**Dementia and Cognitive Impairment in the Older Prisoner Population of England and Wales: Identifying Individual Need and Developing a Skilled, Multi-Agency Workforce to Deliver Targeted and Responsive Services**

**PARTICIPANT INFORMATION SHEET FOR INDIVIDUALS CONSIDERING TAKING PART IN THE EXPERT PANELS**

**Introduction**

My name is\_\_\_\_\_\_\_\_\_\_\_\_\_\_. I am a researcher working at the University of Manchester. At the moment we are working on a project which will look at how many older prisoners in England and Wales have problems with their memory and thinking (cognitive impairment). We also want to look at what their needs are during their time in prison and after release.

**What is Cognitive Impairment?**

Cognitive impairment means that someone might have trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life.

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

Lots of projects are looking at how people with these problems can be identified and cared for but very few of them have been based in prisons.

The aim of this project is to find out how common cognitive impairment is among older prisoners in England and Wales. We will also look at how prison and healthcare staff can make sure that prisoners with these difficulties are cared for properly. We want to find out what needs prisoners with cognitive impairment have and what kind of help they receive. We will also explore whether staff need more training to be able to support these prisoners.

**Why have I been invited?**

You have been invited to take part in this study because you will be able to provide valuable information regarding the support prisoners with suspected cognitive impairment and dementia should receive throughout their time in prison and on release.

**Do I have to take part?**

No, taking part is voluntary. If you would prefer not to take part you do not have to give a reason. No pressure will be put on you to try and change your mind. You can change your mind about taking part at any time. If you decide not to take part or withdraw at any stage, your legal and parole rights and your access to health and social care will not be affected.

**What will I happen to me if I take part?**

This part of the study will involve you participating in a workshop to develop and validate care pathways for older prisoners with cognitive impairment and dementia. Each care-planning workshop is expected to last approximately 90 minutes and will involve two activities. The workshops will be audio-recorded.

**What are the possible disadvantages and risks of taking part?**

For all participants there is the risk that you may become distressed during the workshop as we may talk about how prisoners with dementia and cognitive impairment manage day-to-day in prison. If you are upset you can talk to the researcher, a listener, a member of prison staff or a member of healthcare staff, as appropriate. If you feel you require further support they will be able to tell you about other people or places to go to for help or advice.

**What are the possible benefits of taking part?**

Findings from the project may help to improve services for future older prisoners who have cognitive impairment.

**If I agree to take part what happens to the information?**

The information we collect will take the form of notes and/or audio recordings and will include any views or statements you make during the care-planning workshops.

The information you give us will be kept confidential and will be used in a way that will not allow you to be identified individually. However, data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, to make sure the study is being carried out as planned. The information will be kept in a locked filing cabinet for no longer than five years, after which time it will be securely destroyed.

Please also be aware that the researcher has a duty to inform prison staff of the following:

Behaviour that is against prison rules;

Undisclosed illegal acts;

Behaviour that is harmful to you (e.g. intention to self-harm or end your life);

Information that raises concerns about terrorist, radicalisation or security issues;

Information that refers to a new crime committed or plan to commit and

Information that suggests a risk of harm to yourself or others.

If the researcher is worried that you are having difficulties as a result of cognitive impairment and does not think you are getting the help you need, they will speak with you about their concerns and ask for your permission to pass details to the prison healthcare manager.

If the researcher is worried that you are having difficulties AND that you or anyone else is at risk because of these difficulties, he or she will speak with the healthcare manager without asking for your permission. This is because the researcher MUST tell staff about problems which put people at risk.

**What will happen to the results of the research study?**

It is hoped that the results of the study will be used to improve services for older prisoners with cognitive impairment.

**What if there is a problem?**

***Complaints***

**Minor complaints**

If you have a minor complaint then you need to contact the researcher(s) in the first instance:

**[research team contact details]**

**Formal Complaints**

**If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact** [research complaints information and contact details inserted here]

***Harm***

In the event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against The University of Manchester but you may have to pay your legal costs. The normal National Health Service complaints service will still be available to you.

**Who is organising and funding the research?**

This study is funded by The National Institute for Health Research and is being carried out by the University of Manchester.

**Who has reviewed the study?**

This study has undergone an independent external review by The National Institute for Health Research who are the funders. The Research Ethics Committee (REC) for Wales and local Trust Research Governance groups have also reviewed the study.

**What do I do now?**

Think about the information on this sheet and ask me about anything that you are not sure about. If you agree to take part, we will go ahead.

**THANK YOU FOR READING THIS**