British Fertility Society

PET
Fertility • Genomics • Clarity

Briefing on the Necessity of Updating the Law Governing Fertility

The British Fertility Society (BFS) and the Progress Educational Trust (PET) urge you to move to update the Human Fertilisation and Embryology Act.

The Human Fertilisation and Embryology Act was first passed in 1990 and the last significant update to this piece of legislation was in 2008.

Who has prepared this briefing?

The British Fertility Society (BFS) is the leading national multidisciplinary organisation representing professionals practising in the field of reproductive medicine.

The objectives of the BFS are

- To promote high quality practice in the provision of fertility treatment.
- To provide a common forum for members of various disciplines having an interest in the science and treatment of infertility.
- To promote high quality scientific and clinical research in the causes and treatment of infertility.
- To provide professional leadership in the provision and regulation of infertility services.
- To promote the increase of NHS funding for and equity of access to fertility treatments.
- To work with patients to provide safe and effective fertility treatment.

The Progress Educational Trust (PET) is a registered charity and up to her death in 2019 Baroness Mary Warnock was its patron. PET was founded in 1992, as an independent voice informing debate on assisted conception and genetics. PET has no financial stake in research or clinical practice. The ultimate beneficiaries of the charity's work are families and individuals threatened by infertility and genetic disease, including people wanting an opportunity to give birth to healthy children.

Background

On her appointment in 2021, Julia Chain, Chair of the Human Fertilisation and Embryology Authority (HFEA), indicated that the Human Fertilisation and Embryology Act 1990 as amended (HFE Act) needed to be modernised as it no longer reflected the needs of patients, medical practice and scientific developments.

The BFS and PET agree that the HFE Act needs to be thoroughly reviewed and updated.

Following this announcement the BFS' Special Interest Group on Law, Policy and Ethics conducted a thorough review of the Act to develop a comprehensive set of proposals for the areas of the HFE Act in most need of law reform. The Special Interest Group is multidisciplinary including clinicians, nurses, scientists, practising and academic lawyers, counsellors, a sociologist and a bioethicist. The issues were considered from the perspective of the various stakeholders to ensure that opinion and interests of everyone were reflected in the proposals.

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Since the law was developed in 1990 fertility treatment and in particular IVF has changed significantly from a treatment that was novel and used only by a few, to a routine procedure. According to the HFEA's latest Fertility Trends Report around 52,500 patients had IVF at HFEA licensed fertility centres in the UK in 2022. To contextualise this figure, acute appendicitis is the most common abdominal surgical emergency in the world, with around 50,000 acute appendicectomies performed annually in the UK.

Furthermore, societal attitudes towards fertility treatment and who should be able to access it have changed too. There has been an increase in same sex couples and single people accessing treatment.

What needs to change?

The updating for the legislation must be a priority for the Government for many reasons but one compelling example of why the law should be reformed in this parliament is outlined in the box below.

Compromising Patient Safety

Patient safety is compromised because of an anachronistic provision in the HFE Act relating to patient confidentiality.

At present, the law states that the only professionals who are entitled to access patient-specific fertility treatment information are staff at the relevant fertility clinic and staff at the HFEA (plus, in certain circumstances, the Registrar General or a court). Except in a medical emergency, this information cannot be disclosed to anyone else – not even the patient's GP – unless the patient has given specific consent for disclosure.

This situation is almost unique in UK law. The only comparable restrictions on disclosure concern sexually transmitted infections and gender reassignment. By contrast, information concerning termination of pregnancy – an area which involves as much sensitivity and need for confidentiality as assisted conception, if not more so – is not subject to such restrictions.

Partitioning fertility treatment records from a patient's other medical records leads to problems.

Separate sets of notes need to be kept, even within the same medical facility (for example if a fertility clinic is embedded in an NHS Trust). This is not good medical practice, in terms of either safety, efficiency or cost.

It can also lead to confusion – on the part of patients and health professionals alike – as to what information has been disclosed, or can be disclosed, and to whom.

Fertility professionals aspire to offer – and increasingly, are expected to offer – a seamless service, from GP referral through investigation to appropriate treatment. The mandatory secrecy of fertility treatment makes such a service difficult, if not impossible, to achieve.

Furthermore, in a context where health services are increasingly expected to be digital, the partitioning of fertility patient notes involves contorted and onerous uses of IT. Not only can this be costly, but it can also increase the risk of mistakes.

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Compromising Patient Safety (continue)

The status of medical secrecy is a holdover from the early years of IVF and relates to sensitivities that are no longer relevant now that assisted conception is mainstream.

Maintaining the status quo would strongly suggest that there is still a stigma associated with infertility, and that fertility treatment is a taboo subject which should be hidden even from medical professionals (who are in any case bound by patient confidentiality).

None of this is to deny the importance of recording, handling and storing patient information in secure and diligent ways. Rather, it is to say that fertility treatment information should be subject to the same standards as – and, where appropriate, should be integrable with – other forms of patient information.

There is strong support for this change from patients as well as professionals and the HFEA.

This one change alone would:

- **Improve patient safety** by providing data access consistent with optimal healthcare
- **Reduce the stigma** attached to fertility treatment and infertility
- **Introduce efficiencies** in record keeping
- **Reduce the number** of consent documents that patients and professionals must complete
- Allow **a more streamlined service** for patients

Some of the further changes required include:

- Consent to creation, use and storage of embryos and gametes
- Posthumous use and storage of embryos and gametes
- Legal Parenthood
- Research, Training and Innovation
- The Person Responsible and Licence Holder
- Enforcement and Sanctions
- The HFEA Register
- Duplication of HFEA Functions

For more information about why the HFE Act needs to be revised in this parliament or to discuss this briefing in more detail, please contact:

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