

Summary of SEED Review Stakeholder Meeting

Held on 26 July 2004 at the HFEA, 21 Bloomsbury Street.

Attendees:

HFEA Steering Group:

Walter Merricks (chair), Jennifer Hunt, Emily Jackson

HFEA staff: Peter Mills, Cathleen Schulte, Kerri Treston

Stakeholders:

Alan Pacey (British Fertility Society), Sheila Pike (British infertility Counselling Association (BICA)), Olivia Montuschi (Donor Conception Network), Brian Lieberman (Manchester Fertility Services), Debbie Barber (Fertility Nurses Group), Marilyn Crawshaw (British Association of Social Workers Project Group on Assisted Reproduction (PROGAR)), Eric Blyth (PROGAR), Liz Scott (BICA), Simon Thornton (CARE at the Park Hospital, Nottingham), Andrew Drukely (Liverpool Women's Hospital), Paul Williams (The Bridge Centre, London), Vanessa Smith (London Women's Clinic), Gwen Skinner (Department of Health), Kriss Fearon (National Gamete Donation Trust (NGDT)), Pip Morris (NGDT), Laura Spoelstra (NGDT), Kamal Ahuja (Cromwell Hospital, London), Peter Bowen-Simpkins (Royal College of Obstetricians & Gynaecologists).

Purpose of the meeting

- to establish stakeholders' views on proposals to be included in a public consultation on sperm, egg and embryo donation to be published in the Autumn.

Age limits for gamete donors

- NGDT representatives reported findings of a survey of egg donors which found the average age of egg donors to be ~32 years and that 72% of these donors were willing to donate again although a common reason for not doing so was the current age limit.
- The steering group's proposal for consultation was that the HFEA should leave guidance relating to the age of donors to professional bodies, although it could continue to regulate compliance with this guidance.
- There was some support for this proposal. The view was also expressed that there should be more flexibility to allow the appropriateness of particular donors to be decided in individual clinical situations.
- On the other hand it was suggested that the HFEA should continue to set limits in view of the extra-clinical factors that might not be taken into account by bodies comprising only medical professionals.
- **Two options were proposed for consultation: (1) the HFEA should retain responsibility for setting and enforcing age limits; (2) the HFEA should leave the stipulation of age limits to guidance produced by professional bodies.**

Selection of donors

- It was noted that it is important for those seeking treatment to receive certain non-identifying information about donors available to them.
- However the value of guidance designed to avoid those seeking treatment using this information to 'design' a child in a manner that would be not consistent with that child's welfare was also noted (notwithstanding the fact that owing to the limited range of donors available this was unlikely to be an option in practice).
- The SEED Review Steering Group had identified the main issue as being whether the selection of donors should preclude use of a donor from a different ethnic background to the recipient. It was suggested that the HFEA should consult on a proposal to limit guidance to raising issues, including those relating to ethnic identity, that should be discussed with those seeking treatment prior to treatment taking place. (It was noted that this issue would be taken up in the course of the review of the 'welfare of the child' guidance.)
- **Participants agreed that the emphasis should be placed on counselling and advice given to those seeking treatment.**
- It was noted further that whilst prospective recipients receive limited information about donors, donors do not receive any information about the outcome of their donation. This is due to legal obstructions which have yet to be resolved. However it was also noted that many egg donors do not want to know the outcome of their donation especially if they are involved in an egg sharing arrangement.

Changes in the law

- It was noted that the Human Fertilisation and Embryology Authority (Disclosure of Information) Regulations 2004 allow previous donors the option to re-register as identifiable donors.
- Some participants pointed out that this was a significant disappointment for past recipients who had expected anonymity to be maintained.

Screening of donors

- The Steering Group had proposed that the HFEA should rely on professional guidelines in this area.
- **There was general agreement that the HFEA should adopt professional guidelines where definitive guidelines exist.**

Live birth limit

- It was noted that the statistical risk of consanguinity would support a limit much higher than 10 live birth events specified in current HFEA guidance.
- However concern was expressed about the emotional and psychological effect on donor-conceived people of knowledge that there may be a large number of half-siblings. On the other hand, a higher limit would increase the availability of treatment.
- There was general support for maintaining an upper limit rather than removing it entirely.

- The Steering Group proposed that the HFEA's policy be amended so that the limit is calculated in terms of families using a given donor rather than live birth events.
- **This approach was supported, although there was no consensus on the limit to be adopted. Limits of four families (as in New Zealand) and 10 families (the maximum currently possible in UK) were suggested.**

Storage limits

- Participants agreed that current Regulations, which do not allow extended storage for gametes or embryos, results in gametes often being discarded without being used.
- Extension of storage limits would be particularly useful for sperm from rare donor types, which may be required infrequently.

Distribution of sperm between UK licensed centres

- Licensed clinics do not currently benefit financially from the service they provide in recruiting sperm donors where samples are supplied to other clinics owing to HFEA Directions which limit payment between clinics for supplying gametes strictly to covering costs. It was reported that there is evidence of centres undercharging for this service.
- The Steering Group proposed that HFEA policy should permit clinics to make reasonable profit from recruiting donors to provide gametes to other clinics as a business incentive to encourage better national distribution of gametes.
- The issue was raised whether sperm from rare donor types would attract higher charges as this would reflect difficulty in recruiting these donors. It was noted that this cost would be passed on to the patient.
- There was also concern that it might seem anomalous if clinics can make a profit out of gamete donation whilst donors must donate altruistically.
- Participants noted that the requirements of the EU Tissues and Cells Directive must be taken into account, in particular Article 12(2) which states: "Member States shall endeavour to ensure that the procurement of tissue and cells as such is carried out on a non-profit basis".

Payment to donors

Expenses

- It was an agreed principle that donors should be compensated for legitimate expenses incurred as a result of donating. There was some evidence that egg donors in particular were not being genuinely compensated for the real cost of donation (including childcare, loss of earnings, holiday time taken, etc.) and that this should be addressed.
- However, there was some concern that if income differentials were taken into account this may be reflected in the cost of gametes from certain donors.
- Some participants suggested that no guidance was necessary on expenses other than that they should be reasonable or fair. However it was noted that in the absence of guidance it would be difficult for HFEA licence committees to compare the equity of different reimbursement

arrangements. There was also some concern that if there were a difference in expense payments between clinics this might lead to donors 'shopping around' for the best expense arrangements on offer.

- It was noted that discussion of expenses should be kept separate from the issue of inconvenience payments.

Inconvenience

- The Steering Group proposed that compensation for inconvenience, consistent with the requirements of the EU Tissues and Cells Directive, should be permitted. Values suggested were: £15 per donation for sperm donors (as at present); £200 - £300 for egg donors; no additional compensation payments for egg sharers (beyond the reduction in cost of treatment).
- Concern was raised over the possibility that women from poorer countries might come to the UK to donate and that the compensation for inconvenience and the opportunity of a foreign visit might be seen as an incentive to donate.
- **It was generally agreed that egg sharers should not be eligible for additional expenses; the suggested sum for altruistic, non-patient egg donors was £300-£500.**

Egg sharing

- The Steering Group had not made any proposals to amend existing HFEA policy regarding egg sharing arrangements. It was noted that the regulation of charges made to patients for treatment services was not within the HFEA's regulatory remit.
- The view was confirmed that it would not be acceptable for clinics to charge both donors and recipients for a full IVF cycle.
- It was noted that the majority of treatments using eggs provide by a third party are egg-sharing arrangements and that adding additional restrictions to egg-sharing guidance could dramatically affect the availability of treatment.