




Tips for Researchers Presenting to People with Lived Experience of Dementia, Stroke and Epilepsy

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Phase	Guiding Principles				
	Be accessible	Welcome feedback	Be accountable	Ask for help	Be open to sharing
Before the presentation (planning and preparing) 	<ul style="list-style-type: none"> Record meetings Pay attention to details (time of day, room layout) Plan for breaks Be flexible and reschedule if needed Tailor messages to the audience Use guidelines on font type and size, colours, amount of text. Minimize jargon, acronyms, and technical language Use colors and color contrasts that are compliant with Web Content Accessibility Guidelines (WCAG) Use large captions (e.g., subtitles) in your recorded presentations (20pt or larger) Use icons and images to generate interest Don't use flashing graphics or videos Use a slide at the start of the presentation to provide a glossary of some key terms Consider using a slide at the end of the presentation to sum up your key messages Be succinct; review your presentation for brevity and clarity Don't rely on slides for the whole presentation Consider breaking presentations down per topic 	<ul style="list-style-type: none"> Ensure people can communicate with you via email, text or chatbox Consider whether you have a specific ask for people with lived experience (e.g., are you looking for their feedback or suggestions); state this in the presentation Be clear on the purpose of the presentation for the audience (e.g., introducing a topic, providing an update, asking for feedback) 	<ul style="list-style-type: none"> Ensure people have what they need to participate (written materials or other documents at least 1 week prior) Have a support person available to direct questions about the meeting Use inclusive and respectful language; refer to language guidelines (e.g., don't talk about people who are "demented" or "epileptic", don't talk about people as "patients" outside specific care contexts, don't describe other people as "suffering" due to their condition) Use a content warning for triggering material (including topics, videos or illustrations) Be clear on your role (e.g., as a researcher) 	<ul style="list-style-type: none"> Ask for input on details (time of day, room layout, microphones, temperature) If you don't know about something, don't be afraid to ask people with lived experience Consult literature or other resources to prepare your content for an audience of people with lived experience Get feedback from others, including from those not involved in your field of research 	<ul style="list-style-type: none"> Share draft presentations, documents Welcome feedback Expect varied responses Be prepared for challenging discussions Have a plan to navigate differences in opinion if it occurs Don't underestimate people's intelligence or expertise
During the presentation (delivering) 	<ul style="list-style-type: none"> Talk face to face where possible Use good body language (e.g., eye contact) Pause/repeat if needed or if someone requests Ask if people need breaks Keep sentences short Use active, rather than passive language Speak slowly and clearly Explain technical language and concepts with an easy-to-understand example Be sure to speak to the information that is written on slides; point out if you digress (e.g., in answering a question or sharing personal story) Avoid slang and jargon Speak with the audience and not "at" them (e.g., patronizing tone) Be succinct in your delivery (i.e., be clear) Take the time to explain figures, charts, images 	<ul style="list-style-type: none"> Be clear about how feedback and discussion will take place (e.g., virtual hands up, or unmuting) Welcome interruptions Lead discussions by welcoming feedback from various perspectives and lenses Admit if something is unknown to you or to science Invite all kinds of feedback, even if you think it's unrelated to the topic Wherever possible, answer questions in a way that your entire audience will understand 	<ul style="list-style-type: none"> Acknowledge and validate different experiences and perspectives Don't underestimate the power you have speaking to people with lived experience Acknowledge power dynamics Be aware of people's pronouns, social locations, racial and ethnic identities; acknowledge that experiences and perspectives are intersectional. When faced with individual medical questions, refer back to their physician 	<ul style="list-style-type: none"> If you did not understand a comment, ask for clarification 	<ul style="list-style-type: none"> Introduce yourself as a scientist/researcher and as a person (e.g., if consider sharing your own lived experience or why you're interested in your area of research) Be yourself, connect on a personal level Be enthusiastic about your work and the involvement of people with lived experience Invite conversation at break times Tell a story or use storytelling to communicate
After the presentation (following up) 		<ul style="list-style-type: none"> Ask how you can improve your presentation Welcome critical feedback and commit to doing better next time 	<ul style="list-style-type: none"> Offer to meet one-on-one during or after meetings to debrief Commit to following up with people Reflect on the experience and how it may impact your research and/or your perspectives as a researcher 		