2

Mapping the Landscape

2.1 Introduction

The aim of this chapter is to provide a picture of the practical and theoretical landscape in which the impacts of information subjects' access to bioinformation about themselves are currently recognised and debated. This will give a fuller sense of the practical, conceptual, and normative gaps, introduced briefly in the previous chapter, that this book seeks to address. Here, I will first review the existing areas of law, regulation, and policy that purport to protect information subjects' entitlements to personal bioinformation on identity grounds. This will highlight the narrow scope of these protections, as well as some limitations and unresolved tensions in the way the law currently characterises the relationship between bioinformation in identity. I will explore what this means for clarity about the nature of the interests involved and the efficacy and inclusivity of the available protections. In the later sections of the chapter, I will turn to consider whether, if existing legal protections are lacking, some prominent bioethical and social science treatments of the relationship between personal bioinformation and self-characterisation might offer a more robust and inclusive foundation for conceptualising our identity-related interests. I will argue that while several of these provide valuable signposts to elements of such a foundation, as they stand, they lack the requisite scope and clarity about the normative nature of this relationship.

2.2 Legal Entitlements to Bioinformation

I will start by looking at the extent to which laws and policies that apply in the UK recognise and seek to protect information subjects' identity-related interests in accessing bioinformation, specifically in contexts where it is plausible that identity is intended to mean something like

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the self-characterisation sense in which I am interested.[1] When it comes to legal entitlements to protection of means of self-characterisation, this is chiefly the domain of international and European human rights law.

International Human Rights Law

At the broadest level, Article 22 of the *Universal Declaration of Human Rights* holds that everyone is entitled to 'the economic, social and cultural rights indispensable for his dignity and the free development of his personality'.[2] However, this makes no explicit connection to information access entitlements. For something approaching this, we can look instead to the *International Declaration on Human Genetic Data*, which holds that '[n]o 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'.[3] 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.[4] However, this still leaves some inferential leaps to be made if we wish to understand how access to genetic data might impact how one characterises oneself. This right is echoed in provisions under the *European (Oviedo) Convention on Human Rights and Biomedicine*, which has as its core aim the protection of the 'dignity and identity of all human beings'.[5] This convention contains the specific provision that '[e]veryone is entitled to know any information collected about his health. However, the wishes of an individual not to be so

[1] I will largely restrict my discussion of law and policy in this book to that which operates in UK jurisdictions. While recognising that entitlements in other jurisdictions will vary, I will take it that the UK provides an illustration that is not markedly anomalous in the protections it offers. The conceptual conclusions of this enquiry are not intended to be jurisdiction-specific but – in principle – universally applicable.

[2] UN General Assembly, 'Universal Declaration of Human Rights' (10 December 1948), 217 A (III).

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

[4] UNESCO, 'International Declaration on Human Genetic Data' (16 October 2003), Article 4.

[5] 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.

informed shall be observed.'[6] However, again the precise meanings of identity and link to information access remain to be guessed at.

Moving away from instruments specifically concerned with biomedicine, Article 8 of the *United Nations Convention on the Rights of the Child* (UNCRC) recognises a child's right 'to preserve his or her identity, including nationality, name and family relations'.[7] George Stewart argues that this article covers the right to know one's 'biological identity' – itself an inherently ambiguous phrase.[8] Stewart suggests this could include entitlements to medical information, but only insofar as these directly pertain to conditions inherited from one's genetic parents. Meanwhile, Article 7 of the UNCRC protects the right to birth registration, which the UN Committee on the Rights of the Child has interpreted as protecting a child's right to know their genetic parentage.[9] It is not the only human rights provision that has been interpreted in this way, as we will see.

Article 8 and the 'Right to Identity'

The previously cited instruments have distinct limitations when it comes to protecting any putative identity-related interests in accessing bioinformation about oneself. Not only do they leave the relationships between identity and information opaque, but they lack direct enforcement routes – the UK has neither signed nor ratified the Oviedo Convention. In contrast, the 'right to know one's origins' under Article 8 of the European Convention on Human Rights (ECHR) offers the most explicit protection of an identity-based right to information.[10] The rights conferred under the ECHR are given further effect in the UK under the Human Rights Act 1998 (HRA).

The right to know one's origins is situated in the right to identity, itself nested within the Article 8 right to respect for private and family life. The 'right to identity' has been interpreted in a number of ways, including those concerned with public image, the right to retain one's name, and rights

[6] 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 10(2). The 2008 Additional Protocol contains a parallel provision for results of genetic testing and that these be in 'comprehensible form'.

[7] UN General Assembly, 'Convention on the Rights of the Child' (20 November 1989), United Nations, Treaty Series, vol. 1577.

[8] Stewart 1992.

[9] Besson 2007.

[10] Council of Europe, 'European Convention for the Protection of Human Rights and Fundamental Freedoms, as Amended by Protocols Nos. 11 and 14' (4 November 1950).

relating to recognition and expression of cultural, religious, gender, and sexual identity.[11] Most pertinently for the current discussion, it has also been invoked with respect to rights to self-knowledge and self-development.[12] These rights have been held to be engaged when applicants have been denied access to information about their early life or parentage – their 'origins'. The European Court of Human Rights (ECtHR) has held that 'everyone should be able to establish details of their identity as individual human beings'[13] and emphasised the importance of being able to 'retrace one's personal history'.[14] As a result, a specific kind of informational right has evolved within the broader right to identity – the 'right to know [one's] origins'[15] or 'the right to know one's parentage'.[16] The vast majority of ECtHR jurisprudence relating to these rights concern applicants' 'vital interest' in knowing, or having confirmed in law, their *genetic* parentage.[17] These rights have been found to be engaged, for example, when children or adults have been denied the opportunity to know or register the identities of their genetic fathers[18] and where domestic law permits mothers to place their babies for adoption anonymously.[19] The ECtHR has described information about genetic parentage as having 'formative implications for [the applicant's] personality'[20] and has held that denying access to this could infringe the 'right to personal development and to self-fulfilment'.[21] It has also held that people have a 'vital interest' in receiving information about genetic parentage as this 'uncover[s] the truth about an important aspect of their personal identity'.[22]

Rights falling under Article 8 of the ECHR are not absolute. Interference with the right to know one's origins may be justified under Article 8(2), where doing so is lawful, necessary to protect a specified suite of other public and private interests, and proportionate. For example, in one of the leading 'origins cases', the privacy interests of

[11] Marshall 2014.
[12] *Bensaid* v. *United Kingdom* (no. 44599/98) (2001) ECHR 82.
[13] *Gaskin* v. *United Kingdom* (no. 10454/83) (1989) ECHR 13, [39].
[14] *Odièvre* v. *France* (no. 42326/98) (2003) ECHR 3, Dissenting Opinion, [3].
[15] *Odièvre* v. *France* (no. 42326/98) (2003) ECHR 3, concurring opinion of Judge Ress and Judge Curis, [2].
[16] *Jaggi* v. *Switzerland* (no. 58757/00) (2008) 47 EHRR 30, [37]; Callus 2004.
[17] *Jaggi* v. *Switzerland* (no. 58757/00) (2008) 47 EHRR 30, [38].
[18] *Jaggi* v. *Switzerland* (no. 58757/00) (2008) 47 EHRR 30.
[19] *Odièvre* v. *France* (no. 42326/98) (2003) ECHR 3.
[20] *Mikulic* v. *Croatia* (no. 53176/99) (2002) 2 WLUK 216, [54].
[21] *Odièvre* v. *France* (no. 42326/98) (2003) ECHR 3, Dissenting Opinion, [3].
[22] *Jaggi* v. *Switzerland* (no. 58757/00) (2008) 47 EHRR 30, [38].

the applicant's genetic mother and siblings and the public interest in providing opportunities for anonymous birth were judged to outweigh the applicant's right to know about her genetic mother.[23] Nevertheless, Article 8 operates as a positive right with horizontal effect, meaning that states' obligations extend not only to refraining from obstructing access to information about origins in their own activities but also to taking steps to support citizens in their enjoyment of this right, 'in the sphere of the relations of individuals between themselves'.[24] Moreover, the right to identity is seen as an 'essential feature' 'within the inner core' of the right to respect for private life.[25] Two significant consequences of this are that 'the fairest scrutiny' must be applied in balancing this right against countervailing considerations and in allowing states some local discretion – a 'margin of appreciation' – in discharging their obligations.[26] The ECtHR provides the highest appellate court in Europe and is charged with adjudicating on matters of core human values. What it has to say about the relationship between identity and bioinformation carries significant weight. It not only influences domestic law and policy but also has the capacity to promulgate ethical norms.[27] The sense of identity invoked by the ECtHR in respect of this right does indeed appear to closely resemble self-characterisation. So, at first sight, it looks as if Article 8 could offer broad and robust protection for accessing bioinformation about oneself in the service of the kind of interests with which I am concerned. However, the scope and adequacy of these protections are questionable for a number of reasons.

The first of these reasons is that the relationship between information and identity presented in many of the origins cases is problematic. Jill Marshall argues that the ECtHR jurisprudence reflects a view of identity as preordained rather than self-constructed and that knowledge of genetic origins is presented as essential, not merely useful, for knowing who one is.[28] This is indeed suggested by some of the language used in the judgment in *Mikulic* v. *Croatia*, where information about genetic parentage is described as 'necessary to *uncover the truth* about an important aspect of their personal identity'.[29] And the dissenting

[23] *Odièvre* v. *France* (no. 42326/98) (2003) ECHR 3.
[24] *Jaggi* v. *Switzerland* (no. 58757/00) (2008) 47 EHRR 30, [33]; Akandji-Kombe 2007.
[25] *Odièvre* v. *France* (no. 42326/98) (2003) ECHR 3, Dissenting opinion, [11] and [3].
[26] *Odièvre* v. *France* (no. 42326/98) (2003) ECHR 3, Dissenting opinion, [11]; Callus 2004.
[27] Marshall 2014.
[28] Marshall 2014.
[29] *Mikulic* v. *Croatia* (no. 53176/99) (2002) 2 WLUK 216, [54], emphasis added.

judgment in *Odièvre* v. *France* described this information as pertaining to the 'essence' of identity.[30] Marshall argues such an essentialist view is potentially stigmatising – implying that those unaware of their origins have incomplete identities – and restrictive – presenting a picture of identity as 'fixed and unchanging' rather than self-created.[31] The problems inherent to genetic essentialist conceptions of identity are explored further below.

The evidence that the ECtHR invariably treats identity as genetically determined is perhaps more equivocal than Marshall suggests. The jurisprudence refers not only to discovery but also to the developmental and 'formative' value of knowing about one's origins.[32] Furthermore, the ECtHR has not always found the right to identity to be engaged by knowledge of genetic parentage – for example, where the information was sought for inheritance purposes,[33] or when a child's interests were held to lie in not knowing and retaining the undisturbed 'social reality' of their family.[34] These counterexamples to Marshall's critique notwithstanding, the court's view of the relationship between information about genetic parentage and identity is undeniably ambiguous, which is in itself a problem if what we are looking for is clarity about the nature and scope of our identity-related interests.

A second limitation to the protections currently afforded under Article 8 is that there seems to be a mismatch between the 'vital interest' in identity development that it is supposed to protect and the perfunctory remedies recommended by the court. For example, in *Mikulic* v. *Croatia*, it was held that if the assumed genetic father would not comply with genetic testing, then a presumption of parentage by domestic courts would fulfil the appellant's right to identity.[35] This seems strikingly inadequate if, as Richard Blauwhoff suggests, the moral right invoked by the origins cases purports to be something like that 'not to be left to one's own imagination as far as the story surrounding the circumstances at conception and birth'.[36] It is questionable whether a right characterised in this way could be adequately met by the results of a DNA test or mere amendments to administrative records. This highlights an

[30] *Odièvre* v. *France* (no. 42326/98) (2003) ECHR 3, Dissenting opinion, [3].
[31] Marshall 2014.
[32] *Mikulic* v. *Croatia* (no. 53176/99) (2002) 2 WLUK 216, [54].
[33] For example, *Haas* v. *the Netherlands* (no. 36983/97) (2004) 1 FCR 147.
[34] For example, *Mizzi* v. *Malta* (no. 26111/02) (2006) 1 FLR 1048.
[35] *Mikulic* v. *Croatia* (no. 53176/99) (2002) 2 WLUK 216.
[36] Blauwhoff 2008, p. 104.

important gap – to which I will return in Chapter 7 – that many debates about information rights focus on the sheer fact of access or 'right to know', whereas the form, manner, and context in which information is conveyed may be just as, if not more, important to how it affects our sense of who we are.

The third limitation to the protections offered by Article 8 – and the most significant, if we are concerned with access to bioinformation *beyond* genetic parentage – is the extremely narrow scope of information recognised as engaging the right to know. This identity-based right originated in a case in which the applicant sought not bioinformation but access to local authority records of his upbringing in care.[37] But subsequent judgments regarding information subjects' right to identity appear not to have extended beyond these kinds of records or information about genetic parentage. Of course, the court can only address the kinds of cases brought before it. But there are instances where the right to identity seems particularly germane, in which it has not been considered. For example, in *KH and Others* v. *Slovakia* – a case concerning Roma women's access to records of their covert, non-consensual sterilisations – the applicants' desire for these records, to help them understand their lives and address their profound loss, echoes the interests in self-understanding and personal development evoked in the genetic origins cases.[38] Yet, while the ECtHR judgment did find the women were entitled to access their health records under Article 8, the right to identity was not raised. Given the instrumental role of information in meeting the more fundamental right to identity, we might expect a range of information to be found as fulfilling this role, perhaps where applicants seek confirmation of genetic relationships to their children or where a right *not* to know is involved.[39] This has not been the case. Such absences lend some weight to Marshall's critique that the ECtHR regards genetic heritage as uniquely and essentially defining who we are.

Regulation of Donor Conception in the UK

The right to identity under Article 8 and the ECtHR's judgments in the origins cases described above have influenced the law governing donor-assisted conception in the UK. The limited entitlements of donor-conceived

[37] *Gaskin* v. *United Kingdom* (no. 10454/83) (1989) ECHR 13.
[38] *KH and Others* v. *Slovakia* (no. 32881/04) (2009) ECHR 709.
[39] See, for example, *Mizzi* v. *Malta* and *Anayo* v. *Germany* (no. 20578/07) (2012) 55 EHRR 5.

individuals to access records of their donor conception and details about their gamete donors represent the sole examples of information rights under UK law explicitly rooted in recipients' identity interests. In the 2002 case of *Rose* v. *Secretary of State for Health*, which helped precipitate the end to gamete donor anonymity in the UK, the donor-conceived claimants sought information about their gamete donors.[40] The judge held that this case was 'really an identity case and involves the Claimants' rights to know about their origins'.[41]

The judge found the right to identity under Article 8 of the HRA was engaged but deferred judgment because a UK government consultation on donor anonymity was imminent.[42] Regulations removing donor anonymity subsequently came into force in 2005 and were later incorporated into the Human Fertilisation and Embryology Act 1990 (as amended) (HFE Act).[43] This change in the law means that, provided their parents were treated in a licensed UK clinic using gametes donated after April 2005, donor-conceived individuals can request non-identifying donor information from the UK regulator – the Human Fertilisation and Embryology Authority (HFEA) – once they turn sixteen. They can request identifying information when they turn eighteen. There are also provisions to facilitate mutually consenting contact between adult donor siblings.[44]

Of course, being in a position to request donor information requires knowing, or at least suspecting, that one was donor-conceived. In common with many other jurisdictions that require open-identity donation, disclosure of the use of donor gametes to resulting children is not legally mandated in the UK.[45] However, those eighteen or over are entitled to apply to the HFEA to find out if they are donor-conceived.[46] And, in contrast to the early days of fertility treatment – when professional advice was usually to conceal donor conception – licensed fertility clinics in the UK are now required by law to advise intended parents of the importance of telling their children early in their lives, to offer advice on how to do so, and to provide opportunities to seek counselling.[47] The HFEA and the

[40] *Rose* v. *Secretary of State for Health* [2002] EWHC 1593.
[41] *Rose* v. *Secretary of State for Health* [2002] EWHC 1593, [28].
[42] *Rose* v. *Secretary of State for Health* [2002] EWHC 1593; Department of Health 2001.
[43] HFEA (Disclosure of Donor Information) Regulations 2004.
[44] Human Fertilisation and Embryology Act 1990 (as amended) s.31ZA. Identifying information may be more readily available where donors have voluntarily relinquished their anonymity.
[45] Blyth and Frith 2009.
[46] Human Fertlisation and Embryology Act 1990 (as amended) s.31ZA.
[47] Human Fertlisation and Embryology Act 1990 (as amended) s.13; Appleby et al. 2012.

advocacy body the Donor Conception Network recommend that parents begin to talk to children about their donor conception at preschool age.[48] This reflects what Tabitha Freeman describes as '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'.[49] These interests are sometimes articulated in terms of enhanced psychological well-being or strengthened familial relationships and trust.[50] In some instances, they are also articulated in terms of the benefits to donor-conceived individuals' identities – in particular the benefits to children being able to integrate the information into their developing sense of self.[51] This emerging consensus notwithstanding, it is ultimately left to parents to decide whether to tell.[52]

Where does this leave us with respect to the legal recognition and protection of identity interests? The picture is somewhat equivocal. On one hand, the connection between this information and identity is present in the rationale behind the abolition of donor anonymity and donor-conceived individuals' access entitlements law. The regulatory reforms took place in a context of public, professional, and legal debates in which identity interests were widely invoked.[53] For example, an HFEA policy working paper notes that information about donor origins 'can help people complete a picture of their identity and it is natural to seek it'.[54] On the other hand, parents remain the chief gatekeepers of this knowledge. For diverse reasons, described further in Chapter 5, the majority of parents do not tell their children about their donor conception.[55] And it is still the case that most donor-conceived people do not know about their donor

[48] HFEA, 'Talk to Your Child about Their Origins', www.hfea.gov.uk/donation/donor-conceived-people-and-their-parents/talk-to-your-child-about-their-origins/ (accessed 18 July 2021).
[49] Freeman 2014, p. 14.
[50] Ilioi et al. 2017.
[51] Nuffield Council on Bioethics 2013.
[52] Proposals to do so in the United Kingdom have been met with concerns that this is an unwarranted incursion into family privacy and autonomy and risks exclusion and harm in families and communities where donor conception is stigmatising or taboo; see Nuffield Council on Bioethics 2013.
[53] Turkmendag 2012.
[54] HFEA, 'HFEA Paper 485: Opening the Register Policy: A Principled Approach' (21 January 2009).
[55] Nuffield Council on Bioethics 2013; one study found that by the time children in participating families were seven only 29 per cent who had used sperm donors had started to tell (Blake et al. 2014).

origins.[56] While non-disclosure of the use of donor gametes remains commonplace and minimum age limits for consulting the HFEA Register apply, the reality is a rather limited fulfilment of any interests donor-conceived people may have in knowing.

Like the ECtHR jurisprudence, the UK law is also vulnerable to concerns that it reflects, or even promulgates, a geneticised conception of identity. The HFEA's language of identity 'completion' does little to dispel this worry. And this impression is deepened by subsequent legal measures governing donor identifiability in mitochondrial replacement therapy (MRT). MRT involves the use of two eggs from different donors in the in vitro creation of an embryo, with the purpose of avoiding transmission of serious mitochondrial disease. One egg supplies healthy mitochondria; the other provides the nuclear DNA.[57] Under UK law, adults born using MRT can request identifying information about the donors of eggs that supplied the nuclear DNA, but not those that supplied the healthy mitochondria.[58] The UK government's reasoning is that the 'mitochondrial donor does not contribute in any material or significant way to the identity, personal characteristics or traits of the person born'.[59] This betrays the view that whatever identity significance donor information has, this is attributable and limited to only certain kinds of genetic connections and to traits inherited through nuclear DNA. I shall return in Chapter 5 to question this rationale.

Wider Access Entitlements

The sketch thus far of information subjects' legal entitlements to access particular kinds of bioinformation on explicitly self-characterisation-related grounds reveals a picture of conditional access to a markedly narrow tranche of information types, possibly based on problematic conceptions of the relationship between specific kinds of information and identity. What if it were possible to show that we have identity-related interests in accessing other categories of personal bioinformation than those about genetic parentage? For example, where does this leave Ilana and her desire to know about her potential risk of passing degenerative eye disease to her children, or about what her brain scans might reveal about signs of incipient Alzheimer's disease? Perhaps the narrow entitlements set

[56] Tallandini et al. 2016.
[57] Appleby 2018.
[58] Human Fertilisation and Embryology Act 1990 (as amended) s.31ZA (2A). The entitlement to non-identifying information includes that about mitochondrial donors.
[59] Department of Health 2014, pp. 29–30.

out above need not be an insurmountable obstacle here. After all, if we do indeed have interests in accessing a wider range of personal bioinformation for the purposes of understanding or developing who we are, there may be other routes open that do not depend on expressly identity-related entitlements. If this is so, it maybe does not matter if identity is not invoked, or its relationship to bioinformation is narrowly conceived. I will briefly look here at the scope of some such alternative routes.

In healthcare contexts, under most circumstances, patients will receive results from medical investigations carried out upon them for the purposes of their own healthcare. If the information is recorded in their medical records, then patients in the UK have a legal entitlement to request access.[60] This is underpinned by subject access provisions in the Data Protection Act 2018 (DPA) and the European General Data Protection Regulation (GDPR). Under UK data protection law, information subjects' entitlements extend – with some conditions and exceptions discussed below – beyond health records to 'personal data', which includes identifiable health, genetic, and biometric data processed for other purposes.[61] Withholding patient information could also constitute a breach of information subjects' right to protection of private life under Article 8, which the ECtHR has held includes 'practical and effective' access to one's health records.[62] And healthcare professionals may be found negligent if they fail to offer information about 'material risks' to those under their care if the recipient could reasonably find these pertinent to their healthcare decision-making and where a failure to do so could result in serious material, physical, or psychological harm.[63]

Being entitled to access the results of medical tests of course does not mean that such tests will be conducted. In healthcare contexts, this will be constrained by, amongst other things, the availability of the necessary licencing, resources, and skills, as well as professional judgements about the appropriateness of testing. For example, the UK National Screening Committee requires that in order to institute a screening programme, there should be, inter alia, an 'effective intervention', 'evidence that intervention at a pre-symptomatic phase leads to better outcomes', and benefits should not be outweighed by risks arising from 'overdiagnosis,

[60] British Medical Association 2019.
[61] Data Protection Act 2018, s.45 and s.94.
[62] Eijkholt 2010.
[63] *Montgomery* v. *Lanarkshire Health Board* [2015] UKSC 11, [87]. The law here has developed specifically in relation to information provision in respect of consent to treatment.

overtreatment, false positives, false reassurance, uncertain findings and complications'.[64] Concerns about causing psychological distress in the absence of effective preventative or treatment options are often core to decisions about offering genetic tests.[65] Identity considerations do not yet play an explicit part in such decisions. However, where genetic testing programmes *are* available, clinical geneticists and genetic counsellors will support patients' and family members' decisions about whether to be tested or to receive test results. Genetic counselling is marked by its non-directive nature and is a notable point at which features intimately connected with identity, in the self-characterisation sense, are part of the picture. For example, potential impacts of test results on self-esteem, stigma, familial roles and relationships, and body image may well be raised.[66]

Genetic information about carrier or risk status may also be obtained from the known status of close blood relatives. The idea that genetic information does not belong to just one person but is shared or part of a 'joint account' is widely embraced in genetic counselling and medical ethics.[67] Clinicians and counsellors are likely to advise those who test positive for inherited genetic disorders about the value of discussing the result with their close relatives, though they cannot compel them to do so.[68] When family communication does not happen, professionals' duties of care may be implicated. In 2020, the English High Court ruled that healthcare professionals have a legal duty to conduct a balancing exercise – weighing the opportunity to prevent or mitigate a significant risk of serious harm through disclosure against patients' and publics' interests in respecting patient confidentiality – when deciding whether to disclose patient information to family members with whom they also have close professional relationships.[69] What might count as serious harm under this new duty, and whether this would ever extend to detrimental impacts on identity, remains to be seen. The instant case indicated that it could at least extend beyond the realm of harm to physical or psychological health, to include opportunities for family members to make reproductive decisions, at least where serious monogenic disorders are concerned.[70]

[64] UK National Screening Committee 2015.
[65] Parens and Appelbaum 2019.
[66] Esplen et al. 2009; Pinto-Basto et al. 2010.
[67] Parker and Lucassen 2004, p. 165.
[68] Dove et al. 2019.
[69] *ABC* v. *St Georges Healthcare and Others* [2020] EWHC 455 (QB).
[70] The instant case concerned Huntington's disease, a serious, fatal neurological disorder. The patient did not wish his daughter to be told of her risk of inheriting the Huntington's

Turning now to research contexts, a substantial proportion of personal bioinformation is produced by health research, not only by clinical trials but also, increasingly, by data-driven research involving secondary uses of patient data and data repositories and exploratory, rather than hypothesis-driven, enquiries.[71] This markedly increases the quantities of both 'intended' and 'incidental' findings produced about individual information subjects.[72] Feedback of aggregate results at the end of a study, or research phase, is commonplace. But when it comes to identifiable participant-specific findings, communication to participants will depend on the feedback policy of the study in question and participants' agreement to receiving them.[73] Researchers are not subject to a specific legal duty to return individual findings, though it is possible they could be found negligent in not communicating clinically actionable findings of a serious nature.[74] There is, however, a growing consensus that researchers have *ethical* responsibilities, albeit conditional ones, to offer research findings to participants.[75] Guidelines tend to propose responsibilities that extend only to findings that are clinically actionable or inform reproductive decision-making.[76] For example, the Council for International Organizations of Medical Sciences (CIOMS) guidelines state that '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 clinical significance would not qualify for communication to the participant'.[77] Nevertheless, some commentators have suggested that feedback might be warranted where findings have broader 'personal utility' to recipients, which could include identity value.[78] However, the nature of this identity value is not further unpacked, and it is not clear if such recommendations are ever reflected in practice. It does not seem unlikely that – without

gene in case she terminated her pregnancy. The Court found the healthcare team were not negligent as they had conducted a satisfactory balancing exercise.

71 Eckstein et al. 2014.

72 'Intended findings' refer to those that are central to the aims of a study. 'Incidental findings' – secondary or unanticipated findings – are individually relevant observations generated through research, but lying outwith the aims of the study. The practical and ethical relevance of this distinction to feedback policies is increasingly questioned.

73 Postan 2021.

74 Johnston and Kaye 2004.

75 Berkman et al. 2014.

76 Wolf et al. 2008.

77 CIOMS 2016, p. 45.

78 Eckstein et al. 2014.

further clear explanation of its nature and gravity – any professed identity value would be judged insufficient to outweigh concerns about diversion of research resources to validating and communicating individual findings. This is perhaps particularly so in large, long-running studies and those using banked or secondary-use data, where the sheer logistics of reidentifying and contacting participants could be substantial.[79]

This map of the access landscape would be incomplete without noting that consumer technologies, including DTC testing services and personal and wearable self-tracking technologies, are an ever-expanding source of information about our own health, well-being, and non-health-related traits, dispositions, states, behaviours, biomarkers, and genetic relationships.[80] As illustrated by the example of Sam in the previous chapter, alongside welcome insights, users may be assailed by unanticipated information they find distressing.[81] In consumer contexts, it is particularly apparent why ethical concerns might extend not only to what users are able to access but also to whether they are sufficiently protected from potentially harmful information and whether they have adequate interpretive support or counselling to minimise the risk of distress or misinterpretation. In 2013, the US Food and Drug Administration (FDA) sought to limit the availability of several tests offered by online DTC genomics services – including *APOE* and *BRCA* testing for late-onset Alzheimer's disease and cancer risk, respectively – given the risk of 'unreasonable harm' from 'incorrect test results or unsupported clinical interpretations'.[82] While some commentators have raised unease about identity-related impacts of DTC genomics – Anders Nordgren and Eric Juengst refer to the risk of essentialising and distorting user's experience of their identities – these were not apparent amongst the FDA's concerns.[83] Approval to resume marketing these tests in the USA has since been granted.[84] Similar restrictions have not been imposed by UK regulators, and at the time of writing, UK consumers can access DTC genomic tests for

[79] Eckstein et al. 2014.
[80] Sharon and Lucivero 2019.
[81] Harper et al. 2016.
[82] US FDA, 'Inspections, Compliance, Enforcement, and Criminal Investigations, Warning Letter to 23&Me, Document Number: Gen1300666' (22 November 2013); Annas and Elias 2014.
[83] Nordgren and Juengst 2009.
[84] US FDA, Press Release, 'FDA Allows Marketing of First Direct-to-Consumer Tests That Provide Genetic Risk Information for Certain Conditions' (6 April 2017).

serious multifactorial conditions including *BRCA*-related cancers and late-onset Alzheimer's.[85]

Where Does This Leave Protection of Identity Interests?

This brief sketch illustrates that the broader landscape of subject access entitlements is unlikely to fill the gaps left by the narrow legal entitlements to personal bioinformation on explicit identity grounds. Each of these entitlements and protections is conditional and includes exceptions. For example, subject access rights under the DPA apply only to 'personal data' as defined by this Act – meaning the data must be identifiable and processed in a structured form – and are subject to exemptions where processing is conducted for research or where disclosure would cause 'serious harm' to the subject's or others' 'physical or mental health' or reveal someone else's data without consent.[86] Similarly, the right to access one's health records under Article 8 must be weighed against conflicting rights, including others' privacy, and can be restricted if it is deemed lawful, necessary, and proportionate to do so.[87] Meanwhile, the success of negligence actions depends on the existence of a duty of care; a causal relationship between denial of information and a relevant category of serious physical, material, or psychiatric harm; and the absence of overriding duties to protect confidentiality.[88] It is of course entirely appropriate that interests other than those in self-characterisation are part of the regulatory landscape and that information subjects' interests in access are weighed against competing considerations. However, if information subject's identity-related interests are not explicitly recognised as part of this landscape they cannot feature in any such weighing. And where their nature and scope are ambiguous or characterised in problematic ways, their relative relevance and gravity cannot be appropriately assessed.

There are two significant implications of this for my line of enquiry. The first is practical – that effective protections currently afforded by the law in the UK to any identity-related interests we might have in accessing personal bioinformation, other than that about genetic origins, are lacking. The second is that existing legal protections, even the relatively

[85] 23andMe, '23andMe Genetic Health Risk Reports', www.23andme.com/en-gb/test-info/genetic-health (accessed 18 July 2021).
[86] DPA 2018, s.3, s.45, and Schedule 3, paragraph 2.
[87] HRA 1998, Article 8(2).
[88] See, for example, *ABC* v. *St Georges Healthcare and Others* [2020] EWHC 455 (QB).

well-developed jurisprudence of the ECtHR, do not themselves offer a clear or satisfactory picture of the nature of these interests, due in no small part to the narrow scope of protection offered. Of course, the first of these gaps does not matter – or, rather, is not a gap at all – if our informational identity interests are themselves as narrowly confined as the law seems to suppose. But, while I have yet to provide grounds for persuading sceptics otherwise, I would at least suggest that there is something suspect about the exceptionalism of arguing that our identity interests are uniquely engaged by information about our genetic origins – and only the origins of our nuclear genetics at that. To justify such exceptionalism, it would need to be the case not only that our identities are defined by our genetic parentage – itself a problematic premise – but also that they are *solely* defined by this and, therefore, that knowledge of our biological origins exhausts all our identity-related bioinformation needs. Such contentious assumptions would, at the very least, require further defence than the law currently offers.

The narrow scope and limitations of existing legal protection for our explicitly identity-related interests in accessing personal bioinformation expose the gap that the arguments to be presented in this book aim to fill. For reasons I will explain shortly, I agree with Hauskeller and Marshall that it is indeed problematic if the law or policy instantiates or entrenches 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 bodily and 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 a fundamental question: what is the relationship between bioinformation and identity?

2.3 Seeking Conceptual and Normative Foundations

It is clear from what has been said so far that we cannot look to the law to supply a clear, unambiguous picture of the relationship between the impacts of encounters with personal bioinformation and self-characterisation or of the nature of any interests engaged. In the hunt for such a picture, I turn now to consider instead what the bioethical, philosophical, and social science literature might offer. Here, suggestions – sometimes passing references, sometimes more in-depth treatments – that insights into our bodies, health, or biological relationships could affect our identities are much more

plentiful.[89] I cannot hope to capture or do justice to their breadth and variety here, but I will attempt to give a flavour of some prominent themes.

Once again, scholarly claims of the relevance of bioinformation to identity are perhaps most frequently voiced in relation to genetic parentage, extending also to discussions of genetic traits and to disease susceptibility.[90] For example, with respect to knowledge of donor conception, Vardit Ravitsky is just one commentator to articulate a version of the view that '[t]he development of personal identity requires understanding "where you came from"'.[91] This quotation indicates that Ravitsky herself conceptualises knowledge of genetic origins as playing something like a biographical and developmental role in identity. However, more generally, the Nuffield Council on Bioethics has observed that despite the widespread view that not knowing about one's donor conception could cause 'harm to identity', the nature of this harm remains largely unexplained.[92] Moreover, claims to the identity value of knowing, and harms of not knowing, are far from universal. For example, in the case of knowledge of donor origins, there are some who are profoundly sceptical about the intrinsic value of information about genetic origins to our identities.[93] And, as discussed below, others argue that it may be frankly detrimental.[94] What is needed is some way to adjudicate between, or reconcile, these different perspectives.

In some instances, disagreements about value occur because it is unclear, or there is a lack of common ground about, precisely what is meant by identity in assertions of information's value or harm. This is particularly acute in discussions that invoke the concept of 'genetic identity'. This phrase is sometimes used in a way synonymous with genetic parentage, while in other cases it is used to refer to the entire genomic makeup of an individual, the role of genetic markers in picking out numerically distinct people, or to characteristics that are attributable to an individual's genetic inheritance.[95] These have dramatically different implications when it comes to the ethical significance of encounters with genetic information. And only some are

[89] My focus here is on discussions of possible effects of information subjects' own encounters with bioinformation about themselves. As mentioned in the previous chapter, there are also ample discussions of how others might use this information to categorise, judge, or manage the information subject, but these do not capture my current focus.
[90] Henschke 2010; Zeiler 2009.
[91] Ravitsky 2010, p. 674.
[92] Nuffield Council on Bioethics 2013, p. 65.
[93] Lillehammer 2014.
[94] de Melo-Martín 2016.
[95] Henschke 2010; Richards 2014.

pertinent to identity understood as self-characterisation. Even when the focus is expressly on self-characterisation, many analyses focus on describing how encounters with bioinformation can contribute new modes of self-description, rather than making explicit claims about the value, or otherwise, of this. For example, there are myriad empirical studies that report ways in which receipt of genetic information may lead recipients to change or adopt new labels – for example, shifting their sense of themselves from 'healthy' to 'unwell', or 'at risk', or 'a cancer survivor'.[96] And much has been written about the rise of the conception of the 'genetic self', with genetic information used as routes to self-understanding or self-description.[97] These analyses provide important clues as to why we might care if someone has the opportunity to (re)describe themselves in particular genetically informed – or other biologically informed – ways. However, taken on their own, they do not yet provide sufficient reasons for understanding the nature and gravity of the harm, benefits, and interests that might be tied up in these means and modes of self-description. In order to provide just such reasons, I will return to explore further examples of these kinds of empirical observations in Chapter 5 and to assess them in light of a particular, normative conception of the relationship between bioinformation and identity. For the roots of this conception though we need to look elsewhere. We might perhaps be tempted to look to a biologically essentialist view of identity for these.

Biological Essentialism

Biologically essentialist views of identity combine determinism – the idea that our defining traits are caused by our genomes, brains, or other aspects of our biological existence – with reductionism – the assumption that these biologically determined characteristics lie at the heart of who we *really* are.[98] One implication of such a view is that access to certain kinds of bioinformation can play a valuable role in our abilities to characterise ourselves because they *reveal* our real, or essential, nature. In seeking to locate possible roots of the value in knowing, it is worth briefly reviewing whether biological essentialism might then provide a satisfactory answer. Before dismissing this possibility as a straw person – it is indeed rare to find allegiance with biologically essentialist views of the self seriously endorsed

[96] McGuinness et al. 2010; Zeiler 2009.
[97] Rose 2007; Widdows 2013.
[98] Wachbroit 2002.

in the academic literature – it is worth remembering that essentialist positions are implicit in several of the legal contexts discussed earlier in this chapter. And, as briefly noted in the previous chapter, the idea that our genes determine a wide range of human traits and dispositions – and thus that genetic information can provide direct insights into our identities – has considerable purchase in the popular imagination. As noted above, Nordgren and Juengst document the prominence of genetic-essentialist assumptions in DTC genomics.[99] They observe this not only in the ways that companies market their services as offering windows into users' identities but also in the testimonies of satisfied customers, one of whom they quote as saying, '[k]nowing these traits are the nuclei composition of my DNA puts all the pieces of who I am instinctually into place'.[100] These kinds of claims are not limited to genetic and genomic information. The brain is also widely seen as having special significance to identity, due both to popular views of this organ as the origin of our personalities and to the potentially grave and pervasive implications of its (mal)functioning for our cognition, mood, and sense of self. Indeed, it is sometimes treated as synonymous with the self, as when we talk of a 'depressed brain'.[101] Neuroimaging findings about the structure or activity of the brain are commonly presented as revealing the roots of our motives, personalities, or interpersonal differences and thus as offering insights into what we are 'really like'. For example, Eric Racine and colleagues have observed widespread neuroessentialism in reporting of neuroscientific research in the popular media.[102] This is evidenced by headlines such as 'Long-Term Offenders Have Different Brain Structure, Study Says'.[103] Similarly neuro-reductive views are reflected in fears that if emerging neurotechnologies are able to measure neural activity at sufficiently fine-grained levels, this will permit 'mind-reading' and incursions into 'an unassailable fortress' of our thoughts and true selves.[104] The reflexive corollary of these suggestions – which I will discuss further in Chapter 4 – is that these kinds of findings could potentially provide information subjects themselves with useful correctives to misplaced beliefs about their motives or values.[105] Biologically essentialist views of the self remain tenacious in the popular

[99] Nordgren and Juengst 2009.
[100] Nordgren and Juengst 2009, p. 262.
[101] Dumit 2003, p. 42.
[102] Racine et al. 2010.
[103] Davis 2020.
[104] Ienca and Andorno 2017, p. 1.
[105] Walker 2012

imagination, although some commentators have noted that people's everyday beliefs are often more nuanced and less deterministic than is sometimes assumed.[106] Might it be the case that neuro- and genetic essentialisms – perhaps expanded to a more generalised biological essentialism grounded in wider assumptions about biological roots of our defining characteristics – could provide the explanation for personal bioinformation's identity value? Is it the case that we need this information if we are to have a full and clear picture of who we really are?

The short answer is no – for several reasons. The first of which is that the central deterministic empirical premise of biological essentialism is true only on rare occasions. Interactions between multiple factors including other aspects of our bodies and our social and physical environments play key roles in the functioning and contents of our minds and – in all but highly penetrant monogenic conditions – on how our genes are expressed.[107] Further empirical grounds for rejecting biological essentialism as a premise for the identity significance of bioinformation are that it certainly appears that all of us manage to have a good sense of who we are without exhaustive knowledge of every aspect of how our bodies and minds work. Indeed, many of us are able to occupy intelligible, satisfying, and functional identities while omitting or actively rejecting self-definition in terms of biological characteristics such as our genetic parentage, susceptibility to illness, or the sexed aspects of our bodies.

Additional reasons to reject a biologically essentialist view of the self are that it is not just empirically flawed but conceptually and ethically problematic. Such a view does not admit the possibility that we define ourselves, let alone define ourselves in ways that omit or repudiate aspects of our bodies or biology. More troublingly, essentialist views of the self, when adopted by or imposed upon information subjects, not only limit self-characterisation by framing traits as predetermined and by presenting only a limited pallet of ways in which they may describe and view themselves, they are also potentially oppressive and stigmatising. This is the case, for example, where purported associations are drawn between particular genetic variants, characteristics assumed to have negative social connotations – such as propensity to antisocial behaviour or lower educational attainment – and the prevalence of these variants in populations already living under oppressive conditions – such as

[106] Pickersgill et al. 2011; Weiner et al. 2017.
[107] Glannon 2009; Weiner et al. 2017.

indigenous peoples or people of colour.[108] Biological essentialism also implies that those who choose to define themselves in ways that depart from facts about their bodies – for example, rejecting their biological sex or susceptibility to hereditary disease – are in some sense occupying mistaken or inauthentic identities.[109]

These are reasons enough to reject an essentialist explanation of the relationship between personal bioinformation and identity. Moreover, if such an explanation were to be instantiated in policies and laws governing access to this information, this would, as Marshall argues, 'unduly restrain the development of our freedom to be and become our own persons'.[110] Laws of this kind would not only restrict the kinds of information we are entitled to access on identity-related grounds but also – recognising the expressive capacities of laws and rules – communicate and potentially promulgate the view that there are a limited number of correct ways to be and to understand who one is.[111] In suggesting that there is currently a gap in protections for our identity interests in bioinformation governance, my suggestion is emphatically not that we need laws that prescribe what kinds of people we can be. So, again, we need to look elsewhere.

Beyond Biological Essentialism

There is, I would suggest, a tendency at this juncture towards polarisation in debates about the identity significance of personal bioinformation, framing this as a choice between two mutually exclusive options: either our identities are determined by our bodies, brains, and genomes, meaning that personal bioinformation has identity value because it reveals truths about who we are; or we reject this view in favour of the idea that we create who we are, in which case personal bioinformation lacks any particular identity value, being at best an optional extra in this creative process, often irrelevant, and at worst positively harmful. At the more modest end of the scale, Bronwyn Parry and Margaret Lock argue that even though the language of genetics and genetic risk has infiltrated our modes of self-description, contrary to hyperbolic promises that genetic testing and DTC genomics will deliver enhanced self-knowledge, test results actually add little to recipients' existing lay-understandings of

[108] Sabatello and Juengst 2019.
[109] de Melo-Martín 2014.
[110] Marshall 2014, p. 125.
[111] Sunstein 1996.

their inherited traits or associated ideas of who they are.[112] Yet more polarised positions are apparent in debates about knowledge of donor origins and uses of personal health-tracking technologies. For example, Sally Haslanger and Inmaculada de Melo-Martín, amongst others, have argued that insistence on, and legal endorsement of, the importance of knowing one's genetic parentage are not only misplaced but run a serious risk of stigmatising those who do not know and placing unwarranted emphasis on genetic relationships and inherited traits at the expense of the social family and chosen identifiers.[113] A parallel dichotomy is apparent in discussions of self-tracking technologies such as Fitbit or sleep monitoring apps. Here, on one side, there are those enthusiastic about possibilities of 'quantifying the self' and associated enhanced understanding of their capacities, health, and well-being. Meanwhile, on the other, there are sceptics who are concerned that – in Deborah Lupton's evocative phrase – the 'optic has come to take pre-eminence over the haptic', and that we rely on quantified data for self-understanding at our peril lest they replace more direct, and the putatively more trustworthy and authentic, evidence of our own senses and phenomenological experience.[114]

I will return in Chapter 3 to address some of these concerns about exclusion and quantification. The assumption I wish to counter here though is that the only available options are that contributions of personal bioinformation to identity are either essential or else trivial, irrelevant, or harmful. I also wish to challenge the assumption that recognising the possibilities of identity value or identity harm depends upon and neatly tracks divergent views of our identities as either discovered or created respectively. Such polarised conceptions are unhelpful to thinking about the relationship between personal bioinformation and identity and the nature and shades of the ethical significance of this relationship. My aim in this book is to offer a perspective from which we may escape this limited polarity. I will explore the possibility that, while we create and develop our identities in ways that may happily depart in many respects from the brute facts of our bodily selves, there are also some tools that we may use in this creation that make our identities more or less inhabitable and suitable as frameworks through which to engage with the world. In the remainder of this chapter, I will briefly survey further potential non-essentialist

[112] Lock 2008; Parry 2013.
[113] Haslanger 2009; de Melo-Martín 2014.
[114] Lupton 2013, p. 398; Sharon 2017.

candidates from the literature as to the relationship between various kinds of personal bioinformation and our self-characterisation – broadly understood – and assess their capacities to account satisfactorily for our interests in information access.

I will first briefly review three further, somewhat interconnected, analyses of the ways that bioinformation – chiefly genetic information – may be used in our practices of self-characterisation. The first of these, as described by Christine Hauskeller, involves the use of genetic information to naturalise and reinforce existing social identities or group descriptors – what Hauskeller terms 'intra-species classifications'.[115] While this kind of reinforcing impulse may be based on a geneticised view that the traits and category boundaries in question are determined by genetic distinctions, it is not necessarily a reductive position. The important feature at work is that perceived authority of genetic knowledge lends weight to and thereby entrenches 'prevailing classification patterns of origins, race, ethnicity, or disease'.[116] In this way, genetic information is seen as serving to introduce or cement existing self-descriptors, modes of group identification, and ways of aligning or distinguishing ourselves from others.

Another kind of analysis holds that particular kinds of bioinformation, perhaps particularly those conveying disease susceptibility or diagnoses, introduce *new* means of active, practical identification and self-classification. For example, Ian Hacking has suggested that behavioural and biomarker data associated with developmental or cognitive differences, in conditions such as autism, may seed new 'human kinds' or ways of categorising people. Those living with these conditions are then active in sustaining and modifying these categories through the ways they use and enact these labels.[117] The discovery of the link between mutations to the *BRCA* gene and significantly elevated risk of breast and ovarian cancers may be seen as an example of this. Sahra Gibbon has coined the idea of the 'iconic figure of the *BRCA* carrier', in which the carrier is seen both as burdened with risk and as an activist in their own health protection.[118] This is reflected in press coverage, for example, of the actor Angelina Jolie's *BRCA*-positive status and subsequent double mastectomy.[119] These phenomena may be seen as particular instances

[115] Hauskeller 2004, p. 291.
[116] Hauskeller 2004.
[117] Hacking 1995.
[118] Gibbon 2007.
[119] Kamenova et al. 2014.

of wider adoption of novel modes of practical self-characterisation introduced by predictive genetics. One of these modes could be 'being genetically at risk'. Carlos Novas and Nikolas Rose describe a 'risk identity' 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'.[120] For example, these strategies might include researching one's condition, participating in clinical studies, pursuing therapeutic interventions, or undertaking protective behaviours. Elsewhere Rose uses the phrase 'somatic identity' similarly to capture ways in which genetic information may lead us to think of ourselves in new, biologically defined ways that are closely linked to practical activities of self-constitution.[121] Rose and Joelle Abi-Rached have made parallel observations that advances in the neurosciences present us with novel forms of self-description, providing 'a rich register for narratives of self-fashioning', leading to the emergence of the 'neurobiological self'.[122]

Intersecting with these analyses are those highlighting the role of bioinformation in what Gibbon and Novas term 'biosocial identity-making'.[123] This concept captures the emergence of particular kinds of practical identities, built around and enacted through engagement in collaborative social activities, which themselves coalesce around shared biological traits, such as disease susceptibility, genetic carrier status, or diagnosis. These activities might, for example, include patient activism, membership of online forums dedicated to discussing results from DTC genomic testing, or participation in health research to identify causes of rare diseases. Alondra Nelson has observed biosociality amongst users of DTC genetic geographical ancestry testing services. Nelson uses the phrase 'affiliative self-fashioning' to describe the kinds of self-making practices that she has observed in the course of her research amongst Black British and African American 'root-seekers' who have used DTC services in an effort to trace their ancestral origins to particular African nations or peoples, to find distant relations, and to build connections with those on similar quests.[124]

[120] Novas and Rose 2001, pp. 487, 502.
[121] Rose 2007, pp. 186, 187.
[122] Rose and Abi-Rached 2013, p. 220.
[123] Gibbon and Novas 2007, p. 8. The phrase biosociality was coined by Paul Rabinow, see Rabinow 2010.
[124] Nelson 2008, pp. 761, 771.

As will become clear in the picture I will go on to develop, each of the analyses surveyed here could contribute to identifying and explaining some of the ways and reasons why we may have ethically significant interests in accessing personal bioinformation. However, these accounts cannot on their own do all the necessary conceptual and normative work of characterising these interests across a broad spectrum of bioinformation. This is, in part, because the vast majority refer only to genetic information. It is not always clear to what extent they are, or could be, generalisable to other kinds of bioinformation. What is needed is not only grounds for conceptualising the potential identity significance of personal bioinformation in non-essentialist terms, but also ways that are not *exceptionalist*, or at least not arbitrarily so.

The proposed impacts and uses of genetic information sketched in this section do, however, go quite some way towards moving us beyond thinking about bioinformation simply as a conduit for adopting inert labels or precipitating (re)description. They indicate the more active, practical, and relational roles information may play and, in doing so, move us towards a more substantial and normative conception of its potential personal significance. Nevertheless, they do not get us quite far enough along this path. This is because the picture they paint of the identity-related *value* of such uses of bioinformation often remains ambiguous or unresolved. For example, when it comes to Hauskeller's 'intra-species classifications' or engaging in the biosocial activities such as patient activism, genetic information might, at first sight, appear to make positive contributions – perhaps by adding focus or meaning to the information subject's life, or a sense of connection to others. However, the authors highlighting these identity practices are often inclined to more negative assessments, for example, echoing concerns – familiar from the objections to biological essentialism reviewed in the previous section – that tying self-classification to the perceived authority of biomedical science risks restricting self-definition.[125] More troublingly, Hauskeller suggests, these classifications can be personally and socially harmful where they bind us to retrograde norms relating to gender or health or are used as grounds for exclusion and discrimination.[126] Provocatively, Hauskeller refers to genetically reified classification as a form of racism.[127] Indeed, racism, in its most literal sense, may be

[125] Hauskeller 2006; Nordgren and Juengst 2009.
[126] Hauskeller 2006.
[127] Hauskeller 2006.

both motivator and consequence of many attempts to perpetuate the naturalisation of racial distinctions and associated unjust and discriminatory social hierarchies, through abject misuses of genetic science.[128] Such misuses have undeniably serious and far-reaching harms, but we might question whether all biologically informed means of self-classification and affiliation are necessarily and inevitably troubling in the same way.

Displaying similar value ambivalence, Novas and Rose's characterisation of 'risk identity' suggests this might be viewed largely positively in terms of active, engaged self-efficacy in the face of disease risk.[129] However, again there remain suspicions, shared by Novas and Rose, of the colonisation of self by the language and objectives of biosciences.[130] Meanwhile others have observed that managing disease risk may be experienced as a restrictive and distressing obligation rather than as empowering and that responsibilisation for one's health may be accompanied by anxiety and self-blame.[131] To be clear, my reservations about the conceptual and practical limitations of the accounts I have just reviewed rest not on the sheer ambiguity or disagreement about the value of potential impacts of information-led practices of self-characterisation. That there may be a variety of identity impacts, both good and bad, seems highly plausible. What is missing though is a clear and robust picture of what good and bad *mean* and how we can and should adjudicate between competing value claims.

This brings me to the third and most fundamental reason why these otherwise useful and illuminating accounts cannot on their own provide the conceptual and normative basis for thinking about the ethical significance of the impacts of personal bioinformation on our identities. They do not, on their own, provide a clear picture of our *identity-related interests*. This is first because they concern monadic identifiers, largely discussed in isolation from the totality of who someone is. They do not speak to the impacts of bioinformation on identities as multifaceted, intersectional *wholes* or address the question of why it might matter for someone's self-conception, taken in all of its complexity and dynamism, if they were to describe themselves in one way rather than another or to add or subtract particular descriptors, classifications, affiliations, or practical roles. Second, and relatedly, it is not always clear from these analyses

[128] Saini 2019.
[129] Novas and Rose 2001.
[130] Rose 2007.
[131] Hallowell 1999; Walker and Rogers 2017.

why particular methods or modes of self-classification or biosocial affiliations might be better or worse for information subjects' identities qua identities, and not only for reasons of social justice, or for the individual's emotional well-being or their health – though these other kinds of impacts may also matter a great deal. What is missing from the pictures outlined in this section 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 an ethically significant difference to developing, understanding, and inhabiting an identity that constitutes the whole of who one is.

Narrative Proposals

I will now turn to introduce a family of arguments that offer a promising means of addressing the limitations noted in the previous sections. These are arguments that, in various ways, suggest that a particular category of personal bioinformation can play an important role in the construction of our stories of who we are – in our *identity narratives*. It is not uncommon to encounter claims that personal bioinformation of several kinds can play a part in our narrative accounts of who we are. For example, Novas and Rose talk of genetic susceptibility testing giving rise to 'biographical narration in genetic terms'.[132] Robert Klitzman talks of individuals trying to fit their test results into 'their previous understandings of, and narratives about, themselves'.[133] And the language of 'illness narratives' is widespread in the medical humanities, underpinned by empirical narrative methodologies that aim to capture the personal, lived experiences of patients.[134] The familiar, vernacular resonance of 'stories' or 'narratives' and associated ideas as 'disruption' or 'contribution' lends a kind of an intuitive plausibility to claims about a narrative role for illness experiences, diagnoses, or risk status. However, appealing though these framings are, we need to go beyond evocative metaphor if we are to explain the nature of the relationship between narrative and identity and the ethical implications of this relationship. 'Contribution' sounds broadly good, and 'disruption' suggests something undesirable, but is this really so, and why? In order to get

[132] Novas and Rose 2001, p. 503.
[133] Klitzman 2009, p. 887.
[134] Riessman 2008.

a better feel for the work that the concept of narrativity could do for us, we need to move beyond metaphor to something more substantial.

Narrative-based arguments for the value – even the necessity – of information about one particular kind of personal bioinformation have been proposed by several writers who return us to the now-familiar topic of knowledge of genetic parentage. Here, however, they do not argue that this knowledge reveals one's true or pre-existing identity. Rather, its value lies in providing a critical tool in actively constructing an 'acceptable' or 'intelligible' account of who one is. Each of these analyses offers a somewhat different picture of the role and value of this knowledge. The most theoretically developed of them is that presented by the philosopher David Velleman.[135] Velleman maintains that direct acquaintance with one's genetic parents – not merely information about one's parentage – is necessary to the development of a worthwhile identity as part of a 'flourishing life'.[136] Velleman's reasons for this are rooted in the particular challenges he believes we face in reconciling our internal experiences of ourselves with our experiences of ourselves as objective things in the world – for example, the person we literally see in the mirror or metaphorically reflected in other's reactions to us – and accommodating these in a single, coherent narrative of who we are.[137] Velleman argues that acquaintance with our genetic parents provides opportunities to observe connections between their psychology and bodies and our own and to witness how they live and cope with their given traits. This, he claims, helps us understand our place, as physical beings, in a chain of heredity and causality and avert alienation from our 'bodily selves'.[138] And this, in turn, allows us to undertake 'the task of identity formation' by understanding how 'someone like me come[s] to be living in a body like this'.[139]

In a similar vein, Jamie Nelson 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 also important to our ability to make sense of our lives as cohesive wholes. In Nelson's words, if we lack understanding of the early stages of our biographies, 'we cannot read well what is going on in the part occurring now'.[140] Meanwhile, Sarah Wilson claims a more straightforward

[135] Velleman 2005b, 2008.
[136] Velleman 2005b, p. 375.
[137] Velleman 2006.
[138] Velleman 2008, p. 260.
[139] Velleman 2008.
[140] Nelson 1992, p. 81.

epistemic role for genealogical information. She suggests that this information can fill explanatory and interpretive gaps in the identity narratives of adopted, abducted, and donor-conceived individuals, 'alleviat[ing] uncertainty with respect to the past' in a way that supports the accuracy or completeness of their identity narratives.[141] Wilson's proposal is echoed by the empirical work of psychologist Maggie Kirkman, who argues that ignorance of donor conception may lead to the development of a 'misleading' identity narrative.[142]

This family of arguments is considerably more promising as the basis for a robust normative conceptualisation of the relationship between personal bioinformation and identity than the candidates considered in the preceding section for several reasons. They focus on identity not only in the sense of self-characterisation but also in a global sense of an individual's whole self-concept, rather than as a discrete descriptor, social identity, or mode of classification. Moreover, by making claims about the value of information to our identity narratives and offering reasons for this, they provide potential routes to interrogating the nature of the interests involved. As will become clear from what I will go on to say in the chapters to come, my own proposals about the narrative roles of personal bioinformation share elements with, and owe much to, each of the accounts introduced here.

However, as they stand, these accounts are not yet quite sufficient to explain if, when, and why information subjects' access to the varied array of personal bioinformation mentioned in the opening chapter might engage ethically significant, sui generis, identity-related interests. For one thing, these accounts do not speak to the roles of knowledge beyond that about genetic parentage, and they tie its value closely to features specific to this category of knowledge, such as family resemblances and childhood memories. More also remains to be said about why it *matters* if our identities are 'misleading', contain 'uncertainty', or are connected to those of others; what it means for an identity to be 'rich' or 'worthwhile'; how such an identity contributes to a flourishing life; and, crucially, whether bioinformation of other kinds might also contribute to these ends. Furthermore, these accounts focus on the positive contributions of knowledge of genetic parentage to our identities. However, as I shall return to discuss in Chapter 5, it is far from clear that everyone welcomes either this or other kinds of information or experiences these as

[141] Wilson 1997, p. 290.
[142] Kirkman 2003, p. 2238.

enhancing their sense of who they are. For example, Jackie Leach Scully has suggested that knowledge of conception using a mitochondrial donor could, in certain circumstances, contribute to a stigmatising self-narrative.[143] And Mary Walker and Wendy Rogers have argued that information conveying diagnoses of asymptomatic disease may precipitate anxiety-inducing narrative adjustments.[144] We may also recall here the distress and confusion experienced by Sam in the fictional vignette at the start of Chapter 1. Any plausible and robust proposal will, therefore, need to address and account for the possibility that some encounters with personal bioinformation are detrimental to our identities.

These are the gaps I seek to fill over the coming chapters. But, before I can do so, I need to establish firm foundations for the precise conception of identity on which my argument will be based. It is not enough to invoke the importance of narrative identity, or the narrative self in claims about the ethics of information disclosures without being transparent about what one understands by these terms and unpacking any implicit normativity. And it is critical that the conception adopted is clear and plausible when held against the mirror of human experience. 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.[145]

In the next two chapters, I shall establish this picture. It is one grounded in philosophical theories in which our identities – our practical self-characterisations of the particular individuals we are – are constituted by self-constructed narratives. This conception provides ways of understanding both why being able to develop and inhabit one's self-narrative plays a foundational role in a full and fulfilling human life and the conditions on which serving such a role depends. I will propose that this picture of the self, once recognised as an inescapably embodied and relational one, also offers persuasive grounds for recognising the ethically significant nature of the impacts that personal bioinformation may have on our self-conceptions.

[143] Scully 2017. I return to discuss this further in Chapter 6.
[144] Walker and Rogers 2017.
[145] Widdows 2013, p. 6.