



# Building Research Initiatives by Developing Group Effort (BRIDGE)

October 19-20, 2018  
Real Time Record

## VOICES OF HOPE FOR APHASIA

**Clinicians**

- Best Practices
- Tool Box
- Building Trust
- Community Training
- Development of Aphasia-Friendly Resources

**INDIVIDUALS & FAMILIES AFFECTED by APHASIA**

- Balance
- Collaborators
- Defining Excellence and Success
- Advocates for Change

**RESEARCH**

- Patient-Driven
- Most Collaborative
- Most Engaged
- Non-Traditional Research Techniques
- Securing Funding?
- Data Partners

- LIFE COACHING BEFORE REHABILITATIVE DISCHARGE
- BEST FORMAT FOR CO-SURVIVOR SUPPORT
- PERSONAL NARRATIVE TRAINING FOR CLINICIANS
- VIDEO MODULE TRAINING
- VIDEO DOCUMENTATION
- HOW DOES REGULAR YOGA HELP?

- YOUTUBE VS CLINICIAN-DIRECTED TRAINING
- RTMS VS TRADITIONAL WORD FINDING THERAPY
- APHASIA'S EFFECTS ON FRIENDSHIP
- POST-DISCHARGE EXPERIENCES
- THRIVING IN PEOPLE WITH APHASIA

**SPICES**

- Advocacy
- Technology
- Dogs!

## Executive Summary

Thank you for participating in the Building Research Initiatives by Developing Group Effort (BRIDGE) 2018 Conference. Below are highlights of your two-day conference. The subsequent pages of this Real-time Record provide the supporting details documenting the presentations, discussions, and activities engaged in by attendees.

BRIDGE Conference attendees gathered on October 19<sup>th</sup> and 20<sup>th</sup>, 2018 to participate in this inaugural Aphasia Researcher-Clinician-Patient Partners Collaboration effort. Attendees represented the following stakeholder groups as identified by conference leadership:

<b>Aphasia Stakeholder Groups</b>	
Researchers	Consumers
Clinicians	Family Members

The conference kicked-off with Lisa Stewart of Patient Centered Outcomes Research Institute (PCORI) delivering the Keynote Address on the topic of The Vision of Patient Partners-Researcher-Clinician Collaborations and How it Would Change Things. At the core of her message was the need for patient-centered, patient-driven collaborative efforts. The keynote was followed by a panel discussion touching on topics including; the need to move away from old research methods; the benefits of an expanded focus of success factors beyond impairment; and a look back at the impact of the 1990 passing of the Americans with Disabilities Act (ADA) as a pretext to what is next in Aphasia research. Panelists included:

- Audrey Holland, Ph.D., CCC/SLP, BC-ANCDS
- Kathryn M. Yorkston, PhD, BC-ANCDS
- Jackie Hinckley, Ph.D., CCC-SLP, BC-ANCDS

Day One concluded with attendees participating in three-rounds of research topic exploration to select a topic to collaborate on with other attendees in research teams. Attendees "shopped" from seventeen possible research topics (fourteen topics predetermined by conference leadership and an additional three topics proposed by conference attendees) and ultimately selected eleven topics to move forward to Day Two.

Day Two activities engaged conference attendees in the collaborative process of evolving topics and related brainstorming among newly formed research teams into actualized research questions. Of the eleven topics selected and listed below in the table, one is an attendee proposed topic – Educating Stakeholders.

Captured in the table on the next page are final research questions by topic/team.

<b>Top Research Topics</b>	<b>Research Question</b>
<b>Identity After Aphasia</b>	Does starting a life coaching program before rehabilitation discharge improve self-esteem, communication interaction, and quality of life?
<b>Caregiver Training</b>	What is the best format of co-survivor support at each phase of the aphasia journey?
<b>Stories of Recovery or Stories of Aphasia</b>	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?
<b>Recovery Trajectory</b>	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 to usual care?
<b>Yoga</b>	In people with aphasia and co-survivors, will eight 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?
<b>Telepractice</b>	Do people with aphasia report increased scores on the Patient Specific Functions Scale following aphasia-friendly YouTube versus clinician-directed training with selected applications and technology?
<b>Naming Treatment</b>	Are RTMS or other brain stimulation approaches more effective than traditional word-finding therapy for improving word-finding?
<b>What Happens in the Long Term for Patients With Aphasia</b>	How does aphasia effect maintenance and development of friendship over time?
<b>Life Participation Approach</b>	What do people with aphasia experience at and post-discharge from acute care using survey methodologies and semi-structured interviews?
<b>Strategies for Quality of Life Interventions</b>	What are our themes that define thriving in PWA and what are the strategies they are using to support/achieve that?
<b>Educating Stakeholders</b>	Does video module training improve stakeholders' understanding of comfort with aphasia?

Day Two concluded with attendees working in their research teams to develop priority next steps necessary to launching their team's research project. Teams documented next steps to include team member responsibilities, deliverables