

Attending to Identity

1.1 Introduction

Two Friends

Let us imagine two friends, who find themselves in situations that are at once similar and strikingly different. Ilana is a proud participant in a national research biobank project. Over several years, she has attended a clinic to provide blood and saliva samples, to undergo various observations, tests, and scans. She has filled in lifestyle questionnaires and agreed to grant access to her medical records. The biobank stores the data collected from her, and health and social researchers can apply to use them in their studies, in pseudonymised form and subject to conditions.¹ As she nears the age at which her late mother had a number of small strokes and started to experience problems with her memory and eyesight, Ilana wonders if she, and her daughters, might be similarly at risk. She would like to know if her brain scans show any abnormalities and whether she carries genetic variants associated with Alzheimer's disease or degenerative eye conditions. The biobank has not contacted her about any health concerns. But she knows that they will only do so if they find 'potentially serious abnormalities' in observations or scans, and she will not be contacted at all if subsequent research studies find, even serious, risk factors. Meanwhile, her friend Sam has been excited about receiving the results of her 'full health and ancestry' report from an online direct-to-consumer (DTC) genomic testing service. When Sam's results eventually arrive, she is fascinated to learn of unexpected southern Indian ancestry and amused to see she is disposed to fear public speaking. She is relieved she does not carry the cancer-related *BRCA* mutations but is not sure how to interpret her percentage risk of Alzheimer's disease – it seems

¹ Pseudonymisation replaces identifying details with, for example, a reference number so that personal data cannot be easily attributed to a specific data subject.

scarily high. Overshadowing all this, though, is Sam's acute distress to learn that the results indicate she is not related to her father.

There are undoubtedly many differences between these two examples. Ilana is a volunteer in an endeavour intended to deliver social benefits; Sam is a customer of a commercial business. Receiving results of genomic analyses is an explicit part of Sam's customer agreement, whereas Ilana assented to the biobank's limited feedback policy. The biobank, researchers using the banked data, and the DTC genomics service each have different aims and resources for analysing and reporting back findings. And, while we might want to take issue with any such differences, the legal duties and standards of care each of these parties owes to Sam and Ilana are also likely to differ. Yet the *kinds* of information Ilana is unable to access and Sam is simply sent and what this information *means* to them are not so dissimilar. Both involve insights relevant to the friends' health and well-being, some of which are significant. They include findings that both women might want to know despite being neither strongly predictive nor clinically actionable. Both include information that could affect how the friends feel about and describe themselves, their familiarity and confidence in their bodies and mental capacities, and their hopes and plans for their futures. Some findings could help explain recent experiences, and others might affect how the women see and conduct their relationships with those close to them. This is most starkly so in Sam's case, but Ilana too feels an urgent need to know if her experiences and anxieties are like her mother's and she feels guilty about failing in her parental responsibilities to protect her daughters from threats to their happiness and health.

The contextual differences listed above account for much, but not every aspect, of the friends' dramatically different access stories and the questions these raise. For example, why does the biobank only report back 'potentially serious' abnormalities, and what are the appropriate criteria for deciding seriousness? How does the genomic testing service justify providing results directly to customers without professional support, while the biobank sends serious findings via participants' doctors? Which, if either, arrangement is best protecting the friends' interests? Is it true to say that the DTC service provides insights into users' identities, as its advertising strapline 'Getting to know the real you!' shouts, while the biobank only collects and generates data about health?

This sketch is not simply about the so-called rights to know or not to know.² It is about the particular kinds of interests that are affected by

² See Chadwick et al. 2014.

'knowing' – or not – and also by the manner and context in which information subjects come to know.³ It invites us to consider whether serious health threats are the only or most important consideration when presenting us with insights into our health and traits, or whether it also matters how these affect our understanding of 'who we are'. And what does that last question even mean? Are learning of serious disease risks and knowing who one is easily separable? Are matters of genetic relatedness and ancestral origins paradigm identity concerns? More so than a fear of public speaking or risk of Alzheimer's disease? Or are these all equally reductive, restrictive misconceptions about what actually makes us *us*? Ilana and Sam themselves do not quite agree on these questions. When confiding her shocking news to her friend, Sam says, 'I know your health is important, but this is different, it's about my *identity*. I am not sure I know who I am anymore.' Ilana comforts her but thinks to herself, 'This feels like it's about my identity too. At this point in my life, I feel oddly at sea. Knowing more about my body and what mum went through would help me feel close to her, to understand and plan some important things for me and my family, and to be more at home in myself.' Over the following chapters, I will explore the potentially valuable insights reflected in each of their perspectives.

The Bioinformation Explosion

Observations, accompanied by awe or trepidation, of the sheer quantity and variety of health and bio-related data being generated are now customary in bioethics and related fields of study.⁴ The ubiquity of these observations should not, however, desensitise us to their truth or to the personal, social, ethical, and regulatory implications of the richness of this ever-expanding reservoir of data.⁵ These data supply sources of information about our physical and mental health and well-being; our cognitive and physical traits; the states, functions, and capacities of our bodies and minds; the relationships between our bodies and those of other people; the ways we differ from others; and the traits we share. It is these kinds of information, our encounters with them, and, specifically,

³ In what follows, I shall use the term 'information subject' to refer to an individual person to whom particular personal bioinformation pertains and to whom it is understood to pertain. This does not preclude the possibility that the same information may have more than one information subject and thus be 'personal' to each of them.

⁴ See, for example, Raghupathi and Raghupathi 2014; Sharon and Lucivero 2019.

⁵ Xafis et al. 2019.

how these encounters shape who we are that I am concerned with in this book.

To get some idea of the range of information in question, we can start by imagining those that are collected and recorded in the course of observations and tests conducted in healthcare. The quantity and variety of these are amplified by the uses of biotechnologies in delivering care. For example, genome sequencing, neuroimaging, biosensors, self-administered diagnostic tests, and implanted smart technologies are all increasingly part of screening, treatment, patient monitoring, public health surveillance, and targeting of interventions. Our health data are stored in electronic patient records, which in turn facilitates their subsequent use in health and social research. Vast amounts of data are also generated through health research itself, which includes clinical and observational studies, but also increasingly involves secondary uses of health records, data linkage, and biobanking projects. These methods offer the promise of new diagnostics and therapies, of delivering 'precision medicine' that targets subgroups of patient populations, and of informing public health interventions.⁶

The collection and analysis of information from and about our bodies are not, however, limited to healthcare or health research settings.⁷ They extend to public health, administrative, justice, and surveillance applications, including biometric passports, forensic DNA databases, apps and databases designed to track the spread of pandemics, and uses of gait analysis or facial recognition technologies in law enforcement.⁸ We are also active participants in the generation and dissemination of information about ourselves, for example, when we send off – as Sam did – saliva samples to commercial genomic testing services; use wearable devices and apps to track our own behaviours, fitness, or well-being; or share experiences and photographs on social media. The role of technology in all of this extends beyond methods of gathering fresh data. Data science, including uses of artificial intelligence (AI) and machine learning, plays an increasingly central role in generating new health-related, phenotypic,⁹ or behavioural profiles from existing data collections that may be applied to people far beyond those who were the sources of the original data.

⁶ Xafis et al. 2019.

⁷ Sharon and Lucivero 2019.

⁸ Henschke 2017.

⁹ Phenotypic traits are observable, measurable characteristics of an organism such as eye colour or the symptoms of a genetic disease.

The proliferation of all these kinds of data and the insights they offer into our health, well-being, traits, behaviours, and relationships invite questions about how they should be used and how these uses should be governed. For example, who should be able to access and use them? How can their clinical, social, or economic value be realised? How can potential abuses and harms be averted? The network of laws, regulations, policies, guidelines, and professional and institutional norms governing how health and biological data may be collected, deployed, and disclosed include data protection regimes, laws governing human tissues and fertility treatment, property and personality rights, and laws protecting information subjects' confidentiality and privacy alongside others' interests in information access.¹⁰ It is reasonable to expect that this network of laws, policies, and guidelines governing who can gather, use, and access information about our health, bodies, and biology and for what purposes will be informed by an appropriate, context-responsive, and well-grounded framework of relevant ethical considerations. This framework would account for all private and public interests that could be significantly affected by, amongst other things, disclosures of and access to these kinds of information.

The central concern of this book is to highlight one set of interests that, I will argue, belongs squarely in this framework but has not yet received sufficiently robust or clearly conceived attention in practical governance settings or academic debate. Specifically, my intentions over the following chapters are to characterise the impacts of our encounters with information about our own health, bodies, and biology – which I will collectively term 'personal bioinformation' – on our *identities*; to interrogate the nature and strength of our interests in whether and how we encounter this information; and to highlight when and why these interests are engaged. I will argue that our access, or lack of access, to bioinformation about ourselves can affect our capacities to develop, make sense of, and occupy our own narrative accounts of who we are. And because these capacities play a foundational role in many aspects of well-being and of a rich and engaged practical life, our encounters with this information can engage ethically significant interests. I will say more about what I mean by 'identity' and 'personal bioinformation' shortly.

¹⁰ Those of particular relevance to the arguments in this book are discussed in detail in Chapters 2 and 5.

Retraining Our Focus

In focusing on the impacts of information subjects' own encounters with personal bioinformation, the arguments presented in this book look in a different direction from many of the most prominent debates about governance of health information and biodata. They look inwards rather than outwards. What I mean by this is that often, when proposals are mooted, for example, to make patient records available for research or to introduce a mobile app to track exposure or immunity during a pandemic, the value of such initiatives tend to be framed in terms of the benefits they will deliver for patient care, public health, or perhaps public administration and security. Meanwhile, the most commonly voiced ethical concerns tend to be whether such initiatives could threaten the privacy of those whose data are gathered and processed and whether uses of these data might be stigmatising or discriminatory, infringe upon participants' dignity and freedoms, or erode public trust.¹¹ In short, attention usually turns first to what *others* might do with bioinformation about us. Here, I am concerned instead with the less well-trodden territory of what *information subjects themselves* might do with this information and how this might have profound effects on who they are.

This is not to suggest that information subjects' interests in accessing bioinformation have been wholly neglected. For example, in recent decades, medical law and ethics have seen a shift in what patients can expect to be told about their health and care options, turning from what healthcare professionals think they need to know, towards what the patient themselves might want to know.¹² Health research ethics continues to wrestle with dilemmas about feeding back individually relevant research findings to participants, though increasingly, the focus is on what should be fed back, rather than whether it should happen at all.¹³ There are contemporary debates about the extent and basis of information subjects' 'right to know' and 'right not to know', particularly in the context of disclosures of genetic information to close blood relatives.¹⁴ And discussions about benefits and risks to users of DTC services or consumer technologies to find out about their genetic traits or to track their lives are vigorously pursued.¹⁵

¹¹ See, for example, Carter et al. 2015; Dubov and Shoptawb 2020.

¹² Chan et al. 2017.

¹³ Eckstein et al. 2014.

¹⁴ Chadwick et al. 2014.

¹⁵ See, for example, Kreitmair 2019.

Nevertheless, despite growing attention to subjects' own interests in accessing, or being shielded from, bioinformation about themselves, closer examination reveals that a relatively small cluster of concerns and interests dominate the landscape.¹⁶ For example, when it comes to legal obligations to disclose health-related findings and to weigh the value of disclosure against countervailing concerns; when policy decisions are made about whether to offer health screening or which individual findings from health research should be returned to participants; or when those undergoing genetic testing are encouraged to share their results with their relatives, it is – perhaps unsurprisingly – the clinical actionability of the findings and their utility for reproductive decision-making that tend to be the foremost considerations.¹⁷ Meanwhile, reasons for *protecting* information subjects from, for example, uncertain indications of susceptibility to genetic disease in healthcare or DTC contexts tend also to focus on clinical actionability – or rather its absence – alongside the risks of harm to health and psychological well-being from misleading, vague, or hard-to-interpret results, false reassurances, or the absence of effective prevention or treatment options.¹⁸ Appeals to information subjects' privacy and the protection of a metaphorical 'private space' from impositions of unwelcome information feature in academic proposals for a robust theoretical grounding for the right not to know.¹⁹ And information subjects' autonomy – understood either as the bald exercise of choice (not) to know or as a capacity for self-determination enhanced by judicious information provision – also plays a prominent role in legal and academic reasoning. For example, European human rights law emphasises individual 'rights to know' and 'not to know' information gathered about them in healthcare.²⁰ And judgments of UK courts increasingly emphasise patients' entitlement to receive the information that a reasonable patient would deem relevant to their care and that would allow them to make choices reflecting their own values.²¹

¹⁶ Here, I am referring specifically to the interests of information subjects as (prospective) recipients. The list of protections and recognised interests that follows would look somewhat different if the concern was how information subjects are affected by *others'* access.

¹⁷ Wolf et al. 2008; UK National Screening Committee 2015.

¹⁸ Bunnik et al. 2011.

¹⁹ Laurie 2002, p. 67.

²⁰ See, for example, *K.H. and others v. Slovakia* (no. 32881/04) (2009) ECHR 2009/13; Council of Europe, 'Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine' (4 April 1997), Article 1.

²¹ Chan et al. 2017.

This brief sketch illustrates the prominence of clinical actionability, protection of psychological and physical health, autonomy, and, to some extent, privacy as the core considerations most commonly invoked when it comes to assessing information subjects' interests in accessing bioinformation about themselves. I am not seeking here to take a position on the extent to which these should be part of the ethical framework governing when information subjects can access information about their health or bodies. They are indeed likely to be relevant and important considerations. Rather, I want to highlight that by comparison there is a lack of consistent, serious, or well-developed attention to the ways that our own encounters with bioinformation may affect our *identities* – with a few notable exceptions, which will be discussed over the following chapters.²²

At this stage, of course, I have yet to say what I mean by identity or identity-related interests, let alone explain why, if there is indeed an identity-shaped gap, anyone should care about it. Nevertheless, I would hazard that many of us have encountered the idea, in one form or another, that some kinds of insights into our biological selves can have a bearing on who we are or at least on how we view ourselves. The arts, media, commerce, and popular imagination are littered with insinuations and bald claims about the importance of particular kinds of bioinformation to our identities. These are perhaps most prevalent with respect to genetic information, including the discovery of genetic relationships. For example, in the UK, assumptions that knowledge of genetic 'origins' provides insights into the self are evidenced in the popularity of amateur genealogy and television shows documenting celebrities' search for their ancestry.²³ UK courts have erred towards protecting children's right to know their genetic parentage, even in absence of existing social bonds.²⁴ Searches for genetic parents populate the plots of literature and films.²⁵ And documentaries and memoirs bear witness to personal quests for genetic 'parentage' or ancestry in the context of adoption, donor-assisted conception, or where family histories have been shattered by legacies of

²² I will return in Chapter 6 to map the relationships between our identity-related interests and the other more commonplace considerations I have listed here.

²³ For example, the BBC series *Who Do You Think You Are?* in which celebrities trace their family history is in its seventeen series at the time of writing.

²⁴ Fortin 2011.

²⁵ The feature film *The Kids are All Right*, in which adolescent siblings build relationships with their sperm donor, and the Scottish poet Jackie Kay's memoir 'Red Dust Road' in which she recounts searching for her birth parents, Kay 2011, are just two such examples.

enslavement, colonialism, or conflict.²⁶ Meanwhile, DTC genomics services play upon ideas that our genes reveal or shape our identities in promoting their tests for genetic markers associated with disease and non-disease traits and ancestral heritage with marketing straplines such as ‘getting to know you’ and ‘a story about you’.²⁷ Similar assumptions are evident in popular discussions of what images from brain scans or data gathered about neural activity might reveal. For example, reporting of neuroscience in the non-specialist media is notorious, and often criticised, for enthusiastic, credulous, and reductive treatments of the putative capacities of neuroscience to explain differences in behaviour, attitudes, or personality types or to read our minds.²⁸

We might be justifiably sceptical that popular tropes and preconceptions such as those just described are reliable indicators of whether ethically significant identity-related interests are in fact engaged by encounters with personal bioinformation. Nevertheless, they join an accretion of bioethical and social science discussions that further signal that something worthy of investigation is afoot. In the early years of the twenty-first century, there was a considerable wave of bioethical and social science writing, both theoretical and empirical, exploring the relationship between genetic or genomic information – about disease risk, traits, or relatedness – and our identities, in which both this relationship and identity itself are construed in a wide variety of ways.²⁹ For example, Christine Hauskeller considers, with some concern, the ways genetics could be used to naturalise and reinforce social distinctions.³⁰ Meanwhile, in a different vein, Vardit Ravitsky argues that donor-conceived individuals are wronged when they are not told of their origins and denied the opportunity ‘to choose what meaning they assign to the genetic components of their identity’.³¹ Academic discussions of the

²⁶ Again, just a few examples are: Georgina Lawton’s memoir ‘Raceless’ in which she explores her family history and sense of racial identity, Lawton 2021; the personal stories recounted in Alondra Nelson’s discussion of the entanglements of genetic science and the history and politics of race in the USA, Nelson 2016; and the 2020 documentary *Enslaved with Samuel L Jackson*, in which actor Samuel L. Jackson and journalist Afua Hirsch trace connections to Jackson’s African heritage.

²⁷ iSpot.TV websites ‘23andMe TV Commercials’ www.ispot.tv/brands/Ias/23andme (accessed 18 July 2021).

²⁸ O’Connor et al. 2012; Racine et al. 2005.

²⁹ Unless, otherwise specified, in what follows I will use ‘genetic’ as an umbrella term to refer both to information about specific genes and about features of an individual’s entire genome, even though the latter could more accurately be referred to as ‘genomic information’.

³⁰ Hauskeller 2004.

³¹ Ravitsky 2014, p. 36.

relationship between genetic information and identity have been joined more recently by those suggesting that insights into our brain states and functions may provide fresh ways of seeing ourselves. For example, Nikolas Rose and Joelle Abi-Rached observe how the adoption of concepts from neuroscience can offer fresh tools for self-characterisation, while Mary Walker sceptically explores propositions that brain data might be able to reveal our 'real' attitudes and motivations.³² I will consider these and other views about the impacts of bioinformation on identity in the following chapters, where they will provide some of the illustrations, critical tools, and comparators for the conceptual and normative picture that I will develop.

Given both popular beliefs and scholarly discussions about the possible roles of genetic or neuro-information in understanding or developing our identities, it is perhaps striking that currently the only legal entitlements to access bioinformation about oneself on explicitly identity-related grounds in the UK are donor-conceived individuals' limited rights to knowledge of genetic parentage.³³ I will discuss these provisions in greater detail in Chapters 2 and 5. I raise them here because it was the ongoing debate about donor-conceived individuals' putative identity-based interests and legal entitlements to know about their conception and their donors that provided the original motivation for the enquiry at the heart of this book. This debate piqued my interest in finding out what such claims might mean and on what grounds they might be justified.³⁴ But my curiosity was matched by corresponding scepticism about the apparent exceptionalism of these claims. It seemed both arbitrary and implausible that, if we do indeed have significant identity interests in knowing about our genetic parentage, these interests uniquely attach to this one category of information. Furthermore, any claim to identity value must contend with the corresponding critique that proposing an important role for knowledge of genetic parentage depends on a troublingly deterministic and biologically essentialist view of the self that risks being exclusionary and oppressive.³⁵ Either way, this debate demanded closer scrutiny of the nature of any supposed identity value or detriment.

³² Rose and Abi-Rached 2013; Walker 2012.

³³ Marshall 2014; Human Fertilisation and Embryology Act 1990, as amended. Hereafter, I will use the phrases genetic parentage, without inverted commas, and genetic origins to mean genetic progenitor while recognising that in many cases neither the legal nor the social relationship is one of a parent.

³⁴ I examine these reported experiences in detail in Chapter 5.

³⁵ For example, de Melo-Martín 2014.

As I will argue in the next chapter, the meaning of identity and its relationship to knowledge of genetic parentage – the very things existing legal provisions purport to be concerned with – remain ambiguous in existing legal and regulatory provisions. Some of the pictures of the relationships between identity and particular kinds of bioinformation proposed in academic debates are considerably more developed and nuanced. However, as I shall go on to explore, many still remain open to charges that the connections drawn are, in some cases, exceptionalist; while in others, they are ambiguous, contentious, or lacking in normative heft. This leaves us, and those responsible for governing access to personal bioinformation in particular, ill-equipped. We lack the necessary tools to conceptualise and formulate well-justified, consistent, and practical ethical approaches to providing access to personal bioinformation in ways that protect recipients' identity interests. In the course of the arguments to be presented, I will explain why I think this is a significant gap that warrants serious attention. I will suggest that it is not only a practical gap, inasmuch as existing laws and policies are inadequate to protect our bioinformation-related identity interests. More fundamentally, there is a lack of conceptual and normative clarity about the nature of the impacts of personal bioinformation on our identities, the strength and scope of the interests engaged, and, thus, how these interests might be appropriately recognised and met. Filling this more fundamental gap is essential to addressing the practical one, and it is my aim over the following chapters.

Aims of This Enquiry

My objective in this book is to offer a plausible, conceptually robust, normative account of the roles of personal bioinformation in our self-conceptions that is consistent with people's lived experiences. This will be an account that is capable of explaining why and how our encounters with this information can impact our identities in ways that engage ethically significant interests, without recourse to biologically essentialist claims.³⁶ The picture I will develop will be applicable across all 'personal bioinformation'

³⁶ By biologically essentialist claims, I will mean those that hold that our identities as individual persons are 'given', determined by particular biological characteristics such as our genetic inheritance, rather than created by other means and malleable.

conceived as a broad, inclusive category, rather than being limited to any one specific kind. However, it will also be capable of accounting for the diverse impacts of different kinds of bioinformation in different circumstances. Building from this conceptual and normative foundation, I will argue that our identity-related interests warrant serious attention when decisions are made about disclosures of personal bioinformation to those to whom it pertains. I will explain why these interests are engaged beyond the usual suspects – namely, information about genetic origins and genetic disease risk. I will further demonstrate that identity concerns are neither reducible to nor coextensive with those interests more commonly accounted for in decisions about disclosure – health protection, psychological well-being, autonomy, and privacy – and thus require attention in their own right.

My central claim will be that personal bioinformation, understood as a broad and inclusive category, plays critical roles in the development and maintenance of comfortably inhabitable and sustainable self-narratives – the narratives that constitute our identities. These roles, and their ethical significance, are accounted for by the practical functions of our self-narratives in our inescapably embodied and relational lives. I will argue that personal bioinformation can help us in the population and interpretive work of building narratives that are responsive to, and intelligible in light of, our embodied, relational experiences and that support us in making sense of and navigating these. I will also account for those instances in which bioinformation fails to fulfil these roles. In presenting and defending these claims, this book will contribute a vital plank in the ethical frameworks that guide laws, policies, and practices governing disclosures of personal bioinformation, equipping them to protect our identity interests. It will offer not only a picture of the nature of information subjects' interests in accessing this information but also a means of discerning when, why, and how these interests are engaged in different circumstances. It will also characterise the nature and extent of the corresponding obligations accruing to those who hold personal bioinformation about us.

1.2 Terminology

Before I can proceed with this argument, however, it is necessary to lay some groundwork by explaining what I will mean by 'personal bioinformation' and 'identity'. This will help to establish the conceptual and practical scope of the discussions to come.

Personal Bioinformation

This chapter opened with a brief sketch of the kinds of ‘personal bioinformation’ with which I am concerned. That provided some indication of the breadth and variety of information to which the arguments in this book are intended to apply. However, it will be useful to say a bit more about what I intend this phrase to include. My aim here is not to provide necessary and sufficient conditions for a precise definition, but rather a working understanding that will inevitably leave some fuzzy edges. I will also introduce the three categories of personal bioinformation that will serve as illustrative examples in the coming chapters. It is perhaps easiest first to say what ‘personal bioinformation’ is *not* intended to signal. I am not using it to introduce a novel or bespoke category distinction. Nor should the word ‘personal’ be understood as building in intrinsic identity-significance in a way that would be question-begging. The phrase is simply a contraction of ‘personal biological information’, adopted here for the purposes of brevity. It is intended to capture a broad and diverse set of information about our health, bodies, biological traits, and relationships to others – that is, the kinds of information about which the law, clinicians, policymakers, and bioethicists already ask questions regarding who may access it and for what purposes.

Information

In what I have said so far I have not been disciplined in distinguishing between data and information, slipping between the two as we often do in ordinary language. There is, however, a useful distinction to be made. The General Definition of Information (GDI) defines information as data plus interpretation.³⁷ Interpretation involves the processing, organisation, structuring, classification, and aggregation of data in a particular context and with a particular purpose such that it becomes about something.³⁸ The GDI further stipulates that information must comprise more than one datum and be ‘well-formed’ – that is, arranged so that it is ‘meaningful’.³⁹ Data may be thought of as observed or recorded states of affairs that provide source material for information. The discussions in

³⁷ Taylor 2012. I am concerned here with semantic information communicated between people, not the information conveyed by genetic material for the construction of proteins, or transmitted by neural signals.

³⁸ Rowley 2007.

³⁹ Floridi 2019.

this book do not concern access to raw, unformed, and uninterpreted data but information that is comprehensible, at least in principle, to the person to whom it pertains – the information subject. All personal bioinformation will have meaning, which is not to say that it will always be useful or *meaningful* – in the sense of significant – to the recipient. It may not even be true or reliable.⁴⁰

Interpretation is not a one-off event. Different and successive interpretations can be applied to the same data or information, resulting in new information with new meanings. Consequently, information is not inert but dynamic and changeable as successive layers of interpretation supplant each other or accumulate palimpsest-like. In his discussion of genetic data, Mark Taylor observes that we can think of information as having an ‘interpretive pedigree’ – that is, the interpretation(s) that has or have already been applied to it – and ‘interpretive potential’ – referring to the ways that it could go on to be further interpreted.⁴¹ I will follow Taylor in terming the context in and purpose for which interpretation takes place the ‘interpretive framework’.⁴² The nature and meaning of the information derived depends on the framework applied. Recognising the dynamic and cumulative nature of information will be useful when it comes to thinking in later chapters about the ways in which the impacts of personal bioinformation and its relevance to identity can vary in different contexts.

Due to the interpretive and dynamic nature of information, we cannot assume that the meaning invested by the party conveying it will be the same as that of the person receiving it. Each will bring different interpretive frameworks, including background knowledge, experiences, expectations, and interest perspectives. These are not limited to different capacities to make sense of complex, technical aspects of the information. For example, both discloser and recipient could be clinical geneticists. But, if one is a patient and the other their doctor, the same ‘item’ of genetic information conveyed – for example, that the patient has tested positive for the mutation responsible for the serious neurological disorder Huntington’s disease – will have different meaning and significance for each.⁴³ And disclosures of the same kind of genetic test result to

⁴⁰ Some accounts hold that semantic information must, by definition, be true (see Floridi 2019). Here, I adopt an ordinary usage approach according to which information can be described as false, or indeed meaningless in the sense of being irrelevant or trivial.

⁴¹ Taylor 2012, pp. 41–42.

⁴² Taylor 2012, p. 53.

⁴³ For this reason, any suggestion that disclosing information entails handing over an inert information ‘item’ is misleading.

three different patients – for example, one with children, one aware of their family history of Huntington’s, and one with emerging symptoms – are likely to convey three diverse meanings. As will be explored in later chapters, the context and manner of communication are themselves likely to further contribute to the interpretive framework.

Biological

‘Bioinformation’ is used here to capture more than information about health and disease. It is intended to extend to any information about ourselves as embodied, biological, and biologically connected human beings, our dispositions, states, functions, and capacities. Taylor’s taxonomy of genetic data offers a valuable device here. Taylor proposes that ‘genetic data’ includes not only data derived from analysis of genetic material – those with a genetic source – but also those that have been, or could be, interpreted to be about genetic states of affairs – that is, with a genetic interpretive pedigree or interpretive potential.⁴⁴ The following discussion will adopt a parallel understanding of personal bioinformation, whereby this includes not only information derived from observation or monitoring of someone’s body, tissues, or biomarkers but also that which conveys something about their bodily and biological characteristics. This means, for example, that information about having been conceived using donor gametes will count as bioinformation, insofar as it is understood to speak to the donor-conceived individual’s origins as an organism and their genetic relationships, even if the information source is an administrative record rather than a genetic test. Conversely, a mental health diagnosis based on neuroimaging data will count as personal bioinformation when it is derived from data recorded from the individual’s brain and has implications for their medical care, even if mental health is not reducible to purely biological states of affairs.

Personal

The ‘personal’ aspect of bioinformation is intended here to signal that the information has been interpreted as applying to an identifiable individual and purports to reveal something about that person’s own health, body, or biological existence. This is not to overlook, however, that some personal bioinformation – most notably, genetic – is inescapably shared with others and that these others may have interests in whether or not it is

⁴⁴ Taylor 2012.

disclosed and to whom. It also leaves space for recognising that the meaning and significance of particular bioinformation to the information subject may depend – perhaps a great deal – on what it reveals about others and their relationships to the subject, how it might be used to group the subject with or distinguish them from others, or how it might contribute to characterising groups to whom the individual belongs. Furthermore, personal bioinformation may be derived from analysis of data gathered wholly, or in part, from other people. For example, genetic information may be understood as being about a particular individual, even though they themselves have not undergone testing, where its relevance to them can be inferred from family history or tests conducted on close blood relatives. Similarly, with the increasing use of big health data, AI, and machine learning in healthcare and research, it is increasingly likely that personal bioinformation, such as disease susceptibility estimates, will be based upon risk profiles built from data collected from many, perhaps thousands, of other individuals.⁴⁵ For the purposes of the following discussion then, being ‘personal’ does not preclude this information being shared with others, being personal to more than one person, or being derived from data from sources other than the body of the individual in question. What is relevant is that it has been interpreted to be about at least one identifiable individual – whom I shall refer to as the ‘information subject’ – in a way that is apparent, or easily discoverable, to both whoever currently controls it and the information subject if they were to encounter it. The focus of this enquiry is on the effects of such encounters on information subjects’ capacities to develop, understand, and occupy their identities. However it is based neither on an individualistic picture of bioinformation nor on an individualistic conception of identity and identity interests.

Encounters with Bioinformation

The kinds of bioinformation with which this book is concerned include those about an individual’s past, present, and possible future health and well-being; their susceptibility to disease and illness; the states, functioning, capacities, and dispositions of their bodies and minds; and their biological relationships to and commonalities with others. These may be generated through healthcare, research, commercial, administrative, or recreational activities. They may be conveyed verbally or in writing.

⁴⁵ Raghupathi and Raghupathi 2014.

They could comprise text, numerical data, figures, charts, or images – as in the case of brain or body scans. As this suggests, personal bioinformation ranges from the complex, detailed, and technical – such as that conveyed by a magnetic resonance imaging (MRI) scan that requires specialist knowledge and techniques for its generation and interpretation – to that conveyed by bald statements such as ‘he is your biological father’. In many cases, these kinds of information will be conveyed by another person. However, the following discussions will also apply to alerts or findings communicated directly to users by devices such as medical implants and wearable health-tracking devices, by mobile device apps, or by the online portals of DTC services.

Of course, the vast majority of the information and knowledge we have of our embodied and biological characteristics are not obtained from other people or devices, and our access to them does not require expert analytical techniques – rather, they are acquired directly from our own senses. To be of interest for this enquiry, personal bioinformation does not necessarily need to uncover what is deeply hidden or convey wholly new insights. Some of it may be confirmatory of, complementary to, or at odds with knowledge we already have about our health or traits. The salient feature is that the bioinformation under scrutiny has an external source, and other actors’ choices and agency lie between it and our encounters with it – hence practical, legal, and ethical questions about disclosure and access arising at all. These other actors include those who generate, hold, and manage our bioinformation and those who devise policies about what will be offered and fed back to information subjects. These actors may be individuals operating in their professional or institutional capacity, such as clinicians or health researchers. They might include developers and engineers who design the algorithms and information interfaces that determine what our wearable devices tell us about our sleep, activity, blood oxygen, or mood and in what format. At an institutional and state level, relevant actors might be research ethics committees, professional bodies responsible for – for example – deciding which health screening programmes should be run, or regulators who determine what kinds of tests a DTC genomics company can market. These actors might also include private individuals, for example, a parent who knows that their own carrier status for Huntington’s disease means that their children each have a 50 per cent chance of being affected.

The following discussions are concerned to a considerable extent with circumstances in which access is not inevitable or is somehow obstructed – as in the example of Ilana’s experience above. But they are

no less pertinent to circumstances such as Sam's, in which information is readily or routinely available to its subject. The account of identity-related interests to be developed over the following chapters will look at identity-related reasons both for and against disclosing bioinformation. It will characterise interests that need to be weighed alongside other considerations currently guiding disclosure decisions and require us to think not only about *whether* to disclose but also about *how* information is communicated. The following list provides some examples of the kinds of questions and debates into which the following discussions might feed:

- What is the scope of research data repositories' or researchers' ethical duties to return individually relevant research findings to participants?⁴⁶
- When should genetic screening be offered for conditions that cannot be effectively treated?⁴⁷
- Which factors should healthcare professionals consider when encouraging a patient to inform family members about a shared risk of genetic disease or in deciding when it is acceptable to break the patient's confidence if they refuse?⁴⁸
- Should individuals conceived via mitochondrial replacement therapy be entitled to know the identities of the donor of the egg that provided their healthy mitochondria?⁴⁹
- Which kinds of tests – using which methods and for which conditions and traits – should consumers be able to access through DTC genomics or imaging services?⁵⁰
- When are quantified health, well-being, and behavioural data supplied by wearable personal technologies beneficial or detrimental to their users, and what kinds of user interfaces might influence their value?⁵¹
- Which categories of patients would be suitable candidates for the use of implanted smart technologies, such as brain-computer interfaces (BCIs) that provide predictive information about the onset of adverse health events such as seizures?⁵²
- What are the utilities and risks of digital phenotyping techniques, which use algorithmic analysis of our online activity and behaviours

⁴⁶ Eckstein et al. 2014

⁴⁷ Roberts 2012.

⁴⁸ Dove et al. 2019.

⁴⁹ Appleby 2018.

⁵⁰ Bunnik et al. 2011.

⁵¹ Kreitmair 2019.

⁵² Gilbert et al. 2019.

captured by our digital devices to make inferences about, for example, our mental health?⁵³

- What concerns might be raised by novel categorisation of people by the algorithms used in, for example, precision medicine or public health surveillance?⁵⁴

This list is indicative, rather than exhaustive. It includes examples of circumstances in which legal and ethical debates about information provision are ongoing, as well as those in which such debates are emerging, or assumed to be long since settled. Some of these debates are ones in which identity impacts are already invoked with greater or less cogency, while identity talk is wholly absent from others. What these questions have in common is that they illustrate contexts in which, I will argue, consideration of clearly and robustly conceptualised identity interests are likely to be critical to ethical information governance. There will not be space to describe in detail the specific implications of my arguments for each of these questions in the following chapters, but they provide indications of the kinds of contexts in which the coming analysis and recommendations are intended to apply. There are, however, three areas in which I will explore the potential impacts and associated identity interests in some depth.

Three Illustrative Examples

In Chapter 5, I will explore in detail information subjects' views and experiences of encountering three kinds of bioinformation – as reported in published empirical studies – to illustrate and sense-test my arguments. These will be the following:

- *Knowledge of having been conceived using donor gametes (sperm and/or eggs).* Donor-assisted conception is used by some intended parents who have been unable to conceive with their own gametes because of infertility or because they are single parents or in same-sex relationships.⁵⁵ In the UK this may involve treatment at a licensed fertility clinic or use of privately sourced donor sperm for self-insemination.
- *Results from testing for genetic variants associated with increased susceptibility to serious multifactorial diseases.* Genetic testing

⁵³ Huckvale et al. 2019.

⁵⁴ Vayena et al. 2018.

⁵⁵ Where single men and gay couples use donor gametes, surrogacy will also be used.

involves the analysis of blood or tissue samples to detect ‘the presence or absence of, or alteration in, a particular gene, chromosome or gene product’.⁵⁶ Based on this – and often other data such as family history of disease – an individual’s susceptibility, typically as lifetime percentage risk, is calculated. These tests are not predictive but provide probabilistic risk estimates. The tests I will focus on are those to detect mutations of the *BRCA* gene, associated with an elevated risk for breast and ovarian cancer, and variants of the *APOE* gene, associated – though less strongly – with elevated risk of late-onset Alzheimer’s disease in some populations.

- *Findings from psychiatric applications of neuroimaging.* This concerns research uses and potential clinical applications of neuroimaging to gather data about functional and structural features of participants’ brains, from which – in combination with other data sources and using machine learning techniques – researchers hope that predictive, diagnostic, or prognostic inferences to participants’ mental health status, relating to conditions including depression, psychosis, and schizophrenia, will be derivable.⁵⁷

In Chapter 5, I will return to describe the characteristics of these three categories of bioinformation further and to outline the extent to which each is currently accessible to information subjects and on what grounds. I have not selected these examples because of their assumed or preeminent identity significance. Rather, they have been chosen to help paint a picture of the diverse nature of identity impacts and how these coincide or differ across different kinds of bioinformation. This will then provide clues to how we might generalise beyond these examples to other kinds of bioinformation and identify the variables on which identity value and significance depend. Before I can engage with questions of identity impacts, however, I need to explain the sense in which ‘identity’ will be used in this enquiry.

Identity

This book is an interdisciplinary project drawing on arguments, examples, and conceptual frameworks from bioethics, philosophy, law, and the social sciences. Across these disciplines, ‘identity’ is used in myriad divergent and overlapping ways. Efforts in the literature to

⁵⁶ Pinto-Basto et al. 2010, p. 33.

⁵⁷ Lawrie et al. 2019.

distinguish its various connotations generate taxonomies that themselves lump and split the various uses of the term differently. As Adam Henschke observes in developing his own taxonomy, ‘different disciplines will form different ideas when a phrase like “genetic information is necessary for identity formation” is used’.⁵⁸

Amongst these ‘different ideas’ of identity are several that are perfectly cogent, thought-provoking, and ethically and legally significant in their own way but nevertheless differ from my central focus in this book. Therefore, some disambiguation is needed. Details of the particular ‘narrative’ conception of identity, on which I will ground my arguments, will receive close attention in Chapter 3. Here I wish to start by drawing some more basic lines of distinction and connection between the understanding of identity that comprises the heart of this project and other prominent senses. The following taxonomy is not intended to be definitive, but it usefully maps the landscape of common usage in medical law and bioethics for my present purposes.

First, I want to set aside two senses of identity that will not be addressed by this book – *species identity* and *public persona* or *image*. Although bioinformation could be potentially implicated by concerns about each of these senses of identity – for example, where genomic analysis is used to help answer questions about the humanness of a human/animal chimeric embryo or where publicity reporting a celebrity’s ill health damages their reputation – these concerns are not engaged by an information subject’s *own* access to their personal bioinformation and they are not my focus here.

Numerical Identity

Biometric data in a passport is used to identify whether the passenger at the immigration desk is who they claim to be, and a DNA profile may be used to find out whether the suspect held in custody is the person who left a bloodstain at the crime scene. These examples pertain to what is referred to as *numerical identity*, that is, the metaphysical or logical kind of identity concerned with questions of sameness.⁵⁹ Here, sameness may be understood in terms of ‘persistence’ or ‘reidentification’ – that is, questions about when one thing is the very same entity as that located at a different time or in a different context. It is also used to capture the corresponding idea of ‘individuation’, which concerns what makes

⁵⁸ Henschke 2010, p. 450.

⁵⁹ Parfit 1984.

something itself and distinct from other things. In the examples above, personal bioinformation is used to ascertain whether the person in the custody cell or at the border check is the very same as the person who was at the crime scene or who is described in their travel documents. Uses and abuses of bioinformation in ascertaining numerical identity are often proper concerns of bioethics and law. However, situations in which someone would have an interest in accessing bioinformation *about themselves* to determine their *own* numerical identity – to answer the question ‘was that me?’ – are likely to be quite limited. Bioinformation such as distinctive birthmark or DNA analysis might perhaps serve such a purpose when someone wishes to ascertain whether they are the individual captured in an old photograph when records and memories are unable to make this connection.⁶⁰ Such examples notwithstanding, matters of strict, logical sameness or difference are not, or at least not directly, my concern here.

Personal Identity

Questions of numerical identity where these apply specifically to *persons*, and particularly to questions about the sameness or reidentification of persons over time and through physical or mental qualitative changes, are commonly termed questions of *personal identity*.⁶¹ Concerns about personal identity in this sense notoriously arise in bioethics and medical law when, for example, we ask questions about the continued validity of consent to treatment or an advanced care directive when someone has lost capacity between the point of giving consent or making their directive and the relevant intervention. These questions arise especially when the person has undergone marked cognitive or personality changes. These kinds of questions are often treated as ones about logical sameness – about when the person-as-entity at an earlier time can be understood as being the very same person-as-entity at a later time.⁶² However, the validity of an advanced directive can also be interpreted as a question that relates to a somewhat different sense of personal identity, one closer to that with which I am concerned in this book, as I shall now explain.

Perhaps confusingly, the phrase ‘personal identity’ is used in both ordinary language and philosophy to capture not only the logical sameness of persons but also the set of qualities that characterise a person,

⁶⁰ Strictly speaking, this would only reliably confirm personal identity if one adopted a bodily criterion for the persistence of a person.

⁶¹ Schechtman 2014.

⁶² Cf. Buchanan 1988.

those that make them who they distinctively are and different from other people. By teasing apart the distinct kinds of logical, practical, and ethical concerns falling under the banner of 'personal identity', Marya Schechtman and Catriona Mackenzie have contributed to reducing the potential for this confusion while shining much-needed light on matters of identity that had been occluded by a focus on numerical identity.⁶³ In discussing the relevant distinctions, Mackenzie suggests that when we ask questions about, for example, the continued validity of someone's wishes after they have lost competence or undergone a profound change in values, we are usually chiefly interested with what she terms 'practical and evaluative considerations', such as whether the wishes and values of the younger person should bind those of the older, or which treatment option accords with the kind of life the younger person hoped to lead in their later years.⁶⁴ These authors argue that it is a mistake to imagine that these questions can be appropriately or wholly addressed by thinking about whether strict conditions for the metaphysical sameness of an entity at two different times are fulfilled. Rather, what we are usually concerned about – and, indeed, what someone writing an advanced directive is themselves likely to be concerned about – is the extent to which the older person remains relevantly like the younger person, shares the same values and hopes, and feels a connection with and understanding of their younger self. We are interested in the extent to which the younger self's imagined projection of their later self's values and priorities was in line with those they in fact come to hold. These kinds of concerns engage what Schechtman's terms the 'characterization question' – that is, the question of which characteristics, beliefs, values, and actions are 'truly attributable' to a person and make them the particular person they are.⁶⁵ And as such, Schechtman argues, the answer to whether someone's identity remains the same will admit of degrees and have irreducibly diachronic or evolving aspects that are not captured by trying to see if two frozen 'time slices' or snapshots of a person at different points in their life match.⁶⁶ Further explanation of what it means for matters of identity to admit of degrees or have importantly diachronic aspects will have to wait until Chapter 3.

⁶³ Mackenzie 2008a; Schechtman 1996.

⁶⁴ Mackenzie 2008a, p. 1.

⁶⁵ Schechtman 1996, pp. 74, 76.

⁶⁶ Schechtman 1996, p. 77.

Practical Identity

Schechtman's and Mackenzie's analyses serve to bring to light the sense of identity that comprises the heart of my enquiry here. This book is concerned with the impacts of encounters with personal bioinformation on identity understood as *characterisation*. An individual's 'identity' in this sense refers to the constellation of characteristics that are really *theirs*. It captures those characteristics that make them the particular individual that they are, about which we may sensibly ask what role the characteristics play in distinguishing and defining that individual.⁶⁷ It is the impacts of encounters with personal bioinformation on identity in the characterisation sense that I will be concerned with in what follows. While detailed discussion of what these impacts look like and why they matter is the subject of the chapters to come, it is possible to get at least a sense here of how personal bioinformation – for example, a diagnosis of diabetes or the revelation that one's father is not one's genetic parent – could shape insights and understandings that feed into how one characterises oneself.

Three features of identity, understood in this characterisation sense, are key to the arguments that I will go on to make. The first two of these are that the narrative account of self-characterisation is of a *normative* and *practical* kind.⁶⁸ That is, according to this conception, identity is not merely an inert label or set of descriptors. Rather one's identity provides the foundation for individual perspective on and engagement with the world. It is, in Christine Korsgaard's words, '[the] description under which you value yourself, a description under which you find your life to be worth living and your actions to be worth undertaking'.⁶⁹ Our practical identities provide the frameworks for our evaluations of ourselves, our circumstances, and our motives. They provide us with reasons to act in some ways rather than others. And they are themselves constituted, or undermined, to the extent that we do, or do not, act in these ways.⁷⁰ As Mackenzie notes, this makes our practical identities 'both a precondition for and a product of our agency'.⁷¹ I will return to explain further what this entails in Chapter 3. The third crucial feature, also to be described further in Chapter 3, is that I will be using 'identity' to refer to a single – albeit a complex and multifaceted – thing, bound together as

⁶⁷ Schechtman 1996, p. 77.

⁶⁸ Korsgaard 1996.

⁶⁹ Korsgaard 1996, p. 101.

⁷⁰ Korsgaard 2009.

⁷¹ Mackenzie 2008a, p. 11.

a narrative. Someone's identity is to be understood as the totality of who they are and the myriad interacting and intersectional traits and experiences by which they characterise themselves and that make them who they are.

Social Identity

When I talk of 'identity' then, I intend it to be understood in this global sense, rather than to refer to aspects of who someone is or to specific descriptors. As such, it differs from the concept of *social identity*, where this refers to particular social identifiers, group memberships, roles, or markers of belonging and exclusion that we ourselves and others might use to describe, group, or distinguish us – such as gender, ethnicity, sexuality, political affiliation, nationality, social class, or religious faith.⁷² Having said this, personal bioinformation will often play a part – for better or worse – in the adoption, affirmation, or allocation of these group and social modes of identification in ways I will go on to describe. And our social identifiers and group memberships are very likely to be amongst the prominent characteristics that make up identity in the practical, multistranded sense with which I am concerned. In distinguishing identity in a global characterisation sense from social identity, then, my intention is not to claim these concepts are wholly unconnected.

Practical Self-characterisation

Why is it that I will focus on identity in this global, practical 'characterisation' sense in this book? The short answer is that – as I will go on to demonstrate – it is this kind of identity that is most plausibly and profoundly impacted by information subjects' own encounters with bioinformation about themselves. And it is with respect to identity understood in this way – what it looks like, how it changes, whether it is sustainable, what it feels like to inhabit, and its role in our practical lives and lived experiences – that our interests are often most plausibly and profoundly engaged. As Schechtman argues, characterisation captures the respect in which 'personal identity matters to us at all'.⁷³ By this, she means that many of the ethical and practical questions with which questions of identity tend to be concerned – for example, the questions of whether I would still exist following the loss of cognitive capacities or

⁷² Jenkins 2014.

⁷³ Schechtman 1996, p. 1.

which of my behaviours I may be held morally responsible for – are properly answered by reference to the degree of continuity and coherence amongst the combination of characteristics that make us who we are.⁷⁴ This is what is understood to be in jeopardy and what we are concerned about when we talk about someone having an ‘identity crisis’ or wishing to express ourselves and act in ways that are ‘true to who we are’.⁷⁵ We are invested in the qualities that make us the particular individuals we are, in our capacities to maintain or change these, and in our abilities to inhabit and enact them. For these reasons, this is the version of identity where the most plausible, interesting, far-reaching, and ethically pressing questions about our interests in our encounters with bioinformation about ourselves arise. I will argue that personal bioinformation can play a critical part in our abilities to construct, make sense of, and inhabit our own accounts of who we are and what we are like. To be more specific then, this book is concerned with identity in the sense of *self*-characterisation.

Shared and Group Identity

It will be helpful before closing this chapter to clarify some questions that lie outwith the scope of the discussions that follow, including questions pertaining to the relational impacts of bioinformation access. As indicated at the start of this chapter, this book is not directly or chiefly concerned with the impacts of *other* people’s or institutional access to and (ab)use of personal bioinformation on information subjects’ identities. This is not to deny that these impacts are often significant and warrant serious ethical attention. For example, retention on a forensic database of the genetic data of suspects who have never been charged, or uses of biometric data by border forces to ‘verify’ refugees’ countries of origin, could be degrading or alienating and undermine valued modes of self-definition that are core to the information subjects’ self-conceptions.⁷⁶ Nor will this book address cases in which others’ uses of our personal bioinformation could negatively affect group identity as, for example, in the case of genetic research involving the North American Havasupai people. The Havasupai’s ancestral origin story and religious beliefs, key foundations of their collective understanding of who they are,

⁷⁴ In her more recent work, Schechtman’s position has evolved. She still holds that our narrative self-characterisations are germane to the phenomenology of selfhood and to practical questions but no longer maintains that they are sufficient to answer all questions about the metaphysical identity of persons. See Schechtman 2014.

⁷⁵ DeGrazia 2005.

⁷⁶ See, for example, Ajana 2010; Machado and Granja 2020.

were contradicted by non-consensual genetic analyses of blood samples several members had contributed while participating in research purporting to explore the incidence of diabetes.⁷⁷ Similarly, I will not directly address ways in which information subjects' access to or uses of their own personal bioinformation might affect the identities of other individuals, or of the groups to which they belong. For example, someone living with a rare genetic disease might agree to participate in research investigating how preimplantation diagnosis could be used to screen for and select against the genetic variant responsible – research that others living with the condition might experience as stigmatising and discriminatory. Each of these (ab)uses of personal bioinformation could have ethically significant consequences for individual or group identities. Other writers have valuably discussed the potential identity threats arising from the kinds of second- and third-person transactions in and uses of personal bioinformation just described. And much of what I will go on to say will have indirect implications for understanding and characterising these kinds of impacts on our individual and shared identities. But it is first-person access and first-person impacts with which I am primarily concerned in this book.

In placing these wider questions outwith the scope of this project, it may seem that I am embarking on an unsatisfactorily and unrealistically individualistic journey. As Heather Widdows observes – with specific reference to genetic information – conceiving of this information as belonging only to us and engaging our interests as discrete individuals risks missing or misrepresenting the shared values and interests at stake, including those relating to identity. As such, it risks failing to provide adequate foundations for the protection of these interests.⁷⁸ This is an important objection. And, while it is most obviously pertinent to inherently shared genetic information, uses of big health data and bioinformatics mean that we are all increasingly implicated in the processing and use of each other's data. Potential identity-related interests in the uses of bioinformation are not, therefore, limited or reducible to those of people who act as information sources. For example, as Widdows observes, we risk missing the particular nature and severity of the harm done to the Havasupai people, if we conceive of the harm to their group identity solely in terms of its impacts on individual members.⁷⁹ Recognising the

⁷⁷ Van Assche et al. 2013.

⁷⁸ Widdows 2013.

⁷⁹ Widdows 2013.

reality and significance of group identity interests, however, does not preclude recognising that there are important, neglected ethical matters to attend to in respect of the identity impacts of information subjects' own encounters with shared categories of bioinformation. And it is the task of this enquiry to draw attention to and address these. However, taking Widdows's warning seriously, if we are to understand the nature and range of these impacts on individuals, we will need to look beyond the individual taken in isolation.

The account of identity to be presented in this project is not an individualistic one. The inherently relational nature of identity development, and the roles played by bioinformation in this, will be central to my argument. Our identities are inextricably bound up with the understandings, knowledge practices, and identities of others and of the groups to which we belong or to which we are assumed to belong by others. By this, I mean at least three things. First – as I will go on to describe – we do not and cannot build our identities in isolation from our relationships with others and the ways they recognise and respond to our own self-conceptions or fail to do so. Second – as will be illustrated in Chapter 5 – how we interpret personal bioinformation and the effects it has on our identities cannot be separated from our relationships, relational roles, and group memberships. Third – as I will describe in Chapter 6 – the interpretations and significance with which others invest particular kinds of personal bioinformation will inform or shape our perceptions of its relevance to our identities and the kinds of impacts it has.

1.3 Guide to the Following Chapters

Over the following chapters, I will develop and defend the argument that because of the possible impacts – both positive and negative – of personal bioinformation on the inhabitability of our identity narratives, we have ethically significant interests in respect of whether and how we are able to access a wide variety of such information. The form and significance of these impacts are shaped by the embodied and socially embedded nature of our lives. I will argue that the identity-related interests characterised by this argument are sufficiently strong to give rise to responsibilities amongst those who hold potentially identity-significant personal bioinformation about us and to be taken into account by information disclosure policies and practices. The strength of these interests and the scope of these responsibilities will vary depending on the type of bioinformation

in question, as well as individual, contextual, relational, and institutional factors. Laws, policies, and practices governing information subjects' access to bioinformation will need to remain responsive to this variation. For this reason, the task of specifying precise policy or legal reforms across every context in which decisions about access to and disclosures of personal bioinformation arise lies beyond the capacities of this project. My central aim is to provide the conceptual basis and ethical framework on which any such reforms could be grounded. Without such a foundation, attempts to offer robust, defensible, and non-arbitrary protection for our informational identity interests in policy or law are jeopardised from the start. The following provides a brief roadmap to the chapters that follow.

Chapter 2 establishes the practical, conceptual, and normative gaps that this book seeks to fill by exploring the limited existing opportunities and legal entitlements that information subjects have to access personal bioinformation on explicitly identity-related grounds and the ways that identity interests are reflected in these provisions. This chapter then reviews the extent to which existing theoretical framings of impacts of particular kinds of bioinformation in our self-characterisations are capable of providing satisfactory alternatives to the law's exceptionalist and sometimes essentialist representation of our identity-related interests in bioinformation. It identifies the need for a clear, robust, and non-exceptionalist account of the relationship between identity and personal bioinformation.

Chapter 3 builds on the suggestion, with which Chapter 2 closes, that a conception of identity as self-narrative could provide a promising and plausible basis for understanding the nature and significance of the roles of personal bioinformation in our identities. Following this premise, it reviews the key features of various prominent philosophical accounts of narrative constitution of practical identity. In particular, it highlights the normativity implicit in many of these accounts, setting out both the role that an identity narrative plays in supporting important experiential, evaluative, and practical capacities and also the qualities that an identity-constituting narrative will exhibit if it is to function in this way.

Chapter 4 presents the case that our lives and experiences are inescapably those of embodied beings. As such, it argues that any satisfactory theory of narrative self-constitution must be one that takes account of our embodiment and what this means for the kinds of self-narratives that we construct and that equip us to navigate our lives. This chapter presents the argument at the heart of this book: that personal bioinformation has critical roles to play in helping us to construct self-narratives that are

capable not only of remaining coherent, meaningful, and inhabitable in the context of our embodied and socially embedded lives, but also of supporting us in making sense of and navigating our experiences.

Chapter 5 examines in detail information subjects' attitudes to and experiences of encountering three different kinds of personal bioinformation, as reported by a range of empirical social science studies. These three kinds of information are, as described above: disclosures of donor conception; results from genetic tests indicating disease susceptibility; and findings from psychiatric applications of neuroimaging. The aims of looking to empirical accounts are threefold: to illustrate and bring to life my theoretically based claims about identity roles of bioinformation presented in Chapter 4; to sense-test these claims against people's actual experiences; and to refine the claims in light of reported expectations and reactions.

Chapter 6 builds upon my characterisation the nature and strength of our foundational interest in developing inhabitable self-narratives to specify our associated information-related identity interests in whether and how we are able to access personal bioinformation. In doing so, it moves beyond the general picture of the narrative roles of personal bioinformation taken as a broad category to develop a more granular and practically applicable picture of what makes different kinds of bioinformation in different disclosure contexts more or less pertinent, valuable, or detrimental to our identities. It reviews the grounds for recognising the ethical significance of our identity interests in bioinformation, and establishes that these are not coextensive with or reducible to the other interests that currently inform disclosure policies and practices, thus making the case for the need to attend to these interests in their own right.

Chapter 7 spells out the practical implications of the analysis and arguments of the preceding chapters by setting out the basis and extent of the responsibilities of those who generate or hold our personal bioinformation to manage its disclosure to us in ways that take our identity interests seriously. These responsibilities involve recognising and responding to these interests appropriately, whilst weighing them alongside other interests and concerns. This chapter emphasises the necessity of attending to identity impacts not only in decisions about what is disclosed and when but also in planning the context and manner of disclosure.

Chapter 8 concludes this book by indicating what the arguments presented across the preceding chapters could mean for disclosure policies and practices, in general terms and in relation to five select areas in which current debates about the ethics of providing access to or withholding personal bioinformation are particularly live and pressing.