Establishing reporting standards for participant characteristics in post-stroke aphasia research: an international e-Delphi exercise and consensus meeting

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Abstract

Objective: To establish international, multidisciplinary expert consensus on minimum participant characteristic reporting standards in aphasia research (DESCRIBE project).

Methods: An international, three-round e-Delphi exercise and consensus meeting, involving multidisciplinary researchers, clinicians, and journal editors working academically or clinically in the field of aphasia.

Results: Round one of the DESCRIBE e-Delphi exercise (n=156) generated 113 items, 20 of which reached consensus by round three. The final consensus meeting (n=19 participants) established DESCRIBE's 14 participant characteristics that should be reported in aphasia studies: age; years of education; biological sex; language of treatment/testing; primary language; languages used; history of condition(s) known to impact communication/cognition; history of previous stroke; lesion hemisphere; time since onset of aphasia; conditions arising from the neurological event; and, for communication partner participants, age, biological sex, and relationship to person with aphasia. Each characteristic has been defined and matched with standard response options to enable consistent reporting.

Conclusion: Aphasia research studies should report the 14 DESCRIBE participant characteristics as a minimum. Consistent adherence to the DESCRIBE minimum reporting standard will reduce research wastage and facilitate evidence-based aphasia management by enabling replication and collation of research findings, and translation of evidence into practice.

Introduction

Better post-stroke interventions must be supported by high-quality reporting. Reporting standards can scaffold the design and subsequent reporting of research studies, enhance their validity, and strengthen the amassed value of the wider evidence base. Post-stroke impairments such as aphasia, an acquired language impairment that affects up to 38% of stroke survivors[1], can result in long-term unmet needs[2] and poor quality of life[3]. Replication, implementation, and secondary data analysis of aphasia research are limited by sub-optimal reporting, particularly in relation to participant characteristics[4]. In addition to contributing to research waste, poor reporting impedes the translation of research into practice[5]. People with aphasia are a heterogenous population and individualised, evidence-based intervention is difficult to prescribe when research and clinical populations cannot be easily compared[6].

Over the past four decades, audits of aphasia research have revealed persistently poor participant reporting. In a 1983 audit, Brookshire[7] found that participant age was reported in 90% of studies, with no other characteristic observed with >65% consistency. Twenty years later, Roberts, Code and McNeil[8] again found age to be the most frequently reported characteristic (92%), with only gender (91%) also exceeding the 90% benchmark. Most recently, in the context of developing the Rehabilitation and recovery of peopLE with Aphasia after StrokE (RELEASE) individual patient database, Williams et al[4] found >90% consistency in the reporting of participant age (97%) and sex (91%). No other characteristic was reported with >75% consistency.

We aimed to establish international, multidisciplinary consensus on minimum reporting standards for participant characteristics in post-stroke aphasia research studies. As the challenge of achieving quality research reporting extends to rehabilitation more broadly[9], our study offers an important blueprint for establishing reporting standards to benefit rehabilitation beyond aphasia.

Methods

Across two stages of research, we conducted an international e-Delphi exercise followed by a consensus meeting. The Delphi method is an iterative decision-making process that uses a series of progressively targeted surveys to reach agreement on a topic[10]. It is an effective way of establishing

standardisation in health research[11] and is increasingly conducted electronically for convenience, cost-effectiveness, and geographic reach[12]. We received ethical approval from The University of Queensland Human Research Ethics Committee (ref. 2019003024).

Participants were researchers, clinicians, and academic journal editors, all recruited internationally and required to have English proficiency. Researchers were recruited through professional networks (e.g., Collaboration of Aphasia Trialists) and social media (e.g., Twitter), under the eligibility criteria of having published aphasia research. Clinicians were recruited through professional bodies (e.g., Speech Pathology Australia), clinical networks (e.g., Speech Pathology Email Chats), social media, and word-of-mouth, under the eligibility criteria of being an allied health, nursing, or medical professional working clinically with people affected by aphasia. Journal editors were recruited through direct email to current and former editors-in-chief of peer-reviewed journals publishing stroke and/or aphasia research, inviting their participation or nomination of associate/academic editors of their journal. We identified relevant journals through manual screening of search results generated by the terms "health professionals" and "neuroscience" on SCImago Journal Rankings (https://www.scimagojr.com). Participant information provision and consenting procedures were embedded within the e-Delphi round one survey; continued participation in subsequent rounds of the e-Delphi exercise and in Stage 2 of the study was invited but optional.

Stage 1: e-Delphi exercise

After piloting with a small group of clinicians and researchers, then refining the content, wording, and sequence of survey questions, we conducted the e-Delphi exercise on Qualtrics, an online survey platform, as follows:

Round one (generating ideas). Participants (n=156) were asked to respond to two open-ended questions:

1. *"If you were reading a study that reported a treatment for aphasia, what information about the participants with aphasia would you expect to be included?"*

2. *"If the treatment study included participants who were carers/significant others/communication partners of a person with aphasia, what information about these participants would you expect to be included?"*

Analysis. Inductive qualitative content analysis was performed to identify distinct items pertaining to participant characteristics. This involved coding the data for units of meaning, grouping codes into categories and subcategories of similar meaning, then organising the categories and subcategories under themes[13]. For rigour, we performed peer debriefing and peer review: data coding and categorisation performed by one author (MI) was checked by co-authors (SW, MA); coding/categorisation discrepancies were resolved by unanimous decision after group discussion. We also kept an audit trail of version-controlled records of the analysis.

Round two (rating). With reference to the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system[14], participants (n=106) were asked to rate a list of items as '*essential*' (7-9), '*important but not essential*' (4-6), or '*limited importance*' (1-3) for reporting in aphasia treatment studies. The list was a collation of items generated in round one, and items identified from aphasia and stroke research databases (e.g., RELEASE[15], Predicting Language Outcome and Recovery After Stroke (PLORAS)[16], Moss Aphasia Psycholinguistics Project Database[17], The Stroke Data Bank[18]) and published audits[8]. Items were organised by theme, and themes were presented in random order to reduce bias as an effect of ordering. Participants could also provide additional items in their response. ***Analysis.*** The number and percentage of votes for each rating level for each item was calculated. Pre-determined criteria for consensus was ≥70% votes of '*essential*' and <15% votes of '*limited importance*'. Items with 50-69% votes of '*essential*' were deemed inconclusive. Additional comments provided by participants were compiled for review in Stage 2.

Round three (re-rating). Participants (n=88) were again asked to rate the round two items that reached consensus or were inconclusive. Participants did this after viewing a summary of de-identified round two results with median ratings of each item, and instructions to consider the group

ratings as well as the feasibility of reporting each item in every aphasia treatment study. ***Analysis.*** Calculations were performed as per round two.

Stage 2: Consensus meeting

Separate participant information provision and consenting procedures were performed with individuals who volunteered to continue to this stage in June 2020. To maximise attendance of geographically dispersed participants, the meeting was conducted virtually using videoconferencing. Asynchronous participation via email was also available.

Participants (n=20) were presented with a list of items reaching consensus by round three of the e-Delphi exercise, each item was accompanied by possible variations in its definition and response options, based on data dictionaries (e.g., National Institute of Neurological Disorders and Stroke (NINDS) Common Data Elements). For example, Item: Age; Definition: The person's completed age in years; Response option value/s: YY. Moderated by the authors (SW, MI), participants were prompted to discuss whether any items should be combined, added, or removed, and invited to suggest alternative values, wording, or references.

Based on the meeting discussion and written input from participants contributing via email (n=3), a refined list of items annotated with points for and against, together with detailed minutes of the consensus meeting, were sent to participants for final voting. Participants (n=19) cast their final vote of '*yes*' for inclusion or '*no*' for exclusion of each item, with criteria for final consensus on each item for minimum reporting pre-determined as ≥70% of votes for inclusion.

Results

Information on the demographic and professional background of our initial participant pool at round one of the e-Delphi exercise are described in table 1. Participant response rates are presented in table 2, attrition was low across rounds.

Table 1. Round 1 Participant Characteristics (n=156)

Participant Characteristics	Number of Participants (%)
Gender	
Female	136 (87)
Male	20 (13)
Discipline*	
Speech pathologist	133 (85)
Clinical linguist	16 (10)
Psychologist	10 (6)
Neurologist	5 (3)
Nurse	1 (<1)
Other	14 (9)
Research role*	107 (69)
Career stage:	
Pre-doctoral	27 (17)
Post-doctoral: Early career researcher (≤8 years since PhD)	25 (16)
Post-doctoral: Mid-career researcher (9-15 years since PhD)	21 (14)
Post-doctoral: Late researcher (≥16 years since PhD)	34 (22)
Main research methodology:	
Quantitative	46 (44)
Qualitative	18 (17)
Mixed methods	42 (27)
Systematic review / meta-analysis	1 (<1)
Clinical role*	93 (60)
Years of experience:	
≤ 1 year	2 (1)
1-3 years	6 (4)
3-5 years	8 (5)
≥5 years	77 (49)
Work setting	
Hospital - Acute service (accepts patients acutely but discharges early, usually within 7 days)	20 (13)
Hospital - Inpatient rehabilitation service	21 (13)
Community rehabilitation - Day hospital or outpatients or community centre or home-based care	28 (18)
University clinic	19 (12)
Private practice	5 (3)
Other	2 (1)
Journal editorial role*	20 (13)
Editor	6 (4)
Associate editor	14 (9)

Years of experience:	
1-3 years	5 (3)
3-5 years	2 (1)
≥5 years	13 (8)
Country	
Australia	46 (30)
United Kingdom	23 (15)
United States	23 (15)
Japan	7 (5)
Sweden	7 (5)
Netherlands	6 (4)
Canada	5 (3)
India	4 (3)
Ireland	4 (3)
Malaysia	4 (3)
Germany	3 (2)
Spain	3 (2)
Turkey	3 (2)
Italy	2 (1)
Denmark	2 (1)
New Zealand	2 (1)
Norway	2 (1)
Saudi Arabia	2 (1)
The Bahamas	2 (1)
Egypt	1 (<1)
France	1 (<1)
Georgia	1 (<1)
Morocco	1 (<1)
Portugal	1 (<1)
Vietnam	1 (<1)

*Participants could select more than one response.

Table 2. Participation in e-Delphi Exercise and International Consensus Meeting

Activity	Invited	Participated	Response Rate (%)
Round 1 e-Delphi	NA	156	NA
Round 2 e-Delphi	151	106	70.1
Round 3 e-Delphi	106	88	83
International Consensus Meeting	31	23*	74.2
Final Voting	23	19	82.6

*n = 20 participants attended the meeting; n = 3 participated asynchronously. Count excludes authors MI, SW, MA, and MB.

E-Delphi exercise

In round one, after exclusion of 10 survey responses irrelevant to our research question, 151 responses yielded 113 codes pertaining to people with aphasia. These fit under six themes (see table 3 for detail): personal factors, environmental factors, pre-morbid presentation, neurological event, treatment/intervention data, activities and participation, and current health status. We also identified 122 codes pertaining to communication partners. These fit under six themes, two of which overlap with the aforementioned (see table 4 for detail): personal factors, environmental factors, health, communication, communication partner role, and information about the participant with aphasia.

Table 3. Content Analysis of Responses to the Question: "If you were reading a study which reported a treatment for aphasia, what information about the participants with aphasia would you expect to be included?"

Themes	Categories	Codes
Personal Factors (n=508)[#]	Age, Gender & Identity (n=301)	Age (n=140)
		Biological Sex (n=102)
		Gender Identity (n=2)
		LGBTIQ Status (n=1)
		Handedness (n=35)
		Resilience (n=1)
		Personality (n=1)
		Attitude Toward Therapy (n=1)
		Ethnicity (n=12)
		Cultural Background (n=6)
	Education (n=92)	Education (n=42)
		Years of Education (n=6)
		Highest Level Attained (n=44)
	Occupational History (n=62)	Occupational History (n=4)
		Occupation (n=48)
		Employment Status (n=10)
	Socio-economic History (n=53)	Domestic/Social/Cultural Roles (n=1)
		Socio-economic Status (n=13)
		Living Arrangements (n=24)
		Rural/Regional/Metropolitan (n=8)
		Country of Residence (n=5)
		Residency Status (n=1)
		Health Insurance (n=1)
Environmental Factors (n=51)	Physical Environment (n=5)	Available Health Facilities (n=2)
		Access to/use of Transport (n=1)
		Environmental Barriers (n=1)
		Environmental Facilitators (n=1)
	Social Environment (n=46)	Social Status (n=10)
		Marital Status (n=9)
		Gender of Spouse/Partner (n=1)
		Family Structure (n=13)
		Social Supports (n=9)
		Carer Support (n=4)

Pre-Morbid Presentation (n=143)	Language History (n=106)	Language History (n=7) Language Status (n=12) First Language (n=14) Primary Language (n=7) Language of Treatment/Testing (n=3) Languages Known (Spoken/Written) (n=30) Language Use (n=9) Degree of Proficiency (n=10) Premorbid Language Abilities) (n=9) History of Language Disorder (n=3) History of Motor Speech Disorder (n=2)
	Cognition (Pre-Morbid) (n=6)	Cognitive Abilities (n=4) History of Learning/Other Developmental Disorder (n=2)
	Other (n=31)	Pre-Morbid Functional Status (n=1) Medical History (n=24) Mental Health History (n=5) Technology Use & Competence (n=1)
Neurological Event (n=668)	Stroke Characteristics (n=274)	Time Post Onset (n=115) Type of Neurological Event (n=49) If Stroke – Classification (n=29) Number of Strokes/Lesions in Event (n=5) Stroke Severity (n=19) Lesion Information (n=5) Lesion Site (n=43) Lesion Size (n=4) Supporting Imaging Data (n=3) Initial Symptoms (n=1) Initial Place of Presentation (i.e. GP, hospital) (n=1)
	Aphasia Characteristics (n=216)	Aphasia Classification (n=63) Aphasia Severity (n=83) Language Profile (n=53) Literacy (n=7) Connected Speech (n=1) Everyday Functional Language Abilities (n=8) Current Communication Strategies (n=1)

	Co-Morbidities (n=155)	Co-Morbidities (n=37)
		Fatigue (n=1)
		Motor Impairments (n=9)
		     Hemiparesis (n=5)
		     Hemiplegia (n=4)
		Motor Speech (n=6)
		     Apraxia of speech (n=8)
		     Dysarthria (n=4)
		Sensory Deficits (n=1)
		     Neglect (n=4)
		     Agnosia (n=1)
		Dysphagia (n=2)
		Cognitive Abilities (Post-Morbid) (n=36)
		     Attention (n=1)
		     Memory (n=2)
		     Executive Function (n=1)
		     IQ (n=2)
		     Insight (n=1)
		     Motivation (n=2)
		Mental Health/Psychological Factors (n=7)
		     Depression (n=9)
		     Anxiety (n=1)
		     Mood (n=7)
		     Affect (n=1)
		     Emotional State (n=3)

Treatment/ Intervention Data (n=43)		Treatment for Neurological Event (e.g. TPA, clot-retrieval) (n=6) Current Medications (n=2) History of Speech Pathology/Aphasia Treatment (n=30) History of Previous Rehabilitation (Other than SP) (n=1) Primary Treatment Concern (n=1) Compliance/Response to Previous Therapy (n=1) Motivation for Study Participation (n=1) Previous Research Participation (n=1)
Participation & Activities (n=29)		Mobility (n=4) Global Functioning/Independence (e.g. FIM) (n=2) Degree of Disability (e.g. mRS) (n=5) Impact of Aphasia/Co-Morbidities on Participation & Activities (n=9) ADLs (n=1) Hobbies and Interests (n=2) Quality of Life (n=6)
Current Health Status (at time of research participation) (n=44)		Hearing (n=16) Vision (n=15) Measure of General Health Status (n=4) Current Neurological Status (n=1) Stage of Recovery (n=8)

n= number of times coded

Table 4. Content Analysis of Responses to the Question: If the treatment study included participants who were carers/significant others/communication partners of a person with aphasia, what information about these participants would you expect to be included?"

Themes	Categories	Subcategories

Personal Factors (n=479)[#]	Age, Gender & Identity (n=240)	Age (n=124)
		Biological Sex (n=95)
		Gender Identity (n=2)
		Handedness (n=3)
		Ethnicity (n=9)
		Cultural Background (n=3)
		Resilience (n=1)
		Attitudes
		    Readiness to Provide Care (n=1)
		    Attitudes Toward Therapy (n=2)

	Education (n=81)	Education (n=37)
		    Years of Education (n=4)
		    Highest Level Attained (n=40)

	Occupational History (n=73)	Occupational Hx (n=5)
		    Occupation (n=47)
		    Job Satisfaction (n=1)
		    Employment Status (FT, PT, Retired, Unemployed etc) (n=20)

	Social History (n=30)	Socio-economic Status (n=9) Other Life Roles and Responsibilities (e.g. spouse, parenting, community roles) (n=5) Living Arrangements (n=10) Rural/Regional/Metropolitan (n=3) Country of Residence (n=3)

	Language History (n=47)	Language History (n=5)
		    Language Status (n=8)
		    L1 (n=6)
		    Primary Language (n=1)
		    Languages Known (Spoken/Written) (n=17)
		    Languages Used (n=6)
		    Degree of Proficiency (n=4)

	Other (n=8)	Quality of Life (n=6) Impact on Participation/Activities (n=2)
Environmental Factors (n=130)	Physical Environment and Access to Services (n=3)	Available Health Facilities (n=1) Environmental Barriers (n=1) Environmental Facilitators (n=1)

	Social Environment (n=127)	Social History & Supports (n=3)
		    Marital Status (n=2)
		    Family Structure and Support (n=3)
		Social Supports (n=2)
		Support Network (e.g. support groups, professional services) (n=5)

		Relationship with PwA (n=91)
		Duration of Relationship (n=19)
		Impact of Neurological Event on Relationship (n=2)
Health (n=105)		Presence of Health Impairment (NOS) (n=3)
	Cognition (n=16)	Cognitive Abilities (n=12)
		Executive Function (n=1)
		IQ (n=1)
		Insight (n=1)
		History of Learning Disorder (n=1)
	Sensory Function (n=18)	Hearing (n=8)
		Vision (n=8)
		Neglect (n=1)
	Motor Function (n=2)	Mobility (n=1)
		Motor Impairments (n=1)
	Psychological Health (n=40)	Psychological/Mental Health Status (n=11)
		Emotional Well-Being (n=3)
		Capacity to Provide Care (n=2)
		Personal Challenges (n=2)
		Coping Abilities (n=1)
		Caregiver Burden or Strain (n=7)
		Depression (Presence or Hx) (n=7)
		Mood (n=6)
	Medical History (n=26)	Medical History (n=5)
		Hx of Neurological Disorder (n=5)
		Current Health Status (n=16)
Communication (n=19)	Communication Partner's Language Profile (n=12)	Language Abilities (n=7)
		Literacy (n=4)
		Technology Literacy (n=1)
	Communication with PwA (n=7)	Preferred Communication Strategies with PwA (n=1)
		Competence in Use of Supported Communication Strategies (n=1)
		Self-Rated Competence as Communication Partner (n=1)
		Joint Communication Style (n=1)
		Nature of Communication with PwA (n=1)
		Primary Communication Modality (i.e. face-to-face, phone, video-conference) (n=1)
		Communication Success (with PwA) (n=1)
Communication Partner Role (n=65)	Knowledge, Experience, and Training (n=41)	Experience as Carer, Communication Partner or Relevant Health (n=6)
		Experience supporting communication disorders (n=1)
		Time to Date in Carer/CP Role (n=11)
		Previous Completion of CPT/Supported Communication Training (n=8)
		Previous Involvement in Communication Interventions (n=2)

		Previous Participation in Aphasia Research (n=1)
		Degree of Engagement in Previous Therapy (n=2)
		Relevant Study/Qualifications (n=2)
		Knowledge of Aphasia/Stroke (n=6)
		Health Literacy (n=1)
		Knowledge of Information Sources/Available Support Services (n=1)
	Responsibilities (n=11)	Participation/Role in Therapy Activities (Current) (n=5)
		Carer/CP Responsibilities with PwA (e.g. Communication support, mobility, medication, personal care) (n=4)
		Rehabilitation Priorities of CP (n=1)
		Nature of Contact with PwA (e.g. grandchild visiting for conversation, spouse providing social, financial, and domestic support) (n=1)
	Time Management (n=13)	Daily or Weekly Work Schedule (n=1)
		Time Available as CP (n=2)
		Other Carers/CPs Available to PwA (n=1)
		Care Required by PwA (n=1)
		Frequency of Contact with PwA (n=6)
		Average Hours/Day with PwA (n=1)
		Average Days/Week with PwA (n=1)
Information About PwA (n=55) (when CP is focus of study)		Information about PwA (n = 1)
	Personal Factors (n=14)	PwA Age (n=3)
		PwA Gender (n=2)
		PwA Gender Identity (n=1)
		PwA Attitude Toward Tx (n=1)
		PwA Education (n=2)
		PwA Occupation (pre/post aphasia) (n=2)
		SES (n=1)
		Country of Residence (n=1)
		Rural/Regional/Metropolitan Residence (n=1)
	PwA Language History (n=5)	PwA Language History (n=1)
		Language Status (n=1)
		Level of Proficiency (n=1)
		Languages Used (n=1)
		L1 (n=1)
	PwA Medical History (n=4)	PwA Health Status (n=1)
		PwA Neurological History (Other than current aphasia aetiology) (n=1)
		PwA Cognitive Status (n=1)
		PwA Mental Health Status (n=1)
	Neurological Event (n=29)	Type of Neurological Event (n=2)
		Stroke Severity (n=1)
		Time Post Onset (n=13)
		Aphasia Classification (n=3)
		Severity of Aphasia (n=3)
		Language Profile (n=1)

Literacy (n=1)	
Motor Impairment (n=1)	
Neglect (n=1)	
History of SLP/Aphasia Intervention (n=2)	
History of Intervention Compliance and Response (n=1)	
PwA QoL (n=1)	

n= number of times coded

In round two, items from round 1 were combined with additional items identified from research databases and audits. From the list of 192 items presented for rating, 31 reached consensus and 57 were inconclusive. Additional comments submitted by participants most frequently expressed their concerns that some participant description reporting items are essential only in the context of specific research aims, while others are difficult to reliably measure (e.g., resilience, personality, motivation).

In round three, from the list of 88 items presented for re-rating, 21 reached consensus (see table 5 for detail).

Table 5. Participant characteristics reaching consensus in e-Delphi round 3.

Participant Characteristics	Rating %			Total participant n
	Of limited importance	Important but not essential	Essential	
People with Aphasia				
1. Age	0	6	94	88
2. First language	1	23	76	86
3. Primary language (Most commonly used)	0	15	85	86
4. Language of treatment/testing	0	5	95	86
5. Mono-/Multilingual status	0	29	71	86
6. Premorbid functional status	2	26	72	86
7. History of dementia	1	13	86	86
8. History of cognitive impairment	0	5	95	86
9. History of neurological condition	2	13	85	86
10. History of Previous Stroke/s	1	13	86	86
11. Date of First Stroke	2	26	72	86
12. Time Post-Onset	0	5	95	86
13. Type of neurological event.	3.5	24.5	72	86
14. Hemisphere Affected	3.5	17.5	79	86
15. Aphasia severity (across all modalities)	1	6	93	84
16. Connected speech abilities	1	24	75	84

17. Everyday functional language abilities	0	30	70	84
18. Language profile (in treatment language)	1	25	74	84
19. Apraxia of speech	0	27	73	86
20. Cognitive impairment	0	10	90	86
Communication Partner of PwA				
1. Relationship to PwA	0	20	80	84

Consensus meeting

Group discussion about the 21 items led to several unanimous decisions. Deliberation over the definition of '*education*' as '*years of education*' versus '*highest level achieved*' resulted in deciding on the former as more suitable because of its extensive use in existing databases and data dictionaries, and the latter as less suitable because of the global variation in terminology for levels of education. Deliberation over the feasibility and reliability of certain items resulted in some being removed (e.g., '*first language*' may not be answerable by bilingual people; highly localised lesion information may not be identifiable by authors lacking access to imaging equipment). Other discussion resulted in decisions to merge some items under broader terms, assign some items with forced choice or binary values, and revise the definitions and values of some items. In addition, there was agreement that the items '*biological sex*' and '*education*' which failed to reach consensus by round three of the e-Delphi exercise, should nonetheless be included in final voting. These decisions were informed by our aim to capture distinctions of significance for aphasia research/practice and eliminate those without, generate a minimally arduous reporting standard and adopt current terminology preferences.

The consensus meeting resulted in a refined list of 13 items pertaining to people with aphasia and five items pertaining to communication partners. These were presented with definitions and proposed response options for final voting. This resulted in a final list of 11 items pertaining to people with aphasia and three items pertaining to communication partners, totalling 14 participant characteristics

(see table 6). Each characteristic is defined and presented with standard response options to enable consistent reporting (see supplementary file 2: the '*DESCRIBE*' checklist).

Table 6. International consensus meeting: Results of final vote for inclusion in minimum reporting standards for participant characteristics in aphasia treatment studies.

Item	Votes to Include (/19)	% Agreement
Participant with Aphasia		
Age	19	100*
Biological Sex	19	100*
Years of Education	18	94.7*
Languages Used	17	89.5*
Language of Treatment/Testing	18	74.7*
Primary Language	15	78.9*
Preferred Language	10	52.6
History of Disease/Disorder/Injury Known to Impact Communication or Cognition	19	100*
History of Previous Stroke	14	73.7*
Onset of Post-Stroke Aphasia	18	94.7*
Type of Neurological Event	11	57.9
Lesion Location (Hemisphere)	17	89.5*
Presence of Co-Morbidities[#]	17	89.5*
Communication Partner of PwA		
Relationship to PwA	19	100*
Age	17	89.5*
Biological Sex	15	78.9*
Years of Education	12	63.2
Living Arrangements	11	57.9

*Reaching criteria for consensus (≥70%). [#] Later renamed "Conditions arising from the neurological event"

Discussion

Our e-Delphi exercise and consensus meeting established international, multidisciplinary expert consensus on 14 participant characteristics that should be reported in every post-stroke aphasia study. Each characteristic has been defined and matched with standard response options for consistent reporting. '*Age*', '*biological sex*', and '*years of education*' are routinely captured in aphasia data repositories (e.g., PLORAS[16]) and basic demographic descriptors are recommended within reporting standards (e.g., Consolidated Standards of Reporting Trials (CONSORT)[19]). The inclusion of these items is supported by literature which suggests an association between older age and higher incidence of aphasia and a possible influence of age, biological sex, and level of education on aphasia outcomes[20,21,22,23]. Nonetheless, the links between aphasia, age, biological sex, and years of education remain tenuous and require consistent collection and reporting to inform future research and secondary data analysis.

Languages have unique phonological, morphological, syntactic, semantic, pragmatic, and paralinguistic features that may interact and manifest variably with aphasia[24]. Reporting '*language of treatment/testing*', '*primary language*', and '*languages used*' can enhance validity in the interpretation of findings and facilitate culturally informed application of evidence in practice. Bi/multilingualism is known to explain certain neurological differences[25] and is hypothesized to influence aphasia outcomes[26]. The evidence however diverges, some studies suggest a protective effect of bilingualism against severe aphasia[27], while others report poorer language outcomes in bilingual stroke survivors[28].

'*History of condition(s) known to impact cognition/communication*' and '*history of previous stroke*' were both included. Many conditions are known to affect communicative and cognitive ability. In particular, the re-occurrence of neural lesions in the contralateral hemisphere is theorised to result in more severe disability[29]. Currently, there is a paucity of literature to provide insight into these mechanisms and many people with a pre-existing stroke are excluded from aphasia research[30]. '*Lesion hemisphere*' is considered a robust predictor of post-stroke recovery[31]. Compared to using behavioural and demographic data alone, adding lesion information in predictive modelling accounts for more

variance in treatment response[32]. Broadly, large lesions in left cortical language structures are associated with poorer language outcomes[31]. Consistent reporting of lesion hemisphere may therefore inform predictions of recovery outcome and treatment response. However, access to neuroimaging equipment was raised as a concern in our meeting. In consideration of this, *'lesion hemisphere'*, which can be reasonably determined through behavioural testing, was chosen over lesion size/site, which cannot be determined without neuroimaging.

Aphasia recovery is known to continue past the sub-acute phase[33], but the interaction of factors related to time, lesion, patient, and treatment remains under investigation. Consistent reporting of '*Time since onset of aphasia'* can enable further insight into possible interactions, as well as a more targeted matching of research findings to sub-populations of people with aphasia in the clinical setting. Interestingly, while aphasia characteristics (classification, severity, language profile) were generated in our process, none were deemed essential. There is mixed opinion about the utility of aphasia classifications, which are often based on over-simplified clinical-anatomical correlations and do not account for the variability seen in the presentation of aphasia[34]. Initial severity of aphasia on the other hand has been associated with improved recovery, however it is possible that the inclusion of measures of aphasia severity within the Research Outcome Measurement in Aphasia core outcome set[11] precluded the need for them in this reporting standard. A final participant characteristic pertaining to people with aphasia in our minimum reporting standard is '*conditions arising from neurological event'*. This encompasses a range of common post-stroke motor, sensory, and cognitive impairments, and psychological impacts that can directly and indirectly affect language ability and outcomes[35,36].

The critical role of communication partners is well recognised in post-stroke aphasia recovery. Inclusive of family members, care partners, and others who have a significant relationship with the person with aphasia, communication partners may contribute to assessment, goal setting, information provision, and treatment planning[37]. Thus, communication partners characteristics of *'age'*, *'biological sex'*, and *'relationship to person with aphasia'* were included. Although not quantified, there is some evidence to suggest that a communication partner's age, biological sex, and relationship

to the person with aphasia shapes not just their own post-stroke experiences, but those of the person with aphasia[38]. While age and biological sex may offer reasonably inferred insights, it is the relationship shared between the communication partner and the person with aphasia that may be most informative of the nature, scope, and implications of the communication partner's involvement in aphasia recovery[39]. While relationship type (e.g., spouse, daughter) does not necessarily provide insight to the quality or closeness of a relationship, it does provide a starting point for considering the impact of communication partner support on recovery.

We acknowledge several limitations that add to the caveats already discussed. Firstly, although we sought international, multidisciplinary expert consensus, we were unable to invite the participation of individuals could not participate in English. These individuals will have relevant perspectives that may have extended or altered our findings, in more culturally sensitive and inclusive ways. Our minimum reporting standard also predominantly represents the views of researchers. With greater input from therapists who work with people with aphasia, the reporting standard may offer greater utility for applying evidence in practice. Lastly, given the ever-evolving nature of research and systemic values, the present minimum reporting standard should be subject to ongoing review and revision to maintain currency.

Clinical messages

- International, multidisciplinary expert consensus established 14 participant characteristics (with standard response options) that should be reported in post-stroke aphasia research.

- Consistent adherence to this minimum reporting standard may reduce research wastage and facilitate evidence-based aphasia management by enabling replication and collation of research findings, and translation of evidence into practice.

Acknowledgements

Author contributions

SW, MA, & MB conceived and designed the research study. SW led the collection and analysis of e-Delphi data with support from MA and MB. The international consensus meeting and voting process was facilitated by SW with support from MI. SW and MI led the analysis of the consensus meeting and voting data. MI led the preparation of the manuscript. All authors contributed to manuscript writing and editing and approved the final version.

Conflict of interest

We declare no conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Supplementary Table 1

DESCRIBE consensus meeting facilitators

Sarah J. Wallace PhD BSpPath (Hons) GradCert Gerontology CPSP National Health and Medical Research Council Emerging Leadership Fellow, Queensland Aphasia Research Centre, The University of Queensland. *Expertise: Post-stroke aphasia rehabilitation, core outcome set development, stakeholder perspectives, consensus processes, ICF.*	**Megan Isaacs PhD BSpPath (Hons)** Postdoctoral Research Fellow Queensland Aphasia Research Centre, School of Health & Rehabilitation Sciences, The University of Queensland, Brisbane, Australia. *Expertise: Post-stroke aphasia rehabilitation.*	**Myzoon Ali PhD** Senior Research Fellow NMAHP Research Unit A433 Govan Mbeki Building Glasgow Caledonian University G4 0BA *Expertise: Post-stroke aphasia, IPD Meta-analysis, secondary analysis of large datasets.*	**Marian Brady PhD BSc (Hons) FRCSLT** Registered SLT, Professor of Stroke Care and Rehabilitation; NMAHP Research Unit, Glasgow Caledonian University, Glasgow G40BA, UK. *Expertise: Stroke care and rehabilitation particularly aphasia, trial design, delivery and reporting, big data, systematic review, and meta-analysis (including IPD and network) and service improvement.*

DESCRIBE consensus panel

Seckin Arslan Neurolinguist. Tenured scientific researcher at Centre National de la Recherche Scientifique CNRS & Université Côte d'Azur, Nice, France. *Expertise: Post-stroke and primary progressive aphasia assessment, multilingualism, multilingual aphasia, event-related potentials, and eye-movement monitoring.*	**Jamie Azios PhD CCC-SLP** Speech-language Pathologist, Associate Professor, Department of Speech & Hearing Sciences, Lamar University, Beaumont, TX, USA. *Expertise: Post-stroke aphasia rehabilitation, Participation-focused interventions, qualitative research, discourse-related measures.*	**Mohamed Azmarul Aziz** Speech-Language Pathologist, Deputy Head Clinical Research Centre, Speech Therapy Unit, Cheras Rehabilitation Hospital, Putrajaya, Malaysia. *Expertise: Post-stroke aphasia rehabilitation.*	**Lucy Bryant PhD** Speech Pathologist, Lecturer, Clinic Service Manager, University of Technology Sydney Graduate School of Health, Faculty of Health, Sydney, Australia. *Expertise: Post-stroke aphasia assessment and rehabilitation, discourse analysis, technology, and rehabilitation.*
Bonnie Cheng PhD BSpPath (Hons) Speech Pathologist, Research Assistant, Queensland Aphasia Research Centre, School of Health & Rehabilitation	**David Copland PhD BSpPath (Hons)** Speech Pathologist, Director Queensland Aphasia Research Centre, School of Health & Rehabilitation	**Madeline Cruice PhD BSpPath (Hons)** Registered Speech and Language Therapist, Reader, Teaching and	**Jonathan Delgado Hernández MSc BSc SLT** Speech and Language Therapist, Rehabilitation Centre CREN Salud,

Sciences, The University of Queensland, Brisbane, Australia. *Expertise: Post-stroke aphasia recovery, clinical communication, qualitative research.*	Sciences, The University of Queensland, Brisbane, Australia. *Expertise: Post-stroke aphasia assessment and rehabilitation, aphasia trial design and conduct, neuroimaging in aphasia*	Research Academic, School of Health Sciences, City University of London, London, UK. *Expertise: Post-stroke aphasia rehabilitation, therapeutic process and evaluation, quality of life evaluation in research and clinical practice, behaviour change.*	Teaching and Research Academic, Department of Developmental and Educational Psychology, University of La Laguna, Tenerife, Spain.
Nevine El Nahas Professor of Neurology and head of Stroke unit and Neuromodulation lab. Faculty of Medicine, Ain Shams University, Cairo, Egypt. *Expertise: Director of post-stroke aphasia research project to study brain connectivity disorders in patients with aphasia and children with dyslexia.*	**Ingrid Henriksson** Certified Speech and Language Therapist, Teaching and Research Academic, Division of Speech and Language Pathology, Institute of Neuroscience and Physiology, The Sahlgrenska Academy University of Gothenburg, Sweden. *Expertise: Post-stroke aphasia assessment and rehabilitation, cognitive processes involved in written language, digital inclusion.*	**Katerina Hilari PhD MRCSLT MHPC** Psychologist, Registered Speech and Language Therapist, Teaching and Research Academic, School of Health Sciences, City, University of London, UK. *Expertise: Outcome measurement development, validation and cultural adaptation, post-stroke aphasia rehabilitation, feasibility RCTs, clinical guideline development.*	**Helen Kelly PhD MIASLT** Registered Speech and Language Therapist, Teaching and Research Academic, Department of Speech and Hearing Sciences, University College Cork, Cork, Ireland. *Expertise: Post-stroke aphasia rehabilitation, self-management, single subject and feasibility RCT trial design and conduct, systematic reviews, PPI, stakeholder perspectives.*
Jordi A Matias-Guiu, PhD MD Neurologist. Department of Neurology, Hospital Clinico San Carlos. Instituto de Investigación Sanitaria San Carlos (IdISSC). University Complutense. Madrid, Spain. *Expertise: assessment and management of patients with aphasia; development and validation of novel tests for assessment and monitoring; non-invasive neuromodulation techniques for aphasia treatment.*	**Laura Murray PhD MSc BSc SLP(C)** Speech pathologist, Teaching and Research Academic, School Director, School of Communication Sciences and Disorders, Western University, London, Canada. *Expertise: Assessment and rehabilitation for aphasia and related, extralinguistic cognitive disorders, the development and evaluation of novel treatments, single subject designs, systematic reviews.*	**Gill Pearl MPhil Dip Hum Commun.** Certified practicing speech and language therapist in role as Chief Executive Officer of Speakeasy - specialist aphasia centre, UK. *Expertise: Development and evaluation of novel approaches to providing long term aphasia support and therapy, facilitator of consumer involvement in research, feasibility studies, case series studies, RCT design and conduct.*	**Anastasia Raymer PhD MA BS SLP CCC-SLP** Speech pathologist, teaching and research faculty, Program director, Department of Communication Disorders and Special Education, Old Dominion University, Norfolk, VA USA *Expertise: Neuroplasticity principles in rehabilitation, evidence-based treatment for aphasia and related disorders, single subject design, systematic reviews.*
Miranda Rose PhD BSpPath FSPA Speech pathologist, Research Professor, Director Centre of Research Excellence in Aphasia Recovery and Rehabilitation, School of Allied Health, Human Services and Sport, La Trobe University, Victoria, Australia.	**Karen Sage PhD Dip DisHumComm BA (Hons) HCPC** Registered Speech and Language Therapist, MRCSLT; Teaching and Research Academic, Faculty of Health and Education, Manchester Metropolitan University, UK.	**Ciara Shiggins PhD DipHEP BSc SLT (Hons) HCPC** Registered Speech and Language Therapist, Post-Doctoral Research Fellow Queensland Aphasia Research Centre, School of Health &	**Kirstine Shrubsole PhD BSpPath (Hons)** Speech Pathologist, Post-Doctoral Researcher, Queensland Aphasia Research Centre, The University of Queensland. *Expertise: Post-stroke*

Expertise: Post-stroke aphasia rehabilitation, aphasia trial design and conduct, single subject designs, consumer perspectives, aphasia rehabilitation guideline development.	*Expertise: Aphasia assessment and management, stroke rehabilitation, single case, case series, mixed methods.*	Rehabilitation Sciences, The University of Queensland, Brisbane, Australia. *Expertise: Aphasia inclusion and accessibility, conversation partner training, patient and public involvement, post-stroke mental health and wellbeing, neuroplasticity and re-learning, qualitative research methods.*	*aphasia rehabilitation, implementation science.*
Eva Soroli, PhD MSc Associate professor of Psycholinguistics, Department of Language Sciences, STL lab, University of Lille & CNRS, France. *Expertise: Post-stroke aphasia, language assessment, cross-linguistic and cross-cultural adaptations of assessment and outcome tools, verbal and non-verbal measures.*	**Mohamed Taiebine, PhD MSc** Clinical neuropsychologist, SLP; Teaching and Research Academic, Alzheimer's centre, The University of Mohammed V, Faculty of medicine and pharmacy, Rabat, Morocco. *Expertise: neuropsychological assessment and neurocognitive stimulation, acquired neurogenic language disorders, neurodegenerative diseases, neurodevelopmental disorders.*	**Mariko Yoshino PhD Disability Sciences** Registered Speech-Language-Hearing Therapist; Teaching and Research Academic, Faculty of Human Sciences, University of Tsukuba, Japan. *Expertise: post-stroke aphasia rehabilitation, assessment and management of acquired cognitive disorders.*	

Establishing Standards for Reporting Participant Characteristics in Aphasia Research.

PARTICIPANT CHARACTERISTICS: PEOPLE WITH APHASIA			
Characteristic	**Definition**	**Values**	**Comment**
Age	The person's completed age in years.	*YY*	
Years of education	Number of years of education (full-time equivalent) completed by the person.	*YY*	Full-time equivalent. Excludes certificate and technical programs, and experiential training (e.g. internships, residencies and fellowships).
Biological sex	The person's sex at birth (where sex is defined as the distinction between male, female, or the combination of male and female biological characteristics).	*Male* *Female* *Intersex* *Other (may specify another term)*	To be captured as written in the medical record. Self-identified sex may be reported in the case of conflict.
Language of treatment/testing	The language used by the person with aphasia during treatment and testing.	*Written Language* *Spoken Language*	
Primary language	The language (including sign language) most frequently used by the person with aphasia for communication.	*Primary spoken language.* *Primary written language.*	

Languages used	The number of languages the person with aphasia used on a regular basis prior to the onset of aphasia.	*Does the person use more than one language on a regular basis? Yes / No* *If yes specify (languages used including modality i.e. spoken/written)*	
History of condition(s) known to impact communication/cognition	History of an acquired or developmental condition known to impact communication (e.g. language, speech, hearing) or cognition (e.g. memory, executive function, attention, visuospatial processing, processing speed). Conditions included here must have been present prior to most recent neurological event (i.e. that from which the aphasia arose). Examples include: • Developmental language disorder/delay • Developmental articulation disorder • Childhood Apraxia of Speech • Childhood stuttering • Encephalitis • Autism Spectrum Disorder • Hearing loss • Multiple Sclerosis • Motor Neuron Disease • Cerebral Palsy • Parkinson's disease • Huntington's disease • Meningitis • Traumatic Brain Injury • Acquired motor speech disorder (e.g. apraxia, dysarthria) • Neurogenic stuttering • Brain tumour • Dementia	*Yes* *No* *If yes please describe the condition and the functional impacts on communication* *Note: History may be obtained from the person's medical record or self-reported if record is unavailable.*	

History of previous stroke	A history of stroke prior to the most recent episode, excluding TIA and silent stroke.	*Yes* *No* *If yes please specify:* *number, months/years post stroke, was aphasia present (Y/N/Unknown).*	
Lesion hemisphere	Hemisphere affected by neurological event.	*Left* *Right* *Both* *Unsure*	
Time since onset of aphasia	The months/days/years between commencement of the treatment under investigation and the onset of aphasia.	*DD/MM/YY as applicable.*	
Conditions arising from neurological event	Presence of conditions that have arisen from the most recent neurological event (i.e. post-stroke). Examples include: • apraxia of speech • non-verbal oral apraxia • dysarthria • hemiplegia • hemiparesis • cognitive impairment • sensory impairment • depression, anxiety, or mood disorder	*Did the person present with other conditions arising from the neurological event at the time of treatment?* *Yes* *No* *If yes specify.*	Conditions may be identified in the person's medical record or self-/significant other- reported

PARTICIPANT CHARACTERISTICS: COMMUNICATION PARTNERS

Characteristic	Definition	Values	Comment
Age	The person's completed age in years.	YY	
Biological sex	The person's sex at birth (where sex is defined as the distinction between male, female, or the combination of male and female biological characteristics).	*Male* *Female* *Intersex* *Other (may specify another term)*	To be captured as written in the medical record. Self-identified sex may be reported in the case of conflict.
Relationship to person with aphasia	Relationship of the carer/significant other/communication partner to the person with aphasia.	*Spouse/partner* *Son/daughter/Child-in-Law* *Other relative** *Friend/associate* *Professional carer*** *Sibling* .	*Other Relative – a person who is related to the patient but not represented by the available selections. This could include a grandparent, step-parent, or foster-parent. **Professional Carers are people who are trained and paid to look after people