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**DEFINING OURSELVES: NARRATIVE
IDENTITY AND ACCESS TO PERSONAL
BIOLOGICAL INFORMATION**

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ABSTRACT

When biological information about an individual is produced in healthcare or research settings, ethical questions may arise about whether the individual herself should be able to access it. This thesis argues that the individual's identity-related interests warrant serious attention in framing and addressing these questions. Identity interests are largely neglected in bioethical, policy and legal debates about information access – except where information about genetic parentage is concerned. Even there, the relationship between information and identity, and the interests involved, remain unclear. This thesis seeks to fill this conceptual gap and challenge this exceptionalism. It does so by developing a normative account of the roles that a wide range of information about our health, bodies and biological relationships – ‘personal bioinformation’ – can play in the construction of our self-conceptions.

This account is developed in two steps. First, building on existing philosophical theories of narrative self-constitution, this thesis proposes that personal bioinformation has a critical role to play in the construction of identity narratives that remain coherent and support us in navigating our embodied experiences. Secondly, drawing on empirical literature reporting individuals' attitudes to receiving three categories of personal bioinformation (about donor conception, genetic disease susceptibility, and neuroimaging-based psychiatric diagnoses), the thesis seeks to illustrate, demonstrate the plausibility of, and to refine this theoretically-based proposition. From these foundations, it is argued that we can have strong identity-related interests in whether and how we are able to access bioinformation about ourselves.

The practical implications of this conclusion are then explored. It is argued that identity interests are not reducible to other interests (for example, in health protection) commonly weighed in information disclosure decisions. They, therefore, warrant attention in their own right. An ethical framework is developed to guide delivery of this. This framework sets out the ethical responsibilities of those who hold bioinformation about us to respond to our identity interests in information disclosure practices and policies. The framework is informed by indications from the illustrative examples that our interests engaged as much by *how* bioinformation is communicated as *whether* it is disclosed. Moreover, these interests are not uniformly engaged by all bioinformation in all circumstances and there is potential for identity detriment as well as benefit. The ethical framework highlights the opportunities for and challenges of responding to identity interests and the scope and limits of potential disclosers' responsibilities to do so. It also makes recommendations as to the principles and characteristics of identity-supporting disclosure practices.

LAY SUMMARY

This thesis argues that information about our own health, body or biological relationships (our ‘personal bioinformation’) can have significant impacts on our identities – in the sense of who we understand ourselves to be. It proposes that when personal bioinformation is produced, for example in healthcare or research settings, the identity-related interests of the individuals to whom the information relates ought to be taken into account by policies and decisions about whether and how they are able to access it.

Currently, the potential impacts of bioinformation on individuals’ identities are largely neglected in policy and legal debates about their own access to it. One exception is knowledge of genetic parentage, where identity interests ground legal entitlements to information. This thesis holds that this is a peculiarly narrow focus and the reasons why knowledge of genetic parentage engages significant identity-related interests have not been adequately articulated. It seeks to address these gaps by offering a particular conception of the relationship between personal bioinformation and identity development. This both explains why access to this information might make a significant difference to our lives, and also accounts for the potential identity significance of a wider range of bioinformation.

The thesis develops this argument in two steps. First it looks to philosophical theories which hold that our identities are constituted by our own evolving accounts of who we are, which provide the foundations for our self-understanding, values and actions. It builds on these theories by arguing that personal bioinformation can help us to develop and maintain the coherence of our identity narratives in the context of our experiences of biological existence. The second step, draws on empirical literature reporting individuals’ attitudes to receiving three kinds of bioinformation (about donor conception, genetic disease susceptibility, and neuroimaging-based psychiatric diagnoses) in order to illustrate, test the plausibility of, and refine the preceding theory-based argument.

On this basis, the thesis proposes that we have significant identity-related interests in our access to bioinformation. However, the illustrative examples highlight that how these interests are engaged can vary in different circumstances. Furthermore, they may involve protection from bioinformation as well as accessing it. And the way in which bioinformation is communicated to us may be as important as whether we receive it. The thesis concludes by providing an ethical framework that sets out the disclosure-related responsibilities of those

who hold our personal bioinformation. This framework is intended to guide the delivery of policies and practices that protect our identity interests. In particular, it makes recommendations about approaches to communicating bioinformation in a way that supports our identity development.

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DECLARATION

As per Regulation 25 of the Postgraduate Assessment Regulations for Research Degrees (Academic Year 2016/17) I declare that this thesis has been composed by me. The work presented is entirely my own, except where explicitly indicated otherwise throughout the thesis by reference or acknowledgment. This work has not been submitted for any other degree or professional qualification.

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A handwritten signature in black ink, appearing to read "Emily Postan", followed by a period.

Emily Postan

26 June 2017

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PART I – THEORETICAL FOUNDATIONS

CHAPTER 1: THE AIMS AND SCOPE OF THIS THESIS

SECTION 1: THE MOTIVATION FOR THIS INQUIRY

This thesis is a bioethical analysis concerned with individuals' access to information about their own health, bodies and biology. It addresses the ethical question of which interests should be taken into consideration by laws, policies and practices that determine whether and how an individual may access these kinds of information. Specifically, the central contention that I will defend over the following chapters is that an individual's identity-related interests should be key consideration in decisions about disclosure to her of – what I shall term – her 'personal bioinformation'.¹

This contention is based on my argument (which I present in Chapter 3) that, given the embodied nature of our existence, personal bioinformation can play a crucial part in the construction of the narratives that constitute our identities. I will go on to provide grounds for holding that this conception of the relationship between bioinformation and identity is commensurate with evidence of people's lived experiences. I shall argue that this relationship carries the requisite normative weight to explain why access to personal bioinformation can give rise to ethically significant interests. By 'ethically significant' I mean that these interests pertain to our capacities to lead rich and fulfilling lives and, as such, are sufficiently great to give rise to responsibilities amongst those who might be in a position to disclose personal bioinformation to us.

My impetus for developing this argument arises from the debate in bioethical, social science and policy-focused literature about the value of knowledge of one's genetic parentage – often discussed specifically in relation to donor-conceived individuals' access to information about their donor origins.² The idea that knowledge of our genetic origins is important to our identities is also reflected in European human rights law and UK policy on donor conception (as I will outline later in this chapter).³ However, this thesis does not unquestioningly accept the (diverse) existing arguments for the identity significance of this particular kind of information.

¹ I explain what I will mean by 'personal bioinformation' and 'identity' in Section 2 below.

² See Chapter 2 and Chapter 5.

³ See Section 3.

On the contrary, I will suggest that, as they stand, many of the arguments relating to genetic origins exhibit one or more of the following three limitations.⁴ The precise nature of the relationship between information about genetic origins and identity often remains underdeveloped. Alternatively the value of this information is premised on questionable assumptions about the necessity of this information to a ‘complete’ identity. The third problem is the implied exceptionalism of many these arguments, which are presented as applying narrowly to information about our genetic origins. It seems arbitrary and implausible that this is the *only* kind of information about our biological existences that is, or could be, significant to our identities. My suspicion about this exceptionalism is one of the central motives for the present research project. But this suspicion is twinned with an optimistic rather than sceptical stance towards intimations of identity-significance. The arguments to be presented in this project are an attempt to rectify the peculiar exceptionalism of the genetic-origins-focused arguments. I seek to extend claims of possible identity-significance to information about our health, bodies and biology more widely, while demonstrating that the assertion of even strong interests in this information need not entail a bio-essentialist or bio-reductive picture of identity.

My research questions

This inquiry is not an abstract exercise. It has a practical and ethical implications for how individuals’ access to personal bioinformation is managed and regulated. In Section 3 of this chapter I will illustrate the relative lack of legal or regulatory attention to individual’s identity-related interests in accessing bioinformation about themselves.⁵ I suggest that the problem is not only one of scope – again, the purview is chiefly confined to information about genetic parentage – but also in the lack of adequate articulation of the relationship between information and identity in these provisions.

The problems or gaps that that this research seeks to address, therefore, are twofold. The first is the limitations of existing normative conceptions of the relationship between identity and personal bioinformation. The second, is the inadequacy of the protection currently offered to information subjects’ identity-related interests in respect of their access to personal bioinformation.⁶ The second cannot be rectified without addressing the first. This project seeks

⁴ See Chapters 2 and 3.

⁵ I restrict my discussion here to examples of policies and laws that apply or have some influence within UK jurisdictions for pragmatic reasons of limited space. The conceptual and ethical conclusions drawn in this project however are intended to be applicable beyond any specific jurisdiction.

⁶ See Section 3 below.

to address the first gap, by developing and defending a plausible, normative account of the role that information about our health, bodies and biology can play in identity – one which explains the ethical significance of this role and avoids arbitrary exceptionalism. This provides a robust basis for starting to address the second gap. To that end, I develop an ethical framework to inform the protection of identity interests through practices and policies governing access to personal bioinformation.⁷ To reach that point, this thesis will address the following four headline research questions:

- i. **How might the relationship between personal bioinformation and our identities be conceptualised?** (Chapters 2, 3 and 8)
- ii. **What grounds are there for holding that the conception of the relationship proposed in this thesis is robust and plausible in light of people’s actual experiences?** (Chapters 4-7)
- iii. **Building on the answers to these questions, what are the nature and scope of our identity-related interests in accessing personal bioinformation?** (Chapters 8 and 9)
- iv. **Given these interests, what ethical responsibilities for disclosure accrue to those who hold personal bioinformation about us?** (Chapter 9)

Aims of this chapter

Having established the defining aims of this research, there are three remaining tasks for this opening chapter. In Section 2, I will set out the scope of this project by clarifying what I will mean by the two phrases/terms that lie at its heart: ‘*personal bioinformation*’ and ‘*identity*’. In doing so, I will also indicate the kinds of circumstances which I will take to be paradigmatic of the instances in which identity interests might arise and warrant attention. In Section 3 I will provide the grounds for my assertion that any identity-related interests that information subjects might have in respect of access to their own bioinformation currently remains inadequately articulated or protected and in law and policy. Finally, in Section 4, I will provide a brief overview of the matters covered in each of the subsequent chapters.

SECTION 2: DEFINING TERMINOLOGY AND SCOPE

My initial task is to set the scene by clarifying the kinds of information and circumstances that I have in mind in posing the research questions above. None of the lines of demarcation suggested in this section are intended to be unique to an inquiry about identity-related interests.

⁷ See Chapter 9.

My aim in this thesis is to interrogate how identity interests operate in broadly the same kinds of circumstances as those in which questions about the ethical uses and handling of information about our health, bodies or biological relationships currently arise.

What is personal bioinformation?

First it is necessary to explain what I will mean by the term ‘personal bioinformation’. My aim is not to provide necessary and sufficient conditions for a precise definition, but rather a practical, working understanding which will inevitably leave some fuzzy edges. The term is intended simply as a contraction of ‘personal biological information’. It is used in this thesis for purposes of brevity – grouping together diverse information, arising in varied contexts. It is not intended to signal a special *subcategory* of health-related or biological information. On the contrary, it is intended to capture something relatively straightforward and familiar – that is, *information about ourselves as individual biological beings*.

One example of a description of the cluster of information I have in mind is provided by the Nuffield Council on Bioethics report ‘*The Collection, Linking and Use of Data in Biomedical Research and Health Care: Ethical Issues*’. That report set its sights on the “...growing accumulation of data, of increasing variety, about human biology, health, disease and functioning, derived ultimately from the study of people.”⁸ The report notes that these data are generated, accumulated and used in and for a number of contexts including: clinical care; research including clinical trials and observational studies; commercial direct-to-consumer (hereafter ‘DTC’) testing services; device-enabled “life-logging”; laboratory analysis; and administrative functions.⁹ The Council’s report concerned the use of large data sets, rather than matters of individual access. Nevertheless, this description of its scope provides a useful sketch of what I intend to capture under ‘personal bioinformation’ in this project. Innocuous though the words ‘personal’, ‘biological’ and ‘information’ might seem, it is necessary to say a bit more about what each denotes in the present context.

Information

According to information systems theory the ‘information hierarchy pyramid’ comprises, in ascending order, data, information, knowledge and wisdom – where each layer depends on the

⁸ Nuffield Council on Bioethics, *The Collection, Linking and Use of Data in Biomedical Research and Health Care: Ethical Issues* (2015), p.7. I shall return to unpack the distinction between data and information below.

⁹ *Ibid.*, p.4.

preceding one and adds value or meaning.¹⁰ In both ordinary and regulatory usage there is often slippage between the terms ‘data’ and ‘information’, with data often used to mean information.¹¹ This project is concerned with transactions in information as defined by the ‘General Definition of Information’, according to which, “information = data + interpretation”.¹²

Data may be thought of as observed states of affairs that provide raw material for interpretation. Interpretation involves the processing, organisation, structuring, classification and aggregation of data in a particular context and with a particular purpose such that it becomes *about* something.¹³ I will follow Mark Taylor in terming this context and purpose, the “interpretive framework”.¹⁴ Interpretation transforms data into potentially meaningful and useful information.¹⁵ Different interpretative frameworks may be applied to the same data. The nature of the information derived, therefore, depends on the nature of the framework applied, such that “...different individuals may extract different realized information from the same fact.”¹⁶ Furthermore, interpretation is not a one-off transformation as the pyramid model might imply. Taylor suggests that we can usefully think of information as having both an “interpretive pedigree” (i.e. the interpretation(s) which have already been applied to it) and “interpretive potential” (i.e. the ways that could go on to be further interpreted).¹⁷ Information, therefore, is not an inert artefact with a fixed meaning, but dynamic and changeable as successive layers of interpretation supplant each other or accumulate like a palimpsest.

This project is concerned with information about our biological existence, particularly insofar as it contributes to knowledge and understanding of this existence. In line with common usage, I will take it that personal bioinformation, like any other information, can be true or false, and more, or less, specific, reliable or comprehensible. As I will argue in Chapters 8, insofar as personal bioinformation’s veracity, specificity, reliability and intelligibility are pertinent to its

¹⁰ J. Rowley (2007), "The Wisdom Hierarchy: Representations of the DIKW Hierarchy" *Journal of Information Science*, 33(2): 163-80.

¹¹ One example of using the term data to refer to information is the Data Protection Act 1998.

¹² M. Taylor, *Genetic Data and the Law: A Critical Perspective on Privacy Protection* (Cambridge Cambridge University Press, 2012), p.42.

¹³ G. Bellinger et al., "Data, Information, Knowledge, and Wisdom," www.systems-thinking.org/dikw/dikw.htm (accessed 9 June 2017).

¹⁴ Taylor (2012), p.53.

¹⁵ Rowley (2007), p171.

¹⁶ R.H. Wagner and É. Danchin (2010), "A Taxonomy of Biological Information" *Oikos*, 119(2): 203-09, p.207.

¹⁷ Taylor (2012), p.41, p.42.

capacity to support knowledge of biological states of affairs, these qualities will also be relevant to its value to our identities.¹⁸

Biological

By ‘bioinformation’ I intend a category much wider than that about our health. In his analysis of what constitutes genetic data, Mark Taylor proposes that this category includes not only data derived from analysis of our genetic material, but also that which has been interpreted to be about genetic states of affairs.¹⁹ Borrowing Taylor’s approach, I shall take personal bioinformation to include both that which has been obtained by observation of, or tests upon, someone’s body or tissues, as well as that which is understood to convey something about someone’s (past, present and possible future) biological existence. Adopting Taylor’s two-strand definition means that, for example, information about a donor-conceived individual’s conception counts as bioinformation, insofar as it is understood to speak to her origins as an organism and her genetic relationships, even if the *source* of this information in a particular instance is administrative records or parents’ memories (rather than for example a genetic paternity test).²⁰ And mental health diagnoses based upon analysis of data about neural activity would also be included. Of course, information’s biological ‘interpretive pedigree’ in no way precludes further ‘interpretive potential’ of a distinct kind. In this project I am specifically interested in subsequent interpretations that add identity significance to biological significance (as I will discuss in Chapter 8).

Personal

Expressed in the most straightforward way, the ‘personal’ aspect of bioinformation is intended here to signal that the information has been interpreted to be about the biology of an *identifiable* individual. It purports to reveal something about an individual’s health, body or biological existence. This is not to overlook that some personal (most notably, genetic) bioinformation is inherently and inescapably shared with others.²¹ This sharing need not undermine its labelling as ‘personal’ – it can be personal to more than one person. Furthermore, genetic bioinformation about me could be derived from analysis of a tissue sample from a close relative, or from studying my family history.²² And in many areas of contemporary

¹⁸ For the purposes of what follows I will take it that *knowledge* cannot be premised on false beliefs. See, J.J. Ichikawa and M. Steup, "The Analysis of Knowledge," in *The Stanford Encyclopedia of Philosophy* ed. E.N. Zalta (Winter, 2016).

¹⁹ Taylor (2012).

²⁰ This is not to say that information about donor origins is only or chiefly about someone’s biology.

²¹ H. Widdows, *The Connected Self: The Ethics and Governance of the Genetic Individual* (Cambridge: Cambridge University Press, 2013).

²² Taylor (2012).

biomedicine, such as genomics or functional neuroimaging, individual disease susceptibility estimates rely on risk profiles built from data collected from many other individuals.²³ Being personal, therefore, does not preclude the derivation of information wholly, or in part, from data from sources other than the body or tissues of the individual in question or being shared with others. What is relevant is whether it is then interpreted to be about one or more particular, identifiable individuals. The focus of this project is on the interests of these individuals in respect of accessing this information. I shall refer to these individuals as 'information subjects'.²⁴

Recognition of the often inherently shared nature of some personal bioinformation notwithstanding, the present focus on its personal nature and the access interests of particular subjects/recipients might still seem unhappily individualistic. As Heather Widdows has argued, conceiving of genetic information as belonging to someone and engaging her interests *qua* discrete individual can lead us to miss or to misrepresent the shared values and interests at stake – including those relating to identity – and thus fail to ground adequate protection for them.²⁵ This is an important objection. Identity-related interests in the uses of bioinformation are indeed not limited or reducible to those incurred by their impacts on individual information subjects *qua* individual recipients. For example, research conducted using genetic data collected from the North American Havasupai people revealed genetic markers that indicated their origins were not in the Grand Canyon as their origins stories told.²⁶ As Widdows argues, the impact of this revelation on the identity and lives of the Havasupai people cannot be captured by thinking of this in terms of its relevance to or impact upon individual members of the tribe.²⁷ If it matters to any individual it does so because it matters to the group.

Having acknowledged this, though, I must set aside issues of the collective identity-related interests of groups here as lying beyond the scope of this project. This is not because they are not real or important, but because the starting point for my research questions is not to ask in what myriad ways bioinformation can affect identity, but to *examine the key interests in play*

²³ See, for example, D. Cooper et al. (2013), "Towards Clinically Useful Neuroimaging in Psychiatric Practice" *The British Journal of Psychiatry*, 203(4): 242-44; A. Vieth (2010), "Conceptual and Ethical Problems in the Epistemology of Genetic Information" *New Genetics and Society*, 29(1): 103-16.

²⁴ I shall use the term 'information subject' in this thesis to refer to the individual to whom the personal bioinformation pertains. It is not my intention to import the specific definition or connotations of this term as used in data protection law.

²⁵ Widdows (2013).

²⁶ K. Van Assche et al. (2013), "Protecting Dignitary Interests of Biobank Research Participants: Lessons from Havasupai Tribe v Arizona Board of Regents" *Law, Innovation and Technology*, 5(1): 54-84.

²⁷ Widdows (2013).

when providing or denying an individual access to bioinformation about herself. However, the account of identity to be presented in this project (and the role of information in this) is not an individualistic one. It will be central to what I will argue that, first, identity development is inherently relational and not something we can undertake in isolation from others.²⁸ And, secondly, how we interpret personal bioinformation and, specifically, the significance and value we understand it as having for our own identities cannot be separated from, *inter alia*: our identification as members of groups and in relation to others; how other people interpret the significance of particular bioinformation; and how bioinformation might impact on the lives and identities of those with whom we share it.²⁹ Widdows contends that genetic information “is not only, and arguably not even primarily, about the individual”.³⁰ While recognising this, I would suggest, there are still important ethical matters to attend to in respect of the impacts of genetic and other bioinformation’s on individual information subjects’ identities, even if in order to understand these we often need to look beyond the individual herself.

What kinds of information and in what contexts?

It is of course possible that some kinds of personal bioinformation that fulfil the above description will be available to us through our own direct observations and experiences. However, because the central ethical question of this project concerns information subjects’ interest in *accessing* information, it will focus upon personal bioinformation that is not readily observable by or directly accessible to the information subject herself, but rather that generated, acquired, or held by other parties. This includes information that requires specialist knowledge or techniques for its generation – for example, where it requires analysis of genomic markers. But it is not confined to this – for example, where parents know that they used donor gametes to conceive, while their offspring do not. The category under scrutiny is also not restricted to information that brings radically *new* news. For example, it could include diagnostic information that adds a fresh angle to someone’s existing understanding of her symptoms.

The focus, then, is upon information about our health, bodies and biology that is in the possession of, or available to, others because of the roles, skills, or opportunities that their positions afford them. These other parties could include those acting in a professional or institutional capacity, such as clinicians, researchers, providers of commercial testing services,

²⁸ See Chapter 2.

²⁹ See Chapter 8.

³⁰ Widdows (2013), p.36.

or regulators (for example where the Human Fertilisation and Embryology Authority (hereafter ‘the HFEA’) administers a register of those treated and gamete donors).³¹ It could also include private individuals, for example, if they are in possession of genetic health information about themselves that also applies to close relatives, or if they have undisclosed knowledge about genetic relationships within their family.

Some examples of the kinds of personal bioinformation with which this project is concerned include the following:

- The results of medical examinations and diagnostic tests;
- Findings from screening for disease susceptibility;
- Probabilistic genomic information about physiological, behavioural or dispositional traits;
- Findings from health-related research that are relevant to individual research participants (both results that the research intended to deliver and incidental findings);³²
- Accounts of treatment and other interventions held in patients’ records;
- Information about inherited disorders in family member’s health records or memories; and
- Information about genetic relationships in administrative records or family memories.

This list is illustrative rather than exhaustive. And it is pertinent that it includes information that is readily available to us – such as the findings from diagnostic tests; that which we are entitled to access even if it is not routinely supplied to us – such as the contents of our health records;³³ and that which we may have neither routine access nor entitlement in law – such as clinically insignificant incidental findings from health research in which we have participated,³⁴ or genetic information about a family member.³⁵ The research questions addressed in this project are relevant across all of these circumstances. They are intended to offer fresh, robust identity-based ethical grounds for providing access to information when the dominant current position is to not to do so (or vice versa). And, in addition, they aim also to

³¹ Human Fertilisation and Embryology Act 1990 (as amended), Section 31.

³² Incidental findings are findings, pertaining to individual participants, generated during research that were not amongst the research’s intended aims or outputs.

³³ Patients have a legal right to apply for access to their own patient records (subject to some conditions and exemptions) under Section 7 of the Data Protection Act 1998.

³⁴ S.M. Wolf et al. (2008), "The Law of Incidental Findings in Human Subjects Research: Establishing Researchers' Duties" *The Journal of Law, Medicine & Ethics*, 36(2): 361-83.

³⁵ R. Gilbar and C. Foster (2016), "Doctors’ Liability to the Patient's Relatives in Genetic Medicine" *Medical law review*, 24(1): 112-23.

signal where attention to identity-interests in the *manner* of disclosure would be warranted, even if they do not provide new positions on *whether* to disclose (as I discuss further in Chapter 9).

The arguments and recommendations of this thesis are intended to apply to information generated in diverse fields of healthcare, medicine and bioscience. It could include, for example, physiological, genetic, neurological, reproductive, metabolic, and developmental information. And it could pertain to facts about individuals' past, present and possible future health, the states, functioning and dispositions of their bodies and biology, and their biological relationships to others. The intention is to start with an inclusive category. However, in chapter 8 I will consider what might account for some categories of personal bioinformation being seen as having greater significance to our identities than others. Crucially, the arguments that I will offer are intended to apply far beyond the usual suspects of circumstances in which connections between bioinformation and identity are most commonly invoked – namely, in relation to genetic parentage, genetic traits, or genetic markers of ancestral provenance.³⁶

Having said this, it is my hope that the analysis offered in this thesis will contribute a fresh and robust perspective to those existing debates, as well as opening up new areas that warrant attention from an identity perspective. Although space precludes specific analysis here, contemporary debates to which the arguments of my thesis might usefully contribute include, for example, those about: the extent of researchers' responsibilities for returning individually-relevant research findings to participants; the interests of mitochondrial donor-conceived individuals in knowing about their donors; ethical issues raised by the introduction of routine non-invasive prenatal testing or whole genome screening at birth; concerns relating to the emerging market in DTC neuroimaging; and the collection and analysis of increasing quantities of data by smart wearable (or implanted) health monitoring technologies.

What do I mean by identity?

This interdisciplinary project spans philosophical and bioethical fields of enquiry, while also drawing on social science literature and legal, regulatory and policy texts. Across these contexts 'identity' is used in a number of different ways. And, in some contexts there may be slippage or ambiguity about which of these different senses is intended.³⁷ The matter of what

³⁶ See, for example, C. Hauskeller, "Human Genomics as Identity Politics," in *Award Paper for Young Scholar Conference, Cornell University 7-9 April 2006* (2006); A. Nordgren and E.T. Juengst (2009), "Can Genomics Tell Me Who I Am? Essentialistic Rhetoric in Direct-to-Consumer DNA Testing" *New Genetics and Society*, 28(2): 157-72.

³⁷ For example, as noted in Section 3 below, in human rights law there may be an elision of numerical identity, identity-as-characterisation and essentialist conceptions of human identity.

I will mean by identity in this project will receive detailed attention in Chapter 2. Here, however, I wish to draw some basic lines of distinction between the conception of identity at the heart of this project and some other senses in which ‘identity’ may be invoked in relation to personal bioinformation.

Identity as characterisation

This thesis is concerned with identity as *characterisation*. ‘Identity’ in this sense is understood to refer to ‘who someone is’ in terms of the totality of the characteristics with which she may be identified and that define her as an individual. As such, identity is used in a global or holistic sense, rather than just to refer to aspects of who someone is or specific *identifiers*. Identity, in this sense is what is at stake in what Marya Schechtman’s terms, the “characterization question” – that is, the question of which characteristics, beliefs, values and actions are “truly attributable” to a person.³⁸ This is the way in which ‘identity’ is perhaps most commonly used in everyday contexts. For example, it is what is understood to be in jeopardy when we talk about someone having an ‘identity crisis’, or acting in a way that is ‘true to who she is’.³⁹

I shall argue in this thesis that it is identity in the characterisation sense that is at stake where matters of an individual’s *own* interests in access to her *own* personal bioinformation are concerned (as contrasted with the six other senses of identity outlined below). This is the sense of identity that is (for the most part) at the heart of the academic and policy discussions about the importance of knowing one’s genetic parentage, in which the value (or lack thereof) of this information to an individual’s ability to make sense of or develop who she is as an individual that is debated.⁴⁰ For reasons I outline in Chapter 2, this thesis will take as its theoretical and normative foundation a conception of identity as constituted by our own self-constructed narratives of who we are. I will argue over the coming chapters that personal bioinformation can play a critical part in our abilities to construct, make sense of and inhabit our own self-narratives. To be more specific, then, this thesis is concerned with identity in the sense of *self-characterisation*.

To further demarcate my focus on identity as self-characterisation, I will briefly say something more about some others senses in which identity may be invoked in relation to personal

³⁸ M. Schechtman, *The Constitution of Selves* (Ithaca: Cornell University Press, 1996), p.74, p.76.

³⁹ D. DeGrazia, *Human Identity and Bioethics* (New York: Cambridge University Press, 2005).

⁴⁰ Nuffield Council on Bioethics, ‘*Donor Conception: Ethical Aspects of Information Sharing*’ (2013). See Section 3 of this chapter and Chapters 3 and 5 below for examples of such arguments.

bioinformation, and how these intersect with, or should be distinguished from identity of the kind on which this thesis will concentrate.

First there are three senses that intersect to some degree with self-characterisation.

Social identity

‘Social identity’ refers to the ways in which we are defined – by ourselves and others – by reference to our membership of specific social groups – for example, gender, ethnicity or health-status.⁴¹ A number of authors whose work informs this thesis have arguments that particular kinds of bioinformation – such as the results from genomic testing – may play a roles in, variously, establishing, shaping, reinforcing, reifying or naturalising categories of social identifiers. I will outline some of these arguments further in Chapter 2.

Practical identity

‘Practical identity’ refers to a means of characterisation that is more than just a descriptive label, it has a normative component connected to agency. A practical identity is, in Christine Korsgaard’s terminology, “a role with a point”.⁴² That is to say, it provides an individual with reasons to act in ways that are characteristic to that a role, and it is reinforced, or undermined, to the extent that we do, or do not, act in such ways.⁴³ ‘Practical identity’ may be used to refer to unitary characteristics, of which we may have several (someone is a daughter *and* an athlete), or with reference to the overarching whole of who someone is.

Personal identity

This sense of identity is at stake when questions arise – chiefly in philosophical contexts, but also legal ones – about the individuation and temporal continuation of persons. For example, what makes an elderly person with severe dementia the same *person* as the seventy year old who wrote an advance directive regarding her care in the event of loss of capacity?⁴⁴ Whether and how personal bioinformation could be implicated in such questions will depend on the definition of person and the identity criterion posited.

⁴¹ M.A. Hogg, 'Social Identity Theory', in *Contemporary Social Psychological Theories*, ed. P.J. Burke: 11-136 (Stanford, CA: Stanford University Press, 2006).

⁴² C.M. Korsgaard, *Self-Constitution: Agency, Identity, and Integrity* (Oxford, New York: Oxford University Press, 2009), p.21.

⁴³ C. Mackenzie and M. Walker, 'Neurotechnologies, Personal Identity, and the Ethics of Authenticity', in *Handbook of Neuroethics* (Dordrecht: Springer, 2015).

⁴⁴ A. Buchanan (1988), "Advance Directives and the Personal Identity Problem" *Philosophy & Public Affairs*: 277-302.

My focus on self-characterisation does not exclude concern with identity understood in the social, or practical senses. There is considerable overlap between these and identity as self-characterisation. On some views (including that which I defend in this project) one's self-characterisation as a whole may be seen as a composite practical identity.⁴⁵ And our broad self-characterisations are very likely to be constituted, in part, by specific social identifiers and normative roles. Nevertheless, over the following chapters I shall demonstrate that the role that personal bioinformation can play in our self-characterisations extends far beyond the ascription of discrete self-descriptors.

Similarly, matters of self-characterisation closely connected to matters of personal identity. Schechtman has maintained that self-characterisation captures the respect in which "personal identity matters to us at all".⁴⁶ By this she means that many the ethical and practical questions with which theories of personal identity tend to be concerned – for example, the questions of whether I would still exist following loss of cognitive capacities, and which of my behaviour I may be held morally responsible for – may be answered by reference to the degree of continuity and coherence of my self-characterisation.⁴⁷

There are also the following three senses in which identity may be used, which are not relevant to the present thesis.

Numerical identity

This sense of identity concerns logical question of whether one thing is literally one and the same thing as another (not just qualitatively the same). Personal bioinformation might be implicated in identity in this sense, for example, when biometric information is used on an ID card to verify that the person in possession of it is the legitimate card-holder, or when genetic analysis is used to ascertain whether, for example, someone is the individual who left a blood stain at a crime scene.⁴⁸

⁴⁵ C. Mackenzie, 'Introduction: Practical Identity and Narrative Agency', in *Practical Identity and Narrative Agency*, ed. C. Mackenzie and K. Atkins (New York: Routledge, 2008).

⁴⁶ Schechtman (1996), p.1. In this respect, the argument I shall present in Chapter 3 entails that access to personal bioinformation could have implications for how we constitute ourselves as persisting persons, but not how we ascertain our own persistence.

⁴⁷ In her more recent work Schechtman's position on has changed somewhat. She still holds that our narrative self-characterisations are germane to the phenomenology of selfhood and to practical questions about agency and concern for our own futures, but no longer maintains that they are sufficient to answer address all metaphysical questions about the "literal" identity of persons. See M. Schechtman, *Staying Alive: Personal Identity, Practical Concerns, and the Unity of a Life*. (Oxford: Oxford University Press, 2014).

⁴⁸ DeGrazia (2005).

Species identity

Questions about whether something – for example, an embryo, or a cyborg – is or is not a member of the human species might plausibly be settled by appeal to personal bioinformation, such as genomic information or phenotypic characteristics.

Public image

In some contexts – for example human rights law – an individual’s public image or persona is referred to as her identity. Personal bioinformation might be taken to engage interests relating to identity in this sense when, for example, images of someone’s face or body are used or disclosed without their consent.⁴⁹

In excluding these three senses from my discussion, my intention is not to deny that personal bioinformation might be implicated in important interests we might have in respect of numerical identity, public image or species questions – for example, where its misuse permits identity fraud, or where public knowledge of one’s health history affects one’s reputation, or even (just about conceivably) where it speaks to the impact of chimeric organ transplants on our human identity. But I would contend that these are unlikely to be engaged by the matter of *our own* access to personal bioinformation about ourselves. Therefore, I will proceed on the basis that if someone has an interest in accessing her own bioinformation for identity reasons, that these reasons are overwhelmingly likely to pertain ultimately its impacts on her self-characterisation.

Questions lying beyond the scope of this thesis

It will be helpful here to clarify some questions that lie outwith the scope of this research. My task will be to conceptualise the nature of an information subject’s *own* interests relating to the impacts that her *own* access to personal bioinformation could have on her self-characterisation. This means that this inquiry is not *directly* concerned with matters of privacy or confidentiality, or with how other peoples’ access to personal bioinformation might impact upon the information subject’s identity.⁵⁰ For example, I will not address concerns about

⁴⁹ For example, *Von Hannover v Germany* (Application no. 59320/00) (2004) 40 EHRR 1.

⁵⁰ See, for example, B. Ajana (2010), "Recombinant Identities: Biometrics and Narrative Bioethics" *Journal of Bioethical Inquiry*, 7(2): 237-58. Ajana address ways in which biometric data may impact indirectly upon the identity narratives of asylum seekers, when these data are used by immigration officials to categorise these individuals or challenge their own accounts of their lives.

matters such as the use of health information to discriminate against individuals, or the potentially stigmatising effects one's genetic data being retained on a forensic database. I will similarly not be *directly* concerned with how other people's interests might be affected by an individual's access to her own personal bioinformation – for example, the distress that parents may feel upon their daughter learning she is donor conceived. Although each of these scenarios raises important ethical questions, they lie beyond the scope of this inquiry.

Having said this, a central aspect of the account to be developed here is that we do not and cannot build our identities in isolation from our relationships with others and the ways that they use or react to information about us. Therefore, despite not addressing others' uses of information or their interests directly, the following three considerations will be key to what I have to say. First, the interpretations that others apply to, or meaning that they invest in, our personal bioinformation may well inform or shape the relevance and value we invest in it for our own identities (see Chapter 8). Secondly, genetic information is personal bioinformation we share with others and this may shape the role it plays in our identities (see Chapters 5 and 6). Thirdly, in disclosure decisions, individuals' interests in (not) accessing their own personal bioinformation must be weighed against the impact this has on the interests of others (see Chapter 9).

Having clarified the scope of this project, I will now turn to consider one of the central gaps that this project seeks to help to address – the paucity of adequate recognition in law or policy of information subjects' identity-related interests in accessing their personal bioinformation. The following section poses the more general question of the extent to which the potential value of personal bioinformation to identity (understood broadly as self-characterisation) is recognised or articulated in law or policy at all.

SECTION 3: EXISTING LEGAL AND POLICY PROTECTION OF IDENTITY-RELATED INTERESTS IN ACCESSING PERSONAL BIOINFORMATION

It would be unwarranted to claim that attention to identity-related interests in accessing biological information about oneself is wholly absent from the legal and policy landscape in the UK. But, as this section will illustrate, the conception of the relationship between bioinformation and identity underpinning the protected interest(s) is problematically narrow, ambiguous and, in some cases, essentialist.

International human rights law

International instruments concerned with human rights and biomedicine

Two international instruments may be seen as drawing a broad, high level connection between the identity significance of genetic or health data and the entitlement of individuals (not) to access it – one more explicitly than the other.

The first is the European (*Oviedo*) *Convention on Human Rights and Biomedicine*, which has the central aim of protecting the “dignity and identity of all human beings”,⁵¹ and holds that:

“Everyone is entitled to know any information collected about his health. However the wishes of an individual not to be so informed shall be observed.”⁵²

This entitlement is not absolute, but may be overridden in “interests of the patient”.⁵³

The second is the *International Declaration on Human Genetic Data* holds that:

“No one should be denied access to his or her own genetic data or proteomic data unless such data are irretrievably unlinked to that person ... or unless domestic law limits such access in the interest of public health, public order or national security.”⁵⁴

This right is associated with the “special status” of human genetic data, which is held to relate, *inter alia*, to its predictive capacities and “cultural significance” in ways that can have a “significant impact” on individuals, families and groups.⁵⁵

These instruments have marked limitations with respect to the protection of a putative identity-related interest in accessing one’s own bioinformation. Not only do they lack direct enforcement routes (indeed, the UK has neither signed nor ratified the Oviedo Convention), it is also unclear exactly what is meant by ‘identity’, ‘significant impacts’ and ‘cultural significance’ in these contexts, or how (in)access one’s own health or genetic information is seen as impacting upon them. Hauskeller has suggested that these instruments instantiate a problematic genetic essentialism:⁵⁶ that is, they reflect an unwarranted assumption that our genetic heritage defines who we are – either as individuals or *qua* human persons.

⁵¹ Council of Europe, 'Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine' (4 April 1997), Article 1.

⁵² *Ibid.*, Article 10(2).

⁵³ *Ibid.*

⁵⁴ UNESCO, 'International Declaration on Human Genetic Data' (16 October 2003), Article 13.

⁵⁵ *Ibid.*, Article 4.

⁵⁶ C. Hauskeller (2004), "Genes, Genomes and Identity: Projections on Matter" *New Genetics and Society*, 23(3): 285-99.

UN Convention on the Rights of the Child

Article 8 of the UN *Convention on the Rights of the Child* (hereafter, UNCRC) recognises a child's right "to preserve his or her identity, including nationality, name and family relations", and Article 7 protects a right to birth registration.⁵⁷ 'Identity' as used in this context refers to some extent to the administrative details that track the numerical sameness of individuals. However, the UN Committee on the Rights of the Child has interpreted Article 7 as protecting a child's right to know her genetic parentage.⁵⁸ And George Stewart argues that Article 8 of the UNCRC includes the right to know one's "biological identity".⁵⁹ In this he includes entitlements to medical information, but only insofar as these directly pertain to conditions inherited from one's genetic parents. Thus, he effectively reduces the protection offered to information-related identity interests to genetic information with clinical utility. This instrument too lacks direct means of enforcement.

European Convention on Human Rights and the 'right to identity'

I will turn now to look at the 'right to know' that falls under the 'right to identity' in European human rights law.⁶⁰ I shall dedicate more space to this provision for two reasons. First, the sense of identity in play is related, if not identical, to the idea of self-characterisation on which the present project is based (although as I outline below the European Court of Human Rights' (ECtHR) conception of this is somewhat problematic). Secondly, because the ECtHR provides the highest appellate court in Europe and is charged with adjudicating on matters of core human value, what it has to say about the relationship between identity and bioinformation really matters. It not only influences domestic law and policy but also has the capacity to promulgate ethical norms.⁶¹ In the UK, the rights conferred under the ECHR are given further effect under the Human Rights Act 1998.

The 'right to identity' is one of the constituent rights nested within the Article 8 right to respect for private and family life.⁶² This right has been interpreted in a number of ways, including

⁵⁷ United Nations 'Convention on the Rights of the Child' (1989)

⁵⁸ S. Besson (2007), "Enforcing the Child's Right to Know Her Origins: Contrasting Approaches under the Convention on the Rights of the Child and the European Convention on Human Rights" *International Journal of Law, Policy and the Family*, 21(2): 137-59; J. Fortin (2011), "Children's Right to Know Their Origins - Too Far, Too Fast?" *Child and Family Law Quarterly*, 21(3): 336-55.

⁵⁹ G.A. Stewart (1992), "Interpreting the Child's Right to Identity in the UN Convention on the Rights of the Child" *Family Law Quarterly*: 221-33.

⁶⁰ J. Marshall, *Human Rights Law and Personal Identity*, Routledge Research in Human Rights Law (London, New York: Routledge 2014).

⁶¹ *Ibid.*

⁶² D. Feldman (1997), "The Developing Scope of Article 8 of the European Convention on Human Rights" *European Human Rights Law Review* 3: 265-74; N.A. Moreham (2008), "The Right to

those concerned with public image, the right to retain one's name, and cultural, religious, gender and sexual identity.⁶³ However, a further sense in which the right to identity has been invoked is that in self-development.⁶⁴ This sense of the right to identity is of particular interest here because it has been held to be engaged by denial of access to information about oneself, specifically, information about one's early life or parentage.⁶⁵ The ECtHR has described this information as having "formative implications for [the applicant's] personality".⁶⁶ And the interests in accessing such information have been linked to the entitlement, under the right to respect for private life, that "everyone should be able to establish details of their identity as individual human beings"⁶⁷ and to the "right to personal development and to self-fulfilment".⁶⁸ Within the right to identity a specific kind of informational right has evolved – the "right to know [one's] origins",⁶⁹ or "the right to know one's parentage".⁷⁰ The vast majority of jurisprudence relating to this right concerns applicants' right to know (or have confirmed in law) their genetic parentage. This right has been held to be engaged, for example, when children or adults have been denied the opportunity to confirm the identities of their genetic fathers,⁷¹ or where domestic law permits mothers to give birth anonymously.⁷² Accessing information about one's origins "and thereby acquiring the ability to retrace one's personal history"⁷³ has been held to engage a "vital interest... in receiving the information necessary to uncover the truth about an important aspect of their personal identity."⁷⁴

As noted above, rights under Article 8 of the ECHR are not absolute. Interference with the right to know one's origins can be justified under Article 8(2) where lawful and necessary to protect a specified suite of other public and private interests. For example, in one case the privacy interests of the applicant's genetic mother and siblings, alongside the public interest

Respect for Private Life in the European Convention on Human Rights: A Re-Examination" *European Human Rights Law Review*, (1): 44-79.

⁶³ Marshall (2014).

⁶⁴ *Bensaid v United Kingdom*, (Application no. 44599/98) (2001) 33 EHRR 205.

⁶⁵ Marshall (2014).

⁶⁶ *Mikulic v Croatia* (Application no. 53176/99) (2002) 1 FCR 720. [54].

⁶⁷ *Gaskin v United Kingdom*, (10454/83) (1989) 12 EHRR 36. [39].

⁶⁸ *Odièvre v France*, (Application no. 42326/98) (2003) 38 EHRR 871, Joint Dissenting Opinion of Judges Wildhaber, Bratza, Bonello, Loucaides, Cabra, Barreto, Tulkens And Pellonpaa [3].

⁶⁹ *Ibid.* Concurring opinion of Judge Ress and Judge Curis [2].

⁷⁰ *Jaggi v Switzerland*, (Application no. 58757/00) (2008) 47 EHRR 30. [37]; T. Callus (2004), "Tempered Hope? A Qualified Right to Know One's Genetic Origin: *Odièvre v France*" *The Modern Law Review*, 67(4): 658-69.

⁷¹ *Jaggi v Switzerland*.

⁷² *Odièvre v France*. In this instance, the infringement of this right was found to be justified under Article 8(2), as outlined in the next paragraph.

⁷³ *Ibid.*, Dissenting opinion [3].

⁷⁴ *Jaggi v Switzerland*. [38]. The German Constitution also contains a right to develop one's personality, of which the one's biological origins is an important part (see, Marshall (2014)). I will not discuss this further here as my chief focus is on law that applies in the UK.

in providing opportunities for anonymous birth, were judged to outweigh the applicant's right to know who her genetic mother was.⁷⁵ Nevertheless, the underlying right to identity has been described as an "essential feature" and "within the inner core" of the right to respect for private life.⁷⁶ And it is held to be a positive right, with horizontal effect.⁷⁷ This means that states' obligations extend not only to refraining from obstructing access to this information in their own activities, but also to take steps supporting citizens in their enjoyment of this right, and to "secur[e] respect for private life in the sphere of the relations of individuals between themselves."⁷⁸ Two significant consequences being considered part of the 'inner core' are that "the fairest scrutiny" must be applied in balancing this right against countervailing considerations and in allowing states a margin of appreciation (local discretion) in discharging their obligations.⁷⁹ So, at first sight it looks as if Article 8 could offer broad and robust protection for interests in accessing bioinformation about oneself. However, the status of the entitlement to information is problematic for four reasons:

- ambiguity about nature of identity interests;
- implications of a genetically essentialist conception of identity;
- remedies that seem to belie the significance of the purported interests; and
- the surprisingly narrow the scope of the right to know.

I shall address these in turn.

The first shortcoming is that judgments appear to slip between, or even elide, various different senses of identity without signalling their very different personal and ethical implications. For example, the judgment in *Daróczy v Hungary* moves between discussion of identity in the numerical sense and self-characterisation.⁸⁰ Judgments also often use the terminology of identity, autonomy and integrity seemingly interchangeably.⁸¹ This signals a lack of clarity about what the right to identity means or covers.

⁷⁵ *Odièvre v France*.

⁷⁶ *Odièvre v France*, Dissenting opinion [11] and [3]; Callus (2004).

⁷⁷ J.-F. Akandji-Kombe, *Positive Obligations under the European Convention on Human Rights: A Guide to the Implementation of the European Convention on Human Rights* (Council of Europe, Human Rights Handbooks (no. 7), 2007).

⁷⁸ See, for example, *Jaggi v Switzerland*. [33].

⁷⁹ *Odièvre v France*, Dissenting opinion [11]; Callus (2004).

⁸⁰ For example, the judgment in *Daróczy v Hungary* (Application no. 44378/05) (2008) moves between discussion of identity in the numerical sense and self-characterisation. This case does not concern access to bioinformation, but rather the applicant's right to retain her name.

⁸¹ J. Marshall, *Personal Freedom through Human Rights Law? Autonomy, Identity and Integrity under the European Convention on Human Rights* (Leiden: Martinus Nijhoff Publishers, 2009).

Secondly, even where it is clear that the interest at stake is viewed as one in self-characterisation, the way the court represents this interest may be problematic. Jill Marshall argues that the ECtHR jurisprudence reflects a view of identity as pre-ordained rather than self-constructed, and that knowledge of genetic origins is presented as not merely useful for knowing who one is, but necessary. This is indeed suggested by the language of the judgment in *Mikulic v Croatia*, which held that information about origins is “information necessary to uncover the truth about an important aspect of their personal identity” [emphasis added].⁸² Meanwhile the dissenting judgment in *Odièvre v France* described this information as pertaining to the “essence” of identity.⁸³ Marshall argues such a view is potentially stigmatising – implying that those unaware of their origins have incomplete identities – and that by enforcing an idea of identity as “fixed and unchanging”, determined by our genes, the ECtHR “unduly restrains the development of our freedom to be and become our own persons”.⁸⁴

I would suggest that the evidence of such an essentialist conception is more equivocal than Marshall suggests. The jurisprudence refers not only to discovery but also the developmental and “formative” value of information to identity.⁸⁵ And some judgments have held that denial of confirmation of genetic parentage did *not* engage the right to identity – for example, where sought for inheritance purposes,⁸⁶ or where a child’s interests were held to lie in the undisturbed ‘social reality’ of her family.⁸⁷ This suggests that the ECtHR has taken the view that identity is not invariably harmed by not knowing. These counterexamples to Marshall’s critique notwithstanding, there is undeniably ambiguity in the Court’s reasoning about the relationship between information about origins and identity, which is in itself a problem for clarity about what is protected and where (non)access constitutes an identity harm.

The third limitation to the protection afforded under Article 8 is that there seems to be a mismatch between the ‘vital interest’ in self-shaping that this right is intended to protect and the perfunctory remedies permitted by the ECtHR. For example, at its most stark, in *Mikulic v Croatia* it is held that, if the presumed genetic father would not comply with genetic testing, then a presumption of parentage by domestic courts would fulfil the appellant’s right to identity.⁸⁸ Richard Blauwhoff suggests that the moral right invoked by the origins cases is that:

⁸² *Mikulic v Croatia* [54].

⁸³ *Odièvre v France*. Dissenting opinion [3].

⁸⁴ Marshall (2014), p.125.

⁸⁵ *Mikulic v Croatia* [54].

⁸⁶ For example, *Haas v the Netherlands*, (Application no. 36983/97) (2004) 1 FCR 147.

⁸⁷ For example, *Mizzi v Malta*, (Application no. 26111/02), (2006) 1 FLR 1048.

⁸⁸ *Mikulic v Croatia*

“not to be left to one’s own imagination as far as the story surrounding the circumstances at conception and birth”.⁸⁹

And it is indeed questionable whether this interest is really met by the mere results of a DNA test, or by amendments to an administrative record. In Chapters 8 and 9 I will consider the importance *how* bioinformation is presented to whether it is valuable to our identities.

The fourth (and most significant as far as this project is concerned) limitation of the ECtHR jurisprudence is that the kinds of information recognised as engaging the right to identity-as-self-shaping are strikingly narrow. It appears to include no categories of personal *bioinformation* other than that about genetic parentage.⁹⁰ For example, cases concerning denial of access to health records have not invoked the right to identity. This is absence is perhaps most striking in a case concerned with access to records of non-consensual sterilisation.⁹¹ One instance in which *non-biological* information has been held to be engaged the right to identity-as-self-development was that in which the identity-based right to know originated. In that case the information sought was local authority records of the appellant’s upbringing in care.⁹² But this judgment appears isolated. If the right to know one’s origins is derived from its instrumental role in fulfilling the right to identity then, I would suggest, one would expect to encounter a wider range of information also fulfilling this role, and perhaps even identity being invoked where a right *not* to know has been recognised under Article 8.⁹³ Such absences are peculiar and lend some weight to Marshall’s critique about the ECtHR’s essentialist conception of identity. The significance of this narrowness for the present project is that we cannot assume that the Article 8 right to identity would cover access to any wider categories of personal bioinformation.

⁸⁹ R.J. Blauwhoff (2008), "Tracing Down the Historical Development of the Legal Concept of the Right to Know One's Origins: Has 'to Know or Not to Know' Ever Been the Legal Question?" *Utrecht Law Review*, 4(2): 99-116, p104.

⁹⁰ This is not to say that the ECtHR has drawn no other connections between Article 8 and ‘bodily’ states of affairs. It has held that retention of genetic information by the state for forensic purposes can engage the right to private life (*S and Marper v United Kingdom* (Application no. 30562/04) (2009) 48 EHRR 50), and that reproductive choices and contact with one’s genetic children can engage the right to identity (*Evans v United Kingdom* (Application no. 6339/05) (2008) 46 EHRR 34 and *Anayo v Germany* (Application no. 20578/07) (2012) 55 EHRR 5 respectively), as can the capacities to express one’s sexuality or gender identity (*Dudgeon v United Kingdom* (Application no. 7525/76) (1981) 4 EHRR 149 and *Goodwin v United Kingdom* (Application no. 28957/95) (2002) 35 EHRR 18 respectively).

⁹¹ *KH and Others v Slovakia*, (Application no. 32881/04) [2009] ECHR 709, (2009) 27 BHRC 373.

⁹² *Gaskin v United Kingdom*; Marshall (2009).

⁹³ Appellants’ interests in not knowing their genetic parentage have been recognised as engaging Article 8(1), but not linked to the right to identity (*Mizzi v Malta*). Parental rights to confirmation of their genetic relationship to children have not been linked to parents’ right to identity *per se*. In one English case this link was actively dismissed, *Leeds Teaching Hospital NHS Trust v A and others* EWHC [2003] 259 (QB) [47].

Each of these shortcomings in what, at first sight, looks like a promising source of protection for individual's identity-related interests in accessing their personal bioinformation provides further impetus for the central aims of this research: to propose a robust, plausible and – importantly – inclusive account of the relationship between identity and bioinformation; and to characterise the associated interests relating to information access.

Regulation of donor conception in the UK

The ECtHR's jurisprudence on the right to identity may be seen as having influenced the law on donor-assisted conception in the UK. In the 2002 case of *Rose and Another v Secretary of State for Health and the Human Fertilisation and Embryology Authority* – in which the donor-conceived claimants sought information about their gamete donors – Justice Scott Baker held that this case was “really an identity case and involves the Claimants' rights to know about their origins”.⁹⁴ The judge found the right to identity under the Article 8 was engaged, but deferred judgment on whether breach was lawful because a UK government public consultation about donor anonymity was imminent.⁹⁵

Following this case and public consultation, revised Regulations came into force in 2005.⁹⁶ These remove donor anonymity, permit donor-conceived individuals to request some information about their donors from the HFEA, and facilitate contact between donor siblings. Access entitlements, however, extend only to those conceived through regulated treatment in the UK who meet statutory age thresholds. Donor-conceived individuals can request non-identifying donor information from sixteen years of age, and identifying information from eighteen, if they were conceived with gametes donated after April 2005.⁹⁷ However, being able to request this information depends on prior parental disclosure of the basic fact of donor-conception, which is not mandated in law. Clinics providing donor conception services are required in law to advise parents of the importance of telling and to provide advice on how to do so.⁹⁸ The HFEA guidance frames the benefits of telling in terms of avoidance of ‘emotional damage’ and harm to family relations.⁹⁹ But the HFEA has also expressed the policy view that

⁹⁴ *Rose v Secretary of State for Health & HFEA* [2002] EWHC 1593 (Admin), [2002] 2 FLR 962, [28].

⁹⁵ *Rose*; Department of Health, 'Donor Information Consultation: Providing Information About Gamete and Embryo Donors' (2001).

⁹⁶ "Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004 (S.I. 2004 No. 1511)." These changes have since been incorporated into the Human Fertilisation and Embryology Act 1990 (as amended) by the Human Fertilisation and Embryology Act 2008.

⁹⁷ Human Fertilisation and Embryology Act 1990 (as amended) s.31ZA. The provision of non-identifying information to offspring of sixteen or over now includes information about mitochondrial donors.

⁹⁸ Human Fertilisation and Embryology Act 1990 (as amended) s.13(6c).

⁹⁹ Human Fertilisation and Embryology Authority, 'Code of Practice' (2015), [20.7].

information about their donor origins “can help people complete a picture of their identity and it is natural to seek it.”¹⁰⁰

If one accepts the premise that personal bioinformation can be important to identity, then this evolution of UK law is welcome. But, as with the ECHR right to identity, in singling out the identity significance of knowledge of one’s genetic parentage it is similarly vulnerable to criticism that it reflects, and even promulgates, reductive genetic conceptions of family and identity.

Where does this leave protection of identity interests?

While it would be untrue to say that potential identity-related interests in some kinds of personal bioinformation are wholly absent from the existing legal and policy and practice landscape, the scope and articulation of these interests is problematic. In some instances the shortcoming amounts to a basic lack of clarity about what ‘identity’ denotes and how our (in)access to our bioinformation might impact on identity. But even where the underlying assumption does appear to be that the information in question contributes to self-characterisation – as in the right to know one’s origins under Article 8 of the ECHR – the scope of the entitlement is so narrow as to suggest an implausible and contentious genetic exceptionalism and essentialism.¹⁰¹

Of course, there are some legal routes by which individuals may obtain personal bioinformation which they might find useful for identity reasons, without the law needing to specify identity as grounds for access. For example, under data protection law, information subjects’ are entitled to access personal data about themselves, including their health records,¹⁰² and the ECHR Article 8 right to respect for privacy and family life includes a right to “practical and effective” access to one’s health records.¹⁰³ There are also common law grounds based in negligence for providing patients with information pertinent to their treatment¹⁰⁴ and these could in some circumstances extend to reporting individual research findings to participants where these carry health implications.¹⁰⁵ These more general

¹⁰⁰ Human Fertilisation and Embryology Authority 'HFEA Paper 485: Opening the Register Policy: A Principled Approach' (21 January 2009), para 10.1.

¹⁰¹ Marshall (2014).

¹⁰² Data Protection Act 1998, s.7; Data Protection (Subject Access Modification) (Health) Order 2000.

¹⁰³ *KH and Others v Slovakia*; M. Eijkholt (2010), "Sterilisation and the Birth of a Right: Effective Access to Medical Records" *Medical Law Review*, 18(1): 96-102.

¹⁰⁴ *Montgomery v Lanarkshire Health Board (Scotland)* [2015] UKSC 11. See Chapter 9 for further discussion of this and related cases.

¹⁰⁵ C. Johnston and J. Kaye (2004), "Does the UK Biobank Have a Legal Obligation to Feedback Individual Findings to Participants?" *Medical Law Review*, 12(3): 239-67.

provisions notwithstanding, it cannot be assumed that they will be sufficient to protect potential identity-related interests. First, they only apply to specific categories of information: ‘personal data’ as defined in law, health records, or to research findings exhibiting clinical utility. The second is that none of these represent absolute entitlements. Each of them allows for exceptions and for the weighing of information subjects’ rights or interest against competing considerations. If identity-related interests are not explicitly recognised they cannot be part of any such weighing.

Access need not be mandated in law for personal bioinformation to be made accessible on ethical or best practice grounds – for example, where a research protocol includes the provision of incidental findings to participants. However, as I shall outline in Chapter 9, the information subject’s interests that are most likely to be taken into account by such policies are those relating to her physical and psychological wellbeing and her autonomy. As I shall argue in that chapter, these interests may overlap with those relating to self-characterisation, but they are not coextensive.

The conceptual and ethical gaps this thesis will fill

The inadequacy of existing provisions exposes the gap that this research seeks to fill. I would concur with Marshall that it is indeed problematic if the law or policy were to instantiate or to entrench a narrow and prescriptive view of identity interests. However, unlike Marshall, I do not wish to hold that recognising and protecting the identity-significance of knowledge about genetic parentage (or any other aspect of one’s biological existence) *necessarily* commits one to an essentialist or exclusionary conception of identity. In order to defend this position it will be necessary for me to address the fundamental question of what the relationship between bioinformation and identity is. This in turn requires clarity about the conception of identity on which the account of this relationship is premised. As Heather Widdows observes:

“Pictures of the self are vitally important. If the picture of the self is wrong so too are the legal ethical and social structures which are built upon it. What matters to human beings is that key goods are protected and that possibilities of flourishing and wellbeing are ensured.”¹⁰⁶

In the next chapter I shall establish the picture of identity on which my subsequent arguments are based. I shall survey some prominent ways in which the relationship between specific kinds of personal bioinformation and identity (understood in ways broadly commensurate with self-characterisation) is characterised in the literature. I shall suggest that these on their own are unable to account for the potential impacts of a broad range of personal bioinformation on our

¹⁰⁶ Widdows (2013), p.6.

identities, or why these impacts matter. I propose that a conception of identity as constituted by our self-narratives provides a way of understanding how access to personal bioinformation can make a real difference to our identities in a way that affects our capacities to lead rich and fulfilling lives.

Over the subsequent chapters I will develop and defend the argument that, because of its possible impacts on the contents and coherence of the narratives that constitute our identities, we will have ethically significant interests in respect of whether and how we are able to access a wide variety of information about our health, bodies and biological relationships. I shall argue that these interests are sufficiently strong to give rise to responsibilities amongst those who hold identity-significant personal bioinformation about us and to be taken into account by information disclosure policies and practices. As I will demonstrate, the character and strength of these interests and the scope of these responsibilities will vary depending on the type of bioinformation in question, as well as individual, contextual and relational factors. Access provisions must be responsive to this diversity. For this reason, specifying precise policy or legal reforms across the many contexts in which issues of access to personal bioinformation arise lies beyond the scope of the present project. My aim in this thesis is to provide the conceptual basis and ethical framework on which any such reforms could be grounded. Without this foundation, attempts to offer adequate and coherent protection for identity interests in policy or law are jeopardised from the start.

SECTION 4: OUTLINE OF THE THESIS BY CHAPTER

Before closing this chapter I will briefly outline what each of the subsequent chapters will cover.

PART I: THEORETICAL FOUNDATIONS

In Part I of the thesis I set out the theory of narrative self-constitution and my own argument as to the role of personal bioinformation in this, to establish the conceptual and normative foundations for my practical recommendations.

Chapter 2: The Theory of Narrative Self-Constitution

Here I outline the philosophical theories of narrative identity on which my argument in this thesis is based. In doing so my aims are to establish what the key features of an identity-constituting self-narrative are, and to lay the normative foundations for my argument by explaining what values are at stake in the development of such a narrative, and the factors on which their attainment depends.

Chapter 3: The Role of Personal Bioinformation in Self-Narratives

I offer my original argument that personal bioinformation (as a broad category) has an important role to play in the construction of our self-narratives. This argument is based on the contention that we lead inescapably embodied existences. Given this and the normative features of identity-constituting narratives outlined in Chapter 2, I argue that personal bioinformation has a vital role to play in helping us to construct self-narratives that remain coherent within the context of embodied experiences and that support us in navigating these experiences.

PART II: THE ILLUSTRATIVE EXAMPLES

In Part II of the thesis I explore evidence, drawn from empirical literature, of people's attitudes to three categories of personal bioinformation. My aims in doing so are threefold: to illustrate the theoretically-based argument of Chapter 3; to assess the plausibility of that argument in light of information subjects' reported experiences; and to refine my claims in line with the evidence.

Chapter 4: Rationale and Methodology for the Illustrative Examples

Here I set out my rationale for looking to the illustrative examples discussed in the three subsequent chapters and my methodology for approaching the empirical literature.

Chapter 5: Illustrative Example I - Information about Donor Origins

I review what the empirical literature indicates about donor-conceived individuals' experiences of (not) having access to information about their donor conception and analyse what might be inferred from this evidence about the impacts of this information on their identities as narratively-conceived and the factors influencing these impacts. This is a category of personal bioinformation about which others have offered narrative explanations of identity-value. This chapter does not, therefore, provide a wholly novel analysis, but explores what my particular narrative perspective brings to understanding the potential identity value of this information, and detriment of not knowing.

Chapter 6: Illustrative Example II - Genetic Susceptibility Testing

I review what the empirical literature indicates about individuals' expectations of and responses to genetic susceptibility testing for two categories of serious, multifactorial disease: late onset Alzheimer's disease and hereditary breast and ovarian cancer. I then analyse what

might be inferred from this evidence about the impacts of this information on the identities (as narratively-conceived) on those tested, and the factors influencing these impacts. Through this narrative analysis I seek to demonstrate that identity impacts extend beyond those most often proposed in the literature, and that they can be decoupled from the clinical utility of this category of bioinformation.

Chapter 7: Example III - Diagnostic Psychiatric Neuroimaging

I review what the empirical literature indicates about individuals' expectations of diagnostic information about serious psychiatric illnesses generated through functional neuroimaging technologies (which are not yet in clinical use). I then analyse what might be inferred from these about the potential impacts of this information on patients' identities as narratively-conceived, and the factors influencing these impacts. I explore what a narrative analysis reveals about the potential identity roles and value of this information. In particular I examine the link between the epistemic limitations of neuroimaging-based diagnoses and identity detriment.

PART III: BUILDING AN ETHICAL FRAMEWORK

In Part III of this thesis I take stock of what the illustrative examples bring to understanding the relationship between identity and personal bioinformation in order to specify the nature of our interests in accessing this information, and the grounds and extent of others' responsibilities to meet these interests. On this basis I develop an ethical framework to guide information disclosure decisions.

Chapter 8: Refining the Theory: Accounting for Identity Value, Detriment and Significance

In this chapter I build on the illustrative chapters to make some refinements to my theoretically-based argument and move from discussion of the role of personal bioinformation (in general) in our identity narratives, to the questions of how and why *particular kinds of instances* of personal bioinformation might impact on our identities. To this end I use the evidence and analyses relating to the three illustrative examples to address three questions. The first asks what refinements the illustrative examples suggest need to be made to my normative argument developed in Chapter 3. The second unpacks what it means for personal bioinformation to play a valuable or a detrimental role in our identities in terms of its impacts on the character and coherence of our self-narratives. And the third considers what contributes to personal bioinformation playing any of these roles at all, that is, to its 'identity-significance'.

These questions provide the foundations for the discussions of interests and responsibilities in the next chapter.

Chapter 9: An Ethical Framework for Protecting Identity Interests in Practice

I review what the discussions of the preceding chapters entail for the nature and strength of our interest in accessing personal bioinformation. I specify a suite of three bioinformation-related identity interests – those in accessing some kinds of bioinformation, in being protected from others and, in receiving bioinformation in a way that supports identity development. Given the strength of these interests and the capacities of those holding bioinformation about us to respond to them, I propose a corresponding suite of *pro tanto* responsibilities accruing to those who hold bioinformation about us and practical recommendations for identity-supportive disclosure. I conclude by drawing all these elements together in an ethical framework for managing information access in a way that responds to identity interests.

Chapter 10: Concluding Remarks and Looking Forward

In the concluding chapter I take stock of the arguments that I have offered and the original contributions that these have made to ethical debates about individuals' interests in accessing their personal bioinformation. I review some key practical changes that are implied by these contributions and make some suggestions as to fruitful areas for further research that would build on the work of this thesis.

CHAPTER 2: THE THEORY OF NARRATIVE SELF-CONSTITUTION

SECTION 1: INTRODUCTION

This chapter addresses the first of the four headline research questions listed at the start of the preceding chapter: **how might the relationship between personal bioinformation and our identities be conceptualised?** The full answer to that question will be provided by my original argument that I will present in Chapter 3. This chapter lays the foundations for that argument. It does so in two steps.

My specific concern in this thesis is the relationship between personal bioinformation and identity in the context of information subjects' own access to this information.

My first step, then, will be briefly to survey some prominent accounts offered in the literature as to the relationship between our access to various kind of personal bioinformation and our identities, where identity is understood broadly in terms of self-characterisation. I will outline why none of these accounts on its own, or in combination, provides an adequate basis for explaining why a wide range of personal bioinformation might have sufficiently significant impacts on our identities to give rise to important interests in information access. I shall then propose that, if we understand our identities as being constituted by self-constructed narratives, to which personal bioinformation may contribute, this could indeed explain why access to this information matters in identity terms. However, I will argue further that in order fully to understand the role that personal bioinformation plays in our identity narratives, and the normative significance of that role, it is essential to understand what is entailed and implied by a theory of narrative self-constitution.

My second step towards laying the foundation for my original argument in this chapter, therefore, will be to outline the key contours of the theory of narrative self-constitution as presented in the philosophical literature. In doing so I will highlight the features of, and gaps in, this established theory on which my own novel propositions regarding the role of bioinformation in our self-narratives will depend. My review of this literature comprises the bulk of this chapter and will serve to reveal the theoretical and normative foundations of the research issue with which this thesis is concerned.

My particular research questions for this chapter are:

- i. In what ways do existing accounts of the relationship between personal bioinformation and identity fail adequately to explain why our access to a range of such information could have ethically significant consequences for how we develop and understand who we are? (Section 2)**

And, according to the narrative theory of identity on which this project is based:

- ii. What is the relationship between identity and self-narrative? (Section 4)**
- iii. What are necessary conditions for an identity-constituting self-narrative? (Sections 5 and 7) and**
- iv. What is at stake in our ability to construct and inhabit a self-narrative of this kind? (Section 6)**

The answers to these questions will inform my argument as to the ethical significance of the role of personal bioinformation in our identity narratives that I will develop in Chapter 3. That, in turn, will explain my subsequent characterisation of the nature of our interests in information access, and provide justification for my proposition that these interests warrant attention in information disclosure practices and policies.

SECTION 2: EXISTING ACCOUNTS OF THE RELATIONSHIP BETWEEN BIOINFORMATION AND IDENTITY

There is no shortage of discussion in the bioethical and social science literature of the ways that insights into aspect of our biology – for example, our health, bodies, genes, brains, genetic relationships or genealogy – can affect how we might describe or think of ourselves. This thesis cannot hope to provide a comprehensive review of all this work. Nor is it necessary to do so. Many of these discussions use ‘identity’ in a general and thin sense of ‘descriptor’. And many are descriptive, noting that bioinformation might alter our self-descriptions, without making claims about the *value* (or otherwise) of this. As such, this literature does not speak to the particular focus of the present project, that of locating and characterising a normative relationship between identity, understood as ‘who one is’, and personal bioinformation. Where this literature *is* relevant to my thesis I will refer to it in context in the coming chapters, rather than previewing it here.

There are, however, some kinds of account that do inject (to a greater or lesser extent) a degree of normativity into their framing of the relationship between our access to some particular kinds of personal bioinformation and identity (*qua* self-characterisation). I will briefly review

some prominent examples of these accounts here, grouping them under the following five headings so as to draw out the relevant features of that relationship in each:

- i) Bioinformation as the basis for specific social or group identifiers
- ii) Diagnostic and predictive health information as the basis for constituting practical roles
- iii) Bioinformation as a source of insights into who we ‘really are’
- iv) Knowledge of genetic parentage as *essential* to identity development
- v) Knowledge of genetic parentage as *contingently valuable* to identity development

For each, I will outline the nature of the claims made about the relationship between personal bioinformation in self-characterisation. I will consider the extent to which the relationship presented in each could provide a plausible and robust basis for arguing that access to a broad range of personal bioinformation could engage significant identity-related interests.

i) Bioinformation and social identifiers

The accounts grouped under this heading capture the role of bioinformation in providing new, or cementing existing, ways of classifying ourselves under a shared label, or describing ourselves in terms of our membership of a group. The emphasis differs between accounts. For example, Christine Hauskeller talks in terms of categorisation and the use of genetic information to affirm and to “fix prevailing classification patterns of origins, race, ethnicity, or disease” into what she calls “intra-species classifications”.¹⁰⁷ Similarly, Carlos Novas and Nikolas Rose argue that predictive genetics has introduced the possibility of “biographical narration in genetic terms”,¹⁰⁸ for example, through classifying oneself as being “genetically at risk”.¹⁰⁹ Meanwhile, Alondra Nelson presents a relational picture, referring to the use of commercial genetic ancestry testing services to locate shared African ancestry in terms of “affiliative self-fashioning”.¹¹⁰ And Heather Widdows emphasises how genetic information, by virtue of being shared, can contribute to our understanding of ourselves as members of our

¹⁰⁷ Hauskeller (2004), p.291; C. Hauskeller (2006) “Human genomics as identity politics” Award Paper for Young Scholar Conference, Cornell University 7-9 April 2006, p.3. See also J.R. Fishman and M.L. McGowan, 'Will Personal Genomic Information Transform One's Self?', in *Genetics as Social Practice: Transdisciplinary Views on Science and Culture*, ed. B. Prainsack, et al. (London, New York: Routledge, 2016).

¹⁰⁸ C. Novas and N. Rose (2001), "Genetic Risk and the Birth of the Somatic Individual" *Economy and Society*, 29(4): 485 - 513, p.503.

¹⁰⁹ N. Rose, *Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* (Princeton: Princeton University Press, 2007), p.106.

¹¹⁰ A. Nelson (2008), "Bio Science Genetic Genealogy Testing and the Pursuit of African Ancestry" *Social Studies of Science*, 38(5): 759-83, p.771.

families or ethnic groups.¹¹¹ Ian Hacking extends the frame beyond genetic information in arguing that other means of categorising people for the purposes of care, administration or research (for example, behaviourally-based diagnostic categories such as that for Attention deficit hyperactivity disorder (ADHD)) may come to be more widely understood as designating “human kinds”, which individuals within these groups may then use to classify themselves,¹¹²

ii) Health information and practical roles

According to several accounts referred to under the previous heading, the means of self-description offered by diagnostic or predictive health information do not function merely as passive labels, but provide the basis for an individual’s motives, conduct and “ways of being”, which in turn serve further to constitute their mode of identification.¹¹³ For example, Novas and Rose describe a ‘risk identity’ (as might be adopted after a positive test for susceptibility to genetic illness) as “a grid of perception which informs decisions on how to conduct one’s life” and as inextricably bound up with engagement with “life strategies”, such as researching the disease in question and pursuing therapeutic interventions.¹¹⁴ Elsewhere Rose uses the phrase “somatic identity” and “neurochemical selves” to capture ways in which – according to his account – genetic and neurological information may lead us to think of ourselves in new, biologically-defined and bodily-responsible ways.¹¹⁵ Intersecting with these accounts are those which describe bioinformation as providing a potential impetus or means to engage in what Sahra Gibbon and Carlos Novas term “biosocial identity-making”.¹¹⁶ That is to say, collaborative and group activities – such as patient activism or participation in health research – which have as their focus a particular sources of biomedical knowledge about oneself and which provide relationships and contexts within which a particular kind of self-characterisation is fostered.

¹¹¹ Widdows (2013).

¹¹² I. Hacking, 'The Looping Effect of Human Kinds', in *Causal Cognition: A Multi-Disciplinary Debate*, ed. D. Sperber, et al. (New York: Oxford University Press, 1995); I. Hacking, *The Social Construction of What?* (Cambridge, MA: Harvard University Press, 1999); I. Hacking (2004), "Between Michel Foucault and Erving Goffman: Between Discourse in the Abstract and Face-to-Face Interaction" *Economy and Society*, 33(3): 277-302.

¹¹³ Hacking (1999), p.103.

¹¹⁴ Novas and Rose (2001), p.502, p.487.

¹¹⁵ Rose (2007), p.186, p.187; N.S. Rose and J.M. Abi-Rached, *Neuro: The New Brain Sciences and the Management of the Mind* (Princeton: Princeton University Press, 2013).

¹¹⁶ S. Gibbon and C. Novas, 'Introduction', in *Biosocialities, Genetics and the Social Sciences: Making Biologies and Identities*, ed. S. Gibbon and C. Novas (London: Routledge, 2008), p.8; P. Rabinow, 'Artificiality and Enlightenment: From Sociobiology to Biosociality', in *Anthropologies of Modernity: Foucault, Governmentality, and Life Politics*, ed. J.X. Inda (Oxford: Blackwell Publishing, 2005).

Could the kinds of accounts summarised under headings (i) and (ii) above provide sufficient bases for understanding why we might have significant identity-related interests in accessing a broad range of bioinformation about ourselves? I want to suggest that that they each provide important elements of the picture (as I will demonstrate in discussing the illustrative examples in Part II and in Chapter 8). However, they do not do all the necessary work. This is, in part, because many of these accounts pertain to specific categories of genetic or health-related bioinformation and are not necessarily generalisable to bioinformation more widely. It is also, in part, because the accounts are often ambivalent or sceptical about the value of defining aspects of ourselves using biological information. For example, Hauskeller holds that the value to the individual of genetically-reinforced (re)classifications is ambiguous, either because it has yet to be demonstrated, or because the classifications may be hurtful or unwelcome.¹¹⁷

A more fundamental reason why these accounts cannot fully explain why access to personal bioinformation might have ethically significant consequences for our understanding of who we are, is that they concern unitary identifiers discussed in isolation from other aspects, or from the totality of someone's self-characterisation. They do not speak to the matter of why it might matter for someone's self-characterisation *as a whole* if it includes some kinds of descriptors, classifications or roles rather than others. For example, why does it matter if someone is able to characterise herself in terms of her ADHD diagnosis? One answer is that this could offer opportunities to access treatment or experience solidarity with other sufferers. My intention is not to question the value of these ends. But it is not clear why they are *identity* benefits as opposed to health or social ones. What is missing, for my purposes, is a global theory of identity that explains the role and value of these identifiers *in identity terms* – that is, why having access to personal bioinformation might make a difference to developing, understanding and inhabiting *who one is*.

I will now turn, then, to consider three further kinds of account present in the literature which do purport to speak to the relationship between specific kinds of personal bioinformation and identity understood in a global sense.

iii) Bioinformation as a source of insights into pre-existing identities

It might be claimed that access to some kinds of bioinformation is important to our identities because it reveals pre-existing truths about 'who we really are'. Essentialist assumptions – for example, about the power of our genes or our brains to determine a wide range of human traits

¹¹⁷ Hauskeller (2006).

and disposition and, thus, for genetic or neurological information to provide insights into our identities – are largely the target of critique in the academic literature.¹¹⁸ Nevertheless, they may have some purchase in the popular imagination.¹¹⁹ And the suggestion, for example, that genetic information reveals aspects of our identities is ubiquitous in the marketing materials used by DTC genomic testing services.¹²⁰ And, as noted in Chapter 1, the special protection afforded to genetic data in some legal contexts may reflect genetic essentialist assumptions.¹²¹

Genetic- or neuro-essentialist conceptions of the self cannot, I submit, provide a robust basis for understanding the potentially significant impact of personal bioinformation on identity. These conceptions do not admit even the possibility of defining ourselves, let alone defining ourselves in contrast to our biology. As such they close off options for us in terms of how we make sense of ourselves, and suggest there is only one route to knowing about who we ‘really’ are (often based on illegitimate assumptions about the bio-deterministic nature of our genes or brains). In seeking an account of identity as self-constructed, then, this avenue is both limiting and limited. If we are to explore our intuition that our identities are something that we construct, rather than something we discover, then this approach cannot be the basis on which to do so.

iv) Knowledge of genetic parentage as essential to identity development

More subtle than the argument that bioinformation directly *reveals* one’s true identity, are those which present a case that a specific kind of personal bioinformation is necessary for the developing a full and flourishing *understanding* of who one is. This kind of argument has been made in respect of knowledge of one’s genetic parents. David Velleman maintains that this knowledge is essential to forging relationships with one’s genetic family, and observing connections between one’s own and one’s family’s existence and embodied states, which in turn allows one to:

“...identify objectively with the objective reality of the creature that I am, by seeing how that creature’s place in reality can possibly be mine.”¹²²

¹¹⁸ Fishman and McGowan (2016); W. Glannon (2009), "Our Brains Are Not Us" *Bioethics*, 23(6): 321-29.

¹¹⁹ D. Nelkin and M.S. Lindee, *The DNA Mystique: The Gene as Cultural Icon* (New York: Freeman, 1995); C. O'Connor et al. (2012), "Neuroscience in the Public Sphere" *Neuron*, 74(2): 220-26.

¹²⁰ Nordgren and Juengst (2009).

¹²¹ See, for example, UNESCO, 'Universal Declaration on the Human Genome and Human Rights' (1997)

¹²² J.D. Velleman (2008), "The Gift of Life" *Philosophy & Public Affairs*: 245-66, p.262.

He maintains that if this is necessary for the development of a sense of who one is, for finding “meaning in the events of one’s life” and for leading a flourishing existence.¹²³ James Lindemann Nelson offers a similar argument, rooted in a narrative conception of identity.¹²⁴ He holds that we have an interest in “perceiving the connections between our lives and the lives of others” and that this not only adds “depth and richness” to our identity narratives, but is important to our abilities to make sense of our lives as a cohesive wholes.¹²⁵

As will become clear from what I will say in Chapter 3, my own proposal as to the relationship between personal bioinformation and identity has much in common with both Velleman’s and Nelson’s propositions. However, as they stand and in their own terms, these arguments do not provide a convincing justification for a claim that we have significant interests in accessing a wide range of bioinformation. This is, firstly, because they do not purport to speak to the identity significance of any kinds of information other than that about genetic parentage. Furthermore, their claims in respect of the necessary value of this information are themselves dubious given that the suggestion that everyone’s identity suffers from not knowing their genetic parents is open to readily available counterexamples (as will be illustrated in Chapter 5). These accounts hold some promise in helping us to think about why personal bioinformation might be valuable to self-understanding, but they cannot do so to the full extent needed for the present inquiry.

v) Knowledge of genetic parentage as contingently valuable to identity development

Distinguishable from Velleman’s and Nelson’s positions, but still relating specifically to knowledge of one’s genetic parents, are suggestions that this knowledge could play a valuable role in the construction of a complete, “acceptable”,¹²⁶ or “virtuous”¹²⁷ account of who one is because it provides accurate knowledge of the circumstances of one’s life and existence. The key distinction from the preceding claims is that in this cluster of arguments, this knowledge is *not held to be essential* to the construction of such an account. Its value is presented as being contingent upon the individuals’ personal and social circumstances. For example, Sarah

¹²³ J.D. Velleman (2005), "Family History" *Philosophical Papers*, 34(3): 357-78, p.375.

¹²⁴ J.L. Nelson (1992), "Genetic Narratives: Biology, Stories, and the Definition of the Family" *Health Matrix*, 2: 71-83

¹²⁵ *Ibid.*, p.81.

¹²⁶ G. Pennings (2001), "The Right to Privacy and Access to Information About One’s Genetic Origins " *Medicine and Law*, 20(1): 1-15, p.12.

¹²⁷ H. Lillehammer, "Who Cares Where You Come From?", in *Relatedness in Assisted Reproduction: Families, Origins and Identities*, ed. T. Freeman, et al. (Cambridge: Cambridge University Press, 2014), p.101.

Wilson maintains that genealogical information may be important if it allows donor-conceived individuals, or those separated from their parents in infancy, to fill interpretive gaps in their identity narratives by “alleviat[ing] uncertainty with respect to the past”.¹²⁸ Hallvard Lillehammer, meanwhile, argues that knowledge of genetic parentage is valuable to an individual to the extent that this allows them to construct a “virtuous practical identity” which requires that “disclosure of further facts about themselves would not subvert their general sense of who they are and what they ought to be.”¹²⁹ Similarly, Maggie Kirkman suggests that ignorance of donor origins may lead to the development of a “misleading” identity narrative.¹³⁰

This family of arguments is considerably more promising than any of the previous candidates. The sense in which identity is invoked is that of self-characterisation in a holistic sense, rather than that of a discrete identifier. The value of the information in question is premised on its instrumental rather than essential role in making sense of who one is in the context of one’s experiences. And as such, this at least leaves open the possibility that other kinds of bioinformation could occupy a similar role. I too wish to ground my argument as to our interests in accessing personal bioinformation in a narrative account of identity. And I will return in Chapter 3 to explain how my own argument relates to those summarised under this heading.

However, I would suggest that, as they stand, the positions outlined above do not provide a rich enough picture of the relationship between information about genetic parentage and identity to explain in depth what is at stake in accessing this information. They do not yet permit us to understand whether and why ethically significant interests might be engaged. For that, what is needed is a more fully developed account of what it means for identity to be ‘acceptable’ or ‘virtuous’; why it matters if our identities are misleading, contain uncertainties or are vulnerable to subversion; and an account of the precise nature of the roles that bioinformation may play in achieving or averting these ends and contexts in which and reasons why it might do so. Crucially, a more developed argument would also clarify the extent to which other kinds of bioinformation might fulfil a similar role to that assigned to genetic parentage. I suggest that these each of these features is required if an account of the relationship between personal bioinformation and identity is going to provide an adequate explanation of our interests in information access.

¹²⁸ S. Wilson (1997), "Identity, Genealogy and the Social Family: The Case of Donor Insemination" *International Journal of Law, Policy and the Family*, 11(2): 270-97, p.290.

¹²⁹ Lillehammer (2014), p.101.

¹³⁰ M. Kirkman (2003), "Parents' Contributions to the Narrative Identity of Offspring of Donor-Assisted Conception" *Social Science & Medicine*, 57(11): 2229-42, p.2238.

A narrative proposal

I wish to propose that an account in which our identities are understood to be constituted by self-constructed narratives of who we are, is capable of providing just such a picture. As I shall argue over the coming chapters, if we appreciate the critical role that personal bioinformation may play in the development of a coherent self-constituting self-narrative, we may understand the importance of access to this information to the richness and character of our lives (see Chapter 3). A narrative-based account addresses identity understood as the whole of ‘who one is’. It permits us to understand how identity is something that can ‘go better or worse’, with non-trivial consequences for the richness and scope of our lives (see Sections 5-7 below). It is therefore able to account for the value and detriment of access, or lack of access, to personal bioinformation in way that goes beyond, and engages more profound concerns than, the acquisition of discrete identifiers. I shall suggest that a narrative-based account is capable of explaining how a range of different kinds of personal bioinformation may fill important identity roles (see Chapters 3 and 8), while also illuminating how different kinds of bioinformation may do so to different extents – without recourse to essentialism or arbitrary exceptionalism (see Chapter 8). Importantly, I shall also seek to demonstrate that the narrative roles of personal bioinformation is plausible in that it broadly corresponds with the ways people report responding to and using this information (see Chapters 5-7). On these bases, I will argue that a narrative-based account of identity development is capable of grounding the claim that access to a range of personal bioinformation can engage ethically significant interests (see Chapter 9).

To provide the foundations for that argument, however, I need to go back to the detail of the philosophical accounts of narrative identity to provide the kind of more fully-developed account that, I have suggested, is lacking from the existing arguments relating to genetic parentage. This will entail unpacking what an identity narrative looks like (Section 4), what makes a narrative self-constituting (Sections 5 and 7), and why it matters that we have the means necessary to construct such a narrative (Section 6). These are the tasks for the remainder of this chapter. Crucially, however, the theories outlined below do not themselves argue for a role for personal bioinformation in constructing our identity narratives. That is an additional and original step taken in this thesis, which I will go on to defend in Chapter 3.

The purpose of this thesis is not to provide a fresh or unassailable defence of narrative identity theory. The contribution I aim to make lies in applying this theory to an argument that we

potentially have ethically significant interests in relation to our access to personal bioinformation. It must be acknowledged that readers who remain unconvinced by a narrative conception might find it hard to accede to my arguments in later chapters. However, it is my hope that the empirical literature to be reviewed in Part II will lend further weight to their plausibility and defensibility.

SECTION 3: SCOPE OF THE REVIEW OF NARRATIVE IDENTITY THEORY

Narrative theories of identity are found in a number of disciplines, including philosophy¹³¹, philosophical bioethics,¹³² psychology¹³³ and sociology.¹³⁴ This chapter will focus upon the philosophical literature because it offers the kind of detailed, conceptual account of the nature of identity and how it is constituted, that is capable of providing normative foundations for the ethical argument I wish to make in subsequent chapters. However this literature is not abstracted from social or psychological contexts. The chief source on which I draw here is the influential account developed by Marya Schechtman across several publications, but most prominently in her 1996 monograph '*The Constitution of Selves*'.¹³⁵ Schechtman's account is primarily philosophical but incorporates psychological insights. One of her aims is to develop a theory that accommodates key aspects of the first person experience of the phenomenology of selfhood, such as concern for one's own future.¹³⁶ Meanwhile, Charles Taylor's account,

¹³¹ See, for example, D. Dennett, *Consciousness Explained*, Little Brown and Company (Boston: 1991); A.C. MacIntyre, *After Virtue : A Study in Moral Theory*, 2nd corr. ed. (London: Duckworth, 1985); C. Mackenzie, 'Personal Identity, Narrative Integration, and Embodiment', in *Embodiment and Agency*, ed. S. Campbell, et al. (University Park: The Pennsylvania State University Press, 2009); C. Mackenzie and J. Poltera (2010). "Narrative Integration, Fragmented Selves, and Autonomy" *Hypatia*, 25(1): 31-54; P. Ricoeur (1991), "Narrative Identity" *Philosophy Today*, 35(1): 73-81; Schechtman (1996); C. Taylor, *Sources of the Self : The Making of the Modern Identity* (Cambridge: Cambridge University Press, 1989); C. Taylor, *The Ethics of Authenticity* (Cambridge, MA: Harvard University Press, 1992).

¹³² See, for example, F. Baylis (2003), "Black as Me: Narrative Identity" *Developing World Bioethics*, 3(2): 142-50; DeGrazia (2005); H. Lindemann Nelson, *Damaged Identities, Narrative Repair* (London: Cornell University Press, 2001); Mackenzie and Walker (2015)

¹³³ See, for example, K.J. Gergen and M.M. Gergen (1988), "Narrative and the Self as Relationship" *Advances in experimental social psychology*, 21(1): 17-56; V.G. Hardcastle, *Constructing the Self* (Amsterdam ; Philadelphia: John Benjamins Pub. Co., 2008); D.P. McAdams and K.C. McLean (2013), "Narrative Identity" *Current Directions in Psychological Science*, 22(3): 233-38.

¹³⁴ See, for example, A. Giddens, *Modernity and Self-Identity : Self and Society in the Late Modern Age* (Cambridge: Polity Press, 1991); M.R. Somers (1994), "The Narrative Constitution of Identity: A Relational and Network Approach" *Theory and society*, 23(5): 605-49.

¹³⁵ Schechtman (1996) See also, M. Schechtman (2007), "Stories, Lives, and Basic Survival: A Refinement and Defense of the Narrative View" *Royal Institute of Philosophy Supplements*, 60: 155-78; M. Schechtman, 'The Narrative Self', in *The Oxford Handbook of the Self*, ed. S. Gallagher (Oxford: Oxford University Press, 2011); M. Schechtman (2012), "Making the Truth: Self-Understanding, Self-Constitution, Neuroscience, and Narrative" *AJOB Neuroscience*, 3(4): 75-76.

¹³⁶ As noted in fn. 47 above, in her more recent work Schechtman's position is that her account of self-narrative continues to address these questions, though not questions of literal (numerical) identity of persons, see Schechtman (2014).

for example, is inextricably embedded in his analysis of the impact of social context on how we conceive of ourselves.¹³⁷ In addition to these authors, the following discussion draws (chiefly, though not exclusively) on the work of Françoise Baylis, David DeGrazia, Alasdair MacIntyre and Catriona Mackenzie (and her co-authors).¹³⁸ I focus upon these theorists because they are prominent in this field, but also because they represent a spread of emphases on matters such as the role of value, relationality and embodiment in identity, and thus help to fill-out a rounded account. These authors call upon narrativity to address a range of different ethical, metaphysical and social questions which inevitably brings different emphases.

Restrictions of space here necessarily mean that many interesting avenues must remain unexplored. The aim of this chapter is to capture core commonalities, highlight relevant divergences, and address counterarguments, insofar as these are pertinent to answering the second research question (and its sub-parts) set out in Section 1. In particular, I wish to draw out what I shall term the ‘double normativity’ of narrative self-constitution theories. What I mean by this is, first, that valuable consequences maybe seen as following from the development of one’s identity (as explored in Section 6 below). And, secondly, that these consequences are contingent on one’s self-narrative having particular qualities (as outlined in Sections 5 and 7). I shall argue that this double normativity is essential to understanding the ethical significance of the role that personal bioinformation can play a role our self-narratives (see Chapter 3).

SECTION 4: WHAT IS A SELF-NARRATIVE?

Identity-constituting

First it is necessary to establish the relationship between narrative and identity. According to the accounts reviewed here, our identities (in the characterisation sense) are not pre-existing, awaiting discovery. And one’s self-narrative does not merely reflect or describe who one is. We *create* our own identities through understanding ourselves as the protagonists in the ongoing stories of our lives. Our narratives *constitute* our identities (subject to conditions I shall go on to describe). The answer to the question of what makes me ‘me’ lies in the contents and interpretations of my autobiographical narrative. And characteristics are mine because (and to the degree to which) they are included in my narrative. Schechtman expresses the core contention of her theory as follows:

¹³⁷ C. Taylor (1989); C. Taylor (1992)

¹³⁸ Baylis (2003); DeGrazia (2005); MacIntyre (1985); Mackenzie (2009)

“On this view a person’s identity (in the sense at issue in the characterization question) is constituted by the content of her self-narrative, and the traits, actions and experiences included in it are, by virtue of that inclusion, hers.”¹³⁹

According to this view, narrative is the form that our self-understanding takes and the means by which we bind together the constituent parts of our lives.¹⁴⁰ In doing so we ascribe meaning and significance to these parts according to the roles we see them as occupying in the overarching story of who we are. As Mackenzie describes it:

“By appropriating our past, anticipating our future actions and experiences, and identifying or distancing ourselves from certain characteristics, emotions, desires and values, we develop a self-conception that brings about the integration of the self over time.”¹⁴¹

As this suggests, the accounts reviewed here are not merely concerned with identity in terms of an inert description of what someone is like. Rather this is identity of a *practical* kind.¹⁴² That is, it provides the basis for our agency, and is constituted by the ways we act and the motives we act from (see Chapter 1). These practical implications that key to the normative features of the narrative self-constitution theories that I describe below. Before we can appreciate these, however, it is necessary to understand what a self-narrative is and looks like.

What does a self-narrative look like?

There is some ambiguity in the literature about the extent to which one’s self-narrative can be understood as a life story. However, it is emphatically not a straightforward comprehensive or chronological catalogue of everything that happens in someone’s life.¹⁴³ I will outline here the key features of identity-constituting narratives that are of particular relevance to this project. These are their:

- i) First-person perspective;
- ii) Relational construction;
- iii) Varied contents;
- iv) Selective and interpretive nature; and
- v) Active and ongoing development.

¹³⁹ Schechtman (1996), p.94.

¹⁴⁰ Ibid.

¹⁴¹ Mackenzie (2008), p.12.

¹⁴² Ibid.

¹⁴³ Schechtman (1996).

i) First-person perspective

According to the accounts reviewed here, our self-narratives are our own self-told stories of who we are, constructed from a subjective, internal perspective.¹⁴⁴ These accounts hold that only this perspective adequately captures the phenomenology – the ‘what it is like’ – of selfhood.¹⁴⁵ We are (in most cases) best positioned to capture the kinds of characteristics that make up our own stories (I say more about what a characteristic is below).¹⁴⁶ And, crucially, narrating is an interpretive undertaking. The role and significance of the various constituents of our stories are interpreted in relation to each other and to the whole from the perspective of the subject who experiences them all.¹⁴⁷ This does not mean that our self-narratives are, or could be, constructed through isolated introspection, but the emphasis on first-person narration represents resistance to suggestions that our own stories have no greater claim to authority in defining who we are than those of others,¹⁴⁸ and to accounts that hollow-out selfhood by presenting identity as constituted largely by the public performance of roles.¹⁴⁹

ii) Relational construction

It is a key aspect of narrative theories of self-constitution that we do not and cannot work out who we are in isolation and that our self-narratives are socially and culturally embedded. There are three senses in which this is the case: our relationships, social and relational roles contribute contents to our stories; social contexts and relationships provide the language and contexts that make self-narration possible; and the stories other people tell about us shape and constrain those we are able to tell about ourselves. Taking the first to be relatively self-explanatory, I will briefly expand on the second and third senses.

¹⁴⁴ DeGrazia (2005).

¹⁴⁵ Mackenzie (2008); C. Taylor (1989).

¹⁴⁶ There is some divergence between theorists about whether traits or motives unacknowledged by the subject herself are part of her self-narrative. It is not necessary to resolve this debate for the purposes of this project. It will suffice to recognise two key points on which there is agreement: that the extent to which aspects of our lives are part of who we are can admit of degree; and (as I will describe below) the stories we choose to tell are subject to external checks.

¹⁴⁷ DeGrazia (2005).

¹⁴⁸ Hilde Lindemann Nelson, for example, argues that our own accounts do not necessarily have precedence over those others tell about us and the legitimacy of each must be adjudicated by external criteria Nelson’s conception of narrative identity may this be distinguished from that discussed in this chapter, as it relinquishes the importance of a subjective story, internally unified by the subject’s own interpretations, see H Lindemann Nelson, *Damaged Identities, Narrative Repair*. (London: Cornell University Press, 2001).

¹⁴⁹ See, for example, E. Goffman, *The Presentation of Self in Everyday Life* (New York: Doubleday, 1959).

With reference to the facilitative role of our social contexts, Macintyre's observes that, "the story of my life is always embedded in the story of those communities from which I derive my identity."¹⁵⁰ Taylor expresses a related idea in arguing that our communities supply us with a "common language" that gives us the means to reflect upon and articulate what it means to have an identity and, more specifically, what it is that we value and what kind of selves we are.¹⁵¹ Like any language, this derives its meaning in public arenas and needs to be practiced amongst others. In the terminology introduced in the previous chapter we might construe this as our communities providing the 'interpretive frameworks' within which we are able to construct our self-narratives.

Individual interactions are also seen as playing crucial facilitative roles. Macintyre maintains that "[t]he asking for and giving of accounts itself plays an important part in constituting narratives."¹⁵² This is echoed in Taylor's argument that we learn how to reflect on who we are and want to be through living amongst, and in discussion with, others.¹⁵³ He holds that our lives are "fundamentally *dialogical*".¹⁵⁴ Taylor assigns an important role to close and supportive relationships in which, he suggests, we come to understand what, for example, our values or beliefs are.¹⁵⁵¹⁵⁶

In saying that we, "define [ourselves] always in dialogue with and sometimes in struggle against the identities our significant others want to recognise in us"¹⁵⁷ Taylor alludes to the fact that others not only facilitate, but also constrain, our self-conceptions. The accounts others (not only significant ones) give of who we are can either challenge, or reflect, our own self-conceptions and, thus, potentially undermine, or reinforce, the stories we tell about ourselves and our capacities to act accordingly.¹⁵⁸ Schechtman notes that in order to live socially, "one needs is a self-concept that is basically in synch with the view of one held by others."¹⁵⁹

¹⁵⁰ MacIntyre (1985), p.221.

¹⁵¹ C. Taylor (1989), p.35.

¹⁵² MacIntyre (1985), p.218.

¹⁵³ C. Taylor (1992).

¹⁵⁴ Ibid.

¹⁵⁵ Ibid.

¹⁵⁶ Parallels may be observed here with the literature on relational autonomy, in which it is argued that socialisation and personal relationships are necessary in order to develop the "competency" for being autonomous. See, for example, D.T. Meyers, *Self, Society, and Personal Choice* (New York: Columbia University Press, 1989); L. Barclay, 'Autonomy and the Social Self', in *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*, ed. C. Mackenzie and N. Stoljar (New York: Oxford University Press, 2000). I return to the relationship between self-constitution and autonomy further in Section 6.

¹⁵⁷ C. Taylor (1992), p.33.

¹⁵⁸ DeGrazia (2005); MacIntyre (1985).

¹⁵⁹ Schechtman (1996), p.95.

What such synchronicity might involve varies between narrative theorists. I return in Section 5 to discuss Schechtman's requirement that our narrative must realistically reflect the world as others experience it. Françoise Baylis, meanwhile, argues the requirement is for "equilibrium" between how we see ourselves and how others see us.¹⁶⁰ I would suggest this might concede too much, because (as indicated above) a defining feature of a self-constituting narrative is its first-person interpretive perspective. Furthermore, concessions to others' perspectives seem like something we might want to resist if these are oppressive or harmful.¹⁶¹ As I shall go on to describe in this and the next chapter, what seems most important is not equilibrium *per se*, but that our self-conceptions remain intelligible and inhabitable in the context not only of other's perspectives, but also our own experiences.

iii) Contents

Schechtman enumerates the possible components of an identity narrative as including "...actions, experiences, beliefs, values, desires, character traits..." and "other psychological features" – which she refers to collectively as "characteristics".¹⁶² The list includes things we might not ordinarily label as 'characteristics', but this terminology signals that these are to be understood as constituents of the stories that *characterise* us. Crucially, these potential contents only contribute to someone's identity to the extent that they are included and interpreted as part of her self-narrative, not just because they occur in the course of her life. This notwithstanding, in Chapter 3 I will argue that the absence of explicit references to bodily characteristics, such as gender or health status, from this list represents a significant omission.

iv) Selection and interpretation

This brings us to perhaps the most distinctive feature of identity-constituting narratives – they are not comprehensive or "crude, literal reproductions" of everything that one does and experiences.¹⁶³ Nor yet are they just reflections of ready-structured proto-narratives presented to us by the world – in Schechtman's terminology they are not cut from "wholecloth".¹⁶⁴

¹⁶⁰ F. Baylis, 'The Self in Situ: A Relational Account of Personal Identity', in *Being Relational: Reflections on Relational Theory and Health Law* ed. J. Downie and J.J. Llewellyn (Vancouver, Toronto: UBC Press, 2012), p.118.

¹⁶¹ J. Christman, 'Telling Our Stories in the Master's Tongue: Narrative Selves and Oppressive Circumstance', in *Philosophy of Autobiography*, ed. C. Cowley (Chicago, IL: University of Chicago Press, 2015); H. Lindemann Nelson (2001)

¹⁶² Schechtman (1996), p.2, p.73.

¹⁶³ *Ibid.*, p.125.

¹⁶⁴ Schechtman (2012), p.75.

Instead, a self-narrative is *constructed* from disparate, selected and inter-interpreted components.

Schechtman maintains that, as authors of our narratives, we select their contents by “appropriating” or excluding contents.¹⁶⁵ This need not be (and is perhaps only intermittently) a conscious endeavour. Our existing accounts of who we are provide the interpretive framework through which we encounter experiences and thus through which the relevance and importance of potential contents strike us. Identity development is reflexive – the creator and created are the same, existing in a cycle of self-constitution.¹⁶⁶ One implication of all this is that not all our characteristics occupy equally prominent or enduring positions in our narratives; this relationship “admits of degree” and the extent to which we are *identifiable* with particular characteristics varies accordingly.¹⁶⁷ I will return to consider objections to the ideas of active construction shortly.

The constituent parts of a narrative themselves are not just collated, but changed by the interpretive framework of narrativity. Schechtman suggests that an apt metaphor here is not the accumulation of a library, but cooking.¹⁶⁸ Like ingredients in a stew, the meaning and significance of narrative elements are shaped by being viewed in light of the overall narrative of which they are a part. As Schechtman says:

“...creating an autobiographical narrative is not simply composing a story of one’s life – it is organizing and processing one’s experience in a way that presupposes an implicit understanding of oneself as an evolving protagonist. A large part of what that entails is that the remembered past and anticipated future exert an influence on the present – that they serve as its interpretive context, the lens through which it is experienced.”¹⁶⁹

Similarly, present experiences may also lead us to re-interpret our remembered past and also shape our expectations of the future.¹⁷⁰ The interpretive and integrative nature of a self-narratives may be seen as operating in two directions – one that draws together the synchronic experience of self at any one time and one that connects the persisting experience of self over a lifetime.

¹⁶⁵ Schechtman (1996), p.125.

¹⁶⁶ DeGrazia (2005).

¹⁶⁷ Schechtman (1996), p.76.

¹⁶⁸ Ibid.; Mackenzie (2009).

¹⁶⁹ Schechtman (1996), p.142.

¹⁷⁰ DeGrazia (2005).

v) **Active and ongoing**

As the above considerations suggest, an identity narrative is something that an individual *does* – that she creates, sustains and modifies through her interpretations, choices and actions – not just “static and passive features that she *has*”.¹⁷¹ Furthermore, our self-narratives are never constructed once-and-for-all. In Genevieve Lloyd’s terms, narrativity entails the “perpetual weaving of fresh threads”.¹⁷² Therefore, the role and integration of particular elements within our narratives is never more than conditional, responding to new experiences and priorities.¹⁷³ Our identities evolve and change accordingly. Charles Taylor emphasises this, saying that “our condition can never be exhausted for us by what we *are*, because we are always changing and *becoming*.”¹⁷⁴ This process will, of course, eventually come to an end with our death or loss of cognitive capacities.

Two objections

The account outlined thus far describes what self-narratives look like, without (yet) making normative claims about what qualities they must exhibit in order to be self-constituting, or what outcomes depend on having such a narrative (I address these matters in subsequent sections). Two principal kinds of objection have been raised in respect of the picture outlined so far.¹⁷⁵ There is insufficient space comprehensively to consider narrative theorists’ rejoinders to these, but I hope to indicate that they need not be fatal for the purposes of the present project.

Not everyone’s experience

Galen Strawson objects that it is simply empirically false to assert that everyone experiences their lives and thinks of themselves in the form of a continuing, thematically-linked narrative. He himself professes instead to have only “episodic” self-experiences,¹⁷⁶ maintaining that:

“...I have absolutely no sense of my sense of a narrative with a form, or indeed as a narrative without a form...Nor do I have any great or special interest in my past. Nor do I have a great deal of concern for my future.”¹⁷⁷

¹⁷¹ Schechtman (1996), p.117.

¹⁷² G. Lloyd, *Being in Time: Selves and Narrators in Philosophy and Literature* (London: Routledge, 2003), p.144.

¹⁷³ Mackenzie (2008).

¹⁷⁴ C. Taylor (1989), p.47 (emphasis in source).

¹⁷⁵ G. Strawson, 'Against Narrativity', in *Real Materialism and Other Essays*, ed. G. Strawson (Oxford: Clarendon Press, 2008).

¹⁷⁶ *Ibid.*, p.430.

¹⁷⁷ *Ibid.*, p.433.

Jonathan Glover, meanwhile, raises a related but less thoroughgoing concern that “[m]ost of us do not spend our lives on endless landscape-gardening of the self.”¹⁷⁸ Narrative theories might indeed appear to paint an unattractive and unrealistically rationalist, onerous and self-absorbed picture of self-constitution. They might also seem to depend on one having the luxury of time for self-examination and self-interpretation, or living in a culture in which such activities are normal or valued.

Narrative theorists, however respond that such objections imagine too high and literal a threshold for what counts as a self-narrative and narrative construction.¹⁷⁹ The suggestion is not that self-narratives are like polished literary texts with well-defined plots.¹⁸⁰ And their construction need be neither self-conscious nor explicit. Narrativity neither entails that we constantly mull over our pasts, nor that we explicitly think of our identities as narratives.¹⁸¹ Identity development takes place through the business of living and acting, and in making connections between, and finding significance in, aspects of our lives. As Schechtman explains “[narrative] is the lens through which we filter our experiences and plan for actions, not a way we think about ourselves in reflective hours.”¹⁸² The connections we forge between the parts of our stories are rooted in as much in felt significance, practical concerns and perceptions of emotional resonance, as rational analysis.¹⁸³ Furthermore, the conception reviewed in this chapter is distinct from the (caricature of) atomistic, narcissistic, self-actualising individualism of contemporary liberal western life.¹⁸⁴ As indicated above, identity development is, crucially, a relational pursuit not one of isolated, individualistic navel-gazing.

However, it is acknowledged that our self-narratives may well not be lucid and undisturbed at all times. Mackenzie observes that many of us will have experiences that are fragmented or hard to understand and the maintenance of an intelligible self-narrative might sometimes require effort. But, rather than being grounds for rejecting a narrative conception, these are indications that “the integration of selfhood across time is fragile”.¹⁸⁵ So, even if Strawson’s wholesale scepticism is unwarranted, it is indeed the case that maintenance of a coherent self-

¹⁷⁸ J. Glover, *I: The Philosophy and Psychology of Personal Identity* (London: Penguin, 1988), p.132.

¹⁷⁹ C. Mackenzie and J. Poltera (2010); Schechtman (2007).

¹⁸⁰ Schechtman (2007).

¹⁸¹ Mackenzie and Poltera (2010).

¹⁸² Schechtman (1996), p.113.

¹⁸³ Mackenzie (2008); Schechtman (1996).

¹⁸⁴ Charles Taylor argues that a conception of authenticity as living free from the value norms of our community is a “travesty” of the concept and that authenticity, Taylor (1992), p.22.

¹⁸⁵ Mackenzie (2008), p.14.

narrative is not inevitable and perhaps, for some with limited cognitive capacities or very challenging lives, not even possible (as I will discuss further in Section 7).

Fabrication

Strawson's second objection is that the selection and structuring of experiences into a narrative would not result in a faithful account of 'who one really is', but rather an artificial confection.¹⁸⁶ I will briefly outline three parallel responses to this.

First, it is not obvious how we could make sense of all the different aspects of our lives *without* prioritisation and interpretation.¹⁸⁷ Excessive inclusivity or richness of detail would seem to militate against, rather than support, self-understanding.¹⁸⁸ The second response is that, if we understand our narratives as *constituting* our identities, rather than describing them, then an individual simply does not have a more basic, or more 'true' pre-existing identity with respect to which self-narrative could found inauthentic.¹⁸⁹ This does not preclude the possibility of self-deception or error about what characteristics are prominent in constituting who one is. But – turning to the third response – narrative theories incorporate checks upon unfettered invention, misappropriations and misinterpretations. An individual's freedom to choose what goes into her narrative (and, therefore, create who she is) is constrained.

Schechtman proposes two "constraints" upon what counts as an identity-constituting narrative. The first is that it must be amenable to "articulation".¹⁹⁰ The second is that it must "cohere with reality".¹⁹¹ These constraints are broadly endorsed by other prominent proponents of a narrative conception of identity.¹⁹² These constraints also supply key steps in the argument I propose in subsequent chapters, so warrant further attention here.

SECTION 5: CONSTRAINTS ON IDENTITY-CONSTITUTING NARRATIVES

Articulation constraint

Schechtman's 'articulation constraint' requires that our self-narratives are intelligible and explicable to and by their subjects. This does not mean that we must literally, self-consciously or perpetually recount our self-narratives, but the connections between our experiences, actions, beliefs and values and their places in our narratives must at least be *amenable* to "local

¹⁸⁶ Strawson (2008).

¹⁸⁷ Mackenzie and Poltera (2010).

¹⁸⁸ Schechtman (1996).

¹⁸⁹ Schechtman (2012).

¹⁹⁰ Schechtman (1996), p.114.

¹⁹¹ *Ibid.*, p.119.

¹⁹² See, for example, DeGrazia (2005); Mackenzie (2009).

articulation”.¹⁹³ That is, we must be able to explain why we feel, believe and do as we do. We must be in a position to explain how these elements fit into “...an intelligible life story with a comprehensible and well-drawn subject as its protagonist.”¹⁹⁴

Articulation is not, however, presented as an all-or-nothing condition. An inability to make sense of some parts of one’s life would not necessarily compromise one’s capacity to have an identity altogether.¹⁹⁵ Nevertheless, if, for example, someone frequently acts from unacknowledged motive, this might indeed mean that sufficient portions of her life lie outwith her control and are less than fully identifiable with who she is, and thus threaten the integrity of her identity.¹⁹⁶

The justification for the articulation constraint is grounded in the fact that being able to understand the role that the constituent characteristics of our narratives play in shaping and constituting the whole is key to our abilities to make sense of who we are, what we care about and the motives from which we act. It is thus key to our capacity to be responsible for ourselves, our conduct and our ongoing self-creation – in Schechtman’s terms, our capacity to live “the life of a person”.¹⁹⁷ I shall return to discuss further what this means in Section 6.

Reality constraint

The second constraint that Schechtman imposes is that our self-narratives “cohere with the basic contours of reality”.¹⁹⁸ The reality in question here is the world of facts as observed by others – facts about us as human organisms (rather than selves),¹⁹⁹ other people, our environment, and relationships between these. Importantly this constraint does not entail a requirement for maximum inclusion of all such facts. Rather it highlights the threat that serious departures from these poses to maintaining and inhabiting an identity-constituting narrative. The reality constraint is justified by the need for us to have an identity that supports us in living in the world with others which, Schechtman argues, requires “[f]undamental agreement on the most basic features of reality.”²⁰⁰ She goes on to say that:

¹⁹³ Schechtman (1996), p.114.

¹⁹⁴ Ibid., p.114.

¹⁹⁵ Ibid.

¹⁹⁶ There is debate about the degree to which unconscious motives comprise elements of our self-narratives. It is not necessary for me to address this for the purposes of this project.

¹⁹⁷ Schechtman (1996), p.114. Schechtman’s more recent work allows for a more inclusive criteria for personhood (including infants and people with dementia). See Schechtman (2014) and fn. 47 above.

¹⁹⁸ Ibid., p.123.

¹⁹⁹ It would be circular to apply this constraint to facts about our identities, as these are dependent on a realistic narrative.

²⁰⁰ Schechtman (1996), p.119.

“The failure to be tuned into basic facts about the world one inhabits – and hence the failure to inhabit a world in common with one’s fellows – interferes with the capacities and activities that define the lives of persons.”²⁰¹

As with the articulation constraint, departures from reality that threaten identity can be distinguished from those that may reasonably be accommodated within a coherent self-narrative. In the first category are gross and “recalcitrant” delusions about matters of fact or interpretations of facts, such as the belief that one is Napoleon, or reading everything as a sign that one is under surveillance.²⁰² These may be seen rendering someone’s narrative so dysfunctional that it can no longer constitute an identity in a meaningful, practical sense, and make “taking one’s place in the world of persons virtually impossible” (see Section 6).²⁰³ However, most human lives include innumerable mistakes of observation, memory, or interpretation. Schechtman holds that such errors do not compromise someone’s identity if they are of a kind that she would correct if they were drawn to her attention and if she is able (without too much difficulty) to revise her narrative accordingly.²⁰⁴ And interpretive idiosyncrasies – for example seeing life through an anxious or optimistic lens – are not held to threaten identity, but rather part of the individual and interpretive nature of the narrative endeavour.²⁰⁵

These constraints will play a significant role in what I go on to say about the value of personal bioinformation in identity construction. However, I will suggest that the requirements for intelligibility and realism might extend in a direction that Schechtman herself neglects. Schechtman emphasises the need for our identities broadly to cohere with the world as experienced by others because we lead social lives. But, in Chapter 3 I will present my own argument, which builds upon but goes beyond, the accounts of identity outlined here. I will argue that, because we also lead inescapably embodied lives, there is also a need for our identities to be comprehensible in light of, and to cohere with, our *own embodied experiences*.

SECTION 6: WHY HAVING COHERENT IDENTITY NARRATIVE MATTERS

The conception of identity outlined in this chapter is more than a mere description of who someone is, it is a normative, *practical* one. That is to say, it is the foundation from which we interpret our experiences, evaluate, act and continue to constitute who we are. And the ability of a self-narrative to occupy these practical roles is contingent upon it having certain qualities.

²⁰¹ Ibid., p.122.

²⁰² Ibid., p.123. These are Schechtman’s own examples.

²⁰³ Ibid., p.127.

²⁰⁴ Ibid.

²⁰⁵ Ibid.

According to the various accounts on which I draw in this chapter, it is variously argued that they must be: coherent, intelligible, realistic, amenable to articulation, explicable, unified, stable and integrated. For the remainder of this project, in the interests of brevity, I shall use ‘coherence’ to refer to this suite of qualities. In doing so my intention is to exploit the dual connotations of ‘coherence’ – suggestive of both unification, and also of intelligibility. I return to unpack further what coherence entails in Section 7. In this section I will summarise the reasons indicated in the literature why it is that having a coherent self-narrative is held to matter for the richness and character of an individual’s own life.

The valuable capacities

The value to the individual of developing and maintaining a coherent self-narrative is held to lie in the kind of life that it supports. According to some accounts this value is described in terms of the life of a ‘person’.²⁰⁶ I shall not use the language of personhood here for three reasons.²⁰⁷ First I wish to avoid conflation with a different kind of debate in bioethics, where personhood is associated with third-person adjudication of questions about which kinds of lives, or whose choices, warrant respect. Secondly, in drawing together the nature of outcomes that are variously held to be contingent on the coherence of our self-narratives, I wish to cast my net wider than those narrative accounts which explicitly invoke personhood. Thirdly, the desirability of ‘being a person’ to an individual may be somewhat opaque. My intention is to illuminate why it matters *to the individual herself* that she has a coherent identity narrative. Here, then, I will unpack a suite of six (interconnected) valuable capacities that emerge from the literature as those which are contingent upon the coherence of our self-narratives.²⁰⁸ These are, our capacities for:

- i) self-understanding;
- ii) investment in our own pasts and futures;
- iii) strong evaluation;
- iv) autonomy;
- v) moral outlook and commitments and
- vi) self-creation.

²⁰⁶ Mackenzie (2009); Schechtman (1996). In her more recent work Schechtman holds that narrative self-constitution is a foundation for many of the practical and first-personal experiential aspects of being a person (including those I list in this section), but she no longer holds that it is a necessary condition for personhood, see Schechtman (2014)

²⁰⁷ My intention is not to contest the personhood claims in the literature, but rather to unpack them expose to what might be valuable from an individual’s perspective about living the life of a person.

²⁰⁸ This label of valuable capacities is not one used in the literature.

I shall briefly describe each of these.

i) Self-understanding

Perhaps the most obvious function that our self-narratives serve, is allowing us to understand and reflect upon who we are. As Catriona Mackenzie and Mary Walker describe it,

“Because self-narratives are selective and interpretive, they enable us to make psychological and evaluative sense of our selves, forging patterns of coherence and psychological intelligibility in response to the changing and fragmentary nature of our lived experience.”²⁰⁹

They help us to locate our “central qualities” within the bewildering array accrued over a life-course.²¹⁰ A narrative framing permits one to think of our lives as a whole and to interpret our experiences in light of our pasts and in anticipation of our futures and can accommodate diversity and evolution within unity.²¹¹

ii) Investment in our own pasts and futures

The interpretive connections of narrativity provide the basis upon which I can understand how the ‘me’ in the past is continuous with the present ‘me’, despite having undergone (perhaps significant) changes. This sense of temporal connectedness is key to underpinning concern for our own past and future commitments or relationships and indeed to the fact that we are invested in long-term projects at all.²¹² Schechtman argues that our “self-interested concern” for what will happen in the future is explicable because it will be part of one’s story and have interpretive implications for other parts of this story.²¹³ Within this picture there is room for my identification with different parts of one’s life to admit of degrees.²¹⁴ But it is also conceivable that my characteristics might undergo such thoroughgoing changes that it is impossible to locate a thread that joins one part of my life to another, such that I might be justified in feeling that I was indeed a different individual.

iii) Strong evaluation

It is argued that our narratives provide us with the interpretive perspective from which we work out what we value and what a worthwhile life looks like – in Charles Taylor’s terms:

²⁰⁹ Mackenzie and Walker (2015), p.380.

²¹⁰ DeGrazia (2005), p.83.

²¹¹ C. Taylor (1989).

²¹² DeGrazia (2005); Ricoeur (1991).

²¹³ Schechtman (1996).

²¹⁴ Ibid.

“To know who I am is a species of knowing where I stand.”²¹⁵ Taylor argues that our narratives support our capacity for, what he calls “strong evaluation”.²¹⁶ They provide the foundation from which we can develop and articulate stable preferences, based in reflective judgements about what course of action, or ways of living, are worthwhile. Having, in Harry Frankfurt’s phrase, “second-order desires” – that is, not just to want, but to *want* to want something – requires knowing who we are and having a conception of ourselves as invested in the future direction of self-stories.²¹⁷ The alternative is to be blown around by unreflective desires and *ad hoc* choices of a “simple weigher”.²¹⁸ As this suggests, this capacity for evaluation is intimately tied to our autonomy and our identities as agents.

iv) Autonomy

Autonomy here is intended in the thick sense of a capacity of a person, rather than the property of an isolated choice.²¹⁹ While the latter, thin, sense of autonomy could be exhibited by someone ‘simply weighing’ options in an *ad hoc* fashion, autonomy in the former sense may be seen as reliant on possession of an identity-constituting narrative for a number of reasons. On many accounts, at least one condition for being an autonomous agent is that one’s motives, desires, beliefs and values are ‘really one’s own’ because they are the product of critical reflection.²²⁰ Meanwhile, Robert Young describes autonomy as the “means to our working out our projects in the world”.²²¹ Autonomous actions are those that are expressive of an individual “working as an integrated whole” in a way that permits multiplicity of roles and motives, but precludes compartmentalisation or deep conflict.²²² On these grounds, the maintenance of a coherent self-narrative may be seen as the necessary foundation for autonomy insofar as it provides the basis for our strong evaluations, our investment in enduring projects, and the binding medium within which the mutual interpretation and accommodation of diverse motives is possible.²²³ A coherent self-narrative provides the foundation for us to be the authors of our own actions.²²⁴ This does not entail an individualistic conception of autonomy.

²¹⁵ C. Taylor (1989), p.27.

²¹⁶ *Ibid.*, p.42; see also C. Taylor, 'Responsibility for Self', in *Free Will* ed. G. Watson (Oxford: Oxford University Press, 1982).

²¹⁷ H.G. Frankfurt, 'Freedom of the Will and the Concept of a Person', in *Free Will*, ed. G. Watson (Oxford: Oxford University Press, 1982), p.82.

²¹⁸ Taylor (1982), p.116.

²¹⁹ O. O'Neill, *Autonomy and Trust in Bioethics* (Cambridge: Cambridge University Press, 2002).

²²⁰ G. Dworkin, *The Theory and Practice of Autonomy* (Cambridge: Cambridge University Press, 1988).

²²¹ R. Young (1982). "The Value of Autonomy" *The Philosophical Quarterly*, 32(126): 35-44, p.43

²²² Korsgaard (2009), p18. See also, Meyers (1989).

²²³ Mackenzie (2008).

²²⁴ MacIntyre (1985).

The narrative foundation on which our evaluations and priorities are based is one that is necessarily developed through our relationships with others.²²⁵

v) Moral outlook and commitments

The significance of knowing who one is, where one stands on matters of value and priority, and being in a position to make strong evaluations ought not to be seen as reducible solely to one's capacity for autonomous agency. It may also be seen as the foundation for our moral outlook or vision and our conception of what constitutes a good life. As Iris Murdoch observes, our moral character is not constituted only by our will or our actions, but also by how we attend to the world and to other people.²²⁶ The idea that the construction of our self-narratives is intimately bound up with our articulation and pursuit of what we judge to be a good and worthwhile life is particularly associated with the accounts offered by MacIntyre and Taylor.²²⁷ Taylor holds that "[o]ur identity is what allows us to define what is important to us and what is not."²²⁸ Furthermore, the integrity and continuity of our self-narratives may be seen as the necessary substrate that supports our investment in the kinds of long-term projects, commitments and relationships that help to give our lives depth and meaning.²²⁹ Though these aspects of a rich life might entail acting in particular ways, they are not wholly reducible to action.

vi) Ongoing self-creation

Being in possession of a coherent self-narrative is also key to our capacities to *continue* to create who we are, to consolidate the characteristics we value and to evolve.²³⁰ Our abilities to make strong evaluations, and to act on our autonomous choices may be seen not only as the products of our self-narratives, but also as the means by which we select the components of our self-narratives and shape their course into the future.²³¹ This reflexivity is central to the narrative conception of self-constitution. DeGrazia characterises it thus: "...self-creation projects flow from narrative identity and, as they do so, continue to write and often edit the

²²⁵ Mackenzie (2008); C. Taylor (1989).

²²⁶ I. Murdoch, 'The Idea of Perfection', in *The Sovereignty of Good* (London: Routledge and Kegan Paul, 1970).

²²⁷ MacIntyre (1985); C. Taylor (1989).

²²⁸ C. Taylor (1989), p.30.

²²⁹ Ibid.

²³⁰ DeGrazia (2005).

²³¹ C. Taylor (1989).

narratives from which they flow.”²³² On this view, the capacities listed above may be seen as both a means of narrative construction and an outcome of this.

The ‘double normativity’ of identity-constituting narratives

The purpose of this section has been to answer the fourth of the research questions posed at the start of this chapter: *what is at stake in our ability to construct and inhabit an identity-constituting self-narrative?* The answer provided by the theories reviewed here is that what is at stake is the possibility of developing the six capacities outlined above (or in Schechtman’s terms, being able fully to live the life of a ‘person’). Schechtman stops short of saying that a life of someone who has authorship of her own actions and is invested in her own past and future is objectively better than that of someone who does not.²³³ However, she allows that, when our lives do have these features, retaining them does indeed matter to us. And she takes their value as basic, rather than something for which we need to (or could) seek further justification. In this thesis I will hold that knowing who one is and who one wants to be, and being in a position potentially to realise this through one’s actions, commitments, judgements and ongoing self-development, are things that we value and are key to leading rich, fulfilling and engaged human lives. I shall take this claim as relatively uncontroversial, particularly as this position is neutral as to the specific contents, pursuits or priorities of such a life. I would, however, readily concede that the six capacities are not *sufficient* for a flourishing existence, and that a life lived without them could be a content one, if not one that most of us would choose.

At the start of Section 3, I suggested that narrative theories of self-constitution exhibit a ‘double normativity’. The ‘outcome’ aspect of this double normativity is, then, that something valuable depends on the development and maintenance of our self-narratives: the ability to understand who we are and thereby to develop and sustain a cluster of capacities that contribute to the richness and fulfilment of our lives. The second aspect of the double normativity is that this outcome is contingent upon developing a particular kind of self-narrative – one that is intelligible, unified and realistic, in short, coherent. Narrative coherence is not inevitable. As outlined above, it is intimately tied up with the articulability and realism of someone’s account of who they are and how parts of this story connect to and colour others. It pertains to both internal integration and intelligibility with respect to the world. It is both synchronic and diachronic, binding together a “persisting subject” over time.²³⁴ This means that it is possible

²³² DeGrazia (2005), p.106.

²³³ Schechtman (1996).

²³⁴ Ibid., p.94.

to fail, to a greater or lesser extent, to develop or to maintain a self-narrative that is sufficiently coherent to support the valuable capacities. In the next section I shall turn to consider what is entailed by the requirement for narrative coherence.

SECTION 7: COHERENCE AND SELF-CONSTITUTION

The first matter I will address here is scepticism about whether narrative coherence is necessary to support the kind of identity-constituting narrative that is capable of underpinning the valuable capacities outlined above. I will then consider the assertions made in the literature about the degree of coherence that is deemed necessary and the kinds of factors that might impinge on our abilities to achieve it. This will start to expose the reasons why, as I shall argue in Chapter 3, personal bioinformation may play an important role in our construction of our self-narratives.

The importance of narrative coherence

Some commentators challenge the suggestion that narrativity, let alone narrative coherence, is necessary for a rich or fulfilling life.²³⁵ For example, Galen Strawson cites his facility for commitment and friendship despite the apparent episodic phenomenology of his life.²³⁶ It is hard to counter such an *ad hominem* claim. Again, one response to sceptics is that they are addressing a straw man by setting too high a threshold for what counts as coherent identity-constituting and capacity-supporting narrative.²³⁷

Another kind of response is to consider the importance of coherence from the opposite perspective – that of the challenges of living without a reasonably unified and intelligible foundation from which to interpret our experiences, to judge, decide, act, and to navigate our lives. At the extreme end of this, Mackenzie and Poltera offer the example of Elyn Saks's memoir of living with schizophrenic psychosis as an example of the "real suffering" a disintegrated and disrupted narrative can cause. They describe Saks recounting how her illness removed any "vantage point" or "core" from which she was able to organise or interpret her experiences or locate herself amongst them.²³⁸

More commonplace is the example invoked by Taylor of the ephemeral, but still distressing, experience of undergoing an "identity crisis" following the loss of a job or relationship, during

²³⁵ J. Christman (2004). "Narrative Unity as a Condition of Personhood" *Metaphilosophy*, 35(5): 695-713; Strawson (2008).

²³⁶ Strawson (2008).

²³⁷ Schechtman (2007).

²³⁸ E.R. Saks, *The Centre Cannot Hold* (Virago, 2007), p.12 cited in Mackenzie and Poltera (2010).

which one loses the parameters within which one is able to determine who one is or what one values.²³⁹ And Jonathan Glover captures the value of one's identity narrative as a stable foundation for our agency in saying that:

“Our inner story lets us get our bearings when we act. Without it, all decisions would be like steering at sea without a map or compass.”²⁴⁰

The coherence of our self-narratives matters because they are the interpretive frameworks through which we make sense of and conduct our lives. Nevertheless, the theories considered here do not require absolute coherence for a self-narrative to be identity-constituting.

How much coherence is required?

Views differ about how much coherence is required for a self-narrative to be identity-constituting. Schechtman asserts that a “high degree” is needed.²⁴¹ But she acknowledges that “perfect intelligibility” is an unattainable ideal.²⁴² Some, though, regard Schechtman's requirement as too demanding.²⁴³ Mackenzie and Poltera point to the complex, multifaceted nature of our lives and their duration, which mean that, for example, tensions between our commitments, or alienation from some of our roles or motivations are almost inevitable. They suggest, therefore, that a narrative need only be “relatively integrated”.²⁴⁴ Furthermore, because we must respond to new experiences any coherence is only ever “dynamic and provisional”.²⁴⁵ Mackenzie argues that:

“...part of what is involved in constituting oneself as a persisting subject is to create an identity that has *a degree of* permanence and coherence. This identity takes the form of character or a set of *relatively* stable and integrated traits, habits, dispositions, and emotional attitudes.”²⁴⁶ [emphasis added]

Coherence entails neither bland homogeneity nor immutability. What matters is that a self-narrative has a “meaningful” or “satisfying” unity, such that its constituent parts “hang together” in a way that make sense as parts of a whole (unfolding) story that is “psychologically intelligible” to us.²⁴⁷

²³⁹ C. Taylor (1989), p.27.

²⁴⁰ Glover (1988), p.152.

²⁴¹ Schechtman (1996), p.98.

²⁴² Ibid., p.97.

²⁴³ Mackenzie and Poltera (2010).

²⁴⁴ Ibid., p.33.

²⁴⁵ Mackenzie and Walker (2015), p.381.

²⁴⁶ Mackenzie (2009), p.107.

²⁴⁷ Mackenzie (2008), p.12; Mackenzie and Poltera (2010), p.47; Schechtman (1996), p.97.

The (in)coherence of our self-narratives may admit of degree and can be more or less pervasive. At one extreme someone might struggle to make sense of who she is at all, or what characteristics are attributable to her, for example, as a result of cognitive and affective disturbances associated with severe psychosis.²⁴⁸ More localised incoherence, for example where an individual is unable to reconcile particular desires with her account of who she is, may be more commonplace. The latter is not held fatally to threaten identity-constitution.²⁴⁹ But it is suggested that there are limits to which the intelligibility of the whole can be quarantined from local dis-integrity. For example, Taylor holds that repudiating one's entire childhood "is to accept a kind of mutilation as a person."²⁵⁰

According to the narrative theories of self-constitution reviewed here, a total inability to construct an intelligible self-narrative places the valuable capacities I have listed above beyond someone's reach. However, arguments as to *how much* coherence and integration of one's self-narrative are needed to sustain these various corollary capacities vary between different accounts of narrative self-constitution. For example, Mackenzie and Poltera maintain that the conditions for preserving a sense of who one is may be less demanding than those for having a capacity for full autonomy.²⁵¹ Meanwhile Schechtman suggests that one's continued subjective sense of self may be more vulnerable to narrative disintegration than, for example, having a general sense of connection to one's past actions.²⁵² These distinctions notwithstanding, the broad implication of the theoretical accounts discussed here is that possession of an "internally troubled and divided" narrative threatens one's capacities to have a clear sense of who one is, one's value and priorities and sense of authorship of one's own conduct and existence.²⁵³ Moreover, the way in which it does so is a matter of degree. My thesis will chiefly be concerned with the ways in which moderate and relatively common sources of disruption to narrative coherence could interrupt or diminish our capacities to make sense of, to inhabit and to enact who we are, rather than with sources of catastrophic narrative disintegration that would entail wholesale loss of identity.

Factors affecting coherence

This then leaves the question of what kinds of factors are held to influence (for better or worse) the coherence of our self-narratives. This question is crucial for the present project – I will

²⁴⁸ Mackenzie (2009); Mackenzie and Poltera (2010).

²⁴⁹ Schechtman (1996).

²⁵⁰ C. Taylor (1989), p.51.

²⁵¹ Mackenzie and Poltera (2010)

²⁵² Schechtman (2007)

²⁵³ Schechtman (1996), p.129.

argue in the next chapter that access to personal bioinformation may be seen as playing a critical role in this. Here, though, I focus only on the influences indicated by the literature. These may broadly be broken down into:

- i) Personal agency;
- ii) Other people;
- iii) Events;
- iv) Body and health; and
- v) Moral teleology.

The relevance of the first four of these factors to the role that I will propose that personal bioinformation may play in our identity narratives will become plain over the coming chapters

i) Personal agency

The development of an integrated identity is widely framed as “an achievement of agency” rather than being inevitable.²⁵⁴ This does not mean that achieving coherence needs to be one’s explicit aim. But narrative construction is presented in the literature as the application of an organising, interpretive activity. And coherence is achieved or undermined to the extent that an individual is able to reconcile, for example, her personal values with her professional ones,²⁵⁵ or act in ways consistent with the normative descriptors or roles she applies to herself.²⁵⁶ Achieving or maintaining a coherent sense of self is something we *do*. But, as emphasised in Section 4, it is not something we necessarily do in a self-conscious or self-absorbed way. In some circumstances, however, such as the restoration of coherence following the disruption of serious mental illness, it might require a considerable and “fraught” effort of will.²⁵⁷ But coherence is by no means wholly in our control, as the remaining four factors indicate.

ii) Other people and social contexts

It is only necessary briefly here to review the ways that other people can detract from or support the coherence of our self-narratives, as I have already discussed this in Section 4. Support comes in the form of the relationships within which we develop who we are and may see our own self-conceptions reflected, and the wider social contexts that provide the language and interpretive tools with which we work out what kind of individuals we are.²⁵⁸ Meanwhile

²⁵⁴ Mackenzie and Poltera (2010), p.38.

²⁵⁵ DeGrazia (2005).

²⁵⁶ Korsgaard (2009).

²⁵⁷ Mackenzie and Poltera (2010), p.48.

²⁵⁸ Schechtman (1996).

others may disrupt our self-conceptions by resisting our own self-characterisations.²⁵⁹ As Macintyre observes:

“...what the agent is able to do or say intelligibly as an actor is deeply affected by the fact that we are never more (and sometimes less) than the co-authors of our own narratives.”²⁶⁰

Inevitably, the actions of others also impact on our existing narratives by introducing new plotlines, opportunities or constraints.

iii) Events

Schechtman suggests that significant or unexpected events can disrupt formerly well-integrated narratives by throwing new light and interpretations on what has gone before, or derailing their anticipated future trajectories.²⁶¹ Coherence may be restorable. But Schechtman suggests that some particularly disorienting events could interfere with our capacities to articulate our narratives altogether.

iv) Body and health

Our mental health and cognitive and affective functioning are critical to our ability to construct and maintain a coherent self-narrative. Dementia or serious mental illness, by interfering with memory or the ability to organise experience into a comprehensible, temporal structure may lead to “fragmentation of the self”.²⁶² And, as I shall go on to illustrate in subsequent chapters, it is likely that prominent amongst the events and experiences that can disrupt our self-conceptions are those affecting our bodies or health. However, our bodies are not just a source of potential disruption. Mackenzie argues that our continuous (though evolving) awareness of ourselves as physical beings also provides a kind of substrate or anchor for the (particularly diachronic) integration of our identities and “one of the background conditions for the ongoing unity and intelligibility of our lives.”²⁶³

I shall argue that these connections between body, health and biology, on one hand, and narrative coherence, on the other, is at the heart of the potential identity-value of personal bioinformation. For this reason, though, more detailed exposition must await Chapter 3.

²⁵⁹ DeGrazia (2005).

²⁶⁰ MacIntyre (1985), p.231.

²⁶¹ Schechtman (1996).

²⁶² Mackenzie and Poltera (2010), p.41.

²⁶³ Mackenzie (2009), p.115.

v) *Moral teleology*

MacIntyre and Taylor argue that an identity-constituting narrative derives a unifying purpose from the “quest” for a morally good life.²⁶⁴ This moral teleology is absent from many other accounts, including Schechtman’s. I will not attempt to adjudicate this difference. My arguments that follow will not depend on there being a necessary connection between pursuit of morally virtuous life (or any single grand *telos*) and a coherent narrative.

Beyond Coherence

The discussion in this chapter has focused on what we might think of as the ‘structural conditions’ necessary for a self-constituting narrative – that is the interpretive relationships and ‘fit’ between the constituent parts of the narrative and reality and the relative coherence of the whole. Many narrative theories, including Schechtman’s, are largely silent on the *qualities* of the actions, values, beliefs or commitments that can make up a self-narrative.²⁶⁵ Taylor is somewhat more directive, arguing that an identity built solely upon our own individualistic or ephemeral concerns, divorced from social commitments and contexts, is a limited and impoverished one.²⁶⁶ Nevertheless, Taylor does not prescribe the precise nature of characteristics that can contribute to an identity-constituting narrative.²⁶⁷

The features of these theories of narrative self-constitution on which this thesis will depend are the requirement for achieving and maintaining a reasonable degree of narrative coherence and the implications this holds for a self-narrative to function as a practical narrative, grounding our sense of who we are, agency and navigation of lived experiences. The neutrality of many such theories as to the characteristics that can make up an identity-constituting story may be seen as contributing to their plausibility and range of applicability to many different kinds of lives and choices. Nevertheless, I would suggest that it must be recognised that from a first-person perspective it is not only the coherence of our identities that matters us. It also matters how I feel about the kind of person I am. It matters to me that I have particular kinds of desires and values, that I do particular things, occupy particular roles and have particular relationships. The *contents* of our narratives also matter. The relevance of this will become

²⁶⁴ MacIntyre (1985), p.219; C. Taylor (1989).

²⁶⁵ They are silent to the extent the nature of the contents does not impinge on a narrative’s articulability or realism.

²⁶⁶ C. Taylor (1992).

²⁶⁷ Hilde Lindemann Nelson adopts a more socially-constructed and externalist conception of narrative identity than the one I have outlined here. Nevertheless, she argues that some means of narrative self-constitution may be oppressive and, in being so, interfere with someone’s capacity for agency, see H. Lindemann Nelson (2014).

clearer when I come to consider what it means for personal bioinformation to be significant and valuable to our identities in Chapter 8.

SECTION 8: CHAPTER CONCLUSION

I began this chapter by suggesting that existing accounts of the relationship between our access to various kind of personal bioinformation and our identities do not their own provide adequate bases for explaining why a wide range of personal bioinformation might have sufficiently significant impacts on our identities to give rise to important interests in information access. I have proposed that an account in which personal bioinformation is understood as potentially playing a crucial role in the construction of our identity narratives could provide just such an explanation. However, in order to understand why this is so, it is necessary to have a well-developed appreciation of what is entailed by a theory of narrative identity. Outlining the relevant contours of such a theory has been the second key task of this chapter.

The normativity of the theories outlined above will be key to understanding my case for the nature and weight of our interests in accessing personal bioinformation. This argument will be based on the premise that we all have a strong interest in developing and inhabiting coherent self-narratives that provide us with an understanding of who are, which of our characteristics make us who we are, what we value and how we are connected to our own pasts and futures. This is a narrative that brings an interpretive framework and binding logic to these various characteristics, such that they comprise a global identity that is unified (while admitting of complexity and change), that makes sense to us, and provides a foundation for our judgements, actions, relationships and commitments. The strength of the interest in narrative self-constitution is not grounded in the valorisation of the vain or individualistic pursuit of self-understanding or self-perfectionism. Rather its justification lies in the proposition that the development of a coherent self-narrative is a condition for the development of a suite of valuable capacities that are necessary for leading rich, fulfilling and engaged lives. This interest is, therefore, considerable. For this reason, I will argue, we have concomitant interests in the means to develop, maintain or restore narrative coherence. I will expand on this claim in the next chapter by suggesting that personal bioinformation is one such means.

CHAPTER 3: THE ROLE OF PERSONAL BIOINFORMATION IN OUR SELF-NARRATIVES

SECTION 1: AIMS OF THIS CHAPTER

In this chapter I build on the philosophical account of narrative identity outlined in the previous chapter by presenting my own argument that personal bioinformation has a significant role to play in the development of our identity narratives. This argument will provide support for my central contention in this thesis: that our identity-related interests warrant serious ethical attention in policies and practices governing our access to this kind of information.

As such, this chapter continues the work of addressing the first of my four headline questions set out in Chapter 1: **how might the relationship between personal bioinformation and our identities be conceptualised?** Specifically, it aims to make clear the source of the normativity in the relationship. The particular research questions that I will answer in this chapter are:

- i. **Why is personal bioinformation relevant to our self-narratives?**
- ii. **In what ways could personal bioinformation benefit the development of our identities?**

I begin this chapter by setting the context for my argument by observing that many, though not all, existing philosophical theories of narrative self-constitution accord surprisingly little significance to the fact that we are materially embodied beings. I outline why this is an important omission. I then review the approaches of narrative theories that do accommodate embodiment, while noting these do not extend to recognising a particular role for personal bioinformation in narrative construction. (Section 2). I then present my own original argument that, given the inescapably embodied nature of our existence and experiences, personal bioinformation provides important tools for the construction of self-narratives that maintain their coherence in light of these experiences, and support us in navigating them. On this basis, I explain why the ‘double normativity’ of narrative identity theory supports my contention that access to personal bioinformation engages ethically significant interests. (Section 3). In proposing a role for personal bioinformation in the construction of our self-narratives I aim to contribute a fresh angle to the literature on narrative identity theory. In Section 4 I outline how my theory is distinguishable from four arguments in the literature with which it shares some similarities. In the final substantive section of this chapter I respond to two sets

of possible concerns that might be raised about the suitability of bioinformation as a tool of self-conception (Section 5).

The arguments that follow in this chapter are intended to apply to personal bioinformation as a broad category, not necessarily to every type or token of it. The factors that help to shape and differentiate the significance and value of particular kinds and instances of personal bioinformation will be discussed in Chapter 8, drawing on the evidence from the illustrative examples in Part II.

SECTION 2: EMBODIED IDENTITY

Disembodied narratives

Despite my proposal in the previous chapter that a narrative conception of identity has the appropriate qualities to ground an explanation of the role and value of personal bioinformation in self-characterisation, this theoretical foundation might seem a surprising choice. This is because many of the best-known theories of narrative self-constitution, including those of Marya Schechtman in 'The Constitution of Selves', Charles Taylor and Alasdair MacIntyre, have little or nothing to say about the relevance of our existence as biological beings to our identities. These canonical versions have been critiqued by some as being (excessively) rationalist and dualist in the ways they construe self-narrative.²⁶⁸ They appear to pay little attention to the ways that our bodies and embodied existence might contribute to and shape our experiences of ourselves and our lives and thus the accounts we give, or are able to give, of who we are. They paint a picture of self-constitution that takes place in the mind, while the body is relegated to the vehicle through which we happen to enact our stories of who we are. MacIntyre merely notes that birth and death bookend our narratives.²⁶⁹ Meanwhile Schechtman in her earlier work restricts the identity-related role of the human body to the means by which others may (re)identify us, thus permitting the kinds of social interactions that contribute to self-building.²⁷⁰ Not all theories of narrative identity, however, are similarly disembodied, as I will return to discuss later in this section.

Given their dualism, it is hardly surprising that these prominent theories do not themselves argue for, or acknowledge, a role for personal bioinformation in informing self-constitution.

²⁶⁸ Mackenzie (2009); P. Brandon (2016), "Body and Self: An Entangled Narrative" *Phenomenology and the Cognitive Sciences*, 15(1): 67-83; A. Witz (2000), "Whose Body Matters? Feminist Sociology and the Corporeal Turn in Sociology and Feminism" *Body & Society*, 6(2): 1-24.

²⁶⁹ MacIntyre (1985)

²⁷⁰ Schechtman (1996). In her more recent work, Schechtman does recognise that our bodies and physical attributes play a role in what constitutes us as persons, see M. Schechtman (2014).

Nevertheless, I would suggest, they do not explicitly *preclude* such a role. For example, Schechtman lists the contents of self-narratives as being “...actions, experiences, beliefs, values, desires, character traits...”²⁷¹ and “other psychological features”.²⁷² This list in principle leaves open the possibility that some of these contents might sometimes be supplied by information about one’s body or biology.

However, there is one reason these accounts might seem to preclude a role for personal bioinformation. This is because personal bioinformation pertains to bodily states, functions, or relationships which are only ‘ours’ or ‘about us’ in a passive, default sense. In an analogous observation, Harry Frankfurt says, “of course, every movement of a person’s body is an event in his history... But this is only a gross literal truth.”²⁷³ According to the theories of narrative identity outlined in the previous chapter, our self-narratives are precisely not just made up of the ‘givens’ of our biological lives or the totality of all the facts about what inexorably goes on in and around us. Rather they are constructed and interpreted – we *make* them.²⁷⁴ Therefore, positing the identity-relevance of bioinformation might seem illegitimately to confuse information relevant to our identities – who we are as individual selves, persons and agents – on one hand, with information that is merely relevant to us as human organisms, on the other.

Schechtman herself lodges a related objection when she argues that findings about the neurological correlates of choices or behaviour should not necessarily be seen as threatening our own narrative explanations of our motivations where they diverge from these.²⁷⁵ Her rejection is not dependent on such findings being poorly evidenced or otherwise dubious. Rather she holds that, because identity is *constituted* by narrative, these neuroscientific findings have no claim on being “prenarrative truth about the self”.²⁷⁶

The argument to be developed in this chapter has no quarrel with Schechtman’s position. My position will not be premised on an assumption that personal bioinformation reveals existing facts about an individual’s *identity*, but rather that it supplies knowledge of her biology, body, or health, which she may then interpret as being relevant (or not), and choose to use (or not), in developing her self-narrative. So in positing, for example, that someone could have an identity-related interest in accessing findings from a neuroimaging study in which she has

²⁷¹ Schechtman (1996), p.73.

²⁷² *Ibid.*, p.2.

²⁷³ H. Frankfurt, 'Identification and Externality', in *The Identities of Persons*, ed. A. Rorty (Berkeley: University of California Press, 1976), p.243.

²⁷⁴ See Chapter 2.

²⁷⁵ Schechtman (2012).

²⁷⁶ *Ibid.*, p.75.

participated pertaining to her own brain functions, my suggestion is not that these results somehow reveal ‘who she really is’ in the unmediated raw, but rather that they might provide material she could use in developing her interpretation of who she is. I shall argue here that bioinformation should be seen as relevant to identity in an instrumental rather than intrinsic sense.

Inescapable embodiment

What positive grounds, then, do I have for proposing that personal bioinformation could play a valuable part in our self-narratives? The answer, I will suggest, rests on the inescapably materially-embodied nature of our existence. As such, I shall argue, knowledge of our health, bodies and biology provides both potential contents and crucial interpretive tools for the construction of our self-narratives. I will return to justify this claim in Section 3. But first, I shall outline what I mean by the ‘embodied nature of existence’.

What I mean by this is that our experiences of ourselves and of the world, our abilities to act in the world, and the ways other people react to us are all shaped by the fact that we exist as material beings and material beings with particular physical attributes. We experience our lives from an embodied perspective and navigate them as embodied beings. Claims about the significance of embodiment may be found in diverse disciplines. Philosophers of mind and neurobiologists have argued that the fact that we exist as bodies inescapably shapes the ways in which we encounter, perceive and understand the world. For example, Quassim Cassam suggests that “the fantasy of the disembodied self is just that: a fantasy”.²⁷⁷ Consciousness itself, it is argued, can be seen as essentially embodied.²⁷⁸ Phenomenologists have argued that our experience of being embodied gives meaning and form both to the body itself and to the world. For example, Merleau-Ponty holds that –

“The body is the vehicle of being in the world, and having a body is, for a living creature, to be involved in a definite environment, to identify oneself with certain projects and be continually committed to them.”²⁷⁹

In recent years there has also been a ‘material turn’ in sociological theories of self – one that seeks to (re)assert and emphasise “the way material aspects of our embodiment condition our

²⁷⁷ Q. Cassam, ‘The Embodied Self’, in *The Oxford Handbook of the Self*, ed. S. Gallagher (Oxford: Oxford University Press, 2011), p.154.

²⁷⁸ C. Shilling, *The Body and Social Theory* (Sage, 2012), p.x.

²⁷⁹ M. Merleau-Ponty, *Phenomenology of Perception*, trans. C. Smith (London: Routledge, 1962 repr. 2003), p94.

lived subjectivity”.²⁸⁰ An emphasis upon the importance of the lived experience of the body to the self also makes up a significant strand in feminist theory.²⁸¹ Judith Butler, for example, explores the interrelationship between materiality and performativity in the emergence of the categories of gender and sex,²⁸² while Margrit Shildrick holds that “the being, or rather the becoming, of the self is always intricately interwoven with the fabric of the body”.²⁸³ Meanwhile, feminist theorists Stacy Alaimo and Susan Hekman observe that our bodies and biology exert both “active” and “recalcitrant” forces upon our lives that serve to shape, enable, and place limits upon what we are able to do and how we are able to define ourselves.²⁸⁴ Because of the role of our bodies in shaping both the nature of our experiences and the directions our lives can take, I will argue that any adequate theory of identity must be one that reflects the phenomenology, the ‘what it is like’, of human existence and thus acknowledge the significance of embodiment to who we are and who we can be.

Embodiment in narrative identity theory

The dualism implied by the theories of narrative identity discussed above notwithstanding, other narrative theories have not ignored the material turn in accounts of the self. Several more recent narrative conceptions of identity recognise the extent to which our embodiment plays a central role in shaping our self-narratives.²⁸⁵ One of most developed accounts is offered by Catriona Mackenzie.²⁸⁶ Mackenzie is clear that her view is not that our identities are reducible to our bodily states or attributes. But, because our experiences of the world are necessarily those of embodied beings, our “bodily perspective” provides a crucial interpretive framework and counterpoint for the construction of our stories of who we are.²⁸⁷ She takes this to mean that our sense of continuous material embodiment supplies an important background condition for our sense of the unity of our self-narratives. But she also suggests that making sense of

²⁸⁰ K. Lennon et al., 'Introduction', in *Embodied Selves*, ed. S. Gonzalez-Arnal, et al. (Basingstoke: Palgrave Macmillan, 2012), p.3. This reassertion is a response to the deconstruction of the significance of the material reality of the body in the sociological literature.

²⁸¹ For an overview of the history of this strand of feminist thought see, for example, K. Lennon, "Feminist Perspectives on the Body" in *The Stanford Encyclopedia of Philosophy*, ed. E.N. Zalta (Fall 2014); S. Alaimo and S.J. Hekman, 'Introduction: Emerging Models of Materiality in Feminist Theory', in *Material Feminisms*, ed. S. Alaimo and S.J. Hekman (Bloomington: Indiana University Press, 2008).

²⁸² J. Butler, *Bodies That Matter: On the Discursive Limits of Sex* (New York: Routledge, 1993).

²⁸³ M. Shildrick, 'Introduction: Beyond the Body of Bioethics', in *Ethics of the Body: Postconventional Challenges*, ed. M. Shildrick and R. Mykitiuk (Cambridge MA:MIT Press, 2005), p.1

²⁸⁴ Alaimo and Hekman (2008), pp.3-4.

²⁸⁵ For example, Ajana (2010); K. Atkins, 'Narrative Identity and Embodied Continuity', in *Practical Identity and Narrative Agency*, ed. C. Mackenzie and K. Atkins (Taylor & Francis, 2010); Baylis (2003); DeGrazia (2005); Mackenzie (2009).

²⁸⁶ Mackenzie (2009).

²⁸⁷ *Ibid.*, p.103.

who one is requires making sense of the biological realities of one's life, such that, "developing an integrated and ongoing narrative of one's embodied subjectivity is central to the activity of self-constitution."²⁸⁸

Françoise Baylis emphasises the importance not only of subjective embodied experience to our self-narratives, but also of the way that others recognise and respond to our physical selves. She argues that aspects of our bodies such as the colour of our skin or our sex "influence[s] who we are and how we can be in the world", by shaping the stories others tell about us, and thus constraining those we are able to tell about ourselves.²⁸⁹ Meanwhile, Priscilla Brandon argues that our embodiment not only influences our self-narratives, but that these narratives can also affect how we carry ourselves or modify our bodies.²⁹⁰ Her position serves as valuable reminder that self-narratives are not epiphenomenal, but have consequences for how we conduct ourselves in the world.

My own argument builds on these moves towards recognising the significance of embodiment within theories of narrative identity. However, the positions outlined in the previous paragraphs do not themselves include arguments for the value of *personal bioinformation* in narrative self-constitution. Indeed, these positions are chiefly concerned with how our existing, *direct* experiences of embodiment shape the stories we can and do tell about ourselves. In contrast, this thesis is concerned with our access to information that is not currently in our possession. How, then, might additional, as yet unknown, insights into our biological lives conveyed by this information be relevant or valuable to our self-conceptions? To understand this, I suggest, we need to recognise two things: first, the roles that personal bioinformation could play in helping us to make sense of, and navigate, embodied experience; and, secondly, the importance of constructing a self-narrative that is intelligible and coherent in the context of these experiences. I will unpack these steps in the following section.

SECTION 3: BIOINFORMATION AND NARRATIVE COHERENCE IN AN EMBODIED LIFE

Navigating embodied existence

Our material embodiment is the unavoidable context within which self-constitution takes place. As such it is also a source of opportunities for, and boundaries upon, self-creation. As Ian Hacking observes, however strongly inclined we are to the idea that we invent who we are,

²⁸⁸ Ibid., p.103.

²⁸⁹ Baylis (2012), p.112.

²⁹⁰ Brandon (2016).

we must nevertheless recognise that in doing so we are, to some extent, constrained by our environment.²⁹¹ This environment includes our own bodies and biology. As Hacking says:

“We push our lives through a thicket in which the stern trunks of determinism are entangled in the twisting vines of chance.”²⁹²

One need not subscribe to Hacking’s language of determinism for his metaphor to remain apt. In constituting ourselves we will inevitably bump up against the realities and constraints of our material selves. As noted above, our bodies may be seen as both “active” and “recalcitrant” in ways that enable and place limits on our capacities to act and define ourselves.²⁹³ Embodiment impinges on who we are and can be because it has real, material consequences for us. This is readily apparent when thinking about the observable markers of potential social identifiers such as gender, ethnicity, disability or illness.²⁹⁴ Here our bodily attributes may affect the ways in which others’ respond to characterise us, thus potentially constraining the ways we can characterise ourselves.²⁹⁵ But it is equally the case where the materiality of our bodies enables or limits our interactions with and perceptions of our environment (both physical and social), its impact on us, and ours upon it. And this role may extend to the less visible aspects of our embodiment, such as our reproductive, cognitive, and affective capacities, the functioning of our autonomic systems, and our biological relationships to others. And, crucially for my present argument, the role of our health, bodies and biology in shaping the kinds of accounts we are able to give of who we are, and our abilities to inhabit these accounts, may extend to aspects of our biological lives about which we ourselves might not (yet) be directly aware, such as the latent risk of an inherited disease or one’s genetic parentage.

I wish to suggest that personal bioinformation is important to our identities precisely because our bodies both frame our subjective experiences and play an active part in shaping ‘how our lives go’. My core proposition is that personal bioinformation can play an invaluable role by helping us to negotiate some (though not all) of our ‘recalcitrant’ materiality, by alerting us to the whereabouts of some of the ‘stern trunks’ and ‘twisting vines’, and by helping us to explain or anticipate their impacts, and embrace or navigate around them. The value of personal bioinformation to our self-narratives, I suggest, lies in its capacity to provide context, explanations, or predictions in respect of our more direct encounters with our bodies, their

²⁹¹ Hacking (2004).

²⁹² *Ibid.*, p.282.

²⁹³ Alaimo and Hekman (2008) pp.3-4.

²⁹⁴ Shilling (2012), p.xii.

²⁹⁵ Baylis (2012).

capabilities, limitations and connections to the bodies of others. It also lies in its potential to make intelligible or accessible to us aspects of our material existence that are ambiguous, uncertain or only partially apprehended. Though Mackenzie does not herself suggest that personal bioinformation is important to our self-narratives, the role for this information that I am proposing here echoes her statement that:

“Making sense of who we are, and making sense of our lived embodiment, involves constructing an identity that is shaped by, and responsive to, biological realities”²⁹⁶

My suggestion in this thesis is that personal bioinformation has a critical role to play in this sense-making. My claim here is not simply that this information will introduce narrative contents and plot-lines involving our health, bodies and biological relationships – although this seems very likely. According to the relationship between identity and personal bioinformation that I am proposing, bioinformation does not only (potentially) supply the raw descriptive building blocks of a self-narrative – for example, “I am the individual with biological attribute *x*”. More particularly, my contention is that information about one’s biological existences has the potential to provide valuable *interpretive* narrative tools for making sense of and constructing one’s wider account of who one is in light of one’s embodied experiences. According to the account outlined in the previous chapter, a self-narrative is itself an interpretive framework. My suggestion is that personal bioinformation is both the object to which this framework is applied, and amongst the tools that shape it. That is, it can provide the means of making sense of, connecting or prioritising aspects of the individual’s embodied experiences and thus their role in the story of who she is.

In Part II of this thesis I will provide illustrative examples – based on analysis of information subjects’ experiences reported in the empirical literature – of the potential constitutive and interpretive narrative roles that specific kinds of personal bioinformation might play. The focus of the present chapter is to establish the broad basis on my conceptual and normative argument in relation to personal bioinformation as an inclusive category.

Contributing to a coherent self-narrative

What I have said so far explains why personal bioinformation might be useful, but it might still be queried why having the opportunity to access and to use personal bioinformation in the construction of one’s self-narrative engages *ethically significant interests*. That is, why might

²⁹⁶ Mackenzie (2009), p.121.

access to this information have sufficiently great an impact on what is important in our lives to warrant the attention and intervention of those who hold this information?

The answer, I wish to argue, is located in, what I have termed, the ‘double normativity’ of theories of narrative self-constitution (as outlined the previous chapter). That is, a self-narrative is more than just someone’s life story, it is a constructed account that is constitutive of her identity. This means that maintaining and inhabiting an identity-constituting self-narrative has important consequences in terms of securing valuable aspects of human existence. However, being in a position to realise these valuable consequences depends on a self-narrative exhibiting coherence, which depends in turn on it meeting the twin conditions of being both intelligible to the individual herself and also reasonably consistent with the world as experienced by others. These are the conditions that Schechtman terms the “articulation” and “reality” constraints.²⁹⁷

According to the picture I outlined in the previous sub-section, personal bioinformation can support the development of self-narratives that exhibit these two important, intertwined, aspects of coherence. Firstly, personal bioinformation can play a role in helping an individual to meet (or preventing her falling foul of) the articulation constraint by informing her understanding, selection, prioritisation and mutual interpretation of those health-related and embodied experiences, physical and behavioural traits and biological relationships that provide some of the contents of her self-narrative. In doing so it supports the internal intelligibility of her story. Meanwhile, it can also support her in constructing a story that broadly accords with other people’s perceptions, understanding and experience of states of affairs pertaining to her health, body and biology – thus helping her identity to meet the reality constraint.

However, I want to argue that Schechtman’s version of, and rationale for, the reality constraint does not go far enough. According to Schechtman, the reality constraint requires that our narratives are reasonably consistent with the world *as experienced by others*, because we cannot function effectively in social contexts if our self-characterisations seriously conflict with how others see us.²⁹⁸ However, I would argue that it is just as important that our self-conceptions are reasonably consistent with *our own experiences of our embodied, biological lives* – both those aspects we have already encountered and those that are likely to assail us. This is because the coherence and life-navigating capacities of our self-narratives are not only

²⁹⁷ Schechtman (1996), p.114, p.119.

²⁹⁸ Ibid.

potentially jeopardised by their discordance with how others perceive the world, but also by their discordance with our *own* experiences of our embodiment. I wish to argue that avoiding such jeopardy is critical to making sense of who we are and to functioning in the context of embodied existence. I suggest that personal bioinformation not only helps us to make sense of our identities when faced by the vagaries and onslaught of embodied existence. It also permits us to construct self-narratives that support us in navigating and acting in the world as embodied beings. Our identities are not only those of rational, social beings, but also of embodied ones.

This brings me back to the ‘outcome’ aspect of the ‘double normativity’ of narrative identity theory. Supporting the fulfilment of the reality and articulation constraints is no trivial matter. To the extent that these are routes to developing a reasonably intelligible and coherent self-narrative, they are conditions for realising what I have termed ‘the valued capacities’ – the capacities for knowing who I am and what I value, and thereby being a position (all other things being equal) to be the author of my own judgements, actions and self-creation, to feel a connection to my own history and unfolding future, and thus to sustaining enduring commitments and projects.²⁹⁹ Personal bioinformation may play a vital part in my capacity to develop, maintain or restore an identity-constituting narrative at all, and thus being able to exercise the practical aspects of this identity in ways that contribute to richness and character of my life.

So part of my contention in this chapter is that it is important to recognise that, because we lead inescapably embodied lives, personal bioinformation is likely to contribute to and inform many of the (to use Schechtman’s term) ‘characteristics’ that comprise the contents of our identity-constituting narratives. But, it is precisely because this is so, that my more fundamental, normative claim bites. I have argued here that it is not merely satisfying or interesting if our self-narratives include plotlines that involve features of our biology. The incorporation of these is key to meeting the conditions of a robust, coherent, identity-constituting narrative in the context of embodied existence. And this, in turn, is key to developing the capacities that contribute to a fulfilling and self-realising life. It is on this basis that I wish to argue that access to personal bioinformation engages ethically significant interests, interests that I will characterise in more detail in Chapter 9.

The preceding paragraphs outline the core of my conceptual and normative argument that personal bioinformation can potentially provide a valuable tool in the construction of our narrative identities. It is important to be clear about the nature of the claim I am making here.

²⁹⁹ See Chapter 2.

I am not seeking to argue that every particular kind or instance of personal bioinformation will be valuable in the ways described above. As I shall go on to illustrate in Part II of this thesis, some of this information may be of little or no value, or even detrimental to our identities. Rather, what I am offering is a way of conceptualising why personal bioinformation as a broad class can make vital contributions to our developing identities, and why our access to it may, therefore, engage ethically considerable interests. I will return in Chapter 8, informed by the empirical literature reviewed in the intervening chapters, to discuss the factors that might contribute to or detract from the value of *particular* instances of bioinformation under this conception.

SECTION 4: DISTINGUISHING MY ARGUMENT

In order to unpack further what is and what is not implied by my argument, and to make clear my contribution to analysis in this field, it will be useful to differentiate my claims from those of four arguments in the bioethical literature with which it shares some features. The first three of these pertain specifically to the role of knowledge of genetic parentage in identity development and have already been introduced in Chapter 2. These are:

- i) The necessity of genealogical knowledge to understanding one's embodied existence;
- ii) The potential value of genealogical knowledge to a complete biography; and
- iii) The potential value of genealogical knowledge and avoiding subversion of one's identity.

I will also differentiate my position from a fourth argument, which holds that:

- iv) The only (bio)information that is necessary for narrative coherence is that revealing our 'real' motives.

As indicated by what I have said in the preceding chapters, a rich seam of theoretically-based normative arguments for the value of personal bioinformation to identity may be found in debates about the importance of knowing about one's genetic parentage. Some of these share key features of the position I have outlined in the first half of this chapter, but none of them is identical with it.

i) Genealogical knowledge and understanding one's embodied existence

The first argument from which I wish to distinguish my own is proposed by David Velleman.³⁰⁰ As noted in Chapter 2, Velleman argues that knowledge of one's genetic parentage helps us make sense of our embodied "predicament" and "distinctive features" and to build identities which accord with our biological existence, rather than being alienated from it.³⁰¹ He also argues that the ability to incorporate knowledge and understanding of our biological selves into our identities is linked to our capacities to lead full and fulfilling lives. In these respects Velleman's rationale for the value of one specific kind of bioinformation looks very close to my own.

My position differs from Velleman's, however, in that he does not invoke the concept or constraints of narrativity in building his argument. This in itself might not perhaps be so material were it not for the inclusivity and flexibility that this conception affords my own account and which is absent from his. The most important distinction, then, is that Velleman argues that acquaintance with one's genetic family is *essential* to making sense of our bodily reality and in developing a self-conception that supports human flourishing. This claim is premised on what he takes to be our universal, specific and *sui generis* identity-related needs to recognise shared traits and to know about our origins. He does not intimate that any other kind of information about our biological existence could fulfil comparably significant, parallel roles pertaining to other aspects of our lives. In contrast I do not seek to argue that any particular kind of personal bioinformation is essential to identity development, or that our "genetic endowment" is uniquely relevant to our identities.³⁰² Rather my assertion is that personal bioinformation is *instrumentally* important to us only and insofar as it contributes to the coherence of our self-narratives in light of our particular experiences of embodiment. And, this role could be fulfilled (or not) by many different kinds of information about our health, bodies or biological relationships (as I shall illustrate in Part II and analyse further in Chapter 8).

ii) Genealogical knowledge and biographical completeness

Given what I have just said, my position looks somewhat closer to that adopted by Sarah Wilson, who holds that identifying and biographical information about one's genetic parents could play a contingent, instrumental role in some individuals' self-narratives by filling in

³⁰⁰ Velleman (2005); Velleman (2008). Velleman is specifically concerned with knowledge by acquaintance with one's genetic relatives.

³⁰¹ Velleman (2008), p.258.

³⁰² *Ibid.*, p.258.

biographical gaps.³⁰³ In doing so Wilson acknowledges that not everyone will find this knowledge important to their story of who they are. There are two chief differences between Wilson's account and my own, however. First, she attributes the narrative value of information to one very narrow retrospective explanatory role – that of “alleviation of uncertainty with respect to the past”.³⁰⁴ Although this is indeed one of the narrative roles which I am suggesting that personal bioinformation might play, here my proposition is that the range of interpretive and contextualising functions that personal bioinformation could provide extends far wider than this, and be performed by a much wider range of bioinformation than solely that about genealogy (as I will illustrate in Part II). The second difference is that Wilson does not explain why it *matters* if we have uncertainty about our past. It may seem intuitive that self-narratives, like the plots of novels, are better for not having gaps in them, but Wilson herself does not explain why this might apply to our own self-narratives or what might be at stake in their coherence.

An explanation of precisely this kind is offered by James Lindemann Nelson.³⁰⁵ Nelson holds that knowledge of our genealogy provides:

“...the earlier chapters of [our story] which are part of the ongoing narrative, and without which we cannot read well what is going on in the part occurring now.”³⁰⁶

He argues that filling in these earlier chapters is important because our identity narratives provide the “the structures of meaning through which we try to make sense of our lives.”³⁰⁷ Nelson's position closely resembles my own in this respect. I too wish to hold that the coherence of our self-narratives is important because they provide the interpretive framework for our lives and that understanding of our biological existence is important to constructing the kinds of frameworks that support us in making sense of our embodied experiences. However, as with Velleman, the key difference between Nelson's position and my own is that I neither wish to argue that knowledge of genetic parentage invariably fulfils this kind of sense-making role for everyone, nor that it is uniquely important in this respect. And, as with Wilson, I do not wish to limit the value of bioinformation to its retrospective explanatory power.

³⁰³ Wilson (1997).

³⁰⁴ *Ibid.*, p.285.

³⁰⁵ J. L. Nelson (1992).

³⁰⁶ *Ibid.*, p.81.

³⁰⁷ *Ibid.*, p.81.

iii) Genealogical knowledge and identity subversion

Thirdly, I wish to acknowledge similarities between the argument I have proposed here and that offered by Hallvard Lillehammer in respect, again, of knowledge of one's genetic parentage.³⁰⁸ As outlined in Chapter 2, Lillehammer proposes that this information is valuable to the extent that this allows one to construct a "virtuous practical identity" which, he holds, is a condition for leading a flourishing life.³⁰⁹ In framing this argument, Lillehammer leaves open the possibility that any information about oneself could contribute in the same way (though he does not specify other bioinformation). Lillehammer accounts for the harm of lacking genealogical information, not in its essential role in identity development, but in the possibility that this could leave one's identity vulnerable to 'subversion' from receipt of further information that would undermine beliefs on which one's existing self-conception is premised. This accords closely with my own position (to be fleshed-out further over the coming chapters) that the value of bioinformation lies to a considerable degree in enhancing the resilience and coherence of our identities in light of embodied experience. Lillehammer's position, however, is something of a black box with respect to the ways in which self-knowledge, a virtuous identity, and flourishing life are connected. The argument based in narrative identity that I am proposing here offers one way of filling-out such an account.

In Chapter 5 I will consider what the empirical literature suggests about the role of information about genetic parentage – specifically gamete donor origins – in the individuals' construction of their identities. In that chapter I shall illustrate how Lillehammer's position and my own intersect in more detail in discussing the potential narrative jeopardy incurred by failing to tell donor-conceived individuals of their donor origins.

iv) Knowledge of one's motives and narrative coherence

I turn now to distinguish my position from quite a different kind of argument, while also indicating that such an argument is based on a misunderstanding of how personal bioinformation could contribute to narrative coherence.

This is an argument presented by Lisa Bortolotti in response to a strand of reasoning in the debate about the 'right not to know' genetic information, a strand that holds that it is not possible to justify such a right on autonomy grounds because knowledge of genetic

³⁰⁸ Lillehammer (2014) This is not an account based in a narrative conception of identity, at least not overtly.

³⁰⁹ Ibid., p.101.

dispositions or health risks are necessary to our capacities to be self-determining.³¹⁰ In rejecting this contention, Bortolotti appeals to Schechtman's account of a coherent and realistic identity narrative as the foundation for our capacity to live autonomous lives. Bortolotti holds that there is only one kind of information that would be essential to our capacities to be self-determining. That is information that would ensure one's self-narrative remained aligned with one's real reasons and motives of action, and thus met Schechtman's reality constraint. Therefore, the only kind of information (genetic or otherwise) is ever necessary for achieving a coherent, autonomy-supporting, self-narrative is that would provide an individual with "knowledge of [her] own mind" by revealing her "behavioural dispositions", "biases in deliberation" and "attitudes and dispositions" – for example, as revealed by psychological tests or neurological data.³¹¹ In contrast, Bortolotti holds that genetic information, for example, about a serious disease risk, would merely affect the plot of someone's story, but not her capacity to build a an identity-constituting story at all.

My responses to Bortolotti's position are not only that her category of potentially identity-valuable bioinformation is too narrow, but that it rests on a misunderstanding about how it is that we come to understand our motives, priorities and values. And, as such, I wish to distinguish it from my own position. I do not seek to claim that bioinformation is important to the coherence of our self-narratives because it reveals our 'real' motives or facts about who we really are *qua* selves or agents. Such a claim is not coherent under a narrative account. Under a narrative view of self-constitution Bortolotti's contention that "knowledge of the self matters to accurate and coherent narratives" is circular.³¹² Of course we *can* be mistaken or self-deceiving about our motives and attitudes. And this does matter for our narratives' coherence.³¹³ But these motives and attitudes are not discrete psychological or neurological events, separate or separable from the stories of who we are.³¹⁴ They are constituted and given their meaning by these very stories.³¹⁵ Locating 'extra-narrative' motives in neurological or psychological facts is misplaced.

³¹⁰ L. Bortolotti (2013), "The Relative Importance of Undesirable Truths" *Medicine, Health Care and Philosophy*, 16(4): 683-90. For an example of the kind of arguments to which Bortolotti is responding, see J. Harris and K. Keywood (2001), "Ignorance, Information and Autonomy" *Theoretical medicine and bioethics*, 22(5): 415-36).

³¹¹ Bortolotti (2013), p.687, p.688.

³¹² *Ibid.*, p.687.

³¹³ Schechtman (1996).

³¹⁴ See Schechtman's rejoinder to the suggestion that neurological data can falsify our narratives, noted in Section 2 above, Schechtman (2012).

³¹⁵ MacIntyre (1985).

My argument is that many different kinds of information are potentially important to constructing an identity-constituting self-narrative and to securing the intelligibility and compatibility of our motives. Personal bioinformation can support us in making sense of our motives and priorities (and many other aspects of who we are) to the extent that it helps us to shape the narratives from which our motives derive their significance and meaning, and to secure the extent to which our narratives make sense to us in light of our embodied experiences. And this could very well include information about our genetic dispositions or health risks (as I will illustrate in Chapter 6).

The conceptual and ethical argument that I have presented in this chapter shares some commonalities with aspects of arguments about the value of particular kinds of bioinformation that are present in the literature, but it is not identical with any of them. I shall return in Chapter 9 to consider in more detail how identity-based interests grounded in the argument I have offered here are distinguishable from a range of other interests - including those in developing and exercising our autonomy – that are commonly invoked in policy contexts and ethical debates about information subjects' access to bioinformation.

SECTION 5: ADDRESSING POSSIBLE OBJECTIONS

Before I conclude this chapter I wish to address some concerns or objections that might be invited by the position I have outlined above. These, I suggest, fall into two categories:

- i) The first includes concerns that my argument is based on a bio-essentialist premise that we are, or ought to be, defined by our biology.
- ii) The second cluster of concerns questions the suitability of personal bioinformation to fulfil the epistemological role I have proposed for it.

I shall take these in turn.

i) Concerns about bio-essentialism

The first possible set of objections are those based on the concern that arguments which hold that bioinformation is valuable to self-constitution necessarily embrace a limited and limiting conception of identity as *defined* by biology, one that reduces who we are to only our biology, or assumes that knowledge of particular aspects of our biology is essential to understanding who we are.

Conceptions of personal identity as self-created are often contrasted with those in which it is seen as pre-defined.³¹⁶ Accounts that propose a significant role for knowledge of one's biology are often taken to fall in the latter camp, the presumption being that claims for the identity-value of bioinformation must be based in the assumed role of the information in uncovering or bringing to fruition a pre-existing essence.³¹⁷ As such, accounts that accord significance to particular kinds of bioinformation are sometimes treated as objectionable for denigrating the choices of those who characterise themselves in ways that diverge from their biology, or taken to imply that those who lack this information are in some sense incomplete or defective.³¹⁸

Bio-reductionist or essentialist conceptions of identity are seen as objectionable and limiting for many reasons. For example, feminist resistance to the suggestion that our identities are defined by our bodies may be understood as a reaction against implications that women's identities are more in the thrall of their biology than those of men and therefore less rational and less self-made.³¹⁹ There are similarly good reasons to resist identity being reduced to our skin colour or our physical (dis)abilities. Not only might we object to others defining us according to our biology or physicality, we ourselves might also feel alienated from, rather than identification with, aspects of our bodies such as our biological sex, our reproductive (in)capacities, or our ill-health.

In this section my aim is to show that in arguing for the value of personal bioinformation I am committing myself to neither a bio-reductionist nor bio-essentialist conception of identity. Here I will set out two responses to these concerns by indicating that according to my account:

- a) Personal bioinformation is not the only information potentially valuable to a coherent identity; and
- b) It is possible to develop a coherent identity while rejecting or omitting aspects of one's biological existence.

a) *Personal bioinformation is not uniquely valuable*

First, my argument does not entail the position that personal bioinformation is *sufficient* for the construction of a coherent, embodied self-narrative. As Hallvard Lillehammer observes:

³¹⁶ C. Hauskeller et al. (2013), "Genetics and the Sociology of Identity" *Sociology*, 47(5): 875-86.

³¹⁷ See, for example, Marshall (2009)

³¹⁸ See, for example, I. de Melo-Martín (2014), "The Ethics of Anonymous Gamete Donation: Is There a Right to Know One's Genetic Origins?" *Hastings Center Report*, 44(2): 28-35.

³¹⁹ K. Lennon, "Feminist Perspectives on the Body" in *The Stanford Encyclopedia of Philosophy*, ed. E.N. Zalta (Fall 2014).

“There are many things that could make more of a difference to how I think of myself than facts that determine how I was constituted as a biological entity.”³²⁰

I have no quarrel with this assertion. Our narratives will inevitably and appropriately also be woven from strands that have nothing to do with our biology. My aim in this project is to contribute to existing bioethical and policy debates about which interests are relevant to ethical practices relating to the disclosure of bioinformation in clinical, research, commercial and regulatory settings, by making a case for the significance of identity-related interests. It is not to suggest that bioinformation is the only or most important contributor to our self-conceptions.

b) Excluding and omitting bioinformation

To reiterate the distinction that I drew at the start of this chapter: the present account frames bioinformation as a source of knowledge about aspects of our biological lives, not about our identities. This notwithstanding, it might still be a source of concern that my argument ties the attainment of narrative coherence and intelligibility to broad concordance between someone’s self-narrative and biological states of affairs. This might seem to be a capitulation to a requirement that we define ourselves directly accordance our biological attributes. And this could appear to present problems in two kinds of cases: first, where someone wishes to exclude an aspect of biological existence from her self-definition; and secondly, where someone is simply unaware of aspects of her biology. Neither of these scenarios seems at all unlikely. It would, therefore, be problematic if my argument entailed the position that such circumstances are an inevitable barrier to someone having the kind of self-conception that was capable of supporting the capacities that make for a rich and fulfilling life. However, as I shall outline here, I do not believe it does entail this.

First, my argument is compatible with someone refusing to be defined by aspects of her material self – for example, by choosing not to make her risk of hereditary breast cancer part of how she understands herself, relates to others or conducts her life. Provided the self-narrative she constructs on this basis is both internally intelligible and retains its coherence when confronted by states of affairs in the world, including her own changing health, then the exclusion of this information need not threaten the coherence of her identity. Indeed, the editing and prioritisation of contents is inherent to the concept of narrativity.³²¹ One of the conceptual strengths of a narrative-based account of the relationship between identity and personal bioinformation is that it allows us to understand that information need not contribute

³²⁰ Lillehammer (2014), p.103

³²¹ See Chapter 2.

solely by providing self-descriptors or blunt building blocks of identity. Instead it may play an interpretive role. And this could involve relegating aspects of one's health to the status of brute facts of one's biology, according them no place in one's self-characterisation.³²² Repudiation of personal bioinformation need not jeopardise narrative coherence, although I will return in Chapter 8 to consider circumstances in which it might do so.

Turning to the second possibility, it is inevitable that all of us will have self-narratives that have been constructed in ignorance of much of our biology. This in itself need not be a threat to their coherence. Indeed, I would suggest, that any attempt at factual completism is more likely to militate against this. Making sense of who one is is an inherently interpretive undertaking, and it seems likely that the more detail one attempts to build in, the harder it is to tell a coherent story of who one really is and which features are most prominent in shaping one's priorities and values. However, there is an important distinction to be made here between a mere lack of information and the incorporation of false beliefs. Lillehammer draws attention to this in observing that:

“It is one thing to develop a virtuous practical identity in conditions where facts about one's genealogical origins play little or no role while being aware that there are significant gaps in one's knowledge of those facts. It is quite another to develop such an identity in the false belief that one's knowledge of these origins is accurate or complete.”³²³

Lillehammer's implication is that the former is innocuous, whereas the latter represent the kind of harm to identity that interferes with its capacity to provide a platform for a flourishing life. I wish to suggest that, according to my narrative-based argument, the latter could be harmful for two reasons. First, it could render one's self-narrative vulnerable to being undermined when one stubs one's toe against one's existence as a biological being. And, secondly, such misconceptions make our self-narratives unreliable foundations from which to navigate and make sense of our experiences of embodiment because they are premised on false assumptions. So ignorance of personal bioinformation is not in itself a problem, but it could be insofar as it fosters self-characterisations that are at odds with ours and others' experiences. I will return to illustrate these claims in Chapters 5 and 7.

Though these defences have necessarily been brief, I would suggest that nothing that I have said so far inevitably precludes the possibility of being able to construct a coherent and intelligible self-narrative, while defining myself in ways that omit or depart from facts about my health, body or biology. However, as I shall return to discuss in the chapters that follow,

³²² See Chapter 7 for an illustration of this.

³²³ Lillehammer (2014), p.106.

misplaced faith in the veracity or reliability of the bioinformation to which we do have access may pose a threat.

ii) **Concerns about the epistemic limitations of bioinformation**

I will now turn to the second set of possible concerns. These pertain to my claims above, that bioinformation is valuable to our identities because it expands the interpretive toolboxes of self-construction, by helping us to explain, anticipate, contextualise or otherwise make sense of our experiences of embodied, biological existence. The concerns I will respond to here are those that are sceptical about the suitability of personal bioinformation – specifically that generated by the biomedical sciences – to fulfil the interpretive role I have proposed for it. That role depend on this information extending our knowledge and understanding of our material existence beyond the limits of what we are able to perceive with our own senses. These concerns might be grounded in any of the following three positions:

- a) Biomedical information does not tell us about biological reality.
- b) Biomedical information does not capture the phenomenology of embodied existence.
- c) Biomedical information does not provide any new insights.

I shall respond to these in turn.

a) *Bioinformation does not tell us about biological reality*

What I have said so far has taken as its unspoken assumption that personal bioinformation, much of which is likely to be derived from the biomedical sciences, can make a valuable contribution to our identities because it delivers reliable knowledge about the world – specifically about states of affairs relating to our health, bodies and biology. However, antirealist perspectives call into question the assumption that science is “the paradigmatic knowledge-producing enterprise”.³²⁴ There are various antirealist positions. These need not entail denying the existence of a material world altogether. But they do (for diverse reasons) deny that science can, or does, provide knowledge of the world as it really is.³²⁵ If biomedical science does not provide knowledge about biological states of affairs in the world, then it is not obvious that the information it supplies could help us to construct narratives that are any more intelligible in light of, or any better for negotiating, these states of affairs.

³²⁴ A. Goldman, "Social Epistemology," in *The Stanford Encyclopedia of Philosophy*, ed. E.N. Zalta (Winter 2016 Edition), p.4.

³²⁵ See, for example, T.S. Kuhn, *The Structure of Scientific Revolutions (50th Anniversary Edition)* (Chicago: University of Chicago Press, 2012); B. Latour and S. Woolgar, *Laboratory Life: The Social Construction of Scientific Facts* (Beverly Hills: Sage Publication, 1979).

I will not engage with the realist/antirealist debate here. It is sufficient to note that my argument does not depend on a “naïve realism” in which “[t]he picture which science gives us of the world is a true one, faithful in its details”.³²⁶ Indeed, this would be unwise, given the relative youth of some of the information-producing disciplines – such as genomic and neurological medicine – with which this project is concerned. And my argument need not deny that some personal bioinformation will incorporate constructed categories such as ‘being depressed’.³²⁷ Neither of these concessions preclude the potential interpretive utility of personal bioinformation. It is sufficient for my purposes that biomedical sciences can provide the kind of “empirically adequate” theories that generate personal bioinformation that accords broadly with the world as it is experienced.³²⁸ It is enough that personal bioinformation can provide reasonably reliable “instrumental knowledge” about how observable phenomena are likely to behave, in which, in Bas van Fraassen’s phrase, our actual and potential experiences can “find a home”.³²⁹ This position is consistent with recognising that developments in biomedicine could bring new ways of thinking about our embodied existence and interpreting phenomena. For example, as Margaret Lock observes:

“...molecularized genetics has brought about a fundamental transformation in the ways that the body is conceptualized and that this change has implications not only for what constitutes a normal body and the labeling and management of disease but also for insights into self and identity.”³³⁰

It must be acknowledged, however, that not all bioinformation – for example, about our health risks, diagnoses, genetic relationships or traits – will confer equally useful or reliable means for interpreting embodied existence. Some of it may be unsound or misleading because of immature methodologies or invalid inferences.³³¹ And some of it, while analytically sound, does not trade in certainties, but complex probabilistic risk assessments.³³² And while some bioinformation might well exhibit ‘empirical adequacy’, this still demands the question – adequate for what? Findings that are sufficiently explanatory to meet the aims of population-level research, for example, might not be sufficient to meet the needs of individual participants who wish to have more definitive knowledge about their own particular health risks. The

³²⁶ B.C. Van Fraassen, *The Scientific Image* (New York: Oxford University Press, 1980), p.6, p.7

³²⁷ Ian Hacking argues that there is no contradiction in recognising that while such classifications are indeed social constructions, this does not mean that the states of affairs to which they refer are not real, see Hacking (1999)

³²⁸ Van Fraassen (1980), p12.

³²⁹ R. Boyd, 'On the Current State of Scientific Realism', in *The Philosophy of Science*, ed. R. Boyd, et al. (Cambridge, MA: The MIT Press, 1991), p.205; Van Fraassen (1980), p. 86.

³³⁰ M. Lock (2005), "Eclipse of the Gene and the Return of Divination" *Current Anthropology*, 46(S5): 47-70, p.51.

³³¹ See Chapter 7.

³³² See Chapter 6.

question of when particular personal bioinformation provides a ‘good enough’ chart of the submerged trunks of someone’s embodied existence, such that it provides a useful tool for narrative construction seems likely to be something that will admit of degrees. I will return in Chapter 8 to discuss the potential identity detriment of false and unreliable personal bioinformation.

b) Missing phenomenology

A different kind of concern about personal bioinformation being able to fulfil the coherence-conferring role in our self-narratives that I am proposing, is that biomedical information is unlikely to capture the *phenomenology* of bodily state of affairs or ill-health to which they pertain.³³³ It might plausibly be claimed that this is what someone cares about when hoping to make sense of her experiences as part of constructing and inhabiting her identity. It could be objected that I have conflated Merleau-Ponty’s distinction between the biological body and the body as lived, and that bioinformation it is incapable of providing the kinds of useful interpretive context for embodied experience that I have suggested.³³⁴

My response to this is that the account of identity-value offered in the previous sections does not rely on the claim that bioinformation provides the complete story of someone’s experiences of embodiment, with all the personal, experiential nuances this entails. For example, findings about neurological correlates of symptoms of depression, taken in isolation, might indeed not equip someone with everything she needs to understand or navigate her experience of mental illness. However, this does not mean that these findings could not be of use in helping her to make sense of what her symptoms mean for who she is.³³⁵ Loughlin et al. draw a useful distinction, arguing that:

“there is a difference between saying that looking at the world in a certain way can help you understand aspects of the truth about your predicament, and saying that looking at the world in a particular way, understood through the lens of scientism, provides the only truth,”³³⁶

The former of these positions is close to the view I wish to defend. However, it seems likely that whether biomedical findings are in fact useful interpretive tools for navigating the phenomenology of embodied existence will, to a considerable extent, depend on support the

³³³ H. Carel (2011), "Phenomenology and Its Application in Medicine" *Theoretical Medicine and Bioethics*, 32(1): 33-46; F. Mazanderani et al. (2013), "Biographical Value: Towards a Conceptualisation of the Commodification of Illness Narratives in Contemporary Healthcare" *Sociology of Health & Illness*, 35(6): 891-905.

³³⁴ Merleau-Ponty (1962)

³³⁵ See Chapter 7.

³³⁶ M. Loughlin et al. (2013), "Science, Practice and Mythology: A Definition and Examination of the Implications of Scientism in Medicine" *Health Care Analysis*, 21(2): 130-45, p.143.

subject is given to understand the epistemic qualities and limitations of that information. I return to this matter in Chapter 9.

c) No new insights

The third epistemological objection is that my account subscribes to a misconception that bioinformation is “revelatory” and renders the functioning and future states of our bodies more “legible”, when in fact it may be nothing of the sort.³³⁷ For example, Bronwyn Parry has suggested that “in most instances” the results of genomic testing are no more potent and revelatory than the vernacular knowledge that was available to us long before genetic medicine, through everyday observation of patterns of inheritance within families.³³⁸ There are several responses I wish to make to this. First, my intention is not to imply that information derived from genetic or other biomedical sciences will *necessarily* offer greater insights than that provided by our unaided senses. Much of our narrative content will indeed come from direct experiences. Furthermore, as noted above, ‘bioinformation’ as a class is clearly not of uniform quality or epistemic value. Parry’s scepticism may well be warranted with respect to some claims made, for example, by commercial genetic testing services in respect of tests for common complex disorders, in which genetic factors play only a small and poorly understood role.³³⁹ And some inferences drawn from genetic analysis to, for example, our ancestral origins may well be spurious.³⁴⁰ However, it seems clear that in other instances biomedicine *can* provide us with knowledge of our health, bodies and biology that we would not otherwise have had, and in a form that is useful to us. Moreover, the narrative role that I have posited does not depend on bioinformation heralding radically *new* news. As I shall illustrate in Part II of this project, its value may sometimes lie precisely in providing context for, or new ways of interpreting, our existing beliefs about, for example, one’s disease-risk or diagnostic status.

SECTION 6: CHAPTER CONCLUSION

In this chapter I have outlined the argument that any account of narrative self-constitution that reflects the realities of our lives must be one that reflects the inescapably embodied nature of our existence. From this starting point I have proposed my own argument that personal bioinformation (as a broad category) can play a vital role in helping us to construct self-

³³⁷ B. Parry, 'Knowing Myself™: Personalized Medicine and the Economization of Prospective Knowledge About Bodily Fate', in *Knowledge and the Economy*, ed. P. Meusburger, et al. (Dordrecht: Springer, 2013), p.162.

³³⁸ Ibid.

³³⁹ R.R. Kalf et al. (2013), "Variations in Predicted Risks in Personal Genome Testing for Common Complex Diseases" *Genetics in Medicine*, 16(1): 85-91.

³⁴⁰ C.D. Royal et al. (2010), "Inferring Genetic Ancestry: Opportunities, Challenges, and Implications" *The American Journal of Human Genetics*, 86(5): 661-73.

narratives are responsive to the vagaries, limitations and opportunities of embodied existence. This information supports us in constructing self-narratives that not only make sense when confronted by our embodied experiences, but also provide the foundations from which we are able to interpret and navigate our embodied lives. In doing so, personal bioinformation helps us to develop, maintain or restore the kind of narrative coherence and intelligibility that is necessary if our identities are to ground our capacities to have a strong sense of who we are, and thus to have a solid foundation from which to make judgements and choices and to be the authors of our own actions and ongoing self-creation. As noted in the previous chapter, I take these capacities to be central to leading a rich, fulfilling and engaged human life. On these grounds, I submit, we may understand why access to personal bioinformation could engage ethically significant interests that warrant attention by those who hold this information when making decisions about whether to disclose it. I will specify the nature of these interests in Chapter 9, having refined my account in light of the illustrative examples yet to come.

The argument presented in this chapter is not intended to assert that every kind or instance of bioinformation is valuable to our self-conceptions, but to explain why bioinformation as a class has an important role to play. I have sought in this chapter to address concerns that such an argument endorses a bio-essentialist conception of identity. My position is that this information is valuable not because it *reveals* who we already are, but because it can offer ways of understanding of our embodied states that can provide potentially useful *tools* for interpreting and developing who we are. As this indicates, not all personal bioinformation will be of equal (or indeed any) value to this end and no particular kinds of bioinformation are intrinsically identity-relevant. Particular personal bioinformation will be instrumentally valuable only insofar as it serves the ends of helping an individual to construct a self-narrative that is coherent in the context of embodied experience. I have suggested that the capacity of bioinformation to fulfil this role does not depend on it providing us with comprehensive or unassailable facts about the objective reality of our health, bodies and biology, or of every aspect of the phenomenology of lived experiences, but rather on its supplying reliable knowledge that helps to navigate and make sense of these. The possibility remains that some bioinformation will just not be very good at fulfilling this role. Some might even be detrimental to our efforts to construct coherent embodied self-characterisations. I will return to unpack these possibilities over the coming chapters.

If this account of the relationship between personal bioinformation and identity is to provide a sound foundation for ethical decision-making and policies about providing access to personal bioinformation, it is vital that it is plausible in light of people's experiences of their encounters

with and uses of this information. To this end, my next step in this project is to turn to the empirical literature for examples that, while not in any way proving the theory-based argument I have outlined here, nevertheless indicate that this argument is not wildly at odds with people's experiences. My intention is that exploring individual information subjects' reported attitudes and reactions to access, or lack of access, to diverse kinds of personal bioinformation will serve to illustrate, and also to refine, the assertions I have made. I shall describe my approach to these illustrative examples in detail in the next chapter.

PART II: THE ILLUSTRATIVE EXAMPLES

CHAPTER 4: RATIONALE AND METHODOLOGY FOR THE ILLUSTRATIVE EXAMPLES

SECTION 1: INTRODUCTION

This short chapter provides the introduction to Part II of this three part thesis. In this middle section of the project I turn to look at findings from empirical literature that may tell us something about information subjects' attitudes and reactions to three different categories of bioinformation. My purpose in doing so is to address the second of the four high-level research questions set out in Chapter 1: **what grounds are there for holding that the conception of the relationship between personal bioinformation and identity proposed in Chapter 3 is robust and plausible in light of people's actual experiences?**

My intention is that my analysis of people's reported experiences of encountering diverse kinds of personal bioinformation in diverse circumstances will lend *plausibility* to and *illustrate* my central claim that personal bioinformation can play important roles in an individual's development of her narrative identity in the context of embodied existence (as argued the preceding chapter). My further intention is that the empirical findings will allow the further *refinement* of this claim, such that it provides a robust and realistic foundation for my characterisation of information subjects' interests in accessing personal bioinformation and the corresponding responsibilities of those who may be in a position to disclose it.

These intentions will be pursued over the coming chapters. The purposes of the present chapter are to:

- i. **Explain the relationship between the evidence considered in the illustrative chapters and my theoretical and normative argument** (Sections 2 and 4)
- ii. **Set out my approach to sourcing and analysing relevant empirical findings** (Section 3)

SECTION 2: THE ROLE OF EMPIRICAL EVIDENCE IN THIS THESIS

The use of the empirical literature in this project seeks to respond to one of the concerns motivating the so-called 'empirical turn' in bioethics.³⁴¹ That is, if the ethical arguments and conclusions of this discipline are to be relevant and practical they ought to engage with social scientific findings, so that they are connected with, and are responsive to, the realities of

³⁴¹ P. Borry et al. (2005), "The Birth of the Empirical Turn in Bioethics" *Bioethics*, 19(1): 49-71.

people's experiences and practices.³⁴² If the present project is to make a meaningful contribution to practical, normative questions about the governance of access to information, its claims must at very least be consistent with people's experiences and what matters to them.

The contention that I am subjecting to scrutiny over the coming three chapters is that outlined in Chapter 3, that personal bioinformation can play important roles in the development, maintenance or restoration of a coherent self-narrative in the context of embodied existence. This claim is not a purely empirical one. It incorporates a particular conception of how our identities are constituted and the conditions and value implied by this. Nevertheless, it is a position that could be undermined by empirical observations – for example, were it to be found that no one ever reports feeling differently about how they characterise themselves having received information about their health, bodies or biological relationships. Similarly, it gains credence if there is readily available evidence, across a range of different types of bioinformation, that people value these kinds information in seeking to understand and develop who they are. It is also the kind of claim that is amenable to caveats or conditions, if evidence indicates that it holds in some circumstances but not others. A key purpose of exploring the three illustrative examples, therefore, is to demonstrate that – and the extent to which – my theoretically-based claim as to the narrative role of personal bioinformation is congruent with people's lived experiences of encountering or being denied this kind of information.

For each of the illustrative examples in the following three chapters I will ask the following three questions:

- i. What evidence is there that access (or in-access) to personal bioinformation can have an effect on individuals' accounts of who they are?
- ii. What might this indicate about the extent and nature of the narrative roles played by this information?
- iii. What factors affect the nature and extent of these impacts and roles?

My intentions in asking these questions are threefold. First, if there is indeed evidence – which can be shown to be neither trivial, wildly anomalous, nor vanishingly rare – that access to personal bioinformation does sometimes play an important role in information subjects' development of their self-conceptions, then this adds strength and plausibility to the

³⁴² P. Borry et al. (2004), "What Is the Role of Empirical Research in Bioethical Reflection and Decision-Making? An Ethical Analysis" *Medicine, Health Care and Philosophy*, 7(1): 41-53; A.M. Hedgecoe (2004), "Critical Bioethics: Beyond the Social Science Critique of Applied Ethics" *Bioethics*, 18(2): 120-43.

theoretically-based argument as to the potential identity value of information. Secondly, examples from the empirical literature will illustrate this argument, raising it beyond theoretical abstraction and making it more concrete. In doing so these examples may also reveal diversity and common-ground amongst different individuals' experiences and the diverse impacts of different kinds of bioinformation. This will help to achieve my third aim of refining my theoretically-based argument. Thus far I have offered this argument with respect to the narrative role of personal bioinformation *in general*, taken as a broad class. The illustrative examples will allow me to refine this argument, by exposing any diversity of reactions to different categories of bioinformation encountered in different circumstances. Ultimately, then, my goal is to develop a more nuanced picture of what might account for the identity-significance and value of *particular* kinds of instances of personal bioinformation. This is a task I shall undertake in Chapter 8.

I wish to be clear here about which aspects of my argument the empirically-based examples in the following chapters are *not* intended to speak to directly. The evidence I will draw upon is not intended to offer support for the veracity of the narrative theory of identity-constitution itself. I do not seek to defend this theory by empirical means in this thesis, rather to take it as a premise which the reader may of course reject. At the other end of my argument is my practical conclusion – that identity-based interests ought to be taken into account in governing information subjects' access to personal bioinformation. Again, my aim in looking to the empirical literature is not to locate evidence of express support for this recommendation amongst information subjects or potential disclosers. As outlined above, the evidence I shall consider is intended to help build the normative argument that provides my rationale for this conclusion as the outcome and practical contribution of this thesis.

SECTION 3: APPROACHING THE EVIDENCE

The specific evidence in which I am interested in this thesis is that which reports the expectations, attitudes and reactions of individuals to receiving, or being denied, personal bioinformation about themselves. And I am interested in these responses insofar as they might tell us something about the roles of this information in information subjects' identity narratives

I have adopted a theory-led approach to my selection both of the kinds of studies and findings to which I look for this evidence, and also to the categories of bioinformation to which these studies pertain. I have done this in order to focus my attention on findings of most relevance to addressing my headline research question (as cited above), while also looking at findings relating to a sufficiently varied kinds of bioinformation to permit me to generalise from my

analysis and to reduce the risk that the conclusions I draw are peculiar only to a narrow subset of bioinformation.

As such, my approach to identifying the empirical literature and findings on which I will draw is analogous to that of ‘purposive sampling’ in social science research.³⁴³ Purposive sampling is a strategic and selective approach to acquiring data, driven by the research questions at hand, meaning that:

“...the researcher establishes criteria concerning the kinds of cases needed to address the research questions, identifies appropriate cases, and then samples from those cases that have been identified.”³⁴⁴

Theoretical conclusions are then drawn from the analysis of the evidence generated by the selected cases. I do not wish to overstate the formality of the sampling method I have used here: first, because purposive sampling applies, typically, to the collection of primary data in qualitative research, and is not so readily applicable to the selection of the kinds of tertiary data (data already analysed by others) from existing literature; and, secondly, because the relationships between my theoretical starting point and the selection, interpretation and application of empirical evidence is perhaps more circular than the inductive rationale of purposive sampling normally permits (as I address further below). However, my approach – insofar as it is intended to refine my initial theoretical position – does share something with the more iterative and theory-refining ‘theoretical sampling’ version of purposive sampling.³⁴⁵

Selecting the kinds of bioinformation

The first kind of ‘sampling’ judgement I have made is to select three categories of bioinformation on which to focus. These are:

- Information that an individual was conceived using donor gametes (Chapter 5)
- Results from genetic susceptibility testing for serious, multifactorial conditions (Chapter 6)
- Diagnoses of psychiatric disorders based on functional neuroimaging findings (Chapter 7)

My approach in Part II of this thesis is to examine evidence of the degree of potential significance to identity, and factors affecting this, of each of these categories on its own terms. But the wider aim is to gain insights that apply to personal bioinformation as a general

³⁴³ A. Bryman, *Social Research Methods* (Oxford: Oxford University Press, 2015).

³⁴⁴ *Ibid.*, p.413.

³⁴⁵ *Ibid.*

category. My intention is that using three diverse examples will support some generalisable conclusions, while permitting a depth of attention to each. I will explain the rationale for choosing each example in more detail in the three chapters that follow but, in brief, my reasons for selecting these examples are as follows. First, my aim is to move beyond the ‘usual suspects’ in existing ethical and policy-focused debates about *access* to bioinformation and identity. Therefore, this set includes one category of information about which debates about the importance of access are widespread (donor conception)³⁴⁶, and two where these are less common. Secondly, these examples allow me to challenge assumptions that identity significance might just be reducible to the significance of health-decisions, the brain and genes, as none of these is a universal feature of all three. This spread of examples also concerns information that arises in different settings, is not currently equally accessible to its subjects, and exhibits varying degrees of reliability in terms of providing knowledge of subjects’ embodied states. This variety is useful in identifying features-in-common that could indicate the potential identity-significance of other kinds of bioinformation which share these, and differences that might indicate factors that amplify or detract from bioinformation’s identity-significance (see Chapter 8).

Identifying suitable studies and findings

My second ‘sampling’ choice concerns which kinds of studies and findings to include in my research.

The evidence on which I draw is from published social science research. This includes both qualitative and quantitative studies of various sizes and methodologies, for example encompassing both large policy-focused studies and small, highly theorised ethnographic projects. I have also looked at systematic reviews and meta-analyses.³⁴⁷ The unifying feature is that these sources report empirical research that describes the actual or potential impacts on individuals of (not) receiving the three kinds of personal bioinformation listed above.

The purposive nature of my approach means I have actively sought to identify findings that speak to the potential impacts of (not) receiving bioinformation on individuals’ self-narratives. However, doing so has necessitated looking beyond research that sets out specifically to explore identity impacts, let alone impacts on narrative identity, for three reasons. One is that there are relatively few studies that do the former. Even fewer do the latter. Secondly, participants sometimes raise identity-relevant matters even if this is not the study’s focus.

³⁴⁶ See Chapters 1 and 5.

³⁴⁷ See the ‘Sources and analytical approach’ sections of Chapters 5-7.

Thirdly, researchers' and participants' conceptions of identity are often narrower, or different from, that which I am using in this project – for example that might use identity to mean a discrete social identifier. This means that my approach to selection of relevant studies and findings is inherently inferential, and takes in a range of personal and practical impacts that might not be explicitly reported as identity impacts. These inferences are informed by a narrative conception of identity (as described in Chapter 2) and my claims about the role of personal bioinformation in this (Chapter 3).

For the most part the research I focus upon records the self-reported views and reactions of information subjects/recipients collected through surveys, interviews or observational studies. However, for some categories of bioinformation this still results in a very small pool of research. Furthermore, where individuals are unaware they lack information, this presents a clear obstacle to gathering their views. For these reasons, I also widened my net, where necessary, to include studies that report the views of other parties, such as clinicians or parents, insofar as these provide useful insights into (potential) information recipients' reactions. To the extent that I have successively widened the frame of evidence I have examined, in the ways described in this section, my method resembles 'sequential purposive' sampling.³⁴⁸

Analysing the evidence

Having selected the relevant empirical literature, I have analysed it to address my research questions. In each of the three chapters my analysis has three parts.

I first set out and categorise the empirical findings that are relevant to addressing my research questions. This categorisation is not a formal thematic analysis, but is informed by the research participants' own ways of characterising and explaining their experiences, as well as the interpretations applied by the social scientists conducting the empirical research.

My second step is to draw inferences as to what these findings might tell one about the possible roles that the bioinformation in question play, or could play, in recipients' identity narratives. This approach I take is an inferential and *interpretive* one – where this involves "...constructing or documenting a version of what you think the data mean or represent".³⁴⁹ My interpretation is informed, once again, by the conception of embodied and narratively constituted identity that I have set up in the preceding chapters. My own theoretical lens does not operate in isolation here. Depending on the study, the researchers themselves will to a

³⁴⁸ C. Teddlie and F. Yu (2007), "Mixed Methods Sampling: A Typology with Examples" *Journal of mixed methods research*, 1(1): 77-100.

³⁴⁹ J. Mason, *Qualitative Researching* (London: Sage, 2002), p.149.

greater or lesser extent have contributed their own conceptual analyses to their findings – sometimes focusing upon impacts on recipients’ identities. I also draw upon (or differentiate my position from) arguments made in the wider theoretical literature about the potential identity significance of the category of bioinformation in question. In each case I clearly signal where the empirical findings stop, and where my own, or others’, interpretative analyses of these begin. As this process implies, my approach to assessing the potential identity-significance of the bioinformation does not take a purely internalist perspective. That is, it does not just take identity impacts as those that (potential) recipients of these categories of information report. For example, I also infer them from other kinds of responses or reflect on how different circumstances might change participants’ attitudes.

My third step is to consider what inferences maybe drawn from the empirical literature about the kinds of factors, either those intrinsic to the category of bioinformation, or those dependent on the contexts in which it is generated or communicated, that might be seen as influencing the nature or extent of the impact it has on recipients’ self-conceptions.

Methodological caveats

This approach to the selection of sources and their analysis might raise three particular concerns about the robustness of any conclusion drawn from them.

The first concern is that, by extending my scope beyond evidence of attitudes and reactions in which identity is explicitly invoked, I allow such a wide conception of potential identity impacts that my inquiry becomes trivially self-affirming. This is indeed a risk. However, I would argue that it is necessary to throw the net wide precisely because this opens up a richer, more dynamic, multi-stranded and normative conception of identity (and thus the contributions of bioinformation to it), going beyond the narrow understanding of identity as social identifier or genealogy. This broadening of focus is inherent to the aims of this project. Nevertheless, it does mean proceeding with care. A narrative conception is not licence to include every fleeting impression or emotion under the label ‘identity impact’. On the contrary, what the idea of narrativity brings is the condition that to count as having identity-significance, something must make an interpretive, substantive or structural difference (albeit not necessarily a permanent one) to someone’s account of who she is and the characteristics of which it comprises. This requires that relevant impacts must have a degree of stickiness and weight, that the roles they play in someone’s life are not trivial or ephemeral. These considerations provide a vital filter in selecting and analysing the relevant evidence.

The second concern is that my approach is question-begging, because it uses the conceptual lens of narrative identity to select and analyse evidence, which is then intended to lend support to my hypothesis that personal bioinformation can play an important role in identity narratives. I concede that there is circularity here, but would suggest that this reflects the reflexive and mutually-informing nature of the relationship in this inquiry, between the real-life examples and the underlying theory. Given this reflexivity, it is not possible to treat the empirical findings as theory-independent proof of bioinformation's identity-significance. To do so would indeed be problematic. But the empirical findings cited in the following chapters are not being used to *prove* that personal bioinformation plays important roles in individuals' construction of their identity narratives. Nor is it used to quantify the proportion of people who do invest particular bioinformation with identity-significance, much less make claims to unanimity of such views. Instead, these illustrative examples are offered in order to demonstrate that this theoretically-based claim is at least congruent with the evidence of people's lived experiences – that these support, or at least do not undermine, its cogency and plausibility.

The third concern relates to the fact that my approach to the literature is not comprehensive. What follows is indeed not a systematic or exhaustive review of all the empirical literature that report the impact of three categories of information on its subjects/recipients. For the reasons outlined in the previous paragraph, fulfilling my aims of illustrating and lending plausibility to my hypothesis does not require a systematic account of all possible perspectives. These aims can be fulfilled by looking at a sufficient number of widely cited, peer-reviewed sources which allow me to obtain a rich selection of attitudes and responses, draw out common themes, and to gather examples of responses that not only support my claims, but also of those that challenge it.

The empirical literature on which I draw is exclusively English-language, and chiefly reports studies conducted in Western Europe, North America and Australasia. The attitudes reported may not, therefore, be more widely representative or support my proposition outwith the particular cultural contexts in which the research was conducted.

SECTION 4: THE RELATIONSHIP BETWEEN THE EVIDENCE AND NORMATIVE CONCLUSIONS

A different kind of concern might be that I am seeking to use empirical information to support a claim as to the value of personal bioinformation to identity, which, as noted above, is not itself solely factual, but includes normative assumptions. The challenges inherent to accounting for the relationship between matters of fact and value are notorious and

longstanding.³⁵⁰ There is not space to pursue that debate here. However, they are challenges commonly wrestled with in the field of empirical bioethics. As noted above, my reasons for including evidence from the empirical literature in this project shares the desire of empirical bioethics to anchor normative conclusions in evidence of how the world is. And empirical bioethics has made various attempts to categorise how the relationship between ethical propositions and social scientific data might be negotiated in this field.³⁵¹ Even though my project is not itself one of empirical bioethics,³⁵² it is nevertheless possible to draw on one such taxonomy broadly to characterise the relationships between empirical findings and bioethical arguments in this thesis.

Using the taxonomy devised by Bert Molewijk *et al*, the relationship between the evidence and the ethical argument of this project may be seen as lying somewhere between what these authors characterise as a “theorist” approach and a “critical applied ethicist” approach.³⁵³ Exemplifying the ‘theorist’ approach, the locus of ethical authority in this project lies in the theoretical premise of the research. It is my underlying account of embodied narrative identity, rather than attitudes revealed by empirical research, that carries the weight of the normative argument. Meanwhile, in line with the ‘critical applied ethicist’ approach, this project has the practical goal of applying the ethical argument to making recommendations about the policies and practices governing disclosure of personal bioinformation to individual information subjects. Finally, in common with both these approaches, this thesis seeks to apply empirical evidence to checking the cogency and nuance of the more factually-based elements of the central normative argument and making such refinements to its claims as are necessary.

In the next three chapters I will explore what the social science literature indicates about the roles that three categories of personal bioinformation may play in information subjects’ self-conceptions. As I have outlined above, the findings reported in this literature cannot *prove* the importance of this information to our identities or to the richness and character of our lives. And they cannot *prove* that we consequently have ethically significant interests in accessing

³⁵⁰ See, for example, Hume’s critique of the derivation of moral principles from matters of fact – D. Hume, *A Treatise of Human Nature*. Analytical Index by La Selby–Bigge. Text revised and notes by PH Nidditch. (Oxford: Oxford Univeristy Press, 1978).

³⁵¹ R. Davies et al. (2015), "A Systematic Review of Empirical Bioethics Methodologies" *BMC Medical Ethics*, 16(1): 1.

³⁵² Two main features distinguish my methodology from empirical bioethics in the strictest sense. First my project has no integral empirical methodology, but relies on others’ findings and interpretations of these. Secondly, as described above, my use of these sources is theory-driven and inferential.

³⁵³ B. Molewijk et al. (2004), "Scientific Contribution. Empirical Data and Moral Theory. A Plea for Integrated Empirical Ethics" *Medicine, Health Care and Philosophy*, 7(1): 55-69.

this information. My intention, however, is that they will illustrate these claims and provide grist to their plausibility. Furthermore, exploration of specific examples will supply texture and detail that may permit the development of a more refined account of how different kinds of bioinformation might affect individual's self-conceptions in different circumstances. This will allow me to move forward on a sound footing to practical questions of when and how individuals' interests in identity development might be engaged by access to personal bioinformation. In Part III of this thesis I will bring together the findings from the three examples to consider what generalisable lessons might be drawn from these in terms of the identity-significance and value of particular kinds and instances of bioinformation and what this means for the interests and responsibilities relating to its disclosure.

CHAPTER 5: ILLUSTRATIVE EXAMPLE I - INFORMATION ABOUT DONOR ORIGINS

SECTION 1: TOPIC AND AIMS OF THIS CHAPTER

This chapter is the first of the three illustrative examples I draw upon in this project, with the aims of assessing the plausibility of, illustrating, and refining my theory-based argument as to the importance of personal bioinformation to developing a coherent self-narrative (as made in Chapter 3). This example focuses upon information about donor origins (also referred to as donor conception) – that is, information conveying to an individual that she was conceived using donor gametes or a donor embryo. Under the definition of ‘personal bioinformation’ provided in the Chapter 1, this category of information is ‘biological’ because of its ‘interpretative pedigree’, rather than its source.³⁵⁴ That is, it is biological because it understood *to about* the beginning of an individual’s embodied existence and her genetic relationships to others – not because it is necessarily derived from analysis of biological material (its source is more likely to be parental knowledge or administrative records).³⁵⁵

Reasons for choosing this example

There are three reasons that I have chosen this category of bioinformation as my first case study. First this is, as noted in preceding chapters, an area in which claims about the identity-significance of a particular kind of bioinformation appear to be most prevalent in academic, legal and public discourse, so the basis for such claims warrants interrogation.³⁵⁶ Secondly, there is a reasonably large body of empirical literature regarding donor-conceived individuals’ experiences of (not) knowing about their donor origins.³⁵⁷ And, finally, this is a category where health-related implications of the information are not the chief theme, so it usefully complements my two other illustrative examples which are concerned with health.³⁵⁸

³⁵⁴ See Chapter 1.

³⁵⁵ This chapter will only address donor-conceived individuals’ attitudes to information *about* their gamete donors insofar as it sheds light on our understanding of the impacts of information about conception.

³⁵⁶ See Chapters 1 and 2.

³⁵⁷ See Section 3 below.

³⁵⁸ Some of the inferences drawn in this chapter might also apply to information about genetic parentage beyond the present example – for example in circumstances of adoption, surrogacy, mitochondrial donation, or unknown paternity. My intention here is not to make claims for the *sui generis* significance of information about donor conception, but to use this as an illustrative example with potentially generalisable implications.

Research questions

This chapter directly addresses the second of the four headline research questions set out in Chapter 1: *what grounds are there for holding that the conception of the relationship between personal bioinformation and identity developed in Chapter 3 is robust and plausible in light of people's actual experiences?* In order to answer this, my specific research questions for this chapter will be:

- i. **What do findings reported in the empirical literature indicate about the impacts upon donor-conceived individuals of discovering and knowing about their donor origins?** (Section 4)
- ii. **What might be inferred from this about the roles that information about donor origins could play in donor-conceived individuals' self-narratives?** (Section 5)
- iii. **What kinds of factors appear to influence whether it plays these roles?** (Section 6)

Answering these questions will provide insights into the potential identity-significance of information about donor origins. My broader objective is to gain insights into what factors shape the identity roles, significance and value of many different kinds or instance of personal bioinformation (see Chapter 8). This in turn will contribute to asking my third and fourth headline research questions outlined in Chapter 1: *what are the nature and scope of our identity-related interests in accessing personal bioinformation?;* and *what ethical responsibilities for disclosure accrue to those who hold personal bioinformation about us?* I will address these further questions in Chapter 9.

Before looking at the evidence it will be instructive first to review the current legal and practical status of donor-conceived individuals' access to information about their donor conception (Section 2) and to outline my approach to sourcing and analysing findings from the empirical literature (Section 3).

SECTION 2: CURRENT ACCESSIBILITY OF INFORMATION ABOUT DONOR ORIGINS

Regulatory position

Although 'open-identity donation' (where identifying information *about* gamete donor is to some extent available to offspring) is now required in law in a number of jurisdictions, including the UK,³⁵⁹ very few states have taken statutory steps to encourage disclosure of the

³⁵⁹ I have outlined the UK regulatory position with respect to donor-conceived individuals' access to information about their gamete donors in Chapter 1.

underlying fact of donor conception.³⁶⁰ One exception is the Australian state of Victoria, where donor conception is recorded on birth certificates.³⁶¹ In the UK, once an individual turns eighteen (if born after 1991) they are entitled to apply to the regulator, the HFEA, to find out if they are donor-conceived (presumably if they have unconfirmed suspicions).³⁶² However, proactive disclosure of donor conception is not mandated in UK law.

Tabitha Freeman observes that:

“...there is an emerging consensus in professional and policy discourse in the UK, the USA, Australia and some other Western countries that parental disclosure in early childhood of the fact of donor conception, if not the identity of the donor, is in the best interests of the child.”³⁶³

This is reflected in the regulatory position in the UK. Licensed clinics offering donor-assisted conception are required in law to advise prospective parents of “the importance of informing any resulting child at an early age” of their donor-conception and to provide guidance and information and direction to services that could support them in doing so.³⁶⁴ Nevertheless, it is ultimately left to parents to decide whether to tell. This may reflect unwillingness to impose coercive legal measures in private areas of family life,³⁶⁵ or caution about the invariable benefits of openness.³⁶⁶

Knowing that one is donor-conceived is clearly a condition for exercising legal entitlements to access information *about* one’s donor. However, in this chapter my intention is to interrogate the potential identity-value of knowledge of donor origins in its own right, not merely as a step to donor information.

³⁶⁰ E. Blyth and L. Frith (2009), "Donor-Conceived People's Access to Genetic and Biographical History: An Analysis of Provisions in Different Jurisdictions Permitting Disclosure of Donor Identity" *International Journal of Law, Policy and the Family*, 23(2): 174-91

³⁶¹ *Ibid.*

³⁶² Human Fertilisation and Embryology Act 1990 (as amended) s.31.

³⁶³ T. Freeman, 'Introduction', in *Relatedness in Assisted Reproduction: Families, Origins and Identities*, ed. T. Freeman, et al. (Cambridge: Cambridge University Press, 2014), p.14.

³⁶⁴ Human Fertilisation and Embryology Act 1990 (as amended) s.13 (6c); Human Fertilisation and Embryology Authority, 'Code of Practice' (2015),

³⁶⁵ A proposal for annotated birth certificates was rejected in the UK during the drafting phases of the Human Fertilisation and Embryology Act 2008., see, Department of Health 'Government Response to the Report from the Joint Committee on the Human Tissue and Embryos (Draft) Bill (8 October 2007)'.

³⁶⁶ Nuffield Council on Bioethics (2013)

Parental disclosure

Until relatively recently the norm was for parents not to tell their children about donor conception.³⁶⁷ In the early days of fertility treatment, secrecy was assumed to protect children's wellbeing and family relationships.³⁶⁸ Attitudes about the benefits of openness are changing, in what may be seen as part of a wider social trend toward according significance to genetic inheritance.³⁶⁹ Nevertheless, it is currently the case that the majority of donor-conceived people do not know their donor origins.³⁷⁰

Indications from the UK are that heterosexual parents are increasingly telling their donor-conceived children about their origins (same-sex and single parents have historically been more open).³⁷¹ However, not all parents share the view that disclosure is in children's interests, and telling can be personally challenging.³⁷² Intentions to tell do not always lead to disclosure.³⁷³ The majority of parents in heterosexual couples still do not disclose.³⁷⁴ For example, one recent study found that by the time children in the participating families were seven (the age by which most parents who intend to tell do so)³⁷⁵ only 29% (n=10) who had used sperm donors and 41% (n=13) who had used egg donors had started the process of disclosure.³⁷⁶ It is not yet clear whether the introduction of open-identity donation is likely to encourage or discourage parental openness.³⁷⁷ Of course disclosure of donor origins does not

³⁶⁷ J.B. Appleby et al., 'Is Disclosure in the Best Interests of Children Conceived by Donation?', in *Reproductive Donation: Practice, Policy and Bioethics*, ed. M. Richards, et al. (Cambridge: Cambridge University Press, 2012),

³⁶⁸ T. Freeman and S. Golombok (2012), "Donor Insemination: A Follow-up Study of Disclosure Decisions, Family Relationships and Child Adjustment at Adolescence" *Reproductive biomedicine online*, 25(2): 193-203.

³⁶⁹ Freeman (2014); M. Richards, 'A British History of Collaborative Reproduction and the Rise of the Genetic Connection', in *Relatedness in Assisted Reproduction: Families, Origins, and Identities* (Cambridge: Cambridge University Press, 2014).

³⁷⁰ Nuffield Council on Bioethics (2013).

³⁷¹ Ibid.; D. Beeson et al. (2011), "Offspring Searching for Their Sperm Donors: How Family Type Shapes the Process" *Human Reproduction*, 26(9): 2415-24.

³⁷² J. Readings et al. (2011), "Secrecy, Disclosure and Everything in-Between: Decisions of Parents of Children Conceived by Donor Insemination, Egg Donation and Surrogacy" *Reproductive biomedicine online*, 22(5): 485-95.

³⁷³ Ibid.

³⁷⁴ S. Zadeh (2016), "Disclosure of Donor Conception in the Era of Non-Anonymity: Safeguarding and Promoting the Interests of Donor-Conceived Individuals?" *Human Reproduction*, 31(11): 2416-20.

³⁷⁵ L. Blake et al. (2010), "'Daddy Ran out of Tadpoles': How Parents Tell Their Children That They Are Donor Conceived, and What Their 7-Year-Olds Understand" *Human Reproduction*, 25(10): 2527-34.

³⁷⁶ L. Blake et al. (2014), "Parent Psychological Adjustment, Donor Conception and Disclosure: A Follow-up over 10 Years" *Human Reproduction*, 29(11): 2487-96.

³⁷⁷ T. Freeman et al., 'Identifiable Donors and Siblings: Implications for the Future', in *Reproductive Donation: Practice, Policy and Bioethics* ed. M. Richards, et al. (Cambridge: Cambridge University Press, 2012).

only occur in planned ways or early in a child's life. Events such as divorce or the death of one parent may precipitate later revelations.³⁷⁸ And offspring may find out from other relatives, family friends, by accident, or reach their own inferences.³⁷⁹ As discussed later in this chapter, unplanned and later disclosures may affect the impacts of the information.

As indicated in Chapter 1, recognition of donor-conceived individuals' identity-related interests were part of the rationale for the change in the law ending anonymous gamete donation in the UK. I shall return at the end of Chapter 9 to reflect on what, if any, difference thinking about these interests in terms of *narrative* identity might make to practices and policies in respect of provision of information about donor origins.

SECTION 3: SOURCES AND ANALYTICAL APPROACH

As I have indicated in the preceding chapters, there is no shortage of assertions in legal, policy and academic (both theoretical and empirical) sources that knowledge of donor origins can be important to donor-conceived individuals' identities.³⁸⁰ To take just three examples, Guido Pennings argues that:

“...information about one's genetic lineage is needed in order to be able to construct an acceptable life story, i.e., a story of who one is.”³⁸¹

Vardit Ravitsky maintains that:

“The development of personal identity requires understanding “where you came from”...”³⁸²

And the HFEA has stated that information about “genetic origins” -

“...can help people complete a picture of their identity and it is natural to seek it.”³⁸³

However, assertions such as these cannot (or at least not on their own) provide the kind of evidential support that I am seeking in this chapter. Not only are such claims not uniformly evidence-based, but it is not always safe to assume that they invoke identity in a sense sufficiently similar to the conception at the heart of this project. Furthermore, though abundant,

³⁷⁸ K. Daniels et al. (2011), "Factors Associated with Parents' Decisions to Tell Their Adult Offspring About the Offspring's Donor Conception" *Human Reproduction*, 26(10): 2783-90; Kirkman (2003).

³⁷⁹ Nuffield Council on Bioethics (2013).

³⁸⁰ See, Chapters 1 and 3.

³⁸¹ Pennings (2001), p.12.

³⁸² V. Ravitsky (2010), "Knowing Where You Come From: The Rights of Donor-Conceived Individuals and the Meaning of Genetic Relatedness" *Minn. JL Sci. & Tech.*, 11(2): 665-84, p.674.

³⁸³ Human Fertilisation and Embryology Authority 'HFEA Paper 485: Opening the Register Policy: A Principled Approach' (21 January 2009) [10.1].

such arguments are not without detractors. Some authors query the universality of an identity-related interest in knowing,³⁸⁴ while others challenge the objective basis or ethical significance of such an interest.³⁸⁵

I have outlined my broad methodological approach to analysing the empirical evidence for all three illustrative examples in Chapter 4. Here I will set out my specific approach in this chapter.

Empirical literature

There is a relatively large body of empirical research looking at the experiences, attitudes and wellbeing of donor-conception families. To navigate this field, I have taken as starting point the sources that informed the detailed evidence-review conducted by the Nuffield Council on Bioethics for their 2013 report, '*Donor Conception: ethical aspects of information sharing*',³⁸⁶ supplementing these with more recent studies and reviews where appropriate. Here I draw upon 21 publications reporting primary research gathered through a range of qualitative and quantitative methods. The largest of these reports qualitative and quantitative findings from 741 participants.³⁸⁷ Many are smaller; the smallest involving 16 participants.³⁸⁸ Some studies were longitudinal and others, snapshots. They chiefly involve participants from the UK, Australia, New Zealand, North America and Western Europe. A sizeable proportion of these studies are co-authored by members of the Centre for Family Research at the University of Cambridge, a leading centre for empirical work in this field.³⁸⁹ I have also drawn upon several evidence reviews. It is necessary to raise two caveats in respect of applying the findings of this literature to my research questions listed in Section 1.

Limitations of research findings

The first caveat is that that participants in studies looking at donor-conceived individuals' reactions to information about their origins research may not be representative of all donor-conceived individuals. The difficulties of studying those who do not know they are donor-

³⁸⁴ See, for example, Lillehammer (2014).

³⁸⁵ See, for example, de Melo-Martín (2014); S. Haslanger (2009), "Family, Ancestry and Self: What Is the Moral Significance of Biological Ties"; K. Leighton (2014), "The Right to Know Genetic Origins: A Harmful Value" *Hastings Center Report*, 44(4): 5-6.

³⁸⁶ Nuffield Council on Bioethics (2013).

³⁸⁷ Beeson et al. (2011).

³⁸⁸ A.J. Turner and A. Coyle (2000), "What Does It Mean to Be a Donor Offspring? The Identity Experiences of Adults Conceived by Donor Insemination and the Implications for Counselling and Therapy" *Human Reproduction*, 15(9): 2041-51.

³⁸⁹ University of Cambridge Centre for Family Research website 'New Families Research Group', www.cfr.cam.ac.uk/groups/ntf (accessed 9 June 2017)

conceived means that participants are often drawn from networks that facilitate contact between donor-relatives, amongst whom pro-information attitudes may be more prevalent.³⁹⁰ Individuals conceived with donor eggs or embryos are less well-represented than those conceived using donor sperm.³⁹¹ Given the relatively recent introduction of open-identity donation, there are also limited findings from those who know who their donors are.³⁹² And few of the larger studies are longitudinal or conducted with adults, limiting the insights into the longer-term impacts of this information.³⁹³

The second caveat relates to the specific challenges of illustrating impacts on identity-narratives. Few studies investigate identity-related effects directly;³⁹⁴ though, they are sometimes indirectly inferred from findings relating to the psychological wellbeing and quality of relationships within donor-conception families.³⁹⁵ Even where identity effects *are* explicitly mentioned, these are more commonly invoked either in a broad, undefined sense, or in the more technical terms of developmental psychology.³⁹⁶ One exception to this is research conducted by Maggie Kirkman, in which she applies a narrative conception of identity to her own findings – albeit not the philosophical one on which this thesis is based.³⁹⁷ Kirkman’s analysis informs my own in Section 5.

These limitations will be taken into account in my analysis of the empirical evidence below.

Analytical approach

In Section 4 I will summarise findings from published empirical studies insofar as these report the experiences, attitudes and expectations of donor-conceived individuals in relation to having, receiving or lacking information about their donor origins. This is conducted with a view to gaining insights into the impact of this information (or its absence) on the way donor-conceived individuals see themselves, their relationships and their lives in a way that might allow me to draw inferences about its possible narrative roles.

³⁹⁰ T. Freeman (2015), "Gamete Donation, Information Sharing and the Best Interests of the Child: An Overview of the Psychosocial Evidence" *Monash Bioethics Review*, 33(1): 45-63.

³⁹¹ Ibid.

³⁹² Ibid.

³⁹³ E. Blyth et al. (2012), "Donor-Conceived People's Views and Experiences of Their Genetic Origins: A Critical Analysis of the Research Evidence" *Journal of law and medicine*, 19(4): 769-89.

³⁹⁴ Nuffield Council on Bioethics (2013).

³⁹⁵ Freeman and Golombok (2012).

³⁹⁶ See for example, J. Slutsky et al. (2016), "Integrating Donor Conception into Identity Development: Adolescents in Fatherless Families" *Fertility and sterility*, 106(1): 202-08; Turner and Coyle (2000).

³⁹⁷ Kirkman (2003); M. Kirkman (2004), "Genetic Connection and Relationships in Narratives of Donor-Assisted Conception" *Australian Journal of Emerging Technologies and Society*, 2(1).

Having gathered and summarised the relevant findings, I shall then turn (in Section 5) to analyse this more specifically through the conceptual framework of the current project – according to which I have hypothesised that personal bioinformation may not only contribute contents and plotlines to our self-narratives, but also the interpretive context that helps us construct *coherent* self-narratives, which make sense and support us in navigating our embodied lives and experiences.

In Section 6 I will consider what the empirical literature indicates, first, about which features of information about donor origins contribute to its identity-relevance and, secondly, what factors appear to account for diversity amongst the ways in which individuals respond to it.

As outlined in the previous chapters, there is already a theoretical literature that frames individuals’ interests in knowing about their genetic origins in terms of narrative identity.³⁹⁸ And as noted above, there are a small number of empirical studies in which the findings are analysed with reference to effects on identity.³⁹⁹ My intention in this chapter is to go beyond the conclusions reached in either of these literatures by bringing together my own theoretically-based conception of the role of personal bioinformation in identity development with the findings reported in the empirical literature to provide a distinctive and evidence-informed normative account of the role that information about donor origins might play in someone’s self-conception. As such, my narrow aims are to provide a robust response to those who question any identity value in information about donor origins,⁴⁰⁰ and to meet the need, noted by the Nuffield Council on Bioethics, for an adequate articulation of what “harm to identity” means in ethical terms in this context.⁴⁰¹ My wider aim is further to develop the picture of how and why access to personal bioinformation may engage ethically significant identity-based interests.

SECTION 4: THE EVIDENCE

In this section I will present what I take to be the key pertinent findings from the literature I have surveyed. In order to highlight what these findings indicate about the possible impacts on donor-conceived individuals of having or lacking information about donor origins I will divide these findings into the reported effects of three ‘epistemic states’, those of:

- Not knowing about donor origins;
- Discovering donor origins; and

³⁹⁸ J. L. Nelson (1992); Wilson (1997). See Chapters 2 and 3 above.

³⁹⁹ Freeman (2015); Kirkman (2003); Turner and Coyle (2000).

⁴⁰⁰ For example, Leighton (2014).

⁴⁰¹ Nuffield Council on Bioethics (2013), p.65.

- Living with the knowledge of donor origins.

Impacts of not knowing

There are clear inherent difficulties facing researchers seeking to ascertain the effects of not knowing on those who do not know they are donor-conceived. One possible source of insights are large-scale observational studies comparing psychosocial measures of wellbeing and familial relationships in disclosing and non-disclosing families.⁴⁰² These studies have not investigated identity impacts directly. But they have found no significant differences in children's wellbeing between those who know and those who do not.⁴⁰³ Although mother-child relationships have been observed to be somewhat more positive in disclosing families while children are young,⁴⁰⁴ the direction or nature of any causal link is not known.⁴⁰⁵ These studies do not currently extend into adulthood, so do not speak to any longer-term consequences of not knowing.

Another source of insights are the retrospective reflections of donor-conceived individuals, who learnt of their origins in adolescence or adulthood, upon their experiences *prior* to this. A number of sources report donor-conceived individuals as having felt anomalous within their family with respect to their appearance or character traits.⁴⁰⁶ For example, one participant describes that –

“I'd always known that something wasn't quite right that there was something different about me but I just didn't know what,”⁴⁰⁷

⁴⁰² S. Golombok et al. (1996), "Children: The European Study of Assisted Reproduction Families: Family Functioning and Child Development" *Human Reproduction*, 11(10): 2324-31; S. Golombok et al. (2002), "The European Study of Assisted Reproduction Families: The Transition to Adolescence" *Human Reproduction*, 17(3): 830-40; S. Golombok et al. (2005), "Families Created by Gamete Donation: Follow-up at Age 2" *Human Reproduction*, 20(1): 286-93; S. Golombok et al. (2011), "Children Conceived by Gamete Donation: Psychological Adjustment and Mother-Child Relationships at Age 7" *Journal of Family Psychology*, 25(2): 230; E. Lycett et al. (2004), "Offspring Created as a Result of Donor Insemination: A Study of Family Relationships, Child Adjustment, and Disclosure" *Fertility and sterility*, 82(1): 172-79.

⁴⁰³ E.C. Ilioi and S. Golombok (2015), "Psychological Adjustment in Adolescents Conceived by Assisted Reproduction Techniques: A Systematic Review" *Human reproduction update*, 21(1): 84-96.

⁴⁰⁴ Golombok et al. (2011); Ilioi and Golombok (2015); Lycett et al. (2004).

⁴⁰⁵ Nuffield Council on Bioethics (2013).

⁴⁰⁶ Beeson et al. (2011); Daniels et al. (2011); G. Hewitt (2002), "Missing Links: Identity Issues of Donor Conceived People" *Journal of Fertility Counselling*, 9: 14-19; Kirkman (2003); V. Jadva et al. (2009), "The Experiences of Adolescents and Adults Conceived by Sperm Donation: Comparisons by Age of Disclosure and Family Type" *Human Reproduction*, 24(8): 1909-19; O. Montuschi, *Telling and Talking* (Donor Conception Network, 2006); Turner and Coyle (2000).

⁴⁰⁷ Nuffield Council on Bioethics (2013), p.87.

And another that:

“I sensed that my social father wasn’t my biological father and I began asking questions.”⁴⁰⁸

While another says that learning that she was donor-conceived:

“...explained so many unanswered questions I had [and] resolved a fog of confusion”.⁴⁰⁹

Some donor-conceived individuals describe the sense of disconnection they felt prior to learning about their conceptions as “blighting” their lives or damaging their self-esteem.⁴¹⁰ It is, however, not possible to disentangle such views from the colourings of hindsight, adolescent disaffection, or distress at how they found out.⁴¹¹

It has been posited that concealing donor conception within a family can itself cause tensions, or affect parental behaviour in ways that are palpable to offspring.⁴¹² One donor-conceived individual reports that the withholding of information in her family:

“...created a ‘shroud of secrecy’ and a ‘sense of shame’ but something I could sense, but of what I had no real knowledge”.⁴¹³

One self-evident consequence of non-disclosure in childhood is that it leaves open the possibility of late or accidental discovery which, as I shall now go on to discuss, is often a negative experience.⁴¹⁴

Experiences of discovery

Reactions to discovery of donor origins vary markedly by the age at which this occurs.⁴¹⁵ Although some parents fear that disclosure will confuse very young children or cause psychological problems, the most common reactions amongst those who are told before reaching school-age are indifference, pleasure or curiosity.⁴¹⁶ And for many the experience is one of ‘always having known’.⁴¹⁷ In contrast, it has been observed that those who learn of their donor conception when they were adolescents or adults are more likely to react with shock,

⁴⁰⁸ Hewitt (2002), p.3.

⁴⁰⁹ Kirkman (2003) p.2229.

⁴¹⁰ Montuschi (2006), p.4; Turner and Coyle (2000).

⁴¹¹ Nuffield Council on Bioethics (2013).

⁴¹² Golombok et al. (2002).

⁴¹³ Turner and Coyle (2000).

⁴¹⁴ Zadeh (2016).

⁴¹⁵ Nuffield Council on Bioethics (2013).

⁴¹⁶ Freeman et al. (2012); Jadvá et al. (2009); Nuffield Council on Bioethics (2013).

⁴¹⁷ Freeman (2015).

confusion, numbness or anger.⁴¹⁸ One individual, told when she was eighteen, describes finding out as:

“...one of the most shocking and upsetting moments of my life.”⁴¹⁹

Participants in several studies report anger and a sense of betrayal that they had been lied to, or that their “entire life [has been] based on a lie”.⁴²⁰ Several participants in another small study, told during their teens or adult years, expressed the wish that they had been told earlier.⁴²¹

There are also some explicit references to identity. One individual told in her thirties describes becoming very depressed because she felt “I wasn’t the person I thought I was” and having to “redevelop her sense of identity”.⁴²² One younger individual says that, “I knew I was still loved. But I think I felt like “who am I?” Another reports feeling angry because, “...I felt that I did not know myself”.⁴²³

Not all experiences of disclosure in adolescence or adulthood are negative. Some report curiosity or joy upon learning of their donor conception.⁴²⁴ Some are excited to gain a new living ‘parent’⁴²⁵ or to receive an explanation for lifelong feelings of ‘non-belonging’.⁴²⁶ Others, meanwhile, report a mixture of positive and negative reactions. For example, in more than one study participants report that despite feeling shocked or disoriented, they also felt “liberated” or “relieved”.⁴²⁷ Again, identity impacts are sometimes explicitly invoked. Several participants in one study talk of having to “reappraise” their identities, but frame this as a positive opportunity.⁴²⁸

Experiences of living with the knowledge

This sub-section looks at individuals’ reactions to or experiences of living with knowledge of donor-conception beyond initial discovery (although indications are that the manner of

⁴¹⁸ Beeson et al. (2011); Hewitt (2002); Jadvá et al. (2009); Nuffield Council on Bioethics (2013); Turner and Coyle (2000).

⁴¹⁹ Jadvá et al. (2009), p.1913.

⁴²⁰ Blyth et al. (2012); Turner and Coyle (2000), p.2045; Kirkman (2003); Ilioi and Golombok (2015).

⁴²¹ Hewitt (2002).

⁴²² Kirkman (2003), p.2229, p.2230.

⁴²³ Hewitt (2002), p.3.

⁴²⁴ Ibid.; Jadvá et al. (2009); Nuffield Council on Bioethics (2013).

⁴²⁵ Jadvá et al. (2009); Kirkman (2003).

⁴²⁶ E. Blyth (2012), "Genes R Us? Making Sense of Genetic and Non-Genetic Relationships Following Anonymous Donor Insemination" *Reproductive biomedicine online*, 24(7): 719-26; Kirkman (2003).

⁴²⁷ Kirkman (2003); Turner and Coyle (2000), p.2044, p.2045.

⁴²⁸ Turner and Coyle (2000), p.2045.

discovery may colour their ongoing feelings about the information). In order to illustrate the different facets of the effects that this information might have, I will divide the evidence here into the following four categories:

- i) Effects on psychological wellbeing;
- ii) Impacts on relationships;
- iii) Responses explicitly invoking identity; and
- iv) Express preferences for knowing.

i) Effects on psychological wellbeing

As noted above, large-scale studies comparing the psychosocial wellbeing of children and young adolescents in disclosing and non-disclosing families have found no differences in their psychological adjustment, leading researchers to conclude that knowing about donor conception “does not create significant difficulties” amongst these age groups.⁴²⁹ Early disclosure often seems to be associated with an unproblematic longer-term accommodation of the knowledge. For example one research participant felt that being told early “allowed [their donor origins] to be a ‘normal’ kind of thing”.⁴³⁰ A parent providing evidence to the Nuffield Council on Bioethics reported their child (told when she was four) remained “comfortable” and “unfazed” by the knowledge.⁴³¹ However, it is noted that people’s attitudes can change throughout their lives.⁴³²

The longer-term reactions of those that learn of their donor origins in adolescence or adulthood may be less sanguine. One large study observes that, even after any initial shock or confusion had subsided, anger often persists.⁴³³ However, it has been suggested that this may be attributable to the perception that they were lied to, or the circumstances disclosure, rather than knowledge of donor conception *per se*.⁴³⁴

ii) Impacts on relationships

Impacts on family relationships have been observed to be similarly diverse. As noted above, early disclosure has been observed to be associated with more positive mother-child relationships while children are young.⁴³⁵ However, large longitudinal, comparative studies have

⁴²⁹ Freeman and Golombok (2012), p.202; Ilioi and Golombok (2015).

⁴³⁰ Hewitt (2002), p.3.

⁴³¹ Nuffield Council on Bioethics (2013), p.56.

⁴³² Freeman (2015).

⁴³³ Beeson et al. (2011); Jadvá et al. (2009).

⁴³⁴ Blyth et al. (2012).

⁴³⁵ Golombok et al. (2011); Ilioi and Golombok (2015); Lycett et al. (2004).

also observed the emergence of lower father-child warmth and more mother-daughter conflict during early adolescence.⁴³⁶ The authors comment that this coincides with a development stage of “questioning one’s identity”.⁴³⁷ They stress, however, that the problems observed do not count as dysfunctional and are not necessarily attributable to disclosure.⁴³⁸ Other studies have observed that openness about donor conception can enhance family relationships. For example, one participant reports that it has made their family closer because it provided a “special bond”.⁴³⁹ And some parents report that being open with their children has cemented trust.⁴⁴⁰

It is widely reported that later disclosure appears to be particularly associated with enduring anger amongst donor-conceived offspring, directed at parents who they regard as having lied, dismissed their earlier suspicions, or prioritised their (the parents’) own interests over those of their children.⁴⁴¹ Trust between parents and offspring may be a casualty of later disclosure.⁴⁴² And some describe their relationships with their parents as permanently damaged.⁴⁴³

Knowledge of donor origins also introduces the possibility of reconfigured or new personal relationships. Several studies report participants as feeling a sense of loss and grief at having to relinquish what they had assumed to be their family or genetic heritage.⁴⁴⁴ However, other reactions are more positive. For example, in more than one study participants report relief upon learning that they are not genetically related to a parent towards whom they feel antipathy.⁴⁴⁵ Some donor-conceived individuals are also excited by the prospect of donors as imagined ‘fantasy parents’ or of meeting and building relationships with donors or donors siblings.⁴⁴⁶ For example, one participant reports that:

“I also felt excited, because it meant I might have a living “father” (my social father died when I was quite young), and half-siblings as well.”⁴⁴⁷

⁴³⁶ Freeman and Golombok (2012).

⁴³⁷ Ibid., p.201.

⁴³⁸ Ibid.

⁴³⁹ Hewitt (2002), p.3.

⁴⁴⁰ J.E. Scheib et al. (2003), "Choosing Identity-Release Sperm Donors: The Parents' Perspective 13–18 Years Later" *Human Reproduction*, 18(5): 1115-27.

⁴⁴¹ Beeson et al. (2011); Blyth et al. (2012); Jadvá et al. (2009); Kirkman (2003); Turner and Coyle (2000).

⁴⁴² Blyth et al. (2012); Hewitt (2002); Turner and Coyle (2000).

⁴⁴³ Hewitt (2002); Kirkman (2003).

⁴⁴⁴ Blyth (2012); Beeson et al. (2011).

⁴⁴⁵ Beeson et al. (2011); Jadvá et al. (2009); Turner and Coyle (2000).

⁴⁴⁶ Jadvá et al 2009.

⁴⁴⁷ Jadvá et al 2009, p.1913.

However, for regulatory, practical and personal reasons, hopes of identifying or contacting donors or donor siblings may not always be realisable or have positive outcomes.⁴⁴⁸

iii) Explicit identity impacts

Based on its own review of empirical studies and direct engagement with donor-conceived offspring and support networks, the Nuffield Council on Bioethics observes that:

“...some donor-conceived people have expressed very strongly the view that knowledge of their biological origins, in the sense both of the truth about the circumstances of their conception and of the knowledge of their donor, is essential to both their sense of self and to their social identity: their understanding of ‘who they are’ and of where they fit in the world.”⁴⁴⁹

For some, donor conception appears to occupy a central part of how they define themselves. For example, one research participant who had ‘always known’ about her origins reports that:

“My conception is who I am, it is who I will always be, it will never change... My hair is black my parents divorced when I was three. I am an only child, and I was conceived through DI [donor insemination].”⁴⁵⁰

But, for others, donor conception plays no part in their self-characterisation. For example, a participant on one study reports that:

“I am no different than any other person. How we are born does not make us who we are. I do not define myself by that trait.”⁴⁵¹

A more ambiguous position is reflected by the response that –

“It doesn’t bother me at all. I live life like I would’ve if I wasn’t a ‘donor sperm’ person.”⁴⁵²

Some report that their donor conception is something that marks them out in positive ways, or makes them feel “special”.⁴⁵³ However, positive reactions are not universal. Some parents report a fear that their children will suffer stigma if their donor conception is widely known.⁴⁵⁴ One large study found several participants felt ashamed, with some (statistically non-significant) correlation between this and later discovery.⁴⁵⁵ The label of ‘donor-conceived’ is

⁴⁴⁸ Freeman et al. (2012).

⁴⁴⁹ Nuffield Council on Bioethics (2013), p.89.

⁴⁵⁰ Kirkman (2003), p.2238.

⁴⁵¹ Jadvá et al. (2009), p.1913.

⁴⁵² Hewitt (2002), p.3.

⁴⁵³ Ibid., p.3; Nuffield Council on Bioethics (2013).

⁴⁵⁴ Nuffield Council on Bioethics (2013).

⁴⁵⁵ Jadvá et al. (2009).

sometimes experienced as a negative or marginalising characteristic. For example, one young person reports:

“I felt like a commodity that has been commissioned...I genuinely felt that I am different to other people.”⁴⁵⁶

The threat of stigma is thought to be greater in communities in which, for example, infertility is seen as shameful.⁴⁵⁷ However, it has been suggested that feared experiences of otherness or discrimination often fail to materialise.⁴⁵⁸ And Kirkman observes that the negative reactions of participants in her study to discovering their origins was usually not related to negative feelings about *being* donor-conceived.⁴⁵⁹

Knowledge of donor conception is also reported as having impacts – both constructive and detrimental – on donor-conceived individuals’ capacities to make sense of who they are. As described above, some participants feel that learning of their donor conception brings fresh intelligibility to their traits or experiences of their place within their families.⁴⁶⁰ In contrast, however, one small study reports that many participants responded that learning of their donor conception left them feeling as if their identity was ‘incomplete’.⁴⁶¹ Similarly, Kirkman (who brings a narrative-identity-based analysis to her data) has suggested that, following later disclosure, some (even if they do not feel negatively about *being* donor-conceived) have trouble reconstructing a satisfying narrative of who they are – one that either comfortably accommodates or excludes ‘being donor-conceived’.⁴⁶²

iv) Preferring to know

Despite the varied range of reactions to information about donor origins, two studies indicate a strikingly widespread preference for knowing, even amongst those for whom the experience has not been wholly positive. For example, in one large study in which the participants reported a range of good and bad experiences of learning they were donor-conceived, only one percent (of a total of 164) said that they wished that they had not found out.⁴⁶³ It must be noted, however, that this study recruited participants from a network facilitating donor and sibling

⁴⁵⁶ Hewitt (2002), p.4.

⁴⁵⁷ Ibid.; Nuffield Council on Bioethics (2013).

⁴⁵⁸ Nuffield Council on Bioethics (2013).

⁴⁵⁹ Kirkman (2003) Rather, individuals’ distress instead related to, for example, to the circumstances of concealment or disclosure or impacts on family relationships.

⁴⁶⁰ Blyth et al. (2012); Kirkman (2003).

⁴⁶¹ The total number of participants in this small study was forty-seven; Turner and Coyle (2000).

⁴⁶² Ibid.

⁴⁶³ Jadvá et al. (2009).

contact, so those disposed to welcome information may well be overrepresented. In another study (a qualitative one with 12 offspring participants) the author reports that:

“Without exception participants who are adult offspring of donor-assisted conception argued the necessity of developing an identity that accurately reflected their conception”⁴⁶⁴

For example, one of these participants says that despite having to “redevelop” her sense of identity upon learning about her conception, she is glad to have done so because “truth is always better”, and it helped to explain some of her prior experiences.⁴⁶⁵

The findings summarised in the sub-sections above already go some considerable way to indicating what the potential impacts of information about donor origins on a donor-conceived individual’s identity might look like. Indeed, although the views cited above indicate that by no means all donor-conceived individuals experience this category of personal bioinformation as making straightforwardly welcome or important contributions to their identities, my more modest intention – to demonstrate that at least some do – might seem to be adequately fulfilled by the Nuffield Council on Bioethics’ observation (quoted above) that some individuals feel strongly that knowledge of their genetic origins is essential to their sense of self.⁴⁶⁶ However, the present project is not simply interested in identity impacts conceived in just *any* sense, but specifically in the potential for this category of bioinformation to play roles in the construction of a coherent self-narrative that underpins both one’s sense of who one really is and one’s interpretive outlook on the world. So, although it will entail some repetition, in this section it is my aim to interpret the findings above through the lens of a narrative conception of identity. In this, my analysis is informed by empirical researchers who explicitly invoke identity narratives in their interpretations of their own findings, as well as theory-led commentaries that posit a narrative role for knowledge of genetic parentage.

SECTION 5: INTERPRETING THE FINDINGS IN TERMS OF IMPACTS ON NARRATIVE IDENTITY

I wish to propose that the evidence summarised above suggests the following six, sometimes interconnected, ways that information about donor conception can play a role – not always a positive one – in donor-conceived individuals’ self-narratives:

- i) Self-labelling;
- ii) Reconfiguration of relationships;

⁴⁶⁴ Kirkman (2003), p.2238.

⁴⁶⁵ Ibid., p.2229, p.2230.

⁴⁶⁶ Nuffield Council on Bioethics (2013), p.89.

- iii) Biographical beginnings;
- iv) Explaining experiences;
- v) Disrupting existing narratives; and
- vi) Jeopardising narrative coherence.

i) Self-labelling

Self-ascription of the label of being ‘a donor-conceived individual’ does not emerge as one of the more widely invoked consequences of individuals learning that they are donor-conceived. While a few report that this is how – for better or worse – they think of themselves, others repudiate any such label. One important angle that a narrative conception of identity opens up, however, is a picture self-characterisation that extends beyond the acquisition of self-labels, to characterisations that are constituted by what someone *does*. Behind many of the findings cited above lie descriptions or implications of the pursuit of donor information, and active engagement with support networks and donor and donor-sibling voluntary contact registries by some donor-conceived individuals.⁴⁶⁷ And, although it is necessarily speculative without first person testimony speaking to such a conclusion, I would tentatively suggest that such activities could constitute portions of these individuals’ self-narratives in a way that is inextricably bound up with the means of their conception.

ii) Relational roles and relationships

As noted in Chapter 3, James Lindemann Nelson suggests that the narrative value of understanding how our lives connect with those of others may be seen as lying in the “depth and richness” which these connections bring “to the continuing story in which we participate”⁴⁶⁸ This is reflected in the views of those research participants who report marked curiosity or excitement at learning of genetic relatives – both donors and siblings – beyond their social families. There are indications that information about donor origins invites not only new ways for donor-conceived individuals to think of themselves in terms of their relational roles, but also new relational contexts and wider family narratives within which they may (re)interpret their accounts of who they are.

The findings discussed above indicate that the addition of new relationships and relational roles to one’s story is not inevitably at the expense of existing ones. However, this is sometimes the case, either as a matter of choice – where the individual uses the information as

⁴⁶⁷ Ibid.

⁴⁶⁸ J. L. Nelson (1992), p.81.

grounds to write an existing parent out of their story – or more involuntarily and perhaps unwelcome – where the new information precipitates a breakdown in trust or closeness between the individual and other family members, or because the individual feels severed from her previously assumed genetic connection to others. As Kirkman observes, these disturbances may have a doubly detrimental effect upon an individuals’ self-narratives: upsetting both the former shape and contents of their account of who they are and the nature of the very familial relationships which had hitherto provided the crucible within which they had hitherto worked out who they were.⁴⁶⁹

iii) Biographical beginnings

The Nuffield Council on Bioethics suggests that one role that information about donor origins can play is in filling aspects of the beginnings of an individuals’ biography.⁴⁷⁰ The evidence considered above does indeed suggest that one aspect of the importance of this information to its recipients lies in its capacity to supply the starting point for their accounts of themselves and help them to locate their own biological existences within the contexts of choices made by their parents and gamete donors. Kirkman argues that:

“Family stories of birth and conception, stories of “how our family came to be,” are fundamental to the idea of narrative identity.”⁴⁷¹

This is illustrated in another source by the view of the donor-conceived individual who says:

“... who wants to start a book on Chapter 2? I want Chapter 1, the Introduction and the Prologue as well!”⁴⁷²

Part of the value of the filling-in of these early chapters appears to lie in the capacity of this information to provide context and explanation of other experiences – as described under the next sub-heading.

iv) Explaining experiences

The role that this information can play in contributing to the coherence of individuals’ accounts of who they are, are vividly illustrated by the examples of individuals who report how learning about their donor origins helped to explain disparities between their own appearance or

⁴⁶⁹ Kirkman (2003).

⁴⁷⁰ Nuffield Council on Bioethics (2013), p.14.

⁴⁷¹ Kirkman (2003), p.2231.

⁴⁷² Donor Sibling Registry ‘*Voices of the Donor Conceived, Donors and Parents: Advice, Stories, and Thoughts from Donor Families*’ (2008)

www.donorsiblingregistry.com/sites/default/files/files/voices%20of%20the%20donor%20conceived.pdf (accessed 9 June 2017)

character traits and those of family members, or features of prior family dynamics, or “resolved a fog of confusion”.⁴⁷³ To some extent these testimonies support Sarah Wilson’s suggestion that knowledge of donor origins is valuable because it helps “...with the alleviation of uncertainty with respect to the past”.⁴⁷⁴ Wilson’s characterisation seems plausible. But it perhaps misses the mark where it is not so much a felt historical gap that is a problem, but enduring dissonances. The examples above appear consistent with my broader narrative-based contention that it is important that our self-narratives accord broadly with, and thus help us to live in and navigate, the world as experienced by others (especially those close to us amongst whom we work out who we are) and with our own experiences of embodied existence, and that personal bioinformation can be an vital means of securing this concordance.

v) Disrupting existing narratives

It is clear that not all experiences of receiving information about donor origins are wholly positive. Following Kirkman, I would submit that this distress may be sometimes be understood within a framework of narrative identity, as being associated with disruption to an individual’s existing self-narrative or, what Eric Blyth calls, “disjunctions in their biographies”.⁴⁷⁵ Disclosure might mean, for example, that an individual is forced, abruptly and involuntarily, to relinquish her self-conception as the “biological product of both her parents”,⁴⁷⁶ or as someone who has an open, honest relationship with her family. This explanation of distress in terms of identity disruption is further supported by the considerable body of evidence that indicates that disclosure is much less likely to cause distress when it occurs in early childhood.⁴⁷⁷ Kirkman and Freeman both posit that, when someone is told early, and donor conception is part of her “family narrative”, her own identity narrative may be better able to develop consistently with this.⁴⁷⁸

However, the implications of the idea of narrative disruption for any conclusions I wish to draw about the potential identity-value or detriment of this information, warrant interrogation. The empirical literature indicates that, for some, the disruptive impacts of late disclosure may have deep and enduring impacts, with individuals reporting that they have since found it impossible to reconstruct a satisfying account of who they are. However, this is not invariably the case. Despite initial shock, some individuals report welcoming the opportunity to

⁴⁷³ Kirkman (2003) p.2229.

⁴⁷⁴ Wilson (1997), p.285. I have outlined and distinguished my position from Wilson’s in Chapter 3.

⁴⁷⁵ Blyth (2012), p.10; Kirkman (2003).

⁴⁷⁶ Turner and Coyle (2000), p.2045

⁴⁷⁷ Nuffield Council on Bioethics (2013).

⁴⁷⁸ Freeman (2014); Kirkman (2003), p.2238.

reappraise their identities and their relationships to others. This is in line with the account of narrative identity offered in the preceding chapters, according to which self-narratives are not inert things, which once made can only be preserved or broken. Rather they are ever-evolving in response to new experiences and interpretations. And short-term disruption might sometimes serve longer-term narrative coherence when it is associated with someone's reinterpretation of her experiences equipped with fuller information about her origins and relationships.

vi) Jeopardising narrative coherence

Given the findings from comparative studies of children's and adolescents' psychological wellbeing and family relationships, which indicate little evidence of ill-effects amongst donor-conceived individuals who grow up not knowing that they are donor-conceived, one might be inclined to draw the conclusion that there are no grounds for inferring detrimental identity impacts from not knowing that one is donor-conceived. However, a narrative conception of identity – by emphasising both the longitudinal nature of identity and the importance of interpretation and coherence across its temporal span – suggests another possibility. It is conceivable the harm implicit in constructing a self-narrative without information about donor origins may well be latent (in a temporal rather than psychoanalytical sense) – lying in the construction of, what Kirkman terms, a “misleading identity”.⁴⁷⁹

It might reasonably be objected here that there are infinite possible facts about our lives and circumstances of which we are unaware without our being *misled* as to who we are.⁴⁸⁰ In this respect, though, I would suggest that ignorance of one's donor origins differs from lacking knowledge of many other kinds of personal bioinformation. This is not based upon assumptions about its intrinsic identity-significance. Rather it is attributable to the fact that not-knowing and false belief are likely to coincide in this context, because where it is the norm for one's social parents also to be one's genetic parentage – in the absence of information to the contrary – most people would assume this is true of their own family.⁴⁸¹ In the case of donor-conceived individuals this assumption would be (wholly or partly) false. Of course, it is possible that one's beliefs about one's parentage might play no significant role at all in one's self-narrative. In which case this assumption may have no notable identity-related

⁴⁷⁹ Kirkman (2003), p.2238.

⁴⁸⁰ de Melo-Martín (2014).

⁴⁸¹ A. Shaw, 'The Contingency of the 'Genetic Link' in the Construction of Kinship and Inheritance: An Anthropological Perspective', in *Freedom and Responsibility in Reproductive Choice*, ed. J. Spencer and A. du Bois-Pedain (Oxford: Hart Publishing, 2006).

consequences. However, where it does comprise part of one's self-conception, then in Kirkman's words:

“the story of where I came from and who I am, constructed, developed, and amended on the assumption of consistent social and genetic parentage, [is] based on a false premise.”⁴⁸²

I would suggest that there is a significant difference between choosing to ignore, exclude, or contradict aspects of one's biological existence in the construction of one's self-narrative, on one hand, and building such a narrative around an (unrecognised) false belief, on the other. This is because, where such a belief comprises part of the interpretive framework of and for her self-narrative, the internal integrity of this narrative, its intelligibility with respect to lived, embodied, relational experiences, and its capacity to support coherent navigation of these experience (in her judgements, commitments and actions) are in all placed in jeopardy. The individual in these circumstances is placed in a situation in which, as succinctly captured by Harvald Lillehammer –“disclosure of further facts about themselves” could “subvert their general sense of who they are and what they ought to be.”⁴⁸³

So, not-knowing *could* be impact-free. But my suggestion here is that it potentially leaves an individual's self-conception vulnerable either to incremental dissonance or to the more thoroughgoing disruption. And the routes by which this could happen are neither far-fetched nor unpredictable, as illustrated by the research findings considered above. I would suggest that indications of such subversions may be observed in some individuals' struggles (of more, or less, enduring or critical kinds) to make sense of who they are, either in the face of their everyday experiences of anomalies in familial interactions or traits, or following disclosure. As I have noted above, narrative disruption, where short-lived, need not necessary imply lasting harm to identity. But insofar as – as posited in Chapter 2 – narrative coherence is necessary to support our capacities for self-understanding and leading autonomous, evaluative, engaged lives, we may understand it is not a trivial matter when it is placed in predictable jeopardy.⁴⁸⁴

⁴⁸² Kirkman (2003), p.2239.

⁴⁸³ Lillehammer (2014), p.101.

⁴⁸⁴ My argument here is distinct from the controversial theory of “genealogical bewilderment”, which holds that normal psychological development suffers from not knowing our genetic parents, because this prevents us from knowing our ‘true’ identities. My position does not rest on the claim that information about of donor origins provides direct knowledge of who someone ‘really is’. Rather my suggestion is that ignorance of this information may render precarious the coherence of her identity-narrative – and thus her *understanding* of who she is. See, H.J. Sants (1964), “Genealogical Bewilderment in Children with Substitute Parents” *British Journal of Medical Psychology*, 37(2): 133-42.

This and the previous subsection indicate an important consideration in seeking to infer potentially valuable or detrimental effects of personal bioinformation on identity – that psychological harm and identity detriment are not necessarily synonymous or coextensive. This much has been noted by Freeman, who has herself conducted extensive empirical research with donor conceived individuals. She cautions that:

“An absence of evidence of psychological ‘harm’ should not be equated with an absence of evidence of psychological ‘wrong’. Conversely, a negative outcome cannot necessarily be equated with a ‘wrong’”⁴⁸⁵

I wish to suggest that an analysis of the impacts on identity of receiving or being denied information about donor origins provides one way of understanding the possible disjunction between readily observable imminent harm, on one hand, and identity detriment, on the other. Distress and disorientation upon learning of donor origins (provided these are short-term) could be compatible with a constructive reassessment of one’s self-narrative and the restoration of a more coherent or resilient sense of who one is. Meanwhile, conversely, it is possible to understand how someone’s identity may be harmed if the coherence of their self-narrative is placed in a position of probable and non-trivial jeopardy, even if this is not manifest in contemporary psychological distress. This indicates the need for care in approaching the empirical literature in considering the identity significance of any particular category of personal bioinformation. While the evidence it supplies contributes valuable texture and detail to our understanding of this significance, it may not supply the whole picture.

This brings to a close my analysis of what the empirical literature indicates about the potential impacts of information about donor origins on the identities of donor-conceived individuals, where their identities are conceived in terms of evolving, embodied self-narratives. I would suggest that, although it is not possible to conclude that this category of personal bioinformation is of universal significance, let alone value, to individual’s identities, the findings reported above indicate that for some – perhaps many – donor-conceived individuals it does play an important role in their understanding who they are. This then raises the questions of what the empirical literature indicates about the kinds of factors contribute to how recipients respond to this category of bioinformation and the nature and extent of the role it plays in their self-conceptions. These questions will be the focus of the next, and final, section. Addressing them will be useful both in generalising beyond the conclusions of this chapter to other categories of personal bioinformation (see Chapter 8), and in assessing the significance

⁴⁸⁵ Freeman (2015), p.60. This assertion should be distinguished from that which holds that a moral wrong may be done to someone who is not told of her origins even if there is never any ostensible harm, see, for example, Ravitsky (2010).

of individual and contextual factors in recognising and responding to identity-related interests in accessing this information (see Chapter 9).

SECTION 6: FACTORS POTENTIALLY INFLUENCING IDENTITY IMPACTS

The aim of this final section before my concluding remarks is to return to the empirical literature for indications of the kinds of factors that might influence the nature and extent of the impact that information about donor conception has on a recipient's self-conception.

This aim breaks down into two questions:

- What does the empirical evidence indicate about which features of information about donor origins might contribute to its playing a role in donor-conceived individuals' self-conceptions?
- What factors appear to account for diversity amongst individuals' responses to this information?

Accounting for the possible narrative significance of this information

The first possibility that warrants consideration here is the pertinence of the *genetic* nature of this information to individuals' perceptions of its relevance to their accounts of who they are. I submit that the empirical literature indicates that this may have some role to play, but this is not necessarily straightforward.

Even if the hypothesis at the heart of this project does not depend on a bio-essentialist conception of identity, it is undeniably the case that some of the reasons given by some donor-conceived individuals for investing significance in information about their conception are rooted in genetically essentialist and determinist assumptions. That is, they appear to view their donors' attributes as straightforwardly 'about them', as if appearance, personality traits, and even cultural heritage, are uncomplicatedly genetically inherited and define who they are.⁴⁸⁶

However, the Nuffield Council on Bioethics observes that:

“... when people talk about their ‘genetic origin’, this should not be narrowly understood as concern about their genetic inheritance, or that they understand their identity as genetically determined. It should be understood, rather, much

⁴⁸⁶ A. Ravelingien et al. (2015), "Open-Identity Sperm Donation: How Does Offering Donor-Identifying Information Relate to Donor-Conceived Offspring's Wishes and Needs?" *Journal of Bioethical Inquiry*, 12(3): 503-09.

more broadly in terms of their own story, including their biography, background and family connections.”⁴⁸⁷

This draws an important and subtle distinction by highlighting that the identity-significance of this information may track genetic connections without being reducible to them.⁴⁸⁸ And I would suggest that this is borne out by some, if not all, of the kinds of potential identity roles outlined above. For example, some donor-conceived individuals welcome the insights that knowledge of their donor origins brings to making sense of discrepancies between their own traits and those of their family members.⁴⁸⁹ This does not necessarily mean that they take these traits as wholly defining who they are, but rather they value being able to account for how these traits comprise part of a story, with a particular kind of beginning and in which they stand in particular kinds of relationships to their family members.

I wish to suggest a further critical factor in the perceptions of the importance of information about donor origins is that it is seen as *true*. This is signalled by the virtually unanimous position in two of the studies cited above, that participants would rather know about their donor origins than not. The implication is that this information is valuable to their identities, not because it is necessarily welcome, but because it is true. No doubt, what some individuals might mean by truth is that this information reveals their ‘true’ identity or ‘real’ parentage. But, as noted in the previous paragraph, where this information is valued for explanatory and biographical reasons truth need not signal dubious essentialist assumptions and need not be hedged with quotation marks. What it refers to are truth about the circumstances of someone’s conception, and where it is contrasted with the falsehood of misplaced beliefs about relatedness.

A further influential factor is social context. A number of researchers investigating the impacts of knowledge of donor origins on donor-conceived individuals observe that the perceived significance of this knowledge to their individual’s identities cannot be understood in abstraction from the meaning assigned to genetic and family relationships in societies in which these individuals live.⁴⁹⁰ Indeed, it has been suggested by some researchers that policies that encourage openness about donor origins may themselves further feed to perceptions of this

⁴⁸⁷ Nuffield Council on Bioethics (2013), p.14.

⁴⁸⁸ See also Richards (2014).

⁴⁸⁹ These inferences may still be somewhat contentious given that some of the traits concerns are likely to be multifactorial rather than straightforwardly inherited.

⁴⁹⁰ Freeman (2014); Pennings (2001).

information's importance.⁴⁹¹ I will return to consider the role of social construction in ascriptions of identity significance of personal bioinformation in Chapter 8.

Accounting for diversity in identity impacts

A different question – intersecting somewhat with that just posed – is what kinds of factors appear to account for *differences* amongst donor-conceived individuals' reactions to and ascriptions of identity significance to knowledge of their donor origins. I wish to suggest that the literature provides indications of the relevance of the following six factors:

- i) Age of discovery;
- ii) Manner of discovery;
- iii) Life-stage;
- iv) Family relationships;
- v) Sperm or egg donor; and
- vi) Availability of donor information.

i) Age of discovery

It is widely thought that one of the most significant factors in determining the nature of someone's reaction to learning they are donor-conceived is the age at which this happens.⁴⁹² The majority of published research indicates that the older someone is, the more difficult the experience tends to be.⁴⁹³ The HFEA and Donor Conception Network recommend telling before a child is five.⁴⁹⁴ The explicit reasons given tend to not to be the value of the knowledge *per se*, but rather avoiding distress from late disclosure.⁴⁹⁵

ii) Manner of discovery

How someone finds out is also thought to be a factor.⁴⁹⁶ Guidance for parents published by bodies such as the Donor Conception Network suggests, planned disclosure in early childhood

⁴⁹¹ Freeman (2015).

⁴⁹² Ilioi and Golombok (2015).

⁴⁹³ Nuffield Council on Bioethics (2013). One study that found no straightforward correlation between age and experience of discovery was P.P. Mahlstedt et al. (2010), "The Views of Adult Offspring of Sperm Donation: Essential Feedback for the Development of Ethical Guidelines within the Practice of Assisted Reproductive Technology in the United States" *Fertility and sterility*, 93(7): 2236-46.

⁴⁹⁴ Donor Conception Network website 'Telling Your Child', www.dcnetwork.org/telling-your-child (accessed 9 June 2017); Human Fertilisation and Embryology Authority website, 'Talk to Your Child About Their Origins', www.hfea.gov.uk/116.html#DCN (accessed 9 June 2017).

⁴⁹⁵ Ibid. A recent review of the evidence reported that the link between age of disclosure and children's wellbeing was inconclusive G. Pennings (2017), "Disclosure of Donor Conception, Age of Disclosure and the Well-Being of Donor Offspring" *Human Reproduction*, 32(5): 969-73.

⁴⁹⁶ Ilioi and Golombok (2015); Freeman (2015).

allows parents to introduce the topic incrementally, and children to assimilate it gradually.⁴⁹⁷ In contrast, several of the studies discussed above indicate that abrupt, late disclosure precipitated by family crises, such as divorce or bereavement, are often experienced in particularly negative ways.⁴⁹⁸

iii) Life-stage

Individuals' feelings about their donor conception and what they wish to know about their donors may change throughout their lives. It is noted that adolescence is a critical time for identity exploration.⁴⁹⁹ One study reports that adolescents are likely to be especially curious about what traits they share with their donors, while adults are more likely to want health information.⁵⁰⁰ Life-changes, such as parenthood, have been noted as a potential spur to individuals wanting to know more about their own origins.⁵⁰¹

iv) Family relationships

Family relationships appear to play a key part in how donor-conceived individuals regard and assimilate information about their origins. One aspect of this relates to the structure of their social families. Several studies have found that offspring in families without social fathers are more curious about their donor-conception.⁵⁰² But it is not clear if this is about 'filling a gap' (relational or biographical), or because those with fathers feel inhibited about expressing an interest.⁵⁰³

A key factor in positive reactions to finding out about donor origins, and the impacts of this knowledge upon identity in particular, is thought to be the presence of emotional and interpretive support within the family. One study has suggested that openness in a family may assist adolescents in assimilating knowledge of their origins.⁵⁰⁴ And two studies emphasise the importance of parental relationships in the making sense of the information in identity terms. Kirkman observes that all the participants in her study indicated that their parents were important collaborators in helping them to make sense of what their donor conception means

⁴⁹⁷ Montuschi (2006).

⁴⁹⁸ Jadva et al. (2009); Kirkman (2003); Turner and Coyle (2000).

⁴⁹⁹ Freeman and Golombok (2012).

⁵⁰⁰ V. Jadva et al. (2010), "Experiences of Offspring Searching for and Contacting Their Donor Siblings and Donor" *Reproductive biomedicine online*, 20(4): 523-32.

⁵⁰¹ Freeman et al. (2012).

⁵⁰² Beeson et al. (2011); Jadva et al. (2010); Jadva et al. (2009); J.E. Scheib et al. (2005), "Adolescents with Open-Identity Sperm Donors: Reports from 12–17 Year Olds" *Human Reproduction*, 20(1): 239-52.

⁵⁰³ Beeson et al. (2011).

⁵⁰⁴ Freeman and Golombok (2012).

for their identities.⁵⁰⁵ And another study has found that adolescents' sense of secure attachment with respect to their parents is associated with greater curiosity about their origins, and confidence to explore of whether to integrate it (or not) within, their own "growing sense of identity".⁵⁰⁶

v) Sperm or egg donor

It has been noted that offspring of sperm donation are more likely to invest their donor origins with personal significance than those conceived using donor eggs, and to show greater interest in contacting their donors.⁵⁰⁷ It has been hypothesised that this could be due to asymmetry in prevalent cultural perceptions that fatherhood is conferred at conception, while motherhood is constituted by gestation and care.⁵⁰⁸ However, the relative paucity of research with those conceived from donor eggs means that further insights are not available. I shall return in Chapter 8 to discuss the wider contribution of socially-constructed aspects of identity-significance.

vi) Availability of donor information

In order to keep the discussion of this chapter within a reasonable scope I have avoided widening it to include questions about the potential narrative roles of information *about* donors or donor siblings. But there is one important respect in which individuals' reactions to information about their origins and their attitudes to information about their donor relatives may be closely entangled. Several researchers suggest that access to information about, or contact with, their donors may be an important factor in determining the extent to which some donor-conceived individuals are able to reconcile knowledge of their donor conception with their identities.⁵⁰⁹ Kirkman, for example, has suggested that a lack of donor information may leave individuals "unable to make sense of themselves".⁵¹⁰ However, this is not to imply that individuals only ever value information about their conception as a means to knowing about their donors. The findings cited above are from research conducted for the most part in jurisdictions where access to identifying donor information is not (yet) available to donor-

⁵⁰⁵ Kirkman (2003).

⁵⁰⁶ Slutsky et al. (2016).

⁵⁰⁷ Freeman (2014).

⁵⁰⁸ T. Freeman et al., 'Making Connections: Contact between Sperm Donor Relations', in *Relatedness in Assisted Reproduction: Families, Origins and Identities*, ed. T. Freeman, et al. (Cambridge: Cambridge University Press, 2014); Richards (2014).

⁵⁰⁹ Blyth et al. (2012); Ilioi and Golombok (2015); A. Ravelingien et al. (2013), "Donor-Conceived Children Looking for Their Sperm Donor: What Do They Want to Know?" *Facts, Views & Vision in ObGyn*, 5(4): 257; Turner and Coyle (2000).

⁵¹⁰ Turner and Coyle (2000), p.2047.

conceived individuals, thus signalling that where this information is deemed significant, it must be for its own sake.

Highlighting the six factors above signals that the potential identity impacts of information about donor origins is not determined by the nature of this information alone. Whether, and to what extent, it has beneficial, detrimental or no effects on an individual's self-conception is likely to depend not only on her own circumstances and characteristics, but also on the manner and context in which she receives and interprets the information. This is a crucial finding for this project because it signals that meeting identity-related interests will require more than the identification of categories of identity-significant bioinformation. It will mean attending also to the specific circumstances of (possible) disclosure. In Chapter 8 I shall return to consider (in combination with indications drawn from the remaining two case studies) the range of factors that might shape the identity significance and value of personal bioinformation in any particular case.

SECTION 7: CHAPTER CONCLUSION

On the basis of evidence from the empirical literature, it is not possible to conclude that knowledge of donor origins makes universally welcome or valuable contributions to the identities of all donor-conceived individuals. However, this is not necessary for my research aims. What I need is to be able to demonstrate is that the evidence of people's experiences is at least consistent with my contention that that this information can play a significant role in some individuals' conceptions of who they are and that it is plausible to interpret this in terms of the contribution the information makes to the construction of a coherent and sustainable self-narrative. It is also necessary that this evidence is not wholly trivial or wildly anomalous. I would suggest that these aims are fulfilled by the evidence reviewed in this chapter. Moreover, the interpretation of the evidence I have offered here indicates that in order for information about donor origins to be important to someone's identity it is neither necessary to hold that knowledge of genetic origins is intrinsically important to *everyone's* identity, nor that 'being donor conceived' needs to be a defining aspect of that individual's self-characterisation. Rather, as I have sought to demonstrate, this information may be important to the extent that it plays a contributory and instrumental role in her self-understanding. Indeed, although there are indications that this information might modify the 'contents' of a recipient's account of who she is – for example, her self-descriptors or relational roles – perhaps even more important is the role the information can play in filling-out and rendering more intelligible aspects of her existing account.

The example of information about donor origins explored in this chapter brings to light three key lessons that are potentially transferrable to considering the significance to identity of other categories of personal bioinformation. First, that it is important to attend not only to the immediate impacts of disclosure of information about donor origins, but also its longer-term consequences. A disrupted self-narrative may only represent harm to identity where the individual lacks the personal, relational or informational means to reconstruct a (more) coherent account of who she is. Secondly, it is not so much the *absence* of knowledge of donor origins that may jeopardise the resilience and coherence of someone's self-narrative, but rather the construction of this narrative around a false belief about an aspect of one's embodied existence. And, thirdly, it is not possible to talk of the inevitable or uniform identity-impacts of knowledge of donor origins, only its *potential* impacts, which may be shaped by the particular context and manner of its disclosure and the circumstances of the individual concerned. All three of these lessons will be critical when I come to consider the considerations that shape or limit the identity value of particular instances of personal bioinformation in Chapter 8.

CHAPTER 6: ILLUSTRATIVE EXAMPLE II - GENETIC SUSCEPTIBILITY TESTING

SECTION 1: TOPIC AND AIMS OF THIS CHAPTER

This chapter provides the second of my three illustrative examples. Its purpose, as with that discussed in the previous chapter, is to explore people's attitudes and reactions to a particular category of personal bioinformation – as reported in the empirical social science literature – in order to lend plausibility to, to illustrate, and to refine my theoretical argument about the role that this information might play in its subjects' identity narratives.

The category of personal bioinformation to be examined here is findings from genetic susceptibility testing for serious complex, or multifactorial, disorders with a known genetic component. These are disorders that are not caused by a single gene, but by interactions between multiple genetic and environmental factors.⁵¹¹ Testing involves the analysis of an individual's blood or tissue samples to detect “the presence or absence of, or alteration in, a particular gene, chromosome or gene product”.⁵¹² Based on this (and, often, other data such as family history) an individual's susceptibility to the disorder is calculated, typically taking the form of a probabilistic percentage lifetime risk.⁵¹³ Accordingly, susceptibility testing can be understood as:

“...a type of genetic testing that provides less predictive value than testing for typically Mendelian conditions, but that may nonetheless be of interest and use to at-risk individuals.”⁵¹⁴

I shall take it that such test results fall under the definition of ‘personal bioinformation’ both because of their source – they are derived (in part) from analysis of an individual's tissues – and their ‘interpretive pedigree’ – they are understood as telling someone about her possible future health (albeit in probabilistic terms). I take it that such results are no less personal for also potentially revealing genetic relatives' susceptibility, or for being calculated not solely

⁵¹¹ "Multifactorial Disease," in *Encyclopedia of Public Health*, ed. W. Kirch (New York: Springer, 2008).

⁵¹² J. Pinto-Basto et al. (2010), "Scope of Definitions of Genetic Testing: Evidence from a Eurogentest Survey" *Journal of Community Genetics*, 1(1): 29-35, p.33.

⁵¹³ Ibid.

⁵¹⁴ J.S. Roberts and W.R. Uhlmann (2013), "Genetic Susceptibility Testing for Neurodegenerative Diseases: Ethical and Practice Issues" *Progress in Neurobiology*, 110: 89-101, p.89-90. A Mendelian condition or trait is one that may be caused by a mutation on a single gene.

from an individual's own genotype, but also on the basis of risk profiles developed from epidemiological data.

The chief example to be discussed in this chapter are attitudes to results for genetic tests for:

Susceptibility to late-onset Alzheimer's disease based on genotyping for variants of the Apolipoprotein E (*APOE*) gene (henceforth, '*APOE* testing')⁵¹⁵

The ϵ 4 allele (variant) of the *APOE* gene is thought to be a "robust risk factor" for increased risk of late-onset Alzheimer's disease.⁵¹⁶ However, late-onset Alzheimer's is a multifactorial disease, and the relative contributions of genetics and other factors are only partially understood.⁵¹⁷ So, although testing reliably detects variants of the *APOE* gene,⁵¹⁸ a positive test result for one or two copies of the ϵ 4 allele indicates an increased relative risk, rather than that the individual will inevitably develop the disease.⁵¹⁹ One copy of the ϵ 4 allele is thought to increase risk to about three times that of the general population, while two copies increases the risk to somewhere between eight and 30 times greater than the population risk.⁵²⁰ A negative test does not signal no risk, as Alzheimer's can occur in the absence of the ϵ 4 allele.⁵²¹ Late onset Alzheimer's disease is a condition for which no effective preventative measures or treatments are yet available. These factors mean, at present, *APOE* testing is held to lack clinical utility.⁵²²

For the purposes of comparison, I will also consider attitudes to results from tests for:

Susceptibility to breast and ovarian cancer based on genotyping for mutations to the *BRCA 1* and *BRCA 2* genes (henceforth, '*BRCA* testing')

⁵¹⁵ In this chapter, unless specified otherwise, 'Alzheimer's disease' and 'Alzheimer's' will be used to refer to the late-onset condition.

⁵¹⁶ E.R. Atkins and P.K. Panegyres (2011), "The Clinical Utility of Gene Testing for Alzheimer's Disease" *Neurology International*, 3(1): 1-3.

⁵¹⁷ Ibid.; J.S. Roberts et al. (2011), "Using Alzheimer's Disease as a Model for Genetic Risk Disclosure: Implications for Personal Genomics" *Clinical Genetics*, 80(5): 407-14.

⁵¹⁸ Roberts et al. (2011).

⁵¹⁹ Atkins and Panegyres (2011).

⁵²⁰ L.A. Farrer et al. (1997), "Effects of Age, Sex, and Ethnicity on the Association between Apolipoprotein E Genotype and Alzheimer Disease: A Meta-Analysis" *Jama*, 278(16): 1349-56. Within these risk ranges there is variation in the association between the ϵ 4 allele and late-onset Alzheimer's in different ethnic groups.

⁵²¹ J.S. Roberts (2012), "Genetic Testing for Risk of Alzheimer's Disease: Benefit or Burden?" *Neurodegen. Dis. Manage*, 2(2): 141-44.

⁵²² Atkins and Panegyres (2011).

The mutations on the *BRCA1* and *BRCA2* genes are responsible for a greatly elevated lifetime risk of developing hereditary forms of breast and ovarian cancer in female carriers.⁵²³ In men they increase the risks of breast and prostate cancer.⁵²⁴ A positive result (confirming carrier status) indicates increased susceptibility to these cancers, but not their inevitability. For example, a previously unaffected woman who tests positive for the *BRCA1* mutation has a 60 to 90 percent lifetime risk of developing breast cancer and a 40 to 60 percent lifetime risk of developing ovarian cancer.⁵²⁵ A negative test result does not signal no risk, only 5-10 percent of breast cancers cases are caused by *BRCA* mutations.⁵²⁶ Possible preventative strategies following a high risk estimate include prophylactic mastectomy or hysterectomy, or access to screening regimes.⁵²⁷ For these reasons *BRCA* testing is judged to have clinical utility.⁵²⁸

Reasons for choosing these examples

There are two key reasons I have chosen *APOE* testing for susceptibility to late-onset Alzheimer's disease as the chief example for this chapter. First a large, longitudinal study – the 'Risk Evaluation and Education in Alzheimer's Disease' (REVEAL) Study – specifically set out to examine the personal impacts of receiving the results of this category of test, and this provides a valuable resource on which to draw here (as I shall describe further below).⁵²⁹ Secondly, it is precisely the lack of clinical utility of this test that allows me to investigate the degree to which the identity-value of personal bioinformation is entangled with clinical utility and, where the latter is absent, whether there might nevertheless be justification for disclosure of information about disease susceptibility on grounds of its potential identity value. However, in order to unpick these questions, it will be helpful to contrast the findings relating to *APOE* testing with those pertaining to a test which *is* held to have clinical utility. This is why I will also look at reactions to *BRCA* test results. My less in-depth treatment of the *BRCA* literature will reflect the fact that it serves chiefly as a comparator. It is through my analysis of the less well-traversed *APOE*-related literature that I hope to contribute useful insights into

⁵²³ The Royal Marsden NHS Foundation Trust, 'Patient Information: A Beginner's Guide to BRCA 1 and BRCA 2' (2013).

⁵²⁴ Ibid.

⁵²⁵ Ibid. The lifetime risk of breast cancer for women in the general population is 12.5 percent, and for ovarian cancer it is 2 percent.

⁵²⁶ Ibid.

⁵²⁷ National Institute for Health and Care Excellence, 'NICE Guidelines: Familial Breast Cancer: Classification and Care of People at Risk of Familial Breast Cancer and Management of Breast Cancer and Related Risks in People with a Family History of Breast Cancer (CG164)' (2013).

⁵²⁸ Ibid.

⁵²⁹ J.S. Roberts et al. (2005), "Genetic Risk Assessment for Adult Children of People with Alzheimer's Disease: The Risk Evaluation and Education for Alzheimer's Disease (REVEAL) Study" *Journal of Geriatric Psychiatry and Neurology*, 18(4): 250-55.

understanding the nature and scope of the potential identity impacts of genetic susceptibility testing.

Research questions

As with the previous chapter, this chapter addresses the second of the four headline research questions set out in Chapter 1: *what grounds are there for holding that the conception of the relationship between personal bioinformation and identity developed in Chapter 3 is robust and plausible in light of people's actual experiences?* In order to answer this, my specific research questions for this chapter will be:

- i. What do findings reported in the empirical literature indicate about recipient's attitudes and reactions to receiving results from genetic susceptibility testing?** (Sections 4 and 5)
- ii. What might be inferred from these findings about the roles that genetic susceptibility test results could play in individuals' self-narratives?** (Section 6)
- iii. What kinds of factors appear to influence whether it plays these roles?** (Section 7)

Again, answering these questions will both provide insights into the potential identity-significance of this specific category of personal bioinformation, while also informing my wider analysis of what factors shape the identity roles, significance and value of personal bioinformation more broadly (see Chapter 8). This in turn will contribute to asking my third and fourth headline research questions outlined in Chapter 1: *what are the nature and scope of our identity-related interests in accessing personal bioinformation?* and *what ethical responsibilities for disclosure accrue to those who hold personal bioinformation about us?* I will address these further questions in Chapter 9.

Before looking to the empirical evidence it will be instructive first to understand the existing circumstances in which the results of *APOE* and *BRCA* testing can be accessed (Section 2). I will then outline my approach to the empirical literature (Section 3).

SECTION 2: CURRENT ACCESSIBILITY OF GENETIC SUSCEPTIBILITY INFORMATION

In this section I will briefly outline the current regulatory and practical circumstances regarding individuals' access to findings from susceptibility testing. This will help to establish to context into which identity-based interests in (not) knowing might play, were they to be recognised.

Testing in healthcare

Whether a validated genetic test for susceptibility to a particular disorder is offered in clinical practice will be subject to conditions including costs and licencing.⁵³⁰ It is also likely to depend on assessment of the clinical utility of the test and the ratio of benefit to harm. For example, the UK National Screening Committee's criteria for appraising the appropriateness of offering a screening programme requires that the benefits of screening outweigh the risks which means, *inter alia*, that "there should be an effective treatment or intervention for patients identified".⁵³¹ In the UK, in accordance with National Institute for Health and Care Excellence (NICE) guidelines, *BRCA* testing is only offered to the group for whom it is judged to have greatest clinical utility – adults with both a family history of breast or ovarian cancer and a genetic relative who has received a positive *BRCA* test.⁵³² In contrast, the current advice of clinicians and Alzheimer's advocacy groups is to recommend against provision of *APOE* testing.⁵³³ Because this test lacks clinical utility, it has been assumed that the potential distress associated with testing outweighs any benefits.⁵³⁴ The identity-related impacts of testing are not given as grounds for decisions about whether to provide genetic testing, but are likely to play a part in genetic counselling when testing is offered.⁵³⁵

Access by other routes

APOE testing for late-onset Alzheimer's disease is commercially available in the UK through some DTC services, such as '23andMe'.⁵³⁶ This service formerly also offered *BRCA* testing.⁵³⁷ In 2013 the US Food and Drug Administration (FDA) took action against '23andMe',⁵³⁸

⁵³⁰ M.K. Cho et al. (2003), "Effects of Patents and Licenses on the Provision of Clinical Genetic Testing Services" *The Journal of Molecular Diagnostics*, 5(1): 3-8.

⁵³¹ Public Health England, 'UK National Screening Committee Guidance: Criteria for Appraising the Viability, Effectiveness and Appropriateness of a Screening Programme' (2015).

⁵³² National Institute for Health and Care Excellence, 'NICE Guidelines: Familial Breast Cancer: Classification and Care of People at Risk of Familial Breast Cancer and Management of Breast Cancer and Related Risks in People with a Family History of Breast Cancer (CG164)' (2013).

⁵³³ Alzheimer's Research UK, 'Genes and Dementia' (2014); Alzheimer's Society website, 'Genetic Testing', www.alzheimers.org.uk/info/20091/what_we_think/153/genetic_testing (accessed 9 June 2017).

⁵³⁴ Roberts (2012). This is an assumption that the REVEAL study set out to test.

⁵³⁵ H. Käriäinen et al., 'Eurogentest: Recommendations for Genetic Counselling Related to Genetic Testing' (Eurogentest, 2009).

⁵³⁶ 23andme UK website, 'Health Reports', www.23andme.com/en-gb/health/reports/ (accessed 9 June 2017).

⁵³⁷ M.L. McGowan and J.R. Fishman (2008), "Using Lessons Learned from BRCA Testing and Marketing: What Lies Ahead for Whole Genome Scanning Services" *The American Journal of Bioethics*, 8(6): 18-20.

⁵³⁸ 23andMe was only one of the companies against whom action was taken, but it is a leading provider in the DTC genomics market.

requiring them to discontinue marketing personal genome testing for serious disease risks, including those for cancer and Alzheimer's disease.⁵³⁹ The FDA judged that in these areas there was a risk of "unreasonable harm" from "incorrect test results or unsupported clinical interpretations".⁵⁴⁰ 23andMe ceased marketing predictive *medical* tests in the US, but has recently regained FDA approval to provide testing for late-onset Alzheimer's disease and nine other conditions, not including *BRCA* testing.⁵⁴¹

It is conceivable that, if individually-relevant susceptibility information is generated by a research study, these findings could be reported to participants. Whether this occurs is likely to depend on the clinical utility of the results, and the protocol and the consent conditions of the particular study.⁵⁴²

A further source of indications of one's own susceptibility to disorders with a genetic component may be the risk status of close blood relatives. Clinicians and genetic counsellors are likely to advise those who test positive for some conditions of the value of discussing the result with their close relatives, though they cannot compel them to do so.⁵⁴³ European data protection law recognises that for some purposes genetic data should be seen as the personal data of more than one person.⁵⁴⁴ And the idea that genetic information does not belong to just one person, but is shared or part of a "joint account", is commonplace in the academic literature.⁵⁴⁵ Nevertheless, at present, individuals are not entitled in law to know a relative's genetic risk status where the relative does not wish to divulge it. The English High Court found that doctors who refused to go against the claimant's father's wishes by informing the claimant of her father's Huntington's disease diagnosis (and thus her own possible risk) had been neither negligent, nor unlawfully breached the her right to respect for private and family life

⁵³⁹ U.S. Food and Drug Administration 'Inspections, Compliance, Enforcement, and Criminal Investigations, Warning Letter to 23&Me, Document Number: Gen1300666' (22 November 2013), www.fda.gov/iceci/enforcementactions/warningletters/2013/ucm376296.htm (accessed 9 June 2017).

⁵⁴⁰ *Ibid.*

⁵⁴¹ US Food and Drug Administration Press Release 'FDA Allows Marketing of First Direct-to-Consumer Tests That Provide Genetic Risk Information for Certain Conditions' (6 April 2017) www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm551185.htm (accessed 17 June 2017).

⁵⁴² V. Ravitsky and B.S. Wilfond (2006), "Disclosing Individual Genetic Results to Research Participants" *American Journal of Bioethics*, 6(6): 8-17. See Chapter 1 above.

⁵⁴³ K. Forrest et al. (2003), "To Tell or Not to Tell: Barriers and Facilitators in Family Communication About Genetic Risk" *Clinical Genetics*, 64(4): 317-26.

⁵⁴⁴ European Commission, 'Article 29 Working Party on the Protection of Individuals with Regard to the Processing of Personal Data: Working Document on Genetic Data (12178/03/En)' (17 March 2004); Taylor (2012)

⁵⁴⁵ M. Parker and A.M. Lucassen (2004), "Genetic Information: A Joint Account?" *BMJ: British Medical Journal*, 329(7458): 165; Widdows (2013)

under Article 8 of the Human Rights Act 1998.⁵⁴⁶ An appeal against this judgment has been allowed.⁵⁴⁷

It is my intention that this thesis (as a whole – not solely the discussion of the present illustrative example) will provide grounds for asserting that individuals' identity-related interests in accessing personal bioinformation ought to be relevant considerations in the kinds of policies and practices outlined above. I will return in Chapter 9 to consider what my conclusions imply for access to genetic information about disease susceptibility.

SECTION 3: SOURCES AND ANALYTICAL APPROACH

I will outline here the literature upon which I draw in this chapter and my approach to analysing it.

Empirical literature

My chief source of evidence regarding attitudes to *APOE* testing are publications reporting the findings from the US-based REVEAL Study.⁵⁴⁸ This ongoing longitudinal study is a series of randomised clinical trials involving asymptomatic adults with first degree relatives with late-onset Alzheimer's disease.⁵⁴⁹ The aim of REVEAL has been, *inter alia*, to investigate the psychological and behavioural effects of receiving genetically-based risk estimates of developing late-onset Alzheimer's, calculated using their *APOE* carrier status and other data.⁵⁵⁰ The findings discussed here are from the first two phases, conducted in the early 2000s, involving a total of 442 participants.⁵⁵¹ Participants were provided not only with their risk estimate, but also with counselling and educational materials regarding the predictive capacities and limitations of these risk estimates and the absence of effective interventions for

⁵⁴⁶ *ABC v St George's Healthcare NHS Foundation Trust* [2015] EWHC 1394 (QB).

⁵⁴⁷ *ABC v St George's Healthcare NHS Foundation Trust* [2017] EWCA Civ 336. The appeal went to trial on 16 May 2017, no judgment had been reached at the time of submission of this thesis.

⁵⁴⁸ "The Risk Evaluation and Education for Alzheimer's Disease (REVEAL) Study Website" <http://hbhegenetics.sph.umich.edu/research-project/risk-evaluation-and-education-alzheimers-disease-study>.

⁵⁴⁹ Roberts (2012).

⁵⁵⁰ Roberts et al. (2011); Roberts and Uhlmann (2013).

⁵⁵¹ M. Lock et al. (2007), "Susceptibility Genes and the Question of Embodied Identity" *Medical Anthropology Quarterly*, 21(3): 256-76.

this disease.⁵⁵² Participants' attitudes to their test results were gathered both before and after testing through both qualitative and quantitative methods.⁵⁵³

The REVEAL study provides valuable material for the present project for a two reasons. First, it is a large, widely-cited study which had amongst its aims the exploration participants' personal and emotional reactions to test results beyond their clinical application.⁵⁵⁴ Secondly, by comparing participants' attitudes to risk estimates before and after receiving them (and accompanying counselling and education) it offers insights into how the context of disclosure might affect these attitudes.⁵⁵⁵ The REVEAL findings do, however, also have some limitations for my purposes. The study was not designed specifically to investigate identity impacts – although some REVEAL-based publications do analyse the findings in this light.⁵⁵⁶ There are also issues of representativeness. In particular, it does not capture the views of individuals who declined to be tested, participants were not socioeconomically or ethnically diverse,⁵⁵⁷ and (of course) it can only tell us about one kind of test.

I attempt to address this last limitation to a modest degree by also looking at studies reporting participants' attitudes to receiving results from *BRCA* testing for breast and ovarian cancer in clinical settings.⁵⁵⁸ Because this further example functions chiefly as a comparator, I only draw on a small number of *BRCA*-focused studies and have selected those which speak particularly to the identity-related impacts of this kind of susceptibility testing. Two of these are qualitative and small (involving around 50 participants),⁵⁵⁹ two are larger (with several hundred participants).⁵⁶⁰ I also draw upon one systematic review,⁵⁶¹ and findings from the development

⁵⁵² K.D. Christensen et al. (2011), "Changes to Perceptions of the Pros and Cons of Genetic Susceptibility Testing after *APOE* Genotyping for Alzheimer Disease Risk" *Genetics in Medicine*, 13(5): 409-14.

⁵⁵³ Ibid.; A.C. Hurley et al. (2005), "Genetic Susceptibility for Alzheimer's Disease: Why Did Adult Offspring Seek Testing?" *American Journal of Alzheimer's Disease and Other Dementias*, 20(6): 374-81; M. Lock et al. (2006), "When It Runs in the Family: Putting Susceptibility Genes in Perspective" *Public Understanding of Science*, 15(3): 277-300

⁵⁵⁴ Roberts (2012).

⁵⁵⁵ Roberts et al. (2011).

⁵⁵⁶ Lock et al. (2007). See Section 6 below.

⁵⁵⁷ For further discussion of the methodology see Roberts et al. (2011).

⁵⁵⁸ Participants in these studies were predominantly women.

⁵⁵⁹ L. d'Agincourt-Canning (2006), "Genetic Testing for Hereditary Breast and Ovarian Cancer: Responsibility and Choice" *Qualitative Health Research*, 16(1): 97-118; J. Lim et al. (2004), "Short- and Long-Term Impact of Receiving Genetic Mutation Results in Women at Increased Risk for Hereditary Breast Cancer" *Journal of Genetic Counseling*, 13(2): 115-33.

⁵⁶⁰ M. den Heijer et al. (2011), "The Contribution of Self-Esteem and Self-Concept in Psychological Distress in Women at Risk of Hereditary Breast Cancer" *Psycho-Oncology*, 20(11): 1170-75; H.T. Lynch et al. (2006), "Patient Responses to the Disclosure of *BRCA* Mutation Tests in Hereditary Breast-Ovarian Cancer Families" *Cancer Genetics and Cytogenetics*, 165(2): 91-97.

⁵⁶¹ P.N. Butow et al. (2003), "Psychological Outcomes and Risk Perception after Genetic Testing and Counselling in Breast Cancer: A Systematic Review" *Medical Journal of Australia*, 178(2): 77-81.

of the ‘*BRCA* Self-Concept Scale’ – an evidence-based tool designed to be used in counselling and determining care pathways for those undergoing *BRCA1/2* testing – which was subject to validation testing with 241 women.⁵⁶²

Analytical approach

I will start by outlining findings relating to attitudes and reactions to *APOE* and *BRCA* test results in Sections 4 and 5 respectively. For the most part these do not make explicit reference to identity, even less so to identity narratives. So, as with the previous chapter, my prioritisation and inclusion of the findings I take to be relevant to the present inquiry will involve inferences on my part, informed by the theoretical interest perspective of this project. In Section 6, I will then offer my own interpretation of the evidence in terms of how these test results might be seen as impacting on recipients’ identity-narratives. And in Section 7 I will take stock of factors which appear to influence whether and how results from genetic susceptibility testing affect someone’s sense of who she is. In Sections 6 and 7 I will reflect upon the references to identity in the empirical literature that I am considering, as well as some prominent arguments in the theoretical literature about the identity roles that genetic susceptibility testing might play. In doing so I shall make it clear what a narrative analysis might add to our understanding of the potential identity-significance of this category of personal bioinformation.

SECTION 4: ATTITUDES TO *APOE*-BASED TEST RESULTS

In this section I will provide an overview of the REVEAL findings that are most relevant to my research aims. To expose evolution in participants’ views I will divide the summary of relevant findings here into:

- Participants’ motivations for testing and expectations of test results prior to undergoing testing or receiving genetic counselling and educational materials; and
- Participants’ attitudes and reactions to their test results (after also receiving genetic counselling and educational materials).

⁵⁶² M.J. Espplen et al. (2009), "The *BRCA* Self-Concept Scale: A New Instrument to Measure Self-Concept in *BRCA1/2* Mutation Carriers" *Psycho-Oncology*, 18(11): 1216-29 This tool is based on a ‘self-schema model’ based in social psychology) which differs in a number of ways from the theory of narrative identity underlying my own project.

Motivations and expectations

Most participants in REVEAL cited the desire to find out their own genotype as a major motivation for taking part and most felt broadly optimistic about the value of this information.⁵⁶³ Some participants expressed a naked desire “to know”.⁵⁶⁴ Many of the most highly endorsed reasons⁵⁶⁵ for being tested were rooted in beliefs that the personal risk estimates would be practically useful.⁵⁶⁶ Some of this perceived utility was health-related, for example, it would provide a spur to finding out about preventive measures, or undertaking health-improvement behaviours.⁵⁶⁷ And some wanted to be prepared should effective prevention or treatment become available.⁵⁶⁸ Other practical motivations went beyond health-protection. Some wanted to know if they should arrange their personal and financial affairs or purchase health insurance.⁵⁶⁹ Others gave less specific, but still future-focused reasons. For example, one participant said if she knew she was at high risk of Alzheimer’s disease, “[t]here are some things that I haven’t done that I might want to start doing”.⁵⁷⁰

This last comment points towards another category of reported motivations, which had little to do with specific practical decisions, and more to do with susceptibility estimates offering the basis for reflection or reprioritisation. So, for example, one participant reported that the information could be useful for “see[ing] where I am at”, and another wondered whether “maybe it will make me look at my life in a different way”.⁵⁷¹

All of the REVEAL participants had a family history of Alzheimer’s. The pertinence of this may be seen reflected in the widely expressed hope that genetic risk estimates would supply a means of confronting and taking control of a suspected, though unquantified, heritable risk of this disease and assessing their priorities accordingly.⁵⁷² Several interviewees reported that (because of their family history) they were “scared to death” that they were “already doomed” to a future with Alzheimer’s, or believed they were already exhibiting signs of impaired

⁵⁶³ Lock et al. (2006), p.290. 91% of participants gave this as a reason.

⁵⁶⁴ Hurley et al. (2005), p.378.

⁵⁶⁵ Participants selected these reasons from a closed list of options.

⁵⁶⁶ Hurley et al. (2005).

⁵⁶⁷ Ibid.

⁵⁶⁸ S.J. Roberts et al. (2003), "Reasons for Seeking Genetic Susceptibility Testing among First-Degree Relatives of People with Alzheimer Disease" *Alzheimer Disease & Associated Disorders*, 17(2): 86-93.

⁵⁶⁹ Hurley et al. (2005).

⁵⁷⁰ Ibid., p378.

⁵⁷¹ Ibid., p.378.

⁵⁷² M. Lock, 'Biosociality and Susceptibility Genes: A Cautionary Tale', in *Biosocialities, Genetics and the Social Sciences: Making Biologies and Identities*, ed. S. Gibbon and C. Novas (London: Routledge, 2008), p.63.

memory.⁵⁷³ And many viewed genetic testing as a possible means of confirming or dispelling such fears.⁵⁷⁴ One of the more commonly cited motivations was “put[ting] my mind at ease”.⁵⁷⁵ And, for some, participating in the REVEAL study itself offered a way of coping with an uncertain risk status, providing a sense of purpose, where there had hitherto been doubt and impotence.⁵⁷⁶

A second category of motivations also linked to the shared nature of genetic susceptibility were those rooted in feelings of responsibility for, or connections with, others. The motivation that provided the best predictor for participants that actually went on to get tested was the need to prepare their family members for the possibility of Alzheimer’s, for example, in terms of future care requirements.⁵⁷⁷ And one participant reported having undergone testing as an expression of solidarity with her sister.⁵⁷⁸ Participants knew that the genetic data gathered by REVEAL would be used in epidemiological research.⁵⁷⁹ The wish to contribute to research emerges strongly in the literature, with some interviewees cited the desire to reciprocate indirectly for the care that their relatives had received, or an expression of solidarity with other families affected by Alzheimer’s.⁵⁸⁰

I will now turn to look at participants’ reactions to their risk estimates based on their *APOE* carrier status and how these related to their prior expectations.⁵⁸¹ I shall return to consider possible reasons for any differences between pre- and post-testing attitudes in Section 7 below.

Reactions to results

The post-testing/education findings reveal a “slight discordance” between how participants expected they would use genetic risk information and how they actually ended up doing so.⁵⁸² This mismatch manifests in three ways that are of particular interest here.

First, responses to the post-testing questionnaire tended to be less enthusiastic about the *practical* utility of the results for informing preventative action or preparing for the future.⁵⁸³ The second change was that in some cases – and contrary to participants’ prior expectations – the results

⁵⁷³ Hurley et al. (2005), p379.

⁵⁷⁴ Ibid., p379.

⁵⁷⁵ Christensen et al. (2011), p.412.

⁵⁷⁶ Hurley et al. (2005); Roberts (2012), p.142.

⁵⁷⁷ Roberts et al. (2003).

⁵⁷⁸ Lock (2008), p.75.

⁵⁷⁹ Roberts et al. (2003).

⁵⁸⁰ Christensen et al. (2011); Hurley et al. (2005).

⁵⁸¹ The findings reflect patterns of change, rather than tracking changes in individual attitudes.

⁵⁸² Christensen et al. (2011), p. 413.

⁵⁸³ Ibid.

failed to supplant their existing risk perceptions.⁵⁸⁴ Several discounted the evidence of their low risk estimates – for example, in the words of one interviewee, “[s]o technically I should feel better. But I don’t believe it.”⁵⁸⁵ While some, who had received high risk estimates, reacted with equanimity, viewing the results as ‘nothing new’ to worry about.⁵⁸⁶

The third striking finding pertains to individual’s medium-term retention of details of their test results. A year after receiving their results, about half the participants remembered the general gist of their risk estimate, but around three quarters could not recall it accurately, and about a quarter misremembered or had wholly forgotten.⁵⁸⁷ Even where participants could recall which versions of the *APOE* gene they carried, many could not explain its significance.⁵⁸⁸ As Margaret Lock describes it:

“Risk estimates provided in the REVEAL study rarely displace ‘lay knowledge’ that participants bring with them... Rather this ‘scientific’ information is either nested into pre-existing knowledge, simply forgotten, or even actively rejected.”⁵⁸⁹

The post-test findings do not, however, indicate a total eradication of the personal significance of the test results, even if their immediate practical utility was diminished.⁵⁹⁰ One of the headline conclusions from REVEAL is that the traditional assumption – that genetically-based risk estimates provided in the absence of effective clinical options leads chiefly to distress – may be misplaced. The REVEAL study found that *APOE*-based risk estimates generally brought greater benefits than harm to those tested.⁵⁹¹ Many recipients, particularly those who had thought Alzheimer’s disease was their inevitable fate, reported relief and a reduction in distress.⁵⁹² And high risk estimates sometimes prompted behaviour changes (which, though innocuous, would be ineffectual against this disease).⁵⁹³ Although there was some evidence of misplaced reassurance amongst those told they did not carry the $\epsilon 4$ allele (misplaced, given that this is only one risk factor for late-onset Alzheimer’s), there was no evidence of fatalism amongst recipients high risk estimates.⁵⁹⁴ However, it is worth noting that a separate, more recent, study has observed that participants who were informed that they had a genotype

⁵⁸⁴ Lock et al. (2006); Lock et al. (2007).

⁵⁸⁵ Lock et al. (2006), p.292.

⁵⁸⁶ Ibid.

⁵⁸⁷ Lock et al. (2007).

⁵⁸⁸ S.L. Eckert et al. (2006), "Recall of Disclosed Apolipoprotein E Genotype and Lifetime Risk Estimate for Alzheimer's Disease: The REVEAL Study" *Genetics in Medicine*, 8(12): 746-51.

⁵⁸⁹ Lock (2008), p.75.

⁵⁹⁰ Christensen et al. (2011), p.412.

⁵⁹¹ Roberts (2012).

⁵⁹² Lock et al. (2007).

⁵⁹³ Roberts (2012).

⁵⁹⁴ Roberts and Uhlmann (2013).

associated with increased risk of late-onset Alzheimer's disease not only underestimated their performance in memory tests, but actually performed worse.⁵⁹⁵ This was despite those participants having been informed of the predictive limitations of *APOE* testing. This provides a warning about the risk of 'anticipatory dementia' as an unintended consequence of genetic testing for this condition.⁵⁹⁶

The significance of the results in terms of family relationships also persisted for many. For example, several participants reported being pleased that they and their children now knew "where they stood".⁵⁹⁷ One respondent felt that the results would have held greater significance for her had she been a parent.⁵⁹⁸ And, while one participant reported particular distress at learning of her sister's higher risk status given painful family memories of Alzheimer's,⁵⁹⁹ others found it helpful to gain what they felt was an explanation of their parents' illness.⁶⁰⁰ Some participants reported that discussing their results with family members exacerbated their distress at higher risk estimates, which, the researchers hypothesise, might be attributable to anxiety about what this implied for their relationships and familial responsibilities.⁶⁰¹

Echoing the findings regarding donor conception discussed in the previous chapter, some simply regarded it as preferable to have the information, as illustrated by the following statement from one REVEAL participant:

"Knowledge is power...I don't think you can necessarily change your destiny, but certainly to go through life with your eyes only half open doesn't help you at all..."⁶⁰²

One of the key conclusions that the lead investigators have drawn from the REVEAL study is that the information provided by *APOE* testing for late-onset Alzheimer's disease can have "personal value" for those tested.⁶⁰³ I would suggest the kinds of motivations for, and reactions to, testing cited above indicate that the potential to use this information in construction of a self-narrative could be seen as constituting one aspect of this personal value. I will return to

⁵⁹⁵ T.T. Lineweaver et al. (2014), "Effect of Knowledge of *APOE* Genotype on Subjective and Objective Memory Performance in Healthy Older Adults" *American Journal of Psychiatry*, 171(2): 201-08.

⁵⁹⁶ Roberts et al. (2003).

⁵⁹⁷ Lock (2005), p.59.

⁵⁹⁸ Lock et al. (2006), p.290.

⁵⁹⁹ Lock (2008).

⁶⁰⁰ Lock (2005); Lock et al. (2006).

⁶⁰¹ S. Ashida et al. (2010), "The Role of Disease Perceptions and Results Sharing in Psychological Adaptation after Genetic Susceptibility Testing: The REVEAL Study" *European Journal of Human Genetics*, 18(12): 1296-301

⁶⁰² Lock et al. (2006), p.290.

⁶⁰³ Roberts (2012), p.142.

discuss this in Section 6. First I will consider what the literature relating to attitudes to *BRCA* test results might add to this picture.

SECTION 5: ATTITUDES TO *BRCA* TEST RESULTS

In this section I will consider the findings from a handful of studies looking, this time, at individuals' expectations of and reactions to receiving the results from susceptibility estimates for breast and ovarian cancer based on detection of the *BRCA* mutations. As noted above, my intention here is not to provide a detailed or thorough review of the *BRCA*-related literature, but rather to highlight similarities and differences between attitudes to *BRCA* test results compared with *APOE* testing. My hope is that this comparison will expose any ways in which differences between these tests, particularly, their clinical utility, might affect recipients' attitudes and the roles that these test results play in their self-conceptions. Again I shall again divide the findings by:

- Motivations and expectations; and
- Attitudes and reactions to receiving and reflecting upon test results.⁶⁰⁴

Motivations and expectations

One angle that the REVEAL study does not address is why individuals might choose *not* to be tested. One *BRCA*-focused study found that some did so because of the fear that results confirming carrier status would impact negatively on their lives.⁶⁰⁵ For example, one participant cites the worry that “cancer [would become] this consuming thing in your life”.⁶⁰⁶ And another study observed that some believe that the available clinical interventions for hereditary breast and ovarian cancer are insufficient to make the anxieties associated with testing worthwhile.⁶⁰⁷

When it comes to positive reasons for seeking *BRCA* testing, as with *APOE* testing, planning, control and mitigating uncertainty about possible risk emerge as common themes.⁶⁰⁸ Participants in one ethnographic study reported that “knowing gives you more control”, and “the more I know, the more I can help myself”.⁶⁰⁹ Altruistic motivations, similar to those observed by the REVEAL study, are also in evidence, with some individuals reporting seeking

⁶⁰⁴ As the findings discussed under each of these headings come from diverse studies, they do not reflect evolutions in the same cohort's views in the same way as the REVEAL study does.

⁶⁰⁵ d'Agincourt-Canning (2006).

⁶⁰⁶ Ibid., p.110.

⁶⁰⁷ Esplen et al. (2009).

⁶⁰⁸ d'Agincourt-Canning (2006); Lynch et al. (2006).

⁶⁰⁹ Canning d'Agincourt-Canning (2006), p.104, p.105.

testing because of the results' possible utility to close relatives, or because these results could contribute to research.⁶¹⁰ However, others express the contrary concern that, if they tested positive, their relatives might feel "almost like a person who's been diagnosed".⁶¹¹

Reactions to results

Evidence of responses to *BRCA* testing are diverse and there is no straightforward correlation between adverse reactions and mutation-positive results, or between positive attitudes and mutation-negative results.⁶¹² One large study (660 participants) found "a generally low level of potential distress" and an "overwhelming positive attitude toward genetic testing".⁶¹³ And, while many studies report mutation-negative results bringing relief,⁶¹⁴ a "renewed appreciation for life", or a feeling of finally being "part of the normal population",⁶¹⁵ others have more complex reactions. For example, some report feeling numb, dislocated or guilty, having 'escaped' the threat faced by family members.⁶¹⁶

Recalling the caveat noted in the previous chapter, it is important not to assume that the presence or absence of distress is indicative or exhaustive of the range of potential wider and longer-term impacts of receiving personal bioinformation.⁶¹⁷ Recognising and responding to potential impacts beyond emotional distress was a key motivation for the development of the *BRCA* Self-Concept Scale.⁶¹⁸ This validated, evidence-based tool measures impacts across seventeen indicators under the three headings of "self-mastery", "stigma" and "vulnerability" (the third includes feelings about impacts on relatives and relational roles).⁶¹⁹

In contrast to the REVEAL findings, *BRCA* test results have been observed to make differences to individual's health-related behaviours. Receipt of mutation-positive test results

⁶¹⁰ Ibid.; C. Foster et al. (2002), "Genetic Testing for Breast and Ovarian Cancer Predisposition: Cancer Burden and Responsibility" *Journal of Health Psychology*, 7(4): 469-84; N. Hallowell et al. (2003), "Balancing Autonomy and Responsibility: The Ethics of Generating and Disclosing Genetic Information" *Journal of Medical Ethics*, 29(2): 74-79.

⁶¹¹ d'Agincourt-Canning (2006), p.111; S. Scott et al. (2005), "Repositioning the Patient: The Implications of Being 'at Risk'" *Social Science & Medicine*, 60(8): 1869-79.

⁶¹² Lim et al. (2004).

⁶¹³ Lynch et al. (2006), p.95.

⁶¹⁴ Butow et al. (2003).

⁶¹⁵ Esplen et al. (2009), p.1217; Lim et al. (2004); *ibid.*, p.122.

⁶¹⁶ Lim et al. (2004).

⁶¹⁷ See Chapter 5.

⁶¹⁸ den Heijer et al. (2011).

⁶¹⁹ The *BRCA* Self-Concept Scale categorises its indicators under the three headings of 'self-mastery', 'stigma' and 'vulnerability' (the third includes feelings about impacts on relatives), M. Esplen et al., (2009) "The *BRCA* Self-Concept Scale: A New Instrument to Measure Self-Concept in *BRCA*1/2 Mutation Carriers". *Psycho-Oncology* 18(11): 1216-29.

are observed to be associated with an increase in uptake of prophylactic surgery and screening.⁶²⁰ Uptake of more general kinds of health protection behaviours are also reported.⁶²¹

However, as with *APOE* testing, the perceived utility of (both positive and negative) *BRCA* test results extends beyond health-related or other practically-focused decisions and actions. The receipt of positive test may be experienced as “life-changing”, or as precipitating “re-evaluation of priorities”.⁶²² One systematic review reports that test results improve recipients’ perceptions of their own risk.⁶²³ Some individuals report that (given their family health histories) even positive results provide welcome relief from uncertainty, or represent a validation of their own pre-testing self-perception that they were at risk.⁶²⁴ And some value knowledge of their risk status so they can emotionally and psychologically prepare for illness.⁶²⁵ Others report simply needing to know “what’s going on with my body”.⁶²⁶ However, this is not a straightforward picture. The developers of the *BRCA* Self-Concept Scale suggest that learning one is a carrier could in some circumstances interfere with capacities for future planning.⁶²⁷

One adverse impact of high risk estimates, which is not evident in the REVEAL findings, is that of negative self-labelling. It is reported that reactions to positive *BRCA* status could include feelings of stigmatisation, alienation and difference.⁶²⁸ Positive results may also affect recipients’ body image, for example by undermining their confidence and trust in their bodies, or causing them to see themselves as “damaged goods” or reproductively “impaired”.⁶²⁹

While, for some recipients, obtaining their risk estimates is a way of enacting their care and responsibilities for close relatives, for others it may be experienced as disruptive to family relationships or the fulfilment of relational roles.⁶³⁰ For example, parents sometimes report feelings of guilt upon receiving a positive *BRCA* test result because of the fifty percent chance of their children inheriting the mutation, or a failure in their parental role because they feel it undermines their capacity to protect their children.⁶³¹ But guilt is not confined to positive test

⁶²⁰ Lynch et al. (2006).

⁶²¹ Lim et al. (2004).

⁶²² Esplen et al. (2009), p.1217.

⁶²³ Butow et al. (2003).

⁶²⁴ Lim et al. (2004), p.129.

⁶²⁵ Esplen et al. (2009).

⁶²⁶ d'Agincourt-Canning (2006), p.106.

⁶²⁷ Esplen et al. (2009).

⁶²⁸ Ibid.; Lim et al. (2004).

⁶²⁹ Esplen et al. (2009), p.1217.

⁶³⁰ M.L. Underhill et al. (2012), "Living My Family's Story: Identifying the Lived Experience in Healthy Women at Risk for Hereditary Breast Cancer" *Cancer nursing*, 35(6): 493.

⁶³¹ Esplen et al. (2009); Ibid; Lynch et al. (2006).

results. Some receiving negative results report experiencing guilt at escaping risk when others in their family have not.⁶³² Similar, observations have also been made in families following testing for Huntington's disease, where different risk status has been observed to be a source of conflict and alienation within some families.⁶³³

Carrier status may also give rise to group affiliations beyond immediate family relationships. Sahra Gibbon has noted that hereditary breast cancer is particularly associated with patient activism and awareness-raising activities.⁶³⁴ A further, relational angle that emerges in the *BRCA* context is the possibility that testing might be seen as a means of enacting and constituting a particular aspect of one's cultural identity. The *BRCA* mutations associated with cancer risk have been observed to occur with greater frequency in Ashkenazi Jewish populations.⁶³⁵ It has been suggested that carrying these mutations (and what their prevalence is taken to imply about a shared history of oppression and migration) may be perceived as providing a connection between members of Ashkenazi communities and a "reiteration of Jewish identity".⁶³⁶ For example, one campaign group portrays being tested for *BRCA1/2* mutations as one way of contributing to protecting the survival of future generations of Jewish people.⁶³⁷

One study found that in general recipients' reactions to test results – irrespective of whether they were positive or negative – manifested in various kinds of "turmoil".⁶³⁸ Yet over time this dissipated and most participants came to take a more optimistic and constructive view of their results, seeing them as having initiated "important and positive life changes."⁶³⁹ Some observations relating to the longer-term impacts of negative results, also throw up interesting findings that echo those from REVEAL. For example, some people's prior assumptions that their family history of cancer placed them at high risk proved remarkably resilient to the

⁶³² Esplen et al. (2009); Lim et al. (2004).

⁶³³ M. Konrad, *Narrating the New Predictive Genetics: Ethics, Ethnography, and Science* (Cambridge: Cambridge University Press, 2005).

⁶³⁴ S. Gibbon, 'Charity, Breast Cancer Activism and the Iconic Figure of the *BRCA* Carrier', in *Biosocialities, Genetics and the Social Sciences: Making Biologies and Identities*, ed. S. Gibbon and C. Novas (London: Routledge, 2008).

⁶³⁵ E. Levy-Lahad et al. (1997), "Founder *BRCA1* and *BRCA2* Mutations in Ashkenazi Jews in Israel: Frequency and Differential Penetrance in Ovarian Cancer and in Breast-Ovarian Cancer Families" *American Journal of Human Genetics*, 60(5): 1059.

⁶³⁶ J. Mozersky and G. Joseph (2010), "Case Studies in the Co-Production of Populations and Genetics: The Making of 'at Risk Populations' in *BRCA* Genetics" *BioSocieties*, 5(4): 415-39, p.423. Other authors have warned about the misleading 'biologisation' of ethnic or population distinctions (see, T. Caulfield et al. (2009), "Race and Ancestry in Biomedical Research: Exploring the Challenges" *Genome medicine*, 1(1): 1-8).

⁶³⁷ Jews Against Cancer of the Breast (JACOB) website, www.jacobintl.org (accessed 9 June 2017).

⁶³⁸ Lim et al. (2004), p.129.

⁶³⁹ *Ibid.*, p.129.

information that they were not carriers.⁶⁴⁰ And another study found that some who received negative test results felt vulnerable in their liminal ‘lower risk’ status – neither eligible for follow-up screening, nor wholly free from risk.⁶⁴¹ These observations are a valuable warning that, as with information about donor conception and susceptibility to Alzheimer’s disease, it is important not to assume that information recipients’ initial reactions tell us everything we might want to know about the role of bioinformation in their lives.

As the examples in this and the previous section illustrate, there is considerable diversity amongst individuals’ reactions to receiving the genetic susceptibility test results. In the next section I shall turn to consider what might be inferred from the findings relating to both *BRCA* and *APOE* testing about the impacts of genetic susceptibility estimates on recipients’ identity narratives.

SECTION 6: INTERPRETING THE FINDINGS IN TERMS OF IMPACTS ON NARRATIVE IDENTITY

My intention in this section is to suggest that one way we might interpret the findings above is in terms of the contribution (or lack thereof) of genetic susceptibility estimates to an individual’s construction of her own identity. In the following analysis I will suggest that existing proposals about the role of susceptibility testing in identity-formation may reflect aspects of what makes this category of information potentially identity-significant, but that they fail to capture the full picture. I wish to suggest that viewing the evidence of individuals’ reactions to their genetic susceptibility estimates through the lens of its role in their identity narratives may provide a wider perspective on the ways in which the identity impacts of this category of personal bioinformation may be understood. I will unpack this claim under the following headings:

- i. The adoption and enactment of a ‘risk identity’;
- ii. Changing or reinforcing the labels an individual applies to herself;
- iii. Impacts on relational aspects of self-characterisation; and
- iv. Revised outlook and priorities.

i) Risk identity

One kind of response to receiving (positive) test results that is considerably more evident in the *BRCA*-related literature, though not wholly absent from the REVEAL findings, is the

⁶⁴⁰ Ibid.

⁶⁴¹ Scott et al. (2005).

adoption of behaviour changes or healthcare measures undertaken by recipients to protect or to feel in greater control of their health and their lives.

It might be assumed that the role of test results in instigating health protection measures simply indicates the clinical utility of this information and is quite separate from its potential significance to identity. However, it is too swift to treat clinical value and (potential) identity value as mutually exclusive. On the contrary, I would suggest that the narrative role of personal bioinformation could sometimes be predicated on its clinical utility in two ways. The first is that health protection measures could comprise part of recipients' efforts to imagine whether and how their narratives might unfold into the future – I will return to discuss this under the fourth sub-heading below. The second is that the activities directed at protecting one's health could themselves constitute key practical aspects of one's self-narrative.

The second of these suggestions draws upon Carlos Novas's and Nikolas Rose's account of the constitution of a particular form of 'identity' centred on knowledge of one's risk status (introduced in Chapter 2 above). According to their account, learning of one's risk of genetic disease may be a spur to adopting the self-characterisation of being "a person genetically at risk" of illness.⁶⁴² These authors posit that an individual's awareness of her own risk, her sense of agency and responsibility in respect of her health, and the activities she undertakes to understand and manage her risk, may be constitutive of a particular kind of practical identifier, that of being 'at risk'.⁶⁴³ Although Novas and Rose's proposal is not based in an explicitly narrative conception of identity, it is possible to view a 'risk identity' as potentially contributing a strand of someone's story of who she is – a strand that is enacted and constituted by the priorities and activities that it informs. And, (insofar as the limited *BRCA*-related literature considered in this chapter permits) it is plausible to interpret some of the responses to positive *BRCA* tests, whereby individuals' come to think of themselves as '*BRCA* carriers', undertake health-protection measures, or participate in patient activism, as exemplifying the adoption and constitution of risk identities.⁶⁴⁴

The same kinds of practically-focused, health-protective response are, however, not evident in the REVEAL literature. This leads Lock and her co-authors to conclude that:

⁶⁴² Novas and Rose (2001), p.485. See also Rose (2007)

⁶⁴³ See also G.A. Sulik (2009), "Managing Biomedical Uncertainty: The Technoscientific Illness Identity" *Sociology of Health & Illness*, 31(7): 1059-76.

⁶⁴⁴ Gibbon (2008); Sulik (2009).

“...it is an open question whether these [REVEAL] volunteer subjects experienced anything remotely approaching a profound personal or identity change based on the test results.”⁶⁴⁵

and

“...little if any significant changes take place with respect to their sense of identity...”⁶⁴⁶

However, I would counter that these conclusions are dependent on a particularly narrow conception and high threshold for what an identity-impact looks like. Lock and her co-authors appear to take Novas’s and Rose’s conception of a risk identity as their sole measure of identity impact. Furthermore, they demand that in order for an identity impact to be worthy of note it must involve significant *change*. I will indicate, over the following sub-sections, how a narrative conception of identity challenges each of these assumptions. First, such a conception highlights that undertaking health protective behaviours and the formation of a risk identity are by no means exhaustive of the potential identity impacts of genetic susceptibility testing. Secondly, it illustrates that the identity significance of this information may be just as evident in the reinterpretation or reinforcement of existing self-characterisations as in the adoption of new ones.

The REVEAL literature frequently describes the less practically-focused explanations that participants gave for valuing their test results as their ‘emotional’ reasons.⁶⁴⁷ I will suggest that this inadequately captures the nature of some of these participants’ reactions and proposed uses of their results. Furthermore, it highlights precisely the kind of gap that needs to be filled in securing the appropriate recognition of the possible *identity* impacts of health information. I submit that it is possible to interpret participants’ reactions to their results as having personal significance not merely because they affected their *feelings*, but because these results affect how some participants think about who they are shape the lens through which they view the world and assess their priorities. I shall illustrate what I mean by this over the following three sub-sections.

ii) Self-labelling

There are indications that genetic susceptibility information may play a role in changing or reinforcing a range of labels or self-descriptors which recipients use in characterising themselves. These may be concrete and specific as in instances where someone comes to think

⁶⁴⁵ Lock (2005), p.58.

⁶⁴⁶ Lock (2008), p.72.

⁶⁴⁷ Roberts et al. (2003); Roberts et al. (2011).

of themselves as a ‘*BRCA* carrier’ or where their sense of themselves as a member of a family, or a wider community, of those living with the threat of Alzheimer’s. Or they may be broader or more value-laden, for example, where someone testing positive for a *BRCA* mutation comes to think of herself as ‘damaged goods’ or where a high risk estimate for Alzheimer’s disease leads someone to think of themselves as already cognitively impaired. These observations echo Christine Hauskeller’s suggestion that genetic disease testing can provide the basis for individuals to adopt or reinforce “intra-species classifications” along risk or diagnostic category lines, which they then use to group themselves with or differentiate themselves from others (as introduced in Chapter 2).⁶⁴⁸ And, lending weight to Hauskeller’s ambivalence about the identity value of such genetically-informed self-classifications, it is apparent that the impacts on someone’s self-conception could be positive – as in cases where such classifications underpin solidarity with others – or negative – for example where the acquired label is experienced as stigmatising.

It might be objected here that it is plausible to hold that genetic susceptibility estimates can provide the basis for new or reinforced, welcome or unwelcome, modes of self-description, but that this does not in itself speak to a specifically *narrative* role for this category of information. However, I would suggest that we can only appreciate why such self-classifications *matter* to someone, and understand why they take one form rather than another – why coming to think of oneself as ‘a carrier’ is undermining or empowering in any particular instance – when we attend at how this descriptor interacts with and is interpreted in the light of other aspects of that individual’s existing story of who she is.

So, while the suggestion that genetic susceptibility testing can impact upon how we categorise ourselves is not a new one, I would argue the ethical significance (for good or ill) of this for the individual is inadequately captured when we think of this only in terms of unitary identifiers. The nature of the impact on the individual and the ethical significance of this only really comes to light when we look at it in the context of someone’s wider narrative – for example, when we understand that undermining someone’s self-conception as a parent does not merely subtract a discrete ‘label’, but has repercussions throughout the web of values, commitments and other aspects of self-characterisation that exist in mutual-interpretation with this self-descriptor. One aspect of self-characterisation for which this may be most readily apparent is that relating to the impacts of disease susceptibility information on the way in

⁶⁴⁸ Hauskeller (2006), p.3.

which our self-narratives intersect with those of other's and are informed by the relational and group roles that we occupy – as I shall now outline.

iii) Relational aspects of self-characterisation

One theme that emerges as much from the REVEAL findings as *BRCA* literature is the way in which undergoing genetic susceptibility testing may function in part as a means by which individuals enact and reinforce their conceptions of themselves as members of families, or wider social groups with whom they share the experience or threat of hereditary disease. For example, the wish to contribute to genetic research through being tested – cited by many in the research reviewed above – may be seen the desire to engaged in activities through which a mode of group identification, such as family membership, Jewishness, or affiliation with a patient group, might be reinforced. In the terminology coined by Paul Rabinow, these may be characterised as the means by which individuals engage in identity-development through “biosocial” means, that is activities centred around shared biological attributes.⁶⁴⁹ As signalled by what I intimated under the first sub-heading above, the significance of the way that genetic test results might contribute to these relational aspects of recipients' self-characterisations is not diminished because it reinforces existing affiliations rather than introducing new modes of identification.

Further identity-related effects may be observed in this information's impacts on how some recipients characterise themselves in terms of their relationships with and responsibilities to particular others. I would submit that the findings outlined above indicate that test results can have important impacts – both positive and negative – on those aspects of individuals' identities that are constituted by familial roles and relationships. As Lori d'Agincourt-Canning notes with respect to participants in her own study (who had undergone *BRCA* testing) –

“Participants did not view their decision to seek testing in isolation from everyone else. Rather, obtaining genetic information allowed them to express their identity as embodied selves as well as selves-in-relation.”⁶⁵⁰

I would, however, go further than this. In accordance with the explanation of practical identity that I outlined in earlier chapters, I would argue that undergoing testing could be more than merely *expressive* of identity; it could be seen as (partially) *constitutive* of particular relational modes of self-characterisation. For example, seeking testing in order to gain information of wider benefit to one's family may be understood as expressing the kind of care that makes one a loving sister or daughter. Conversely, someone might experience discovering that she is at

⁶⁴⁹ Rabinow (2005)

⁶⁵⁰ d'Agincourt-Canning (2006), p.113.

high risk (and could have passed this risk to her child) of hereditary cancer as undermining her capacity to fulfil a particular conception of herself as ‘a parent’ insofar as this entails protection and care.⁶⁵¹

iv) Outlook and priorities

I finally wish to suggest that the empirical literature highlights a range of further identity-related impacts that might escape attention outwith a narrative analysis, because they are not reducible to particular self-classifications or programmes of activity. I would offer instances on which individuals report that their genetic test results have served to change their priorities and outlook as archetypal indications of identity impacts. It is precisely these kinds of shifts in perspective that can alter the interpretive framework through which someone’s self-narrative is constructed. Similarly, I would suggest, that indications that genetic test results can sometimes help recipients to deal with the uncertainty that accompanies coming from a family with a history of genetically-linked illness, explain the experiences of illness that have shaped their family narratives and this their own, or to prepare psychologically for the possibility of future illness, are also plausible manifestations of this information’s narrative roles. In each of these cases, I would suggest that we might conceptualise the role played by the test results as one in which the information recipient is equipped to bring her self-narrative closer into line with what her embodied future might hold in terms of the onset of illness, or the diminution of this threat. And this may (though not inevitably) help to protect the coherence of her self-conception from present uncertainty and future disruption.

I do not seek to suggest it is necessarily the case that susceptibility estimates are welcome or useful to all recipients in the ways described above. For some, this information may be experienced as upsetting or stigmatising and it may do little to alleviate some recipients’ epistemic insecurity about their embodied future. Nor do I wish to deny the importance of Lock and her co-author’s findings from the REVEAL study, which indicate that the specifics of participants’ susceptibility estimates were no longer at the forefront of their minds a year later.⁶⁵² However, I would like to offer a possible alternative interpretation of this observation – that this need not necessarily indicate that this information has *no* identity impacts, but rather the kind of interpretive and selective digestion of information that is integral to the narrative-building endeavour. According to such a view, identity development does not necessarily

⁶⁵¹ A. McConkie-Rosell and B.M. DeVellis (2000), "Threat to Parental Role: A Possible Mechanism of Altered Self-Concept Related to Carrier Knowledge" *Journal of Genetic Counseling*, 9(4): 285-302.

⁶⁵² Lock (2008).

entail wholesale disruption or reinvention. Furthermore, it is best understood as a bi-directional process, whereby the individual's conception of herself may be seen not only as being shaped by new personal bioinformation, but also as the prism through which information passes, bending and colouring the eventual role it plays in her life. Bioinformation that facilitates non-seismic changes in perspective or priorities are no less important if these adjustments contribute to a narrative that better equips its subject to make sense of her embodied experiences.

Having said this, it is undeniable that the REVEAL participants' reactions to their test results were in many cases more moderate than their prior expectations, and also differed in several ways from responses to *BRCA* testing. These contrasts offer an opportunity to interrogate the question of what kinds of factors might contribute to the nature and extent of the identity impacts of genetic susceptibility tests for different disorders. This is a task I will undertake in the next, and final, section.

SECTION 7: FACTORS POTENTIALLY INFLUENCING IDENTITY IMPACTS

In this final section I will consider what the empirical literature indicates about the factors that may influence the roles that the results from genetic disease susceptibility tests play (or do not play) in individuals' self-conceptions. As in the previous illustrative chapter I will divide this into two questions:

- What does the empirical evidence indicate about the features of the results from genetic susceptibility tests that might contribute to their playing a role in individuals' self-conceptions?
- What factors appear to account for diversity amongst individuals' responses to this information?

I will address these in turn.

Accounting for the potential narrative significance of this information

As in the previous chapter, one question that presents itself here is the extent to which it is the *genetic* character of this category of personal bioinformation that contributes to it playing a role (where indeed it does) in recipients' self-conceptions. Perhaps surprisingly, the literature reviewed in this chapter does not indicate widespread genetic essentialist assumptions amongst participants, such that they believe that their test results *reveal* something about who they really are. However, what does emerge from the empirical research, and the analyses applied to this by the investigators, is that the genetic nature of the test results is not incidental to the

significance that recipients invest in them either. The literature suggests that three features of genetic information might account for the roles that, I have suggested, susceptibility tests results can play recipients' self-narratives. These are its:

- i) Predictive capacities;
- ii) Perceived credibility and authority; and
- iii) Shared nature.

i) *Predictive capacities*

The first relevant feature of genetic information is its capacity to provide predictions of risk long before symptoms appear. Monica Konrad notes that

“...one way or another predictive medicine makes us ‘see’ ourselves in a different light”.⁶⁵³

This might involve adopting the “anticipatory status” of being “at genetic risk”.⁶⁵⁴ Or it might permit someone to prepare practically or psychologically for future ill-health, or reassess her priorities and outlook. In any if these respects it may assist someone in interpreting her present self-conception in light of her possible future embodied experiences. However, as I will indicate in the next sub-section, the extent to which this is possible, or possible to any useful extent, may be contingent on the predictive precision of the risk estimate and what practical options are available for addressing it.

ii) *Perceived credibility and authority*

It has been suggested (in the context of testing for genetic markers of neurodegenerative disease) that individuals might look to genetic testing as a source of “credible” information.⁶⁵⁵ So even if someone already has a belief about her own risk based on her family history, genetic testing is often seen as having the authority to overturn or confirm these.⁶⁵⁶ Similarly, Anders Nordgren and Eric Juengst talk about “the glamour” of genetic test results.⁶⁵⁷ A number of authors, however, question the capacity of genetic testing, especially for common complex disorders to provide information about health that is markedly more prescient or authoritative than information from other sources.⁶⁵⁸ Indeed, the findings discussed above, particularly the

⁶⁵³ Konrad (2005), p.146.

⁶⁵⁴ Gibbon and Novas (2008), p2.

⁶⁵⁵ Roberts and Uhlmann (2013), p.1225.

⁶⁵⁶ Esplen et al. (2009).

⁶⁵⁷ Nordgren and Juengst (2009), p.169.

⁶⁵⁸ Lock (2008); Office for Official Publications of the European Communities, 'Ethical, Legal and Social Aspects of Genetic Testing: Research, Development and Clinical Applications' (2004); Parry (2013)

resilience of some individuals' prior beliefs about their risk, indicate that some recipients of genetic susceptibility estimates take the same view. Nevertheless, D'Agincourt-Canning suggests that the truth might lie often somewhere between belief in the unassailable authority of susceptibility testing and its banality. She suggests that many approach *BRCA* testing "pragmatically", recognising its limitations, but also embracing it because it represented their best hope of taking control of their state of epistemic insecurity in the face of the threat of cancer.⁶⁵⁹

iii) Shared information

Finally, but perhaps less equivocally than the previous two factors, it is suggested that inherently shared nature of genetic information is central to the kind of personal impacts that I have identified as being identity-significant.⁶⁶⁰ As d'Agincourt Canning observes:

"...within genetics, people might see their selves inscribed onto the lives of others."⁶⁶¹

These others include not only family members whose own risk status may also be implicated, but also wider patient groups who might be befitted by research to which individual susceptibility data can contribute.⁶⁶² D'Agincourt Canning argues that because of this, decisions about being tested and are not solipsistic concerns, but call upon the individual to exercise the 'moral' aspects of her identity. Similarly, Konrad argues that evidence of people's motivations and responses to predictive testing for Huntington's disease give lie to the "myth of pre-emptive individualism" – that is, that genetic tests are only valuable (or harmful) insofar as they inform our solo choices.⁶⁶³ As outlined above, the empirical literature indicates that it is precisely these other-regarding aspects of individuals' motivations for and reactions to their test results that may be seen as having particular salience for the relational (familial, social and cultural) threads of people's self-narratives.

These three shared features of the results of genetic susceptibility test results notwithstanding, it is plainly not the case that every recipient responds to or uses their results in the same way. And there are marked differences between how recipients respond to *APOE* testing as compared to *BRCA* testing for hereditary cancer. This then leads me to the final question for

⁶⁵⁹ d'Agincourt-Canning (2006), p.113.

⁶⁶⁰ Widdows (2013).

⁶⁶¹ d'Agincourt-Canning (2006), p.111.

⁶⁶² Widdows (2013).

⁶⁶³ Konrad (2005), p.151.

this chapter – what does the literature suggest about the kinds of features that might account for these differences?

Accounting for diversity in identity impacts

I would suggest that four factors emerge particularly strongly from the empirical literature as those that might influence recipients' reactions to genetic susceptibility test results in ways that (I would posit) are relevant to the roles these results play in their self-narratives. These are:

- i) The clinical utility and predictive precision of the information;
- ii) The wider informational and interpretive context in which the results are conveyed;
- iii) The nature of the disorder in question; and
- iv) The family history and role of the recipient.

i) Clinical utility and predictive precision

I have suggested in Section 6 that the absence of clinical utility in genetically-based risk estimates does not necessarily obviate all identity-value. However, contrasts between recipients' reactions to *BRCA* and *APOE* testing suggest that it could play some role in the form this value takes. Similarly the complexity, relative lack of predictive precision and provisional nature of the *APOE*-based risk estimates for Alzheimer's disease does not seem to remove all identity impacts. But, the divergences in the 'before' and 'after' findings from the REVEAL study indicate the recipients' appreciation of the epistemic and practical limitations of *APOE* testing did have some marked impacts on the personal significance that they invested in this information.⁶⁶⁴ This is evident not only in respect of their views about its practical utility, but also, for example, in downgrading its capacity to unseat their own prior risk assumptions. However, it is useful to note that it has been observed that even where a particular genotype, such as that for Huntington's disease, indicates an inevitable disease risk, recipients do not invariably interpret a positive test result as self-defining.⁶⁶⁵ This suggests that although recipients' beliefs about a test's predictive strength might contribute to its identity significance, it is not determinative.

⁶⁶⁴ Christensen et al. (2011).

⁶⁶⁵ Konrad (2005).

ii) Wider interpretive context

The above point signals a second possible key factor in shaping the impacts of susceptibility estimates on recipients' self-conceptions – the contextual and explanatory information provided to help them interpret their results. The REVEAL literature attributes both the lack of distress amongst participants and their more ambivalent reactions to receiving their risk estimates to the educational element of REVEAL delivered to participants, in which the “provisional and probabilistic” nature of the risk estimates was emphasised, alongside the complex, multifactorial nature of late-onset Alzheimer's disease.⁶⁶⁶ Accordingly, Michael Arribas-Ayllon has argued that communicating genetic susceptibility for common complex diseases like Alzheimer's carries inherent challenges and responsibilities in terms of managing recipients' expectations.⁶⁶⁷

Two other aspects of the manner and context of the informational transaction might be relevant are the language used and the quantity of information conveyed. For example, it has been suggested that using the language of ‘mutations’ and ‘abnormalities’ might contribute to negative self-image.⁶⁶⁸ And Roberts and his co-authors speculate that the relatively distress-free experiences of REVEAL participants might not be sustained in contexts where risk factors for multiple conditions to be simultaneously disclosed.⁶⁶⁹

Contextual information provided at the point of disclosure might not be the only relevant factor. For example, Lock and her co-authors also speculate that REVEAL participants' phlegmatic responses to their *APOE* test results could be attributed to their existing appreciation of the multifactorial nature of late-onset Alzheimer's disease as a result of, for example, coverage of the condition in the popular media.⁶⁷⁰

iii) The nature of the disorder

A further factor cited as potentially influencing recipients' reactions to genetic risk estimates is nature of the disorder itself. Researchers on the REVEAL study suggests that a number of variables might be at work in this respect, including, whether the disease affects one's mental capacities, whether it is particularly debilitating, and the typical age of onset.⁶⁷¹ Hereditary

⁶⁶⁶ Christensen et al. (2011); Lock et al. (2006), p.282.

⁶⁶⁷ M. Arribas-Ayllon (2011), "The Ethics of Disclosing Genetic Diagnosis for Alzheimer's Disease: Do We Need a New Paradigm?" *British Medical Bulletin*, 100(1): 7-21.

⁶⁶⁸ Esplen et al. (2009), p.1217.

⁶⁶⁹ Roberts et al. (2011).

⁶⁷⁰ Lock M. Lock et al., 'Genetic Susceptibility and Alzheimer's Disease: The Penetrance and Uptake of Genetic Knowledge', in *Thinking About Dementia: Culture, Loss, and the Anthropology of Senility*, ed. A. Leibing and L. Cohen (Rutgers University Press, 2006).

⁶⁷¹ Lock et al. (2007); Roberts et al. (2003).

breast and ovarian cancer and Alzheimer's disease present a mixed picture with respect to these attributes. However, it is also suggested that the significance attributed to a particular condition might not be due not only to its intrinsic biological features, but also with how the condition is popularly perceived. For example, in this respect, some have posited that *BRCA*-linked breast cancer may be particularly "captivating".⁶⁷²

iv) Family history and roles

Turning from the information and the condition it concerns, the fourth factor that appears – unsurprisingly – to help shape recipients' reactions are characteristics of recipients themselves. As d'Agincourt-Canning observes:

"...facts (e.g. information that a genetic mutation exists in one's family) are not received neutrally. People interpret them differently according to their understandings, life contexts and experiences."⁶⁷³

Presumably many contexts and experiences could be instrumental here, but two aspects particularly highlighted by the findings discussed above are, first, experiences of illness in the family and, secondly, an individual's role within her family.

The first of these is apparent both in individuals' stated motivations for being tested and their responses to their results. For example, Lock hypothesised that the tempering of REVEAL participants' reactions to their results has been may be attributable in part to their existing assumptions about their risk. She maintains that:

"...[l]earning about one's *APOE* status does not provide information about a highly probably future; it only raises a possible scenario, one that anyone living in a family where AD [Alzheimer's disease] is present has already entertained."⁶⁷⁴

I have already discussed how, particularly high risk, susceptibility estimates may impact upon individuals' conceptions of themselves as fulfilling particular familial roles. This is illustrated by the observations of their gendered nature of such impacts.⁶⁷⁵ For example, one analysis of the REVEAL findings posits that female participants were more likely to invest value in *APOE* because they were more likely to have cared for affected relatives.⁶⁷⁶

⁶⁷² Lock (2008), p.74. See also, Gibbon (2008).

⁶⁷³ d'Agincourt-Canning (2006), p.108.

⁶⁷⁴ Lock (2008), p.63.

⁶⁷⁵ Esplen et al. (2009). See also L. d'Agincourt-Canning (2001), "Experiences of Genetic Risk: Disclosure and the Gendering of Responsibility" *Bioethics*, 15(3): 231-47.

⁶⁷⁶ Roberts et al. (2003).

I will return in Chapter 8 to consider the features outlined in this section, alongside those which emerge from the other two illustrative examples, in my analysis of the factors that seem most likely to shape the identity significance of personal bioinformation more widely. That analysis will indicate where extrapolation of conclusions drawn from these illustrative examples may be warranted and inform my recommendations in Chapter 9 regarding the responsibilities of those who hold our personal bioinformation to respond to our identity interests in accessing it.

SECTION 8: CHAPTER CONCLUSION

The suggestion that genetic susceptibility test results might affect recipients' self-conceptions is not radically new – this much is already recognised in genetic counselling practice, specific counselling tools such as the *BRCA* Self-concept Scale, as well as (to some extent) in the theoretical literature. However, my intention in this case study has been to draw out how we might recognise and interpret the scope and significance of identity impacts if one adopts a *narrative* conception of identity – and, in particular – if one does so in the context of tests presumed to be of little clinical value.

The empirical literature offers a clear warning against assuming that the impacts of this category of personal bioinformation will be the same for all recipients or in all circumstances. I do not seek to argue here that genetic susceptibility test results invariably have significant, much less, positive, impacts on recipients' identities. Furthermore there are not always obvious or straightforward correlations between the degree of risk conveyed and whether the contribution of this information to the recipient's self-narrative is welcome. Nevertheless, I would suggest that, it is apparent that, for many recipients, information about genetic disease susceptibility can impact on individuals' identities in ways that are neither trivial nor ephemeral. Furthermore, the REVEAL findings, in particular, demonstrate the breadth of potential identity impacts, which do not depend on the clinical utility of the results or practical decision-making. Amongst such impacts are shifts in self-labelling (not always in welcome ways), outlook, priorities and psychological preparedness. But perhaps most prominent is the way that this information can play a significant role in shaping the relational aspects of recipients' identities. This is a valuable reminder of the intertwined nature of the relational and embodied aspects of our accounts of who we are, and the way that genetic personal bioinformation might feed into both.

Nevertheless, while the REVEAL findings hint at the breadth of possible identity impacts, they also signal the kinds of factors that might limit the depth or profundity of some of these. The empirical literature indicates that, amongst the several factors that appear to shape the nature and extent of the narrative roles played by genetic risk estimates, the most influential

appear to be how precise predictive capacities of these estimates are and how much they change the recipient's existing perception of her own risk. This observation is in keeping with the hypothesis that I proposed in Chapter 3 – that personal bioinformation can make important contributions to our self-narratives because it helps us to construct identities that remain coherent within, and support us in navigating, embodied experiences. So, it makes sense that it only fulfils this role insofar as it provides reliable insights into our embodied states and dispositions. This is a theme that I will explore further in my third and final illustrative example, to which I now turn.

CHAPTER 7: ILLUSTRATIVE EXAMPLE III – DIAGNOSTIC PSYCHIATRIC NEUROIMAGING

SECTION 1: TOPIC AND AIMS OF THIS CHAPTER

This chapter contains my third and final illustrative example. As with the previous two chapters, my aim here is to consider the empirical literature reporting individuals' attitudes to a particular category of personal bioinformation in order to lend plausibility to, to illustrate and to refine my argument that personal bioinformation can play a significant role in our construction of coherent identity narratives. This argument provides the basis for the central contention of this thesis: that policies and practices governing our access to bioinformation about ourselves ought to attend to the impacts of this information on our identities. With this third illustrative example, I seek to lend weight to this claim by exploring a further context in which bioinformation may have such impacts, and extend my analysis beyond genetics, to neurological information.

The category of bioinformation on which this chapter will focus is findings from functional neuroimaging that purport to offer insights relevant to individual diagnoses of serious psychiatric disorders such as major depressive disorder (MDD), bipolar disorder or schizophrenia. Currently, psychiatric diagnoses depend chiefly on subjective judgements by clinicians applying to categorisations of different disorders.⁶⁷⁷ However, neuroimaging studies have identified statistically significant differences in the structural or functional features of the brains of ill or at-risk or groups when compared with healthy controls, indicating possible associations between these biomarkers and a range of psychiatric disorders.⁶⁷⁸ Some commentators express the hope that neuroimaging could provide means of identifying pre-symptomatic at-risk individuals, making more precise diagnoses, revising diagnostic categories, or developing better-targeted therapies.⁶⁷⁹ Other commentators, however, are sceptical about the practicality or desirability of clinical applications, for reasons I will review

⁶⁷⁷ American Psychiatric Association, 'Diagnostic and Statistical Manual of Mental Disorders (Dsm-5®)' (2013).

⁶⁷⁸ Cooper et al. (2013); D.E. Linden and A.J. Fallgatter (2009), "Neuroimaging in Psychiatry: From Bench to Bedside" *Frontiers in human neuroscience*, 3(49): 1-7.

⁶⁷⁹ M.J. Farah and S.J. Gillihan (2012), "The Puzzle of Neuroimaging and Psychiatric Diagnosis: Technology and Nosology in an Evolving Discipline" *AJOB Neuroscience*, 3(4): 31-41; S. Kapur et al. (2012), "Why Has It Taken So Long for Biological Psychiatry to Develop Clinical Tests and What to Do About It?" *Molecular psychiatry*, 17(12): 1174-79.

in Sections 2 and 7).⁶⁸⁰ Research investigating potential clinical applications of neuroimaging is ongoing.⁶⁸¹

According to the definition established in Chapter 1, diagnostic information produced by functional neuroimaging can be understood as personal bioinformation on the grounds of both its source and interpretive pedigree. That is, this information is based (in part) upon data sourced from observations of activity in an individual's brain and are interpreted, and purport, to tell that individual something about her health.⁶⁸² It is possible that the form in which neuroimaging-based diagnoses could be communicated to patients might include images as well as verbal advice. Functional neuroimaging (fMRI) generates images showing cross-sections of a brain, shaded or coloured to represent the analyses of data about blood oxygenation levels (and thus inferred neural activation) in different brain regions.⁶⁸³ These images are not literal pictures of individuals' brains, but rather graphical representations of statistical analyses of, often highly processed, data.⁶⁸⁴ Nevertheless, it is reported that individuals may be keen to see these images.⁶⁸⁵ And such images may play a part in recipients' interpretations of and responses to their diagnoses (see section 6).⁶⁸⁶

Reasons for choosing this example

There are four reasons that I have chosen diagnostic psychiatric neuroimaging as my third illustrative example. The first is that this is a field in which there is considerable interest in clinical applications, amongst both psychiatric professionals and prospective patients.⁶⁸⁷ Given the global prevalence of psychiatric disorders such as depression,⁶⁸⁸ and the possibility that

⁶⁸⁰ J. Giordano (2012), "Neuroimaging in Psychiatry: Approaching the Puzzle as a Piece of the Bigger Picture (S)" *AJOB Neuroscience*, 3(4): 54-56; R.T. Ramos (2012), "The Conceptual Limits of Neuroimaging in Psychiatric Diagnosis" *AJOB Neuroscience*, 3(4): 52-53.

⁶⁸¹ See, for example, H.C. Whalley et al. (2006), "Functional Imaging as a Predictor of Schizophrenia" *Biological Psychiatry*, 60(5): 454-62; H.C. Whalley et al. (2013), "Prediction of Depression in Individuals at High Familial Risk of Mood Disorders Using Functional Magnetic Resonance Imaging" *PloS one*, 8(3): 1-8

⁶⁸² Individual findings, however, are not based solely or directly on neurological data obtained from the individual, but are the result of "extensive signal processing and statistical analysis" and dependent on profiles developed using many people's data. See, M.J. Farah (2014), "Brain Images, Babies, and Bathwater: Critiquing Critiques of Functional Neuroimaging" *Hastings Center Report*, 44(2): 19-30, p.24.

⁶⁸³ Ibid.

⁶⁸⁴ Ibid.

⁶⁸⁵ S. Cohn, 'Picturing the Brain inside, Revealing the Illness Outside: A Comparison of the Different Meanings Attributed to Brain Scans by Scientists and Patients', in *Technologized Images, Technologized Bodies*, ed. J. Edwards, et al. (New York: Berghahn Books, 2010).

⁶⁸⁶ Ibid.

⁶⁸⁷ Farah and Gillihan (2012).

⁶⁸⁸ World Health Organisation, 'Fact Sheet 369: Depression' (April 2016).

clinical applications could be developed in the foreseeable future, it is timely to examine what, if any, the identity-related impacts of providing this kind of information might be. The remaining three reasons pertain to the instrumental value of this example for the wider research aims of this thesis. My second reason, then, is that this example looks at *neurological* information and thus allows me to depart from the genetic focus of the previous two examples. The third reason is that, by looking at diagnostic information and the attitudes of recipients who might have existing psychiatric diagnoses it provides a useful opportunity to examine the impacts of bioinformation that does not necessarily bring radically *new* news about ill-health, but the possibility of reinterpreting existing beliefs. The fourth reason is that psychiatric neuroimaging is at a relatively early developmental stage, and this provides a useful opportunity to interrogate what the current limitations in the validity and reliability of this information might mean for any identity-value that recipients invest in it (see Section 7).

Research questions

As with the previous two illustrative examples, the headline research question from Chapter 1 to be addressed here is: what grounds are there for holding that the narrative conception of the relationship between personal bioinformation and identity developed in Chapter 3 is robust and plausible in light of people's actual experiences? In order to answer this, my specific research questions for this chapter will be:

- i. What do findings reported in the empirical literature indicate about recipient's attitudes and reactions to receiving neuroimaging-based psychiatric diagnoses?**
(Section 4)
- ii. What might be inferred from these findings about the roles that neuroimaging-based diagnoses could play in individuals' self-narratives?** (Section 5)
- iii. What kinds of factors appear to influence whether it would play these roles?**
(Section 6)

My intentions in addressing these questions are not only to consider what viewing the findings from the empirical literature through the lens of narrative identity might tell us about the identity significance of this particular category of personal bioinformation. My wider aim is to consolidate insights from the prior examples that speak to the *practical* objective of this thesis – that of addressing what responsibilities fall to those in a position to disclose personal bioinformation. Two matters upon which the present example will shed further light are the importance of the manner and context in which personal bioinformation is communicated to the nature of its identity impacts, and the relevance of the epistemic qualities of the information

to these impacts. For this reason, I will pose a further research question in respect of this illustrative example:

iv. How might the current epistemic limitations of neuroimaging-based diagnoses affect the role of this information in recipients' self-narratives? (Section 7)

I will turn to address each of these research questions shortly, but before doing so I will briefly review the extent to which this category of personal bioinformation is currently accessible to information subjects (Section 2) and my approach to the empirical literature (Section 3).

SECTION 2: CURRENT ACCESSIBILITY OF NEUROIMAGING-BASED DIAGNOSES

Clinical and research contexts

Diagnostic applications of functional neuroimaging are not yet available in clinical psychiatric practice in the UK.⁶⁸⁹ This technology is not considered ready for clinical translation for a number of reasons, including methodological limitations.⁶⁹⁰ For example, research tends to focus on comparisons between healthy controls and participants with known psychiatric diagnoses, which is a cruder comparison than is likely to be useful in differentiating diagnoses in a clinical context.⁶⁹¹ There is also little standardisation of methods, including those for data acquisition, device settings, experimental tasks, and the statistical analyses applied – each of which can impact significantly on findings.⁶⁹² Furthermore, findings tend not to exhibit sufficient sensitivity (to individual differences) or specificity (to distinguish between different conditions).⁶⁹³ This carries the risk of high incidence of false negative or positive results,⁶⁹⁴ which in some studies has been observed to be high as 40 percent.⁶⁹⁵ There are therefore grounds to doubt the clinical validity (whether it identifies the clinical status of interest)⁶⁹⁶ and reliability of neuroimaging-based diagnoses at present. The methodological limitations are not thought to be irresolvable.⁶⁹⁷ However, there may be more fundamental reasons to question whether neuroimaging can provide a suitable psychiatric tool (see Section 7).

⁶⁸⁹ *Structural* neuroimaging is used in the clinical care of dementia and to rule out significant abnormalities such as tumours as causes of psychiatric symptoms.

⁶⁹⁰ Cooper et al. (2013); T.J. Reilly and P.K. McGuire (2013), "Translating Neuroimaging Findings into Psychiatric Practice" *The British Journal of Psychiatry*, 203(6): 397-98.

⁶⁹¹ Kapur et al. (2012).

⁶⁹² Farah and Gillihan (2012).

⁶⁹³ *Ibid.*

⁶⁹⁴ See, for example, Whalley et al. (2013), in which the rate of false positives was 25%.

⁶⁹⁵ S.M. Lawrie, "Can We Predict Who Will Suffer from Mental Illness and Prevent It?" (Mason Institute Seminar, University of Edinburgh, 14 January 2014)

⁶⁹⁶ W. Burke (2014), "Genetic Tests: Clinical Validity and Clinical Utility" *Current Protocols in Human Genetics* 81: 9-15.

⁶⁹⁷ Farah and Gillihan (2012).

The developmental stage of this application of neuroimaging means that research studies are currently the principal setting in which diagnostic neuroimaging findings are generated. Clinical utility remains the dominant arbiter of whether participants are informed of individual research findings.⁶⁹⁸ It is unlikely that at this developmental stage that research findings would meet this criterion, so it is unlikely they would be offered to participants. For example, in one study, participants were advised, as part of consent procedures, that they could expect *incidental* findings of clinically significant *structural* abnormalities to be disclosed to their GPs, but they were not given an option to receive individual findings relating to the study's investigation of the links between neural activity and depression risk.⁶⁹⁹

Commercial contexts

Some commercial services in North America and Japan purport to provide neuroimaging-based diagnoses for conditions such as depression or ADHD using single-photon emission computed tomography (SPECT).⁷⁰⁰ There are concerns, however, that results from these services are of dubious scientific merit or value to consumers – not least for the reasons outlined in the preceding paragraphs.⁷⁰¹

I shall return in Chapter 9 to consider what my ethical framework implies for accessing findings given the current state of the art and in future.

SECTION 3: SOURCES AND ANALYTICAL APPROACH

As with the previous two illustrative examples, the discussion below draws on findings in the empirical literature which indicate information subjects' (likely) attitudes to receiving this particular category of personal bioinformation, before considering what these might tell us about the roles it might play in recipients' identity narratives.

⁶⁹⁸ S.M. Wolf, 'Incidental Findings in Neuroscience Research: A Fundamental Challenge to the Structure of Bioethics and Health Law', in *Oxford Handbook of Neuroethics*, ed. B.S. Judy Illes (Oxford: Oxford University Press, 2011).

⁶⁹⁹ University of Edinburgh, Division of Psychiatry 'Brain Function in Relatives of People with Bipolar Disorder: Information and Consent Form' (20 December 2008).

⁷⁰⁰ S. Alpert (2012), "The Specter of Commercial Neuroimaging" *AJOB Neuroscience*, 3(4): 56-58; D. Cyranoski (2011), "Neuroscience: Thought Experiment" *Nature*, 469: 148-49.

⁷⁰¹ Alpert (2012).

Empirical literature

The empirical literature I draw upon in this chapter is that which provides insights into how recipients (might) react to psychiatric neuroimaging findings that purport to provide diagnoses of their own psychiatric disorders (chiefly MDD and schizophrenia).

There appear to be few empirical studies exploring this topic.⁷⁰² And, given the context outlined in the previous section, it is unsurprising that even fewer studies involve participants who have actually received neuroimaging-based diagnoses (here I cite three).⁷⁰³ For this reason I have extended my scope to include two studies eliciting patients' *speculative* attitudes to hypothetical receipt of this information.⁷⁰⁴ For the same reason I have also included findings from three further studies reporting clinicians', neuroimaging researchers', parents' and the general public's views about the (possible) impact on patients.⁷⁰⁵ Given the lessons from the previous chapters about the potential divergence between recipients' prior expectations and subsequent reactions to information, and the diversity of possible reactions, these speculative and proxy views must be treated with some caution. Another reason to be cautious about generalising from these findings is that most of these studies are small,⁷⁰⁶ they are also substantially mutually-referencing and several share authors. Nevertheless, with appropriate caution, this limited evidence is sufficient to serve my research purposes outlined in Chapter 4, which entail neither proving nor quantifying identity significance of this category of bioinformation.

⁷⁰² M.S. Lebowitz (2014), "Biological Conceptualizations of Mental Disorders among Affected Individuals: A Review of Correlates and Consequences" *Clinical Psychology: Science and Practice*, 21(1): 67-83.

⁷⁰³ J.A. Anderson et al. (2013), "Triangulating Perspectives on Functional Neuroimaging for Disorders of Mental Health" *BMC Psychiatry*, 13(1): 208-18; Cohn (2010); J. Dumit, *Picturing Personhood: Brain Scans and Biomedical Identity* (Princeton: Princeton University Press, 2004). See also J. Dumit (2003), "Is It Me or My Brain? Depression and Neuroscientific Facts" *Journal of Medical Humanities*, 24(1-2): 35-47.

⁷⁰⁴ D.Z. Buchman et al. (2013), "Neurobiological Narratives: Experiences of Mood Disorder through the Lens of Neuroimaging" *Sociology of Health & Illness*, 35(1): 66-81; J. Illes et al. (2008), "In the Mind's Eye: Provider and Patient Attitudes on Functional Brain Imaging" *Journal of Psychiatric Research*, 43(2): 107-14.

⁷⁰⁵ E. Borgelt et al. (2011), "'This Is Why You've Been Suffering': Reflections of Providers on Neuroimaging in Mental Health Care" *Journal of Bioethical Inquiry*, 8(1): 15-25; E.L. Borgelt et al. (2014), "In Search of 'Anything That Would Help' Parent Perspectives on Emerging Neurotechnologies" *Journal of Attention Disorders*, 18(5): 395-401; E.L. Borgelt et al. (2012), "Neuroimaging in Mental Health Care: Voices in Translation" *Frontiers in Human Neuroscience*, 6: 1-5. The second of these concerns diagnosis of attention disorders rather than depression or psychotic illness and the third is a review of existing research.

⁷⁰⁶ For example, the largest of the studies looking at patients' speculative attitudes reports questionnaire responses from 72 patient participants (Illes et al. (2008)).

Analytical approach

Having outlined what the empirical literature indicates about how individuals might react to or use neuroimaging-based diagnoses (Section 4), I will address what this might tell us about the potential narrative roles of this information (Section 5). Some, though not all, of the empirical studies I have drawn upon already frame the findings in terms of the impact on recipients' identities or sense of self – invoked in a range of ways that do not necessarily coincide with the conception of narrative self-constitution that underpins this thesis. In my own analyses of these findings I do not, therefore restrict my attention to findings that make explicit reference to identity impacts. I bring my wider conception of narrative identity to consider what people's reported attitudes might tell us about the range of roles that neuroimaging-based diagnoses might play in the construction of information subjects' accounts of who they are how they make sense of an inhabit these accounts in the context of their illness experiences.

SECTION 4: EVIDENCE OF ATTITUDES TO NEUROIMAGING-BASED DIAGNOSES

The empirical literature reports that both patients who have used commercial neuroimaging services and those speculating about the clinical availability of diagnostic neuroimaging are, for the most part enthusiastic about what these (might) offer.⁷⁰⁷ As I shall return to discuss in Section 6, healthcare professionals and researchers' views are somewhat more sceptical about the value to patients of neuroimaging-based diagnoses.⁷⁰⁸ In the following paragraphs I break down the attitudes, expectations and reactions expressed by all research participants under the following eight (often interconnected) roles that these diagnoses could play in individuals' lives:

- i) Providing robust diagnosis;
- ii) Explaining and legitimising illness experiences;
- iii) Encouraging treatment access and compliance;
- iv) Permitting dissociation of self from illness;
- v) Reducing stigma and self-blame;
- vi) Contributing to prognostic pessimism;
- vii) Instigating identification with a disordered brain; and
- viii) Underpinning self-descriptors,

⁷⁰⁷ Anderson et al. (2013); Illes et al. (2008).

⁷⁰⁸ Borgelt et al. (2012).

I shall expand on each of these here.

i) Robust diagnosis

Many participants report that (what they perceived as) the greater authority and objectivity of neuroimaging-based assessment would provide, or had provided, them with a more “clear and objective”, “certain” or “concrete” diagnosis.⁷⁰⁹ One study found that the majority of participants believed neuroimaging results would help them accept their condition and understand its biology.⁷¹⁰

ii) Explaining and legitimising experiences

Several participants report that the (perceived) objectivity and authority of a neuroimaging-based diagnosis would also help them better to explain, understand and cope with the experiences of serious mental illness.⁷¹¹ Buchman *et al* describe one participant’s hopes that neuroimaging would offer the means by which he could “reconfigure the meaning of his experience [of illness]”.⁷¹² These kinds of views are echoed by responses from mental healthcare providers, who hope that this information could provide a “meaningful explanation” for their patients, or provide a kind of “existential relief” by offering biological reasons for their mental suffering.⁷¹³ However, one study found that a small proportion of patients were concerned that a neuroimaging-based diagnosis might increase their worry about their illness.⁷¹⁴

Closely related to the explanatory power invested in this category of bioinformation, is its perceived capacity to validate or legitimise individuals’ experiences of mental illness – both in their own eyes and in those of others, including their families and clinicians.⁷¹⁵ It is seen by many as potentially alleviating others’ scepticism about the reality of the illness, facilitating acceptance, or reframing its nature.⁷¹⁶ For example, Buchman *et al* cite one participant with MDD as saying that he would welcome neuroimaging as “acknowledgement of what I am going through” and proof that he was not “just crazy”.⁷¹⁷

⁷⁰⁹ Anderson et al. (2013), p.7; Buchman et al. (2013), p.74.

⁷¹⁰ Illes et al. (2008).

⁷¹¹ Buchman et al. (2013); Illes et al. (2008).

⁷¹² Buchman et al. (2013), p.74.

⁷¹³ Borgelt et al. (2011), p.10, p.9.

⁷¹⁴ Illes et al. (2008).

⁷¹⁵ Buchman et al. (2013); Cohn (2010); Dumit (2003).

⁷¹⁶ Anderson et al. (2013); Cohn (2010).

⁷¹⁷ Buchman et al. (2013), p.74.

Several accounts indicate that the visual nature of *neuroimages* themselves may be an important part of their perceived power to legitimise an individual's experiences of mental illness, not least by offering a way to communicate the illness's 'reality' to family or friends.⁷¹⁸ For example, one individual living with schizophrenia describes the printed neuroimage he had been given as:

“...proof now about my schizophrenia... It's there on the scan, no one needs question it any more.”⁷¹⁹

Simon Cohn hypothesises that such images provides a means by which a patient is able to “convey private subjective suffering within the social world”.⁷²⁰ However, Cohn's study also illustrates that such efforts may prove futile if patients' significant others do not regard what neuroimages conveys as supplanting their existing beliefs or prejudices about the nature of mental illness. And some patients themselves express scepticism about the power of neuroimages to explain or legitimise their experiences, for example, seeing neuroimages as mere “crude limitation of what constitutes their illness”.⁷²¹ Similarly Joseph Dumit quotes an individual with bipolar disorder as saying that he finds functional neuroimages as

“genuinely exciting but... [they] do not explain my madness, nor do they guide me in what I can do about it.”⁷²²

Nevertheless, as the following sections indicate, not all patients share this view.

iii) Treatment access and compliance

Several studies note speculation amongst both patients themselves and mental healthcare professionals that neuroimaging-based diagnoses could lead to improved access to, uptake of, or compliance with health-protective behaviours and treatment.⁷²³ These findings run contrary to the commonly expressed concern that a biologised explanations of mental illness might encourage greater reliance on medical treatments such as psychopharmaceuticals, at the expense of psychotherapy, or other (possibly more effective) protective strategies.⁷²⁴ Indeed, one study found that far from biasing patients towards medicalised interventions, the majority of participants in one study with patients with MDD reported that a neuroimaging-based diagnosis would make them more likely to attend psychotherapy and to examine the role of

⁷¹⁸ Cohn (2010); Dumit (2004).

⁷¹⁹ Cohn (2010), p.76.

⁷²⁰ *Ibid.*, p.79.

⁷²¹ *Ibid.*, p.77.

⁷²² Dumit (2003), p.43.

⁷²³ Anderson et al. (2013); Buchman et al. (2013); Illes et al. (2008); Borgelt et al. (2011)

⁷²⁴ Rose and Abi-Rached (2013), p.220.

their own thinking patterns in their illness.⁷²⁵ Based as they are on hypothetical scenarios, these findings cannot tell us what patients would actually do were they to receive a neuroimaging-based diagnosis.

iv) Separation of self from illness

Moving from more practical concerns to those more explicitly associated with identity and self-characterisation – a number of studies have observed that some patients hope that the attribution of a psychiatric disorder to a structural or functional features of the brain might help them to externalise their illness, so it becomes less part of *who* they are and more just feature of their brain as part of their body.⁷²⁶ Cohn describes this as the power of brain scans to facilitate patients in making a “a categorical separation” of themselves from their disease.⁷²⁷

v) Reduced self-blame and stigma

One hoped-for advantage of this kind of separation, cited by both patients and clinicians, is the alleviation of self-blame.⁷²⁸ The reasoning is that, by reducing mental illness to biology – to a “brain disease” – it becomes reclassified as just a “normal” physical illness like any other.⁷²⁹ Cohn argues that this interpretation can help to redress individuals’ “narratives of responsibility” for their own illness and recovery.⁷³⁰ Indeed, in one study, 71% of patients who reported feeling self-blame for their depression expected that a diagnostic brain scan would have a significant impact on mitigating this.⁷³¹

Similarly, in another study, patients with MDD express the hope (one promulgated by mental health charities)⁷³² that neurological diagnoses might reduce the extent to which their illness is the object of stigma or fear.⁷³³ Though this expectation is reported as widespread, some research indicates that increased awareness the role of *genetic* factors in mental illness could instead increase fear and prejudice.⁷³⁴ This is attributed to the perception that disorders with a genetic basis are more serious and intractable (because this places the cause outwith the

⁷²⁵ Illes et al. (2008).

⁷²⁶ Buchman et al. (2013); Dumit (2004), Illes et al. (2008).

⁷²⁷ Cohn (2010), p.74.

⁷²⁸ Buchman et al. (2013).

⁷²⁹ Dumit (2003), p.37.

⁷³⁰ Cohn (2010), p.67.

⁷³¹ Illes et al. (2008).

⁷³² Dumit (2003).

⁷³³ Buchman et al. (2013).

⁷³⁴ J.C. Phelan (2005), "Geneticization of Deviant Behavior and Consequences for Stigma: The Case of Mental Illness" *Journal of Health and Social Behavior*, 46(4): 307-22; J. Read (2007), "Why Promoting Biological Ideology Increases Prejudice against People Labelled “Schizophrenic”" *Australian Psychologist*, 42(2): 118-28.

patients' control), and it is plausible that this perception might extend also to neurological accounts of mental illness.

vi) Prognostic pessimism

Some commentators express a related concern that a possible negative corollary of patients' relegation of their illness to 'mere biology' might be fatalism about their own capacity to manage their illness.⁷³⁵ The studies considered here provide mixed indications of such "prognostic pessimism".⁷³⁶ In one study, many of the participants who had used commercial neuroimaging services said they subsequently felt more in control of their health, with only a few reporting decreased hope.⁷³⁷ And, as indicated above, widespread optimism is reported that a neuroimaging-based diagnosis would encourage treatment uptake. However, one study observes that some participants view their illnesses as permanent, intrinsic biological 'defects'.⁷³⁸

vii) Identification with a disordered brain

In contrast with the roles just outlined, some sources speculate that rather than facilitating a separation of an individual's sense of who she is and her illness, neuroimaging-based diagnoses might have precisely the opposite effect. The concern is that, because of the widely perceived close association between the brain and the self, evidence of a demonstrably disordered brain might lead patients to think of themselves as being inherently disordered.⁷³⁹ For example, Dumit cites one individual's account of her depression in which she questions the very possibility of disassociating *who* she is from her 'sick brain', given its role in her consciousness and agency.⁷⁴⁰ Fears that neuroimaging might lead patients to think of themselves as essentially defective, *qua* whole selves or persons, appears (in the empirical literature reviewed here at least) to be restricted to clinicians – for example, one of whom fears that it might lead patients might feel there is "an error in them".⁷⁴¹ This view is not prominent amongst the reported views of patients.⁷⁴² Nevertheless, this is not a straightforward picture. Buchman *et al* note that their empirical findings reflect:

⁷³⁵ Borgelt et al. (2011).

⁷³⁶ Lebowitz (2014).

⁷³⁷ Anderson et al. (2013).

⁷³⁸ Buchman et al. (2013).

⁷³⁹ *Ibid.*

⁷⁴⁰ Dumit cites the experiences major depression reported by journalist Tracy Thompson as recorded in her memoir of her illness, Dumit (2003).

⁷⁴¹ Borgelt et al. (2011), p.6.

⁷⁴² Illes et al. (2008).

“...the complex and sometimes contradictory ways in which people integrate notions of a disordered brain into a concept of self that at once *has* a brain and *is* a brain.”⁷⁴³

This tension, or ambivalence, has also been observed in empirical studies addressing the wider relationship between neuroscience and self-conceptions.⁷⁴⁴ For example, Pickersgill *et al* observe that, while participants in their study report being drawn to neuroscientific accounts of selfhood or personal development, they also often continue to view their brains not as a “magnificent epicentre of subjectivity” but as “an object of mundane significance”.⁷⁴⁵

viii) Self-description

Finally, some studies indicate that some patients may use neuroimaging-based diagnoses as the basis for applying a descriptor relating to their diagnosis to themselves, for example, seeing themselves as ‘a depressed person’ or someone with defective brain chemistry.⁷⁴⁶ This is a less thoroughgoing kind of self-characterisation than that captured under the previous heading. Dumit, for example, suggests that patients may engage in what he calls “objective-self fashioning” whereby they use neuroimages to construct their sense of themselves as *biological* beings or objects in the world, which may then in turn inform their social identities and their own accounts of who they are.⁷⁴⁷

This ends my extraction of the key themes in the empirical literature, which provide insights into the ways that neuroimaging-based psychiatric diagnoses might impact on recipients’ self-characterisations. Care needs to be taken in drawing conclusions from any of the findings summarised above given that, in many cases, they report speculative responses to questions about hypothetical information availability. Moreover, in most cases the responses are predicated on the assumption that neuroimaging delivers robust and reliable diagnoses in a way that that it probably cannot yet do. Nevertheless, bearing these caveats in mind, the range of findings sketched above already takes me some considerable way into unpacking the ways in which a neuroimaging-based diagnosis of psychiatric disorders *could* impact on recipient’s identities were it to be validated in a way that supported its being offered in clinical settings. The task for the next section is to explore more specifically what these kinds of observations

⁷⁴³ Buchman et al. (2013), p.73 (emphasis in source).

⁷⁴⁴ M. Pickersgill et al. (2011), "Constituting Neurologic Subjects: Neuroscience, Subjectivity and the Mundane Significance of the Brain" *Subjectivity*, 4(3): 346-65; E. Martin (2010), "Self-Making and the Brain" *Subjectivity*, 3(4): 366-81.

⁷⁴⁵ Pickersgill et al. (2011), p.361.

⁷⁴⁶ Buchman et al. (2013); Dumit (2003).

⁷⁴⁷ Dumit (2003), p.38.

and analyses might mean in terms of the role of this category of personal bioinformation in identity as narratively-conceived.

SECTION 5: INTERPRETING THE FINDINGS IN TERMS OF IMPACTS ON NARRATIVE IDENTITY

In this section I will suggest some of the ways that one might interpret the findings outlined above through the framework of identity conceived in terms of narrative self-constitution. As I have indicated there are legitimate questions about the capacity for functional neuroimaging to provide robust diagnostic information. The analysis here will first proceed on the provisional, ‘naïve’ assumption that it does. In Section 7 I will return to (re)consider what its current epistemic limitations mean for its possible identity impacts.

I wish to suggest that the findings summarised above indicate that diagnoses based in neuroimaging could play two kinds of broad roles in the construction of someone’s self-narrative:

- i. It could provide grounds for an individual to edit or modify the characteristics that comprise her self-narrative by appropriating, enacting or rejecting specific self-descriptors associated with mental illness; and
- ii. It could help an individual to achieve, maintain or restore some degree of coherence in her self-narrative in the face of her experiences of mental illness.

i) Modifying self-descriptors

Nikolas Rose and Joelle Abi-Rached suggest that the neurosciences have joined genetics and psychology by “becom[ing] a rich register for narratives of self-fashioning”, heralding the emergence of the “neurobiological self”.⁷⁴⁸ The attitudes reported in the empirical literature outlined in the previous section endorse this claim to some extent, indicating that neuroimaging-based diagnostic findings could provide a tool with which individuals describe and seek to make sense of who they are in the context of their experiences of mental illness. And this might indeed involve (re)describing themselves in terms of their diagnostic status or the functioning of their brains.

However, I submit that it may be misleading to frame this use of diagnostic information as a *wholesale* neuro-information-driven reinvention of how an individual characterises herself. Someone need not, for example, come to think of herself as ‘a depressed person’ to the exclusion of all other self-descriptions. While such an outcome is not impossible, the evidence

⁷⁴⁸ Rose and Abi-Rached (2013), p.220.

considered above suggests rather that this category of bioinformation is more likely to provide (for some) the impetus or the means for editing, modifying or enacting the characteristics, contents, or self-descriptors that *contribute* to their wider self-narratives. Thus where this information invites the self-description of being depressed or being someone with defective brain chemistry, this may be more appropriately understood (for reasons I will explore under the next sub-heading) as just one thread woven into and contributing to the interpretation of their narrative as whole and its relationship to their lived experiences.

Furthermore, I would suggest that the present example usefully illustrates the potential roles of this category of personal bioinformation in someone's self-characterisation are not limited to the *introduction of new* self-descriptors. In several of the studies, individuals had existing psychiatric diagnoses. Their experiences may be viewed less in terms of the acquisition of wholly new elements of their self-narratives. Rather they anticipated that this information could change the meaning and connotations of their diagnosis and thus the nature and weight of the role it plays in how they think about themselves and present themselves to others – for example, where it is hoped that it could reduce stigma or self-blame, or encourage better self-care. These interpretive modifications are not inevitably positive. Although patients' views reflected in the empirical literature are broadly optimistic or pragmatic, it is possible that a neurological explanation of mental illness could be experienced it as more stigmatising, or as undermining an individual's sense of control over her own health.

The literature also illustrates the possibility that a neuroimaging-based diagnosis could support someone's exclusion of mental illness from her self-characterisation. For example, the biologisation of mental illness putatively afforded by neuroimaging might allow someone to reject characterisation of being 'crazy'. Or it might permit her to relegate her illness to a mere bodily fact – in Dumit's terminology, an aspect of her "objective self"⁷⁴⁹ – rather than something that contributes to the story of who she really is as a person, and the characteristics and values that are attributable to her. I suggest that using bioinformation to exclude an aspect of one's life from one's self-narrative is no less a manifestation of this information's identity-significance insofar as this edit shifts the interpretive relationships between other aspects of her story of who she is, the way she interprets experiences and the sources of her motives and values.

As I have suggested in my discussions in the preceding two illustrative chapters, the kinds of narrative roles that we might understand personal bioinformation as occupying are not limited

⁷⁴⁹ Dumit (2004), p.164.

to the modification of the particular characteristics that make up our accounts of who we are. Bioinformation might also play a wider interpretive role in supporting an individual in making sense of her self-narrative as a whole and, specifically, in relation to her experiences of her embodied existence, her health and her interactions with others. I suggest that the attitudes reported in the empirical literature reflect – at least the hope – that neuroimaging-based diagnoses could occupy a similar explanatory and sense-making role, as I shall now outline.

ii) Supporting narrative coherence

My suggestion in this sub-section is that the evidence reviewed above indicates that diagnostic findings from psychiatric neuroimaging could also support an individual to make sense of some of the cognitive, affective and behavioural experiences of mental illness and how these impinge upon her sense of who she is. And in doing so, these findings might help her to develop, maintain or restore a degree of narrative coherence and to thus to construct an identity that allows her to navigate her lived experiences, including those of her illness.

First person accounts given by those living with mental illness sometimes characterise the experiences of illness in terms of a struggle to manage identity.⁷⁵⁰ The onset of serious mental illness has been described as a bifurcation in an individual's self-narrative.⁷⁵¹ For example, as referred to in Chapter 2, Mackenzie and Poltera cite Helen Saks's account of living with schizophrenia in which she describes experiencing her sense of who she is as fragmented by the illness.⁷⁵²

These profoundly distressing experiences of a "loss of self" are unlikely to be comprehensively addressed by the availability of neuroimaging-based diagnoses.⁷⁵³ Nevertheless, the responses outlined in Section 4 above, and discussions of the relationship between self-narratives and mental illness in the wider literature, suggest ways in which (what are perceived to be) reliable and definitive diagnostic categories and explanations of mental illness symptoms might support some restoration of narrative coherence. For example, both patients and clinicians contributing to several of the studies cited above report the hope that neuroimaging-based diagnoses would provide welcome explanation, legitimisation and context for individuals' illness experiences – demonstrating that they are not 'just crazy' and that the source of their

⁷⁵⁰ J.P. Wisdom et al. (2008), "Stealing Me from Myself: Identity and Recovery in Personal Accounts of Mental Illness" *Australian and New Zealand Journal of Psychiatry*, 42(6): 489-95.

⁷⁵¹ D. Roe and L. Davidson (2005), "Self and Narrative in Schizophrenia: Time to Author a New Story" *Medical Humanities*, 31(2): 89-94.

⁷⁵² Mackenzie and Poltera (2010).

⁷⁵³ Wisdom et al. (2008), p.491.

distress is real and a physical disease just like any other. Some authors have suggested that acknowledgement of the reality of illness and being able to accommodate this within one's account of who one is may be both therapeutic and contribute to the restoration of a coherent sense of self in the face of the disruptive experiences of mental illness. For example, some psychiatric research indicates that those living with psychosis may benefit from the construction of 'recovery narratives', in which the individual acknowledges her illness and incorporates understanding of this into the construction of a self-narrative that helps her to make sense of its effects on her life.⁷⁵⁴ Meanwhile, Mackenzie and Poltera describe how, by "appropriating her illness as part of herself", Saks was able to undertake treatment which helped her to bring some coherence to her self-narrative and "enable[d] her to be the self she wants to be".⁷⁵⁵

The kinds of identities we are able to sustain and inhabit are influenced and constrained by the ways that others characterise us. For this reason, it is important that our self-narratives are not only intelligible on their own terms and in relation to our experiences of our embodiment and our health, but that they also broadly accord with how others view us and the world (see Chapters 2 and 3). The findings outlined in Section 4 indicate that the value that some research participants invest in neuroimaging-based diagnoses may be rooted in the desire to achieve this kind of relational coherence. Here the information's anticipated value lies in its perceived objectivity and legitimising power. This power relates both to its capacity to reinforce the individual's own account of who she is (as ill, or 'not just crazy'), and also in its potential to persuade others to adjust their view of the nature of her illness (including its cause and associated stigma) and its reality (and the reality of her suffering), and thus their view of her. As noted above, however, the success of this last endeavour is contingent on other's investing neuroimaging findings with the same meaning and explanatory power as the patient herself.⁷⁵⁶

My intention in this section has been to explore what the attitudes reported in the empirical literature indicate about the potential impacts of neuroimaging-based psychiatric diagnoses might be on individuals' identities, were one to adopt a narrative conception of identity. Echoing themes emerging in the preceding two chapters, I have suggested that this particular category of personal bioinformation could play a role in modifying the characteristics that comprise someone's identity narrative – in this instance the extent and ways in which mental illness features amongst these. It might also play a role in supporting an individual in making sense of her own and others' experiences of her mental illness and accommodating these

⁷⁵⁴ Roe and Davidson (2005); Wisdom et al. (2008).

⁷⁵⁵ Mackenzie and Poltera (2010), p.40.

⁷⁵⁶ Cohn (2010).

within her self-narrative in a way that helps (to some extent) to maintain or restore its coherence. My suggestion is not that the impacts of this category of information on an individual's self-conception will always be welcome, on the contrary they could be distressing or challenging. Nevertheless, my contention is that the possible consequences of these impacts are neither trivial – to the extent that they shape her understanding of who she is and her capacity to inhabit and enact this self-conception – nor are they reducible to the role of this information in shaping her health behaviours or healthcare choices.

However – and this is no small caveat – the suggestions made in this section are premised on the provisional assumption that the diagnoses generated by psychiatric neuroimaging *do* provide individuals with robust information about their mental health. I have indicated in Section 2 why this is unlikely currently to be the case. And in Section 7 I will turn to consider what this entails for the capacity of this information to fulfil the kinds of narrative roles that I have suggested in this section. Before doing so it will be instructive to at the factors that appear to be influential in (potential) recipients according neuroimaging-based diagnosis significance in their self-conceptions. Exploring these factors will inform both generalisable insights into what shapes the identity-significance of personal bioinformation, and the specific sceptical critique of Section 7.

SECTION 6: FACTORS POTENTIALLY INFLUENCING IDENTITY IMPACTS

As in the previous illustrative chapters, I will divide this section of my analysis into two questions:

- What does the empirical evidence indicate about which features of neuroimaging-based diagnoses might contribute to their playing a role in individuals' self-conceptions?
- What factors appear to account for diversity amongst individuals' responses to this information?

I will address these in turn.

Accounting for the potential narrative significance of this information

I have already indicated the kinds of factors that may to contribute neuroimaging-based diagnosis playing a role in an individual's self-characterisations in my discussion of the findings from the empirical literature, so it just remains to bring these together here for the purposes of clarity. I suggest that two possible reasons emerge (albeit equivocally) from the literature:

- i) The assumed close association between the brain and the self, and
- ii) The perceived objectivity and reliability of neuroimaging findings.

i) Close association of brain and self

Some of the significance that individuals invest in this category of personal bioinformation could be attributable to the perceived close relationship between the brain and self – a perception possibly fed by the way in which the research outputs from the neurosciences are represented in popular culture and the non-specialist media as providing insights into our minds and characters.⁷⁵⁷ There is not space to explore the problems of neuro-reductive view of the self here.⁷⁵⁸ And I shall return in Chapter 8 to the question of the extent to which the perceived significance of personal bioinformation to our self-narratives can be attributed to social constructions of identity-significance. However, it is important to note here that neither the reported attitudes reviewed above, nor the wider literature on neuroscience and the self, indicate that neuro-reductive or neuro-essentialist views of the self are universally or straightforwardly held. On the contrary, this literature points instead to widespread ambivalence about the extent to which who we are is shaped by the functioning of brains.⁷⁵⁹

ii) Perceived objectivity and reliability

There are indications that patients invest neuroimaging-based diagnoses with personal significance because they view these as providing authoritative and reliable insights into the nature and cause of their mental illness. Specifically, the studies discussed above suggest that, because these diagnoses are based on putatively objective data about brain activity, they are seen as more dependable than diagnoses based on the clinical judgements of mental health professionals. This belief seems to lie behind participants' perception that that findings derived from neuroimaging have the power to explain, legitimise and help them make sense of their experiences of mental illness.

This factor echoes indications in the previous two illustrative examples that the bioinformation in question is valuable to the recipients' self-conception because it is true⁷⁶⁰ or carries the authority of genetic science.⁷⁶¹ And this accords with my proposal in Chapter 3 that the value of personal bioinformation to narrative self-constitution lies in its capacity to explain or

⁷⁵⁷ O'Connor et al. (2012); S. Choudhury and J. Slaby, *Critical Neuroscience : A Handbook of the Social and Cultural Contexts of Neuroscience* (Chichester: Wiley Blackwell, 2012).

⁷⁵⁸ For discussion of this, see G.R. Gillett (2009), "The Subjective Brain, Identity, and Neuroethics" *The American Journal of Bioethics*, 9(9): 5-13; Glannon (2009)

⁷⁵⁹ Dumit (2004); Pickersgill et al. (2011).

⁷⁶⁰ See Chapter 5.

⁷⁶¹ See Chapter 6.

anticipate embodied and health-related experiences and thus help individuals to construct identities that make sense in the context of the realities of embodied existence. However, as I shall go on to discuss in Section 7, the problem in this instance is that neuroimaging does not, or at least does not yet, provide robust or reliable diagnostic information. And I will suggest that this carries important consequences for its value to patients' self-conceptions and ethical implications for provision of this category of personal bioinformation. Before unpacking these claims, though, I will review what the studies discussed above indicate about which factors influence *differences* in individuals' expectations of the impacts and value of this information.

Accounting for diversity in identity impacts

The evidence regarding which variables influence (potential) information recipients' differing attitudes to neuroimaging-based diagnoses is thinner here than in the previous two illustrative examples. Some very tentative inferences might be drawn from single studies. For example, one study (addressing the role of neuroscience in general in informing self-conceptions) posits that neuro-explanations for experiences or behaviour may have greater traction with individuals who have had personal experience of brain damage or disorders.⁷⁶² And, as I have noted above, scepticism amongst friend and family about the explanatory power of neuroimaging could undermine an individual's own optimism about its capacity to reconfigure what their mental illness means to them.⁷⁶³ However, two further factors that emerge more clearly from several studies. These are the parts played by:

- i) The medium in which the information is conveyed, and
- ii) Awareness of the information's epistemic limitations.

i) Information medium

The availability of actual, printed *neuroimages* appears to contribute to the meaning and significance with which patients invest in psychiatric neurological findings. Cohn's study indicates that the materiality and portability of these images were key to their deployment by patients in bearing witness to their suffering and attempts to deploy them in legitimising and explaining their experiences of schizophrenia.⁷⁶⁴ Similarly Dumit describes neuroimages as "potent objects", whose power to persuade and to designate people into categories according to their diagnosis lies in their compelling visual nature and apparent simplicity and

⁷⁶² Pickersgill et al. (2011).

⁷⁶³ Cohn (2010).

⁷⁶⁴ Ibid.

objectivity.⁷⁶⁵ This phenomenon has been observed more widely in relation to medical imaging technologies.⁷⁶⁶ I shall return in Section 7 to discuss why this potency may be problematic.

ii) Awareness of epistemic limitations

It has been observed that patients' enthusiasm and optimism about the capacities of neuroimaging to manage their illness and its relationship to their sense of who they are is in marked contrast to the much more cautious expectations of neuroscience researchers working in this field.⁷⁶⁷ And a similar, though less stark, contrast can be observed between the expectations of patients and some healthcare professionals.⁷⁶⁸ It might be surmised that this is attributable to researchers and clinicians having greater insight into the current (un)reliability and epistemic limitations of psychiatric neuroimaging.

The two variables outlined here are clearly closely connected to the role that the assumed reliability and objectivity of neuroimaging-based diagnoses plays in patients' expectations of their value, as outlined in the previous sub-section. It is to the problems with these assumptions and the consequences of these for recipients' self-conceptions that I turn in the final section.

SECTION 7: NEUROIMAGING-BASED DIAGNOSES AND NARRATIVE JEOPARDY

My aims in this section are, first, to review the chief reasons why neuroimaging may not in fact yet – and (on some views) perhaps not ever – provide reliable psychiatric diagnoses and, secondly, what this implies for the kind of impacts this category of personal bioinformation could have on recipients' self-conceptions. I suggest that, contrary to the useful self-descriptive and interpretive roles outlined in Section 4 on the basis of the naïve assumption of their reliability, these diagnoses could instead have detrimental narrative impacts.

Epistemic limitations of findings

The first reason that psychiatric neuroimaging is not able to provide the kind of unambiguous or dependable diagnoses on which many of the hopes and expectations reflected in Section 3 depend is that, as already noted, this application of the technology is still at a developmental phase. There are currently problems with producing replicable or reliable findings.⁷⁶⁹ Some

⁷⁶⁵ Dumit (2004), p.133. See also, A.L. Roskies (2008), "Neuroimaging and Inferential Distance" *Neuroethics*, 1(1): 19-30.

⁷⁶⁶ K. Joyce (2005), "Appealing Images: Magnetic Resonance Imaging and the Production of Authoritative Knowledge" *Social Studies of Science*, 35(3): 437-62.

⁷⁶⁷ J.A. Anderson and J. Illes (2012), "Neuroimaging and Mental Health: Drowning in a Sea of Acrimony" *AJOB Neuroscience*, 3(4): 42-43; Borgelt et al. (2012).

⁷⁶⁸ Borgelt et al. (2012).

⁷⁶⁹ Cooper et al. (2013).

commentators maintain that, with methodological and analytical improvements, these kinds of problems might yet be effectively addressed.⁷⁷⁰ However, other challenges to the putative authority of psychiatric neuroimaging, rooted at a deeper, ontological level, may not be quite so easily overcome.

Clearly if one were to take a thoroughgoing antirealist position on mental illness, then psychiatric neuroimaging would appear wholly misguided.⁷⁷¹ However, even if one allows that the brain has some role to play in mental illness, but that brain facts are insufficient to capture everything about its causes, aetiology or phenomenology,⁷⁷² one might still be sceptical that neuroimaging can provide a more reliable or appropriate means of diagnosis than existing clinical methods.⁷⁷³ To provide just one illustration – psychiatric diagnostic categories do not pick out biologically homogenous natural kinds by ‘carving nature at its joints’, but are normative categories, dependent on clinical judgements.⁷⁷⁴ This means that neural biomarkers are unlikely to align neatly with existing classifications, presenting challenges for unambiguous diagnosis and appropriate care. Furthermore, if mental illness is more than a brain disorder, it is problematic to reduce psychiatric disorders and their associated phenomenology to biological categories based on neural activity, especially if the effect of this is to ignore or occlude the wider embodied, social or environmental nature of the causes and experiences of disease.⁷⁷⁵

These caveats apply to an even greater extent with respect to bioinformation in the form of graphical neuroimages themselves. As noted above, when made available to patients, these images may be instrumental in giving the impression that an accompanying diagnosis is objective and incontrovertible. However, as noted in Section 1, neuroimages are the result of statistical analyses and therefore both less immediate and less objective than their pictorial form suggests.⁷⁷⁶ Meaningful clinical differences are unlikely to be visible from them.⁷⁷⁷

⁷⁷⁰ Farah and Gillihan (2012); M. Lifshitz et al. (2012), "Lengthy and Expensive? Why the Future of Diagnostic Neuroimaging May Be Faster, Cheaper, and More Collaborative Than We Think" *AJOB Neuroscience*, 3(4): 48-50.

⁷⁷¹ Such antirealist positions are associated with, for example, the work of Thomas Szasz, and Foucault's writing on psychiatry. Wholesale scepticism about the reality of mental illness and the role of the brain in it is, however, increasingly marginal. For further discussion, see C. Perring, "Mental Illness," in *The Stanford Encyclopedia of Philosophy (Winter 2016 Edition)*, ed. E.N. Zalta.

⁷⁷² Giordano (2012); M. Pickersgill (2011), "'Promising' therapies: Neuroscience, Clinical Practice, and the Treatment of Psychopathy" *Sociology of Health & Illness*, 33(3): 448-64.

⁷⁷³ For discussion of further ontological and epistemology problems see, Giordano (2012); Ramos (2012).

⁷⁷⁴ Ramos (2012),

⁷⁷⁵ Glannon (2009).

⁷⁷⁶ Roskies (2008).

⁷⁷⁷ Cooper et al. (2013), p.242.

Clinicians in one study acknowledged that, despite giving neuroimages to research participants as thanks for taking part, they were meaningless.⁷⁷⁸ This illustrates how someone's intention in supplying personal bioinformation may be very different from the meaning invested in the information by the recipient. This echoes findings in the previous illustrative example which highlighted the crucial role played by the wider informational and interpretive context within which genetic test results are conveyed in the significance that recipients invest in them and the uses to which they apply them. The ethical consequences of effective communication of the epistemic limitations of personal bioinformation come into sharp focus as I now turn to consider what a failure to appreciate the epistemic limitations of psychiatric neuroimaging might mean for the impacts that it has on someone's self-narrative.

Potential for identity detriment

One response to this question is simply to conclude that if neuroimaging cannot, or does not yet provide reliable diagnoses, or reflect the complex, multifactorial nature of mental illness, then its outputs may simply fail to fulfil the kinds of narrative roles that I have proposed in Section 6. However, I wish to argue, that this overlooks the possible *negative* consequences for someone's identity, were she to place great faith in the abilities of a neuroimaging-based psychiatric diagnosis to inform the role of mental illness in her self-narrative, *without being aware* of its epistemic limitations.

The most obvious identity-related consequence of someone investing misplaced faith in objectivity and authority of a neuroimaging-based diagnosis is that it might lead her erroneously to adopt a particular kind of self-description – 'I am someone with illness x'. But I wish to suggest that the detrimental impacts may also be woven more deeply into the intelligibility and integrity of her account of who she is than this implies.

This may be most readily appreciated where the contribution of the information to a recipient's identity is predicated upon its clinical utility. I suggest that if a misleading diagnosis, or a neuroreductive conception of a disorder, leads someone to undertake unsuitable preventative behaviours or treatments, this might then jeopardise her capacities to construct a coherent self-narrative in one of two ways. First, the pursuit of effective interventions might contribute to protecting the very capacities for memory, and cognitive and affective interpretation that make the construction of a coherent, enduring self-narrative possible at all. Secondly, someone's specific diagnosis and pursuit of associated therapeutic strategies may be integral to her

⁷⁷⁸ Cohn (2010).

particular mode of practical self-characterisation.⁷⁷⁹ If someone's diagnosis is unsound and the strategies she adopts are inappropriate and ineffective, then her enactment and constitution of this self-characterisation may be critically undermined.

The pursuit of inappropriate therapies is not, however, the only way in which someone's orientation towards her illness and recovery could be misdirected by her assumption that her illness is of one kind rather than another. For example, misdiagnosis might ill-prepare someone to anticipate or tackle the particular experiences of living with her disorder and their impact on her sense of who she is. Or, if a neuro-reductive perspective leads someone to overlook or devalue bodily, environmental, or social contributors to her mental illness, she may struggle to make sense of or respond to the ways that these impinge, for good or ill, upon her own illness experiences and account of who she is. A welcome 'meaningful explanation' of one's illness is no kind of explanation if it is partial, to the occlusion of other more significant factors. My suggestion here is that, to the extent that someone uses misplaced assumptions about the nature of her disorder to construct and interpret her self-narrative she is, in effect, building her identity on precarious foundations. What I mean by this is (as argued in Chapter 5) even if her sense of who she is not is not inevitably or immediately rendered incoherent, it is nevertheless vulnerable to challenge and disruption by her experiences of illness, and provides a self-conception that ill-equips the individual to navigate and make sense of these experiences as they assail her.

This analysis casts doubt on the potential, given the current state of the art, for findings from psychiatric neuroimaging to fulfil the kind of useful or welcome narrative roles suggested by the discussion in Section 4. Indeed, it raises the question of whether, given that its epistemic limitations may not be wholly dependent on the developmental state of this technology, this category of personal bioinformation could ever provide a suitable foundation for making sense of who one is. But, at the very least, it points to the critical importance of making recipients aware of the limitations of neuroimaging-based diagnoses so that they have the opportunity to revise, or at least reflect upon, their expectations or hopes about how they might use these to interpret the role of mental illness in their accounts of who they are. I will return in the remaining chapters to discuss what this entails for the responsibilities of those who disclose personal bioinformation.

⁷⁷⁹ Rose (2007).

SECTION 8: CHAPTER CONCLUSION

There are indications that those living with psychiatric disorders may be keen to access neuroimaging-based diagnostic information for reasons that extend beyond its health utility. These reasons may include the desire to reinterpret the meaning of their illness and their sense of who they are in light of neurological information. I have suggested that evidence of people's attitudes to this information offers *prima facie* grounds for positing that the outputs of diagnostic neuroimaging could contribute to recipients' construction of their self-narratives in two broad ways – by providing particular modes of self-categorisation, or by helping to locate illness experiences within a wider, intelligible, sense of who they are.

However, at its current developmental stage psychiatric neuroimaging is unlikely to provide robust diagnostic information. My suggestion has been that where individuals invest value in this as a means of self-conception, this is often dependent their perceptions that it is authorities and objective. While it lacks these qualities, its capacity to contribute constructively to recipients' identities is undermined. Moreover, where these limitations are not appreciated by information recipients, reliance on the authority of the bioinformation could be actively detrimental to their construction of coherent self-narratives. The unwitting use of misleading or inadequate bioinformation is a key consideration in developing an account of the role of personal bioinformation in identity development. This underscores two central propositions of this thesis that I shall develop further in chapter 8. The first is that personal bioinformation contributes to the construction of a coherent self-narrative only insofar as it provides a reliable and useful means of interpreting lived, embodied experiences. Secondly (and relatedly) the way that bioinformation is communicated, and the interpretative support that is provided when it is, could be crucial in shaping the impact it has on the recipient's self-conception. Individual's identity-related interests extend beyond *whether* they receive particular information, to the *manner, medium and context* in which they do.

This chapter is the last of my three illustrative examples. My task in Part III of this thesis is to bring together my analyses of all three and apply them to addressing the central ethical and practical aims of this thesis – those of justifying my assertion that policies and practices governing information subject's access to personal bioinformation should attend to their identity-related interests, and of providing an ethical framework to guide these policies and practices in doing so. In Chapter 8 I will build on my analyses in these illustrative chapters to refine my theoretically-based argument from Chapter 3 and to demonstrate the way in which the potential narrative roles of the three categories of bioinformation explored here may be fulfilled by a wider range of personal bioinformation. I will also draw on the lessons from

these examples to address why any particular instance or kind of personal bioinformation is significant or valuable to someone's identity. These steps will then set the scene for Chapter 9 in which I will characterise the specific nature of our identity-related interests in accessing personal bioinformation and the corresponding responsibilities of those who could disclose it to us, and propose an ethical framework to guide disclosure decisions.

PART III – BUILDING AN ETHICAL FRAMEWORK

CHAPTER 8: REFINING THE THEORY: ACCOUNTING FOR IDENTITY VALUE, DETRIMENT AND SIGNIFICANCE

SECTION 1: AIMS OF THIS CHAPTER

In the preceding three chapters my aim has been to demonstrate that the argument I developed in Chapter 3 – that personal bioinformation can play an important part in the development of embodied identity narratives – is consistent with people’s actual experiences as reported in the empirical literature. I have suggested that it does indeed appear to be broadly consistent – a conclusion I will further underline in this chapter. My purpose in exploring the three illustrative examples was also to refine my theoretically-based argument in light of empirical evidence. This chapter will consolidate my analyses (from each of the illustrative chapters) of the nature and extent of the roles played by those three kinds of personal bioinformation in information subjects’ self-narratives. From this I will build a more nuanced picture of the normative relationship between bioinformation and identity.

Whereas the argument I presented in Chapter 3 focused upon the significance of personal bioinformation as a broad category, here my intention is to drill beneath this, to the question of what shapes the impacts of particular kinds or instances of personal bioinformation on our self-narratives. My aims in doing so are not only to permit generalisation beyond the specific examples discussed in the preceding chapters, but also to suggest ways we can discriminate between circumstances in which personal bioinformation is likely to be relevant and valuable to our identities from those in which it is not. To this end, I will develop the conceptions of *‘identity value’*, *‘identity detriment’* and *‘identity significance’*. Clarifying the nature of these qualities will enhance the analytical insights offered by the normative argument I have offered thus far and will provide the foundations for the practical goal of this thesis. That goal is to construct an ethical framework to guide decision-making about how access to personal bioinformation might be managed and regulated in light of individual information subjects’ identity-related interests. That framework will follow in Chapter 9.

To prepare the ground for the framework, this chapter will address the following three questions:

- i. **What refinements are needed to my central claim that personal bioinformation has an important part to play in our self-narratives?** (Section 2)

- ii. **What does my analysis suggest about what it means for particular personal bioinformation to be *valuable* or *detrimental* to our identities?** (Section 3)
- iii. **What factors contribute to our experiencing particular personal bioinformation as being *significant* to who we are, such that it has valuable or detrimental identity impacts at all?** (Section 4)

The answers to these questions will help me to answer the third and fourth of the headline research questions posed in Chapter 1. Those are respectively: **what are the nature and scope of our identity-related interests in accessing personal bioinformation?** and **what ethical responsibilities for disclosure accrue to those who hold personal bioinformation about us?** I will address these questions in Chapter 9.

The three substantive sections of this chapter will take the following form:

In Section 2 I will first take stock of the potential narrative roles of personal bioinformation suggested by my illustrative examples. I will group these into seven categories. On the basis of this analysis I will then outline the four key refinements that are needed to take my normative argument through to its practical application.

In Section 3 I will build on these refinements by suggesting that the value and detriment of personal bioinformation to our self-narratives are attributable to two kinds of impact: that of the information on the constituent *contents* of someone's self-narrative; and that on the narrative's *overall coherence*. I will argue that recognising this duality is important to understanding the scope and ethical significance of identity impacts, the relevance of bioinformation's epistemic qualities, and the pertinence of how information is presented to its value.

In Section 4 I will turn to the question of what the illustrative examples suggest about the factors that contribute to whether we experience particular kinds or instances of personal bioinformation as significant to who we are. I will suggest that there are four key factors at work, the combination of which carries implications for the predictability of identity significance and the role of others in shaping it.

I will now turn to address the first of my three research questions listed above.

SECTION 2: REVIEWING THE NARRATIVE ROLES OF PERSONAL BIOINFORMATION AND REFINING MY ARGUMENT

This section will review and consolidate the suggestions I have made over the previous three chapters as to the range of possible narrative roles that diverse kinds of personal

bioinformation can play. This will provide the basis both for identifying the refinements needed to my theoretically-based argument in this section, and for my two-strand analysis of what constitutes identity value and detriment under a narrative conception in Section 3.

Diverse narrative roles

As the three preceding illustrative chapters indicate, where personal bioinformation *does* affect the identity narratives of those to whom it pertains, it does so in many different ways. Nevertheless, I would suggest that some common themes emerge, which permit me to group these effects under seven broad headings, corresponding to the possible roles that personal bioinformation may play in our self-narratives:

- i) Editing self-descriptors;
- ii) Fulfilling normative self-descriptors;
- iii) Changing relationships;
- iv) (Re)interpreting experiences;
- v) Projecting oneself into the future;
- vi) Disrupting one's narrative; and
- vii) Changing one's outlook and priorities.

These categories are based on my analysis of the findings reviewed in Part II. As such they are not purely inductively derived, but the product of interpreting this evidence through the framework of narrative identity and its normative implications.⁷⁸⁰ These categories are intended to capture the range and diversity of possible narrative roles, not to provide definitive, discrete or exhaustive categorisations. On any given occasion, bioinformation might occupy none, or more than one, of these roles.

i) Editing self-descriptors

In an important sense the entire multi-stranded web of an identity narrative is a complex, composite self-descriptor. But incorporated within it may be more specific identifiers or labels relating to, for example, particular aspects of our health, our relationships, or group memberships. The illustrative examples indicate that bioinformation can play a part in changing the possible self-descriptors available to us – for example, revealing disease risk status⁷⁸¹ – or by modifying existing descriptors – for example, by reducing the stigma of a

⁷⁸⁰ As such, the examples given under each role below are illustrative, and not intended to signal the limits of its applicability.

⁷⁸¹ See Chapter 6.

prior psychiatric diagnosis.⁷⁸² These edits could be welcome – for example, learning she is donor-conceived makes someone feel special – or is painful – for example, where this information severs an assumed and valued genealogy.⁷⁸³

ii) Fulfilling normative self-descriptors

Some, perhaps many, of the self-descriptors referred to under the previous heading will be normative (or ‘practical’) ones – meaning that they are not just passively acquired, but constituted or undermined by the kinds of motives we pursue and how we conduct ourselves.⁷⁸⁴ Personal bioinformation sometimes operates as a means of constituting such an identifier. For example, obtaining information about genetic disease susceptibility in order to share this with family members, or contribute to health research, might be integral to someone’s role as a loving daughter or sister.⁷⁸⁵ Conversely, for someone else, acquisition of the same information could lead someone to feel they have failed in their parental role to protect their children.⁷⁸⁶

iii) Changing or reinforcing relationships

There are a number of different ways that personal bioinformation can impact on relational aspects of identity and the ways in which someone sees her narrative as entwined with those of others, or as part of wider, shared narratives. It might reinforce or undermine relationships with particular others where these roles constitute self-descriptors – for example by revealing genetic relationships, or (as indicated under the previous heading) permitting or inhibiting someone’s ability to enact her relational roles within her family. On a broader scale, personal bioinformation might contribute to the acquisition (or loss) of a group identifier, such as that of being a ‘BRCA carrier’.⁷⁸⁷ Or information about disease risk status might play a role in underpinning ‘biosocial’ activities – that is group activities centred around shared biological attributes – such as patient activism, that serve to contribute to someone’s self-conception.⁷⁸⁸ As this last example illustrates, the relationships that are served (or undermined) by the acquisition of bioinformation may not only contribute to how we characterise ourselves, but provide the contexts in which we do so.

⁷⁸² See Chapter 7.

⁷⁸³ See Chapter 5.

⁷⁸⁴ See Chapter 1.

⁷⁸⁵ See Chapter 6.

⁷⁸⁶ See Chapter 6.

⁷⁸⁷ See Chapter 6.

⁷⁸⁸ Gibbon and Novas (2008), p.8

iv) (Re)interpreting experiences

Personal bioinformation can provide fresh or additional interpretive context that permits an individual to fill out or make sense of aspects of her existing self-narrative and how these relate to her lived experiences. This might apply where personal bioinformation helps someone to account for tensions, anomalies or gaps. For example, donor-conceived individuals may welcome learning of their donor conception because it helps to resolve questions and confusion about family resemblances or interactions.⁷⁸⁹ Similarly, the perceived authority of a neuroimaging-based diagnosis may help someone to make sense of her symptoms and to think of herself as ill rather than ‘crazy’.⁷⁹⁰

v) Projecting oneself into the future

The stories we tell of who we are, are coloured not only by what has already happened to us, but also by our anticipation of what could yet happen. For example, probabilistic information about the risk of future disease, might help an individual to imagine and plan for how her narrative could unfold and to orient and reinterpret her current self-narrative accordingly. Some of this might amount to psychological preparedness, or alleviation of a burdensome uncertainty about the risk of developing a condition like Alzheimer’s disease.⁷⁹¹ Practical steps such as health-protective measures or financial planning, are no less part of someone’s identity development, if for example, these serve to avert or mitigate future narrative disruption by the onset of hereditary cancer, or constitute the ways in which someone enacts conceptions of themselves as ‘at risk’.⁷⁹² The role of bioinformation in reorienting one’s self-narrative towards a possible future is not inevitably positive. For example, learning that one is of elevated risk of a serious genetic illness could lead to reinterpretation of current experiences in light of imagined symptoms or feelings of being doomed.⁷⁹³

vi) Disrupting one’s narrative

It is possible that the divergence is so great between someone’s existing narrative and the state of affairs conveyed by her personal bioinformation that it disrupts her existing narrative, making it difficult for her to locate who she is. For example, some donor-conceived individuals report enduring disorientation in their self-conceptions upon discovering their donor.⁷⁹⁴

⁷⁸⁹ See, Chapter 5.

⁷⁹⁰ See Chapter 7.

⁷⁹¹ See, Chapter 6.

⁷⁹² See Chapter 6; see Novas and Rose (2001).

⁷⁹³ See Chapter 6; see Konrad (2005).

⁷⁹⁴ See Chapter 5.

Similarly, learning that one is at high inherited risk of breast and ovarian cancer could disrupt someone's prior self-conception as a healthy person, or a prospective parent, or hinder someone's inability to see her self-narrative persisting in a recognisable or desirable form.⁷⁹⁵ As noted in Chapter 5, with respect to revelations of donor origins, narrative disruption need be neither permanent nor entirely unwelcome if the individual is able to reconstruct a new and satisfying account of who they are with the new information available.

vii) *Changing one's outlook and priorities*

The narrative impacts of personal bioinformation need not be connected to clearly defined actions. Instead they may amount to changes in outlook or interpretation. For example, predictive information about possible future illness that lacks clinical utility may nevertheless instigate reflection on priorities and values.⁷⁹⁶ And, as illustrated by the example of information about donor conception, some individuals may welcome the opportunity to place elements of their narratives in a wider context, or to reassess how aspects of their stories fit together.⁷⁹⁷

What do these roles indicate?

Corralling the analyses of the range of bioinformation's potential roles in our self-narratives from Part II of this thesis under the seven categories above helps to bring some order to the detail within the illustrative examples. The list above is not intended to be exhaustive. But I would submit that it both illustrates and offers support for my claim that *personal bioinformation can impact in important ways on an individual's development, maintenance or restoration of her identity narrative in the context of her embodied existence.*

Furthermore, I submit that outlining these roles in generic, high-level terms serves to open up the space to imagine how each of them could potentially be filled by many different kinds of personal bioinformation – other than the three specific examples discussed in the illustrative chapters. Any further examples will inevitably be piecemeal, but, for example, we might imagine how, for someone with a rare, undiagnosed disease, the identification of the genetic mutation associated with their condition could galvanise their sense of hope and commitment to research participation. Or suppose that research involving whole-body imaging incidentally reveals that a participant has extensive scarring on her fallopian tubes consistent with a prior infection – this finding could both initiate a reassessment of her past sexual relationships and

⁷⁹⁵ See Chapter 6.

⁷⁹⁶ See Chapter 6.

⁷⁹⁷ See Chapter 5.

alter her conception of herself as a future parent. And results obtained from an online genetic ancestry tracing service might provide means for someone to feel connections to, and solidarity with, those with whom she shares (apparently) similar genealogical geography.⁷⁹⁸

The transferability of my analysis beyond the specific examples of Part II is critical to my claim that, in principle, very many different kinds of personal bioinformation could contribute to or detract from our development of our self-narratives. However, it is not my intention to suggest that all and every instance of personal bioinformation could or would make a difference, let alone a valuable difference, to its subject's self-narrative – as I shall now go on to discuss.

Refining my central claim

This section now turns to address the first of my research questions for this chapter, outlined above. Even though the preceding review of the potential narrative role of personal bioinformation broadly supports my central claim to the potential importance of this information to our identities, I wish to suggest that the evidence from the illustrative examples also provides texture and nuance, which indicate the need for some refinements to that claim. I shall outline here what I take to be the four most important clarifications and refinements. These pertain to:

- The diversity of narrative roles;
- Limits to authorial control;
- The possibility of negative impacts; and
- Impacts on contents and coherence.

Diversity

The first of these clarifications is to note the sheer number and variety of possible identity-related roles that personal bioinformation might play. Furthermore, it appears that this information may affect our accounts of who we are with varying degrees of pervasiveness or gravity. And sometimes it will have little or no effect. This variation holds both between different kinds of bioinformation and between different information subjects and disclosure contexts. This presents a formidable challenge to any attempt to govern information access in a way that supports and protects subjects' development of their identities. The conceptions of

⁷⁹⁸ I note my concerns with the epistemic limitations, and thus the identity value, of genetic ancestry information in Section 3 below.

identity value and identity significance that I will develop in Sections 3 and 4 respectively will provide some indications of how this complex terrain might be charted.

Authorial control

Secondly, the illustrative examples make it clear that, although we are the chief authors of our own identity narratives, we do not have absolute control over the roles that personal bioinformation plays in our self-conceptions. For example, some information might precipitate the involuntary severing of relationships, or we may have only a limited capacity to resist the stigmatising connotations of some self-descriptors. In these cases, the narrative consequences of receiving the information might be better thought of as passive incursions, rather than active uses. In Section 4 I shall consider the factors that influence whether particular personal bioinformation plays any role in a recipients' self-narrative and the degree to which she herself and others may control or shape this. Before turning to that question, however, I wish to address two further refinements that lie at the very heart of understanding the nature of the impacts that personal bioinformation can have on our identities, and which will provide the basis for my analysis in Section 3.

Positive and negative impacts

The third refinement, then, is the need to relinquish the purely positive picture sketched in Chapter 3. There I proposed that personal bioinformation can contribute constructively to our self-narratives because it enhances their congruence with our embodied experiences. However, it is clear that the impacts on our self-narratives of receiving personal bioinformation are more complex than this. These impacts are not always welcome or constructive. The account I will build from here needs to accommodate the possibility of negative effects, and to be grounded in a robust understanding of what it means for personal bioinformation to be *valuable* or *detrimental* to our identities.

Impacts on contents and coherence

The fourth refinement will be key to my characterisation of identity value and detriment. I wish to suggest that, amongst the seven roles listed above, it is possible to identify two broad ways in which personal bioinformation can affect our identities for good or ill. It may impact upon specific *contents* of our self-narratives or our abilities to develop, maintain or restore the *coherence* of the overarching narrative. Broadly speaking, the first three of the roles listed above – editing and enacting self-descriptors and changing our relationships – may be seen as chiefly falling in the former category, while the remaining four fall under the latter. However, it is not possible to make a clean division of this kind and, as I will return to discuss in Section

3, there will be cross-over and interdependency between impacts on the contents and coherence of our identities.

This thesis is concerned with how access to personal bioinformation should be managed so as to best protect information subjects' abilities to develop and inhabit their identities. Therefore, the first challenge emerging from the refinements above is to address the second of my research questions listed at the start of this chapter: what does it mean under the account I am developing for personal bioinformation to be valuable or detrimental to our identities?

SECTION 3: CHARACTERISING IDENTITY VALUE AND DETRIMENT

My aim in this section is to unpack what it means under a narrative account of identity – refined in light of the illustrative examples I have considered – for personal bioinformation to be either valuable or detrimental to our identities. Addressing this question is a basic condition for appropriately characterising and responding to information subjects' identity-related interests in information access.⁷⁹⁹

Two dimensions of identity value and detriment

I wish to suggest that the matter of whether particular personal bioinformation is valuable or detrimental to an individual's self-narrative may be understood as coming down to one or both of the following factors:

- i) How the bioinformation affects the quality or character of particular constituent characteristics, roles, relationships or self-descriptors that make up her narrative, i.e. its contents.
- ii) The role the bioinformation plays in her being able to develop, maintain or restore the coherence of her self-narrative seen as an identity-constituting whole.

In this section I will first describe these two dimensions of identity value and detriment, and intersections between them. I will then turn to consider four important contributions that recognising these dual-aspects makes to the practical task of responding to possible identity impacts.

i) Impacts on constituent contents

Under this first dimension, personal bioinformation can be seen as being valuable to someone's personal narrative when it contributes to her being able to adopt, develop, reinforce, constitute or maintain self-descriptors, roles, relationships, projects or commitments that she

⁷⁹⁹ This is a task for Chapter 9.

finds pleasing, worthwhile or important. It helps her to tell the kind of narrative that, in terms of its substance, she wants to tell and is comfortable inhabiting. Conversely then, information can be detrimental to someone's self-narrative when it threatens valued modes of self-characterisation or contributes unwelcome, oppressive or distressing contents that make her feel negatively about herself. It is information that prevents someone from constructing the kind of account of who she is that she would like to tell, understood from a qualitative perspective. However, I would suggest, that it would be a mistake to assume that contents-related value is necessarily synonymous with an especially pleasurable experience of *receiving* information. For example, undergoing *BRCA* testing may be very trying, but valued nevertheless insofar as it allows someone, for example, to enact and demonstrate familial commitments that are important to her sense of who she is.

ii) *Impacts on the coherence of the narrative as a whole*

This dimension of identity value or detriment pertains not to the impacts of personal bioinformation on any discrete self-descriptors or 'contents' of someone's self-narrative, but on the relationships between these contents on one hand, and between her self-narrative and her experiences of her health, body and biological relationships, on the other. This dimension is therefore to do with the *interpretive process* of identity development and the *structure* of the individual's overall self-narrative in that it concerns the impacts of receiving or being denied bioinformation that impinge for good or ill on her capacity to construct and to inhabit a narrative that makes sense on its own terms, and when confronted by her embodied experiences. Valuable bioinformation is, therefore, that which allows someone to develop, maintain or restore a coherent self-narrative and to understand how its parts add up to a totality that is 'who she is'. It also includes that which helps to make her narrative resilient (as far as this is ever possible) to probable and non-trivial disruption by lived experiences. Detrimental personal bioinformation, on this view, includes that which seriously disrupts someone's existing self-narrative. It also includes that which leaves her narrative exposed and vulnerable to such disruption, for example by leading her to premise her self-conception on false or misplaced beliefs. I will return in the discussion of the relevance of bioinformation's epistemic qualities to this last kind of detriment later in this section.

The interdependence of contents and coherence

The reason that I do not wish simply to assert that the first three of the seven narrative roles listed in Section 2 map neatly to the contents-related value of personal bioinformation, while the remainder map onto coherence-related value, is that it is not possible to quarantine roles

that affect the content of our self-narratives from those that serve their overall coherence. The very nature of a narrative is that its contents and its coherence are interdependent.

What I mean by this is that, on one hand, the value of welcome narrative contents is likely to be contingent on the intelligibility of the wider story to which they contribute. For example, a misplaced but cherished belief that one is never likely to succumb to Alzheimer's disease is of questionable value if one is then unable to accommodate the incipient symptoms of illness within a stable overall sense of who one is. Meanwhile, profoundly distressing or alienating contents could threaten the integrity of someone's wider account of who she is. For example, if someone thinks of herself as 'doomed' to a serious neurological disorder, she might experience this as being so stigmatising and upsetting that its impact pervades and undermines her capacity to make sense of or feel at home in who she is.⁸⁰⁰ And some kinds of bioinformation may simultaneously impact on the contents and structural conditions of someone's self-narrative in different ways. For example, a revelation of donor origins may not only reconfigure the recipient's relational self-descriptors, but also alter the nature of the very relationships that had provided the supportive contexts within which she negotiated and developed her sense of who she was.⁸⁰¹

One implication of the interdependency of these two dimensions, I would suggest is that when it comes to characterising the kind of self-narrative one might aspire to, the outcome is not an unremittingly delightful story. Rather it is one that reflects the light and shade of ordinary life and is, as such, a realistic and intelligible account of who one is. For this reason, in the remainder of this project I shall refer to the desired outcome as *the development, maintenance or restoration of a coherent and satisfying self-narrative*. 'Satisfying' here is intended to capture the modest goal of realistically desirable contents given what we are (unable) to control about our lives and experiences. 'Coherence', meanwhile, refers to an ideal goal which perhaps none of us will ever achieve, but which we may aspire to and approach.

I have suggested here that the two dimensions of identity value and detriment are often closely intertwined. This notwithstanding, I want to suggest that recognising that there are two dimensions at work is key to effective and thorough mapping of the ethical landscape, as I shall now outline.

⁸⁰⁰ Hilde Lindemann Nelson holds that some of the kinds of self-characterisation that are socially-available to us – and to some marginalised groups in particular – may be oppressive or limiting as to constrain our capacities for agency, H. Lindemann Nelson (2001).

⁸⁰¹ See Chapter 5.

The importance of recognising both contents-related and structural impacts

What does this two-stranded conception of identity value and detriment bring to this project that is lacking from other theoretical accounts of the relationship between bioinformation and identity? I wish to suggest that this analysis brings four insights – each of which contributes to a more robust and thorough mapping of the ethical terrain. These insights serve to:

- broaden the scope of attention to relevant identity impacts;
- locate the ethical weight of these impacts;
- highlight the importance of bioinformation’s epistemic qualities; and
- signal how value and detriment might be influenced by the manner in which bioinformation is communicated.

I shall unpack each of these in turn in the remainder of this section.

Broadening the scope of attention

Many prominent non-narrative accounts of the roles that bioinformation might play in identity construction focus on the ways in which knowledge of our health, biology or biological relationships can invite, sustain or undermine identity ‘contents’ – for example, self-descriptors, roles or social identifiers (see Chapter 2). As indicated by what I have said in Section 2, these are entirely plausible characterisations of *some* potentially valuable or detrimental roles fulfilled by this information, but they not the complete picture. They ignore, or at least underplay, the fact that our identities are not made up of discrete islands of characteristics and labels. In doing so, they pay insufficient attention to the effects of bioinformation on the interpretive and structural features of our identities operating as dynamic wholes.

Having said this, it is equally the case that focusing solely on what is entailed by theories of narrative self-constitution, as I have in Chapter 3, might lead one to miss the importance of the nature of the contents that make up our identities. The normativity inherent in these theories emphasise the importance of an identity narrative being articulable and realistic, but is silent on what the contents of the story should look like. However, as the illustrative examples considered in Part II make plain, we do not just care about being able to give a coherent story of who we are, but also about being able to develop, maintain and inhabit a particular kind of story, comprising particular kinds of characteristics, relationships, activities and commitments.

Omitting to attend to *both* dimensions of identity value and detriment means that one risks failing to recognise a tranche of identity impacts that could make a significant difference to

someone's life. Furthermore, as I shall outline towards the end of this section, responding to coherence- and contents-related impacts may make distinct demands on those disclosing bioinformation. Perhaps most importantly, a solely contents-focused analysis of the identity impacts fails to account for, or to properly characterise, why the question of whether we are able to access personal bioinformation can be a matter of profound ethical significance, as I shall now discuss.

Locating the ethical weight of bioinformation's impacts

If we only think of bioinformation as impacting on discrete self-descriptors, we might be inclined to shrug at the prospect that someone is (or is not) able to describe themselves in a specific bio-informed way (excepting, perhaps, cases where these are markedly stigmatising or oppressive). After all, someone in these circumstances can still give an account of who she is, just a qualitatively different one. As sceptics about the value of knowledge of donor origins are swift to point out, there are myriad ways that various kinds of information could change how we think about ourselves – why would one way be more, or less, valuable than another?⁸⁰² Part of the answer, as noted above, is that it *is* likely to matter to us that we can tell a story with a specific plot or tenor, and the personal implications of this are not negligible. But it might still be queried whether deep interests in (not) accessing information are engaged – deep enough to warrant attention and responses from others.

I hold that such deep interests are indeed engaged. The weight of this argument is grounded in the interpretive and contextualising roles that personal bioinformation may play in enhancing or undermining the overall intelligibility and coherence of our self-narratives. It is here that (what I have termed) the 'double normativity' of the narrative conception of identity on which this project is based comes into play.⁸⁰³ The intelligibility and coherence of our self-narratives are necessary conditions for supporting a range of valuable capacities, including those for self-understanding and autonomy (as outlined in Chapter 2). This explains why being able to access information that helps one to develop, maintain or restore intelligibility and coherence – or to be protected from that which would critically undermine them – are not trivial matters. They impinge upon our very abilities to understand who we are and to lead fulfilling, engaged lives. The coherence dimensions of identity value and detriment strike at the heart of what is at stake in developing and maintaining an identity-constituting self-narrative.

⁸⁰² See, for example, de Melo-Martín (2014)

⁸⁰³ See, Chapter 3.

This does not mean that impacts of bioinformation on narrative contents are of no ethical significance. On the contrary, they may matter a great deal. But their importance may be best understood by viewing their role in an identity understood as a whole, not in relation to atomised descriptors. For example, we might more fully understand why accessing results from a genetic disease susceptibility test is so important to someone, when we appreciate not only how this impacts on her self-conception as a loving, protective parent, but how this self-conception fits into her wider story, to which it lends and by which it is leant, meaning. The ramifications of the test results extend beyond the impact on her perception of her parental role to the way her story fits together and makes sense to her as a whole. Again, I would emphasise, it is artificial to think of the impacts of personal bioinformation on the contents of our identities as wholly separable from its impacts on their coherence.

Recognising the importance of bioinformation's epistemic qualities

The third reason that it is instructive to recognise that identity value and detriment depends on bioinformation's impacts on the coherence as well as the contents of our self-narratives, is that the former carries crucial implications for the relationship between identity value and the epistemic qualities of the bioinformation in question. By 'epistemic qualities' I mean those relating to the information's "fit with the world" and its "adequacy for the practical purposes for which [it] is used".⁸⁰⁴ I wish to suggest that identity value is contingent on bioinformation providing its subject with reliable and empirically robust insights into her past, present or (likely) future health, bodily states or functions, and biological relationships. This is because these qualities are necessary for the information to contribute to a self-narrative that makes sense in the context of her embodied experiences and supports an individual in navigating them.

The kinds of bioinformation that would fail to fulfil this criterion extend beyond the straightforwardly false. I would include information which lacks – in the terminology of clinical genetics – 'clinical validity', by failing accurately or reliably to predict the presence of the characteristic, disorder or disease risk of interest,⁸⁰⁵ or that which generates risk predictions that are so broad as to be meaningless.⁸⁰⁶ I would also include information that

⁸⁰⁴ J. De Winter, *Interests and Epistemic Integrity in Science: A New Framework to Assess Interest Influences in Scientific Research Processes* (Lanham: Rowman & Littlefield, 2016), p.79). In the present context, I take 'purposes' to mean those of understanding biological states of affairs.

⁸⁰⁵ Burke (2014).

⁸⁰⁶ There is a grey area here. It is possible (as suggested by the example of *APOE* testing in Chapter 6) that, when properly contextualised, information that is deemed to have insufficient clinical validity for a national screening programme might nevertheless be useful to individuals for identity-related

draws unwarrantedly reductive or deterministic inferences from biological findings to the presence of complex multifactorial conditions or traits, or that which is incapable of speaking relevantly to the state of affairs that it purports to. An example of this last kind would be the results from so-called ‘genetic ancestry tracing’ services, which not only are unable to provide meaningful insights into ancestral geographical, ethnic or national origins at an individual scale, but also implicitly reduce substantially socially constructed categorisations such as ethnicity or nationality to biological categories.⁸⁰⁷ In each of these cases it is not solely the epistemic limitations of the information that matters here, but the recipient’s lack of appreciation of these limitations.

In the case of this last example, ancestral information seems likely merely to lack identity value. However, I wish to suggest that sometimes, when an individual wrongly believes bioinformation to be a reliable source of knowledge about her health, body or biological relationships, and depends on this information in the construction of her self-narrative, this may render her identity vulnerable to dissonance with, or disruption by, her experiences, and thus threaten its coherence. As such, if the aspects of her narrative that are premised on this information are core to her self-conception and implicated in values, activities and commitments that are central to her life then, I wish to suggest, false, unreliable or meaningless bioinformation may not just lack value, but be actively detrimental to her identity. For example, in Chapter 7 I suggested that, if neuroimaging cannot (yet) provide definitive psychiatric diagnoses or account for the complex aetiology and phenomenology of mental illness, those who premise their story of who they are on the authority of such diagnoses as to the organic cause and nature of their condition, may find that their capacity to inhabit this story is challenged by the ineffectiveness of medical interventions, or the continued impact of social and environmental factors on their experiences of illness. Anders Nordgren and Eric Juengst raise a similar concern when they argue that the misleading and “inadequate” health information supplied by some DTC genetic testing services may serve to “distort rather than clarify [their] clients’ subjective experience of their identities.”⁸⁰⁸ But I would hold that it is not just the *subjective experience* of identity that is distorted. What suffers is the coherence and sustainability of the resultant identity narrative as basis for living and acting in the world and as the framework through which we continue to interpret and constitute who we are.

purposes. So, my intention here is not to rule out all information that does not meet the strictest clinical criteria.

⁸⁰⁷ Royal et al. (2010); M.D. Shriver and R.A. Kittles (2004), "Genetic Ancestry and the Search for Personalized Genetic Histories" *Nature Reviews Genetics*, 5(8): 611-18

⁸⁰⁸ Nordgren and Juengst (2009), p.166

My argument in this sub-section parallels that made by Bunnick *et al*: in which they hold that genetic test results from DTC services that lack clinical validity, are meaningless, or otherwise uninterpretable, cannot be said to have ‘personal utility’.⁸⁰⁹ Their argument is based on the premise that the normativity implicit in ‘utility’ means that test results displaying this quality must at least “answer the question with which testing was initiated”.⁸¹⁰ If personal utility is taken to include identity-related purposes (as it sometimes is),⁸¹¹ then my argument adds a further source of normativity and grist to their contention.⁸¹² It also goes beyond their argument by highlighting why providing access to false or meaningless bioinformation (not only findings from DTC genetic testing services) represents not just an absence of utility, but a possible source of harm.

I am not seeking to claim here that simply being true, reliable or meaningful is *sufficient* for personal bioinformation to be valuable. Much bioinformation, no matter how robust, will simply be irrelevant or otiose to our self-narratives. And some of it may invite unwelcome contents. Selectivity is intrinsic to narrative self-constitution. As noted in Chapter 3, it is not better (and perhaps much worse) for the intelligibility of one’s self-narrative to attempt to include all available insights into one’s biological existence.

The possibility that true or reliable bioinformation could introduce unwelcome contents, however, poses a challenge for the dual-aspect picture of identity value that I have presented. It raises the possibility that contents-value and coherence-value could pull in different directions. For example, we might imagine how disclosing to a research participant incidental findings of brain lesions consistent with serious illness might be distressing and undermine her sense of herself as a healthy person, but also offer her the opportunity to reconfigure her narrative around the possibility and symptoms of ill-health, thus protecting its future coherence and sustainability. This then demands the question of which carries greater ethical weight on my account – the detriment to her narrative contents or possible benefit to its coherence? I do not claim to have a definitive answer here. I am inclined to suggest that a self-narrative comprising comforting contents is not a desirable end at any cost to its concordance with biological states of affairs. This is because being able to develop a coherent narrative that permits one to navigate embodied existence is the more basic value – it is the condition upon which (at its most extreme) having an identity-constituting narrative at all depends. This

⁸⁰⁹ E.M. Bunnick et al. (2014), "Personal Utility in Genomic Testing: Is There Such a Thing?" *Journal of Medical Ethics*, 41(4): 322-26.

⁸¹⁰ *Ibid.*, p.325

⁸¹¹ Ravitsky and Wilfond (2006)

⁸¹² I return to the topic of the relationship between personal utility and identity interests in Chapter 9.

suggests that ‘true and distressing’ trumps ‘false and comforting’. But, this conclusion may be too swift and blunt, given the interdependence of contents and coherence noted above. Perhaps inevitably, the answer to this question is likely to be context-dependent – depending at least in part on how the information is communicated (as I shall discuss further in Chapter 9). This brings me to the fourth, and final, reason why it is useful to attend to the two dimensions of identity value.

Influencing value and detriment

As will be clear from what has been said so far, the identity value or detriment any particular kind of personal bioinformation is not a fixed property. The evidence reviewed in the illustrative examples suggests that this variability may be, at least in part, amenable to influence by the manner in which the information is presented to an individual.

Both the contents-related and coherence-related impacts of personal bioinformation may be equally susceptible to this kind of influence, though each might entail somewhat different considerations. Contents-related value may be chiefly susceptible to particular normative connotations acquired through the manner of presentation. For example, couching genetic test results in the language of ‘mutations’ and ‘abnormalities’ may lead recipients’ to see themselves as impaired.⁸¹³ Meanwhile, value or detriment to the *coherence* of the recipient’s identity could be influenced by what the disclosing party contributes by way of wider informational context and interpretive tools to support the recipient in accommodating or rejecting the bioinformation in ways that minimises the risk of narrative disruption. For example, explanation of the epistemic limitations of susceptibility testing may help to avert someone’s unwarranted reliance on the results in orienting her self-conception towards the future.⁸¹⁴ Or a donor-conceived individual may find revelation of her conception more disorienting if she is not able also to access information about her donor.⁸¹⁵ I shall address further the ways in which the manner of communication might influence recipients’ perceptions of the relevance of personal bioinformation to their identities in the following section and return, in Chapter 9, to consider what these observations imply for the responsibilities of those disclosing information.

This brings to a close my characterisation of identity value and detriment and the implications of their two, interconnected, dimensions. I now wish to turn to the third and last research

⁸¹³ See Chapter 6.

⁸¹⁴ See Chapter 6.

⁸¹⁵ See Chapter 5.

question for this chapter and what is, in a sense, the more basic matter of what accounts for our experiencing personal bioinformation as contributing or detracting from the contents or coherence of our self-narratives at all? That is, what factors influence whether we experience particular personal bioinformation as being *significant* to who we are?

SECTION 4 – ACCOUNTING FOR IDENTITY SIGNIFICANCE

I start here from the premise that identity significance is not an intrinsic feature of any particular kind of bioinformation; it is an interpretive matter, determined from the perspective of each information subject. This section concerns the question of what factors are likely to contribute to someone experiencing a particular kind or instance of personal bioinformation as being seen as sufficiently relevant or important to play a role (either valuable or detrimental) in the contents or coherence of her self-narrative. I shall label this quality ‘identity significance’.

In this I will first enumerate the four factors that appear most likely to influence ascriptions of identity significance I will then address two concerns arising from my acknowledgement that identity significance is likely to be, to some extent, socially constructed. Unpacking the nature of identity significance is an essential step towards developing the ethical framework in Chapter 9. It highlights some of the challenges and opportunities facing those required to make disclosure decisions in ways that respond to the information’s potential identity impacts. It does so by emphasising that attributions of identity significance will vary between individuals, but these attributions may nevertheless sometimes be somewhat anticipatable, and amenable to influence by others, including potential disclosers.

Factors contributing to identity significance

In assessing which factors are likely to contribute to identity significance, I have drawn on the findings discussed in the examples in Part II and the narrative conception of identity at the heart of this project, as well as wider literature regarding the relationship between bioinformation and identity. On these bases I wish to suggest that four factors plausibly make considerable joint and interacting contributions to the identity-significance of a particular instance or kind of personal bioinformation. These are:

- i) The information subject’s existing self-narrative and personal circumstances;
- ii) The scale of what the information implies for human existence;
- iii) How authoritative and reliable the information subject perceives the bioinformation to be; and
- iv) Prior social constructions of identity significance.

I will expand each of these here.

i) Existing narrative and personal circumstances

Whether someone sees, or would see, particular personal bioinformation as pertinent to her identity will depend to a great extent on how it relates to her existing self-narrative and the descriptors, plotlines, roles, relationships, concerns and values of which it comprises, and how she imagines this narrative unfolding into the future. This might look somewhat circular. But it is crucial to appreciate that internal to the very concept of narrativity is that the (potential) constituents of someone's identity acquire their meaning and significance by virtue of the role they play in her self-narrative.⁸¹⁶ The contribution of personal factors to identity significance is captured by Lori d'Agincourt-Canning's assertion that it is not possible to understand the significance a *BRCA* test for susceptibility to breast and ovarian cancer holds for someone without understanding how the result will impact on her relationships and relational roles within her family.⁸¹⁷ Similarly, an authoritative psychiatric diagnosis may be important to someone's account of who she is, precisely because it offers a way of removing imputations of guilt and 'craziness' from her existing self-narrative.

ii) The scale of its implications for human existence

The idea that specific categories of personal bioinformation are inherently identity-significant is not supportable given the evidence reviewed in the preceding chapters. Nevertheless, it does seem plausible that our investment in some features of our lives might transcend the particularity of each of our self-narratives. That is to say, because of the embodied, relational, rational and mortal nature of human existence, there will be some biological states of affairs that are likely to encroach upon our lives, and thus our self-narratives, more than others. For example, serious illness, perhaps especially illness that affects not only our bodies but our cognitive and affective capacities, will make a substantial difference to how we live and experience our lives. And our family relationships, roles and responsibilities also seem likely to play a central role in our daily lives and personal development. The suggestion here, then, is that personal bioinformation relating to such central or pervasive aspects of human life is particularly likely to be seen as significant to our identities. Illustrating this, it has been observed that people's reactions to the 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

⁸¹⁶ See Chapter 2.

⁸¹⁷ d'Agincourt-Canning (2006).

capacities.⁸¹⁸ This is not to claim that bioinformation with ‘big’ implications will *inevitably* be seen as identity-significant. For example, it has been observed that, despite the debilitating and terminal nature of the disease, some carriers of the mutation responsible for Huntington’s disease refuse to be defined by their carrier status.⁸¹⁹ It is, however, to suggest that some ascriptions of identity significance will be widespread despite our individual differences.

iii) Perceptions of information’s epistemic qualities

A third factor that appears to make a difference to ascriptions of identity-significance is the extent to which particular bioinformation is perceived by its subject to be authoritative and reliable as a source of knowledge about her health, body or biological relationships.⁸²⁰ There are several indications in the illustrative chapters of this contributory factor in operation. The baldest of which is the importance invested by many donor-conceived individuals in (re)building their self-conceptions around the truth about their conceptions.⁸²¹ A further example is provided by the accounts of patients’ attitudes to the potential for psychiatric neuroimaging to change the role of their mental health diagnosis in their sense of who they are, which appear to be intimately connected to their perceptions – albeit perceptions that are (at present) probably misplaced – that neuroimaging offers superior objectivity and authority as a diagnostic method.⁸²² A further illustration is provided by the REVEAL study, in which participants’ expectations about the ways in which genetic testing for susceptibility to Alzheimer’s disease would alter their behaviour and risk perception were notably tempered once the limitations of the test in precisely or reliably pinpointing their individual risk has been explained to them.⁸²³ However, this example also illustrates that the relationship between epistemic capacities and identity significance is not all-or-nothing – with some kinds of less practically-focused narrative roles (such as those based on feelings of solidarity) persisted even when the limitations of the test results had been explained.⁸²⁴

iv) Socially-constructed identity significance

I wish to suggest that the fourth potential contribution to ascriptions of identity significance might come from the bioinformation arriving pre-freighted with these connotations. In the

⁸¹⁸ Lock et al. (2007); Roberts et al. (2003).

⁸¹⁹ Konrad (2005).

⁸²⁰ This example highlights that *perceptions* of bioinformation’s identity significance and its likely value to narrative coherence could diverge where information subjects do not appreciate the epistemic limitations of the information.

⁸²¹ See Chapter 5.

⁸²² See Chapter 7.

⁸²³ Christensen et al. (2011).

⁸²⁴ See Chapter 6.

terminology introduced in Chapter 1, this is bioinformation with an identity-related ‘interpretive pedigree’, such that it purports to speak not only to biological states of affairs, but who someone is. It will be helpful to unpack two possible ways in which this pedigree could be obtained: it might be the product of socially-pervasive constructions, or occur at the level of individual informational transactions.

Socially-pervasive constructions

The suggestion here is that some biological states of affairs have, in Jeanette Edwards’s phrase, been “socially activated” to have particular meanings and connotations – in the present context, a connotation of identity relevance.⁸²⁵

One way in which this might be manifest is where ways of categorising people for healthcare or research purposes come to be understood as ways of describing or understanding who we are. As Ian Hacking observes, classifications developed by the human sciences as means of studying or seeking to intervene in the lives of the people thus classified do not always remain sequestered in the disciplines that coined them.⁸²⁶ They may “break free” into the wild, where they are taken up by those to whom they pertain, for whom they function as modes of self-definition, or “human kinds”.⁸²⁷ Similarly, Nikolas Rose argues that predictive and diagnostic information generated by genetic science and neuroscience are widely used as tools of self-understanding and self-development.⁸²⁸ And Andreas Veith holds that “*genetic scientism* has won the status of an individual and cultural *hermeneutics*”.⁸²⁹

There is not the space to explore the mechanisms by which aspects of our biology (and thus the information reporting these) may come to be seen as speaking to who we are as persons, or providing means of self-classification. However, just taking the example of neuroscientific information, it is possible to find suggestions of myriad social practices – for example in the criminal justice system, policy, education or popular media – which (mis)use neurological research to explain differences between people, or behavioural, cognitive or affective phenomena, and thereby contribute to widespread views that findings from neuroscience can tell us something about our identities as persons.⁸³⁰ For example, Racine *et al* note that reports

⁸²⁵ J. Edwards, 'Undoing Kinship', in *Relatedness in Assisted Reproduction*, ed. T. Freeman, et al. (Cambridge: Cambridge University Press, 2014), p.46.

⁸²⁶ Hacking (1995); Hacking (1999)

⁸²⁷ Hacking (1995), p.359.

⁸²⁸ Rose (2007) See Chapter 2.

⁸²⁹ Vieth (2010), p.108 (emphasis in source).

⁸³⁰ S. Choudhury et al. (2009), "Critical Neuroscience: Linking Neuroscience and Society through Critical Practice" *BioSocieties*, 4(1): 61-77; C. O'Connor and H. Joffe (2013), "How Has Neuroscience Affected Lay Understandings of Personhood? A Review of the Evidence" *Public*

of functional neuroimaging in print media commonly frame research findings in neuroessentialist ways, presenting the phenomena reified by their neurological correlates to be constitutive of who we ‘really’ are.⁸³¹

Similarly, it is widely noted that it is not possible to understand the significance of knowledge of donor conception to donor-conceived individuals in abstraction from the meaning assigned to genetic and family relationships in their cultures.⁸³² It is suggested that, to the extent that donor-conceived individuals *do* view information about their donor origins as important to their identities, this may be fostered, *inter alia*, by the provision of assisted reproduction services, trends towards asserting children’s interests in knowing their biological parentage in family law, the popular interest in genealogy and ancestry.⁸³³ Indeed, some have posited that open-identity gamete donation policies that seek to respond to the possible identity-value of information about donor origins might themselves drive a feedback loop, reinforcing the perception that this information *is* important to donor-conceived individuals’ self-understanding.⁸³⁴

Clues that socially constructed insinuations of identity-significance do play a role in individuals’ attitudes towards some kinds of personal bioinformation emerge most vividly where distinct types of information are observed to be assigned markedly different significance, where the implications they carry for our health, bodies or biological relationships would seem to be very similar. For example, there are indications that individuals conceived using donor sperm tend to invest more importance in knowing about their donors, than those conceived using donor eggs.⁸³⁵ And, in contrast to other serious genetically-linked cancers, *BRCA*-linked breast and ovarian cancer have been observed to have particular power to “captivate”,⁸³⁶ and to generate biosocial activity and group affiliations.⁸³⁷

Transaction-specific constructions

In addition to the operation of wider social associations of biology and identity (and playing against the background of them), it is also possible that the context and manner in which

Understanding of Science, 22(3): 254-68; M. Pickersgill (2013), "The Social Life of the Brain: Neuroscience in Society" *Current Sociology*, 61(3): 322-40.

⁸³¹ E. Racine et al. (2005), "fMRI in the Public Eye" *Nature Review Neuroscience*, 6(2): 159-64, p.3

⁸³² See, for example, Freeman (2014); Pennings (2001)

⁸³³ See, for example, Fortin (2011); T. Freeman and M. Richards, 'DNA Testing and Kinship: Paternity, Genealogy and the Search for the ‘Truth’ of Our Genetic Origins', in *Kinship Matters*, ed. F. Ebtahaj, et al. (Oxford: Hart, 2006); Richards (2014)

⁸³⁴ Freeman (2015).

⁸³⁵ Freeman et al. (2014)

⁸³⁶ Lock (2008), p.73.

⁸³⁷ Gibbon (2008)

particular bioinformation is conveyed to an individual might be such as to invest it with an interpretive pedigree of identity significance (or, indeed, insignificance).

DTC genomic testing provides a possible illustration here. The language used in the marketing materials, customer testimonials, and online interfaces for accessing results often implies that the information conveyed will tell users who they are.⁸³⁸ Nordgren and Juengst note that these services frequently play on a combination of genetic essentialism regarding identity and “the cachet of genetics” as a source of authoritative knowledge in appealing to customers.⁸³⁹ For example, the strapline for the *23andMe* service is “Welcome to you” and its website proclaims: “23 pairs of chromosomes. One unique you”.⁸⁴⁰ Meanwhile, the homepage of *Ancestry.com* invites users to “discover what makes you uniquely you”.⁸⁴¹ And Bronwyn Parry describes the way in which the online environments in which users share and discuss their results provide settings in which these users are active in fostering the meaning of their results as tools for “scripting the self”.⁸⁴²

Ethical concerns about DTC genomics often include the lack of counselling provided to customers, counselling which might mitigate unqualified perceptions of identity-significance.⁸⁴³ However, I would tentatively suggest that it seems possible that in clinical contexts, the sheer provision and tone of genetic counselling, even if non-directive, could be taken as conveying the identity-significance of the test results in question precisely because it focuses on the impacts of test results on factors such as personal resilience and fulfilment of familial roles.⁸⁴⁴

The *medium* in which personal bioinformation is conveyed might also be pertinent to its investment with identity significance. For example, Joseph Dumit refers to the images derived from neuroimaging as “potent objects” which, because of their visual nature and apparent immediacy, may foster a conflation of brain and identity amongst those viewing their own scans.⁸⁴⁵

⁸³⁸ Nordgren and Juengst (2009); Parry (2013)

⁸³⁹ Nordgren and Juengst (2009), p.162.

⁸⁴⁰ 23andMe UK website, ‘Ancestry testing’ www.23andme.com/en-gb/ancestry/ (accessed 9 June 2017).

⁸⁴¹ Ancestry.com US website, www.ancestry.com/ (accessed 9 June 2017).

⁸⁴² Parry (2013), p.164.

⁸⁴³ H. Skirton et al. (2012), “Direct to Consumer Genetic Testing: A Systematic Review of Position Statements, Policies and Recommendations” *Clinical Genetics*, 82(3): 210-18.

⁸⁴⁴ Kääriäinen et al. (2009)

⁸⁴⁵ Dumit (2004), p.109.

This indicates that it is not only whether bioinformation has valuable or detrimental impacts on an information recipient's self-narrative that might be influenced by the context and manner in which the information is conveyed, but the matter of whether it has any impact at all. This serves to underscore that information subjects' identities may be affected not only by whether they can access particular bioinformation, but how they do so. This will be a critical consideration in characterising the responsibilities accruing to information disclosers in Chapter 9.

Concerns about socially-constructed significance

Before taking stock of what the identification of these four possible contributory elements to identity significance might mean for practical questions of governing access to personal bioinformation, I first wish to deal with several concerns or misapprehensions about the potential role that I have accorded to socially-constructed significance here. The first of these is that social construction undermines claims to bioinformation's identity value. The second is that it challenges the very idea that we are authors of our own identities.

Does social construction undermine identity value?

Some sceptics about the identity significance of knowledge of donor origins suggest that this significance is the product of "culturally dominant narratives", and would dissolve were these narratives to be challenged.⁸⁴⁶ The implication is that the reality and depth of this information's identity value are somehow less real for being culturally shaped. I would contend, however, that the contribution of social factors to ascriptions of identity significance does not inevitably render the identity value of the information in question illusory. I would suggest that scepticism of the kind just outlined is based on two misconceptions. The first is that if social construction is a factor, then it must be the *only* factor. The second is that any interests in accessing bioinformation must be grounded in the *inherent* identity value of that information. The account of value and significance I have outlined in this chapter challenges each of these assumptions. First, I have suggested that ascriptions of significance may have multiple sources, so may transcend the vagaries of, for example, popular genetic essentialism. Secondly, it locates the value of knowing in the instrumental roles that the information could play in its subject's self-narrative, and this value is not necessarily diminished just because it occupies these roles (in part) for socially contingent reasons. Acknowledging that identity

⁸⁴⁶ de Melo-Martín (2014), p.33.

significance may be somewhat socially constructed is not in itself a reason to dismiss individuals' potentially considerable interests in accessing it.

Does social construction undermine self-authorship?

The question here is whether the role of wider social narratives about what aspects of our biology are relevant to who we are in our own ascriptions of identity significance undermines our authorship of our own identity narratives?

Of course, it is conceivable that the power of socially constructed identity significance is such that the information subject is unable to resist its effects on her self-conception. Indeed, the same might hold if it conveys devastating news about her health. However, it is unwarranted to hold that we are *always* passive in respect of the ways that we interpret and use the personal bioinformation that we encounter, or that individuals cannot adopt a critical stance with respect to what it means for them.⁸⁴⁷ For example, as noted in Chapter 7, despite the prevalence of 'neuroexplanations' for aspects of our lives intimately connected with the self, Pickersgill *et al.* found that participants in their study displayed mixed and ambivalent attitudes to the role of their brain in their subjectivity.⁸⁴⁸ And some actively resisted defining themselves in neurobiological terms, choosing instead to attribute their experiences to social and environmental factors. The authors conclude that:

“Neuroscientific concepts compete with, integrate into and only occasionally fully supplant, pre-existing ideas about subjectivity.”⁸⁴⁹

This signals that we ought not to be too swift in assuming that everyone's narrative self-conceptions are inevitably subsumed by socially pervasive ascriptions of identity significance to particular aspects of our biological lives.⁸⁵⁰

A further reason why concern is misplaced that socially constructed identity significance undermines self-authorship is that the conception of narrative identity, on which this project is based, does not depend on an individual constructing her self-narrative in isolation (see Chapter 2). On the contrary, the language and forms of self-understanding that we share with those around us and that are common within the culture or “tradition” in which we live are essential tools in our capacities to articulate and make sense of who we are.⁸⁵¹

⁸⁴⁷ Ajana (2010)

⁸⁴⁸ Pickersgill et al. (2011).

⁸⁴⁹ *Ibid.*, p.354.

⁸⁵⁰ Pickersgill (2013).

⁸⁵¹ MacIntyre (1985), p.222; Taylor (1989)

A related anxiety might be raised here – perhaps particularly by those of a Foucauldian bent – that socially constructed identity significance facilitates the colonisation of our self-narratives by the knowledge claims of the biomedical sciences.⁸⁵² I would submit, however, that the implication that any such ‘colonisation’ is invariably problematic is insufficiently nuanced. I would hold that it is positively advantageous to incorporate empirically robust understanding of one’s embodied state, dispositions and relationships into one’s self-narratives insofar as this helps us to construct identities that are resilient to and help us to navigate embodied existence. What *is* of concern, however, is if those whose skills properly extend to interpreting matters of biomedical significance, overstep their epistemic authority by purporting to know, and to tell us, which bioinformation defines who we are and if they do so in ways that inhibit our own critical and interpretive role in using this information.

Practical implications of this view of identity significance

It is my contention that an individual’s perception that particular bioinformation is significant on any particular occasion – meaning that the information has, or would have an impact (either beneficial or detrimental) on her self-narrative – is attributable to a combination of the four factors listed above (in variable proportions).⁸⁵³ Highlighting the multifaceted nature of this quality has practical implications for the governance of access to personal bioinformation. First, it is instructive as to some of the opportunities, obstacles and risks confronting those faced with disclosure decisions in anticipating whether disclosure would impact on the information subject’s identity. The account I have offered here cautions against too swift an extrapolation from paradigm examples of identity-significant bioinformation – or the illustrative examples I have provided in this project – on simple category grounds. For example, it cannot be safely assumed that all genetic information or even all information about genetic disease susceptibility will be accorded the same significance. Rather it is necessary to attend to the possible constellation of all four factors.

The fact that amongst these four factors are the particular narrative contexts of individual information subjects undoubtedly presents a challenge to anticipating ascriptions of significance in every instance. However, this four-factor account of significance also indicates that this maze of variability is not without signposts. Specifically, both the socially-ascribed significance of the biological state of affairs in question and the scale of its impact on any

⁸⁵² Sulik (2009). See also Rose (2007).

⁸⁵³ These four factors might not capture all possible influences. Empirical research would be useful for identifying others. As it stands, though, this list is sufficient to highlight that identity-significance is a multifactorial and variable quality.

human life will be discernible to potential disclosers, and may therefore provide clues (albeit broad ones that might not be borne out in every circumstance) of bioinformation that is particularly likely to be seen as significant.

The second way this account of identity significance may be of practical utility is that it highlights the opportunities for potential disclosers to influence (for good or ill) the extent to which recipients see particular bioinformation as significant. They may do so through what they themselves communicate about its relevance to the recipient's identity and in their explanation of its epistemic qualities. I shall return in Chapter 9 to consider how each of these insights feeds into ethical information disclosure practices and policies. I shall now take stock of the groundwork that this chapter has laid for that final chapter and my ethical framework.

SECTION 5: CHAPTER CONCLUSION

In this chapter I have sought to bring together the theoretical argument developed in Chapter 3 with the examples considered in Part II, with the aim of refining the former in the light of the evidence of how information subjects' view and respond to personal bioinformation, while also extracting some broad lessons from the particularity and detail of the illustrative examples. In doing so I have addressed three questions. What refinements to my central normative argument are suggested by the evidence of the illustrative examples? What does it mean to say that bioinformation is either valuable or detrimental to our identity development? And, what are the factors that contribute to this information being seen as significant to who we are, such that it has valuable or detrimental impacts on our identities at all?

My aim in addressing these questions has in part been to develop a clearer normative conception of the relationship between personal bioinformation and identity – one that both accords with the available evidence of how information subjects respond to this information and allows us to understand how and why it is that bioinformation might contribute to the development of our self-narratives going better or worse. But my aims extend beyond conceptual clarity. The analyses I have offered in this chapter provide four insights that are particularly useful for the purposes of developing my ethical framework in the next chapter.

First and most fundamentally, I aim to have demonstrated that personal bioinformation can indeed impact on our self-narratives in a range of positive and negative ways, and that these impacts are neither esoteric nor trivial. These impacts may affect the character of the constituent parts of our accounts of who we are *and* the way these stories are bound together and function as coherent wholes. It is important to recognise both of these dimensions of bioinformation's potential identity impacts in order to develop a rounded picture of our

information-related identity interests and the ethical significance of what is at stake in being able to develop, maintain or restore a satisfying and coherent self-narrative.

Secondly, whether any particular kind of bioinformation plays a valuable or detrimental role in our self-narratives, or none at all, is likely to vary between individuals and contexts. This is an important observation in itself and one that should be reflected in any recommendations about managing access to personal bioinformation in light of potential identity interests. But it also presents challenges to those responsible for disclosure decisions in determining when and how potential recipients' identities might be affected. However, as the next two points suggest, these challenges are not insurmountable.

Thirdly, the analyses I have offered in this chapter suggest some ways that potential disclosers might identify factors contributing to the value, detriment or significance that transcend specific circumstances and thus navigate the variability of identity impacts. For example, false, unreliable or meaningless bioinformation is unlikely to be valuable to our identities and may indeed be detrimental. And it may be possible to discern, for example, where widespread social ascriptions of identity significance, or the scale what the information implies for any human life make it more likely that the bioinformation would have identity impacts.

Fourthly, it is apparent that both identity value and significance are malleable properties. The preceding discussion highlights several ways in which potential disclosers might themselves play a part in shaping the nature and extent of bioinformation's impacts on recipients. For example, by supporting recipients' understanding of the epistemic qualities of the information conveyed, or by refraining from pre-empting the recipient's own assessment of its identity significance. This point highlights that it is not just whether someone can access personal bioinformation that matters, but also the context and manner in which they do so. This is a key theme to be developed in the next chapter.

This chapter offers insights into the importance of appreciating the ethical significance of our (not) being able to access personal bioinformation, and of the opportunities and capacities of those who hold this information to help meet our needs. My task in the next chapter is to develop these insights further in applying them to the development of an ethical framework for delivering policies and practices that respond to identity-related informational interests.

CHAPTER 9: AN ETHICAL FRAMEWORK FOR PROTECTING IDENTITY INTERESTS IN PRACTICE

SECTION 1: INTRODUCTION

In the preceding chapters I aim to have demonstrated that information relating to our health, bodies and biological relationships can impact in various ways, which are neither trivial nor obscure, on the coherence and contents of our identity narratives. The proposition with which I started this project was that policies and practices related to information subjects' access to their personal bioinformation ought to take account of their potential identity-related interests. In this final chapter my intention is to bring together the arguments and observations from those chapters to address the questions of what it means to protect those interests and how protection may be achieved in practice. To this end, this chapter will provide the final step in answering the third of my four headline questions from Chapter 1: **what are the nature and scope of our identity-related interests in accessing personal bioinformation?** Building on this, I will then address the fourth of those questions: **what ethical responsibilities for disclosure accrue to those who hold personal bioinformation about us?** The answers to these questions will then provide the basis for the ethical framework for guiding information disclosure decisions that I propose at the end of this chapter.

In Chapter 8 I characterised the ways in which personal bioinformation may be valuable or detrimental to individuals' construction of their own identities and the kinds of factors that influence these impacts. My first task in this chapter is to make the conclusions of these arguments concrete by identifying three specific interests relating to information access (Section 2). I will demonstrate that these identity interests are neither reducible nor coextensive with those interests more commonly invoked in respect of access to bioinformation, and therefore warrant attention in their own right (Section 3). Reframing my discussion in terms of interests is the first step in grounding the practical focus of the current chapter in which I turn my attention to the nature of responsibilities relating to information disclosure and to the kinds of ethical considerations that policies, practices and the law must take into account if they are to respond appropriately to the impacts of personal bioinformation on identity.

I will propose three broad responsibilities relating to information disclosure, corresponding to our three interests relating to information access. I argue that these responsibilities arise because of the strength of our interests in developing and making sense of our identities and

because those who could provide us with bioinformation about ourselves are in a position to promote or undermine these interests (Section 4). Nevertheless, I hold that these responsibilities are *pro tanto* – conditional on the absence of strong countervailing interests and the practicability and propriety of discharging them within particular contexts and relationships (Section 5). A key contribution of this project is to demonstrate that attending to the identity impacts of personal bioinformation emphasises that the *manner* of disclosure is just as ethically significant as the question of *whether* or not to disclose. Indeed, an inability to disclose in a way that supports identity development could in some instances recommend not doing so at all. In Section 6 I unpack the principles and practical considerations that are integral to discharging the responsibility to disclose bioinformation in a way that supports recipients' capacities to develop coherent and satisfying accounts of who they are.

I shall close this chapter by bringing together the preceding characterisation of identity interests, associated responsibilities, and recommendations in an ethical framework intended to guide practical decisions about disclosure of personal bioinformation (Section 7) and consider what this framework implies for responsibilities in respect of managing access to the three categories of bioinformation considered in my three illustrative chapters (Section 8).

SECTION 2: THE NATURE AND STRENGTH OF IDENTITY INTERESTS

This section picks up the baton of what I have said in Chapter 8 about the nature of personal bioinformation's identity value or detriment. Here I reframe the argument in terms of interests pertaining to information access, and specify the nature of these interests with a view to serving the practical policy-focused aims of this chapter. In this section I will first identify our three core interests in respect of access to bioinformation about ourselves and their foundation in our basic interest in narrative self-constitution. I will then clarify four features of the nature and scope of these interests that will be relevant to my subsequent discussion. Finally I will indicate the further steps to be taken in this thesis to demonstrate how recognising identity interests makes a concrete difference to the ethical landscape.

When I talk of interests here, what I mean is that an individual has a stake in a particular kind of outcome. The outcome that is the central concern of this thesis is that of developing, maintaining or restoring a coherent and satisfying self-narrative. The bioinformation-related interests I specify below hold to the extent that access to bioinformation serves this outcome, or fails to do so. Unlike some kinds of interests, which may be predicated on individual preferences, in this thesis I take it that our interest in the coherence and tone of our self-narratives is something that is common to all of us in virtue of the kinds of beings we are. This might suggest that talk of 'rights' would be appropriate here. However, I will focus on interests

rather than rights for two 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, because this is where the values, objects of value, activities or relationships at stake are detailed.⁸⁵⁴ Secondly, rights imply inevitable correlated duties. In this chapter I will argue that identity interests do indeed give rise to responsibilities. Nevertheless, these responsibilities do not inevitably follow in all circumstances, and I do not want to short-circuit discussion of why and when they may do so by using the language of entitlement.

Bioinformation-related identity interests

On the basis of the arguments presented in the previous chapter I propose that we have the following three interests in respect of our access to our own personal bioinformation:

- I. An interest in being able to access personal bioinformation that would contribute to our development, maintenance or restoration of a coherent and satisfying self-narrative.**

- II. An interest in being protected from exposure to personal bioinformation that would undermine our development, maintenance or restoration of a coherent and satisfying self-narrative.**

And, given that both our perception of the identity-significance of particular personal bioinformation and the extent to which it has valuable or detrimental impacts on the contents and coherence of our self-narratives are interpretive matters, subject to influence by the way in which it is conveyed to us, I would further suggest that each of the above entails:

- III. An interest in receiving personal bioinformation in a manner that supports us in using it in, or excluding it from, our development, maintenance or restoration of coherent and satisfying self-narratives.**

I shall term these, our '*bioinformation-related identity interests*' (or '*identity interests*' for brevity). My contention is that they are all significant interests that warrant serious ethical attention when deciding whether and how to disclose personal bioinformation to those whom

⁸⁵⁴ For a discussion of the relationships and tensions between rights talk and bioethics, see R. Ashcroft, 'The Troubled Relationship between Bioethics and Human Rights', in *Law and Bioethics: Current Legal Issues Vol. 11*, ed. M. Freeman: 31-51 (Oxford: Oxford University Press, 2008).

it concerns.⁸⁵⁵ They warrant this attention because they are derived from and serve the more fundamental interest:

An interest in developing, maintaining and restoring a coherent and satisfying self-narrative (which I shall refer to as ‘*the basic identity interest*’).

Claims to the strength and basic nature of this interest lie in the argument that being unable to develop, maintain or restore a reasonably coherent identity narrative threatens one’s capacities for leading a full, meaningful and practically engaged human existence (see Chapter 2).⁸⁵⁶ This is an argument that I have refined in Chapter 8 by observing that, although a coherence is a condition for developing an identity-constituting narrative, we are neither indifferent to the qualities of the contents that make up our self-narratives, nor can our attitudes to these contents be neatly quarantined from our abilities to make sense of and comfortably inhabit coherent accounts of who we are. Therefore, our identity interests are also engaged where personal bioinformation contributes to or detracts from narratives that are, as far as possible, satisfying, rather than alienating or distressing. The strength of our bioinformation-related identity interests is derived from the fact that, and the extent to which, they serve our basic identity interest.

Features of our bioinformation-related identity interests

There are four observations I would wish to make about the *nature* of bioinformation-related interests before moving on to consider what they imply for others’ responsibilities.

First, these are interests held by an individual in virtue of her role as the author of her own identity-constituting self-narrative. However, while individual, they are not *individualistic*. We do not and cannot build our identities alone (see Chapter 2). And the significance and value of particular bioinformation to our identities is influenced by the interpretation and activities of those around us (see Chapter 8). Moreover, the way in which particular bioinformation engages someone’s identity interests may well not be separable from the meaning it has for others around her, or how its disclosure affects them and her relationships with them. In this thesis I focus on how individual interests should be addressed, while remaining aware that these will often be interdependent with, or compete with, those of others.

⁸⁵⁵ It is possible that an individual’s interests in identity development could also be engaged by disclosure of genetic information to those with whom she shares it, but this concern lies outwith the direct focus of this thesis.

⁸⁵⁶ As such I take it that it is a foundational interest in that it makes no sense to ask further why one would want to be in a position to develop these capacities.

Secondly, whether particular personal bioinformation is valuable to someone's identity in any particular case is a contingent matter dependent on the individual information subject and the wider circumstances in which it is revealed. However, it would be a mistake to conclude from this that her identity interests in accessing this information in any given situation are themselves weak, just because the information might not be similarly valuable to someone else. Where the bioinformation in question would impact on someone's account of who she is, or capacity to give an intelligible account at all; it fulfils a particular, non-fungible, role in the complex, interwoven whole of her self-narrative. Its contribution is, therefore, not trivial.

Thirdly, as described in Chapter 2, narrative coherence admits of degree. A failure to meet bioinformation-related interests on any particular occasion will not necessarily entail a total *loss of identity*. But, such a catastrophic outcome is not necessary for the basic identity interest still to be harmed and to be a legitimate matter of ethical concern, insofar as the impacts of (not) accessing the bioinformation means that the individual has difficulty making sense of who she is and what she values and in navigating her embodied existence. As this implies, some failures to meet identity-related interests will be more serious, with more far-reaching or enduring consequences than others.

Fourthly, according to this account, the development of a coherent and satisfying self-narrative is a constant work-in-progress, subject to external influence and impacts, re-evaluations and reinterpretations. So our associated interests are ever-present and ever-evolving.

Realising the practical implications of this thesis

My aim in this section has been to bring to a conclusion my argument, built over the preceding chapters, that the matter of whether we are able to access personal bioinformation, and to do so in manner that supports us in using it constructively, can impact on our self-conceptions in ways that can make a real difference to our capacities to construct and inhabit our sense of who we are, and thus to the richness and quality of our lives. In the preceding chapters I aim to have demonstrated that many different kinds of bioinformation could have such impacts in a wide range of settings and circumstances.

A significant tranche of the practical value of my contribution, therefore, lies simply in highlighting, first, that information subjects' identity interests are not trivial and, secondly, that they are potentially widely engaged. These two insights are valuable in themselves because they counsel against complacency that, in any given situation, provided the clinical utility of the bioinformation, or the recipient's expressed wishes, or other parties' privacy interests, have each been taken into account, the relevant ethical landscape has been

exhaustively mapped. My contention is that, if identity interests have not also been accounted for, then there remains an important gap. These interests could either add grist to, or provide significant countervailing reasons against, the ethical case for (non)disclosure.

In order for this observation to have practical teeth and make a difference to disclosure policies and practices, however, two things need to hold. First, it must be possible for those who control our access to our personal bioinformation to know *when* identity interests are engaged and should be taken into account. I will return to deal with that question in Section 4. Secondly, it must be the case that responding to identity interests would *change* something about deliberations and practices of information disclosure decisions. When it comes to laws and policies governing our access to bioinformation about ourselves, and ethical debates about these provisions, a number of interests (other than those in identity development) are commonly invoked as reasons to provide or withhold access. In the next section I will outline how the identity interests proposed here differ from, or relate to, the existing suite of interests more commonly invoked in this context. This is an important step because it will make it clear what attention to interests grounded in a narrative conception of identity *adds* to the current ethical landscape and where attending to these might recommend a different course of action.

SECTION 3: DISTINGUISHING IDENTITY INTERESTS FROM OTHER INTERESTS

Here I will consider the relationship between identity interests (as characterised in this thesis) and five other interests that are currently commonly invoked in relation to information subjects' access to bioinformation, either in existing legal or policy provisions, or in the bioethical literature.⁸⁵⁷ These are interests pertaining to:

- i) Avoidance of distress or psychological harm;
- ii) Health protection;
- iii) Personal utility;
- iv) Developing or exercising autonomy; and
- v) Privacy protection.

There is insufficient space to characterise the nature or ethical basis of each of these in any detail here. My intention is to sketch how the identity-related interests I am proposing intersect with or diverge from each, with the aim of indicating where identity interests would not be met by attention to these other interests alone.

⁸⁵⁷ In the literature these discussions often focus narrowly upon genetic information.

i) Distress or psychological harm

Avoidance of distress, or more strongly, psychological harm, is sometimes invoked as grounds for *not* providing individuals with information about themselves. For example, prevention of unnecessary anxiety may be considered grounds for not offering genetic tests that lack clear clinical utility.⁸⁵⁸ Under UK data protection law a data subject may request that her personal data is not processed on the grounds that this would cause her “substantial distress”.⁸⁵⁹ And there is an exception to subjects’ legal entitlements to access their medical records if it is judged that it would cause “serious harm” to their mental health.⁸⁶⁰

Someone may indeed experience the detrimental impacts of access to bioinformation on her identity as distressing, but I have argued that the significance of these impacts are not reducible to this distress. They extend well beyond this to encompass our very abilities to understand who we are and what we value. Furthermore, as I have argued in the preceding chapters, distress is neither straightforwardly correlated with identity detriment, nor its absence with identity value. Bioinformation that someone actively seeks on identity grounds could nevertheless be distressing to receive (for example learning of the risk of serious disease).⁸⁶¹ Conversely, as I argued with respect to knowledge of donor origins, identity interests may be harmed even if there is no synchronous psychological harm (for example, where false bioinformation places the future coherence of someone’s self-narrative in probable, non-trivial jeopardy).⁸⁶² Therefore, policies or practices that simply seek to protect us from situations in which (in)access to personal bioinformation would cause distress will not, on their own, meet all possible identity interests.

ii) Health protection

When it comes to provision of bioinformation to information subjects in healthcare or research contexts, disclosure is often conditional upon the information having ‘clinical utility’ – the capacity to inform healthcare-related decisions. For example, the Additional Protocol to the European Convention on Human Rights and Biomedicine concerning Genetic Testing for Health Purposes, holds that clinical utility is “an essential criterion” offering a genetic test.⁸⁶³ Similarly, the UK National Screening Committee recommends that screening programmes

⁸⁵⁸ Roberts (2012).

⁸⁵⁹ Data Protection Act 1998, s.10(1).

⁸⁶⁰ Data Protection (Subject Access Modification) (Health) Order 2000, s.5.

⁸⁶¹ See Chapter 6.

⁸⁶² See Chapter 5.

⁸⁶³ Council of Europe (2008) Article 6.

should only be offered if they support reproductive decision-making or are effective in reducing mortality or morbidity.⁸⁶⁴ And the Council for International Organizations of Medical Sciences (CIOMS) ethical research guidelines recommend that:

“In general... life-saving information and data of immediate clinical utility involving a significant health problem must be offered for disclosure, whereas information of uncertain scientific validity or meaning would not qualify for communication to the participant.”⁸⁶⁵

I have indicated in the preceding chapters that, although some identity interests may be predicated upon the bioinformation’s clinical utility, identity interests are neither equivalent nor wholly reducible to interests in protecting or improving one’s health.⁸⁶⁶ Identity concerns may run contrary to such interests (as where someone would prefer not to know about her risk of cancer), or be present where no health-related interest is served (as where someone wants to know if she has genetic siblings, or wishes to participate in genetic research for reasons of solidarity). The key implication of this for information access policies and practices is that it challenges any assumption that assessments of the information’s clinical utility exhaust all possible ethically relevant reasons for providing personal bioinformation. And, as I have argued, although identity-related considerations may not be a matter of life or death, they protect basic elements of a rich and fulfilling human life and, as such, they are capable of giving health-related interests a run for their money in terms of ethical significance.

iii) Personal utility

In the bioethical literature, it is increasingly common to encounter suggestions that ‘personal utility’ could justify access, for example, to individually-relevant research findings or to genetic test results.⁸⁶⁷ Personal utility is often only loosely defined in terms of information that the individual might find useful, fun, or simply be curious about, despite its lack of clinical utility.⁸⁶⁸ Some authors include unspecified identity-related value.⁸⁶⁹

⁸⁶⁴ Public Health England, 'UK National Screening Committee Guidance: Criteria for Appraising the Viability, Effectiveness and Appropriateness of a Screening Programme' (2015).

⁸⁶⁵ CIOMS, 'International Ethical Guidelines for Biomedical Research Involving Humans' (2016), commentary to Guideline 11. This narrows the previous guideline, which recommended that participants be informed of “any finding that relates to their particular health status”, CIOMS, 2002: Guideline 5(7).

⁸⁶⁶ See Chapter 6.

⁸⁶⁷ A.L. Bredenoord et al. (2011), "Disclosure of Individual Genetic Data to Research Participants: The Debate Reconsidered" *Trends in Genetics*, 27(2): 41-47; M.W. Foster et al. (2009), "Evaluating the Utility of Personal Genomic Information" *Genetics in Medicine*, 11(8): 570-74.

⁸⁶⁸ Bunnik et al. (2014); E. Vayena et al. (2012), "Experiences of Early Users of Direct-to-Consumer Genomics in Switzerland: An Exploratory Study" *Public Health Genomics*, 15(6): 352-62.

⁸⁶⁹ Ravitsky and Wilfond (2006).

I have argued elsewhere that the kind of identity value I am proposing here could (with some provisos) be considered a species of personal utility – one that would add ethical weight to claims to utility.⁸⁷⁰ And, in principle, policies that would permit information access on grounds of personal utility might serve interests in accessing identity-valuable bioinformation. However, it is not clear the extent to which such policies already operate in healthcare or research settings (outwith commercial contexts such as direct-to-consumer genomics).⁸⁷¹ Moreover, providing bioinformation solely on the basis of its personal utility (where this is simply taken as synonymous with fulfilling curiosity or a desire to know) could fail to protect recipients' identity interests by supplying false or unreliable information, or failing to attend to how the manner in which it is disclosed affects its meaning or significance to recipients. A more refined, normative conception of personal utility might perhaps meet these concerns.⁸⁷² This thesis could contribute to such a conception.

iv) Autonomy – three kinds

Where autonomy-related interests are invoked in relation to (in)access to our personal bioinformation, this could refer to any one of three different kinds of interests or principles:

- a) An interest in receiving bioinformation to inform a discrete healthcare-related, personal or practical choice;
- b) Respecting an individual's choice about which bioinformation she does (not) want to receive; or
- c) An interest in being able to access bioinformation that supports the development of autonomy where this is understood as a global capacity for self-determination.

I shall compare each of these with the identity interests I am proposing.

a) Informing discrete choices

This permutation has been largely dealt with under the previous two headings in which I have maintained that identity interests are not coextensive with those in having access to information that would allow us to make healthcare-related or personal choices. One thing that

⁸⁷⁰ E. Postan (2016). "Defining Ourselves: Personal Bioinformation as a Tool of Narrative Self-Conception" *Journal of Bioethical Inquiry*, 13(1): 133-51.

⁸⁷¹ One example of information provision decoupled from clinical utility (though not explicitly invoking personal utility) is a pilot policy adopted by UK Biobank, in which incidental findings from whole-body imaging were reported to participants if these revealed "potentially serious" health impacts even if these were not clinically actionable. UK Biobank Ethics and Governance Council, 'UK Biobank Ethics and Governance Council Review' (2009), p.9.

⁸⁷² As noted in Chapter 8, Bunnik et al. (2014) offer a persuasive counterargument to indiscriminate ascriptions of personal utility.

remains to be said is that, according to my account, our identity interests in accessing information extend far beyond desires to use this information in making discrete, identifiable, imminent choices. Identity interests may be engaged where there is no particular practical choice to be made and where receipt does not directly lead to obvious or immediate action – for example, where the information is valued because it allows the recipient to reinterpret her past experiences or revise her values and moral outlook.

b) Respecting individual choices about information access

To some extent this second autonomy-related permutation has also been covered by the discussion of personal utility. I shall unpack the relationship between bioinformation-related identity interests and choice a little further here.

Several legal instruments make an information subject's choice '(not) to know' the basis for information access. For example, the Oviedo Convention on Human Rights and Biomedicine provides that "[e]veryone is entitled to know any information collected about his health. However the wishes of an individual not to be so informed shall be observed."⁸⁷³ Meanwhile, UK data protection law entitles information subjects to access their personal data without giving specific reasons for wishing to do so (although there are exemptions to this entitlement).⁸⁷⁴

Arguments for the 'right to know' based on "informational self-determination" are also made in the bioethics literature.⁸⁷⁵ However, such arguments notoriously struggle to account for what should be done, or why non-disclosure might be wrong, when an information subject does not know the information exists.⁸⁷⁶ Moreover, as I shall go on to argue in this chapter, there is no necessary connection between an information subjects' choice to know something and whether that information serves her identity interests. Perhaps most obviously, an individual's choices (not) to know and her identity interests do not necessarily coincide if the information she desires is false or unreliable.⁸⁷⁷ And the manner and context in which information is conveyed could also be critical to its identity impacts. So approaches that seek solely to respect

⁸⁷³ Article 10(2) of Council of Europe (Oviedo) Convention on Human Rights and Biomedicine (1997).

⁸⁷⁴ Data Protection Act 1998, Section 7. For key exemptions see Schedule 7 to this act and The Data Protection (Miscellaneous Subject Access Exemptions) Order 2000.

⁸⁷⁵ R. Andorno (2004). "The Right Not to Know: An Autonomy Based Approach" *Journal of Medical Ethics*, 30(5): 435-39, p.436.

⁸⁷⁶ G.T. Laurie, *Genetic Privacy: A Challenge to Medico-Legal Norms* (Cambridge: Cambridge University Press, 2002).

⁸⁷⁷ See Chapter 8.

someone's choices (not) to know could harm identity interests. I discuss the relationship between identity value and choice further in Sections 5 below.

c) Supporting the capacity for autonomy

There is indeed an intimate relationship between bioinformation-related identity interests (as I have framed them) and the interest in developing autonomy, where this is understood in the “thick” sense of a broad capacity for critical reflection on one's motives and “working out our projects in the world”.⁸⁷⁸ According to my argument, identity interests are rooted in being able to develop the kind of self-narrative that supports the capacity for autonomy understood in this thick sense.⁸⁷⁹ One difference is that I do not take autonomy to be as the *only* valuable capacity supported. A coherent self-narrative also underpins, *inter alia*, being in a position to have a clear sense of who one is and what one values, being invested in one's own past and future, and in our commitments to projects and to other people. To unpack further distinctions, it is necessary to look more closely at the kinds of information and circumstances in which autonomy-related interests in (not) knowing are understood to bite. Inevitably, these vary between their different instantiations in law and the literature.

Article 8 of the European Convention on Human Rights (ECHR) provides an entitlement to “practical and effective” access to one's own medical records.⁸⁸⁰ Medical data are held to be of “fundamental importance” for the right to respect for private and family life.⁸⁸¹ This right is intimately connected to the protection of autonomy in the ECHR jurisprudence.⁸⁸² However, this entitlement alone would not guarantee protection of identity interests. Rights under Article 8 are not absolute; interference may be justified if lawful and necessary for the protection of other rights and specified interests.⁸⁸³ Moreover, medical records represent only a subset of the kinds of personal bioinformation that, I have argued, can engage our identity interests.

There is also a close connection between provision of medical information and autonomy in UK negligence law. Several cases in the past two decades have found clinicians negligent for failing to provide information about health or reproductive matters, which would have allowed the patient to exercise her autonomy.⁸⁸⁴ In these, autonomy has been construed as extending

⁸⁷⁸ Dworkin (1988); Young (1982), p.43.

⁸⁷⁹ See Chapter 2.

⁸⁸⁰ *KH and Others v Slovakia* (Application no.32881/04) (2009), [44]; Eijkholt (2010).

⁸⁸¹ *Z v Finland* (Application no.22009/93), (1997) 25 EHRR 371.

⁸⁸² *Pretty v United Kingdom* (Application no.2346/02), (2002) 35 EHRR 1; Marshall (2009)

⁸⁸³ European Convention on Human Rights, Article 8(2).

⁸⁸⁴ See, for example, *Mcfarlane v Tayside Health Board*, [2000] A.C. 59, 2000 SC 1, HL; *Rees v Darlington Memorial Hospital NHS Trust* [2004] AC 309, (2003) 75 BLMR 69; *Chester v Afshar* [2004] UKHL 41, [2005] 1 AC 134; *Montgomery v Lanarkshire Health Board (Scotland)* [2015]

beyond making discrete treatment choices, to having the opportunity to deliberate in self-expressive and self-constituting ways.⁸⁸⁵ It is unclear whether this signals the emergence of a stand-alone harm-to-autonomy tort.⁸⁸⁶ However, insofar as these cases pertain specifically to provision of health-related information in contexts of medical misfortune, they would be unlikely to protect the full scope of the identity interests that I have proposed. Furthermore, a recent judgment has adopted a restrictive interpretation of what is “fair, just and reasonable” in determining the scope of a clinician’s duty of care in respect of the provision of health-related genetic information to genetic relatives.⁸⁸⁷ The consequence of that judgment is that a failure to supply information of personal significance to a family member would not be found negligent if this would involve breaching the confidentiality of the patient who was the principle source of the bioinformation.⁸⁸⁸ I do not seek to argue that identity interests are immune to being weighed against competing interests (see Section 5 below). Nevertheless, by highlighting the potential strength of identity interests, and the ethical responsibilities of those who hold potentially identity significant information about us (see Section 4 below), my analysis in this thesis could potentially contribute to assessment both of what constitutes ‘fair, just and reasonable’ when determining the scope of duty of care and of the expected standard of care in such circumstances.

Moving from specific legal provisions to a more theoretical footing, positing a connection between autonomy and access to personal bioinformation demands the question of whether there is a straightforwardly positive correlation between receiving bioinformation and realising one’s capacity for self-determination. The bioethical literature relating to this question (usually in the context of genetic information) is too large to do justice to here,⁸⁸⁹ but it will be instructive briefly to compare what my account entails with two contrasting answers.

UKSC 11; A.M. Farrell and M. Brazier (2016), "Not So New Directions in the Law of Consent? Examining *Montgomery v Lanarkshire Health Board*" *Journal of Medical Ethics*, 42(2): 85-88

⁸⁸⁵ *Chester v Afshar* [18] per Lord Steyn.

⁸⁸⁶ G.T. Laurie, 'Personality, Privacy and Autonomy in Medical Law', in *Rights of Personality in Scots Law: A Comparative Perspective*, ed. N.R. Whitty and R. Zimmermann (Dundee: Dundee University Press, 2009).

⁸⁸⁷ *ABC v St George's Healthcare NHS Trust and Others*, [2015] EWHC 1394 (QB). [29]

⁸⁸⁸ E. Dove (2016), "ABC v St George's Healthcare NHS Trust and Others: Should There Be a Right to Be Informed About a Family Member's Genetic Disorder?" *Rev Der Gen H*, 44: 91-112; Gilbar and Foster (2016). As noted in Chapter 6, an appeal has been granted in this case.

⁸⁸⁹ See, for example, M. Häyry and T. Takala (2001), "Genetic Information, Rights, and Autonomy" *Theoretical Medicine and Bioethics*, 22(5): 403-14; E. Vayena (2014), "Direct-to-Consumer Genomics on the Scales of Autonomy" *Journal of Medical Ethics*, 41(4): 310-14; J. Wilson (2005), "To Know or Not to Know? Genetic Ignorance, Autonomy and Paternalism" *Bioethics*, 19(5-6): 492-504.

One kind of argument, as proposed by Jurgen Husted, holds that imposition of unsought personal bioinformation is inherently inimical to autonomy and to autonomous self-development.⁸⁹⁰ In contrast, my account recognises that unsought bioinformation *could* be detrimental to our self-narratives, but that is not necessarily so. Indeed, I would suggest that Husted's position is both premised on an implausibly individualistic conception of autonomy and sets an unattainably high bar for achieving autonomy or self-creation in a world in which we act with and amongst others, and are perpetually assailed by unsought information. According to the present account, our identity interests lie not in the impossible goal of maintaining an undisturbed self-narrative, but in being able to interpret shifting experiences and averting serious and enduring disruption.

My position can also be distinguished from the inverse position which holds that ignorance of potentially decision-guiding personal bioinformation (even if unsought) undermines one's capacity for autonomy. For example (referring specifically to genetic information) John Harris and Kirsty Keywood argue that:

“...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.”⁸⁹¹

On this basis the authors hold that an autonomy-based interest in ‘not knowing’ genetic information is incoherent.⁸⁹² My own position overlaps with this position to the extent that I recognise that identity interests (and by association, those in developing one's capacity for self-governance) could indeed sometimes be served by receiving unsought bioinformation. But I would deny that positing an identity-linked interest in not being exposed to particular bioinformation is internally contradictory. Maintenance of a desirable and coherent identity does not entail exposing oneself to, let alone incorporating, as many facts about one's body, health or biological relationships as possible. As emphasised in Chapter 2, narrativity is necessarily a selective process. What matters is the intelligibility of the resultant self-narrative. And I would hold that, while this *could* be jeopardised by an absence of information, it could equally be threatened by information that undermines a valued narrative thread, or by

⁸⁹⁰ J. Husted, 'Autonomy and a Right Not to Know', in *The Right to Know and the Right Not to Know: Genetic Privacy and Responsibility*, ed. R. Chadwick, et al. (Cambridge: Cambridge University Press, 2014).

⁸⁹¹ Harris and Keywood (2001), p.421.

⁸⁹² *Ibid.*

attempted factual completism which inhibits our ability to make sense of what we do know about ourselves or to establish priorities.

In addition to the distinctions I have drawn above, what each of these conceptions of the relationship between autonomy and bioinformation again appears to neglect is that the extent and way in which personal bioinformation impacts on our capacity for self-governance and self-development may be shaped as much by the manner in which it is communicated and how the information subject then interprets it, as by the sheer fact of disclosure. This highlights the inadequacy of framing the debate simply in terms of the ‘right’ (not) to know.

v) Privacy

Privacy interests can provide grounds in law for *withholding* personal information from an individual, if doing so would infringe *someone else’s* privacy.⁸⁹³ Graeme Laurie observes, the information subject’s *own* privacy does not appear to have been used as a legal basis for protecting her *own* so-called ‘right not to know’ information about herself.⁸⁹⁴ Nevertheless, Laurie argues that protection of privacy – understood specifically as a metaphorically spatial “state of (psychological) separateness from others” – could in principle provide the rationale for an initial, though not unassailable, presumption against imposing unknown unsought genetic information on someone.⁸⁹⁵ Laurie suggests that privacy derives its value from other interests that it protects. One candidate he proposes is that privacy serves a “...valuable instrumental role ... in creating space to develop one’s own sense of identity and personality.”⁸⁹⁶

However, although some conceptions of identity development might support a presumption against invading privacy,⁸⁹⁷ the account I have offered here does not. Narrative self-constitution, in this thesis, does not depend on a state of separateness. First, as outlined in the preceding sub-section, unsought information may well serve our identity interests. Secondly, narrative self-constitution is inherently a relational undertaking, dependent on interaction, negotiations and collaboration with others (see Chapter 2). Disclosure of unknown unsought

⁸⁹³ See for example, *Odièvre v France*.

⁸⁹⁴ G. Laurie, 'Privacy and the Right Not to Know: A Plea for Conceptual Clarity', in *The Right to Know and the Right Not to Know: Genetic Privacy and Responsibility*, ed. R. Chadwick, et al. (Cambridge: Cambridge University Press, 2014).

⁸⁹⁵ *Ibid.*, p.41. See also, Laurie (2002).

⁸⁹⁶ G. Laurie (2014), "Recognizing the Right Not to Know: Conceptual, Professional, and Legal Implications" *The Journal of Law, Medicine & Ethics*, 42(1): 53-63, p.7.

⁸⁹⁷ See, for example, J. Kupfer (1987), "Privacy, Autonomy, and Self-Concept" *American Philosophical Quarterly*, 24(1): 81-89; P. Widmer (1994), "Human Rights Issues in Research on Medical Genetics" *Ethics and Human Genetics*: 175-88.

bioinformation is contrary to a recipient's identity interests *if* it is detrimental to the coherence or contents of her self-narrative, not because it invades a state of separateness. In Section 6 below I shall consider how others could support the development of our identities in the ways they provide personal bioinformation.

In this section I have indicated that attending to identity interests – conceived of as those supporting the development of a coherent, satisfying self-narrative – would indeed bring something new to the ethical landscape regarding information subjects' access to their own personal bioinformation. They are neither reducible to nor coextensive with the other interests that are prominent in legal, policy or bioethical defences of information subjects' interests in (not) knowing. Furthermore, the 'other interests' considered in this section tend to be invoked as grounds for or against information disclosure *tout court*. As I will go on to unpack in the next section, meeting identity-related interests extends beyond this to the manner and interpretive context in which the information is conveyed. In the remaining sections of this chapter my aim is to outline the basis and scope of the corresponding ethical responsibilities held by those who hold and control our access to our personal bioinformation.

SECTION 4: THE ETHICAL BASIS FOR IDENTITY-RELATED RESPONSIBILITIES

As will be apparent from the examples in Part II of this thesis and the analysis of identity value and detriment in Chapter 8, the ways in which identity interests are engaged will vary widely between different kinds of personal bioinformation, individuals and contexts. My intention in the remaining sections is, therefore, not to make broad legal or policy recommendations, but rather to offer suggestions about the source and nature of the responsibilities that might inform these practical considerations. The responsibilities I am concerned with here are ethical, rather than legal, ones. However, they could be useful in assessing the reasonable extent of legal responsibilities.

In this section I will first outline what I take to be the broad shape of the ethical responsibilities that fall to those who hold our personal bioinformation. I will then outline the way in which these responsibilities fall within a relatively modest requirement to act beneficently. Finally, I will address one of the key challenges facing those seeking to protect the identity interests of others – knowing when and how these interests are engaged.

Broad responsibilities relating to information disclosure

Given the wide range of contexts in which personal bioinformation might be generated, and the fact that we share genetic bioinformation with family members, a wide range of actors may

be in a position to provide us with personal bioinformation. This thesis is, therefore, not only concerned with responsibilities that accrue by reason of professional or administrative roles. It is concerned with *ethical* responsibilities that could fall to clinicians, researchers, regulators, institutions, family members, and commercial actors such as DTC testing services. I shall return in Section 5 to consider how various factors might vary the extent of the responsibilities that fall to different kinds of actors.

I will argue over this and the next two sections that those who hold our personal bioinformation have the following three broad responsibilities, corresponding to the three interests outlined in Section 2:

- I. To provide information subjects with opportunities to access personal bioinformation that could contribute to their development, maintenance or restoration of coherent and satisfying self-narratives;**
- II. To protect information subjects from exposure to personal bioinformation that could be detrimental to their development, maintenance or restoration of coherent and satisfying self-narratives; and**
- III. When offering or disclosing bioinformation that is likely to be identity-significant, to do so in a manner that supports information subjects in using it in, or excluding it from, their development, maintenance or restoration of coherent and satisfying self-narratives.**

I shall refine this broad sketch further over the following three sections. As I will unpack in Section 5, I take these to be *pro tanto* responsibilities, meaning that they will not hold where there are sufficiently strong grounds for acting otherwise.⁸⁹⁸ I will detail what is entailed by ‘supportive manner’ under the third responsibility in Section 6. In Section 7, I will bring together the analyses of this chapter to propose an ethical framework for guiding decisions about disclosure of personal bioinformation so that they take due account of potential identity interests.

My first step, however, is to clarify what I see as the ethical basis for the three responsibilities above.

⁸⁹⁸ As I shall discuss in Section 6, I see the third responsibility – to disclose in an identity-supporting way – to be somewhat less conditional than the others. That is, it may sometimes be better not to disclose than to do so in a detrimental manner.

The ethical foundation for these responsibilities

Given the myriad, diverse interests each of us has and the implausibility of claiming that all of these impose responsibilities on others to meet them, the question that immediately presents itself is, why should this be the case where bioinformation-related identity interests are concerned?

The answer, I submit, lies first in the strength of these interests, grounded as they are upon the basic identity interest and its necessary connection to the conditions for living a full and fulfilling human life. Further to this, because narrative self-constitution is an inherently relational process, it is not something we can do alone.⁸⁹⁹ So we are all potentially implicated in the identity projects of those around us. And this is especially so where one party holds specific means to make those projects go better or worse, not only because they are in a position to provide or withhold tools of narrative development, but also because they may be able to support us in interpreting and using these constructively. The kind of information I am concerned with in this thesis is that to which information subjects do not otherwise have unmediated access – even if it is not in itself particularly technical knowledge. Therefore, they are reliant on others, and the insights that their expertise or position affords them, to provide, withhold or interpret it. In practice, the ways and extent to which particular actors are able to support others' identity interests will vary and so will the extent of their responsibilities – I shall return to this in Section 5.

A beneficence-based responsibility to help

As described above, the responsibilities to respond to others' bioinformation-related identity interests are based in the principle of beneficence – the moral obligation to act for the benefit of others and support them in furthering their significant and legitimate interests.⁹⁰⁰

I have argued that our needs in relation to identity development are important, but it must be conceded that they are unlikely to be either acute or urgent. The corresponding responsibilities, therefore, are not ones to *rescue*, but rather to aid and support. I propose that a conception of beneficence that neatly captures the nature of the responsibilities I have in mind here is the 'Principle of Helpfulness' as formulated by Thomas Scanlon (with some qualifications, which

⁸⁹⁹ See Chapter 2.

⁹⁰⁰ T. Beauchamp, "The Principle of Beneficence in Applied Ethics," in *The Stanford Encyclopedia of Philosophy*, ed. E.N. Zalta (Winter 2016 Edition).

I shall provide below).⁹⁰¹ Scanlon sets out the justifying rationale for this principle using the following example:

“Suppose I learn, in the course of conversation with a person, that I have a piece of information that would be of great help to her because it would save her a great deal of time and effort in pursuing her life’s project. It would surely be wrong of me to fail (simply out of indifference) to give her this information when there is no compelling reason not to do so. It would be unreasonable to reject a principle requiring us to help others in this way (even when they are not in desperate need), since such a principle would involve no significant sacrifice on our part.”⁹⁰²

Scanlon’s formulation highlights the relative modesty of the kinds of responsibilities I am proposing. They hold where the ratio of benefit to the information subject to costs to the potential discloser is high, and they are not absolute. Compelling countervailing reasons and significant sacrifices could be sufficient to override them. The passage from Scanlon quoted above is useful because its constituent steps allow me to structure and clarify what I wish to say about the nature and extent of responsibilities to respond to bioinformation-related identity interests, and where these might depart from Scanlon’s proposal of a general duty to be helpful.

“It would surely be wrong of me to fail...to give”

First I wish to clarify that, although Scanlon’s example happens to be framed in terms of information *provision*, it is not my intention that this should be translated literally into what I have to say. I would hold that beneficence also involves offering or withholding potentially identity-significant bioinformation and in supplying it in a manner that supports the basic identity interest.

“I have a piece of information that would be of great help to her...”

The actors or institutions to whom I would ascribe identity-supporting responsibilities are those that are in, if not a unique, at least a particularly suitable or privileged position to benefit or harm the way an individual’s self-narrative reflects her embodied existence. This is because they are in possession of, or could easily come by, bioinformation to which the individual herself would not otherwise have direct access.

⁹⁰¹ T. Scanlon, *What We Owe to Each Other* (Cambridge, MA: Belknap Press of Harvard University Press, 1998), p.224. Miller *et al* similarly consider the possibility that researchers’ duties to disclose incidental findings to research participants is grounded in part in Scanlon’s Principle of Helpfulness, although they conclude that on its own this principle would give rise to too broad an obligation to disclose, F.G. Miller et al. (2008), "Incidental Findings in Human Subjects Research: What Do Investigators Owe Research Participants?" *The Journal of Law, Medicine & Ethics*, 36(2): 271-79. I, however, will suggest below that Scanlon’s principle as stated itself includes sufficient checks on implausible breadth of responsibilities.

⁹⁰²Scanlon (1998), p.224.

“...because it would save her a great deal of time and effort in pursuing her life’s project”

As I have argued, the development of a satisfying and coherent identity narrative is neither a luxury, nor just a contingent and inconsequential appropriation of a cluster of social identifiers. It is the underpinning condition for finding meaning and purpose in life and the source of our motives and commitments. The ‘effort’ that is ‘saved’ is that of struggling to make sense of who one is and to inhabit this self-conception as one navigates the experience of embodied existence.

“Suppose I learn...”

It would be unreasonable to posit identity-related responsibilities if those potentially in a position (not) to disclose personal bioinformation had no way of knowing when information subjects’ identity interests are engaged and whether disclosure would serve or undermine them. Being able to anticipate when these interests are engaged is also important to ensure that resources expended in protecting them are allocated where they are most likely to make a difference. In the following subsection I will outline the opportunities and challenges facing potential disclosers in this regard.

Discerning others’ identity interests

In contrast to, for example, the clinical utility of bioinformation, it is undoubtedly not straightforward for potential disclosers to know when personal bioinformation would be valuable or detrimental to the self-narrative of a particular individual. These qualities are neither intrinsic, nor universally and uniformly ascribed attributes of any particular kind of bioinformation (see Chapter 8). This does not mean that discerning someone’s identity interests is impossible. The first-person, interpretive aspects of ascriptions of identity significance and value mean that, in many cases the information subject herself will know whether access would be beneficial or detrimental to her identity and be able to communicate this to potential disclosers. Nevertheless, there are, two reasons why this will not always be the case.

First, as indicated in Chapter 8, an individual is not an infallible authority as to her identity interests. This might be because the impact of the bioinformation on her self-narrative might surprise her.⁹⁰³ Or she might be mistaken about the suitability of the bioinformation as a means of explaining her experiences or anticipating her future. For example, she may desire

⁹⁰³ Findings from the REVEAL study indicate how people’s reactions to information may differ markedly from their expectations (see Chapter 6).

information which is false or misleading about biological states of affairs and is therefore unlikely to benefit, and might indeed harm, the coherence of her self-narrative. Or she may resist exposure to bioinformation, which could help to rectify a non-trivial misapprehension about her health, body or biological relationships that is itself detrimental to the coherence of her identity.⁹⁰⁴

The second reason why disclosers cannot necessarily rely on cues from information subjects themselves as to where their interests lie is that sometimes these individuals will be unaware that there is information to be known at all, and asking them if they want to know would effect precisely the disclosure one might wish to avoid.⁹⁰⁵

Despite these two challenges, I do not wish to overstate the impossibility of potential disclosers being able to anticipate where identity interests are likely to be engaged. It may be possible to make some broad population-level predictions about likely identity significance and detriment. This is because, as argued in Chapter 8, as well as being shaped by the nature of an individual's existing self-narrative, identity significance is also likely to be substantially influenced by publicly discernible factors. These include the social meaning ascribed to the information and the scale of the impact on embodied and relational existence that it conveys. Similarly, it may well be possible to anticipate when a category of information is likely to be detrimental, for example because it is widely seen as stigmatising, or likely to incur unwarranted fatalism about health outcomes. It will also often be possible for potential disclosers to know when bioinformation is false, unreliable or fails to speak to the state of affairs it purports to, and therefore could be detrimental. Indeed, insofar as their professional skills or position affords them insights into the information's epistemic qualities, potential disclosers might sometimes be better placed than information subjects to discern when information is unlikely to contribute to the narrative coherence. In addition to these more general insights, tools such as the *BRCA* Self-Concept Scale referred to in Chapter 6, offer possible, evidence-based means of identifying how different individuals or population sub-groups are likely to be affected by the receipt of particular kinds of bioinformation.⁹⁰⁶

These various means might not deliver infallible insights at an individual level. Recipients' reactions could still be idiosyncratic. However, they could help to mark out territory in which attention to identity impacts is particularly warranted. And they could be useful for developing high-level policies about making information and interpretive support available. Moreover,

⁹⁰⁴ Examples of these scenarios are offered in Section 5 below.

⁹⁰⁵ Laurie (2002).

⁹⁰⁶ Esplen et al. (2009).

the fact that potential disclosers cannot always rely on potential recipients' assertions of where their interests lie carries an important implication for the scope of responsibilities. It further highlights why it is crucial that disclosure practices are not seen as discrete events of un-negotiated 'revelation', but rather as discursive and deliberative transactions. I shall return to discuss the nature of identity-supportive transactions in Section 6. First, I wish to consider the limits that apply to the responsibilities of those who might be in a position to provide us with bioinformation about ourselves.

SECTION 5: LIMITS OF RESPONSIBILITIES

“When there is no compelling reason not to do so...”

Scanlon's Principle of Helpfulness does not entail an absolute obligation to help in all circumstances. And I similarly do not wish to suggest that potential disclosers' ethical responsibilities to support others' identity interests are without limits. They are *pro tanto* responsibilities, which hold in the absence of stronger countervailing reasons to do otherwise, and carry a greater imperative in some contexts than others. In this section I will consider three factors which are each relevant to assessing the limits of responsibilities to protect identity interests in any given situation:

- Countervailing individual, shared and public interests;
- The nature of the roles of and relationships between disclosers and information subjects; and
- Information subjects' choices (not) to know.

Limits of responsibilities I: countervailing interests

Responsibilities to offer, provide or withhold bioinformation on identity grounds will need to be weighed against other interests that might be infringed by such actions. Perhaps the most obvious competing interests are those of third parties for whom the bioinformation is also personal. For example, an individual's identity interests in knowing who her genetic mother is will need to be assessed against the interests of that woman in maintaining her own privacy and undisturbed familial role. And someone's desire to maintain a self-conception unmarked by the shadow of hereditary cancer needs to be assessed against other family members' interests in being tested to protect their own health. As these examples indicate, it is possible that identity interests could be in play on both sides of these equations. It is also conceivable that an individual's own interests – for example in protecting her health – could pull in a different direction from her identity interests. There will also be cases in which the

impracticability of discharging a responsibility to protect someone's identity interest will be prohibitive due to the personal or material costs of doing so. For example, concealing one's cancer risk from a genetic relative could place overwhelming restrictions on one's life. Or, ensuring that individual research findings are sufficiently robust and comprehensible to be returned to participants might be prohibitively resource-intensive.

The obvious challenge in these kinds of circumstance is assessing when identity interests are sufficiently weighty that they should prevail. I do not pretend that the arguments I have provided in this thesis will provide an easy or uncontroversial way of resolving this. My intention here is, more modestly, to acknowledge that potential disclosers' responsibilities to protect others' identity development are not without limits. The weighing of diverse, incommensurable and sometimes indeterminate competing interests engaged by information (non)disclosure is a notoriously difficult problem – one which is not unique to my identity-based argument.⁹⁰⁷ But what I hope to have demonstrated in this thesis is that identity-related interests are serious contenders, which need to be addressed alongside the other interests that are traditionally considered in such dilemmas. Given their role in serving the fundamental nature of the basic identity interest, bioinformation-related identity interests are not trivial. They engage disclosers' ethical responsibilities in ways, for example, that vaguer appeals to 'personal utility' do not.

Limits of responsibilities II: roles and relationships

I have suggested that identity-related responsibilities for disclosure are not restricted to those acting in a professional capacity. But the nature and scope of the responsibilities accruing to different kinds of actors in different contexts will vary. And, I suggest, it may vary, in part, because of the professional or institutional role that the potential discloser occupies and their relationship (professional or personal) to the information subject. These factors could influence, for example, the regularity with which a potential discloser is in a position to generate or come into possession of personal bioinformation, or is able to interpret its possible identity significance.⁹⁰⁸ The nature of these roles and relationships will also contribute to determining what counts as a "compelling" countervailing reason or a "significant sacrifice"

⁹⁰⁷ See, for example, essays in R. Chadwick et al., *The Right to Know and the Right Not to Know: Genetic Privacy and Responsibility* (Cambridge: Cambridge University Press, 2014).

⁹⁰⁸ Miller et al have offered a similar argument (though not one based upon identity interests) that researchers have a particular ethical duty to disclose incidental findings because of the vulnerability of research participants, the privileged access that researchers' position have to potentially significant findings, and and researchers' capacity to interpret the possible pertinence of the findings to participants' lives, F.G. Miller et al. (2008)..

and thus the limits of an actor's responsibilities.⁹⁰⁹ For example, clinicians may be particularly likely to encounter or generate potentially identity-significant information. Meanwhile, unlike clinicians, researchers' need to ensure that efforts to protect participants' interests do not threaten the achievement of their research aims, while also avoiding incurring the therapeutic misconception amongst participants.⁹¹⁰ And the sacrifice potentially incurred by someone resisting family pressure to participate in genetic ancestry testing could be greater than that of a doctor refusing to refer a patient for useless genetic tests. I shall return in Section 6 to consider how the different relationships between disclosers and subjects could also influence responsibilities with respect to the *manner* of disclosure.

Ethical responsibilities to disclose based in beneficence may also be strengthened by the wider ethical or legal responsibilities that potential disclosers hold in respect of their professional or personal roles or relationships with information subjects. For example, parents may be seen as having a particular kind of responsibility to support their children's identity development. And some commentators have argued (in relation to information about donor origins) that the state has responsibilities for providing information where it is its own administrative actions that have created the circumstances in which individuals are separated from this information.⁹¹¹ Protection of bioinformation-related identity interests is not currently part of the professional, legally enforceable, duty of care expected of clinicians. But, as noted above, there is a growing expectation that the expected standard of care includes supplying information to support patients' autonomy.⁹¹²

Limits of responsibilities III: information subjects' choices

The discussion thus far still leaves the question of the extent of potential disclosers' responsibilities in two kinds of hard cases:

- Where the information subject's choice (not) to know appears contrary to her identity interests; and
- Where the subject is unaware that potentially identity-significant information exists.

⁹⁰⁹ Scanlon (1998), p.224.

⁹¹⁰ F.A. Miller et al. (2008), "Duty to Disclose What? Querying the Putative Obligation to Return Research Results to Participants" *Journal of Medical Ethics*, 34(3): 210-13.

⁹¹¹ Pennings (2001); V. Ravitsky (2016), "Donor Conception and Lack of Access to Genetic Heritage" *The American Journal of Bioethics*, 16(12): 45-46.

⁹¹² Farrell and Brazier (2016).

Navigating the tension between choice and identity value

It seems plausible that there could be circumstances in which potential disclosers have strong reason to believe that an individual's choice either to seek, or to refuse, particular bioinformation runs contrary to her identity interests. An example of the former might be where a participant in a psychiatric neuroimaging study wants to receive the results of her scan to allay her fears of mental illness, but the researchers know these would provide no reliable diagnostic or predictive information. The latter might be illustrated by someone who has an implacable belief that her healthy lifestyle will protect her from hereditary cancer and resists approaches from her sister to reveal her own (high) risk status.

Going against the information subjects' wishes in each of these cases would be paternalistic, because it would prioritise (what are assumed to be) their identity interests over their autonomous choices. However, it is not obvious why autonomy (thinly-conceived as choice) should be a trump card when choices can be misguided, trivial or fail to protect important values.⁹¹³ I would reiterate my earlier assertions that narrative self-constitution is a relational undertaking, which entails supporting others' identity projects, not abandoning them to their own devices. The significant word here, though, is 'supporting'. The account of responsibilities that I have sketched above are not those of *rescuing* information subjects, or seeking to *perfect* their self-narratives, but of helping them to achieve accounts of who they are that are satisfying and coherent for them.

Where does this leave the above dilemmas? Pierre Widmer argues that one has a "right to adopt and maintain a subjective image of oneself, which may objectively be false".⁹¹⁴ However, talk of rights unhelpfully collapses the matter of where our interests lie with how we should respond to them. I would contend that it is unlikely to be in our interests to inhabit self-narratives built around false beliefs about substantial aspects of our embodied existence. And paternalism may be justifiable – particularly if the interests served by infringing autonomy are considerable and very likely to be met by doing so, and any infringement of autonomy is minimised and is small relative to the interests benefited.⁹¹⁵ Given the ethical significance of identity interests, I would submit that overriding information subjects' choices

⁹¹³ N.C. Manson and O. O'Neill, *Rethinking Informed Consent in Bioethics* (Cambridge University Press, 2007).

⁹¹⁴ Widmer (1994), cited in R. Chadwick et al., *The Right to Know and the Right Not to Know* (Brookfield, VT: Avebury, 1997), p.19.

⁹¹⁵ Beauchamp (Winter 2016 Edition).

could be justifiable, but the picture of interests and responsibilities sketched in this chapter does not offer a single, simple answer and much will depend on the particular circumstances.⁹¹⁶

I would suggest that in the two examples above a key determinative factor is the confidence with which the potential discloser can be sure that contravening the subject's wishes would best serve her identity interests. In the latter example, it is not clear that unwanted information about the hereditary risk of cancer would be unequivocally valuable to the individual's self-narrative such that it provided sufficient grounds to require her sister to divulge her risk status. Furthermore, exposure to her sister's results might not be the only or best way to disabuse her of her misconceptions about cancer susceptibility. Information imposition here looks more like a potentially misfiring attempt to perfect someone's self-conception, rather than supporting her self-understanding. In contrast, I would suggest that the detriment to narrative coherence of providing false or misleading neuroimaging research findings to an individual is somewhat more predictable. Furthermore, disclosure of these results without explanation of their inability to tell the participant about her mental health interferes with the recipient's capacity to use her own values and judgement in selecting her tools of her narrative construction. Therefore, withholding the information could be justifiable in this instance, especially if a clear explanation of its epistemic limitations is also provided.

Unknown unsought information

The second kind of hard case is where an information subject does not know there is information to be known (and offering it would amount to *de facto* disclosure), but the potential discloser has good reason to believe that disclosing it could have a significant impact on the information subject's self-narrative. For example, where does a parent's responsibility lie in respect of telling her adult donor-conceived offspring about the circumstances of her conception, or a researcher's responsibility to tell a participant about an incidental finding with potentially serious health implications? These are longstanding dilemmas in the 'right not to know' debate.⁹¹⁷ Does attending to identity interests add anything new?

First I would suggest that *if* the potential discloser has good grounds (for example based on their knowledge of the individual's priorities or awareness of pervasive social norms) to believe that the information could be valuable to the individual's identity, then the fact the information is unsought is not necessarily reason enough to withhold bioinformation – any

⁹¹⁶ It is somewhat artificial to arbitrate these examples on the basis that autonomy and identity interests are the only things at stake.

⁹¹⁷ See, for example, papers in Chadwick et al. (2014).

more than it would were the information to have clear clinical utility. But, on the same basis, likely identity detriment could plausibly provide countervailing reasons against unsought disclosure that might otherwise be justified on health-related grounds. For example, if it was likely that someone would react to learning of a high risk of heart disease by withdrawing from family activities and imagining their future curtailed, then avoiding these consequences could be more important than giving her the opportunity to adopt health-improvement behaviours.

If the potential discloser cannot be sure whether the information would be valuable or detrimental, recognising the possibility of significant identity impacts will not on its own contribute to settling the question of *whether* to disclose. Indeed, I would suggest that the likely presence of substantial, but unpredictable, identity impacts accounts for much of the weight and difficulty of the classic dilemma regarding disclosure of unsought unknown information. This does not mean that recognising the possibility that identity interests are engaged – albeit in an indeterminate way – is without value in such contexts. It alerts potential disclosers to the fact that, even if disclosure is, for example, pursued on clinical grounds, this does not exhaust the significant interests in play. The manner of disclosure still needs to be managed in such a way as to minimise potential harm to the recipients’ self-narrative.

Indeed, each of these examples in this sub-section indicates that responsibilities to protect others’ identity interests cannot be met solely by attending to the bald questions of whether or not to disclose personal bioinformation (the ‘whether’ of disclosure). The manner and interpretive context within which information is conveyed (the ‘how’ of disclosure) is just as important, particularly where seeking to avert possible identity harms. This means that in order to complete an ethical framework to guide disclosure decisions, I need to unpack what identity-supporting disclosure practices might look like. That is the task for the next section.

SECTION 6: PRINCIPLES AND FEATURES OF IDENTITY-SUPPORTING DISCLOSURE

Commentators have noted (in the context of genetic research) that ethical attention is increasingly turning from the question of *whether* to share findings with participants, to *how* this should be done.⁹¹⁸ The position I have outlined in this and the previous chapter add grist to this turn (and does so beyond a narrow focus on genetic research). Attending to the manner and context in which personal bioinformation is disclosed is essential to meeting information subjects’ identity interests. In this section I shall briefly review why I take this to be the case,

⁹¹⁸ For example, K. Simm, 'Biobanks and Feedback', in *The Right to Know and the Right Not to Know: Genetic Privacy and Responsibility*, ed. R. Chadwick, et al. (Cambridge: Cambridge University Press, 2014).

before outlining what I will take to be the central ethical considerations for transactions in personal bioinformation which would support the basic identity interest. To this end I will:

- Propose what I take to be the two core principles guiding the manner of disclosure of any personal bioinformation that has the potential to be identity-significant;
- Unpack four key elements of delivering these principles; and
- Outline some of the ways in which these elements might be realised in practice.

First, though, I will address the matter of whether it is problematic to suggest that potential disclosers have a legitimate and useful role to play in contributing to, or supporting, information subjects' self-conceptions.

Justifying intervention

It might appear inappropriate to propose an ethical responsibility to support information subjects in how they interpret and use personal bioinformation in the construction of their identities. These might seem to be undertakings properly led and shaped by the individual herself. Internal to the very idea of narrative self-constitution is the idea that the significance and meaning of elements of someone's self-conception cannot be determined independently of what these mean in the context of an individual's particular story.⁹¹⁹

The inherently personal nature of identity development notwithstanding, I would maintain that there are five reasons for holding that the basic identity interest implies an interest in being supported in how one interprets and uses personal bioinformation. The first of these is that, as discussed in the previous section, an individual's choices about what she wants (not) to know and her identity interests can sometimes diverge. I would suggest that the manner and context of disclosure offers possible means of narrowing this gap. Secondly, exposure to potentially identity-detrimental bioinformation may not always be avoidable. Here the manner and context of disclosure might similarly be used to mitigate potential identity detriment. Thirdly, some personal bioinformation will be complex or technical, and its implications for our health and bodies may not be unambiguous or easily understood without support. Fourthly, as Jackie Leach Scully notes (in discussing disclosure of genetic information), "information is not exchanged in an unmediated form".⁹²⁰ The identity significance, value or detriment of personal bioinformation are not wholly within the recipient's control, nor are they necessarily fixed

⁹¹⁹ See Chapter 2.

⁹²⁰ J.L. Scully, 'Receiving and Interpreting Information: A Joint Enterprise', in *Disclosure Dilemmas. Ethics of Genetic Prognosis after the 'Right to Know/Not to Know' Debate*, ed. C. Rehmann-Sutter and H. Müller: 205-217 (Burlington: Ashgate, 2009), p.206.

prior to disclosure. They are rather matters of interpretation to which the context of disclosure can contribute. Fifth, and finally, the construction of our self-narratives is a relational undertaking.⁹²¹ Making sense of the identity significance and possible narrative impacts of any new experiences – including encounters with personal bioinformation – will often depend on discussion with others, drawing on shared experiences and common sources of meaning.

I would argue, therefore, that those responsible for information disclosure have not only a legitimate, but potentially an indispensable role to play in shaping whether and how particular personal bioinformation is or is not used in the development, maintenance or restoration of a coherent and satisfying self-narrative. This role needs to be one that respects the tension between the demands of supporting a self-narrative that makes sense to and ‘works’ for its subject, while recognising that this end might not be something that she can achieve alone. It is on this basis that I propose that the following two principles should underlie all offers or disclosures of potentially identity-significant personal bioinformation.

Two guiding principles of identity-supporting disclosure

- I. A discloser should not seek to *tell* the recipient what roles the personal bioinformation in question ought (not) to occupy in her self-conception or foreclose the kind of story she wishes to construct, but *support* her own (re)construction of her self-narrative in light of the information and what it tells her about her health, body and biological relationships.**

- II. The process should be *discursive* and *collaborative* in a way that permits the discloser to appreciate the particularities of the recipient’s perspective and vulnerabilities, while also providing the recipient the tools and space to work out what the bioinformation means for her life and identity.**

These principles reflect the likelihood that some disclosers will be well-placed to help the information subject to understand what the bioinformation means in terms of her health, body or biological relationships. But, this same professional authority potentially creates a context in which the recipient might also be similarly inclined to defer to the discloser on matters of identity significance. Even if disclosers are experts in their field of biomedicine, their epistemic authority stops short of knowing its relevance and value to others’ identities. These principles operate to guide conduct that is responsive to the particularities of the informational and narrative needs and comprehension levels of individual recipients. As such, they echo

⁹²¹ See Chapter 2.

Leach Scully's characterisation of the ideal disclosure of *genetic* information as a "joint interpretive and ethical enterprise", one which embodies "respect for the ontological 'otherness' of the other" and permits both parties "to comprehend as fully as possible the others' worldviews, and recognize their own cognitive and imaginative limits."⁹²² They also bear close resemblance to the principles of shared decision-making and non-directiveness that traditionally underpin genetic counselling practices.⁹²³ However, the principles I am proposing are intended to have a wider scope: applying beyond the communication of genetic information, beyond clinical contexts, and to disclosures by actors other than specially trained counsellors.

Four elements of identity-supportive disclosure

Although I have suggested that non-directiveness is an important aspect of supporting an individual's narrative interpretation, use or rejection of personal bioinformation, this does not mean abandoning information subjects entirely to their own devices. Given what I have said up to this point about the kinds of factors that contribute to the identity value or detriment of personal bioinformation, I would suggest that it is possible to specify some practices that would honour the above principles, while also actively supporting an individual's identity development. The recommendations below aim to maintain an approach that is sufficiently flexible to respond to individual circumstances, while acknowledging that there are some basic ways in which personal bioinformation can contribute to or detract from the satisfying nature and coherence of our self-narratives in the context of embodied existence. I propose that delivering the principles above will entail (as far as possible, and where applicable) the following four practical elements:

Supporting understanding of biological implications

- I. Explain what the information means for the recipient's past, present or future health, bodily states and functions, and biological relationships.**
- II. Explain what the bioinformation *does not or cannot* tell the recipient about these same things.**

⁹²² Scully (2009), p.206, p.214, p.215.

⁹²³ G. Elwyn et al. (2000), "Shared Decision Making and Non-Directiveness in Genetic Counselling" *Journal of Medical Genetics*, 37(2): 135-38.

Supporting identity-related interpretations

- III. Seek to offset or ameliorate distressing or disempowering interpretations of what the information means for the recipient's development and inhabitation of her own satisfying self-conception.**
- IV. Support the recipient in finding ways to integrate or reject the information from her self-narrative in ways that preserve or restore its intelligibility and coherence.**

The first and second of these recommendations might not necessarily be straightforward to deliver. But their meaning and intention as part of this project should be plain, given what I have said in Chapters 8 about the centrality of the epistemic qualities of personal bioinformation to its identity value.

What is entailed by the third and fourth recommendations may be a little less obvious. To illustrate what these might entail, I offer an indicative list below. This list is not intended to exhaust all ways in which the basic identity interest might be protected or promoted. But I hope to capture some of the ways in which more predictable and universal benefits and harms could be, respectively, pursued or minimised.

Examples of practical interpretive support

In order to be proactive in supporting the basic identity interest, while not pre-empting information subject's self-authorship, disclosers could:

- Challenge stigmatising connotations directly and by signposting to sources of peer and familial support.
- Divert recipients from reductionist and fatalistic interpretations by highlighting the range and complexity of factors contributing to disease susceptibility / traits / kinship and to our identities overall.⁹²⁴
- Minimise recipients' feelings of inefficacy or insecurity, by providing advice on practical steps the recipient might take, for example, pursuing clinical interventions, health protection behaviours, or engagement with patients' groups.
- Consider how the timing of the disclosure might affect the nature of its narrative impacts. For example, would early disclosure facilitate narrative integration (as is indicated for knowledge of donor origins)⁹²⁵ or risk undermining the recipients' sense

⁹²⁴ See the discussion of the REVEAL study in Chapter 6.

⁹²⁵ Freeman (2014)

of having an ‘open future’ (a risk posited in respect to childhood testing for late-onset conditions).⁹²⁶

- Ensure, as far as possible, that the extent of the information provided is suitable for the identity-related role the recipient hopes it will fulfil. For example, someone’s desire to know their genetic origins may be poorly served by merely receiving a legalistic confirmation of paternity.⁹²⁷ And what some without dependents might want to know about her risk of disease risk could differ from someone who identifies closely with her role as a carer.⁹²⁸
- When providing genetic information with potential significance to more than one member of a family, provide support and advice to the recipient on whether and how she might share this information with those other members.⁹²⁹
- Provide further information and support where this might help to ameliorate or repair disruption to a recipient’s existing self-conception. For example, some donor-conceived individuals report that disorientation resulting from discovery of their origins is exacerbated by lacking information about their donors.⁹³⁰

These are only preliminary suggestions based on the literature reviewed for this project. Empirical work is needed to develop more detailed, concrete advice on what measures would be most beneficial in supporting identity development, to understand which individuals or groups might have particular or unexpected needs and vulnerabilities, and to map the challenges raised by particular categories of bioinformation.⁹³¹

Limits to capacities to provide support

The picture of responsibilities I have sketched in this section is intended to extend beyond relationships where concern for, and a collaborative role in, the self-development projects of others is normally assumed. Traditionally these might be recognised as extending to family

⁹²⁶ D.S. Davis (1997), "Genetic Dilemmas and the Child's Right to an Open Future" *Hastings Center Report*, 27(2): 7-15.

⁹²⁷ Blauwhoff (2008).

⁹²⁸ d’Agincourt-Canning (2001).

⁹²⁹ C. Dupras and V. Ravitsky (2013), "Disclosing Genetic Information to Family Members: The Role of Empirical Ethics" *eLS*

⁹³⁰ See Chapter 6.

⁹³¹ The interpretive contexts that contribute in both positive and negative ways to the meaning that particular personal bioinformation have for someone’s self-conception extend well beyond specific disclosures. It might be considered that ethical responsibilities could hold in respect of the way that various actors contribution to this wider interpretive framework in ways that impact negatively on the basic identity interest. However, as the focus of this thesis is interests and responsibilities relating to information *access*, these arguments lie beyond its scope.

members and, on some views, clinicians.⁹³² As I have stated, it is my intention that the recommendations and principles suggested above apply (as far as possible) to all groups of potential disclosers – including professionals and those acting in a personal capacity. However, it is undeniable that there are likely to be disparities in skills and capacities that will place some limits on the practicability and legitimacy of different groups of disclosers fulfilling the above principles and recommendations the same way or to the same extent. In particular, the resources required to disclose information in an identity-supportive way may be prohibitive in some contexts.

It is not possible to unpack all the nuances of difference here. But, for example, we might appreciate that clinicians could be better equipped in terms of analytical skills than family members or researchers to discern and communicate information's reliability as a source of insights into one's health. Meanwhile, family members may well be better equipped than other disclosers to help recipients work out what the information implies for their future and their relationships, particularly if the discloser and recipient have shared experiences of a family history of a particular condition.⁹³³ And there may also be disparities in the resources available to different categories of discloser. For example, provision of counselling might be accounted for as part of clinical care, but represent a significant diversion of limited personnel or funds in a research context.

This means that it may be unrealistic or unreasonable to expect every disclosure of potentially identity-significant personal bioinformation to adhere to the principles and recommendations outlined above. This then raises the question of whether, if a potential discloser does not or cannot adhere to the principles proposed above, information provision would be ethically justifiable. In contrast with what I have said in Section 5 above – where the presence of strong countervailing reasons could relieve an actor of the responsibility to disclose or withhold bioinformation – I wish to suggest here that where a potential discloser is unable to adhere to the principles and recommendations of identity-supportive disclosure, this does not mean that they would be justified in proceeding with disclosure with impunity. On the contrary, in cases in which doing so would incur significant identity detriment, I submit that it could provide sufficient grounds for a responsibility *not* to disclose. In Section 8 I offer some examples of instances in which this may be the case.

⁹³² A. Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge*, Cambridge Law, Medicine, and Ethics. (Cambridge: Cambridge University Press, 2009).

⁹³³ See Chapter 5.

This brings to a close my discussion of the broad considerations underlying the ethical responsibilities of those who (potentially) hold personal bioinformation about others. I wish now to bring together everything I have said up to this point in the chapter in an ethical framework for the protection of information subjects' identity interests.

SECTION 7: AN ETHICAL FRAMEWORK TO GUIDE DISCLOSURE

The following framework is intended to inform and guide decisions-making, policies and practices about disclosure of personal bioinformation to information subjects in light of the potentially significant impacts of this information on the identities of those to whom it pertains. This framework is founded on the basic and bioinformation-related interests as characterised in Section 2. It unpacks the practical implications of the broad responsibilities outlined in Section 4 and the limits to these, as discussed in Section 5.

THE BASIC IDENTITY INTEREST

- An interest in developing, maintaining and restoring a coherent and satisfying self-narrative.
 - Where the coherence of the self-narrative pertains particularly to the extent to which an individual is able to make sense of and inhabit who she is in the context of her embodied and relational existence and experiences. And where perfect coherence is likely, in practice, to be an unattainable ideal.
 - And a satisfying self-narrative is one that comprises descriptive, relational and role-based characteristics and contents with which the individual is comfortable, as far as this is possible within the constraints of coherence.

BIOINFORMATION-RELATED IDENTITY INTERESTS

- I. The information subject's interest in being able to access personal bioinformation that would contribute to her development, maintenance or restoration of a coherent and satisfying self-narrative
- II. The information subject's interest in being protected from exposure to personal bioinformation that would undermine her development, maintenance or restoration of a coherent and satisfying self-narrative

- III.** The information subject's interest in receiving personal bioinformation in a manner that supports her in using it in, or excluding it from, her development, maintenance or restoration of a coherent and satisfying self-narrative.

OUTLINE OF KEY ETHICAL RESPONSIBILITIES

- A. There is an ethical responsibility to *provide* personal bioinformation when:
- i. The information subject seeks access to it on identity grounds and there are no good reasons to believe that it would be detrimental to her identity; or
 - ii. The information subject does not know that the bioinformation exists, but there are good reasons to believe it could be of significant value to her identity, and offering it would entail *de facto* disclosure.
 - Each of these is subject to the following conditions:
 - disclosing this personal bioinformation would not disproportionately harm the recipient's*, the discloser's**, or third parties'*** legitimate interests; and
 - disclosure can**** be conducted in a manner likely to support the recipient's basic identity interest, where this entails adherence to the principles and practical considerations listed below.
- B. There is an ethical responsibility to *offer* personal bioinformation when the information subject does not know the bioinformation exists, but there are good reasons to believe that it could be of value to her identity and offering can be achieved without disclosure,
- Provided that:
 - disclosing the bioinformation would not disproportionately harm the recipient's, the discloser's, or third parties' legitimate interests;
 - the subject is made aware of any possibility of identity detriment; and
 - disclosure can be conducted in a manner likely to support the recipient's basic identity interest.
- C. There is an ethical responsibility to *withhold* personal bioinformation when:
- i. The information subject seeks access to it on identity grounds, but there are good reasons to believe disclosure could be detrimental to her identity; or

ii. The information subject does not know that the bioinformation exists, offering it would entail de facto disclosure, and there are good reasons to believe that it could be detrimental to her identity.

- Each of these is subject to the following conditions:
 - withholding would not disproportionately harm the recipient's, the discloser's, or third parties' legitimate interests; and
 - it is not possible to disclose it in a way likely to reduce or mitigate this detriment.

D. It may be *permissible* to disclose personal bioinformation to the information subject when there are reasons to believe disclosure could be somewhat detrimental the information subject's identity,

- If:
 - withholding would disproportionately harm the recipient's other legitimate interests; and
 - provided disclosure is conducted in a in a way likely to reduce or mitigate this detriment.⁹³⁴

* Information subjects' interests that could operate as a limiting condition might include, for example, those in protecting her health.

** Where the disclosers' interests appear as a limiting condition, these might involve, for example, the disproportionate effort or cost of preparing the information or locating the information subject. Where disclosers are private individuals these interests could include, for example, those in their own privacy or identity development.

*** Where third parties' interests operate as a limiting condition, these might include the interests of other individuals – for example the privacy or health-related interests of genetic relatives – and also those of groups and the public interest in, for example, protecting patient confidentiality, or the disproportionate expenditure of public resources.

****If disclosure cannot be conducted in a manner likely to support the recipient's basic identity interest (for example because it is disproportionately costly or burdensome to do so) then providing or offering personal bioinformation might not be justifiable.

⁹³⁴ This framework does not spell out all the *permissible* courses of action implied by the conditions attaching to the responsibilities. For example, it might be permissible to withhold potentially identity valuable information of it would disproportionately harm someone else's privacy to disclose it.

GUIDING PRINCIPLES OF IDENTITY-SUPPORTING DISCLOSURE

- I. A discloser should not seek to *tell* the recipient what roles the personal bioinformation in question ought (not) to occupy in her self-conception or foreclose the kind of story she wishes to construct, but *support* her own (re)construction of her self-narrative in light of the information and what it tells her about her health, body and biological relationships.
- II. The process should be *discursive* and *collaborative* in a way that permits the discloser to appreciate the particularities of the recipient's perspective and vulnerabilities, while also providing the recipient the tools and space to work out what the bioinformation means for her life and identity.

PRACTICAL ELEMENTS OF IDENTITY-SUPPORTING DISCLOSURE

- I. Explaining what the information means for the recipient's past, present or future health, bodily states and functions, and biological relationships.
- II. Explaining what the bioinformation *does not or cannot* tell the recipient about these same things.
- III. Seeking to offset or ameliorate distressing or disempowering interpretations of what the information means for the recipient's development and inhabitation of her own self-conception.
- IV. Supporting the recipient in finding ways to integrate or reject the information from her self-narrative in ways that preserve or restore its intelligibility and coherence.

It is not possible to provide examples to illustrate every permutation of this summary of the ethical responsibilities that emerge from this framework. But in the final section of the last substantive chapter of the thesis I will now revisit the three examples discussed in Part II to sketch in brief what this framework brings to consideration of potential disclosers' ethical responsibilities and associated disclosure practices in each of these contexts.

SECTION 8: APPLYING THE ETHICAL FRAMEWORK TO THE ILLUSTRATIVE EXAMPLES

The ethical framework that I am proposing will not usually generate single, blanket (non)disclosure policy for any particular category of personal bioinformation. The recommended course of action is likely to vary depending on the particularities of any given situation. The following reflections on the existing accessibility of the three categories of personal bioinformation discussed in the illustrative examples are, therefore, necessarily schematic. I seek chiefly to indicate where my analysis provides a useful fresh emphasis or perspective.

Illustrative example I: Information about donor origins

The regulation of donor-conceived individuals' access to information about the fact of their donor conception in the UK is already explicitly informed by consideration of its impacts on these individuals' identities.⁹³⁵ I have argued that the precise nature of identity interests has hitherto been inadequately articulated in this context.⁹³⁶ Nevertheless, given that the sense in which identity appears to be intended is broadly that of self-characterisation, it is unsurprising that there are intersections between the current legal and regulatory position and what the present thesis would recommend. However, I suggest that current provisions may not go far enough, in ways I will indicate below.

The existing policy position in the UK, that parents must be advised of the importance of telling their donor-conceived children about their conception as early as possible and offered guidance doing so, accords with the contention of this thesis that allowing someone to premise their self-narrative on false beliefs represents an identity harm, which should be averted where possible.⁹³⁷ However, positing such an identity harm might seem to recommend the stronger requirement of a legally-enforceable *obligation* on parents or the regulator, the HFEA, to disclose donor conception.⁹³⁸ Despite the threat to narrative coherence from false beliefs, I would suggest that coercive measures to secure or pre-empt parental disclosure (such as annotating birth certificates) are likely to be disproportionate and insufficiently context-sensitive. They could infringe parents' identity, autonomy or privacy and interests. Moreover, if enforced disclosure increased the likelihood of donor-conceived individuals' being

⁹³⁵ See Chapters 1 and 5.

⁹³⁶ See Chapter 1.

⁹³⁷ Human Fertilisation and Embryology Authority, 'Code of Practice' (2015).

⁹³⁸ Some have argued that there are plausible grounds for the state having such an obligation, given that it too has the information and is complicit in activities which mean that donor offspring lack it. See, Ravitsky (2016).

confronted by information about their origins in unsupported ways, it is not clear that it would serve their interests in constructing coherent, satisfying self-narratives.

Attending to the potential role of this information in the development of donor-conceived individuals' self-narratives could, however, be a reason to revisit the minimum age at which they are legally entitled to apply to the HFEA to learn if they are donor-conceived, or for identifying information about their donors. This is currently eighteen in each case.⁹³⁹ The arguments in this thesis suggests that the age threshold should be informed by empirical evidence of: what donor-conceived individuals wish to know and when; when access to this information is likely best to support identity-development; and the impacts of knowing about one's donor origins while lacking information about one's donor.

It is already a legal requirement that those seeking information from the HFEA about the fact of their donor conception or for information about their donors or donor siblings must "be given suitable opportunity to receive proper counselling about the implications of compliance with the request".⁹⁴⁰ This is broadly in tune with my recommendations for identity-supportive disclosure. But again it may not go far enough. In recognition of the difficulties many parents experience in telling and the strength of their children's potential identity interests, this thesis endorses recommendations from the Nuffield Council on Bioethics that the state should fund specialist support and counselling to help parents to tell, and donor-conceived individuals to make sense of what they are told.⁹⁴¹

Illustrative example II: Genetic disease susceptibility testing

Current policies, practices and professional obligations to supply information subjects with the results of genetic analysis for susceptibility to multifactorial conditions vary widely depending on the context in which this information arises. My ethical framework generates similarly diverse, context-dependent recommendations. So, it is not possible to speak comprehensively to how the latter would modify the former.

One headline implication of my position, however, is that information about genetic disease risk could have identity value, and therefore potentially warrant disclosure, even when it lacks clinical utility. This would have implications for, for example, decisions about which intended or incidental findings should be offered or fed back to research participants. This might raise concerns about an impossibly broad requirement to provide such findings. However, it is

⁹³⁹ Human Fertilisation and Embryology Act 1990 (as amended), s.31.

⁹⁴⁰ Ibid.

⁹⁴¹ Nuffield Council on Bioethics (2013).

important to recall that responsibilities to disclose on identity grounds are subject to limits. First, for identity interests to be engaged, the results must exhibit clinical validity – that is, they must provide reliable and meaningful information about health risks or traits in question. Secondly, the identity interests served must be sufficiently probable and significant to warrant the costs, effort, and potential harm to competing interests entailed by providing the test results. And this includes the costs and effort of meeting the corollary responsibility to communicate potentially identity-significant results in ways that accord with the principles of identity-supportive disclosure outlined in Section 6. So, my ethical framework might indeed recommend returning findings about a genetic risk of Alzheimer’s disease to participants in primary research involving families of Alzheimer’s patients. In contrast, the framework is likely to recommend against feeding back similar findings generated in secondary analysis of biobank data where doing so in a way that managed any potentially detrimental identity impacts would be disproportionately burdensome.

My ethical framework might also recommend the *prohibition* of some kinds of susceptibility testing by DTC genomic testing services, at least at their current stage of development and under existing marketing practices. Currently, DTC services potentially represent a ‘perfect storm’ of identity-detrimental circumstances. These include a communication environment in which the identity significance of test results is accentuated; the provision of results of questionable clinical validity or that are so broad as to be meaningless; obfuscation about these epistemic limitations; multiple results delivered concurrently; and the absence of clinical support or counselling to help recipients interpret their results.⁹⁴² As noted in Chapter 6, the US Food and Drug Administration took action to stop some commercial operators offering tests for some conditions, including *BRCA*-linked cancers, because of the risk of “unreasonable harm” to health from “incorrect test results or unsupported clinical interpretations”.⁹⁴³ This action has been criticised by some as paternalistic.⁹⁴⁴ And supra-clinical interests are sometimes invoked as justification for the value of DTC genomic testing.⁹⁴⁵ I would hold, however, that attending to identity interests strengthens the ethical justification for such regulatory restrictions.

⁹⁴² Kalf et al. (2013); Skirton et al. (2012).

⁹⁴³ "U.S. Food and Drug Administration - Inspections, Compliance, Enforcement, and Criminal Investigations - Warning Letter to 23&Me - Document Number: Gen1300666 22 November 2013".

⁹⁴⁴ N.A. Farahany (2014), "The FDA Is Overcautious on Consumer Genomics" *Nature*, 505: 286-87; P.J. Zettler et al. (2014), "23andme, the Food and Drug Administration, and the Future of Genetic Testing" *JAMA Internal Medicine*, 174(4): 493-94.

⁹⁴⁵ Vayena (2014).

Illustrative example III: Psychiatric neuroimaging

Currently, in the UK, the only context in which neuroimaging findings indicative of psychiatric diagnoses could plausibly be made available is in studies investigating the clinical applicability of this technology.⁹⁴⁶ The evidence considered in Chapter 7 indicates that neuroimaging-based diagnoses are likely to be accorded considerable identity-significance by patients. But with this comes potential for identity detriment. Neuroimaging is not yet able to provide robust, unambiguous diagnoses. And features of the research environment (including limited resources or clinical skills) could present obstacles to participants receiving findings in a way that explains their epistemic limitations and averts unwarrantedly deterministic or neuro-reductive inferences by participants.

According to my ethical framework, this constellation of factors implies a responsibility not to offer findings from psychiatric neuroimaging studies to participants. There is no indication that such findings are routinely offered. But I would suggest that practices, such as giving research participants printed neuroimages as thanks for taking part, could be unethical if they are likely to result in unwarranted personal investment in diagnostically meaningless information.⁹⁴⁷ The same conclusion would apply *a fortiori* to direct-to-consumer diagnostic neuroimaging, where the same constellation of detrimental factors seems even more likely to obtain.

Even if current methodological problems with neuroimaging-based diagnostic techniques are rectified, concerns about neuro-reductive explanations of mental illness may persist.⁹⁴⁸ This means that patients' reliance on such diagnoses in the construction of their self-narratives could remain problematic to the extent that these narratives might still fail to accord with their lived experience of mental illness or to include unwelcome or disempowering fatalism about the nature of their illness. If these concerns are warranted and psychiatric neuroimaging enters clinical practice, the ethical framework I have proposed would recommend that this is an area in which it would be particularly important to attend to the possibility of identity detriment, and to seek to mitigate this through the manner of information disclosure.

SECTION 9: CHAPTER CONCLUSION

In this thesis I have argued that we all have an ethically significant interest in developing, maintaining and restoring a coherent and satisfying account of who we are, because this is a

⁹⁴⁶ See Chapter 7.

⁹⁴⁷ Cohn (2010).

⁹⁴⁸ See Chapter 7.

condition for leading a rich, fulfilling and practically engaged life. And, because our embodied experiences impinge on our lives, and our self-narratives provide the foundations from which we navigate these experiences, this basic interest is engaged both by whether and how we are able to access bioinformation about our health, bodies and biological relationships. In this chapter I have proposed that, as a consequence, we have three derived bioinformation-related interests: in receiving bioinformation which would serve the basic identity interest; in being protected from that which would undermine it; and in receiving bioinformation in a manner that supports our narrative development.

It is my contention that these three interests warrant ethical attention in policies and practices concerned with disclosure of personal bioinformation, alongside the attention currently given to the impacts of bioinformation on our health-related decisions, our emotional wellbeing, our privacy and on our capacities to act in self-determining ways. In this chapter, I have sought to demonstrate that our identity interests are not reducible to or coextensive with any of these existing considerations. Therefore, protection of these other interests does not provide sufficient protection of our identity interests – attending to identity impacts brings something new to the ethical landscape.

On these grounds I have argued that bioinformation-related identity interests are sufficient to give rise to distinct ethical responsibilities amongst those who are in a position to generate or who hold personal bioinformation about us. These responsibilities hold in virtue of the strength of the identity interests involved and the capacities of those who hold bioinformation about us to promote or harm these interests through their decisions about whether to make this information available to us and, no less importantly, the manner in which they do so.

Despite the ethical weight of identity interests in whether and how we access bioinformation about ourselves, it is not my position that they should trump all other legitimate considerations in defining the responsibilities of potential disclosers. They must be considered alongside and weighed against the other interests and costs associated with providing or withholding bioinformation. Furthermore, the capacities of different potential disclosers to discern and respond to these interests will vary depending on the nature of the bioinformation in question, their role, skills, resources, and relationships to the information subject. Moreover, I have argued that whether or not identity interests prevail in decisions about *whether* bioinformation should be disclosed, the sheer fact that they are engaged at all provides grounds to attend to identity impacts in the manner in which bioinformation is communicated. I have proposed here a suite of principles and practical considerations to guide disclosure practices that would support the development of coherent and satisfying self-narratives.

It is not possible in abstract terms to specify a single, uniform policy in respect of the disclosure of all personal bioinformation or even particular categories. Much will depend on the kind of bioinformation in question, the needs and circumstances of the particular information subject and the contexts in which bioinformation arises and is communicated. This is not to say that, in any particular context, policies or best practice guidance directed at protecting identity interests could not be developed – whether these are national policies such as those on access to information about donor origins or, more local ones, such as a research study’s policy on feedback of individual findings to participants. It is my intention that the ethical framework proposed in this chapter will provide a robust conceptual and normative foundation for working out how such policies or guidance might be developed and the matters they ought to take into account.

CHAPTER 10: CONCLUDING REMARKS AND LOOKING FORWARD

In this thesis I have set out to address a gap in the ethical landscape surrounding the governance of individuals' access to information about their own health, bodies and biological relationships. This gap is a lack of attention to, and thus protection of, the identity-related interests of information subjects. I have sought to fill this gap by developing a normative account of the impacts of personal bioinformation on identity construction, and by providing an ethical framework to guide information disclosure practices in responding to the interests arising from these impacts.

In this final concluding chapter I will first review the arguments and recommendations of this thesis. I will then highlight the original contributions I have sought to make. I will indicate where my conclusions entail changes in existing information disclosure practices and policies. Finally, I will outline fruitful areas for applying my arguments and pursuing further research.

SECTION 1: MY ARGUMENT AND CONCLUSIONS

Questions about whether personal bioinformation can or should be provided to those to whom it pertains arise in myriad healthcare, research, commercial, administrative and familial contexts. Yet, currently, it is only access to information about genetic parentage that receives legal protection on explicitly identity-related grounds. And, even in that context, the role of information in identity remains contested, ambiguous, and peculiarly exceptionalist. Corresponding to the four headline research questions in Chapter 1, my aims in this thesis have been: to develop a plausible and robust conception of the relationship between a broad range of personal bioinformation and identity (*qua* self-characterisation); to characterise the nature and scope of individuals' interests in accessing their personal bioinformation and the corresponding responsibilities of parties who hold this information; and thus to make recommendations as to how information disclosure practices can protect information subjects' capacities to develop their identities.

I have argued that personal bioinformation can impact on our development of our own identities in ways that are sufficiently significant to warrant attention in decisions about our access to this information. My argument is rooted in philosophical accounts that hold that our identities are constituted by self-constructed narratives. As outlined in Chapter 2, these accounts entail, what I have termed, a 'double normativity'. First they indicate why being able

to develop, sustain and inhabit an identity-constituting narrative is necessary to leading a rich, fulfilling and practically engaged life. Secondly, they hold that, in order to be identity-constituting, a self-narrative must be reasonably coherent. My own argument, in Chapter 3, builds on this conceptual foundation. I have proposed that, given the embodied nature of our lives, personal bioinformation has a critical role to play in helping us to develop, maintain or restore coherent self-narratives, because the information helps us to anticipate, make sense of and navigate our embodied experiences. The normativity of the underlying theory explains why access to bioinformation *matters*.

To test the plausibility of, to illustrate, and to refine my theoretically-based argument, I have drawn on empirical social science literature reporting information subjects' attitudes and responses to three categories of personal bioinformation (Chapters 4-7). These were: information about donor conception; results from genetic disease susceptibility tests; and diagnostic indications from psychiatric neuroimaging. These categories were chosen to represent diverse kinds of bioinformation, thereby allowing me to draw generalisable inferences beyond the specifics of each, as well as highlighting the variation between them and the limits of identity value.

My analysis of these examples suggests that individuals' responses to these categories of personal bioinformation are broadly congruent with my proposition that diverse kinds of bioinformation can play important roles in the development of our self-narratives. However, as detailed in Chapter 8, these examples also introduce refinements to my starting proposition. They indicate that the impacts of bioinformation on our self-narratives are neither uniform nor universal, but vary between kinds of information, individuals and contexts. They also highlight the potential for bioinformation to be detrimental as well as valuable to our self-conceptions. And the examples indicate that multiple factors may be instrumental in shaping whether bioinformation is experienced as being relevant to someone's identity at all. Importantly, these factors include the manner in which it is communicated, insofar as it contributes to the interpretive and supportive context for recipients' narrative use of this information

I have argued that the valuable and detrimental roles that personal bioinformation can play in on our self-narratives extend beyond contributing narrative 'contents' in the form of discrete, revised self-descriptors. This information can also play an interpretive and structural role by enhancing or detracting from the coherence of our identities as a whole. While the effects of bioinformation on the contents and coherence of our self-conceptions may well be intertwined and interdependent, I have suggested that – given the importance of narrative coherence to our

capacities to lead full and practically-engaged lives – it is the latter that chiefly accounts for ethical weight of our interests in accessing personal bioinformation.

Based on my analysis of the three illustrative examples, I have concluded that whether and how we are able to access diverse kinds of personal bioinformation can impact on our basic interest in developing coherent and satisfying self-narratives in ways that are neither improbable nor trivial. I have proposed that we have three specific bioinformation-related interests derived from this basic interest (Chapter 9). The *first* of these is that in having the opportunity to access bioinformation that would enhance the coherence and satisfying nature of our self-narratives. The *second* lies in being protected from bioinformation that would be detrimental to this end. And, *thirdly*, we have an interest in receiving bioinformation in a manner that supports our identity development. I have indicated how these identity interests differ sufficiently from the other interests (for example, in exercising our autonomy or protecting our health) currently taken into account by laws, policies and practices governing disclosure of bioinformation, that they warrant attention in their own right.

What is this ‘attention’ entails is captured by the ethical framework that I have proposed in Chapter 9. This framework characterises the nature and extent of the interests, responsibilities, principles and practical considerations that ought to inform identity-supporting disclosure. I have argued that those who are in possession of potentially identity-significant personal bioinformation have *pro tanto* responsibilities corresponding to each of the three identity-related interests. These responsibilities arise when a potential discloser is in a position to supply and help to interpret bioinformation to which the potential recipient would not otherwise have access. And they are rooted in the principle of beneficence and in the relational nature of narrative self-constitution. These responsibilities are strong, but not absolute. They must be weighed against responsibilities to protect competing interests. And, the costs of meeting them ought not to be disproportionate.

In constructing this ethical framework I have acknowledged the variability in the precise location of different individuals’ bioinformation-related identity interest presents challenges in discharging responsibilities to protect them. However, I have suggested these challenges not insurmountable and have proposed ways in which some of these may be negotiated. Not least amongst these is recognising the value of discursive, collaborative, non-directive disclosure practices. I have held that such practices must play a central role in the governance of potentially identity-significant personal bioinformation. I have concluded Chapter 9 by offering high-level principles and concrete recommendations to indicate what identity-supporting disclosure practices would look like and to guide their delivery.

SECTION 2: ORIGINAL CONTRIBUTIONS OF THIS THESIS

This thesis makes four original contributions to bioethical and policy debates about individuals' interests in accessing their personal bioinformation: the *first* establishing identity interests as a relevant and significant ethical consideration; the *second* providing a fresh conceptual and normative analysis of these interests; the *third* broadening the field of attention beyond information about genetic origins; and the *fourth* offering practical ethical guidance. In doing so, I have also contributed a fresh angle to narrative identity theory.

My first contribution has been to add to existing debates about our interests in accessing bioinformation about ourselves by articulating the nature of the one of the key interests that may be at stake – that in developing a coherent and satisfying account of who one is. Recognition of identity interests brings something new to the ethical landscape. This thesis highlights that failures to attend to the possibility that identity interests might be engaged by decisions about disclosure of personal bioinformation represent a significant omission.

My second contribution has been to provide a plausible means for conceptualising the normative role of personal bioinformation in our identities. There are plentiful existing discussions in the literature of the ways in which some specific kinds of personal bioinformation could make a difference to specific aspects of self-characterisation. This thesis, however, has sought to explain why our access to personal bioinformation (of many kinds) can affect our abilities to make sense of and inhabit identities *as a whole*, in ways that make a real difference to our lives and, therefore, engage significant interests. My claims do not depend upon the contentious premise that any particular kind of bioinformation is uniquely important or essential to understanding who we are, and can accommodate diverse means of self-characterisation.

My third contribution has been to demonstrate that potentially identity-significant bioinformation extends beyond the 'usual suspects' on which policy-makers and the law have hitherto focused – chief amongst these being information about genetic origins. Through the illustrative examples I have provided, I have indicated that the kinds of bioinformation considered in these examples are significant to individuals' self-conceptions to the extent that they occupy a range of roles in the construction of our self-narratives. The information in those examples occupy these narrative roles by virtue of exhibiting a range of explanatory, predictive, descriptive or interpretive qualities, linked but not restricted to the particular genetic and neurological nature of this information. This means that these roles could be occupied by a wide variety of bioinformation. In broadening the field of attention in this way,

I have also offered an analysis of why some kinds or instances of bioinformation may be seen by information subjects as especially significant to their self-conceptions.

My fourth contribution has been to deliver an ethical framework for addressing the impacts of personal bioinformation on identity. This framework applies my argument to practical ends. It characterises the nature and extent of the ethical responsibilities of potential disclosers. It pinpoints the possibility of identity impacts as a significant reason why information providers' responsibilities to protect the interests of information subjects do not stop at the decision of *whether* to disclose, and extend to the *manner* in which they do so. This ethical framework proposes both high-level principles and concrete recommendations intended to guide identity-supporting disclosure practices in ways that support the constructive application of personal bioinformation to self-development, and minimise its detrimental impacts.

In constructing this account, I have also sought to contribute to philosophical discussions of narrative identity. I have argued that, because we lead embodied lives (not only rational and relational ones), the coherence of our self-narratives depends not only on their internal intelligibility and congruence with how others see the world, but also upon these narratives making sense in light of *our own experiences of embodiment*. This exposes a narrative role for information about our embodied states, previously unacknowledged in the narrative identity literature. Personal bioinformation does not *tell* us who we are, but it can help us to develop self-narratives that are resilient and intelligible in the face of embodied experiences.

SECTION 3: WHAT WOULD CHANGE AS A CONSEQUENCE?

If the arguments and recommendations of this thesis were taken up, how would this change the management of personal bioinformation?

The chief change would be that consideration of information subjects' identity interests would comprise a standard aspect of bioinformation disclosure practices or policies (for example, those relating to returning individual findings from health research to participants) alongside the other interests currently taken into account. This still allows those making assessments about disclosure to judge that identity interests are unlikely to be affected to a significant degree in the given circumstances. And it does not preclude the assessment that meeting them would be disproportionately burdensome or impracticable, or that other interests carry more weight. But a wholesale failure to consider potential identity-related impacts would be recognised as a significant omission.

This change requires identity interests being dealt with on their own terms, not subsumed within – for example – nascent moves to take the 'personal utility' of bioinformation into

account in disclosure decisions. The meaning and normative significance of the portmanteau concept of personal utility remains unsatisfactorily inchoate, and identity ends are unlikely to be well-served by being bundled within it.

A further significant change entailed by my arguments is a greater emphasis on the manner and informational context of information disclosure practices across a broader range of bioinformation and, by association, the nature of the relationship between the information subject and the disclosing party. The kind of interpretive support I have proposed involves a greater level of explanation and provision of supplementary information than is common outwith genetic counselling. This relationship implied is closer to that of an interpretive partnership than that of mere provider and recipient.

My recommendations relating to provision of interpretive support are in step with increased emphasis in bioethics on relational autonomy and shared decision-making.⁹⁴⁹ Nevertheless, these recommendations undoubtedly carry significant implications for training, resource allocation and cultural change. This poses important questions about the practicability of providing identity-supportive disclosure in some settings – for example, in large-scale research projects. Addressing these questions has not been possible within the scope of this thesis. This is an area where further, empirically-informed, research could be fruitfully pursued: first, to explore in greater detail what communicating bioinformation in an identity-supporting way would entail; and, secondly, to determine the opportunities for, or barriers to, delivering such an approach in different clinical, research or administrative contexts. I indicate additional areas for further research below.

The arguments of this thesis do not point to a need for legislative changes to secure blanket (non)disclosure policies in particular sectors or in relation to particular categories of bioinformation. Legislation is likely to be too blunt an instrument to protect the kinds of interests I have described. These interests will often vary according to the needs of individual recipients, the nature of the bioinformation, and the contexts and relationships within which the information is communicated. I have suggested that protection of bioinformation-related identity interests is likely to be best achieved through policies and professional guidelines, which can be more flexible and sensitive to needs arising in particular contexts.

⁹⁴⁹ A. Donchin, 'Autonomy and Interdependence: Quandaries in Genetic Decision Making', in *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*, ed. C. Mackenzie and N. Stoljar: 236-58 (New York: Oxford University Press, 2000); Maclean (2009).

SECTION 4: AREAS FOR FURTHER RESEARCH

Beyond the illustrative examples

The conclusions of this thesis are intended to apply to personal bioinformation far beyond my three illustrative examples. I would suggest that they could make useful contributions to contemporary debates about provision of bioinformation in several other contexts, including but not limited to the following:

- **Mitochondrial donation:** The arguments I have presented in this thesis carry implications for the bioinformation-related interests of individuals conceived using mitochondrial donation.⁹⁵⁰ Under UK law these individuals would be entitled to request *non-identifying* information about their donors.⁹⁵¹ Scepticism about identity interests related to mitochondrial donation often focuses on the assumption that mitochondrial DNA is not trait-conferring.⁹⁵² However, I have argued that when viewed from a narrative perspective, the interest in knowing one's genetic origins is not necessarily narrowly focused on inherited traits, but on wider biographical concerns and the ability to construct an identity that accords with facts about one's embodied existence.⁹⁵³ This suggests that there could be identity-based grounds for treating access to knowledge of mitochondrial donor origins and donors as analogous to information about gamete donation.⁹⁵⁴
- **Prenatal and neonatal genetic screening:** Further work is needed to unpack what a narrative account entails for children's identity interests and parental responsibilities beyond the narrow scope of information about genetic origins. Non-invasive prenatal testing and whole genome screening of new-borns pose a potential dilemma for my analysis. Does the potential availability of large quantities of health information from,

⁹⁵⁰ No individuals have yet been conceived in this way in the UK.

⁹⁵¹ The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015.

⁹⁵² J.B. Appleby (2016), "Should Mitochondrial Donation Be Anonymous" *Journal of Medicine and Philosophy*, Forthcoming; Department of Health 'Mitochondrial Donation: Government Response to the Consultation on Draft Regulations to Permit the Use of New Treatment Techniques to Prevent the Transmission of a Serious Mitochondrial Disease from Mother to Child' (2014).

⁹⁵³ See Chapter 5.

⁹⁵⁴ John Appleby argues that 'sense of self' could ground an interest in knowledge of mitochondrial donor origins, though his argument is not based on a narrative conception, Appleby (2016). Jackie Leach Scully discusses the impacts of mitochondrial donation on narrative identity, focusing on the social availability narratives from which those conceived this new way might construct their stories, J.L. Scully (2017), "A Mitochondrial Story: Mitochondrial Replacement, Identity and Narrative" *Bioethics*, 31(1): 37-45.

or before, birth represents an opportunity for its early narrative integration, or foreclose an individual's "open future" and ability to define herself?⁹⁵⁵

- **‘The quantified self’:** I have highlighted the importance of identity-protecting interpretive support where potentially identity-significant bioinformation is disclosed. One context in which concerns about the unmediated availability of vast quantities of such information are especially acute is that of wearable digital devices for monitoring and measuring our bodies and biology. It would be timely to explore the identity-significance of the information generated in this way, who should be responsible for managing the quality of this information and how it is interpreted by users, and by what means.
- **Diagnosis of rare diseases:** There is some scepticism that whole genome sequencing offers a panacea to the distressing ‘diagnostic odysseys’ of families with rare diseases, if diagnosis does not bring clinical benefits.⁹⁵⁶ A narrative identity analysis offers a possible means of understanding how such odysseys need not be in vain, if they meet interests in obtaining information that may fill narrative gaps by supplying valued self-descriptors or opportunities for solidarity.

These examples are only indicative of some further fields of application of my analysis. There is not space to do them justice here. They each represent areas in which further research might be usefully pursued to explore what fresh angles a narrative conception of identity impacts might bring to current ethical and regulatory debates about which (and whose) interests are at stake in these contexts. These inquiries, in turn, could benefit from empirical research that explores the extent and nature of the identity impacts of the kinds of personal bioinformation in question.

Considering a role for the law

If the law is to have a role in protecting identity development, it seems most likely to be through offering remedy for failures of those who hold bioinformation about us to provide or withhold this information. Remedy might be sought through two routes. The first of these would be through appeal to the right to identity *qua* self-development, nested within the Article 8 right to respect for private life under the European Convention on Human Rights and, in the

⁹⁵⁵ Dena S Davis, "Genetic Dilemmas and the Child's Right to an Open Future," *Hastings Center Report* 27, no. 2 (1997).

⁹⁵⁶ J.P. Evans et al. (2011), "Deflating the Genomic Bubble" *Science*, 331(6019): 861-62

UK, the Human Rights Act 1998. However, information subjects' entitlements to *bioinformation* under this right have hitherto only been recognised in respect of that about genetic parentage and are limited in a number of other respects outlined in Chapter 1. The second route would be through action in negligence. However, this would depend on identity detriment being recognised as a relevant category harm or head of damage, and the responsibility to prevent it being conceived as a duty that it would be fair, just and reasonable to expect of non-disclosing parties.⁹⁵⁷ It is unlikely that these conditions would be met as the law currently stands.⁹⁵⁸ This presents a further area in which research could be usefully pursued. Legal analysis of the relationship between the duties of potential disclosers as currently recognised in law, and the ethical responsibilities I have proposed here, would be a valuable next step towards addressing the practical application of my arguments.

Beyond individual access

Finally, in this thesis I have had to set aside a number of important questions about the impacts on identity of uses and communication of personal *bioinformation* that lie outwith its specific concern with individual information subjects' access to information. For example, it has not been possible to consider how information subjects' identity narratives might be impacted by the ways that other people use personal *bioinformation* about them. Conversely, it has not been possible to address how individuals' uses of *bioinformation* in their self-conceptions might impact upon others, including groups with whom they share means of self-characterisation. These are each questions that warrant further attention, not only because they illuminate interests that may need to be weighed against individuals' identity interests, but also because they further unpack the relational nature of our identity interests that I have started to explore here.

In this thesis I have sought to meet Heather Widdows's challenge quoted in Chapter 1 – the challenge to present a picture of the self that is 'right', such that the legal and ethical structures built upon it protect the interests that really matter.⁹⁵⁹ It is not possible to prove that a narrative conception of identity, and the role of personal *bioinformation* in it, that I have developed here are true. But I hope to have demonstrated that it least accords with our intuitions and experiences of what it means, and what it takes, to develop, to make sense of and to inhabit

⁹⁵⁷ G.T. Laurie et al., *Mason and Mccall Smith's Law and Medical Ethics (10th Edition)*, 8th ed. (Oxford: Oxford University Press, 2016).

⁹⁵⁸ See Chapter 9.

⁹⁵⁹ Widdows (2013)

who we are in light of our health, bodily experiences and biological relationships. And, in doing so, I have offered a robust and plausible conception of identity interests, the recognition of which would make a concrete difference to how our personal bioinformation is governed.

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