

"I like the idea that residents have the opportunity to be consulted about their quality of life. It's a good way of gathering information about things that matter." **Resident**

"...feel that it has given the home the opportunity to be transparent as we have nothing to hide" **Staff**

"I'm more than happy to take part in research, especially if it's applicable" **Relative**

"I discussed the research with my mum, and although she didn't understand, she has always been one to want to take part in research and to help people learn more. I feel as though participation in research is something I have gained thanks to my mum. I understand this won't directly change anything now, but I hope to be part of things that will develop for people in the future" **Relative**

South Staffordshire and Shropshire Healthcare **NHS**
NHS Foundation Trust
A Keele University Teaching Trust

Research & Care Homes: A Collaboration

Why do research in care homes?

Half of people with dementia experience symptoms of agitation every month. Symptoms of agitation include restlessness, pacing, shouting and verbal or physical aggression.

Many people with agitation are admitted to care homes as families find they cannot care for them at home. Within the care home, staff also often find managing people with agitation difficult. Agitated behaviour takes up staff time and emotional and physical energy but they do not always know how to respond.

"[It's] good to know that research is being undertaken in this specific area of dementia, feels good to know that this home is involved." **Staff**

The MARQUE Study

The MARQUE study is led by University College London. The South Staffordshire & Shropshire NHS Trust research team recruited 3 care homes where residents with dementia were identified. After the research team obtained informed consent, we asked residents who were well enough about their quality of life. We then asked staff and relatives about the quality of life of the person with dementia, and staff were asked additional questions about levels of agitation, severity of dementia symptoms and about how they cope with caring stresses.



We will return to ask follow up questions 4 times over 16 months. UCL will use the results to test their theory that agitation is an important factor in determining residents quality of life and that the ways staff cope with stress affect the impact that agitation has on quality of life.

The Future

Due to excellent collaboration with SSSFT all 3 care homes said they would be happy to participate in future research, so we will actively aim to involve them in other research studies. When asked about taking part in future research, one resident replied:

"Yes certainly. I really like the idea of having the opportunity to voice my opinion. It's good to be able to give my view point and be consulted about my feelings". **Resident**

Positives

- ◆ Well supported by Trust Community Psychiatric Nurses, they were keen, enthusiastic and facilitated our entry into the homes
- ◆ Interesting environment to work in and each of the 3 care homes were so different
- ◆ The study took a holistic view by getting perspectives from staff, relatives and residents
- ◆ Overwhelmingly positive response from staff and relatives. Staff were able to express how they felt about their caring roles; the confidentiality of the study gave them confidence. None of the relatives withheld their consent, and said it gave them confidence in the care home

"I felt it was an extremely positive thing, keen to be involved in such a positive thing." **Staff**

Challenges

- ◆ The size of the project was daunting but exciting - we recruited **181** participants!
- ◆ Logistics – contacting all the relatives and staff
- ◆ Change of management within the care homes
- ◆ Keeping key staff in the care homes engaged, particularly in view of their conflicting priorities and workloads
- ◆ Sensitivity and changing needs of the client group made SSSFT research team reflect on how we communicated with care home staff and relatives

"...care home had issues throughout the study with staffing levels. Needed to rely heavily on agency staff, so we had to prioritise resident care rather than research" **Staff**

Skills Needed

To make the study a success the SSSFT research team had to have excellent interpersonal skills to communicate with residents, relatives and staff. They had to be very organised, manage their time well and be flexible to accommodate the care homes. Research staff were already very experienced in dementia care, but also received study specific training from UCL.