



THE 65+ DEMENTIA STUDY CONSENT FORM

Version 4 (30/10/17)

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Telephone: 0131 537 1980

Name of patient:.....Participant ID:.....

Please
initial
box

1. I have read and understand the information leaflet version 3 (dated 30/10/17) for the above study and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without my medical care being affected.
2. I agree to a clinical assessment by the research team and to answer some questions about my past medical history and any family history of dementia, the answers to which will be recorded on a questionnaire form.
3. I agree to have a magnetic resonance imaging (MRI) scan of my brain.
4. I agree to my General Practitioner and consultant being contacted to inform them of my participation in this study, for follow-up and for the researchers to examine my GP and hospital medical records.
5. I agree to give a blood sample from which genetic material will be extracted and used for codon-129 typing.
6. I agree to the storage of genetic material from the blood sample and its use in future genetic research into neurological conditions, including whole genome scanning, with appropriate ethical approvals.
7. I agree that if a blood sample cannot be obtained, to give a mouth (inner cheek) swab from which genetic material will be extracted and used for codon-129 typing.
8. I agree to the use of the hospital's patient management system by responsible individuals from the research team to follow my progress. I agree to the researchers contacting me on a regular basis to see how I am getting on and if necessary undergo further clinical assessment.
9. I understand that I will not routinely be informed of the outcome of my research investigations, unless there is evidence of prion disease or incidental findings that could have an impact on my patient management or care. In this event then I understand the researchers will discuss the findings with the local doctor(s) in charge of my care.

10. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the regulatory authorities and from the Sponsors (The University of Edinburgh and NHS Lothian) where it is relevant to my taking part in this research. I give permission for those individuals to have access to my records.

11. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Please provide copies as follows:

1x original – NCJDRSU study file; 1x copy – Medical records; 1x copy – Participant; 1x copy – Brain Research Imaging Centre