Centre for Mental Health Research
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City, University of London
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Date

Risk Assessment and Increasing Safety in Dementia – The RAISe-Dementia study

IRAS Project ID: 253119

Information sheet for people living with memory problems

Risk assessment and individual interviews

We are inviting you to take part in a research study about assessing risk for people with memory problems. Before you decide whether to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

People who have problems with their memory are often seen as being more vulnerable to risks than other people. This can affect their safety or the safety of others. These risks include accidents such as tripping and falling over, leaving a pan on the stove, forgetting to eat and drink properly, or to take their medication. There may also be risks of harm from other people, who are trying to hurt them or steal their property. Our risk assessment tool helps measure the risks affecting people with dementia's ability to live at home safely. It is used to produce a care-plan that can help reduce and monitor these risks. We want to see how well our risk assessment does this and if it helps people to live at home for longer.

Why have I been invited?

You are being invited to take part in our research study, because you have recently been referred to the Dementia Navigator Service in Islington. Dementia navigators (DNs) are experienced dementia workers who support people with dementia living at home and help guide you and your family carer through options for your care, monitor your wellbeing and ensure that you receive appropriate information and support services. If you have a family member who lives with you, or that you are close to and rely on for support, we would also like to interview them about any risks they may be concerned about. We would like to interview you both separately, but if you prefer to be interviewed together, we will do that.

We will pay for any travel costs, if you need to travel to meet with research staff. To say thank you for taking part in our research, we would also like to give you a gift token for £30.

What will taking part involve?

All interviews will be carried out by researchers who have knowledge about dementia and experience of interviewing people with memory problems. The researcher will contact you to arrange a convenient time to visit you at home, or see you at the university if you prefer. If English is not your first language then we can use an NHS interpreter to help with the interview.

The research study will be undertaken in three parts. Some people may only want to agree to visit 1 taking place and that is okay. Visit 1 is an important part of the research and your involvement can be carried out as a single visit. When we have completed visit 1, we will ask if we can contact you again to carry out visit 2 and 3. Please let us know if you prefer not to do visits 2 and 3.

- **Visit 1** First we would like to do a joint visit with a dementia navigator from Islington Dementia Navigator Service to see you at home. During the visit the dementia navigator will ask you about how you are managing at home. They will ask you some questions about any concerns you have about your safety, and what help and support you need to manage the risks identified. The dementia navigator and researcher will each complete the risk assessment separately and compare their results. The dementia navigator will create a care plan to manage any risks identified and agree this plan with you. This visit usually takes about an hour.

- **Visit 2** We would then like to contact you 1-2 weeks later to talk with you about the risks you identified and what impact this has on the way you live. We want to know about any concerns you have about your safety, how these risks are managed and any help you receive with this. We will ask you about the risk assessment done in visit 1 and the care-plan created to reduce or manage the risks identified and whether you found this useful. We want to know if you think your views were listened to, if you agree with the risks identified and if you found the process helpful in supporting you to live at home safely. The interview will be tape-recorded and take about 30 minutes and the whole visit should last no longer than an hour.

- **Visit 3:** We would like to visit you again after 6 months to ask you again about the risks identified and any new risks and how you are managing these. This will be the same procedure as for visit 2. In this visit we will ask about how you are managing at home and how the situation has changed or if it is the same. We will ask you if the risks identified have been reduced, or if they have increased and if it has impacted on your ability to live at home safely. We will ask about your satisfaction with the process overall and whether you have found it helpful, or think that any changes should be made to the risk assessment process. Again, the interview will be tape-recorded and take about 30 minutes and the whole visit should last no longer than an hour.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get might help us immediately develop ways to improve risk assessment for people with memory problems and allow them to live at home more safely and for longer.

What are the possible disadvantages and risks of taking part?

We do not think the interviews will be upsetting, but if taking part brings up issues about risk that you would like to talk about, you can ask to speak to one of our team. You may also find it helpful to ring one of the following helplines. The Admiral Nursing Dementia helpline (0845 888 6678) is open from 9am to 9pm Monday to Friday and 9am to 5pm on Saturday and Sundays. The Alzheimer's Society National Dementia Helpline (0300 222 1122) is open from 9am to 5pm Monday to Friday and Saturday and Sunday 10am – 4pm.

What will happen if I don't want to carry on with the study?

It is up to you to decide whether or not to take part in our study. If you do, you will be asked to sign a consent form. You are free to withdraw at any point, and you do not have to give us a reason. You can also refuse to answer individual questions that you do not want to answer.

What if something goes wrong?

If you have any problems or concerns about this study, you should ask to speak to Dr Juanita Hoe (principal investigator for the study on Tel: 020 7040 5485), who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through City's complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: **Risk Assessment and Increasing Safety in Dementia – RAISe-Dementia study.** You could also write to the Secretary at:

Anna Ramberg
Research Governance & Integrity Manager
Research & Enterprise
City, University of London
Northampton Square
London, EC1V 0HB
Email: Anna.Ramberg.1@city.ac.uk

City holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

How will my information be kept confidential?

All interviews are confidential and you will not be identified in any report/publication.

Whilst we respect confidentiality, we cannot keep it a secret if anyone is being seriously harmed or neglected. If any person in the study tells us that they or someone else is at significant risk of harm or neglect we are obliged to report any concerns and will do so to the

service which referred you or the necessary statutory agency. They will consider what support or help is needed and act to provide it.

How will you use my personal information?

Information about how we will process your personal information for research and your rights under the law are provided in a separate document, which goes with this participant information sheet.

What will happen to the results of this study?

We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. You will not be identified in any report/publication.

Who is organising and funding this study?

City, University of London

How have patients and the public been involved in this study?

We have talked with members of the Alzheimer's Society research network about the planning and design of this study and we have included their comments. We plan to consult with these members further through focus groups about the wider use of the risk assessment. A former family carer and research network member helped develop the protocol and is a co-applicant. He will be a member of our project management committee.

Who has reviewed this study?

All research in the NHS 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: **Bromley NRES Committee, London**

Further information and contact details

Please contact Dr Monica Manela, Research Fellow on Tel: 020 7679 9219 for further information.

For independent advice please contact the Alzheimer's Society National Dementia Helpline (0300 222 1122), or your local NHS Advice and Complaints Service (formerly PALS).

Camden and Islington NHS Foundation Trust
Advice and Complaints Service
1st Floor, East Wing
St Pancras Hospital
4 St Pancras Way
London, NW1 0PE

Phone number: **020 3317 7102**
Email address: feedback@candi.nhs.uk

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