

The Human Fertilisation and Embryology Authority is undertaking a consultation on changes to its Code of Practice 9th Edition.

The Consultation document can be found [here, https://www.hfea.gov.uk/media/2580/hfea-code-of-practice-consultation-survey-pdf-version-2.pdf](https://www.hfea.gov.uk/media/2580/hfea-code-of-practice-consultation-survey-pdf-version-2.pdf)

The following is CMF's submission to this consultation

### **Survey responses:**

Q9 4.4 (a) must include risk of a subsequent pre-term birth and the consequences of a subsequent pre-term birth for the woman and any child conceived.

4.4 (c) must include information on the limited tracking and follow up of women once they have left the clinic and thus the lack of reliable data available on the longer-term effects of OHSS.

4.4 (d) must include information provision on the lack of long-term data and research into moderate to severe OHSS in the UK and ensure women are aware of the limitations of the available long-term data on OHSS because of the lack of tracking of women.

4.4 (f) Remove word 'potential'. The word 'risk' adequately covers the fact that emotional distress is possible but not actual or certain.

Q21 The CMF is opposed to any form of egg sharing, if it can even be called that. We regard it as a deliberate inducement to women to give away eggs for no personal health benefit for the woman, but at risk to her own health. It is striking that most women targeted for egg sharing and donation are those who are economically vulnerable (including students). Wealthy women do not generally risk their own health in this way. In reality, it is a method of bartering and egg selling, dressed up as 'donation' or 'sharing'. Our greatest concern with this is for the health of young vulnerable women.

Q24 While we support any improvement in the collection of data on OHSS, these proposals are totally reliant on good working relationships with local hospitals and on women self-referring. This is therefore still insufficient and inadequate. Particularly if women do not present to their local hospital, or present but they or the hospital do not link symptoms to prior treatment. There must be mandatory follow up and mandatory tracking of women long-term by the clinics where fertility treatment is given.

The definitions of 27.1 must also include 'moderate' symptoms, as these can be significant for women and should be central to ensuring fully informed consent. Both clinics and the HFEA are failing to take seriously enough their responsibility for tracking women after fertility treatment.

Furthermore, there is a need to track women's health and well-being long-term, in order to assess their emotional well-being as well as physical. In particular, follow up of women who have donated eggs or shared eggs for research or treatment.

The most vulnerable women are those who share eggs that result in another woman's pregnancy and yet who do not conceive themselves. Also women who are lower-income or vulnerable in other ways (ethnicity, age, educationally etc). It is essential that these women are followed up long term and are invited for counselling later on, not just in the short-term.

We ask the HFEA to take significantly greater responsibility in ensuring that every clinic takes much more seriously the long-term welfare of women whom they treat.