



MEDICAL AND HEALTH SCIENCES

School of Medicine
The University of Auckland Private Bag 92019
Department of Psychological Medicine
22-30 Park Road,
Grafton
Auckland 1142 New Zealand
Telephone: +64 9 923 4938
l.reynolds@auckland.ac.nz

Well-being and distress in people with an advanced illness

Primary Investigator: Dr Lisa Reynolds (Health Psychologist/Senior Lecturer)¹

Co-investigators: Alesha Wells¹, Eva Morunga^{1,2}, Hineatua Parkinson¹, Suresh Muthukumaraswamy¹

Affiliations: ¹University of Auckland, ²Auckland District Health Board

PARTICIPANT INFORMATION

Kia ora,

My name is Alesha Wells, and I am a PhD student in the Department of Psychological Medicine at The University of Auckland. I have included a short video clip telling you a little about myself, to view it please [follow this link](#).

I am part of a team looking for individuals with an advanced illness diagnosis, including cancer, lung, heart, kidney, and liver disease to complete a survey about mental health and wellbeing. Please read this information before deciding whether or not to take part. Feel free to take some time and engage in your cultural or spiritual practice before continuing with the survey, whatever that may be for you. If you decide to participate, thank you. If you decide not to participate, thank you for considering this request.

What is the aim of this study?

In this study we are exploring the factors that impact distress experienced by people with advanced illness, including cancer, lung, heart, kidney, and liver disease. Previous research has highlighted the large impact that advanced illness progression can have on mental wellbeing. As a result, it is important to expand our understanding of what influences the experience of distress, i.e. what might increase or decrease it.

Nāu te rourou, nāku te rourou, ka ora ai te iwi

With your food basket and my food basket the people will thrive

Your participation will support this research by providing us with insight into your experience. It is through your participation that makes research such as this possible. Your perspective is valued and allows us to understand people's lived experience which will contribute to further work to benefit

our community. In this case, that may mean improvements in how we identify those with significant distress, or to help us design better and more effective interventions for those who need them.

If you choose to complete the survey, you may choose to go into the draw to win one of five \$200 Countdown vouchers in thanks for your valued participation. You may also choose to receive a video and/or written summary of findings. To indicate your interest in entering the draw and receiving a summary of findings you can enter your contact details on the Contact Sheet provided, these details will not be linked to your survey data in any way. Your survey will remain entirely anonymous.

How can you help?

If you agree to take part, you will complete a confidential survey either online or in writing. The survey will take 20 minutes to complete and will ask questions about you, your diagnosis, and your mental health and wellbeing. You can withdraw your participation at any time prior to the completion of the survey by not submitting the survey. We do not expect any explanation or follow-up from you if you decide not to complete it. Submission of a complete survey will be taken as recognition of your consent.

If you are completing the questionnaire online, there is a link at the bottom of the page that will direct you to the survey. After you complete the survey and submit it, you will be taken to a contact sheet page. Again, this is separate from your survey data.

If you are completing the questionnaire on paper, you will be provided with two pre-paid and addressed envelopes containing this information sheet, the questionnaire, and contact sheet. To maintain your anonymity, after you fill in the contact sheet (optional) this can be placed into one of the two envelopes. Your completed survey can be placed into the other envelope. These can then be mailed to us.

We also encourage our participants to use the contact details at the end of this sheet if they are feeling distressed and would like to discuss anything with us. These include the researcher contact details and relevant helplines.

What will happen to the information you give?

This research is confidential and de-identified. This means that nobody, including the researchers will be able to link any contact information provided by you to your survey response. If you agree to participate, your anonymised information may be used for future research related to life-limiting illnesses. Your anonymised information may also be used for other medical and/or scientific research that is unrelated to the current study. This future research may be conducted overseas. You will not be told when future research is undertaken using your information. Your information may be shared with other researchers or companies. Your information may also be added to information from other studies, to form much larger sets of data. However, governance of your data will remain in New Zealand, with a New Zealand based researcher remaining involved in data analysis. Your answers will remain completely unidentifiable. Once you submit the survey, it will be impossible to retract your answer. Please do not include any personal identifiable information in your responses.

All personal details provided on the optional Contact Sheet will be received separately from the survey data and will be entered and held securely in a password protected database. All paper copies of contact details will be shredded and disposed of. This ensures that your answers to the survey questions will not be linked to your identity. At the end point of this research, once we have completed the prize draw and sent the summary of results, your personal contact details will be

deleted from the database, unless you indicate on the contact sheet you want to be contacted for future research.

The survey data will be stored securely on the University of Auckland server for 10 years from completion of the research and then destroyed according to the University of Auckland research code of conduct guidelines. The final report will be disseminated via journal publications and presented at national and international conferences.

What will the project produce?

The information from this research will be used in academic publications and presented at national and international conferences. The findings of this study may inform the development of future clinical trials. I will also send out a video exploring the results of this research to those who are interested. Please feel free to watch this video with your whānau or loved ones, as it is your contribution that made this possible.

How is this research funded?

This research is funded by an annual stipend provided from the University of Auckland to doctoral students to cover direct research costs. There is no external funding source.

If you have any questions or problems, who can you contact?

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

Alesha Wells
Department of Psychological Medicine
The University of Auckland
Telephone: 021 064 8489
Email: alesha.wells@auckland.ac.nz

Dr. Lisa Reynolds
Department of Psychological Medicine
The University of Auckland
Telephone: 09 923 6221
Email: l.reynolds@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.

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 this information or completing the survey has brought up any concerning thoughts or feeling for you, please reach out to the following services for support:

Talk to your GP or health care professional

If you do feel distress, please ask for help from your GP or cancer care clinician. They may not realise you need some additional support. They will be able to refer you to the most appropriate

support service for your needs.

Cancer Society

For cancer related support for you or your family - Monday to Friday, 8am–5pm Call 0800 CANCER (0800 226 237) or go to: <https://cancernz.org.nz/>

Healthline

Healthline is staffed by experienced registered nurses who can provide you with health information and advice on care.

Call 0800 611 116 or go to: <https://www.health.govt.nz/your-health/services-and-support/health-care-services/healthline>

Lifeline

For free, confidential support for any distressing situation – 24 hours a day, 7 days a week.

Call 0800 LIFELINE (0800 543 354) or text HELP (4357) or go to <https://www.lifeline.org.nz/>

Family Services Directory

A directory of service providers that can help you and your family

<https://www.familyservices.govt.nz/directory/>

If you would like to participate in the survey, please follow the link below or scan the QR code:

<https://redcap.fmhs.auckland.ac.nz/surveys/?s=K4N9J33CRD>

