Editing out the embryo: the debate over "human genome editing" in the United Kingdom

Abstract

Two conferences on "genome editing" held in December 2015 offer a lens through which to analyse bioethics policies in the United Kingdom, in contrast with those in the United States. The "Progress Educational Trust", which hosted the London conference, has no parallel in the USA. It illustrates the close collaboration between UK government departments, scientific bodies, funding organisations, and lobby groups. The rhetoric of responsible regulation used in the UK serves to protect, not the embryo, but the practice of embryo destruction. Advocates of embryo experimentation in the UK are eager to "lead the way in the debate about genome editing". It would be perilous for the international community to allow the UK to frame the debate in this way.

A tale of two cities

In December 2015 two conferences were held on the topic of human genome editing,[1] one in Washington DC, the other in London. In Washington, the US National Academies of Sciences, Engineering and Medicine, in collaboration with the Chinese Academy of Sciences and the UK's Royal Society, hosted a three-day *International Summit on Human Gene Editing*.[2] In London, less than a week later, a one-day conference was held on the same theme under the title *From Three-Person IVF to Genome Editing: The science and ethics of engineering the embryo*.[3]

Following the Washington summit, the US National Academies convened a multidisciplinary committee of experts to produce a consensus study on *Human Gene Editing: Scientific, Medical, and Ethical Considerations.* This was published on 14 February 2017.[4]

The London conference did not lead to a report, but at the same time as that conference was being held, the Nuffield Council on Bioethics, also based in London, was itself considering the same topic. In July 2015 the Nuffield Council had announced the formation of a working group to explore the ethical issues raised by novel techniques for genome editing. They invited contributions from experts and held an open call for evidence that ran from November 2015 until February 2016.[5] The initial report, *Genome editing: an ethical review*,[6] published in September 2016, covered human health (understanding disease, treating disease, avoiding genetic disease, and human enhancement) as well as food, the impact on the natural environment, and other applications. Following this

[1] There are differences in connotation between "gene editing" and "genome editing", as the latter places the genetic intervention in the context of the genome as a whole. Nevertheless these differences do not amount to differences in what is proposed and hence the two terms will be used interchangeably in this paper.
[2] Steven Olson; Committee on Science, Technology, and Law; Policy and Global Affairs; National Academies of Sciences, Engineering, and Medicine; *International Summit on Human Gene Editing: A Global Discussion* (Washington DC: National Academies Press, 2016) https://www.nap.edu/catalog/21913/international-summit-on-human-gene-editing-a-global-discussion
[3] Progress Educational Trust, "Events: From Three-Person IVF to Genome Editing: The Science and Ethics of Engineering the Embryo" http://www.progress.org.uk/conference2015
[4] National Academies of Sciences, Engineering, and Medicine, *Human Genome Editing Science, Ethics, and Governance* (Washington, DC: National Academies Press, 2017). http://www.nationalacademies.org/gene-editing/consensus-study/index.htm
[5] Nuffield Council on Bioethics, *Genome editing: an ethical review – a short guide* (London: Nuffield Council on Bioethics, 2016).
[6] Nuffield Council on Bioethics *Genome editing: an ethical review* (London: Nuffield Council on Bioethics, 2016).

general overview a second working group was established specifically to consider *Genome Editing and Human Reproduction*. [7] At the time of writing this second working group has yet to report.

The parallel initiatives in London and in Washington, both in relation to the hosting of conferences and in relation to the commissioning of reports, offer a lens through which to compare discussion of bioethics and public policy in the United Kingdom and that in the United States. The focus of the present paper is the approach taken in the UK with the US approach presented primarily as a foil for that discussion. This method will highlight some of the shortcomings of the UK approach to bioethical discussion of the human embryo. It will also help explain why the UK remains such a persistent promotor, within the international arena, of lethal experimentation on embryonic human beings.

Bioethicists or scientists?

The UK equivalent of the US National Academy of Sciences is the Royal Society, and this was a co-sponsor of the international summit in Washington from which emerged the expert working group. However, within the UK, the national discussion of human genome editing has not been led by the Royal Society. Rather, a prominent role in the UK debate has been played by the Nuffield Council on Bioethics. The UK has no national bioethics committee but the Nuffield Council fulfils this role for some purposes.

It is entirely appropriate that a national bioethics committee should discuss an issue so manifold in its bioethical and public policy implications as human genome editing. This raises the question of why the US discussion has not also been led by the equivalent national committee, that is, by the Presidential Commission for the Study of Bioethical Issues. The fact this has not happened is particularly striking given the prominent cultural position of bioethics within the USA. Bioethics as a discipline emerged in the USA in the 1970s,[8] and it remains, to a very large extent, a discourse framed by American concepts and concerns.[9]

The lack of engagement of the Presidential Commission on the issue of gene editing is perhaps best understood as a transient effect and one that may represent a reaction to the prominence of the President's Council on Bioethics at the time of President George W Bush. Members of the Obama administration were unhappy with some of arguments presented by the previous President's Council, especially in relation to human cloning,[10] human embryonic stem cell research,[11] and concept of human dignity.[12] To prevent conservative voices in bioethics from influencing policy during the tenure of this administration, the Presidential Commission for the Study of Bioethical Issues was not only reconstituted in membership but was also directed to less politically

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[7] Nuffield Council on Bioethics, "Working Party on genome editing and human reproduction" http://nuffieldbioethics.org/project/genome-editing/working-party/

[8] Albert R. Jonsen, "American moralism and the origin of bioethics in the United States," *Journal of Medicine and Philosophy* 16.1 (1991): 113-130.

[9] Carolina Pereira-Sáez, "Philosophical Imperialism? A Critical View of North American Principlist Bioethics," in *Bioethical Decision Making and Argumentation*, eds. Pedro Serna Bermúdez, and José-Antonio Seoane (Dordrecht: Springer, 2016), 43-56.

[10] The President's Council on Bioethics, *Human Cloning and Human Dignity: An Ethical Inquiry* (Washington DC: Government Printing Office, 2002).

[11] The President's Council on Bioethics, *Monitoring Stem Cell Research* (Washington DC: Government Printing Office, 2004).

[12] The President's Council on Bioethics, *Human Dignity and Bioethics: Essays Commissioned by the President's Council on Bioethics* (Washington DC: Government Printing Office, 2008).

controversial areas. The issue of gene editing was therefore considered not by the national bioethics body but by a body representing scientists: the National Academy of Sciences.

It may seem that, in relation to the current gene-editing debate, the approach of United Kingdom is preferable, for in the UK it is a national bioethics body that is helping to lead the discussion. Nevertheless, this apparent contrast underestimates the influence of scientists, science funding bodies, and government in framing the bio-policy debate in the United Kingdom. This is even more evident when one considers the organisation that hosted the London conference on genome editing in December 2015: the Progress Educational Trust.

What is "progress"?

The Progress Educational Trust has no parallel in the USA and helpfully illustrates the links between government, the scientific establishment and non-governmental actors in shaping policy on embryo research in the United Kingdom. To understand the character and role of this organisation it is necessary to revisit, at least briefly, the formative period of UK policy on embryo experimentation.

The context for this debate was the birth in 1978 in the North of England of Louise Brown the first child born as a result of in vitro fertilisation. Margaret Thatcher became Prime Minister in 1979 and her Conservative government was strongly supportive of this technology. Thatcher was herself the first, and to date the only, British Prime Minister to hold a degree in a scientific discipline. From 1943 to 1947 she read chemistry at Oxford and in her final year applied X-ray crystallography to determine the structure of the antibiotic gramicidin.[13] This was just six years before similar techniques led scientists in London and Cambridge to discover the double helix structure of DNA. However, while Thatcher and her government wished to protect the practice of In Vitro Fertilisation and thus of embryo experimentation, they were aware of concerns expressed by members of the public, elements of the media, and members of parliament including many MPs within the Conservative Party itself.

The Conservative government addressed these concerns in 1982 by establishing a Committee of Inquiry into Human Fertilisation and Embryology chaired by the philosopher Mary Warnock. The Committee reported[14] in 1984 and its recommendations led to the establishing in 1985 of an interim voluntary licensing authority. However, also in 1985, the former Conservative MP Enoch Powell introduced the Unborn Children (Protection) Bill which would have prohibited destructive experimentation on human embryos. The Bill passed its first reading with a large majority (238 to 66).[15] This vote caused alarm among supporters of IVF and led directly to the establishment of the "Progress Campaign for Research into Human Reproduction." The Campaign had but one aim: "to make sure that human embryo research was protected by law so that IVF treatment could continue."[16]

According to Fritz Schumacher, "progress . . . can be said to be an essential feature of all life. The whole point is to determine what constitutes progress."[17] Nevertheless, the rhetorical force of the term "progress" in political discourse typically functions to beg this question. The word implies,

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[13] Jon Agar, "Thatcher, scientist," *Notes and Records of the Royal Society* 65.3 (2011): 215-232.
[14] Mary Warnock (chair) *Report of the committee of inquiry into human fertilization and embryology*, London: HM Stationery Office, 1984.
[15] Hansard HC Deb 15 February 1985 vol 73 cc637-702, see also Michael Mulkay, "Political parties, parliamentary lobbies and embryo research," *Public Understanding of Science* 4.1 (1995): 31-55.
[16] Progress Educational Trust: "About us: Background" http://www.progress.org.uk/background
[17] E.F. Schumacher, *Small is Beautiful* (London: Vintage, 1993 [original 1973]), 130.

insinuates, or at least suggests, that technical innovation leads necessarily to real benefits for individuals and for society. It is precisely for these connotations that the "Progress Campaign for Research into Human Reproduction" was so named. The name implies that to oppose experimentation on human embryos is to oppose "progress".

It is not true, as some have asserted, that efforts to prohibit embryo experimentation in 1985 were "very nearly successful."[18] The size of the majority is in this respect deceptive. Most MPs had not taken part in the vote and Private Member's Bills which are at all contentious "have little chance of passage without the aid of Government."[19] It is a simple matter to talk such bills out of time. The problem for the government was that it was not enough to block all such attempts at prohibition. To implement the recommendations of the Warnock Committee the government would need to bring forward its own bill, and such a bill would be open to amendment by members of parliament. The strategy of the government was therefore to delay the introduction of legislation until it was confident that it had the backing of sufficient MPs. To achieve this, the government needed the help of scientists and campaigning organisations to shift public opinion, to reframe the dominant narrative presented by the media, and to lobby MPs. The founding of the Progress Campaign was the beginning of a long history of co-operation, sometimes overt, sometimes tacit or even covert, between government departments, scientific bodies, and lobby groups to secure the practice of embryo experimentation in the United Kingdom.

By 1990 a sustained media campaign, and work both alongside and independent of the government, had shifted opinion within Parliament. A major media boost was the story of the first successful pregnancy after sex-selection to prevent the inheritance of a sex-linked genetic disease.[20] This reinforced the image of the technology as beneficial for parents at the same time as showing the UK at the cutting edge of scientific innovation. In the lead-up to the final vote the Progress Campaign arranged for 200 families affected by genetic disease to visit parliament and, as a result of such activities, "in the crucial debates in late 1989 and early 1990, 75 per cent of those arguing for embryo research made significant reference to its potential contribution to the prevention of genetic disorder."[21]

In the final vote in the House of Commons on 21 June 1990, the Human Fertilisation and Embryology Act 1990 was passed comfortably by 303 to 65.[22] The two main political parties allowed their MPs a "free vote" but this political luxury was permitted in part because the outcome was not in doubt. The bill had cross-party support and a clear steer in favour from the front benches both of the government and of the official opposition. The passing of this Act effectively fixed UK policy on human embryo experimentation and related issues for the next quarter of a century. In 1992, in recognition that the single aim of the Progress Campaign had substantially been achieved, but also that it had been achieved only through very active media engagement, the Campaign gave way to a new organisation: the Progress Educational Trust. This was the body that hosted the London conference in 2015.

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[18] Emily Jackson, *Regulating Reproduction: Law, Technology and Autonomy* (Oxford: Hart, 2001), 183. Echoed by the Progress Educational Trust, "Background".

[19] D. Marsh, P. Gowin, and M. Read,. "Private member's bills and moral panic the case of the video recordings bill (1984)". *Parliamentary Affairs* 39 (1986): 179- 190 cited by Mulkay "Political parties", 33.

[20] A.H. Handyside, E.H. Kontogianni, K. Hardy, and R.M. Winston, "Pregnancies from biopsied human preimplantation embryos sexed by Y-specific DNA amplification," *Nature* 344 (1990): 768–770.

[21] Michael Mulkay, *The Embryo Research Debate: Science and the Politics of Reproduction* (Cambridge: Cambridge University Press, 1997), 63.

[22] Hansard HC Deb 21 June 1990 vol 174 cc1178-224

Over time the settlement represent by the Human Fertilisation and Embryology Act 1990 has become only more deeply entrenched. Scientific developments and legal challenges have led to the passing of further regulations (especially in 2001 and 2015), and to one major revision of the Act (in 2008), but these have all occurred within the frame established by the 1990 Act. These developments have not represented a change in direction but rather a further extension of the approach taken by the Act.

The approach of UK legislation may be characterised as bureaucratic permissiveness ornamented by cosmetic prohibitions. The law is designed to have an inclusive scope for the activities referred to, so that all experimentation on human embryos falls within its remit. Within this, the law grants permission for a very broad range of research and treatments, but only under licence. On the other hand it prohibits absolutely only those activities which have little or no support from scientific bodies. Hence such prohibitions are cosmetic, intended to give public reassurance without restricting any action for which there is scientific support. The changes that have occurred since 1990 have not altered this pattern but have only widened the scope of the Act and increased the number and kinds of controversial activities permitted under licence.

Currently germline gene therapy of human beings by means of gene editing is prohibited by the Human Fertilisation and Embryology Act 1990 (as amended 2008). This is simply because hitherto bodies representing scientists have not expressed interest in pursuing this activity. Genome editing in the context of reproduction would require a further amendment of the 1990 Act. Nevertheless, such an amendment would conform to an established pattern of previous incremental extensions of the law. Debate on this issue is therefore almost certain to follow the same contours as previous debates.

Divergences in development

It is helpful at this point to compare the development of UK legislation with the formation of policy on embryo research in the USA. Prima facie it might seem that the context for such policy was very similar. Both Great Britain[23] and the United States have permissive regimes for abortion which have remained unchanged in their fundamentals for over forty years (since 1967 and 1973 respectively). Similarly, in both countries in vitro fertilisation is widely available and scientists are permitted not only to use but also to create human embryos for research purposes. In both countries the national legal and policy approach for embryo experimentation has been shaped by the previous settlement on abortion. However, it is precisely this similarity that reveals a deeper dissimilarity.

The fundamental rationale for the liberalisation of abortion law in Britain was utility or harm reduction both in relation to the woman and to society. Hence the law requires that two doctors certify a quasi-medical indication for termination of pregnancy. These indications include not only a risk of injury to the physical or mental health of the mother but also a "substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped."[24]

The explicit inclusion of disability as an indication for abortion reflects a eugenic mentality that runs deep in the British psyche (though certainly, it is not always overt). Indeed, the term "eugenic" was

[23] The United Kingdom includes Great Britain and Northern Ireland and but the Abortion Act 1967 does not apply in Northern Ireland, hence in relation to abortion policy it is more accurate to refer to Great Britain rather than to the UK.

[24] Abortion Act 1967 (as amended 1990) section 1(1)(d)

coined by an Englishman, Francis Galton, in 1883.[25] So too the First International Eugenics Congress occurred in London in 1912.[26] The eugenics movement in England also attracted support from some prominent members of the established Church, perhaps most prominently Rev William Inge, Lady Margaret's Professor of Divinity in Cambridge and later Dean of St Paul's Cathedral. He was a founder member of the Eugenics Education Society in 1907.[27] An important element to the background of the Abortion Act 1967 was public sympathy for the victims of thalidomide. The drug, prescribed for morning sickness, was introduced in the UK in 1958 and in use until 1961. It was withdrawn following reports that it caused children to be born with limb deficiencies and a variety of other disabilities. According to advocates of abortion "thalidomide was the motor that reinvigorated the Abortion law Reform association and which paved the way for reform."[28] Support for eugenic abortion thus helped secure support for the bill as a whole.

The passing of the Human Fertilisation and Embryology Act 1990 followed a similar pattern. Support for this law was also based on the utility of IVF, both as a treatment of infertility and for the control of genetically inherited disease. As with the Abortion Act 1967, the eugenic possibilities of this technology *increased* political support for the law.[29] Also, as with the Abortion Act, while destruction of unborn life was permitted on the basis of supposed utility, the law also required particular authorisation (from two doctors in the case of abortion or from the licensing authority in the case of embryo experimentation). These laws are permissive but within limits: cases that fall clearly outside the respective laws are prohibited.[30]

Both Britain and the USA both have very permissive regimes on abortion, effectively allowing abortion for any reason until 24 week (in Great Britain) or 26 weeks (in the USA) and allowing abortion until birth in some circumstances (not limited to cases where the mother's life is in danger). In this respect they have more in common with one another than they do with most European jurisdictions, and represent the far extreme from the more restrictive legislative approach that predominates in South America or Africa. However, in relation to the mechanism, rationale, and public support of legalisation, Britain and the USA are radically different.

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[25] Francis Galton, *Inquiries into Human Faculty and Its Development* (London, England: Macmillan and Co., 1883)

[26] "First International Eugenics Congress" *Br Med J* 2 (3 August 1912): 253.

[27] William R. Inge, "Some Moral Aspects of Eugenics," *Eugenics Review* 1.1 (April 1909): 26–36. See also William R. Inge, "Eugenics and Religion," *Eugenics Review* 12.4 (January 1921): 257–65; F. Hale, "Debating the New Religion of Eugenics," *Heythrop Journal* 52.3 (2011): 445–57; David Albert Jones "Apostles of Suicide: Theological Precedent for Christian Support of 'Assisted Dying'," *Studies in Christian Ethics* 29.3 (2016): 331–338. Other prominent Christian eugenicists in this period include Ernest Barnes, the Anglican Bishop of Birmingham, see T. Merricks, "'God and the Gene': E.W. Barnes on Eugenics and Religion," *Politics, Religion & Ideology* 13.3 (2012): 353–74.

[28] K. Hindell and M. Simms, *Abortion Law Reformed* (London: Peter Owen, 1971), 108 cited in David Albert Jones, *The Soul of the Embryo: An Enquiry into the Status of the Human Embryo in the Christian Tradition* (London: Continuum, 2004), 204.

[29] For example, the most prominent opposed of embryo experimentation, Enoch Powell, was neverthless a strong supporter of eugenic screening, see Anastasia A. Theodosiou, and Martin H. Johnson, "The politics of human embryo research and the motivation to achieve PGD," *Reproductive biomedicine online* 22.5 (2011): 457-471.

[30] In relation to abortion, however, there is often little interest in enforcing such prohibitions even where they exist. For example, the sex of a child is not a legal basis for abortion in the United Kingdom (except where the child carries a sex-linked disease) and yet when abortions have been performed explicitly to avoid giving birth to a girl, doctors have not been prosecuted.

In Britain legalisation of abortion was by Act of Parliament. The Act had a large degree of parliamentary and public support and the rationale was primarily harm reduction. The rhetoric of choice, self-determination and privacy had relatively little influence either in the public debate or in the final shape of the law. In contrast abortion was legalised in the USA not by a positive law endorsed by democratic process and supported by the public but by a judgement of the Supreme Court which declared existing restrictions on abortion to be unconstitutional.[31] The basis of this decision was not utility, harm reduction or "reproductive health" but privacy and freedom from state coercion. An important implication of this rationale is that, while States are not permitted to outlaw the practice of abortion, they have no constitutional duty to provide abortion, and the Hyde Amendment of 1976, which restricted federal funding for abortion, was upheld by the Supreme Court in 1980.[32]

When, in 1979, the US Ethics Advisory Board (EAB) considered "Research Involving Human In Vitro Fertilization and Embryo Transfer",[33] the question was therefore not whether embryo experimentation should be permitted but whether embryo experimentation should receive federal funding. In contrast to Margaret Thatcher, Ronald Reagan, who came to power in 1981, was opposed to destructive experimentation on human embryos and so the recommendations of the EAB were side-lined, a policy maintained by President George HW Bush. President Bill Clinton publicly expressed support for funding research on "surplus" embryos but nevertheless signed into law the Dickey-Wicker Amendment in 1995 which denied public funds to research in which the embryo was destroyed. The issue of federal funding for embryo experimentation, and for experimentation that presupposed embryo destruction, became contested only after stem cells were derived from human embryos in 1998. However, the issue was successfully evaded by Clinton, leaving it to his successor, President George W Bush to be the first President to provide federal funds for experimentation that presupposed embryo destruction, albeit not to the extent that his critics wished.[34]

While the theory of eugenics was developed in the United Kingdom, it was not applied in practice in Britain in the 1920s and 1930s, in part because of the vocal opposition of G.K. Chesterton[35] and others, but more importantly (in political terms) because of its associations with Prussian Nationalism.[36] In contrast, the United States is one of a few countries to develop large scale programmes of eugenic sterilisation.[37] Perhaps for this reason, eugenic considerations played little

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[31] *Roe v. Wade*, 410 U.S. 113 (1973).

[32] *Harris v. McRae*, 448 U.S. 297 (1980).

[33] Ethics Advisory Board, *Report and Conclusions: HEW Support of Research Involving Human In Vitro Fertilization and Embryo Transfer* (Washington DC: Department of Health, Education, and Welfare, 1979); See also Thomas Banchoff, *Embryo Politics: Ethics and Policy in Atlantic Democracies* (Ithaca NY: Cornell University Press, 2011), 35-40.

[34] See O. Carter Snead, "The Law and Politics of Embryo Research in America," *Human Reproduction and Genetic Ethics* 17.1 (2011): 40–52, also Thomas Banchoff *Embryo Politics*, 175-181.

[35] G. K. Chesterton, *Eugenics and other evils* (London: Cassell and Co., 1922).

[36] A point brought out by Chesterton: "It has gradually grown apparent, to my astounded gaze, that the ruling classes in England are still proceeding on the assumption that Prussia is a pattern for the whole world. If parts of my book are nearly nine years old, most of their principles and proceedings are a great deal older. They [the eugenicists] can offer us nothing but the same stuffy science, the same bullying bureaucracy and the same terrorism by tenth-rate professors that have led the German Empire to its recent conspicuous triumph." *Eugenics and other evils*, preface.

[37] See, for example: Edwin Black, *War against the Weak: Eugenics and America's Campaign to Create a Master Race*, (New York: Four Walls Eight Windows, 2003); Paul A. Lombardo, ed., *A century of eugenics in America: from the Indiana experiment to the human genome era* (Bloomington IN: Indiana University Press, 2011);

or no part in shaping the Supreme Court judgements on abortion or the subsequent debates over funding for abortion and for embryo experimentation. It is notable that while various iterations of the Hyde Amendment have permitted federal funding for abortion in exceptional circumstances, such as rape, incest and danger to the mother's life, the disability of the child has never been included as a reason for funding abortion.

It seems that the "shameful era"[38] of compulsory eugenic sterilisation in the USA has at least helped American commentators to acknowledge the possibility that eugenic ideas can reinforce discrimination and lead to new forms of injustice, even in a democracy. In contrast, there is little awareness in a UK context of the role England played in promoting eugenics and its associated historical injustices. Hence, while the international summit in Washington included prominent reflection on the history of eugenics,[39] the subject was only mentioned in the London conference in passing, and then through a question from the floor.[40]

From a Catholic perspective there are fundamental problems with the framing of the debate both in the United States and in Britain. The history of debate over abortion and embryo experimentation in the United States has led to a focus on the question of federal funding rather than on the possibility of legal prohibition. Such a frame is not conducive to assessing the arguments for the prohibition of, or even a moratorium on, certain forms of research even when this would clearly be beneficial. The approach of the United Kingdom appears at least to be concerned with the right question, which is whether certain forms of activity should be prohibited or permitted (not merely whether or not they should be funded). On the other hand, the law in Britain is much more overtly favourable to eugenic interventions, whether by selective abortion or by screening out of human embryos. The model provided by UK legislation has as its default setting the legal permissibility of controversial research and treatment, subject to licence. Thus, while American and British models of addressing embryo experimentation differ, neither is adequate to the issue of justice to the human embryo and neither is helpful in a situation where a prohibition seems the most effective measure to secure the common good. In this respect the model provided by German,[41] and to a lesser extent the models in France [42] and in Italy,[43] while each imperfect, are more adequate to principles of justice and the dignity of the human embryo.

Calum MacKellar, and Christopher Bechtel, eds., *The ethics of the new eugenics* (Oxford: Berghahn Books, 2014); A.G. Winfield, *Eugenics and education in America: Institutionalized racism and the implications of history, ideology, and memory* (New York: Peter Lang, 2007).

[38] Michael G. Silver, "Eugenics and compulsory sterilization laws: Providing redress for the victims of a shameful era in United States history," *Geo. Wash. L. Rev.* 72 (2003): 862.

[39] Daniel J. Kevles, "The History of Eugenics" in *International Summit on Human Gene Editing, A Global Discussion: Commission Papers*, (Washington DC: US National Academies of Sciences, Engineering and Medicine, Chinese Academy of Sciences and the Royal Society, 2015), 9-11.

[40] See Sarah Pritchard, "Why the UK should be leading the discussion on embryo engineering" *Bionews* 834 (11 January 2016) http://www.bionews.org.uk/page_603809.asp

[41] Herbert Gottweis, "Stem cell policies in the United States and in Germany," *Policy Studies Journal* 30.4 (2002): 444-469. Jan P. Beckmann, "On the German debate on human embryonic stem cell research," *Journal of Medicine and Philosophy* 29.5 (2004): 603-621. See Banchoff *Embryo Politics*, 97-106.

[42] Stéphane Viville, and Yves Ménézo, "Human embryo research in France," *Human Reproduction* 17.2 (2002): 261-263; Giovanni Maio, "The embryo in relationships: a French debate on stem cell research," *Journal of Medicine and Philosophy* 29.5 (2004): 583-602. See Banchoff *Embryo Politics*, 106-119.

[43] Laura Palazzani, "Embryo Research in Italy: The Bioethical and Biojuridical Debate," *Human Reproduction and Genetic Ethics* 17.1 (2011): 28–39.

Public engagement as 'strategic public relations'

In relation to human gene editing technology the primary danger in the United States is not governmental or professional action but is rather a lack of action. By default, what is not prohibited is permitted, and debates about federal funding will not prevent clinicians offering gene editing technology where there is a market for this. In contrast, in the United Kingdom, germline gene editing is currently illegal and will remain so unless the law changes. However, the pattern of government intervention has consistently favoured extension of the law in favour of further genetic control over reproduction.

In this context, it is hard to overemphasise the prestige that biotechnology, and especially embryo experimentation and reproductive technologies, has enjoyed in the eyes of successive British governments. While Britain may have lagged behind other countries in space exploration and in other scientific projects requiring very high levels of government spending, it can boast not only the discovery of the double helix structure of DNA in 1953 but the first child born after IVF in 1978, the first children born following pre-implantation genetic diagnosis in 1990 and the first cloned mammal in 1997. In 2007 a British scientist, Martin Evans, shared a Nobel Prize for his work on embryonic stem cells.

Successive governments are also proud of the way government policy overcame public concerns about this technology after a long period of engagement including co-ordination with non-government actors culminating in the Human Fertilisation and Embryology Act 1990. Unlike the situation in USA, the ethical acceptability of abortion and embryo experimentation is not a matter on which public opinion is finely divided or a matter on which the two main political parties differ substantially. In the UK, governments of the right and of the left have sought to maintain the status quo on abortion and have shown strong support for embryo experimentation. Those who express principled opposition to such practices do so from the political margins.

The 1990 Act not only established the Human Fertilisation and Embryology Authority (HFEA) as the vehicle for maintaining public trust. It also established a pattern of public engagement that was pro-active, strongly directed towards securing a desired policy goal, and more-or-less co-ordinated between government and non-governmental bodies. Having been successful in achieving the legal settlement this approach became a model for future public engagement by the government, the HFEA, and other actors. This approach is well analysed by the Canadian bioethicist Francoise Baylis, remarking of a particular consultation by the HFEA that it showed "a clear policy preference in support of research …[and that], in many respects, the HFEA consultation process can be seen as an exercise in strategic public relations".[44]

This model of "strategic public relations" is also evident in the purported rationale of the Act, for it achieved its aim *under the guise of doing precisely the opposite*. The effective political rationale for the Act, well-expressed by the Progress Campaign was "to make sure that human embryo research was protected by law",[45] that is, to protect practices that involve destroying human embryos. However, the purported rationale of the Act was to uphold the "special status" of the human

[44] Françoise Baylis, "The HFEA Public Consultation Process on Hybrids and Chimeras: Informed, Effective, and Meaningful?" *Kennedy Institute of Ethics Journal* 19.1 (2009): 41–62, 47. For similar comments in relation to the House of Commons Science and Technology Committee see Pauline Gately, "The Commons Science and Technology Committee inquiry into hybrid embryo research 2007: credible, reliable and objective?" *Human Reproduction & Genetic Ethics* 17.1 (2011), 84-109.

[45] Progress Educational Trust, "Background".

embryo. It has become customary to repeat this supposed rationale each time the Act is revisited, for example:

> The starting point for consideration of the ethics of research on human embryos is the status of the early embryo.[46]
>
> We have concluded that the embryo should be accorded special status in common with the Warnock Committee.[47]
>
> We acknowledge that the special status of the embryo means regulation of both research and treatment continues to be appropriate and desirable.[48]

I have argued elsewhere that for this reason UK policy on human embryo research is disingenuous at a fundamental level. The claimed "special status" of the human embryo disguises a purely instrumentalist view of the embryo and, what is more, a purely instrumentalist view of public engagement. Discussion of the status of the human embryo is, in reality, "a cipher for other concerns, principally the maintenance of public confidence."[49]

Sometimes in international discussion the UK presents itself as a moderate middle way between the deregulation of countries such as the United States and the restrictive approach of some European nations. The analysis presented here shows that this is misleading. The UK is not somewhere in the middle but rather at the most extreme position both in what is permitted by law and in relation to aggressive pursuit of novel forms of embryo experimentation. In a UK context, regulation is thus supported not because it inhibits or restricts experimentation on human embryos but precisely because it helps facilitate such experimentation. It is "deregulation via regulation".[50] This explains the pattern of British engagement, both governmental and non-governmental, in international discussions of embryo experimentation or genetic engineering. The attitude of the US government in such discussions varies depending on the administration in power whereas the attitude of the UK government is consistently the most vocal in opposing international restrictions on embryo experimentation or genetic engineering.[51]

This approach to public engagement is by no means unique to bioethical issues. It is an established trope in British political life. So often, neither the final decision nor the overall direction of travel will genuinely be open to revision. The decision will have been made in advance and "consultation" will not be directed to criticism or improvement of a proposal but to persuasion of the consultees. Such a pattern of practice exemplifies an elitist and anti-democratic aspect of British political life that

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[46] Select Committee of the House of Lords, *Stem Cell Research* (London: HMSO, 2002), 4.4.
[47] House of Commons Science and Technology Committee, Fifth Report of Session 2004-05. *Human Reproductive Technologies and the Law. Vol.I* (London: HMSO., 2005), para. 49.
[48] Joint Committee on the Human Tissue and Embryos (Draft) Bill. *Report Volume I, HL Paper 169-I and HC Paper 630-I,* (London: HMSO., 2007), para. 105.
[49] David Albert Jones, "The 'Special Status' of the Human Embryo in the United Kingdom: An Exploration of the Use of Language in Public Policy," *Human Reproduction and Genetic Ethics* 17.1 (2011): 66–83, 80.
[50] Svea L. Herrmann, "Deregulation via Regulation: On the Moralisation and Naturalisation of Embryonic Stem Cell Research in the British Parliamentary Debates of 2000/2001." *Österreichische Zeitschrift für Politikwissenschaft* H.2 (2003): 149–61, cited by Jones "'Special Status' of the Human Embryo", 77.
[51] See, for example, Jones "'Special Status' of the Human Embryo", 68.

remains within its democratic processes. Were it to be made explicit as a philosophy it would perhaps be what Bernard Williams has termed "government house utilitarianism".[52]

Un-Wellcome influence

Another difference between the UK and the USA is the great influence in the UK context of a few nongovernmental funding bodies which have become politicised. This is true of some medical research charities but most especially of the Wellcome Trust, the UK's largest non-governmental source of funds for biomedical research, with an endowment currently worth more than £18 billion.[53]

In the proposed revision of the Human Fertilisation and Embryology Act in 2008, perhaps the most controversial proposal was to legalise the creation of admixed (or hybrid) human-nonhuman embryos. The Wellcome Trust was strongly in favour of this change in the law and engaged actively with the media and with politicians to promote this aspect of the bill. According to Dr Mark Walport, the Director of the Trust at that time, "We wanted to explain both the need for research, and the science underlying the proposals, including the creation of hybrid embryos… work with the media on the issue began many months prior to the publication of the actual Bill. This ensured that the press was ready to respond when controversy arose."[54]

An important mechanism for this "work with the media" was the Science Media Centre, itself part-funded by the Wellcome Trust. The Science Media Centre was founded "to provide accurate, independent scientific information for the media" but in practice "its views are largely in line with government scientific policy."[55] The Wellcome Trust also worked closely with the Medical Research Council, the Association of Medical Research Charities, and the Academy of Medical Sciences, as well as with individual scientists and journalists. In addition, Mark Walport, as Director of the Trust, himself frequently spoke to the media and issued press statements. Characteristically these statements appealed to the prestige of embryo experimentation and emphasised the alleged consensus of "the scientific community" in favour of this particular avenue of research.

> The award of the 2007 Nobel Prize in Physiology or Medicine to Martin Evans and colleagues signals the strength of the UK in embryo and stem cell research. It is therefore timely that Government has now taken on board the concerns of the scientific community in its response to the Joint Committee Report.[56]

As with previous government sponsored embryo-related legislation, the 2008 revision of the Human Fertilisation and Embryology Act passed comfortably (by 355 to 129).[57] However, it is far from clear that the intense campaigning in favour of the 2008 Act succeeded in "achieving an informed public

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[52] Bernard Williams, *Utilitarianism For and Against* (Cambridge: Cambridge University Press, 1983), 139, cited by Jones "'Special Status' of the Human Embryo", 78.
[53] The Wellcoem Trust, "About us: Investments" https://wellcome.ac.uk/about-us/investments
[54] Mark Walport, "Beyond soundbites: the research funder's view" in *Hype, hope and hybrids: Science, policy and media perspectives of the Human Fertilisation and Embryology Bill* ed. Geoff Watts (London: Academy of Medical Sciences/ Medical Research Council / Science Media Centre/ Wellcome Trust, 2009), 34.
[55] John Crace "Peer trouble: How failsafe is our current system at ensuring the quality and integrity of research? Not Very" *The Guardian,* 11 February 2003.
[56] Science Media Centre, "Scientists react on Government's response to the Joint Committee on Human Tissue and Embryos (draft) Bill" Press release (8 October 2007) http://www.sciencemediacentre.org/scientists-react-on-governments-response-to-the-joint-committee-on-human-tissue-and-embryos-draft-bill-2/
[57] Edward White, "Human Fertilisation and Embryology Bill - What Happened?" Commons Library Standard Note SN/SC/4886 (11 November 2008).

debate". [58] Analysis of the media reporting[59] shows that, of over 100 newspaper reports analysed, 72% included some exaggerated or misleading scientific claims, for example, that the research aimed to "cure" or "provide treatment" for certain named diseases, or that it was to "save lives". Indeed, 22% of these reports made claims that were clearly unfounded, for example, asserting that such research "is necessary" to make medical progress or that patients "will benefit" if the research goes ahead, for example, "for illnesses like motor neurone disease, hybrid embryos *will make* a huge difference."[60]

Having convinced of the public of the great and urgent scientific "need" for creating hybrid embryos, it came as a shock to many when, even before the Act came into force, this avenue of research was abandoned by the only teams in the UK working in this area. The research had failed to secure funding through the process of scientific peer review. The pubic were unprepared for this as only 18% of news reports about the research acknowledged that there were scientific reservations about the techniques and only 8% mentioned that there were alternative avenues of research being developed.[61] While the expenditure of funds and of time and energy by the Wellcome Trust and other funding bodies were successful in winning the media battle and the parliamentary vote to allow hybrid embryo experimentation, it would seem that, "this victory was won largely at the expense of the public understanding of science."[62]

It is not only critics of embryo experimentation who have expressed misgivings about the influence of the Wellcome Trust in shaping policy on biomedical research in the United Kingdom. Professor Marcus Pembrey, a founder of the Progress Educational Trust and at one time a principal investigator of the Wellcome Trust Case Control Consortium gave the following evidence to the House of Lords Select Committee on Science and Technology:

> Increasingly—by default—the Wellcome Trust is having a disproportionate influence on policy and yet is answerable to just a few governors. With its huge financial resources the Wellcome Trust has become the major lead on research in genomic medicine and this has led to the WT trying to dictate policy in a number of areas… [sometimes] naively, in my opinion…[63]

Another instance of the Wellcome Trust appearing to "dictate policy" is in relation to maternal spindle transfer (MST) and pro-nuclear transfer (PNT) to prevent transmission of mitochondrial disease. These techniques, together termed "mitochondrial donation" by the government[64] but popularly described as "three parent IVF"[65] had been included in the Human Fertilisation and

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[58] Walport, "Beyond soundbites", 34.
[59] David Albert Jones, and Pauline Gately, "Over-egging your cybrid: Newspaper coverage of the scientific debate over cytoplasmic hybrids" Poster presentation at Cesagen/ ESRC Genomics Network Conference *Mapping the Genomic Era: Measurements and Meanings*, 7-9 October 2009.
[60] J. Randerson, F. Schlesinger, J. Adetunji, and P. Dominiczak "Ethical concerns in embryos bill divide MPs: Significant numbers still undecided on key issues" *The Guardian* 12 May 2008.
[61] Jones and Gately, "Over-egging your cybrid".
[62] Jones and Gately, "Over-egging your cybrid".
[63] Marcus Pembrey "Memorandum by Professor Marcus Pembrey FMedSci" in House of Lords Science and Technology Committee *2nd Report of Session 2008–09: Genomic Medicine* Volume II, HL Paper No 107–II, 561-563.
[64] The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015; See also S. Barber, and P. Border, "Mitochondrial donation", Commons Library Standard Note SN06833 (29 January 2015).
[65] Referred to as "three-parent" In the "vast majority of cases" of media reports according to R. Watermeyer, and G. Rowe, *Evaluation of Human Fertilisation and Embryology Authority (HFEA): mitochondrial*

Embryology Act 2008 as a possible subject for future regulations.[66] The process of consultation in preparation for such regulations began in 2012. However, the events of 19 January 2012 seemed to betray a level of choreography in the actions of supposedly independent bodies. In the first place the Secretaries of State for Health tasked the Human Fertilisation and Embryology Authority to seek public views on these techniques.[67] On the very same day, the Nuffield Council on Bioethics announced that it would conduct its own ethical review of the techniques.[68] Finally, also on the same day, the Wellcome Trust announced its decision to grant £4.4 million in funding to a centre to carry out research in this area.[69]

This apparent co-ordination was particularly troubling given that the Wellcome Trust is one of the three major funders of the Nuffield Council on Bioethics.[70] The coincidence of these announcements creates the impression of the Wellcome Trust was not only laying down the agenda for the Council but presenting the Council with a fait accompli, an ethical review after the fact of research that the Trust had already, very publicly, agreed to fund.

The Nuffield Council on Bioethics duly produced a report that was supportive of MST and PNT. This report was used to frame the HFEA consultation and together these helped smooth the way for the passing of the Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015.[71] As in previous cases, the Regulations were passed by a large majority.[72] However, by endorsing the research funded by its own funder, without declaring an interest, the Nuffield Council "undermine[d] the credibility of its conclusion and threaten[ed] the reputation of the Nuffield Council for independence."[73] In effect, the national bioethics committee appeared to be used by a funding body as an instrument of public policy.[74]

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replacement consultation (Cardiff UK and Norwich UK: Human Fertilisation and Embryology Authority, 2013), 78. On the resistance to "three parent" language by government, scientists and lobby groups see Caroline Jones, and Ingrid Holme, "Relatively (im)material: mtDNA and genetic relatedness in law and policy," *Life sciences, society and policy* 9.1 (2013): 1. For a defence of "three parent" language see David Albert Jones "The other woman: Evaluating the language of 'three parent' embryos," *Clinical Ethics* 10.4 (2015): 97–106. For a critique of the language of mitochondrial donation see also Françoise Baylis, "Human Nuclear Genome Transfer (So-Called Mitochondrial Replacement): Clearing the Underbrush." *Bioethics* 31.1 (2017): 7-19.

[66] Human Fertilisation and Embryology Act 1990 as amended, Section 35A

[67] Department of Health, and Anne Milton, "Government to seek public views on changing the law to find cures for inherited diseases" Press Release 19 January 2012 https://www.gov.uk/government/news/government-to-seek-public-views-on-changing-the-law-to-find-cures-for-inherited-diseases--2

[68] Nuffield Council on Bioethics, "Call for evidence on mitochondrial donation," Press Release, 19 January 2012 http://nuffieldbioethics.org/news/2012/call-for-evidence-on-mitochondrial-donation/

[69] The Wellcome Trust, "Techniques to prevent transmission of mitochondrial diseases to be assessed in new £5.8 million Wellcome Trust centre," Press Release, 19 January 2012 http://www.wellcome.ac.uk/News/Media-office/Press-releases/2012/WTVM054145.htm

[70] Nuffield Council on Bioethics, "About: Funding," http://nuffieldbioethics.org/about/how-council-funded/

[71] HFEA, "Statement on mitochondrial donation," Press Release, 24 February 2015 http://www.hfea.gov.uk/9606.html

[72] On 3 February 2015 by 382 votes to 128, http://www.parliament.uk/business/news/2015/february/commons-debate-statutory-instrument-on-mitochondrial-donation/

[73] David Albert Jones, "Invited response to the Nuffield Council on Bioethics report, 'Techniques to prevent the transmission of inherited mitochondrial DNA disorders: ethical issues'" Grand Committee Room, Palace of Westminster, 12 June 2012.

[74] On the threat of such instrumental use to bioethics bodies more generally, see Heather Strange, *Non-invasive prenatal diagnosis and testing: perspectives on the emergence and translation of a new prenatal*

Given the extent of Wellcome Trust involvement in shaping embryo policy in the UK in the last decade, it is not surprising that, on the question of human genome editing, the Trust has already undertaken proactive steps to fund "a number of initiatives in this space and [is] actively participating in discussions in the UK, Europe and globally".[75] These initiatives include funding for the Washington summit and working group set up by the US National Academies, as well as for the Progress Educational Trust[76] and ongoing funding for the Nuffield Council on Bioethics.

While the Welcome Trust states that it "strongly supports open and inclusive discussions", it already expresses support for "gene editing in a research context" where this is legal and is "ethically and scientifically justified".[77] Since 2008 the law in the UK has permitted the genetic modification of human embryos for research, subject to a licence, so such research would now be "legal" in the UK. The standard for what is deemed "ethically and scientifically justified" may be gauged by the strong public support that the Wellcome Trust provided to the proposal to use hybrid embryos in research, even though this proposal raises serious ethical questions[78] and was eventually abandoned because it did not pass the test for funding by anonymous scientific peer review.[79]

It certainly seems from these statements that the Wellcome Trust is signalling its opposition to the call for a moratorium on gene editing of human embryos in a research context. This would hardly be surprising as this stance would cohere with the dominant policy approach pursued in the UK since 1990. In the words of Sarah Norcross, director of the Progress Educational Trust, "banning is not the answer",[80] a conclusion about "the answer" that is asserted with confidence even before the adequate articulation of the question. There are prohibitions on certain forms of embryo experimentation in UK law but, it has been argued here, these are cosmetic, intended not to restrict research activity but to give a reassuring impression to the public. If the Wellcome Trust is perceived to be taking a position against a moratorium, it will be interesting to see whether the working group

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testing technology. Unpublished PhD Thesis, Cardiff University, 2015: "Although bioethics may tell 'a heroic story about its origins and purpose' it has been suggested that mainstream bioethical approaches may have come to be so closely aligned with political and regulatory processes that the field has 'moved from occupying the perspective of a critical outsider to enjoying the status of a respected insider, whose primary role is to defend existing institutional arrangements and its own privileged position'" (Strange, Non-invasive prenatal diagnosis, 109 citing Rachel Haliburton, *Autonomy and the Situated Self: A Challenge to Bioethics* (Lanham MD: Lexington Books, 2013), 1.

[75] The Wellcome Trust, "What we do: Our work: Gene editing in research," https://wellcome.ac.uk/what-we-do/our-work/our-policy-work-gene-editing

[76] Funding for the Progress Education Trust is not explicitly mentioned on the Wellcome website among its "initiatives in this space". However, the most recent annual report from Progress (up to March 2015) expresses gratitude "for grant funding received from the Wellcome Trust which contributed to the significant increase in incoming resources [up 65% in comparison to the previous financial year]". Of this funding, "part is to be utilised in the next financial year" i.e. the year of the December 2015 conference on "three person IVF" and genome editing (Progress Educational Trust, "Trustees' Report for the year ended 31 March 2015," http://www.progress.org.uk/trusteesreport2015).

[77] Wellcome Trust, "Gene editing in research".

[78] David Albert Jones, "Is the creation of admixed embryos 'an offense against human dignity'?" *Human Reproduction & Genetic Ethics* 16.1 (2010): 87-114; Calum Mackellar, and David Albert Jones, *Chimera's Children: Ethical, philosophical and religious perspectives on human-nonhuman experimentation* (London and New York: Continuum, 2012).

[79] Ian Sample, "Rival Stem Cell Technique Takes the Heat out of Hybrid Embryo Debate: Stem cell Scientists Reject Claims that Grant Applications to Create Hybrid Embryos Were Turned Down for Ethical Reasons," *The Guardian*, 13 January 2009.

[80] Sarah Norcross, "Genome editing raises complex issues – banning it is not the Answer," *The Guardian* 6 September 2015.

of the Nuffield Council, an organisation that is part-funded by the Wellcome Trust, chooses to follow that lead.[81]

A study in contrasts

The different content and approach of the conferences on gene editing in Washington and London reveals features about the bioethics landscape in the two countries. One difference that is immediately apparent is that the summit in Washington was international, and indeed was advertised as such. It drew on knowledge and experience not only from the USA, the UK, and China (the sponsoring academies), but also Canada, Egypt, Israel, Korea, Nigeria and a number of countries in Europe.[82] In contrast, the conference in London included not one speaker based outside the UK.[83] This reflects a common pattern: the Progress Educational Trust annual conference for 2016 also includes no speakers from outside the UK.[84] Given this insularity, it is remarkable that a number of speakers at the London conference extolled the virtues of the system of regulation in the UK as a model for other countries.

Related to this difference in perspective is a difference in tone. The tone of the Washington summit is perhaps best exemplified by the contribution of Eric Lander:

> Bottom line: My prescription is humility. It is always good to remind ourselves, especially when we have in our hand an amazingly powerful tool like CRISPR gene editing, that we exist in a state of very limited knowledge, and human genetic disease is complex. We still have a lot to learn, and it might, might, might be a good idea that—before we make permanent changes to the human gene pool—we should exercise considerable caution.[85]

In contrast the tone of the London conference was often self-congratulatory, for example in arguing that the UK was "the best place" for "mitochondrial donation"[86] and that the UK should "lead the way in the debate about genome editing of human embryos".[87] Furthermore, any note of caution was immediately qualified, "There is a need for caution, but…"[88] In the same vein, limited knowledge was used as an argument not to slow down but to accelerate research, and hence as a reason to resist any moratorium on research "which is in any case unlikely to be effective".[89]

The questioning of the effectiveness of international moratoria betrays the parochial frame of the discussion. The limited effectiveness of moratoria is contrasted with the benefits of "appropriate

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[81] The stance of the National Academies of Sciences report *Human Genome Editing* is discussed in the conclusion of the present paper.
[82] National Academies of Sciences, Engineering, and Medicine, "International Summit on Human Gene Editing: A Global Discussion, Planning Committee, Speaker, and Moderator Biographies," http://www.nationalacademies.org/cs/groups/genesite/documents/webpage/gene_169461.pdf
[83] Progress Educational Trust, "From Three-Person IVF to Genome Editing".
[84] Progress Educational Trust, "Events: Rethinking the Ethics of Embryo Research: Genome Editing, 14 Days and Beyond," http://www.progress.org.uk/conference2016
[85] Eric S. Lander, "What we don't know" in *International Summit on Human Gene Editing, A Global Discussion: Commission Papers*, (Washington DC: US National Academies of Sciences, Engineering and Medicine, Chinese Academy of Sciences and the Royal Society, 2015), 27.
[86] Sally Cheshire quoted by Cathy Herbrand "Three-person IVF: What makes mitochondrial donation different?" *BioNews* 834 (11 January 2016) http://www.bionews.org.uk/page_604026.asp
[87] Mark Walport quoted by Sarah Pritchard "Why the UK should be leading the discussion".
[88] Robin Lovell-Badge, "Editing human embryos," *BioNews* 799 (27 April 2015) http://www.bionews.org.uk/page_519962.asp
[89] Lovell-Badge, "Editing human embryos".

and proportionate regulations to govern the use of these powerful and important techniques".[90] However, if it is difficult to secure an effective international moratorium on some technique (or its application) securing one is at least imaginable. There are some moratoria, self-imposed by scientific bodies, which have been in place for many years. In contrast, there is not the slightest chance of an international consensus on bureaucratic structures of regulation. There is no international super-regulator for licensing research and national approaches are not harmonious even across Europe.

Without any agreement on what, when, how or who to enforce "proportionate regulations", the impact of the UK decision to approve a particular technique, subject to licence, is simply to undermine the prohibition of that technique in other countries. The UK influence is thus corrupting even on its own terms, for it undermines the prohibition in other jurisdictions without any way to mitigate this by regulation. That this adverse influence is not perceived to be a problem attests to the narrowly national focus of bioethical discussion in the UK. Some speakers at the London conference acknowledged that "different European countries have fundamentally different views about technology".[91] However, the conference structure showed no awareness that a UK audience might benefit from hearing these "different views" expounded by people from these different countries. Institutions in the UK typically show interest in the effects that their policies have on other countries only insofar as these affect the UK through international agreements or court cases, or through health tourism.

The precedent of 'three-parent IVF'

Another difference between the two conferences is evident from the titles. The London conference used the debate surrounding "three-person IVF" (that is, "mitochondrial donation" by MST or PNT) as a model for considering gene editing techniques. In contrast, whereas the US National Academies commissioned a separate piece of work on these mitochondrial techniques, it did not consider these techniques at the Washington summit. Furthermore, the US National Academies report, entitled *Mitochondrial Replacement Techniques* (MRT), when it appeared on 17 March 2016, was at pains to distinguish these techniques from gene editing.

> The significant and important distinctions between modification of mtDNA to prevent transmission of mtDNA disease through MRT and modification of nDNA (1) have implications for the ethical, social, and policy issues associated with MRT, and (2) could allow justification of MRT independent of decisions about heritable genetic modification of nDNA.[92]

The report thus resists the claim that acceptance of MRT sets a precedent for the acceptance of gene editing. This allows the authors of the report to set to one side discussion of the ethics of gene editing.

In contrast the London conference was framed deliberately to bring out similarities between "mitochondrial donation" techniques and gene editing. The reason "why [the Progress Educational

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[90] Lovell-Badge, "Editing human embryos".

[91] Mark Walport quoted by Sarah Pritchard "Why the UK should be leading the discussion".

[92] Anne Claiborne, Rebecca English, and Jeffrey Kahn; Committee on the Ethical and Social Policy Considerations of Novel Techniques for Prevention of Maternal Transmission of Mitochondrial DNA Diseases; Board on Health Sciences Policy; Institute of Medicine; National Academies of Sciences, Engineering, and Medicine, *Mitochondrial Replacement Techniques: Ethical, Social, and Policy Considerations* (Washington DC: National Academies Press, 2016), 107.

Trust] decided to produce this conference"[93] is succinctly expressed by Sarah Norcross, director of Progress. Rather than a "temporary ban" on the gene editing of human embryos, Norcross urges that "a better model to follow is the parallel scientific, ethical and public consideration of mitochondrial donation."[94]

Note here that the regulation of "mitochondrial donation" is offered as a model not only or even primarily for the substantive ethical issue of germline modification. It is a model first for the consideration of these techniques by scientists and the public. Scientists in the UK have yet to attempt MST or PNT in a clinical setting. Nevertheless, the "public consideration" was deemed successful in that it facilitated the passing of the desired Regulations. The clear implication of this "better model" is that the public should first be persuaded of "the need for research"[95] for human genome editing and that such techniques should then be brought within the scope of the UK's permissive bureaucracy.

When scientists were lobbying for a change in the law to allow MST and PNT, they suggested that these techniques did not constitute germline gene therapy.

> Germline gene therapy is a term used for modifying genes in the *nuclear* genome at the beginning of development with the intention of changing the organism in a specific way and for potentially transmitting this change to subsequent progeny. Due to the complexity of the nuclear genome, there are risks associated with modifying it, thus only gene therapy that avoids the germline is currently permitted. Replacing diseased mitochondria with healthy ones is an inherently less complicated procedure.[96]

However, the report from the Nuffield Council on Bioethics admitted that PNT and MST were forms of germline gene therapy. This admission placed the British government in a difficult position because it wished to pass the Regulations but also to uphold an EU-wide prohibition on human germline modification. The government resolved this problem, to its own satisfaction, by adopting a "working definition" according to which "genetic modification involves the germ-line modification of nuclear DNA (in the chromosomes) that can be passed on to future generations".[97]

While the government thus argued that "the proposed mitochondrial donation techniques do not constitute genetic modification",[98] some scientists expressed doubts about the significance of this distinction. "The decision to allow three-parent babies is right. But the fact is, opponents were also right to describe this as a step towards tinkering with the rest of our genome… I suspect many biologists harbour similar views, but not many say so openly. Instead, they back three-parent babies but say it isn't really genetic engineering."[99] Indeed, even before the regulations were passed, the Progress Educational Trust were arguing that these techniques "can be characterised accurately as a

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[93] Progress Educational Trust, "From Three-Person IVF to Genome Editing".
[94] Norcross "banning it is not the answer".
[95] Walport, "Beyond soundbites", 34.
[96] Doug Turnbull, The North East England Stem Cell Institute, "Briefing paper on the need to protect the future possibility of treating mitochondrial disease and other conditions by a procedure that involves mitochondrial transplantation" 29 May 2008, emphasis in the original.
[97] Public Health Directorate/Health Science and Bioethics Division, *Mitochondrial Donation, Government response to the consultation on draft regulations to permit the use of new treatment techniques to prevent the transmission of a serious mitochondrial disease from mother to child* (London: Department of Health, July 2014), 15.
[98] Public Health Directorate *Mitochondrial Donation, Government response*, 15.
[99] M. Le Page, "Crossing the germ line – facing genetics' great taboo," *New Scientist* 06 February 2015.

form of human germline genetic modification", while maintaining that this "does not make [them] ethically problematic."[100]

There are important practical differences between the use of gene editing techniques on nuclear DNA and "mitochondrial donation". MST and PNT, the techniques of "mitochondrial donation", produce a new combination of nuclear DNA from one woman and mitochondrial DNA from another woman, but neither the nuclear DNA nor the mitochondrial DNA is modified. The novel features of gene editing technology may well affect how the risk of using it is as weighed in the context of human reproduction. However, if both "mitochondrial donation" and gene editing are forms of germline genetic modification, then the techniques are analogous at least in principle. If the former is now permitted, subject to licence, then this provides clear precedent for the other also to be permitted.

Conclusion

The Washington summit ended with a series of four recommendations:

1. Basic and preclinical research (including research using human embryos) should proceed, "subject to appropriate legal and ethical rules and oversight";
2. Clinical use as somatic therapy should be "appropriately and rigorously evaluated within existing and evolving regulatory frameworks for gene therapy";
3. Clinical use for germline gene therapy "would be irresponsible… unless and until (i) the relevant safety and efficacy issues have been resolved… and (ii) there is broad societal consensus"; and
4. There is a need for an ongoing international forum to debate this issue "to establish norms concerning acceptable uses of human germline editing and to harmonize regulations".[101]

Neither the London conference nor the preliminary Nuffield Council report included recommendations. It is clear, nevertheless, that recommendation 1 would find strong support within the UK. It is highly regrettable that the Washington summit was not stronger in resisting genetic modification of human embryos for "basic" research. What is "appropriate" and "ethical" in this area is the legal prohibition of such research.

Recommendation 2 is not ethically controversial.

It is with recommendation 3 that there emerges a distinction between the Washington summit and the attitude shown in the London conference, and in UK policy more generally. Based on the analysis of this paper, it seems likely that recommendation 3 would only gain support in the UK if it were adopted precisely as a means to help build a "societal consensus" in favour of the in-principle acceptability of germline gene therapy.

Similarly, recommendation 4 would be likely to find support only if it were interpreted to mean, "harmonize regulations" to the norms and practices acceptable to the research establishment within the United Kingdom. In general, the impetus to international engagement by the UK stems not from

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[100] Progress Educational Trust, "Correspondence submitted by the Progress Educational Trust (MIT0001)" in *House of Commons Science and Technology Committee Mitochondrial donation: Correspondence received relating to the evidence hearing on 22 October 2014*, 7. http://www.parliament.uk/documents/commons-committees/science-technology/Mitochondrial donation/MITCorrespondence.pdf

[101] Olson et al. *International Summit on Human Gene Editing* pp 6-7.

a desire to learn from others[102] but from the same strategic approach that informs public engagement at a national level. As with national engagement, it appears in the guise of openness and consultation but is directed towards a goal that has already been decided. The UK model for novel biomedical technologies is to default to permissibility, subject to licence. This is therefore the default UK model for germline genetic modification.

At first sight it would seem that the National Academies of Sciences report *Human Genome Editing* takes a step further than the Washington conference and supports a view closer to that of the UK. In relation to germline (heritable) genome editing the report recommends that clinical research trials could be permitted in future, though "only for compelling purposes of treating or preventing serious disease or disabilities, and only if there is a stringent oversight system able to limit uses to specified criteria".[103]

This may seem like an endorsement of germline gene therapy, but the authors of the report admit that there are those who doubt their criteria could ever be met. In particular, "once germline modification had begun, the regulatory mechanisms instituted could not limit the technology to the uses identified in the recommendation."[104] The authors' response is that "if it is indeed not possible to satisfy the criteria in the recommendation, the committee's view is that germline genome editing would not be permissible".[105]

If germline genome editing were to go ahead, it is naïve to believe that its use could be restricted to only a few serious conditions. Experience shows that once a bright line has been crossed then technology extends to more and more uses further and further from the original proposal. In the area of germline modification of human beings the precautionary principle remains the safest ethical guide. Thus while the report of the National Academies of Sciences goes somewhat further that the Washington conference, it is far from the enthusiastic promotion of germline interventions that is prevalent in the United Kingdom.

In relation both to the pernicious path of eugenics and to the protection of embryonic human beings, the approach of the UK is deeply problematic. Those who bear witness to these issues within the United Kingdom are voices crying in the wilderness. They are included in consultation exercises to help provide the impression of balance but they have little if any effect on the outcome. In most cases, the outcome is substantially determined in advance of consultation.

The rhetoric of moderation and responsible regulation which characterises embryo policy in the UK should not be allowed to obscure the radical instrumentalisation of the human embryo in UK practice. Long before considering the topic of gene editing, the UK has effectively "edited out" the human embryo as an object of ethical concern. In the UK, law and policy in this area is set by a powerful alliance of forces in favour of embryo experimentation. These have had the support of successive governments and have had no effective internal opposition.

In relation to ongoing international discussion on these issues, it is important for those outside the United Kingdom to be aware of the way that language is used and policy is pursued within the UK. The language of respect for the "special status" of the embryo is used to achieve the opposite, that

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[102] The lack of interest in learning from other countries is evident from statements made at the London conference and indeed from its very structure.
[103] *Human Genome Editing* p 10, see also pp 102-104, 145-147.
[104] *Human Genome Editing* p 103.
[105] ibid

is, to promote destructive experimentation on human embryos, and the discourse presupposes the context of a highly-regulated nation. Internationally it has the potential to cause even greater harm, undermining prohibitions that protect the embryo without even the inhibition of regulation.[106] The same desire to overcome principled ethical opposition is evident in the prevalent UK attitude to eugenics and germline gene therapy. The only ethical considerations are safety (of adults or of children who have been born) and public confidence. It is to be hoped, therefore, that people of good will from different nations will engage vigorously on the issue of genome editing so that it is not left to the advocates of embryo experimentation in the United Kingdom to "lead the way in the debate about genome editing of human embryos."[107]

[106] The regulation of activities by licensing, while it may inhibit these activities, involves problems of cooperation that do not occur with simple prohibitions. This is an issue that is explored in Helen Watt, "Cooperation and immoral laws: Preventing without prescribing harm," *National Catholic Bioethics Quarterly* 12: 241-248.

[107] Mark Walport quoted by Sarah Pritchard "Why the UK should be leading the discussion".