



British Fertility Society

response to the

Human Fertilisation and Embryology Authority

public consultation on

Tomorrow's Children

A consultation on guidance to licensed fertility clinics on taking in account
the welfare of children to be born of assisted conception treatment

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Summary of Opinions and Questions

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Interest in the Welfare of the Child Review: The British Fertility Society is a multi-disciplinary organization representing professionals with an interest in reproductive medicine. The objectives of the society are:

- To promote high quality practice in the provision of fertility treatment.
- To provide a common forum for members of various disciplines having an interest in the science and treatment of infertility.
- To promote high quality scientific and clinical research in the causes and treatment of infertility.
- To provide professional leadership in the provision and regulation of infertility services.
- To promote the increase of NHS funding for and equity of access to fertility treatments.

The provision of assisted conception is an important part of the workload of BFS members and as such the society has an interest in policy developments in this area.

The society **agrees** to the making its responses publicly available by the HFEA in accordance with the Cabinet Office Code of Practice on Written Consultation. In addition the society will be making this response available on its website (<http://www.fertility.org.uk>).

This document represents the British Fertility Society's members views to the consultation on guidance to licensed fertility clinics on taking in account the welfare of children to be born of assisted conception treatment. The BFS membership were circulated by email and asked to send in their replies to the HFEA questionnaire. This response represents the majority view of those who replied and was compiled by Anthony Rutherford on behalf of the Executive Committee.

General

- 1. Please give any general comments you might have about the current guidance in the code of practice regarding welfare of the child assessment.***

The current guidance is more detailed than previous editions but does not explain how an assessment should be performed.

Enquiries to be made

- 2. Which of the following options best reflect your view on the enquiries that clinics should be expected to make in order to gather relevant information for the welfare of the child assessment?***

Option C: Information about risk factors provided by the patient, plus follow up to a third party if a problem is identified.

People often already feel stigmatised by infertility, and there is no justification for intrusive vetting in the absence of awareness of factors that cause concern. However, patients should be provided with clear advice about the information required, the reasons why this is necessary, and the penalties for withholding information. Uniformity of approach across all clinics throughout the UK is essential.

- 3. Do you think that refusal by a patient to give consent for a centre to contact their GP should be taken into account when deciding whether or not to provide treatment?***

Yes.

The reason why a patient may withhold consent to contact the GP needs to be clarified. Refusal without sound reasons may be seen as a way of obstructing the clinic from gaining important relevant information. As the General Practitioner has normally referred the couple, or patient for investigation and treatment, they should be kept informed at all times as customary in medicine. The risks are reduced when the GP is aware of intended management, and the GP can play a supportive role. If consent is refused, the centre may feel unable to fulfil their obligation to perform a proper assessment, and as such, could withhold treatment.

Factors to be taken into account

- 4. Which of the following options best reflects your view on the factors that should be taken into account during the welfare of the child assessment?**

Option C: *Risk factors for medical, physical and psychological harm and social circumstances should be taken into account.*

Although each of these factors may play a role in making an assessment, social factors should only be taken into account if the information provided by the patient suggests a potential problem that warrants further inquiries from a third party.

- 5. Would you welcome guidance from the HFEA on how to take into account the factors [in 4] above?**

Yes

It is essential that there is equity and uniformity of approach nationally. Clear guidance on how perceived conflicts between the welfare of different parties, including prospective parents, existing children, and children yet to be born should be provided, informed by best practice in child and family welfare.

Welfare of the child assessments for particular treatments

- 6. Which of the following options best reflects your view on the assessment that should be carried out during donor conception treatment?**

Option B: *When patients are having donor conception treatment, the same welfare of the child assessment as patients using their own gametes should be used. However, donor conception patients should receive extra information and preparation for becoming the parent(s) of a donor conceived child.*

There was strong agreement that extra information, preparation and support was required for those receiving donor gametes, because of the particular tasks facing them as potential parents. There will be differing issues for heterosexual couples, lesbian couples and single women.

- 7. If you opted for either 6 (a) or 6 (b) what kind of assessment and/or preparation for donor conception patients is desirable?**

There is no reason why any additional welfare of the child assessment is necessary for those receiving donor gametes, as compared to those patients receiving other forms of treatment. However, they do need specific help and information, particularly about how to disclose the nature of their conception to their children, and the emotional impact of not being the genetic parent. Counsellors are likely to be the source of this information

and help, although not all agreed that mandatory counselling was necessary. This help and information should be freely available, and not charged separately.

8. Which of the following options best reflects your view on the assessment that should be carried out for patients undergoing unlicensed treatments in licensed clinics?

Option A: *When patients are undergoing unlicensed treatments, the same welfare of the child assessment, as those undergoing licensed treatments should be used.*

The general opinion, taking into account the overall views already expressed on the welfare of the child assessment, was that there needed to be uniformity of approach irrespective of the type of infertility.

9. Please give any general comments you might have about the welfare of the child principle and its interpretation in clinical practice.

Doctors and nurses working in infertility find it difficult to make judgemental decisions about an individual couple's suitability to receive treatment.

A mandatory assessment stigmatises further those suffering from infertility. The assessment currently taking place varies enormously from centre to centre, across the country. Out of principle some GP's refuse to take part in the assessment process, creating inequity of approach.

It is anomalous that a patient receiving treatment in an unlicensed centre with the same principle condition, infertility does not require any formal assessment.

If a formal assessment is considered necessary, it needs to be standardized with clear guidance from the HFEA, perhaps with a protocol and/or proforma/s.

Further research is necessary into the benefit of performing a formal assessment, including what factors would constitute a risk.

One of the foremost concerns that has clearly affected the welfare of the child over the last decade is iatrogenic, namely multiple pregnancy. This is outside the scope of this consultation.

It is important to make provision to support families of children conceived after gamete donation over time.