

Concussion and Neurodegenerative Diseases in New Zealand

Participant Information Sheet- Focus Group I

You are invited to take part in a study about Concussion and Neurodegenerative Diseases (NDDs). This study is being led by Dr Grace Chen from the Centre for Public Health Research (CPHR) at Massey University. Whether or not you take part is your choice. This Participant Information Sheet is designed to help you decide; please take as much time as you need. We will also answer any questions you may have. You may wish to discuss the study with other people, such as whānau, friends, and colleagues. Thank you for taking the time to consider being a part of this research study.

What is this study about?

The purpose of this part of the study is to gain an in-depth understanding of people's experiences, views and perceptions around concussion and the awareness about the role of concussion in the development of NDDs (Motor Neurone Disease, Parkinson's disease and Dementia (including Alzheimer's disease)). It is intended that the results will identify opportunities for change and suggestions on how to reduce the occurrence of concussions in terms of preventing NDDs. We are inviting family members of patients with Motor Neurone Disease, Parkinson's disease and Dementia (including Alzheimer's disease) to participate in the study.

What would your participation involve?

If you would like to take part, we will arrange a time for you to meet Dr. Grace Chen for a Kōrero (chat) in person, or over Zoom if you prefer. This can be any time of day, or in the evening or on the weekend if that suits you better. The focus group discussion will take 40-60 minutes and will be a conversation about your thoughts on concussions and NDDs in New Zealand. Prior to the focus group discussion, we will ask you to read and sign a consent form. Any opinions you express will be kept strictly confidential and will be combined with other participants' discussions to help us build a picture of concussion and NDDs in New Zealand. You can withdraw from the study at any time up until the point that data is anonymised and combined for analysis (four weeks post-focus Group discussion). If you choose to withdraw, all data you have provided will be deleted/destroyed.

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What information will be collected and what use will be made of it?

The conversation will be recorded, and this will be transcribed into text by the researcher for combination with other focus group discussions for analysis. Everything you say will be kept confidential. We will also collect basic information on a paper form, which will include gender, age, and ethnicity.

The data will be securely stored in such a way that only the researchers will be able to gain access to it. Electronic documents will be stored on a password-protected computer, and paper documents will be stored in a locked filing cabinet in a key-card access building. At the end of the project, any raw data on which the results of the project depend will be retained in secure storage for ten years, after which it will be destroyed.

We plan to use the information provided to us to develop documentation about the current views on people's awareness of concussions and NDDs in New Zealand and potential approaches to reducing the risk of concussion-associated NDDs in the NZ community. This may involve reports to the government, scientific journal articles, and/or conference abstracts. Direct quotes from the focus group discussions may be used to highlight findings from the research. In this case, no identifying information will be included with the quote.

What are the rights of participants in the study?

You are under no obligation to accept this invitation. Your participation is voluntary. If you decide to participate, you have the right to:

- decline to answer any question(s);
- ask questions about the study at any time during participation;
- withdraw from the study at any time up to four weeks after the focus group discussion (at which point data will be anonymised and combined for analysis);
- review a summary of our conversation and provide feedback;
- be given access to a summary of the study findings at the conclusion of the study.

Who has reviewed the study?

This project has been reviewed and approved by the Massey University Human Ethics Ohu Matatika 1, Application OM1 24/52. If you have any concerns about the conduct of this research, please contact A/Prof Louise Brough, Chair, Massey University Human Ethics Ohu Matatika 1, email humanethics1@massey.ac.nz.

What if I have any other questions?

If you have any questions about the study, please contact one of the researchers below.

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Thank you very much for your time in considering this study.