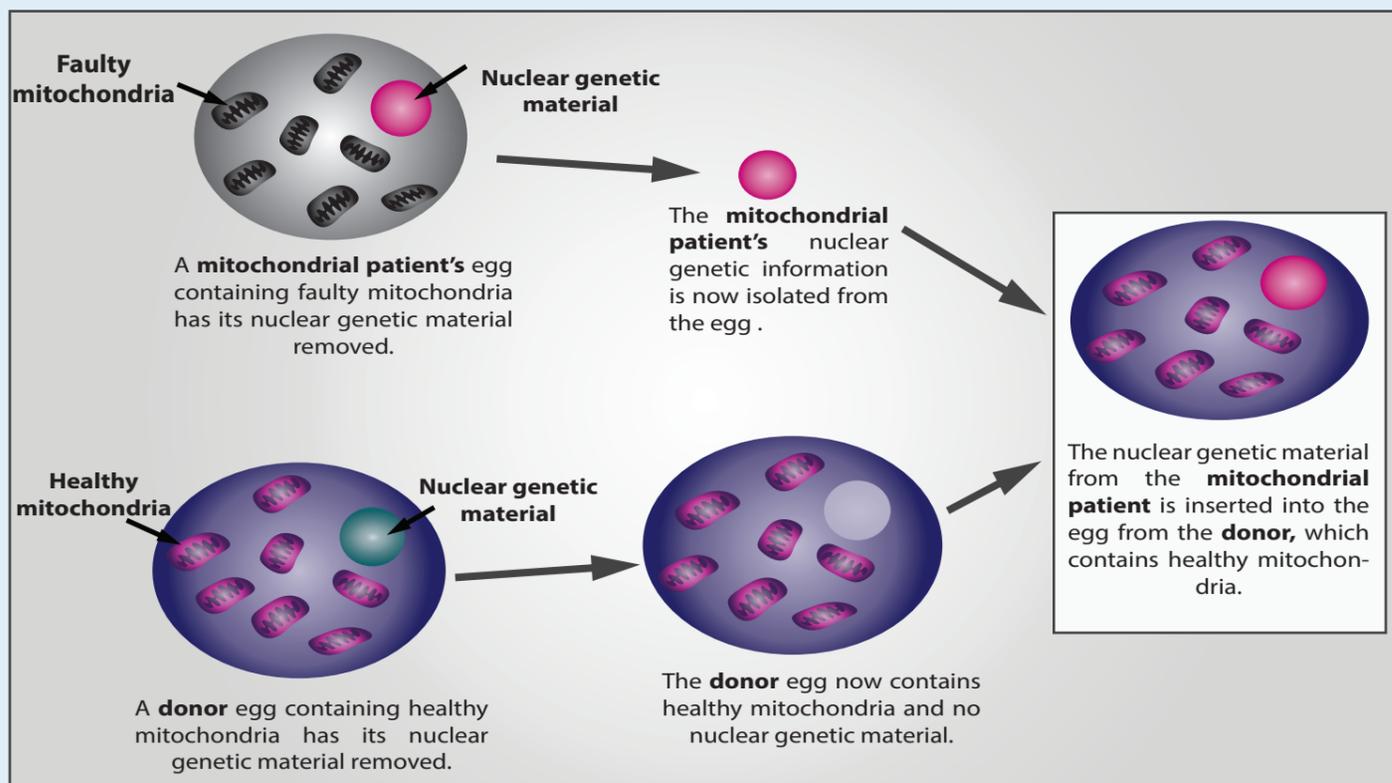


Have **your** say

The Government would like to find out what the public in the UK think about new specialist IVF techniques being developed by scientists at Newcastle University to prevent mitochondrial DNA disease. Here is your quick guide describing what it's about and how you can make sure your views are represented.

What is the science behind this new technique?



Will this technique alter the patient's nuclear DNA?

This technique will not alter the nuclear DNA but will allow a donor to donate healthy mitochondrial DNA to a patient with mitochondrial disease. The combination of healthy mitochondrial DNA from the donor and nuclear DNA from the patient will enable women who are affected by mitochondrial DNA disease to have children genetically related to them but free of mitochondrial disease. As the technique does not alter nuclear DNA, it will not alter a child's unique identifying features such as hair, eye or skin colour.

99.9%

of genes are found within the nucleus. **None** of the mitochondrial genes that will be replaced by the donor mitochondrial DNA will contribute to personal characteristics such as eye colour and height.

Why respond?

The law currently does not allow this type of technique to be used in humans. The government would like the public's opinion about changing the law to allow these techniques to be used. This could allow specialist doctors to gain a license to perform this technique and offer it to mitochondrial patients who request it. It is important that, as patients, your views are represented and we would encourage **you, along with your family and friends**, to respond to this consultation. It is important that MPs understand the human side of mitochondrial disease.

How do I respond?

If you would like to have your views heard, and want to respond to the consultation directly, please go to the website highlighted below. As well as responding online to the consultation or instead (if you do not want to respond online), you could also follow one, or all of the suggestions below:

- Respond directly via the website below
- Discuss mitochondrial disease, your personal experiences and this new IVF technique with your local MP.
- Write a letter to your MP; to find out who your MP is please visit: <http://findyourmp.parliament.uk>
- Write to Jane Ellison (Parliamentary Under-Secretary of State for Public Health). For her contact details please see: www.janeellison.net/index/contact

<https://www.gov.uk/government/consultations/serious-mitochondrial-disease-new-techniques-to-prevent-transmission>

Our response

If you log onto the website above and click on the 'response form' link, this will give you access to respond directly to the consultation. To help you understand what they are asking, and how we are responding, please see the answers below.

Question 1 refers to the removal of the nuclear genetic material from the patient and donor eggs as illustrated in the diagram on the page opposite, we agree with this definition.

Question 2 refers to the removal of nuclear DNA and we agree with this description.

Question 3 describes the role the HFEA (Human Fertilisation and Embryology Authority) will play in regulating this technique. We agree that the HFEA should have this role. We also believe it is important at this stage to consider the regulation of access to the technique once it is established and becomes routine.

Question 4 refers to how the technique should be regulated. We agree that the HFEA should oversee the use of this technique, and that the HFEA should provide licences to regulate its use. We hope that the long term regulation of this technique would not unnecessarily delay patients' access to it.

Question 5 asks for your opinion on how the donation of mitochondrial DNA should be viewed. We believe that donors who donate mitochondria for this technique should be considered in the same way as organ/tissue donors. They should not have the same status as those donating eggs for fertility treatment.

Question 6 and 7 asks what information should be available to a person born following mitochondrial donation, and what information should be provided by the donor. We believe that the information made available should be in line with that available to recipients of organ and tissue donation.

Question 8 refers to what information the donor should receive about children born from this technique. In principle we agree with this approach, although we wish to highlight that we do not believe the donors should have any parental rights.

Question 9 is one of the most important questions as it asks for your comments. This is your opportunity to give your views and personal experience of mitochondrial disease.

This is only a guide, the Government want to hear **your** opinions. If you want to respond but do not want to answer all the questions you don't need to, you can answer as many or as few as you like. Question 9 is the most important question and is your opportunity to describe your experience of mitochondrial disease and your view on the technique. **The deadline for responding is the 21st of May**