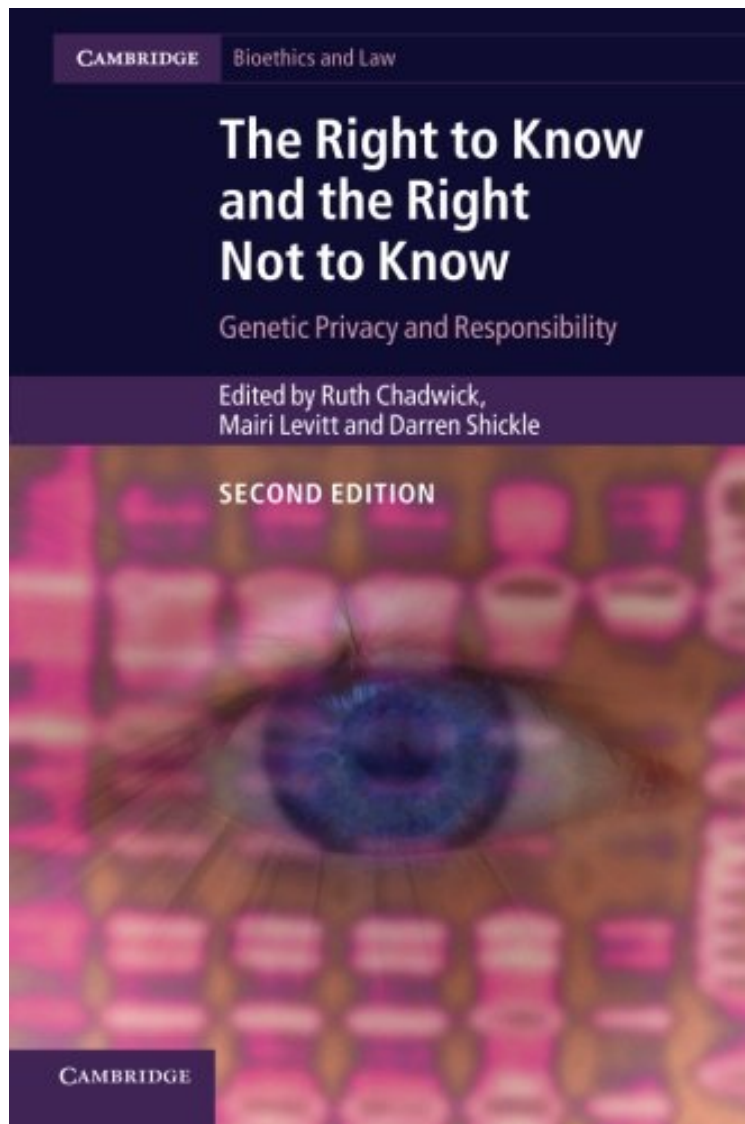


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The Right to Know and the Right Not to Know: Genetic Privacy and Responsibility (Cambridge Bioethics and Law)

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(Cambridge Bioethics and Law):

The privacy concerns discussed in the 1990s in relation to the New Genetics failed to anticipate the relevant issues for individuals, families, geneticists and society. Consumers, for example, can now buy their personal genetic information and share it online. The challenges facing genetic privacy have evolved as new biotechnologies have developed, and personal privacy is increasingly challenged by the irrepressible flow of electronic data between the personal and public spheres and by surveillance for terrorism and security risks. This book considers the right to know and the right not to know about your own and others' genomes. It discusses new privacy concerns and developments in ethical thinking, with the greater emphasis on solidarity and equity. The multidisciplinary approach covers current topics such as biobanks and forensic databases, DIY testing, group rights and accountability, the food we eat and the role of the press and the new digital media.

About the Author Ruth Chadwick is Professor of Bioethics at Manchester University and chair of the Human Genome Organisation (HUGO) Committee on Ethics Law and Society. She directed the ESRC Centre for Economic and Social Aspects of Genomics (Cesagen) from 2002 to 2013. Mairi Levitt is a senior lecturer in the Department of Politics, Philosophy and Religion at Lancaster University, where she works in empirical bioethics and researches ethical and social issues in genetics. Darren Shickle is Professor of Public Health at the University of Leeds, where his research interests include public health ethics, public health genetics, ophthalmic public health and HIV and sexual health.