Editing Out the Embryo

The Debates over Human Genome Editing in the United Kingdom and the United States

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Abstract. Two conferences on genome editing held in December 2015 offer a lens through which to contrast bioethics policies in the United Kingdom and the United States. The Progress Educational Trust, which has no parallel in the United States, hosted the London conference and illustrates the close collaboration between government departments, scientific bodies, funding organizations, and lobby groups in the United Kingdom. The rhetoric of responsible regulation used in the United Kingdom protects not the embryo, but the practice of embryo destruction, and advocates of embryo experimentation are eager to guide the debate about genome editing. It would be perilous for the international community to allow the United Kingdom to frame the debate in this way. *National Catholic Bioethics Quarterly* 17.1 (Spring 2017): 83–105.

A Tale of Two Cities

In December 2015, two conferences were held on the topic of human genome editing, one in Washington, DC, the other in London.[1] In Washington, the

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1. There are differences in connotation between gene editing and genome editing. 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.

US National Academies of Sciences, Engineering, and Medicine, in collaboration with the Chinese Academy of Sciences and the United Kingdom's Royal Society, hosted the three-day International Summit on Human Gene Editing.[2] In London, less than a week later, a one-day conference hosted by the Progress Educational Trust, titled "From Three-Person IVF to Genome Editing: The Science and Ethics of Engineering the Embryo," addressed the same theme.[3]

Following the Washington summit, the US National Academies convened a multidisciplinary committee to produce a consensus study, *Human Gene Editing: Scientific, Medical, and Ethical Considerations*, which was published on February 14, 2017.[4] The London conference did not lead to a report, but at the same time that the conference was being held, the Nuffield Council on Bioethics, also based in London, was 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 of 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*, published in September 2016, covered human health—understanding disease, treating disease, avoiding genetic disease, and enhancing biological function and performance—as well as food, environmental effects, and other applications.[6] Following this general overview, a second working group was established specifically to consider genome editing and human reproduction.[7] At the time of this writing, the second working group has yet to report.

The parallel initiatives in London and Washington offer a lens through which to compare the discussions of bioethics and public policy in the United Kingdom and in the United States. This paper focuses on the United Kingdom, with the American 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

2. Steven Olson et al., *International Summit on Human Gene Editing: A Global Discussion—Meeting in Brief* (Washington, DC: National Academies Press, 2015), doi: 10.17226/21913.

3. Progress Educational Trust, "From Three-Person IVF to Genome Editing: The Science and Ethics of Engineering the Embryo," Annual Conference 2015, London, December 9, 2015, 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.nap.edu/24623.

5. Nuffield Council on Bioethics, *Genome Editing: Open Call for Evidence*, November 27, 2015, http://nuffieldbioethics.org/wp-content/uploads/NCOB_GenomeEditing-CallForEvidence1.pdf.

6. Nuffield Council on Bioethics, *Genome Editing: An Ethical Review* (London: Nuffield Council on Bioethics, 2016). A short guide and summary are also available at http://nuffieldbioethics.org/project/genome-editing/ethical-review-published-september-2016.

7. See "Working Party on Genome Editing and Human Reproduction," Nuffield Council on Bioethics, accessed February 24, 2017, http://nuffieldbioethics.org/project/genome-editing/working-party.

embryo. It will also help explain why the United Kingdom remains such a persistent international promotor of lethal experimentation on embryonic human beings.

Bioethicists or Scientists?

The Royal Society, the United Kingdom's equivalent of the US National Academy of Sciences, cosponsored the Washington summit. In the United Kingdom, however, the national discussion of human genome editing has not been led by the Royal Society. Rather, a prominent role has been played by the Nuffield Council. The United Kingdom has no national bioethics committee, but the Nuffield Council fulfills this role for some purposes.

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

The lack of engagement by the Presidential Commission on the issue of gene editing is perhaps best understood as a transient effect, a reaction to the prominence of the President's Council on Bioethics during the presidency of George W. Bush. Members of the Obama administration were unhappy with some of arguments presented by the President's Council, especially in relation to human cloning, human embryonic stem cell research, and the concept of human dignity.[9] To prevent conservative voices in bioethics from influencing policy during the Obama administration, the Presidential Commission not only reconstituted its ship but focused on less controversial areas. Gene editing was therefore considered not by the national bioethics body but by an organization representing scientists: the National Academy of Sciences.

It may seem that, in relation to the current gene-editing debate, the approach in the United Kingdom is preferable, where a national bioethics body helps 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 influence is even more evident when one considers the organization that hosted the London conference on genome editing in December 2015: the Progress Educational Trust.

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8. Albert R. Jonsen, "American Moralism and the Origin of Bioethics in the United States," *Journal of Medicine and Philosophy* 16.1 (February 1991): 113–130, doi: 0.1093/jmp /16.1.113; and Carolina Pereira-Sáez, "Philosophical Imperialism? A Critical View of North American Principlist Bioethics," in *Bioethical Decision Making and Argumentation*, ed. Pedro Serna Bermúdez and José-Antonio Seoane (Dordrecht, Switzerland: Springer, 2016), 43–56.

9. President's Council on Bioethics, *Human Cloning and Human Dignity: An Ethical Inquiry* (Washington, DC: Government Printing Office, 2002); President's Council on Bioethics, *Monitoring Stem Cell Research* (Washington, DC: Government Printing Office, 2004); and President's Council on Bioethics, *Human Dignity and Bioethics: Essays Commissioned by the President's Council on Bioethics* (Washington DC: Government Printing Office, 2008).

What Is Progress?

The Progress Educational Trust, which has no parallel in the United States, illustrates how the links between government, the scientific establishment, and nongovernmental actors shape policy on embryo research in the United Kingdom. To understand the character and role of this organization, it is necessary to revisit, at least briefly, the formative period of UK policy on embryo experimentation.

The birth of Louis Brown in 1978 in England, the first child born through IVF, provides the context for this debate. Margaret Thatcher became prime minister in 1979, and her Conservative government strongly supported this technology. Thatcher is the only British prime minister to hold a degree in a scientific discipline. From 1943 to 1947, she studied chemistry at Oxford and in her final year used x-ray crystallography to determine the structure of the antibiotic gramicidin.[10] 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 IVF and thus embryo experimentation, they were aware of concerns expressed by members of the public, the media, and parliament, including many members of Parliament within the Conservative Party itself.

The Conservative government addressed these concerns in 1982 by establishing the Committee of Inquiry into Human Fertilisation and Embryology, chaired by the philosopher Mary Warnock. The Committee's 1984 report[11] led to the establishment of an interim voluntary licensing authority in 1985. However, in the same year, former Conservative MP Enoch Powell introduced the Unborn Children (Protection) Bill, prohibiting destructive experimentation on human embryos. The bill passed its first reading with a large majority on a vote of 238 to 66.[12] This vote caused alarm among supporters of IVF and led directly to the establishment of the Progress Campaign for Research into Human Reproduction, whose only aim was "to make sure that human embryo research was protected by law so that IVF treatment could continue."[13]

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."[14] Nevertheless, in political discourse the rhetorical force of the term "progress" typically functions to beg this question. The word implies, insinuates, or at least suggests that

10. Jon Agar, "Thatcher, Scientist," *Notes and Records: The Royal Society Journal of the History of Science* 65.3 (September 20, 2011): 215–232, doi: 10.1098/rsnr.2010.0096.

11. Mary Warnock et al., *Report of the Committee of Inquiry into Human Fertilisation and Embryology* (London: Her Majesty's Stationery Office, 1984).

12. *Unborn Children (Protection) Bill*, Parliamentary Debates, Commons, 6th ser. (1985), vol. 73, cols. 637–702. See also Michael Mulkay, "Political Parties, Parliamentary Lobbies and Embryo Research," *Public Understanding of Science* 4.1 (January 1, 1995): 31–55, doi: 10.1088/0963-6625/4/1/003.

13. "Background," Progress Educational Trust, accessed February 24, 2017, http://www.progress.org.uk/.

14. E. F. Schumacher, *Small Is Beautiful: Economics as if People Mattered* (New York: Harper Perennial, 2010), 167.

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."[15] The size of the majority was deceptive. Most MPs had not taken part in the vote, and contentious private members' bills "have little chance of passage without the aid of Government."[16] 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 Parliament. The government's strategy was therefore to delay the introduction of legislation until it was confident that it had the backing of sufficient MPs. To achieve this, it needed the help of scientists and campaigning organizations to shift public opinion, reframe the dominant narrative presented by the media, and lobby MPs. The founding of the Progress Campaign was the beginning of a long history of cooperation, 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. The campaign received a major media boost after the first successful sex-selective pregnancy to prevent the inheritance of a sex-linked genetic disease.[17] This reinforced the beneficial image of the technology and established the United Kingdom at the cutting edge of scientific innovation. During the lead-up to the final vote, the Progress Campaign arranged for two hundred families affected by genetic disease to visit Parliament. 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."[18]

15. Emily Jackson, *Regulating Reproduction: Law, Technology and Autonomy* (Oxford: Hart, 2001), 183. This belief is echoed in "Background" on the Progress Educational Trust's website.

16. D. Marsh, P. Gowin, and M. Read, "Private Members' Bills and Moral Panic: The Case of the Video Recordings Bill (1984)," *Parliamentary Affairs* 39.2 (1986): 179–196, cited in Mulkay, "Political Parties, Parliamentary Lobbies and Embryo Research," 33.

17. A. H. Handyside et al., "Pregnancies from Biopsied Human Preimplantation Embryos Sexed by Y-Specific DNA Amplification," *Nature* 344.6268 (April 19, 1990): 768–770, doi: 10.1038/344768a0.

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

In the final vote in the House of Commons on June 21, 1990, the Human Fertilisation and Embryology Act was passed comfortably on a vote of 303 to 65.[19] The two main political parties allowed their MPs a free vote, but this luxury was permitted in part because the outcome was not in doubt. The bill had cross-party support and a clear steer in favor from the front benches of both the government and the official opposition. This act effectively fixed UK policy on human embryo experimentation and related issues for the next quarter century. In 1992, recognizing that the single aim of the Progress Campaign had substantially been achieved, but only through very active media engagement, the campaign gave way to a new organization, the Progress Educational Trust. This is the body that hosted the London conference in 2015.

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 passage of further regulations, especially in 2001 and 2015, and to one major revision in 2008, but these have all occurred within the framework 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 original act.

The UK legislative approach may be characterized as bureaucratic permissiveness ornamented by cosmetic prohibitions. The law is designed to have an inclusive scope so that all experimentation on human embryos falls within its remit. Consequently, the law grants permission for a very broad range of research and treatments but only under license. On the other hand, it prohibits absolutely only those activities that 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 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 license.

Currently, human germline gene therapy is prohibited by the Human Fertilisation and Embryology Act. 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. Nevertheless, such a measure would conform to the established pattern of incremental extensions of the law. Debate on this issue is therefore almost certain to follow the same contours as previous ones.

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 United States. Prima facie, it might seem that the context for such policy was very similar. Both Great Britain and the United States have permissive regimes for abortion that have remained unchanged in

19. *Amendment of Law Relating to Termination of Pregnancy*, Debates, Commons, 6th ser. (1990), vol. 174, cols. 1178–1224.

their fundamentals for over forty years, since 1967 and 1973 respectively.[20] Similarly, IVF is widely available in both countries, and scientists are permitted to create and use human embryos for research. 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 liberalization of abortion law in Britain was utility or harm reduction for both women and society. Hence, the law requires that two doctors certify a quasi-medical indication before a pregnancy is terminated. 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."[21]

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 coined by an Englishman, Francis Galton, in 1883.[22] So too the First International Eugenics Congress took place in London in 1912.[23] The eugenics movement in England also attracted support from prominent members of the established Church, perhaps most notably Rev. William Inge, Lady Margaret Professor of Divinity at Cambridge and later dean of St. Paul's Cathedral. He was a founding member of the Eugenics Education Society in 1907.[24]

Public sympathy for the victims of thalidomide was another important element in the background of the Abortion Act 1967. Prescribed for morning sickness, the drug was introduced in the United Kingdom in 1958 and used until 1961. It was withdrawn following reports that it caused a variety of birth defects, including limb deficiencies. According to abortion advocates, "thalidomide was the motor that reinvigorated the

20. The United Kingdom includes Great Britain and Northern Ireland, 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 United Kingdom.

21. *Abortion Act 1967*, ch. 87, §1(1)(d).

22. Francis Galton, *Inquiries into Human Faculty and Its Development* (London: Macmillan, 1883).

23. "First International Eugenics Congress," *British Medical Journal* 2.2692 (August 3, 1912): 253–255.

24. 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): 257–265; F. Hale, "Debating the New Religion of Eugenics: Catholic and Anglican Positions in Early Twentieth-Century Britain," *Heythrop Journal* 52.3 (May 2011): 445–457, doi: 10.1111/j.1468-2265.2011.00665.x; and David Albert Jones, "Apostles of Suicide: Theological Precedent for Christian Support of 'Assisted Dying,'" *Studies in Christian Ethics* 29.3 (August 2016): 331–338, doi: 10.1177/0953946816642994. Another prominent Christian eugenicist in this period was Ernest Barnes, the Anglican Bishop of Birmingham; see Patrick T. Merricks, "'God and the Gene': E. W. Barnes on Eugenics and Religion," *Politics, Religion and Ideology* 13.3 (September 11, 2012): 353–374, doi: 10.1080/21567689.2012.698978.

Abortion Law Reform Association and which paved the way for reform."[25] Support for eugenic abortion thus helped secure support for the bill as a whole.

The passage of the Human Fertilisation and Embryology Act followed a similar pattern. Support for this law was also based on the utility of IVF both as a treatment for infertility and as a means to control genetically inheritable disease. As with the Abortion Act, the eugenic possibilities of the technology increased political support for the law.[26] Also in keeping with the Abortion Act, while the destruction of unborn life was permitted on the basis of supposed utility, the law required particular authorization, in this case from the licensing authority. Both laws are permissive but within limits: cases that clearly fall outside the respective laws, for example, abortion without authorization from two doctors, or experimentation on embryos after the fourteenth day of development, are prohibited.[27]

Both Britain and the United States have very permissive policies on abortion, effectively permitting it for any reason until twenty-four weeks in Great Britain, twenty-six weeks in the United States, and in both countries 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 each other than with most European jurisdictions, and they represent the far extreme from the more restrictive legislative approaches that predominate in South America and Africa. However, in relation to the mechanism, rationale, and public support for legalization, Britain and the United States are radically different.

In Britain, abortion was legalized by an act of Parliament that had widespread parliamentary and public support, and the rationale was primarily harm reduction. The rhetoric of choice, self-determination, and privacy had relatively little influence on either the public debate or the final shape of the law. In contrast, abortion was legalized in the United States not by a positive law endorsed by democratic process and supported by the public, but by a judgment of the Supreme Court, which declared existing restrictions on abortion to be unconstitutional.[28] 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

25. 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.

26. For example, the most prominent opponent of embryo experimentation, Enoch Powell, was nevertheless 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 (May 2011): 457–471, doi: 10.1016/j.rbmo.2011.01.008.

27. 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, yet when abortions have been performed explicitly to avoid the birth of a girl, doctors have not been prosecuted.

28. *Roe v. Wade*, 410 US 113 (1973).

are not permitted to outlaw the practice of abortion, they have no constitutional duty to provide it, and the Hyde amendment of 1976, which restricted federal funding for abortion, was upheld by the Supreme Court in 1980.[29]

When the Ethics Advisory Board of the US Department of Health, Education, and Welfare considered research involving human in vitro fertilization and embryo transfer in 1979, the question was therefore not whether embryo experimentation should be permitted but whether it should receive federal funding.[30] In contrast to Thatcher, Ronald Reagan, who became president in 1981, was opposed to destructive experimentation on human embryos and sidelined the recommendations of the advisory board, a policy maintained by President George H. 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 that destroyed human embryos. The issue of federal funding for embryo experimentation and for experimentation that presupposed embryo destruction was contested only after stem cells were derived from human embryos in 1998. However, Clinton successfully evaded the issue, leaving his successor, 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.[31]

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 vocal opposition from G. K. Chesterton and others, but more importantly, in political terms, because of its associations with Prussian nationalism.[32] In contrast, the United States is one of a few countries that developed large-scale programs of eugenic sterilization.[33]

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29. *Harris v. McRae*, 448 US 297 (1980).

30. Ethics Advisory Board, *Report and Conclusions: HEW Support of Research Involving Human In Vitro Fertilization and Embryo Transfer* (Washington, DC: US 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.

31. See O. Carter Snead, "The Law and Politics of Embryo Research in America," *Human Reproduction and Genetic Ethics* 17.1 (2011): 40–52, doi: 10.1558/hrge.v17i1.40; and Thomas Banchoff, *Embryo Politics*, 175–181.

32. Chesterton notes, "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" (G. K. Chesterton, "To the Reader," *Eugenics and Other Evils* (London: Cassell, 1922).

33. See Edwin Black, *War against the Weak: Eugenics and America's Campaign to Create a Master Race*, expanded edition (Washington, DC: Dialog Press, 2012); 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); Calum MacKellar and Christopher Bechtel, eds., *The Ethics of the New Eugenics* (Oxford: Berghahn Books, 2014); and A. G. Winfield, *Eugenics and Education in America: Institutionalized Racism and the Implications of History, Ideology, and Memory* (New York: Peter Lang, 2007).

Perhaps for this reason, eugenic considerations played little or no part in shaping the Supreme Court judgments on abortion or the subsequent debates over funding. 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 unborn child has never been included as a reason.

It seems that the shameful era of compulsory eugenic sterilization in the United States at least helped American commentators acknowledge the possibility that eugenic ideas can reinforce discrimination and lead to new forms of injustice, even in a democracy.[34] In contrast, there is little awareness in the United Kingdom of England's role in promoting eugenics and its associated historical injustices. Hence, while the Washington summit in December included prominent reflections on the history of eugenics,[35] the subject was mentioned at the London conference only in passing, in a question from the floor.[36]

From a Catholic perspective there are fundamental problems with the framing of the debate both in the United States and in Britain. The United States focuses on the question of federal funding rather than the possibility of legal prohibition. Such a framework 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 in the United Kingdom appears at least to be concerned with the right question, which is whether certain activities should be prohibited or permitted, not merely whether they should be funded. On the other hand, the law in Britain overtly favors eugenic interventions, whether by selective abortion or by preimplantation genetic diagnosis. The model provided by UK legislation is legal permissibility of controversial research and treatment subject to license. Thus, while American and British models for addressing embryo experimentation differ, neither adequately guarantees the justice due the human embryo, and neither is helpful in a situation where prohibition seems the most effective measure to secure the common good. In this respect, the models provided by Germany and to a lesser extent by France and Italy, while imperfect, better reflect the principle of justice and the dignity of the human embryo.[37]

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34. Michael G. Silver, "Eugenics and Compulsory Sterilization Laws: Providing Redress for the Victims of a Shameful Era in United States History," *George Washington Law Review* 72.4 (April 2004): 862–892.

35. Daniel J. Kevles, "The History of Eugenics," in *International Summit on Human Gene Editing: A Global Discussion—Commissioned Papers*, ed. Steven Olson et al. (Washington, DC: National Academies Press, 2015), 9–12, http://nationalacademies.org/cs/groups/pgasite/documents/webpage/pga_170455.pdf.

36. See Sarah Pritchard, "Why the UK Should Be Leading the Discussion on Embryo Engineering," *BioNews* 834 (January 11, 2016).

37. Herbert Gottweis, "Stem Cell Policies in the United States and in Germany," *Policy Studies Journal* 30.4 (November 2002): 444–469, doi: 10.1111/j.1541-0072.2002.tb02158.x; Jan P. Beckmann, "On the German Debate on Human Embryonic Stem Cell Research," *Journal of Medicine and Philosophy* 29.5 (November 2004): 603–62; 10.1080/03605310490518113; Stéphane Viville, and Yves Ménézo, "Human Embryo Research in France," *Human Reproduction* 17.2 (February 2002): 261–263, doi: 10.1093

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 a lack of action. By default, what is not prohibited is permitted, and debates about federal funding will not prevent clinicians from offering gene editing technology where a market exists for it. In contrast, germline gene editing is currently illegal in the United Kingdom and will remain so unless the law changes. However, the pattern of government intervention has consistently favored extending the law to increase genetic control over reproduction.

In this context, it is hard to overemphasize the prestige that biotechnology, 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 other scientific projects that require very high levels of government spending, it can boast not only the discovery of DNA's double helix structure in 1953 but the first child born through IVF in 1978, the first children born following preimplantation genetic diagnosis in 1990, and the first cloned mammal in 1997. In 2007, British scientist Martin Evans shared a Nobel Prize for his work on embryonic stem cells.

Successive governments are also proud of the way policy has coordinated with nongovernmental actors to overcome public concerns about this technology, culminating in the Human Fertilisation and Embryology Act. Unlike in the United States, the ethical acceptability of abortion and embryo experimentation is not a matter on which public opinion is finely divided or one on which the two main political parties differ substantially. In the United Kingdom, governments of the right and of the left have maintained 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 created the Human Fertilisation and Embryology Authority (HFEA) as the vehicle for maintaining public trust; it also established a proactive pattern of public engagement that was strongly directed toward securing a desired policy goal and was more or less coordinated between government and nongovernmental bodies. Having successfully achieved the legal settlement, this approach became a model for future public engagement by the government, the HFEA, and other actors. This strategy was well analyzed by the Canadian bioethicist Françoise Baylis, who remarked that a particular consultation by the HFEA showed "a clear policy preference in support of research … [and], in many respects, the HFEA consultation process can be seen as an exercise in strategic public relations."[38]

/humrep/17.2.261; Giovanni Maio, "The Embryo in Relationships: A French Debate on Stem Cell Research," *Journal of Medicine and Philosophy* 29.5 (November 2004): 583–602, doi: 10.1080/03605310490518096; and Laura Palazzani, "Embryo Research in Italy: The Bioethical and Biojuridical Debate," *Human Reproduction and Genetic Ethics* 17.1 (2011): 28–39, doi: 10.1558/hrge.v17i1.28; and Banchoff, *Embryo Politics*, 97–119.

38. Françoise Baylis, "The HFEA Public Consultation Process on Hybrids and Chimeras: Informed, Effective, and Meaningful?," *Kennedy Institute of Ethics Journal* 19.1

This model of strategic public relations is also evident in the purported rationale for 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," that is, to protect practices that involve destroying human embryos.[39] However, the act was supposed to uphold the special status of the human embryo. It has become customary to repeat this claim each time the act is revisited: "The starting point for consideration of the ethics of research on human embryos is the status of the early embryo."[40] "We have concluded that the embryo should be accorded special status in common with the Warnock Committee."[41] "We acknowledge that the special status of the embryo means regulation of both research and treatment continues to be appropriate and desirable."[42]

I have argued elsewhere that UK policy on human embryo research is, for this reason, fundamentally disingenuous. The claimed special status disguises a purely instrumentalist view both of the embryo and, what is more, 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."[43]

Sometimes in international discussion, the United Kingdom presents itself as a middle ground between deregulated practices, as in the United States, and the restrictive approach of some European nations. This characterization is misleading. The United Kingdom is not somewhere in the middle but, rather, defends the most extreme position on what should be permitted by law and how aggressively researchers should pursue novel forms of embryo experimentation. In this context, regulation is supported not because it inhibits or restricts experimentation on human embryos but precisely because it facilitates such experimentation. It is "deregulation via regulation."[44] This explains the pattern of British engagement, both governmental and nongovernmental, in international discussions of embryo experimentation and

(March 2009): 47, doi: 10.1353/ken.0.0273. 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 and Genetic Ethics* 17.1 (2011), 84–109, doi: 10.1558/hrge.v17i1.84.

39. "Background," Progress Educational Trust.

40. House of Lords Select Committee on Stem Cell Research, *Stem Cell Research: Report* (February 13, 2002), 4.3.

41. House of Commons Science and Technology Committee, *Human Reproductive Technologies and the Law*: *5th Report of Session 2004–2005*, vol. 1, March 14, 2005, para. 49.

42. Joint Committee, *Human Tissue and Embryos (Draft) Bill*, vol. 1, *Report*, August 1, 2007, para. 105.

43. 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): 80, doi: 10.1558/hrge.v17i1.66.

44. 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* 32.2 (2003): 149–61, cited in Jones, "'Special Status' of the Human Embryo," 77.

genetic engineering. The attitude of the US government in such discussions varies depending on the administration, whereas the attitude of the UK government is consistently the most vocally opposed to international restrictions on embryo experimentation or genetic engineering.[45]

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 determination nor the overall direction of travel will genuinely be open to revision. The decision will have been made in advance, and consultation does not solicit criticism or suggestions from members of the public, but attempts to persuade them. Such a pattern exemplifies a residual elitist and anti-democratic aspect of British political life. Explicitly expressed as a philosophy, it would perhaps be what Bernard Williams has termed "government house utilitarianism."[46]

Unwelcome Influence

Another difference between the United Kingdom and the United States is the great influence of a few politically active nongovernmental funding bodies on UK policy. This is true of some medical research charities, but most especially of the Wellcome Trust, the United Kingdom's largest nongovernmental source of funds for biomedical research, with an endowment currently worth more than £18 billion.[47]

Perhaps the most controversial proposal in the 2008 revision of the Human Fertilisation and Embryology Act was the legalization of admixed, or hybrid, human–nonhuman embryos. The Wellcome Trust strongly favored this change and actively engaged the media and politicians to promote it. According to 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."[48]

An important mechanism for this work with the media was the Science Media Centre, itself partially funded by the Wellcome Trust. The 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."[49] 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, Walport frequently spoke to the

45. See Jones, "'Special Status' of the Human Embryo," 68.

46. Bernard Williams, *Ethics and the Limits of Philosophy* (Cambridge, MA: Harvard University Press, 1985), 108, cited in Jones, "'Special Status' of the Human Embryo," 78.

47. "Investments," Wellcome Trust, accessed February 24, 2017, https://wellcome.ac.uk/.

48. 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, 2009), 34.

49. John Crace, "Peer Trouble," *Guardian,* February 11, 2003, https://www.theguardian.com/.

media and issued press statements. Characteristically these statements appealed to the prestige of embryo experimentation and emphasized the alleged consensus of the scientific community: "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."[50]

As with previous government-sponsored embryo-related legislation, the 2008 revision of the Human Fertilisation and Embryology Act passed comfortably on a vote of 355 to 129.[51] However, it is far from clear that the intense campaigning in its favor succeeded in "achieving the informed public debate."[52] Analysis of the media reporting shows that, of over one hundred newspaper reports analyzed, 72 percent included some exaggerated or misleading scientific claims, for example, that the research aimed to cure or provide treatment for certain diseases or that it would save lives.[53] Indeed, 22 percent of these reports made claims that were clearly unfounded, such as the assertion that such research is necessary to make medical progress or that patients will benefit if the research goes ahead: "For illnesses like motor neurone disease, hybrid embryos *will make* a huge difference."[54]

Having convinced the public of the great and urgent scientific need for creating hybrid embryos, it shocked many when, even before the act went into effect, this avenue of research was abandoned by the only teams in the United Kingdom working in this area. The research had failed to secure funding through the process of scientific peer review. The public was unprepared for this, as only 18 percent of news reports about the research acknowledged scientific reservations about the techniques, and only 8 percent mentioned alternative avenues of research. While the expenditure of funds, time, and energy by the Wellcome Trust and other bodies successfully won the media battle and the parliamentary vote, it would seem that "this victory was won largely at the expense of the public understanding of science."[55]

Not only critics of embryo experimentation have expressed misgivings about the Wellcome Trust's influence on biomedical research policy in the United Kingdom. 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

50. "Scientists React on Government's Response to the Joint Committee on Human Tissue and Embryos (Draft) Bill," Science Media Centre, October 8, 2007, http://www.sciencemediacentre.org/.

51. Edward White, "Human Fertilisation and Embryology Bill: What Happened?," Commons Library Standard Note, SN/SC/4886, last updated November 11, 2008, 7.

52. Walport, "Beyond Soundbites," 34.

53. 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*, Cardiff, October 7–9, 2009.

54. James Randerson et al., "Ethical Concerns in Embryos Bill Divide MPs," *Guardian*, May 11, 2008, https://www.theguardian.com/, emphasis added.

55. Jones and Gately, "Over-egging Your Cybrid."

evidence to the House of Lords Select Committee on Science and Technology: "Increasingly—by default—the Wellcome Trust (WT) 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.[56]

The Wellcome Trust also appeared to dictate policy in favor of maternal spindle transfer (MST) and pronuclear transfer (PNT), mechanisms for preventing the transmission of mitochondrial disease. These techniques, together termed mitochondrial donation by the government[57] but popularly described as three-parent IVF,[58] were included in the Human Fertilisation and Embryology Act 2008 as a possible subject for future regulations.[59] The consultation process began in 2012, but the events of January 19, 2012, seem to betray a certain choreography in the actions of supposedly independent bodies. In the first place, the Secretaries of State for Health tasked the HFEA with seeking public views on these techniques.[60] On the same day, the Nuffield Council announced that it would conduct its own ethical review.[61] Finally, also on the same day, the Wellcome Trust announced its decision to grant £4.4 million for research in this area.[62]

56. Marcus Pembrey, "Memorandum" (April 23, 2008), 1.1, in *Written Evidence: Genomic Medicine,* House of Lords Science and Technology Committee, session 2008–2009, June 2, 2009, https://www.publications.parliament.uk/.

57. The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015 No. 572. See also Sarah Barber and Peter Border, "Mitochondrial Donation," *Commons Library Standard Note*, SN/SC/6833, last updated January 29, 2015.

58. Referred to as three-parent babies in the vast majority of media reports according to Richard Watermeyer and Gene Rowe, *Evaluation of the Project: "Mitochondrial Replacement Consultation"* (London: Human Fertilisation and Embryology Authority, 2013), 78. For resistance to three-parent language from 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* 9.4 (May 28, 2013): 1, doi: 10.1186/2195-7819-9-4. For a defense of three-parent language, see David Albert Jones, "The Other Woman: Evaluating the Language of 'Three Parent' Embryos," *Clinical Ethics* 10.4 (September 1, 2015): 97–106, doi: 10.1177/1477750915599721. 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 (January 2017): 7–19, doi: 10.1111/bioe.12309.

59. Human Fertilisation and Embryology Act 2008, §35(1).

60. UK Department of Health and Anne Milton, "Government to Seek Public Views on Changing the Law to Find Cures for Inherited Diseases," news release, January 19, 2012, http://www.gov.uk/.

61. "Call for Evidence on Mitochondrial Donation," Nuffield Council on Bioethics, January 19, 2012, http://nuffieldbioethics.org/.

62. "Techniques to Prevent Transmission of Mitochondrial Diseases to Be Assessed in New £5.8 Million Wellcome Trust Centre," Wellcome Trust, January 19, 2012, https://wellcome.ac.uk/.

This apparent coordination was particularly troubling because the Wellcome Trust is one of the Nuffield Council's three major funders.[63] The coincidence of these announcements creates the impression that the Wellcome Trust was not only laying down the agenda for the Council but presenting it with a fait accompli, an ethical review of research the Trust had already very publicly agreed to fund.

The Nuffield Council duly produced a report supporting MST and PNT, which framed the HFEA consultation and smoothed the way for the Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015.[64] As in previous cases, the regulations were passed by a large majority.[65] However, by endorsing the research paid for by its own funder without declaring an interest, the actions of the Nuffield Council only served to "undermine the credibility of its conclusion and threaten the reputation of the Nuffield Council for independence."[66] In effect, the national bioethics committee appeared to be used by a funding body as an instrument of public policy.[67]

Given the extent of Wellcome Trust involvement in shaping embryo policy in the United Kingdom over 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."[68] These initiatives include funding the Washington summit, the National Academies working group, and the Progress Educational Trust[69] as well as providing ongoing support to the Nuffield Council.

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63. "Funding," Nuffield Council on Bioethics, accessed February 24, 2017, http://nuffieldbioethics.org/.

64. "Statement on Mitochondrial Donation," HFEA, February 24, 2015, http://www.hfea.gov.uk/.

65. On February 3, 2015, the regulation was approved by the House of Commons on a vote of 382 to 128. See "Commons Debate Statutory Instrument on Mitochondrial Donation," UK Parliament, February 3, 2015, http://www.parliament.uk/.

66. 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, June 12, 2012.

67. On the general threat of such instrumentalization of bioethics bodies, see Heather Strange, "Non-invasive Prenatal Diagnosis and Testing: Perspectives on the Emergence and Translation of a New Prenatal Testing Technology" (doctoral dissertation, Cardiff University, 2015), 119, http://orca.cf.ac.uk/. "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.'"

68. "Gene Editing in Research," Wellcome Trust, accessed February 27, 2017, https://wellcome.ac.uk/.

69. Funding for the Progress Educational Trust is not explicitly mentioned on the Wellcome website. However, the organization's most recent trustees' report expresses gratitude "for grant funding received from the Wellcome Trust which contributed to the significant increase in incoming resources," up 65 percent in comparison to the previous financial year.

While the Welcome Trust states that it "strongly supports open and inclusive discussions," it already supports "gene editing in a research context" where this is legal and "ethically and scientifically justified."[70] Since 2008, UK law has permitted the genetic modification of human embryos for research subject to a license, so such research would now be legal in the United Kingdom. The standard for what is ethically and scientifically justified may be gauged by the strong public support that the Wellcome Trust garnered for the proposal to use hybrid embryos in research, even though the proposal raised serious ethical questions and was eventually abandoned for failing anonymous scientific peer review.[71]

From these statements, it certainly seems that the Wellcome Trust is signaling its opposition to a moratorium on the genetic modification of human embryos in a research context. This is hardly surprising, since the stance of the trust coheres with the dominant policy approach pursued in the United Kingdom since 1990. In the words of Sarah Norcross, director of the Progress Educational Trust, "Banning it is not the answer"[72]—a conclusion about the answer that is asserted with confidence even before the question is adequately articulated. UK law contains cosmetic prohibitions against certain forms of embryo experimentation, which are intended not to restrict research activity but to reassure 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 of the US National Academies or the working group of the Nuffield Council, both of which are funded in part by the Wellcome Trust, choose to follow that lead.[73]

A Study in Contrasts

The different content and approaches of the Washington and London conferences reveal features about the bioethics landscape in both countries. It is immediately apparent that the Washington summit was international—and, indeed, it was advertised as such. It drew on knowledge and experience from the sponsoring academies not only in the United States, the United Kingdom, and China, but also in Canada, Egypt,

Of this funding, "part is to be utilised in the next financial year," that is, the year of the December 2015 conference on three-person IVF and genome editing. Progress Educational Trust, "Trustees' Report for the Year Ending 31 March 2015," December 11, 2015, http://www.progress.org.uk/.

70. "Gene Editing in Research," Wellcome Trust.

71. David Albert Jones, "Is the Creation of Admixed Embryos 'An Offense Against Human Dignity'?," *Human Reproduction and Genetic Ethics* 16.1 (2010): 87–114, doi: 10.1558/hrge.v16i1.87; Calum MacKellar and David Albert Jones, *Chimera's Children: Ethical, Philosophical and Religious Perspectives on Human–Nonhuman Experimentation* (London: Continuum International, 2012); and Ian Sample, "Rival Stem Cell Technique Takes the Heat out of Hybrid Embryo Debate," *Guardian*, January 13, 2009, https://www.theguardian.com/.

72. Sarah Norcross, "Genome Editing Raises Complex Issues: Banning It Is Not the Answer," *Guardian*, September 5, 2015, https://www.theguardian.com/.

73. The stance of the National Academies report, *Human Genome Editing*, is discussed in the conclusion of the present paper.

Israel, Korea, Nigeria, and a number of countries in Europe.[74] In contrast, the London conference did not include a single speaker based outside the United Kingdom.[75] This reflects a common pattern: the annual conference of Progress Educational Trust in 2016 also included no speakers from outside the United Kingdom.[76] Given this insularity, it is remarkable that a number of speakers at the London conference extolled the virtues of the United Kingdom's regulatory system as a model for other countries.

These different perspectives are accompanied by a divergence in tone. The attitude at 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."[77]

In contrast, the London conference was often self-congratulatory, for example, arguing that the United Kingdom is "the best place for mitochondrial donation"[78] and "should lead the way in the debate about genome editing of human embryos."[79] Furthermore, any note of caution was immediately qualified. 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, "which is in any case unlikely to be effective."[80]

Questioning the effectiveness of international moratoria betrays the discussion's parochial framework. The limited effectiveness of moratoria is contrasted with the benefits of "appropriate and proportionate regulations to govern the use of these powerful and important techniques."[81] However, if it is difficult to secure an effective international moratorium on a technique or its application, obtaining one is at least imaginable. Some scientific bodies have operated under self-imposed moratoria for many years. In contrast, there is not the slightest chance of an international consensus

74. National Academies of Sciences, Engineering, and Medicine, *International Summit on Human Gene Editing: A Global Discussion—Planning Committee, Speaker, and Moderator Biographies*, accessed February 27, 2017, http://www.nap.edu/html/21913/gene_bios.pdf.

75. Progress Educational Trust, "From Three-Person IVF to Genome Editing," *BioNews*, events, accessed May 5, 2017, http://www.progress.org.uk/conference2015#booking.

76. Progress Educational Trust, "Rethinking the Ethics of Embryo Research: Genome Editing, 14 Days and Beyond," *BioNews*, events, accessed February 27, 2017, http://www.progress.org.uk/conference2016.

77. Eric S. Lander, "What We Don't Know," in Olson et al., *International Summit—Commissioned Papers*, 27.

78. Cathy Herbrand, "Three-Person IVF: What Makes Mitochondrial Donation Different?," comment, *BioNews* 834 (January 11, 2016), reporting on address by Sally Cheshire.

79. Pritchard, "Why the UK Should Be Leading the Discussion," reporting on keynote address by Mark Walport.

80. Robin Lovell-Badge, "Editing Human Embryos," *BioNews* 799 (April 27, 2015).

81. Ibid.

on bureaucratic regulatory structures. There is no international super-regulator for licensing research and national approaches, which are not harmonious even across Europe.

Without any agreement on what, when, how, or who to enforce proportionate regulations, the effect of the United Kingdom's decision to approve a particular technique subject to license simply undermines restrictions established by other countries. The influence of the United Kingdom is thus corrupting even on its own terms, because it undercuts prohibitions in other jurisdictions without mitigating this influence by regulation. That this adverse influence is not perceived to be a problem attests to the narrow national focus of bioethical discussion in the United Kingdom. Some speakers at the London conference acknowledged that "different European countries have fundamentally different views about technology."[82] However, the conference structure showed no awareness that a UK audience might benefit from hearing these views expounded by people from other countries. Institutions in the United Kingdom typically show interest in the effects that their policies have on other countries only insofar as they affect the United Kingdom through international agreements, court cases, or 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 as a model for considering gene editing techniques. In contrast, the National Academies commissioned a separate piece of work on these mitochondrial techniques instead of considering them at the Washington summit. Furthermore, when the National Academies report, *Mitochondrial Replacement Techniques*, was published on March 17, 2016, it took 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."[83] The report resists the claim that accepting MRTs sets a precedent for accepting gene editing. This allows its authors to set aside discussion of the ethics of gene editing.

In contrast, the London conference was deliberately framed to bring out similarities between mitochondrial donation techniques and gene editing. The reason why the Progress Educational Trust decided to produce this conference is succinctly expressed by Sarah Norcross, director of the trust. Rather than support a temporary ban on the genetic modification of human embryos, Norcross urges that "a better model to follow is the parallel scientific, ethical and public consideration of mitochondrial donation."[84]

82. Pritchard, reporting on Walport address.

83. Anne Claiborne, Rebecca English, and Jeffrey Kahn, eds., *Mitochondrial Replacement Techniques: Ethical, Social, and Policy Considerations* (Washington, DC: National Academies Press, 2016), 107.

84. Norcross, "Genome Editing Raises Complex Issues."

Notice 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 United Kingdom have yet to attempt MST or PNT in a clinical setting. Nevertheless, the public consideration was deemed successful in that it facilitated the passage of the desired regulations. This "better model" clearly implies that the public should first be persuaded of "the need for research"[85] into human genome editing as a first step toward bringing such techniques within the scope of the permissive bureaucracy of the United Kingdom.

When scientists were lobbying for the legalization of MST and PNT, they suggested that these techniques do 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."[86]

However, the report from the Nuffield Council admits that PNT and MST are forms of germline gene therapy. This admission placed the British government in a difficult position because it wished to pass the regulations but also wanted to uphold an EU-wide prohibition on human germline modification. The government resolved this problem to its own satisfaction by adopting a working definition that states, "Genetic modification involves the germ-line modification of nuclear DNA (in the chromosomes) that can be passed on to future generations."[87]

While the government thus argued that "the proposed mitochondrial donation techniques do not constitute genetic modification,"[88] 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."[89] Indeed, even before the regulations were passed, the Progress Educational Trust was arguing that these techniques "can be characterised

85. Walport, "Beyond Soundbites," 34.

86. Doug Turnbull et al., "Briefing Paper on the Need to Protect the Future Possibility of Treating Mitochondrial Disease and Other Conditions by a Procedure that Involves Mitochondrial Transplantation," North East England Stem Cell Institute, May 2008, http://www.ncl.ac.uk/, original emphasis.

87. 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.

88. Ibid.

89. Michael Le Page, "Crossing the Germ Line: Facing Genetics' Great Taboo," *New Scientist*, February 6, 2015, https://www.newscientist.com/.

accurately as a form of human germline genetic modification," while maintaining that this "does not make [them] ethically problematic."[90]

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 risks of using it are 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 license, a clear precedent exists for the other to be permitted as well.

Divergent Conclusions

The Washington summit ended with 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 of somatic therapy should be "appropriately and rigorously evaluated within existing and evolving regulatory frameworks for gene therapy." (3) Clinical use of 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) an ongoing international forum should debate this issue "to establish norms concerning acceptable uses of human germline editing and to harmonize regulations."[91]

Neither the London conference nor the preliminary Nuffield Council report include recommendations. It is clear, nevertheless, that recommendation 1 from the Washington summit would find strong support within the United Kingdom. It is highly regrettable that the Washington summit did not offer stronger resistance to the genetic modification of human embryos for basic research. Legal prohibition of such research is the appropriate and ethical solution.

Recommendation 2 is not ethically controversial.

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

Similarly, recommendation 4 would probably find support only if it were interpreted as harmonizing regulations to the norms and practices accepted by the research establishment in the United Kingdom. In general, the impetus for international

90. 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, https://www.parliament.uk/.

91. Olson et al., *International Summit—Meeting in Brief*, 6–7.

engagement by the United Kingdom stems not from a desire to learn from others but from the same strategic approach that informs public engagement at a national level.[92] It appears in the guise of openness and consultation but is directed toward a goal that has already been decided. The UK model for novel biomedical technologies is permissibility subject to license. This is therefore the default UK model for germline genetic modification.

At first sight, it would seem that the National Academies report *Human Genome Editing* takes a step further than the Washington summit and supports a view closer to that of the United Kingdom. In relation to germline genome editing, the report recommends that clinical research trials could be permitted in the 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."[93]

This may seem like an endorsement of germline gene therapy, but the authors admit that some experts doubt whether 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." The authors respond, "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."[94]

It is naive to believe that, if germline editing proceeds, its use could be restricted to only a few serious conditions. Experience shows that once a bright line has been crossed, technology extends to more and more uses further and further from its original purpose. In the area of germline modification of human beings, the precautionary principle remains the safest ethical guide. Thus, while the National Academies report from February 2017 goes somewhat further than the Washington summit, it is far from the enthusiastic promotion of germline interventions that prevails in the United Kingdom.

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

The rhetoric of moderation and responsible regulation that characterizes embryo policy in the United Kingdom should not be allowed to obscure the radical instrumentalization of the human embryo in practice. Long before considering the topic of gene editing, the United Kingdom effectively edited out the human embryo as an object of ethical concern, and both law and policy are set by a powerful alliance

92. The lack of interest in learning from other countries is evident from statements made at the London conference and, indeed, from its very structure.

93. National Academies, *Human Genome Editing*, 10; see also the conclusions and recommendations on pp. 102–104 and 145–147.

94. Ibid., 103.

of forces that favor embryo experimentation. This alliance has had the support of successive governments and no effective internal opposition.

In relation to the ongoing international discussion of 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 in that country. The language of respect for the special status of the embryo is used to achieve the opposite—that is, to promote destructive experimentation on human embryos—and the discourse presupposes the context of a highly regulated nation. Internationally, the discourse has the potential to cause even greater harm, undermining prohibitions that protect the embryo without even the inhibition of regulation.[95] The same desire to overcome principled ethical opposition is evident in the prevalent UK attitude toward eugenics and germline gene therapy. The only ethical considerations are public confidence and the safety of adults and children who have been born. 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."

95. While it may inhibit these activities, regulation by licensing involves problems of cooperation that do not occur with simple prohibitions. This issue is explored in Helen Watt, "Cooperation and Immoral Laws: Preventing without Prescribing Harm," *National Catholic Bioethics Quarterly* 12.2 (Summer 2012): 241–248.