

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.

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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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Protecting Identity Interests through Ethical
Governance of Bioinformation

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CONTENTS

<i>Foreword</i>	page ix
JACKIE LEACH SCULLY	
<i>Acknowledgements</i>	xii
<i>Table of Cases</i>	xiv
1 Attending to Identity	1
1.1 Introduction	1
1.2 Terminology	12
1.3 Guide to the Following Chapters	28
2 Mapping the Landscape	31
2.1 Introduction	31
2.2 Legal Entitlements to Bioinformation	31
2.3 Seeking Conceptual and Normative Foundations	46
3 Narrative Self-Constitution	61
3.1 Introduction	61
3.2 Identity Narratives	62
3.3 Two Objections	70
3.4 Limits on Identity-Constituting Narratives	72
3.5 Practical and Evaluative Capacities	75
3.6 The Trouble with Coherence	79

3.7	Beyond Coherence	86
3.8	A Practical, Normative Conception of Identity	88
4	Bioinformation in Embodied Identity Narratives	89
4.1	Introduction	89
4.2	Embodied Lives, Embodied Selves	90
4.3	Bodies in Narrative Identity Theory	94
4.4	Personal Bioinformation as a Narrative Tool	98
4.5	The Suitability of Bioinformation: Responding to Concerns	110
4.6	Moving Beyond Theory	118
5	Encounters with Bioinformation: Three Examples	120
5.1	Introduction	120
5.2	Illustrative Example I: Encounters with Donor Origins	124
5.3	Illustrative Example II: Encounters with Genetic Risk	141
5.4	Illustrative Example III: Encounters with Psychiatric Neuroimaging	158
5.5	Narrativity across the Three Examples	172
6	Locating Identity Interests	181
6.1	Introduction	181
6.2	Our Identity Interests	181
6.3	Sources of Identity Significance	190
6.4	Filling a Conceptual and Normative Gap	197
6.5	Relationships between Structure and Contents	205

CONTENTS

vii

6.6 Distinguishing Identity from Other Interests	208
6.7 A Fresh Ethical Dimension	217
7 Responsibilities for Disclosure	218
7.1 Introduction	218
7.2 Responsibilities of Potential Disclosers	219
7.3 Ethical Foundations	221
7.4 Limiting Considerations	229
7.5 Ascertaining Where Interests Lie	232
7.6 Identity-Supporting Communication	238
7.7 Shared Social Responsibilities	244
8 Protecting Identity in Practice	247
8.1 Introduction	247
8.2 What Would Change?	248
8.3 Five Disclosure Contexts	252
8.4 Future Challenges	262
<i>Bibliography</i>	264
<i>Index</i>	287

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 neuroimaging 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

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xiii

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TABLE OF CASES

<i>ABC v. St Georges Healthcare and Others</i> (2020) EWHC 455 (QB)	42, 88
<i>Anayo v. Germany</i> (no. 20578/07) (2012) 55 EHRR 5	37
<i>Bensaid v. United Kingdom</i> (no. 44599/98) (2001) ECHR 82	34
<i>Gaskin v. United Kingdom</i> (no. 10454/83) (1989) ECHR 13	34, 37
<i>Haas v. the Netherlands</i> (no. 36983/97) (2004) 1 FCR 147	36
<i>Jaggi v. Switzerland</i> (no. 58757/00) (2008) 47 EHRR 30	34–35
<i>KH and Others v. Slovakia</i> (no. 32881/04) (2009) ECHR 709	7, 37
<i>Mikulic v. Croatia</i> (no. 53176/99) (2002) 2 WLUK 216	34–36
<i>Mizzi v. Malta</i> (no. 26111/02) (2006) 1 FLR 1048	36–37
<i>Montgomery v. Lanarkshire Health Board</i> (2015) UKSC 11	41, 214, 256
<i>Odièvre v. France</i> (no. 42326/98) (2003) ECHR 3	34–36, 230
<i>Rose v. Secretary of State for Health</i> (2002) EWHC 1593	38