

## Resident Information Sheet

### Research Study Title - Supporting people living with Dementia in Extra Care Housing

You have received this information sheet because we are inviting you to take part in our research study. We are researchers at the University of Worcester and we are undertaking some research at your Extra Care Housing scheme. The following information explains what the research study is, and what it will mean for you if you decide to be involved. Please take time to read over it and discuss the information with other people before you make your decision.

### What is the purpose of the 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 to take part?

We are inviting you to take part as you have direct experience of living in Extra Care Housing. We want to ask people for their knowledge and experience of living in different types of Extra Care Housing and how it supports people living with dementia.

### **Do I have to take part?**

No, you do not have to take part in the study if you do not want to. If you decide against it, it will have no impact on your living arrangements in Extra Care Housing. You can change your mind about being involved in the study at any time and without giving a reason. You also have the right to withdraw your data after participation, in which case it will be destroyed on request.

If you decide that you would like to take part in this research study, you will first be asked to sign a consent form and then we will arrange with you the next steps of taking part.

### **What will happen if I wish to take part?**

If you would like to take part, one of our Research Team will be in touch to discuss this with you. You will be invited to take part in an interview which will be arranged at a time to suit you. The interview will be held in a private location and is likely to take approximately one hour.

The interview will discuss your experiences of living in Extra Care Housing. This will include your perspectives on the advantages and disadvantages of Extra Care Housing for people living with dementia. This might include topics such as design, technology, other residents, location, staffing, activities, support, and independent living.

You can invite a friend or relative to support you during the interview if you prefer.

### **The research study and COVID-19**

We hope to be able to hold interviews in person, but this is dependent on the COVID-19 restrictions. We are hopeful that in the near future it will be safe for us to visit each Extra Care Housing scheme. If so, we will abide by all current local and national guidance on

what is safe to do when visiting. If this is not possible, then we will carry out our interviews using online meeting technology (such as via Zoom), or by telephone and email.

Even if we can attend Extra Care Housing schemes, you can let us know whether you would prefer an online method, such as Zoom.

### **How will we use information about you?**

We will need to use information from you 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 age and gender as part of the research. This will be stored with your interview data, but will not include your name and date of birth. Your data will have a code number instead.

If you disclose any information that might put yourself 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 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 you took part in the study.

## **What are your choices about how your information is used?**

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

We need to manage your 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 you.

## **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 you provide 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](mailto: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](mailto:infoassurance@worc.ac.uk))

## **What are the possible disadvantages to taking part?**

If you choose to take part, we will talk to you about your experience 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 wellbeing. You can pause, or stop the interview at any point without giving reason. You can also refuse to answer any question at any point without giving reason.

### **What are the possible benefits of taking part?**

By taking part in this study, you will be providing valuable information that we can learn from, to help other Extra Care Schemes to be a success. You get to share your opinions on how people with dementia are best supported to live well in Extra Care Housing. You may also help your own Extra Care Housing scheme, by helping us to understand how it works best for people living with dementia and what else can help in the future.

We hope that you will find taking part in interviews or making a video with us interesting and enjoyable.

### **What will happen to the results of the study?**

The results will give us the information to make recommendations to other Extra Care Housing schemes across the UK. The results of the study will be written up in a final report and shared with the NIHR School for Social Care Research, who are funding the study. The results will also be used to write articles, reports or include in presentations. We will make sure our results are made available to share with you once the study is complete.

### **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 **National Institute for Health Research (NIHR) School for Social Care Research**.

### **Who has reviewed the study?**

This research study has been reviewed and approved by the 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?**

#### **Teresa Atkinson (Principal Investigator)**

[t.atkinson@worc.ac.uk](mailto:t.atkinson@worc.ac.uk)

Association for Dementia Studies  
University of Worcester  
Henwick Grove  
Worcester  
WR2 6AJ

#### **Becky Oatley (Research Associate)**

[r.oatley@worc.ac.uk](mailto:r.oatley@worc.ac.uk)

Association for Dementia Studies  
University of Worcester  
Henwick Grove  
Worcester  
WR2 6AJ

### **How can I make a complaint or raise a concern about the research team?**

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 (Deputy Pro Vice Chancellor Research)  
University of Worcester  
Henwick Grove  
Worcester WR2 6AJ  
01905 542196  
[j.wilson@worc.ac.uk](mailto:j.wilson@worc.ac.uk)

**Thank you for taking time to read this information sheet.**