Participant Information Sheet

Title of project: ASAP: Assessment of Sensation in the Adult Population

Principal investigator
A/Prof Cathy Stinear, Department of Medicine, Principal Investigator

Co-investigator
A/Prof Hannah Block, Indiana University Bloomington

Student researchers
Benjamin Chong, University of Auckland PhD Candidate
Harry Jordan, University of Auckland PhD Candidate
Benjamin Scrivener, Physiotherapist

The above named researchers would like to invite you to take part in the above study. Please take your time to read and think about the information below. Feel free to discuss it with your whanau, family or other support people. Taking part is completely voluntary and you may withdraw at any time without giving a reason. This study is part of PhDs by Benjamin Chong and Harry Jordan, and includes an assessment developed by researchers at Indiana University.

What is the study about?
- The ASAP study will include up to 150 participants, consisting of 50 healthy young adults, 50 healthy older adults, and 50 adults who have experienced a stroke 6 or more months ago.
- We will measure people’s sensation of touch, movement, and position in both hands.
- We will also measure people’s hand dexterity and coordination between their two hands.
- The results of this study will show the reliability of these tests and provide important reference data for comparison with people recovering from stroke.

Can I take part?
You may be eligible to participate if you
- Are between 18 and 38, or 50 and 90 years old
- Have not had a stroke, or other condition which affects the sensation of your hands or arms
What does the study involve?

The study involves two 2 hour visits about 1 week apart. The visits may take place at Auckland City Hospital. Each visit will involve completing the following assessments twice on each side, performed by different researchers.

- Light touch sensation, using thin filaments of plastic, while you are blindfolded
- Two-point sensation, using two points of plastic, while you are blindfolded
- Dynamic position sense, using a protractor and dial to guess the position of your wrist
- Static position sense, using a tablet application to guess the position of your index finger
- Two-hand coordination, by completing a set of 9 everyday tasks
- Hand dexterity, by transporting wooden blocks from one box to another
What are the risks and benefits?

- There are no specific risks associated with the tests and equipment used in this study.
- As a koha for your participation, you will be offered a $20 grocery voucher on completion of your participation.
- You will be offered a written summary of your personal results, and a written summary of the overall results.
- If you are a student at the University of Auckland, participation, non-participation, or withdrawal from this study will not affect your grades.

Data storage/retention/destruction/future use

Data will be stored for 6 years in secure filing cabinets and on password protected PCs on secure University of Auckland servers. Only the investigators will have access to this information, and your data will be de-identified by giving it a unique code. After 6 years, paper data will be destroyed with confidential document destruction, and electronic data will be permanently deleted.

Participation

Your participation is entirely voluntary (your choice). You are encouraged to take your time to discuss your participation in this study with your friends, family or whanau. Your agreement to participate in this project will be obtained in writing on a Consent Form. If you do agree to take part, you may withdraw from the study at any time without giving a reason. You may also withdraw your data from the study within three months of your participation.

In total, taking part involves 200 minutes of your time over 2 sessions at either Auckland City Hospital, or your home. To the best of our ability, assessments will be scheduled at a time that suits you, and we will contact you before each one to confirm.

Confidentiality

As participants’ identity will be known to the researcher, we cannot preserve anonymity. Instead, your identity will be kept confidentially and only be able to be accessed by the researchers. The data will be used as aggregate statistics and possibly as de-identified individual data for publication and a PhD thesis. No information that could personally identify you will be used in any reports on this study.

Compensation

If you were injured in this study, which is unlikely, you would be eligible to apply for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in
your recovery. If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won’t affect your cover.

Summary of Your Rights

- Your participation is entirely voluntary.
- You may withdraw from the project at any time without providing a reason.
- You may have members of your whanau, family, or other support people, with you during the assessments.
- You may have your data withdrawn from the study within three months of your participation.
- You may obtain results regarding the outcome of the project from the researchers upon completion of the study.
- Your identity will be kept strictly confidential. During the study, your data will be de-identified by assigning it a random code. Neither you nor your data will be identified when publishing the research findings.
- Ongoing problems have not been reported from any of the procedures that will be used in this project. However, if the procedures cause you concern, you may withdraw from the project at any time.
- You are encouraged to consult with your whanau/family, hapu or iwi regarding participation in this study.

Who should I contact if I have further questions?
If you have any further questions about the study, or would like to participate in this study, please contact:

Harry Jordan Prof Cathy Stinear
h.jordan@auckland.ac.nz c.stinear@auckland.ac.nz
09 923 3779

If you feel that the assurances made to you were not met, you may contact the Academic Head of Department of Medicine,
Professor Phillippa Poole, p.poole@auckland.ac.nz, Ph 09 923 6440

For any queries regarding ethical concerns you may contact:
The Chair,
The University of Auckland Human Participants Ethics Committee, The University of Auckland Research Office, Private Bag 92019, Auckland 1142, Telephone 09 373-7599 ext 83711.
Email: ro-ethics@auckland.ac.nz

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE on 29/03/2018 for a period of 3 years. Reference Number 020915