



Measuring Quality of Life in Care Homes

Study Information for Care Home Managers

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 the quality of life of care home residents.

We are using the **Adult Social Care Outcomes Toolkit (ASCOT)** to measure care home residents' quality of life. ASCOT has been used in care homes before and was designed specifically to measure the aspects of quality of life most affected by social care. We are interested in finding out how care homes manage pain, anxiety and depression and exploring the impact that this has on residents' quality of life. 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.

As well as observing and talking to the residents themselves, we will be asking key workers and family representatives (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. Some staff will be asked to help us with this, by completing a questionnaire, taking part in a short interview or helping us contact a family member. This is completely voluntary. Staff don't have to take part in the research if they don't want to and even if they do, they can withdraw at any time.

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 point of contact and will collect most of the research data. Nick Smith and Ann-Marie Towers will also visit some homes.

What does the research involve?

As you have already expressed an interest in working with the research team, we will ask you to complete a short survey about how the home helps residents to manage

pain, anxiety and depression. Information will be collected about the home and the residents who agree to take part using a variety of methods. Before we collect information about residents' quality of life, we will ask you to complete:

- A questionnaire about the needs and characteristics of each resident taking part in the research (e.g. about their health and ability to perform activities of daily living). This information will be completed by staff on behalf of the residents and will remain completely confidential.

Information about residents' quality of life, pain, anxiety and depression will be collected directly by the researchers during a visit to the home. This involves researchers spending up to two days in the home collecting information about participating residents through:

- Two-hour periods of observations. These will be conducted as unobtrusively as possible, causing minimal disruption to the normal routine of those who live and work in the home.
- Interviews with staff; one staff interview per resident that takes part in the research.
- Interviews with the residents, and family members where possible.

Each care home that completes the research, will receive £200. We ask that care homes invoice us for this payment once all data has been collected. Each resident that takes part will also receive a £10 high street voucher as a thank you for their time.

What will happen to the information?

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

- 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 project has ended. 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).

What happens next?

If you are interested in taking part, or have any questions, please send us an email or give us a call (contact details below). If we do not hear from you within the next couple of weeks, we will call you.

If you decide that your care home would like to take part, the first stage would be to agree a date for a meeting so the research team (either one of the researchers on the next page, or a NIHR Clinical Research Nurse) can provide you with the paperwork needed for recruitment. We will ask you to help us recruit at least 10 residents to the research. We will provide instructions of how to choose residents, along with all the consent forms and information sheets needed. For residents who do not have the capacity to give informed consent themselves, we ask that you send out the study information to a personal consultee (most likely a close family member, or someone who knows them well), on our behalf. We ask you to address and post the letters to family members as we will not have access to their contact details. We will provide return-paid envelopes for any completed information. The payment of £200 per home is to thank you for your time helping us with the project and to cover any additional expenses, such as postage.

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 contact a member of the team.

[Research team contact details and photos here]