



Learning lessons in design and delivery of Care Home research: A survey

Thank you for your interest in taking part in this online survey. You have been invited to participate as you work in a care home, live in a care home, have family members who live in a care home or have conducted research studies in a care home environment in the United Kingdom (UK). Please read through this information carefully before agreeing to participate.

Care homes are an important part of the health and social care system. They provide a home and care to some of the most vulnerable members of society. There are lots of things about life in care homes that we can only fully understand by doing research in and with the care home sector.

The last two decades have seen a rapid expansion in care home research but research done in care homes, and other social care settings, still makes up a small minority of what UK research organisations fund each year. Particularly, it's rare for clinical trials, where we test one treatment by comparison with another using carefully measured outcome measures, to be conducted in care homes.

This study is being done by Dr Annabelle Long a researcher from the University of Nottingham. We are investigating the opportunities and challenges of conducting clinical research in care homes and we want to better understand these so that we can enable more care home residents to benefit from the type of research that can only be conducted in this setting.

The survey consists of up to 23 questions which take about 10 mins to complete. The questions are a mixture of tick boxes and free-text answers.

Privacy Notice

How will your data be used?

Your answers will be completely anonymous and we will use all reasonable endeavours to keep them confidential. The data generated will be securely stored in a password-protected file and all participants' data will be anonymised using a unique study number. Your IP address will not be stored.

This survey is part of a bigger study and some participants may be chosen to take part in the next stage of the study which involves interviews and focus groups. Taking part in the survey does not obligate you to take any further part in the research. This data will be used for research purposes only. Your participation in the research is voluntary and you are free to withdraw at any point during the questionnaire before final submission by clicking the Exit button/closing the browser. The data will only be uploaded on completion of the questionnaire by clicking the SUBMIT button.

Who will have access to your data?

The University of Nottingham is the data controller for the purposes of Data Protection. Your data may be shared with study staff, investigators and any relevant regulatory authorities. We believe there are no known risks associated with this research study; however, as with any online-related activity, the risk of a breach is always possible. We will do everything possible to ensure your answers in this study will remain anonymous. We will minimize any risks by storing all survey data on a secure dedicated web server. Access will be restricted by user identifiers and passwords (encrypted using a one-way encryption method). The results of the study may be published in scientific journals and presented at academic conferences. The data will be reported anonymously, with any identifying information removed. If you have any questions about this project, please don't hesitate to contact the lead researcher Dr Annabelle Long at annabelle.long@nottingham.ac.uk or if you have any concerns about any aspect of this study please contact Dr Caroline Rick at caroline.rick@nottingham.ac.uk or Mr Garry Meakin at garry.meakin@nottingham.ac.uk.

If you remain unhappy and wish to complain formally, you should then contact the FMHS Research Ethics Committee Administrator, c/o The University of Nottingham, Faculty PVC Office, E41, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH. E-mail: FMHSResearchEthics@nottingham.ac.uk.

This survey has been reviewed and given a favourable opinion by the University of Nottingham, Faculty of Medicine & Health Sciences Research Ethics Committee (FMHS 124-0224). By continuing, you acknowledge that you have read and understood the above information and agree to participate in this survey.

Thank you very much for your participation in this research project. If you are happy to proceed with the survey please press NEXT.

About you

Firstly we would like to know a bit more about you. This information is highly confidential and is for internal research purposes only. This information will not be shared externally.

1. How old are you?

- ☐ 18 - 25
- ☐ 26 - 40
- ☐ 41 - 55
- ☐ 56 - 70
- ☐ 71 - 85
- ☐ 85+
- ☐ Prefer not to say

2. What is your sex

- ☐ Male
- ☐ Female

3. Is your gender the same as your sex assigned at birth

- ☐ Yes
- ☐ No

4. What best describes your gender

- ☐ Female
- ☐ Male
- ☐ Prefer to self-describe in another way
- ☐ Prefer not to answer

5. Please write here

6. Which of the following best describes your role?

- ☐ Academic researcher
- ☐ Care home owner
- ☐ Care home staff member
- ☐ Care home resident
- ☐ Family member of a care home resident
- ☐ Manager/Director of a care home chain
- ☐ Manager of a single care home
- ☐ Clinical academic researcher
- ☐ Other

7. How many years have you worked in the care home sector? (round up to nearest whole number)

8. How many years have you worked with the care home sector? (round up to the nearest whole number)

9. How familiar are you with clinical trials/research

- | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Very unfamiliar | Unfamiliar | Somewhat familiar | Familiar | Very familiar |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

10. Have you been involved in a research trial in a care home?

- ☐ Yes
- ☐ No

11. Can you tell us more about how you were involved?

12. Can you tell us why you have not been involved in research

Issues to consider when conducting a trial

In the next few sections, we will outline some issues that might be important to consider when conducting trials in the care home sector. We will ask you to rate their importance on a scale. We have also added a box where you can add any further comments you may have on each section as to why they might be important and what could be done to address each issue

Resident Characteristics

13. How importantly would you rate each of the following resident's characteristics when it comes to running trials in care homes?

	Very unimportant	Unimportant	Not sure	Important	Very important
Residents cognitive abilities (memory and ability to reason)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Residents with multiple medical conditions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Residents with frailty	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Residents who need help with activities of daily living	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Residents with sensory impairments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

14. Do you have any further comments about why these may be important and how clinical trials could take this into account when running trials in this setting

Relatives of Residents

15. How importantly would you rate each of the following characteristics of resident family members when it comes to running trials in care homes?

	Very unimportant	Unimportant	Not sure	Important	Very important
Geographical location of family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family members who have physical or cognitive impairments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family members who work full time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. Do you have any further comments about why these may be important and how clinical trials could take this into account when running trials in this setting

Care home staff

17. How importantly would you rate each of the following characteristics for care home staff when it comes to running trials in care homes?

	Very unimportant	Unimportant	Not sure	Important	Very important
Experience of research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Training in specific aspects of research (e.g. consent, site files, Good Clinical Practice)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Electronic care records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Handling, dispensing and recording medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18. Do you have any further comments about why these may be important and how clinical trials could take this into account when running trials in this setting

Payment

19. How important is it for care home provider organisations to be paid for their involvement in research

Very unimportant	Unimportant	Not sure	Important	Very important
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20. How important is it for care home staff to be paid directly for their involvement in research

Very unimportant	Unimportant	Not sure	Important	Very important
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21. Do you have any thoughts on how payments to care home providers or staff should be organised

22. In this question we list some examples of how care home staff have been paid in the past for their work on research projects? We would like you to rate each of these in terms of appropriateness

	Very inappropriate	Slightly inappropriate	Not sure	Appropriate	Very appropriate
Backfill payments made to organisation - staff work normal hours no additional payment to staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Backfill payments made to organisation - staff work additional hours and receive additional payment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Care home staff seconded to support research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Care home staff take on roles such as 'research champion' or 'research link' for additional payment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recognising individual staff contributions with gift vouchers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recognising staff contributions with gifts for whole care home (e.g chocolates, cakes)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

23. Do you have any further comments on how care home staff and providers are paid for their involvement in research?

Delivering Research in Care Homes

24. If care home staff are appropriately paid, then they may be expected to help deliver research in care homes. Below we list some tasks that care home staff have helped with in the past. We want to understand how appropriate you think each of these tasks are for care home staff to undertake with appropriate training

	Very inappropriate	Slightly inappropriate	Not sure	Appropriate	Very appropriate
Sharing details of research with residents and relatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asking relatives and residents if they would like to be involved in research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Identifying relatives and residents who may be eligible to participate from care records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being present to support residents and relatives during consent process	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Conducting baseline measurements (e.g. questionnaires about memory or physical function or taking measurements such as weight and height)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helping to collect follow up information (e.g. questionnaires about pain, recording falls or GP visits)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helping to randomise residents in a trial by entering their information into a computer system	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Giving medications or other treatments as part of a trial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reporting any adverse events that happen as part of a trial.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. Do you have any further comments about tasks that care home staff can undertake as part of research delivery?

Thank you for your responses

26. If you have any further comments you would like to make about research in care homes please let us know below.

27. Would you like to be entered into the prize draw to win one of four £50 vouchers?

☐ Yes

☐ No

28. Please leave your contact details below

29. We will be contacting some participants to discuss their responses in more detail in either an interview or a focus group. If you are interested in taking part in this part of the study tick yes

☐ Yes

☐ No

30. If you would like to take part in the next part of the study please provide your contact details below

31. If you would be interested in taking part in future research studies please provide your contact details below

Thank you for taking part in this survey. We would like to emphasise that all of your responses will be kept anonymous, regardless of whether you have provided us with your contact details or not.

Please press submit below to finish the survey

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