Debates on the human-rights implications of new and emerging technologies have been hampered by the lack of a comprehensive theoretical framework for the complex issues involved. This volume provides that framework, bringing a multidisciplinary and international perspective to the evolution of human rights in the digital and biotechnological era. It delves into the latest frontiers of technological innovation in the life sciences and information technology sectors, such as neurotechnology, robotics, genetic engineering, and artificial intelligence. Leading experts from the technological, medical, and social sciences as well as law, philosophy, and business share their extensive knowledge about the transformation of the rights framework in response to technological innovation. In addition to providing a comprehensive, interdisciplinary, and international state-of-the-art descriptive analysis, the volume also offers policy recommendations to protect and promote human rights in the context of emerging socio-technological trends.

Marcello Ienca is a philosopher and cognitive scientist who leads the Intelligent Systems Ethics Group at the College of Humanities (CDH) of the Swiss Federal Institute of Technology in Lausanne (EPFL), Switzerland.

Oreste Pollicino is Full Professor of Constitutional Law and Member of the Executive Committee, European Agency for Fundamental Rights and Director of the LLM in Law of Internet Technology, Bocconi University.

Laura Liguori is a partner in the Italian law firm Portolano Cavallo focusing on data protection matters privacy and new technologies.

Elisa Stefanini is PhD in Constitutional law and partner in the Italian law firm Portolano Cavallo focusing on regulatory matters in the life sciences sector.

Roberto Andorno is Associate Professor of biomedical law at the School of Law, and Research Fellow at the Institute of Biomedical Ethics of the University of Zurich, Switzerland.
The Cambridge Handbook of Information Technology, Life Sciences and Human Rights

Edited by

MARCELLO IENCA
Swiss Federal Institute of Technology in Lausanne (EPFL), College of Humanities

ORESTE POLLICINO
Bocconi University (Italy) Faculty of Law

LAURA LIGUORI
Portolano Cavallo (Law Firm)

ELISA STEFANINI
Portolano Cavallo (Law Firm)

ROBERTO ANDORNO
University of Zurich Faculty of Law
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/9781108477833
doi: 10.1017/9781108775038

© Cambridge University Press 2022
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 2022
A catalogue record for this publication is available from the British Library.

Library of Congress Cataloging-in-Publication Data
Title: The Cambridge handbook of information technology, life sciences and human rights / edited by Marcello Ienca, Swiss Federal Institute of Technology in Lausanne (EPFL), College of Humanities; Oreste Pollicino, Bocconi University (Italy) Faculty of Law; Laura Liguori, Portolano Cavallo (Law Firm); Elisa Stefanini, Portolano Cavallo (Law Firm); Roberto Andorno, University of Zurich Faculty of Law.
Description: Cambridge, United Kingdom; New York, NY: Cambridge University Press, 2022. | Series: Cambridge law handbooks | Includes index
Identifiers: LCCN 2021053920 (print) | LCCN 2021053921 (ebook) | ISBN 9781108477833 (hardback) | ISBN 9781108775038 (epub)
Classification: LCC K487.T4 C36 2022 (print) | LCC K487.T4 (ebook) | DDC 344/.095-dc23 eng/20211220
LC record available at https://lccn.loc.gov/2021053920
LC ebook record available at https://lccn.loc.gov/2021053921

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

List of Tables ix
List of Contributors xi
Acknowledgements xv

Introduction 1
Marcello Ienca, Oreste Pollicino, Laura Liguori, Elisa Stefanini
and Roberto Andorno

Part I Life Sciences and Human Rights

1 M-Health at the Crossroads between the Right to Health and the
Right to Privacy 11
Oreste Pollicino, Laura Liguori and Elisa Stefanini

2 Neurorights and the Chilean Initiative 26
Emily Einhorn and Rafael Yuste

3 Persuasive Technologies and the Right to Mental Liberty: The ‘Smart’
Rehabilitation of Criminal Offenders 32
Sjors Ligthart, Gerben Meynen and Thomas Douglas

4 The Ethics and Laws of Medical Big Data 48
Hrefna Dögg Gunnarsdóttir, I. Glenn Cohen, Timo Minssen and Sara Gerke

5 The Right to Have a Child: Through the Lens of the Third Phase
Reproductive Technologies 56
Judit Sándor

6 Medical Robots and the Right to Health Care: A Progressive Realization 70
Robin L. Pierce and Eduard Fosch-Villaronga

7 Life-Maintaining Technology and the Right to Die 86
Federico Gustavo Pizzetti
## Contents

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>The Spread of Telemedicine in Daily Practice: Weighing Risks and Benefits</td>
<td>102</td>
</tr>
<tr>
<td></td>
<td>Carlo Botrugno</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Reproductive Technologies and Reproductive Rights: The Role of Law and Ethics</td>
<td>113</td>
</tr>
<tr>
<td></td>
<td>Belinda Bennett and Bernadette Richards</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>The Right to Internet Access: A Comparative Constitutional Legal Framework</td>
<td>125</td>
</tr>
<tr>
<td></td>
<td>Oreste Pollicino</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Face Recognition and the Right to Stay Anonymous</td>
<td>139</td>
</tr>
<tr>
<td></td>
<td>Clare Garvie</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Artificial Intelligence and the Right to Algorithmic Transparency</td>
<td>153</td>
</tr>
<tr>
<td></td>
<td>Marc Rotenberg</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Machine Learning, Cognitive Sovereignty and Data Protection Rights with Respect to Automated Decisions</td>
<td>166</td>
</tr>
<tr>
<td></td>
<td>Lee A. Bygrave</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Going Dark or Living Forever: The Right to Be Forgotten, Search Engines and Press Archives</td>
<td>189</td>
</tr>
<tr>
<td></td>
<td>Peggy Valcke and Simon Verschaeve</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Artificial Intelligence and Children’s Rights</td>
<td>215</td>
</tr>
<tr>
<td></td>
<td>Ronny Bogani and Burkhard Schafer</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Internet of Things Devices, Citizen Science Research and the Right to Science: Ethical and Legal Issues</td>
<td>231</td>
</tr>
<tr>
<td></td>
<td>James Scheibner, Anna Jobin and Effy Vayena</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Connected but Still Excluded? Digital Exclusion beyond Internet Access</td>
<td>244</td>
</tr>
<tr>
<td></td>
<td>Sofia Ranchordás</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Technological Changes and Rights Evolution in the Bio-digital Era: A Philosophical Overview</td>
<td>261</td>
</tr>
<tr>
<td></td>
<td>Marta Bertolaso and Alfredo Marcos</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Human Dignity, Life Sciences Technologies and the Renewed Imperative to Preserve Human Freedom</td>
<td>273</td>
</tr>
<tr>
<td></td>
<td>Roberto Andorno</td>
<td></td>
</tr>
<tr>
<td>Contents</td>
<td>vii</td>
<td></td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-----</td>
<td></td>
</tr>
<tr>
<td>20 Human–Machine Symbiosis and the Hybrid Mind: Implications for Ethics, Law and Human Rights</td>
<td>286</td>
<td></td>
</tr>
<tr>
<td>Christoph Bublitz, Jennifer Chandler and Marcello Ienca</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marcello Ienca</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Tables

6.1 Robots and AI applications for healthcare \hspace{1cm} page 74
6.2 Some core obligations under the right to health for medical robots \hspace{1cm} 78
Contributors

Roberto Andorno is an associate professor at the Faculty of Law, University of Zurich (Switzerland) and a research fellow at the University's Institute of Biomedical Ethics and Medical History, where he also coordinates the PhD Program in biomedical ethics and law.

Belinda Bennett is Professor of Health Law and New Technologies at the School of Law, Queensland University of Technology, Brisbane, Australia.

Marta Bertolaso is a professor of Philosophy of Science and Human Development at Campus Bio-Medico, Rome, Italy.

Ronny Bogani is a PhD candidate at the University of Edinburgh, UK.

Carlo Botrugno is a research fellow at the Department of Legal Sciences of the University of Florence, Florence, Italy.

Christoph Bublitz is a research fellow at the University of Hamburg, Hamburg, Germany.

Lee A. Bygrave is a professor of Law and the Director of the Norwegian Research Center for Computers and Law, Department of Private Law, University of Oslo, Norway.

Jennifer Chandler is a professor of Law at the Centre for Health Law, Policy and Ethics, University of Ottawa, Canada.

I. Glenn Cohen is the Deputy Dean and James A. Attwood and Leslie Williams Professor of Law at Harvard Law School and Faculty Director of the Petrie-Flom Center, Harvard University, United States.

Thomas Douglas is Professor of Applied Philosophy at the University of Oxford and the Director of Research and Development at the Oxford Uehiro Centre for Practical Ethics, Oxford, United Kingdom.

Emily Einhorn is a community coordinator at Newlab and a development coordinator at the NeuroRights Initiative at Columbia University, United States.

Eduard Fosch-Villaronga is an assistant professor at the eLaw Center for Law and Digital Technologies, Leiden University, the Netherlands.

Clare Garvie is a distinguished fellow with the Center on Privacy & Technology at Georgetown Law, United States.
Sara Gerke is an Assistant Professor of Law at Penn State Dickinson Law, Carlisle, PA, United States.

Hrefna Dögg Gunnarsdóttir is a PhD candidate at the Centre for Advanced Studies in Biomedical Innovation Law (CeBIL), Faculty of Law, University of Copenhagen.

Marcello Ienca leads the Intelligent Systems Ethics Group at the College of Humanities (CDH), Swiss Federal Institute of Technology in Lausanne (EPFL), Switzerland. Previously, he was a senior research fellow at the Department of Health Sciences & Technology at ETH Zurich in Switzerland.

Anna Jobin is a senior researcher at the Alexander von Humboldt Institute for Internet and Society (HIIG), Berlin, Germany.

Sjors Ligthart is assistant professor of criminal law, Tilburg University, and postdoctoral fellow, Utrecht University, Willem Pompe Institute.

Laura Liguori is partner to the Italian firm Portolano Cavallo, Rome, Italy, focusing on personal data protection, privacy and new technologies.

Alfredo Marcos is a professor of Philosophy of Science at the University of Valladolid, Valladolid, Spain.

Gerben Meynen is a professor of Forensic Psychiatry (Utrecht University) and endowed professor of Ethics and Psychiatry (VU University Amsterdam).

Timo Minssen is a professor of Law at the University of Copenhagen (UCPH) and the Founding Director of UCPH’s Center for Advanced Studies in Biomedical Innovation Law (CeBIL).

Robin L. Pierce is an associate professor at the Tilburg Institute for Law, Technology, and Society (TILT), Tilburg University, the Netherlands.

Federico Gustavo Pizzetti is a full professor of Public Law and Biolaw, University of Milan, Italy.

Oreste Pollicino is a professor of Constitutional Law and Director LLM in Law of Internet Technology, Bocconi University, Milan, Italy.

Sofía Ranchordás is a professor of European and Comparative Public Law at the Faculty of Law, University of Groningen, Groningen, The Netherlands.

Bernadette Richards is an Associate Professor of Ethics and Professionalism at the Medical School, University of Queensland, Brisbane, Australia.

Marc Rotenberg is the President and Founder of the Center for AI and Digital Policy and adjunct professor at Georgetown Law. He is a member of the OECD AI Group of Experts.

Judit Sándor is a full professor at the Central European University Budapest, Vienna.

Burkhard Schafer is Professor of Computational Legal Theory, Law School, University of Edinburgh, UK.

James Scheibner is a lecturer at Flinders Law School and a former postdoctoral research fellow at the Health Ethics and Policy Laboratory, D-HEST, ETH Zürich, Switzerland.
List of Contributors

Elisa Stefanini is partner to the Italian firm Portolano Cavallo, Milan, Italy, focusing on regulatory matters in the life sciences sector.

Peggy Valcke is Professor of Technology and Law and vice dean of research at the Faculty of Law & Criminology at KU Leuven, Leuven, Belgium. She is a member of the management board of CiTiP (Centre for IT & IP Law) and of Leuven.AI (the Leuven Centre for Artificial Intelligence), and principal investigator in the Security & Privacy Department of imec.

Effy Vayena is a professor of Bioethics at the Swiss Federal Institute of Technology in Zurich (ETHZ), Zurich, Switzerland.

Simon Verschaeve is a lawyer at law firm DLA Piper, Brussels, Belgium, focusing on privacy, data protection and technology regulation. He is also a teaching assistant for the Law & Technology research group at Ghent University, Ghent, Belgium.
Acknowledgements

A co-edited volume is always the product of collective work. The editors would like to thank Matt Gallaway, Senior Editor at Cambridge University Press, who supported this book project from the beginning and was a fundamental guide during the writing process. We would also like to thank all of the authors for having the patience and resilience to write their chapters during one of the largest global pandemics of the last century. We are also grateful to the law firm Portolano Cavallo, which supported our work, and in particular to Erica Benigni, Sofia D’Arena, Marianna Riedo, Luca Russo and Eleonora Vita for their precious help. Finally, we would like to gratefully acknowledge financial support to Dr Ienca through the funding scheme ELSA-JTC2020 “Neuroethics” – ERA-NET NEURON.