

Case Study

Dialogue on hybrid and chimera embryos for research

Vital statistics

Commissioning body:

Human Fertilisation and Embryology Authority (HFEA), commissioned by the Department of Health

Duration of process:

11 months: January 2007 - November 2007

Number of public participants:

More than 3,000, comprising:
deliberative dialogue = 104
written consultation = 810
public meeting = 153 and
opinion poll = 2,073

Number of experts/stakeholders involved:

Experts/stakeholders = 25
Advisory Group members = 16

Cost of project: £140,000 total,
Sciencewise-ERC funding = £60,000

Human/animal embryos may be termed hybrids where they are created by mixing human sperm and animal eggs, or human eggs and animal sperm; or chimeras where animal cells are added to a human embryo during early development (or human cells to an animal embryo). The use of human/animal embryos in research was proposed as potentially leading to the development of new treatments for many diseases for which there were currently no effective cures. The proposed research using embryos with both human and animal DNA was potentially highly controversial, raising some profound moral and ethical issues.

The responsibility for regulating this research lay with the Human Fertilisation and Embryology Authority (HFEA), which was keen to explore how people balanced the ethics, risks and benefits of mixing human and animal genetic material.

Key messages from the public

There were three themes running through the different elements of the dialogue processes: the necessity for the research, the effectiveness of creating animal/human embryos for research and the desirability of the research:

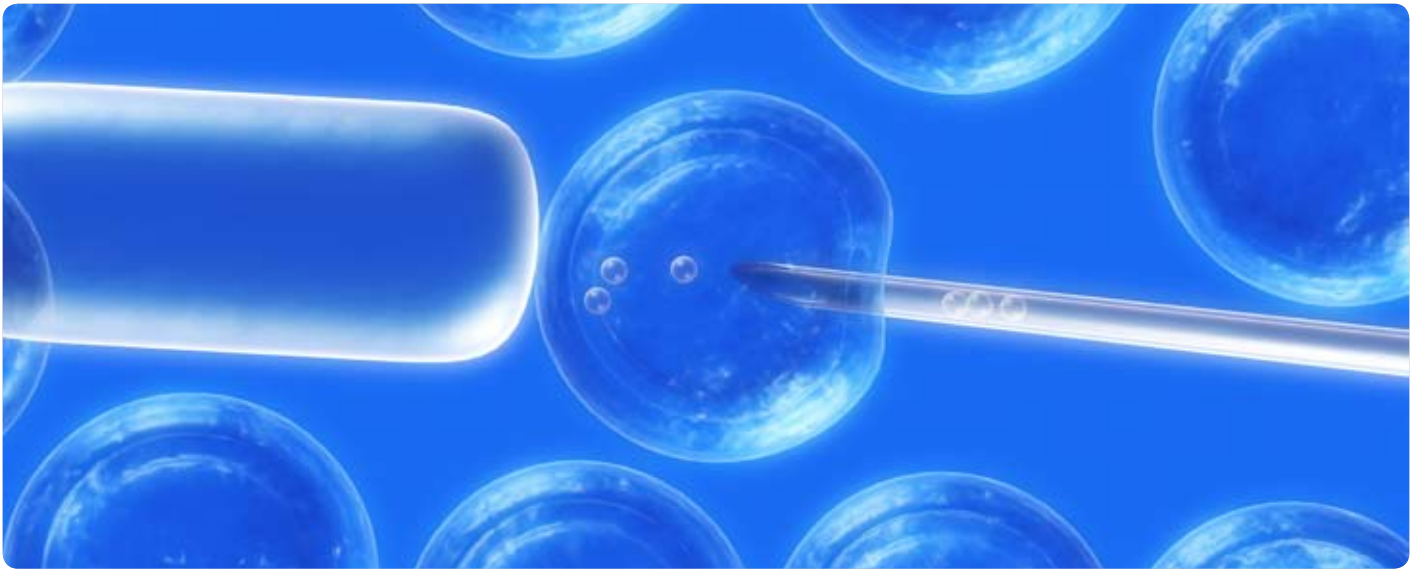
- The necessity of creating animal/human embryos for research purposes when other sources of stem cells were available (namely human embryonic, adult and cord blood cells), was strongly debated at the open public meeting, resulting in mixed views
- In the deliberative research, the majority felt that although adult and umbilical cord stem cells did not have the same

ethical implications as embryonic stem cells, it was worthwhile pursuing all avenues if there was a potential for greater understanding of diseases

- Participants involved in the deliberative research felt it was necessary for scientists to use animal eggs. They were influenced by the argument that scientists need to create a biological model to study certain diseases and felt that using animal eggs would negate the shortage of human eggs
- Most of the participants in the deliberative research and omnibus survey supported the creation of cytoplasmic hybrid embryos¹ if there was a clear rationale for the research

- People wanted reassurance that any research conducted on cytoplasmic hybrid embryos would, or could, provide useful understanding of human diseases. There was concern that, because the cells that the embryos were derived from were not completely human, the results would not be transferable
- Most participants in the deliberative research believed that, although the embryo was special, it did not warrant the same level of respect as human beings. As such, it was acceptable to use embryos in research if the research had a clear potential benefit

¹Cytoplasmic hybrid embryos are created by removing the nucleus of an animal egg and inserting the nucleus of an adult cell from a different individual (and possibly of a different species)



Background

Researchers around the world have been using stem cells from human embryos in research to develop their understanding of a number of different diseases. Many scientists believe that embryonic stem cells may also, in future, lead to new therapies. The availability of human eggs and embryos is a major limiting factor for investigating and utilising this technique in humans. One alternative is to derive stem cells from hybrid or chimera embryos, created by mixing human and animal genetic material.

In 2000, the Government's Chief Medical Officer concluded that the creation of hybrid embryos should not be allowed. However, a House of Lords Select Committee in 2002 suggested that human-animal embryos would be useful for research purposes. In November 2006, the HFEA received two research applications to derive stem cells from hybrid embryos using animal eggs.

Before reaching its decision, the HFEA decided to explore the issues with the public to test how people balanced the ethics, risks and benefits of the research.

- Initially there was an aversion to mixing human and animal genetic material as this gave rise to thoughts about creating 'monsters' and concerns about where it might lead next. However, although some concerns were still evident after deliberation, most believed that the potential benefits of being able to study serious diseases outweighed the initial aversion towards the mixing of genetic material
- In the omnibus survey, although most people supported the creation of cytoplasmic hybrid embryos if it may help to understand diseases, many still had concerns about it
- As a result of concerns, participants in the deliberative research stressed the need for strict regulation and monitoring of licensed activities.
- The dialogue gave the HFEA confidence in its final decision, as it accorded with informed public views and there was also a rich understanding of why people held the views they did
- Dialogue increased the accountability of decision-making by opening up the process and making it more responsive as well as more transparent.

The dialogue activities

The objective of the dialogue was to examine the ethical and social issues arising from the creation of hybrid and chimera embryos for research.

The specific aims of the dialogue consultation were to:

- Engage stakeholders in the scoping and development of the dialogue process in collaboration with the HFEA, and in line with the wider written and web consultation process
- Undertake a deliberative process with a diverse set of the public which accords with the Government's Guiding Principles for Public Dialogue on Science and Technology
- Capture, analyse and report the results of the dialogue project so that they can be easily understood by policy makers and can inform the HFEA's policy recommendations along with the results of the written and web consultation.

There were four distinct strands to the overall consultation: deliberative public dialogue, an open public meeting, an opinion poll and a formal written consultation. The development of these

Policy influence

- After careful consideration of the evidence gathered through the public dialogue, the HFEA decided that cytoplasmic hybrid embryo research should be allowed to move forward, with caution and careful scrutiny. In addition, any specific applications for licences to carry out such research had to demonstrate, to the satisfaction of an HFEA licence committee, that the research project was 'both necessary and desirable'. These caveats directly related to public concerns expressed in the dialogue
- The dialogue improved policy and decision-making: gaining access to a wider range of views and so creating stronger evidence to achieve a more robust decision

strands was assisted by a Stakeholder Advisory Group, which advised and commented on the plans for the work and the development of materials to be used with members of the public. The Stakeholder Advisory Group members represented a range of organisations with diverse interests and knowledge in the area.

The main focus of the public deliberative dialogue was to explore and understand various public perceptions, motivations and attitudes to creating human-animal embryos for research. The first stage of this work involved 12 small discussion groups held in London, Manchester, Newcastle, Belfast, Glasgow and Swansea. These involved a total of 104 people recruited to represent a diverse set of the public in terms of age, gender, social class, ethnicity and religious views (known to influence opinions on embryo research). In these groups, participants were taken through the different types of human-animal embryos and the science behind them, and initial reactions were gathered.

The second part of the deliberative dialogue consisted of a full-day workshop attended by 44 of those who participated in the small groups: participants were selected at random and then reviewed to ensure a representative sample. The aim of this second stage was to explore the views and opinions of participants in more detail. A very diverse mix of expert speakers illustrated the different relevant issues and arguments. The workshop was recorded and a short film of the day was shown to the audience at the public meeting. This film was also made available for viewing via the HFEA website.

The open public meeting was held one evening in London. Widely publicised through a range of networks, the meeting attracted 153 participants. In addition, an opinion poll was conducted to gauge the views of a demographically representative sample of the UK population (with 2,037 respondents). The questions for the poll were developed with the assistance of the Stakeholder Advisory Group and built on the early findings of the deliberative work. The formal written and online consultation received 810 responses.

The results of the dialogue project were recorded in detail at each stage. The findings were analysed and summarised by Opinion Leader to HFEA in a series of reports. All reports and documents from the consultation were published on the HFEA website, and the HFEA made its final decision on allowing hybrid/chimera embryo research in principle, at a meeting held in public. All of this maximised openness and transparency.

Summary of good practice and innovation

- The consultation process involved a diverse set of public in terms of age, gender, social class, ethnicity and religious views
- Two-stage iterative dialogue process gave participants time to absorb complex scientific information
- Deliberative public dialogue was part of a larger consultation process, which included a range of other engagement approaches (opinion poll, public meeting, formal consultation). The mix of methods provided lots of different ways to engage people and provided a broad range of data which allowed the HFEA to compare, integrate and triangulate views from the public and stakeholders
- The information provided to participants was clear, well-used and understood by all
- The range of speakers at the reconvened deliberative public event and the open public meetings provided diverse perspectives for and against the use of embryos for research

- The whole consultation process was open and transparent, which reduces cynicism and distrust about these types of engagement process
- There was a clear line from the dialogue to the final policy decision
- The quality of the dialogue process positively impacted the credibility of the results with policy makers.

Lessons for future practice include:

- It takes time and resources to establish and support an effective Stakeholder Advisory Group, but this input can be invaluable in terms of the legitimacy and accountability of the dialogue, and the balance of views in the information provided to the public
- Effective recording and reporting processes create confidence in dialogue findings, leading to confidence in later decision-making using the findings as evidence
- With careful design and appropriate information provision, contentious subjects can be discussed calmly and productively
- Participants want to know about the impacts and influence of their input.

Impacts

Influence on policy is covered in the summary on the second page. This section describes the impacts on all the participants in the process.

Impacts on policy makers

- The success of this project has encouraged greater use of dialogue among the HFEA and associated policy makers
- The dialogue process helped policy makers further develop their plans to improve future communications with the public.

Impacts on public participants

- The project increased the willingness of participants to get involved in these sorts of event in the future. 95% of participants at the reconvened event said they were more likely to get involved in such events as a result of attending this one
- The project had a major impact on understanding and awareness, both in terms of new learning and in helping public participants to think clearly about the issues
- The project had a major impact on participants' views on the issues, with 70% saying the events had made a difference to what they had previously thought about the issues
- The process resulted in high levels of trust that HFEA would take notice of what the public said
- Participants valued being able to take part in an important discussion on an important issue.

Impacts on scientists/experts and other stakeholders

- Stakeholders learnt about the value and practicalities of public dialogue
- The dialogue increased expert/stakeholder confidence in the ability and willingness of the public to discuss complex scientific and moral issues.

“ It is so difficult to provide balanced and unbiased information, to provide enough information for people to be able to discuss, but not too much so they can't take it all in. But in the end, I was very impressed. ”

Stakeholder Advisory Group member

“ Well it definitely helped the Authority come to a robust decision as it gave in-depth knowledge of public opinion and the reasoning behind it. With questionnaires you don't get the rationale behind it. ”

Policy maker interviewee

“ This was the most successful consultation that I have been involved in during my five years as a member of HFEA. I felt that it successfully dissected the strands of opinion, highlighting the differences between informed opinion and instinctive responses in the general public... ”

HFEA member

“ It reinforced that public engagement is a good thing, and that we need to carry on with it against the odds and the opposition. ”

Stakeholder interviewee

Overall impacts

The dialogue project has directly impacted policy, culminating in the HFEA announcing on 5 September 2007 that, having taken account of all the views, it had decided to allow hybrid/chimera embryo research in principle, under strict guidelines. In January 2008, the HFEA went on to grant licence applications from researchers to two UK universities to carry out research using hybrid/chimera embryos. In November 2007, the Human Fertilisation and Embryology Bill was introduced into the House of Lords which allowed the creation of hybrid embryos for research. The Bill received Royal Assent in November 2008.

The objectives of the project were met in full and the project also successfully created a greater breadth of public understanding in what is a highly contentious issue. The dialogue also demonstrated to the HFEA that there is a clear demand from people to know more about what researchers are doing and their plans for future work. A need for better communication about science and research from both the scientific community and HFEA was highlighted. As a result of this project, the HFEA further developed its plans to improve future communication.

Contacts and links

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Reports

Full project and evaluation reports available from Sciencewise-ERC at www.sciencewise-erc.org.uk/cms/hybrids-and-chimeras