THE UNIVERSITY OF QUEENSLAND

AUSTRALIA

Improving Research Outcome Measurement in Aphasia (ROMA): Development of a Core Outcome Set

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Bachelor of Speech Pathology (Hons I)

Graduate Certificate in Gerontology

A thesis submitted for the degree of Doctor of Philosophy

at The University of Queensland in 2016

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Abstract

Aphasia treatment research lacks a consistent approach to outcome measurement. There is heterogeneity in the outcome measures used across treatment trials and a lack of research evidence exploring the outcome constructs which are most important to key stakeholders. The efficiency, relevancy, transparency, and overall quality of aphasia treatment research could be increased through the development of a core outcome set (COS)—an agreed standardised set of outcomes for use in treatment trials. The overarching aim of this research was to generate evidence-based recommendations for outcome constructs and outcome measures for a COS for aphasia treatment research.

The thesis is comprised of a review of the literature (chapter 2) and two phases of research: (1) a trilogy of stakeholder consensus studies and a synthesis of the results; and (2) a scoping systematic review of studies reporting the measurement properties of standardised outcome instruments validated with people with aphasia. The World Health Organization International Classification of Functioning Disability and Health (ICF) was used across all studies to provide a common framework for the analysis of results.

Study 1 aimed to gain consensus on important aphasia treatment outcomes from the perspective of people with aphasia and their families. A total of 39 people with aphasia and 29 family members participated in one of 16 nominal groups across seven countries. Qualitative content analysis revealed six themes describing: (1) Improved communication; (2) Increased life participation; (3) Changed attitudes through increased awareness and education about aphasia; (4) Recovered normality; (5) Improved physical and emotional well-being; and (6) Improved health services (people with aphasia) and Improved health and support services (family members). Prioritised outcomes for both participant groups linked to all ICF components; primarily Activity/Participation (39%) and Body Functions (36%) for people with aphasia, and Activity/Participation (49%) and Environmental Factors (28%) for family members. Outcomes prioritised by family members relating to the person with aphasia, primarily linked to Body Functions (60%).

Study 2 aimed to gain consensus on important aphasia treatment outcomes from the perspective of aphasia treatment researchers. Purposively sampled researchers were invited to participate in a three-round e-Delphi exercise. Eighty researchers commenced round 1, with 72 completing the entire survey. High response rates (≥85%) were achieved in subsequent rounds. Researchers reached consensus that it is essential to measure language function and specific patient-reported outcomes (impact of treatment; communication-related quality of life; satisfaction with intervention; satisfaction with ability to communicate; and satisfaction with participation) in all aphasia treatment research. Outcomes reaching consensus linked to all ICF components.

Study 3 aimed to gain consensus on important treatment outcomes from the perspective of aphasia clinicians and managers, again using a three-round e-Delphi exercise. In total, 265 clinicians and 53 managers (n=318) from 25 countries participated in round 1. A total of 51 outcomes reached consensus after the third round. The two outcomes with the highest levels of consensus both related to communication in the dyad. Outcomes relating to people with aphasia most frequently linked to the ICF Activity/Participation component (52%), whilst outcomes relating to significant others were evenly divided between the Activity/Participation component (36%) and Environmental Factors (36%).

The results of studies 1-3 were synthesised through a comparison of ICF coding (study 4). Results revealed that important outcomes from aphasia treatment occur at all levels of the ICF. Within these components, congruence across three or more stakeholder groups was evident for outcomes which related to Mental functions (Emotional functions, Mental functions of language, Energy and drive functions); Communication (Communicating by language, signs and symbols, receiving and producing messages, conversations, and using communication devices and techniques); Services, systems, and policies (Health services, systems and policies), and quality of life.

Study 5 was a scoping systematic review of studies reporting the measurement properties of standardised outcome instruments which have been validated with people with aphasia. In total, 184 references for 79 outcomes instruments were included in the review. The vast majority of outcome instruments related to Body Functions (n=49). No outcome instruments were reported to primarily measure constructs relating to Environmental Factors. A number of outcome instruments measured constructs which did not fall within the ICF, these included measures of quality of life (n=7), life satisfaction (n=1), and knowledge about aphasia and stroke (n=1).

This program of research identified that important aphasia treatment outcomes span the ICF and also go beyond – encompassing quality of life. Stakeholders reported outcomes relating to: language; emotional wellbeing; communication; health services; and quality of life should be measured routinely. This research has highlighted the large number of outcome instruments available for use with people with aphasia, which predominately measure Body Functions. Targeted development of appropriate instruments is required in some construct areas. Outcome constructs

identified in phase 1 of this research were paired with outcome instruments identified in phase 2, to provide recommendations for an international COS consensus meeting.

Declaration by Author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my research higher degree candidature and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

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Publications During Candidature

Peer-Reviewed Papers

1. **Wallace, S. J.,** Worrall, L., Rose, T., & Le Dorze, G. (In press). Core outcomes in aphasia treatment research: An e-Delphi consensus study of international aphasia researchers. *American Journal of Speech-Language-Pathology*.

2. Worrall, L., Simmons-Mackie, N., **Wallace, S. J.,** Rose, T., Brady, M., Pak-Hin Kong, A., & Murray, L., on behalf of the Aphasia United Advisory Committee. (2016). Let's call it "aphasia": Rationales for eliminating the term "dysphasia". *International Journal of Speech-Language-Pathology*, doi:10.1177/1747493016654487

3. **Wallace, S. J.,** Worrall, L., Rose, T., & Le Dorze, G. (2016). Which treatment outcomes are most important to aphasia clinicians and managers? An international e-Delphi consensus study. *Aphasiology*, Advance online publication. doi:10.1080/02687038.2016.1186265

4. **Wallace, S. J.,** Worrall, L., Rose, T., Le Dorze, G., Cruice, M., Isaksen, J., Pak Hin Kong, A., Simmons-Mackie, N., Scarinci, N., & Alary Gauvreau, C. (2016). Which outcomes are most important to people with aphasia and their families? An international nominal group technique study framed within the ICF. *Disability and Rehabilitation,* Advance online publication. doi:10.1080/09638288.2016.1194899

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1. Worrall, L., Rose, T., Brandenburg, C., Rohde, A., Berg, K., & **Wallace, S. J.** (2015). *Aphasia in Later Life.* In A. N. Pachana (Ed.), Encyclopedia of Geropsychology (pp. 1-7). Singapore: Springer Singapore. doi: 10.1007/978-981-287-080-3_346-1

Conference Abstracts

1. Rose, T., Worrall, L. & **Wallace, S. J.** (2016, August). Aphasia education: Speech pathologists' perspectives regarding current and desired practice. Paper presentation at the International Association of Logopedics and Phoniatrics (IALP), Dublin, Ireland.

2. **Wallace, S. J.,** Worrall, L., Rose, T., & Le Dorze, G. (2015, November). Core aphasia treatment outcomes: An international e-Delphi consensus study of clinicians and managers. Paper presented at The University of Queensland Postgraduate Research Conference, Brisbane, Australia.

3. Hilari, K., Klippi, A., Constantinidou, F., Horton, S., Penn, C., Raymer, A., **Wallace, S. J.,** Zemva, N., & Worrall, L. (2015, November). Quality of life in aphasia: International perspectives. Seminar session at American Speech, Language and Hearing Association (ASHA) Annual Convention 2015, USA.

4. **Wallace, S. J.,** Worrall, L., Rose, T., & Le Dorze, G. (2015, May). Core outcomes in aphasia treatment research? An e-Delphi consensus study of international aphasia researchers. Paper presented at the Clinical Aphasiology Conference (CAC), California, USA.

5. **Wallace, S. J.,** Worrall, L., Rose, T., Le Dorze, G., Cruice, M., Simmons-Mackie, N., Isaksen, J., Kong, A. & Scarinci, N. (2015, May). Which outcomes are most important to people living with aphasia? An international nominal group technique study. Poster presentation at the Clinical Aphasiology Conference (CAC), California, USA.

6. **Wallace, S. J.,** Worrall, L., Rose, T., Le Dorze, G., Cruice, M., Simmons-Mackie, N., Isaksen, J., Kong, A. & Scarinci, N. (2014, June). Which outcomes are most important to people living

with aphasia? Development of a core outcome set for aphasia research. Paper presented at the 16th International Aphasia Rehabilitation Conference (IARC), The Hague, The Netherlands.

7. **Wallace, S. J.,** Worrall, L., Rose, T., & Le Dorze, G. (2014, June). Measuring outcomes in aphasia treatment research: A review of current practice and an agenda for standardization. Paper presented at the 16th International Aphasia Rehabilitation Conference (IARC), The Hague, The Netherlands.

8. **Wallace, S. J.,** Worrall, L., Rose, T., Le Dorze, G. (2013, November). Which outcomes are most important to stakeholders in aphasia rehabilitation? Development of a core outcome set for aphasia research. Paper presented at The University of Queensland Postgraduate Research Conference, Brisbane, Australia.

9. Klippi, A., Penn, C., Constantinidou, F., Zemva, N., Hilari, K., Horton, S., Raymer, A., **Wallace, S. J.** & Worrall, L. (2013, August). Quality of life in aphasia: An international perspective. 29th World Congress of the International Association of Logopedics and Phoniatrics (IALP), Torino, Italy.

Publications Included in This Thesis

Wallace, S. J., Worrall, L., Rose, T., & Le Dorze, G. (2014). Measuring outcomes in aphasia research: A review of current practice and an agenda for standardisation. *Aphasiology, 28*(11), 1364-1384. doi:10.1080/02687038.2014.930262
Incorporated in its entirety as Chapter 2.

Contributor	**Statement of contribution**
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Author: Linda Worrall	Edited the paper (40%)
Author: Tanya Rose	Edited the paper (40%)
Author: Guylaine Le Dorze	Edited the paper (20%)

Wallace, S. J., Worrall, L., Rose, T., Le Dorze, G., Cruice, M., Isaksen, J., Pak Hin Kong, A., Simmons-Mackie, N., Scarinci, N., & Alary Gauvreau, C. (2016). Which outcomes are most important to people with aphasia and their families? An international nominal group technique study framed within the ICF. *Disability and Rehabilitation,* Advance online publication. doi:10.1080/09638288.2016.1194899
Incorporated in its entirety as Chapter 3.

Contributor	**Statement of contribution**
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Author: Linda Worrall	Study design (10%) Data collection (30%) Data analysis (5%) Edited the paper (30%)
Author: Tanya Rose	Study design (5%) Data collection (5%) Data analysis (15%) Edited the paper (30%)

Contributor	Statement of contribution
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Author: Nerina Scarinci, The University of Queensland, Australia	Data collection (5%) Data analysis (2%) Edited the paper (3%)
Author: Madeline Cruice, City University, London, UK	Data collection (5%) Data analysis (2%) Edited the paper (5%)
Author: Christine Alary Gauvreau, University of Montreal, Canada.	Data collection (2.5%) Edited the paper (2%)
Aileen Thompson, Netcare Rehabilitation, Johannesburg, South Africa.	Data collection (2.5%)
Carole Anglade, The University of Montreal, Canada.	Data collection (2.5%)
Ms Michèle Masson-Trottier, The University of Montreal, Canada.	Data collection (2.5%)
Karen Sage, University of the West of England, Bristol, UK	Data collection (5%)

Wallace, S. J., Worrall, L., Rose, T., & Le Dorze, G. (In press). Core outcomes in aphasia treatment research: An e-Delphi consensus study of international aphasia researchers. *American Journal of Speech Language Pathology.*

Incorporated in its entirety as Chapter 4.

Contributor	**Statement of contribution**
Author: Sarah J. Wallace (Candidate)	Study design (80%)
	Data collection (100%)
	Data analysis (80%)
	Wrote the paper (100%)
Author: Linda Worrall	Study design (10%)
	Edited the paper (40%)
Author: Tanya Rose	Study design (5%)
	Data analysis (20%)
	Edited the paper (40%)
Author: Guylaine Le Dorze	Study design (5%)
	Edited the paper (20%)

Wallace, S. J., Worrall, L., Rose, T., & Le Dorze, G. (2016). Which treatment outcomes are most important to aphasia clinicians and managers? An international e-Delphi consensus study. *Aphasiology,* Advance online publication. doi:10.1080/02687038.2016.1186265

Incorporated in its entirety as chapter 5.

Contributor	**Statement of contribution**
Author: Sarah J. Wallace (Candidate)	Study design (90%)
	Data collection (100%)
	Data analysis (70%)
	Wrote the paper (100%)
Author: Linda Worrall	Study design (5%)
	Data analysis (5%)
	Edited the paper (40%)
Author: Tanya Rose	Study design (5%)
	Data analysis (20%)
	Edited the paper (40%)
Author: Guylaine Le Dorze	Data analysis (5%)
	Edited the paper (20%)

Contributions by Others to the Thesis

The PhD candidate was primarily responsible for: the concept and design of the studies, gaining ethical approval, participant recruitment, data collection, analysis and interpretation, and manuscript preparation. The PhD candidate acknowledges the intellectual input of her advisors and co-authors. Significant contributions have been made to the thesis as a whole by Professor Linda Worrall, Dr Tanya Rose, and Professor Guylaine Le Dorze who had input into the concept and design of each study, the analysis and interpretation of the data, and critical appraisal of written work.

The following individuals assisted with data collection at international sites:

- Professor Nina-Simmons Mackie, Southeastern Louisiana University, USA;
- Professor Karen Sage, Bristol Speech and Language Therapy research unit, North Bristol National Health Service Trust and University of the West of England, Bristol, UK and
- Associate Professor Anthony Pak Hin Kong, University of Central Florida, United States of America (USA);
- Dr Nerina Scarinci, The University of Queensland, Australia;
- Dr Madeline Cruice, City University, London, United Kingdom (UK);
- Ms Carole Anglade, The University of Montreal, Canada;
- Ms Michèle Masson-Trottier, The University of Montreal, Canada;
- Ms Jytte Ivaksen, University of Southern Denmark, Denmark;
- Ms Aileen Thompson, Netcare Rehabilitation Hospital, Johannesburg, South Africa.

The PhD candidate acknowledges the contribution of Caitlin Brandenburg (The University of Queensland, Australia) in performing independent assessment of titles, abstracts, and full text articles in the systematic review (chapter 7) study selection process.

To the best of my knowledge and belief, no person who has offered contributions consistent with the above has been excluded as an author.

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Statement of Parts of the Thesis Submitted to Qualify for the Award of Another Degree

None.

Acknowledgements

Dear reader,

I hope that you will tarry a moment and indulge me while I acknowledge a few people without whom, this project simply would not have been possible. Let's begin with the advisory team.

And Professor Linda Worrall…although advisor is perhaps the wrong descriptor for Linda. Allow me to explain. I first met Professor Linda Worrall as an undergraduate student. I was at the time taken to frequent outbursts of opinion and enjoyed nothing better than pointing out Linda's oversights and errors. Seemingly unconcerned by my precocious displays of tenacity she bade her time, waiting until the end of fourth year to make me the subject of an impromptu "practice viva"—with the entire 4th year cohort as an audience. I am pretty sure that particular learning activity was *not* listed in the ECP… It would be some 10 years before we would meet again. When our paths did cross, Linda gave me a job and encouraged me to undertake a PhD. The cynic in me sometimes wonders whether this was part of her payback 'end-game'…fortunately my inner optimist trumps my inner cynic and so to return to my earlier comment about descriptors, I must say that Linda is not just an advisor, she is the true definition of a teacher. She sees a spark of something in a person and encourages it to grow. Linda has helped and inspired me to become the teacher and researcher that I am, and still on occasions, reminds me of who I was. Over the past four years, her support has been unwavering and her generosity without limits. I feel incredibly fortunate to have shared this experience with you Linda. Thank you for everything.

To Dr Tanya Rose, thank you for helping me to become a better researcher. Your methodological expertise and attention to detail have been instrumental to this project and I am a better researcher for your advice and guidance. Thank you for the opportunities that you have provided, particularly within the realm of teaching. Your generosity and support have been very much appreciated.

To Professor Guylaine Le Dorze, thank you for joining this project and lending an invaluable international perspective to these works. Throughout this project your input and commentary have been so incredibly insightful (and sometimes it took me several days to actually realise *just how* insightful). Thank you for making me think.

To Dr Madeline Cruice (the unofficial advisor), thank you for supporting me and this project from start to finish—for no other reason than you believed in me and believed in this work. I am indebted to you and look forward to future international collaborations.

Thank you also to the speech pathology team within the School of Health and Rehabilitation Sciences, particularly Dr Anne Hill and Dr Tony Angwin for the opportunities and your support over the past year (again, I'm not leaving). Special thanks to those people who helped to get me through this last stretch: Adriana Penman for listening and hamburgers; Kirstine Shrubsole for listening and coffee; and Professor David Copland for listening. (There was a lot of listening). Thank you also to all the lovely members of the aphasia research group, the Communication Disability Centre, and to all my PhD sisters.

To the research participants…Thank you to the people with aphasia and their families; the clinicians, managers, and researchers; from around the world who participated in this project. This research could not have happened without your generosity and support. Thank you for your time and willingness to share your unique perspectives.

On a personal note… To my husband David, to quote the Mountain Goats:

The most remarkable thing about you standing in the doorway is that it's you/

And that you are standing in the doorway/

Thank you for being here and being you. Thank you for your endless support and encouragement. Thank you for the excellent coffee. Thank you for the stretches of solo parenting which allowed me to venture out into the world. Thank you for helping me to pursue my dreams. I could not have done this without you.

Thank you to my beautiful and spirited daughters, Poppy and Audrey, who never fail to remind me what is important in life. I love you two rascals. Thank you to my parents Fran and Peter, for instilling in me a love of books and words, and a strong work ethic. Thank you also Nana Fran for your intensive school holiday visits, you can have a rest now. Thank you to Nana Jean and Puppa for your support, and for representing at school events. Thank you to my friends Mila-Ludmila-Luddy Andersson, Marcela Lapertosa, Annie Rolfe, and Elisa Edridge, you are remarkable women and wonderful friends. Thank you to all of my friends and family for your ongoing support, both in verbal and practical forms. You're good people.

Finally, I acknowledge that this work was conducted with the support of an Australian Postgraduate Award (APA) scholarship.

And so, dear reader, delay no further─for the world of aphasia outcome measurement awaits… Sarah Jane Wallace, October 5th 2016.

Keywords

Aphasia, outcome measurement, core outcome set, ICF, consensus, research.

Australian and New Zealand Standard Research Classifications (ANZSRC)

ANZSRC code: 110321 Rehabilitation and Therapy (excl. Physiotherapy) 100%

Fields of Research (FoR) Classification

FoR code: 1103 Clinical Sciences 100%

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List of Abbreviations Used in Thesis

AASP	Acute Aphasia Screening Protocol
AAT	Aachen Aphasia Test
ABC	Aphasia Battery in Chinese
ABS	Affect Balance Scale
ACESA	The Assessment of Communicative Effectiveness in Severe Aphasia
ACL	The Aphasia Checklist
ACOM	Aphasia Communication Outcome Measure
ACTS	Auditory Comprehension Test for Sentences
ADRS	Aphasic Depression Rating Scale
A-FROM	Living with Aphasia: Framework for Outcome Measurement
ALA	Assessment for Living with Aphasia
ALA	Aphasia Language Assessment Test
ALPS	The Thai Aphasia Language Performance Scales
ALQI	Aachen Life Quality Inventory
ANELT	Amsterdam-Nijmegen Everyday Language Test
APA	Australian Postgraduate Award
APA	American Psychological Association
ART	The Aphasia Rapid Test
ASHA-FACS	American Speech-Language and Hearing Association Functional Assessment of Communication Skills for Adults
AST	The Aphasia Screening Test
AusTOMs	Australian Therapy Outcome Measures
BAT	Bilingual Aphasia Test
BAE	Brief Aphasia Evaluation
BDAE	Boston Diagnostic Aphasia Examination
BDI	Beck Depression Inventory
BNT	Boston Naming Test
BOA	Behavioural Outcomes of Anxiety scale
BOSS	Burden of Stroke Scale
CADL	Communication Abilities of Daily Living
CAL	Communicative Activity Log
Carer COAST	Carer Communication Outcome After Stroke Scale
CAT	Comprehensive Aphasia Test

CATs	Collaboration of Aphasia Trialists
CCRSA	Communication Confidence Rating Scale for Aphasia
CDP	The Communication Disability Profile
CETI	Communicative Effectiveness Index
CFCP	Chinese Functional Communication Profile
CGI-S	Clinical Global Impressions Rating Scale
CHSPT	Caplan and Hanna Sentence Production Test
CILT	Constraint Induced Language Therapy
CIQ	Community Integration Questionnaire
COAST	Communication Outcome After Stroke Scale
COMACT	The Communication Activities Checklist
COMET	Core Outcome Measures in Effectiveness Trials Initiative
CONSORT	Consolidated Standards of Reporting Trials
COS	Core Outcome Set
COSMIN	COnsensus-based Standards for the selection of health Measurement INstruments.
CRIR	Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal
CRG	Cochrane Review Group
CRRCAE	Chinese Rehabilitation Research Centre Aphasia Examination
CR-QoL	Communication Related Quality of Life
CRS	Conversational Rating Scale
CRS	Center for Rehabilitering og Specialrådgivning
DA	Discourse Analysis
EATT	English Aachen Aphasia Test
EU COST	European Co-operation in Science and Technology
FAST	Frenchay Aphasia Screening Test
FCP	Functional Communication Profile
FDA	Food and Drug Administration
FOQ-A	The Functional Outcome Questionnaire for Aphasia
GHQ	General Health Questionnaire
GRADE	Grading of Recommendations Assessment, Development and Evaluation
HADS	Hospital Anxiety and Depression Scale
HARC	Houston Aphasia Recovery Centre
HOME	Harmonising Outcome Measures of Eczema

IALP	International Association of Logopaedics and Phoniatrics
ICF	International Classification of Functioning, Disability and Health
IMMPACT	Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials
KAT	Kentucky Aphasia Test
K-CAL	Korean Communication Activity Log
K-WAB	Korean Western Aphasia Battery
LAST	Language Screening Test
LISAT-9	Life Satisfaction Questionnaire – Dutch version
LTC	Long Term Care
MAACL	Multiple Adjective Affect Check-List
MADRS	Montgomery-Asberg Rating Scale
MAST	Mississippi Aphasia Screening Test
MAST	Mobile Aphasia Screening Test
MCTAC	Multiple-Choice Test of Auditory Comprehension
MEASURE	Measurement in Autism Spectrum Disorder
MPC	Measure of Participation in Conversation
MTDDA	Minnesota Test for Differential Diagnosis of Aphasia
MTL-BR	Montreal-Toulouse Language Assessment Battery – Brazilian version
NAVS	Northwestern Assessment of Verbs and Sentences
NAVS-C	Northwestern Assessment of Verbs and Sentences - Chinese
NEWSQOL	Newcastle Stroke-Specific Quality of Life measure
ND	Non-Definable
NC	Not Coded
NGT	Nominal Group Technique
NGTA	The Norsk Grunntest for Afasi
NIHSS	National Institutes of Health Stroke Scale
NHMRC	National Health and Medical Research Council
NHP	Nottingham Health Profile
NHS	National Health Service
NGA	Norsk Grunntest for Afasi
ONT	Object Naming Test
OMERACT	Outcome Measures for Rheumatology Clinical Trials
PAAT	Portuguese Aachen Aphasia Test
PCORI	Patient-Centered Outcomes Research Institute

PedIMMPACT	Pediatric Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials
PICA	Porch Index of Communicative Abilities
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PRO	Patient Reported Outcomes
PWA	Person with aphasia
QoL	Quality of Life
QLQA	Quality of Life Questionnaire for Aphasics
RCBA	Reading Comprehension Battery for Aphasia
RCT	Randomised Control Trial
ROMA	Improving Research Outcome Measurement in Aphasia
RTT	Revised Token Test
PALPA	Psycholinguistic Assessments of Language Processing in Aphasia
PCB	Philadelphia Comprehension Battery
PCORI	Patient-Centred Outcomes Research Institute
PDSM	Picture Description with Structured Modeling
PICA	Porch Index of Communicative Ability
PPVT	Peabody Picture Vocabulary Test
PRO	Patient Reported Outcome
RCBA	Reading Comprehension Battery for Aphasia
RCT	Randomised Control Trial
SAD	Stroke and Aphasia Scale
SADQ	Stroke Aphasic Depression Questionnaire
SADQ-10	Stroke and Aphasia Depression Questionnaire – 10 items
SADQH	Stroke and Aphasia Depression Questionnaire Hospital
SADQH-10	Stroke and Aphasia Depression Questionnaire Hospital – 10 items
SAS	Sklar Aphasia Scales
SAT	Semantic Association Test
SAQOL-39	Stroke and Aphasia Quality of Life Scale
SAQOL-39g	Stroke and Aphasia Quality of Life Scale – general population
SF-36	Short Form 36 Health Survey
SHGBD	Self Help Group for the Brain Damage
SIS	Stroke Impact Scale
SLP	Speech Language Pathologist

SNSS	Stroke Social Network Scale
SOCAT	Social Activities Checklist
SODS	Signs of Depression Scale
SPIRIT	Standard Protocol Items: Recommendations for Interventional Trials
SS-QOL	Stroke Specific Quality of Life Scale
SPT	Sentence Production Test
SST	Sheffield Screening Test for Acquired Language Disorders
tDCS	Transcranial Direct Current Stimulation
THAI-AAT	Thai Aachen Aphasia Test
TOMs	Therapy Outcome Measures
TT	Token Test
UAS	Ullevaal Screening Test
UK	United Kingdom
UN	United Nations
USA	United States of America
VAMS	Visual Analogue Mood Scales
VASES	Visual Analogue Self Esteem Scales
WAB	Western Aphasia Battery
WABAQ	Western Aphasia Battery Aphasia Quotient
WHO	World Health Organization

Chapter 1: Introduction

This chapter introduces both the topic of the thesis and the research studies that are included. More specifically, section 1.1 summarises the background and significance of this research, and provides a rationale for the development of a core outcome set (COS) for aphasia treatment research. Section 1.2 details the aims of the research and provides an overview of the structure of the thesis.

1.1 Background and Significance

Aphasia is an acquired language disorder which occurs most commonly as a result of stroke. The incidence of aphasia from a first ischaemic stroke is estimated to be 30% (Engelter et al., 2006). People with aphasia are a heterogeneous population who may experience difficulty with verbal expression, auditory comprehension, written expression, reading comprehension, and/or numeracy. These modalities may be affected in any combination, with severity of impairment ranging from mild to profound. The use of language to communicate is a defining human characteristic and is intrinsic to daily life. Communication permeates activities of daily living, relationships, and life roles; it is a vehicle for the experience and expression of self, and as such, the impacts of aphasia can be all-encompassing. Sarno explains:

> Aphasia can be perceived as a disorder of communication leading to a disorder of person. The deep and unexpected changes associated with aphasia initiate a series of reactions that impact on every aspect of the individual, including reactions to illness, disability, sense of self, ability to cope with being socially different, feelings of loss, lowered self-esteem, and possible depression in the face of impaired behaviour (Sarno, 1993, p. 323).

A growing body of research confirms the widespread impact of aphasia. Aphasia negatively impacts quality of life (Lam & Wodchis, 2010), psychological wellbeing (Code & Herrmann, 2003; De Ryck, Brouns, Fransen, & Geurden, 2013; Kauhanen et al., 2000), and social participation (Davidson, Howe, Worrall, Hickson, & Togher, 2008; Le Dorze, Salois-bellerose, Alepins, Croteau, & Hallé, 2013). Aphasia may also negatively impact the functioning of family members and significant others (Grawburg, Howe, Worrall, & Scarinci, 2014; Le Dorze & Signori, 2010).

Aphasia rehabilitation is provided by health professionals that have different discipline names in different countries. In Australia, the profession is called speech pathology. Rehabilitation is a broad construct which the World Health Organization defines as, “A set of measures that assists individuals who experience or are likely to experience disability to achieve and maintain optimal functioning in interaction with their environment" (World Health Organization, 2011, p. 308). Aphasia rehabilitation encompasses a wide range of treatments which aim to maximise an individual's language and/or ability to communicate in interaction with their environment (Brady, Kelly, Godwin, & Enderby, 2016). Best practice treatment should be informed by research evidence (Hoffmann, Bennett, & Del Mar, 2010), which enables clinicians, people with aphasia and their significant others to make informed decisions to guide recovery. PCORI, the Patient-Centred Outcomes Research Institute, have developed methodological standards for patient-centred research which include the recommendation that research should measure and communicate outcomes which, "people representing the population of interest notice and care about (e.g., survival, function, symptoms, health-related quality of life) and that inform an identified health decision." (PCORI Methodology Committee, 2013, p. 26). There is variability in the outcomes measured in aphasia treatment research and heterogeneity in the tools with which outcomes are measured. This variability was the impetus for the current program of research and is exemplified by the 2012 Cochrane Review of Speech and Language for Aphasia Following Stroke, which reported the use of more outcome measures (n=42) than trials (n=39) (Brady et al., 2012). The production of incompatible data limits the efficient use of research outcomes beyond the individual study, constraining the comparison and combination of findings across trials.

In health research, there is growing recognition of the crucial role of outcome measurement in study design. Across a variety of health areas, Core Outcome Sets (COSs) have been, and are continuing to be, developed to increase consistency in outcome measurement. A COS is a minimum set of outcomes that should be measured and reported in research trials of a specific health condition or population (Prinsen et al., 2014). The use of a COS does not preclude the measurement of additional outcomes, but rather represents the minimum outcomes that should be collected and reported (Williamson et al., 2012). The use of a COS may improve the quality of treatment research in a particular health condition by:

1. Assisting designers of research trials to select the most appropriate and best quality tool to measure a given outcome construct.
2. Requiring the reporting of a minimum set of outcomes; increasing the transparency of research and the reliability of research findings.
3. Producing compatible data which can be efficiently synthesised in future analyses (e.g., systematic reviews).

4. Reducing research wastage through the measurement of outcomes which are relevant to end users and consequently are more likely to inform treatment decision-making.

The Core Outcomes in Effectiveness Trials (COMET) Initiative is a guiding body in COS development, which seeks to: (1) raise awareness of research outcome measurement issues; (2) encourage COS development and uptake; (3) provide resources to support COS development; and (4) encourage evidence-based COS development. The COMET initiative has developed methodological guidelines for COS development (see Williamson et al., 2012). Reporting standards for COS development studies (COS-STAR; Core Outcomes Set-STAndards for Reporting) and guidelines for the selection of outcome measurement instruments for COSs (COMIS; The Core Outcome Measurement Instrument Selection project) are also currently in development (Kirkham et al., 2015; Prinsen et al., 2014). COS development occurs in two phases. The first phase uses consensus processes to determine *what* should be measured and reported (i.e., which outcome constructs) in all trials of a particular health condition. This is followed by determining how these outcome constructs should be measured (i.e., which outcome tools or instruments should be used).

The current research project sought to develop recommendations for a COS for aphasia treatment studies in order to increase the efficiency, relevancy, transparency, and overall quality of research outcomes; while allowing researchers to also explore outcomes specific to their own research.

1.2 Research Aims and Thesis Overview

The overarching aim of the thesis was to recommend a COS for aphasia treatment research studies. Specifically, the research aimed to: (1) obtain the perspectives of people with aphasia, their family members, aphasia researchers, and aphasia clinicians/managers in order to identify important outcome constructs for inclusion in a COS for aphasia treatment research; and (2) identify existing outcome measures that relate to these important outcome constructs which could be routinely incorporated in treatment studies to increase the efficiency, relevancy, and transparency of research outcomes.

The thesis is comprised of a review of the literature (chapter 2) and two phases of research. The review of the literature explores outcome measurement practices in aphasia treatment research and examines the potential benefits and challenges of COS development for this field. Phase 1 consists of three studies of stakeholder perspectives regarding important outcomes from aphasia treatment (chapters 3-5). These stakeholder perspectives are synthesised in chapter 6 to produce recommendations for outcome constructs which should be routinely measured in research. Phase 2 is a scoping systematic review of validated, existing outcome measures (chapter 7). Chapter 8 discusses the strengths and limitations of this research project. Future directions are presented, including recommendations for an international consensus meeting of aphasia researchers, informed by the thesis findings.

The research methodologies used throughout the thesis are based on the recommendations of the COMET Initiative (Sinha, Smyth, & Williamson, 2011; Williamson et al., 2012). Additionally, in both phase 1 and 2 of this research the World Health Organization International Classification of Functioning, Disability and Health (ICF; World Health Organization, 2001) has been used as a conceptual framework and classification tool. The ICF is a framework for considering health and health related states. Its utility lies in its consideration of both impairment arising from a health condition and the impacts of that health condition on all aspects of an individual’s life. The ICF has been widely used in aphasia research as a means of: describing communicative functioning, disability and the impact of contextual factors (e.g., Howe, Worrall, & Hickson, 2008); classifying the content of assessments and outcome instruments (e.g., Brandenburg, Worrall, Rodriguez, & Bagraith, 2015); describing third-party disability (e.g., Grawburg, Howe, Worrall, & Scarinci, 2014); and analysing and comparing data (e.g., Worrall et al., 2011).

The ICF has two parts, each containing multiple components: (1) Functioning and Disability (comprising Body Functions and Structure; Activity and Participation) and (2) Contextual factors (including Environmental Factors and Personal Factors) (see figure 1-1).

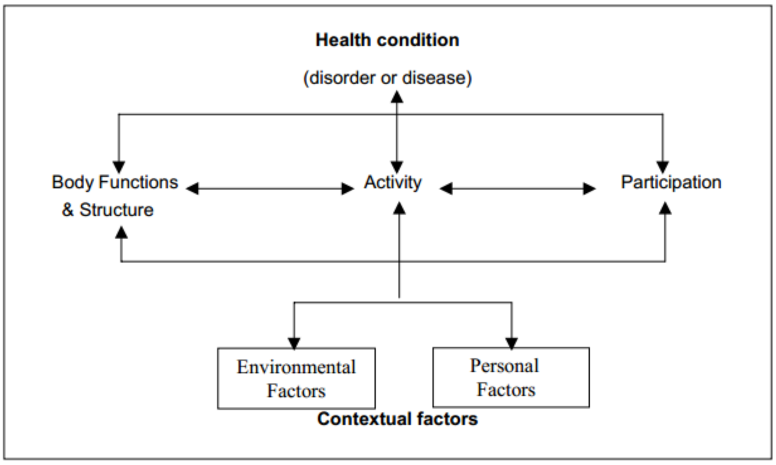

Figure 1-1. The World Health Organization International Classification of Functioning, Disability and Health (ICF). (From World Health Organization, 2001). Reprinted with permission.

Within each of the ICF components there is a hierarchy of codes and categories organised in increasingly detailed and specific levels. These levels are described as chapters (first level) and second-, third-, and fourth-level categories. An example of this hierarchy is presented in figure 1-2.

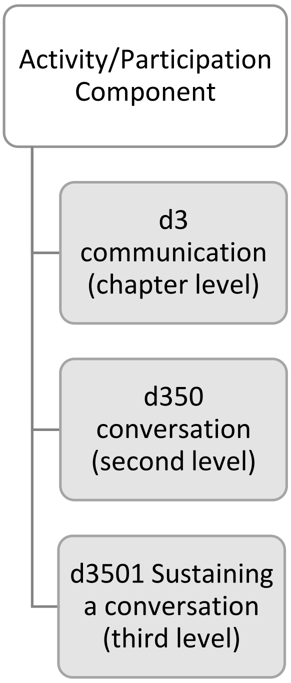

Figure 1-2. Example of the ICF Coding Hierarchy

In the current research ICF coding has been used as a method of data analysis. In this approach, information is linked to ICF codes and categories using standard rules. This provides a common nosology through which data can be compared within and across studies. Standard rules for ICF coding have been developed (see Cieza et al., 2002; Cieza et al., 2005) and were adhered to throughout the current research.

1.2.1 Literature Review

The thesis begins with a review of the literature which was published as the lead article in an *Aphasiology* forum and is included in its entirety as chapter 2. The aims of the review were to: (1) explore best practice considerations in treatment research outcome measurement; (2) describe the current state of outcome measurement in aphasia treatment research; (3) examine the use of COSs in other health disciplines and to discuss the potential benefits and challenges of this approach for aphasia treatment research; and (4) to provide an overview of the COS development process. Publication of the literature review within the context of a forum also served as a means of stimulating debate on the topic of outcome measurement in aphasia research through invited commentary (see Brady et al., 2014; Hula, Fergadiotis, & Doyle, 2014; MacWhinney, 2014). The review concludes with an agenda for the development of a COS in aphasia treatment research and as such, three required phases of research. Phase 1 comprises a series of consensus based processes to reach international agreement on outcomes of importance from the perspective of different stakeholder groups. Phase 2 is a scoping systematic review of available studies reporting the measurement properties of standardised outcome instruments which have been validated with people with aphasia. Phase 3 (which does not form part of this thesis) is an international consensus meeting informed by recommendations stemming from phase 1 and 2. Phase 3 is beyond the scope of the thesis, requiring the participation of multiple stakeholders and being less amenable to a systematic research process.

1.2.2 Phase 1

Phase 1 of this research sought to gain consensus on important outcomes from aphasia treatment from the perspective of key stakeholder groups. This was accomplished using a trilogy of stakeholder consensus studies examining the perspectives of: (1) people with aphasia and their families; (2) aphasia researchers; and (3) aphasia clinicians/managers; regarding important aphasia treatment outcomes.

1.2.2.1 Study 1. Study 1 is an international nominal group technique study which aimed to identify important treatment outcomes from the perspective of people with aphasia and their families. Both people with aphasia and their families were included as aphasia intervention should address the needs of the family as well as the person with aphasia (Howe et al., 2012). A total of 39 people with aphasia and 29 family members participated in one of 16 nominal groups across seven countries to identify and rank important treatment outcomes from aphasia rehabilitation. Outcomes were analysed using qualitative content analysis and ICF coding. Study 1 is presented in chapter 3 of the thesis. This study has been published in the journal *Disability and Rehabilitation* (Wallace, Worrall, Rose, Le Dorze, et al., 2016) and is incorporated in its entirety in the thesis.

1.2.2.2 Study 2. Study 2 is an international e-Delphi exercise which aimed to identify the outcome constructs which aphasia researchers consider essential to measure in all aphasia treatment research. Purposively sampled researchers were invited to participate in a three-round e-Delphi exercise. Eighty researchers commenced round 1 of the e-Delphi process, with 72 completing the first round in its entirety. High response rates (≥85%) were achieved in subsequent rounds. In round 1, responses to an open-ended question were analysed using inductive content analysis. In rounds 2 and 3, participants rated the importance of each outcome generated in round 1 using a nine-point rating scale. Outcomes reaching predefined consensus criteria were further analysed using ICF coding. Study 2 is presented in chapter 4 of the thesis. This study has been published in the *American Journal of Speech Language Pathology* (Wallace, Worrall, Rose, & Le Dorze, in press) and is incorporated in its entirety in the thesis.

1.2.2.3 Study 3. Study 3 is an international e-Delphi exercise which aimed to gain consensus on important aphasia treatment outcomes from the perspective of aphasia clinicians and managers. Inclusion of the manager perspective was deemed important in order to capture outcomes which may be important to decision and policy makers. A three-round e-Delphi exercise was conducted with aphasia clinicians and managers. In total, 265 clinicians and 53 managers (n = 318) from 25 countries participated in round 1. In round 1, responses to an open-ended question were analysed using inductive content analysis. In rounds 2 and 3, participants rated the importance of each outcome generated in round 1 using a nine-point rating scale. Outcomes reaching predefined consensus criteria were further analysed using ICF coding. Study 3 is presented as chapter 5 of the thesis. This study has been published in the journal *Aphasiology* (Wallace, Worrall, Rose, & Le Dorze, 2016) and is incorporated in its entirety in the thesis.

1.2.2.4 Study 4. The findings of studies 1-3 were synthesised, compared, and contrasted to produce recommendations for outcome constructs which should be measured in all aphasia treatment research. The ICF classification system was used as a common language and framework against which the outcomes reaching consensus in studies 1-3 were compared. Recommendations are provided for outcome constructs which should be included in a COS. This research synthesis is presented in chapter 6.

1.2.3 Phase 2

1.2.3.1 Study 5. Study 5 of this research aimed to systematically identify all available studies reporting the measurement properties of standardised outcome instruments which have been validated with people with aphasia. This study was conducted in alignment with PRISMA (Moher, Liberati, Tetzlaff, & Altman, 2009) and COSMIN guidelines (see http://www.cosmin.nl/). PUBMED, EMBASE, and CINAHL databases were searched using a pre-defined search strategy. The search returned a total of 1834 articles; an additional 159 articles were identified via hand searching of journals. Following the removal of duplicates, 1531 articles were screened by title and abstract; a total of 350 articles underwent full text review. Secondary searches were run on individual outcome measures generated in the first search. A total of 79 outcome instruments were identified. Measures were grouped by ICF component based on the aim of the instrument, as defined by the instrument author/s. Study 5 is presented as chapter 7 of the thesis.

1.2.4 Recommendations for a COS

Chapter 8 concludes the thesis. This chapter provides a summary of the research and recommendations for outcome constructs and outcome instruments for a COS for aphasia treatment research. The strengths and limitations of the project are discussed and future directions for research are outlined.

1.3 Ethical Approval

Overarching ethical approval for this research was obtained from the Behavioural and Social Sciences Ethical Review Committee at The University of Queensland in accordance with National Health and Medical Research Council guidelines. Additional approvals for international sites in study 1 were obtained in accordance with local requirements. Additional approvals were granted by The University of West England, United Kingdom, and the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal (CRIR), Canada (see Appendix A). Local ethical approval was not required at any other sites.

1.4 Formatting

This thesis has been formatted according to the Publication Manual of the American Psychological Association, 6th edition (American Psychological Association [APA], 2010). References are provided at the end of each chapter.

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Chapter 2: Measuring Outcomes in Aphasia Research: A Review of Current Practice and an Agenda for Standardisation

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This chapter provides a review of the literature relating to outcome measurement in aphasia treatment research. A rationale and agenda for the development of a COS is provided.

This chapter has been published by the peer-reviewed rehabilitation journal, Aphasiology: Wallace, S. J., Worrall, L., Rose, T., & Le Dorze, G. (2014). Measuring outcomes in aphasia research: A review of current practice and an agenda for standardisation. *Aphasiology, 28*(11), 1364-1384. doi:10.1080/02687038.2014.930262.

The content included in this chapter is identical to the published manuscript; however, the formatting has been modified to match the style of this thesis.

2.1 Abstract

Background: Aphasia treatment research lacks a uniform approach to outcome measurement. A wide range of outcome instruments are used across trials and there is a lack of research evidence exploring the outcomes most important to stakeholders. This lack of standardisation produces research outcomes which are difficult to compare and combine, limiting the potential to strengthen treatment evidence through meta-analysis and data pooling. The current heterogeneity in aphasia treatment research outcome measurement may be addressed through the development of a core outcome set (COS)—an agreed standardised set of outcomes for use in treatment trials.

Aim: This paper aims to provide a rationale and agenda for the development of a COS for aphasia treatment research.

Main Contribution: A review of the literature reveals heterogeneity in the way outcome measurement is performed in aphasia treatment research. COSs have been developed in a wide range of health fields to introduce standardisation to research outcome measurement. Potential benefits of COSs include easier comparison and combination of research outcomes (Williamson & Clarke, 2012), improved quality of systematic reviews (Kirkham, Gargon, Clarke, & Williamson, 2013) and greater transparency in research reporting (Chan et al., 2013). The use of broad stakeholder consultation also supports the development of research outcomes which are meaningful (Williamson et al., 2012). It is proposed that a COS for aphasia treatment research could be developed in three stages. First, consensus based techniques would be used to reach international agreement on the outcomes which are most important to stakeholders. Second, a systematic review and meta-analysis of outcome instruments would provide synthesised evidence to support the choice of tools to most effectively capture the effects of aphasia treatments. Third, final agreement on a COS would be sought through an international consensus conference.

Conclusions: There is an identified need for standardisation in the way outcomes are selected and measured in aphasia treatment research. COS development may provide an effective, consensus-based solution to this need.

Keywords: aphasia, outcome measures, research, core outcome set.

2.2 Introduction

How a successful outcome is defined and measured is critical in the interpretation of research results. Aphasia treatment research lacks a uniform approach to outcome measurement. There are many outcome instruments in use and insufficient research exploring the outcomes that are most important to stakeholders. These issues impact the ability of researchers to demonstrate the value and effectiveness of aphasia interventions. This review aims to: (1) explore best practice considerations in treatment research outcome measurement, (2) describe the current state of outcome measurement in aphasia treatment research, (3) examine the use of Core Outcome Sets (COSs) in other health disciplines and discuss the potential benefits and challenges of this approach for aphasia treatment research, and (4) present a research agenda for the development of a core outcome set (COS) for aphasia treatment trials.

2.3 Considerations in Treatment Research Outcome Measurement

Treatment research uses scientific methodology to investigate and provide evidence of the benefits of an intervention (Olswang & Bain, 2013). This branch of research explores the causal relationship between treatment and behaviour (efficacy research), as well as the benefits of treatment in the context of the natural environment (effectiveness research) (Olswang & Bain, 2013). Treatment research provides an empirical foundation to service delivery and supports clinical decision-making and professional accountability.

Outcomes are end-points or results. In treatment research, a primary outcome is selected to draw conclusions regarding the overall effectiveness of an intervention (Stanley, 2007). The choice of an outcome and an instrument with which to measure it is crucial to the success of a research study. Poorly chosen outcomes and outcome instruments may be unable to capture, or may even distort, research results (Coster, 2013). There are many different outcomes which may be measured in the evaluation of a treatment or intervention. Using the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) framework (World Health Organization, 2001), outcomes may reflect results in areas of functioning and disability (Body Functions and Structures; and activities and participation) and contextual factors (Environmental Factors and Personal Factors). Outcomes may also be ‘client-defined’, pertaining to concepts such as satisfaction and quality of life (Frattali, 2013). The effectiveness of an intervention may also be measured in terms of administrative or financial constructs, such as value for money, length of stay, and occasions of service (Frattali, 1998). While the constructs chosen to measure the effectiveness of interventions may vary, they should share the commonality of possessing meaning and relevance to stakeholders (Chalmers & Glasziou, 2009; Williamson et al., 2012).

The outcome chosen to demonstrate the effects of an intervention should reflect the result considered most important to the relevant stakeholders (Moher et al., 2010) and the area of the stakeholder's life in which this result is most likely to be apparent (Coster, 2013). The breadth of outcomes which may be measured in treatment research reflect the equally broad range of stakeholders with a vested interest in the development of effective interventions. Stakeholders may include consumers, such as people with disabilities, their carers, family, and friends. Stakeholders may also be people involved in service delivery, such as clinicians and their managers. Additionally, policy makers and funders have their own stake in the development of effective health treatments. Each of these different stakeholder groups has unique priorities, perspectives, and motivations. As Long, Dixon, Hall, Carr-Hill, and Sheldon (1993) state, "…what actually gets measured will largely depend on who wants the data and for what purpose" (p. 199). It is this very diversity of opinion and perspective however, which may help to improve the quality, relevancy, and translation of research findings.

2.3.1 Incorporating Stakeholder Perspectives in Outcome Measurement

A growing number of studies examining research outcomes have sought the perspectives of multiple stakeholder groups. This approach has been pioneered by the OMERACT (Outcome Measures for Rheumatology Clinical Trials) initiative and increasingly is being adopted in a range of other health fields. Table 2-1 provides an overview of studies examining research outcomes which incorporate the perspectives of multiple stakeholder groups. These studies have used a variety of methods including focus groups, meetings, surveys, nominal groups, and Delphi exercises to capture the views of a broad range of stakeholders. Stakeholder groups most commonly comprise consumers (patients and caregivers) and clinical experts; however also extend to pharmaceutical and regulatory representatives, support group representatives, and policy makers.

Table 2-1

Consensus Methods and Stakeholder Involvement in Selected Core Outcome Projects

Health Condition	Reference	Method(s)	Stakeholder Groups
Asthma	Sinha, Gallagher, Williamson, and Smyth (2012)	Delphi process (questionnaire)	Consumers (patients) Consumers (caregivers) Clinical experts
Bipolar disorder	Carlson et al. (2003)	Semi structured discussion (conference meeting)	Consumers (caregivers) Clinical experts Researchers Pharmaceutical industry representatives Governmental agencies
Chronic pain	Turk et al. (2008)	Survey Focus group	Consumers (patients)
Cystic fibrosis	European Medicines Agency. (2012)	Semi structured discussion	Consumers (patients) Clinical experts Regulatory agency representatives Pharmaceutical industry representatives
Degenerative ataxias	Serrano-Aguilar et al. (2009)	e-Delphi process	Consumers (patients)
Eczema	Schmitt et al. (2012)	Consensus meeting	Consumers (patients); Clinical experts; Pharmaceutical industry representatives Methodologists

Health Condition	Reference	Method(s)	Stakeholder Groups
	Schmitt, Langan, Stamm, Williams, and Harmonizing Outcome Measurements in Eczema Delphi (2011)	e-Delphi process	Consumers (patients); Consumers (caregivers) Clinical experts Regulatory agency representatives Journal editors
	Schmitt, Langan, and Williams (2007)	Survey	Consumers (patients) Clinical experts
Fibromyalgia	Arnold et al. (2008) Mease et al. (2008)	Focus group	Consumers (patients)
	Mease et al. (2008)	Delphi process (questionnaire)	Consumers (patients) Clinical experts
Genetic disorders	McAllister, Dunn, and Todd (2011)	Focus group Interview	Consumers (patients) Clinical experts Patient/ support group representatives Service commissioners
	McAllister et al. (2008)	Focus group(s) Interview	Consumers (patients) Clinical experts Patient/ support group representatives

Health Condition	Reference	Method(s)	Stakeholder Groups
	Payne et al. (2007)	Delphi process	Consumers (patients) Clinical experts Patient/ support group representatives
	McAllister et al. (2007)	Focus group	Consumers (patients); Clinical experts Patient/ support group representatives
Guillain-Barre syndrome	Khan, Amatya, and Ng (2010)	Interview	Consumers (patients)
Low back pain	Mullis, Barber, Lewis, and Hay (2007)	Survey	Consumers (patients)
Maternity care	Devane, Begley, Clarke, Horey, and Oboyle (2007)	e-Delphi process	Consumers (patients) Clinical experts Researchers Policy makers Service providers
Multiple sclerosis (MS)	Khan, McPhail, Brand, Turner-Stokes, and Kilpatrick (2006)	Survey Interview	Consumers (patients) Consumers (caregivers) Clinical experts
Rheumatoid arthritis	Sanderson et al. (2012)	Interview	Consumers (patients)
	Sanderson, Morris, Calnan, Richards, and Hewlett (2010a, 2010c)	Interview	Consumers (patients)

Health Condition	Reference	Method(s)	Stakeholder Groups
	Sanderson, Morris, Calnan, Richards, and Hewlett (2010c)	Interview	Consumers (patients)
	Hewlett et al. (2005)	Survey	Consumers (patients)
	Kirwan et al. (2003)	Semi structured discussion (conference)	Consumers (patients)
	Carr et al. (2003)	Focus group	Consumers (patients)
Vitiligo	Eleftheriadou, Thomas, Whitton, Batchelor, and Ravenscroft (2012)	Survey	Consumers (patients) Clinical experts

The need to include the perspectives of consumers in research is increasingly highlighted in the literature. The rationale is two-fold, (1) consumers have a right to have a voice in research that concerns them and (2) the unique perspectives of consumers may increase the effectiveness of research, policy, and health care (Boote, Telford, & Cooper, 2002). In accordance with the United Nations Convention on the Rights of Persons with Disabilities, people who live with disability have a right to full participation and inclusion in society (UN General Assembly, 2006). The Australian National Disability Research and Development Agenda (Disability Policy and Research Working Group, 2011) states that this right extends to research and as such, research should be based upon, "…the premise that the lived experience of people with disability should influence the development, design, conduct, analysis, dissemination and application of research and evaluation" (p. 14). This is particularly relevant to people with aphasia, who are often excluded from research on the very basis of their communication disability (Dalemans, Wade, van den Heuvel, & de Witte, 2009). In addition to the fundamental right of people with disability to have their voices heard in the research that concerns them, there is also evidence that consumer perspectives may differ from those of other stakeholders and that their inclusion may therefore increase the depth and relevancy of research findings (Kirwan et al., 2003; Sanderson, Morris, Calnan, Richards, & Hewlett, 2010b; Sinha, Gallagher, Williamson, & Smyth, 2012; Williamson et al., 2012).

2.3.2 Consumer Perspectives on Outcomes

Research in a variety of health fields has found that consumers prioritise outcomes of importance differently to other stakeholders and identify novel outcomes, previously unincorporated in treatment trials. In the field of rheumatology for example, Carr et al. (2003) examined the treatment outcomes important to people with rheumatoid arthritis through a series of focus groups. In this study, participants identified traditionally recognised outcomes relating to pain and disability as important, but also raised new outcomes, such as fatigue and a general feeling of wellness, for which outcome measures did not exist at that time. Sanderson, Morris, Calnan, Richards, and Hewlett (2010c) investigated the outcomes of pharmacological treatments that were important to people with rheumatoid arthritis. Again, whilst patients identified commonly accepted outcomes relating to pain, function, and overall well-being, they also generated a further 60 outcomes that they considered to be important, many of which were not included in commonly used COSs. The uniqueness of the consumer perspective was also noted by Sinha et al. (2012) who used a two-round Delphi exercise to identify and rank outcomes of importance in the field of childhood asthma. The authors identified outcomes considered important by both clinicians and parents and young people. Whilst parents and clinicians generally agreed on the outcomes that were most important, their perspectives differed with regards to long-term treatment outcomes. Parents were noted to score long-term outcomes more highly than clinicians, reflecting parental concerns regarding the effects of treatments on children later in life. This result suggests that the prioritisation of outcomes may differ between different stakeholder groups. Consumers have also identified outcomes and health issues of importance that were previously un-researched in their respective fields. Serrano-Aguilar et al. (2009) conducted an e-Delphi exercise to identify and gain consensus on the health problems considered important by people with degenerative ataxias. This study uncovered a range of important health issues for people with degenerative ataxias (such as activities of daily living, social relationships, disease acceptance, and quality of life), that previously had not been investigated in the field.

These studies from a variety of health disciplines demonstrate that stakeholder perspectives on outcomes of importance may differ. In particular, consumers have been shown to contribute unique and novel insights to research. Broad stakeholder involvement is essential if research is to capture meaningful and relevant outcomes.

2.3.3 Cultural Perspectives

If research results are to be applied globally, it is necessary to give consideration to the differences in perspective which may exist across cultures and populations. International collaboration is crucial to such an endeavour. Article 32 of the United Nation's Convention on the rights of persons with disabilities (UN General Assembly, 2006) recognises the importance of international cooperation in ensuring the rights and freedoms of people with disability. The convention mandates that appropriate and effective measures should be taken to, "facilitate cooperation in research and access to scientific and technical knowledge" (UN General Assembly, 2006, Article 32(1c)). The WHO's World Report on Disability echoes this sentiment, citing benefits of international collaboration which include the sharing of good practices and learning and research opportunities (World Health Organization, 2011). Comparing and combining data from multiple international locations can produce stronger interpretations of research results and more definitive evidence for the effectiveness of interventions (World Health Organization, 2011). If research is to present global solutions to issues, it is essential that the impact of cultural background on perspective is considered. Sanderson et al. (2012) explored whether the outcomes considered important by people with rheumatoid arthritis differed between people of Punjabi and white British origin in the United Kingdom. In this study, women of Punjabi origin, identified 74 treatment outcomes; including 21 outcomes previously unidentified by white British patients. For Punjabi women, outcomes relating to the social impact of rheumatoid arthritis (e.g. improved ability to carry out family duties) were identified as new important outcomes. The authors raised the need to consider the cultural validity of core outcomes, noting that if patient samples are not culturally diverse they may not be globally valid. This finding has important implications for aphasia rehabilitation, suggesting that any agenda for the improvement of research outcome measurement must incorporate a range of not only stakeholder, but also cultural perspectives.

2.3.4 Selecting Outcome Instruments for Treatment Research

Outcome instruments are used to, "…target the areas addressed by the intervention to illustrate and provide evidence of change" (Xiong, Bunning, Horton, & Hartley, 2011, p. 2287). There are a number of desirable properties that should be present in outcome instruments. Outcome instruments should be valid (relevant and able to measure the desired outcome), reliable (consistent), and sensitive (able to detect change) (Greenhalgh, Long, Brettle, & Grant, 1998). In addition, they should be feasible to use, giving consideration to factors such as length and participant acceptability and burden (Wade, 2003). Poorly chosen outcome instruments may be unable to capture research results (Coster, 2013). Conversely, outcome instruments with sound measurement properties can detect smaller treatment effects and draw stronger conclusions; ultimately resulting in superior result interpretation (Mokkink et al., 2009). If an outcome instrument is to authentically capture treatment results it must not only be psychometrically robust, but must also measure relevant concepts. Information regarding the content of outcome instruments, at an item level, is therefore necessary to ensure that an instrument is appropriate to measure a particular construct (Schepers, Ketelaar, Igl, Visser-Meily, & Lindeman, 2007).

Outcome instruments are often associated with a particular domain of the WHO ICF (World Health Organization, 2001), for example, an outcome instrument may be regarded as an impairment measure or a participation measure. Studies have used the ICF to examine the content of outcome instruments. For example, Schepers et al. (2007) linked the content of a selection of Activity and Participation outcome instruments used in stroke rehabilitation to the ICF. Despite specifically choosing outcome instruments with an Activity and Participation focus, 27% of the instrument constructs linked to ICF body function domain. This finding highlights the importance of giving careful consideration to the content of outcome instruments at an item level when selecting a tool for research.

A number of studies have also found heterogeneity in the content of instruments which measure the same ICF domain. For example, Noonan et al. (2009) examined the content of participation instruments using the ICF as a reference. In the eight instruments assessed, 1351 meaningful ICF concepts were identified. The instruments were found to contain concepts from between six and eight of the nine Activity and Participation ICF domains, however there were important differences in the sub-categories of the domains that were represented. While all of the outcome instruments included concepts from the domains of “Domestic life”, “Interpersonal interactions and relationships”, “Major life areas” and “Community, social and civic life”, other domains such as “Communication”, “Self-care” and aspects of “Mobility” were not consistently represented. Variations in the content of outcome instruments illustrate the different ways in which the same domain or construct can be defined. There is a need for in-depth understanding of the content of outcome instruments in order to select the most appropriate tool for use in research.

2.4 State of Outcome Measurement in Aphasia Treatment Research

2.4.1 Ultimate Outcome

In order to determine whether aphasia treatments are effective, the primary outcome sought must be established. Is the primary desired outcome of aphasia rehabilitation the remediation of impairment, improvement in function, life participation, quality of life, or something more process-driven, such as ensuring value for money, or maximising occasions of service? Wade (2003) examined this question in his analysis of outcomes measures for clinical rehabilitation trials. In this article, the author discussed that rehabilitation research is inherently different to other clinical trials, as multiple outcomes are often of interest, and the focus of treatment is usually at a behaviour or activity level. This is in contrast to some trials in the field of medicine for example, which tend to focus on ‘body function’ or impairment level treatments.

The primary aim of aphasia rehabilitation has not been defined through a consensus process. Despite this, there is growing agreement that improvements in functional communication (measured through improvements in communication at the Activity or Participation level of the ICF) form the primary aim of aphasia rehabilitation. Brady and associates (2012) expressed this sentiment in their recent systematic review of speech and language therapy for aphasia concluding that, “The primary outcome measure chosen to indicate the effectiveness of an intervention that aims to improve communicative ability must reflect the ability to communicate in real world settings, that is functional communication”(Brady et al., 2012, p. 5). However, in seeming contrast to the suggestion that functional communication is the best indicator of communicative success, a review of the literature shows a preponderance of impairment level outcome measures in aphasia treatment trials. Xiong et al. (2011) examined the outcome measures used in randomised control trials (RCTs) relating to adults with communication disorders (including aphasia). The authors explored the key concepts examined by the outcome measures used in these trials by linking test items to the ICF (World Health Organization, 2001). Of the 24 RCTs examined, 15 related to interventions for post-stroke aphasia. Of these outcome measures most were found to relate to the body function domain of the ICF. As Xiong et al. (2011) suggest, on this basis it could be surmised that impairment level outcomes, rather than Activity or Participation outcomes, form the primary aim of aphasia rehabilitation interventions. These findings suggest a mismatch between what is often conceptualised as the primary aim of aphasia rehabilitation - functional communication, and the outcome measures used to illustrate the results of aphasia treatments in research that focus on impairment. There is a need for consensus on the level or levels of functioning or disability, which are most appropriate to assess improvement in language and communication ability.

2.4.2 Stakeholder Important Outcomes

There is little research exploring the desired outcomes of stakeholders in aphasia rehabilitation. The terms ‘desired outcome’ and ‘goal’ however are often conceptualised in the same way. Hersh et al. (2012) found that speech language pathologists (SLPs) consider the notion of a ‘goal’ as both concrete steps towards a greater goal or end-point and as desired endpoints themselves. That is, goals are often thought of as both the journey and the destination. Wade (2009) also describes the dual nature of rehabilitation goals, discussing them as both intended future states and intended consequences of rehabilitation. Given the limited research exploring stakeholder outcomes in aphasia rehabilitation, insights may be gained by examining research into stakeholder goals.

Worrall et al. (2011) examined the goals of people with aphasia in Australia in reference to the ICF. A broad range of goals were identified that could be linked to all domains of the ICF. Major goal categories included: return to pre-stroke life; communicating opinions; obtaining more information about aphasia, stroke, and services; receiving more therapy; increased independence and respect; participation in altruistic activities; improvements in physical health; and engagement in social, leisure, and work activities. The authors found that the majority of these goals linked to Activity and Participation domains of the ICF, confirming the importance of everyday life activities to people with aphasia.

The goals and perspectives of SLPs have also been examined. Verna, Davidson, and Rose (2009) conducted a survey of Australian SLPs. In this study, respondents most frequently indicated that they considered effectiveness of intervention to be measured by a change in functional communication ability. Hersh et al. (2012) conducted in-depth interviews with Australian SLPs to investigate how they conceptualised the nature of goals in aphasia rehabilitation. In this study, participants described goals both in terms of impairment and functional goals. The authors noted that functional goals were often communicated as being more client-driven. Hersh et al. (2012) described that goal setting was also impacted by the stage of the care continuum in which SLPs worked. Goals in the acute sector were more likely to be impairment-based, reflecting the medical model of intervention, whereas goals in rehabilitation and outpatient settings were more likely to be functional.

Studies have also shown differences in consumer and clinician goal setting. Rohde, Townley-O'Neill, Trendall, Worrall, and Cornwell (2012) compared client and therapist goals for people with aphasia. In this study, SLPs were found to focus on impairment-based communication outcomes e.g., increasing expressive language abilities, while people with aphasia expressed a desire to work on goals pertaining to previously valued activities e.g., hobbies.

Studies have also explored the goals of family members of people with aphasia and the effects of third party disability on family members as a result of aphasia. Third party disability refers to disability experienced by significant others (e.g. family, friends and caregivers) as a consequence of a family members' health condition (World Health Organization, 2001). Howe et al. (2012) investigated the rehabilitation goals that family members of individuals with aphasia have for themselves using in-depth semi-structured interviews. Family members expressed goals for themselves which included: to be involved in rehabilitation; to be provided with hope and positivity; to be able to communicate and maintain their relationship with the person with aphasia; to be given information; to be given support; to look after their own well-being; and to be able to cope with new responsibilities. Investigations into third party disability have also found that aphasia may have a broad range of effects on the family members of people with aphasia. Systematic reviews of literature regarding third party disability in aphasia reveal that the family members of people with aphasia experience both positive and negative outcomes as a result of aphasia and that these outcomes can be linked to the Body Functions and Activity and Participation domains of the ICF (Grawburg, Howe, Worrall, & Scarinci, 2012; Grawburg, Howe, Worrall, & Scarinci, 2013).

Stakeholders in aphasia rehabilitation have a variety of goals and experience varied outcomes as a result of aphasia. Research which specifically examines the desired rehabilitation outcomes of stakeholders is required to inform and guide research and clinical practice.

2.4.3 Outcome Instruments in Aphasia Treatment Research

Numerous outcome instruments are used in aphasia treatment research. The Cochrane Collaboration's recent review of speech and language therapy for aphasia following stroke (Brady et al., 2012) provides a prime example of the diffuse array of outcome measures used in aphasia treatment research. In this review, RCTs designed to improve language or communication in aphasia were examined. In the 39 trials included in the review, 42 different outcome instruments were employed (refer to table 2-2). In addition to this number, a range of informal, individualised and insufficiently described assessments were used to measure the effects of treatment. The authors make note of the wide range of outcome instruments across trials and highlight the need for improvements in the quality of speech language therapy trials; full and unbiased reporting and the use of standardised outcome instruments is recommended (Brady et al., 2012). Cherney, Patterson, Raymer, Frymark, and Schooling (2008) encountered similar issues in their systematic review examining evidence for intensity of treatment and constraint induced language therapy in people with stroke-induced aphasia. The authors reported difficulties comparing results across studies due to the variability in the outcome measures used. Further, where Activity or Participation level measures were used they were typically found to be individualised with information on validity and reliability lacking. The variability evident in the outcome instruments used in aphasia rehabilitation research may be attributed to an increasing number of available instruments in the absence of synthesised information regarding their psychometric properties and content. At a global level, the need for assessments to suit specific language and cultural requirements may also increase variability in outcome instruments used and act as a further impediment to comparisons between instruments. Greater uniformity in the outcome instruments used in research is required to facilitate the combination and comparison of research results and the meta-analysis of research outcomes.

Table 2-2

Outcome Instruments in Included Studies in the Cochrane Review of Speech-Language Therapy for Aphasia (Brady, Kelly, Godwin, & Enderby, 2012)

Outcome Instrument	Number of Studies using Instrument
Porch Index of Communicative Abilities (PICA) (Porch, 1967, 1971, 1981)	13
Token Test (shortened and standard versions) (TT) (DeRenzi & Vignolo, 1962) (Spreen & Benton, 1969) (Lincoln, 1979)	10
Communication Abilities of Daily Living (CADL) (Holland, 1980) (Holland, Frattali, & Fromm, 1998)	7
Western Aphasia Battery (WAB) (Kertesz, 1982a)	5
Western Aphasia Battery Aphasia Quotient (WABAQ) (Kertesz, 1982a)	5
Boston Diagnostic Aphasia Examination (BDAE) (Goodglass & Kaplan, 1972) (Goodglass & Kaplan, 1983)	4
Object Naming Test (ONT) (Oldfield & Wingfield, 1965)	4
Word Fluency (Borkowski, Benton, & Spreen, 1967)	4
Aachen Aphasia Test (AAT) (Huber, Poeck, & Willmes, 1984b)	3
Aphasia Battery in Chinese (ABC) (Reference unavailable)	3
Amsterdam-Nijmegen Everyday Language Test-A (subscale) (Blomert, Kean, Koster, & Schokker, 1994a)	3
Auditory Comprehension Test for Sentences (ACTS) (Shewan, 1979a)	3
Chinese Rehabilitation Research Centre Aphasia Examination (CRRCAE); Reference unavailable	3
Functional Communication Profile (FCP) (Sarno, 1969)	3
General Health Questionnaire (GHQ) (Goldberg, 1972)	3
Minnesota Test for Differential Diagnosis of Aphasia (MTDDA) (Schuell, 1965b)	3
Psycholinguistic Assessments of Language Processing in Aphasia (PALPA) (Kay, Lesser, & Coltheart, 1992)	3
Reading Comprehension Battery for Aphasia (RCBA) (LaPointe & Horner, 1979a)	3
Chinese Functional Communication Profile (CFCP); Reference unavailable	2
Communicative Effectiveness Index (CETI) (Lomas et al., 1989c)	2
Discourse Analysis (words per minute; content information units per minute) (DA) (Nicholas & Brookshire, 1995)	2
Semantic Association Test (SAT) (Visch-Brink, Denes, & Stronks, 1996)	2
Affect Balance Scale (ABS) (Bradburn, 1969)	1

Outcome Instrument	Number of Studies using Instrument
Amsterdam-Nijmegen Everyday Language Test (ANELT) (Blomert et al., 1994a)	1
Boston Naming Test (BNT) (Kaplan, Goodglass, & Weintraub, 1983a)	1
Caplan and Hanna Sentence Production Test (CHSPT) (Caplan & Hanna, 1998)	1
Carer Communication Outcome After Stroke Scale (Carer COAST) (Long, Hesketh, & Bowen, 2009)	1
Communicative Activity Log (CAL) (Pulvermuller et al., 2001)	1
Communication Outcome After Stroke Scale (COAST) (Long, Hesketh, Paszek, Booth, & Bowen, 2008b)	1
Communicative Readiness and Use Scale and Psychological Wellbeing Index; (Lyon et al., 1997)	1
Conversational Rating Scale (CRS) (Wertz et al., 1981)	1
EQ-5D (Brooks, 1996)	1
Functional-Expression scale (FE Scale) (Prins, 1980)	1
Aphasia Quotient (Castro-Caldas, 1979)	
Multiple Adjective Affect Check-List (MAACL) (Zuckerman & Lubin, 1965)	1
National Institutes of Health Stroke Scale (NIHSS) (Brott et al., 1989)	1
Nottingham Health Profile (NHP) (Ebrahim, Barer, & Nouri, 1986)	1
Norsk Grunntest for Afasi (NGA) (Reinvang, 1985a)	1
Peabody Picture Vocabulary Test (PPVT) (Dunn, 1959)	1
Philadelphia Comprehension Battery (PCB) (Saffran, Schwartz, Linebarger, Martin, & Bochetto, 1988)	1
Picture Description with Structured Modeling (PDSM) (Fink et al., 1994)	1
Therapy Outcome Measures (TOMs) (Enderby, John, & Petheram, 2007)	1

2.4.4 Current Work in Aphasia Research Outcome Measurement

Growing acknowledgement of the central role of outcomes in the interpretation of research results has prompted calls for new approaches to research outcome measurement. The World Report on Disability (World Health Organization, 2011) highlights an urgent need for more robust and comparable data collection in the field of disability, calling for the development of disability research methodologies which are tested cross-culturally and allow international comparison of data. Ali and associates (2013) also recently issued a call for consistent data collection across stroke rehabilitation trials. The authors drew attention to the multitude of assessment tools in use, which impede the combination and comparison of data across trials. The need to improve the quality of aphasia research has also been highlighted by the recent development of the European Co-operation in Science and Technology (EU COST) Collaboration of Aphasia Trialists (http://www.cost.eu/domains_actions/isch/Actions/IS1208). This collaboration seeks to enhance knowledge, skills, and methodology relating to aphasia research. In the collaboration's memorandum of understanding, the authors acknowledge the need for increased consistency in aphasia outcome measurement to facilitate international, collaborative research (European Cooperation in the field of Scientific and Technical Research, 2012). The Cochrane Collaboration, in their Handbook for Systematic Reviews of Interventions, also recognise the benefit of standardisation in outcome measurement noting that, "several clinical areas are developing agreed core sets of outcome measures for use in randomized trials, and consideration of these in defining the detail of measurement of outcomes selected for the review is likely to be helpful" (Higgins & Green, 2011, s5.4.1). There is consensus in areas of disability, stroke, and aphasia rehabilitation that there is a need to improve outcome measurement in health research through standardisation.

2.5 Core Outcome Sets

Heterogeneity in outcome measurement is not unique to aphasia treatment research. Other health disciplines have sought to address this issue through the development of COSs for use in research. A COS is an agreed standardised set of outcomes for use in clinical trials of a particular condition. Once agreed upon, COSs are intended to be used routinely by researchers. The use of a COS does not preclude the use of additional outcome measures, but rather represents the minimum outcomes that should be collected and reported (Williamson et al., 2012) (Refer to figure 2-1 for an overview of the COS development process). The development of COSs is championed by the Core Outcome Measures in Effectiveness Trials (COMET) initiative. The COMET initiative seeks to connect people interested in the development of COSs. The COMET website houses a database (see http://www.comet-initiative.org) which currently contains 296 references of planned, ongoing, and completed work on COSs. COSs have been developed or are being developed in over 50 fields including chronic pain (Dworkin et al., 2005; McGrath et al., 2008; Turk et al., 2008), systemic sclerosis (Khanna, 2008; Khanna et al., 2008), childhood asthma (Sinha et al., 2012) and Eczema (Schmitt, Langan, Stamm, Williams, & Harmonizing Outcome Measurements in Eczema delphi panel, 2011). The development of COSs is also increasing in rehabilitation and neurology fields. For example, COS development is underway for trials of hip fracture, rehabilitation following critical illness, neurodegenerative diseases including Alzheimer's disease and Parkinson's disease, visual impairment after stroke, chronic pain after total knee replacement, reconstructive breast surgery, and Autistic spectrum disorder (MeASURe).

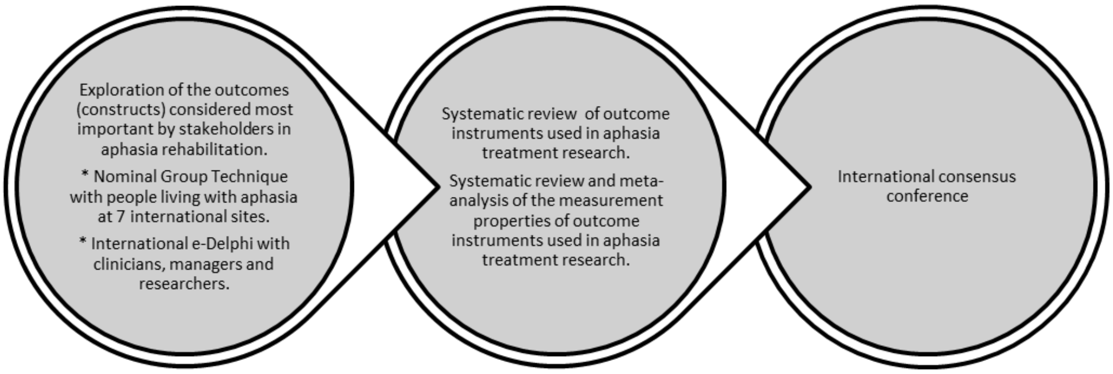

Figure 2-1. Improving Research Outcome Measurement in Aphasia (ROMA) Overview

2.5.1 Benefits of COS Development

There are many reported benefits to the use of COSs. Primarily, the standardisation of outcomes may facilitate the comparison and combination of research data across studies while also allowing researchers to explore study specific outcomes (Clarke, 2007; Williamson et al., 2012). An additional benefit of COS development is the use of consensus-based decision making and multiple stakeholder engagement. A variety of techniques have been used to reach consensus on outcomes of importance including Delphi studies, nominal groups techniques, focus groups, individual interviews, surveys, and expert panels (refer to table 2-1). A growing number of studies have also incorporated the perspectives of a wide range of stakeholders, with particular emphasis on consumer involvement (refer to table 2-1). These processes allow a broad range of stakeholders to achieve agreement on outcomes of importance, increasing the relevancy and meaningfulness of research. COSs have also been identified as a means of reducing missing outcome data in effectiveness trials and improving the quality of systematic reviews. Kirkham et al. (2013) recently investigated missing patient data in Cochrane systematic reviews, and surveyed the co-ordinating editors of Cochrane Review Groups (CRGs) regarding the standardisation of outcomes. Of the co-ordinating editors, 73% indicated that a COS for effectiveness trials should be used routinely in

Summary of Findings tables. Reasons for adopting COSs in effectiveness trials included: measuring and reporting relevant outcomes, comparability of outcomes, better interpretation of outcomes, standardisation of outcomes, and reduction in risk of bias (Kirkham et al., 2013).

2.5.2 Challenges of COS Development

Challenges associated with developing COSs have also been identified. Kirkham et al. (2013) investigated the opinions of the Cochrane Review co-ordinating editors in relation to perceived challenges associated with standardising outcomes in their particular Cochrane Review Group (CRG). The reported challenges primarily related to the process of developing COSs and uptake amongst researchers (Kirkham et al., 2013). A further challenge, perhaps most relevant to the field of aphasia rehabilitation, relates to scope. Specifically it was noted that the diversity of interventions within certain fields may present a barrier to the development of a single COS within that field. In these cases it was suggested that further refinement through the development of multiple COSs may be necessary to cater for distinct intervention approaches (Kirkham et al., 2013). This may be required in the field of aphasia rehabilitation to cater for the wide range of interventions which are utilised.

2.6 An Agenda for Change

It is proposed that a COS for aphasia rehabilitation research could be developed in three stages. The first stage would use consensus based processes to reach international agreement on outcomes of importance and the ultimate desired outcome of aphasia rehabilitation, taking into account a wide range of stakeholder and cultural perspectives. The second stage would comprise a systematic review of the outcomes instruments currently used in aphasia treatment research, including analysis of content and psychometric properties. Final consensus on the outcome instruments to be included in the COS would be facilitated through an international consensus conference.

2.7 Summary and Conclusions

A review of literature confirms heterogeneity in the way in which outcome measurement is performed in aphasia treatment research. Consensus on what constitutes important outcomes in aphasia rehabilitation is needed to ensure that research is relevant and accurately interpreted. It is proposed that the standardisation of aphasia research outcome measures through development of a COS would reduce the current variability in reported outcomes and improve the quality of outcome measurement. This would facilitate the comparison of research outcomes through meta-analyses such as systematic reviews (Clarke, 2007) and facilitate the combination of research data across studies. The incorporation of core outcomes in research studies may also deter the selective reporting of results (Chan et al., 2013) and encourage greater transparency in research reporting. Involving a broad range of stakeholders throughout the process of developing the COS would ensure that the outcomes that are measured and reported in aphasia research are meaningful to all key stakeholders (Williamson et al., 2012). Above all, the standardisation of aphasia research outcome measures would facilitate greater rigour in the evaluation of aphasia treatments and improve the quality of data available about treatment efficacy and effectiveness.

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Chapter 3: Which Outcomes are Most Important to People with Aphasia and Their Families? An International Nominal Group Technique Study Framed Within the ICF

This chapter reports the findings of an international nominal group technique study to identify important treatment outcomes from the perspective of people with aphasia and their families.

This chapter has been published in the peer-reviewed journal, *Disability and Rehabilitation*: Wallace, S. J., Worrall, L., Rose, T., Le Dorze, G., Cruice, M., Isaksen, J., Pak Hin Kong, A., Simmons-Mackie, N., Scarinci, N., & Alary Gauvreau, C. (2016). Which outcomes are most important to people with aphasia and their families? An international nominal group technique study framed within the ICF. *Disability and Rehabilitation,* Advance online publication. doi:10.1080/09638288.2016.1194899.

The content included in this chapter is identical to the submitted manuscript; however, the formatting has been modified to match the style of this thesis.

3.1 Abstract

Purpose: To identify important treatment outcomes from the perspective of people with aphasia and their families using the ICF as a frame of reference.

Methods: The nominal group technique was used with people with aphasia and their family members in seven countries to identify and rank important treatment outcomes from aphasia rehabilitation. People with aphasia identified outcomes for themselves; and family members identified outcomes for themselves and for the person with aphasia. Outcomes were analysed using qualitative content analysis and ICF linking.

Results: A total of 39 people with aphasia and 29 family members participated in one of 16 nominal groups. Inductive qualitative content analysis revealed the following six themes: (1) Improved communication; (2) Increased life participation; (3) Changed attitudes through increased awareness and education about aphasia; (4) Recovered normality; (5) Improved physical and emotional well-being; and (6) Improved health (and support) services. Prioritised outcomes for both participant groups linked to all ICF components; primarily Activity/Participation (39%) and Body Functions (36%) for people with aphasia, and Activity/Participation (49%) and Environmental Factors (28%) for family members. Outcomes prioritised by family members relating to the person with aphasia, primarily linked to Body Functions (60%).

Conclusions: People with aphasia and their families identified treatment outcomes which span all components of the ICF. This has implications for research outcome measurement and clinical service provision which currently focuses on the measurement of Body Function outcomes. The wide range of desired outcomes generated by both people with aphasia and their family members, highlights the importance of collaborative goal setting within a family-centred approach to rehabilitation. These results will be combined with other stakeholder perspectives to establish a core outcome set for aphasia treatment research.

MeSH Keywords: Aphasia, Patient-Relevant Outcome, Treatment Outcome, ICF, Patient Involvement, Family Caregivers.

3.2 Introduction

Achieving outcomes that are important to consumers is a key factor in maximising the value of healthcare (Porter & Lee, 2013). This conceptualisation of value reflects a broader shift in health care towards person-centred services which seek to meet individual needs in holistic ways (World Health Organization., 2007). In aphasia rehabilitation, the value of measuring consumer-important outcomes has steadily gained momentum in the realm of clinical outcome measurement, evident in the development of the person-centred, aphasia-specific framework Living with Aphasia: Framework for Outcome Measurement (A-FROM) (Kagan et al., 2008). Underpinning A-FROM are values which affirm the integral role of consumers in both determining the relevancy of outcomes and in judging when meaningful life change has occurred. In research, the outcomes selected to demonstrate the effects of an intervention must reflect the research question; they must also be able to capture the effects of a treatment in a manner which is meaningful to end-users. If research is to translate to practice — informing individual, clinical, and policy decision making; outcomes must communicate treatment effectiveness in terms which are meaningful to consumers, clinicians, and policy makers. Currently, there is a lack of evidence to inform the selection of stakeholder-important aphasia treatment outcomes and a lack of consensus amongst aphasia researchers about what constitutes a meaningful treatment outcome.

The Cochrane Collaboration have conducted systematic reviews of studies assessing the effectiveness of speech and language therapy (Brady, Kelly, Godwin, & Enderby, 2012) and transcranial direct current stimulation (tDCS) (Elsner, Kugler, Pohl, & Mehrholz, 2015) for the improvement of aphasia following stroke. While both reviews designated functional communication (i.e., communication in real-life situations) as the primary review outcome, none of the studies included in the review of tDCS (n=12), and less than half (n=23 of 51, 45%) of the studies included in the review of speech and language therapy measured this construct. Further, in randomised control trials of aphasia treatments, impairment or Body Function outcomes have been more often measured, with less emphasis on broader constructs such as quality of life, functional communication, or psychosocial outcomes (Brady et al., 2012; Elsner et al., 2015; Xiong, Bunning, Horton, & Hartley, 2011). The incongruence between the primary outcomes selected in systematic reviews and those measured in individual studies highlights a lack of consensus within the research community regarding important treatment outcomes in aphasia rehabilitation. Core outcome set (COS) development is one approach being used across a variety of health fields to gain consensus on research outcomes.

A COS is an agreed standardised set of outcomes and outcome measures which should be measured in all research trials of a given health condition (Williamson & Clarke, 2012). COS development seeks the perspectives of multiple stakeholder groups and uses consensus processes to reach agreement on a minimum set of outcomes (Clarke, 2007; Williamson et al., 2012) (see Core Outcome Measures in Effectiveness Trials Initiative (http://www.comet-initiative.org/). Core outcomes do not restrict the measurement of study specific outcomes, but rather enable efficient use of research findings beyond the individual study, in for example systematic reviews (Brady et al., 2014). A key benefit of COSs is increased compatibility of data across studies, enabling data pooling and data comparisons; standard elements in outcome measurement may also deter the selective reporting of outcomes in research. Furthermore, the use of COSs is increasingly encouraged by funding bodies (European Commission; 2016). In COS development, inclusion of the consumer perspective is deemed particularly important to ensure that relevant and meaningful outcomes are represented (Williamson et al., 2012).

Seeking the perspectives of consumers regarding important research outcomes is both ethical and effective (Boote, Telford, & Cooper, 2002). Foremost, it is right to include consumers in research which concerns them. This moral imperative is reflected in The United Nations’ Convention on the Rights of Persons with Disabilities (UN General Assembly, 2006) and the World Health Organization World Report on Disability (World Health Organization., 2011). People who live with disability have a right to full participation and inclusion in society, including the right to contribute to services, policy, and research. Furthermore, consumer participation in health care and research is no longer merely an ideal; it is increasingly policy (Department of Health., 2010; National Health and Medical Research Council and The Consumers Health Forum of Australia Inc., 2002, 2005), as well as a recommendation of funding bodies (National Institute for Health Research., 2015; O'Donnell & Entwistle, 2004) and reporting standards (Chan et al., 2013; Higgins & Green, 2011). Consumer involvement in the selection of research outcomes is also effective. The involvement of patients and their family members in COS development has been found to have a significant impact on research (de Wit, Abma, Koelewijn-van Loon, Collins, & Kirwan, 2013). Patients have contributed to research agendas by identifying novel outcomes of importance (Arnold et al., 2008; Carr et al., 2003; Kirwan et al., 2003; Mease et al., 2008;

Sanderson et al., 2012; Sanderson, Morris, Calnan, Richards, & Hewlett, 2010; Serrano-Aguilar et al., 2009), have provided a unique perspective in the prioritisation of outcomes (Bartlett et al., 2012; Morris et al., 2014; Sinha, Gallagher, Williamson, & Smyth, 2012), and have contributed to the development of patient-reported outcome measures (Kirwan et al., 2011; Morris et al., 2014). Additional reported benefits of consumer involvement include improved communication between researchers and patients, mutual empowerment, and improvements in research culture and stakeholder attitudes (de Wit, Abma, Koelewijn-van Loon, Collins, & Kirwan, 2014).

There has been a lack of research investigating the outcomes which are most important to people with aphasia and their families. Existing research examining goal setting and living successfully with aphasia has demonstrated that people living with aphasia (people with aphasia and their families) frame their goals, perspectives, and experiences within the broader context of their lives. Worrall and colleagues (Worrall et al., 2011) examined the goals of people with aphasia in Australia against the framework of the ICF. Participant goals spanned all components of the ICF; however the majority of goals linked to the Activity/Participation component, highlighting the importance of communication in real-life situations for people with aphasia. Brown and colleagues (Brown, Worrall, Davidson, & Howe, 2011) investigated the meaning of living successfully with aphasia from the perspectives of people with aphasia, their family members, and treating speech pathologists. The authors' synthesis of qualitative data from three separate studies found that living successfully with aphasia requires communication to be considered from a holistic point of view. Participation in meaningful activities and relationships, support from family and friends, and communication across these contexts, were all identified as important factors in living successfully with aphasia. Research has also explored the effects of third-party disability (disability experienced by significant others, as a result of a family members' health condition) on family members of people with aphasia, as well as their own goals for rehabilitation. Grawburg and associates (Grawburg, Howe, Worrall, & Scarinci, 2013b) examined third-party disability in aphasia, finding that family members experience widespread negative outcomes which linked to the Body Functions and Activity/Participation components of the ICF. Third-party disability relating to Body Functions linked exclusively to the ICF mental functions chapter, relating predominantly to emotional functions such as anxiety, frustration, stress, guilt, sadness, and loneliness. Negative outcomes relating to Activity/Participation covered a broader range of ICF chapters including general tasks and demands, communication, self-care, domestic life, interpersonal interactions and domestic relationships, major life areas, and community, social and civic life. Family members of people with aphasia have also identified a broad range of goals for themselves relating to participation in rehabilitation, communication, relationships, information and support, well-being, and coping; again demonstrating the broad impacts of aphasia (Howe et al., 2012b). Hence, both people with aphasia and their family members frame their goals, experiences, and perspectives about living with aphasia holistically, within the broader context of their lives. Therefore, there is a need to determine whether people living with aphasia frame desired treatment outcomes with similar scope.

Studies investigating outcomes that are important to consumers are increasingly including an international perspective (Bartlett et al., 2012; Heiligenhaus et al., 2012; Schmitt, Langan, Stamm, Williams, & Harmonizing Outcome Measurements in Eczema Delphi, 2011). Around the world, the lived experience of disability differs under the influence of unique social, economic, and cultural factors (Ginsburg & Rapp, 2013). The need to consider the global validity of outcomes has been highlighted by COS developers (Sanderson et al., 2012) who found different outcomes of importance across cultural groups. The experience of aphasia and resulting communication disability can be expected to vary around the world, being influenced by the conceptualisation of disability, availability, and access to health services and socio-cultural factors. The global validity of research findings may therefore be maximised by sampling international perspectives.

The international applicability of research findings can also be improved through the use of a common metric. In stroke and aphasia research the International Classification of Functioning, Disability and Health (ICF) (World Health Organization., 2001) is widely used as a: framework for describing functioning and disability (including third-party disability) (Cruice, 2008; Grawburg, Howe, Worrall, & Scarinci, 2013a; Howe, Worrall, & Hickson, 2008); means for classifying categories of outcome measures (Salter, Jutai, Teasell, Foley, & Bitensky, 2005; Salter, Jutai, Teasell, Foley, Bitensky, et al., 2005; Salter et al., 2005); classification tool for analysing the content of outcome measures (Brandenburg, Worrall, Rodriguez, & Bagraith, 2015; Xiong et al., 2011); and data linking tool (Grawburg, Howe, Worrall, & Scarinci, 2014; Worrall et al., 2011). Recent research examining the goals of people with aphasia (Worrall et al., 2011) and the outcomes experienced by family members of people with aphasia (Grawburg et al., 2014) have used ICF data linking. Using this method of data analysis, concepts can be coded to the ICF using standard rules (Cieza et al., 2002;

Cieza et al., 2005), allowing a systematic and standardised exploration of concepts which uses a universal language and can be compared across studies.

The current study is part of a program of research known as ROMA (Improving Research Outcome Measurement in Aphasia; (see Wallace, Worrall, Rose, & Le Dorze, 2014)) which aims to develop a COS for aphasia treatment research. Development of a COS is sought through an international consensus conference informed by two phases of research: 1) consensus on stakeholder-important outcomes; and 2) a systematic review of the measurement properties of aphasia outcomes measures. The present study is one of three studies in phase 1. Consensus processes with aphasia researchers (Wallace, Worrall, Rose, & Le Dorze, submitted) and aphasia clinicians and managers (Wallace, Worrall, Rose, & Le Dorze, In press) have been conducted and are reported elsewhere. The current study aimed to identify important outcome domains for people with aphasia and their family members using consensus processes, qualitative analysis, and ICF linking.

3.3 Methods

3.3.1 Study Design

This international study used a multiple methods research design, comprising nominal group ranking, qualitative content analysis, and ICF linking. To maximise the diversity of participants sampled, sites were established in seven countries: Australia, Canada, Hong Kong (China), Denmark, South Africa, the United Kingdom (UK), and the United States of America (USA); representing four of the six world regions as defined by the World Health Organization (World Health Organization., 2014). Overarching ethical approval for this project was obtained from the Behavioural and Social Sciences Ethical Review Committee at The University of Queensland in accordance with the National Health and Medical Research Council's guidelines. Ethical approval was obtained at international sites in accordance with local requirements. Additional approvals were granted by The University of West England, United Kingdom, and the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal (CRIR), Canada.

3.3.2 Participants

Participants were recruited at each site by a local speech pathologist. A total of 39 people with aphasia and 29 family members of people with aphasia participated in the current study. Method of recruitment varied across sites; people with aphasia were recruited through:

research registries, aphasia research centres, rehabilitation centres, and community aphasia groups. Family members were recruited using convenience sampling, with each participant with aphasia invited to nominate a family member to participate in a separate group discussion.

Inclusion criteria for people with aphasia were: (a) aged 18 years or over; (b) diagnosis of aphasia as a result of stroke (presence and severity of aphasia confirmed by a speech pathologist or by diagnostic assessment results); (c) able to participate in the nominal group technique process (as judged by the local speech pathologist); and (d) living in the community. Exclusion criteria were comorbid cognitive, sensory, neurological, and/or mental health impairments (e.g., dementia, severe depression, Parkinson’s disease). People with aphasia of any severity level were eligible for inclusion in this study. Classification of severity was based on the local speech pathologists own assessment records and/or clinical judgement. Severity was broadly categorised as either mild-moderate or severe and was recorded for the purposes of ensuring that people with more severe aphasia were represented in the sample. No inclusion or exclusion criteria were applied to the family member nominated by the person with aphasia. Participant characteristics for both groups are detailed in tables 3-1 and 3-2. In total, nine nominal groups were held with people with aphasia and seven groups with family members. Each group contained between three and six participants.

Table 3-1

Participant Characteristics – People with Aphasia (n=39)

Participant Characteristics	Number of Participants (%)
Age	
Range, 42-86 years; mean ± SD = 64 ± 10.6	
< 70 years	26 (66.7)
≥ 70 years	13 (33.3)
Gender	
Male	27 (69.2)
Female	12 (30.8)
Aphasia severity	
Mild - Moderate	31 (79.5)
Severe	8 (20.5)
Months since onset of aphasia	
Range, 4 - 204 months; mean ± SD = 57.4 ± 47.3	
< 18 months	10 (25.6)
≥ 18 months to < 36 months	5 (12.8)
≥ 36 months	24 (61.5)
Country	
United Kingdom	10 (25.6)
Australia	8 (20.5)
Hong Kong, China	6 (15.4)
United States of America	5 (12.8)
Denmark	4 (10.3)
Canada	3 (7.7)
South Africa	3 (7.7)

Participant Characteristics	Number of Participants (%)
Main language spoken	
English	24 (61.5)
Cantonese	6 (15.4)
Danish	4 (10.3)
French	3 (7.7)
Spanish	1 (2.6)
Zulu	1 (2.6)
Highest level of education completed	
Tertiary	20 (51.3)
Secondary	13 (33.3)
Primary	5 (12.8)
Not reported	1 (2.6)
Employment status	
Not engaged in paid employment	37 (94.9)
Engaged in paid employment	2 (5.1)
Currently receiving speech therapy	
No	23 (59)
Yes	16 (41)

Table 3-2

Participant Characteristics – Family Members (n=29)

Participant Characteristics	Number of Participants (%)
Age	
Range, 17-85 years; mean ± SD = 63.3 ± 14.5	
< 70 years	20 (69)
≥ 70 years	8 (27.6)
Not reported	1 (3.4)
Gender	
Female	23 (79.3)
Male	6 (20.7)
Country	
Australia	7 (24.1)
Hong Kong, China	6 (20.7)
Denmark	5 (17.2)
United States of America	5 (17.2)
Canada	3 (10.3)
South Africa	3 (10.3)
Main language spoken	
English	14 (48.3)
Cantonese	6 (20.7)
Danish	5 (17.2)
French	3 (10.3)
Zulu	1 (3.4)
Highest level of education completed	
Tertiary	13 (44.8)

Participant Characteristics	Number of Participants (%)
Secondary	13 (44.8)
Primary	3 (10.3)
Employment status	
Not engaged in paid employment	22 (75.9)
Engaged in paid employment	7 (24.1)

3.3.3 Informed Consent

In accordance with recommendations for obtaining informed consent from research participants with aphasia (Kagan & Kimelman, 1995), information about the study was provided both verbally and in writing. Information sheets and consent forms were designed using “aphasia friendly” principles to maximise comprehension (Rose, Worrall, Hickson, & Hoffmann, 2010). Translations of written materials were prepared for non-English speaking participants.

3.3.4 Procedure

3.3.4.1 The nominal group technique. This study used the structured group decision-making process known as the nominal group technique (NGT) (Delbecq, Van de Ven, & Gustafson, 1975a). In this technique a group of participants are asked to respond to a question posed by a group facilitator, taking turns to give responses until saturation occurs. Participants then rank or prioritise their responses, and individual votes are tallied to identify the ideas rated highest by the group as a whole. The NGT was selected for this study as it has previously been used as a means of achieving consensus on outcomes, outcome domains, and outcome instruments for inclusion in COSs (Douglas et al., 2009; Heiligenhaus et al., 2012; Khanna et al., 2008; Lamb et al., 2005). Importantly, the NGT is an appropriate and effective technique for use with people with aphasia. The structured, round-robin process of idea presentation inherently supports communication by allowing equal participation across group members, a particularly important consideration when a group is comprised of participants with varying levels of aphasia severity. The turn-taking approach used in the NGT also provides time for communication to be facilitated using supported conversation techniques (Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001), again enabling the participation of individuals with diverse communication abilities. A further advantage of this technique is that it encourages ‘hitchhiking’, the stimulation of ideas in response to other group member responses (Delbecq, Van de Ven, & Gustafson, 1975b). Hitchhiking further increases opportunities for participation and allows people with aphasia to easily express congruence with a comment and/or to build on the ideas of other group members. The NGT has been previously used successfully with groups of two to nine people with aphasia (Garcia, Laroche, & Barrette, 2002; Lomas, Pickard, & Mohide, 1987). Studies using the NGT have reported increased difficulty in prioritisation as group numbers increase (Aspinal, Hughes, Dunckley, & Addington-Hall, 2006; Vella, Goldfrad, Rowan, Bion, & Black, 2000), accordingly group size was capped at a maximum of six people.

3.3.4.2 The nominal question. The nominal question was piloted in two stages, with multiple iterations of the question resulting from pilot feedback. The first iteration of the nominal question was developed through: (1) examination of existing research in a range of health areas which have used the NGT with consumers to identify important outcomes; and (2) discussion amongst the authors of the current study. The resulting question was then piloted with a group of aphasia clinicians and researchers. The pilot group identified that the nominal question should be: (1) broad enough to not be leading; (2) able to capture a range of outcomes without restricting discussion to specific aspects of language or communication; (3) relevant and meaningful to both the person with aphasia and their family members; and (4) specific enough to stimulate discussion regarding outcomes relevant to aphasia treatment. The revised question (which differed slightly between participant groups) was then piloted with people with aphasia and their family members in Australia: (1) People with aphasia: What would you most like to change about your communication and the way aphasia affects your life? (2) Family members of people with aphasia: What would you most like to change about your family member’s communication and the way aphasia affects your life? All participants received the nominal question in writing prior to attending their face-to-face nominal group meeting to allow additional time for reflection and understanding of the question. The nominal question was presented to people with aphasia in multiple modalities and using supported conversation techniques (Kagan, 1998). No further changes were made to the nominal questions following the pilot groups in Australia, hence the data from these groups are included in the current study.

3.3.4.3 Methodological consistency. To ensure methodological consistency across sites, a detailed manual outlining procedures for organising and running the nominal groups was developed. Site co-ordinators were also given access to a video recording of the pilot group held in Australia. A member of the primary investigation team was present to co-facilitate data collection at four of the seven international sites. Each nominal group was video and/or audio recorded to enable data checking.

3.3.4.4 Nominal group procedures. Nominal groups were conducted in the primary language of group participants. Groups in Australia, South Africa, the USA, and the UK were conducted in English; groups in Hong Kong were conducted in Cantonese; groups in Quebec, Canada were conducted in a combination of English and French; and groups in Denmark were conducted in Danish. Each group was facilitated by speech pathologist experienced in aphasia research. Facilitators who conducted the group in a language other than English translated the results to English. Two hours was allocated for the running of each nominal group. The following process was used in the group sessions:

1. The nominal question was presented in multiple modalities and in an “aphasia friendly” format to optimise the participants’ comprehension of the question. Supported conversation techniques for adults with aphasia (Kagan, 1998) were used throughout the groups. Specifically: (1) multi-modal communication including the use of gesture, written key words, and drawing, were used to facilitate comprehension and to clarify the ideas communicated by participants; (2) techniques such as the provision yes/no or fixed-choice questions, provision of appropriate avenues for response, and adequate time to respond, were used to ensure that participants with aphasia could express themselves and respond to questions; and (3) participant responses were verified, e.g. using writing to reflect, expand or summarise what has been communicated (Kagan, 1998).

2. Following a period of quiet reflection and individual response generation, each participant was invited to share one response with the group. This continued in rounds until saturation of ideas was reached (i.e., no new ideas were able to be generated by the group).

3. If necessary, responses were clarified and consolidated by the group facilitator, with similar responses grouped together and duplicates combined or deleted.

4. Participants selected and ranked the three outcomes they considered most important, in order of importance (see figure 3-1).

3.3.5 Analysis

3.3.5.1 Nominal group rankings. To present results quantitatively, participants' rankings were scored and summed. The outcome that was ranked as the most important was given a score of 3, the second most important was scored as 2, and the third most important was scored as 1. These scores reflected the relative importance of the outcomes to the participants. Scores were then summed to provide a prioritised list of the most important outcomes for each group.

3.3.5.2 Content analysis. The list of prioritised outcomes generated by each nominal group was analysed using inductive content analysis procedures (Graneheim & Lundman, 2004). Content analysis was used to gain an in-depth understanding of the desired outcomes of participants. Meaning units within outcomes were identified and organised into content codes, sub-categories, categories, and themes.

Rigour. A process of peer debriefing was used to enhance the rigour and trustworthiness of the content analysis. A full content analysis was completed by one author using the procedures of Granheim and Lundman (Graneheim & Lundman, 2004). At the completion of this analysis, 100% of participant responses were examined and discussed with a co-author to ensure that reasonable interpretations had been made and to check the accuracy and appropriateness of coding, categorization, and higher order themes. As the interpretation of some prioritised outcomes was highly contextually dependent, the analysis of the outcomes from each data collection site was further checked by the co-author who collected that data. This additional process ensured that the interpretation and classification of participant responses were culturally and linguistically appropriate and reflected the context of the preceding discussion within the nominal groups. An ‘audit trail’ (see Koch, 2006) was maintained to provide a full record of the analysis process from raw data (i.e., list of outcomes generated by participants), to data reduction and interpretation (i.e., identification and interpretation of meaning units), to analysis products (i.e., codes, sub-categories, categories and themes).

3.3.5.3 ICF coding. ICF coding was used to systematically classify outcomes using an internationally comparable framework. Each code generated in the content analysis was linked to the ICF (World Health Organization., 2001) using the linking process outlined by Cieza and associates (Cieza et al., 2002; Cieza et al., 2005) and additional rules devised by Worrall and associates (Worrall et al., 2011). Content codes were linked to the most precise

ICF code possible, where necessary more than one code was used. Coding was performed by one author, with peer checking by all co-authors. The resulting ICF codes were analysed in terms of their representation across ICF components and between stakeholder groups.

3.3.5.4 Inter-rater reliability. In order to assess the reliability of coding, a 30% sample of content codes was independently linked to the ICF by another researcher experienced in use of the ICF. Level of agreement was assessed using the kappa statistic (Cohen, 1960). Kappa statistic provides a measure of agreement beyond that which would be expected by chance alone (Cohen, 1960). Using this statistic, a value of 1 indicates perfect agreement and 0 indicates chance agreement. Bootstrapping (using Stata® statistics/data analysis) was used to generate 95% confidence intervals for the kappa statistic.

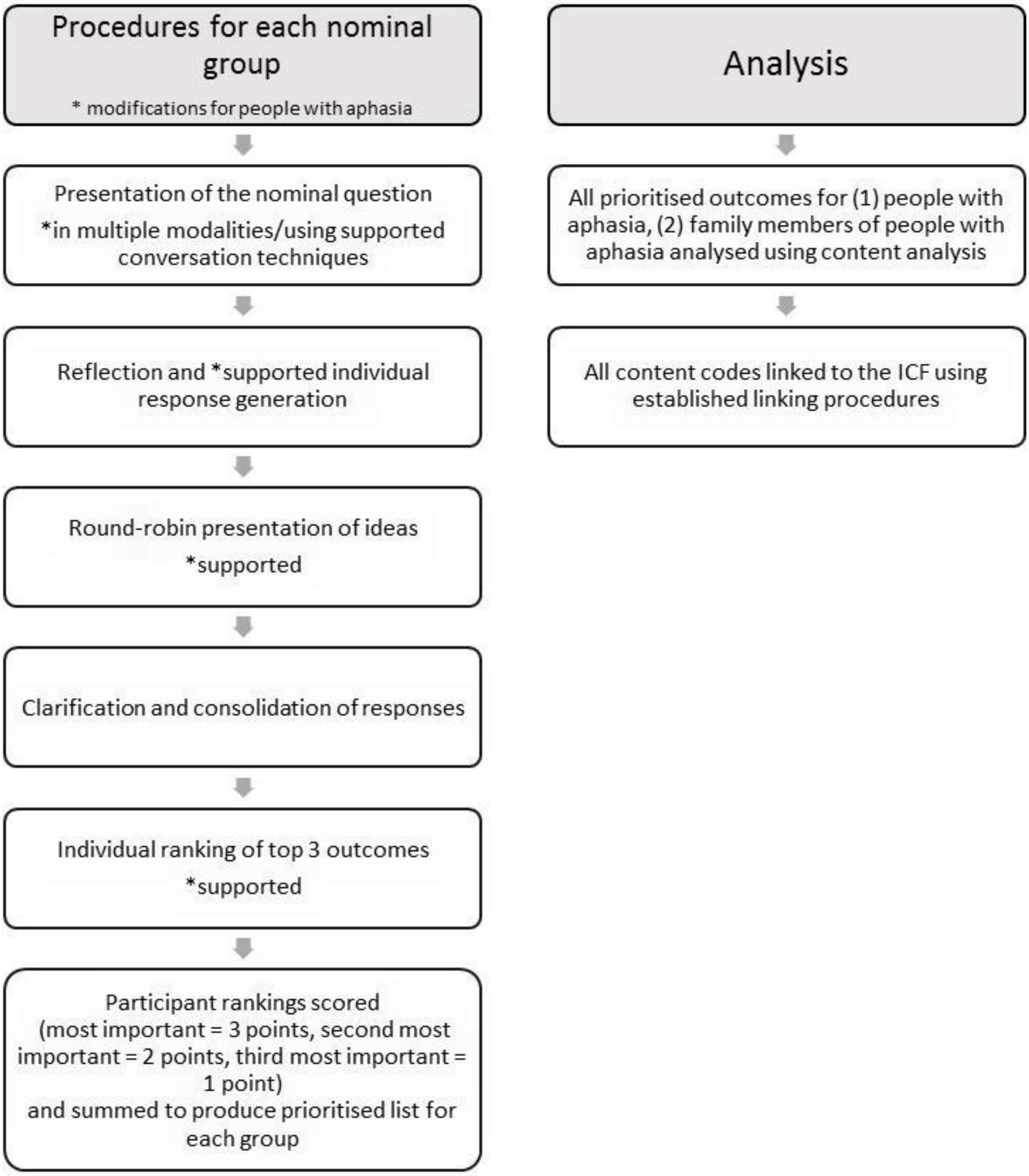

Figure 3-1. Procedures and Analysis for Nominal Groups

3.4 Results

Thirty-nine people with aphasia and 29 of their family members participated in one of 16 nominal groups. The participants with aphasia generated a total of 172 outcomes. During the ranking procedure, 83 of these outcomes were prioritised by participants (i.e., ranked 1, 2, or 3). Family members generated a total of 167 outcomes; prioritising 63 of these outcomes in the ranking procedure. The outcomes identified by family members related to both themselves, i.e., in relation to the impact of aphasia on their own lives and to their family member with aphasia. The outcomes identified by people with aphasia related only to themselves. The outcomes prioritised by participants using the NGT were analysed using both qualitative content analysis and ICF linking and are reported below.

3.4.1 Qualitative Content Analysis

3.4.1.1 Desired outcomes for people with aphasia. Outcomes for people with aphasia were generated by both the participants with aphasia and their family members, in their separate groups. Inductive content analysis of the 83 outcomes prioritised by the participants with aphasia resulted in 120 content codes. These codes were categorised into six themes, 20 categories and 42 sub-categories (refer to tables 3-3a and 3-5). Inductive content analysis of the 63 outcomes generated by family members resulted in 43 content codes which related to outcomes for the person with aphasia and 60 content codes relating to the family member themselves. Codes relating to the person with aphasia were categorised into four themes, 12 categories and 22 sub-categories (refer to tables 3-3b and 3-5). The results from both participant groups that related to the person with aphasia are integrated and discussed below.

Improved communication. Responses most frequently related to the theme of improved communication for the person with aphasia. People with aphasia prioritised outcomes which related to improved language function e.g., “To speak in longer words and sentences” (participant with aphasia, Denmark). These outcomes related to a wide range of language modalities encompassing verbal and written expression, auditory and reading comprehension, discourse, word finding, and numeracy. Also frequently prioritised, were outcomes relating to participation in conversation e.g., “Understand or improve phone conversations” (participant with aphasia, USA) and effective communication e.g., “To be able to express myself loud and clear” (participant with aphasia, Denmark). People with aphasia expressed a desire to communicate their emotions, reduce communication breakdown and stress, to communicate independently, and to ‘keep up’ in conversation. Participants with aphasia also expressed a desire to participate in ‘normal’ and more complex conversations, including discussions, conversation in groups, and conversations via the telephone. Other important outcomes for participants with aphasia related to a desire to use technology to support communication e.g., “Use technology (e.g. Facebook and Skype) to stay in touch” (participant with aphasia, Australia).

Family members generated outcomes relating to the person with aphasia that also related to both language function and communication more broadly. The vast majority of outcomes reflected a desire for their family member with aphasia to have improved language function e.g., “Learning key words – speaking and/or writing” (family member participant, Australia). Family members also wanted the person with aphasia to be able to communicate effectively. Reflective of the desired outcomes of the participants with aphasia, family members wanted the person with aphasia to be able to communicate beyond the level of basic needs to be able to express their thoughts, wishes, and emotions e.g., “That she verbally or non-verbally could communicate the thoughts and wishes she is stuck with inside” (family member participant, Denmark). Family members also wanted the person with aphasia to be able to use multi-modal communication and to improve other communicative functions including speech and hearing.

Increased life participation. Outcomes relating to the person with aphasia’s participation in life and life roles were important to both participant groups. People with aphasia prioritised outcomes relating to maintaining and increasing social networks and friendships, participating in their own interests, and having the ability to work and complete education e.g., “I would like to have a social life/friends” (participant with aphasia, USA), “To return to the ‘Welcome Choir’” (participant with aphasia, UK), and “Get to work; including evaluation of being able to work” (participant with aphasia, UK). Family members generated outcomes relating to life participation for the person with aphasia which related primarily to participation in relationships e.g., “Expand communication for a better social life” (family member participant, South Africa).

Both participant groups prioritised outcomes relating to a desire for the person with aphasia to have increased independence in various life roles e.g., “To be able to take medication on time without others’ help” (participant with aphasia, Hong Kong) and “More independence in communication and activities” (family member participant, USA).

Changed attitudes through increased awareness and education about aphasia. People with aphasia identified outcomes which related to a desire for increased awareness and education about aphasia and associated impacts e.g., “People don’t know what aphasia is. Awareness about aphasia” (participant with aphasia, Australia) and “To educate family, and carers, doctors and nurses about effect of aphasia…” (participant with aphasia, UK). Participants also wanted changed attitudes towards people with aphasia through increased awareness, e.g., “Attitude and awareness of aphasia” (participant with aphasia, Australia).

Recovered normality. Outcomes relating to the person with aphasia’s recovery or return to ‘normal’ were prioritised by both the people with aphasia and their family members. These outcomes related to acceptance of changed circumstances; and recovery of communication skills, pre-morbid identity, personality, and life roles e.g., “To be seen as the same person I was before” (participant with aphasia, UK) and “Communicate things he did before – car servicing” (family member participant, South Africa).

Improved physical and emotional well-being. People with aphasia and their family members prioritised outcomes which related to the physical and emotional well-being of the people with aphasia. This included desired improvements in confidence, physical and cognitive functions, and feelings about self, e.g., “More dignity and respect” (participant with aphasia, Australia) and “…not the end of the world/not be so hard on self” (family member participant, USA).

Improved health services. Outcomes relating to improving health services were important to people with aphasia. This included a desire for greater access to both health services and health-related equipment e.g., “For software and aids to be freely available and used in the NHS so everyone gets it” (participant with aphasia, UK). Family members also prioritised outcomes relating to health services, however these were in reference to themselves and not the person with aphasia.

Table 3-3a

Content Analysis of Outcomes Prioritised by Participants with Aphasia – "What would you most like to change about your communication and the way aphasia affects your life?"

Themes	Categories	Sub-categories
Improved communication (person with aphasia)	To have improved language function	▪ To have improved verbal expression ▪ To have improved comprehension and auditory comprehension ▪ To have improved word finding ▪ To have improved reading and reading comprehension ▪ To have improved written expression ▪ To have improved discourse at sentence level ▪ To have improved use of numbers
	To communicate effectively	▪ To express myself clearly, ask questions and write lists ▪ To help my communication partners communicate, including tools to support communication ▪ To communicate my emotions ▪ To reduce communication breakdown and stress ▪ To be able to communicate independently and be understood by others ▪ To use/understand money when shopping

Themes	Categories	Sub-categories
	To be able to participate in conversation	▪ To keep up with conversation and change in topic ▪ To have complex conversations, including giving explanations and conversation via the telephone ▪ To be included in conversations and group conversations ▪ To have normal and meaningful conversations
	To use technology to support communication	▪ To use Facebook and Skype to communicate ▪ To use the telephone and answering machine to communicate
	To have improved speech function	▪ To have improved articulation and speech volume
	To have improved hearing	
Increased life participation (person with aphasia)	To participate in relationships	▪ To have increased social life/friendships and less isolation ▪ To maintain existing relationships
	To be able to work and complete my education	▪ To return to work/complete my schooling ▪ To have greater workplace flexibility and tolerance
	To participate in my own interests	▪ To participate in specific activities e.g. sport, singing ▪ To participate in my own interests and hobbies
	To have increased independence with activities including medication management	

Themes	Categories	Sub-categories
Changed attitudes through increased awareness and education about aphasia	To have increased education about aphasia and stroke	▪ To have increased aphasia education for the general public and the workplace ▪ To have increased aphasia education for families, children and carers ▪ To have increased aphasia education for health professionals ▪ To have increased stroke education for families and children
	To change attitudes about aphasia	▪ To have improved public attitudes towards aphasia ▪ To receive more respect from others
	To increase public awareness of aphasia	
Recovered normality (person with aphasia)	To recover communication	▪ To regain, maintain and improve communication ▪ To use my own dialect again ▪ To recover more easily and quickly
	To return to 'normal'	▪ To regain my pre-morbid identity and not be defined by aphasia ▪ To regain and feel my pre-morbid confidence
	To be able to accept my changed circumstances	

Themes	Categories	Sub-categories
Improved physical and emotional well-being (person with aphasia)	To have improved physical function	▪ To have improved mobility and energy ▪ To have improved physical function including hand function
	To have improved cognitive function	▪ To have improved thinking and concentration ▪ To have improved memory
	To have more self-confidence, dignity and determination	
Improved health services	To have greater access to health services and equipment	▪ To have access to and funding for services, software and aides

Table 3-3b

Content Analysis of Outcomes Prioritised by Family Members (Relating to the Person with Aphasia) – "What would you most like to change about your family member's communication…"

Themes	Categories	Sub-categories
Improved communication (for the person with aphasia)	For the person with aphasia to have improved language function	▪ For the person with aphasia to have improved verbal expression ▪ For the person with aphasia to have improved written expression ▪ For the person with aphasia to have improved discourse – sentence level
	For the person with aphasia to be able to communicate effectively	▪ For the person with aphasia to communicate thoughts and wishes and understanding ▪ For the person with aphasia to communicate effectively with family ▪ For the person with aphasia to express emotions
	For the person with aphasia to use multi-modal communication	
	For the person with aphasia to have improved speech function	

Themes	Categories	Sub-categories
Recovered normality (for the person with aphasia)	For the person with aphasia to be able to accept their changed circumstances	▪ For the person with aphasia to adjust to and accept new circumstances ▪ For the person with aphasia to be open to assistance and the opinions of others ▪ For the person with aphasia to rest when needed
	For the person with aphasia to return to ‘normal’	▪ For the person with aphasia to regain their pre-morbid identity and personality ▪ For the person with aphasia to fulfil their pre-morbid communication roles
	For the person with aphasia to recover their communication	
Improved physical and emotional wellbeing (for the person with aphasia)	For the person with aphasia to have more positive feelings	▪ For the person with aphasia to reduce their frustration ▪ For the person with aphasia to maintain a good mood ▪ For the person with aphasia to have increased optimism and appreciation of others
	For the person with aphasia to have improved cognitive function	▪ For the person with aphasia to have improved memory ▪ For the person with aphasia to have improved concentration
	For the person with aphasia to have improve physical function	▪ For the person with aphasia to have improved mobility

Themes	Categories	Sub-categories
Increased life participation (for the person with aphasia)	For the person with aphasia to participate in activities and relationships	▪ For the person with aphasia to have improved social life ▪ For the person with aphasia to maintain routines ▪ For the person with aphasia to have safe participation in activities
	For the person with aphasia to have increased independence	▪ For the person with aphasia to be more independent in activities and communication ▪ For the person with aphasia to take personal responsibility for their learning

3.4.1.2 Family members – desired outcomes for themselves. Family members identified desired outcomes for themselves, relating to the impact of aphasia on their own lives. Inductive content analysis of 63 outcomes resulted in 60 content codes relating to outcomes for the family member themselves. These outcomes were organised into six themes, 13 categories and 33 sub-categories (refer to tables 3-4 and 3-5). These results are presented below in order of frequency:

Improved communication. Family members generated outcomes for themselves which related to their role as a communication partner. They expressed a desire to communicate effectively with the person with aphasia, to engage in conversation with the person with aphasia, and to use technology to support communication with the person with aphasia. Family member participants also expressed a desire for a better understanding of how to facilitate and support communication, and reduce communication breakdown e.g., "Family understand more about how to communicate (give more time etc)" (family member participant, USA). Family members also wanted to be able to effectively express more abstract concepts such as emotions and feelings in a way that could be understood by their family members with aphasia e.g., "To express our feelings" (family member participant, Canada).

Family members prioritised outcomes relating to participation in conversation focusing on a desire for meaningful conversation between spouses. This included a desire for conversation and discussion with their loved one with aphasia which surpassed the exchange of basic needs e.g., "Deeper conversation/more in-depth discussion" (family member participant, USA).

Increased life participation. Family members identified outcomes which related to life participation, specifically being able to participate in activities of interest and to be able to participate in activities as a couple e.g., "To be able to enjoy outings to different places of interest" (family member participant, Australia). Family member participants also emphasised outcomes relating to their own participation in family relationships and friendships, expressing a desire to socialise more, feel less isolated, have more support, and to have greater balance and independence in spousal relationships e.g., "More balance between partners" (family member participant, Denmark) and "To take time for ourselves" (family member participant, Canada).

Improved health and support services. Family members prioritised outcomes which related to improving health and social support services. These outcomes focused on the delivery of services like, holistic rehabilitation and case management as well as access to therapies, counselling, and respite, e.g., “Routine respite/counselling for family” (family member participant, Australia).

Changed attitudes through increased awareness and education about aphasia. Outcomes relating to increased aphasia awareness and education and changed family attitudes about aphasia were important to family members. This included a desire to feel better understood in family relationships and to have increased education for the general public and family members, e.g., “To enhance public awareness of aphasia, so that the general public will understand the communication needs of PWA (person with aphasia) as well as the pressure of PWA's family members” (family member participant, Hong Kong).

Improved emotional well-being. For family members, outcomes relating to their emotional well-being were important. Family members expressed a desire to have more enjoyment, optimism, and positivity in life; as well as fewer feelings of anxiety and frustration, e.g., “Less frustration/ more patience” (family member participant, Australia) and “Constantly worried – is he comfortable, is he in pain? All the responsibility on your shoulders” (family member participant, South Africa).

Recovered normality. Family members prioritised outcomes relating to their own desire to return to ‘normal’ and to recover communication with their family member living with aphasia. This included returning to previous activities, having hope for the future, enjoying life, and regaining a sense of individuality, e.g., “To have individuality back” (family member participant, Australia) and “To know that things will improve” (family member participant, Canada).

Table 3-4

Content Analysis of Outcomes Prioritised by Family Members (for Themselves) – "What would you most like to change about … the way aphasia affects your life?"

Themes	Categories	Sub-categories
Improved communication (family members)	To be able to communicate effectively with the person with aphasia	▪ To have communication and mutual understanding ▪ For family to understand how to facilitate and support communication ▪ To have tools to support communication, comprehension and cognition ▪ To reduce communication breakdown ▪ To understand the person with aphasia's emotions and to express my emotions in a way that can be understood
	To be able to participate in conversation with the person with aphasia	▪ To have spousal conversation ▪ To have deeper conversation and in-depth discussion ▪ To participate in meaningful conversation
	To use technology to support communication with the person with aphasia	

Themes	Categories	Sub-categories
Increased life participation (family members)	To participate in family relationships and friendships	▪ To have independence, balance, and less responsibility in spousal relationships ▪ To socialise with family and friends and feel less isolated ▪ To have family support ▪ Family adjustment to living with a person with aphasia
	To participate in activities	▪ To participate in activities as a couple ▪ To participate in outings to places of own interest ▪ To have financial support for activities
Improved health and support services	To have access to health and support services	▪ To have access to family respite and counselling ▪ To have access to physical and psychological therapy
	To have appropriate delivery of services	▪ To have holistic rehabilitation which includes family ▪ To have case management
Changed attitudes through increased awareness and education about aphasia	Increased education about aphasia	▪ To have increased aphasia education for the general public ▪ To have increased aphasia education for families
	Changed family attitudes about aphasia	▪ To have understanding and improved attitudes in spousal relationships ▪ To feel understood by family
	Increased public awareness of aphasia	

Themes	Categories	Sub-categories
Improved emotional well-being (family members)	To have positive feelings	▪ To have more enjoyment and positivity ▪ To have increased optimism and determination ▪ To reduce frustration and increase patience
	To have less anxiety	
Recovered normality (family members)	To return to ‘normal’	▪ To return to pre-morbid activities ▪ To enjoy life again ▪ To have my individuality back
	To recover communication	▪ To know communication will improve and have hope for the future ▪ To improve communication

Table 3-5

Desired Outcomes: Themes by Participant Group

People with aphasia	Family members	
	For the person with aphasia	For themselves
1. Improved communication	1. Improved communication	1. Improved communication
2. Increased life participation	2. Recovered normality	2. Increased life participation
3. Changed attitudes through increased awareness and education about aphasia	3. Improved physical and emotional well-being	3. Improved health and support services
4. Recovered normality	4. Increased life participation	4. Changed attitudes through increased awareness and education about aphasia
5. Improved physical and emotional well-being		5. Improved emotional well-being
6. Improved health services		6. Recovered normality

3.4.2 ICF Linking

3.4.2.1 People with aphasia. The outcomes prioritised by participants with aphasia were linked to the most specific level of the ICF possible; resulting in a total of 121 linkages (refer to table 3-6). Important outcomes for people with aphasia spanned all ICF components. The majority of codes linked to the Activity/Participation (39%) and Body Functions (36%) components. Codes also linked to the contextual factor components of the ICF, with 22% linking to Environmental Factors and 3% relating to Personal Factors.

Family member outcomes relating to the person with aphasia were linked to the ICF, resulting in 40 linkages in total (refer to table 3-6). The majority of codes linked to the Body Functions (60%) and Activity/Participation (33%) components. A small number of codes linked to Environmental (2%) and Personal Factors (5%). ICF linkages for people with aphasia are presented in tables 3-7a and 3-7b.

Table 3-6

Distribution of Linkages to ICF Components

ICF component	People with aphasia n (%)	Family members Relating to the person with aphasia n (%)	Family members Relating to themselves n (%)
Body Functions	44 (36.4)	**24 (60)**	11 (18)
Activity/Participation	**47 (38.8)**	13 (32.5)	**30 (49.2)**
Environmental Factors	63 (21.5)	1 (2.5)	17 (27.9)
Personal Factors	4 (3.3)	2 (5)	3 (4.9)
Total linkages	121	40	61

Table 3-7a

ICF Linkages: Important Outcomes to Participants with Aphasia

ICF component (number of codes linked to component)	ICF chapter (number of codes linked to chapter)	ICF code	ICF category description (number of codes linked to category)
Body Functions (44)	b1 Mental functions (37)	b1266	Confidence (2)
		b1300	Energy level (1)
		b1301	Motivation (1)
		b1400	Sustaining attention (1)
		b144	Memory functions (1)
		b1442	Retrieval of memory (1)
		b152	Emotional functions (3)
		b160	Thought functions (1)
		b1670	Reception of language (3)
		b16700	Reception of spoken language (3)
		b16701	Reception of written language (3)
		b16710	**Expression of spoken language (8)**
		b16711	Expression of written language(1)
		b1672	**Integrative language functions (8)**
	b2 Sensory functions and pain (1)	b230	Hearing functions (1)

ICF component (number of codes linked to component)	ICF chapter (number of codes linked to chapter)	ICF code	ICF category description (number of codes linked to category)
	b3 Voice functions (4)	b3100	Production of voice (1)
		b320	Articulation functions (2)
		b340	Alternative vocalization functions (1)
	b7 Neuromusculoskeletal and movement-related functions (2)	b7	Neuromusculoskeletal and movement-related functions (2)
Activities/Participation (47)	d1 Learning and applying knowledge (4)	d1551	Acquiring complex skills (1)
		d166	Reading (1)
		d170	Writing (2)
	d2 General tasks and demands (4)	d2102	Undertaking a single task independently (1)
		d2202	Undertaking multiple tasks independently (2)
		d240	Handling stress and other psychological demands (1)
	d3 Communication (24)	**d3**	**Communication (8)**
		d310	Communicating with – receiving – spoken messages (1)
		d330	Speaking (1)
		d350	**Conversation (7)**
		d355	Discussion (1)
		d3504	Conversing with many people (1)
		d360	**Using communication devices and techniques (4)**
		d3602	Using communication techniques (1)

ICF component (number of codes linked to component)	ICF chapter (number of codes linked to chapter)	ICF code	ICF category description (number of codes linked to category)
	d4 Mobility (1)	d4	Mobility (1)
	d5 Self-care (1)	d5702	Maintaining one's health (1)
	d7 Interpersonal interactions and relationships (2)	d720	Complex interpersonal interactions (1)
		d7500	Informal relationships with friends (1)
	d8 Major life areas (4)	d810-839	Education (1)
		d845	Acquiring, keeping and terminating a job (1)
		d8450	Seeking employment (1)
		d860	Basic economic transactions (1)
	d9 Community, social and civic life (7)	d9	Community, Social and Civic life (1)
		d920	Recreation and leisure (1)
		d9204	Hobbies (2)
		d9205	Socializing (3)
Environmental Factors (26)	e1 Products and technology (3)	e1250	General products and technology for communication (1)
		e1251	Assistive products and technology for communication (2)
	e3 Support and relationships (6)	e310	Support and relationships: Immediate family (3)
		e330	Support and relationships: People in positions of authority (1)
		e340	Support and relationships: Personal care providers and personal assistants (1)
		e355	Support and relationships: Health professionals (1)

ICF component (number of codes linked to component)	ICF chapter (number of codes linked to chapter)	ICF code	ICF category description (number of codes linked to category)
	e4 Attitudes (5)	e4	Attitudes (1)
		e430	Individual attitudes of people in positions of authority (1)
		e460	Societal attitudes (3)
	e5 Services, systems and policies (12)	e565	Economic services, systems and policies (1)
		e5800	Health services (1)
		e5801	Health systems (1)
		e585	**Education and training services, systems and policies (7)**
		e5900	Labour and employment policies (1)
		e5902	Labour and employment services (1)
Personal Factors (4)	Personal Factors (4)	pf	Dialect (1)
		pf	Coping skills (1)
		pf	Identity (2)

Table 3-7b

ICF Linkages: Important Outcomes to Family Members (Relating to the Person with Aphasia)

ICF component (number of codes linked to component)	ICF chapter (number of codes linked to chapter)	ICF code	ICF category description (number of codes linked to category)
Body Functions (24)	b1 Mental functions (23)	b1	Mental functions (1)
		b1301	Motivation (1)
		b1400	Sustaining attention (1)
		b144	Memory functions (1)
		b152	**Emotional functions (5)**
		b1521	Regulation of emotion (1)
		b1670	Reception of language (1)
		b16710	**Expression of spoken language (7)**
		b16711	Expression of written language (3)
		b1672	Integrative language functions (2)
	b3 Voice functions (1)	b320	Articulation functions (1)
Activity/Participation (13)	d2 General tasks and demands (2)	d2202	Undertaking multiple tasks independently (1)
		d230	Carrying out daily routine (1)
	d3 Communication (7)	**d3**	**Communication (6)**
		d360	Using communication devices and techniques (1)
	d4 Mobility (1)	d4	Mobility (1)

ICF component (number of codes linked to component)	ICF chapter (number of codes linked to chapter)	ICF code	ICF category description (number of codes linked to category)
	d5 Self-care (1)	d570	Looking after one's health (1)
	d7 Interpersonal interactions and relationships (2)	d7	Interpersonal interactions and relationships (1)
		d7101	Appreciation in relationships (1)
Environmental Factors (1)	e3 Support and relationships	e340	Personal care providers and personal assistants (1)
Personal Factors (2)	Personal Factors (2)	Pf	Pre-morbid roles
		Pf	Pre-morbid personality

3.4.2.2 Family members. The desired outcomes of family members for themselves were linked to the ICF, resulting in 61 linkages (refer to table 3-6). The majority of codes linked to the Activity/Participation component (49%) and Environmental Factors (28%). The remaining codes linked to the Body Functions component (18%) and 5% of linkages were classified as Personal Factors. ICF linkages for family members are presented in table 3-8.

Table 3-8

ICF Linkages: Important Outcomes to Family Members (Relating to Themselves)

ICF component (number of codes linked to component)	ICF chapter (number of codes linked to chapter)	ICF code	ICF category description (number of codes linked to category)
Body Functions (11)	b1 Mental functions (11)	**b1265**	**Optimism (4)**
		b130	Energy and drive functions (1)
		b152	**Emotional functions (5)**
		b1521	Regulation of emotion (1)
Activity/Participation (30)	d1 Learning and applying knowledge (1)	d1	Learning and applying knowledge (1)
	d2 General tasks and demands (2)	d240	Handling Stress and other psychological demands (2)
	d3 Communication (13)	**d3**	**Communication (6)**
		d350	Conversation (2)
		d3503	Conversing with one person (1)
		d355	Discussion (1)
		d360	Using communication devices and techniques (3)
	d5 Self-care (1)	d570	Looking after one's health (1)
	d6 Domestic life (2)	d6602	Assisting others in communication (2)

ICF component (number of codes linked to component)	ICF chapter (number of codes linked to chapter)	ICF code	ICF category description (number of codes linked to category)
	d7 Interpersonal interactions and relationships (9)	d7102	Tolerance in relationships (1)
		d7500	Informal relationships with friends (2)
		d760	Family relationships (2)
		d7701	**Spousal relationships (4)**
	d9 Community, social and civic life (2)	d9202	Arts and culture (1)
		d9205	Socializing (1)
Environmental Factors (17)	e1 Products and technology (2)	e1	Products and technology (1)
		e1650	Financial assets (1)
	e3 Support and relationships (4)	**e310**	**Support and relationships – immediate family (4)**
	e4 Attitudes (3)	e410	Individual attitudes of immediate family members (1)
		e415	Individual attitudes of extended family members (1)
		e460	Societal attitudes (1)
	e5 Services, systems and policies (8)	e5750	General social support services (3)
		e5800	**Health services (5)**
Personal Factors (3)	Personal Factors (3)	Pf	Individuality
		Pf	Pre-morbid activities
		pf	Independence

3.4.3 Inter-Rater Reliability

Inter-rater reliability ranged from 0.73 (ICF component-level) to 0.52 (ICF chapter and 2nd level) (see table 3-9). Considered in reference to criteria for interpreting kappa values (Landis & Koch, 1977) this indicates substantial agreement (0.61-0.80) at a component-level and moderate agreement (0.41-0.60) at a the chapter and second level of the ICF.

Table 3-9

ICF Coding: Inter-Rater Reliability

ICF level	Percentage agreement	Kappa (95%CI)*
Component (e.g. Body functions)	81.08	0.73 (0.55-0.91)
Chapter (e.g. b1 Mental functions)	59.46	0.52 (0.35-0.69)
Second level (e.g. b160 Thought functions)	54.05	0.52 (0.38-0.70)

*Bias corrected bootstrapped confidence intervals (1000 replications)

3.5 Discussion

This study aimed to identify important treatment outcomes from the perspectives of people with aphasia and their family members in order to contribute to a COS for aphasia treatment research. At an overarching level, the results show that the desired treatment outcomes of people with aphasia and their family members span all components of the ICF framework. This finding provides confirmation and validation that whilst aphasia is, at the most fundamental level, a disorder of language function, its consequences are far-reaching. Both participant groups identified outcomes for themselves, which most frequently linked to the Activity/Participation component of the ICF, and within this component, to the Communication chapter. This suggests that people with aphasia and their family members consider participation in communication activities to be a key desired outcome of treatment. These results are consistent with research from Worrall and associates (Worrall et al., 2011) who found that the goals of people with aphasia span the full spectrum of the ICF, primarily linking to the Activity/Participation component. Furthermore, this finding is in step with systematic reviews of aphasia treatments which have selected functional communication as the primary review outcome (Brady et al., 2012; Elsner et al., 2015).

Whilst the outcomes identified by both participant groups most frequently linked to the Activity/Participation level of the ICF, Body Function outcomes were also very highly represented. Furthermore, where family members identified communication outcomes for the person with aphasia, those outcomes most frequently linked to language functions. The complementary nature of the outcomes identified by participants with aphasia and their family members highlights the synergistic relationship between the remediation of language impairment and communication in activities and everyday life. The need to consider communication from a holistic point of view, with emphasis on language function as well as communication more broadly in everyday contexts, has previously been identified as a key aspect of living successfully with aphasia (Brown et al., 2011).

The results of this study have important implications for aphasia treatment research which currently focuses on the measurement of Body Function outcomes. If aphasia research is to maintain relevancy and translate to clinical practice, it is essential to measure constructs that matter to people living with aphasia. The results of this study indicate that important treatment outcomes for people with aphasia and their family members occur across all components of the ICF; most frequently at Activity/Participation and Body Function levels.

At a thematic level, there was broad consistency in the desired outcomes of people with aphasia and those of their family members. The desired outcomes of both stakeholder groups encompassed the same overarching themes relating to: (1) Improved communication; (2) Increased life participation; (3) Changed attitudes through increased education and awareness about aphasia; (4) Increased emotional (and physical) well-being; (5) Improved health (and support) services; and (6) Recovered normality. Consistent with other COS development studies reporting multiple stakeholder perspectives (Bartlett et al., 2012; Morris et al., 2014; Sinha et al., 2012), the stakeholder groups in the current study differed in their prioritisation of outcomes. Of fundamental importance to both stakeholder groups was having improved communication and life participation; however family members prioritised improved health and support services more highly, whilst people with aphasia placed greater emphasis on outcomes relating to attitudes, awareness and education about aphasia, and recovery.

3.5.1 Important Outcomes for People with Aphasia

Not surprisingly, the outcomes desired by and for people with aphasia primarily related to improved communication. Outcomes related to the full spectrum of communication encompassing receptive and expressive language functions, participation in conversation, strategies to promote effective communication, communication partner skills, and use of technology to support communication. Both participant groups also expressed a desire for the person with aphasia to be able to communicate at a level beyond the expression of basic needs. Participants with aphasia and their family members shared a desire for the person with aphasia to have communicative abilities which allowed the expression of deeper thoughts and emotions. The prioritisation of this outcome by both participant groups exemplifies the integral role of communication in relationships and mirrors the body of literature documenting the negative impacts of aphasia on marital satisfaction (Williams, 1993), social relationships (Parr, 2007), and overall quality of life (Cruice, Worrall, & Hickson, 2006). Also of great importance to people with aphasia was increased life participation. Participants with aphasia prioritised outcomes which related to returning to work and schooling, and participation in their own interests and hobbies. There was again overlap in the desired outcomes of the participants with aphasia and their family members, with both groups wanting increased independence and reduced social isolation for the person with aphasia. The impact of aphasia on friendships and relationships is well documented in the literature (Davidson, Howe, Worrall, Hickson, & Togher, 2008; Northcott & Hilari, 2011); these results again highlight the importance of active participation in social networks for people with aphasia.

3.5.2 Third-Party Disability

The results of this study confirm the widespread impact that aphasia may have on families. In the current study, family member participants identified a wide range of desired outcomes for themselves relating to the impact of their family member's aphasia. This finding adds weight to research from Grawburg and associates (Grawburg et al., 2013a) which shows that the third-party disability (changes to functioning and disability as a result of another person's health condition) experienced by family members of people with aphasia can be attributed to the health condition of the person with aphasia.

The most important outcomes for family members related to Activity/Participation and Environmental Factor domains. Spousal and family relationships were of high importance to family members, with outcomes relating to a desire for increased independence, and greater balance and appreciation in relationships. Previous research has detailed the impact of aphasia on relationships citing: role changes and increased dependence from the person with aphasia (Grawburg et al., 2013a); negative changes in marital satisfaction following the onset of aphasia (Williams, 1993); and spousal stress as a result of communication impairment (Michallet, Tétreault, & Le Dorze, 2003). Family members also wanted increased involvement in rehabilitation, expressing a desire to learn more ways to support communicative interactions; to have tools to support communication, comprehension and cognition; and to be able to reduce communication breakdown. Improved health and support services were key desired outcomes for family members, who articulated a need for holistic family-based aphasia services, family respite and counselling, access to physical and psychological therapy and co-ordinated case management. These findings add weight to existing research which has examined the impact of stroke on family members (Pellerin, Rochette, & Racine, 2011) and the goals that family members of people with aphasia have for themselves (Howe et al., 2012a), and has identified the need for family-centred approaches to rehabilitation, including access to support and respite (Le Dorze & Signori, 2010).

3.6 Clinical Implications

The results of this study indicate a broad role for clinicians in aphasia rehabilitation which primarily focuses on remediation of language impairment and communication disability but which also extends to aphasia education; supporting clients in accepting their changed circumstances; and facilitating and coordinating access to complementary health and support services. Importantly clinicians should have a role in facilitating the achievement of outcomes in these areas not only for the person with aphasia but also for their family members. The wide range of treatment outcomes identified by family members in this study suggests a need for family-centred aphasia services which not only seek to meet the needs of people with aphasia, but also to define and address the specific goals of family members and significant others in rehabilitation. There is a clear and necessary role for clinicians in the provision of communication partner training and in ensuring appropriate access to support and health services, particularly those directed at supporting emotional wellbeing and family relationships. The complementary nature of the outcomes generated by the participants with aphasia and their family members highlights the importance of collaborative goal setting which includes family members. The categories of outcomes identified in this study may be used clinically as a starting point for goal-setting discussions.

3.7 Limitations and Future Research

While it was not the intention of this research to examine differences in outcome prioritisation between countries, this may be an area for future research. Subsequent studies examining cultural/country specific variations in outcomes and outcome prioritisation would require larger sample sizes. Future international research may also contribute additional data from other countries and participants that could validate the findings of this study.

This study represents the first stage of a larger project to develop a COS for aphasia treatment research. Further stakeholder perspectives are needed to gain a comprehensive picture of important outcomes from aphasia treatments. Accordingly two further studies have been conducted examining clinician (Wallace, Worrall, Rose, and Le Dorze, 2016a).and researcher perspectives on treatment outcomes (Wallace, Worrall, Rose, and Le Dorze, 2016b). This information will be paired with a systematic review and meta-analysis of outcome measures in a final consensus process to develop a COS for aphasia treatment research.

3.8 Conclusions

People with aphasia and their family members identified important treatment outcomes which linked to all components of the ICF. Participants with aphasia prioritised outcomes which primarily linked to the Activity/Participation and Body Function ICF components. Family members prioritised outcomes for themselves which predominantly linked to the Activity/Participation component, and outcomes for their family member with aphasia which primarily linked to the Body Function component of the ICF. These findings have implications both in terms of research outcome measurement and clinical service provision. In research, the relevancy and translation of findings may be increased by measuring and reporting research outcomes which are important to people living with aphasia. The breadth of outcomes identified by participants provides a mandate for holistic, family-centred aphasia services that address the needs of both people with aphasia and their significant others.

3.9 Acknowledgments

The authors would like to acknowledge the invaluable contribution of the people living with aphasia who participated in this research. Many thanks also to Aileen Thompson and Netcare Rehabilitation Hospital, Johannesburg, South Africa; the Houston Aphasia Recovery Center (HARC), Houston, USA; Self Help Group for the Brain Damage (SHGBD), Hong Kong;

Center for Rehabilitering og Specialrådgivning (CRS), Odense, Denmark; Karen Sage (University of the West of England, Bristol, United Kingdom); the Stroke Association Communication Support Groups of the West of England, United Kingdom; and the participating rehabilitation institution of the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal, Canada for their assistance with recruitment and data collection as well as Carole Anglade and Michèle Masson-Trottier. The authors acknowledge the use of The University of Queensland's Communication Research Registry (www.crregistry.org.au) in recruiting participants in Australia.

3.10 Declaration of Interest Statement

This work was supported by an Australian Postgraduate Award (APA) scholarship awarded to Sarah J. Wallace. The authors have no other declarations of interest to report.

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Chapter 4: Core Outcomes in Aphasia Treatment Research: An e-Delphi Consensus Study of International Aphasia Researchers

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This chapter reports the findings of an international e-Delphi exercise to gain consensus on important aphasia treatment outcomes from the perspective of aphasia researchers.

This chapter has been published in the peer-reviewed journal, *American Journal of Speech Language Pathology*: Wallace, S. J., Worrall, L., Rose, T., & Le Dorze, G. (In press). Core outcomes in aphasia treatment research: An e-Delphi consensus study of international aphasia researchers. *American Journal of Speech Language Pathology*.

The content included in this chapter is identical to the submitted manuscript; however, the formatting has been modified to match the style of this thesis.

4.1 Abstract

Purpose: To identify outcome constructs which aphasia researchers consider essential to measure in all aphasia treatment research.

Methods: Purposively sampled researchers were invited to participate in a three-round e-Delphi exercise. In round 1, an open-ended question was used to elicit important outcome constructs; responses were analysed using inductive content analysis. In rounds 2 and 3, participants rated the importance of each outcome using a 9-point rating scale. Outcomes reaching pre-defined consensus criteria were further analysed using ICF coding.

Results: Eighty researchers commenced round 1, with 72 completing the entire survey. High response rates (≥85%) were achieved in subsequent rounds. Consensus was reached on six outcomes: 1) language functioning in modalities relevant to study aims; 2) impact of treatment from the perspective of the person with aphasia (PWA); 3) communication-related quality of life; 4) satisfaction with intervention from the perspective of the PWA; 5) satisfaction with ability to communicate from the perspective of the PWA; and 6) satisfaction with participation in activities from the perspective of the PWA.

Conclusions: Consensus was reached that it is essential to measure language function and specific patient-reported outcomes in all aphasia treatment research. These results will contribute to the development of a core outcome set.

Keywords: Outcome measurement, Aphasia, e-Delphi, Core outcome set, ICF.

4.2 Introduction

Aphasia treatment research requires improved, coordinated approaches to outcome measurement (Brady et al., 2014a; Hula, Fergadiotis, & Doyle, 2014; MacWhinney, 2014; Wallace, Worrall, Rose, & Le Dorze, 2014). Presently, the quality, efficiency, and transparency of treatment research is constrained by the use of heterogeneous outcome measures across studies, a lack of agreement regarding important treatment outcomes, and incomplete reporting of outcome data. Outcome measurement practices in aphasia treatment studies will (and should) reflect the specific aims of each individual study. The compatibility of research data and the overall strength of treatment evidence however, may be improved through the measurement of a minimum set of outcomes, with consistent outcome measures, across treatment studies.

Efficient outcome measurement not only allows the detection of meaningful change within individual studies, but also facilitates data comparison, aggregation, and synthesis across trials (Brady et al., 2014b). The multitude of outcome measures used across aphasia treatment studies has been widely cited as an impediment to the synthesis of data in systematic reviews. The Cochrane review of speech and language therapy for aphasia following stroke (Brady, Kelly, Godwin, & Enderby, 2012); and four independent systematic reviews of: 1) intensity of treatment and constraint-induced language therapy (CILT) (Cherney, Patterson, Raymer, Frymark, & Schooling, 2008); 2) communication partner training in aphasia (Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010); 3) treatment for bilingual individuals with aphasia (Faroqi-Shah, Frymark, Mullen, & Wang, 2010) and, 4) outpatient and community-based aphasia group interventions (Lanyon, Rose, & Worrall, 2012); have all identified the use of heterogeneous outcome measures as an obstruction to the synthesis of research findings. Encouraging the use of some core outcome measures may allow data to be more easily compared and combined across studies.

The efficiency of research is further reduced by a lack of consistency in the outcome constructs measured across studies. Systematic reviews reveal that Body Function (impairment level) outcomes are most often measured in aphasia treatment studies (Brady et al., 2012; Elsner, Kugler, Pohl, & Mehrholz, 2015; Xiong, Bunning, Horton, & Hartley, 2011), while broader outcomes relating to Activity and Participation, quality of life, psychosocial wellbeing, satisfaction, and economic costs are measured infrequently (Brady et al., 2012; Cherney et al., 2008; Elsner et al., 2015; Lanyon, Rose, & Worrall, 2013;

Simmons-Mackie et al., 2010). The emphasis on body function outcomes in individual treatment studies suggests that researchers most often equate treatment success with a change in impairment. In systematic reviews however, treatment success in the form of the primary review outcome, is often defined as communication in everyday activities, i.e. functional communication. This is exemplified by the recent Cochrane review of transcranial direct current stimulation (tDCS) for improving aphasia after stroke (Elsner et al., 2015). In this review, none of the 12 included studies addressed the selected primary review outcome of functional communication, defined as the measurement of aphasia in real-life communication settings (Elsner et al., 2015). While it is possible that the infrequent measurement of functional communication relates to the availability of appropriate outcome measure tools; this mismatch suggests a need for research examining the outcomes which aphasia researchers consider to be the most important indicators of treatment success.

The quality and transparency of aphasia treatment research is further impeded by incomplete reporting of outcome data. In the Cochrane review of speech and language therapy for aphasia, over 40% of trials failed to report final outcome measures on all participants (Brady et al., 2014b; Brady et al., 2012). The selective reporting of outcomes has also been identified as a burgeoning issue in treatment studies. A recent appraisal of 788 Cochrane reviews published between 2007 and 2011, found that 37% of specified outcomes were not reported (Smith, Clarke, Williamson, & Gargon, 2015). Missing outcome data and selective reporting of outcomes can result in the overestimation of treatment effects, biasing research findings (Smith et al., 2015). Requiring researchers to report on a minimum set of outcomes across studies may help to increase the quality and transparency of aphasia research.

Across a diverse range of health fields, core outcome set (COS) development is being used to improve study design, reduce research wastage, and maximise the translation of research findings to practice (see The Core Outcome Measures in Effectiveness Trials Initiative (COMET) http://www.comet-initiative.org/). A COS is a standardised set of outcomes and outcome measures for use in research trials of a particular health condition (Williamson et al., 2012). The inclusion of a minimum set of outcomes in research trials facilitates data aggregation and comparison across studies, allowing research results to be used with maximum efficiency in systematic reviews and meta-analyses. The process of COS development emphasises stakeholder input, particularly consumer perspectives, increasing relevancy of research to end-users and the likelihood that research will translate to clinical practice. The reported benefits of COSs include; increased consistency in outcome measurement and reporting across trials (Kirkham, Boers, Tugwell, Clarke, & Williamson, 2013; Sautenet, Caille, Halimi, Goupille, & Giraudeau, 2013), and increased relevancy of research through broadened research agendas and the identification of new patient relevant outcomes (de Wit, Abma, Koelewijn-van Loon, Collins, & Kirwan, 2013). COSs have also been recommended as a means of discouraging the selective reporting of outcomes (Kirkham, Gargon, Clarke, & Williamson, 2013).

The present study is part of a program of research known as ROMA (Improving Research Outcome Measurement in Aphasia; see Wallace et al. (2014)) which aims to develop a Core Outcome Set (COS) for aphasia treatment research. Consensus on a COS is sought through an international consensus conference informed by two phases of research: 1) investigation of stakeholder-important outcomes using consensus processes; and 2) a systematic review of the measurement properties of aphasia outcomes measures. The current study is one of three studies examining stakeholder perspectives on aphasia treatment outcomes. The perspectives of people with aphasia and their families (Wallace, Worrall, Rose, Le Dorze, et al., 2016a), and aphasia clinicians and managers have also been gathered (Wallace, Worrall, Rose, & Le Dorze, 2016b). The current study aimed to identify outcome constructs which aphasia researchers consider essential to measure in all aphasia treatment research.

4.3 Methods

4.3.1 Study Design

This study used a multiple methods research design, comprising a three-round e-Delphi exercise, qualitative content analysis, and International Classification of Functioning Disability and Health (ICF; (World Health Organization., 2001)) coding. A three-round e-Delphi exercise was carried out between March 2014 and February 2015. Ethical approval was obtained from the Behavioural and Social Sciences Ethical Review Committee at The University of Queensland, Australia.

4.3.2 The Delphi Technique

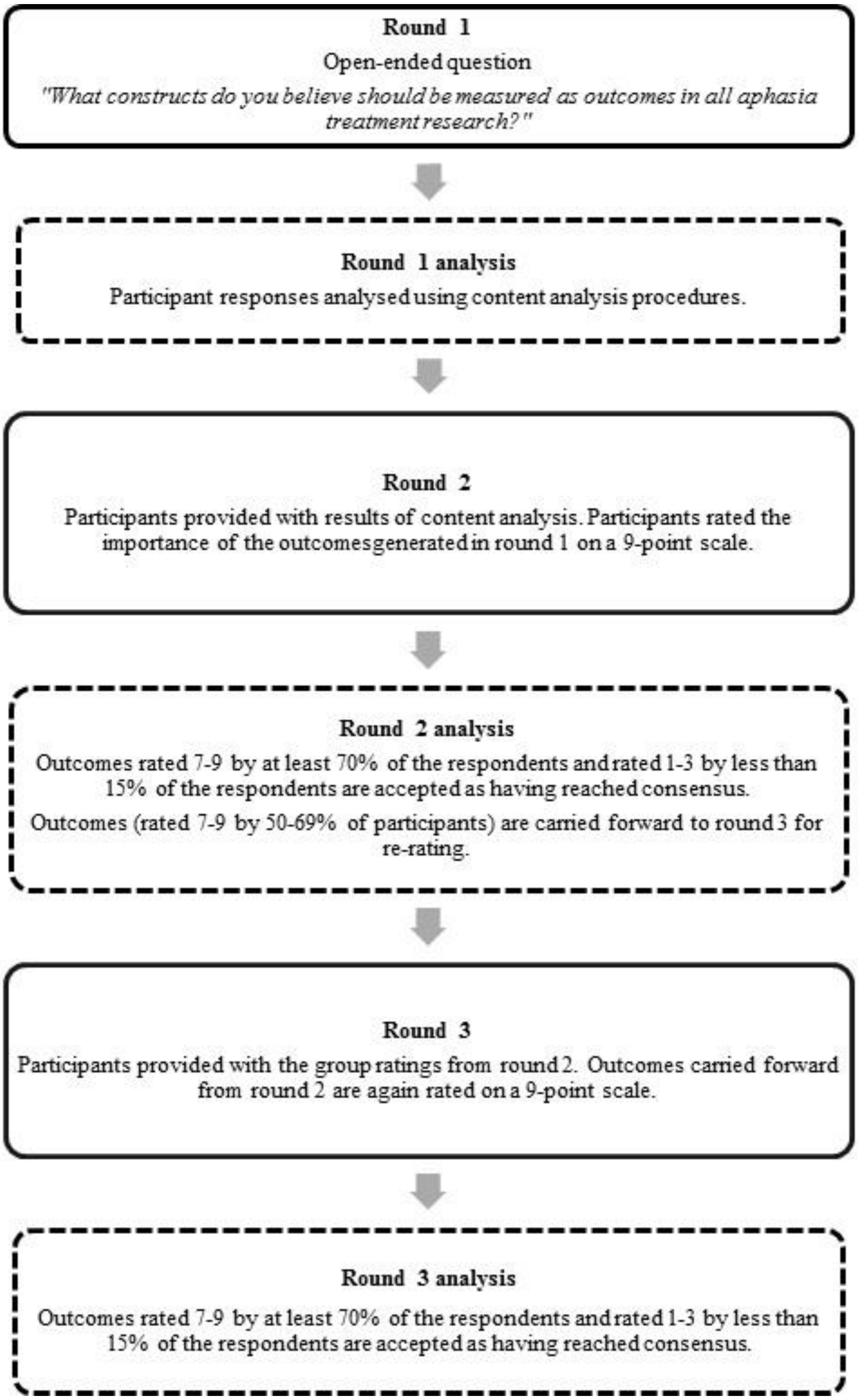
The Delphi technique was used to identify and gain consensus on essential treatment outcomes. The Delphi technique is a structured decision making process which uses a series of questionnaires, which progressively become narrower in focus to reach a consensus (Delbecq, Van de Ven, & Gustafson, 1975). Use of the electronic or e-Delphi has increased in research due to its convenience, cost and time effectiveness, and ability to accommodate geographically disparate participants (Donohoe, Stellefson, & Tennant, 2012). Methodological considerations and reporting guidelines for using the Delphi technique in the development of COSs (see Sinha, Smyth, & Williamson, 2011) were adhered to throughout the current study. The Delphi technique has been used to gain consensus on COSs in numerous health disciplines including; upper limb amputation rehabilitation (Nimhurchadha, Gallagher, Maclachlan, & Wegener, 2013), childhood ischaemic stroke (Edwards, Dunlop, Mallick, & O'Callaghan, 2015), eczema (Schmitt, Langan, Stamm, Williams, & Harmonizing Outcome Measurements in Eczema Delphi, 2011), and migraine treatment (Smelt et al., 2014).

4.3.3 Participants

Purposively sampled aphasia researchers were invited to participate in this study. A list of researchers working in the field of aphasia treatment research was compiled from two sources: (1) the authors of studies included in the Cochrane Collaboration review of "Speech and language therapy for aphasia following stroke" (Brady et al., 2012), and (2) the 100 most highly published aphasia treatment researchers in the Web of Science database. The database search was conducted on the 12th December 2013 using the following search strategy: Title=(Aphasia) AND Topic=(rehabilitation); Title=(Aphasia) AND Topic=(treatment); Title=(Aphasia) AND Topic=(intervention). Timespan was restricted to the last twenty years (1993-2013) in order to maximise the likelihood that potential participants would still be actively engaged in research. No other restrictions were applied.

4.3.4 Procedures and Analysis

Procedures for each e-Delphi round were developed in accordance with the methodological recommendations of Sinha et al. (2011). In each round participants were emailed a unique link to a survey developed using the commercially available online survey system, SurveyMonkey (www.surveymonkey.com). Surveys contained both free-text, open-ended questions, and Likert rating scales (see Appendix B). Participants were also provided with an opportunity to make additional comments in each round. Figure 4-1 provides an overview of the procedures and methods of analysis used across the three rounds of the e-Delphi exercise.



Round 1

Open-ended question

"What constructs do you believe should be measured as outcomes in all aphasia treatment research?"

Round 1 analysis

Participant responses analysed using content analysis procedures.

Round 2

Participants provided with results of content analysis. Participants rated the importance of the outcomes generated in round 1 on a 9-point scale.

Round 2 analysis

Outcomes rated 7-9 by at least 70% of the respondents and rated 1-3 by less than 15% of the respondents are accepted as having reached consensus.

Outcomes (rated 7-9 by 50-69% of participants) are carried forward to round 3 for re-rating.

Round 3

Participants provided with the group ratings from round 2. Outcomes carried forward from round 2 are again rated on a 9-point scale.

Round 3 analysis

Outcomes rated 7-9 by at least 70% of the respondents and rated 1-3 by less than 15% of the respondents are accepted as having reached consensus.

Figure 4-1. Overview of the E-Delphi Process

4.3.4.1 Round 1: Idea generation. In round 1, participants were asked, “What constructs do you believe should be measured as outcomes in all aphasia treatment research?". An open-ended question was used to reduce the risk of bias through prompting or guiding participant responses (Sinha et al., 2011). This question was piloted and refined prior to distributing the survey. Participants recorded their responses in a free-text box, with no restriction on length of response.

Analysis. Participant responses were analysed using inductive qualitative content analysis procedures (Graneheim & Lundman, 2004). Each participant response was analysed for meaning units (i.e., words, phrases, or sentences expressing an idea). Meaning units were subsequently organised into codes, sub-categories, categories, and themes based on the presence of common meaning elements. An example of this process is provided in table 4-1. Content analysis was performed by two authors.

Rigour. To enhance the rigour and trustworthiness of the content analysis procedures, a process of ‘peer debriefing’ was employed. A full content analysis was initially completed by one author. At the completion of this analysis, all participant responses were examined and discussed with a co-author to check the coding, categorization, and higher order themes to ensure the reasonableness of the interpretations made. An ‘audit trail’ (see Koch, 2006) was maintained demonstrating the full analysis process: raw data (i.e., survey responses), data reduction and interpretation (i.e., identification of meaning units and interpretation of meaning), and analysis products (i.e., the resulting themes, categories and sub-categories).

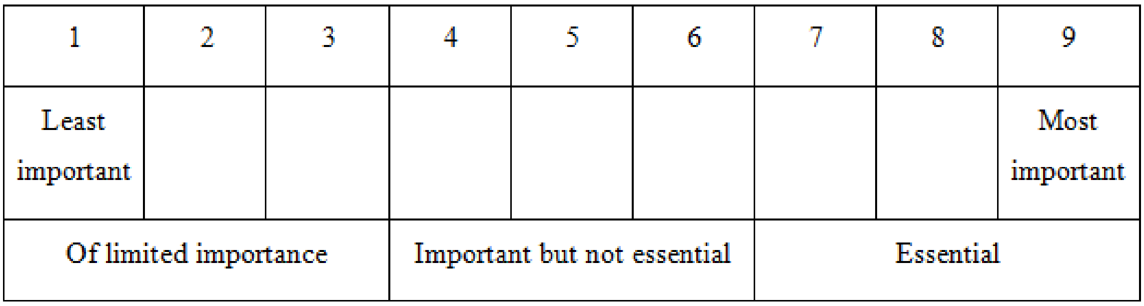
Table 4-1

Example of Content Analysis

Meaning unit	Code	Sub-category	Category	Theme
“…personal financial well-being, costs and cost-effectiveness to society”	1. Personal financial wellbeing	The impact of a treatment should be measured in terms of the costs incurred by the person with aphasia	The impact of a treatment on resources and finances should be measured	Outcome constructs
	2. Costs and cost-effectiveness to society	The impact of a treatment should be measured in terms of cost/benefit to the wider community		

4.3.4.2 Round 2. The results of the content analysis were provided to all participants who completed round 1 in order to allow them to consider their own responses in reference to those of the wider group. Participants were then asked to rate the importance of each outcome (at a sub-category level), using a modified version of the GRADE working group 9-point rating scale (see www.gradeworkinggroup.org) (refer to figure 4-2). The presentation of outcomes was randomised to prevent any order effect.

Analysis. The number and percentage of participants rating each outcome as, 'of limited importance' (1-3), 'important but not essential' (4-6), and 'essential' (7-9) was calculated. Consensus that an outcome was essential to measure in all aphasia treatment research was predefined as a rating of 7-9 by at least 70% of the respondents and 1-3 by less than 15% of the respondents (Williamson et al., 2012). Outcomes that reached consensus in round 2 were identified and were not carried forward for further rating. Outcomes rated 7-9 by 50-69% of participants were considered inconclusive and these items formed the basis of round 3.



1	2	3	4	5	6	7	8	9
Least important								Most important
Of limited importance			Important but not essential			Essential		

Figure 4-2. Modified GRADE Working Group 9-Point Rating Scale

4.3.4.3 Round 3. A summary of the round 2 ratings was provided to all participants to allow them to consider their individual ratings in reference to the wider group ratings. The inconclusive outcomes from round 2 were presented for re-rating using the same 9-point scale.

Analysis. The number and percentage of outcomes rated, 'of limited importance' (1-3), 'important but not essential' (4-6) and 'essential' (7-9) were calculated. The same predefined consensus criteria used in round 2, was again used in round 3.

ICF coding. All outcomes reaching consensus were further analysed using ICF coding. Classification of outcomes using the common metric of the ICF was used to enable the comparison of results from this study, with the results from other participant groups within the ROMA project (Wallace, Worrall, Rose, & Le Dorze, 2016a; Wallace, Worrall, Rose, Le Dorze, et al., 2016b). ICF linking rules developed by Cieza and associates (2002; 2005), and Worrall and associates (2011) were used to code each outcome to the most precise ICF code/s possible.

Reliability of coding. Each outcome reaching consensus was independently linked to the ICF by a second researcher experienced in ICF coding. While the use of the kappa statistic is recommended when assessing the inter-rater reliability of ICF coding (Cieza et al., 2005), it is generally agreed that sample sizes should not consist of less than 30 comparisons (McHugh, 2012). Accordingly, a group agreement method was used to ensure the reliability of coding for the small number of outcomes linked to the ICF in the current study. Using this approach, any differences in ICF coding were examined by a third independent rater; all three raters then discussed coding discrepancies and made corresponding amendments to produce a final dataset.

4.4 Results

4.4.1 Description of Participants

A pool of 138 aphasia treatment researchers was compiled. Nine potential participants were removed as they had either retired, were ineligible (i.e., were authors of the current study), or their contact details could not be located. In total, 129 researchers were invited to participate in round 1. Eighty aphasia researchers commenced this round equating to a 62% response rate. Of these participants, the majority reported that they primarily conducted aphasia research in the United States of America (n = 33, 42%), the United Kingdom (n = 20, 25%), and Australia (n = 12, 15%) (see table 4-2). One participant was disqualified as they indicated that they had not published an aphasia treatment study, despite being a published aphasia treatment researcher. In total, 72 researchers completed all of the questions in round 1 and consented to receiving subsequent surveys in the e-Delphi process. The majority of these aphasia researchers had published between 1 and 4 (n = 33, 45%) aphasia treatment studies. Response rates of 88% and 85% were achieved in the second and third e-Delphi rounds respectively. Response rates and attrition across rounds are detailed in figure 4-3.

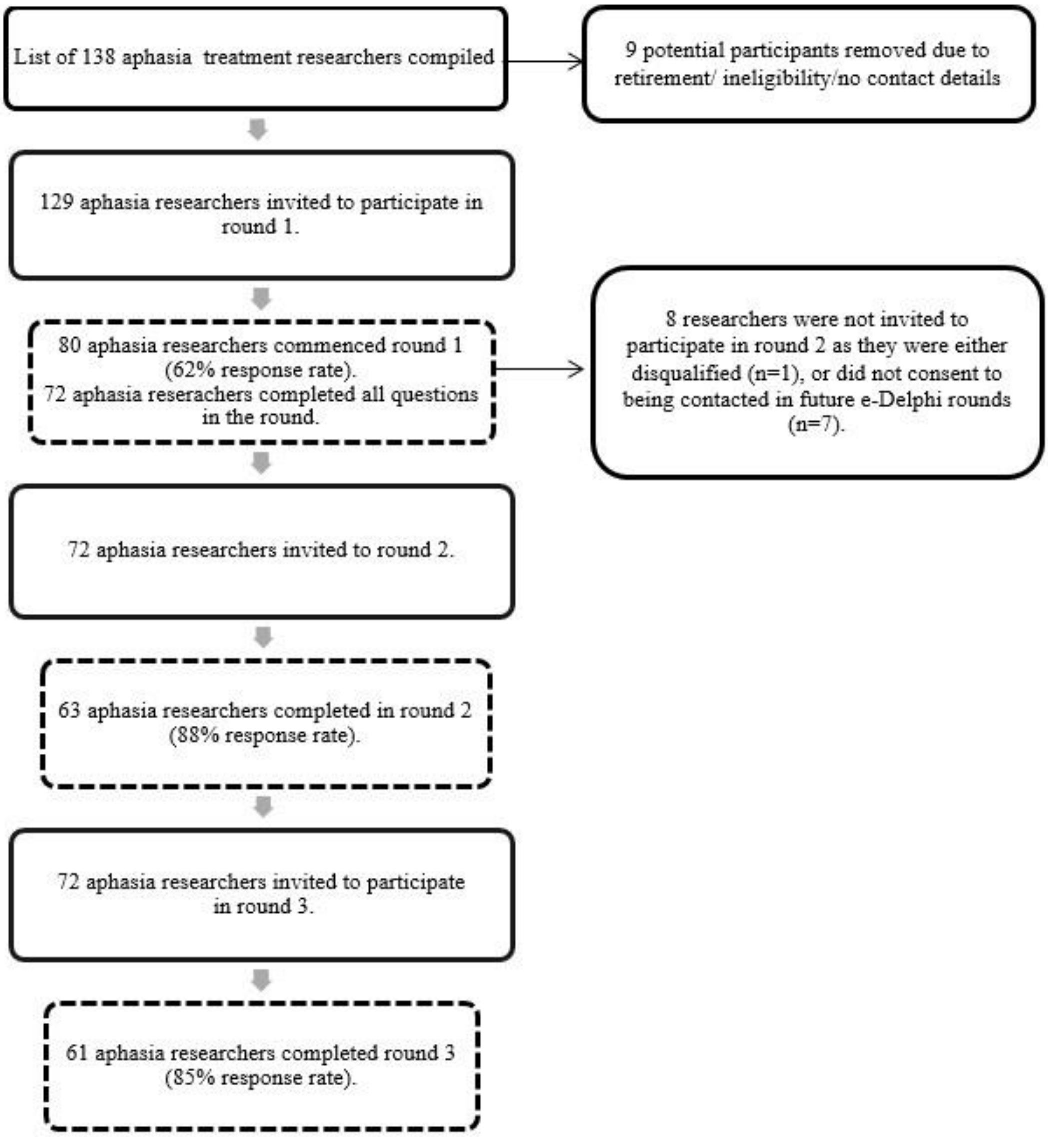


Figure 4-3. Participant Response Rates and Attrition Across Three e-Delphi Rounds

Table 4-2

Participants Commencing Round 1 by Country (n = 80)

Country in Which Research is Primarily Conducted	Number of Participants (%)
United States of America	33 (42)
United Kingdom	20 (25)
Australia	12 (15)
Canada	4 (5)
Germany	4 (5)
Did not state	2 (3)
Finland	1 (1)
Ireland	1 (1)
New Zealand	1 (1)
Spain	1 (1)
Sweden	1 (1)

4.4.2 Round 1

The responses generated in round 1 were analysed using inductive qualitative content analysis. Analysis of participant responses produced 564 codes which were organised into sub-categories, categories, and themes. Two themes were identified: outcome constructs (i.e., what specific constructs should be measured); and outcomes principles (i.e., items which focused on how outcomes should be measured e.g., from whose perspective or in what context an outcome should be measured) (see table 4-3). The outcomes within these two themes were presented at a sub-category level for rating in round 2.

Table 4-3

Round 1 Content Analysis Results: Themes and Categories

Themes	Categories
1. Outcome principles	1. Outcomes should be measured across all ICF domains, in a variety of contexts, with a variety of communication partners
	2. The satisfaction of the person with aphasia should be measured
	3. The satisfaction of partner/significant others/family should be measured
	4. The impact of a treatment should be measured from a range of perspectives
	5. The impact of a treatment on everyday communication should be measured
	6. Generalisation of treatment outcomes should be measured
2. Outcome constructs	7. Linguistic function
	8. Neural structure and function and extra-linguistic function
	9. Discourse
	10. Functional communication
	11. Psychosocial impact
	12. Impact on family members/significant others/carers
	13. Resources and finances

4.4.3 Round 2

Forty-nine sub-categories of outcomes formed the items rated in round 2 (refer to table 4-4). The outcomes which reached consensus were: 1) The impact of every treatment should be measured from the perspective of the person with aphasia; 2) In every study, satisfaction with ability to communicate should be measured from the perspective of the person with aphasia; 3) In every study, satisfaction with participation in activities should be measured from the perspective of the person with aphasia, and 4) The impact of a treatment on communication-related quality of life should be measured in every aphasia treatment study. The ratings of a further 17 outcomes were inconclusive and were examined further in round 3.

Additional comments: Participants were able to make additional comments in each e-Delphi round. In round 2, a frequently raised issue was the need to make a distinction between the measurement of language function in modalities relevant to the aims of a study versus routine measurement of language in all modalities. This led to the inclusion of two new outcomes, "language functioning in modalities relevant to study aims"; and "language functioning in all modalities" in round 3.

4.4.4 Round 3

In round 3, two further outcomes reached consensus, "Language functioning (in modalities relevant to study aims) should be measured in every treatment study" and "In every study, satisfaction with the intervention should be measured from the perspective of the person with aphasia". No further outcomes reached consensus (refer to table 4-5).

Table 4-4

Round 2 Participant Ratings and Response Counts

Outcome sub-categories	Participant ratings												Response count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 total	4	5	6	4-6 total	7	8	9	7-9 total	
1. The impact of every treatment should be measured from the perspective of the person with aphasia (n=21)#	2	0	1	3 (5%)	0	5	4	9 (14%)	16	11	24	51 (81%)*	63
2. Communication-related quality of life (n=6)	2	0	2	4 (7%)	2	2	6	10 (16%)	16	13	18	47 (77%)*	61
3. In every study, satisfaction with ability to communicate should be measured from the perspective of the person with aphasia (n=3)	1	0	3	4 (6%)	2	5	7	14 (22%)	13	9	23	45 (71%)*	63
4. In every study, satisfaction with participation in activities should be measured from the perspective of the person with aphasia (n=1)	2	0	3	5 (8%)	3	5	6	14 (22%)	22	5	17	44 (70%)*	63

Outcome sub-categories	Participant ratings												Response count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 total	4	5	6	4-6 total	7	8	9	7-9 total	
5. In every study, satisfaction with the intervention should be measured from the perspective of the person with aphasia (n=9)	3	0	0	3 (5%)	1	5	11	17 (27%)	15	11	17	43 (68%)**	63
6. The impact of every treatment should include measurement at the Activity/Participation level of the ICF (n=15)	1	0	1	2 (3%)	4	8	7	19 (30%)	14	13	15	42 (67%)**	63
7. Ability to engage in conversation (n=22)	4	0	1	5 (8%)	3	4	8	15 (25%)	19	9	13	41 (67%)**	61
8. Participation in social interactions and social networks (n=21)	4	0	1	5 (8%)	5	5	7	17 (28%)	15	12	11	38 (63%)**	60
9. Participation in activities (n=8)	3	0	1	4 (6%)	3	7	9	19 (31%)	11	17	11	39 (63%)**	62
10. The impact of every treatment on functional communication should be measured (n=40)	1	0	2	3 (5%)	4	4	14	22 (35%)	9	14	15	38 (60%)**	63

Outcome sub-categories	Participant ratings												Response count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 total	4	5	6	4-6 total	7	8	9	7-9 total	
11. Overall quality of life and well-being (n=36)	4	0	0	4 (7%)	1	7	13	21 (34%)	12	9	15	36 (59%)**	61
12. Discourse (e.g. Conversation, elicited, procedural, propositional discourse) (n=6)	3	1	1	5 (8%)	6	5	10	21 (34%)	19	7	9	35 (57%)**	61
13. Generalisation of treatment outcomes across contexts should be measured in every study (n=2)	2	0	6	8 (13%)	2	5	12	19 (30%)	15	10	11	36 (57%)**	63
14. In every study, satisfaction with information provided should be measured from the perspective of the person with aphasia (n=1)	3	2	6	11 (17%)	4	7	7	18 (29%)	14	6	14	34 (54%)**	63
15. Communication confidence (n=6)	3	0	3	6 (10%)	4	3	14	21 (34%)	10	14	11	35 (56%)**	62
16. Aphasia severity (n=3)	4	1	3	8 (13%)	4	3	13	20 (32%)	11	12	11	34 (55%)**	62

Outcome sub-categories	Participant ratings												Response count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 total	4	5	6	4-6 total	7	8	9	7-9 total	
17. Communication partner effectiveness (n=4)	4	0	6	10 (16%)	4	4	10	18 (29%)	11	17	6	34 (55%)**	62
18. Autonomy /independence (n=4)	4	1	2	7 (11%)	5	4	14	23 (37%)	17	10	5	32 (52%)**	62
19. Verbal expression (n=14)	7	0	1	8 (13%)	7	6	10	23 (37%)	16	8	7	31 (50%)**	62
20. In every study, satisfaction with ability to communicate with the person with aphasia should be measured from the perspective of the partner/significant others/family (n=2)	2	0	7	9 (14%)	5	10	9	24 (38%)	12	15	3	30 (48%)	63
21. The impact of every treatment should be measured from the perspective of family members/significant others/carers (n=14)	2	0	5	7 (11%)	6	12	9	27 (43%)	13	13	3	29 (46%)	63
22. General confidence/ self-esteem (n=7)	3	1	1	5 (8%)	10	3	16	29 (47%)	10	10	8	28 (45%)	62

Outcome sub-categories	Participant ratings												Response count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 total	4	5	6	4-6 total	7	8	9	7-9 total	
23. In every study, outcomes should be measured in a range of communication contexts (n=4)	1	0	4	5 (8%)	6	9	15	30 (48%)	12	9	7	28 (44%)	63
24. In every study, outcomes should be measured across all World Health Organization International Classification of Functioning, Disability and Health (ICF) domains (n=12)	5	1	5	11 (17%)	6	10	9	25 (40%)	10	11	6	27 (43%)	63
25. Mood (including depression and anxiety) (n=9)	4	1	2	7 (11%)	8	7	16	31 (50%)	12	7	5	24 (39%)	62
26. Generalisation of treatment outcomes across linguistic domains should be measured in every study (n=12)	5	0	8	13 (21%)	8	5	13	26 (41%)	9	8	7	24 (38%)	63

Outcome sub-categories	Participant ratings												Response count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 total	4	5	6	4-6 total	7	8	9	7-9 total	
27. In every study, satisfaction with inclusion in decision making should be measured from the perspective of the person with aphasia (n=1)	3	0	3	6 (10%)	11	11	12	34 (54%)	9	6	8	23 (37%)	63
28. In every study, satisfaction with information provided should be measured from the perspective of the partner/significant others/family (n=1)	5	0	5	10 (16%)	7	13	10	30 (48%)	13	5	5	23 (37%)	63
29. Participation in previous life roles (n=9)	6	1	4	11 (18%)	7	5	17	29 (47%)	12	7	3	22 (35%)	62
30. Auditory comprehension (n=12)	7	0	2	9 (15%)	9	10	11	30 (50%)	12	5	4	21 (35%)	60
31. Identity and adjustment to new circumstances (n=9)	6	2	3	11 (18%)	6	10	14	30 (49%)	11	6	3	20 (33%)	61

Outcome sub-categories	Participant ratings												Response count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 total	4	5	6	4-6 total	7	8	9	7-9 total	
32. In every study, satisfaction with the intervention should be measured from the perspective of the partner/significant others/family (n=5)	2	1	6	9 (14%)	7	10	16	33 (52%)	14	5	2	21 (33%)	63
33. In every study, satisfaction with interpersonal relationships should be measured from the perspective of the person with aphasia (n=2)	4	0	7	11 (17%)	8	13	11	32 (51%)	7	4	9	20 (32%)	63
34. Cognitive function (n=13)	6	1	5	12 (20%)	9	9	12	30 (49%)	12	3	4	19 (31%)	61
35. The impact of every treatment should be measured from the perspective of the speech-language pathologist/others (e.g. naive raters) (n=5)	6	1	6	13 (21%)	4	15	13	32 (51%)	10	5	3	18 (29%)	63

Outcome sub-categories	Participant ratings												Response count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 total	4	5	6	4-6 total	7	8	9	7-9 total	
36. The impact of every treatment should be measured in terms of cost/benefit to service providers (n=20)	4	3	8	15 (24%)	12	10	8	30 (48%)	11	4	3	18 (29%)	63
37. The overall quality of life and wellbeing of family/significant others/carers (n=12)	6	0	8	14 (23%)	6	7	17	30 (48%)	12	5	1	18 (29%)	62
38. The impact of every treatment should be measured in terms of costs incurred by the person with aphasia (n=3)	2	6	9	17 (27%)	8	10	11	29 (46%)	8	5	4	17 (27%)	63
39. Sub-components of language (e.g. Lexical retrieval, retrieval latency) (n=12)	4	1	5	10 (16%)	13	14	9	36 (58%)	8	3	5	16 (26%)	62
40. The impact of every treatment should be measured in terms of cost/benefit to the wider community (n=8)	4	2	10	16 (25%)	12	13	6	31 (49%)	11	4	1	16 (25%)	63

Outcome sub-categories	Participant ratings												Response count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 total	4	5	6	4-6 total	7	8	9	7-9 total	
41. Ability of family/significant others/carers to participate in daily life (n=6)	6	0	8	14 (23%)	8	9	17	34 (55%)	11	2	1	14 (23%)	62
42. The mood (e.g. Depression, anxiety) of family/significant others/carers (n=7)	7	0	9	16 (26%)	7	10	16	33 (53%)	6	5	2	13 (21%)	62
43. Ability to use multi-modal communication (n=5)	7	1	2	10 (16%)	13	11	13	37 (61%)	7	5	2	14 (23%)	61
44. In every study, satisfaction with inclusion in decision making should be measured from the perspective of the partner/significant others/family (n=1)	4	4	10	18 (29%)	9	12	10	31 (49%)	7	5	2	14 (22%)	63
45. In every study, outcomes should be measured with a variety of communication partners (n=5)	5	1	9	15 (24%)	8	12	17	37 (59%)	7	4	0	11 (17%)	63
46. Written expression (n=4)	6	3	2	11 (18%)	10	13	15	38 (63%)	6	3	2	11 (18%)	60

Outcome sub-categories	Participant ratings												Response count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 total	4	5	6	4-6 total	7	8	9	7-9 total	
47. Reading comprehension (n=5)	6	1	3	10 (16%)	14	11	16	41 (67%)	4	4	2	10 (16%)	61
48. Neural structure and function (n=7)	8	4	13	25 (40%)	11	7	15	33 (53%)	3	1	0	4 (6%)	62
49. The impact of every treatment should be measured using biomarkers (e.g. physical stress indicators such as cortisol levels) (n=5)	15	12	11	38 (60%)	13	7	2	22 (35%)	2	1	0	3 (5%)	63

*Rated 7-9 by ≥ 70% and 1-3 by ≤ 15% of participants (i.e., consensus)

**Rated 7-9 by 50-69% of participants (i.e., inconclusive)

n= number of codes within sub-category

Table 4-5

Round 3 Participant Ratings and Response Counts

Outcome sub-categories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
1. In every study, satisfaction with the intervention should be measured from the perspective of the person with aphasia	2	1	0	3 (5%)	2	5	4	11 (18%)	17	17	13	47 (77%)*	61
2. Language functioning (in modalities relevant to study aims) should be measured in every aphasia treatment study	1	2	2	5 (8%)	2	3	5	10 (16%)	8	11	27	46 (75%)*	61
3. The impact of every treatment on functional communication should be measured	1	0	1	2 (3%)	2	7	8	17 (28%)	12	9	21	42 (69%)**	61
4. The impact of every treatment should include measurement at the Activity/Participation level of the ICF	2	0	1	3 (5%)	5	6	7	18 (30%)	12	17	11	40 (66%)**	61
5. Overall quality of life and well-being	1	0	2	3 (5%)	4	8	12	24 (39%)	11	14	9	34 (56%)**	61

Outcome sub-categories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
6. Generalisation of treatment outcomes across contexts should be measured in every study	2	2	2	6 (10%)	6	9	7	22 (36%)	8	13	12	33 (54%)**	61
7. Participation in activities	1	0	2	3 (5%)	5	6	15	26 (43%)	13	14	5	32 (52%)**	61
8. Ability to engage in conversation	1	1	1	3 (5%)	6	6	15	27 (44%)	7	14	10	31 (51%)**	61
9. Discourse (e.g. conversation, elicited, procedural, propositional discourse)	1	1	6	8 (13%)	6	6	10	22 (36%)	11	12	8	31 (51%)**	61
10. Aphasia severity	4	3	7	14 (23%)	7	4	8	19 (31%)	11	8	9	28 (46%)	61
11. Participation in social interactions and social networks	1	1	3	5 (8%)	9	9	11	29 (48%)	10	9	8	27 (44%)	61
12. In every study, satisfaction with information provided should be measured from the perspective of the person with aphasia	2	2	0	4 (7%)	5	12	13	30 (49%)	11	9	7	27 (44%)	61

Outcome sub-categories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
13. Communication confidence	1	0	3	4 (7%)	9	8	14	31 (51%)	8	12	6	26 (43%)	61
14. Verbal expression	1	2	6	9 (15%)	6	9	12	27 (44%)	10	10	5	25 (41%)	61
15. Autonomy/independence	1	0	2	3 (5%)	11	16	13	40 (66%)	9	6	3	18 (30%)	61
16. Communication partner effectiveness	4	2	6	12 (20%)	9	12	12	33 (54%)	9	5	2	16 (26%)	61
17. Language functioning (in ALL modalities) should be measured in every aphasia treatment study	3	5	9	17 (28)	5	15	8	28 (46%)	7	5	4	16 (26%)	61

*Rated 7-9 by ≥ 70% and 1-3 by ≤ 15% of participants (i.e., consensus)

**Rated 7-9 by 50-69% of participants (i.e., inconclusive)

4.5 Overall Results

In total, six outcomes reached consensus as being essential to measure in all aphasia treatment research (see table 4-6). Consensus was reached that it is essential to measure language functioning in modalities relevant to study aims. The remaining five outcomes reflected patient reported outcomes (PROs) encompassing communication-related quality of life, the person with aphasia's perception regarding the impact of the intervention and their satisfaction with their communication ability, participation in activities, and the intervention.

Table 4-6

Outcomes Reaching Consensus

1. The impact of every treatment should be measured from the perspective of the person with aphasia (81%)
2. Communication-related quality of life should be measured in every aphasia treatment study (77%)
3. In every study, satisfaction with the intervention should be measured from the perspective of the person with aphasia (77%)
4. Language functioning (in modalities relevant to study aims) should be measured in every aphasia treatment study (75%)
5. In every study, satisfaction with ability to communicate should be measured from the perspective of the person with aphasia (71%)
6. In every study, satisfaction with participation in activities should be measured from the perspective of the person with aphasia (70%)

4.5.1 ICF Coding

The six outcomes reaching consensus were linked to the ICF at the most specific level possible. Some outcomes contained multiple concepts and were linked to more than one ICF code. The outcomes reaching consensus linked to eight ICF codes, which spanned all ICF components (i.e. Body Functions, Activity/Participation, Environmental and Personal Factors). Two concepts could not be coded to the ICF, and were classified as non-definable quality of life (refer to tables 4-7 and 4-8).

Table 4-7

ICF Linkages for Outcomes Reaching Consensus

ICF code	ICF description	Number of times coded
b	Body Functions	1
b167	Mental functions of language	1
d	Activity/Participation	2
d3	Communication	1
e	Environmental Factors	1
e5800	Health services	1
pf	Personal Factors	1
Nd-qol	Non-definable quality of life	2

Table 4-8

Distribution of Linkages to ICF Components

ICF component	ICF linkages n (%)
Body Functions	2 (20)
Activity/Participation	3 (30)
Environmental Factors	2 (20)
Personal Factors	1 (10)
Non-definable quality of life	2 (20)
Total linkages	10 (100)

4.6 Discussion

This international study describes a three-round e-Delphi exercise which aimed to identify outcome constructs which aphasia researchers considered essential to measure in all aphasia treatment research. Consensus was reached that it is essential to measure each of the following six outcomes: The impact of treatment from the perspective of the person with aphasia; communication-related quality of life; satisfaction with the intervention from the perspective of the person with aphasia; language functioning in modalities relevant to the study's aims; satisfaction with ability to communicate from the perspective of the person with aphasia; and satisfaction with participation in activities from the perspective of the person with aphasia. ICF coding revealed that these outcomes spanned all ICF components (Body Functions, Activity/Participation, Personal, and Environmental Factors) and also extended to quality of life. The outcomes reaching consensus are discussed further below.

4.6.1 Patient-Reported Outcomes

The majority of outcomes reaching consensus in this study were patient-reported outcomes (PROs). The United States Food and Drug Administration (FDA) (Food and Drug Administration, 2009) defines PROs as, "…any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else" (p. 2). The inclusion of PRO measures in clinical trials is increasingly recommended (Food and Drug Administration, 2009). A recent review of registered clinical trials in the United States' ClinicalTrials.gov database demonstrated that of 96,736 registered trials, 26,337 (27%) used one or more PRO measures. Growing use of PRO measures has prompted the development of a range of guidelines for their use in clinical trials (Calvert et al., 2014), most notably the methodological standards produced by PCORI (the Patient-Centered Outcomes Research Institute) (Methodology Committee of PCORI, 2012) and the extension of the CONSORT (Consolidated Standards of Reporting Trials) statement to include specific PRO reporting requirements (Calvert, Blazeby, Altman, & et al., 2013; Calvert, Brundage, Jacobsen, Schünemann, & Efficace, 2013).

4.6.1.1 Impact of treatment. Consensus was reached that it is essential to measure the impact of treatment from the perspective of the person with aphasia in all aphasia treatment studies. "Impact of treatment" is a broad construct which, when considered in reference to the ICF, may relate to the impact of a treatment on some or all ICF components: Body Functions and Structures, Activity/Participation, Environmental, and Personal Factors. It may also describe the impact of treatment on broader constructs not captured within the ICF, such as quality of life. Consensus on this outcome suggests recognition from aphasia researchers of an overall need to measure outcomes from the patient perspective. This finding supports the notion that the perspectives of people with aphasia themselves are essential indicators of the effectiveness of a treatment and acknowledges that some important outcomes cannot be observed, but must be gauged through the perceptions, feelings, and experiences of patients themselves (de Riesthal & Ross, 2015).

4.6.1.2 Satisfaction with communication and participation. Consensus was reached that it is essential to measure patient satisfaction at an ICF Activity/Participation level, specifically in relation to communication and participation in activities. These findings are consistent with research examining important outcomes from the perspective of people living with aphasia (Wallace, Worrall, Rose, Le Dorze, et al., In press). In this related study, the outcomes prioritised by people with aphasia most frequently linked to the ICF Activity/Participation component and, within this component, to the communication chapter. Despite evidence that people with aphasia and aphasia researcher consider functional outcomes to be important, these constructs are still infrequently measured in aphasia research (Brady et al., 2012; Cherney et al., 2008; Elsner et al., 2015; Lanyon et al., 2013; Simmons-Mackie et al., 2010). There is a need to determine whether suitable tools exist for measuring patient satisfaction with activities and participation.

4.6.1.3 Communication-related quality of life. Consensus was reached that communication-related quality of life should be measured in all aphasia treatment research. Communication-related quality of life is defined as, “the extent to which a person’s communication acts—influenced by personal and environmental factors, and filtered through a person’s own perspective—allow meaningful participation in life situations.” (Paul et al., 2004, p. 1). The identification of communication related quality of life as an essential treatment outcome reflects the wide body of evidence demonstrating the correlation between aphasia and reduced quality of life. In a large study of over 65,000 hospital-based long-term care (LTC) residents in Canada, aphasia had the greatest negative relationship (of 60 diseases and 15 health conditions) to quality of life (Lam & Wodchis, 2010). This finding is mirrored within the stroke population, with lower ratings of quality of life reported for people with aphasia compared with post-stroke patients without aphasia (Hilari, 2011). The impact of aphasia on quality of life is also recognised by clinicians. In a recent international survey of speech-language pathologists who work with people with aphasia, 74% of respondents (n=307/413) identified improving quality of life as the main aim of aphasia rehabilitation (Hilari et al., 2015). Despite a weight of evidence to support the correlation between the presence of aphasia and reduced quality of life, systematic reviews show that quality of life (communication-related or otherwise) is rarely measured in randomised control trials of aphasia treatments (see Brady et al., 2012; Simmons-Mackie et al., 2010). The identification of this construct as an essential outcome suggests recognition that aphasia impacts on all areas of life and that aphasia treatment may have beneficial effects across these areas.

4.6.1.4 Satisfaction with intervention. Consensus was reached that satisfaction with the intervention should be measured in all aphasia treatment research. Treatment satisfaction describes an individual's experience of a treatment compared with their expectations of that treatment. This PRO has been identified as a useful means of comparing the benefits of equally efficacious treatments and as an important factor influencing patient compliance with intervention (Albrecht & Hoogstraten, 1998; Wiklund, 2004). Satisfaction with intervention is a complex and multi-factorial construct which can be difficult to measure. However, PRO measures of satisfaction must meet the same standards expected of all outcome tools: validity, reliability, and sensitivity. In order to assess the face validity of satisfaction measures, it is necessary to have a clear definition of the precise construct desired to be measured, e.g., satisfaction with treatment outcomes, as distinct to satisfaction with treatment processes. Graham, Green, James, Katz, and Swiontkowski (2015) illustrated this distinction by providing the example of a treatment considered successful in terms of outcomes, but unsatisfactory due to cost or inconvenience; versus treatment which has been unsuccessful in achieving a particular desired outcome, but which was highly satisfactory due to the caring way in which it was delivered. There is a need to clearly establish the specific aspects of treatment satisfaction which researchers consider essential to measure. There is also a need to determine whether suitable measures of treatment satisfaction exist for use with people with aphasia.

4.6.2 Language Functioning in Modalities Relevant to Treatment Aims

Consensus on "language functioning in modalities relevant to treatment aims" reflects the importance of measuring study-specific outcomes in research and highlights the central role of remediating language in aphasia treatment. Research examining the desired outcomes of people with aphasia and their families within the ICF framework (World Health Organization., 2001) found that many of the outcomes prioritised by people with aphasia, and most of the outcomes prioritised by family members relating to the person with aphasia, linked to the body functions component of the ICF (Wallace, Worrall, Rose, Le Dorze, et al., In press). The identification of language functioning in "modalities relevant to study aims" reflects the importance of measuring study specific language outcomes in aphasia treatment research. Consensus on the importance of measuring study specific language outcomes, may relate to the common misperception that a COS prescribes all of the outcomes which should be measured in a study. It is important to note that COSs do not restrict the measurement of study specific outcomes, but rather provide an opportunity to increase the compatibility of research by ensuring that core and common elements in specific health areas are routinely measured.

4.7 Implications for Research and Clinical Practice

Perhaps the greatest implication of the current findings is that the majority of outcome constructs reaching consensus in this study are presently rarely measured in aphasia research. Furthermore, and perhaps in association with this finding, few validated tools exist with which to measure these constructs. There is a need for a systematic appraisal of patient reported outcome measures validated for use with people with aphasia.

In addition to the outcomes reaching consensus in this study, researchers identified a wide range of important treatment outcomes. Some of these outcomes, such as functional communication and measurement at the Activity/Participation level of the ICF, fell just below the pre-defined cut-off scores for consensus. This list of outcomes may form a useful starting point when considering outcome measurement in both research and clinical settings.

4.8 Conclusions

Consensus was reached for six outcome constructs that aphasia researchers consider essential to measure in all aphasia treatment research. Patient-reported outcomes predominated, with five of the six outcomes pertaining to the person with aphasia’s communication-related quality of life, satisfaction, and perception of treatment impact. Language functioning in modalities relevant to study aims reached consensus, acknowledging the central role of measuring improvements in language impairment in aphasia treatment. While measures of language function are frequently included in aphasia treatment trials, communication-related quality of life, patient satisfaction, and the patient perspective on treatment impact are infrequently measured. Identification of the importance of measuring these constructs, without actualisation of this need, may reflect a lack of awareness of existing tools, or the need for more appropriate measures, designed for use with people living with aphasia. Future research should explore why the majority of the identified outcomes are infrequently measured and how their inclusion in research may be better facilitated.

4.9 Limitations and Future Directions

Whilst response rates were high across all three rounds of the e-Delphi exercise, first round participant numbers may have been further increased through amendments to the study methodology. Researchers from ten countries participated in this study; however six of these countries were predominantly English-speaking. Conducting the study in English only, may have deterred non-English speaking researchers from responding to the initial invitation to participate.

It should also be noted that the outcomes which emerged from this study represent the perspectives of the participants and may therefore not be exhaustive. This study however forms just one element of a broader project to develop a COS. The perspectives of other stakeholder groups, and the results of a systematic review will inform a final international consensus meeting in which an expert panel will seek to produce a COS for aphasia treatment research.

4.10 Declaration of Interest Statement

This work was supported by an Australian Postgraduate Award (APA) scholarship awarded to Sarah J. Wallace. The authors have no other declarations of interest to report.

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Chapter 5: Which Treatment Outcomes are Most Important to Aphasia Clinicians and Managers? An International e-Delphi Consensus Study

This chapter reports the findings of an international e-Delphi exercise to gain consensus on important aphasia treatment outcomes from the perspective of aphasia clinicians and managers.

This chapter has been published in the peer-reviewed journal, *Aphasiology*: Wallace, S. J., Worrall, L., Rose, T., & Le Dorze, G. (2016). Which treatment outcomes are most important to aphasia clinicians and managers? An international e-Delphi consensus study. *Aphasiology,* 1-31. doi:10.1080/02687038.2016.1186265.

The content included in this chapter is identical to the submitted manuscript; however, the formatting has been modified to match the style of this thesis.

5.1 Abstract

Background: Clinicians have expressed frustration at the lack of strong evidence for aphasia treatments. Inconsistent outcome measurement practices across treatment trials have negatively impacted the quality and strength of evidence for aphasia interventions. Core Outcome Sets (COSs; minimum sets of outcomes/outcome measures) are increasingly being used to maximise the quality, relevancy, transparency, and efficiency of health treatment research. The current study is the third in a trilogy of stakeholder perspectives to inform the development of a COS for aphasia treatment research.

Aim: To identify essential aphasia treatment outcomes from the perspective of an international sample of clinicians and managers working in aphasia rehabilitation.

Methods and Procedures: A three-round e-Delphi exercise was conducted with aphasia clinicians and managers. In total, 265 clinicians and 53 managers (n = 318) from 25 countries participated in round 1. In round 1, participants responded to the open-ended question, "In your opinion, what are the most important outcomes (results) from aphasia treatment?" Responses were analysed using inductive content analysis. In rounds 2 and 3, 153 and 137 participants respectively rated the importance of each outcome generated in round 1 using a nine-point rating scale. Outcomes reaching predefined consensus criteria were further analysed using ICF coding.

Outcomes and Results: Analysis of round 1 participant responses produced 1709 codes, which were condensed into 90 subcategories, 25 categories, and 4 themes. In rounds 2 and 3, a total of 51 outcomes reached consensus. The two outcomes with the highest levels of consensus both related to communication between the person with aphasia and their family/carers/significant others. Outcomes relating to people with aphasia most frequently linked to the ICF Activity/Participation component (52%), whilst outcomes relating to family/carers/significant others were evenly divided between the ICF Activity/Participation component (36%) and Environmental Factors (36%).

Conclusions: Consensus was reached on 51 essential aphasia treatment outcomes. Very high levels of consensus (97-99%) between clinicians were achieved for outcomes relating to communication between the person with aphasia and their communication partner/s, suggesting that in the clinical environment improved dyadic communicative interaction is an important indicator of treatment success. The high proportion of outcomes linking to the

ICF Activity/Participation component highlights the importance of measuring outcomes beyond impairment, both in clinical and research settings. These findings will be combined with other stakeholder perspectives and a systematic review of outcome measures to develop a COS for aphasia treatment research.

Keywords: Outcome Measurement, Aphasia, e-Delphi, Core Outcome Set, Speech-Language Pathologist, ICF.

5.2 Introduction

Clinicians are frustrated by the lack of strong evidence to support aphasia rehabilitation practices (Guo, Togher, & Power, 2014; Rose, Ferguson, Power, Togher, & Worrall, 2014). Clear evidence to guide clinicians in the choice of the aphasia treatments is lacking (Brady et al., 2012). Although aphasia therapists will often use an analytic approach to tailor their treatments alongside scientific evidence, systematic reviews provide the highest level of evidence for healthcare interventions (National Health and Medical Research Council [NHMRC], 2000). The methodical identification, appraisal, and synthesis of data from individual studies that takes place in a systematic review provides an unbiased and impartial assessment of overall treatment effectiveness (Higgins & Green, 2011). In systematic reviews of aphasia treatments however, the use of heterogeneous outcome measures is frequently cited as a major obstacle to the synthesis of research data across studies (Brady et al., 2012; Cherney, Patterson, Raymer, Frymark, & Schooling, 2008; Faroqi-Shah, Frymark, Mullen, & Wang, 2010; Lanyon, Rose, & Worrall, 2013; Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010). The use of incompatible outcome measures across research studies limits cross-study comparisons and opportunities for data aggregation, constraining the efficient use of data beyond the individual study.

The outcome constructs measured in research must also be relevant to end users if evidence is to translate to clinical practice. Currently, there is little evidence to guide researchers in the selection of stakeholder-important outcomes. This is apparent in the lack of agreement between the outcomes measured in individual treatment studies and those chosen to operationalise treatment success in systematic reviews. Whilst individual aphasia research trials primarily measure outcomes at an International Classification of Functioning Disability and Health (ICF; World Health Organization, 2001) body function or impairment level (Xiong, Bunning, Horton, & Hartley, 2011), systematic reviews frequently designate functional communication (i.e., communication in real-life settings) as the primary measure of aphasia treatment effectiveness (Brady et al., 2012; Elsner, Kugler, Pohl, & Mehrholz, 2015). These issues have been the impetus for an international research project to introduce elements of standardisation to aphasia research outcome measurement.

Improving Research Outcome Measurement in Aphasia (ROMA; see Wallace, Worrall, Rose, and Le Dorze (2014b)) is an international research project which seeks to develop a Core Outcome Set (COS) for aphasia treatment research. A COS is a minimum set of outcomes and outcome measures for use in treatment trials of a particular health condition (Williamson et al., 2012). COS development pairs stakeholders' perspectives with analyses of outcome measures to identify a minimum set of outcomes and outcome measures which can be measured across research trials of a given health condition. Importantly, COSs do not restrict the measurement of study-specific outcomes, but rather provide a means of increasing the efficiency of research through the incorporation of common outcomes. For example, if a treatment efficacy study targeted a specific component of language function, the primary outcome may relate to that same component of language however, core outcomes would also be measured so that some comparisons across studies could be made. The Core Outcome Measures in Effectiveness Trials Initiative (COMET) has been instrumental in providing leadership in COS development and application. The COMET website (see http://www.comet-initiative.org/) houses a database of COS projects spanning a wide range of health intervention areas including upper limb rehabilitation post stroke, autism spectrum disorder, and neurodegenerative diseases. The reported benefits of COSs include increased consistency in the outcomes measured across research trials (Kirkham, Boers, Tugwell, Clarke, & Williamson, 2013; Sautenet, Caille, Halimi, Goupille, & Giraudeau, 2013); and greater research relevancy through the identification of patient-important outcomes and research priorities (de Wit, Abma, Koelewijn-van Loon, Collins, & Kirwan, 2013). The transparency of research may also be increased as the inclusion of core outcomes reduces opportunities for selective reporting (Kirkham, Gargon, Clarke, & Williamson, 2013). The advantages and disadvantages of a COS for aphasia treatment research have debated in a forum and are reported elsewhere (See Brady et al., 2014; Hula, Fergadiotis, & Doyle, 2014; MacWhinney, 2014; Wallace, Worrall, Rose, & Le Dorze, 2014a; Wallace et al., 2014b)

The ROMA project comprises two phases: (a) investigation of stakeholder-important outcomes using consensus processes; and (b) a systematic review of the measurement properties of the outcomes measures used with people with aphasia. The current study is the third in a trilogy of stakeholder perspectives in Phase 1. International consensus processes have been conducted with: (a) people with aphasia and their families; and (b) aphasia researchers. In the first study (Wallace, Worrall, Rose, Le Dorze, et al., In press), 39 people with aphasia and 29 family members participated in one of 16 nominal groups held across Australia, Canada, Hong Kong (China), Denmark, South Africa, the United Kingdom (UK), and the United States of America (USA). The nominal group technique was used to identify and rank important aphasia treatment outcomes. The resulting outcomes were analysed using qualitative content analysis and ICF linking. In the second study (Wallace, Worrall, Rose, & Le Dorze, In press), 80 purposively sampled aphasia researchers participated in an international three-round e-Delphi exercise. Important treatment outcomes were elicited using an open-ended question and were analysed using inductive content analysis. In subsequent rounds, participants rated the importance of measuring each outcome using a nine-point rating scale. The current study completes this trilogy by examining the perspectives of a final stakeholder group, clinicians and managers working in aphasia rehabilitation.

Chalmers and associates (2014) argue that research can be wasted if the needs of end users are ignored. As primary users of research, the needs of clinical service providers should be considered when research studies are designed. Gaining an understanding of clinically relevant outcomes is also integral to improving clinical outcome measurement. In recent years, approaches to aphasia treatment have broadened from traditional impairment-based language interventions to include approaches which focus on participation in communication activities and life roles; psychosocial well-being; and the impact of aphasia on significant others. Studies from around the world have shown that clinicians use an eclectic mix of aphasia treatment approaches often within an analytic model of treatment (Guo et al., 2014; Johansson, Carlsson, & Sonnander, 2011; Klippi, Sellman, Heikkinen, & Laine, 2012; Rose et al., 2014; Verna, Davidson, & Rose, 2009). However, in parallel with research outcome measurement, there is often a mismatch between the treatment approaches favoured by clinicians and the outcome measures used to gauge their effectiveness (Guo et al., 2014; Johansson et al., 2011; Klippi et al., 2012; Verna et al., 2009).

Several country-specific surveys of aphasia management practices have been conducted, providing valuable insights into clinical treatment approaches and outcome measurement practices around the world. Verna et al. (2009) conducted a survey of 70 Australian speech-language pathologists (SLPs) providing services to people with aphasia. SLPs working across a range of health settings most frequently identified adopting a ‘functional’ (ICF Activity/Participation component) approach to therapy. Complementing this finding, the vast majority of respondents (97.1%) most often indicated that they considered the effectiveness of intervention to be signalled by a change in functional communication ability. With regard to outcome measurement, participants most frequently identified using the TOMS (Enderby et al., 2007) and AusTOMs (Perry et al., 2004). Whilst these tools provide ratings across all ICF components, those ratings are often informed by informal and formal assessments. When the assessments used by participants were examined, impairment-based language assessments (36.1%) and screening tools (30%) dominated, with measures of functional communication (8.3%), quality of life (1.7%), client satisfaction (0.5%), communication partner ratings (1.7%), and discourse analysis (1%) infrequently used. These findings demonstrate the current conundrum in aphasia outcome measurement. Australian SLPs most often use functional approaches to aphasia treatment and associate the success of these approaches with functional changes; however they still primarily administer impairment-based outcome measures.

Guo and colleagues identified similar aphasia practices in Singapore (2014). The authors surveyed 36 SLPs working across a variety of health settings for people with aphasia. SLPs rated their knowledge, confidence, and use of functional and social/life participation approaches and interventions applying neuroplasticity principles, most highly. Again, despite high use of both impairment and functional approaches to treatment, impairment-based language assessments and outcome measures were predominantly used. Few SLPs reported using functional communication assessments and there were no reports of SLPs using assessments to measure communication partner ratings, quality of life, or client satisfaction. The mismatch is further demonstrated by Klippi et al. (2012) who conducted surveys with SLPs in Finland to examine aphasia clinical practices. In this study, 75% of respondents identified the primary aim of aphasia therapy to be the enhancement and improvement of everyday communication and interactional skills of the person with aphasia. Whilst participants identified the main aim of therapy as relating to Activity/Participation, Finnish SLPs most frequently reported using impairment-based language assessments, again, with functional communication and quality of life assessments rarely used. The dominant use of impairment-level outcome measures was also identified by Simmons-Mackie, Threats, and Kagan (2005), who conducted an online survey of North American SLPs to investigate aphasia outcome measurement practices. Again SLPs most commonly reported using linguistic/cognitive assessments (45.5%). The authors also reported a lack of consistency across SLPs with regard to specific outcome measures used, citing "…a large and bewildering variety of tools and methods used to measure outcomes, as well as a gap related to measures that specifically targeted actual life participation, consumer satisfaction, or quality of life" (p18).

Recent years have seen a diversification in approaches to aphasia treatment, with clinicians around the world increasingly pairing impairment-based treatment with functional communication approaches. Whilst clinical treatment practices have broadened, outcome measurement practices have maintained a narrow focus, with outcomes infrequently measured beyond the level of impairment. Although this may relate to a lack of appropriate outcome measurement tools, especially in languages other than English, there is a need for greater understanding of the clinical perspective regarding important aphasia outcomes, to inform both clinical and research outcome measurement. Therefore, the present study aimed to identify essential aphasia treatment outcomes from the perspective of clinicians and managers working in aphasia rehabilitation.

5.3 Methods

5.3.1 Study Design

This study used a multiple methods research design, comprising a three-round e-Delphi exercise, qualitative content analysis, and ICF coding. The e-Delphi exercise was conducted between July 2014 and October 2015. Ethical approval for this study was granted by the Behavioural and Social Sciences Ethical Review Committee at The University of Queensland, Australia.

5.3.1.1 The Delphi technique. The Delphi technique is an iterative decision-making process which uses a series of surveys which gradually narrow in focus to generate consensus (Delbecq, Van de Ven, & Gustafson, 1975). Guidelines for the use of the Delphi technique in the development of COSs have been produced and were adhered to throughout the current study (see Sinha, Smyth, & Williamson, 2011). The authors of the present study have previously used the Delphi technique to gain consensus on important aphasia treatment outcomes from the perspective of another stakeholder group, aphasia researchers (Wallace, Worrall, Rose, & Le Dorze, In press).

5.3.1.2 Participants. Two participant groups were recruited to this study: (a) clinicians (n=265) and (b) managers (n=53) working in aphasia rehabilitation. Inclusion criteria required that clinicians be working with people with aphasia and/or their conversation partners to improve communication. Managers were required to be currently coordinating services for people with aphasia (including clinical supervision of staff and/or development or management of policies and procedures). No restrictions were placed on clinical/educational background; location/country of work; or length of time post onset of client population for either participant group.

The majority of participants reported that their role working with people with aphasia was primarily clinical in nature (n=265, 83%). The remaining participants reported working primarily as managers, both with (n=39, 12%) and without (n=14, 4%) concurrent clinical caseloads. Participants were asked to identify their clinical/educational background from a list of professions commonly involved in the provision of communication services to people with aphasia. More than one option could be selected and alternative responses could be provided using free text. Speech therapy/pathology (n=305) was the most frequently reported clinical/educational background; a small number of participants identified themselves as being a clinical linguist (n=23) and/or a neuropsychologist (n=4). Fifteen participants used free text comments to describe their clinical/educational background, which included: occupational therapy, audiology, rehabilitation medicine, and neurolinguistics and/or neurology. Participants reported working with people with aphasia across acute and chronic stages, with roughly even representation in the following categories of time post onset: less than three months (n=260), 3-6 months (n=228), 6-12 months (n=203), and more than 12 months (n=181). In total, 318 participants from 25 countries participated in round 1. Response rates of 60% and 53% were achieved in the second and third rounds, respectively (see figure 5-1). Participants from Australia (n=62, 20%), the UK (n=44, 15%), the Netherlands (n=37, 12%), and the US (n=25, 8%) were most highly represented. Participant characteristics are presented in table 5-1.

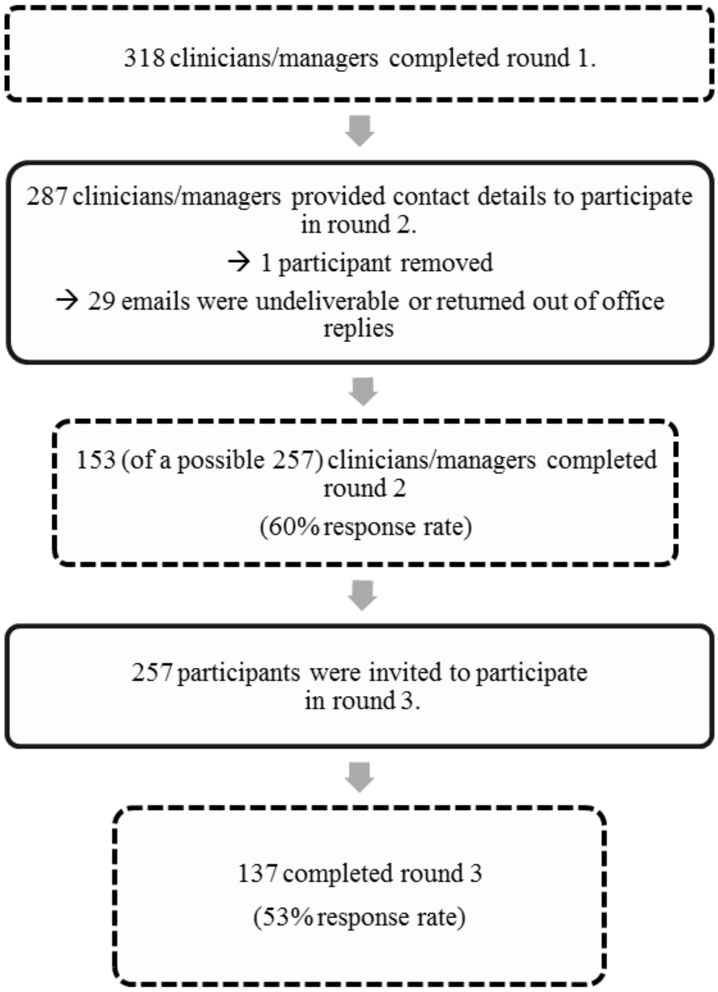


Figure 5-1. Participant Response Rates and Attrition Across Three e-Delphi Rounds.

Table 5-1

Round 1 Participant Characteristics

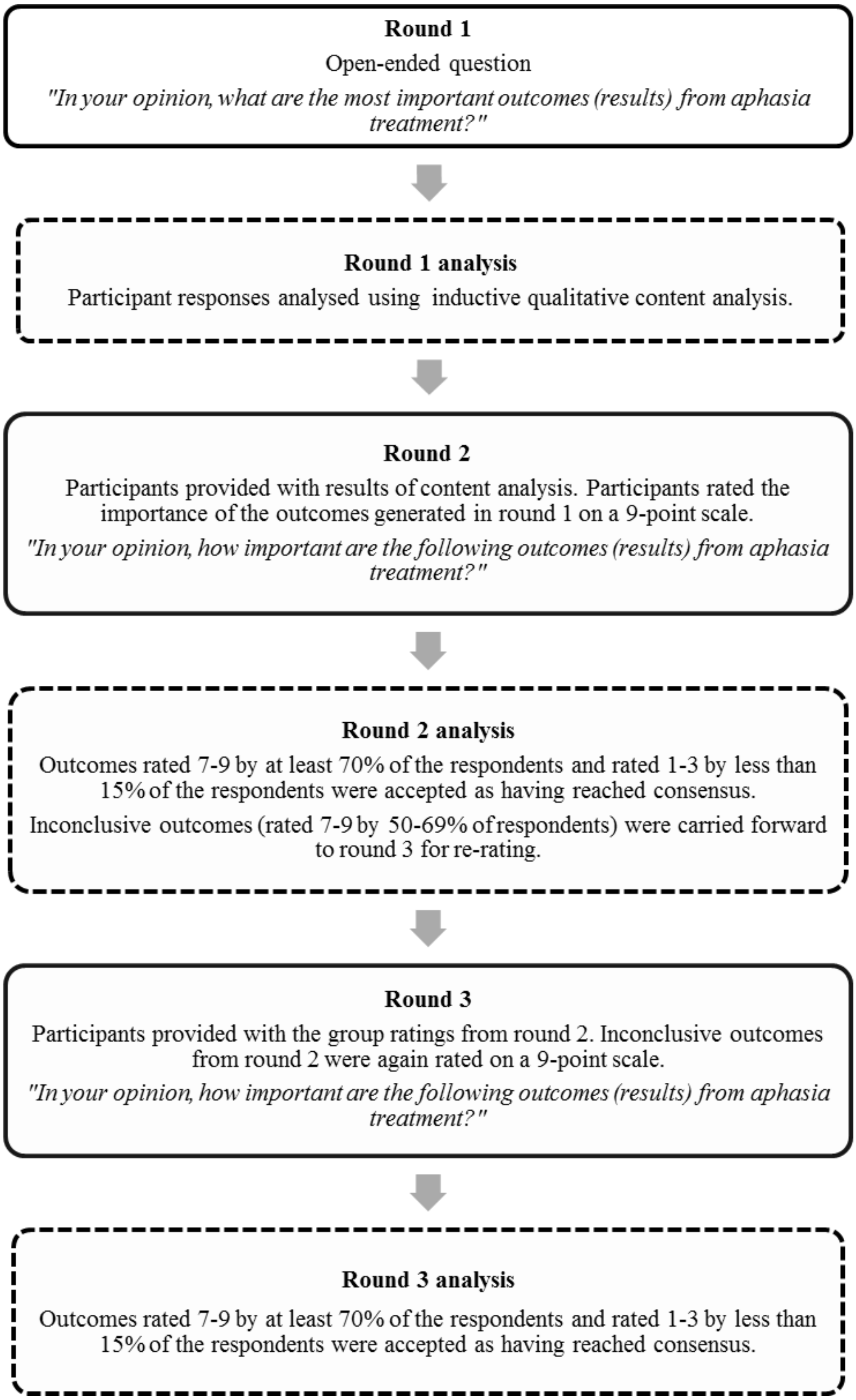
Participant Characteristics	Number of Participants (%)
Role working with people with aphasia (n=318 respondents)	
Clinician	265 (83)
Manager	14 (4)
Manager with clinical caseload	39 (12)
Length of time working in aphasia rehabilitation (n=318 respondents) (years)	
0-1	16 (5)
2-5	85 (27)
6-9	75 (24)
more than 10 years	142 (45)
Clinical/educational background (n=310 respondents)	
Speech therapist/pathologist	305 (98)
Clinical linguist	23 (7)
Neuropsychologist	4 (1)
Other	15 (5)
Length of time post-onset of client population (n=318 respondents) (months)	
< 3	260 (82)
3-6	228 (72)
6-12	203 (64)
> 12	181 (57)
Country (n=318 respondents)	
Australia	62 (20)
UK	44 (14)
Netherlands	37 (12)
US	25 (8)
Portugal	18 (6)
Canada	17 (5)
Denmark	16 (5)
Finland	12 (4)

Participant Characteristics	Number of Participants (%)
Belgium	11 (3)
New Zealand	11 (3)
South Africa	11 (3)
Sweden	10 (3)
Ireland	9 (3)
Israel	8 (3)
Turkey	8 (3)
Germany	6 (2)
Slovenia	4 (1)
Norway	2 (1)
Argentina	1 (<1)
Austria	1 (<1)
Bahrain	1 (<1)
France	1 (<1)
Greece	1 (<1)
India	1 (<1)
Poland	1 (<1)

5.3.1.3 Recruitment. Clinicians and managers were invited to participate in this study via advertisement through national and international SLP and aphasia networks (e.g., professional associations and special interest groups). Snowball sampling was used, with potential participants encouraged to recruit other eligible clinicians and managers from their places of work and own professional networks.

5.3.2 Procedures and Analysis

In each e-Delphi round, participants were emailed a unique survey link created using the commercially available online survey system, SurveyMonkey (www.surveymonkey.com) (See Appendix C). Figure 5-2 provides an overview of the procedures and methods of analysis used across the three rounds of the e-Delphi exercise.



Round 1

Open-ended question

"In your opinion, what are the most important outcomes (results) from aphasia treatment?"

Round 1 analysis

Participant responses analysed using inductive qualitative content analysis.

Round 2

Participants provided with results of content analysis. Participants rated the importance of the outcomes generated in round 1 on a 9-point scale.

"In your opinion, how important are the following outcomes (results) from aphasia treatment?"

Round 2 analysis

Outcomes rated 7-9 by at least 70% of the respondents and rated 1-3 by less than 15% of the respondents were accepted as having reached consensus.

Inconclusive outcomes (rated 7-9 by 50-69% of respondents) were carried forward to round 3 for re-rating.

Round 3

Participants provided with the group ratings from round 2. Inconclusive outcomes from round 2 were again rated on a 9-point scale.

"In your opinion, how important are the following outcomes (results) from aphasia treatment?"

Round 3 analysis

Outcomes rated 7-9 by at least 70% of the respondents and rated 1-3 by less than 15% of the respondents were accepted as having reached consensus.

Figure 5-2. Overview of e-Delphi exercise.

5.3.2.1 Round 1. In the first round participants were asked, “In your opinion, what are the most important outcomes (results) from aphasia treatment?” An open-ended question was selected (in lieu of providing a predetermined list of outcomes) to avoid the introduction of bias through guiding participant responses (Sinha et al., 2011). Participants were invited to respond to the question using free text; no restrictions were placed on length of response.

Analysis. Two authors analysed participant responses using inductive qualitative content analysis procedures (Graneheim & Lundman, 2004). Each participant response was analysed for meaning units (i.e., words, phrases, or sentences expressing an idea). Meaning units were subsequently organised into codes, subcategories, categories, and themes.

Rigour. Peer debriefing was used to maximise the rigour and trustworthiness of the content analysis. All 318 participant responses to the round 1 open-ended question were analysed by one author using the methodology described by Graneheim and Lundman (2004). Following this analysis, all responses were again examined and discussed with a second author to ensure that reasonable interpretations had been made and that codes had been accurately classified into subcategories, categories, and themes. An ‘audit trail’ (see Koch, 2006) was maintained documenting the full analysis process from raw data (i.e., survey responses), to data reduction and interpretation (i.e., identification of meaning unites and interpretation of meaning), to final analysis products (i.e., the resulting themes, categories, subcategories, and codes).

5.3.2.2 Round 2. Participants were provided with a de-identified summary of the round 1 content analysis and asked to rate the importance of each outcome (at a subcategory level), using a modified version of the GRADE working group nine-point rating scale (www.gradeworkinggroup.org) (see figure 5-3). The outcomes were presented in a random order for each participant to prevent an order effect.

<table>
<tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>8</td><td>9</td></tr>
<tr><td>Least important</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>Most important</td></tr>
<tr><td colspan="3">Of limited importance</td><td colspan="3">Important but not essential</td><td colspan="3">Essential</td></tr>
</table>

Figure 5-3. Modified GRADE Working Group 9-point Rating Scale.

Analysis. The number and percentage of participants rating each outcome as, *of limited importance* (1-3), *important but not essential* (4-6) and *essential* (7-9) was calculated. Consensus was defined *a priori* as a rating of 7-9 by at least 70% of the respondents and 1-3 by less than 15% of the respondents (Williamson et al., 2012). Inconclusive outcomes were defined as those rated as 'essential' (7-9) by 50-69% of participants. Outcomes reaching consensus and inconclusive outcomes were identified.

5.3.2.3 Round 3. The compiled round 2 results were provided to participants to allow consideration of their individual ratings in reference to the wider group. Participants were asked to re-rate inconclusive outcomes using the same nine-point scale as used in round 2.

Analysis. The number and percentage of participants rating items as, *of limited importance* (1-3), *important but not essential* (4-6) and *essential* (7-9) were again calculated. The same pre-defined consensus criteria were applied.

5.3.3 ICF Coding.

Outcomes reaching the pre-defined consensus criteria were further analysed using ICF linking. Systematic classification using the ICF was used to classify the outcomes reaching consensus using an internationally comparable metric. Linking rules developed by Cieza and associates (Cieza et al., 2002; Cieza et al., 2005), and Worrall and associates (Worrall et al., 2011) were used to code each outcome to the most precise ICF code/s possible. The ICF codes were then analysed in terms of their distribution across ICF components.

5.3.4 Inter-Rater Reliability.

Each outcome reaching consensus was independently linked to the ICF by a second researcher experienced in ICF coding. Inter-rater reliability was determined using percent agreement and the kappa statistic (Cohen, 1960). Bootstrapping (using Stata® statistics/data analysis) was used to generate 95% confidence intervals.

5.4 Results

5.4.1 Round 1

A total of 318 participants completed round 1. One participant response was removed as it reflected a misunderstanding of the research question. Analysis of responses to the open ended question exploring important aphasia treatment outcomes produced 1709 codes, which were condensed into 25 categories (refer to table 5-2). The 25 categories contained a total of 90 subcategories (refer to tables 5-3 to 5-6). These 90 subcategories formed the items rated in round 2. Four themes were revealed, in that important outcomes from aphasia treatment related to: (1) the person with aphasia; (2) family/carers/significant others of the person with aphasia; (3) health services; and (4) health professionals.

5.4.1.1 Theme 1: Outcomes for the person with aphasia. The vast majority of codes (n=1503, 88%) related to outcomes for the person with aphasia. These codes were grouped into 16 categories and 69 subcategories. A broad range of constructs were generated spanning: participation; communication; psychosocial well-being; language function; quality of life; awareness about aphasia; patient reported satisfaction; and enhancement of the communicative environment. The three most highly represented categories were:

1. The person with aphasia is able to participate in different roles and contexts (n=328).
2. The person with aphasia has good psychosocial well-being (n=222).
3. The person with aphasia has improved language (n=169).

5.4.1.2 Theme 2: Outcomes for the family/carers/significant others of people with aphasia. A total of 190 codes related to outcomes for family/carers/significant others of people with aphasia. These codes were condensed into 6 categories and 15 subcategories. Outcomes related to: communication-partner skills; third-party disability; knowledge and attitudes about aphasia; goal setting; and engagement in therapy. The three most highly represented categories were:

1. Family/carers/significant others are better communication partners (n=83).
2. Family/carers/significant others experience less third-party disability (i.e., disability occurring as a result of their family member's health condition) (n=46).
3. Family/carers/significant others have good knowledge about aphasia and better attitudes towards people with aphasia (n=39).

5.4.1.3 Theme 3. Outcomes related to health services. A small number of codes (n=12) related to health services. These codes were organised into two categories and five subcategories. The most highly represented category was:

1. Clients have access to services and funding (n=7).

5.4.1.4 Theme 4. Outcomes for health professionals. Four codes related to outcomes for health professionals. These codes formed one category:

1. Health professionals have greater awareness about aphasia and how to support communication (n=4).

Table 5-2

Content Analysis of Responses to the Question: "In your opinion, what are the most important outcomes (results) from aphasia treatment?"

Themes	Categories
Outcomes for the person with aphasia (PWA) (n=1503)[#]	1. The PWA is able to participate in different roles and contexts (n=328)
	2. The PWA has good psychosocial well-being (n=222)
	3. The PWA has improved language function (n=169)
	4. The PWA has improved quality of life (n=124)
	5. The PWA has improved communication (n=109)
	6. The PWA is able to use multimodal communication/strategies to support communication (n=101)
	7. The PWA is able to participate in conversation (n=79)
	8. The PWA has greater awareness about aphasia (n=67)
	9. The PWA is able to communicate information of varying complexity (n=66)
	10. The PWA is able to communicate in different contexts (n=61)
	11. The PWA is satisfied and feels they have improved (n=52)
	12. The PWA has positive feelings about communication (n=32)

Themes	Categories
	13. The goals of the PWA have been met (n=32)
	14. The PWA has increased communicative self-awareness (n=27)
	15. The PWA has improved functioning, reduced disability and is able to be discharged (n=21)
	16. The communicative environment of the PWA is enhanced (n=13)
Outcomes for the family/carers/ significant others of people with aphasia (n=190)	17. Family/carers/significant others are better communication partners (n=83)
	18. Family/carers/significant others experience less third party disability (n=46)
	19. Family/carers/significant others have good knowledge about aphasia and better attitudes towards people with aphasia (n=39)
	20. Family/carers/significant others perceive improvement /change (n=16)
	21. Family/carers/significant others engage in the therapy for the PWA (n=4)
	22. The goals that are important to family/carers/significant others have been met (n=2)
Outcomes related to health services (n=12)	23. Clients have access to services and funding (n=7)
	24. Resources are used efficiently and outcomes are measured (n=5)
Outcomes for health professionals (n=4)	25. Health professionals have greater awareness about aphasia and how to support communication (n=4)

n= number of codes within theme and category

Table 5-3

Round 2 Participant Ratings for Subcategories in Theme 1 Relating to Outcomes for the Person with Aphasia and Response Counts

Outcomes: Subcategories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
1. The PWA can communicate with relevant communication partners (n=35)[#]	0	0	0	0 (0%)	0	0	4	4 (3%)	28	36	79	143 (97%)*	147
2. The PWA is able to communicate in daily life activities (n=45)	0	0	0	0 (0%)	0	2	4	6 (4%)	36	39	64	139 (96%)*	145
3. The PWA is able to communicate their basic needs (n=37)	0	0	1	1 (1%)	0	2	4	6 (4%)	21	31	87	139 (95%)*	146
4. The PWA experiences successful communication (n=12)	0	0	0	0 (0%)	1	3	4	8 (5%)	37	32	69	138 (95%)*	146
5. The PWA is able to participate in life (n=48)	0	1	0	1 (1%)	0	2	6	8 (5%)	21	38	80	139 (94%)*	148

Outcomes: Subcategories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
6. The PWA has a positive & supportive communication environment and environmental barriers are reduced (n=13)	0	0	0	0 (0%)	0	4	5	9 (6%)	37	43	54	134 (94%)*	143
7. Strategies/ techniques used by the PWA generalise from therapy to real life (n=1)	0	0	0	0 (0%)	0	2	6	8 (6%)	31	44	62	137 (94%)*	145
8. The PWA has effective communication (n=16)	0	0	0	0 (0%)	2	1	7	10 (7%)	39	36	62	137 (93%)*	147
9. The PWA has improved functional communication (n=52)	0	0	0	0 (0%)	1	2	7	10 (7%)	27	38	70	135 (93%)*	145
10. The goals that have been set are important to the PWA (n=16)	0	0	1	1 (1%)	2	1	6	9 (6%)	19	34	84	137 (93%)*	147
11. The PWA can cope with their aphasia (n=9)	0	0	0	0 (0%)	0	3	10	13 (9%)	32	42	60	134 (91%)*	147

Outcomes: Subcategories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
12. The PWA is able to reintegrate and participate in community/ society (n=35)	0	0	2	2 (1%)	0	5	7	12 (8%)	45	39	49	133 (90%)*	147
13. The PWA has improved quality of life (n=113)	1	0	0	1 (1%)	1	3	9	13 (9%)	20	34	79	133 (90%)*	147
14. The PWA feels in control and is involved in decision making (n=25)	0	0	0	0 (0%)	0	4	11	15 (10%)	37	31	63	131 (90%)*	146
15. The PWA has a sense of identity, self-worth and self-esteem (n=36)	0	0	0	0 (0%)	1	6	9	16 (11%)	28	29	74	131 (89%)*	147
16. The PWA has opportunities to communicate (n=4)	0	0	1	1 (1%)	1	3	11	15 (10%)	37	30	63	130 (89%)*	146
17. The PWA experiences enjoyable communication (n=7)	0	0	0	0 (0%)	1	3	14	18 (12%)	29	46	54	129 (88%)*	147
18. The PWA has reduced frustration when communicating (n=12)	0	0	0	0 (0%)	2	5	11	18 (12%)	42	37	48	127 (88%)*	145

Outcomes: Subcategories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
19. The PWA is able to summon help/ can reduce risks caused by their communication disability (n=5)	0	1	0	1 (1%)	2	5	11	18 (12%)	42	29	57	128 (87%)*	147
20. The PWA has improved communication (n=41)	0	0	0	0 (0%)	3	5	13	21 (14%)	33	31	62	126 (86%)*	147
21. The PWA is able to participate in meaningful activities (n=52)	0	0	1	1 (1%)	0	6	13	19 (13%)	24	37	63	124 (86%)*	144
22. The PWA is able to socialize more and is less isolated (n=92)	0	0	0	0 (0%)	2	6	13	21 (14%)	35	43	48	126 (86%)*	147
23. The PWA is able to use strategies to support communication (n=36)	0	0	0	0 (0%)	2	3	17	22 (15%)	58	31	36	125 (85%)*	147
24. The PWA is satisfied with their community participation, roles and relationships (n=2)	0	1	0	1 (1%)	1	8	14	23 (16%)	40	40	42	122 (84%)*	146

Outcomes: Subcategories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
25. The PWA has improved functioning and reduced disability (n=18)	0	0	0	0 (0%)	4	8	13	25 (17%)	38	32	51	121 (83%)*	146
26. The PWA is able to engage in conversation (n=31)	0	0	1	1 (1%)	2	8	14	24 (16%)	43	30	48	121 (83%)*	146
27. The PWA has improved mood and emotional well-being (n=24)	0	0	2	2 (1%)	4	5	15	24 (16%)	40	40	41	121 (82%)*	147
28. The PWA feels empowered/ able to advocate for him/herself (n=3)	0	0	1	1 (1%)	2	9	16	27 (18%)	41	32	46	119 (81%)*	147
29. The PWA feels confident when communicating (n=41)	0	1	0	1 (1%)	1	3	24	28 (19%)	40	40	37	117 (80%)*	146
30. The PWA is able to communicate beyond their basic needs e.g., feelings/memories/opinions/personality/hopes/thoughts (n=24)	0	0	1	1 (1%)	1	5	22	28 (19%)	38	38	41	117 (80%)*	146

Outcomes: Subcategories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
31. The PWA has increased independence (n=49)	0	0	2	2 (1%)	2	5	22	29 (20%)	45	33	38	116 (79%)*	147
32. The goals that are important to the PWA have been achieved (n=16)	1	0	3	4 (3%)	1	8	18	27 (19%)	31	45	36	112 (78%)*	143
33. The PWA is satisfied with their level of confidence and independence (n=1)	0	1	1	2 (1%)	1	11	19	31 (21%)	36	36	41	113 (77%)*	146
34. The PWA accepts aphasia and adjusts to changed circumstances (n=26)	1	0	1	2 (1%)	3	8	21	32 (22%)	46	35	32	113 (77%)*	147
35. The PWA is satisfied with life (n=15)	1	0	0	1 (1%)	7	8	21	36 (25%)	34	29	45	108 (74%)*	145
36. The PWA is able to participate in family/community/pre-stroke roles (n=19)	1	0	3	4 (3%)	3	12	22	37 (25%)	40	31	34	105 (72%)*	146
37. The PWA has a desire to communicate (n=1)	3	0	4	7 (5%)	3	10	21	34 (23%)	27	29	48	104 (72%)*	145

Outcomes: Subcategories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
38. The PWA is satisfied with their ability to communicate (n=12)	0	0	0	0 (0%)	2	7	33	42 (29%)	38	29	37	104 (72%)*	146
39. The PWA has supportive relationships (n=6)	0	1	1	2 (1%)	5	11	26	42 (29%)	37	30	35	102 (70%)*	146
40. The PWA is able to communicate in health care environments (n=5)	0	0	0	0 (0%)	4	13	30	47 (32%)	45	34	21	100 (68%)**	147
41. The PWA is satisfied with their treatment (n=11)	0	0	1	1 (1%)	8	17	22	47 (32%)	28	40	31	99 (67%)**	147
42. The PWA feels they have improved (n=11)	1	0	0	1 (1%)	4	8	37	49 (33%)	39	28	30	97 (66%)**	147
43. The PWA has good health and well-being (n=11)	1	2	6	9 (6%)	7	10	26	43 (29%)	41	23	31	95 (65%)**	147
44. The PWA has insight into their communication abilities (n=17)	0	1	3	4 (3%)	2	21	26	49 (34%)	43	23	26	92 (63%)**	145
45. The PWA is able to repair communication breakdown (n=10)	0	0	3	3 (2%)	2	14	37	53 (36%)	44	28	19	91 (62%)**	147

Outcomes: Subcategories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
46. The PWA is aware of support and aphasia associations in the community (n=9)	1	0	3	4 (3%)	9	18	25	52 (35%)	41	27	23	91 (62%)**	147
47. The PWA has good family/spousal relationships (n=9)	1	2	2	5 (3%)	7	17	29	53 (36%)	28	26	35	89 (61%)**	147
48. The PWA is willing and able to use multimodal communication and Alternative and Augmentative Communication as needed (n=57)	0	0	2	2 (1%)	5	15	36	56 (38%)	41	25	23	89 (61%)**	147
49. The PWA has improved language function – overall (n=40)	0	1	4	5 (3%)	6	13	34	53 (36%)	39	28	21	88 (60%)**	146
50. The PWA has knowledge about aphasia and stroke (n=54)	0	0	2	2 (1%)	6	14	37	57 (39%)	30	27	29	86 (59%)**	145
51. The PWA is aware of options for aphasia intervention (n=4)	0	5	4	9 (6%)	10	15	31	56 (39%)	35	20	23	78 (55%)**	143

Outcomes: Subcategories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
52. The PWA has increased motivation and determination (n=3)	2	1	3	6 (4%)	5	17	37	59 (41%)	30	27	23	80 (55%)**	145
53. The PWA is able to initiate conversation (n=8)	0	0	2	2 (1%)	9	23	31	63 (43%)	31	27	22	80 (55%)**	145
54. The PWA is able to take turns in conversation (n=5)	0	1	2	3 (2%)	10	18	37	65 (45%)	32	18	26	76 (53%)**	144
55. The PWA is able to return "home"/live in their desired location (n=3)	1	2	4	7 (5%)	9	19	34	62 (42%)	27	23	27	77 (53%)**	146
56. The PWA is able to participate in employment/ education/ voluntary activities (n=50)	1	0	7	8 (5%)	5	28	32	65 (44%)	29	24	21	74 (50%)**	147
57. The PWA has improved language function - specific to deficit (n=9)	1	0	7	8 (5%)	14	21	31	66 (45%)	37	14	21	72 (49%)	146
58. The PWA engages in health care (n=16)	5	1	11	17 (12%)	10	17	34	61 (42%)	30	20	18	68 (47%)	146

Outcomes: Subcategories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
59. The PWA has improved auditory comprehension (n=32)	1	1	6	8 (6%)	12	27	35	74 (51%)	33	17	13	63 (43%)	145
60. The PWA has recovered/is able to be discharged (n=3)	3	3	13	19 (13%)	17	25	23	65 (45%)	28	15	19	62 (42%)	146
61. The PWA has improved verbal expression (n=30)	0	3	9	12 (8%)	11	19	44	74 (50%)	35	18	8	61 (42%)	147
62. The PWA is able to educate others about aphasia and the best ways to communicate with him/her (n=7)	2	2	13	17 (12%)	10	25	37	72 (49%)	30	14	13	57 (39%)	146
63. The PWA connects with other people with aphasia (n=4)	3	1	9	13 (9%)	14	24	46	84 (57%)	32	11	7	50 (34%)	147
64. The PWA has improved word finding skills (n=18)	0	3	9	12 (8%)	13	31	45	89 (61%)	26	11	9	46 (31%)	147
65. The PWA has improved high-level language and cognitive skills (n=5)	2	2	20	24 (16%)	12	37	32	81 (55%)	24	10	8	42 (29%)	147

Outcomes: Subcategories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
66. The PWA is able to communicate using different technologies (n=7)	3	5	9	17 (12%)	18	36	34	88 (61%)	22	11	7	40 (28%)	145
67. The PWA experiences neuroplasticity (n=2)	5	9	18	32 (23%)	14	34	23	71 (50%)	21	6	11	38 (27%)	141
68. The PWA has improved reading comprehension (n=17)	2	3	14	19 (13%)	19	33	42	94 (64%)	21	8	4	33 (23%)	146
69. The PWA has improved written expression (n=16)	6	3	22	31 (21%)	20	38	32	90 (61%)	16	5	5	26 (18%)	147

* Rated 7-9 by ≥ 70% of participants (i.e., consensus)

**Rated 7-9 by 50-69% of participants (i.e., inconclusive)

[#] n= number of codes within subcategory

Table 5-4

Round 2 Participant Ratings for Subcategories in Theme 2 Relating to Outcomes for the Family/Carers/Significant Others of People with Aphasia and Response Counts

Outcomes: Subcategories	Participant ratings												Response count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 total	4	5	6	4-6 total	7	8	9	7-9 total	
1. Family/carers/significant others understand how to communicate with people with aphasia (n=16)[#]	0	0	0	0 (0%)	0	0	2	2 (1%)	13	33	95	141 (99%) *	143
2. Family/carers/significant others understand the nature and extent of the PWA's communication impairment (n=14)	0	0	0	0 (0%)	3	2	3	8 (6%)	29	44	61	134 (94%) *	142
3. Family/carers/significant others have reduced burden/frustration and improved coping/ acceptance (n=11)	1	0	0	1 (1%)	0	6	10	16 (11%)	31	45	50	126 (88%) *	143
4. Family/carers/significant others have improved communication skills and confidence (n=53)	2	0	2	4 (3%)	1	6	12	19 (13%)	30	44	46	120 (84%) *	143

Outcomes: Subcategories	Participant ratings												Response count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 total	4	5	6	4-6 total	7	8	9	7-9 total	
5. Family/carers/significant others have better attitudes towards people with aphasia (n=2)	0	0	0	0 (0%)	0	8	15	23 (16%)	25	38	56	119 (84%) *	142
6. Family/carers/significant others have good knowledge about aphasia (n=37)	0	0	0	0 (0%)	1	3	19	23 (16%)	36	34	50	120 (84%) *	143
7. Family/carers/significant others are aware of / able to access support and counselling (n=9)	0	0	1	1 (1%)	1	8	17	26 (18%)	37	34	45	116 (81%) *	143
8. Family/carers/significant others engage in the therapy for the PWA (n=4)	0	2	1	3 (2%)	2	12	25	39 (27%)	34	40	27	101 (71%) *	143
9. Family/carers/significant others have improved quality of life (n=19)	1	2	2	5 (3%)	3	16	23	42 (29%)	34	32	30	96 (67%) **	143
10. Family/carers/significant others have good well-being (n=5)	1	2	4	7 (5%)	6	14	23	43 (30%)	38	25	29	92 (65%) **	142

Outcomes: Subcategories	Participant ratings												Response count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 total	4	5	6	4-6 total	7	8	9	7-9 total	
11. Family/carers/significant others are able to perceive improvement (n=6)	1	2	1	4 (3%)	2	20	31	53 (37%)	42	25	19	86 (60%) **	143
12. Family/carers/significant others are satisfied with PWA's communication skills and therapy (n=10)	0	1	1	2 (1%)	8	14	34	56 (39%)	39	30	16	85 (59%) **	143
13. The goals that are important to family/carers/significant others have been met (n=2)	0	0	3	3 (2%)	6	17	36	59 (41%)	28	33	20	81 (57%) **	143
14. Family/carers/significant others are able to socialise more (n=1)	4	4	8	16 (11%)	6	17	24	47 (33%)	31	32	17	80 (56%) **	143
15. Family/carers/significant others have increased independence (n=1)	6	2	9	17 (12%)	5	16	30	51 (36%)	32	29	14	75 (52%) **	143

*Rated 7-9 by ≥ 70% of participants (i.e., consensus)

**Rated 7-9 by 50-69% of participants (i.e., inconclusive)

[#] n= number of codes within subcategory

Table 5-5

Round 2 Participant Ratings for Subcategories in Theme 3 Referring to Outcomes Related to Health Services and Response Counts

Outcomes: Subcategories	Participant Ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
1. Clients can access services/ ongoing services (n=5)[#]	1	0	0	1 (1%)	1	7	12	20 (14%)	31	31	58	120 (85%)*	141
2. Clients can access funding for resources and services (n=2)	4	0	2	6 (4%)	5	12	13	30 (21%)	41	31	33	105 (75%)*	141
3. Being able to measure the difference made by aphasia treatment (n=1)	0	1	3	4 (3%)	4	10	15	29 (21%)	23	36	49	108 (77%)*	141
4. High-impact outcomes are achieved with the least resources (n=2)	1	3	8	12 (9%)	11	20	20	51 (37%)	22	28	26	76 (55%)**	139
5. The length of stay of PWA is reduced (n=2)	4	6	8	18 (13%)	15	32	24	71 (51%)	21	15	15	51 (36%)	140

* Rated 7-9 by ≥ 70% of participants (i.e., consensus)

**Rated 7-9 by 50-69% of participants (i.e., inconclusive)

[#] n= number of codes within subcategory

Table 5-6

Round 2 Participant Ratings for Subcategories in Theme 4 Relating to Outcomes for Health Professionals and Response Counts

Outcomes: Subcategories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
Health professionals have greater awareness about aphasia and how to support communication (n=4)[#]	0	1	0	1 (1%)	1	4	6	11 (8%)	17	37	75	129 (91%)*	141

* Rated 7-9 by ≥ 70% of participants (i.e., consensus)

n= number of codes within subcategory

5.4.2 Rounds 2 and 3

A total of 153 and 137 participants completed rounds 2 and 3, respectively. Participant attrition was likely increased by a longer than anticipated gap between rounds 1 and 2. Twenty-nine survey invitation e-mails were undeliverable or returned out-of-office replies. One participant was removed as their round 1 response reflected a misunderstanding of the research question. In round 2, 51 outcomes were rated as *essential* by ≥70% of participants and *of limited importance* by ≤15% of participants (see tables 5-3 to 5-6). No further outcomes reached consensus in round 3 (see tables 5-7 to 5-9). These results are outlined by theme:

5.4.2.1 Theme 1: Outcomes for the person with aphasia. In total, 39 outcomes (at a subcategory level) reached consensus (see table 5-3). The outcome with the highest level of consensus within this theme (rated as *essential* by 97% of participants) related to the ability of the person with aphasia to communicate with relevant communication partners. Other outcomes reaching very high levels of consensus (≥90%) were: communication in daily life activities; communication of basic needs; successful communication; participation in life; positive and supportive communication environments and reduction of environmental barriers; generalisation of therapy strategies to real life; effective communication; functional communication; patient-important goal setting; coping with aphasia; reintegration and participation in community/society; improved quality of life; and feeling in control and involved in decision-making (see table 5-3).

Considered at a category level, outcomes within this theme most frequently related to psychosocial well-being (n=9; 23%) (see table 5-10). Outcomes spanned a range of areas including: coping; quality of life; decision making; identity, self-worth and self-esteem; improved mood and emotional well-being; empowerment; confidence; and independence.

5.4.2.2 Theme 2: Outcomes for family/carers/significant others. In total, eight outcomes within theme 2 reached consensus (see table 5-4). The outcome with the highest level of consensus in this theme, and across all themes (i.e., rated *essential* by 99% of participants), related to family/carers/significant other understanding about how to communicate with people with aphasia. One further outcome reached a very high level of consensus (≥90%); 94% of respondents rated that it is essential for family/carers/significant others to understand the nature and extent of the person with aphasias’ communication impairment.

Considered at a category level, outcomes within this theme most frequently related to family/carers/significant others being better communication partners (n=3; 38%) (see table 5-10). Improved communication partner knowledge and understanding was also a central component of two further outcome categories: family/carers/significant others have good knowledge about aphasia and better attitudes towards people with aphasia and family/carers/ significant others experience less third-party disability.

5.4.2.3 Theme 3: Outcomes related to health services. Three outcomes within theme 3 reached consensus (see table 5-5): client access to services/ongoing services; being able to measure the difference made by aphasia treatment; and client access to funding for resources and services.

5.4.2.4 Theme 4: Outcomes for health professionals. One outcome within this theme reached consensus (see table 5-6): health professionals have greater awareness about aphasia and how to support communication.

Table 5-7

Round 3 Participant Ratings for Subcategories in Theme 1 Relating to Outcomes for the Person with Aphasia and Response Counts

Outcomes: Subcategories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
1. The PWA has insight into their communication abilities	0	0	1	1 (1%)	6	11	24	41 (30%)	45	34	16	95 (69%)	137
2. The PWA has knowledge about aphasia and stroke	0	0	2	2 (1%)	11	12	18	41 (30%)	50	22	21	93 (68%)	136
3. The PWA is satisfied with their treatment	0	1	2	3 (2%)	3	15	25	43 (32%)	46	22	21	89 (66%)	135
4. The PWA is aware of support and aphasia associations in the community	0	2	3	5 (4%)	3	16	26	45 (33%)	42	21	22	85 (63%)	135
5. The PWA is able to communicate in health care environments	0	1	3	4 (3%)	6	14	26	46 (34%)	46	25	14	85 (63%)	135
6. The PWA feels they have improved	0	0	1	1 (1%)	7	19	26	52 (39%)	42	24	16	82 (61%)	135

Outcomes: Subcategories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
7. The PWA is willing and able to use multimodal communication and Alternative and Augmentative Communication as needed	0	1	5	6 (4%)	9	21	23	53 (39%)	34	29	14	77 (57%)	136
8. The PWA is aware of options for aphasia intervention	0	3	0	3 (2%)	8	23	26	57 (42%)	39	17	19	75 (56%)	135
9. The PWA is able to repair communication breakdown	0	0	2	2 (1%)	9	17	33	59 (43%)	45	20	11	76 (55%)	137
10. The PWA has increased motivation and determination	0	0	6	6 (4%)	12	19	24	55 (40%)	26	35	14	75 (55%)	136
11. The PWA is able to initiate conversation	0	0	1	1(1%)	8	15	39	62 (46%)	36	16	20	72 (53%)	135
12. The PWA has good health and well-being	0	2	5	7 (5%)	8	18	31	57 (42%)	38	15	19	72 (53%)	136
13. The PWA is able to take turns in conversation	0	3	1	4 (3%)	6	22	32	60 (44%)	44	14	13	71 (53%)	135
14. The PWA has improved language function - overall	0	1	7	8 (6%)	8	22	29	59 (43%)	32	23	14	69 (51%)	136

Outcomes: Subcategories	Participant ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
15. The PWA has good family/spousal relationships	0	0	4	4 (3%)	9	23	34	66 (48%)	24	27	16	67 (49%)	137
16. The PWA is able to participate in employment/ education/ voluntary activities	0	3	2	5 (4%)	11	22	33	66 (48%)	31	21	14	66 (48%)	137
17. The PWA is able to return "home"/live in their desired location	0	5	6	11 (8%)	7	26	32	65 (48%)	24	18	18	60 (44%)	136

Table 5-8

Round 3 Participant Ratings for Subcategories in Theme 2 Referring to Outcomes for the Family/Carers/Significant Others of People with Aphasia and Response Counts

Outcomes: Subcategories	Participant ratings												Response count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 total	4	5	6	4-6 total	7	8	9	7-9 total	
1. Family/carers/significant others have improved quality of life	1	1	4	6 (4%)	11	17	28	56 (41%)	34	24	17	75 (55%)	137
2. Family/carers/significant others have good well-being	1	2	5	8 (6%)	12	14	31	57 (42%)	39	20	13	72 (53%)	137
3. Family/carers/significant others are satisfied with PWA's communication skills and therapy	0	2	2	4 (3%)	7	18	35	60 (44%)	40	21	12	73 (53%)	137
4. Family/carers/significant others are able to perceive improvement	0	1	4	5 (4%)	6	16	42	64 (47%)	36	24	8	68 (50%)	137

Outcomes: Subcategories	Participant ratings												Response count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 total	4	5	6	4-6 total	7	8	9	7-9 total	
5. The goals that are important to family/ carers/significant others have been met	0	3	1	4 (3%)	8	27	39	74 (54%)	30	17	12	59 (43%)	137
6. Family/carers/significant others have increased independence	0	2	8	10 (7%)	11	22	40	73 (53%)	31	17	6	54 (39%)	137
7. Family/carers/significant others are able to socialise more	2	3	11	16 (12%)	10	26	35	71 (53%)	24	15	9	48 (36%)	135

Table 5-9

Round 3 Participant Ratings for Subcategories in Theme 3 Referring to Outcomes Related to Health Services and Response Counts

Outcomes: Subcategories	Participant Ratings												Response Count
	Of limited importance				Important but not essential				Essential				
	1	2	3	1-3 Total	4	5	6	4-6 Total	7	8	9	7-9 Total	
High-impact outcomes are achieved with the least resources	3	0	5	8 (6%)	14	31	28	73 (53%)	31	14	11	56 (41%)	137

Table 5-10

Final List of Outcomes Reaching Consensus by Theme and Category and Participant Ratings

Theme	Category	Outcomes reaching consensus	Participants rating the outcome essential
Outcomes for the Person with Aphasia (PWA)	The PWA has good psychosocial well-being	1. The PWA can cope with their aphasia	134 (91%)
		2. The PWA has improved quality of life	133 (90%)
		3. The PWA feels in control and is involved in decision making	131 (90%)
		4. The PWA has a sense of identity, self-worth and self-esteem	131 (89%)
		5. The PWA has improved mood and emotional well-being	121 (82%)
		6. The PWA feels empowered/ able to advocate for him/herself	119 (81%)
		7. The PWA feels confident when communicating	117 (80%)
		8. The PWA has increased independence	116 (79%)
		9. The PWA accepts aphasia and adjusts to changed circumstances	113 (77%)
		10. The PWA has supportive relationships	102 (70%)
	The PWA is able to participate in different roles and contexts	1. The PWA is able to participate in life	139 (94%)
		2. The PWA is able to reintegrate and participate in community/ society	133 (91%)
		3. The PWA is able to participate meaningful activities	124 (86%)
		4. The PWA is able to socialize more and is less isolated	126 (86%)
		5. The PWA is able to participate in family/community/pre-stroke roles	105 (72%)

Theme	Category	Outcomes reaching consensus	Participants rating the outcome essential
	The PWA has positive feelings about communication	1. The PWA experiences successful communication	138 (95%)
		2. The PWA experiences enjoyable communication	129 (88%)
		3. The PWA has reduced frustration when communicating	127 (88%)
		4. The PWA has a desire to communicate	104 (72%)
	The PWA is satisfied and feels that they have improved	1. The PWA is satisfied with their community participation, roles and relationships	122 (84%)
		2. The PWA is satisfied with life	108 (74%)
		3. The PWA is satisfied with their level of confidence and independence	113 (77%)
		4. The PWA is satisfied with their ability to communicate	104 (71%)
	The PWA is able to communicate information of varying complexity	1. PWA is able to communicate their basic needs	139 (95%)
		2. The PWA is able to summon help/ can reduce risks caused by their communication disability	128 (87%)
		3. The PWA is able to communicate beyond their basic needs e.g., feelings/ memories/ opinions/ personality /hopes/ thoughts	117 (80%)
	The PWA has improved communication	1. The PWA has effective communication	137 (93%)
		2. The PWA has improved functional communication	135 (93%)
		3. The PWA has improved communication	126 (86%)
	The person with aphasia is able to participate in conversation	1. The PWA can communicate with relevant communication partners	143 (97%)
		2. The PWA is able to engage in conversation	121 (83%)

Theme	Category	Outcomes reaching consensus	Participants rating the outcome essential
	The PWA is able to communicate in different roles and contexts	1. The PWA is able to communicate in daily life activities	139 (96%)
		2. The PWA has opportunities to communicate	130 (89%)
	The PWA is able to use multimodal communication/ strategies to support communication	1. Strategies/ techniques used by the PWA generalise from therapy to real life	137 (94%)
		2. The PWA is able to use strategies to support communication	125 (85%)
	The goals of the PWA have been met	1. The goals that have been set are important to the PWA	137 (93%)
		2. The goals that are important to the PWA have been achieved	112 (78%)
	The communicative environment of the PWA is enhanced	1. The PWA has a positive & supportive communication environment and environmental barriers are reduced	134 (94%)
	The PWA has improved functioning, reduced disability and is able to be discharged	1. The PWA has improved functioning and reduced disability	121 (83%)

Theme	Category	Outcomes reaching consensus	Participants rating the outcome essential
Outcomes for the family/carers /significant others of people with aphasia	Family/Carers/significant others are better communication partners	1. Family/carers/significant others understand how to communicate with people with aphasia	141 (99%)
		2. Family/carers/significant others understand the nature and extent of the PWA's communication impairment	134 (94%)
		3. Family/carers/significant others have improved communication skills and confidence	120 (84%)
	Family/carers/significant others have good knowledge about aphasia and better attitudes towards people with aphasia	1. Family/carers/significant others have good knowledge about aphasia	120 (84%)
		2. Family/carers/significant others have better attitudes towards people with aphasia	119 (84%)
	Family/carers/significant others experience less third party disability	1. Family/carers/significant others are aware of / able to access support and counselling	116 (81%)
		2. Family/carers/significant others have reduced burden/frustration and improved coping/ acceptance	126 (88%)
	Family/carers/significant others engage in the PWA’s therapy	1. Family/carers/significant others engage in the therapy for the PWA	101 (71%)

Theme	Category	Outcomes reaching consensus	Participants rating the outcome essential
Outcomes Related to Health Services	Clients have access to services and funding	1. Clients can access services/ ongoing services	120 (85%)
		2. Clients can access funding for resources and services	105 (75%)
	Resources are used efficiently and outcomes are measured	1. Being able to measure the difference made by aphasia treatment	108 (77%)
Outcomes for Health Professionals	Health Professionals have greater awareness about aphasia and how to support communication	1. Health professionals have greater awareness about aphasia and how to support communication	129 (91%)

5.4.3 ICF Coding

Each outcome reaching consensus was linked to the ICF. Outcomes were linked to the most specific level of the ICF possible and to more than one ICF code where necessary. ICF coding of the 51 outcomes resulted in a total of 68 linkages (refer to tables 5-11 to 5-13). Outcomes relating to people with aphasia spanned three ICF components; however, the majority of linkages were to the Activity/Participation (52%) component (see table 5-12). The remaining linkages were to the Body Functions component (16.5%) and Environmental Factors (15%). No outcomes linked to Personal Factors. Some outcomes/elements of outcomes were unable to be linked to a corresponding ICF code. These outcomes encompassed broad concepts relating to goal setting, general independence, and satisfaction in life.

Outcomes for family members/carers/significant others reaching consensus were coded to the ICF, resulting in 14 linkages (see tables 5-11 and 5-13). The majority of linkages were equally divided between the Activity/Participation (36%) component and Environmental Factors (36%). Again, a small number of outcomes/elements of outcomes were unable to be linked to a corresponding ICF code. These outcomes related to constructs such as knowledge about health conditions.

Table 5-11

Distribution of Linkages to ICF Components of All Outcomes Reaching Consensus

ICF component	People with aphasia n (%)	Family/carers/significant others n (%)
Body Functions	9 (16.5)	1 (7)
Activity/Participation	28 (52)	5 (36)
Environmental Factors	8 (15)	5 (36)
Nd/Nc*	9 (16.5)	3 (21)
Total Linkages	54	14

*Nd/Nc = Non-definable or not coded

Table 5-12

Results of ICF Linkages for Consensus Items Relating to Persons with Aphasia

ICF code	ICF Description	Number of times coded
b126	Temperament and personality functions	1
b1263	Psychic stability	1
b1266	Confidence	3
b1301	Motivation	1
b152	Emotional functions	1
b1521	Regulation of emotion	1
b1800	Experience of self	1
d	Activities and participation	5
d177	Making decisions	1
d240	Handling stress and other psychological demands	1
d3	Communication	16
d350	Conversation	1
d3602	Using communication techniques	2
d910	Community life	1
d9205	Socializing	1
e	Environmental factors	2
e3	Support and relationships	1
e4	Attitudes	1
e450	Individual attitudes of health professionals	1
e5800	Health services	2
e5801	Health systems	1
nc	Not coded	3
nd-hc	Non-definable health condition	4
nd-qol	Non-definable quality of life	2

Table 5-13

Results of ICF Linkages for Consensus Items Relating to Family/Carers/Significant Others

ICF code	ICF Description	Number of times coded
b1266	Confidence	1
d1	Learning and applying knowledge	3
d2401	Handling stress	1
d3	Communication	1
e410	Individual attitudes of immediate family members	1
e420	Individual attitudes of friends	1
e440	Individual attitudes of personal care providers and personal assistants	1
e5750	General social support services	1
e5800	Health services	1
nd-hc	Non-definable health condition	3

5.4.4 Inter-Rater Reliability

Inter-rater reliability was calculated using percentage agreement and the kappa statistic. Kappa values ranged from 0.75 (ICF component level) to 0.54 (ICF second level) (see table 5-14). This indicates substantial agreement (0.61-0.8) at a component and chapter level and moderate agreement (0.41-0.6) at the second level of the ICF.

Table 5-14

Inter-Rater Reliability Results of ICF Coding

ICF level	Percentage agreement	Kappa (95%CI)*
Component (e.g., body functions)	82.35	0.753 (0.628 - 0.861)
Chapter (e.g., b1 mental functions)	76.47	0.696 (0.562 - 0.803)
Second level (e.g., b160 thought functions)	75.00	0.536 (0.347 - 0.696)

*Bias corrected bootstrapped confidence intervals (1000 replications)

5.5 Discussion

The present study aimed to identify essential aphasia treatment outcomes from the perspective of an international sample of aphasia clinicians and managers in order to contribute to a COS for aphasia treatment research. Examined in reference to the ICF, the outcomes reaching consensus primarily linked to Activity/Participation (for people with aphasia) and Activity/Participation and Environmental Factors (for family/carers/significant others). These findings suggest that clinicians and managers often equate treatment effectiveness with a change in functional status. This has implications for both clinical practice and research where outcomes are currently primarily measured at a body function level. Treatment approaches at body function and activity/participation levels have a complementary relationship. Research has confirmed that impairment-based therapy may result in functional gains (Carragher, Conroy, Sage, & Wilkinson, 2012). However, if outcomes at an activity/participation level are deemed important, they should also be measured at this level. The results of the present study indicate that clinically relevant research should include the measurement of outcomes which include, but also go beyond impairment, particularly at an ICF Activity/Participation level.

5.5.1 Dyadic Communication

In the current study, the two outcomes with the highest levels of consensus both related to communication between the person with aphasia and their communication partners. Communication partner training is an area of burgeoning interest in aphasia treatment. A systematic review of this approach by Simmons-Mackie et al. (2010) provides evidence of its effectiveness in improving communication activities/participation for the communication partners of people with aphasia. The review further concludes that communication partner training is also likely to be effective in improving the communication and participation of people with aphasia themselves, in interactions with trained communication partners. Country-specific studies of clinical aphasia services reveal varying practices in the use of communication partner training. Johansson and colleagues’ (2011) survey of Swedish SLP practices revealed that whilst family intervention was described as important by the majority of respondents, interventions including the provision of information to families and significant others, and the training of families in the use of communication strategies, comprised very little of the time allocated to intervention. SLPs who did provide services to family members cited a lack of resources, methods, and skills as factors preventing the training of family members in use of communication strategies (Johansson et al., 2011). In contrast, studies of aphasia services in Australia and Singapore have reported high use of communication partner training. In all three studies however, outcomes relating to communication partner training were rarely measured (Guo et al., 2014; Johansson et al., 2011; Verna et al., 2009). The current study confirms the clinical importance of outcomes relating to the success of interactions between people with aphasia and their communication partners. There is a need for further research examining currently available measures of communicative interaction, as well as barriers and facilitators to their use, in both clinical and research settings.

5.5.2 Psychosocial Wellbeing for People with Aphasia

For people with aphasia, outcomes reaching consensus most frequently related to psychosocial well-being. These outcomes included: coping with aphasia; feeling in control and involved in decision-making; having a sense of identity, self-worth and self-esteem; having improved mood and emotional well-being; feeling empowered and able to advocate for themselves; feeling confident when communicating; having increased independence; accepting aphasia and adjusting to changed circumstances; and having the support of others. Psychological distress and mood disorders are a common sequelae of stroke (De Ryck, Brouns, Fransen, & Geurden, 2013) and occur with increased frequency post stroke in those with co-occurring speech and language disorders (De Ryck et al., 2013; Hilari et al., 2010). A recent survey of Australian SLPs examined current practice in managing psychological well-being in people with aphasia post stroke (Sekhon, Douglas, & Rose, 2015). Whilst nearly all SLPs (108 of 110 respondents) believed they had a role in addressing the psychological well-being of people with aphasia, the majority did not feel knowledgeable, confident, or satisfied in this role. All respondents reported informally assessing psychological well-being however, only 56% of SLPs reported using formal means of assessment. Commonly reported assessment tools included the AusTOMS (Perry et al., 2004), the Stroke and Aphasia Quality of Life Scale (SAQOL; Hilari, Byng, Lamping, and Smith (2003a)), the Visual Analogue Mood Scale (VAMS; Folstein and Luria (1973)), the Comprehensive Aphasia Test (CAT) disability questionnaire (Swinburn, Porter, & Howard, 2005), and the Visual Analogue Self-Esteem Scales (VASES; Brumfitt and Sheeran (1999a). As Sekhon and colleagues (2015) conclude, a greater focus on addressing the psychological well-being of people with aphasia is needed; through student training, professional development for current clinicians, and via the development of clinical guidelines. Synthesised information regarding the measurement properties of available assessments targeting psychosocial well-being in people with aphasia may also assist clinicians to feel more confident in this role. The concentration of psychosocial outcomes reaching consensus in the current study also highlights the importance of measuring outcomes more broadly in research through the inclusion of measures of emotional well-being and quality of life. Systematic reviews of aphasia treatments demonstrate that psychosocial outcomes are rarely measured (Brady et al., 2012). The inclusion of psychosocial and quality-of-life measures in treatment trials may help to improve the relevancy and meaning of research to end users.

5.5.3 Communication Partner Knowledge and Understanding

In addition to the previously discussed findings regarding dyadic communication outcomes, the current study has also identified increased communication partner knowledge and understanding as an important clinical outcome. Half of the outcomes for family/carers/significant others which reached consensus related to knowledge and understanding. Specifically outcomes related to: understanding how to communicate with people with aphasia; understanding the nature and extent of the communication impairment of the person with aphasia; having better attitudes towards people with aphasia; having good knowledge about aphasia; and being aware of available support and counselling. These findings reflect previous research which has identified that family members of people with aphasia have unmet information requirements (Le Dorze & Signori, 2010). The information needs of family members have been determined to differ according to time post onset of aphasia; common to all stages of recovery was: a desire for time-relevant aphasia information; information about psychosocial support and counselling; and information which communicates positive expectations about the future and hopefulness (Avent et al., 2005). SLPs have also identified the provision of education and information to people with aphasia and their families as a key component of SLP services that influences living successfully with aphasia (Brown, Worrall, Davidson, & Howe, 2011). Importantly, knowledge and understanding about aphasia has been recognised by SLPs as a precursor to families accepting changed communication; and family roles and responsibilities (Brown et al., 2011). Whilst family members and SLPs have identified information and education as important aspects of aphasia service provision, there is little evidence to suggest that knowledge and understanding is measured as an outcome. There is a need to establish whether tools exist for measuring knowledge and understanding in aphasia. Information regarding available tools may assist clinicians to better capture outcomes relating to communication partner knowledge.

5.6 Limitations and Future Directions

Participant retention rates across the e-Delphi exercise were likely impacted by a longer than anticipated gap between rounds 1 and 2. Participant attrition in e-Delphi studies is a commonly reported issue (Sinha et al., 2011). In the current study, 10% of potential participants were unable to be contacted in round 2, reflected in out-of-office email replies. Higher response rates may have been achieved through a quicker transition from the first to second e-Delphi round. A further limitation of this study relates to the representativeness of the sample. Whilst participants from all six world regions (as defined by the World Health Organization (2014)) were represented, participants numbers from Eastern Mediterranean, African, and South East Asian regions were low. Greater representation from these regions may have impacted the results. It is acknowledged that a social desirability response bias may occur in the initial stage of an e-Delphi process, if respondents are aware of the predominant research focus of the researchers. However, the present study generated 90 different outcomes, linked to all ICF components (with the exception of ‘Personal Factors’). The diversity and variability in responses has reflected a full spectrum of potential outcome constructs.

The current study demonstrates a need for synthesised information regarding existing outcome measures for people with aphasia in order to assist clinicians and researchers to choose the most appropriate tool for their needs. To address this gap, a systematic review of the measurement properties of outcomes measures used with people with aphasia is currently underway. The outcomes identified in this paper may form the basis for future research focusing on clinical outcome measurement. Investigation of the factors motivating clinicians’ choice of clinical outcome measures may form an important component of this process.

5.7 Conclusions

Clinicians and managers working in aphasia rehabilitation gained consensus on 51 essential treatment outcomes which linked to Body Function, Activity/Participation and Environmental Factor components of the ICF. Very high levels of consensus (97-99%) were achieved for outcomes relating to communication between the person with aphasia and their communication partner/s. This finding confirms that in the clinical environment, improved dyadic communicative interaction is a very important indicator of treatment success. Outcomes relating to people with aphasia primarily linked to the Activity/Participation ICF components, while outcomes relating to family members/carers/significant others were predominantly and equally linked to the Activity/Participation component and Environmental Factors. At a thematic level, outcomes for people with aphasia most frequently related to psychosocial well-being and to improved communication partner skills and knowledge for significant others. While these constructs are often identified as important aspects of treatment, they are rarely measured. The results of this study confirm that clinicians value outcomes which go beyond the level of impairment. In both the clinical setting and in treatment research there is a need to ensure that clinically relevant outcomes are measured through the inclusion of broader outcomes, particularly those which relate to Activity/Participation, psychosocial well-being, and the success of communication between the person with aphasia and their significant others. Synthesised evidence regarding available outcome measures in these areas may assist researchers and clinicians to make informed decisions regarding the selection of these tools.

5.8 Acknowledgements

We acknowledge the invaluable contribution of the international community of aphasia clinicians and managers who participated in this study. We thank you for your time, your expertise, and for the unique perspectives you have brought to this research. The enthusiasm with which you approached this study was inspiring and very much appreciated.

5.9 Declaration of Interest Statement

This work was supported by an Australian Postgraduate Award (APA) scholarship awarded to Sarah J. Wallace. The authors have no other declarations of interest to report.

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Chapter 6: A Comparison of Stakeholder Perspectives

This chapter synthesises the findings of chapters 3-5. The perspectives of people with aphasia, family members, aphasia researchers, and clinicians/managers are examined within the framework of the World Health Organization International Classification of Functioning, Disability and Health (ICF; World Health Organization, 2001).

This chapter will be submitted for publication: Wallace, S. J., Worrall, L., Rose, T., & Le Dorze, G. (In preparation). A Comparison of Stakeholder Perspectives.

6.1 Abstract

Purpose: This study aimed to synthesise and compare the findings of three separate consensus processes which explored the perspectives of key stakeholder groups (people with aphasia and their family members, aphasia researchers, and aphasia clinicians/managers) about important aphasia treatment outcomes. This synthesis was conducted with the goal of generating recommendations for outcome domains to be included in a core outcome set (COS) for aphasia treatment research.

Methods: In three previous consensus studies: (1) people with aphasia and their families, (2) aphasia researchers, and (3) aphasia clinicians/managers reached consensus on important aphasia outcomes. Outcomes were linked to the World Health Organization International Classification of Functioning Disability and Health (ICF) using established linking procedures. In the current study, the ICF was again used to identify shared and distinct outcomes of importance across the stakeholder groups.

Results: Synthesis of results from three separate consensus studies revealed that important outcomes from aphasia treatment occur at all levels of the ICF (i.e., Body Functions, Activity/Participation, Environmental and Personal Factors). Within these components, congruence across three or more stakeholder groups was evident for outcomes relating to Mental functions (Emotional functions, Mental functions of language, Energy and drive functions), Communication (Communicating by language, signs and symbols, receiving and producing messages, conversations, and using communication devices and techniques); and Services, systems, and policies (Health services, systems and policies). Quality of life was explicitly identified as an important construct by clinicians/managers and researchers, while people with aphasia and their families identified multiple outcomes known to be determinants of quality of life.

Conclusions: A COS for aphasia treatment research should include measures relating to: language; emotional wellbeing; communication; health services; and quality of life. Existing, validated outcome measures relating to these constructs will be identified in a systematic review and presented at an international consensus meeting to develop a COS for aphasia treatment research.

Keywords: Aphasia, Outcomes, ICF, Patient Involvement, Family, Caregivers.

6.2 Introduction

The decision of what to measure in treatment research cannot be made by researchers alone. Ultimately, the goal of treatment research is to produce evidence which will inform the health care decisions of consumers, health professionals, and policy makers. The outcomes measured in treatment research must therefore not only be relevant to these stakeholders, but also must be able to be meaningfully applied to the health care decisions which matter to them. Core outcome sets (COS; an agreed, minimum set of outcomes and outcome measures) are increasingly being used to maximise the relevancy and consistency of the outcomes measured in treatment trials, across a range of health areas (Gargon, Williamson, Altman, Blazeby, & Clarke, 2014). The inclusion of stakeholder perspectives in determining which constructs should be routinely measured is central to this process (Williamson et al., 2012).

Research across a number of health areas has demonstrated that different stakeholder groups identify and prioritise outcomes in different ways (e.g., Carr et al., 2003; Schmitt, Langan, Stamm, & Williams, 2011; Sinha, Gallagher, Williamson, & Smyth, 2012). Accordingly, current methodological recommendations for COS development highlight the imperative to involve multiple stakeholder groups, including patients, health care practitioners, and researchers (Williamson et al., 2012). When multiple stakeholder groups are included in the process of creating a COS, it is necessary to consider how each groups' priorities will be balanced when producing a final list of core outcome constructs. With COS development methodology in its infancy, there are currently no recommendations to guide this process. However, two main approaches to synthesising the opinions of different groups in COS development have been identified in the literature. The first approach uses a single consensus panel with multiple stakeholder representatives, to produce recommendations for outcome constructs (e.g., Schmitt et al., 2011). Using this method, the aim is to achieve agreement amongst stakeholders regarding important outcomes through the one consensus process. The second approach uses separate stakeholder group consensus processes and then integrates group findings in further separate analyses or consensus processes (e.g., Harman et al., 2015). The current study has adopted the latter approach as the use of multiple separate stakeholder consensus processes allows a larger and more representative sample of participants to be engaged, increasing the likelihood that the outcomes reaching consensus will be representative of each stakeholder groups' views.

The current study is part of a broader research project known as, 'Improving Research Outcome Measurement in Aphasia (ROMA)'. This project aims to increase consistency in research outcome measurement through the development of a COS for aphasia treatment research (see Wallace, Worrall, Rose, & Le Dorze, 2014a; Wallace, Worrall, Rose, & Le Dorze, 2014b). In order to identify the outcomes which are most important to stakeholders in aphasia treatment research, a series of three separate consensus studies were conducted. In each of the three consensus studies, the question presented to each stakeholder group was worded slightly differently to capture that stakeholder groups' perspective. The underlying intention of each question was to identify, and subsequently gain consensus on, the most important outcomes from aphasia treatment. The following questions were asked:

1. People with aphasia: *"What would you most like to change about your communication and the way aphasia affects your life?"*

2. Family members of people with aphasia: *"What would you most like to change about your family member's communication and the way aphasia affects your life?"*

3. Aphasia researchers: *"What constructs do you believe should be measured as outcomes in all aphasia treatment research?"*

4. Aphasia clinicians/managers: *"What are the most important outcomes (results) from aphasia treatment?"*

Across all three studies outcomes reaching consensus were analysed using ICF coding. ICF linking rules (Cieza et al., 2002; Cieza et al., 2005; Worrall et al., 2011) were used to code each meaning unit, within each outcome, to the most precise ICF code/s possible. ICF coding was used with the intention of enabling results to be synthesised and compared across stakeholder groups.

In study 1, people with aphasia (n=39) and their family members (n=29) in Australia, Canada, Denmark, Hong Kong (China), South Africa, the United States of America, and the United Kingdom, participated in one of 16 groups. Within each group, participants used the nominal group technique (Delbecq, Van de Ven, & Gustafson, 1975) to identify and rank important aphasia treatment outcomes (see Wallace, Worrall, Rose, Le Dorze, et al., 2016). Supported conversation techniques for adults with aphasia (Kagan, 1998) were used to assist people with aphasia to participate authentically in this process. Following a round-robin presentation of ideas, each participant selected and ranked the three outcomes they considered most important, in order of importance. Scores were summed to provide a prioritised consensus list for each group. Prioritised outcomes across all 16 groups were analysed using qualitative content analysis (Graneheim & Lundman, 2004) and ICF coding (Cieza et al., 2005). Participants with aphasia identified outcomes for themselves; and family member participants identified outcomes for themselves and for the person with aphasia. Prioritised outcomes for both participant groups linked to all ICF components; predominately Activity/Participation (39%) and Body Functions (36%) for participants with aphasia, and Activity/Participation (49%) and Environmental Factors (28%) for family member participants. Outcomes prioritised by family members relating to the person with aphasia, most frequently linked to Body Functions (60%). Thematically, the outcomes prioritised by both participants groups related to: (1) improved communication; (2) increased life participation; (3) changed attitudes through increased awareness and education about aphasia; (4) recovered normality; (5) improved physical and emotional well-being; and (6) improved health (and support) services.

In study 2, purposively sampled aphasia researchers were invited to participate in a three-round e-Delphi exercise (Wallace, Worrall, Rose, & Le Dorze, in press). Procedures for each e-Delphi round were developed in accordance with the methodological recommendations of Sinha, Smyth, and Williamson (2011). Eighty researchers commenced round 1, with 72 completing the entire survey. In round 1, an open-ended question was used to generate important outcome constructs. Responses were analysed using qualitative content analysis (Graneheim & Lundman, 2004). In rounds 2 and 3, the aphasia researchers rated the importance of each outcome using a 9-point rating scale (1= least important; 9= most important). Consensus that an outcome was essential to measure in all aphasia treatment research was defined a priori as a rating of 7-9 (essential) by at least 70% of the respondents and 1-3 (of limited importance) by less than 15% of the respondents (Williamson et al., 2012). Outcomes reaching this pre-defined consensus criteria were further analysed using ICF coding. The aphasia researchers in the study reached consensus on six outcomes: 1) language functioning in modalities relevant to the study aims; 2) impact of treatment from the perspective of the person with aphasia (PWA); 3) communication-related quality of life (PWA); 4) satisfaction with intervention from the perspective of the PWA; 5) satisfaction with ability to communicate from the perspective of the PWA; and 6) satisfaction with participation in activities from the perspective of the PWA. These outcomes linked to all ICF components and emphasised the importance of measuring the patient-reported outcomes.

In study 3, a three-round e-Delphi exercise was conducted with aphasia clinicians/ managers (see Wallace, Worrall, Rose, & Le Dorze, 2016). In total, 265 clinicians and 53 managers (n = 318) from 25 countries participated in round 1. In the first round, participants responded to an open-ended question; responses were analysed using qualitative content analysis (Graneheim & Lundman, 2004). In rounds 2 and 3, aphasia clinicians/managers rated the importance of each outcome generated in round 1 using the same 9-point rating scale utilised in study 2. Again, consensus was defined a priori as a rating of 7-9 by at least 70% of the respondents and 1-3 by less than 15% of the respondents (Williamson et al., 2012). Outcomes reaching the predefined consensus criteria were further analysed using ICF linking (Cieza et al., 2005). Clinicians and managers gained consensus on 51 essential treatment outcomes which linked to Body Function, Activity/Participation, and Environmental Factor components of the ICF. Very high levels of consensus (97-99%) were achieved for outcomes relating to communication between the person with aphasia and their communication partner/s. At a thematic level, outcomes for people with aphasia most frequently related to psychosocial well-being, whilst outcomes for significant others centred on improved communication partner skills and knowledge.

Across these three consensus processes, ICF linking was intentionally used to provide a common framework which would allow the identification of shared and distinct outcomes of importance. Therefore the current study aimed to compare the perspectives of people with aphasia, their family members, aphasia researchers, and aphasia clinicians/managers regarding important treatment outcomes. Areas of congruence were distilled into recommendations for outcome domains to be included in a COS for aphasia treatment research.

6.3 Methods

The current study was informed by three separate studies which aimed to gain consensus on important aphasia treatment outcomes from the perspective of multiple stakeholder groups. Ethical approval for each of these studies was gained from the Behavioural and Social Sciences Ethical Review Committee at The University of Queensland in accordance with the National Health and Medical Research Council's guidelines.

ICF categories generated through linking processes in the three preceding studies, were examined to identify where the groups of: (1) participants with aphasia, (2) family member participants, (3) aphasia researchers, and (4) aphasia clinicians/managers, demonstrated congruence and divergence in their perspectives. Outcomes relating to (a) people with aphasia, and (b) significant others of people with aphasia, were analysed separately. The distribution of ICF categories was analysed at component level (i.e., Body Functions and Structures; Activity/Participation; Environmental Factors; and Personal Factors; see figure 6-1) and then at the more detailed chapter (e.g. b1 Mental functions) and second level (e.g., b167 Mental functions of language) (see figure 6-2). Using the common taxonomy of the ICF, important outcome constructs were identified within and across participant groups. Congruence was required across three or more participant groups at ICF second level for a construct to be recommended for inclusion in the COS.

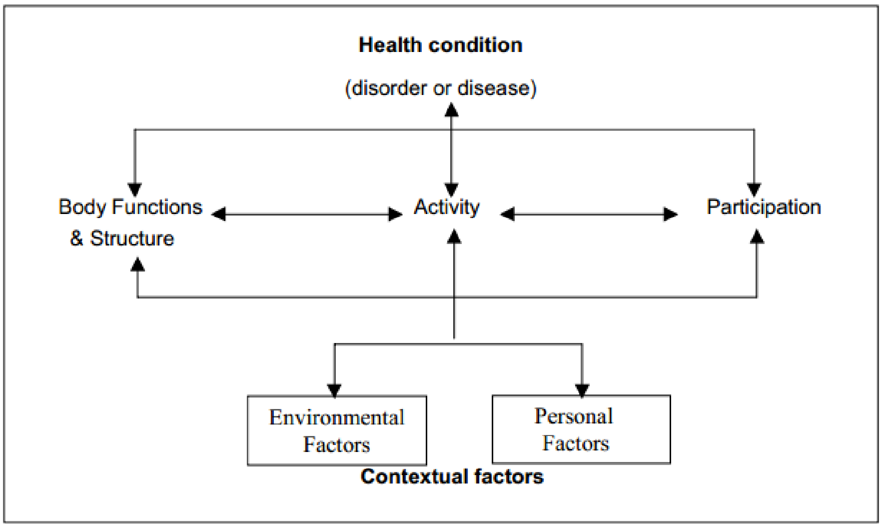

Figure 6-1. The World Health Organization International Classification of Functioning, Disability and Health (ICF). (From World Health Organization, 2001). Reprinted with permission.

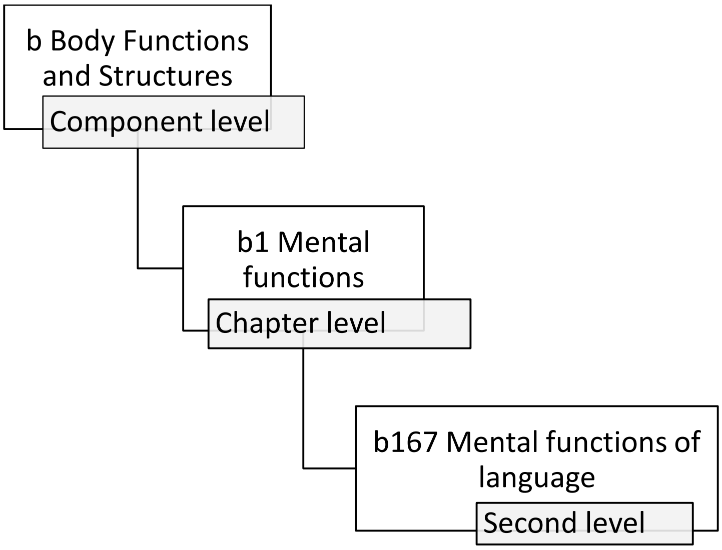

Figure 6-2. Example of the ICF Coding Hierarchy

6.4 Results

6.4.1 Overview of Studies Informing Synthesis

In the three studies informing the current synthesis, participant groups identified outcomes which related to: 1) people with aphasia, and 2) significant others of people with aphasia. Table 6-1 provides an overview of: (1) the total number of outcomes that each participant group reached consensus on; and (2) the number of resulting ICF linkages (demarcated by whether the outcomes related to people with aphasia or significant others). Some outcomes contained multiple concepts and linked to more than one ICF category, resulting in more ICF linkages than outcomes.

Participants with aphasia reached consensus on several very specific and personally relevant outcomes (n=83) and accordingly they linked to numerous detailed ICF categories, often at second and third ICF levels (n=121). Participants with aphasia only reached consensus on outcomes relating to themselves and did not generate outcomes which related to significant others. In contrast, aphasia researchers identified few outcomes which reached consensus (n=6) and these were broadly expressed, often only able to be linked to ICF component and chapter levels (n=10). Aphasia researchers also only reached consensus on outcomes relating to people with aphasia, and not their significant others. Consensus outcomes identified by family members and clinicians/managers linked to fewer ICF categories than those generated by participants with aphasia; but to more detailed levels of the ICF (second and third levels) than those generated by researchers. Family member participants and clinicians/managers reached consensus on outcomes for *both* people with aphasia and their significant others.

Table 6-1

Total Number Outcomes Reaching Consensus by Participant Group

	Participant Group			
	Participants with aphasia	Family member participants	Researchers	Clinician/ Managers
Total number of outcomes reaching consensus	83	63	6	51
Outcomes relating to people with aphasia (Number of ICF linkages).	121	40	10	54
Outcomes relating to significant others. (Number of ICF linkages).	0	61	0	14

In the following synthesis, results are presented first for outcomes relating to people with aphasia; and second for significant others.

6.4.2 Outcomes Relating to People with Aphasia

6.4.2.1 ICF component level. Table 6-2 shows the distribution of outcomes by ICF component and participant group. All participant groups reached consensus on outcomes which linked to ICF Body Function, Activity/Participation, and Environmental Factor components. Outcomes prioritised by three participant groups; people with aphasia, family members, and aphasia researchers linked to ICF Personal Factors. The outcomes linking to Personal Factors were highly individualised.

The outcomes generated by participants with aphasia, clinicians/managers, and researchers most frequently linked to Activity/Participation (39%, 52%, and 30% respectively). Contrastingly, the outcomes produced by family member participants (relating to the person with aphasia), most often linked to Body Functions (60%). Approximately one third (36%) of the outcomes identified by participants with aphasia linked to Body Functions.

Some outcomes could not be classified within the ICF framework. Both researcher and clinician/manager participant groups identified outcomes relating to the person with aphasia's quality of life, a construct not captured within the ICF. No outcomes generated by participants with aphasia or family members made specific reference to 'quality of life', however the use of this term would not be expected amongst consumer populations. Many of the outcomes identified by these participant groups however are factors known to impact health-related quality of life in people with aphasia, including emotional wellbeing, communication disability, engagement in activities and size of social networks (Hilari, Needle, & Harrison, 2012). Clinicians/managers also reached consensus on outcomes that could not be coded to the ICF. These related to life satisfaction, participation in goal setting, and a regained sense of independence.

Table 6-2

Outcomes for People with Aphasia: Distribution of ICF linkages at Component level, by Participant Group

		Participant group			
		People with aphasia n (%)	Family members n (%)	Clinicians/ managers n (%)	Aphasia researchers n (%)
ICF Component	Body Functions	44 (36)	**24 (60)**	9 (16.5)	2 (20)
	Activity/ Participation	**47 (39)**	13 (33)	**28 (52)**	**3 (30)**
	Environmental Factors	26 (22)	1 (2)	8 (15)	2 (20)
	Personal Factors	4 (3)	2 (5)	0 (0)	1 (10)
Not-definable within the ICF	Quality of Life	0 (0)	0 (0)	2 (3.5)	2 (20)
	Other - Not Coded	0 (0)	0 (0)	7 (13)	0 (0)
Total number of linkages		121 (100)	40 (100)	54 (100)	10 (100)

* largest proportion in bold

6.4.1.2 ICF chapter and second level. Table 6-3 shows ICF linkages at component, chapter, and second level, by participant group. At a chapter level, greatest consistency (across three or more groups) was seen for; b1 Mental functions (Body Functions component), d3 Communication (Activity/Participation component), and e5 Services, systems and policies (Environmental Factors component).

Mental functions (b1). Within the Mental functions chapter, there was consistency across three or more participant groups that important outcomes from aphasia treatment relate to language functions, emotional functions, and energy and drive functions. Outcomes from participants with aphasia, family members, and clinicians/managers linked to the following second level ICF categories; 1) Energy and drive functions (b130), and 2) Emotional functions (b152). Energy and drive functions encompasses constructs relating to energy levels and motivation towards the achievement of goals, while emotional functions pertains to specific mental functions related to feeling and affective processes including regulation and range of emotion and affect. In the words of the participants themselves, these outcomes related to adjustment and acceptance of circumstances, feelings of dignity and joy, reduced frustration, and greater energy and motivation to communicate.

Also within the Mental functions chapter, participants with aphasia, family members, and aphasia researchers all prioritised outcomes which linked to the second level category Mental functions of language (b167). This category relates to the mental functions of recognising and using signs, symbols, and other components of a language, and includes reception and expression of language. Within this category people with aphasia and family members identified outcomes relating to multiple specific modalities of language. In contrast, aphasia researchers discussed language function at a broader level. It was of interest that the clinician/manager group identified outcomes relating to language function in the first round of their e-Delphi exercise, but did not reach consensus in subsequent rounds that improved language function was an essential outcome of treatment.

Communication (d3). All four participant groups reached consensus on outcomes which linked specifically to the d3 Communication chapter. This chapter relates to communication by language, signs and symbols; including receiving and producing messages, carrying on conversations, and using communication devices and techniques. In the words of the participants, outcomes related to communication in activities, effective communication of a message, communication in the dyad, communication of emotions, satisfaction with communication, positive feelings about communication, and multi-modal communication.

At the ICF second level, greatest consistency across stakeholder groups was evident for d360 Using communication devices and techniques. Outcomes linked to this category primarily related to the use of strategies to support functional communication.

Services, systems and policies chapter (e5). Within the Services, systems and policies chapter participants with aphasia, clinicians/managers, and aphasia researchers reached consensus on outcomes linking to the second level category e580 Health services, systems and policies. This category relates to services, systems, and policies for preventing and treating health problems, providing rehabilitation and promoting a healthy lifestyle. According to participants these outcomes related to satisfaction with treatment, the patient perspective regarding the impact of treatment, and access to and funding for treatment and services.

Table 6-3

Outcomes for People with Aphasia: Distribution at ICF Component, Chapter, and Second Level, by Participant Group

			People with aphasia	Family members	Clinicians/ managers	Researchers
BODY FUNCTIONS						•
b1 Mental Functions	b1	Mental functions		•		
	b126	Temperament and personality functions	•		•	
	b130	Energy and drive functions*	•	•	•	
	b140	Attention functions	•	•		
	b144	Memory functions	•	•		
	b152	Emotional functions	•	•	•	
	b160	Thought functions	•			
	b167	Mental functions of language	•	•		•
	b180	Experience of self and time functions			•	
b2 Sensory functions and pain	b230	Hearing functions	•			
b3 Voice and speech functions	b310	Voice functions	•			
	b320	Articulation functions	•	•		
	b340	Alternative vocalization functions	•			
b7 Neuromusculoskeletal and movement-related functions			•			

			People with aphasia	Family members	Clinicians/ managers	Researchers
ACTIVITY/ PARTICIPATION					•	•
d1 learning and applying knowledge	d155	Acquiring skills	•			
	d166	Reading	•			
	d170	Writing	•			
	d177	Making decisions			•	
d2 General tasks and demands	d210	Undertaking a single task	•			
	d220	Undertaking multiple tasks	•	•		
	d230	Carrying out daily routine		•		
	d240	Handling stress and other psychological demands	•		•	
d3 Communication	d3	Communication	•	•	•	•
	d310	Communicating with – receiving – spoken messages	•			
	d330	Speaking	•			
	d350	Conversation	•		•	
	d355	Discussion	•			
	d360	Using communication devices and techniques	•	•	•	
d4 Mobility	d4	Mobility	•	•		
d5 Self-care	d570	Looking after one's health	•	•		

			People with aphasia	Family members	Clinicians/ managers	Researchers
d7 Interpersonal interactions and relationships	d7	Interpersonal interactions and relationships		•		
	d710	Basic interpersonal relationships		•		
	d720	Complex interpersonal interactions	•			
	d750	Informal social relationships	•			
d8 Major life areas	d810-839	Education	•			
	d845	Acquiring, keeping and terminating a job	•			
	d860	Basic economic transactions	•			
d9 Community, social and civic life	d9	Community, social and civic life	•			
	d910	Community life			•	
	d920	Recreation and leisure	•		•	
ENVIRONMENTAL FACTORS					•	•
e1 Products and technology	e125	Products and technology for communication	•			

			People with aphasia	Family members	Clinicians/ managers	Researchers
e3 Support and relationships	e3	Support and relationships			•	
	e310	Immediate family	•			
	e330	People in positions of authority	•			
	e340	Personal care providers and personal assistants	•	•		
	e355	Health professionals	•			
e4 Attitudes	e4	Attitudes			•	
	e430	Individual attitudes of people in positions of authority	•			
	e450	Individual attitudes of health professionals			•	
	e460	Societal attitudes	•			
e5 Services, systems and policies	e565	Economic services, systems and policies	•			
	e580	Health services, systems, and policies	•		•	•
	e585	Education and training services, systems and policies	•			
	e590	Labour and employment policies	•			

	People with aphasia	Family members	Clinicians/ managers	Researchers
PERSONAL FACTORS	•	•		•
QUALITY OF LIFE	■	■	•	•

• = Participant group reached consensus on outcomes linking to presented ICF category/construct.

■ = Participant group reached consensus on determinants of construct

*Shaded areas indicate consistency across three or more stakeholder groups.

6.4.3 Outcomes Relating to Significant Others

6.4.3.1 ICF component level. Table 6-4 shows the distribution of outcomes by ICF component and participant group. Two participant groups; 1) family members, and 2) clinicians/managers, reached consensus on outcomes which related to the significant others of people with aphasia. People with aphasia did not identify outcomes for their significant others and while researchers did generate outcomes for significant others in initial rounds of their e-Delphi process, no outcomes for significant others reached consensus.

Both family members and clinicians/managers reached consensus on outcomes which linked to ICF Body Function, Activity/Participation, and Environmental Factor components. At an ICF component level, the outcomes generated by family members for significant others (i.e., themselves), most frequently related to Activity/Participation (49%). The outcomes identified by clinicians/managers for significant others most frequently related to Activity/Participation (36%) and Environmental Factors (36%).

Family member participants reached consensus on a small number of outcomes (5%) for themselves which linked to Personal Factors, such as independence and a desire to regain a sense of their own individuality. Clinicians/managers reached consensus on outcomes for significant others which could not be coded to the ICF (21%). These outcomes related to concepts such as knowledge about aphasia.

Table 6-5 shows the distribution of outcomes for significant others at ICF component, chapter, and second level, by participant group. At an ICF chapter and second level, no categories were consistent across three or more stakeholder groups. Therefore no specific recommendations have been formulated for this group.

Table 6-4

Number of ICF linkages for Significant Others: Distribution of ICF Linkages by Stakeholder Group

		Stakeholder group	
		Family members	Clinicians/managers
ICF Component	Body Functions	11 (18)	1 (7)
	Activity/Participation	**30 (49)**	**5 (36)**
	Environmental Factors	17 (28)	**5 (36)**
	Personal factors	3 (5)	0 (0)
Unable to be coded		0 (0)	3 (21)
Total number of linkages		61 (100)	14 (100)

Table 6-5

Outcomes for Significant Others: ICF Component, Chapter and Second Level by Stakeholder Group

			People with aphasia	Family members	Clinicians/ managers	Researchers
BODY FUNCTIONS						
b1 Mental functions	b126	Temperament and personality functions		•	•	
	b130	Energy and drive functions		•		
	b152	Emotional functions		•		
ACTIVITY/PARTICIPATION						
d1 Learning and applying knowledge	d1	Learning and applying knowledge		•	•	
d2 General tasks and demands	d240	Handling stress & other psychological demands		•	•	
d3 Communication	d3	Communication		•	•	
	d350	Conversation		•		
	d355	Discussion		•		
	d360	Using communication devices & techniques		•		
d5 Self-care	d570	Looking after one’s health		•		
d6 Domestic life	d660	Assisting others		•		

			People with aphasia	Family members	Clinicians/ managers	Researchers
d7 Interpersonal interactions and relationships	d710	Basic interpersonal relationships		•		
	d750	Informal social relationships		•		
	d760	Family relationships		•		
	d770	Intimate relationships		•		
d9 Community, Social and civic life	d920	Arts and culture		•		
ENVIRONMENTAL FACTORS						
e1 Products and technology	e1	Products and technology		•		
	e165	Assets		•		
e3 Support and relationships	e310	Immediate family		•		
e4 Attitudes	e410	Individual attitudes of immediate family members		•	•	
	e415	Individual attitudes of extended family members		•		
	e420	Individual attitudes of friends			•	

			People with aphasia	Family members	Clinicians/ managers	Researchers
	e440	Individual attitudes of personal care providers and personal assistants			•	
	e460	Societal attitudes		•		
e5 Services, systems and policies	e575	General social support services, systems and policies		•	•	
	e580	Health services, systems and policies		•	•	
PERSONAL FACTORS				•		
QUALITY OF LIFE				■	■	

• = Stakeholder group reached consensus on outcomes linking to presented ICF category.

■ = Participant group reached consensus on determinants of construct

6.5 Summary

Table 6-6 shows the chapter and second level ICF categories which were common to three or more participant groups.

6.6 Recommendations

The following statements provide recommendations for outcome domains and constructs which should be included in a COS for aphasia treatment research. Congruence was required across three or more participant groups at ICF second level for a construct to be recommended for inclusion in the COS. These recommendations are not intended to be prescriptive or exhaustive, but rather are intended to provide an empirical basis for further research and discussion.

In relation to the person with aphasia, the impact of aphasia treatment should be measured:

1. at ICF Body Function level, including measurement of mental functions e.g., energy and drive functions, emotional functions, and mental functions of language;
2. at ICF Activity/Participation level, including measurement of communication e.g., communicating by language, signs and symbols, receiving and producing messages, conversations, and using communication devices and techniques;
3. at ICF Environmental Factor level, including measurement of outcomes relating to health services, systems, and policies; and
4. beyond the ICF, including measurement of quality of life.

Table 6-6

Summary of ICF Second level Categories Informing COS Recommendations, by Stakeholder Group

ICF component	ICF chapter	ICF code and category		People with aphasia	Family members	Clinicians/ managers	Researchers
Body Functions	b1 Mental functions	b130	Energy and drive functions	✓	✓	✓	
		b152	Emotional functions	✓	✓	✓	
		b167	Mental functions of language	✓	✓		✓
Activity/ Participation	d3 Communication	d3	Communication	✓	✓	✓	✓
		d360	Using communication devices and techniques	✓	✓	✓	
Environmental Factors	e5 Services, systems and policies	e580	Health services, systems, and policies	✓		✓	✓
Non-ICF Constructs: Quality of life (or determinants of QOL across multiple ICF categories)				✓	✓	✓	✓

✓ Participant group reached consensus on outcomes linking to presented ICF category.

6.7 Conclusions

Important treatment outcomes identified by stakeholders in aphasia rehabilitation have been distilled into recommendations for constructs to be included in a COS. It is recommended that a COS include the measurement of outcomes for people with aphasia at ICF Body Function, Activity/Participation and Environmental Factor levels. Specifically, the impact of a treatment on language; emotional wellbeing; communication; and quality of life should be measured routinely. Outcomes relating to health services (e.g., treatment satisfaction and treatment impact) should also be measured.

In addition to providing recommendations for outcome constructs which could be routinely measured in research, the current synthesis may provide a useful clinical resource. The ICF categories listed in tables 6-3 and 6-5 may be used as an empirical base to guide goal setting, assessment, therapy, and outcome measurement in the clinical setting. The outcomes generated by consumer participant groups may also provide insight into priority areas for further research.

6.8 Limitations and Future Directions

While the classification system of the ICF has provided a common framework for considering the perspectives of different groups of stakeholders, it must be acknowledged that by the very virtue of using this standard linking process, nuances of meaning may be lost. As such the findings of this synthesis should be considered in reference to the full content analysis of participant responses reported in the preceding stakeholder-specific consensus processes.

Also worthy of consideration are the subtle differences in the questions posed within the individual studies which informed this synthesis. The questions used to elicit stakeholder perspectives on outcomes of importance were phrased to be meaningful and specific to each stakeholder group; while the underlying intention of each question was the same (i.e., to identify the most important outcomes from aphasia treatment) differences in question wording may have impacted the responses generated. Similarly, while the same e-Delphi consensus process was used with clinician/manager and aphasia researcher groups, the very nature of aphasia as a disorder of communication, necessitated face-to-face processes to be used with people with aphasia. Again, differences in the processes used to achieve consensus should be considered.

Differences in methodology or assumed knowledge may have accounted for many more outcomes that were reported by the aphasia groups and family member groups compared to the other groups. For example, people with aphasia and family members identified outcomes which related to several different language components (reading, writing, talking, and understanding). Perhaps aphasia clinicians/managers and researchers knew that there are language assessments which measure such language components together, therefore they did not report outcomes according to specific language modalities.

While this synthesis and preceding trilogy of consensus studies have identified important outcomes from aphasia treatment, the feasibility of measuring these outcomes in research must also be considered. Accordingly, the recommendations arising from the current synthesis should not be viewed as prescriptive. Given the low number of outcomes identified by researchers in their e-Delphi process (compared with consumer and clinician groups) it is possible that the researchers may have taken feasibility and existing measurement tools into account.

The pairing of the identified outcome constructs with appropriate and psychometrically robust outcome measures forms the next stage of this project. The next study in this project will entail systematically identifying existing, validated outcome measures which could be used to measure the outcome constructs identified in the current study. This information will be presented to an international panel of aphasia treatment researchers in late 2016 as an evidence-base for the selection of outcomes and outcomes measures for a core outcome set for aphasia treatment research.

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Chapter 7: A Scoping Review of Studies Reporting the Measurement Properties of Standardised Outcome Instruments for People with Aphasia

This chapter presents the findings of a scoping review of studies reporting the measurement properties of standardised outcome instruments which have been validated with people with aphasia.

This chapter will be submitted for publication: Wallace, S. J., Worrall, L., Rose, T., Le Dorze, G. & Brandenburg, C. (In preparation). A Scoping Review of Studies Reporting the Measurement Properties of Standardised Outcome Instruments for People with Aphasia.

7.1 Abstract

Purpose: The aim of this review was to systematically identify all available studies reporting the measurement properties of standardised outcome instruments which have been validated with people with aphasia.

Methods: Full text journal articles were identified through searches of PUBMED, EMBASE, and CINAHL databases and through hand searching of journals. Secondary searches were performed for outcome instruments identified in the initial search. The review was conducted in alignment with PRISMA guidelines and COSMIN recommendations for systematic reviews of health measurement instruments.

Results: A total of 1834 articles were identified through database searches; an additional 159 articles were identified via hand searching of journals. Following the removal of duplicates, 1531 articles were screened by title and abstract; with a total of 351 articles undergoing full text review. Secondary searches were run on outcome instruments identified in the initial search. In total, 184 references for 79 outcomes instruments were ultimately included in this review. These outcome instruments were broadly classified within the ICF framework based on published descriptions of each instrument’s purpose. The vast majority of outcome instruments related to Body Functions (n=49).

Conclusions: This systematic scoping review has identified a wide range of outcome instruments which have been validated with people with aphasia. These tools predominately measure constructs within the Body Functions component of the ICF. No instruments were identified which measure patient-reported treatment impact or treatment satisfaction.

Keywords: Aphasia, outcome measures, validation studies, psychometrics, systematic review.

7.2 Introduction

The outcome measures used in aphasia treatment studies are many and varied. This heterogeneity produces incompatible data which are not easily synthesised, limiting opportunities to amass treatment evidence across trials. In systematic reviews of aphasia treatments, variability in outcome measures is frequently cited as a key factor limiting the combination and comparison of research results. There have been eight recent systematic reviews related to aphasia treatment: 1) speech and language therapy for aphasia following stroke (Brady, Kelly, Godwin, Enderby, & Campbell, 2016); 2) transcranial direct current stimulation (Elsner, Kugler, Pohl, & Mehrholz, 2015); 3) intensity of treatment and constraint-induced language therapy (Cherney, Patterson, Raymer, Frymark, & Schooling, 2008); 4) communication partner training in aphasia (Simmons-Mackie, Raymer, & Cherney, 2016); 5) treatment for bilingual individuals with aphasia (Faroqi-Shah, Frymark, Mullen, & Wang, 2010); 6) outpatient and community-based aphasia group interventions (Lanyon, Rose, & Worrall, 2012); 7) semantic feature analysis (Maddy, Capilouto, & McComas, 2014); and 8) computer therapy for aphasia (Zheng, Lynch, & Taylor, 2016); which have all identified the heterogeneous use of outcome measures as an impediment to data analysis and synthesis. The Cochrane Collaboration review of Speech and Language Therapy for Aphasia Following Stroke (Brady, Kelly, Godwin, & Enderby, 2012; Brady et al., 2016) exemplifies this issue. In the 2012 review, across 39 included trials, 42 different outcome measures were used, as well as many informal or poorly described measures. The 2016 update of this review demonstrates little improvement in the consistency of outcome measurement practices. In the 2016 review update, across 57 included trials, 44 different outcomes measures were used. In the field of aphasia research where sample sizes are typically small, inconsistent outcome measurement further prohibits opportunities to build a body of evidence regarding aphasia treatments.

In addition to diversity in individual outcome measurement instruments, there is also an imbalance in the outcome constructs measured by the tools used in aphasia treatment research. Considered in reference to the World Health Organization (WHO) International Classification of Functioning Disability and Health (ICF; World Health Organization, 2001), aphasia treatment outcomes are most often measured at a Body Function level (Brady et al., 2012; Brady et al., 2016; Elsner et al., 2015; Xiong, Bunning, Horton, & Hartley, 2011). However, previous research by the current authors (Wallace, Worrall, Rose, & Le Dorze, 2016; Wallace, Worrall, Rose, & Le Dorze, In press; Wallace, Worrall, et al., 2016), has identified that the outcomes considered important by stakeholders in aphasia rehabilitation link to all components of the ICF. An international nominal group technique study was conducted with people with aphasia and their families in seven countries (Wallace, Worrall, et al., 2016). A total of 39 people with aphasia and 29 family members participated in one of 16 nominal groups to identify and gain consensus on the most important outcomes from aphasia treatment. Important treatment outcomes linked to all ICF components; primarily Activity/Participation (39%) and Body Functions (36%) for people with aphasia, and Activity/Participation (49%) and Environmental Factors (28%) for family members. Outcomes prioritised by family members relating to the person with aphasia, primarily linked to Body Functions (60%).

The perspectives of researchers were sought using an international e-Delphi exercise (Wallace et al., in press). Eighty purposively sampled researchers commenced round 1 of the e-Delphi process. Again, outcomes linked to all ICF components; researchers emphasised the importance of measuring language function and specific patient-reported outcomes (e.g., quality of life, satisfaction, and patient perspective on impact) in all aphasia treatment research.

A three-round e-Delphi exercise was also conducted with aphasia clinicians and managers (Wallace, Worrall, Rose, & Le Dorze, 2016). A total of 265 clinicians and 53 managers (n=318) from 25 countries participated in the first round of this process. Clinicians and managers identified outcomes which linked to Body Function, Activity/Participation, and Environmental Factor ICF components. Outcomes for people with aphasia most frequently linked to Activity/Participation (52%), whilst outcomes relating to family/carers/significant others were evenly divided between Activity/Participation (36%) and Environmental Factors (36%).

Across this trilogy of stakeholder perspectives important treatment outcomes linked to all ICF components, suggesting that while it is important to measure outcomes at a Body Function level, it is equally important to measure outcomes more broadly. The imperative to consider the perspectives of end-users of research in the selection of outcome measures is based in the philosophy that research should assist patients and clinicians to make decisions about issues that matter to them. This sentiment is reflected in the patient-centred guidelines produced by the Patient-Centred Outcomes Research Institute (PCORI) which include the recommendation that research should measure outcomes that, “people representing the population of interest notice and care about (e.g., survival, function, symptoms, health-related quality of life) and that inform an identified health decision." (PCORI Methodology Committee, 2013, p. 26).

Core outcome set (COS; standardised outcomes and outcome measures for use in treatment trials) development is increasingly being used to improve the quality of treatment trials in a range of health areas through the consensus-based identification of outcomes which can be routinely measured in research. Outcome constructs are paired with outcome measures to improve the consistency of both what is measured in research and how it is measured. The current study forms the second phase of the ROMA (Improving Research Outcome Measurement in Aphasia) project which aims to develop a COS for aphasia treatment research. Phase 1, as previously described, comprised a trilogy of consensus processes examining stakeholder perspectives about important treatment outcomes. Through synthesis of the findings from these studies, recommendations were produced that Body Functions (mental functions including language function, emotional functions, and energy and drive functions); Activity/Participation (relating to communication); Environmental Factors (relating to health services, systems and policies); and quality of life; should be routinely measured in aphasia treatment research.

Consensus-based guidelines for the selection of outcome measurement instruments for outcomes included in a COS have recently been published (Prinsen et al., 2016). The authors outline four steps which should be undertaken in this process: (1) consideration of constructs to be measured (Phase 1 in the current study); (2) finding existing outcome measures; (2) quality assessment of outcome instruments; and (3) selection of outcome instruments using a final consensus procedure. The current study reflects step 2 in the above process. To date a number of systematic reviews of aphasia assessment instruments, in discrete construct domains, have been performed. Systematic reviews have been completed for: 1) instruments assessing depression in patients with aphasia after stroke (van Dijk, de Man-van Ginkel, Hafsteinsdóttir, & Schuurmans, 2015); 2) screening tests for aphasia (El Hachioui et al., 2016); 3) standardised tests of short term memory and working memory (Murray, Salis, Martin, & Dralle, 2016); and participation instruments (Dalemans, de Witte, Lemmens, van Den Heuvel, & Wade, 2008). These systematic reviews have focused on distinct outcome constructs, predominately relating to impairments associated with aphasia (e.g., depression, language, memory). To the authors' knowledge no previous studies have sought to broadly identify and review outcome instruments that have been validated with people with aphasia irrespective of the construct measured. Therefore the aim of the current study was to identify all available studies reporting measurement properties of standardised outcome instruments which have been validated with people with aphasia. Through a systematic scoping review of these studies, the authors sought to identify: (1) which standardised outcome instruments have been validated with people with aphasia; and (2) what constructs are measured by these instruments. This information forms the initial stage of the identification of outcome instruments for a COS.

7.3 Methods

7.3.1 Protocol, Registration, and Data Management

The protocol for this systematic review was registered on PROSPERO (CRD42014007397) at: http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42014007397

This systematic review was conducted in accordance with PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009) and COSMIN (COnsensus base Standards for the selection of health Measurement Instruments; http://www.cosmin.nl) recommendations for systematic reviews of health measurement instruments.

Primary searches were run using PUBMED, EMBASE, and CINAHL databases on 10 November 2015. Secondary searches of individual outcome instruments were conducted between March and August 2016. The full electronic search strategy for all databases is available at Appendix D. The search strategy incorporated filters developed by Terwee, Jansma, Riphagen, and Vet (2009) for the identification of studies reporting the measurement properties of health outcome measures.

Title and abstract screening and full text review were conducted using Covidence systematic review software, Veritas Health Innovation, Melbourne, Australia (available at www.covidence.org). Data extraction was managed within Microsoft Office Excel.

7.3.2 Eligibility Criteria

The following study inclusion criteria were applied:

1. Studies focusing on the psychometric properties of measurement instruments.

2. Studies including participants with aphasia or stroke patients where participants with aphasia were not specifically excluded.
3. Studies including proxies of people with aphasia (i.e., caregiver/significant others or clinicians)
4. Studies reported in full text journal articles.
5. Studies reported in English.

The following exclusion criteria were applied:

1. Studies evaluating the effectiveness of interventions where an outcome measure is used as an endpoint (without studying the measurement properties).
2. Measurement instruments which primarily measure neurological function associated with, but not central to aphasia; consciousness; general health; motor speech, cognition, or memory.
3. Studies reporting normative data without examining other measurement properties.
4. Non-standardised outcome measures (e.g. discourse analysis).
5. Studies reported in test manuals.

7.3.3 Study Selection

Two reviewers independently assessed titles, abstracts, selected full-text articles, and reference lists of the studies retrieved by the literature search. In case of disagreement between the two reviewers, a third reviewer made a decision regarding inclusion of the article. Figure 7-1 presents an overview of the study selection process.

7.3.4 Data Extraction

The following data were extracted from the included studies: name of outcome instrument (and abbreviation), version, number of items, subtests, scoring system, and study reference. The purpose of the outcome instrument (as described by author) was extracted for the purpose of categorising all instruments according to the ICF framework (World Health Organization, 2001). If the purpose of the outcome instrument was not described within the study additional searches were performed to identify a published article containing a description of the instrument’s purpose. The extraction and synthesis of instrument measurement properties and assessment of each study’s methodological quality will be performed in a subsequent study.

7.4 Results

7.4.1 Study Selection

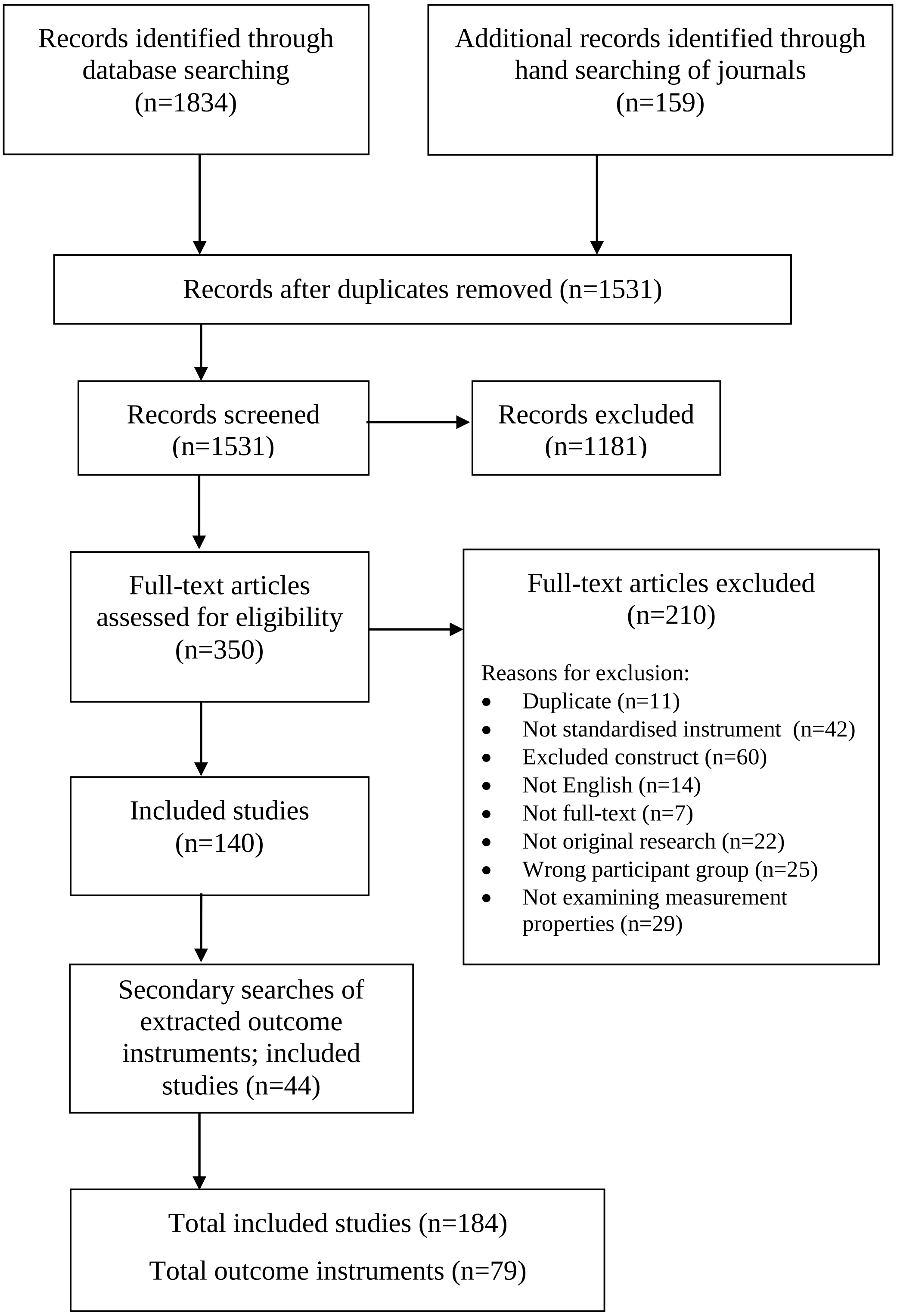

Figure 7-1. Study Selection Flowchart

7.4.2 Identified Instruments

A total of 79 outcome instruments were identified which have been validated with people with aphasia. These outcome instruments were broadly classified within the ICF framework based on published descriptions of each instrument's purpose. The vast majority of outcome instruments related to Body Functions (n=49). Within this component most instruments were measures of language function comprising: screening tools (n=12); comprehensive tests of language function (n=15); and measures of individual language modalities (n=9). Also categorised within the Body Functions component were measures of psychological function (n=13). These encompassed measures of depression, anxiety, confidence, mood, and self-esteem. Within the Activity/Participation ICF domain 17 outcome instruments were identified. These related to communication in activities/everyday life, community integration, social networks, and participation in conversation. No outcome instruments were reported to primarily measure constructs which could be categorised as Environmental factors; however it should be noted that measures of the caregiver's perspective or burden/disability experienced by caregivers of people with aphasia, were not within the scope of this review. A number of outcome instruments measured constructs which did not fall within the ICF, these included measures of quality of life (n=7), life satisfaction (n=1), and knowledge (n=1). A total of four instruments were identified as being intended to measure constructs across multiple ICF categories, these were: The Assessment for Living with Aphasia (ALA), the Therapy Outcomes Measures (TOMS), the Comprehensive Aphasia Test (CAT), and the Stroke Impact Scale (SIS). Tables 7-1 to 7-4 report the characteristics of the extracted outcome instruments. Outcome instruments are presented by ICF component.

7.4.3 Outcome Instruments by ICF Component: Characteristics and Validation Studies

Table 7-1

Multiple ICF Categories: Outcome Instrument Characteristics and Validation Studies

Outcome Instrument (Abbreviation; test reference) [Language if not English]	Purpose (as described by test author(s))	Subtests	Method of report	Scoring system	Validation studies
Assessment for Living With Aphasia (ALA; Kagan et al., 2011)	"The Assessment for Living with Aphasia was developed in order to address the need for a communicatively accessible, psychometrically sound, aphasia-related QoL measure….Questions on the ALA were designed to address the A-FROM adapted ICF domains of language impairment, participation, personal factors, and environmental factors within a dynamic interaction referred to as "living with aphasia"." (Simmons-Mackie et al., 2014, p. 83)	37 items in 5 domains: 1. Language 2. Participation 3. Environment 4. Personal 5. Moving on with life question.	Patient reported.	• 0–4 scale (with 0.5 point intervals). • Items are summed to give sub-test totals.	Simmons-Mackie et al. (2014)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
The Comprehensive Aphasia Test (CAT; Swinburn, Porter, & Howard, 2004)	"The test is designed to (1) screen for associated cognitive deficits, (2) assess language impairment in people with aphasia, (3) investigate the consequences of the aphasia on the individual's lifestyle and emotional well-being, and (4) monitor changes in the aphasia and its consequences over time." (Howard, Swinburn, & Porter, 2010, p. 56)	34 subtests divided into 3 parts: 1. The cognitive screen 2. The language battery: • Language comprehension • Repetition • Spoken output • Reading aloud • Writing. 3. The disability questionnaire.	Performance based / patient-reported.	• Most items scored on a 0-2 scale. • The disability questionnaire is patient reported. Each item is rated on a scale 0-4. • Scores from subtests can be combined to give modality summary scores. • Comparison of scores in different subtests and modalities is enabled through T-score transformation.	Howard et al. (2010)

<u>Validated translations/adaptations/versions:</u>

- Arabic: Abou El-Ella et al. (2013)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
Stroke Impact Scale 2.0 (SIS)	"The Stroke Impact Scale (SIS) is a new stroke specific outcome measure that is a comprehensive measure of health outcomes." (Duncan, Bode, Min Lai, & Perera, 2003, p. 950)	64 items assessing 8 domains: 1. Strength 2. Hand function 3. ADL/IADL 4. Mobility 5. Communication 6. Emotion 7. Memory and thinking 8. Participation	Patient-reported.	• Items are scored on a 1 to 5-point Likert scale. • Scores for each domain are transformed to a score out of 100 using a formula. • Higher scores indicate better self-reported health.	Duncan et al. (1999) Edwards and O'Connell (2003) Duncan et al. (2003)

<u>Validated translations/adaptations/versions:</u>

Stroke Impact Scale 2.0:

- French: Caël et al. (2015)

Stroke Impact Scale 3.0 (59-items):

- English: Lin et al. (2010); Richardson, Campbell, Allen, Meyer, and Teasell (2016)
- Portuguese: Carod-Artal, Coral, Trizotto, and Moreira (2008); Carod-Artal, Ferreira Coral, Stieven Trizotto, and Menezes Moreira (2009)
- Italian: Vellone et al. (2015)
- Hausa: Mohammad, Al-Sadat, Siew Yim, and Chinna (2014)

Stroke Impact Scale Short Form (8-item): Jenkinson, Fitzpatrick, Crocker, and Peters (2013); MacIsaac et al. (2016)

Telephone/mail administration: Duncan et al. (2002); Duncan et al. (2005)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
Therapy Outcome Measures (TOM; Enderby & John, 1997; Enderby & John, 2015; Enderby, John, & Petheram, 2006)	"The TOM allows therapists to reflect their clinical judgement on the dimensions of impairment, disability/activity, handicap/participation and well-being on an 11-point ordinal scale." (Enderby, 2000, p. 287)	• Scales are available for speech, language, voice, fluency, swallowing, and cognitive communication. • Each scale is rated in four domains: 1. Impairment 2. Activity Limitation 3. Participation Restriction 4. Distress/Wellbeing.	Clinician rated.	• Each domain of the TOMs scales has six levels (0-5), where "0" represents "complete difficulty" and 5 represents "no difficulty". • Scales points are chosen according to "best fit" and half-points may be used.	Enderby and John (1999) John and Enderby (2000) Hesketh, Long, Patchick, Lee, and Bowen (2008)
Validated translations/adaptations/versions: Australian Therapy Outcome Measures (AusTOMS; Perry & Skeat, 2004): Unsworth et al. (2004)					

Table 7-2

<u>ICF Body Functions:</u> Language. Outcome Instrument Characteristics and Validation Studies

(a) Screening Tools

Outcome Instrument (Abbreviation/reference) [Language if not English]	Purpose (as described by test author(s))	Subtests	Scoring system	Administrator/ administration time	Validation studies
Acute Aphasia Screening Protocol (AASP)	"…two relevant purposes of the AASP are: (1) estimating the severity of acute aphasic impairment, and (2) profiling the patient's abilities across general aspects of communicative abilities." (Crary, Haak, & Malinsky, 1989, p. 613).	1. Attention/ Orientation to Communication. 2. Auditory Comprehension. 3. Expressive Abilities. 4. Conversational Style.	• A binary scoring system (1 or 0). • Subtest cores summed to provide a total score (range 0-50). • Total score is then expressed as a percentage to give a 'Cumulative score (index of aphasia severity).	Specialist/ 10 minutes.	Crary et al. (1989)

Outcome Instrument	Purpose	Subtests	Scoring system	Administrator/ administration time	Validation studies
The Aphasia Rapid Test (ART) [French]	“The Aphasia Rapid Test (ART) is a 26-point scale developed as a bedside assessment to rate aphasia severity in acute stroke patients in <3 min.” (Azuar et al., 2013, p. 2110).	1. Execution of simple and complex orders. 2. Word repetition. 3. Sentence repetition. 4. Object naming. 5. Dysarthria. 6. Verbal semantic fluency task.	• 26 items scored from 0-2, 0-3, or 0-4. • Subtest scores are summed to provide a total score (range 0-26). • Higher scores indicate greater impairment.	Specialist/ < 3 minutes.	Azuar et al. (2013)
Brief Aphasia Evaluation (BAE) [Spanish]	“The BAE was designed to quickly detect the basic resources of verbal communication (minimum verbal performance) in patients with aphasia...” (Vigliecca, Peññalva, Molina, & Voos, 2011, p. 396).	1. Comprehension. 2. Expression. 3. Naming. 4. Repetition. 5. Reading. 6. Writing. 7. Attention. 8. Memory. 9. Orophonatory Praxis.	• 72 items scored from 0-3. • Total score range 0-216.	Specialist / 30 minutes.	Vigliecca et al. (2011)

Outcome Instrument	Purpose	Subtests	Scoring system	Administrator/ administration time	Validation studies
Frenchay Aphasia Screening Test (FAST, Enderby, 2006)	"The Frenchay Aphasia Screening Test (FAST) was devised to provide those working with aphasic patients, but not trained in speech and language therapy, to have a short, simple and standardized method of identifying and gauging language deficit." (Enderby & Crow, 1996, p. 238).	Full form: 1. Comprehension. 2. Expression. 3. Reading. 4. Writing. Short form: 1. Comprehension. 2. Expression.	• Items scored on completeness/ correctness of response. • Scores from each subtest are summed to provide total score (range 0-30 full form; 0-20 short form). • Lower scores indicate greater impairment.	Non-specialist / 10 minutes (full form); 3 minutes (short form).	Enderby, Wood, Wade, and Hewer (1986) O'Neill, Cheadle, Wyatt, McGuffog, and Fullerton (1990) Enderby and Crow (1996) Al-Khawaja, Wade, and Collin (1996)
Language Screening Test (LAST) [French]	"LAST was developed as a formalized quantitative scale for screening language functions, including comprehension and expression." (Flamand-Roze et al., 2011, p. 1225).	Expression Index: 1. Naming. 2. Repetition. 3. Automatic speech. Receptive Index: 4. Recognition. 5. Verbal instructions.	• A binary scoring system (1 or 0) is used. • Scores from each subtest are summed to provide total score (range 0-15). • Sub-scores can be calculated for the Expression Index and Receptive Index.	Non-specialist / 2 minutes.	Flamand-Roze et al. (2011)

Outcome Instrument	Purpose	Subtests	Scoring system	Administrator/ administration time	Validation studies
The Mississippi Aphasia Screening Test (MAST)	"The Mississippi Aphasia Screening Test (MAST) was developed as a brief, repeatable screening measure for individuals with severely impaired communication/language skills." (Nakase-Thompson et al., 2005, p. 686)	1. Naming. 2. Automatic speech. 3. Repetition. 4. Yes/No Accuracy. 5. Object Recognition. 6. Following Verbal Instructions. 7. Reading Instructions. 8. Verbal Fluency. 9. Writing/Spelling to Dictation.	• Scores can be summed to provide Receptive and Expressive Index scores (range 0-50) and a global score (range 0-100). • Lower scores indicate greater language impairment.	Specialist/ 5-10 minutes.	Nakase-Thompson et al. (2005)

<u>Validated translations/adaptations/versions:</u>

- Czech (MASTcz): Kostalova et al. (2008)
- Persian (MASTp): Khatoonabadi, Nakhostin-Ansari, Piran, and Tahmasian (2015)

Outcome Instrument	Purpose	Subtests	Scoring system	Administrator/ administration time	Validation studies
The Mobile Aphasia Screening Test (MAST) [Korean]	"We developed a mobile aphasia screening test (MAST) for patients with stroke, with an emphasis on cost-effectiveness, portability, and ease of use. We accomplished this by modifying the Korean language version of the FAST (K-FAST) as a mobile version." (Choi, Park, Ahn, Son, & Paik, 2015, p. 730)	1. Expression. 2. Comprehension.	1. Scored on completeness/ correctness of response. 2. Total score range 0-20.	Non-specialist/ 3 minutes.	Choi et al. (2015)
The Reitan-Indiana Aphasia Screening Test (Reitan & Wolfson, 1985)	"…intended to assess language and other neurocognitive abilities." (Jasinski & Podell, 2011, p. 2143)	1. Reception. 2. Expression. 3. Comprehension.	• 32 items. • Items receive a score of 0 or 1. • Points are awarded for impaired rather than correct responses. • Items are summed to provide a total score.	Specialist /	Snow (1987)

Outcome Instrument	Purpose	Subtests	Scoring system	Administrator/ administration time	Validation studies
ScreeLing [Dutch]	"The ScreeLing was developed as a screening test to measure impairment at the semantic, phonological and/or syntactic level in 15 minutes." (Doesborgh et al., 2003, p. 978)	1. Semantics. 2. Phonology. 3. Syntax.	• Binary scoring system. • Items summed for a total subtest score (0-24). • Subtest scores are summed to provide a global score (0-72). • Lower scores indicate greater impairment.	Specialist/ 15 minutes.	Doesborgh et al. (2003)
Sheffield Screening Test for Acquired Language Disorders (SST; Syder, Body, Parker, & Boddy, 1993)	"The SST was developed as a non-specialist clinical aid to help identify dysphasia and to enable an appropriate referral to a speech and language therapist." (Blake, McKinney, Treece, Lee, & Lincoln, 2002, p. 452)	1. Receptive skills. 2. Expressive skills.	• Total score range 0-20.	Non-specialist/ 3-5 minutes.	Al-Khawaja et al. (1996) Blake et al. (2002)
Sklar Aphasia Scales (SAS; Sklar, 1983)	"The revised Sklar Aphasia Scale provides a brief assessment of the aphasic patient's abilities along four dimensions: Auditory decoding, visual decoding, oral encoding, and graphic encoding." (Spreen & Risser, 2003, p. 83)	1. Auditory decoding. 2. Visual decoding. 3. Oral encoding. 4. Graphic encoding.	• Each item is scored on a 5-point scale. • An impairment score is obtained by finding the mean value of the four subtests (0=no impairment, 100=full impairment).	Specialist /	Cohen, Engel, Kelter, List, and Strohner (1977)

Outcome Instrument	Purpose	Subtests	Scoring system	Administrator/ administration time	Validation studies
Ullevaal Aphasia Screening Test (UAS) [Norwegian]	The UAS is a "…simple method to be used by nurses to detect aphasia in the acute stage of stroke." (Thommessen, Thoresen, Bautz-Holter, & Laake, 1999, p. 110)	1. Expression. 2. Comprehension. 3. Repetition. 4. Reading. 5. Reproduction of a string of words. 6. Writing. 7. Free communication.	• Overall rating of performance as having normal language ability or mild, moderate, or severe language disorder.	Non-specialist/ 5-15 minutes.	Thommessen et al. (1999)

b) Comprehensive Tests of Language Functioning

Outcome Instrument (Abbreviation/reference) [Language if not English]	Purpose (as described by test author(s))	Subtests	Scoring system	Validation studies
Aachen Aphasia Test (AAT, Huber et al., 1984) [German]	"The Aachen aphasia test is a test of language functioning after brain injury, and as such aims to: reliably identify the presence of aphasia; provide a profile of speakers' language functioning according to different language modalities (speaking, listening, reading, writing) and different levels of linguistic description (phonology, morphology, semantics and syntax); and give a measure of severity of any breakdown." (Miller, Willmes, & De Bleser, 2000, p. 683)	1. Spontaneous language sample. 2. Token Test. 3. Repetition. 4. Written language. 5. Confrontation naming. 6. Comprehension.	• Spontaneous language sample rated on 6-point scale. • Token Test is marked on a binary right-wrong basis. • All items in the repetition, written language, naming and comprehension subtests are scored on a 4-point scale.	Willmes, Poeck, Weniger, and Huber (1983) Huber, Poeck, and Willmes (1984)

Validated translations/adaptations/versions:

- English (EAAT): Miller et al. (2000)
- Portuguese (PAAT): Lauterbach et al. (2008)
- Thai (THAI-AAT): Pracharitpukdee, Phanthumchinda, Huber, and Willmes (2000)

Outcome Instrument	Purpose	Subtests	Scoring system	Validation studies
The Aphasia Checklist (ACL) (Kalbe, Reinhold, Ender, & Kessler, 2002) [German]	“The ACL is a …test battery for aphasia diagnosis. It can assess the presence of aphasia and its severity, provides a profile of essential language functions as well as an estimation of verbal communicative abilities. Furthermore, impairments in cognitive domains relevant for language functions and aphasia rehabilitation can be detected.” (Kalbe, Reinhold, Brand, Markowitsch, & Kessler, 2005, p. 789)	Language: 1. Automatic speech. 2. Verbal instructions. 3. Colour-figure test. 4. Word generation tasks. 5. Specific linguistic abilities. 6. Rating of verbal communication. 7. Number processing. Cognition: 1. Non-verbal memory. 2. Attention task Reasoning.	• Colour-figure test, automatic speech, and verbal instructions subtests are scored 0-2. All other language subtests are scored 0-3. • Word generation - number of correct words forms raw score which is then age-corrected. • Memory task is scored by subtracting false positives from the hits. • Attention task is scored on the total number of processed signs, total number of processed signs minus errors, and the percentage of mistakes. • The reasoning task is scored on the number of correctly solved lines.	Kalbe et al. (2005)

Outcome Instrument	Purpose	Subtests	Scoring system	Validation studies
Aphasia Language Assessment Test (ALA) [Turkish]	The ALA has been "…developed as a specific language test for Turkish language and culture…" (Toğram & Maviş, 2012, p. 97). "ALA aims to identify the language area-related performance in individuals suffering from left brain damage, to diagnose aphasia and to help select appropriate therapeutical targets." (Toğram & Maviş, 2012, p. 98)	1. Spontaneous language and speech. 2. Auditory understanding. 3. Repetition. 4. Naming. 5. Reading. 6. Grammar. 7. Speech act writing.	Scoring: • Correct (C) / Independent Reaction (2 Points). • Missing / Insufficient / Assisted Reaction (M) (1 Point). • Incorrect (I) Reaction or No Response (NR) (0 Point). Two types of scores: • Test score (TSCORE) (Test score consists of the sum of all the subtests of ALA (292 points)). • Language score (LSCORE) (sum of the subtests: spontaneous language and speech assessment, auditory understanding assessment, repetition assessment and naming assessment' (162 points)).	Toğram and Maviş (2012)

Outcome Instrument	Purpose	Subtests	Scoring system	Validation studies
The Thai Aphasia Language Performance Scales [Thai]	"The screening instrument that was developed consisted of two parts: (a) a translated and adapted version of the Aphasia Language Performance Scales (ALPS) (Keenan & Brassell, 1975) and (b) a communication checklist that tapped the perceptions of Thai SOs and/or speech pathologists about aphasic individuals' functional communication behaviours." (Manochiopinig, Reed, Sheard, & Choo, 1996, p. 23)	• Translated and adapted version of the ALPS (scales: listening, talking, reading and writing); and • Communication checklist.	• Adapted ALPS scoring right/wrong/partial. • Communication checklist can be rated by clinicians and significant others. Communication behaviours are rated as either: appropriate, inappropriate or not applicable.	Manochiopinig et al. (1996)
The Aphasia Screening Test (AST, Whurr, 2011)	"The Aphasia Screening Test (AST) systematically evaluates different aspects of language function: listening, speaking, reading and writing." (Whurr, 2011, p. 3)	1. Tests of language comprehension. 2. Tests of language production. 3. Calculation tests.	• Items are summed to give overall language comprehension level (max. score 100) and overall language production level (max score 150). • Scores for comprehension and production subtests are summed to give an overall level of severity (Overall Aphasia Index; max score 250).	

<u>Validated translations/adaptations/versions:</u>

Panjabi: Mumby (1988); Mumby (1990)

Outcome Instrument	Purpose	Subtests	Scoring system	Validation studies
Bilingual Aphasia Test (BAT; Paradis, 1987)	"The Bilingual Aphasia Test (BAT) was designed to assess each of the languages of a bilingual or multilingual individual with aphasia in an equivalent way. The various versions of the BAT are thus not mere translations of each other, but culturally and linguistically equivalent tests."	1. History of bilingualism questionnaire. 2. Language specific test (auditory comprehension, verbal expression, reading and writing). 3. Test for each specific language pair.	• Scores may be combined by linguistic component (phonology, morphology, syntax, lexicon and semantics) or by language skill (comprehension, repetition, judgement, lexical access, propositionising, reading or writing).	
<u>Validated translations/adaptations/versions:</u> • Greek: Peristeri and Tsapkini (2011) • Modified short form in Russian: Ivanova and Hallowell (2009)				

Outcome Instrument	Purpose	Subtests	Scoring system	Validation studies
The Boston Diagnostic Aphasia Examination (BDAE; Goodglass & Kaplan, 1972; Goodglass & Kaplan, 1983; Goodglass, Kaplan, & Barresi, 2001)	The Boston Diagnostic Aphasia Examination is extensively used in clinical evaluations for the measurement of aphasic patients' performance in all aspects of language functions, identifying the specific language deficits and the exact profile of differential aphasic syndromes." (Tsapkini, Vlahou, & Potagas, 2010, p. 111)	Language domains: 1. Conversational and expository speech. 2. Auditory comprehension. 3. Oral expression. 4. Reading. 5. Writing. 6. Praxis.	• Individual items are summed to provide subtest scores. • Additionally, the BDAE provides three broader measures: 1. The Severity Rating Scale (a rating of the severity of observed language/speech disturbance). 2. The Rating Scale Profile of Speech characteristics (a rating of observed speech characteristics and of scores in two main language domains). 3. Language Competency Index (a composite score of language performance on BDAE-3 subtests.	Nicholas, Maclennan, and Brookshire (1986) Crary, Wertz, and Deal (1992) Powell (2006) Palsbo (2007) Theodoros, Hill, Russell, Ward, and Wootton (2008) Hill, Theodoros, Russell, Ward, and Wootton (2009)

<u>Validated translations/adaptations/versions:</u>

- BDAE Finnish: Laine et al. (1993)
- BDAE (2nd edition) Portuguese: Radanovic and Mansur (2002); Mansur, Radanovic, Taquemori, Greco, and Araújo (2005)
- BDAE (3rd edition) Greek: Tsapkini et al. (2010)
- BDAE (3rd edition) Short Form in Greek: Peristeri and Tsapkini (2011)

Outcome Instrument	Purpose	Subtests	Scoring system	Validation studies
Ege Aphasia Test [Turkish]	"…aphasia test for the Turkish language, which would be compatible with the socio-cultural context of Turkey. The main purpose of the test was to evaluate comprehensively the major aspects of language functions including conversational speech; oral and written expression, with tests of repetition, naming and fluency; and auditory comprehension and reading." (Calis, On, & Durmaz, 2013, p. 158)	1. Praxia. 2. Spontaneous language. 3. Auditory and verbal comprehension. 4. Repetition. 5. Naming. 6. Reading. 7. Writing. 8. Calculating.	• Scores for each subtest can be calculated by summing up the items with a score ranging from 0 to 100. • 100 indicates the highest degree of impairment and 0 the lowest degree of impairment in communication skills.	Calis et al. (2013) (English)
Kentucky Aphasia Test (KAT)	"The KAT is an impairment-based, objective measure of language functioning for use with individuals with aphasia secondary to a stroke." (Marshall & Wright, 2007, p. 296)	1. Orientation test. 2. Picture description task. 3. Expressive language. 4. Receptive language.	• Responses to the 10 items on the orientation test and six subtests are scored 0-6. • The 10 scores for each subtest are summed to provide a subtest score (maximum = 50). • The subtest scores are summed to provide a total score for the test (maximum 350).	Marshall and Wright (2007)

Outcome Instrument	Purpose	Subtests	Scoring system	Validation studies
Luria-Nebraska Language Scales in Aphasia	"… assess highly specific language skill deficits through the construction of a series of factor scales derived from the language-related items of the Luria-Nebraska battery." (Goldstein & Shelly, 1984, p. 143 &144)	1. Receptive speech. 2. Expressive speech scale. 3. Reading scale. 4. Writing scale.	• T-score conversion.	Ryan, Farage, Mittenberg, and Kasprisin (1988)
The Minnesota Test for Differential Diagnosis of Aphasia (MTDDA; Schuell, 1965)	The MTDDA was designed to, "permit the examiner to observe the level at which language performance breaks down in each of the principal language modalities, since this is essentially what there is to observe in aphasia.'' (Schuell, 1965, p. 3)	46 subtests within: 1. Auditory Disturbances. 2. Visual and Reading Disturbances. 3. Speech and language disturbances. 4. Visuomotor and writing disturbances. 5. Numerical relations/ arithmetic	• In addition to subtest scores, a clinical rating (0-6) and a diagnostic scale (0-4) are calculated. • The MTDDA identifies five categories of aphasia.	Schuell, Jenkins, and Carroll (1962) Powell, Bailey, and Clark (1980) Nicholas et al. (1986)

<u>Validated translations/adaptations/versions:</u>

- Greek: Tafiadis (2006)

Outcome Instrument	Purpose	Subtests	Scoring system	Validation studies
Montreal-Toulouse Language Assessment Battery – Brazilian version (MTL-BR) [Brazilian Portuguese]	"The Montreal-Toulouse Language Assessment Battery (MTL-BR) was developed to assess components of spoken and written language, praxis and arithmetical skill after brain damage, and has been recently translated and adapted from French to Brazilian Portuguese." (Pagliarin et al., 2014, p. 463)	1. Oral expression. 2. Comprehension. 3. Reading. 4. Writing. 5. Repetition. 6. Naming. 7. Praxis. 8. Mathematical skills.	• On most tasks items receive a score of 0 or 1. • In the two tasks involving a narrative, the number of words produced is assessed, as is the number of information units present.	Pagliarin et al. (2014) Pagliarin et al. (2015)
The Norsk Grunntest for Afasi (NGTA; Reinvang, 1985) [Norweigan]	"The NGTA is based on the Boston terminology, is similar to the Western Aphasia Battery (WAB) (Kertesz, 1982b), and measures fluency, comprehension, naming and repetition in addition to writing and reading. (Laska, Bartfai, Hellblom, Murray, & Kahan, 2007, p. 39)	1. Spontaneous speech. 2. Auditory comprehension. 3. Repetition. 4. Naming. 5. Reading. 6. Syntax. 7. Writing. 8. Aphasia severity (Coefficient).	• Items are summed to give a total score which provides the aphasia coefficient (Coeff). • Coeff is a measure of the severity of language impairment and degree of aphasia.	Laska, Bartfai, et al. (2007)

Outcome Instrument	Purpose	Subtests	Scoring system	Validation studies
Porch Index of Communicative Ability (PICA; Porch, 1967, 1971, 1981)	"The purpose of this test is to quantify language comprehension, language production, reading, writing, gesture, object awareness, and copying." (Neils-Strunjaš, 1998, p. 77)	18 subtests: • Verbal. • Gestural. • Graphic.	• 16-category scale describing accuracy, promptness, responsiveness, completeness and efficiency. • Scale ranges from 'complex score' (16) to 'no response' (1). • Items are summed to give subtest scores. • Mean scores for gestural, verbal and graphic modalities and the overall response level. • Index of communication ability.	DiSimoni, Keith, Holt, and Darley (1975) Clark, Crockett, and Klonoff (1979) Ross and Wertz (2003) Ross and Wertz (2004)
The Western Aphasia Battery (WAB; Kertesz, 1982b; Kertesz, 2007)	"The Western Aphasia Battery (WAB) is a diagnostic tool used to assess the linguistic skills and main non-linguistic skills of adults with aphasia. This provides information for the diagnosis of the type of aphasia and identifies the location of the lesion causing aphasia."	1. Spontaneous speech. 2. Auditory comprehension. 3. Repetition. 4. Naming. 5. Reading. 6. Writing. 7. Praxis. 8. Construction.	• Aphasia Quotient (AQ): a weighted average of the WAB spoken language subtest scores. • Cortical Quotient (CQ): a weighted average of both the language and non-language subtest scores. • The Language Quotient (LQ): reflects auditory comprehension, oral expression, reading, and writing performance.	Shewan and Kertesz (1980) Fromm, Greenhouse, Holland, and Swindell (1986) Shewan (1986) Crary and Gonzalez Rothi (1989) Nicholas et al. (1986)

Outcome Instrument	Purpose	Subtests	Scoring system	Validation studies
				Crary et al. (1992) Ross and Wertz (2003) Ulatowska et al. (2003) Ross and Wertz (2004) Hula, Donovan, Kendall, and Gonzalez-Rothi (2010) Roger and Code (2011)

<u>Validated translations/adaptations/versions:</u>

- Cantonese (WAB): Yiu (1992)
- Korean (WAB): Kim and Na (2004)
- Bangla (WAB): Keshree, Kumar, Basu, Chakrabarty, and Kishore (2013)
- Tagalog (WAB-R): Ozaeta, Kong, and Ranoa-Javier (2013)
- Brazilian Portuguese (WAB-R): Neves, Van Borsel, Pereira, and Paradela (2014)

c) Tests of Individual Language Modalities

Outcome Instrument (Abbreviation/ reference) [Language of outcome instrument]	Purpose (as described by test author(s))	Subtests	Scoring system	Validation studies
Multiple-Choice Test of Auditory Comprehension (MCTAC)	“The MCTAC is a multiple-choice test based on an adaptation of the RTT (Revised Token Test) designed by Hallowell (2009). The traditional RTT is a standardised test for the assessment of auditory comprehension for adults with neurogenic language disorders.” (Hallowell & Ivanova, 2009, p. 85)	• 8 subtests • Patients are required to point to the item matching the verbal stimulus.	• Scoring is binary (correct/incorrect). • Subtest and total scores – percentage of correct items.	
Validated translations/adaptations/versions: • Russian: Hallowell and Ivanova (2009)				

Outcome Instrument	Purpose	Subtests	Scoring system	Validation studies
The Reading Comprehension Battery for Aphasia (RCBA, RCBA-2; LaPointe & Horner, 1979b; LaPointe & Horner, 1998)	"Recently, LaPointe and Horner (1979) published the Reading Comprehension Battery for Aphasia (RCBA), a test specifically designed for the aphasic population, taking into account such known variables as word frequency and length, and allowing for an entirely nonverbal response mode. The test items cover a wide range of difficulty, from single words through complex paragraphs, and numerous aspects of reading are assessed, including word order, factual vs. inferential reading, and synonym recognition. Of particular clinical interest is a subtest which measures functional reading of such items as signs, calendars, and checkbook and telephone book entries." (Van Demark, Lemmer, & Drake, 1982, p. 288)	The RCBA contains 10 subtests: • Single-word comprehension (3). • Functional reading. • Nouns and verb synonym matching. • Reading comprehension of sentences and paragraphs (3). • Morphosyntactic reading skills.	• Items scored as correct or incorrect. • One point is awarded for each correct response (maximum score of 100).	Van Demark et al. (1982) Nicholas et al. (1986)

Outcome Instrument	Purpose	Subtests	Scoring system	Validation studies
The Token Test (De Renzi & Vignolo, 1962)	"…a method to detect slight disturbances of auditory verbal comprehension…" (van Dongen & van Harskamp, 1972, p. 129)	61 oral commands of varying complexity.	• Items scored as correct (1) or incorrect (0). • Maximum score of 61.	De Renzi and Vignolo (1962) van Dongen and van Harskamp (1972) Coupar (1976) De Renzi and Faglioni (1978)
The Revised Token Test (RTT; McNeil & Prescott, 1978)	"The RTT is a tool designed for assessing auditory processing and comprehension." (Chen, McNeil, Hill, & Pratt, 2013, p. 38)	Ten subtest with ten linguistically homogeneous and equally difficult commands.	• The RTT employs a 15-point multidimensional scoring system. • Each critical element in the sentence receives a score from 1 to 15	McNeil, Hageman, and Matthews (2005) Odekar and Hallowell (2005) Hula, Doyle, McNeil, and Mikolic (2006) Odekar and Hallowell (2006) Doyle, McNeil, Hula, and Mikolic (2003)

Outcome Instrument	Purpose	Subtests	Scoring system	Validation studies
Validated translations/adaptations/versions: • 5-item: Park, McNeil, and Tompkins (2000) • Computerised Revised Token Test: McNeil et al. (2015) • Mandarin Chinese Computerised Revised Token Test: Chen et al. (2013) • 36 item: Paci, Lorenzini, Fioravanti, Poli, and Lombardi (2015)				
The Boston Naming Test (BNT) (Kaplan, Goodglass, & Weintraub, 1983)	“The Boston Naming Test is a 60-item confrontation naming test which is widely used to assess the word retrieval performance of adults with brain damage.” (Nicholas, Brookshire, Maclennan, Schumacher, & Porrazzo, 1989)	60-items	• Responses are transcribed, coded and scored. • Credit is given is item is named within 20 seconds either spontaneously or following stimulus cue. • No credit is given following a phonemic cues. • Score is compared to normative data.	Pedraza, Sachs, Ferman, Rush, & Lucas (2011)
Validated translations/adaptations/versions: • BNT-Aphasia Short Form: del Toro et al. (2011) • Tele-rehabilitation: Hill, Theodoros, Russell, Ward, and Wootton (2009); Theodoros, Hill, Russell, Ward, and Wootton (2008) • The Groote Schuur Naming Test: Mosdell, Ameen, and Balchin (2010)				

Outcome Instrument	Purpose	Subtests	Scoring system	Validation studies
Northwestern Assessment of Verbs and Sentences (NAVS)	"The Northwestern Assessment of Verbs and Sentences (NAVS) was designed to provide a comprehensive assessment of production and comprehension of verbs and sentences." (Cho-Reyes & Thompson, 2012, p. 1254)	The NAVS consists of five subtests: 1. the Verb Naming Test (VNT). 2. the Verb Comprehension Test (VCT). 3. the Argument Structure Production Test (ASPT). 4. the Sentence Production Priming Test (SPPT). 5. the Sentence Comprehension Test (SCT).	• VCT and SCT correct identification of the picture. • VNT, ASPT, and SPPT all responses were transcribed verbatim. • ASPT responses scored as correct if the target verb and all required verb arguments produced in the correct order.	Cho-Reyes and Thompson (2012)

<u>Validated translations/adaptations/versions:</u>

- Chinese (NAVS-C): Wang and Thompson (2016)

Outcome Instrument	Purpose	Subtests	Scoring system	Validation studies
The Philadelphia Naming Test (PNT)	The Philadelphia Naming Test (PNT; Roach et al., 1996) is a prominent naming test that was developed as part of a larger set of studies investigating models of lexical retrieval in normal processing and aphasia.	• 175 high, medium and low-frequency nouns that range in length from 1 to 4 syllables. • Items are digitised for computerised display.	• Up to three response on each trial are identified – initial attempt, first complete attempt and final complete attempt. • Each response given a two-level code.	Fergadiotis, Kellough, and Hula (2015) Hula, Kellough, and Fergadiotis (2015) Walker and Schwartz (2012)
Syntax comprehension test in Hindi Language [Hindi]	"The study was carried out with the aim to develop a test of syntax comprehension in Hindi language for persons with aphasia."(Kumar & Goswami, 2013, p. 346)	10 items in two domains: • Auditory comprehension. • Written comprehension.	• Score of '2', '1', and '0' for every correct response without prompt, correct response with prompt, and incorrect/no response even after prompt respectively.	Kumar and Goswami (2013)
Sentence Production Test (SPT)	The aim of the present study was to develop and investigate the validity and usefulness of a new, freely accessible sentence production test (SPT) based on simple pictured event description." (Wilshire, Lukkien, & Burmester, 2014, p. 658)	• Single noun pretest. • Sentence Production Test.	• In the single noun pretest, the first complete attempt at the picture is score. • First complete attempt scored. Each individual sentence element was scored for accuracy.	Wilshire, Lukkien, and Burmester (2014)

d) *Measures of psychological function*

Outcome Instrument (Abbreviation/reference) [Language of outcome instrument]	Purpose (as described by test author(s))	Subtests	Method of report	Scoring system	Validation studies
Aphasic Depression Rating Scale (ADRS)	"…The Aphasic Depression Rating Scale (ADRS) was developed to detect and measure depression in aphasic patients during the subacute stage of stroke." (Benaim, Cailly, Perennou, & Pelissier, 2004, p. 1692)	9 items	Rated by rehabilitation staff.	• 3-point scale.	Benaim et al. (2004) Benaim et al. (2010)
Clinical Global Impressions rating scale for Severity (CGI-S)	"The CGI-Severity (CGI-S) asks the clinician one question: "Considering your total clinical experience with this particular population, how mentally ill is the patient at this time?" (Busner & Targum, 2007, p. 30)	1 question	Clinician rated.	• 7 point scale (1-7).	Laska, Mårtensson, Kahan, von Arbin, and Murray (2007) Berg, Lonnqvist, Palomaki, and Kaste (2009)
Beck Depression Inventory (BDI)	"This report describes the development of an instrument designed to measure the behavioral manifestations of depression." (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961, p. 561)	21 symptoms and attitudes	Patient reported.	• 4-point rating scale (0-3).	Berg et al. (2009)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
Hamilton Rating Scale for Depression	"…for use in assessing the symptoms of patients diagnosed as suffering from depressive states." (Hamilton, 1960, p. 61)	17 items	Clinician rated.	The variables are measured either on five-point or three-point scales.	Berg et al. (2009)
Behavioural outcomes of anxiety scale (BOA)	"…the BOA provides a set of anxiety descriptors, which are rated by someone who knows the patient well, usually a carer." (Linley-Adams, Morris, & Kneebone, 2014)	10 items	Two versions: patient reported and carer reported.	Four response options: often (3 points), sometimes (2 points), rarely (1 point), never (0 points).	Linley-Adams et al. (2014)
Communication Confidence Rating Scale for Aphasia (CCRSA)	"We developed the Communication Confidence Rating Scale for Aphasia (CCRSA) to assess confidence in communicating in a variety of activities." (Cherney, Babbitt, Semik, & Heinemann, 2011, p. 352)	10 items.	Patient reported.	• Ordinal rating scale with number markings every 10 points from 0 to 100.	Cherney et al. (2011) Babbitt, Heinemann, Semik, and Cherney (2011)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
Hospital Anxiety and Depression Scale (HADS)	“The Hospital Anxiety and Depression Scale (HADS) was used to measure the presence and severity of anxiety and depression in both stroke patients and carers.” (Hoffmann, Worrall, Eames, & Ryan, 2010)	14 items.	Patient/ caregiver reported.	• 4-point response category. • Total possible score of 0–21 for the anxiety subscale and 0–21 for the depression subscale. • Lower scores indicate lower levels of the emotion that is being measured.	Hoffmann et al. (2010)
Montgomery-Åsberg Depression Rating Scale (MADRS)	“…a depression scale consisting of the 10 items.” (Montgomery & Asberg, 1979, p. 382)	10 item structured interview.	Clinician rated.	• 0 to 6 rating scale. • Score of 6 indicates severest degree of depression.	Laska, Mårtensson, et al. (2007)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
Stroke and Aphasia (SAD) Scale	"The tool was constructed in order to assess the presence of depression and the subjects' perceptions of their own emotional state." (Smollan & Penn, 1997, p. 57)	30 items in four domains: 1. Communication. 2. Expression of emotion. 3. Sense of self. 4. Physical symptoms of depression.	Patient reported.	• Visual analogue scale.	Smollan and Penn (1997)
Signs of Depression Scale (SODS)	"…a brief observer-based screening test for depression." (Hammond, O'Keeffe, & Barer, 2000, p. 512)	6 items	Clinician rated.	• Yes/no format.	Bennett, Thomas, Austen, Morris, and Lincoln (2006) Lightbody et al. (2007)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
Stroke Aphasic Depression Questionnaire (SADQ)	"… the Stroke Aphasic Depression Questionnaire (SADQ), was developed based on observable behaviours thought to be associated with depressed mood and included items derived from questionnaire measures of depression." (Sutcliffe & Lincoln, 1998, p. 507)	21 items	Clinician rated.	• 0-3 rating scale • Higher score indicates lower mood.	Sutcliffe and Lincoln (1998) Lincoln, Sutcliffe, and Unsworth (2000)
Validated translations/adaptations/versions: • SADQ-10: Sutcliffe and Lincoln (1998); Lincoln et al. (2000); Leeds, Meara, and Hobson (2004); • SADQH: Lincoln et al. (2000); Bennett et al. (2006) • SADQH-10: Bennett et al. (2006); Cobley, Thomas, Lincoln, and Walker (2012)					
Visual Analogue Self-Esteem Scale (VASES)	"The aim of the present research was to develop a measure of self-esteem that does not require sophisticated use of language." (Brumfitt & Sheeran, 1999, p. 389)	10 items	Patient reported.	5-point visual self-assessment scale.	Brumfitt and Sheeran (1999)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
Visual Analogue Mood Scale (VAMS; Stern, 1997)	"…a set of seven Visual Analogue Mood Scales (VAMS) specifically created for use with post-stroke and other neurologically impaired patients with aphasia and other communication disorders." (Stern, 1997, p. 60)	8 items	Patient reported.	Visual self-assessment scale.	Arruda, Stern, and Somerville (1999) Bennett et al. (2006) Benaim et al. (2010) Haley, Womack, Harmon, and Williams (2015)
Validated translations/adaptations/versions: • VAMS single item: Berg et al. (2009) • VAMS-R: Kontou, Thomas, and Lincoln (2012)					

Table 7-3

ICF Activity/Participation: Outcome Instrument Characteristics and Validation Studies

Outcome Instrument (Abbreviation/reference) [Language of outcome instrument]	Purpose (as described by test author(s))	Subtests	Method of report	Scoring system	Validation studies
Aphasia Communication Outcome Measure (ACOM)	"..a patient reported outcome measure of communicative functioning for persons with aphasia." (Hula, Doyle, et al., 2015, p. 906)	177 items describing various communication activities.	Patient-reported.	Four-point scale.	Doyle et al. (2013) Hula, Doyle, et al. (2015)
American Speech-Language and Hearing Association Functional Assessment of Communication Skills for Adults (ASHA-FACS) (Frattali, Thompson, Holland, Wohl, Ferketic, et al., 1995)	"The ASHA-FACS is a measure of communication disability." (Frattali, Thompson, Holland, Wohl, & Ferketic, 1995, p. 42)	43 items in four categories of: 1. Functional communication. 2. Social communication. 3. Communication of basic needs. 4. Reading, writing and number concepts; and daily planning.	Clinician rated.	Each item rated on two scales: • Communicative Independence 7-point scale. • The Qualitative Dimensions of Communication 5-point scale.	Frattali, Thompson, Holland, Wohl, and Ferketic (1995) Donovan, Rosenbek, Ketterson, and Velozo (2006) Ross and Wertz (2003) Ross and Wertz (2004) Muò et al. (2015)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
Amsterdam-Nijmegen Everyday Language Test (ANELT) [Dutch]	“The Amsterdam-Nijmegen Everyday Language test (ANELT) is designed to measure, first, the level of verbal communicative abilities of aphasic patients and, second, changes in these abilities over time. The level of communicative effectiveness is determined by the adequacy of bringing a message across.” (Blomert, Kean, Koster, & Schokker, 1994b, p. 381)	The person with aphasia is presented with everyday scenarios and asked what they would say in response to a given situation. Responses are given in monologue, with the clinician acting as a listener only.	Clinician rated.	The response is audio recorded and rated by the clinician on a 5-point scale of: (a) How well the message is understood (content); (b) Intelligibility (B-Scale).	Blomert et al. (1994b) Ruiter, Kolk, Rietveld, Dijkstra, and Lotgering (2011)

Validated translations/adaptations/versions:

English: Crockford and Lesser (1994)

Swedish: Laska, Bartfai, et al. (2007)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
The Assessment of Communicative Effectiveness in Severe Aphasia (ACESA)	"The Assessment of Communicative Effectiveness in Severe Aphasia (ACESA) was developed to provide, as evident from its name, a more suitable assessment of communicative effectiveness for people with a severe aphasia. Communicative effectiveness, in this context, was defined as the ability to use non-verbal skills such as gesture, facial expression, pointing, intonation, the use of social skills and contextual information, and any limited verbal skills.." (Cunningham, Farrow, Davies, & Lincoln, 1995, p. 2)	Two sections: 1. Structured conversation. 2. Objects and pictures.	Clinician rated.	• Communicative effectiveness is rated on a 0-4 scale of recognisability. • The scores are added for each section to give an overall total score out of 200.	Cunningham et al. (1995)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
The Communication Activity Log (CAL)	"These situations can be used to evaluate the communicative activity of PWA in the past week with the help of a caregiver." (Kim et al., 2016)	36 questions • quantity (18 items); • quality (18 items).	Caregiver rated.	• 6-point scale. • The total score for the quality or quantity domain is 90 points. • A higher score on the CAL means better communication of PWA in daily life.	
Korean (K-CAL): Kim et al. (2016)					
The Communication Outcome After Stroke (COAST; Long et al., 2008)	"… a patient-centred outcome measure of everyday communication effectiveness for people with communication problems (aphasia and/or dysarthria) following stroke." (Long, Hesketh, Paszek, Booth, & Bowen, 2008, p. 1084)	20 items: • 15 items relate to communication effectiveness. • 5 relate to the impact of communication difficulties on quality of life.	Patient-reported.	Each item rated on a 5-point scale. (0 = the worst and 4 = the best scenario).	Long et al. (2008) Hesketh, Long, and Bowen (2011)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
The Communicative Activities Checklist and the Social Activities Checklist (COMACT; SOCACT),	“The COMACT measures the frequency and the types of communicative activities engaged in by participants.” (Aujla, Botting, Worrall, Hickson, & Cruice, 2015, p. 901) “The SOCACT measures the range and frequency of social activities.” (Aujla et al., 2015, p. 902)	• The COMACT has 45 communication activities with subscales of Talking, Listening, Reading, and Writing. • The SOCACT contains 20 social activities with subscales of Leisure, Informal, and Formal.	Patient-reported.	• A score of 1 is given for every activity engaged in. • The frequency of participation is reported. • The maximum score is 45.	Aujla et al. (2015)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
The Communication Disability Profile (CDP)	The Communication Disability Profile (CDP) is an aphasia focused, aphasia-friendly PRO measure. The CDP aims: to facilitate individuals with a wide range of aphasia severities and types in expressing the impact of aphasia on their lives; to quantify aspects of living with aphasia; to support joint-planning and therapy goal setting; and to explore and validate the individual's identity as someone living with aphasia." (Chue, Rose, & Swinburn, 2010, p. 942)	Four sections: 1. Activities (20 items). 2. Participation (13 items). 3. External influences. 4. Emotions (14 items).	Patient-reported.	• Quantifiable data are only available for: Activities, Participation, and Emotions sections. • Participants provide a self-rating on a 5-point pictorial rating scale.	Chue et al. (2010)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
The Communication Effectiveness Index (CETI)	“Therefore, we developed a measure of functional communication for the adult with aphasia that could measure change in performance over time--the Communicative Effectiveness Index (CETI).” (Lomas et al., 1989, p. 113)	16 items.	Report from significant other.	• 10cm visual analogue scale • Anchors: ‘not at all able’ and ‘was as able as before the stroke’.	Lomas et al. (1989) Penn, Milner, and Fridjhon (1992) Crockford and Lesser (1994) Fucetola and Tabor Connor (2015)
<u>Validated translations/adaptations/versions:</u> • Danish: Pedersen, Vinter, and Olsen (2001)					
Community Integration Questionnaire (CIQ)	“The CIQ is intended as a brief, reliable measure of a person’s level of integration into the home and community.” (Dalemans, de Witte, Beurskens, van den Heuvel, & Wade, 2010, p. 395)	15 questions in 3 subcategories: 1. Integration in home. 2. Social integration. 3. Productivity.	Patient-reported.	• Most items are scored on a scale of 0 to 2. • The overall score can range from 0 to 29. • A higher score indicates better integration.	Dalemans et al. (2010)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
Communication Activities of Daily Living (CADL; CADL-2; Holland, Frattali, & Fromm, 1999)	"…determine how closely a given aphasic individual's CADL score approximates normal functional communication" (Holland, 1980, p. 32)	50 test items in 7 areas: 1. Reading, writing, and using numbers. 2. Social interaction. 3. Divergent communication. 4. Contextual communication. 5. Nonverbal communication. 6. Sequential relationships. 7. Humor/metaphor/ absurdity.	Clinician rated.	• Items scored as correct (2 points), adequate (1 point) or wrong (0 points). • Total Raw Score (maximum score =100). • Percentile Rank. • Stanine Score.	Ross and Wertz (2003) Ross and Wertz (2004)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
The Functional Outcome Questionnaire for Aphasia (FOQ-A)	"The FOQ–A is a rationally derived, caregiver-completed questionnaire designed to assess the impact of aphasia treatment on the functional communication of patients with left hemisphere stroke in naturalistic settings." (Ketterson et al., 2008, p. 217)	32 items rating the person with stroke's ability to perform various communication behaviours.	Caregiver completed.	• 5-point scale. • The total score for the FOQ-A is reported as a mean of all completed items.	Glueckauf et al. (2003) Ketterson et al. (2008)
Stroke Social Network Scale (SNSS)	"… patient-reported measure of a person's social network following a stroke." (Northcott & Hilari, 2013, p. 829)	19 items in five domains: 1. Satisfaction with social network. 2. Children. 3. Relatives. 4. Friends. 5. Groups.	Patient-reported.	• Raw scores are converted to have a range of 0–100. • The overall score is the mean score of all items. • Lower scores are indicative of a participant having fewer social ties.	Northcott and Hilari (2013)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
Measure of participation in conversation (MPC)	"…the MPC, provides an index of participation in conversation by the person with aphasia in terms of his/her ability to interact or socially connect with a partner and to respond to and/or initiate specific content." (Kagan, Winckel, Black, Duchan, SimmonsMackie, et al., 2004)	The MPC is used to rate the level of participation in conversation by the person with aphasia in the areas of: 1. Interaction, or social connection 2. Transaction, or content related to the ability to exchange information, opinions, and feelings.	Clinician rated.	• The rater scores the person on a 9-point scale (0 to 4 with 0.5 levels).	Kagan, Winckel, Black, Duchan, Simmons-Mackie, et al. (2004) Correll, van Streenbrugge, and Scholten (2010)
The Scenario Test [Dutch]	"…a new aphasia test designed to assess multimodal communication." (van der Meulen, van de Sandt-Koenderman, Duivenvoorden, & Ribbers, 2010, p. 425)	18 items, representing daily-life communicative situations. Items grouped into 6 scenarios (shopping, visit to doctor, taxi, visit to friend, domestic help, restaurant).	Clinician rated.	Test sessions are video-recorded and scored after on a 4-point scale (0-3).	van der Meulen et al. (2010)

Outcome Instrument	Purpose	Subtests	Method of report	Scoring system	Validation studies
The Speech Questionnaire	“a means of obtaining a rating of aphasic patients’ functional communication skills from professionals who are not speech therapists.” (Lincoln, 1982, p. 116)	19 items in two sections: • Speech • Understanding.	Clinician rated.	4-point rating scale.	Lincoln (1982)

Table 7-4

Quality of Life and Other Constructs Not Captured within the ICF: Outcome Instrument Characteristics and Validation Studies

Outcome Instrument (Abbrev.) [Language of outcome measure]	Purpose (as described by test author(s))	Subtests	Method of report	Scoring system	Validation studies
Aachen Life Quality Inventory (ALQI; Hutter, 2001). [German]	"Quality of life was assessed for stroke patients with aphasia in post-acute and chronic stages by means of the Aachen Life Quality Inventory (ALQI), a German adaptation of the Sickness Impact Profile (SIP)." (Engell, Hutter, Willmes, & Huber, 2003, p. 383)	117 items in four categories: 1. Physical 2. Psychosocial 3. Cognition 4. Language. Two versions: 1. Pictorial (line drawing) version. Used by people with aphasia. 2. Written version. Used by caregivers..	Patient reported or proxy-rated.	• The respondent is required to judge statements as being either true or false. • Each question has an additional 3-item scale for measuring the degree of burden experienced.	Engell et al. (2003)

Outcome Instrument (Abbrev.) [Language of outcome measure]	Purpose (as described by test author(s))	Subtests	Method of report	Scoring system	Validation studies
Burden of Stroke Scale (BOSS; Doyle et al. (2004))	"The BOSS is a patient-reported, health-status assessment designed to quantify the consequences of stroke on functioning and psychological well-being." (Doyle et al., 2004, p. 998)	65 items across 12 health domains: • 7 scales: Patient-reported difficultly in functioning across mobility, self-care, swallowing, energy and sleep, communication, cognition, and social relations. • 3 scales: Associated psychological distress scales. • Negative mood scale. • Positive mood scale.	Patient-reported.	• Five-point scale.	Doyle et al. (2003) Doyle et al. (2004) Doyle, Matthews, Mikolic, Hula, and McNeil (2006) Doyle et al. (2007)
Knowledge of stroke questionnaire	"The Knowledge of Stroke Questionnaire was used to assess both patients' and carers' knowledge about stroke." (Hoffmann et al., 2010, p. 122)	30-item questionnaire.	Patient/carer reported.	• Scored true/false/don't know.	Hoffmann et al. (2010)

Outcome Instrument (Abbrev.) [Language of outcome measure]	Purpose (as described by test author(s))	Subtests	Method of report	Scoring system	Validation studies
Life satisfaction questionnaire (LISAT-9) [Dutch]	"The life satisfaction questionnaire (LISAT-9) was developed by Fugl-Meyer et al. (1991) as an instrument to assess life satisfaction." (Boonstra, Reneman, Stewart, & Balk, 2012, p. 154)	Nine items: • One question about general life satisfaction. • Eight questions about life satisfaction for domains of: self-care ability, leisure situation, vocational situation, financial situation, sex life, relationship with partner, family life and contacts with friends and acquaintances.	Patient-reported.	• Six-point scale.	Boonstra et al. (2012)
The Newcastle Stroke-Specific Quality of Life Measure (NEWSQOL)	"The aim of this study was to develop an acceptable and psychometrically sound interviewer-administered, stroke-specific QOL measure, using patient-centred methods". (Buck et al., 2004, p. 144)	56 items in 11 domains: 1. Feelings 2. Activities of daily living/self-care 3. Cognition 4. Mobility 5. Emotion 6. Sleep 7. Interpersonal relationships 8. Communication 9. Pain/sensation 10. Vision 11. Fatigue.	Patient-reported.	• Four-point scale.	Buck et al. (2004)

Outcome Instrument (Abbrev.) [Language of outcome measure]	Purpose (as described by test author(s))	Subtests	Method of report	Scoring system	Validation studies
Short Form 36 Health Survey (SF-36)	"The Short Form-36 Health Survey (SF-36) is a widely used measure of health-related quality of life…" (Stadnyk, Calder, & Rockwood, 1998, p. 827)	The SF-36 assesses eight health concepts: (1) limitations in physical activities because of health problems; (2) limitations in social activities because of physical or emotional problems; (3) limitations in usual role activities because of physical health problems; (4) bodily pain; (5) general mental health (psychological distress and wellbeing); (6) limitations in usual role activities because of emotional problems; (7) vitality (energy and fatigue); and (8) general health perceptions. It yields eight subscale scores across physical and mental health.	Patient-reported.	• The SF-36 contains yes/no questions, true/false questions and frequency questions. • For all of the 8 SF-36 subscales, a scale of 0–100 is used, wherein higher scores indicate a better state of HRQOL.	Cruice, Worrall, and Hickson (2010)

Outcome Instrument (Abbrev.) [Language of outcome measure]	Purpose (as described by test author(s))	Subtests	Method of report	Scoring system	Validation studies
Stroke and Aphasia Quality of Life Scale (SAQOL-39)	"The SAQOL-39…can be used to assess HRQL in most stroke survivors, including people with aphasia, in clinical practice, and in research." (Hilari, Byng, Lamping, & Smith, 2003b, p. 1950)	39 items in four sub-domains: 1. Physical 2. Psychosocial 3. Communication 4. Energy.	Patient-reported.	• Two response formats, on a 5-point scale. • Overall and subdomain scores range from 1 to 5. • Overall SAQOL score: items summed /number of items.	Hilari et al. (2003b) Hilari, Owen, and Farrelly (2007) Hilari et al. (2009)

Validated translations/adaptations/versions:

- Dutch: Manders, Dammekens, Leemans, and Michiels (2010); van Ewijk, Versteegde, Raven-Takken, and Hilari (2016)
- Chilean Spanish: Diaz, Gonzalez, Salgado & Perez (2013)
- Greek: Kartsona and Hilari (2007)
- Hindi: Mitra and Krishnan (2015)
- Italian: Posteraro et al. (2004); Posteraro et al. (2006)
- Japanese: Kamiya, Kamiya, Tatsumi, Suzuki, and Horiguchi (2015)
- Kannada: Kiran and Krishnan (2013)
- Malayalam: Raju and Krishnan (2015)
- Spanish: Lata-Caneda et al. (2009)
- Turkish: Atamaz Calis, Celik, Demir, Aykanat, & Yagiz On (2016)
- Telephone administration: Hoffmann et al., (2010)
- SAQOL-39g Telephone and postal administration: Caute, Northcott, Clarkson, Pring, & Hilari (2012)
- SAQOL-39g Greek: Efstratiadou et al. (2012); Ignatiou, Christaki, Chelas, Efstratiadou, and Hilari (2012)
- SAQOL-39g/SAQOL-CSg Mandarin (Singapore): Guo, Togher, Power, & Koh (2016)

Outcome Instrument (Abbrev.) [Language of outcome measure]	Purpose (as described by test author(s))	Subtests	Method of report	Scoring system	Validation studies
Stroke Specific Quality of Life Scale (SS-QOL)	"The aim of this study was to begin the process of developing a patient-derived, responsive stroke-specific quality of life (SS-QOL) measure, designed for use in stroke clinical trials." (Williams, Weinberger, Harris, Clark, & Biller, 1999, p. 1363)	49 items assessing 12 domains: 1. Energy 2. Family roles 3. Language 4. Mobility 5. Mood 6. Personality 7. Self-care 8. Social roles 9. Thinking 10. Upper extremity function 11. Vision 12. Work/productivity.	Patient-reported.	• Five-point scale. • Lower scores represent lower health related quality of life.	Williams et al. (1999) Hilari and Byng (2001) Lin et al. (2010) Boosman, Passier, Visser-Meily, Rinkel, and Post (2010)
<u>Translations/adaptations/versions:</u> • Dutch: Muus and Ringsberg (2005) • German: Ewert and Stucki (2007)					

Outcome Instrument (Abbrev.) [Language of outcome measure]	Purpose (as described by test author(s))	Subtests	Method of report	Scoring system	Validation studies
Quality of life questionnaire for aphasics (QLQA) [Italian]	"…a QL questionnaire for aphasics (QLQA), in which we focused particularly on difficulties in interpersonal relationships, on loss of independence, and on abilities in daily life as a result of language disorders." (Spaccavento et al., 2014, p. 28)	37 questions: • Communication (22 items which evaluate ability to express and understand in real life and pragmatic situations). • Psychological condition (six items evaluating the impact of aphasia on emotional status). • Autonomy (nine items evaluating independence in activities of daily life).	Patient-reported.	• Five-point scale. • The QLQA score is calculated by summing the items. • Higher scores indicate better health related quality of life.	Spaccavento et al. (2014)

7.5 Discussion

The current review aimed to identify all available evidence on the measurement properties of outcome instruments which have been validated for use with people with aphasia. A total of 79 different outcome instruments were identified and many of these had multiple validated language translations and versions. The current review did not include studies published within assessment manuals or in languages other than English; broader inclusion criteria would have likely further increased the already large number of instruments identified. When considered in reference to the ICF, the instruments identified in the current review predominately measured Body Functions (n=49; 62%). These findings provide further evidence to support the notion that outcome measures in aphasia treatment are both prolific in number and narrow in scope. The ready availability of impairment level outcome instruments may in part account for the high reported use of these tools in aphasia treatment trials (Brady, Kelly, Godwin, & Enderby, 2012; Brady, Kelly, Godwin, Enderby, & Campbell, 2016; Xiong, Bunning, Horton, & Hartley, 2011). The results of this systematic review are reflective of the state of research outcome measurement more broadly in stroke and stroke rehabilitation trials. Systematic reviews of acute stroke drug intervention (Duncan, Jorgensen, & Wade, 2000), functional outcome measures in stroke trials (Quinn, Dawson, Walters, & Lees, 2009) and upper limb measures in stroke rehabilitation trials (Santisteban et al., 2016) have all reported the use of many and varied outcome instruments, with little consistency in use across trials. Inconsistency in research outcome measurement is a widespread issue, and the Core Outcome in Effectiveness Trials (COMET) website shows that a large number of projects have been completed or are in progress in this area of outcome measurement standardisation. A 2014 systematic review of COS development studies identified 198 studies which related to health areas including neurology, cancer, rheumatology, heart and circulation, dentistry and oral health (Gargon et al., 2014). This number has increased exponentially over the intervening years, the COMET database now houses over 800 references of planned, ongoing and completed work in COS development.

The searches used within the current systematic review did not include limits in terms of year of study publication, accordingly, studies from as early as 1962 (e.g., the Token Test) were included. It must be considered whether all of these assessments maintain relevancy in contemporary treatment research. Also worthy of consideration is the purpose for which instruments were created. As Xiong and associates (2011) surmise, many of the instruments used in research were developed to be assessments used by clinicians, and not all assessments are good measures of research outcome. Research should measure outcomes that reflect what "people representing the population of interest notice and care about (e.g., survival, function, symptoms, health-related quality of life) and that inform an identified health decision." (PCORI Methodology Committee, 2013, p. 26). The research of the current authors suggests that important treatment outcomes for people with aphasia relate to a diverse range of areas spanning the ICF. Synthesis of outcomes that are important to a range of stakeholders in aphasia treatment suggests that outcomes should be routinely measured in the ICF categories of Mental functions (Emotional functions, Mental functions of language, Energy and drive functions); Communication (communicating by language, signs and symbols, receiving and producing messages, conversations, and using communication devices and techniques.); and Services, systems, and policies (Health services, systems and policies) and also in terms of quality of life. In reference to the outcome instruments identified in the current review a major gap exists in terms of the measurement of outcomes relating to health services, such as standardised and validated measures of treatment satisfaction or patient perception of treatment impact. With health systems increasingly placing value on patient centred care and consumer-based notions of value, the development of tools in this area will become increasingly important. A further gap in outcome instruments relates to tools which may be used to measure the success of communication in the dyad. In this review, the Measure of Participation in Conversation (MPC) (Kagan et al., 2004) was the only instrument which primarily aimed to measure this construct. Additionally, this review has only considered standardised outcome instruments. Future research may also consider a broader range of measures e.g., imaging and bio-markers.

The inclusion of patient-reported outcome measures in treatment trials is increasingly recommended (Food and Drug Administration, 2009) and guidelines for their use have been produced by the Patient-Centered Outcomes Research Institute (PCORI) and through the extension of the CONSORT (Consolidated Standards of Reporting Trials) statement (Calvert, Blazeby, et al., 2013; Calvert, Brundage, Jacobsen, Schünemann, & Efficace, 2013). The current review has identified a number of available patient-reported outcome measures. A total of 25 of the 79 identified outcome instruments were patient reported outcome measures or contained patient reported components. The majority of these were measures of psychological function or quality of life.

Research in aphasia treatment occurs in many countries and languages. Information regarding the translation and cultural adaptation of instruments is therefore essential. While a number of instruments in the current review had published validation studies for translation of tools into other languages, many did not. Undoubtedly translations for many of these instruments exist, however without published validation studies, this information is difficult to reliably obtain. The development of a COS may also targeted translation of key outcome instruments into a wide range of languages.

The current study did not seek to evaluate the quality of the measurement properties of each included outcome instrument and merely having undergone some process of measurement validation is not a guarantee of quality. The Core Outcome Measurement Instrument Selection (COMIS) guidelines produced by Prinsen et al. (2016) recommend that following the identification of potential outcome instruments for inclusion in a COS, a quality assessment must be conducted. Quality assessment should include consideration of each instrument's: (1) measurement properties and (2) the feasibility of use. This process is currently underway and will be reported elsewhere.

7.6 Conclusions

The aim of this review was to identify studies reporting the measurement properties of outcome measurement instruments which have been validated for use with people with aphasia. A total of 79 instruments were identified which have been validated with people with aphasia. The outcomes measured in aphasia treatment studies often do not reflect outcomes which are known to be important to people living with aphasia and clinicians. There is also little consistency in the tools used across studies. The majority of these measures relate to Body Function constructs such as language and psychological function. Few exist for quality of life, satisfaction, and knowledge. There is a need to evaluate the measurement properties from these instruments and to targeted development of measures of patient-reported treatment impact and treatment satisfaction.

7.7 References

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Chapter 8: Conclusion

8.1 Summary of the Research

This research provides recommendations for a core outcome set (COS) for use in aphasia treatment research studies. A trilogy of stakeholder consensus studies and the synthesis of these findings produced recommendations for outcome constructs which could be routinely measured in aphasia treatment research. A systematic review identified existing outcome instruments, as well as gaps in the tools that are currently available.

In chapter three (study 1) people with aphasia and their family members identified important treatment outcomes which linked to all components of the ICF. Participants with aphasia prioritised outcomes which primarily linked to the Activity/Participation and Body Function ICF components. Family members prioritised outcomes for themselves which predominantly linked to the Activity/Participation component, and outcomes for their family member with aphasia which primarily linked to the Body Function component of the ICF. Thematically, outcomes related to: (1) Improved communication; (2) Increased life participation; (3) Changed attitudes through increased awareness and education about aphasia; (4) Recovered normality; (5) Improved physical and emotional well-being; and (6) Improved health (and support) services. The breadth of outcomes identified by participants in this study has implications for both aphasia research outcome measurement and clinical service provision. Currently, outcomes in aphasia treatment research are most often measured at an impairment or ICF Body Function level. This study indicated that outcomes should be measured at a Body Function level, but also more broadly, particularly at an Activity/Participation level. Clinically, the results of this study highlight the need for holistic, family-centred aphasia services that seek to achieve outcomes relevant for both people with aphasia and their significant others.

In chapter four (study 2) aphasia researchers reached consensus on six outcome constructs that should be measured in all aphasia treatment research. These outcomes were predominately patient-reported, relating to communication-related quality of life, satisfaction, and patient perception of treatment impact. Language functioning in modalities relevant to study aims also reached consensus, confirming the importance of measuring the impact of treatment on language function. These findings have important implications for research. While language function is a frequently measured construct in aphasia treatment trials, communication-related quality of life, patient satisfaction, and the patient perspective on treatment impact are not. This study highlighted the need to determine why these outcomes are not currently being measured in research and whether this relates to a lack of suitable outcome instruments for the measurement of patient-reported outcomes.

In chapter five (study 3) clinicians/managers working in aphasia rehabilitation gained consensus on 51 essential treatment outcomes which linked to Body Function, Activity/Participation and Environmental Factor components of the ICF. Participants from 25 countries demonstrated the highest levels of agreement (97-99%) for outcomes relating to communication between the person with aphasia and their communication partner/s. Interestingly, clinicians/managers did not consider improved language function to be an essential outcome of aphasia treatment. This finding confirms that in the clinical environment, improved communication between the person with aphasia and their significant others is perceived to be a key treatment outcome. Thematically, clinicians/managers reached consensus on outcomes for people with aphasia which most frequently related to psychosocial well-being, improved communication partner skills and knowledge. Again, these findings are relevant to both clinical and research outcome measurement, where the impact of treatment on psychosocial well-being and communication in the dyad are rarely measured.

Synthesis of studies 1-3 (Study 4) in chapter six provided recommendations for outcome constructs which should be routinely measured in aphasia treatment research. Congruence across three or more stakeholder groups was evident for outcomes for the person with aphasia which related to the ICF categories of Mental functions (Emotional functions, Mental functions of language, Energy and drive functions); Communication (communicating by language, signs and symbols, receiving and producing messages, conversations, and using communication devices and techniques); and Services, systems, and policies (Health services, systems and policies). Additionally, two participant groups (clinicians/managers and researchers) reached consensus on outcomes relating to quality of life and participants with aphasia and family members identified multiple outcomes reported to be determinants of quality of life. It is therefore recommended that the impact of a treatment on language; emotional wellbeing; communication; and quality of life should be measured routinely. Outcomes relating to health services (e.g., treatment satisfaction and treatment impact) should also be measured.

In chapter 7, a scoping systematic review of studies reporting the measurement properties of standardised outcome instruments (Study 5) identified a large number of available outcome instruments (n=79) which primarily related to Body Functions (n=49). No outcome instruments were reported to primarily measure constructs which could be categorised as Environmental Factors. These findings demonstrate that measures of Body Functions, particularly language functions, are by far the most commonly available form of outcome instruments which have been validated with people with aphasia. This may in part explain why impairment level outcome tools are used more often in research. While several communication Activity/Participation and quality of life instruments were evident, no outcome instruments were identified which measured constructs relating to health services (e.g., treatment satisfaction or patient-reported impact of treatment). Hence, the systematic review has identified gaps in outcome measure development for aphasia. This systematic review has also provided a pool of outcome instruments which have been paired with outcome constructs identified in the phase 1 synthesis of stakeholder perspectives (chapter six). The outcome constructs and outcome instruments will form the basis of a final international consensus process to develop a COS (see table 8-1). Further assessment of the measurement properties of these outcome instruments is needed to assist in the identification of the best tools to measure a given construct.

Table 8-1

Recommendations for Outcome Constructs and Outcome Instruments for a COS for Aphasia Treatment Research

ICF Component/ Outcome Domain	ICF Category	Outcome Instrument
Body Functions	Mental functions of language	**Screening Instruments**
		Acute Aphasia Screening Protocol (AASP)
		The Aphasia Rapid Test (ART)
		Brief Aphasia Evaluation (BAE)
		Frenchay Aphasia Screening Test (FAST)
		Language Screening Test (LAST)
		The Mississippi Aphasia Screening Test (MAST)
		The Mobile Aphasia Screening Test (MAST)
		The Reitan-Indiana Aphasia Screening Test
		ScreeLing
		Sheffield Screening Test for Acquired Language Disorders (SST)
		Sklar Aphasia Scales (SAS)
		Ullevaal Aphasia Screening Test (UAS)

ICF Component/ Outcome Domain	ICF Category	Outcome Instrument
Body Functions	Mental functions of language	**Comprehensive Instruments** Aachen Aphasia Test (AAT) The Aphasia Checklist (ACL) Aphasia Language Assessment Test (ALA) The Thai Aphasia Language Performance Scales (ALPS) The Aphasia Screening Test (AST) Bilingual Aphasia Test (BAT) The Boston Diagnostic Aphasia Examination (BDAE) Ege Aphasia Test Kentucky Aphasia Test (KAT) Luria-Nebraska Language Scales in Aphasia The Minnesota Test for Differential Diagnosis of Aphasia (MTDDA) Montreal-Toulouse Language Assessment Battery – Brazilian version (MTL-BR) The Norsk Grunntest for Afasi (NGTA) Porch Index of Communicative Ability (PICA) The Western Aphasia Battery (WAB)

ICF Component/ Outcome Domain	ICF Category	Outcome Instrument
Body Functions	Mental functions of language	**Individual Language Modality Instruments** Multiple-Choice Test of Auditory Comprehension (MCTAC) The Reading Comprehension Battery for Aphasia (RCBA; RCBA-2) The Token Test (TT) The Revised Token Test (RTT) The Boston Naming Test (BNT) Northwestern Assessment of Verbs and Sentences (NAVS) The Philadelphia Naming Test (PNT) Syntax Comprehension Test in Hindi Language Sentence Production Test (SPT)
Body Functions	Emotional functions and Energy and drive functions	Aphasic Depression Rating Scale (ADRS) Clinical Global Impressions rating scale for Severity (CGI-S) Beck Depression Inventory (BDI) Hamilton Rating Scale for Depression Behavioural Outcomes of Anxiety Scale (BOA) Communication Confidence Rating Scale for Aphasia (CCRSA) Hospital Anxiety and Depression Scale (HADS) Montgomery-Asberg Depression Rating Scale (MADRS) Stroke and Aphasia (SAD) Scale Signs of Depression Scale (SODS)

ICF Component/ Outcome Domain	ICF Category	Outcome Instrument
Body Functions	Emotional functions and Energy and drive functions	Stroke Aphasic Depression Questionnaire (SADQ) Visual Analogue Self-Esteem Scale (VASES) Visual Analogue Mood Scale (VAMS)
Activity/Participation	Communicating by language, signs and symbols, including receiving and producing messages, carrying on conversations, and using communication devices	Aphasia Communication Outcome Measure (ACOM) American Speech-Language and Hearing Association Functional Assessment of Communication Skills for Adults (ASHA-FACS) Amsterdam-Nijmegen Everyday Language Test (ANELT) The Assessment of Communicative Effectiveness in Severe Aphasia (ACESA) The Communication Activity Log (CAL) The Communication Outcome After Stroke (COAST) The Communicative Activities Checklist (COMACT) The Social Activities Checklist (SOCACT) The Communication Disability Profile (CDP) The Communication Effectiveness Index (CETI) Community Integration Questionnaire (CIQ) Communication Activities of Daily Living (CADL) The Functional Outcome Questionnaire for Aphasia (FOQ-A) Stroke Social Network Scale (SNSS) Measure of participation in conversation (MPC) The Scenario Test The Speech Questionnaire

ICF Component/ Outcome Domain	ICF Category	Outcome Instrument
Environmental Factors	Health services, systems and policies	
Quality of life		Aachen Life Quality Inventory (ALQI) Burden of Stroke Scale (BOSS) The Newcastle Stroke-Specific Quality of Life Measure (NEWSQOL) Short Form 36 Health Survey (SF-36) Stroke and Aphasia Quality of Life Scale (SAQOL-39) Stroke Specific Quality of Life Scale (SS-QOL) Quality of Life Questionnaire for Aphasics (QLQA)
Multiple ICF Components		Assessment for Living With Aphasia (ALA) The Comprehensive Aphasia Test (CAT) Stroke Impact Scale 2.0 (SIS) Therapy Outcome Measures (TOM)

8.2 Strengths and Limitations

A major strength of study 1, the nominal group technique study with people with aphasia and their families, was the inclusion of participants from multiple international locations. The COS recommendations generated in this research are intended for an international audience, and as such the global validity of the study was maximised by recruiting people with aphasia and their families from as many international sites as possible. The authors sought to establish data collection sites in each of the world regions as defined by the World Health Organization (World Health Organization., 2014); ultimately sites were established in seven countries: Australia, Canada, Hong Kong (China), Denmark, South Africa, the United Kingdom, and the United States of America; representing four of the six world regions as defined by the World Health Organization (World Health Organization., 2014). A further strength of this study related to the use of the nominal group technique (Delbecq, Van de Ven, & Gustafson, 1975). The structured turn-taking used in this technique allowed participants to contribute equally and provided opportunity for the incorporation of supported communication techniques. This facilitated the participation of people with severe forms of aphasia who are often excluded from research. A limitation of study 1, was that differences in outcome prioritisation between countries was not examined. This may form an area for future research; larger sample sizes would be required to examine country specific variations in outcome prioritisation. Future research could also incorporate data from a larger range of countries in order to validate the findings of this study.

A strength of study 2, an international e-Delphi exercise with aphasia researchers, was the sampling method. The inclusion of active aphasia treatment researchers ensured that contemporary perspectives on treatment research outcome measurement were obtained. Inclusion of researchers who would be in a position to use the resulting COS was also an important consideration in terms of the potential uptake of recommendations. It is acknowledged that response rates in study 2, may have been limited by conducting the study in English only. While aphasia researchers from ten countries participated in this study; six of these countries were predominantly English-speaking. Conducting this study in English only, may have prevented the participation of researchers from a broader range of locations. Despite this, it must be acknowledged that the international language of science is English and the majority of invited participants had published in English regardless of their primary spoken language. Although sampling was designed to capture the views of researchers across a range of treatment areas, demographic information regarding each participant’s primary area of research was not recorded. Therefore it is unknown whether the results were influenced by participant area of research / treatment philosophy.

A strength of study 3, an international e-Delphi exercise with aphasia clinicians/managers, was the large numbers of clinicians/managers recruited across 25 countries. It is acknowledged that participant attrition may have resulted from a delay between rounds 1 and 2. A total of 10% of potential participants were unable to be contacted in round 2, which may have been avoided through a faster transition between rounds. A further limitation of this study was the representativeness of the sample. While large numbers of participants were recruited from a diverse range of countries, recruitment in Eastern Mediterranean, African, and South East Asian world regions was low and it must be considered whether higher participant numbers from these regions may have altered the results.

The use of the ICF in the phase 1 studies and their synthesis (study 4) was both a strength and potential limitation in this program of research. While the ICF provided a common framework for the synthesis of results within and across diverse participants groups, use of the standard linking process may have resulted in loss of context and nuances of meaning. Furthermore the wording differences in the questions used in the three consensus studies must be acknowledged. The questions used to elicit stakeholder perspectives were phrased to be meaningful to each stakeholder group, however differences in question wording may have impacted the responses generated. Finally, a lack of current methodological guidance regarding the combination of stakeholder perspectives may also have influenced the results. In the synthesis, congruence was defined as agreement across three or more participant groups. However, with COS methodology being a developing area of enquiry it is not known whether this is the preferred way of interpreting findings, or whether particular stakeholder perspectives should take precedence.

A strength of the systematic review (study 5) was adherence to internationally recognised methodological and reporting standards (i.e., PRISMA and COSMIN). Adherence to these standards was important in ensuring the quality and transparency of reporting. A limitation of the review, was that the scope of the current project did not allow for the critique of the methodological quality of each identified study, nor for the extraction and synthesis of measurement properties for each identified outcome instrument. These processes will be reported separately. A further limitation is that the systematic review excluded studies not published in English and those published within assessment manuals. These factors may have restricted the number of outcome instruments identified.

8.3 Future Directions

Future directions for this project include quality assessment of the studies and outcome instruments identified in the systematic review. The Core Outcome Measurement Instrument Selection (COMIS) project, a partnership between The Core Outcome Measures in Effectiveness Trials (COMET) initiative and Consensus-based Standards for the selection of health Measurement INstruments (COSMIN), has produced standards for the quality assessment of outcome instruments being considered for inclusion in COSs (Prinsen et al., 2016; Prinsen et al., 2014). The recently published consensus-based guidelines (Prinsen et al., 2016) state that in order to assess the quality of outcome instruments two factors should be considered: (1) measurement properties and (2) the feasibility of using a given outcome instrument. With regards to measurement properties, the COMIS guidelines (Prinsen et al., 2016) recommend the measurement of (in order of importance): (1) content validity; (2) internal structure (i.e., structural validity and internal consistency, Item Response Theory, Rasch model fit); and where applicable (3) reliability, measurement error, hypotheses testing, cross-cultural validity, criterion validity, and responsiveness. In terms of feasibility, the COMIS guidelines recommend consideration of factors including: (1) comprehensibility (patient and clinician), (2) interpretability, (3) ease of administration, (4) length of the outcome instrument/completion time, (5) cost, and (6) copyright. Final selection of outcome instruments is guided by the following recommendations: (1) one measurement instrument for each outcome construct should be selected; (2) minimum requirements for inclusion are high quality evidence for: good content validity, good internal consistency and feasibility. It is further stated that a final consensus procedure should be employed to obtain agreement on the outcome instruments for each outcome construct to be included in a COS.

Assessment of outcome instrument quality for the measures identified in this doctoral research is currently underway in accordance with COMIS guidelines. This information will be combined with findings from the completed program of research to inform an international COS consensus meeting to be held at City University London in late 2016. The consensus meeting will be supported by the European Cooperation in Science and Technology (EU COST) Collaboration of Aphasia Trialists (CATs) and The British Aphasiology Society (BAS). Ethical approval for this meeting has been granted by one of the human ethics committees of The University of Queensland. Participants from study 2 of the doctoral research project – an international e-Delphi exercise of aphasia researchers have been invited to participate in this process, sampled according to area of expertise and geographic location. The COS consensus meeting will comprise: (1) a summary of results (stakeholder consensus studies, synthesis, systematic review, and studies of measurement instrument quality); (2) a facilitated discussion (discussion of important outcome domains/ outcome instruments); and (3) voting yes/no on outcome constructs and outcome instruments, requiring 70% consensus for inclusion in the COS. The primary outcome of the international consensus meeting will be agreement on a COS for aphasia treatment research studies. It should also be noted that COS development is an ongoing process and that the outcome constructs and outcome instruments agreed upon in this meeting will be updated and reviewed periodically.

Of key importance following COS development are issues surrounding implementation. One of the longest running examples of COS development and use is that of OMERACT (Outcome Measures in Rheumatology); an initiative which has been supporting the use of COSs in rheumatology trials since 1992. Kirkham, Boers, Tugwell, Clarke, and Williamson (2013) conducted an observational review of 350 randomised control trials for the treatment of rheumatoid arthritis (RA) to determine if trends existed in the proportion of trials reporting the RA COS over time. After the RA COS publication, increases were found in the measurement of the full set of RA core outcomes. Reasons for non-use primarily related to researchers being unaware of the COS during the design phase of their trial. These findings highlight the key role of awareness in uptake of COS use. Potential issues with COS implementation will be discussed at the international consensus meeting and also at a round table workshop in late 2016 at an international aphasia conference. Aphasia researchers will be engaged in these forums to identify barriers and facilitators to COS use and to define criteria (e.g., scope of study types) for the use of the COS.

Finally, further research in this field may also involve targeted development of outcome instruments to fill gaps highlighted in this doctoral research. These are particularly warranted in regards to measures of patient-reported treatment impact and treatment satisfaction. The COS development methodology used in the current research has the potential to be applied to other areas of speech pathology practice, as well as more broadly within condition-specific areas of research such as stroke rehabilitation, where core outcome sets do not currently exist.

8.4 Conclusion

There is a need for greater standardisation in outcome measurement practices in aphasia treatment research. This body of research has provided insight into the outcomes which are most important to key stakeholders in aphasia treatment – people with aphasia, their families, aphasia treatment researchers, and clinicians/managers. This research has highlighted the large number of outcome instruments available for use with people with aphasia and suggests the need for targeted development of appropriate instruments in particular construct areas. It is hoped that the legacy of this research will be improved quality of evidence for aphasia treatments through increased relevancy, efficiency, and transparency of research outcome measurement.

8.5 References

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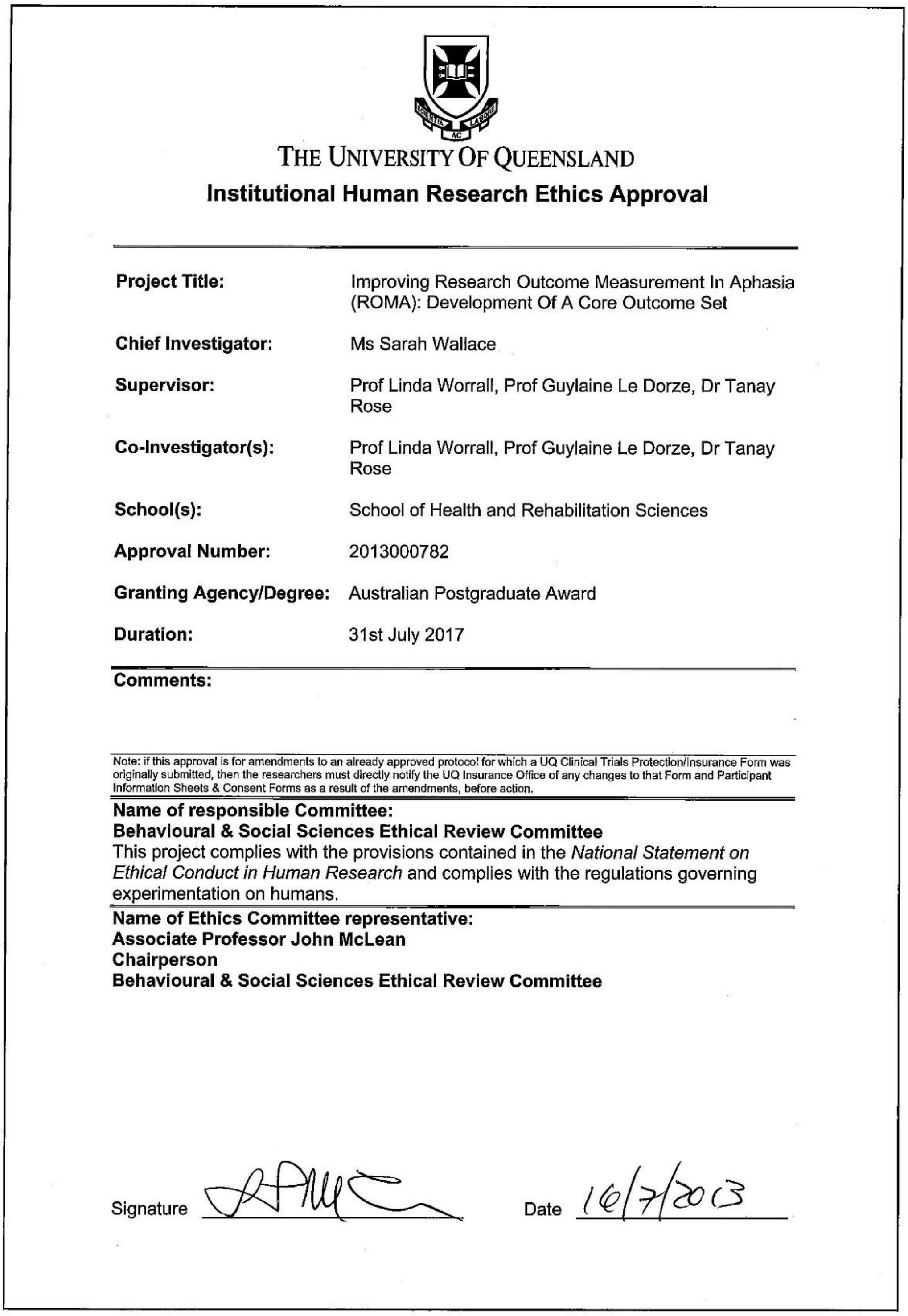
Appendix A: Ethical Approval Letters



THE UNIVERSITY OF QUEENSLAND

Institutional Human Research Ethics Approval

Project Title:	Improving Research Outcome Measurement In Aphasia (ROMA): Development Of A Core Outcome Set
Chief Investigator:	Ms Sarah Wallace
Supervisor:	Prof Linda Worrall, Prof Guylaine Le Dorze, Dr Tanay Rose
Co-Investigator(s):	Prof Linda Worrall, Prof Guylaine Le Dorze, Dr Tanay Rose
School(s):	School of Health and Rehabilitation Sciences
Approval Number:	2013000782
Granting Agency/Degree:	Australian Postgraduate Award
Duration:	31st July 2017

Comments:

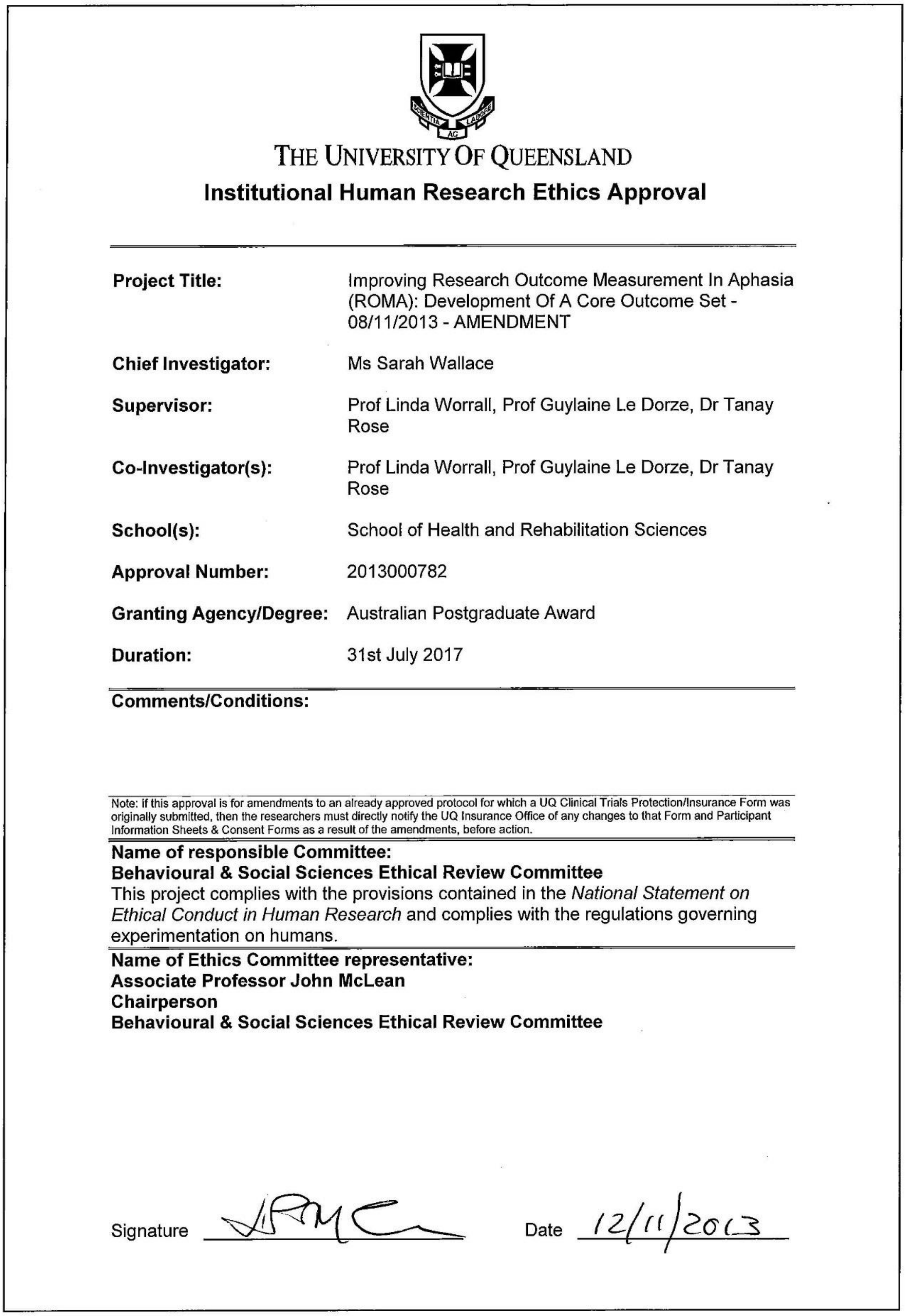
Note: if this approval is for amendments to an already approved protocol for which a UQ Clinical Trials Protection/Insurance Form was originally submitted, then the researchers must directly notify the UQ Insurance Office of any changes to that Form and Participant Information Sheets & Consent Forms as a result of the amendments, before action.

Name of responsible Committee:
Behavioural & Social Sciences Ethical Review Committee
This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:
Associate Professor John McLean
Chairperson
Behavioural & Social Sciences Ethical Review Committee

Signature

Date 16/7/2013



THE UNIVERSITY OF QUEENSLAND

Institutional Human Research Ethics Approval

Project Title:	Improving Research Outcome Measurement In Aphasia (ROMA): Development Of A Core Outcome Set - 08/11/2013 - AMENDMENT
Chief Investigator:	Ms Sarah Wallace
Supervisor:	Prof Linda Worrall, Prof Guylaine Le Dorze, Dr Tanay Rose
Co-Investigator(s):	Prof Linda Worrall, Prof Guylaine Le Dorze, Dr Tanay Rose
School(s):	School of Health and Rehabilitation Sciences
Approval Number:	2013000782
Granting Agency/Degree:	Australian Postgraduate Award
Duration:	31st July 2017

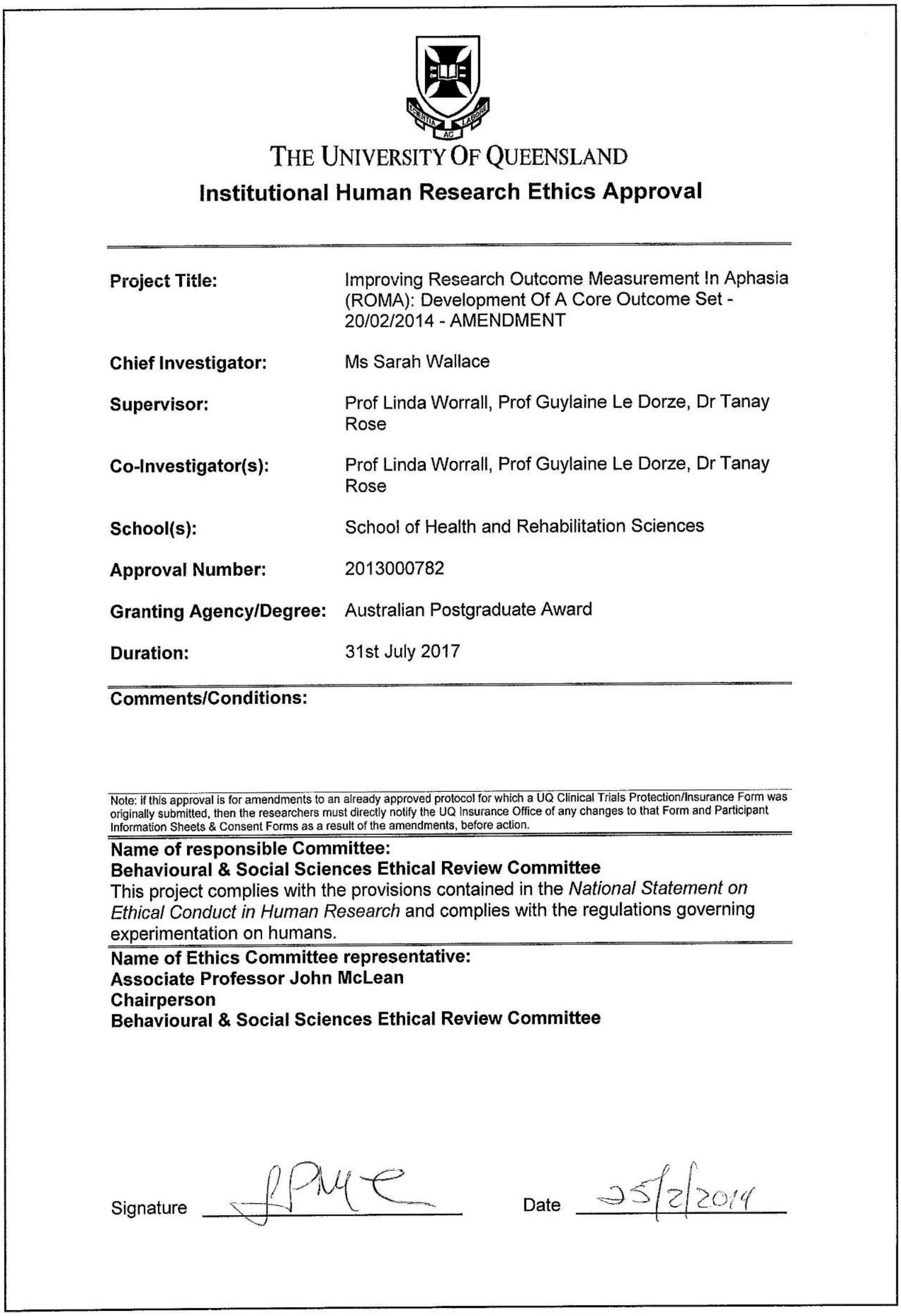
Comments/Conditions:

Note: If this approval is for amendments to an already approved protocol for which a UQ Clinical Trials Protection/Insurance Form was originally submitted, then the researchers must directly notify the UQ Insurance Office of any changes to that Form and Participant Information Sheets & Consent Forms as a result of the amendments, before action.

Name of responsible Committee:
Behavioural & Social Sciences Ethical Review Committee
This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:
Associate Professor John McLean
Chairperson
Behavioural & Social Sciences Ethical Review Committee

Signature ______________ Date 12/11/2013



THE UNIVERSITY OF QUEENSLAND

Institutional Human Research Ethics Approval

Project Title:	Improving Research Outcome Measurement In Aphasia (ROMA): Development Of A Core Outcome Set - 20/02/2014 - AMENDMENT
Chief Investigator:	Ms Sarah Wallace
Supervisor:	Prof Linda Worrall, Prof Guylaine Le Dorze, Dr Tanay Rose
Co-Investigator(s):	Prof Linda Worrall, Prof Guylaine Le Dorze, Dr Tanay Rose
School(s):	School of Health and Rehabilitation Sciences
Approval Number:	2013000782
Granting Agency/Degree:	Australian Postgraduate Award
Duration:	31st July 2017

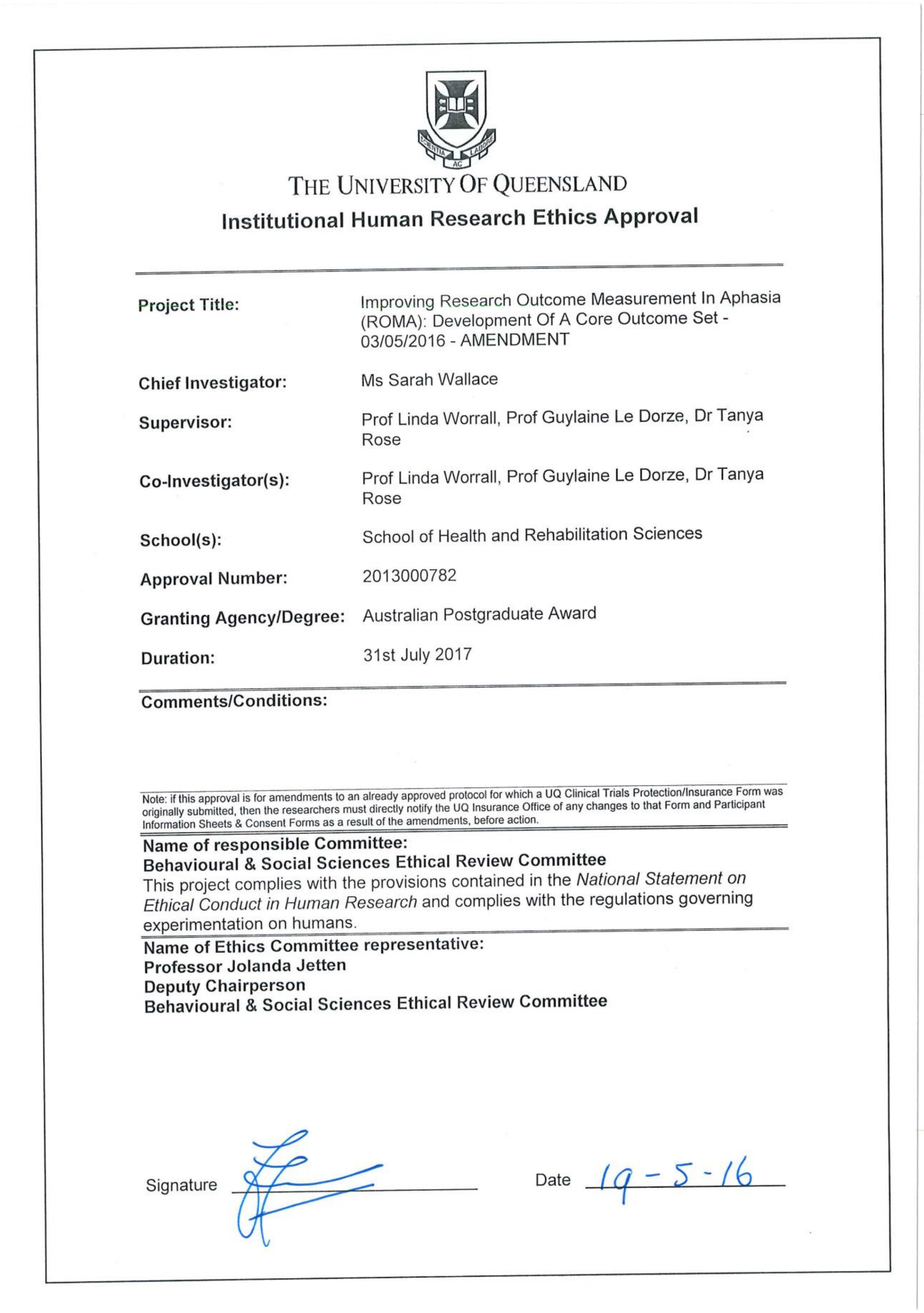
Comments/Conditions:

Note: if this approval is for amendments to an already approved protocol for which a UQ Clinical Trials Protection/Insurance Form was originally submitted, then the researchers must directly notify the UQ Insurance Office of any changes to that Form and Participant Information Sheets & Consent Forms as a result of the amendments, before action.

Name of responsible Committee:
Behavioural & Social Sciences Ethical Review Committee
This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:
Associate Professor John McLean
Chairperson
Behavioural & Social Sciences Ethical Review Committee

Signature ______________ Date 25/2/2014



THE UNIVERSITY OF QUEENSLAND

Institutional Human Research Ethics Approval

Project Title:	Improving Research Outcome Measurement In Aphasia (ROMA): Development Of A Core Outcome Set - 03/05/2016 - AMENDMENT
Chief Investigator:	Ms Sarah Wallace
Supervisor:	Prof Linda Worrall, Prof Guylaine Le Dorze, Dr Tanya Rose
Co-Investigator(s):	Prof Linda Worrall, Prof Guylaine Le Dorze, Dr Tanya Rose
School(s):	School of Health and Rehabilitation Sciences
Approval Number:	2013000782
Granting Agency/Degree:	Australian Postgraduate Award
Duration:	31st July 2017

Comments/Conditions:

Note: if this approval is for amendments to an already approved protocol for which a UQ Clinical Trials Protection/Insurance Form was originally submitted, then the researchers must directly notify the UQ Insurance Office of any changes to that Form and Participant Information Sheets & Consent Forms as a result of the amendments, before action.

Name of responsible Committee:
Behavioural & Social Sciences Ethical Review Committee
This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:
Professor Jolanda Jetten
Deputy Chairperson
Behavioural & Social Sciences Ethical Review Committee

Signature ______________________ Date 19-5-16

University of the
West of England
BRISTOL

Faculty of Health & Applied Sciences
Glenside Campus
Blackberry Hill
Stapleton
Bristol BS16 1DD

Tel: 0117 328 1170

UWE REC REF No: HAS/14/04/75

Date: 7th May 2014

Karen Sage
Bristol Speech and Language Therapy Research Unit
Frenchay Hospital
Bristol
BS16 1LE

Dear Karen

Application title: Which outcomes are most important to people living with aphasia?

Your ethics application was considered by the Faculty Research Ethics Committee and, based on the information provided, has been given ethical approval to proceed.

You must notify the committee in advance if you wish to make any significant amendments to the original application using the amendment form at

http://www1.uwe.ac.uk/hls/research/researchethicsandgovernance.aspx

Please note that any information sheets and consent forms should have the UWE logo. Further guidance is available on the web: http://www1.uwe.ac.uk/aboutus/departmentsandservices/professionalservices/marketingandcommunications/resources.aspx

The following standards conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.

2. You must notify the University Research Ethics Committee if you terminate your research before completion;

3. You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

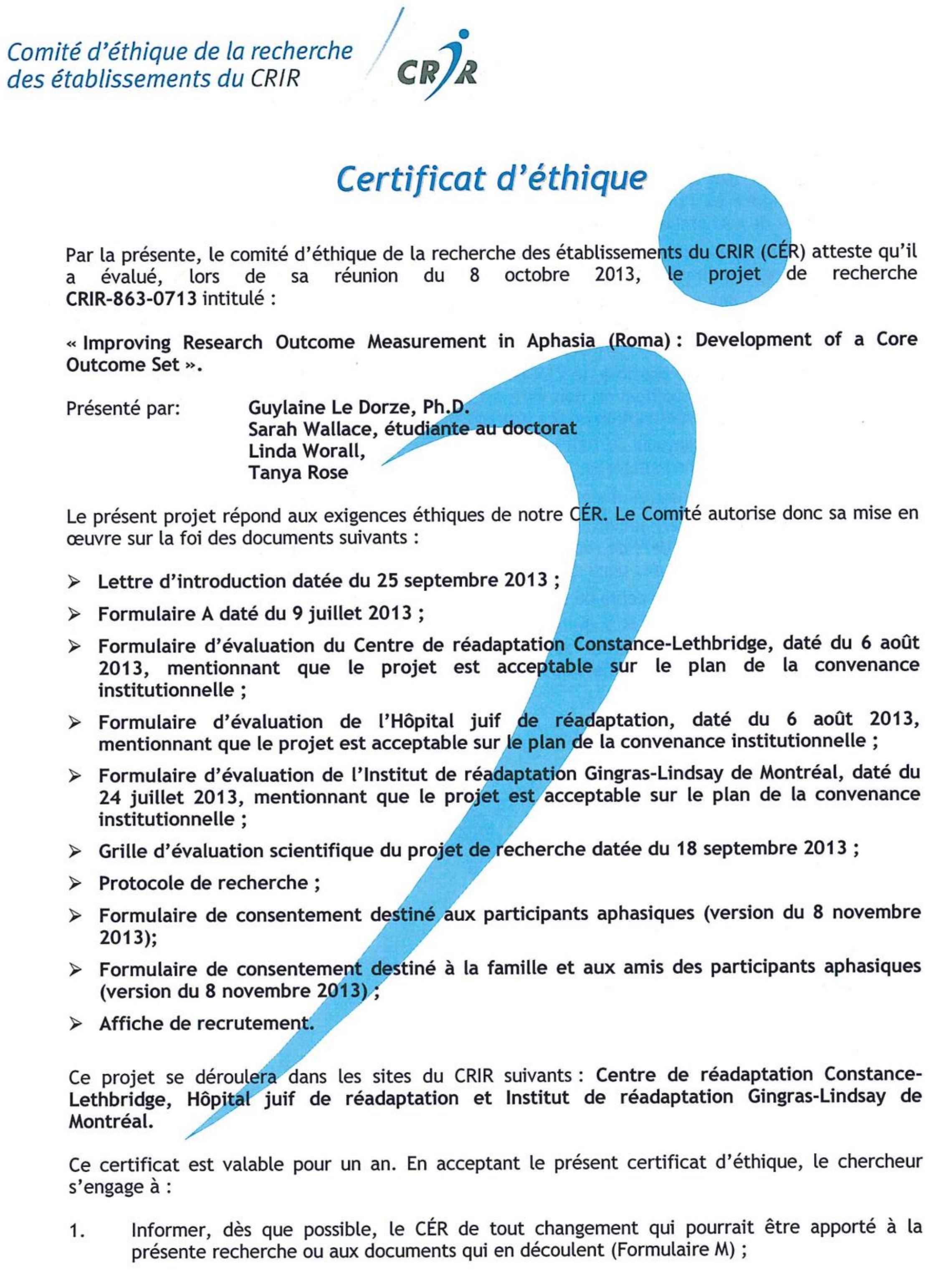
We wish you well with your research.

Yours sincerely

Julie E Woodley

Dr Julie Woodley
Chair
Faculty Research Ethics Committee

c.c *(supervisor, where applicable)*



Comité d'éthique de la recherche des établissements du CRIR

Certificat d'éthique

Par la présente, le comité d'éthique de la recherche des établissements du CRIR (CÉR) atteste qu'il a évalué, lors de sa réunion du 8 octobre 2013, le projet de recherche **CRIR-863-0713** intitulé :

« Improving Research Outcome Measurement in Aphasia (Roma) : Development of a Core Outcome Set ».

Présenté par: **Guylaine Le Dorze, Ph.D.**
Sarah Wallace, étudiante au doctorat
Linda Worall,
Tanya Rose

Le présent projet répond aux exigences éthiques de notre CÉR. Le Comité autorise donc sa mise en œuvre sur la foi des documents suivants :

- **Lettre d'introduction datée du 25 septembre 2013 ;**
- **Formulaire A daté du 9 juillet 2013 ;**
- **Formulaire d'évaluation du Centre de réadaptation Constance-Lethbridge, daté du 6 août 2013, mentionnant que le projet est acceptable sur le plan de la convenance institutionnelle ;**
- **Formulaire d'évaluation de l'Hôpital juif de réadaptation, daté du 6 août 2013, mentionnant que le projet est acceptable sur le plan de la convenance institutionnelle ;**
- **Formulaire d'évaluation de l'Institut de réadaptation Gingras-Lindsay de Montréal, daté du 24 juillet 2013, mentionnant que le projet est acceptable sur le plan de la convenance institutionnelle ;**
- **Grille d'évaluation scientifique du projet de recherche datée du 18 septembre 2013 ;**
- **Protocole de recherche ;**
- **Formulaire de consentement destiné aux participants aphasiques (version du 8 novembre 2013);**
- **Formulaire de consentement destiné à la famille et aux amis des participants aphasiques (version du 8 novembre 2013) ;**
- **Affiche de recrutement.**

Ce projet se déroulera dans les sites du CRIR suivants : **Centre de réadaptation Constance-Lethbridge, Hôpital juif de réadaptation et Institut de réadaptation Gingras-Lindsay de Montréal.**

Ce certificat est valable pour un an. En acceptant le présent certificat d'éthique, le chercheur s'engage à :

1. Informer, dès que possible, le CÉR de tout changement qui pourrait être apporté à la présente recherche ou aux documents qui en découlent (Formulaire M) ;

2. Notifier, dès que possible, le CÉR de tout incident ou accident lié à la procédure du projet ;
3. Notifier, dès que possible, le CÉR de tout nouveau renseignement susceptible d'affecter l'intégrité ou l'éthicité du projet de recherche, ou encore, d'influer sur la décision d'un sujet de recherche quant à sa participation au projet ;
4. Notifier, dès que possible, le CÉR de toute suspension ou annulation d'autorisation relative au projet qu'aura formulée un organisme de subvention ou de réglementation ;
5. Notifier, dès que possible, le CÉR de tout problème constaté par un tiers au cours d'une activité de surveillance ou de vérification, interne ou externe, qui est susceptible de remettre en question l'intégrité ou l'éthicité du projet ainsi que la décision du CÉR ;
6. Notifier, dès que possible, le CÉR de l'interruption prématurée, temporaire ou définitive du projet. Cette modification doit être accompagnée d'un rapport faisant état des motifs à la base de cette interruption et des répercussions sur celles-ci sur les sujets de recherche ;
7. Fournir annuellement au CÉR un rapport d'étape l'informant de l'avancement des travaux de recherche (formulaire R) ;
8. Demander le renouvellement annuel de son certificat d'éthique ;
9. Tenir et conserver, selon la procédure prévue dans la *Politique portant sur la conservation d'une liste des sujets de recherche*, incluse dans le cadre réglementaire des établissements du CRIR, une liste des personnes qui ont accepté de prendre part à la présente étude ;
10. Envoyer au CÉR une copie de son rapport de fin de projet / publication ;
11. En vertu de l'article 19.2 de la *Loi sur les services de santé et les services sociaux*, obtenir l'autorisation du Directeur des services professionnels de l'établissement sollicité avant d'aller consulter les dossiers des usagers de cet établissement, le cas échéant.

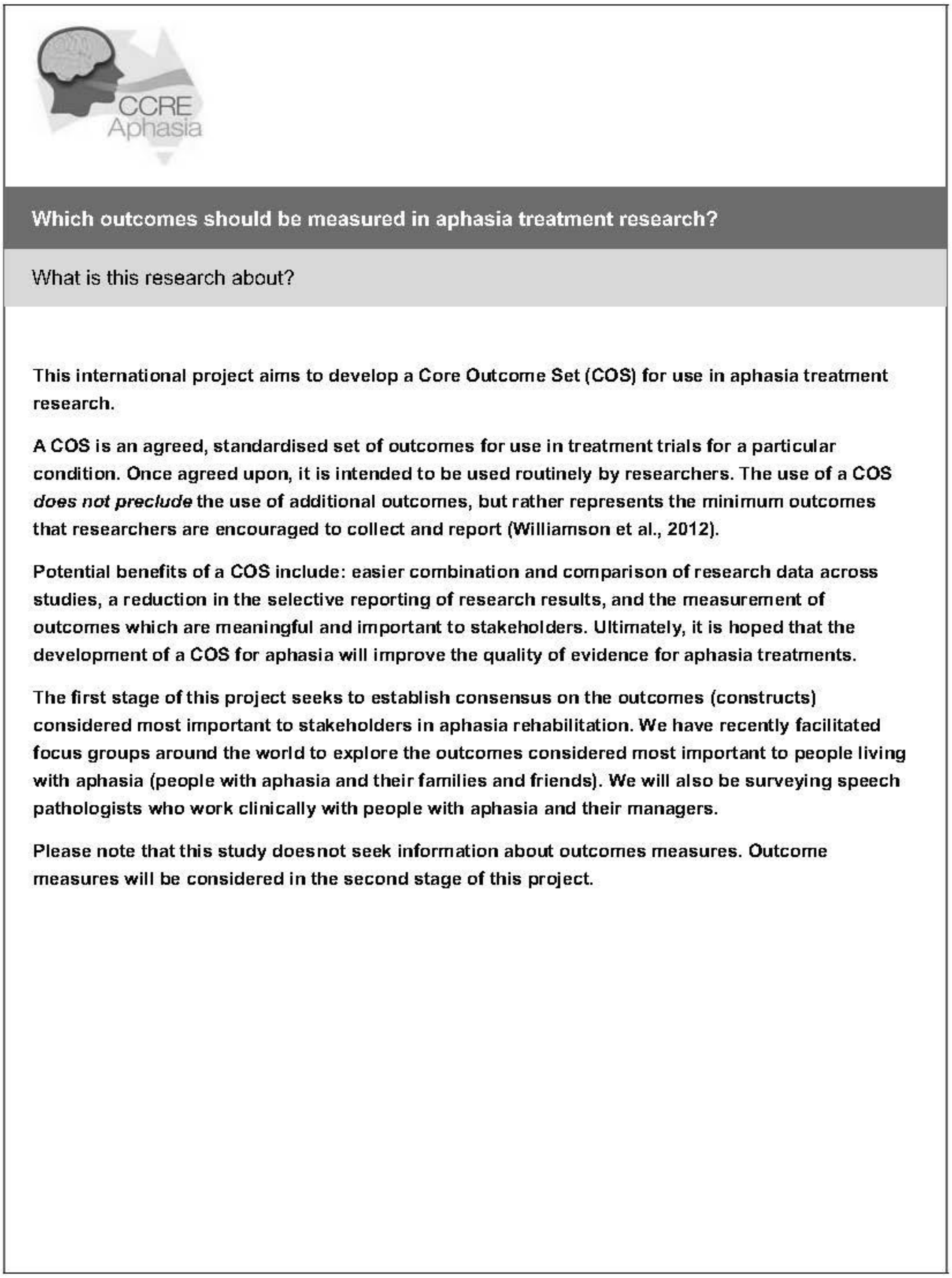
Michel T. Giroux

Me Michel T. Giroux
Président du CÉR

Date d'émission
8 novembre 2013

Appendix B: Study 2 e-Delphi Survey

Chapter 4: Core outcomes in aphasia treatment research: An e-Delphi consensus study of international aphasia researchers. Example of round 1 e-Delphi survey.



Which outcomes should be measured in aphasia treatment research?

What is this research about?

This international project aims to develop a Core Outcome Set (COS) for use in aphasia treatment research.

A COS is an agreed, standardised set of outcomes for use in treatment trials for a particular condition. Once agreed upon, it is intended to be used routinely by researchers. The use of a COS *does not preclude* the use of additional outcomes, but rather represents the minimum outcomes that researchers are encouraged to collect and report (Williamson et al., 2012).

Potential benefits of a COS include: easier combination and comparison of research data across studies, a reduction in the selective reporting of research results, and the measurement of outcomes which are meaningful and important to stakeholders. Ultimately, it is hoped that the development of a COS for aphasia will improve the quality of evidence for aphasia treatments.

The first stage of this project seeks to establish consensus on the outcomes (constructs) considered most important to stakeholders in aphasia rehabilitation. We have recently facilitated focus groups around the world to explore the outcomes considered most important to people living with aphasia (people with aphasia and their families and friends). We will also be surveying speech pathologists who work clinically with people with aphasia and their managers.

Please note that this study doesnot seek information about outcomes measures. Outcome measures will be considered in the second stage of this project.

Which outcomes should be measured in aphasia treatment research?

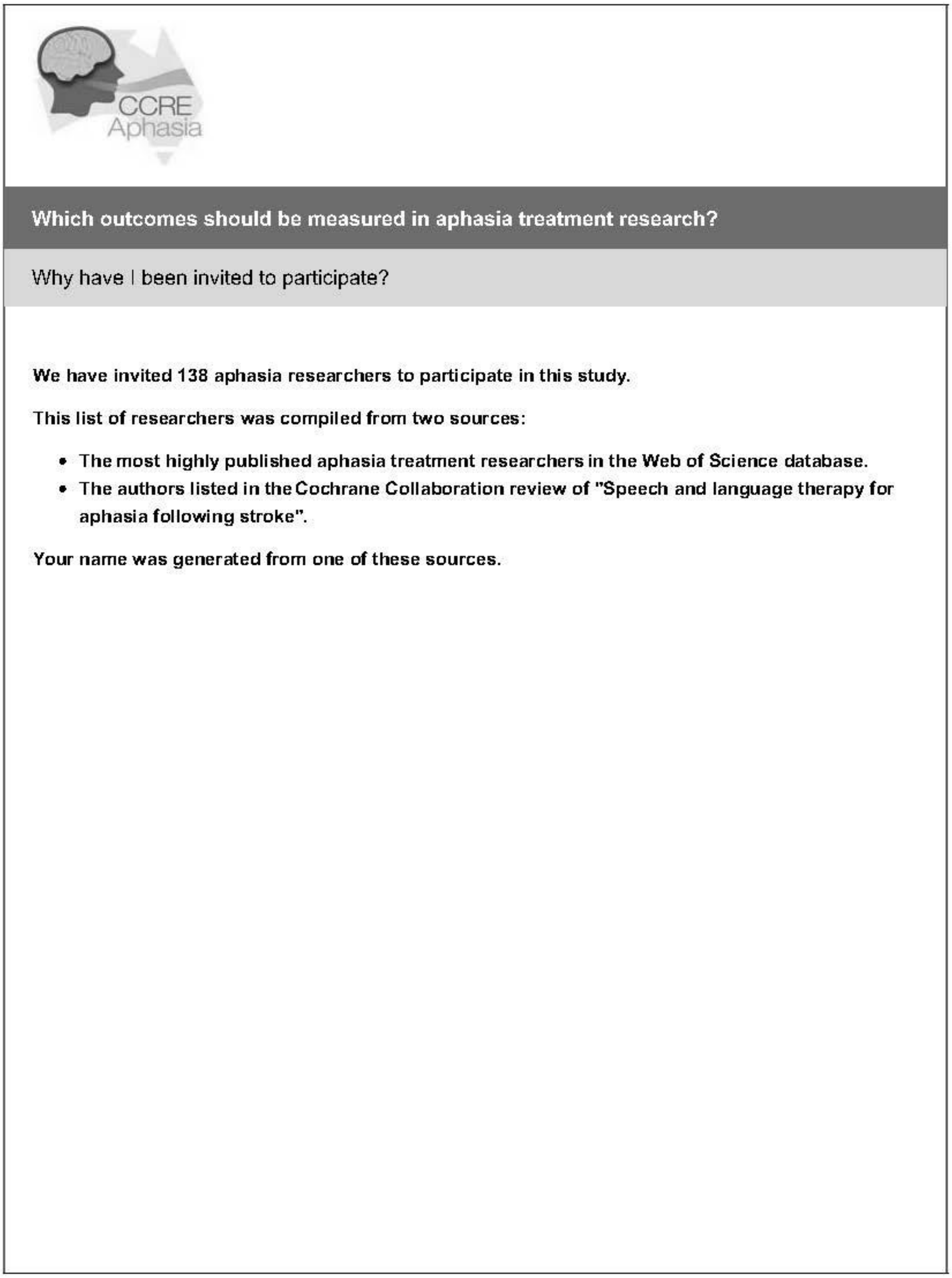
Who are the investigators?

Chief Investigator: Sarah Wallace - The University of Queensland, Australia

Co-Investigators: Professor Linda Worrall – The University of Queensland, Australia

Professor Guylaine Le Dorze – The University of Montreal, Canada

Dr Tanya Rose – The University of Queensland, Australia



Which outcomes should be measured in aphasia treatment research?

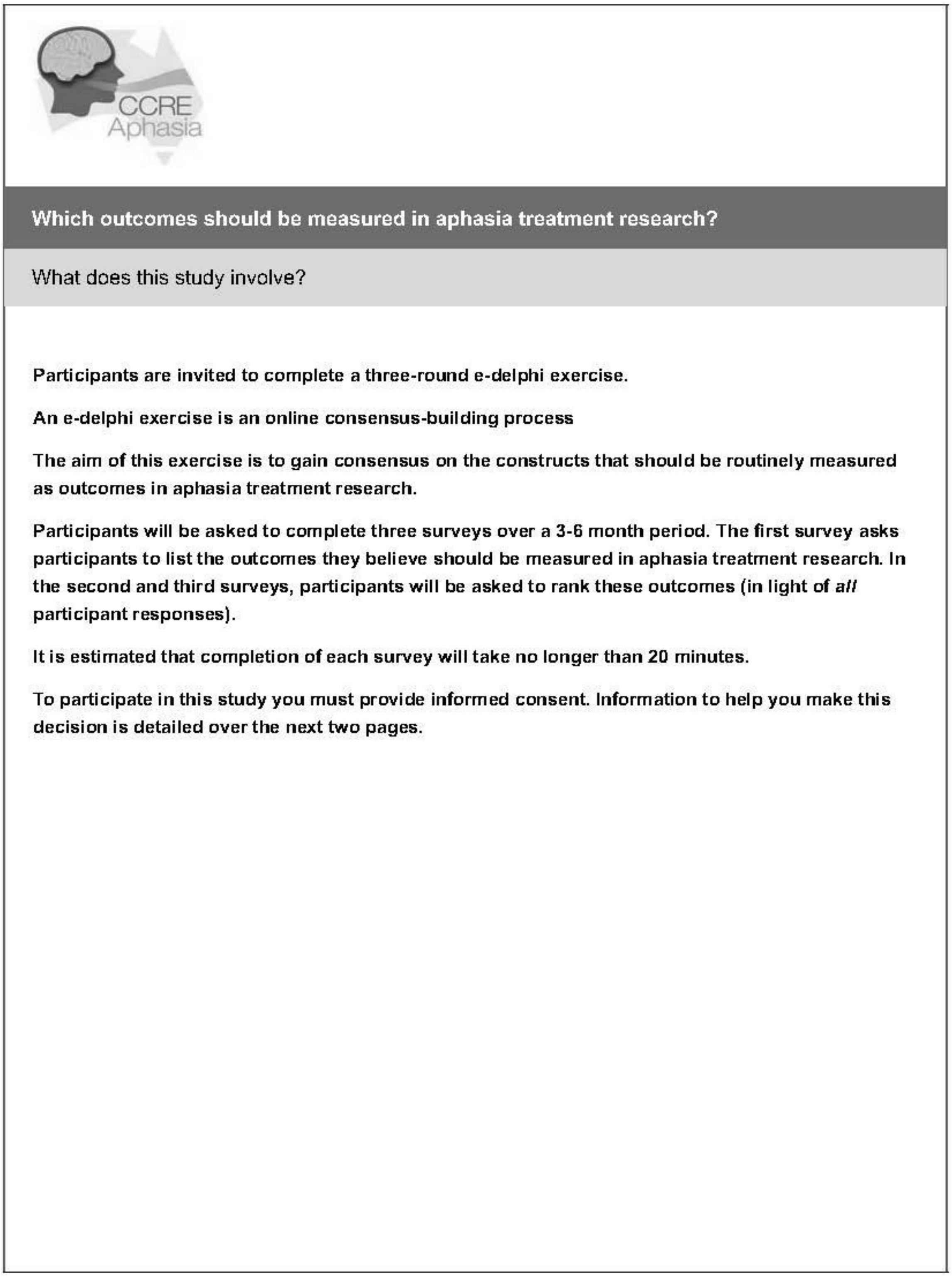
Why have I been invited to participate?

We have invited 138 aphasia researchers to participate in this study.

This list of researchers was compiled from two sources:

- **The most highly published aphasia treatment researchers in the Web of Science database.**
- **The authors listed in the Cochrane Collaboration review of "Speech and language therapy for aphasia following stroke".**

Your name was generated from one of these sources.



Which outcomes should be measured in aphasia treatment research?

What does this study involve?

Participants are invited to complete a three-round e-delphi exercise.

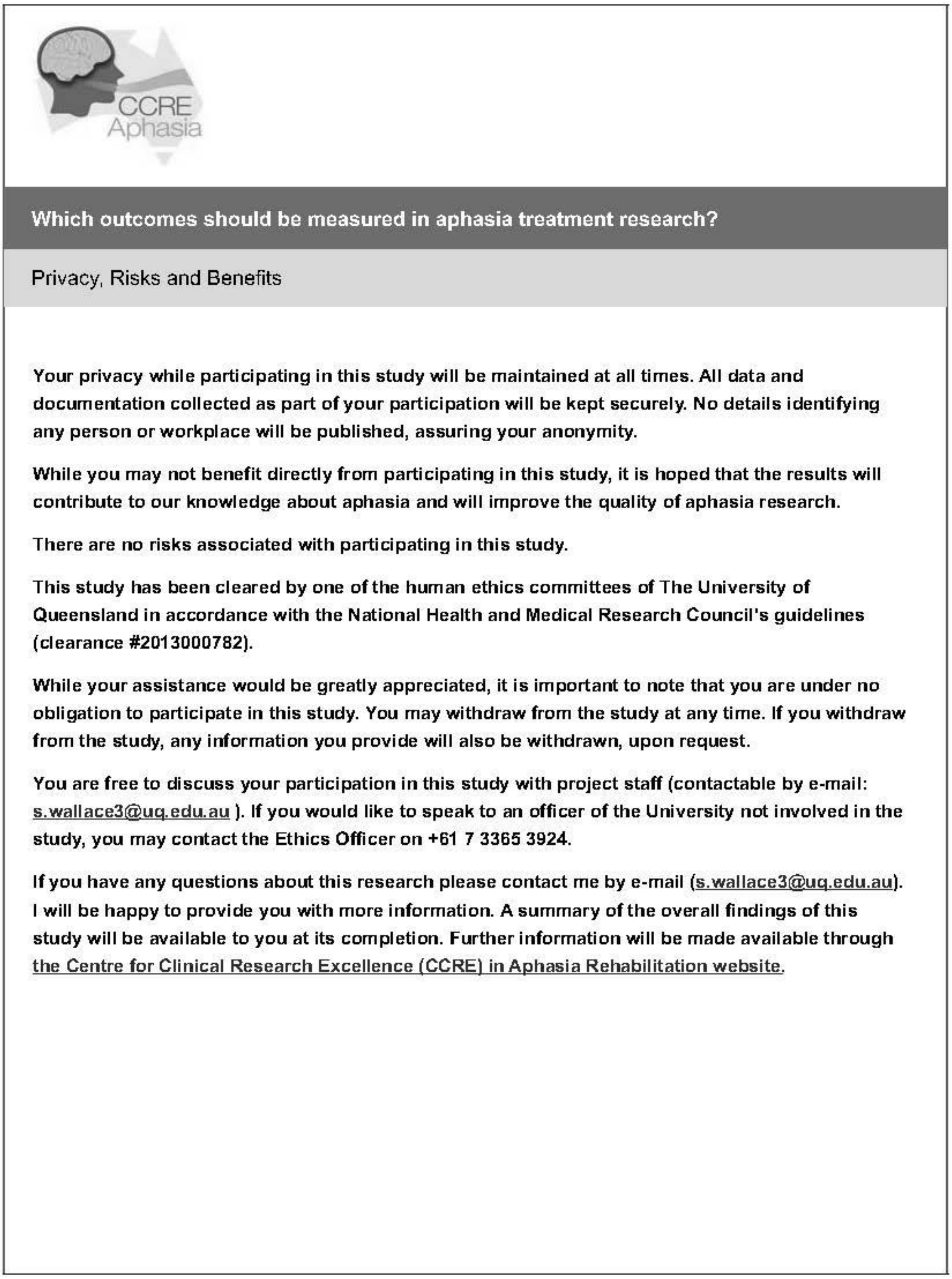
An e-delphi exercise is an online consensus-building process

The aim of this exercise is to gain consensus on the constructs that should be routinely measured as outcomes in aphasia treatment research.

Participants will be asked to complete three surveys over a 3-6 month period. The first survey asks participants to list the outcomes they believe should be measured in aphasia treatment research. In the second and third surveys, participants will be asked to rank these outcomes (in light of *all* participant responses).

It is estimated that completion of each survey will take no longer than 20 minutes.

To participate in this study you must provide informed consent. Information to help you make this decision is detailed over the next two pages.



CCRE Aphasia

Which outcomes should be measured in aphasia treatment research?

Privacy, Risks and Benefits

Your privacy while participating in this study will be maintained at all times. All data and documentation collected as part of your participation will be kept securely. No details identifying any person or workplace will be published, assuring your anonymity.

While you may not benefit directly from participating in this study, it is hoped that the results will contribute to our knowledge about aphasia and will improve the quality of aphasia research.

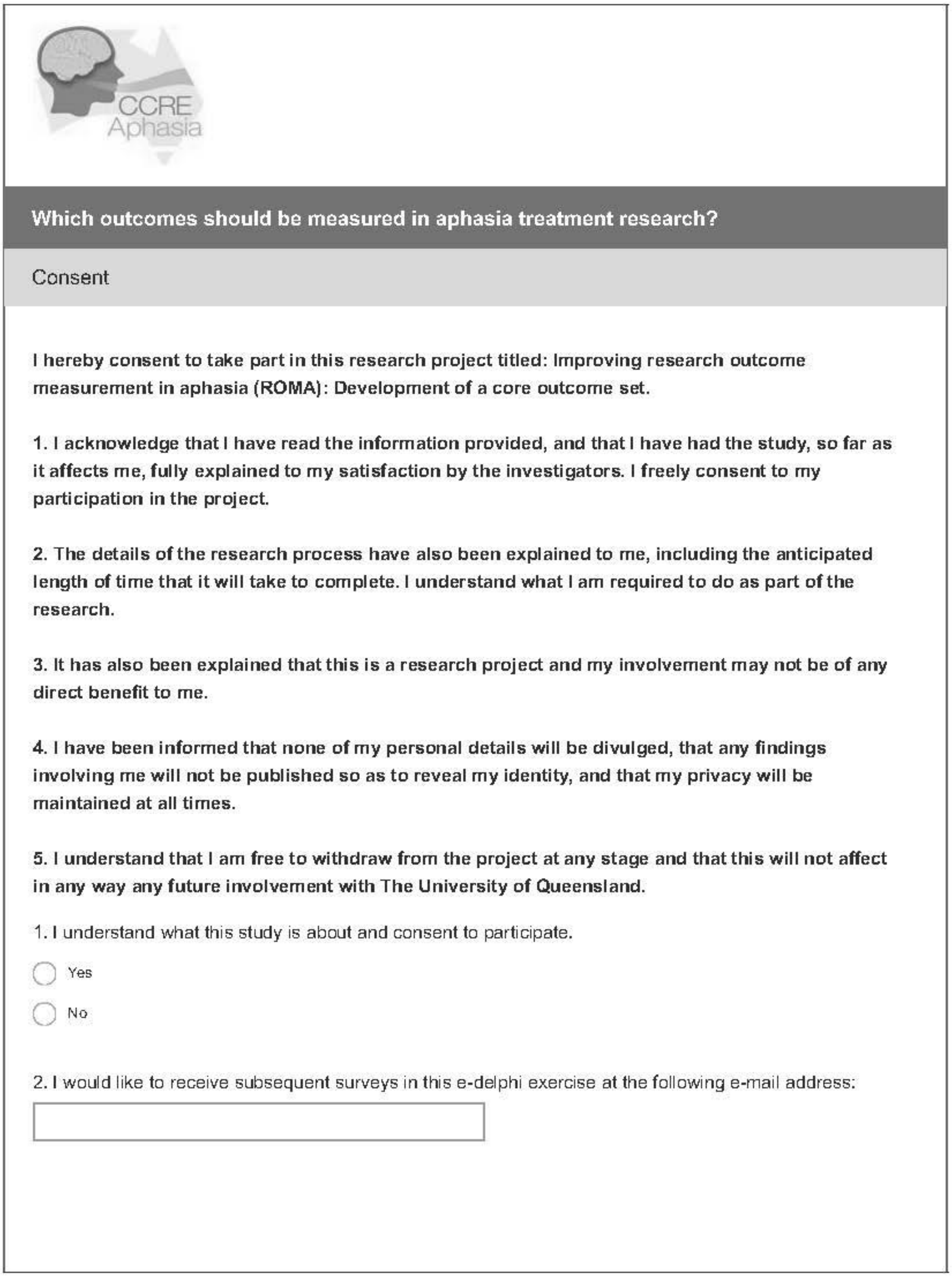
There are no risks associated with participating in this study.

This study has been cleared by one of the human ethics committees of The University of Queensland in accordance with the National Health and Medical Research Council's guidelines (clearance #2013000782).

While your assistance would be greatly appreciated, it is important to note that you are under no obligation to participate in this study. You may withdraw from the study at any time. If you withdraw from the study, any information you provide will also be withdrawn, upon request.

You are free to discuss your participation in this study with project staff (contactable by e-mail: s.wallace3@uq.edu.au). If you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Officer on +61 7 3365 3924.

If you have any questions about this research please contact me by e-mail (s.wallace3@uq.edu.au). I will be happy to provide you with more information. A summary of the overall findings of this study will be available to you at its completion. Further information will be made available through the Centre for Clinical Research Excellence (CCRE) in Aphasia Rehabilitation website.



Which outcomes should be measured in aphasia treatment research?

Consent

I hereby consent to take part in this research project titled: Improving research outcome measurement in aphasia (ROMA): Development of a core outcome set.

1. I acknowledge that I have read the information provided, and that I have had the study, so far as it affects me, fully explained to my satisfaction by the investigators. I freely consent to my participation in the project.

2. The details of the research process have also been explained to me, including the anticipated length of time that it will take to complete. I understand what I am required to do as part of the research.

3. It has also been explained that this is a research project and my involvement may not be of any direct benefit to me.

4. I have been informed that none of my personal details will be divulged, that any findings involving me will not be published so as to reveal my identity, and that my privacy will be maintained at all times.

5. I understand that I am free to withdraw from the project at any stage and that this will not affect in any way any future involvement with The University of Queensland.

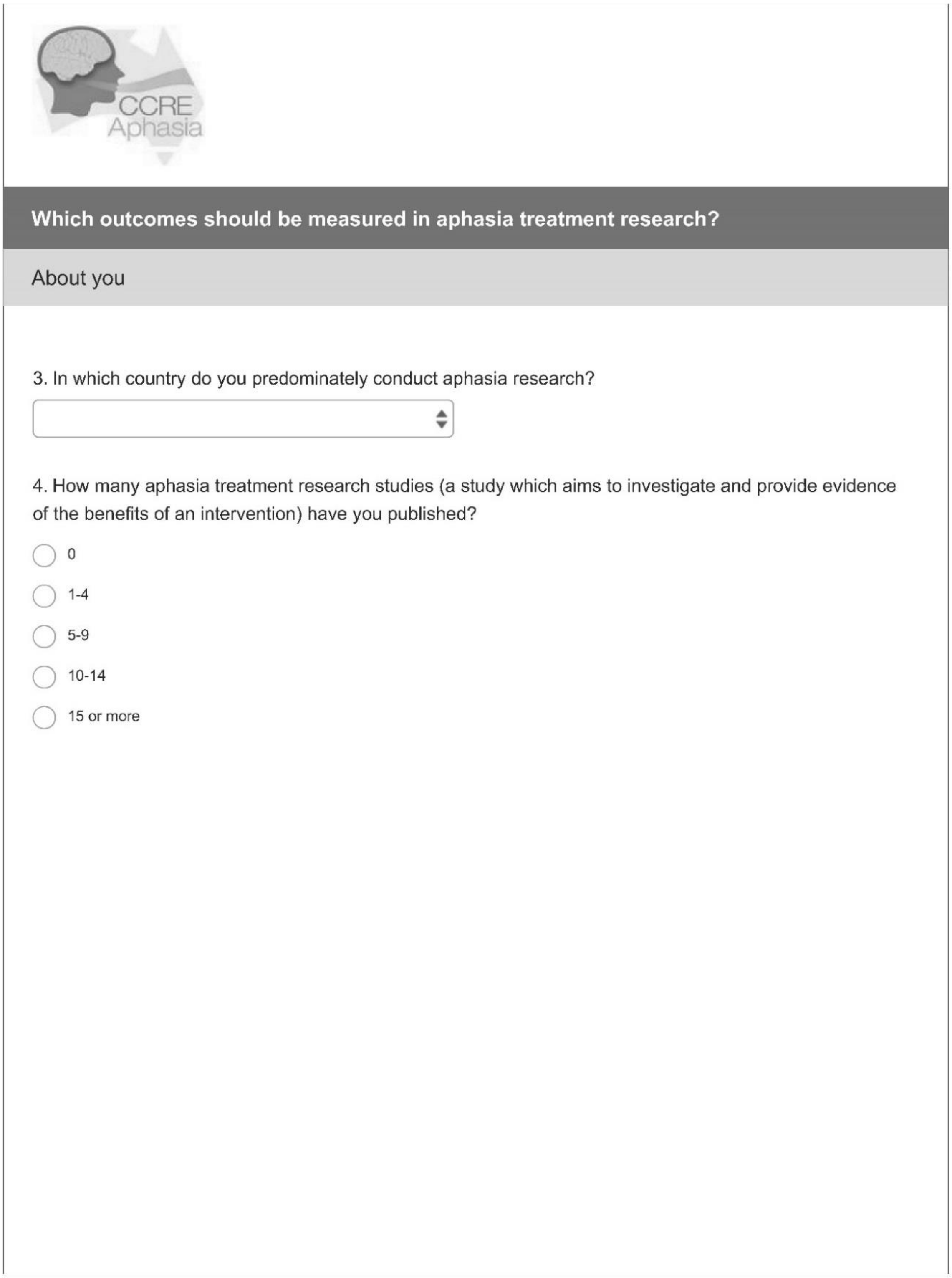
1. I understand what this study is about and consent to participate.

○ Yes

○ No

2. I would like to receive subsequent surveys in this e-delphi exercise at the following e-mail address:

☐



Which outcomes should be measured in aphasia treatment research?

About you

3. In which country do you predominately conduct aphasia research?

4. How many aphasia treatment research studies (a study which aims to investigate and provide evidence of the benefits of an intervention) have you published?

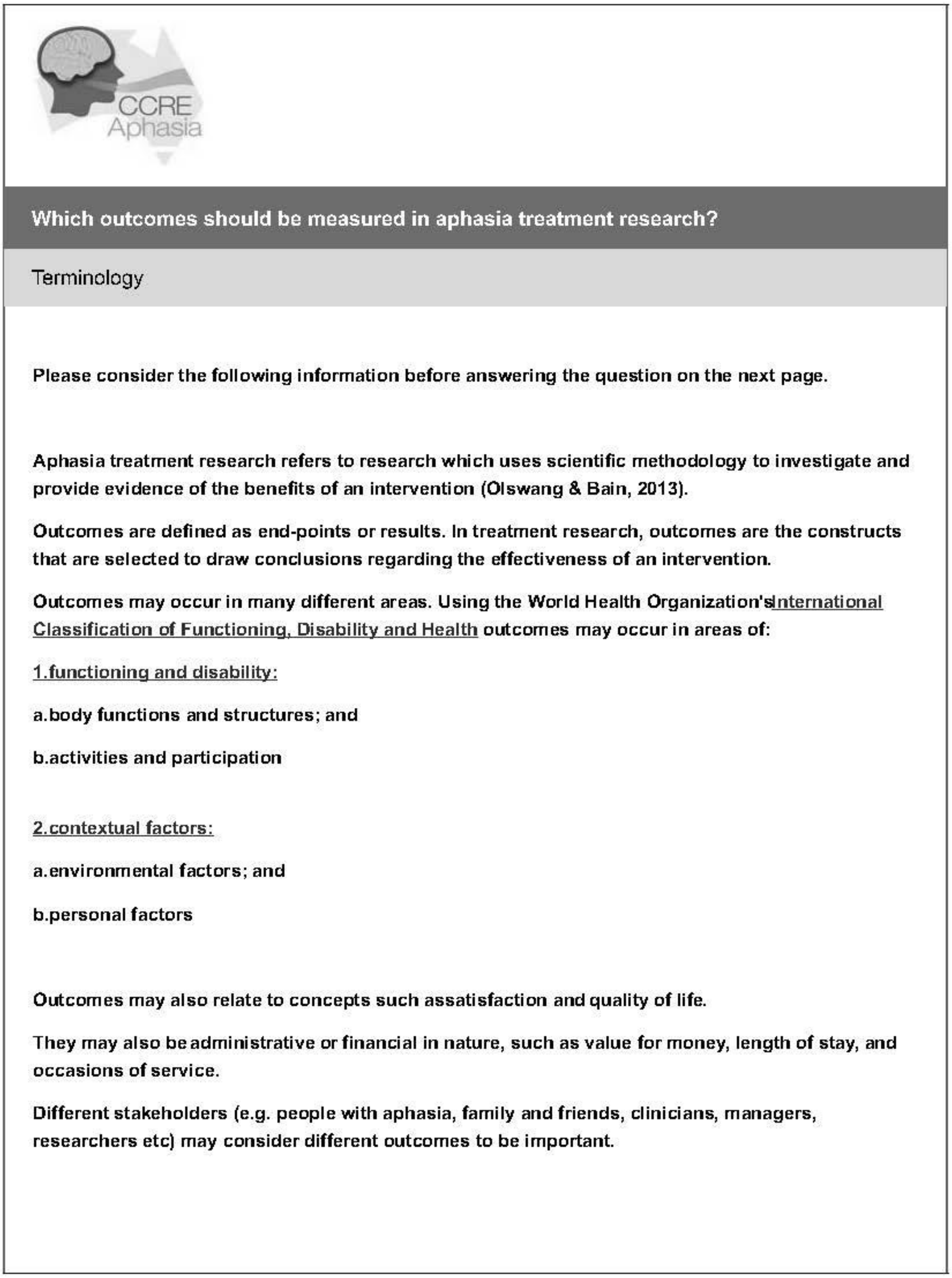
○ 0

○ 1-4

○ 5-9

○ 10-14

○ 15 or more



Which outcomes should be measured in aphasia treatment research?

Terminology

Please consider the following information before answering the question on the next page.

Aphasia treatment research refers to research which uses scientific methodology to investigate and provide evidence of the benefits of an intervention (Olswang & Bain, 2013).

Outcomes are defined as end-points or results. In treatment research, outcomes are the constructs that are selected to draw conclusions regarding the effectiveness of an intervention.

Outcomes may occur in many different areas. Using the World Health Organization'sInternational Classification of Functioning, Disability and Health outcomes may occur in areas of:

1.functioning and disability:

a.body functions and structures; and

b.activities and participation

2.contextual factors:

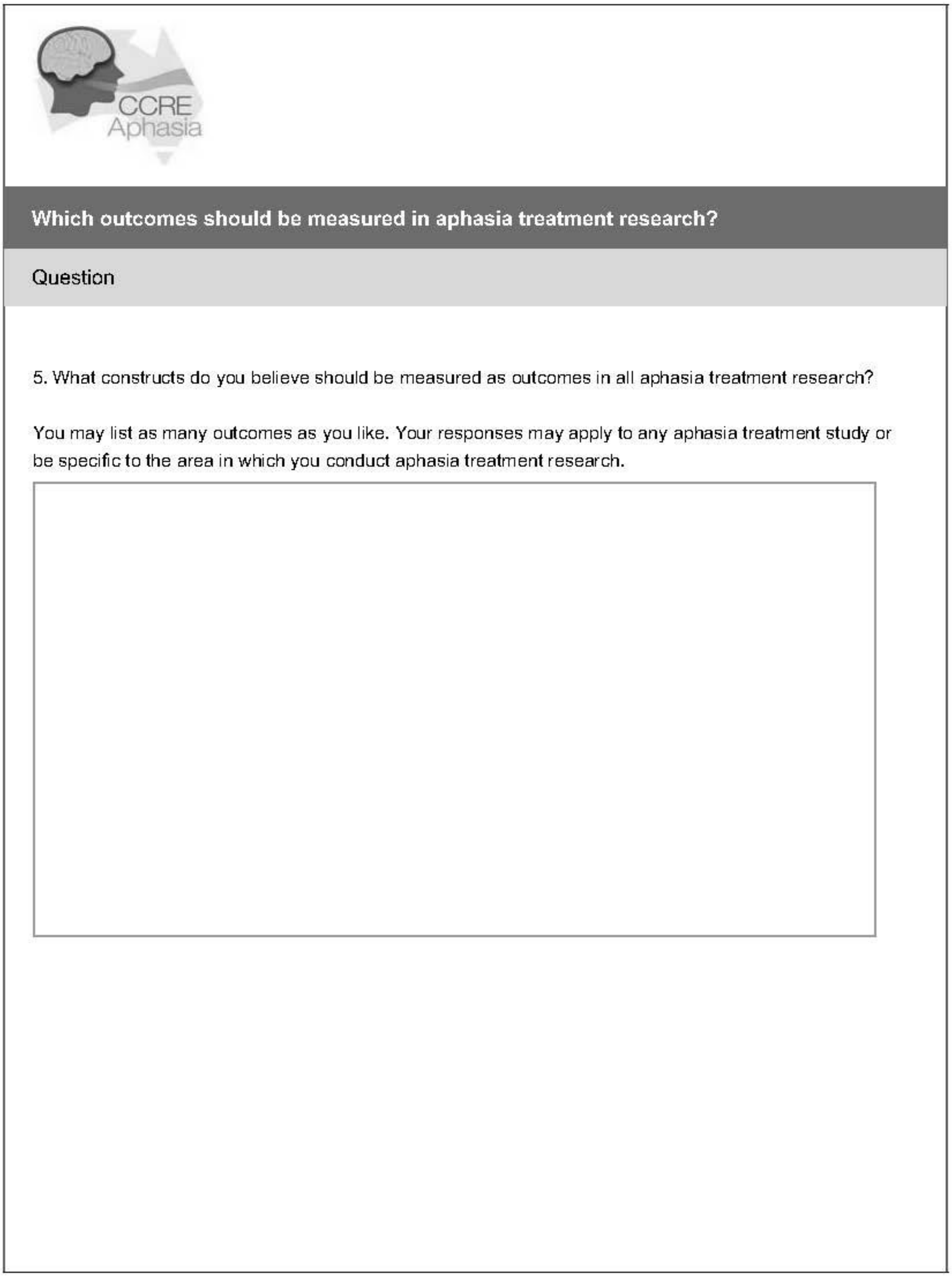
a.environmental factors; and

b.personal factors

Outcomes may also relate to concepts such assatisfaction and quality of life.

They may also be administrative or financial in nature, such as value for money, length of stay, and occasions of service.

Different stakeholders (e.g. people with aphasia, family and friends, clinicians, managers, researchers etc) may consider different outcomes to be important.

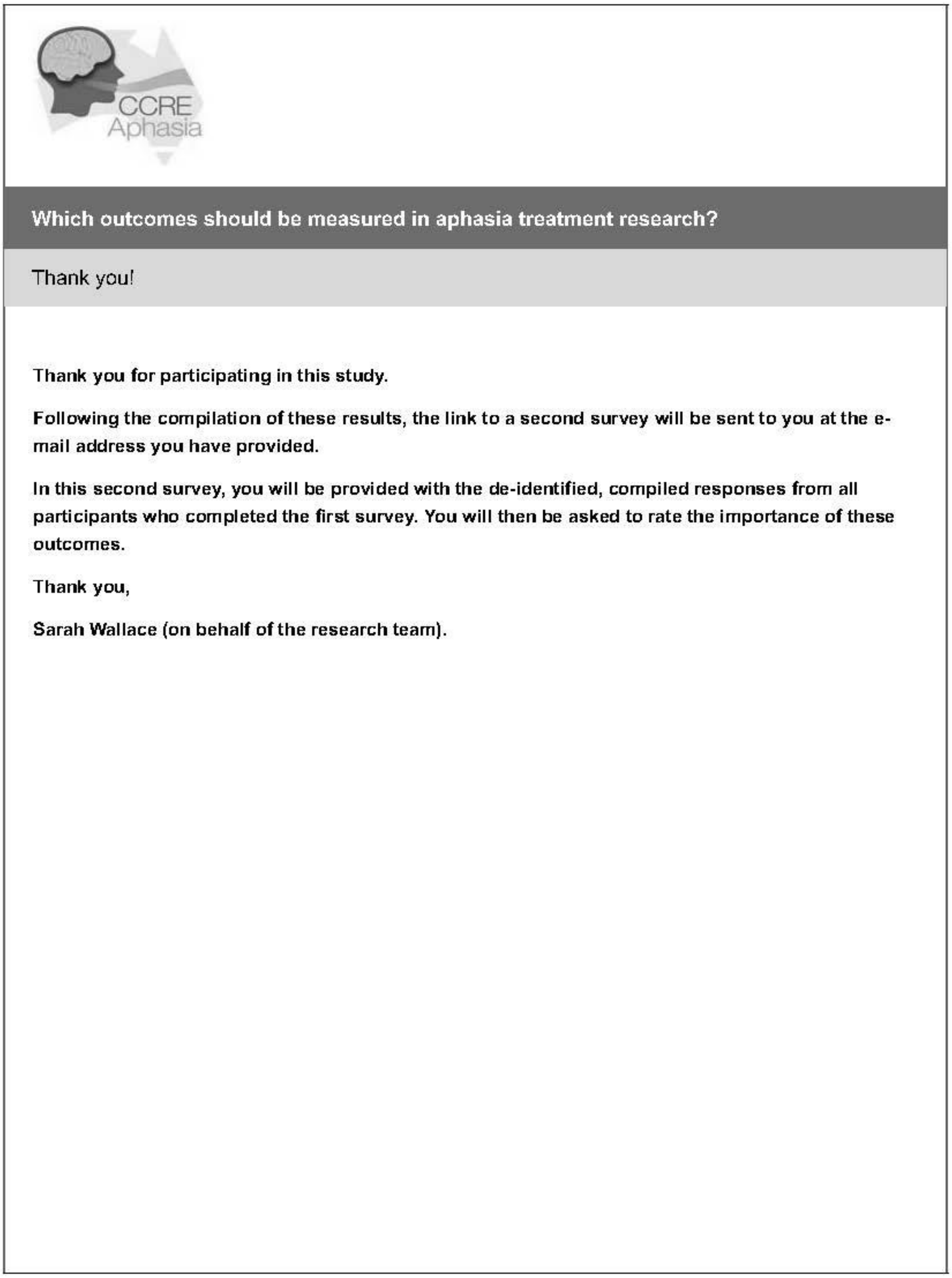


Which outcomes should be measured in aphasia treatment research?

Question

5. What constructs do you believe should be measured as outcomes in all aphasia treatment research?

You may list as many outcomes as you like. Your responses may apply to any aphasia treatment study or be specific to the area in which you conduct aphasia treatment research.



Which outcomes should be measured in aphasia treatment research?

Thank you!

Thank you for participating in this study.

Following the compilation of these results, the link to a second survey will be sent to you at the e-mail address you have provided.

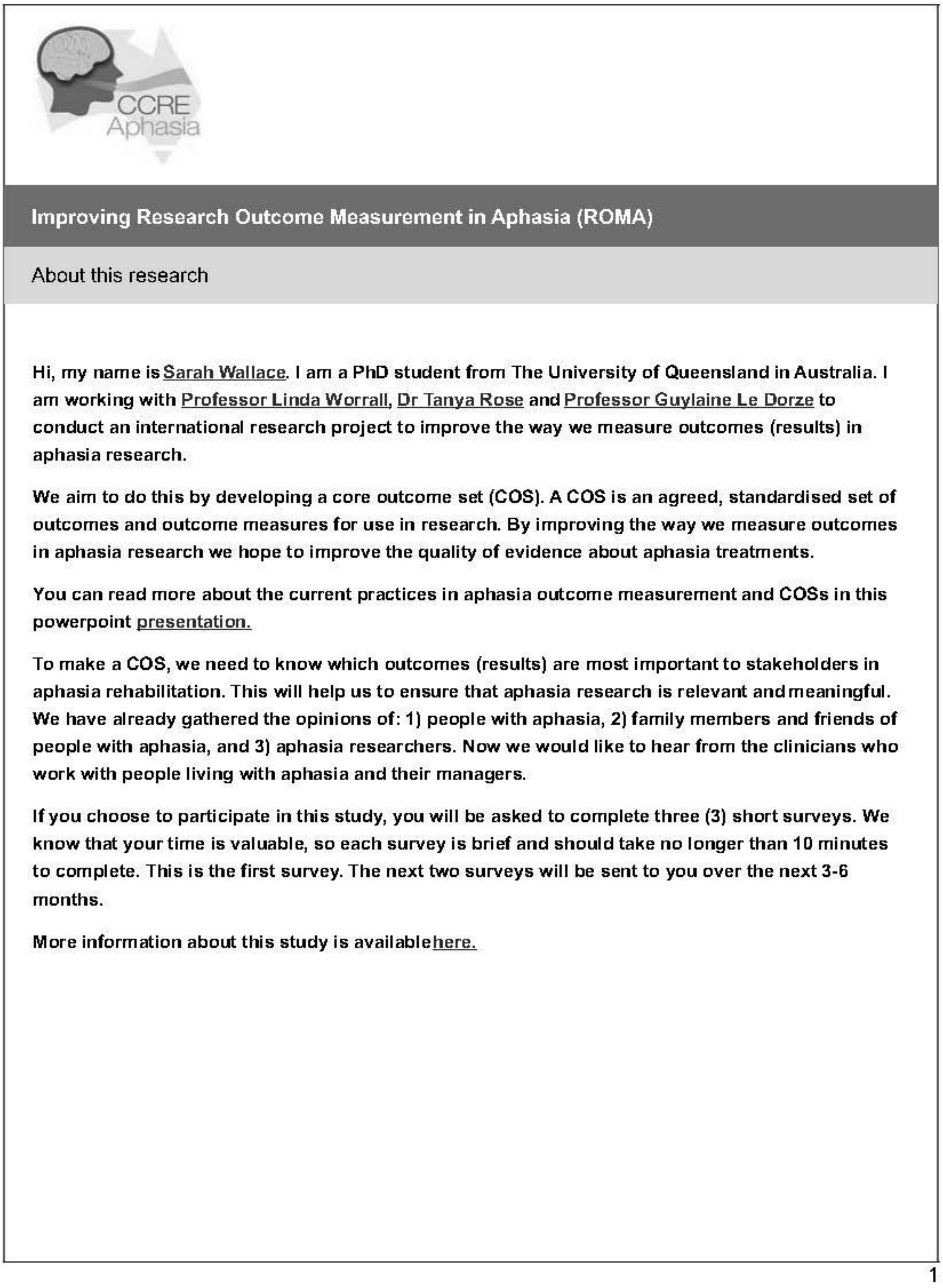
In this second survey, you will be provided with the de-identified, compiled responses from all participants who completed the first survey. You will then be asked to rate the importance of these outcomes.

Thank you,

Sarah Wallace (on behalf of the research team).

Appendix C: Study 3 e-Delphi Survey

Chapter 5: Which Treatment Outcomes are Most Important to Aphasia Clinicians and Managers? An International e-Delphi Consensus Study. Example of round 1 e-Delphi survey.



CCRE Aphasia

Improving Research Outcome Measurement in Aphasia (ROMA)

About this research

Hi, my name is Sarah Wallace. I am a PhD student from The University of Queensland in Australia. I am working with Professor Linda Worrall, Dr Tanya Rose and Professor Guylaine Le Dorze to conduct an international research project to improve the way we measure outcomes (results) in aphasia research.

We aim to do this by developing a core outcome set (COS). A COS is an agreed, standardised set of outcomes and outcome measures for use in research. By improving the way we measure outcomes in aphasia research we hope to improve the quality of evidence about aphasia treatments.

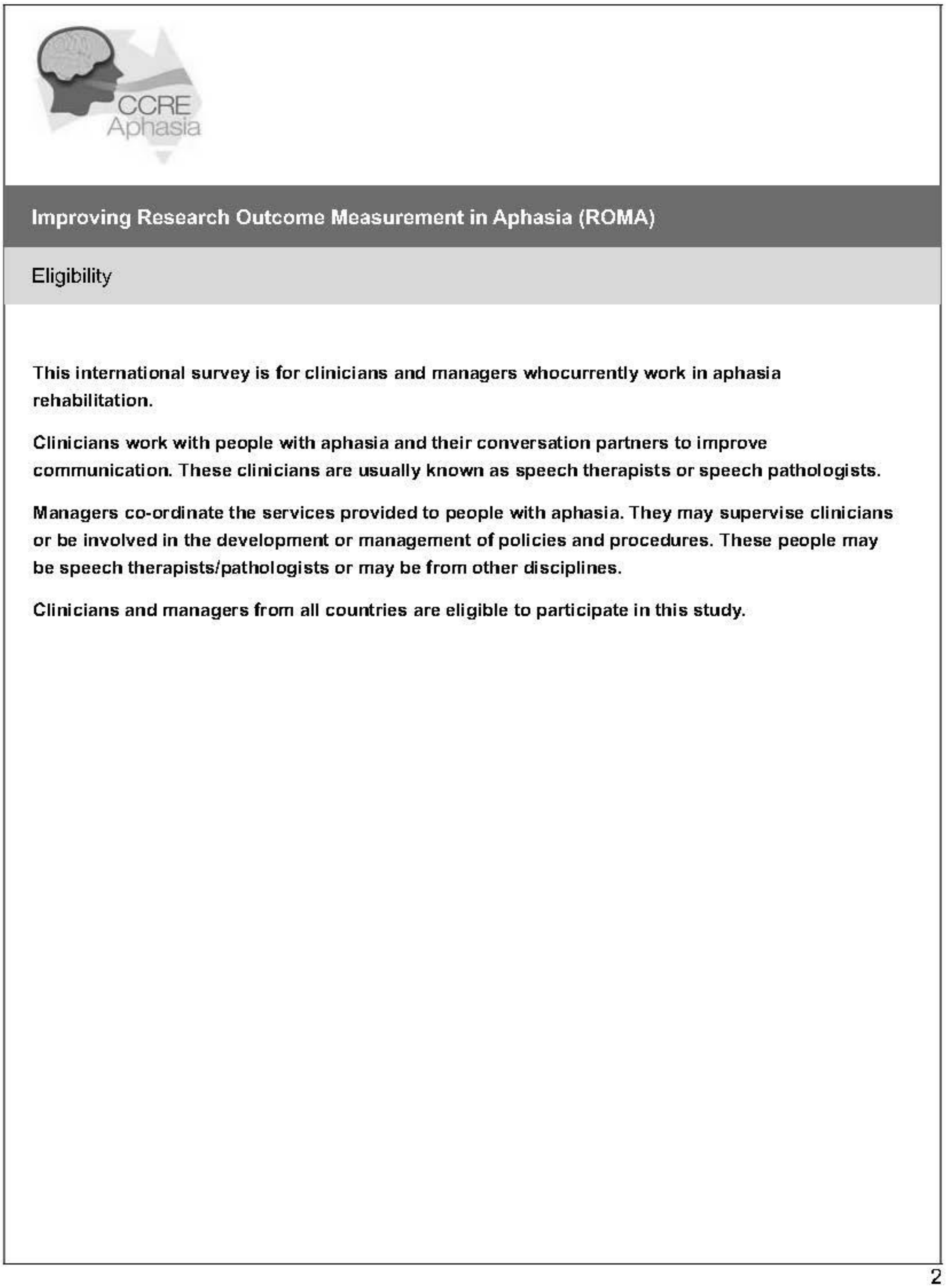
You can read more about the current practices in aphasia outcome measurement and COSs in this powerpoint presentation.

To make a COS, we need to know which outcomes (results) are most important to stakeholders in aphasia rehabilitation. This will help us to ensure that aphasia research is relevant and meaningful. We have already gathered the opinions of: 1) people with aphasia, 2) family members and friends of people with aphasia, and 3) aphasia researchers. Now we would like to hear from the clinicians who work with people living with aphasia and their managers.

If you choose to participate in this study, you will be asked to complete three (3) short surveys. We know that your time is valuable, so each survey is brief and should take no longer than 10 minutes to complete. This is the first survey. The next two surveys will be sent to you over the next 3-6 months.

More information about this study is available here.

1



CCRE Aphasia

Improving Research Outcome Measurement in Aphasia (ROMA)

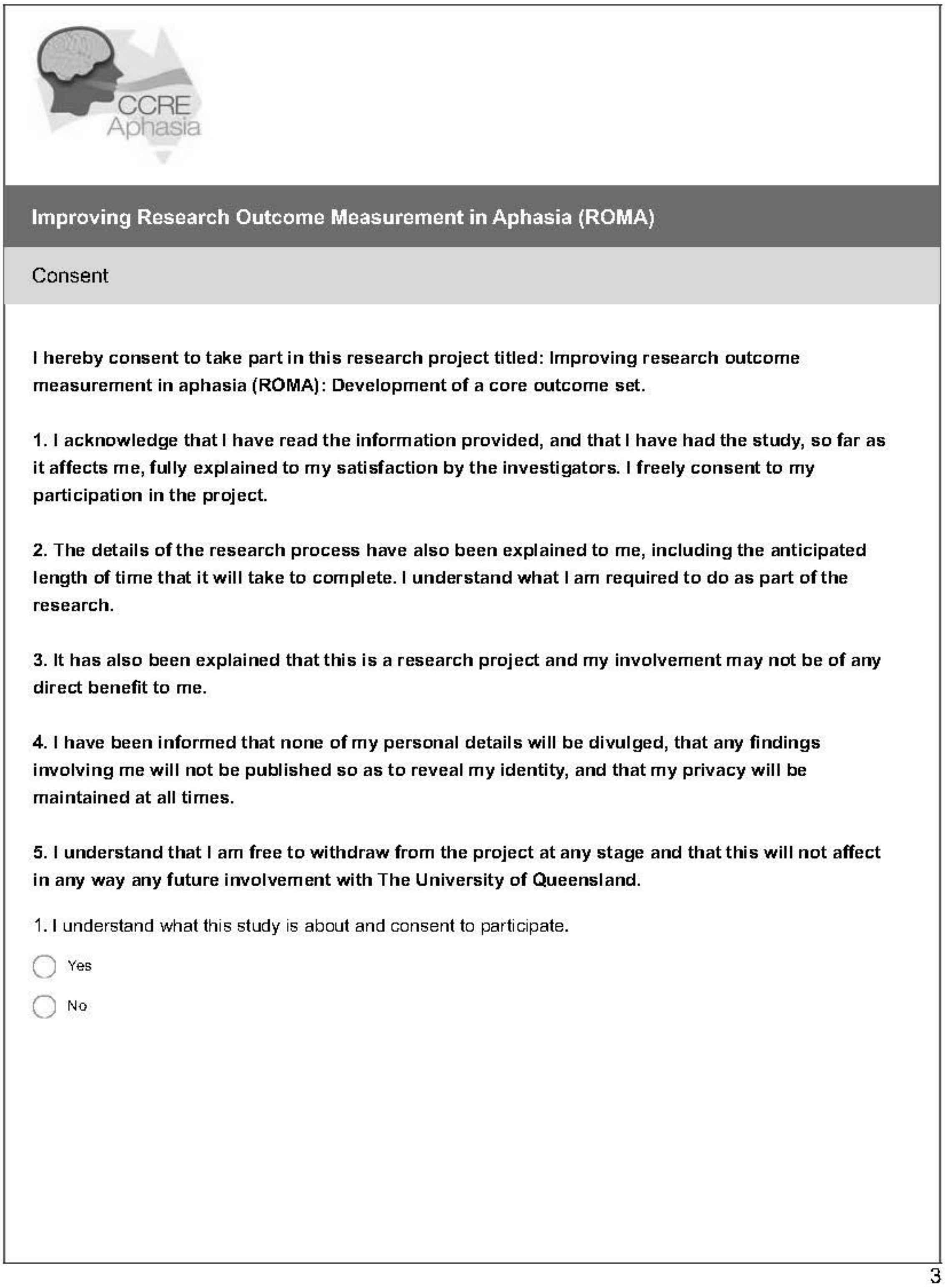
Eligibility

This international survey is for clinicians and managers whocurrently work in aphasia rehabilitation.

Clinicians work with people with aphasia and their conversation partners to improve communication. These clinicians are usually known as speech therapists or speech pathologists.

Managers co-ordinate the services provided to people with aphasia. They may supervise clinicians or be involved in the development or management of policies and procedures. These people may be speech therapists/pathologists or may be from other disciplines.

Clinicians and managers from all countries are eligible to participate in this study.



Improving Research Outcome Measurement in Aphasia (ROMA)

Consent

I hereby consent to take part in this research project titled: Improving research outcome measurement in aphasia (ROMA): Development of a core outcome set.

1. I acknowledge that I have read the information provided, and that I have had the study, so far as it affects me, fully explained to my satisfaction by the investigators. I freely consent to my participation in the project.

2. The details of the research process have also been explained to me, including the anticipated length of time that it will take to complete. I understand what I am required to do as part of the research.

3. It has also been explained that this is a research project and my involvement may not be of any direct benefit to me.

4. I have been informed that none of my personal details will be divulged, that any findings involving me will not be published so as to reveal my identity, and that my privacy will be maintained at all times.

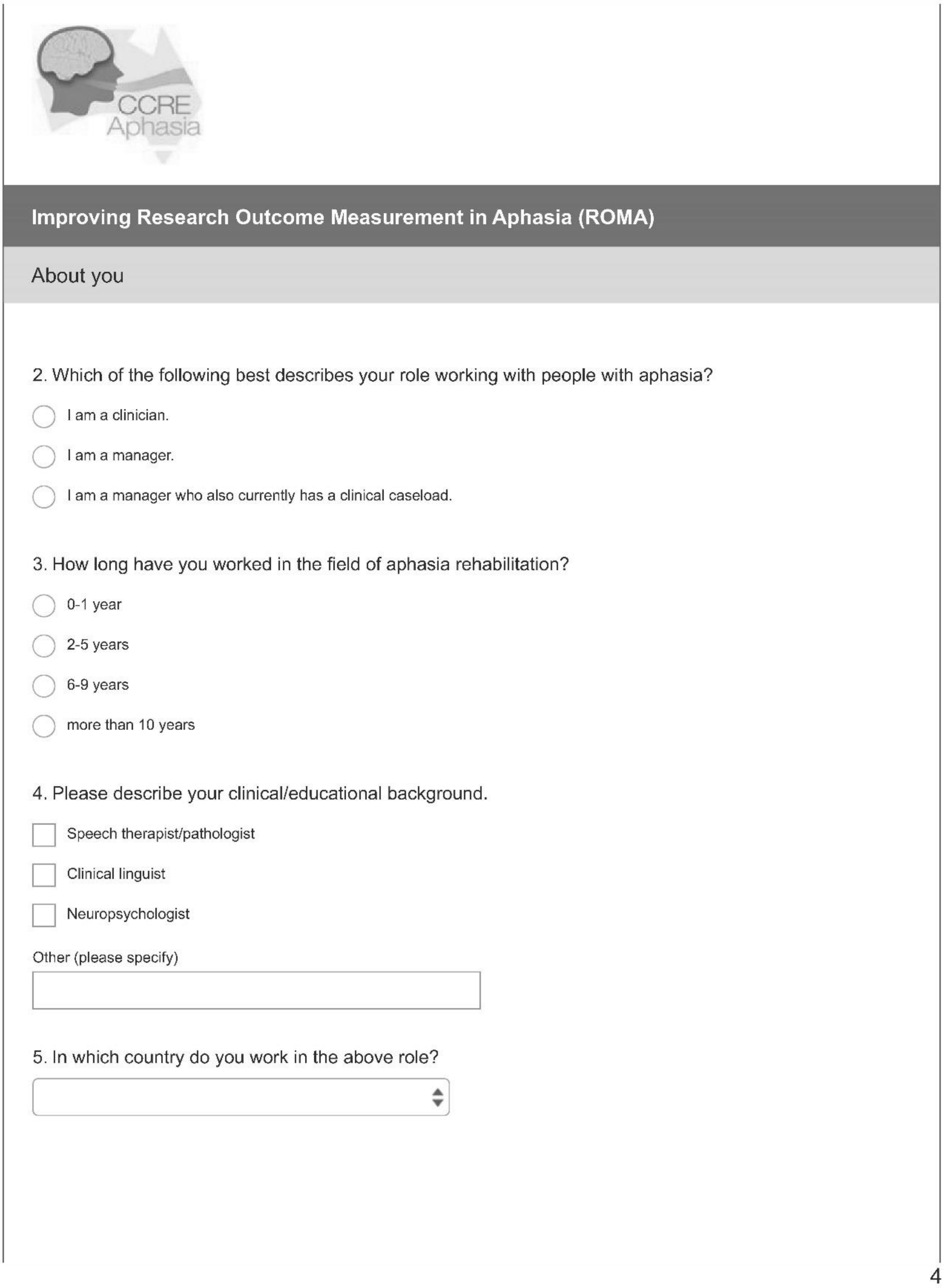
5. I understand that I am free to withdraw from the project at any stage and that this will not affect in any way any future involvement with The University of Queensland.

1. I understand what this study is about and consent to participate.

○ Yes

○ No

3



CCRE
Aphasia

Improving Research Outcome Measurement in Aphasia (ROMA)

About you

2. Which of the following best describes your role working with people with aphasia?

○ I am a clinician.

○ I am a manager.

○ I am a manager who also currently has a clinical caseload.

3. How long have you worked in the field of aphasia rehabilitation?

○ 0-1 year

○ 2-5 years

○ 6-9 years

○ more than 10 years

4. Please describe your clinical/educational background.

☐ Speech therapist/pathologist

☐ Clinical linguist

☐ Neuropsychologist

Other (please specify)

5. In which country do you work in the above role?

4

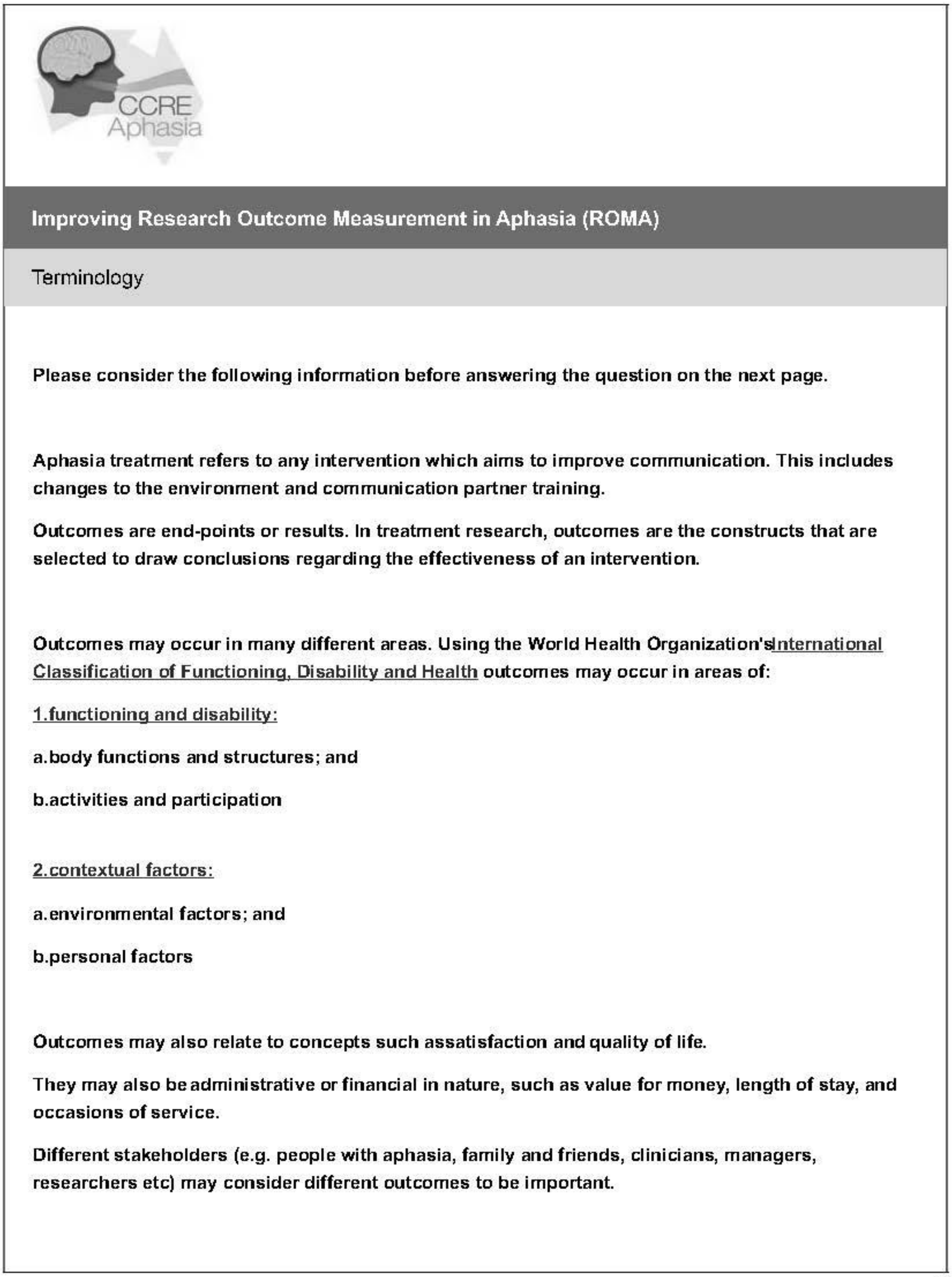
6. How far post-onset of aphasia are your clients? (You may choose more than one answer)

☐ Less than 3 months

☐ 3-6 months

☐ 6-12 months

☐ More than 12 months



CCRE Aphasia

Improving Research Outcome Measurement in Aphasia (ROMA)

Terminology

Please consider the following information before answering the question on the next page.

Aphasia treatment refers to any intervention which aims to improve communication. This includes changes to the environment and communication partner training.

Outcomes are end-points or results. In treatment research, outcomes are the constructs that are selected to draw conclusions regarding the effectiveness of an intervention.

Outcomes may occur in many different areas. Using the World Health Organization'sInternational Classification of Functioning, Disability and Health outcomes may occur in areas of:

1.functioning and disability:

a.body functions and structures; and

b.activities and participation

2.contextual factors:

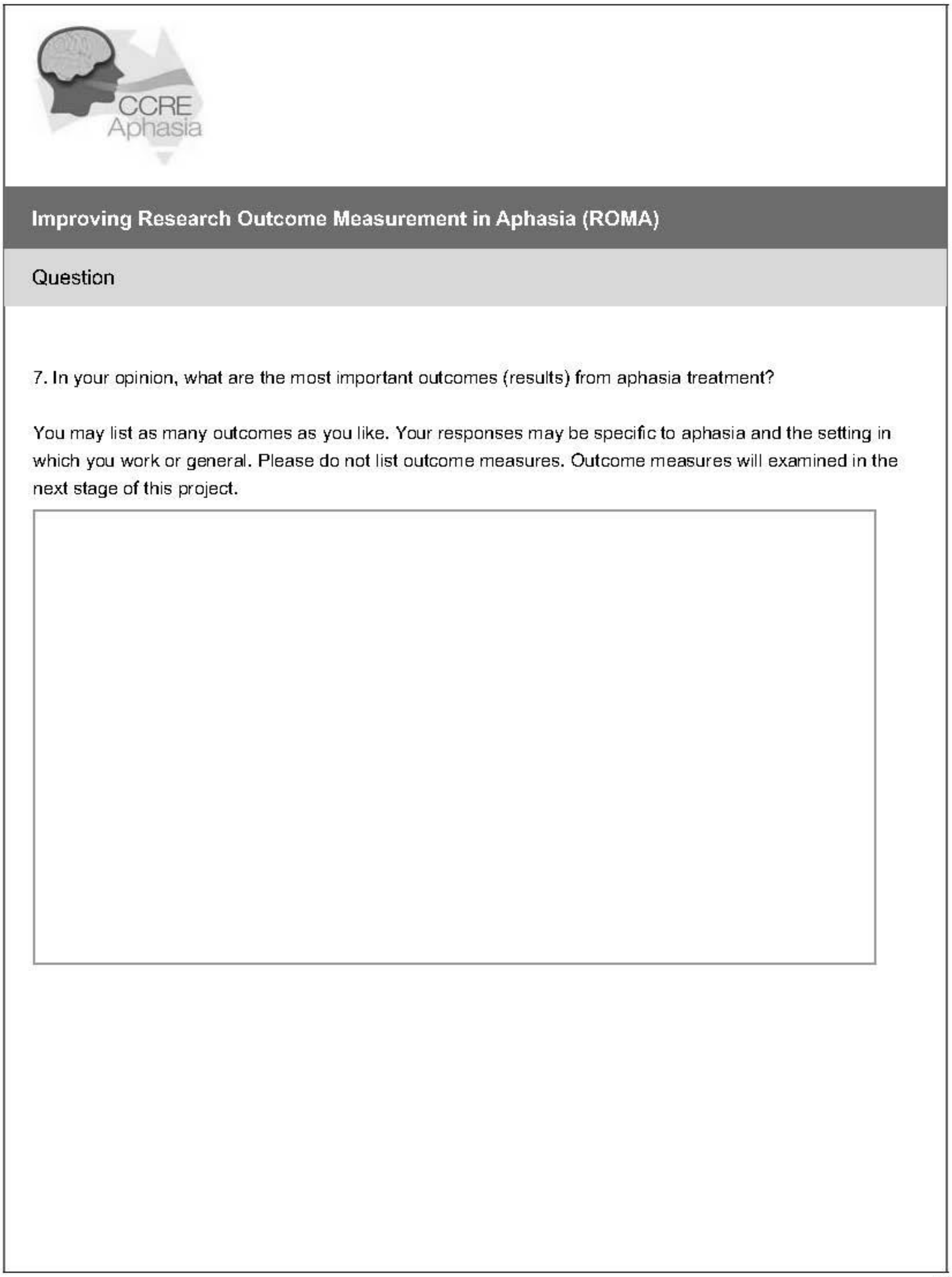
a.environmental factors; and

b.personal factors

Outcomes may also relate to concepts such assatisfaction and quality of life.

They may also be administrative or financial in nature, such as value for money, length of stay, and occasions of service.

Different stakeholders (e.g. people with aphasia, family and friends, clinicians, managers, researchers etc) may consider different outcomes to be important.

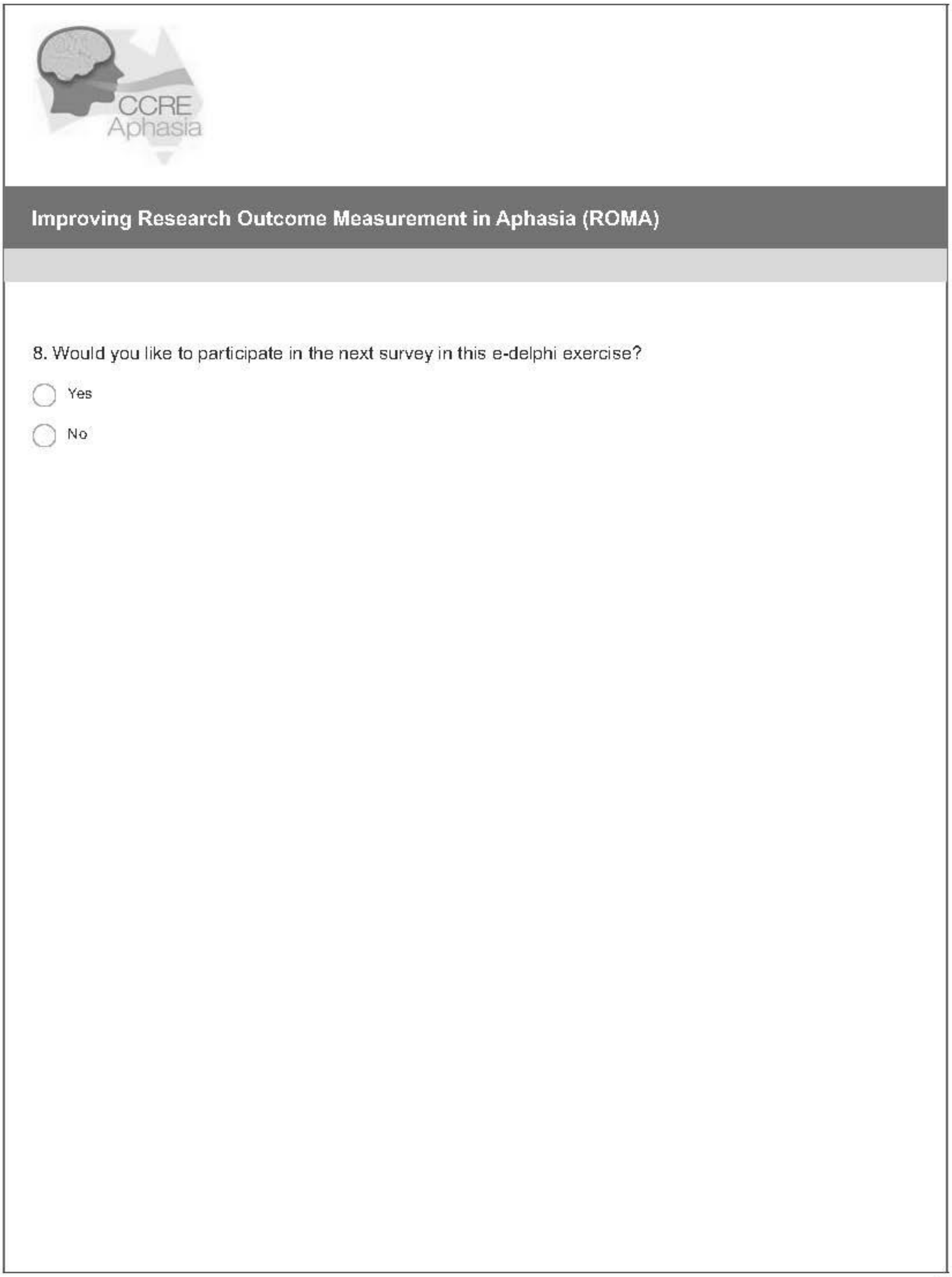


Improving Research Outcome Measurement in Aphasia (ROMA)

Question

7. In your opinion, what are the most important outcomes (results) from aphasia treatment?

You may list as many outcomes as you like. Your responses may be specific to aphasia and the setting in which you work or general. Please do not list outcome measures. Outcome measures will examined in the next stage of this project.

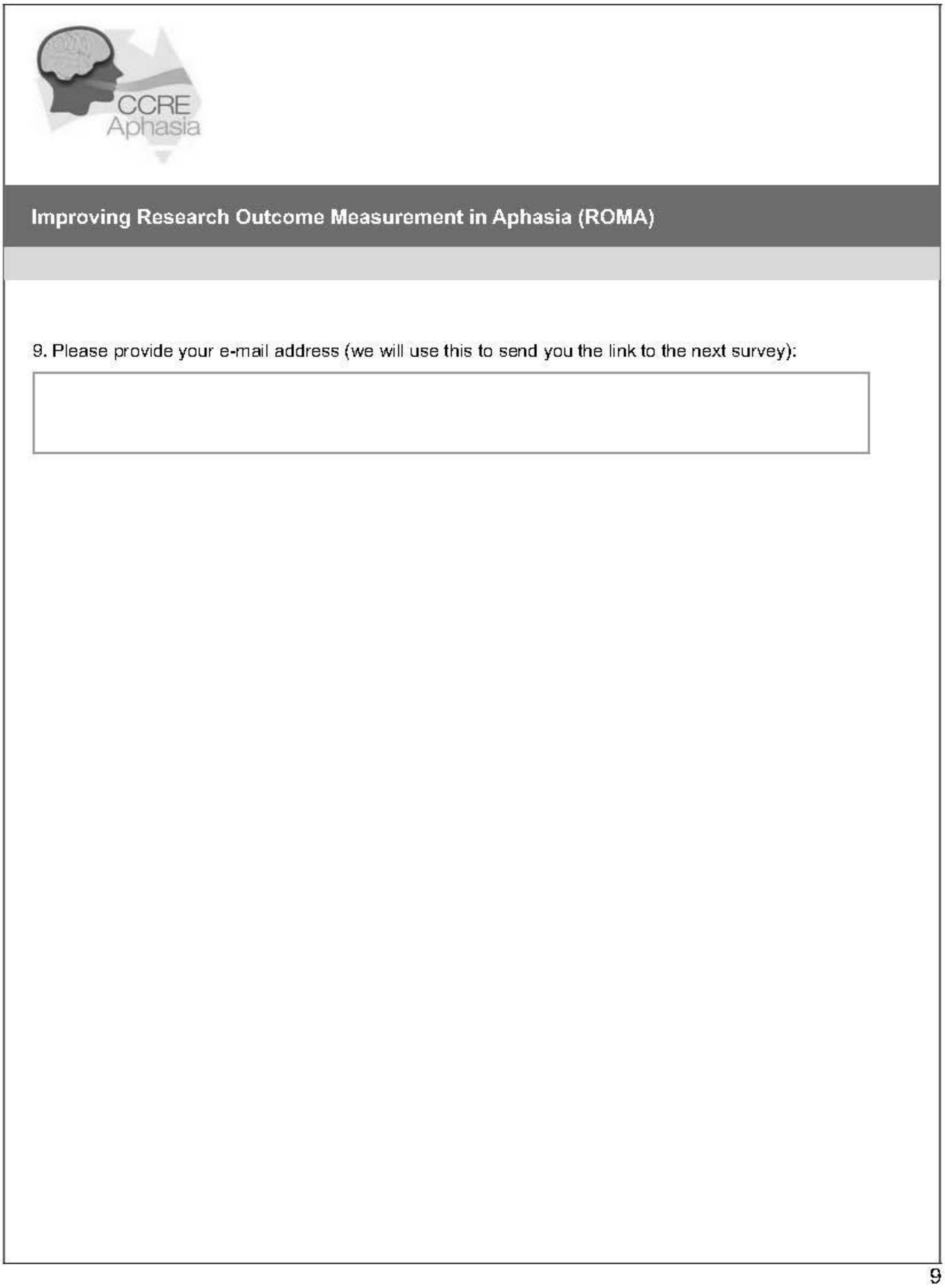


Improving Research Outcome Measurement in Aphasia (ROMA)

8. Would you like to participate in the next survey in this e-delphi exercise?

○ Yes

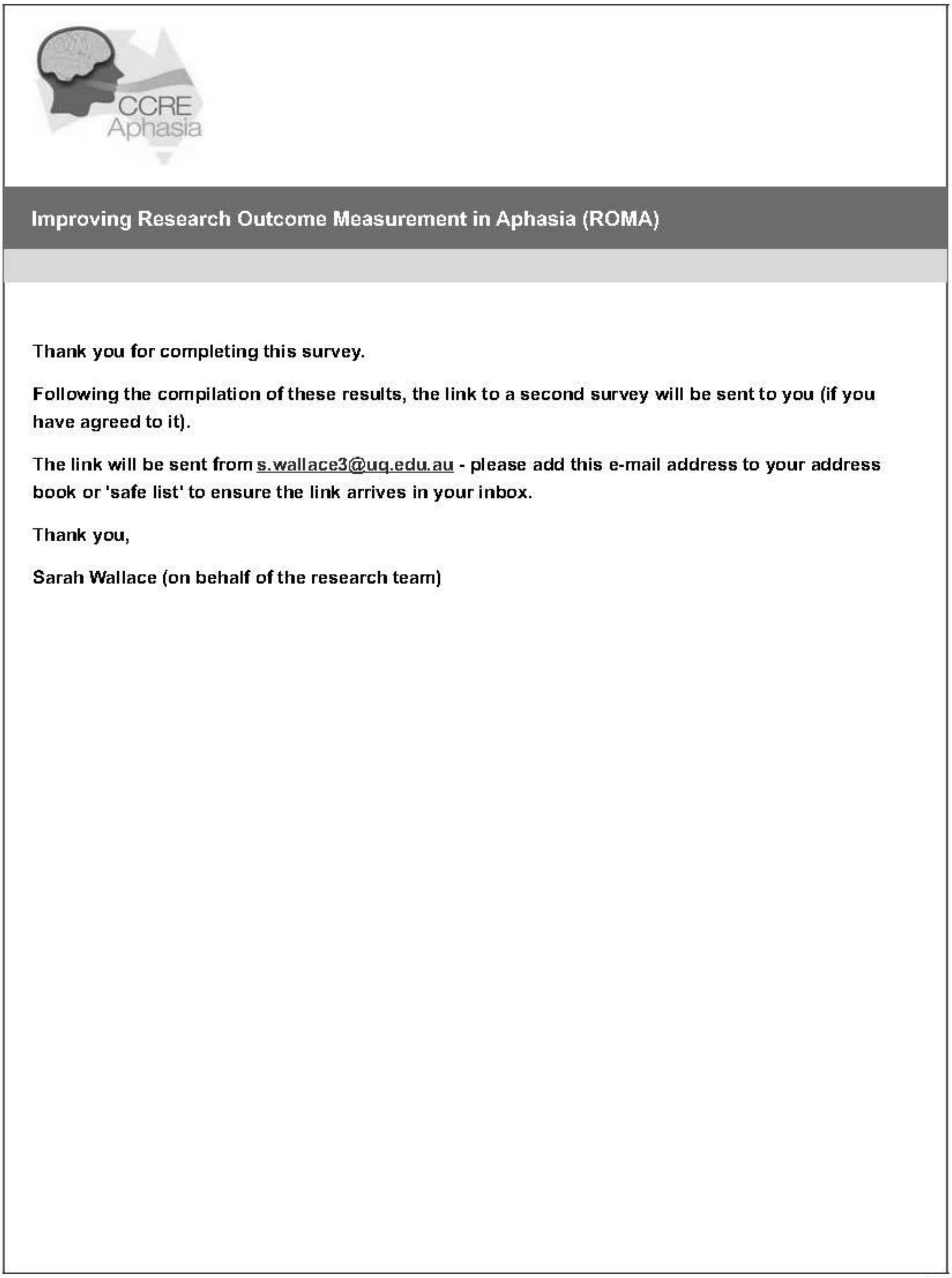
○ No



Improving Research Outcome Measurement in Aphasia (ROMA)

9. Please provide your e-mail address (we will use this to send you the link to the next survey):

9



Improving Research Outcome Measurement in Aphasia (ROMA)

Thank you for completing this survey.

Following the compilation of these results, the link to a second survey will be sent to you (if you have agreed to it).

The link will be sent from s.wallace3@uq.edu.au - please add this e-mail address to your address book or 'safe list' to ensure the link arrives in your inbox.

Thank you,

Sarah Wallace (on behalf of the research team)

Appendix D: Systematic Review Search Strategy

PUBMED

Aphasia OR dysphasia AND stroke

AND

(instrumentation[sh] OR methods[sh] OR Validation Studies[pt] OR Comparative Study[pt] OR ''psychometrics'' [MeSH] OR psychometr*[tiab] OR clinimetr*[tw] OR clinometr*[tw] OR ''outcome assessment (health care)''[MeSH] OR outcome assessment[tiab] OR outcome measure*[tw] OR Qual Life Res (2009) 18:1115–1123 1121 123 ''observer variation''[MeSH] OR observer variation[tiab] OR ''Health Status Indicators''[Mesh] OR ''reproducibility of results''[MeSH] OR reproducib*[tiab] OR ''discriminant analysis''[MeSH] OR reliab*[tiab] OR unreliab*[tiab] OR valid*[tiab] OR coefficient[tiab] OR homogeneity[tiab] OR homogeneous[tiab] OR ''internal consistency''[tiab] OR (cronbach*[tiab] AND (alpha[tiab] OR alphas[tiab])) OR (item[tiab] AND (correlation*[tiab] OR selection*[tiab] OR reduction*[tiab])) OR agreement[tiab] OR precision[tiab] OR imprecision[tiab] OR ''precise values''[tiab] OR test– retest[tiab] OR (test[tiab] AND retest[tiab]) OR (reliab* [tiab] AND (test[tiab] OR retest[tiab])) OR stability[tiab] OR interrater[tiab] OR inter-rater[tiab] OR intrarater[tiab] OR intra-rater[tiab] OR intertester[tiab] OR inter-tester[tiab] OR intratester[tiab] OR intra-tester[tiab] OR interobserver[tiab] OR inter-observer[tiab] OR intraobserver[tiab] OR intraobserver[tiab] OR intertechnician[tiab] OR inter-technician[tiab] OR intratechnician[tiab] OR intra-technician[tiab] OR interexaminer[tiab] OR inter-examiner[tiab] OR intraexaminer[tiab] OR intra-examiner[tiab] OR interassay[tiab] OR inter-assay[tiab] OR intraassay[tiab] OR intra-assay[tiab] OR interindividual[tiab] OR inter-individual[tiab] OR intraindividual[tiab] OR intra-individual[tiab] OR interparticipant [tiab] OR inter-participant[tiab] OR intraparticipant[tiab] OR intra-participant[tiab] OR kappa[tiab] OR kappa's[tiab] OR kappas[tiab] OR repeatab*[tiab] OR ((replicab*[tiab] OR repeated[tiab]) AND (measure[tiab] OR measures[tiab] OR findings[tiab] OR result[tiab] OR results[tiab] OR test[- tiab] OR tests[tiab])) OR generaliza*[tiab] OR generalisa*[tiab] OR concordance[tiab] OR (intraclass[tiab] AND correlation*[tiab]) OR discriminative[tiab] OR ''known group''[tiab] OR factor analysis[tiab] OR factor analyses[tiab] OR dimension*[tiab] OR subscale*[tiab] OR (multitrait[tiab] AND scaling[tiab] AND (analysis[tiab] OR analyses[tiab])) OR item discriminant[tiab] OR interscale correlation*[tiab] OR error[tiab] OR errors[tiab] OR ‘‘individual variability’’[tiab] OR (variability[tiab] AND (analysis[tiab] OR values[tiab])) OR (uncertainty[tiab] AND (measurement[tiab] OR measuring[tiab])) OR ‘‘standard error of measurement’’[tiab] OR sensitiv*[tiab] OR responsive*[tiab] OR ((minimal[tiab] OR minimally[tiab] OR clinical[tiab] OR clinically[tiab]) AND (important[tiab] OR significant[tiab] OR detectable[tiab]) AND (change[tiab] OR difference[tiab])) OR (small*[tiab] AND (real[tiab] OR detectable[tiab]) AND (change[tiab] OR difference[tiab])) OR meaningful change [tiab] OR ‘‘ceiling effect’’[tiab] OR ‘‘floor effect’’[tiab] OR ‘‘Item response model’’[tiab] OR IRT[tiab] OR Rasch[tiab] OR ‘‘Differential item functioning’’[tiab] OR DIF[tiab] OR ‘‘computer adaptive testing’’[tiab] OR ‘‘item bank’’[tiab] OR ‘‘cross-cultural equivalence’’[tiab])

EMBASE

aphasia OR dysphasia AND stroke

AND

'intermethod comparison'/exp OR 'data collection method'/exp OR 'validation study'/exp OR 'feasibility study'/exp OR 'pilot study'/exp OR 'psychometry'/exp OR 'reproducibility'/exp OR reproducib*:ab,ti OR 'audit':ab,ti OR psychometr*:ab,ti OR clinimetr*:ab,ti OR clinometr*:ab,ti OR 'observer variation'/exp OR 'observer variation':ab,ti OR 'discriminant analysis'/exp OR 'validity'/exp OR reliab*:ab,ti OR valid*:ab,ti OR 'coefficient':ab,ti OR 'internal consistency':ab,ti OR (cronbach*:ab,ti AND ('alpha':ab,ti OR 'alphas':ab,ti)) OR 'item correlation':ab,ti OR 'item correlations':ab,ti OR 'item selection':ab,ti OR 'item selections':ab,ti OR 'item reduction':ab,ti OR 'item reductions':ab,ti OR 'agreement':ab,ti OR 'precision':ab,ti OR 'imprecision':ab,ti OR 'precise values':ab,ti OR 'test-retest':ab,ti OR ('test':ab,ti AND 'retest':ab,ti) OR (reliab*:ab,ti AND ('test':ab,ti OR 'retest':ab,ti)) OR 'stability':ab,ti OR 'interrater':ab,ti OR 'inter-rater':ab,ti OR 'intrarater':ab,ti OR 'intra-rater':ab,ti OR 'intertester':ab,ti OR 'inter-tester':ab,ti OR 'intratester':ab,ti OR 'intratester':ab,ti OR 'interobeserver':ab,ti OR 'inter-observer':ab,ti OR 'intraobserver':ab,ti OR 'intraobserver':ab,ti OR 'intertechnician':ab,ti OR 'inter-technician':ab,ti OR 'intratechnician':ab,ti OR 'intratechnician':ab,ti OR 'interexaminer':ab,ti OR 'inter-examiner':ab,ti OR 'intraexaminer':ab,ti OR 'intraexaminer':ab,ti OR 'interassay':ab,ti OR 'inter-assay':ab,ti OR 'intraassay':ab,ti OR 'intra-assay':ab,ti OR 'interindividual':ab,ti OR 'inter-individual':ab,ti OR 'intraindividual':ab,ti OR 'intra-individual':ab,ti OR 'interparticipant':ab,ti OR 'inter-participant':ab,ti OR 'intraparticipant':ab,ti OR 'intraparticipant':ab,ti OR 'kappa':ab,ti OR 'kappas':ab,ti OR 'coefficient of variation':ab,ti OR repeatab*:ab,ti OR (replicab*:ab,ti OR 'repeated':ab,ti AND ('measure':ab,ti OR 'measures':ab,ti OR 'findings':ab,ti OR 'result':ab,ti OR 'results':ab,ti OR 'test':ab,ti OR 'tests':ab,ti)) OR generaliza*:ab,ti OR generalisa*:ab,ti OR 'concordance':ab,ti OR ('intraclass':ab,ti AND correlation*:ab,ti) OR 'discriminative':ab,ti OR 'known group':ab,ti OR 'factor analysis':ab,ti OR 'factor analyses':ab,ti OR 'factor structure':ab,ti OR 'factor structures':ab,ti OR 'dimensionality':ab,ti OR subscale*:ab,ti OR 'multitrait scaling analysis':ab,ti OR 'multitrait scaling analyses':ab,ti OR 'item discriminant':ab,ti OR 'interscale correlation':ab,ti OR 'interscale correlations':ab,ti OR ('error':ab,ti OR 'errors':ab,ti AND (measure*:ab,ti OR correlat*:ab,ti OR evaluat*:ab,ti OR 'accuracy':ab,ti OR 'accurate':ab,ti OR 'precision':ab,ti OR 'mean':ab,ti)) OR 'individual variability':ab,ti OR 'interval variability':ab,ti OR 'rate variability':ab,ti OR 'variability analysis':ab,ti OR ('uncertainty':ab,ti AND ('measurement':ab,ti OR 'measuring':ab,ti)) OR 'standard error of measurement':ab,ti OR sensitiv*:ab,ti OR responsive*:ab,ti OR ('limit':ab,ti AND 'detection':ab,ti) OR 'minimal detectable concentration':ab,ti OR interpretab*:ab,ti OR (small*:ab,ti AND ('real':ab,ti OR 'detectable':ab,ti) AND ('change':ab,ti OR 'difference':ab,ti)) OR 'meaningful change':ab,ti OR 'minimal important change':ab,ti OR 'minimal important difference':ab,ti OR 'minimally important change':ab,ti OR 'minimally important difference':ab,ti OR 'minimal detectable change':ab,ti OR 'minimal detectable difference':ab,ti OR 'minimally detectable change':ab,ti OR 'minimally detectable difference':ab,ti OR 'minimal real change':ab,ti OR 'minimal real difference':ab,ti OR 'minimally real change':ab,ti OR 'minimally real difference':ab,ti OR 'ceiling effect':ab,ti OR 'floor effect':ab,ti OR 'item response model':ab,ti OR 'irt':ab,ti OR 'rasch':ab,ti OR 'differential item functioning':ab,ti OR 'dif':ab,ti OR 'computer adaptive testing':ab,ti OR 'item bank':ab,ti OR 'cross-cultural equivalence':ab,ti

CINAHL

aphasia OR dysphasia AND stroke

AND

TI psychometr* OR TI observer variation OR TI reproducib* OR TI reliab* OR TI unreliab* OR TI valid* OR TI coefficient OR TI homogeneity OR TI homogeneous OR TI “internal consistency” OR AB psychometr* OR AB observer variation OR AB reproducib* OR AB reliab* OR AB unreliab* OR AB valid* OR AB coefficient OR AB homogeneity OR AB homogeneous OR AB “internal consistency” OR (TI cronbach* OR AB cronbach* AND (TI alpha OR AB alpha OR TI alphas OR AB alphas)) OR (TI item OR AB item AND (TI correlation* OR AB correlation* OR TI selection* OR AB selection* OR TI reduction* OR AB reduction*)) OR TI agreement OR TI precision OR TI imprecision OR TI “precise values” OR TI test-retest OR AB agreement OR AB precision OR AB imprecision OR AB “precise values” OR AB test-retest OR (TI test OR AB test AND TI retest OR AB retest) OR (TI reliab* OR AB reliab* AND (TI test OR AB test OR TI retest or AB retest)) OR TI stability OR TI interrater OR TI interrater OR TI intrarater OR TI intra-rater OR TI intertester OR TI inter-tester OR TI intratester OR TI intra-tester OR TI interobserver OR TI inter-observer OR TI intraobserver OR TI intra-observer OR TI intertechnician OR TI inter-technician OR TI intratechnician OR TI intra-technician OR TI interexaminer OR TI inter-examiner OR TI intraexaminer OR TI intra-examiner OR TI interassay OR TI inter-assay OR TI intraassay OR TI intra-assay OR TI interindividual OR TI inter-individual OR TI intraindividual OR TI intra-individual OR TI interparticipant OR TI inter-participant OR TI intraparticipant OR TI intra-participant OR TI kappa OR TI kappa’s OR TI kappas OR TI repeatab* OR AB stability OR AB interrater OR AB inter-rater OR AB intrarater OR AB intra-rater OR AB intertester OR AB inter-tester OR AB intratester OR AB intra-tester OR AB interobserver OR AB inter-observer OR AB intraobserver OR AB intra-observer OR AB intertechnician OR AB inter-technician OR AB intratechnician OR AB intra-technician OR AB interexaminer OR AB inter-examiner OR AB intraexaminer OR AB intra-examiner OR AB interassay OR AB inter-assay OR AB intraassay OR AB intra-assay OR AB interindividual OR AB inter-individual OR AB intraindividual OR AB intra-individual OR AB interparticipant OR AB inter-participant OR AB intraparticipant OR AB intra-participant OR AB kappa OR AB kappa’s OR AB kappas OR AB repeatab* OR ((TI replicab* OR AB replicab* OR TI repeated OR AB repeated) AND (TI measure OR AB measure OR TI measures OR AB measures OR TI findings OR AB findings OR TI result OR AB result OR TI results OR AB results OR TI test OR AB test OR TI tests OR AB tests)) OR TI generaliza* OR TI generalisa* OR TI concordance OR AB generaliza* OR AB generalisa* OR AB concordance OR (TI intraclass OR AB intraclass AND TI correlation* or AB correlation*) OR TI discriminative OR TI “known group” OR TI factor analysis OR TI factor analyses OR TI dimension* OR TI subscale* OR AB discriminative OR AB “known group” OR AB factor analysis OR AB factor analyses OR AB dimension* OR AB subscale* OR (TI multitrait OR AB multitrait AND TI scaling OR AB scaling AND (TI analysis OR AB analysis OR TI analyses OR AB analyses)) OR TI item discriminant OR TI interscale correlation* OR TI error OR TI errors OR TI “individual variability” OR AB item discriminant OR AB interscale correlation* OR AB error OR AB errors OR AB “individual variability” OR (TI variability OR AB variability AND (TI analysis OR AB analysis OR TI values OR AB values)) OR (TI uncertainty OR AB uncertainty AND (TI measurement OR AB measurement OR TI measuring OR AB measuring)) OR TI “standard error of measurement” OR TI sensitiv* OR TI responsive* OR AB “standard error of measurement” OR AB sensitiv* OR AB responsive* OR ((TI minimal OR TI minimally OR TI clinical OR TI clinically OR AB minimal OR AB minimally OR AB clinical OR AB clinically) AND (TI important OR TI significant OR TI detectable OR AB important OR AB significant OR AB detectable) AND (TI change OR AB change OR TI difference OR AB difference)) OR (TI small* OR AB small* AND (TI real OR AB real OR TI detectable OR AB detectable) AND (TI change OR AB change OR TI difference OR AB difference)) OR TI meaningful change OR TI “ceiling effect” OR TI “floor effect” OR TI “Item response model” OR TI IRT OR TI Rasch OR TI “Differential item functioning” OR TI DIF OR TI “computer adaptive testing” OR TI “item bank” OR TI “cross-cultural equivalence” OR TI outcome assessment OR AB meaningful change OR AB “ceiling effect” OR AB “floor effect” OR AB “Item response model” OR AB IRT OR AB Rasch OR AB “Differential item functioning” OR AB DIF OR AB “computer ad