

# Combining Stakeholder-Engaged Research and the Life Participation Approach to Aphasia

## A Pilot Survey on the Aphasia Group Experience

*Gretchen Szabo, Jessica Obermeyer, Angelique Cauthorn, Michael Hornbostel, and Joe Flacco*

Stakeholder-engaged research (SER) is common in many health-related fields and is gaining momentum in aphasiology. Stakeholder-engaged research shares many of the same goals and values as the Life Participation Approach to Aphasia (LPAA). The aim of this article is to identify how these two frameworks complement each other and can be applied to aphasia research. This is accomplished by first defining SER and highlighting associated benefits and challenges and then exploring the ways that SER and LPAA's core values support each other. The authors' SER project is discussed to illustrate the synergy between SER and LPAA and highlight the potential research and clinical impacts of expanding the use of SER in aphasiology. **Key words:** *aphasia, Life Participation Approach to Aphasia, LPAA, patient and public involvement, person-centered, PPI, research partners, SER, stakeholder-engaged research*

**A**TREND toward engaging stakeholders in research is evident across health professions and builds naturally from an increased

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**Author Affiliations:** *Adler Aphasia Center, Maywood, New Jersey (Ms Szabo); Department of Communication Sciences & Disorders, University of North Carolina at Greensboro, Greensboro (Dr Obermeyer); and Aphasia Advocate and Stroke Survivor with Aphasia, Adler Aphasia Center, Maywood, New Jersey (Ms Cauthorn and Messrs Hornbostel and Flacco).*

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focus on translational research and implementation science (Ahmed & Palermo, 2010; Goodman & Sanders Thompson, 2017). Despite this, true engagement of stakeholders in research related to communication disorders, particularly in aphasiology, has not been routine practice and has only recently begun to gain momentum (McMenamin & Pound, 2019). Although engaging stakeholders in aphasia research does present a unique set of challenges, preliminary tools and supports exist to begin to address those challenges (Hinckley et al., 2019; Hinckley

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**Corresponding Author:** *Gretchen Szabo, MA, Adler Aphasia Center, 60 W Hunter Ave, Maywood, NJ 07607 ([gszabo@adleraphasiacenter.org](mailto:gszabo@adleraphasiacenter.org)).*

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& El Khouri, 2021; Malendowski et al., 2021; McMenamin & Pound, 2019; McMenamin et al., 2021). Further, stakeholder engagement in research complements participation-based approaches to aphasia intervention, such as the Life Participation Approach to Aphasia (LPAA) (Chapey et al., 2000). In this article, we (1) define stakeholder-engaged research (SER) and its potential benefits and challenges; (2) examine how the principles of SER and LPAA complement and support one another; and (3) describe an example SER project to illustrate how SER studies are consistent with LPAA.

### STAKEHOLDER-ENGAGED RESEARCH

This section presents a working definition of SER, highlights SER benefits and challenges reported broadly across health care research and specifically related to aphasia research, and introduces the connection between SER and LPAA.

#### SER definition

Stakeholder engagement in research incorporates a range of approaches that involve shared decision-making opportunities among stakeholders across all phases of research (Goodman & Sanders Thompson, 2017). Stakeholders include individuals or organizations with an interest in the research or who may affect or be affected by its outcomes (Heiden & Saia, 2021). Key stakeholders in aphasia research often include researchers, survivors with aphasia, co-survivors/care partners, speech-language pathologists (SLPs), student clinicians/researchers, and related professionals. The stakeholders can also vary based on the project. For example, hospital administrators may be stakeholders for a research project on the value of training nurses in the neurointensive care unit to use supported conversation techniques but would not be stakeholders for a project on community-based aphasia group participation.

Various operational definitions are used to discuss stakeholder engagement. Goodman

and Sanders Thompson (2017) propose a three-tiered categorization of stakeholder engagement with categories representing either stakeholders with genuine engagement (*engaged participation*) or stakeholders without meaningful engagement (*nonparticipation* and *symbolic participation*). The *engaged participation* category includes three subgroups: collaboration, patient-centered, and community-based participatory research. Engagement in the form of collaboration involves the active involvement of researchers and other stakeholders in the project's design and implementation, interpretation of data, and reporting of findings with shared benefits across all involved stakeholders. In patient-centered engagement, patient stakeholders set the research priorities and have control of all stages of the research with researchers helping guide the project forward. Lastly, community-based participatory research provides for equitable partnerships and shared decision-making among all stakeholder partners. Categories that do not involve meaningful engagement incorporate outreach and education efforts (*nonparticipation* category) and seeking feedback or assistance for a portion of the project or at specific stages of research (*symbolic participation* category). The operational definition of SER used herein reflects engagement that falls under Goodman and Sanders Thompson's (2017) *engaged participation* category. For a visual breakout and expanded description of these stakeholder engagement categories, refer to Goodman and Sanders Thompson (2017, p. 487).

#### Benefits of SER

The process of engaging stakeholders has been documented across a range of health care research and preliminary research has begun to evaluate some of the benefits. Brett et al. (2014) found that engaging patients and the public increased the relevance of research topics and outcomes, supported cultural relevance of research topics and methods, expanded recruitment networks, and increased accessibility, dissemination, and

implementation of research findings. Esmail et al. (2015) identified improved research quality, relevance, and dissemination related to stakeholder engagement. In addition to reported improvements to the research itself, stakeholders and communities involved in research report feeling empowered and valued (Brett et al., 2014; Esmail et al., 2015).

Within aphasiology, similar benefits have been reported. Notably, Shiggins et al. (2022) reported both on the process of codeveloping an aphasia-accessible survey to assess feedback from survivors with aphasia who participate in research and on team members' perceived benefit from participating in collaborative research. McMenamin et al. (2021) shared the experience of two people with aphasia who worked as coresearchers and reported benefits including increased intellectual engagement, camaraderie, motivation, and confidence. Similarly, stakeholders engaged with Project BRIDGE, a national effort to enhance stakeholder engagement in aphasia research in the United States, have reported benefits related to SER including enhancing research relevance and representativeness, providing opportunities to apply experiences, reframing professional priorities, and offering synergy that motivated projects (Hinckley & El Khouri, 2021; Malendowski et al., 2021).

Despite preliminary research offering support for SER, the need for systematic measurement and evaluation of the impact of SER has been identified. To address this, evaluation frameworks and tools to measure the stakeholder experience and impact of engagement have been proposed. Proposed tools and frameworks come from the general health care literature (Concannon et al., 2014; Esmail et al., 2015; Tembo et al., 2019) and the aphasia literature (Shiggins et al., 2022).

### **Barriers to and facilitators of SER**

Despite the theoretical and reported benefits of SER, numerous implementation barriers have been identified across health care research. The increased time that is required to successfully engage stakeholders has been consistently noted as a barrier across research

disciplines (Martínez et al., 2022; Ocloo et al., 2021), including aphasiology (Hinckley & El Khouri, 2021; Malendowski et al., 2021). Additional barriers that have been identified in both aphasia and broader health care research include: the lack of knowledge or awareness of or access to research by the lay public, the need to adapt existing or implement new procedures to support the collaboration, competing agendas, and existing beliefs or biases about the research process (Hinckley & El Khouri, 2021; Malendowski et al., 2021; Martínez et al., 2022; Ocloo et al., 2021).

Strategies to facilitate successful SER may help address some of the barriers. Facilitators identified across disciplines include training *all* research team members, clearly identifying roles and expectations, planning for collaboration, willingness to participate, and formalizing the engagement process (Martínez et al., 2022; Ocloo et al., 2021). Additional strategies to facilitate successful engagement of coresearchers with aphasia have also been reported and include using aphasia-friendly trainings and supports, expanding beyond traditional communication methods, training team members in aphasia and communication strategies, and identifying the language demands of different roles (Hinckley et al., 2019; Hinckley & El Khouri, 2021; Malendowski et al., 2021; McMenamin et al., 2021; McMenamin & Pound, 2019).

### **SER and aphasia research**

Although participation-based intervention and patient-centered care are increasingly commonplace in aphasia service delivery, the adoption of SER is not as prevalent in aphasiology. Stakeholders, particularly survivors with aphasia and co-survivors/care partners, have traditionally served as research participants or consultants rather than as research partners (Hersh et al., 2021). As a result, engagement of stakeholders in aphasia research has not broadly achieved Goodman & Sanders Thompson's (2017) definition of genuine engagement. However, there are growing examples of *engaged participation* of stakeholders in aphasia research (Bislick

et al., 2022; Cruice et al., 2021; Horton et al., 2021; McMenamin et al., 2015; Shiggins et al., 2022).

### **SER and LPAA**

As a consumer-driven model, LPAA seeks to empower consumers to participate and collaborate in their recovery to achieve meaningful participation in life (Chapey et al., 2000). In describing the LPAA model, Chapey et al. (2000) identified five core values intended to guide aphasia research, assessment, and intervention:

1. Enhancement of life participation is the goal.
2. All who are affected by aphasia have a right to services.
3. Measures of success include documented life changes.
4. Intervention targets include personal and environmental factors.
5. Services are available at all stages of aphasia.

LPAA includes a call to action for both clinicians *and* researchers to broaden and refocus their scope. Although LPAA has significantly shaped the content of aphasia research by expanding the scope of assessment instruments, outcome measures, and clinical service delivery approaches, the application of LPAA principles to the aphasia research process has been more narrowly applied. Similar to LPAA, SER seeks to enhance research outcomes by empowering stakeholders to influence and direct all stages of research.

### **OUR PROJECT**

Considering the SER framework, benefits, and facilitators discussed earlier, we suggest that LPAA's core values and the principles of SER complement and support one another. To explore this, we present an example SER project completed by the authors in 2019. The project aimed to describe the group experience of people with aphasia and represents the patient-centered subgroup within Goodman and Sanders Thompson's (2017) engaged participation category.

### **The idea**

This project was initiated by coauthor J.F. J.F. participated in an aphasia group, which included reviewing aphasia-friendly versions of research as one of its activities. While doing this, he expressed an interest in presenting at a professional conference, and this idea immediately piqued the interest of another group member, coauthor A.C. Working with co-author J.O., an SLP and researcher who was the group facilitator, the team decided to focus the project on better understanding the aphasia group experience for people with aphasia by surveying them on what they like about attending aphasia groups, what they would want to change about their aphasia groups, and if attending an aphasia group impacted the communication of people with aphasia. This topic was relevant to all of them.

### **The team**

The group reached out to coauthor G.S., Adler Aphasia Center's research coordinator and program director for community-based aphasia groups, to recruit other members with aphasia who were interested in being part of the research team. After these initial stages, the research team was finalized and included three research partners with aphasia (A.C., J.F., and M.H.) and two SLP research partners (J.O. and G.S.). Only one of the team members had participated in SER prior to this project. The team had additional support from another Adler Aphasia Center member with aphasia and two Adler Aphasia Center staff members during the data collection and analysis stages.

### **Design**

The project concept and focus were initiated by the research partners with aphasia, and the next stage of the project included defining the roles of all the members. The team felt it was important for the project to be a true collaboration and that research partners with aphasia should have the opportunity to define their level of involvement in each stage of the research process. The team decided that the best method of answering

the proposed research questions would be to complete an interview and survey using aphasia-friendly methods. The SLP research partners would be in charge of making the aphasia-friendly survey with input from the research partners with aphasia on question content and format. The research partners with aphasia would administer the survey while the SLP research partners or other Adler Aphasia Center staff assisted with writing notes during the interview to facilitate data collection. Recruitment was completed by all members of the team from Adler Aphasia Center's community-based aphasia groups.

### **Procedure**

The research partners with aphasia surveyed 15 members of these groups and data analysis was completed by the SLP research partners. The results suggested that the majority of respondents attend groups for social reasons such as the chance to meet people (12), practice talking (13), seeing friends (12), and helping others (11). Over half of the participants also reported that attending groups made them feel better about their communication, more confident, and less nervous. The most reported factors that participants did not like about aphasia groups were that they were not long enough (7), had boring activities (5), and were not one-on-one therapy (4).

An abstract was written primarily by the SLP research partners with editing and input by the research partners with aphasia. The abstract was accepted at the 2019 Aphasia Access Summit in Baltimore, after which a poster was created for presentation by all members of the team. The research partners with aphasia took the lead on presenting the results at the Aphasia Access Conference, which met life participation goals for the research partners with aphasia.

### **Beyond the pilot project**

After the project concluded, each of the team members participated in ongoing efforts to increase stakeholder engagement in aphasia research. An SLP research partner (G.S.)

and a research partner with aphasia (M.H.) each served in leadership roles with Project BRIDGE's ongoing efforts, and all team members served as Project BRIDGE mentors. The research partners with aphasia also expanded their participation in new activities related to aphasia research and advocacy at various levels, including coauthoring additional conference presentations and sharing their experiences with various aphasia groups.

One research partner with aphasia (A.C.) now identifies as an aphasia advocate, core-searcher, cohost of a podcast (<https://www.buzzsprout.com/1959705>), member of the board for an aphasia nonprofit, and president and cofounder of the Aphasia Resource Collaboration Hub (ARCH), a community of aphasia stakeholders dedicated to sharing information on aphasia services and research in the greater Philadelphia region. When reflecting on her involvement in this project, A.C. notes that it "showed me there was a need and a path forward and showed what I could bring to the equation. It allotted me the opportunity and confidence to go off and do my own thing because without that, maybe the things that came next, like ARCH and Brain Friends, don't happen. I needed to engage in it [the SER project] as part of the process of shedding the old and becoming the new. It allowed me to flourish in other aspects of my recovery and advocacy."

### **LAYERING SER ONTO LPAA'S CORE VALUES**

Our team's pilot project serves as an example of engaging stakeholders in research while also using the research as a method to achieve and expand the participation goals of research partners with aphasia. Further, when considered through the lens of LPAA, our project reflects some of the ways that LPAA's core values complement SER and how SER may be a way to address LPAA goals. A discussion of each of the LPAA core values has been layered onto our research team's experience with SER to demonstrate the synergy between the two frameworks.

### **Core value 1: Enhancement of life participation is the goal**

A fundamental component of LPAA is promoting consumer-driven health care and supporting participation goals that are meaningful to the person with aphasia. Similarly, by engaging stakeholders in research, research may better address the needs, priorities, and interests of people affected by aphasia and result in improved clinical implementation. Further, participation in SER may be an avenue to enhance life participation for some people with aphasia.

Enhancement of life participation was central to our research project because the project was initiated by a team member with aphasia and the other team members with aphasia were recruited because the project supported their self-identified, life-participation goals. As a salesperson prior to his stroke, J.F.'s words regularly influenced others. The project gave him the opportunity for his words to have influence again. As he states, "Salesman. Stroke hurt bad. People [at conference] got it." Similarly, A.C. reflects, "It gave me the opportunity to do that [present at a conference], and it is still providing those opportunities for me to get the word out about aphasia . . . and to be helpful to the clinicians, researchers and my fellow aphasians to do better, and to be better, to know that better communication is attainable." Further M.H., who was an editor prior to his stroke, reflects on how the project gave him tools to reengage and rebuild language when he notes, "I heard the same sort of things as others in the community [survivors with aphasia] hear. Like you're never going to talk or write again; that this is your life now. It really bummed me out a lot, but instead of having mountains [standing in the way], stuff like this project was the climbing gear to push over those mountains."

### **Core value 2: All who are affected by aphasia have a right to services**

LPAA expanded the scope of aphasia intervention to support all people affected by

aphasia by including immediate and broad social networks and community or social systems that may facilitate or be impeding achievement of enhanced life participation in much of the same manner that SER seeks to engage all stakeholders impacted by research. Expanding our research teams and clinical scope to acknowledge the interconnected nature of our needs and goals can impact the individuals and communities we serve.

Although our project did not examine traditional services or seek to examine programming available through Adler Aphasia Center for co-survivors/care partners or the community (e.g., co-survivor/care partner support groups, education/outreach), the stakeholders on our team represented the key individuals involved with the program we were examining, a twice monthly, community-based, aphasia support group for survivors with aphasia. Had the scope of the project been larger, we would have identified additional stakeholders who should have been represented. There are documented examples of SER teams in the aphasia literature that represent broader engagement of stakeholders. See Bislick et al.'s (2022) "Team Yoga" for a representative example.

Reflecting on the need to engage stakeholders, M.H. notes, "There is data but in a lot of ways it is the wrong data for people with aphasia. Researchers mostly look at this stuff from afar, and the only way to get better results is to talk to the people who actually have aphasia." A.C. further suggests that researchers should "get as many voices in the room that expand your way of thinking, not necessarily your knowledge, but your way of thinking and include those voices in your research so the research has a full array of experiences, thoughts, and approaches represented."

This core value can also be more broadly layered onto SER when we consider that access to research findings by the lay public has traditionally been limited, in terms of both the access to published research articles and the presentation and language used in the articles. Further, the need to enhance access

to research findings also complements LPAA's inclusion of environmental factors, which has been discussed later under core value 4.

The primary intended audience for our team's project was clinical and research SLPs at a professional conference. Although we did not expect stakeholders representing other categories, such as survivors or co-survivors, to be present, our team summarized the findings in an aphasia-friendly format to support the presentation of the poster by the research partners with aphasia and to facilitate their sharing the project with their individual aphasia support groups and with members of other Adler Aphasia Center programs.

Furthermore, the research partners with aphasia prioritized the need for aphasia-friendly summaries for all subsequent presentations they were involved in, recognizing the need to balance the professional standards of clinical/academic conferences with access to the information by the lay public, especially survivors with aphasia. All the research partners with aphasia noted that involvement in this project opened their eyes to the available aphasia research and the need to get information about aphasia research to "everyone we possibly can" by expanding where and how research is reported. J.F. further stressed that the opportunity to partner on a research team changed his view of research when he noted, "Before research hard. Now understand. Fun. Like it!"

### **Core value 3: Measures of success include documented life changes**

LPAA stresses that outcome measures should address quality of life and achievement of individual life participation goals. Similarly, SER also seeks to strengthen research outcomes through the identification of measures that are meaningful to the stakeholders who will be directly impacted by them. The growth of assessments that measure beyond the language impairment represents a key application of LPAA to research practice (select examples include Haley et al., 2010; Hilari et al., 2003; Simmons-Mackie

& Damico, 2001; Simmons-Mackie et al., 2014). Importantly, LPAA-informed assessment is consistent with what stakeholders identify as important treatment outcomes and is reflected in the Research Outcome Measurement in Aphasia (ROMA) consensus statement, which identifies a core outcome set for aphasia treatment research that includes measures of language, communication, quality of life, emotional well-being, and patient-reported satisfaction with treatment and impact of treatment (Wallace, Worrall, Rose, & Le Dorze, 2019; Wallace, Worrall, Rose, Le Dorze, Breitenstein, et al., 2019). Stakeholder identification of meaningful outcomes may facilitate researchers' ability to better measure and evaluate what is important to people with aphasia.

While our research project itself did not seek to broadly document life changes for the participants completing the survey, it did aim to understand the perceived experience and impact of participation in an aphasia group. Most of the group members we surveyed identified psychosocial aspects of aphasia groups as the most rewarding and wanted a variety of activities offered. When reflecting on why examining the aphasia group experience was a research priority, our coresearchers with aphasia highlighted their beliefs that aphasia groups have the potential to significantly impact life participation for individuals with aphasia. M.H. noted that the topic was important because he felt his participation in an aphasia group helped him more than individual speech-language therapy but that it seemed there was more research on and funding for individual therapy.

Including research partners with aphasia in the data collection was intended to make research participants more comfortable sharing information about their group experience. Responding to questions asked by their peers should facilitate sharing more than discussing the group experience with an SLP (Porter et al., 2009). Additionally, for the research partners with aphasia, the opportunity to participate on the research team and present the results met their identified life enhancement

goals and served as a springboard to identifying and pursuing additional life participation goals, as previously discussed. M.H. embraced additional opportunities to use his prior editing experience to offer valuable feedback on Project BRIDGE training materials, additional conference posters he coauthored, and aphasia-friendly summaries. Reflecting on the impact of his participation, M.H. notes that it allowed him to “achieve goals I didn’t know I wanted.”

**Core value 4: Intervention targets include personal and environmental factors**

LPAA and SER both function within a framework that promotes consumer participation and engagement. LPAA’s inclusion of personal and environmental factors has expanded the scope of research and clinical focus over the past two decades and is reflected across the clinical research that has been conducted over that period. We suggest that layering LPAA onto SER may allow the research process itself to become an avenue to targeting personal and environmental factors for research partners with aphasia.

Our project incorporated both personal and environmental factors. As mentioned in the previous section, the data collected aimed to examine the firsthand experiences of people with aphasia participating in groups and our findings noted personal gains that were attributed to participation. Beyond that, the coresearchers with aphasia all perceived personal gains from their engagement in the research process and noted improved confidence and self-esteem and reduced anxiety as some examples. A.C. notes that participation made her feel “very accomplished, victorious, and very good about not only what I had participated in but that I had enhanced and helped, where my opinion mattered. There’s not many opportunities when you have brain damage for that to occur. You wind up isolating yourself in a way that your footprint becomes smaller and smaller, and this gave me an opportunity for my footprint to enlarge.” Similarly, J.F. noted the broad impact of participation when he shares, “After stroke,

sad, lonely, frustrated. Now, happy. Try new things.”

Similarly, our project incorporated environmental supports across all aspects of the research process to improve access by research partners with aphasia and survey participants. Aphasia-friendly materials were used to share information with coresearchers with aphasia, in-person meetings were used rather than relying solely on email, and the survey used in the project incorporated a range of communication supports and response modalities. Importantly, and as previously noted in the section earlier that discusses LPAA core value 2, aphasia-friendly summaries were created to ensure that the survey results were accessible by individuals with aphasia and the lay public. All the research partners with aphasia noted that the environmental supports provided were sufficient to maintain their participation throughout the project. A.C. reflected that the SLP research partners on the team kept her “involved, engaged, informed” and that the research partners with aphasia “were never an afterthought but in the room, which is why we feel a sense of pride and responsibility” related to the project.

**Core value 5: Services are available at all stages of aphasia**

In the same way that LPAA broadened the clinical and research community’s consideration of services across stages of aphasia and recovery, SER highlights the need to expand engagement to all stages of research. Hersh et al. (2021) proposed a model to support the ethical inclusion of research partners with aphasia across the research lifecycle and noted that preparing for involvement is a critical stage that informs all elements of the research process. Further, engagement in research does not require that all research partners serve all roles and all members of the team should plan for the loss or addition of various stakeholders throughout the project lifecycle. Engagement of stakeholders may also be key to ensuring that aphasia research is identifying and addressing the needs and gaps across all stages of aphasia. Another



consideration to how LPAA and SER may work in tandem across stages of recovery relates to the impact of the engagement process on stakeholders. Stakeholder participation in research can serve as a catalyst to returning to clinical services due to increased knowledge of available interventions/supports or interest in supporting goals related to research partnership itself.

Although participants in our project were in the chronic stage of aphasia, with a mean post-onset time of 62 months, and the majority had been participating in aphasia groups for over 2 years (average length of participation = 31 months), we did not include time post-onset as exclusion criteria and sought to include as wide a range of aphasia participants as possible. Further our team's research partners with aphasia were at various times post-stroke (A.C.: 1 year, J.F.: 10 years, and M.H.: 4 years). For individuals with aphasia with an interest in research partnership, it could be that there is a certain point in the recovery process that research engagement may have the greatest impact or be of more interest. J.F., who initiated the project with his desire to present at a conference, was further post-stroke and had been speaking with graduate students about aphasia once a semester for a few years prior. A.C. notes the opportunity was at the right time to "pique my interest and allow me to flourish in other aspects of my recovery" whereas M.H. believes if he had the opportunity to participate in research from the beginning, the early years of recovery would have been "different in a lot of ways" and he would have "known what was possible sooner."

## IMPLICATIONS AND FUTURE DIRECTIONS

The purpose of this article was to explicitly explore how LPAA and SER frameworks complement each other and apply to the research process. In addition to piloting the aphasia group survey, our project introduced the process of SER to most of our team. Our experience serves as an example of the potential synergy between SER and LPAA. Compared with other health-related fields and when considering the incorporation of LPAA principles into assessment and clinical practice, aphasia research has lagged in incorporating stakeholders as true research partners. However, there are a growing number of SER projects in aphasiology that demonstrate the potential that comes with engaging those impacted by aphasia research and begins to address the challenges associated with SER. As stakeholder engagement in aphasiology continues to gain momentum, consideration of measures to document and evaluate the engagement process and assess the outcomes are critical to ensure that we are achieving the intended benefits and meeting stakeholder needs and expectations. Importantly, future SER projects should consider documenting the SER experience itself and including detailed methodology on the engagement process (see Shiggins et al., 2022, for example). Greater adoption of SER practices may further develop and expand on existing research that incorporates LPAA values ensuring that future research truly has the greatest impact on those affected by aphasia.

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