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Notes

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Chapter 6: Freedom of research and constitutional law: Some critical points

- 1 Earlier research on the themes of this chapter was published in A. Santosuosso, V. Sellaroli & E. Fabio 'What Constitutional Protection for Freedom of Scientific Research?' *Journal of Medical Ethics*, 2007; 33 (6):342–344.
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- 3 In the paragraphs 2–5 I draw on previous research. See Santosuosso, Sellaroli & Fabio 'What Constitutional Protection for Freedom of Scientific Research?'.
- 4 This chapter does not aim to be a full review of constitutions worldwide. It rather focuses on some aspects of freedom of research and, in this light, some constitutions simply work as a point of view or starting point in order to illuminate those aspects.
- 5 However, some authors question the existence of something called 'scientific speech' that merits distinctive constitutional treatment: see below under par. 3.
- 6 The Italian *Assemblea Costituente* discussed in depth the opportunity to introduce an explicit provision in order to protect freedom of scientific research. Some were critical about the possibility of dedicating a part of the constitutional text to liberties of culture and thought, considered different from the traditional constitutional rights. Others doubted the need of consecrating too gravely such an activity that is free *in itself*, so diminishing its own value. Ultimately, the importance of letting the social community be free from the fascist cultural subjection prevailed and article 33 of Italian Constitution was introduced, protecting freedom of art and science and their teaching as means assuring human cultural and spiritual growth. More about the debate that took place in *Assemblea Costituente* can be found in Chieffi L. *Ricerca scientifica e tutela della persona*. Napoli: Edizioni scientifiche italiane, 1993:28 ff.

- 7 The Treaty of Lisbon made the European Union's Bill of Rights, the Charter of Fundamental Rights, legally binding. The Lisbon Treaty (Treaty of Lisbon amending the Treaty of the European Union and the Treaties establishing the European Community) adopted in Lisbon on December 13, 2007 and entered into force on December 1, 2009.
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- and engaged. The point of distinguishing the regulation of 'scientific speech' from the regulation of 'scientific research' is that research seems to involve what most would regard as conduct. Yet different forms of scientific research will possess different constitutional properties that will raise different constitutional questions. A law banning the 'research' of a mathematician, for example, would seem to prohibit reading and would for that reason likely trigger First Amendment coverage. A law banning the use of anthrax bacteria, by contrast, would likely not trigger First Amendment coverage, even though it may shut down the research of particular scientists. 'Scientific research,' in other words, is not a single, coherent constitutional category. It embraces many different phenomena that are differently connected to First Amendment values.
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 - (1) Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.

- (2) Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

International Covenant On Economic, Social And Cultural Rights, New York 1966 (Article 15):

1. The States Parties to the present Covenant recognize the right of everyone:

- (a) To take part in cultural life;
- (b) To enjoy the benefits of scientific progress and its applications;
- (c) To benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author...

- 26 On May 12, 2009, the ACLU (The American Civil Liberties Union) and the Public Patent Foundation (PUBPAT) filed a lawsuit in New York Federal Court. 'The lawsuit, Association for Molecular Pathology, v. U.S. Patent and Trademark Office, was filed on behalf of researchers, genetic counselors, women patients, cancer survivors, breast cancer and women's health groups, and scientific associations representing 150,000 geneticists, pathologists, and laboratory professionals. The lawsuit was filed against the U.S. Patent and Trademark Office, as well as Myriad Genetics and the University of Utah Research Foundation, which hold the patents on the genes, BRCA1 and BRCA2. The lawsuit charges that patents on human genes violate the First Amendment and patent law because genes are "products of nature" and therefore can't be patented': Dov Greenbaum, 'Patentable Subject Matter: Morally Neutral and Context Free', in *Recent Patents on DNA & Gene Sequences* 2011, 5, 72–80. See also Mildred Cho, 'Patently unpatentable: implications of the Myriad court decision on genetic diagnostics', *Trends in Biotechnology* (Article in Press, at July 17, 2011).
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Chapter 7: Legal methodologies for maximizing freedom of scientific research

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Chapter 8: Human tissue providers for stem cell research: Freedom, fairness and financial recompense

- 1 Wilmut I, Schnieke AE, McWhir J, Kind AJ, Campbell KH. 'Viable Offspring Derived from Fetal and Adult Mammalian Cells', *Nature* 385(6619) (1997) p. 810–3; and in relation to the large amounts of ova used in unsuccessful research by Professor Hwang Woo-Suk of South Korea see Seoul National University, 'Summary of the Final Report on Hwang's Research Allegation' (as reproduced in *New York Times* on 9 January 2006) http://www.nytimes.com/2006/01/09/science/text-clonereport.html?pagewanted=1&_r=1 [accessed 11 March 2011] and Chong S, 'Investigations Document Still More Problems for Stem Cell Researchers', *Science* 311(5762) (2006) pp. 754–755.
- 2 In this chapter the focus will be on the law of the UK. However, the arguments made will be of relevance to any jurisdiction seeking to determine whether or not to provide recompense to tissue providers.
- 3 See section 4, 1990 Act.
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Chapter 9: Ideology, fundamentalism and scientific research

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Chapter 10: The future of scientific research: compromises or ways forward?

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Chapter 11: Science, society and democracy: freedom of science as a catalyzer of liberty

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Chapter 12: Religion and scientific freedom

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- 21 This way of defining a secular state also allows for states with an established religion to be counted as secular. Norway and Denmark are thus secular according to this definition, despite having an established religion, because the democratic machinery is fully secular. In contrast the UK is not secular since some English bishops hold automatic seats in the House of Lords.
- 22 Rawls J. *Political Liberalism* (With a New Introduction and the 'Reply to Habermas'), p. 243.
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- 25 Audi R, Wolterstorff N. *Religion in the Public Square*, p. 28.
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- 35 Even if I am uniquely talented and could make a great contribution to society by pursuing this specific career.
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- 37 In a fully deliberative democracy that was also fully participative this issue would not arise, since every citizen would be fully engaged in the actual decision making and would not need representation.
- 38 We seem even sometime to forgive politicians for lacking this understanding, especially if they are just 'ordinary' politicians and not specialists in taxation etc.
- 39 Examples include the 'Christian Motorcyclists Association UK' the 'Maccabi Southern Football League' and the 'Islamic Foundation for Ecology & Environmental Science' just to mention a few.
- 40 Here it is important not to get confused by the fact that some religious groups claim that you can never really exit. You may be 'lapsed' but you still belong. This is a spiritual and not a sociological claim. Even from those groups it is clearly possible to exit in a social sense.
- 41 The ideal deliberative democracy would not require every person actually to participate and would not rule out, for instance a system of representation. It would require each and every citizen to have equal, effective access to the public debate leading to decision making.
- 42 Apart from the issue of whether religious reasons are different which we have discussed previously.
- 43 But see note 17.
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Chapter 13: Should we strive for total scientific freedom?

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- 31 Different ethical issues, outside the scope of this chapter, arise with privately-funded projects.
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Chapter 14: The ethical limitations on scientific research

- 1 My exposition of the Principle of Plenitude is not meant to be a faithful representation of Lovejoy's intent in his expression of the principle. Rather, I am taking his principle and applying it to the issue of how scientists view their mission in their activity in the context of Lovejoy's principle. Arthur O. Lovejoy, *The Great Chain of Being* (Cambridge, MA: Harvard University Press, 1936).
- 2 There has been much written about scientific revolutions. One starting point is with Thomas Kuhn, *The Structure of Scientific Revolutions* (Chicago: University of Chicago Press, 1962). Two prominent critiques of Kuhn's notions are Imre Lakatos and Alan Musgrave, eds., *Criticism and the Growth of Knowledge*, (Cambridge: Cambridge University Press, 1970) and Karl Popper, *Conjectures and Refutations: The Growth of Scientific Knowledge* (New York: Harper and Row, 1965), esp. 232ff.
- 3 The rise of individualism and its corresponding corollaries (such as the depiction of private property) has been documented by Matthew H. Kramer, *John Locke and the Origins of Private Property: Philosophical Explorations of Individualism, Community and Equality* (Cambridge: Cambridge University Press, 1997).
- 4 Unless one is an extreme act utilitarian.
- 5 'Herophilus and Erasistratus acted in by far the best way: they cut open living men—those who were condemned criminals released by the king for such purposes. These prisoners were observed while they still breathed: their body parts previously hidden were now exposed ... to cut open a living man is cruel and unnecessary, but to cut open the dead is essential for medical students.' Celsus, 'Prooemium' in *De Medicina* ed. by F. Marx (Leipzig: Teubner, 1915): 23, 74. The translation is mine.
- 6 Michael Boylan and Kevin E. Brown, *Genetic Engineering: Science and Ethics on the New Frontier* 2nd edition (Upper Saddle River, N.J.: Prentice Hall, 2012), ch. 2.
- 7 The word 'primary' here denotes one subclass of the basic goods of agency. The primary goods of agency are universal and can be defined scientifically according to the parameters of human necessity. For example,

humans generally die when their core temperature drops below a certain temperature for a given interval. Humans also, for the most part, die when they do not receive x amount calories per kilogram of weight. Likewise, humans generally lose their ability to maintain mental health when they are subject to y amount of gratuitous violence and fear. All of these can (within certain ranges) be defined for all humanity. A second level of basic goods is relative to each society. These are the goods necessary to be an effective agent within that society. For example, in the United States today it is hard to be an effective agent without a certain level of education and the protection of basic human rights (including the right not to be used as a means only). For more discussion on this see Michael Boylan, *A Just Society* (Lanham, MD and Oxford: Rowman and Littlefield, 2004) and Michael Boylan, *Morality and Global Justice: Justifications and Applications* (Boulder, CO: Westview, 2011).

- 8 Of course, as further advances in technology have occurred, investigators have been able to use even less invasive techniques so that patient risk has dropped substantially. This is always important, since risk to patient health is a relative snapshot of the state-of-the-art that researchers should always strive to improve.
- 9 Two contemporary discussions of the Tuskegee experiment that fill out the horrific details are: James Howard Jones, *Bad Blood, The Tuskegee Syphilis Experiment* (New York: Free Press, 1993) and Susan Reverby and James H. Jones, eds., *Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study* (Chapel Hill, NC: University of North Carolina Press, 2000).
- 10 There are, unfortunately, many such examples. The United States asked military personnel to act as guinea pigs during atomic bomb testing in order to determine the effect of radiation upon unprotected human subjects. This was an inhumane and immoral action comparable to the vivisection cases discussed earlier. Similar atrocities have been committed against citizens of many different countries who have tested biological and chemical warfare agents upon their own citizens.
- 11 Henry Beecher, 'Ethics and Clinical Research' *New England Journal of Medicine*, 274 (1966):1354–60.
- 12 Ezekiel J. Emanuel and Christine Grady 'Four Paradigms of Clinical Research Oversight' *Cambridge Quarterly of Healthcare Ethics*. 16 (2006): 82–96.
- 13 Sheryl Gay Stolberg, 'U.S. AIDS Research Abroad Sets Off Outcry Over Ethics' *New York Times*, September 18, 1997: A 32–33.
- 14 A. J. Jacobs, *The Guinea Pig Diaries* (New York: Simon and Schuster, 2009).
- 15 *Lancet* 'HIV-1-Vaccine-Trial Go-Ahead Reawakens Ethics Debate' 351: June 13, 1998: 1789; *Lancet* 'The Trials of Tenofovir Trials' 365: March 26, 2005: 1111, and Praphan Phanuphak, 'Ethical Issues in Studies in Thailand of the Vertical Transmission of HIV' *New England Journal of Medicine* 338.12, 19 March 2011: 834–835.
- 16 C. N. Milford, C. N. Barsdorf, and Z. Kafaar, 'What Should South African HIV Vaccine Trials do about Social Harms?' *AIDS Care* 19.9 (2007): 1110–1117.

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- 18 Matti Häyry, Tuija Takala, and Peter Herissone-Kelly, *Ethics in Biomedical Research* (Amsterdam: Rodopi, 2007).
- 19 N. Amariglio, *et al.*, 'Donor-Derived Brain Tumor Following Neural Stem Cell Transplantation in an Ataxia Telangiectasia Patient.' *PLoS Medicine* 6.2 (2009): 1029; A. Bjorklund, *et al.*, 'Risk Factors for Fatal Infectious Complications Developing Late After Allogeneic Stem Cell Transplantation.' *Bone Marrow Transplantation* 40.11(2007): 1055–62; D. Cyranoski, 'Strange Lesions After Stem-Cell Therapy.' *Nature* 465.7301 (2010): 997; Janet A. Englund, *et al.*, 'Brief Communication: Fatal Human Metapneumovirus Infection in Stem-Cell Transplant Recipients.' *Annals of Internal Medicine* 144.5 (2006): 344–9; André Tichelli, Smita Bhatia, and Gérard Socié, 'Cardiac and Cardiovascular Consequences After Haematopoietic Stem Cell Transplantation.' *British Journal of Haematology* 142.1 (2008): 11–26 and A. Tuffs, 'Stem Cell Treatment in Germany is Under Scrutiny After Death of 18 Month Old Child.' *British Medical Journal* 341.7780 (2010): 960.
- 20 Deryck Beyeleve and Shaun Pattinson, 'Precautionary Reason as a Link to Moral Action' in Michael Boylan, ed. *Medical Ethics* (Upper Saddle River, N.J., 2001): 39–52.
- 21 Secondary goods are those goods that are less necessary for basic human action than are other sorts of goods. For a discussion of this see Boylan (2004) and Boylan (2011).
- 22 Boylan 2004 Ch. 5.
- 23 Joseph Cirincione, Jon B. Wolfsthal, and Miriam Raikuman, *Deadly Arsenals: Nuclear, Biological, and Chemical Threats*, revised edition. (Washington, DC: The Carnegie Endowment for Peace, 2005) and Edward M. Spiers, *A History of Chemical and Biological Weapons* (London: Reaktion, 2010).
- 24 This is because the atomic bomb is not a *target bomb*. It cannot be used surgically against a particular target, but instead is broad in its effects killing and destroying everything within a given radius.
- 25 This argument depends upon an understanding of traditional Just War Theory. For a survey of some important issues at stake see: Michael Walzer, *Just and Unjust Wars* (New York: Basic Books, 1977); Richard B. Miller, *Interpretations of Conflict: Ethics, Pacifism, and the Just War Tradition* (Chicago: University of Chicago Press, 1991); A. J. Coates, *The Ethics of War* (Manchester, UK: University of Manchester Press, 1997); F.M. Kamm, 'Failures of Just War Theory' *Ethics* 114.4 (2004): 650–692; Jeff McMahan, 'The Ethics of Killing in War' *Ethics* 114.4 (2004): 693–733; David Rodin, 'Terrorism Without Intention' *Ethics* 114.4 (2004): 752–771; C.A.J. Coady, 'Terrorism, Morality, and Supreme Emergency' *Ethics* 114.4 (2004): 772–789; Seumas Miller, *Terrorism and Counterterrorism* (Malden, MA and Oxford: Blackwell, 2009).

- 26 Most philosophers consider the work of Willard Van Orman Quine to be pioneering with respect to opaque contexts. Basically, an opaque context is created when a construction resists the substitutivity of identity. Quine uses the example, (1) “‘Tully was a Roman’ is trochaic”. (1) is a true proposition. Now Tully is identical to Cicero, so it would seem as if you could create the proposition (2) “‘Cicero was a Roman’ is trochaic”. But (2) is false since ‘Cicero’ is a dactyl. For a more complete discussion see: Willard Van Orman Quine, *Word and Object* (Cambridge, MA: M.I.T. Press, 1960), pp. 141ff.
- 27 According to the *Encyclopedia Americana* (Danbury, CT: Grolier, 1995), the number of people killed at Hiroshima was 271,000 and at Nagasaki 71,000. For further background on this devastation see: John Hershey *Hiroshima* (New York: Vintage, rpt. 1989); Robert Jay Lifton and Greg Mitchell *Hiroshima in America: A Half Century of Denial* (New York: Avon, 1996), and Kyoko Selden Mark Selden, eds., *The Atomic Bomb: Voices from Hiroshima* Armonk (NY: M.E. Sharpe, 1997).
- 28 Michael Boylan, *Basic Ethics* 2nd edition (Upper Saddle River, NJ: Prentice Hall, 2009).
- 29 The situation of the Trolley Problem is this: you are the engineer of a trolley and the trolley has gotten almost out of control. You cannot stop your trolley. You are approaching Lincoln Junction. On the right track is a school bus filled with children. On the left track is a homeless person whose poorly fitting shoes have caught in the track. As the engineer, you have the choice of moving your lethal train from the right track to the left. This is your only choice. What do you do? Is there an ethical justification for your choice?
- 30 The numbers of civilian Japanese casualties would have been miniscule. Even including the deaths of Japanese combatants, this strategy would have killed the fewest number of people. Yet, few know about this option.
- 31 Dietrich Bonhoeffer, *Letters and Papers from Prison*, Eberhard Bethge ed. (New York: Macmillan, 1997) and Eberhard Bethge and Victoria J. Barnett, eds., *Dietrich Bonhoeffer: A Biography* (Philadelphia: Fortress Press, 2000).
- 32 J. Robert Oppenheimer, *Atom and Void: Essays on Science and Community* (Princeton, NJ: Princeton University Press, 1989).
- 33 Of course there are some that believe that the sin of Odysseus was thirst for knowledge. Alfred Lord Tennyson frames his poem ‘Ulysses’ upon the thesis that the lack of self-control toward the acquisition of new knowledge was the cause of ‘Ulysses’ long journey home.

Chapter 15: What’s special about *scientific* freedom?

- 1 Hans Jonas, ‘Freedom of Scientific Inquiry and the Public Interest,’ *Hastings Center Report* (1976) 6:4, 15–17, p. 15.
- 2 *Ibid.*
- 3 *Ibid.*
- 4 Cf. Robert Paul Wolff, *In Defense of Anarchism (with a new preface)*, (University of California Press, 1998).
- 5 John Gray, *Two Faces of Liberalism*, (Cambridge: Polity Press, 2000).

- 6 Harvey Brooks, 'The Problem of Research Priorities,' (1978) *Daedalus* 107:2, 171–190.
- 7 *Ibid.*, pp. 171–172.
- 8 *Ibid.*, p. 182.
- 9 *Ibid.*
- 10 I.e. there will be independent reasons why scientists (and others) will demand that their peers conform with the norms of science ethics.
- 11 Mary M Cheh, 'Government Control of Private Ideas—Striking a Balance Between Scientific Freedom and National Security,' *Jurimetrics Journal* (1982) 23, 1–32, p. 1.
- 12 Lewis C Mainzer, 'Scientific Freedom in Government-Sponsored Research,' *Journal of Politics* (1961) 23, 212–230, p. 213.
- 13 Loren R Graham, 'Concerns about Science and Attempts to Regulate Inquiry,' *Daedalus* (1978) 107:2, 1–21.
- 14 Jonas, 'Freedom of Scientific Inquiry and the Public Interest,' p. 16.
- 15 *Ibid.*, p. 15.
- 16 *Ibid.*, p. 16.
- 17 Peter Singer, 'Ethics and the Limits of Scientific Freedom,' *Monist* (1996) 79:2, 218–229.
- 18 Heather E Douglas, 'The Moral Responsibilities of Scientists (Tensions between Autonomy and Responsibility),' *American Philosophical Quarterly* (2003) 41:1, 59–68.
- 19 *Ibid.*, p. 63.
- 20 *Ibid.*
- 21 *Ibid.*, p. 64.
- 22 *Ibid.*
- 23 Sissela Bok, 'Freedom and Risk,' *Daedalus* (1978) 107:2, 115–127.
- 24 Cf. John Coggon, *What Makes Health Public?* (Cambridge: Cambridge University Press, 2012), chapter 7. See also Madison Powers, 'Bioethics as Politics: The Limits of Moral Expertise,' *Kennedy Institute of Ethics Journal* (2005) 15:3, 305–322.
- 25 Singer, 'Ethics and the Limits of Scientific Freedom,' p. 229.
- 26 Bok, 'Freedom and Risk,' p. 124.
- 27 See John Rawls, *A Theory of Justice – revised edition*, (Oxford: Oxford University Press, 1999).
- 28 Raymond Geuss, *Philosophy and Real Politics*, (Princeton and Oxford: Princeton University Press, 2008).
- 29 *Ibid.*, p. 85.
- 30 *Ibid.*
- 31 See for example John Harris, 'Scientific research is a moral duty,' *Journal of Medical Ethics* (2005) 31:4, 242–248.
- 32 See Matti Häyry, *Rationality and the Genetic Challenge – Making People Better?* (Cambridge: Cambridge University Press, 2010).
- 33 See also John Coggon, 'Confrontations in "Genethics": Rationalities, Challenges and Methodological Responses,' *Cambridge Quarterly of Healthcare Ethics* (2011) 20:1, 46–55.

- 34 See Gray, *Two Faces of Liberalism*.
- 35 *Ibid.*
- 36 See Coggon, *What Makes Health Public?*, Part III.
- 37 Cheh, 'Government Control of Private Ideas,' p. 18.
- 38 James W Nickel, 'Who Needs Freedom of Religion?' (2005) *University of Colorado Law Review* 76, 941–964.
- 39 *Ibid.*, p. 941.
- 40 *Ibid.*, p. 943.
- 41 *Ibid.*
- 42 *Ibid.*, pp. 950–951.
- 43 *Ibid.*, p. 951.
- 44 *Ibid.*
- 45 *Ibid.*, p. 959.

Conclusion: A short history of this Anthology

- 1 We wish to thank Silvia Celestini for reading and commenting on this contribution.
- 2 Further petitions will address the problem of clinical trials, sexual and reproductive rights, assisted reproduction and end-of-life decisions in Europe. Any citizen, acting individually or jointly with others, may at any time exercise his right of petition to the European Parliament under Article 194 of the EC Treaty. Our petitions can be signed on <http://www.freedomofresearch.org/>