

CASE STUDIES IN BIOETHICS & SOCIETY

Indicative syllabus

Credits: 30

Module Convenor: [Dr Silvia Camporesi](#)

Office: D6, 3rd floor, East Wing, King's Building

Consultation time: TBD

Semester: Second

Lecture time and venue: TBD

MODULE DESCRIPTION

This module offers students a critical introduction to key concepts and topics in bioethics, using a bottom-up approach based on case studies and grounded in current debates and controversies surrounding the developments of biomedicine and neuroscience. Through the case-study approach, the module aims to enable students to understand how such controversies and proposed solutions emerge in unique social, political and regulatory contexts. Some of the concepts and topics covered include well-being, reproductive freedom, and enhancement.

The course will run over 10 weeks for 3 hours weekly: 1.5 hours of lecture, and 1.5 hours of presentation and discussion of an illustrative case study when appropriate.

The module is compulsory for students of the MA in Bioethics & Society, but is also open and of interest for students taking other postgraduate programmes at SSHM. It is designed to be complementary to the module 'Foundations in Bioethics & Society' that is a core module for the MA in Bioethics & Society in the first term.

Assessment methods and deadlines

Written formative essay: one x 2,000-word essay (only formative)

Written summative essay: one x 4,000-word essay (100 % total grade)

OUTLINE OF CONTENTS AND READINGS

Week 1: Respect for autonomy and Informed Consent

Where we critically discuss, with the aid of a relevant case study from clinical ethics, the fundamental concepts of autonomy and informed consent, the relations between the two and the grounds that have been proposed as legitimate to override autonomy.

Readings:

Required:

Varelius, J. (2003). Autonomy, subject-relativity, and subjective and objective theories of well-being in bioethics. *Theoretical Medicine and Bioethics*, 24(5), 363-379.

Manson, N. C., & O'Neill, O. (2007). *Rethinking informed consent in bioethics* (Vol. 1). Cambridge: Cambridge University Press. (Chapter 7: 154-171)

Faden, R and Beauchamp T (1986), *A History and Theory of Informed Consent*, New York: Oxford University Press. (Chapter 7, pp 235-273).

Veatch, R. M. (1996). Which grounds for overriding autonomy are legitimate?. *Hastings Center Report*, 26(6), 42-43.

Recommended:

de Melo-Martín, I, and A Ho. 2008. Beyond informed consent: the therapeutic misconception and trust. *Journal of Medical Ethics* 34, no. 3 (March): 202-205. doi:10.1136/jme.2006.019406.

O'Neill, O. (2002). *Autonomy and trust in bioethics*. Cambridge University Press.

Taylor, James. 2005. *Personal autonomy : new essays on personal autonomy and its role in contemporary moral philosophy*. New York: Cambridge University Press.

Weeks 2: Choosing Children: the Non-Identity Problem, and the Right to an Open Future

Where we critically discuss, through the aid of a case study of genetic technologies applied to use children's traits in pre-implantation genetic diagnosis, the 'non-identity problem' and the right to an open future in bioethics.

Readings:

Required:

Feinberg, J. (1980). *Freedom and fulfillment: Philosophical essays*. Princeton, NJ: Princeton University Press (Chapter 3, pp 73-97)

Mills, C. (2003). The child's right to an open future?. *Journal of Social Philosophy*, 34(4), 499-509.

Lotz, M. (2006). Feinberg, mills, and the child's right to an open future. *Journal of social philosophy*, 37(4), 537-551.

Glover, J. (2006). *Choosing Children: Genes, Disability, and Design: Genes, Disability, and Design*. Oxford University Press (Chapter 2: pp 37-62)

Camporesi, S. (2010). Choosing deafness with preimplantation genetic diagnosis: an ethical way to carry on a cultural bloodline?. *Cambridge Quarterly of Healthcare Ethics*, 19(01), 86-96.

Recommended:

Parfit, D. (1984). *Reasons and persons*. Oxford University Press. (Chapter 16: 351-377)

Velleman D (2008) The identity problem, *Philosophy & Public Affairs*, pp 221-224 DOI: 10.1111/j.1088-4963.2008.00139_1.x <http://onlinelibrary.wiley.com/doi/10.1111/papa.2008.36.issue-3/issuetoc>

Hope, T., & McMillan, J. (2012). Physicians' duties and the non-identity problem. *The American Journal of Bioethics*, 12(8), 21-29.

Shoemaker, D. (2010). The insignificance of personal identity for bioethics. *Bioethics*, 24(9), 481-489.

Velleman, J. D. (2011). Forget What Might Have Been. *Available at SSRN 1917383*.

Weeks 3: Human Nature and Personhood at the cross-roads of Ability, Disability and Super-Ability: Towards a Post-Human future?

Where we critically discuss, with the aid of a relevant case study from disability studies, the fundamental concepts of human nature and personhood, and the implications that new biomedical technologies have on them within the bioethics debate of a post-human future.

Readings:

Required:

Scully, J. L. (2008). *Disability bioethics: Moral bodies, moral difference*. Rowman & Littlefield.

Shakespeare, T. (2013). *Disability Rights and Wrongs Revisited*. Routledge.

Juengst, E. T. (2013). Subhuman, Superhuman, and Inhuman: Human Nature and the Enhanced Athlete. In *Athletic Enhancement, Human Nature and Ethics* (pp. 89-103). Springer Netherlands.

Camporesi, S. (2008). Oscar Pistorius, enhancement and post-humans.

Recommended:

Garland-Thomson, R. (2012). The Case for Conserving Disability. *Journal of bioethical inquiry*, 9(3), 339-355.

Nayar, P. K. (2013). *Posthumanism*. Polity.

Week 4: Human Rights to Health/Healthcare, Justice and Equality

Where we critically discuss, with the aid of a relevant case study from the allocation of scarce healthcare resources, possible justifications for a human right to health or healthcare, and how this plays out with the concepts of justice and equality in healthcare.

Readings:

Required:

Brock, D. W., Daniels, N., & Wikler, D. (2001). *From chance to choice: Genetics and justice*. Cambridge University Press (Chapter 3, pp 61-99)

Verweij, M. (2009). Moral principles for allocating scarce medical resources in an influenza pandemic. *Journal of Bioethical Inquiry*, 6(2), 159-169.

Sandel, M. J. (2010). *Justice: What's the right thing to do?*. Macmillan (Chapter 6: 140-166; Chapters 8-9: 184-243)

Recommended:

Cochrane, A. (2012). Evaluating 'bioethical approaches' to human rights. *Ethical theory and moral practice*, 15(3), 309-322.

Wenar, L. (2013). The Nature of Claim-Rights. *Ethics*, 123(2), 202-229.

Week 5: Enhancement, Complicity and Authenticity

Where we discuss, through the aid of the case study of the use of Ritalin and Adderall in children and adults, the concept of enhancement, and the ethical and social issues that it raises.

Readings:

Little, M. O. (1998). Cosmetic surgery, suspect norms, and the ethics of complicity. *Enhancing human traits: ethical and social implications*, 162-176.

Parens, E. (2005). Authenticity and ambivalence: Toward understanding the enhancement debate. *Hastings Center Report*, 35(3), 34-41.

Harris, John. (2007). *Enhancing evolution : the ethical case for making better people*. Princeton NJ: Princeton University Press (Chapter 3: pp 36-58)

Singh, I. (2013). Not robots: children's perspectives on authenticity, moral agency and stimulant drug treatments. *Journal of medical ethics*, 39(6), 359-366.

Week 6: Well-being, Paternalism and Personal responsibility

Where we discuss, through the aid of a case study of a health-incentive or nudge to organ donation, the concept of well-being and how it relates to paternalism and personal responsibility in bioethics.

Readings:

Thaler, R. H., & Sunstein, C. R. (2008). *Nudge: Improving decisions about health, wealth, and happiness*. Yale University Press.

Schlag, P. (2010). Nudge, choice architecture, and libertarian paternalism. *Mich. L. Rev.*, 108, 913-919.

Verweij, M., & Hoven, M. V. D. (2012). Nudges in public health: paternalism is paramount. *The American Journal of Bioethics*, 12(2), 16-17.

Truog, R. D. (2012). When does a nudge become a shove in seeking consent for organ donation?. *The American Journal of Bioethics*, 12(2), 42-44.

Saghai, Y. (2013). Salvaging the concept of nudge. *Journal of medical ethics*.

Wikler, D., & Eyal, N. (2013). Nudges and Noodges: The Ethics of Health Promotion—New York Style. *Public Health Ethics*, pht033.

Week 7: Governance in science and biomedicine

Where we discuss, through a historical lens at genetic engineering from Asilomar 1975 up-to-now and discussion of synthetic biology, the issue of the governance of science and biomedicine in a democratic society.

Readings:

Berg, P., Baltimore, D., Brenner, S., Roblin, R. O., & Singer, M. F. (1975). Summary statement of the Asilomar conference on recombinant DNA molecules. *Proceedings of the National Academy of Sciences of the United States of America*, 72(6), 1981-1984

Berg, P. (2001). Reflections on Asilomar 2 at Asilomar 3: Twenty-five years later. *Perspectives in Biology and Medicine*, 44(2), 183-185.

Ferber, D. (2004), Time for a Synthetic Biology Asilomar? *Science* Vol. 303 no. 5655 p. 159
DOI: 10.1126/science.303.5655.159

Fukuyama, F. (2005). Human biomedicine and the problem of governance. *Perspectives in biology and medicine*, 48(2), 195-200.

Hindmarsh, R., & Gottweis, H. (2005). Recombinant regulation: the Asilomar legacy 30 years on. *Science as Culture*, 14(4), 299-307.

Abels, G. (2005). The long and winding road from Asilomar to Brussels: science, politics and the public in biotechnology regulation. *Science as Culture*, 14(4), 339-353.

Marris, C., & Rose, N. (2012). Let's get real on synthetic biology. *New Scientist*, 214(2868), 28-29.

Week 8: Advancement in brain imaging technologies: ethical and social implications

Where we critically discuss, through the aid of the case study of functional magnetic resonance to measure chronic pain, the ethical and social implications of the most recent advancement in brain imaging technologies.

Readings:

Required:

Dumit, J. (1999). Objective brains, prejudicial images. *Science in Context*, 12(01), 173-201.

Kolber, A. (2007). Pain detection and the privacy of subjective experience. In *American Journal of Law & Medicine (Brain Imaging & The Law Symposium)* (Vol. 33, p. 433).

Camporesi, S. (2011). Can We Finally See Pain?: Brain Imaging Techniques and Implications for the Law. *Journal of Consciousness Studies*, 18(9-10), 9-10.

Farahany, N. (2011). Incriminating thoughts. *Stanford Law Review*, 64, 11-17.

Recommended:

Rose, N., & Abi-Rached, J. M. (2013). *Neuro: The New Brain Sciences and the Management of the Mind*. Princeton University Press.

Khoshbin, L. S., & Khoshbin, S. (2007). Imaging the mind, minding the image: an historical introduction to brain imaging and the law. *Am. JL & Med.*, 33, 171.

Borsook, D., Sava, S. & Becerra, L. (2010) The pain imaging revolution: Advancing pain into the 21st century, *Neuroscientist*, 16 (2), pp. 171–185

Week 9: Reproductive freedom, self-determination and medical tourism

Where we critically discuss, through the aid of the case study of reproductive tourism across borders, the important and interrelated concepts of reproductive freedom and self-determination as they relate to the individual's choices in reproduction.

Readings:

Required:

Snyder, J., Crooks, V. A., & Johnston, R. (2012). Perceptions of the ethics of medical tourism: Comparing patient and academic perspectives. *Public health ethics*, 5(1), 38-46.

Cohen, I. G. (2012). How to regulate medical tourism (and why it matters for bioethics). *Developing World Bioethics*, 12(1), 9-20.

Meghani, Z. (2013). The Ethics of Medical Tourism: From the United Kingdom to India Seeking Medical Care. *International Journal of Health Services*, 43(4), 779-800.

Snyder, J., Crooks, V., JOHNSTON, R., & Kingsbury, P. (2012). Beyond sun, sand, and stitches: Assigning responsibility for the harms of medical tourism. *Bioethics*.

Recommended:

Markens, S. (2012). The global reproductive health market: US media framings and public discourses about transnational surrogacy. *Social Science & Medicine*, 74(11), 1745-1753.

Kingsbury, P., Crooks, V. A., Snyder, J., Johnston, R., & Adams, K. (2012). Narratives of emotion and anxiety in medical tourism: on State of the Heart and Larry's Kidney. *Social & Cultural Geography*, 13(4), 361-378.

Buzinde, C. N., & Yarnal, C. (2012). Therapeutic landscapes and postcolonial theory: A theoretical approach to medical tourism. *Social Science & Medicine*, 74(5), 783-787.

Week 10: What future for Bioethics?

Where we reflect on the current state and future directions for the discipline of Bioethics, through a critical discussion of the views of prominent scholars.

Readings:

Required:

Susan Sherwin (2011) Looking backwards, looking forward: hopes for 'Bioethics' next twenty-five years. *Bioethics* 25(12):75-82

John H. Evans (2012) *The History and Future of Bioethics: A Sociological View*. New York, NY: Oxford University Press (Chapters 4-5)

Brody, H. (2009). *The future of bioethics*. Oxford^ eNew York New York: Oxford University Press.

Dawson, A. (2010). The future of bioethics: three dogmas and a cup of hemlock. *Bioethics*, 24(5), 218-225.

Recommended:

Pellegrino, E. D. (1999). The origins and evolution of bioethics: some personal reflections. *Kennedy Institute of Ethics Journal*, 9(1), 73-88.

Callahan, C. (1973) Bioethics as a Discipline. *The Hastings Center Studies* 1(1):66-73