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Information Provision on UK Fertility Clinic Websites

Addressing Key Needs, Priorities, and Challenges

Dr Manuela Perrotta, Dr Marcin Smietana

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Recent research indicates that fertility clinic websites serve as the primary source of information for patients regarding their treatments, including add-ons. However, analyses of these clinic websites reveal that the information provided is often inconsistent and outdated, and frequently partial, overstating benefits and minimising risks. The workshop discussion has centred on enhancing the quality of information available on clinic websites, their role in delivering information to patients, and strategies for managing patient expectations regarding the presentation 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. Following the initial workshop, which centred on the challenges posed by the lack of evidence in disseminating information, the focus of this second workshop shifted to the provision of information through fertility clinic websites. This second research digest encapsulates the discussions held during the workshop.

Context

Both the Human Fertilisation and Embryology Authority (HFEA, 2022), national patients survey and recent research commissioned by the Competition and Markets Authority (CMA, 2020, 2022a) indicate that patients primarily turn to fertility clinic websites for information about treatment, including add-ons.

In 2021, the CMA published guidance for clinics on their obligations under consumer law. It did so to improve compliance and to help address some of the concerns identified in the sector, such as patients not being properly informed by clinics of the limited evidence base for add-on treatments increasing the chances of a live birth, or the risk associated with certain add-on treatments. However, both the compliance review conducted by the CMA (2022b) and our recent study (Perrotta et al., 2023) on the provision of information on **time-lapse imaging (TLI)** confirmed concerns remain.

For example, our study highlights that:

- ▶ **A significant majority of websites (90%)**

claim or strongly imply enhanced clinical outcomes with TLI
- ▶ **Almost half of the websites (47%)**

did not provide a link to the HFEA website
- ▶ **Nearly a third of the websites (29.6%)**

lacked information on the cost of TLI

Workshop Insights



The quality of information on fertility clinic websites

UK fertility clinics are legally mandated to disclose their success rates and costs on their websites, with oversight from both the Care Quality Commission (CQC) and HFEA inspections. They also have obligations under consumer law. However, challenges in updating clinic websites and ensuring the presentation of reliable information were identified during the workshop. This sparked a broader discussion on the role of fertility clinic websites in comparison to other sources of information.

Some participants noted that maintaining up-to-date fertility clinic websites posed difficulties, often exceeding staff capacities due to time and financial constraints. Some participants observed that clinics often lack dedicated website staff.

“

I guess the website is the shop front. It is there to show patients what treatments and prices are offered and also to portray the culture of the clinic.”

– workshop participant 1

Numerous workshop participants raised the question of whether fertility clinic websites should be viewed as educational. While a consensus emerged that these websites should refrain from offering misleading information, some participants noted that these online platforms serve as the 'front window' of clinics, influencing patients' choices. Consequently, websites often portray treatments and procedures in a positive light.

“

Should clinic websites be an educational tool? I don't think they should be. But the key thing would be to say, whether this treatment is appropriate for you will be discussed with you at that appointment.”

– workshop participant 2

This prompted discussions about the appropriate level of discourse regarding potential harm and uncertainty in medical treatments on clinic websites. Acknowledging that all medical treatments inherently carry risks, including seemingly routine procedures, raised questions about how extensively these risks should be addressed on clinic websites.

Moreover, a discussion unfolded regarding the contemplation of locally produced clinic data as an alternative evidence base to the HFEA assessment. While some participants argued that these data would provide accurate information to patients, others expressed concerns about using them as evidence, citing the challenge for patients to assess their accuracy.

Several workshop participants emphasised that information presented on clinic websites is intended to be general. Accurate and personalised information can only be provided during a clinical patient-doctor consultation, where the suitability of a specific treatment is discussed in light of the patient's medical history. However, other participants expressed concern, noting that prioritising personalisation risks neglecting evidence-based and statistical data. There was some consensus on the necessity of finding a balanced approach that considers both individualised treatment and evidence-based practices.

In conclusion, many participants emphasised that patients actively seek information from diverse online sources on a global scale, including blogs, forums, personal websites, and social media. Monitoring these sources proves challenging due to their vastness. These platforms present conflicting information, significantly influencing patients' perceptions of various treatments. This underscores the crucial need for unbiased and independent educational sources to guide patients.

“

Are we required to put every tiny little thing on the website or is it down to us in clinic to be providing all of that information and the risks? I would say that it is down to us in clinic, not listing every possibility on a website.”

– workshop participant 3

Needs, Priorities and Challenges

In conclusion, the workshop has pinpointed crucial needs, priorities, and challenges that the project is committed to addressing. The upcoming phase will involve collaborative endeavours to formulate effective solutions.



Ensuring clinics comply with information standards:

Despite existing guidelines and assessment procedures for clinic websites, disseminating clear, transparent and up-to-date information remains a challenge. Addressing this issue is essential to enhance the overall accuracy and currency of information provided by clinics.



Role of clinic websites:

Patients perceive clinic websites as reliable sources of information that heavily influence their decisions on treatment. Meanwhile, professionals view these websites as external representations of their clinics, emphasising the need to portray treatments positively. Resolving the misalignment of expectations, particularly in the presentation of risks, stands out as a crucial priority.



Supporting patients in assessing information reliability:

Patients should be informed about compliance concerns and be encouraged to consult independent and reliable sources, like the HFEA rating system, to make well-informed decisions about their treatment.

References

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Underpinning research

Perrotta, M., Zampino, L., Geampana, A. and Bhide, P. (2023) [The provision of information on time-lapse imaging: A systematic analysis of UK fertility clinics websites](#), pre-print.

Dr Manuela Perrotta

Reader in Technology and Organisation
Queen Mary University of London

 [LinkedIn](#)

 [Academic profile](#)

 m.perrotta@qmul.ac.uk

Dr Marcin Smietana

Postdoctoral researcher
Queen Mary University of London

 [LinkedIn](#)

 m.smietana@qmul.ac.uk

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