

Contents

<i>Preface</i>	<i>page vii</i>
<i>Acknowledgements</i>	<i>xii</i>
I Consent: Nuremberg, Helsinki and beyond	I
Introduction	I
Beginning at Nuremberg	2
Extending scope: from research ethics to clinical ethics	4
Raising standards: explicit and specific consent	6
Improving justifications: the quest for autonomy	16
Regulatory reinforcement: consent requirements	22
Conclusion	24
2 Information and communication: the drift from agency	26
Framing informed consent	27
Two layers of distortion	34
Information and the drift from agency	34
What the conduit and container metaphors hide	38
Conclusion	48
3 Informing and communicating: back to agency	50
Agency	50
Communicative actions	54
Communicative norms	57
Two 'models' of information and communication	64
4 How to rethink informed consent	68
Introduction: two models of informed consent	68
Why consent transactions matter: beyond autonomy	69
Justifying consent transactions: consent as waiver	72
Scope and standards	77
Consent transactions: standards for communication	84
Consent transactions: commitments	90
Conclusion: consent in practice	94

5	Informational privacy and data protection	97
	Informational privacy	100
	Informational rights and obligations	101
	Informational privacy as a right over content	105
	Data protection legislation: second-order informational obligations	111
	Rethinking informational privacy	121
	Confidentiality: regulating communicative action rather than information content	123
	Conclusion	128
6	Genetic information and genetic exceptionalism	130
	Questions about genetic information	131
	Genetic privacy and genetic exceptionalism	133
	Is Genetic information contained within DNA?	145
	Conclusion	149
7	Trust, accountability and transparency	154
	Consent, paternalism and trust	154
	Placing and refusing trust intelligently	159
	Accountability and trustworthiness	167
	Accountability, trustworthiness and trust in biomedicine	169
	Accountability with transparency	177
	Appendix: the structure of accountability	181
	Some conclusions and proposals	183
	Informed consent and epistemic norms	184
	Informed consent and individual autonomy	185
	Informed consent as waiver	187
	Practices and policies for informed consent	189
	After rethinking: the possibility of change	198
	<i>Bibliography</i>	201
	<i>Institutional sources and documents</i>	207
	<i>Index</i>	211