

Study Title: Partnership in Safeguarding People with Dementia from Primary and Social Care Perspectives

Participant Information Sheet

1. The invitation. You are invited to take part in a **research study**.

To take part in an interview



Before you decide, it is **important** for you to **understand** why the research is being done and **what it will involve**.

Please take the time to read the following information.

Please ask if anything is **not clear** or if you would like **more information**.



Study Contact: Ms Katarzyna (Kasia) Szulewska

Email: katarzyna.szulewska@manchester.ac.uk

Telephone: 0161 30 67689

2. Who is carrying out the research?

Dr Reena Lasrado – Division of Nursing, Midwifery and Social Work, The University of Manchester

Ms Katarzyna Szulewska - Division of Nursing, Midwifery and Social Work, The University of Manchester

3. What is the purpose of the study?

We want to talk to you about your experiences of the safeguarding process.

So that we can understand how the process works from **your point of view** as a person **living with dementia**. This could help inform policies and future practices for adults living with dementia.



4. Why have I been chosen?

You are an adult who has a diagnosis of **dementia**.

You have previously been involved in the **safeguarding process**.

5. Do I have to take part?

No. It is **up to you** to decide whether or not to take part.



The **standard of care** you receive will not be affected in any way.

6. What will be involved if I agree to take part?

You will attend one interview, which will last up to 90 minutes.



It is up to you to decide where you would like to be interviewed, e.g. face to face at your property, at a local NHS site or at the University of Manchester.

You can also choose to be interviewed over telephone or video call (ZOOM).

You will also complete a short questionnaire, indicating your ethnicity, gender, age etc.

7. What are the risks of taking part?

The risks are low.

However, the interview might bring up difficult and potentially upsetting memories.

You may pause  or stop  the interview at any time.

You are free to withdraw from the study at any time.

8. Will I be compensated for taking part?

Yes, you will be compensated for your time with a £25 gift voucher or bank transfer and any costs incurred will be reimbursed.



9. Will my taking part in the study be kept confidential?

Yes, all your **personal information** (name, address, telephone number), demographic information (ethnicity, gender etc) and your **voice recordings** will be kept confidential.



Your name will not be shown. You will be identified by a number. Only **authorised** people will be **allowed** to see your information.

With your consent, we will retain your contact details (e.g email address), to send you a summary of the study findings and an invitation to an end-of-study seminar.

10. What will happen if I do not want to carry on with the study or I lose capacity to consent?

You are **free to withdraw** from the **study** at **any time**



If you do not want us to use your information, please tell us and they will be destroyed.

If you withdraw **after** the interviews have been made **anonymous**, we will use the information already collected in the final analysis.

If you **lose capacity to consent**, you will be **withdrawn** from the study. Any data collected from you **before** you lost your capacity to consent, will be **retained**, and used in the research.

11. Who is organising and funding the research?

This study is **organised** by the Nursing, Midwifery and Social Work Division at the **University of Manchester**.

The study is **funded** by the **National Institute for Health and Care Research (NIHR)**



This study has been **approved** by an **NHS Research Ethics Committee**

12. What will happen to the results of the research study?

We will **publish** the **study results** in academic and professional journals.

The results may be **presented** at **conferences**.

You will **not be identified** in any publication.



13. Disclosures:

- If during the study we have **concerns about your safety or the safety of others**, we will inform your **care team/family member**. We will **not** inform the individual who the concern is raised against or appoint them as your key contact.
- If a **new safeguarding issue** arises during interview (e.g. you let us know that you are experiencing abuse), we will need to follow **safeguarding procedures and inform local authority**.

13. What if I need more information or there is a problem?



If you need further **information**

or have any concerns about the study please contact the research team on:
0161 30 67689

If you decide you would like to take part, please read and sign the consent form.



You will be given a copy of this information and signed consent form to keep.

Please take time to decide whether you want to take part.

Thank you for reading about this study.

Please now turn the page to read information about your privacy.

The law says that we must have a **legal basis** to collect your data.

This means we need to have a particular **reason** for collecting your data. We can collect your data under two legal bases:

- 1) A task carried out in the public interest
- 2) A process necessary for scientific research purposes

The University of Manchester is the **data controller** for this research.

This means the University of Manchester is **responsible** for making sure your data is:

- 1) Kept securely and confidentially
- 2) Only used in the way the researchers tell you it will be used

Your data will be **anonymised** as soon as possible. This means any personal information which could identify you will be **removed**.

The data remaining will be kept for 5 years after the publication.

You can learn more about your data privacy by reading [The University privacy notice](#)