



Talk to the people who know – consulting widely before starting care home research

We talked to Danni Collingridge Moore, Research Associate, at Lancaster University about her work on the PACE project. The research team consulted a number of stakeholders before starting the project to develop their research tools and overall approach. They expect this to make the study more successful.

Background

The PACE project, a five year programme which began in January 2014, aims to compare the effectiveness of palliative care for elderly people in care homes across Europe. Danni is working on the first stage of the project, which started in September 2014. This stage will involve looking at the palliative care received by 200 residents who have died during the last three months, in a random sample of 50 care homes across England. Questionnaires will be sent to relatives as well as to the GPs and care home staff most closely involved with each resident's care. The overall picture will be compared to the palliative care provided in Belgium, Italy, the Netherlands, Finland, and Poland.

Before starting the project, Danni consulted a number of stakeholders and sources of expert advice. Danni believes, 'Our project is a lot stronger as a result'. This case study summarises the advice and support the PACE team received from a wide range of experts.

The Health Research Authority (HRA)

The team were aware they needed ethical approval, but were uncertain as to where they needed it from - did they come under a social care or an NHS ethics committee? "The quickest way to find out is to ring up and ask! We called the HRA and sent them a copy of our proposal. They told us we needed to go through the NHS. They would be my first point of call from now on," Danni explained. "We also contacted our local ethics committee to say 'When you receive this application you might query whether you need to see it, but we've already checked, and here's the HRA's response'."

Care Home Staff

Danni spoke to senior staff in two care homes, who the team had worked with previously. She discussed the different stages of the project and asked for their feedback on what they thought was feasible. "I only asked for half an hour of their time because they're



Danni Collingridge Moore, Research Associate, at Lancaster University

very busy, but that half an hour was like gold dust for us," Danni explained. The staff provided valuable comments on information sheets and questionnaires as well as making helpful practical suggestions. For example, they recommended sending one of the questionnaires in advance of care home visits, so that staff would have time to collect the information required. They also recommended not approaching homes that were marked 'at risk' by the Care Quality Commission (CQC), because this would be likely to prevent their successful participation.

A research partners' forum

One of the main ethical questions for the team was deciding when would be the best time to contact the relatives of residents who had died. Based on a previous study which had ethical approval, and where the response rate had been high, they assumed waiting until three months after the resident's death would be acceptable. To be certain, they consulted their Research Partners' Forum at Lancaster University. This Forum consists of members of the public who have an interest in research; some also have relatives in care homes. Danni described how they helped, "We explained why we'd decided to wait until three months and asked how they would feel about that. The feedback was positive. They felt that would be appropriate."

The Forum also commented on other aspects of the study that involved relatives. They very helpfully gave feedback on the research documents, for example, rewording the information sheet to make it easier to understand.

GPs

Again, Danni approached GPs who she'd already worked with, to ask for their feedback on GP

questionnaires. "The GPs said it would be easy to fill in - they either knew the answers or could get the data. However, they couldn't guarantee their colleagues would take part!" Danni reported. "We're aware that response rates can be low, so it's important to make the questionnaire the best that you can, so that's not the reason people don't respond".

ENRICH

The PACE team have been in contact with ENRICH throughout the set-up phase and advertised their study through the ENRICH website. They believe ENRICH offers care homes a valuable source of independent advice to help staff decide whether to take part in research, as Danni described, "We send out ENRICH leaflets with our information packs to introduce the wider issues around research in care homes. Care homes that are new to research may not be sure what it involves or if it's right for them. ENRICH gives them somewhere to go with their questions. That's beneficial for researchers and for care homes".

Key Messages

- Seek feedback on questionnaires, information sheets, leaflets and invitation letters from people in your target audience
- Seek feedback from people who you hope will to take part in your study to check the study is acceptable and feasible for them
- Think about how you can use your existing networks for early consultation
- Think about working with ENRICH – it's a useful resource for care homes as well as researchers

April 2015

For further information, contact:

Danni Collingridge Moore, Email: pace@lancaster.ac.uk

Or visit the news pages on the ENRICH website.