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# Ensuring Cost Transparency and Fully Informed Decision-making

## Addressing Key Needs, Priorities, and Challenges

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Research has uncovered a significant information gap concerning the costs associated with fertility treatments, hindering patients' ability to make informed comparisons. The workshop discussion has focused on ensuring transparency in sharing information about fertility treatment costs and empowering patients to make well-informed decisions within an increasingly commercialised market.

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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. Previous workshops addressed the effects of evidence gaps in disseminating information and the quality of information provision on fertility clinic websites.

This research insight encapsulates the discussions held during the third workshop on ensuring cost transparency and fully informed decision-making.

## Context

Research has revealed a significant information gap in fertility treatment costs. Reliable data on actual patient expenses are scarce, although anecdotally patients typically pay £5,000 to £20,000 or more per treatment cycle (CMA, 2022).

Treatment cost seem to have minimal impact on demand (Keller et al. 2023), as patients are often willing to invest significantly to explore all available treatment avenues. A recent study (Carrick et al. 2023) highlights that a third (34%) of participants were willing to use an add-on treatment even though they believed it would not improve the probability of having a baby, confirming that often patients want to 'try everything possible' to avoid future regret (Perrotta and Hamper, 2021).

To address these concerns, we invited participants to discuss ensuring transparency and informed patient decision-making within an increasingly commercialised market. Topics included clinic pricing strategies, the sale of treatment add-ons and marketing and advertising techniques to attract patients.

**Fertility Network UK's 2023 survey revealed that**

**80%** 

**of respondents funded their treatment privately.**

Of these, 28% used life savings, 19% sought help from friends or family, 16% relied on credit cards, and 14% sold belongings. Our research (Hamper and Perrotta 2023) unveils that many postponed major expenses such as cars, holidays or home moves to finance IVF.

# Workshop Insights



## Ensuring transparency and informed decision-making

Several workshop participants concurred that the lack of standardisation of fertility treatment costs across the sector hinders patients' ability to compare. However, other participants highlighted the difficulty in standardising treatment prices due to significant differences in expenses that clinics incur, such as rent for local premises or consultants' fees varying by seniority.

“

*What we lack in the sector is standardisation in terms of the costs of treatment and add-ons. I have a lot of patients saying they didn't get any information”*

– workshop participant 1

Several participants also emphasised that price differences per se were inherent in all markets, suggesting that attention should be focused instead on the transparency of information about treatment costs provided by clinics. Some of the participants expressed concerns about the impact of commercial interests on the ways in which treatment price mark-ups are established, highlighting concerns regarding the potential upselling of fertility treatments.

“

*For me it's about the money - if you're talking about things that are costing an awful lot of money or have potential risks, I think there are really significant problems”*

– workshop participant 2

These considerations sparked a discussion about patient informed decision-making and the consent process. Some participants observed that fertility patients often find themselves in a vulnerable position, making them willing to pay for any treatments that offer hope. Some of the workshop participants reported that patients they had dealt with had not received any clear information about their treatments and costs. Additionally, some participants emphasised that the financial struggles of fertility patients, discussed during the workshop, could undermine their psychological health.

“

*From the patient perspective, getting a sense of what you're realistically likely to pay, and a sense of value for money is much more useful than the clinic's profits. Does a clinic where you pay £20,000 per cycle have significantly better results than clinics where you pay £5,000?”*

– workshop participant 3

In conclusion, workshop participants underscored the importance of providing precise written information about treatment costs to enhance patients' informed decision-making and consent. Several participants stressed that patients should have the opportunity to take this information home, fostering open discussions with others, including fertility counsellors and individuals within their social networks, before committing to treatment. This information should include signposting to reliable sources such as the NHS and the HFEA and include an average cost list from authoritative sources to facilitate comparison.

# Needs, Priorities and Challenges

In conclusion, the workshop has identified crucial needs, priorities, and challenges that the project is committed to addressing. The upcoming phase will focus on collaborative endeavours to articulate effective solutions.



## Lack of cost information:

Concerns were raised about the provision of treatment cost details and its impact on patients' ability to compare across clinics. Ensuring that patients receive clear, transparent and precise information about these costs before committing to treatment is crucial.



## Pricing strategies:

Concerns were voiced regarding substantial cost variations and the impact of commercial interests on treatment price mark-ups. Although standardising fertility treatment costs across the sector may be challenging, providing the option to assess them against an average cost list from authoritative sources would enhance patients' informed decision-making.



## Ensuring patient informed decision-making and consent:

The lack of transparency and inconsistent presentation of treatment costs across clinics create difficulty for patients in effectively assimilating this information. Patients should receive written information and have adequate time and space to comprehend details about their treatments and associated costs, including the opportunity to discuss with others.

## References

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*.  
CMA (2022) [Patients' experiences of buying fertility treatment](#). Qualitative research report.  
Fertility Network (2023) [The impact of the cost-of-living crisis on UK fertility patients](#).  
Keller, E., Botha, W. and Chambers, G. M. (2023) [What Features of Fertility Treatment do Patients Value? Price Elasticity and Willingness-to-Pay Values from a Discrete Choice Experiment](#), *Applied Health Economics and Health Policy*.


# Underpinning research

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

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

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