

Residents Research-Active in Care Homes

Guidance for researchers and research partners: involving older care-home residents in research as advisers or collaborators

Be positive. Older care-home residents have been involved in research as advisors on a variety of projects or as partners working together with other parties on participatory action research projects focused on their own care homes. Interview data with residents also shows that there are residents who are interested in research and in collaborating with and/or advising researchers.

Be realistic. Research is unlikely to be a top priority for the majority of residents and care homes. Although some residents are interested in playing an active part in research and others are willing to be consulted, many residents are not interested in research and/or feel unable to give advice or choose to spend their time in other ways. We found that at most a handful of people in a medium-size care home are interested in becoming involved in various parts of the research process.

Be flexible about how to involve residents. Residents have many different motivations for taking part (while some actively seek to have a voice and want to contribute to improve care homes for the future, for others the main motivation might be doing "something different" and mental stimulation or because they value being asked for help). The extent to which people want to be involved varies accordingly, so be flexible in the nature and type of involvement – and avoid presenting potential partners with structures that are rigid. For example, residents might prefer to be involved in the design phase and look at data, others might want to be involved in data collection, recruitment of Research Associates or dissemination of findings. Residents may want, or only be able, to be involved in different ways and at different times, so offer a variety of choices about levels of involvement.

Support and respond to residents' needs. Older care-home residents often have complex physical, cognitive and emotional needs. Accessible venues are thus not the only aspects of support that need to be considered. Allow extra time for appropriate support to be provided to residents and adapt to residents' preferences and abilities. Extra time might be needed to explain the research and respond to residents' own agendas that they might have. Some residents prefer one-to-one or small group meetings and might need additional reassurance

in a larger group setting. The health and capacity of residents can fluctuate, which may mean that planned PPI activities have to be revised and adapted accordingly.

Involve care homes and their staff. Some residents are happy to be contacted individually, but most prefer being contacted via the care home. Residents typically view care-home managers as sources of advice and support and trust them to ensure their welfare. Although managers could select residents for participation, thereby making choices for them, most residents trust their managers and staff and prefer not to bypass them. Additionally, care homes can sometimes be used as venues for research meetings. Residents often also need support that goes beyond actual meetings; for example they might want somebody to re-explain information to them afterwards or need reassurance about suitable care support being in place at meetings. Such support cannot be given by researchers in isolation. Care-home staff can provide support and reassurance for residents before, during and after involvement. For events outside the home residents may require a carer to be with them. In addition, care-home staff might feel disempowered if they are not fully informed about the research. We recommend establishing and maintaining strong links with care-home managers and staff.

Effective recruitment through networks. Our experience has shown that the most effective route to recruit care-home residents to collaborate on research projects is through existing networks. The support of area managers can facilitate the involvement of care homes, which are part of larger organisations by making first contact with managers, who in turn can help recruit residents. Health networks (e.g., infection control meetings; networks such as ENRICH) can also support the recruitment of patient and public involvement (PPI) members. Using the media and sending letters to care-home managers have proved less effective, but may also lead to individual residents becoming involved.

Plan for resident involvement costs. Not all care homes have resources to cover the costs of research-related support. The time spent on maintaining and supporting PPI relations is also likely to be considerably higher compared to PPI relations with some other groups. Transport costs for specialist vehicles could also be greater for this group. We recommend including the cost of residents' involvement in research budgets to cover staff members' time to provide support, extra researcher time to maintain relationships, and/or to offer specialist transport.

Acknowledge the residents' contributions. Older care-home residents contribute in numerous ways to the conduct and outputs of research. It is more than a courtesy to acknowledge the impact made by their contributions; it validates their input, demonstrates the co-equal value they bring to the research and indicates to them the difference they make to the academic researchers' experience and knowledge. Such acknowledgement can take many forms, including maintaining contact with the residents and staff throughout the research, properly thanking them for their contributions and time, offering them choices

around their involvement (*e.g.*, increase or decrease it; choose different tasks) and including their names and / or participation in dissemination. Such acknowledgement may make the residents' and care home's future involvement in research activities more likely.

Persevere. Involving older care-home residents in research may require time and resources to build and maintain relationships, to respond to the needs of this group and ensure appropriate support is in place, but the results are extremely worthwhile. The research will benefit from their input and the study will likely become more focused on and relevant to residents' concerns. Resources such as information sheets or findings summaries for participants can become more effective following resident involvement or feedback. In becoming more attuned to residents' ideas and preferences, academic researchers will be better positioned to pursue future research that reflects the real needs of residents and care homes and to benefit the experience of residents and staff in these environments.

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