



## **Participant Information Sheet**

<b>Study title:</b>	Oral function and oral health experiences in stroke survivors	
<b>Principal investigator:</b>	<b>Name: Carolina Loch</b> <b>Department: Oral Sciences</b> <b>Position: Senior Lecturer</b>	<b>Contact:</b>  carolina.loch@otago.ac.nz

### **Introduction**

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

### **What is the aim of this research project?**

This study aims to explore stroke survivors' experiences of oral function and oral health post-stroke with a focus on access to care and pathways to rehabilitation. By finding out more we hope to improve the care of oral health and function post-stroke.

### **Who are we seeking to participate in the project?**

We are seeking a total of 10 participants who live with the consequences of stroke (>18+ years). We are seeking people with a history of ischaemic or haemorrhagic stroke occurring more than 6 months ago, who live in the wider Dunedin region. Participants should be able to communicate independently in English.

### **If you participate, what will you be asked to do?**

Should you agree to take part in this project, you will be asked to:

Complete two questionnaires about your ability to perform activities of daily living in relation to oral function and oral health. These questionnaires should take about 5 minutes each.

Attend a face-to-face interview held at the Faculty of Dentistry. It will take 1 hour maximum and will be arranged at a time suitable for you. You are welcome to have a support person at the interview. This interview will be recorded and will be transcribed for analysis.

You will be asked about your experiences with management of oral function (involving biting, chewing, and swallowing) and oral health post-stroke. See below some examples of the questions you will be asked:

- *What new challenges have arisen when cleaning your teeth? i.e. impairment of arm function, two handed tasks (dispensing toothpaste)*
- *Can you still bite into an apple? Or are there any foods you can think of that are difficult to bite?*

As a thank you for your participation, a supermarket voucher will be given. Participation is voluntary.

## **Is there any risk of discomfort or harm from participation?**

Talking about your experiences around stroke and the management of oral health and function you received within the New Zealand healthcare system may be uncomfortable for you. You can take a break from the interview at any time or decline to answer specific questions. You are welcome to withdraw from the study at any time.

The information we gather from you will remain confidential. For publication purposes, all data will remain anonymous.

In case we identify major oral function or oral health issues that need attention, we will contact your general practitioner or oral health provider.

## **What specimens, data or information will be collected, and how will they be used?**

We will collect data about you (e.g. age gender, time since stroke, health services you usually use) and your experiences with the NZ health system regarding the management of oral function and health.

The interviews will be voice recorded, transcribed and coded by themes. Quotes from the interview will be used but your identity will be kept confidential. The data collected will be securely stored in such a way that only those mentioned below will be able to gain access to it.

Data obtained as a result of this research will be retained for at least 10 years in secure storage, i.e. in a password secured computer. Any personal information will be destroyed at the completion of the research even though the data derived from the research will, in most cases, be kept for much longer or possibly indefinitely.

If you do not wish to have the interview recorded, you can refuse to participate in this research project.

## **What about anonymity and confidentiality?**

The results of the project may be published, but every attempt will be made to preserve your anonymity. We will provide an electronic copy (or a hard copy if you prefer) of the final report to all participants who you wish to receive this document, once the study is accepted for publication by a scientific journal.

You are able to review your interview recording if you wish. Only the research assistant, primary investigator and co-supervisors will have access to the data for analysis and report writing.

## **If you agree to participate, can you withdraw later?**

You may withdraw from the project before its completion and without any disadvantage to yourself. If you do wish to withdraw, your interviews will be immediately deleted and will not be included in the final findings of the study or used in the next study. You will not be able to withdraw your information (which will be de-identified) if it has already been integrated into the study.

## **Any questions?**

If you have any questions now or in the future, please feel free to contact either:

<b>Stroke Research Team</b>	Contact phone number:  Email:  stroke.research@otago.ac.nz
<b>Name: Carolina Loch</b> <b>Position: Senior Lecturer + Primary Investigator</b> <b>Department: Oral Sciences</b>	Contact:  carolina.loch@otago.ac.nz  <b>479-9255</b>
<b>Name: Esther Cheong</b> <b>Position: Orthodontic Postgraduate student</b> <b>Department: Oral Sciences</b>	Contact:  chees183@student.otago.ac.nz

*This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.*