Experiences of Stakeholder-Engaged Research
A Survey of People with Aphasia, Family Members, Clinicians, and Researchers

Background

What is stakeholder-engaged research (SER)?
- Collaboration between the individuals who are affected by research and the researchers.
- Relies on shared decision-making about research priorities, methods, measures, and dissemination[1].
- It is a person-centered approach, which we believe brings the elements of LPAA to research practice.

What is Project BRIDGE?
- National research network dedicated to providing the training and supports needed for people with aphasia, their families, aphasia clinicians and researchers to engage in collaborative research[2, 3].
- Was initiated with a conference in October 2018, and it is currently continuing with four regional centers around the U.S.

Purpose

Gather the perceptions of people who participated in Project BRIDGE training about the facilitators, barriers, advantages, and disadvantages of stakeholder-engaged research.

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Sample Questions

Facilitators (Researcher and Clinicians version)
- What facilitators are there that can help people living with aphasia and researchers to collaborate on research? (Check all that apply)

Barriers (Aphasia-Friendly version)
- What makes designing research with clinicians, researchers, and people with aphasia **difficult**?

Advantages (Researcher and Clinicians version)
- What do you perceive as the advantages of research that is collaboratively planned with aphasia researchers and people living with aphasia? (Check all that apply)

Disadvantages (Aphasia-Friendly version)
- What are **disadvantages** of designing research with clinicians, researchers, and people with aphasia? (Check all that apply)

Results

Both groups (100% PWA; 93% researchers and clinicians) agreed on the following:

Facilitators to collaborative research:
- Willingness to participate
- Aphasia-friendly supports.

Advantages of SER:
- Representativeness of research
- Relevance of the research.

Barrier to collaborative research:
- Lack of research information available to people with aphasia

Disadvantage of SER:
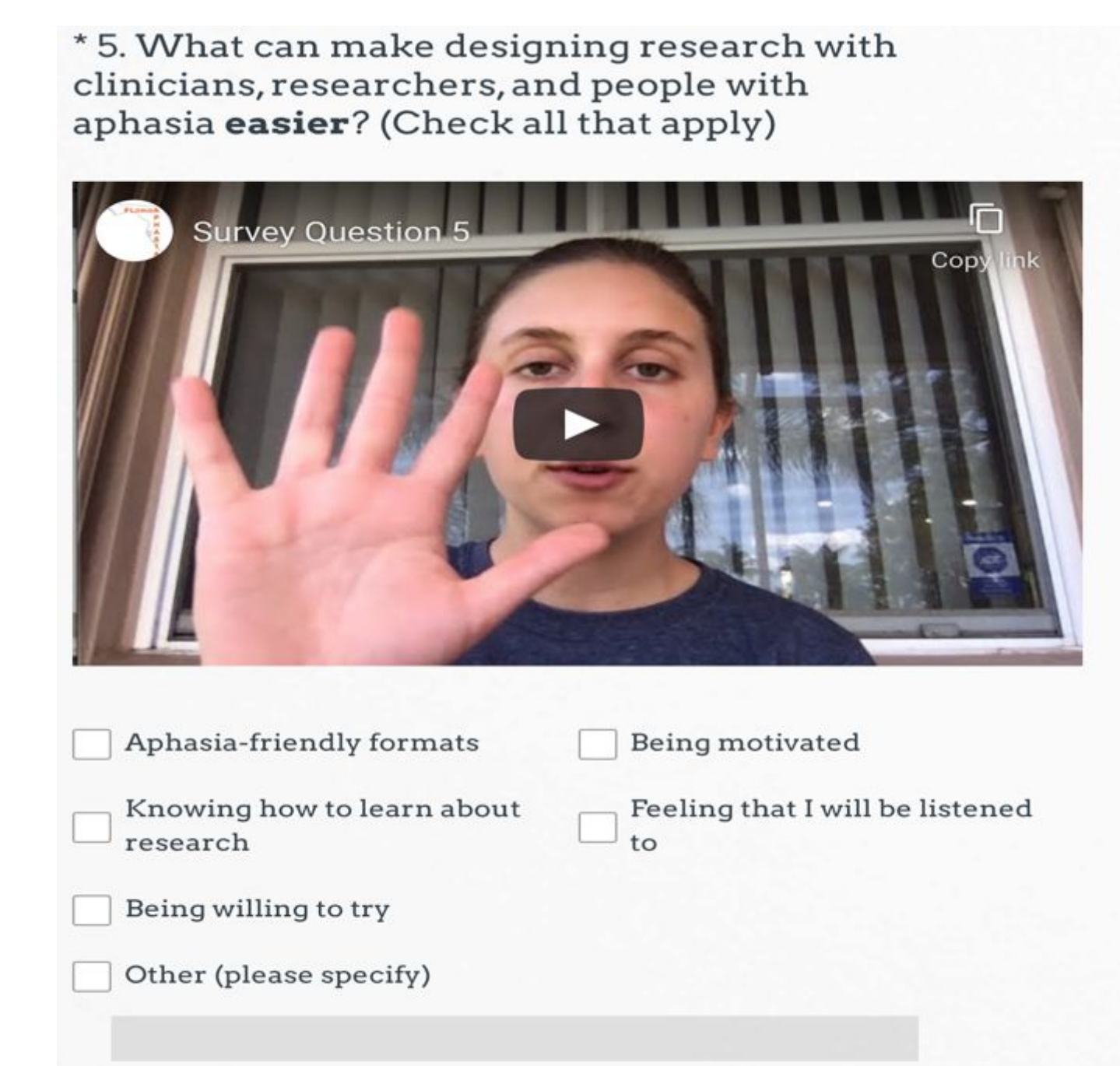- SER is time-consuming.

Methods

Participants
- People with aphasia, family members, researchers, and clinicians

Design
- A pre-conference survey was sent out one month prior to the conference.
- A follow-up survey was sent out 18 months after the conference.
- Survey questions were designed to be aphasia-friendly in terms of vocabulary and reading ease.
- Respondents were provided with audio, video, and text options.

Measures:
- Questions addressed the likelihood of participation, facilitators, barriers, advantages, and disadvantages of stakeholder-engaged research.

Analysis
- 14 people with aphasia and family members completed the survey both pre-conference and at follow-up.
- 14 clinicians and researchers completed the survey both pre-conference and at follow-up.

Discussion

- Participants' **overall willingness to engage collaborative research** did not change over time with experience.
- People with aphasia/family members and researchers/clinicians **agreed about the primary facilitators, barriers, advantages, and disadvantages of stakeholder-engaged research** both before and after they had experience in it.
- These results are consistent with similar efforts outside of aphasiology[4, 5].
- The implications for training and supports that can help stakeholders work together will be discussed.

** Please refer to the handout for a list of references