

Pain Phenotyping in People Living with Dementia (CAPPPeD Study)

Summary Participant Information Sheet

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What is it about?

We want to understand more about how pain is linked to certain mood and behaviour symptoms, and how these affect the daily experiences of people living with dementia.

What does taking part it involve?

A researcher will arrange to meet with you and a close relative or friend who agrees to take part together with you. They will help you to go through some short questionnaires about pain, mood and behaviour symptoms and daily living tasks, and take note of dementia or memory problems you have been having.



Do I have to take part?

Taking part is up to you. If you decide not to take part, this will not affect your care. If you agree to take part, you can change your mind at any time, and the researcher will stop the questionnaires.

What are the risks and benefits?

You may find talking about pain and other problems upsetting. If this happens, we will support you and can stop going through the questionnaires. However, you could help us to understand how pain affects people with dementia, and plan future studies to tackle this.



What will be done with the information?

In this research study we will use information from you and your GP. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

At the end of the study we will save some of the data for future research. We will make sure no-one can work out who you are from the reports we write. The information pack tells you more about this.

Who can I contact if I want to take part or know more?

Please contact by the CAPPPeD team by email: capped@nottingham.ac.uk or by Phone: **07557 197497**

