

## **The experiences and support needs of veterans living with dementia in their own homes**

### **Participant Information Sheet (PIS)**

You are being invited to take part in a research study exploring the support needs of veterans living with dementia. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part, and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

### **About the research**

#### **Who will conduct the research?**

The research is being conducted from the University of Manchester and is led by Dr Lydia Morris, based in the Division of Psychology and Mental Health, The University of Manchester. The research is also led by Professor Anthea Innes, based at McMaster University, Canada (formerly based at University of Salford). Dr Anamaria Churchman will be collecting the data.

For any questions or queries please contact Dr Anamaria Churchman at:

Phone: **07721 654 897**

Email: [anamaria.churchman@manchester.ac.uk](mailto:anamaria.churchman@manchester.ac.uk)

#### **What is the purpose of the research?**

The purpose of this research is to understand the everyday lived experiences of **veterans living with dementia** who live in the community and their ability to access support as required.

We aim to conduct interviews with both 15-20 veterans with a diagnosis of dementia and their care partners in order to understand the care and support needs of veterans living with dementia.

#### **Am I suitable to take part?**

You are invited to take part in this study if you are involved in the care and support of a veteran living with dementia. You are suitable to take part if you are regularly in touch with the veteran living with dementia and are offering support regularly (at least 3 times a week).

#### **Will the outcomes of the research be published?**

At the end of the study, with your permission, we would like to share our findings. The project findings will be shared in a variety of ways including poster presentations to groups/forums that may be interested, academic journal articles, conference presentations, teaching at universities and newsletters.

We may use word-for-word quotations from your interview. You will be given anonymity in any direct quotes that are used. You will not be recognisable from any presentations of findings.

### **Who has reviewed the research project?**

All research in the University of Manchester is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by the University of Manchester Research Ethics Committee (UREC).

### **Who is funding the research project?**

This project is funded by the Forces in Mind Trust.

### **What would my involvement be?**

#### **What would I be asked to do if I took part?**

If you decide to take part in the study, you will be invited to talk to the researcher about the support needs of the veteran living with dementia you are currently supporting. The researcher will ask you questions regarding your experience of caring for a veteran living with dementia and accessing the support they need.

We would like to invite both veterans living with dementia and their care partners/family members to talk to the researcher during the same meeting. However, if any individuals have any preferences for this to be done separately, this will be arranged.

You will be invited to take part in two separate interviews around 4 months apart. This will enable us to note any changes in the needs and support required for veterans living with dementia over time. The interviews are not expected to last longer than 1 hour during each instance.

The interviews would be held at a time that is convenient for you. They could take place in person or online. If you decide that meeting in person is convenient, we will meet in a community center where you might access services or at our office at the University of Manchester. If you prefer to meet online, the camera will be on unless you request cameras to be turned off. With your permission these interviews will be audio-recorded.

There are no expected risks to taking part in the interview. We hope the findings of our overall project will be useful in improving services for veterans living with dementia and their families.

#### **Will I be compensated for taking part?**

If you have an interview with the veteran living with dementia that you are supporting then we will offer them a £20 voucher for them to share with you.

If you need to travel for your interview, we will be able to reimburse reasonable travel expenses on production of a valid receipt.

#### **What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part. If you do wish to take part, please contact the study coordinator directly: Dr Ana Churchman at [anamaria.churchman@manchester.ac.uk](mailto:anamaria.churchman@manchester.ac.uk)

If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form or to provide verbal consent (if your interview is via Zoom or Teams). If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. However, we will not be able to remove your information from the project after it has been made anonymous. This will happen at the end of the study between October and December 2023 when we have looked at all the study data. If you decide not to take part you do not need to do anything further.

If you decide to take part in the interviews, it is helpful if this can be audio-recorded. We want you to be comfortable with the recording process at all times and you are free to stop recording at any time.

## **Data Protection and Confidentiality**

### **What information will you collect about me?**

In order to participate in this research project we will need to collect information that could identify you, called “personal identifiable information”. Specifically we will need to collect: your name. We will also need your contact details in order to contact you (phone number, email address).

Other information that we collect will be pseudonymised (your name and any other identifying information will be removed and replaced with a random ID number).

This will include:

- Demographic information (age, gender and ethnicity)
- A transcript of your interview (if your interview is recorded); or notes from your interview

We will use a secure spreadsheet to record your ID number with your contact details. This will be password protected and only accessed by authorised members of the research team.

As soon as interview data has been transcribed and checked, you will be given full anonymity– this means that your data can no longer be linked to your name.

If you consent to have your individual interview recorded, then we will take an audio recording of your voice. If you consent to being recorded and have an online interview, then interviews will be transcribed (with consent) using the in-built transcription function and checked by the researcher conducting the interview.

### **Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with UK data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

### **What are my rights in relation to the information you will collect about me?**

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including audio recordings.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our [Privacy Notice for Research \(https://documents.manchester.ac.uk/display.aspx?DocID=37095\)](https://documents.manchester.ac.uk/display.aspx?DocID=37095).

**Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

The project team at The University of Manchester will have access to your personal information and they will give you anonymity as soon as possible. Your name and any other identifying information will be removed and replaced with a random ID number. Personal identifiable information will be removed from the final transcript of your interview.

Only the research team will have access to the key that links this ID number to your personal information. The list that matches your name to the unique study number that is used on your research-related information will not be released without your consent unless required by law.

Anonymised data will be shared with Professor Anthea Innes (one of the lead researchers on this project).

Your consent form will be retained for 5 years in a locked cabinet on University of Manchester premises for audit purposes.

So that we can provide the shopping/Amazon voucher as a thank you for your time, your email address will be shared with our Finance department who will send the voucher to you. Your email address will be securely retained by Finance department for a period of up to 7 years for audit purposes only and then destroyed. It will not be used by them for any other purpose.

With your consent, we would also like to retain your contact details for 2 years to invite you to a workshop related to this project and provide you with a summary of the findings for this study. If you agree to this, your details will be safely stored on University of Manchester servers in a digital folder only accessible to the study team and used only for the purposes described above.

We will use an external company to type up the interviews and they will also keep all details confidential. The company is a University of Manchester approved supplier which has confidentiality clauses within its contract with the University. Only the research team and the individual typing up the audio recordings will have access to them. Audio recordings will be deleted after they have been typed up. Diary entries will also be destroyed after they have been typed up and anonymously added to the data set.

If you participate in an online interview, your participation in this research will be recorded in Zoom (or Teams) and your personal data will be processed by Zoom (or Microsoft). This may mean that your personal data is transferred to a country outside of the European Economic Area, some of which have not yet been determined by the United Kingdom to have an adequate level of data protection. Appropriate legal mechanisms to ensure these transfers are compliant with the Data Protection Act 2018 and the UK General Data Protection Regulation are in place. The recordings will be removed from the above third party platform and stored on University of Manchester managed file storage as soon as possible following the completion of data collection.

Data may need to be shared in certain circumstances:

- If, during the study, you disclose information about you or others being at risk of significant harm, we have a professional obligation to report this and will therefore need to inform your relevant services.
- If, during the study, you disclose information about any current or future illegal activities, we have a legal obligation to report this and will therefore need to inform the relevant authorities.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

## **What if I have a complaint?**

### **➤ Contact details for complaints**

If you have a complaint that you wish to direct to members of the research team, please contact:

**the study co-ordinator Dr Ana Churchman (Researcher) at**  
**[anamaria.churchman@manchester.ac.uk](mailto:anamaria.churchman@manchester.ac.uk)**

**If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact**

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: [research.complaints@manchester.ac.uk](mailto:research.complaints@manchester.ac.uk) or by telephoning 0161 306 8089.

If you wish to contact us about your data protection rights, please email [dataprotection@manchester.ac.uk](mailto:dataprotection@manchester.ac.uk) or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioner's Office about complaints relating to your personal identifiable information \(https://ico.org.uk/make-a-complaint/\)](https://ico.org.uk/make-a-complaint/)

Tel 0303 123 1113

**Are there any additional considerations that I need to know about before deciding whether I should take part?**

You should not take part in any face-to-face activities if you are in a vulnerable group or if you have symptoms of COVID. There is the option of completing the interview online.

**What if I have additional queries?**

### **Contact Details**

If you have any queries about the study or if you are interested in taking part then please contact **the study co-ordinator Dr Ana Churchman at [anamaria.churchman@manchester.ac.uk](mailto:anamaria.churchman@manchester.ac.uk)**.