Helping care home residents and staff to participate in clinical research

Older people who are housebound or living in care homes seldom take part in research. Some traditional research tools are unsuitable for this older, frail population with cognitive difficulties. Involving care home staff and residents in research can help to improve care.

The research team at Solent Trust works in partnership with 30 care homes. So far 500 care home residents have participated in five trials.

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Abstract Solent Trust provides community and mental health services in the south of England and one of its priorities is to care for patients in the community. The trust’s research team is, therefore, keen to build an evidence base around community care. In 2015, it launched a research partnership with local care homes to offer residents the opportunity to participate in research. The Solent Care Home Research Partnership has recruited 30 care homes and 500 residents have participated in five trials. The partnership has now been extended to domiciliary care agencies, schools, colleges and the University of Portsmouth Dental Academy.

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and more than 200 residents and their families participated. Our initial aims were to deliver research in partnership with care homes and identify ways of making this possible. We also wanted to learn more about what would make research useful for those who live in, work in or visit care homes. The success of the first study led to further trials on topics including genetic sequencing for dementia, bacteria carriage rates and antibiotic resistance in respiratory infection; there was also a falls prevention intervention.

“A unique application that demonstrates how clinical research nurses can use their skills and autonomy to develop research with seldom-heard patient groups” (Judges’ feedback)

Method
So how does the partnership work? The care home managers and/or matrons and our older person’s mental health team agree on potential studies. These are run either by our local research partners at the Universities of Southampton and Portsmouth, or across a number of sites nationally with partners from other healthcare and academic organisations.

Each home joining the partnership signs a letter of agreement outlining the roles of each party and giving assurance that the trust will be responsible for managing and overseeing the trial. The research nurses liaise with the care homes and research teams about logistics and any training needed. Training is given to the research nurses and care home staff – and to relatives, where appropriate. This was the case, for example, in the interventions on falls prevention and on reducing agitation in residents with dementia.

Participants, relatives and staff receive regular updates on study progress and findings. The research nurses discuss with the care homes what has worked well, what could be improved and what further initiatives could be useful.

Challenges
One of the challenges we encountered was that, because clinical research was a new activity in the care homes, we had to build new relationships and explain the many aspects of research, including governance.

We found that certain tools and methods traditionally used in research (such as patient information sheets using complicated language, complex consent forms and the need to sign them in triplicate) were not suitable for patients who were frail or had communication and/or cognitive difficulties. It quickly became apparent that we would need to adapt these tools to the study population.

Another challenge was ensuring that participation would have benefits for all – not only the research team but also residents, families, care homes and care home staff – while always giving priority to residents’ care. A range of factors helped us create and grow the partnership, including the care home managers’ openness and the research nurses and clinical trials assistants’ skills, understanding of the setting and residents’ conditions, humour, compassion and ability to interact with patients.

Outcomes
To date, we have recruited nearly 30 care homes and over 500 participants. The Solent Care Home Research Partnership has given a seldom-heard population access to research and has strengthened relationships between clinical teams in care homes and NHS settings. The quality of care has always taken priority over research targets.

The care home teams have told us that the quality of the care they deliver has improved. One example of this was the introduction of risk assessments (as part of the study on falls prevention); another was the teaching of techniques to help residents, families, care homes and care home staff – while always giving priority to residents’ care. A range of factors helped us create and grow the partnership, including the care home managers’ openness and the research nurses and clinical trials assistants’ skills, understanding of the setting and residents’ conditions, humour, compassion and ability to interact with patients.

Advice for setting up similar projects
- Build on existing relationships with potential research partners
- Make sure you have something to offer the care homes
- Make clear the trust’s responsibilities in terms of governance, ethics and oversight
- Listen and adapt to the needs of the care homes, residents and relatives
- Do not get bogged down in the complexities of research
- Keep eliciting feedback about what is working and what is not
- Question traditional research methods that may be unsuitable for your population
- Work with research teams early on to reduce the burden on participants

Staff and relatives care for residents (as part of the study on agitation in dementia). Care home staff have also gained a better understanding of how evidence behind interventions and treatments is collected and applied.

Since the first trial, we have been working with academic partners on the accessibility of information and more suitable trial designs, including new methods for consent. We now work with them on applications for future research in the care home population.

The partnership has afforded us:
- Evidence of the acceptability of research in the care home population;
- Knowledge on how to do research in this population;
- A clearer view of the implications of conducting research in a population with communication and cognitive difficulties, notably regarding consent;
- Strong relationships with academic teams leading to new research.

Extending our reach
The Solent Care Home Research Partnership has worked well in Portsmouth. Our collaboration with care home teams now also includes joint quality-improvement projects and we are in the process of extending the partnership to Southampton and, possibly, the Isle of Wight.

We have also launched the Solent Community Research Partnership, whereby we work with various community partners in the same way as with care homes. We collaborate with the University of Portsmouth’s Dental Academy, extending our reach into public health and dental research, as well as with schools and colleges in our catchment area. Over 1,000 additional participants have already been recruited via this extended partnership.

These collaborations support the growth of community-based research and reinforce our position as a centre for running studies in the community, rather than in the hospital setting. The partnership has grown into a proof-of-concept initiative to demonstrate the acceptability and feasibility of running research in all kinds of community settings.

- For more about the Solent Care Home Research Partnership, go to: vimeo.com/169087179

Contact
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