The privacy concerns discussed in the 1990s in relation to the New Genetics failed to anticipate the relevant issues for individuals, families, geneticists and society. Consumers, for example, can now buy their personal genetic information and share it online. The challenges facing genetic privacy have evolved as new biotechnologies have developed, and personal privacy is increasingly challenged by the irrepressible flow of electronic data between the personal and public spheres and by surveillance for terrorism and security risks.

This book considers the right to know and the right not to know about our own and others’ genomes. It discusses new privacy concerns and developments in ethical thinking, with the greater emphasis on solidarity and equity. The multidisciplinary approach covers current topics such as biobanks and forensic databases, DIY testing, group rights and accountability, the food we eat and the role of the press and the new digital media.

**Ruth Chadwick** is Professor of Bioethics at the University of Manchester. She directed the ESRC Centre for Economic and Social Aspects of Genomics (Cesagen) from 2002 to 2013.

**Mairi Levitt** is a senior lecturer in the Department of Politics, Philosophy and Religion at Lancaster University, where she works in empirical bioethics and researches ethical and social issues in genetics.

**Darren Shickle** is Professor of Public Health at the University of Leeds, where his research interests include public health ethics, public health genetics, ophthalmic public health, and HIV and sexual health.
Cambridge Bioethics and Law

This series of books was founded by Cambridge University Press with Alexander McCall Smith as its first editor in 2003. It focuses on the law's complex and troubled relationship with medicine across both the developed and the developing world. Since the early 1990s, we have seen in many countries increasing resort to the courts by dissatisfied patients and a growing use of the courts to attempt to resolve intractable ethical dilemmas. At the same time, legislatures across the world have struggled to address the questions posed by both the successes and the failures of modern medicine, while international organisations such as the WHO and UNESCO now regularly address issues of medical law.

It follows that we would expect ethical and policy questions to be integral to the analysis of the legal issues discussed in this series. The series responds to the high profile of medical law in universities, in legal and medical practice, as well as in public and political affairs. We seek to reflect the evidence that many major health-related policy debates in the UK, Europe and the international community involve a strong medical law dimension. With that in mind, we seek to address how legal analysis might have a trans-jurisdictional and international relevance. Organ retention, embryonic stem cell research, physician-assisted suicide and the allocation of resources to fund health care are but a few examples among many. The emphasis of this series is thus on matters of public concern and/or practical significance. We look for books that could make a difference to the development of medical law and enhance the role of medico-legal debate in policy circles. That is not to say that we lack interest in the important theoretical dimensions of the subject, but we aim to ensure that theoretical debate is grounded in the realities of how the law does and should interact with medicine and health care.

Series Editors

Professor Margaret Brazier, University of Manchester
Professor Graeme Laurie, University of Edinburgh
Professor Richard Ashcroft, Queen Mary, University of London
Professor Eric M. Meslin, Indiana University

Books in the series

Marcus Radetzki, Marian Radetzki, Niklas Juth Genes and Insurance: Ethical, Legal and Economic Issues
Ruth Macklin Double Standards in Medical Research in Developing Countries
Donna Dickenson Property in the Body: Feminist Perspectives
Matti Häyry, Ruth Chadwick, Vilhjálmur Árnason, Gardar Árnason The Ethics and Governance of Human Genetic Databases: European Perspectives
Ken Mason The Troubled Pregnancy: Legal Wrongs and Rights in Reproduction
Daniel Sperling Posthumous Interests: Legal and Ethical Perspectives
Keith Syrett Law, Legitimacy and the Rationing of Health Care
Alastair Maclean Autonomy, Informed Consent and the Law: A Relational Change
Heather Widdows, Caroline Mullen The Governance of Genetic Information: Who Decides?
David Price Human Tissue in Transplantation and Research
Matti Häyry Rationality and the Genetic Challenge: Making People Better?
Anne-Maree Farrell, David Price and Muireann Quigley Organ Shortage: Ethics, Law and Pragmatism
Sara Fovargue Xenotransplantation and Risk: Regulating a Developing Biotechnology
Mark Taylor Genetic Data and the Law: A Critical Perspective on Privacy Protection
Anne-Maree Farrell The Politics of Blood: Ethics, Innovation and the Regulation of Risk
Stephen Smith End-of-Life Decisions in Medical Care: Principles and Policies for Regulating the Dying Process
Michael Parker Ethical Problems and Genetics Practice
William W. Lowrance Privacy, Confidentiality, and Health Research
Kerry Lynn Macintosh Human Cloning: Four Fallacies and Their Legal Consequence
Heather Widdows The Connected Self: The Ethics and Governance of the Genetic Individual
Amel Alghrani, Rebecca Bennett and Suzanne Ost Bioethics, Medicine and the Criminal Law Volume I: The Criminal Law and Bioethical Conflict: Walking the Tightrope
Danielle Griffiths and Andrew Sanders Bioethics, Medicine and the Criminal Law Volume II: Medicine, Crime and Society
Margaret Brazier and Suzanne Ost Bioethics, Medicine and the Criminal Law Volume III: Medicine and Bioethics in the Theatre of the Criminal Process
Sigrid Sterckx, Kasper Raus and Freddy Mortier Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives
A. M. Viens, John Coggon, Anthony S. Kessel Criminal Law, Philosophy and Public Health Practice
Ruth Chadwick, Mairi Levitt and Darren Shickle The Right to Know and the Right Not to Know: Genetic Privacy and Responsibility
The Right to Know and the Right Not to Know

*Genetic Privacy and Responsibility*

Edited by

Ruth Chadwick, Mairi Levitt and Darren Shickle
Contents

List of contributors     page ix
Acknowledgements      xiii

Introduction     1
RUTH CHADWICK, MAIRI LEVITT AND DARREN SHICKLE

Part I:     Philosophical and legal issues     11
1     The right to know and the right not to know: the emerging debate     13
RUTH CHADWICK, MAIRI LEVITT AND DARREN SHICKLE
2     Autonomy and a right not to know     24
JØRGEN HUSTED
3     Privacy and the right not to know: a plea for conceptual clarity     38
GRAEME LAURIE

Part II:     Issues in genetics     53
4     Biobanks and feedback     55
KADRI SIMM
5     Suspects, victims and others: producing and sharing forensic genetic knowledge     70
ROBIN WILLIAMS AND MATTHIAS WIENROTH
6     Empowered by choice?     85
MAIRI LEVITT
7     DIY genetics: the right to know your own genome     100
BARBARA PRAINSACK
Contents

8 Genomics, inconvenient truths and accountability 116
JEANTINE LUNSHOF AND RUTH CHADWICK

Part III: Emerging issues 131

9 The right to know and the right not to know in the era of neoliberal biopolitics and bioeconomy 133
HENK TEN HAVE

10 The parental love argument against ‘designing’ babies: the harm in knowing that one has been selected or enhanced 151
ANCA GHEAUS

11 The press and the public interest 165
JOACHIM ALLGAIER

12 The inescapability of knowing and inability to not know in the digital society 180
RICHARD WATERMEYER

13 The food we eat: the right to be informed and the duty to inform 196
MICHIEL KORTHALS

Index 209
Contributors

JOACHIM ALLGAIER is a sociologist and media and communications researcher. He is a senior scientist at the Institute of Science, Technology and Society Studies at the Alpen-Adria-Universität Klagenfurt in Austria. Previously he was an Honorary Fellow at the School of Journalism and Mass Communication at the University of Wisconsin-Madison, USA, and he was employed at the Research Center Jülich in Germany, the University of Vienna in Austria, and the Open University in the UK, where he was awarded a PhD in sociology. He studied sociology at LMU Munich in Germany, and Science and Technology Studies at Maastricht University in the Netherlands. His research interests are Science and Technology Studies, Public Communication of Science, Technology and Medicine, and (New) Media, Communication and Popular Culture.

RUTH CHADWICK is Professor of Bioethics at the University of Manchester and directed the ESRC Centre for Economic and Social Aspects of Genomics (Cesagen) from 2002 to 2013. She co-edits *Bioethics and Life Sciences, Society and Policy* and has served on the Council of the Human Genome Organisation, the Panel of Eminent Ethical Experts of the Food and Agriculture Organisation of the United Nations (FAO), and the UK Advisory Committee on Novel Foods and Processes (ACNFP). She is Academician of the Academy of Social Sciences and Fellow of the Hastings Center, New York; of the Royal Society of Arts; and of the Society of Biology. In 2005 she won the World Technology Network Award for Ethics.

ANCA GHEAUS holds a De Velling Willis fellowship in the Department of Philosophy at Sheffield University. Her research is in moral and political philosophy, with a special focus on the importance of caring relationships for theories of distributive justice. Recent publications include ‘Care drain: who should provide for the children left behind?’ in *Critical Review of International Social and Political Philosophy*, ‘Is the family uniquely valu-
List of contributors

ABLE?’ in Ethics and Social Welfare and ‘The right to parent one’s biological baby’ in The Journal of Political Philosophy.

JØRGEN HUSTED is Associate Professor of Philosophy at Aarhus University, Denmark, and a former member of the Danish Council of Ethics. Among his recent publications are books on Kierkegaard, Wittgenstein and J. S. Mills. In the area of applied ethics he has published Ethics, Morality and Values (2006); Ethics and Values in Social Work (2009) and Ethics and Values in Nursing (2013).

MICHEL KORTHALS (1949) studied Philosophy, Sociology and German at the University of Amsterdam and the Karl Ruprecht University in Heidelberg (FRG). He analysed the Frankfurt School (Marx, Adorno and Horkheimer, Marcuse and Habermas) and issues of moral education and societal development. As Professor of Applied Philosophy, Wageningen University, he contributes to the philosophy of food and agriculture, of both local and global significance. Main publications include Pragmatist Ethics for a Technological Culture (with Keulartz et al. 2002); Before Dinner. Philosophy and Ethics of Food (2004); PÉPÉ GRÉGOIRE, A Philosophical Interpretation of his Sculptures (2006); Genomics, Obesity and the Struggle over Responsibilities (2011).

GRAEME LAURIE is Professor of Medical Jurisprudence in the School of Law, University of Edinburgh. His research interests relate to the regulation and promotion of medicine, science and technology. Among his publications relevant to this collection are Genetic Privacy: A Challenge to Medico-Legal Norms (Cambridge University Press, 2002), and his co-authorship of Law and Medical Ethics (with J. K. Mason), now in its 9th edition (Oxford University Press, 2013). His policy work has included Chairmanships of the UK Biobank Ethics and Governance Council (2006–2010) and the Privacy Advisory Committee in Scotland (2005–2013).

MAIRI LEVITT is Senior Lecturer in the Department of Politics, Philosophy and Religion at Lancaster University. She is a social scientist working in empirical bioethics with a particular interest in researching ethical and social issues in genetics through engagement with different publics, from children to pensioners and from legal professionals to readers of a local newspaper. Her current research is looking at the implications of behavioural genetics for notions of responsibility, blame and fairness. Earlier projects include a schools-based project on the ethics of ‘Making humans better and making better humans’; ‘Barcoded children’ (on the National DNA Database); commercial genetic screening; and young people’s ideas.
List of contributors

JEANTINE LUNSHOF studied Philosophy and Health Law in Hamburg and in Amsterdam. She obtained her PhD from VU University Amsterdam. As a philosopher and bioethicist, her research focus is on the conceptual and normative aspects of systems and synthetic biology. Based with Molecular Cell Physiology at VU University Amsterdam, she works as a Marie Curie Fellow at Harvard Medical School, conducting research on systems biology-based concepts of health and disease, and the development of a systems approach for ethics. In 2006, she developed the innovative model of ‘open consent’ that forms the normative backbone of the Personal Genome Project.

BARBARA PRAINSACK is a Professor at the Department of Social Science, Health & Medicine, King's College London. A political scientist by background, Barbara has published widely on the societal, regulatory, and ethical dimensions of genetic and genomic science and technology in medicine and forensics. From 2011 to 2013, she chaired the ESF ‘Forward Look on Personalised Medicine for the European Citizen’ alongside Stephen Holgate and Aarno Palotie. Barbara is also a member of the Austrian National Bioethics Commission, and of the British Royal Society of Arts.

DARREN SHICKLE is Professor of Public Health at the University of Leeds. He has previously worked at the University of Sheffield and University of Wales College of Medicine. As part of a Harkness Fellowship in 1996/7 he was based at the Bioethics Institute at the Johns Hopkins School of Public Health and the Kennedy Institute of Ethics at Georgetown University, USA. He has worked for the Department of Health and Human Services in Washington DC and the Department of Health in London on a range of ethics issues related to genetics, privacy and end-of-life. He is also a research ethics expert for the European Commission and the European Research Council Executive Agency. His research interests are public health ethics, public health genetics, ophthalmic public health, and HIV/sexual health.

KADRI SIMM is an Associate Professor in Practical Philosophy at the Institute of Philosophy and Semiotics, University of Tartu, in Estonia. Having graduated from history, gender studies and philosophy, her main research interests and publications relate to bioethics (especially biobanking and ethical and social implications of genetics), political philosophy (theories of justice) and feminist theory.
HENK TEN HAVE is Director of the Center for Healthcare Ethics at Duquesne University in Pittsburgh, USA. He studied medicine and philosophy in the Netherlands and worked as professor in the Faculty of Medicine of the Universities of Maastricht and Nijmegen. From 2003 until 2010 he joined UNESCO in Paris as Director of the Division of Ethics of Science and Technology. His recent publications include *Contemporary Catholic Healthcare Ethics* (with David Kelly and Gerard Magill, Georgetown University Press, 2013) and *Handbook of Global Bioethics* (with co-editor Bert Gordijn, Springer, 2013). He is Editor-in-Chief of the journal *Medicine, Health Care and Philosophy*.

RICHARD WATERMEYER is Research Fellow in Impact and Engagement studies at the School of Social Sciences, Cardiff University, and Director of PIER Logistics – an academic consultancy specialising in impact evaluation and evidence review in Higher Education contexts. He is currently seconded to the Chief Scientific Adviser for Wales as a Science Policy Research Analyst, leading research responding to the policy priorities of *Science for Wales* and *Innovation Wales*. Research is focused on academics’ strategy in exploiting the economic and social impact of their research, specifically in science domains; and STEM careers guidance by secondary science teachers and the interface with ITT, teachers’ CPD and science enrichment and engagement activity.

MATTHIAS WIENROTH studies cross-epistemic identities and relationships of new and emergent technosciences. He is a post-doctoral Research Fellow at the Faculty of Health & Life Sciences at Northumbria University and in the FP7 European Forensic Genetics Network of Excellence. Here, he explores prevalent narratives and practices around emergent forensic genetics technologies and their uses. Previous work includes analysis of the production of the field of nanotechnology through identity building and collaboration; the governance of scientific conduct and research outcomes; collaboration across knowledge boundaries; and failure of technology. He is currently lead-editing a book on social convergences in the new biotechnologies.

ROBIN WILLIAMS is Professor Emeritus in the School of Applied Social Sciences at Durham University, Professor in the Faculty of Health & Life Sciences at Northumbria University, and a Visiting Professor at the Policy, Ethics and Life Sciences Research Centre, Newcastle University. He has published widely on the police uses of forensic science, is the Northumbria University lead investigator on the FP7 European Forensic Genetics Network of Excellence, and also holds a Wellcome Trust grant for a study of the use of ‘familial searching’ in support of criminal investigations in the UK and USA.
Acknowledgements

The editors would like to thank all the contributors and the contacts at Cambridge University Press for their assistance with this volume.