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