

Dr Aileen Ho
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18 January 2018

Dear Aileen

UREC 16/30: Understanding adjustment in neurodegenerative disease. Favourable opinion

Thank you for the response (your email, dated 10 January 2018, refers) addressing the issues raised by the UREC Sub-committee at its June 2016 meeting (*my Provisional Opinion email of 10 June 2016 including attachments refers*). On the basis of these responses, I can confirm that the Chair is pleased to confirm a favourable ethical opinion.

Separately (*and **not** as a condition of approval*), the Committee would like to ask you to consider the recent advice and example statements – from UREC and the University’s Research Data Manager, and given via Heads of Schools – to include a statement in the Data Section of the Information Sheet and Consent form that would facilitate the ‘downstream’ sharing of data. The advice was that the researcher should check that:

“The consent form asks the research participant for permission to preserve some or all of the data they provide over the long term, and to make the data available, in anonymised form if required, either openly or subject to appropriate safeguards, so that they can be consulted and re-used by others, in accordance with the University’s Research Data Management Policy.”

Two examples of wording which can be used are below, one is anonymised data and the latter is not-anonymised:

‘I understand that the data collected from me in this study will be preserved and made available in anonymised form, so that they can be consulted and re-used by others.’

OR

‘I understand that the data collected from me in this study will be preserved, and will be made available to other authenticated researchers only if they agree to maintain the confidentiality of the information provided to them.’

Please note that the Committee will monitor the progress of projects to which it has given favourable ethical opinion approximately one year after such agreement, and then on a regular basis until its completion.

Please also find attached Safety Note 59: Incident Reporting in Human Interventional Studies at the University of Reading, to be followed should there be an incident arising from the conduct of this research.

The University Board for Research and Innovation has also asked that recipients of favourable ethical opinions from UREC be reminded of the provisions of the University Code of Good Practice in Research. A copy is attached and further information may be obtained here:

<http://www.reading.ac.uk/internal/res/QualityAssuranceInResearch/reas-RSgar.aspx>.

Yours sincerely

A handwritten signature in black ink that reads "Mike Proven". The signature is written in a cursive, slightly slanted style.

Dr M J Proven
Coordinator for Quality Assurance in Research (UREC Secretary)
cc: *Dr John Wright (Chair); Professor Laurie Butler (Head of School);*