

Session #: 2000

Day/Time: Saturday, November 23, 2019 5:00 – 6:00 pm

**Title: Clinicians, Researchers, & Consumers Collaborating: Project BRIDGE**

Authors: Jacqueline Hinckley, Alejandro Brice, Lauren Bislick, Tom Broussard, Mike Caputo, Amy Engelhoven, Jennifer Kurnal, Kerry Lenius, Elizabeth Madden, Jodi Morgan

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**Learning Objective:** At the end of this session, the learner will be able to discuss at least 2 methods for facilitating consumer-researcher partnerships.

## **Introduction**

When patients or others who will be affected by research are incorporated into planning, prioritizing, or preparing research methods or activities, research is improved in quality, relevance, and efficiency, among other benefits (Ahmed & Palermo, 2010; Oliver, Armes, & Gyte, 2009; Tallon, Chard & Dieppe, 2000; IOM, 2011; Tallon, Chard, & Dieppe, 2000).

Recommended practices for including consumers in research (Dudley et al, 2015; Elberse, Caron-Flinterman, & Browerse, 2011; Panofsky, 2011) include 1) preparing patient partners and researchers beforehand in separate meetings, and 2) maintaining ongoing relationships between informed researchers and patient partners through regular meetings, workshops, or conferences.

***Project BRIDGE: Building Research Initiatives by Developing Group Effort*** was funded through an Engagement Award of the Patient-Centered Outcomes Research Institute (PCORI) to apply these principles to the process of creating research collaborations between researchers, clinicians, people with aphasia, and their families.

## **Project Description**

Webinar preparation for all participants were three webinars for PWAs and their families that included understanding the purposes of research, basic scientific method, questions to ask a researcher, and roles of consumers and researchers in a collaborative project. The three webinars that were developed for researchers included models for collaboration, resources and techniques for facilitating collaborative research, and roles of consumers and researchers in a collaborative project. The two-day conference was designed based on an Appreciative Inquiry approach.

The webinars were publicly available online and participants were asked to complete an online survey for each webinar. Thirty-three PWAs, 25 family members, 18 clinicians, and 26 researchers who had completed the webinar trainings attended a two-day conference in October, 2018 in Clearwater, FL. At the end of the conference, 11 research teams were formed. Each team included at least one researcher, one PWA and family member. Each team

generated a completely formed research question along with several action steps to take in the immediate few months after the conference.

## **Lessons Learned**

Our experience has highlighted several critical features that can ensure communication accessibility. First, techniques of universal design have predictably been critical (Rios, Magasi, Novak & Harniss, 2016). Just like providing ramps or assistive technology for those with mobility, vision, or hearing impairments, “communication ramps” can be provided for those with language-based communication disabilities and differences. Beyond these techniques, however, this project has taught us the importance of other processes, such as interactional techniques and dynamics, which make it possible for individuals with communication issues to contribute to research planning and priorities.

### Some Strategies that Worked

- Training communication support volunteers
- Timely meeting agendas
- Getting out of the email rut: using video for agendas, meeting summaries, announcements
- Seeking, and then using, individual feedback between meetings
- Establishing an “Accountability Partner” (often a patient partner), who reminds the team about timelines
- Drafting “job descriptions” for different roles, involvement levels, and contribution types

### Some Important Leadership Attributes

- Being adaptable: listening and adjusting based on input from all team members
- Follow-up on action items with individuals
- Prepared for meetings
- Protective of the group: Some of our teams did not want new members who had not been trained to join the group
- Attuned to group dynamics: When members leave or join, the leader should acknowledge and plan for changes in the group dynamic.

-Compiled from Project BRIDGE participants

## **Resources/Tools**

More information about the project is available at: <https://www.aphasia.org/research-bridge/>

## **Acknowledgements**

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