Participant Information Sheet for Participants
UCL Research Ethics Committee Approval ID Number: 14277/001

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study: Development of an application to log triggers of spasticity
Department: Aspire Centre for Rehabilitation Engineering and Assistive Technology

Name and Contact Details of the Researcher(s):
Sarah Massey (sarah.massey.13@ucl.ac.uk)
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Name and Contact Details of the Principal Researcher:
Anne Vanhoestenberghe (a.vanhoest@ucl.ac.uk)

Invitation Paragraph
You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the project’s purpose?
Spasticity is a neurological disorder which causes increased tone and involuntary muscle contractions. It is present in populations with spinal cord injury, and those who have suffered a stroke. Symptoms of spasticity can be triggered by: temperature; pressure on the skin; a full bladder and stress. Although there are interventions which ease the symptoms, it is unclear how they affect the triggers, if at all.

We would therefore like to create an accessible smartphone application (app) for people with spasticity to be able to easily input the triggers for their spasticity as and when they experience it in their everyday life. The app will process this information into easy-to-read statistics, which we hope will support patient education and self-management, as well as increase our understanding. It is important that this app has a simple user interface to encourage user acceptance.

To meet this goal, we would like to send you information about the current design of the app and an anonymous online questionnaire to people with spasticity and clinicians who work with them. In this questionnaire, we will ask you to identify triggers of spasticity, how you would use the app and whether you think the app would be useful for the self-management of spasticity. The answers to this questionnaire will be used to develop the app and its interface.

Why have I been chosen?
You have been chosen to participate in this study because you have been identified as a person with spasticity or a clinician who works with people with spasticity. We feel that your input is precious to the development of this app.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep. You can withdraw 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. The questionnaire you fill in will not ask
for any information that will make you identifiable. You do not have to complete all questions if you do not wish to do so.

**What will happen to me if I take part?**
If you choose to take part, you will be asked to watch a short video explaining what the app does and how it would work. After this, you will be asked to fill in a short, anonymous online questionnaire.

**What are the possible disadvantages and risks of taking part?**
There are no disadvantages or risks of taking part.

**What are the possible benefits of taking part?**
Whilst there are no immediate benefits to participating in this project, it is hoped that this work will help to develop an effective app which will help people to manage their own spasticity at home.

**What if something goes wrong?**
Please inform the investigator if you have any concerns about your participation in this research. If you wish to raise a complaint this study, please contact the principal researcher (Dr Anne Vanhoestenberghe). If you feel your complaint has not been handled to your satisfaction, you may contact the Chair of the UCL Research Ethics Committee (ethics@ucl.ac.uk).

**Will my taking part in this project be kept confidential?**
All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications.

**Limits to confidentiality**
Confidentiality will be respected subject to legal constraints and professional guidelines.

**What will happen to the results of the research project?**
The results will be disseminated through seminars, conference presentations and publications. You will not be identified in any report or publication. The data collected may also be used for additional or subsequent research.

**Data Protection Privacy Notice**
The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data and can be contacted (data-protection@ucl.ac.uk). UCL’s Data Protection Officer can also be contacted (data-protection@ucl.ac.uk). Further information on how UCL uses participant information can be found here: www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice

Your personal data will not be used for this research study. We will contact you via email or in person and your questionnaire will be completed anonymously online. Your results will not be connected to your email in any way and so you will not be identifiable from your data.

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. If you remain unsatisfied, you may wish to contact the ICO. Contact details, and further details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

**Who is organising and funding the research?**
This research is being organised and sponsored by UCL. The research is funded by the Leslie Trust.
Contact for further information
If you would like further information on the study, please contact Sarah Massey (sarah.massey.13@ucl.ac.uk). You will be given a copy of this information sheet.

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