

'It's not really our thing' Lessons in engaging care homes in palliative care research.

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Background

There are just under half a million older adults resident in care homes with the median length of stay in a UK care home around 15 months before death^{1,2}. In England, 16% of all deaths take place in care homes³. Despite this, there is evidence that palliative care received by care home residents varies within and between care homes⁴.

Aims of the PACE study

The PACE study, an EU FP7 funded project (2014 -2019) aims to describe and compare the effectiveness of health care systems within care homes in six EU countries in terms of patient and family outcomes (quality of dying, quality of life and quality of palliative care), cost effectiveness and staff knowledge, practices and attitudes. This poster will discuss the methodological challenges of recruitment to the PACE Study in England.

Results

Challenges included approaching care homes through random sampling. Care home managers were either not contactable, too busy to discuss the study or were unsure as to whether taking part in the study would benefit their care home or its residents. Only 30 of the 49 care homes recruited were approached through random sampling, compared to 19 initially approached through the ENRICH network. The average number of deaths over a three month period was estimated as four, this was found to be lower (3.4) in practice. Care home managers who did agree to take part in the study raised concerns regarding the anonymity of data published on the care home, the legalities of contacting the relatives of deceased residents and a lack of time and resources to support the study. Response rates were higher among care home staff completing questionnaires on specific care home residents compared to questionnaires on generic knowledge and attitudes towards palliative care.

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Acknowledgements

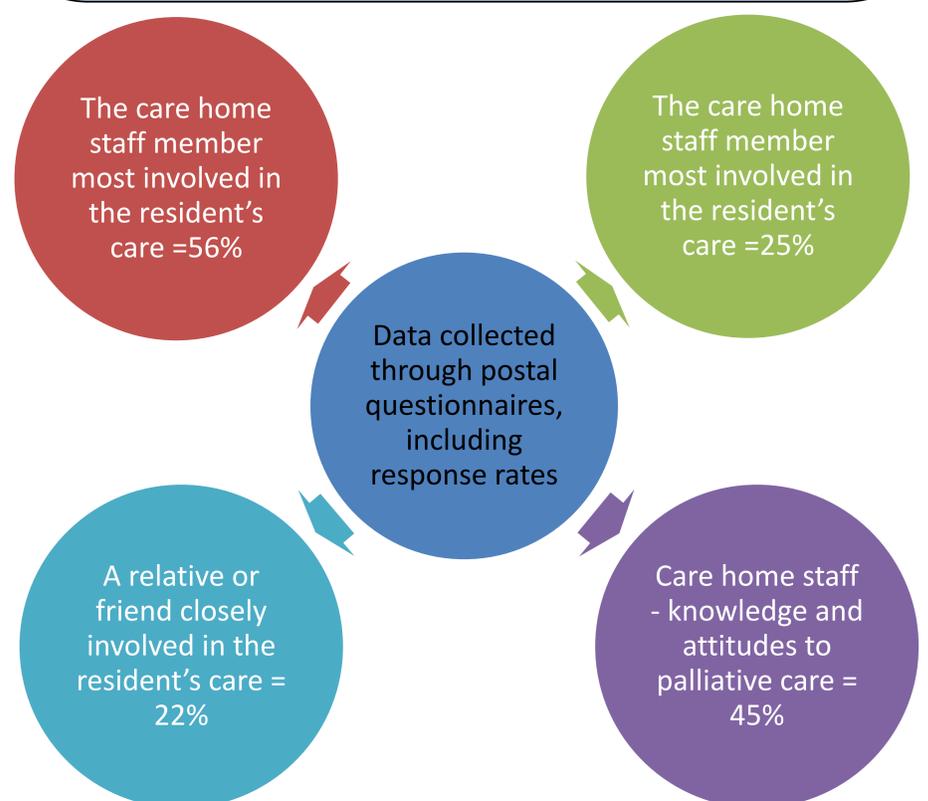
This research project has received funding from the European's Seventh Framework Programme (FP7/2007-2013) under grant agreement number 603111-2.

We would like to thank the PACE Consortium, led by Lieve Van den Block.



Methods

The study used a representative, retrospective cross-sectional design to examine all resident deaths over the past three months in fifty care homes. The care homes were identified using proportional stratified random sampling of the Care Quality Commission dataset. Sampling was based on the following criteria: region, type (residential/nursing), size (≥ 30 / < 30 beds) and funding (private/not for profit). For each deceased resident identified, a postal questionnaire was posted to three key persons. In addition, a questionnaire on knowledge and attitudes to palliative care was posted to all care home staff on duty at the time of the research visit.



Conclusions

1. Using national/regional care home networks and informal contacts can facilitate recruitment and representativeness of a sample.
2. Establishing trust between the research team and care home managers can reduce attrition rates.
3. Seasonal variation in the average number of deaths per care home could be incorporated into the study timeline.
4. Clarifying confidentiality and data protection issues at an early stage is paramount, as is providing accurate expectations of the time and resource commitment required from the care home.
5. Response rates were higher among care home staff completing questionnaires on specific care home residents compared to the response rates of general practitioners and relatives.