



PARTICIPANT INFORMATION SHEET

Study title: ARFID Research Priorities in New Zealand

Locality: University of Otago, Christchurch

UO ethics ref. H22/074

Lead investigators: Dr Hannah Kennedy and Associate Prof. Jennifer Jordan

INTRODUCTION

You have been invited to take part in a survey to identify the research priorities of the New Zealand community impacted by avoidant/restrictive food intake disorder (ARFID). Your participation is entirely voluntary, and you don't need to give any reason for not wanting to participate. If you want to take part now, but later change your mind you may pull out of the study at any time.

This participant information sheet will help you decide if you would like to take part. It sets out the purpose of the study, what your participation involves, what the benefits and risks to you might be, and what happens after the study ends. Before you decide you may want to talk about the survey with other people, such as family, whānau, friends, or healthcare providers.

This information sheet is 1 page long. Please make sure you have read and understood this. If you agree to take part in this study, you will be asked to sign a separate Consent. You will be able to save a copy of this Participant Information Sheet and Consent Form (PISCF) to keep.

WHAT IS THE AIM OF THIS STUDY?

The main purpose of this survey is to record the views of those most impacted by ARFID, and understand what you consider to be the important areas of further research.

WHO CAN JOIN THIS STUDY?

The study is open to anyone who has experienced ARFID personally, or in their caregiver/support network/family member role and is at least 16 years of age. A clinical ARFID diagnosis is not required. Participants must be able to read and understand the information sheet and consent form to provide informed consent, and to comprehend content of survey questions in English. The exclusion criteria are participants under the age of 16, or those not residing in NZ at the time of completing the survey.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

You will be asked to complete a short survey identifying and prioritising ARFID research

areas. We will also collect details on your age, gender, and ethnicity. All of this information will be stored in a secure database confidentially. This survey should take no more than 20 minutes to complete.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

The views you express in this survey may help direct future research in ARFID, to better meet the needs of people directly impacted.

Your survey answers will be stored securely on the University of Otago server, in a password protected format and will only be accessible to researchers directly analysing the data. You will not be identifiable in any publication arising from the study.

You will not receive any payment for participating in this survey.

WHAT HAPPENS TO MY SURVEY INFORMATION?

After the study, we will retain the data securely for at least 10 years after publication. Your data will be recorded in a password protected database, stored on the University of Otago server, and only accessible to the named researchers. You will not be identifiable in any publication arising from the study.

Coded study information may be shared with other researchers in the future.

We will send you a summary of the results of the study when available, if you opt to receive them.

WHAT ARE MY RIGHTS?

You may withdraw from the study at any time. In the event of withdrawal, data already collected for the study will continue to be analysed

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

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

Dr Hannah Kennedy

Hannah.kennedy@otago.ac.nz

A/Prof Jenny Jordan

Jenny.jordan@otago.ac.nz

For information/support relating to eating disorders, you can contact EDANZ 0800 2 EDANZ or (09) 5222679. If you are feeling distressed, you can contact 1737, a (free) 24 hours counselling line or your general practitioner, who also has access to referral pathways if you need more ongoing support.

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.