



Measuring and Improving Care Home Quality

Study Information for Family Members

What is this study about?

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 community engagement and the quality of life of care home residents. We are interested in finding out how care homes manage pain, anxiety and depression exploring the impact that this has 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.

What does the research involve?

The research team from PSSRU will be visiting the care home in which your relative lives, and will be carrying out observations and interviews in order to see what their quality of life is like. This will only happen in your relative has given consent for us to do this, or if they are unable to consent for themselves, we will have sought advice from a consultee, such as yourself, as to whether they would want to take part.

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.

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.

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 will happen with the information?

The information that we collect will be analysed and the 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.

We will not use your name, the name of your family member 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.

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]