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## 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.<sup>1</sup> 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

<sup>1</sup> 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.<sup>2</sup> It is about the particular kinds of interests that are affected by

<sup>2</sup> See Chadwick et al. 2014.

‘knowing’ – or not – and also by the manner and context in which information subjects come to know.<sup>3</sup> 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.<sup>4</sup> 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.<sup>5</sup> 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,

<sup>3</sup> 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.

<sup>4</sup> See, for example, Raghupathi and Raghupathi 2014; Sharon and Lucivero 2019.

<sup>5</sup> 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.<sup>6</sup>

The collection and analysis of information from and about our bodies are not, however, limited to healthcare or health research settings.<sup>7</sup> 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.<sup>8</sup> 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,<sup>9</sup> or behavioural profiles from existing data collections that may be applied to people far beyond those who were the sources of the original data.

<sup>6</sup> Xafis et al. 2019.

<sup>7</sup> Sharon and Lucivero 2019.

<sup>8</sup> Henschke 2017.

<sup>9</sup> 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.<sup>10</sup> 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.

<sup>10</sup> 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.<sup>11</sup> 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.<sup>12</sup> 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.<sup>13</sup> 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.<sup>14</sup> 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.<sup>15</sup>

<sup>11</sup> See, for example, Carter et al. 2015; Dubov and Shoptawb 2020.

<sup>12</sup> Chan et al. 2017.

<sup>13</sup> Eckstein et al. 2014.

<sup>14</sup> Chadwick et al. 2014.

<sup>15</sup> 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.<sup>16</sup> 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.<sup>17</sup> 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.<sup>18</sup> 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.<sup>19</sup> 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.<sup>20</sup> 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.<sup>21</sup>

<sup>16</sup> 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.

<sup>17</sup> Wolf et al. 2008; UK National Screening Committee 2015.

<sup>18</sup> Bunnik et al. 2011.

<sup>19</sup> Laurie 2002, p. 67.

<sup>20</sup> 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.

<sup>21</sup> 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.<sup>22</sup>

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.<sup>23</sup> UK courts have erred towards protecting children's right to know their genetic parentage, even in absence of existing social bonds.<sup>24</sup> Searches for genetic parents populate the plots of literature and films.<sup>25</sup> 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

<sup>22</sup> 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.

<sup>23</sup> 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.

<sup>24</sup> Fortin 2011.

<sup>25</sup> The feature film *The Kids are All Right*, in which adolescent siblings build relationships with their sperm donor, and the Scottish poet Jackie Kaye'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.<sup>26</sup> 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’.<sup>27</sup> 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.<sup>28</sup>

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.<sup>29</sup> For example, Christine Hauskeller considers, with some concern, the ways genetics could be used to naturalise and reinforce social distinctions.<sup>30</sup> 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’.<sup>31</sup> Academic discussions of the

<sup>26</sup> 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.

<sup>27</sup> iSpot.TV websites ‘23andMe TV Commercials’ [www.ispot.tv/brands/Ias/23andme](http://www.ispot.tv/brands/Ias/23andme) (accessed 18 July 2021).

<sup>28</sup> O’Connor et al. 2012; Racine et al. 2005.

<sup>29</sup> 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’.

<sup>30</sup> Hauskeller 2004.

<sup>31</sup> 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.<sup>32</sup> 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.<sup>33</sup> 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.<sup>34</sup> 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.<sup>35</sup> Either way, this debate demanded closer scrutiny of the nature of any supposed identity value or detriment.

<sup>32</sup> Rose and Abi-Rached 2013; Walker 2012.

<sup>33</sup> 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.

<sup>34</sup> I examine these reported experiences in detail in Chapter 5.

<sup>35</sup> For example, de Melo-Martin 2014.