

Project BRIDGE: Building Research Initiatives by Developing Group Effort

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BACKGROUND

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).

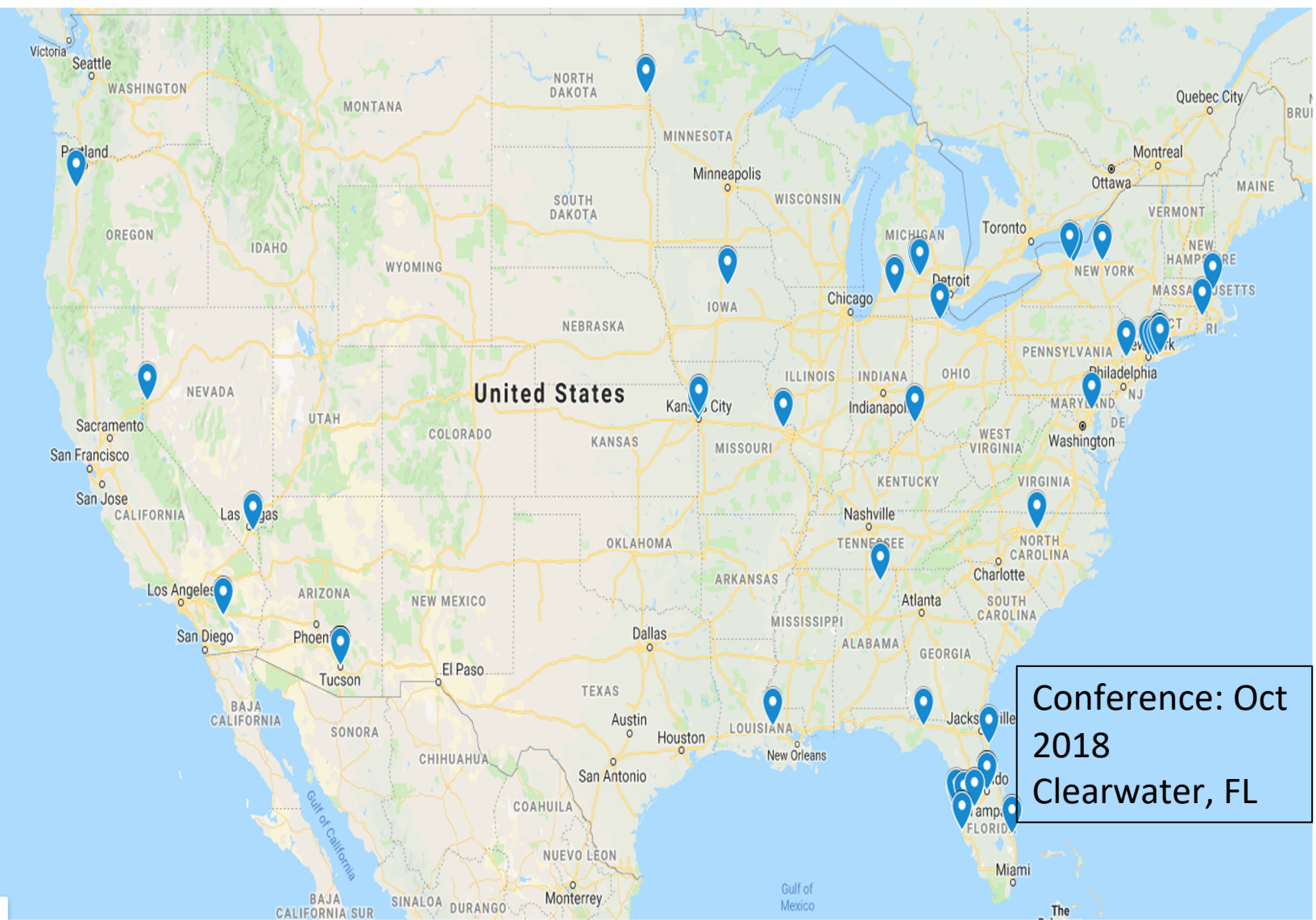
Recommended practices for including consumers in research (Dudley et al, 2015; Elberse, Caron-Flinterman, & Brower, 2011; Panofsky, 2011) involve

- 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.

METHODS

Open Access to
Project and Training
Webinars

3 webinars
completed



102 participants:

33 patient partners, 25 family members, 18 clinicians, 26 researchers created

11 research teams



RESULTS

A Model for Collaborative Research



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

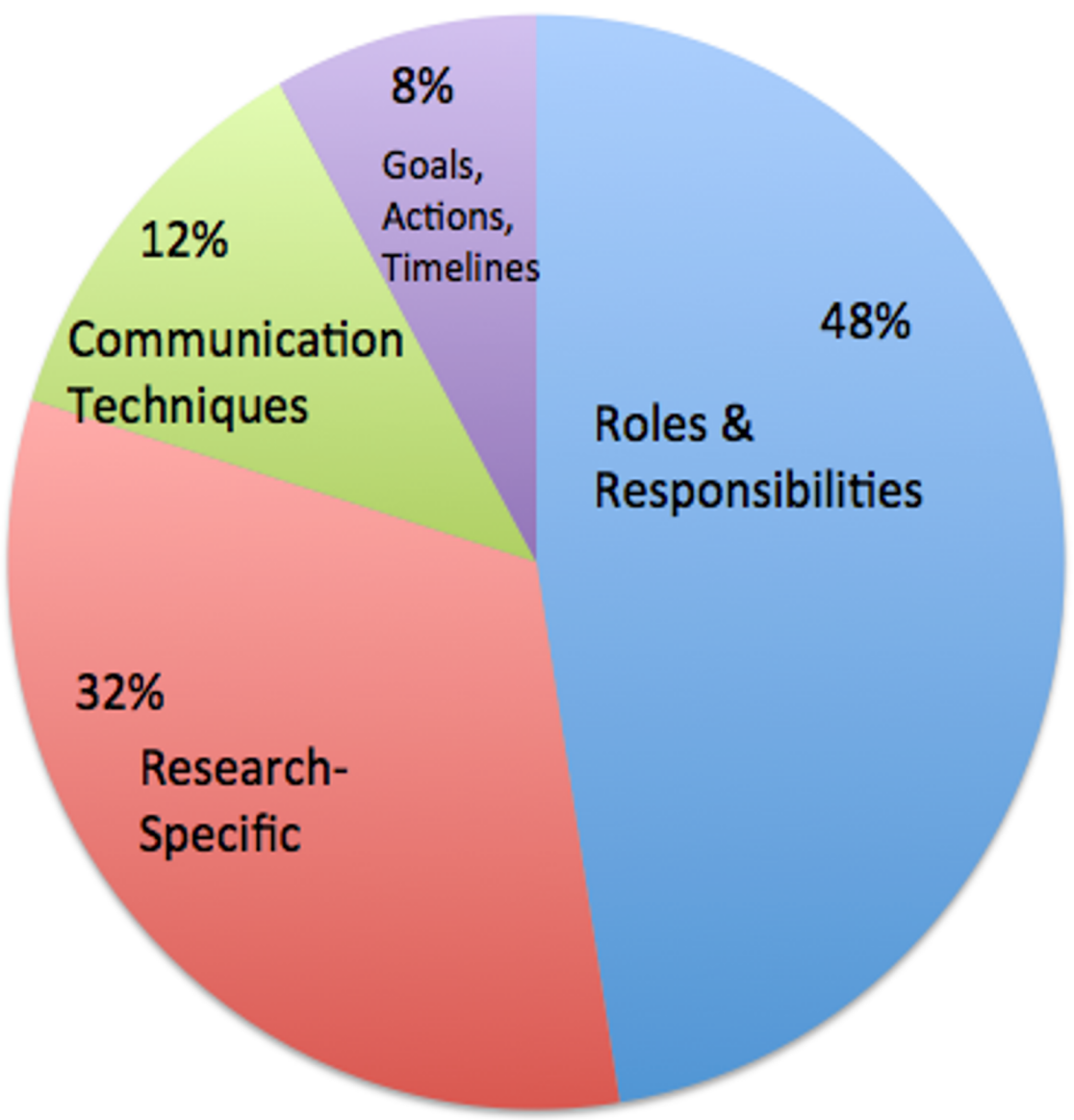
Table 1. Examples of experiences reflected by selected project groups.

Name	Role	Reflections from experiences
Jennifer	Person with aphasia	"I love research! In fact, I was working on several journal articles in my field when I had the stroke. I want to be a voice for all stroke survivors because I had Global Aphasia (now Fluent Aphasia). I couldn't express my thoughts verbally and I found Project BRIDGE. I could participate with my disability and I felt truly valuable as a research team member! I got another chance at life to relearn how to do research. This way I could give to all the other stroke survivors and make a difference!"
Kerry	Clinician	Project BRIDGE is the first experience I have seen where there is a true collaboration between academics directly involved in research and people living with aphasia. Everyone on the team has a unique contribution to the project."
Lauren	Researcher	"Project BRIDGE opened my eyes to an innovative way of conducting research. I enjoyed working alongside stroke survivors, co-survivors, and professional colleagues to create a research project stemming from our combined interests and/or experience."
Kathy	Family member	"important to determine an individualized approach to capturing the thoughts and feelings of the people with Aphasia that are participating in the research project."

Team Leaders' Conversations: Follow-Up #1 4 months later



Team Leaders' Conversations: Follow-Up #2 7 months later



WHY IS THIS IMPORTANT?

People with communication disabilities, such as aphasia, and communication differences, like low English proficiency, are often excluded from research participation or collaboration. For example:

- People with aphasia were excluded in over 70% of trials addressing information and education after stroke (Brady, Frederic, & Williams, 2013), and
- People with low English proficiency were excluded in 20% of all clinical trials in Australia in 2015 (Stanaway, Cumming, & Blythe, 2017).

An estimated **14% of the US population experiences some type of communication disability** (American Speech-Language-Hearing Association), and **roughly 8% of the US population was considered "Limited English Proficient"** in 2013 (www.migrationpolicy.org).

Therefore, insights, processes, and approaches to including individuals with communication disabilities and/or differences in research planning can be relevant to at least **1/5 of the US population**.

WHAT RESEARCH TEAMS SHOULD KNOW

After an initial investment of time and energy on **communication techniques**, engaged research teams can later focus more on research-specific issues. **Team Leadership and determination of roles and responsibilities** within each team continues to play a critical role in the functioning of the collaborative research team.

Collaboration with patient partners and family members can change research priorities, recruitment methods, consent procedures, measurement selection, and dissemination choices. Collaboration can make research projects more applicable to the people who will be affected by the research, more usable, and more efficient.

PROJECT ADVISORY TEAM

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Mr. Tom Boyle
Person with aphasia, Co-Founder of the Suncoast Aphasia Support Group in Sarasota, FL

Mrs. Erika Boyle
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Mr. Mike Caputo
Person with aphasia, and co-Founder of Voices of Hope for Aphasia in St. Petersburg, FL

Mrs. Kathy Caputo
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MORE INFORMATION

Access transcripts, webinars, and other materials at:

www.aphasia.org/projectbridge/overview
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