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Nota di contenuto	Introduction; Deborah Mascalzoni -- Biobanks: a definition; Barbara Parodi -- A participatory space beyond the "autonomy versus property" dichotomy; Mariachiara Tallacchini -- Intellectual Property and Biobanks; Naomi Hawkins -- Consent, Privacy and Property in the Italian Biobanks Regulation: A Hybrid Model within EU?; Matteo Macilotti, Simone Penasa, Marta Tomasi -- Data Protection Principles and Research in the Biobanks Age; Roberto Lattanzi -- The New General Data Protection Regulation – where are we are and where might we be heading?; Jane Reichel and Anna-Sara Lind -- The Tension between Data Sharing and the Protection of Privacy in Genomics Research; Jane Kaye -- Incidental findings: the time is not yet ripe for a policy for biobanks; Jennifer Viberg, Mats G. Hansson, Sophie Langenskiöld, Pär Segerdahl -- Biobanking across borders: the challenges of harmonization; Ruth Chadwick, Heather Strange -- Governing Biobanks Through A European Infrastructure; Emmanuelle Rial-Sebbag, Anne Cambon-Thomsen -- EU governance for research and ethics in biobanks; Jane Reichel -- A Bold Experiment: Iceland’s Genomic Venture ; David Winickoff -- The Estonian Genome Center, University of Tartu; Aime Keis -- The management of the ethical

aspects of a local mental diseases biobank for research purposes. An Italian experience; Corinna Porteri -- Biobank governance in Spain: From the autonomy of research ethics committees to the autonomy of lay people; Antonio Casado da Rocha -- Public deliberation and the role of stakeholders as a new frontier in the governance of science: the British Columbia Biobank Deliberation and the DePGx Project; Claudio Corradetti, Gillian Bartlett -- Making researchers moral; Linus Johnsson, Stefan Eriksson, Gert Helgesson, Mats G. Hansson.

Sommario/riassunto

Biobank research and genomic information are changing the way we look at health and medicine. Genomics challenges our values and has always been controversial and difficult to regulate. In the future lies the promise of tailored medical treatments and pharmacogenomics but the borders between medical research and clinical practice are becoming blurred. We see sequencing platforms for research that can have diagnostic value for patients. Clinical applications and research have been kept separate, but the blurring lines challenges existing regulations and ethical frameworks.Then how do we regulate it? This book contains an overview of the existing regulatory landscape for biobank research in the Western world and some critical chapters to show how regulations and ethical frameworks are developed and work. How should international sharing work? How design an ethical informed consent? An underlying critique: the regulatory systems are becoming increasingly complex and opaque. The international community is building systems that should respond to that. According to the authors in fact, it is time to turn the ship around. Biobank researchers have a moral responsibility to look at and assess their work in relation to the bigger picture: the shared norms and values of current society. Research ethics shouldn’t only be a matter of bioethicists writing guidelines that professionals have to follow. Ethics should be practiced through discourse and regulatory frameworks need to be part of that public discourse. Ethics review should be then not merely application of bureaucracy and a burden for researchers but an arena where researchers discuss their projects, receive advice and practice their ethics skills.