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978-1-107-00711-6 - Genetic Data and the Law: A Critical Perspective on Privacy Protection

Mark Taylor

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## Genetic Data and the Law

Research using genetic data raises various concerns relating to privacy protection. Many of these concerns can also apply to research that uses other personal data, but not with the same implications for failure. The norms of exclusivity associated with a private life go beyond the current legal concept of personal data to include genetic data that relate to multiple identifiable individuals simultaneously and anonymous data that could be associated with any number of individuals in different, but reasonably foreseeable, contexts. It is the possibilities and implications of association that are significant, and these possibilities can only be assessed if one considers the interpretive potential of data. They are missed if one fixates upon its interpretive pedigree or misunderstands the meaning and significance of identification. This book demonstrates how the public interest in research using genetic data might be reconciled with the public interest in proper privacy protection.

MARK TAYLOR is a senior lecturer at the University of Sheffield and Deputy Director of the Sheffield Institute for Biotechnological Law and Ethics. His primary research interest concerns the legal and ethical issues raised by scientific developments in genetic testing and screening technologies.

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### *Cambridge Bioethics and Law*

This series of books was founded by Cambridge University Press with Alexander McCall Smith as its first editor in 2003. It focuses on the law's complex and troubled relationship with medicine across both the developed and the developing world. In the past twenty years, we have seen in many countries increasing resort to the courts by dissatisfied patients and a growing use of the courts to attempt to resolve intractable ethical dilemmas. At the same time, legislatures across the world have struggled to address the questions posed by both the successes and the failures of modern medicine, while international organisations such as the WHO and UNESCO now regularly address issues of medical law.

It follows that we would expect ethical and policy questions to be integral to the analysis of the legal issues discussed in this series. The series responds to the high profile of medical law in universities, in legal and medical practice, as well as in public and political affairs. We seek to reflect the evidence that many major health-related policy debates in the UK, Europe and the international community over the past two decades have involved a strong medical law dimension. With that in mind, we seek to address how legal analysis might have a trans-jurisdictional and international relevance. Organ retention, embryonic stem cell research, physician assisted suicide and the allocation of resources to fund health care are but a few examples among many. The emphasis of this series is thus on matters of public concern and/or practical significance. We look for books that could make a difference to the development of medical law and enhance the role of medico-legal debate in policy circles. That is not to say that we lack interest in the important theoretical dimensions of the subject, but we aim to ensure that theoretical debate is grounded in the realities of how the law does and should interact with medicine and health care.

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## Preface

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This book represents a collection of thoughts that date back to the completion of my doctoral studies in 2004. Given its genesis, this seems an appropriate time and place to thank publicly my Ph.D. supervisor, Professor Roger Brownsword, for the extremely generous, illuminating, and supportive, advice he offered me during that period and has continued to offer me since.

Since I wrote my Ph.D. thesis on the subject of genetic discrimination and contractual freedom, I have weaved, or perhaps stumbled, my way towards a broader position on the regulation of genetic data in research. I am especially keen to encourage a critical evaluation of the weight placed upon the idea of ‘personal data’ in the area of privacy protection. Frankly, I think it is a concept that has been forced to shoulder a disproportionate burden of work and it has made a rather convenient vehicle to transport us from some difficult questions. Rather than continue to pretend that this concept, and the regulatory frameworks that orbit it, are up to the task of fully protecting privacy, and also striking the right balance between the (at times) competing interests engaged by research uses of genetic data, we should recognise both its strengths and its weaknesses, and strengthen weaknesses where we can while, at all times, ensuring that apparent strengths do not undermine our ability to qualify particular protections where appropriate.

The position that I seek to describe in what follows is one that has been reached through linking together thinking stimulated by many different people and involvement in a number of different research projects. Some of the ideas have already found expression, in piecemeal fashion, through a number of articles over the past several years. While it is impossible personally to acknowledge everybody that has progressed my thinking in this area, I sincerely hope that they each realise I appreciate my indebtedness to them and am truly grateful for their support, their insight, and, quite often, their challenge. It would not have been possible to bring together a number of the ideas that have found previous published expression without the generous agreement of the

editors of the respective journals. Although most of the ideas have inevitably been developed and revised before inclusion here, there are, at times, particular recidivist paragraphs or sections that have escaped reform. They are reproduced here in their original form and I am grateful for the permission to do so. To some greater or lesser extent, Chapter 5 draws upon an argument first presented in M. J. Taylor, 'Data protection, shared (genetic) data and genetic discrimination', *Medical Law International* 8(1) (2006), 51–77. Chapter 7 draws upon the section I authored for a paper written with Professor Deryck Beyleveld, and published most recently as D. Beyleveld and M. J. Taylor, 'Patents for biotechnology and the data protection of biological samples and shared data', in Jean Hervé (ed.), *The Protection of Medical Data: Challenges of the 21st Century* (Louvain-la-Neuve: Anthemis, 2008), 127–48. A shorter version was earlier published as D. Beyleveld and M. J. Taylor, 'Data protection, genetics and patents for biotechnology', *European Journal of Health Law* 14(2) (2007), 177–87. Chapter 8 draws upon an argument first described in M. J. Taylor, 'Problems of practice and principle if centring law reform on the concept of genetic discrimination', *European Journal of Health Law* 1(4) (2004), 365–80; and Chapters 2 and 9 both contain thoughts first expressed (by me at least) in M. J. Taylor, 'Health research, data protection and the public interest in notification', *Medical Law Review* 19(2) (2011), 267–303. I am also glad to acknowledge that the idea for the cover picture, an anatomical theatre as a metaphor for the public examination of 'internal' aspects of human life occurring when research uses genetic data, was an idea used by Professor Giuseppe Testa in a seminar while visiting the University of Sheffield.

I am particularly grateful to colleagues and students, past and present, who have helped me to clarify and further my thinking on these issues. Specific and heartfelt thanks must be extended to Professor Deryck Beyleveld, Professor Roger Brownsword, Dr Fiona Douglas, Jamie Grace, Dr Richard Kirkham, Dr Ruth Stirton, David Townend and Daniel Wand. Special mention must go to Professor Graeme Laurie who has been typically generous with both his comments and his encouragement. Each of these individuals has, in various ways, been crucial to bringing these ideas forward in their current form. It should be made clear, however, that none of them is responsible for any errors that remain in the final version. Finally, I should thank Dr Natasha Semmens and Mrs Natasha Taylor. For me, together, they represent every reason to do anything.

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