Research Involvement and Engagement

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A global multilingual cocreation of aphasia priority topics through patient and public involvement

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Abstract

Background People living with chronic aphasia (PWA) face long-term challenges that go well beyond communication difficulties, including emotional, social, and societal barriers. To ensure that research and policy efforts address what matters to them, it is vital to directly involve PWA in setting priorities. This international initiative adopted the patient and public involvement (PPI) approach to co-create a research agenda with PWA and health professionals across countries and languages.

Aim This study was initiated by a person with aphasia and three laypersons. We aimed to i) collaboratively identify and prioritize topics of greatest importance to PWA through a multilingual PPI process for orienting future research and ii) evaluate the participation and adherence of strongly involved PWA (both Patient Authors (PAs), and PWA who participated in co-design sessions)

Methods The project involved more than 100 people living with aphasia (PWA) from 14 countries, with 11 countries contributing to the voting process. It utilised the PAOLI (People with Aphasia and Other Layperson Involvement) framework and inclusive communication strategies. The three-phase process included (1) an online consultation phase to generate initial topics, (2) a development phase through national-level co-design sessions to refine and rank topics and that concluded with international voting of four top priorities, and (3) a multilingual translational phase. Aphasia-friendly materials and real-time translation ensured accessibility.

Results PWA played key roles in proposing topics, organizing and summarizing national and international voting, and promoting dissemination. Eleven out of the 14 participating countries (78%) voted. PAs rated their influence as optimal (5/8) or good (3/8), with a mean rating of 3.6/4. Notably, 11 of the 12 proposed topics originated from PWA. Four priorities emerged: (1) raising awareness of aphasia among families and society; (2) psychological changes, including impacts on intimacy and relationships; (3) rebuilding self-confidence after aphasia; and (4) improving therapy and hospital attitudes towards treatment.

^Jernej Sluga: Deceased in June 2025.

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Conclusion This multilingual, PPI-led initiative demonstrates that PWA can meaningfully co-create thematic priorities when supported by inclusive, accessible methods. These priorities, selected by PWA, corroborate and expand upon the conclusions of earlier research, particularly the pressing necessity to enhance public awareness of aphasia. The results also underscore a comprehensive perspective on living with aphasia, emphasising the social, emotional, and communicative dimensions that should guide future research, clinical care, and policy.

Plain English summary

Aphasia is a condition that makes speaking, understanding, reading, and writing hard. It often happens after a stroke. Aphasia affects more than language. People with aphasia can feel lonely, sad, and misunderstood.

An international study included more than 100 people with aphasia and health workers from 13 countries. The study asked two questions:

• What aphasia topics are most important to people with aphasia around the world?.

• Can people with aphasia help with international research through online meetings in different languages? And can they stay involved until the end?.

In this study, people with aphasia were the leaders. They were not just helping the researchers. This follows the patient and public involvement (PPI) approach.

The study had three steps.

1. First, people shared ideas online.
2. Next, small groups in each country talked about the ideas and chose the most important ones.
3. Finally, everyone voted for the top ideas.

The team used simple words, helpful pictures, and translations. This helped everyone understand and take part. Even with online meetings and different languages, most people stayed involved.

Four main ideas were chosen:

• People need more awareness about aphasia. Families, friends, and society should understand it better and act in a supportive way.

• Aphasia-related changes in emotions and intimate relationships must be better screened and treated.

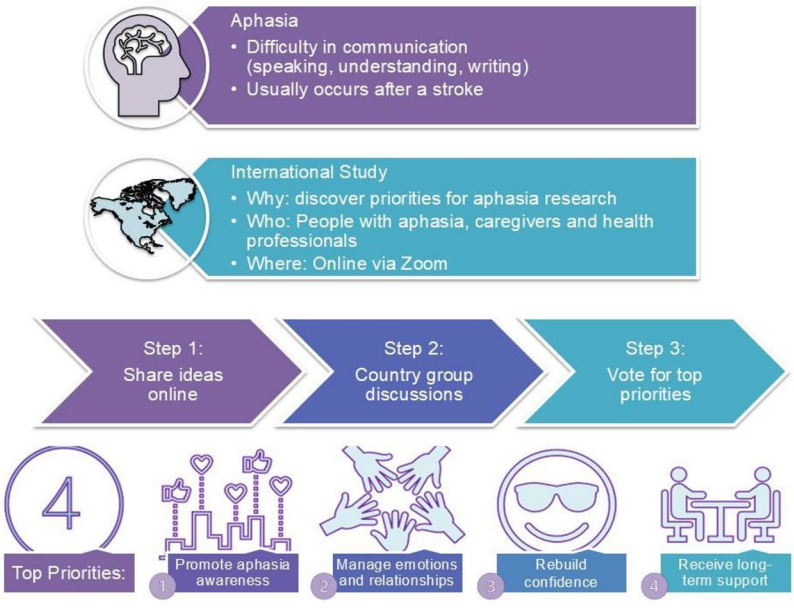
• People with aphasia need support to feel confident again.

• Therapy and support must improve.

This study shows that with the right support, people with aphasia can clearly say what matters to them. Their voices show not only medical needs but also the whole experience of living with aphasia. They can guide researchers, health workers, and policy-makers.

Keywords Aphasia, Stroke, Patient and public involvement, Patient experience, Topics, Awareness

Graphical Abstract



Introduction

In recent decades, the active involvement of individuals with lived experience as core researchers and decision-makers in health research has gained momentum, particularly through the advancement of patient and public involvement (PPI) methodologies. This paradigm shift is driven by ethical imperatives, democratic values, and the recognition that research is more relevant, effective, and impactful when shaped by those directly affected by the outcomes [1, 2]. The 2022 report by the Council for International Organizations of Medical Sciences (CIOMS) further underscores this shift, outlining international guidance on involving patients in all stages of research, from setting priorities to designing studies and disseminating findings [3].

In the field of aphasia, PPI presents both a necessity and a challenge. Aphasia, a communication disorder most often caused by stroke, has historically excluded individuals from research roles because of perceived language and cognitive barriers [4]. However, inclusive research frameworks now demonstrate that people living with chronic aphasia (PWA) can meaningfully participate in co-design and co-production when supported by accessible and adapted methods [4, 5]. PPI in aphasia research is especially important for enhancing the relevance of research topics, fostering empowerment, and promoting patient-centred services that reflect real-life needs and experiences [6].

Among chronic neurological conditions, aphasia is uniquely suited for developing and testing inclusive PPI models. Research on how communication, participation, and collaboration are structured is challenging. Involving PWA in the act of priority setting also helps ensure that emerging research agendas address not only clinical or linguistic outcomes but also broader psychosocial and identity-related issues that are central to quality of life [7, 8]. Previous national and international studies which have also included PWA partners (e.g., spouse, husband, family members, associations volunteers, health specialists such as therapists, social workers and other stakeholders implicated in aphasia), have highlighted recurring concerns, such as the need to increase public awareness of aphasia, improve psychological support, and increase the availability of meaningful speech therapy and communication access [9–13]. Some studies which include severely affected PWA, have highlighted the importance of developing optimal language therapies [14]. Many of these studies have demonstrated how PWA can be meaningfully involved as co-designers through aphasia-friendly meetings with supported communication, trained facilitators, and consensus-based methods [15, 16]. A number of these works are national in scope; however, less attention has been given to global and multilingual consensus-building led by PWA. This burden could explain why stroke survivor representatives tend to be involved primarily in an advisory role rather than as co-researchers.

The project was initiated by three co-authors: (i) JS, a former engineer and co-founder of an informatics company in Ljubljana, Slovenia, a stroke survivor who has been living with aphasia for nearly 30 years, and president of the Association Internationale Aphasia (AIA); (ii) JMA, a neurologist,former vice-president of Aphasie Suisse and board member of AIA; and (iii) SR, a linguist and advocate for the Fundación Argentina de Afasia "Charlotte Schwarz" in Buenos Aires, as well as promoter of the Spanish American League (Liga Hispanoamericana de Personas con Afasia, LIHA), which is dedicated to raising aphasia awareness in Spanish-speaking countries. They were assisted by MC, a speech therapist and member of the AIA board, specialising in aphasia rehabilitation and PPI principles.

AIA is a nonprofit organization founded in 1983 by a Belgian person with aphasia. AIA brings together national aphasia-related associations from different countries with the mission of strengthening links among them, encouraging initiatives to promote aphasia awareness and care, and sharing experiences across various projects. A distinctive feature of AIA is that each country is represented by a person who is usually a person with aphasia, accompanied by a carer or family member. The deceased president who initiated the project was Jernej Sluga (JS), while the current president, Alexia Kountouri (AK), also identifies as a person with aphasia. The board additionally includes three other PWAs and four laypersons (i.e., individuals who work with PWA, professional representatives, or volunteers in aphasia associations) who support administrative tasks such as legal, financial, and website-related matters. The designated contact person is either the person with aphasia or a family member/carer.

The Liga Hispanoamericana de Personas con Afasia (LIHA) also aims to create an alliance among different groups and health professionals specialising in aphasia rehabilitation. This alliance includes PWA, family members and friends, and individuals interested in raising awareness about aphasia and helping to prevent it through improved control of risk factors.

We initiated a global, multilingual project grounded in the PPI methodology. Through close collaboration with PWA, carers, and allied health professionals in 13 countries, and guided by inclusive strategies such as aphasia-friendly materials and real-time translation, we co-created a set of shared thematic priorities for the aphasia community to guide future research. The aim of this study was to collaboratively identify and rank the research topics that considered most important to PWA,through a multilingual PPI process conducted

across diverse cultural and linguistic contexts. However, we recognised that a project involving PWA from different linguistic backgrounds could create additional challenges related to preparation, discussion, and consensus-building. Therefore, participant adherence throughout the research process was considered an important issue.

The two research questions (RQs) guiding this initiative were as follows:

RQ1: Which aphasia-related topics are considered most important and most widely shared across countries, as identified by PWAs themselves, to guide future research?

RQ2: What were the levels of global participation and adherence among PWA and laypersons throughout the completion of an online multilingual research protocol initiated by a non-academic international aphasia association?

Methods

Ethics

The study was conducted online and internationally and received ethical approval from the Cyprus Bioethics Committee, the institution of the second corresponding author: CNBC EP 2023.01.02.

Design

This study followed a three-phase qualitative design, guided by patient and public involvement (PPI) principles and the PAOLI (People with Aphasia and Other Layperson Involvement) framework [4]. The project was conducted by a research team that included PWA and laypersons (mostly clinical neuroscientists with aphasia-related expertise and board members of aphasia associations). PWA were also engaged as experts through national aphasia associations across the globe that involved PWA in local co-design meetings. In all phases, accessible communication (e.g. visual aids, online translation, reformulation, etc.) was used. We particularly favoured the inclusion of multiple languages and co-decision-making among PWA, carers, and health professionals. The study is reported in accordance with the GRIPP2-LF (Guidance for Reporting Involvement of Patients and the Public – Long Form). See GRIPP-LF in Appendix 1.

In the PAOLI framework, phase 1 is the foundation. The foundation involves items and statements related to the creation of a support system for PWA to function independently within the research team and to establish functional communication by proposing the use of various communication means. Phase 2, called development, is characterized by the meaningful involvement of PWA in the conceptualisation and the identification of the topics most important to them using co-design methodology. In particular, voting procedures are part of this phase. Phase 3 is called translational and is based on the implementation, dissemination, and sustainability of the findings. There is also a 4th phase called ongoing processes, which includes items for PWA to self-evaluate their involvement in the research and is described at the end of the Methods section. The following actions were taken in each phase.

- Phase 1 (Foundation Phase): Consultation meetings, which were communication-accessible online meetings to generate initial important topics.
- Phase 2 (Development Phase): Discussion and voting for top priorities. This phase was characterized by a dual-level process: *i)* national-level co-design meetings, which involved group activities to refine and rank the topics, followed by *ii)* an online meeting with representatives of the national associations to vote on and share the final priorities.
- Phase 3 (Translational Phase): Planning international online to promote the dissemination of priority topics.

At the conclusion of the research, a retrospective self-evaluation phase was conducted.

Participants

In total, 14 national aphasia associations (including those representing two different linguistic areas of Switzerland) joined the project. The following persons were involved.

1) Author Researchers and Patient Authors (PAs): This project was led by PWA and health professionals affiliated with national aphasia associations as equal partners in the research team. The PAs were eight PWA, and five health professionals. These professionals contributed to the study design, thematic development, voting procedures, and writing of the manuscript. PAs played key roles within the research team, including organising discussions in national associations and national and regional aphasia groups, which we termed local aphasia communities. They also shared the results and their perspectives in online meetings and contributed to decisions regarding the dissemination of the findings. In accordance with the most recent international standards for characterising participants in post-stroke aphasia research, data were collected on 14 clinical and demographic variables for all individuals with PWA who took part in the study [17]. These data included age, years of education, biological sex, language of treatment/testing, primary language, other languages spoken, history of neurological or cognitive conditions, stroke history, lesion hemisphere, time since onset of aphasia, and comorbidities [17]. As a precaution against the inadvertent disclosure of individually

Table 1a Demographic and clinical characteristics of the coauthors with aphasia

Patient Autor (PA)	CM	JS	JG	RS	CL	DC	HM	AK
Age (Y)	Different ages; 35, 45, 52, 59, 62, 63,65,NA,							
Years of schooling	Mean 18.25 years (between 16 and 20)							
Level	BA (3) MA (3), MS (2),							
Profession	Admin, Architect, Engineer (2), Psychologist, Social Worker,Teacher,							
Post aphasia RTW	No Activity (3), Charity founder, Director Office, Social Admin, Therapist (2)							
Role related to aphasia	Member of national aphasia association: 7/8 yes 1/8 no							
Marital Status	Married (2 PAs) Divorced (4 PAs) Single (1 PA), Widowed (1 PA)							
Biological sex (M/F/O)	F (3), M (5)							
Native language	Greek, English, French, German, Greek, Italian, Slovenian, Spanish SwissGerman,							
Actual Language	French	Slovenian/English	Spanish/English	Swiss German	English	Italian	English	Greek, English
Cause of aphasia	Ischaemic strokes (5 PAs) Haemorrhagic Strokes (3 PAs)							
Months post-stroke	Mean 162 ± 107							
Lesion Side	Left Hemisphere (7), Right Hemisphere (1)							
Hemiplegia	Right (3 PAs) Left (1 PA) None (4 PAs)							
ASRS	2 PAs rated 2/4, 4 PAs rated 3/4, 2 PAs rated 4/4							

Information is presented at the group level to avoid providing personally identifiable data. Only sponken languages are personalised, since such aspects are discussed in the manuscript. Concerning acronyms: PA: patient Author; BA: bachelor of arts, MA: master of Arts; MS: master of Science, FNAF: French aphasia Association; RTW: return to Work; AITA: Italian aphasia Association; AIA: aphasia international Association; L: Left; R: Right; I: Ischaemic; H; NA: not available; M: Male; F: female. ASRS: aphasia severity rating Scale from the Boston Diagnostic aphasia Examination. BA: bachelor of arts, MS: master of Science; AIA: aphasia international Association; M: Male; F: female

Table 1b Health professional authors' demographics (refer to table 1A for acronyms)

Health Professionals	JMA	MC	FE	CB	SR
Age (Y)	Different Ages 34, 45, 57, 68, 84				
Years of education (YY)	Mean 20.6 years (between 19 and 22)				
Education	MS, MD, PhD (3)				
Profession	Music Therapist, Neurolinguist, Neurologist, Speech therapist (2)				
Employment	University (3), Hospital,, Rehabilitation				
Role related to aphasia	Board member National Aphasia Associations; 4 yes, 1, no				
Marital Status	Married (3), Widowed (1) NA (1)				
Biological sex	F (4), M (1)				
Native language	Cypriot, French/Italian, English, Hungarian, Spanish				
Actual Language	French, Italian, German, English	Cypriote, English	Hungaria, English	English	Spanish, French

sensitive information, we present individual data at a group level, except for native language, as this subject is addressed repeatedly throughout the manuscript (Table 1A). Additionally, aphasia severity of the PAs was documented by the clinician authors (JMA, MC, and FE) during online meetings and through informal discussions via the Aphasia Severity Rating Scale (ASRS) from the Boston Diagnostic Aphasia Examination [18]. This scale, which was determined from conversational speech samples, provides rankings from "no usable speech or auditory comprehension" (score of 0) to "minimal discernible speech handicaps" (score of 4) in PWA's native language.

The five health professional authors were clinicians and academics who were also members of AIA and different national aphasia associations. As a precaution against inadvertent disclosure of sensitive information, health professional data is also presented at a group level, with the exception of the native language, since this aspect is addressed throughout the manuscript. (Table 1B).

1) Expert Laypersons and PWA : in this context, the term 'layperson' refers to an individual working with people living with PWA or volunteering for an aphasia association. Our integrated clinicians have responsibility for aphasia associations, as well as carers, members of national aphasia associations, or those representing or co-representing these associations. PWA who participated in national and international discussions as representatives of their Aphasia Associations were named here Expert PWA. These individuals participated in the consultation and voting meetings, as well as the translational phase. All of the aforementioned parties were members of the international aphasia networks AIA and LIHA. All these persons, PWA, carers, and health professionals, were considered experts since they could be active during both online meetings in phases 1 and 2 and national/local discussions in phase 2. Each country is represented by one to three individuals in the overall expert group. In addition to the PA, a total of 11 PWA and seven laypersons participated as representatives in at least one of the online meetings. Participants from Chile, Bolivia and Uruguay also participated as observers during phase

3, but did not vote due to the unavailability of their respective aphasia national associations.

2) Involved PWA were members of national aphasia communication groups with previous experience in group discussions or advocacy work. They took part in national-level co-design sessions in their respective countries. In total, 91 involved PWA participated in the discussions during these national-level co-design sessions (see Table 2).

The distribution of representatives by country for participation in at least one meeting is presented in Table 2. A total of 122 PWA from 13 countries participated in at least one phase of the process, 105 of whom were in some manner involved in the final vote (see Table 2).

Project's trajectory

PAOLI phase I – foundation

The consultation phase was initiated in September 2023 and comprised two 90-minute online meetings with participants from the AIA and LIHA networks. In the initial phase of the project, JS, JMA and SR, with the assistance of MC, communicated with AIA members and explained the project in an aphasia-friendly manner (see Appendix 2 for the sent message),

Invitations were disseminated via email in English, French, and Spanish to facilitate comprehension and retention among participants. The original text was in English, and the translation was created using the DeepL basic pro version program (https://www.deepl.com/en/translator) and controlled by JMA for French and SR for Spanish. Representatives from each participating nation were invited to deliberate on two or three pivotal subjects that ought to be addressed by researchers, clinicians, and health professionals working with PWA. Furthermore, participants were encouraged to contact members of their national aphasia association and to submit selected topics to one of the corresponding authors, MC or JMA, via mail. The email addresses used were the contact details of the representative of national aphasia associations to AIA, predominantly personal email addresses (see Contact - Aphasie International). These contributions were aimed at generating an initial pool of potentially important topics. The representative could reflect alone or in their aphasia groups on which topic(s) to propose. The important point is that the proposal should be made by a PWA or a group of PWA. The organisation of these online meetings was undertaken by JMA, a corresponding author of the present study, utilising the Zoom platform for virtual meeting facilitation. The selection of this particular collaboration tool was proposed by the majority of participants, who expressed a satisfactory level of comfort with it. As was noted in the report of the inaugural meeting in September 2023, participants included representatives from 12 countries, both from the PWA community and from the general

Table 2 Description and total number of AIA members who participated in the study

Country	PAs and authors representing their national aphasia associations	Expert PWA and/or layperson representing national aphasia associations	Additional involved PWA members of local aphasia associations involved in the national-level co-design sessions
Argentina*	1 A	1 PWA (ASRS 3)	7
Australia	1 A	1 PWA (ASRS 4)	0
Cyprus	1 PA and 1 A	1 PWA (ASRS 3) and 1 L	6
Estonia	0	1 PWA and 1 L (ASRS 2)	0
France	1 PA	1 PWA (ASRS 4)	40
French Switzerland	1 A*	3 PWA (mean ASRS 3)	8
German Switzerland	1 PA and 1 A*	0	7
Hungary	1 A	1 PWA (ASRS 2)	8
India	0	1 L	0
Italy*	1 PA	1 PWA (ASRS 3)	0
Mexico	0	1 L	13
Slovenia	1 PA	1 L	1
Spain	0	2	0
United Kingdom:	2 PAs	1 PWA (ASRS 4) and 1 L	1
USA (Virginia)	1 PA	1 L	0
Total	8 PAs + 5 As	11 PWA (mean ASR = 3,1) + 7 Ls	91

PAs are patient authors, authors are health professional authors, PWA (19) and layperson (12) authors or experts participated in the international online meetings in the consultation phase and/or the voting day. PWA who were members of local aphasia associations participated in individual national discussions and national rankings. PAs were evaluated during the online meetings through aphasia severity rating Scale (ASRS) from the Boston Diagnostic aphasia Examination [18] and ASRS scores of expert PWA are reported in the table. *the same author represented both groups. The total number of participants (PAs, As, experts, and involved PWA) was 122, of whom 110 were PWA. However, since two countries did not vote, the effective total number of countries directly or indirectly participating in the final voting is 105

public. The session followed the principles to facilitate oral conversation for PWA [19], as also summarized by the stroke association (2012 https://www.stroke.org.uk/sites/default/files/accessible_information_guidelines.pdf1_.pdf), and opened with a structured introductory segment intended to support participant self-introductions and to foster renewed engagement among members. The topics were proposed, and the online participants noted whether they had also thought of a similar topic or if the topic's wording needed to be adjusted or modified. Representatives of PWA were encouraged to share significant personal experiences to explain and support their topic choices. The meeting lasted 90 minutes; however, this duration proved excessive, as several participants left after approximately one hour. Furthermore, language barriers posed challenges for participants who were not native English speakers, despite real-time translation support provided by two team members (JMA translated from English into French, Italian, and German; SR translated between French and Spanish). Following a period of deliberation, it was agreed that a second online meeting would be scheduled in November 2023 with the objective of confirming the selection of topics. The total number of participants included 12 PWA and nine laypersons. The second meeting, and all subsequent meetings, were each limited to a duration of one hour. The subjects of discussion were briefly outlined on PowerPoint slides. The group also employed a standard professional Zoom profile, which facilitated written translation. At the end of each meeting, JMA sent an English summary with aphasia-friendly principles [20] in English, in a size 14 font and using graphics (see Appendix 4a) to support participants' understanding [21] and retention translated into different languages (French, Spanish, Italian and German) with the help of the DeepL program, basic pro version (https://www.deepl.com/en/translator).

PAOLI phase 2 – development phase

Between January and May 2024, each country developed and refined its list of priorities independently via national-level co-design sessions to refine and rank topics [22], tailored to the local context, language, and participant needs. MA, SR and JS requested that the representatives of the national federations organise meetings with PWA from their respective national organisations so that they could discuss the initially proposed topics. It was imperative that each Federation selected a specific number of topics, with the understanding that these would be ranked in order of importance. The only guidance provided was that they should arrive at the final meeting with possibly four topics, ranked in order of importance, chosen among the topics proposed at the end of Phase 1. The fact of choosing four priority topics was proposed at the end of the Phase 1 meetings in order to maintain a variety of options while simultaneously restricting the choice to allow discussion in the final meetings. The authors and expert PWA and laypersons contacted their respective aphasia groups and organised meetings to discuss the various topics and to vote on which ones were the most significant. The selection and ranking of topics were not imposed by researchers but emerged from facilitated local discussions, reflections, and consensus among PWA and their supporters. Different formats were used across countries, including structured in-person focus groups, informal discussions within national associations, and one to three online meetings, depending on accessibility and participant preferences. This flexible and inclusive approach enabled meaningful contributions from participants across the spectrum of aphasia severity and technological access. Some countries used an in-person format (German CH: nine PWA and two laypersons, Mexico: 13 PWA and one layperson, French-speaking Switzerland: 10 PWA and one layperson, and Cyprus: seven PWA and one layperson), which allowed for a richer exchange and discussion. Other countries used online meetings to involve more PWA (for example, France completed two online meetings with 41 French PWA via Zoom in different groups).

Topic Prioritization Procedure : during the final month of the development phase, each participating country ranked up to four priority topics from the original list of the twelve chosen topics during phase 1 (between first and second online meeting). Countries were permitted to rank fewer than four topics if appropriate. Rankings were weighted using a predefined point system (4 points for the first-ranked topic, 3 for the second, 2 for the third, and 1 for the fourth). Each country was represented by an expert and/or author, who submitted their ranked selections to the JMA by mail -except one country (representative had difficulties writing) who presented orally its ranking at the beginning of the online consensus meeting on June 3rd, 2024.

An international online consensus meeting was subsequently held on June 3, 2024, via Zoom. At the beginning of the session, the number of participating countries and attending representatives—including persons with aphasia (PWA) and lay experts—was documented. JMA recalled the 12 themes under consideration. A representative from each country was then invited to confirm and provide a brief overview of the four nationally prioritised topics. Attending PWA and lay experts, acting as national representatives, were invited to verify and, where necessary, clarify or supplement the recorded information.

During the meeting, JMA presented the provisional aggregated rankings and finalised the dataset. The aggregated scores were reviewed to identify the four topics most consistently prioritized across countries. Representatives also presented the rationale for their national

prioritizations, as derived from prior co-design sessions involving experts and PWA.

Following the meeting, JMA verified the ranking calculations by summing the weighted scores for each topic. The final results, including the four highest-ranked topics, were disseminated in five languages (English, French, Spanish, Italian, and German) using DeepL Pro (basic version) to facilitate accessibility across participating countries.

PAOLI phase 3 – translational

The final phase, from September to October 2024, focused on translating priorities into action and implementing dissemination. Specifically, PWA and laypersons were asked to suggest and propose a dissemination plan. In this phase, PWA from non-English speaking countries found English-only meetings too difficult and requested that the discussion be held in different languages to make the involvement more meaningful. Six language-specific online meetings were subsequently held to further refine the four highest-ranked topics and to co-develop strategies for disseminating these priorities at both national and international levels.

Two meetings were held for each language group, with three language groups in total: English-speaking, Spanish-speaking, and French/Italian-speaking. This arrangement allowed some PWA to participate in a second language when appropriate. For example, the PWA expert from Cyprus (and PA) had completed her PhD in England and was therefore able to participate effectively in the English-language meetings. The Italian PWA experts joined the French-speaking meetings, as both were familiar with using Zoom's AI Companion instant translation feature. The Hungarian PWA ZG was accompanied by a therapist who was fluent in English (FE). This therapist provided translation into Hungarian for ZG and translated ZG's answers and thoughts into English for the other participants. In addition, the meeting chair facilitated communication by providing translation between Italian and French when needed.

The participants discussed possible initiatives such as promoting the most important topics, sharing lived experience testimonies at conferences and proposing multilingual, aphasia-friendly educational campaigns (see Fig. 1 for the timeline of the three-step co-design process). With regard to the present manuscript, it was wholly

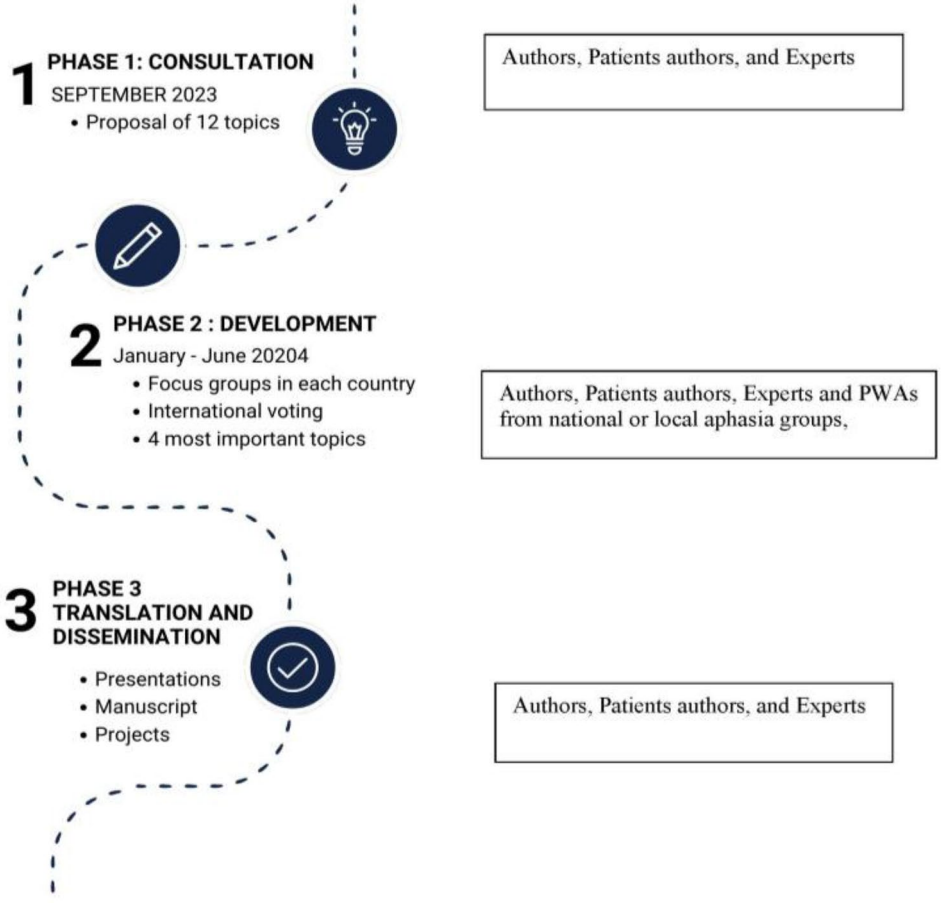


Fig. 1 The timeline of the co-design process, as detailed in the methods section

authored by researchers and perused extensively by PAs. In order to provide support for any residual language difficulties, the majority of PAs concentrated their critical review on specific sections of the manuscript, whilst all of the author researchers undertook a review of the entire document.

Translation and note-taking

JMA has French and Italian as its first languages and has C1-level proficiency in English and German. This means that JMA is capable of using the language fluently and effectively in complex academic, professional and social contexts. He possessed the ability to translate from French, Italian, German, and English. SR, who has Spanish as their first language and a C1 level in French, translated between Spanish and French. CF, who has German as their first language and a B2 level in English and Spanish, translated between Spanish and English. Furthermore, JMA used of AI-generated summaries, which were then distributed to the participants. These summaries are typically produced in English and subsequently translated into French and Spanish, with Italian and German translations available when required, utilising the basic pro version of the DeepL translation tool.

Paoli's ongoing process: qualitative and quantitative evidence of the impact of PPI

Evaluating the impact of patient and public involvement (PPI) on the whole process, experts, and outcomes is essential in participatory studies [2, 23, 24]. In this project, this impact was assessed in three ways:

1. Topic generation and adherence: The analysis sought to determine the proportion of the initial 12 topics proposed that were derived directly from PWA compared with those suggested by carers or laypersons. Furthermore, the adherence of participants during international online meetings at the time of voting was measured. The initial step in this process entailed the enumeration of the number of representatives in attendance at the international online voting meeting held on 3 June 2024 compared with the first meeting held in September 2023. Second, an analysis was conducted to ascertain the number of countries that had cast their votes among the participants of the meeting on 3 June.
2. PAs feedback: Persons who could not participate indicated by mail or in a following meeting the reasons for their absence. At the end of the study, an internally developed questionaire was sent to the PAs, asking them to reflect on their perceived role in shaping the results, their sense of being understood, and their understanding of the discussions. This self-rating questionaire asked particularly the following two questions: *How much did you feel listened to by others? How much did you understand what the others said*. Answer was written by the PA with a number: *0 = no; 1 = little; 2 = could be better; 3 = OK; 4 = very much).* The number was associated to a logo for better comprehension (see Appendix 4b). All PAs completed the questionnaire themselves, except for JS, who passed away before receiving it. For him, JMA and MC conducted the heteroevaluation, since they had been acquainted with JS for six years, during which time they had all served on the AIA Board. They had maintained consistent communication with JS via Zoom, WhatsApp (at approximately 20 instances) and during three face-to-face meetings.
3. Comparison with other studies: In the Discussion section, the results of this project are compared with findings from similar studies to contextualise the impact of PPI.

Results

The results of this study are presented in accordance with the three phases of the PAOLI (People with Aphasia and Other Layperson Involvement) framework [4], ensuring that the findings reflect each stage of consultation, co-design, and international voting, as described in the Methods section.

PAOLI phase I – foundation outcomes

Participation

In the initial two Zoom meetings, conducted in September and November 2023, the participating group comprised 11 PWA and 11 carers or laypersons (22 representatives in total), representing a total of 12 countries, out of the 24 national members of AIA: Argentina, the United Kingdom, French Switzerland, Mexico, Hungary, India, Estonia, France, Slovenia, Belgium, the United States of America, and Cyprus (Table 2). English was the common language used during the meetings. When participants encountered substantial challenges with the English language, the layperson or the translator (see Methods) provided assistance, either through translation or reformulation. Reasons for challenges reported by the other countries included difficulties in mobilising members for additional tasks, a lack of interest in international associations, a decline in collaborative habits following the COVID-19 pandemic, and challenges for some PWA in accessing virtual meetings rather than in-person formats.

A number of key proposals were put forward : CM & JDJ (France) emphasized the importance of addressing psychological and behavioural issues related to aphasia, such as emotional and social impacts. CL & NK (UK) suggested a comparative analysis of speech therapy

approaches across countries to identify best practices. AMP (French Switzerland) focused on understanding and documenting the intact capacities of PWA to challenge stereotypes and highlight functional strengths. JS (Slovenia) highlighted the overlooked area of aphasia's effects on sexual and intimate life, underscoring the need for support in this aspect of daily living. RV (Estonia), a speech therapist, stressed the issue of age-related hearing loss in PWA, which can complicate communication and therapy outcomes.

Proposed topics

A total of 12 topics were proposed across participating countries. These choices were derived from the majority of the participating countries that attended the inaugural Zoom meeting on 23 September, and were deliberated and endorsed in a subsequent meeting in November 2023. Of the twelve topics under consideration, one was proposed by a non-specialist and eleven by PWA. The subjects to be discussed are listed below, with the order of presentation determined by three factors: personal impact, interpersonal impact, and social consequences.

- Aphasia support in the hospital: the way in which caregivers and administrators integrate aphasia-friendly communication in their activities.
- Global speech and language therapy services: a comparison between countries.
- Hearing loss in PWA: the necessity of assessment and correction with hearing aids.
- The power of singing together: the way in which choirs of PWA and music therapies enhance the quality of life and communication skills of PWA.
- Self-confidence in aphasia: PWA need to regain not only communication skills but also self-confidence.
- Finding the energy to disagree: this issue is of particular pertinent to individuals living with aphasia who experience difficulties in mustering the necessary energy to express disagreement with others.
- Intimacy and sexual life after aphasia: this issue is relevant to PWA who experiencechallenges in their intimate and sexual lives following to the onset of the condition.
- Psychological changes specifically related to aphasia: this issue is particularly relevant for PWA who experience with psychological changes associated to the condition.
- Finding and selecting a job: the employment challenges encountered by PWA in the workforce, including identifying of suitable roles and accessing support services.
- State support: the role of government in enhancing the quality of life for PWA, encompassing the facilitation of administrative processes such as tax declarations, the provision of care support, and organising emergency medical transportation.
- The promotion of awareness of aphasia within society and within family units.
- The positive attributes of PWA and the strategies employed to built on these qualities.

The selection and ranking of topics were not imposed by researchers but emerged from facilitated local discussions, reflection, and consensus among PWA and their supporters. These findings reinforce the value of inclusive national-level PPI structures that allow individuals with communication disabilities to take the lead in defining what matters most.

PAOLI phase 2 – development phase

Participation and adherence

Representatives from Australia, German-speaking Switzerland, and Italy joined the initial expert group of 12 countries. The Belgian PWA withdrew. In total 14 National associations joined phase 2 (Table 3). In light of the fact that the various countries were able to organise their internal votes independently, the number of voting members within each country varied. A total of 122 participants, 110 of whom were PWA, participated in the national-level co-design sessions (see Table 2 from method section). An informal survey revealed that nearly all the PWA involved in the project had been living with the condition for at least two years.

At the June 3rd, 2024, online voting meeting, Argentina, India and Italy, although actively contributing to the discussions, were unable to submit votes. Consequently, among the initial 22 representatives present in September 2023, 15 representatives from 11 countries expressed national favourite topics. In instances where two representatives from a given national aphasia association were present, the national choice was presented and voted on by the leading representative only.

- Regarding the participation rate of the national aphasia associations, 11 out of the 14 national aphasia associations cast their vote, resulting in a country voting participation rate of 78% (see Table 4). All present countries participated in the discussion.
- Concerning the participants themselves, 15 participants from the 11 voting countries had all been present in phase 1 meetings, except for the Australian representative who was new. A comparison of the data from the September 2023 meeting, which was attended by 22 participants, with the data from the present meeting (15 participants)

Table 3 Countries in which the national aphasia association participated to the research project in the different phases: phase 1 (foundation Phase); phase 2 (development phase) and phase 3 (translational phase). The number of participants is described in the methods (Table 2)

Country	Aphasia Association and MR	Website	Phase of participation
*Argentina***	Fundación Argentina de Afasia "Charlotte Schwarz" MR : Paula Ryan[#] and Silvia Rubio	https://www.facebook.com/FundacionArgentinaDeAfasia/	Phase 1, 2, 3
Australia	Australian Aphasia Association MR : Damir Muftic[#] and Claire Bennington	https://aphasia.org.au/	Phase 2, 3
*Belgium**	F.E.B.A.F. (dissolved) Now Stroke and go	https://www.stroke-go.be	Phase 1 (observer)
Cyprus	The Aphasia Communication Team MR : Alexia Kountouri[#] and Marina Charalambous	http://www.stroke.org.cy	Phase 1, 2, 3
Estonia	Eesti Afaasialiit MR : Raili Vaidlo and Kulli Roth	http://www.afaasia.ee	Phase 1, 2, 3
France	Fédération Nationale des Aphasiques de France MR : Clotilde Marteel[#] and Jean Dominique Journet[#]	http://www.aphasie.fr	Phase 1, 2, 3
Hungary	AFÁZIA – Az Újrabeszélők Egyesülete MR : Zoltán Gáspár[#] and Fanni Eckhart	http://www.aphasie.hu	Phase 1, 2, 3
*India***	Aphasia and Stroke Association of India (ASAI) MR : Subhash Bhatnagar	http://www.aphasiastrokeindia.com	Phase 1, 2**, 3
*Italy***	Federazione Associazioni Italiane Afasici MR : Davide Crovetti[#] and Giuseppe Bobbo[#]	http://www.aitafederazione.it	Phase 2, 3
Mexico	Afasia Contacto MR : Beatriz González Ortuño	https://afasiacontacto.com/contacto/	Phase 1,2,3
Slovenia	Aphasia group of Združenja CVB MR : Jernej Sluga[#]	http://www.zdruzenjecvb.com	Phase 1, 2, 3
Switzerland (German)	aphasie suisse MR : Reto Strähler[#] and Jean marie Annoni	https://aphasie.org	Phase 2, 3
Switzerland (French)	aphasie Suisse MR : Joël Jeckelman[#] and Jean Marie Annoni	https://aphasie.org/fr/	Phase 1, 2, 3
United Kingdom	Aphasia Alliance UK MR : Colin Lyall[#], Hanka Mayhew[#] and Melanie Derbishire	https://aphasiaalliance.org	Phase 1, 2, 3
USA (Virginia)	National Aphasia Association MR : Javier Gil[#] and Maura English Silverman	http://www.aphasia.org	Phase 1, 2, 3

We added here the main representative(**s**) (MR) for the project quoted with a [#] if they were PWA. The Belgian participant* was not affiliated with a national association due to the dissolution of the Belgian national aphasia Association (F.E.B.A.F.) at that time, and he did not participate. Argentina, India and Italy ** initiated but did not contribute in phase 2, so did not vote. NB: some observers from different countries (chile, Uruguay, Bolivia) were sporadically present and showed interest in phase 3 meetings but did not participate to the research. Two members of Spanish national aphasia association (Asociación ayuda Afasia) integrated the discussion as observers in a later stage of phase 3 and are not reported in the current table since they did not participate to topics choice and voting

revealed that the adherence rate of participants had been 69%.

Participants who did not participate generally communicated via mail or WhatsApp or were excused by another national representative. There were several key reasons for declining participation. Firstly, there could be another representative present. Secondly, difficulties were encountered in attending meetings at fixed times because of the need to accommodate multiple time zones. Thirdly, fatigue and medical problems or therapies could impede with participation. The number of participating PWA was, however, nearly equal to that in the phase 1 meeting (10 instead of 11). Some PWA reported issues with understanding the content, despite the use of translation tools, both automatic and human. This ultimately could lead to their premature exit from a meeting before its conclusion.

Topic prioritization

The results of the voting are summarized in Table 4. As mentioned in the Methods section, each country allocated points to up to four priority topics. The country members rankings were sent to JMA (who organised the online meetings across the different phases). However, the decision was taken some countries to present only two or three priorities. During the final voting meeting, it was agreed that the topics of 'Intimacy and Sexual Life after Aphasia' would be integrated into the broader category of *Psychological Changes* to ensure appropriate representation.

The vote rankings obtained are given in Table 4. The aggregated results were as follows:

Table 4 Summary of first- to fourth-choice topics voted on by each participating country

Country	1st choice	2nd choice	3rd choice	4th choice
Argentina	No vote	-	-	-
Australia	Raising awareness	Psychological changes	Aphasia hospital support	State support
Cyprus	Raising awareness	Psychological changes	Aphasia hospital support	State support
Estonia	Hearing loss	State support	-	-
France	Raising awareness	Psychological changes	Aphasia hospital support	Energy to disagree
Hungary	Finding a job	State support	Raising awareness	Speech therapy
India	No vote	-	-	-
Italy	No Vote			
Mexico	Raising awareness	Speech therapy	Self-confidence	-
Slovenia	Intimacy/sex (integrated in Psychological changes)	Self-confidence	-	-
Switzerland (*German*)	Self-confidence	Raising awareness	Positive qualities	Psychological changes
Switzerland (*French*)	Self-confidence	Psychological changes	Raising Awareness	Positive qualities
United Kingdom	Raising awareness	Self-confidence	Finding a job	Singing together
USA (Virginia)	State support	Finding a job	-	-

Each 1st choice is given 4 points, the 2nd choice is given 3 points, the 3rd choice is given 2 points, and the 4th choice is given 1 point. Empty votes were counted as 0

1. Raising Awareness of Aphasia in the Family and Society: 27 points
2. Psychological Changes (including Intimacy and Sexual Life): 17 points
3. Self-Confidence After Aphasia: 16 points

The voting distribution showed some differences and heterogeneity between countries; for example, a topic such as "finding a job" was highlighted in Hungary and the USA but not in most other countries (see Table 4).

Justifications for priority topic selection

During the international Zoom meeting held on June 3, 2024, representatives from each participating country explained the rationale behind their selection of priority topics. These explanations, which were shared either directly by PWA or jointly with carers/health professionals, revealed common themes across countries. The key reasons are summarized below according to each prioritized topic.

Raising awareness of aphasia in society and families

This topic emerged as the highest priority across countries. The rationale included the following:

- Difficulty explaining aphasia: PWA consistently reported that aphasia remains poorly understood, even among close relatives and friends. Increased awareness was seen as a foundational step towards more inclusive communication and services.
- Impact on societal engagement: improving public understanding of aphasia could support better interaction between PWA and the general population, including guidance for both PWA and conversation partners on effective communication strategies.
- Accessible environments: several experts and involved PWA noted the need for better use of pictograms and visual support in public spaces, which would improve autonomy and participation for PWA.

Some examples of quotes concerning aphasia awareness included "*It's hard to explain aphasia because people don't know and don't have time to listen" or "We often don't dare to explain" (Joel Jeckelmann/JJ)* . Some national aphasia associations (like German Switzerland) proposed even suggestions from involved PWAs to improve knowledge on aphasia: "*First announce that you've had a stroke, then say : I have lost my words"; or "Use aphasia Card; Raise awareness, especially among people who know something about aphasia : explain that each person with aphasia* is *different*" *(Reto Straheler/RS).*

Psychological changes (including intimacy and sexuality)

Psychosocial adaptation after stroke has been highlighted as a major concern. Reasons included the following:

- Emotional isolation and vulnerability: experts and involved PWA described how aphasia disrupts spontaneity and leads to social withdrawal, with an increased risk of depression or suicidal ideation. Moreover, some PWA reported a sense of liberation from rigid social norms.
- Limited psychological support: there is a widespread lack of psychologists trained to work with aphasia, compounding emotional challenges.
- Intimacy and relationships: changes in romantic and sexual relationships, especially for those not in stable partnerships, were seen as important yet often neglected aspects of poststroke life. These were viewed as integral to the broader category of psychological changes.

Examples of quotes concerning Psychological Changes brought by some representative (particularly from French Federation) included : "*To break down preconceived notions and regain a normal quality of life with those around them, people with aphasia need kindness as they rebuild their lives step by step …*"; "*We must trust in time. it i s always important to maintain communication by being creative*"; or "*Population's challenge is to trust people with aphasia" (Clotilde Marteel/CM)* .

Self-confidence and identity after aphasia

This topic addressed the internal challenges PWA face when trying to rebuild their confidence and assert themselves:

- Loss of self-esteem: many experts and involved PWA described significant reduction in self-confidence and feelings of social inadequacy.
- Group communication challenges: it was identified that the commencement of meetings, in particular those occurring in unfamiliar or more substantial group settings, represented a pivotal instance of discomfort.
- Need for communication strategies: experts and involved PWA emphasized the value of learning how to convey their views, assert disagreement, and actively participate in group contexts.

A 4th important subject was discussed, although not ranked in the top three*: awareness of speech therapy and hospital engagement with aphasia*

This topic addressed health care system gaps and inconsistencies in poststroke support for PWA:

- Rehabilitation disparities: experts and involved PWA wished to reflect on their rehabilitation journeys and compare their experiences across countries, especially regarding the availability and quality of speech therapy and psychoeducation.
- Self-training and autonomy: there was interest in exploring national differences in self-management approaches and the role of structured self-directed therapy.
- Training for communication partners: a recurring suggestion was the need for training programs for conversation partners (e.g., carers, health professionals, and the public) to improve dialogue with PWA.

PAOLI phase 3 – translational phase

The third phase focused on translating the identified priorities into action. Plans for dissemination were developed following three online meetings conducted in French, Spanish and English between September and October 2024. These meetings targeted the top two priority topics and aimed to explore practical initiatives for raising awareness and support.

Participation and adherence

The online meetings were split into sessions by language. Participation increased to more than 50 individuals total across language-specific sessions (19 in the English-speaking session, 8 in the French-speaking session, and up to 40 in the Spanish-speaking session) in comparison to the non-specific language sessions. With this language specificity and a higher number of participants, the participants were more willing to express themselves, and the chairperson was forced to limit the speaking time of each participant. Moreover, it was necessary to summarize the contribution of each participant so that every participant could understand.

Proposed actions and disseminations

Actions for the top priority: *Raising awareness of aphasia in society and the family*

The participants (PAs, Authors, Expert Laypersons and PWA) collectively proposed a series of initiatives, including the following:

- A formal proposal to establish an annual AIA Aphasia Day was presented at the 2024 AIA General Assembly Following this, 3 dates were proposed and a subsequent email vote was organised the following month to determine the final date. The majority of associations voted in favour of 20 October (a date which corresponds approximately to the date of the AIA General Assemblies). The objective of this event is to promote political and media advocacy for aphasia awareness.
- It was recommended that greater inclusion of individual PWA and regional associations in AIA activities be facilitated by formalising the status of AIA observers. These are participants who are not official members and cannot vote at general assemblies, but who can listen, participate and express themselves in our meetings. New members (National federations of Croatia, Belgium again, Canada/Quebec) and observer (association of Bosnia Cameroon) have joined AIA.
- Participants advocated that encouraging testimonies from PWA should be presented at international conferences in order to promote real-life experience and visibility. For instance, the AIA board organised a symposium called "Communication challenges in long-term stroke" at the 2025 Life After Stroke forum in Prague (https://www.elasf.org/wp-content/uploads/2025/04/Programme-ELASF2025-web.pdf). At this event, two PWA experts explained the importance of

increasing awareness. In 2026, AIA has proposed and been granted approval for two events: a symposium at the 2026 Science of Aphasia International Meeting and a seminar at the 2026 conference of the French Aphasia Association.

- The development of aphasia-friendly educational campaigns must be a collaborative effort between AIA and LIHA members. Particularly in the context of the first International Aphasia Day on 20 October 2025, AIA has been active in promoting an International Aphasia Awareness Campaign led by Queensland University https://www.justgiving.com/campaign/qarc-uq-aphasia-awareness?utm_medium=CA%26utm_source=CL and the Aphasia Friendly Teaching programme for learning how to communicate with people living with aphasia (https://aphasiafriendlycanada.ca/aphasia-friendly-world-training/),

Actions for the second priority: psychological and intimate changes after aphasia

This theme was addressed in November 2024 and later through the following initiatives:

- Three short online presentations were given by three stroke survivors, two of whom were professional psychologists with residual aphasia. These talks highlighted the following:

  1 The importance of personal agency, such as engagement in physical and social activities.
  2 The role of trust, resilience, and long-term psychological adjustment.
  3 The concept of "narrative reconstruction" as a therapeutic and identity-building strategy. A further online conference (title: Aphasia and its implication in daily life) has been prepared and is proposed in May 2026 by one of the PAs (JG), for teaching purposes.

- In addition, further personal testimonies were shared by two PAs (JS and HM) during a symposium called "Communication challenges in long-term stroke" at the 2025 Life After Stroke forum in Prague. Another PA (AC), and a member of French National Aphasia Federation, will present aphasia-related psychological challenges at the 2026 Science of Aphasia Conference. Such interventions can contribute to the identification of practical support strategies and promote dialogue between countries.

Next steps: dissemination

Health professionals expressed a strong interest in publishing the findings of this co-creation and priority-setting process in a specialised PPI peer-reviewed journal. These actions would support the broader dissemination of outcomes and advocacy for international collaboration in aphasia-focused initiatives. PWA proposed a series of initiatives to enhance awareness of aphasia. These include the delivery of educational courses and the presentation of lived experience testimonies at scientific meetings. Furthermore, the PWA has suggested the organisation of awareness-raising actions in each country during national aphasia days.

The translational phase further emphasized the leadership role of PWA in shaping awareness and advocacy goals. By guiding dissemination priorities and proposing concrete actions, PWA demonstrated that PPI in aphasia research can extend beyond consultation into sustained, empowered engagement.

Measurement of the impact of PPI on the whole process

Topic generation and adherence to the process

In total, among the 12 proposed topics (see below), 11 were proposed by PWA, and one was proposed by a health professional participant. The early discussions laid the foundation for a genuinely co-produced process, where lived experience shaped the direction of the study from the outset. With respect to adherence, as mentioned before, the number of PWA was quite stable across the meetings (11 PWA participants at the first meeting and 10 at the voting meeting) but increased when language-specific meetings were proposed during PAOLI phase 3. In the meetings of September and October 2024, which were split into sessions by language, participation increased to more than 50 particpants. In the first meetings, some PWA reported difficulties with comprehension due to translation issues, despite the use of automatic translation tools.

PAs feedback:

The involvement and self-ratings of the eight PAs, based on the internally developed questionaire are presented in Table 5. Five PAs were present and meaningfully involved in all phases of the project, while three were active in two of the three phases. Among the eight PAs, five actively proposed topics, all participated in national voting, seven took part in the final international voting, and all contributed to the translational phase. Three PAs presented the results of this study in a dedicated session at the 2025 European Stroke Forum, which was held in Prague in March 2025 and was attended by 150 persons.

The overall self-rating of impact was rated as "optimal" by five PAs and "good" by three (mean rating: 3.6 out of 4) in the questionaire.

While none of the PAs wrote the manuscript, they were given explanations about how it was constructed

Table 5 Roles of coauthors with aphasia across the different phases of the process and their self-ratings of effective participation

Authors	Presence	Role	Self-rating of impact	Self-rating of being listened to
JS	All phases	Lead, Pr, NV, IV, A, AF	4*	3*
CM	All phases	Pr, NV, IV, A	3	4
JG	All phases	Pr. NV, IV, A	3	3
RS	Phase 2, 3	NV, IV, A,	4	4
CL	All phases	Pr, NV, IV, A	4	3
DC	Phase 2, 3	NV, A, D	4	3
HM	Phase 2, 3	NV, IV, D	4	4
AK	All phases	Pr. NV, IV, A, D	3	3

Note: Pr is the initial proposal of topics; AF = aphasia-friendly communication; NV stands for national discussions and vote; IV is the international final vote on June 3rd, 2024; A is the presentation of actions; and D is dissemination through presentation. Ratings are assigned from 0 to 4 (0 = not at all; 1 = insufficient; 2 = sufficient; 3 = good; 4 = very good).*The rating for JS (deceased before manuscript submission) was evaluated by the two corresponding authors

and made efforts to read it as best as they could (i.e., the plain English summary and the part they felt important for them, such as their name, bibliographic informations, and the precise paragraph were they were mentioned, or where the first authors asked to control). It took them more than one week to read the manuscript. All the PAs felt satisfied with their feeling of being listened to. Only three out of eight felt that they optimally understood the discussions during the online meetings; three others rated their comprehension as good, and two rated it as sufficient. (See Table 5 for role and rating details).

Discussion

This study on aphasia research priorities presents a unique collaborative experience involving PWA, health professionals, and carers from 14 different countries to confirm the ability of PWA to play an active role in a participatory research project and to identify their own thematic priorities. The methodology adhered to the PAOLI phases, encompassing co-design [4], and involved a structured, two-step communication process: digital meetings for global exchange facilitated discussions among diverse international stakeholders, and local decision-making through national meetings. Eleven of the 14 countries (78% of countries) voted on ranking priority topics. The four primary topics identified were as follows: 1) raising awareness of aphasia in society/family, 2) psychological changes in aphasia, 3) self-confidence after aphasia, and 4) raising awareness of the need for speech therapy and hospital attitudes towards aphasia. The first three topics were not directly related to language impairment but rather to the social and personal consequences of this loss of communication efficacy. This finding reinforces the value of inclusive national-level PPI structures that allow individuals with communication disabilities to take the lead in defining what matters most.

This initiative also demonstrates that PWA can actively participate in, and lead, the identification of international research priorities when supported through inclusive and accessible methods [25]. It also shows that PWA are generally not confident in writing or correcting a scientific or clinical manuscript. This study provides a concrete example of how PPI principles can be applied across multiple countries and languages, moving beyond consultation to co-production.

Our results also suggest that PPI has a significant impact on the selection of priority topics [26], particularly in shaping research directions [11]. While members of AIA acknowledged and supported the importance of rehabilitation approaches and aphasia therapy, as well as psychological well-being (including the impact of aphasia), they also stressed the importance of aphasia awareness among families and society [11] and discussed the topic of self-confidence and resilience in social relationships. In particular, awareness was seen as essential for improving communication performance and fostering a greater understanding of communication impairments.

One of the key points discussed in this study was adherence to online meetings and participation in voting. After the first meeting, the adherence of PWA decreased to 69% and then remained relatively stable throughout the process, and the number of participants even increased during phase 3, particularly after the introduction of language-specific sessions. The initial decrease has also been reported in other patient organizations [27]. The subsequent stability of the initial PWA experts after eight months at the final international voting online meeting demonstrates the feasibility of engaging PWA in sustained international co-creation processes [28], providing that they could rely on clear messages, efficient translation systems (through participants or artificial intelligence). Moreover, during the third phase of the project, the participants requested that meetings be conducted in their native language. This demonstrated the challenges associated with using a non-native language during online meetings for PWA.

The voting participation of 78% (11 countries voted out of the 14 countries that participated in the meeting) in the vote on June 3rd, 2024, an online international meeting, confirms the enthusiasm to participate of PWA representing their national associations and of the laypersons involved in the process. This finding indicates that PWA can participate actively despite communication challenges, provided that conditions are supportive. The three national associations who did not vote have provided retrospective explanations for their decision, citing insufficient local support during the process: one association had insufficient communication channels to increase

the number of national members; the other was not prepared, and there was no time to organize national-level co-design sessions; and for the third national aphasia association, the co-design sessions were not sufficiently structured and led, so no conclusion could be drawn from the discussion. Five of the eight PAs were active in all three phases of the process, and three presented their experiences and data at international conferences, together with layperson co-authors. Their involvement in the decision-making process was rated between good and optimal. The self-rating of "being listened to" was consistently reported as sufficient to optimal. The findings of the study indicated that PWA participation in online sessions is more effective when conducted in the PWA's native language. Furthermore, in Phase 3, a French-speaking online meeting was conducted in a small group of seven participants, and it was determined that in this session the engagement was more efficient. Finally, the leader's use of goodwill during online sessions fosters greater PWA involvement, but each intervention must be meticulously controlled and summarised to ensure a meaningful exchange.

As is the case in other PPI studies, the primary challenge encountered was the promotion of participation at the inception of the project [29]. Initially, only 12 out of 22 AIA country members participated in the project. As mentioned in the results, the reasons included difficulties in mobilising members and a decline in collaborative habits following the COVID-19 pandemic, as well as challenges for some PWA in accessing virtual meetings rather than in-person formats. PWA may face more barriers in meeting online due to limited experience, skills or support with technology, and may find it more difficult to communicate, build a connection and express themselves. Using a combined approach of online and face-to-face interactions could increase participation [30] but this option was not possible in our study. It was a priority for the organising team to foster a sense of friendship, informality, and a supportive communication environment during online meetings, as has been demonstrated when creating peer-led aphasia support groups [31]. Moreover, although people with communication difficulties may feel more effective in local projects than in international online-supported projects, the positive experiences of "Aphasia Cafés" have shown that PWA may become very involved in both online and in-person regular social get-togethers [32]. Rather than viewing non-participation as a limitation, these challenges stress the need to overcome specific barriers before initiating research with PWA and reflect on the need for the continued development of flexible, accessible models of PPI suited to populations with communication difficulties [33]. The fact that all the authors, laypersons and PWA participated in their free time and received no financial compensation could also have prevented a larger implication in terms of project initiation. The participation and adherence through project completion could be considered sufficient, despite the multilingual and multicultural context of PWA [29]. The non-participation of some individuals was attributed to various issues, including the logistical challenges of attending meetings at designated times, owing to the necessity of adjusting to different time zones. For example, particularly in the initial phase, priority was given to PWA in South America and Europe, so PWA in Australia, where it was 3 AM, could not attend. In the 2nd and 3rd phases, we could better distribute the timetables, particularly by adapting them to the language used in the different discussion meetings (e.g., English, French or Spanish). It is known that health-related issues, such as fatigue, particularly during afternoon meetings, contribute to non-attendance [34]. We observed that although difficult, trans-linguistic communication is possible in the aphasic population with a supportive and tailored environment [35]. One of the authors (JMA) attempted to translate the messages into different languages. The recent development of artificial intelligence translation has involved the use of Zoom digital tools. Notwithstanding their presence, several PWA were found to be incapable of formulating adequate responses or arguments for discussion, particularly in instances where they had not received sufficient coaching or preparation [36]. This challenge echoes the findings of other studies highlighting the varying abilities of PWA to participate actively in discussions, depending on their level of aphasia severity and prior experience in academic settings [34]. PWA may be more active in proposing research ideas than in proposing priorities and data analyses [36]. PWA with mild to moderate chronic aphasia were generally able to contribute meaningfully, particularly during semi-structured discussions.

From a logistical perspective, national associations face challenges in securing appropriate structures and funding to support onsite meetings. However, several groups favoured online meetings, which were more cost-effective and flexible. Notably, participants with experience in PPI research emphasized the importance of building relationships before meetings through one-on-one introductions, short sessions, and regular breaks. In our experience, reunions lasting 1.5 hours with a 10-minute break in the middle were optimal for in-person events, whereas 60-minute sessions were optimal for online meetings [37]. PWA usually mentioned difficulties during meetings, such as ignoring background noise, controlling negative emotional reactions, focusing, slowing down/taking breaks [38], and possibly necessitating specific training before digital meetings. Several strategies have been employed to address these challenges. For example, a speaking participant (Reto Straehler) prepared written

comments on psychological changes following aphasia, using approximately 90 hours to prepare his seven-minute speech. Another participant, who was preparing for a presentation at the Prague European Life After Stroke Forum (ELASF) by the Stroke Alliance for Europe, rehearsed her talk 30 times to ensure that it fit within the allocated 10-minute timeframe.

Thematic priorities: aphasia awareness and psychological issues

The first thematic priority, 'raising awareness of aphasia', was particularly emphasized by two-thirds of the participating countries. This focus reflects the widespread issue of low aphasia awareness, with studies consistently reporting that fewer than 20% of the general population, including many health professionals, is familiar with aphasia. This convergence in high ranking for social priorities shows how challenging the social impact of chronic aphasia remains. In the above cited study, the highest priority was to "improve communication", which is one of the reasons mentioned by our PWA to increase aphasia awareness. The priorities found in our study are different than the ones reported by the International Collaboration of Aphasia Trialists (CATs), which is a global collaboration of multidisciplinary aphasia researchers. According to this research network spanning 33 countries, the overarching research themes were : (i) evidence-based interventions for people with aphasia, (ii) effective interventions to support those communicating with people with aphasia, (iii) cross-linguistic assessment and core outcomes for aphasia research, (iv) predictors of language recovery, and (v) clinical implementation of research findings [9]. The differences between our results and CATs' conclusions are probably due to due to methodological differences.

As reported by PWA, poor awareness was not considered a health problem but may have disastrous consequences (see, for example quotes in the results section). It decreases the self-esteem of PWA and prevents the development of strategies to improve communication. Enhancing awareness of aphasia and providing effective communication resources contributes to increased confidence among communication partners, particularly between PWA and other peoples, and improves the overall effectiveness of their interaction [35]. Changing society's attitude towards stroke survivors with aphasia is important, according to PWA and family members. This change could be achieved through increased awareness and education about aphasia [39]. Recent studies have concluded that "aphasia awareness", as seen by PWA, involves understanding that aphasia does not affect intelligence and insisting on the importance of communicating effectively with someone with aphasia [40, 41]. These points were frequently highlighted during the group discussions, underscoring the need for public education and training in aphasia communication strategies. The proposal to establish an Aphasia International Day has been put forward to identify a suitable time for the international community to coordinate aphasia-specific actions. Despite the prevalence of national days, weeks, and months dedicated to raising awareness of aphasia, it seemed beneficial to designate a specific time for international collective action, such as awareness campaigns and personalised resources for communication training [42]. The co-created priorities arising from this study demonstrate that when PWA are empowered to influence research agendas, they place significant emphasis on psychosocial and environmental issues that may be overlooked in clinically driven research. This finding emphasises the importance of maintaining inclusive PPI approaches in aphasia and stroke care.

The second priority, 'psychological changes associated with aphasia', was also discussed in depth, given the high frequency of mood disorders associated with aphasia [43]. According to an Australian organizational survey and a clinical audit with retrospective extraction of medical records PWA are less likely to have their mood assessed after stroke (23% versus 30% in stroke patients without aphasia) but, when reported in the medical files, show higher mood impairment (38% versus 28%) [44]. The specific psychological guidelines addressing long-term emotional disturbances in patients with aphasia reflect a gap in clinical practice. Specific therapy for mental health support, in person or via telehealth, such as that proposed by the Aphasia PRISM program, can offer valuable intervention cues during the acute phase [45]. While some systematic studies have explored interventions for diagnosed mood disorders, their efficacy is generally limited to mild depression, with less success in addressing moderate or severe depression [46]. Such psychological changes may lead to suicidal ideations, which may go unnoticed in people with communication disorders, and aphasia is also perceived by professionals as a barrier to assessments and interventions for suicidality [47].

Despite repeated efforts to develop comprehensive screening and assessment scales for the psychological aspects of PWA patients, such scales seem to be surprisingly absent in the literature [48]. Rehabilitation interventions such as goal setting, psychosocial support, communication partner training, and narrative therapy have been found to be beneficial, but these areas may be underprioritized by caregivers. Competence in both suicidality- and aphasia-friendly communication strategies should be improved in stroke care and rehabilitation [47], including participation in meaningful and accessible nonverbal activities [49] (see, for example, the personal reflections of RS in Appendix 3).

Furthermore, specialised social networking within community groups for PWA, including communication with psychologists who have experienced aphasia, appears to play a significant role in enhancing awareness of psychological changes. These professionals utilise their personal experiences to offer valuable insights into the psychological aspects of living with aphasia. One health professional participant (Javier Gill) emphasized the importance of narrative frameworks for understanding aphasia: the chaos narrative (characterised by a loss of hope), the restitution narrative (focused on recovery), and the quest narrative (viewing illness as an opportunity for growth). This framework seems to help the spontaneous rebirth of PWA [50]. Another psychologist PWA in the group (Clotilde Marteel) insisted on trusting the PWA mourning process to find a new "self" and project [51]. These frameworks resonated with participants and contributed to a broader understanding of the psychological impact of aphasia.

The topic of 'intimacy and sexual relationships' also emerged, with younger PWA more actively contributing to the discussion. There were diverging opinions on the relevance of this issue, with some individuals in stable marital relationships feeling that it was less important, whereas those without partners argued for its inclusion in the aphasia community discourse, both in terms of sexuality and self-knowledge. It has been established that acquired communication impairments can have hamper sexual life. Nevertheless, this subject is rarely addressed in research on acquired communication disorders [52]. This gap suggests that incorporating discussions of intimacy and sexuality into aphasia care may be beneficial.

Language barriers and technological solutions

An additional challenge discussed was the language barrier in international meetings. While English was chosen as the common language for communication, participants who were non-native English speakers, particularly those from French- and Spanish-speaking countries, required simultaneous translation. This accommodation added complexity and time to discussions, particularly during the first meetings, as it took a couple of sessions to the participant (whether with or without aphasia) to learn how to use the zoom translation system. Progressively technological solutions, such as artificial intelligence (AI)-driven translation tools, were introduced to facilitate communication. While these tools were effective for participants who understood written language, they significantly enhanced the inclusivity of the discussions, allowing for more authentic exchanges. Instant oral translation was repeatedly discussed throughout the project. However, its implementation remained challenging at that time. The success of AI-based tools and multilingual facilitation in this study shows that technology can enable rather than hinder participatory research with people who have communication needs. This finding is particularly relevant as PPI expands into global, multilingual settings.

Limitations

A key limitation of this study is the 69% participation rate at the first meeting, which could be due to logistical challenges such as time zone differences, health issues, or a lack of preparation. Some PWA experts struggled to engage meaningfully in discussions, especially those with more severe aphasia. One example was ZG, from the Hungarian expert group, who had a very low expressive capacity (a severity of 2 on the Aphasia Severity Rating Scale) and could only express himself through a therapist who helped him through the process (FE). Future studies could address these issues by offering more flexible schedules, preparatory sessions, and support for experts with varying degrees of aphasia severity. Additionally, language barriers pose challenges, particularly for non-English speakers. While translation efforts helped, they extended meeting times and may have hindered engagement. Future research could benefit from advanced multilingual tools to facilitate communication. Additionally, the narrow focus of this study on three, eventually four, thematic priorities may have overlooked other important issues, such as employment or social participation. It should be noted that, the decision to select 4 priority topics was proposed at the end of the Phase 1 meetings in order to maintain a variety of options while simultaneously limiting the number of topics to facilitate discussion in the final meetings. Future studies should broaden the scope to include these areas. Notably, these limitations reflect broader systemic challenges in operationalising inclusive PPI, especially across linguistic, cultural, and cognitive differences. Nonetheless, the ability of many experts living with aphasia and locally involved PWA to contribute actively, even across these barriers, demonstrates the viability of inclusive international research coproduction.

Future directions

Future research should focus on increasing participation by offering flexible meeting times or asynchronous participation options. Tailored communication support and training sessions in small groups could improve meaningful involvement. Addressing language barriers through better multilingual tools or providing dedicated translators for each group would enhance inclusivity. Furthermore, studies should include a broader range of themes, such as the impact of aphasia on communication, social awareness, psychological consequences, and self-esteem, to provide a more comprehensive understanding of PWA's needs. Evaluating the effectiveness of

aphasia awareness campaigns and training programs for health care professionals would also provide valuable insights for improving aphasia care across different cultural and regional contexts. This project offers a scalable, replicable model for embedding PPI into international aphasia research. Finally, future work should explore how co-created research priorities influence funding decisions, policy development, and clinical innovation.

Conclusion

Despite the complexities of coordinating a multilingual, international, and inclusive PPI initiative, participation throughout the process was strong, and the engagement of PWA was both active and meaningful. The high-quality discussions reflected the impact of accessible materials, careful preparation, and sustained support. The priorities identified, ranging from societal awareness and emotional well-being to intimacy and therapy access, highlighted the psychosocial realities of living with chronic aphasia and the need for person-centred rehabilitation. The study also revealed a widespread desire for reassurance about personal competence and the availability of quality, ongoing aphasia care. Crucially, the project moved beyond discussion to real-world action, including the proposal of an International Aphasia Awareness Day, public education campaigns, and training initiatives for the wider community. These outcomes exemplify what is possible when PWA are not only included but also empowered to co-create research. Above all, this work highlights that PWA are not just capable contributors; they are essential partners in shaping the future of aphasia research and services. The multilingual, cross-national, and co-produced nature of this study offers a replicable model for inclusive, impactful research in aphasia and related fields.

Appendix 1. The Guidance for Reporting Involvement of Patients and Public 2 Long Form (GRIPP2-LF) reporting checklist

Section and topic	Item	Reported on page No
Section "PAOLI'S ONGOING PROCESS: qualitative and quantitative evidence of the impact of PPI": Abstract of the paper		
1a: Aim	Report the aim of the study	3
1b: Methods	Describe the methods used by which patients and the public were involved	3
1c: Results	Report the impacts and outcomes of PPI in the study	3
1d: Conclusions	Summarise the main conclusions of the study	4
1e: Keywords	Include PPI, "patient and public involvement," or alternative terms as keywords	1–2
Section "Psychological changes (including intimacy and sexuality)": Background to the paper		
2a: Definition	Report the definition of PPI used in the study and how it links to comparable studies	6
2b: Theoretical underpinnings	Report the theoretical rationale and any theoretical influences relating to PPI in the study	7–9
2c: Concepts and theory development	Report any conceptual or theoretical models or influences used in the study	7–9
Section 3: Aims of the paper		
3: Aim	Report the aim of the study	8–10
Section 4: Methods of the paper		
4a: Design	Provide a clear description of the methods by which patients and the public were involved	10–16
4b: People involved	Provide a description of patients, carers, and the public involved with the PPI activity in the study	13–20
4c: Stages of involvement	Report how the PPI is used at different stages of the study	13–20
4d: Level or nature of involvement	Report the level or nature of PPI used at various stages of the study	14–23
Section 5: Capture or measurement of PPI impact		
5a: Qualitative evidence of impact	If applicable, report the methods used to qualitatively explore the impact of PPI in the study	n/a
5b: Quantitative evidence of impact	If applicable, report the methods used to quantitatively measure or assess the impact of PPI	18–19
5c: Robustness of measure	If applicable, report the rigour of the method used to capture or measure the impact of PPI	n/a
Section 6: Economic assessment		
6: Economic assessment	If applicable, report the method used for an economic assessment of PPI	n/a
Section 7: Study results		

Section and topic	Item	Reported on page No
7a: Outcomes of PPI	Report the results of PPI in the study, including both positive and negative outcomes	23–32
7b: Impacts of PPI	Report the positive and negative impacts that PPI has had on the research, the individuals involved (including patients and researchers), and wider impacts	23–35
7c: Context of PPI	Report the influence of any contextual factors that enabled or hindered the process or impact of PPI	35–38
7d: Process of PPI	Report the influence of any process factors that enabled or hindered the impact of PPI	35–38
7ei: Theory development	Report any conceptual or theoretical development in PPI that emerged	n/a
7eii: Theory development	Report the evaluation results for theoretical models, if any	n/a
7f: Measurement	If applicable, report all aspects of instrument development and testing (e.g., validity, reliability, feasibility, acceptability, responsiveness, interpretability, appropriateness, precision)	n/a
7 g: Economic assessment	Report any information on the costs or benefits of PPI	n/a
Section 8: Discussion and conclusions		
8a: Outcomes	Comment on how PPI influenced the study overall. Describe the positive and negative effects	38–42
8b: Impacts	Comment on the different impacts of PPI identified in this study and how they contribute to new knowledge	38–42
8c: Definition	Comment on the definition of PPI used (reported in the Background section) and whether or not you would suggest any changes	n/a
8d: Theoretical underpinnings	Comment on any ways that your study adds to the theoretical development of PPI	n/a
8e: Context	Comment on how contextual factors influenced PPI in the study	38–44
8f: Process	Comment on how process factors influenced PPI in the study	38–44
8 g: Measurement and capture of PPI impact	If applicable, comment on how well PPI impact was evaluated or measured in the study	n/a
8 h: Economic assessment	If applicable, discuss any aspects of the economic cost or benefit of PPI, particularly any suggestions for future economic modelling.	n/a
8i: Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so that others can learn from this study	42–46

Appendix 2. Message sent by mail to AIA members at the launch of the project (start of the foundation phase)

"We would like to invite you to a Zoom meeting with people with aphasia from different countries*, as well as carers or professionals (to help with the translation/discussion).*

During this meeting, we will ask you to share 2–3 topics *that you feel are* most important *to discuss.*

Before the Zoom meeting, please talk to your local aphasia and choose a person to represent your country/region at the meeting on September 25th, 2023.

The meeting will be in English. We will do our best to translate the most important points into French and Spanish".

Appendix 3. Personal experience of psychological changes after aphasia (German-speaking participant, RS)

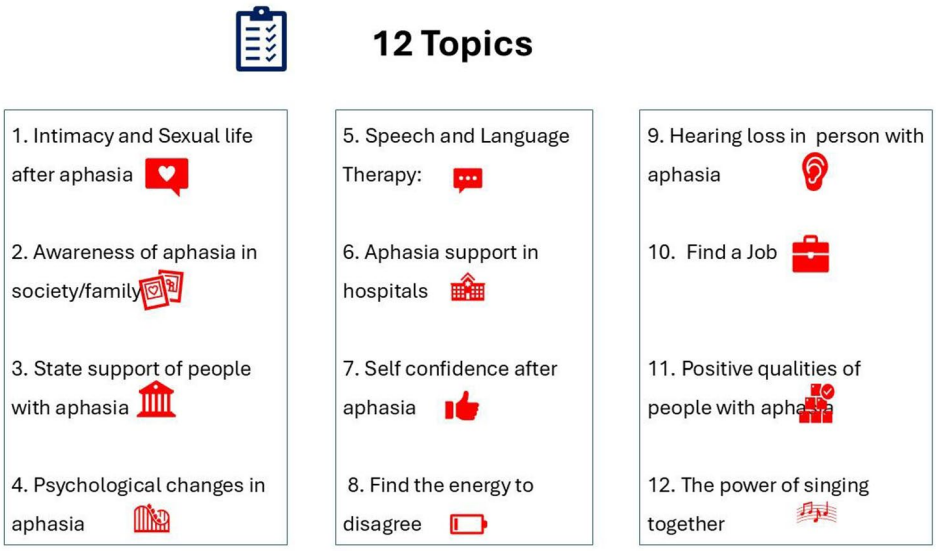
a. Aphasia can prevent spontaneity: tendency to isolate
   - From my experience I agree that spontaneity is limited also depending on grade of aphasia.
   - Friends and family have to be involved from day one. Someone has to take the lead and be able to understand and "translate" in order to prevent misunderstandings.
   - Friendships need to be cultivated from my side.
   - I need to keep up my friendships and not wait till someone else takes the first step.
   - Invite, call or write family and friends.
   - Be nice and thankful to them otherwise you will lose them.
   - I also agree that aphasia can lead to isolation, especially when living alone.
   - The possibility to fall into depression is high.
   - There is a risk of committing suicide.

b. At the same time, people may feel freer
   - In my opinion I don't feel freer because of aphasia.
   - I have a responsibility of what I am saying.
   - On the other hand, I may have changed my view of things and see those more relaxed.
   - With aphasia I am not able to always express myself very clearly and may say things in incorrect ways. This could hurt my opponents, but because I am suffering from aphasia, they take it easier.

c. Need to mourn in order to start a new life
   - No matter how you approach aphasia, most importantly you have to accept the illness.
   - A new chapter in your life has begun.
   - Only with acceptance will you be able to improve your life .
   - Mourning may lead to depression; a negative down spiral starts.
   - My aim is to reach a good speaking level.
   - In my case mourning would prevent me from improving my skills.
   - Gain a positive attitude and work with apps on tablets or phones as much as possible in order to improve your aphasia.
   - I work around 30 hours weekly with exercises in apps or on paper.
   - I also work hard on my physical condition.
   - In my opinion the combination of sport, physio and working on my language has helped me immensely to improve my skills.

Appendix 4. Example of Graphic used for the questionnaires and summaries of the online meeting

a) Summary of the meeting, example of PPT slide :



b) Self rating questionnaire : Answer sheet.

Abbreviations

PPI	Patient and Public Involvement
PWA	People with Aphasia (in general; in the present text = Persons living with chronic aphasia)
GRIPP	Guidance for Reporting Involvement of Patients and the Public
PAOLI	People with Aphasia and Other Layperson Involvement
ASRS	Aphasia Severity Rating Scale
BDAE	Boston Diagnostic Aphasia Examination

Acknowledgements
We acknowledge the AIA and LIHA thematic group members : Paula Ryan (Buenos Aires, ARG, paulavpryan@gmail.com), Othmar Walser (Bregenz, AT), Damir Muftic (Townsville, AUS), Renata Mancopes (Santa Maria, BR), Jean Maurice Mordasini (Lausanne, CH), Joël Jeckelman (Fribourg, CH, anne.joel@sunrise.ch), Crisanto Farese (Luzern, Switzerland, info @aphasie.org), Olivier Grandjean (Chatel-Saint Denis, CH & BE), Jelena Bartolovic Vuckovic (Zagreb, CR) Helena Briales (Madrid, ES), Paloma Blanco (Madrid, ES), Raili Vaidlo and Külli Roht (Tallinn, EST, info@afaasia.ee), Jean-Dominique Journet (FNAF, Dompierre-sur-Besbre FR), Zoltán Gáspár (Budapest, HU), Giuseppe Bobbo (Udine, IT, https://www.aita-fvg.it), Beatriz González Ortuño, DrHC (Ciudad de México, MEX, hola@afasiacontacto.com), Subhash Bhatnagar PhD (Milwaukee, USA & New Delhi, IND, subhash.bhatnagar@mu.edu), Hariklia Proios PhD (Thessaloniki, GR), Melanie Derbyshire (Sevenoaks, UK, maderbyshire@gmail.com), Nick Cann (Chepstow, UK), and Maura English Silverman, MS (Apex, USA, maura@aphasia.org) for their effective presence and participation in the discussion. We also honour with deep sorrow our coauthor, Jernej Sluga, President of the Aphasia International Association and a Slovenian disability rights champion, who initiated and participated in this work and died unexpectedly in June 2025.

Author contributions
With respect to the role of the authors, SR, JMA, MC and JS initiated the project and organized the meetings. All the authors participated actively in the meetings and proposed the initial 12 topics. CM, JS, JG, FE, CL, DC, AK, HM, JMA, MC and SR organized voting and/or voted across countries and contacted the members of the expert group. JMA and FE provided meeting summaries, and JMA and MC wrote the main manuscript text and prepared the figures. CB edited the manuscript and corrected two paragraphs in the discussion. CM and JG participated in the discussion on psychological consequences. All the authors reviewed the manuscript according to their reading capacities.

Funding
No external or internal funding was received, except for au support of 400 Euros to JS and HM for participation in an in-presence meeting.

Data availability
The data were generated during the current study and support the conclusions of this article. Any data queries and requests should be submitted to the corresponding author, Prof Jean-Marie Annonie MD PhD, for consideration.

Declarations

Ethical approval
The study was conducted online and internationally; it received ethics approval from the Cyprus Bioethics Committee institution of the second corresponding author: CNBC EP 2023.01.02.

Consent for publication
All the authors and the experts in the group gave consent for publication of the manuscript, including JS, who gave his consent for publication before his passing.

Consent to participate
The authors and members of the expert group participated in the discussions and the voting and wanted to have the results of their votes published. All the authors provided consent to participate in the preparation of the manuscript

and expert groups provided consent for their information to be reported there.

Competing interests
The authors declare no competing interests.

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Received: 11 August 2025 / Accepted: 22 May 2026
Published online: 08 June 2026

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