CAMBRIDGE Bioethics and Law

The Right to Know and the Right Not to Know

Genetic Privacy and Responsibility

Edited by Ruth Chadwick,
Mairi Levitt and Darren Shickle

SECOND EDITION

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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/9781107076075

First edition published by Avebury 1997
Second edition Cambridge University Press 2014

Printed in the United Kingdom by Clays, St Ives plc

A catalogue record for this publication is available from the British Library

Library of Congress Cataloguing in Publication data
The right to know and the right not to know : genetic privacy and responsibility / edited by Ruth Chadwick, Mairi Levitt and Darren Shickle. – Second edition.
pages cm – (Cambridge bioethics and law)
First published: Aldershot; Brookfield, VT: Avebury, 1997.
Includes bibliographical references and index.
ISBN 978-1-107-07607-5 (hardback)
1. Human chromosome abnormalities–Diagnosis–Moral and ethical aspects. 2. Genetic disorders–Diagnosis–Moral and ethical aspects. 3. Privacy, Right of. I. Chadwick, Ruth F., editor. II. Levitt, Mairi, editor. III. Shickle, Darren, editor.
RB155.6.R53 2014
174.2'96042–dc23
2014020711

ISBN 978-1-107-07607-5 Hardback
ISBN 978-1-107-42979-6 Paperback

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Acknowledgements

The editors would like to thank all the contributors and the contacts at Cambridge University Press for their assistance with this volume.

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Introduction

Ruth Chadwick, Mairi Levitt and Darren Shickle

The first edition of *The Right to Know and the Right Not to Know* was published in 1997 as an output of the Euroscreen projects (1994–6; 1996–9), funded by the European Commission. The idea for the book emerged over dinner at a conference in Turku, where Ruth Chadwick had given a talk on the topic of the right to know and the right not to know, and discussion in the management team of Euroscreen concluded that there were so many interesting associated issues that a volume could and should be prepared. As the publication was an output of a project on genetic screening, it did not seem necessary to specify in the title that the issues were to be understood in the genetic context. At the time, it was a hot topic in genetics: in the 1990s there had been much discussion about disclosure (or not) in the clinic. At the beginning of the decade, for example, the Royal College of Physicians published its *Ethical Issues in Clinical Genetics* (1991), which identified a number of possible scenarios, and in the same year the results of the empirical survey of disclosure dilemmas, conducted by Dorothy Wertz and John Fletcher, was published in the journal *Bioethics* (Wertz and Fletcher 1991).

There had been developments, however, in the 1980s, which paved the way for discussions related to wider population screening (Shickle and Harvey 1993). The Nuffield Council on Bioethics published its report on genetic screening in 1993. Of the two Euroscreen projects that were funded by the European Commission, the first (1994–6) examined ethical issues in predictive medicine. The second was concerned with insurance, commercial testing and public awareness. Clearly, issues of rights to know and not to know were implicated in all of these, in different ways.

In the clinic the principal issues discussed concerned potential tensions between the interests of family members, and the right (not) to know about late onset disorders. A commonly discussed scenario was where one member of a family wished to undergo genetic testing but another (their parent, for example) did not, the implication being that disclosure for the one would also give an indication of the genetic status

of the parent. Findings of non-paternity in genetic testing in the clinic also gave rise to potentially difficult situations.

In relation to late onset disorders, some people would prefer to know about their risk of developing diseases such as cancer or dementia, even though the onset might be decades into the future, so that they could structure their lives accordingly (even though the predictions would be fraught with more or less uncertainty, depending on the condition in question). For some individuals with a strong family history of genetic disease, the uncertainty of not knowing was difficult to bear, and hence a genetic test that helped to provide more clarity helped to alleviate these anxieties, even if the recalculated risk was higher. The contrary position, held by other individuals, was a preference *not* to know, and to live in the hope of a long and healthy life. There were also particularly challenging issues about genetic testing of children (Clarke 1994). These issues remain.

The wider issues addressed in projects such as Euroscreen 2 included the rights of third parties such as insurers and employers to what they perceived as information relevant to insurability or employability; the rights of individuals to access genetic information in the marketplace rather than in the clinical context (and without the professional safeguards associated with a clinic); and the right of society (including but not confined to patient groups) both to be informed about the direction of science and to have a voice.

In this book we aim to update the debate by further critiquing philosophical principles of privacy and autonomy, reviewing changes in the genetic privacy debate since the 1990s and discussing new arenas of the privacy concern.

Part I: Philosophical and legal issues

Part 1 sets the scene with an overview of the philosophical and legal debate around the right to know and the right not to know. In the first chapter the editors explore developments since the first edition of the book in 1997. There have been changes in context with the completion of the Human Genome Project, the establishment of large-scale population biobanks and social and political change, with an increase in surveillance and an explosion in social media, emerging issues and trends in ethical approaches. Genomic research has opened up the potential of personalised health advice, in the context of medication (pharmacogenomics) and nutrition (nutrigenomics). Whole genome sequencing has meant that rather than disclosing just single incidental findings there is now the prospect of knowing everything in the genome. Thinking about

the ownership of genetic information has expanded from the implications of the right to know and right not to know for the individual's sense of identity to include the implications for collective identity. In ethical approaches there is now a greater emphasis on solidarity and equity and a trend towards rethinking the concept of privacy, over and above developments in data protection.

Next, in the only chapter reprinted from the last edition, Jørgen Husted focuses on the specific issue of unsolicited disclosure of genetic information to hitherto unsuspecting relatives, who thereby irreversibly lose their 'genetic innocence' and thus their right not to know. In thinking about the moral acceptability of this – about whether it can be justified in terms of a right to know – he distinguishes between two senses of autonomy: a thin and a thick conception. From the point of view of the thin conception the disclosure appears to enhance autonomy by providing information to facilitate decision making. This analysis is flawed, however, if a thick conception allowing for autonomy as self-*definition* is acknowledged, because it takes away from the individual the very decision of whether to know or not to know. There are dangers here of moralism as well as paternalism.

Graeme Laurie's analysis of privacy and the right not to know is in contrast to that of Husted. He argues that while the right to know is typically underpinned by an autonomy argument, the right not to know cannot be so underpinned, except in situations where an individual has expressed a prior wish not to know. For Laurie the difficult cases of disclosure concern those instances where there is no prior expression of preference, and to disclose the option of knowing/not knowing will in itself make clear that there is something to know. Here the interests at stake are best construed as privacy interests. Privacy here is explained as a genuine state of separateness from others, which also includes *psychological separateness* from others. The chapter proceeds to examine what legal protection of such interests is possible and concludes that the role of the law here should be approached with caution: 'Professional discretion, rather than legally imposed duty, is likely to be the optimal way to navigate this particular maze'.

Part II: Issues in genetics

The second part contains five chapters on contemporary issues in genetics. Kadri Simm reviews the ethical debates when large population biobanks were being established and the lack of discussion at that time of the possibility of incidental findings, that is, the discovery of DNA information that might be relevant to a donor but was not the aim

of the research. Simm discusses why 'incidentalome' has now become a hot topic in biobanking. As genetic research is more commonplace and biobanks share information across global networks the challenge of feedback looms large and researchers and institutions consider what is the right thing to do and who should do it. Whereas most biobanks had no mechanisms for the feedback of personal information to donors when they were set up, sociological research has indicated that donors would like such feedback. Simm considers the arguments for and against the disclosure of relevant research results to donors and the proposals for guidelines in this area. The focus is now on the 'how and when' of feedback, rather than 'if and whether' it should be given. In a future where whole genome sequencing becomes cheaper and part of routine medical care, it cannot be assumed that individuals will act on the information that is disclosed and that their quality of life will improve.

Robin Williams and Matthias Wienroth focus on forensic databases and who has the right to commission, deploy and share this information. Having considered the complex and divergent legislation that limits the uses of forensic DNA profiles in different jurisdictions, the authors look at recent controversial developments that promise the ability to infer relatedness through familial searching, population group origins and physical attributes of the person whose sample has been analysed. It might be presumed that legally sanctioned criminal investigations have a right to know but whether such intrusive interventions may be considered legitimate depends on who is to have access to the knowledge and their overall value orientation, the purposes for which it will be used and the categories of people to be subject to these interventions. The authors conclude with a discussion of the claims of the individual either to be known or to be forgotten.

Mairi Levitt argues that in order to exercise a right to know or a right not to know, it is necessary to have the right information to facilitate this choice. The problem is that in many areas of everyday life, choices have proliferated: some choices may be trivial, others have more importance. At the more significant end of the spectrum, patients and parents are bombarded with information about health and child rearing. The assumption is frequently made that an individual will be empowered by choice and in turn that empowerment is a means to improving the quality of individuals' lives. Choice has also been portrayed by governments as the key mechanism in driving quality and value for money in public services. However, as Levitt points out, individuals who are economically deprived may also be relatively choice deprived. Levitt describes the effects on the chooser, both positive and negative, of an

ever-increasing range of choices. In particular, there are psychological consequences for making decisions under uncertainty and where there are implications for health and well-being of self and family. In recognition of this, many societies evolve socially acceptable ways of doing things that remove the need for individuals to decide how to act in every situation. Levitt concludes by discussing the implications of an increasing range of options arising from genetic technologies and how third parties may seek to influence these choices through more or less subtle messages about what the good parent or the responsible person should do.

One expanded area of choice is the emergence of commercial companies offering knowledge of one's own genome. Barbara Prainsack discusses seven instances of knowing, sharing and storing data on one's own genome; from genetic analysis within a clinical context to making one's own genomic data public. Although the right to know one's own genetic constitution might be seen as relatively unproblematic, there are new issues to consider, including the portability of genetic data and the availability of raw data that individuals might analyse, make sense of using online tools, share with others or make accessible for research. Prainsack discusses the risks inherent in these practices and comes to the conclusion that there are no compelling reasons to deny a person the right to know his or her own genome. Individuals should be able to enforce a right not to know in relation to institutions, but they should not be able to enforce this right vis-à-vis other individuals who may disclose information that, at least partially, applies also to them.

The last chapter in this part sets out to investigate the intricate relationship between science, ethics and accountability against the background of developments in the genomic sciences. To whom are scientists accountable with respect to the content and outcomes of their work? Highly 'inconvenient truths' may result from meticulous empirical observation and rigorous theoretical analysis. What to do if carefully derived, robust research findings clash with the deep convictions and key components of people's traditional knowledge – in particular if it concerns vulnerable populations? Can people be expected to consent to the confrontation with 'enlightenment'? Respect for persons and populations requires respect for choosing to adhere to tradition and narrative. The case study of the Havasupai is used to explore the ways in which scientific findings about communities can clash with fundamental beliefs they have about themselves. Scientists should adhere to the values of science that, according to Ismail Serageldin, presuppose 'freedom to enquire, to challenge, to think, and to envision the unimagined' and they may thereby reveal some inconvenient truths.

Part III: Emerging issues

In the third and final part Henk ten Have sets the scene for the discussion of emerging issues by a consideration of the rise of the genetic framework for human existence, used not only for viewing health and disease but also for human behaviours and interactions. He shows that this geneticisation is one part of a dominant ideology which has often remained unanalysed in bioethics but is becoming subject to criticism in some areas of science. Within this dominant ideology of neo-liberalism, globalisation is focused on empowering autonomous individuals, who should be free to choose what they want, rather than on the interconnectedness of humans with each other and the environment. As bioethics becomes global bioethics, ten Have discusses the consequences of this change, drawing on Foucault's concept of biopolitics that subjects autonomous individuals to new and pervasive forms of discipline, monitoring and surveillance, self-regulation, nudging and incentives. In this context of individual responsibility the protective role of the state is deliberately decreased, and economic and social determinants of health become irrelevant. In the second part of the chapter, ten Have finds areas where neo-liberalism is under critique as the public domain is being redefined and expanded. He discusses changes in the patenting system, increases in data sharing and open access publishing as evidence of the emergence of a new ethos of science. However, as a more open science maximises the right to know, it is important to reflect on the implications for the protection of privacy and whether privacy is viewed from an individual or social perspective. In conclusion, ten Have discusses the critical role of bioethics today.

The next four chapters focus on four emerging issues. First, Anca Gheaus discusses 'designer babies' and the possibility of harm in knowing that one has been selected or enhanced. Parents may speculate what their unborn children will be like when they grow up – what will they look like? will they be clever? what occupation will they have? – but Anca Gheaus explores the consequences for the parent–child relationship if children were selected for particular traits or genetically enhanced. She argues that they might feel as though the love that they receive from their parents is conditional on them growing up to manifest the selected traits. Gheaus's argument is underpinned by an understanding of adequate parental love which includes several characteristics: parents should not make children feel they are loved conditionally for features such as intelligence, looks or temperament; they should not burden children with parental expectations concerning particular achievements; and parental love is often expressed in spontaneous enjoyment and discovery of

children's features. Gheaus concludes by arguing that this understanding of parental love provides a reason to question the legitimacy of parental use of selection and enhancement and to explain why parents should not engage on a quest for the 'best child'.

The next two chapters consider the role of traditional and digital media in the right to know and the right not to know debate. First Joachim Allgaier considers what have been the main sources of information about medical and scientific development: television and the press. These have framed the public debate about the ethical and legal issues associated with such technologies. However, the inter-relationship and inter-dependence of scientists, journalists and public are complex, requiring deeper investigation. Allgaier notes that genetic manipulation and biotechnology became a topic of mass interest in the mid-1990s, most notably in the context of genetically modified food and cloning. This time was also marked by a divergence in the debate around biotechnology, with a separation between agri-food (green) and biomedical (red) biotechnology. This distinction has consequences for how the different technologies were portrayed in the mass media, and consequently how they were perceived by the public. Allgaier analyses the media coverage of these different manifestations of biotechnology and genetics over the last twenty years and presents data on how public opinion and attitudes towards genetic biotechnology have also evolved.

Richard Watermeyer argues that in the age of the Internet, information is both ubiquitous and instant – instantly populated, repopulated and retrieved. Science dialogue has been opened up to social actors with disparate socio-political orientations. The public are able to interact directly with scientists, bypassing the mediation of science journalists. The fluidity of online interactions provides for a more integrated, informed and efficient republic of choice makers compared to traditional forms of public consultation. This represents a unique opportunity for the online citizen to emerge as a scientific citizen or citizen scientist, beyond the control of dialogue sponsors and regulators who may wish to inhibit, contain or direct public debate. However, Watermeyer recognises that online public dialogue in science is not without risk or drawback. User-generated scientific information is particularly susceptible to inconsistency or factual error caused by unscientific, subjective interpretations, but also to manipulation by online authors seeking to align scientific 'truths' or re-imagine 'facts' in line with their particular agenda or interests. The dialogue, or as Watermeyer calls it, the 'polylogue', may be inchoate and fragmentary and the multitude of perspectives may still coalesce around the same concerns as arise from face-to-face dialogue. Indeed, the sheer abundance and heterogeneity of digital publics may