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Evidence Gaps and Information Provision in Fertility Care

Addressing Key Needs, Priorities and Challenges

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The adoption and growing popularity of additional treatments and interventions, often referred to as "add-ons", have sparked extensive debate within the fertility care field about the gaps in their evidence base. However, there has been little discussion focusing on how the lack of evidence affects the quality of information.

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Overview: The Building Bridges Project

In partnership with the Progress Educational Trust (PET), the Building Bridges project aims to tackle the persistent challenges of inclusively addressing, learning from, and integrating the needs and priorities of fertility patients, professionals, and regulators.

As part of this project, the team invites groups of relevant participants to engage in dedicated workshops, where they discuss some of the challenges identified through previous research and analysis of available data.
This initial research digest summarises the discussions held during the first workshop, which focused on the lack of evidence and its impact on available information.

Context

In the field of fertility, add-ons are elective supplementary treatments available for patients, usually at an extra cost.

While some studies suggest their potential efficacy in improving live birth rates, there is often a lack of robust and reliable evidence to substantiate their effectiveness for the majority of fertility patients.

Concerns have been raised about potential misrepresentation of these treatments, primarily due to the additional financial burden they impose on patients.

Workshop Insights

How does the lack of evidence impact the quality of information?

Evidence gaps are a common occurrence in the medical and fertility fields. They are not inherently problematic, as long as patients receive clear information. However, the absence of evidence creates challenges in ensuring that patients receive trustworthy and transparent information, which is crucial for making informed decisions about their treatment.

During the workshop, participants shared diverse perspectives on how treatment decisions should be approached. Some believe that patients should have the freedom to choose their treatment from a list of available options, guided by healthcare professionals. On the other hand, some argue that clinical expertise should guide treatment decisions, and due to the additional cost involved, transferring this decision to patients is considered unfair.

> *I think the concept of add-ons is the most ethical way to handle it is to say: ‘this is interesting, we don’t have evidence if it’ll work in your case, but we can add it apart from our evidence-based care’. I think it’s the most honest way of speaking to the patient about something that’s uncertain.”*
>
> – workshop participant 1

All participants agreed on the importance of providing patients with accurate information to make informed choices. Nevertheless, the underlying lack of evidence presents challenges in offering clear and transparent information.

Conflicting evidence is frequently regarded as uncertain, with the common perception that “it might work or not work”, often with little attention given to the potential for harm (“it might make things worse”). For instance, early versions of add-ons like PGT-A have appeared to decrease the likelihood of a successful pregnancy for patients who opted for and paid for them.

Emphasising that uncertainty should be acknowledged as encompassing both potential benefits and potential risks would equip patients with a more comprehensive understanding of their treatment choices.

> *With new techniques, you have no choice but to charge cost price, as without charging the patient in the short run you can’t produce evidence.”*
>
> – workshop participant 3

> *For patients the cost is all important, so you have to be clear about it upfront. They totally understand what an add-on is, most will have done a whole lot of research. They’re usually desperate and want to try, but the cost is crucial for them, but often they will not be able to understand how much, no comparison, so they have a feeling of being ripped-off by the clinics.”*
>
> – workshop participant 2

Emphasising that uncertainty should be acknowledged as encompassing both potential benefits and potential risks would equip patients with a more comprehensive understanding of their treatment choices.

Fertility treatments come with associated costs, which are either borne by patients or covered by the healthcare system. The potential financial burden on patients emphasises the need for transparency concerning these costs. Patients must be fully aware of the financial implications of their choices before starting the treatment, enabling them to make informed decisions aligned with their personal circumstances.

Concerns about the lack of transparent information regarding the evidence base, risks, and costs have eroded trust between patients and healthcare providers. Trust is critical for the patient-doctor relationship, and some participants have highlighted the importance of rebuilding trust in this field.

Needs, Priorities and Challenges

In summary, the workshop has identified critical needs, priorities, and challenges that the project is committed to addressing. The next phase will entail collaborative efforts to craft effective solutions.

Conflicting information:

The presence of conflicting information regarding the costs, effectiveness, and risks of add-ons heightens patients' feelings of uncertainty. It is imperative that patients receive reliable, comprehensive information about the costs, evidence base, and potential risks associated with add-ons before embarking on their treatment.

Financial apprehensions:

Patients express concerns about the high costs of treatments, along with the uncertainty surrounding their effectiveness. They also worry that treatment recommendations may be influenced by commercial interests rather than purely medical considerations. Addressing these financial apprehensions is a key priority.

Potential trust erosion:

Pervasive concerns about the quality of information have the potential to erode the trust patients place in the fertility sector. This erosion of trust within the field may render individual clinics' efforts to provide clear and transparent information and improve communication about treatment decisions fruitless. Regulatory initiatives, such as standards for information provision, have already been implemented to address these concerns. Nevertheless, re-establishing trust in the field is essential to ensure patients feel fully supported when making informed choices about their treatments.

Underpinning research

Perrotta, M. and Geampana, A. (2021) Enacting evidence-based medicine in fertility care: Tensions between commercialisation and knowledge standardisation. *Sociology of Health and Illness*.

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

Perrotta, M. and Hamper, J. (2022) 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*.

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