Critical connections: Policy and perspectives on 'visiting' and palliative care during the COVID-19 pandemic

New Zealanders’ experiences of hospital ‘visiting’ during COVID-19 restrictions

Participant Information Sheet

The COVID-19 pandemic has meant restrictions were placed on ‘visitors’ to health care institutions to limit the spread of the virus among those most at risk, the health care staff caring for them as well as the wider community. Sometimes this meant no ‘visitors’ were allowed. Policies underpinning ‘visiting rules’ are highly variable nationally and internationally as well as between and even within institutions. For example, visiting guidelines for people who are dying in Aotearoa New Zealand differ according to hospital or hospice in patient unit and aged residential care facilities. Understanding the best approaches to competing risks of ‘visitors’ to health care institutions along with the most effective strategies and opportunities to counter these risks is critical to providing safe high quality palliative care. There is an urgent need for evidence to underpin decisions made about visitors to health care institutions. You are invited to participate because of your involvement in visiting a hospital during the COVID-19 pandemic.

An invitation…
♦ We are inviting you to take part in a study that aims to uncover experiences of and perspectives on visiting to healthcare institutions during the COVID-19 pandemic.
♦ We will explore this within a semi-structured interview. We will ask you questions about your hospital visiting experiences during COVID-19 restrictions.
♦ We are inviting you to participate because you are someone who visited (or attempted to visit) a hospital of any sort during the COVID-19 restrictions.

Is it your choice to participate?
♦ Yes, you do not have to take part in this study. It is your choice.
♦ If you do agree to take part, you can withdraw from the study at any time, without having to give a reason.
♦ Take as much time as you need to decide whether or not to take part.

Who is doing the study?

Approved by the University of Auckland Human Participants Ethics Committee on 24 August 2020 for three years. Ref: 022172, & Amendment 21/12/20 Ref: UAHPEC20032
Who is being invited to be in the study?
A wide range of people (up to 30 patients or family/whānau) with diverse experiences in a variety of hospital contexts.

What is involved if you decide to take part?
You will be interviewed by one of the researchers listed previously or a research assistant.
In that interview, you will be asked questions about your experiences of visiting – whether as a patient or as a family or whānau. The interview will take between 45-60 minutes. You will also be asked to share any hospital experiences you had during the COVID-19 restrictions. The interviews will be recorded and conducted via a platform such as Zoom or by telephone, or can be kanohi ki te kanohi (face to face) if preferred.

How will the information be stored?
The confidentiality of your responses is assured. No personal information, such as your name, place of employment, email address will be released by the researchers. All information which you provide will be used for the purposes described above. All data collected will be stored securely on password protected computers in the School of Nursing, University of Auckland. Information (including consent forms and de-identified data) will be stored separately in locked filing cabinets or password protected data storage units managed by the University of Auckland for six years and only members of the research team will have access to them. No material that could personally identify you or the facility/place of employment, residents, or staff will be used in any reports on this study. You will have a two week opportunity to review your audio transcript and make changes once you have received it.

What is the time-span for the study?
Data collection will begin in February 2021 and continue through October 2021.

Are there any risks?
There are no known risks associated with participating in this study. However, if the interview makes you feel uncomfortable or upset in any way you can stop at any time. Should you need extra support after taking part in this study, please refer to the list of numbers at the end of this form. Counselling assistance may also be obtained through the facility.

Are there any benefits?

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There may be no direct benefits to you as an individual. However, our previous research has shown that others taking part in this kind of study have found it to be a positive experience. A summary of findings useful for internal review and discussion will be posted on the Te Arai website https://tearairesearchgroup.org.

**What will happen to the results of the study?**
Aside from the Te Arai website, our findings will be reported in a range of professional and academic journals and conferences. It is anticipated the findings will inform the development of further future research.

Finally, …
If you require further information about the study, please contact Assoc. Prof Rachael Parke or Dr Aileen Collier

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**Ethics Chair:** For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, Office of Research Strategy and Integrity, The University of Auckland, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 ext. 83711. Email: humanethics@auckland.ac.nz

**Other Support**

All the following services are free.

**Lifeline:** Phone 0800 543 354 | www.lifeline.org.nz.
Lifeline provides free, private telephone counselling 24 hours a day, 7 days a week.

Samaritans:  Phone 0800 726 666 at any time | www.samaritans.org.nz. Samaritans offer non-judgemental, confidential support to anyone in emotional distress and are available 24 hours a day.

Depression Helpline: Phone 0800 111 757 | www.depression.org.nz Talk to a trained counsellor who can discuss your situation and find you the right support. Available 24 hours a day, 7 days a week.