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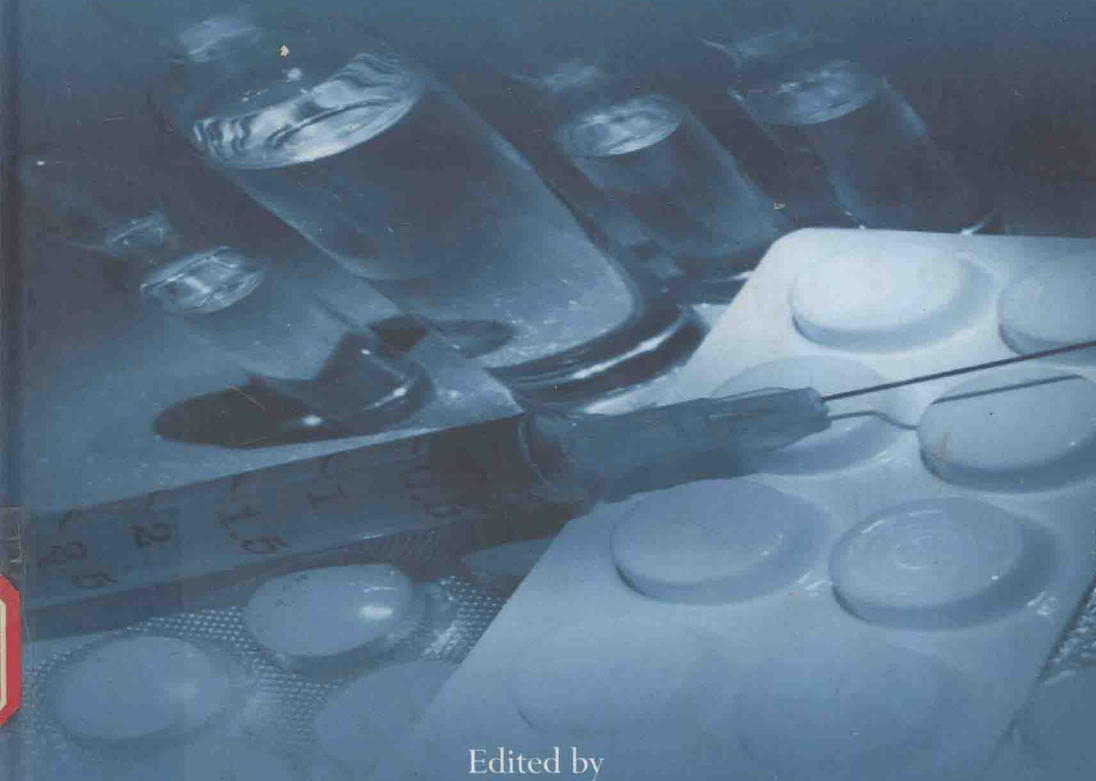
Ethics of Genetic Prognosis after the 'Right to Know/Not to Know' Debate



Edited by
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Published by
Ashgate Publishing Limited
Wey Court East
Union Road
Farnham
Surrey, GU9 7PT
England

Ashgate Publishing Company
Suite 420
101 Cherry Street
Burlington
VT 05401-4405
USA

www.ashgate.com

British Library Cataloguing in Publication Data
Disclosure dilemmas : ethics of genetic prognosis after the 'right to know/not to know' debate. -- (Medical law and ethics)
1. Medical genetics--Moral and ethical aspects. 2. Genetic screening--Moral and ethical aspects. 3. Disclosure of information--Law and legislation. 4. Confidential communications--Physicians. 5. Informed consent (Medical law) 6. Genetic disorders--Patients--Psychology.
I. Series II. Rehmann-Sutter, Christoph, 1959- III. Müller, Hj. (Hansjakob)
174.2'96042-dc22

Library of Congress Cataloging-in-Publication Data
Disclosure dilemmas : ethics of genetic prognosis after the 'right to know/not to know' debate / [edited] by Christoph Rehmann-Sutter and Hansjakob Müller.
p. cm. -- (Medical law and ethics)
Includes bibliographical references and index.
ISBN 978-0-7546-7451-1
1. Genetic screening--Law and legislation. 2. Genetic counseling--Law and legislation. 3. Medical ethics. I. Rehmann-Sutter, Christoph, 1959- II. Müller, Hj. (Hansjakob)

K3611.G46D575 2009
344.04'196--dc22

2009002176

ISBN 978-0-7546-7451-1

Printed and bound in Great Britain by
TJ International Ltd, Padstow, Cornwall

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Wolf Langewitz is Professor of Internal Medicine at the University of Basel and Deputy Head of the Department of Psychosomatic Medicine. He studied medicine at the Universities of Freiburg i. Brsg. and Berlin. After a year in Pathology, he trained as an Internist at the University of Bonn (D), Board Certificate 1986, and in 1990 he received a degree in Psychotherapy. From 1990 until now he has worked at the Department of Psychosomatic Medicine, and was head of the department from 1998–2007. Since 1996 he has been co-editor of the German textbook *Uexküll: Lehrbuch der Psychosomatischen Medizin* (Elsevier: Munich, 2003). In 2006 he was elected President of the European Association for Communication in Health Care (EACH). Since 2008 he has also been Visiting Professor at the Faculty of Communication in Health Care at the University of Lugano (Head: Professor P. Schultz). His research interests include theoretical questions of the interplay of mind and body in psychosomatic medicine, application of semiotic and phenomenological thinking in medicine, physician patient communication and somatoform disorders. A list of his publications can be found at <www.psychosomatik-basel.ch>.

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Rouven Porz is a biologist and philosopher and is and is currently Head of the Ethics Unit at the Inselspital (University Hospital) in Bern, Switzerland. He is working in a qualitative interview study, investigating patients' perspectives in IVF and their ideas about egg sharing, embryo donation, human embryonic stem cell research from an ethical point of view. He did his PhD in Bioethics on the Absurdity of Genetic Testing. This research work was carried out in Basel at the Unit for Ethics in Biosciences, working in a qualitative interview study on genetic diagnosis, with Jackie Leach Scully and Christoph Rehmann-Sutter. He is the Editor of the EACME newsletter (European Association of Centres of Medical Ethics, with Guy Widdershoven) and Visiting Research Fellow at the Institute for Biomedical Ethics in Zürich, Switzerland. His research interests include genetic diagnosis, genomics, stem cell research and, from an ethical point of view, narrative reconstruction of life stories, boundary situations and existentialism. He has a strong interest in ethical methodologies, mainly focusing on questions of how to bridge empirical investigation and normative argumentation.

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Acknowledgements

The editors thank the Käthe Zingg-Schwichtenberg Fonds and the Swiss Academy of the Medical Sciences for generous financial support. The Swiss National Science Foundation funded a bioethical research project *Time as a contextual element in ethical decision-making in the field of genetic diagnostics* (11-64956.01 and 101311-10306), which was carried out at the Unit of Ethics in the Biosciences, University of Basel by Jackie Leach Scully, Rouven Porz and Christoph Rehmann-Sutter. This project provided the intellectual framework, in which Hansjakob Müller's initial idea for the book could develop. At different stages of the conception and materialization of the book (first as an international conference on a sunny spring day in 2001 at Wenkenhof in Riehen near Basel, then through the invitation and inclusion of new authors), the supportive and inspiring collaboration of Irina Miletskaja, Rouven Porz and Franziska Genitsch was indispensable. Rowena Joy Smith, Jackie Leach Scully and Monica Buckland reviewed the English of several chapters. Special thanks go to Gabriela Brahier, who guided the manuscript carefully and with the necessary patience through the final steps. In 1997, Ruth Chadwick, Mairi Levitt and Darren Shickle edited a book in the Avebury Series in Philosophy for Ashgate on the ethical and philosophical implications of genetic screening, with the title *The Right to Know and the Right Not to Know*. We are grateful to Ashgate for accepting and producing our new volume that takes a fresh look, a decade on, at some of the same topics. Our special thanks go to Carolyn Court, Alison Kirk, Kate Brown and many other supportive staff at Ashgate, and to two helpful external reviewers.

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Introduction

Christoph Rehmann-Sutter and Hansjakob Müller

'Why did you make me see what I can't change anyway?'
(Friedrich Schiller, *Kassandra*, 1802, line 53 f. – our translation)

In many cases, genetic testing and screening can provide diagnostic information for improving health care. But the logic of the genes implies that diagnoses may be pre-emptive. Genetic information may be essentially prognostic information; its practical implications may be diverse and only partly predictable. The genome can rarely be 'read' (a difficult term in this context) in such a clear way that future events of health and disease can be forecast with security. Rather, in most cases the information takes the form of probabilities. This partial knowledge can clearly be useful; but because it is, at the same time, a new non-knowledge it can also be difficult to interpret and to handle. Furthermore, there may be stakeholders other than the patient themself involved: at-risk family members, carers, even institutions with interests. The construction, disclosure and exchange of personal genetic information that reveals things about one's likely future in terms of potential disease is an emerging new space of 'biosociality' (Paul Rabinow's term; cf. Rose 2007) in which ethical dilemmas arise.

We all sometimes grapple with fate, with what we see as the unchangeable and often unforeseeable course of events. To tame the unpredictable by foreseeing and understanding the future has been a powerful motive throughout history for the advancement of the sciences and technologies (Toulmin 1961). However, divining the future has also been a reason to turn to auguries, prophets and clairvoyants of many kinds, some of them very dubious. Omens, unlucky black cats and lucky horseshoes have also served in attempts to tame the unpredictable. One of the outcomes of the scientific and rational strand in the development of foresight-and-understanding tools is modern genetics and genomics. Today, personal genetic information of various forms and relevance for predicting the future is becoming available with increasing ease. Genetic tests are now being used to divine the future and to plan lives. Here, genetics meets the complexities of social life.

The medical value of personal genetic information is equivalent to its potential for preventing disease. But its personal utility is often ambiguous and ambivalent. Predictive genetic information, when known, can have a profound impact on those who request or get it. A truth, once it has been told, cannot be untold. And it is often unclear to those involved exactly what 'the truth' is when it comes to test results. There may be different 'truths' in the raw data, and there is a potential for over- and misinterpretation. Professional expertise is needed. Genetic counselling

has been developed to accompany genetics. And genetic counsellors or medical geneticists have developed a rich technical literature about, and ethical reflection on, the ambivalences and dilemmas that arise in their practice.

This interdisciplinary book starts from the professional discourse about 'disclosure dilemmas' in genetic counselling, but goes beyond the professional ethics of genetic counsellors. It brings together and confronts the new contributions of social scientists, philosophers, lawyers, medical doctors, geneticists and bioethicists who reflect on disclosure dilemmas from different angles and with different expertise and complementary experiences. The idea for the book included the aim of enlarging the focus of bioethical discussions about disclosure dilemmas. New problems have arisen that were not visible 10 years ago, problems which perhaps only become apparent if one adopts a patient's perspective and investigates how dilemmas 'feel' if experienced in their concrete, local settings and histories. Some of the new issues relate to recent developments in science, technology and medical practice. Many more diseases can now be tested for, with the number of available tests rapidly increasing. Tests cover not only monogenetic but also multifactorial diseases, some of them very common disorders such as diabetes, obesity, heart diseases or cancers. It should soon be possible to test for some psychiatric disorders. One striking example of recent developments is the introduction of routine risk assessment based on ultrasound and maternal blood in prenatal diagnosis. Before offering an invasive genetic test to the pregnant woman, the risk assessment is provided as an element of informed decision making. But this changed much more for the women concerned than just the amount of information available.

Recent publications in bioethics have indicated a need for further inter-disciplinary research and discussion about genetic dilemmas. From many possible examples we mention Monica Konrad (2005), who did in-depth interviews with families affected by Huntington's disease. She demonstrates how 'the exchange of genetic information between kin entails unresolved processes of moral decision making within and across the generations' (4). This may be unsurprising, but her study shows clearly that bioethics can only meet the local understandings of what knowledge is 'good' to know and what knowledge is 'bad' to tell and share with others, in the context of a close understanding of subjective illness experiences that can not be provided by 'thin' descriptions in case vignettes or theoretical imagination. This opens a new field for empirically-based bioethics that takes the perspectives of participants into account and treats patients as moral pioneers, to use Rayna Rapp's term.

A second groundbreaking contribution is the book by Neil C. Manson and Onora O'Neill (2007). They attempt to rethink informed consent in bioethics on the basis of a developed theoretical approach to 'information' that goes beyond the assumption that information is 'something' (meaning, ideas) that can be conveyed or transferred from one mind to the other. Information is better understood as the result of processes of interaction and communication involving both sides of the encounter. This account of information was first developed in genetics (by