**PARTICIPANT INFORMATION SHEET**

## Participant Information Sheet Survey Phase 1b Person/Whānau

**Research Title** Clinical Utility of InterRAI Data

Lead researcher: Dr Jo Hikaka, Senior Research Fellow, Te Kupenga Hauora Māori, University of Auckland

Kia Ora, you are invited to take part in this study to explore your or your family members’ experience of being assessed for clinical support needs, an interRAI assessment. A member of your family can help you to fill out this form, or can fill it out on your behalf.

Some older people have had a needs assessment to see what might be needed to help with everyday life. This would have involved talking to an assessor who would have asked you questions about how you go about things like showering, walking and socialising with others and may have led to you having home help. Everyone in an aged care facility or rest home in NZ also had this type of assessment done, but it is usually done by one of the staff members. These assessments are known as interRAI assessments.  If you, or someone close to you, has ever had this type of assessment please read on as your views and experiences are important.

Do i have to take part in this study?

No, you don’t. You can choose if you want to take part in this survey. If you don’t want to take part, you don’t have to give a reason. You can change your mind and pull out of the survey at any point up to entering data. You can ask questions about the study at any point before or after participating.

This Information Sheet will help you decide if you’d like to take part. You can contact the lead researcher if you have any questions, and they will answer any questions you may have. You do not have to decide today whether or not you will take part in this study. Before you decide you may want to talk about the study with other people, such as your family members or someone at your facility. Feel free to do this. If you agree to take part in this study, you will be asked to complete an electronic Consent Form.

There is an option to win a prize draw for entering in this survey.

What is this study about?

You have been asked to take part because you (or your whānau/family member) have had an interRAI needs assessment.

We would like to understand how you received the results of the assessment. Whether we could make it easier for you to understand the results, or if there are better ways of giving out the results. We would like to know the best ways assessments can be used to help create a person’s care plan.

We also want to explore your level of comfort in using AI (artificial intelligence, such as ChatGPT) technology to summarise interRAI data for reporting back to you, or generating a plain language summary. This information could help us to develop software for interRAI users which could be useful in New Zealand and internationally.

You are eligible to take part in this study if you are i) 18 years or older AND ii) able to complete a survey electronically AND iii) able to read and respond in English AND iv) have had an interRAI assessment OR are a family member of someone who has had an interRAI assessment

What will i be asked to do?

You will be asked to answer some questions in an online survey. We recommend you set aside 10-15 minutes to complete.

WHAT WILL HAPPEN TO THE INFORMATION I PROVIDE?

During this study the researchers will record information about you and your study participation.

**Identifiable Information**

Identifiable information is any data that could identify you (e.g. your name, date of birth, or address). No identifiable data is collected in the survey, however, if you choose to enter the prize draw, or request a summary of the survey results, we will hold identifiable data for a short time (3 months), and then this information will be deleted. Identifiable data for prize draw or results will not be linked to survey responses.

**Anonymous Information**

As we are not collecting any identifiable information in the survey, all your responses in the survey will be anonymous. The information you provide will be collated with all responses and stored for 10 years before being destroyed.

However, if you choose to enter the prize draw, or request a summary of the survey results, we will hold identifiable data, such as your name and email for a maximum of 3 months, in a password protected file, and then it will be deleted. Identifiable information is not linked to survey results.

**Security and Storage of your information**

Your data is held at the University of Auckland during the study. After 3 months when the results have been sent and prize draw confirmed, the identifiable information will be deleted. After the study it is transferred to a secure archiving site and stored for ten years and then destroyed. Recordings and any other data collected during this project will be password protected and stored on a secure drive at The University of Auckland for ten years. After that, all data will be destroyed by deletion of electronic files and shredding of any paper copies.

**Sending of Data Overseas**

Anonymised data may be sent overseas to Canada, Australia, or USA, when the results are published. These countries also use interRAI data and are likely to want to understand how we intend to make changes to interRAI data in NZ, to make the information more useful.

There may be a small risk and cultural issues associated with sending [and storing] data overseas, and that there may be no New Zealand representation on overseas governance committees.

**Risks**

Although efforts will be made to protect your privacy, absolute confidentiality of your information cannot be guaranteed. Even with coded and anonymised information, there is no guarantee that you cannot be identified. The risk of people accessing and misusing your information is currently very small but may increase in the future as people find new ways of tracing information.

**Rights to Withdraw and Access Your Information**

You have the right to change or delete any of your survey responses at any time **prior to completing** the survey. Because the survey is anonymous, we will not be able to identify it as your responses or be able to delete any information you complete in the survey.

**Ownership Rights**

Information from this study may lead to discoveries and inventions or the development of a commercial product. The rights to these will belong to The University of Auckland. You and your organisation will not receive any financial benefits or compensation, nor have any rights in any developments, inventions, or other discoveries that might come from this information.

POSSIBLE BENEFITS AND RISKS OF THIS STUDY

The information gathered will be used to improve health information from the interRAI assessments. The data will be published in academic papers/reports and findings could be used to inform what aspects are important for the implementation of interRAI data assessments.

There should not be any risks to you being involved in this study. If you find thinking about the assessment results upsetting, you do not need to continue with the survey. You can stop answering the questions at any time. Only surveys that are fully completed will be used in the results. If you need support because there is something upsetting about the survey, or you would like cultural support, please contact Dr Joanna Hikaka, Principal Investigator (contact details at bottom of sheet).

There is an option to win a prize draw for a koha supermarket voucher (worth $50).

WILL ANY COSTS BE REIMBURSED?

You should not incur any costs by being involved in this study.

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

As discussed above, you cannot withdraw your responses after you have completed your survey. Prior to this point you can decide not to participate, even if you have already consented or started completing the survey.

CAN I FIND OUT THE RESULTS OF THE STUDY?

We will send results out to those who requested a summary. We will publish the results of this study and make a summary available through the working group throughout 2024 and 2025

WHO IS FUNDING THE STUDY?

This study is funded by the **University of Auckland.** The funders have no control over the design, analysis or reporting of the study. The researchers are associated with the University of Auckland.

WHO HAS APPROVED THIS STUDY?

This study has been approved by an independent group of people called the Auckland Health Research Ethics Committee (AHREC), who check that studies meet established ethical standards. The Auckland Health Research Ethics Committee has approved this study.

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

If you have any questions, concerns or complaints about the study at any stage, you can contact the lead researcher, Dr Jo Hikaka.

For concerns of an ethical nature, you can contact the Chair of the Auckland Health Research Ethics Committee at ahrec@auckland.ac.nz or at 373 7599 ext. 83711, or at Auckland Health Research Ethics Committee, The University of Auckland, Private Bag 92019, Auckland 1142

If you would like cultural support, please contact Dr Jo Hikaka.

|  |
| --- |
| **CONTACTS** |
|  **Lead Researcher:** | Dr Jo Hikaka Ph: 093737599 Email: j.hikaka@auckland.ac.nz |
| **Other Investigator** | Prof Ngaire Kerse, Dept of General Practice and Primary Health Care, University of Auckland.Dept General Practice and Primary Health Care, Head of Department, Dr Susan Wells, s.wells@auckland.ac.nz |
| **Auckland Health Research Ethics Committee:** |  Email: ahrec@auckland.ac.nz |

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@hdc.org.nz

APPROVED BY THE AUCKLAND HEALTH RESEARCH ETHICS COMMITTEE Date: 16th Dec 2024; Ref:28693.