

HUMAN FERTILISATION AND EMBRYOLOGY ACT 2008

EXPLANATORY NOTES

COMMENTARY ON SECTIONS

Part 1: Amendments of Human Fertilisation and Embryology Act 1990

Section 25: Restrictions on disclosure of information

157. This section inserts into the 1990 Act new section 33A which will replace the current section 33. New section 33A retains the prohibition on the disclosure of the information falling within section 31(2) of the 1990 Act.
158. Section 33 of the 1990 Act distinguishes between information which can be disclosed by the HFEA and information which can be disclosed by licence holders and persons to whom directions have been given. New section 33A places all persons who might hold information which is on the HFEA's register on a similar footing when it comes to lifting the prohibitions on disclosure. Information which has been obtained by any person as a member or an employee of the HFEA, a person to whom a licence applies, including those covered by third party agreements, those to whom directions from the HFEA have been given, and authorised people who are carrying out functions which have been contracted out to them by the HFEA (and their members of staff or employees), may not be disclosed except to the categories of person or in the circumstances specified in new section 33A(2).
159. Section 33A(2) lifts the prohibition on disclosure which section 33A(1) imposes in certain circumstances. Previously the exceptions to the prohibitions have been listed in section 33 of the 1990 Act, as amended by the Human Fertilisation and Embryology (Disclosure of Information) Act 1992 and the 2007 Regulations. Most of the current section 33 exceptions are being retained. Some are however being replaced, and additional exceptions have been included in new section 33A(2). For example, now section 33A(2) lifts the prohibition on disclosure where disclosure is to other persons or bodies discharging a regulatory function and or is to a person who is performing functions contracted out to them by the HFEA, or under third party agreements, or with the consent of those to whom the information relates (in certain circumstances). Anyone considering whether it is lawful to disclose the relevant information will still need to satisfy themselves that the disclosure would not breach the Data Protection Act 1998 or any confidentiality rights. New section 33C provides a regulation-making power to make further exceptions to 33A(1).
160. New section 33D enables the Secretary of State to make provision, in regulations, requiring or regulating the disclosure of information falling within section 31(2) for research purposes. Information can be disclosed for the purposes of medical research where the Secretary of State considers it necessary or expedient in the public interest or in the interests of improving patient care. Information can be disclosed for other research purposes if the Secretary of State considers it necessary or expedient in the public interest. Fees may be charged in accordance with regulations made by the

Secretary of State for these purposes. The regulations may make provision requiring fees of a prescribed amount to be paid to the HFEA by persons in relation to the disclosure of protected information to them under the regulations. It is intended that the fees charged would recover all or part of the costs of providing the information. Such research could include follow-up studies on the safety of IVF. The regulations may make provision for disclosure to be lawful despite any duty of confidentiality owed in relation to the information. It is expected that this power would only be used in such circumstances where it would not be possible to obtain consent to the disclosure.

161. Before making the regulations, the Secretary of State must consult, to the extent that he considers appropriate, such bodies who appear to represent the interests of those who are likely to be affected by the regulations. The regulations may make provision for the establishment of a body which will have the function of considering whether disclosure should be authorised, should the Secretary of State consider this to be appropriate.