

**PARTICIPANT INFORMATION SHEET FOR ADULTS**  
UCL Research Ethics Committee Approval ID Number: 6860/013

**YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET**

**Title of Study:**

An investigation of smartphone accessibility for people with Spinal Cord Injuries

**Department:** Division of Surgery and Interventional Science, Faculty of Medical Science

**Name and Contact Details of the Researcher(s):**

Stephanie Panousis, stephanie.panousis.20@ucl.ac.uk

Richard Armstrong-Wood, Richard.armstrong-wood.17@ucl.ac.uk

**Name and Contact Details of the Principal Researcher:**

Dr Tom Carlson, t.carlson@ucl.ac.uk

You are being invited to take part in an MSc group research project with University College London's Division of Surgery. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. One of our team members will go through the participation information sheet with you. Ask us if there is anything that is not clear or if you would like more information. Please take your time to decide whether you wish to take part.

*This is a UCL master's project which has been reviewed and approved by UCL Research Ethics Committee (REC).*

**What is the project's purpose?**

Each year, between 250 000 and 500 000 people globally suffer a spinal cord injury (SCI)<sup>1</sup>, which can limit their upper limb mobility. Tablets and smartphones are generally devices designed to be operated by touch and as such are inaccessible to people who have no or restricted movement in their hands or arms. With a range of smartphones, each produced by different manufacturers, this project aims to better understand the user experience when it comes to accessing a smartphone through assistive technology.

The objectives of this study are to understand how people might use their functional abilities, such as hand or arm movement, or voice, in combination with assistive technology to interact with their smartphones. We would like to know if these methods meet their day to day activities, focusing on making and receiving phone calls and texts, and using social media. Through this, we hope to identify potential gaps in user requirements and existing assistive technology capabilities.

**Why have I been chosen? Inclusion and Exclusion Criteria.**

You have been invited to take part in this study because you responded to either an email or a social media advertisement and:

1. Are over the age of 18.
2. Are able to independently consent to take part in this study.
3. Have no known cognitive impairments
4. Are able to speak and understand English proficiently.
5. Have identified yourself as a person with a Spinal Cord Injury (SCI) at a spinal location of C8 or above.

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<sup>1</sup> <https://www.who.int/news-room/fact-sheets/detail/spinal-cord-injury>

6. Have indicated that you have used a smartphone within the last 6 months.

We expect there to be around 100 participants for the online questionnaire and approximately 20 participants for the “virtual” interview, which will be conducted online using video-conferencing software (Microsoft Teams).

### **Do I have to take part?**

It is up to you to decide if you wish to take part in this study. If you do decide to participate, you will be given this information sheet to keep and be asked to complete an informed consent form. You can withdraw from the interview at any time without giving a reason and without it affecting any benefits that you are entitled to. If you decide to withdraw, you will be asked what you wish to happen to the data you have provided up to that point. However, please note that approximately one week after completing the virtual interview, we will create a fully anonymised transcript and delete the original video footage. As the transcript is anonymous, it will no longer be possible to withdraw your data from this point onward. Once you have participated in the survey questionnaire, data cannot be withdrawn as submission is anonymous.

### **What will happen to me if I take part?**

The study involves two sections, and you can consent to either or both of them: a short questionnaire and a semi-structured interview.

The **questionnaire** is hosted securely on Microsoft Forms. These will range from asking about your typical daily activities on your smartphone to the specific technology you use to access it. It will also ask for some personal information, such as high-level questions about your injury, as well as gender and age. No identifying data will be recorded, and all answers will remain confidential and anonymous. The questionnaire should take no more than 15 minutes. By submitting the questionnaire, you consent to us using the data you have provided. You will also be given the option to be entered into a prize draw to win a £50 Amazon voucher. To take part in the prize draw, you will need to provide an email address, which: will be stored separately from your questionnaire data; will only be used for the purpose of contacting you about the prize draw; and will be deleted after the draw has taken place and the winner has been informed.

The **semi-structured interview** will be conducted remotely via a UCL approved Microsoft Teams channel, this interview should last no longer than an hour. During the interview we aim to gain a better understanding of how you use your smartphone: which apps, how you interact with it, and how your spinal cord injury affects this. The interview will be semi-structured with open-ended questions. If you take part in the interview, you will be compensated for your time with a £15 Amazon voucher. Due to COVID-19, all participation in this study will be done online and as such there are no associated travel costs.

### **Will I be recorded and how will the recorded media be used?**

We will record the audio and video from your interview. These recordings will be transcribed and only used for analysis. This transcript will be used during data analysis to identify themes across the study and will be completely anonymised. All recordings and transcripts will be saved in an encrypted, password-protected storage in compliance with the General Data Protection Regulation (GDPR). No one outside the study will have access to the data collected. No other use of the recorded material will be permitted unless the permission of the participant is given.

### **What are the possible disadvantages and risks of taking part?**

Within the questionnaire and interview, some questions will address your spinal cord injury in broad terms. This may cause emotional discomfort if the topic is distressing to you. It is important to remember that you can stop at any point in the questionnaire or interview, without giving any reason. You are under

no obligation to continue. Within the interview, our researchers will not push any topics that make you uncomfortable and will regularly check with you to ensure you are comfortable answering.

The questionnaire requires some short-written answers. This could be difficult and frustrating to complete if your access to a smart device or computer is limited. You may skip any questions that cause you frustration or discomfort, and this will not affect your ability to participate in the rest of the questionnaire or interview.

### **What are the possible benefits of taking part?**

Whilst there are no immediate benefits for participating in the project, it is hoped that this work will contribute to the development of more efficient assistive technology for accessing smart devices with decreased upper limb mobility. As previously discussed, there will be a prize draw of one £50 Amazon voucher for participation in the questionnaire, while all participants who complete an interview will be given a £15 Amazon voucher.

### **What if something goes wrong?**

If you wish to make a complaint regarding the way you were approached or treated during this research, please contact Dr Tom Carlson, Principle Investigator on

Telephone: 020 208 016 8575 or Email: [t.carlson@ucl.ac.uk](mailto:t.carlson@ucl.ac.uk).

If you feel your complaint is not adequately addressed, then you may escalate it to the Chair of the UCL Research Ethics Committee – [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)

### **Will my taking part in this project be kept confidential?**

All data received from the questionnaire will be anonymised at the point of collection, and as such, you will not be able to be identified. To enter into the prize draw for the £50 Amazon voucher, we will collect your email on a separate Microsoft Form that is not linked to any other data you provide for the study. For the interview, we will aim to perform transcription (thus anonymising your data) as soon as possible and we aim to do this within a week. The transcripts will be fully anonymous, and once they are created, we will delete any audio and/or video recordings from your interview.

We may share the data we collect with researchers at other institutions, including Universities and commercial research organisations, in the UK and abroad. However, any information that leaves the Centre will be anonymised. You will not be able to be recognised from it. In any sort of report, we might publish, we will not include information that will make it possible for other people to identify you in any way. If you join the study, some parts of your records and the data collected for the study may be looked at by authorised persons from the university, for the purposes of monitoring and auditing. We may share information with external collaborators, but all this information will contain no identifiable information about you.

### **Limits to confidentiality**

1. Confidentiality will be respected unless there are compelling and legitimate reasons for this to be breached. If this was the case, we would inform you of any decisions that might limit your confidentiality.

Confidentiality may be limited and conditional, and the researcher has a duty of care to report to the relevant authorities possible harm/danger to the participant or others. Additionally, confidentiality may not be guaranteed due to the limited size of the participant sample.

### **What will happen to the results of the research project?**

This study makes up part of a Postgraduate research project. The results will be presented in a report to the project supervisors and may be passed on to external organisations. We may also present the results at seminars or conferences or publish the results online. We would be happy to discuss the

results of the study with you and send you a copy of the report. It will not be possible to identify you in any report or publication.

## Local Data Protection Privacy Notice

### Notice:

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, click [here](#)  
For participants in research studies, click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of special category personal data used will be as follows:

1. Gender
2. Age
3. Nationality
4. Living situation
5. Information relating to your spinal cord injury

The lawful basis used to process *special category personal data* will be for scientific and historical research or statistical purposes.

*Your personal data will be processed so long as it is required for the research project.*  
We will anonymise your personal data as quickly as possible and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

## Who is organising and funding the research?

This study is funded and organised by UCL.

## Contact for further information

For further information, you may contact the project supervisor, Dr Tom Carlson.  
Telephone: 020 208 016 8575  
Email: [t.carlson@ucl.ac.uk](mailto:t.carlson@ucl.ac.uk).

**Thank you for reading this information sheet and for considering to take part in this research study.**