

Ethics Committee

Ms Jo Belcher
School of Sociology
FAHS

01 October 2012

Dear Ms Belcher

Online Support Spaces for UK-resident Parents of People with a Rare Syndrome: How do they work, who are they for and how are they used? EC/2012/96/FAHS

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: 1 October 2012.

The final list of documents reviewed by the Committee is as follows:

Document
Summary of the project
Detailed protocol for the project
Information sheet for participants
Invitation to Rett UK members
Consent forms
The Internet, Online support and You: a survey
Correspondence with Rett UK
Risk assessment
Recruitment advert
Summary of Key Information (for dissemination on online support spaces)
Record of Online Support Space Use
Interview Schedule
Online Support for Parents of People with Rett Syndrome – Stage Two
Further information and support
CRB

This opinion is given on the understanding that you will comply with the University's Ethical Guidelines for Teaching and Research. If the project includes distribution of a survey or questionnaire to members of the University community, researchers are asked to include a statement advising that the project has been reviewed by the University's Ethics Committee.

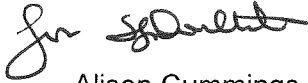
If you wish to make any amendments to your protocol please address your request to the Secretary of the Ethics Committee and attach any revised documentation.

The Committee will need to be notified of adverse reactions suffered by research participants, and if the study is terminated earlier than expected with reasons. Please be advised that the Ethics Committee is able to audit research to ensure that researchers are abiding by the University requirements and guidelines.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Alison Cummings', written in a cursive style.

Alison Cummings
Secretary, University Ethics Committee
Academic Registry