# The public must speak up about gene editing – beyond embryo modification

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Gene editing has many potential applications that are not discussed enough. Credit: Pixabay

Researchers led by the Francis Crick institute recently applied to the Human Fertilisation and Embryology Authority for a licence to genetically modify human embryos. The research would use the genome editing technique CRISPR/Cas9 to shed light on the genetic causes of defect of miscarriages in pregnancy.

This is a controversial move, which would make the UK the only country in the world apart from China to carry out such research. It is absolutely crucial that we have an informed debate about it, consulting the public in a meaningful way, before scientists and policymakers set its parameters. To this end, a team of researchers working with the website WhatIsBiotechnology.org are running a pilot survey to gather people's views on the new technology. This will include its use in human embryo modification but also look beyond that to other applications.

## HFEA's expanding remit

The HFEA has been regulating in-vitro fertilisation and research on human embryos and human embryonic stem cells in the UK since 1990. That year, a 14-day cut-off for research to take place in-vitro was established following the recommendations put forward in the Warnock report.

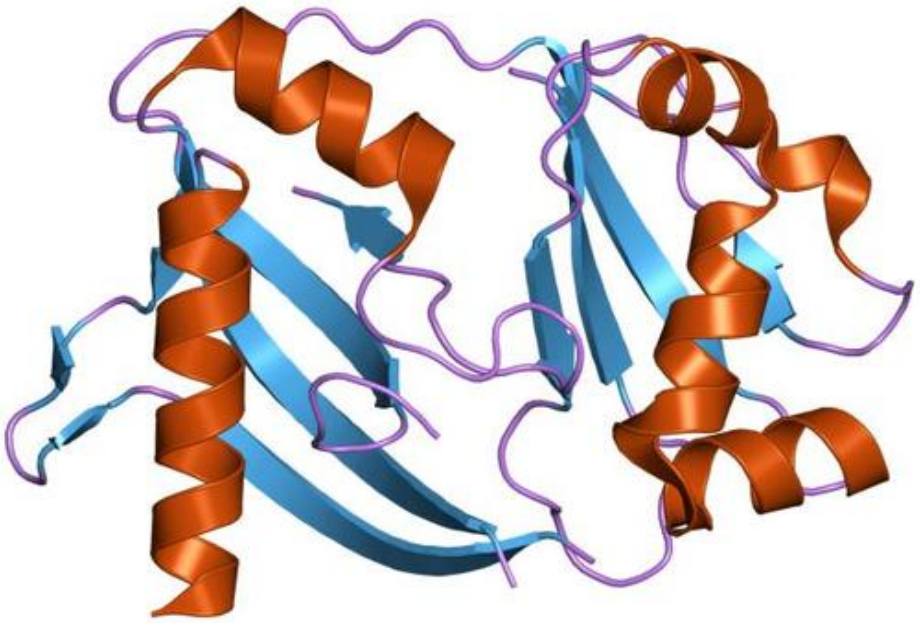
The question now in the minds of many is whether the UK needs new regulations. In the past ten years, the scope of the HFEA regulation has been expanding, not narrowing. For example, in 2006 scientists from King's College London and Newcastle University applied to the HFEA to work on cybrids. Also known as cytoplasmic hybrid embryos, cybrids are embryos derived from creating an egg in the laboratory using the nucleus of a human cell derived from a patient and the mitochondria from a rabbit or cow. The goal was to create patient-specific human cell lines to model human diseases in-vitro.

The HFEA approved this work in 2008 by amending the Human Fertilisation and Embryology Act of 1990 to specify the definition of "human admixed embryos". The applications of cybrids were soon superseded by the introduction of other techniques. One of these was induced pluripotent stem cells – cells that have the ability to form nearly all the cells and tissues in the body – which seemed to avoid many of the

ethical conundrums raised by crossing different species.

In 2015, the HFEA scope was further expanded to allow mitochondrial DNA replacement techniques, which use genetic material from three people to create an embryo free of mitochondrial disease.

The scope of HFEA regulation could very well be expanded again to include applications of CRISPR/Cas9 to embryo research. If this happens, it will provide for licences for very specific applications of the technology. This is unlikely to be a "blanket licence" or to go beyond the 14-day limit of research in-vitro.



Credit: wikimedia

## International divide

The recent call by US scientists for a temporary pause "in the application of germ-line modification for clinical application in humans while the implications of such activity are discussed"has added a new intensity to the debate and reveals a potential bioethical divide between the US and the UK.

The proposed moratorium has been hailed in some quarters as a positive step toward preserving the public's trust and safety but because of its narrow focus on the germ-line, it also prevents alternative views from surfacing in the debate and constrains the boundaries of the much called-for public engagement with the issue.

Until now, the debate around the use of CRISPR/Cas9 has been framed in two opposing ways. On the one hand the technology is seen as a promising tool for advancing medical knowledge and treatment. Counter-balancing this is the view that it poses serious risk to the future because of its eugenic potential to create "designer babies". This way of framing the debate can be harmful, as it elicits a particular public response. It also prevents engagement with other issues raised by CRISPR/Cas9 beyond the germ-line. These include important work such as creating humanised animal models for organ transplant, genetically modifying insects to eliminate those that carry diseases, including malaria, and creating better engineered crops.

Parallels have been drawn between the action of the US scientists and the Asilomar conference in Caifornia in 1975. The conference was set up to discuss the biohazards presented by a new technique published in

1973 for producing recombinant DNA. The meeting called for scientists to temporarily halt use of the technology while guidelines were deliberated. Drawing parallels with the Asilomar conference, however, is inappropriate. Although the conference has gained memorable, almost mythical, status in the eye of scientists, who treat it as a model for scientific responsibility and control, 40 years of science and technology studies have challenged this view.

Some scholars have argued that the conference and the guidelines it established can be read as an attempt to keep the regulation of biotechnology within the professional boundaries of science. In this way, external regulation and tough questions about science in society were avoided. Going forward, the conference also set in motion a particular approach in how to handle new technological challenges.

As the historian of science and medicine Ben Hurlbut, reminds us: "Technological controversies have come and gone, but modes of reacting to them have come to be patterned and institutionalised." This highlights the need to be critical of reactive patterns in bioethics and for active public engagement. It is also a reminder of such debates are framed by particular economic, social and political factors in different countries.

## Seeing the full picture

At a time when the genome editing technology is still in its infancy and its applications remain unclear, it is important to engage the public in a dialogue that moves beyond considerations of the use of the technology in the germ-line. While predictions about the evolution of the technology are always hazardous and often wrong, it is vital to capture what people think about it before decisions are made.

To this end we have launched a pilot survey to gauge what different members of the public think about what genome editing is and can do,

what sources of information they use to understand the technology and how well informed they feel on the issue.

The survey also aims to capture what images, ideas or associations people have when they think about CRISPR/Cas9. Capturing this aspect of the public response is important as it can shape the boundaries of the ethical debate and the thinking of policy-makers.

Aiming to provide a more reflective and less reactive and "institutionalised" mode of doing bioethics, the pilot survey aims to capture responses from as large a population as possible. It is aimed at university students, school students, industry experts, scientists, healthcare practitioners, patient groups and charity workers from the UK, continental Europe, US, and China.

To contribute to the survey please go to:
http://www.whatisbiotechnology.org/survey/index/670a773b/conv12
Results are to be published both online through WhatisBiotechnology.org and other media outlets.

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