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## Editing embryos – Could you? Would you? Should you? Views from Genetic Counsellors

*This blog has been reposted from the [Sanger Institute](https://sangerinstitute.blog/2017/08/03/editing-embryos-could-you-would-you-should-you-views-from-genetic-counsellors/).*  
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**Anna Middleton** (<http://blogs.biomedcentral.com/on-biology/author/annamidleton>) 4 Aug 2017



Image credit: Dr Anna Middleton

Genetic counsellors sit on the front line of genomics – translating (literally) the science for people who are trying to make sense of it. They help people to figure out if testing in pregnancy is right for them or whether to proceed with embryo selection to ensure a family condition is not passed on. Genetic counsellors work

at the intersection between science and society, helping people cope and manage the most potent aspects of grief and helping to make meaning out of a genetic test result that has implications for biological relatives.

Genomics really is a family affair, as many genes are shared between family members. Genetic counsellors, dealing with the reality of genetic technology, understand the questions that are important to patients and their families. They also understand how genetic disease impacts on us as individuals, as parents, as communities and, as decreed in their code of ethics, they have our collective interests at heart.

The [American Society of Human Genetics](http://linkinghub.elsevier.com/retrieve/pii/S0002929717302471) issued a policy (<http://linkinghub.elsevier.com/retrieve/pii/S0002929717302471>) this week on the application of germline editing – the ability to use ‘genetic scissors’ to cut and paste genes in early stage embryos. These changes would be passed onto further generations, unlike somatic cell editing, where the changes would only occur in the patient, and would not be passed onto their children. The policy supports the research endeavour to understand how germline editing might be applied in practice and believes such research should be publicly funded, transparent and open to ethical scrutiny.

The authors of the policy statement agreed that it is not appropriate to perform germline gene editing that culminates in human implantation or pregnancy. They also agreed however that there is currently no reason to prohibit *in vitro* (outside of a living organism) germline genome editing research, with appropriate oversight and consent, or to prohibit public funding for such research.

Critics of germline editing speak of ‘playing god’, ‘designer babies’ and ‘crossing a line’, fearing that by even engaging in research, the creation of a eugenic underclass will materialise. However, what genetic counsellors see is a well-established discipline of Medical and Clinical Genetics, which has existed for the last 50 years, with the potential for a new toolkit to be added that could help prevent suffering and disease.

Familiar with the ethical issues raised by genetics in practice, genetic counsellors aren’t interested in applying a new technology for enhancing frivolous conditions. They are interested in promoting science and medicine that can treat real people with serious, life-threatening conditions.

It is this motivation behind the policy statement that says – let’s at least research where germline editing can take us. This policy does not commit us to translating germline editing into clinical practice, but mandates the support for research that will give us the evidence to say whether it is feasible for the future or not. The policy very clearly states that no edited human embryos should be implanted and thus no pregnancies will result – and indeed this is illegal in many countries anyway.

The policy statement also agreed that a compelling medical rationale with evidence and an ethical justification should be required before any future clinical application of germline genome editing takes place, with transparent and public input from all stakeholders.

What is particularly exciting about this policy is that its first author and the main professional bodies represented in the writing of the policy, are all international genetic counsellors. This is actually quite unusual in policy making that so many diverse professional genetic counselling bodies have aligned. Whilst the policy has been endorsed and supported by many other groups, at the core of this work are basic principles of genetic counselling. By using genetic technology and information to serve individuals and families, genetic counsellors help individuals at risk from genetic disease make choices about their and their family's future health. As a society we can only do this if we support, enable and publicly fund the scientific and social science work that needs to explore how this might work in reality.

Genetic counsellors, working in one of the professions predicted to have the largest growth in the job market over the coming years, are in a strong position to comment on how genomic technology should be used in the future. It is incredibly exciting that a topic as important as embryo editing should be where they unite globally.

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**Relevant links:**

Anna Middleton's webpage :

<http://www.sanger.ac.uk/people/directory/middleton-anna>  
(<http://www.sanger.ac.uk/people/directory/middleton-anna>)

Society and Ethics research group:

<http://societyandethicsresearch.wellcomegenomecampus.org/>  
(<http://societyandethicsresearch.wellcomegenomecampus.org/>)

Anna Middleton's blog: <https://genomethicsblog.org/>  
(<https://genomethicsblog.org/>)

Connecting Science at the Wellcome Genome Campus:

<https://connectingscience.wellcomegenomecampus.org>  
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