



## **Welfare of the Child Review**

***Report of a public consultative meeting held at Jury's Inn  
Hotel, Glasgow, 23 February 2005***

## **1. Aim of the consultative meetings**

In June 2004, the HFEA launched a review of its guidance on welfare of the child assessments in licensed fertility clinics. In order to gather the views of clinic staff, patients and other stakeholders, a public consultation was held between January and April 2005. This consultation consisted of a written consultation document, *Tomorrow's Children*, and a series of public consultative meetings held in Westminster, Glasgow, London and Manchester during February and March 2005.

The main purpose of the consultative meetings was to offer clinic staff, patients and other stakeholders an alternative method of feeding their experience and view into the review. The meeting also helped to:

- promote discussion and debate on this key policy issue, thereby understanding differences in perspective and opinion;
- involve practitioners, patients and other interested parties in the policy making process; and
- encourage practitioners, patients and other interested parties to respond to the written consultation document.

## **2. Programme**

The meeting in Glasgow started at 1pm with a lunch, during which HFEA staff and delegates were able to meet and discuss the issue on an informal basis.

HFEA Chair, Suzi Leather opened the meeting with a 10-minute introduction (see Appendix A for a transcript), explaining the reasons for conducting a review of welfare of the child assessments in licensed centres. She also outlined both the current guidance and the options in the consultation document for revising that guidance. The delegates were then split into three discussion groups, each containing an even spread of interests (doctors, patients, counsellors, nurses etc.). The groups took 30 minutes to discuss each of the three main areas of the welfare of the child guidance which are under review. Those areas are:

- What risk factors should be taken into account during a welfare of the child assessment?
- To whom should enquiries be made in order to gather relevant information?
- Do patients undergoing donor conception treatment or unlicensed treatments need a different kind of assessment?

## **3. Audience**

Because the review focused mainly on the welfare of the child guidance in the *Code of Practice*, the majority of participants were professionals or people with a personal experience of welfare of the child assessments. However, a

number of other stakeholders attended the meeting and provided a useful perspective in the discussions.

A total of 49 people registered for the consultative meeting, with 39 attending on the day. The drop-out rate of 20% was partly explained by bad weather and would otherwise have been 11%. The breakdown, according to interest, of the 39 who attended was as follows:

Interest category	No.	%
Nurse	9	23%
Other	8	20%
Counsellor/social worker	6	15%
Academic	5	13%
Embryologist	5	13%
Clinician	3	8%
Patient	3	8%

All of the six Scottish HFEA-licensed clinics were represented in the original delegate list, although staff from the Aberdeen clinic were prevented from attending by bad weather. See Appendix B for a full delegate list.

#### 4. Audience feedback

Of the 39 delegates at the meeting, 10 (25%) completed a feedback form. Of those who responded, 90% had heard about the meeting either from an HFEA mailing or from the HFEA website (the other person heard about the event from the Fertility Friends website). When asked an open question about why they were interested in attending, 40% said it was to hear the views of others and to discuss an interesting topic; 30% stated professional interest; 10% stated personal interest and 10% came to address a particular problem (the lack of consistency between clinics). All respondents rated both the opening presentation and the meeting format as excellent or good. When asked how they prefer to respond to an HFEA consultation, 20% preferred to contribute through a workshop, 20% preferred to submit a written response and the remaining 60% liked to use both methods.

When asked to give general feedback on the consultative meeting, delegates said that they welcomed the opportunity to discuss these issues and to share experiences with colleagues in other clinics. One respondent said that the meeting was ‘useful for generating ideas and “on the ground” views, not just from the usual suspects who get asked to respond on behalf of organisations’.

#### 5. Summary of the discussions

Before delegates focused upon the policy options put forward in the consultation document, they were asked to discuss their views on the welfare

of the child principle in the Human Fertilisation and Embryology (HFE) Act 1990 and how we should interpret it in the clinic.

Part of the discussion considered the standard of parenting that we might expect of IVF patients. Some preferred a minimal threshold, perhaps seeking to avoid the creation of lives which are so poor that the child would have been better off not existing. One delegate preferred this minimal threshold of likely harm to the child because, otherwise, we would be in the peculiar situation of preventing a child from being born in order to save it from harm.

Most delegates agreed that it is not appropriate for IVF practitioners to judge a patient's ability to be a good parent. They felt that this was both impractical, because predicting parenting ability is crystal ball gazing, and inappropriate, because we shouldn't judge prospective parents just because we can. Some members of the team asked whether there is any evidence that current welfare of the child guidance does anything to protect children and questioned whether assessments are needed at all. In countries where assessments are not performed, is there any evidence that the children born of IVF are disadvantaged?

One of the patients at the meeting challenged the fairness of welfare of the child assessments, given that those who do not need medical assistance have no such checks. She said that there would be absolute outrage if everyone had to go for an interview and had to have a police check before they were allowed to have a child and asked what it is about the infertile that warrants such an approach. Most delegates were sympathetic to this view, but felt that the involvement of a medical team brings with it some moral responsibilities, thereby distinguishing assisted conception from natural conception.

The discussion concluded by an agreement that whatever level of assessment we have, clinics should be open and honest with patients about why assessments happen, what questions they will be asked and how decisions are made.

### **5.1 What risk factors should be taken into account during a welfare of the child assessment?**

Current HFEA guidance expects clinics to take into account a wide range of medical, psychological and social factors which might impact upon the welfare of the child to be born. The consultation document presented the following options for amending the section of the guidance referring to risk factors:

- A only risk factors for medical harm should be taken into account
- B risk factors for medical, physical and psychological harm should be taken into account
- C risk factors for medical, physical and psychological harm and social circumstances should be taken into account

#### *Medical or social factors?*

The delegates agreed that it is important to consider the medical risks associated with each patient. Assessment criteria could be whether a

pregnancy would harm or worsen a patient's condition or prognosis. Most delegates agreed that social factors should be considered, although they could not agree upon which ones. But, with the possible exception of a history of child sex abuse, delegates couldn't agree on any circumstances in which a particular risk factor would, by itself, preclude someone from being offered treatment. One delegate representing the General Medical Council reminded delegates that GMC guidance to doctors states that medical decisions should not be based upon a patient's lifestyle or economic status.

One delegate said that their clinic would normally refuse to treat patients with a drug or alcohol problem, but others questioned the fairness of such a blanket approach. Instead, many agreed, assessment should be based upon the severity of the problem and its likely effect upon any child born.

#### *Are criminal records relevant?*

The group considered whether a patient's criminal record should be taken into account and agreed that although sex offences are important, other convictions may be irrelevant. They also wondered how relevant convictions should be taken into account. If they were some years ago and any sentence has been served, is it fair to keep punishing people? Should there be a period of time, after which convictions should not be taken into account? Ultimately, it's very hard to predict what a patient will be like in the future. If criminal records are to be consulted, clinics may need a standard policy on how to use the information in deciding whether or not to offer treatment.

A distinction was made between what information is gathered and what a clinic then does with that information. Delegates were concerned that different clinics are taking risk factors into account in different ways. However, they couldn't agree on any lists or even categories of risk that should be considered. They also acknowledged that there will always be a disparity between the judgement of individual cases in different clinics. However, the group suggested that the HFEA produce a more detailed list of factors to be considered, to avoid gross inconsistencies.

#### *Qualifications of IVF practitioners*

Delegates also discussed whether IVF practitioners are qualified to make welfare of the child assessments. Some said that they are very well placed to make assessments because they know the patients well, have built up a relationship with them (often over a number of treatment cycles) and are experienced in thinking about welfare issues. However, some were concerned that IVF practitioners often rely upon their intuition to detect problems and wondered whether more objective assessment criteria might be needed. In the past, a hospital social worker might have been available to help with an assessment. It may be possible to develop welfare of the child risk assessment procedures, perhaps based upon best practice from social work. This might be more useful than the current practice of referring difficult cases to an ethics committee.

## 5.2 To whom should enquiries be made to gather relevant information?

Currently, clinics are expected to contact a patient's general practitioner to gather information relevant to the welfare of the child. The consultation document asked whether this practice should continue or whether guidance should in future expect clinics either to carry out a less extensive or a more extensive method of information gathering.

Delegates agreed that some form of enquiry should be made, but could not come to any consensus on to whom enquiries should be made. Group views ranged from relying on information provided by the patient to maintaining the current practice of routine GP enquiries. According to some of the legal academics present it would not be possible to remove all social enquiries because the 1990 Act mentions the child's need for a father, which makes social enquiries an explicit aspect of welfare of the child assessments.

### *Making enquiries to GPs*

The group discussed whether clinics should continue to contact patients GP's routinely to gather information. Some delegates from clinics found GPs in their area responsive and able to provide useful information. Others had experience either of uncooperative GPs or GPs who didn't know their patients well enough to be able to provide information about social issues. Some GPs charge a fee for providing information, but most thought this was caused by new GP contracts and would soon pass. A few delegates questioned the fairness of GP enquiries, when those patients who do not have a GP are able to avoid having enquiries made about them.

A lack of clear guidance for GPs may explain situations where they appear uncooperative. If routine GP enquiries are to continue, delegates agreed that it should be made clear to them that they are being asked to provide information to help the clinic make an assessment, not to make an assessment themselves. Many agreed that a standardised form and guidance from the HFEA about how to complete it would be very helpful.

A few delegates suggested that since the GP usually refers the patient for treatment, their referral should be taken as an implicit statement that they have no welfare of the child concerns about the patient. Some suggested that GPs could be asked to carry out a more explicit assessment at the point of referral, but most thought this was impractical and difficult to enforce.

The group considered what should happen if a patient refuses to consent to the clinic contacting the GP. Most agreed that the patient should be asked why they are refusing. Their answer should be taken into account, but it should not necessarily be grounds for denying the patient treatment. Delegates noted that there are often good reasons for such refusals, particularly in donor conception treatment when patients often wish to limit the number of people who know what kind of treatment they are having.

### *Making enquiries to social services and other agencies*

Delegates from licensed clinics reported that, at present, they rarely contact social services or other agencies such as the Criminal Records Bureau (CRB)

for more information about their patients. From views expressed by all delegates, there was little appetite for any change to the guidance which would require clinics to gather information routinely from these sources. Most thought that patients would be resentful if such enquiries were to become routine, particularly if the cost of doing so was passed on to them.

Most delegates regarded routine enquiries to other agencies as unappealing from an ethical point of view (one delegate described them as 'pretty scary'). Some thought that it may be the most reliable way to gather information because it doesn't rely on patients to be honest or on patchy information from GPs. However, the current difficulty of getting social services to respond just to occasional requests for information makes this approach seem unfeasible.

### **5.3 Do patients undergoing donor conception treatment need a different kind of assessment?**

The current guidance expects clinics to take into account a number of additional factors when considering whether or not to offer donor conception treatment. However, it does not make it clear whether these additional factors relate to the assessment of donor conception patients or to the information and preparation that they need. The consultation document asked whether there should be any distinction between the assessment of donor conception patients and those using their own gametes.

Almost all delegates agreed that the welfare of the child assessment should not be any more rigorous in donor conception than it is in other assisted conception treatments. Although there are different aspects of donor conception treatment, the patients undergoing it pose no greater risk to their prospective child than do other patients. Most delegates thought that any extra assessment of donor conception patients would be unfair and potentially discriminatory.

However, there was agreement that donor conception patients do need good preparation. This could include discussion about the implications of having a child that is not genetically related to both parents; reassurance for patients that social parenthood is just as important as genetic parenthood; obtaining acknowledgement from the patient(s) of the need to discuss the issue with their child at a suitable child and giving suggestions about how to do so.

Preparation, which was regarded as the responsibility of the whole team, should be distinguished from counselling, which is provided by a qualified counsellor. Although, in practice, preparation is often provided by the counsellor and most clinics make counselling a precondition of donor conception treatment, guidance should be careful not to conflate them. Although one delegate suggested that HFEA guidance should require donor conception patients to take up the offer of counselling, most delegates felt that counselling should continue to be voluntary.

#### **5.4 Do patients undergoing unlicensed treatments need a different kind of assessment?**

The Human Fertilisation and Embryology (HFE) Act requires that the welfare of the child be considered prior to the offer of 'treatment services'. This means that a welfare of the child assessment should be carried out before any treatment designed to assist a woman to carry a child is carried out in a licensed clinic, even if the proposed treatment itself does not require a licence under the Act. Examples of treatments falling into this category are intrauterine insemination (IUI) and gamete intrafallopian transfer (GIFT).

The consultation document asked whether unlicensed treatments should continue to require a welfare of the child assessment or be subject to a less thorough form of assessment.

Delegates agreed that if the welfare of the child is important in IVF, it should be regarded as equally important in treatments like IUI. The involvement of a medical team to assist conception brings with it some responsibility for the welfare of the child that is born as a result of treatment. Because it is the fact of this involvement and not the degree of intervention which is relevant, it should make no difference whether the treatment is IVF or IUI. For the same reason, delegates thought it would be inappropriate to argue for welfare assessments on all prospective parents (i.e. those able to conceive naturally) because there is no third-party assistance with the conception.

Although everyone agreed that patients undergoing unlicensed treatments should have the same welfare of the child assessment as those undergoing IVF, some delegates questioned how far this should be extended. Should a welfare assessment be carried out when someone is undergoing ovulation induction, for instance?

A small number of delegates felt that, in order to be completely consistent, welfare of the child assessments should also be carried out for IUI performed in clinics not licensed by the HFEA, although this would require a change in the law to bring about.

## **Appendix A: Introductory talk by Suzi Leather**

Thank you to you all for coming along to today's consultative meeting about our public consultation on how to take into account the welfare of children born of assisted reproduction. My role is to set the scene for today's discussions: to explain why we are holding this public consultation; what questions we are asking and what we plan to do after the consultation.

But our primary goal today is not talk at you. We really want to hear about your experiences of using the guidance in your day-to-day practice and your views about how we might change the guidance in the future.

Why carry out a review now? Although it has been added to in the light of new developments, the guidance has not been thoroughly reviewed since the 1st Code of Practice in 1991. We know that clinics have some difficulties with aspects of the current guidance – we want the new guidance to address those concerns. But we also want to capture more than a decade of experience of carrying out welfare of the child assessments, experience that wasn't available when the first Code of Practice was drafted.

As you probably already know, the Department of Health will be carrying out a review of the legislation, the Human Fertilisation and Embryology Act 1990. However, we felt that we have to look at the guidance now because any changes in legislation probably won't happen until 2008.

What is welfare of the child? When Parliament passed legislation it decided that no group of people would be excluded from treatment. But instead clinics have to take into account the welfare of the child to be born of assisted conception. Parliament also decided that the HFEA as the regulator must produce guidance on what should be taken into account and how the assessment should be performed.

This puts a responsibility on clinics to take into account the welfare of the child for all treatments and also puts a responsibility on the HFEA to produce the guidance. In fact, welfare of the child is the one area of licensing that the Act obliges the HFEA to produce guidance on.

The welfare of the child principle is an important principle, but we know from talking to centre staff and patients that it is difficult to put into practice. Patients sometimes feel that they are being judged as parents and they can find the assessment difficult. After all, those conceiving naturally do not have any form of assessment.

What does our current welfare of the child guidance contain? In the current guidance, the treating clinician should discuss with their patients a range of issues. They're quite a jumble of different types of issues looking at medical, physical, psychological and social factors. They are the commitment to raise children; the ability to provide a stable, supportive environment; immediate and family medical histories; the age, health and ability to provide for the child; and the risk of harm to children including inherited disorders or transmissible

disease, multiple births, neglect or abuse and the effect of a new baby upon any existing child.

In the current guidance, who should be contacted to gather further information about the patient's medical and social history? At the moment, as most of you know, clinics are expected to contact the patient's GP, with the patient's consent, in order to gather relevant information and to ask the GP whether they know of any reason why the patient might not be suitable for treatment.

In our research leading up to the launch of the consultation, we identified a number of problems with this requirement:

- GPs often don't know their patient well enough to make an assessment
- Some GPs feel assessments are inappropriate or beyond their expertise
- Some patients don't have GPs
- Some clinics spent a lot of time and expense contacting and chasing GPs

During the course of the consultation – at today's meeting in particular – we want to discuss these issues in more detail.

Currently, clinics are expected to discuss a range of issues with patients undergoing donor conception treatment: a child's potential need to know about their origins and whether or not the prospective parents are prepared for the questions which may arise while the child is growing up; family attitudes towards a child; the implications if the donor is known within the family; and the possibility of disputed fatherhood.

But the guidance is a little unclear about whether these are issues which need to be discussed in order to prepare patients for donor conception parenthood, or whether these are issues which should be taken into account when deciding whether or not to offer treatment. As you'll see from our policy options, we want to clarify the situation for these patients.

In our consultation document, *Tomorrow's Children*, we consider three areas of the current guidance and lay out options for revising them. Under 'factors to be taken into account', the options are to focus upon:

- Risk factors for medical harm only (for instance, transmissible diseases)
- Risk factors for medical, physical and psychological harm (by physical or psychological harm, we mean neglect or abuse)
- Risk factors for medical, physical and psychological harm and social factors, which is the current practice (by social factors, we mean a stable relationship or the commitment to having children)

Under 'enquiries to be made', the options are:

- No social enquiries
- Medical and social enquiries made of the patient(s)
- Medical and social enquiries to be made of the patient(s), with enquiries to third party if a problem (such as a mental health problem) is identified

- Medical and social enquiries to be made of the patient(s), with enquiries to GP routinely (this is current practice)
- Medical and social enquiries to be made of the patient(s), with enquiries to the GP and other agencies (such as social services or Criminal Records Bureau) routinely.

In our consultation, we are also looking at whether we should make a distinction between patients having IVF and those using donor conception treatment. So, we are looking at whether those using donated sperm, egg or embryos should be given extra information such as discussing how they might tell their child that they are born from donated sperm, eggs and embryos.

We are also looking at patients who are having unlicensed treatment in licensed fertility clinics: treatments such as intra uterine insemination (IUI) or gamete intrafallopian transfer (GIFT). Currently, patients having these treatments must have a welfare of the child assessment - should this continue to be the case?

Your participation in today's meeting is very useful, but we would also encourage you to respond in writing too: via our website, email or by post.

The public consultation ends on 7 April 2005 and new guidance will be published in the summer.

## Appendix B: delegate list

Gordon Asher	University of Strathclyde
Mary Campbell	Glasgow Nuffield Hospital
Julie Clague	Glasgow Royal Infirmary Ethics Committee
Ben Collins	GMC Scotland
Christine Cumming	Royal Infirmary of Edinburgh
Mark Docherty	University of Glasgow
Sarah Elliston	University of Glasgow
Richard Fleming	Glasgow Royal Infirmary
Marguerite Galloway	Royal Infirmary of Edinburgh
Dr Colin Gavaghan	University of Glasgow
Nicole Gibson	Glasgow Nuffield Hospital
Elaine Grossart	Glasgow Royal Infirmary
Dr Maybeth Jamieson	Glasgow Royal Infirmary
Alison Kennedy	Glasgow Nuffield Hospital
Joanne Leitch	Glasgow Nuffield Hospital
Mrs Sheena M Leith	
Eileen Macdonald	Royal Infirmary of Edinburgh
Anne McConnell	Ninewells Assisted Conception Unit
Maureen McGuire	Lanarkshire Acute Hospital NHS Trust
Susan McLaren	Glasgow Nuffield Hospital
Ciara McNamara	Royal Infirmary of Edinburgh
Alison Mills	Ninewells Assisted Conception Unit
Isobel O'Neill	Glasgow Royal Infirmary
Carrie Pretsell	Southmead Hospital
Elaine Pritchard	Ninewells Assisted Conception Unit
Joanne Ramsay	University of Glasgow
Heather Reid	Ninewells Assisted Conception Unit
Kathleen Robertson	Glasgow Royal Infirmary
Susan Seenan	Infertility Network UK
Alison Sheils	
Mr Ian Smith	Lanarkshire Acute Hospital NHS Trust
Jennifer Speirs	
Dr KJ Tong	Royal Infirmary of Edinburgh
Isabel Traynor	Glasgow Royal Infirmary
Helen Walton	Glasgow Royal Infirmary
Shanti Williamson	University of Glasgow
Joanna Wright	Scottish Executive
Mr Robin Yates	Glasgow Royal Infirmary
Sheena Young	Infertility Network UK
Katy Berry	Human Fertilisation and Embryology Authority
Suzi Leather	Human Fertilisation and Embryology Authority
Charles Lister	Human Fertilisation and Embryology Authority
John Paul Maytum	Human Fertilisation and Embryology Authority
Juliet Tizzard	Human Fertilisation and Embryology Authority
Sarah Marsh	Human Fertilisation and Embryology Authority
Avril MacLennan	Human Fertilisation and Embryology Authority