

Bioinformation in Embodied Identity Narratives

4.1 Introduction

The previous chapter outlined the key features of the conception of narrative identity constitution that will provide the foundations for the analysis and arguments that follow. Those discussions set out not only the self-constructed, interpretive, and selective nature of our identity narratives but also their normativity – the valuable practical and evaluative capacities that they sustain and the qualities that allow them to do so. I now turn to address the relationship between our self-narratives and the kinds of information about our health, bodies, and biology that I have grouped under the heading of personal bioinformation. I will propose not only that personal bioinformation plays a number of roles in our self-narratives but also that there is something personally and ethically important at stake when it does so. This argument provides the basis for my motivating claim in this book – that our identity-related interests in accessing bioinformation about ourselves warrant serious ethical attention in the law, policies, and practices governing whether and how we are able to access it.

The previous chapter highlighted the social and relational aspects of our self-narratives. In this chapter, I will argue that it is also necessary to recognise the comparable significance of their *embodied* nature – a feature that has not always been given due regard by prominent narrative identity theories. I will then set out my central argument: that personal bioinformation can contribute in ethically significant ways to the construction of coherent and inhabitable embodied identity narratives. In doing so, I will respond to concerns that invoking a role for bioinformation in our identities reignites an implausible biologically essentialist conception of self or erroneously conflates the objective biological body with the phenomenological lived body. The analysis and claims of this chapter are intended to apply to personal bioinformation taken as a broad, inclusive category, which does not mean that they

will apply universally or equally to each type or token of information in practice. I will return to address the factors that help shape and differentiate the specific identity roles and varying value of encounters with specific instances and kinds of personal bioinformation in Chapter 6, drawing on findings from empirical studies to be explored in Chapter 5.

4.2 Embodied Lives, Embodied Selves

I will begin setting the context for my argument by briefly stepping back from the specifics of narrative self-constitution to examine in broader terms why we have good grounds for recognising that our lives and our identities are necessarily those of embodied beings. I will take this to mean that our experiences of ourselves and of the world, our relationships to others, and the ways we interact with and navigate our environment are all shaped by the fact that we exist as material beings with particular bodily attributes. Claims about the nature and significance of the role of embodiment in our lives arise in diverse disciplines including neuroscience, philosophy, bioethics, and social theory. Different approaches place different emphases on our bodies' roles in enabling and mediating cognition and feeling, the fact of our objective materiality, and the subjective lived experience of living as a body.¹ I take each of these aspects to be relevant to what I will go on to say and I will offer a brief flavour of this spread of views here.

To embrace an embodied conception of human existence is, at its most basic, to reject dualist conceptions of persons, according to which our experiences, cognitive faculties, and sense of self are seen as solely the product of our minds. Dualism relegates our bodies to no more than the fleshy housing in which our minds just happen to be located, or the mere instruments through which mental processes are enacted and our identities are expressed.² In contrast, accounts that emphasise the embodied nature of cognition hold that 'the mind is always embodied, it is generated through the corporeal and sensory relations of the body to its world'.³ The claim here is that consciousness and thought are made possible by and organised according to schema that are shaped by our bodily functions and the ways we encounter the world as material bodies operating in space.⁴ Similarly, the ways we perceive the world and

¹ Lennon 2019.

² Shildrick 2005.

³ Mackenzie and Scully 2007, p. 342.

⁴ Wilson 2002.

interpret our perceptions are determined by how our senses work, our physiology, and mobility. For example, we literally see the world in a particular way because of the position of our eyes and the kind of vision we have.⁵ Our affective responses and emotions are also bound up with our visceral reactions and their physical manifestations in, for example, a racing pulse or laughter.⁶

Philosophers working in the phenomenological tradition hold that embodiment 'is our mode of being-in-the-world' and the 'condition for the possibility of perception and action'.⁷ As embodied beings, we are inescapably located in our physical environment and perceive, think, feel, and interact with this environment through our bodies. For example, Maurice Merleau-Ponty holds that '[t]he body is the vehicle of being in the world, and having a body is, for a living creature, to be intervolved in a definite environment, to identify oneself with certain projects and be continually committed to them'.⁸ As this suggests, theories of embodiment are concerned not just with the embodiment of consciousness or thought but also with the ways that our perspective on the world – our subjectivity – and sense of self are embedded in and shaped by our materiality and the particular form it takes. In Margrit Shildrick's words, 'the subject's very being – or more accurately, becoming – is dependent on the body. It is not simply a matter of having or owning a body, or of using it as an instrument, where the subject might yet be seen as a controlling overseer, but one in which embodiment is the condition of being a self at all'.⁹ Phenomenologists tend to distinguish the *lived* body, encountered from a first-person perspective, from the objective body as seen by others and treated as the subject of scientific study and medicine.¹⁰ However, we may recognise that our material bodies themselves – not only our experiences of and through them – frequently shape and constrain our lives, how we behave, and who we can be. Recent years have seen a 'material turn' in sociological and feminist theories of self – one that seeks to (re)assert 'the way material aspects of our embodiment condition our lived subjectivity'.¹¹ Assertions of these kinds do not claim that the material body wholly determines who we are

⁵ Gallagher 2006.

⁶ Niedenthal 2007.

⁷ Carel 2016, p. 27.

⁸ Merleau-Ponty 1962, p. 94.

⁹ Shildrick 2005, p. 6.

¹⁰ Lennon et al. 2012.

¹¹ Lennon et al. 2012, p. 1; Witz 2000.

but rather that our bodies and biology are an irreducible part of our ongoing development as particular kinds of selves. As Stacy Alaimo and Susan Hekman observe, our bodies and biology exert both 'active' and 'recalcitrant' forces upon our lives that serve to shape, enable, and place limits upon what we are able to do and how we are able to define ourselves.¹² Some features of our bodies present opportunities – for example, only people with particular kinds of bodies can become pregnant, and an especially wide handspan may provide additional dexterity as a pianist. Others can impose limitations – for example, someone with chronic obstructive pulmonary disease may struggle with activities involving physical exertion. And many features, including parenthood and (dis)abilities, present a mixture of positive and negative influences – colouring our experiences, influencing our behaviours and expectations, and altering our sense of what is valuable, in myriad subtle or more prominent ways.

Embodied theories of self challenge, for example, the cogency of thought experiments that ask one to imagine being *precisely the same* person while existing as a disembodied brain in a tank or occupying a body radically different than one's own. They also provide the basis for ethical and epistemological enquiries about the ways that, for example, sex, (dis)ability, or illness affect our ways of being in, and navigating, the world.¹³ Differences between our bodies, their forms, functions, and capacities can result in divergent experiences of the world and differences in the patterns of meaning we bring to these experiences. As such, we should be cautious about making too ready assumptions that others' experiences and interpretations are the same as our own, or that our own will remain stable.¹⁴ As aspects of our own bodies and health change, as they inevitably do, so might our outlook and way of being. For example, Havi Carel – drawing on phenomenological theory and her own experiences of living with chronic respiratory illness – argues that the manner in which our particular embodiments shape our ways of being is brought into sharp focus when illness disrupts former certainties and replaces these with 'bodily doubt', which threatens our abilities to make sense of the world and find meaning in our lives.¹⁵ And Shildrick suggests that the impacts of our bodies on our sense of self are not limited to features such as serious illness that we might most immediately think

¹² Alaimo and Hekman 2008, pp. 3–4.

¹³ Mackenzie and Scully 2007.

¹⁴ Mackenzie and Scully 2007.

¹⁵ Carel 2016, p. 92.

of as life-changing.¹⁶ Navigating life with a relatively minor and temporary injury such as a broken ankle might be no less instrumental in changing the way we perceive the world and our place in it. To say that our embodiment shapes our perspectives and sense of self is not, of course, the same as saying that everyone who shares similar bodily attributes shares the same embodied perspective. It is important to recognise that the impacts and meaning of different intersecting aspects of our embodied and social existences – for example, our sex, skin colour, and socio-economic status – will mediate each other in shifting permutations, modifying and diversifying our experiences accordingly.¹⁷

As this suggests, our embodied nature is closely entwined with the social and relational aspects of our lives.¹⁸ Our materiality unavoidably connects us to others and renders us dependent upon, responsible for, and vulnerable to them. This is perhaps most readily recognised with respect to our genetic, sexual, and family relationships. It is also true of more formal relationships, such as those with healthcare professionals or colleagues. Our bodies and bodily traits play a further key role in our sense of who we are to the extent that they shape how other people respond to us. For example, when others fail to recognise our ‘invisible’ chronic pain or make assumptions about our personalities from our weight, this can affect not only the significance and meaning these attributes have for us and our sense of who we are but also how these inform our engagement with the world. What was said above about the brute, material ways that our bodies can affect us notwithstanding, the meaning and significance we invest in aspects of our material bodies, and the roles these play in our lives are rarely, if ever, inherent or universal but rather socially constructed and socially inscribed to a greater or lesser extent. This highlights a further respect in which the bodily and social are enmeshed – where ‘there is an entanglement of nature/culture, matter and meaning’.¹⁹ As Iris Marion Young observes, differential experiences of embodiment and our embodied capacities are often not due to features of our anatomy per se, or not solely to these, but rather to what these features are taken to mean in particular social circumstances.²⁰ I shall return to these themes in discussing the differential identity significance afforded to different kinds of personal bioinformation in Chapter 6.

¹⁶ Shildrick 2005.

¹⁷ Shildrick 2005.

¹⁸ Baylis 2012.

¹⁹ Lennon 2019.

²⁰ Young 2005.

The core lesson I wish to take forward from these various perspectives into the arguments to come is that, in Quassim Cassam's neat turn of phrase, 'the fantasy of the disembodied self is just that: a fantasy'.²¹ Any adequate theory of identity must reflect: the phenomenology, the 'what it is like', of biological, material human existence; the embodied perspective from which we construct our sense of who we are; and the entanglement of bodily opportunities and constraints within which we do so. These factors require that we acknowledge the significance of embodiment to the stories we can meaningfully and sustainably construct about who we are.

4.3 Bodies in Narrative Identity Theory

Given what has just been said, it is striking that many of the prominent theories of narrative self-constitution cited in the previous chapter have little to say about the relevance of our embodied and biological existence to our identity-constituting narratives and our roles as narrators.²² The influential accounts developed by Marya Schechtman in *The Constitution of Selves* and by Charles Taylor and Alasdair MacIntyre can seem peculiarly rationalist or dualist in the ways they construe self-narrative. They paint a picture of self-constitution that takes place in the mind, while the body is relegated to the vehicle through which we happen to enact our stories of who we are, or perhaps at most, the source of practical limits on the kinds of narratives we can construct. For example, MacIntyre merely notes that birth and death inevitably bookend our self-narratives.²³ Schechtman makes only a little more space for the body in noting that 'the life of a person' – which in her account marks the minimal requirement for the shape of an identity constituting narrative – is an embodied one.²⁴ Beyond this, however, Schechtman restricts the relevance of our human bodies to their role in allowing *others* to (re) identify us. As such, she admits an indirect significance for the body in self-constitution, inasmuch as others' capacities to recognise us are important as a precondition for the kinds of social interactions that contribute to the development of a practical narrative identity.²⁵

²¹ Cassam 2011, p. 154.

²² MacIntyre 1985; Schechtman 1996; Taylor 1989.

²³ MacIntyre 1985.

²⁴ Schechtman 1996.

²⁵ In her more recent work, Schechtman recognises that our bodies and physical attributes play a role in what constitutes us as persons for the purposes of reidentification and

As Catriona Mackenzie points out, abstracted views of identity which locate the business of self-characterisation solely in our psychology overlook 'the first-personal significance of the body in the constitution of identity'.²⁶ However, not all theories of narrative identity marginalise the body in this way. Several influential accounts, including Mackenzie's own, place the lived experience of our bodies at the heart of narrative self-constitution.²⁷ Here, I shall review what this 'first-personal significance' amounts to.

Asserting that our practical, narrative self-characterisations are inescapably embodied does not mean that our narratives are reducible to or wholly populated by our bodily and biological attributes. Rather, it involves recognising that because we exist as material beings and our cognition, feelings, and experiences of ourselves and of the world are – in all the ways described above – framed by our particular embodied perspective, the context in which we construct our narratives is a necessarily embodied one.²⁸ Perhaps the most readily appreciated way in which our bodies contribute to and shape our identity narratives is by providing some of the palette and scope of characteristics with which we can practically, intelligibly, and sustainably define ourselves.²⁹ Many of our bodily attributes inform, even if they do not determine, the nature and mix of self-descriptors we weave into our narratives. For example, these might include our sex, skin colour, height, physical fitness, or health. Many of these embodied attributes also affect the ways in which others characterise us. For example, as Françoise Baylis argues, aspects of our bodies such as the colour of our skin 'influence who we are and how we can be in the world'.³⁰ This is in no small part because the stories others tell about us inform – and sometimes problematically limit – the stories we are able intelligibly to tell about ourselves, tying them to some degree to the stories that others are prepared to recognise and permit us to enact.

Our material embodiment is also the unavoidable context within which self-constitution takes place. As noted above, our bodies, their

survival and in the relationships of recognition that support personhood in the absence of self-conscious self-narration. See Schechtman 2014.

²⁶ Mackenzie 2009, p. 103.

²⁷ For example, Atkins 2008; Baylis 2012; Mackenzie 2009; Ricoeur 1992; and Velleman 2006. In other respects, several of these treatments – most notably Mackenzie's and Atkins's – share core features with Schechtman's analysis.

²⁸ Mackenzie 2009.

²⁹ Mackenzie 2008b.

³⁰ Baylis 2012, p. 112.

states, and functions operate as both 'active' and 'recalcitrant' forces in our capacities to act and define ourselves. As such, they are a source of opportunities for, and boundaries upon, self-creation. As Ian Hacking observes, '[w]e push our lives through a thicket in which the stern trunks of determinism are entangled in the twisting vines of chance'.³¹ One need not subscribe to Hacking's language of determinism for his metaphor to remain apt. No matter how strongly we adhere to the idea that we create our own identities, we must nevertheless recognise that in doing so we are constrained to a degree by our environment, which includes the environment of our own bodies and biology. Embodiment impinges on who we are and who we can be because it has real, concrete consequences for us. In constituting ourselves, we will inevitably bump up against, become ensnared by, or must find ways around the capacities and limits of our material selves. This is just as true of the less visible aspects of our embodiment, such as our reproductive and cognitive capacities, as it is of the kinds of characteristics that are readily visible to others. And, as I shall go on to explore below, the resilience of the accounts we are able to give of who we are, and our ability to comfortably inhabit these accounts, are also vulnerable to aspects of our biological lives about which we might not (yet) be directly aware, such as the latent risk of a serious inherited disease.

Our bodies not only contribute to the contents and scope of our self-narratives but also shape our perspective as narrators and indeed make narration possible at all. For example, they enable the cognitive skills that allow us to interpret and arrange our experiences into a meaningful account of who we are. Mackenzie further holds that our experiences of our 'bodies as lived' and sense of our continuous material embodiment provide reference points for our sense of self and anchor the unity of our self-narratives.³² In the previous chapter, I introduced the idea that our self-narratives provide each of our particular, idiosyncratic, interpretive frameworks through which we make sense of experiences and continue to constitute ourselves. Mackenzie supplements this by highlighting the irreducible role of the body in these frameworks, which she describes as providing our 'bodily perspectives'.³³ We approach the world as beings whose interests and interest perspectives are bound up with our bodily needs and vulnerabilities and whose agency is realised through bodies

³¹ Hacking 2004, p. 282.

³² Mackenzie 2009.

³³ Mackenzie 2009, p. 103.

with particular capacities and dispositions. In Atkins's pithy phrase, 'the first person perspective is corporeal'.³⁴ And, as Mackenzie asserts, 'making sense of oneself involves making sense of one's embodied subjectivity'.³⁵ Priscilla Brandon, meanwhile, underlines the reflexive nature of narrative self-constitution by observing not only that our embodiment influences our accounts of who we are but also that these accounts can in turn affect our bodies, for example, by informing how we hold, use, care for, or modify them.³⁶ This serves as a valuable reminder that our self-narratives are not epiphenomenal. They do more than just describe what we are like. They play a practical role in how we make sense of, engage with, and conduct ourselves in the world, in how we view and act upon our bodies, and in who we become.

As narrators, we cannot ignore our materiality. And it may be no less true that, as material beings, identity construction requires a narrative approach. Atkins – reflecting on the work of Paul Ricoeur – argues that narrative, with its inherently interpretative and diachronic nature, is the form that our self-conceptions must take if we are to be capable of unifying and making sense of the complexity and temporal dimensions of our biological bodies and lives in all their messy, changing natures and mortality.³⁷ She holds that in constructing narrative accounts of who we are, we have the opportunity to square our lived experiences with the objective chronology of our material existence and to make causal and explanatory connections between bodily events and experiences. Thinking about identity in terms of narrative helps explain why the beginnings and ends of our lives may be significant to our self-conceptions. It also provides clues as to why it might matter if there are abrupt changes in our bodies or explanatory gaps in understanding how they work or why they are like they are – for example, why we have particular symptoms or look the way we do – and why we might value being able to anticipate biological events that lie in our futures. Atkins emphasises the importance of narrativity in permitting us to integrate and, as far as possible, reconcile multiple perspectives on who and what we are, perspectives that include our internal experiences of ourselves, our own 'as-if third-personal' encounters with ourselves as objects in the world, and other people's reactions to us.³⁸ This incorporation and

³⁴ Atkins 2008, p. 80.

³⁵ Mackenzie 2009, p. 118.

³⁶ Brandon 2016.

³⁷ Atkins 2008; Ricoeur 1992.

³⁸ Atkins 2008.

accommodation is not automatic. Atkins argues for the necessity of a kind of self-attribution or endorsement of the bodily and biological features that we take to characterise who we are.³⁹ Constructing stories and finding meaning when our bodies undergo sudden or major changes, for example, following serious illness, injury, ageing, or childbirth, may also offer a way of averting alienation from aspects of our material selves.

Atkins recognises that while an embodied view of narrative self-constitution treats bodily features as legitimate elements of our identities, their inclusion – as with all narrative elements – is still a matter of selection and meaning-making. This underscores the claim introduced in the previous chapter: that the development and maintenance of a coherent, inhabitable identity narrative are, in Atkins's words, 'something I must achieve, something that I have to integrate, recuperate, and finally attest to'.⁴⁰ As such, we may be more, or less, successful in these endeavours. Our bodily characteristics and perspectives are not static; they evolve and shift with changes in our bodies and biology. This affects the self-narratives that they constrain, enable, and inform. This in turn brings the constant possibility of fresh interpretive frameworks and gains and losses in terms of narrative integration, intelligibility, and meaning. And where these changes are dramatic or unanticipated – such as at the acute onset of serious disease – the tone and coherence of our embodied narratives may be abruptly altered or disrupted. These changes matter. They have personal and ethical significance because – as described in the previous chapter – of the practical, experiential, and evaluative capacities that depend on the structural and substantive qualities of our self-narratives. As Mackenzie asserts, 'developing an integrated and ongoing narrative of one's embodied subjectivity is central to the activity of self-constitution'.⁴¹ These moves towards placing embodiment at the heart of theories of narrative self-constitution are central to my own argument for the narrative role of personal bioinformation – as I shall now describe.

4.4 Personal Bioinformation as a Narrative Tool

The preceding discussion leads me to my reasons for holding that personal bioinformation – taken as a broad category – can play a number of ethically significant roles in narrative self-constitution.

³⁹ See also Velleman 2006.

⁴⁰ Atkins 2008, p. 91.

⁴¹ Mackenzie 2009, p. 103.

The argument presented in the remainder of this chapter will focus chiefly on the conceptual grounds for these claims. I will return in Chapter 5 to consider detailed illustrative examples of what these roles might look like in practice.

Existing theoretical accounts of narrative identity – with a few exceptions to which I will return – are notably silent on the potential identity significance of bioinformation that comes from ‘external sources’ – for example, medical tests or research findings – rather than from our own senses.⁴² This is perhaps unsurprising when it comes to the more disembodied theories like Schechtman’s, but it is also evident amongst those that place considerable emphasis on the bodily perspective. Sometimes, this is simply because it lies beyond their scope of interest. However, it could also be attributable to perceptions that positing a narrative role for objective or technical sources confuses information that is merely relevant to us as human organisms, with the kinds of experiential input that is relevant to our *identities* as embodied persons.⁴³ As such, it might appear that proposing the identity significance of personal information rests on a basic misunderstanding of the central premises of embodied views of identity, wrongly conflating these views with reductive materialism. To make clear why this concern is misplaced, I want to consider the roles that personal bioinformation could play in helping us develop self-narratives that are integrated, intelligible, and meaningful when occupied in the context of embodied existence, and also equipped to support us in navigating the vagaries of this existence.

Offering Contents

First, I want to suggest that, by conveying insights into, for example, our health and susceptibilities to disease, our physical, cognitive, or affective traits, previous events that have assailed our bodies, when and how our stories began and might end, our relationships, and the traits we share with others, personal bioinformation can contribute the characteristics, contents, and plotlines that populate our self-narratives.⁴⁴ This may seem

⁴² Exceptions include the claims made for narrative roles for knowledge of genetic parentage introduced in Chapter 2. Most such analyses focus on single categories of information. Mary Walker has notably offered critical views of the potential narrative roles of both neuro information and diagnoses of asymptomatic disease, as discussed further below.

⁴³ Ajana 2010.

⁴⁴ These uses of bioinformation may occur irrespective of whether these ‘insights’ are reliable. What I say here is premised on the assumption that they are and I return to discuss the consequences if they are not, below.

almost too obvious. After all, conveying these kinds of insights is integral to the very definition of personal bioinformation established in Chapter 1. However, as noted in the last chapter, the inclusion of these kinds of characteristics as paradigm narrative constituents is not a given. My intention here is to highlight that once we appreciate the embodied nature of our lives, it is virtually impossible to imagine our identity narratives – with which we organise our defining traits and experiences and make sense of who we are – without the inclusion of health-related, biological, and bodily characteristics. These are the kinds of identity stories we tell because of the kinds of beings we are. Moreover, the materials we use to compose these stories are likely to include bioinformation about ourselves generated or revealed by others. In this respect, self-understanding and self-interpretation are no different from other epistemic or hermeneutic endeavours in that these rely not only on our direct experiences but also on the observations and testimonies of others and on propositional, qualitative, quantitative, or graphical information. For example, an individual may come to characterise themselves as someone at risk of colon cancer because they have experienced a familial history of this disease. Alternatively they may do so following receipt of test results revealing genetic mutations associated with Lynch syndrome. Or someone may think of themselves as physically fit in part because of the ease with which they can complete a five-kilometre run but also because their wearable fitness tracker records a healthy heart rate while they do so.

No doubt, insights into and understanding of our bodies derived from externally received bioinformation are likely to differ qualitatively – for example, in perspective, immediacy, complexity, and, perhaps, reliability – from those gained from direct experience.⁴⁵ However, I would suggest that these differences influence, but do not necessarily obviate, the contributions of bioinformation to the plot and content of our identity narratives. Moreover, I want to suggest that it is precisely the relationship and interaction between our direct experiences of our bodies and our identities that signals a further, perhaps less obvious, narrative role for bioinformation, as I will now explain.

Providing Interpretive Context

According to the theories outlined in the previous chapter, narrativity is an intrinsically interpretive endeavour. The appropriation of characteristics,

⁴⁵ I return in Chapter 6 to discuss the relevance of these qualitative differences.

locating their place and priority within our accounts of who we are, the mutual reconciliation of narrative elements, and the unification of these elements within a broadly intelligible and coherent self-conception, all involve selection, shaping, and meaning-making. My second core claim, then, is that personal bioinformation provides not only potential raw building blocks of identity – ‘I am someone at risk of colon cancer’ – but also the *interpretive* tools for making sense of and constructing one’s wider account of who one is in light of beliefs about an elevated risk of cancer. It can play useful roles in contextualising, explaining, or connecting our disparate experiences and other sources of understanding or insight. For example, receiving a long-sought diagnosis may help explain not only symptoms of concern but also other experiences that the individual had perhaps attributed to other causes, as well as other more broadly connected aspects of their lives and biographies, such as a family history of illness. These interpretive roles may also extend beyond explanation to include alteration of the connotations and significance of particular embodied experiences or characteristics, by supplying comparators, filters, or lenses. For example, receiving a diagnosis may cast someone’s symptoms in a fresh light, perhaps making them a source of anxiety that dominates their self-conception, or leading them to feel new commonality with a similarly affected parent.

These examples concern the interpretation of prior or existing experiences. However, it is just as likely that personal bioinformation could play a part in drawing attention to or providing an interpretive context for processes or events of which we are not (yet) directly aware. For example, a diagnosis of Asperger’s syndrome might provide someone with a means of reading future social and professional encounters and appreciating that others do not necessarily share their experiences of particular situations as easy or stressful. Bioinformation can also help us anticipate the ways that our bodies and embodied experiences may yet come to impinge in significant ways on our self-narratives. For example, learning that one has early warning signs of rheumatoid arthritis could throw someone’s existing self-conception of themselves as athletic or an adventurous traveller into disarray, upending several of roles and projects with which they closely identify. However, it could also allow them to reconfigure their expectations of how their narratives could unfold and how this informs how they currently see themselves.

In each of the examples outlined here, the interpretive roles played by personal bioinformation can be seen as operating across several planes – connecting contemporary experiences, explaining past ones, casting

existing self-descriptors in a new light, flagging future narrative disruption, or instigating a review of projected storylines in anticipation of things yet to come. It is possible that the impacts of encountering some information could extend across all of these dimensions. And, importantly, while it might be the case that this involves the reframing of a single descriptor or experience, it seems much more likely, given the interconnected and mutually informing nature of the strands of our identity narratives, that the impacts of encountering bioinformation will ripple wider and will serve to knit together or unpick multiple experiences, beliefs, descriptors, and themes in different ways.

Fulfilling Normative Roles

What I have said so far aims to explain why personal bioinformation might play a part in the narratives that comprise our identities, why it might change their content or configuration, and why it might fulfil expository, interpretive, contextualising, or prognostic roles. But the hypothesis with which I began this enquiry was that having access to personal bioinformation, and thus the opportunity to reflect on and use it in the construction of one's self-narrative, engages *ethically significant interests*. And it might not yet be clear why this stronger claim is justified. Why might access to this information have sufficient impact on what is important in our lives and engage interests strong enough to warrant the attention of, let alone action on the part of, those who hold this information about us?

The answer to this question is located in the inherent normativity of theories of narrative self-constitution, as described in the previous chapter. A self-narrative is not simply someone's life story; it is a selective and interpretive account that is constitutive of their practical identity. And maintaining, sustaining, and inhabiting a reasonably coherent and comfortable identity-constituting narrative has important consequences in that it provides the foundations for a number of valuable practical and evaluative capacities and experiences. I wish to suggest that personal bioinformation – by contributing to the scope and tenor of the contents and plotlines of our self-narratives and by providing interpretive and contextual tools for making sense of and configuring these narratives in the context of our embodied lives – may play all or any of the following four closely entwined roles.

The first way that personal bioinformation may contribute in normatively significant ways to our self-narratives is by providing a means of

developing, maintaining, or restoring their internal coherence and intelligibility as we are confronted by the realities and vagaries of embodied life. I have suggested that many of the characteristics that make up our identities will themselves be derived from our embodied perspectives and characteristics. Given this, bioinformation has the capacity to support internal narrative coherence – or, to use Schechtman’s terminology, ‘articulability’ – by informing our selection, prioritisation, and interpretation of the health-related, physical, cognitive, or behavioural traits, and biological relationships that contribute to our self-conceptions, and by enhancing the explicability of these in relation to each other and our overall sense of who we are.⁴⁶ For example, a blood test that reveals an overactive thyroid may help someone reinterpret their recent sleeplessness, work-related anxiety, and shortness of temper at home, attribute this to excess thyroxine, and, thus, understand how their experiences are reconcilable with their sense of themselves as a relatively calm and patient person, with a good aptitude for their job, and loving family relationships.

Internal intelligibility is not all that matters to the practical aspects of our identities. If our self-narratives are to support us in functioning as evaluators, planners, and agents, they also need to be intelligible with respect to our engagement with the world. Personal bioinformation can assist in this regard too by supplying insights that help us construct identities that are responsive to the realities of our own biology and materiality, or at least not vulnerable to being rendered incoherent when confronted by these. For example, an implanted device that provides early warning of the onset of epileptic seizures, allowing the user to take appropriate action, may help them inhabit an account of themselves as an active and self-reliant person capable of recognising and managing the risks posed by unexpected seizures. Or learning of a medical cause of infertility may help someone understand their difficulties in conceiving, somewhat alleviate their feelings of confusion or self-blame, and rethink the ways they may wish to fulfil the role of parent in which they invest great value. This support for ‘external coherence’ is the second normatively significant role that, I want to suggest, personal bioinformation can play.

The suggestion that bioinformation can help us maintain narratives that are broadly intelligible in light of objective bodily facts echoes Schechtman’s ‘reality constraint’ as described in the previous chapter.

⁴⁶ Schechtman 1996.

To recap, according to Schechtman this constraint requires that our narratives are reasonably consistent with the contours of reality because we cannot function effectively in *social* contexts if our self-characterisations are unintelligible to other people.⁴⁷ I do not want to reject Schechtman's premise or its applicability to the narrative roles of bioinformation. It may well be the case that personal bioinformation can help us construct self-narratives that accord with other people's understandings of our particular embodied qualities in ways that help us function comfortably in social contexts and avoid the risk that our self-conceptions are not recognised by others. This is not a trivial benefit and may account for some of bioinformation's utility. However, Schechtman's characterisation of the reality constraint is silent on other reasons why a degree of external consistency might be valuable to us. My suggestion is that, because our identities are not only socially embedded and relationally constituted but also those of embodied, biological beings who operate in a material world, it also matters to us that the intelligibility and inhabitability of our self-narratives are not jeopardised by being at odds with *our own* encounters with our bodies, biology, and health. Our own abilities to make sense of our self-narratives and to function practically within them when confronted by our materiality matter at least as much, perhaps more, than their social plausibility. My suggestion then is that personal bioinformation plays a valuable role in supporting us in developing, maintaining, or restoring identity narratives that are reasonably consistent with, and intelligible and sustainable in light of, the material realities of our embodied lives. And it does so to the extent it offers *reliable* insights into the biological and bodily contexts, causes, and implications of our embodied encounters, capabilities, and experiences.

To be clear, the 'coherence value' of personal bioinformation appealed to here is not just about making our *bodies* more intelligible to us but also about making our *identities* and their constituent parts intelligible and resilient when faced with the vagaries and onslaught of embodied existence. In this respect, it is perhaps artificial to separate, as I have done above, the contributions of bioinformation to the internal and external coherence of our self-conceptions. Furthermore, the pursuit of (reasonable) coherence should be thought of as operating both synchronically and over time. For example, it matters not only that our identities are intelligible now but also that they are – as far as this is possible – not easily or imminently vulnerable to being rendered unintelligible and fractured

⁴⁷ Schechtman 1996.

by future bodily events or encounters.⁴⁸ While the sheer preservation of one's identity in an unchanging form is neither realistic nor desirable – by their very nature self-narratives do and must evolve in response to changing circumstances – abrupt and far-reaching disruptions may be distressing and disorienting and take considerable effort to resolve. Access to personal bioinformation could enhance the resilience of the coherence and sustainability of our self-conceptions over time by alerting us to how our capabilities or experiences may change. Avoiding such prospective jeopardy is important to comfortably and sustainably inhabiting who we are.

The normative roles played by personal bioinformation in the construction of our identities are not restricted solely to 'structural' features – that is, those supporting the internal, external, or future coherence of our self-narratives. The third way in which personal bioinformation may make an ethically significant, not merely a qualitative, difference to our identity-constituting narratives rests on the fact that our identity narratives provide the interpretive frameworks, or 'bodily perspectives', through which we encounter the world. My contention here is that bioinformation can play a valuable role in informing self-narratives that provide suitable interpretive frameworks with which to make sense of the material world, and seaworthy vessels within which to navigate, and conduct ourselves as embodied beings. Bioinformation can help us construct identities that are responsive to and developed in 'dialogue' with our biological and bodily lives. It does so by providing insights beyond our inevitably limited direct experiences. It thereby helps us understand and negotiate some – though undoubtedly not all – of our 'recalcitrant' materiality by alerting us to the whereabouts of some of the 'stern trunks' and 'twisting vines' that our bodily and biological form places in our path. It can help us anticipate these features of the landscape and embrace, tackle, or steer around them. For example, blood tests revealing high levels of antibodies consistent with early stages of rheumatoid arthritis may allow someone to build the risk of disease into their self-narrative, to anticipate and make sense of experiences of pain and reduced mobility as these emerge, and to map their future narrative with the prospect of this illness on their horizon.

⁴⁸ Hallvard Lillehammer makes a parallel suggestion with respect to the value of knowledge of genetic parentage to our identities. While Lillehammer is sceptical that this knowledge is valuable in itself, he allows that *erroneous* beliefs about our parentage could set one's identity up to be 'subverted' by the later discovery of the truth in ways that are detrimental to our well-being (Lillehammer 2014).

We should not be surprised that as embodied beings our self-narratives and our needs and capacities as narrators are enabled and limited by our physical and mental strengths and vulnerabilities and by the arc of our biological biographies that are bounded by conception and death and waymarked by – amongst many other things – growth, strength, illness, reproduction, and dependency. As such, we are the kinds of beings for whom insights into our bodily states and functions, our health, and our relationships to others can impact upon and colour how we characterise ourselves. This brings me to the fourth way in which bioinformation can make a normatively significant contribution to our identities. This one is more equivocal, or double-edged, than the previous three, in that it more obviously entails detrimental as well as positive impacts. It quite simply involves the contribution made by personal bioinformation of fresh or reconfigured descriptors, contents, and plot-lines in which we either invest value or take no pleasure. These may include features that help make our narratives meaningful and add to their detail and texture and those that, in contrast, introduce burdensome, demeaning, frightening, or limiting contents. The fact that these impacts on the tone, comfort, and qualities of our narratives may be positive *or* negative – which is not to say that they need be either – does not detract from their potential significance. Either way, they affect the inhabitability and meaning of our identities in non-trivial ways.

Though Mackenzie does not herself explicitly discuss a role for externally sourced personal bioinformation in identity construction, the various narrative roles that I am proposing here echo her position that '[m]aking sense of who we are, and making sense of our lived embodiment, involves constructing an identity that is shaped by, and responsive to, biological realities'.⁴⁹ My contention, as set out above, is that personal bioinformation has several important, interconnected roles to play in achieving this sense-making and responsiveness. Something important – to the individual in question – is at stake in these roles being filled. At stake are, as described in Chapter 3, our abilities to make sense of who we are, to engage in practical and evaluative ways with the world, to be active and critical in our ongoing self-constitution, to sustain enduring projects and commitments, and to have a reasonably stable and useful interpretive perspective through which to make sense of our experiences and navigate the world. These are experiences and capacities that we have strong interests in cultivating and exercising because they contribute to

⁴⁹ Mackenzie 2009, p. 121.

the quality and richness of our lives. But being in a position to cultivate and exercise them is not inevitable. As I have suggested, these practical and evaluative capacities depend not simply on a reasonably intelligible, integrated, and resilient self-narrative but also on one that is capable of exhibiting and maintaining these features and supporting us in the context of embodied existence and as particular selves with our own particular forms of embodiment. This is the basis for my claim that personal bioinformation – taken as a wide category – has a number of important normative roles to play in the composition of our identities. I will return in subsequent chapters to discuss when and why particular kinds and instances of information may or may not fulfil these roles in the same ways or to the same extent.

The claims made above resonate with aspects of those concerning the narrative roles of knowledge of genetic parents introduced at the end of Chapter 2 – for example, Sarah Wilson’s proposal that this knowledge plays an explanatory role and can contribute to ‘alleviation of uncertainty with respect to the past’⁵⁰ and Jamie Nelson’s claim that knowledge of our origins fills a gap by supplying the opening pages of our biographies, ‘without which we cannot read well what is going on in the part occurring now’.⁵¹ My position also shares features with Velleman’s argument that acquaintance with our genetic parents provides tools to make sense of our particular form of embodiment and the ways our particular physicality and psychology contribute to and constrain who we are.⁵² The arguments made by these three authors point us in a fruitful direction. However, my proposals go further. First, they posit epistemic and hermeneutic roles for bioinformation that extend beyond filling in gaps about our past or averting alienation from our materiality. Second, the suggestions I have made here encompass far more than information about genetic parentage, to embrace any kinds of personal bioinformation that help us make sense of who we are in the context of our embodied lives. But my claims are also more conservative, in not assuming that knowledge of genetic parentage will invariably fulfil these roles – I shall return in Chapter 5 to interrogate the narrative roles played by this specific category of information. And finally, while the idea that self-narratives – like novels and memoirs – are better for having clear beginnings and lacking gaps has intuitive metaphorical appeal, metaphor alone

⁵⁰ Wilson 1997, p. 285.

⁵¹ Nelson 1992, p. 81.

⁵² Velleman 2005.

is not enough. It is not enough to explain why access to information that fulfils these functions. We also need to know why this *matters* in ways that engage important interests and deserve ethical attention. Over the preceding sections, I have offered a set of pictures that seek to explain the potential value of personal bioinformation to our narrative undertakings and thus to our identities. This includes its potential explanatory value, but also derives from its selecting, evaluating, contextualising, interpretive, prognostic, and enriching roles. And I have grounded this value in the normativity inherent to narrative constitution of embodied, practical identity. The account I have offered above helps us appreciate why there are important capacities and experiences at stake in being able to develop and maintain an identity narrative that remains reasonably coherent, intelligible, and inhabitable in the context of our embodied, relational, and temporally extended lives.

Constituting, Not Revealing Identity

Before turning to consider some possible concerns that might arise in response to the claims I have made above, I want to differentiate my position from a line of reasoning to which it may initially appear similar. This is the proposition that some kinds of insights into the functions of our brains or psychology can supply vital correctives to our self-narratives, revealing the truth about who we are and what we are really like. For example, Mary Walker examines the possibility that findings from neuroscience and cognitive psychology – which, for example, purport to indicate that our effective motives differ from our acknowledged ones, our memories are unreliable, or our self-descriptions are biased – challenge the ‘truth’ of our self-narratives by revealing where our ‘real’ identities depart from the stories we tell about them.⁵³ Walker herself is sceptical about the cogency of this hypothesis and adopts a critical stance to the conception of objective truth at its heart. However, Lisa Bortolotti is more optimistic that findings from psychological research which purport to provide ‘knowledge of [our] own mind[s]’ and to reveal our ‘behavioural dispositions’, ‘biases in deliberation’, and ‘attitudes’ could be essential to constructing coherent identity narratives that align with our ‘real motives’ and support our autonomy.⁵⁴

⁵³ Walker 2012.

⁵⁴ Bortolotti 2013, pp. 687–688.

The prima facie similarity between these kinds of claims and my own is that they each appear to hold that personal bioinformation – albeit of narrowly specific kinds – is of value to our identities because it can help us develop identity narratives that are more consistent with the ways our brains and minds actually work. My position, however, is not that bioinformation’s value lies in its role as a *corrective* revealing the ‘real’ nature of our identities. There are two reasons for rejecting a corrective model. First, according to a narrative conception, our identities are *constituted* by our self-narratives. It therefore is not cogent to hold that scientific investigation can reveal what Schechtman terms ‘prenarrative truth about the self’, as there is no such truth.⁵⁵ This means that Bortolotti’s contention that ‘knowledge of the self matters to accurate and coherent narratives’ is circular.⁵⁶ Second, the suggestion that neurological or behavioural data alone reveal the true nature of our motives and attitudes, let alone our identities, rests on a misplaced view of what accounts for this ‘true nature’. Motives and attitudes are not discrete neurological or behavioural events, separable from the stories we tell about who we are. It is with reference to their place in the contents and arc of our embodied, relational self-narratives that these features of our evaluative and practical lives acquire their meaning and become explicable. This is not to say that we can never be confused or self-deluding about what characterises us. And according to the account I have given above, findings of causal or contributory factors in our traits or behaviours could lead us to revisit our self-characterisations. However, this is not because these findings *reveal* our real identities. It is rather because they offer contextual insights that may assist us in the interpretive activity of identity construction. Furthermore, contrary to Bortolotti’s claims that bioinformation about our minds and motives are unique amongst personal bioinformation in playing a valuable role in self-understanding and self-determination – while, for example, information about genetic disease risks can only make cosmetic alterations to narrative contents – my position is that the interpretive and reconciliatory capabilities of bioinformation extend much wider. These capabilities may be fulfilled not only by neurological information, but also by genetic and many other kinds of information about our bodies and biology. And the contributions they can make are far from merely cosmetic.

⁵⁵ Schechtman 2012, p. 75.

⁵⁶ Bortolotti 2013, p. 687.

4.5 The Suitability of Bioinformation: Responding to Concerns

Having drawn these important distinctions, in this final section of this chapter I wish to address some concerns or objections that might be invited by the proposals I have made above. These fall into two categories. The first is that despite earlier protestations, my argument is based on a biologically essentialist premise after all. The second concern questions the suitability of personal bioinformation for fulfilling the epistemological and hermeneutic roles I have proposed. I shall take these in turn.

Biological Essentialism Revisited

Accounts that propose an ethically significant role for information of one's health, body, or biology in identity are often viewed with suspicion as they are assumed to cleave to a view of identity as reducible to and ready-defined by our biology rather than created by its subject.⁵⁷ The presumption seems to be that any claim to value must be based on the premise that this information is necessary for revealing or bringing to fruition a pre-existing essential self. As noted in Chapter 2, there are both empirical and ethical reasons for resisting the idea that our identities are defined and determined by our bodies and our biology. The argument I have presented above, however, does not commit me to a biologically reductionist or biologically essentialist conception of identity. The first thing to say is that focus on *bioinformation* in this book should not be taken as signalling that this – out of all possible sources of narrative materials and interpretations – makes, or should make, an unparalleled contribution to our identities. It is only one amongst many possible constitutive, epistemic, or hermeneutic tools in identity development – albeit an important one. My focus on the 'bio' here is motivated instead by the roots of this enquiry, which lie in bioethical and policy debates about which interests should inform policies and practices governing the disclosure of bioinformation in clinical, health research, and consumer contexts. And my claim is not that unfettered access to personal bioinformation would be sufficient for the construction of a coherent, inhabitable self-narrative. Our narratives will inevitably and appropriately also be woven from strands that have nothing to do with our bodies or biology. To this extent, I concur with Hallvard Lillehammer, who, in expressing his scepticism about the universal value of knowing one's

⁵⁷ For example, Marshall 2014.

genetic parentage, observes, '[t]here are many things that could make more of a difference to how I think of myself than facts that determine how I was constituted as a biological entity'.⁵⁸ Furthermore, as I have emphasised, my account takes bioinformation to be a potential source of insights into aspects of our health, bodies, or biology, not into our *identities* themselves. So, in positing, for example, that someone could have an identity-related interest in accessing genetic test results, my suggestion is not that these will reveal what that person is really like but rather that the results might provide material they could use, or not, in developing and enacting their sense of who they are. Bioinformation is relevant and valuable to identity in a *potential* and *instrumental* sense rather than in an inevitable and essential one.

These responses notwithstanding, it might still be a source of concern that my position emphasises the desirability of coherence between someone's self-narrative and their material, biological attributes. This might look like a capitulation to a requirement that we define ourselves in close accordance with our biological attributes on pain of a debilitating, or at least an unhelpful, lack of intelligibility. Yet many of us actively exclude aspects of our bodies and health from our self-definitions or characterise ourselves in ways that run contrary to our embodied forms and biological traits. Even where some aspects of our embodiment are part of our self-conceptions, we may perhaps resent this or reject the implication that this is the most important aspect of who we are. And, in countless cases, we will simply omit aspects of our health or biology from our self-narratives because we are unaware of them or see them as incidental. It would be problematic, therefore, if my analysis implied that any of these circumstances represent a necessary barrier to developing and occupying a meaningful and intelligible practical identity. However, this is not the implication of my claims.

My argument does not preclude refusing to be defined by particular aspects of our bodily existence – for example, phenotypic sex or chronic illness – or defining oneself in opposition to these. Active rejection of aspects of our embodiment from our identities need not jeopardise narrative coherence or intelligibility. To understand how this can be so, we can return to the useful analysis of dramatic personal changes offered by Mary Walker, which I briefly mentioned in Chapter 3. Walker explains how someone can retain a unified and intelligible self-narrative through an experience like a dramatic religious conversion.

⁵⁸ Lillehammer 2014, p. 103.

She proposes that this continuity requires that the individual is able reflectively to access, respond to, and explain their former now repudiated values and behaviours in the light of their conversion and current characteristics, with the result that they can still make sense of themselves as someone who was once ‘that’ and is now ‘this’.⁵⁹ Under a similar principle – and one that may apply to synchronous complexities no less than it does to change over time – it is possible that particular bodily or biological characteristics may inform our identity narratives without becoming *defining parts* of us. This is the case when we are able to offer meaningful accounts of who we are that exclude unwanted traits or minimise their role, while also being able – in principle – to explain the relationship or journey between these and our defining characteristics and to anticipate and account for the ways these rejected traits may sometimes impinge upon our embodied lives.⁶⁰

These kinds of selection, prioritisation, and mutual explicability of narrative threads are inherent to the concept of narrativity. And one of the key conceptual strengths of a narrative-based account of the relationship between identity and personal bioinformation is that it allows us to understand that bioinformation can play a valuable *instrumental* role, as a tool of identity development, without itself directly supplying the substantive building blocks and self-descriptors of our self-characterisations. In such cases, it may fulfil interpretive or editorial functions that help restore or preserve intelligibility amongst diverse experiences and traits. These functions might involve, for example, relegating aspects of one’s health to the status of brute bodily states of affairs rather than parts of one’s identity, charting the submerged boulders of biology to be navigated around, or providing the point of tension against which one can build a counter-story that allows one to make sense of one’s embodied experiences. For example, learning that they are at high risk of hereditary colorectal cancer may help someone relegate this risk to serious but a largely pragmatic matter to be clinically managed, so that it impinges on their self-conception as little as possible rather than defining them.

As to the sheer omission of details about our bodies and biology from our self-narratives, this is inevitable and is not in itself a threat to the

⁵⁹ Walker 2019.

⁶⁰ Walker herself makes a slightly different argument about the place of illness in our self-narratives, holding that while they cannot be ‘regarded as expressions of one’s characteristics . . . we can still integrate them into our narratives’ through reflecting on and responding to them (Walker 2019, p. 87).

intelligibility and integrity of our identities. Indeed, any attempt at factual completism is more likely to militate against intelligibility and our abilities to discern which features are key to shaping our priorities and values. My contention that personal bioinformation can provide valuable explanatory, interpretive, or contextualising tools does not mean that any *particular* aspect of our embodiment, or any particular kind of personal bioinformation, is universally essential or invariably valuable to the development of our practical identities. However, there is a critical distinction to be made here between a mere lack of bioinformation or rejection of its proffered descriptors, as contrasted with the unwitting incorporation of frankly false beliefs. Lillehammer captures this in observing that:

It is one thing to develop a virtuous practical identity in conditions where facts about one's genealogical origins play little or no role while being aware that there are significant gaps in one's knowledge of those facts. It is quite another to develop such an identity in the false belief that one's knowledge of these origins is accurate or complete.⁶¹

Lillehammer's concession – with which I concur and would extend to bioinformation beyond 'genealogical origins' – is that the former situation is often innocuous, whereas the latter could harm one's identity and interfere with its capacity to support a flourishing life. The narrative-based account I have offered in this chapter suggests that this harm could take two forms. First, false beliefs could render one's self-narrative vulnerable to being undermined when one stubs one's toe against biological reality. And, second, such misconceptions make one's self-narrative an unreliable foundation from which to navigate and make sense of one's experiences of embodiment because these are then premised on false assumptions. Misapprehensions of aspects of our bodies, biology, or health are not necessarily problematic in themselves, but they could be insofar as they foster self-characterisations that we struggle to make sense of or sustain. I will return to the threats posed by false and unreliable information in the next chapter.

Epistemic Suitability

Turning now to the second set of concerns: those that question the suitability of personal bioinformation – perhaps especially that generated

⁶¹ Lillehammer 2014, p. 106.

by the biomedical sciences – to fulfil the roles I have proposed. These concerns are grounded in scepticism that objective, quantified, and theory-laden bioinformation does not reveal the truth about our bodies and biology and, even if it does, it is not an appropriate tool for interpreting the phenomenology of embodied existence. I shall respond to each of these in turn.

What I have said so far takes as its unspoken assumption that personal bioinformation can make valuable contributions to the coherence and interpretive capacities of our identities because it delivers relevant reliable knowledge of our health, bodies, and biology. However, anti-realist perspectives call into question – for diverse reasons – the assumption that science provides knowledge of the world ‘as it really is’.⁶² If this is so, then it is not obvious that the information biomedical sciences and technologies supply could help us construct narratives that are more intelligible in light of, or better for negotiating, our materiality. It is not possible to engage with the detail of debates about scientific antirealism here.⁶³ It is sufficient to note that my argument does not depend on a naïve realism that assumes ‘[t]he picture which science gives us of the world is a true one, faithful in its details’.⁶⁴ This would be unwise, particularly given the relative youth and rapid developments of some of the disciplines and techniques, such as machine-learning-driven association studies in genomics or neuroimaging, with which this project is concerned. It is also the case that some personal bioinformation will incorporate constructed categories such as ‘depressive illness’ that do not correspond to neatly defined biological categories.⁶⁵ This does not, however, obviate the potential interpretive utility of personal bioinformation. It is sufficient for my purposes that the biomedical sciences can provide the kind of ‘empirically adequate’ theories that generate findings that broadly accord with the world as we experience it.⁶⁶ It is enough that personal bioinformation offers reasonably reliable instrumental knowledge about how observable phenomena are likely to behave, in which, in Bas van Fraassen’s phrase, our actual experiences can ‘find a home’.⁶⁷ This leaves space for recognising that we may yet find better and more reliable and

⁶² For example, Kuhn 2012; Latour and Woolgar 1979.

⁶³ For discussion, see Rowbottom 2019.

⁶⁴ Van Fraassen 1980, pp. 6–7.

⁶⁵ It is possible to recognise that labels such as this are social constructions, without conceding that the states of affairs to which they refer are not real (see Hacking 1999).

⁶⁶ Van Fraassen 1980, p. 12.

⁶⁷ Van Fraassen 1980, p. 86.

explanatory ways to, for example, identify and categorise diseases, while allowing that current observations and inferences retain utility for now. Of course, not all bioinformation will confer equally useful or reliable means for interpreting embodied existence. Some of it may be frankly false or otherwise unsound or misleading because of unsuitable or immature analytic methods. And much of it will deal not in certainties but instead in broad probabilistic claims. I will return in Chapter 6 to interrogate the limits of particular kinds of bioinformation as useful epistemic and hermeneutic tools.

The second category of concern I want to address is that even if one is sympathetic to the idea that we have an interest in constructing and making sense of an embodied identity narrative, one might imagine that this entails a self-conception woven from first-personal, subjective, experiential material, not one built from the kinds of third-personal propositional, quantified, and technical information generated by medicine, health research, or biotechnologies. In suggesting that biomedical information has a role to play in our embodied identity narratives, I may seem to have committed a category mistake by conflating the biological body with the 'body as lived'. It may appear that I have incorrectly elided the kinds of information pertinent to numerical identity – as concerned with sameness and brute facts about us as organisms – with those pertinent to identity in the sense of characterisation and practical selfhood.⁶⁸ Or it might appear that I have overlooked the lack of equivalence between objective symptoms of disease and our experiences of illness. These concerns are rooted in doubts that personal bioinformation – as I have defined it – captures the phenomenology of the bodily states of affairs or ill-health to which they pertain.⁶⁹ This might mean, at the very least, that bioinformation is not well-suited to providing the kinds of explanatory and interpretative tools for embodied identity development that I have suggested. More pessimistically, it could be objected that reliance on 'external' information over our own direct experiences of ourselves and our characteristics is to the serious detriment of our well-being and understandings of who we are. For example, as noted in the last chapter, Mary Walker and Wendy Rogers have proposed that when the advent of unexpected bioinformation – their example is a diagnosis of asymptomatic disease – does not correspond with the recipients' experiences, the urge to restore narrative coherence

⁶⁸ See Ajana 2010.

⁶⁹ Carel 2011.

may force them to distort other aspects of their self-conceptions. They may, for example, start to habitually doubt their own perceptions of their health.⁷⁰ Deborah Lupton and others have raised related concerns that objective, quantified data supplied by consumer health technologies such as sleep-monitoring apps might unhelpfully replace more ‘authentic’ phenomenological experiences of self.⁷¹

My responses to these concerns about epistemic suitability and usurped phenomenology are twofold. First, as Mackenzie argues, it is a mistake to conflate characteristics with respect to which we are non-autonomous – for example, our inherited genetic traits – with characteristics that have no relevance to our identities.⁷² Even though our biological and bodily states and capacities are ‘given’, they – and, by association, information about them – may nonetheless be pertinent to our subjective experiences of self, our abilities to construct our self-narratives, and the particular shape and nature of our resultant identities, in all the ways described above. Second, my claim for the identity value of personal bioinformation relies neither on assumptions that it invariably provides the correct or complete story of someone’s embodied existence – with all the personal, experiential nuances this entails – nor the contention that it ought to replace our own experiences in the construction of our identities. Lupton’s anxiety might indeed be justified if quantified bioinformation were wholly to usurp embodied experience in narrative self-constitution. But here Michael Loughlin and his co-authors offer a useful distinction, observing that ‘there is a difference between saying that looking at the world in a certain way can help you understand *aspects of* the truth about your predicament, and saying that looking at the world in a particular way, understood through the lens of scientism, provides the only truth’.⁷³ With due caution about the reference to ‘truth’ here, the former claim in this passage is close to the view I wish to defend. It is undeniable that externally sourced personal bioinformation will usually be qualitatively and functionally different from that delivered by our experiences and senses. My suggestion, however, is that it is a mutually informing combination of our experiences and bioinformation that provides the fruitful material for our self-narratives. For example, findings about structural neurological explanations for psychiatric illness,

⁷⁰ Walker and Rogers 2017.

⁷¹ Lupton 2013; Kreitmair and Cho 2017. I do not myself use the language of authenticity in this discussion because of its ambiguity and unwanted associations with both individualistic and essentialist conceptions of identity.

⁷² Mackenzie 2009.

⁷³ Loughlin et al. 2013, p. 143 (emphasis added).

taken in isolation, are unlikely to equip someone with everything they need to understand or navigate their illness experiences. However, this does not mean that these findings could not be of use in helping them make sense of the onset of their recent symptoms and how these have affected their personality and relationships.

While drawing attention to precisely the differences between the experience of one's own ill body and clinical knowledge that motivates the above concern, Carel notes that it is nevertheless an advantage to a patient to have access to both. As she says, '[t]he claim here is that the unique ability to oscillate between the two perspectives gives the patient a deeper understanding of the illness experience and potentially to the dual nature of the body'.⁷⁴ The combination of experience and information allows the patient to know both the 'how' and the 'that' of their body or illness. Carel's position echoes the position of some narrative identity theorists that, because we are embodied beings, identity construction entails a dialogue or reconciliation between the contrasting viewpoints of our bodies as objects in the world and our subjective experiences of them 'from the inside'.⁷⁵ For example, we can recall here Velleman's suggestion that observing family resemblances can help us identify with our objective materiality, to 'com[e] to terms with our bodily selves'.⁷⁶ Developing our embodied accounts of who we are may require external epistemic and hermeneutic resources beyond our phenomenological experiences to help us interpret these and work out whether and how they feature in our stories of who we are. In this way these external resources may help make our stories inhabitable and recognisably our own.

Nevertheless, Walker and Roger's warning about the risks of distortion is an important one. Not only does it remind us that pursuit of narrative coherence above all else may be neither an unalloyed good nor valuable at any cost. It also flags the possibility that personal bioinformation could, for various reasons, carry a greater gravitational pull – greater than other epistemic and hermeneutic tools and perhaps greater than its contributions warrant – when it comes to recipients' pursuit of coherence. And this may come at the expense of the comfort or sustainability of their sense of who they are. I will return in Chapter 6 to consider the relationships between the qualities of narrative coherence and comfort.

⁷⁴ Carel 2016, p. 50. See also Sharon 2017.

⁷⁵ See, for example, Atkins 2008; Ricoeur 1992; Velleman 1996.

⁷⁶ Velleman 2008, p. 260.

Whether particular information generated by medicine, health research, or biotechnologies does in fact offer useful interpretive tools for navigating embodied existence and experience will vary between information types, disclosure contexts, and recipients. The possibility remains that some bioinformation will just not be very good at fulfilling these roles. Some might even be detrimental to our efforts to construct coherent, inhabitable self-characterisations. Over the coming chapters, I will explore in greater detail the diversity of information's effects on recipients' self-conceptions, how we might identify when these are likely to be beneficial or detrimental, and what might be done to manage the proportionate influence of bioinformation and to achieve a helpful dialogue and accommodation between diverse narrative contributions and interpretive tools.

4.6 Moving Beyond Theory

In this chapter I have outlined my central contention that personal bioinformation, taken as a broad category, can play a number of vital roles in helping us construct self-narratives that are responsive to the vagaries, limitations, and opportunities of embodied existence. My claim is that personal bioinformation is important to our identities because our material, biological, vulnerable, and capable bodies frame our subjective experiences and play an active part in shaping 'how our lives go'. Therefore they can play key roles in the contents, scope, and context of the narratives that constitute our lived, practical identities. This information supports us in constructing self-narratives that not only make sense when confronted by our embodied experiences but also provide the foundations from which we are able to interpret and navigate our embodied lives. It does so by acting as a contributory and interpretive tool, not necessarily by straightforwardly installing self-descriptors but by assisting us in the task of meaning-making across the threads that make up the stories of who we are. In fulfilling these roles, personal bioinformation helps us develop, maintain, or restore the kind of narrative integration, intelligibility, and inhabitability that are necessary if our identities are to ground our capacities to have a strong sense of who we are, provide a solid foundation from which to make judgements and commitments, and support us in being the authors of our own actions and ongoing self-creation. As established in the previous chapter, I take these capacities to be central to leading a rich, fulfilling, and practically engaged life. On these grounds, I submit, we may understand why access

to personal bioinformation could engage ethically significant interests that warrant attention by those who hold this information when they make decisions about whether to disclose it to us. I will specify the nature of these interests in Chapter 6, having refined my account in light of the illustrative examples to come.

If this account of the relationship between personal bioinformation and identity is to provide a sound foundation for practical ethical decision-making, if it is to inform policies and practices governing disclosure of personal bioinformation to information subjects, then it is vital that it remains plausible when held up to people's actual experiences of encountering this information and is responsive to the kinds of factors that affect the nature of these encounters. To these ends, my next step is to turn to the empirical social science literature for examples of information subjects' attitudes and reactions to receiving three different kinds of personal bioinformation. My intention is to check that the conceptual and ethical analysis I have presented here is at least congruent with people's experiences. These examples will also serve to bring to life and further refine the claims I have made so far. I shall describe these illustrative examples and my approach to them in detail in the next chapter.