Regulating mitochondrial donation: seeking expert views

Survey: https://www.surveymonkey.com/s/mito-web


Licensing mitochondrial donation

Before answering these questions please refer to the section on 'Licensing mitochondrial donation' in the 'Regulating mitochondrial donation: seeking expert views' background document.

Before a clinic can be licensed to carry out PNT and/or MST they must be able to demonstrate they have the necessary skills and competency.

Do you think the proposed approach for assessing the competency of a clinical embryologist is appropriate?

Do you have any suggestions for alternative or additional evidence that could demonstrate the competency of a clinical embryologist intending to perform one or both of these techniques?

Please refer to page four of the background document.

MST and/or PNT can only be carried out for a specific patient where there is a ‘particular risk’ of the egg or embryo having a mitochondrial abnormality caused by mitochondrial DNA.

Do you think the proposed approach for assessing the ‘particular’ risk by reference to the presence of mutant mitochondria is appropriate?

Please provide details of any other relevant measures, evidence or criteria that could be used to determine the presence of a ‘particular’ risk.

Please refer to page five of the background document.
mutant mitochondria is appropriate?

Please provide details of any other relevant measures, evidence or criteria that could be used to determine the presence of a ‘particular’ risk.

*Please refer to page five of the background document.*

Does this proposed process take into account all aspects relevant to the risk of and seriousness of the disease and mitochondria disease biology?

Please provide details of any other relevant information that could support an application for a particular patient.

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**Best practice guidance and other requirements**

Before answering these questions please refer to the section on ‘Best practice guidance and other requirements’ in the ‘Regulating mitochondrial donation: seeking expert views’ background document.

Mitochondrial donors will be providing their eggs in the same way as women donating eggs for fertility treatment. What should women donating their mitochondria be screened for?

*Please refer to page seven of the background document.*

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Age may be an important consideration when selecting mitochondrial donors. Professional guidelines state that eggs, for fertility treatment, should not be taken from donors aged 36 or over.

Do you think the proposed approach to apply the same age limit for women donating their mitochondria is appropriate? Please provide reasons for your answer.

*Please refer to page seven of the background document.*

Age may be an important consideration when selecting mitochondrial donors. Professional guidelines state that eggs, for fertility treatment, should not be taken from donors aged 36 or over.

Do you think the proposed approach to apply the same age limit for women donating their mitochondria is appropriate? Please provide reasons for your answer.

*Please refer to page seven of the background document.*

The family limit refers to the number of families a single donor can help to create. Sperm and egg donors can donate to create a maximum number of 10 families.
Do you think the proposed approach to apply the same 10 family limit to women donating their mitochondria is appropriate? Please provide reasons for your answer.

*Please refer to page seven and eight of the background document.*

The family limit refers to the number of families a single donor can help to create. Sperm and egg donors can donate to create a maximum number of 10 families.

Do you think the proposed approach to apply the same 10 family limit to women donating their mitochondria is appropriate? Please provide reasons for your answer.

*Please refer to page seven and eight of the background document.*

We set out the information that should be provided to fertility patients before consent to treatment is obtained.

Before patients give their consent to treatment involving mitochondria donation, what information should clinics provide?

*Please refer to page eight of the background document.*

We set out the information that should be provided to fertility patients before consent to treatment is obtained.

Before patients give their consent to treatment involving mitochondria donation, what information should clinics provide?

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We set out the information that should be provided to prospective sperm, egg and embryo donors before their consent to donation is obtained.

Before women give their consent to donating their mitochondria, what information should clinics provide?

*Please refer to page eight of the background document.*

**Follow-up studies**

Before answering these questions please refer to the section on 'Follow-up studies' in the 'Regulating mitochondrial donation: seeking expert views' background document.
Many experts recommend that families using mitochondrial donation techniques should be encouraged to take part in long-term follow-up studies to monitor any possible effects on children born and future generations. We propose that clinics must submit their process for following-up children to us.

Do you think this approach is appropriate? What do you think this process should cover?

*Please refer to page 10 of the background document.*

If you have any additional comments about the regulation of mitochondrial donation please provide them below.