

Participant Information Sheet

Care Planning – Developing a guide for the family and friends of care home residents

University of Kent Ethics Committee Approval Reference: 1006, approved on 09/04/24

We would like to invite you to participate in a focus group. Before you decide, it is important for you to understand why the focus group is being conducted and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask if there is anything that is not clear or if you would like more information.

Why is the research being conducted?

Care homes in England are legally required to develop a 'clear care and/or treatment plan, which includes agreed goals' and make this document 'available to all staff and others involved in providing the care'. The Care Quality Commission (CQC) has defined care planning as a process 'focused on the person's whole life, including their goals, skills, abilities and how they prefer to manage their health'. According to the CQC, Care Planning should 'empower [people] to make choices and have as much control and independence as possible'. We understand from speaking to care home staff that care plans' contents can vary considerably as can the involvement of care home residents and their family or friends. Therefore, this study aims to gather feedback from care home residents' friends or family members about a short document relating to care planning.

Who is conducting this project?

The project is being conducted by researchers based at the University of Kent, the University of Bristol, the University of Liverpool, the University of Oxford and the London School of Economics and Political Science. The Principal Investigator is Dr Nick Smith.

Why have I been sent this information sheet?

You have been sent this information sheet because you have a family member or friend aged over 65 who is currently living in a care home in England, or who has lived in one within the past 12 months.

Do I have to take part?

No. It is up to you to decide whether or not to take part. You can ask questions about the project before deciding whether or not to participate. If you do agree to participate, you may withdraw at any time, without giving a reason, by advising the researchers of this decision. If you decide to withdraw from the study after the focus group has been held, we will be able to destroy the data that you have provided via your consent form and will ensure that your data are not quoted when the study is reported. It will not be possible, however, to remove your data from the audio recording or the accompanying transcript.

What will happen to me if I decide to take part?

If you would like to take part in this project, please contact Jonathan Taylor on jonathan.taylor@ndph.ox.ac.uk. Jonathan, or another member of the research team, will then arrange a brief phone call to explain a bit more about the project and answer any questions that you may have.

If, having spoken to a member of the research team, you wish to take part, you will be invited to participate in a focus group which is expected to last 60 minutes. This focus group will take place online using MS Teams. Before attending the focus group, you will be:

- Asked to provide informed consent and provided with a copy of your consent form.
- Provided with a draft document relating to care planning.
- Asked to provide some information about yourself - such as your age and your relationship with the person in resident care - through an online survey. When answering these questions, you will be able to select a “prefer not to say” option.

The focus group will involve other people who are friends or family members of a care home resident. With your consent, we will record the group discussion. This is to help us keep an accurate record of the discussion and assist in analysing and writing up our project.

During the focus group, we will ask about:

- Your views and feedback on the draft document relating to care planning that will be provided to you before the focus group.

What are the disadvantages / risks of taking part?

The risks in taking part in this project are very low. There is a small risk that you may find some of the questions upsetting as contributing to a care plan may be challenging. The researchers will provide you with information of where to seek further support.

None of your personal data will be linked with any quotations used in reporting the findings of this project and information about you would only be disclosed in the very rare circumstance that you or someone else was judged to be at immediate risk of serious harm.

What are the possible benefits of taking part?

There will be no personal benefit to you. Benefits to the wider community would reflect the impact of the research such as improving care homes’ care planning practices.

Expenses and payments

Eligible participants who read the document and join the focus group will receive a £30 voucher as a thank-you for their participation.

Where will the focus group be conducted?

The focus groups will be conducted online. A researcher from one of the participating universities will contact you to arrange a suitable day and time.

What will happen to the data provided?

The recordings will be made on an encrypted Dictaphone. Audio files will be transferred by the researcher to secure, University of Oxford servers, and deleted from the portable device as soon as is practical.

The data collected will be typed up word by word by a professional transcriber with a confidentiality agreement with the University of Oxford. The typed documents (transcripts) will be securely returned to the research team, have all personal information removed (i.e. anonymised), and stored electronically in secure internal computer drives. Upon receipt of the transcripts, the researchers will listen to the recordings and make any necessary amendments to the transcripts to ensure anonymity. Once this is done, the audio recordings will be deleted.

Any information from which you can be identified, such as your name or contact details, is known as personal data. Care will be taken to ensure that your personal data are safe. Consent forms will be stored in electronic format. Electronic consent forms will be stored on a secure University of Oxford server that will only be accessible to the researchers. Consent forms will be destroyed three months after the study has finished. Your contact details will be stored confidentially in secure University of Oxford internal computer drives and destroyed securely at the end of the project.

The transcripts will be fully anonymised, meaning any personal information will be removed. These transcripts, known as research data, will be retained and may be used by the research team for future relevant research purposes. This helps to ensure that data usage can be maximised, thereby increasing the likely impact of the research, without placing undue burden on research participants by asking them to participate in similar studies.

Your personal data will not be included in any reports, publications or presentations of the project findings. We would like your permission to use direct quotes from your interview, and these will be anonymised. The project team and designated professional transcriber will have access to the personal and research data. Research data may also be accessed by authorised personnel of the University of Oxford for audit purposes.

Archiving the data

We believe that the focus group will be an important source of information for future researchers. For this reason, we would like to send the transcript of the focus group to an organisation called the UK Data Service (UKDS). Information shared with the UKDS can only

be accessed and used by approved users, for example researchers working at other universities. You can still participate in this study even if you don't want us to share your data with UKDS. If you do not consent to your focus group contributions being shared with the UKDS, and other focus group participants do consent to share their contributions with the UKDS, we will remove your focus group contributions from the transcript before sharing it with the UKDS.

Data Protection

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study. The University will process your personal data for the purpose of the project outlined above. Research is a task that is performed in the public interest. Further information about your rights with respect to your personal data are available from: <https://compliance.admin.ox.ac.uk/>

Will the project be published?

We plan to publish a finalised key principles guide on care planning at the end of the project. The project findings may be published in academic journals and presented at conferences. Participants and quotations will remain anonymised (meaning you cannot be identified) in all reports, presentations and publications of findings, and any other information (e.g. geographical location, place of work) which could help identify you will also be removed.

Who is funding the project?

This project is being conducted by researchers at the University of Kent, the University of Bristol, the University of Liverpool, the University of Oxford and the London School of Economics and Political Science. The study is funded by the NIHR ARC National Priority Programme: <https://arc-kss.nihr.ac.uk/npp-adult-social-care-social-work>

Who has reviewed this project?

This project has been reviewed by and received ethics clearance from the Division for the Study of Law, Society, and Social Justice School Research Committee (SRC) Ethical Panel at the University of Kent (Ethics reference: 1006, approved on 9/04/24).

Who can I contact if I have a concern about the project or I wish to complain?

If you have a concern about any aspect of this study, please speak to the Principal Investigator (Nick Smith, email N.J.Smith@kent.ac.uk), who will do his best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact Tegan Coleman who will seek to resolve the matter as soon as possible:

Email: T.Coleman-581@kent.ac.uk

Address: Tegan Coleman, Senior Research Ethics and Governance Officer, The University of Kent, Canterbury, Kent, CT2 7NZ

Further Information and contact details

If you would like to take part or discuss the project with someone beforehand (or if you have any questions afterwards), please contact Jonathan Taylor (Tel: 01865 617912, email jonathan.taylor@ndph.ox.ac.uk) at the University of Oxford.