The Ethics and Governance of Human Genetic Databases

*European Perspectives*

The Medical Biobank of Umeå in Sweden, deCODE’s Health Sector Database in Iceland, the Estonian Genome Project and the UK Biobank were planned to contain health data and genetic data from large populations. Some include genealogical or lifestyle information. They are resources for research in human genetics and medicine, exploring interaction between genes, lifestyle, environmental factors and health and diseases.

The collection, storage and use of this data raise ethical, legal and social issues. In this book, 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. The ethical issues of social justice, genetic discrimination, informational privacy, trust in science and consent to participation in database research are analysed, whilst an empirical survey, conducted in the four countries, demonstrates public views of privacy and related moral values in the context of human genetic databases.

The research presented in this book was conducted within the project ‘Ethical, Legal and Social Aspects of Human Genetic Databases: A European Comparison’, funded by the European Commission’s 5th Framework Programme (QLG6-CT-2001-00062).

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Cambridge Law, Medicine and Ethics

This series of books was founded by Cambridge University Press with Alexander McCall Smith as its first editor in 2003. It focuses on the law’s complex and troubled relationship with medicine across both the developed and the developing world. In the past twenty years, we have seen in many countries increasing resort to the courts by dissatisfied patients and a growing use of the courts to attempt to resolve intractable ethical dilemmas. At the same time, legislatures across the world have struggled to address the questions posed by both the successes and the failures of modern medicine, while international organizations such as the WHO and UNESCO now regularly address issues of medical law.

It follows that we would expect ethical and policy questions to be integral to the analysis of the legal issues discussed in this series. The series responds to the high profile of medical law in universities, in legal and medical practice, as well as in public and political affairs. We seek to reflect the evidence that many major health-related policy debates in the UK, Europe and the international community over the past two decades have involved a strong medical law dimension. Organ retention, embryonic stem cell research, physician assisted suicide and the allocation of resources to fund healthcare are but a few examples among many. The emphasis of this series is thus on matters of public concern and/or practical significance. We look for books that could make a difference to the development of medical law and enhance the role of medico-legal debate in policy circles. That is not to say that we lack interest in the important theoretical dimensions of the subject, but we aim to ensure that theoretical debate is grounded in the realities of how the law does and should interact with medicine and healthcare.

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