Supplementary Table S1

*Survey Questions*

|  |
| --- |
| **Decision to take part in research** |
| There are many reasons for people to participate in research or to decline participation in research. How important would the following reasons be ***to you*** when deciding whether or not to participate? Please rate the level of importance from 1= not important at all to me, to 7= Extremely important to me.   * The study is likely to benefit me in a way that is important to me * Although I might not benefit personally, the research is likely to benefit current or future people similar to me * I will gain more information about my condition * I will gain more information about new ways to cope with or manage my condition * Being involved in the study will give me better access to care * I am encouraged to enroll in the study by a health professional I trust (e.g., doctor or health care provider) * Participating in the research is the only way to get access to a new treatment, medication or device * Financial or other type of compensation * The research project is something I really believe in, so I want to support it. * I follow the work and involvement of the project researchers within my specific community of disability (e.g. the stroke community or the deaf community), and therefore want to support their project. * Peers with disability recommend the research project to me. * Other (please specify) |
| Have you ever declined to participate in a research study? Yes/No   1. If Yes, what were your reasons for declining to participate? (please tick all that apply)  * I would have to stop current treatment (including medication treatment) * I did not want to risk the possibility of experiencing adverse events * I did not want to risk receiving placebo treatment * I did not understand what it meant to be randomly allocated to different care/treatment in the study * I thought that the research would remind me of a traumatic event in my life and I wanted to avoid that * The time that I was required to give to the research was inconvenient for me * I believe the research venue was difficult for me to travel to and/or access. * I was not interested in the research topic * I felt uncomfortable about disclosing personal information to the researchers. * I could not afford the travel costs to participate in the research and these had not initially been offered to be covered * I had to travel to participate in the research and I was worried that weather conditions (e.g. cold/heat) would affect my health * There was no indication that the research could be undertaken in smaller manageable segments in case I needed to take a break for a while * I have difficulty with communication, and I did not know how accommodating the research would be * I have difficulty with mobility, and I did not know how accessible the site would be * I experience anxiety and I didn’t know how supportive the researchers would be of me if my anxiety was being problematic * There was something in the consent forms I did not wish to consent to * Other (please specify) |
| **Experience of Participating in Research** |
| Approximately how many research projects have you participated in? |
| Thinking about the research you took part in, or, if you have taken part in more than one project, think about the average experience of these projects. Overall, how safe have you felt when participating in research projects? Please rate your level of safety from 1=not safe at all to 7=very safe. |
| If you have participated in more than one research project, did you feel the same level of safety in all the research projects? Yes/No/not applicable |
| If you had to complete the research in an unfamiliar environment, how comfortable did you feel in the space/area/room where the research was being conducted? Please rate the level of comfort from 1= not comfortable at all, to 7=very comfortable. |
| How important is a trusting relationship with the researcher/s to you? Please rate the level of importance from 1=not important at all to me, to 7=very important to me. |
| With regard to research you have participated in in the past, how trustworthy were the researcher/s? Please rate the level of trust from 1=complete trust, to 7=not at all trustworthy. |
| How much did you feel that the researcher/s understood you and your individual needs? Please rate from 1=I felt totally misunderstood, to 7=I felt totally understood. |
| How important is it for you to feel understood by the researcher/s? Please rate from 1=not important at all, to 7=very important. |
| Reflecting back on the information that researchers gave you before you agreed (or declined) to be involved in the research:   * 1. How well do you think what you were being asked to do was explained? Please rate from 1=totally didn’t understand what was required of me, to 7=totally understood what was required of me.   2. Did you receive adequate information about the study to enable you to make an informed decision about your likely participation or not?” Yes or No   3. Throughout the study, was information provided in an accessible format for you to understand it/to meet your needs? Yes/No |
| In general, would you say your expectations of the research prior to starting was accurate of your actual experience of the research? Yes/No |
| Have you ever felt duped, tricked or misled by researchers? Yes/no/not applicable/prefer not to say |
| Have you ever felt pressured or coerced to participate in research? yes/no/not applicable/prefer not to say |
| Were you given information about what would happen with your results after the research was finished? Yes/No   1. If No, would you have liked to have been informed? Yes/No |
| Did the researcher/s share outcomes from the research with you? Yes/No   1. If Yes, was the information that you received easily to understand? Yes/No 2. If No, would you have liked that to have happened? Yes/No |
| Were you invited to ask the researcher/s questions about the findings from the research? Yes/No |
| Was the research adapted to meet any individual needs you may have had e.g. involving speech or thinking difficulties? For example, did they adapt interview or surveys for your needs? Yes/No/Unsure |
| If you were receiving a new treatment, or access to a new device, as part of the research, were you able to continue with the new treatment or access to the new device when the research was over? Yes/No.   1. If No, would you have liked to continue with the new treatment or have access when the research was over? Yes/No |
| Has having access/not having access to the treatment or device made a difference to you? Yes/No |
| **Same Research on More Than One Occasion** |
| With regard to the study that you were involved in, was data collected about you on more than one occasion (e.g. a month or year between data collection)? Yes/No   1. If Yes, did you have an opportunity to ask questions about the research every time you were involved? Yes/No 2. If No, would you have liked to have had that opportunity? Yes/No 3. Did researchers check with you that you were still consenting to being involved in each of the ongoing research phases? Yes/No |