

INFORMATION SHEET FOR PERSONAL CONSULTEE

A personal consultee is someone who advises on the preferences and wishes of a person who is no longer able to give informed consent.

Research Study Title: Supporting people living with dementia in Extra Care Housing

We are researchers at the University of Worcester. We are carrying out some research on supporting people living with dementia in Extra Care Housing. This research is funded by the NIHR School for Social Care Research.

We feel your relative/friend is unable to decide for himself/herself whether to participate in our research study.

To help decide if he/she should join the study, we'd like to ask your opinion whether or not they would want to be involved. We'd ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide your relative/friend would have no objection to taking part we will ask you to read and sign the consultee declaration on the last page of this information leaflet. We'll then give you a copy to keep. We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/friend should be withdrawn.

If you decide that your friend/relative would not wish to take part it will not affect them in any way.

If you are unsure about taking the role of consultee you may seek independent advice.

We will understand if you do not want to take on this responsibility.

The following information is the same as would have been provided to your relative/friend.

What is the purpose of this study?

This study will look at how Extra Care Housing can support people to live well with dementia. It will look at what are the advantages and disadvantages of different models of Extra Care Housing. This is important so that we can develop knowledge that can be shared to support professionals, family carers, and people living with dementia to make informed decisions about moving into an Extra Care Housing scheme.

Why am I being asked about this study?

We would like to involve your friend/relative in our study. Due to the fact that your friend/relative may be unable to decide for himself/herself, we are asking you to advise us on their behalf. We are asking them to take part as they have direct experience of living in Extra Care Housing as a person living with dementia.

Does my relative/friend have to take part?

No. We are asking for your advice about whether they might object to taking part. They do not have to take part and their position at their Extra Care Housing scheme will not be affected if they do/do not take part.

You may want to consider if the person previously expressed an interest in taking part in research. If you think that they would **not object** to taking part, please complete the Consultee Declaration Form and return to the Research Team.

You can change your mind as to whether you feel your friend/relative would like to take part at any time and without giving reason.

What does taking part involve for my relative/friend?

If you say yes to your friend/relative taking part, the following things will happen:

1. After reading this information sheet, you will be asked to complete a Consultee Declaration Form.
2. A member of the Research Team will verbally explain the study to you and your friend/relative and re-confirm all parties are happy with proceeding.
3. You and your friend/relative will be invited to take part in an interview. This will take place in a private location and will be audio recorded.
4. You might want to be present during the interview, but you do not have to be if you don't want to. The interview will take up to one hour.
5. The interview will discuss what it is like to live in Extra Care Housing. This might include topics such as what works well, and what doesn't work so well. It might also include discussing aspects of the environment, talking about staff and other people who live in the scheme, and activities/facilities that the scheme has.
6. The research team will integrate the information provided by your friend/relative into the findings that will be produced by this research.

The research study and COVID-19

We hope to be able to carry out interviews on a face-to-face basis. However, we will abide by all current local and national guidance on what is safe to do when visiting (e.g. use PPE, social distancing). We can offer to undertake videos by video conferencing (e.g. Microsoft Teams), or telephone to reduce the risks associated with face-to-face contact.

How will we use information about you?

We will need to use information from you and your relative for this research project.

This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. We will also record your relative's age and gender as part of the research. This will be stored with your relative's interview data, but will not include your relative's name and date of birth. Your relative's data will have a code number instead.

If you or your relative discloses any information that might put themselves or another person at risk, we have a duty to report this to the relevant person under UK safeguarding legislation.

We will keep all information about you and your relative safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that your relative took part in the study.

What are your choices about how your information is used?

Your relative can stop being part of the study at any time, without giving a reason, but we will keep information that we already have.

We need to manage your relative's records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data that we hold about your relative.

How long will my data be stored?

Your name and contact details will be stored for the duration of the project. These will be stored on a secure server at the University of Worcester and will be destroyed within three months of the project completion.

All other data your relative provides will be anonymised, coded by number, and stored on a secure server at the University of Worcester for ten years after the project completion.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- By asking one of the research team
- By sending an email to t.atkinson@worc.ac.uk or calling 01905 542530
- The University's Data Protection Officer (Helen Johnstone, Head of Information Assurance – 01905 855014 or infoassurance@worc.ac.uk)

Are there any disadvantages to taking part?

There are no obvious disadvantages to your friend/relative taking part in the research. This research is not an evaluation of the specific Extra Care Housing scheme in which they live, nor is it an evaluation of how appropriate that scheme is for your friend/relative. In no way will participation impact upon your friend/relative's lease/tenancy or care provision.

If your relative does take part, we will talk to them about their experiences of living in Extra Care Housing. This might bring up topics that are personal, sensitive, embarrassing or upsetting. Researchers are experienced in dealing with sensitive topics and will always be mindful of your relative's wellbeing. If your relative becomes upset, we will cease the interview and liaise with yourself and/or staff as appropriate.

What are the benefits of taking part?

By taking part in the study, your friend/relative will be providing valuable information about how Extra Care Housing can support people to live with dementia. Your friend/relative will be able to have their say on what works well and what does not work so well within their Extra Care Housing Scheme. They will be able to share ideas on how Extra Care Housing might work best for people living with dementia. By being involved, they will help the Extra Care Housing provider that they live with, and other Extra Care Housing providers across the UK to make informed choices as to how they can best support people living with dementia.

What will happen to the results of the study?

The results will give us information about how living in Extra Care Housing can support people to live well with dementia. The results will be written into a final report, which will be shared with the National Institute of Health Research (NIHR), who are funding the study. The results will also be used to write articles, reports or be included in presentations. We will also be developing three Key Insight booklets so that all professionals and people living with dementia can make informed decisions about living in Extra Care Housing.

Who is organising or funding the study?

This study is being led by the Association for Dementia Studies at the University of Worcester. It is funded by the NIHR School for Social Care Research.

Who has reviewed this study?

This research study has been reviewed and approved by Social Care Research Ethics Committee (part of the Health Research Authority). A research ethics committee is a group of people who review research studies to ensure they protect the dignity, rights, safety and well-being of researchers and research participants.

How can I contact the research team?

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Complaints or concerns:

If you would like to speak to an independent person who is not a member of the research team, please contact Dr John-Paul Wilson at the University of Worcester, using the following details:

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