

## **Planning ahead for research participation: stakeholders' views about advance research planning (CONSULT-ADVANCE Study)**

### **Survey Home Page**

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others, if you wish.

Thank you for your interest in the CONSULT-ADVANCE study.

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

Research is essential in order to improve the treatment and care for people with conditions that affect memory or understanding, such as dementia or stroke. People with these conditions may be invited to take part in a research study, but their condition may affect their ability to make a decision about taking part, and so other people need to be involved in helping to make the decision on their behalf. In such situations, the researchers ask a relative or friend to be involved, as they are best able to provide advice to the researchers about what the person's wishes and feelings would be about taking part in the research study. Family members have told us that it is sometimes difficult to know what their wishes and feelings would be as it is rarely talked about.

There has been a growing focus on advance care planning that provides people with the opportunity to discuss their future preferences about treatment and care should they be unable to decide for themselves. However in the UK this does not currently include their preferences about research, although some other countries do have processes for planning for research participation in advance. We would like to develop ways to help people to express what their wishes about future research participation are in circumstances where they are unable to make their own decision, and who they would like to make a decision about research on their behalf. This will ensure that future decisions about research are based on their wishes and preferences. In this survey we want to find out what people living with conditions such as dementia, their families, and other members of the public think about planning for research participation in advance.

We are inviting you to take part in an online survey and answer questions about your views on planning for research participation in advance of any loss of capacity. The findings will be used to inform future research, including the development of interventions to support advance planning for research.

#### **Why have I been invited to take part?**

You have been invited as you are either living with a condition that may affect your memory or understanding such as dementia, Parkinson's, or stroke, or have a friend or relative who has such a condition, or are another member of the public interested in this topic.

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

No, your participation in this survey is entirely voluntary and it is up to you to decide whether or not to take part. You are free to withdraw from the study at any time without giving a reason.

### **What will taking part involve?**

This survey is in three parts. Part one contains questions about yourself and your interest in this topic. Part two asks for your views about different aspects of research. Part three asks for your views about advance research planning. You will also be able to provide your contact details if you are happy to be contacted about taking part in an optional interview in the next stage of the project. There will be no direct advantages or benefits to you from taking part, but your contribution will help us understand more about advance research planning. There will not be any risks to you from taking part.

### **Will my taking part in this research study be kept confidential?**

All information collected from (or about) you during the study will be kept confidential and any personal information you provide will be managed in accordance with data protection legislation. Please see 'What will happen to my Personal Data?' (below) for further information.

### **What will happen to my Personal Data?**

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. Further information about Data Protection, including:

- your rights
- the legal basis under which Cardiff University processes your personal data for research
- Cardiff University's Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner's Office

may be found at <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>

### **What happens to the data at the end of the research project?**

After 3 years following the end of the project, the research team will anonymise all the personal data it has collected from, or about, you in connection with this research project. Anonymised information will be kept for a minimum of 5 years following the end of the project.

The survey data may be shared with other researchers in the University and outside the University who are also exploring research involving people who have problems with their memory or understanding . Any personal data will be removed before any data is shared.

### **What will happen to the results of the research project?**

At the end of the study the results will be published in medical journals and presented at academic conferences. Quotes from survey responses may be used, but neither you nor anyone you talk about will be identified. Your name will not be included in any reports or presentations.

### **What if there is a problem?**

If you wish to complain, or have grounds for concerns about any aspect of the manner in which you have been approached or treated during the course of this research, please contact **Dr Victoria Shepherd** using the contact details below. If your complaint is not managed to your satisfaction, please contact the Centre for Trials Research (via [ctr@cardiff.ac.uk](mailto:ctr@cardiff.ac.uk)).

### **Who is organising and funding this research study?**

The research is organised by Dr Victoria Shepherd and the Centre for Trials Research in Cardiff University. The research is funded through an NIHR Advanced Fellowship funded by Health and Care Research Wales

### **Who has reviewed this research study?**

This research project has been reviewed and given a favourable opinion by the School of Medicine Research Ethics Committee at Cardiff University (ref. 22/84).

### **Who do I contact for more information?**

If you have any questions or at any time you would like to discuss this study, please contact:

**Principal Investigator:** Dr Victoria Shepherd, Centre for Trials Research, Cardiff University

**Email:** [ShepherdVL1@cardiff.ac.uk](mailto:ShepherdVL1@cardiff.ac.uk)

**Tel no:** 02920687641

**Thank you for considering taking part in this study.**