The Ethics and Governance of Human Genetic Databases

Matti Häyry
University of Manchester
Ruth Chadwick
Cardiff University
Vilhjálmur Árnason
University of Iceland, Reykjavík
and Gardar Árnason
University of Central Lancashire, Preston

Human genetic databases raise many ethical, legal and social questions. How can we ensure that information about participants in database research will be stored securely? Would it be justifiable to grant insurance companies and employers access to this information? What are the appropriate requirements for consenting to participate in database research? A group of bioethics scholars examine whether existing ethical frameworks and social policies reflect people’s concerns, and how they may need to change in light of new scientific and technological developments.

- Focuses on four existing projects: The Medical Biobank of Umeå in Sweden, deCODE’s Health Sector Database in Iceland, the Estonian Genome Project and the UK Biobank
- Involves a range of disciplines and national perspectives
- Deals with cutting edge issues affecting the future of health care

Contents


Cambridge Law, Medicine and Ethics, 4
2007 228 x 152 mm 280pp
978-0-521-85662-1 • Hardback • c. £55.00
Property in the Body
Feminist Perspectives
Donna Dickenson
Birkbeck College, University of London

New developments in biotechnology radically alter our relationship with our bodies. Body tissues can now be used for commercial purposes, while external objects, such as pacemakers, can become part of the body. Property in the Body: Feminist Perspectives transcends the everyday responses to such developments, suggesting that what we most fear is the feminisation of the body. We fear our bodies are becoming objects of property, turning us into things rather than persons. This book evaluates how well-grounded this fear is, and suggests innovative models of regulating what has been called ‘the new Gold Rush’ in human tissue.

This is an up-to-date and wide-ranging synthesis of market developments in body tissue, bringing together bioethics, feminist theory and lessons from countries that have resisted commercialisation of the body, in a theoretically sophisticated and practically significant approach.

‘Donna Dickenson has done a brilliant job of bringing sophisticated philosophical analysis together with feminist critique to help us understand the meaning of the ‘body as property’ in the 21st century. Prof. Dickenson’s book is a gem, of both brilliance and clarity, rare in its ability to traverse the worlds of feminist theory, philosophy, ethics, and cultural anthropology in search of deeper understandings of the librarial as well as exploitative potential of the concept of the ‘body as property.’ This work of nuance and complexity can help us understand the challenges modern biotechnologies bring to the world of human relationships – in stem cell research, umbilical cord blood banks, genetic patenting, the ‘harvesting’ of eggs, and trafficking in kidneys. Dickenson literally travels the world to such distant places as Tonga to bring us a rethinking of the tired old dichotomies which have dominated discussions of bodily property. Her book is a stellar example of how feminist theorizing can illuminate universal questions about the human condition – for both men and women.’

CYNTHIA DANIELS, ASSOCIATE PROFESSOR, POLITICAL SCIENCE, DEPT. RUTGERS UNIVERSITY, NEW BRUNSWICK, NJ

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Acknowledgements; Preface; 1. Do we all have ‘feminised’ bodies now? 2. Property, objectification and commodification; 3. The Lady Vanishes; what’s missing from the stem cell debate; 4. Umbilical cord blood banks: seizing surplus value; 5. The gender politics of genetic patenting; Biobanks: consent, commercialisation and charitable trusts; 6. The new French resistance: commodification rejected?; 7. Tonga, the genetic commons and No Man’s Land; 8. Afterword; Bibliography.

Cambridge Law, Medicine and Ethics, 3
2007 228 x 152 mm 280pp 978-0-521-86792-4 • Hardback • c. £60.00 978-0-521-86732-4 • Paperback • c. £23.99

The Troubled Pregnancy
Legal Wrongs and Rights in Reproduction
J. K. Mason
University of Edinburgh

Mason looks at the legal response to those aspects of the troubled pregnancy which require or involve medico-legal intervention. The unwanted pregnancy is considered particularly in the light of the Abortion Act 1967, s.1(1)(d) and the related action for so-called wrongful birth due to faulty ante-natal care. The unexpected or unanticipated birth of a healthy child resulting from failed sterilisation is approached through an analysis of the seminal case of McFarlane and associated cases involving disability in either the neonate or the mother.

The disabled neonate’s right to sue for its diminished life is discussed and the legal approach to the management of severe congenital disease is analysed – thus following Baroness Hale in believing that care of the newborn is an integral part of pregnancy. Aspects are considered from historical and comparative perspectives, including coverage of experience in the USA, the Commonwealth and Europe.

• Provides a wide-ranging analysis of the legal reaction to management of undesired children born as a result of medical negligence
• Aspects are considered from historical and comparative perspectives
• Considers the legal regulation of the treatment of the disabled fetus or newborn child

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Cambridge Law, Medicine and Ethics, 5
2007 228 x 152 mm 300pp 978-0-521-85075-9 • Hardback • c. £60.00 978-0-521-61624-9 • Paperback • c. £23.99

Illegal Beings
Human Clones and the Law
Kerry Lynn Macintosh
Santa Clara University, California

Many people think human reproductive cloning should be a crime. Illegal Beings discusses the pros and cons of laws against human reproductive cloning. It argues that if it becomes possible for human clones to be born, laws made against cloning now are a bad idea. The laws won’t stop cloning but they will stigmatize human clones. Macintosh argues that anti-cloning laws violate the equal protection guarantee, and are unconstitutional.

• Discusses the controversial topic of human cloning and examines the pros and cons of related laws
• The only book to comprehensively examine how laws against cloning will hurt human clones
• Creates a new topic within constitutional law – existential segregation: the practice of discriminating by preventing the existence of a disfavoured class

Contents
Part I. Five Common Objections to Human Reproductive Cloning
Part II. Anti-Cloning Laws Are Bad Public Policy
Part III. Anti-Cloning Laws Violate the Equal Protection Guarantee and Are Unconstitutional
10. Anti-cloning laws classify human clones and are subject to strict scrutiny; 11. Anti-cloning laws inflict judicially cognizable injuries that confer standing; 12. Anti-cloning laws violate the equal protection guarantee; Conclusion.

2005 228 x 152 mm 280pp 978-0-521-85328-6 • Hardback • £16.99

Related Titles
Abortion and the Law
From International Comparison to Legal Policy
Albin Eser
Max-Planck-Institut für ausländisches und internationales Strafrecht
and Hans-Georg Koch
Max-Planck-Institut für ausländisches und internationales Strafrecht
Translated by Emily Silverman

This volume presents a compact summary of the results of a world-wide survey on abortion law and practice in a total of 64 countries, carried out by the Max-Planck Institute for Foreign and International Criminal Law in Freiberg, Germany. The work provides a summary of social conditions and historical developments, followed by a detailed comparison of legal regulations, and is supplemented by statistics on the termination of pregnancy. The final chapter contains reflections from a legal policy perspective.

- A new look at the contemporary issue of abortion and its legal implications
- Makes recommendations for future legal policy based on social conditions and historical developments
- Includes statistics and comparisons of legal regulations

Contents
Part I. Framework: 1. Introduction; 2. System and standard of social services; 3. The position of women in society; 4. Assessment and significance of family planning and termination of pregnancy; 5. Remarks on historical developments
Part II. Current Laws Regulating the Termination of Pregnancy: II.0 Introduction; II.1 Legal sources and regulatory methodology behind the law on the termination of pregnancy; II.2 Basic concepts in legal regulation; II.3 Permissible termination of pregnancy; II.4 Impermissible termination of pregnancy; II.5 Special role of the physician; II.6 Preventive measures; II.7 Role of termination of pregnancy in the prosecutorial arena
Part III. Statistical Information: III.0 Introduction; III.1 Termination statistics; III.2 Crime statistics; III.3 Judicial statistics and trends in prosecution
Part IV. Concluding Reflections from a Legal Policy Perspective: IV.0 Preliminary remarks; IV.1 Review: findings – insights – trends; IV.2 Outlook: starting points – guidelines; IV.3 A proposed regulation; Appendix A: Country reports; Appendix B: Publications; Index

This is a T.M.C Asser Press Publication, exclusively distributed by Cambridge University Press

Black Markets
The Supply and Demand of Body Parts
Michele Goodwin
Depaul University, Chicago

This book offers a contemporary view of organ and tissue supply and demand. It is the first book of its kind to fully engage race in the debate about organ procurement. The book explores the legal, racial, and social nuances of institutionalized procurement schemes, suggesting that the best alternative model for procurement is a market approach. Black Markets contends that exclusive reliance on the present altruistic tissue and organ procurement processes in the United States is not only rife with problems, but also imprudent.

- Illuminates the significant procurement problems in the current altruistic regime, which result in pernicious forms of rationing, delays and deaths
- Exposes the racial disparities in the current altruistic regime
- Provides a better understanding of how the current procurement process creates demands which spread into unattractive subsystems

Contents
Part E. 2. Institutional supply and demand; 3. Nuances, judicial authority, and legal limits of altruism; 4. Equal opportunity rationing: racial and economic disparities
Part II. Legal Frameworks and Alternatives: 5. The legal process of procurement and allocation: regulatory frame; 6. Presumed consent; 7. Commodification

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Human Genetics, Bioethics and Intellectual Property
International Perspectives
William Cornish
University of Cambridge

A clear and accessible analysis of the highly contested area of intellectual property in the life sciences. The text draws on a range of thought-provoking perspectives provided by international experts and in so doing seeks to clarify the scientific, historical, legal and ethical issues that have led to the deep-seated disagreements. Ultimately the authors reject the extreme standpoints of the patent and anti-patent lobbies. They argue that with incremental improvements, modern intellectual property is sufficiently nuanced to avoid accusations of over broad patents, free-riding and crude commodification of life.

2007 216 x 138 mm 300pp
978-0-521-86481-7 • HB • c. £55.00

Parental Responsibility, Young Children and Healthcare Law
Jo Bridgeman
University of Sussex

This book provides a comprehensive examination of the legal regulation of the provision of healthcare to young children in England and Wales. Consideration is given to the everyday management of the health of children, to the legal duties of parents whose child has a life-threatening illness or long-term disability and to decisions about the future care of children with life-limiting impairments. Taking responsibility presents the argument for a legal framework grounded in a moral theory of responsibilities informed by practices of caring for the health of young children.

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