
1. Authority oversight

- 1.1.** The HFEA Register Research Panel (RRP) was set up in 2010 after the law changed to allow the disclosure to external researchers of patients' identifying information. The Authority remains the statutory Oversight Committee and therefore has a duty to exercise oversight of the work of the RRP. This paper fulfils this statutory requirement and has one main purpose: to report on the work of the panel since January 2015.

2. Register Research Panel activity since January 2015

- 2.1.** Since the last report in January 2015, the Panel has received and approved one new application (see 3.5). The Panel has sat on two occasions, to consider a new application. The Executive has continued to meet and correspond with prospective researchers.
- 2.2.** One member of the Panel, the Head of Governance and Licensing, has left the HFEA. His role on the Panel, and as Caldicott Guardian, will be replaced by the new Head of Corporate Governance when in post.

3. Update on studies approved in previous years

Cancer risk and mortality in women after IVF, UCL (approved 2010)

- 3.1.** The principal investigator, Professor Alastair Sutcliffe, presented some of the results of this study at the American Society for Reproductive Medicine in October 2015. The abstract can be found on page e37 of the conference abstract book here:

www.asrmannualmeeting.org/tyfoon/dnld/pe6afeb6186f44fe80f/abstracts.pdf

The study reported that there was a small increase in the rate of ovarian cancer in women who had received IVF. This was thought to be linked to the causes of infertility women were seeking treatment for, rather than exposure to the drugs, but the researchers did leave open the possibility that IVF affected the risk. The remainder of the analysis (covering breast and uterine cancer) should be published soon.

Mortality and general health in children born after IVF, UCL (approved 2012)

- 3.2.** After some delays last year, and some changes in research team staff, we are currently preparing the data to be transferred to the HSCIC for linkage later this month.

Development and validation of statistical models to predict pregnancy outcomes following in-vitro fertilisation (IVF) treatment, University of Aberdeen (approved 2013)

- 3.3.** The researchers have completed their analysis and have two papers planned for publication this year.

EpiHealth Outcomes Project: The effect of maternal age, embryo cryopreservation and culture on perinatal outcomes and child health, University of Manchester (approved 2013)

- 3.4.** The researchers are still working on their analysis of the data we provided and plan to start writing up in the next few months.

Investigating the impact of culture media on IVF treatment and child health outcomes: A national culture media questionnaire and HFEA Register data linkage study, University of Manchester (approved 2015)

- 3.5.** This study aims to identify the impact of different culture media on subsequent live birth rates and birth weights by linking together register data with a questionnaire completed by clinics detailing their media regimes. The researcher will be attending the HFEA offices to complete the linkage and analyses at the end of the month.

4. Other papers using HFEA data published this year

Live birth rate associated with repeat in vitro fertilisation treatment cyclesⁱ

- 4.1.** This study aimed to determine the live birth rate both per egg stimulation and with repeated cycles. It was published in the Journal of the American Medical Association in December 2015. The researchers found that among women in the United Kingdom undergoing IVF, the cumulative live-birth rate after six cycles was 65.3%, with variations by age and treatment type. Their findings suggest there is evidence to support the efficacy of extending the number of IVF cycles beyond three or four. The paper is available freely online here: <http://jama.jamanetwork.com/article.aspx?articleid=2478204> and received significant press coverage, being reported in The Times, Daily Mail, Daily Express and on BBC radio.

Treatment cycles factors affecting embryo viability and uterine receptivityⁱⁱ

- 4.2.** This statistical modelling study was published in the Reproductive BioMedicine Online in November 2015 and attempted to distinguish between factors acting on the embryo directly and those acting through the uterine environment. This found that (as would be expected) maternal age has a major effect, mainly on the embryo, but also on the uterine factors to a lesser extent. This work suggests that embryo culture has both direct effects of the in-vitro environment during the first few days of the embryo's life; but also the delay in transfer following extended culture or cryopreservation may well lead to an altered

uterine environment for the embryo post-transfer. The paper is available online to subscribers only: [http://www.rbmojournal.com/article/S1472-6483\(15\)00546-5/abstract](http://www.rbmojournal.com/article/S1472-6483(15)00546-5/abstract)

ⁱ Smith A, Tilling K, Nelson S, Lawlor D. Live birth rate associated with repeat in vitro fertilization cycles. *Journal of American Medical Association*. 2015;314(24):2654-2662.

ⁱⁱ Roberts S, Hann M, Brison D. Factors affecting embryo viability and uterine receptivity: Insights from an analysis of the UK registry data. *Reproductive Biomedicine Online*. 2015;0,0