

Contents

	<i>List of contributors</i>	<i>page x</i>
1	Introduction: some lessons of ELSAGEN VILHJÁLMUR ÁRNASON	1
Part I Background		9
2	On human genetic databases GARDAR ÁRNASON	11
3	American principles, European values and the mezzanine rules of ethical genetic databanking MATTI HÄYRY AND TUIJA TAKALA	14
4	The languages of privacy SALVÖR NORDAL	37
Part II Social concerns		43
5	A sociological perspective: public perceptions of privacy and their trust in institutions managing and regulating genetic databases KJELL E. ERIKSSON, MARGRÉT LILJA GUDMUNDSDÓTTÍR, KÜLLIKI KORTS AND SUE WELDON	45
6	Estonia KÜLLIKI KORTS	47

viii	Contents	
7	Iceland	
	MARGRÉT LILJA GUDMUNDSDÓTTIR AND SALVÖR NORDAL	53
8	Sweden	
	KJELL E. ERIKSSON	59
9	United Kingdom	
	SUE WELDON	66
10	Public discourses on human genetic databases	
	PIIA TAMMPUU	73
Part III Legal issues		89
11	Regulating human genetic databases in Europe	
	JANE KAYE	91
12	Consent and population genetic databases: a comparative analysis of the law in Iceland, Sweden, Estonia and the UK	
	HÖRDUR HELGI HELGASON	97
13	Third parties' interests in population genetic databases: some comparative notes regarding the law in Estonia, Iceland, Sweden and the UK	
	LOTTA WENDEL	108
14	Transforming principles of biolaw into national legislation: comparison of four national laws in three aspects	
	ANTS NÖMPER	120
15	Governance of population genetic databases: a comparative analysis of legal regulation in Estonia, Iceland, Sweden and the UK	
	SUSAN M. C. GIBBONS	132
16	The legal jigsaw governing population genetic databases: concluding remarks on the ELSAGEN legal findings	
	JANE KAYE	141

Part IV Ethical questions	147
17 Introduction: ethical questions VILHJÁLMUR ÁRNASON	149
18 Pursuing equality: questions of social justice and population genomics SARAH WILSON AND RUTH CHADWICK	150
19 Benefit-sharing and biobanks KADRI SIMM	159
20 Genetic discrimination LENA HALLDENIUS	170
21 Privacy SALVÖR NORDAL	181
22 Trust MARGIT SUTROP	190
23 Informed consent and human genetic database research SIGURDUR KRISTINSSON AND VILHJÁLMUR ÁRNASON	199
Part V Political considerations	217
24 The impact of biobanks on ethical frameworks RUTH CHADWICK AND MARK CUTTER	219
25 Genetics, rhetoric and policy GARDAR ÁRNASON	227
26 Genetic databases and governance RAINER KATTEL	236
Part VI Conclusion	247
27 Bioethical analysis of the results: how well do laws and regulations address people's concerns? MATTI HÄYRY AND TUIJA TAKALA	249
<i>Bibliography</i>	257
<i>Index</i>	276