

“Why didn’t I think of this before?” Perceptions of Stakeholder Engaged Research

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Stakeholder-engaged research (SER) means involving the people who are going to be affected by research into its planning and design (Bergold & Thomas, 2012). SER results in more relevant and inclusive research (Pearl & Cruice, 2017). Although SER is becoming more common across health conditions, there are very few examples of SER in communication disorders.

One example of purposeful integration of stakeholder engaged research in aphasia research is Building Research Initiatives by Developing Group Effort (Project BRIDGE). Project BRIDGE was a PCORI grant funded project led by Jacqueline Hinckley, Ph.D., CCC-SLP. Project BRIDGE equips people with aphasia, family members, clinicians and researchers with the skills necessary to work in collaborative teams that design, conduct, and disseminate research.

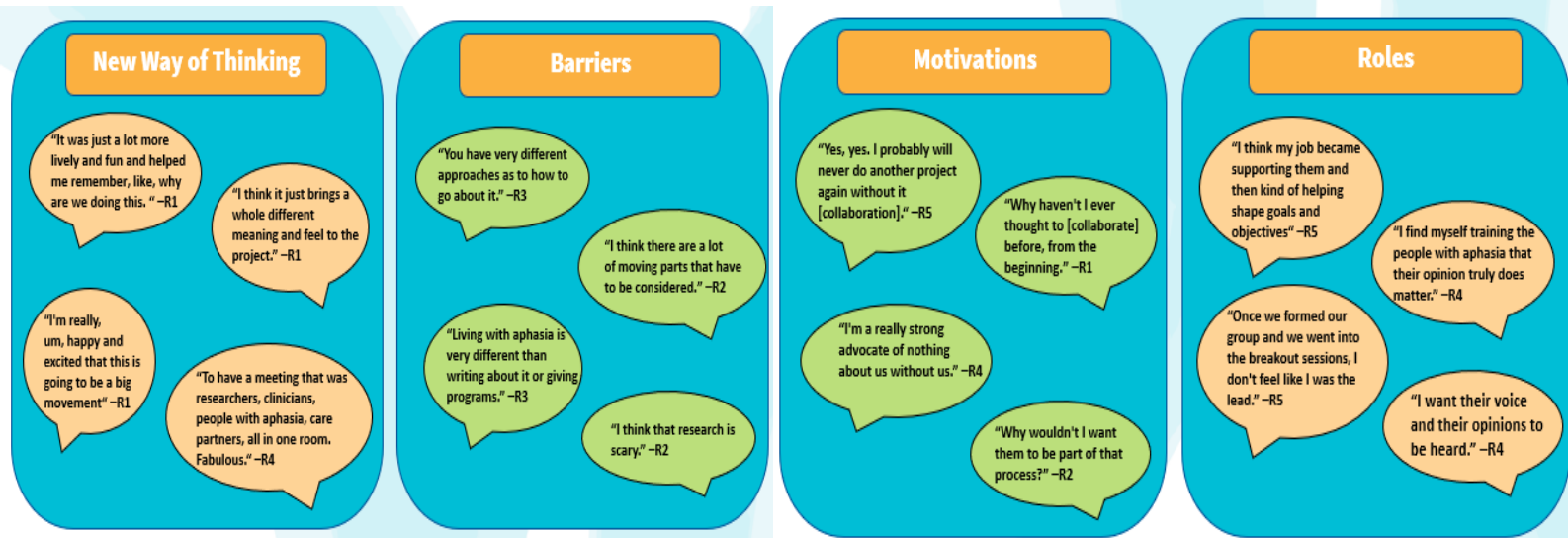
The purpose of this project was to explore the perceptions of researchers who have become involved in conducting stakeholder-engaged research in aphasia. We wanted to gather their ideas about advantages, disadvantages, facilitators, and barriers.

Methods

A phenomenological qualitative analysis was used to describe an individual’s lived experience. This project received ethical approval by Nova Southeastern University (#2020-266) and Central Michigan University (#2020-737). Semi-structured interviews were conducted with five participants to investigate their experiences after participating in the 2018 BRIDGE Conference.

Results

Using Graneheim and Lundman’s (2004) qualitative content analysis, main themes and subthemes were created.



Key Findings

The four major themes are consistent with SER literature in other disciplines. They, nonetheless, shine a light in the details on how to conduct this in aphasia research. This project uniquely contributes to applying SER to aphasia research.

Themes are underlined, and subthemes are bolded and italicized:

- New Way of Thinking and Doing: Participants agreed that SER training had a ***positive lasting impression*** on them, and some indicated they would not consider future projects without SER. Additionally, researchers reported ***navigating research directions*** and ***expanding their collaborative network*** as they began to view persons with aphasia, family members, and clinicians as research partners.
- Barriers: While SER was well received, it was not without barriers. Gaps in ***knowledge and communication*** of team members were identified. Additionally, participants reported a lack of ***preparation*** and ***resources*** as barriers. ***Competing agendas***, such as time, other research projects, and other job responsibilities interfered with SER. Participants also identified the lack of ***momentum*** of the team as a barrier.
- Motivations: SER was viewed as instrumental in ***making better researchers and clinicians***. The experience was also viewed as ***shaping future research endeavors***. Participants reported ***past personal experiences*** influenced their participation in SER. Participants agreed that ***starting with stakeholders*** increased their research interest. Lastly, ***synergy as a driving force*** provided fuel for the team.
- Roles: Team formation required ***establishing roles*** of team members which was a different process than other research experiences. Participants reported ***evolving leadership*** roles with teams.

Resources

- Resources of engaging people with communication disabilities into research, including training and support: <https://www.projectbridge.online/>
- Get involved with Project BRIDGE! Contact your local regional center: <https://www.projectbridge.online/about-regional-centers/>
- The Patient Centered Outcomes Research Institute (PCORI) provides funding for research, engagement, and dissemination projects. <https://www.pcori.org/>
- PCORI Engagement Resources, including a series of courses on “Research Fundamentals” for non-researcher stakeholders: <https://www.pcori.org/engagement/engagement-resources>
- Get involved with PCORI by becoming a PCORI Ambassador: <https://www.pcori.org/engagement/engage-us/pcori-ambassador-program>

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Please refer to the poster for the reference list.