Increasing quantities of information about our health, bodies, and biological relationships are being generated by health technologies, research, and surveillance. This escalation presents challenges to us all when it comes to deciding how to manage this information and what should be disclosed to the very people it describes. This book establishes the ethical imperative to take seriously the potential impacts on our identities of encountering bioinformation about ourselves. Emily Postan argues that identity interests in accessing personal bioinformation are currently under-protected in law and often linked to problematic bio-essentialist assumptions. Drawing on a picture of identity constructed through embodied self-narratives, and examples of people’s encounters with diverse kinds of information, Postan addresses these gaps. This book provides a robust account of the source, scope, and ethical significance of our identity-related interests in accessing – and not accessing – bioinformation about ourselves and the need for disclosure practices to respond appropriately. This title is also available as Open Access on Cambridge Core.

Emily Postan is a Chancellor’s Fellow in Bioethics at the University of Edinburgh Law School and a deputy director of the J Kenyon Mason Institute for Medicine Life Sciences and the Law. Her principal research interests lie in the ethical and regulatory implications of the impacts of health technologies and health data on our identities, group memberships, and relationships with others. Her wider research includes work in neuroethics, reproductive ethics, and regulation of health research.
This series of books – formerly called Cambridge Law, Medicine and Ethics – 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 and bioethics 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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EMBODIED NARRATIVES

Protecting Identity Interests through Ethical Governance of Bioinformation

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