

Participant Information Sheet

Care Planning: Developing a set of key principles

Ethics reference: 1006, approved on 9/04/24

We would like to invite you to complete two online surveys to provide us with feedback on an information resource that we have developed. Before you decide whether you would like to participate, it is important for you to understand what this research will involve. Please take time to read the following information carefully and talk to others about the study if you wish. If there is anything that is not clear or if you would like more information, please contact us using the details at the end of this document.

Why is the research being conducted?

English care homes 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 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 on a draft "key principles" 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 Nick Smith.

Why have I been sent this information sheet?

You have been sent this information sheet because you have knowledge and/or experience of care planning in older adult care homes in England, and are aged 18 years or older.

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.

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

The table below sets out the steps involved in this research.

1. You will be sent a draft “key principles” document.	<p>This document contains seven sections relating to care planning.</p> <p>It is important to refer to this document while completing the survey. If you would like to receive a hard copy of this document please contact Jonathan Taylor (Tel: 01865 617912, email: jonathan.taylor@ndph.ox.ac.uk) who can arrange for this to be posted to you.</p>
2. You will be sent a link to the first online feedback survey and a briefing document which will provide a bit more background information	<p>The briefing document will explain how the draft “key principles” document has been developed and how to complete the survey. The survey will ask you about each of the sections presented in the draft document. You will be asked to rate the information provided using a five-point Likert scale, ranging from ‘not at all important’ to ‘extremely important’. You will also be asked to provide written feedback through a series of free text boxes.</p> <p>If you would prefer, you can provide feedback over the telephone or by emailing your responses to the survey as a Word document.</p> <p>Contributors will have four weeks to provide their feedback and can complete the online survey in multiple sittings.</p>
3. Review feedback and revise the document	<p>The research team will analyse the feedback received through the online survey and amend the “key principles” document accordingly.</p>
4. You will be sent updated documents	<p>You will be provided with:</p> <ul style="list-style-type: none"> - A revised “key principles” document - An explanation of the changes that have been made - A copy of your answers to the first survey - A summary of other people’s responses to the first survey <p>It is important to refer to the revised “key principles” document while completing the survey. If you would like to receive a hard copy of this document please contact Jonathan Taylor (Tel: 01865 617912, email: jonathan.taylor@ndph.ox.ac.uk) who can arrange for this to be posted to you.</p>
5. You will be sent a link to a second online feedback survey	<p>The survey will ask you about each of the sections presented in the revised document. You will be asked to rate the information provided using a five-point Likert scale, ranging from ‘not at all important’ to ‘extremely important’.</p> <p>If you would prefer, you can provide feedback over the telephone or by emailing your responses to the survey as a Word document.</p> <p>Contributors will have four weeks to provide their feedback and can complete the online survey in multiple sittings</p>
6. Review feedback and, if necessary, revised the document	<p>The research team will analyse the feedback received through the online survey and amend the document accordingly.</p>

Following step 6, the revised “key principles” document will be shared with residents’ family and friends. Their feedback will be gathered through a series of focus group discussions groups with a view to developing a related document for the family and friends of care home residents. With your consent, we are happy to provide you with a copy of the finalised “key principles” document. You can still take part in this research even if you do not consent to being contacted, after the second round of the survey has been completed, with information about the project.

What are the disadvantages / risks of taking part?

The risks in taking part in this study are very low. There is a small risk that you may find some of the questions upsetting as being involved in care planning may be challenging. While completing the online survey you can take a break or withdraw at any time.

Any of your personal data will not 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

You will be offered a £25 voucher for each survey that you complete. You can complete a maximum of two surveys and receive a total of £50 in vouchers. The research team reserves the right to withhold one or more vouchers if they reasonably believe the survey response has been fraudulently submitted.

How will the research be conducted?

The survey will be conducted online. If you would prefer, you can provide feedback over the telephone or by emailing your responses to the survey as a Word document, these responses will then be input into the online survey.

What will happen to the data provided?

To safeguard your rights, we will use the minimum personally identifiable information possible, and act according to the principles of the General Data Protection Regulation (GDPR) as outlined in the University Privacy Notice (GDPR Privacy Notice). All data are kept on password-protected databases sitting on a restricted access computer system. Your research data may be used 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. Research data may also be accessed by authorised personnel of the University of Kent for audit purposes.

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 Kent server that will only be accessible to the researchers. Consent forms will be stored for 3 months and then securely destroyed. Your contact details will be stored confidentially in secure University internal computer drives and destroyed securely at the end of the project.

We believe that your survey responses will be an important source of information for future researchers. For this reason, we would like to send the survey responses 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.

Data Protection

The University of Kent 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 is available from [Data Protection Rights and Subject Access Requests - Assurance and Data Protection - University of Kent](#).

Will the project be published?

We plan to publish a finalised "key principles" document 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 Research Committee 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.