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.

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Narrating the New Predictive Genetics

Ethics, Ethnography and Science

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For my mother

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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
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Introduction

Predictive genetic testing technology is still very much in its infancy in Western healthcare systems. However, as geneticists continue to establish links between the location of genes and particular disease aetiology, so further scientific knowledge may occasion more encompassing social definitions of who legitimately can be classified as 'pre-ill' or 'pre-symptomatic'. Potentially all of us may be transformed into 'genetic citizens' with one kind or another of genetic 'profile', either before birth or sometime during our life course. But what exactly does it mean to be classified as a person with a predisposition to illness and how are the life sciences and technologies creating pre-symptomatic persons as new forms of social value?

This book is a critical exploration of the emerging pre-emptive cultures that shape the new predictive genetics. Based on original materials from fieldwork in contemporary Britain, it argues there is a pressing need for the social sciences to analyse conceptually, empirically and pragmatically how we think through the links that bind together the ideals of prophecy and health in such predictive contexts.

The ethical controversies surrounding genetic testing have largely emerged since the development of tests based on the direct analysis of a person's DNA. This has only been possible since the identification of bio-molecular markers enabled geneticists to begin the work of tracing correlations between particular disease-causing agents and specific genes. Though successful linkage applies still mainly to the 'single-gene' disorders whose genetic mutations are considerably simpler to study than the more common polygenic conditions, scientific understanding of the nature of multiple interactions between different sets of genes in disease formation is commonly heralded as the next genetics 'revolution'. The possibility for genetic diagnosis itself, though, is not entirely new. Antenatal testing for chromosomal abnormalities such as Down's

syndrome has been offered routinely to older pregnant women and genetic screening already has some routine applications. In the UK, all newborn babies are screened for phenylketonuria, a genetic condition that can lead to serious learning difficulties unless counteracted by a special diet. For babies that test positively, the adverse effects can be pre-empted by early treatment.

It is this kind of example about the merits of early illness prevention and treatment that underpins rationalisations for the promise of a 'golden age' of new predictive healthcare. These rationalisations are underwritten by many of the late-capitalist economies of the West that aim to link advances in future health provision with supremacist ideas of cultural progress and power. The biosciences and life technologies are endowed in many of these visions with an implicit civilising mission. Britain, for example, aspires 'to lead the world in the discovery and realisation of the maximum benefits of genetics in healthcare', with the British government pledged to invest £50 million in genetic research, genetics-based health services and professional training between 2003–6, with further funding to follow (Department of Health 2003:8). Elevating in this way the gene to the newly enhanced status of visible cultural icon, it is only by appreciating the wider social implications of the predictive testing era that the claims of the original guiding promise will be open to critical scrutiny and ongoing evaluation (see figure page 3).

Taking a strong integrative approach that draws out some of the possibilities for a productive synthesis between social anthropology, cultural analysis and a critical bioethics, *Narrating the New Predictive Genetics* introduces a number of important empirical findings that extend the parameters of existing critiques of 'geneticisation' in significant new directions. The aim here is to contribute to a growing social science scholarship on the anthropology, sociology and psychology of the new genetics (e.g., Rabinow 1999; Conrad and Gabe 1999; Marteau and Richards 1996) by paying attention to how we formulate questions about the meaning of predictive genetic knowledge for definitions of society. Both the anthropology of biomedicine and the cultural analysis of new genetic technologies are relatively recent topics within the social sciences. A few anthropologists, for instance, have turned their attention to women's experiences of prenatal screening techniques as well as interpretations of risk amongst those undertaking predispositional screening for breast cancer (Rapp 1999; Finkler 2000; Lock 1998; for other monographs addressing the new genetics see Rabinow 1996, 1999; Fujimura 1996; see also Franklin and Lock 2003). However there has been no critical study devoted to the shift from treatment to prevention-based medicines, and in particular no anthropological study exploring how the making of the 'pre-symptomatic person' reconfigures current definitions of sociality and social identity in complex, technologically

Gee! Gnomes!
"And **thus** we can see how you were **born**, how you **live** and how you'll **die**!"
12 February 2001
Reproduced by kind permission of *The Guardian*. © Martin Rowson 2001.

This political cartoon uses the 'breakthrough' of the first so-called 'rough draft' of the sequenced human genome to illustrate the potentially determinist reasoning behind predictive claims to genetic supremacy. In this case, a satirical play on the nature of political power depicts the internal rivalry between two government figures from the current Labour Party in Britain: the Chancellor of the Exchequer, Mr Gordon Brown, is shown finally to supersede the Prime Minister, Mr Tony Blair whose genome comically reveals next to no genes.

advanced societies. This is a somewhat strange omission, for ever since E. E. Evans-Pritchard's (1937) seminal *Witchcraft, Oracles, and Magic among the Azande*, social anthropologists have attended to the many ways that divinatory knowledge across non-Western cultures is believed to have transformative effect through the medium of manipulated human bodies and other ritualised objects. Revisiting then something of an 'old' anthropological interest, this book offers a critical commentary on the new oracular predispositional 'truths' of twenty-first century prophetic biology and the relation of these truths to changing popular conceptions of persons, bodies and notions of genetic inheritance in biomedical Britain today.

By way of detailed case studies of families affected by Huntington's Disease (HD) – a monogenic (single-gene) inherited and late-onset condition for which there is presently no known cure – we will examine how the exchange of genetic information between kin entails unresolved processes of moral decision-making within and across the generations. Understanding, however, why such local moralities of information disclosure generate dilemmas over what knowledge is 'good' to know and what knowledge is 'bad' to tell and share with others, raises questions of wide relevance beyond the specifics of HD cases and subjective illness experiences. To date, anthropologically informed commentaries of the new medical technologies have largely neglected the conceptual question of how, and to what extent, the choices informing people's reproductive and genetic decision-making comprise so-called 'ethnographies of morality' (Howell 1997). As a consequence, anthropologists interested in this area have tended to avoid asking how, and indeed how adequately, their conceptual apparatus can address the working premises of mainstream Western bioethics. In the context of predictive genetic testing technology where consanguineal ('blood') kin who have chosen not to get tested may find another's test result implicates their own health status, such issues become especially germane. In the light of these difficult disclosure dilemmas, this study reconsiders the conceptual premises of individual autonomy informing the 'right to know' debates of contemporary Western bioethics. It finds the interrelatedness of interests informing local practices particularly suggestive for the conceptualisation of a 'genealogical ethics', which in turn may be seen as part of a wider relational amalgam (a 'relational ethics'). Additionally, I have wanted to introduce certain cross-cultural data from the existing medical anthropological record to show why such materials are salient to the wider discussion of human embodiment and identity in the genome era. Since the inclusion of comparative data has been noticeably absent from previous ethnographies of the new medical technologies, such comparisons hopefully yield additional interest and broaden the terms of debate, for anthropologists and non-anthropologists alike.

In the course of researching this book, I have lost track of the number of times people have asked questions about my intellectual allegiances. For whom does one write? To whom is one talking? For all authors, these are important, inescapable questions. As indicated, the following pages are attuned to particular anthropological sensibilities, however I want to stress that the book is written at the same time with a broader non-anthropological readership in mind. Indeed one main aim is to bring together the usually disparate domains of ethics, ethnography and science as the beginning of a critical exploration in interdisciplinary dialogue between medical and non-medical practitioners. During their daily rounds, clinical geneticists, genetic counsellors and academic

bioethicists usually do not 'talk with' social scientists. Just the same might be said of the latter: social scientists rarely find themselves positioned as well-integrated or long-term fixtures within mainstream scientific or medical research communities. Issues of access to clinical settings by non-clinicians are often the first impediment to such cross-dialogue. But these disciplinary and inter-institutional 'gaps' between the different practices and scholarly communities seem, if anything, more essential to address now as shifts towards so-called 'Mode-2' distributed knowledge production demand new transparency and participatory structures.

When an ethnographer chooses to work with and through certain publics – when he or she purposely mediates the creative space of the 'agora' (Nowotny *et al*. 2002) – then engaging the professional interest of scientists, clinical geneticists and other health professionals seriously matters. Let me be specific. Since the rate of uptake of predictive genetic testing has been far lower amongst the HD community than was originally expected by clinicians, there is a dearth of social knowledge relating to the real life experiences of genetically predisposed (i.e., 'at risk') but untested individuals. There is also very little public awareness of what it means for affected families and individuals to live with a 'pre-symptomatic' diagnosis. Living life pre-symptomatically is a skill few us might have heard about at the present time. Indeed, clinicians themselves have cited evidence suggesting that those who experience the greatest difficulty in coping with an adverse test result are also the likeliest client group to drop out of clinical follow-up studies. Similarly, although policy specialists often pay lip service to the 'ethical dilemmas' of predictive genetic testing technology, the normative formulation of bioethical statements on predictive testing by various expert committees has been delimited extremely narrowly. Across Euro-America, relevant ethical bodies have not to date focused on broad inclusive questions such as how revised diagnostic tools in clinical genetics are creating 'pre-symptomatic' persons as new social identities. In the media too, there has been next to no debate addressing how the effects of these genetic testing technologies are creating new prognostic moralities of 'foreknowledge' at the level of ordinary lived experience. Based on the 'expert' accounts of those who have tested positively as well as those receiving good news, this book by contrast reorients the focus through illustrative examples and stories from specific contexts. With its close attention to narrativisation and issues of temporality it hopes to supplement the quantitative research which clinicians routinely consult and analyse.