



## Press release

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### **Does fertility treatment still need to be a medical secret?**

**#IVFsecret**

Fertility and genetics charity the Progress Educational Trust (PET) highlights today, at its free-to-attend #IVFsecret event, the issues around fertility treatment remaining a medical secret – not routinely included on a patient's medical records.

Sarah Norcross, director of PET, said: 'It's over 40 years since IVF was pioneered in the UK and over 8 million babies have been born worldwide via IVF, yet fertility treatment is still treated as so special and sensitive that details of it are not routinely documented as part of a patient's medical records. Hiding a patient's fertility journey from many of the healthcare practitioners providing their ongoing care, whether they have been successful or not after fertility treatment, can hinder care and potentially harm patients. PET believes it is time for change: fertility treatment should not be a medical secret.'

The #IVFsecret event will hear from chair Dr Sarah Martins da Silva, consultant obstetrician and gynaecologist at Ninewell's hospital assisted conception unit; Dr Martins da Silva is one of the BBC's most inspiring and influential women of 2019. Speakers include: Dr Jane Stewart, chair of the British Fertility Society, Gwenda Burns, chief executive of patient charity Fertility Network and Dr Catriona McMillan, senior research fellow in medical law and ethics at the University of Edinburgh's Mason Institute for Medicine, Life Science and the Law.

Dr Jane Stewart, chair of the British Fertility Society, said: 'Historically, fertility problems were a taboo subject and licensed treatment was controversial; that's why it was felt there was a need to keep entirely separate medical records within the licensed fertility centres. Now, though, infertility is, quite rightly, much more talked about and treatment is widespread and generally accepted. While patients are, of course, entitled to the same confidentiality as for any other medical issue, the idea that fertility

treatment records should be kept separate from the rest of a patient's medical record creates a number of issues.'

'Firstly, it is not good medical practice to keep separate notes, and for fertility centres embedded in NHS trusts it makes no sense to have a completely separate notes mechanism which requires IT contortions to achieve in our increasingly paperless environment, particularly frustrating when trying to provide a seamless service from GP referral, through investigation to appropriate treatment licensed or otherwise. Secondly, continuing to treat licensed fertility services as a special case, set apart from other medical services, has potentially contributed to its isolation in commissioners' minds allowing for IVF funding to be picked off as an easy target.'

Gwenda Burns, chief executive of patient charity Fertility Network UK, said: 'Not having details of a person's fertility journey on their medical records – whether they have been successful following IVF or not – can have a big impact on a patient's mental health and wellbeing. For patients who have been successful following IVF, levels of anxiety are often increased, the fear of anything going wrong is multiplied, and if midwives and other healthcare professionals, including health visitors after a birth, do not know about their fertility struggles, treatment can suffer. Fertility Network advises midwives to include mentioning fertility struggles in initial consultations with people so that they can have a full understanding of their patient's care needs.'

Dr Sarah Martins da Silva, consultant gynaecologist at Ninewells assisted conception unit, said: 'In this day and age, this additional layer of confidentiality does seem to be unnecessary and nonsensical. Confidentiality is embedded within every area of medicine. It's also not very helpful for patients to put infertility in this secret box. I welcome this conversation about whether fertility treatment still needs to be a medical secret; it will be very interesting to hear what patients think.'

Dr Catriona McMillan, senior research fellow in medical law and ethics at the University of Edinburgh said: 'This topic encourages us to have important conversations about whether record sharing enables continuity of care in this context, and the need for open, public discourse about stigma surrounding female and male fertility, and fertility treatment. It also fits into a broader, crucial conversation that is needed about updating the Human Fertilisation and Embryology Act 1990 in light of changes in societal attitudes, and scientific development.'

The free-to-attend event on 26 November 2019 at 18.00 at Riddle's Court, 322 Lawnmarket, Edinburgh EH1 2PG is open to the public, patients and professionals, and is produced by the Progress Educational Trust in partnership with the Scottish Government. If tweeting about the event, please use the hashtag #IVFsecret Register for the event at <https://sforce.co/32iK0xm>

ENDS

**Notes for editors**

For interviews with participants and case studies, contact Catherine Hill, PET head of communications on 07305-091466 [chill@progress.org.uk](mailto:chill@progress.org.uk)

Case studies: Fertility patient Breffni Nicholl, 30, said: 'I believe all medical treatment should be on your medical record regardless of what it is. Our experience of this was appalling as we were between a consultant at a fertility clinic, and a consultant for recurrent miscarriages. Because of my fertility records being private, we had to be the go-between for the consultants, both of which we were seeing through the NHS. On one occasion this involved us passing results of investigative tests done on one of our losses between the two consultants. Infertility and recurrent loss are hard enough things to experience without the added pressure of having to make sure information is conveyed correctly. Plus, keeping fertility treatment information secret only adds to the feeling that infertility shouldn't be talked about.'

Grace (a pseudonym), then 28, developed ovarian hyperstimulation syndrome (OHSS) three days after embryo transfer during NHS fertility treatment. After consulting her NHS fertility clinic, she was admitted to the main hospital's A&E with breathing difficulties and a high temperature. However, the A&E team did not know that she was going through fertility treatment because it was not written down in her medical notes. The A&E team thought she might be at risk of a pulmonary embolism (PE) and, after an hCG pregnancy test was positive, suggested to Grace that she could terminate her pregnancy and have another baby later. 'They could not understand why I was saying it's not a PE, it's because of my fertility treatment. I was breaking down when they discussed termination; I had been trying to get pregnant for 7 years; they eventually got hold of my fertility consultant and she confirmed I was having fertility treatment.' said Grace.

Later in Grace's pregnancy, she lost one of the twins she was carrying and was distressed by the insensitive comments medical staff made because of a lack of understanding of her years of infertility. 'I lost a twin and there were some very hurtful comments, like: "you can have another one"; and "it's best to only have one at a time". No one should have to experience what I went through: fertility treatment should be recorded in your medical notes.'

1. Information concerning a person's fertility treatment is subject to special legal considerations in the UK, over and above the sensitivity with which all medical information must be handled. This means that such information does *not* automatically form part of the medical records that can be accessed by various health professionals.

The only professionals who are entitled to access patient-specific fertility treatment information are staff at the relevant fertility clinic and staff at the fertility regulator (plus, in certain circumstances, the Registrar General or a court). Except in a medical emergency, this information cannot be disclosed to anyone else unless the relevant fertility patient has given specific consent for disclosure. (By way of

comparison, other areas of medicine where special legal restrictions sometimes apply to the disclosure of patient information are sexually transmitted disease and gender reassignment.)

2. The Progress Educational Trust (PET) is a UK charity working to advance public understanding of, and engagement with, science, law and ethics in the fields of human genetics, human reproduction, embryology and stem cell research. Funded by grants and public donations, PET aims to improve the choices for people affected by infertility or genetic conditions. <https://www.progress.org.uk/>

3. PET organises free-to-attend events debating the responsible application of reproductive and genetic science and publishes BioNews, a free comment and news service. Subscribe to BioNews at <https://www.bionews.org.uk/subscribe>

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