

Participant Information Sheet

Project title:	Sustaining and enhancing Quality of Life for people in later life, through personalised computer-based models and sensor-driven data capture
Principal investigator:	Professor Jacques Fleuriot
Researcher collecting data:	Longfei Chen, Ricardo Contreras
Funder (if applicable):	Advanced Care Research Centre

This study was certified according to the Informatics Research Ethics Process, reference number 558534. Please take time to read the following information carefully. You should keep this page for your records.

Who are the researchers?

Jane Hillston, Professor, School of Informatics

Jacques Fleuriot, Professor, School of Informatics

Bob Fisher, Professor, School of Informatics

Ram Ramamoorthy, Professor, School of Informatics

Longfei Chen, Research Associate, School of Informatics

Ricardo Contreras, Research Associate, School of Informatics

All researchers are collectively referred as the Integrated Technologies of Care team members.

What is the purpose of the study?

The purpose of the study is to identify the characteristic behaviours of an individual in later life, their preferences and needs, and to capture data about their Activities of Daily Living (ADLs) and other daily routines. Here ADLs are defined as tasks that an individual performs daily. For simplicity, we will just call them Activities for the rest of this information sheet. In the study, events are captured using unobtrusive sensors and/or cameras. This data will support a combination of quantitative and qualitative analyses which will ultimately allow the development of rich, person-centred,



computer-based models that aim to sustain/enhance quality of life for people in later life through the development of models that will allow the detection of change in a person's pattern of Activities.

Why have I been asked to take part?

The research target group is people in later life and carers providing services to people in later life. Participation in the study will allow researchers to better understand what forms of data collection are acceptable and effective.

Do I have to take part?

No – participation in this study is entirely voluntary. You can withdraw from the study at any time, up until the last visit without giving a reason and your data will be deleted. After this point, personal data will still be deleted but your anonymised data will be combined in a way such that it will be impossible to remove individual information from the analysis.

Your rights will not be affected. If you wish to withdraw, contact the PI. We will keep copies of your original consent, and of your withdrawal request.

What will happen if I decide to take part?

If you are a person in later life and you have agreed to be interviewed.

If you are a person in later life, a semi-structured interview will be conducted prior to the installation of the devices and a second after the data collection process is finished. These interviews will ask about the activities you perform as part of your daily routine, and the associated needs, present and future.

Interviews will be carried out by a researcher and are expected to last up to an hour but will be adjusted in length and complexity to suit your needs and preferences. With your permission, interviews will be audio recorded to ensure all information is accurately captured. The recordings will be deleted once they have been transcribed and the data has been encoded and anonymised. Your responses will be combined with that of other volunteers, so that no personally identifiable information will be kept. This is to preserve your privacy.



In the first interview, the researcher will ask you about your Activities and other daily routines, the context in which these are performed and any needs you may have. The researcher will also ask you about your general sense of well-being and any Activities you might like to include in your daily routine in the future. If you agree to have the camera or sensors in your home for a period, there will be a second interview when the equipment is removed, and possibly a third interview a month later. These last two interviews will be about your experiences and thoughts about the monitoring.

If you are a person in later life and you have agreed to keep an Activity logbook.

The researcher will also ask you whether you would like to use an Activity logbook to record when Activities are performed during the data collection phase.

If you agree to keep a record of your daily activities over the study period, a logbook will be provided. This will be a paper-based document although, depending on availability, we may provide a digital logbook (e.g., a basic tablet), if you prefer. The physical logbook will be split by day, with boxes where you can record times and locations of the Activities. The digital logbook will take the form of a phone/tablet application that captures information about Activities by clicking on pre-specified ones, with an option for typing in additional activities. For both types of logbooks, you will also be given the option of recording your sense of wellbeing on the day.

It would be perfect if you recorded the day, time, and length of time whenever you finished an activity. However, do not worry if you forget, or if you find this too demanding. It is fine to only keep records sometimes or to stop at any time.

If you are a person in later life and you have agreed to have ambient sensors installed in your home.

We will show you the available sensors and talk about them at the first interview. These are all small, battery-powered and wireless. You can choose to have some or all of these installed.

Magnetic contact sensors	Doors, cupboards, drawers, etc. being opened/closed
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Motion sensors	Movement within a designated space e.g., room
Smart plugs	Appliances e.g., TV being turned on/off

The researcher will install sensors in one or more rooms in your home, respecting your privacy and any other constraints you may have. The sensors will be installed in a way that does not damage your home and are not a safety risk. These sensors will be installed following the first interview at a date and time convenient to you and will capture data for an agreed period, typically one to three months, depending on your preferences and willingness.

The sensors will be fixed in place using double-sided, removable tape or inserted between power sockets and plugs for electrical devices, to prevent damage to property. These sensors will be used to capture your actions when performing your daily activities. The type of ambient sensors intended to be used in this study include magnetic sensors that will detect things like doors or cupboards opening and closing, motion sensors that will detect movement, and smart plug power consumption devices.

Additional visits will be arranged as required at a time convenient to you for sensor removal and/or repair. As part of these visits the researcher will perform upkeep of the sensors to ensure their proper functioning. A small power-efficient computer, looking like a small box, will be connected to a power supply to collect the data from the different sensors. All data captured by the sensors will be anonymised. This ensures that no personal identifiable information from you, such as name or location, will be included in the collected data. As mentioned above, your data will be combined with that of other volunteers so that it will not be possible to identify you.

You can stop data collection at any time by pressing the power button until the lights on the box are off; this will shut down the computer. You can restart data collection by pressing the power button; this will turn the computer back on (the lights on the box will turn on).

At the end of the data collection period, based on your availability, the researcher will conduct another interview to collect your thoughts, opinions, and any concerns that



were triggered by the monitoring and/or the devices. This will be done with the aim of gaining further insights into your perceptions, feelings, and overall experience.

If you are a person in later life and you have agreed to have a camera installed in your home.

For the camera-based sensor, the researcher will visit your home to install the camera system. The camera system will monitor your movements as you sit on a couch or your favourite chair. This camera will be placed to capture the designated area (with some adjustability) and is connected to a small computer through a cable. The camera will be fixed in place using paper tape or a tiny tripod stand in such a way to be out of the way, and to not damage the room. The low amount of power needed for the system will be supplied via an electric socket. We estimate that the system will use about £2 of electricity for a month of use, which you can claim back. The system will be running continuously and automatically without any interaction with the participants. It will focus on the person occupying the couch or chair, capturing their behavioural patterns for subsequent analysis by the processor. Following the extraction of behavioural and environmental features, the camera video data will be promptly deleted. The sole remaining records will consist of descriptions of the motion. This data will be stored locally and anonymously, devoid of any internet connectivity. No personal information about the participants will be retained. Any identifiers, such as ID, name, face, and location, will be removed, and the data will be referenced solely by a unique participant ID.

You have the right to pause the system by pressing the power button on the box processor, unplugging the power cable, or covering the camera with objects like a cloth at any time you do not wish to be monitored.

Upon the completion of the monitoring period, the system will be taken away. There might be occasional visits to ensure that the camera is working correctly. We will arrange these visits at a time convenient to you.

If you are a person in later life and you have agreed for your carer to be interviewed.

If you have agreed for your carer to be interviewed, we will interview them if they consent to take part in the study. They will be asked about the Activities you perform



as part of your daily routine. This will include the support you are given, any unforeseen situations that may have required their assistance, and their perception of your overall healthiness and fitness. You may decide with your carer on the aspects of your care they are allowed to share with us.

If you are a carer and you have agreed to participate in interviews.

If you are a carer of someone who has consented for us to speak to you concerning their Activities, one semi-structured interview will be conducted to elicit information concerning their behaviour and their associated needs, present and future. We will be collecting identifiable information about the people in your care.

The researcher will ask you about i) the Activities support given to the person(s) in your care, ii) any episodes (and how often they seem to occur) leading to the occurrence of unforeseen situations that require your assistance/intervention, iii) overall healthiness and fitness of the person(s) in your care. The researcher will also ask for any additional information you feel comfortable sharing (e.g., about your perception of frailty, loneliness, isolation, etc.) that may complement our understanding of Activities of the person in your care. You may agree beforehand with the person in your care on the information that can be shared. Both your identity and that of the supported person will be anonymised in such a way that neither are identifiable.

Interviews will be carried out by a researcher and are expected to last up to an hour but will be adjusted in length and complexity to suit your preferences. With your permission, interviews will be audio recorded to ensure all information is accurately captured. The recordings will be deleted once they have been transcribed and the data has been encoded. The interviews will take place in a location chosen by you, such as a community centre, park, or your home.

Compensation. [only required if applicable]

There is no compensation for participating in the study.

Are there any risks associated with taking part?



There are no anticipated risks associated with participation.

Are there any benefits associated with taking part?

No

What will happen to the results of this study?

The results of this study may be summarised in published articles, reports and presentations. Quotes or key findings will be anonymized: We will remove any information that could, in our assessment, allow anyone to identify you. With your consent, information can also be used for future research. Your data may be archived for a maximum of four years. All potentially identifiable data will be deleted within this timeframe if it has not already been deleted as part of anonymization.

Data protection and confidentiality.

Your data will be processed in accordance with Data Protection Law. All information collected about you will be kept strictly confidential. Your data will be referred to by a unique participant number rather than by name. Your data will only be viewed by the Integrated Technologies of Care research team members.

All electronic data will be stored on a password-protected encrypted computer, on the School of Informatics' secure file servers, or on the University's secure encrypted cloud storage services (DataVault), where they will only be accessible to the researchers. All paper records will be stored in a locked filing cabinet in the PI's office. Your consent information will be kept separately from your responses to minimise risk.

What are my data protection rights?

The University of Edinburgh is a Data Controller for the information you provide. You have the right to access information held about you. Your right of access can be exercised in accordance Data Protection Law. You also have other rights including rights of correction, erasure and objection. For more details, including the right to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk. Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer at dpo@ed.ac.uk.



Who can I contact?

If you have any further questions about the study, please contact the lead researcher, Jacques Fleuriot, jdf@ed.ac.uk.

If you wish to make a complaint about the study, please contact inf-ethics@inf.ed.ac.uk. When you contact us, please provide the study title and detail the nature of your complaint.

Updated information.

If the research project changes in any way, an updated Participant Information Sheet will be made available on <http://web.inf.ed.ac.uk/infweb/research/study-updates>.

[NB: the PI should notify the Ethics panel on inf-ethics@ed.ac.uk to upload any updated PIS to the website]

Alternative formats.

To request this document in an alternative format, such as large print or on coloured paper, please contact Jacques Fleuriot, jdf@ed.ac.uk.

General information.

For general information about how we use your data, go to: edin.ac/privacy-research

