

THE GOVERNANCE OF GENETIC INFORMATION

This volume maps the areas of ethical concern in the debate regarding the governance of genetic information, and suggests alternative ethical frameworks and models of regulation in order to inform its restructuring. Genetic governance is at the heart of medical and scientific developments, and is connected to global exploitation, issues of commodification, commercialisation and ownership, the concepts of property and intellectual property and concerns about individual and communal identity. Thus the decisions that are made in the next few years about appropriate models of genetic governance will have knock-on effects for other areas of governance. In short, the final answer to ‘Who decides?’ in the context of genetic governance will fundamentally shape the ethical constructs of individuals and their networks and relationships in the public sphere.

HEATHER WIDDOWS is Professor of Global Ethics at the University of Birmingham, where she teaches moral philosophy and bioethics.

CAROLINE MULLEN is a research officer at the Centre for European Law and Legal Studies, School of Law, University of Leeds.

CAMBRIDGE LAW, MEDICINE AND ETHICS

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. In the past twenty years, 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 over the past two decades have involved a strong medical law dimension. 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.

General Editors

Professor Margaret Brazier, *University of Manchester*

Professor Graeme Laurie, *University of Edinburgh*

Editorial Advisory Board

Professor Richard Ashcroft, *Queen Mary, University of London*

Professor Martin Bobrow, *University of Cambridge*

Dr Alexander Morgan Capron, *Director, Ethics and Health, World Health Organisation, Geneva*

Professor Jim Childress, *University of Virginia*

Professor Ruth Chadwick, *Cardiff Law School*

Dame Ruth Deech, *University of Oxford*

Professor John Keown, *Georgetown University, Washington, DC*

Cambridge University Press & Assessment
978-0-521-50991-6 — The Governance of Genetic Information
Edited by Heather Widdows, Caroline Mullen
Frontmatter
[More Information](#)

Dr Kathy Liddell, *University of Cambridge*
Professor Alexander McCall Smith, *University of Edinburgh*
Professor Dr Mónica Navarro-Michel, *University of Barcelona*

Books in the series
Marcus Radetzki, Marian Radetzki, Niklas Juth
Genes and Insurance: Ethical, Legal and Economic Issues
978 0 521 83090 4

Ruth Macklin
Double Standards in Medical Research in Developing Countries
978 0 521 83388 2 hardback 978 0 521 54170 1 paperback

Donna Dickenson
Property in the Body: Feminist Perspectives
978 0 521 86792 4

Matti Häyry, Ruth Chadwick, Vilhjálmur Árnason, Gardar Árnason
The Ethics and Governance of Human Genetic Databases: European Perspectives
978 0 521 85662 1

Ken Mason
The Troubled Pregnancy: Legal Wrongs and Rights in Reproduction
978 0 521 85075 9

Daniel Sperling
Posthumous Interests: Legal and Ethical Perspectives
978 0 521 87784 8

Keith Syrett
Law, Legitimacy and the Rationing of Health Care
978 0 521 85773 4

Alastair Maclean
Autonomy, Informed Consent and the Law: A Relational Change
978 0 521 89693 1

Heather Widdows, Caroline Mullen
The Governance of Genetic Information: Who Decides?
978 0 521 50991 6

THE GOVERNANCE OF GENETIC INFORMATION

WHO DECIDES?

Edited by
HEATHER WIDDOWS
and
CAROLINE MULLEN



CAMBRIDGE
UNIVERSITY PRESS

Cambridge University Press & Assessment
 978-0-521-50991-6 — The Governance of Genetic Information
 Edited by Heather Widdows, Caroline Mullen
 Frontmatter
[More Information](#)

CAMBRIDGE UNIVERSITY PRESS

University Printing House, Cambridge CB2 8BS, United Kingdom
 One Liberty Plaza, 20th Floor, New York, NY 10006, USA
 477 Williamstown Road, Port Melbourne, VIC 3207, Australia
 314-321, 3rd Floor, Plot 3, Splendor Forum, Jasola District Centre, New Delhi - 110025, India
 103 Penang Road, #05-06/07, Visioncrest Commercial, Singapore 238467

Cambridge University Press is part of the University of Cambridge.
 It furthers the University's mission by disseminating knowledge in the pursuit of
 education, learning and research at the highest international levels of excellence.

www.cambridge.org
 Information on this title: www.cambridge.org/9780521509916

© Cambridge University Press 2009

This publication is in copyright. Subject to statutory exception
 and to the provisions of relevant collective licensing agreements,
 no reproduction of any part may take place without the written
 permission of Cambridge University Press.

First published 2009

A catalogue record for this publication is available from the British Library

Library of Congress Cataloging in Publication data

The governance of genetic information : who decides? / [edited by]

Heather Widdows, Caroline Mullen.

p. cm. — (Cambridge law, medicine and ethics)

Includes bibliographical references.

ISBN 978-0-521-50991-6 (hardback) 1. Genetic screening—Moral and ethical
 aspects. 2. Genetic screening—Government policy. 3. Privacy, Right of. 4. Medical
 records—Access control. I. Widdows, Heather, 1972— II. Mullen, Caroline. III. Series:
 Cambridge law, medicine and ethics.

[DNLM: 1. Genetic Privacy—ethics. 2. Decision Making—ethics. 3. Genetic Privacy—
 legislation & jurisprudence. 4. Public Policy. QZ 21 G721 2009]

RB155.65.G68 2009

362.196'04207—dc22

2009018067

ISBN 978-0-521-50991-6 Hardback

Cambridge University Press has no responsibility for the persistence or
 accuracy of URLs for external or third-party internet websites referred to in
 this publication, and does not guarantee that any content on such websites is,
 or will remain, accurate or appropriate.

CONTENTS

Notes on contributors page ix
Preface xi

Introduction 1
HEATHER WIDDOWS AND CAROLINE MULLEN

SECTION I Problematising governance of genetic information 13

1 The medium and the message: tissue samples, genetic information and data protection legislation 15
NEIL C. MANSON, LANCASTER UNIVERSITY

2 Me, myself, I – against narcissism in the governance of genetic information 37
SØREN HOLM, CARDIFF UNIVERSITY

3 Decisions, consent and expectations of the individual 51
CAROLINE MULLEN, UNIVERSITY OF LEEDS

SECTION II Ethical frameworks of governance 73

4 Constructing communal models of governance: collectives of individuals or distinct ethical loci? 75
HEATHER WIDDOWS, UNIVERSITY OF BIRMINGHAM

5 Rights, responsibility and stewardship: beyond consent 99
ROGER BROWNSWORD, KING’S COLLEGE, LONDON

6 Who decides what? Relational ethics, genetics and well-being 126
SARAH WILSON, UNIVERSITY OF CENTRAL LANCASHIRE

| | | | |
|---|---|-------------------------------|------------|
| | SECTION III | Redesigning governance | 149 |
| 7 | Involving publics in biobank governance: moving beyond existing approaches | 151 | |
| | KATHRYN G. HUNTER AND GRAEME T. LAURIE, UNIVERSITY OF EDINBURGH | | |
| 8 | Genetic information and public opinion | 178 | |
| | ANDREW EDGAR, CARDIFF UNIVERSITY | | |
| 9 | Harmonisation and standardisation in ethics and governance: conceptual and practical challenges | 201 | |
| | RUTH CHADWICK AND HEATHER STRANGE, CARDIFF UNIVERSITY | | |
| | <i>Bibliography</i> | 214 | |
| | <i>Index</i> | 229 | |

NOTES ON CONTRIBUTORS

ROGER BROWNSWORD is Director of the Centre for Technology, Ethics and Law in Society (TELOS) and Professor of Law, King's College London, and Honorary Professor in Law at the University of Sheffield.

RUTH CHADWICK is Director of the Economic and Social Sciences Research Council (ESRC) Centre for Economic and Social Aspects of Genomics (Cesagen), Cardiff University. She also holds a Link Chair between Cardiff Law School and the School of English, Communication and Philosophy (ENCAP). She was editor-in-chief of the award winning *Encyclopedia of Applied Ethics* (1998), of which a second edition is now being prepared, and co-edits the journal *Bioethics* and the online journal *Genomics, Society and Policy*. She is Chair of the Human Genome Organisation Ethics Committee and has served as a member of several policy making and advisory bodies. She is an Academician of the Academy of Social Sciences and a Fellow of the Hastings Center, New York; of the Royal Society of Arts; and of the Royal Society of Medicine. In 2005 she was the winner of the World Technology Network Award for Ethics for her work on the relationship between scientific developments and ethical frameworks.

ANDREW EDGAR is Director of the Centre for Applied Ethics, Cardiff University. His research interests include the philosophy of medicine and German philosophy. He has recently published books on Habermas. He is currently the editor of *Health Care Analysis*.

SØREN HOLM is Professorial Fellow at Cardiff Law School, Cardiff University. He is also a permanent visiting Chair at the Section for Medical Ethics, University of Oslo.

KATHRYN G. HUNTER is the Standing Researcher at the Arts and Humanities Research Council Research Centre for Studies in Intellectual Property and Technology Law (AHRC/SCRIPT) at the University of

Edinburgh, and is currently completing her PhD on the governance of genetic databases.

GRAEME T. LAURIE is Professor of Medical Jurisprudence in the School of Law at the University of Edinburgh. He is currently Director of the Arts and Humanities Research Council Research Centre for Studies in Intellectual Property and Technology Law (AHRC/SCRIPT), also in the University of Edinburgh.

NEIL C. MANSON is a senior lecturer in the Department of Philosophy at Lancaster University and is the co-author (with Onora O'Neill) of *Rethinking Informed Consent in Bioethics* (Cambridge University Press, 2007).

CAROLINE MULLEN is a research officer at the Centre for European Law and Legal Studies, School of Law, University of Leeds. Her research interests and publications are in areas of ethics and political philosophy.

HEATHER STRANGE is a research assistant at the Economic and Social Sciences Research Council (ESRC) Centre for Economic and Social Aspects of Genomics (Cesagen), Cardiff University.

HEATHER WIDDOWS is a senior lecturer in the Department of Philosophy at the University of Birmingham. In 2005 she was awarded a visiting fellowship at Harvard University, where she worked on issues of moral neo-colonialism. She serves as a member of the UK Biobank Ethics and Governance Council and she is Lead Editor of the *Journal of Global Ethics*. Her publications include a monograph on *The Moral Vision of Iris Murdoch* and an edited collection on *Women's Reproductive Rights*, and articles and book chapters on all her areas of interest from bioethics to moral theory.

SARAH WILSON is a research associate in ethics at the School of Pharmacy and Pharmaceutical Sciences, University of Central Lancashire. Her current projects include ethics and professionalism in pharmacy practice, innovations in pharmacy practice around public health initiatives, and the implications of new technologies for the pharmacy profession. She has previously worked on projects looking at the ethical, legal and social dimensions of genetic technologies, including issues of social justice as they relate to human genetic research databases. She is author of several articles on ethical aspects of genomic technologies.

P R E F A C E

Heather Widdows and Caroline Mullen worked together as the lead investigators of the Property Regulation in European Science, Ethics and Law (PropEur) project, an EC funded project that ran for three years and finished in 2007. This volume is not an outcome of that project, but it was the experience of working on the project that provided the inspiration for it. In particular, the dearth of critical theorising which spoke to practice became abundantly clear, as did the need for comprehensive thinking which crossed disciplines and governance jurisdictions and interrogated the foundational assumptions of such governance. It is hoped that this volume, which was conceived as a concept volume with all its chapters commissioned, goes some way to addressing this gap. While it may not definitively answer ‘Who should decide?’, it does challenge existing practices and suggest alternatives.

We would like to acknowledge the Philosophy Department at the University of Birmingham for welcoming the PropEur project, and particularly to thank Helen Harris, Donna Dickenson, Dita Wickins-Drazilova and Louise Jelf, for their work on the project. The editors would also like to thank Phil Champion and Matthew Hilton.