

## Exploring the impact of coronavirus related closures of social care services on the lives of people with dementia and family carers.

### SURVEY INFORMATION SHEET

**Chief Investigator: Dr Katarzyna Lion**

*Menzies Health Institute Queensland, Griffith University*  
07 373 58440 [k.lion@griffith.edu.au](mailto:k.lion@griffith.edu.au)

**Co-Investigators:****Prof. Wendy Moyle**

*Griffith University*  
07 3735 5526  
[w.moyle@griffith.edu.au](mailto:w.moyle@griffith.edu.au)

**Dr Monica Cations**

*Flinders University*  
08 8201 3058  
[monica.cations@flinders.edu.au](mailto:monica.cations@flinders.edu.au)

**Ms Jenny Murfield**

*Griffith University*  
07 373 57855  
[j.murfield@griffith.edu.au](mailto:j.murfield@griffith.edu.au)

**Ms Lihui Pu**

*Griffith University*  
07 373 53812  
[lihui.pu@griffithuni.edu.au](mailto:lihui.pu@griffithuni.edu.au)

**Ms Sally Day**

*Flinders University*  
02 9351 9172  
[sally.day@flinders.edu.au](mailto:sally.day@flinders.edu.au)

### Why is the survey being conducted?

The purpose of this survey is to explore the effects of coronavirus related closures of social care services on the lives and well-being of older people, people with dementia, and unpaid carers.

### What does the survey involve?

The study involves you completing an online survey three times over 12 weeks. The first time you complete the survey will take approximately 45 minutes, and the second and final time will take up to 30 minutes. We will ask questions about you (i.e. gender, ethnicity, type of dementia) and about your use of social support services (i.e. what type of services did you accessed? do you self-isolate? how often do you meet with your family/friends? How do you assess your memory?)

Alternatively, a telephone conversation can be scheduled, instead of completing the survey on-line, after contacting the research team. During the survey conducted over the phone, the researcher will make sure that you feel comfortable i.e. they will repeat questions and answers as many times as you need to help you to understand so that you can chose the most appropriate one; you can also skip a question you do not want to answer.

### Who can participate in this survey?

This survey is open to older people (aged 65 years or older) from Australia, people living with dementia and informal carers of people living with dementia (or older people). Participants need to read and write in English and want to contribute to the study about COVID-19 related changes in social care service closures.

### The expected benefits of the research

By taking part in the survey, you can share your experiences of social care service closures on your life and on your well-being, helping raise awareness of the effects that the coronavirus might have on the daily lives of those usually benefitting from social support services.

## **Risks to you**

There are no disadvantages to you participating in the survey. You will be asked to give up some of your time to participate in the survey, which will last between 30 and 45 minutes. There are no direct risks to participants. As you will be completing the questionnaire from your own home you will be in your own safe environment. The nature of the questions should not cause you any distress. However, if you feel distressed after the online survey, you can also contact support organisations like Lifeline on 13 11 14 or National Dementia Helpline on 1800 100 500 for free and confidential counselling.

## **Your consent**

Completion and submission of the survey online and via telephone implies your formal consent to take part in the research. It also permits your responses, including any written comments, to be reported and/or published in a non-identifiable way in research outputs.

## **How will we use any personal information?**

### **What is Personal Information?**

Personal information is defined as information or an opinion, including information or an opinion forming part of a database, whether true or not, and whether recorded in a material form or not, about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion. Personal Information can be almost any information that is associated with an identifiable living individual. It can include a name, address, date of birth, gender, correspondence, audio recordings, images, alpha-numerical identifiers and combinations of these.

### **How are we going to use your Personal Information?**

We will ask for your initials, day and month of your birth to be able to compare the data obtained when you filled the survey for the first, second and third time. We will request your contact details (e-mail address or telephone number) to remind you to fill the survey the second and the third time. After completing the 3<sup>rd</sup> survey we will delete your personal information. Your name will not be reported in any research publications or outputs arising from the study.

There is an option for you to be contacted after the study if you wish to receive information about what we find from the survey. You can register for this at the end of the survey. In this instance, your contact details will be stored separately from your submitted survey, so that you cannot be linked in any way to your survey responses and will preclude any identification by third parties.

### **Who are we going to give this Personal Information to?**

Your survey responses will be available only to the named research team identified on the informed consent materials. Researchers from the University of Liverpool (the UK), Wroclaw Medical University (Poland) and the University of Bologna (Italy) may be granted an access to the research analysis to enable comparison between countries.

### **How will this Personal Information be stored?**

All data will be entered into an electronic database that will be kept in a secure Griffith University research data drive, and any hard copies will be stored in a locked cabinet within a restricted access area at Griffith University (Nathan campus, Australia). All data will be

retained for five-years from the end of the project or, if later, the date of the last publication. It will then be shredded and disposed of using a secure confidential document disposal service.

Your personal contact details (initials/day and month of birth as well as e-mail address or mobile phone) will be collected at the end of the survey. These are required to contact you in 6 and 12 weeks to ask you to fill the survey again and to match your responses. Please note that storage of all electronic data is within the cloud (we are using GU system called LimeSurvey) and, as a result, this information may be stored overseas. Griffith University has entered into arrangements that protect the privacy of this data; however, any data stored outside of Australia may be subject to compulsory access through process of law, under the relevant jurisdiction in which it is stored.

### **Your participation is voluntary**

Completion of this survey is entirely voluntary. You do not need to answer every question unless you wish to do so, and you are free to stop or withdraw from the survey at any time, without penalty.

### **Questions / further information**

For further information, or if you have any questions, please contact:

**Dr Katarzyna Lion**, Chief Investigator

07 373 58440; k.lion@griffith.edu.au

### **The ethical conduct of this research**

Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Human Research. If you have any concerns or complaints about the ethical conduct of this research project, please contact: The Manager, Research Ethics, Office for Research, Bray Centre, Nathan Campus, Griffith University (Tel: 07 3735 4375 or research-ethics@griffith.edu.au).

### **Feedback to you**

We will produce a 1-2-page lay summary of the findings, which we are happy to send to you. If you opt in to receive a summary of our findings at the end of the survey (optional), you will receive a copy. Alternatively, you are free to contact the research team to receive a summary of the findings and can do so without explanation for your request.

### **Privacy Statement**

As outlined elsewhere in this information sheet, your deidentified personal information may be transmitted, stored or appear in the publications/reports arising from this research that may be available to overseas recipients. This is occurring with your consent. Any additional personal information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes, including publishing openly (e.g., in an open access repository). However, your anonymity will at all times be safeguarded, except where you have consented otherwise. For further information consult the University's Privacy Plan at <http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan> or telephone 07 3735 4375.