1. **What is the research study about?**

You are invited to take part in this research study. The research study is an important mixed-methods research study focused on understanding the perspectives of stroke survivors like yourself, regarding the adoption and application of low-cost motion capture technology in the assessment of upper limb function following a stroke.

The purpose of this research is to explore, from both clinician and patient perspectives, the perceived benefits, barriers, and facilitators to the adoption of motion capture technology in post-stroke upper limb rehabilitation. By participating, you will provide invaluable insights into how this technology can be effectively integrated into clinical practice, helping to shape the future of rehabilitation services.

This Participant Information Sheet tells you about the research. It explains what you will do if you are a part of the study, so that you can decide if you want to join. Please read this carefully. Ask questions to the study Researcher (contact details at the end of this information sheet) about anything that you don’t understand or want to know more about.

If you decide you want to take part in the study, you will be asked to sign a consent form. By signing this form, you are telling us that you:

* understand what you have read
* consent to take part in the study
* consent to complete the interview that is described in this information sheet
* consent for the use of your personal and health information as described in the information sheet

You will be given a copy of this Information Sheet to keep.

1. **Who is conducting this research?**

The study is being carried out by the following researchers: Dr Xiaoying Chen and Mr Jarrad Fisher

**Research Funder:** This research is being supported by in-kind resources provided by UNSW Sydney and The George Institute for Global Health.

1. **Inclusion/Exclusion Criteria**

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who meet the following criteria:

* Inclusion Criteria: Individuals aged 18 and above who have experienced a stroke and undergone upper limb rehabilitation. Participants must be at least 3 months post-stroke to ensure they have had some experience with rehabilitation processes.

Participants who meet the following criteria will be excluded from the study:

* Exclusion Criteria: Patients with severe cognitive impairments or communication barriers that would preclude meaningful participation in interviews or focus groups.
1. **Do I have to take part in this research study?**

Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

If you decide you want to take part in the research study, you will be asked to:

* Read the information carefully (ask questions if necessary);
* Sign and return the consent form if you decide to participate in the study;
* Take a copy of this form with you to keep.

1. **What does participation in this research require, and are there any risks involved?**

If you agree to participate you will be asked to complete the following research procedures.

**Screening:** A screening questionnaire asking about your background and experience in post-stroke rehabilitation will determine if you are eligible to take part. Completing the screening measures will take approximately 10 minutes. The screening questionnaire will be administered to you via a telephone interview. If the screening questionnaire shows that you meet the criteria for inclusion, then you will be able to start the research project. If the screening questionnaire shows that you cannot be in the research project, you will be notified by email, which will include a thank you note for your interest and time, along with a brief explanation of why you do not meet the criteria. Screening will only occur once consent to participate has been obtained.

**Questionnaire/Survey:** An online questionnaire/survey will be conducted via the Redcap Survey Platform asking you to answer questions about your views on the technology's usability, benefits, and integration into your rehabilitation practice.. You will be asked to complete this survey on one occasion. The survey should take approx. 15 minutes to complete.

**Interview:** An online video interview will be completed, and you will be asked questions to delve deeper into your experiences with and perspectives on motion capture technology in rehabilitation.]. The interview will take place online using Zoom or MS Teams and will take approximately 60 minutes. With your permission the research team would like to audio and video record the interview. If you do not wish to be recorded but you would like to participate you advise the research team and written notes will be taken. You may experience some discomfort due to the duration of these sessions. You are encouraged to take breaks as needed, and the sessions will be conducted in a comfortable setting to minimize any discomfort.

**Focus Group:** All focus group sessions will take place online using Zoom or MS Teams and will take approximately 60 minutes. During the focus group you will be with other fellow patients and asked to discuss experiences, perceptions, and suggestions regarding motion capture technology in rehabilitation settings. With your permission the research team would like to audio and video record the interview. If you decide to participate in the focus group, your comments along with other participants will be recorded during the group discussions. Because of the way in which the focus group discussions are recorded, the research team will not be able to withdraw or destroy individual participant responses. You may experience some discomfort due to the duration of these sessions. You are encouraged to take breaks as needed, and the sessions will be conducted in a comfortable setting to minimize any discomfort.

**Additional Costs and Reimbursement:** There are no costs associated with participating in this research project, nor will you be paid. Participants will not be compensated financially; however, your valuable contribution to the field of stroke rehabilitation and technology integration will be highly acknowledged.

1. **What will happen to information about me?**

By signing the consent form, you consent to the research team collecting and using information about you for the research study.

The research team will store the data collected from you for this research project for:

* A minimum of 5 years after the publication of the research results;

The information about you will be stored in an/a: All data collected will be securely stored and only accessible to the research team. Personal information will be de-identified, and findings will be presented in a manner that ensures participant confidentiality is maintained.

The data will be analysed by the researchers at the George Institute. All audio files will be retained for a minimum of 5 years from the day the study is completed. This retention period is in line with the UNSW guidelines for non-clinical research. This duration ensures that the data is available for any necessary follow-up, validation, or audits, and allows sufficient time for the dissemination of research findings and potential further analysis while maintaining compliance with institutional policies.

The handling of data will differ based on the type of data collection method used:

**Survey Data:**

* **Anonymity:** The data obtained from the survey will be anonymous, meaning no personal identifiers will be collected or linked to the responses.
* **Storage:** Survey data will be stored electronically on a secure, password-protected server. Since the data is anonymous, there will be no need for de-identification.

**Interview and Focus Group Data:**

* **Identifiable Information:** Audio and video recordings from interviews and focus groups will contain identifiable information.
* **Transcription and De-identification:** Identifiable information in the recordings will be transcribed and then de-identified. This involves removing or coding any personal identifiers, ensuring participants cannot be readily identified from the dataset.
* **Use of De-identified Data:** Only the de-identified transcripts will be used for analysis and reporting purposes. Identifiable information will not be included in any reports or publications.
* **Secure Storage:** The original audio and video recordings will be securely stored on a password-protected server and will only be accessible to the research team for transcription and verification. These recordings will be retained for a minimum of 5 years in accordance with UNSW guidelines for non-clinical research.

You will be asked to provide your consent for the research team the share or use the information collected from you in future research that:

* Will be an extension of, or closely related to, the original project; or is in the same general area of research;

Your information will only be shared in a format that will not identify you. You can indicate your agreement to this on the Consent Form. Additionally, if you would like to withdraw consent for your data to be shared for use in future research, you can do so by completing the ‘Form for Withdrawal of Participation’ at the bottom of this document.

* Information collected from you in an electronic format stored on a UNSW password protected OneDrive only accessible to the approved research investigators.
* Audio or video recordings will be stored for a duration of 5 years after publication, on a UNSW password protected OneDrive only accessible to the approved research investigators. Data collected in this research be stored in an non-identifiable format. Access to the audio/video recordings in this research will be restricted to the investigators listed on this form.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [**UNSW Privacy Management Plan**](https://www.legal.unsw.edu.au/compliance/privacyhome.html).

1. **How and when will I find out what the results of the research study are?**

The research team intend to publish and/ report the results of the research. All Information will be published in a way that will not identify you.

If you would like to receive a copy of the results you can let the research team know by inserting your email or mailing address in the consent form. We will only use these details to send you the results of the research.

1. **What if I want to withdraw from the research study?**

If you do consent to participate, you may withdraw at any time. You can do so by completing the ‘Withdrawal of Consent Form’ which is provided at the end of this document or you can ring the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney, The George Institute for Global Health or any of the investigators.. If you decide to leave the research study, the researchers will not collect additional information from you. You can request that any identifiable information about you be withdrawn from the research project.

1. **What if I have a complaint or any concerns about the research study?**

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

**Complaints Contact**

|  |  |
| --- | --- |
| **Position** | UNSW Human Research Ethics Coordinator |
| **Telephone** | + 61 2 9385 6222 |
| **Email** | humanethics@unsw.edu.au  |
| **HC Reference Number** | Project ID: iRECS6524 |

1. **What should I do if I have further questions about my involvement in the research study?**

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

**Research Team Contact Details**

|  |  |
| --- | --- |
| **Name** | Jarrad Fisher |
| **Position** |  PhD Candidate, University of New South Wales and The George Institute for Global Health. |
| **Telephone** |  +61 2 8052 4549 |
| **Email** | jarrad.h.fisher@unsw.edu.au  |

**Chief Investigator**

|  |  |
| --- | --- |
| **Name** | Dr Xiayoing Chen |
| **Position** | Senior Research Fellow, Brain Health Program |
| **Telephone** | +61 2 8052 4549 |
| **Email** | xiaoying.chen@unsw.edu.au  |

**Consent Form – Participant providing own consent**

**Declaration by the participant**

* I understand I am being asked to provide consent to participate in this research study;
* I have read the Participant Information Sheet, or someone has read it to me in a language that I understand;
* I understand the purposes, study tasks and risks of the research described in the study;
* Recordings: I understand that the research team will audio/video record the semi-structured interviews and focus groups; I agree to be recorded for this purpose.
* I provide my consent for the information collected about me to be used for the purpose of this research study only.
* I provide my consent for the information collected about me to made available to other researchers as described at section 6 of this document.
* I have had an opportunity to ask questions and I am satisfied with the answers I have received;
* I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
* I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only;
* I understand that I will be given a signed copy of this document to keep.
* I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only.

**Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Address: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Email Address: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Optional Consent for reuse of data and future research:**

* I provide my consent for my name and contact details to be retained in a register so I can be contacted about other research projects in the future.

**Participant Signature**

|  |  |
| --- | --- |
| Name of Participant (please print) |  |
| Signature of Research Participant  |  |
| Date |  |

**Declaration by Researcher\***

* I have given a verbal explanation of the research study; its study activities and risks and I believe that the participant has understood that explanation.

**Researcher Signature\***

|  |  |
| --- | --- |
| Name of Researcher (please print) |  |
| Signature of Researcher  |  |
| Date |  |

**+An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.**

**Note: All parties signing the consent section must date their own signature.**

**Form for Withdrawal of Participation**

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales,The George Institute for Global Health or other professional(s)..

* I am withdrawing my consent and I would like any identifiable information collected about me which I have provided for the purpose of this research study withdrawn.
* I am withdrawing my consent to participate in further components of this research and provide my permission for the research team to retain and/or use information collected about me which I have provided for the purpose of this research.
* I am withdrawing my consent and I understand that any information already published and/or not linked to my identity cannot be withdrawn from the research.

**Participant Name**

|  |  |
| --- | --- |
| Name of Participant (please type) |  |
| Date |  |

**The section for Withdrawal of Participation should be forwarded to:**

|  |  |
| --- | --- |
| CI Name: | Dr. Xiaoying Chen |
| Email: |  xiaoying.chen@unsw.edu.au |
| Phone: | +61 2 8052 4549 |
| Postal Address: |  Level 18, International Towers 3, 300 Barangaroo Ave, Sydney NSW 2000 AustraliaPO Box M201, Missenden Rd, NSW 2050 Australia |