

Contents

1	Introduction: A Law and Technology Approach to the Law of Biobanking	1
	Umberto Izzo, Matteo Macilotti, and Giovanni Pascuzzi	
Part I Property and Privacy in Biobanking		
2	Research Biobanks Meet Synthetic Biology: Autonomy and Ownership	11
	Stephen R. Munzer	
3	Regulating Biobanks: Another Triple Bottom Line	41
	Roger Brownsword	
4	Health Insurance, Employment, and the Human Genome: Genetic Discrimination and Biobanks in the United States	63
	Eric A. Feldman and Chelsea Darnell	
5	Ownership of Biomedical Information in Biobanks	77
	Naomi Hawkins, Nadja Kanellopoulou, Jane Kaye, Karen Melham, Paula Boddington, Liam Curren, and Heather Gowans	
6	Human Tissues in the “Public Space”: Beyond the Property/Privacy Dichotomy	87
	Mariachiara Tallacchini	
7	Should Privacy Be Abolished in Genetics and Biobanking?	105
	Amedeo Santosuosso	
8	Biobanks and Electronic Health Records: Open Issues	131
	Paolo Guarda	
9	Informed Consent and Research Biobanks: A Challenge in Three Dimensions	143
	Matteo Macilotti	

Part II Intellectual Property and Biobanks

10 The Challenges of Achieving Open Source Sharing of Biobank Data	165
Donna M. Gitter	
11 Beyond Open Source: Patents, Biobanks and Sharing	191
E. Richard Gold and Dianne Nicol	
12 Opening Research Biobanks: An Overview	209
Roberto Caso and Rossana Ducato	
13 The Roles of Material Transfer Agreements in Genetics Databases and Bio-Banks	231
Thomas Margoni	
14 Quasi-Patents and Semi-Patents in Biobanking	251
Gideon Parchomovsky and Michael Mattioli	
15 Accessing Accessions: Biobanks and Benefit-Sharing	267
Mark Perry	
16 Conveying Information, Generating Trust: The Role of Certifications in Biobanking	281
Matteo Ferrari	

Part III Biobanks: The Perspective of Biobanker's

17 Scientific and Managerial Premises and Unresolved Issues in Tumour Biobanking Activities	301
Mattia Barbareschi, Silvia Fasanella, Chiara Cantaloni, and Silvia Giuliani	
18 The Italian Prototype Networks of Research Biobanks	311
Giuliano D'Agnolo and Elena Bravo	
19 Governance of Biobanks for Cancer Research: Proposal for a Material Transfer Agreement	327
Barbara Parodi, Paola Visconti, Tiziana Ruzzon, and Mauro Truini	
Index	333

Comparative Issues in the Governance of Research
Biobanks

Property, Privacy, Intellectual Property, and the Role of
Technology

Pascuzzi, G.; Izzo, U.; Macilotti, M. (Eds.)

2013, VIII, 339 p. 7 illus., Hardcover

ISBN: 978-3-642-33115-2