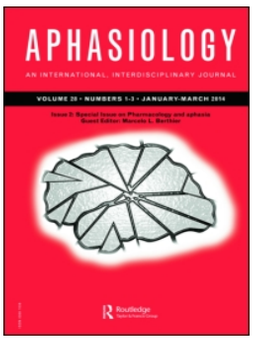

Aphasiology

ISSN: 0268-7038 (Print) 1464-5041 (Online) Journal homepage: http://www.tandfonline.com/loi/paph20

Measuring outcomes in aphasia research: A review of current practice and an agenda for standardisation

Sarah J. Wallace, Linda Worrall, Tanya Rose & Guylaine Le Dorze

To cite this article: Sarah J. Wallace, Linda Worrall, Tanya Rose & Guylaine Le Dorze (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

To link to this article: https://doi.org/10.1080/02687038.2014.930262

Aphasiology, 2014
Vol. 28, No. 11, 1364–1384, http://dx.doi.org/10.1080/02687038.2014.930262

Routledge
Taylor & Francis Group

Measuring outcomes in aphasia research: A review of current practice and an agenda for standardisation

Sarah J. Wallace[1], Linda Worrall[1], Tanya Rose[1], and Guylaine Le Dorze[2]

[1]Centre for Clinical Research Excellence in Aphasia Rehabilitation, School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, Queensland, Australia
[2]School of Speech-Language Pathology and Audiology, Faculty of Medicine, University of Montreal, Montreal, Quebec, Canada

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 that 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.
Aims: This article 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, improved quality of systematic reviews and greater transparency in research reporting. The use of broad stakeholder consultation also supports the development of research outcomes that are meaningful. 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 that 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.

Address correspondence to: Linda Worrall, Centre for Clinical Research Excellence in Aphasia Rehabilitation, School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, Queensland, Australia. E-mail: l.worrall@uq.edu.au

This work was supported by an Australian Postgraduate Award (APA) scholarship, awarded to Sarah Wallace.

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 COS for aphasia treatment trials.

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 that 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 that 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.

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 Outcome Measures for Rheumatology Clinical Trials initiative and increasingly is being adopted in a range of other health fields. Table 1 provides an overview of studies examining research outcomes that 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.

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).

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

TABLE 1
Consensus methods and stakeholder involvement in selected core outcome projects

Health condition	*Reference*	*Method(s)*	*Stakeholder groups*
Asthma	Sinha et al. (2012)	Delphi process (questionnaire)	Consumers (patients) Consumers (caregivers) Clinical experts
Bipolar disorder	Carlson et al. (2003)	Semistructured 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)	Semistructured 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
	Schmitt, Langan, Stamm, Williams, and Harmonizing Outcome Measurements in Eczema Delphi panel (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

(*Continued*)

TABLE 1
(Continued)

Health condition	*Reference*	*Method(s)*	*Stakeholder groups*
End-stage kidney disease	Howell, Tong, Wong, Craig, and Howard (2012)	Focus group/nominal group technique (NGT)	Consumers (patients)
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
	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

(*Continued*)

TABLE 1
(Continued)

Health condition	*Reference*	*Method(s)*	*Stakeholder groups*
Multiple sclerosis	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)
	Sanderson et al. (2010b)	NGT	Consumers (patients)
	Sanderson et al. (2010c)	Interview	Consumers (patients)
	Hewlett et al. (2005)	Survey	Consumers (patients)
	Kirwan et al. (2003)	Semistructured 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

also raised new outcomes, such as fatigue and a general feeling of wellness, for which outcome measures did not exist at that time. Sanderson et al. (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 both by clinicians and by parents and young people. Whilst parents and clinicians generally agreed on the outcomes that were most important, their perspectives differed with regard 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 into research. Broad stakeholder involvement is essential if research is to capture meaningful and relevant outcomes.

Cultural perspectives

If research results are to be applied globally, it is necessary to give consideration to the differences in perspective that may exist across cultures and populations. International collaboration is crucial to such an endeavour. Article 32 of the United Nations' 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 that 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 Punjabi people and white British origin people 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.

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 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 that 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, 1,351 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 subcategories 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 to select the most appropriate tool for use in research.

STATE OF OUTCOME MEASUREMENT IN APHASIA TREATMENT RESEARCH

Ultimate outcome

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, that 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, Kelly, Godwin, and Enderby (2012, p. 5) 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". 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 poststroke 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.

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 end points 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 prestroke 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 in terms of both 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, for example, increasing expressive language abilities, while people with aphasia expressed a desire to work on goals pertaining to previously valued activities, for example, 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 semistructured 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, 2013).

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

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). 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. Furthermore, 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.

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 that 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

TABLE 2
Outcome instruments in included studies in the Cochrane Review of speech-language therapy for aphasia (Brady et al., 2012)

Outcome instrument	*Number of studies using instrument*
Porch Index of Communicative Abilities (PICA) (Porch, 1967; Porch, 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, 1982)	5
Western Aphasia Battery Aphasia Quotient (WABAQ) (Kertesz, 1982)	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, 1984)	3
Aphasia Battery in Chinese (ABC) (Reference unavailable)	3
Amsterdam–Nijmegen Everyday Language Test-A (subscale) (Blomert, Kean, Koster, & Schokker, 1994)	3
Auditory Comprehension Test for Sentences (ACTS) (Shewan, 1979)	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, 1965)	3
Psycholinguistic Assessments of Language Processing in Aphasia (PALPA) (Kay, Lesser, & Coltheart, 1992)	3
Reading Comprehension Battery for Aphasia (RCBA) (LaPointe & Horner, 1979)	3
Chinese Functional Communication Profile (CFCP); Reference unavailable	2
Communicative Effectiveness Index (CETI) (Lomas et al., 1989)	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
Amsterdam-Nijmegen Everyday Language Test (ANELT) (Blomert et al., 1994)	1
Boston Naming Test (BNT) (Kaplan, Goodglass, & Weintraub, 1983)	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, 2008)	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 (FE) Scale (Prins, 1980)	1
Aphasia Quotient (Castro-Caldas, 1979)	
Multiple Adjective Affect Checklist (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, 1985)	1
Peabody Picture Vocabulary Test (PPVT) (Dunn, 1959)	1

(*Continued*)

TABLE 2
(Continued)

Outcome instrument	*Number of studies using instrument*
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

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.

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 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) that currently contains 508 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 et al., 2011). The development of COSs is also increasing in rehabilitation and neurology fields.

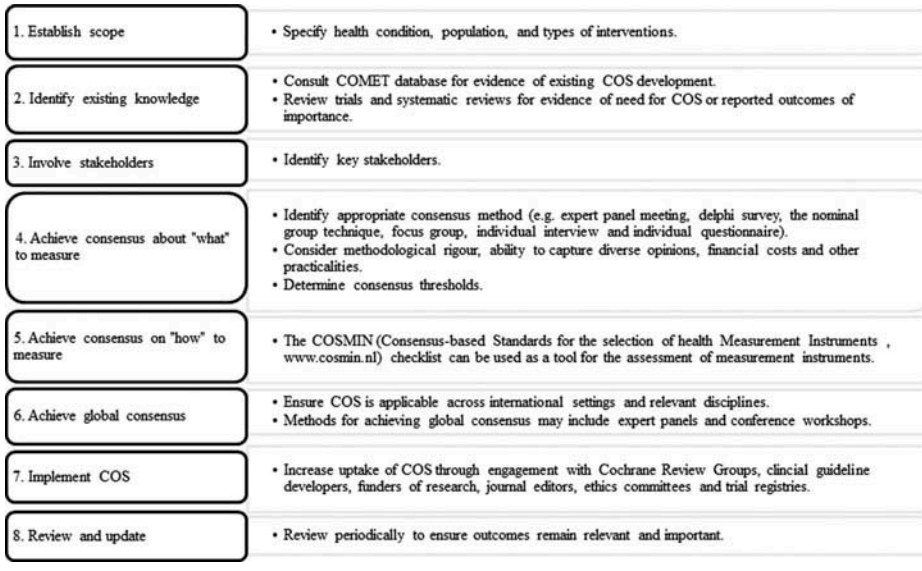

Figure 1. The process of core outcome set development (based on Williamson et al., 2012).

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.

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 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 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, Gargon, Clarke, and Williamson (2013) recently investigated missing patient data in Cochrane Systematic Reviews and surveyed the coordinating editors of Cochrane Review Groups (CRGs) regarding the standardisation of outcomes. Of the coordinating 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).

Challenges of COS development

Challenges associated with developing COSs have also been identified. Kirkham et al. (2013) investigated the opinions of the Cochrane Review coordinating editors in relation to perceived challenges associated with standardising outcomes in their particular 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 that are utilised.

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.

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.

REFERENCES

Ali, M., English, C., Bernhardt, J., Sunnerhagen, K. S., Brady, M., & VISTA-Rehab Collaboration. (2013). More outcomes than trials: A call for consistent data collection across stroke rehabilitation trials. *International Journal of Stroke*, *8*, 18–24. doi:10.1111/j.1747-4949.2012.00973.x

Arnold, L. M., Crofford, L. J., Mease, P. J., Burgess, S. M., Palmer, S. C., Abetz, L., & Martin, S. A. (2008). Patient perspectives on the impact of fibromyalgia. *Patient Education and Counseling*, *73*, 114–120. doi:10.1016/j.pec.2008.06.005

Blomert, L., Kean, M. L., Koster, C., & Schokker, J. (1994). Amsterdam–Nijmegen Everyday Language Test: Construction, reliability and validity. *Aphasiology*, *8*, 381–407. doi:10.1080/02687039408248666

Boote, J., Telford, R., & Cooper, C. (2002). Consumer involvement in health research: A review and research agenda. *Health Policy*, *61*, 213–236. doi:10.1016/S0168-8510(01)00214-7

Borkowski, J. G., Benton, A. L., & Spreen, O. (1967). Word fluency and brain damage. *Neuropsychologia*, *5*, 135–140. doi:10.1016/0028-3932(67)90015-2

Bradburn, N. M. (1969). *The structure of psychological well-being*. Chicago, IL: Aldine.

Brady, M. C., Kelly, H., Godwin, J., & Enderby, P. (2012). Speech and language therapy for aphasia following stroke. *Cochrane Database of Systematic Reviews*. Advance online publication. doi:10.1002/14651858.CD000425.pub3

Brooks, R. (1996). EuroQol: The current state of play. *Health Policy*, *37*, 53–72. doi:10.1016/0168-8510(96)00822-6

Brott, T., Marler, J. R., Olinger, C. P., Adams Jr., H. P., Tomsick, T., Barsan, W. G., … Walker, M. (1989). Measurements of acute cerebral infarction: Lesion size by computed tomography. *Stroke*, *20*, 871–875. doi:10.1161/01.STR.20.7.871

Caplan, D., & Hanna, J. E. (1998). Sentence production by aphasic patients in a constrained task. *Brain and Language*, *63*, 184–218. doi:10.1006/brln.1998.1930

Carlson, G. A., Jensen, P. S., Findling, R. L., Meyer, R. E., Calabrese, J., DelBello, M. P., & Youngstrom, E. A. (2003). Methodological issues and controversies in clinical trials with child and adolescent patients with bipolar disorder: Report of a consensus conference. *Journal of Child and Adolescent Psychopharmacology*, *13*, 13–27. doi:10.1089/104454603321666162

Carr, A., Hewlett, S., Hughes, R., Mitchell, H., Ryan, S., Carr, M., & Kirwan, J. (2003). Rheumatology outcomes: The patient's perspective. *Journal of Rheumatology*, *30*, 880–883.

Castro-Caldas, A. (1979). *Diagnostico e Evolucao das Afasias de Causa Vascular*. Lisboa: Faculdade de Medicina de Lisboa.

Chalmers, I., & Glasziou, P. (2009). Avoidable waste in the production and reporting of research evidence. *Obstetrics and Gynecology*, *114*, 1341–1345. doi:10.1097/AOG.0b013e3181c3020d

Chan, A.-W., Tetzlaff, J. M., Gøtzsche, P. C., Altman, D. G., Mann, H., Berlin, J. A., & Moher, D. (2013). SPIRIT 2013 explanation and elaboration: Guidance for protocols of clinical trials. *British Medical Journal*, *346*. doi:10.1136/bmj.e7586

Cherney, L. R., Patterson, J. P., Raymer, A., Frymark, T., & Schooling, T. (2008). Evidence-based systematic review: Effects of intensity of treatment and constraint-induced language therapy for individuals with stroke-induced aphasia. *Journal of Speech Language and Hearing Research*, *51*, 1282–1299. doi:10.1044/1092-4388(2008/07-0206)

Clarke, M. (2007). Standardising outcomes for clinical trials and systematic reviews. *Trials*, *8*. doi:10.1186/1745-6215-8-39

Coster, W. J. (2013). Making the best match: Selecting outcome measures for clinical trials and outcome studies. *The American Journal of Occupational Therapy*, *67*, 162–170. doi:10.5014/ajot.2013.006015

Dalemans, R., Wade, D. T., van den Heuvel, W. J., & de Witte, L. P. (2009). Facilitating the participation of people with aphasia in research: A description of strategies. *Clinical Rehabilitation*, *23*, 948–959. doi:10.1177/0269215509337197

DeRenzi, E., & Vignolo, L. A. (1962). The Token Test: A sensitive test to detect receptive disturbances in aphasics. *Brain*, *85*, 665–678. doi:10.1093/brain/85.4.665

Devane, D., Begley, C. M., Clarke, M., Horey, D., & Oboyle, C. (2007). Evaluating maternity care: A core set of outcome measures. *Birth*, *34*, 164–172. doi:10.1111/j.1523-536X.2006.00145.x

Disability Policy and Research Working Group. (2011). National disability research and development agenda. Retrieved from http://www.pda.org.au/uploads/documents_for_download/item_1_national_rd_agenda_web.pdf

Dunn, L. M. (1959). *Peabody Picture Vocabulary Test*. Minneapolis, MN: American Guidance Service.

Dworkin, R. H., Turk, D. C., Farrar, J. T., Haythornthwaite, J. A., Jensen, M. P., Katz, N. P., & Immpact. (2005). Core outcome measures for chronic pain clinical trials: IMMPACT recommendations. *Pain*, *113*, 9–19. doi:10.1016/j.pain.2004.09.012

Ebrahim, S., Barer, D., & Nouri, F. (1986). Use of the Nottingham Health Profile with patients after a stroke. *Journal of Epidemiology and Community Health*, *40*, 166–169. doi:10.1136/jech.40.2.166

Eleftheriadou, V., Thomas, K. S., Whitton, M. E., Batchelor, J. M., & Ravenscroft, J. C. (2012). Which outcomes should we measure in vitiligo? Results of a systematic review and a survey among patients and clinicians on outcomes in vitiligo trials. *British Journal of Dermatology*, *167*, 804–814. doi:10.1111/j.1365-2133.2012.11056.x

Enderby, P., John, A., & Petheram, B. (2007). *Therapy outcomes measures for rehabilitation professionals: Speech and language therapy, physiotherapy, occupational therapy* (2nd ed.). Chichester: Wiley.

European Cooperation in the field of Scientific and Technical Research. (2012). *Memorandum of understanding for the implementation of a European Concerted Research Action designated as COST Action IS1208: Collaboration of AphasiaTrialists (CATs)*. Brussels: Author.

European Medicines Agency. (2012). *Report of the workshop on endpoints for cystic fibrosis clinical trials*. Retrieved from http://www.ema.europa.eu/

Fink, R. B., Schwartz, M. F., Rochon, E., Myers, J. L., Socolof, G. S., Bluestone, R., & Sobel, P. R. (1994, October 23–25). *Picture description with structure modelling (PDSM): A procedure for measuring syntactic generalisation*. Paper presented at the Academy of Aphasia, Boston, MA.

Frattali, C. M. (1998). *Measuring outcomes in speech-language pathology*. New York, NY: Thieme.

Frattali, C. M. (2013). Outcomes measurement: Definitions, dimensions, and perspectives. In L. C. Golper & C. M. Frattali (Eds.), *Outcomes in speech-language pathology* (2nd ed.). New York, NY: Thieme.

Goldberg, D. (1972). *The detection of psychiatric illness by questionnaire*. London: Oxford University Press.

Goodglass, H., & Kaplan, E. (1972). *Boston Diagnostic Aphasia Examination*. Philadelphia, PA: Lea and Febiger.

Goodglass, H., & Kaplan, E. (1983). *The assessment of aphasia and related disorders*. Philadelphia, PA: Lea and Febiger.

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2012). A systematic review of the positive outcomes for family members of people with aphasia. *Evidence-Based Communication Assessment and Intervention*, *6*, 135–149. doi:10.1080/17489539.2012.739383

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013). Third-party disability in family members of people with aphasia: A systematic review. *Disability and Rehabilitation*, *35*, 1324–1341. doi:10.3109/09638288.2012.735341

Greenhalgh, J., Long, A. F., Brettle, A. J., & Grant, M. J. (1998). Reviewing and selecting outcome measures for use in routine practice. *Journal of Evaluation in Clinical Practice*, *4*, 339–350. doi:10.1111/j.1365-2753.1998.tb00097.x

Hersh, D., Sherratt, S., Howe, T., Worrall, L., Davidson, B., & Ferguson, A. (2012). An analysis of the "goal" in aphasia rehabilitation. *Aphasiology*, *26*, 971–984. doi:10.1080/02687038.2012.684339

Hewlett, S., Carr, M., Ryan, S., Kirwan, J., Richards, P., Carr, A., & Hughes, R. (2005). Outcomes generated by patients with rheumatoid arthritis: How important are they? *Musculoskeletal Care*, *3*, 131–142. doi:10.1002/msc.3

Higgins, J., & Green, S. (2011). *Cochrane handbook for systematic reviews of interventions*, Version 5.1.0 [updated March 2011]. Retrieved from www.cochrane-handbook.org

Holland, A. (1980). *Communicative abilities in daily living*. Baltimore, MD: University Park Press.

Holland, A., Frattali, C., & Fromm, D. (1998). *Communication activities of daily living* (2nd ed.). Austin, TX: Pro-Ed.

Howe, T., Davidson, B., Worrall, L., Hersh, D., Ferguson, A., Sherratt, S., & Gilbert, J. (2012). You needed to rehab … families as well': Family members' own goals for aphasia rehabilitation. *International Journal of Language & Communication Disorders*, *47*, 511–521. doi:10.1111/j.1460-6984.2012.00159.x

Howell, M., Tong, A., Wong, G., Craig, J. C., & Howard, K. (2012). Important outcomes for kidney transplant recipients: A nominal group and qualitative study. *American Journal of Kidney Diseases*, *60*, 186–196. doi:10.1053/j.ajkd.2012.02.339

Huber, W., Poeck, K., & Willmes, K. (1984). The Aachen Aphasia Test. *Advances in Neurology*, *42*, 291–303.

Kaplan, E., Goodglass, H., & Weintraub, S. (1983). *Boston Naming Test*. Philadelphia, PA: Lea and Febiger.

Kay, J., Lesser, R., & Coltheart, M. (1992). *Psycholinguistics Assessments of Language Processing in Aphasia*. Hove: Lawrence Erlbaum Associates Ltd.

Kertesz, A. (1982). *Western Aphasia Battery*. New York, NY: Grune and Stratton.

Khan, F., Amatya, B., & Ng, L. (2010). Use of the International Classification of Functioning, Disability and Health to describe patient-reported disability: A comparison of Guillain–Barre syndrome with multiple sclerosis in a community cohort. *Journal of Rehabilitation Medicine*, *42*, 708–714. doi:10.2340/16501977-0592

Khan, F., McPhail, T., Brand, C., Turner-Stokes, L., & Kilpatrick, T. (2006). Multiple sclerosis: Disability profile and quality of life in an Australian community cohort. *International Journal of Rehabilitation Research*, *29*, 87–96. doi:10.1097/01.mrr.0000194393.56772.62

Khanna, D. (2008). A standardized core set for systemic sclerosis clinical trials. First step in development of combined response index. *Rheumatology*, *47*, 31–32. doi:10.1093/rheumatology/ken266

Khanna, D., Lovell, D. J., Giannini, E., Clements, P. J., Merkel, P. A., Seibold, J. R., & Scleroderma Clinical Trials Consortium. (2008). Development of a provisional core set of response measures for clinical trials of systemic sclerosis. *Annals of the Rheumatic Diseases*, *67*, 703–709. doi:10.1136/ard.2007.078923

Kirkham, J. J., Gargon, E., Clarke, M., & Williamson, P. R. (2013). Can a core outcome set improve the quality of systematic reviews? A survey of the co-ordinating editors of Cochrane Review Groups. *Trials*, *14*, 21. doi:10.1186/1745-6215-14-21

Kirwan, J., Heiberg, T., Hewlett, S., Hughes, R., Kvien, T., Ahlmen, M., & Taal, E. (2003). Outcomes from the Patient Perspective Workshop at OMERACT 6. *The Journal of Rheumatology*, *30*, 868–872.

LaPointe, L. L., & Horner, J. (1979). *Reading Comprehension Battery for Aphasia*. Tigard, OR: CC Publications.

Lincoln, N. B. (1979). *An investigation of the effectiveness of language retraining methods with aphasic stroke patients* (Unpublished doctoral dissertation). University of London, London.

Lomas, J., Pickard, L., Bester, S., Elbard, H., Finlayson, A., & Zoghaib, C. (1989). The Communicative Effectiveness Index: Development and psychometric evaluation of a functional communication measure for adults. *Journal of Speech and Hearing Disorders*, *54*, 113–124.

Long, A., Hesketh, A., & Bowen, A. (2009). Communication outcome after stroke: A new measure of the carer's perspective. *Clinical Rehabilitation*, *23*, 846–856. doi:10.1177/0269215509336055

Long, A., Hesketh, A., Paszek, G., Booth, M., & Bowen, A. (2008). Development of a reliable self-report outcome measure for pragmatic trials of communication therapy following stroke: The Communication Outcome after Stroke (COAST) scale. *Clinical Rehabilitation*, *22*, 1083–1094. doi:10.1177/0269215508090091

Long, A. F., Dixon, P., Hall, R., Carr-Hill, R. A., & Sheldon, T. A. (1993). The outcomes agenda: Contribution of the UK clearing house on health outcomes. *Quality in Health Care*, *2* 49–52. doi:10.1136/qshc.2.1.49

Lyon, J. G., Cariski, D., Keisler, L., Rosenbek, J., Levine, R., Kumpula, J., … Blanc, M. (1997). Communication partners: Enhancing participation in life and communication for adults with aphasia in natural settings. *Aphasiology*, *11*, 693–708. doi:10.1080/02687039708249416

McAllister, M., Dunn, G., & Todd, C. (2011). Empowerment: Qualitative underpinning of a new clinical genetics-specific patient-reported outcome. *European Journal of Human Genetics*, *19*, 125–130. doi:10.1038/ejhg.2010.160

McAllister, M., Payne, K., MacLeod, R., Nicholls, S., Donnai, D., & Davies, L. (2008). Patient empowerment in clinical genetics services. *Journal of Health Psychology*, *13*, 895–905. doi:10.1177/1359105308095063

McAllister, M., Payne, K., Nicholls, S., MacLeod, R., Donnai, D., & Davies, L. (2007). Improving service evaluation in clinical genetics: Identifying effects of genetic diseases on individuals and families. *Journal of Genetic Counseling*, *16*, 71–83. doi:10.1007/s10897-006-9046-3

McGrath, P. J., Walco, G. A., Turk, D. C., Dworkin, R. H., Brown, M. T., Davidson, K., … Zeltzer, L. (2008). Core outcome domains and measures for pediatric acute and chronic/recurrent pain clinical trials: PedIMMPACT recommendations. *The Journal of Pain*, *9*, 771–783. doi:10.1016/j.jpain.2008.04.007

Mease, P. J., Arnold, L. M., Crofford, L. J., Williams, D. A., Russell, I. J., Humphrey, L., & Martin, S. A. (2008). Identifying the clinical domains of fibromyalgia: Contributions from clinician and patient delphi exercises. *Arthritis and Rheumatism*, *59*, 952–960. doi:10.1002/art.23826

Moher, D., Hopewell, S., Schulz, K. F., Montori, V., Gøtzsche, P. C., Devereaux, P. J., & Altman, D. G. (2010). CONSORT 2010 explanation and elaboration: Updated guidelines for reporting parallel group randomised trials. *British Medical Journal*, *340*. doi:10.1136/bmj.c869

Mokkink, L., Terwee, C., Stratford, P., Alonso, J., Patrick, D., Riphagen, I., & Vet, H. W. (2009). Evaluation of the methodological quality of systematic reviews of health status measurement instruments. *Quality of Life Research*, *18*, 313–333. doi:10.1007/s11136-009-9451-9

Mullis, R., Barber, J., Lewis, M., & Hay, E. (2007). ICF core sets for low back pain: Do they include what matters to patients? *Journal of Rehabilitation Medicine*, *39*, 353–357. doi:10.2340/16501977-0059

Nicholas, L. E., & Brookshire, R. H. (1995). Presence, completeness, and accuracy of main concepts in the connected speech of non-brain-damaged adults and adults with aphasia. *Journal of Speech and Hearing Research*, *38*, 145–156.

Noonan, V. K., Kopec, J. A., Noreau, L., Singer, J., Chan, A., Masse, L. C., & Dvorak, M. F. (2009). Comparing the content of participation instruments using the International Classification of Functioning, Disability and Health. *Health and Quality of Life Outcomes*, *7*, 93. doi:10.1186/1477-7525-7-93

Oldfield, R. C., & Wingfield, A. (1965). *A series of pictures for use in object naming*. Oxford: Psycholinguistics Research Unit.

Olswang, L. B., & Bain, B. A. (2013). Treatment research. In L. C. Golper & C. M. Frattali (Eds.), *Outcomes in speech-language pathology* (2nd ed.). New York, NY: Thieme.

Payne, K., Nicholls, S. G., McAllister, M., MacLeod, R., Ellis, I., Donnai, D., & Davies, L. M. (2007). Outcome measures for clinical genetics services: A comparison of genetics healthcare professionals and patients' views. *Health Policy*, *84*, 112–122. doi:10.1016/j.healthpol.2007.03.005

Porch, B. (1967). *Porch Index of Communicative Ability*. Palo Alto, CA: Consulting Psychologists Press.

Porch, B. E. (1971). *Porch Index of Communicative Ability* (2nd ed.). Palo Alto, CA: Consulting Psychologists Press.

Porch, B. E. (1981). *Porch Index of Communicative Ability* (3rd ed.). Palo Alto, CA: Consulting Psychologists Press.

Prins, R. S. (1980). Psycho Linguistische aspekten van afasie diagnostiek en therapie [Psycholinguistic aspects of aphasia diagnosis and therapy]. *Gerontologie*, *11*, 22–28.

Pulvermuller, F., Neininger, B., Elbert, T., Mohr, B., Rockstroh, B., Koebbel, P., & Taub, E. (2001). Constraint-induced therapy of chronic aphasia after stroke. *Stroke*, *32*, 1621–1626. doi:10.1161/01.STR.32.7.1621

Reinvang, I. (1985). *Aphasia and brain organisation*. New York, NY: Plenum Press.

Rohde, A., Townley-O'Neill, K., Trendall, K., Worrall, L., & Cornwell, P. (2012). A comparison of client and therapist goals for people with aphasia: A qualitative exploratory study. *Aphasiology*, *26*, 1298–1315. doi:10.1080/02687038.2012.706799

Saffran, E. M., Schwartz, M. F., Linebarger, M., Martin, N., & Bochetto, P. (1988). *The Philadelphia Comprehension Battery for Aphasia*. Unpublished manuscript.

Sanderson, T., Hewlett, S., Calnan, M., Morris, M., Raza, K., & Kumar, K. (2012). Exploring the cultural validity of rheumatology outcomes. *British Journal of Nursing*, *21*, 1015–1023. doi:10.12968/bjon.2012.21.17.1015

Sanderson, T., Morris, M., Calnan, M., Richards, P., & Hewlett, S. (2010a). "It's this whole picture, this well-being": Patients' understanding of "feeling well" with rheumatoid arthritis. *Chronic Illness*, *6*, 228–240. doi:10.1177/1742395310377672

Sanderson, T., Morris, M., Calnan, M., Richards, P., & Hewlett, S. (2010b). Patient perspective of measuring treatment efficacy: The rheumatoid arthritis patient priorities for pharmacologic interventions outcomes. *Arthritis Care and Research*, *62*, 647–656. doi:10.1002/acr.20151

Sanderson, T., Morris, M., Calnan, M., Richards, P., & Hewlett, S. (2010c). What outcomes from pharmacologic treatments are important to people with rheumatoid arthritis? Creating the basis of a patient core set. *Arthritis Care and Research*, *62*, 640–646. doi:10.1002/acr.20034

Sarno, M. T. (1969). *The Functional Communication Profile: Manual of directions*. New York, NY: Institution of Rehabilitation Medicine.

Schepers, V. P. M., Ketelaar, M., van de Port, I. G. L., Visser-Meily, J. M. A., & Lindeman, E. (2007). Comparing contents of functional outcome measures in stroke rehabilitation using the International Classification of Functioning, Disability and Health. *Disability & Rehabilitation*, *29*, 221–230. doi:10.1080/09638280600756257

Schmitt, J., Langan, S., Stamm, T., Williams, H. C., & Harmonizing Outcome Measurements in Eczema Delphi panel. (2011). Core outcome domains for controlled trials and clinical recordkeeping in eczema: International multiperspective Delphi consensus process. *The Journal of Investigative Dermatology*, *131*, 623–630. doi:10.1038/jid.2010.303

Schmitt, J., Langan, S., & Williams, H. C. (2007). What are the best outcome measurements for atopic eczema? A systematic review. *Journal of Allergy and Clinical Immunology*, *120*, 1389–1398. doi:10.1016/j.jaci.2007.08.011

Schmitt, J., Spuls, P., Boers, M., Thomas, K., Chalmers, J., Roekevisch, E., & Williams, H. (2012). Towards global consensus on outcome measures for atopic eczema research: Results of the HOME II meeting. *Allergy*, *67*, 1111–1117. doi:10.1111/j.1398-9995.2012.02874.x

Schuell, H. (1965). *Minnesota Test for Differential Diagnosis of Aphasia*. Minneapolis: University of Minnesota Press.

Serrano-Aguilar, P., Trujillo-Martín, M. M., Ramos-Goñi, J. M., Mahtani-Chugani, V., Perestelo-Pérez, L., & Posada-de la Paz, M. (2009). Patient involvement in health research: A contribution to a systematic review on the effectiveness of treatments for degenerative ataxias. *Social Science & Medicine*, *69*, 920–925. doi:10.1016/j.socscimed.2009.07.005

Shewan, C. M. (1979). *The Auditory Comprehension Test for Sentences (ACTS)*. Chicago, IL: Biolinguistics.

Sinha, I. P., Gallagher, R., Williamson, P. R., & Smyth, R. L. (2012). Development of a core outcome set for clinical trials in childhood asthma: A survey of clinicians, parents, and young people. *Trials*, *13*, 103. doi:10.1186/1745-6215-13-103

Spreen, O., & Benton, A. (1969). *Neurosensory Center Comprehensive Examination for Aphasia*. Victoria: Neuropsychology Laboratory, University of Victoria.

Stanley, K. (2007). Design of randomized controlled trials. *Circulation*, *115*, 1164–1169. doi:10.1161/circulationaha.105.594945

Turk, D. C., Dworkin, R. H., Revicki, D., Harding, G., Burke, L. B., Cella, D., & Rappaport, B. A. (2008). Identifying important outcome domains for chronic pain clinical trials: An IMMPACT survey of people with pain. *Pain*, *137*, 276–285. doi:10.1016/j.pain.2007.09.002

UN General Assembly. (2006). *Convention on the rights of persons with disabilities*. Retrieved from http://www.un.org/

Verna, A., Davidson, B., & Rose, T. (2009). Speech-language pathology services for people with aphasia: A survey of current practice in Australia. *International Journal of Speech-Language Pathology*, *11*, 191–205. doi:10.1080/17549500902726059

Visch-Brink, E. G., Denes, G., & Stronks, D. (1996). Visual and verbal semantic processing in aphasia. *Brain and Language*, *55*, 130–132. doi:10.1006/brln.1996.0097

Wade, D. T. (2003). Outcome measures for clinical rehabilitation trials: Impairment, function, quality of life, or value? *American Journal of Physical Medicine & Rehabilitation*, *82*, S26–S31. doi:10.1097/01.PHM.0000086996.89383.A1

Wade, D. T. (2009). Goal setting in rehabilitation: An overview of what, why and how. *Clinical Rehabilitation*, *23*, 291–295. doi:10.1177/0269215509103551

Wertz, R. T., Collins, M. J., Weiss, D., Kurtzke, J. F., Friden, T., Brookshire, R. H., & Resurreccion, E. (1981). Veterans Administration cooperative study on aphasia: A comparison of individual and group treatment. *Journal of Speech and Hearing Research*, *24*, 580–594.

Williamson, P., & Clarke, M. (2012). The COMET (Core Outcome Measures in Effectiveness Trials) Initiative: Its role in improving Cochrane Reviews. *Cochrane Database of Systematic Reviews*, *5*. doi:10.1002/14651858.ED000041

Williamson, P. R., Altman, D. G., Blazeby, J. M., Clarke, M., Devane, D., Gargon, E., & Tugwell, P. (2012). Developing core outcome sets for clinical trials: Issues to consider. *Trials*, *13*, 132. doi:10.1186/1745-6215-13-132

World Health Organization. (2001). *World Health Organization: International Classification of Functioning, Disability and Health (ICF)*. Geneva: Author.

World Health Organization. (2011). *The world report on disability*. Retrieved from www.who.int

Worrall, L., Sherratt, S., Rogers, P., Howe, T., Hersh, D., Ferguson, A., & Davidson, B. (2011). What people with aphasia want: Their goals according to the ICF. *Aphasiology*, *25*, 309–322. doi:10.1080/02687038.2010.508530

Xiong, T., Bunning, K., Horton, S., & Hartley, S. (2011). Assessing and comparing the outcome measures for the rehabilitation of adults with communication disorders in randomised controlled trials: An International Classification of Functioning, Disability and Health approach. *Disability and Rehabilitation*, *33*, 2272–2290. doi:10.3109/09638288.2011.568666

Zuckerman, M., & Lubin, B. (1965). *Manual for the Multiple Affect Adjective Checklist*. San Diego, CA: Educational and Industrial Testing Service.