EMBODIED NARRATIVES

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.
CAMBRIDGE BIOETHICS AND LAW

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.

Series Editors

Professor Graeme Laurie, University of Edinburgh
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EMBODIED NARRATIVES

Protecting Identity Interests through Ethical Governance of Bioinformation

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FOREWORD

Reading Embodied Narratives: Protecting Identity Interests through Ethical Governance of Bioinformation is a salutary reminder of how recently the circulation of mass data about our own and others’ bodies has become a normal part of everyday life. Despite this relative novelty, bioethics has already generated an impressive body of literature on the ethical and legal issues connected with making human bioinformation easily available. Most of this existing work examines the actionable consequences of acquiring data about a person’s genome, microbiomic profile, or neural architecture: how such knowledge might affect someone’s cancer diagnosis, treatment choices, their chances of crossing a border, getting insurance, or being convicted in a court of law.

Much less attention has been given to the possibility that knowledge from and of one’s body might have other important effects. There is curiously little discussion, for example, of why patients might find it important to know (or not to know) some aspect of personal bioinformation, even if that knowledge has seemingly no influence on their subsequent choices or actions. In this book and in clear and engaging style, Emily Postan demonstrates how the collection of information from and about the human body – and sometimes even just the expectation that such bioinformation will be gathered and used – affects our individual and collective identities in profound and often unexpected ways.

What does it mean to ‘know who you are’, and how is that affected by the historically unprecedented health and bio-related data now available to us? What we are concerned with here is identity as the set of characteristics that make each person a distinct and particular individual. Postan’s view is that while information about our bodies has always played an important role in self-constitution, the massively expanded availability and variety of bioinformation, and the extent to which it is now generated and controlled by other people, fundamentally alters the landscape and tools of personal identity.
With this as her starting point, Postan draws on theories of identity as constituted through narrative, and the claim that a meaningful identity narrative is essential to making sense of our lives, to our capacity for self-determination, and to our exercise of agency. The argument then is that because of the role that knowledge and experience of the body play in our narratives about ourselves, personal bioinformation has profound consequences for our ability to ‘occupy our own narrative accounts’ of who we are. The abstraction that we call ‘health data’ is a confirmation of the embodied nature of identity: that the material actuality of body form and function provides a good part of who you feel you are. Personal bioinformation can provide a way to make sense of and articulate embodied experience and, in doing so, make it available to the composition of an inhabitable self-narrative.

This view differs in two important respects from more familiar claims in law, policy, and scholarship about the effect of knowledge about our bodies on identity. First, it directs attention away from concerns about how others’ use of our information might affect us and towards our own reactions to and uses of such information. Second, in doing so, it directly confronts the easy assumption that if bioinformation has significance for building a sense of self, then that must mean personal identity in some way flows directly from, and is fixed by, bodily materiality. Postan’s argument is that what people do with bioinformation is rather more sophisticated and complex than that, and to demonstrate this, Embodied Narratives tests out the emerging theory of bioinformation and identity against empirical evidence. This key part of the book uses three case studies of bioinformation, involving knowledge of donor origins, genetic predisposition to disease, and neuroimagery in psychiatric diagnosis, to examine how those involved talk about the effect of the personal information they receive on their self-conception and understanding of their past and future.

Recognising the importance of body knowledge to the construction of a working identity clearly has major ramifications for those public and private agencies that generate, hold, or control access to our personal bioinformation. Part of Emily Postan’s argument is that people have real, justifiable, and ethically significant interests in their identity-relevant biodata, whether or not access to that information appears objectively ‘useful’ in terms of guiding healthcare or other decisions. This is an important conclusion not just for ethics and law but also for anyone trying to make sense of the bioinformation-saturated society in which we...
live. It sets a starting point for a detailed exploration of the governance and law that will be needed to protect these interests appropriately.

The appearance of Embodied Narratives is a milestone in the development of data ethics and in building a deep understanding of how technology can change individual and collective identities. More generally, it marks a significant evolution in empirically informed normative ethics. There will be bioethicists, bioinformatics specialists, and philosophers of identity who disagree with its arguments and conclusions, but what Emily Postan has provided them with is an account that is worth engaging with: serious, nuanced, and provocative.

Jackie Leach Scully
This book owes its existence to the many friends, colleagues, students, reviewers, and family members who have shared with me their wisdom and inspired and supported me. In addition to those named elsewhere on these pages, thank you to my friends and colleagues in the Liminal Spaces team, in the Mason Institute, and at Edinburgh School of Law – Ted Dove, Murray Earl, Anne-Maree Farrell, Isabel Fletcher, Steph Lewis, Katy MacMillan, Gerard Porter, Sam Taylor-Alexander, and Shauna Thompson – for their solidarity and humour. Particular thanks to Alexandra Braun, Niamh Nic Shuibhne, and Anna Souhami for pushing me to keep on keeping on. Thank you also to my friends and erstwhile colleagues at the Nuffield Council on Bioethics secretariat, including Rosie Beauchamp, Ran Svenning Berg, Kate Harvey, Cath Joynson, Pete Mills, Carol Perkins, Hugh Whittall, and Katharine Wright, from whom I learnt invaluable lessons about thinking, writing, and finishing.

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I am grateful to the series editors at Cambridge University Press for giving me the opportunity to develop my ideas into this monograph and, in doing so, to join the Press’s Bioethics and Law Series, which includes works of authors from whom I have learned so much. Thank you to Laura Blake, Marianne Nield, Finola O’Sullivan, Esakki Thangam, and all in the editorial and production teams at Cambridge University Press for their calm expertise. And particular thanks to Rebecca Richards for bringing her tireless, forensic eye to proofreading the manuscript, and to my father, Basil, for his additional readings and support. Much of the research contributing to this book was conducted with the support of an Arts and Humanities Research Council studentship award while the manuscript was written as part of the Wellcome-funded ‘Confronting the Liminal Spaces of Health Research Regulation’ project led by Graeme Laurie. I am grateful to these funders and, of course, to Graeme. Many thanks also to Wellcome for supporting open access publication of this book.

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