Barriers and mitigations for the inclusion of people with aphasia in stroke research

Resource from the Supplementary files of the article below.

Shiggins, C., Ryan, B., O'Halloran, R., Power, E., Bernhardt, J., Lindley, R.I., McGurk, G., Hankey, G., & Rose, M.L. Towards the consistent inclusion of people with aphasia in stroke research irrespective of discipline

This table outlines some of the common barriers to inclusion of people with lived experience of aphasia in research and can be used to address many communication barriers. It provides ideas of how to mitigate each identified barrier and where you can find resources to support facilitation.

Barrier	Mitigation	Resource
Policies and Procedures		
Funding / grant bodies Ethics boards Journals Policy makers / legislators	Advocate for guideline and policy changes that promote aphasia inclusive research practices	World Stroke Organization advocacy toolkit: https://www.world-stroke.org/world-stroke-day-campaign/world-stroke-campaign/advocacy-toolkit [68]
Across all stages of the research process: from design to dissemination		

Misconceptions about aphasia	Increase knowledge about aphasia, the heterogeneity of the disorder and its presentation Change, challenge and address negative attitudes towards people with aphasia [69] Acknowledge aphasia as a 'disorder of masked competence' [70] Speak with and learn from speech and language therapists Speak with and learn from people with aphasia	National Aphasia Association – aphasia definitions: https://www.aphasia.org/aphasia-definitions/ [71] TED-Ed: Aphasia: The disorder that makes you lose your words. Susan Wortman-Jutt: https://www.youtube.com/watch?v=-GsVhbmecJA [72] Speaking with and learning from people with aphasia. https://www.aphasiavic.org.au/understanding-aphasia/ [73]
The accessibility of the research process Lack of knowledge about communication accessibility	Consider the 'environmental factors' of the *International Classification of Functioning, Disability and Health* [54] Consider communication accessibility across the research process – from design to dissemination. Take deliberate steps to ensure that people with aphasia can access the research process [32] and tailor the research process, across all stages, to 'fit' a person with aphasia's needs [69] Review your research protocol and plan and identify components of the research process that may be inaccessible to people with aphasia (e.g., due to linguistical complexity, high language load or parts of the research process that rely on communication). Once these components have been identified, develop a plan and strategy to address these issues. This should be done early in the research process and be reviewed regularly. (For specific information on aphasia-friendly written information and supported communication techniques, see Supplementary file 2) Collaborate with or consult people with aphasia and speech and language therapists when designing and developing research projects and plans	International Classification of Functioning, Disability and Health (ICF) E-Learning tool: https://www.icf-elearning.com/ [74] **Definition:** Accessibility is defined as something ''that can readily be reached, entered, or used''[75]. Communication accessibility: How easily something can be 'reached entered or used' with a communication disability [44] Australian Aphasia Rehabilitation Pathway. Creating communicatively accessible environments: http://www.aphasiapathway.com.au/?name=Creating-communicatively-accessible-environments [76] SCOPE Australia. Communication Access: https://www.scopeaust.org.au/services-for-organisations/access-and-inclusion-for-businesses/communication-access/ [77]

	Talk to the people with aphasia you are recruiting to your research as participants, or who are involved in your research, to better understand their individual communication strengths and needs. Discuss with them and offer different options for making the process more accessible, so they can choose what works best for them and adaptations and accommodations can be tailored accordingly	Refer to Supplementary file 2 (below) for tips on how to make information aphasia-friendly
	Establish with people with aphasia their preferred medium for communication. For example, a person with aphasia may want all communication through email rather than phone	
	Make and implement adaptations and accommodations to the research process that address communication accessibility	
	Regularly audit the research process to ensure that communication accessibility is being achieved	
	Provide people with aphasia opportunities to feed back on their experience of the research process (in accessible ways). Ask them to highlight components of the research process that were not communicatively accessible or where they faced barriers to participation, so processes can be developed and enhanced in future studies	
	To promote good practice, report the communication supports that enabled inclusion (65)	
	Work collaboratively with and consult speech and language therapists Work collaboratively with and consult people living with aphasia	
Inaccessible written research materials, resources, and communication (e.g., emails)	Consider the accessibility of all written research materials, resources, and communication (e.g., emails)	
	Collaborate with or consult people with aphasia when designing and developing research materials and resources	
	Collaborate with or consult a speech and language therapist	
	Consult evidenced-based guidelines on making information accessible for people with aphasia	
	Provide written information in different formats and through different mediums. For example, make a video that explains the research project rather than providing information through handouts or leaflets only	

	(See Supplementary file 3 for an example)
	Use applications and technology that support communication accessibility (e.g., provide written materials electronically in PDF format, so the read
	aloud function can be used)
Spoken communication with people with aphasia	Increase supported communication skills, knowledge, and competencies
	Use supported communication techniques when communicating with people with aphasia
	Allow more time when communicating with a person with aphasia
	Work collaboratively with and consult a speech and language therapist
	Ask people with aphasia what supported communication techniques work best for them
Misconceptions about a person with aphasia's capacity to consent	Distinguish between 'those for whom competence itself is in question and those for whom competence is masked' by the person with aphasia's language difficulties' (32 p66)
Completing capacity assessments with people with aphasia and obtaining consent	Be conscious about blanket statements about any population in research, including those with aphasia. For example, do not perpetuate misconceptions about people with aphasia's incapacity to consent in literature or presentations
for research projects	
	Read consent guidelines and legislation, particularly focused on the
	inclusion of vulnerable adults in research
	When designing and developing consent procedures for a study, consider
	ethical guidance and legislation around consent in the state, territory,or
	country where the research will be conducted

	Consider how information and consent documentation is presented (see guidance on aphasia-friendly written information in the section above)
	Consider how the dialogue integral to the consent procedure is conducted and supported (see guidance on supported communication techniques above)
	Allow more time when completing a capacity assessment or obtaining consentfrom a person with aphasia
	Consider how a person will indicate their consent and will this method be accessible to stroke survivors, including those with aphasia
	Consider adopting a model of facilitated consent where a person designated by the person with aphasia also participates in the informed consent process to ask questions, but the actual consent is still provided by the person with aphasia (36)
	Consider proxy / surrogate consent, when needed, and what steps you may need to take to be able to use proxy / surrogate consent in your study. For example, is there a need for a guardianship tribunal prior to using this method
	Always obtain assent from the person with aphasia no matter how consent is obtained and consider how you will do this Work collaboratively with and consult a speech and language therapist Work collaboratively with and consult people with aphasia
Outcome measurement	Consider if people with aphasia were included in the development of an outcome measure Consider if the outcome measure has been validated with people with aphasia Consider if the formatting of the outcome measure can be adapted to make it aphasia-friendly (see guidance on aphasia-friendly written information in the section above)

	Use supported communication techniques when administering the outcome measure (see guidance on supported communication techniques in the section above)	
	Work collaboratively with and consult a speech and language therapist	
Dissemination	Report the inclusion of people with aphasia in studies in the related publications. Report the number of people with aphasia included in the study and clearly state if people with aphasia have been excluded from the study.	
	Consider how and where you plan to disseminate your research and consider adapting your research findings into an aphasia-friendly video / written summary	
	Review examples of aphasia-friendly research dissemination videos Review guidelines on how to make dissemination videos aphasia-friendly	