

Participant Information Sheet/Consent Form

Title	Consumer views of aged care in-home support services
Principal Investigator	Dr Sarah Russell
Associate Investigator(s)	Professor Velandai Srikanth, Dr Kristy Siostrom, Mr Iain Edwards

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called Consumer views of aged care in-home support services. You have been invited because you have been approved for a Home Care Package. Your contact details were obtained Community Health at Peninsula Health.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

The aim of the study is to investigate firsthand experiences of in-home care for older people who have a Home Care Package or use Commonwealth Home Support Program. We want to know what is working well, and what is not working well. We also want to hear your suggestions about how home care services can be improved. This information will help Home Care Packages and Commonwealth Home Support Program to better meet people's needs.

3 What does participation in this research involve?

If you decide to take part in our study, you will be asked to participate in a face-to-face interview in your own home. The interview will last about 30-45 minutes. The interview will take place at a time that suits you.



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During this interview, you will be asked to talk about your experiences of home care. With your consent, the interview will be tape-recorded so that we can ensure what you say is recorded accurately.

You will be asked to reflect on both positive and negative aspects of home care. What do you like about home care? What don't you like? How could things be done better?

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way. There are no costs associated with participating in this research project, nor will you be paid.

4 Other relevant information about the research project

There will be 40 people participating in this study.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine care, your relationship with professional staff or your relationship with Peninsula Health.

6 What are the possible benefits of taking part?

We cannot guarantee that you will personally benefit from this research; however, a potential benefit is you will be contributing to research that may help to improve the future delivery of Home Care Packages and Commonwealth Home Support Program.

7 What are the possible risks and disadvantages of taking part?

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

8 What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. If you do withdraw, you will be asked to complete and sign a 'Withdrawal of Consent' form; this will be provided to you by the research team.

9 Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as the principal researcher becoming unwell.



10 What happens when the research project ends?

A copy of the final report will be mailed to you in January 2019.

Part 2 How is the research project being conducted?

11 What will happen to information about me?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. The personal information that the research team collect and use will be the transcript from the recorded interview.

Any information obtained in connection with this research project that can identify you will remain confidential and be securely stored. Your contact details will only be kept with your permission so we can send you a copy of the final report about the project.

Your information will only be used for the purpose of this research project. The data you provide will be permanently de-identified; this means that it will not be possible for the researcher to match recorded interviews to particular individuals.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, you will be referred to by a pseudonym.

In accordance with relevant Australian and/or Victorian State privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

12 Complaints and compensation

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact: Ms Lee-Anne Clavarino from the Research Office at Peninsula Health. Ms Clavarino's contact details are: Phone 9784 2679 or Email: LClavarino@phcn.vic.gov.au

13 Who is organising and funding the research?

This project has been funded by a grant from the Commonwealth Department of Health. The researcher is independent. She has no affiliation with the government or any provider of home care services.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).

The ethical aspects of this research project have been approved by the HREC of Peninsula Health.



This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

If you would like further information, please do not hesitate to contact Dr Russell by phone or email.

Research contact person

Name	Dr Sarah Russell
Position	Principal Researcher
Telephone	9489 5604 or 0435 268 357
Email	sarahrussell@comcen.com.au

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	Peninsula Health
HREC Executive Officer	<i>[Name]</i>
Telephone	<i>[HREC Executive Officer Phone number]</i>
Email	<i>[HREC Executive Officer Email address]</i>

Local HREC Office contact

Name	Ms Lee-Anne Clavarino
Position	Manager, Office of Research
Telephone	9784 2679
Email	LClavarino@phcn.vic.gov.au

Consent Form - *Adult providing own consent*

Title Consumer views of aged care in-home support services

Principal Investigator Dr Sarah Russell

Associate Investigator(s) Professor Velandai Srikanth, Dr Kristy Siostrom, Mr Iain Edwards

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) _____

Signature _____ Date _____

Declaration by Researcher[†]

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher[†] (please print) _____

Signature _____ Date _____

[†] An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation – *Adult providing own consent*

Title Consumer views of aged care in-home support services

Principal Investigator Dr Sarah Russell

Associate Investigator(s) Professor Velandai Srikanth, Dr Kristy Siostrom, Mr Iain Edwards

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine care, or my relationships with the researchers or Peninsula Health.

Name of Participant (please print) _____

Signature _____ Date _____

In the event that the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher[†]

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Researcher (please print) _____

Signature _____ Date _____

[†] An appropriately qualified member of the research team must provide information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.