

Bioethics for Bioinformaticists

If bioethics was a publicly listed company its share price would be rising faster than some biotechnology companies. Societal debate about the ethical implications of biotechnology is increasing in synchrony with the claims made by the more optimistic advocates of biotechnology. Biotechnologists are beginning to realise that ethical and social constraints on research and technology are likely to influence their success as much technical feasibility, venture capital, and access to legal expertise to “capture” the intellectual property that they generate. There is a need for biotechnologists in general, and bioinformaticists in particular, to understand ethical concepts and to effectively contribute to public debate about the ethical and social implications of their work.

Course Aims:

The course aims to do the following:

- (1) To introduce bioinformaticists to some basic concepts in bioethics, such as, the nature of bioethics, leading theories of ethics (e.g. utilitarianism, deontology, rights-based), and leading ethical principles (autonomy, beneficence, non-maleficence and justice);
- (2) To illustrate these concepts in a contemporary ethical debate, the debate about research on human embryonic stem cells which exemplifies the relevance of ethical principles to public policy formulation and biotechnology regulation;
- (3) To apply these concepts to ethical issues that arise in bioinformatics, such as:
 - (i) Ethical issues that arise in accessing individual level patient records and genealogical data, namely, individual consent, patient privacy, confidentiality, and third party use of genetic information;
 - (ii) Ethical issues in commercialising genetic discoveries made in the course of bioinformatic research, such as, patenting DNA sequences, secrecy, copyright on software;
 - (iii) Ethical issues that arise in the use of genetic information in public and personal health, such as, population screening for susceptibility alleles and pharmacogenetics.
- (4) To learn to apply these concepts in everyday decision making in bioinformatic research and practice.

Intended audience

The primary audience is bioinformaticists employed in university research centres and in the biotechnology sector who have an interest in understanding ethical issues and in contributing more effectively to public policy in these areas. Others who may be interested include molecular and genomic biologists and people in professions with an interest in the regulation of biotechnology, such as, lawyers and administrators. The course will not assume any prior acquaintance with bioethics. All that is required is an interest in mastering some basic ethical concepts, a capacity to think critically about policy issues and an ability to contribute to group discussions about these topics.

Instructor:

Wayne Hall is Professorial Research Fellow and Director, Office of Public Policy and Ethics, Institute for Molecular Bioscience, University of Queensland where he is researching the policy and ethical implications of human embryonic stem cell research, and the genetics of addictive behaviour, cancer and mental disorders. He also has Professorial appointments in the Schools of Psychology and Political Science and International Relations. He was formerly Professor and Executive Director of the National Drug and Alcohol Research Centre at the University of New South Wales (1994-2001). He has held appointments in the Medical Schools of Universities of Western Australia (1983-1986) and New South Wales (1986-1988) where he introduced bioethics into the undergraduate medical curriculum. He has been an Adviser to the World Health Organization on: the health implications of cannabis use (1993-1996); drug substitution treatment (1995-6); the contribution of illicit drug use to the Global Burden of Disease (2000-2002); the ethics of risk management (2001), vaccines against drug addiction (2001) and neuroscience research on the addictions (2002). He is a Fellow of the Australian Academy of the Social Sciences.

Teaching experience:

Wayne Hall has taught a wide variety of undergraduate and postgraduate courses to students from a wide range of disciplines (biology, law, medicine, nursing, psychology, political science, philosophy, and public health) since 1975. He has given seminars on ethical issues (such as, the human embryonic stem cell debate, gene patenting, genetic discrimination, drug vaccines, and the global AIDS pandemic) to undergraduate and postgraduate students in philosophy, social policy, psychology, political science, biotechnology and molecular biology at the University of Queensland since taking up his current appointment in 2001.

Course Outline

1. What is bioethics?
2. Major ethical theories: utilitarianism, deontology, rights based theories
3. Major ethical principles: autonomy, beneficence, non-malificence, and justice.
4. An example of a contemporary ethical debate: the human embryonic stem cell debate
5. An overview of ethical issues that may arise in bioinformatics, namely, data linkage, individual consent, privacy, confidentiality, and third party use of genetic information; patenting DNA sequences, scientific secrecy, copyright on software; population screening for susceptibility alleles and pharmacogenetics.
6. A guided discussion of an ethical issue selected by the class from the preceding list

The first 5 topics will be presented in a didactic way with student participation and interaction encouraged. The last topic will be addressed in the second half of the tutorial in small groups with the assistance of four staff from the Office of Public Policy and Ethics.