

“Measuring and reporting on what matters most to consumers with the Happy Life Index”.

1. What is this project about?

Decisions about access into aged care services are often made during difficult times. With a growing aged population requiring increasing access to aged care, the availability of meaningful information to consumers and their families about the quality of care is more important than ever. There is a need for quick and easy surveys to allow us to understand the quality of care provided to our aged care residents.

A quality-of-life survey, the Happy Life Index©, was developed in a collaboration between an Australian company, CarePage and the Aged Care Guild (an Australian aged care peak body that has since disbanded) in 2019, to encourage aged care service providers to measure and publish information on the quality of life of their residents. It measures aspects of aged care which providers can modify to improve residents' quality of life.

2. What is the purpose of this project?

This University of South Australia (UniSA) project aims to look at the reliability or stability of the Happy Life Index™ (HLI) responses over time. The HLI has been widely used in the Australian aged care sector.

3. What is involved?

You have been approached because your family member in residential aged care, has agreed to participate in this study and has also agreed to let us approach you to see if you would also like to participate.

If you agreed to participate, you will have been requested by the UniSA research assistant via a text message to complete a short digital survey with the same questions as that your family member has undertaken. However, you should answer the survey with your perceptions of the care of your family member in residential aged care ie from their point of view.

Completion of the survey and its submission is deemed to be implied consent of your participation.

The research assistant will be available to contact on the mobile number that the text is sent from to assist with any difficulties in accessing the survey. Although they may not be able to provide sufficient remote support to resolve the issue.



There are 13 survey questions, it should take less than 10 minutes to complete. You will also be asked to repeat the survey within 1 week to assess the repeatability of the survey.

Basic identifying demographic data including your name and contact details, your family members name (RACF resident), facility name and room number will also be collected and used temporarily during data collection only for project management purposes (to match you with your repeat test results, and to match you with your corresponding resident). At the end of the data collection, your identifying information will be replaced with a unique study ID to protect your confidentiality, and your identifying information will be destroyed. Your anonymous survey responses will be securely stored. Only anonymous and collated results will be presented when reporting the findings of the project, and no one, other than the research team during the initial data collection will be aware of who has participated in the project.

4. Your participation is voluntary.

Your participation is entirely optional and independent of your family members involvement in the study. Participation in this project is completely voluntary and you can always change your mind at any stage during the survey submission and retest process. Please contact the UniSA research team should you wish to withdraw.

There is no obligation to participate in this project. The project is being undertaken by the University of South Australia for research purposes, the residential care facility your family member resides in is only minimally involved as it is their place of residence. Choosing not to take part in this project, or choosing to participate and answering the questions in the survey, will not affect their current and future medical or residential care in any way.

5. Your withdrawal from the project

You may change your mind at any time about participating in the project, you do not need to provide a reason. If you withdraw from the project before its analysis step, no further information about you will be collected for the project, and any data collected will not be used and will be destroyed.

Your withdrawal is completely independent to that of your family member.

You should however be aware that where your information has already been analysed and/or the results published, it may not be possible for your information to be withdrawn from the project or destroyed. In such circumstances, your information will continue to form part of the project records and project results. Your privacy will continue to be protected at all times.



Withdrawing from the project will have no bearing on the medical care your family member receives.

6. Who is organising and funding the project?

The project is being run by a team headed by A/Prof Steve Milanese from the University of South Australia. The project is funded by the Digital Health CRC.

7. Are there risks to me in taking part in this project?

Participation in this project should not cause you any discomfort however everyone's experience is different. Whilst the researchers are only seeking reliability data, you are still being prompted to reflect on your relative's levels of 'happiness' and quality of life which may be upsetting. If you find anything stressful or upsetting you can stop at any time. BeyondBlue is a free counselling and support service should you wish to talk to someone about your concerns: 1300 22 4636.

The research project is completely independent from the delivery of care in the facility. You can withdraw from the project at any time for any reason with no impact on the current care your family member receives.

8. Will I benefit from the project?

There is no direct benefit to the participant, their family member in residential aged care or the research team. The only potential future benefit of the project is improved information about care quality to future residents of aged care.

9. How will my confidentiality be protected?

The facility will not be told that your family member is participating or if you choose to participate. Your privacy, and that of your family member, will be maintained at all times. Since family data collection is undertaken remotely the assignment of a study ID to enable de-identification will be undertaken after survey responses are submitted. In the first instance, family members are asked to provide their name, resident name, facility and room number are recorded so that they can be matched to the corresponding resident participants. However, all survey responses are entered using an anonymous PIN that is provided. Identifying information is destroyed shortly after data collection step is complete. The de-identified survey response information will be securely stored on a password protected secure server and only anonymous and collated results will be presented when reporting the findings of the project.

10. What happens with the results?

The UniSA project team plan to discuss the deidentified results with the Health Research Ethics Committee for monitoring purposes; and with CarePage, the company



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Human Research Ethics Committee
PARTICIPANT INFORMATION SHEET

who own the HLI for quality improvement activities. They also plan to publish the results in scientific journals, presentations at conferences and other professional forums as appropriate at a later date. In any publication, information will be provided in such a way that you cannot be identified. Results of the project can be provided to you, if you wish, by contacting the principal researcher.

11. What if I have questions regarding this project?

If you have any questions, please contact your local RACF care staff or the project team:

A/Prof Steve Milanese
steve.milanese@unisa.edu.au
08 8302 1053

12. Who should I contact if I have concerns about the conduct of this project?

This project has been approved by the University of South Australia's Human Research Ethics Committee (Ethics Protocol 203995). If you have concerns or complaints about the conduct of this project you should contact Tel: 08 8302 6330; Email: humanethics@unisa.edu.au

This information sheet is for you to keep.