

Conscience or consultation? The Human Fertilisation and Embryology Act: a retrospective

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How are matters of conscience involving scientific issues handled in public debate? How can science be reconciled with ethics? What is the role of public consultation on issues of an abstruse scientific nature?

These were some of the questions raised during an event organised by the ESRC Genomics Policy and Research Forum to examine the public debate and policymaking process leading up to the Human Fertilisation and Embryology (HFE) Act 2008. The conference, which took place during the ESRC Festival of Social Science 2009, was attended by a lively audience of politicians, researchers, ethicists and representatives from special interest groups.

In an overview of the key issues that arose during the day, Professor Steve Yearley, Director of the Genomics Forum, said that the progress of the Bill had highlighted the tension between the objectivity of the scientific approach and ethical positions based on a principle of individual discretion. 'Where should we look for moral expertise in these complex questions?' he asked. The debate had raised questions about the nature of public opinion and the weight which should be given to the so-called 'yuck factor' as evidence of public moral outrage. 'You don't want a knee-jerk response from the public, but neither do you want to exclude the vast majority of the public by saying that you need qualifications to speak on a topic,' Professor Yearley said.

In the first session of the day, Dr Katy Berry, Department of Health, who is responsible for the implementation of the 2008 Act, gave a crisp account of the character of the pre-legislative scrutiny and the legislative process. She said: 'Many steps were involved in getting this legislation into the shape that it is in. There was lots of debate, consultation, lobbying and enquiries and committees during which the Government listened to concerns. Ultimately this has resulted in a better piece of legislation.' Dr Berry gave a number of examples where the Government had moved its position in response to public consultation, relating to the terminology used to describe hybrids, the use of embryos, and tissue typing. Another area which had prompted a great deal of debate was parenting. Eventually the 'need for a father' was changed to the 'need for supportive parenting', which was more appropriate because single mothers and same-sex couples were now eligible for IVF treatment.

Looking at the differences between the new Act and its 1990 predecessor, Dr Berry said that more procedures were now available and that attitudes to

eligibility for fertility treatment and informing children about donors had changed since 1990. Summing up, she said: 'Consent from donors is, however, the cornerstone of the 2008 legislation as it was in 1990; the 14-day rule on the destruction of hybrid embryos is still in place; and the special status of the embryo is still acknowledged. As a result of the consultation and the efforts of all the stakeholders, many of whom are here today, we are confident that the 2008 Act is well placed to stand the test of time.'

Phil Willis MP, who chaired the Joint Committee on the Draft Human Tissue and Embryos Bill, commented that the Bill had been the most interesting process he had been involved in since coming into Parliament. He agreed with Katy Berry that it was 'a good example of how sound legislation can be produced despite the complex nature of the subject matter and the hugely divergent parliamentary, scientific and public views. The principle behind this piece of legislation was to engage the science community, the public and the media – there is a huge lesson to be learned,' he told the meeting.

On the controversial topic of ethics, Phil Willis said the Committee had been guided by a profound statement by Baroness Warnock in 1984: 'The law must not outrage the feelings of too many people; but it cannot reflect the feelings of them all. It must therefore be drawn with a view to the common good.' He added: 'The development of the new Act demonstrated how you can get legislation which appeases some of the people some of the time and a great many people a lot of the time.' Mr Willis also warned of the need to future-proof legislation so that it is not obsolete by the time it is passed: 'This is particularly important when new and emerging science and morality are involved.'

Because it was deemed to be an 'issue of conscience,' MPs were allowed a free vote on the HFE Bill, but according to Philip Cowley, Professor of Politics at the University of Nottingham, the outcome of free votes is still largely determined by the political parties. He said it was easier to list issues of conscience than define them. Hunting, war criminals, censorship, fluoridation, homosexuality and the wearing of seat belts had all been subject to free vote, but they had little in common. 'There is a vague sense of God and bedroom, but that doesn't cover hunting or seatbelts. The reality is that the difference between a whipped vote and a free vote is fuzzy and usually boils down to calculations of party advantage,' Professor Cowley reported. Describing his research on voting patterns on both the HFE Bill and the 1967 Abortion Bill, Professor Cowley said that the outcome reflected the party composition in the House of Commons. 'Is this a good way to make policy?' he wondered. 'It is true that Parliament becomes more lively and important but there are real problems because allowing MPs to vote how they want breaks the accountability linkage with their constituents.'

As Director of Progress Educational Trust (PET), a charity working to facilitate balanced debate on assisted reproduction, embryo research and human genetics, Sarah Norcross said that PET is a small charity but it had punched above its weight in this debate by informing policymakers about this complex issue. In her account of the four public debates that had fed into policy for the HFE Bill as it passed through Parliament, Sarah Norcross said that despite very little marketing and a limited budget, the debates each attracted an

audience of 100 and were heavily oversubscribed. 'Our debates aim to tease out the issues so that the lay public as well as professionals get something out of the event. From the first one we realised we were reaching new people, from peers to nurses and teachers,' she explained.

Sarah Norcross also described the activities of the 'strategy group' – a unique coalition of individuals and organisations including clinicians, scientists, patient support groups and medical research charities – which met to discuss the Bill and the amendments to it 'to decide what, if anything, should be done.' The group operated through regular meetings and email contact and by sharing briefings. They also wrote joint letters to the press, and had taken part in a show of support for the Bill on the Green. 'It was an odd group who didn't all agree on everything but we were all interested in the issues and we did the best we could,' said Sarah Norcross.

Speaking from the perspective of a pioneering stem cell scientist, Dr Stephen Minger, King's College London, said that he had trained in the United States where there was no overarching regulation on how embryos are obtained and used to create cell lines for research. 'The UK is a model system for embryo research regulation,' he asserted. Dr Minger told the meeting that the scientific community had drawn on lessons from the debate on genetically modified foods: 'At that time scientists were running away from the debate and that is why the government and the public said "no" to GMOs.' When it came to the hybrid embryo debate, 'We could see that it was essential to engage actively with the media and other groups,' he insisted. Great efforts had been made to convince the Government that hybrid embryo research was worth pursuing. Dr Minger concluded that the eventual success of the Act could be attributed to a number of factors: the scientists stood up and fought; there was strong support within the scientific community, scientific and medical societies, patient organisations and disease charities; media coverage was scientifically accurate and supportive; the consultation process was effective; and there was a strong ministerial lead which encouraged the participation of scientists in the parliamentary process.

Details of the media campaign, and the active participation of leading stem cell scientists, were presented by Fiona Fox, Director of the Science Media Centre. Discussing the campaign from 2005 to 2008, she explained that it had changed the narrative of science and the media, which had been very negative over issues such as GMOs, BSE and the MMR vaccine. 'Scientists now see communication with the media as part of their job, particularly when they are working in a controversial area.'

The principle of the communications strategy in relation to hybrid embryo research was to pre-empt media coverage so that journalists first heard the news from scientists. 'One of the most difficult moments was when the scandal of the South Korean cloning research broke in January 2006 and everyone wanted to know if there were any implications for research in the UK. We responded with an immediate press briefing by key players,' Fiona Fox explained. In January 2007 the scientists held another high-profile briefing in response to a Government threat to ban hybrids research because of the 'yuck' factor.

Fiona Fox described the media frenzy that followed: 'Hardly a week went by for the next 18 months without some coverage. Top scientists made themselves available to talk to the public on radio phone-ins and chat shows at every opportunity and no question was too silly to answer. Then when the Catholic Church condemned the research in April 2008 a letter from hundreds of medical research charities became news and kept the issue alive.' The success of the campaign was demonstrated by an HFEA [Human Fertilisation and Embryology Authority] poll, which showed 61 per cent support from the public when they were told the reason for creating human-animal hybrids,' Fiona Fox reported.

Dr Calum MacKellar, from the Scottish Council on Human Bioethics, took issue with some of the previous speakers. He said that the Scottish Council on Human Bioethics had been one of the first ethical committees in Europe to do a report on interspecies embryos in 2004. The report had emphasised the need to decide which kinds of human/animal embryos should come under human or animal legislation. Claiming that the scientific lobby had become too dominant after the press conference in January 2007, Dr MacKellar said that opponents of the research had no longer wanted to speak out for fear of losing funding. He also believed that the media coverage had been unbalanced: 'There were only two lines against hybrids in the average article.'

Dr MacKellar felt 'deep disquiet' because chimeras were seldom discussed in the debates leading to the Bill. This was in contrast to cybrids and true hybrids, he said. In the US, however, it was mainly chimeras that were being discussed in the National Academy of Science. 'Even now I remain unsure whether some forms of chimeras come under human legislation or animal legislation. This is something I was always afraid of. On the very last day the Bill was discussed, concerns were raised about embryos where the DNA was majority animal, and would come under animal legislation, but which had a predominately human brain. The topic was discussed at the last minute and it remains an open question,' he told the meeting.

Dr MacKellar was also worried that the Government had changed its mind so often during the drafting of this legislation, and thought that the Science and Technology Committee had not had enough time to consider some important issues. 'In general, the scientific perspective seemed to trump everything. Issues such as human dignity, which are taken seriously by other organisations such as the Council of Europe, were not considered,' he told the meeting. 'There have been recent moves towards a form of scientific dominance – a policy in which anything not to do with science is put aside. I would support a form of ethics in which all possible views are taken into account, valued, and solutions are found which are least offensive to all parties.'

The ethical debate was taken up by speakers from the floor, one of whom had been taken aback by 'the heavily conservative agenda of the bioethicists, who were often assertive, dogmatic, and even patriarchal in style.' Fiona Fox replied that she wanted a balanced debate but ethicists might need to 'get their act together'. She said: 'I am glad to hear that the scientists were "dominant." The British public said no to GM plants because the best plant scientists ran away from the debate.' Other questioners wondered whether

scientists would still be prepared to engage in debate with the public in the same way when the private sector was involved. There was some discussion about how the UK was regarded by other countries. Why were hybrids not popular in the rest of the world? Dr MacKellar commented that other countries were shocked at the speed at which things are moving in the UK. He thought that the issue of human dignity had been put aside because nobody knew what it was. 'Even though we can't define it, this doesn't mean that it isn't crucial and shouldn't be respected.'

The social science perspective on the debate was presented by Dr Joan Haran, Cardiff University, and Dr Nik Brown, University of York. Dr Haran had analysed the media coverage of the research and queried if it was appropriate for science journalists to be advocates for science. She gave examples of references to 'war on terror language' in relation to the public consultation. 'Words like "assault" and "onslaught" and "hijack" were used to conflate any critique or protest to the extremist wing of the anti-science point of view,' she reported. 'Unpacking' the puns used in tabloid headlines, Dr Haran said that it was clear that the framing had been humorous – although stories about Frankenbunnies and 'mootants' had also given a factual account of what was going on. Having also looked at various claims about the influence of media coverage on Government, she wondered if public consultation was being used 'to elicit new opportunities for persuading people?'

In the final session, Dr Nik Brown explored how relations between humans and other species are being renegotiated in the light of scientific change. He said that developments in bioscience had forced us to rethink boundaries and contradictions, not just between humans and animals, but between science and politics, and the sacred and profane. His presentation illustrated the complexity of the debate and the contradictions and paradoxes in how we define and characterise ourselves as human beings. This was particularly evident from the quotes which had arisen during discussions of the statistical composition of hybrid embryos. It was paradoxical that the exceptional status of the hybrid made it more special than a human embryo, Dr Brown said.

The 'Retrospective' provided a valuable opportunity for people with very different views to express their appreciation for or frustration with the process of the HFE Bill. By the end of the day, it was clear that despite the imminent implementation of the Act there were still some unanswered ethical questions. Criticism was also expressed about some aspects of the consultation process and the debate that followed, although most speakers from the platform agreed that it had been a good example of democracy in action, given the complexity of the subject matter.