Welfare of the Child Review

Report of a public consultative meeting held at Manchester Metropolitan University, Manchester, 22 March 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 Manchester started at 1pm with a lunch, during which HFEA staff and delegates were able to meet and discuss the issue on an informal basis.

Juliet Tizzard, HFEA Policy Manager, 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 upon 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 42 people registered for the consultative meeting, with 33 attending on the day (drop-out rate of 21%). See Appendix B for a full delegate list. The breakdown, according to interest, of the 33 who attended was as follows:

Interest category	No.	%
Nurse	5	15%
Other	5	15%
Counsellor/social worker	14	42%
GP	2	6%
Embryologist	1	3%
Clinician	2	6%
Patient	4	12%

4. Audience feedback

Of the 33 delegates at the meeting, 22 (67%) completed a feedback form. Of those who responded, 50% had heard about the meeting from an HFEA mailing; 14% from the HFEA website; 23% from their workplace and the remaining 23% heard about the meeting from miscellaneous sources (Fertility Friends, BioNews and British Infertility Counselling Association).

When asked an open question about why they were interested in attending, 45% said it was to contribute to the consultation or to gain knowledge; 41% stated professional interest and 14% stated personal interest. All respondents but one rated both the opening presentation and the meeting format as excellent or good. When asked how they prefer to respond to an HFEA consultation, 14% preferred to contribute through a workshop, 18% preferred to submit a written response and 68% liked to use both methods.

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 Act and how we should interpret it in the clinic.

The welfare of the child has always been an issue in assisted conception, even before the HFEA was created. In the future, as NHS funding expands and a wider range of patients are treated, it may be more of an issue. Many delegates felt that, ultimately, a balance needs to be found between the interests of the individual seeking treatment and that of society.

Setting aside the welfare principle in the Act, delegates felt that HFEA needs to be clarified in future. At present, it is not clear whether the assessments are designed to exclude some people for treatment or to prepare them for parenthood.

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 guidance:

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

Many delegates felt that risk factors should focus upon medical and social aspects. It is clear that the word welfare implies much more than purely medical issues.

At present, patients are rarely turned down for treatment on welfare of the child grounds. Where they are refused treatment, it is usually because of alcohol abuse, previous child abuse convictions or psychological illness. Sometimes, patients pull out of treatment, because they realise that it is not the best option for them or they don't want to address their own problem.

Counsellors at the meeting reported an increase in their workload over the years because of welfare of the child assessments. In some clinics, counsellors are involved in the assessment of patients about whom concerns have been raised, either by the GP or by the fertility clinician. Such cases take up 10% of the counselling workload in one clinic and 6% in another.

Most delegates agree that, whatever the risk factors, they should be clear and useful. Most importantly, guidance from the HFEA should seek to encourage consistency between clinics. Currently, if a patient is declined treatment, they may seek treatment elsewhere.

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

Current HFEA guidance expects clinics to write to the GP of each patient before treatment is offered to ask them for any information about factors which might adversely affect the welfare of any child to be born. If problems are raised, either by the GP or by the patient themselves, clinics are expected to contact other professionals or agencies for further information. The consultation document presented the following options for amending the guidance:

A no welfare of the child enquiries should be made
B information about risk factors should be provided by the patient themselves
C information about risk factors should be provided by the patient and enquiries should be made to a third party if a problem is identified

D information about risk factors should be provided by the patient and enquiries should be made to GPs routinely

E information about risk factors should be provided by the patient and enquiries should be made to any third party routinely

Making enquiries to GPs

Current systems for making GP enquiries vary from clinic to clinic. Some ask patients to take a welfare of the child form to their GP and return the completed form to the clinic. Other clinics send the form directly to the GP and request that the GP replies to them.

Many delegates reported difficulties in getting GPs to respond:

- some do not return the form when they have concerns;
- some are willing only to discuss the case over the telephone;
- some automatically sign the form without checking for any relevant factors;
- some charge for signing a welfare of the child form and there is no uniformity of charges.

There was extensive discussion about the effectiveness of making enquiries to GPs. Some delegates said that the GP rarely provides the clinic with information that the clinic has not picked up already. Others observed that GPs often don't know much about their patient's social circumstances. These delegates suggested that, in the light of this, GPs should only be consulted by fertility clinics selectively.

The different members of staff in the fertility clinic spend a significant amount of time with their patients and therefore often have a high level of awareness. This makes their assessments more informed than the GP's. One delegate said that many patients will provide information through direct questioning, particularly if trust is built up between the patient and members of staff in the clinic.

However, some delegates considered enquiries to GPs to be helpful. Occasionally, GPs hold information that the clinic has not picked up. If a filtering mechanism is needed, enquiries to the GP is the best available one. Sometimes, learning that the GP will be consulted prompts a patient to pull out of treatment themselves.

All agreed that whatever approach is adopted, GPs should be told that they will not be liable for the outcome and that a request for further information doesn't necessarily mean that the patient will be refused treatment.

Making enquiries to social services and other agencies

Most delegates agreed that, of all the possible professionals or agencies that could be contacted, GPs are the most reliable. However, they may not hold child protection information. Social services are often reluctant to respond to enquiries about children who have not yet been born because of their heavy workload.

There was a mixed response by delegates to the question about whether criminal records checks should be carried out routinely. Most thought it was an inappropriate check for someone to look after their own child. It would also be so unpopular with patients, that they would be less willing to cooperate than to answer honestly to questions from the clinic. However, a few delegates who did not work in a clinic argued that patients will be honest with clinics about problems. Therefore, an external view is needed.

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

Current HFEA guidance lists additional factors that should be taken into account when assessing patients embarking upon treatment with donor eggs or sperm (gametes) or embryos. The consultation document presented the following options for amending the guidance:

A donor conception patients should have the same assessment and information as patients using their own gametes or embryos

B donor conception patients should have the same assessment as patients using their own gametes or embryos, but they should receive extra information and preparation

C donor conception patients should have a more thorough assessment and extra information and preparation

Most delegates agreed that patients using donated gametes should be treated no differently from other patients. However, a few thought that a different assessment was required in order to obtain evidence that donor conception patients have a greater insight into their situation.

Research on children shows that the outcomes are good, even when children don’t know their donor conception status. However, we also know that if people who are donor conceived find out later in life about their origins, it can be very damaging. Delegates agreed that patients should be given this information and encouraged to be open with their children.

Finally, delegates discussed the assessment needs of those undergoing unlicensed treatments, such as intrauterine insemination. Most agreed that if welfare of the child assessments are necessary for IVF, they should also be necessary for other assisted conception treatments. However, there was some concern about where the line should be drawn. Delegates questioned whether ovulation induction or reversal of sterilisation should be included.

Appendix A: Introductory talk by Juliet Tizzard, Policy Manager

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 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 issue 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 raise while the child is growing up; family attitudes towards a child; the implications if the donor is know 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 'enquires to be made', the options are:

- No social enquires
- 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

Name	Organisation
Jacqui Barber	
Caron Barnes	Shared Journey
Sue Bedigan	Queen Elizabeth Hospital, Gateshead
Alastair Bissett-Johnson	University of Dundee
Jane Blower	Leicester Royal Infirmary
Deborah Braden	Shared Journey
Jay Carter	Cots
Robin Carter	Cots
Marilyn Crawshaw	Univeristy of York/PROGAR
Paul Crowther	CARE Manchester
Ann Curley	St Mary's Hospital, Manchester
Lesley Daniels	University of Leeds
Sarah Devaney	University of Manchester
Jenny Dunlop	St Mary's Hospital, Manchester
Janice Elson	
Patricia Gilbert	
Kate Grieve	University Hospitals Coventry & Warwickshire NHS
Caroline Henretty	CARE Nottingham
Carolyn Higgin	CARE Manchester
Lorrie Hudson	Liverpool Women's Hospital
Ruth Lancaster	CARE Manchester
Brian Lieberman	Manchester Fertility Services
Caroline Lindsay	CARE Manchester
Marsalli MacDonald	CARE Nottingham
Laura Machin	
Dr Jim Monach	British Fertility Counselling Association
Jackie Nunn	CARE Nottingham
Janet Owen	Cromwell IVF & Fertility Centre
Dr Elizabeth Pease	St Mary's Hospital, Manchester
Angela Pierce	Queen's Medical Centre, Nottingham
Sheila Pike	Centre for Reproductive Medicine & Fertility, Sheffield
Jonathan Skull	Centre for Reproductive Medicine & Fertility, Sheffield
Sue Smith	CARE Manchester
Fiona Stirling	National Gamete Donation Trust
Mo Thomas	Leicester Royal Infirmary
Jeanette Wilburn	National Gamete Donation Trust
Dr Stephen Wilkinson	Centre for Professional Ethics, Keele University
Marian Williams	Leicester Royal Infirmary
Dr Roger Worthington	General Medical Council
Debra Bloor	Human Fertilisation and Embryology Authority
Stephanie Croker	Human Fertilisation and Embryology Authority
Jenny Dimond	Human Fertilisation and Embryology Authority
James Healy	Human Fertilisation and Embryology Authority
Suzi Leather	Human Fertilisation and Embryology Authority
Sarah Marsh	Human Fertilisation and Embryology Authority
Juliet Tizzard	Human Fertilisation and Embryology Authority