

# Contents

---

## *Preface*

page xii

1	Introduction	1
	Genetic data	3
	The legal protection of genetic privacy	5
	Assessing privacy protection	7
	Public cf. private interest	8
	Structure	10

## **Part I The context** 11

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

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	83
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	94
Relational variable	96
Reflections	97
 <b>Part II The critique</b>	 <b>101</b>
 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 <i>genetic</i> 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
<i>Durant v. FSA</i> [2003]	120
Passing the threshold	121
Problems with <i>not</i> 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

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
<b>7 Human tissue</b>	<b>157</b>
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 DISTINCTION?	175
Advantages to treating biological samples as 'personal data'	176
Reflection	178
<b>8 Genetic discrimination</b>	<b>180</b>
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 <i>within</i> 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
<b>Part III The consequence</b>	<b>199</b>
<b>9 Potential, promise and possibility</b>	<b>201</b>
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
<i>Index</i>	222