

# INFORMATION SHEET FOR ONLINE SURVEY

## PARTICIPANTS

### **What is the project about?**

We are undertaking a research study (the DYNAMIC study) to better understand social care planning and provision for people living with young-onset dementia (where the first symptoms occur under the age of 65). We will use this information to help us develop recommendations and resources to improve social care for people living with young-onset dementia.

This survey is designed to be completed by those who have a role in or an awareness of adult/older adult social care planning, provision, management or commissioning.

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

You don't have to take part. It is up to you to decide.

### **What is involved in taking part?**

You will need to complete a **10 minute** survey. It asks about your experiences of social care planning and provision for people living with young-onset dementia. It also asks about your job role so that we can better understand who is involved in social care planning and provision.

You don't have to complete all the questions. You have the right to skip any question. You will have the option of saving your survey responses midway through so you can finish it later.

At the end of the survey, you can choose to provide us with your contact details so we can invite you to join in later parts of the study. You can also give us your contact details so you can be informed about the findings of the study.

By completing this survey, you will be giving your consent to take part in the study.

If you would prefer to complete a paper or telephone version of this survey please contact the researcher (details below).

### **How will taking part affect me?**

We don't think there are any risks involved in taking part. If any of the questions make you feel uncomfortable, you don't have to answer them. The information you provide will help to develop recommendations to improve the care people

receive. If you experience any distress or need further support we have collated a list of relevant organisations which you can access through the link within the survey. You can also contact the researcher.

### **How will the researchers look after my information?**

All information you provide will be kept private and stored securely. The findings will be anonymised so no-one will be identifiable from the answers that they have given. We will look at the information you provide alongside that provided by others. If we use anonymised quotations in study publications or presentations it will not be possible to identify you from them.

You may choose to give us your contact details so that we can let you know about follow-up research or about the study findings. If this is something you do, we will store this information in a separate file. We will keep this information until 12 months after the end of the study.

At the end of the survey, we will ask your consent to add the study information to a national data archive so that other researchers can also make use of it. We will make sure that none of your personal information is included. This is optional and you can say if you don't want to do this.

### **What will happen to my information if I withdraw from the study?**

You have the right to withdraw at any point of the survey until you submit your responses.

### **When do I have to make a decision?**

You can have as much time as you like to decide whether or not to take part. Depending on the number of responses it is likely we will close the survey on 31<sup>st</sup> May 2024.

## **Additional Information**

### **Who is responsible for the research?**

The University of Bradford is responsible for making sure the research is conducted properly.

### **Who is paying for the research?**

The study is funded by the National Institute for Health and Care Research (NiHR).

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

This study was reviewed and authorised by the Health Research Authority Social Care Research Ethics Committee on 20<sup>th</sup> September 2023.

## **Protecting your personal data and safeguarding your rights**

### **How will my information be stored?**

All information we collected will be kept strictly confidential and stored either on an encrypted password protected computer, or in a locked cabinet in a secure office at the University of Bradford, which can only be accessed by the research team. You will be allocated a unique number, to ensure your information will be protected and cannot be identified outside of the research team. Any personally identifiable information will be stored separately and securely from information obtained from the research. Personal information will be retained at the University of Bradford for 12 months following the final publication of the study. The anonymised research data will be held at the University of Bradford for 10 years.

### **What will happen to my information if I withdraw from the study?**

You will be able to withdraw from the study until you submit the survey. After then your anonymised data will be included in our analysis. To safeguard your rights, we will use the minimum personally-identifiable information possible.

### **What will happen to my information after the end of the study?**

After the study ends, with your consent we will add the information gained from the research to a national data archive so that other researchers can also make use of it. We will make sure that none of your personal information is included. No-one will be able to identify you personally from the data we add to the archive. No information will be used for other studies prior to transfer to the archive at the end of the study.

### **Where can I find out more information?**

If you require help or have questions about any aspect of this research, or would like to request a paper/telephone version of the survey please contact the researcher:

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Email: [h.young@bradford.ac.uk](mailto:h.young@bradford.ac.uk)  
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