recommendations. *Research in Nursing & Health*, 30(4), pp.459-467.
- Post, M.W., de Witte, L.P., Reichrath, E., Verdonschot, M.M., Wjlhuizen, G.J. and Perenboom, R.J. (2008). Development and validation of impact-s, an icf-based questionnaire to measure activities and participation. *Journal of Rehabilitation Medicine*, 40(8), pp.620-627.
- Preminger, J.E. (2003). Should significant others be encouraged to join adult group audiologic rehabilitation classes? *Journal of the American Academy of Audiology*, 14(10), pp.545-555.
- Preston, C.C. and Colman, A.M. (2000). Optimal number of response categories in rating scales: Reliability, validity, discriminating power, and respondent preferences. *Acta Psychologica*, 104(1), pp.1-15.
- Prieto, L., Alonso, J. and Lamarca, R. (2003). Classical test theory versus rasch analysis for quality of life questionnaire reduction. *Health and quality of life outcomes*, 1(1), pp.1-13.
- Prochaska, J. and DiClemente, C. (1983). Self-change processes, self-efficacy and decisional balance across five stages of smoking cessation. *Progress in Clinical and Biological Research*, 156, pp.131-140.
- Pronk, M., Deeg, D.J.H., Smits, C., van Tilburg, T.G., Kuik, D.J., Festen, J.M. and Kramer, S.E. (2011). Prospective effects of hearing status on loneliness and depression in older persons: Identification of subgroups. *International Journal of Audiology*, 50(12), pp.887-896.
- Pronk, M., Deeg, D.J. and Kramer, S.E. (2013). Hearing status in older persons: A significant determinant of depression and loneliness? Results from the longitudinal aging study amsterdam. *American Journal of Audiology*, 22(2), pp.316-320.
- Pryce, H., Metcalfe, C., Hall, A. and Claire, L.S. (2010). Illness perceptions and hearing difficulties in king-kopetzky syndrome: What determines help seeking? *International Journal of Audiology*, 49(7), pp.473-481.
- Punch, R., Hyde, M. and Power, D. (2007). Career and workplace experiences of australian university graduates who are deaf or hard of hearing. *Journal of Deaf Studies and Deaf Education*, 12(4), pp.504-517.
- Pusic, A.L., Klassen, A.F., Scott, A.M., Klok, J.A., Cordeiro, P.G. and Cano, S.J. (2009). Development of a new patient-reported outcome measure for breast surgery: The breast-q. *Plastic and Reconstructive Surgery*, 124(2), pp.345-353.

- Rattray, J. and Jones, M.C. (2007). Essential elements of questionnaire design and development. *Journal of Clinical Nursing*, 16(2), pp.234-243.
- Raykov, T. and Marcoulides, G.A. (2011). Introduction to psychometric theory, Routledge.
- Reagan, T. (1995). Language, culture, and world view: a sociocultural understanding of deafness: American sign language and the culture of deaf people. *International Journal of Intercultural Relations*, 19(2), pp.239-251.
- Reeve, B.B., Wyrwich, K.W., Wu, A.W., Velikova, G., Terwee, C.B., Snyder, C.F., Schwartz, C., Revicki, D.A., Moinpour, C.M. and McLeod, L.D. (2013). Isoqol recommends minimum standards for patient-reported outcome measures used in patient-centered outcomes and comparative effectiveness research. *Quality of Life Research*, 22, pp.1889-1905.
- Reise, S.P., Waller, N.G. and Comrey, A.L. (2000). Factor analysis and scale revision. *Psychological Assessment*, 12(3), pp.287.
- Resnik, L. and Plow, M.A. (2009). Measuring participation as defined by the international classification of functioning, disability and health: An evaluation of existing measures. *Archives of Physical Medicine and Rehabilitation*, 90(5), pp.856-866.
- Robinson, K., Gatehouse, S. and Browning, G.G. (1996). Measuring patient benefit from otorhinolaryngological surgery and therapy. *The Annals of Otology, Rhinology, and Laryngology*, 105(6), pp.415-422.
- Robinson, S., McQuaid, J., Viirre, E., Betzig, L., Miller, D., Bailey, K., Harris, J. and Perry, W. (2002). Relationship of tinnitus questionnaires to depressive symptoms, quality of well-being, and internal focus. *The international tinnitus journal*, 9(2), pp.97-103.
- Rolfe, C. and Gardner, B. (2016). Experiences of hearing loss and views towards interventions to promote uptake of rehabilitation support among uk adults. *International Journal of Audiology*, 55(11), pp.666-673.
- Rosenstock, I. (1966). Why people use health services. *The millbank memorial fund quarterly*, 44, 94-127.
- Rosner, B. (2005). Fundamentals of biostatistics 6th edition, Brooks/Cole, Belmont, CA.
- Roth, T.N., Hanebuth, D. and Probst, R. (2011). Prevalence of age-related hearing loss in europe: A review. *European Archives of Oto-Rhino-Laryngology*, 268(8), pp.1101-1107.

- Rothman, M., Burke, L., Erickson, P., Leidy, N.K., Patrick, D.L. and Petrie, C.D. (2009). Use of existing patient-reported outcome (pro) instruments and their modification: The ispor good research practices for evaluating and documenting content validity for the use of existing instruments and their modification pro task force report. *Value in Health*, 12(8), pp.1075-1083.
- Rothrock, N., Kaiser, K. and Cella, D. (2011). Developing a valid patient-reported outcome measure. *Clinical Pharmacology and Therapeutics*, 90(5), pp.737-742.
- Ruben, R.J. (2000). Redefining the survival of the fittest: Communication disorders in the 21st century. *The Laryngoscope*, 110(2), pp.241-241.
- Rydberg, E., Gellerstedt, L.C. and Danermark, B. (2010). The position of the deaf in the swedish labor market. *American Annals of the Deaf*, 155(1), pp.68-77.
- Saito, H., Nishiwaki, Y., Michikawa, T., Kikuchi, Y., Mizutari, K., Takebayashi, T. and Ogawa, K. (2010). Hearing handicap predicts the development of depressive symptoms after 3 years in older community-dwelling japanese. *Journal of the American Geriatrics Society*, 58(1), pp.93-97.
- Salter, K., Jutai, J.W., Teasell, R., Foley, N.C., Bitensky, J. and Bayley, M. (2005). Issues for selection of outcome measures in stroke rehabilitation: lcf participation. *Disability and Rehabilitation*, 27(9), pp.507-528.
- Saris, W.E., Revilla, M., Krosnick, J.A. and Shaeffer, E.M. (2010). Comparing questions with agree/disagree response options to questions with item-specific response options. *Survey Research Methods*, 4(1), pp.61-79.
- Saunders, G.H., Chisolm, T.H. and Abrams, H.B. (2005). Measuring hearing aid outcomes - not as easy as it seems. *Journal of Rehabilitation Research & Development*, 42(4), pp.157-168.
- Saunders, G.H., Frederick, M.T., Silverman, S. and Papesh, M. (2013). Application of the health belief model: Development of the hearing beliefs questionnaire (hbq) and its associations with hearing health behaviors. *International Journal of Audiology*, 52(8), pp.558-567.
- Saunders, G.H., Frederick, M.T., Silverman, S.C., Nielsen, C. and Laplante-Lévesque, A. (2016). Health behavior theories as predictors of hearing-aid uptake and outcomes. *Int J Audiol*, 55(sup3), pp.S59-S68.
- Savikko, N., Routasalo, P., Tilvis, R.S., Strandberg, T.E. and Pitkälä, K.H. (2005). Predictors and subjective causes of loneliness in an aged population. *Archives of Gerontology and Geriatrics*, 41(3), pp.223-233.

- Scarinci, N., Worrall, L. and Hickson, L. (2008). The effect of hearing impairment in older people on the spouse. *International Journal of Audiology*, 47(3), pp.141-151.
- Scarinci, N.A., Hickson, L.M. and Worrall, L.E. (2011). Third-party disability in spouses of older people with hearing impairment. *SIG 7 Perspectives on Aural Rehabilitation and Its Instrumentation*, 18(1), pp.3-12.
- Schneider, J., Gopinath, B., Karpa, M.J., McMahon, C.M., Rochtchina, E., Leeder, S.R. and Mitchell, P. (2010). Hearing loss impacts on the use of community and informal supports. *Age and Ageing*, 39(4), pp.458-464.
- Scholtes, V.A., Terwee, C.B. and Poolman, R.W. (2011). What makes a measurement instrument valid and reliable? *Injury*, 42(3), pp.236-240.
- Schulz, K.A., Modeste, N., Lee, J., Roberts, R., Saunders, G.H. and Witsell, D.L. (2016). Factors influencing pursuit of hearing evaluation: Enhancing the health belief model with perceived burden from hearing loss on communication partners. *International Journal of Audiology*, 55(S3), pp.S69-S78.
- Seekins, T., Ipsen, C. and Arnold, N.L. (2007). Using ecological momentary assessment to measure participation: A preliminary study. *Rehabilitation Psychology*, 52(3), pp.319-330.
- Seekins, T., Shunkamolah, W., Bertsche, M., Cowart, C., Summers, J.A., Reichard, A. and White, G. (2012). A systematic scoping review of measures of participation in disability and rehabilitation research: A preliminary report of findings. *Disability and Health Journal*, 5(4), pp.224-232.
- Sharpe, L. and Curran, L. (2006). Understanding the process of adjustment to illness. *Social Science & Medicine*, 62(5), pp.1153-1166.
- Shaw, L., Tetlaff, B., Jennings, M.B. and Southall, K.E. (2013). The standpoint of persons with hearing loss on work disparities and workplace accommodations. *Work*, 46(2), pp.193-204.
- Sheer, V.C. (2014). A meta-synthesis of health-related self-efficacy instrumentation: Problems and suggestions. *Journal of Nursing Measurement*, 22(1), pp.77-93.
- Shiffman, S., Stone, A.A. and Hufford, M.R. (2008). Ecological momentary assessment. *Annual Review of Clinical Psychology*, 4(1), pp.1-32.
- Sinha, I., Smyth, R. and Williamson, P. (2011). Using the delphi technique to determine which outcomes to measure in clinical trials: Recommendations for the future based on a systematic review of existing studies. *PLoS Med*, 8(1 (e1000393)).

- Slocumb, E.M. and Cole, F.L. (1991). A practical approach to content validation. *Applied Nursing Research*, 4(4), pp.192-195.
- Smith, E.V. (2002). Understanding rasch measurement: Detecting and evaluating the impact of multidimensionality using item fit statistics and principal component analysis of residuals. *Journal of Applied Measurement*, 3(2), pp.205-231.
- Smith, G.T. (2005). On construct validity: Issues of method and measurement. *Psychological assessment*, 17(4), pp.396-408.
- Smith, R.M. (1996). A comparison of methods for determining dimensionality in rasch measurement. *Structural Equation Modeling: A Multidisciplinary Journal*, 3(1), pp.25-40.
- Smith, S.L. and West, R.L. (2006a). The application of self-efficacy principles to audiologic rehabilitation: A tutorial. *American Journal of Audiology*, 15(1), pp.46-56.
- Smith, S.L. and West, R.L. (2006b). Hearing aid self-efficacy of new and experienced hearing aid users. *Seminars in Hearing*, Vol. 27(4), pp. 325-329.
- Smith, S.L., Pichora-Fuller, K.M., Watts, K.L. and La More, C. (2011). Development of the listening self-efficacy questionnaire (lseq). *International Journal of Audiology*, 50(6), pp.417-425.
- Smith, S.L. (2014). Promoting self-efficacy in patient-centered audiologic rehabilitation for adults with hearing loss. *SIG 7 Perspectives on Aural Rehabilitation and Its Instrumentation*, 21(1), pp.24-32.
- Sniehotta, F.F., Presseau, J. and Araújo-Soares, V. (2014). Time to retire the theory of planned behaviour. *Health Psychology Review*, 8(1), pp.1-7.
- Southall, K., Gagné, J.-P. and Jennings, M.B. (2010). Stigma: A negative and a positive influence on help-seeking for adults with acquired hearing loss. *International Journal of Audiology*, 49(11), pp.804-814.
- Spitzer, R.L., Kroenke, K., Williams, J.W. and Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: The gad-7. *Archives of Internal Medicine*, 166(10), pp.1092-1097.
- Stam, M., Kostense, P., Festen, J. and Kramer, S. (2013). The relationship between hearing status and the participation in different categories of work: Demographics. *Work*, 46(2), pp.207-219.
- Stephens, D. and Kerr, P. (2003). The role of positive experiences in living with acquired hearing loss. *International Journal of Audiology*, 42, pp.S118-S127.

- Stephens, S., Lewis, P.A., Charny, M.C., Farrow, S. and Francis, M. (1990). Characteristics of self-reported hearing problems in a community survey. *Audiology*, 29(2), pp.93-100.
- Stephens, S.D.G. (1980). Evaluating the problems of the hearing impaired. *Audiology*, 19(3), pp.205-220.
- Stewart, B.J. and Archbold, P.G. (1993). Nursing intervention studies require outcome measures that are sensitive to change: Part two. *Research in Nursing & Health*, 16(1), pp.77-81.
- Strawbridge, W.J., Wallhagen, M.I., Shema, S.J. and Kaplan, G.A. (2000). Negative consequences of hearing impairment in old age a longitudinal analysis. *Gerontologist*, 40(3), pp.320-326.
- Streiner, D.L. (2003). Starting at the beginning: An introduction to coefficient alpha and internal consistency. *Journal of Personality Assessment*, 80(1), pp.99-103.
- Streiner, D.L. and Norman, G.R. (2008). Health measurement scales: A practical guide to their development and use, Oxford University Press.
- Sung, Y.-k., Li, L., Blake, C., Betz, J. and Lin, F.R. (2015). Association of hearing loss and loneliness in older adults. *Journal of Aging Health*
- Sutton, S. (2001). Back to the drawing board? A review of applications of the transtheoretical model to substance use. *Addiction*, 96(1), pp.175-186.
- Swanepoel, D. W. and Hall III, J. W. (2010). A systematic review of telehealth applications in audiology. *Telemedicine and e-Health*, 16(2), pp.181-200.
- Tabachnick, B.G. and Fidell, L.S. (2001). Using multivariate statistics. Boston, Allyn and Bacon.
- Tambs, K. (2004). Moderate effects of hearing loss on mental health and subjective well-being: Results from the nord-trøndelag hearing loss study. *Psychosomatic Medicine*, 66(5), pp.776-782.
- Tennant, A. and Pallant, J. (2006). Unidimensionality matters! (a tale of two smiths?). *Rasch Measurement Transactions*, 20(1), pp.1048–1051.
- Tennant, A. and Conaghan, P.G. (2007). The rasch measurement model in rheumatology: What is it and why use it? When should it be applied, and what should one look for in a rasch paper? *Arthritis Care & Research*, 57(8), pp.1358-1362.
- Terwee, C.B., Bot, S.D., de Boer, M.R., van der Windt, D.A., Knol, D.L., Dekker, J., Bouter, L.M. and de Vet, H.C. (2007). Quality criteria were proposed for measurement properties of health status questionnaires. *Journal of Clinical Epidemiology*, 60(1), pp.34-42.

- Tesch-Römer, C. (1997). Psychological effects of hearing aid use in older adults. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 52B(3), pp.P127-P138.
- Tesio, L. (2003). Measuring behaviours and perceptions: Rasch analysis as a tool for rehabilitation research. *Journal of Rehabilitation Medicine*, 35(3), pp.105-115.
- Thomas, P.D., Hunt, W.C., Garry, P.J., Hood, R.B., Goodwin, J.M. and Goodwin, J.S. (1983). Hearing acuity in a healthy elderly population: Effects on emotional, cognitive, and social status. *Journal of Gerontology*, 38(3), pp.321-325.
- Thorén, E.S., Andersson, G. and Lunner, T. (2012). The use of research questionnaires with hearing impaired adults: Online vs. Paper-and-pencil administration. *BMC Ear, Nose, and Throat Disorders*, 12, pp.12-12.
- Tilden, V.P., Nelson, C.A. and May, B.A. (1990). Use of qualitative methods to enhance content validity. *Nursing Research*, 39(3), pp.172-175.
- Tugwell, P., Boers, M., Brooks, P., Simon, L., Strand, V. and Idzerda, L. (2007). Omeract: An international initiative to improve outcome measurement in rheumatology. *Trials*, 8, pp.38.
- Tully, M.P. and Cantrill, J.A. (2000). The validity of the modified patient generated index – a quantitative and qualitative approach. *Quality of Life Research*, 9(5), pp.509-520.
- Turk, D., Dworkin, R., Allen, R., Bellamy, N., Brandenburg, N., Carr, D., Cleeland, C., Dionne, R., Farrar, J., Galer, B., Hewitt, D., Jadad, A., Katz, N., Kramer, L., Manning, D., McCormick, C., McDermott, M., McGrath, P., Quessy, S., Rappaport, B., Robinson, J., Royal, M., Simon, L., Stauffer, J., Stein, W., Tollett, J. and Witter, J. (2003). Core outcome domains for chronic pain clinical trials: Immpact recommendations. *Pain*, 106, pp.337 - 345.
- Turk, D.C., Dworkin, R.H., Burke, L.B., Gershon, R., Rothman, M., Scott, J., Allen, R.R., Atkinson, J.H., Chandler, J. and Cleeland, C. (2006). Developing patient-reported outcome measures for pain clinical trials: Immpact recommendations. *Pain*, 125(3), pp.208-215.
- Turner, R.R., Quittner, A.L., Parasuraman, B.M., Kallich, J.D. and Cleeland, C.S. (2007). Patient reported outcomes: Instrument development and selection issues. *Value in Health*, 10(s2), pp.S86-S93.
- Tye-Murray, N., Purdy, S.C. and Woodworth, G.G. (1992). Reported use of communication strategies by shhh membersclient, talker, and situational variables. *Journal of Speech, Language, and Hearing Research*, 35(3), pp.708-717.

- Tye-Murray, N., Spry, J.L. and Mauzé, E. (2009). Professionals with hearing loss: Maintaining that competitive edge. *Ear and Hearing*, 30(4), pp.475-484.
- Uijen, A.A., Heinst, C.W., Schellevis, F.G., van den Bosch, W.J., van de Laar, F.A., Terwee, C.B. and Schers, H.J. (2012). Measurement properties of questionnaires measuring continuity of care: A systematic review. *PLoS One*, 7(7 e42256).
- Üstün, T., Kostanjsek, N., Chatterji, S. and Rehm, J. (2010a). Measuring health and disability: Manual for who disability assessment schedule whodas 2.0. Geneva, World Health Organization.
- Üstün, T.B., Chatterji, S., Kostanjsek, N., Rehm, J., Kennedy, C., Epping-Jordan, J., Saxena, S., Korff, M.v. and Pull, C. (2010b). Developing the world health organization disability assessment schedule 2.0. *Bulletin of the World Health Organization*, 88(11), pp.815-823.
- Vallejo, M.A., Jordán, C.M., Díaz, M.I., Comeche, M.I. and Ortega, J. (2007). Psychological assessment via the internet: A reliability and validity study of online (vs paper-and-pencil) versions of the general health questionnaire-28 (ghq-28) and the symptoms check-list-90-revised (scl-90-r). *Journal of Medical Internet Research*, 9(1), pp.e2.
- Van den Brink, R., Wit, H., Kempen, G. and Van Heuvelen, M. (1996). Attitude and help-seeking for hearing impairment. *British Journal of Audiology*, 30(5), pp.313-324.
- van der Velde, G., Beaton, D., Hogg-Johnston, S., Hurwitz, E. and Tennant, A. (2009). Rasch analysis provides new insights into the measurement properties of the neck disability index. *Arthritis Care & Research*, 61(4), pp.544-551.
- Van Uffelen, J.G., Heesch, K.C., Hill, R.L. and Brown, W.J. (2011). A qualitative study of older adults' responses to sitting-time questions: Do we get the information we want? *BMC Public Health*, 11(1), pp.1.
- Vas, V., Akeroyd, M.A. and Hall, D.A. (under review). A systematic review of domains relating to the everyday impact of hearing loss, as reported by patients or their communication partner(s). *Ear and Hearing*.
- Velicer, W.F., Prochaska, J.O., Fava, J.L., Norman, G.J. and Redding, C.A. (1998). Smoking cessation and stress management: Applications of the transtheoretical model of behavior change. *Homeostasis in Health and Disease*, 38(5-6), pp.216-233.
- Ventry, I.M. and Weinstein, B.E. (1982). The hearing handicap inventory for the elderly: A new tool. *Ear and Hearing*, 3(3), pp.128-134.
- Victor, C., Scambler, S., Bond, J. and Bowling, A. (2000). Being alone in later life: Loneliness, social isolation and living alone. *Reviews in Clinical Gerontology*, 10(04), pp.407-417.

- Vos, T., Allen, C., Arora, M., Barber, R.M., Bhutta, Z.A., Brown, A., Carter, A., Casey, D.C., Charlson, F.J., Chen, A.Z., Coggeshall, M. and al., e. (2016). Global, regional, and national incidence, prevalence, and years lived with disability for 310 diseases and injuries, 1990–2015: A systematic analysis for the global burden of disease study 2015. *The Lancet*, 388(10053), pp.1545-1602.
- Wallhagen, M.I., Strawbridge, W.J., Shema, S.J. and 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), pp.S190-S196.
- Wallhagen, M.I. (2010). The stigma of hearing loss. *Gerontologist*, 50(1), pp.66-75.
- Wang, H.-X., Karp, A., Winblad, B. and Fratiglioni, L. (2002). Late-life engagement in social and leisure activities is associated with a decreased risk of dementia: A longitudinal study from the kungsholmen project. *American Journal of Epidemiology*, 155(12), pp.1081-1087.
- Weinstein, B.E. and Ventry, I.M. (1982). Hearing impairment and social isolation in the elderly. *Journal of Speech and Hearing Research*, 25(4), pp.593-599.
- Weinstein, B.E. and Ventry, I.M. (1983). Audiometric correlates of the hearing handicap inventory for the elderly. *Journal of Speech and Hearing Disorders*, 48(4), pp.379-384.
- Weinstein, B.E., Spitzer, J.B. and Ventry, I.M. (1986). Test-retest reliability of the hearing handicap inventory for the elderly. *Ear and Hearing*, 7(5), pp.295-299.
- Weinstein, B.E.S., Lynn S; Moser, Sarah (2015). Perceived social and emotional loneliness: Do hearing aids make a difference? 8th International Adult Aural Rehabilitation Conference, St Pete Beach, Florida.
- Weng, L.-J. (2004). Impact of the number of response categories and anchor labels on coefficient alpha and test-retest reliability. *Educational and Psychological Measurement*, 64(6), pp.956-972.
- West, R. (2005). Time for a change: Putting the transtheoretical (stages of change) model to rest. *Addiction*, 100(8), pp.1036-1039.
- West, R.L. and Smith, S.L. (2007). Development of a hearing aid self-efficacy questionnaire. *International Journal of Audiology*, 46(12), pp.759-771.
- Whiteneck, G. and Dijkers, M.P. (2009). Difficult to measure constructs: Conceptual and methodological issues concerning participation and environmental factors. *Archives of Physical Medicine and Rehabilitation*, 90(11, Supplement), pp.S22-S35.

- Whiteneck, G.G. (2010). Issues affecting the selection of participation measurement in outcomes research and clinical trials. *Archives of Physical Medicine and Rehabilitation*, 91(9, Supplement), pp.S54-S59.
- Whiteneck, G.G., Dijkers, M.P., Heinemann, A.W., Bogner, J.A., Bushnik, T., Cicerone, K.D., Corrigan, J.D., Hart, T., Malec, J.F. and Millis, S.R. (2011). Development of the participation assessment with recombined tools—objective for use after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 92(4), pp.542-551.
- Whitmer, W.M., Howell, P. and Akeroyd, M.A. (2014). Proposed norms for the glasgow hearing-aid benefit profile (ghabp) questionnaire. *International Journal of Audiology*, 53(5), pp.345-351.
- WHO (2001). International classification of functioning, disability and health: Icf. World Health Organization, Geneva.
- WHO (2002). Towards a common language for functioning, disability and health: The international classification of functioning, disability and health. World Health Organization, Geneva, pp.1-22.
- WHO. (2015, March 2015). "Deafness and hearing loss: Fact sheet n°300 " Retrieved 11/07/2015, from <http://www.who.int/mediacentre/factsheets/fs300/en/>.
- Wilkerson, D. (2000). Current issues in rehabilitation outcome measurement: Implications for audiological rehabilitation. *Ear and Hearing*, 21(4), pp.80S-88S.
- Williams, B., Brown, T. and Onsman, A. (2012). Exploratory factor analysis: A five-step guide for novices. *Australasian Journal of Paramedicine*, 8(3), pp.1-13.
- Williamson, P.R., Altman, D.G., Blazeby, J.M., Clarke, M., Devane, D., Gargon, E. and Tugwell, P. (2012). Developing core outcome sets for clinical trials: Issues to consider. *Trials*, 13(1), pp.132.
- Willis, G.B. (2004). Cognitive interviewing: A tool for improving questionnaire design: A tool for improving questionnaire design, Sage Publications.
- Wilson, S. and MacLean, R. (2011). Research methods and data analysis for psychology, McGraw-Hill Higher Education.
- Wong, L. and Hickson, L. (2012). Evidence-based practice in rehabilitative audiology evaluating: Interventions for children and adults with hearing impairment. San Diego, Plural Publishing.
- Woodcock, K. and Pole, J.D. (2008). Educational attainment, labour force status and injury: A comparison of Canadians with and without deafness and hearing loss. *International Journal of Rehabilitation Research*, 31(4), pp.297-304.

- Wright, B. (1994). Unidimensionality coefficient. *Rasch Measurement Transactions*, 8(3), pp.385.
- Wright, B.D. and Linacre, J.M. (1989). Observations are always ordinal; measurements, however, must be interval. *Archives of Physical Medicine and Rehabilitation*, 70(12), pp.857-860.
- Wright, B.D. (1996). Comparing rasch measurement and factor analysis. *Structural Equation Modeling: A Multidisciplinary Journal*, 3(1), pp.3-24.
- Yamada, M., Nishiwaki, Y., Michikawa, T. and Takebayashi, T. (2012). Self-reported hearing loss in older adults is associated with future decline in instrumental activities of daily living but not in social participation. *Journal of the American Geriatrics Society*, 60(7), pp.1304-1309.
- Yamasoba, T., Lin, F.R., Someya, S., Kashio, A., Sakamoto, T. and Kondo, K. (2013). Current concepts in age-related hearing loss: Epidemiology and mechanistic pathways. *Hearing Research*, 303, pp.30-38.
- Yardley, L. (2008). Demonstrating validity in qualitative psychology. *Qualitative psychology: A practical guide to research methods*. Smith, J.A. London, Sage Publications. 2: 235-251.
- Yardley, L., Morrison, L.G., Andreou, P., Joseph, J. and Little, P. (2010). Understanding reactions to an internet-delivered health-care intervention: Accommodating user preferences for information provision. *BMC Medical Informatics and Decision Making*, 10(1), pp.1.
- Yorgason, J.B., Piercy, F.P. and Piercy, S.K. (2007). Acquired hearing impairment in older couple relationships: An exploration of couple resilience processes. *Journal of Aging Studies*, 21(3), pp.215-228.
- Yorke, J., Horton, M. and Jones, P.W. (2012). A critique of rasch analysis using the dyspnoea-12 as an illustrative example. *Journal of Advanced Nursing*, 68(1), pp.191-198.
- Yueh, B., Souza, P.E., McDowell, J.A., Collins, M.P., Loovis, C.F., Hedrick, S.C., Ramsey, S.D. and Deyo, R.A. (2001). Randomized trial of amplification strategies. *Archives of Otolaryngology-Head & Neck Surgery*, 127(10), pp.1197-1204.
- Zigmond, A.S. and Snaith, R.P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67(6), pp.361-370.
- Zulkosky, K. (2009). Self-efficacy: A concept analysis. *Nursing Forum*, 44(2), pp.93-102.
- Zunzunegui, M.-V., Alvarado, B.E., Del Ser, T. and Otero, A. (2003). Social networks, social integration, and social engagement determine cognitive decline in community-dwelling spanish older adults. *The*

Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 58(2), pp.S93-S100.