Contents

	Preface	page xii
1	Introduction Genetic data The legal protection of genetic privacy Assessing privacy protection Public cf. private interest Structure	1 3 5 7 8 10
Pa	art I The context	11
2	Privacy What is privacy? Privacy as control Value and control Privacy as a norm of exclusivity Norms and the transactional variable Norms, transactions and the relational variable Privacy, public interest and legitimacy Public expectations and genetic research Reflection	13 14 17 22 25 26 28 29 34 38
3	Genetic data Data and information Genetic data cf. genetic information What is genetic information? What cf. whether Genetic information as an indicator A composite understanding of genetic information Private vs. observable cf. sensitive vs. non-sensitive Personal genetic information vs. human genetic information Changing access to genetic information Reflection	41 41 43 44 47 48 53 55 57 57 58 60
4	The law SECTION I A LEGAL CONCEPT OF PRIVACY Universal Declaration of Human Rights	62 64 64

x Contents

The European Convention for the Protection of Human Rights	
and Fundamental Freedoms	66
Research and proportionate interference	73
Research and data protection	74
The Data Protection Directive (95/46/EC)	76
What is personal data?	78
Multiple data subjects and biological samples	80
Personal data and norms of exclusivity	82
Legitimate data processing	
Supplementary material?	85
Other principles of data protection	87
Rights to access and to object	89
SECTION II INTERNATIONAL LEGAL STANDARDS APPLICABLE	
SPECIFICALLY TO GENETIC DATA	93
Transactional variable	
Relational variable	96
Reflections	

Part II The critique

101

5	Data in common	103
	Terminology	104
	Family members (and other affected individuals)	106
	Structure	107
	SECTION I DATA SUBJECTS AND GENETIC DATA IN COMMON	109
	Defining data subjects	110
	Can data 'relate to' more than one individual?	111
	Can genetic data 'relate to' more than one individual?	113
	SECTION II WHY MIGHT RECOGNISING MULTIPLE (GENETIC) DATA	
	SUBJECTS BE PROBLEMATIC?	116
	English law and secondary data subjects	119
	Durant v. FSA [2003]	120
	Passing the threshold	121
	Problems with not recognising multiple data subjects	122
	Inadequate protection	122
	Alternative responses	124
	SECTION III ADDRESSING THE BALANCE	126
	How should data be understood to 'relate to' another individual in order	
	for that data to be personal data?	127
	Expanding the exemptions	129
6	Anonymity	131
	Structure	131
	SECTION I TERMINOLOGY	134
	SECTION II DATA PROTECTION AND ANONYMOUS DATA	138
	The burden of compliance and the UK implementation of identifiability	140
	Can a data controller meet responsibilities to an anonymous data subject?	142
	Notification	142
	Access and objection	143
	Reasons to protect anonymous data	145

	Contents	xi
	Zorro's mask and re-identification	146
	Fresh association	149
	Anonymity and failure to protect group interests	150
	Private data cf. identifiable data	151
	Are we overprotecting identifiability?	153
	Reflection	155
7	Human tissue	157
	Structure	160
	SECTION I HUMAN BIOLOGICAL MATERIAL, SAMPLES,	
	DATA AND INFORMATION	161
	SECTION II PERSONAL DATA, BIOLOGICAL SAMPLES	
	AND NORMATIVE EXPECTATIONS	164
	Normative expectations	165
	Convention on Human Rights and Biomedicine	167
	The Declaration of Helsinki	169
	International Declaration on Human Genetic Data	172
	International guidance on the use of genetic data within biobanks	174
	SECTION III THE FINITE NATURE OF DATA – A RELEVANT	1.7.5
	DISTINCTION? Advantages to treating biological samples as 'personal data'	175 176
	Reflection	170
	Kencetton	170
8	Genetic discrimination	180
	Structure	182
	SECTION I TERMINOLOGY	183
	Three kinds of genetic discrimination	185
	SECTION II PROBLEMS OF DISTINCTION AND DEFINITION	188
	An alternative approach?	190
	Drawing a distinction within different kinds of discrimination	191
	Drawing a line within primary genetic discrimination	192
	Drawing a line within secondary or tertiary genetic discrimination	193
	SECTION III IMPLICATIONS FOR REGULATORY REFORM	197
~		
Pa	art III The consequence	199
9	Potential, promise and possibility	201
	Personal information and privacy protection: a dysfunctional relationship	202
	The limits of personal information	203
	The interpretive pedigree of recorded information	204
	Consent	206
	Anonymisation	210
	Implications for reform: short term	211
	Implications for reform: medium term	216
	Implications for reform: long term	219
	Index	222
		444