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UNIVERSITY OF OXFORD

Assessing mental capacity and cognition in clinical practice

Central University Research Ethics Committee Approval Reference: R91126/RE001

Participant Information Sheet

We would like to invite you to take part in our research study. Before you decide whether or not to take part, it is important that you understand why the research is being done and what it would involve for you. Please take time to read this information and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please ask us.

1. Why is this research being conducted?

The freedom for someone to make an autonomous decision depends on their mental capacity to make this decision at a particular point in time. Assessing mental capacity in clinical practice is known to be very challenging.

We want to find out how and to what extent healthcare professionals take into account a person's *cognitive abilities* – including their language, memory, and attention skills – when making a decision about their mental capacity in clinical practice. We are particularly interested in this question in the context of patients with neurological conditions, like stroke and dementia.

2. Why have I been invited to take part?

You have been invited because you are a healthcare professional working in the United Kingdom. We would like to talk to you about your experiences assessing mental capacity in clinical practice, or your experience being part of a clinical team that assesses mental capacity.

3. Do I have to take part?

No, it is up to you whether or not to take part. You can ask questions about the research before deciding whether to participate. You may withdraw from the research

at any time if you do agree to participate, although it will not be possible to withdraw your data once it has been anonymised. You do not need to provide a reason for withdrawing from the study.

4. What will happen to me if I take part in the research?

If you decide to take part, you will be invited to complete a consent form and to provide your contact details (telephone number and/or email address). A member of the research team will contact you by phone or email, depending on your preference, to invite you to take part in a single online (Microsoft Teams) research session lasting 30-60 minutes. You will be able to choose a time to participate that is most convenient for you.

During the research session, you will be asked some questions about yourself (e.g., age, gender, job title). Then, you will be asked about your (or your team's) experience assessing mental capacity in clinical practice, with a particular focus on how/to what extent you (or your team) consider/assess cognitive abilities when assessing mental capacity. There are no right or wrong answers to any of these questions. We want to find out your experiences and opinions.

The research session will be audio recorded with your consent so that we can transcribe your responses and analyse them in detail. All identifiable information (e.g., your name) will be redacted from the interview transcript and only the research team will have access to the recording and the transcript. The recording will be deleted as soon as it has been transcribed and checked for accuracy by a second member of the research team.

5. What are the risks or disadvantages of taking part?

Since the research is conducted online and your data will not be shared outside the research team, there is minimal personal risk to you.

6. Are there any benefits in taking part?

While there are no immediate benefits for those participating in the research, it is hoped that this research will help us better understand how mental capacity assessments are conducted in clinical practice. We are particularly interested in understanding barriers and facilitators to assessing cognition in the context of mental capacity assessments and identifying potential areas for quality improvement.

Exploring these topics and identifying examples of 'good practice' may ultimately inform recommendations to improve in clinical practice.

7. What information will be collected and why is the collection of this information relevant for achieving the research objectives?

The information you provide as part of the study is research data. Any research data from which you can be identified are known as personal data. The research team will have access to the research data.

Identifiable personal data are collected when you consent to take part in the research (name, contact details). These data will be stored and associated with a unique participant identifier on an electronic linkage list. These data will be password-protected and stored separately from your research data on a password-protected computer with an encrypted hard drive and a University of Oxford OneDrive account.

Your research data will be stored confidentially. The audio recording of your research session will be transferred from the recording device and stored as a password-protected file on a password-protected computer with an encrypted hard drive and a University of Oxford OneDrive account immediately after the research session has finished. The recording will then be deleted from the original recording device and transcribed by a member of the research team. Any identifiable information within the transcript will be redacted. The transcript will be stored as a password-protected file on a password-protected computer with an encrypted hard drive and a University of Oxford OneDrive account. The file will be labelled with your unique participant identifier. Once the recording has been transcribed and the transcript checked for accuracy by a second member of the research team, the recording of your research session will be deleted from all locations.

Research data (including consent data) will be stored for three years after publication or release of the research. All collected research data is essential in the analyses of the finished project. Your contact details will be deleted after all data are analysed, unless you have agreed to being informed about future research studies. We will keep your consent data with your contact details, as your consent is our legal basis for recontacting you under UK data protection law. If you decline to have your contact details stored to be contacted about future research, we will remove these from our database.

Responsible members of the University of Oxford may be given access to data for monitoring and/or audit of the study to ensure we are complying with guidelines.

8. Will the research be published? Could I be identified from any publications or other research outputs?

The results of this research may be published in a peer-reviewed academic journal and presented at academic conferences. Direct quotes from your research session may be included in publications and/or presentations but you will not be personally identifiable in any journal articles or presentations. Some of the research will also contribute to the fulfilment of an educational requirement (MSc thesis).

9. Data protection

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the research. The University will process your personal data for the purpose of the research outlined above. Research is a task that is performed in the public interest. Further information about your rights with respect to your personal data is available from the University's Information Compliance web site at https://compliance.admin.ox.ac.uk/individual-rights.

10. Who has reviewed this research?

This research has received ethics approval from a subcommittee of the University of Oxford Central University Research Ethics Committee (Approval Reference: R91126/RE001).

7. Who do I contact if I have a concern about the research or I wish to complain?

If you have a concern about any aspect of this research, please contact Prof Nele Demeyere (telephone: 01865 271340, email: nele.demeyere@ndcn.ox.ac.uk) and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Research

Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible:

The Chair, Medical Sciences Interdivisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Boundary Brook House, Churchill Drive, Headington, Oxford OX3 7GB

8. Further information and contact details

If you would like to discuss the research before you decide whether or not to take part or if you have questions afterwards, please contact:

Primary researcher:
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