

## PERSONALISED MEDICINE, INDIVIDUAL CHOICE AND THE COMMON GOOD

Hippocrates famously advised doctors, 'it is far more important to know *what person the disease has* than *what disease the person has*'. Yet 2,500 years later, 'personalised medicine', based on individual genetic profiling and the achievements of genomic research, claims to be revolutionary. In this book, experts from a wide range of disciplines critically examine this claim. They expand the discussion of personalised medicine beyond its usual scope to include many other highly topical issues, including:

- human nuclear genome transfer ('three-parent IVF')
- stem cell-derived gametes
- private umbilical cord blood banking
- international trade in human organs
- biobanks such as the US Precision Medicine Initiative
- direct-to-consumer genetic testing
- health and fitness self-monitoring

Although these technologies often prioritise individual choice, the original ideal of genomic research saw the human genome as 'the common heritage of humanity'. The authors question whether personalised medicine actually threatens this conception of the common good.

BRITTA VAN BEERS is an associate professor at VU University Amsterdam. As a legal philosopher she explores the notions of personhood and corporality within the regulation of biomedical technologies, such as assisted reproductive technologies, markets in human body materials and biomedical tourism. In 2011 she received the Praemium Erasmianum Research Prize for her PhD dissertation on the legal relationship between persons and their bodies in the era of medical biotechnology (2009). Recent publications include the co-edited volumes *Humanity in International Law and Biolaw* (Cambridge University Press, 2014) and *Symbolic Legislation and Developments in Biolaw* (2016).

SIGRID STERCKX is a founding member of the Bioethics Institute Ghent. Her current research projects focus on ethical and legal aspects of: human tissue research and biobanking; patenting in biomedicine and genomics; organ transplantation; medical end-of-life practices; neuroethics; and global justice. She has published more than 150 articles, book chapters

Cambridge University Press

978-1-108-47391-0 — Personalised Medicine, Individual Choice and the Common Good

Edited by Britta van Beers, Sigrid Sterckx, Donna Dickenson

Frontmatter

[More Information](#)

---

and books on these issues, including the co-authored book *Exclusions from Patentability* (Cambridge University Press, 2012) and the co-edited volume *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press, 2013). Sigrid also serves on various advisory committees, including the Ethics Committee of Ghent University Hospital.

DONNA DICKENSON is the author of one of the first books to take a balanced critical stance on personalised medicine, *Me Medicine vs We Medicine: Reclaiming Biotechnology for the Common Good* (2013). She is Emeritus Professor of Medical Ethics and Humanities at the University of London and a research associate at the HeLEX Centre at the University of Oxford. Previously she taught at Imperial College School of Medicine, London. For many years she served on the Ethics Committee of the UK Royal College of Obstetricians and Gynaecologists. She has written or edited twenty-five books, as well as over one hundred articles and chapters. In 2006 she became the first woman to win the international Spinoza Lens Award for her contribution to public debate on current ethical issues about the impact of biotechnology on our society.

Cambridge University Press

978-1-108-47391-0 — Personalised Medicine, Individual Choice and the Common Good

Edited by Britta van Beers, Sigrid Sterckx, Donna Dickenson

Frontmatter

[More Information](#)

#### 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 and 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 Graeme Laurie, *University of Edinburgh*

Professor Richard Ashcroft, *Queen Mary University of London*

Cambridge University Press

978-1-108-47391-0 — Personalised Medicine, Individual Choice and the Common Good

Edited by Britta van Beers, Sigrid Sterckx, Donna Dickenson

Frontmatter

[More Information](#)

---

PERSONALISED  
MEDICINE, INDIVIDUAL  
CHOICE AND THE  
COMMON GOOD

Edited by

BRITTA VAN BEERS

*VU University Amsterdam*

SIGRID STERCKX

*Ghent University*

DONNA DICKENSON

*Birkbeck College, University of London*



CAMBRIDGE  
UNIVERSITY PRESS

Cambridge University Press  
978-1-108-47391-0 — Personalised Medicine, Individual Choice and the Common Good  
Edited by Britta van Beers, Sigrid Sterckx, Donna Dickenson  
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

79 Anson Road, #06–04/06, Singapore 079906

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](http://www.cambridge.org)

Information on this title: [www.cambridge.org/9781108473910](http://www.cambridge.org/9781108473910)

DOI: 10.1017/9781108590600

© Britta van Beers, Sigrid Sterckx and Donna Dickenson 2018

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 2018

Printed and bound in Great Britain by Clays Ltd, Elcograf S.p.A.

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

*Library of Congress Cataloging-in-Publication Data*

Names: Beers, Britta Chongkol van, 1977– editor. | Sterckx, Sigrid, editor. | Dickenson,  
Donna, editor.

Title: Personalized medicine, individual choice and the common good / edited by Britta van  
Beers, Sigrid Sterckx, Donna Dickenson.

Description: Cambridge, United Kingdom; New York, NY: Cambridge University Press,  
2018. | Includes bibliographical references and index.

Identifiers: LCCN 2018022368 | ISBN 9781108473910 (hardback)

Subjects: | MESH: Precision Medicine | Personhood | Genome – ethics | Ethics, Clinical |  
Philosophy, Medical

Classification: LCC R733 | NLM WB 102 | DDC 610–dc23

LC record available at <https://lcn.loc.gov/2018022368>

ISBN 978-1-108-47391-0 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

<i>List of Contributors</i>	<i>page ix</i>
<b>1 Introduction</b>	<b>1</b>
DONNA DICKENSON, BRITTA VAN BEERS AND SIGRID STERCKX	
<b>2 Personalised Medicine and the Politics of Human Nuclear Genome Transfer</b>	<b>17</b>
FRANÇOISE BAYLIS AND ALANA CATTAPAN	
<b>3 Stem Cell-Derived Gametes and Uterus Transplants: Hurray for the End of Third-Party Reproduction! Or Not?</b>	<b>37</b>
HEIDI MERTES	
<b>4 Personalising Future Health Risk through ‘Biological Insurance’: Proliferation of Private Umbilical Cord Blood Banking in India</b>	<b>52</b>
JYOTSNA AGNIHOTRI GUPTA	
<b>5 Combating the Trade in Organs: Why We Should Preserve the Communal Nature of Organ Transplantation</b>	<b>77</b>
KRISTOF VAN ASSCHE	
<b>6 When There Is No Cure: Challenges for Collective Approaches to Alzheimer’s Disease</b>	<b>113</b>
ROBIN PIERCE	
<b>7 Lost and Found: Relocating the Individual in the Age of Intensified Data Sourcing in European Healthcare</b>	<b>133</b>
KLAUS HOEYER	

8	<b>Presuming the Promotion of the Common Good by Large-Scale Health Research: The Cases of care.data 2.0 and the 100,000 Genomes Project in the UK</b>	155
	SIGRID STERCKX, SANDI DHEENSA AND JULIAN COCKBAIN	
9	<b>My Genome, My Right</b>	183
	STUART HOGARTH, JULIAN COCKBAIN AND SIGRID STERCKX	
10	<b>‘The Best Me I Can Possibly Be’: Legal Subjectivity, Self-Authorship and Wrongful Life Actions in an Age of ‘Genomic Torts’</b>	200
	BRITTA VAN BEERS	
11	<b>I Run, You Run, We Run: A Philosophical Approach to Health and Fitness Apps</b>	226
	MARLI HUIJER AND CHRISTIAN DETWEILER	
12	<b>The Molecularised Me: Psychoanalysing Personalised Medicine and Self-Tracking</b>	245
	HUB ZWART	
	<i>Bibliography</i>	261
	<i>Index</i>	302

## CONTRIBUTORS

KRISTOF VAN ASSCHE is a research professor in health law and kinship studies at the University of Antwerp, Belgium. His research and numerous publications focus on the legal aspects of organ trafficking, surrogacy and experimental assisted reproductive technologies. He is a member of the Declaration of Istanbul Custodian Group, a member of the Ethics Committee of The Transplantation Society, and a member of the working group established by the Belgian government to implement the Council of Europe Convention against Trafficking in Human Organs.

FRANÇOISE BAYLIS is Professor and Canada Research Chair in Bioethics and Philosophy at Dalhousie University. She is an elected fellow of the Royal Society of Canada and the Canadian Academy of Health Sciences. At the centre of her research lie questions of justice, especially intergenerational justice as it applies to our responsibilities to future generations when we undertake research programmes that may alter the nature of humans.

BRITTA VAN BEERS is an associate professor in the Department of Legal Theory at the VU University Amsterdam. A recurring theme in her work is the legal relationship between persons and their bodies in various biomedical contexts, such as assisted reproductive technologies, markets in human body materials and biomedical tourism. Recent publications include the co-edited volumes, *Humanity in International Law and Biolaw* (Cambridge University Press, 2014) and *Symbolic Legislation and Developments in Biolaw* (2016).

ALANA CATTAPAN is an assistant professor at the Johnson Shoyama Graduate School of Public Policy at the University of Saskatchewan. A long-time feminist researcher and activist, she studies women's participation in policymaking, identifying links between the state, the



Cambridge University Press

978-1-108-47391-0 — Personalised Medicine, Individual Choice and the Common Good

Edited by Britta van Beers, Sigrid Sterckx, Donna Dickenson

Frontmatter

[More Information](#)

## X

## LIST OF CONTRIBUTORS

commercialisation of the body, biotechnologies and reproductive labour. She is currently co-editing a volume on surrogacy in Canada and conducting research on the concept of 'women of childbearing age' in public health policy and biomedical research.

JULIAN COCKBAIN is a consultant European patent attorney based in Ghent, Belgium, and Oxford, UK. He has written numerous articles on patent-related matters and co-authored the book *Exclusions from Patentability: How Far has the European Patent Office Eroded Boundaries?* (Cambridge University Press, 2012) with Sigrid Sterckx. He is also frequently invited to lecture on patent law and innovation policies.

CHRISTIAN DETWEILER is a design lecturer and researcher at The Hague University of Applied Sciences. His current research focuses on normativity in personal informatics technologies and its implications for design. Christian was previously a PhD candidate at Delft University of Technology, where he worked on his dissertation project, *Accounting for Values in Design*.

DONNA DICKENSON is Emeritus Professor of Medical Ethics and Humanities at the University of London. Her writings comprise over seventy academic articles and twenty-five books, including her study of personalised medicine, *Me Medicine vs. We Medicine: Reclaiming Biotechnology for the Common Good* (2013).

SANDI DHEENSA is a research associate at the Cardiff School of Social Sciences, Cardiff University. A common theme throughout her career so far has been the ethical and social challenges that evolving technologies pose, especially in the genomics field.

JYOTSNA AGNIHOTRI GUPTA is an assistant professor in gender and diversity (emerita) and a senior research associate at the University of Humanist Studies in Utrecht, The Netherlands. She is the author of *New Reproductive Technologies, Women's Health and Autonomy: Freedom or Dependency?* (2000), and of numerous published articles. Her research has concentrated on reproductive technologies and reproductive health issues from a gender and diversity perspective.

## LIST OF CONTRIBUTORS

xi

KLAUS HOEYER is Professor of Medical Science and Technology Studies at the University of Copenhagen. His research interests include ethics as policy work and the social organisation of health data, biobanks and transplant services. He has published in a variety of journals and is the author of *Exchanging Human Bodily Material: Rethinking Bodies and Markets* (2013).

STUART HOGARTH is a lecturer in sociology of science and technology in the Department of Social Science at the University of Cambridge. His research focuses on the political economy of diagnostic innovation. His work combines empirical research on the development, assessment and adoption of diagnostic technologies with normative analysis of public policy and commercial strategy. He has produced reports on intellectual property rights and regulatory frameworks in personalised medicine for the European Commission, Health Canada and the Human Genetics Commission.

MARLI HUIJER is a professor of philosophy at Erasmus University Rotterdam. In early 2015 she was named Thinker Laureate of The Netherlands. Her books include *Rhythm: In Search of a Recurring Time* (in Dutch, 2011) and *Discipline: Survival in Surfeit* (in Dutch, 2013).

HEIDI MERTES is a professor of ethics at Ghent University, a founding member of the Bioethics Institute Ghent (BIG) and a researcher at the Research Foundation – Flanders. Her main area of interest is bioethics, more specifically the topics of embryo research, stem cell research, reproductive medicine, fertility preservation and prenatal genomics. She has published numerous articles on these issues.

ROBIN PIERCE is an associate professor at the Tilburg Institute for Law, Technology and Society (TILT) of Tilburg Law School. She obtained her PhD from Harvard University in Health Policy, with a focus on comparative genetic privacy. She also holds a Juris Doctor from Boalt Hall School of Law at the University of California at Berkeley. Her research and numerous publications explore policy, legal and ethical issues of translational research in the life sciences, most recently involving synthetic biology, neuroscience and nanomedicine.

SIGRID STERCKX is a professor of ethics and political and social philosophy at the Department of Philosophy and Moral Sciences of

Cambridge University Press

978-1-108-47391-0 — Personalised Medicine, Individual Choice and the Common Good

Edited by Britta van Beers, Sigrid Sterckx, Donna Dickenson

Frontmatter

[More Information](#)

---

Ghent University. Her current research projects focus on: global justice (with particular attention to climate change); human tissue research and biobanking; patenting in biomedicine and genomics; organ transplantation; neuroethics; and end-of-life decisions. She has published more than 150 books, book chapters and articles in international academic journals on these issues, including the co-edited volume *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press, 2013). Sigrid is a member of the Belgian Advisory Committee on Bioethics, which advises the Federal Government.

HUB ZWART is a professor of philosophy at the Faculty of Science of the Radboud University Nijmegen. In 2004, he established the Centre for Society and Genomics (CSG) in this department, and acted as CSG's scientific director. In 2005, he established the Institute for Science, Innovation and Society (ISIS). He is also Editor-in-Chief of the journal *Life Sciences, Society and Policy*. He has published ten books and seventy-five articles.