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

Service User

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 and 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, as well as 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 are resident in one of the prisons where this study is being carried out and you are aged 50 or over. We would like to invite you to take part whether or not you have any problems with your memory or thinking.

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 and 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 to withdraw at any stage, your legal and parole rights and your access to health and social care will not be affected.

If you agree to take part, we will also ask you to indicate what you would like to do if you lose the ability to make your own decisions during the study. We would like to know whether you would like to continue to take part or if you would prefer to stop involvement if this happens If you do lose the ability to make your own decisions during the research, we will consider your wishes and will seek the advice of someone else who knows you in deciding whether you should continue with or be withdrawn from the study. If you are withdrawn from the study, we will keep and still use the data you have already agreed to give us but will not collect any further information about you or from you.

What will I happen to me if I take part?

There are three parts of the project which you may be invited to take part in. We will stop and ask you if you are happy to continue at each stage of the project, so by agreeing to take part today, you are only agreeing to complete one set of questions. You can choose whether you want to answer each question or not.

If you agree to take part today then I will ask you some questions. This should take about fifteen minutes and you can have as many breaks as you like. The questions will involve things like recognising shapes and remembering words, as well as some basic information about you and your health.

Depending on your answers to the first questions, we may want to come back and speak with you again. If we would like to do this, we will take some time to explain what is involved and you can choose whether you want to take part or not. These questions will take around an hour and a half.

If we do come back again, we would also like to look at your healthcare records to check if anyone has ever been worried about your memory, thinking or concentration and if so, if you have received any support for this. It is also important for us to know about any other issues which might affect your responses to the questions Examples of these issues are reading difficulties, hearing loss, being prescribed strong medication). In addition, we would like to ask your offender manager about your risk and to record your NHS number, name and date of birth. These details would allow us to find out what happened to your health and if you had re-offended at a later date in the future. We will explain all of this in more detail if we come back again after today and you can choose not to give us access to this information.

How long will the study last?

The study will last for three years in total and how long you are involved for will depend on your answers to our questions. We expect the first set of questions to take 15 minutes then if we would like to come back and see you again, we aim to do this within the next 3 weeks.

There are some other parts of the project which we may invite you to be involved in over the next 1-2 years, but we will only be asking around 10 individuals to do this.

What are the possible disadvantages and risks of taking part?

For all participants there is the risk that you may become distressed during the interview as we may talk about how you feel and how you manage activities 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. 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.

There is no need to worry about how you answer the questions. It is important to answer as honestly and clearly as you can. As this is a study is the first one looking at whether these questions are useful in prisons, a low score might not mean that you have a cognitive impairment.

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 include details you give us about yourself, your answers to our questions and relevant information we get from reviewing your healthcare records.

This information 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 at the university 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:

a. Behaviour that is against prison rules;
b. Undisclosed illegal acts;
c. Behaviour that is harmful to you e.g. intention to self-harm or end your life;
d. Information that raises concerns about terrorist, radicalisation or security issues;
e. Information that refers to a new crime committed or plan to commit; and
f. 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

If you have a concern about any aspect of this study, you should ask to speak to the prison Healthcare Manager who will then contact the research team for you. If the research team are unable to resolve your concerns or you wish to make a complaint regarding the study, please do so via the prison Healthcare Manager, who will then contact the University Research Practice and Governance Co-ordinator.

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