
Locating Identity Interests

6.1 Introduction

In this chapter, I will draw together the various elements of the preceding discussions to set out what I take to be the nature and scope of our identity-related interests in accessing personal bioinformation. These are the interests that, I wish to argue, need to be taken into account by those who generate and manage our personal bioinformation when making decisions or developing laws and policies about disclosing this information to us, the subjects of this information. The characterisation of identity interests that follows is supported by three pillars. The first of these is the normative conception of a narrative self-constitution set out in Chapters 3 and 4. This entails that an identity narrative is not just something inert that we have by default but something that may fare better or worse and serve us better or worse. The second is the fact that we lead inescapably embodied and social existences that shape our experiences, the kinds of stories we can and do tell about ourselves, and the context in which we inhabit and enact these stories. The third pillar is provided by the insights provided by the three illustrative examples explored in the previous chapter. In what follows I will first set out the underlying interest in narrative self-constitution and its various facets, before specifying three information-related interests that are predicated upon and serve this more basic one. I will then unpack several features that are relevant to the practical application of these interests, including the qualities of the particular kinds of bioinformation that are likely to serve them. This chapter concludes by reviewing the ways in which the appropriate characterisation and recognition of these identity interests add an important and unmet dimension to the ethical landscape of bioinformation governance.

6.2 Our Identity Interests

To say someone has an interest in a particular state of affairs or outcome is to say that they have something at stake in it; they have something to

lose or gain depending on whether it comes to pass or how it goes.¹ They are harmed if their interests are not met, though the way and degree to which this is so will depend on the nature and strength of the interests in question. Our interests and desires will frequently overlap. However, in what I go on to say, I will take it that an interest is not precisely the same as a desire or preference insofar as many of our interests, particularly those predicated on the conditions for our basic survival and functioning, hold irrespective of particular wishes. Interests can be of different strengths. And they may be ephemeral or life-long, vital or trivial. We may have interests that are specific to particular roles or situations – for example, a clinical trial participant with an unmet treatment need has an interest in being assigned to the group receiving the active therapy rather than the placebo control. We may also have those that apply to everyone simply by virtue of being human, for example, the interest in being mentally and physically healthy. As this suggests, some interests are more fundamental than others. And the fulfilment of some context-specific interests – for example, that in being assigned to the active arm of a trial – may serve other more basic ones – such as being healthy – and gain their ethical significance from this more basic interest. At this more fundamental end of the spectrum, interests shade into ‘vital interests’ or ‘needs’, which must be fulfilled if we are to survive.

I will take it that the identity interests described below are ones held by everyone in virtue of the kinds of embodied, social beings we are and that they are ethically significant because of their connection to the development and exercise of the kinds of experiential, evaluative, and practical capacities that contribute rich, fulfilling, and engaged lives, as described in Chapter 3. As such, I will argue they are not as strong as the vital interests related to basic survival, such as those for food or shelter. However, their fulfilment is core to our well-being, to leading a flourishing life, and to pursuing other important interests and goals.

What I have just said might suggest that the language of rights would be appropriate here. However, I will not talk in terms of identity rights for three reasons. First, I take it that interests are conceptually prior to rights. Characterising the nature of interests is, therefore, the more immediate and illuminating task. It is where the values, objects of value, activities, or relationships at stake are unpacked and described. Second, rights talk brings with it a kind of endgame inflexibility that implies stand-offs between putatively competing rights and can obscure

¹ Feinberg 1984.

the importance of the ways in which they are fulfilled. Third, rights imply inevitable correlated duties. While I will argue in the next chapter that our information-related identity interests are often sufficiently strong to create responsibilities for others to meet them, I do not want to short-circuit the discussion of why and when these responsibilities obtain by using the language of entitlement.

Fundamental Identity Interest

Before I can characterise our specifically information-related interests, it is necessary first to establish the more basic interest in narrative self-constitution that they serve. On the basis of the picture developed over the preceding chapters, my claim is that we each have a *fundamental interest in developing and maintaining an inhabitable self-narrative, that is, one that is coherent, sustainable, meaningful, and comfortable when occupied and enacted in the course of our embodied and socially embedded lives.*

I take it that each of the four adjectives – coherent, sustainable, meaningful, and comfortable – signals a distinctively important quality, but that these are also interdependent such that it may not be possible to realise any to a satisfactory degree in the complete absence of others. At the same time, they also place limits on each other in ways discussed further below. Collectively, they comprise the quality I will refer to as ‘inhabitability’. I will say a little more here about what is entailed by each of these qualities.

The first of these – *coherence* – was addressed in detail in Chapters 3 and 4, and I will not rehearse all of those discussions here. To recap, it may be recalled that I am using coherence to encompass connotations of both integration and intelligibility. These qualities matter because our self-narratives provide the perspective from which we view and navigate the world and the foundation for working out who we are and what matters to us. The importance of narrative coherence is illustrated across all three illustrative examples in the previous chapter, where it is captured, for example, by the welcome explicability of family memories and relationships, reconciliation of symptoms with self-descriptors, management of uncertainty, and validation or bearing witness to the suffering of mental illness. Achieving narrative coherence does not require a neat structuring of contents, homogeneity, or total transparency. Perfect coherence is not required, probably not attainable, and may not always be desirable where it entails ignoring the tensions that may accompany

intersectionality or forcing a fit between contrasting experiences. But a realistic and valuable level of coherence does require that different aspects of our narratives should have interpretive access to each other and be reasonably explicable in light of our experiences of our own embodiment and environment. We also benefit to the extent that our self-characterisations are intelligible to others, as this allows us to occupy and sustain them in our relationships and interactions. However, given that others may refuse or lack the imagination or tools to recognise our self-narratives, our own capacities to make sense of them in the light of our experiences is generally of principal importance.

Closely related to this is the requirement that our self-narratives are *sustainable*. By this, I mean that they should be resilient and – as far as possible – equipped to maintain or regain their integrity and intelligibility when confronted by our experiences, including experiences of, and mediated by, our health and bodies. Identity narratives suffer when they are built on precarious foundations, for example when they include fundamental misconceptions about the basis or nature of the characteristics core to our stories, which render them vulnerable to extensive disturbance by lived experiences. However, sustainability does not require that our identities remain rigidly unchanging. On the contrary, to remain coherent and intelligible and useful frameworks for interpreting and navigating our lives, they must respond to our experiences and evolve accordingly. Sudden or big changes in our lives, such as the onset of serious illness, may precipitate dramatic changes in our self-narratives. These disruptions – particularly when they sever threads that are bound deeply and widely into the fabric of our self-conceptions – may render our existing narratives unintelligible or hard to inhabit. And this damage may be disabling or challenging to resolve. However, narrative disruption is not necessarily unwelcome or irresolvable, as illustrated by some individuals' evolving experiences of learning of their donor origins or of elevated risk of serious disease. What matters is that we have access to the resources – within ourselves or in the form of personal, epistemic, and hermeneutic support – to restore a reasonable degree of coherence, meaning, and comfort following disruption.

Our self-narratives best support our experiential, practical, and evaluative capacities and allow us to locate ourselves in our past and project ourselves into our own futures when they contain characteristics, roles, and experiences that we find *meaningful* or *worthwhile*. This does not mean they have to be wholly concerned with highbrow or other-regarding concerns. But we benefit when our narrative 'contents' motivate us and

provide us with a sense of what we value. These kinds of contents contribute to the kind of self-esteem that equips us with the drive and confidence to be able to enact and develop our values and life projects in ways that permit continuing identity development. They also support the kinds of enduring commitments – to people, projects, or causes – that are not only valuable in themselves but also help support narrative coherence and sustainability over time. The examples in the previous chapter illustrate self-descriptors and relational roles that provide meaning, shape, and direction to people's self-conceptions that are grounded in, often shared, biological traits – those of being a parent, a member of a family affected by Alzheimer's, or *BRCA* activist. If someone is frustrated in their enactment of meaningful narrative contents, or if valued roles and descriptors are threatened or undermined by new information or circumstances, then something important is lost.

Meaningfulness is important, but it would be artificial and set the bar unreasonably high to demand that all aspects of our identity narratives are a source of joy and pride. As Mary Walker and Wendy Rogers note, '[e]lements of one's self-conception are not, however, necessarily things one endorses or even approves of.'² This signals the importance of a *comfortable* self-narrative. As with meaningfulness, there will be substantial variation in what a 'comfortable' narrative looks like to each of us. Nevertheless, I want to suggest that stigmatising, alienating, distressing, frightening, or oppressive characteristics, roles, and experiences are antithetical to narrative comfort. For example, we are unlikely to be comfortable in self-descriptors or roles that we are ashamed to lay claim to or enact because we experience them as having negative or stigmatising associations – for example, those of being 'a mutant' carrier of a disease-causing gene, 'doomed' by genetic risks, or a 'commodity' traded through a surrogacy contract. Similarly, we may feel alienated from descriptors in which we do not recognise ourselves but that are imposed on us – for example, 'crazy' or 'illegitimate'. Comfortable self-narratives will be enhanced by characteristics that are rewarding and cause us little friction in our daily lives – for example, those of being a much-wanted child, a responsible parent, or a contributor to vital health research. However, there will also be characteristics that we strongly embrace and would like to experience as a source of pride that we nevertheless find challenging to occupy and enact, perhaps because others do not recognise them as 'real' or respect-worthy. For example, in

² Walker and Rogers 2017, p. 314.

some contexts, this might include being a person of colour, a trans father, or a competent professional living with schizophrenia. In proposing that narrative comfort matters, it is important to leave space for recognising the value of sustaining valued narrative threads such as these that nevertheless face disrespect or lack of recognition by others.

I will collectively refer to the interactive combination of the four qualities described above as comprising an *inhabitable* self-narrative. A fractured, unintelligible, unsustainable self-narrative, populated chiefly by characteristics and experiences that we find alienating, trivial, or unwelcome, is unlikely to be one that we are comfortable occupying, or one that provides a supportive and useful framework through which to interpret and navigate our lives. An inhabitable self-narrative need not be an unremittingly joyous story in which we take unalloyed pleasure and pride. Ricoeur's description of the necessity of having a 'bearable' identity narrative is closer to the mark, though perhaps rather too downbeat.³ 'Inhabitability' here is intended to capture the achievable ideal of a self-narrative with realistically welcome and desirable contents given what we are able, and unable, to control about our lives and the meanings attaching to our experiences and characteristics. An inhabitable narrative is one that accommodates diversity amongst intersecting characteristics and reflects the light and shade of real life.

My claim is that our interest in achieving and maintaining an inhabitable self-narrative is a fundamental and ethically significant one, shared by each of us to the extent we have, or can be supported in having, the cognitive and affective and relational capacities to construct such an account. The strength of this interest is attributable to the importance of the narrative qualities of coherence, sustainability, meaning, and comfort for realising and exercising our experiential, evaluative, and practical capacities for self-understanding and ongoing self-creation; interpreting and evaluating our experiences; and developing autonomous agency, long-term commitments, and our own critical outlook and style of attention.

Information-related Interests

I now want to turn to the specific information-related interests that serve the more fundamental interest in narrative self-constitution just

³ Ricoeur 1992, p. 158.

described. I will set out here what I take to be our three principal information-related interests.⁴

Our first information-related identity interest is that in *being able to access personal bioinformation that would contribute to developing and maintaining an inhabitable self-narrative that is coherent, sustainable, meaningful, and comfortable when occupied and enacted in the course of an embodied and socially embedded life*. Or, more pithily, *we each have an interest in accessing personal bioinformation that would contribute to an inhabitable self-narrative*.

The second information-related identity interest is that in *not being exposed to personal bioinformation that would threaten an inhabitable self-narrative*.

However, it is not simply by supplying or withholding bioinformation that harms to the inhabitability of our self-narratives may be averted or mitigated, and not all disclosures will support inhabitability equally effectively. These outcomes are also influenced by the *manner* in which information is offered and disclosed. This brings me to a crucial third information-related identity interest – that in *being offered, and potentially given, personal bioinformation in a way that supports the development and maintenance of an inhabitable self-narrative in the course of an embodied and socially embedded life*.

In a purely conceptual sense it is not surprising that, if we have interests connected to our encounters with and uses of bioinformation, then the manner and context in which this information is conveyed also becomes crucially relevant. This is because, according to the definition of information presented in Chapter 1, the communication context can contribute in no small way to the explanatory and interpretive framework that shapes the semantic content or meaning of the information, thus producing what should – strictly speaking – be thought of as *new information*.⁵ For example, when a doctor conveys the results from a biopsy, the information the patient receives is not identical with that written in their patient records, nor yet with the doctor's own interpretation of the results. It is shaped by the patient's circumstances, how the doctor conveys the result, and the wider explanatory and interpretive context in which communication takes place. Furthermore, according to

⁴ In proposing these interests, I am neither suggesting that they necessarily take precedence over other interests nor that they entail imposing or withholding personal bioinformation against the information subject's wishes. I will return to consider the responsibilities of others to meet and weigh such interests in Chapter 7.

⁵ Floridi 2019.

the picture I have developed over the preceding chapters, narrativity is itself an interpretive and meaning-making endeavour. So, if we are concerned with managing the effects of people's encounters with particular bioinformation on their self-narratives, it follows that this concern will extend to the factors that shape how the information is understood by the recipient and the ways in which it subsequently informs their self-narrative. Prominent amongst these factors are the ways that the information is presented and explained at the point of communication and receipt.

The experiences discussed in the previous chapter offer vivid illustrations of the ways in which disclosure context can make significant differences to how recipients' underlying identity interests are affected. For example, the UK regulator and leading researchers in the field recommend introducing the topic of donor conception to donor-conceived children early and in incremental, age-appropriate ways, allowing them to assimilate it gradually.⁶ And family members' willingness to discuss the meaning and significance of donor conception, as well as the availability of further information about gamete donors, have both been observed to make a difference to how well adult recipients respond to discovery of their conception and whether they are able to restore a satisfying and coherent sense of who they are.⁷ The importance of interpretive context also emerges from the REVEAL study investigating genetic testing for Alzheimer's risk. REVEAL researchers attributed participants' relative lack of distress and fatalism in response to their risk estimates to prior receipt of educational materials that emphasised the probabilistic and conditional nature of these estimates and the complex, multifactorial nature of late-onset Alzheimer's disease.⁸ In contrast, the visual nature of brain images has been observed to lend them an apparent immediacy and objectivity that makes them a particularly 'potent' and persuasive communication medium and heightens the personal significance of what they seem to convey.⁹

My focus in this chapter and the next is on describing the nature of our identity interests and how these might be met. The three information-related interests listed above are held by individual information subjects

⁶ Human Fertilisation and Embryology Authority, *Talk to your child about their origins*, <https://www.hfea.gov.uk/donation/donor-conceived-people-and-their-parents/talk-to-your-child-about-their-origins/> (accessed 18 July 2021); Golombok 2017.

⁷ Blyth 2012; Freeman and Golombok 2012; Ravelingien et al. 2013.

⁸ Christensen et al. 2011.

⁹ Dumit 2004, p. 109.

by virtue of being authors of their own identity-constituting self-narratives. However, meeting these interests requires recognising that they are often interdependent or in tension with the needs and interests of others. As noted in earlier chapters, we do not and cannot build our identities in isolation. And, as I shall go on to discuss below, the ways in which particular bioinformation engages and impacts upon the information subject's fundamental identity interest are not separable from how others around them understand and use this information or from how disclosure affects other people and the recipient's relationships with them.

It is also important to recognise that the fulfilment of our fundamental interest in developing and maintaining an inhabitable self-narrative is not all-or-nothing nor a once-and-for-all achievement. The coherence of an identity narrative admits of degrees. The same is true of its meaningfulness, sustainability, and comfort. Failure to fulfil all the dimensions of the overarching inhabitability of one's self-narrative to a perfect degree is inevitable in the course of any recognisably human life. And this does not necessarily entail a *loss of identity*. But such a catastrophic outcome is not necessary for our underlying identity interest to be engaged and for legitimate ethical concerns to arise. Similarly, contributions towards enhancing or supporting narrative coherence, meaningfulness, sustainability, and comfort are valuable and worthy of attention, even when these would not achieve perfect inhabitability or avert total disintegration. That is to say, incremental losses and gains in the various dimensions of inhabitability can make ethically significant differences that still demand our attention. The development of an inhabitable self-narrative is a constant work in progress, frequently progressing and regressing, and subject to external influence and impacts, re-evaluations, and reinterpretations. These factors mean that our associated information-related identity interests are ever-present and may be engaged in different ways at different times.

These, then, are the central qualities of the three information-related interests which, I propose, should comprise a central and routine part of ethical frameworks that govern bioinformation disclosure practices and policies in healthcare, research, consumer, administrative, and interpersonal contexts. Before moving on to map the shape of the ethical and practical gap that would be filled by recognising and responding to these identity-focused interests, I want first to examine more closely the factors that influence when particular kinds or instances of bioinformation might fulfil or undermine them. Understanding these factors and

knowing how to recognise them are essential steps in making protection of information-related identity interests a realistic and practicable prospect.

6.3 Sources of Identity Significance

I have argued over the preceding chapters that personal bioinformation, taken as a broad and inclusive class, has the potential to contribute to the inhabitability of our identity-constituting self-narratives. However, it is clear that not all kinds or instances do so to the same extent, or on all occasions. Some may indeed threaten inhabitability. I want to look more closely at the kinds of factors that shape when and why these differences occur. The first step in doing this is to examine what accounts for the quality of ‘identity significance’.

I take identity significance to be the quality of a particular instance of bioinformation, without which it would not have a noteworthy effect on someone’s identity – either good or bad. In practice, it seems most likely that information’s identity significance and its positive or negative impacts will be experienced in tandem rather than sequentially, each bound together in subjects’ perceptions of its value or detriment to their account of who they are. But it is worth decoupling them for the purposes of this stage of the enquiry, as identity significance may be attributable to some reasonably discernible and predictable factors, even when the precise positive or negative qualities of the effects on narrative inhabitability are less readily predicted. With some possible exceptions discussed below, it seems most plausible – given the variety of experiences reviewed in the previous chapter – that the matter of whether any particular type of personal bioinformation in any particular circumstance is experienced as having identity significance and then, further to this, whether it serves or threatens the information recipient’s basic identity interest is not inherent to the information itself. Instead, it is largely a contingent matter, dependent on a cluster of factors that we might think of as embodied context, communication context, social context, and narrative context.

Embodied Context

Turning to the first of these, it seems likely that the nature of the health, biological, or bodily state of affairs conveyed by particular bioinformation will often be a considerable contributory factor in its perceived

identity significance – even if it is not determined by this alone. Specifically, the greater the gravity, scale, or pervasiveness of the effects of particular kinds of bodily states, functions, and susceptibilities on the lives, experiences, and well-being of embodied beings – given, for example, the ways we use our senses, our physical and mental capacities and vulnerabilities, our reproductive capabilities, and our lifespan – the greater the likelihood that these will impinge on our self-narratives. And, by the same reasoning, bioinformation conveying insights into these ‘weighty’ biological or bodily states of affairs – such as diagnosis of serious chronic illness – seems particularly likely to be experienced as having identity significance. For example, it has been observed that people’s reactions to results from genetic susceptibility testing tend to vary relative to the severity and nature of the condition tested for, including its age of onset, amenability to treatment, the severity of its symptoms, or whether it affects mental capacities.¹⁰ This is not to claim that all bioinformation with marked health or functional implications will inevitably be seen as identity-significant, or be significant in the same ways to different people. Observations of the ‘disability paradox’ – in which the quality of life reported by those living with disabilities is often considerably higher than imagined by able-bodied people – provide a clear warning against assuming that people’s experiences of different forms of embodiment are universal or straightforwardly predictable.¹¹ We may also witness disparities in the connotations of apparently similar information in the ways in which carrier status for the *BRCA* mutations linked to breast and ovarian cancer are often seen as particularly frightening and closely associated with patient activism – associations that are perhaps not as widely shared by genetic susceptibility to hereditary bowel cancer, despite these diseases having comparably severe health risks.¹²

Communication and Social Context

This last example points towards the extent to which bodily states of affairs – while perhaps presenting as brute matters of fact – are nevertheless susceptible to being shaped by the stories we tell about them and the interpretations and associations we invest in them. As Iris Marion Young, Donna Haraway, and others have observed, the meaning and

¹⁰ Roberts et al. 2003.

¹¹ Scully 2008, p. 56.

¹² Lock 2008, p. 73.

significance of features of our material bodies are often neither inherent nor wholly socially constructed but rather the result of entwined 'nature/culture'.¹³ I have indicated above how the immediate communication environment can influence the meaning of particular bioinformation and its roles in recipients' self-narratives. It is no less important to recognise that the wider social contexts in which the disclosure takes place – in which I include cultural, medical, political, institutional, and legal environments and structures – can have similar effects by contributing further layers to the interpretive frameworks within which the identity relevance, or lack thereof, of particular kinds of bioinformation are viewed.

It is not possible to explore here in depth the many means by which this entanglement of biology and social context can come about. However, over the previous chapters, we have encountered several examples in which it is manifest. For example, it has been suggested that it is not possible fully to understand the significance of knowledge of donor conception to donor-conceived individuals in abstraction from the importance assigned to genetic relatedness, infertility, or marital fidelity in the cultures into which these individuals were born.¹⁴ Indeed, Tabitha Freeman and others have posited that gamete donation policies that require donor identifiability could themselves contribute to a feedback loop, reinforcing the perception that knowledge of genetic parentage is important to donor-conceived individuals' self-understanding.¹⁵ Further indications are supplied by research findings that suggest that individuals conceived using donor sperm tend to invest more importance in knowing about their donors than those conceived using donor eggs.¹⁶ Freeman and her co-authors surmise that this could be due to culturally prevalent perceptions that fatherhood is conferred at conception, while motherhood is constituted by gestation and care.¹⁷ The attitudes examined in the previous chapter suggest that beliefs about the particular authority, objectivity, and reliability of particular kinds of bioinformation – for example, findings generated by genomics or neuroimaging – can also make a substantial difference to whether information subjects treat these findings as relevant to their accounts of who they are. These 'entanglements of meaning' may occur at the point

¹³ Haraway 2006, p. 128; Young 2005.

¹⁴ Freeman 2014.

¹⁵ Freeman 2015.

¹⁶ Freeman et al. 2014.

¹⁷ Freeman et al. 2014.

of disclosure – for instance, introduced by the disclosers’ apparent expertise and authority – as well as being woven in the wider communication environment. For example, commonplace beliefs that functional neuroimaging can provide robust insights into our character traits and behaviours might be explained in part by the prominence in the public realm – including popular media and social policy – of neuroscientific explanations for differences between people and their characteristics.¹⁸ And perceptions of the divergent identity significance of different kinds of bioinformation may extend to yet more concrete social and cultural factors. For example, diagnosis of a serious disease may take on a very different narrative complexion in settings where treatment is provided by a tax-payer funded health service and one in which healthcare provision is sparse or treatment is prohibitively expensive.

Narrative Context

In light of the examples just outlined, it is possible to see how information about our bodies, health, or biological relationships may arrive ready-packaged with value judgements and attributions of identity significance. However, while recognising this, it is crucial that we do not overlook or afford too little weight to the role of the interpretive framework supplied by the individual subject’s own identity narrative. The contents and connections of their existing narrative will be instrumental in shaping whether particular personal bioinformation is experienced by them as being relevant to who they are, or when it is seen as supporting or threatening the coherence, sustainability, meaning, and comfort of their identity. In Marya Schechtman’s words, a self-narrative is the ‘lens through which we filter our experience and plan for actions’.¹⁹ To this list we may add that it is also the lens through which we interpret new incoming information. What a particular item of personal bioinformation means to us will be dependent on the ways we already characterise ourselves; the relative priorities and accommodation we have previously forged between different intertwined and intersecting aspects of ourselves; and the priorities, concerns, and values arising from these. The role played by this narrative lens is perhaps most obvious where bioinformation gains significance through corroborating or posing a direct threat to existing, valued narrative contents. But it also operates as

¹⁸ O’Connor and Joffe 2013.

¹⁹ Schechtman 1996, p. 113.

a broader interpretive framework. For example, the experiences explored in Chapter 5 demonstrated that it is not possible to understand the significance of a *BRCA* test result to a recipient without understanding their family's history of cancer, their existing beliefs about their risk, and how they imagine serious illness or treatment will impact the projects, roles, and relationships that sustain and define them.

My suggestion is that our own identity narratives are the ultimate – though neither the sole nor necessarily the dominant – factor shaping the significance and identity value or detrimental character of personal bioinformation. This is in no way to underestimate the parts played by communication and cultural contexts. These 'external' factors may contribute aspects – sometimes really substantial aspects – of the meaning of the features, group memberships, susceptibilities, diagnoses, or relationships that bioinformation conveys. And, sometimes, their influence may be hard to resist and doing so may demand substantial personal and social resources.²⁰ However, potential self-descriptors are rarely if ever – in Diana Meyers's vivid phraseology – 'implanted' as ready-made 'trait nuggets . . . as if our psyches swallowed social inputs whole and never metabolized them'.²¹ The relationship between identity and bioinformation is best understood as a bidirectional process, whereby our self-narratives should be seen both as being shaped by bioinformation and also as being the prism through which this information passes, bending and colouring the eventual roles information plays in our self-conceptions. These roles may be substantive – adding or subtracting contents and descriptors – or interpretive – adjusting the relationships between existing contents and descriptors. The edits made may be prominent or trivial, and sometimes, the information will be excluded altogether.

The Reality of Constructed Significance

One possible line of critique warrants addressing at this point. It is sometimes implied that if the identity significance and consequent value of particular kinds of personal bioinformation are not intrinsic to the information but rather contingent – constructed by, amongst other things, changeable social norms and personal idiosyncrasies – then any supposed identity-based interests attached to receiving it are artefactual

²⁰ Lindemann 2001.

²¹ Meyers 2000, p. 163.

and of questionable ethical importance. For example, Inmaculada de Melo-Martín argues that, because perceptions of the identity significance of knowing one's donor origins are the product of 'culturally dominant narratives' and these perceptions carry the risk of stigmatising those who do not know their genetic parentage, it would be better to resist the contingent significance of this knowledge than to recognise it and give it credence and influence.²² However, objections of this kind are, I want to suggest, based on a misunderstanding about *what* is contingent in this picture. Our information-related identity interests are no less real and significant for being contingently engaged in any particular instance. This is because if and when particular bioinformation *does* substantially enhance the inhabitability of the recipient's self-identity, it fulfils a particular, non-fungible role in the complex, interwoven whole and particularity of that individual's self-narrative given the particularities of their existing narrative, their embodied and relational circumstances, and the cultural and social context in which they live. And, in doing so, it contributes to meeting a fundamental interest. This is no less true of bioinformation that is not inherently identity-significant. Only under a strangely individualistic and inert conception of narrative self-constitution, in which the forms our self-narratives take must be untouched by external influences and play no role in shaping the meaning of incoming information, would the sheer operation of partially socially constructed significance undermine the reality of the information's identity value to its recipient, or make its value to some more suspect than its stigmatising impacts on others.

Similarly, the socially constructed aspects of identity significance should not be seen as obviating the selective, interpretive authorship of information subject. Undoubtedly, authorial and interpretive control over our identities will sometimes be constrained or involve a struggle. For example, this might be the case when others refuse to recognise our own accounts of who we are, or when bioinformation conveys health news associated with particularly oppressive or stigmatising tropes. However, these real and serious possibilities do not mean that we are *always* powerless in how we respond to external influences on identity significance. The diverse accounts of rejecting or reconfiguring the results of genetic tests or neuroimaging findings discussed in the previous chapter indicate that, despite the perceived objectivity and authority of the source material, bioinformation may still be reinterpreted and shaped

²² de Melo-Martín 2014, p. 33.

by recipients' exiting narratives. Alondra Nelson observed just such practices amongst users of DTC genomic ancestry tracing services.²³ Participants in her study hoped that the findings supplied by these services would provide insights into their ancestral roots in Africa. Nelson notes that these 'roots seekers' 'actively draw together and evaluate many sources of genealogical information (genetic and otherwise) and from these weave their own ancestry narratives'.²⁴ The perceived authority and objectivity of this information and its profound significance to these peoples' lives did not obviate their role as authors of their own identities.

Not only do we have the capacity to reflect upon, resist, or subvert socially constructed identity significance, I would suggest that it is also a mistake to assume that we can be effective, intelligible narrators *without* access to shared cultural storytelling tools. As discussed in Chapter 3, our self-narratives are constructed in dialogue with others. And this necessarily involves using shared language and modes of self-understanding, including those about the range of forms that we imagine human lives can take and the kinds of characteristics that can populate the stories of these lives. Some of the templates or 'master narratives' available in our communities may be restrictive and challenging to resist, such as Hilde Lindemann's example in which female nurses are habitually seen and treated as 'Earth Mother[s] with the Bedpan'.²⁵ However, many other templates are enabling. For example, shared accounts of what it is like to be a teenager may help young people understand that their feelings of frustration and alienation are, usually, not moral failings or signs of mental ill health but widely shared and useful parts of developing independence. Or it might be hoped that increasing visibility of non-binary ways of living and characterising oneself will support people who do not feel gendered along traditional lines to feel more able to develop and inhabit their own accounts of who they are.

Lindemann is sympathetic to Diana Meyers's view that, '[t]o some extent, people are captives of their culture's repertory of figurations'.²⁶ However, she points out that it is 'neither possible nor desirable' to extricate ourselves from or eschew these shared figurations and understandings altogether.²⁷ In her words,

²³ Nelson 2008.

²⁴ Nelson 2008, p. 762.

²⁵ Lindemann 2001, pp. 3, 6.

²⁶ Meyers 2000, p. 239.

²⁷ Lindemann 2001, p. 85.

[t]hese understandings are narrative understandings, made up of the stories and fragments of stories that circulate widely in the community and that allow us to make sense not only of ourselves but also of those around us In our found communities there exists not only what besieges, deprives and violates us but also our moral good: a considerable portion of the richness and variety of life lies in the given.²⁸

Without the shared tools of narration, we struggle to construct our identities at all, to recognise or find meaning in them, or to have them recognised and understood by others. For example, Jackie Leach Scully suggests that one of the challenges that might face the first generation of people conceived using MRT – a reproductive technique described in Chapter 2 that uses eggs from two women to create an embryo – is the absence of ‘a vocabulary to match some crucial areas of her experience that arise out of the special way she was conceived, and a story that enables her to make sense of those aspects of her life and eventually to describe and account for them to others’.²⁹ Here, we might call to mind Marian Wright Edelman’s maxim that ‘it is hard to be what you cannot see’.³⁰ Edelman is speaking to the importance of role models, but her words also resonate with the importance of being able to reach for positive, publicly available templates for the stories we can and want to tell about who we are. Scully emphasises that we hold collective responsibilities for generating positive, enabling, and recognisable master narratives – in Lindemann’s terms ‘counterstories’ – that children conceived using MRT could use, to avert the risk that the void is instead filled by stories in which they are seen as ‘so unusual as to be morally suspect, possibly even “monstrous”’.³¹ This imperative clearly applies far beyond our obligations to those conceived using MRT.

6.4 Filling a Conceptual and Normative Gap

In Chapter 2, I undertook the first steps towards identifying the conceptual and practical gaps in the landscape of explicit regulatory protections and prevalent bioethical characterisations of our identity-related interests in accessing bioinformation about ourselves. I noted that, in the current landscape, the precise nature of the relationship between bioinformation and identity, and the normative dimensions of this relationship, often

²⁸ Lindemann 2001, p. 187.

²⁹ Scully 2017, p. 42

³⁰ Edelman 2015.

³¹ Lindemann 2001, p. 6; Scully 2017, p. 44.

remain ambiguous, exceptionalist, or reliant on biologically essentialist views of identity. Having developed a picture of the nature and strength of our information-related identity interests I want now to take stock of what recognition of these interests would add to the ethical landscape and why it is crucial that we attend to identity interests in their own right.

Widening the Aperture

I have sought to demonstrate over this and the preceding chapter that our identity-related interests in our encounters with personal bioinformation are real, ethically significant, and engaged by a range of different kinds of bioinformation. Recognising the roles played by bioinformation in enhancing or undermining our capacities to develop and maintain inhabitable identity-constituting narratives offers a useful and plausible perspective that – I suggest – does not do violence to the reported experiences of information subjects. It not only introduces a clear basis for understanding the ethical significance of bioinformation's impacts on and roles in our identities but also widens the scope of what these impacts and roles might look like. Not least – as the illustrative examples in the previous chapter indicate – it suggests that it is necessary to be alert to effects that might not already be recognised and labelled as 'identity related' by information subjects, those who manage our bioinformation, or academic commentators. Similarly, it highlights that the kinds of effects that warrant serious ethical attention can include, but also extend far beyond, many of the most commonplace tropes associated in the literature with 'identity impacts' of health-related or genetic information – namely disruption, labelling, or the adoption of biologised or geneticised self-conceptions. Shifts in information recipients' understanding of their identities instigated by encounters with bioinformation do not need to adhere to these tropes, much less entail wholesale personal reinvention, to be keenly felt and make meaningful differences to values, outlook, and engagement with the world.

Adopting a narrative lens makes insights into this wider nature of identity impacts possible because this lens refocuses our attention on the experiences of living with identities that are complex, multifaceted, intersectional wholes, with crucially interpretive, diachronic, and evolving natures. Our identities are not just loose bundles of discrete identifiers. Nor are they monolithic entities simply to be preserved or lost. And the kinds of impacts that warrant ethical attention are not limited to 'identity loss' or to the addition and replacement of labels and contents.

Just as important are the advent and loss of interpretive tools that help us make sense of or reframe existing characteristics and the relationships between these characteristics and our experiences. Even where labels or characteristics are acquired or revised, this is rarely an isolated event or best thought of in this way. Rather, a narrative conception of identity allows us to recognise that it is part of reciprocal shaping and meaning-making amongst the many intersecting threads that make up the fabric of someone's story of who they are. For example, diagnostic testing may lead someone to newly describe themselves as 'diabetic', but this may also, in turn, shape, what it means for them to be 'a father', 'healthy', 'a long-distance cyclist', and 'much like my grandfather'. Because of this wider network of interpretive and sense-making effects and the associated consequences for the intelligibility and inhabitability of the *whole* of the information subject's identity, we are able to recognise why changes to aspects of someone's self-characterisation *matter*. They are neither merely aesthetic nor simply about preserving a preferred persona. They go deeper and wider. When personal bioinformation supports someone in developing, understanding, occupying, and enacting who they are as an entire person, and thus in enabling them to realise and exercise their experiential, practical, and evaluative capacities, it engages ethically significant interests and has real value.

Foreseeable Identity Harms

In addition to allowing us to recognise the nature and scope of *valuable* identity roles played by bioinformation, a narrative conception also shines a light on the possibility of real identity *harms*. As noted above, the identity significance, value, and detriment of particular information encounters are not intrinsic qualities, but rather are dependent on a range of variables, several of which arise from the interpretive framework supplied by the communication context and specific self-narrative of the individual recipient. It therefore may not be at all straightforward reliably to predict a priori whether or to what extent particular personal bioinformation will prove valuable to a particular individual. As I shall explore in the next chapter, this presents challenges, though not necessarily insurmountable ones, to meeting identity interests in practice. However, I want to suggest that there are at least two circumstances in which the likelihood of non-trivial identity *harm* may be reliably foreseen. These circumstances involve the communication of misleading

information and the communication of information that would introduce oppressive or degrading narrative threads.

Misleading Information

The picture of identity interests I have presented above has implications for the epistemic qualities of the kinds of bioinformation that are likely to serve us well. By ‘epistemic qualities’, I mean those relating to information’s fit with the world and its ‘adequacy for the practical purposes for which [it] is used’.³² The practical purpose here is the construction of an inhabitable identity. This undertaking entails interpretation and navigation of a material, biological, relational life. For this reason, I want to suggest that the identity value of bioinformation – its capacity to fulfil our basic identity interest – depends to a great extent on it providing us with *dependable* insights into our past, present, or (likely) future health, bodily states or functions, and biological relationships. Information that would fail to meet this criterion is not limited to that which is straightforwardly false. It includes ambiguous and misleading information, for example estimates of disease risk with high percentages of false positives and negatives; vague or under-contextualised prognoses; test results that draw unwarrantedly deterministic conclusions about complex multifactorial traits; and ‘findings’ that are incapable of speaking meaningfully to the state of affairs they purport to.

To illustrate the problem with misleading information, we can imagine someone who uses a novel automated blood testing service offered by their high-street pharmacist, a test which fraudulently purports to be able to detect a range of health-related biomarkers when it is actually unable to do so with any reliability or accuracy.³³ We can further imagine that this customer receives false positive results for, amongst other things, syphilis antibodies and an overactive thyroid. Consequently, they experience distress about their health and a sense of unfamiliarity and loss of confidence in their own body. They come to mistrust their partner and their own judgement and feel ashamed. They had been seeing a counsellor to address mood swings and sleeplessness but now believe these are most likely to be symptoms of hyperthyroidism, so decide not to continue with counselling. And they had been trying to get pregnant but can no longer imagine parenthood as part of their future.

³² De Winter 2016, p. 79.

³³ This example is based on tests offered by the now discredited Theranos’s ‘Edison machine’ that was used in-store in Walgreens pharmacists in the USA. See Topol 2018.

I would suggest that the suite of effects just described could constitute non-trivial identity harms. Anders Nordgren and Eric Juengst raise a similar concern about provision by DTC genetic testing services of misleading, 'inadequate' information about health risks or ancestral heritage. They suggest that such information may 'distort rather than clarify [their] clients' subjective experience of their identities'.³⁴ This is a valuable insight. But I want to suggest that it is not just the individual's 'subjective experience' of identity that is distorted by vague and under-contextualised DTC genomic tests or by the inaccurate blood test described above. More fundamentally, it is the coherence, intelligibility, and sustainability of recipients' identity narratives that suffer. This threat has four dimensions.³⁵ First, there is the possibility of unnecessary stigma, alienation, and hopelessness in response to erroneous results. Second is the, also unnecessary and potentially distressing, work of narrative reconfiguration and reinterpretation by the recipient. Third, the resulting misconceptions about their health, bodily states of affairs, or relationships may render the recipient's self-narrative an unreliable foundation from which to live and act in the world and through which to continue to interpret and constitute who they are. In the above example, they have withdrawn from plans and commitments that provided meaning and sustenance to their sense of self. Fourth, the self-narrative they come to occupy is premised on misleading beliefs about their health, body, and relationships. This renders it vulnerable to being further undermined when they run up against their own embodied experiences and others' conceptions of the world. For example, the person in the above vignette is now liable to misattribute future episodes of poor mental health and fail to address these in suitable ways. And if further tests reveal they were never infected with syphilis, their sense of themselves as betrayed and principled may be abruptly replaced by an uncomfortable picture of themselves as untrusting and judgemental.³⁶

The depth and severity of identity detriment in cases such as this will depend on how central the newly acquired, precariously founded characteristics and reinterpretations are to the recipient's self-conception.

³⁴ Nordgren and Juengst 2009, p. 166.

³⁵ Adam Henschke argues that a self-characterisation based on falsehoods is no less worthy of respect. I will return to consider whether this is so in relation to others' responsibilities to enable such a characterisation in the next chapter, Henschke 2017.

³⁶ While, as noted in this and the preceding chapter, not all narrative disruptions are detrimental, they are often undesirable, particularly if the path to reconstruction is painful or overwhelming.

And it is clear that what matters is not solely the epistemic limitations of the information itself, but these coupled with the recipient's lack of awareness of these limitations and their uncritical accommodation of the information as presented.

To be clear, I am not seeking to claim here that simply being *true* is *sufficient* for personal bioinformation to be relevant or valuable to our self-narratives. Much of it, no matter how robust, will be irrelevant, superfluous, or unwelcome. Rather, my suggestion is that only under very limited circumstances could it be in our identity interests to receive false, unreliable, or meaningless bioinformation. Furthermore, the narrative harms associated with misleading bioinformation may obtain even, and perhaps especially, if this information is welcome and keenly sought. This possibility is only revealed if we appreciate – as a narrative lens allows us to do – the importance of the structure and interpretive features of our identities alongside the desirability of their 'contents'. I will return to examine possible tensions between desired yet structurally problematic narrative contributions shortly.

Damaging Narrative Contents

Whether particular kinds of bioinformation contribute meaningful or comfortable narrative contents will – for all the reasons described above – vary between individuals and circumstances. However, might it be possible to say something, if not wholly a priori then at least widely applicable, about some kinds of information that would invariably make for *less* inhabitable and practically enabling self-narratives?

I want to suggest that there are two further sets of potentially overlapping circumstances in which this would be the case. The first concerns bioinformation that is uncritically presented to the information subject as deterministic or revealing who they essentially are. Even if, for example, a disease prognosis or revelation of a genetic relationship is true as far as biological matters of fact are concerned, these matters of fact do not, at least without further narrative work, define the subject's identity. When they are presented by others as doing so, however, they risk not only constraining the individual's self-authorship but could also sow seeds of narrative fractures and discomfort. This is illustrated, for example, by donor-conceived individuals who remain uncomfortable with the knowledge of their origins, distressed that their wider family does not know who they 'really are'.

The second set of predictably identity-damaging circumstances are those in which bioinformation arrives ready-invested with stigmatising,

demeaning, or oppressive connotations. These may be connotations that are derived from the wider social and institutional environment or the immediate communication context. For example, some traits or conditions – such as those relating to particular disabilities or those marking departures from sex, gender, cognitive, or aesthetic norms – may, due to racism, ableism, or other kinds of prejudice, be associated with negative stereotypes. We might think here of the potentially stigmatising connotations of schizophrenia, differences in sex development (DSD),³⁷ or the ways in which the language of genetic ‘mutations’ to describe test results might contribute to negative self-image to those receiving diagnoses or positive test results.³⁸ Where the negative associations of such traits are sufficiently evident in others’ reactions or prominent in public debate or cultural representations, these may be incorporated into recipients’ self-narratives alongside the purported ‘bio’ state of affairs reported by the information.

When we experience bioinformation as contributing stigmatising or degrading self-descriptors or interpretive lenses that colour wider narrative threads, this not only threatens the comfort or desirability of our identities.³⁹ It can also undermine our abilities to make sense of or sustain our own experiences of, and beliefs about, who we are and what we are like, where these are at odds with the associated negative stereotype, or where these stereotypes undermine our self-esteem or authorial control.⁴⁰ As Catriona Mackenzie notes, oppressive social forces, non-recognition of our chosen self-descriptors, and lack of self-worth undermine our confidence and capacity to be authors of our own identities, not least by ‘curtail[ing] our imaginative explorations of alternative possibilities of action, emotion, belief, and desire’.⁴¹

Information subjects may sometimes have the personal and interpretive resources to resist the narrative harms invited by bioinformation that carries particularly stigmatising or degrading associations. And it may be possible for others to help avert or ameliorate such harms by using particular communication strategies or offering interpretive support.

³⁷ DSDs include, for example, having physiology, genitals, or internal sexual organs more commonly found in people of a different chromosomal sex.

³⁸ Esplen et al. 2009.

³⁹ Mackenzie 2000.

⁴⁰ It is not only the identities of *recipients* of bioinformation with demeaning or oppressive associations that will be affected by these associations but potentially anyone who shares the same traits or counts themselves, or is counted by others, as belonging to the relevantly same group.

⁴¹ Mackenzie 2000, p. 144.

However, more troubling, and potentially less tractable, identity harms may arise where the bioinformation plays into, or itself purports to convey, intersections between biomarkers associated with stigmatising or otherwise negatively perceived traits or conditions and membership of populations that already face prejudice and social injustice. Here, the risk is that these intersections compound the narrative harms of existing oppressive forces. Encounters with bioinformation that introduce harmful identity contents or negative interpretive lenses may be particularly damaging for those whose self-narratives already contend with negative stereotypes and discrimination. For example, an unexpected diagnosis of sickle cell disease or psychosis may disturb anyone's account of who they are. However, these diagnoses may take on particular significance and potential for harm for recipients of African or Caribbean heritage, where the diagnoses occur in a context of racialised assumptions about the incidence of these conditions amongst people of colour, and where they compound the narrative impacts of multiple intersecting sources of oppression, including racism, underserved health needs, and epistemic injustices in which recipients' own accounts of their experiences and priorities go unheard or are given less credence.⁴²

Health research involving large-scale association studies, such as those used in genomics or behavioural neuroscience, further extend the scope for negative stereotyping, where these methods – either inadvertently or motivated by problematic or vicious assumptions and hypotheses – purport not only to identify biomarkers associated with particular negatively associated traits such as low educational attainment or propensity to antisocial behaviour but also make claims about the prevalence of these traits amongst particular population groups.⁴³ For example, at the start of this century, researchers claimed to have identified a now widely criticised connection between being a carrier of variants of the *MAOA* gene – variants often observed in Maori populations – and a propensity to aggression.⁴⁴ Institutional information practices outside healthcare and health research may be no less implicated in contributing to the degrading, damaging connotations of certain kinds of bioinformation. For example, controversial practices of racial or ethnic profiling for forensic purposes using data held in DNA databases, such as have been used in the UK, risk stigmatising particular populations by falsely

⁴² Bulgin et al. 2018; Nazroo et al. 2020.

⁴³ Saini 2019.

⁴⁴ Henschke 2010.

imputing connections between criminality, membership of particular racial or ethnic groups, and genetic inheritance.⁴⁵ The connections between biomarkers, negatively associated traits, and memberships of particular groups do not need to be true or based in sound science to shape the normative frameworks within which personal bioinformation is conveyed, received, and narratively deployed. Indeed, much of their harm lies precisely in their falsehood and the unthinking or malign uses for which they are employed. Narrative harms associated with bioinformation that introduces stigmatising or oppressive narrative tools may not be inevitable but they will often be predictable given our understanding of contributory factors such as prevalent prejudices and sources of oppression. This predictability has important implications for responsibilities and practices associated with disclosure, as will be explored in the next chapter.

6.5 Relationships between Structure and Contents

The conception of identity interest I have proposed above emphasises the importance of both the structure of our identities – their coherence, integration, intelligibility, and sustainability – and the qualities of their contents – how comfortable, welcome, and meaningful these are. Recognising these two dimensions poses a challenge when it comes to determining the identity value of information that seems to contribute to one dimension while detracting from the other. What should we say about bioinformation that is fervently sought but unreliable, or true but painful?

To explore the first of these permutations, we might imagine someone who receives a ‘diagnosis’ of attention-deficit hyperactivity disorder (ADHD) from a private, commercial neuroimaging clinic. They are delighted to receive this, unaware of the lack of validity or reliability of the diagnostic techniques used. In their eyes, it validates their existing beliefs about their impulsive and distracted behaviour and appears to counter friends’ suggestions that they are prone to being emotionally immature and thoughtless. Does receipt of these results serve, or undermine, their identity interests?

Any assessment of the identity value of results, such as those just described and those detailed below, will of course depend on the

⁴⁵ Racial profiling involves conducting searches for genetic markers associated with a family membership, shared ancestry, or particular inherited traits. See Skinner 2020.

context and manner in which they are communicated and the existing self-narrative of the recipient. And none of what I say here is intended to second-guess the perspectives and wishes of actual recipients, but rather to illustrate the complex and variable relationship between the veracity, desirability, and identity value of personal bioinformation. Allowing for this, I would suggest that in the example above, the 'contents' value of the ADHD diagnosis is unlikely to outweigh the structural deficiencies it introduces. This is in part because its perceived value is dependent on its truth and would presumably dissolve if its falsity were exposed. It is also because the risks, that a narrative built around this misleading diagnosis will be undermined by future experiences and provide a poor basis for the recipient's management and interpretation of their behaviours and traits, are neither unlikely nor trivial. If this is so, the diagnosis, while welcome, at the very least fails to serve the recipient's identity interests and it could well threaten them.

However, if we look at another example of welcome but unreliable findings, the balance of identity benefit to harm might look quite different. In this instance, let us imagine someone who uses a DTC genomic ancestry tracing service to find out where their enslaved ancestors were trafficked from. This person embraces their results, which report a high proportion of genomic markers associated with Ghanaian ancestry. They experience the opportunity to discover Ghanaian roots, to honour the suffering and survival of their forebears, and to make connections with others who share this heritage as contributing valued meaning and purpose to their sense of who they are and as helping to fill in the missing history and self-descriptors that slavery and colonialism have denied them.⁴⁶ However, these results trace only the maternal line in each generation, so account for a tiny fraction of the individual's heritage, they rely on markers also present in populations of other countries, and they cannot account for population movements prior to trans-Atlantic slavery.⁴⁷ Let us also imagine the recipient is not made adequately aware of how partial and unreliable their results are.

⁴⁶ This example is borrowed, with some adjustments and simplification, from the experiences reported by participants in Alondra Nelson's research with 'roots seekers'. For a more detailed discussion of participants' experiences and Nelson's own nuanced interpretation of the identity role of this information, see Nelson 2008.

⁴⁷ Given population movement and limitations in the genomic markers and reference data sets used by DTC genomic ancestry services, they are generally unable to provide

Here, the likelihood of overall identity benefit might be somewhat greater than in the previous example, though not inevitable. This is in part because – in this imagined example – the ‘contents value’ to the recipient of being able to build Ghanaian heritage into their identity narrative is so substantial. A narrative constructed around misplaced beliefs about ancestry is also less likely to be easily falsified by, or present obstacles to navigating, everyday experiences. Furthermore, these beliefs may not wholly replace others the recipient has about their ancestry. As noted above, Nelson observes that many people in circumstances like those imagined here do not build their identities on the reports supplied by the DTC ancestry tracing services alone, but rather compare and combine genomic results with other genealogical information.⁴⁸ However, *if* the substantial personal and identity value invested by the recipient were to be premised wholly on the veracity of the genomic ancestry tracing, the risk of serious narrative harm may well be substantial.

What then of instances in which personal bioinformation is reliable but unwelcome and distressing? Here again, much will depend on the specifics of the situation. So, on one hand, we might say that an individual’s identity interests are served overall by an authoritative diagnosis of type 1 diabetes because of the benefits for their health and also in terms of being able to construct a narrative that anticipates and accommodates experiences of and ill health and ways of planning for and managing these. This overall value may plausibly be sustained despite the diagnosis also bringing unwelcome stigma, a sense of vulnerability, anxiety, the daily burden of blood-sugar monitoring and insulin injections, and loss of the valued characteristics of being a long-distance cyclist and an invulnerable partner and father. However, overall identity value is less plausibly sustained in other circumstances. For example, we might imagine an athlete who is required to undergo genetic testing for so-called sex verification purposes to determine their eligibility to compete in women’s elite athletics.⁴⁹ Here, likely narrative harms include distressing disruption of the individual’s characterisation of their sex and gender, the stigma of being marked out as someone who is not ‘female enough’, implied doubt about the legitimacy of their athletic achievements, and being obstructed from competing in a sport that gives their life meaning.

meaningful insights into ancestral geographical origins at an individual level. For discussion of the limitations of genetic ancestry tracing, see Royal et al. 2010.

⁴⁸ Nelson 2008.

⁴⁹ See, for example, Camporesi 2019.

It is not hard to imagine these identity harms being so great as to be too high a price to pay for any potential interpretive benefits of accounting for particular traits associated with a diagnosis of a difference in sex development or of being able to seek medical advice and support for any health or reproductive implications of living with this condition.⁵⁰

The first thing I want to take from these four examples is that there is no rigid rule about whether bioinformation that contributes to the coherence of our self-narratives is more valuable than that which contributes to its comfort. However, these examples also indicate the difficulties of conceiving of lives in which an identity narrative is alienating but still largely coherent, or unintelligible but nevertheless truly comfortable. Here, we may recall Walker and Rogers's observation that, when seeking to make sense of and restore narrative coherence following unexpected diagnoses of asymptomatic illness, some people experience anxiety or become uncomfortably hypervigilant about their health.⁵¹ This observation and the imagined examples above suggest that we should think of the 'structural' and 'contents' dimensions of our self-narratives as deeply intertwined and mutually limiting aspects of their inhabitability not as separable features. Bioinformation that affects one dimension of inhabitability for the worse is unlikely to leave other dimensions wholly undiminished. So, while coherence and comfort may sometimes exist in tension, the impacts of bioinformation on each cannot be considered in isolation.

6.6 Distinguishing Identity from Other Interests

Having closely examined the nature of our information-related identity interests I now want to turn to address the question of what being able to recognise and appreciate the strength of these interests adds to the ethical landscape of bioinformation governance. It is all very well characterising the strength of our information-related identity interests and the circumstances in which these are engaged, but this endeavour would not be a practical priority if identity interests were sufficiently protected by the suite of ethical concerns that already inform disclosure policies and practices. In this section, I will explain why information subjects' identity

⁵⁰ This example is not premised on the assumption that chromosomal or other kinds of testing can be used to determine sex, which is not a binary category, but it does assume that some kinds of testing may reveal differences in sex development that might be useful, for example in explaining amenorrhoea or infertility.

⁵¹ Walker and Rogers 2017.

interests are neither reducible to nor coextensive with the other interests most commonly invoked when it comes to ethical governance of subjects' access to personal bioinformation.

As highlighted in Chapters 2 and 5, the interests and concerns most commonly invoked include protection of information subjects' health, avoidance of psychological distress, promotion of autonomy, and respect for privacy and private life, with the idea of personal utility attracting increasing attention. It will not be possible to provide comprehensive mappings of all the ways each of these differs from our interest in narrative self-constitution. However, I will provide a sketch of the broad contours of divergence and intersection to demonstrate that our informational identity interests would not be met by attention to these other interests alone and that identity, therefore, requires attention in its own right and on its own terms.

Psychological Distress

As previously noted, the risk of psychological distress is often cited as grounds for *not* providing non-actionable, probabilistic genetic test results. And there is an exception to information subjects' legal entitlements to access their personal health data in UK data protection law if it would cause 'serious harm' to their 'mental health'.⁵² As the discussions of the preceding chapters make clear, although threats to the inhabitability of our self-narratives may indeed be experienced as distressing, their personal and ethical significance is not reducible to this distress. Nor is it necessary for narrative harms to manifest in distress or psychological damage for them to have serious ramifications for our well-being and practical capacities. As previously noted, distress is not straightforwardly correlated with identity harms. Valued insights into our biological lives may initially be deeply upsetting to hear, and welcome but ill-founded self-descriptors may end up jeopardising narrative sustainability and intelligibility. Thinking in terms of identity impacts, therefore, requires us to look beyond emotional distress as the sole or paradigmatic harm associated with encounters with personal bioinformation. Conversely, if we are equipped to recognise when identity harms might be at the root of someone's distress or anxiety, we may then be in a stronger position to assess whether offering epistemic, interpretive, or personal tools of

⁵² Data Protection Act 2018, Schedule 3, Part 2(5).

narrative reconstruction might be an effective means of averting or alleviating this distress.

Clinical Actionability

Many legal provisions and policies governing subjects' access to bioinformation – from instituting of screening programmes, to duties to weigh relatives' interests in knowing about genetic risk, or return of individual research findings – make clinical actionability, including reproductive decision-making, the condition of disclosure.⁵³ As described in the previous chapter, there are important areas of overlap between personal bioinformation that is clinically actionable or useful for health-related decision-making and that which serves the inhabitability and sustainability of our identity narratives. For example, health protective behaviours may contribute important narrative contents and threads. And restoring health may be prerequisite for having the capacities to engage in self-definition. However, our identity interests extend far beyond preserving or restoring health, for example when it comes to understanding our non-health traits and our relationships to others, or when bioinformation informs the trajectory of our biographies and life projects. And some health insights may be unhelpful or otiose to our self-narratives. The nature and strength of our interests in narrative self-constitution present a credible challenge to assumptions that clinical actionability exhausts or is invariably foremost amongst the ethical grounds for offering findings. Although identity development is not a matter of life or death, it supports capacities that comprise core elements of a rich practical and moral life and, as such, carries comparable ethical weight to many health-related concerns.

Personal Utility and Preparedness

The concepts of 'psychological preparedness' and 'personal utility' are sometimes invoked in attempts to capture information's value beyond its clinical utility. Personal utility is broadly understood as a quality of information that the subject finds useful for reasons other than addressing their health concerns, that they find entertaining, or that piques their curiosity.⁵⁴ While it is increasingly common to encounter academic

⁵³ See discussion in Chapter 2.

⁵⁴ Bunnik et al. 2014.

proposals that personal utility or preparedness could provide grounds for disclosing some categories of bioinformation, for example individual research findings, it is not clear the extent to which these proposals are reflected in actual healthcare or research practices. Clinical actionability certainly appears to remain the principal consideration.⁵⁵ As indicated in Chapter 5, preparedness – understood as adjusting expectations and plans to accommodate future illness – could be one dimension of identity value. Personal utility too may overlap with identity value, but the two are not equivalent. Providing bioinformation solely because it fulfils the recipient's curiosity or assists practical preparedness could be contrary to the recipient's identity interests when the findings are unreliable or when the manner of communication is negligent as to how it impacts valued self-characterisations.⁵⁶ Nevertheless, it could be possible to see identity value as a more tightly specified sub-species of personal utility.⁵⁷ And the characterisation of narrative identity interests offered here could contribute conceptual focus, cautionary notes, and normative heft to at least some dimensions of the arguments that are already made for the provision of personal bioinformation on grounds of personal utility and preparedness.

Privacy

Privacy interests may not seem immediately relevant here. When it comes to the governance of personal bioinformation, privacy is most commonly invoked in relation to *others'* access to and uses of information about us, rather than our own encounters with it. However, there is one clear sense in which privacy may appear pertinent to disclosures *to* information subjects. Conceptual accounts of what privacy means and the source – if any – of its personal and public value are numerous and vigorously debated.⁵⁸ Amongst these are the suggestions that it involves the 'right of the individual to be let alone'⁵⁹ and to be 'free from some kinds of intrusions'.⁶⁰ These ideas are echoed by Graeme Laurie, who argues that protection of privacy – understood as a metaphorically spatial

⁵⁵ Ravitsky and Wilfond 2006.

⁵⁶ A more refined conception of personal utility that takes the implicit normativity of 'utility' seriously might avert some of these concerns – see Bunnik et al. 2014.

⁵⁷ Postan 2016.

⁵⁸ Solove 2002.

⁵⁹ Brandeis and Warren 1890, p. 193.

⁶⁰ Scanlon 1975, p. 315.

‘state of (psychological) separateness from others’ – provides the rationale for a strong initial, although defeasible, presumption against invading that space by imposing unknown and unsought genetic information on information subjects.⁶¹ Laurie suggests that this kind of spatial privacy is not *intrinsically* valuable but derives value from the instrumental role it can play in protecting other interests. These include ‘creating space to develop one’s own sense of identity and personality’.⁶² The substantial influence of this analysis within bioethics and legal scholarship notwithstanding, spatial privacy does not yet appear to have been used in law to justify upholding the so-called right not to know.⁶³

Laurie’s conception of spatial privacy and its ethical justification in identity-development terms diverges, however, from the picture of identity development I have presented. Narrative self-constitution does not depend on spatial, social, or epistemic separation. It is an inherently relational undertaking, dependent on interaction, negotiations, and collaboration with others, and is often reliant on their contributions to helping us construct intelligible accounts of ourselves. Furthermore, the arrival of previously unknown and unsought bioinformation may sometimes serve our identity interests. As I shall discuss in the next chapter, it may indeed be difficult to justify unthinkingly imposing personal bioinformation on people on the assumption that they will welcome it. However, such unsought disclosures are contrary to recipients’ identity interests when they are detrimental to the inhabitability of their self-narratives, not simply because they violate a necessary state of separateness. The information-related identity interests that I have proposed may be distinguished from interests in spatial privacy because the latter cannot account for the fact that we sometimes have identity interests in receiving unsought bioinformation. A more promising counterpart to identity interests might be found in a different conception of privacy, where privacy is understood in terms of informational control.⁶⁴ However, as I shall explain shortly, the exercise of informational control may also fail to track our identity interests.

Autonomy

This brings me to the final comparator: that between identity interests and those in developing and exercising autonomy. This comparison

⁶¹ Laurie 2002; Laurie 2014a, p. 41.

⁶² Laurie 2014b, p. 58.

⁶³ Laurie 2014b, p. 58.

⁶⁴ Solove 2002.

requires negotiation not only of diverse conceptions of what autonomy means and the conditions for achieving and exercising autonomy, but also of remarkably different claims made about the role of autonomy in relation to information access. These diverse conceptions may be broadly categorised as: those focusing on information subjects' entitlement to choose which information they wish to receive;⁶⁵ the value of information as a means for informing discrete autonomous choices and conduct; and the role of information in the development and exercise of the capacities for being an autonomous person. I shall address these three framings in turn, looking first at the choice to know or not to know.

The idea that autonomy is equivalent to the mere exercise of discrete 'consumer' choice is in itself problematic, representing an impoverished view of autonomy and its moral value.⁶⁶ Furthermore, while it is easy enough to understand how an 'interest in knowing' can be met through choice, it is notoriously difficult to understand how positions that prioritise 'informational self-determination' would characterise the nature and location of our interests when we do not know that particular information exists at all.⁶⁷ Even allowing for its inherent problems, there are clear divergences between this choice model of autonomy and the fulfilment of our identity interests. Chiefly, it is plausible that someone could really want to access personal bioinformation that goes against their underlying identity interest, or reject that which could serve it. And bioinformation that someone is, as yet, unaware of and cannot request could have marked impacts on the inhabitability of their identity. Positing these divergences between presumptively autonomous desires (not) to know and the fulfilment of identity interests is not paradoxical. It is a consequence of adopting a conception of identity interests in which these are not simply equivalent to the fulfilment of preferences but depend on further criteria based in the maintenance of an inhabitable self-narrative. This notwithstanding, recognising that our desires to know and identity interests may diverge does not necessarily mean that protection of identity should prevail in all circumstances – for example, that unwanted information should be forced on subjects on identity grounds.

The version of the relationship between bioinformation and autonomy that is perhaps most familiar in medical law and ethics is that reflected in

⁶⁵ This framing is exemplified by human rights instruments, such as the 1997 European Convention on Human Rights and Biomedicine, Article 10(2), which enshrine an individual's right to know and to not know biomedical information about themselves.

⁶⁶ O'Neill 2002.

⁶⁷ Andorno 2004, p. 436; Laurie 2004.

the principle of informed consent, where information about our health and bodies is often seen as important to exercising self-determination in healthcare decisions.⁶⁸ Again, equating autonomy with informed consent reflects a disappointingly thin, individualised conception of autonomy. However, it is possible to see, in both bioethics and also in developments in the common law regarding the information provision obligations of healthcare professionals, moves towards a richer construal of the importance of offering information that supports recipients not merely to make choices but to make ones that ‘express [their] own character’ and contribute to a ‘life structured by [their] own values’.⁶⁹ Some of our identity interests in accessing bioinformation could coincide with, or be premised upon this objective of making healthcare-related or practical choices that reflect and enact our values. As such, a subset of identity interests might indeed be protected by recognition of the value of personal bioinformation to autonomous agency and informed self-expression in healthcare, and by holding healthcare professionals responsible, under threat of negligence, for providing this information as part of their duty of care.⁷⁰ However, this still leaves a substantial tranche of identity interests unrecognised and unprotected. These extend not only to interests in not knowing. It also includes those in accessing information that lacks immediate clinical utility or does not support imminent, discrete, practical decisions, or where withholding it would not lead to clear identifiable material, physical, or psychiatric harm of the kind required to prove negligence.⁷¹ This would leave unprotected less concrete or agency-focused identity harms, such as those associated with being unable to make sense of one’s past experiences or to re-evaluate one’s personal and moral commitments.

This brings me to the most intricate of the three comparisons, that between self-constitution and our interest in being autonomous, self-determining persons and moral agents. This is intricate because there are such diverse views about what this conception of autonomy involves and what conditions must be fulfilled for someone to be deemed an autonomous person. For example, is it a capacity or result of the exercise of competencies? Does it require substantive independence from outside influences or instead depend on relational contexts? Is it a function of the internal structure of our motives, our reflective processes, or the source

⁶⁸ O’Neill 2002.

⁶⁹ Ronald Dworkin quoted by Lord Steyn in *Chester v. Afshar* [2004] UKHL 41 [2004] 4 All ER 587 at para.18. See also Chan et al. 2017.

⁷⁰ *Montgomery v. Lanarkshire Health Board* [2015] UKSC 11.

⁷¹ *Montgomery v. Lanarkshire Health Board* [2015] UKSC 11.

and substantive character of our values?⁷² This is not the place to unpack, let alone adjudicate, these debates. However, what is clear is that there is an intimate relationship between the bioinformation-related identity interests, as I have characterised them, and our capabilities to develop and exercise the capacity for autonomy. Here, autonomy is understood in terms of relational practices of critical reflection on one's values and motives, acting in accordance with these within the constraints afforded by embodied and socially embedded lives, and thus 'working out our projects in the world'.⁷³ Having the capacity for autonomy under this brief definition is, as described in Chapter 3, both a condition for narrative self-constitution and a product of it. However, as also noted in that chapter, autonomy is not the only valuable capacity supported by an inhabitable identity-constituting narrative. Our self-narratives also shape more passive but no less important capacities. They allow us to have a more or less clear sense of who we are and how this is connected to who we have been and who we will be in the future. Our narratives create investment in our own past and future and in our enduring commitments and projects and underpin our loyalties to and relationships with other people, our roles in their lives and theirs in ours, and our membership of groups with shared interests beyond our own agency and control. Our identity interests are entwined with our agency, but they are much more than this. They are also connected to our outlook, interpretations of the world, the nature of our experiences, and our sense of self and self-esteem. Therefore effective recognition of identity interests would protect far more than just our autonomy.

In addition to there being a wide variety of conceptions of personal and moral autonomy there are also differing views about the relationship between information and the development and exercise of autonomy. It will be instructive briefly to compare my account of our information-related identity interests with two contrasting views. At one end of the spectrum sit positions such as that offered by Jurgen Husted, who argues that imposition of unsought personal bioinformation is inherently inimical to autonomy and to autonomous self-development because of its unbidden and uncontrolled impacts.⁷⁴ While my account recognises that unsought bioinformation *could* be detrimental to our self-narratives and thus our capacity for autonomy, this is far from necessarily the case. Indeed,

⁷² For further discussions, see Christman 1989 and Dworkin 1988.

⁷³ Mackenzie and Stoljar 2000; Young 1982, p. 43.

⁷⁴ Husted 2014.

Husted's position is premised on an implausibly individualistic conception of autonomy and sets an unattainably high bar for achieving autonomy or self-development in a world in which we are perpetually assailed by unsought information. As previously noted with respect to spatial privacy, our identity interests lie not in the impossible goal of maintaining an undisturbed self-narrative but in being able to make sense of shifting experiences, minimising and managing risks of deep and enduring disruption, and being supported by others in doing so.

My account also differs from accounts of the relationship between bioinformation and personal autonomy occupying the other end of the spectrum. In contrast to Husted's position, these hold that any epistemically robust bioinformation has the potential to expand options and guide decisions – particularly with respect to our future health and well-being – and so can only enhance autonomy.⁷⁵ For example, John Harris and Kirsty Keywood argue, 'where the individual is ignorant of information that bears upon rational life choices she is not in a position to be self-governing. If I lack information, for example about how long my life is likely to continue I cannot make rational plans for the rest of my life.'⁷⁶ This perspective resembles the picture I have drawn to the extent that it also makes space for recognising that even unanticipated or unsought bioinformation can enhance our capacities to be authors of our own lives, for example when it provides fresh insights into the risk of future illness. However, Harris and Keywood go further than this. They hold that reliable genetic information about health and future risks is *inherently* and *inevitably* valuable to our capacity for autonomy. This leads them to conclude that an autonomy-based interest in 'not knowing' is a paradox or contradiction in terms. Here, their position diverges from my own. I have drawn a picture of narrativity as a necessarily selective process. What matters is not the comprehensiveness of our self-narratives but their intelligibility and inhabitability. So, while these qualities *can* be jeopardised by gaps in knowledge and understanding, they are equally threatened by attempted factual completism or by incorporating oppressive modes of self-characterisation.

Our information-related identity interests are closely linked to those in having, developing, and exercising the capacity for self-determination but they are not reducible or identical to them. It is not clear to what extent the law or policies governing information disclosure are currently concerned

⁷⁵ Harris and Keywood 2001; Vayena 2015.

⁷⁶ Harris and Keywood 2001, p. 421.

to protect our interests in developing autonomy understood as the multifaceted capacity of a whole person, or if the focus remains on the thin conception of autonomy as exercise of discrete choices. If laws and policies were to expand into this more ambitious aim, they would need ways of discerning how much and under what circumstances personal bioinformation makes a valuable contribution to being an autonomous person. I want to suggest that the account of identity interests I have offered in this chapter could usefully contribute to judgements of this kind.

Looking at the ways that concerns for autonomy play out in debates about ethical information disclosures and at all the other ‘usual suspects’ of information disclosure ethics explored above, it is striking the extent to which these focus on the bald question of whether or not to disclose. Many of the discussions of these concerns in the literature are couched in the unhelpful and oppositional language of the ‘right to know’ and the ‘right not to know’. Attending to identity-related interests brings a further important dimension to the ethical landscape by highlighting the central importance of the context and manner in which bioinformation is conveyed. This is a topic to which I will return in the next chapter.

6.7 A Fresh Ethical Dimension

In this chapter, I have brought to a conclusion my case that our encounters with personal bioinformation engage ethically significant interests – interests that cut to the heart of our well-being and the richness of our lives, even though the circumstances and ways in which they are engaged vary between us. These interests are rooted in a multifaceted conception of identity that is not made up of discrete self-descriptors but an interwoven and dynamic whole, the inhabitability of which depends both on the qualities of its contents and also the ways these relate to each other and to our lived experiences. My aims have not only been to highlight the significance of our information-related identity interests but also to demonstrate that these interests introduce a fresh dimension to the ethical landscape. My claim has been that these interests occupy a gap that is neither adequately mapped by existing conceptions of identity value and harm nor sufficiently covered by the suite of other interests and principles that currently dominate ethical frameworks for governance of bioinformation. In the next chapter, I will turn to examine the responsibilities of those who generate and manage our bioinformation to fill this gap by responding to our identity interests, and to consider how they might do so in practice.