

Cambridge University Press

0521540666 - Narrating the New Predictive Genetics: Ethics, Ethnography and Science

Monica Konrad

Frontmatter

[More information](#)

---

## **Narrating the New Predictive Genetics**

This book explores the way changes in technology have altered the relationship between ethics and medicine. For some inherited diseases, new genetic testing technologies may provide much more accurate diagnostic and predictive information which raises important questions about consent, confidentiality and the use of information by family members and other third parties. What are the implications of this knowledge for individuals and their families? And for society more widely? How should this new information be used? How do people deal with the apparent choices that new knowledge and technologies offer? Drawing on extensive ethnographic research with families affected by Huntington's Disease and using perspectives from medical and cultural anthropology, the author explores the huge disparity between the experience of living with the results of genetic testing and the knowledge and expertise which are drawn on to develop policy and clinical services.

MONICA KONRAD teaches at the Department of Social Anthropology, University of Cambridge and directs the PLACEB-O research group (Partners Linked Across Collaborations in Ethics and the Biosciences – Orbital). Her research addresses the relevance of contemporary anthropology for global governance in science, international ethics and interdisciplinary studies. She is the author of *Nameless Relations: Anonymity, Melanesia and Reproductive Gift Exchange between British Ova Donors and Recipients* and currently acts as anthropological advisor to bioethics councils in the UK and for the UN.

Cambridge University Press

0521540666 - Narrating the New Predictive Genetics: Ethics, Ethnography and Science

Monica Konrad

Frontmatter

[More information](#)

---

## Cambridge Studies in Society and the Life Sciences

### *Series Editors*

Nikolas Rose, *London School of Economics*

Paul Rabinow, *University of California at Berkeley*

This interdisciplinary series focuses on the social shaping, social meaning and social implications of recent developments in the life sciences, biomedicine and biotechnology. It places original research and innovative theoretical work within a global, multi-cultural context.

### Other titles in series

Adam Hedgecoe, *The Politics of Personalised Medicine: Pharmacogenetics in the Clinic*

Amade M'charek, *The Human Genome Diversity Project: An Ethnography of Scientific Practice*

Cambridge University Press

0521540666 - Narrating the New Predictive Genetics: Ethics, Ethnography and Science

Monica Konrad

Frontmatter

[More information](#)

---

# Narrating the New Predictive Genetics

## Ethics, Ethnography and Science

MONICA KONRAD  
*University of Cambridge*



**CAMBRIDGE**  
UNIVERSITY PRESS

Cambridge University Press  
0521540666 - Narrating the New Predictive Genetics: Ethics, Ethnography and Science  
Monica Konrad  
Frontmatter  
[More information](#)

---

PUBLISHED BY THE PRESS SYNDICATE OF THE UNIVERSITY OF CAMBRIDGE  
The Pitt Building, Trumpington Street, Cambridge, United Kingdom

CAMBRIDGE UNIVERSITY PRESS  
The Edinburgh Building, Cambridge, CB2 2RU, UK  
40 West 20th Street, New York, NY 10011-4211, USA  
477 Williamstown Road, Port Melbourne, VIC 3207, Australia  
Ruiz de Alarcón 13, 28014 Madrid, Spain  
Dock House, The Waterfront, Cape Town 8001, South Africa

<http://www.cambridge.org>

© Monica Konrad 2005

This book 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 2005

Printed in the United Kingdom at the University Press, Cambridge

*Typeface* Times 10/13 pt.    *System* L<sup>A</sup>T<sub>E</sub>X 2<sub>ε</sub> [TB]

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

ISBN 0 521 83314 0 hardback  
ISBN 0 521 54066 6 paperback

Cambridge University Press

0521540666 - Narrating the New Predictive Genetics: Ethics, Ethnography and Science

Monica Konrad

Frontmatter

[More information](#)

---

*For my mother*

---

## Contents

---

<i>Acknowledgements</i>	<i>page xi</i>
<b>Introduction</b>	1
I ETHNOGRAPHY AS LINKAGE MAP	
<b>1 Thinking futures</b>	9
Lives to come	9
Bodies into oracles	15
Ethno-ethics and the encounter with biology	20
Narrating Huntington's Disease families	22
Organisation of the book	26
<b>2 Approaching translocations</b>	29
Cross-talking value	29
Sociobiology as a new modern synthesis?	39
Code words	47
A genetics synthesis for the 21 <sup>st</sup> century?	50
II 'HOME TRUTHS'	
<b>3 Foretelling foreknowledge</b>	61
Verbal missiles and disclosure talk	61
Experimental technology as anticipatory ritual	65
What does it mean to be 'pre-symptomatic'?	83
<b>4 Tracing genealogies of non-disclosure</b>	87
Dilemmas of truth telling in conventional bioethics	87
Embodiment and moral knowledge	90
Foreknowledge and the liabilities of veracity	100

## III RELATIONAL ETHICS IN PRACTICE

<b>5</b>	<b>Reproducing exclusion</b>	109
	Testing kin loyalty	110
	Blood may be thicker than water, but genes don't only cross sexes . . .	117
	Discussion: refiguring heredity as social anatomies of interdependence	121
<b>6</b>	<b>Relinquishing exclusion</b>	124
	Pre-implanting a story	124
	De-selecting life and redescribing relative disloyalties	134
	Summary: the 'new genetic family'	143
<b>7</b>	<b>Concluding remarks</b>	146
	Predictive medicine is a complex art	146
	Contexts teach	148
	(The myth of) pre-emptive individualism	151
	Linkage by translocation	158
	<i>Appendix</i>	160
	<i>Notes</i>	164
	<i>Bibliography</i>	180
	<i>Index</i>	197

## Acknowledgements

---

This project had its genesis in an Economic and Social Research Council funded research study I began in 1997–98 ('Culture, Kinship and Ethics in the Context of the New Reproductive and Genetic Technologies' [R000222290]). Over the years numerous organisations have made this research possible and numerous others have facilitated its progression. I thank first all the families who agreed to take part in the research and welcomed me into their lives, often in trying circumstances. Most of all to everyone who insisted on sharing their insights and made the research 'theirs', so to speak. The members of the HDA (Huntington's Disease Association) Dorset Branch were good enough to invite me to their support group activities and committee meetings. I must thank Hedley Thomas for his warm hospitality during my visits. Thanks also to Trudi Smith and the HDA South Hampshire Branch for their invitations to present work-in-progress. Sue Watkin and Cath Stanley of the HDA helped with such enthusiasm and kindness at the early stages of the research, putting me in touch with many of their friends and colleagues, and I was fortunate to be able to consult with Wendy Watson of the Hereditary Breast Cancer National Helpline who opened my eyes to other realities. For their assiduous attention to detail, I thank all the assistants who helped to transcribe the lengthy transcripts of taped interviews.

Mention too must be made of the dedicated campaign work of Human Genetics Alert, the Genetics Interest Group and GeneWatch UK whose staff have helped to keep me on track. Learning also about the strategy of 'horizon scoping' has provided another welcome entry route into the world of predictive science. The openness of the Human Genetics Commission (HGC), an advisory body reporting to the UK government, to expose its working methods and the willingness of Commissioners to debate before the public at its open plenary meetings gives fresh hope to the immanence of ethical accountability within all committee life. I thank Baroness Helena Kennedy, QC, Chair of the HGC and Professor Alexander McCall Smith, Vice-Chair, for setting the example.



Cambridge University Press

0521540666 - Narrating the New Predictive Genetics: Ethics, Ethnography and Science

Monica Konrad

Frontmatter

[More information](#)

Additional thanks to the HGC Secretariat for help with research enquiries along the way.

For letting me shadow them periodically in 1998 during their clinical interactions with patients, I extend my appreciation to Professor Kay McDermott and nurse genetic counsellor Wendy Chorley at the Royal Free Hospital, London. Chris Mathew and Liz Green, Division of Medical and Molecular Genetics, Guy's Hospital, London and Alison Lashwood, Guy's Hospital, also showed and explained the more technical side of things inside laboratory space. Professors Peter Harper, University of Wales College of Medicine in Cardiff and Bernadette Modell, University College London Medical School, Gerrit Dommerholt of International Huntington's Association, Dr Nancy Wexler, Columbia University, New York and Prof Ira Shoulson, University of Rochester, were kind enough to respond to points of concern and generously forwarded relevant publications. And in the 'in-between' spaces where science and ethics properly intersect, the intellectual inspiration of colleagues from the International Council for Science, especially their commitment to the future of international, cross-cultural and multi-disciplinary endeavours, has helped again to keep me on track.

Small parts of Chapters 3 and 4 were used to a different purpose in my journal articles, 'Predictive genetic testing and the making of the pre-symptomatic person: prognostic moralities amongst Huntington's affected families', *Anthropology and Medicine*, 10(1):23–49 (2003); and 'From secrets of life to the life of secrets: tracing genetic knowledge as genealogical ethics in biomedical Britain', *The Journal of the Royal Anthropological Institute*, 9(2):339–58 (2003). I am grateful to the Royal Anthropological Institute of Great Britain and Ireland and the editors and publishers of this material for permission to use it here. My thanks to Martin Rowson for permission to reproduce his wonderful cartoon in the Introduction.

Monica Konrad  
London  
December 2003