

Participant Information Sheet

Healthy ageing in adults with cerebral palsy

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This study has been approved by the Northern A Health and Disability Ethics Committee on 12 Feb 2024 for 3 years (reference 18972).

Kai ora, thank you for taking an interest in this research project.

You are invited to take part in a study on healthy ageing with cerebral palsy. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

The information provided here will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. If you wish to discuss the study with us, we will review this information with you and answer any questions you may have. You do not have to decide today whether to participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Please feel free to do this.

If you agree to take part in this study, you will be asked to complete the Consent Form, which will be sent to you electronically. A copy of this is provided on the last page of this document. You will be given a copy of the Participant Information Sheet to keep.

This document is 8 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

WHAT IS THE STUDY ABOUT?

Cerebral palsy (CP), or hōkai nukurangi, is the most common childhood onset physical disability. Adults with CP experience unique and ongoing physical health care needs across their life, however there is often a lack of information and services available to support adults with CP in navigating their evolving physical healthcare needs. It is important to understand the health needs of adults with CP so that those adults can understand how aging will affect them and also so health professions can be informed about the effects of ageing for adults with CP and provide appropriate health advice and care.

In addition to being physically healthy, adults with CP also value holistic wellbeing in their life that includes mental health and social wellbeing. We currently know little about what it is like to live through adulthood with CP and what it means to age well.

This research aims to explore the diverse ways adults with CP view and experience ageing across adulthood life stages in Australia and New Zealand. Health and ageing experiences will be out with a broad definition of health and wellbeing and include mental health and social wellbeing.

Information from adults with CP about their health and ageing experiences is very important to answer our study questions.

If you choose to participate, the questions you will be asked will be about your health and ageing experiences, needs and what healthy ageing means to you. The answers to these questions will form early learnings relevant to other adults with CP to inform holistic wellbeing, health outcomes and self-advocacy. The new knowledge may also be used to inform adult health service planning and support healthcare professionals working in this space.

Participation is completely voluntary; you may decide not to take part it will not affect the treatments or health services you receive. You do not need to provide a reason.

WHO CAN TAKE PART IN THE STUDY?

This study focuses on adults with CP and their ageing experiences. You can take part in this study if you are:

- An adult 30 years or older with cerebral palsy or hōkai nukurangi
- Live permanently in either New Zealand or Australia (for at least 7 years)
- Have capacity to participate in the study activities (questionnaire and interview) either by yourself or with support

IF I DECIDE TO TAKE PART, WHAT WILL I BE ASKED TO DO?

There are two parts to this research, a questionnaire and an interview, to be held over zoom.

Step 1: Complete a simple questionnaire

We are asking adults, 30 years and older living in Australia or New Zealand, to complete a short questionnaire that would take approximately 20 minutes.

The questionnaire can be completed **online**. You will be welcome to ask for adaptations to make it possible for you to participate, for example you can ask to complete the questionnaire over the **phone**.

We will ask you about your gender, ethnicity, age, medical information, and brief questions about your health. The questions have multiple choices and the option for you to provide your own comment.

You can complete the questionnaire at any time suitable for you before the interview. If you prefer, you can opt to complete the questionnaire at the start of the interview with the researcher.

Step 2: Take part in an interview (on-line)

We will invite you to a conversation about your experiences ageing with CP that takes approximately 1 hour. The researcher will ask you questions about your health and ageing experiences, your health needs and what would support you in ageing well. If you would like an outline of the questions prior to the interview, then this can be arranged for you.

These conversations will start with the researcher introducing themselves, sharing and overview of the study and describing the content of the questions. The flow of the interview will be flexible so that you can share what is important to you. The nature of questions will be broad. You will have control over what information you share and how much detail you wish to provide. You may like to have your whānau present, or a support person with you. You may take a break at any time in the interview.

The interview will be completed over zoom. Please ensure you are in a comfortable place to participate in the interview. You will be welcome to ask for adaptations to the interview to enable you to participate.

After the interview, you will receive a \$50 voucher as a thank you. You will also receive a written copy of your interview and can return any comments within 14 days of receiving it.

At the end of the study, you will receive a written summary of the findings. If you like, you may ask to have a conversation about the study findings with the researcher(s). The study findings are expected in 2025.

WHAT ARE THE POSSIBLE BENEFITS OF THIS STUDY?

You may not directly benefit from participating in this study.

The questions in the questionnaire and survey may contribute to your personal understanding of ageing with CP. At the completion of the study, you will receive a summary of the findings and any learnings. This may be of benefit for you, providing helpful information to support you in ageing well and self-advocacy. The findings of this study will be shared with the CP community, and other adults with CP and their families may benefit from your contribution in the same way.

If found to be appropriate, the findings will also be shared with health professionals working in this space, supporting them in their service provision.

The findings of this study will contribute new knowledge in this field, which will be published in scientific journals benefiting adults with CP internationally, researchers and inform policy.

WHAT ARE THE POSSIBLE RISKS OF THIS STUDY?

Sharing of personal information

The interview questions are open ended and allow you control over what and how much you wish to share. The questions seek a discussion of personal views and experiences that may not

often be discussed in everyday life, and the researchers will provide a safe environment for these conversations.

The questions ask about your health needs, ageing experiences and what would support you in ageing well. If you are feeling upset or anxious because of a question, you do not need to answer it. You can also choose to return to a question later. We encourage participants to have whānau or a support person present if that is what they wish.

If help is needed, the researcher will provide guidance and information about obtaining help from a counsellor or a health care professional if that would help. You of course can choose to talk to your own health professional.

In addition to ethics approval, this research study has been developed with review and input from an advisory group, made up of adults 30 years or older with CP. This is to make sure that the questions and running of the study are relevant to adults with CP and are safe.

WHAT WILL HAPPEN TO MY INFORMATION?

Use of the data

Information provided by participants is treated confidentially and with respect for your privacy. To make sure your information is kept confidential, information you provide in the questionnaire and interview will be assigned a study code. Then all information that identifies you, including your name, address and date of birth, will be removed. This means there will be nothing in the data that identifies you when the data is analyzed.

Information used to contact you will be stored separately from the study data so that we can send you the study results.

Any publications or reports resulting from this study will not contain any information to identify you. When published, use of any quotes will be completely de-identified from give-away phrases that may identify the individual. This is done with care and multiple rounds of review prior to publishing. There is a small chance that some individuals in the community may still be able to identify a quote as likely from a certain person. However, this chance is very small.

Although every effort will be made to protect your privacy, absolute confidentiality of your information cannot be guaranteed. Even with anonymized information, there is no guarantee that you cannot be identified. The risk of people accessing and misusing your information is currently very small.

Written copy

The interview audio recordings will be made into a written copy by a professional transcriptionist. It is important that interviews are audio recorded to make sure we can do this

accurately. If completed on zoom, audio recording will be done using the recording function. If completed in a written form, then this will be saved.

You will be sent a copy of your transcript. You may return any comments or corrections within 14 days. The audio recordings will then be deleted.

All digital study information will be stored securely on the University of Auckland databases for a minimum of 7 years.

If you agree, your de-identified information may be used for future research related to adults with cerebral palsy. You will not be told when future research is undertaken using your information. You will not get reports or other information about research that is done using your information.

Your information may be used indefinitely for future research unless you withdraw your consent. However, it may be extremely difficult or impossible to access your information, or withdraw consent for its use, once your information has been shared for future research.

Treating study data with care

Māori data sovereignty is about protecting information or knowledge that is about (or comes from) Māori people. We recognize the taonga of the data collected for this study. To help protect this taonga:

- We consult with a Māori Engagement Lead throughout the study to who provides input on collection, use and feedback of study data
- We consulted with the Māori Advisory Group at the Liggins Institute about the collection, ownership, and use of study data
- We allow Māori organizations to access de-identified study data, for uses that may benefit Māori

Your information will not be shared with other researchers or sent overseas; however de-identified data may be accessed by a member of the research team (investigator: Dr Sian Williams) in Australia through a secure multi-factor authorization network.

The study team respect and understand the concepts of Māori sovereignty and harm that can affect any at-risk minority from misinterpretation. This study has also been reviewed by the Māori Advisory Group at the Liggins Institute in the University of Auckland. The study team includes a Māori engagement lead who has been involved in the study development and will be involved in the analysis and interpretation.

The study is centred in positive views of ageing and values that promote ageing well. Recognizing the harm from deficit framing, the study team will continue to promote strength-based framing and minimize any potential harm.

WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?

You may withdraw your questionnaire and interview transcript from the study at any time up until your data has been de-identified and combined with the data from other participants (approximately 1 month after you participate). When the study data is de-identified (i.e. your name is removed and replaced with a code), we will not be able to identify and remove your data if you decide to withdraw after that.

You may withdraw your consent by informing the researcher who has been in contact with you or any other researcher on the team. The contact details are on page 6.

If you withdraw your consent, your study participation will end, and the study team will delete the questionnaire you completed and any interview data.

If your data is de-identified, it will not be possible to withdraw your information, even if you change your mind about it being used.

CAN I FIND OUT THE RESULTS OF THE STUDY?

You will receive a plain English summary of the study results at the completion of the study. This is expected to happen in 2025.

WHO IS RUNNING THIS STUDY?

This research is being carried out by Woroud Alzaher, who is working towards a Doctor of Philosophy at the University of Auckland, focusing on health and wellbeing in adults with cerebral palsy or hōkai nukurangi. She is supervised by Dr Sian Williams, a Senior Research Fellow at the University of Auckland and Senior Lecturer at Curtin University, Australia, Professor Sue Stott, a paediatric orthopaedic surgeon and professor at the University of Auckland, and Ms Amy Hogan, a Lead Researcher and Member Support Advisor at the Cerebral Palsy Society (New Zealand).

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions or concerns about the study at any stage, you can contact the researcher who has reached out to you or contact any one of the researchers:

Ms. Woroud Alzaher, PhD student

Email: woroud.alzaher@auckland.ac.nz

Liggins Institute, University of Auckland, Private Bag 92019, Auckland 1142, New Zealand

Dr. Sian Williams, Senior Research Fellow

Email: sian.williams@auckland.ac.nz

Tel +64 9373 7599 Ext 86929

Liggins Institute, University of Auckland, Private Bag 92019, Auckland 1142, New Zealand

Prof. Susan Stott, Professor – Medical Surgery and Orthopaedic Surgeon

Email: s.stott@auckland.ac.nz

Faculty of Medical and Health Science, University of Auckland, Private Bag 92019, Auckland 1142, New Zealand

Ms. Amy Hogan, Researcher and member support

Email: amy@cpsociety.org.nz

Ms. Jenny Rogers, Māori Advisor

Email: jenny.rogers@auckland.ac.nz

Tel +64 21 98 0913

Liggins Institute, University of Auckland, Private Bag 92019, Auckland 1142, New Zealand

If you require emotional support, please call Lifeline on 0800 543 354 for free counselling.

For a list of other helpful services, visit the Mental Health Foundation page to find the service that is right for you: <https://mentalhealth.org.nz/helplines>.

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050

Email: advocacy@advocacy.org.nz

Website: <https://www.advocacy.org.nz/>

For Māori whānau who require cultural support, talk to your whānau first.

Or you may contact your local Māori health Support Service. The contact details for the Māori health Support Services are listed in the table below.

District	Contact details
Northland	Te Poutokomanawa (Māori Health Service) Phone: (09) 430 4101 ext. 3239
Waitemata	He Kamaka Waiora (Māori Health Team) Phone: 09 486 8324 ext 2324
Auckland	
Counties Manukau	Ian Kaihe-Wetting, Service Manager - Te Kaahui Ora Maori Health CMH Phone: (09)276 0138
Waikato	Te Puna Oranga Phone: (07) 8398899 ext 97528 or 021806171
Lakes	Te Huinga Takiora Maori (Lakes DHB Māori Health Team) Phone: (07) 3497858
Bay of plenty	Regional Maori Health Services, Tauranga Hospital Phone: 07 579 8560
Taranaki	Te Puna Oranga: Phone: (07) 8398899 ext 97528 or 021806171
Capital and Coast / Hutt Valley	Whanau Care Services Phone: (04) 806 0948
Hawke's Bay	Maori Health Unit at Hawkes Bay District Health Board: Laurie Te Nahu Tel: 06 878 8109 (ext2413) Pou Arahi Querida Whatuira – Strickland Tel: 06 878 8109 (ext 2884) Kaitakawaenga - Women, Children and Youth Service
Canterbury / West Coast	Canterbury Māori Health Services He Waka Tapu Phone: (03)373- 8150 or 0800 HEWAKA

For ethical concerns, you can also contact the health and disability ethics committee (HDEC) that approved this study on:

Email: hdec@health.govt.nz
Phone: 0800 400 569 (Ministry of Health general enquiries)

This study has been approved by the Northern A Health and Disability Ethics Committee on 12 Feb 2024 for 3 years (reference 18972).

Thanks for reading this information sheet. If you have any questions or wish to participate, please contact Woroud (Woroud.alzaher@auckland.ac.nz).

CONSENT FORM

Please tell us if you need an interpreter.

Healthy ageing in adults with cerebral palsy

- I have read the Participant Information Sheet, or have had it read to me in a language I understand, and I fully comprehend what it says.
- I have been given sufficient time to consider whether or not to participate in this study.
- I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.
- I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.
- I consent to my discussion being audio recorded.
- If I decide to withdraw from the study after my information is de-identified, I agree that the information collected about me will continue to be processed.
- I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.
- I know who to contact if I have any questions about the study in general.
- I understand my responsibilities as a study participant.

If you identify as Māori, I agree to my de-identified information to be made available to Māori organizations if requested Yes ☐ No ☐

I agree to my de-identified information being used in future research Yes ☐ No ☐

I wish to receive a summary of the results from the study Yes ☐ No ☐

Declaration by participant: I, _____(full name) hereby consent to taking part in this study.

Signature _____ Date _____

Declaration by member of research team: I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it. I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: _____

Signature: _____ Date: _____