

The changing landscape of donation

1. What action, besides amending HFEA policy, do you think could be taken to increase the availability of donated sperm and eggs in the UK? (please select more than one if appropriate):

- **Increasing people's awareness of, and educating people about, donation**
- **Carrying out national donor recruitment campaigns**

2 a) Do you think we have accurately captured the principles relevant to donation?

- **No**

2 b) Do you think there are other relevant principles that should be considered?

- **Yes (please specify)** *1600 character limit*

The formulation of respect for family life does not adequately capture the question of whether such respect imposes positive obligations on the state to facilitate founding a family, or merely to refrain from interfering. This is a significant issue in human rights law (e.g. under Arts 8, 12 ECHR). It is not necessarily the role of the state to ensure an adequate supply of gametes. The concept of 'free choice' is too simplistic and needs to be developed to take into account the relationships in question and draw on concepts such as vulnerability and exploitation. A person does not need to be 'vulnerable' to be exploited and equally people who are vulnerable are not necessarily exploited. While the limitation of the welfare principle to 'serious harm' is understandable in the context of s 13(5) where it concerns the suitability of recipients, it is less clear that it is relevant to the supply of gametes where a broader definition and more emphasis on long-term welfare issues would be appropriate. All of the above relate to the underlying assumption in the consultation that supply needs to be increased, which is not justified by the statistics offered in the background document. The definition of 'openness' is dominated by compliance with the current law and is not considered beyond this narrow scope. There need to be principles relating to concepts of identity and kinship as these issues are absent at present.

2 c) Do you think there are principles outlined that should not be considered?

- **Yes (please specify)** *1600 character limit*

The concept of 'altruism' is problematic; such motivation is very difficult to assess and test, it is not necessarily more incompatible with financial matters than with other factors. The term 'pragmatism' does not fit with what is described, which is primarily concerned with clarity and efficiency.

*One further factor which we thought should be considered – **and given the lack of space in the above section and the absence of a 'further comments' section we thought it best placed to be entered here in the context of 'the changing landscape'** – there have been examples where donors have subsequently found out that they have a genetic condition which raises obvious ethical considerations regarding informing any children conceived through the use of their gametes. As genetic testing is further refined or 'fine tuned' for rare or minor conditions and micro arrays, it is anticipated that the continued development of these technologies is likely to have an impact on sperm and egg donation.*

Donor compensation, reimbursement and benefits in kind

This questionnaire will ask separate questions on expenses, earnings, inconvenience and benefits in kind.

Expenses

1a) In principle, do you think donors should be compensated for expenses they incur during the process of making a donation (eg, the cost of a train fare to the clinic)?

- Sperm donors – **Yes**
- Egg donors – **Yes**

1b) In practice, how do you think a donor's expenses should be compensated (select a scheme for sperm donors and a scheme for egg donors)?

Sperm donors

- **A variable amount of money according to the donor's actual expenses**

Egg donors

- **A variable amount of money according to the donor's actual expenses**

It's important for us to understand the reason(s) for your answers above.

Please give a brief explanation. *1600 character limit*

If donors' actual expenses are reimbursed it stands to reason that these will be variable amounts.

1c) Do you think donors should be compensated for expenses they incur outside the UK (eg, the cost of travel to a clinic in the UK from Asia or Europe)?

- Sperm donors – **Yes**
- Egg donors – **Yes**

Please give an explanation of your answer or provide any further comments, including how compensation should apply to overseas donors, whose eggs or sperm are imported in to the UK. *1600 character limit*

If actual expenses are reimbursed, there should be no restriction on where they were incurred. However, the prospect of international travel raises concerns over the risks of trafficking of donors, confirmation of identity and possibly safety and efficacy that suggest that careful regulation would be needed in this area.

Earnings

2a) In principle, do you think donors should be compensated for earnings they lose during the process of making a donation (eg, for time off work to attend clinic appointments)?

- Sperm donors – **Yes**
- Egg donors – **Yes**

2b) In practice, how do you think a donor's loss of earnings should be compensated for (select a scheme for sperm donors and a scheme for egg donors)?

Sperm donors

- **A fixed amount of money that is the same for all sperm donors** (please

specify an amount in £) **commensurability with jury service seems appropriate** [on the actual questionnaire only figures could be inserted here, therefore we ticked 'other' with these comments instead]

Egg donors

- Other (please specify) *1600 character limit*

There should be a fixed 'rate' per day but the amount claimed will differ between donors as some will take different lengths of time to recover from the process.

It's important for us to understand the reason(s) for your answers above.

Please give a brief explanation. *1600 character limit*

Payment needs to reflect the value of the donation and the risk undertaken by donors (including comparative risks of sperm and egg donation). However, the level needs to be sufficiently low to avoid encouraging people to take on risks that they are unhappy to accept because they are economically vulnerable (there is a close analogy here with compensation for participants in clinical trials). Levels of compensation should not reflect earnings as this would reward people for their careers rather than for donation.

Inconvenience

3a) In principle, do you think donors should be compensated for the disruption and discomfort associated with the process of making a donation (eg the inconvenience and side effects of hormone injections for egg donors and the inconvenience of numerous clinic visits for sperm donors)?

Sperm donors – No

Egg donors – Yes

3b) In practice, how do you think a donor should be compensated for the routine disruption and discomfort associated with the process of making a donation (select a scheme for sperm donors and a scheme for egg donors)?

Sperm donors

- N/A

Egg donors

- Other (please specify) *1600 character limit*

There should be a core fixed amount, with variable additions to reflect inconvenience above expectations. Risks of additional inconvenience could also be met through insurance of all donors.

It's important for us to understand the reason(s) for your answers above.

Please give a brief explanation. *1600 character limit*

Egg donation is more intrusive and risky than sperm donation although the actual burden on individuals will vary.

Benefits in kind

4a) In principle, should donors be offered benefits in kind for their donation?

Sperm donors – Yes

Egg donors – Yes

4b) In practice, what do you think benefits in kind should include (select more than one if necessary) (select a scheme for sperm donors and a scheme for egg donors)?

Sperm donors

- Reduced price or free storage of sperm

Egg donors

- Reduced price or free fertility treatment
- Reduced price or free storage of eggs

It's important for us to understand the reason(s) for your answers above.

Please give a brief explanation. *1600 character limit*

It is appropriate for people subjecting themselves to technology to have the opportunity to benefit from the episode, thus making the 'products' available to both the donor and potential recipients rather than merely the latter could be beneficial in some cases. However some concern was expressed about the differential impact on donors (ie with regard to potential risks) according to gender, and the possibility that benefits in kind might be viewed by some as a far greater incentive than monetary compensation. Also, some members expressed concern over offering anything that might be considered to be an 'incentive'.

4c) In practice, do you think the value of benefits in kind should be limited and if yes, how should it be limited?

Sperm donors

- No, the value should not be limited
- **Yes, the value should not exceed other types of compensation (expenses, loss of earnings, routine disruption and discomfort)**
- Yes, the value should not exceed that of an average cycle of fertility treatment, eg, £5000 for a cycle of IVF
- Yes, the value should be limited (please specify an amount in £)

Egg donors

- No, the value should not be limited
- **Yes, the value should not exceed other types of compensation (expenses, loss of earnings, routine disruption and discomfort)**
- Yes, the value should not exceed that of an average cycle of fertility treatment, eg, £5000 for a cycle of IVF
- Yes, the value should be limited (please specify an amount in £)

It's important for us to understand the reason(s) for your answers above.

Please give a brief explanation. *1600 character limit*

There was no consensus on the appropriate limits that could or 'should' be set.

NB. The options to this question did not provide an 'other' category where we could simply state that we had not reached a consensus view and therefore did not wish to indicate one way or the other regarding possible limitations. Forcing respondents to select one of the options to this question without an 'other' category is problematic (and respondents are forced to do so as without choosing an option we cannot submit an answer to this questionnaire), and our choice above does not therefore accurately reflect our views. We would like this to be noted.

Equality impact

HFEA policies (like other public bodies) must not unlawfully discriminate on the basis of age, disability, ethnicity or race, sexual orientation, religion or gender, or infringe upon the human rights of any group. We need to identify whether any groups of people who fall into the above categories (for instance, young people, women or disabled people) would be disproportionately affected by any of the changes.

5. Do you think any of the compensation, reimbursement and benefit in kind scheme options would have a disproportionate effect on any groups of people on the basis of their age, disability, ethnicity or race, religion, gender or sexual orientation?

- No

If you answered 'Yes' or 'No' please tell us why *1600 character limit*

Differences in gender are not disproportionate. We do not see different impacts in the other dimensions.

Donor Family Limit

1. What do you think should be the maximum number of families that can be created using one donor's sperm or eggs?

- A limit of 10 families

It's important for us to understand the reason for your answer above. Please give a brief explanation. *1600 character limit*

We are not aware of evidence on which a change of policy could be based. Consideration might be given to whether there should be a limit on the size of 'individual' families conceived by assisted conception, but there was no clear conclusion on this issue from the discussions of our group.

Equality impact

HFEA policies (like other public bodies) must not unlawfully discriminate on the basis of age, disability, ethnicity or race, sexual orientation, religion or gender, or infringe upon the human rights of any group. We need to identify whether any groups of people who fall into the above categories (for instance, young people, women or disabled people) would be disproportionately affected by any of the changes.

2. Do you think any of the family limit options would have a disproportionate effect on any groups of people on the basis of their age, disability, ethnicity or race, religion, gender or sexual orientation?

- No

If you answered 'Yes' or 'No' please tell us why *1600 character limit*

No further comment.

Family Donation

1. Which of the following approaches do you think we should take towards mixing sperm and eggs between family members? (Please select one option)

- **No further regulatory control**

- Prohibit the mixing of gametes between close relatives who are either genetically related or unrelated
- Prohibit the mixing of gametes between close relatives who are genetically related

It's important for us to understand the reason for your answer above. Please give a brief explanation. *1600 character limit*

In the absence of the supporting document this was an ambiguous question (e.g. some members initially thought it might refer to the 'mixing' of gametes so as to create 'doubt' as to the identity of the genetic progenitors), which may create some difficulties if respondents have been directed immediately to the questionnaire and have not had sufficient opportunity to reflect on what the question may mean. Whereas - in light of the supporting document - members thought it referred to the im/permissibility of allowing family donation per se. There was no consensus within the group on changes to the current regulatory position.

NB. Again - in the absence of an 'other' option - we were forced to select an option that does not accurately reflect the group's views simply in order to be able to submit our response to this questionnaire - this is very unsatisfactory.

2. Which of the following approaches do you think we should take towards donation between family members? (Please select more than one if necessary)

- No further regulatory control
- Issue guidance to clinics on handling donation between family members
- Invite the counselling profession to produce guidance for clinics on handling donation between family members
- **Require clinics to have a strategy in place to deal with cases of donation between family members**

It's important for us to understand the reason for your answer above. Please give a brief explanation. *1600 character limit*

As we are not aware of the evidence base on which either the HFEA or the counselling professions could develop guidance, we suggest that clinics should develop a strategy for raising awareness of the questions that concern people about close family donation. This strategy should include taking steps to collect evidence on which guidance could be based in the future.

Equality impact

HFEA policies (like other public bodies) must not unlawfully discriminate on the basis of age, disability, ethnicity or race, sexual orientation, religion or gender, or infringe upon the human rights of any group. We need to identify whether any groups of people who fall into the above categories (for instance, young people, women or disabled people) would be disproportionately affected by any of the changes.

3. Do you think any of the family donation options would have a disproportionate effect on any groups of people on the basis of their age, disability, ethnicity or

race, religion, gender or sexual orientation?

- Yes

If you answered 'Yes' or 'No' please tell us why *1600 character limit*

There may be a differential impact in communities where marriage patterns commonly involve close relationships which are permitted in law (cousin marriages).