

# 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



#### '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

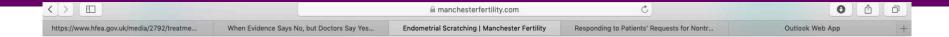
- Patients are permitted to decide what to do with, and what may be done to their bodies
- The corresponding obligation on the part of the physician is to obtain voluntary informed consent
- For this to be valid, the quality of communication and information provided have to be adequate

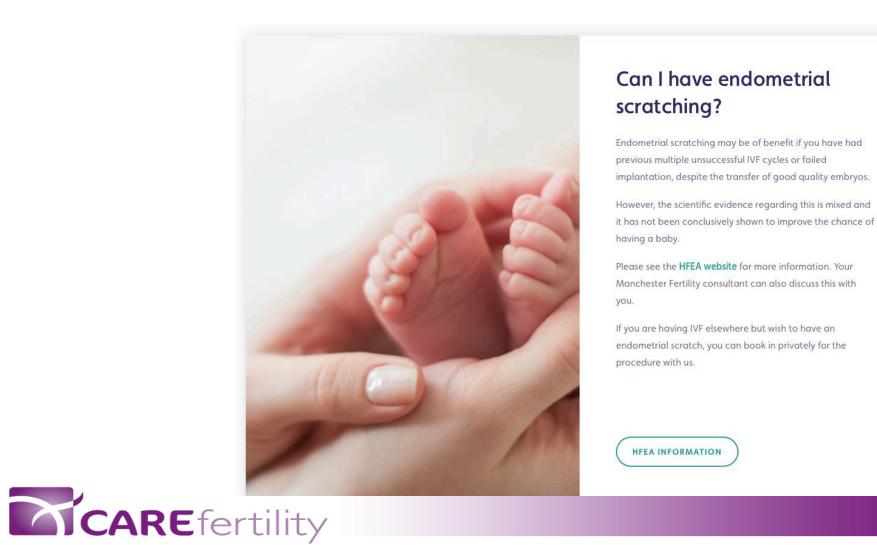


#### Providing information about add-ons

- 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







#### 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.





## **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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