

Mitochondrial Donation

A consultation on draft regulations to permit the use of new treatment techniques to prevent the transmission of a serious mitochondrial disease from mother to child

Response Form

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This consultation asks for feedback on draft regulations concerning mitochondrial donation. I am responding to this consultation as an individual. I am responding to questions 5, 6, 7 and 8 of the consultation document. My response is informed by my research about mitochondrial disease, developments in genetic technologies and patient, family and professional responses to reproductive risk. I am currently funded through ESRC Future Research Leaders grant, and previously through ESRC Centre for Economic and Social Aspects of Genomics (Cesagen) core grant.

Key points:-

- 1.1 The health and well-being of the child should remain paramount. This includes recognising the right of the child to access their own information if they wish and for their identity as a child born through these techniques to be protected.
- 1.2 I recommend that the implementation of the regulations be kept under review, so that if it is subsequently discovered that the donated mitochondria is biologically or socially significant to the child, then changes can be made accordingly.

Question 5: Do you agree that people donating eggs and embryos for the purposes of mitochondrial donation should *not* have the same status as those

donating eggs and embryos for use in fertility treatment but rather regarded more like organ or tissue donors?

Your Comments:

I agree that the mitochondria donor should not have the same status as those donating eggs and embryos. At the moment there is no evidence to suggest that the donated mitochondria will be biologically significant to the child, and therefore the donor might be seen as more similar to organ or tissue donation than egg or embryo donation.

However, I draw your attention to section 2.38 of the consultation document which refers to the fact that these treatments are 'akin to germ line therapy to the extent that mitochondrial donation may have implications not only for the children born as a result of the procedure but for their descendants'.

The consultation document therefore highlights that there might be health implications for the child and descendants. If there was subsequent evidence that the donated mitochondria was biologically significant to the child, then this recommendation should be reviewed.

Question 6: Regulation 10 provides that the HFEA should tell a person aged 16, on request, if they were born following mitochondrial donation. Do you agree with this?

Your Comments:

I agree that any person born following mitochondrial donation has the right to access this information. Here there is the potential for consistency with policies covering adoption and egg and sperm donation.

However, the child will only be able to access this information if they are aware of the circumstances around their conception. We should not assume that all families are open about the circumstances, or know how to talk to their child about it.

Although section 2.36 to 2.41 refers to 'monitoring and follow up', the focus is only on the health of the child and the requirements of future medical research. I suggest that facilitating access to counselling should be a high priority. This would mean the child and family can be supported at key stages such as talking to the child about their conception, helping them understand potential implications, supporting them in accessing information about the donor if they wish and potentially forming relationships with the donor through voluntary arrangements with the clinic (as mentioned in section 2.31).

Offering support and counselling is in line with the findings from Nuffield Council on Bioethics report which concluded that it was ethical for families to utilise the techniques if they were safe to use and the families were offered adequate support.

Question 7: Regulation 10 also provides that the information that the HFEA should provide in response to such a request should not identify the mitochondrial donor and be limited to screening tests carried out on the donor and about her family medical history, and any other non-identifying information that the donor has provided with the intention that it is made available in these circumstances. Do you agree with this approach?

Your Comments:

I agree with this approach because there is currently no evidence to suggest that the donated mitochondria will be biologically significant to the child, and therefore this is in line with policies covering organ and tissue donation. However, if it proves to be the case that the donated mitochondria is biologically significant to the child, then this regulation should be reviewed, with subsequent children born through these techniques having the right to access identifying information about the mitochondria donor, which would then be more in line with egg or sperm donation policies.

Question 8: Regulation 13 provides that the HFEA should tell a mitochondrial donor, on request, when a child has been born from their donation, how many and their sex. Do you agree with this approach?

Your Comments:

I do not agree that the mitochondria donor has the right to access information about whether a child has been born from their donation. The child's right to privacy must remain paramount. As these techniques are experimental and have attracted a great deal of media attention, it is highly likely that there will also be interest in the first children born. In addition, mitochondria disease is rare which might make it easier for a child to be identified through local connections. It would therefore be in the child's interest to keep this knowledge from the donor if requested.

In conclusion, I recognise the value of undertaking this public consultation at this stage. These techniques are experimental and have raised strong opinions. However, as they are novel, it is difficult to compare mitochondria 'donation' to other types of donation such as egg donation or organ donation. I therefore urge the Department of Health to keep these regulations under review. It will only be when children are born using these techniques that answers to some of these questions will be provided. This is particularly so in relation to the biological significance of the donated mitochondria to the child and subsequent generations, but also whether the child and family perceive the mitochondria donor as biologically or socially significant. Their experiences will bring new insight into this process which could shape future regulations.

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