

Accessibility of information and quality of evidence in the fertility sector

KEY FINDINGS

- Our research shows that there is a lot of information available about infertility and fertility treatments, including conflicting information on the evidence available to support additional treatments (add-ons)
- This abundance of information provision can be difficult to navigate and identifying good quality information can be challenging
- Women undergoing or preparing for fertility treatment will generally undertake substantial online research into treatment options
- Google search, fertility clinic websites and social media emerged as particularly important sources of information
- Women often described difficulties in finding up-to-date and geographically specific information about how to access fertility treatment in their area
- Women sometimes found it difficult to understand the available information about IVF treatment add-ons and do not always feel equipped to evaluate their effectiveness
- Many women did not know that the Human Fertilisation and Embryology Authority website provides information about add-ons specifically for patients
- There is no consensus in the medical community on how to assess evidence and what sort of evidence should be considered, when evaluating IVF treatment add-ons
- Professionals and patients understand evidence in different ways and this has a potential impact on the quality of care

FURTHER CONTRIBUTION

As our study focuses on reproduction, we would be interested in making further contributions to the next open consultation on reproductive health

This submission responds to the government's development of a Women's Health Strategy drawing on the findings from empirical research with fertility patients and their partners as well as fertility professionals. Focusing on in vitro fertilisation (IVF) in particular, this document addresses core themes Two (the quality and accessibility of information) and Five (how evidence is used in medical practice) as stated in the call for evidence. We believe this consultation presents an opportunity to dramatically improve the experience of IVF patients.

The research, based at Queen Mary University of London and funded by the Wellcome Trust, is unique in its ability to provide insights both into the perspectives of professionals who provide fertility treatment and patients/partners' experiences of receiving fertility treatment. The geographical focus of the study is England.

POLICY IMPLICATIONS

- Women need a more coordinated provision of up-to-date information about IVF, especially information about novel IVF treatment add-ons
- Improving the clarity, visibility and accessibility of already available information is a relatively low-cost measure that will bring timely positive change for IVF patients
- There is an opportunity for the NHS A-Z website to direct IVF patients to the Human Fertilisation and Embryology Authority's website for information specifically about new IVF treatment add-ons
- Different understandings of evidence should be considered to improve the quality of information on new treatment add-ons
- Accurate information about the nature of available evidence should be provided when treatment add-ons are experimental

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About the research

Our research shows that identifying good quality information about infertility and fertility treatments can be challenging, especially regarding conflictual information on the evidence available to support IVF treatment add-ons. Add-ons are additional investigations and treatments offered on top of standard fertility treatments such as IVF. As the fertility sector is highly privatised, concerns have been raised on the quality of information available for patients on fertility clinic websites and how this can influence patients' decisions on treatments (Spenser et al., 2016; Galiano et al., 2021; Lensen et al., 2021; Stein and Harper, 2021; Van de Wiel et al., 2020). Our research considered IVF provided both by NHS and private fertility clinics.

Quality and accessibility of information

Women seek information about infertility and fertility treatment from a wide range of sources. The majority of these are online.

- Women's choice of information source was strongly directed by the kind of information they were looking for and they were critical of the reliability of information on many websites.
- Online resources from well-known public health institutions, such as the NHS Health A-Z directory, were generally highly regarded. These were considered to be reliable, well balanced and a good starting point for information. However, general information is limited in its applicability and does not provide insights into an individual's needs. This means that women will look elsewhere for more specific information or advice.
- Women would raise specific questions with their fertility clinic in person or over the phone, but they often commented on there

not being time to discuss questions in depth and that their consultations would be supplemented with substantial online research.

- Many women used fertility clinic websites to find information about fertility treatment, including available tests and treatments that may not be included in routine IVF.
- Many women said that other IVF patients are an important source of information and experience. This included IVF patients who they knew personally as well as people in online support groups, such as private groups on Facebook or patient advocate organisations such as the Fertility Network.
- Some women accessed guidance provided on the Human Fertilisation and Embryology Authority's (HFEA) website, especially regarding treatment add-ons, but many others did not know that the HFEA provides information tailored specifically to patients.
- A few women reported accessing medical journals to read current and highly specialised information regarding new or experimental tests and treatments in IVF.

There were three aspects of fertility treatment that women found challenging to navigate in terms of available information.

- Women did not always know what to expect upon raising the issue of infertility with their GP. Uncertainties at this first point of care included what examinations, tests or referrals to expect or request via the GP, and what to expect in terms of waiting times for procedures.
- Women described difficulties in finding up-to-date information about how to access fertility treatment that is specific to their area (or local Clinical Commissioning Group) and circumstances. They were also often unsure about whether they could choose a fertility clinic and how to access potential funding for IVF.
- Women sometimes found it difficult to understand the available information about IVF treatment add-ons. Firstly, treatment add-ons

are very diverse. Secondly, the responsibility for choosing or declining treatment add-ons falls to individuals who do not always feel equipped to evaluate their effectiveness. Other studies (Spenser et al., 2016; Stein and Harper, 2021) have shown concerns regarding the accuracy of the information offered by British IVF clinic websites, especially regarding the quality of evidence supporting the use of treatment add-ons.

Different understandings of evidence

There is a lack of consensus among fertility professionals regarding how to assess the evidence supporting the use of IVF treatment add-ons and what sort of evidence should be considered when determining if an intervention is effective.

- Some IVF professionals follow the tenets of evidence-based medicine (Repping, 2019) and believe that the only acceptable evidence is a meta-analysis of numerous quality randomised-control trials (RCTs). In this view, treatment add-ons should be offered only when more than one quality RCT demonstrates their effectiveness.
- To inform patients about the evidence available without denying them access to treatment add-ons, the HFEA introduced a “traffic light system”, which is also based on an evidence-based medicine approach.
- According to the traffic light system: a green light is for add-ons with more than one quality RCT that demonstrates the procedure is safe and effective at improving live birth rates (no treatments are currently green); an amber light is for treatments with a small or conflicting body of evidence and further research required (five treatments are marked amber); red light, where no evidence of safety or effectiveness exists (six treatments are marked red).

- Our research shows that the interpretations of this traffic light system vary among professionals. Some believe that treatments marked red are problematic due to insufficient evidence, while treatments marked amber are less problematic given that early studies are showing promising results. For others, treatments marked amber are problematic as they do not have sufficient evidence but there is ambiguity around their potential benefit.
- Some IVF professionals have a broader understanding of evidence, which includes non-RCT research, peer reviewed publications and their clinical experience. For this group, some treatment add-ons have other benefits and might be beneficial for some groups of patients (Perrotta and Geampana, 2020).
- As the production of evidence in the fertility sector is not standardised yet, some professionals underline that common ground rules have to be established on how to conduct RCTs in IVF and how to report their results.
- The HFEA has promoted the responsible use of treatment add-ons in fertility services, requesting clinics to provide accurate information to patients and not charge patients when procedures are experimental (i.e. there is no evidence of safety or effectiveness).
- In the current situation, patients are burdened with the decision about whether an add-on can be useful in their treatment or not.

Our research shows that IVF patients also assess the evidence to support add-ons in different ways and this can cause misunderstandings between professionals and patients, with a potential negative impact on the quality of care.

- Medical evidence takes on diverse and highly personal meanings for patients in the context of fertility treatment.
- Considerations about evidence were often raised in relation to add-on tests or treatments in IVF, but also in other contexts, such as what evidence is there for side effects of IVF (e.g. the

impact of hormones on cancer risk) or the health of IVF babies.

- Women's evaluations of the evidence to support certain add-ons were closely tied to their knowledge of IVF, their health history and what might be causing infertility, their fertility treatment history and length of time trying to conceive, and whether or not they were paying for treatment.
- Whereas some of the women interviewed were highly critical of any add-on marked as red or amber in the HFEA's traffic light system, others believed that certain add-ons may be beneficial for certain patients, and others were willing to accept unproven treatments in the hope that they may improve their chances of having a baby from IVF.
- Patients often described difficulty in evaluating the evidence of benefit versus the risk of harm connected to unproven add-ons.
- In addition to evaluating the evidence to support add-ons, women often wanted to understand the evidence-base for certain health and lifestyle changes, such as diet or vitamin supplements, that might improve their wellbeing and reproductive health more generally.

Why this matters

We underline the importance of current, clear and honest information and advice for people entering or undergoing IVF. This is especially important given the rapid development of new treatments and technologies in reproductive medicine, including add-ons.

Based on the findings presented above, we recommend a more coordinated approach to the provision of information across key organisations (the NHS, HFEA, fertility clinic and patient advocacy). This will help fertility patients to navigate the information available according to their specific circumstances and treatment course. Questions around how to assess the evidence-base for novel treatments in IVF are a significant concern for both fertility professionals and patients.

Men and infertility

While the focus of this document is on women's experiences, the research study also included male partners and found that men often struggle to find information and support specific to men's needs and experiences of IVF. It is essential that men and their physical and mental health are not forgotten in the provision of information and care in the fertility sector.

Methodology

The research adopted a qualitative and ethnographic research methodology to explore the introduction of new biomedical technologies in the field of IVF. It analysed the emerging processes of knowledge production and the implications for the experience of IVF patients (both men and women). Part of our research explicitly focused on how some treatments add-ons are used in IVF clinics and how patients approach them. More specifically, methods included the following:

- Interviews with 51 IVF patients and partners
- Interviews with 43 fertility professionals
- Three focus groups with 17 IVF patients and partners
- Three focus groups with 18 fertility professionals
- Online survey with 314 IVF patients and partners
- 250h+ of ethnographic observation at six fertility clinics
- Analysis of policy documents and professional statements

The study received approval from the Health Research Authority, Queen Mary's research ethics committee, and locally at the participating fertility clinics. Further details about these approvals can be provided upon request.

Remaking the Human Body

The project “Remaking the Human Body: Biomedical Imaging Technologies, Professional and Lay Visions” (2016/2022) investigates the introduction of new technologies in IVF and their consequences for professionals and patients. The project aims to analyse different points of view in the field of IVF and foster a deeper mutual understanding among people with differing perspectives, concerns and experience.

The project is headed up by Dr Manuela Perrotta, Senior Lecturer in Technology and Organisation at QMUL’s School of Business and Management, and is being funded through the Wellcome Trust’s Investigator Award in Medical Humanities/Society and Ethics.



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Visit our blog for more information and updates on the research



Further information

Perrotta M. and Geampana A. (2020), The trouble with IVF and randomised control trials: Professional legitimisation narratives on time-lapse imaging and evidence-informed care, *Social Science & Medicine*, Volume 258, August 2020, 113115, <https://doi.org/10.1016/j.socscimed.2020.113115> (open access)

Further publications are currently under review and will be updated on the project website.

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About Queen Mary University of London

Queen Mary University of London is a world-leading research-intensive university with over 25,000 students representing more than 160 nationalities.

A member of the prestigious Russell Group, we work across the humanities and social sciences, medicine and dentistry, and science and engineering, with inspirational teaching directly informed by our research.

In the most recent exercise that rated research in the UK, we were ranked 5th in the country for the proportion of research outputs that were world-leading or internationally excellent. We offer more than 240 degree programmes and our reputation for excellent teaching was rewarded with a silver in the 2017 Teaching Excellence Framework (TEF) awards. Queen Mary’s history dates back to 1785, with the foundation of the London Hospital Medical College. Our history also encompasses the establishment of the People’s Palace in 1887, which brought accessible education, culture and recreation to the East End of London. We also have roots in Westfield College, one of the first colleges to provide higher education to women.