



Measuring and Improving Care Home Quality

Information for Family members acting as Personal Consultees

Why have I been sent this information?

The Brighton and Sussex Medical School (BSMS), in partnership with Personal Social Services Research Unit (PSSRU) at the University of Kent and the School of Education and Social work at the University of Sussex is conducting a study about the quality of life of care home residents. We are interested in finding out how care homes manage pain, anxiety and depression and exploring whether this has a positive impact on residents' quality of life. To do this well, we are hoping to include as many care home residents as possible, including those who have dementia and those who might be unable to speak for themselves. If we do not include people with dementia, or people who are very frail in the study, we will not be able to judge how well the care home is meeting their needs.

You have been sent this information because your family member, or the person you represent, lives in a care home that is taking part in a research study and lacks the capacity to give his or her own informed consent. We would really like to include this person in the research because we think it is important that research evaluates how well care homes are meeting everyone's needs, not just the most able who can tell us themselves.

What is a personal consultee?

The Mental Capacity Act requires us by law to seek the advice of an appropriate personal consultee on occasions like this. Usually this is a close family member or friend. The care home suggested that you would be the best person to fulfil this role. We are asking you for advice: *In your opinion, would the person you are representing want to take part in the research, if they could decide for themselves?*

Please be guided by what you know about the person. Try to think about the risks and benefits of taking part. For example, some people like having new people visit them in their home, other do not. As well as asking for your advice, when we visit the home, we will always check that people are happy to talk to us and are comfortable in our

presence. For people lacking the capacity to consent, this is called 'assent' and we will always stop if we think this has been withdrawn.

What will happen during the research?

We will use the **Adult Social Care Outcomes Toolkit (ASCOT)** to measure care home residents' quality of life. ASCOT has been used in care homes many times before and was designed specifically to measure the aspects of quality of life most affected by social care. The research team will be using a version of ASCOT that involves carrying out observations as well as interviews to capture the 'lived experience' of care home residents. This means that everyone can take part, not just those who can tell us how they feel in interviews.

As well as observing and talking to the residents themselves, we will be asking care workers and family members (where available) to tell us about residents' lives, through short interviews and questionnaires. This should give us a full picture of residents' quality of life from different perspectives.

What information do you collect and how?

We will collect information about:

- Residents' symptoms of pain, anxiety and depression.
- Residents' health and care needs, including their ability to perform daily activities, such as eating, washing, using the toilet and dressing. This information is important in helping us understand the results because care homes care for people with a wide range of needs.
- Residents' weekly fees. This is important because care homes charge different amounts and we need to take this into account when we compare results across homes.
- Residents' quality of life through:
 - Conversations with residents: people living in care homes vary enormously in their ability to tell us these things and we adapt our conversations to suit their needs. Some people cannot tell us anything and this is ok.
 - Interviews with staff and, where possible, family members. If you are able and willing to be interviewed, please let us know.

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- Observations: we will conduct a two hour period of observation in the lead up to and including lunch. We will always stop observations if residents appear at all distressed by our presence. We never observe personal care and most of what we observe takes place in communal areas (unless the resident is unable to leave their bed).

The researchers will:

- Talk to the resident about the notes they have taken, if they want them to and are able to understand.
- Leave if the resident asks them to at any time.
- Send the care homes and participants information about the project when it is completed.
- Write to the care home after the visit to thank people for taking part.
- Give the person you are representing a high street gift voucher of £10 as a thank you for taking part in the research.

The research team has a lot of experience conducting research in care homes. Their names, photos and contact details are on the back on this sheet. Madeline Naick and Grace Collins will be the main points of contact and will collect most of the research data. Nick Smith and Ann-Marie Towers will also visit some homes.

What should I do now?

Think about and discuss with the staff and other key people the benefits and risks of your relative taking part in this research. Please bear in mind that we will not observe any personal care in bedrooms or bathrooms. During the observations, if there was any reason to believe your relative was becoming distressed or uncomfortable with our presence, we would stop the observation and leave that area of the home. We have been given ethical approval for this research under the Mental Capacity Act.

Please fill out the form enclosed. You can either send it back to us directly in the pre-paid envelope enclosed, or you can give it to a member of staff or the manager of the home. If you would like to learn more about the study, please feel free to contact the research team (details below).

Will this affect the placement or the quality of care provided?

Not in any negative sense. It will not be used to affect the placement of specific people. We hope that the research will positively affect the quality of support provided for care home residents in the future.

What will happen with the information?

The information that we collect will be analysed and results shared with others to increase knowledge, share learning and have an impact on policy and practice. We will do this by:

- Writing a report for the funder of this research.
- Publishing the findings in academic journals.
- Presenting the results at conferences and commissioner and provider events.
- Sharing summaries of the results with the residents, managers, staff and family members that took part in the research.
- Trying to raise awareness of the results by writing blogs, using social media and linking with local organisations working with care homes.

The researchers will not use individuals' names or the name of their care home in any reports of this work. Names and contact details will not be recorded on information collected through observations, interviews and questionnaires, and or on anything we write about the study afterwards. All identifiable information (e.g. contact name and details) will be kept securely in a locked filing cabinet and discarded 3 months after the study ends. The research data (excluding names and contact details) will be retained in an electronic format by the PSSRU at the University of Kent and could be used by the research team and other researchers in the PSSRU at the University of Kent for other research in the future.

Anonymity will only be waived if someone is at risk from abuse or harm and then we would contact the local authority safe guarding team and possibly the Health and Social Care regulator, the Care Quality Commission (CQC).

Questions about the study

If you have any questions about the study and you would like to speak to a member of the research team please let us know when we visit your home or you can contact us on the details below. [Research team contact details and photos here]

Personal Consultee Declaration Form

Residents' name: _____

Your name _____

Your address/phone number/email address (*we may contact you in relation to this research project. If you would prefer not to be contacted again, please leave blank*):

What is your relationship to the person you are representing (e.g. son/daughter/spouse) _____

If you have talked this through with people before deciding, please list the their names (and their relationship to the person you represent) _____

Please indicate whether or not you think it is OK for the person you represent to be involved in the research

Yes, to the best of my knowledge, the person named above would choose to take part in the research if they could. They would be happy for the researcher to observe them and to ask their keyworker for information about their needs and characteristics. I understand that even though I give this agreement, he/she can choose to withdraw at any time if he/she is not happy with being observed or included in the research.

No, I do not think the person would choose to take part if they were willing to do so.

In signing this form you are confirming that you have read and understood the accompanying information about the study.

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Signed _____

Date _____