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# The Virtues of National Ethics Committees

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The United Kingdom has many bodies that play their part in carrying out the work of national ethics committees, but its nearest equivalent of the United States' Presidential Commission for the Study of Bioethical Issues is the Nuffield Council on Bioethics, established in 1991. The Council is charged with examining ethical questions raised by developments in biological and medical research, publishing reports, and making representations to appropriate bodies in order to respond to or anticipate public concern. It is a nongovernment organization with no defined or guaranteed channels of influence. Unlike the U.S. bioethics commission, it is not part of executive government, nor is it constituted to contribute to the legislative branch, as does the French Comité Consultatif National d'Éthique (National Consultative Ethics Committee). Its nongovernmental status notwithstanding, the Nuffield Council's work affects the U.K. government and the British public, and the Council has achieved international recognition for its reports. I was the chairperson from 2012 to 2017 and draw on my experience in this piece to consider three key audiences: governments, publics, and the international community.

## Government

The Nuffield Council has no authority merely by virtue of the position it holds. Rather, it has established *relational* authority based on its reputation. A recent evaluation suggested that stakeholders perceive that our work is influential in a “quiet way” but usually takes some time to come to fruition.<sup>1</sup> It was suggested that the council shaped thinking and culture among opinion formers, but did not always communicate very accessibly, and its reports were reflective in style rather than providing precise recommendations that got quickly taken up. Almost

all our reports do in fact include specific recommendations to specific bodies, with follow-up by the Council. However, responding to the recommendations is discretionary. One policy-maker observed that we sometimes write recommendations as would a parliamentary select committee, even though we do not carry similar authority (p. 32). Despite this, our work has been directly influential in both executive and legislative actions. One recent and very clear example of its influence is the decision in the United Kingdom to make provision in law for the use of mitochondrial replacement therapies.

We believe that our influence arises from our character, our ways of working, and the quality of outputs. In a document titled *Strategic Plan 2012-2016*, we set out our values: an *inclusive* approach that hears all voices but scrutinizes them for *coherence and rationality*, thereby developing a position that is intellectually *rigorous* and consistent with the best available evidence.<sup>2</sup> Underpinning this approach are three core virtues that a national bioethics committee needs: independence, courage, and practical engagement.

**Independence.** The committee must not be beholden to, or under the influence of, others as it develops its conclusions or selects the topics that it will examine. For the Nuffield Council, this matters because two of its funders—the Medical Research Council and the Wellcome Trust—also fund research on the sort of technologies that bioethics commissions consider. Without independence, the Council could be accused of providing false assurance that the technologies are ethically acceptable. While this is specific to Nuffield, the issue is relevant to all national bioethics committees in countries that seek to promote the advancement of science. A further importance of independence lies in the distinctive contribution that collective deliberation offers. Unless a national ethics committee moves from an open mind to its conclusions, it adds little to policy-making beyond what could be achieved by its members acting individually. A committee that merely re-presented preestablished views would fail to

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*We have not shied away from criticizing national policies, such as in relation to the use of biodata. Nor do we believe that respect for public opinion permits uncritical acceptance of it.*

add significant value. Independence of thought and action is therefore a key virtue that national bioethics committees should display.

**Courage.** The committee must be able to speak its mind. We have not shied away from criticizing national policies, such as in relation to the use of biodata.<sup>3</sup> Nor do we believe that respect for public opinion permits uncritical acceptance of it. Respecting people means challenging them when we conclude that they are wrong, but on the basis of reason, not merely disagreement. At our report launches, this has sometimes led to vigorous debate with families personally affected by the matters at issue.<sup>4</sup>

**Practical engagement.** The committee must address current policy positions, connect recommendations with prevailing concepts and terminology, and facilitate discussion through round tables, workshops, and the development of follow-up position statements. Thus, our report *Public Health: Ethical Issues* (2017) adapted a Millian framework because of its fit with the contemporary anxiety about the “nanny state.” This offered hope of a constructive engagement with opinion formers.<sup>5</sup> Our report on biodata was followed up by written and oral evidence to a parliamentary committee and also a hosted workshop for the Department of Health.<sup>6</sup> We engage in conversations, not just commentary, and we use our past work to inform policy and public discussions even where we have not established a specific working party (as in our briefing note on Zika, issued in February 2016).<sup>7</sup>

### The People

The Nuffield Council’s terms of reference from 1991 to 2017 included working “with a view to promoting public understanding and discussion.”<sup>8</sup> The Council has explored various approaches in this effort, including a video competition for young people and work with poets, but it has not developed an account of how public engagement connects with normative bioethical work. The excellent *Bioethics for Every Generation*,<sup>9</sup> by the Presidential Commission for the Study of Bioethical Issues, and the exemplary openness and transparency that come from this commission’s constitutional status offer attractive models. However, two areas where the committees’ experiences diverge merit consideration.

**Addressing the past.** Henry Beecher and Maurice Henry Pappworth exposed similar research misconduct in the United States and the United Kingdom. More recently, however, the United Kingdom has been concerned with the failure to do research, misconduct (a problem of compliance, not moral uncertainty), and mistrust (especially in industry research). These challenges are different from those typically addressed by national bioethics committees because substantive moral questions are not the issue. The statutory remit of England’s Health Research Authority, which (amongst other functions) oversees research ethics committees, includes reinforcing prevailing ethical standards and promoting proportionality in research regulation.<sup>10</sup> The legislative assumption is that research ethics is reasonably stable but that regulation can be improved. Although it has the National Research Ethics Advisors Panel to assist its work, this is not constituted to operate as a national bioethics committee but to assist with ensuring that the practicalities of research regulation are consistent with generally accepted standards of research ethics.

The shadow of historic research scandals seems darker in the United States, and stronger acknowledgment of them may be required before national bioethical discussions can move on to focus on emerging questions. The report “*Ethically Impossible*” *STD research in Guatemala*, by the Presidential Commission for the Study of Bioethical Issues, is an example of this in action.<sup>11</sup> This sort of work has not been a function of the Nuffield Council on Bioethics, and could not easily be done by a nongovernment body, but it seems an important component of a comprehensive framework of governance. The best U.K. comparison probably concerns an organ retention scandal that came to light in the 1990s.<sup>12</sup> Tissue samples and organs had been kept after pediatric postmortem examination without the consent or knowledge of parents. This scandal led to a major public enquiry, creation of the Retained Organs Commission to oversee the institutional responses to the recommendations, and finally, a statutory regulator (the Human Tissue Authority) to administer the legislation that followed. This was therefore addressed as a service failure requiring investigation as a matter of public accountability and regulation rather than as a specifically bioethical issue.

Bioethics governance should provide a process for truth and reconciliation in relation to past failures. However, national ethics committees may not be resourced or equipped

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to carry out that kind of work, which requires detailed documentary analysis, judgments on personal responsibility and liability, and historical insight to avoid anachronistic assessments. The U.K. approach to the organ retention scandal comprised three components that do not sit neatly with the way in which national bioethics commissions have usually operated: forensic investigation, administrative oversight of transition to good practice, and regulatory oversight for the future. However, there are also benefits to using a national ethics committee for this work. The dignity conferred by a national committee enables a show of contrition on behalf of the nation, which is itself a significant matter of justice.

*Looking ahead.* The origins of the Nuffield Council on Bioethics lie in an era of “hostility to science . . . based more than anything on fear and ignorance.”<sup>13</sup> The Council was established “to identify and define ethical questions . . . in order to respond to, and to anticipate public concern.”<sup>14</sup> This position is associated with a “catch-up model” of public bioethics and science rushing ahead of public deliberation, ethical reflection, and regulation.

The recent exploration of mitochondrial DNA replacement therapies illustrates a different model. Scientists facilitated public consideration of these therapies well in advance of their availability, allowing for fifteen years of public discourse and ethical debate before clinical usage became technically possible. Through a 2008 amendment to the United Kingdom’s Human Fertilisation and Embryology Act, regulation was put in place before a decision was needed. And the desire to use the technology was driven by a partnership of affected families, researchers, and clinicians—not the exploitation of unsuspecting guinea pigs, but families demanding the opportunity to use innovative therapies.

This scenario flips the Nuffield Council’s founding assumptions on their head. As we put it,

The question that parliamentarians must consider is not whether they would want to use this technology themselves, but whether there are good grounds to prevent affected families from doing so. We believe that those who know what it is like to care for, and sometimes to lose, an extremely sick child are the people best placed to decide whether this technology is right for them, with medical advice and within the strict regulatory framework proposed. They have been waiting for the science for long enough. They should not have to wait for the law to catch up.<sup>15</sup>

The case has come from the people, based on the right to benefit from science. National ethics committees are now concerned with the justification of regulation as well as the

ethics of technologies, and patients are one of their audiences.

One implication of this “bottom-up” approach might be the enhanced role of the third branch of government. The U.K. Supreme Court recently suggested that human rights limit communal bioethical debate in favor of constitutional liberty.<sup>16</sup> Such judicial appropriation of bioethics has the potential to put issues beyond the constitutional competence of both executives and legislatures, and presumably also beyond that of national ethics committees. The judicial discourse privileges arguments about protection of the vulnerable over those about the dignity of human life and rules certain mainstream bioethical positions out of court.<sup>17</sup> It has been argued that, in the United Kingdom, this activity has typically been amoral, in that it decides ethical issues by applying rules designed for quite different purposes.<sup>18</sup> Any resemblance to bioethical reflection is coincidental.

### Global Bioethics Governance?

National ethics committees are country specific, yet many developments at the cutting edge of medicine and science are increasingly international in nature. The science of mitochondrial DNA therapies and genome editing techniques is discussed collaboratively, yet “official” bioethics discussions of the science are largely conducted in parallel, with separate reports and regulatory responses (albeit with some conversation between them). The Human Fertilisation and Embryology Authority and the Nuffield Council have undertaken consultations and published reports covering territory very similar to that explored by the U.S. National Academy of Medicine, for example.

Many issues, such as safety and effectiveness, are likely to raise the same considerations across nations. On these issues, working in parallel—each national bioethics commission examining the science on its own—seems a wasted effort. Some other questions, however, may be seen differently in different societies, and for these issues, national bioethics commissions can ensure that the philosophical substance is debated and explored, providing more than conflict management and diplomacy. This kind of examination is required if bioethics governance is to be more than a response to moral disagreement—the challenge of pluralism. These disagreements must be worked through in a way that avoids mere relativism.<sup>19</sup>

Nuffield is working on two topics that raise global questions: the “rule” that germ-line gene therapies are inconsistent with human dignity as that concept is understood in the United Nations Educational, Scientific, and Cultural Organization’s Declaration on Bioethics and Human Rights,<sup>20</sup> and the rule—in this case, concrete legislation in the United Kingdom—that research on human embryos

should not be conducted on those that are fourteen or more days old. Although both rules are long established, they constrain scientific research that we now have reasons to think might be fruitful.

As a community of national ethics committees, we should work out whether there are sound moral arguments behind the current positions or whether they were no more than a consensus formulation that enabled the debate to be deferred to a future time. Perhaps that time is now.

The U.K. legislation links the fourteen-day rule with the appearance of the embryo's primitive streak. The Warnock report, on which the legislation is based, suggested that this linkage met the need for a "precise decision" that could allay public anxiety about research on embryos because the appearance of the primitive streak "marks the beginning of individual development"<sup>21</sup> This scientific fact drew its normative significance from acceptance. The U.K. experience may plausibly be characterized as a compromise that has been stable because it remained broadly acceptable both to the interested publics and to scientists. The UNESCO Declaration has been the subject of academic critique, but it has endured as a document around which bioethics debate can revolve. It could be described as philosophically problematic but practically useful. Together, we need to ask whether bioethics is a matter for harmonization on a global scale or national differentiation.

I sometimes wonder whether the United Kingdom should be considered a rogue bioethics state—it has no formal national bioethics committee and has not signed the European bioethics document, the Oviedo Convention. However, we take bioethics governance very seriously. The Nuffield Council seeks to display some distinctive virtues— independence, courage, inclusiveness, openness, and a particular type of practical wisdom that is pragmatic but has integrity. We are pleased to share them with other effective national bioethics commissions.

1. Firetail, *Nuffield Council on Bioethics Evaluation*, June 2015, at <http://nuffieldbioethics.org/wp-content/uploads/Nuffield-Council-on-Bioethics-Evaluation-2015.pdf>.

2. Nuffield Council on Bioethics, *Strategic Plan 2012-2016: Exploring Ethical Issues in Biology and Medicine*, 2012, accessed April 19, 2017, [http://nuffieldbioethics.org/wp-content/uploads/2014/06/Strategic\\_Plan\\_2012-20161.pdf](http://nuffieldbioethics.org/wp-content/uploads/2014/06/Strategic_Plan_2012-20161.pdf).

3. Nuffield Council on Bioethics, *The Collection, Linking and Use of Data in Biomedical Research and Health Care: Ethical Issues*, 2015, [https://nuffieldbioethics.org/wp-content/uploads/Biological\\_and\\_health\\_data\\_web.pdf](https://nuffieldbioethics.org/wp-content/uploads/Biological_and_health_data_web.pdf).

4. Nuffield Council on Bioethics, *Donor Conception: Ethical Aspects of Information Sharing*, 2013, at <http://nuffieldbioethics.org/project/donor-conception>; Nuffield Council on Bioethics, *Non-invasive Prenatal Testing: Ethical Issues*, 2017, at <http://nuffieldbioethics.org/>

project/non-invasive-prenatal-testing; C. Joynson, "Reflections on Reactions to the Council's Report on NIPT," Nuffield Council on Bioethics blog, March 9, 2017, <http://nuffieldbioethics.org/blog/reflections-reactions-councils-report-nipt>.

5. See J. Montgomery, "Reflections on the Nature of 'Public Ethics,'" *Cambridge Quarterly of Healthcare Ethics* 22, no. 1 (2013): 9-21, at 13-14.

6. Nuffield Council on Bioethics, Symposium on Building Sustainable Public Trust in the Responsible Use of Health and Care Data, London, June 19, 2015; a note about the symposium is available at [http://nuffieldbioethics.org/wp-content/uploads/NCoB-Roundtable-on-trust-note\\_FINAL\\_22-Sept-15.pdf](http://nuffieldbioethics.org/wp-content/uploads/NCoB-Roundtable-on-trust-note_FINAL_22-Sept-15.pdf).

7. Nuffield Council on Bioethics, [briefing note] Zika: Ethical Considerations, February 9, 2016, <http://nuffieldbioethics.org/wp-content/uploads/NCOB-briefing-note-zika-ethical-considerations.pdf>.

8. These terms of reference can be found in Nuffield Council on Bioethics, *Strategic Plan 2012-2016*, p. 1. They have recently been amended; for the revised wording, see Nuffield Council on Bioethics "Exploring Ethical Issues in Biology and Medicine," accessed April 19, 2017, <http://nuffieldbioethics.org/about>.

9. Presidential Commission for the Study of Bioethical Issues, *Bioethics for Every Generation: Deliberation and Education in Health, Science, and Technology* (Washington, D.C.: PCSBI, 2016).

10. Care Act 2014, ss 110(6), 111(3).

11. Presidential Commission for the Study of Bioethical Issues, "Ethically Impossible" STD Research in Guatemala from 1946 to 1948 (Washington, D.C.: PCSBI, 2011).

12. U.K. government, Royal Liverpool Children's Inquiry, *The Royal Liverpool Children's Inquiry Report* (HMSO HC12-II), January 30, 2001.

13. M. Warnock, "A National Ethics Committee: To Meet the Growing Public Demand for Candour," *BMJ* 297 (1988): 1626-27.

14. Nuffield Council on Bioethics, *Strategic Plan 2012-2016*, p. 1; see note 8.

15. J. Sulston et al. [cosigned by the author as chair on behalf of the Nuffield Council on Bioethics], letter, *Times* (London), January 28, 2015.

16. *R (Nicklinson) v Min Justice* [2014] UKSC 38.

17. See J. Montgomery, "The Legitimacy of Medical Law," in *First Do No Harm: Law Ethics and Medicine*, ed. S. Maclean (Aldershot, England: Ashgate, 2006), 1-16.

18. J. Montgomery, "Law and the Demoralisation of Medicine," *Legal Studies* 26 (2006): 1-26. For a critique, see C. Foster and J. Miola, "Who's in Charge? The Relationship between Medical Law, Medical Ethics and Medical Morality," *Medical Law Review* 23, no. 4 (2015): 505-30.

19. See J. Montgomery, "Bioethics as a Governance Practice," *Health Care Analysis* 24, no. 1 (2016): 3-23.

20. United Nations Educational, Scientific and Cultural Organization, Declaration on Bioethics and Human Rights, October 19, 2005, at <http://www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/bioethics-and-human-rights/>.

21. Department of Health & Social Security, *Report of the Committee of Inquiry into Human Fertilisation and Embryology* (HMSO Cmnd. 9314), July 1984, paragraphs 11.19 and 11.22. The report is commonly called the Warnock report after the committee chairperson, Mary Warnock.