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Experiences of people with aphasia communicating with healthcare providers

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Experiences of People with Aphasia Communicating with Healthcare Providers

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Abstract

Aphasia is an acquired communication disorder, often resulting from a stroke, that impacts millions of Americans. People with aphasia (PWA) may frequent the hospital for a number of services poststroke and are often accompanied by their primary communication partners (PCP), the person with whom the PWA communicates with the most. This qualitative study explored the experiences of four dyads of PWA and their PCPs' perspectives on communicating with healthcare providers (HCPs). Findings indicated that there are attributes of HCP interactions which contribute to patient-perceived success, such as collaboration with PCPs, and aphasia knowledge. These attributes were also associated with patient-centered care. In addition, dyads spoke about the importance of their PWA-PCP teamwork in approaching HCP interactions, with PCP advocacy, background, and flexibility contributing to successful teamwork. This study suggests that areas in which participants were dissatisfied with HCP services may be remedied by communication partner training for HCPs and PCPs.

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Chapter 1: Introduction

Purpose and Objectives of the Study

Over the last decade, there has been increased interest in the impact of various communication partner training methodologies on healthcare providers and primary communication partners (PCPs) of people with aphasia (PWA). However, there is still a need for increased qualitative research investigating the experiences of PWA and their PCPs with providers, to inform the kinds of communication partner training that will best suit the needs of PWA. It has been suggested that speech-language pathologists (SLPs) should take a more active role in bridging communication barriers between PWA and healthcare providers (HCPs) by providing therapy strategies for PWA to approach these potential barriers and educating their fellow HCPs in interacting with PWA (Burns, 2015; Hersh, 2015), to create a "communicatively accessible environment" (Simmons-Mackie, 2013, p. 99). SLPs may also play a valuable role in modifying environmental factors influencing communication, such as acting as advocates for PWA and educating providers on ways to reduce environmental barriers for PWA in hospitals. Bridging the communication gap that exists between HCPs and PWA is especially important when it is taken into consideration that PWA are more vulnerable to receiving poorer healthcare as a result of their limited ability to give feedback to HCPs (Hersh, 2015), which further supports the need for increased studies revealing the experiences of PWA with healthcare providers. This research could serve as a starting point for HCPs and SLPs in particular, to begin working together to develop new protocols and ways of approaching care with PWA, which will create more accessible healthcare that will be applicable to other communication vulnerable populations.

In addition to clinical relevance, this study fills a need in stroke research, as PWA are often excluded due to their communication-related impairments (Brady et al., 2012; Townend et al., 2007). This is especially unsettling when an estimated 88% of patients admitted into acute hospital stroke units were reported as having one or more types of communication-related impairment; 69% of which had multiple communication-related impairments (O'Halloran et al., 2008). This means that though the majority of stroke survivors have communication impairments, they remain an under-researched population within stroke research. Further research exploring the communication healthcare-related needs of PWA are needed to further inform stroke literature on problems that should be addressed in future stroke studies.

Although SLPs may represent a potential solution to bridge the communication barriers between PWA and HCPs, they are not consistently utilized in the study designs and treatment involved in stroke research (Pearl & Cruice, 2017). The current study can inform researchers outside of the realm of speech and language of the importance of involving SLPs in the treatment of PWA, whose inclusion would therefore be crucial to the design and procedure of stroke research.

Research Question

This research study explored the experiences of PWA and their PCPs with HCPs, to reach a better understanding of how PWA and their PCPs feel their needs are being met by their various providers, how HCPs adjust to their needs, and what (if any) changes providers should make to better treat patients with aphasia and their families.

Chapter 2: Review of Literature

People with Aphasia & Healthcare

In healthcare settings, it is crucial that patients and HCPs are able to effectively communicate, to facilitate a good working relationship and trust between patient and provider, and to allow providers to meet basic standards of care (O'Halloran et al., 2012). Developing effective communication is especially important for HCPs working with people with communication disorders, whose impairments increase their risk for communication breakdowns, which can result in medical errors (Blackstone et al., 2015; The Joint Commission, 2010). As communication is the "medium" through which traditional healthcare is provided (Lipkin, 2010, p. 3), patients with communication disorders experience reduced autonomy in making health-related decisions, including decreased opportunities to participate in shared decision-making about their care (Murphy, 2006; Pound et al., 2007). The presence of communication disorders has also been linked to reduced accessibility to healthcare services (Ziviani et al., 2004), and decreased satisfaction with services provided, compared to other patient populations (Hoffman et al., 2005).

Communication breakdowns and resulting medical errors are more prevalent with patients who are deemed "communication vulnerable," like those with aphasia (Blackstone, 2015). Aphasia is a communication disorder which results in impairments to a person's ability to express and understand language (National Aphasia Association, n.d.). Aphasia is caused by various brain injuries, the most common of which is stroke (National Institute on Deafness and Other Communication Disorders, n.d.). According to the National Aphasia Association (n.d.), around 750,000 strokes occur each year, and about one third result in aphasia. Due to their communication impairments, PWA experience difficulties communicating their medical questions and needs, making them highly vulnerable to reduced health-related quality of life compared to other populations of patients (Bartlett et al., 2008; Hilari et al., 2012).

O'Halloran et al. (2009) explored how patients poststroke with communication impairments communicated with their HCPs. More than half of patients (55%) admitted into hospital acute stroke units experienced difficulties communicating their healthcare needs with HCPs. Interestingly, even with direct assistance from a communication partner or assistive communication device, 51% of patients continued to demonstrate difficulties communicating their health-related needs to providers. This indicates the continued need for effective means of facilitating communication between PWA and HCPs. In addition, increased severity of patients' communicative impairment was associated with an increase in the severity of difficulty communicating with HCPs. This puts those with more severe communication impairments at greater risk for communication difficulties and misunderstandings with HCPs. While the ability to communicate forms a barrier for PWA to receive adequate healthcare, environmental barriers within the healthcare system also pose challenges for HCPs treating PWA.

Barriers in Healthcare

Various barriers that exist between PWA and their medical providers have been identified in recent literature. O'Halloran et al. (2012) indicated that there are several environmental factors that influence communication between patients with communication disorders and their HCPs in hospitals, including: the HCPs' knowledge, skills and attitudes, the patient's family, the physical environment and hospital services, and hospital systems and policies. Environmental barriers for people with communication impairments include high levels of background noise interfering with comprehension of speech, limited accessibility of assistive listening devices, and lack of written materials in accessible formats. Though environmental and systemic barriers were observed in the study, it was the barriers in HCPs' knowledge and skills in treating those with communication disorders that was most detrimental to patient-provider communication (O'Halloran et al., 2012). In fact, one barrier to communication was the HCP's lack of awareness that their patient had a communication disorder at all. Of the seven barriers to communication observed, four were related to HCPs (O'Halloran et al., 2012). These findings suggest that elimination or modification of environmental barriers may enable patients with communication disorders to more effectively communicate with their HCPs (Cameron et al., 2017b; O'Halloran et al., 2008, 2012; Simmons-Mackie et al., 2010).

However, many providers face challenges securing the necessary resources to create a communicative environment with reduced barriers. In acute hospital settings, nursing staff are the most frequent communicative partners, after family members, of patients in hospital poststroke (Hersh et al., 2016). In observing the role nurses play in communication interactions with patients poststroke, it was found that nurses often act as the primary initiators and controllers in conversations with patients, and that conversations were often limited to the topic of physical care (Hersh et al., 2016). Older adults with aphasia living in long-term care facilities also reported feeling their social needs were often ignored by staff members, and that communication was often reserved for task-focused interactions (Saldert et al., 2018). Nurses' control of conversation and limited social interaction with patients is likely due to high patient caseload and time constraints, but it nevertheless results in patient-provider conversations that are neither therapeutic nor individual in nature (Hersh et al., 2016). Patients also experience difficulties communicating with HCPs when they feel the encounter is rushed (Ziviani et al., 2004). This is especially impactful as patients may be more cognitively and socially active when provided with an enriched environment, or one which actively promotes physical, mental, and language-rich stimulation, during their hospital stay (Janssen et al., 2014). Hersh et al. (2016) further postulated that through their lack of individualized linguistic engagement, nurses may contribute to a person with aphasia's learned non-use of language. This occurs when limited verbal conversation results in decreased language stimulation, and subsequent reduced language use (Pulvermüller & Berthier, 2008). These findings further highlight the necessity for communication partners of PWA to be effective communicators.

Service Delivery Methods

Effective communication in interactions with HCPs is correlated to patient satisfaction (Green et al., 1994; Hall et al., 1988), which has become increasingly important in healthcare, as a significant indicator of patient outcomes, and an overall measure of health care quality (Körner, 2013). A service delivery approach that is well-known and utilized widely in healthcare settings, is patient-centered care (PCC). As its name suggests, PCC involves incorporating individuals as members of their own care, which includes integrating patients' needs, values and preferences (Institute of Medicine, 2001). PCC is also associated with higher patient satisfaction and adherence to treatment, as well as positive treatment outcomes (Rathert et al., 2013; Stewart, 2001). As defined by the Picker Institute, these facets of PCC are (a) respect for the patient's values, preferences, and expressed needs; (b) information and education; (c) access to care; (d) emotional support, empathy, and respect; (e) involvement of family and friends; (f) continuity and secure transition between health care settings; (g) physical comfort; and (h) coordination of care (Gerteis et al., 1993). PCC may also be achieved through patient-centered communication, which may include the use of communication strategies, such as providing clarification when needed, using gestures and writing down key words, and speaking at a comprehension level that is appropriate to the individual (Beck et al., 2002). However, achieving patient-centered communication with patients with communication disorders has proven especially difficult for HCPs (Law et al., 2005; Nordehn et al., 2006; Ziviani et al., 2004). In addition, there is little known about the use of PCC with PWA (Morris et al., 2015).

A model which aims to improve the communication between HCPs and PWA, is communication partner training. When HCPs participate in communication partner training to better facilitate communication with PWA, both PWA and HCPs report positive experiences in growing their understanding of aphasia and improving communicative interactions (Cameron et al., 2017a, 2017b, 2018; Horton et al., 2016; Simmons-Mackie et al., 2010). Though there are studies to support the efficacy of communication partner training with HCPs, physicians have reported receiving limited training related to communicating with patients with disabilities, including communication disorders (Duggan et al., 2009). As a technique to improve patient-provider communication, communication partner training may also represent a feasible method for HCPs to deliver PCC. As consistent implementation of PCC remains a challenge for hospitals (de Haes & Koedoot, 2003), communication partner training may offer HCPs a reasonable way to institute PCC.

People with Aphasia & Primary Communication Partners

The PCP of a person with aphasia is the person with whom they communicate the most with. This might be a spouse, significant other, close family member, or caregiver, amongst others. PCPs have the most contact with the PWA and often attend medical appointments and therapy sessions with the PWA, where they may find themselves acting as an advocate (Burns et al., 2015). Moreover, diminished patient satisfaction with HCP communication suggests that PWA may benefit from the support of an advocate when in acute hospital settings (O’Halloran et al., 2008). Therefore, understanding both the perspectives of PWA as well as the experiences of their PCPs with HCPs is essential in presenting a well-rounded understanding of PCC and evidence-based practice.

Burns et al. (2015) interviewed patients with communication disorders, family members involved with the patient's care, and practicing physicians to explore their perspectives and experiences interacting with one another in a healthcare setting. Though findings revealed that all patients and family members reported positive communication experiences with physicians, participants did describe some challenges and frustrations, which were divided into three themes: (a) patients and family members work as a team, (b) patients and family members want physicians to just try to communicate with the patient, and (c) physicians want to interact with patients but may not know how (Burns et al., 2015). These findings are supportive of previous qualitative studies which revealed PWA want to feel respected, acknowledged, treated with sensitivity, and given access to information and services (Parr et al., 1997; Worrall et al. 2011).

Considerations for Decision-Making

The ability to make healthcare decisions is an important aspect of patient autonomy. The communication difficulties caused by aphasia often diminishes this autonomy and places family members in an active role in the consultations and decision-making processes between PWA and their HCPs. Often family members or caregivers are present and actively involved in medical interactions of people with communication disorders (Karnieli-Miller et al., 2012). This can present complex considerations to the dynamic of PWA and their medical care, as family members can provide important insight into the PWA's communication abilities and desires for therapy. The presence of family members can increase the likelihood of providers prioritizing communicating with the family member, thereby reducing the autonomy of the person with aphasia (Burns et al., 2015; Laidsaar-Powell et al., 2013).

Difficulties in discerning PWA's opinions and decisions from their PCP's is reflected in research with PWA as well. The communication challenges inherent in interviewing PWA often results in the integration of a PCP in the interview process (Croteau et al., 2007; Philpin et al., 2005). However, PCPs may possess different perspectives than those of the PWA (Dalemans et al., 2009; Paterson & Scott-Findlay, 2002). Croteau et al. (2007) conducted interviews with six dyads of PWA and their spouses and found all six spouses demonstrated speaking for another behaviors, in which spouses answered questions addressed to the PWA. Manzo et al. (1995) also observed that spouses of PWA often engaged in competitive conversation, in which they often answered questions that were directed to the PWA. Taken together, this suggests that interviews with PWA and their PCP should focus on asking interview questions to each individual, thereby allowing each participant to speak for themselves and share their own perspective. Effective interviewing strategies with PWA include using pictograms, large font, reducing question length, and highlighting relevant information (Dalemans et al., 2009; Rose et al., 2011a, 2011b). Interviewing PWA and their PCPs is not without its challenges but considering the collaborative efforts PWA and their PCPs employ in healthcare interactions and in their daily life, interviewing the dyad together is a naturalistic way to capture their interactions with HCPs.

Chapter 3: Methods

Study Design

A qualitative research design was employed utilizing phenomenology, which is an approach that explores how people make meaning of their lived experience (Starks & Trinidad, 2007). This study sought to frame the narratives of PWA and their PCPs in relation to their HCP experiences, and a qualitative framework is best suited to analyze the themes of the collected feelings and perspectives of participants (Patton, 2002). To mitigate potential exposure to COVID-19, data were collected through virtual interviews with a person with aphasia and their PCP over Zoom. Interviews lasted from 30 to 90 minutes and took place over 1-2 sessions. Interviews were semi-structured to allow participants to share their experiences with HCPs, which consisted of incorporating open-ended questions and follow-up questions as necessary. Examples of interview questions may be found in Appendix A. Interviews were audio-recorded with permission from the participants, and then transcribed by a professional transcriptionist for data analysis. Field notes were collected during interviews, which consisted of salient information not captured by audio recording (e.g., facial expressions, body language, emotional reactions). All study procedures were approved by the Eastern Michigan University Institutional Review Board (see Appendix B).

Data were analyzed using a qualitative phenomenological analysis. Interview transcripts were analyzed for salient events, phrases, or patterns of behavior which supported the research question. A coding system was developed in which codes were grouped into larger themes and analyzed for consistencies or discrepancies (Bogdan & Biklen, 2007). For a theme to be considered valid, at least 3 out of 4 dyads’ perspectives were included. Subthemes required a minimum of two dyads to constitute validity. These themes were used to create a larger narrative which organized the findings of the perspectives and experiences of PWA and their PCPs with providers (Creswell, 1997).

Study Population

Four dyads of PWA and their PCPs were recruited from an aphasia program for the present study. Dyads were each made up of one male, and one female, and all PCPs were romantic partners of the PWA. Participants' ages ranged from 49 to 75 years of age. The following inclusion criteria for participants with aphasia was developed: (a) a diagnosis of mild to moderate aphasia by the referring SLP, (b) onset of aphasia at least six months or more, and (c) at least 18 years of age. People with severe aphasia were omitted from the study due to increased communication-related impairments, which may impact the individual's ability to respond to interview questions, making them less reliable participants.

A recruitment email outlining the study's details was sent to clinicians and clinic directors working with PWA, offering participation in this study. The aphasia program's clinic director referred PWA to the primary investigator. PWA were asked to identify a PCP, who may include, but are not limited to, a spouse, close family member, or caregiver. Once the person with aphasia and PCP were determined to be eligible as study participants, they were emailed consent forms to sign. Consent was facilitated by modified consent forms that included: (a) the use of simplified terms and sentence structures to increase reading comprehension; (b) the use of visual aids, such as pictures and large text (Brennan et al., 2005). See Appendix C for the modified consent form. Once consent forms were completed, they were emailed back to the primary investigator. Participants, including those mentioned by participants, were assigned pseudonyms to ensure confidentiality.

Participants

Table 1 outlines the participants' demographic information, role in dyad, occupational background, and relationship status.

Table 1

Summary Table of Participants

	Name	Role	DOO*	Sex	Age	Occupation	Relationship
Dyad 1	John	PWA	2019	Male	49	Former VP of Sales	Married 24 years
	Laurel	PCP		Female	50	Nurse	
Dyad 2	Nicole	PWA	April 2020**	Female	56	Not disclosed	Dating for 1.5 years
	Derrick	PCP		Male	58	Not disclosed	
Dyad 3	Thomas	PWA	September 2020**	Male	75	Retired Engineer	Married 50 years
	Anna	PCP		Female	72	Microbiologist	
Dyad 4	Henry	PWA	2018	Male	73	Not disclosed	Married 48 years
	Charlotte	PCP		Female	71	Retired Resource Teacher	

*Date of (CVA) Onset
**Participants with aphasia who had their strokes in 2020 experienced treatment during the COVID-19 pandemic and may have encountered hospital restrictions as a result.

Chapter 4: Results

Data analysis of interviews indicated factors which influenced participants' positive or negative feelings regarding HCP interactions. Results of the qualitative thematic analysis revealed three themes: HCP service delivery style, teamwork between PWA and PCPs, and shared communicative responsibility. Table 2 outlines the study's themes and subthemes.

Table 2

Summary of Themes and Subthemes

Theme	Subthemes
HCP Service Delivery Style	Degree of Individualized Care HCP-PCP Teamwork Aphasia Knowledge Proficiency Assuming Competency Telepractice
Teamwork between PWA and PCPs	PCP Advocacy Advocacy during COVID-19 PCP Background PCP Flexibility
Shared Communicative Responsibility	

All PWA-PCP dyads were also romantic partners, or significant others, and either married or in a relationship. However, PCPs' involvement in their partners' care and their opinions as to what precipitated successful and not successful HCP interactions varied. Laurel is an ICU nurse, now working part-time, and is the mother of her and John's two children. Laurel reports being very involved with John's treatment and attends all of his meetings with HCPs. While Derrick was initially very active in Nicole's aphasia treatment after her stroke, he has since taken on a more supportive role to Nicole's treatment, as Nicole is quite independent. Charlotte and Anna are both quite involved with their respective husbands', Henry's and Thomas's, aphasia treatment. Anna has had to advocate to be included as an essential team member in Thomas's appointments with HCPs, and Charlotte has served as Henry's advocate by educating HCPs on aphasia.

Healthcare Provider Service Delivery Style

As participants reflected on their experiences with HCPs, this first theme emerged as various aspects of HCP service delivery methods were highlighted and explored. When asked about their general satisfaction with HCPs, all participants responded with appreciation and satisfaction for their HCPs. Nicole stated, "Oh, service is great for me," and continued, "I can't say enough about [my HCPs'] communication." Derrick agreed, "They are a good hospital," referencing all the HCPs the couple interacted with during Nicole's stay. Likewise, Laurel and John found their HCPs to be effective communicators. When asked if they noticed any differences in communication styles between providers, Laurel stated, "They are all very good." When asked about his interactions with providers, Henry replied similarly, that his providers were "very good." Lastly, on an impromptu rating scale suggested by Thomas and Anna, Thomas noted HCP effectiveness was a 4.5 out of 5 (with 5 being perfect communicators). Anna agreed with this rating, elaborating further:

> I would agree with [Thomas] that the majority are 5 but if they are not, then they're down to a 4, and it's not that they don't try. People are people. No one is perfect. And everybody is different… But all in all, we are satisfied with ours.

Participants were generally satisfied with their experiences with HCPs, and factors which characterized success were investigated and elaborated upon. However, as participants shared anecdotes of HCP interactions and openly discussed HCP practices, they reflected on some negative interactions with providers and, in doing so, revealed characteristics which contributed to the likelihood of PWA and their communication partners' success in HCP interactions. These subthemes included degree of individualized care, HCP-PCP teamwork, aphasia education proficiency, and telepractice.

Degree of Individualized Care

Participants shared both positive and negative experiences in which HCPs either provided care that was individualized to meet the needs of the PWA or care that was generalized and did not meet the needs of the PWA. The latter was determined a signifier of a negative HCP experience. One such experience was described by John, who when asked to share his experience communicating with HCPs said, “Speech therapy… one was good, and one was bad. She was on the computer the whole time and the one was good. Younger one was good. She helped me and she was a great advocate.” Laurel elaborated on John’s dissatisfaction with the older SLP:

> I guess in the early-on, you know how sensitive they are with the noise and concentration, so she would give him a paper or an activity that you fill in but while he was doing that, she was continuing doing her other documentation that needed or other computer work, and he didn’t say it to her, but it was a bad experience for him.

Charlotte shared a similar experience in which she felt as though a social worker assigned to their case “just went through the motions” and was unconcerned with incorporating Charlotte or Henry’s opinions into her treatment plan. Like John and Laurel, Charlotte also recalled interacting with an SLP providing generic treatment, calling Henry’s early speech therapy sessions “really boring.” She went on, explaining, “We did nothing but be shown pictures and having to name whether it was a cookie or a shoe or a lamp.” Charlotte acknowledged that while naming was a difficulty of Henry’s, she wished the SLP had incorporated naming in a more functional capacity, such as conversation. The sentiment for functional therapy activities was further reiterated when Charlotte was asked to describe what she thought made for good HCP interactions, and she responded, “Interest in working on skills that have real life applications like conversation, as opposed to just doing drills about naming objects and synonyms and things like that.”

However, when Charlotte brought up her concerns over the goals Henry was working on in speech therapy to the SLP, they were able to collaboratively create new, functional goals which targeted skills Charlotte and Henry were interested in improving. When asked whether this change in goals improved his experience, Henry replied that they did. In another instance in their interview, in which Henry was asked about the effectiveness of his providers, he mentioned that after seeing his interest in singing, an SLP recommended he join the international aphasia choir, which is a pastime Henry continues to enjoy. In this way, when participants were treated with personalized care, which sometimes required a collaborative effort between PCP and HCP, this contributed to their feelings of satisfaction with providers.

HCP-PCP Teamwork

Another attribute that contributed to the perceived effectiveness of HCPs, was the HCPs’ ability to collaborate with PCPs. When asked about what factors contributed to positive HCP experiences, Charlotte highlighted the importance of HCPs’ “openness to suggestions and input” as an indicator of successful HCP interactions. She also emphasized the importance of HCPs valuing their patients and their family members’ humanity and emotional needs: “That’s one. Respect! I mean real respect for you and what you can do, and all of your mental and emotional capacities: your intellect, your feelings, your thoughts, who you are. That makes a huge difference.” Charlotte continued, emphasizing the importance of HCPs providing an emotional aspect to their collaboration:

> We don’t have to talk about it, but some understanding of the emotional aspects for both of us, and empathy with what we each are going through collectively and individually. I say that is also true not just with speech language pathologists, but physical therapists. You [addressing Henry] have one, Sam, who says she always applies the standard of, ‘Would I want this for my loved one’?

Laurel shared an experience in which a HCP incorporated counselling, the emotional support involved in collaborating with PWA and PCPs, as part of her role in John’s care. Laurel and John’s neurologist checked in with her after John’s stroke to ensure she was adequately coping with the strains of her new role:

> I worked with the neurologist that we chose for [John], and she actually set me aside, not in front of John, and asked me how I was doing, just to make sure I don’t need to see [any] doctors. I guess just making sure I’m not depressed or over-stressed with what’s going on.

Laurel continued discussing John’s role before the stroke, and the unexpectedness of the stroke: “Prior to the stroke… [John] was the VP of sales, traveling everywhere. And then basically Tuesday through Thursday, he was home. We didn’t expect this to happen.” Laurel’s new role as an active participant and advocate in her husband’s healthcare due to his aphasia meant that collaborating with HCPs was essential in obtaining the best standard of care for John.

Anna also shared her positive experience working with HCPs, in which HCPs’ ability to adapt to her feedback contributed to the overall success of their interactions. Anna recounted a meeting she and Thomas had with his gastroenterologist, in which the doctor attempted to speak to Thomas alone about his procedure. Anna tried to impart to the doctor the importance of her being present for the meeting, otherwise Thomas may have difficulty comprehending the information and retelling it to her later. She remembered that he was “sort of dismissive” of her request at first, but after speaking with the gastroenterologist’s nurse, the doctor adjusted his approach to include her in Thomas’s care:

> He wasn’t going to include me and I’m sure the nurse says, ‘She’s adamant, you better pay attention,’ and he changed. Every time I’ve asked that I would really like to be there, because I need to be part of it, they’ve changed their methodology and usually it’s not much back[lash].

Anna was able to successfully advocate for her own inclusion as a necessary team member of Thomas’s treatment, though not without some pushback from HCPs. Laurel shared a similar sentiment, that she advocates for her involvement in John’s care: “If he is going to have a doctor’s appointment, I have to be there so I kind of know what they say.” However, Laurel did not note experiencing any pushback to her involvement in John’s appointments.

Feedback was not solely limited to PCPs to HCPs only, however. When describing her communication with HCPs on John’s behalf, Laurel recounted an experience in which HCPs gave her feedback encouraging John’s participation in HCP meetings. Laurel explained that she often spoke for John in their interactions with HCPs, especially in the early stages of the onset of his stroke. However, Laurel later revealed that this behavior was challenged by her HCPs: “After the second appointment, they would tell me to have John answer. To see how he is. I have to restrain myself from answering the question, to just give him time. And then I would jump in.” HCPs’ efforts to involve Laurel in John’s care and engage in open feedback with her contributed to Laurel’s satisfaction with HCP interactions.

Charlotte explained that the main reason for her dissatisfaction with Henry’s social worker was the HCP’s inability or disinterest in including her in the decision-making process of Henry’s care:

> That was what was wrong with the social worker primarily. Every effort was made not [include her] to by that one person at least. Not to include. Like I said, to go through the motions of having this meeting. But I pictured it as one where we would have a give and take. And it was more, this is the way it is, and this is the way it’s going to be, and this is goals and this is the steps.

Charlotte added that there was some variation in the amount of inclusion she felt from HCPs: “It varied. The rehab director was very open and very receptive. And some of the physical therapists were and so again, same answer. I felt incorporated or not incorporated depending on who I was talking to.” Having experienced some variation in the degree of collaboration HCPs were willing to participate in with her as Henry’s PCP, Charlotte’s level of satisfaction with HCPs was at least partially contingent on their ability to incorporate her as a team member addressing Henry’s healthcare.

Aphasia Knowledge Proficiency

When asked to describe any aphasia education or communication strategies HCPs imparted to them, participants shared their experiences with HCPs’ knowledge or lack of knowledge surrounding aphasia. The degree of HCP aphasia knowledge contributed to the overall success of the dyads’ interactions with their providers.

All participants noted aphasia education or communication strategies that HCPs shared, that contributed to positive overall HCP experiences. Laurel shared that she was given information on aphasia, but being an ICU nurse, she admitted that often she “knows where [a conversation’s] heading to,” and therefore asks clarifying questions as needed. Anna also recalled that Thomas brought home a “packet” upon his discharge from the hospital post stroke, which may have held some information on his aphasia diagnosis, but neither Anna nor Thomas could not remember what it had been about. Anna also noted the absence of instructions or details on how to use the packet: “Because Thomas brought home a packet, but he did not know what to do with it,” highlighting the necessity of including written instructions in take-home materials. When they were later asked whether HCPs ever sent them home with written materials to aid them in remembering what transpired in medical meetings, Thomas responded that it depends on the HCP, and their services. Anna nodded in agreement, clarifying, “Usually the doctors don’t send you home with anything.”

One of the positive HCP education tactics that resonated with Nicole and Derrick, was being given realistic expectations. Derrick shared the impact Nicole’s SLP had in shaping their expectations: “She gave us a lot of guidance as to what to expect: don’t set the bar too high, things are going to be a little difficult for a little while.” Nicole added, “Dr. Trent, who was my aphasia doctor too, and he was so, so good and he would say too, ‘Just take time, take time, take time’.” Derrick agreed, adding, “Patience.” Charlotte and Henry shared a similar strategy involving patience surrounding communication, one which Charlotte explained came from the National Aphasia Association, which was “giving him all the time in the world to formulate whatever it is you want to formulate.” Henry interjected, “If that takes two to three minutes, so be it.” He explained that being given this extra time from communication partners was helpful in eliciting the most accurate messages.

Charlotte shared another communication strategy she found helpful in communicating with Henry, which she called “verifying.” She explained that this strategy involved corroborating verbal answers to questions. For example, in speaking about Henry, she said, “You said you wanted ice cream for dessert, but did you mean ice cream, or did you mean chocolate cake?” The other communication strategy Charlotte utilized she described as, “Us[ing] any means you can to communicate.” For example, if Henry is trying to name the restaurant he wants to eat at, Charlotte may cue Henry to describe the street it is on or have him point to it on a map, thereby using verbal and visual modalities to elicit communication. Thomas shared a similar strategy he was taught: “I guess the best thing to do was taking some words and giving me an idea of what it was. More than anything else.” Thomas was describing the helpfulness of being given semantic and phonemic cues to describe words. Derrick also recounted that in the early weeks of her recovery, Nicole’s SLP also shared the strategy of phonemic cueing with him to elicit Nicole’s speech: “Very good guidance as to try to draw the words.” He elaborated, explaining he would “sort of give her little jump starters like, ‘the word begins with ‘J’.”

Participants also discussed instances in which a lack of aphasia knowledge contributed to negative experiences with HCPs. Charlotte and Henry recounted that there were a few times in which they needed to educate their HCPs on aphasia. Henry could not remember the details of the interactions, but he did remember educating HCPs on his aphasia diagnosis in the past. When asked if he felt successful in his ability to communicate what aphasia is to HCPs, Henry responded, “I don’t know… It can [be hard] when you have just two or three minutes [to explain].” Charlotte thought back on a few instances in which she educated HCPs about Henry’s aphasia, specifically noting that nurses and healthcare aides in particular, are among those she had educated:

> Some people would say they’ve studied aphasia and they know what it is and I don’t have to tell them… the thing that I’ve had to educate healthcare providers for – or try to – is

> that it's not dementia. I think that one of the reasons why it's hard for home healthcare aides is because primarily, that's who they deal with: people with dementia. They say they get it, but I picture them rolling their eyes.

Charlotte also recalled creating her own communication strategy to facilitate communication between Henry and HCPs: "I think another way in which I've tried to educate healthcare professionals is at one point—and it was exhausting—I made a list of tips of how to converse with [Henry]." She continued,

> So, for example, I would say if you wanted to get a conversation started, talk about baseball. And I talked about something [Henry] do[es] much less of now, but… [Henry] would often say a number as sort of a cue for a whole thought. So, you might say 3 and that would mean, I don't know, my three exercises for the day. It could be lots of different things but [it was] sort of an anchor.

Not only did Charlotte feel as though it was her role to educate HCPs on aphasia, but she has also been met with resistance to her feedback, which negatively impacted her experience with those HCPs. This may have also influenced her later response to the question, "What can HCPs do to better communicate with you?":

> I guess if I had to pick only one, my perspective, it's to treat [Henry] with respect and understand that this is aphasia, not an intellectual … this is a language impairment. It doesn't affect your global understanding of the world of life, the ability to empathize, the ability to think critically and deeply. And to treat you accordingly.

When reflecting on her own experience learning about aphasia, Charlotte found that she could not recall being educated on aphasia by any HCPs:

> My impression about learning about aphasia for [Henry] was that I'm not sure anybody said, 'This is what he has and it's called aphasia'. I'm not sure that they did. And I don't think I did. [HCPs] said other things like you have this language… I know you struggle with language but you're going to recover a lot.

Charlotte continued, explaining that knowledge of aphasia and its treatment made a big difference in her ability to support Henry, once she obtained it:

> I'm not even 100% sure that they didn't [educate me], but I don't recall anybody actually doing it either. Including me… I mean, I can tell you why I didn't [educate myself]. I didn't think it would be as helpful as it was when you finally did know.

Henry could not recall being educated about his aphasia either, until later in his speech therapy sessions.

Assuming Competency. Another subtheme that emerged when participants spoke about HCP aphasia knowledge, was that HCPs sometimes over- or underestimated PWA's competency with various skills. In Anna's experience advocating for her presence in Thomas's appointment with his gastroenterologist, the doctor had assumed Thomas's competence in his ability to comprehend what was being said to him in that meeting. What the HCP did not understand, because he had not asked, was that Thomas had difficulties understanding and expressing important details, which could have negatively impacted his health and safety. The HCP's inability to anticipate Thomas's communication needs, were likely related to his limited understanding of aphasia.

Charlotte also shared an experience in which a HCP presumed her competence insofar as aphasia knowledge: "I do remember in the outpatient unit… one of the speech pathologists was saying some of the characteristics of aphasia are [that] you perseverate on certain things… but they kind of assumed you knew what aphasia was." Charlotte also shared another negative experience she had with Henry's SLPs, which stemmed from her perception that the SLPs "expected too little of [Henry]." She elaborated that the SLP developed most of Henry's therapy goals around reading and writing skills, while Charlotte and Henry both wanted to work on Henry's verbal communication, like conversation. Charlotte explained, "It's almost saying, 'Okay you can read but you can't talk, so let's assume that you're never going to talk." Charlotte expressed her frustration that this kind of therapy "was setting too low of a floor," or, expecting too little communicative competency from Henry.

Another example Charlotte shared in which an HCP expected too little of Henry's skills, was a healthcare aid who provided an excess of praise for completed tasks:

> We did have one healthcare aide who was great in so many ways but initially complimented you on the slightest little thing. Like if you combed your hair [the aid said], 'Great job!' So, to [the aid] I said, 'It's nice that you praise him, but if someone were to say to you, 'What is 2+2?' and you said, '4,' and I told you, 'Good job'?"

By over-praising Henry for tasks he could easily accomplish, the HCP was unknowingly underestimating Henry's capabilities and therefore reducing the treatment's efficacy and impact on Henry. This also negatively impacted the dyads' satisfaction with services.

Telepractice

When asked about their satisfaction with their virtual healthcare meetings, all participants with aphasia replied that they were satisfied with their telepractice services. Many of the PWA continue to attend virtual speech therapy sessions, some of which included synchronous group sessions. These meetings consisted of people with varying severities of aphasia, which John and

Thomas appreciated. When asked about his satisfaction with his ability to communicate in group sessions, Thomas replied,

> I've got to get to the point where everything makes sense as far as I am. Some of these people I think seem to do better than I do, but some of [th]em take [*sic*] more time, depending on who they are. But it's another way of communication that we're talking about. It[s] words.

Thomas brought up a good point, which is that teletherapy, being virtual, forces communication partners to rely much more heavily on verbal communication. This is because a lot of the nonverbal communication which often aids communication in face-to-face interactions is mostly omitted in virtual meetings. Another difficulty that arose in participants' teletherapy group sessions was verbal turn-taking. When John was asked how he participated in virtual group conversations, he replied, "When I can," implying that it can be difficult to participate in virtual group sessions. He continued, saying that he is looking forward to being back in-person, as he finds his teletherapy sessions "a little bit confusing." When Henry was asked how he finds telepractice compared to in-person services, he answered, "They are pretty much the same… may[be] 5% [more] difficult."

Teamwork Between PWA and PCPs

As participants discussed their experiences interacting with HCPs, it became clear that the PWA and their PCPs worked as a team in these medical meetings, approaching communication difficulties, medical challenges, and HCPs, together. The subthemes that emerged included PCP advocacy, PCP background, and PCP flexibility.

PCP Advocacy

When asked how PCPs were involved with their partners' aphasia treatment, all PCPs shared experiences in which they had actively advocated for the medical and communicative needs of their partners with aphasia. When Nicole was asked about how her communication and care has changed since the initial onset of her stroke, she replied, "Oh my goodness it was different, different, different! I can only say 'konnichiwa!'" Derrick elaborated, "Yeah, after the stroke, that was really the only word Nicole spoke was 'konnichiwa.' Do you want a pizza? 'Konnichiwa!' Do you want to take a walk around the block? 'Konnichiwa!'" Nicole explained that the reason she may have perseverated on "konnichiwa" during this time was that there was a "character on a *Different World*" who "was saying konnichiwa, and I started saying konnichiwa all the time now!"

During this time of Nicole's limited speech, Derrick reported taking a more active role in Nicole's treatment. He explained that much of the communication between Nicole and her HCPs occurred through him and Nicole's brother and sister, stating that "it was sort of a tag team effort." Laurel seconded this sentiment when speaking on John's recovery journey: "It helps a lot that we have a lot of friends and family who are there for us."

Though Nicole had difficulty communicating her needs in her early treatment, Derrick explained that in terms of advocating for Nicole in HCP meetings, Derrick was the one fighting to keep up with Nicole: "Nicole has her mind set and she is going to do…" Nicole interjects with a laugh, "What she wants!" Derrick agreed,

> So, the pedal is down, I'm going fast. I'm going to go as fast as I can. So, she didn't need much help as far as coercion or prompting. Nicole was going to do full steam ahead. And if I couldn't catch up…

Like Nicole, John also faced major difficulties communicating after sustaining his stroke, "Speech is… I can't speak for three months afterwards." Laurel went on to describe her own role in John's care, which involved taking off work for the "first four months since John had his stroke" and attending John's appointments with HCPs:

> I've been going with him to all the appointments because of his aphasia. He cannot really communicate well or ask questions or communicate whatever the physician told him. It's better to be there to better understand the care for him. Almost every time he's had a doctor's appointment, I go with him.

Anna also frequently attends Thomas's healthcare appointments, to ensure the clarity of HCP messages and instructions, and to later reiterate these points to Thomas. Though she is sometimes met with resistance to her involvement, she continues to be there:

> I'm always in there. Always, always. Even when [HCPs] don't want me there, I look at them and… it's okay but if you ask Thomas any questions, he may tell you not the truth because he can't get the words out. Or he doesn't remember.

Anna explained that Thomas also experiences difficulties comprehending medical information, which can impede his ability to relay the goings-on of his medical meetings. One of the ways Anna finds herself advocating for Thomas's needs during HCP interactions, is by asking questions for confirmation and clarity: "So if there are any questions, I bring them up. At the end of the [meeting], I do my question things. And mostly I need to be clear about what we're doing."

Laurel's perspective, being a HCP herself, also contributed to her role as John's advocate during meetings: "I guess being in the medical field, I do a lot of explanation. I kind of know where it's heading to, and I just ask questions that I'm not sure about. A lot of explaining." John confirmed Laurel’s comments when he was asked to describe his communication with providers: “It’s very difficult communicating. The thought process I can understand, but I can’t communicate very well.” John went on to later comment, “Well I can’t communicate [with HCPs], but Laurel can.” When asked about Laurel’s accuracy in anticipating his needs, and communicating for him, John replied, “She messes up two times or three times,” with a chuckle.

Nicole had a similar response when she was asked whether Derrick and her family were successful in anticipating her needs, saying, “Yes, but sometimes not.” Nicole explained that she could understand why her family tried to communicate for her, and subsequently why communication misunderstandings took place, because she recognized that they were doing their best to compensate for her reduced communication capabilities. As Nicole continued to recover and regain aspects of her speech, Derrick explained how Nicole made her communicative needs known during word finding:

> Again, [Nicole] being very independent, I don’t try to walk over her speech or when she is struggling with a few words or phrase[s]. Nicole says, “No, no, no, no, no, no!!!” Meaning, “I’ll get it. You just sit there and shut up for a minute.”

Nicole agreed that being given the time to try to discover words on her own was a beneficial technique that helped her advocate for her own communication needs.

In describing her role as Henry’s advocate, Charlotte shared her experiences procuring necessary services for Henry’s communication:

> And also, I pursued [services] during the pandemic… I investigated whether it was possible for any virtual options, and turns out that there were, so part of my involvement has been looking for places, ways that Henry can get better and better. We found a neurologist that way. He’s great.

Another service Charlotte had to advocate for was the continuation of speech-language services:

> They discharged Henry from speech a week early, and then they didn't prescribe speech therapy as a form of home therapy. I had to look at it and say it wasn't on the list, and said we weren't leaving until they put it back on.

Charlotte's persistence in acquiring services for Henry poststroke, and not his HCPs, was the main reason he continued to receive services after his stay in acute care.

Advocacy During COVID-19. Another factor which influenced participants' satisfaction with their in-hospital experiences with HCPs was associated with the impact of COVID-19 on service delivery. In an attempt to mitigate the spread of the coronavirus, hospitals implemented visitor restrictions, which varied in their flexibility as to which visitors were allowed in hospital, and under what circumstances (Silvera et al., 2021). Participants' experiences revealed that one contributing factor to the success of HCP interactions during COVID-19, was the presence of PCPs. Laurel shared her positive experience with John's neurosurgeon, with whom he had a surgery during the pandemic: "She was a great advocate for me to stay in the hospital with him because no one was allowed. No visitors [were] allowed to come and see him, but I stayed there the whole time." Laurel continued, explaining that this was especially important to them both following John's hospitalization and subsequent injuries and confusion:

> I stayed for John because of his aphasia and the painful surgery that he had in January. He knew what to expect so that would give him a sense of safety knowing that I would be there for him. I did most of the care.

Anna also recounted her experience while Thomas was in the hospital after his stroke in 2020. She was unable to visit him at all in the intensive care unit (ICU) during that time, but she recalls her experience bringing Thomas to the emergency room (ER):

> So, I'm sure that was difficult for him because he couldn't communicate with anybody and when we first took him to the ER, and they were wonderful, wonderful at the ER, but he was getting a little frustrated and confused, and he was anxious. The whole thing. He was in crisis and within a few minutes, the nurse was trying to do something, and I said, "I think he has to pee." So, she brought the thing, and he did, and she said, "Well, I'll be…" Because sometimes when you live with someone, you sort of… so it made it very difficult because you don't know what's going [on].

Anna's experience as Thomas's long-term communication partner, meant that she was able to anticipate his needs, just by his gestures and facial expressions. Anna also remarked on what Thomas's emotional state must have been: frustrated, confused and anxious, which may have been somewhat remediated if Anna were allowed to join Thomas for the duration of his stay. Unfortunately, Thomas does not remember much from his hospital stay immediately poststroke, so he was not able to fully detail his experience with HCPs from that time.

PCP Background

Three out of four PCPs spoke about the importance of their professional backgrounds in positively contributing to their ability to advocate and care for their partners with aphasia. Laurel's background as a nurse contributed to her comprehensive knowledge of John's aphasia diagnosis, and allowed her to explain it to other HCPs in common medical terminology. It also positively impacted John's aphasia treatment, Laurel noted, "Yeah, I think that helps a lot being a nurse and handling the way we go about his treatments."

Anna's medical background also positively impacted her role as a team member in Thomas's aphasia care: "I'm a microbiologist and it just came easy. Antibiotics, symptoms, treatments; it was second nature." Thomas added that Anna's father was a doctor, which contributed to her medical knowledge. Anna concurred, adding that listening to diagnostic explanations is something she is “used to from my dad.” Anna also explained that her role as Thomas’s PCP and her involvement in his interactions with HCPs existed before Thomas’s stroke: “When it came to health/medical, I was always in charge. That was my domain in the household.” For Anna, taking over the role of PCP and medical advocate for Thomas, was a process that began long before aphasia came into their lives.

When asked about what she thought contributed to positive interactions with HCPs, Charlotte shared some of her professional background, which influenced the way she viewed medical professionals:

> I have a wee bit of background. I’d heard of aphasia but never worked with anybody who has aphasia until the big event of 2018 when Henry had his stroke. But I have worked as a resource educator… working with kids with dyslexia. I have worked with people to help them read and I’ve worked with kids on the high-functioning end of the autism spectrum, all in helping make the most of their potential. So, it didn’t feel all that different to me to be working with speech language pathologists and Henry.

Charlotte’s background teaching children to improve their reading skills and her collaboration with other professionals to reach this shared goal, gave her a foundation for the teaching skills she used to aid Henry in his reacquisition of communication skills. The significance of Charlotte’s background in her success as Henry’s PCP likely played a role in how she answered the question, “What contributes to a good HCP experience?” Charlotte replied, “curiosity and interest in your past,” to which Henry seconded.

PCP Flexibility

Another indicator of successful PWA-PCP teamwork in HCP interactions included the PCP's ability to modulate their support over the course of their partner's aphasia recovery. This was especially prevalent throughout Derrick and Nicole's interview, as Derrick's ability to adjust the amount of support he gave Nicole, to best suit her communicate needs, was consistently noted. When asked about his involvement in Nicole's aphasia treatment, Derrick said,

> Initially, when the aphasia kicked in, I was very involved but now that we're sort of… I don't want to say coming out of the woods, but Nicole's been pretty good about keeping up with her own stuff and I jump in on phone calls with the aphasia group that Nicole is involved with. So, you could say I'm involved.

While Laurel continues to play an integral part in John's aphasia treatment, she too demonstrated an ability to be flexible in modulating her communication style to suit John's communicative needs. Laurel reflected, "Sometimes I get so used to how… like in the beginning… I did most of the speaking for him," whereas now Laurel tries to let John speak for himself whenever possible.

Charlotte also commented on the trajectory of her involvement with Henry's treatments: "In the very early phases of rehab, I attended all of the speech therapy sessions, so I tried to be unobtrusive about it; sort of hide behind closed doors so [Henry] wouldn't know," she laughed, "And then gradually… Now I don't attend, but I come in the last ten minutes and talk to the speech therapists." In Charlotte's experience, even though she spends less time and less proximity to Henry's sessions than she did immediately following his stroke, her role has changed to an even more collaborative one, as she is consulted by therapists regarding Henry's progress, instead of "hid[ing] behind closed doors." PCPs' roles as team members were dynamic and evolved as their partner with aphasia's communication skills improved. This highlights the close relationship that PCPs and PWA share in the aphasia rehabilitation journey.

Shared Communicative Responsibility

As participants shared their experiences with HCPs, one of the themes that emerged was their own feelings of responsibility surrounding their communication with HCPs. Participants with aphasia reflected on their interactions with HCPs and, in retelling their experiences, spoke with some sense of regret over their inability to communicate with providers. When asked whether there was anything HCPs could work on to improve their service delivery, Thomas implicated himself as the reason for any barriers to communication in HCP interactions in-hospital:

> I would say they were good for what I had to get taken care of. I gotta blame some on me, because I didn't do all the things maybe I should've. It had nothing to do with them; it's with me, not… them.

Anna clarified, explaining that the HCPs were "great communicators, but [Thomas's] understanding and retaining is what was, you know, what he found lacking. But there is nothing we can do about that, right?" Thomas emphatically agreed with her statements, saying, "Yes! She hit it!" This sense of passivity regarding what participants see as beyond their control was also present in Thomas's later recollection of his time in the ICU following his stroke: "I just … when in doubt, I went with everything … It's what [*sic*] it is; nothing I can [*sic*] do about it so that's the only way to do it." When the concept of patient compliancy arose, Thomas replied that he did not feel like he was being compliant at the time, but rather would just "do what [he] do[es], and that's it." Anna's reply confirms this dichotomy of poststroke confusion masquerading as compliance: "When you're handicap[ped] like that, you get compliant because you don’t really know what’s happening. He is not ‘Mr. Compliant,’” she laughed, “That’s why he went walking around without permission. But I’m sure he was told, ‘You can’t do it,’ and [his] brain wasn’t…” Thomas filled in, “There.” Anna nodded, finishing her thought, “Wasn’t totally comprehending what they were saying to him.”

Nicole also seemed to shoulder the responsibility of the communication breakdowns caused by her communication difficulties when she discussed if she felt her communication needs were met by HCPs in-hospital: “No, I don’t think so, but I can kind of relate to it because … they didn’t know what I wanted. And I couldn’t talk so…” Nicole did not feel as though her needs were met, but she was hesitant to blame the HCPs for this, because she felt as though *she* was the one who could not talk, so ultimately some blame fell to her. When asked if her communication difficulties were alleviated by any strategies, Nicole confirmed that yes, she was given some basic AAC such as yes/no pictures, but she admitted that this was not enough to bridge the communication gap between her, her family, and HCPs. Derrick commented that he “imagine[d] that it’s not uncommon” for this to occur in situations like Nicole’s, which is a sobering thought.

Henry also framed his experience communicating with HCPs from the lens of his own perceived communicative shortcomings. When asked whether his HCPs could have helped him understand his diagnosis better, Henry responded, “I think they probably could, but they had to realign with whatever it was I was enduring. Cause I didn’t know.” Coming to terms with having aphasia, Henry notes, is perhaps one of the reasons HCPs may have done a worse job explaining his aphasia diagnosis to him. Later, in response to being asked whether HCPs ever exhibited any speaking for behaviors, Henry answered, “Yeah. It was marginally [so], but probably, yeah. Because they have a limited time, and if you already have five minutes and you come up with two sentences, that’s not very helpful.” Charlotte nodded in agreement, saying, “That’s a really good point. I mean, I have all the time in the world. Doctors have ten to fifteen-minute slots.” Time constraints on HCP-PWA-PCP meetings may represent a reason PWA and their PCPs diminish the importance of their needs.

Chapter 5: Discussion, Directions for Future Research, and Conclusion

Discussion

This study was conducted to explore the experiences of PWA and their PCP with HCPs, to better understand the healthcare needs of PWA and their loved ones. Data indicated that there were many factors at play in facilitating a successful healthcare experience with PWA and PCPs. These factors were represented by the following themes: HCP service delivery style, teamwork between PWA and PCPs, and shared communicative responsibility.

Healthcare Provider Service Delivery Style

Participants shared their positive and negative experiences with HCPs and identified areas of strength and weaknesses with their various providers. From this, the following subthemes that emerged to characterize experiences with HCPs included: degree of individualized care, HCP-PCP teamwork, aphasia education proficiency, and telepractice. An analysis of the attributes that contributed to positive and negative HCP service found that factors influencing the success of HCP interactions aligned with aspects of patient-centered care (PCC). Participants’ perspectives on HCP services were either in accordance or disagreement with the following aspects of PCC: (a) respect for the patient's values, preferences, and expressed needs; (b) information and education; (c) emotional support, empathy, and respect; and (d) involvement of family and friends (Gerteis et al., 1993). These findings are organized in Table 3.

Table 3

Subthemes Which Corresponded With Patient-Centered Care Principles

Subtheme	Patient-Centered Care Principle
Degree of Individualized Care	Respect for the patient’s values, preferences, and expressed needs
HCP-PCP Teamwork	Involvement of family and friends Emotional support, empathy, and respect
Aphasia Education Proficiency	Information and education

Degree of Individualized Care. The first of these PCC principles observed was respect for the patient's values, preferences, and expressed needs, which aligns most similarly with the findings of HCP degree of individualized care. Participants spoke about the degree to which the specificity and functionality of therapy goals impacted their satisfaction with HCP experiences. In particular, treatment goals and materials that were perceived as being generalized were associated with negative HCP experiences. This may represent an oversight on HCPs’ part, as an increase of communication regarding patients’ goals and treatment rationale may have improved participant satisfaction with services. This is supported by literature in which PWA reported that the direction of therapy can be confusing, and the content can seem irrelevant when not properly explained (Hersh, 2004, 2009; Parr et al., 1997; Worrall et al., 2011). Participants also raised the importance of targeting functional skills in treatment, an attitude replicated by PWA in a study by Worrall et al. (2011) in which participants wanted speech therapy that met their needs at different stages of recovery, and that were relevant to their life.

Interestingly, participants’ dissatisfaction with provider services occurred with SLPs and social workers, providers who participants may have expected to implement more individualized care, perhaps based on the therapeutic aspect of these disciplines. A common sentiment between the participants, was that they did not feel consulted or valued in their interactions with clinicians and, as a result, felt disconnected from their treatment and their provider. Specifically, participants were not asked for their input in their own goals, which is an oversight on the clinicians' part, as patients and their family's recovery goals after stroke may be different from their therapists (Becker & Kaufman, 1995; Bendz, 2000). In addition, patients poststroke are not often invited to participate in the goal setting process, which results in a mismatch of goals between the therapist and their client (Rhode et al., 2012; Wressle et al., 1999).

Findings from Rhode et al. (2012) revealed that this may be due to a multitude of reasons on the clinician's part, including impaired communication due to aphasia negatively impacting goal setting collaboration as well as institutional service delivery differences in approaches to goal setting (i.e., hospital policies regarding treatment are often impairment-based in nature). According to Rhode et al. (2012) findings, mismatched goals were influenced by SLP's tendency to focus on impairment-based task performance, as opposed to client's goals. This is further supported by earlier aphasia literature (Bendz, 2000; Leach et al., 2010; Levack et al., 2011; Worrall et al., 2011). By not developing an open line of communication with patients, and not including participants in goal-making, clinicians did not effectively communicate their reasoning for patient goals and session objectives and materials, which resulted in patient dissatisfaction and demotivation.

On the other hand, those HCPs who did incorporate participants' goals and personal interests, contributed to the overall perceived success of their interaction with participants. Including patients' views in the rehabilitation process is a vital aspect of providing patient-centered care, and contributes to improved therapy outcomes and increased quality of care (Parry, 2004; Wressle et al., 1999). This is further supported by Ponte-Allen and Giles (1999) findings in which clients who collaboratively made functional and independence-focused goals with providers on admission to rehabilitation, achieved slightly higher functional outcomes at discharge. Thus, involving patients in the goal-setting process positively impacts patient motivation and participation (Bergquist & Jacket, 1993; Carlson, 1996) and improves patient satisfaction with therapy (Cott, 2004; Peri et al., 2004), which further highlights the importance of clinicians practicing PCC. This includes incorporating patients with aphasia and PCPs' views and preferences into the goal-setting process.

HCP-PCP Teamwork. Degree of collaboration between providers and participants created another theme of the study: HCP-PCP teamwork. This theme aligns most closely with the second PCC principle: involvement of family and friends in treatment. When participants were asked to reflect on their encounters with HCPs and identify aspects of care which make for good HCP experiences, teamwork between PCPs and HCPs was identified as a necessary aspect of the participants' involvement with HCPs. Participants expressed the need to be involved with the care of their partner with aphasia, which is consistent with previous literature highlighting PWA's spouses and family members' goals for aphasia rehabilitation (Howe et al., 2012; Michallet et al., 2001). Paul and Sanders (2010) found that spouses of PWA also expressed the need to be directly involved in therapy sessions. In the current study, Anna and Laurel were both insistent that they be in the room with their spouse while HCPs imparted healthcare information, a request that was sometimes met with pushback from HCPs. When PCPs were not integrated into their partner with aphasia's intervention, they conveyed dissatisfaction with their HCP service. Charlotte also identified a mismatching of expectations going into the meeting: that she went into her medical appointment imagining there would be a "give and take" of opinions and interests, but instead, the meeting consisted more of an explanation of intervention goals and next steps, with no input from Charlotte. This further highlights the importance of incorporating PCPs into care decision-making for PWA.

In investigating the dynamic relationship between PCPs and HCPs in aphasia rehabilitation, data analysis revealed that the common subthemes of successful HCP-PCP teamwork included the HCP's flexibility, communication transparency, and emotional support. HCP flexibility was a factor which contributed to Charlotte's success in HCP interactions. Her positive experiences with HCPs were marked by their openness and receptiveness. However, HCPs' willingness to include PCPs in their partners with aphasia's treatment varied depending on the provider and the setting. This indicates some lack of standardization in HCP approaches to care in hospitals, including PCC (de Haes & Koedoot, 2003). HCP flexibility was also present in Anna's interaction with her gastroenterologist, who originally was hesitant to include her in Thomas's treatment, but after receiving some prompting from his nurse, the gastroenterologist was willing to include Anna in Thomas's care. It may be hypothesized that other HCPs' opinions hold more weight than the patients' when making medical decisions about PCP inclusion, which also may explain Laurel's reports of experiencing no pushback when advocating for her presence in John's sessions. As a nurse and a HCP herself, it is possible that HCPs felt more comfortable incorporating her as a member of John's treatment team.

Another positive area of HCP-PCP teamwork which was identified was HCP communication transparency. As previously mentioned, HCP willingness to form an open line of communication with participants impacted the PCPs' perceived success of the interaction. Interestingly, the participant who experienced one of the most successful give-and-take relationships with HCPs was Laurel. Laurel was the only PCP to recount a time in which HCPs pushed back on her current communication style and gave her advice on how to elicit John's communication with HCPs more effectively. Whether this was based on the trust and rapport HCPs built with her, or the inherent understanding and respect for Laurel's job as a nurse, this proved an effective way to prompt Laurel to try to allow John to speak for himself.

HCP emotional support was another aspect identified by PCPs as a positive indicator of success in HCP-PCP teamwork. Emotional support is also one of the elements of PCC. Participants identified the importance of an understanding of the emotions of PWA and PCPs, as well as empathy for their experiences. A term that encompasses this concept is that of emotional intelligence, which includes capacities such as emotional perception and management, empathy, and stress management (Cherry et al., 2014; Petrides & Furnham, 2001; Petrides et al., 2007). The presence of emotional intelligence in HCPs is associated with more empathetic and compassionate care, increased patient trust in providers, and better communication skills, which result in strengthened patient-provider relationships and improved satisfaction in services (Arora et al., 2010). Charlotte mentioned that one of Henry's physical therapists uses the standard "Would I want this for my loved one?" when treating patients. This vocalized empathy resonated with Charlotte as the gold standard of care and is a great example of how incorporating emotional intelligence into practice is another way to implement PCC (Arora et al., 2010).

Respect also emerged as a factor which contributed to participant satisfaction with HCP interactions. Worrall et al. (2011) interviewed PWA who reported feeling disempowered by their communication challenges, which made their desire to be respected and seen as still competent people, that much stronger. Likewise, Mangset et al. (2008) identified that two of the factors contributing to stroke patients' satisfaction with rehabilitation following stroke, included being treated with humanity, and being acknowledged as individuals. Taken together, this indicates the importance of treating PWA and PCPs with respect and dignity and that the presence of these in

HCP interactions positively impacted the participants' relationship with HCPs and their satisfaction with HCP services.

Another experience in which HCP emotional support influenced PCP satisfaction with care, was Laurel's interaction with her neurologist. Shortly after John's stroke, Laurel was approached by John's neurologist, who offered her emotional support and asked about her mental state. This suggests the presence of a therapeutic alliance between HCP and PCP. Therapeutic alliances, or the quality of therapeutic relationships forged by HCPs to instill a sense of trust with patients, are an aspect of counselling that is associated with higher therapy outcomes (Horvath et al., 2011; Howell, 2016; Martin et al., 2000). There is also emerging literature that suggests the positive impacts of therapeutic alliances on aphasia rehabilitation in the areas of patient satisfaction (Tomkins et al., 2013) and treatment outcomes (McLellan et al., 2014). Laurel's positive experience being counselled by John's neurologist may suggest the positive impact of HCP-PCP therapeutic alliances, which remains an area which is under-researched in aphasia literature.

The potential benefits of HCP-PCP therapeutic alliances may extend to supporting PCPs through the tumultuous role change and stress that often follows stroke. While John was the partner diagnosed with aphasia, Laurel was impacted by the aphasia diagnosis as well, taking on new responsibilities to adjust to John's "new normal." Laurel emphasized the unexpectedness of John's stroke, highlighting her movement into this role with little warning. Such a sudden shift in identity and responsibilities leaves little time for psychological adjustment (Kim et al., 2006; Marwitt & Kaye, 2006). Caregivers of PWA are also at greater risk for increased stress levels, and decreased emotional-wellbeing, sleep quality, and energy level (Lingraphica, 2021), all of which represent common risk factors in the development of a psychiatric disorder like depression or anxiety (American Mental Wellness Association, n.d.). The combination of role changes and emotional challenges PCPs face further support the need for emotional support from HCPs. Howe et al. (2012) found that family members of PWA identified their own goals for aphasia rehabilitation, which included coping with new responsibilities and being given adequate support from HCPs. This indicates that PCPs have their own goals for aphasia rehabilitation, including the need to be supported and effectively communicated with through the treatment process. SLPs may aid PWA in achieving this support by engaging in counselling practices, referring patients and their PCPs to allied health professionals, or by advocating for the planning and implementation of support services (Howe et al., 2012). SLPs may also acknowledge the stress and role change PWA and PCPs face by incorporating this knowledge into their counselling and educating fellow HCPs on ways to support dyads following the onset of stroke.

Aphasia Education Proficiency. Another factor which influenced participants' perceived satisfaction with HCPs was the degree of HCP knowledge of aphasia and their effectiveness in educating participants about aphasia. This aligns with the PCC principle of information and education. Participants unanimously felt that gaining education and communication strategies from providers was a positive attribute of HCP service delivery. Conversely, when participants experienced a lack of knowledge about aphasia, this negatively impacted their experiences with HCPs. It is well documented that increased information is a need that is shared by family members (Avent et al., 2005; Denman, 1998; Le Dorze & Signori, 2010), spouses (Michallet el al., 2001), and PCPs of PWA (Paul & Sanders, 2010). PWA also require an increase in the amount and accessibility of information about aphasia and stroke, especially as their communication challenges impact their understanding and retention of their diagnosis (Worrall et al., 2011).

This disparity of aphasia knowledge is palpable in Charlotte and Henry’s difficulty recalling being explicitly told that Henry’s language difficulties were characterized by an aphasia diagnosis. This experience was shared by participants with aphasia in a study by Worrall et al. (2011), who reported not being told that the specific disorder used to describe their communication difficulties was “aphasia,” and when the term was mentioned, it was rarely explained clearly. This is also consistent with several studies in which families of PWA reported receiving inadequate information and explanation about the nature of stroke and its consequences while in the acute and sub-acute phases following stroke (Anderson & Marlett, 2004; Wachters-Kaufmann et al., 2005). Neglecting to educate patients and their families about aphasia is especially concerning, considering that the majority of the public have not heard of aphasia (Flynn et al., 2009; Simmons-Mackie et al., 2002). According to the recent Aphasia Awareness Survey, about 82% of Americans have never heard the term “aphasia” (National Aphasia Association, 2020). This means that many PWA, along with their loved ones, are unlikely to know what aphasia is when they are first diagnosed with it. Therefore, the responsibility of HCPs to effectively share aphasia knowledge with PWA and PCPs is crucial.

Though HCPs are responsible for educating PWA and their PCPs on aphasia, participants acknowledged that not all HCPs knew what aphasia was, and this impacted their ability to share aphasia knowledge. Charlotte and Henry encountered multiple HCPs who were unfamiliar with aphasia or confused the disorder with dementia. Henry also remarked on the added challenge that limited time played in his ability to effectively communicate his diagnosis with HCPs. This indicates the need for HCPs to allocate more time to spend with PWA, as their communication disorder may cause them to take longer to communicate (Kagan et al., 2001; Law et al., 2005; Nordehn et al., 2006). It also highlights the importance of effective aphasia knowledge and training for HCPs, who may not always understand an aphasia diagnosis. In addition, these findings suggest that when the burden of aphasia education was placed on the PWA and their loved ones, their experiences with HCPs were negatively impacted.

When HCPs do share aphasia education, it is important that it is done consistently, clearly, and across all stages of rehabilitation. When asked about the aphasia education she was provided, Anna recalled that Thomas brought home an information packet from the hospital upon his discharge, but that it was rendered pretty useless to them because neither knew its use. This has a few implications. The first is the importance of providing PWA with clear, written resources and instructions to understand the materials they are given. Alternatively, a variety in the presentation of materials (e.g., emails, pamphlets, website recommendations) may be a way to ensure the retention and dissemination of aphasia education (Paul & Sanders, 2010). Second, there is the need to better integrate PCPs of PWA in the discharge planning and transition. A lack of PCP consultation at discharge is also associated with decreased satisfaction with service providers (Perry & Middleton, 2011).

These aspects of aphasia education may be carried out by SLPs, whose scope of practice includes educating PWA on their communication disorder (American Speech-Language-Hearing Association [ASHA], 2016). SLPs may provide PWA and PCPs with information in a variety of forms, systematically throughout the aphasia rehabilitation process to ensure understanding (Howe et al., 2012). This includes the discharge phase, in which SLPs can aid patients and their PCPs’ retention of aphasia knowledge by providing them with materials which list relevant provider and service recommendations. In addition, SLPs should also prepare themselves to explain aphasia to PWA and PCPs multiple times, as dyads may not understand an aphasia diagnosis upon the first time they learn of it (Howe et al., 2012). Without the input of Charlotte and Henry’s HCPs, it is difficult to know whether Charlotte and Henry were educated on aphasia and do not remember or if they truly did not receive adequate aphasia education. What is clear from their experience is that they were not educated on aphasia with enough frequency to grasp its meaning and implications. By providing dyads with aphasia knowledge over multiple interactions and through a variety of materials, SLPs may achieve increased aphasia knowledge. SLPs may also educate other HCPs on aphasia, providing them with resources and communication strategies to improve their interactions with PWA.

One component of aphasia education participants appreciated was being given realistic expectations in relation to aphasia rehabilitation and recovery. Nicole and Derrick’s SLP described the challenges to expect poststroke, and the dyad expressed that this helped prepare them to meet these challenges head-on, which contributed to their feelings of satisfaction with their HCP experiences. This is consistent with research which suggests that knowledge about what to expect following a stroke can foster a sense of hope (Cross & Schneider, 2010), which is associated with a family-centered approach to aphasia rehabilitation (Howe et al., 2012).

Another important aspect of HCP aphasia knowledge that was identified by participants was the usefulness of being given specific, functional communication strategies for eliciting effective communication with PWA. PCPs commented on the effectiveness of using cues to help PWA identify various objects or concepts. These “jump starters” for responses were reported as being helpful ways for PCPs to support their partners’ communication. Nicole and Derrick also shared the importance of integrating patience into their communication styles poststroke. Charlotte utilized a similar strategy, though she identified her source as the National Aphasia Association website. This relates to findings from Rose et al. (2019) in which family members of PWA who were dissatisfied with the limited aphasia information they received sought out information themselves, which included online resources. This suggests that when PWA and their PCPs are not given sufficient education surrounding their aphasia diagnosis, they may look to alternative methods of educating themselves. This idea is further supported by Charlotte's development and employment of her own communication strategies to facilitate communication between Henry and HCPs. This is a replication of findings from Howe et al. (2012) in which family members of PWA developed their own communication activities and materials when they were not given sufficient directions on how to reinforce their loved ones' communication.

Charlotte's creativity and commitment to facilitating effective communication between Henry and his prospective communication partners, while commendable, is a role that is better suited for SLPs, whose job it is to address communication needs of PWA. Charlotte's experience suggests that SLPs can better address PWA's communication needs, which may include incorporating strategies to communicate with HCPs more effectively. HCPs also report having a lack of tools or strategies to help them facilitate communication with PWA (Burns et al., 2015; Hemsley et al., 2008), which negatively impacts their ability to support PWA and PCPs. SLPs may facilitate effective communication between PWA and HCPs by advocating for the implementation of communication partner training for HCPs in hospitals. Communication partner training is associated with improved patient-provider aphasia knowledge and communication, and thus may represent a feasible method of delivering PCC (Cameron et al., 2017a, 2017b, 2018; Horton et al., 2016a; Simmons-Mackie et al., 2010).

Assuming Competency. Participants also identified that an area of need in HCP aphasia knowledge is an understanding of the correct level of communication necessary to facilitate effective communication with PWA. Participants' experiences with HCPs who either incorrectly assumed PWA's competence, or underestimated PWA's ability to perform various skills, were associated with negative HCP experiences. One of the commonalities between participants' experiences is that HCPs did not ask participants what the PWA's communication needs were, or at what level of difficulty they should present communication or feedback. In Anna and Charlotte's experiences in which HCPs were giving aphasia information, HCPs wrongly assumed competence, which impeded understanding of the information. An underestimation of skills also resulted in participants' decreased satisfaction with providers, and negatively impacted the patient-provider therapeutic relationship.

These findings suggest the importance of informational check-ins, whereby HCPs probe the aphasia knowledge of PWA and PCPs. HCPs' difficulty modulating their communication style to the needs of PWA may also be explained by the communication accommodation theory (Simmons-Mackie, 1998). The communication accommodation theory suggests that participants in conversation adjust their communication style to adapt to that of their communication partner (Simmons-Mackie, 2018). This is accomplished by implementing "accommodations," or adjustments in communication style, depending on the needs of the communication partner. These accommodations either serve to minimize or highlight social differences, since the way a person consciously or subconsciously chooses to accommodate their communication style often reveals their belief in their status, or social membership (Simmons-Mackie, 2018).

Burns et al. (2015) found that HCPs over or under-accommodated PWA in their interactions. Or the way in which HCPs communicated information was perceived by PWA as either far above or below the PWA's comprehension. HCPs' difficulty in using the appropriate degree of accommodations with PWA may be exacerbated by two factors: a lack of understanding of the characteristics of a patient's communication disorder and a lack of communication about patients' communication preferences (Burns et al., 2017). Therefore, a combination of HCP knowledge of aphasia and awareness of a patients' communication strengths and weaknesses may be the best strategy to ensure appropriate communication accommodations by HCPs. Communication partner training may also offer a solution for resolving the difficulties participants observed HCPs having with making adequate communication accommodations. Simmons-Mackie (1998) found that when communication partners deliberately initiate relevant communication supports such as gestures, drawings, and slower speaking rate, PWA felt more empowered to also use those strategies. Therefore, communications partners who are given communication partner training may more appropriately accommodate their communication style to suit the needs of PWA.

Telepractice. Participants all expressed feeling satisfied with their virtual HCP services. Participants were satisfied with their one-on-one telepractice sessions with SLPs, but some participants voiced challenges associated with group therapy sessions. Recent literature suggests the feasibility of telepractice for SLP services with PWA (Weidner & Lowman, 2020), who may be especially well suited for telepractice given the audiovisual nature of their treatment (Brennan et al., 2002; Getz et al., 2016). It is worth mentioning, however, the limitation of a lack of control groups in telepractice literature. In a systematic review of SLP telepractice services for adults, Weidner and Lowman (2020) found that only 34% of intervention studies included a control group. This is significant because utilizing a control group with face-to-face SLP services to compare treatment outcomes and satisfaction with services to telepractice results would improve the validity of telepractice research. A lack of control groups is also noticeable in the limited research studying PWA in virtual group speech therapy sessions.

While emerging literature suggests the use of telepractice as a successful medium for improving communication outcomes and treatment satisfaction (Pitt et al., 2017; Steele et al., 2015), there were observed challenges that are consistent with the present study's findings. Pitt et al. (2017) found that turn-taking was made more difficult during telepractice group sessions due to the virtual nature of the intervention medium. SLP participants explained that in a face-to-face group session, it's usually easy to see when patients are pausing in a natural conversation context or experiencing difficulties word finding. This is, however, more challenging to observe virtually. Audio delays also impacted participants' ability to recognize the end of their patients' turns, which further impacted the overall naturalness of conversation. These factors made it difficult for SLPs to manage turn-taking in a group teletherapy session as well as recognizing expressions and gestures and managing the pace of conversation exchanges (Pitt et al., 2017). In the present study, turn-taking was also identified as an area of improvement for group teletherapy. Thomas also highlighted the prioritization of speech, in telepractice, implying the loss of nonverbal communication usually implicit in conversation.

Teamwork Between PWA and PCPs

One of the markers for communicative success in HCP interactions that emerged from the data, was the significance of teamwork between PWA and their PCP. Data analysis revealed that PCP advocacy, PCP flexibility, and PCP background, were the components of effective teamwork between the dyads in maneuvering HCP interactions.

PCP Advocacy. Across all interviews, PCPs spoke about their experiences advocating for their partners with aphasia. PCPs acted as communication conduits for their partners' interactions with HCPs, especially in the early phases of their recovery poststroke when their communication was most impaired. Derrick and Laurel shared their experiences taking on roles as advocates early in their partners' stroke rehabilitation, and that their partners' severely impacted communication necessitated the adoption of this role. This is consistent with findings that family members perceive their role in HCP interactions as one of advocacy (Shafer et al., 2019), which included speaking for their loved one when they were unable to do so, especially early in their stroke recovery (Burns et al., 2015). This is reminiscent of John's characterization of his early communication difficulties, which necessitated Laurel's role in communicating for him, implying the need for PCPs to ensure their partners with aphasia's "voice" is heard (Burns et al., 2015, p. 347).

There is, however, a problem that arises when PCPs verbally communicate for their partners with aphasia, which is the observation of speaking for behaviors, in which PCPs answer questions or comments addressed to PWA (Croteau et al., 2004; 2007). Participants with aphasia noted that their PCPs did engage in some speaking for behaviors, and that while communication misunderstandings were infrequent, they did occur. Burns et al. (2015) also observed that family members were sometimes inconsistent in their interpretations of their partners' perspectives, and that they do not always "get it right" (p. 354). While there is evidence that suggests that the use of speaking for behaviors by spouses of PWA reduces the PWA's subsequent participation in the conversation (Croteau et al., 2004; 2007), participants in the present study relayed their experience of their PCPs' speaking for behaviors with a lightness and familiarity that indicated that the communicative assistance provided by the PCPs, overall, was more beneficial to the pursuit of understanding than not (Croteau et al., 2007). This was most palpable in Nicole's response, in which she expressed her appreciation for her family's efforts to improve communication and empathized with their difficulties in doing so.

SLPs may decrease the frequency of speaking for behaviors by providing partners of PWA with communication partner training. Research suggests that communication partner training is effective in improving communication between PWA and their communication partners (Simmons-Mackie et al., 2010), and the facilitation of more effective communication between dyads may result in PCPs who are more reliable communicators and advocates for PWA.

Dyads also emphasized the importance of accompanying their partners with aphasia to their meetings with HCPs to ensure the validity of medical information that is relayed to them. Laurel and Anna shared their active role in accompanying John and Thomas to their HCP appointments and therapies to gain a better understanding of the care provided. Anna also mentioned asking clarifying questions to ensure her own comprehension of medical information. Laurel added that she also substantiates her own medical knowledge by asking questions when necessary, but that her role also includes a great deal of explanation in relaying this information to John in a way he will understand. In this way, the responsibility to facilitate and support communication with HCPs often falls to the PCP (Burns et al., 2015).

Participants also shared experiences communicating collaboratively with HCPs, which indicate that the role of advocacy in dyads evolves given the PWA's personality and communication needs. Nicole's motivation to participate in her treatment and her advocacy for her communication needs challenged Derrick's role as an advocate. Nicole's advocacy in her own services shaped the role that Derrick took on, which was, especially as her communicative faculties continued to recover, secondary to Nicole's self-advocacy.

Notably, PCP advocacy was not limited solely to the treatment phase but included the discharge process as well. Charlotte shared that her role as Henry's advocate extended to procuring necessary services for him upon his discharge from the hospital. She sought the continuation of SLP services, which had not been originally included in Henry's recommendations, and also virtual options for services. Shafer et al. (2019) noted similarly that caregivers of PWA may be forced into the role of advocate, which may include advocating for additional services. PCP feelings of unpreparedness and lack of support and information during the discharge phase, are associated with dissatisfaction with care (Ellis-Hill et al., 2009; Lutz et al., 2011; Perry & Middleton, 2011). In addition to contributing negatively to their experience with HCPs, Charlotte and Henry's experience is troubling because without Charlotte's advocacy, Henry would likely not have sought services post-discharge, which likely would have contributed negatively to his stroke recovery.

Advocacy During COVID-19. Another aspect that was found to contribute to the perceived success of participants in HCPs interactions was the extent to which PCPs were able to accompany participants with aphasia in-hospital during COVID-19. Due to the varying degree of visitor restrictions of hospitals across the United States, PCPs were either able to accompany their partner with aphasia to their medical interventions or forced to wait until their loved one was discharged. Laurel shared her appreciation for her neurologist's advocacy in letting her stay with John throughout the entirety of his surgery, as she felt it made him feel safer and more comfortable, having her there and able to perform some of his care tasks. In contrast, Anna was not able to visit Thomas in the ICU at all after Thomas sustained his stroke, but she does recall his confusion, frustration, and anxiety at having difficulty communicating with HCPs. She described his state as being "in crisis," and she recounted an instance in the ER in which she helped a nurse anticipate Thomas's needs. Though Thomas cannot recall much of his stay or feelings surrounding his experience in the ICU, it is likely that it was an emotionally challenging time, which may have been ameliorated by Anna's presence and ability to anticipate and advocate for his needs.

While there is limited research exploring the impact of COVID-19 on PWA and their PCPs in acute settings, recent findings suggest that hospitals with closed visitations (i.e., no visitors allowed) were associated with poorer patient satisfaction versus hospitals that either remained unrestricted or partially limited their visitations (Silvera et al., 2021). In a study by Silvera et al. (2021), patient experience and safety outcomes of a national sample of hospitals were obtained from hospitals with varying visitor restrictions during 2020. Results of the study found that not only did hospitals with closed visitations report worse patient experience when compared to pre-pandemic experiences in 2019, these hospitals also reported higher deficits in the areas of medical staff responsiveness, fall rates, and sepsis rates. Furthermore, hospitals which preserved some degree of patient visitation either maintained or improved upon 2019 performance. Though this area requires further investigation, these initial findings strongly suggest the importance of the presence of family members or care partners in the care process.

These findings also seem to support previous research with communication disorders, which has found that family members of those with communication disorders like cerebral palsy and complex communication needs feel a strong need to protect and support their loved one (Hemsley et al., 2008), which results in family members feeling compelled to advocate for the safety of their loved one (Hemsley et al., 2016). In addition, successful advocacy, of either family members or patients, is correlated to reduced negative effects of “undesirable events,” like falls, injuries, or poor discharge planning (Hemsley et al., 2016). Hemsley et al. (2013) also studied the impact of undesirable events with PWA and their spouses. The authors found that spouses expressed the need to be present to act as advocates for their loved ones’ safety, which was a worry that was perhaps justified as eight of the ten PWA reported undesirable events occurring when their spouse was not present. This research, while limited, further supports the importance of PCP presence in reducing negative aspects of care, providing patients with communication disorders support and advocacy, and improving patient satisfaction. As a result, HCPs, including SLPs, may advocate for the inclusion of PCPs in their partner with aphasia's care as a means of improving PCC.

PCP Background. Another factor which contributed to the success of teamwork between PWA and PCPs was identified as PCPs' personal and professional backgrounds. Laurel, Anna, and Charlotte all identified previous experience in the sciences or medical fields, or previous work with people with communication impairments. As previously mentioned, Laurel's professional background as a nurse lent her a unique perspective in caring for her partner with aphasia. Laurel also believes her role as a nurse positively influenced John's aphasia rehabilitation, as she played a key role as a member of the intervention team. Likewise, Anna's background as a microbiologist, as well as her experience interacting with her doctor father growing up, contributed to her ability to understand medical information. It is important to highlight however, that Anna's role in Thomas's health and medical needs was not new. She explained that it was her "domain in the household." Having been married and in a partnership for as long as Anna and Thomas have, the delegation of household responsibilities is inevitable, and Anna's previous experience collaborating with Thomas with his HCPs likely strengthened their teamwork in tackling Thomas's aphasia treatment. Though Laurel did not say as much, it is likely that, as a nurse, she too holds this position in her household. Moving forward, it may be important for HCPs to understand the pre-stroke dynamics of PCP-PWA relationships to anticipate the poststroke dynamic of care between the dyad.

Charlotte also shared her experience as a former resource teacher, working with children with dyslexia and autism improve their reading. She explained that she felt her background gave her the confidence to teach Henry his communication skills and prepared her to collaborate with SLPs among other HCPs. Having some perceived shared skills and professional common ground with HCPs is something all female PCPs spoke on, which may indicate that HCPs should try to understand PCPs' professional backgrounds and promote a sense of shared interests with PCPs. Charlotte shared that a sense of curiosity and interest into her and Henry's background contributed to positive HCP experiences, which may pose as a starting point for HCPs attempting to understand the PCP-PWA care dynamic. Specifically, HCPs may incorporate interview questions inquiring about the professional backgrounds and interests of PCPs. It may also be worth investigating if there is any correlation between PCPs' backgrounds and feelings of readiness and preparedness in taking on the role as PCP in medical interactions.

PCP Flexibility. While participants reflected on their collaborative efforts in working together with HCPs, PCPs shared instances in which their role as a team member adapted to fit the needs of their partner with aphasia. PCPs recognized that their supporting role changed to suit the evolving needs of their partners as they progressed in their aphasia rehabilitation. Derrick and Charlotte shared that their role as active decision-makers in the early phases of aphasia rehabilitation, supporting and facilitating their partners with aphasia's communication, had adapted to that of monitoring and consulting their partners' treatment. Laurel's role as John's "voice" also shifted as he regained some communicative faculties. She reflected that after being used to communicating for John for some time, she began restraining herself from automatically speaking for John, and instead learned to give him time to try answering for himself.

These findings are consistent with those by Burns et al. (2015), who observed that family members of PWA noticed that their roles communicating in medical interactions evolved over time. As participants with aphasia began recovering their communication skills, family members' roles shifted from advocating for their loved ones in conversations, to being physically nearby to support PWA when needed. This was characterized by one spouse as being his wife's "safety net," which may be an accurate description of the roles Derrick and Charlotte described currently practicing (Burns et al., 2015, p. 348).

The implications of PCPs' role change and resulting need for flexibility of support are significant for HCPs. To ensure a smooth transition for both PWA and PCPs, HCPs should prepare PCPs for their role in their partner's aphasia rehabilitation. SLPs, whose scope of practice includes counselling (ASHA, 2016), may be especially suited to this role and may offer PCPs counselling services and strategies to cope with their own dynamic aphasia rehabilitation journey.

Shared Communicative Responsibility

One of the most interesting themes to emerge from the participants' experiences with HCPs was their own feelings of responsibility surrounding their communication with HCPs. Participants with aphasia expressed compassion and understanding for HCPs' inability to effectively communicate with them and blamed their own communication difficulties as the reason for communication breakdowns. This indicates that PWA and their PCPs may shoulder the burden of their communication difficulties when HCPs are not equipped to effectively communicate with them. They even blame their own communication shortcomings for negative HCP interactions and have empathy for HCPs attempting to "realign" their communication style to meet that of the participants with aphasia. Even when participants observed the frequency with which communication breakdowns between HCPs and PWA occur, they were hesitant to criticize or blame HCPs for these breakdowns, or even highlight breakdowns as an area of improvement. This phenomenon of participants taking responsibility for communication breakdowns in interactions with HCPs may be explained by a few hypotheses. First, participants may have some feelings of guilt and shame surrounding their communication disorder, and for this reason, they may be more willing to take blame for what they perceive to be their own disability. Though it is well documented that there are harmful psychosocial impacts related to aphasia (Hilari & Northcott, 2017; Kauhanen et al., 2000; Northcott et al., 2016), there is little research studying the impact of shame and guilt on PWA. This may be an area that constitutes as requiring further research, given what the findings of this study suggest.

Another possible hypothesis is that older patients, who may have grown up surrounded by a traditional medical model of healthcare, may view their treatment as impairment-based and as such, place blame on their perceived impairments as barriers to communication (Byng et al., 2002). Given that the participants who expressed these feelings of communicative responsibility are between the ages of 56 and 75, a difference in expectation for inclusion in HCP interactions may have influenced the PWA's interpretation of communication breakdowns. Byng et al. (2002) found that SLPs who cultivated an impairment-based service delivery model may have inadvertently promoted a medical model of care, thereby reinforcing patients' belief in SLPs playing a curative role in their treatment. This may represent yet another area for future research, which investigates PWA feelings of communicative responsibility: generational differences in expectations of providers and service model preferences.

Lastly, the communication accommodation theory mentioned earlier may also account for participants' feelings of responsibility for communication breakdowns with HCPs. Research suggests that this theory may serve as an explanation for the communication breakdowns PWA experience (Simmons-Mackie, 1998). Simmons-Mackie (2018) proposed that PWA may accommodate to the standard (or typical) communication pattern of partners not knowledgeable about aphasia or communication strategies. It is also worth noting that the presence of a communication disorder like aphasia may make participants feel less powerful in conversations, and participants who view themselves as less powerful or less confident, are more likely to accommodate to power powerful partners (West & Turner, 2014). This has important implications given PWA and PCPs may view HCPs in a position of power. What this means is that if PWA subconsciously accommodate to the communication style of HCPs, they may expect themselves to be proficient at that communication level. Then when they are not successful, and a communication breakdown occurs, they may blame themselves for not being proficient, thereby taking ownership of communication breakdowns. Whether the communication accommodation theory explains this phenomenon or not, communication partner training may give HCPs the strategies necessary to appropriately accommodate communication for PWA (Simmons-Mackie, 2018). SLPs may work to increase advocacy for the implementation of communication partner training in hospitals, in order to promote access to communication (ASHA, 2016). These proposed explanations of data analysis require further research, but may offer a unique insight into communication between PWA and HCPs.

Study Limitations

Limitations that pertain to the participant pool and population include the reduced number of participants, the severity level of the participants with aphasia (ranging from mild to moderate severity), and the relationship of PCPs to PWA (significant others). These factors negatively impact the ability of this study to represent people with severe aphasia, and PCPs who are not significant others of PWA.

Limitations to the study design are as follows. HCP perspectives were not incorporated into the study. HCP perspectives may have clarified some participants’ recounting of events, thereby strengthening results. This constitutes an area for future research. In addition, grouping all HCPs as a homogenous group does not give a clear understanding of the responsibilities and role of each HCP moving forward in their own discipline. Future studies may investigate how PWA and PCPs interact with different HCPs. Also, virtual interviews constituted a limitation to the research, as aphasia results in language impairments, as well as it may be accompanied by physical and cognitive impairments, all of which are barriers to computer use (Kelly et al., 2016).

Directions for Future Research

Giving patients access to effective communication with healthcare providers is necessary to providing quality care. This study lays a foundation for future directions in exploring how people with aphasia and their care partners communicate with providers. While PCC was identified as being aligned with positive HCP experiences, future studies may investigate the ways in which HCPs engage in PCC with PWA and PCPs, including investigating HCP perspectives utilizing PCC. These studies may also include PCPs of varying backgrounds, for example, including family members and friends, to get a diverse profile of PCP interactions with PWA. Research utilizing communication partner training between HCPs, PCPs, and PWA constitutes another area of further investigation. The potential impact of communication partner training on HCP communication accommodations is another area that could be explored.

In addition, while there is emerging literature which suggests the positive impact of therapeutic alliances on aphasia rehabilitation in the areas of patient satisfaction (Tomkins et al., 2013) and treatment outcomes (McLellan et al., 2014), there remains a gap in the literature in the description of therapeutic alliances between HCPs and PCPs. Likewise, there is limited research on the relationship between PCPs' backgrounds and their feelings of readiness in taking on the

PCP role in medical interactions. In addition, future research may investigate the relationship between pre-stroke and poststroke dynamics of PCP-PWA relationships in the domain of care management.

Conclusion

This study highlights the experiences of people with aphasia and their care partners in communicating with their healthcare providers. The study reveals areas in which HCPs can improve their care, which includes adjusting their own role in service delivery, as well as their role in supporting PCPs of PWA. This study further explored the extent to which PCPs are involved in PWA's care as well as the flexible nature of this dynamic. It was also found that PWA and their PCPs may harbor feelings of guilt and responsibility over communication breakdowns due to poor HCP communication. The study's findings also highlighted gaps in aphasia literature as it pertains to HCP interactions with PWA and their PCPs and provides future directions for the exploration of these aspects. These findings may be utilized by SLPs and HCPs to inform the provision of more effective services for PWA. Findings may also serve to educate PWA and their loved ones on their rights and potential role in aphasia rehabilitation.

References

American Speech-Language-Hearing Association. (2016). *Scope of practice in speech-language pathology*. https://www.asha.org/policy/sp2016-00343/

American Mental Wellness Association. (n.d.). *Risk and protective factors*. https://www.americanmentalwellness.org/prevention/risk-and-protective-factors/

Anderson, S., & Marlett, N. J. (2004). The language of recovery: How effective communication of information is crucial to restructuring post-stroke life. *Topics in Stroke Rehabilitation*, *11*(4), 55-67. https://doi.org/10.1310/NPC4-01YV-P66Q-VM9R

Arora, S., Ashrafian, H., Davis, R., Athanasiou, T., Darzi, A., & Sevdalis, N. (2010). Emotional intelligence in medicine: A systematic review through the context of the ACGME competencies. *Medical Education*, *44*, 749-764.

Avent, J., Glista, S., Wallace, S., Jackson, J., Nishioka, J., & Yip, W. (2005). Family information needs about aphasia. *Aphasiology*, *19*(3-5), 365-375.

Bartlett, G., Blais, R., Tamblyn, R., Clermont, R. J., & MacGibbon, B. (2008). Impact of patient communication problems on the risk of preventable adverse events in acute care settings. *Canadian Medical Association Journal*, *178*(12), 1555-1562. https://doi.org/10.1503/cmaj.070690

Beck, R. S., Daughtridge, R., & Sloane, P. D. (2002). Physician-patient communication in the primary care office: A systematic review. The *Journal of the American Board of Family Practice*, *15*(1), 25-38.

Becker, G., & Kaufman, S. (1995). Managing an uncertain illness trajectory in old age: Patients' and physicians' views of stroke. *Medical Anthropology Quarterly, 9*, 165–187.

Bendz, M. (2000). Rules of relevance after a stroke. *Social Science and Medicine, 51*, 713–723.

Bergquist, T. F., & Jacket, M. P. (1993). Awareness and goal setting with the traumatically brain injured. *Brain Injury*, *7*, 275-282.

Blackstone S. W. (2015). Issues and challenges in advancing effective patient-provider communication. In Blackstone S., Beukelman D., Yorkston K. (Eds.), *Patient provider communication* (pp. 9-35). Plural Publishing.

Blackstone, S. W., Yorkston, K. M., & Beukelman, D. R. (2015). *Patient-provider communication: Roles for speech-language pathologists and other health care professionals*. Plural Publishing, Inc.

Bogdan, R. C., & Biklen, S. K. (2007). *Qualitative research for education: An introduction to theory and methods* (5th ed.). Allyn & Bacon.

Brady, M. C., Frederick, A., & Williams, B. (2012). People with aphasia: Capacity to consent, research participation and intervention inequalities. *International Journal of Stroke*, *8*, 193-196.

Brennan, A., Worrel, L., & McKenna, K. (2005). The relationship between specific features of aphasia-friendly written material and comprehension of written material for people with aphasia. *Aphasiology*, *19*, 693-711.

Brennan, D., Georgeadis, A., & Baron, C. (2002). Telerehabilitation tools for the provision of remote speech-language treatment. *Topics in Stroke Rehabilitation*, *8*(4), 71–78.

Burns, M., Baylor, C., Dudgeon, B. J., Starks, H., & Yorkston, K. (2015). Asking the stakeholders: Perspectives of individuals with aphasia, their family members, and physicians regarding communication in medical interactions. *American Journal of Speech-Language Pathology (Online)*, *24*(3), 341-357. https://doi.org/10.1044/2015_AJSLP-14-0051

Burns, M., Baylor, C., Dudgeon, B. J., Starks, H., & Yorkston, K. (2017). Heath care provider accommodations for patients with communication disorders. *Topics in Language Disorders, 37,* 311-333. https://doi.org/10.1097/TLD.0000000000000134

Byng, S., Cairns, D., & Duchan, J. (2002). Values in practice and practising values. *Journal of Communication Disorders, 35*, 89-106.

Cameron, A., Hudson, K., Finch, E., Fleming, J., Lethlean, J., & McPhail, S. (2018). “I've got to get something out of it. And so do they”: Experiences of people with aphasia and university students participating in a communication partner training programme for healthcare professionals. *International Journal of Language & Communication Disorders, 53,* 919-928. https://doi.org/10.1111/1460-6984.12402

Cameron, A., McPhail, S., Hudson, K., Fleming, J., Lethlean, J., *&* Finch, E. (2017a). A pre-post intervention study investigation the confidence and knowledge of health professionals communicating with people with aphasia in a metropolitan hospital. *Aphasiology, 31*(3), 359-374. https://doi-org.ezproxy.emich.edu/10.1080/02687038.2016.1225277

Cameron, A., McPhail, S. M., Hudson, K., Fleming, J., Lethlean, J., Tan, N. J., *&* Finch, E. (2017b). The confidence and knowledge of health professionals when interacting with communication partner in a hospital setting. *Disability and Rehabilitation, 40*(11), 1288-1293. https://doi-org.ezproxy.emich.edu/10.1080/09638288.2017.1294626

Carlson, J. L. (1996). Evaluating patient motivation in physical disabilities practice settings. *American Journal of Occupational Therapy*, *51*, 347-351.

Cherry, M. G., Fletcher, I., O'Sullivan, H., & Dornan, T. (2014). Emotional intelligence in medical education: A critical review. *Medical Education*, *48*, 468-478.

Cott, C. A. (2004). Client-centred rehabilitation: Client perspectives. *Disability and Rehabilitation*, *26*, 1411-1422.

Creswell, J. W. (1997). *Qualitative inquiry and research design: Choosing among five traditions*. Sage.

Cross, A., & Schneider, M. (2010). A preliminary qualitative analysis of the impact of hope on stroke recovery in women. *Topics in Stroke Rehabilitation, 17*, 484-495.

Croteau, C., Le Dorze, G., & Baril, G. (2007). Development of a procedure to evaluate the contributions of persons with aphasia and their spouses in an interview situation. *Aphasiology*, *21*(6-8), 791-801.

Croteau, C., Vychytil, A., Larfeuil, C., & Le Dorze, G. (2004). “Speaking for” behaviours in spouses of people with aphasia: A descriptive study of six couples in an interview situation. *Aphasiology*, *18*(4), 291-312.

Dalemans, R., Wade, D.T., van den Heuvel, W.J., & de Witte, L.P. (2009). Facilitating the participation of people with aphasia in research: A description of strategies. *Clinical Rehabilitation*, *23*(10), 948-959.

de Haes, H., & Koedoot, N. (2003). Patient-centred decision-making in palliative cancer treatment: A world of paradoxes. *Patient Education Counselling*, *50*, 43–49.

Denman, A. (1998). Determining the needs of spouses caring for aphasic partners. *Disability and Rehabilitation*, *20*(11), 411-423.

Duggan, A., Bradshaw, Y., Carroll, S., Rattigan, S., & Altman, W. (2009). What can I learn from this interaction? A qualitative analysis of medical student self-reflection and learning in a standardized patient exercise about disability. *Journal of Health Communication, 14,* 797-811.

Ellis-Hill, C., Robison, J., Wiles, R., McPherson, K., Hyndman, D., & Ashburn, A. (2009). Going home to get on with life: Patients and carers experiences of being discharged from hospital following a stroke. *Disability and Rehabilitation*, *31*(2), 61–72. https://doi.org/10.1080/ 09638280701775289

Flynn, L., Cumberland, A., & Marshall, J. (2009). Public knowledge about aphasia: A survey with comparative data. *Aphasiology*, *23*(3), 393-401.

Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T. L. (1993). *Through the patient's eyes: Understanding and promoting patient-centered care.* Jossey-Bass.

Getz, H., Snider, S., Brennan, D., & Friedman, R. (2016). Successful remote delivery of a treatment for phonological alexia via telerehab. *Neuropsychological Rehabilitation*, *26*(4), 584-609.

Green, M. G., Adelman, R. D., Friedman, E., & Charon, R. (1994). Older patient satisfaction with communication during an initial medical encounter. *Social Science & Medicine*, *38*, 1279-1288.

Hall. J. A., Roter, D. L., & Katz, N. R. (1988). Meta-analysis of corelates of provider behavior in medical encounters. *Medical Care*, *26*, 657-675.

Hemsley, B., Balandin, S., & Togher, L. (2008). Family caregivers discuss roles and needs in supporting adults with cerebral palsy and complex communication needs in the hospital setting. *Journal of Developmental and Physical Disabilities*, *20*, 257–274.

Hemsley, B., Georgiou, A., Hill, S., Rollo, M., Steel, J., & Balandin, S. (2016). An integrative review of patient safety in studies on the care and safety of patients with communication disabilities in hospital. *Patient Education and Counseling*, *99*(4), 501–511. https://doi.org/10.1016/j.pec.2015.10.022

Hemsley, B., Werninck, M., & Worrall, L. (2013). “That really shouldn’t have happened”: People with aphasia and their spouses narrate adverse events in hospital. *Aphasiology, 27*(6), 706-722. https:// doi.org/10.1080/02687038.2012.748181

Hersh, D. (2004). Ten things our clients might say about their aphasia therapy ... if only we asked. *ACQ, 6*, 102-105.

Hersh, D. (2009). How do people with aphasia view their discharge from therapy? *Aphasiology, 23*, 331–350.

Hersh, D. (2015). “Hopeless, sorry, hopeless.” *Topics in Language Disorders, 35*(3), 219-236. https://doi.org/10.1097/TLD.0000000000000060.

Hersh, D., Godecke, E., Armstrong, E., Ciccone N., & Bernhardt, J. (2016). “Ward talk”: Nurses’ interaction with people with and without aphasia in the very early period poststroke. *Aphasiology, 30*(5), 609-628. https://doi.org/doi: 10.1080/02687038.2014.933520

Hilari, K., Needle, J. J., & Harrison, K. L. (2012). What are the important factors in health-related quality of life for people with aphasia? A systematic review. *Archives of Physical Medicine and Rehabilitation, 93*(1), 86-95. https://doi-org.ezproxy.emich.edu/10.1016/j.apmr.2011.05.028

Hilari, K., & Northcott, S. (2017). “Struggling to stay connected”: Comparing the social relationships of healthy older people and people with stroke and aphasia. *Aphasiology, 31*(6), 674-687. https://doi.org/10.1080/02687038.2016.1218436

Hoffman, J., Yorkston, K., Shumway-Cook, A., Ciol, M.,Dudgeon, B., & Chan, L. (2005). Effect of communication disability on satisfaction with health care: A survey of Medicarebeneficiaries. *American Journal of Speech-Language Pathology, 14*, 221-228.

Horton, S., Clark, A., Barton, G., Lane, K., & Pomeroy, V. M. (2016). Methodological issues in the design and evaluation of supported communication for aphasia training: A cluster controlled feasibility study. *British Medical Journal Open, 6*(4). https://doi.org/10.1136/bmjopen-2016-011207

Horvath, A. O., Del Re, A., Fluckiger, C. & Symonds, D. (2011). Alliance in individual psychotherapy. *Psychotherapy*, *48*, 9–16.

Howe, T., Davidson, B., Worrall, L., Hersh, D., Ferguson, A., Sherratt, S., & Gilbert, J. (2012). "You needed to rehab … families as well": Family members' own goals for aphasia rehabilitation. *International Journal of Language & Communication Disorders*, *47*, 511-521. https://doi.org/10.1111/j.1460-6984.2012.00159.x

Howell, C. (2016). *Listening, learning, caring and counselling: The essential manual for psychologists, psychiatrists, counsellors and other healthcare*. Exisle Publishing.

Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st Century*. National Academy Press.

Janssen, H., Ada, L., Bernhardt, J., McElduff, P., Pollack, M., Nilsson, M., & Spratt, N. J. (2014). An enriched environment increases activity in stroke patients undergoing rehabilitation in a mixed rehabilitation unit: A pilot non-randomized controlled trial. *Disability and Rehabilitation*, *36*(3), 255–262. https://doi.org/10.3109/09638288.2013.788218

The Joint Commission. (2010). *Advancing effective communication, cultural competence, and patient and family centered care: A roadmap for hospitals*.

Kagan, A., Black, S. E., Duchan, F. J., Simmons-Mackie, N., Square, P. (2001). Training volunteers as conversation partners using "Supported Conversation for Adults with

Aphasia" (SCA): A controlled trial. *Journal of Speech, Language, and Hearing Research*, *44*(3), 624-638.

Karnieli-Miller, O., Werner, P., Neufeld-Kroszynski, G., & Eidelman, S. (2012). Are you talking to me?! An exploration of the triadic physician-patient-companion communication within memory clinics encounters. *Patient Education and Counseling, 88*(3), 381-390. https://doi-org.ezproxy.emich.edu/10.1016/j.pec.2012.06.014

Kauhanen, M. L., Korpelainen, J. T., Hiltunen, P., Maatta, R., Mononen, H., Brusin, E., Sotaniemi, K. A., & Myllyla, V. V. (2000). Aphasia, depression, and non-verbal cognitive impairment in ischaemic stroke. *Cerebrovascular Disease*, *10*(6), 455-461.

Kelly, H., Kennedy, F., Britton, H., McGuire G., & Law, J. (2016). Narrowing the "digital divide": facilitating access to computer technology to enhance the lives of those with aphasia: A feasibility study. *Aphasiology, 30*(2-3), 133-163. https://doi.org/10.1080/02687038.2015.1077926

Kim, Y., Baker, F., Spillers, R. L., & Wellisch, D. K. (2006). Psychological adjustment of cancer caregivers with multiple roles. *Psycho-Oncology*, *15*, 795-804. https://doi.org/ 10.1002/pon.1013

Körner, M. (2013). Patient-centered care through internal and external participation in medical rehabilitation. *Health*, *5*, 48–55.

Laidsaar-Powell R., Butow P., Bu S., Charles C., Gafni A., Lam W., Jansen, J., McCaffery, K. J., Shepherd, H. L., Tattersall, M. H. N., & Juaskova, I. (2013). Physician-patient-companion communication and decision-making: A systematic review of triadic medical consultations. *Patient Education and Counseling, 91*(1), 3-13. https://doi-org.ezproxy.emich.edu/10.1016/j.pec.2012.11.007

Law, J., Bunning, K., Byng, S., Farrelly, S., & Heyman, B. (2005). Making sense in primary care: leveling the playing field for individuals with communication difficulties. *Disability & Society, 20*(2), 169-184.

Le Dorze, G., & Signori, F. (2010). Needs, barriers and facilitators experienced by spouses of people with aphasia. *Disability and Rehabilitation*, *32*(13), 1073-1087.

Leach, E., Cornwell, P., Fleming, J., & Haines, T. (2010). Patient centred goal-setting in a subacute rehabilitation setting. *Rehabilitation in Practice*, *32*, 159-172.

Levack, W. M., Dean, S. G., Siegert, R. J., & McPherson, K. M. (2011). Navigating patient-centred goal setting in inpatient stroke rehabilitation: How clinicians control the process to meet perceived professional responsibilities. *Patient Education and Counseling*, *85*, 206-213.

Lingraphica. (2021). *The 2021 Aphasia caregiver report*. https://devices.aphasia.com/hubfs/Downloadable_Content/AphasiaCaregiversReport2021_WEB.pdf

Lipkin, M. (2010). The history of communication skills knowledge and training. In D. W. Kissane, B. D. Bultz, P. M. Butow, & I. G. Finlay (Eds.), *Handbook of communication in oncology and palliative care* (pp. 3-12). Oxford University Press.

Lutz, B. J., Young, M. E., Cox, K. J., Martz, C., & Creasy, K. R. (2011). The crisis of stroke: Experiences of patients and their family caregivers. *Topics in Stroke Rehabilitation*, *18*(6), 786-797. https://doi.org/ 10.1310/tsr1806-786

Mangset, M., Tor Erling, D., Forde, R., & Wyller, T. B. (2008). "We're just sick people, nothing else": Factors contributing to elderly stroke patients' satisfaction with rehabilitation. *Clinical Rehabilitation*, *22*(9), 825-835.

Manzo, J. F., Blonder, L. X., & Burns, A. F. (1995). The social-interactional organisation of narrative and narrating among stroke patients and their spouses. *Sociology of Health & Illness*, *17*, 307-327.

Martin, D. J., Garske, J. P., & Davis, M. K. (2000). Relation of the therapeutic alliance with outcome and other variables: A meta-analytic review. *Journal of Consulting and Clinical Psychology*, *68*, 438-450.

Marwitt, S. J., & Kaye, P. N. (2006). Measuring grief in caregivers of persons with acquired brain injury. *Brain Injury*, *20*(13– 14), 1419-1429.

Mclellan, K. M., Mccann, C. M., Worrall, L. E., & Harwood, M.L. N. (2014). "For Mundefinedori, language is precious. And without it we are a bit lost": Mundefinedori experiences of aphasia. *Aphasiology*, *28*, 453–470. https://doi.org/10.1080/02687038.2013.845740

Michallet, B., Le Dorze, G., & Tetreault, S. (2001). The needs of spouses caring for severely aphasic persons. *Aphasiology*, *15*(8), 731-747.

Morris, M. A., Clayman, M. L., Peters, K, J., Leppin, A. L., & LeBlanc, A. (2015). Patient-centered communication strategies for patients with aphasia: Discrepancies between what patients want and what physicians do. *Disability and Health Journal*, *8*(2), 208-215. https://doi.org/10.1016/j.dhjo.2014.09.007.

Murphy, J. (2006). Perceptions of communication between people with communication disability and general practice staff. *Health Expectations*, *9*, 49-59.

National Aphasia Association. (n.d.). *Aphasia statistics*. https://www.aphasia.org/aphasia-resources/aphasia-statistics/

National Aphasia Association. (n.d.). *What is aphasia?* https://www.aphasia.org/aphasia-definitions/

National Aphasia Association. (2020). *2020 Aphasia awareness survey*. https://www.aphasia.org/2020-aphasia-awareness-survey/

National Institute on Deafness and Other Communication Disorders. (n.d.). *Aphasia*. https://www.nidcd.nih.gov/health/aphasia

Nordehn, G., Meredith, A., & Bye, L. (2006). A preliminary investigation of barriers to achieving patient-centered communication with patients who have stroke-related communication disorders. *Topics in Stroke Rehabilitation*, *13*(1), 68-77.

Northcott, S., Marshall, J. & Hilari, K. (2016). What factors predict who will have a strong social network following a stroke? *Journal of Speech, Language and Hearing Research*, *59*(4), 772-783. https://doi.org/10.1044/2016_JSLHR-L-15-0201

O'Halloran, R., Hickson, L., & Worrall, L. (2008). Environmental factors that influence communication between people with communication disability and their healthcare providers in hospital: a review of the literature within the International Classification of Functioning, Disability and Health (ICF) framework. *International Journal of Language and Communication Disorders, 43*(6), 601-632. https://doi.org/10.1080/13682820701861832

O'Halloran, R., Worrall, L., & Hickson, L. (2009). The number of patients with communication-related impairments in acute hospital stroke units. *International Journal of Speech-Language Pathology, 11*(6), 438–449.

O'Halloran R, Worrall L, & Hickson L. (2012). Stroke patients communicating their healthcare needs in hospital: a study within the ICF framework. *International Journal of Language* *and Communication Disorders, 47*(2), 130-143. https://doi.org/10.1111/j.1460-6984.2011.00077.x

Parr S., Byng S., Gilpin S., & Ireland C. (1997). *Talking about aphasia*. Open University Press.

Parry, R. H. (2004). Communication during goal setting in physiotherapy treatment sessions. *Clinical Rehabilitation*, *18*, 668-682.

Paterson, B., & Scott-Findlay, S. (2002). Critical issues in interviewing people with traumatic brain injury. *Qualitative Health Research*, *12*(3), 399-409.

Patton, M. Q. (2002). *Qualitative research & evaluation methods*. Sage Publications.

Paul, N., & Sanders, G. (2010). Applying an ecological framework to education needs of communication partners of individuals with aphasia. *Aphasiology*, *24*(9), 1095-1112.

Pearl, G., & Cruice, M. (2017). Facilitating the involvement of people with aphasia in stroke research by developing communicatively accessible research resources. *Topics in Language Disorders*, *37*(1), 67-84.

Peri, J., Kerse, J., & Halliwell, J. (2004). *Goal-setting for older people: A literature review and synthesis*. Auckland UniServices Limited.

Perry, L., & Middleton, S. (2011). An investigation of family carers' needs following stroke survivors' discharge from acute hospital care in Australia. *Disability and Rehabilitation, 33*(19-20), 1890-1900. https://doi.org/10.3109/09638288.2011.553702

Petrides, K.V., & Furnham, A. (2001). Trait emotional intelligence: Psychometric investigation with reference to established trait taxonomies. *European Journal of Personality*, *15*, 425–448.

Petrides, K.V., Pita, R., & Kokkinaki. F. (2007). The location of trait emotional intelligence in personality factor space. *British Journal of Psychology, 98*, 273–289.

Philpin, S. M., Jordan, S. E., & Warring, J. (2005). Giving people a voice: reflections on conducting interviews with participants experiencing communication impairment. *Journal of Advanced Nursing*, *50*(3), 299-306.

Pitt, R., Theodoros, D., Hill, A. J., Rodriguez, A. D., & Russell, T. (2017). The feasibility of delivering constraint-induced language therapy via the internet. *Digital Health*, *3*, 1-11. https://doi.org/10.1177/2055207617718767

Ponte-Allan, M., & Giles, G. M. (1999). Goal setting and functional outcomes in rehabilitation. *American Journal of Occupational Therapy*, *53*, 646-649.

Pound, C., Duchan, J., Penman, T., Hewitt, A., & Parr, S. (2007). Communication access to organisations: Inclusionary practices for people with aphasia. *Aphasiology*, *21*, 23-38. https://doi.org/10.1080/02687030600798212

Pulvermüller, F., & Berthier, M. L. (2008). Aphasia therapy on a neuroscience basis. *Aphasiology*, *22*(6), 563–599. https://doi.org/10.1080/02687030701612213

Rathert, C. Wyrwich, M. D., & Boren, S. A. (2013). Patient-centered care and outcomes: A systematic review of the literature. *Medical Care Research and Rev*iew, *70*, 351–379.

Rhode, A., Townley-O'Neill, K., Trendall, K., Worrall, L., & Cornwell, P. (2012). A comparison of client and therapist goals for people with aphasia: A qualitative exploratory study. *Aphasiology*, *26*(10), 1298-1315. https://doi.org/10.1080/02687038.2012.706799

Rose, T., Wallace, S., & Leow, S. (2019). Family members' experiences and preferences for receiving aphasia information during early phases in the continuum of care. *International Journal of Speech Language Pathology*, *21*(5), 470–482. https://doi.org/10.1080/17549507.2019

Rose, T., Worrall, L., Hickson, L., & Hoffmann, T. (2011a). Aphasia friendly written health information: Content and design characteristics. *International Journal of Speech-Language Pathology*, *14*(4), 335-347.

Rose, T., Worrall, L., Hickson, L., & Hoffmann, T. (2011b). Exploring the use of graphics in written health information for people with aphasia. *Aphasiology*, *25*(12), 1579-1599.

Saldert, C., Bartonek-Åhman, H., & Bloch, S. (2018). Interaction between nursing staff and residents with aphasia in long-term care: A mixed method case study. *Nursing Research and Practice*, *2018*, 1-11. http://doi.org/10.1155/2018/9418692

Shafer, J. S., Shafer, P. R., & Haley, K. L. (2019). Caregivers navigating rehabilitative care for people with aphasia after stroke: A multi-lens perspective. *International Journal of Language & Communication Disorders*, *54*, 634-644. http://doi.org/10.1111/1460-6984.12467

Silvera, G. A., Wolf, J. A., Stanowski, A., & Studer, Q. (2021). The influence of COVID-19 visitation restrictions on patient experience and safety outcomes: A critical role for subjective advocates. *Patient Experience Journal*, *8*(1), 30-39. http://doi.org/10.35680/2372-0247.1596

Simmons-Mackie, N. (1998). In support of supported conversation for adults with aphasia. *Aphasiology*, *12,* 831-838. http://doi.org/10.1080/02687039808249576

Simmons-Mackie, N. (2018). Communication partner training in aphasia: Reflections on communication accommodation theory. *Aphasiology*, *32*(10), 1215-1224. http://doi.org/10.1080/02687038.2018.1428282

Simmons-Mackie, N., Code, C., Armstrong, E., Stiegler, L., & Elman, R. J. (2002). What is aphasia? Results of an international survey. *Aphasiology*, *16*(8), 837–848.

Simmons-Mackie, N., Raymer, A., Armstrong, E., Holland, A., & Cherney, L. (2010). Communication partner training in aphasia: A systematic review. *Archives of Physical Medicine and Rehabilitation, 91*(12), 1814-1837. http://doi.org/10.1016/j.apmr.2010.08.026

Simmons-Mackie, N. (2013). Frameworks for managing communication support for people with aphasia. In N. Simmons-Mackie, J. M. King, & D. R. Beukelman (Eds.), *Supporting communication for adults with acute and chronic aphasia* (pp. 11-51). Paul H. Brookes.

Starks, H., & Trinidad, S. B. (2007). Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research, 17*(10), 1372-1380.

Steele, R. D., Baird, A., McCall, D., & Haynes, L. (2014). Combining teletherapy and on-line language exercises in the treatment of chronic aphasia: An outcome study. *International Journal of Telerehabilitation, 6*(2), 3-20. http://doi.org/10.5195/ijt.2014.6157

Stewart, M. (2001). Towards a global definition of patient centred care. *British Medical Journal, 322*, 444-445.

Tomkins, B., Siyambalapitiya, S., & Worrall, L. (2013). What do people with aphasia think about their health care? Factors influencing satisfaction and dissatisfaction. *Aphasiology, 27*(8), 972-991. doi:10.1080/02687038.2013.811211

Townend, E., Brady, M., & McLaughlan, K. (2007). Exclusion and inclusion criteria for people with aphasia in studies of depression following stroke: A systematic review and future recommendations. *Neuroepidemiology, 29*, 1-17.

Wachters-Kaufmann, C., Schuling, J., The, H., & Meyboom-de Jong, B. (2005). Actual and desired information provision after a stroke. *Patient Education and Counselling*, *56*(2), 211-217. https://doi. org/10.1016/j.pec.2004.02.012

Walker, Judy P., Price, K., & Watson, J. (2018). Promoting social connections in a synchronous telepractice, aphasia communication group. *Perspectives of the ASHA Special Interest Groups*, *3*(18), 32-42. https://doi.org/10.1044/persp3.sig18.32

Weidner, K., & Lowman, J. (2020). Telepractice for adult speech-language pathology services: A systematic review. *ASHA*, *5*(1), 326–338. https://doi.org/10.1044/2019_PERSP-19-00146

West, R., & Turner, L. (2014). Communication accommodation theory. In R. West & L. Turner (Eds.), *Introducing communication theory: Analysis and application* (5th ed., pp. 492-509). McGraw-Hill.

Worrall, L., Sherratt, S., Rogers, P., Howe, T., Hersh, D., Ferguson, A., & Davidson, B. (2011). What people with aphasia want: Their goals according to the ICF. *Aphasiology, 25*, 309-322. https://doi.org/10.1080/02687038.2010.508530.

Wressle, E., Öberg, B., & Henriksson, C. (1999). The rehabilitation process for the geriatric stroke patient: An exploratory study of goal setting and interventions. *Disability and Rehabilitation*, *21*, 80-87.

Zijlmans, L. J. M., Embregts, P. J. C. M., Gerits, L. Bosman, A. M. T., & Derksen, J. J. L. (2011). Training emotional intelligence related to treatment skills of staff working with clients with intellectual disabilities and challenging behavior. *Journal of Intellectual Disability Research*, *55*, 219-230.

Zijlmans, L. J. M., Embregts, P. J. C. M., Gerits, L. Bosman, A. M. T., & Derksen, J. J. L. (2015). The effectiveness of a staff training focused on emotional intelligence and interaction between support staff and clients. *Journal of Intellectual Disability Research*, *59*, 599-612.

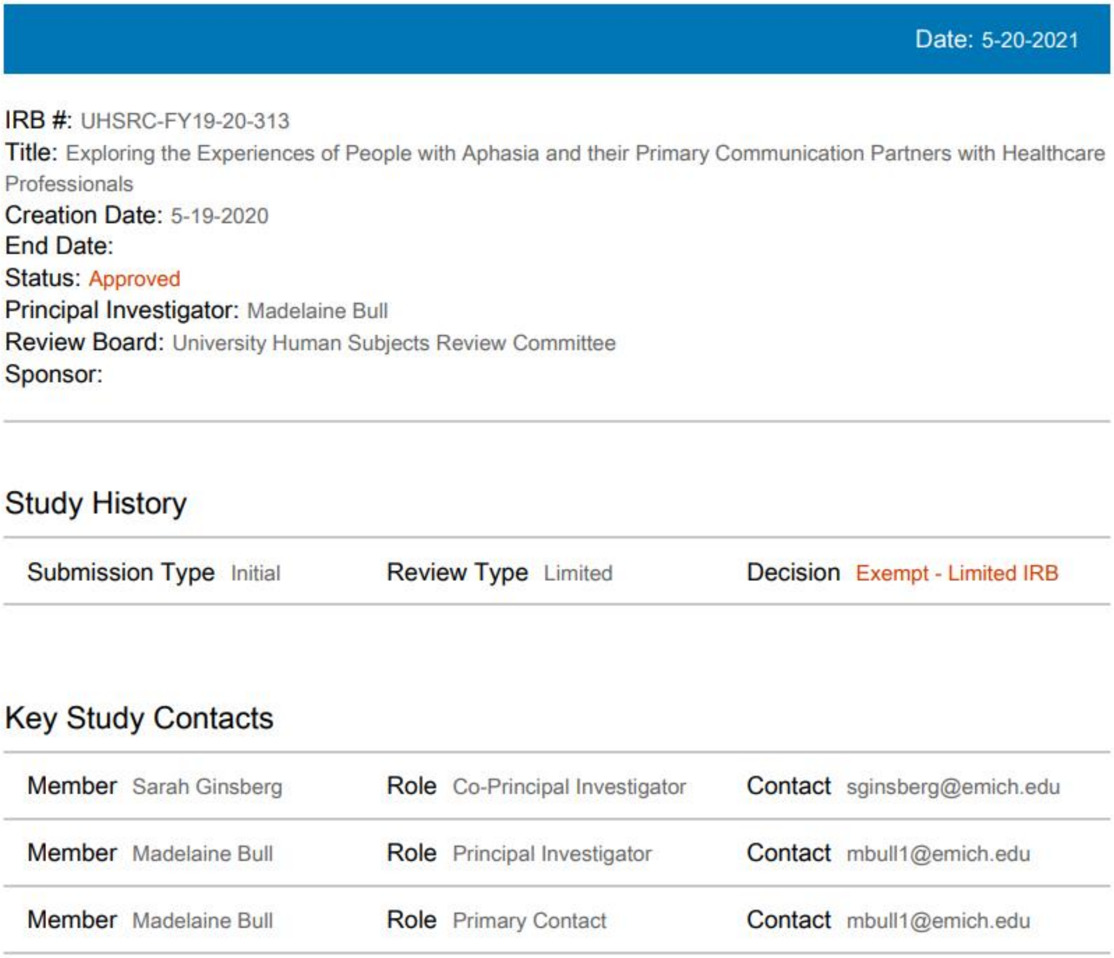
Ziviani, J., Lennox, N., Allison, H., Lyons, M., & Del Mar, C. (2004). Meeting in the middle: Improving communication in primary health care consultations with people with an intellectual disability. *Journal of Intellectual & Developmental Disability*, *29*, 211–225.

APPENDICES

Appendix A: Interview Questions

1. How would you describe your interactions with doctors, therapists, and other providers?
   - Follow-up questions as needed
2. How effective do you think your healthcare providers are at communicating with you?
   - Follow-up questions as needed
3. Can you describe an instance in which your healthcare provider changed their communication style to better meet your needs?
   - Follow-up questions as needed
4. What do you think healthcare providers can do to better communicate with you?
   - Follow-up questions as needed

Appendix B: IRB Approval Letter



Date: 5-20-2021

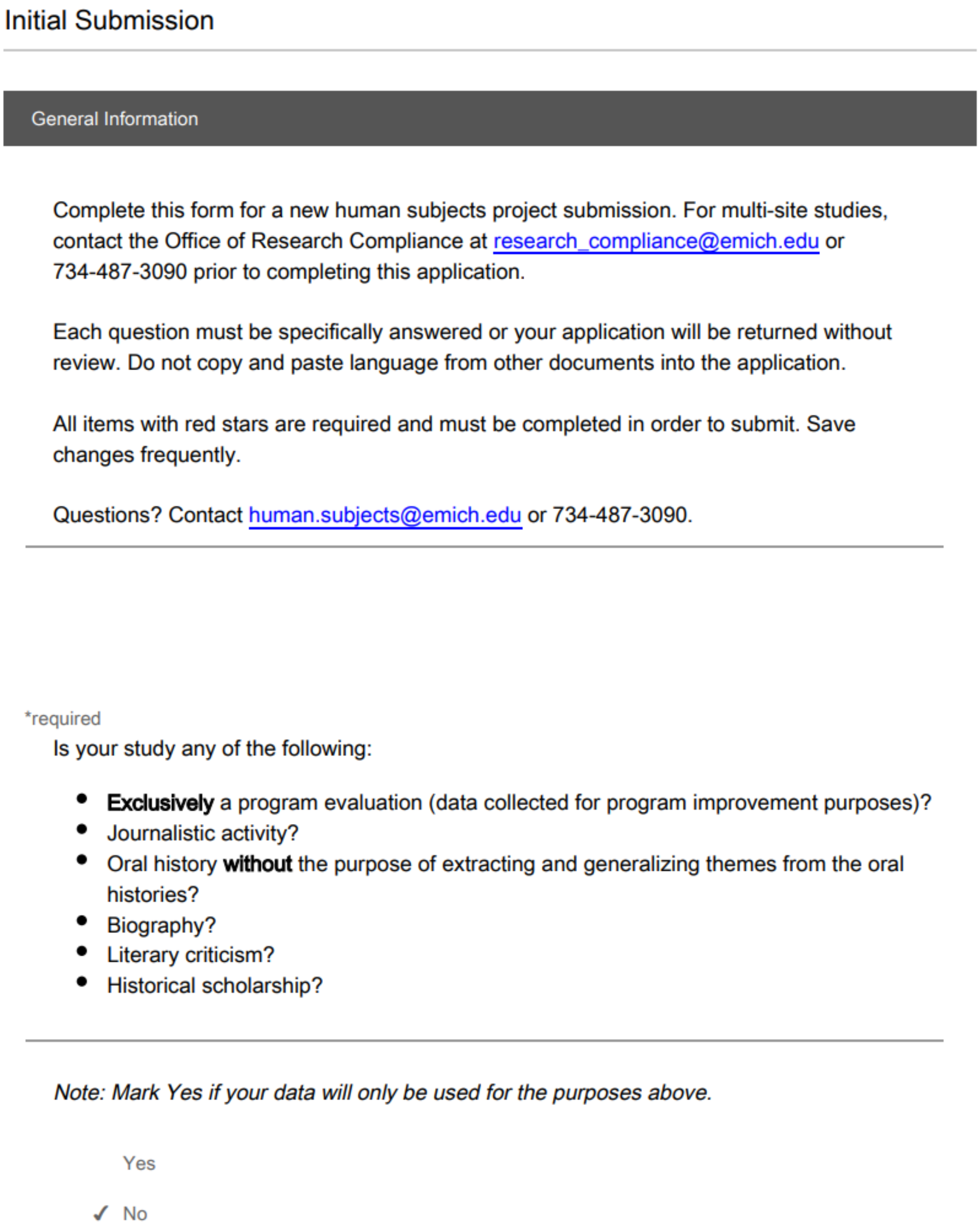
IRB #: UHSRC-FY19-20-313
Title: Exploring the Experiences of People with Aphasia and their Primary Communication Partners with Healthcare Professionals
Creation Date: 5-19-2020
End Date:
Status: Approved
Principal Investigator: Madelaine Bull
Review Board: University Human Subjects Review Committee
Sponsor:

Study History

Submission Type Initial	**Review Type** Limited	**Decision** Exempt - Limited IRB

Key Study Contacts

Member Sarah Ginsberg	**Role** Co-Principal Investigator	**Contact** sginsberg@emich.edu
Member Madelaine Bull	**Role** Principal Investigator	**Contact** mbull1@emich.edu
Member Madelaine Bull	**Role** Primary Contact	**Contact** mbull1@emich.edu



Initial Submission

General Information

Complete this form for a new human subjects project submission. For multi-site studies, contact the Office of Research Compliance at research_compliance@emich.edu or 734-487-3090 prior to completing this application.

Each question must be specifically answered or your application will be returned without review. Do not copy and paste language from other documents into the application.

All items with red stars are required and must be completed in order to submit. Save changes frequently.

Questions? Contact human.subjects@emich.edu or 734-487-3090.

*required

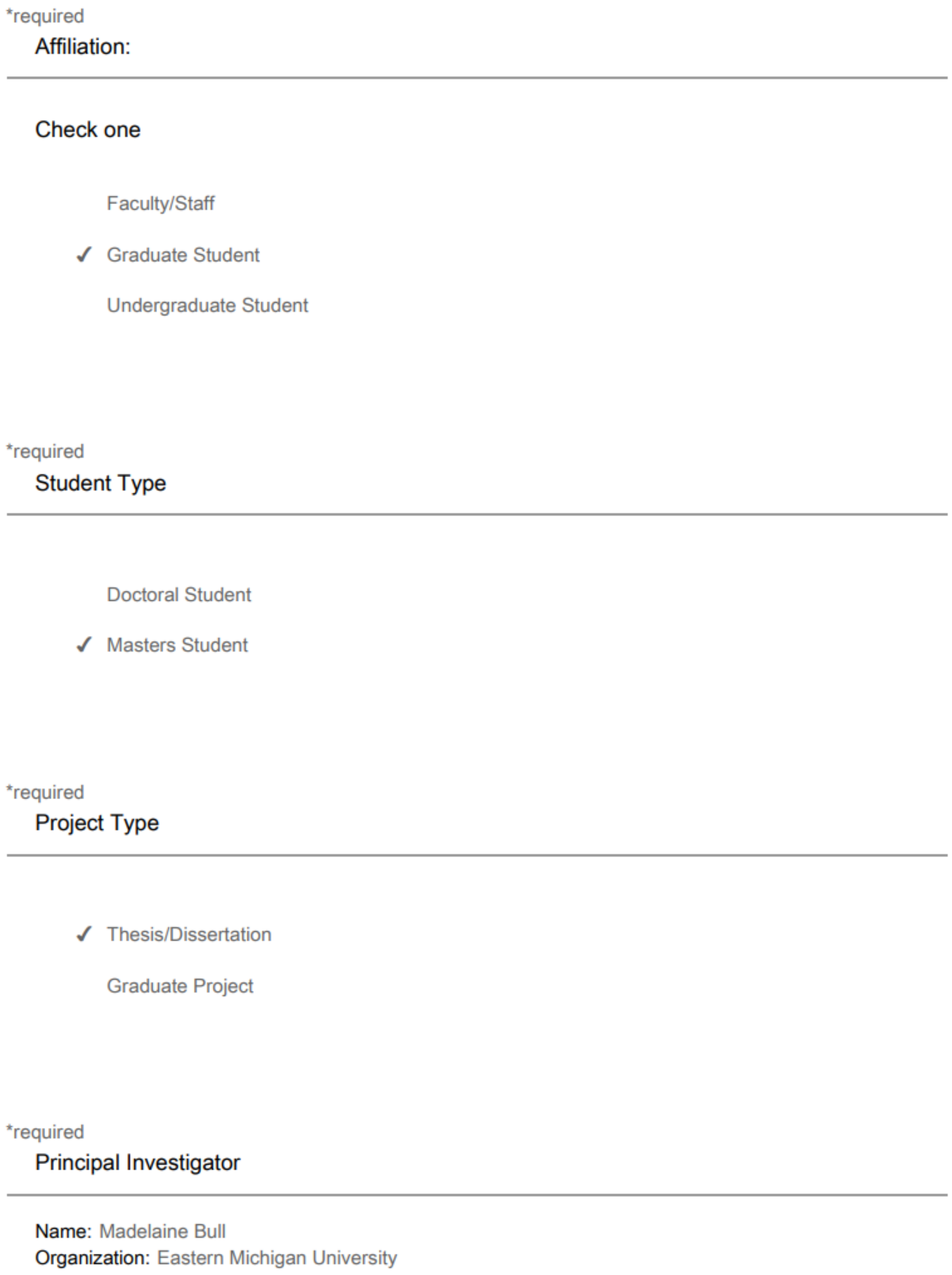
Is your study any of the following:

- **Exclusively** a program evaluation (data collected for program improvement purposes)?
- Journalistic activity?
- Oral history **without** the purpose of extracting and generalizing themes from the oral histories?
- Biography?
- Literary criticism?
- Historical scholarship?

Note: Mark Yes if your data will only be used for the purposes above.

Yes

✓ No



*required

Affiliation:

Check one

Faculty/Staff

✓ Graduate Student

Undergraduate Student

*required

Student Type

Doctoral Student

✓ Masters Student

*required

Project Type

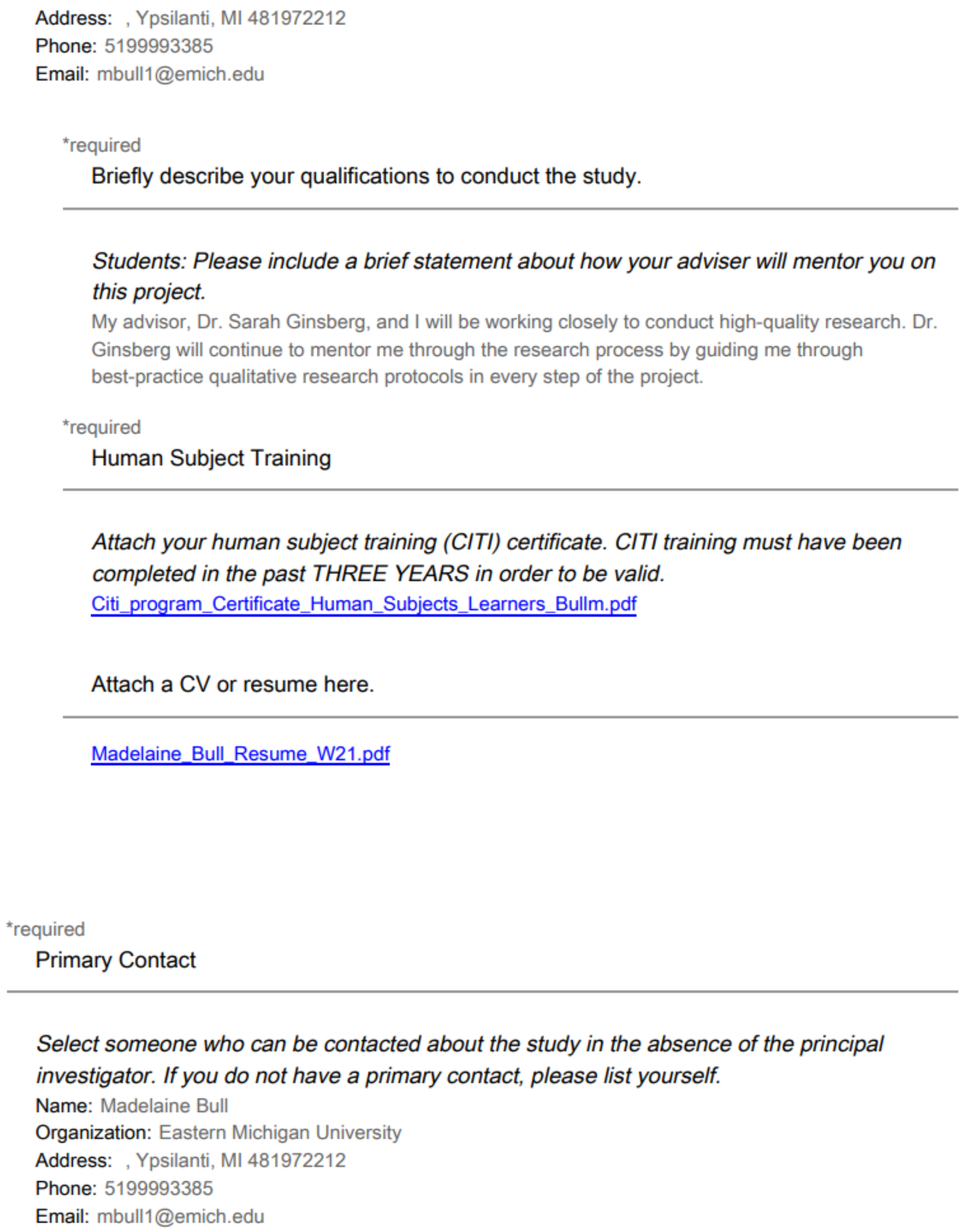
✓ Thesis/Dissertation

Graduate Project

*required

Principal Investigator

Name: Madelaine Bull
Organization: Eastern Michigan University



Address: , Ypsilanti, MI 481972212
Phone: 5199993385
Email: mbull1@emich.edu

*required

Briefly describe your qualifications to conduct the study.

Students: Please include a brief statement about how your adviser will mentor you on this project.

My advisor, Dr. Sarah Ginsberg, and I will be working closely to conduct high-quality research. Dr. Ginsberg will continue to mentor me through the research process by guiding me through best-practice qualitative research protocols in every step of the project.

*required

Human Subject Training

Attach your human subject training (CITI) certificate. CITI training must have been completed in the past THREE YEARS in order to be valid.

Citi_program_Certificate_Human_Subjects_Learners_Bullm.pdf

Attach a CV or resume here.

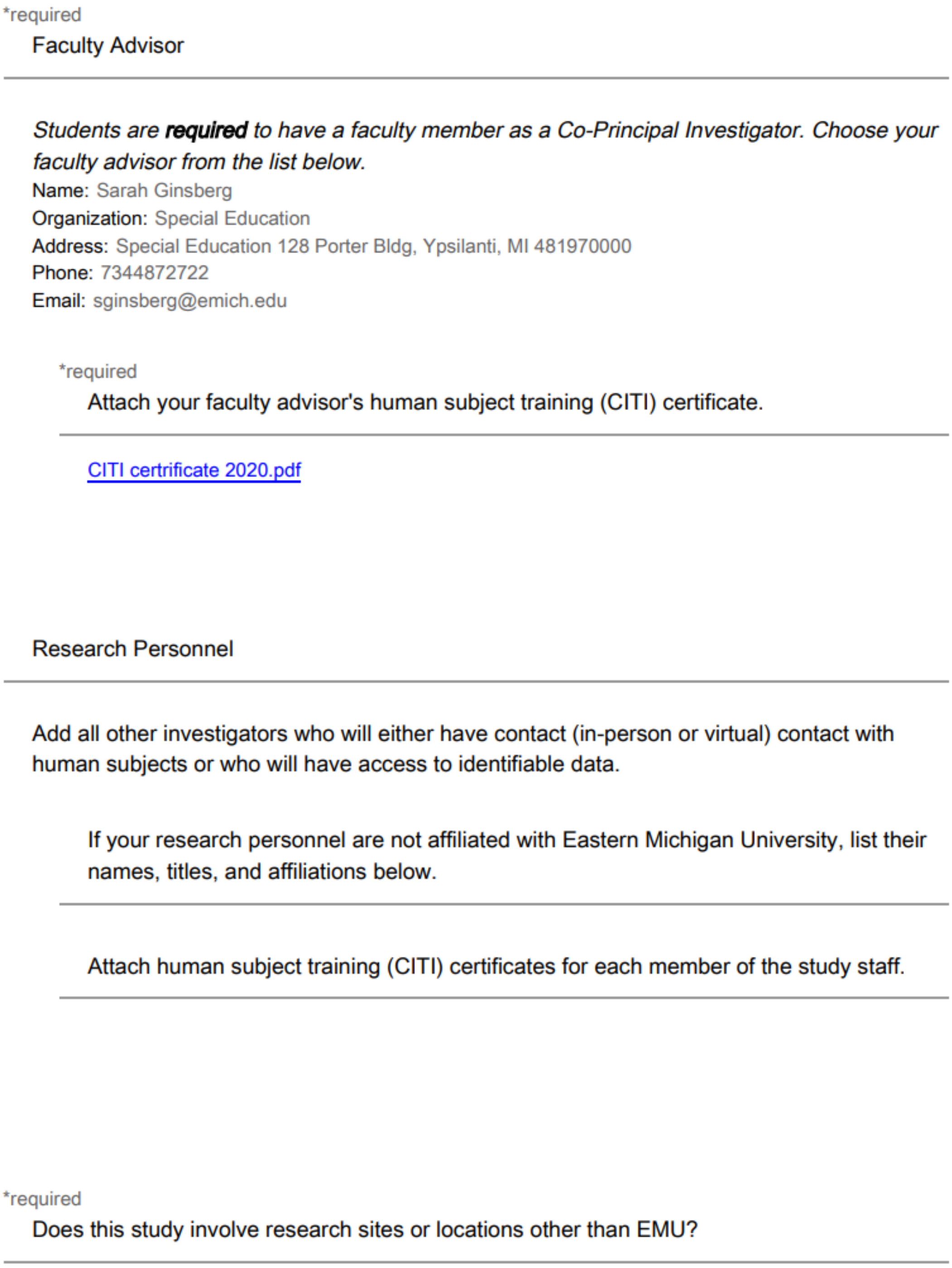
Madelaine_Bull_Resume_W21.pdf

*required

Primary Contact

Select someone who can be contacted about the study in the absence of the principal investigator. If you do not have a primary contact, please list yourself.

Name: Madelaine Bull
Organization: Eastern Michigan University
Address: , Ypsilanti, MI 481972212
Phone: 5199993385
Email: mbull1@emich.edu



*required
Faculty Advisor

---

*Students are **required** to have a faculty member as a Co-Principal Investigator. Choose your faculty advisor from the list below.*

Name: Sarah Ginsberg
Organization: Special Education
Address: Special Education 128 Porter Bldg, Ypsilanti, MI 481970000
Phone: 7344872722
Email: sginsberg@emich.edu

*required
Attach your faculty advisor's human subject training (CITI) certificate.

CITI certrificate 2020.pdf

Research Personnel

Add all other investigators who will either have contact (in-person or virtual) contact with human subjects or who will have access to identifiable data.

If your research personnel are not affiliated with Eastern Michigan University, list their names, titles, and affiliations below.

Attach human subject training (CITI) certificates for each member of the study staff.

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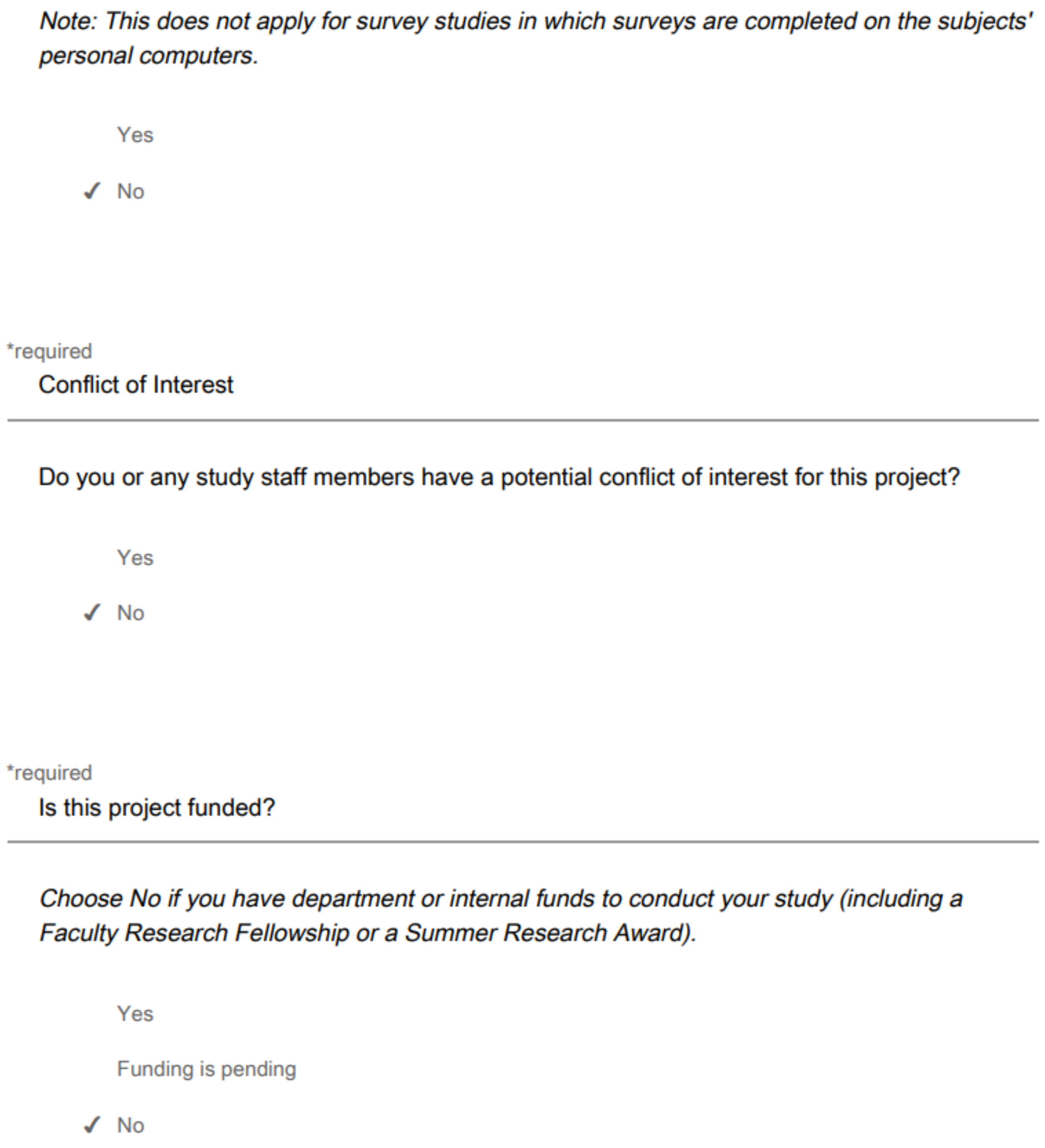
*required
Does this study involve research sites or locations other than EMU?



Note: This does not apply for survey studies in which surveys are completed on the subjects' personal computers.

Yes

✓ No

*required

Conflict of Interest

Do you or any study staff members have a potential conflict of interest for this project?

Yes

✓ No

*required

Is this project funded?

Choose No if you have department or internal funds to conduct your study (including a Faculty Research Fellowship or a Summer Research Award).

Yes

Funding is pending

✓ No

Study Abstract and Summary

*required

Abstract

Provide a brief abstract of your study procedures in non-technical terms. Limit this abstract to no more than 300 words.

Patients with communication disorders face greater risks to their health and quality of life while in hospital settings, and report difficulty accessing healthcare services and communicating their healthcare needs with healthcare providers (Bartlett et al., 2008; Hilari et al., 2012). Aphasia is an acquired communication disorder, often resulting from a stroke, and impacts millions of Americans (National Aphasia Association, n.d.). People with aphasia (PWA) may frequent the hospital for acute services following a stroke, to attend check-ups or appointments, or to receive rehabilitation services. A PWA is often accompanied by their primary communication partners (PCP), the person with whom the PWA communicates with the most. Unfortunately, many healthcare providers do not receive training on effective methods of facilitating communication with PWA, so PCPs often act as advocates for patients with aphasia. This can cause frustration and communication breakdowns between PWA, their PCPs, and healthcare providers.

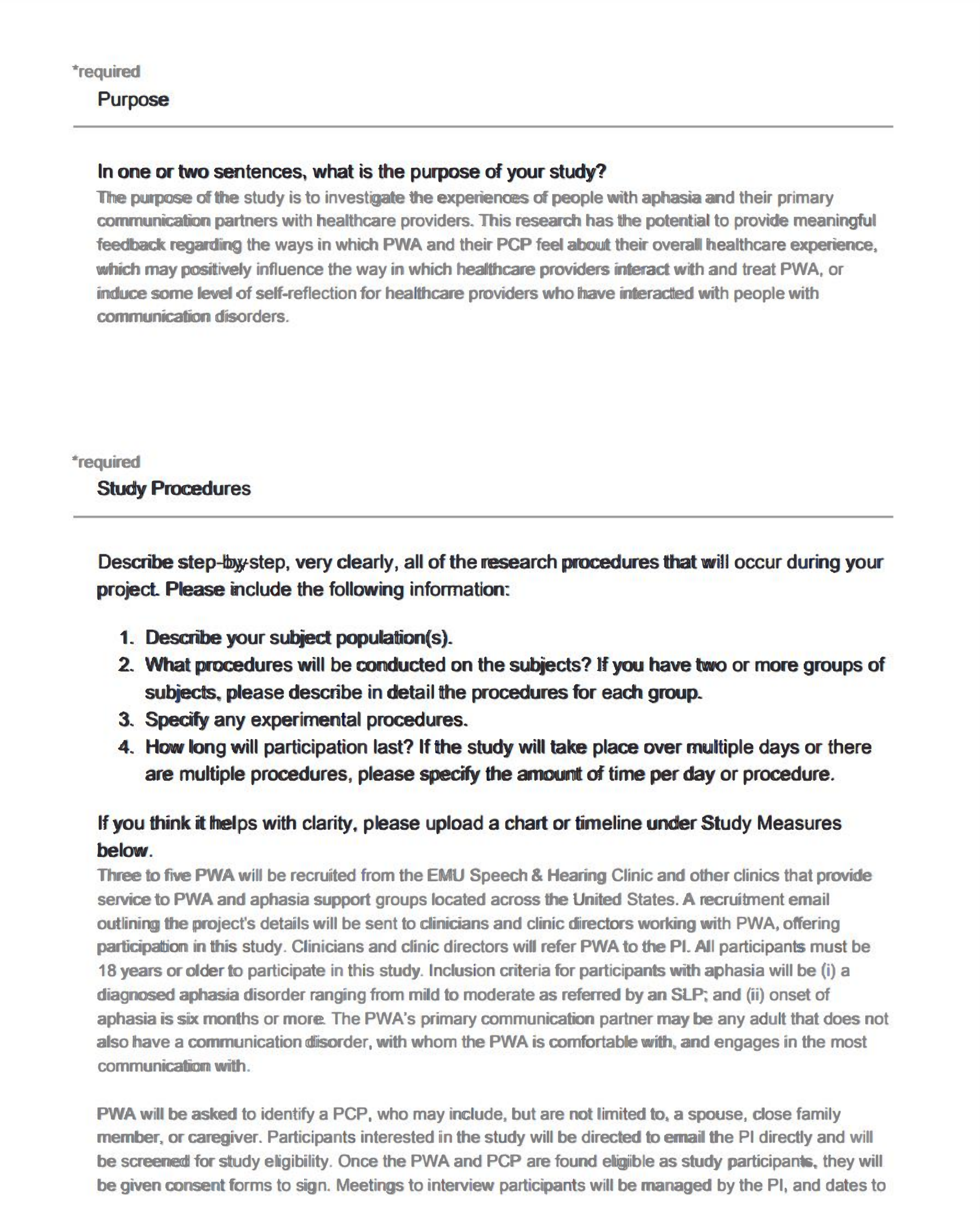
This research study is designed to explore the experiences of people with aphasia and their primary communication partner with healthcare providers, to reach a better understanding of how PWA and their PCP feel their needs are being met by their various healthcare providers, how healthcare providers attenuate to their needs, and what (if any) changes healthcare providers should make to better treat patients with aphasia and their families.

References

Bartlett, G., Blais, R., Tamblyn, R., Clermont, R. J., & MacGibbon, B. (2008). Impact of patient communication problems on the risk of preventable adverse events in acute care settings. *Canadian Medical Association Journal*, *178*(12), 1555–1562. https://doi.org/10.1503/cmaj.070690

Hilari, K., Needle, J. J., & Harrison, K. L. (2012). What are the important factors in health-related quality of life for people with aphasia? A systematic review. *Archives of Physical Medicine and Rehabilitation, 93*(1), 86–95. https://doi.org/10.1016/j.apmr.2011.05.028

National Aphasia Association. *2020 Aphasia Awareness Survey*. Retrieved February 5, 2021, from https://www.aphasia.org/2020-aphasia-awareness-sur...



*required

Purpose

In one or two sentences, what is the purpose of your study?

The purpose of the study is to investigate the experiences of people with aphasia and their primary communication partners with healthcare providers. This research has the potential to provide meaningful feedback regarding the ways in which PWA and their PCP feel about their overall healthcare experience, which may positively influence the way in which healthcare providers interact with and treat PWA, or induce some level of self-reflection for healthcare providers who have interacted with people with communication disorders.

*required

Study Procedures

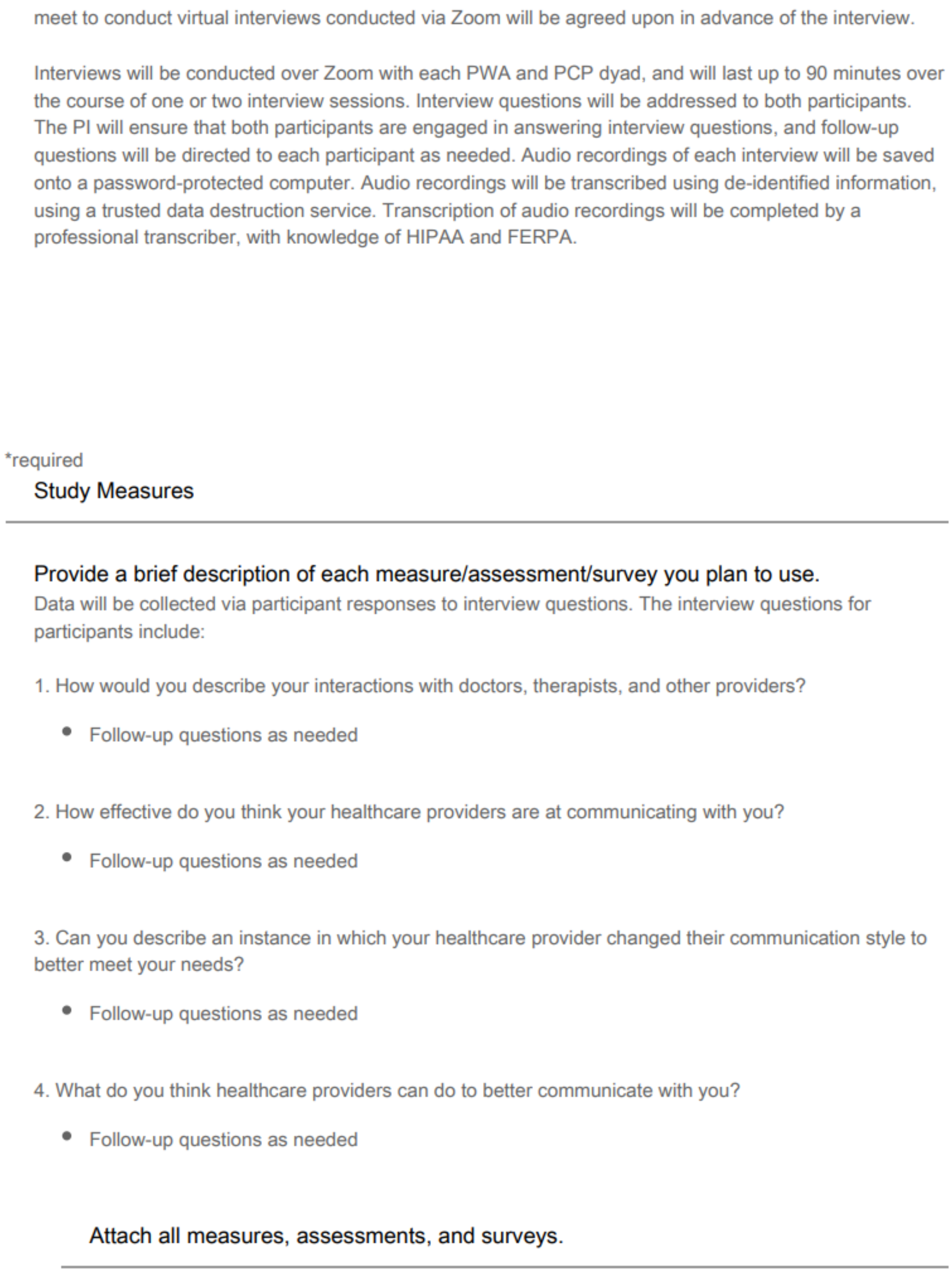
Describe step-by-step, very clearly, all of the research procedures that will occur during your project. Please include the following information:

1. **Describe your subject population(s).**
2. **What procedures will be conducted on the subjects? If you have two or more groups of subjects, please describe in detail the procedures for each group.**
3. **Specify any experimental procedures.**
4. **How long will participation last? If the study will take place over multiple days or there are multiple procedures, please specify the amount of time per day or procedure.**

If you think it helps with clarity, please upload a chart or timeline under Study Measures below.

Three to five PWA will be recruited from the EMU Speech & Hearing Clinic and other clinics that provide service to PWA and aphasia support groups located across the United States. A recruitment email outlining the project's details will be sent to clinicians and clinic directors working with PWA, offering participation in this study. Clinicians and clinic directors will refer PWA to the PI. All participants must be 18 years or older to participate in this study. Inclusion criteria for participants with aphasia will be (i) a diagnosed aphasia disorder ranging from mild to moderate as referred by an SLP; and (ii) onset of aphasia is six months or more. The PWA's primary communication partner may be any adult that does not also have a communication disorder, with whom the PWA is comfortable with, and engages in the most communication with.

PWA will be asked to identify a PCP, who may include, but are not limited to, a spouse, close family member, or caregiver. Participants interested in the study will be directed to email the PI directly and will be screened for study eligibility. Once the PWA and PCP are found eligible as study participants, they will be given consent forms to sign. Meetings to interview participants will be managed by the PI, and dates to



meet to conduct virtual interviews conducted via Zoom will be agreed upon in advance of the interview.

Interviews will be conducted over Zoom with each PWA and PCP dyad, and will last up to 90 minutes over the course of one or two interview sessions. Interview questions will be addressed to both participants. The PI will ensure that both participants are engaged in answering interview questions, and follow-up questions will be directed to each participant as needed. Audio recordings of each interview will be saved onto a password-protected computer. Audio recordings will be transcribed using de-identified information, using a trusted data destruction service. Transcription of audio recordings will be completed by a professional transcriber, with knowledge of HIPAA and FERPA.

*required

Study Measures

Provide a brief description of each measure/assessment/survey you plan to use.

Data will be collected via participant responses to interview questions. The interview questions for participants include:

1. How would you describe your interactions with doctors, therapists, and other providers?

- Follow-up questions as needed

2. How effective do you think your healthcare providers are at communicating with you?

- Follow-up questions as needed

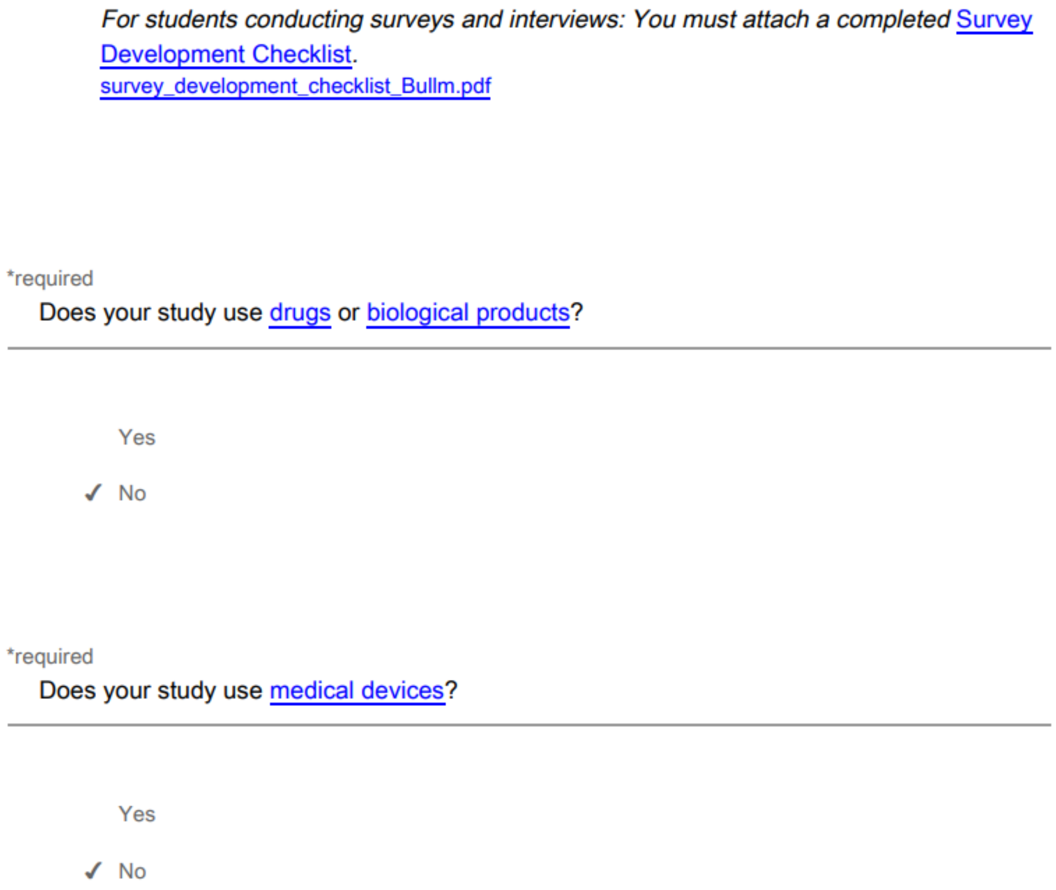
3. Can you describe an instance in which your healthcare provider changed their communication style to better meet your needs?

- Follow-up questions as needed

4. What do you think healthcare providers can do to better communicate with you?

- Follow-up questions as needed

Attach all measures, assessments, and surveys.



For students conducting surveys and interviews: You must attach a completed Survey Development Checklist.

survey_development_checklist_Bullm.pdf

*required

Does your study use drugs or biological products?

Yes

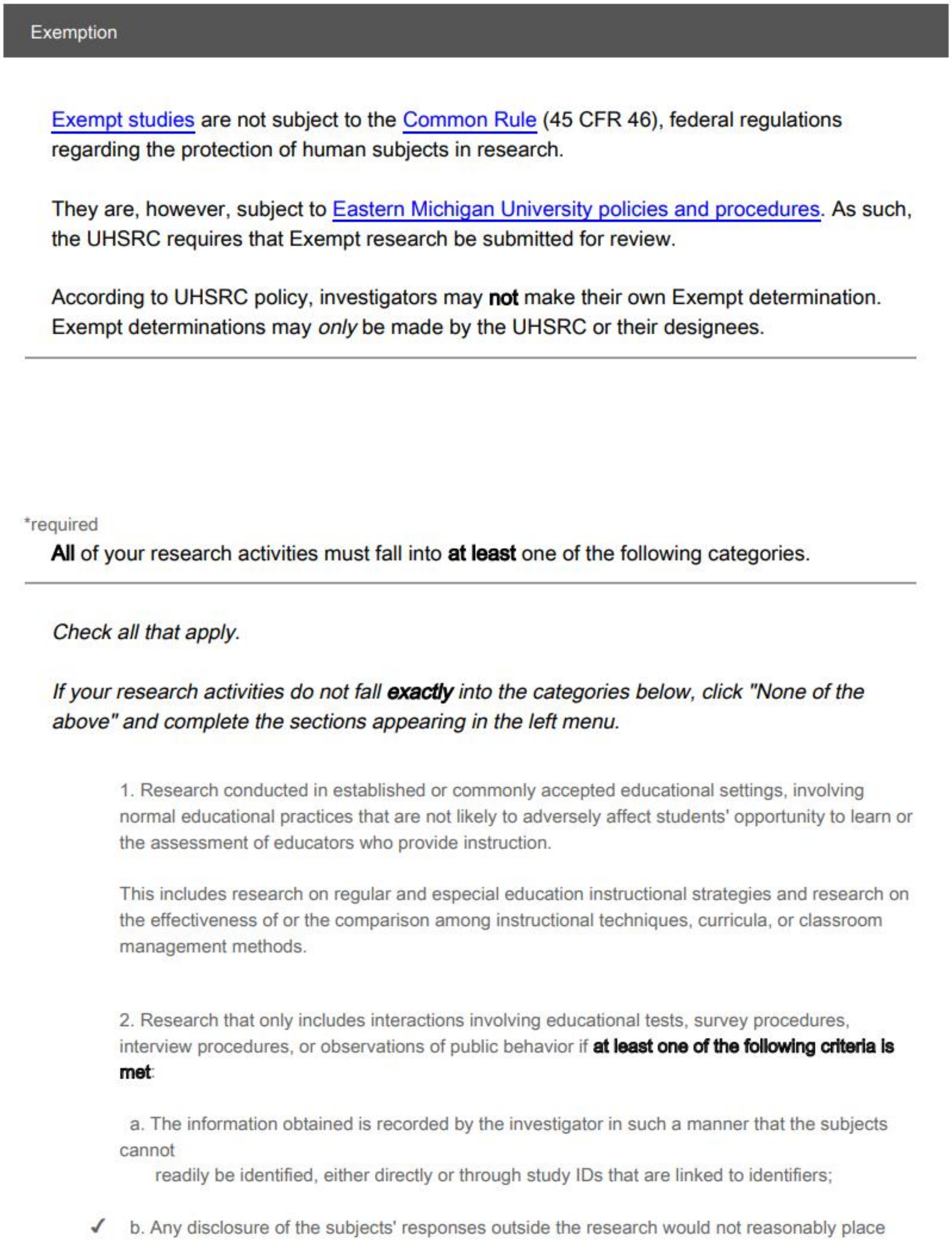
✓ No

*required

Does your study use medical devices?

Yes

✓ No



Exemption

[Exempt studies]() are not subject to the [Common Rule]() (45 CFR 46), federal regulations regarding the protection of human subjects in research.

They are, however, subject to [Eastern Michigan University policies and procedures](). As such, the UHSRC requires that Exempt research be submitted for review.

According to UHSRC policy, investigators may **not** make their own Exempt determination. Exempt determinations may *only* be made by the UHSRC or their designees.

---

*required

All of your research activities must fall into **at least** one of the following categories.

Check all that apply.

If your research activities do not fall ***exactly*** *into the categories below, click "None of the above" and complete the sections appearing in the left menu.*

1. Research conducted in established or commonly accepted educational settings, involving normal educational practices that are not likely to adversely affect students' opportunity to learn or the assessment of educators who provide instruction.

This includes research on regular and especial education instructional strategies and research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.

2. Research that only includes interactions involving educational tests, survey procedures, interview procedures, or observations of public behavior if **at least one of the following criteria is met**:

a. The information obtained is recorded by the investigator in such a manner that the subjects cannot
readily be identified, either directly or through study IDs that are linked to identifiers;

✓ b. Any disclosure of the subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability, or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; **or**

c. The information obtained is recorded by the investigator such that subjects can be identified, **and** the UHSRC has reviewed the privacy and confidentiality provisions in the study.

Note: This category is only applicable to adults age 18+. Educational tests, survey procedures, interview procedures, or observation of public behavior involving minors ***cannot*** *be Exempt* ***except for*** *educational tests and observation of public behavior if the investigator's presence will not in any way affect the behavior of the research subjects in conditions a and b above only. Condition c above can never be Exempt if the research involves minors.*

---

3. Research involving benign behavioral interventions using **adult** subjects provided that the subject provides consent/permission to participate beforehand and at least one of the following criteria is met:

a. All information collected about the subject (research data) is anonymous (not directly or indirectly identifiable).

b. Any disclosure of the subjects' data would not reasonably place subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; **or**

c. The information obtained is recorded by the investigator such that subjects can be identified, **and** the UHSRC has reviewed the privacy and confidentiality provisions in the study.

Note: Benign behavioral interventions are brief in duration, harmless, painless, not physically invasive, not likely to have an adverse lasting impact on the subjects, and the investigator has no reason to think the subjects will find the interventions embarrassing or offensive. Research involving deception cannot be Exempt unless the subject authorizes the deception beforehand during the consent/permission process.

---

4. Secondary research for which consent is not required.

This category can include identifiable private information or identifiable biospecimens provided that at least one of the following criteria is met:

a. The information or biospecimens are publicly available;

b. The information is recorded by the investigator so that subjects cannot be directly or indirectly identified (i.e., the investigator's data set is anonymous), the investigator does not contact the subjects, **and** the investigator will not re-identify subjects;

c. The research is subject to HIPAA regulation and conducted under a HIPAA-covered entity; **or**

d. The research is conducted by, or on behalf of, a Federal department or agency using government-generated or government-collected information obtained for non research activities.

5. Research and demonstration projects which are conducted by or subject to the approval of Federal department or agency heads, and which are designed to study, evaluate, or otherwise examine:

a. Public benefit or service programs;

b. Procedures for obtaining benefits or services under those programs;

c. Possible changes in or alternatives to those programs or procedures; **or**

d. Possible changes in methods or levels of payment for benefits or services under those programs.

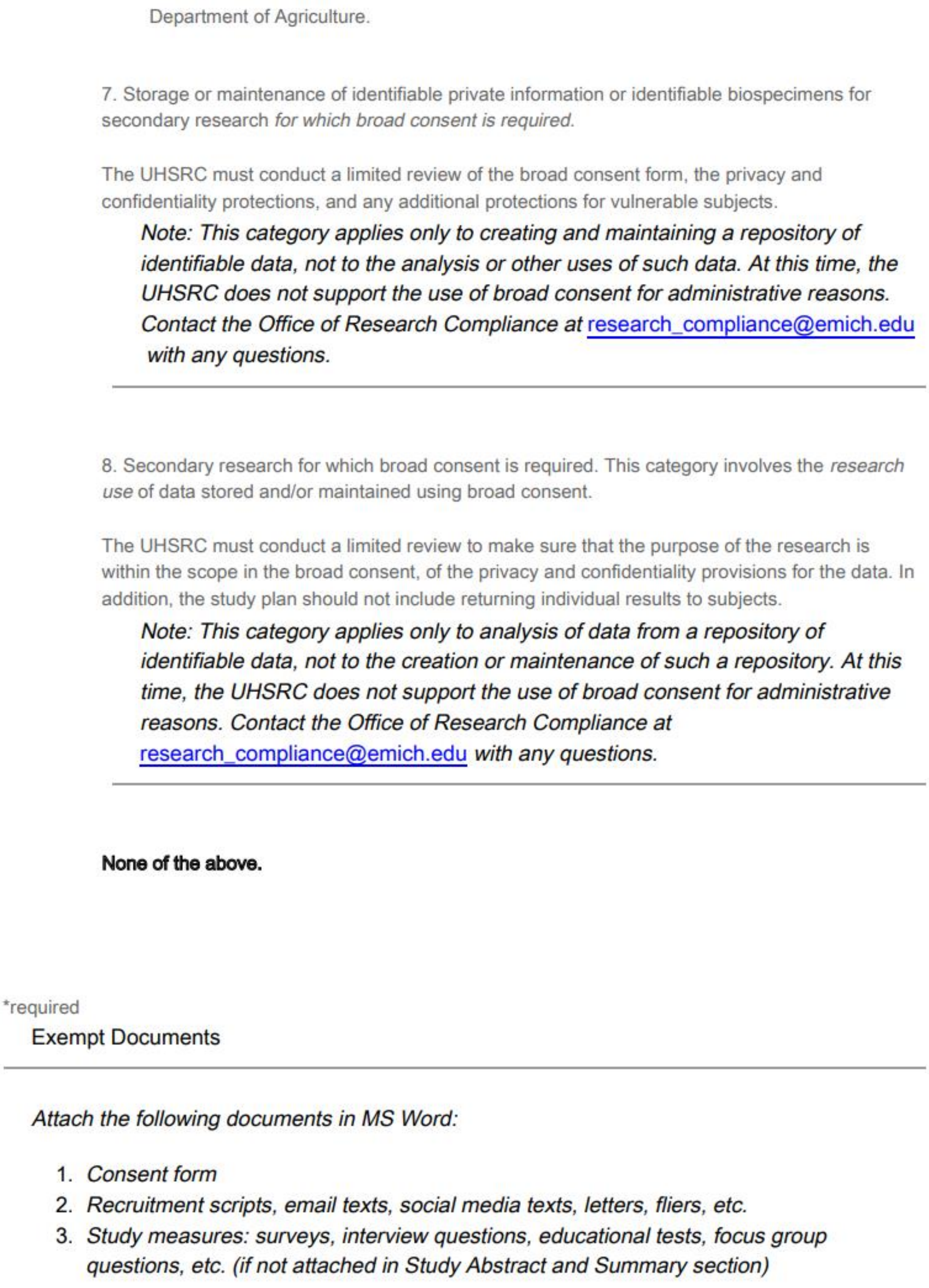
Note: All projects under this Exempt category must be published on public list maintained by the Federal department or agency before any human subject research begins.

---

6. Taste and food quality evaluation and consumer acceptance studies, if:

a. Wholesome foods without additives are consumed; **or**

b. A food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the Food and Drug Administration or approved by the Environmental Protection Agency or the Food Safety and Inspection Service of the U.S.



Department of Agriculture.

7. Storage or maintenance of identifiable private information or identifiable biospecimens for secondary research *for which broad consent is required.*

The UHSRC must conduct a limited review of the broad consent form, the privacy and confidentiality protections, and any additional protections for vulnerable subjects.

> *Note: This category applies only to creating and maintaining a repository of identifiable data, not to the analysis or other uses of such data. At this time, the UHSRC does not support the use of broad consent for administrative reasons. Contact the Office of Research Compliance at* research_compliance@emich.edu *with any questions.*

8. Secondary research for which broad consent is required. This category involves the *research use* of data stored and/or maintained using broad consent.

The UHSRC must conduct a limited review to make sure that the purpose of the research is within the scope in the broad consent, of the privacy and confidentiality provisions for the data. In addition, the study plan should not include returning individual results to subjects.

> *Note: This category applies only to analysis of data from a repository of identifiable data, not to the creation or maintenance of such a repository. At this time, the UHSRC does not support the use of broad consent for administrative reasons. Contact the Office of Research Compliance at* research_compliance@emich.edu *with any questions.*

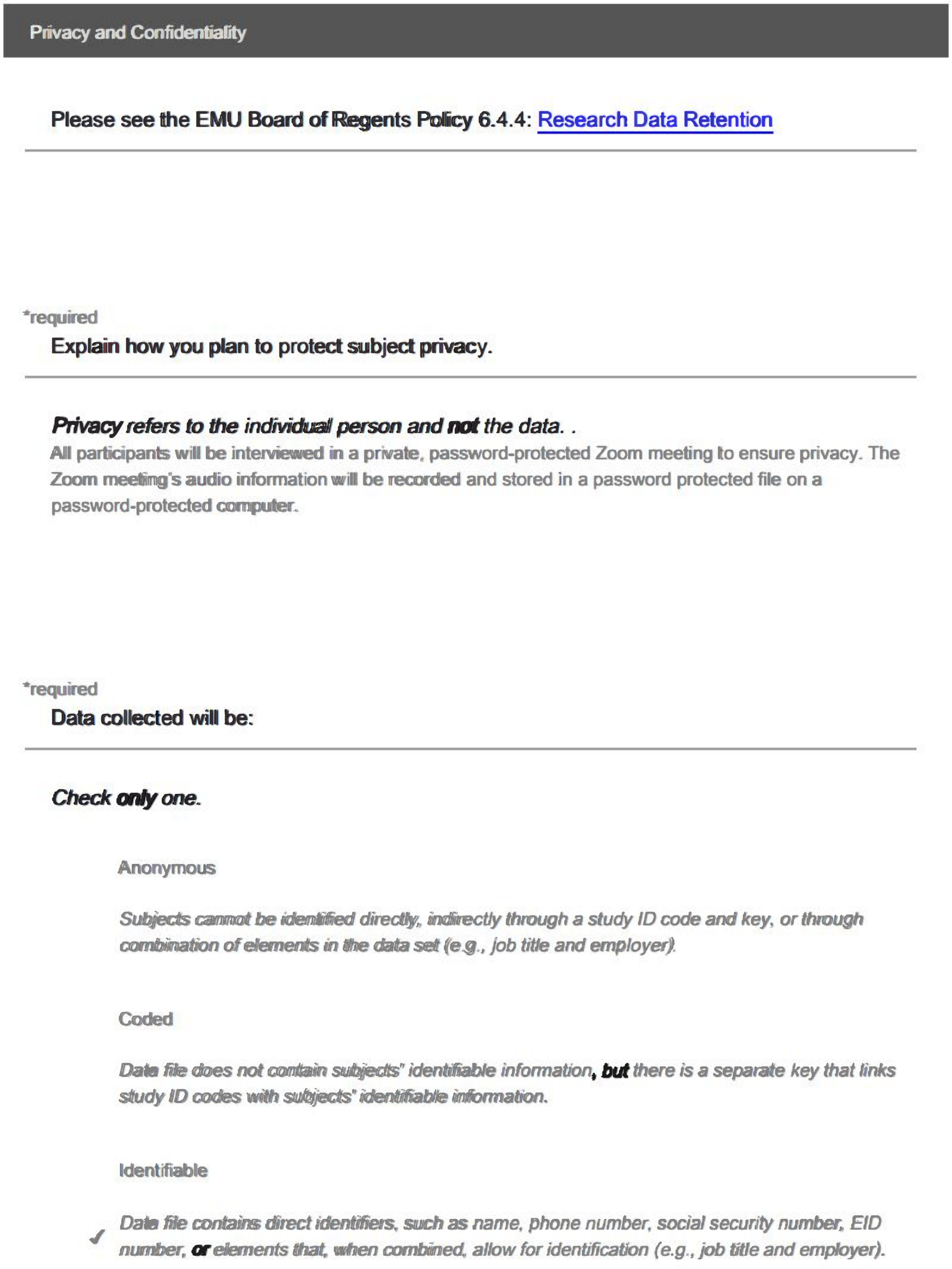
None of the above.

*required

Exempt Documents

Attach the following documents in MS Word:

1. *Consent form*
2. *Recruitment scripts, email texts, social media texts, letters, fliers, etc.*
3. *Study measures: surveys, interview questions, educational tests, focus group questions, etc. (if not attached in Study Abstract and Summary section)*



Privacy and Confidentiality

Please see the EMU Board of Regents Policy 6.4.4: Research Data Retention

*required

Explain how you plan to protect subject privacy.

***Privacy** refers to the individual person and **not** the data. .*

All participants will be interviewed in a private, password-protected Zoom meeting to ensure privacy. The Zoom meeting's audio information will be recorded and stored in a password protected file on a password-protected computer.

*required

Data collected will be:

*Check **only** one.*

Anonymous

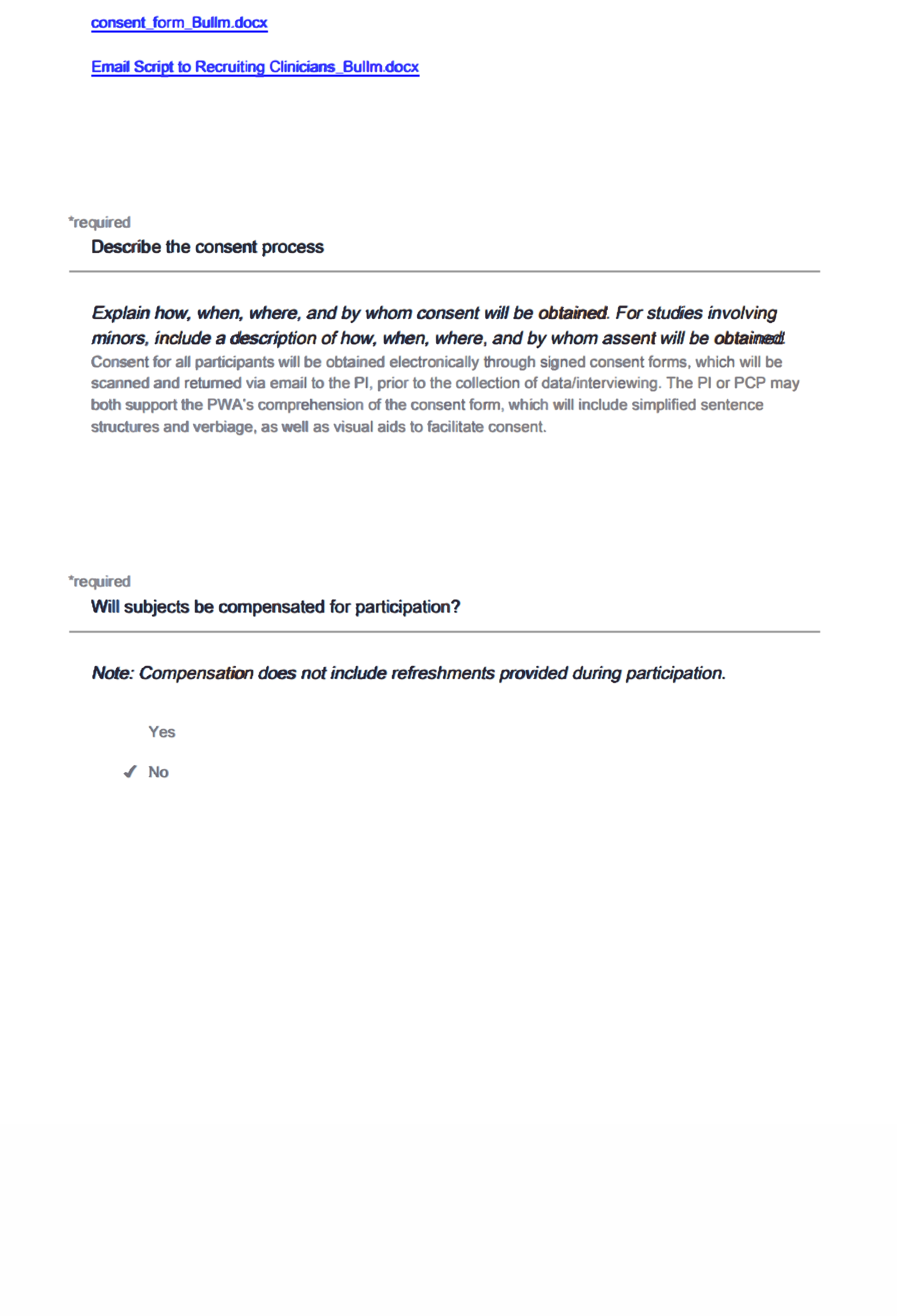
Subjects cannot be identified directly, indirectly through a study ID code and key, or through combination of elements in the data set (e.g., job title and employer).

Coded

*Data file does not contain subjects' identifiable information**, but** there is a separate key that links study ID codes with subjects' identifiable information.*

Identifiable

✓ *Data file contains direct identifiers, such as name, phone number, social security number, EID number, **or** elements that, when combined, allow for identification (e.g., job title and employer).*



consent_form_Bullm.docx

Email Script to Recruiting Clinicians_Bullm.docx

*required

Describe the consent process

Explain how, when, where, and by whom consent will be obtained. For studies involving minors, include a description of how, when, where, and by whom assent will be obtained.

Consent for all participants will be obtained electronically through signed consent forms, which will be scanned and returned via email to the PI, prior to the collection of data/interviewing. The PI or PCP may both support the PWA's comprehension of the consent form, which will include simplified sentence structures and verbiage, as well as visual aids to facilitate consent.

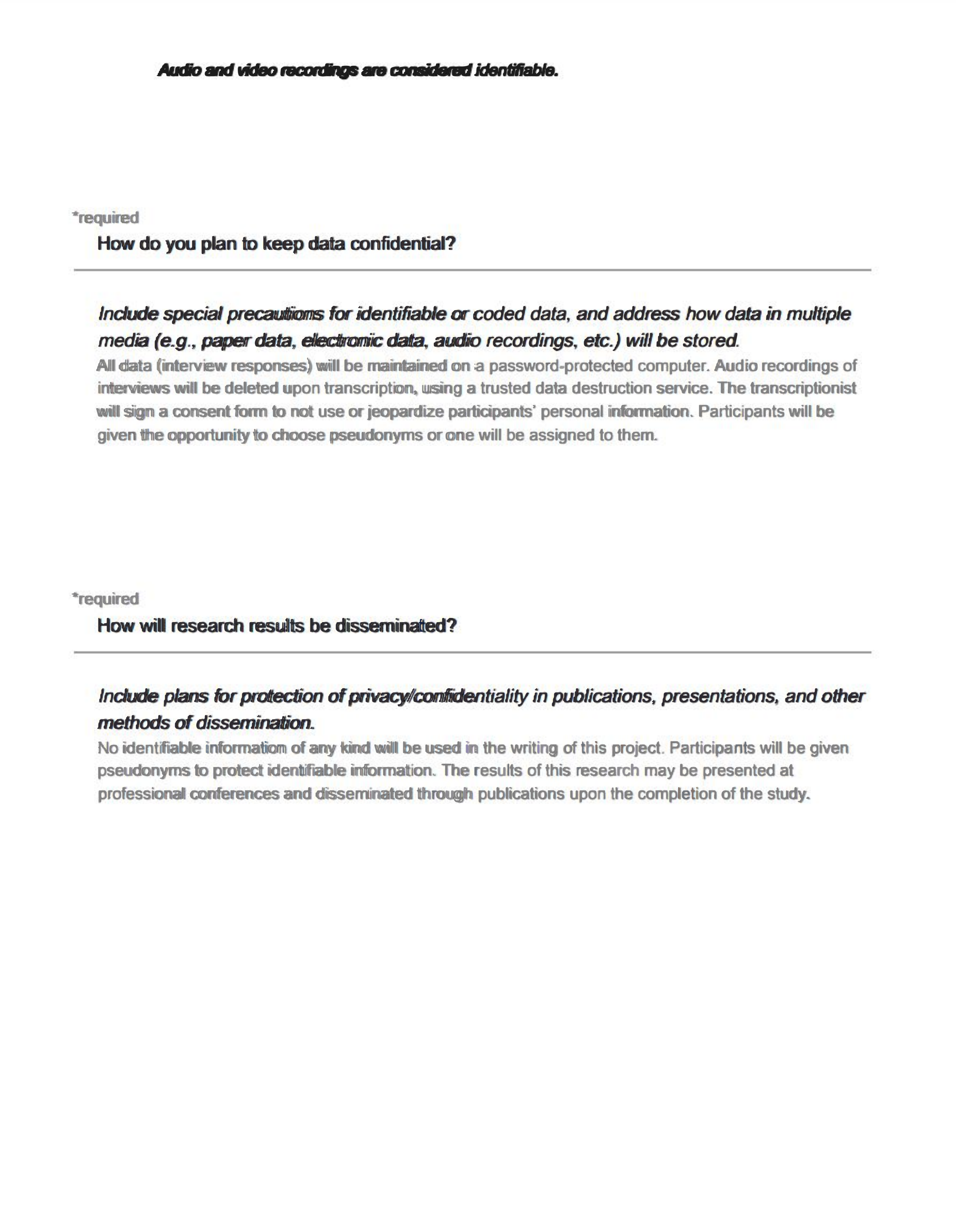
*required

Will subjects be compensated for participation?

Note: Compensation does not include refreshments provided during participation.

Yes

✓ No



Audio and video recordings are considered identifiable.

*required

How do you plan to keep data confidential?

Include special precautions for identifiable or coded data, and address how data in multiple media (e.g., paper data, electronic data, audio recordings, etc.) will be stored.

All data (interview responses) will be maintained on a password-protected computer. Audio recordings of interviews will be deleted upon transcription, using a trusted data destruction service. The transcriptionist will sign a consent form to not use or jeopardize participants' personal information. Participants will be given the opportunity to choose pseudonyms or one will be assigned to them.

*required

How will research results be disseminated?

Include plans for protection of privacy/confidentiality in publications, presentations, and other methods of dissemination.

No identifiable information of any kind will be used in the writing of this project. Participants will be given pseudonyms to protect identifiable information. The results of this research may be presented at professional conferences and disseminated through publications upon the completion of the study.

Attachments

Faculty Advisor CITI certificate

CITI certificate 2020.pdf

PI CV

Madelaine_Bull_Resume_W21.pdf

PI CITI certificate

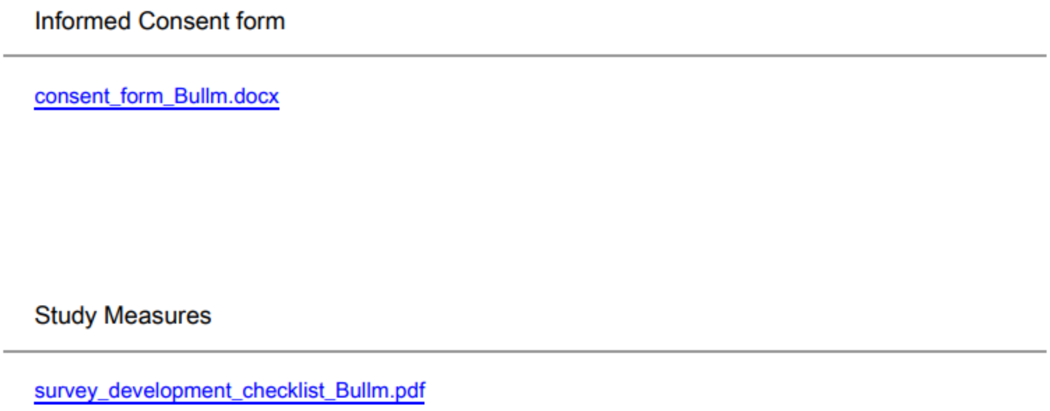
Citi_program_Certificate_Human_Subjects_Learners_Bullm.pdf

Research Staff CITI certificates

Exempt forms: consent/assent, recruitment, study questions if applicable

consent_form_Bullm.docx

Email Script to Recruiting Clinicians_Bullm.docx



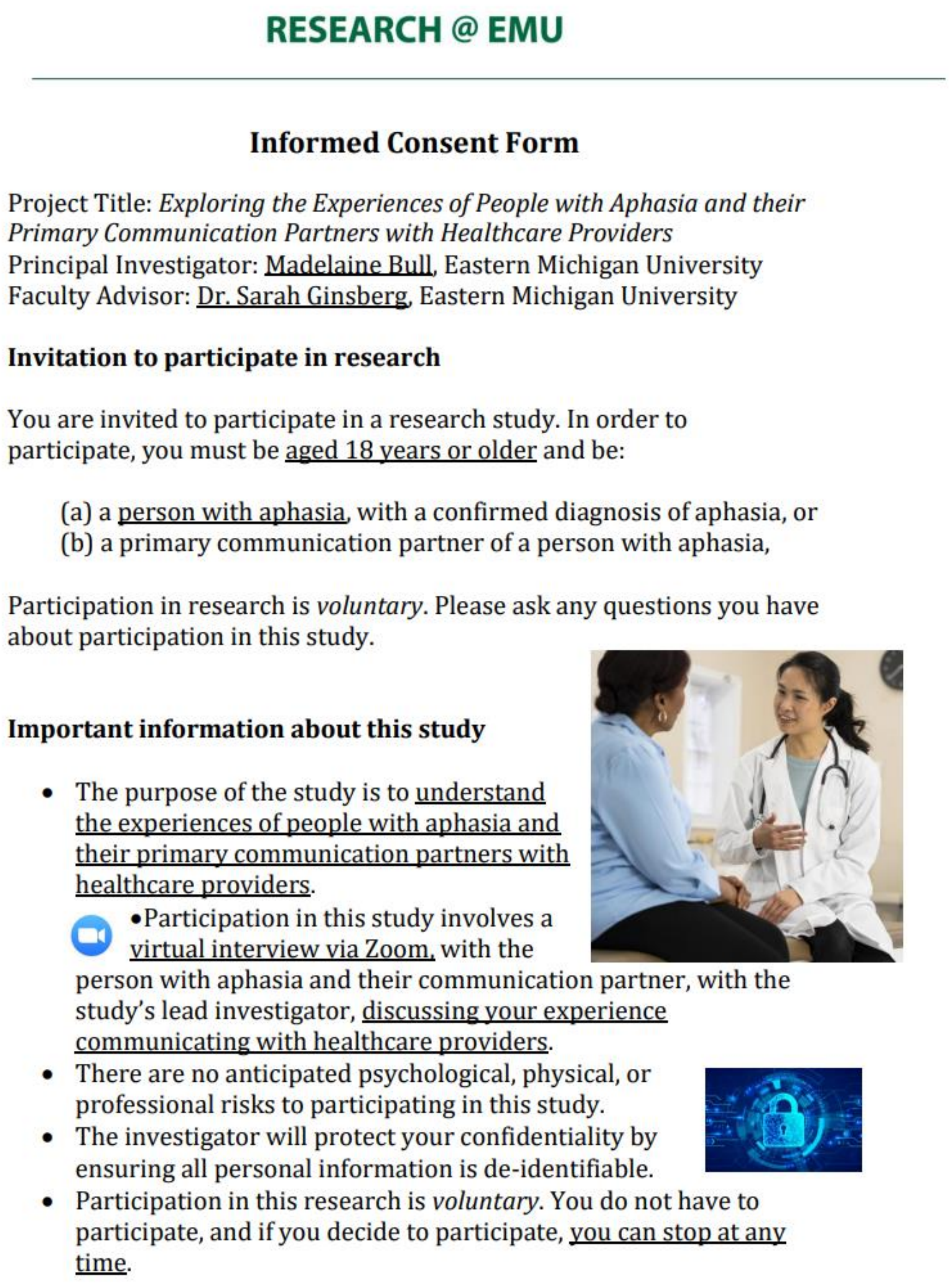
Informed Consent form

consent_form_Bullm.docx

Study Measures

survey_development_checklist_Bullm.pdf

Appendix C: Informed Consent Form



RESEARCH @ EMU

Informed Consent Form

Project Title: *Exploring the Experiences of People with Aphasia and their Primary Communication Partners with Healthcare Providers*
Principal Investigator: Madelaine Bull, Eastern Michigan University
Faculty Advisor: Dr. Sarah Ginsberg, Eastern Michigan University

Invitation to participate in research

You are invited to participate in a research study. In order to participate, you must be aged 18 years or older and be:

(a) a person with aphasia, with a confirmed diagnosis of aphasia, or
(b) a primary communication partner of a person with aphasia,

Participation in research is *voluntary*. Please ask any questions you have about participation in this study.

Important information about this study

- The purpose of the study is to understand the experiences of people with aphasia and their primary communication partners with healthcare providers.
- Participation in this study involves a virtual interview via Zoom, with the person with aphasia and their communication partner, with the study's lead investigator, discussing your experience communicating with healthcare providers.
- There are no anticipated psychological, physical, or professional risks to participating in this study.
- The investigator will protect your confidentiality by ensuring all personal information is de-identifiable.
- Participation in this research is *voluntary*. You do not have to participate, and if you decide to participate, you can stop at any time.

Are there any benefits to participating?

You will not directly benefit from participating in this research.

This study may reveal areas of communication breakdown between people with aphasia, their primary communication partners, and their healthcare providers. This may improve awareness of people with aphasia and their primary communication partners' healthcare experiences and highlight ways in which healthcare providers may improve their services to better meet the healthcare needs of people with aphasia in the future.

How will my information be kept confidential?

We plan to publish the results of this study. We will *not* publish any information that can identify you.

We will keep your information confidential by de-identifying all personal information in transcription, analysis, and paper publication. We will store your information for at least *five years* after this project ends, but we may store your information *indefinitely*.

We will make every effort to keep your information confidential, however, we cannot guarantee confidentiality. The principal investigator and the research team will have access to the information you provide for research purposes only. Other groups may have access to your research information for quality control or safety purposes. These groups include the University Human Subjects Review Committee, the Office of Research Development, the sponsor of the research, or federal and state agencies that oversee the review of research, including the Office for Human Research Protections and the Food and Drug Administration. The University Human Subjects Review Committee reviews research for the safety and protection of people who participate in research studies.

What is this study about?

The purpose of the study is to understand the experiences of people with aphasia and their primary communication partners with healthcare providers.

What will happen if I participate in this study?

Participation in this study involves:

- 1-2 virtual interview sessions via Zoom with questions regarding your experiences with healthcare providers (e.g., doctors, nurses, speech-language pathologists, etc.)
    - Interviews may last up to 90 minutes, and may occur within one sitting, or be spread out over 2 sessions.
    - We would like to audio record you for this study. If you are audio recorded, it will be possible to identify you through your voice.

What types of data will be collected?

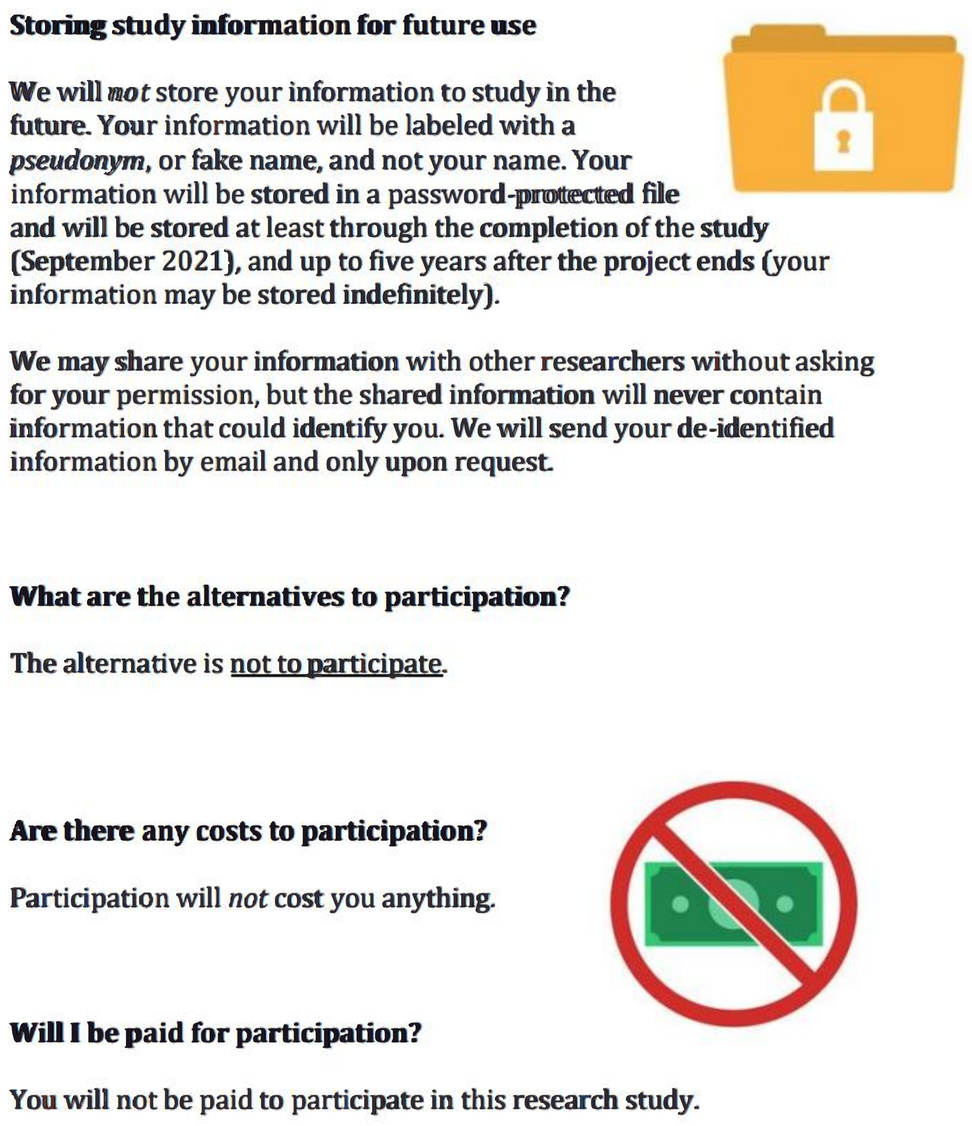
We will collect data about your *experience with healthcare providers.*

What are the expected risks for participation?

There are no expected physical or psychological risks to participation.

The primary risk of participation in this study is a potential loss of confidentiality, though all audio transcripts will contain de-identifiable personal information (or, the information will be stripped of identifiers).

Some of the interview questions are personal and may make you feel uncomfortable. You do not have to answer any questions that make you uncomfortable or that you do not want to answer. If you are upset, please inform the investigator immediately.



Storing study information for future use

We will *not* store your information to study in the future. Your information will be labeled with a *pseudonym*, or fake name, and not your name. Your information will be stored in a password-protected file and will be stored at least through the completion of the study (September 2021), and up to five years after the project ends (your information may be stored indefinitely).

We may share your information with other researchers without asking for your permission, but the shared information will never contain information that could identify you. We will send your de-identified information by email and only upon request.

What are the alternatives to participation?

The alternative is not to participate.

Are there any costs to participation?

Participation will *not* cost you anything.

Will I be paid for participation?

You will not be paid to participate in this research study.

Study contact information

If you have any questions about the research, you can contact the:

- Principal Investigator, Madelaine Bull, at mbull1@emich.edu or by phone at 519-999-3385.
- You can also contact Madelaine Bull's adviser, Dr. Sarah Ginsberg, at sginsberg@emich.edu or by phone at 734-487-2722.

For questions about your rights as a research subject, contact the Eastern Michigan University Human Subjects Review Committee at human.subjects@emich.edu or by phone at 734-487-3090.

Voluntary participation

Participation in this research study is your choice. You may refuse to participate at any time, even after signing this form, without repercussion. You may choose to leave the study at any time without repercussion. If you leave the study, the information you provided will be kept confidential. You may request, in writing, that your identifiable information be destroyed. However, we cannot destroy any information that has already been published.

Statement of Consent

I have read this form. I have had an opportunity to ask questions and am satisfied with the answers I received. I give my consent to participate in this research study.

Signatures

____

Name of Participant

___________________________________ _____________________

Signature of Participant Date

I have explained the research to the subject and answered all their questions. I will give a copy of the signed consent form to the subject.

____

Name of Person Obtaining Consent

_____________________________________ _____________________

Signature of Person Obtaining Consent Date