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## The co-creation of the functional rating of interaction engagement needs and difficulties scale (FRIENDS) with people with aphasia

Marina Charalambous<sup>1</sup><sup>a</sup>, Stavroulla Eftimiou<sup>a</sup>, Elena Andreou<sup>a</sup>, Marianna Tsiakoulia<sup>a</sup>, Phivos Phylactou<sup>b</sup> and PPI Partners - The Aphasia Communication Team (TACT)<sup>c</sup>

<sup>a</sup>Department of Rehabilitation Sciences, School of Health Sciences, Cyprus University of Technology, Limassol, Cyprus; <sup>b</sup>School of Physical Therapy, University of Western Ontario, London, Canada; <sup>c</sup>The Aphasia Communication Team (TACT), Communication Support Group for People with Aphasia, Limassol, Cyprus

### ABSTRACT

**Background:** Friendship is vital for the well-being and social integration of people with aphasia (PWA) post-stroke. The impact of chronic aphasia on the friendships and social engagement of PWA is often overlooked by rehabilitation clinicians. Aim: To co-create the Functional Rating of Interaction Engagement Needs and Difficulties Scale (FRIENDS), a self-report aphasia-friendly tool, in collaboration with PWA, and test its psychometric properties.

**Methods:** A Patient and Public Involvement approach was adopted, involving 3 PWA and a caregiver as research partners across eight co-design meetings. FRIENDS' psychometric properties were evaluated with reliability and validity measures. The psychometric study involved 166 participants: 62 PWA, 50 people with stroke without aphasia, and 54 healthy controls.

**Results:** FRIENDS demonstrated excellent internal consistency (Cronbach's  $\alpha > 0.960$ ) and high test – retest reliability (ICC  $\geq 0.99$ ). The results demonstrated a significant difference amongst the three groups ( $p < 0.001$ ), which verified known-groups validity. Significant correlations between FRIENDS and measures of aphasia severity, functional communication, and quality of life supported the tool's convergent validity. Results derived from analyzing the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) report supported its content validity.

**Conclusion:** FRIENDS is a psychometrically sound, patient-reported outcome measure, developed to rate changes in the friendships of PWA. Co-created with PWA, FRIENDS offers a broad view of chronic aphasia's impact on friendships, aiding clinicians in co-developing functional intervention plans, enabling person-centered care, and improving the social life of PWA.



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**CONTACT** Marina Charalambous  [marina.charalambous@cut.ac.cy](mailto:marina.charalambous@cut.ac.cy)  Faculty of Health Sciences, Department of Rehabilitation Sciences- Speech and Language Therapy Sector, Cyprus, University of Technology, Limassol, CY, 3041, Cyprus

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## Introduction

The Burden of Stroke in Europe reports 1.12 million strokes per year, 9.53 million stroke survivors, and 7.06 million Disability-Adjusted Life Years (DALYs) lost because of stroke (Wafa et al., 2020). There is an estimate that by 2047, there will be a 27% increase in the number of people surviving a stroke in the EU, with a marked rise in individuals aged 25 to 44 years (+43.8%) due to environmental pollution and lifestyle changes (Béjot et al., 2016). Stroke has a lifelong impact on daily activities and social participation, including community-based activities and maintaining friendships (Demers et al., 2025; Gopaul et al., 2022). People with lived experience of stroke often encounter challenges in maintaining or developing friendships due to physical, cognitive, emotional, and communication difficulties (Ford et al., 2023). Approximately one-third of stroke survivors experience aphasia (Kristinsson et al., 2022), which impairs their linguistic abilities, affects everyday communication, and can, over time, lead to disconnection from social networks and friends (Fernandes et al., 2022).

Effective communication is fundamental to sustaining social relationships and friendships, as it enables reciprocity, shared experiences, and the negotiation of social roles (Hilari & Northcott, 2017). In aphasia, reduced communicative effectiveness has been shown to disrupt friendship networks and contribute to social isolation, with friends often withdrawing when communicative exchanges become effortful or unequal (Northcott & Hilari, 2011). These challenges frequently lead to reduced social participation and impact their quality of life (Pike et al., 2017). This underscores that communication is not only a linguistic skill but also a critical mediator of participation and psychosocial. To pursue a holistic approach to assess these restrictions, the International Classification of Functioning, Disability and Health (ICF; World Health Organization [WHO], 2001) framework allows us to determine the impact of stroke aphasia on the individual's health status (impairment), activity and participation, as well as other personal and environmental (contextual) factors that influence the person's level of engagement within their social circle. The Activity and Participation domain (ICF; WHO, 2001) focuses on assessing the level of involvement of people with aphasia (PWA) in everyday life events. Specifically, Activity (WHO, 2001) considers the life activities in which PWA engage and how aphasia affects the individual's participation in these (Galletta & Barrett, 2014). In addition, Participation (WHO, 2001) classifies PWA's participation level in society and describes the effects of aphasia on social roles and life situations, including barriers to participating in activities with friends (Doedens & Meteyard, 2022). Aphasia impacts Activity and Participation in an interactive way, as it affects both social and personal life, for people living with chronic aphasia (Matos et al., 2014).

### *Aphasia and friendship*

Recent evidence shows that PWA who engage in social activities with friends report enhanced emotional well-being and a stronger sense of belonging (Douglas et al., 2023). Correspondingly, meaningful friendships are associated with significant benefits in mental health and overall welfare in people with chronic aphasia (Douglas et al., 2023). However, the degree of closeness in friendships is not always the same, as it depends on the quality of the relationship and the context in which it develops after the stroke event

(Azios et al., 2021). Recognizing the critical role of friendship enables healthcare professionals to develop tailored interventions aimed at strengthening social networks, thereby supporting the overall quality of life of PWA after stroke.

While PWA typically continue interacting with family members after a stroke, the nature and the number of their friendships often change significantly, bringing unfavourable changes to their social networks and interpersonal relationships (Northcott et al., 2016). In a recent international survey on why aphasia awareness is important, 47% of PWA voted that aphasia awareness is important because “*aphasia affects not only the person with aphasia but also their family and friends*” (Bennington et al., 2024, 1925). Similarly, the thematic analysis by Archer et al. (2024), on the perspectives and experiences of PWA about their friendship, highlighted that if friends knew some basic information about aphasia, bonds would stay stronger. Further, research has shown that PWA struggle to maintain or form new friendships compared to stroke survivors without aphasia (Hilari & Northcott, 2017; Northcott & Hilari, 2011). The study by Hilari and Northcott (2006) on social support in people with chronic aphasia showed that 63.9% of the participants with aphasia had less contact with friends than before the stroke, while 30% were unable to identify a solitary close friend.

People with chronic aphasia often attribute their shrinking social circles and friendships to aphasia-related communication difficulties, unresponsive or unsupportive behaviour from others, changes in social priorities, a lack of shared experiences, decreased energy, physical limitations, and environmental barriers Northcott and Hilari (2011). Additionally, demographic characteristics including age, aphasia severity, gender, race, and time post-stroke play a crucial role in their ability to maintain friendships (Madden et al., 2023). Still, the detrimental effects of losing friends and having trouble making new ones are pervasive (Azios et al., 2021). According to Madden et al. (2023), friendships are more likely to be maintained when there is a shared history, when friends express concern, and when the friendship focuses on the bond itself rather than shared activities. Additionally, the study by Ford et al. (2023) highlights that PWA benefit from having friends who give them more time, slow down, and simplify their speech.

The limitation in social interactions and encounters with friends is further reflected in their emotional well – being as PWA experience higher levels of depression compared to those without aphasia (Azios et al., 2021). The Supporting Well-Being through Peer Befriending (SUPERB) trial by Hilari et al. (2021) tested the benefits of befriending, a supportive intervention in which trained PWA, known as befrienders, offer companionship, emotional support, and practical help to other PWA. The study found that peer – befriending was feasible and well-received, with early evidence suggesting potential benefits in reducing depressive symptoms and enhancing long-term mood changes for people with chronic aphasia (Hilari et al., 2021).

Around that time, Madden’s et al. (2023) study on friendship and aphasia highlights that severe expressive aphasia correlates with reduced friendship support. Therefore, maintaining or developing functional communication skills is crucial for PWA, as they significantly impact their ability to preserve friendships and engage in social interactions (Fernandes et al., 2022). This not only enhances the quality of their everyday life but also strengthens their emotional resilience (Therrien et al., 2021). “Functional communication” refers to the ability to convey and understand messages in everyday contexts using all available modalities, including verbal, nonverbal, and multimodal strategies (Doedens &

Meteyard, 2022). From the perspective of caregivers, functional communication skills are vital for fostering meaningful everyday connections with peers and ensuring the emotional health of PWA (Charalambous, Phylactou, et al., 2024). Conversely, higher levels of communicative participation are associated with better friendship support, underscoring the importance of functional communication abilities in maintaining social connections (Doedens & Meteyard, 2022).

### ***Published tools rating friendship***

Very few published questionnaires address friendship as a stand-alone subject. The Friendship Scale (FS; Hawthorne, 2006), a six-item questionnaire designed for the general population, measures social isolation rather than the broader dimensions of friendship. The FS is suitable for older adults and people with chronic conditions, but not for people with communication impairments. The SUPERB trial used the FS to measure outcomes post-intervention (Hilari et al., 2021). Similarly, MyCommunication – Adults by Ter Wal et al. (2024) is an item bank designed to measure communicative participation in adults with communication difficulties, including those with aphasia, dysarthria, and apraxia. However, it does not report any psychometric properties and does not specifically address friendship, but rather the communication in the domain of Activity and Participation in general. Further, the McGill Friendship Questionnaire (MFQ; Mendelson & Aboud, 1999) evaluates the quality of friendships in late adolescents and young adults, and was used in a study to assess friendship quality in a small sample of adults with traumatic brain injury and their informant friend (Flynn et al., 2018). The Friendship Questionnaire (FQ; Baron-Cohen & Wheelwright, 2003) was developed to assess friendship patterns among individuals with Asperger syndrome or high-functioning autism, whereas the Lubben Social Network Scale (LSNS; Lubben & Gironde, 2004) focuses on measuring social networks and social connectedness in older adults, with an emphasis on identifying social isolation.

None of these tools specifically captures the unique needs and challenges experienced by people with communication difficulties after stroke. Addressing this gap, Madden et al. (2023) developed a friendship questionnaire tailored to PWA. Their primary objective was to explore how friendships change throughout stroke and aphasia recovery. Unlike previously mentioned brief tools, the Madden et al. (2023) questionnaire comprised 54 open- and closed-ended questions designed to encourage PWA to recall and evaluate the quality of their friendships, the support they received, the nature of their interactions, and their communication experiences both before the onset of aphasia and during the early recovery phase. While this study offers valuable insights into the friendship experiences of PWA, the authors did not provide a detailed account of the questionnaire's formal development process and psychometric validation. They acknowledge the need for further research to refine and validate tools specifically addressing friendship in the context of aphasia.

### ***Foundational theoretical frameworks***

The Person-Centered Care framework (Martín-Sanz et al., 2022) was implemented in this study to improve patient-practitioner interactions through shared decision-making (Nelson et al., 2024). Person-Centered Care is a holistic approach in which people with

stroke aphasia are provided with the support needed to enable them to participate and make decisions about their individual needs (Hinckley & Jayes, 2023). The Person-Centered Care framework was implemented by following a Patient and Public Involvement (PPI) approach and actively involving four PPI partners, three with aphasia and a caregiver (Charalambous et al., 2023). The PPI partners were involved from the beginning until the end of the development of the tool as described in the Methods section. By actively engaging PPI stakeholders for input, feedback, and diverse perspectives, the co-creation of the Functional Rating of Interaction Engagement Needs and Difficulties Scale (FRIENDS) sought to meaningfully reflect the distinct needs, preferences, and lived experiences of the target population, in alignment with the core principles of Person-Centred Care (Terry & Kayes, 2020).

In addition, the ICF framework (WHO, 2001) was foundational in developing FRIENDS, as it captures the importance of assessing the real-life involvement of PWA in meaningful social relationships. Specifically, the ICF Core Sets for Stroke (Geyh et al., 2004) highlight the importance of social participation and engagement in promoting effective rehabilitation by including categories relevant to friendships. For example the the ICF code *d7500: Informal relationships with friends*, which is a subcategory of *d750: Informal social relationships*, provides a more specific description focused on friendships outside the family, such as creating and maintaining friendship relationships that are characterized by mutual support and common interests. This category guided FRIENDS to focus on dimensions such as personal contact, social engagement, and emotional support within friendships. Also, by grounding the tool in the Activity and Participation domain of the ICF, FRIENDS goes beyond measuring impairment or activity limitations to capture how friendships function as both a resource and an outcome in the rehabilitation process.

### ***The importance of developing the functional rating of interaction engagement needs and difficulties scale (FRIENDS)***

The European Disability Forum's manifesto (EDF, 2023) outlines the key priorities for persons with disabilities to be fulfilled by the European Organizations in full respect of the United Nations Convention on the Rights of People with disabilities. The motto of the disability movement, "*Nothing About Us Without Us*," exerts pressure on the European Commission to put forward specific laws to guarantee the independent involvement of people with disabilities in all aspects of life. The FRIENDS project addresses this pan-European challenge by creating a standardized, easy-to-understand resource in collaboration with PWA and significant others from the beginning of the project.

This study developed a patient-reported outcome measure (PROM) to enhance clinicians' understanding of how aphasia affects friendships from the perspective of the person with aphasia. Specifically, a PROM co-created with PWA can capture the distinct lived experiences of social connection and disconnection in ways that are accessible, meaningful, and authentic to their voices and values. Co-creating a PROM fosters empowerment, inclusion, and the development of tools that reflect the everyday realities of PWA (Swinburn et al., 2018). It also strengthens content validity through language, concepts, and formats that resonate with them. In contrast, clinician-reported measures may prioritise professional perspectives over what genuinely matters to PWA. Importantly, co-creation aligns with ethical and participatory principles in health research, advocating for

the active involvement of service users in shaping the tools used to assess their outcomes (Anemaat et al., 2024).

Despite the recognized importance of social connectedness for emotional well-being and recovery (Haslam et al., 2008), there is a notable lack of tools specifically designed to measure the quality and extent of friendship in people with chronic aphasia after stroke (Azios et al., 2021). This gap limits clinicians' and researchers' ability to assess and support the social lives of PWA. To address this need, the present study introduces the Function Rating Interaction and Engagement Needs Difficulties Scale (FRIENDS), a short, aphasia-accessible, psychometrically robust tool co-created with PWA to identify both the needs and difficulties they experience in friendship-related interactions. FRIENDS fills a critical gap in the assessment of social engagement in chronic aphasia by providing a subjective outcome measure that is suitable for use within therapeutic settings, concise enough for clinical use, and grounded in the lived experiences of PWA, who were involved at every stage of its development. By highlighting functional aspects of social connection from their perspective, the tool supports person-centred goal-setting, intervention planning, and outcome monitoring. This paper aims to (a) introduce the FRIENDS tool, (b) describe its iterative development and co-creation with PWA, and (c) report the testing of its psychometric properties.

## **Functional rating of interaction engagement needs and difficulties scale (FRIENDS)**

FRIENDS is a subjective, pictorial, self-report questionnaire co-created for PWA to explore their experiences of friendship and social interaction. It consists of 10 items addressing key dimensions of friendship, including social access, reciprocity, mutual interest, emotional support, acceptance, trust, and social engagement. Each item is presented on a separate page with a consistent layout: the header "During the past four weeks ...", a central statement, a supportive image, and a 5-point pictorial rating scale, 1 = "never", 5 = "always". For example, the item "I felt that I could rely on a particular friend" invites the respondent to select the image that best reflects their experience. The questionnaire is administered with support from a facilitator when needed. FRIENDS prioritizes the subjective experience of living with chronic aphasia and was informed by existing tools such as the AIQ-21 (Swinburn et al., 2018), alongside input from PPI partners throughout the co-creation process.

## **Methods**

### ***Design***

A co-creation approach, grounded in the principles of PPI, was employed to develop FRIENDS, followed by a cross-sectional study to evaluate its psychometric properties.

### ***The research team***

The research team included 12 members: a senior speech and language therapist specialized in aphasia rehabilitation and research (MC), an occupational therapist with clinical expertise in functional social reintegration of people with stroke and aphasia (MT), two

final-year speech and language therapy (SLT) students nearing entry-level professional qualification (who were the facilitators of the group and were managing logistics), three people with chronic stroke-induced aphasia, who were members of The Aphasia Communication Team (TACT) support group, named as PPI 1, PPI 2, PPI 3, a caregiver of a person with aphasia, PPI 4, three communication partners who were supporting PPI partner with aphasia and was supported by a mental health professional (PP) who contributed to advisory and revision stages and oversaw statistical analyses.

PPI 1 was a 50-year-old divorced woman with two children of Greek-Cypriot heritage, with a history of ischemic stroke related to recurrent atrial fibrillation. She presented with chronic moderate expressive aphasia. She lived with her daughter, had not returned to work after her stroke, and was socially isolated. PPI 2 was a 70-year-old retired public officer, married with three children and five grandchildren, who had an active social life. He experienced an ischemic stroke several years ago, which left him with right hemiplegia and mild – moderate anomic aphasia. He retired early following his stroke. PPI 3 was a 62-year-old married man with four children, employed as a public servant, who enjoyed hunting and dancing. He never returned to work or to recreational activities after his stroke and presented with moderate anomic aphasia. Communication partners were 23 years old, final-year SLT students, who identified as female. The demographic characteristics of the PPI partners with aphasia and the caregiver are displayed in Table 1 based on the DESCRIBE checklist (Wallace et al., 2023).

The study group has extensive experience in the psychometric testing of aphasia-related assessment tools and PROMs (Charalambous, Phylactou, Elriz, et al., 2022; Charalambous, Phylactou, Kountouri, et al., 2022; Charalambous, Phylactou, et al., 2024).

**Table 1.** Demographic characteristics of the four PPI research partners.

Characteristics	PPI 1	PPI 2	PPI 3	PPI 4
Age	50	70	62	58
Years of education	12	12	12	12
Gender	Female	Male	Male	Female
Language of testing	Standard Modern Greek	Standard Modern Greek	Standard Modern Greek	Standard Modern Greek
Primary language	Standard Modern Greek* and Cypriot – Greek dialect**	Standard Modern Greek and Cypriot – Greek dialect	Standard Modern Greek and Cypriot – Greek dialect	Standard Modern Greek and Cypriot – Greek dialect
Languages used in treatment	Standard Modern Greek & Cypriot-Greek dialect	Standard Modern Greek & Cypriot-Greek dialect	Standard Modern Greek & Cypriot-Greek dialect	Standard Modern Greek & Cypriot-Greek dialect
History of previous stroke	Ischemic	Ischemic	Ischemic	N/A
Lesion hemisphere	Left	Left	Left	N/A
Time since onset aphasia	Seven years	Nine years	Eight years	N/A
Conditions arising from neurological event	Aphasia and mood disorders	Aphasia and hemiplegia	Aphasia and sensory impairment	N/A

Note: PPI 1–3 are people with aphasia, and PPI 4 is a caregiver; \*Standard Modern Greek is the native language of Greeks living in Greece and is acquired (mainly used) at school in Cyprus, as it is the variety used in formal oral and written communication (Fotiou & Grohmann, 2022). Standard Modern Greek was used during formal testing. \*\*Cypriot Greek, a dialect of Standard Modern Greek, is the mother tongue of Greek Cypriots and is used in informal/everyday interactions (Fotiou & Grohmann, 2022). Cypriot Greek was used during the group sessions and informal assessment procedures (personal stories).

In addition, our team developed the People with Aphasia and Other Layperson Involvement (PAOLI) framework (Charalambous et al., 2023) and has recently conducted a co-design intervention study on aphasia groupwork (Charalambous, Symeou, et al., 2024). The three PPI partners with aphasia had prior experience in aphasia research, having participated as co-creators in a personal narrative intervention study (see Charalambous, Symeou, et al., 2024).

### ***Patient and public involvement methodology***

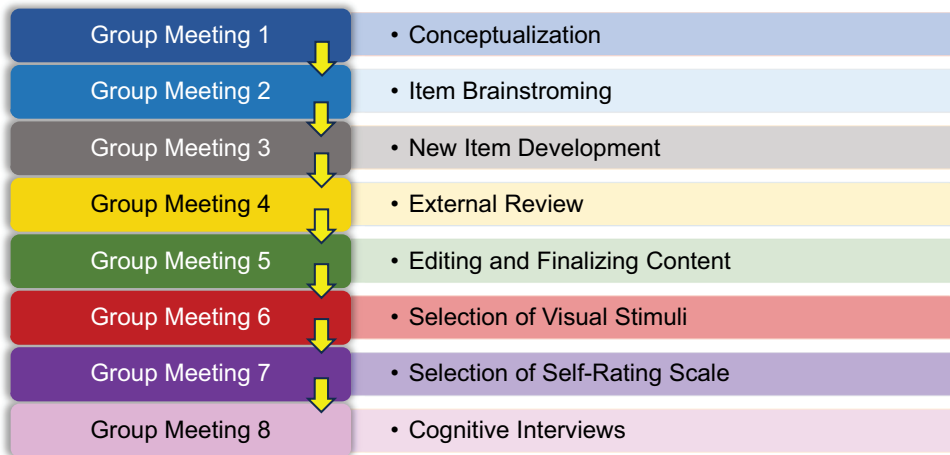
PPI methodology was employed to ensure the meaningful involvement of three people with chronic aphasia (PPI 1, 2, 3) and one caregiver (PPI 4) as equal members of the research team. The team adopted the PAOLI framework (Charalambous et al., 2023) to support the active involvement of individuals with lived experience from the outset of the study and throughout all stages of the research process. Through the adoption of PAOLI, the research team fostered equitable partnerships between researchers and PPI partners, employing co-production methodologies that empowered PWA to participate actively in decision-making regarding the development of the tool items and associated imagery. Consistent with the distinction between involvement and participation in research (McMenamin et al., 2022), all PPI partners were engaged as research team members rather than research participants. Their role was meaningful and active, ensuring that the tool reflected lived experiences. Involvement was voluntary, informed, and non-coerced, with ongoing support to promote choice and maintain independence. The PAOLI framework also guided the team in establishing accessible communication strategies, providing clear and tailored information about the project's methodology. This comprehensive approach enhanced the transparency, inclusiveness, and collaborative nature of the project, enabling PWA to contribute meaningfully and actively to the research process. For this study, the GRIPP-2 Short Form (Staniszewska et al., 2017) checklist was followed to report on PPI (see [Appendix 1](#)).

### ***Development process of FRIENDS***

The study's co-creation protocol was completed in eight 2-hour, weekly group meetings (see [Figure 1](#) for timeline). Seven meetings were conducted at the premises of the Rehabilitation Clinic of the Department of Rehabilitation Sciences of the Cyprus University of Technology, and one meeting was held online.

### ***Group meeting 1: conceptualization***

Meeting 1 served as an introduction among all members of the research team, including the three people with chronic aphasia, their communication partners, the caregiver, and the researchers. During this meeting, the members of the research team discussed the overall aims of the project and collaboratively identified friendship as the central focus for the development of a new assessment tool. It was agreed that a short, accessible, and user-friendly tool should be co-created to specifically measure the concept of friendship in people with chronic aphasia. This decision reflected the shared understanding that social relationships are critical to the quality of life and functional recovery following stroke. The meeting concluded with an agreement on the project's ICF conceptual framework and a commitment to a co-creation process grounded in the principles of PPI.



**Figure 1.** The timeline of developing FRIENDS.

### **Group meeting 2: item brainstorming**

During Meeting 2, the discussion for the development of the items was initiated by presenting the six items from the Friendship Scale (Hawthorne, 2006) to stimulate the discussion. The Friendship Scale (Hawthorne, 2006) was chosen as the basis for FRIENDS, as it was one of the assessment tools used in the SUPERB study by Hilari et al. (2021). The research team began working on each item, collaboratively editing them through a dynamic and interactive discussion. The six items of the FS were edited in the following way:

- (1) It has been easy to relate to others → *"It was easy to hang out with others"*
- (2) I felt isolated from other people → *"I felt that others were avoiding me"*
- (3) I had someone to share my feelings with → *"I had someone I could express my feelings to"*
- (4) I found it easy to get in touch with others when I needed to → *"It was easy to talk to others when I needed to"*
- (5) When with other people, I felt separate from them → *"I felt rejected by my friends"*
- (6) I felt alone and friendless → *"I felt alone, without friends"*

### **Group meeting 3: new item development**

In Meeting 3, the research team continued to refine and expand the list of items developed in Meeting 2. Building on the initial six items, the PPI partners collaboratively contributed four additional items: PPI 4 (caregiver) proposed Item 7, PPI 1 proposed Item 8, PPI 3 proposed Item 9, and PPI 2 proposed Item 10. Below, we present these four items in their original form alongside their revised versions by the end of the meeting.

- (1) I felt that I could rely on someone else → *"I felt I could rely on a friend"*
- (2) I felt that I could express my opinion → *"I felt I could tell what I think to a friend"*
- (3) I felt uncomfortable in a group → *"I felt uncomfortable in a company"*

- (4) I felt that I had difficulty understanding the group → *“I felt it was hard to keep up with the group”*

#### **Group meeting 4: external review**

Meeting 4 was conducted online and included the first author (MC), the two final-year SLT students, an external speech and language therapist practising in aphasia rehabilitation, and a person with chronic mild aphasia, who was not previously involved in the study. The primary focus of this meeting was to review the draft version of the FRIENDS tool and to ensure its consistency and clarity. During the meeting, it was identified that the formation of the responses was inconsistent across items: negative responses did not always align with the ascending order of the rating scale, potentially affecting the interpretation of results. Specifically, this issue was observed in Items 2, 5, 6, 9, and 10, which contained negatively worded elements, leading to an opposite interpretation of the rating scale. To address this inconsistency, the affected items were reworded to maintain positive phrasing throughout the questionnaire as follows:

- (1) I felt that others were avoiding me → *“I felt my friends were looking for me”*
- (2) I felt rejected by my friends → *“I felt accepted by my friends”*
- (3) I felt alone, without friends → *“I felt I had a friend”*
- (4) I felt uncomfortable in a group → *“I felt comfortable in company”*
- (5) I felt it was hard to keep up with the group → *“I felt I could follow the company”*

#### **Group meeting 5: editing and finalizing items**

In Meeting 5, the revised items from Meeting 4 were discussed for approval by the research team. During this final review, minor edits were suggested by PPI partners with aphasia, for example, substituting the word “others” with “friends/friend” and “group” with “company”, to improve clarity and contextual relevance. While three items (Q3, Q8, Q10) address communicative aspects, the remaining items capture other domains of friendship (e.g., reciprocity, trust, shared activities) to reflect the broader construct of participation and social connectedness, in line with the ICF framework. The final set of 10 items, presented in Table 2, captures the aspects of friendship represented in FRIENDS, as conveyed by the research team.

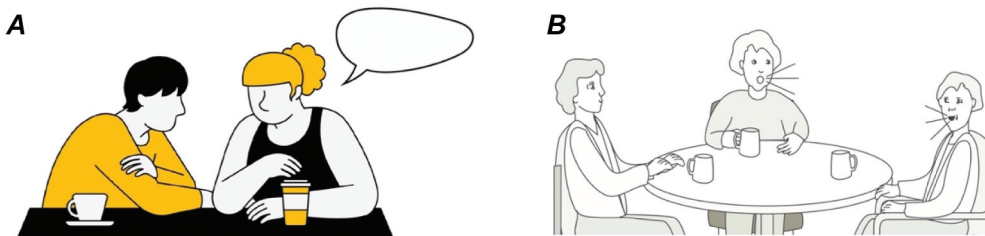
FRIENDS was originally co-created and validated in Greek, and subsequently translated/adapted into English for dissemination and use in international research contexts. Therefore, for the English version of FRIENDS, a forward translation was conducted by a bilingual professor of Speech Pathology with expertise in aphasia assessment and rehabilitation. To ensure the tool remained meaningful and accessible to its target population, a back-translation was carried out independently by two bilingual individuals with aphasia, one with mild expressive aphasia and one with moderate anomic aphasia, ensuring both linguistic and experiential relevance. The final English version of FRIENDS is provided as supplementary material.

#### **Group meeting 6: selection of visual stimuli**

Meeting 6 focused on the selection of visual stimuli to accompany the 10 items of FRIENDS. The two SLT students conducted a search of freely available imagery from the Canva (<https://www.canva.com/>) (Figure 2A) and ParticiPics (<https://www.aphasia.ca/par>

**Table 2.** The different aspects of friendship included in FRIENDS' items.

Item	Aspect of Friendship	Explanation
"It was easy to hang out with friends"	Social Interaction/ Access	the ease of spending time together and engaging socially with friends
"I felt my friends were looking for me"	Reciprocity/ Mutual Interest	the sense of being valued and wanted by friends
"I had someone to talk to about how I felt"	Emotional Support	focuses on sharing personal feelings and receiving support
"It was easy to talk to a friend when I needed to"	Accessibility/ Supportiveness	how available and responsive friends are in times of need
"I felt accepted by my friends"	Acceptance/ Belonging	highlights the sense of being welcomed and understood by friends
"I felt I had a friend"	Perceived Friendship/ Presence	the feeling of social connectedness, ensuring that one has friends
"I felt that I could rely on a friend"	Trust/ Dependability	the trust aspect of friendship, focusing on the ability to depend on a specific friend
"I felt I could tell a friend what I think"	Open Communication/ Authenticity	the level of openness in the relationship, where a person can share their thoughts and opinions without fear of judgment
"I felt comfortable in company"	Social Comfort/ Safety	how at ease someone feels within the social environment and with their friends
"I felt I could follow the company"	Social Integration/ Engagement	the ability to participate in and follow the conversation or group activities



**Figure 2.** Example pictures from (A) canva and (B) ParticiPics.

ticipics/) (Figure 2B) collections, identifying potential images relevant to each item. The selection process ensured that each visual was conceptually aligned with its corresponding statement and easily interpretable by PWA. The research team chose imagery from Canva, as these were perceived to offer a fresher, more contemporary aesthetic. For each item, PPI partners reviewed the proposed options and voted on the image they found most appropriate and representative. The images receiving the highest number of votes were incorporated into the final version.

**Group meeting 7: selection of self-rating scale**

Meeting 7 focused on selecting a self-report rating scale to accompany FRIENDS items and imagery. The goal was to identify a scale that was both accessible and meaningful for individuals with aphasia, facilitating ease of understanding and accurate self-reporting. A 5-point Likert-type pictorial scale (1–5) was selected, shown to be effective for individuals with cognitive or communication disabilities (Swinburn et al., 2018). The scale integrates numbers, words, and pictures. Four different Likert-type scales were presented to PPI



**Figure 3.** FRIENDS pictorial self-rating scale.

partners for selection. Each scale used a consistent numerical system ranging from 1 to 5, with 1 representing “never” and 5 representing “always”, but differed in their visual representations. The first scale used circles with varying degrees of shading to indicate frequency. The second employed an analogue clock design to represent time-related frequency. The third incorporated only hand gesture-based options. The fourth scale depicted five human-like figures, each displaying distinct facial expressions and hand movements corresponding to the five response options. Following the discussion and elimination process, all three PPI partners with aphasia unanimously selected the scale illustrated in [Figure 3](#), noting that the alternative formats were perceived as either too abstract or too confusing.

### **Group meeting 8: cognitive interviews**

Finally, in Meeting 8, cognitive debriefing interviews were conducted to confirm the content validity and cultural relevance of the FRIENDS. Cognitive debriefing refers to structured interviews with PPI partners to evaluate whether the items are relevant, clear, and interpreted as intended (Terwee et al., 2018). All PPI partners were asked to rate FRIENDS by responding to a questionnaire which was developed following the CONsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidelines (Terwee et al., 2018). COSMIN is a framework designed to assess the measurement properties of PROMs (Terwee et al., 2018). The first author (MC), in consultation with a young female stroke survivor with chronic mild-moderate anomic aphasia, co-developed a self-rating questionnaire to assess the comprehensiveness, relevance, appropriateness, and importance of the content of the statements. The content validity questionnaire comprised 18 items, with responses measured on a five-point Likert scale ranging from 0 (Strongly Disagree) to 5 (Strongly Agree). Cognitive interviews were completed by the authors, MC and SE. Sample statements were as follows: This item is relevant to my situation; the item has an appropriate/relevant picture; The item’s content is clear to me; The content of the item is appropriate for me; This is an important item for my life. To assess the relevance of the FRIENDS items, analyses of the median scores were calculated. An item was accepted as “very relevant” if it received a median score of at least 4. Overall, results were expected to confirm that the content of the 10 items of the FRIENDS was appropriate and relevant.

### **Pilot study**

A pilot study was conducted to check the acceptability of the 10 items of FRIENDS, and the time taken for administration and scoring. The pilot sample group consisted of 5

people with chronic aphasia (more than 6 months post-stroke), and 5 people with stroke no aphasia (SNA), recruited from the Cyprus Stroke Association registry. All pilot participants were native Greek speakers. FRIENDS was administered to all participants in one session with an average administration time of 8 minutes, depending on language skills. The pilot study resulted in a wide range of scores (ranging between 18 – 48 out of 50).

## **Psychometric testing**

### ***Eligibility criteria***

Participant eligibility was determined using pre-established inclusion and exclusion criteria. Inclusion criteria varied in each group. For the participants with aphasia, the inclusion criteria involved: being 18 years or older; having experienced a stroke at least six months before participation (i.e., being in the chronic phase); and having a diagnosis of aphasia confirmed by a certified speech and language therapist using the Greek version of the Boston Diagnostic Aphasia Examination (BDAE; Messinis et al., 2013). Participants with stroke but without aphasia were required to be adults with a history of chronic stroke, while healthy controls (HC) were required to be adults with no history of stroke or aphasia. Exclusion criteria were also applied consistently across all three groups. Participants were excluded if they had an additional diagnosis of dementia, another neurological condition, clinical depression, or unilateral spatial neglect (as assessed by Albert's Test; Fullerton et al., 1986), or visual or hearing impairments that could interfere with completing the research protocol.

### ***Recruitment***

Participants were recruited from the Registry of the Cyprus Stroke Association, the caseload of the Adult Rehabilitation Clinic of the Cyprus University of Technology, various regional and national rehabilitation centres, nursing/care homes, and private clinics.

## **Procedures and materials**

For the development and validation of FRIENDS, ethical approval was obtained from the National Bioethics Committee (EEBK EP 2024.01.109). The tests and questionnaires were administered either at the participant's house, in clinics, or in private offices between September 2024 and March 2025. All standardized assessments were administered and scored by three qualified Greek-speaking speech and language therapists, after receiving training on the tool from the study team. Informed consent was documented using an aphasia-accessible written, signed, and dated informed consent form, and demographic information was obtained from each participant before the beginning of the study. All assessments were conducted over two visits: the first lasting 1.5 hours to administer the five measures listed below (see *Measures*), and the second lasting approximately 10 minutes to complete FRIENDS for re-test 7–14 days after the initial administration.

## Measures

A selection of measures related to validating FRIENDS included tools that are standardized and validated in Greek and tapped into language abilities, functional communication, and the impact of aphasia. These were:

- (1) *The Aphasia Severity Rating Scale (ASRS) from the Greek adaptation of the Boston Diagnostic Aphasia Examination Short Form (ASRS-SF; Messinis et al., 2013)*. The ASRS is a rating scale used to measure aphasia severity. This scale was used to evaluate the severity of the observed language and communication difficulties of the participants with aphasia. This included (1) a 10-minute semi-structured interview about their previous employment, their stroke story, and basic demographic information, and (2) a description of the “Cookie Theft” picture, e.g., “Tell me everything you see going on in this picture”. Aphasia severity was evaluated based on the fluency and intelligibility of the spoken output. The scores of the ASRS ranged from 0 to 5, with 0 indicating very severe non-fluent aphasia and 5, very mild aphasia predominantly characterized by naming difficulties. As with other rating scales, ASRS classification relies on rater judgement, and the rating of aphasia severity may therefore vary across clinicians
- (2) *The standardized Greek version of the CETI (CETI-GR; Charalambous, Phylactou, et al., 2024)*. The CETI-GR is a 16-item questionnaire completed by the carers of people with chronic aphasia. The CETI-GR assesses both verbal (10 items) and non-verbal (6 items) communication skills in 16 different daily situations, e.g., “Having coffee-time visits and conversations with friends and neighbors”. Each statement is presented to the respondents using a visual analog scale represented by a horizontal line of 100 mm. Zero means “not able at all” and 100 “as able as before”. For each statement, the caregiver had to mark their response on the visual analog scale with a pencil. Each answer was rated from 0 to 100, and the total score was calculated by dividing the sum of the individual situation ratings by the total number of situations. Lower scores show low abilities in everyday functional communication, and higher scores show better functional communication in everyday life.
- (3) *The standardized Greek version of the Scenario Test (Scenario Test-GR; Charalambous, Phylactou, Elriz, et al., 2022)*. The Scenario Test-GR is a tool that evaluates functional communication in simulated everyday communication situations e.g., “You are going home. Now you want to invite your friend for coffee at your house next time. How do you do that?”. Scoring is completed by the clinician. The Scenario Test-GR consists of 18 items as part of six daily-life scenarios (each scenario has 3 questions) using black and white pictures. The score for each item ranges from 0 to 3 for each question. The total score is calculated from the sum of all questions. The scores range from 0 to 54, with a lower score indicating poor functional communication and a higher score indicating better functional communication.
- (4) *The standardized Greek version of the Aphasia Impact Questionnaire-21 (AIQ-21-GR; Charalambous, Phylactou, Elriz, et al., 2022)*. The AIQ-21-GR is a self-reported questionnaire that evaluates the impact of aphasia on the quality of life of PWA. It includes 21 questions and is divided into three domains: Participation, Communication, and Emotional State e.g., “How were things with friends?”.

Participation includes 7 items, communication includes 6 items, and emotional state includes 11 items. Each item has a 5-point rating scale (0-4), with 0 indicating “no problem” and 4 indicating “impossible”. Total scores range from 0 to 84, with lower scores indicating a lower impact of aphasia on quality of life.

- (5) *The Functional Rating of Interaction Engagement Needs and Difficulties Scale (FRIENDS)* (described in the Development section above). FRIENDS is a self-report questionnaire designed to assess social engagement and the quality of friendship interactions for PWA. The scale consists of 10 items and utilizes a self-rating system with a consistent numerical range from 1 to 5, where 1 represents “never” and 5 represents “always”. Total scores range from 0 to 50, with lower scores indicating fewer or no friendships. See [Figure 4](#) for an example item and its self-rating scale.

Stroke survivors without aphasia (SNA) and healthy controls (HC) were only assessed with FRIENDS. Across all groups, a consent form was signed to ensure informed participation and a case history interview.



**Figure 4.** An example item with its self-rating scale from the FRIENDS questionnaire.

### **Validity assessment**

To assess validity, both convergent validity and known-group validity were examined.

In terms of convergent validity, three hypotheses were formulated:

- (i) Scores of FRIENDS will significantly correlate with measures of language severity, that is, the ASRS of the BDAE-SF (Messinis et al., 2013). Previous studies have shown a close association between language severity after stroke and friendships (Azios et al., 2021).
- (ii) Moderate to high correlation was expected for the Scenario Test-GR (Charalambous, Phylactou, Elriz, et al., 2022) and the CETI-GR (Charalambous, Phylactou, et al., 2024) since both tools assess functional communication. Previous research has shown that functional communication is a key factor in developing and maintaining high-quality friendships, as it fosters engagement and support between friends (Hilari & Northcott, 2017).
- (iii) Scores of FRIENDS will significantly correlate with measures of the psychosocial domain, that is, the AIQ-21-GR (Charalambous, Phylactou, Elriz, et al., 2022), as there is evidence of a link between fewer or no friendships with poor quality of life (Madden et al., 2022).

Known-groups validity was assessed by comparing scores across the three groups (PWA vs SNA vs HC), with the expectation that PWA would obtain lower scores on the FRIENDS compared to SNA, and that both PWA and SNA groups would have lower scores than the HC group.

### **Criteria for psychometric testing**

The following criteria were used to test the reliability and validity of FRIENDS. Generally, a Cronbach's  $\alpha > 0.70$  indicates good internal consistency (Nunnally & Bernstein, 1994). Similar to previous studies measuring the psychometric properties of friendship scales, a rounded Cronbach's  $\alpha \geq 0.8$  was considered excellent (Hawthorne, 2006). ICCs should be  $\geq 0.75$  for good test-retest reliability (Streiner et al., 2014). Correlational analysis (Spearman's  $\rho$ ) was undertaken to test the convergent validity of the measure. Convergent validity refers to how closely an instrument relates to other measures of the same construct (Taherdoost, 2016). Commonly in psychometric testing, correlations between  $0 < \rho < 0.3$  or  $0.3 < \rho < 0.6$  are considered weak, between  $0.4 < \rho < 0.6$  or  $-0.6 < \rho < -0.4$  moderate, and  $\rho > 0.6$  or  $\rho < -0.6$  strong (Akoglu, 2018). Lastly, known-groups validity was assessed using a one-way ANOVA with group (PWA vs SNA vs HC) as a factor. Known-groups validity determines that an instrument can demonstrate dissimilar scores among different groups (Taherdoost, 2016). Pairwise group comparisons were followed using Tuckey corrected  $t$ -tests. An  $\alpha = 0.05$  was used as a threshold for statistical significance for all tests.

### **Statistical analysis**

Statistical analysis was conducted using the JASP (v0.19.3; JASP Team [JASP], 2024) statistics computer software.

## Results

### Participants

One hundred and sixty-six participants (85 female, mean age =  $66.55 \pm 14.80$  *sd*, [min = 23, max = 91]) in total were recruited to test the psychometric properties of FRIENDS. Out of the 166, 62 were assigned to the PWA group, 50 to the SNA group, and 54 served as HC. A detailed breakdown of the participants' demographic characteristics is presented in Table 3.

**Table 3.** Demographic characteristics of participants.

Characteristic	People with Aphasia ( <i>n</i> = 62)	People with Stroke without Aphasia ( <i>n</i> = 50)	Healthy Controls ( <i>n</i> = 54)	Test for group differences
<i>Gender</i>				
Male	34 (55%)	28 (56%)	19 (35%)	$\chi^2_{(2)} = 5.95,$ $p = .05$
Female	28 (45%)	22 (44%)	35 (65%)	
<i>Age</i>				
Mean (sd)	71.42 (13.42)	67.68 (15.86)	59.93 (12.98)	$F = 9.87,$ $p < .001$
Min-Max	25–91	28–88	23–89	
<i>Completed Education</i>				
Primary	21 (34%)	13 (26%)	14 (26%)	$\chi^2_{(10)} = 5.61,$ $p = .85$
Secondary	22 (35%)	23 (46%)	28 (52%)	
High-School	1 (2%)	0	0	
College	6 (10%)	4 (8%)	5 (9%)	
Bachelor's	8 (13%)	6 (12%)	5 (9%)	
Master's	4 (6%)	4 (8%)	2 (4%)	
<i>Years of Education</i>				
Mean (sd)	10.76 (4.16)	10.98 (3.94)	11.33 (3.07)	$F = 0.34,$ $p = .71$
Min-Max	3–18	4–18	5–16	
<i>Marital Status</i>				
Married	41 (66%)	35 (70%)	40 (74%)	$\chi^2_{(6)} = 3.69,$ $p = .72$
Single	5 (8%)	4 (8%)	4 (7%)	
Divorced	3 (5%)	5 (10%)	2 (4%)	
Widowed	13 (21%)	6 (12%)	8 (15%)	
<i>Socioeconomic Status Based on Former or Current Occupation</i>				
Higher managerial	2 (3%)	0	2 (4%)	$\chi^2_{(6)} = 7.75,$ $p = .26$
Intermediate occupation	25 (40%)	16 (32%)	15 (28%)	
Manual occupation	26 (42%)	31 (62%)	32 (59%)	
Unemployed	9 (15%)	3 (6%)	5 (9%)	
<i>Current Employment Status</i>				
Yes	3 (5%)	11 (22%)	34 (63%)	$\chi^2_{(2)} = 49.10,$ $p < .001$
No	59 (85%)	39 (78%)	20 (37%)	
<i>Months Post Stroke Diagnosis</i>				
Mean (sd)	45.19 (51.78)	60.28 (77.37)	–	$t_{(110)} = 1.23,$ $p = .22$
Min-Max	6–276	6–336	–	
<i>Stroke Type</i>				
Ischemic	41 (66%)	39 (78%)	–	$\chi^2_{(2)} = 2.93,$ $p = .23$
Haemorrhagic	19 (31%)	11 (22%)	–	
Other	2 (3%)	0	–	
<i>Lesion Location</i>				
Left	55 (89%)	11 (22%)	–	$\chi^2_{(10)} = 50.89,$ $p < .001$
Right	7 (11%)	39 (78%)	–	
<i>Hemiplegia</i>				
Left	2 (3%)	18 (36%)	–	$\chi^2_{(2)} = 28.82,$ $p < .001$
Right	35 (57%)	8 (16%)	–	
None	25 (40%)	24 (48%)	–	

**Table 4.** Scores for each tool and per group where applicable.

Tool	Group	Mean	sd	Minimum*	Maximum
FRIENDS	PwA	29.10	12.18	10	50
	SnA	41.36	7.39	27	50
	HC	44.87	6.68	24	50
FRIENDS Retest	PwA	28.81	12.31	10	49
Scenario Test	PwA	32.32	17.19	0	54
AIQ-21-GR	PwA	42.48	20.03	7	78
CETI	PwA	67.60	27.29	0.813	100
ASRS	PwA	2.42	1.35	0	5

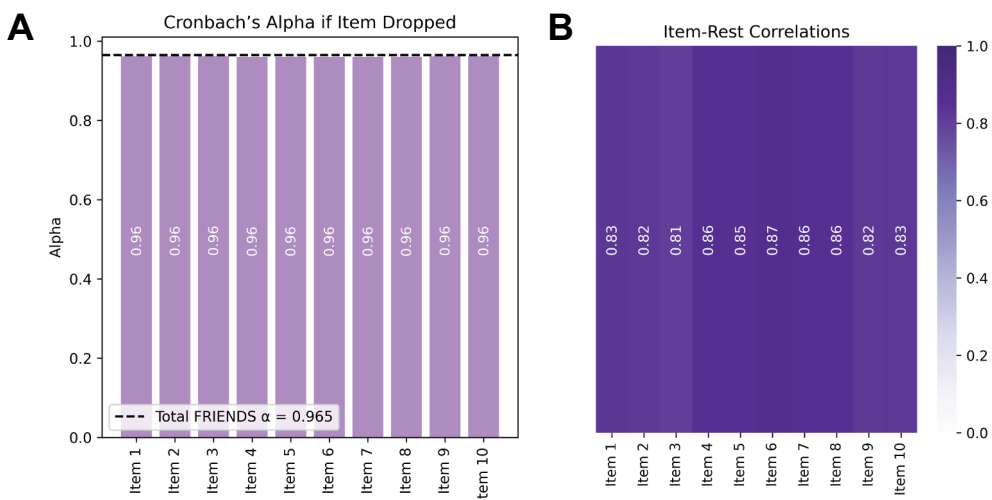
Notes: PWA, People with Aphasia; SNA, Stroke No Aphasia; HC, Health Controls; AIQ, Aphasia Impact Questionnaire; CETI, The Communication Effectiveness Index; ASRS, Aphasia Severity Rating Scale; \* Minimum and Maximum values represent observed ranges in participants, not theoretical score limits.

## Measures

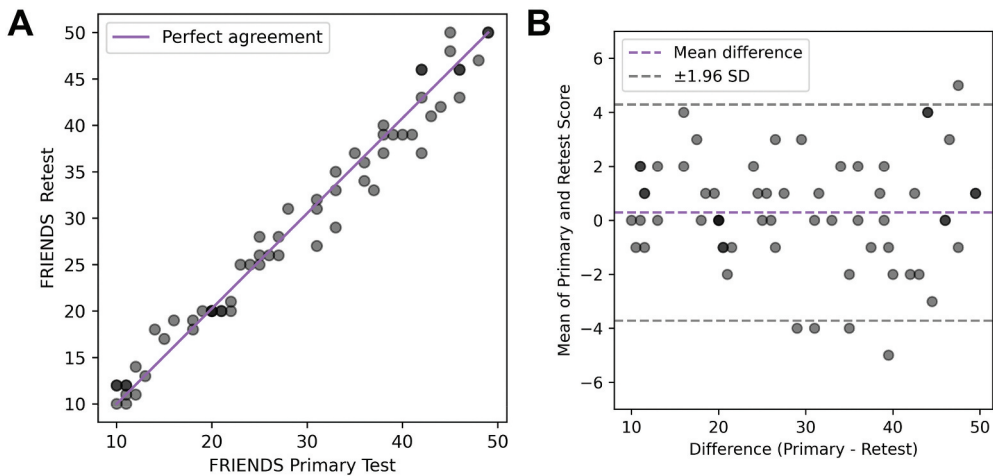
Descriptive statistics for each tool completed by each group (where applicable) are presented in Table 4. When it comes to FRIENDS, PWA reported a mean score of 29.10 ( $sd = 12.18$ ), SNA scored 41.36 ( $sd = 7.39$ ), and HC had a mean score of 44.87 ( $sd = 6.68$ ).

## Internal consistency

To evaluate internal consistency, Cronbach  $\alpha$  statistics were estimated. Overall, FRIENDS demonstrated excellent internal consistency ( $\alpha = 0.965$ , 95% CI = [0.956, 0.972]). Further analyses revealed that reliability remained consistently high ( $\alpha > 0.960$ ), even when excluding each item independently (Figure 5A), and item-rest correlations were excellent for all items ( $\rho > 0.80$ ; Figure 5B).



**Figure 5.** Internal consistency of FRIENDS. (A) overall consistency was excellent and remained high across all item exclusions in an item-drop analysis. (B) item-rest correlations were high across all items.



**Figure 6.** Test-retest reliability of FRIENDS. (A) scatter plot of primary and retest FRIENDS scores plotted in comparison to perfect agreement. (B) bland-altman plot of score differences between primary and retest FRIENDS scores.

### Test-retest reliability

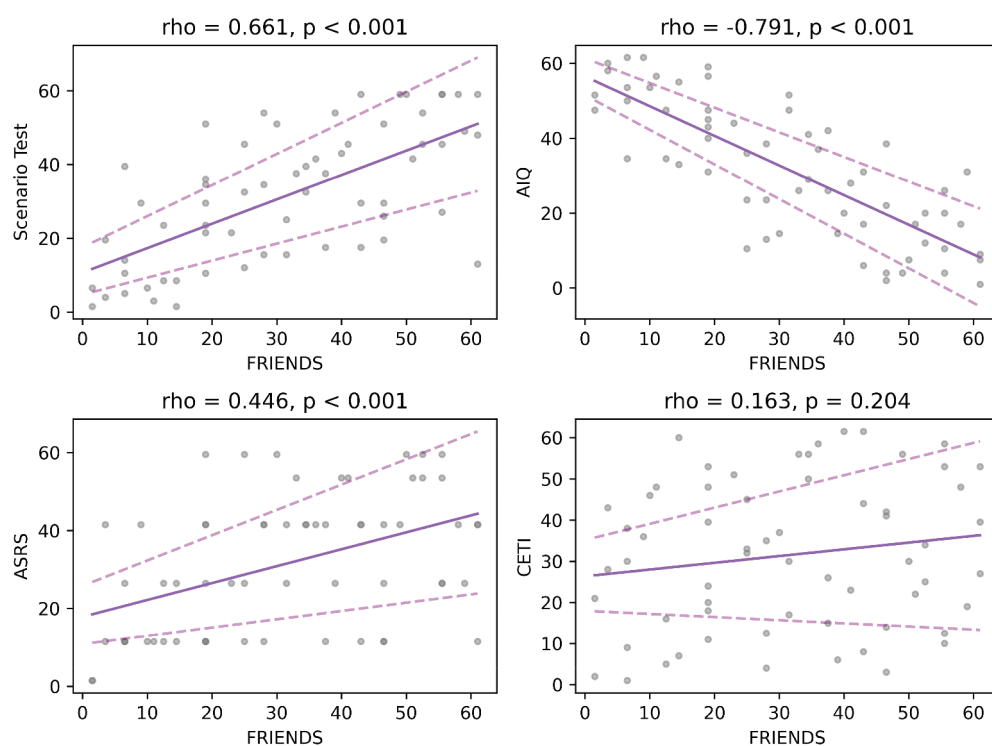
Test-retest reliability was high, as reflected through intraclass correlation analyses ( $ICC_{3,k} = 0.992$ , 95% CI = [0.989, 0.994]; Figure 6A). However, since correlational analyses may fail to capture quantitative differences across measurements (Phylactou et al., 2025), we further conducted a visual inspection of a Bland-Altman plot (Figure 6B) that we accompanied with a paired  $t$ -test between the primary and retest score of FRIENDS, which revealed no significant differences between the two scores ( $t_{(61)} = 1.11$ ,  $p = 0.271$ ).

### Convergent validity analyses

The convergent validity of FRIENDS was examined through non-parametric Spearman's  $\rho$  correlations with other relevant and validated psychometric tools (Figure 7). Aside from CETI ( $\rho = 0.163$ ,  $p = 0.204$ ), FRIENDS correlated positively with the Scenario Test ( $\rho = 0.661$ ,  $p < 0.001$ ) and ASRS ( $\rho = 0.446$ ,  $p < 0.001$ ), and negatively with AIQ ( $\rho = -0.791$ ,  $p < 0.001$ ).

### Known-groups validity

A one-way ANOVA with group (PWA vs SNA vs HC) as a factor was implemented to investigate known-groups validity. The results demonstrated a significant difference amongst the three groups ( $F_{(2, 163)} = 46.44$ ,  $p < 0.001$ ,  $\eta^2_p = 0.363$ ). Post-hoc Tukey corrected  $t$ -test (Figure 8) revealed that the difference was driven by the contrasts between PWA and SNA ( $t_{Tukey} = -6.94$ ,  $p < 0.001$ ) and between PWA and HC ( $t_{Tukey} = -9.12$ ,  $p < 0.001$ ). Notably, no differences were evident between SWA and HC ( $t_{Tukey} = -1.92$ ,  $p = 0.135$ ). As an additional exploratory analysis, the one-way ANOVA was repeated, with the total score of communication-related items (items 3, 8, and 10) serving as the dependent variable. This exploratory analysis replicated the previous ANOVA findings,



**Figure 7.** Spearman rho correlations of FRIENDS with Scenario test (top-left), AIQ-21-GR (top-right), ASRS (bottom-left), and CETI (bottom-right).

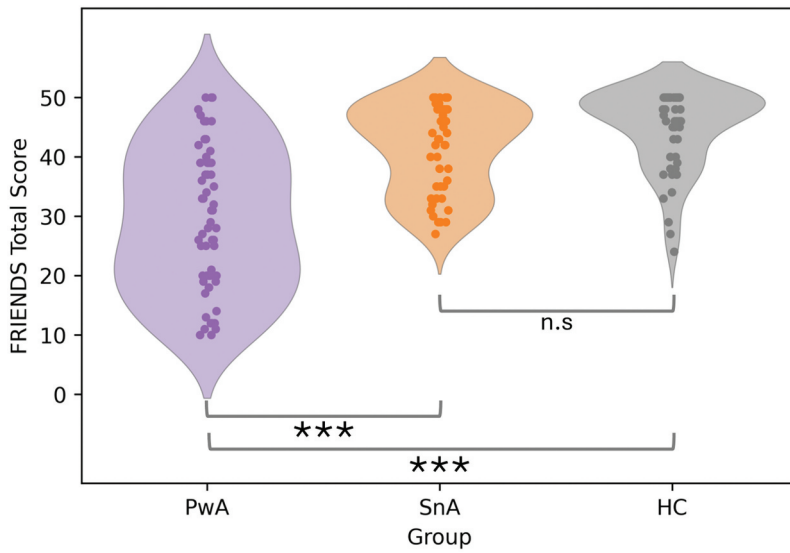
resulting in a significant group difference ( $F_{(2, 163)} = 38.47, p < 0.001, \eta^2_p = 0.321$ ). Post-hoc analyses indicated significant differences between the PWA and SNA ( $t_{Tukey} = -5.94, p < 0.001$ ), as well as between PWA and HC ( $t_{Tukey} = -8.45, p < 0.001$ ), but not between SNA and HC ( $t_{Tukey} = -2.26, p = 0.065$ ).

### Content validity

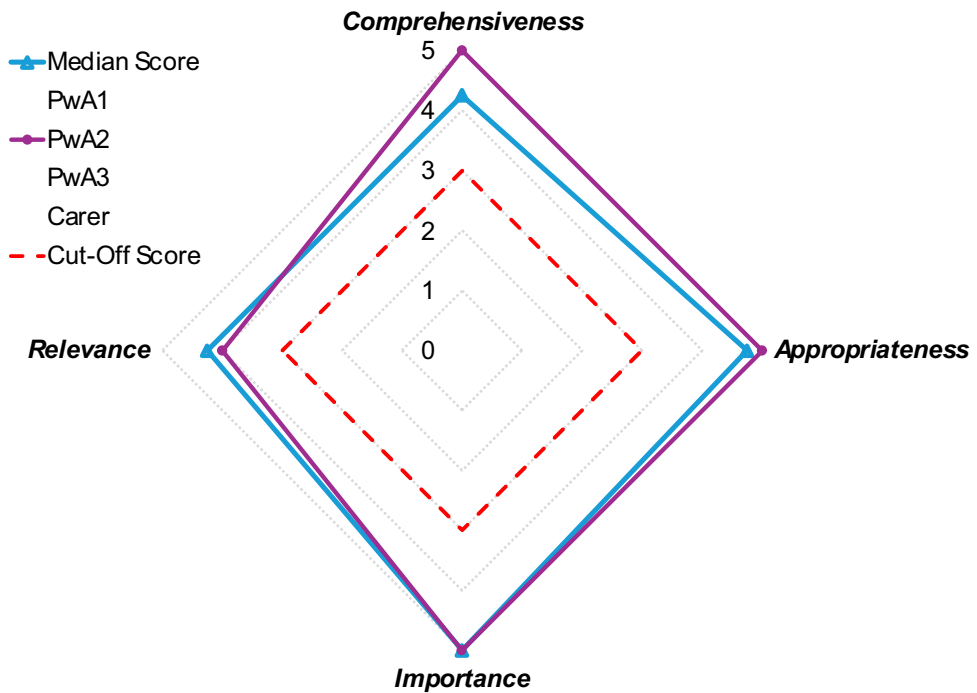
Results derived from analysing the COSMIN report supported the content validity of FRIENDS (Figure 9). All ratings among the four COSMIN dimensions, namely Comprehensiveness (median = 5, percentiles<sub>[25%, 75%]</sub> = [4, 5]), Appropriateness (median = 5, percentiles<sub>[25%, 75%]</sub> = [4, 5]), Importance (median = 5, percentiles<sub>[25%, 75%]</sub> = [5, 5]), and Relevance (median = 4, percentiles<sub>[25%, 75%]</sub> = [4, 4.25]), were above the cut-off score (< 3).

### Discussion

This study developed and validated the Functional Rating of Interaction Engagement Needs and Difficulties Scale (FRIENDS), a 10-item aphasia-accessible PROM (the final version of FRIENDS is provided as supplementary material). It employed a co-creation approach, grounded in Patient and Public Involvement (PPI) principles, to ensure the tool's relevance and accessibility for its target population. The outcomes of this study



**Figure 8.** Differences in FRIENDS scores amongst people with aphasia, people with stroke without aphasia, and healthy controls. Notes. \*\*\* $p < 0.001$ . PWA, People with Aphasia; SnA, Stroke No Aphasia; HC, Health Controls



**Figure 9.** Spider-graph of individual and overall median scores across the four COSMIN dimensions.

highlight the robust psychometric properties of FRIENDS, its clinical implications, and the importance of involving PWA as research partners.

Our findings provide further evidence that communicative effectiveness plays a central role in sustaining friendships. People with aphasia consistently scored lower on FRIENDS compared to those without aphasia, reflecting how communication difficulties can disrupt reciprocity, shared experiences, and the maintenance of social ties. This is consistent with prior work demonstrating that communicative barriers, rather than stroke alone, are strongly associated with reduced social networks and friendship loss (Northcott & Hilari, 2011). By embedding communication within a broader participation framework, FRIENDS captures the ways in which communicative challenges intersect with other dimensions of friendship, offering a more comprehensive perspective than communication-focused measures alone.

### ***FRIENDS and the ICF***

The development of FRIENDS is grounded in the International Classification of Functioning, Disability and Health (ICF) framework (WHO, 2001), which emphasizes real-life participation, social inclusion, and connectness as an indicator for functional rehabilitation. The ICF Core Sets for Stroke (Geyh et al., 2004) further informed the FRIENDS framework by highlighting the central role of social participation in effective rehabilitation. Of the 10 items in FRIENDS, six items focus on involvement in life situations and the relational, emotional, and social dimensions of being included and valued. These include: feeling accepted by friends, being actively sought out, feeling socially connected, experiencing mutual trust, ease of social engagement, and comfort in group settings. The remaining four items focus on what a person can do within the context of friendship. These include: accessing emotional support, communicating when in need, expressing personal views openly, and following conversations or group activities. FRIENDS is designed to capture how friendships function both as a resource and as an outcome in the lives of people with chronic aphasia, supporting a more holistic and person-centered approach to rehabilitation.

### ***Outcomes from PPI***

The co-creation of FRIENDS was a collaborative effort involving three PWA and a caregiver as research PPI partners across eight co-design meetings. This participatory approach ensured that the tool reflected the lived experiences and priorities of PWA and encompassed the principles of the Patient-Centered Care framework (Nelson et al., 2024), similar to other published tools co-developed with PPI methods, such as the AIQ-21 from Swinburn and colleagues (2018). Specifically, the PPI partners contributed to the conceptualization, item development, visual stimuli selection, and the refinement of the rating scale, ensuring the tool's accessibility and relevance to people living with chronic aphasia. Further, PPI partner involvement guided by the People with Aphasia and Other Layperson Involvement (PAOLI) framework (Charalambous et al., 2023) fostered the equitable partnerships and meaningful participation throughout the research process, as reflected by the PPI partners at the final meeting.

## ***Validity and reliability outcomes***

FRIENDS demonstrated excellent psychometric properties, supporting its use as a reliable and valid measure of friendship and social engagement in PWA. Convergent validity was established through significant correlations with measures of aphasia severity, functional communication, and quality of life. These findings underscore the tool's ability to capture the unique social challenges faced by people living with chronic aphasia.

### ***FRIENDS's reliability***

FRIENDS demonstrated excellent reliability, with both internal consistency and test – retest stability exceeding commonly accepted psychometric benchmarks (Nunnally & Bernstein, 1994; Streiner et al., 2014). These findings suggest that the scale produces stable and replicable scores over time, comparable to other widely used measures of social connectedness such as the Friendship Scale (Hawthorne, 2006). Also, these findings are consistent with the results of similar studies such as validation studies of the Lubben Social Network Scale in different contexts (Bincy et al., 2022; Buckley et al., 2022; Burnette & Myagmarjav, 2013; Chan et al., 2023; Lubben et al., 2006).

### ***FRIENDS's validity***

FRIENDS showed good construct validity, distinguishing between groups in expected directions and correlating strongly with functional communication and quality of life measures. These findings align with previous work demonstrating the centrality of communicative participation and psychosocial factors in sustaining friendships in aphasia (Hilari & Northcott, 2017; Madden et al., 2023).

## ***Convergent validity***

### ***Correlation of FRIENDS with aphasia severity (ASRS)***

The first hypothesis proposed a correlation between aphasia severity and friendships. The correlation between FRIENDS and ASRS was significant, considering the diversity in aphasia severity. In this sample, participants with moderate-severe language difficulties (3 and lower on the ASRS) scored lower on FRIENDS, indicating that aphasia severity impacts the amount and quality of friendships, an outcome that aligns with the results by Madden et al. (2023).

### ***Correlation of FRIENDS with functional communication skills (Scenario test-GR)***

The second hypothesis proposed a strong correlation between FRIENDS and the Scenario Test, based on evidence that poor functional communication is associated with reduced social networks and fewer friendships (Doedens & Meteyard, 2022). As expected, a strong correlation was observed between FRIENDS and the Scenario Test, indicating that PWA who experience poorer communication skills tend to report having fewer friends. No correlation was found between FRIENDS and the CETI, likely because the CETI reflects proxy-rated (i.e., ratings completed by caregiver or partner of the person with aphasia) perceptions of communication skills in daily life, which may differ from the self-reported

experiences captured by FRIENDS. Indeed, our earlier work did indicate that CETI scores tended to differ between PWA and proxies (Charalambous, Phylactou, et al., 2024).

### ***Correlation of FRIENDS with aphasia impact measures (AIQ-21-GR)***

The third hypothesis showed a significant correlation between FRIENDS and the AIQ-21, as there is evidence for a link between poor quality of life and reduced friendships in chronic aphasia (Azios et al., 2021). Interestingly, FRIENDS showed a high negative correlation with the AIQ-21, as higher levels of communication-related activity limitations and participation restrictions (as measured by the AIQ-21-GR) were associated with fewer friendships, highlighting the impact of communicative barriers on social connectedness and friendship in PWA. Our result is in line with the results by Cruice et al. (2006), Davidson et al. (2008), and Madden et al. (2023), which highlight the lasting social implications of aphasia on friendships and quality of life.

### ***Known-groups validity***

Known-groups validity was also confirmed, with FRIENDS scores significantly differing between PWA, SNA, and HC. The findings of this study indicate that PWA face greater challenges in maintaining friendships compared to stroke survivors without aphasia, aligning with previous research by Hilari and Northcott (2017) and Northcott and Hilari (2011). Notably, while the majority of participants with aphasia (66%) were married, meaning they were living at home with family members, they reported having fewer friends compared to participants without aphasia who were also married in the majority (70%). This outcome is consistent with Northcott et al. (2016), who found that although PWA often maintain family interactions post-stroke, the number and quality of their friendships frequently change significantly. As PWA had lower scores compared to SNA and compared to HC, SNA did not differ from HC. This finding demonstrates that FRIENDS is sensitive to the specific social challenges associated with aphasia rather than stroke more generally (Azios et al., 2021). It reinforces the tool's specificity and clinical relevance by showing that the reduced friendship experiences are primarily linked to aphasia (Swinburn et al., 2018). Furthermore, the clear differentiation between groups underscores the tool's potential for capturing meaningful social impacts, which is essential for both clinical assessment and research outcomes.

### ***Content validity***

The cognitive interviews conducted in the final meeting further validated the tool's content, with median scores across all COSMIN criteria (Comprehensiveness, Appropriateness, Importance, and Relevance) exceeding the cut-off, confirming its suitability and relevance for the target population. The content validity assessment was deemed as "very relevant", which means that the content of the 10 items accurately represents the construct it is intended to measure (Terwee et al., 2018). Specifically, a high score of importance means that the stakeholders find the items to be highly important for assessing friendship in chronic aphasia. Also, the high score reported for comprehensiveness shows that most items collectively provide a comprehensive view of friendship without omitting critical components. In terms

of relevance, the results show that FRIENDS is directly applicable and meaningful to the target population, reflecting real-life experiences, situations, or behaviors that are pertinent to the construct of FRIENDS. Finally, the high scores regarding the appropriateness of the items confirm that the 10 items are suitable for PWA in terms of language and context, ensuring that respondents understand and reply to the items effectively. In summary, excellent content validity indicates that FRIENDS is a well-designed tool that captures friendship and social support networks in people with chronic aphasia as was also proven in previous studies that assess content validity in the development of PROM tools (e.g., AIQ-21-GR; see Charalambous, Phylactou, Elriz, et al., 2022).

### ***PPI partners' reflections***

The co-creation of the FRIENDS tool was underpinned by a sustained and structured PPI process, involving three people with chronic stroke-induced aphasia and one caregiver as equal and active members of the research team. Guided by the PAOLI framework (Charalambous et al., 2023), the PPI partners contributed meaningfully across all stages of development, from conceptual design and item generation to the selection of visual stimuli, response scale format, and content validation. This level of involvement fostered a strong sense of ownership and agency among the four PPI partners, who described the experience as empowering and motivating. The iterative and supportive structure of the co-design meetings enabled authentic inclusion, facilitated by accessible materials and the presence of trained communication partners. However, challenges were also identified. The intensity of active participation over eight two-hour sessions posed cognitive and physical demands for the PPI partners with aphasia, with some experiencing fatigue. Moreover, while communication scaffolding was effective, the need for more preparatory time and reflection between sessions was noted by the communication partners. The limited number of PPI partners, while deeply engaged, may have constrained the diversity of lived experiences represented. Nonetheless, the FRIENDS study demonstrates that with the appropriate framework, communication support, and mutual respect, meaningful co-production with people with aphasia is both feasible and valuable for the development of relevant and accessible patient-reported outcome measures.

### ***Clinical implications***

FRIENDS fills a critical gap in the assessment of friendships for PWA, providing clinicians with a practical, patient-centered tool to evaluate friendship quality and social engagement. The tool's pictorial format and simplified language make it accessible for people with communication impairments, enabling them to self-report their experiences. Clinicians can use FRIENDS to assess specific social areas, tailor interventions to enhance social activities and participation, and monitor progress over time. By focusing on friendship, the tool aligns with the International Classification of Functioning (ICF) framework, and especially the Core Set for Stroke, emphasizing social participation as a key rehabilitation outcome. Furthermore, FRIENDS can facilitate person-centered care by empowering PWA to voice their social priorities and goals during rehabilitation goal-setting (Archer et al., 2024).

## Limitations of the study

Despite its strengths, this study has limitations. First, the sample primarily consisted of Greek-speaking participants, which may limit the generalizability of the findings to other linguistic and cultural contexts. Future research should validate FRIENDS in diverse populations and various socioeconomic backgrounds. Second, the tool's reliance on self-report may be challenging for people with severe aphasia, necessitating facilitator support. Finally, while the PPI approach enriched the tool's development, the small number of PPI partners may not fully represent the diversity of experiences among PWA.

## Future directions

Future research should focus on cross-cultural validation of FRIENDS to ensure its applicability across different languages and settings. Studies examining the tool's sensitivity to change would strengthen its utility in clinical practice. Additionally, exploring the integration of FRIENDS into telehealth platforms could enhance accessibility for individuals in remote areas. Finally, the PPI and co-creation process can be used to measure social outcomes on friendship by engaging stakeholders in co-design efforts of related interventions (Singh et al., 2024) and in developing social prescribing reintegration programs in community settings (Saragosa et al., 2024).

## Conclusion

FRIENDS represents a significant step forward in the assessment of friendship and social engagement for people living with chronic aphasia. Co-created with PPI partners with aphasia, the tool is psychometrically robust, clinically practical, and rooted in the lived experiences of its target population. By addressing the social dimensions of aphasia, FRIENDS empowers clinicians to deliver person-centered care and supports people with aphasia in achieving meaningful social participation.

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## ORCID

Marina Charalambous  <http://orcid.org/0000-0002-5310-3017>

## Data availability statement

Data generated during the current study and supporting the conclusions of this article are included in the manuscript, with any additional data requests to be directed to the corresponding author, for consideration.

## Ethical approval

The study was conducted in accordance with the Declaration of Helsinki and approved by the National Bioethics Committee (EEBK EP 2024.01.109).

## Informed consent statement

Informed consent was obtained from all participants involved in the study.

## Abbreviations

AIQ-21-GR:	Greek version of the Aphasia Impact Questionnaire-21
AIQ-21:	Aphasia Impact Questionnaire-21
ASRS:	Aphasia Severity Rating Scale
BDAE-SF:	Boston Diagnostic Aphasia Examination Short Form
CETI- GR:	Greek version of the Communicative Effectiveness Index
CETI:	Communicative Effectiveness Index
COSMIN:	Consensus-based Standards for the selection of health Measurement Instruments guidelines
FRIENDS:	Functional Rating of Interaction Engagement Needs and Difficulties Scale
GRIPP:	Guidance for Reporting Involvement of Patients and the Public
ICF:	International Classification of Functioning
PPI:	Patient and Public Involvement
PWA:	People with Aphasia
WHO:	World Health Organization

## References

- Akoglu, H. (2018). User's guide to correlation coefficients. *Turkish Journal of Emergency Medicine*, 18(3), 91–93. <https://doi.org/10.1016/j.tjem.2018.08.001>
- Anemaat, L., Palmer, V. J., Copland, D. A., Binge, G., Druery, K., Druery, J., Mainstone, K., Aisthorpe, B., Mainstone, P., & Wallace, S. J. (2024). Qualitative exploration of speech pathologists' experiences and priorities for aphasia service design: Initial stage of an experience-based co-design project to improve aphasia services. *Health Expectations*, 27(3), e14105. <https://doi.org/10.1111/hex.14105>
- Archer, B., Azios, J. H., Douglas, N. F., Strong, K. A., Worrall, L., & Simmons-Mackie, N. (2024). "I could not talk ... she did everything ... she's now my sister": People with aphasia's perspectives on friends who stuck around. *American Journal of Speech-Language Pathology*, 33(1), 349–368. [https://doi.org/10.1044/2023\\_AJSLP-23-00205](https://doi.org/10.1044/2023_AJSLP-23-00205)
- Azios, J. H., Strong, K. A., Archer, B., Douglas, N. F., Simmons-Mackie, N., & Worrall, L. (2021). Friendship matters: A research agenda for aphasia. *Aphasiology*, 36(3), 317–336. <https://doi.org/10.1080/02687038.2021.1873908>
- Baron-Cohen, S., & Wheelwright, S. (2003). The friendship questionnaire: An investigation of adults with Asperger syndrome or high-functioning autism, and normal sex differences. *Journal of Autism & Developmental Disorders*, 33(5), 509–517. <https://doi.org/10.1023/a:1025879411971>

- Béjot, Y., Delpont, B., & Giroud, M. (2016). Rising stroke incidence in young adults: More epidemiological evidence, more questions to be answered. *Journal of the American Heart Association*, 5(5), e003661. <https://doi.org/10.1161/JAHA.116.003661>
- Bennington, C., Shiggins, C., Isaksen, J., Beesley, E., Beesley, K., & Wallace, S. J. (2024). What does it mean to be aphasia aware? An international survey of stakeholder perspectives and experiences of aphasia awareness. *Aphasiology*, 38(12), 1916–1939. <https://doi.org/10.1080/02687038.2024.2330145>
- Bincy, K., Logaraj, M., & Anantharaman, V. V. (2022). Validation of expanded form of Lubben social network scale among community-dwelling geriatric population in India. *Indian Journal of Community Medicine*, 47(2), 244–248. [https://doi.org/10.4103/ijcm.ijcm\\_827\\_21](https://doi.org/10.4103/ijcm.ijcm_827_21)
- Buckley, T. D., Becker, T. D., & Burnette, D. (2022). Validation of the abbreviated Lubben social network scale (LSNS-6) and its association with self-rated health amongst older adults in Puerto Rico. *Health & Social Care in the Community*, 30(6), e5527–e5538. <https://doi.org/10.1111/hsc.13977>
- Burnette, D., & Myagmarjav, S. (2013). Translation and validation of the 18-item Lubben social network scale with older adults in Mongolia. *International Psychogeriatrics*, 25(9), 1493–1502. <https://doi.org/10.1017/S104161021300080X>
- Chan, S. C. Y., Wong, C. C., Huang, Q. L., & Fung, C. K. (2023). The psychometric properties of the Lubben social network scale (LSNS-6) and its associations with well-being indicators in Hong Kong older adults. *Australasian Journal on Ageing*, 42(4), 683–689. <https://doi.org/10.1111/ajag.13214>
- Charalambous, M., Kountouri, A., Schwyter, J. R., Annoni, J. M., & Kambanaros, M. (2023). The development of the people with aphasia and other layperson involvement (PAOLI) framework for guiding patient and public involvement (PPI) in aphasia research. *Research Involvement and Engagement*, 9(1), 74. <https://doi.org/10.1186/s40900-023-00484-9>
- Charalambous, M., Phylactou, P., Antoniou, E., Christodoulou, M., & Kambanaros, M. (2024). The adaptation of the communicative effectiveness index (CETI) into Greek: A reliability and validity study. *Brain Sciences*, 14(7), 689. <https://doi.org/10.3390/brainsci14070689>
- Charalambous, M., Phylactou, P., Elriz, T., Psychogios, L., Annoni, J. M., & Kambanaros, M. (2022). Adaptation of the scenario test for Greek-speaking people with aphasia: A reliability and validity study. *International Journal of Language & Communication Disorders*, 57(4), 865–880. <https://doi.org/10.1111/1460-6984.12727>
- Charalambous, M., Phylactou, P., Kountouri, A., Serafeim, M., Psychogios, L., Annoni, J.-M., & Kambanaros, M. (2022). Adaptation of the aphasia impact questionnaire-21 into Greek: A reliability and validity study. *Clinical and Translational Neuroscience*, 6(4), 24. <https://doi.org/10.3390/ctn6040024>
- Charalambous, M., Symeou, R. T., Theodorou, E., & Kambanaros, M. (2024). The coproduction of a multilevel personal narrative intervention for people with aphasia in a community communication support group—a pilot study. *Frontiers in Stroke*, 3, 1393676. <https://doi.org/10.3389/fstro.2024.1393676>
- Cruice, M., Worrall, L., & Hickson, L. (2006). Perspectives of quality of life by people with aphasia and their family: Suggestions for successful living. *Topics in Stroke Rehabilitation*, 13(1), 14–24. <https://doi.org/10.1310/4JW5-7VG8-G6X3-1QVJ>
- Davidson, B., Howe, T., Worrall, L., Hickson, L., & Togher, L. (2008). Social participation for older people with aphasia: The impact of communication disability on friendships. *Topics in Stroke Rehabilitation*, 15(4), 325–340. <https://doi.org/10.1310/tsr1504-325>
- Demers, M., Charalambous, M., Kwah, L. K., Thilarajah, S., Bazadona, D., Chapman, S., Nasreldein, A., Yperzeele, L., Amoah, D., Winstein, C., Bernhardt, J., & Gopaul, U. (2025). Unique needs and challenges experienced by young people with stroke: An international qualitative analysis. *Neurology Clinical Practice*, 15(1), e200406. <https://doi.org/10.1212/CPJ.000000000200406>
- Doedens, W. J., & Meteyard, L. (2022). What is functional communication? A theoretical framework for real-world communication applied to aphasia rehabilitation. *Neuropsychology Review*, 32(4), 937–973. <https://doi.org/10.1007/s11065-021-09531-2>

- Douglas, N. F., Archer, B., Azios, J. H., Strong, K. A., Simmons-Mackie, N., & Worrall, L. (2023). A scoping review of friendship intervention for older adults: Lessons for designing intervention for people with aphasia. *Disability and Rehabilitation*, 45(18), 3012–3031. <https://doi.org/10.1080/09638288.2022.2117866>
- Fernandes, A., Fraga-Maia, H., Maso, I., Matos, I. G., Gomes, L., Matos, M., Santana, A., Oliveira-Filho, J., Jesus, P. A. D., & Pinto, E. B. (2022). Predictors of functional communication in people with aphasia after stroke. *Arquivos de Neuro-Psiquiatria*, 80(7), 681–688. <https://doi.org/10.1055/s-0042-1755267>
- Flynn, M. A., Mutlu, B., Duff, M. C., & Turkstra, L. S. (2018). Friendship quality, friendship quantity, and social participation in adults with traumatic brain injury. *Seminars in Speech and Language*, 39(5), 416–426. <https://doi.org/10.1055/s-0038-1670672>
- Ford, A., Douglas, J. M., & O'Halloran, R. (2023). From the inner circle to rebuilding social networks: A grounded theory longitudinal study exploring the experience of close personal relationships from the perspective of people with post stroke aphasia. *Aphasiology*, 38(2), 261–280. <https://doi.org/10.1080/02687038.2023.2185480>
- Fotiou, C., & Grohmann, K. K. (2022). A small island with big differences? Folk perceptions in the context of dialect levelling and koineization. *Frontiers in Communication*, 6, 770088. <https://doi.org/10.3389/fcomm.2021.770088>
- Fullerton, K. J., McSherry, D., & Stout, R. W. (1986). Albert's test: A neglected test of perceptual neglect. *Lancet (London, England)*, 1(8478), 430–432. [https://doi.org/10.1016/s0140-6736\(86\)92381-0](https://doi.org/10.1016/s0140-6736(86)92381-0)
- Galletta, E. E., & Barrett, A. M. (2014). Impairment and functional interventions for aphasia: Having it all. *Current Physical Medicine and Rehabilitation Reports*, 2(2), 114–120. <https://doi.org/10.1007/s40141-014-0050-5>
- Geyh, S., Cieza, A., Schouten, J., Dickson, H., Frommelt, P., Omar, Z., Kostanjsek, N., Ring, H., & Stucki, G. (2004). Icf core sets for stroke. *Journal of Rehabilitation Medicine*, 36, 135–141. <https://doi.org/10.1080/16501960410016776>
- Gopaul, U., Charalambous, M., Thilarajah, S., Kwah, L. K., Chapman, S., Bayley, M., & Demers, M. (2022). Age-specific information resources to address the needs of young people with stroke: A scoping review protocol. *Systematic Reviews*, 11(1), 275. <https://doi.org/10.1186/s13643-022-02147-4>
- Haslam, C., Holme, A., Haslam, S. A., Iyer, A., Jetten, J., & Williams, W. H. (2008). Maintaining group memberships: Social identity continuity predicts well-being after stroke. *Neuropsychological Rehabilitation*, 18(5–6), 671–691. <https://doi.org/10.1080/09602010701643449>
- Hawthorne, G. (2006). Measuring social isolation in older adults: Development and initial validation of the friendship scale. *Social Indicators Research*, 77(3), 521–548. <https://doi.org/10.1007/s11205-005-7746-y>
- Hilari, K., Behn, N., James, K., Northcott, S., Marshall, J., Thomas, S., Simpson, A., Moss, B., Flood, C., McVicker, S., & Goldsmith, K. (2021). Supporting wellbeing through peer-befriending (SUPERB) for people with aphasia: A feasibility randomised controlled trial. *Clinical Rehabilitation*, 35(8), 1151–1163. <https://doi.org/10.1177/0269215521995671>
- Hilari, K., & Northcott, S. (2006). Social support in people with chronic aphasia. *Aphasiology*, 20(1), 17–36. <https://doi.org/10.1080/02687030500279982>
- Hilari, K., & Northcott, S. (2017). "Struggling to stay connected": Comparing the social relationships of healthy older people and people with stroke and aphasia. *Aphasiology*, 31(6), 674–687. <https://doi.org/10.1080/02687038.2016.1218436>
- Hinckley, J., & Jayes, M. (2023). Person-centered care for people with aphasia: Tools for shared decision-making. *Frontiers in Rehabilitation Sciences*, 4, 1236534. <https://doi.org/10.3389/fresc.2023.1236534>
- JASP Team. (2024). JASP (version 0.19.3) [computer software].
- Kristinsson, S., den Ouden, D. B., Rorden, C., Newman-Norlund, R., Neils-Strunjas, J., & Fridriksson, J. (2022). Predictors of therapy response in chronic aphasia: Building a foundation for personalized aphasia therapy. *Journal of Stroke*, 24(2), 189–206. <https://doi.org/10.5853/jos.2022.01102>

- Lubben, J., Blozik, E., Gillmann, G., Iliffe, S., von Renteln Kruse, W., Beck, J. C., & Stuck, A. E. (2006). Performance of an abbreviated version of the Lubben social network scale among three European community-dwelling older adult populations. *Gerontologist*, 46(4), 503–513. <https://doi.org/10.1093/geront/46.4.503>
- Lubben, J., & Gironde, M. (2004). Measuring social networks and assessing their benefits. In C. Phillipson, G. Allan, & D. Morgan (Eds.), *Social networks and social exclusion: Sociological and policy perspectives* (pp. 20–34). Ashgate.
- Madden, E. B., Bislick, L., Wallace, S. E., Therrien, M. C. S., & Goff-Albritton, R. (2023). Aphasia and friendship: Stroke survivors' self-reported changes over time. *Journal of Communication Disorders*, 103, 106330. <https://doi.org/10.1016/j.jcomdis.2023.106330>
- Martin-Sanz, M. B., Salazar de la-Guerra, R. M., Cuenca-Zaldivar, J. N., Salcedo-Perez-Juana, M., Garcia-Bravo, C., & Palacios-Ceña, D. (2022). Person-centred care in individuals with stroke: A qualitative study using in-depth interviews. *Annals of Medicine*, 54(1), 2167–2180. <https://doi.org/10.1080/07853890.2022.2105393>
- Matos, M. A. C., Jesus, L. M. T., & Cruice, M. (2014). Consequences of stroke and aphasia according to the ICF domains: Views of Portuguese people with aphasia, family members and professionals. *Aphasiology*, 28(7), 771–796. <https://doi.org/10.1080/02687038.2014.906561>
- McMenamin, R., Isaksen, J., Manning, M., & Tierney, E. (2022). Distinctions and blurred boundaries between qualitative approaches and public and patient involvement (PPI) in research. *International Journal of Speech-Language Pathology*, 24(5), 515–526. <https://doi.org/10.1080/17549507.2022.2075465>
- Mendelson, M. J., & Aboud, F. E. (1999). Measuring friendship quality in late adolescents and young adults: McGill friendship questionnaires. *Canadian Journal of Behavioural Science/Revue Canadienne des Sciences du Comportement*, 31(2), 130–132. <https://doi.org/10.1037/h0087080>
- Messinis, L., Panagea, E., Papathasopoulos, P., & Kastellakis, A. (2013). *Boston Diagnostic Aphasia Examination-Short Form in Greek language*. Gotsis, Patras.
- Nelson, M. L. A., MacEachern, E., Prvu Bettger, J., Camicia, M., Garcia, J. J., Kapral, M. K., Mathiesen, C., Cameron, J. I., & American Heart Association Stroke Council; Council on Cardiovascular and Stroke Nursing; and Council on Quality of Care and Outcomes Research. (2024). Exploring the inclusion of person-centered care domains in stroke transitions of care interventions: A scientific statement from the American Heart Association. *Stroke*, 55(6), e169–e181. <https://doi.org/10.1161/STR.0000000000000462>
- Northcott, S., & Hilari, K. (2011). Why do people lose their friends after a stroke? *International Journal of Language & Communication Disorders*, 46(5), 524–534. <https://doi.org/10.1111/j.1460-6984.2011.00079.x>
- Northcott, S., Moss, B., Harrison, K., & Hilari, K. (2016). A systematic review of the impact of stroke on social support and social networks: Associated factors and patterns of change. *Clinical Rehabilitation*, 30(8), 811–831. <https://doi.org/10.1177/0269215515602136>
- Nunnally, J. C., & Bernstein, I. H. (1994). *Psychometric theory* (3rd ed.). McGraw-Hill. <https://doi.org/10.1007/BF02301419>
- Phylactou, P., Papadatou-Pastou, M., & Konstantinou, N. (2025). The Bayesian one-sample t-test supersedes correlation analysis as a test of validity. *European Journal of Psychology Open*, 84(1), 1–12. <https://doi.org/10.1024/2673-8627/a000069>
- Pike, C., Kritzinger, A., & Pillay, B. (2017). Social participation in working-age adults with aphasia: An updated systematic review. *Topics in Stroke Rehabilitation*, 24(8), 627–639. <https://doi.org/10.1080/10749357.2017.1366012>
- Saragosa, M., Mulligan, K., Hsiung, S., Biswas, S., Card, K., Hébert, P. C., Welch, V., & Nelson, M. L. A. (2024). A qualitative study of national perspectives on advancing social prescribing using co-design in Canada. *Health Expectations*, 27(4), e14144. <https://doi.org/10.1111/hex.14144>
- Singh, H., Benn, N., Fung, A., Kokorelias, K. M., Martyniuk, J., Nelson, M. L. A., Colquhoun, H., Cameron, J. I., Munce, S., Saragosa, M., Godhwani, K., Khan, A., Yoo, P. Y., & Kuluski, K. (2024). Co-design for stroke intervention development: Results of a scoping review. *PLOS ONE*, 19(2), e0297162. <https://doi.org/10.1371/journal.pone.0297162>

- Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., Altman, D. G., Moher, D., Barber, R., Denegri, S., Entwistle, A., Littlejohns, P., Morris, C., Suleman, R., Thomas, V., & Tysall, C. (2017). GRIPP2 reporting checklists: Tools to improve reporting of patient and public involvement in research. *BMJ*, *358*, j3453. <https://doi.org/10.1136/bmj.j3453>
- Streiner, D. L., N, G. R., & Cairney, J. (2014). *Health Measurement scales: A practical guide to their development and use* (5 ed.). Oxford Academic. <https://doi.org/10.1093/med/9780199685219.001.0001>
- Swinburn, K., Best, W., Beeke, S., Cruice, M., Smith, L., Pearce Willis, E., & McVicker, S. J. (2018). A concise patient reported outcome measure for people with aphasia: the aphasia impact questionnaire. *Aphasiology*, *33*(9), 1035–1060. <https://doi.org/10.1080/02687038.2018.1517406>
- Taherdoost, H. (2016). Validity and reliability of the research instrument: How to test the validation of a questionnaire/survey in research. *International Journal of Academic Research in Management (IJARM)*, *5*. <https://doi.org/10.2139/ssrn.3205040>
- Terry, G., & Kayes, N. (2020). Person centered care in neurorehabilitation: A secondary analysis. *Disability and Rehabilitation*, *42*(16), 2334–2343. <https://doi.org/10.1080/09638288.2018.1561952>
- Ter Wal, N., Terwee, C. B., Visser-Meily, J. M. A., Alons, E., Dijkhuis, L., Gerrits, E., & Ewijk, L. V. (2024). Development and validation of MyCommunication—adults, a self-report communicative participation measure. *International Journal of Language & Communication Disorders*, *59*(6), 2766–2785. <https://doi.org/10.1111/1460-6984.13115>
- 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*(5), 1159–1170. <https://doi.org/10.1007/s11136-018-1829-0>
- Therrien, M. C., Madden, E. B., Bislick, L., & Wallace, S. E. (2021). Aphasia and friendship: The role and perspectives of speech-language pathologists. *American Journal of Speech-Language Pathology*, *30*(5), 2228–2240. [https://doi.org/10.1044/2021\\_AJSLP-20-00370](https://doi.org/10.1044/2021_AJSLP-20-00370)
- Wafa, H. A., Wolfe, C. D. A., Emmett, E., Roth, G. A., Johnson, C. O., & Wang, Y. (2020). Burden of stroke in Europe: Thirty-year projections of incidence, prevalence, deaths, and disability-adjusted life years. *Stroke*, *51*(8), 2418–2427. <https://doi.org/10.1161/STROKEAHA.120.029606>
- Wallace, S. J., Isaacs, M., Ali, M., & Brady, M. C. (2023). Establishing reporting standards for participant characteristics in post-stroke aphasia research: An international e-Delphi exercise and consensus meeting. *Clinical Rehabilitation*, *37*(2), 199–214. <https://doi.org/10.1177/02692155221131241>
- World Health Organization. (2001). *International classification of functioning, disability, and health*. Retrieved April 10, 2025, from <https://icd.who.int/dev11/l-icf/en>

## Appendix 1

**Table A1.** The GRIPP-2 Short form.

Section and Topic	Item	Reported on Page Number
1 <i>Aim</i>	Report the aim of PPI in the study	11
2 <i>Methods</i>	Provide a clear description of the methods used for PPI in the study	12–22
3 <i>Study results Outcomes</i>	Report the results of PPI in the study	32–33
4 <i>Discussion and conclusions on Outcomes</i>	Outcomes—Comment on the extent to which PPI influenced the study overall	34–35
5 <i>Reflections/critical perspective</i>	Comment critically on the study, reflecting on the things that went well and those that did not	37–41