

BEYOND AUTONOMY

Respect for autonomy has become a fundamental principle in human research ethics. Nonetheless, this principle and the associated process of obtaining informed consent do have limitations. This can lead to some groups, many of them vulnerable, being left understudied. This book considers these limitations and contributes through legal and philosophical analyses to the search for viable approaches to human research ethics. It explores the limitations of respect for autonomy and informed consent both in law and through the examination of cases where autonomy is lacking (infants), diminished (addicts), and compromised (low socio-economic status). It examines alternative and complementary concepts to overcome the limits of respect for autonomy, including beneficence, dignity, virtue, solidarity, non-exploitation, vulnerability and self-ownership. It takes seriously the importance of human relationality and community in qualifying, tempering and complementing autonomy to achieve the ultimate end of human research – the good of humankind.

DAVID G. KIRCHHOFFER is Director of the Queensland Bioethics Centre at the Australian Catholic University's Brisbane Campus. He holds a PhD from the Katholieke Universiteit Leuven and an MPhil from St Augustine College of South Africa. He is the author of *Human Dignity in Contemporary Ethics* (2013).

BERNADETTE J. RICHARDS is Associate Professor of Law and Director of the Research Unit for the Study of Society, Ethics and the Law at the University of Adelaide, and a member of the Australian Health Ethics Committee. She is a chief investigator of a current NHMRC-funded Partnership Grant exploring advance care planning and is currently writing a book *Technology, Healthcare and the Law: An evolving relationship*.

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*

BEYOND AUTONOMY

Limits and Alternatives to Informed Consent in
Research Ethics and Law

Edited by

DAVID G. KIRCHHOFFER

Australian Catholic University

BERNADETTE J. RICHARDS

University of Adelaide



CAMBRIDGE
UNIVERSITY PRESS

Cambridge University Press
978-1-108-74130-9 — Beyond Autonomy
Edited by David G. Kirchhoffer, Bernadette J. Richards
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

Information on this title: www.cambridge.org/9781108741309

DOI: 10.1017/9781108649247

© Cambridge University Press 2019

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 2019

First paperback edition 2021

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

Library of Congress Cataloging in Publication data

Names: Kirchhoffer, David G., editor. | Richards, Bernadette, editor.

Title: Beyond autonomy : limits and alternatives to informed consent in research ethics and law /

Edited by David G. Kirchhoffer, Australian Catholic University, Bernadette J. Richards,
University of Adelaide.

Description: New York, NY : Cambridge University Press, 2019.

Identifiers: LCCN 2019014857 | ISBN 9781108491907 (hardback) | ISBN 9781108741309 (pbk.)

Subjects: LCSH: Informed consent (Medical law) | Medicine—Research—Moral and ethical aspects. |

Biology—Research—Moral and ethical aspects. | Bioethics.

Classification: LCC K3611.I5 B49 2019 | DDC 174.2/8—dc23

LC record available at <https://lcn.loc.gov/2019014857>

ISBN 978-1-108-49190-7 Hardback

ISBN 978-1-108-74130-9 Paperback

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 Tables</i>	vii
<i>List of Contributors</i>	viii
<i>Acknowledgements</i>	xiii
Introduction: The Limits of Respect for Autonomy	1
DAVID G. KIRCHHOFFER	
PART I Exploring Problems of Respect for Autonomy in Bioethics, Law and Society	15
1 Autonomy and the Law: Widely Used, Poorly Defined	17
BERNADETTE J. RICHARDS	
2 Lack of Autonomy: Debates Concerning Research Involving Children	33
THOMAS H. MURRAY	
3 Diminished Autonomy: Consent and Chronic Addiction	48
STEVE MATTHEWS AND JEANETTE KENNETT	
4 Compromised Autonomy: Social Inequality and Issues of Status and Control	63
S. STEWART BRAUN	
PART II The Search for Alternative or Complementary Concepts Surrounding Autonomy	79
5 Self-Ownership in Research Ethics	81
GARRETT CULLITY	
6 Beneficence in Research Ethics	96
DAVID G. KIRCHHOFFER, CHRISTI D. FAVOR AND CHRISTOPHER D. CORDNER	

- 7 **Dignity, Being and Becoming in Research Ethics** 117
DAVID G. KIRCHHOFFER
- 8 **Virtues in Research Ethics: Developing an Empirically
Informed Account of Virtues in Biomedical Research
Practice** 133
JUSTIN OAKLEY
- PART III **Beyond Autonomy: Turning to the Community
to Protect the Individual** 151
- 9 **Duties of Shared Membership in Research Ethics** 153
JOSÉ MIOLA
- 10 **Engaging Communities in Human Research in the
Global South** 168
ANITA HO
- 11 **Reducing Shared Vulnerabilities to Data Misuse** 183
WENDY ROGERS
- Index* 200

TABLES

- 6.1 Evidence of Beneficence₁ in human research ethics guidelines 105
- 6.2a Evidence in human research ethics guidelines of the duty derived from Beneficence₂ not to use human beings only as means 107
- 6.2b Requirements in human research guidelines derived from Beneficence₂ to minimise unavoidable harm 110
- 6.3 Requirements in human research guidelines derived from Beneficence₃ to ensure proportionate benefits 112
- 6.4 Conditions and requirements in human research guidelines derived from Beneficence₄ to provide special protection for the vulnerable 114

CONTRIBUTORS

S. STEWART BRAUN is Lecturer in the School of Philosophy at Australian Catholic University (ACU) as well as a member of the Institute for Religion and Critical Inquiry at ACU. He obtained his PhD from the University of Virginia and holds a Master of Arts in Religion from Yale University. His research is focused primarily in the areas of social and political philosophy along with normative and applied ethics. His current research centres around questions regarding distributive justice and the self-development of the person in society. He is co-editor of the book *Virtue's Reasons: New Essays on Virtue, Character, and Reasons* (2017). His articles have appeared in the *Journal of Applied Philosophy* as well as *Law and Philosophy*, among others.

CHRISTOPHER D. CORDNER is Associate Professor of Philosophy at the University of Melbourne. His main area of research interest is moral philosophy, including its intersections with aesthetics and issues about the self, and the Platonic and Judaeo-Christian influences upon western ethics. For ten years Christopher was a member of the Australian Health Ethics Committee, a principal Committee of the National Health and Medical Research Council providing advice to the Federal Health Minister on issues relating to the ethics of health and health research. Christopher has coordinated the MA coursework degree in Professional and Applied Ethics at the University of Melbourne for the last six years. He is also Senior International Consultant at the recently established Centre for Ethics as Study in Human Value at the University of Pardubice in the Czech Republic. He is currently completing a book on simple goodness.

GARRETT CULLITY is Hughes Professor of Philosophy at the University of Adelaide, having taught previously at the universities of Oxford and St Andrews. His work ranges across theoretical and applied moral philosophy. He is the author of *The Moral Demands of Affluence* (2004) and *Concern, Respect and Cooperation* (2018), a co-editor of *Ethics and Practical Reason* (1997) and an associate editor of *Philosophy and Public*

Affairs. He is a former chair of the Human Research Ethics Committee at the University of Adelaide.

CHRISTI D. FAVOR completed her PhD in moral and political philosophy at the University of Arizona, with the thesis *An Expressive Theory of Desert*. For twelve years, Christi coordinated the moral and political theory strand of the Ethics and Human Rights programme at Queensland University of Technology. Since 2010, Christi has been a regular sessional lecturer in the Philosophy Department at the University of Queensland. She has also taught several professional development workshops for members of human research ethics committees for the University of Queensland's School of Historical and Philosophical Inquiry. She also has an interest in philosophy for children and has developed and conducted a number of workshops in this area for children in primary and secondary schools. She has co-authored the 'Distributive Justice' survey for the *Stanford Encyclopedia of Philosophy* and is co-editor and an author for the Stanford collection *Essays on Philosophy, Politics and Economics: Integration and Common Research Projects*.

ANITA HO is an associate professor in bioethics at the Centre for Applied Ethics at the University of British Columbia and an affiliate faculty member in the bioethics program of the University of California, San Francisco. She is also a senior researcher in ethics services at Providence Health Care and a section editor in research ethics for *BMC Medical Ethics*. An international scholar and author of more than sixty publications, Anita's broader research areas include supportive decision-making in diverse healthcare settings, ethical dimensions of incorporating innovative technologies in health care, trust and decision-making in domestic and international clinical and research medicine, organisational and system ethics in medicine, cross-cultural and global health ethics, healthcare access and disparity, professional–patient relationship, ethics education for health professionals, disability and pain experiences, and various concepts of autonomy.

JEANETTE KENNETT is a professor of philosophy at Macquarie University, who works at the intersection of philosophy, psychology and law. She completed her PhD at Monash and held positions at Monash and Australian National University (ANU) before joining Macquarie in 2009. She has held seven Australian Research Council Discovery grants and has published extensively on mental disorder, moral agency, and moral and legal responsibility. She leads the Australian Neurolaw Database Project,

she is co-chair of the Australian Brain Alliance Neuroethics working group and Deputy Director of the Centre for Agency Values and Ethics at Macquarie University.

DAVID G. KIRCHHOFFER is Director of the Queensland Bioethics Centre at Australian Catholic University's (ACU) Brisbane Campus. A member of the Faculty of Theology and Philosophy and the Institute for Religion and Critical Inquiry at ACU, he holds a PhD from the Katholieke Universiteit (KU) Leuven, Belgium, and an MPhil from St Augustine College of South Africa. He has been a post-doctoral researcher at the Centre for Biomedical Ethics and Law at KU Leuven, a senior research associate at the Department of Philosophy at the University of Johannesburg and a senior visiting fellow at the National University of Singapore's Centre for Biomedical Ethics. He is the author of *Human Dignity in Contemporary Ethics* (2013). He is co-chief-investigator on an ACU Research Fund grant titled 'Redeeming Autonomy' considering the limits and prospects for the concept of autonomy in theology, philosophy and ethics.

STEVE MATTHEWS is a philosopher and currently senior research fellow at the Plunkett Centre for Ethics (a joint centre of St Vincent's & Mater Health and Australian Catholic University (ACU) in Sydney Australia), a member of the Department of Philosophy at ACU, a member of the Centre for Moral Philosophy and Applied Ethics at ACU, and also a conjoint member of St Vincent's Clinical School at the University of New South Wales. Prior to ACU he worked at Macquarie University, and before that Charles Sturt University, and before that Monash University, where, also, he wrote his doctorate on personal identity and ethics. His research interests are in moral psychology, personal identity and applied ethics. He has published widely in these areas. Recent research projects include those on the ethics of addiction, and most recently on the ethics of dementia.

JOSÉ MIOLA is Professor of Medical Law at the University of Leicester. He has published widely in the area of medical law and ethics, and his work has been cited by courts and government reports in the United Kingdom, Australia and Singapore. He is the editor of the commentaries section of the *Medical Law Review*, and on the editorial board of *Clinical Ethics*. He also sits on the Wellcome Trust's Social Science and Bioethics Interview Committee and was a member of the General Medical Council's task and finish group, creating ethical guidelines for doctors relating

to cosmetic surgery practice. He has been a visiting scholar at the universities of Melbourne, Otago, Oxford and Adelaide.

THOMAS H. MURRAY is President Emeritus of The Hastings Centre. Prior to returning to Hastings, he was Director of the Center for Bio-medical Ethics at Case Western University School of Medicine and Susan E. Watson Professor of Bioethics (1987–1999). He has held the Chen Su Lan Centennial Chair (Visiting) at the National University of Singapore School of Medicine. He served as Presidential appointee on the National Bioethics Advisory Commission and as chair of its genetics subcommittee, serves on many editorial boards and has been president of the Society for Health and Human Values and the American Society of Bioethics and Humanities. He is a member of the Independent IAAF (International Association of Athletics Federations) Ethics Board and Disciplinary Commission, and on the board of Cure SMA. He is the author of 300 publications, including *The Worth of a Child* and his latest book *Good Sport: Why Our Games Matter . . . and How Doping Undermines Them*.

JUSTIN OAKLEY is Associate Professor and Deputy Director of Monash Bioethics Centre, at Monash University. His publications include *Morality and the Emotions* (1993), *Virtue Ethics and Professional Roles* (with Dean Cocking, 2001), and *Informed Consent and Clinician Accountability: The Ethics of Report Cards on Surgeon Performance* (with Steve Clarke, 2007). Justin has published articles on a variety of topics in ethics, applied ethics and moral psychology, and he is co-editor of *Monash Bioethics Review*. He is currently working on a book-length project on policy applications of virtue ethics in professional practice.

BERNADETTE J. RICHARDS BA, LLB (Hons), PhD is Associate Professor of Law and Associate Dean (Research) at the University of Adelaide, Australia. She teaches in the areas of medical law and ethics, bioethics and tort law and is the Director of the Research Unit for the Study of Society, Ethics and the Law, and a member of Australian Health Ethics Committee, and President of the Australasian Association of Bioethics and Health Law (AABHL). An active researcher, she has completed major projects on organ donation, consent to treatment and legal issues around innovative surgery. She is a chief investigator of a current National Health and Medical Research Council-funded Partnership Grant, 'Strategies for the inclusion of vulnerable populations in developing complex and sensitive public policy: a case study in Advance Care Planning' and is currently writing a book 'Technology, Healthcare and

the Law: An evolving relationship'. She has published over fifty journal articles and book chapters.

WENDY ROGERS is Professor of Clinical Ethics at Macquarie University. Her research focuses on ethical issues in healthcare, using theoretical approaches from moral philosophy, feminist epistemology and feminist bioethics to investigate ethical issues in healthcare. The results of this research are relevant for policy and practice, as well as making contributions to bioethics scholarship. Recently her research has focused on overdiagnosis, investigating the relationship between overdiagnosis and disease definition, and the ethical issues associated with overdiagnosis. Her other current interests include research ethics, the ethics of surgical innovation, and organ donation and organ trafficking.

ACKNOWLEDGEMENTS

This book represents a truly international and interdisciplinary collaboration, which began when we, the editors, were visiting scholars at the National University of Singapore's Centre for Biomedical Ethics in 2015. During this visit, a conversation about autonomy and how it is understood both philosophically and at law was started, and it continues today.

This book represents an extension of that conversation which, thanks to grants provided by Australian Catholic University and The University of Adelaide, took place at a research symposium that we hosted in Brisbane in 2016. At that time, we were able to invite our future collaborators to come along and share their thoughts on autonomy, its limitations and alternative approaches. This dialogue led directly to the collection of the ideas presented here, and we would like to acknowledge the support of our institutions and our authors who all generously shared their time and ideas to make this an interesting, thoughtful and genuinely interdisciplinary collaboration.