

Sir David,

Without doubt an area that must receive consideration in any comprehensive review is the current state of ethical review committees throughout the UK. For those of us who work in rare diseases we must recruit patients from across health boundaries which means many months spent sending off mountains of paperwork to ethics committees all over the country, all of whom want to raise the same reduplicative points over and over again, even if they have already been addressed. Whilst waiting for an MREC to approve my study into motor neurone disease, all the eligible patients at three of the UK's five centres had died by the time approval was granted (seven months later).

The funding can be as streamlined as can be, but without reform these cumbersome and pointless barriers to research will hamstring the government's efforts to improve research. The ethics process alone has put many clinicians off the idea of carrying out their own research; when a simple questionnaire study requires the same 68 page document as a clinical trial, research does not seem like a good use of time. Furthermore the issues that most REC's concern themselves with have nothing to do with ethics or the Declaration of Helsinki, but are usually requests for points of information that are in fact in the documentation already. At one point the Liverpool REC requested I send them 28 copies of all documents relating to my study (1200 pieces of paper) for a simple non-invasive psychology study, I had to have an honorary contract in five places, spent weeks on the phone tracking down authorised signatories, and in the end recruited only seven participants, translating to about 4 weeks of labour per participant.

There should be a national ethics committee which entitles researchers to recruit patients from any region so long as they have a valid CRB check, the permission of the patient's consultant or GP to contact them, and the patient's informed consent.

Yours sincerely,

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