8

Protecting Identity in Practice

8.1 Introduction

Over the preceding chapters, I have sought to demonstrate that information about our health, bodies, and biology, including our biological relationships to others, can make significant contributions to the narratives by which we characterise ourselves, and which constitute our practical identities. I have argued that these contributions are often profoundly valuable. This is not because this information tells us who we are or defines us but because it plays substantive, explanatory, and interpretive roles which contribute to the inhabitability of our identities in the context of our embodied and socially embedded lives. Personal bioinformation can help us develop self-narratives that remain coherent and sustainable when confronted by embodied experience, and that provide robust interpretive frameworks through which to navigate our lives. I have also explored the ways in which personal bioinformation may threaten the sustainability, comfort, and inhabitability of our embodied identities – as occurs when it invites enduring disruption or equips us poorly to cope with and make sense of embodied, social experiences. I have argued that developing and maintaining an inhabitable identity narrative matters a great deal, not only because it means we have a clear sense of who we are but also because it provides the foundations for core experiential, evaluative, and practical capacities. For these reasons, I have argued there is an ethical imperative to attend to the potential identity impacts, both good and bad, of providing or denying information subjects access to their personal bioinformation. Throughout these arguments, I have sought to meet Heather Widdows's challenge quoted in Chapter 2 – to present a 'picture of the self' that is not 'wrong', such that the legal and ethical structures built upon this picture protect the interests that really matter.[1] It is not possible

[1] Widdows 2013, p. 6.

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to prove that the picture of narrative self-constitution and the roles of personal bioinformation in our narrative projects developed over the preceding chapters is *true*. But I hope to have demonstrated that it at least accords with our intuitions and experiences of what it means, and what it takes, to develop and inhabit our own senses of who we are as embodied beings and to navigate our enabling and limiting health, bodies, and biology. In doing so, I have sought to offer a robust and plausible conception of identity interests, the recognition of which would make a concrete difference to how access to and disclosures of our personal bioinformation are governed.

8.2 What Would Change?

In what ways would the bioinformation governance landscape look different if it were to embrace the picture of narrative identity impacts, interests, and responsibilities described and defended in this book? The headline answer to this question is simply that information subjects' identity-related interests in whether and how they encounter information about their bodies, biology, and health would be firmly installed amongst, and routinely weighed alongside, the other interests that currently dominate the ethical, policy, and regulatory landscape. This means that identity interests would join the roll call of core interests that currently include health protection, mental well-being, informational and personal autonomy, privacy, and confidentiality. Identity interests would enjoy parity of attention with the most prominent of these. This does not mean they should necessarily prevail or take centre stage. But it does mean that they must be recognised, carefully assessed, taken seriously, and afforded weight commensurate with the central role played by the development and maintenance of an inhabitable, embodied, and relational self-narrative in leading a full, flourishing, and practically engaged life.

Attending and responding to information subjects' narrative needs adds a fresh, new dimension to the governance landscape that, I have argued, is both more conceptually and normatively robust, and less unwarrantedly exceptionalist, than the kinds of harms or benefits currently spoken of in terms of 'identity'. It moves these conversations beyond the dominant focus on genetic risk and genetic parentage. It decouples identity interests from biologically essentialist and deterministic views of the self, while addressing fears that any appeal to the identity value of bioinformation risks committing ethical and empirical

essentialist fallacies. At the same time, it firmly installs identity as a morally serious concern, rather than a matter of mere aesthetics, preferences, or loose affiliations. Recognising the embodied nature of narrative self-constitution reveals the varied, variable, but nonetheless critical, substantive, structural, and interpretive roles that personal bioinformation plays in our self-narratives. Having said this, responding to embodied narrative identity interests and responsibilities does not entail a wholesale departure from existing bioethical and regulatory flirtations with identity concerns. Rather, it allows us to make space for recognising the value to information subjects of using biological insights as constitutive and interpretive tools in self-understanding, and to appreciate the harms of biological essentialism and fatalism in terms of harm to and constraints upon self-authorship. It reveals the narrative richness that may be derived from familial and biosocial affiliations and the profound risks of subjects building their self-conceptions on unreliable or meaningless findings. It demonstrates why particular biologically informed self-descriptors matter, not necessarily because of any discrete labels lost or gained but because of the effects on the coherence, sustainability, and inhabitability of the inter-interpretive, intersectional whole.

The analysis I have offered demonstrates why identity interests warrant the attention of those who produce, process, and manage our bioinformation in ways that, for example, vaguer appeals that we should recognise 'personal utility', seek to satisfy curiosity, enable 'psychological preparedness', or avert distress might not. But, again, this also does not mean that the ideas and needs referred to in these terms are necessarily without substance. They are often reaching for something interesting and valuable. Being in a position to understand where and how these might overlap with the desire and need to construct an inhabitable self-narrative provides potential disclosers with clarity and legitimate grounds to respond to them if and when they do.

For all these reasons, it might be assumed that attention to identity interests and responsibilities would lead to greater entitlements to personal bioinformation by information subjects and access to wider classes of information on additional grounds. And, in some contexts, this would be true. It would take us beyond the 'usual suspects' that currently provide criteria for disclosure in healthcare and health research – serious health impacts, clinical actionability, or utility in reproductive decision-making. It would also expand upon the relatively isolated recognition afforded to the identity significance of genetic parentage and donor conception. The arguments I have presented provide grounds for the

UK courts and the European Court of Human Rights not only to abandon talk of knowledge of genetic origins 'completing' or providing the 'truth' about applicants' identities but also to recognise and protect 'rights to know' – and, indeed, not to know – under the Article 8 'right to identity' across a much broader range of personal bioinformation. It could point to a richer set of considerations when it comes to introducing susceptibility testing or screening programmes for common complex conditions – such as *APOE* testing for elevated Alzheimer's risk – where the analytic and clinical validity of the genetic test is sound, but the immediate clinical actionability of testing remains somewhat equivocal. In circumstances where there is good evidence of the potential identity value of results and possible identity harms are manageable, this could provide grounds to support screening. I will return below to consider how it might also change feedback policies to participants of individual research findings.

However, recognition of identity interests would not only or inevitably lead to more frequent and widespread disclosures. It would lead to reduced subject access in contexts where there are risks of identity harm that cannot be adequately mitigated by the manner of disclosure. These would not only include disclosures that could cause lasting narrative disruption and distress but also extend to communication of misleading or unreliable bioinformation that would render recipients' narratives vulnerable to future embodied experience. Furthermore, sources of bioinformation that are currently regarded as harmless fun, such as genomic analysis of non-health traits or sleep tracking – where the 'fun' is implicitly connected to something like greater self-knowledge – could prove harder to justify in cases where the epistemic qualities of the information do not support presumptions of narrative value.

In other circumstances, it is less clear whether recognition of identity interest would direct us predominantly towards greater or to less availability of bioinformation. For example, the benefits of widespread adoption of whole genome sequencing in newborn screening programmes could, from one perspective, be viewed as analogous to early disclosure of donor conception – that is, as providing useful tools with which an individual can build a resilient, sustainable self-narrative. However, from another perspective, it may be seen as permitting parents' knowledge of their child's embodied vulnerabilities in ways that preempt the child's own self-authorship. This concern echoes longstanding worries about biomedical practices that foreclose a child's 'open future'.[2]

[2] Davis 1997.

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Arbitrating between these contrasting perspectives on the identity impacts of genomic screening of new-borns will require looking carefully at evidence of families' experiences. The picture of identity impacts presented in this book cannot answer this question on its own, but it can provide an essential tool with which to assess the evidence.

As I have emphasised throughout, responding to identity interests has wider implications than the question of *whether* to disclose. A bioinformation governance landscape informed by my analysis would be one in which much closer attention is paid to the ways in which potentially identity-significant bioinformation is communicated and to the wider interpretive context in which this takes place. Emphasis on the ways in which health information is disclosed has gained increasing prominence over recent years, for example in debates about governance of DTC genomics and discussions of ethical responsibilities to return individual research findings. The latter is increasingly turning from the question of whether to share findings with participants to questions about how this should be done.[3] Attention to identity interests lends grist to these developments and extends their relevance to other disclosure contexts. Informational transactions beyond clinical genetics would benefit from the kinds of skills and personal support currently largely restricted to genetic counselling. As noted in Chapter 7, the requirement to communicate in an identity-supportive manner should not be restricted to instances in which bioinformation is disclosed expressly to meet narrative needs. Just as important, if not more so, is the provision of identity support where disclosure of potentially identity-significant information is necessitated on non-identity grounds.

A key conclusion of this enquiry is that the identity impacts of encounters with personal bioinformation are not uniform: they may be positive, negative, or neutral; different people have varying experiences of similar bioinformation; and impacts differ between types of bioinformation and disclosure contexts. For these reasons, as well as the sheer variety of settings and ways in which we might encounter information about our own health, bodies, and biology, it is not possible to provide uniform recommendations for reforms to policy, practice, or the law to protect and promote identity interests in all instances. It is, however, possible to offer some broad indications for priorities and reforms in a handful of areas in which subject access is widely debated, including some of the

[3] Postan 2021.

illustrative examples that have accompanied and informed my arguments up to this point. I will start here with the issue that initially motivated the questions pursued in this book – donor-conceived individuals' access to information about their conception and their donors.

8.3 Five Disclosure Contexts

Donor Conception

As previously discussed, UK regulation and professional guidance regarding donor-conceived individuals' access to information about their conception and donors are already explicitly informed by the potential value of this knowledge to their identities and the relative benefits of learning of donor origins in early childhood.[4] Parents planning to tell and donor-conceived people hoping to access information are each directed to and encouraged to take up opportunities for advice and counselling. Apart from the sometimes essentialist talk of 'identity completion' underpinning them, these existing measures seem likely to broadly serve donor-conceived individuals' narrative identity interests as I have characterised them. The picture I have presented does, however, suggest some possible adjustments to current regulation and practice.

In view of parents' interests in constructing their own narratives and their invaluable role in supporting those of their children, coercive methods of enforcing early disclosure of donor conception are likely to be disproportionate, insufficiently context-sensitive, and counterproductive. This is particularly so if these methods increased the likelihood of children being confronted by information in uncomfortable, stigmatising, or under-supported ways. However, the importance of being able to make narrative sense of new bioinformation and integrate it early into one's developing identity points to the need, first, for sufficient state funding of counselling and support services and, second, for information availability and provision that appropriately match donor-conceived individuals' needs. Achieving the second of these requires addressing the time lag – which under UK regulations could be more than a decade – between when families are encouraged to introduce the topic of donor conception and when offspring have access to non-identifying and identifying details about the donor. This might be addressed by reducing the minimum age at which non-identifying information is available – it is

[4] See Chapters 2 and 5.

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currently sixteen – and revisiting the age – currently eighteen – at which one is legally entitled to apply to the regulator, the HFEA, to learn if one is donor-conceived or to receive identifying donor information.[5] Any reforms should be based on empirical evidence of what donor-conceived individuals as a group, and particular segments of this group – for example those conceived using donor eggs or embryos, or those from single parent families – wish to know, and of the relevant risks and benefits to all involved.

As noted in Chapter 5, people conceived using MRT in the UK are not currently entitled to identifying information about donors of the eggs that supplied their healthy mitochondria. In light of my claim that the identity value of knowledge of donor origins lies in its biographical, sense-making, and relational narrative roles, rather than in fulfilling a genetically determinist view of identity, there is little justification for any such disparities in the legal entitlements to donor information. Indeed, through its insistence on linking only nuclear DNA to potential identity interests, the current law risks promulgating a restrictive and deterministic view of identity.[6] Those conceived using mitochondrial donation should have the same information entitlements and opportunities to receive support and counselling as those conceived using one egg.[7] As Jackie Leach Scully argues, there is also a responsibility on all of us to help develop master narratives – for example, through media reporting and the arts – that alleviate rather than contribute experiences of stigma or alienation by those conceived using novel assisted reproductive technologies.[8]

Individual Research Findings

As noted in the preceding chapters, health research ethics continues to wrestle with ethical questions surrounding the return of individual research findings to participants.[9] The arguments I have set out in this

[5] Human Fertilisation and Embryology Act 1990 (as amended), s.31ZA.

[6] See Chapter 2 and 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).

[7] See also Appleby 2018.

[8] Scully 2017.

[9] The practical cogency and ethical relevance of the distinction between intended and incidental findings are increasingly questioned – particularly in exploratory and data-led research. See Eckstein et al. 2014.

chapter suggest that researchers have conditional ethical responsibilities to offer participants the option of receiving individual findings – irrespective of whether they are intended or 'incidental' – that could plausibly carry significant identity value. They also have responsibilities, when feeding back any findings – individual or aggregate – to do so in an identity-supporting manner. These proposals go beyond the most widely endorsed recommendations to offer individual findings that are clinically actionable, concern serious health risks, or are necessary for reproductive decision-making. However, requiring researchers to offer potentially identity-significant findings is likely to be less demanding than suggestions that they should return all those exhibiting the amorphous quality of 'personal utility'. The responsibilities recommended here – echoing Franklin Miller and his co-authors – are founded upon the Principle of Helpfulness and researchers' privileged access and interpretive capacities in respect of bioinformation that participants could not otherwise obtain.[10] They also arise from researchers' causal role in participants' vulnerability to the epistemic asymmetry in their relationship. In addition, it is apparent from experiences reported in Chapter 5 that the meaning and comfort of participants' self-narratives are often intimately bound up with their decisions to take part in research at all and the nature of their experiences of participating. For example, they may volunteer to participate in order to express solidarity with others susceptible to the same disease and feel positive about the experience of doing so and optimistic about how findings might help their family members . Proper recognition of participants' narrative investment in and vulnerability to the ways in which research is conducted and its outputs suggests grounds for strong pro tanto responsibilities to respect potential identity impacts in the ways that studies are designed and conducted, including the policies for returning findings.[11]

Widening return policies to include potentially identity-significant findings would impose a greater burden on researchers to assess, verify, quality assure, and communicate a wider range of individual findings. However, as with any feedback policy, it will still be appropriate to weigh the identity benefits to participants against possible risks, including uses of resources that detract from the pursuit and social value of the study. My suggestion is not that identity interests should always prevail, but that they warrant being taken seriously. It is worth noting that there is no obvious reason to limit these recommendations to health research

[10] Miller et al. 2008.
[11] For further discussion see, Postan 2021.

alone. They would extend to all studies producing personal bioinformation with potential identity significance.

These recommendations bring us back to the example of Ilana sketched in the opening chapter. Ilana regrets that the feedback policy of the research biobank in which she is a participant means that she will only be informed of potentially serious abnormalities found during data collection and will not be contacted with subsequent research findings. Her desire to learn of familial genetic disease risks extends beyond any immediate health concerns to encompass the significance of these risks to her values, life plans, relationship with her own mother, and the way she thinks about of her own parental role. Would Ilana's identity interests be sufficiently great to require feedback of these findings? My answer is a conditional one. On one hand, even if findings about, for example, Ilana's *APOE* variant carrier status would only give rise to a probabilistic risk estimate of Alzheimer's disease and would not be clinically actionable, the arguments presented in the intervening chapters urge us to take seriously Ilana's view these would still be of substantial identity value to her. And this value is no less, and perhaps decidedly greater, than her friend Sam's desire to know about her distant ancestry given the epistemic limitations of Sam's genealogical information. If those governing the biobank itself had access to Ilana's *APOE* variant status, and the resources required to verify their quality and meaning were not excessive, they could well have an identity-based responsibility to offer these to Ilana and to do so in an identity-supporting way.[12] However, if they only become apparent in subsequent studies, third-party researchers' responsibilities to report back to Ilana would depend on, amongst other considerations, their temporal and relational proximity to her, the practicability of reidentifying individual data subjects, and the quantity of sufficiently reliable findings produced by their study. Any of these factors could mean that attempts to meet Ilana's identity interests would be prohibitively resource-intensive.

Confidentiality and Consent in Healthcare

Two further areas in which I want to suggest that information subjects' identity interests ought to join protection of their health and reproductive decision-making as key considerations are, first, healthcare

[12] Cf. UK Biobank's policy on the return of potentially serious incidental findings, Gibson et al. 2017.

professionals' deliberations about when it would be justifiable to break the confidence of a patient for whom the bioinformation is also 'personal' and, second, when deciding the kinds of risk information that patients should be given in seeking their consent to medical procedures. As observed in Chapter 2, in the UK health professionals have a legal obligation to weigh the importance of maintaining patient confidentiality against the opportunity to mitigate significant risk of serious harm to family members, with whom they also have professional relationships, by disclosing their patient's health information.[13] And the legal test for the kinds of 'material risk' that patients should be told about when consenting to medical procedures is now based upon what a reasonable patient would want to know in the circumstances, rather than a professional assessment of what is relevant.[14] Failure to weigh in the first context, or to provide the requisite information in the second, may be grounds for action in negligence.

The arguments I have presented suggest that 'significant harm', 'material risk', and 'reasonably want to know' could plausibly be read as encompassing serious epistemic and interpretive threats to the inhabitability of the recipient's self-narrative, given the harm that narrative incoherence and loss of meaning pose to their well-being and capacity to lead a flourishing life. If identity harms are understood in this way, it is possible to see how, for example, a patient's refusal to share their carrier status for a rare genetic disorder with a close family member for whom it could carry significant identity value could ground *ethical* and *legal* responsibilities on the part of the healthcare professionals involved. For these professionals, their responsibilities include the requirement to weigh this identity value against private and public interests in preserving the patient's confidentiality and if, having done so, they were to find the identity value carried greater weight they would be justified in breaking their patient's confidence. Similarly, a care team considering, for example, what should be discussed with a patient due to undergo neurosurgery to alleviate the symptoms of Parkinson's disease, would be obliged to assess the likely identity significance to the patient of knowing that restored independent living and personality impacts could affect their relationship with their life partner, and not only to focus on disclosing the direct physical risks of the neurosurgical procedure.

[13] Dove et al. 2019.
[14] *Montgomery* v. *Lanarkshire Health Board* [2015] UKSC 11, at [87].

For there to be a legal remedy grounded in negligence for a failure to disclose identity-significant information in either of these cases, the courts would need to judge it fair, just, and reasonable to impose such a duty on non-disclosing parties. Furthermore, identity harms would need to be recognised as a relevant category of damage. Currently, these categories include pain, suffering, or loss of capabilities arising from physical and psychiatric injury, or material loss, for example of earnings.[15] Although the arguments presented in this book suggest that identity harms – at their most acute – should be included amongst these on grounds of parity of severity, it is not clear that a court would see it this way. Nevertheless, Graeme Laurie and his co-authors have speculated whether there might be grounds to anticipate courts' greater willingness to recognise a wider class of damages in UK negligence cases. These grounds include the circumstances under which compensation for 'hurt to feelings' is awarded under Scots law, and intimations in recent years that UK courts are taking a more expansive view of relevant categories of harm in negligence cases to include interference with patients' rights to live and plan their lives in accordance with their wishes and values.[16] Identity impacts could plausibly be captured under these wider categories of harm.

DTC Genomics

Online DTC genomics services present a particularly apt context in which to apply the arguments of this book. These services offer a wide variety of potentially identity-significant personal bioinformation, ranging from the presence of genetic variants associated with serious diseases – such as the *BRCA1/2* mutations – to findings that are unrelated to health – for example, ancestral information or susceptibility to early hair loss. And, as previously noted, these services are marketed as providing straightforward insights into users' identities. In doing so, service providers incur reliance and occupy the kinds of causal roles that, I have suggested, engender particular responsibilities to protect the identity interests of those rendered situationally vulnerable by their activities. However, as ample critical analyses of DTC genomics have observed, while the technical capabilities of these services to correctly identify the genomic markers of interest are

[15] Laurie et al. 2019.
[16] Laurie 2009; Laurie et al. 2019, p. 389.

generally not in question, the robustness, certainty, and meaningfulness of the inferences then drawn from these to particular traits, susceptibilities, or ancestral connections are considerably more dubious.[17] Anyone may use these services without prior analysis of family risk or counselling, which would normally precede genetic testing in healthcare settings. And results are reported via online portals accompanied by explanations of their variable detail and quality.[18] Even detailed explanatory materials, however, cannot provide discursive support or interpretations that are responsive to personal circumstances.[19] For these reasons, DTC genomics may be seen as a perfect storm for readily foreseeable identity harms. This risk is heightened by the sheer quantity of results delivered at once. Scott Roberts and his co-authors have suggested that the relatively sanguine and distress-free responses they have observed amongst people learning of susceptibility to single multifactorial disorders – for example, as seen in the REVEAL study – are unlikely to be sustained if findings about multiple conditions were to be simultaneously disclosed.[20] Reports of multiple findings – some serious, some surprising, many meaningless – could stretch users' resilience and capacities to make sense of complex probabilistic, population-risk-relative, and caveated results. This is the situation imagined in the vignette sketched at the start of Chapter 1. Sam's experiences capture the narrative turmoil or insecurity that may arise from unexpected revelations, such as absent genetic relationships within families. They also indicate the disproportionate weight that Sam invests in somewhat speculative 'fun' ancestral or trait information. Meanwhile Sam misunderstands or dismisses her probabilistic disease susceptibility estimates as puzzling or hard-to-interpret, yet these are likely to be of far greater consequence to her embodied and relational experiences.

Much of the current ethical concern about DTC genomics focuses on the risk of serious harm to health from inadequately explained or misunderstood health risk information.[21] Other commentators, however, regard such concerns as excessively paternalistic.[22] And some cite

[17] See, Bunnik et al. 2011; Skirton et al. 2012.
[18] Skirton et al. 2012.
[19] One online DTC service, 23andMe, encourages users to speak to a genetic counsellor or healthcare professionals before and after seeking health-related reports and offers basic advice on, for example, continuing to attend the screening and pursue other healthy behaviours, see '*23andMe Genetic Health Risk Reports: What you should know*' www.23andme.com/en-gb/test-info/genetic-health (accessed 18 July 2021).
[20] Roberts et al. 2011.
[21] See, for example, House of Commons Science and Technology Committee 2021.
[22] Green and Farahany 2014.

'personal utility' as sufficient ethical justification for providing results.[23] The conditions for meeting a test of personal utility might amount to little more than feeding the recipient's curiosity or expanding their practical options. In contrast, the bar set by the preceding analysis for realising identity value and averting narrative harms is considerably higher. And while avoiding paternalism may be desirable, self-efficacy and self-authorship are unlikely to be achieved by abandoning service users to make their own choices and navigate a tangle of perhaps unexpected and overwhelming results with little support. Furthermore, it is evident that the potential for narrative harm extends beyond the threats to identity most commonly raised in relation to DTC genomics – namely encouraging unwarranted geneticised views of the self and naturalising human differences in divisive ways – troubling though these possible consequences are.[24] Chief amongst the wider harms brought to light by a narrative analysis are those of constructing precarious identity narratives upon misunderstood, partially understood, or misleading results in such a way that they invite unnecessary reinterpretation of prior experiences, render the recipients' narrative coherence freshly vulnerable to embodied experiences, or foster a narrative that provides a poor interpretive framework for navigating the world. In a somewhat different vein, user data collected by DTC services is often subsequently sold for commercial and research purposes in ways users do not always fully appreciate.[25] In such cases, user's bodies and narratives may be implicated in projects and purposes that undermine their values and their account of the kind of person they are.[26]

The picture of identity interests and corollary responsibilities developed over this and the preceding chapters suggests that DTC genomics warrants either much stronger regulation or reformed delivery models. At the very least, it points to the need for personal, discursive, identity-supporting feedback of findings, with opportunities for users to ask questions and receive counselling; significant reduction of the numbers and kinds of tests offered to remove those that are incapable of providing reliable or meaningful insights, though these need not be limited only to those that are clinically actionable; greater transparency about the nature and purpose of future analyses and about commercial and third-party uses of the data collected; and straightforward means for users to opt out

[23] Vayena 2015.
[24] Cf. Nordgren and Juengst 2009.
[25] Bunnik et al. 2011.
[26] McMillan et al. 2021.

of such uses.[27] It also supports calls for more honest and measured marketing of these services, so as to make the epistemic limitations of the test results absolutely clear and to remove implications that they reveal predetermined 'truths' about the self.

Personal Devices

DTC genomics is not the only context in which potentially ambiguous, identity-significant bioinformation is delivered directly to information subjects without the intercession of expert guidance and advice. Healthcare delivery is increasingly reliant on self-management of chronic conditions and use of eHealth technologies, driven by resource constraints, ageing populations, and necessities imposed by global pandemics.[28] Uses of personal self-monitoring devices to track behaviours and characteristics associated with health and well-being, including activity levels, sleep quality, concentration, mental health, and fertility, are also rapidly expanding.[29] This means that an increasing proportion of the personal bioinformation we encounter is delivered directly to us by mobile, wearable, and implanted technologies. Some of these such as wearable fitness monitors are widely available consumer devices. Others are highly specialised predictive, diagnostic, or assistive technologies – for example, surgically implanted BCIs that monitor brain activity to warn users of epileptic seizures.[30]

Although people will usually be able to choose whether to use such devices, they are often passive in their exposure to the bioinformation these deliver.[31] This immediacy, combined with the limited scope to provide integrated, personalised, interpretative support through a digital interface, creates a particular imperative to ensure the quality, reliability, and transparency of the bioinformation generated. This is not only important because of the serious health consequences of erroneous

[27] I have suggested above that information providers may reasonably devolve interpretive support to those best equipped to provide it. However, the generic signposting to national genetic health services offered by many existing DTC services hardly fulfils this responsibility and risks overwhelming healthcare providers.

[28] World Health Organization 2021.

[29] Ajana 2020.

[30] Gilbert et al. 2019.

[31] Even this element of choice may not be present if, for example, public health authorities require users to install infection exposure applications on their mobile phones or if social media platforms deliver unsolicited mental health alerts and advice based on algorithmic analysis of users' browsing behaviour, search terms, and keystrokes – see Jain et al. 2015.

medical advice. Attention to potential identity impacts highlights how the information generated may represent more than just health advice or entertainment. For example, some users of BCIs that predict epileptic seizures report that they now feel 'more capable' and as if they have 'found' themselves, while others feel oppressed by reminders of an illness they would prefer to deny.[32] Meanwhile, users of consumer devices may rely on their outputs to explain experiences such as periods of poor concentration or fatigue, anticipate future events such as pregnancy, or characterise themselves as, for example, 'a poor sleeper' or a 'calm person'.

When this occurs, the information supplied by these devices offers ready narrative contents and tools. These may be viewed as having substantial identity value, for all the constitutive, explanatory, and interpretive reasons described in the preceding chapters. As argued in Chapter 4, there are insufficient grounds to assume that bioinformation from personal devices will wholly usurp users' direct, phenomenological experiences of their own bodies and health in their accounts of who they are, rather than complementing these.[33] Similarly, we should not assume that if this information alters users' sense of who they are that this necessarily represents problematic 'estrangement', rather than an integral aspect of dynamic narrative development.[34] However, the potential for harm to users' identities from misleading, intrusive, or distressing alerts or feedback should not be taken lightly. This points to the need to manage users' expectations of what insights their devices can, and cannot, reliably deliver and to assess critically the balance of potential identity harms, especially where the bioinformation supplied is of questionable quality or practical value.[35] It adds weight to existing calls to ensure the suitability of the algorithms and training data used to ensure that these devices provide accurate outputs and advice.[36] It also suggests a need for conscientious decision-making and risk assessment by developers to avoid potentially stigmatising, essentialising, or divisive mean of classifying users' status or performance and highlights the need to design information interfaces that support user's agency in, comprehension of, and critical engagement with the data produced.[37]

[32] Gilbert 2015, p. 5.
[33] Cf. Lupton 2013.
[34] Cf. Gilbert et al. 2019.
[35] Peake et al. 2018.
[36] Fenech et al. 2018.
[37] For further discussion, see Postan 2020.

8.4 Future Challenges

The five contexts discussed above are only a small sample of those in which identity-significant encounters with personal bioinformation occur. It will be possible, to varying degrees, to extrapolate beyond the brief recommendations I have made here to many other settings and scenarios. The arguments I have presented in this book have focused on questions of when, why, and how individual information subjects should have access to information about their health, bodies, and biology on identity grounds. I have intentionally set aside ethical concerns about how other people use these kinds of information to characterise and categorise us, as these matters have hitherto received greater attention in the bioethical and legal literature. I have sought to turn our attention instead to our reflexive uses of our own bioinformation to constitute our embodied identity narratives, as well as to the involuntary impacts that this information may have on our narrative projects. Nevertheless, the preceding discussions have made clear that our projects of self-constitution, the tools we use in these narrative endeavours, and the meanings assigned to these tools are closely entwined with the behaviours, interpretive work, and narrative projects of other people.

It seems that these informational and narrative interdependences will only grow and become more complex over the coming years, as – driven by, amongst other factors, the quest for precision medicine, commercial interests, and public health emergencies including global pandemics – increasing quantities of findings about our traits, susceptibilities, and behaviours are derived not from our own bodies, or even from those of our close relatives, but from analysis of 'big data'.[38] These include not only big *health* data drawn from patient records and health research programmes but also those derived from surveillance in the public sphere and monitoring of our online behaviours, using the powerful analytical capacities of artificial intelligence and machine learning.[39] These developments will not alter the imperative to attend to individual encounters with information derived from our own bodies and those close to us. However, they introduce a new kind of distance between the subjects and sources of personal bioinformation. And they will add weight to the cautions I have voiced – to be alert to the identity impacts of the sheer quantities of personal bioinformation that confront us and to the increasingly remote relationships between those producing and processing our

[38] Henschke 2017; Raghupathi and Raghupathi 2014.
[39] Henschke 2017.

bioinformation and us. These factors have profound implications for the abilities of these actors to anticipate our identity needs, to help us interpret bioinformation in identity-supporting ways, and to know that this information is personal to us at all.

These developments also add fresh dimensions to identity concerns, as algorithm-driven analyses categorise us in new ways, introducing new forms of self-description, grouping us with those with whom we have had no previous connection, and fragmenting longstanding affiliations. It remains to be seen how our embodied, socially embedded self-narratives – and their qualities of inhabitability – respond to these changes, particularly if they contribute to a widening epistemic gap between our lived experiences and what bioinformation conveys. The preceding discussions offer some intimations of how our narrative undertakings might adapt and respond and how we might be protected from some of the possible narrative blows. These discussions also suggest that in fast-evolving, data-driven environments identity concerns supply an added ethical imperative not only to attend when and how our personal bioinformation is communicated to us, the imperative I have focused on in this book, but also to ask with greater urgency why and for whose benefit this information is produced at all.