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Book review: *Embodied Narratives: Protecting Identity Interests through Ethical Governance of Bioinformation*

Emily Postan
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In the midst of a new technological era, it is imperative to meticulously evaluate the profound significance and far-reaching implications that permeate the realm of information concerning our health, bodies and biology. This critical assessment involves understanding and recognising the role that different categories of personal bioinformation play in the composition of our sense of self. To this end, *Embodied Narratives: Protecting Identity Interests through Ethical Governance of Bioinformation*, written by University of Edinburgh Chancellor's Fellow in Bioethics Dr Emily Postan, emerges as an exceptional scholarly contribution. This seminal work not only enriches the fields of medico-legal studies, bioethics, and health law but introduces a new ethical dimension to the existing bioinformation governance landscape.

This well-structured book demonstrates why information-related identity interests are not only legitimate but also ethically significant in bioinformation-disclosure practices. Postan deploys three case studies, each one depicting an encounter with various types of bioinformation, to elucidate and evince this identity-value and analyse the complex interrelated factors in disclosing this information. Undoubtedly, were a future edition of this book to be written, a machine learning model or AI chatbot that manages and delivers personal bioinformation would make for a particularly interesting case study, given that algorithmic-driven analyses are nowadays disclosing bioinformation. I would be interested to know Postan's views, for example, if this unprecedented manner of conveying bioinformation can communicate findings in a way that supports the *inhabitability* of our self-narratives that she describes.

This book is divided into eight substantive chapters. In Chapter 1 ("Attending to Identity"), Postan introduces the core argument in *Embodied Narratives*, namely whether and how we access our personal bioinformation — that is, information about our health, bodies and biology — affects our understanding of ourselves. A peculiarity that distinguishes this publication

from the ongoing discourses on the governance of health information constitutes the adopted narrative approach to assess the impact that bioinformation can bear. Prominent debates often focus on potential misuses and abuses of bioinformation by third parties; whereas *Embodied Narratives* takes a unique lens: “what information subjects *themselves* might do with this information and how this might have profound effects on *who they are*” (p. 6).

Postan argues that the current relationship between identity and knowledge of genetic parentage is limited and ambiguous, at least in existing UK legal frameworks, a claim that is later substantiated further in Chapter 2. Because of the lack of conceptual and normative clarity regarding the nature and strengths of identity interests in the context of personal bioinformation, Postan advocates for a normative account that delves into the intricate ways in which bioinformation plays a role in constructing and sustaining our very own self-conception, specifically one that aligns with our lived experiences.

In Chapter 2 (“Mapping the Landscape”), Postan provides a thorough discussion of the current regulatory landscape —applicable in UK jurisdiction— governing information subjects’ identity-related interests in accessing personal bioinformation, beginning with international human rights law. Her sketch unveils that the scope and adequacy of legal instruments, such as the European Convention on Human Rights, results problematic (when it comes to protecting identity-related interests vis-à-vis access to bioinformation) for several reasons. For instance, she argues that not only does the sense of identity they invoke remains ambiguous but lack direct means to enforce information access entitlements beyond genetic parentage.

Postan challenges her argument by examining alternative routes that “do not depend on expressly identity-related entitlements” (p. 41). She raises the question of whether alternative approaches from bioethics or the social sciences could provide a more comprehensive foundation for understanding identity-

related concerns in relation to personal bioinformation. To that end, Postan argues that while some of these alternate routes “provide valuable signposts to elements of such a foundation ... they lack the requisite scope and clarity about the normative nature of this relationship” (p. 31). Postan then navigates a family of promising contentions that aim to address the aforementioned limitations; however, “they do not speak to the roles of knowledge beyond genetic parentage” (p. 59). Thus, she argues that an account that takes into consideration the prospect that certain encounters with bioinformation can be detrimental to our identity narratives is needed.

In Chapter 3 (“Narrative Self-Constitution”), Postan begins tracing her normative and practical *picture of identity* — by primarily drawing from “philosophical theories of narrative self-constitution” (p. 61) —, to better understand the role and identity-impact bioinformation can have and, most importantly to her discussion, the ethical significance of our identity-related interests when encountering this information. With elegant prose, Postan adeptly navigates the complex literature on identity and convincingly argues that constructing our self-narratives can be portrayed as a practice of meaning-making of our own self-characteristics and lived experiences. In her view, by acknowledging the interpretative aspects of our narratives (which are also “inescapably relationally forged”), we can gain a deeper understanding of the significance of identity-related interests as integral components of a broader story. One could even say it “provides the foundations for our practical judgments and agency” (p. 70). Here, then, we can see how an identity narrative underscores the role of bioinformation in fulfilling our identity-related interests.

In Chapter 4 (“Bioinformation in Embodied Identity Narratives”), Postan expands on the relationship between our self-narratives and personal bioinformation. On this point, she focuses on the *embodied* nature of self-narratives and elucidates in what ways our embodied attributes play a significant

role in our sense of who we are and how others characterise us. This can not only “affect the significance and meaning these attributes have for us ... but also how these inform our engagement with the world” (p. 93). This said, Postan rightly notes that bioinformation has ethical and first-personal significance in constituting ourselves as it provides “interpretative tools for making sense of and constructing one’s wider account of who he is” (p. 101); supports narrative coherence and intelligibility; and plays a valuable and interconnected role in constructing identities that are responsive to and developed attuned to our biological realities.

In Chapter 5 (“Encounters with Bioinformation: Three Examples”), Postan introduces three case studies, each portraying an encounter with different kinds of bioinformation, namely donor origins, genetic tests indicating risk, and psychiatric neuroimaging findings. Through these stories, Postan is able to paint a vivid and emotional picture of the ways in which encounters with bioinformation, subject to the disclosure context in which they occur, may entail significant differences as to how they “contribute to or impact upon our stories of who we are” (p. 123). What this chapter illustrates, guided by thought-provoking empirical insights, is the spectrum of practical identity impacts (not always beneficial or positive but also detrimental or disruptive from a narrativity lens) of *discovering* and *knowing* bioinformation about ourselves — which as she points out, “dilemmas and concerns that may even have intergenerational reverberations” (p. 133). Postan rightly notes the importance of narrative coherence and how the embodied and relational nature of self-narratives is “often closely entwined and mutually constituting, with neither wholly reducible to the other” (p. 177).

In Chapter 6 (“Locating Identity Interests”), Postan turns to characterise the nature and scope of our identity-related interests — those serving a fundamental role in our well-being and, most importantly, to achieving and

maintaining what she names “an inhabitable self-narrative” — when accessing personal bioinformation. By navigating the narrative qualities of coherence, sustainability, meaning, and comfort, this chapter illustrates the importance of recognising information-related identity interests to leading an inhabitable self-narrative in the course of an embodied and relational life. It is interesting to note how the relationship between identity and bioinformation is characterised here as a ‘bidirectional process’, highlighting the ways in which our self-narratives are shaped by personal bioinformation, and simultaneously, the former being the prism through which this information impacts our self-conceptions.

Moreover, Postan addresses the qualities and dimensions of identity value and discusses several circumstances in which foreseeable identity-significant harms surfaces, namely when communicating misleading information and information that would generate oppressive or degrading narrative threads, — harms that, in Postan’s words, “will often be predictable given our understanding of contributory factors such as prevalent prejudices and sources of oppression” (p. 205).

In Chapter 7 (“Responsibilities for Disclosure”), Postan addresses the question of the nature, source, and extent of ethical responsibilities when disclosing bioinformation to meet information subjects’ identity-related interests. Postan’s painted picture of identity-related responsibilities — accruing to those who generate and manage bioinformation — recaptures the ethical significance of developing and maintaining an inhabitable self-narrative. This said, and in recognition of the unpredictable nature of the identity impacts that personal bioinformation can entail to information subjects in different contexts, Postan argues for the need of a disclosure responsibility to:

‘[t]ake reasonable steps to ascertain the likely identity significance of the particular bioinformation to the information subjects in the given context,

and any likely benefit or detriment to the inhabitability of their self-narrative they could experience from encountering it.' (p. 220)

Through an in-depth examination of the ethical foundations for these responsibilities (potentially applicable to a wide array of disclosers such as healthcare professionals, researchers managing healthcare data, research ethics committees, commercial actors, managers of biobanks, and even private individuals), Postan demonstrates its practical applicability in different disclosure contexts. In consequence, she contends that the impact of significant and legitimate identity interests and the gravity of information subject's vulnerabilities "are sufficient to give rise to these *pro tanto* ethical responsibilities in others" (p. 224). However, these ethically significant interests and responsibilities are not absolute and will not always prevail whenever they come up against conflicting disclosure contexts. Postan advocates for a case-by-case assessment that weighs all competing interests (including identity-related ones) in information disclosure practices.

In Chapter 8 ("Protecting Identity in Practice"), Postan reiterates the value of an identity-supporting approach and demonstrates that, if the current bioinformation governance landscape were to incorporate the picture of identity described in this book, information subjects' identity-related interests in accessing personal bioinformation would "join the roll call of core interests that currently include health protection, mental well-being, informational and personal autonomy, privacy, and confidentiality" (p. 248). Notwithstanding the need for broader societal conversation in achieving ethical governance of personal bioinformation, Postan's core argument of attending to individuals' narrative needs and recognising the embodied nature of self-narratives adds to the bioinformation governance landscape as it "installs identity as a morally serious concern" (p. 249).

Postan closes her analysis by suggesting several broad indications for potential reforms to current regulation and practice in different disclosure contexts, such as direct-to-consumer genomics, and personal devices. *Embodied Narratives* aimed to illustrate the contributory, epistemic, and hermeneutic roles that different kinds of bioinformation can play in identity-construction. Overall, Postan succeeds in this aim admirably.

Extrapolating the considerations she voiced in connection to the illustrative examples, and as data-driven neurotechnologies transition from lab environments to commercial markets, it would have been interesting to see a deeper examination of how the narrative analysis and claims apply to brain data when encountering this category of bioinformation outside the clinical realm. Particularly, I would be interested to know more about Postan's views in a consumer neurotechnology context, for example, if encountering neurophysiological-based findings in a commercial setting could institute new categories of contents to information subjects' accounts of who they are. Moreover, it would have been noteworthy to explore on a deeper level in which ways her central contention can contribute to the field of data and AI ethics when it comes to information disclosure practices through algorithmic-driven analyses. The last chapter could have benefited from a greater discussion and analysis of these broad questions, given the ongoing concerns around the field of AI and machine learning.

This critique aside, *Embodied Narratives: Protecting Identity Interests through Ethical Governance of Bioinformation* stands as an impeccably crafted monograph that should not be overlooked by scholars and practitioners immersed in the realm of health ethics and the complex interplay between identity and bioinformation. This remarkable work — through its dexterous use of narrative inquiry — offers a timely and comprehensive ethical framework that significantly enriches our understanding of bioinformation disclosure practices.