Day 1: Welcome and Conference Overview

Rebecca Watson, Facilitator, Collaborative Labs: Good morning, everyone! It’s Friday! Welcome to the BRIDGE conference. I am Rebecca Watson, your facilitator, and I welcome you! On behalf of Collaborative Labs, we are happy to have you here.

I want to introduce you to my team before I turn it over to Dr. Brice. Geoff is our visual illustrator, and his job is to capture the essence of our time together in visual form. Karin is our documenter; she will be capturing the conversations and comments that come up over the two days and creating the most robust meeting notes you have ever seen. Dru is my partner, and he will co-facilitate with me today. Michael is our technologist who makes all of the technology we use work.

Alejandro Brice, Ph. D., Professor, University of South Florida St. Petersburg: Good morning! Welcome to the BRIDGE conference. I am with the University of South Florida, and with my partner, Jackie Hinckley, we are bringing you this conference. This conference brings us all together – patients, caregivers, clinicians, researchers, and speech pathologists. We have a guest speaker and a panel coming up, but first I will turn it over to Dr. Hinckley.

Jackie Hinckley, Ph.D., Executive Director, Voices of Hope for Aphasia: Good morning, thank you for being here! I want to turn it over to Voices for Hope for Aphasia.

MC Daughtry, Treasurer, Voices of Hope for Aphasia: We welcome you to this exciting conference. It is with great pride that our organization is involved with this event. The conference is a milestone in the aphasia community, bringing together people with aphasia, caretakers, family members, clinicians, and
researchers to work as one. We want to thank Dr. Jackie Hinckley, who took the lead on this project and collaborated with the University of South Florida – St. Pete and Dr. Alex Brice. She has been important to our organization and we are blessed to have her in our lives. Make connections and have fun while you are here.

Debbie Yones, Program Director, Voices of Hope for Aphasia: Good morning! I am a speech language pathologist and program director at Voices of Hope for Aphasia. I am eager to meet new people and happy to be here.

There is an auction that I want to tell you about. Proceeds go to programs of Voices of Hope for Aphasia. In the hallway are beautiful handmade items you can bid on to take home as memories of today. We also have a 50/50 lottery drawing. You can win half the pot!

The small cards on the table have a hashtag that you can use on social media; please use #bridgeproject2018. I’d like to introduce our founders Mike and Cathy Caputo.

Mike Caputo: Hi! How are you? Dr. Brice, thank you. Dr. Jackie Hinckley, (patted his heart).

Applause.

Kathy Caputo: Thank you. Those of you that know us know we wear this on our sleeve. The more we know, the better our lives become. Let’s all work together and make this successful. Thank you!

Dr. Hinckley: Welcome, everyone. This is a fabulous day for me. I am happy to introduce our project advisory team. They have been helping us plan this conference before we got the money to do it. I ask them all to stand up as I say their names.
Cheryl Paul, Clinical Instructor, University of South Florida: We ended up getting ASHA CEUs for this conference; we will get up to ten plus hours of content. For the people that want to get it, you will have a green form to sign today and tomorrow. Make sure your email address is correct; you’ll get your certification of completion by email. You can sign in during the break and lunch and turn them in at the end of the day tomorrow. Applause.

Dr. Hinckley: We wanted to thank our partner, the National Aphasia Association. The link to the meeting minutes will be on their website. Many thanks to our partners, Collaborative Labs; I love them already. We will be in this room all morning and lunch will be served here today. We will have signup sheets out for different restaurants in the area for dinner. You can connect with folks in a nearby restaurant. You are welcome to do your own thing as well.
Dr. Hinckley: We have some tools and supports available to you. We have an army of volunteer students; please stand. **Applause.** They come from University of South Florida, University of Central Florida, and Nova Southeastern University. They have attended special training to help you today.

If you have aphasia, you may have a student come up to you and introduce themselves and ask if you would like some support today. They are available to help you. You do not necessarily have to stay with a support person you brought with you today.

We also have handouts on the tables that show pictures and keywords that might be familiar to you from the webinars you watched. Use it, write on it, take it with you. Another resource we have is some blank notebooks. If you benefit from having words written out, or you prefer to draw, or have pictures drawn, ask for a notebook, which you can take home with you. This is like your wipe board, but more permanent.

Later today and tomorrow, each team will have one of these. Each team can write and draw and have a team notebook. We have some other tools, such as pictograph tools, you can look at later.
Dr. Hinckley: What are we all doing here? By the end of the conference tomorrow, we will have research teams, you will have a topic, and know the work you need to do when you leave here. Around February, each team will have a virtual meeting with Dr. Brice and me, to help you and check-in. Then we will do it again. I am sensing a change; it doesn’t seem so fun anymore, does it? *Laughter.* Do not worry it is going to be fun.

We are going to start with our keynote address.

### Keynote Address

**The Vision of Patient Partners-Researcher-Clinician Collaborations and How it Would Change Things**

**Dr. Brice:** Yes, we are going to follow up with you, and it is going to be fun. You might get a Skype of me doing the meringue!

Now, I am excited to announce Lisa Stewart. She is an Engagement Officer at the Patient-Centered Outcomes Research Institute (PCORI). She acts as a liaison between the Engagement and Science programs, helping to manage the organization’s research portfolio and supporting the engagement of patients and other stakeholders throughout the course of research studies. This is her job, but she’s told me she’s been on the other side, and she will talk more about it now.

**Lisa Stewart, Engagement Officer, Patient-Centered Outcomes Research Institute (PCORI):** I am thrilled to be here. I want to thank you for being here. The theme of this talk, “The Vision of Patient-Partners-Researcher-Clinician
Collaborations and How it Would Change Things,” is what we will return to at the end. I want to ask this question to you guys: what is our vision going forward?

Lisa: First, I want to see who is in the room. If you are a person with aphasia or a caregiver, please say, “I am here” or raise your hand. Clinicians and speech pathologists, say, “I am here.” Researchers and non-clinicians, say, “I am here.” Geographically, if you are from outside of Florida, raise your hand (many hands raised). Wow!

Lisa: You all have different pieces of information. My presentation will touch on many areas.

I work for PCORI. “Patient” is the first word. We are an independent organization that funds research. “Independent” is a key word; we are not a government agency. Our research projects compare two or more methods to address a problem: a clinical issue or how care is delivered.

A clinical issue might be around what kind of treatment best works in delivering speech pathology. The more I am in this line of work, the more I understand how novel patient involvement is. User input is vital. We are bringing that element to research and ethics on how it is done.
Lisa: Our work is different because it happens in real-world settings. A lot do not. They are done in labs or simulation environments that simulate ideal settings. For example, taking the bus to get treatment is complicated, and maybe we need to offer it in a home setting. We also have a focus on populations that have been underrepresented, such as women, children, veterans, LGBT, etc.

Lisa: Stakeholders are all involved in PCORI. We have representatives from all groups. The patient engagement advisory panel I run has industry and policy people, because if we do not have everyone involved, we cannot get this done. Sometimes I make recommendations on groups or people that need to be involved.
Lisa: The niche that PCORI is filling is beyond the stakeholders. It is the distinction between efficacy, which asks, does it work, and effectiveness, which asks, could it work better? One guideline may work for certain types or at certain times. They may already be in practice, but the question becomes what works better?

Lisa: Patients must express what is important to them. If you have a research study that asks 100 questions every two months, people are not going to do it. Patient and stakeholder engagement involves everyone meaningfully. Partners are the people who collaborate with researchers.
Lisa: Engagement shows up in many ways in different levels of intensity. You do not always need all forms. As you plan your engagement, the patient input is a low-level of intensity, but high value. Advisory panels can be blended. Collaboration and shared leadership is a high level of intensity. Sometimes there is the appearance of collaboration and shared leadership, but the structure is not in place. The ultimate form is patient-driven collaboration. That is when patients, consumers, and caregivers ask the question and the researchers come to them.

**Words and concepts**

3) **Patient-centered**
   - Research that responds to the needs, values and preferences of patients
   - The patient voice is central
   - The experience of a research participant is low burden

4) **Patient and stakeholder engagement**
   - Meaningfully involving patients, clinicians and other people who have a strong interest in an issue in selecting a research topic, planning and running a research study, and sharing research results

5) **Research Partners**
   - People who collaborate with researchers

**Lisa:** What are key ingredients to working well together? People need to define roles to work together. There needs to be transparency and trust. Trust is a moving target; there may be breakdowns. We need to address any breakdowns.
Lisa: Are there any questions at this point?

Speaker: Has PCORI funded any research projects for people dealing with aphasia?

Lisa: Not specifically. There are cross-cutting projects. We have projects led by OTs and speech pathologists.

Lisa: This is how I got into this business. I share this to create a bridge. I have been on the other side. I worked on a PCORI project and became an advocate. I have two daughters that have differences. My daughter Maya was born with pulmonary hypertension and was hospitalized a lot. As a consequence of her medical issues, she was G-tube (gastrostomy tube) dependent for many years. We are scheduled to get G-tube removed soon. Applause. We have been through many rehab programs.

Lisa: Her sister was born with medical issues as well. She has been receiving OT and PT services since she was one year old and speech-language pathology most of her life. I was in the hospital most of their lives. I was offered a position as a navigator to help families patch into services, give emotional support, and coordinate with doctors.
We have a multi-stakeholder group.

Lisa: One of the projects I worked on shows different experiences and perspectives. I asked people to send a photo of something that creates stress around asthma.

Lisa: In the first picture is a spacer and an inhaler; there is a roach inside it. That is the reality of some people. That opened the researcher up to understanding what was going on in peoples’ lives and thinking about research differently. The second picture is of someone trying to give up smoking. That is real life. The next photo demonstrates the number of medications some people have to take. The picture of traffic shows the fear of being stuck in traffic during an emergency. Some caregivers responded, at least you have a car, we must use the bus and must decide if it is worth calling emergency services. Everyone brings a different set of knowledge or experience to the table.
Lisa: The real world is not about an ideal problem with an ideal solution. What elderly person has only *one* medical problem?
Lisa: We learned people wanted to improve people’s lives.
Lisa: We wanted to make sure a certain voice was at the table and not exclude anyone.

Lisa: As engagement officers, we look for someone that represents both treatment arms, for and against, to balance it out.
Lisa: What happens to people when they partner with researchers? People shared that they grew their circles by participating. Partnering puts your vulnerabilities out there.
Lisa: People at the end stages of life, wanted to leave a legacy of contribution.

Motivations for engaging:  
#3: Support an effective intervention

A belief that the intervention would help other people, based on experience or a sense of importance

“I believe in early intervention of PT/OT as a significant factor in the success rate of patients with traumatic brain injury.”
- Carer

Lisa: This is a mom, a quiet person, and this work brought something out in her. Now she is an author and speaker.

Impacts of engagement on partners:  
#2: Making a meaningful contribution

As an ‘older’ citizen, with mobility limitations, this involvement has allowed me to ... contribute "to the better good". Although I have personal medical issues and challenges... doing what I can in my very limited capacity to improving opportunities for broader patient involvement in healthcare decision making and the shaping of healthcare to reflect patient needs.
- Patient/Consumer
Impacts of engagement on partners:

- #3: Greater knowledge and enthusiasm for research
- #4: Making improvements to health and health care
- #5: Developing skills and professional opportunities

Why this matters?

Helps study teams to better:
- Promote engaged research to potential partners
- Create incentive structures that are meaningful to partners
- Set expectations
- Communicate to patient partners the value of their contributions
Lisa: Make sure the partners represent the people you hope to create benefit from. Researchers need one thing and clinicians may need something else.

Tips for partnering

#1 - Have clear goals and objectives for why you want to partner (why does this partnership make sense?)

#2 – Choose your partners wisely
   • What do they bring to the table?

#3 – Define roles
Lisa: I want to hear from you, how do you think patient-research-clinician collaborations would change aphasia research?

Speaker: If it is patient-driven, especially research, it will be more relevant.

Speaker: It will be more urgent. They want it yesterday.

Lisa: That is part of our mandate also. Speed the uptake of research findings. We do not work hard for it to sit on the shelf. Even in null findings, there is some value. Even if findings do not come out as expected, we encourage researchers to find the value.
**Kathy Caputo:** We need to be understood. Caregivers have a lot to say. We are not living this, however. Mike feels differently than I do, and I cannot communicate for him. I would know things were changed if I saw change in Mike’s behavior and demeanor.

**Lisa:** They are choosing what is measured. Patient outcome would be sense of well-being and quality of life. But how do you measure that? Those are the activities we want to see patients and caregivers do.

**Speaker:** The people living with the diagnosis are the experts, not the researchers and clinicians.

**Speaker:** I am a clinician and people always surprise me in coming up with good ideas. That encourages researchers to keep coming up with new questions.

**Lisa:** Focus groups are different than engagement groups. Engagement groups make sure it is implemented.

**Speaker:** I had a stroke five years ago. I could not spell aphasia; I did not know what is was. Everyone knows what cancer, or a stroke is. The population does not know what aphasia is.

**Lisa:** I think you do that by finding similarities with other groups. My one daughter has neuro processing challenges and it is hard for her to articulate herself. How can we find sameness among the groups?

**Speaker:** I also had a stroke. I just did a study of twenty hospitals in the area. Of twenty hospitals in Florida, in sixteen of those, if you go to their website and search for *aphasia*, it brings up no result. They have not put out any of the good information that they have on hand. People would like to have the conversation that puts that information on the hospitals’ website. In the world at large, most people know nothing about aphasia.

**Speaker:** I am a family member. The difference is in the successes and what seems to work. You talk about collaboration, exercise, nutrition, and all disciplines coming together to share their knowledge.

**Speaker:** I want to go back to the point previously made, that they do not get it. They are not in the room. As we move forward, we must remember the they
are not here. Keep in mind when you were in the hospital and could not talk, there are people today that are in that same scary situation at the beginning and not understanding what is going on.

**Lisa:** There is a challenge of being a representative. You are already in a place of privilege, as you can be in this room today. We need to keep in mind how to represent others.

My final comment is to give thanks to speech pathologists, clinicians, and nutritionists, who give support. A lot of people do not understand the different between researchers and clinicians. I thank you for your support. *Applause.*
Rebecca: Thank you, Ms. Stewart, and thank you for your thoughtful questions. We will take a quick break before we get started with the panel discussion.

Speaker Disclosures

Lisa Stewart: Financial: Employed by PCORI

Alejandro Brice: Financial: Professor, at University of South Florida
Nonfinancial: PI on Project BRIDGE

Jackie Hinckley: Financial: Associate Professor at Nova Southeastern University
Nonfinancial: Co-PI on Project BRIDGE

Audrey Holland: Financial: Project consultant for the Carnegie-Mellon University AphasiaBank project; Consultant on various federal contracts; Financial compensation/honorarium for participation in this conference

Kathryn Yorkston: Financial: Professor, Department of Rehabilitation Medicine at the University of Washington Medical Center; Financial compensation/honorarium for participation in this conference; Funding on the following grants: 1) Yorkston, K. Co-Investigator (.12 FTE) (NIH Grant: 1R01DC012510-01A1) (Baylor, PI) Title: Communicative participation outcomes measurement in neurologic communication disorder Grant Period: 3/1/13-2/28/19 2) Yorkston, K. Co-Investigator (NIH Grant; 1R01CA177635-01A1) (Eadie, PI) Title: Communication Outcomes after Head and Neck Cancer. Grant Period: 04/01/14-02/28/19/