Remaking Fertility

PET
Fertility • Genomics • Clarity

The British Academy

Queen Mary University of London

Building Bridges in Fertility Care:

An Interactive Toolkit for Patient Associations, Clinics and Regulators

Cite as: Perrotta, M., Smietana, M. (2024). Building Bridges in Fertility Care: An Interactive Toolkit for Patient Associations, Clinics and Regulators, Remaking Fertility, Queen Mary University of London Available at www.qmul.ac.uk/remaking-fertility/buildingbridgesproject/interactive-toolkit/

June 2024

The Building Bridges Project

Overview

The proliferation and popularity of additional treatments in fertility care, commonly known as add-ons, has sparked extensive debate within the field. Surprisingly, despite significant gaps in evidence supporting their efficacy and safety, and their substantial costs, it is estimated that over 65% of the 50,000 patients undergoing fertility care annually in the UK use one or more of these treatments (HFEA, 2022).

In partnership with the Progress Educational Trust (PET), the Building Bridges project aimed to tackle the challenges related to the potential overuse of add-ons in the field by inclusively addressing, learning from and integrating the needs and priorities of fertility patients, professionals and regulators. As part of this project, the team has invited groups of relevant stakeholders to engage in a series of dedicated workshops to discuss controversial issues, ensuring that diverse viewpoints were included in the emerging dialogue.

The primary objectives of these workshops were to identify the key needs, priorities and challenges faced by different groups involved in fertility care; develop novel collaborative approaches to address the identified challenges; and produce a set of feasible proposals aimed at tackling the key challenges identified. The results of the project are included in this toolkit, which presents fourteen proposals. This toolkit encapsulates in-depth discussions of these proposals, highlights concerns and offers key recommendations for their effective implementation, forging a comprehensive roadmap for action.

Project Team:

Dr Manuela Perrotta
Reader in Technology and Organisation,
Queen Mary University of London.

Dr Marcin Smietana
Postdoctoral Researcher,
Queen Mary University of London.

Remaking Fertility:

linkedin.com/company/remaking-fertility

www.qmul.ac.uk/remaking-fertility/

remaking-fertility@qmul.ac.uk

We would like to thank the PET team, Sarah Norcross, Sandy Starr and Jen Willows who facilitated the study.

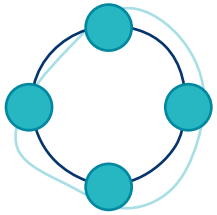
The Building Bridges Project

Advisory Board

We extend our gratitude to the members of our Advisory Board:

- **Dr Sarah Armstrong,** Senior Specialist Registrar in Obstetrics and Gynaecology and member of the Gynaecology and Fertility Group Editorial Board, Cochrane Gynaecology and Fertility
- **Alex Davies-Jones MP,** sponsor of the Fertility Treatment (Transparency) Bill and Shadow Minister for Tech and Digital Economy
- **Clare Ettinghausen,** Director of Strategy and Corporate Affairs at the Human Fertilisation and Embryology Authority (HFEA)
- **Dina Halai,** Head of Regulatory Policy (Scientific) at HFEA
- **Julian Hitchcock,** Of Counsel, Biolawgy
- **Professor Emily Jackson,** LSE Law School
- **Dr Raj Mathur,** Consultant in Reproductive Medicine, Chair of the British Fertility Society (2021–2024)
- **Dr Louise Strong,** Director, Consumer Protection at the Competition and Markets Authority (CMA)

Acknowledgments



Research project: The 'Building Bridges Between Fertility Patients, Clinics, and Regulators: A Collaborative Approach' project is funded by a British Academy Innovation Fellowship 2022/23 awarded to Dr Manuela Perrotta at Queen Mary University of London, in partnership with Sarah Norcross, Director of PET.

Funding bodies: This research was funded by the British Academy (grant number IF2223/230087), while the production of this research toolkit/report was supported by a QMUL Impact grant awarded to Dr Manuela Perrotta.

Participants: We are grateful to all the participants of the seven workshops organised in collaboration with PET during the project.

Editing and design: With thanks to the the Research Retold team.

The Building Bridges Project

Participants' statements

"I am very pleased to see more research is being done and clarity sought."

– workshop participant 1

"Good effort that I sincerely hope leads to some positive effect on the currently unsatisfactory situation."

– workshop participant 3

"A really important piece of research."

– workshop participant 2

"This is a really important project, a subject very close to my heart and this work has the potential to make real change for patients, for the fertility sector in the UK and it's clear there are many stakeholders that want to see this particular area dealt with in a patient-centred way."

– workshop participant 4

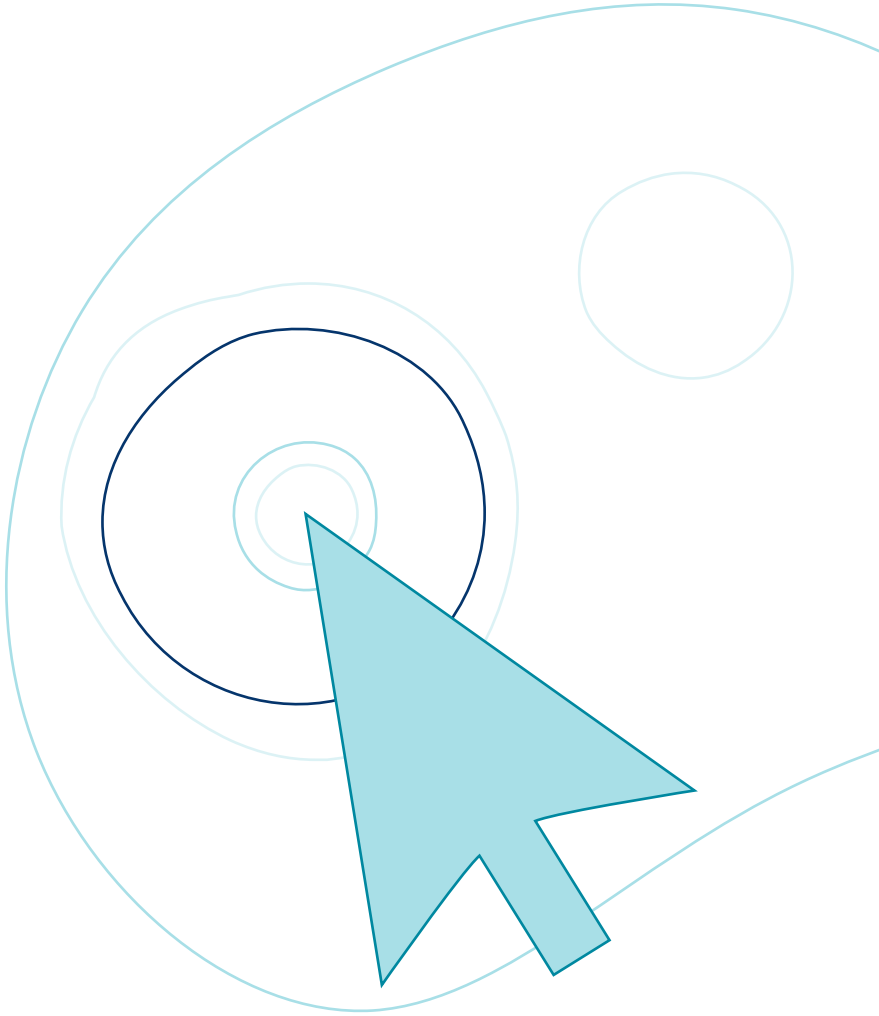
How to navigate this interactive toolkit

This interactive toolkit provides you with the flexibility to navigate directly to the topics that capture your interest.

The toolkit is organised into **sections** and **subsections**:

- Use the menu above or the table of contents to navigate to the topic you wish to explore.
- A blue highlight indicates the current section you are viewing.

- Underlined **headings** indicate the subsection you are in.
- External links to websites are shown in this **style**.
- Clicking on this icon will return you to this page.



About this toolkit

This toolkit serves as a comprehensive resource to support patient associations, clinics and regulators in improving the quality of information in fertility care and empowering patients in their treatment decisions. With a focus on transparency and inclusion, this toolkit presents fourteen collaborative proposals aimed at addressing concerns surrounding the potential overuse of add-ons in fertility care.

Despite ongoing efforts to assist fertility patients in making informed decisions, concerns persist regarding the misuse of add-ons.
The toolkit explores fourteen collaborative proposals that emerged during the project, addressing specific challenges and needs.
Additionally, it discusses concerns raised regarding the implementation of these proposals and provides key recommendations for their effective execution.

While focused on addressing issues related to the proliferation of additional treatments within the fertility sector, the principles that emerged from the research for the wider project, which are elucidated in this toolkit, offer valuable insights that extend beyond the specific concerns raised by the case of add-ons. These insights are applicable to broader patient needs, both within fertility care and in other healthcare sectors.

We want to hear your feedback:

Contact Remaking Fertility at remaking-fertility@qmul.ac.uk to:

- Provide feedback on the research and toolkit
- Discuss the implementation of our proposals
- Explore potential future research collaborations on these topics
- Learn more about our ongoing and upcoming research
- Engage with our work
- Participate in upcoming events

Context

In recent years, fertility care in the UK has been embroiled in a contentious debate surrounding the use of additional treatments, commonly referred to as 'add-ons', offered alongside standard in vitro fertilisation (IVF) cycles to increase likelihood of a successful treatment. These add-ons encompass a range of tests, treatments and clinical interventions, with costs varying from a few to several hundred pounds (for an in-depth discussion see Perrotta, 2024).

While some studies suggest the potential efficacy of add-ons in improving live birth rates under certain circumstances, robust and reliable evidence to substantiate their effectiveness for the majority of fertility patients is often lacking. Concerns have been raised about the overuse of add-ons (Adamson and Rutherford, 2018; Wilkinson et al., 2019), as well as the quality of information provided to patients about these treatments on fertility clinics websites (van de Wiel et al., 2020; Stein and Harper, 2021; Perrotta et al., 2024b).

The debate surrounding add-ons among fertility professionals has become highly polarised, with some expressing concerns about the potential influence of commercial interests on their provision, while others fear that restricting their use could impede medical progress and innovation. It is noteworthy that, unlike other healthcare services, **over 70% of fertility treatments in the UK are currently privately funded by patients themselves (HFEA, 2024)**. Although current evidence assessments (HFEA, 2023a; ESHRE, 2023) indicate that treatment add-ons should not be used routinely, they remain widely available.

According to the Human Fertilisation and Embryology Authority (HFEA) National Patient Survey 2021, **65% of patients had used one or more of these treatments.** Despite several initiatives, as outlined in the following section, concerns regarding add-ons persist. This project sought to generate alternative collaborative proposals to address the key challenges posed by their use.

> *"The fertility sector appears to be held to a different standard than the rest of medicine by the regulator and others in positions of influence. An earlier workshop highlighted that RCT evidence is not a universally achieved or achievable standard. This should be recognised."*
>
> - workshop participant 5

> *"Add-ons should be understood as clinical research, especially as there is a financial component. These are untested treatments that, in the worst-case scenario, could actually cause harm to the patient. For example, if there was an adverse impact from the treatment, or a contraindication if two or more medicines are involved. The financial implication induces hope. If I'm paying for something at a regulated clinic, it must work/be safe/have been tested appropriately. Otherwise, how on earth would it be allowed? And for a cost..."*
>
> – workshop participant 6

Existing guidelines

Recognising the imperative for responsible innovation, the HFEA introduced a rating system for add-ons in 2017, later revamped in 2023, allowing patients to access information on the evidence base of the most commonly used add-ons.

In addition, a consensus statement, representing an agreement between the UK regulator, the HFEA, and key professional bodies and patient associations, was established on the responsible use of add-ons (HFEA, 2019/2023).

In response to concerns about adherence to Consumer Law by fertility treatment providers, of which add-ons were a part, the Competition and Markets Authority (CMA) published guidance for fertility clinics in 2021 (CMA, 2021a) along with a guide for patients (CMA, 2021b) to mitigate the risk of potential mis-selling of add-on treatments. Additionally, an enforcement notice outlining rules for advertising fertility treatment was published jointly by the HFEA and the Advertising Standards Authority (ASA, 2021).

These guidelines clarify clinics' obligations under consumer law, ensuring that information provided to prospective and current patients is clear, accurate, easy to find and enables patients to make properly informed decisions. An overview of these guidelines is available on the following page.

Despite the oversight of most fertility clinics by both the HFEA and the Care Quality Commission (CQC), concerns persist regarding clinics' adherence to information standards (CMA, 2022b; Perrotta et al., 2024). While the HFEA oversees and inspects clinics (see next page), it lacks the powers to address issues like clinic pricing, sale of treatment add-ons and marketing techniques. The HFEA (2023b) suggests amendments to the Human Fertilisation and Embryology Act 1990 (as amended) to address these concerns.

In addition, it is important to note that while most fertility clinics are registered with and inspected by the CQC, treatments and services licensed by the HFEA are exempt from CQC regulation. This exemption applies to fertility treatments aimed at assisting pregnancy, while gynaecological surgeries and diagnostic procedures unrelated to fertility treatment fall under CQC's regulation. In cases where a provider offers both HFEA-licensed fertility treatments and CQC-regulated activities, only the latter are subject to CQC inspection and regulation (see CQC, 2019).

This overview of existing guidelines underscores the pressing need for regulatory intervention, especially concerning the commercialisation of add-ons. This need has been highlighted in the Women's Health Strategy for England policy paper (Department for Health and Social Care, 2022) and previous parliamentary discussions on a bill concerning fertility treatment transparency (Bill 230, 2023).

HFEA guidelines and add-ons rating

Established in 1991 as the world's first statutory body of its kind, the HFEA plays a pivotal role in regulating fertility services and human embryo research in the UK. Governed by the Human Fertilisation and Embryology Act 1990, which was revised in 2008, the HFEA is mandated to license and monitor clinics conducting IVF, donor insemination and human embryo research.

Additionally, it oversees the storage of gametes and embryos, and maintains registers of licensed facilities and treatments. While the Act outlines key policy principles and provides a regulatory framework, the HFEA publishes a detailed Code of Practice to specify regulatory requirements, to adapt to changes in clinical practice.

While this combination of legislative principles and regulatory standards enables the HFEA to regulate the sector within the boundaries of the law, the current legal framework does not equip the HFEA with the necessary powers to oversee the transition to an increasingly commercialised sector, protect patients as consumers, or regulate the introduction of all new treatments into clinics, as demonstrated by the controversies surrounding add-on treatments.

"There are five ratings that indicate whether a treatment add-on is effective at improving treatment outcomes for someone undergoing fertility treatment, according to evidence from studies. To make it easier to understand the scientific evidence for each treatment add-on we have a range of symbols and colours for each rated add-on. [HFEA, 2023a]"

HFEA clinic website inspection checklist

To ensure compliance with industry standards and regulatory guidelines, the HFEA clinic inspection includes an assessment of their websites. This checklist outlines specific criteria that clinics must adhere to regarding the information presented on their websites, focusing on data and success rates as outlined in the Code of Practice (HFEA, 2023c, section 4.10).

- The information should include the most recent data available from the past three years.
- Centres are encouraged to display live birth rate data per embryo transferred where relevant and this may be displayed alongside other success rate measures. The information should not highlight a high success rate that applies only to a small, selected group of patients.
- The data should show split by maternal age and, if appropriate, by treatment type.
- The information should provide raw numbers rather than just percentages.
- The website should provide the national rate and like-for-like comparisons (the same year, maternal age, treatment type, etc.).
- The centre's published success rate data should refer to the HFEA as the source of national information through its *Choose a Fertility Clinic* function.
- The information must state clearly that information on success rates is of limited value in comparing centres and choosing where to seek treatment. It should include a link to the HFEA's advice on choosing a clinic: Choose a fertility clinic.
- If the information refers to comparative costs, it should indicate the likely total cost for a typical cycle, based on the actual costs for recent patients, not individual items in tariffs.

CMA guidelines for clinic websites

According to consumer law obligations (CMA, 2021a), fertility clinics should ensure that their websites provide material information in a clear, accessible and comprehensive manner. This should ensure:

Accessibility: Information should be available in all the places prospective patients are likely to look, with particular emphasis on the clinic's website, which is the primary source for most individuals.

Clarity: Information should be presented in a clear and simple manner that prospective patients can understand and engage with.

Completeness: Material information should be prominently highlighted and complete, ensuring that no essential details are omitted (see misleading omissions).

Transparent pricing: The detailed breakdown of advertised prices should encompass all costs included components and potential extra expenses like medication. Factors influencing price ranges should be clearly explained, particularly those determining individual costs, such as age and medical conditions.

Add-on treatments: Information about the costs, risks, benefits and clinical evidence base for any add-on treatments (with signposting to the HFEA website) should be provided if advertised or offered.

> *It is important that it is understood that providing accurate and up-to-date information on a clinic website, that does not mislead patients, is a requirement. We need to avoid any suggestion that it is OK not to do this if it is too difficult or if there is a lack of clinic resource devoted to ensuring this is done."*
>
> – workshop participant 7

CMA guidelines on misleading omissions

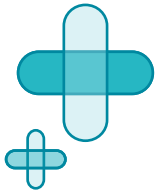
The CMA guide for clinics emphasises the importance of ensuring that information provided does not omit or conceal material details and includes a list of examples of potential misleading omissions (CMA, 2021a, pp. 38–40), particularly focusing on aspects relevant to add-on treatments, such as:

- Omits or hides information, or only provides partial information, about treatment and/or costs on its website, instead directing prospective patients to contact them for such information, or further information, by phone or e-mail.
- Offers, recommends or provides information about optional add-on treatments but omits information about clinical evidence for such treatments, particularly where none exists or is limited in nature; any risks associated with these add-on treatments; and/or the HFEA's information and traffic light system for add-on treatments.
- Omits to explain why certain treatments are necessary or are being recommended – for example, not explaining why intracytoplasmic sperm injection (ICSI) is being recommended.
- Omits to declare a conflict of interest or personal financial interest (such as commission) that a clinician may have with respect to a treatment, product or service they are offering at the clinic or where they are recommending the services of other businesses, for example, businesses that offer complementary therapies, such as acupuncture.
- Makes material information difficult to find or it is unclear, unintelligible, ambiguous or untimely through, for example, putting it on a website that is hard to navigate, providing it in a number of different places, providing links which do not navigate the user to the correct place or burying it in small print.

Consensus statement on the responsible use of treatment add-ons

In 2019, HFEA (2019/2023) published a consensus statement on add-ons, endorsed by ten professional bodies, including the Association of Reproductive and Clinical Scientists, the British Fertility Society, the Royal College of Obstetricians and Gynaecology and the European Society of Human Reproduction and Embryology.

The revised 2023 consensus statement outlines seven main principles for the responsible use of treatment add-ons in fertility services:



Criteria for offering add-ons: Add-ons should only be offered when supported by robust evidence of safety and effectiveness (defined as more than one high quality randomised controlled trial (RCT)). Clinics should monitor outcomes and cease offering add-ons if safety concerns arise. In the absence of evidence supporting safety and efficacy, add-ons should only be offered in a research setting with proper methodology and approval from an ethics committee.

Patient information: Clinics must provide patients with comprehensive information about the evidence supporting add-ons before obtaining consent.

Experimental nature: Patients must be informed if an add-on is experimental and lacks robust evidence of safety and/or effectiveness.

Cost: Patients should not be charged extra to participate in research, including clinical trials.

Charging for add-ons: When patients bear the cost of treatment, charging for a treatment add-on may be suitable if it has proven effective for their particular group or if including its cost in a standard package would considerably raise treatment fees for all patients.

Transparency: Transparent disclosure of financial or other interests is crucial in patient discussions, publications and meetings.

Professional collaboration: The fertility sector should collaborate through professional bodies to promote and adhere to these principles, encourage training and compile evidence for add-ons.

Methodology

This project employed a collaborative approach, engaging key stakeholders throughout its three stages.

1. During the **first stage**, the research team conducted a secondary analysis of available data on add-ons, encompassing patient surveys, qualitative research, social science literature, relevant medical literature, policy reports and other documents.

The results of this analysis were presented in dedicated workshops to stimulate discussions among participants, which were subsequently summarised in research digests (Perrotta & Smietana, 2024a, 2024b, 2024c) and made available on the project website.

2. In the **second stage**, the research team identified six key challenges raised by the discussions in stage one and organised an interactive workshop with 18 participants representing the key stakeholders to generate new ideas to address these challenges. Various techniques and tools were employed in the workshop, including the use of expert facilitators, breakout rooms for discussion in small groups and questions to encourage open participation.

An initial set of thirteen practice- and policy-oriented proposals was generated in the workshop, and feedback on their feasibility and priority was sought.

3. In the **final stage**, the initial proposals were further developed, and three consecutive workshops were held with relevant stakeholders to trial them.

These workshops gathered input from professional and patient associations, clinic managing and financial directors, and relevant policy-makers.

The discussions helped refine the proposals, navigate potential impact and identify barriers.

Feedback from these workshops and follow-up discussions with key stakeholders were incorporated into this toolkit, which now includes a total of fourteen proposals.

Some of these proposals were unanimously considered priorities to enhance patients' experiences in the field, although diverse groups held varying views on the feasibility of implementing certain proposals. To provide a comprehensive view of each proposal, their descriptions include discussions on the needs they address, recommendations for impactful implementation, potential barriers and concerns raised by some participants.

Challenges

The project aimed to address **six key challenges** that emerged during the first stage, revolving around **three main thematic areas**:

Lack of evidence and effects on available information

The quality of information on fertility clinic websites

Ensuring cost transparency and fully informed decision-making

Lack of evidence and effects on available information

The lack of robust evidence surrounding the efficacy and safety of treatment add-ons presents significant challenges for both patients and healthcare professionals. Making informed decisions becomes daunting in the face of widespread uncertainty.

Therefore, prioritising high-quality RCTs to establish add-on effectiveness is imperative. However, conducting these trials demands substantial resources, including funding and expertise. Research funding in this area, typically provided by major national bodies such as the National Institute for Health and Care Research (NIHR), falls short of meeting the necessary needs for conducting many large-scale RCTs. Paradoxically, potential funders often have financial interests in the products being tested, raising risks of bias.

While the add-ons debate has focused on evidence gaps, addressing how the low quality of evidence or its absence impacts the quality of information provided to patients is equally important. The uncertainty stemming from the poor quality or lack of evidence complicates efforts to ensure patients receive reliable and transparent information crucial for informed decision-making.

Additionally, poor, limited or conflicting evidence is often portrayed simply as a lack of certainty regarding intervention benefits, with little consideration for potential harm. Therefore, efforts to fill evidence gaps must be accompanied by initiatives to enhance the quality and transparency of patient information.

Finally, in spite of a volume of anecdotal data and qualitative research, there is limited evidence to show the extent of harm, including emotional and financial, and the potential negative consequences that add-ons might cause patients.

How can we foster better evidence production in the fertility field?

How can we ensure that evidence gaps are portrayed as a lack of knowledge regarding the potential effects of treatments, encompassing both beneficial and detrimental aspects?

The quality of information on fertility clinic websites

Both the national patient surveys conducted by the HFEA (2019b, 2022) and recent research commissioned by the CMA (2020, 2022a) show that patients rely on fertility clinic websites for treatment information, including add-ons.

Despite existing guidelines on website information provision, compliance reviews have confirmed ongoing concerns. For instance, our recent study (Perrotta et al., 2024) on the adherence to guidelines for time-lapse imaging (TLI) information on UK fertility clinic websites highlights that a significant majority of websites (90%) claim or strongly imply enhanced clinical outcomes with TLI, despite the emerging evidence that TLI does not increase success rates (HFEA, 2023a; ESHRE, 2023).

47%

Additionally, almost half of the websites do not provide a link to the HFEA website

29.6%

and nearly a third lack information on the cost of TLI.

However, it is crucial to emphasise that the need to improve clinic website information is complementary, rather than a replacement for, the essential interaction between patients and their clinicians during consultations.

While clinic websites serve as valuable resources for patients seeking information about treatment options, they should not be intended as the sole source for decision-making. Instead, patient-clinician consultations offer a personalised and comprehensive approach to counselling, considering various factors such as each patient's medical history, individual needs and preferences, the latest scientific evidence and the clinician's experience.

How can we support patients in assessing the reliability of the sources they trust?

How can we address compliance issues and supporting fertility clinics in consistently providing clear, transparent and updated information about add-ons?

Ensuring cost transparency and fully informed decision-making

Research has identified a significant information gap in fertility treatment costs. While reliable data on actual patient expenses are scarce, **anecdotal evidence suggests that patients typically pay between £5,000 to £20,000 or more per treatment cycle** (CMA, 2022a).

Both our qualitative research (Hamper & Perrotta, 2023) and a survey conducted by the Fertility Network UK in 2023 highlight the significant negative impact of fertility treatment costs on patients' lives. These effects are expected to proliferate due to the rise in the number of self-funded treatments, which increased to 74% of cycles in 2021 (HFEA, 2024).

Notably, treatment costs seem to have minimal impact on demand (Keller et al., 2023), as patients are often willing to invest significantly to explore all available treatment options.

34%

A recent study (Carrick et al., 2023) indicates that a third of participants were willing to use an add-on treatment despite believing it would not improve their chances of having a baby suggesting a strong desire to exhaust all possibilities to avoid future regret (Perrotta & Hamper, 2021).

While the financial implications for patients have been a focal point of the add-ons debate, there remains a lack of transparency regarding the costs of treatment add-ons. Differing clinic pricing strategies and a lack of consensus on standard package inclusions make it difficult for patients to compare prices across clinics.

This encompasses not only the treatment add-ons identified by the HFEA but also other common procedures such as blastocyst culture and off-label use of drugs used in fertility treatments. Ensuring cost transparency is crucial to improve informed patient decision-making in an increasingly commercialised market.

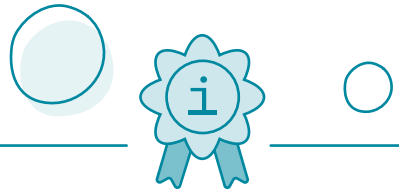
How can we ensure that patients' decisions about their treatment are fully informed amidst significant information gaps?

How can we establish transparent cost information to aid informed decisions?

Proposals

Proposals to foster evidence production

- Create a comprehensive research dataset
- Enhance peer support for appropriate use of treatment add-ons
- Request suppliers to fund large RCT studies with robust methodology
- Encourage clinics to invest profits from treatment add-ons in research



Proposals to improve the quality of information

- Develop information templates for fertility clinic websites
- Produce factsheets to debunk misleading information
- Task dedicated staff with improving clinic websites
- Implement regular audits of website information
- Offer incentives or penalties for clinics based on information accuracy
- Create an independent oversight body to monitor website accuracy

Proposal to further support patients' informed choices

- Enhance existing patient databases to incorporate pricing information
- Create an accessible database for comparing fertility treatment costs across clinics
- Provide detailed information on the pricing of fertility drugs
- Audit consent process and consent forms

Create a comprehensive research dataset

1 2 3 4

Needs addressed

Widespread lack of evidence on add-ons: Establishing a comprehensive high-quality dataset could facilitate researchers in analysing treatment outcomes, enabling a thorough assessment of the effectiveness of various treatments.

Lack of data on usage of each treatment: Beyond evidence production, this initiative would foster transparency regarding treatment usage. It would raise awareness about how clinics use these treatments, potentially creating peer pressure against overuse and ultimately contributing to strengthen trust within the field.

Recommendations for impactful implementation

The HFEA have pledged to consider a voluntary collection of treatment add-ons data in the future, working with professional bodies. Clinics will be encouraged to voluntarily submit their data regarding add-ons, as previously done to reduce multiple births.

Potential barriers

Potential technical barriers could arise in integrating additional information into the recently implemented data collection system (PRISM), which has an established data dictionary.

Concerns raised

Voluntary data sharing could compromise the accuracy and consistency of the database. Additional measures should be implemented to discourage non-reporting, such as establishing mechanisms for accountability, which could entail potential reputational damage for non-compliant clinics.

Relying solely on the collection of retrospective data may not suffice to generate high-quality evidence regarding the effectiveness of add-ons.

Enhance peer support for appropriate use of treatment add-ons

1 2 3 4

Needs addressed

Treatment add-ons overuse: Discouraging the overuse of treatment add-ons outside a research setting and alleviating the burden for patients to make decisions without an established evidence base.

Potential barriers

Peer influence may not have been effective thus far due to the lack of evidence regarding potential harm and negative effects of add-ons, unlike the case of multiple birth rates where such effects were proven.

Recommendations for impactful implementation

Leveraging existing initiatives, such as the consensus statement and recommendations from bodies like HFEA and the European Society of Human Reproduction and Embryology (ESHRE), will encourage appropriate use of treatment add-ons. Simultaneously, stringent measures should be implemented to deter the routine use of add-ons. Mechanisms for monitoring and accountability, similar to those implemented to reduce multiple birth rates, should be established to foster self-regulation in the field.

Concerns raised

While discouraging overuse is important, leveraging peer pressure to support a blanket ban on add-ons treatment may inadvertently disadvantage some patients.

Request suppliers to fund large RCT studies with robust methodology

1 2 3 4

Needs addressed

High cost of evidence production: Requesting suppliers to fund large RCTs with robust methodology addresses the lack of resources available to fund evidence production.

Recommendations for impactful implementation

Advocacy efforts should emphasise the ethical responsibility of suppliers in ensuring the safety and effectiveness of their products before introducing new treatments to the market. Committing funding for independent RCTs that can generate high-quality evidence in fertility care should be encouraged as part of corporate social responsibility.

To mitigate bias concerns in RCTs funded by suppliers with financial interests in the commercialisation of certain interventions, funding should be redirected to and managed by impartial national or international bodies.

Potential barriers

Suppliers lack incentives to fund research beyond regulatory requirements for obtaining licenses. Therefore, establishing forms of reward for their financial support would incentivise their participation.

Since fertility care is a global market, any national initiative aimed at influencing global multinational companies might prove ineffective.

Encourage clinics to invest potential profits from treatment add-ons in research

1 2 3 4

Needs addressed

High cost of evidence production: Encouraging clinics to allocate potential profits generated by treatment add-ons toward funding evidence production could address the lack of resources available.

Recommendations for impactful implementation

Advocacy efforts should highlight the ethical responsibility of clinics in ensuring the safety and effectiveness of the products and services they offer. Encouraging clinics to commit funding for independent RCTs that can generate high-quality evidence in fertility care should be promoted as part of their corporate social responsibility.

To address potential bias in RCTs funded by clinics with commercial interests in particular interventions, funding should be redirected to and overseen by impartial national or international bodies.

Potential barriers

Clinics lack incentives to fund independent research and could see this initiative as against market competition, as many large clinics do conduct research internally to improve their success rates.

Since fertility care is a global market, such a requirement should be expected by all clinics globally rather than on a national basis.

Concerns raised

The assumption that treatment add-ons generate additional profit was questioned, highlighting the difficulty in assessing this without appropriate data.

The notion that some treatments should be offered at non-profit rates was considered a potential hindrance to innovation in a highly privatised sector.

Develop information templates for fertility clinic websites

Needs addressed

Lack of consistency in information provision: Inconsistency in the information provided on fertility clinic websites, leading to conflicting information.

Challenges in website maintenance: Lack of resources for some clinics to maintain their websites.

Recommendations for impactful implementation

There should be a template on how to provide information on add-ons on clinic websites. This should include guidance on consumer law requirements for clinic websites. The template should also provide recommendations on how to convey complex information clearly on websites to minimise the risk of misinterpretation.

Additionally, leverage initiatives led by professional bodies to produce online textual resources for clinics. These resources can be used to create additional multimedia resources (e.g., animations, infographics, podcasts) to reach a broader audience.

All potential resources should be reviewed by professional body representatives for accuracy and patient association representatives for clarity and accessibility of language.

Potential barriers

Keeping these resources updated will require financial resources.There are limitations in reaching a significant portion of patients whose first language is not English.

Concerns raised

While the proposal was generally considered beneficial, concerns were raised regarding reaching consensus on the accuracy of information in a context where evidence supporting information is lacking.

Produce factsheets to debunk misleading information

1 2 3 4 5 6

Needs addressed

Addressing misinformation and meeting patients' need for reliable information: It is crucial to tackle the dissemination of conflicting and inaccurate information, which extends beyond fertility clinic websites. This misinformation permeates various platforms, from social media platforms to influential individuals, and poses a significant challenge in providing accurate guidance to patients.

Recommendations for impactful implementation

Informative factsheets could be used to dispel prevalent misconceptions and provide patients with accurate information. These resources should address the most common myths and unfounded beliefs.

Correction strategies should involve simplified and patient-oriented versions of reliable information, sourced from available guidelines on add-ons such as those provided by the HFEA and ESHRE. Factsheets must undergo scrutiny from representatives from professional bodies to ensure factual accuracy and patient association representatives to ensure clarity and language accessibility.

Potential barriers

Due to the extensive misinformation disseminated online, systematically addressing it would require substantial funding and the involvement of professionals to verify the accuracy of the information provided for correcting misinformation.

Due to the abundance of common myths and the absence of systematic research on anecdotal knowledge circulating online, compiling a comprehensive list and prioritising among the myths could be labour-intensive.

Concerns raised

While the benefits of these proposals were underscored, caution was raised regarding their implementation due to research indicating that repeating misinformation may inadvertently reinforce it by making it more familiar (Ecker et al., 2017; Schwarz et al., 2016).

Task dedicated staff with improving clinic websites

1 2 3 4 5 6

Needs addressed

Compliance issues of clinic websites and lack of effective website maintenance: Recognising their pivotal role as patients' primary source of information, it is essential to ensure that these platforms provide accurate, reliable and legally compliant information to patients.

Recommendations for impactful implementation

While the designated person responsible (PR) at each clinic is formally responsible for all the information provided, including website content, it is unlikely that they will directly oversee website operations.

Therefore, appointing a dedicated staff member to focus on clinic websites could be beneficial. This individual would be responsible for overseeing website content, ensuring compliance with regulatory requirements, initiating updates as necessary and addressing any website-related issues.

Incorporating website management responsibilities could be part of the HFEA reform proposal to introduce PR deputies. Effective implementation hinges on providing these individuals with agreed-upon criteria for information provision and a website maintenance checklist.

Potential barriers

Clinics vary significantly in size and organisational structure, and some may lack the resources to appoint dedicated staff for website management.

Concerns raised

Without a system for regular website inspections or oversight, clinics lack the incentive to implement such a proposal.

Implement regular audits of website information

1 2 3 4 5 6

Needs addressed

Lack of consistency in information provision: Fertility clinic websites often present inconsistent information, leading to confusion and uncertainty among patients seeking reliable guidance regarding treatment options.

Potential mis-selling of treatment add-ons: Inaccurate information on fertility clinic websites may pose a risk of misrepresentation or overselling of treatment add-ons, wherein the benefits of certain procedures or interventions are exaggerated, while associated risks are downplayed.

Recommendations for impactful implementation

Regular audits to ensure the accuracy of information regarding add-ons on clinic websites should be implemented. Before conducting these audits, it is crucial to establish criteria beyond consumer law guidance. This could involve creating a checklist or alternative tools for clinics to follow, ensuring comprehensive evaluation.

Additionally, consider implementing a reward system, such as kitemarks, quality stamps or certifications for compliant websites, incentivising adherence to information standards.

Conversely, penalties could be enforced for non-compliance to encourage accountability. These audits could be integrated into existing regulatory processes, such as HFEA inspections, or conducted independently by reputable bodies dedicated to ensuring transparency and reliability in fertility care services.

Potential barriers

Due to the dynamic nature of websites, continuous monitoring may not be feasible. Therefore, it would be essential to establish additional measures, such as sporadic website inspections, to ensure that information is consistently updated.

Concerns raised

Due to the lack of evidence, determining what constitutes accurate information could pose some challenges, particularly given differing perspectives on effectiveness.

Offer incentives or penalties for clinics based on information accuracy

1 2 3 4 5 6

Needs addressed

Compliance issues of clinic websites: Information on add-ons that deviates from current recommendations or is inaccurate creates confusion and uncertainty for patients seeking reliable guidance on treatment options.

Recommendations for impactful implementation

Incentives or penalties for clinics based on the accuracy of information provided on their websites should be introduced. Incentives such as kitemarks, quality stamps or certifications would be preferable, serving as visible markers of compliance and reliability.

These certifications could be prominently displayed on clinic websites, enhancing their reputation and credibility among patients. Forms of penalties should be introduced in extreme cases, such as repeated offenses or serious violations of accuracy standards.

Penalties could include initiating investigations by regulatory bodies like the Advertising Standards Authority and inclusion in their public list of non-compliant online advertisers, which could lead to potential reputational damage for the clinic.

Potential barriers

Without agreed-upon criteria for information provision and a clear checklist for information accuracy, implementing this proposal would lack a standardised framework for evaluating website content, potentially leading to inconsistent application.

Concerns raised

Caution would be required to avoid fostering practices that could lead to division within the sector while establishing criteria for assessing information accuracy.

Create an independent oversight body to monitor website accuracy

1 2 3 4 5 6

Needs addressed

Addressing the lack of website accuracy monitoring:
Despite information standards being in place, the limited remits and distinct responsibilities of involved authorities create grey areas between audits, resulting in ineffective monitoring of information regarding add-ons on clinic websites.

Recommendations for impactful implementation

There needs to be an independent oversight body dedicated to monitoring and ensuring the accuracy of information presented on clinic websites. This oversight body should consist of experts from relevant fields, such as fertility care, regulatory compliance and patient advocacy, to ensure thorough scrutiny.

Collaborating closely with regulatory agencies, professional associations and patient advocacy groups, this body should develop standardised criteria for assessing website accuracy and facilitate the implementation of corrective measures when necessary. Moreover, the oversight body's responsibilities should include conducting regular audits of clinic websites, verifying the accuracy and consistency of information regarding treatment add-ons and promptly addressing any instances of misinformation or non-compliance. Efforts should be made to ensure that the oversight body works in harmony with existing regulatory frameworks and standards to maximise efficiency and effectiveness in monitoring clinic websites.

Potential barriers

Lack of appropriate resources for staffing, technology and ongoing operations would render it impossible to establish and maintain such a body. Without clear funding mechanisms in place, it is challenging to envision how the operational needs of the oversight body would be met over time.

Concerns raised

Caution should be exercised to avoid potential duplications in oversight efforts, as they could hinder patients' experience and lead to confusion when navigating multiple monitoring systems or criteria for website accuracy.

Enhance existing patient databases to incorporate pricing information

1 2 3 4

Needs addressed

Lack of transparent information on treatment costs:
Without clear and readily accessible information on the costs associated with various fertility treatments, patients may face uncertainty and difficulty in making fully informed decisions.

Recommendations for impactful implementation

Expanding existing patient-reported databases to encompass comprehensive pricing information alongside patient feedback and ratings would help patients to make better informed choices. Advocacy efforts should aim at encouraging patients to actively contribute to the database by reporting their own pricing experiences.

To ensure the database reflects the full spectrum of costs, patients should be encouraged to provide as much detail as possible about pricing, including tests, treatments, add-ons, medications and any additional expenses incurred during their fertility treatment.

To improve the accuracy of pricing information reported by patients, clear guidelines should be provided on how to report pricing information accurately and comprehensively. These guidelines should be made readily available for transparency and verification checks, enabling validation processes to verify the accuracy of reported pricing data.

Potential barriers

Without the support of an acknowledged body to ensure transparency, the reliability of the data could be limited.

Create an accessible database for comparing fertility treatment costs across clinics

Needs addressed

Inability to compare treatment costs across clinics:
Patients encounter difficulties in making fully informed decisions as they lack the ability to compare prices across clinics, thereby impeding their consideration of expenses associated with different fertility treatments and providers.

Recommendations for impactful implementation

Price lists available on fertility clinic websites should be used to create a comprehensive dataset for comparing fertility treatment costs across clinics. Reflecting the significant variation in pricing strategies among clinics, the dataset should include the standard package offered by each clinic and all items that can be added to the invoice. It should cover information on whether a treatment option is available, whether it is included in the package price, or if it is charged separately.

Guidelines for presenting pricing information should be provided to clinics to establish a system for regular updates. Visualisation tools should be implemented to facilitate easy comparison for patients, allowing them to select specific items for comparison and choose a number of selected clinics to compare the final cost effectively. Given the complexity of fertility treatment individualised protocols, information on drug costs should be separate from other expenses.

Potential barriers

Due to the absence of a standardised method for presenting pricing information across fertility clinics, manual data collection could be labour-intensive unless clinics commit to providing data following the requested guidelines.Similarly, continuous monitoring may not be feasible due to price fluctuations. Therefore, it would be essential to establish additional measures to incentivise clinics to provide data in a comparable manner, thus avoiding outdated information.

Concerns raised

Caution was recommended regarding the potential for outdated information to cause confusion among patients. Concerns were expressed that the comparison tool could inadvertently question the commercial strategies of clinics.

Provide detailed information on the pricing of fertility drugs

1 2 3 4

Needs addressed

Lack of transparency regarding the cost of fertility drugs: Fertility drugs are costly, and their prices are not typically included in standard packages due to variations in treatment protocols and individual patient responses. In addition, certain medications are used for purposes beyond their approved indications, often as add-ons to standard treatment. It is challenging to advise patients on the total amount of drugs they will need, prior to commencing treatment. Consequently, there is a widespread lack of transparency surrounding the costs associated with these drugs.

Recommendations for impactful implementation

Comprehensive online resources which detail the pricing of drugs used in fertility treatments, including the mean, median and mode prices for each drug, are needed. Clinics should be encouraged to provide detailed pricing lists for these drugs on their websites, encompassing information on additional services such as prescriptions. Data collection can be supplemented by using cost price lists from ASDA pharmacies, known for their non-profit policy on fertility drugs.

Patients should be made aware that these prices may not encompass all clinic services, such as drug availability, specialised needles and syringes, off-label drug use information and instructions for drug administration.

Potential barriers

Collecting data for individual clinics could be challenging due to the absence of accessible price lists. Therefore, it would be essential to establish additional measures to incentivise clinics to furnish these data, thus avoiding the risk of providing incomplete information.

Concerns raised

Caution has been recommended regarding the discrepancy in contract pricing for drugs used in fertility treatments, which are often negotiated individually by each clinic. There are concerns that sharing price cost information could erode trust, as some clinics may not have the flexibility to lower their prices without facing financial losses. This could potentially present an inaccurate picture of pricing decisions and impact patients' perceptions of clinic pricing practices.

Audit consent process and consent forms

1 2 3 4

Needs addressed

Update consent procedures to include a focus on add-ons: While consent procedures in fertility care are highly detailed and typically involve written consent signed by the individual providing consent, they primarily focus on the use or storage of eggs, sperm or embryos.

Recommendations for impactful implementation

Audits are needed to assess the effectiveness and accuracy of the consent process and associated consent forms used in fertility treatments, especially concerning the inclusion of add-ons. These audits should involve regular evaluations of consent procedures and forms to ensure they adequately cover the information relevant to add-ons, including their potential risks, benefits and alternatives.

Additionally, audits should involve additional materials provided to patients with comprehensive information about add-ons and their implications before obtaining consent.

Potential barriers

Consent procedures in fertility treatment are closely regulated by Section 13 of the Human Fertilisation and Embryology Act 1990 and any formal changes should be considered as part of the law reform process.

With the abundance of information necessary to provide, it might be difficult to prioritise which aspects of the consent process to focus on.

Concerns raised

Patients may feel overwhelmed by the volume of information presented to them, making it difficult for them to fully grasp the details of the consent forms and procedures.

Conclusion

As the field of fertility care continues to evolve, ensuring patients make informed decisions remains a top priority. The proposals outlined in this toolkit, informed by research and aimed at addressing key challenges in the field, represent a step towards fostering transparency, accountability and patient-centred care in fertility treatment.

It is essential to emphasise that patient empowerment in fertility treatment is an ongoing endeavour, with multiple efforts aimed at improving informed decision-making. The proposals outlined in this project address key needs and priorities identified through research, but they are subject to further evolution:

Some proposals complement each other, while others may conflict due to differing approaches to addressing similar challenges.

Feasibility of implementation depends on regulatory changes; for instance, effective website auditing by the HFEA necessitates the ability to enforce rewards and penalties.

Future law reforms may impact the necessity of certain proposals; for instance, if the HFEA gains jurisdiction over protecting patients' interests as consumers, an independent body to assess clinic websites might become redundant.

Overall, the findings of this project align with the HFEA's call for law reform, particularly in safeguarding patients' interests within the fertility market. Addressing conflicts of interest underlying the challenges discussed in this project is crucial for developing a renewed regulatory framework capable of navigating an increasingly commercialised sector.

References and underpinning research

Underpinning research

Hamper, J. and Perrotta, M. (2023) 'Blurring the divide: navigating the public/ private landscape of fertility treatment in the UK', Health & Place, 80: 102992.

Perrotta, M. (2024) Biomedical Innovation in Fertility Care: Evidence Challenges, Commercialization and the Market for Hope. Bristol University Press.

Perrotta, M. and Geampana, A. (2020) 'The trouble with IVF and randomised control trials: professional legitimation narratives on time-lapse imaging and evidence-informed care', Social Science & Medicine, 258: 113115.

Perrotta, M. and Geampana, A. (2021) 'Enacting evidence-based medicine in fertility care: tensions between commercialisation and knowledge standardisation', Sociology of Health & Illness, 43(9): 2015–2030.

Perrotta, M. and Hamper, J. (2021) 'The crafting of hope: contextualising add-ons in the treatment trajectories of IVF patients', Social Science & Medicine, 287: 114317.

Perrotta, M. and Hamper, J. (2023) 'Patient informed choice in the age of evidence- based medicine: IVF patients' approaches to biomedical evidence and fertility treatment add-ons', Sociology of Health & Illness, 45(2): 225–241.

Perrotta, M. and Smietana, M. (2024a) Evidence Gaps and Information Provision in Fertility Care: Addressing Key Needs, Priorities and Challenges, Research Digest #1, Remaking Fertility. Queen Mary University of London. Available at qmul.ac.uk/remaking-fertility/research-digests/.

Perrotta, M. and Smietana, M. (2024b) Information Provision on UK Fertility Clinic Websites: Addressing Key Needs, Priorities and Challenges, Research Digest #2, Remaking Fertility. Queen Mary University of London. Available at remakingfertility.sbm.qmul.ac.uk/index.php/research-digests/.

Perrotta, M. and Smietana, M. (2024c) Ensuring Cost Transparency and Fully Informed Decision-making: Addressing Key Needs, Priorities, and Challenges, Research Digest #3, Remaking Fertility. Queen Mary University of London. Available at remakingfertility.sbm.qmul.ac.uk/index.php/research-digests/.

Perrotta, M., Zampino, L., Geampana, A. and Bhide, P. (2024) 'Analysing adherence to guidelines for time-lapse imaging information on UK fertility clinic websites', Human Fertility, online first. Available at doi.org/10.1080/14647273.2024.2346595.

References

Adamson, G. D. and Rutherford, A. J. (2018) Commercialization of in-vitro fertilization. In Kovacs, G., Brinsden, P. and DeCherney, A. (eds) (2018) In-vitro Fertilization: The Pioneers' History. Cambridge University Press, pp. 240–248.

ASA (2021) Enforcement Notice: Advertising of Fertility Treatments. Available at asa.org.uk/static/cb6c3d82-5bfc-463a-9a9fac5cbfe6d831/f00db49e-0bde-4ccf-940807410ace35d9/Fertility-Treatments-Enforcement-Notice-FINALPDF.pdf.

Bill 230 (2023) Fertility Treatment (Transparency) proposal, Volume 726, debated on Wednesday 18 January 2023. Available at hansard.parliament.uk/commons/2023-01-18/debates/BD41DF93-3E19-43D8-802D-CEFA50892778/FertilityTreatment(Transparency).

Carrick, M., Wilkinson, J., Polyakov, A., Kirkham, J. and Lensen, S. (2023) 'How do IVF patients interpret claims about fertility treatments? A randomised survey experiment', Human Fertility, 26(2): 347–354.

CMA (2020) The Competition and Markets Authority: Self- funded IVF Research, qualitative research report. Available at: assets.publishing.service.gov.uk/media/5fa01b30e90e070420702a1b/IVF_Research_Final_Report.pdf.

CMA (2021a) Guidance for Fertility Clinics on Consumer Law. Available at assets.publishing.service.gov.uk/media/60c233e6e90e07438ee574a7/Final_Guidance_for_Clinics__21.pdf.

CMA (2021b) Fertility Treatment: A Guide to Your Consumer Rights. Available at www.gov.uk/government/publications/fertility-treatment-a-guide-to-your-consumer-rights/a-guide-to-your-consumer-rights.

CMA (2022a) Patients' Experiences of Buying Fertility Treatment. Qualitative Research Report. Available at assets.publishing.service.gov.uk/media/632c2fefe90e073721b08402/Consumer_research_report_160922.pdf

CMA (2022b) Consumer Law Compliance Review of Fertility Clinics. Findings Report. Available at assets.publishing.service.gov.uk/media/632d65af8fa8f51d1f83391a/A._Final_findings_report.pdf.

CQC, (2019) Memorandum of understanding – Human Fertilisation and Embryology Authority (HFEA). Available at cqc.org.uk/what-we-do/our-partnerships/memorandum-understanding-human-fertilisation-embryology-authority-hfea.

Department for Health and Social Care (2022) Women's Health Strategy for England policy paper. Available at gov.uk/government/publications/womens-health-strategy-for-england/womens-health-strategy-for-england.

Ecker, U. K., Hogan, J. L. and Lewandowsky, S. (2017) Reminders and repetition of misinformation: Helping or hindering its retraction? Journal of applied research in memory and cognition, 6(2), 185–192.

ESHRE Add-ons working group, Lundin, K., Bentzen, J. G., Bozdag, G., Ebner, T., Harper, J., Le Clef, N., Moffett A., Norcross S., Polyzos, N. P., Rautakallio-Hokkanen, S., Sfontouris I., Sermon, K., Vermeulen, N. and Pinborg A., (2023) 'Good practice recommendations on add-ons in reproductive medicine', Human Reproduction, 38(11), pp. 2062–2104. Available at doi.org/10.1093/humrep/dead184.

Fertility Network UK (2023) 'The impact of the cost-of-living crisis on fertility patients', Fertility Network Report. Available at fertilitynetworkuk.org/wp-content/uploads/2023/10/Fertility-Network-report-The-impact-of-the-cost-of-living-crisis-on-fertility-patients.pdf.

Hamper, J. and Perrotta, M. (2023) 'Blurring the divide: navigating the public/ private landscape of fertility treatment in the UK', Health & Place, 80: 102992.

HFEA, 2019/2023, The responsible use of treatment add-ons in fertility services: a consensus statement, Version published 19 October 2023. Available at hfea.gov.uk/media/kublgcp3/2023-10-19-treatment-add-ons-consensus-statement.pdf.

HFEA (2019b) Pilot National Fertility Patient Survey. Available at hfea.gov.uk/about-us/news-and-press-releases/2018/our-national-patient-survey-results/.

HFEA (2022) National Patient Survey 2021. Available at hfea.gov.uk/about-us/publications/research-and-data/national-patient-survey-2021/#treatment-add-ons.

HFEA (2023a) Treatment Add-ons with Limited Evidence. Available at hfea.gov.uk/treatments/treatment-add-ons/.

HFEA, (2023b) Modernising fertility law. Available at hfea.gov.uk/about-us/modernising-the-regulation-of-fertility-treatment-and-research-involving-human-embryos/modernising-fertility-law/#the-case-for-change.

HFEA (2023c) Code of practice, 9th Edn (Version 4). Revised October 2023. Available at portal.hfea.gov.uk/media/za0j5qqr/2023-10-26-code-of-practice-v9-4.pdf.

HFEA (2024) HFEA dashboard. Available at www.hfea.gov.uk/about-us/hfea-dashboard/.

Keller, E., Botha, W. and Chambers, G. M. (2023) 'What features of fertility treatment do patients value? Price elasticity and willingness-to- ay values from a discrete choice experiment', Applied Health Economics and Health Policy, 21(1): 91–107.

Perrotta, M. (2024) Biomedical Innovation in Fertility Care: Evidence Challenges, Commercialization and the Market for Hope. Bristol University Press.

Perrotta, M. and Smietana, M. (2024a) Evidence Gaps and Information Provision in Fertility Care: Addressing Key Needs, Priorities and Challenges, Research Digest #1, Remaking Fertility. Queen Mary University of London. Available at www.qmul.ac.uk/remaking-fertility/research-digests/.

Perrotta, M. and Smietana, M. (2024b) Information Provision on UK Fertility Clinic Websites: Addressing Key Needs, Priorities and Challenges, Research Digest #2, Remaking Fertility. Queen Mary University of London. Available at remakingfertility.sbm.qmul.ac.uk/index.php/research-digests/.

Perrotta, M. and Smietana, M. (2024c) Ensuring Cost Transparency and Fully Informed Decision-making: Addressing Key Needs, Priorities, and Challenges, Research Digest #3, Remaking Fertility. Queen Mary University of London. Available at remakingfertility.sbm.qmul.ac.uk/index.php/research-digests/.

Perrotta, M., Zampino, L., Geampana, A. and Bhide, P. (2024) 'Analysing adherence to guidelines for time-lapse imaging information on UK fertility clinic websites', Human Fertility, online first. Available at doi.org/10.1080/14647273.2024.2346595.

Schwarz, N., Newman, E., and Leach, W. (2016) Making the truth stick & the myths fade: Lessons from cognitive psychology, Behavioral Science & Policy, 2(1), 85–95.

Stein, J. and Harper, J. C. (2021) Analysis of fertility clinic marketing of complementary therapy add-ons, Reproductive Biomedicine & Society Online, 13, 24–36.

van de Wiel, L., Wilkinson, J., Athanasiou, P. and Harper, J. (2020) The prevalence, promotion and pricing of three IVF add-ons on fertility clinic websites, Reproductive Biomedicine Online, 41(5), 801–806.

Wilkinson, J., Malpas, P., Hammarberg, K., Tsigdinos, P. M., Lensen, S., Jackson, E., Harper, J. and Mol, B. W. (2019) Do à la carte menus serve infertility patients? The ethics and regulation of in vitro fertility add-ons, Fertility and sterility, 112(6), 973–977.