Human Fertilisation & Embryology Authority

# Case study: Sharing good practice

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# Declaration of interests

- I work in an NHS assisted conception service
- I do private practice at a private unit, Manchester Fertility
- I have received financial support to attend scientific meetings from Merck, Gedeon Richter, Ferring and Access Fertility

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# ‘Add-on’

- No definition on what constitutes an add-on
- But shared understanding that some elements of fertility treatment are not part of a ’standard’ pathway or package and are optional
- HFEA lists 11 items, ranging from laboratory techniques (assisted hatching) to treatment strategies (elective freeze-all)

# The dilemma for clinicians

- Clinical evidence is poor for most add-ons, but awaiting high-quality evidence may disadvantage some patients
- Patient awareness is high
- Not offering add-ons may lead to patients being dissatisfied, complaining or going to another clinic
- Not offering add-ons may make the clinic look like it is behind the times and not 'cutting-edge'

# How do we responsibly deal with this?

- No easy answer
- However, some principles may be helpful
  - Patient autonomy and informed consent
  - Accurate, complete and relevant information
  - A strong doctor-patient relationship
    - These are all connected
  - Professional and peer support
    - Consensus paper on add-ons

# Autonomy and informed consent

- Patients are permitted to decide what to do with, and what may be done to their bodies
- The corresponding obligation on the part of the physician is to obtain voluntary informed consent
- For this to be valid, the quality of communication and information provided have to be adequate

# Providing information about add-ons

- Information should be provided in a manner that reflects the uncertainty or lack of evidence, not in a manner that uncritically promotes the treatment
- Clinicians need to get involved in creating and approving information, eg website pages
- Information should refer to the HFEA website
- The process can be difficult and time-consuming, but we need to recognise the need for this

manchesterfertility.com

https://www.hfea.gov.uk/media/2792/treatme... | When Evidence Says No, but Doctors Say Yes... | Endometrial Scratching | Manchester Fertility | Responding to Patients' Requests for Nontr... | Outlook Web App

## Can I have endometrial scratching?

Endometrial scratching may be of benefit if you have had previous multiple unsuccessful IVF cycles or failed implantation, despite the transfer of good quality embryos.

However, the scientific evidence regarding this is mixed and it has not been conclusively shown to improve the chance of having a baby.

Please see the HFEA website for more information. Your Manchester Fertility consultant can also discuss this with you.

If you are having IVF elsewhere but wish to have an endometrial scratch, you can book in privately for the procedure with us.

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# The doctor-patient relationship

- Often neglected in all the discussion about add-ons
- However, this is central to all treatment
- When patients request add-ons, it is not appropriate to outright refuse them or to stigmatise them
- Not all patients are ‘vulnerable’
- A trusting relationship with good communication is key
- OK to admit uncertainty and lack of knowledge about specific treatments

# An example

- Jane (40) and Henry (47) attend a private IVF clinic requesting IVF with PGT-A. Jane has a good ovarian reserve. They have a 6 year old-daughter. Jane has had 3 miscarriages after that. Standard tests are negative.
- I explained that PGT-A would not increase their cumulative chance of having a baby, and could possibly reduce this, and advised them against it. They understand my view, and start the consenting process.
- However, they return 3 weeks later for a further discussion. Henry's older brother was taken ill with a stroke, and this seems to have led to some re-appraisal of what is important to them.

# Jane and Henry

- The couple feel that PGT-A would lead them to an earlier live birth than otherwise. In my opinion, the evidence for this is poor, but it is 'bio-plausible'
- We go through the risks of embryo biopsy again.
- It emerges that they value the potential reduction in time to live birth and reduction in miscarriage highly, and are willing to accept a possible reduction in overall chance of live birth.
- When I put myself in their shoes, this is not a ridiculous point of view
- Hence, we make a shared decision to go for PGT-A

# Summarising

- Offering add-ons responsibly requires clinicians to become responsible for generating accurate patient information, in line with the consensus statement and HFEA Code of Practice
- The doctor-patient relationship is key
- Can we share and co-develop resources – treatment algorithms, decision trees, information? Professional bodies, RCOG, HFEA all have roles in this.

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# Q&A with the panel

**Yacoub Khalaf,** Guy's and St Thomas' Hospital & Authority Member, HFEA

**Gudrun Moore,** UCL's Great Ormond Street Institute of Child Health & Authority Member, HFEA

**Lynne Nice,** CARE Fertility Northampton

**Raj Mathur,** Manchester NHS Foundation Trust, SCAAC Member, HFEA

**Facilitated by Tony Rutherford, Chair**

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