Changes to legislation: Human Fertilisation and Embryology Act 2008, Cross Heading: Information is up to date with all changes known to be in force on or before 10 September 2024. There are changes that may be brought into force at a future date. Changes that have been made appear in the content and are referenced with annotations. (See end of Document for details)



# Human Fertilisation and Embryology Act 2008

# **2008 CHAPTER 22**

#### PART 1

AMENDMENTS OF THE HUMAN FERTILISATION AND EMBRYOLOGY ACT 1990

# Information

# 24 Register of information

For section 31 of the 1990 Act (the Authority's register of information) substitute—

# "31 Register of information

- (1) The Authority shall keep a register which is to contain any information which falls within subsection (2) and which—
  - (a) immediately before the coming into force of section 24 of the Human Fertilisation and Embryology Act 2008, was contained in the register kept under this section by the Authority, or
  - (b) is obtained by the Authority.
- (2) Subject to subsection (3), information falls within this subsection if it relates to—
  - (a) the provision for any identifiable individual of treatment services other than basic partner treatment services,
  - (b) the procurement or distribution of any sperm, other than sperm which is partner-donated sperm and has not been stored, in the course of providing non-medical fertility services for any identifiable individual,
  - (c) the keeping of the gametes of any identifiable individual or of an embryo taken from any identifiable woman,

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- the use of the gametes of any identifiable individual other than their use for the purpose of basic partner treatment services, or
- the use of an embryo taken from any identifiable woman,
- or if it shows that any identifiable individual is a relevant individual.
- (3) Information does not fall within subsection (2) if it is provided to the Authority for the purposes of any voluntary contact register as defined by section 31ZF(1).
- (4) In this section "relevant individual" means an individual who was or may have been born in consequence of
  - treatment services, other than basic partner treatment services, or
  - the procurement or distribution of any sperm (other than partner-(b) donated sperm which has not been stored) in the course of providing non-medical fertility services.

# 31ZA Request for information as to genetic parentage etc.

- (1) A person who has attained the age of 16 ("the applicant") may by notice to the Authority require the Authority to comply with a request under subsection (2).
- (2) The applicant may request the Authority to give the applicant notice stating whether or not the information contained in the register shows that a person ("the donor") other than a parent of the applicant would or might, but for the relevant statutory provisions, be the parent of the applicant, and if it does show that
  - giving the applicant so much of that information as relates to the (a) donor as the Authority is required by regulations to give (but no other information), or
  - stating whether or not that information shows that there are other persons of whom the donor is not the parent but would or might, but for the relevant statutory provisions, be the parent and if so—
    - (i) the number of those other persons,
    - (ii) the sex of each of them, and
    - (iii) the year of birth of each of them.
- (3) The Authority shall comply with a request under subsection (2) if
  - the information contained in the register shows that the applicant is a relevant individual, and
  - (b) the applicant has been given a suitable opportunity to receive proper counselling about the implications of compliance with the request.
- (4) Where a request is made under subsection (2)(a) and the applicant has not attained the age of 18 when the applicant gives notice to the Authority under subsection (1), regulations cannot require the Authority to give the applicant any information which identifies the donor.
- (5) Regulations cannot require the Authority to give any information as to the identity of a person whose gametes have been used or from whom an embryo has been taken if a person to whom a licence applied was provided with the information at a time when the Authority could not have been required to give information of the kind in question.

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- (6) The Authority need not comply with a request made under subsection (2)(b) by any applicant if it considers that special circumstances exist which increase the likelihood that compliance with the request would enable the applicant—
  - (a) to identify the donor, in a case where the Authority is not required by regulations under subsection (2)(a) to give the applicant information which identifies the donor, or
  - (b) to identify any person about whom information is given under subsection (2)(b).
- (7) In this section—

"relevant individual" has the same meaning as in section 31;

"the relevant statutory provisions" means sections 27 to 29 of this Act and sections 33 to 47 of the Human Fertilisation and Embryology Act 2008.

# 31ZB Request for information as to intended spouse etc.

- (1) Subject to subsection (4), a person ("the applicant") may by notice to the Authority require the Authority to comply with a request under subsection (2).
- (2) The applicant may request the Authority to give the applicant notice stating whether or not information contained in the register shows that, but for the relevant statutory provisions, the applicant would or might be related to a person specified in the request ("the specified person") as—
  - (a) a person whom the applicant proposes to marry,
  - (b) a person with whom the applicant proposes to enter into a civil partnership, or
  - (c) a person with whom the applicant is in an intimate physical relationship or with whom the applicant proposes to enter into an intimate physical relationship.
- (3) Subject to subsection (5), the Authority shall comply with a request under subsection (2) if—
  - (a) the information contained in the register shows that the applicant is a relevant individual,
  - (b) the Authority receives notice in writing from the specified person consenting to the request being made and that notice has not been withdrawn, and
  - (c) the applicant and the specified person have each been given a suitable opportunity to receive proper counselling about the implications of compliance with the request.
- (4) A request may not be made under subsection (2)(c) by a person who has not attained the age of 16.
- (5) Where a request is made under subsection (2)(c) and the specified person has not attained the age of 16 when the applicant gives notice to the Authority under subsection (1), the Authority must not comply with the request.
- (6) Where the Authority is required under subsection (3) to comply with a request under subsection (2), the Authority must take all reasonable steps to give the applicant and the specified person notice stating whether or not the information

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contained in the register shows that, but for the relevant statutory provisions, the applicant and the specified person would or might be related.

#### (7) In this section—

"relevant individual" has the same meaning as in section 31;

"the relevant statutory provisions" has the same meaning as in section 31ZA.

# 31ZC Power of Authority to inform donor of request for information

# (1) Where—

- (a) the Authority has received from a person ("the applicant") a notice containing a request under subsection (2)(a) of section 31ZA, and
- (b) compliance by the Authority with its duty under that section has involved or will involve giving the applicant information relating to a person other than the parent of the applicant who would or might, but for the relevant statutory provisions, be a parent of the applicant ("the donor"),

the Authority may notify the donor that a request under section 31ZA(2)(a) has been made, but may not disclose the identity of the applicant or any information relating to the applicant.

(2) In this section "the relevant statutory provisions" has the same meaning as in section 31ZA.

#### 31ZD Provision to donor of information about resulting children

- (1) This section applies where a person ("the donor") has consented under Schedule 3 (whether before or after the coming into force of this section) to—
  - (a) the use of the donor's gametes, or an embryo the creation of which was brought about using the donor's gametes, for the purposes of treatment services provided under a licence, or
  - (b) the use of the donor's gametes for the purposes of non-medical fertility services provided under a licence.

# (2) In subsection (1)—

- (a) "treatment services" do not include treatment services provided to the donor, or to the donor and another person together, and
- (b) "non-medical fertility services" do not include any services involving partner-donated sperm.
- (3) The donor may by notice request the appropriate person to give the donor notice stating—
  - (a) the number of persons of whom the donor is not a parent but would or might, but for the relevant statutory provisions, be a parent by virtue of the use of the gametes or embryos to which the consent relates,
  - (b) the sex of each of those persons, and
  - (c) the year of birth of each of those persons.
- (4) Subject to subsections (5) to (7), the appropriate person shall notify the donor whether the appropriate person holds the information mentioned in

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- subsection (3) and, if the appropriate person does so, shall comply with the request.
- (5) The appropriate person need not comply with a request under subsection (3) if the appropriate person considers that special circumstances exist which increase the likelihood that compliance with the request would enable the donor to identify any of the persons falling within paragraphs (a) to (c) of subsection (3).
- (6) In the case of a donor who consented as described in subsection (1)(a), the Authority need not comply with a request made to it under subsection (3) where the person who held the licence referred to in subsection (1)(a) continues to hold a licence under paragraph 1 of Schedule 2, unless the donor has previously made a request under subsection (3) to the person responsible and the person responsible—
  - (a) has notified the donor that the information concerned is not held, or
  - (b) has failed to comply with the request within a reasonable period.
- (7) In the case of a donor who consented as described in subsection (1)(b), the Authority need not comply with a request made to it under subsection (3) where the person who held the licence referred to in subsection (1)(b) continues to hold a licence under paragraph 1A of Schedule 2, unless the donor has previously made a request under subsection (3) to the person responsible and the person responsible—
  - (a) has notified the donor that the information concerned is not held, or
  - (b) has failed to comply with the request within a reasonable period.
- (8) In this section "the appropriate person" means—
  - (a) in the case of a donor who consented as described in paragraph (a) of subsection (1)—
    - (i) where the person who held the licence referred to in that paragraph continues to hold a licence under paragraph 1 of Schedule 2, the person responsible, or
    - (ii) the Authority, and
  - (b) in the case of a donor who consented as described in paragraph (b) of subsection (1)—
    - (i) where the person who held the licence referred to in that paragraph continues to hold a licence under paragraph 1A of Schedule 2, the person responsible, or
    - (ii) the Authority.
- (9) In this section "the relevant statutory provisions" has the same meaning as in section 31ZA.

# 31ZE Provision of information about donor-conceived genetic siblings

- (1) For the purposes of this section two relevant individuals are donor-conceived genetic siblings of each other if a person ("the donor") who is not the parent of either of them would or might, but for the relevant statutory provisions, be the parent of both of them.
- (2) Where—

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- (a) the information on the register shows that a relevant individual ("A") is the donor-conceived genetic sibling of another relevant individual ("B"),
- (b) A has provided information to the Authority ("the agreed information") which consists of or includes information which enables A to be identified with the request that it should be disclosed to—
  - (i) any donor-conceived genetic sibling of A, or
  - (ii) such siblings of A of a specified description which includes B, and
- (c) the conditions in subsection (3) are satisfied,

then, subject to subsection (4), the Authority shall disclose the agreed information to B.

- (3) The conditions referred to in subsection (2)(c) are—
  - (a) that each of A and B has attained the age of 18,
  - (b) that B has requested the disclosure to B of information about any donorconceived genetic sibling of B, and
  - (c) that each of A and B has been given a suitable opportunity to receive proper counselling about the implications of disclosure under subsection (2).
- (4) The Authority need not disclose any information under subsection (2) if it considers that the disclosure of information will lead to A or B identifying the donor unless—
  - (a) the donor has consented to the donor's identity being disclosed to A or B, or
  - (b) were A or B to make a request under section 31ZA(2)(a), the Authority would be required by regulations under that provision to give A or B information which would identify the donor.
- (5) In this section—

"relevant individual" has the same meaning as in section 31;

"the relevant statutory provisions" has the same meaning as in section 31ZA.

# 31ZF Power of Authority to keep voluntary contact register

- (1) In this section and section 31ZG, a "voluntary contact register" means a register of persons who have expressed their wish to receive information about any person to whom they are genetically related as a consequence of the provision to any person of treatment services in the United Kingdom before 1 August 1991.
- (2) The Authority may—
  - (a) set up a voluntary contact register in such manner as it thinks fit,
  - (b) keep a voluntary contact register in such manner as it thinks fit,
  - (c) determine criteria for eligibility for inclusion on the register and the particulars that may be included,
  - (d) charge a fee to persons who wish their particulars to be entered on the register,
  - (e) arrange for samples of the DNA of such persons to be analysed at their request,

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- (f) make such arrangements as it thinks fit for the disclosure of information on the register between persons who appear to the Authority to be genetically related, and
- (g) impose such conditions as it thinks fit to prevent a person ("A") from disclosing information to a person to whom A is genetically related ("B") where that information would identify any person who is genetically related to both A and B.
- (3) The Authority may make arrangements with any person by whom a voluntary contact register is kept before the commencement of this section for the supply by that person to the Authority of the information contained in the register maintained by that person.

# 31ZG Financial assistance for person setting up or keeping voluntary contact register

- (1) The Authority may, instead of keeping a voluntary contact register, give financial assistance to any person who sets up or keeps a voluntary contact register.
- (2) Financial assistance under subsection (1) may be given in any form, and in particular, may be given by way of—
  - (a) grants,
  - (b) loans,
  - (c) guarantees, or
  - (d) incurring expenditure for the person assisted.
- (3) Financial assistance under subsection (1) may be given on such terms and conditions as the Authority considers appropriate.
- (4) A person receiving assistance under subsection (1) must comply with the terms and conditions on which it is given, and compliance may be enforced by the Authority."

### **Commencement Information**

I1 S. 24 wholly in force at 1.10.2009; s. 24 not in force at Royal Assent see s. 68; s. 24 in force for certain purposes at 6.4.2009 by S.I. 2009/479, art. 5(d)(h) (with Sch.); s. 24 in force at 1.10.2009 otherwise by S.I. 2009/2232, art. 2(k)

#### 25 Restrictions on disclosure of information

For section 33 of the 1990 Act (restrictions on disclosure of information) substitute—

#### "33A Disclosure of information

- (1) No person shall disclose any information falling within section 31(2) which the person obtained (whether before or after the coming into force of section 24 of the Human Fertilisation and Embryology Act 2008) in the person's capacity as—
  - (a) a member or employee of the Authority,

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- (b) any person exercising functions of the Authority by virtue of section 8B or 8C of this Act (including a person exercising such functions by virtue of either of those sections as a member of staff or as an employee),
- (c) any person engaged by the Authority to provide services to the Authority,
- (d) any person employed by, or engaged to provide services to, a person mentioned in paragraph (c),
- (e) a person to whom a licence applies,
- (f) a person to whom a third party agreement applies, or
- (g) a person to whom directions have been given.

### (2) Subsection (1) does not apply where—

- (a) the disclosure is made to a person as a member or employee of the Authority or as a person exercising functions of the Authority as mentioned in subsection (1)(b),
- (b) the disclosure is made to or by a person falling within subsection (1)(c) for the purpose of the provision of services which that person is engaged to provide to the Authority,
- (c) the disclosure is made by a person mentioned in subsection (1)(d) for the purpose of enabling a person falling within subsection (1)(c) to provide services which that person is engaged to provide to the Authority,
- (d) the disclosure is made to a person to whom a licence applies for the purpose of that person's functions as such,
- (e) the disclosure is made to a person to whom a third party agreement applies for the purpose of that person's functions under that agreement,
- (f) the disclosure is made in pursuance of directions given by virtue of section 24.
- (g) the disclosure is made so that no individual can be identified from the information.
- (h) the disclosure is of information other than identifying donor information and is made with the consent required by section 33B,
- (i) the disclosure—
  - (i) is made by a person who is satisfied that it is necessary to make the disclosure to avert an imminent danger to the health of an individual ("P"),
  - (ii) is of information falling within section 31(2)(a) which could be disclosed by virtue of paragraph (h) with P's consent or could be disclosed to P by virtue of subsection (5), and
  - (iii) is made in circumstances where it is not reasonably practicable to obtain P's consent,
- (j) the disclosure is of information which has been lawfully made available to the public before the disclosure is made,
- (k) the disclosure is made in accordance with sections 31ZA to 31ZE.
- (l) the disclosure is required or authorised to be made—
  - (i) under regulations made under section 33D, or
  - (ii) in relation to any time before the coming into force of the first regulations under that section, under regulations made under section 251 of the National Health Service Act 2006,

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- (m) the disclosure is made by a person acting in the capacity mentioned in subsection (1)(a) or (b) for the purpose of carrying out the Authority's duties under section 8A,
- (n) the disclosure is made by a person acting in the capacity mentioned in subsection (1)(a) or (b) in pursuance of an order of a court under section 34 or 35.
- (o) the disclosure is made by a person acting in the capacity mentioned in subsection (1)(a) or (b) to the Registrar General in pursuance of a request under section 32,
- (p) the disclosure is made by a person acting in the capacity mentioned in subsection (1)(a) or (b) to any body or person discharging a regulatory function for the purpose of assisting that body or person to carry out that function,
- (q) the disclosure is made for the purpose of establishing in any proceedings relating to an application for an order under subsection (1) of section 54 of the Human Fertilisation and Embryology Act 2008 whether the condition specified in paragraph (a) or (b) of that subsection is met,
- (r) the disclosure is made under section 3 of the Access to Health Records Act 1990,
- (s) the disclosure is made under Article 5 of the Access to Health Records (Northern Ireland) Order 1993, or
- (t) the disclosure is made necessarily for—
  - (i) the purpose of the investigation of any offence (or suspected offence), or
  - (ii) any purpose preliminary to proceedings, or for the purposes of, or in connection with, any proceedings.
- (3) Subsection (1) does not apply to the disclosure of information in so far as—
  - (a) the information identifies a person who, but for sections 27 to 29 of this Act or sections 33 to 47 of the Human Fertilisation and Embryology Act 2008, would or might be a parent of a person who instituted proceedings under section 1A of the Congenital Disabilities (Civil Liability) Act 1976, and
  - (b) the disclosure is made for the purpose of defending such proceedings, or instituting connected proceedings for compensation against that parent.
- (4) Paragraph (t) of subsection (2), so far as relating to disclosure for the purpose of the investigation of an offence or suspected offence, or for any purpose preliminary to, or in connection with proceedings, does not apply—
  - (a) to disclosure of identifying donor information, or
  - (b) to disclosure, in circumstances in which subsection (1) of section 34 of this Act applies, of information relevant to the determination of the question mentioned in that subsection, made by any person acting in a capacity mentioned in any of paragraphs (c) to (g) of subsection (1).
- (5) Subsection (1) does not apply to the disclosure to any individual of information which—
  - (a) falls within subsection (2) of section 31 of this Act by virtue of any of paragraphs (a) to (e) of that subsection, and

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- (b) relates only to that individual or, in the case of an individual who is treated together with, or gives a notice under section 37 or 44 of the Human Fertilisation and Embryology Act 2008 in respect of, another, only to that individual and that other.
- (6) In subsection (2)—
  - (a) in paragraph (p) "regulatory function" has the same meaning as in section 32 of the Legislative and Regulatory Reform Act 2006, and
  - (b) in paragraph (t) references to "proceedings" include any formal procedure for dealing with a complaint.
- (7) In this section "identifying donor information" means information enabling a person to be identified as a person whose gametes were used in accordance with consent given under paragraph 5 of Schedule 3 for the purposes of treatment services or non-medical fertility services in consequence of which an identifiable individual was, or may have been, born.

# 33B Consent required to authorise certain disclosures

- (1) This section has effect for the purposes of section 33A(2)(h).
- (2) Subject to subsection (5), the consent required by this section is the consent of each individual who can be identified from the information.
- (3) Consent in respect of a person who has not attained the age of 18 years ("C") may be given—
  - (a) by C, in a case where C is competent to deal with the issue of consent, or
  - (b) by a person having parental responsibility for C, in any other case.
- (4) Consent to disclosure given at the request of another shall be disregarded unless, before it is given, the person requesting it takes reasonable steps to explain to the individual from whom it is requested the implications of compliance with the request.
- (5) In the case of information which shows that any identifiable individual ("A") was, or may have been, born in consequence of treatment services, the consent required by this section does not include A's consent if the disclosure is necessarily incidental to the disclosure of information falling within section 31(2)(a).
- (6) The reference in subsection (3) to parental responsibility is—
  - (a) in relation to England and Wales, to be read in accordance with the Children Act 1989;
  - (b) in relation to Northern Ireland, to be read in accordance with the Children (Northern Ireland) Order 1995;
  - (c) in relation to Scotland, to be read as a reference to parental responsibilities and parental rights within the meaning of the Children (Scotland) Act 1995.

# 33C Power to provide for additional exceptions from section 33A(1)

- (1) Regulations may provide for additional exceptions from section 33A(1).
- (2) No exception may be made under this section for—

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- (a) disclosure of a kind mentioned in paragraph (a) or (b) of subsection (4) of section 33A, or
- (b) disclosure in circumstances in which section 32 of this Act applies of information having the tendency mentioned in subsection (2) of that section, made by any person acting in a capacity mentioned in any of paragraphs (c) to (g) of subsection (1) of section 33A.

# 33D Disclosure for the purposes of medical or other research

- (1) Regulations may—
  - (a) make such provision for and in connection with requiring or regulating the processing of protected information for the purposes of medical research as the Secretary of State considers is necessary or expedient in the public interest or in the interests of improving patient care, and
  - (b) make such provision for and in connection with requiring or regulating the processing of protected information for the purposes of any other research as the Secretary of State considers is necessary or expedient in the public interest.
- (2) Regulations under subsection (1) may, in particular, make provision—
  - (a) for requiring or authorising the disclosure or other processing of protected information to or by persons of any prescribed description subject to compliance with any prescribed conditions (including conditions requiring prescribed undertakings to be obtained from such persons as to the processing of such information),
  - (b) for securing that, where prescribed protected information is processed by a person in accordance with the regulations, anything done by that person in so processing the information must be taken to be lawfully done despite any obligation of confidence owed by the person in respect of it,
  - (c) for requiring fees of a prescribed amount to be paid to the Authority in prescribed circumstances by persons in relation to the disclosure to those persons of protected information under those regulations,
  - (d) for the establishment of one or more bodies to exercise prescribed functions in relation to the processing of protected information under those regulations,
  - (e) as to the membership and proceedings of any such body, and
  - (f) as to the payment of remuneration and allowances to any member of any such body and the reimbursement of expenses.
- (3) Where regulations under subsection (1) require or regulate the processing of protected information for the purposes of medical research, such regulations may enable any approval given under regulations made under section 251 of the National Health Service Act 2006 (control of patient information) to have effect for the purposes of the regulations under subsection (1) in their application to England and Wales.
- (4) Subsections (1) to (3) are subject to subsections (5) to (8).
- (5) Regulations under subsection (1) may not make any provision requiring or authorising the disclosure or other processing, for any purpose, of protected information, where that information is information from which an individual

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may be identified, if it would be reasonably practicable to achieve that purpose otherwise than pursuant to such regulations, having regard to the cost of and technology available for achieving that purpose.

- (6) Regulations under this section may not make provision for or in connection with the processing of protected information in a manner inconsistent with any provision made by or under the Data Protection Act 1998.
- (7) Subsection (6) does not affect the operation of provisions made under subsection (2)(b).
- (8) Before making any regulations under this section the Secretary of State shall consult such bodies appearing to the Secretary of State to represent the interests of those likely to be affected by the regulations as the Secretary of State considers appropriate.
- (9) In this section—

"prescribed" means prescribed by regulations made by virtue of this section,

"processing", in relation to information, means the use, disclosure, or obtaining of the information or the doing of such other things in relation to it as may be prescribed for the purposes of this definition, and

"protected information" means information falling within section 31(2)."

### **Commencement Information**

I2 S. 25 wholly in force at 6.4.2010; s. 25 not in force at Royal Assent see s. 68; s. 25 in force for certain purposes at 6.4.2009 by S.I. 2009/479, art. 5(e)(h) (with Sch.); s. 25 in force at 1.10.2009 for certain further purposes by S.I. 2009/2232, art. 2(I) (with art. 4); s. 25 in force at 6.4.2010 otherwise by S.I. 2010/987, art. 2(a)

### **Status:**

Point in time view as at 01/04/2013.

# **Changes to legislation:**

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