Title:

Development and preliminary validation of a patient-reported outcome measure for Conversation Partner schemes: the Conversation and Communication Questionnaire for People with Aphasia (CCQA)

Abstract

Background: Conversation Partner schemes are increasingly used as a way of addressing the psychosocial and emotional consequences of aphasia, providing opportunities for people with aphasia to engage in authentic conversation and to develop social relationships. As yet, there are no outcome measures, that are theorised to match what is expected to change and how such changes are best identified, and that specifically address the constructs of Conversation Partner schemes.

Aims: This study aimed to develop a new, theoretically motivated and accessible patient reported outcome measure for evaluating the experiences of people with aphasia involved in Conversation Partner schemes, and for assessing the impact of schemes on areas of importance to people with aphasia.

Methods & procedures: A mixed-methods study was undertaken in two phases. Phase 1 (item generation) used semi-structured one-to-one interviews and focus groups, which were subject to thematic analysis; Nominal Group Technique was used to develop and refine the item pool. In Phase 2 cognitive interviews were used to examine content validity; structural validity was examined using statistical methods (exploratory factor analysis; Rasch model analysis).

Outcomes & results: Six themes from interviews and focus groups were developed into 41 candidate items through Nominal Group Technique. Item reduction through cognitive interviewing produced a 30-item scale, which was piloted and then field-tested by 123 community dwelling adults with aphasia; 121 responses were subject to exploratory factor analysis and further item reduction, producing a four factor, 14-item scale. Rasch analysis demonstrated overall fit to the Rasch model and excellent targeting of items to person. Creation of 3 testlets by grouping items together accommodated the dependence found between pairs of items.

Conclusions: The Conversation and Communication Questionnaire for people with Aphasia V3 is a 14-item, patient-reported measure for use with patients with aphasia taking part in Conversation Partner schemes. It is concise, has strong content validity, and has some supporting evidence of construct validity. Further research is needed to test its reliability and responsiveness.

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Background and aims

Conversation is considered “the fundamental site” for language use (Clark, 1996, p.318-19). It is co-constructed and critical for maintaining social relationships, and sustaining a sense of self (Clark, 1996; Schiffrin, 1996). Essentially, dialogic interaction, or conversation is a crucial resource “for the display of self and identity” (Schiffrin, 1996, p.168). The transformation of experience into personal stories (De Fina, Schiffrin & Bamberg, 2006), and the ways in which this is achieved, are key considerations for people with aphasia (PWA), who face major life changes in terms of identity and the loss of personal histories (Parr, 2007). Engaging in conversation can be difficult for many PWA (Simmons-Mackie, Savage & Worrall, 2014), and therefore the personal and social consequences of aphasia are pervasive (Simmons Mackie & Damico, 2007). Faced with often profound disruption to conversational capabilities, PWA have reported feelings of social isolation (e.g. Parr, 2007; Simmons-Mackie *et al*., 2014); boredom, frustration (e.g. Parr, 2007; Worrall, Sherratt, Rogers, Howe, Hersch *et al*., 2011); and depression (e.g. Code & Herrmann, 2003).

Researchers and clinicians involved in investigating or providing services for PWA have increasingly turned their attention to ways of addressing the psychosocial and emotional consequences of aphasia. This direction aligns with the widely accepted view that aphasia rehabilitation should focus on more than the impairment (e.g. Shiggins, Soskolne, Olenik, Pearl, Haaland-Johansen *et al*., 2018; Elman, 2016; Simmons-Mackie & Damico, 2007), providing, among other things opportunities to engage in authentic conversation and to develop social relationships (Elman, 2016). One such approach, the Conversation / Communication Partner (CP) Scheme, inspired by the pioneering work of Jon Lyon and colleagues (1997) was rolled out in the UK in 2001 by Connect, the communication disability network (see McVicker, Parr, Pound & Duchan, 2009). CP schemes have subsequently been deployed through university programmes in the UK (e.g. Horton, McVicker & Stokes, 2010), and the Republic of Ireland (e.g. McMenamin, Tierney & MacFarlane, 2015), as well as in National Health Service (NHS) settings (e.g. Sheffield Teaching Hospitals https://www.sth.nhs.uk/clientfiles/File/Conversation%20Partner%202017.pdf).

CP schemes are essentially environmental interventions, aiming to enhance social connectedness for PWA through access to conversation and social interaction. Access is enabled through visits from a trained volunteer (or volunteers, in the case of university 'peer placements': Conversation Partner/s) to the place where the PWA lives, be it in their own home, nursing or residential care home, with a view to reaching "PWA who are unable or unwilling to access local groups and support networks, and who experience profound isolation and social exclusion" (McVicker *et al*., 2009, 54). PWA referred to CP schemes tend to have a high prevalence of severe aphasia (McVicker *et al*., 2009; Horton *et al*., 2010), and to live alone in their own home, or in a residential / nursing home (McVicker *et al*., 2009; Horton *et al*., 2010). This highlights the scale of the challenge to social connectedness faced by this population compared with, for example, working age (Pound, 2013), or community dwelling PWA (Brown, Davidson, Worrall & Howe, 2013), who may have greater access to friendship networks.

Training for volunteers in Supported Conversation for Adults with Aphasia^{TM} (SCA) (Kagan, 1998; Kagan & Gailey, 1993), known generically as Communication or Conversation Partner Training (CPT) (see Saldert, Jensen, Blom Johansson, & Simmons-Mackie, 2018; Simmons-Mackie, Raymer & Cherney, 2016; Simmons-

Mackie, Raymer, Armstrong, Holland & Cherney, 2010) is a necessary, but not sufficient element of CP schemes. The provision of ongoing opportunities for PWA to engage in conversation and social interaction, and to develop new relationships through weekly volunteer visits, usually over a six-month period is the key mechanism for change in this intervention. The CP scheme is essentially a complex intervention implemented through “a social process of collective action” (May, 2013, 2) involving contributions from and interactions between all participants involved. Visits are tailored to each individual PWA; volunteers adapt their own communication, and conversations are co-constructed as appropriate. There are no expectations of direct work on communicative functioning, nor is ‘work’ on self-esteem or confidence raising part of the remit of volunteers.

The impact of CP schemes has been theorised in a number of ways. These include: improving “the viability of communication with a naive normal adult while concurrently strengthening a more active, self-determined, and controlled role in daily life” (Lyon *et al*., 1997, 695); and aiming “to enhance the quality of life of people with aphasia and to reduce their isolation…[where] people with aphasia would have more confidence in their communication and be more willing to try new things” (McVicker *et al*., 2009, 54). The nature and extent of these effects are presumably predicated on the quality of conversational interactions and the nature of relationships, which develop over the time course of the intervention. These interactions and relationships may, to a greater or lesser extent engender in PWA a sense of greater connectedness through opportunities for social interaction, reduce boredom and frustration, increase communicative confidence and enhance feelings of self-worth. The projected effects relate to a number of domains of the International Classification of Functioning, Disability & Health (ICF) (World Health Organisation, 2001): Body Function (e.g. optimism; confidence; emotional functioning; experience of self); Activity / Participation (e.g. conversation; interpersonal interactions and relationships); Environmental Factors (e.g. support and relationships; attitudes). In qualitative studies, PWA who have taken part in CP schemes report positive experiences in terms of enhanced social relationships, increased self-confidence and positive identity changes (e.g. McMenamin *et al*., 2015; Horton *et al*., 2010; McVicker *et al*., 2009).

The importance of providing evidence of outcomes from aphasia interventions has been emphasised (e.g. Simmons-Mackie, Threats & Kagan, 2005). Careful consideration of mechanisms for change, outcome domains, measurement and selection of measures is seen as crucial (Simmons-Mackie *et al*.,2005; Xiong, Bunning, Horton, & Hartley, 2011; Worrall *et al*., 2011; Coster, 2013; Wallace, Worrall, Rose, & Le Dorze, 2014; Saldert *et al*., 2018), while the value of assessing outcomes, that are of key importance to the person – Patient Reported Outcome Measures (PROMS) – has been underlined (Devlin & Appleby, 2010). Specific PROMS aim to provide a patient's own assessment of a particular aspect of health as they see it (Staniszweska, Haywood, Brett, & Tutton, 2012; Devlin & Appleby, 2010).

PROMS for PWA are well documented in the recent literature (e.g. Kagan, Simmons-Mackie, Rowland, Huibregts, Shumway *et al*., 2011; de Riesthal & Ross, 2015; Swinburn, Best, Beeke, Cruice, Smith *et al*., 2018). A number of PROMS exist that might be relevant to measuring some of the projected outcome domains of CP schemes, but, as Coster (2013) points out, the key questions are whether available measures sample the relevant areas that are expected to be influenced by the intervention; and whether they are sensitive to the degree of change that might be expected. While domains such as ‘confidence’ and ‘self-esteem’ for example, could be addressed using *The Communication Confidence Rating Scale for Aphasia* (Cherney, Babbitt, Semik, & Heinemann, 2011), and *The Visual Analogue Self-Esteem Scale* (Brumfit & Sheeran, 1999) respectively, these measures do not address social connectedness or environmental factors. A number of measures addressing aphasia-related quality of life (*Stroke and Aphasia Quality of Life Scale* [SAQOL-39], Hilari, Byng, Lamping & Smith, 2003; *Assessment for Living with Aphasia* [ALA], Kagan *et al*., 2011; Simmons-Mackie, Kagan, Victor, Carling-Rowland, Mok, *et al*., 2014; the *Aphasia Impact Questionnaire* [AIQ], Swinburn *et al*., 2018) are also potentially relevant. The SAQOL-39 (Hilari *et al*., 2003) however, includes content that would not be expected to change as a result of the CP scheme intervention, such as items related to ‘energy’ and ‘physical function’; the ALA (Kagan *et al*., 2011), while addressing communicative participation, environmental and personal (well-being) factors, includes a relatively high proportion (68%) of items about participation generally, and includes items related to rating individual language modalities, which again are not expected to change as a result of the intervention; the AIQ (Swinburn *et al*., 2018) also contains more general participation items that would not be expected to change, and communication items, which include reading and writing. These measures would therefore be unlikely to be sensitive to changes expected from the CP scheme intervention. Finally, Lyon’s (1987) Psychosocial Well-being Index (PWI), while being patient-reported and addressing a key domain of the CP intervention, is researcher developed rather than being grounded in the experiences of people with experience of CP schemes.

We therefore conclude that no outcome measures exist that match what is expected to change and how such changes are best identified (see Coster, 2013), and that specifically address the theorised constructs of CP schemes. The aim of this study was therefore to develop a new, theoretically motivated and accessible self-report measure for evaluating the experiences of PWA involved in CP schemes, and for assessing the impact of schemes on areas of importance to PWA.

Methods

Study design

We used a mixed-methods study undertaken in two phases, according to well-established methodology for the development of health scales and PROMS in particular (e.g. Streiner, Norman & Cairney, 2014; Yorkston, Baylor, Dietz, Dudgeon, Eadie *et al*., 2008; Terwee, Prinsen, Chiarotto, Westerman, Patrick *et al*., 2018; Patrick, Burke, Gwaltney, Leidy, Martin *et al*., 2011a; 2011b): 1) item generation (qualitative methods); 2) content and construct validity (qualitative and quantitative methods). An overview of the methodology and phases of development of the Conversation and Communication Questionnaire for People with Aphasia (CCQA) is set out in Figure 1 below.

FIGURE ONE ABOUT HERE

Ethical approval for the study was obtained from the University of East Anglia Faculty of Medicine and Health Sciences Research Ethics Committee (Ref: 2009/10-003). Written consent was obtained from participants prior to taking part in phases 1) and 2); while completion and return of questionnaires in phase 2) was taken as implied consent (Burns & Grove, 2005).

Phase 1 Item generation

Interviews and focus groups

According to Terwee *et al*. (2018) content validity is the most important measurement property of a PROM. Content validity encompasses: relevance (within a specific population and context of use); comprehensiveness (with respect to patient concerns); and comprehensibility (being understood by patients as intended) to the construct, target population and context of use. The importance of involving people who experience specific impairments and possible effects of these, has been underlined in reports on the development of communication- and / or aphasia-related PROMS (e.g. Swinburn *et al*., 2018; Baylor, Oelke, Bamer, Hunsaker, Off *et al*., 2016; Long *et al*., 2008) and PROMS more generally (e.g. Staniszweska *et al*., 2012). Therefore, people with aphasia, who had been involved in the Conversation Partner scheme at the University of East Anglia, were invited to take part in developing the outcome measure. Fourteen PWA were invited to participate in interviews or focus groups; twelve consented to take part. Ten PWA were involved in a semi-structured, topic-guided, one-to-one interview, either at the university or in the PWA's own place of residence. Six of these participants also took part in focus group discussions, with a further two PWA taking part in the focus group discussions only. Two topic-guided focus groups (N=4 PWA per group) were conducted at the university (see Table 1 for an overview of characteristics and research participation of people with aphasia taking part in semi-structured interviews and focus group discussions).

TABLE ONE about here

Interview and focus group topic guides (see Appendix) were derived from a structured review of the literature and aphasia-related resources: teaching-learning resources; web-site related references (e.g. Connect – the communication disability network; Speakability; the Stroke Association), and personal recommendations from colleagues / experts. The focus was on the impact of aphasia on life and living deemed to be important to PWA, and the apparent causal mechanisms, including contextual factors, that led to or sustained the identified issues. Key topics were grouped using three of the Living with Aphasia: Framework for Outcome Measurement (A-FROM) categories (Kagan, Simmons-Mackie, Rowland, Huibregts, Shumway *et al*., 2008). In order to develop further understanding of CP schemes themselves beyond the impact of aphasia on participation, personal identity and the experience of communication and language environments, a topic specific to CP volunteer visits and their potential impacts was also included. Prompts and follow-up questions were used in order to enable PWA with limited expression to convey their perceptions and experiences (Luck & Rose, 2007).

Interviews and focus groups were carried out by the lead author and / or SLT dissertation students from the undergraduate programme at the University of East Anglia; all team members were trained in qualitative interviewing and the use of supported communication skills. Interviews and focus groups lasted 30-45 minutes and were recorded using video or digital voice recorder and transcribed for analysis. Field notes were made by the interviewer or co-researcher to enhance understanding of the topics covered for transcription purposes. Transcripts were read and re-read so the researchers became fully immersed in the data (Hsieh & Shannon, 2005); stages and processes of qualitative content analysis were followed (Graneheim & Lundman, 2004): meaning units were identified and codes created to link units, which were organised into higher order themes. Peer validation of coding on a sample of analysed transcripts was used to ensure rigour; any discrepancies were identified and discussed and adjusted accordingly.

Developing candidate items: Nominal Group Technique

Candidate items were derived from consideration of the literature review, analysis of interviews and focus groups using Nominal Group Technique (Jones & Hunter, 1995; Van de Ven & Delbecq, 1972). The processes used to consider the combined findings are set out in Table 2.

TABLE 2 ABOUT HERE

Team members (SH and five U/G SLT dissertation students) reflected on findings and individually wrote down ideas based on these reflections. Ideas were read out and clarified in the group – for example, we discussed whether 'my past life' and 'previous identity' were synonymous, or whether they were important distinctions relevant to how the person felt about themselves? After discussion and suggestions from readings of members of the group the team agreed that they could be merged as 'how I used to be'.

A list of items based on all findings and including ideas from the whole group was developed. Twenty-eight ideas were taken forward and developed into 66 statements. As far as possible these statements were worded verbatim from expressions used by people with aphasia – for example: "I can't get my point across"; "I like talking with people who listen"; "I would love to have a chat". Team members then voted on each item (4 = very important; 3 = important; 2 = slightly important; 1 = not at all important). Any item with a mean score of less than 3 was rejected. This process produced 41 candidate items for a first version of the Conversation and Communication Questionnaire for People with Aphasia (CCQA V1). Readability of items was then examined using tools such as the Flesch-Kincaid readability formula (Cotugna, Vickery & Carpenter-Haefele, 2005) and adjustments made accordingly.

Phase 2 Content and construct validity

This phase comprised two stages. Firstly, cognitive interviews (Yorkston *et al*., 2008; Willis, 2005) were used to assess content validity. PWA were asked how well they understood the instructions, item content and relevance, and means of responding to the CCQA V1, which led to the production of the CCQA V2; secondly, statistical methods were used to examine the construct validity of the new measure, producing CCQA V3 (Mokkink, Terwee, Patrick, Alonso, Stratford *et al*., 2010).

Cognitive interviews

Nineteen PWA, eight of whom had taken part in interviews or focus group discussions took part in the cognitive interviews (see Table 3). These interviews began with participants who had already taken part in interviews or focus group discussions. We were concerned that not enough older PWA or those living alone or in care settings had been recruited to the study thus far. We therefore continued recruitment to the cognitive interviews, purposively targeting PWA from these populations.

TABLE 3 about here

Cognitive interviews were conducted on a one-to-one basis using a structured protocol: at the start of each interview, participants were shown the CCQA's written instruction sheet and asked for feedback on the clarity of the instructions and the appropriateness of the time frame ('in the last month'); instructions were also read aloud by the interviewer. They were then asked three questions about the instructions: 'Do you understand what you are being asked to do?', 'Is it easy to follow what is meant?', and 'Is the 'reference period' you are being asked to think about appropriate?' For the CCQA V1 they were given a choice of two item-response options: a continuous visual analogue scale (chosen by one person), and a discrete Likert-type scale (chosen by the remainder). All participants were presented with the 41 candidate items, one-by-one. After responding to each item, the participant was asked six questions to structure their feedback on the item and the response process. These were: 1) What came to mind when you read this item?; 2) Is this something you consider to be important?; 3) Was it easy to understand?; 4) Was the item too ambiguous, vague or confusing?; 5) Have you any suggestions for rewording?; 6) Is it clear how to respond to the item (using the response format in their particular interview i.e. Likert-type or visual analogue)? Responses were recorded on a form devised for the purpose. Interviews took up to 1½ hours but were concluded sooner if all items had been covered or candidates expressed a wish to stop.

Participant responses to the cognitive interviews were collated, and subject to qualitative analysis by the first two authors. This involved close examination of responses to the questions outlined above in order to: identify potential items for elimination; to make changes to instructions and response options, refine wording as appropriate, thus developing a 30-item CCQA V2, which was piloted with 12 PWA who had already contributed to the study.

Construct validity

Construct validity is defined as the degree to which the scores of an instrument are consistent with the hypothesis regarding internal relationships (structural validity), relationships with other instruments (hypothesis testing validity) or differences between different groups (cross-cultural validity) (de Vet, Terwee, Mokkink & Knol, 2011). In this study we assess only structural validity, collecting prospective data from PWA in a range of community settings to assess how items making up the 30-item CCQA V2 interact. We sent out letters of invitation with 310 packs of CCQA V2 to organisers of community stroke and aphasia groups in the UK, recruiting 123 participants. Completion and submission of the questionnaire by PWA was taken as consent to participate in the study (Burns & Grove, 2005). Participants were presented with the 30-item scale. Responses to the 10 items worded in such a way that agreement with the statement was considered a positive outcome (e.g. ‘I do have good chats’), were coded: ‘Strongly agree’ = 2, Agree = 1, Disagree = -1, Strongly disagree = -2; whereas the 20 items worded in a way that agreement with the statement was considered a negative outcome (e.g. ‘My speech frustrates me’), were coded: ‘Strongly agree’ = -2, Agree = -1, Disagree = 1, Strongly disagree = 2. No zero response was allowed. In this way a positive score indicated a positive outcome.

Statistical analyses

Firstly, we assessed structural validity by performing exploratory factor analysis (EFA). We then used the factor structure suggested to form the basis of a subscale structure and used quantitative methods to decide which items should be retained. In addition, the conceptual importance and logical fit was used to determine whether items should be removed, a process involving discussion and a number of iterations. Quantitative methods made use of the factor loadings, the distribution of individual items, inter-item correlations (Spearman), Cronbach alphas and item-total correlations. High loading items which were not skewed, which were more correlated with items in their own subscale than those in other subscales, which had high item-total correlations and could not be eliminated without reducing the subscale's Cronbach alpha, were favoured. Factors were extracted using the matrix of correlations, with data included if available pairwise, using principal axis factoring and rotated using the promax rotation with Kaiser normalisation. The rotation is oblique which allows factors to be correlated. All analysis was done using SPSS v22.

Secondly, construct validity of the revised 14-item CCAQ V3 was assessed by examining fit to the Rasch measurement model (Rasch, 1960). Its use is advocated in development of new scales as it provides a unified approach to assessing several aspects of a scale's structural validity that are a prerequisite for interpreting a summed score at interval-level. We performed Rasch analysis using RUMM2030 software to test for unidimensionality, local independence, category ordering and to assess targeting of item difficulty to patient ability (Andrich, Lyne, Sheridan & Luo, 2003; Andrich, 1978).

Results

Phase 1 Item generation

Interviews and focus groups

The six key themes, with sub-themes and illustrative quotes from analysis of interviews and focus groups are set out in Table 4.

TABLE 4 ABOUT HERE

Identity and sense of self The onset of stroke and aphasia caused significant or catastrophic disruption to participants' lives. Both physical and communication impairments meant a loss or change of roles in family and at work, engendering negative feelings about self, with participants sometimes experiencing a lack of respect from others. Many talked about becoming dependent on family members, especially a spouse, and having to leave behind their previous life. However, many also talked about more positive changes over time, and a gradual acceptance of a new self.

Participation in social life Social lives were significantly compromised, due to physical and communication impairments. Conversations with strangers became very difficult, and something to be avoided, while many participants also felt ignored. Having fewer opportunities for conversation meant people lost touch, and became disconnected and socially isolated, with consequent impact on their quality of life. The attitudes and capabilities of conversation partners could mean positive or negative experiences; practical and emotional support from family or other PWA was helpful.

Emotional impact The most frequently expressed emotion was frustration, very often caused by speech, language and communication impairments. However, participants also talked about a loss of confidence, sadness, embarrassment and anxiety and depression, especially soon after onset. While some participants talked about fearing negative attitudes of others, many talked about how they had become more positive over time, with their confidence increasing, despite ever-present ups and downs in mood.

Coping strategies Many talked about how they coped generally and in the context of communication – for example, by letting others know about their aphasia. Coping could be about personal determination; not seeing oneself as a victim; or a gradual acceptance of the new self. Many had taken on new challenges and roles – for example, student education or training – which might help re-form a positive identity.

Speech, language and communication Aphasia was “the hardest to deal with”. A person’s speech capability might vary. This was sometimes caused by contextual factors, such as the degree to which other people were aware of their difficulties. This impacted on the quality of conversations and how people felt about themselves, as well as the emotions they experienced.

Participation in the CP scheme Most participants were very positive about their experiences, which gave them opportunities to feel natural, listened to, included, valued and supported. The company of a CP might build confidence or help regain a sense of self identity, although some participants also felt it was an opportunity to educate and support students in training.

Developing candidate items: Nominal Group Technique

The 28 ideas derived from the data (literature review, and analysis of interviews and focus groups) were developed through the Nominal Group Technique into 66 distinct statements (candidate items) e.g. “My speech makes me frustrated”. Voting by team members on the perceived importance of each item produced a mean ‘importance rating’ for each, with any item scoring under 3 being discarded. Twenty-five items scored under 3 and were therefore removed. The voting process produced 41 candidate items for CCQA V1. Scores for each item are set out in Table 5.

TABLE 5 ABOUT HERE

Phase 2 Content validity

Cognitive interviews

Instructions and period of reference The majority of participants found the instructions easy to understand. One person commented that they took “a while to process”, and another required additional verbal explanation from the interviewer. Most comments related to the period of reference. Of the five people who commented on this, four said they felt that a month was too short: periods ranging from two months to the total time post-stroke were suggested as alternatives. The fifth person found one month too long to think about and would have preferred a week or a fortnight.

Consideration of candidate items Participants’ responses were scrutinised in detail by the first two authors to identify possible items for elimination. A combination of factors was used in selecting those for elimination. Items judged as important by a relatively low percentage of participants (e.g. ‘I do feel myself’, which was rated as important by only 50%; ‘I feel frustrated’ – “too broad”), were identified; those perceived as ‘very easy’ to understand by the lowest percentage of people, or identified as ‘too ambiguous’, ‘too vague’ or ‘confusing’ by more than one individual, were considered (e.g. ‘I don’t feel in control’ – “control of what?”). Responses to the question ‘What came to mind?’ were taken into account to ensure that interpretation was consistent with the intended meaning, with most responses suggesting a high level of consistency. Participants’ comments regarding perceived duplication of subject matter between items were also considered at this stage (e.g. ‘I can’t join in with conversations’ / ‘I feel left out during group conversations’; ‘People don’t listen to me when I talk’ / ‘People don’t take time to listen to me’).

The decision on which items to eliminate also allowed for consideration of coverage of the A-FROM domains, to ensure content validation by adequate distribution across the four life categories; many items overlapped two domains (such as ‘I feel sad when I can’t join in conversations’, which relates both to ‘Participation in life situations’ and ‘Personal identity, attitudes and feelings’). At the end of this process, eleven candidate items were targeted as suitable for elimination, thus reducing the number of candidate items to 30 for CCQA V2.

Wording of items Participants’ comments on the readability of each candidate item were considered, as well as their suggestions for possible re-wording. Items containing a negative statement (such as ‘People don’t take time to talk to me’) were felt by some participants to be difficult to rate on the discrete scale (i.e. with options such as ‘not at all’). Some of these were rephrased as positive statements (e.g. ‘Most people take time to talk to me’). In others, the negative form was retained if it was felt to convey an issue of particular importance that would be diluted by a reformulation in the positive (e.g. ‘People don’t listen to me when I talk’); it was postulated that amendments to the response scale would address any remaining difficulties with the use of the negative. The wording of other items was regarded by some participants as too general, with people stating that they would respond differently to the item in different situations (e.g. ‘People leave me out of their conversations’ might apply in the pub but not at a family meal). Such items were re-worded to reflect the fact that respondents are being asked to reflect about situations *in general*, e.g. ‘People *generally* leave me out of their conversations’. The readability of each re-worded item was checked using the Flesch-Kincaid readability formula (Cotunga, Vickery, & Carpenter-Haefele, 2005). Additional modifications were needed in a few cases (e.g. the word ‘generally’ in examples such as the one cited above resulted in low readability scores; such items were therefore re-worded further, for example ‘People *tend to* leave me out of their conversations’).

The remaining, re-worded items were re-ordered to ensure an even spread of all four A-FROM domains throughout the questionnaire. Care was taken to avoid adjacency of items sharing the same domain(s), to reduce response bias between items.

Response scale modification During cognitive interviewing, participants were given the choice at the outset of responding with a visual analogue or discrete, Likert-style scale. The majority of participants opted for the discrete scale. A discrete format, with worded options, was therefore planned for the draft pilot questionnaire. The wording of response options was modified, reflecting the difficulties experienced by some participants in matching item and response wording. The original options of ‘Not at all’, ‘A little’, ‘Quite a bit’, ‘A lot’ and ‘Extremely’ were replaced by: ‘I strongly agree’, ‘I agree’, ‘I disagree’ and ‘I strongly disagree’. Items retaining the negative form, such as ‘People don’t listen to me when I talk’, which could not be appropriately answered by the option ‘extremely’, were more easily addressed by ‘I strongly agree’, as were items describing an act as opposed to a feeling (e.g. ‘I talk to lots of different people’). It was also noted that severely aphasic people whose expression (verbal or non-verbal) was limited to ‘yes’ and ‘no’ tended to restrict themselves to the extreme ends of the scale, rather than the more moderate options. They required clear prompting to consider the moderate options, but then seemed to restrict themselves to those options instead and forget or dismiss the extremes. It was hypothesised that for such severely aphasic people, a staged decision-making process involving two separate, binary choices might be more accessible. We therefore devised a grid-style scale, and two over-arching descriptors (‘True’ and ‘Not true’) were added, separating the four options into pairs, with a gap between the two pairs to reinforce their distinctness:

True	
I strongly agree	I agree

Not True	
I disagree	I strongly disagree

This modification went on to prove successful during piloting of the 30-item CCQA V2, with severely aphasia participants, who required one-to-one support seeming to benefit from the revised response scale. The four boxes at the bottom of the scale could be covered initially, so that the participant had to choose simply between the ‘True’ and ‘Not True’ pairs. Having made this decision, the non-chosen pair could then be covered, leaving the participant to refine their choice between ‘I strongly agree / I agree’, etc.).

Exploratory factor analysis

The 30-item CCQA V2 was returned by 123 PWA. We were not able to consistently collect information on the sex, age, type or degree of aphasia, or time post onset from these individuals; therefore, these data are missing. Some of the measures were completed with support from another person (e.g. husband; daughter; volunteer); some had comments attached regarding aspects of the measure (e.g. “a bit repetitive”) or process of completion (e.g. “facilitated by volunteer”; “completed independently”). One participant responded ‘true’ or ‘not true’ only, while another participant’s responses were all missing. Therefore, these were omitted from the analysis. Of the remaining 121 questionnaires, 98 respondents completed all 30 items; 18 respondents omitted 1-4 items; 2 respondents omitted 5-8 items; 3 respondents omitted 13-17 items. Questionnaire items themselves had between 0 and 6 missing values.

A symmetric, unimodal distribution with mean score of approximately 0, is desirable (Nunnally & Bernstein, 1994). Ten items had skewed scores such that less than 20% disagreed. Of these, 7 items were ones where agreement with the statement was considered a negative outcome, resulting in a mean item score of about -1; and 3 items where agreement with the statement was considered a positive outcome, giving a mean of about 1. No items were such that less than 20% agreed.

In an exploratory factor analysis based on all 30 items, 7 factors had eigenvalues greater than 1 and these accounted for 66.3% of the variance. The first factor accounted for 32.6% of the variance; the second 10.3%; the third 5.8%; and fourth to seventh 4.8%, 4.4%, 3.7% and 3.5% respectively. Except for factor 4 which had low correlations with F1 and F2, all correlations between factors were between 0.2 and 0.65 which is reasonable (Nunnally & Bernstein, 1994). However, we considered seven subscales excessive for a measurement scale and examined a number of alternative solutions with fewer factors. A three-factor solution accounted for 48.7% of the variance; however, inclusion of a fourth factor accounted for 54% of the variance in all. This solution was similar to the three-factor one, but the final factor split into items concerning the behaviour of other people, and items about talking to lots of people, which seemed to be an important distinction. In the four-factor solution all items loaded reasonably highly on at least one factor and each factor included at least three items. Tables 6 and 7 show the pattern and factor correlation matrices respectively for the four-factor solution.

TABLE 6 ABOUT HERE

TABLE 7 ABOUT HERE

Factor 3 had a low correlation with factors 1 and 2 and was clearly different suggesting that it would be unreasonable to combine items in all four factors into a single total score. This is plausible as factor 3 concerned other people's behaviours and not those of the respondent, or the respondent's emotions.

For completeness we considered including an additional factor. In a five-factor solution, factors 3 and 4 remained the same, but three items moved out of factor 2 to form the fifth factor, which corresponded to factor 6 of the seven-factor solution. However, we did not consider this distinction to be useful, with the four-factor solution having greater resonance to domains from the A-FROM for example.

Item reduction

We formed subscales from the item groups suggested by the four-factor solution, and in a series of meetings discussed a number of item reduction possibilities, working through each subscale, considering each item in turn, starting with the highest loading. Items were considered for elimination if they: had high correlations with other items; had a high number of missing values; were skewed positively or negatively; had a low loading; loaded onto more than one factor; had a high alpha if item deleted (suggesting redundancy); or if there were potential problems with lack of logical or conceptual 'fit'.

Cronbach alpha for the first subscale of 16 items was 0.915. All 'alphas if item is removed' were above 0.9. The second subscale (of seven items) had Cronbach alpha of 0.78, where alpha of 0.8 is preferred if there are at least 4-5 items; the third also had Cronbach alpha of 0.78, but only three items; the fourth subscale of four items had Cronbach alpha of 0.718. After the first round of discussions, seven items were eliminated from subscale 1; four from subscale 2; none from subscale 3; and one from subscale 4. The subscales were labelled to convey the conceptual content. Table 8 shows the four subscales and items after a first round of elimination.

TABLE EIGHT ABOUT HERE

Cronbach alpha for the reduced subscale 1 was now 0.862. On discussion we decided items 4 ('People don't listen to me when I talk'), and 25 ('I feel embarrassed by my speech') were more appropriate to subscales 3 and 2 respectively than subscale 1. This was perhaps unsurprising as they were low loaders in the original factor analysis. When items 4 and 25 were both omitted alpha barely reduced to 0.844. Inter-item correlations within the reduced subscale 1 ranged from 0.213 to 0.569 which is acceptable (Nunnally & Bernstein, 1994). However, item 26 (‘It is frustrating when I can’t join in’) in subscale 1 had a correlation of 0.44 with item 19 in subscale 2, and of 0.55 with item 12 in subscale 2. These correlations were high relative to inter-item correlations within subscale 2 of between 0.3 and 0.42. If item 26 was omitted from subscale 1, in addition to items 4 and 25, alpha was still 0.824. On this basis we agreed to omit all of these three items from subscale 1. Alpha reduced if any additional item was removed except that deletion of item 23 (‘I feel lonely’) kept alpha the same. For subscale 1 item-total correlations were all above 0.5 except for item 23 (0.471), corresponding to the effect on alpha on deletion. We therefore agreed to delete item 23.

Inter-item correlations within subscales 3 and 4 ranged from 0.4 to 0.6 which is acceptable (Nunnally & Bernstein, 1994). Item-total correlations for reduced subscales 2, 3 and 4 were between 0.47 and 0.7. Cronbach alpha for the subscales 2, 3 and 4 respectively were 0.70 (3 items), 0.78 (3 items) and 0.73 (3 items). All ‘alphas if item deleted’ were lower than the corresponding whole subscale alpha except that omission of item 11 from subscale 3 increased it. However, given the small number of items in this subscale we decided to retain all items. The final round of discussions produced a 14-item scale (CCQA V3), which is set out in Table 9, showing sub-scales and scoring schema.

TABLE NINE ABOUT HERE

Rasch analysis

Initial analysis of the full 30-item CCQA V2 highlighted significant misfit to the Rasch model (item-trait total Chi-Square 92.9, p<0.0001). A second analysis was conducted on the shortened 14-item version that has been proposed as CCQA V3, which demonstrates overall fit to the Rasch model (total item-trait Chi-Square 17.9, p=0.21). Response thresholds for all 14 items were ordered and item fit residuals were within the accepted thresholds of +/- 2.5 logits. The 14-item CCQA however violates the assumption of independence required for summing all items into a single score. Fourteen pairs of items had residual correlations greater than the mean +0.2. The assumption of unidimensionality was also not met with 20.7% of equating t-tests of positively and negatively loading item subsets being significant at p<0.05 (95% CI: 16.8 to 24.5%). In order to accommodate dependence both a four- and three-subtest solution (testlets) were explored, where items are combined into a super-item. A three-subtest solution was found to fit the Rasch model and the number of significant equating t-tests were within an acceptable threshold (7.2%, 95% CI 3% – 11%). Figure 2 shows person-item threshold distribution after creating 3 testlets, demonstrating the distribution of persons by ability on top and distribution of items by difficulty on the bottom.

FIGURE 2 ABOUT HERE

Person Separation Index (PSI) is high at 83.4 indicating that the CCQA V3 can discriminate between 3 or more subgroups; however, this reduced to 0.67 after creating 3 subtests. Targeting of item difficulty to a persons' ability is excellent as demonstrated in Figure 3.

FIGURE 3 ABOUT HERE

The distribution of responses for some items shows some ceiling and floor effects, where the number of respondents endorsing the lowest or highest category was over 30%.

Discussion

This paper presents the development and preliminary validation of a new self-report measure for evaluating the experiences of PWA involved in CP schemes. This mixed-methods study addressed item generation, as well as content and structural validity of the measure.

Items for the CCQA were developed in ways that demonstrate a robust approach to sampling from the domain of interest (Patrick *et al*., 2011a). By inviting the participation of PWA, who had been involved in a CP scheme, rather than clinical experts we ensured that the pool of experiences was directly relevant to the target population and context of use, with good face validity (de Vet *et al*., 2011). A lack of content validity can impact on other measurement properties of an instrument, while missing concepts may decrease validity and responsiveness (Terwee *et al*., 2018). Although PWA were not involved in the Nominal Group Technique process, the fact that cognitive interviews were conducted with PWA with a reasonable range of demographic variables, living arrangements and aphasia severity ensured that items were subject to close scrutiny in terms of comprehensiveness and contextual relevance (Staniszewska *et al*., 2012; de Vet *et al*., 2011). A third of PWA involved in interviews or focus groups had severe aphasia and were living alone or in residential care; nearly half the PWA involved in cognitive interviews had severe aphasia, while a third were living alone or in residential care. Thus, the communication profile and living arrangements of PWA involved in developing and validating the CCQA were comparable with the profile typical of PWA taking part in CP schemes, so providing content and focus for the CCQA aligned with areas of key importance to participants, and with potential clinical relevance.

The 14-item CCQA V3 represents elements of a construct framework that are both ‘reflective’ (i.e. arising from the construct e.g. ‘stay clear of conversations’; ‘don’t feel confident’), and ‘formative’ (i.e. causative of the construct e.g. ‘people are helpful’) (Fayers & Hand, 1997). Items appear to align well to outcome domains reported in the literature on CP schemes (e.g. confidence; self-determination; active; social relationships). As is true of the A-FROM and unlike the ICF (see Simmons-Mackie et al., 2014), a number of items from the CCQA demonstrate a “dynamic overlap of domains” (Simmons-Mackie et al., 2014, 83), for example: Participation + Body Function (“My speech means I don’t have many conversations”); Body Function (emotional functions) + Participation (“I don’t feel confident to join in conversations”). However, the CCQA is not designed to be a measure of Body Function nor Participation as is understood in ICF terms, but rather is a measure of the subjective experience of those components. Importantly, the CCQA has the potential to provide insights into the PWA’s perspective on their communication, conversational opportunities and experiences – a ‘conversational quality of life’ – which, we would argue, is predicated on a number of interrelated factors arising from the nature and quality of the relationship between CP and PWA, which develops during the course of the intervention. This has parallels in the nature of relationships exemplified in successful friendships of community dwelling and working age PWA (Brown et al., 2013; Pound, 2013).

While other instruments (e.g. Assessment for Living with Aphasia; Aphasia Impact Questionnaire) address constructs relevant to outcomes of CP scheme participation, there is no ‘gold standard’ (see de Vet *et al*., 2011) for CP scheme outcomes against which to test the CCQA. Construct validation, using EFA was therefore appropriate. Due to resource limitations recruitment was dependent on the co-operation and commitment of a number of community stroke / aphasia groups across the UK. While a recruitment rate of 38% is not unreasonable, the rate of recruitment was extremely slow, and we were unable to ensure consistent collection of demographic and clinical data during the field-testing phase. We were therefore unable to carry out differential item functioning analysis relative to subgroups in the sample (e.g. sex; age group; aphasia severity etc). In addition, we did not reach the recommended recruitment target of five cases per item (Streiner *et al*., 2014), although we exceeded the “100 patients as an absolute minimum” recommended by de Vet *et al*., (2011).

The final 14-item CCQA V3 shows good fit to the Rasch model at total as well as individual item level, and excellent targeting of item difficulty to person ability. Furthermore, we found that response categories for all 14 items were ordered indicating that the four-response options work well and that respondents are able to discriminate between these. However, there is some multi-dimensionality due to the local dependence found between some items. Creating 3 subtests (testlets) accommodated this whilst retaining overall Rasch model fit. This means that if the CCQA is used in research, interval level data cannot be assumed from the summed score.

Conclusions

This paper has presented the first stages of development and validation of the CCQA. The CCQA V3 is a 14-item, patient-reported measure for use with PWA taking part in CP schemes. It has strong content validity, is concise and easy to complete. Cronbach alpha shows good internal consistency for each subscale, with good fit to the Rasch model at total as well as individual item level, and excellent targeting of item difficulty to person ability. Further work is needed to examine test-retest reliability, responsiveness, and performance against other measures. Additionally, the views of clinicians as users of the measure with PWA should be sought.

References

Andrich, D. (1978). Rating formulation for ordered response categories. *Psychometrika*, 43, 561–573 1978.

Andrich, D., Lyne, A., Sheridan, B., & Luo, G. (2003). *Rasch Unidimensional Measurement Models (RUMM) 2020*. Perth: RUMM Laboratory.

Baylor, C., Oelke, M., Bamer, A., Hunsaker, E., Off, C., Wallace, S.E., Pennington, S., Kendall, D., & Yorkston, K. (2016). Validating the Communicative Participation Item Bank (CPIB) for use with people with aphasia: an analysis of differential item function (DIF). *Aphasiology*, 31(8), 861-878. DOI: 10.1080/02687038.2016.1225274

Brumfit, S., & Sheeran, P. (1999). *VASES: Visual Analogue Self-Esteem Scale*. Bicester, UK: Winslow Press Limited.

Brown, K., Davidson, D., Worrall, L.E., & Howe, T. (2013). “Making a good time”: the role of friendship in living successfully with aphasia. *International Journal of Speech-Language Pathology*, 15(2), 165-175.

Burns, N., & Grove, S.K. (2005). *The Practice of Nursing Research: Conduct, Critique and Utilization*. 5th Edition, Elsevier Saunders, Missouri.

Cherney, L.R., Babbitt, E.M., Semik, P., & Heinemann, A.W. (2011). Psychometric Properties of the Communication Confidence Rating Scale for Aphasia (CCRSA): Phase 1. *Topics in Stroke Rehabilitation*, 18:4, 352-360, DOI: 10.1310/tsr1804-352

Clark, H. (1996). Conversation. In *Using Language* ('Using' Linguistic Books, pp. 318-352). Cambridge: Cambridge University Press. doi:10.1017/CBO9780511620539.012

Code, C. & Herrmann, M. (2003). The relevance of emotional and psychosocial factors in aphasia to rehabilitation. *Aphasiology*, 13(1/2), 109-132.

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

Cotugna, N., Vickery, C.E., & Carpenter-Haefele, K.M. (2005). Evaluation of literacy level of patient education pages in health-related journals. *Journal of Community Health*, 30(3), 213-219.

Damico, J., Tetnowski, J., Lynch, K., Hartwell, J., Weill, C., Heels, J., Simmons-Mackie, N. (2015). Facilitating Authentic Conversation: an intervention employing principles of constructivism and conversation analysis. *Aphasiology*, 29(3), 400-421.

De Fina, A., Schiffrin, D. & Bamberg, M. (2006). Introduction. In Anna De Fina, Deborah Schiffrin, & Michael Bamberg (Eds.) *Discourse and Identity*, pp. 1-23. Cambridge: Cambridge University Press. https://doi.org/10.1017/CBO9780511584459

de Riesthal, M., & Ross, K.B. (2015). Patient Reported Outcome Measures in Neurologic Communication Disorders: An Update. *Perspectives on Neurophysiology and Neurogenic Speech and Language Disorders*, 25, 114-120.

De Vet, H.C.W., Terwee, C.B., Mokkink, L.B., & Knol, D.L. (2011). *Measurement in Medicine – a practical guide*. New York: Cambridge University Press.

Devlin, J., & Appleby, J. (2010). *Getting the most out of PROMS: Putting health outcomes at the heart of NHS decision-making*. The King’s Fund UK.

Elman, R. (2016). Aphasia Centers and the Life Participation Approach to Aphasia. A Paradigm Shift. *Topics in Language Disorders*, 36(2), 154-167.

Fayers, P. M. & Hand, D. J. (1997). Factor analysis, causal indicators, and quality of life. *Quality of Life Research*, 6(2), 139 –50.

Fowler, F.J. (2002) *Survey research methods*. 3rd Edition. Thousand Oaks: Sage Publications.

Goodglass, H., Kaplan, E., & Barresi, B. (2001) *Boston Diagnostic Aphasia Examination*, 3rd Edition (BDAE-3). Pro-Ed: Austin.

Graneheim, U.H., & Lundman, B. (2004). Qualitative Content Analysis in Nursing Research: Concepts, Procedures and Measures to Achieve Trustworthiness" *Nurse Education Today*, 24. 105-112.

Hilari, K., Byng, S., Lamping, D. L., & Smith, S. C. (2003). Stroke and aphasia quality of life scale-39 (SAQOL-39): Evaluation of acceptability, reliability, and validity. *Stroke*, 34, 1944–1950.

Hsieh, H.F., & Shannon, S.E. (2005). Three Approaches to Qualitative Content Analysis. *Qualitative Health Research,* 15. 1277-1288.

Horton, S., McVicker, S., & Stokes, J. (2010). UK Conversation Partners Network 6 years on. Paper presented at the 14th International Aphasia Rehabilitation Conference, Montreal, June.

Jones, J. & Hunter, D. (1995) Qualitative Research: Consensus methods for medical and health services research. *BMJ*, 311, 376 -380.

Kagan, A. (1998). Supported conversation for adults with aphasia: Methods and resources for training conversation partners. *Aphasiology*, 12(9), 816–830.

Kagan, A., & Gailey, G. (1993). Functional is not enough: Training conversation partners for aphasic adults. In A. Holland & M. Forbes (Eds.), *Aphasia treatment: World perspectives*. London: Chapman & Hall.

Kagan, A., Simmons-Mackie, N., Rowland, A., Huibregts, M., Shumway, E., McEwen, S., Threats, T., & Sharp, S. (2008). Counting what counts: A framework for capturing real-life outcomes of aphasia intervention. *Aphasiology*, 22, 258-280.

Kagan, A., Simmons-Mackie, N., Victor, J. C., Carling-Rowland, A., Hoch, J., Huijbregts, M., et al. (2011). *Assessment for Living with Aphasia. (ALA)*. Toronto, ON: Aphasia Institute.

Long, A., Hesketh, A., Paszak, 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.

Lyon, J.G., Cariski, D., Keisler, L., Rosenbek, J., Levine, R., Kumpula, J., Ryff, C., Coyne, S., & Blanc, M. (1997). Communication partners: Enhancing participation in life and communication for adults with aphasia in natural settings. *Aphasiology*, 11(7), 693-708, DOI: 10.1080/02687039708249416

May, C. (2013). Towards a general theory of implementation. *Implementation Science*, 8, 18.

McMenamin, R., Tierney, R., & McFarlane, A. (2015). Addressing the long-term impacts of aphasia: how far does the Conversation Partner Programme go? *Aphasiology*, 29(8), 889-913, DOI: 10.1080/02687038.2015.1004155

McVicker, S., Parr, S., Pound, C, & Duchan, J. (2009). The Communication Partner Scheme: A project to develop long-term, low-cost access to conversation for people living with aphasia. *Aphasiology*, 23(1), 52-71.

Mokkink, L.B., Terwee, C.B., Patrick, D.L., Alonso, J., Stratford, P.W., Knol, D.L., Bouter, L.M., & de Vet, H.C.W. (2010). The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. *Journal of Clinical Epidemiology*, 63, 737-745.

Nunnally, J.C. & Bernstein, I.H. (1994). *Psychometric theory* (3rd ed.). New York: McGraw-Hill.

Parr, S. (2007). Living with severe aphasia: Tracking social exclusion. *Aphasiology*, 21(1), 98-123.

Patrick, D.L., Burke, L.B., Gwaltney, C.J., Leidy, N.K., Martin, M.L., Molsen, E., & Ring, L. (2011a). Content validity – establishing and reporting the evidence in newly developed patient-reported outcomes (PRO) instruments for medical product evaluation: ISPOR PRO Good Research Practices Task Force report: part 1 – Eliciting concepts for a new PRO instrument. *Value in Health*, 14(8), 967–977.

Patrick, D.L., Burke, L.B., Gwaltney, C.J., Leidy, N.K., Martin, M.L., Molsen, E., & Ring, L. (2011b). Content validity – establishing and reporting the evidence in newly developed patient-reported outcomes (PRO) instruments for medical product evaluation: ISPOR PRO Good Research Practices Task Force report: part 2 – Assessing respondent understanding. *Value in Health*, 14(8), 978–988.

Pound, C. (2013). *An Exploration of the Friendship Experiences of Working-Age Adults with Aphasia*. Thesis submitted for the degree of Doctor of Philosophy. School of Health Sciences and Social Care, Brunel University, UK.

Rasch, G. (1960). *Probabilistic models for some intelligence and attainment tests*. Chicago: University of Chicago Press.

Saldert, C., Jensen, L. R., Blom Johansson, M., & Simmons-Mackie, N. (2018). Complexity in measuring outcomes after communication partner training: alignment between goals of intervention and methods of evaluation, *Aphasiology*, 32(10), 1167-1193, DOI: 10.1080/02687038.2018.1470317

Schiffrin, D. (1996). Narrative as self-portrait: sociolinguistic constructions of identity. *Language in Society*, 25(2), 167-203.

Sheffield Teaching Hospitals NHS Foundation Trust. Volunteer Role: Conversation Partner. https://www.sth.nhs.uk/clientfiles/File/Conversation%20Partner%202017.pdf last accessed on 30th January 2019.

Shiggins, C., Soskolne, V., Olenik, D., Pearl, G., Haaland-Johansen, L., Isaksen, J., Jagoe, C., McMenamin, R. & Horton, S. (2018). Towards an asset-based approach to promoting and sustaining well-being for people with aphasia and their families: an international exploratory study. *Aphasiology*, DOI: 10.1080/02687038.2018.1548690

Simmons-Mackie, N., Raymer, A., & Cherney, L. R. (2016). Communication partner training in aphasia: An updated systematic review. *Archives of Physical Medicine and Rehabilitation*, 97, 2202–2221.e8. doi:10.1016/j.apmr.2016.03.023

Simmons-Mackie, N., Savage, M.C., & Worrall, L. (2014). Conversation therapy for aphasia: a qualitative review of the literature. *International Journal of Language and Communication Disorders*, 49(5), 511-526.

Simmons-Mackie, N., Kagan, A., Victor, J. C., Carling-Rowland, A., Mok, A., Hoch, J. S., Huijbregts, M., Streiner, D. L. (2014). The assessment for living with aphasia: Reliability and construct validity. *International Journal of Speech-Language Pathology*, 16, 82–94.

Simmons-Mackie, N., Raymer, A., Armstrong, E., Holland, A. L., & Cherney, L. R. (2010). Communication partner training in aphasia: A systematic review. *Archives of Physical Medicine and Rehabilitation*, 91, 1814–1837. doi:10.1016/j.apmr.2010.08.026

Simmons Mackie N., & Damico, J. (2007). Access and social inclusion in aphasia: Interactional principles and applications. *Aphasiology*, 21(1), 81-97.

Simmons-Mackie, N., Threats, T.T., & Kagan, A. (2005). Outcome assessment in aphasia: a survey. *Journal of Communication Disorders*, 38(1), 1–27.

Staniszewska, S., Haywood, K.L., Brett, J., & Tutton, L. (2012). Patient and Public Involvement in Patient-Reported Outcome Measures. Evolution Not Revolution. *Patient*, 5, 79-87.

Streiner, D.L., Norman, G.R., & Cairney, J. (2014). *Health measurement scales. A practical guide to their development and use*. 5th Edition. Oxford: Oxford University Press.

Swinburn, K., Best, W., Beeke, S., Cruice, M., Smith, L., Pearce Willis, E., Ledingham, K., Sweeney, J., & McVicker, S.J. (2018). A concise patient reported outcome measure for people with aphasia: the aphasia impact questionnaire 21. *Aphasiology*, DOI: 10.1080/02687038.2018.1517406

Terwee, C.B., Prinsen, C. A. C., Chiarotto, A., Westerman, M. J., Patrick, D. L., Alonso, J., Bouter, L. M., de Vet, H. C. W., & Mokkink, L. B. (2018). COSMIN methodology for evaluating the content validity of patient reported outcome measures: a Delphi study. *Quality of Life Research*, 27, 1159-1170.

Van de Ven, A.H., & Delbecq, A.L. (1972). The nominal group as a research instrument for exploratory health studies. *American Journal of Public Health*, 62, 337-342

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

Willis, G.B. (2005). *Cognitive interviewing: A tool for improving questionnaire design*. Thousand Oaks, CA: Sage Publications.

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

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(3), 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 randomized controlled trials: an International Classification of Functioning, Disability and Health approach. *Disability and Rehabilitation*, Early Online 1-19 (doi:10.3109/09638288.2011.568666) http://informahealthcare.com/eprint/rVWIhe4XHnYheU36gCYV/full?tokenKey

Yorkston, K.M., Baylor, C.R., Dietz, J., Dudgeon, B.J., Eadie, T., Miller, R.M., & Amtmann, D. (2008). Developing a scale of communicative participation: A cognitive interviewing study. *Disability and Rehabilitation*, 30, 425-433.

TABLES

Table 1. Characteristics and research participation of people with aphasia taking part in semi-structured interviews and focus group discussions.

Participant code	Male / female	Semi-structured interview	Focus Group	Age group	Living arrange-ments[1]	BDAE score[2]
P1	M	✓	✓	40-60	H+	1
P2	F	✓	✓	40-60	H+	3
P3	M		✓	81+	H+	5
P4	M	✓	✓	40-60	H	1
P5	M	✓	✓	40-60	H	3
P6	F	✓	✓	61-70	H+	1
P7	F	✓	✓	40-60	H+	3
P8	M	✓		61-70	H+	4
P9	F		✓	40-60	H+	4
P10	M	✓		40-60	R	3
P11	M	✓		40-60	R	2
P12	M	✓		61-70	H+	3

1. H = own home alone; H+ = own home with partner; R = residential
2. Boston Diagnostic Aphasia Examination (Goodglass *et al*., 2001) Severity Rating Scale scores range from: 1 (“all communication is through fragmentary expression”) to 5 (“minimal discernible speech handicap”)

Table 2. The application of Nominal Group Technique: illustrative examples

Raw data: themes from literature review, interviews & focus groups	**Members write down ideas** derived from initial readings	**Members read out ideas,** which are recorded on a flipchart[1]	**Clarification**: ideas discussed and clarified; duplicates merged	**Voting**: members prioritise items	**Action**: plan of action after discussion and consensus reached
Negative feelings, in particular frustration. Frustration arose for a number of reasons: communication impairment; workplace demands; change in abilities.	Negative feelings Frustration Frustrating conversations	My past life Previous identity Barriers to socializing Meeting new people Taking part Impact of speech difficulties Breaking down barriers Being open about aphasia	How I used to be Socializing Feeling lonely Not taking part Impact of speech difficulties Being open about aphasia Etc.	Twenty eight ideas taken forward	Develop ideas into statements: 66 statements developed Further voting and prioritisation
Decreasing participation, through job loss, inability to continue with hobbies, and lack of opportunities or the avoidance of situations where talk was required.	Taking part Loss of taking part Isolation Avoiding talk				

1. See Appendix for examples

Table 3. Characteristics of people with aphasia taking part in cognitive interviews.

Participant code	Male / female	Age group	Living arrange-ments[1]	BDAE score[2]
P1	M	40-60	H+	1
P2	F	40-60	H+	3
P4	M	40-60	H	1
P5	M	40-60	H	3
P6	F	61-70	H+	1
P8	M	61-70	H+	4
P9	F	40-60	H+	4
P10	M	40-60	R	3
P13	F	40-60	H+	3
P14	F	61-70	H+	4
P15	F	40-60	H	2
P16	M	40-60	H+	3
P17	F	71-80	R	1
P18	F	71-80	R	1
P19	F	81+	H+	1
P20	F	71-80	H+	2
P21	F	71-80	H+	3
P22	F	40-60	H+	4
P23	M	71-80	H+	1.5

1. H = own home alone; H+ = own home with partner; R = residential
2. Boston Diagnostic Aphasia Examination (Goodglass *et al*., 2001) Severity Rating Scale scores range from: 1 (“all communication is through fragmentary expression”) to 5 (“minimal discernible speech handicap”)

Table 4 Themes and sub-themes from analysis of interviews and focus groups, with illustrative quotes

Themes	Subthemes	Illustrative quotes [Participant code and location in transcript]
Identity and sense of self	Interrupted life story Dependency on others Lack of respect from others Negative feelings about self Acceptance of new self	“I had I said I could not move that arm at all” [P14, turn 103] “It’s very difficult because I used to work, and now I’m, I’m nobody, I don’t see anybody” [P8, turn 2]
Participation in social life	Social life compromised Avoiding conversations and strangers Attitudes and capabilities of conversation partners Social isolation and losing touch	“And erm, learn to give me time. Whereas immediate family and that overcome it, but the extended family and that gets huffy” [P10, turn 40] “But erm, other than that I’ve got stroke club to go to, I haven’t got anything else” [P6, turn 44] “And she said, oh come on, spit it out” [P9, turn 47]
Emotional impact	Frustration Loss of confidence Sadness Embarrassment Anxiety and depression	“Yes ((nods)) yep, yep. It’s awful, awful ((shaking fist)) because of the frustration. [P1, turn 86] “At first I was crying all the time; I’m fine now” [P8, turn 183]
Coping strategies	Determination and perseverance Not seeing self as a victim Taking on new challenges and roles	“So, er, you’ve got to do your best, er to try and keep up” [P4, turn 13] “…first thing I say is excuse me I’ve had a stroke please bear with me” [P10, turn 145]
Speech, language and communication	Communication difficulties hardest to deal with Others’ awareness helps Impact on conversations Variability in speech	“They...what I’ve got in my head doesn’t come out of my mouth” [P6, turn 115] “A few years ago, not speak at all, so” [P2, turn 530]
Participation in the CP scheme	Opportunities to be oneself and feel included Regaining self identity Company Being listened to	“Because without it you’d be isolated wouldn’t you” [P4, turn 197] “My CP was like friends…very nice, yes, laughing with each other” [P8, turn 259]

Table 5 Nominal Group Technique: candidate item statements and perceived importance scores

Candidate items (not in any particular order)	Very important	Important	Slightly important	Not at all important	Sum	Sum/5
My speech makes me frustrated	16	0	2	0	18	3.6
People don't make an effort to understand me	8	0	6	0	14	2.8
I'm frustrated because other people don't understand me	12	3	2	0	17	3.4
I'm frustrated because I cannot join in	16	3	0	0	19	3.8
I get frustrated	12	6	0	0	18	3.6
I feel isolated	20	0	0	0	20	4
I feel cut off	4	9	0	1	14	2.8
I feel lonely	8	6	2	0	16	3.2
I don’t feel I can join in with conversations	8	6	2	0	16	3.2
I don’t feel I can do things because of my speech	4	6	4	0	14	2.8
I don't have conversations because of my speech	8	9	0	0	17	3.4
I can't get a word in	4	3	4	1	12	2.4
Other people tend to speak for me	0	3	6	1	10	2
I feel excluded from conversations	8	9	0	0	17	3.4
I can't get my point across	8	0	6	0	14	2.8
I have no trouble joining in conversations	12	0	4	0	16	3.2
I can usually make my point heard	4	6	2	1	13	2.6
People don't tend to listen	4	9	2	0	15	3
People don’t take time to listen	8	9	0	0	17	3.4
I get left out	8	3	4	0	15	3
I feel confident talking	8	6	2	0	16	3.2
I like talking with people who listen	4	3	6	0	13	2.6
I avoid conversations	16	3	0	0	19	3.8
I don’t like talking in groups	0	6	4	1	11	2.2
I feel confident talking in groups	0	3	6	1	10	2
I feel confident talking to family	4	6	4	0	14	2.8
I'm happy talking with a companion	0	9	4	0	13	2.6
I feel anxious about talking	4	12	0	0	16	3.2
I love having a chat	4	9	2	0	15	3
I would love to have a chat	4	9	2	0	15	3
I don't talk to many people	8	9	0	0	17	3.4
My speech bothers me	16	0	2	0	18	3.6
Other people are bothered by my speech	0	9	2	1	12	2.4
I find it hard to stay in touch	0	12	0	1	13	2.6

I keep in touch with people	0	6	4	1	11	2.2
I've lost touch with people	0	9	2	1	12	2.4
I don't talk with many people	0	9	4	0	13	2.6
People don’t understand me very well	4	9	2	0	15	3
People react unkindly towards me	4	9	2	0	15	3
I just don't feel myself	12	3	2	0	17	3.4
I feel myself	8	3	4	0	15	3
People don't take time to talk to me	8	3	4	0	15	3
I don't have much opportunity for conversations	8	9	0	0	17	3.4
It's difficult for me to join in conversations	8	9	0	0	17	3.4
I would love to join in more	12	6	0	0	18	3.6
I don't have the confidence to join in	20	0	0	0	20	4
People don't include me in conversations	8	9	0	0	17	3.4
I've always liked to talk	4	9	2	0	15	3
I'm a very sociable person	4	12	0	0	16	3.2
I avoid conversations	16	3	0	0	19	3.8
I feel sad because I can't join in conversations	12	6	0	0	18	3.6
I miss having a chat	8	6	2	0	16	3.2
I miss having a good laugh with other people	4	6	4	0	14	2.8
I feel embarrassed about my speech	4	12	0	0	16	3.2
It's very hard to say what I want	12	0	4	0	16	3.2
I can usually say what I want	4	0	6	1	11	2.2
Having a chat makes me feel good	0	9	4	0	13	2.6
I know how to get my point across	4	6	2	1	13	2.6
I don't know how to get my point across	4	9	0	1	14	2.8
I have good conversations	12	6	0	0	18	3.6
People don't respect me	8	9	0	0	17	3.4
I'm too embarrassed to join in	4	9	0	1	14	2.8
People are helpful when I can't get the words out	12	0	2	1	15	3
I don't feel in control	12	0	4	0	16	3.2
People get impatient with me because of my speech	4	9	0	1	14	2.8
People don’t know what to do to help with my speech	4	9	0	1	14	2.8

Table 6 Pattern matrix[1,2,3] for four-factor solution, with items shown in order of loading

CCQA V2 item	Factor			
	1	2	3	4
20. I feel left out of social events	.825			
30. People tend to leave me out of their conversations	.772		.355	
5. My speech means I don't have many conversations	.750			
28. I don't get much chance to chat	.730			
18. I feel sad when I can't join in conversations	.690			
26. It's frustrating when I can't join in	.659			
7. I miss having a chat	.653			
9. I feel like I'm left out of conversations	.649			
22. It's hard for me to join in conversations	.648	.312		
23. I feel lonely	.597			
2. I tend to stay clear of conversations	.566			.338
4. People don't listen to me when I talk	.546			
25. I feel embarrassed about my speech	.532			
14. I don't feel confident to join in conversations	.518			
21. Some people are thoughtless towards me	.504			
3. I would love to join in more	.425			
19. I feel confident about my speech		.779		
12. My speech concerns me	.351	.524		
29. I feel like my old self again		.520		
15. It's frustrating when people don't understand me		.456		
8. It's generally very hard to say what I mean	.303	.417		
24. I can join in with conversations		.351		.341
1. My speech frustrates me		.339		
27. Most people treat me with respect			.822	
17. Most people are helpful when I can't get the words out			.670	
11. Most people take time to talk to me			.513	
10. I do have good chats				.698
16. I enjoy having a chat				.580
6. I 'm a very sociable person				.519
13. I talk to lots of different people				.511

1. Rotation converged in 10 iterations; 2. Extraction Method: Principal Axis Factoring; 3. Rotation Method: Promax with Kaiser Normalization

Table 7 Factor correlation matrix for four-factor solution: between factor correlations

Factor	1	2	3	4
1	1.000	.600	.152	.349
2	.600	1.000	.061	.359
3	.152	.061	1.000	.358
4	.349	.359	.358	1.000

Table 8 Subscales and items after a first round of elimination

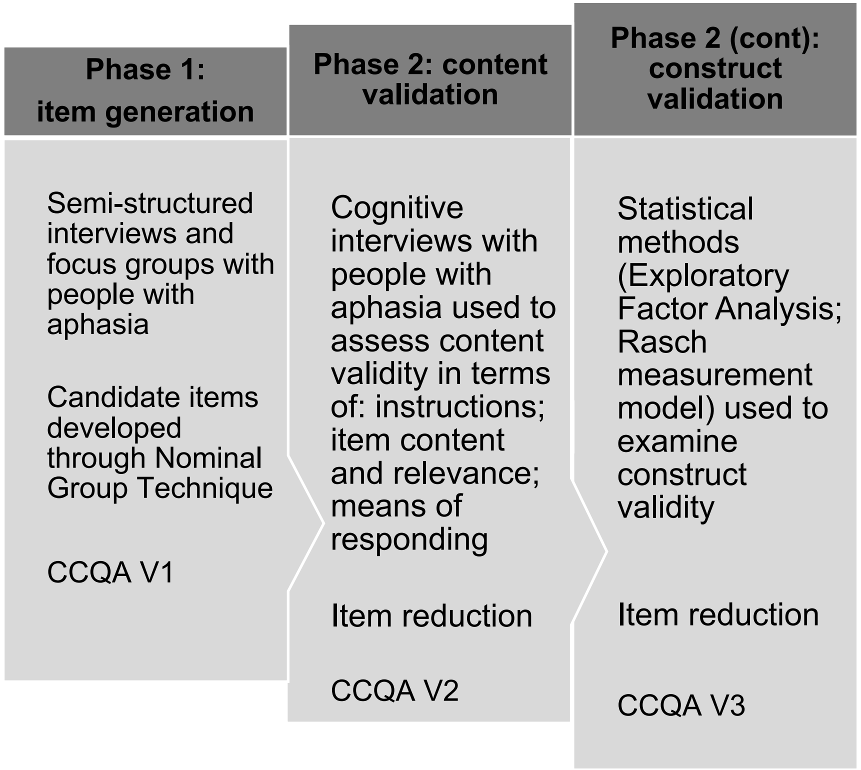
Realising opportunities for participation in conversation	**Feelings about my speech**	**Actions and attitudes of others**	**Experience of participation in conversations**
20. I feel left out of social events	19. I feel confident about my speech	27. Most people treat me with respect	10. I do have good chats
5. My speech means I don't have many conversations	12. My speech concerns me	17. Most people are helpful when I can't get the words out	16. I enjoy having a chat
28. I don't get much chance to chat	8. It's generally very hard to say what I mean	11. Most people take time to talk to me	13. I talk to lots of different people
26. It's frustrating when I can't join in			
23. I feel lonely			
2. I tend to stay clear of conversations			
4. People don't listen to me when I talk			
25. I feel embarrassed about my speech			
14. I don't feel confident to join in conversations			

Table 9 Fourteen-item CCQA V3, showing sub-scale and scoring schema

No.	**Item statement**	**Sub-scale**	**Response and score**			
			I strongly agree	**I agree**	**I disagree**	**I strongly disagree**
1	I tend to stay clear of conversations	1	0	1	2	3
2	My speech means I don't have many conversations	1	0	1	2	3
3	It's generally very hard to say what I mean	2	0	1	2	3
4	I do have good chats	4	3	2	1	0
5	Most people take time to talk to me	3	3	2	1	0
6	My speech concerns me	2	0	1	2	3
7	I talk to lots of different people	4	3	2	1	0
8	I don't feel confident to join in conversations	1	0	1	2	3
9	I enjoy having a chat	4	3	2	1	0
10	Most people are helpful when I can't get the words out	3	3	2	1	0
11	I feel confident about my speech	2	3	2	1	0
12	I feel left out of social events	1	0	1	2	3
13	Most people treat me with respect	3	3	2	1	0
14	I don't get much chance to chat	1	0	1	2	3

FIGURES

Figure 1 Conversation and Communication Questionnaire for People with Aphasia (CCQA) development: methodology overview



Phase 1: item generation

Semi-structured interviews and focus groups with people with aphasia

Candidate items developed through Nominal Group Technique

CCQA V1

Phase 2: content validation

Cognitive interviews with people with aphasia used to assess content validity in terms of: instructions; item content and relevance; means of responding

Item reduction

CCQA V2

Phase 2 (cont): construct validation

Statistical methods (Exploratory Factor Analysis; Rasch measurement model) used to examine construct validity

Item reduction

CCQA V3

Figure 2 Person-item threshold distribution of 14-item CCQA after creating 3 testlets: distribution of persons by ability on top and distribution of items by difficulty on the bottom.

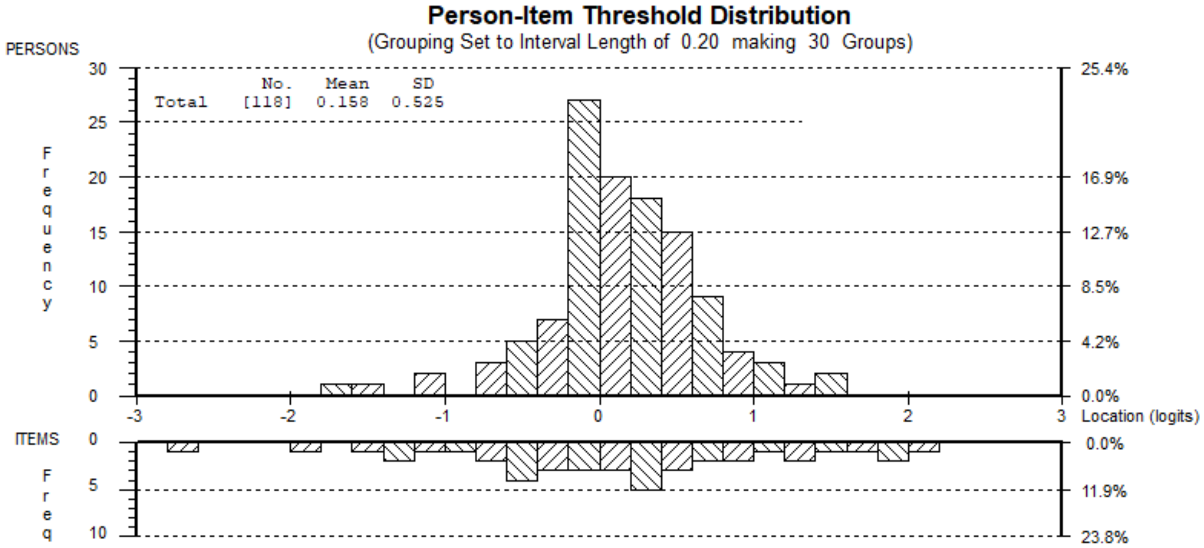


Figure 3 Distribution of responses in the 4-point scale for all 14 items