

1 June 2007

Kate Lawrence
Clerk to the Joint Committee on the
Draft Human Tissue and Embryos Bill
House of Lords
London SW1A 0PW

Dear Ms Lawrence,

Draft Human Tissue and Embryos Bill

Thank you for the opportunity to submit evidence to the Joint Committee on the draft Human Tissue and Embryos Bill. The Nuffield Council on Bioethics has not previously considered many of the issues raised by the proposed legislation and is therefore unable to comment on most of the questions listed in the scope of the Committee's inquiry. The Council has, however, considered issues relating to the proposed changes in the legislation on embryo testing, and consent to use of gametes and embryos. The Council's conclusions in these areas are summarised below.

Embryo testing

10. *What are your views on the provisions in paragraph 3 of Schedule 2 setting out the conditions under which (a) embryos can be tested and (b) sex selection practices can be carried out?*

The Council considered general criteria for embryo testing in its Report *Genetics and human behaviour: the ethical context* (2002).¹ The Report discusses the use of pre-implantation genetic diagnosis (PGD) for both clinical and non-clinical reasons. It recommends that PGD should not be extended to include behavioural traits in the normal range such as intelligence, sexual orientation and personality traits.

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We note that, in accordance with the Council's recommendations, the conditions set out in the draft Bill under which embryo testing may be carried out have not been extended to include behavioural traits in the normal range. As such, we welcome the proposed provision that testing will not be authorised unless there is a particular risk that the embryo may have a gene, chromosome or mitochondrial abnormality, and that there is a risk that a person with the abnormality will develop a serious disability or illness.

Consent to storage and use of gametes and embryos

11. What are your views on the proposed changes to consent provisions?

In the Discussion Paper, *Stem cell therapy: the ethical issues* (2000),² the Council recommended that gamete and embryo donors should be asked explicitly whether or not they consent to embryonic stem cell research and subsequent use of the cell line. We note that this has not been stipulated in the draft Bill. However, the HFEA's Sixth Code of Practice (2003) states "where consent is sought for the use of embryos in stem cell research, donors must be given 'thorough and appropriate information, including that any stem cell lines may continue indefinitely and may be used in different research projects'". The draft Bill does not amend the requirement for a Code of Practice and we urge the new Regulatory Authority for Tissue and Embryos to maintain in future revisions of the Code the HFEA's guidance on seeking consent to use embryos in stem cell research.

All reports of the Council can be downloaded at:

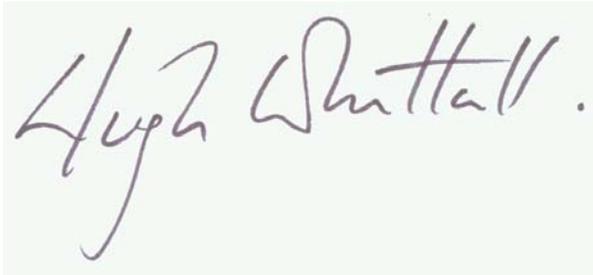
www.nuffieldbioethics.org/go/publications/latest_30.html

Oral evidence

As you know, I have been invited to give oral evidence to the Committee on 5th June 2007. I understand that I have been invited to attend the Committee hearing partly in view of my current position with the Nuffield Council on Bioethics, but largely because of my experience in working at the Human Fertilisation and Embryology Authority, and in working for the Department of Health on legislation and regulation in the area of human tissue. In view of this, I would like to take this opportunity to clarify that the information and views that I will give at the oral hearing will be given in my personal capacity with the exception of the specific Council responses set out above. Accordingly, any views given will, unless I specify otherwise, be mine and not those of the Council.

Please do not hesitate to contact me if you require clarification on any of the information contained in this letter.

Yours sincerely,

A handwritten signature in dark ink on a light green background. The signature reads "Hugh Whittall." with a period at the end. The handwriting is cursive and fluid.

Hugh Whittall
Director

¹ *Genetics and human behaviour: the ethical context* is available at: www.nuffieldbioethics.org/go/ourwork/behaviouralgenetics/introduction. See Chapters 13.57-13.78.

² *Stem cell therapy: the ethical issues* is available to download at: <http://www.nuffieldbioethics.org/go/screen/ourwork/stemcells/introduction>