CAMBRIDGE

Cambridge University Press
978-1-107-62473-3 - Ethics, Medicine, and Information Technology: Intelligent Machines and the Transformation of Health Care
Kenneth W. Goodman
Frontmatter
More information

# Ethics, Medicine, and Information Technology

© in this web service Cambridge University Press www.cambridge.org

CAMBRIDGE

Cambridge University Press
978-1-107-62473-3 - Ethics, Medicine, and Information Technology: Intelligent Machines and the Transformation of Health Care
Kenneth W. Goodman
Frontmatter
More information

© in this web service Cambridge University Press www.cambridge.org

CAMBRIDGE

Cambridge University Press
978-1-107-62473-3 - Ethics, Medicine, and Information Technology: Intelligent Machines and the Transformation of Health Care
Kenneth W. Goodman
Frontmatter
More information

# Ethics, Medicine, and Information Technology

## Intelligent Machines and the Transformation of Health Care

**Kenneth W. Goodman**
Professor and Director, University of Miami Miller School of Medicine Institute for Bioethics and Health Policy, Miami, FL, USA

CAMBRIDGE UNIVERSITY PRESS

© in this web service Cambridge University Press www.cambridge.org

CAMBRIDGE

Cambridge University Press
978-1-107-62473-3 - Ethics, Medicine, and Information Technology: Intelligent Machines and the Transformation of Health Care
Kenneth W. Goodman
Frontmatter
More information

CAMBRIDGE
UNIVERSITY PRESS

University Printing House, Cambridge CB2 8BS, United Kingdom

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/9781107624733

© Kenneth W. Goodman 2015

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 2015

Printed in the United Kingdom by Clays, St Ives plc

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

*Library of Congress Cataloguing in Publication data*
Goodman, Kenneth W., 1954– , author.
Ethics, medicine, and information technology : intelligent machines and the transformation of health care / Kenneth W. Goodman.
p. ; cm.
Includes bibliographical references and index.
ISBN 978-1-107-62473-3 (paperback)
I. Title. [DNLM: 1. Medical Informatics Applications. 2. Biomedical Research – ethics. 3. Confidentiality – ethics. 4. Electronic Health Records – ethics. 5. Telemedicine – ethics. W 26.5]
R858
610.285–dc23

2015012826

ISBN 978-1-107-62473-3 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.

Every effort has been made in preparing this book to provide accurate and up-to-date information which is in accord with accepted standards and practice at the time of publication. Although case histories are drawn from actual cases, every effort has been made to disguise the identities of the individuals involved. Nevertheless, the authors, editors and publishers can make no warranties that the information contained herein is totally free from error, not least because clinical standards are constantly changing through research and regulation. The authors, editors and publishers therefore disclaim all liability for direct or consequential damages resulting from the use of material contained in this book. Readers are strongly advised to pay careful attention to information provided by the manufacturer of any drugs or equipment that they plan to use.

© in this web service Cambridge University Press www.cambridge.org

CAMBRIDGE

Cambridge University Press
978-1-107-62473-3 - Ethics, Medicine, and Information Technology: Intelligent Machines and the Transformation of Health Care
Kenneth W. Goodman
Frontmatter
More information

# Contents

*Preface and acknowledgments* vii

1 **Information technologies and twenty-first-century clinical practice: ethics and the electronic health record** 1

2 **Ancient professions and intelligent machines: the ethical challenge of computational decision support** 17

3 **Health privacy, data protection, and trust** 37

4 **Professionalism, programming, and pedagogy** 53

5 **Safety, standards, and interoperability** 71

6 **The e-health industry: markets, vendors, and regulators** 84

7 **Digital health: ubiquitous, virtual, remote, robotic** 104

8 **Biomedical research, from genomes to populations: Big Data and the growth of knowledge** 121

*Appendix A AMIA's Code of Professional and Ethical Conduct* 147

*Appendix B The IMIA Code of Ethics for Health Information Professionals* 152

*References* 160

*Index* 182

© in this web service Cambridge University Press www.cambridge.org

CAMBRIDGE

Cambridge University Press
978-1-107-62473-3 - Ethics, Medicine, and Information Technology: Intelligent Machines and the Transformation of Health Care
Kenneth W. Goodman
Frontmatter
More information

© in this web service Cambridge University Press www.cambridge.org

CAMBRIDGE

Cambridge University Press
978-1-107-62473-3 - Ethics, Medicine, and Information Technology: Intelligent Machines and the Transformation of Health Care
Kenneth W. Goodman
Frontmatter
More information

# Preface and acknowledgments

The intersection of ethics, computing, and the health professions was rather small nearly two decades ago when an edited volume attempted to plot it (Goodman 1998a). That book seemed to meet and stimulate a need. The subsequent dizzying growth of health information technology, or biomedical informatics, was an evolution from an interesting curiosity to a new professional field at the center of nearly everything in the health professions, and the ethical issues it raised emerged as essential for professional practice, education, and public policy. The present volume tries to identify and address the most significant of those issues.

The field of bioethics, itself also quite young, had been fledged on the introduction of new technologies in clinical care and research. Linking bioethics anew to informatics seemed to be both an opportunity and an obligation.

This book is written for clinicians, researchers, and students who work in health information technology and have an interest in ethics, and for ethics professionals and students who have come to realize the importance and scope of such technology. Only a basic knowledge of the fields forming the intersection is required. I try throughout to introduce useful ethical concepts in such a way as to invite and guide clinicians and scientists without disappointing bioethics experts. Policy makers will also find either something useful or something to be angry about. If any thought, conversation, or improved policy is thereby stimulated, the anger will have been worthwhile.

The eight chapters, enumerated and briefly introduced in Chapter 1, seemed natural subdivisions of our three-way intersection, though it certainly would have been possible to have identified different seams and demarcations. Although a Venn diagram plotting the three fields would be simple enough, different subdivisions are also possible. In addition, some issues demand to be revisited in different places; so Chapter 3, on privacy and confidentiality, must lend some of its content to Chapter 8, on research.

It is a source of some wonderment that the world's bioethics community has not made more hay of health information technology. We enjoy extensive literatures on genetics and ethics, neuroethics, nanoethics, and so on, but there is little comparable when it comes to biomedical informatics. Fortunately, that is changing. A major bioethics journal, *The Cambridge Quarterly of Healthcare Ethics*, now features a section on health information technology (which I edit thanks to the encouragement, gentle suasion, and support of Tomi Kushner); and, as the list of references in this book makes clear, interest in ethics and informatics is increasing across several intellectual divides. If I am right about the scope and importance of ethics and informatics, this is very good news.

To write a book is to incur many debts, and, in this case, all gladly. Several grants have supported the work here. Thus:

- Work on this book was supported by the University of Miami CTSI, funded by the National Center for Advancing Translational Sciences at the National Institutes of Health, grant #1UL1TR000460.
- The discussion of personal health records was supported by a grant from the Robert Wood Johnson Foundation to Project HealthDesign.

© in this web service Cambridge University Press www.cambridge.org

CAMBRIDGE

Cambridge University Press
978-1-107-62473-3 - Ethics, Medicine, and Information Technology: Intelligent Machines and the Transformation of Health Care
Kenneth W. Goodman
Frontmatter
More information



- This work was also supported in part by the Center for Law, Ethics and Applied Research in Health Information (CLEAR; http://clearhealthinfo.iu.edu) at Indiana University, which grants permission for its use in this book.
- Some of the discussion of end-of-life care and its representation in the electronic health record was supported by a grant to the University of Florida and the University of Miami by the Alpha-1 Foundation.
- Philanthropist Adrienne Arsht has provided unparalleled support and encouragement.

The University of Miami has been a supportive and congenial home for such multi- and interdisciplinary work, and I acknowledge several colleagues in the chapters here: I want to signal special thanks to Richard Bookman, Robin N. Fiore, and Joanna Johnson, variously, for support, guidance, encouragement, muse-like assistance, and improvement of the manuscript. Students and faculty at the University of Miami Miller School of Medicine have both endured exposure to some of the material herein and improved it. Ana Bezanilla, Gigi Giobio, and Sara Charles of the school's Institute for Bioethics and Health Policy provided first-rate bibliographic and related support.

I have been fortunate to enjoy the support of a number of organizations and, especially, the people who comprise them. AMIA (formerly the American Medical Informatics Association) has been an intellectual home for more than two decades, supporting the creation of an ethics working group, including ethics in conference programming, featuring ethics in its journal, and taking the counsel of members who include bioethics in their areas of competence and expertise. Election as a Fellow of the American College of Medical Informatics has conferred such recognition that I am convinced it was a mistake. I have enjoyed the friendship, mentorship, and encouragement of several AMIA leaders, including Randy Miller, Ted Shortliffe, Chuck Jaffe, Patti Brennan, Eta Berner, Bill Tierney, and Don Detmer.

Versions and aspects of material from several chapters have been shared and bettered during formal presentations at a number of institutions in addition to several talks at the University of Miami: the American College of Epidemiology, European National Ethics Councils Forum, Fundación Santa Fe of Bogotá, Health Level Seven (HL7), Indiana University School of Medicine, Johns Hopkins University Division of Health Sciences Informatics, New Jersey Medical School, New York University Center for Health Informatics & Bioinformatics, University of Florida College of Medicine, University of Texas Health Sciences Center, the US Food and Drug Administration, and the World Health Organization. Obviously, none of these institutions has endorsed or is in any way responsible for the contents here.

I have tried throughout the book to provide historical context, and, for Chapter 1, for instance, this led me to enjoy the hospitality of, and now extend thanks to, Alice Stevenson, Curator at University College London's Petrie Museum of Egyptian Archaeology, who arranged for me to view the "Kahun Medical Papyrus" there, the oldest known medical record.

I am deeply grateful to my wife, Jackie Schneider, who evinced plenary and Olympian patience and provided inestimable help with the manuscript, and my daughter, Allison Goodman, for reminding me why we do things like write books and that, when one has said enough, one should stop.

© in this web service Cambridge University Press www.cambridge.org