



A Good-Practice-Guide for Involvement of Care Homes in Research

Foreword

Older adults living in care are particularly vulnerable and therefore it can prove a challenge to involve them and their care staff in research. Yet we must not shy away from research in care homes as the health and wellbeing of this vulnerable part of the population deserves study and improvement, moreover, this population will continue to grow due to population ageing. Hence research involving care homes is important: to improve health and well-being of residents and care staff, and to reduce associated costs to the NHS and society as a whole.

Through a number of research studies for which we involved care home residents we have gained experience regarding some of the challenges that need to be overcome in order to involve care homes and their residents in research. Here we share both, challenges we encountered as well as mechanisms we identified that helped facilitate recruitment. We note that this document is underpinned by feedback from both, carers (n=4) and care home residents (n=6), who fed back to us how they perceived the various mechanisms we had put in place to make participation easy. We hope that sharing our experience will prove time-saving to others planning to involve care homes and residents in their research, and we will update this document if and when we receive further input.

Regards,

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Challenges with involving care homes and residents in research

By the very nature of the cohort, i.e. older adults that live in care, recruitment of participants can be subject to multiple challenges, including:

- Meeting the required inclusion criteria: e.g. co-morbidities may result in exclusion.
- Ability to give informed consent: e.g. age-related cognitive decline may be a barrier to give consent.
- Ability to be assessed away from the care home: e.g. if the research requires them to leave their home, lack of confidence to venture into the unknown, and also health problems may make travel difficult. Care staff may be overstretched and not be able to organize transport.
- Willingness to participate: e.g. participating in research is new to them and residents may feel nervous/anxious at the prospect of being assessed. Discussions we had with residents revealed that the reluctance to participate may at least in part be due to fear of change in their care arrangement should they not perform 'satisfactorily', even when the information leaflet explained that findings will not be shared with their relatives/carers, and hence will have no effect on their ongoing care arrangement.

In summary, the population of interest is generally vulnerable and subject to co-morbidities as well as anxiety, all of which pose a challenge to the involvement of care home residents. Hence we found it of great importance to put a number of mechanisms in place that aim to facilitate participation.



Mechanisms that aim to facilitate involvement of care homes and their residents in research

- 1. Meet and Greet Visit at the care home prior to any commitment to participate:**

In many research studies “Information Leaflets” are posted to interested individuals, and they would then call the researcher if they wish to arrange a first assessment. However, due to care home residents’ anxiety to get involved in research and also nervousness to travel to an unknown location when the assessment requires travelling to the university, we introduced Meet & Greet Visits. During such visit, care staff and residents were able to get to know one member of the research team and were able to ask questions without being scheduled for assessment right after. At the end they would be left with the Information Leaflet for them to consider over the next few days. If interested in participating, a research team member would then visit a second time to answer any further questions and, if they wished, to schedule a date for their assessment. Whilst Meet & Greet visits do take up research time we have found them to be essential to a steady recruitment rate. Feedback from carers and residents was unanimous in that these visits were considered useful.
- 2. Arranging a pre-paid taxi for coming to the university and returning them after the assessment:**

Due to their frailty, most care home residents are not able to travel independently to a university. Hence we arranged pre-paid taxi transport so that neither the care staff nor the resident had to worry about making arrangements and paying for them. Our transport method was rated either “Very Good” or “Good” by carers and residents.
- 3. Allowing residents to come with up to 3 residents at a time for back-to-back assessment:**

We offered to schedule as many as 3 residents from the same care home back-to-back for assessment, so that they could all come together if they wished. This alleviated concerns regarding “venturing into the unknown alone” and turned participation into “a nice day out”. Offering multiple assessments back-to-back was perceived useful by both, carers and residents alike.
- 4. Allowing a carer to accompany residents, if they wished, and pay for the carer’s time:**

We offered that a carer could come along and help where needed, e.g. when going to the toilet or managing dietary requirements. Offering for a carer to accompany the residents was perceived as useful by all carers and most residents. Being paid for their time was considered either “very important” or “important” by carers.
- 5. Providing tea/coffee and biscuits in the lab, and taking residents for lunch after the assessment:**

Offering refreshments and having a meal at the end of the assessment aimed to enhance the feeling of “a nice day out”. These arrangements were perceived as “Good” by all carers and residents.
- 6. Offering the resident £20 gratitude per assessment, and also a Certificate of Participation:**

We provided a £20 gratitude cash payment and a Certificate of Participation in Research as a reward for participants’ time and effort. This was well received by all participants, with participants making plans to spend the cash during their next café or pub visit, or to take their carer out, or to buy some essentials, and they were planning to show their certificates when relatives would next come to visit them in the care home.



7. Providing a Certificate of Supporting Research for care homes:

We provided Certificates of Supporting Research for care homes. This was considered to be “Very Important” by all care homes as it allowed them to showcase that they are supporting research for improved health and well-being of those living in care.

8. Providing study outcomes in form of a leaflet:

When the project had finished we developed summary leaflets that provided the background to the research, key findings, and implications in a language understandable to the lay person. All carers and residents found these leaflets to be “Very Important”.

9. Offering a dissemination visit to the care home:

We offered to come for a final visit to the care home, to speak to carers and residents and share insights gained face-to-face. Whilst dissemination visits do take up research staff time, these visits were much appreciated with all carers and residents finding them to be “Very Important”.

Carers Comments:

“The study had a really good process.”

“Everything was really well-planned.”

Residents Comments:

“I really enjoyed the day”.

“It was a nice day out”.