
Responsibilities for Disclosure

7.1 Introduction

In this chapter, I will outline what I take to be the broad shape of the ethical responsibilities that fall to those who generate or manage personal bioinformation in respect of its disclosure to information subjects. It will be principally concerned with the nature, source, and extent of various actors' *ethical responsibilities* to meet information subjects' information-related identity interests. As discussed in Chapter 2, the extent of legal and professional responsibilities to provide, or indeed to withhold, personal bioinformation on explicitly identity-focused grounds is currently remarkably limited. These are confined chiefly to meeting conditional entitlements to information about genetic parentage and donor conception. Of course, as also discussed in that chapter, information subjects may well have legal, regulatory, or policy entitlements to, or protections from, information about their health, biology, or bodies, which might coincidentally meet their identity interests on grounds other than those interests themselves – for example, where they have broad subject access rights to their health records, or where concerns about distress from over-diagnosis or lack of clinical actionability means that screening programmes are restricted. However, as I have noted, if these provisions are developed or delivered in ways that are not informed by a clear and robust understanding of the nature and extent of possible impacts on subjects' identities and the ethical significance of these, then there is a predictable and not insubstantial risk that their identity interests will not be met or that they may even be violated.

It has been the aim of this book to fill this conceptual and normative gap and help avert this risk. This chapter represents the final step in fulfilling this purpose – though there will be much further work to be done beyond the scope of the present project, not least in conducting the empirical studies to inform practice in particular circumstances and to develop practicable and effective policy, regulatory, or legal responses to

respond appropriately to protect identity interests. Given that identity interests will be affected in different ways by different kinds of personal bioinformation in different contexts and vary between individual information subjects, my intention here is not to make rigid regulatory or policy recommendations, but rather to offer a picture of the responsibilities that should inform these. In the final chapter, I will provide brief examples, in five key disclosure contexts, of what these practical responses would look like if we were to take identity-related responsibilities seriously. In this chapter, I will first outline the shape of what I take to be the four core ethical responsibilities accruing to potential disclosers. I will then examine the ethical foundations for these responsibilities, before returning to look in more detail at what meeting them entails and some of the possible challenges in doing so.¹

7.2 Responsibilities of Potential Disclosers

The responsibilities to be discussed here relate to disclosures of personal bioinformation to which the potential recipient, the information subject, would not otherwise have direct access. And my focus is, for the most part, limited to responsibilities that accrue to those who hold or have ready access to personal bioinformation about others. As such, it is concerned with responsibilities to disclose bioinformation that already exists, is predictably likely to exist, or is reasonably readily generated, rather than to generate it *de novo*. Nevertheless, the distinction between conveying existing and generating new information is not a sharp one. This is because whenever information is communicated it will acquire new meanings and connotations, in effect generating new information. And, in order to make it useful, accessible, and comprehensible, almost all of the kinds of bioinformation hitherto mentioned will require analysis and interpretation. I shall argue that the interpretive contributions of disclosers are themselves central to their ethical responsibilities.

The responsibilities that I am proposing correspond to the three information-related interests set out in the previous chapter with some additions and refinements. They may be broadly summarised here as the responsibilities:

To offer, provide, or facilitate, access to personal bioinformation to information subjects where doing so could plausibly contribute to their

¹ I will use the phrase 'potential disclosers' to capture those who might be in a position to disclose, not only those who are ready to do so.

developing and maintaining an inhabitable self-narrative in the context of their embodied and socially embedded life;

To do this in a manner that supports the inhabitability of the recipient's self-narrative; and

To protect information subjects from exposure to personal bioinformation that is very likely to threaten the development or maintenance of an inhabitable self-narrative.

In addition to these, and in recognition of the sometimes unpredictable nature of the impacts of personal bioinformation, I want to propose the prior responsibility:

To take reasonable steps to ascertain the likely identity significance of the particular bioinformation to the information subject in the given context, and any likely benefit or detriment to the inhabitability of their self-narrative they could experience from encountering it.

These headline statements of the four responsibilities are given here by way of introduction only. I will explore further below their ethical basis and what is involved in fulfilling them. I will also unpack some possible complexities and challenges in specifying and discharging them. Two key aspects that I will unpack further are, first, that the responsibilities sketched above are pro tanto ones – not absolute but holding in the absence of stronger countervailing reasons to do otherwise. Second, their precise nature and scope will depend on the role of the potential discloser and their relationship to the information subject, and they will carry a greater imperative in some contexts than others. Before exploring these variables, I want first to review the actors to whom these responsibilities accrue and then to explore the ethical grounds for imposing duties on these actors.

Potential Disclosers

Perhaps the most obvious parties to whom the responsibilities listed above apply are healthcare professionals, who care for us, observe our health and well-being, and conduct tests and diagnoses, and investigators leading health-related research studies, who gather and process new data and generate findings about us as research participants. However, as will be clear from the preceding chapters, potentially identity-significant personal bioinformation is generated in a much wider range of contexts than healthcare and primary health research. The list of actors, therefore, who hold others' personal bioinformation or make decisions about when and how it is conveyed to its subject(s) extends, for example, to

researchers making secondary use of healthcare data, or data collected for previous studies or held in biobanks. These actors may include not only researchers themselves but also those responsible for managing data resources, research ethics committees, and funders. It includes commercial actors, such as those managing DTC services that offer testing, genomic analysis or body and brain imaging, and those developing, designing, and marketing home test kits, health-tracking devices, or mobile apps which provide users with data about, for example, their diabetes risk, sleep quality, or fitness levels. It includes healthcare providers, professional bodies, and advisory committees, such as NICE, Healthcare Improvement Scotland, or the UK National Screening Committee, who are variously responsible for making decisions about, for example, which screening programmes are offered and to whom and which kinds of predictive, diagnostic, or prognostic tests or health monitoring technologies are available to patients. I also want to suggest that the responsibilities above apply beyond those acting in professional capacities. They extend to private individuals who hold personal bioinformation about another individual – for example about a shared family risk of genetic disease – who does not have direct access to it themselves. This may appear to be an implausibly wide list of parties on whom to impose, perhaps quite demanding and subtle, responsibilities for ascertaining and responding to variable and multifaceted narrative impacts. However, it is intended to provide indications of *potential* bearers of communication responsibilities. They will not all be subject to them or tasked with discharging them in all circumstances.

7.3 Ethical Foundations

The above list of potential disclosers extends far beyond those who we normally consider as having professional or legal duties of care for the health and well-being of information subjects, let alone specific duties to protect the inhabitability of their identities. I am concerned here, however, with the ethical rather than the legal foundations for disclosure responsibilities, even if part of my aim is to provide persuasive grounds for some responsibilities that could or should be enforced in law. The ethical rationale I will set out in this section owes something to both an ethics of care perspective, which emphasises our relationships of mutual dependence and the importance of attention to individual embodied and social needs and vulnerabilities, and a particular conception of

beneficence thought of in terms of 'helpfulness', as proposed by Thomas Scanlon.²

Anchoring both of these ethical perspectives is the strength of our information-related identity interests. As described in the previous chapters, this strength is grounded in our fundamental interest in developing and maintaining inhabitable identity-constituting narratives and the conditions this establishes for particular valuable experiences and capacities – including understanding who we are and what we value – which play a central role in our fulfilling, practically engaged, embodied, and socially embedded lives. Our information-related identity interests are, therefore, serious and deserve to be recognised and taken seriously by others. As also described in the preceding chapter, bioinformation will not fulfil, or thwart, this basic interest in the same way in every instance and sometimes it will do neither. But when it does have a marked impact, it fulfils a non-fungible substantive, epistemic, or interpretive function in the particularity of our evolving self-narratives. The strength of others' responsibilities to meet our information-related interests will depend, in part, on the degree to which the disclosure in question serves or undermines our more fundamental identity interest.

Vulnerability and Need

We all have myriad interests and needs. Many of them are strong. And other actors are not generally compelled to try to meet all of these. So we need to look further for the full extent of the ethical roots of disclosure responsibilities. In essence – why should anyone else shoulder burdens associated with development of my identity narrative, even if this pursuit matters to me? The answer to this question involves looking to three key considerations: the inherently relational, interpretative, and dialogical nature of self-constitution; the relative lack of control we have over the availability of and our exposure to many kinds of personal bioinformation; and the ways this information may complement, conflict, or compensate for the identity impacts of our lived, embodied experiences.

Because narrative self-constitution is to a great extent an epistemic and interpretive process, one we do not and cannot undertake alone, we are each potentially implicated in the identity projects of those around us. This is especially so where one party holds specific means to make those projects go better or worse – as when others hold, or are in a position to

² Miller 2013; Scanlon 1998, p. 224.

obtain, bioinformation about us that is not otherwise available to us. In these cases, we are dependent on and vulnerable to their choices about conveying it to us and also to the epistemic asymmetries that their enhanced access to information creates. By this, I mean not only – and perhaps not even chiefly – asymmetries in power that arise from, for example, clinicians, institutions, or family members knowing more about our bodies, minds, or health than we do. As described in Chapter 4, from a narrative perspective particular concerns arise from asymmetries between our own perspectives upon and understandings of the world and the understandings of others – for example mismatches in understandings of our biological biography or our health risks. These mismatches place in jeopardy the correlation between our self-characterisations and how others see us, and thus threaten the externally oriented coherence of our embodied self-narratives and the respectful and supportive recognition of our self-narratives by others. Furthermore, we are often dependent on others for their support in understanding and interpreting new information in constructive ways and, similarly, we are vulnerable to any essentialising, reductive, misleading, stigmatising, or otherwise harmful interpretations that others might apply to it. The nature of this vulnerability warrants closer inspection.

Wendy Rogers, Catriona Makenzie, and Susan Dodds have developed an influential analysis of the concept of vulnerability as it applies to bioethical debates. In accordance with the definition offered by these authors, I understand vulnerability in the present context to mean being ‘susceptible to serious harms (physical, psychological, and emotional) with respect to the meeting of one’s vital needs – harms that impair one’s ability to lead a flourishing life’.³ Applying the taxonomy developed by Rogers and her co-authors, my claim is that as narrators and occupants of self-constituting narratives we each exist in a state of ‘dispositional’ ‘inherent vulnerability’ with respect to the inhabitability of our identities. This is a result of – in their apt description – ‘our corporeality, our neediness, our dependence on others, and our affective and social natures’ and what this entails for the ways in which we construct our self-narratives, the contexts in which we inhabit them, and the kinds of experiences that threaten their inhabitability.⁴ This vulnerability is actualised – becomes ‘occurrent’ – in particular circumstances, for example when we are awaiting results from a diagnostic test for a serious illness. Some of us will additionally be more

³ Rogers et al. 2012, p. 22.

⁴ Rogers et al. 2012, p. 24.

markedly 'situationally' vulnerable if, for example, we live with a mental health disorder that presents particular challenges to our ability to develop a coherent sense of who we are, or if those close to us know something about us that we do not – for example about our genetic parentage – that would sever a key thread in our self-narratives.⁵ And even deeper kinds of 'pathogenic vulnerability' may hold in circumstances where our selected modes of self-characterisation, or the intersectional constellations in which we arrange these, are routinely denied recognition or respect by others, when there are no comfortable, socially available master narrative templates that fit these, or when our core threads of self-characterisations are linked to degrading or oppressive stereotypes.⁶ I propose that the strength of our basic identity interest and the gravity of our associated vulnerabilities are sufficient to give rise to *pro tanto* ethical responsibilities in others – individuals and institutions – to support those who are occurrently inherently, situationally, or pathogenically vulnerable. These are responsibilities to minimise threats to the inhabitability of information subjects' self-narratives, where they have the means to do so.

Perhaps the clearest responsibility is to refrain from actively harming information subjects by providing, or imposing, bioinformation in a way that is likely to damage the inhabitability of their identity narrative or their abilities to develop and maintain one. In some cases, the harmful impacts of particular information encounters will be hard to predict, dependent on the disclosure context and existing identity narrative of the recipient. As I shall return to discuss shortly, this indeterminacy is not in itself grounds for relieving potential disclosers of all identity-related responsibilities. Moreover, as discussed in the previous chapter, there are at least two circumstances in which narrative harm is, if not inevitable, then reasonably predictable. The first of these is the provision of information that the discloser knows to be meaningless or misleading, or at least doing so without adequate explanation of these limitations. This might include, for example, the provision of results from a commercial neuroimaging service that purports to deliver diagnoses of serious, complex psychiatric conditions using techniques that lack the necessary capabilities. The second is the provision of information that is predictably likely to be experienced as degrading, stigmatising, or oppressive in the given context – which may well coincide with false or misleading

⁵ Rogers et al. 2012, p. 24.

⁶ Rogers et al. 2012, p. 25.

information – or doing so in a way likely to exacerbate rather than ameliorate the effects of these qualities. This kind of information could include, for example, results of forensic genetic analysis that are derived and presented in such a way as to imply an innate, familial disposition to criminal behaviour.

A Duty to Help

While the responsibility to refrain from actively harmful disclosures is relatively easy to justify, it may seem less obvious why someone would have an ethical responsibility to positively benefit someone else's identity through provision of information. To explain the ethical basis of this further dimension I want to add a complementary lens to that based on need, vulnerability, and interdependence. The second lens is provided by Thomas Scanlon's justification for instating a 'Principle of Helpfulness', which he sets out using the following example:

Suppose I learn, in the course of conversation with a person, that I have a piece of information that would be of great help to her because it would save her a great deal of time and effort in pursuing her life's project. It would surely be wrong of me to fail (simply out of indifference) to give her this information when there is no compelling reason not to do so. It would be unreasonable to reject a principle requiring us to help others in this way (even when they are not in desperate need), since such a principle would involve no significant sacrifice on our part.⁷

As it happens, Scanlon uses information provision as his example here, but – just as he intends this principle to apply beyond information transactions – I want to hold that it holds not only in instances of offering personal bioinformation, but also those of conveying it in a helpful manner, and withholding bioinformation when doing so would not amount to contemporaneous harm. Scanlon's Principle of Helpfulness takes us beyond moral responsibilities not to harm, which are generally more easily justified, into the realm of responsibilities to those to act for the benefit of others. Moreover, it applies where another's needs are not so urgent as to give rise to a duty to *rescue* but are nevertheless worthy of ethical attention and intervention. The responsibility here is one of supporting others in furthering their significant and legitimate interests. In Scanlon's account this is not intended to include excessively demanding duties. A responsibility to help holds where the ratio of benefit to the

⁷ Scanlon 1998, p. 224.

information subject to cost to the potential discloser is relatively high. The presence of compelling countervailing reasons and 'significant sacrifices' could be sufficient to override this responsibility to help. I shall indicate what such countervailing considerations could look like in the case of identity-significant bioinformation shortly.⁸ As to the nature of the benefit in the context of bioinformation disclosures, this might not be best described in Scanlon's terminology of saving 'time and effort'.⁹ However, his characterisation of the benefit in terms of supporting the beneficiary's 'life's project' is strikingly apt where the benefit is one of supporting narrative authorship and narrative inhabitability.¹⁰

Scanlon's Principle of Helpfulness, with some additional specifications, has been used by Franklin Miller and his co-authors as grounds for researchers' responsibilities to return health-related incidental findings to participants.¹¹ Here, I seek to apply it beyond return of research findings. Miller and his co-authors suggest that Scanlon's principle would be implausibly broad if, for example, it were read as requiring one to give unsolicited health-related advice to a stranger on a bus. So they seek to further specify it by proposing there must be a professional relationship between the parties and that the potential discloser has legitimate 'privileged access to private information' as a result of this relationship.¹² I, however, do not want to insist that identity-related responsibilities depend on the existence of a formal professional relationship.

I submit that it is reasonable to extend the duty to help more widely because of the importance of our information-related identity interests and because of the range of parties who are in a strong position to serve or frustrate these. However, I would follow Franklin and his co-authors in limiting the duty to those actors whose position, skills, and relationship with the information subject place them in a particular kind of privileged, and indeed powerful, position. This is the position of holding, or being readily able to acquire, bioinformation that the subject would not otherwise have – and which could have significant impacts on their narrative projects – and controlling the subject's access to it. Here, we can call again on the concept of vulnerability introduced above. Information subjects are vulnerable to the inaccessibility of particular bioinformation or to the impacts of exposure to it, and reliant on these actors, and the insights that their expertise or position

⁸ Scanlon 1998, p. 224.

⁹ Scanlon 1998, p. 224.

¹⁰ Scanlon 1998, p. 224.

¹¹ Miller et al. 2008.

¹² Miller et al. 2008, p. 276.

affords them, to provide, withhold, or help to interpret it. In practice, the ways and extent to which particular actors are able to support others' identity interests, the sacrifice involved in doing so, compelling reasons not to, and the presence of conflicting or coinciding responsibilities will vary with the circumstances. For these reasons, the extent of actors' identity-based responsibilities will vary too. These kinds of countervailing considerations and reasonable limits provide sufficient checks against implausibly unbounded or onerous duties.

Although I am rejecting the existence of a professional relationship as a necessary criterion, the specific roles and skills of potential disclosers *are* relevant to the nature and extent of their responsibilities in several ways. These roles and skills will shape what bioinformation they hold, the nature of their relationship to the information subject, the part they play in generating and controlling the flow of the information, and the power and authority they wield. For example, those conducting medical research generate vast quantities of findings to which participants do not necessarily have access, and many of these findings will not only be health-related but also potentially identity-significant. This is even more likely to be the case where technologies such as neuroimaging or genome sequencing are used and analyses of data from hundreds or thousands of participants are involved. This kind of privileged informational control does not only depend on professional skills. For example, family members will sometimes have knowledge of their own and other family members' susceptibility to hereditary disease through knowledge of their own status and family history.

Vulnerabilities, dependencies, and consequent responsibilities to ascertain and respond to needs are also intimately bound up with the relationship between potential discloser and recipient and to wider pre-existing responsibilities arising from these relationships. For example, healthcare professionals have a particular duty of care for their patients that, while not explicitly extending to identity protection, does encompass wider well-being. And family members, particularly parents, have special responsibilities to nurture the personal development and flourishing of close relatives, particularly their own children, by reason of their relationships with them and the accompanying moral duties to safeguard their well-being. It is not implausible to hold that for parents these duties encompasses, albeit implicitly, that of providing the tools for their children's independent identity-development.¹³ I would

¹³ The presumption of this kind of responsibility might, for example, be evidenced in the emphasis placed on the importance of early-years development and expectations that parents will support their children's learning and increased independence.

further suggest, as illustrated by all three examples discussed in Chapter 5, that we are often in a special position to anticipate the identity-related needs of family members and act as valuable interpretive partners in making personal narrative sense of the implications of newly received personal bioinformation.¹⁴ If, as I am suggesting, ethical responsibilities to support others' information-related identity interest are grounded in the intersection of these interests, information subjects' vulnerability, and the principle of helpfulness, it is not difficult to see how family members' ethical responsibilities can follow from being in this special position.

I want to follow Rogers and her co-authors in suggesting that the causal history of information subjects' identity-related vulnerabilities also have a bearing on others' ethical responsibilities to contribute to rectifying these. These responsibilities are likely to be greater when the potential discloser has played a role in creating these vulnerabilities, for example by providing misleading or poor-quality information that places the future coherence and sustainability of the subject's narrative in jeopardy. This might be the case where, for example, parents have allowed their children to make misplaced assumptions about their genetic parentage. Similarly, some commentators plausibly suggest that, given the central role that state regulators of fertility treatment play in separating donor-conceived individuals from knowledge of their genetic origins, these actors bear a particular moral responsibility for facilitating access to information about donor origins.¹⁵ In these circumstances the source of the duty perhaps goes beyond helpfulness to something closer to justice.

A related line of reasoning – this time with respect to responsibilities to support the interpretation of bioinformation – may be applied to those who invite particular reliance and trust on the part of information subjects by occupying positions of authority, or by presenting bioinformation as providing especially authoritative and objective insights into subjects' embodied lives. As observed in Chapter 5, there appears to be a close connection between subjects' perceptions of bioinformation's epistemic strength and identity significance, and particular narrative harms may follow from misplaced dependence on unreliable or unsuitable findings. For those who occupy positions of presumed epistemic authority, the responsibility to convey bioinformation in a narrative-supporting fashion

¹⁴ We might reasonably extend this 'special position' beyond family to long-standing friends.

¹⁵ See Ravitsky 2016.

implies two things – a requirement to support information subjects in making sense of and understanding the limitations of any bioinformation one supplies within one's field of expertise, and a requirement to maintain humility about the legitimacy and limits to one's own abilities to prescribe the narrative role that the information subject ascribes to it.

7.4 Limiting Considerations

As indicated above, those who hold or control the generation and dissemination of potentially identity-significant personal bioinformation are not subject to absolute obligations to meet, or strive to meet, information subjects' identity interests in all circumstances. These are *pro tanto* responsibilities which hold in the absence of stronger reasons to do otherwise. Identity-related responsibilities will rarely operate in isolation, they comprise part of a wider suite of considerations, including their relationship to the information subject, which potential disclosers must also take into account. Chief amongst the considerations that operate as limiting factors on identity-related responsibilities is the presence of other competing interests.

The first set of limiting factors are information subjects' own potentially competing interests. For example, a responsibility to avert the risk of identity harm from exposure to a distressing diagnosis or risk information will need to be weighed against any potential health benefits of communicating these results. For example, a brother may be relieved of the responsibility to protect his sister from learning of his own susceptibility to treatment-responsive hereditary cancer when the benefits to her of averting serious illness and premature death are substantial, even if he knows this knowledge threatens to disrupt her life, potentially causing her to feel dissociated from her body and her role as a mother.

Responsibilities to disclose or withhold also need to be weighed against the interests of the potential discloser themselves and those of third parties. So, in the present example, the brother may also be relieved of the responsibility to withhold potentially identity-harming risk information from his sister if he knows that it would be of substantial clinical value to her children to know when they reach adulthood or if the effort to conceal his own risk status and subsequent screening and treatment from her would place unsustainable restrictions on his life and their relationship. These examples illustrate the ways in which our identity interests are entangled with and interdependent upon the needs and

interests of others. And it is possible that identity interests will be in play on both sides of the disclosure equation. For example, an individual's identity interests in knowing the identity of her genetic mother will need to be weighed against the mother's interests in maintaining the inhabitability of her own narrative and privacy, as well as that of her family.¹⁶

Relevant countervailing considerations are not limited to responsibilities to particular identifiable others. Public and group interests are also implicated. For example, ethical responsibilities of researchers to communicate individual, identity-significant research findings to participants must be weighed against the possible threat to realising the socially valuable ends of research that might result from the investment of scarce time and research resources in identifying, validating, offering, and communicating these findings.¹⁷ And it is possible that a particular information subject's identity interests could be in tension with those of other members of groups to whom they belong or of the group qua collective. For example, we might imagine circumstances in which some of those living with mental health diagnoses view neurological explanations of their mental illness as alienating and reductive and thus experience the choices of others to seek neurological diagnoses for the same condition as harming the intelligibility and comfort of their own self-narratives by shifting the meaning and connotations of living with the diagnosis in undesirable ways.

The challenge of course remains in examples such as those sketched above of how to weigh identity interests and responsibilities against competing demands or, more specifically, to decide what weight identity should carry in these cases. The picture I have developed in this book does not provide a neat formula for doing so. Much will depend on the nature of the information in question, the characteristics of the potential recipient, the disclosure context, and the relationships between those involved. Weighing of diverse, incommensurable, and sometimes indeterminate competing interests engaged by information (non)disclosure is a notoriously difficult problem – one which is hardly unique to my identity-based argument. Indeed, these dilemmas are familiar from long-standing discussions of ethical decision-making in clinical genetics and the many pages written about the 'right to know' and 'right not to know' genetic information – for example where its clinical value to the one

¹⁶ Similar reasoning was used in the majority judgment in *Odièvre v. France* – see Chapter 2 for further discussion.

¹⁷ Miller et al. 2008.

subject must be weighed against harm to the privacy of another.¹⁸ Recognising and responding to identity interests does not remove the need to weigh such demands, it adds another important consideration to the mix. However, this does not necessarily mean that this addition further muddies these already obscure waters. On the contrary, thinking in terms of identity will sometimes offer a much-needed means of clarifying and giving substance to several existing, sometimes under-conceptualised, or inchoate ethical concerns that may transpire to be at least in part 'about identity'. For example, if we are equipped to recognise identity interests and the ways in which these can be met, we may be in a stronger position to judge circumstances in which, for example, informational autonomy or spatial privacy do in fact warrant protection, what kinds of personal utility should be taken seriously, or what might lie beneath expressions of distress or anxiety. In these cases, excavating the identity-related roots or aspects of these concerns could offer a way of understanding what is really at stake, the normative heft of privacy or informational control, and how these concerns might best be addressed.

My aim in this book has not been to demonstrate that identity-related interests and responsibilities should always prevail whenever they come up against conflicting demands. Rather I have sought to show that they are a legitimate and ethically significant part of disclosure decision-making practices and policies and warrant being taken seriously alongside other established ethical, legal, and practical considerations. Identity-based disclosure responsibilities may coincide with or run contrary to other obligations, they may function as complementary grounds for disclosure or countervailing reasons not to. They can provide at least as compelling grounds for or against disclosure as privacy, confidentiality, or autonomy concerns do and will indeed often be closely linked to these in the ways described in the previous chapter. While it seems likely that health concerns – especially those with implications for serious illness, death, or profound pain and suffering – will usually carry greater weight, not all health concerns will be this grave. Where health threats are not substantial, identity interests may give considerations of clinical utility a run for their money. This is not solely a matter of competing interests, however. As illustrated in the preceding chapters, people's identity interests often coincide with clinical utility. In these circumstances, the former may provide greater imperatives to provide findings where clinical utility alone is not yet wholly decisive, for example where

¹⁸ See, for example, essays in Chadwick et al. 2014.

there is a decision to be made about the relative benefits of instituting health screening programme.

A key part of potential disclosers' responsibilities is, therefore, to conduct a serious and thoughtful weighing exercise that gives identity interests their due alongside, and in counterpoint to, other interests. However, the idea that these responsibilities start and stop at simply weighing conflicting interests ignores further critical ethical dimensions of decision-making and communication practices. As I shall now discuss, these entail responsibilities, first to attend carefully to where potential recipients' identity interests lie, and subsequently to communicate personal bioinformation in a way that seeks to minimise narrative harm and support narrative development. The second of these holds irrespective of whether identity or another consideration prevails in the decision about whether and what to disclose.

7.5 Ascertaining Where Interests Lie

Before potential disclosers can understand what is ethically required of them, they need to know what information subjects' identity interests might look like and how best these may be met. I have suggested above that our identity-related responsibilities include those to attend to the informational needs and vulnerabilities of others and that this entails taking reasonable steps to ascertain where these lie. In contrast to assessing, for example, clinical utility, this is undoubtedly not a straightforward task. It would be potentially detrimental to recipients to make a wrong call about identity value. However, it would also be unjust to impose disclosure responsibilities on others if they had no reasonable practicable way of ascertaining this value.

The most immediate way of meeting this challenge is clearly to ask the potential recipient what they want or do not want to know and to offer them the option of receiving it. Or rather, it is not simply to *ask* but to engage in a reciprocally informing, collaborative exploration of their needs and desired ends to ascertain whether and how the information might meet these, as part of the process of raising the possibility of and offering access to it. This undertaking needs to be 'reciprocal' and 'collaborative' because, as Jackie Leach Scully highlights – in writing about genetic counselling – there are likely to be epistemic, experiential, and interpretive gaps and divergences on both sides which need to be bridged if recipients' interests are to be effectively and appropriately met.¹⁹ Scully emphasises

¹⁹ Scully 2009.

the importance of attending to and learning from potential recipients, refraining from assuming that their informational needs will be like the discloser's own, and approaching, as far as possible, an appreciation of their particular needs and perspective. This perspective will be 'shaped by a unique constellation' of variables and may be very different from our own.²⁰ This chimes with what was said in Chapter 6 – that the identity significance of particular personal bioinformation and its value, or harmfulness, are ultimately shaped by the interpretive perspective supplied by the particularity of the subject's existing identity narrative and circumstances. Scully argues that understanding informational interests requires 'a particular quality of attention towards the real, embodied other'.²¹ She cautions, however, that the potential discloser's understanding of the needs and perspective of the potential recipient is unlikely ever to be perfect because of the different experiences, social position, and worldviews of the parties involved. Due to the particularity of each of our interpretive perspectives, Scully further suggests that the ethically appropriate attitude and approach of the potential discloser will be one that respects the 'residual unknowability' and 'ontological "otherness"' of the recipient.²² This provides not only a strong rationale for the *practical* necessity of carefully attending to the informational needs of potential recipients but also for the *ethical* requirement to do so. This notwithstanding, potential disclosers' abilities to meet this requirement in practice may face challenges.

Obstacles to Ascertaining

The first such challenge is that, in many cases, information subjects will be unaware that there is something to be known at all. And asking them if they would want to know means effectively revealing, or revealing enough of, precisely what could be detrimental to their identity. For example, it is likely to be difficult to enquire whether someone would find it useful to know more about their parentage or about family medical history without thereby indicating that their existing beliefs about these matters are misplaced or incomplete, thus potentially seeding narrative discord and discomfort. In some circumstances, the challenge of enquiring about 'unknown unknowns' may be a stubborn one. However, it is

²⁰ Scully 2009, p. 224.

²¹ Scully 2009, p. 226.

²² Scully 2009, pp. 225, 227.

not unique to navigating identity interests. It is, for example, a notoriously thorny issue in genetic privacy debates.²³ Indeed, recognising the possibility, nature, and ethical significance of identity interests might offer some useful insights to this long-standing puzzle. The dilemma of disclosing unknown unsought bioinformation is commonly raised where genetic findings could have clinical or practical utility for the recipient, but there is a fear that revelation might be accompanied by ‘undesirable’ personal consequences. The harm implicit in this undesirability is often of vague provenance, scale, or significance. If disclosers are in a position to recognise when these feared harms comprise narrative detriment – as they sometimes will – they will be better placed to assess the risks of disclosure and to put in place the interpretive support that could help avert or ameliorate some of the gravest narrative harms should they arise. I will return to examine what this support could look like shortly.

Sometimes, practicalities or resource constraints will preclude truly individualised, collaborative prior discussion of identity interests – for example, where information-dependent decisions, such as whether to undergo surgery, are time-critical, when it is prohibitively costly and impractical to personalise the feedback practices from a large research study, or where bioinformation is automatically delivered by wearable personal devices. In other cases, meanwhile, individualised consideration of whether to disclose may seem otiose, either because the information has overwhelming clinical value, or because its practical value is negligible and there seems to be a highly likely and serious threat of harm to identity. While remaining mindful of what has been said above about potential disclosers’ limited capacities to imagine others’ identity needs, in cases such as these, it may be necessary and desirable to institute broad identity-responsive disclosure policies.

These policies need not be wholly blunt instruments. Empirical studies of the kinds explored in Chapter 5 can provide valuable insights. Genetic counselling tools, such as the *BRCA* Self-Concept Scale, offer evidence-based means of identifying how different population subgroups may respond to disclosure.²⁴ And, even if it is not possible to predict precise narrative harms or benefits, it may be possible to anticipate when identity impacts of some kind could be afoot. As described in the previous chapter, identity-significance is shaped not only by the narrative

²³ See Laurie 2002.

²⁴ Esplen et al. 2009.

perspectives of recipients but also by a cluster of publicly discernible factors. These include the nature and scale of the consequences for information subjects' health and bodies, and the prior meanings and identity relevance ascribed by shared social and cultural practices to the information and the biological states of affairs it reports. Similarly, it is possible to anticipate when particular kinds of information are likely to be inimical to inhabitable self-narratives because they are false, misleading, stigmatising, or otherwise restrictive of self-authorship. It will also often be possible to discern when particular situational or pathogenic vulnerabilities arising from, for example, living with stigmatising conditions or in the shadow of oppressive stereotypes might make particular kinds of bioinformation particularly valuable or identity-threatening. These various anticipatory methods might not deliver infallible insights at an individual level. However, they can help mark out territory in which attention to identity impacts is particularly warranted and where identity-supporting methods of communication are a high priority. Such disclosure policies will of course need to remain flexible and responsive to individual circumstances and emerging evidence.

Navigating Choice

I have suggested that potential disclosers should discuss with information subjects what they might wish to know. But what should be done when subjects' wishes appear to run sharply contrary to others' careful and thoughtful assessment of their identity interests? This dilemma arises because, as I have argued, our identity interests are located in the development and maintenance of an inhabitable self-narrative, not solely in fulfilment of the sheer choice to know or not to know. This does not mean that inhabitability and choice are unconnected. Being able to exercise choice is a key to the agential skills and self-esteem that allow us to be confident authors of our own narratives. And it is of course the case that we will often be the best judges of our own narrative needs. However, we can also be mistaken. The empirical research discussed in Chapter 5 illustrates how, for example, people's actual and longer-term reactions to learning of disease susceptibility can differ markedly from their prior expectations. And it is possible to imagine, for example, someone fervently seeking access to individual findings from their participation in a psychiatric neuroimaging study, believing these will give them the insights they need to make significant personal and professional

changes, when these findings are simply not reliable or meaningful at an individual level. Conversely, we might imagine genomic research revealing that a participant is a carrier of a serious, rare genetic disorder when they have elected not to receive individual feedback. For the purposes of these examples, let us suppose that receipt or ignorance of findings in each case respectively poses a substantial threat to the future intelligibility, comfort, and meaning of the participants' self-narratives.²⁵ Would the research teams be ethically justified in coercing these participants into maintaining an inhabitable and sustainable identity by denying the findings in the first example and imposing them in the second? I want to suggest that the answer here is not as obviously or invariably in the negative as might sometimes be assumed.

Let us look at some positions from which the answer would be 'no'. Pierre Widmer argues that one has the right to 'adopt and maintain a subjective image of oneself, which may objectively be false'.²⁶ I would submit that talk of rights here is unhelpful. Not only does it demand that we enquire what this right is based upon – Widmer himself suggests it lies in the preservation of a 'desirable picture' of oneself – but it also unhelpfully collapses the matter of where our interests lie with how others should respond to them. I have argued that it is generally not in our interest to occupy a self-narrative that is unsustainable and at odds with embodied experiences and others' understandings of us and the world, even if it is apparently a 'desirable' one in the sense of being currently untroubled and pleasing. However, it is also important that we respect each other's different worldviews and individuality, which suggests a requirement to recognise and support others' narratives and narrative choices. Might there be limits to this recognition – particularly where the coherence, sustainability, and future comfort of someone's narrative are predictably under threat?

In discussing forms of identity harm, Adam Henschke considers the limits to our ethical obligations to recognise and respect others' self-characterisations. He argues that, while we are not obliged to recognise vicious self-characterisations that harm others, merely 'factually unfounded' ones – for example, that one is a vampire – warrant recognition unless they would result in 'fundamental identity

²⁵ As noted in Chapter 6, it is possible that, in some cases, uncertain but strongly welcomed bioinformation could represent an overall identity benefit. For the purposes of these examples, I am assuming that, on balance, the subjects' choices are most likely to be antithetical to an inhabitable self-narrative overall.

²⁶ Widmer 1994, p. 184.

instability'.²⁷ Henschke's conclusion regarding vicious other-harming self-descriptors seems sound. We would not be under a moral obligation to enable a white supremacist to 'prove' their solely European ancestry through genomic analysis – if this were indeed possible – and thus contribute to shoring up their racist commitments. The absence of obligation would hold even if in some sense they might be said to have some kind of thin, individualistically conceived interest in these ends. Here the contrary obligation to prevent the kinds of violence, hate speech, and significant social injustice that could arise from enabling race-based stereotypes and racist activities would outweigh any such identity interest. However, the second part of Henschke's claim seems too strong. Not only would vampire self-characterisation, assuming someone is not in fact a vampire, clearly violate the modified embodied-reality constraint I proposed in Chapter 4 – that an individual's self-narrative should be reasonably consistent with and intelligible in light of both others' experiences of the world and their own experience of their embodiment. It is also likely that, as I have sought to demonstrate, non-trivial identity harms may occur which fall short of Henschke's criterion of fundamental instability. As I have argued, self-characterisations are not discrete identifiers but interdependent threads in a multifaceted identity, and their misleading qualities or fragility have wide practical, personal, and relational repercussions. Properly recognising and, where appropriate, supporting someone's identity development through information disclosure practices, therefore, requires not simply recognising discrete self-descriptors piecemeal but also recognising the inhabitability of the whole of who someone is as a complex intersectional constellation.

For these reasons – while stressing that each case must be considered on its own merits – I would suggest that an information subject's choice to know, or not to know, is not an automatic trump. Rather, potential disclosers have a responsibility to interrogate what is chosen as part of a collaborative exploration of needs and to weigh the competing interests – including the subject's interest in exercising choice and any damage to relationships and trust arising from unwanted impositions or denials – giving identity interests the serious weight they are due. This could, I want to suggest, sometimes lead to withholding desired or imposing unwanted findings. From one perspective, this might be seen as troublingly paternalistic, prioritising others' perceptions of

²⁷ Henschke 2017, pp. 211, 213.

information subjects' well-being over their own choices. However, from the ethical perspective set out in this chapter, it can instead be seen as an appropriate response to the vulnerability of subjects' identities – vulnerability to the onslaught of embodied and social experience and to the significant impacts of bioinformation that could explain, radically reframe, or replace these experiences – and to our dependence on each other when it comes to navigating the world and helping us make sense of who we are.

7.6 Identity-Supporting Communication

The challenges of ascertaining information subjects' needs and predicting the identity value and impacts of particular encounters with personal bioinformation, combined with the fact that in many cases disclosure may be required on other grounds or be otherwise unavoidable, lend a particular imperative to the second of the four responsibilities listed at the start of this chapter. This is the responsibility to communicate personal bioinformation in ways that support narrative benefits and mitigate narrative harms. However, it is not only in these unpredictable and unavoidable circumstances that identity-supporting approaches to disclosure matter. Many of the kinds of bioinformation to which subjects do not have direct access will be probabilistic, ambiguous, or technical. The implications of these for the recipient's health and bodily existence may not be readily understood without professional guidance. Moreover, the identity significance, value, or detriment of personal bioinformation are not necessarily fixed prior to disclosure. These qualities are malleable according to factors including the intentions, focus, and tone of the discloser, the medium in which the information is conveyed, and the accompanying interpretive tools, including further contextualizing information and explanations. As demonstrated by the experiences reported in Chapter 5, the meaning of even non-technical information – for example, about the identity of one's genetic parent – may be altered by the ways and context in which is communicated. Furthermore, as noted throughout this discussion, narrative self-constitution is both an inherently interpretive and relational undertaking. It is not something we can do on our own. It springs from and depends upon discussion and negotiation with others, drawing on divergent and shared experiences and common sources of meaning. We are no less vulnerable to the ways that others help us interpret or hinder us from interpreting the role – or superfluity – of new bioinformation to our self-narratives than we are to

whether we receive it at all. This vulnerability extends to the identity significance that those doing the communicating invest in the information they convey and the recognition and respect they afford to our chosen self-narratives and the tools we use to construct these. For these reasons, the requirement to communicate personal bioinformation to information subjects in an identity-supporting manner is neither 'a duty too far' nor an unwarranted imposition into recipients' private domain. It is an irreducible part of the ethical responsibilities of those who generate, hold, and manage our personal bioinformation. In the following section, I will set out the broad parameters and some examples of what identity-supporting disclosure practices look like.

What Does Identity-Support Entail?

Echoing the recommendations of others, including Scully and Christoph Rehmann-Sutter, for ethical communication practices in genetic counselling, I want to suggest that identity-supportive disclosure involves a respectful, but not disengaged, discursive approach, involving two interconnected activities.²⁸ First, it entails enabling recipients to understand the empirical states of affairs conveyed by information, which Scully refers to as our basic 'conceptualization of causality in the world'.²⁹ And, second, it entails supporting recipients to consider what this might mean for their embodied, relational identities.

The first requirement involves explaining to the recipient what the information conveys about their past, current, or future physical and mental health, their embodied states, experiences, and capacities, and their relationships to others – not only biological relationships but also those of care, trust, and dependency. The kinds of explanation required will depend on how complex, technical, or unfamiliar the information is. It might, for example, involve discussion of the clinical validity of a test – for example, how effective it is in identifying the condition or trait in question and the meaning of complex probabilistic estimates – and its clinical utility – for example, whether it points to a particular prognosis or effective course of treatment. Just as important as explaining what bioinformation *can* tell the recipient is making plain what it *cannot*. The latter might involve, for example, explaining when techniques are not yet sufficiently mature to deliver reliable insights, whether false positive or

²⁸ Rehmann-Sutter 2009; Scully 2009.

²⁹ Scully 2009, p. 218.

false negative results are likely, or whether confounding factors introduce uncertainties. These provisos are familiar from widespread existing recommendations for responsible communication of health findings – for example, those produced by DTC genomics – where the ethical imperative is viewed chiefly as that of averting health threats from misdiagnosis or false reassurance.³⁰ The imperative may be no less strong, however, where potential identity impacts are concerned and where the information concerns traits unrelated to health. Given what I have said in earlier chapters about the risks of false or misleading bioinformation – that these might not only fall short of serving useful explanatory roles in our embodied, relational narratives, but also sow incoherence and jeopardise their future resilience and sustainability – it is clear why transparency about epistemic limitations is relevant to averting not only health harms but identity ones too. Preparing recipients to appreciate bioinformation's epistemic capacities and limitations equips them to use it in a clear-eyed way and to their best advantage in the construction of their self-narratives.

The second requirement is to equip, as far as possible, recipients to assess what the information in question might mean for their accounts of who they are and to enable them to accommodate it in, or reject it from, their ongoing narrative endeavours in as smooth a way as possible. There may not always be a sharp line between this kind of assistance and that of providing guidance about information's empirical robustness. For example, a key aspect of identity-supportive disclosure would be diverting recipients from unwarranted reductionist or essentialising readings of bioinformation that, for example, conveys only probabilistic estimates of susceptibility to disease or dispositions to particular behavioural traits. In such cases deterministic readings might both be factually false and also risk impeding the inhabitability of the recipient's narrative by suggesting that unwanted characteristics are unavoidably self-defining and thereby circumscribing the scope for self-authorship. Averting deterministic readings in such cases straddles factual and self-characterising interpretative support.

At a broad level, acting as an interpretive partner may involve offering ways to counter or ameliorate distressing or disempowering impacts on recipients' defining characteristics and the frameworks within which they evaluate these. It will also involve supporting recipients in finding ways to integrate or reject information from their self-narrative in ways that

³⁰ Bunnik et al. 2011.

preserve or restore its coherence, meaning, comfort, and sustainability. Interpretive and explanatory support should, as far as possible, be delivered as part of a process of ascertaining the recipient's particular informational needs, offering them the opportunity to receive it, preparing them to receive it, and managing the effects of disclosure. Some examples of ways in which this might be achieved could include identifying groups of recipients particularly likely to be vulnerable to stigmatising, oppressive, and distressing impacts of encounters with particular kinds of bioinformation and seeking to challenge these by, for example, offering or helping recipients develop what Hilde Lindemann refers to as 'good counterstories'.³¹ These counterstories are alternative narrative templates that provide a fresh perspective on oppressive social norms and which support people to 'resist' and 'uproot' existing, limiting, or degrading 'master narratives' and to replace these with more intelligible, enabling, and fulfilling alternatives.³² Recipients' feelings of uncertainty and insecurity could be addressed by exploring practical steps they might take to ameliorate these – for example, clinical interventions, protective health behaviours, or engagement with patient groups. Timing of disclosure could also make a difference to the nature of consequences for identity – as illustrated by the markedly different reactions of those learning of donor origins early or later in life.

The experiences explored in Chapter 5 suggest that identity impacts could be substantially influenced for the better by ensuring, as far as possible, that the kinds of information provided correspond to the identity-related role it is likely to fulfil. For example, it is not uncommon for donor-conceived individuals to report that distress and disorientation following disclosure of donor conception is exacerbated by lack of further information about their donors.³³ And someone who hopes that a printed image of a brain scan will help align their family's perception of their mental illness with their own might benefit from counselling about how to discuss their diagnosis with those close to them.³⁴ Information – both the 'core' personal bioinformation itself and supporting contextual information and explanations – should be conveyed in a clear and accessible way. This means, amongst other considerations, not overburdening recipients with unmanageable detail and not treating disclosure as a one-off event or as a defensive maximal information

³¹ Lindemann 2001, p. 66.

³² Lindemann 2001, p. 67.

³³ Ilioi and Golombok 2015.

³⁴ See discussion in Chapter 5.

'dump'. Attention should also be paid to the medium of communication. For example, images and graphical representations of data may aid understanding. However, as they can also invite risks of unwarranted epistemic and personal reliance – as illustrated by common perceptions that neuroimages convey particularly authoritative, objective, or non-negotiable 'truths about the self' – such reliance may itself need to be anticipated and addressed. These are only sketches of preliminary suggestions. Empirical studies exploring differential narrative impacts would make a valuable contribution to developing more detailed, concrete guidance, and to understanding which individuals or groups might have particular or unexpected needs and vulnerabilities.

Recognising Limits

The requirement for wider interpretive support described above may seem to stray far beyond the legitimate professional roles and expertise of healthcare professionals, researchers, managers of biobanks and data repositories, or those designing and marketing DTC services and devices. While family members, genetic counsellors, and other healthcare professionals may be well-placed to provide the kinds of identity-focused interpretive support described here, many actors will be ill-equipped to do so. Indeed, doing so may be a practical impossibility in some circumstances, for example in research studies comprising thousands of participants, or where a health monitoring app has millions of users. However, to reiterate what I have said above, once an actor is in the business of handling and communicating potentially identity-significant bioinformation – whatever that business is – and in the absence of strong countervailing reasons, managing its identity impacts is not an optional extra or an inconvenience but an integral part of their ethical responsibilities. That said, the interpretive responsibilities I am proposing here need not necessarily fall solely upon or be carried out directly by the parties who generate the findings. Implementing robust referral pathways to suitable third-party sources of information and support, and opportunities to reflect upon identity impacts could in some cases be a wholly appropriate part of discharging the responsibilities described above.

It is nevertheless important to recognise reasonable limits to even well-informed and skilled disclosers' insights into the significance of specific bioinformation to a recipient's unique, multistranded identity narrative. Recipients, in deferring to professionals' insights and expertise on empirical states of affairs, may be inclined to defer to them on narrative

matters. This is especially so when disclosers occupy a position of power and authority – as they may well do if they are healthcare professionals, research scientists, or older family members. Thus, there remains a need for humility in the face of individual difference and willingness to listen and learn, not solely to advise and instruct. This takes us back to Scully's valuable warnings about showing 'respect for the ontological "otherness" of the other' and disclosers' responsibilities to 'to comprehend as fully as possible the others' worldviews, and recognize their own cognitive and imaginative limits'.³⁵

For all of these reasons, identity-supportive communication – just like enquiries as to informational needs – should involve an interpretive partnership. In Scully's terms, it is a 'joint interpretive and ethical enterprise', characterised by discussion and by listening and learning on the part of the discloser and the recipient.³⁶ This will allow the former to support the particular narrative needs of the latter as best they can. This kind of approach resembles that used in genetic counselling. However, it implies rather more intervention on the part of the discloser than is commonly associated with genetic counselling, where the principle of 'non-directiveness' is widely viewed as a key aspect of best practice. There is some debate about whether non-directiveness is actually achievable or a virtue in genetic counselling.³⁷ Rehmann-Sutter suggests that it may be neither, given that communication inevitably shapes the meaning of information and that the desired outcome is not non-direction per se but supporting people in realising their agency and leading fulfilling lives.³⁸ What is clear, though, is that if communication practices are to enable recipients to consider what the information implies for their identities and to realise their capacities to be authors of their self-narratives, this is unlikely to mean abandoning information subjects to their own devices. Identity-supporting practices will be those in which possible narrative framings of bioinformation are offered for discussion, collaborative reflection, and rejection as well as adoption. Useful support will not be abstract or generic, but responsive to the particular circumstances, needs, and vulnerabilities of the recipient.

I do not want to go so far as to suggest that if potential disclosers cannot ensure identity-supportive communication, personal bioinformation should not be disclosed at all. This would be too strong

³⁵ Scully 2009, pp. 226, 227.

³⁶ Scully 2009, p. 217.

³⁷ Rehmann-Sutter 2009.

³⁸ Rehmann-Sutter 2009.

a condition. As with all the identity-related responsibilities described here, obligations to provide interpretive support must be weighed alongside and against other legitimate ethical concerns and, where necessary, legal and reasonable practical constraints. Efforts to do so should be commensurate with the likelihood and depth of identity harms and benefits. This does not mean, however, that attending to the context and manner of disclosure is simply gold-plating or an optional extra. It is integral to taking seriously the central role of self-constitution in an engaged, fulfilling, and flourishing life. And, as noted above, it is a responsibility that holds even, or rather especially, when other priorities such as health protection prevail over identity interests in decisions about *whether* to disclose. In such cases, the imperative is to minimise identity harms when the disclosure of information that could be inimical to inhabitability is unavoidable.

Undoubtedly, each of the requirements described in this chapter carries significant resource implications. I do not seek to minimise these or to ignore disparities amongst the opportunities and resources available to different categories of disclosers to provide interpretive support. However, the practical, ethical, and regulatory measures taken to protect health, privacy, confidentiality, and autonomy in the governance of personal bioinformation also require time, care, and resources. The purpose of this book has been to demonstrate why interests in developing and maintaining an inhabitable identity deserve equally serious and committed attention.

7.7 Shared Social Responsibilities

Before closing this chapter, I want briefly to note that, on the basis of what has been said so far, it is also necessary to consider how identity-related responsibilities extend beyond particular information encounters and transactions. There is clearly a vast landscape of social, cultural, structural, institutional, and practical factors – including the ways in which bioethics and the law are conducted – that can contribute to or ameliorate stigmatising and oppressive insinuations and stereotypes associated with particular forms of embodiment and self-characterisation. These in turn influence the identity roles fulfilled by associated personal bioinformation. Addressing the responsibilities and means to tackle these wider environmental contributions to the meanings and impacts of personal bioinformation lies beyond the scope of this book. However, it must be recognised that the practical and ethical concerns explored over the previous chapters do not take place in a vacuum but within a malleable

interpretive environment in which all of us are implicated as contributors.

As noted in Chapter 6, the identity-significance of particular kinds of bioinformation is often, at least in part, socially constructed. Institutional and group practices contribute not only to the potential positive or negative connotations of this bioinformation and what it conveys, but also to the extent to which these connotations gain narrative purchase. For example, several commentators have speculated that laws entitling donor-conceived individuals to know about their gamete donors on explicit identity-related grounds may contribute to a feedback loop that reinforces perceptions that this knowledge is central to identity development and thus to donor-conceived individuals' desires to know.³⁹ The law is, of course, not the only possible socially constructed source of identity significance. As noted in Chapter 1, research studies exploring the connections between specific biomarkers and human traits, and the ways the media report or policy-makers use the findings from such studies have the power to contribute to popular perceptions that particular kinds of biological or health-related findings convey especially direct and useful insights into what we are like as individual persons. For these reasons, the kinds of research questions that are asked, which studies receive funding, the ways that publics and participant groups are engaged, the methods used in analysing the data collected, and how the findings are reported and taken up all play a role in constructing identity significance and, thus, in associated narrative benefits or harms.

Recalling what was said in Chapter 6, it is not only futile but also a misunderstanding of the unavoidable contributions of shared social tools and practices to narrative self-authorship to seek to counter potential identity harms by trying to eliminate potential 'external' sources of identity-significance. It would not just be potentially cruel but also an ineffective and misdirected effort to deny those who want to know about their genetic origins the means to find out in an effort to counter the narrative value invested in connections to genetic origins. However, the responsibility rests on all of us who produce, disseminate, and use bioinformation – not only at a personal but also at an aggregate or population level – to use the tools at our disposal to minimise the potential for narrative harms and to support imaginative authorship of varied forms of coherent, meaningful, comfortable, and sustainable self-narratives. This means, for example, eschewing biologically essentialist or

³⁹ Freeman 2015.

deterministic readings of findings or classifications of persons that limit our capacities to shape our own stories, or stigmatise those whose experiences deviate from those of the majority. And we should reject simplistic or hyperbolic reporting and marketing of biomedical research and technologies that misrepresent the extent to which particular kinds of bioinformation can provide reliable or meaningful insights into our embodied lives. It also means approaching the practices and methods by which bioinformation is produced in ways that challenge and resist hurtful, degrading, and oppressive stereotypes and instead contribute to the production of inspiring and enabling counterstories and a rich array of tools that serve diverse approaches to narrative self-constitution.