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Building Research Initiatives by Developing Group Effort (BRIDGE): Patient-Partners in Aphasia Research

Alejandro Brice, Ph.D.¹ and Jacqueline Hinckley, Ph.D.¹

ABSTRACT

Researcher-initiated research often has little or no input from the groups who will be affected by the results of the research. The aim of this project was to describe practices of embracing patient-partners (i.e., individuals with aphasia and spouses/family members) in research. Six webinars were developed for both researchers and patient-partners that were required prior to participating in a joint conference that focused on collaborative research teams. The conference was designed based on an appreciative inquiry approach. Including patient-partners into research priorities and planning has been accomplished across various health domains in the United States, but this was the first organized national effort, in the United States, to support the inclusion of people with aphasia and their families as active partners in the research process. Consequently, it is hoped that future aphasia researchers also include patient-partner teams into their research process for more ecologically valid outcomes.

KEYWORDS: Aphasia, Patient centered care, Collaborative research teams, Mixed Methods

Learning Outcomes: As a result of this activity, the reader will be able to (1) discuss means for collaborating with people with aphasia, their families, clinicians and researchers in the research process; (2) discuss

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facilitating strategies for increased patient partner involvement and interaction in research teams; (3) discuss facilitating strategies for increased patient partner communication in research teams.

Researcher-initiated investigations often have little or no input from the groups who will be affected by the results of the research. Hinckley et al¹ stated that patient-centered research encompasses the consumers' (i.e., patient, family, caregivers) perspectives in shared decision-making. Patient-centered care in clinical practice incorporates the patient's viewpoint as a priority in all decision-making. Patient-centered care focuses on (1) the patient as an individual; (2) patients are granted a voice in decision-making and not solely by clinicians and researchers; and (3) decision-making becomes a shared responsibility.¹ Patient-centered care incorporates evidence-based practice in that it involves patient engagement and patient perspectives at the forefront of care and research. In addition, Mitchel et al² stated that patient-centered care is the "gold standard" of quality care.

Orgas³ affirmed that more quantitative and qualitative research is needed to document what works best for implementing patient-partners and a patient-centered care approach into the research environment. This approach emphasizes that patients have a right to decision-making in research that affects them and also that research is a shared responsibility between researchers and patients.¹ Involving patients with a patient-centered approach in the entire research process has become mainstream in clinical fields such as medicine.⁴⁻⁶ Turnbull et al⁵ indicated that patient involvement in research is a collaborative process among patients and researchers throughout the entire research endeavor.

The patient-partner research trend was noted in the United Kingdom by researchers in the *British Medical Journal (BMJ)*'s Editorials and Education and Debate sections in 1999 [volume 319(7212)] when they pioneered a thematic issue on this topic. Smith (*BMJ* editor) stated, "More sensibly, there are three ways in which doctors may consult with patients. In the paternalistic model, the doctor decides what to do. In the informed model, the patient decides after the doctor explains the options. This

theme issue of the *BMJ* celebrates and explores a middle way: the shared model, where doctor and patient decide together what action to take."⁷ For example, Wilson⁸ stated that, "... it has long been accepted that a person with a particular condition can play an important, and sometimes a leading, part in their own care and in the management of their disease...." The *BMJ* now requires a patient and public involvement statement in all of its publications. Goodare and Lockwood⁹ stated that, "The implications for medical journals are clear. Besides insisting on informed consent from trial participants, they should set new standards for consumer consultation at all stages of clinical research submitted for publication." Vat et al¹⁰ affirmed that patient-partners are crucial in helping, designing, and managing research projects.

Vat et al¹⁰ also believed that patient-partners can be engaged at all levels of therapeutic care and research. Once considered as individuals who had research performed on them, patients are now included in the entire research process including design, development of research, planning, and dissemination of results.¹¹

Turnbull et al⁵ outlined five levels of patient-partner research participation. These levels can also be applied to patient-centered clinical therapy. Level 1 reflects minimal involvement with no decision-making; levels 2 and 3 reflect family members becoming involved as advisory board members and occasionally as reviewers or consultants; level 4 is where patient-partners act as on-going consultants; level 5 is where patient-partners act as co-researchers; and level 6 is where the researchers serve as ongoing consultants to the patient-partner researchers.

Similar to Turnbull et al,⁵ Singler et al¹¹ provided four models of patient engagement including patients as advisory board members, as steering committee members, and as co-investigators. Singer et al's¹¹ levels of patient involvement include (1) patients as subjects; (2) patients as consultants; (3) patients as advisors; and (4) patients as researchers.

Smith et al⁶ identified numerous instances where patient-partners in research served merely as tokens to the other end of the spectrum where patient-partners are valued with full empowerment and involvement. When patients or others who will be affected by research are incorporated into planning, prioritizing, and/or preparing research methods or activities (i.e., patients as co-investigators), several potential benefits can be achieved.^{4,5,9,12-15} A review of several studies of patient-centered care programs and individuals with aphasia follows; please note that most of these care programs do not fully embrace patient-centered care and their limitations are noted.

PATIENT-CENTERED CARE PROGRAMS AND APHASIA

The patient-centered care approach revolves around the two key principles of patient rights and patient voices. The patient-centered approach to research incorporates these aspects. It is this integration into research that has been problematic for some researchers, that is, patient-centered research is patient driven and not researcher driven.¹ In addition, patient-centered research is clinically focused on patient outcomes. Hence, a review of patient-centered care will provide background for the types of research and communication strategies to use with individuals with aphasia in patient-centered research.

Stroke and aphasia are some of the leading contributors to adult disabilities.¹⁶ Stroke survivors experience long-term difficulties at many points in their recovery and rehabilitation. These difficulties may include memory loss, cognitive impairments, communication difficulties (in any or all modes), social isolation despair, inability to carry out activities of daily living, and other issues.¹⁶ A common complaint among individuals with aphasia and their family members/caregivers is that after short-term therapy is finished, the individual with aphasia and their family/caregivers feel that they are abandoned.¹

Nayeri et al¹⁶ found that patient-centered care programs were more effective than traditional programs with family members being more adherent to rehabilitation programs. Better health outcomes were reported for those who participated in the family and patient-

centered care program, e.g., fewer instances of pneumonia, respiratory infections, reduced bedsores, motor dysfunctions, urinary tract infections, and stroke recurrence. The bridge between patient-centered clinical practice and researching individuals with aphasia still needs to be conducted.

Moffatt et al¹⁷ developed an electronic daily planner using an approach involving active patient participation for individuals with aphasia. Their plan was to develop technology that could be easily used and adopted by individuals with aphasia and support activities of daily living after discharge from a hospital and/or therapy. The study of Moffatt et al¹⁷ provides a minimal person-centered care approach. Although Moffatt et al's¹⁷ intent was to assist individuals with aphasia, the participatory design was still researcher directed as the authors consulted with only one individual with aphasia in identifying areas where technology could be put to use. Hence, patient-centered research should incorporate the voices of multiple individuals with aphasia.

It has been documented that individuals with aphasia after a stroke are more prone to social isolation.¹⁸⁻²⁰ Individuals with aphasia may also experience reduced quality of interactions, less contact with others, and diminished communication opportunities. All communications with individuals with aphasia need to be aphasia-friendly, accessible, and understandable. Reduced abilities to communicate may lead to increased instances of social isolation.

Buhr et al¹⁸ developed an aphasia-friendly social networking application for individuals with aphasia and their family members. They utilized a model that emphasized active participation and action. The participatory action model addresses issues pertinent to the stakeholders: in this case, individuals with aphasia. Buhr et al¹⁸ gained insight into developing their social networking application. Buhr et al¹⁸ found that their web application, AphasiaWeb, was successful in assisting individuals with aphasia interact with friends, share experiences, and share their identity. Even individuals with low linguistic ability were able to access the AphasiaWeb application through the use of photographic posts. Buhr et al¹⁸ addressed

patient-centered therapy through consulting with individuals with aphasia. Both the approaches used by both Moffatt et al¹⁷ and Buhr et al¹⁸ (according to the levels proposed by Singler et al¹¹) are at Singler et al's second level and Turnbull et al's⁵ levels 2 and 3 in patient-partner research, i.e., demonstrating only minimal involvement with patients⁵ as research consultants only. These studies represent only basic levels of patient participation^{4,11} and patient-partner research engagement.²¹⁻²⁶ Other levels include collaboration in the evaluation of treatment programs, participation in data collection, and offering guidance, and the involvement includes participation as co-researchers in the investigation.^{23,24}

Harmon et al¹⁹ incorporated some aspects of patient-partner therapy through the use of social validation and client interviews (i.e., patient voices). Their social validation approach stresses the importance of speech treatments for the "direct consumer" (i.e., the individual with aphasia). The first level of social validation is where goals are important to consumers (i.e., patient driven). Collaborative identification is crucial. Another step was that Harmon et al¹⁹ asked patient-partners what therapy techniques were deemed suitable (i.e., to give the patient choices in their therapy). Harmon et al¹⁹ also provided choice of techniques to patient-partners for use during intervention. The features, lacking by Harmon et al,¹⁹ were to allow the patient-partners to participate in data collection and offer feedback and guidance in forthcoming therapy plans. Consequently, patient rights through patient involvement were missing.

Ross et al²⁵ developed an aphasia-accessible yoga class for individuals with aphasia. Ross et al²⁵ found the following barriers to implementing this patient-centered approach to developing a communicatively accessible group activity: (1) lack of collaboration with key stakeholders; (2) lack of aphasia awareness with yoga instructors; (3) non-aphasia-friendly advertising; (4) limited support from yoga providers; and (5) limited knowledge of aphasia and stroke from the yoga instructors, that is, the complex communication requirements of working with individuals with aphasia. By making communication accessible, Ross et al²⁵ made the point of moving beyond a clinician-directed

approach to a client-directed approach, the key element behind person-centered therapy. While applauding their²⁵ efforts at incorporating patient voices, their study lacked patient involvement other than as research participants. In conclusion, the participatory action model is, in essence, a patient-centered approach to solving clinical problems, but its implementation must be complete by having individuals with aphasia as co-investigators.

When patient-partners experience a communication disability like aphasia, there are special challenges to address in the preparation, training, and collaboration processes.²⁶ Perhaps the first and most obvious challenge is the communication issue itself.²⁷ All aspects of communication must be done in an aphasia-friendly and accessible manner, from the initial invitation to collaborate to training formats, and the processes used to support conversation and collaboration.

Vat et al¹⁰ believed that patient-partners can be engaged at all levels of therapeutic care and research. Once considered as individuals who had research performed on them, patients are now included in the entire research process including design, development of research, planning, and dissemination of results.¹¹ Smith⁷ stated that, "Over the last decade, projects involving patient-partners in research have varied from mere tokenism and undervaluation to full involvement and empowerment of patient participants—the former, a subject of criticism, and the latter, promoted as an ideal."

When patients or others who will be affected by research are incorporated into planning, prioritizing, and/or preparing research methods or activities (i.e., patients as co-investigators), several potential benefits can be achieved. Research activities are typically initiated by the researcher, with often little or only indirect input from the groups who will be affected by the results of such research. Potential benefits can be achieved when involving patient-partners: (1) enhanced quality and relevance of the research¹²; (2) increased research relevance to family members⁵; (3) formulating research questions¹⁰; more attuned research questions¹⁵; (4) enhanced application of findings to practice¹⁵; (5) minimization of logistical problems⁵; (6) measurement and outcome measure selections⁴; (7) increased/

improved recruitment and retention (i.e., less attrition) of research participants^{14,15}; and (8) balancing potential biases stemming from investigator-initiated research.¹³

Recommended practices for incorporating patient-partners in research, based on the current literature, include the following: (1) patient-partners and researchers should be prepared beforehand in separate meetings, so that both can approach a joint dialogue with better understanding of research processes. Overcoming communication barriers is essential.^{28–30} (2) Advance training to prepare researchers and patients should be done with both groups together. Accessibility and active participation in the research process enhance patient-partner continuation in the project.^{18–20} (3) Ongoing relationship between informed researchers and patient-partner groups is one of the most consistently agreed upon recommendations.¹ (5) Ongoing relationships can be accomplished through regular meetings, workshops, or conferences, where patient-partners and researchers come together to discuss research needs and concerns.^{31–34} In summary, Hinckley et al¹ stated that, “Person-centeredness in clinical practice incorporates the values of clients into a shared decision-making approach. The values of person-centeredness can be extended into the realm of research when the views of consumers toward relevant and important research topics are sought”.

APPRECIATIVE INQUIRY

Making communication accessible can be endeavored through the use of appreciative inquiry (AI). Tools such as supported conversation²⁷ and applying evidence-based approaches for aphasia-friendly written materials^{28–30} are other examples. Graphic supports, alternative response modes, and video are also critical elements to engagement.³¹

AI is based on the following principles: (1) “discovery”—a focus on what is going well; (2) “dream”—envisioning an ideal future; (3) “design”—identify what we can do to move to that future; (4) “actions”—creating specific action steps; and (5) implementation.³² AI is a process for enhancing discussions moving through phases: (1) discovery (i.e., exploring the issues of aphasia, patient-partners in research, and

collaboration among patient-partners and researchers); (2) dreaming (i.e., what could happen and what is going well); (3) design (i.e., planning); (4) action (i.e., how do we get there); and (5) implementation. AI is a means by which everyone can participate in meaningful discussions where best practices and valuable experiences are shared and interpreted.³² AI shifts the focus from problems to discovering what works well within a community or organization. It comes from a bottom-up approach framework.^{35–38} Schmied et al³⁹ stated that, “Appreciative inquiry is a transformative approach to change which focuses on collaboration and identifying and working with the positive aspects of organizations, or communities, rather than the problems.” Resulting communication issues may involve cognitive and language impairments, despair from social isolation, difficulties with activities of daily living, and other problems.¹⁶ The examples are few, however, and our knowledge on strategies, tools, and techniques will need to expand.

Despite the communication challenges, people with aphasia can be collaborators, co-developers, and co-researchers given appropriate supports. These levels of participation vary in their degree of involvement and participation. The first level is to serve as an advisor, giving recommendations and guidance. People with aphasia have successfully acted as advisors on research projects and functioned in a research advisory group.^{21,22} People with aphasia can also act as collaborators in the evaluation of a treatment program³¹ or stroke and disability Web sites²³ (i.e., actively participating in collection of information and offering guidance). People with aphasia have also participated as co-researchers by sharing their experiences and perceptions on return to work³² or on therapy discharge²⁴ and offering ideas on research questions and research design. As a final example, people with aphasia have collaborated with researchers to identify their own priorities for research.^{1,36} These examples demonstrate that people with aphasia can participate at every level of research.

AIMS

We wished to address the issue of aphasia research and patient-partners with aphasia

and how patient-partners have typically been neglected in the research process.

The main purpose of this project was to describe methods that were applied in preparing researchers, clinicians, and patient-partners to successfully collaborate on research teams.

Our aim was to describe practices of embracing patient-partners in research through a conference designed to bring patient-partners and researchers together using a process of AI. Specifically, the AI process will be addressed qualitatively (e.g., observations and transcripts) and quantitatively (e.g., webinar survey and conference rating survey) with all participants from the project. Therefore, the specific research aims posed were as follows:

Clinicians and researchers will successfully develop collaborative research teams with patient-partners utilizing the AI process during pre-conference, conference, and post-conference events.

Patient-partners (i.e., individuals with aphasia, spouses, family, and/or caregivers) will successfully develop collaborative research teams with clinicians and researchers utilizing the AI process during pre-conference, conference, and post-conference events.

METHODS

Participants

Project *Building Research Initiatives by Developing Group Effort (BRIDGE)* included stakeholder participation from people with aphasia, their family members, aphasia clinicians, and aphasia researchers in a research conference. The conference included a total of 109 participants with 38 males, 71 females, 63 patient-partners, 23 researchers, and 23 clinicians.

This project abided by the university's IRB policies of informed consent. All participants were informed of all aspects of the project. All participation was voluntary with everyone's complete participation. The authors report no conflict of interest (see Conflict of Interest statement).

Conference Participation

Project *BRIDGE* entailed three phases: a three-part self-study webinar; an in-person 2-day

conference; and follow-up webinar conversations (i.e., to facilitate the group projects). The three-phase experience focused on initiating patient-partner research teams. Phases included pre-conference webinars (65 clinicians and researchers and 81 patient-partners), a live conference (58 patient-partners and 44 clinicians and researchers), and follow-up conference calls after the live conference (33 participants with 3 members for each of the 11 teams consisting of at least one clinician, one researcher, and one patient-partner). Follow-up conference call participants did not include all conference attendees as logistically this would not have been possible. Therefore, a representation of all groups was present for the follow-up conference calls.

Phase 1: Webinars

WEBINAR PURPOSE

The purpose of the webinars was to prepare the participants (researchers, clinicians, and patient-partners, i.e., individuals with aphasia and their family members) for participation as a research team member at the conference. To develop collaborative research teams, a series of three webinars were developed for both researchers/clinicians and patient-partners (i.e., for a total of six webinars).^{40,41} All attendees were required to view the webinars prior to participating in the conference. The three patient-partner webinars and researcher/clinician webinars were developed to parallel each other in terms of content. However, the patient-partner-based webinars were more general.

PATIENT-PARTNER AND RESEARCHER WEBINARS

Patient-partner webinar topics included (1) what is research; (2) what do we know about aphasia research; and (3) how can you contribute to research. The researcher-based webinars were more detailed: (1) how involving patient-partners benefits research; (2) how to involve patient-partners in research—general models and approaches; and (3) tools and strategies for involving people with aphasia (monolingual and bilingual). All webinars were completed in 1 hour or less and included the following format

Table 1 Patient-partner and Researcher Webinar Topics

Patient-partner webinars	Purpose	Researcher webinars	Purpose
1. What is research?	<ol style="list-style-type: none"> 1. Identify three steps of research 2. Know the meaning of “collaborative research” 3. Discuss different ways for consumers and researchers to collaborate 4. List at least two questions one could ask a researcher 	<ol style="list-style-type: none"> 1. How involving patient-partners benefits research 	<ol style="list-style-type: none"> 1. Define collaborative research 2. List levels of consumer participation in research 3. Discuss potential benefits and barriers of collaborating with consumers in research
2. What do we know about aphasia research?	<ol style="list-style-type: none"> 1. Overview of best practice guidelines for aphasia: <ol style="list-style-type: none"> a. Assessment b. Education and counseling c. Treatment 	<ol style="list-style-type: none"> 2. How to involve patient-partners in research: general models and approaches 	<ol style="list-style-type: none"> 1. Discuss role expectations for patient-partners 2. Identify three critical principles of plain language and aphasia-friendly materials 3. List three techniques for ensuring success with a patient advisory group
3. How can you contribute to research?	<ol style="list-style-type: none"> 1. Discuss roles patient-partners can participate in research. 2. List at least two questions one could talk about research 	<ol style="list-style-type: none"> 3. Tools and strategies for involving people with aphasia (monolingual and bilingual) 	<ol style="list-style-type: none"> 1. Explore and discuss available materials that can help researchers support the inclusion of people with aphasia 2. Explore and discuss materials that can help researchers support the inclusion of culturally and linguistically diverse individuals with aphasia (e.g., see Communication Disorders in Spanish Speakers: Theoretical, Research, and Clinical Aspects⁴⁸)

Table 2 Ratings of the Webinars by Conference Participants

Online webinars	Total number of respondents	Response rate (responses/total participants)	Mean content comprehension (scale = 1 to 5; 5 = completely)	Mean quality rating (scale = 1 to 5; 5 = excellent)
Researcher webinars				
1. How involving patient-partners benefits researchers?	64	64/102 = 62.74%	4.48	4.61
2. How to involve patient-partners in research: general models and approaches?	47	47/102 = 46.07%	3.85	4.68
3. Tools and strategies for involving people (monolingual and bilingual) with aphasia in research	35	35/102 = 34.31%	3.96	4.21
Patient-partner webinars				
1. What is research? How do you get involved?	76	76/102 = 74.5%	4.45	4.57
2. What do we know from aphasia research?	81	81/102 = 79.41%	4.08	4.50
3. How can you contribute to research?	64	64/102 = 62.74%	3.98	4.54

of an outline to introduce the lesson topics, content, and webinar satisfaction survey questions. All conference participants completed all required webinars prior to attending the conference (see Table 1).

WEBINAR SURVEYS

The webinars were publicly available online before the conference and all participants were asked to complete a webinar satisfaction survey for each webinar. Each webinar survey contained four to six questions with a 5-point Likert scale response option. Each webinar survey included one question about the overall quality of the webinar (“Overall, how would you rate this webinar?”), where 1 = poor and 5 = excellent. Please see Table 2 for overall mean quality ratings for each webinar. The remaining webinar survey questions were specific to the content of each webinar, and asked the participant to rate their comprehension of topics addressed in the webinar, on a scale where 1 = don’t understand it at all and 5 = completely understand. Table 2 also shows the overall mean comprehension ratings for each of the webinars.

Phase 2: In-Person Conference

We conducted a 2-day conference which was designed based on an AI approach, incorporating the four phases of discovery, dream, design, and actions.³²

Conference outcomes were measured by completing evaluation forms (see Table 3). Eight questions were developed and rated using a 1- to 5-point Likert scale (1 being poor and 5 being excellent) regarding conference satisfaction.

The discovery portion of the conference was addressed through a keynote presentation on “what is going well in collaborative research in aphasia.” A second keynote presentation addressed the “dream” of “what would it be like if aphasia research was collaborative?” During the afternoon of the first day, all conference attendees “shopped” and “shared” research ideas and settled into research teams based on interest. From the end of the first day through the entire second day of the conference, each team created a research question and a set

Table 3 Patient-Centered Outcomes Research Institute (PCORI) Conference Ratings

Questions	Overall (mean; 1–5 point scale)
1. The process facilitated the creation of research teams.	4.38
2. The breaks were the right amount of time.	3.63
3. The meeting space was accessible.	4.44
4. Given the purpose of the meeting, there was the right number of speakers.	4.15
5. Overall, the language used during the conference was aphasia friendly.	3.74
6. By the end of the conference, I believed that our team could make a contribution to research.	4.60
7. It was important to do the webinars in advance of the meeting.	3.99
8. There were enough communication supports at the conference.	3.94

of action steps including people, activities, and estimated dates. The groups were moderated by the invited speakers and the principal investigator and the co-principal investigator (both authors) who circled the rooms and group.

Richardson et al⁴² introduced the *patient intervention comparison outcome (PICO)* system to guide clinical research questions using evidence-based medicine (EBM). Patient was later modified to become population.⁴³ The *PICO* framework (population, intervention, comparison, outcome) was used to help research teams generate measurable and attainable research questions.

APPRECIATIVE INQUIRY

AI is a process for enhancing discussions while moving through groups into four phases. Essential phases include the following: (1) plan exploration (Discovery phase)—exploring the issues of aphasia, patient-partners in research, and collaboration among patient-partners and researchers; (2) plan discussion: what is occurring and what is occurring well (Dream phase); (3) plan formulation and design (Design phase); (4) plan course of actions; and (5) implementation. All conference participant language was audio recorded, transcribed, and analyzed (e.g., from the conference transcripts, conference calls, and email communications).

Phase 3: Follow-up Conference Calls

Two follow-up conference calls with each research team occurred from 4 to 7 months after

the conference and 3 months apart from each other. The purpose of the calls was twofold (i.e., to further each teams' research progress and to monitor participant engagement). Participants on the call included one to two members from each participant types (individual with aphasia, caregiver, researcher, and clinician). Hence, each team typically had between four to six team members on a call.

The conference calls were scheduled for 2-hour blocks with half of the teams (teams 1–6) participating in a morning call and the second half of the teams (teams 7–11) participating in an afternoon call. The researchers participated in all the calls. The conference calls were audio recorded and transcribed. Calls lasted approximately 2 hours each. Structure and format were kept identical as possible among the morning and afternoon calls and across the different time periods (call 1 at 4 months vs. call 2 at 7 months). The calls were structured around each team's "objectives, updates, roadblocks, and suggestions." The topic distributions occurred as a result of the participants' input. Suggestions took the form of action steps to take. All on the conference call were able to offer suggestions. The researchers then summarized the suggestions for the teams to act upon.

RATER RELIABILITY

From the transcripts, the researchers developed four general categories through coding of the responses: (1) roles and responsibilities; (2) goals, actions, and timelines; (3)

communication techniques; (4) research-specific issues. Iterative categorization was used. This is where investigators perform the following steps in data coding: (1) data reduction (simplify the data); (2) data display (organize the data); and (3) data verification (the data are interpreted for plausibility).^{41,44} Each of the steps was followed by the researchers collaboratively.

Coding or indexing the individual comments was tabulated manually. The two researchers met and discussed and agreed upon the coded themes over four sessions (i.e., 4 hours in total) until 100% consensus was achieved for each of the steps 1 to 3. Each rater had performed intra-rater agreement. Reconciliation of items was achieved through discussion and consensual agreement. The researchers matched sentences to the identified general categories (1, roles and responsibilities; 2, goals, actions, and timelines; 3, communication techniques; and 4, research-specific issues) when indexing all the individual comments.⁴⁵ Individuals with aphasia participated in every conference call. Equal representation from all the groups was sought (i.e., individuals with aphasia, patient-partners, researchers, and clinicians) for when the conference calls occurred.

RESULTS

Phase 1: Webinar Development

All webinars were verified for content validity by a review of experts in the fields of aphasia, patient-partner teams, and/or multiculturalism. The reviews were conducted prior to the conference to confirm content validity. Experts included seven researchers, one clinician, and six individuals with aphasia and/or their partners. The review and rating questions inquired about difficulty of the material, understanding of the material, and/or appropriateness of the material. The reviewers were asked the following questions in their appraisal: (1) Does the content address the objectives stated at the beginning of the webinar? (2) Is the content appropriate for the audience? (3) Is the content clearly communicated? (4) Considering the objectives, is there any information that is missing? (5) Other comments you have about

the webinar. The webinars were modified based on the suggestions from the reviewers. Overall, the reviewers rated the webinars as “very good” to “excellent” in quality (average rating for all webinars was 4.52). Comprehension ratings were obtained for both patient participants and researchers (average rating for all content comprehension was 4.37).

Phase 2: Conference Outcomes

At the end of the 2-day conference, 11 research teams were formed. The conference attendees included 33 people with aphasia, 25 family members, 18 clinicians, and 26 researchers. There were a total of 102 participants at the live conference (excluding student communication assistants and speakers). Participants came from across the United States. Conference participants were divided into 11 teams with each team represented by individuals with aphasia, family members, researchers, and clinicians. The 11 research teams that were developed consisted of (1) identity after aphasia; (2) caregiver training; (3) stories of recovery; (4) recovery trajectory; (5) yoga; (6) telepractice; (7) naming treatment; (8) what happens in the long term; (9) life participation approach; (10) strategies for quality intervention; and (11) educating stakeholders.

There were a total of 79 completed conference evaluation forms that were returned at the end of the conference. In one instance, the evaluation form was completed by one couple (the combined views of a person with aphasia and his/her family member). Please note that all family members at the conference were spouses. Of the remaining 78 evaluations, 16 were from clinicians, 17 were from family members, 25 were from individuals with aphasia, 17 were from researchers, and 3 were from speakers. Individuals with aphasia represented the full range of severity (from mild to severe disability). All clinicians worked in medical settings with individuals with aphasia and their patient-partners. All researchers were university based and aphasiologists. Conference ratings ranged from 3.63 to 4.60 on a five-point scale of satisfaction (i.e., 1 being very unsatisfied to 5 being very satisfied). See Table 3 regarding the overall conference ratings.

Table 4 Research Topics and Research Questions

Research Topics	Research Question
1. Identity after aphasia	Does starting a life coaching program before rehabilitation discharge improve self-esteem, communication interaction, and quality of life?
2. Caregiver training	What is the best format of co-survivor support at each phase of the aphasia journey?
3. Stories of recovery or stories of aphasia	Do clinicians who receive training in personal narrative methods have a larger impact than untrained clinicians on communication and quality-of-life measures in patients who have aphasia due to stroke?
4. Recovery trajectory	What is the effect of video documentation on recovery trajectory during the first year for persons with aphasia and their caregivers' perceptions of recovery compared with usual care?
5. Yoga	In people with aphasia and co-survivors, will 8 weeks, twice per week, 90 minutes per session of aphasia-friendly yoga demonstrate benefits on quantitative and qualitative measures of stress, pain management, and relationship mutuality?
6. Telepractice	Do people with aphasia report increased scores on the Patient Specific Functions Scale following aphasia-friendly YouTube vs. clinician-directed training with selected applications and technology?
7. Naming treatment	Are RTMS or other brain stimulation approaches more effective than traditional word-finding therapy for improving word-finding?
8. What happens in the long term for patients with aphasia (friendship)	How does aphasia affect maintenance and development of friendship over time?
9. Life participation approach	What do people with aphasia experience at and post-discharge from acute care using survey methodologies and semistructured interviews?
10. Strategies for quality of life interventions	What are our themes that define thriving in PWA and what are the strategies they are using to support/achieve that?
11. Educating stakeholders	Does video module training improve stakeholders' understanding of comfort with aphasia?

Each team included at least one researcher, one clinician, and at least one person with aphasia and/or family member. Each research team generated a completely formed research question along with several action steps to take in the immediate few months after the conference. Table 4 includes the research topics and research questions.

Phase 3: Follow-up Conference Calls and Communications

The first conference call revealed that most of the conversations centered on roles and responsibilities (32%) and communication techniques (32%). The second conference call revealed a

change in conversations: research-specific issues (30%); roles and responsibilities (27%); and goals, actions, and timelines (24%). See Tables 5 and 6 for these results.

APPRECIATIVE INQUIRY

AI was documented from the conference transcripts and two follow-up call transcripts. Project BRIDGE followed AI steps as patient-partners, researchers, and clinicians completed the webinars and attended the conference (discovery phase), envisioned the future by attending and participating in the conference (dream phase), designed the research studies together in collaboration among all participants (design

Table 5 First team member conference call

Category (percentage of responses)	Examples
1. Roles and responsibilities (32/100 = 32%)	<ul style="list-style-type: none"> • Composition of team is critical • Importance of having an “accountability partner” • Match/Assign key players for particular agenda items/assignments • Give permission to other team members to help move team forward (relates to “accountability partners”) • Be clear on roles and tasks • Role changes: PWA entering clinic bldg. as a “researcher” instead of “just a client” • Role recommendations: how to be a leader of a multi-stakeholder research group
2. Goals, actions, and timelines (23/100 = 23%)	<ul style="list-style-type: none"> • Action list should include video • Frequency of meetings in beginning vs. later in process? • Set the schedule right away • Set small deadlines • Connect research to local people/support group
3. Communication techniques (32/100 = 32%)	<ul style="list-style-type: none"> • Best practices for video documentation and communication • Consistent email organization/template—introduce initially, then use consistently • Options for posting videos, such as private Facebook group or other easily accessible online location • Videoconference resources • Frequent communication • Send out short video clip updates • Sharebox or Dropbox folder
4. Research-specific issues (13/100 = 13%)	<ul style="list-style-type: none"> • Evolution of question • How to complete literature review • Evolution of different types of projects: projects starting from a blank slate, projects that were already started

phase), and created specific action steps to be completed and also began implementation of those steps (e.g., participating in the conference and conference calls).^{45–47}

DISCUSSION

Initial immediate outcomes suggested that the methods used (webinar preparation, small group work, and aphasia-friendly principles) supported the creation of the 11 collaborative research teams for all participants. The first research question stated that researchers and clinicians would be able to form collaborative research teams with patient-partners (i.e., individuals with aphasia, spouses, family, and caregivers). By the culmination of the project, 11 research teams with all groups had formed and

continued to work as teams throughout the entire project cycle. Data from the webinars, conference outcomes, follow-up calls, and AI transcripts indicate moderately high ratings with the webinar trainings and moderately high to very high conference ratings. Comments obtained from the follow-up calls indicated continued support and effort for the research team goals and support for patient-partners.

The second research aim stated that patient-partners (i.e., individuals with aphasia, spouses, family, and caregivers) would be able to form collaborative research teams with researchers and clinicians. The patient-partners demonstrated considerable effort and determination during the webinar trainings with almost 80% completing all three webinars. Some issues

Table 6 Second Team Member Conference Call

Category (percentage of responses)	Examples
1. Roles and responsibilities (27/100 = 27%)	<ul style="list-style-type: none"> • Worked with the concept of caregivers and information that is needed by caregivers and persons with aphasia throughout the continuum of care • Worked on the IRB application • Behind the scenes work, making collaborative connections with a specialist
2. Goals, actions, and timelines (24/100 = 24%)	<ul style="list-style-type: none"> • Made progress on the timeline for the literature review • Made progress on team coaching this summer • Put together (as a team) a survey for SLPs trying to determine the speech-language pathologists' role in assessing and/or managing friendship with their clients with aphasia • A.E. stepped up to be the leader • More planning at the conference before the team left as to roles and responsibilities
3. Communication techniques (19/100 = 19%)	<ul style="list-style-type: none"> • Trouble connecting with team members • Trying to stay in good communication with everybody • Put the essence of all meetings in a video • Communicating via e-mail • Did not plan in how to stay in contact
4. Research-specific issues (30/100 = 30%)	<ul style="list-style-type: none"> • Recognize JK, now who's on this call, who has done a fabulous job of doing some literature search and getting back to her research skills that she had before a stroke • Work through research ideas and narrow down ideas • Looking at some bigger grants to start the study • Examining literature and finding the right research question

from the conference indicated that communication and conference supports needed further enhancing. However, overall patient-partners appeared highly engaged and satisfied with the conference as indicated by their comments obtained in the follow-up call transcripts. Patient-partners were highly engaged before, during, and after the conference (hence, the entire project).

Webinar Outcomes

Project BRIDGE utilized three pre-conference self-study webinars for researchers, clinicians, and patient-partners. The webinars were completed by 65 clinicians and researchers and 81 patient-partners. Table 3 documents greater attendance for the patient-partners and less attrition over the three webinars when compared with researcher and clinician attendance.

The webinar attendance rates were as follows: (1) researcher and clinician Webinar 1: 64; Webinar 2: 47; and Webinar 3: 35 and (2) patient-partner Webinar 1: 76; Webinar 2: 81; and Webinar 3: 64. These results seem to support continued support for webinar engagement among the patient-partners; however, the researchers and clinicians demonstrated an attrition rate of approximately 45%. Time commitments, other work obligations, and/or decreased interest may have contributed to lower participation among the researchers for pre-conference training. However, 55% of the researchers and clinicians completed all three webinar trainings. Eighty-five per cent of all patient-partners completed all three webinar trainings. Satisfaction with the webinar trainings was consistent among both groups. Webinar satisfaction ranged from 3.96 to 4.68 (out of a 1–5 point scale with 1 for low

and 5 for excellent) for the researchers and clinicians and from 3.98 to 4.57 for patient-partners. Webinar participation was highly successful for patient-partners, while it was modestly successful for researchers and clinicians. Webinar satisfaction was high for both groups.

Conference Outcomes

Conference ratings were not broken down by participant group (researcher/clinician; patient-partners) as all participants had joined the resultant 11 research teams. Very high ratings (>4.0 on the five-point scale) were achieved for 4/8 (50%) of the questions (i.e., (1) facilitation of research teams; (2) accessible meeting space; (3) right number of speakers; (4) teams making a contribution to research). Moderately high ratings (3.0–3.9) were achieved for the remaining ratings ((1) break time; (2) language was aphasia friendly; and (3) webinar training; communication supports at the conference). Immediate outcomes suggest that language at the conference was not as “aphasia-friendly” as desired. Speakers, researchers, and clinicians tended to speak too fast as continual reminders were noted for all speakers to be mindful of their rate of speech. Communication issues were also noted by a slightly lower rating (i.e., 3.94/5.0) on not having enough communication supports for individuals with aphasia. Future efforts need to address and incorporate enhanced communication for individuals with aphasia. Overall, all participants seemed generally satisfied with the conference outcomes.

Follow-up Conference Calls

Suggestions for success were gathered from the research teams and the patient-partner teams from the conference call follow-up meeting transcripts. The suggestions were categorized by the authors (see “Methods” section under the “Follow-up Conference Calls and Communication” subheading) into two broad groupings (i.e., communication and participation).

Suggestions for patient-partner communication included (1) having short conversations instead of long conversations; (2) having scheduled conversations; (3) having more frequent

conversations; (4) having conversations that included videos (e.g., Zoom); and (5) developing a social network page such as Facebook for ease of access to information at any time. These comments were made so that people with aphasia felt included and for the research teams to use video clips instead of sending long e-mails.

The participation category included the following suggestions: (1) having small and short-term deadlines; hence, the use of established deadlines was deemed to be important with both short- and long-term timelines; (2) for future reference, to invite members from local aphasia groups for enhanced participation; and (3) to offer some type of compensation for patient-partner teams (other than monetary). These steps are meant to increase patient-partners empowerment.⁵ Patient-partner empowerment allows for individuals with aphasia and their family members to take action and achieve what they desire, allows for advocacy, and creates a voice for those with aphasia.⁵

A possibility to the change in teams communicating more effectively may have been due to less technical guidance and mentoring was needed during the second meeting. This was predicted for the first call since all groups were still forming, communicating, and beginning to organize their research efforts. It was expected that continued communication would alleviate, and conversations would focus more on research issues.

For the second conference call, discussion focused more on research-specific issues (30%), while roles and responsibilities (27%) and goals, actions, and timelines (24%) still dominated group concerns. Comparing the discussion results from the first to second conference calls, communication techniques and communication issues were less talked about. One interpretation is that the change was due to the conversation shifting focus to conversing more about the research projects. It appeared that the teams were completing their research responsibilities and were functioning as cohesive teams in accomplishing their tasks and goals. Research-specific issues increased from 14% of the comments up to 30% of the comments between the two conference calls. Roles and responsibilities and goals, actions, and timelines

remained similar (i.e., high percentages) to the first and second conference calls.

Appreciative Inquiry

Illustrative examples of AI can be found in the conference participants' language. For example, one patient-partner stated at the beginning of the conference the following which illustrates aspects of discovery and dreaming, "Thank you. Those of you that know us know we wear this on our sleeve (i.e., living with aphasia). The more we know, the better our lives become. Let's all work together and make this successful. Thank you!" Another statement of discovery comes from an individual with aphasia, "I had a stroke five years ago. I could not spell aphasia; I did not know what 'is' was. Everyone knows what cancer, or a stroke is. The population does not know what aphasia is." A planning statement is found when the patient-partner stated, "I am a family member. The difference is in the successes and what seems to work. You talk about collaboration, exercise, nutrition, and all disciplines coming together to share their knowledge." Another example of planning involving education about aphasia was said when the person with aphasia detailed, "I had a global stroke eighteen months ago. I want to be a motivational speaker. How do I do that?" During the conference among the 11 established research teams, 236 pertinent research questions were generated and narrowed down to 11 specific questions. Hence, it can be stated that design and action phases were generated.

MANAGING CHALLENGES

Challenges from this project were many. Although many of the challenges may not have been achieved, project BRIDGE may have identified key issues for future research teams to address (i.e., persons with aphasia, patient-partners, clinicians, and researchers). The time that the patient-partners, clinicians, and also the researchers contributed to the project conclusions was notable, that is, all parties contributed significantly time wise to the project outcomes.

It appeared that participants at the BRIDGE conference were committed to ad-

vancing a larger outcome. Perceptions of research and what researchers attempted to accomplish were an understood project challenge for all conference participants. It seemed that the patient-partners initially did not have complete conceptions of clinical research. However, later comments from the patient-partners indicated that this challenge was recognized and at least attended. For example, one individual with aphasia was excited about joining the conference calls and participating. One researcher was noted to have said, "So she's really excited (referring to the person with aphasia). I think for me one of the most exciting next steps is that she is coming here as a researcher and not a participant."

The communication gap (for individuals with aphasia, the clinicians, and researchers) among all the participants was another challenge that was prevalent from the beginning. However, near the end of the project, it appeared that this challenge had been recognized and attempts were being made by the group to address better communication issues. One researcher stated during the first conference call regarding communication issues,

"I think it's so critical that people with aphasia feel included, I think it might be very helpful if the team leads occasionally send out really short video clips to keep us all updated rather than these really long emails."

In response, one of the individuals with aphasia stated,

"Hey, I want to say that, what C. said is really helpful because I was so overwhelmed with the text the length of this email, and I had to get help to understand this email and this is new technology for me after the stroke, and I have a difficult time with this but if a video would really help me. So, thanks C. for suggesting that."

From the second conference call, one of the researchers reported on their team how communication with patient-partners had improved since the first conference call. She stated that,

And one of the things that I guess we can call it a win for our team has been sort of in communication within our team members... but one of the suggestions made by several of our team members was to do a video summary sort of for those meetings especially because

emails are challenging for some of our team members.

In addition, improvement in communication appeared to have improved by the dramatic decrease in comments related to communication issues on the second conference call (i.e., from 32 comments down to 17). By directly focusing on the challenge, the conference participants seemed able to alleviate some of the communication concerns or at minimum bring forth strategies for future communication issues.

A third challenge was establishing concord as a group. Addressing this challenge was noted over the conference and was also noticed with the two follow-up meetings via the conference calls. Some individuals with aphasia served as group spoke-persons for reporting to the other teams at the conference. In addition, one participant's husband later mentioned that she definitely wanted to be a part of the research team. Achieving favorable agreement and concurrence was observed by a researcher on the second conference call when she very enthusiastically stated, "I'm E. and I'm from Team Friendship and I'm the researcher from this team and we've made some good progress since our last check-in." One could hear the pride in her voice by being able to join the group and speaking for them as a group. Cooperrider and Whitney's^{38,46} definition of destiny was defined by completing the group tasks. It is noted that the teams continued to meet throughout the project timelines and completed all tasks.

Group cohesion appeared to be more evident toward the end of the conference by the increased focus on the research questions and participation in their team's research endeavors (i.e., up from 14 to 33 comments). The teams appeared more focused on completion of the research projects.

It appears that patient-partners of project BRIDGE were able to participate across Singer et al's¹¹ highest level of patient involvement, that is, patients as researchers and Turnbull et al's⁵ level 5 designation as co-researchers. Although the project's grant funding ended, it is anticipated that the established research teams will continue in further research efforts.

In conclusion, it can be stated that all of the aforementioned challenges still persist. It is upon all those involved (persons with aphasia,

partners, clinicians, and researchers) to continue to address these challenges. Future projects will need to address these continued issues.

CONCLUSION

The aim was to prepare the participants (researchers, clinicians, and patient-partners, i.e., individuals with aphasia and their family members) for participation as research team members. At the end of the 2-day conference, 11 research teams were formed. Each team included at least one researcher, one clinician, and at least one person with aphasia and/or family member. Each research team generated a completely formed research question along with several action steps to take in the immediate few months after the conference. All research teams achieved Turnbull et al's⁵ level 5, i.e., patient-partners act as co-researchers. It is hoped that the researchers and clinicians serve as ongoing consultants to the patient-partners (level 6). Challenges continued to exist after the conference and follow-up calls; for example, completion of the research projects by the 11 research teams will continue. Research takes time with diverse teams such as this effort focusing on patient-partners. One remedy is that the authors must continue their communication with the teams for completion.

In conclusion, all the research questions that were formed by the teams came initially from the patient-partners. All clinicians and researchers facilitated the patient-partners throughout the entire process. Student assistants participated in the conference as "communication assistants" to those individuals with aphasia who needed help in communicating their ideas. Additional means of communicating were broached and enacted (e.g., using short videos instead of long email communications). Hence, this project seems to have accomplished the overall aims, i.e., to actively involve individuals with aphasia in the research process as full research team members. Researchers, clinicians, and individuals with aphasia and their family fully formed research teams.

Including patient-partners into research priorities and planning has been accomplished across a variety of health domains in the United States, but this was the first organized national effort, in the United States, to support the

inclusion of people with aphasia and their families as active partners in the research process. Consequently, it is anticipated that future aphasia researchers also engage patient-partner teams in their research process for enhanced research practices. This is only the beginning, and more effort is required. It is hoped that the momentum for patient-partner-based research continues.

CONFLICTS OF INTEREST

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REFERENCES

- Hinckley J, Boyle E, Lombard D, Bartels-Tobin L. Towards a consumer-informed research agenda for aphasia: preliminary work. *Disabil Rehabil* 2014;36(12):1042–1050
- Mitchel J, Williams E, Li Y, Tarraf W. Identifying disparities in patient-centered care experiences between non-Latino white and black men: results from the 2008–2016 Medical Expenditure Panel Survey. *BMC Health Sciences Res* 2020;20:1–9
- Orgas F. Implementing the Patient-Centered Care Paradigm in an Academic Research Environment [unpublished dissertation]. San Antonio, TX: University of the Incarnate Word; 2019
- Oliver S, Armes DG, Gyte G. Public involvement in setting a national research agenda: a mixed methods evaluation. *Patient* 2009;2(03):179–190
- Turnbull AP, Friesen BJ, Ramirez C. Participatory action research as a model for conducting family research. *Res Prac Persons Disabilities* 1998; 23:178–188
- Smith E, Bélisle-Pipon JC, Resnik D. Patients as research partners; how to value their perceptions, contribution and labor? *Citiz Sci* 2019;4(01):1–13
- Smith REditor's choice. Take your partners for the dance. *BMJ* 1999;319(7212)
- Wilson J. Acknowledging the expertise of patients and their organisations. *BMJ* 1999;319(7212):771–774
- Goodare H, Lockwood S. Involving patients in clinical research. Improves the quality of research. *BMJ* 1999;319(7212):724–725
- Vat LE, Ryan D, Etchegary H. Recruiting patients as partners in health research: a qualitative descriptive study. *Res Involv Engagem* 2017;3(15):15
- Singler L, McAdams P, Uhlenbrauck G, Jernigan K, Schulman J. Models of engagement: patients as partners in clinical research. *Applied Clinical Trials* 2018. Accessed August, 29, 2022 at: <http://www.appliedclinicaltrialsonline.com/models-engagement-patients-partners-clinical-research>
- Ahmed SM, Palermo AG. Community engagement in research: frameworks for education and peer review. *Am J Public Health* 2010;100(08): 1380–1387
- Tallon D, Chard J, Dieppe P. Relation between agendas of the research community and the research consumer. *Lancet* 2000;355(9220):2037–2040
- Hearld KR, Hearld LR, Hall AG. Engaging patients as partners in research: Factors associated with awareness, interest, and engagement as research partners. *SAGE Open Med* 2017;5(01): 2050312116686709
- Institute of Medicine (US). *Public Engagement and Clinical Trials: New Models and Disruptive Technologies*. Washington, DC: National Academies Press (US); 2012
- Nayeri ND, Mohammadi S, Razi SP, Kazemnejad A. Investigating the effects of a family-centered care program on stroke patients' adherence to their therapeutic regimens. *Contemp Nurse* 2014;47(1-2):88–96
- Moffatt K, McGrenere J, Purves B, Klawe M. The participatory design of a sound and image enhanced daily planner for people with aphasia. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*; April 2004; Vienna, Austria. doi: <https://doi.org/10.1145/985692.985744>
- Buhr H, Hoepner J, Miller H, Johnson C. Development and evaluation of an aphasia-friendly social networking application. *Aphasiology* 2017;31(09): 999–1020
- Harmon T, Hardy L, Haley K. Proactive social validation of methods and procedures used for

- training speech production in aphasia. *Aphasiology* 2018;32(08):922–943
20. Parr S. Living with severe aphasia: tracking social exclusion. *Aphasiology* 2007;21(01):98–123
 21. Palmer R, Paterson G. To what extent can people with communication difficulties contribute to health research? *Nurse Res* 2013;20(03):12–16
 22. Sims S, Brearley S, Hewitt Get al.. How to develop a patient and carer advisory group in stroke care research. *Nurse Res* 2013;20(03):6–11
 23. Moss B, Parr S, Petheram B. 'Pick me up and not a down down, up up': How are the identities of people with aphasia represented in aphasia, stroke, and disability websites? *Disabil Soc* 2004;19:759–768
 24. Nakano EV, Hinckley J. Therapy discharge becomes part of the life story. *Top Stroke Rehabil* 2010; 17(01):39–46
 25. Ross K, Howe T, Jenstad L, Sinden E. Developing a communicatively accessible group yoga class for adults with aphasia post-stroke. *Aphasiology* 2018; 32(01):189–190
 26. Jones I, Marshall J, Lawthorn R, Read J. Involving people with communication disability in research in Uganda: a response to the World Report on Disability. *Int J Speech Lang Pathol* 2013;15 (01):75–78
 27. Kagan A, Black SE, Duchan FJ, Simmons-Mackie N, Square P. Training volunteers as conversation partners using "Supported Conversation for Adults with Aphasia" (SCA): a controlled trial. *J Speech Lang Hear Res* 2001;44(03):624–638
 28. Brenna A, Worrall L, McKenna K. The relationship between specific features of aphasia-friendly written material and comprehension of written material for people with aphasia: an exploratory study. *Aphasiology* 2005;19:693–711
 29. Rose T, Worrall L, McKenna K. The effectiveness of aphasia-friendly principles for printed health education materials for people with aphasia follow stroke. *Aphasiology* 2003;17:947–963
 30. Rose TA, Worrall LE, McKenna KT, Hickson LM, Hoffmann TC. Do people with aphasia receive written stroke and aphasia information? *Aphasiology* 2009;23:364–392
 31. McMennamin R, Tierney E, MacFarlane A. Who decides what criteria are important to consider in exploring the outcomes of conversation approaches? A participatory health research study. *Aphasiology* 2015;29(08):914–938
 32. Cooperrider DL, Whitney D. *Appreciative Inquiry: A Positive Revolution in Change*. San Francisco, CA: Berrett-Koehler; 2005
 33. Dudley L, Gamble C, Allam Aet al.. A little more conversation please? Qualitative study of researchers' and patients' interview accounts of training for patient and public involvement in clinical trials. *Trials* 2015;16:190
 34. Elberse JE, Caron-Flinterman JF, Broerse JE. Patient-expert partnerships in research: how to stimulate inclusion of patient perspectives. *Health Expect* 2011;14(03):225–239
 35. Panofsky A. Generating sociability to drive science: patient advocacy organizations and genetics research. *Soc Stud Sci* 2011;41(01):31–57
 36. Franklin S, Harhen D, Hayes M, McManus SD, Pollock A. Top 10 research priorities relating to aphasia following stroke. *Aphasiology* 2018; 32:1388–1395
 37. Morris J, Franklin S, Menger F. Returning to work with aphasia: a case study. *Aphasiology* 2011; 25:890–907
 38. Reed J. *Appreciative Inquiry: Research for Change*. Thousand Oaks: CA; Sage; 2007
 39. Schmied V, Burns E, Sheehan A. Place of sanctuary: an appreciative inquiry approach to discovering how communities support breastfeeding and parenting. *Int Breastfeed J* 2019;14(25):25
 40. Hasnain R, Kondratowicz D, Borokhovski Eet al.. Do cultural competencies interventions work? *Natl Cntr Dissem Disabil Res*. 2011;31:1–12. Accessed August 29, 2022 at: <http://www.nationalacademies.org/hmd/Reports/2011/Public-Engagement-and-Clinical-Trials-New-Models-and-Disruptive-Technologies-Workshop-Summary.aspx>
 41. Reinke LF, Griffith RG, Wolpin S, Donesky-Cuenco D, Carrieri-Kohlman V, Nguyen HQ. Feasibility of a webinar for coaching patients with chronic obstructive pulmonary disease on end-of-life communication. *Am J Hosp Palliat Care* 2011;28(03):147–152
 42. Richardson WS, Wilson MC, Nishikawa J, Hayward RS. The well-built clinical question: a key to evidence-based decisions. *ACP J Club* 1995;123 (03):A12–A13
 43. Speckman RA, Friedly JL. Asking structured, answerable clinical questions using the population, intervention/comparator, outcome (PICO) framework. *PM R* 2019;11(05):548–553
 44. Neale J. Iterative categorization (IC): a systematic technique for analysing qualitative data. *Addiction* 2016;111(06):1096–1106
 45. Dawson J. Approaches to qualitative data analysis: Intuitive, procedural, and intersubjective. Paper presented at: American Educational Research Association; March 1982; New York, NY
 46. Cooperrider DL, Whitney D. *Collaborating for Change*. San Francisco, CA: Barrett-Koehler; 1999
 47. Cooperrider DL, Whitney D, Stavros JM. *The Appreciative Inquiry Handbook: For Leaders of Change*. San Francisco, CA: Berrett-Koehler; 2008
 48. Centeno J, Anderson R, Obler L. *Communication Disorders in Spanish Speakers: Theoretical, Research, and Clinical Aspects*. Buffalo, NY: Multilingual Matters; 2007