

Participant Information Sheet



**MEDICAL AND
HEALTH SCIENCES**

Survey of lived experience of key support people of those diagnosed with Long COVID

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Ethics committee ref: AH25923

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Kia ora,

My name is Georgia van Vuuren, and I am a Master's student in the Department of Psychological Medicine at the University of Auckland.

I am part of a team investigating the lived experience of key support people of those diagnosed with Long COVID (LC). We are looking for support people of those with LC to participate in our study. Please read this information before deciding whether to take part. It sets out why we are doing the study, what your participation would involve, any benefits and risks to you, and what would happen after the study ends. If you decide to participate, thank you. If you decide not to participate, thank you for considering this request.

WHAT IS THE PURPOSE OF THE STUDY?

The survey aims to understand the lived experience of being a key support person (including partners, parents, children, other relatives and close friends) for those who have Long COVID (LC). Specifically, the study hopes to explore support people's perceptions of LC and caring for someone with LC, specific support needs and preferences and impacts on wellbeing. By doing this, the study hopes to inform resources to help key support people, and by extension, improve the wellbeing of those with LC.

We invite key support people to participate in this study and hope to hear from a wide range of perspectives and experiences including those of suspected LC cases, LC cases that have recovered, and those who do not live with the person they are supporting.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

This study has two parts in which you can participate. The first part of the study involves completing a 30-minute anonymous online survey. You will be asked about your age, gender, ethnicity, as well as questions about the supported person including your relationship with them, their Long COVID (LC) status, how long you have been supporting them and their symptoms. The survey will then ask you about your experiences of support and your perceptions of LC. Finally, the survey will explore the impacts of this experience on you and what support you have received or think would be useful. You can withdraw your participation at any time prior to completing the survey by not submitting the survey.

If you complete the online survey, you will be asked whether you would like to also participate in a videoconference or telephone interview later that suits you. This interview is entirely optional. In this interview we will discuss your experiences in more depth, including your experiences of being a key support person, your support needs and preferences and impacts of this support on your wellbeing. The interview is expected to last between 30 and 45 minutes. The interview will be recorded, and you can ask for the recorder to be turned off at any time. An example of an interview question is, "Are there any types of support you think could help you with supporting this person with Long COVID?"

We expect around 50 people to complete the online survey and 10 to participate in the interview. If you choose to complete the online survey, you will enter a draw to receive one of five \$100 Prezy online cards for your valued participation. If you choose to participate in the interview following the completion of the survey, you will receive a \$40 Prezy online card as acknowledgement of your participation in the interview.

WHAT WILL HAPPEN TO MY INFORMATION?

The online survey is anonymous. That means nobody, including the researchers, will be aware of your identity. For this reason, once you submit the survey it will be impossible to retract your answers and you will not be able to withdraw from the study. Please do not include any personally identifiable information in your responses. By answering the survey, you are giving consent for us to use your responses in this research and share this information with other researchers in the future. Personal details will be collected only for the following three reasons: 1) to enter a draw to receive one of five \$100 Prezy online cards, and/or 2) to receive a copy of the results from the study, and/or 3) if you wish to participate in a videoconference or telephone interview. If you are interested in any of these options, you will be guided to a separate survey at the end of the questionnaire which will collect your name and email.

All personal details will be received and stored separately from the survey data and held in confidence. This ensures that your answers to the survey questions will not be linked to your identity. Only the researchers listed in this study will have access to your contact details. Any contact details stored will be deleted once the Prezy online card has been provided, qualitative interviews are completed, and study results have been sent following study completion.

If you decide to participate in the interview, your responses will be recorded and transcribed by the researcher. What is discussed during the interview will be kept confidential and not repeated to others outside of the research team. To minimise risk of identification, the researchers will allocate code numbers or initials to participants and report sample summary details rather than individual descriptions.

The study data will be stored securely on the University of Auckland server for six years from the completion of the research and then destroyed according to the University of Auckland research code of conduct guidelines. The study is expected to finish by early 2024, after which you will receive a summary of the results if you have requested this. We aim to publish the findings from this research in peer-reviewed journals and present findings at national and international conferences. If you have taken part in the qualitative component of this research, quotes from your transcript may be used in publications and presentations about this study.

WHAT ARE THE POSSIBLE RISKS AND BENEFITS OF THIS STUDY?

There are no discernible risks from participating in the study. Some questions in the survey and interview process are potentially distressing, however if you do experience any sort of distress or concerns, please see the contacts provided below.

Although there are no direct benefits from participation, the study aims to support the development of resources to assist key support people of those with Long COVID.

WHAT ARE MY RIGHTS?

Whether or not you take part is your choice. If you do not want to participate, you do not have to give a reason. If you do want to take part now but change your mind later, you can pull out of the study at any time before submitting the online survey. If you are a student, your participation or non-participation will not affect your grades or relationship with the University of Auckland.

If you participate in the interview and wish to withdraw your data, you may do so within 10 days of the interview. All data collected will be kept confidential and stored on password-protected computers.

Video or audio recordings from the interviews will be transcribed. Any personal information that could identify you or others will be deleted from transcripts and will not be reported in the study. The interview transcript will be sent to you for review; you are free to make any edits within 7 days before the analysis begins. You will be allocated a code number during the transcription of interviews; any information you give will be confidential to the research. All recordings will be deleted once transcripts are completed. You have the right to access the results of this study.

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

If you have any questions, concerns or complaints about the study at any stage, you can contact:

- **Georgia van Vuuren, Department of Psychological Medicine, University of Auckland**
Telephone: 027 4420993
Email: gvan983@aucklanduni.ac.nz
- **Dr. Geraldine Tennant, Department of Psychological Medicine, University of Auckland**
Email: g.tennant@auckland.ac.nz
- **Dr Rosie Dobson, School of Population Health, The University of Auckland**
Email: r.dobson@auckland.ac.nz

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

- **Talk to your GP.**
- **1737:** Free call or text 1737 any time, 24 hours a day. You'll get to talk to (or text with) a trained counsellor. This service is completely free.
- **Healthline:** Healthline is staffed by registered nurses who can provide you with health information and advice on care, call 0800 611 116 anytime.
- If you require Māori cultural support, you may talk to your whānau in the first instance. Alternatively, you may contact the administrator for **He Kamaka Waiora (Māori Health Team)** by telephoning 09 486 8324 ext 2324.

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. Approved by the Auckland Health Research Ethics Committee on 18/05/2023 for three years.

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