

Ethics And Governance Of Human Genetic Databases

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Bioethics scholars examine the ethical, legal and social questions raised by human genetic databases. The Medical Biobank of Umeå in Sweden, deCODE's Health Sector Database in Iceland, the Estonian Genome Project and the UK Biobank 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 analyzed, 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. EAN/ISBN : 9780511282584 Publisher(s): Cambridge University Press Format: ePub/PDF Author(s): Hayry, Matti - Chadwick, Ruth - Arnason, Vilhjalmur

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