

# Contents

<b>Ethics Law and Governance of Biobanking: A Very Complex Normative Puzzle</b> .....	1
Deborah Mascalcioni	
<b>Biobanks: A Definition</b> .....	15
Barbara Parodi	
<b>A Participatory Space Beyond the “Autonomy Versus Property” Dichotomy</b> .....	21
Mariachiara Tallacchini	
<b>Intellectual Property and Biobanks</b> .....	39
Naomi Hawkins	
<b>Consent, Privacy and Property in the Italian Biobanks Regulation: A Hybrid Model Within EU?</b> .....	53
Matteo Macilotti, Simone Penasa and Marta Tomasi	
<b>Data Protection Principles and Research in the Biobanks Age</b> .....	79
Roberto Lattanzi	
<b>The New General Data Protection Regulation—Where Are We Are and Where Might We Be Heading?</b> .....	95
Jane Reichel and Anna-Sara Lind	
<b>The Tension Between Data Sharing and the Protection of Privacy in Genomics Research</b> .....	101
Jane Kaye	

<b>Incidental Findings: The Time Is not yet Ripe for a Policy for Biobanks. . . . .</b>	<b>121</b>
Jennifer Viberg, Mats G. Hansson, Sophie Langenskiöld and Pär Segerdahl	
<b>Biobanking Across Borders: The Challenges of Harmonisation . . . . .</b>	<b>133</b>
Ruth Chadwick and Heather Strange	
<b>Governing Biobanks Through a European Infrastructure . . . . .</b>	<b>139</b>
Emmanuelle Rial-Sebbag and Anne Cambon-Thomsen	
<b>EU Governance for Research and Ethics in Biobanks . . . . .</b>	<b>153</b>
Jane Reichel	
<b>A Bold Experiment: Iceland's Genomic Venture . . . . .</b>	<b>187</b>
David Winickoff	
<b>The Estonian Genome Center, University of Tartu . . . . .</b>	<b>211</b>
Aime Keis	
<b>Management of the Ethical Aspects of a Local Mental Diseases Biobank for Research Purposes: The Italian Experience . . . . .</b>	<b>219</b>
Corinna Porteri	
<b>Biobank Governance in Spain: From the Autonomy of Research Ethics Committees to the Autonomy of Lay People . . . . .</b>	<b>227</b>
Antonio Casado da Rocha	
<b>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 . . . . .</b>	<b>241</b>
Claudio Corradetti and Gillian Bartlett	
<b>Making Researchers Moral . . . . .</b>	<b>261</b>
Linus Johnsson, Stefan Eriksson, Gert Helgesson and Mats G. Hansson	



<http://www.springer.com/978-94-017-9572-2>

Ethics, Law and Governance of Biobanking  
National, European and International Approaches  
Mascalzoni, D. (Ed.)  
2015, VIII, 277 p., Hardcover  
ISBN: 978-94-017-9572-2